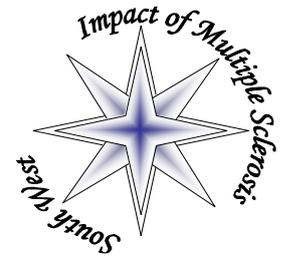


SWIMS News



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.**

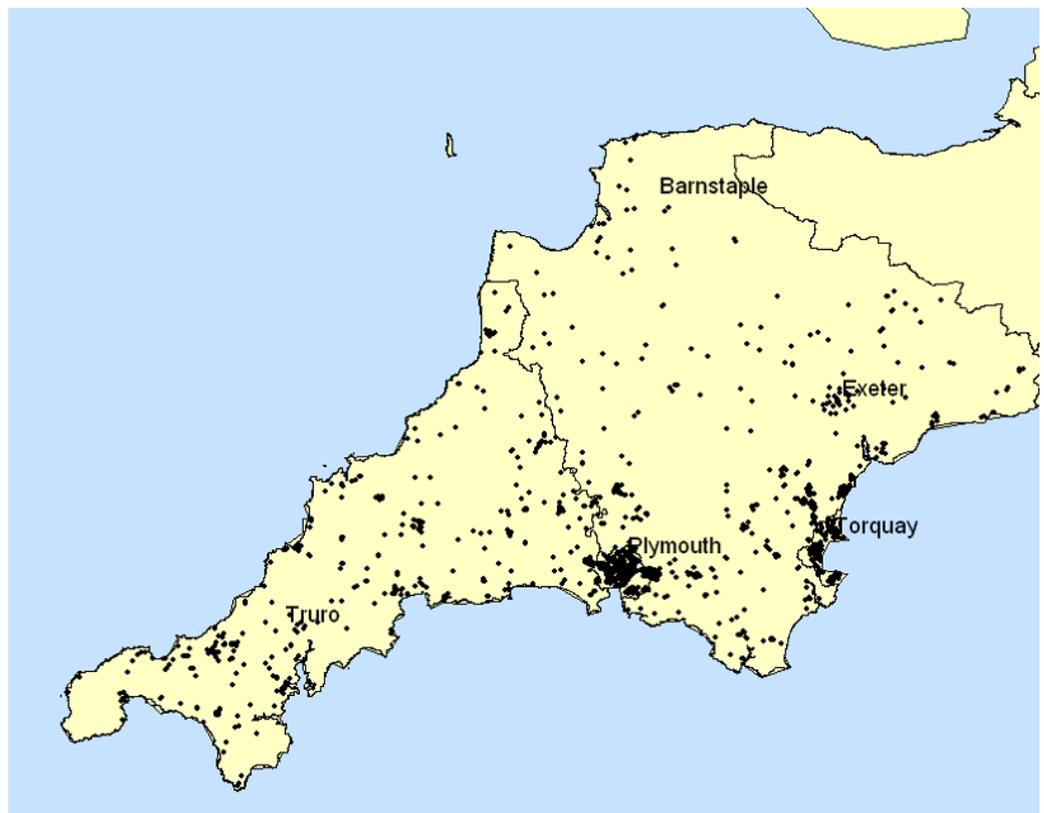
The SWIMS Project is currently funded by the Multiple Sclerosis Society of Great Britain, and through the Peninsula Medical School Foundation

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 April 2016 over 1,750 people with MS or CIS had consented to take part. Some have been participating since 2004 and we want to say “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.



Message from Scotland



Hello from snowy Scotland!

Most people may know that I have now left sunny Devon to take up new challenges in the University of St Andrews. The SWIMS team keep pestering me for a photo in a kilt, well they'll have to wait a while longer!



I will try to maintain my role as Chief Investigator for SWIMS even though I'm a little remote from Devon and Cornwall.

One of the benefits of moving to St Andrews is the expertise in mathematics and statistics that exists here. I hope to be able to tap into that in order to help analyse the crucial information that SWIMS is producing.

The major issue of the moment is how SWIMS can integrate with the UK MS Register. You may know that the MS Society has funded the UK MS Register to nearly £2 million over the last few years, and SWIMS has also been funded by the UK MS Society.

The Society has made it clear that they want to see integration of both projects in the future, so we have been working towards that goal.

We've always known that the longer SWIMS goes on, the more important the information generated will become. This is why it is so crucial for everyone to try and continue to fill in the questionnaires every 6 months.

Our problem is how to keep SWIMS on track, whilst accommodating the aims of the UK MS Register. We appreciate immensely the loyalty of people of Devon and Cornwall to the SWIMS project, and will try not to jeopardise this loyalty in any way.

One of the major differences between the UK Register and SWIMS is that the Register is only available on-line, whereas we know that most people helping with SWIMS prefer to have the paper version of the questionnaires.

You can be assured that we will be working as hard as possible to try and maintain the loyalty of our SWIMmers. I must express my thanks to the SWIMS Steering Committee, and the patient representatives on this committee, for supplying invaluable input into how we can navigate these choppy waters.

Keep up the good work!

John Zajicek

SWIMS Project Progress — CIS

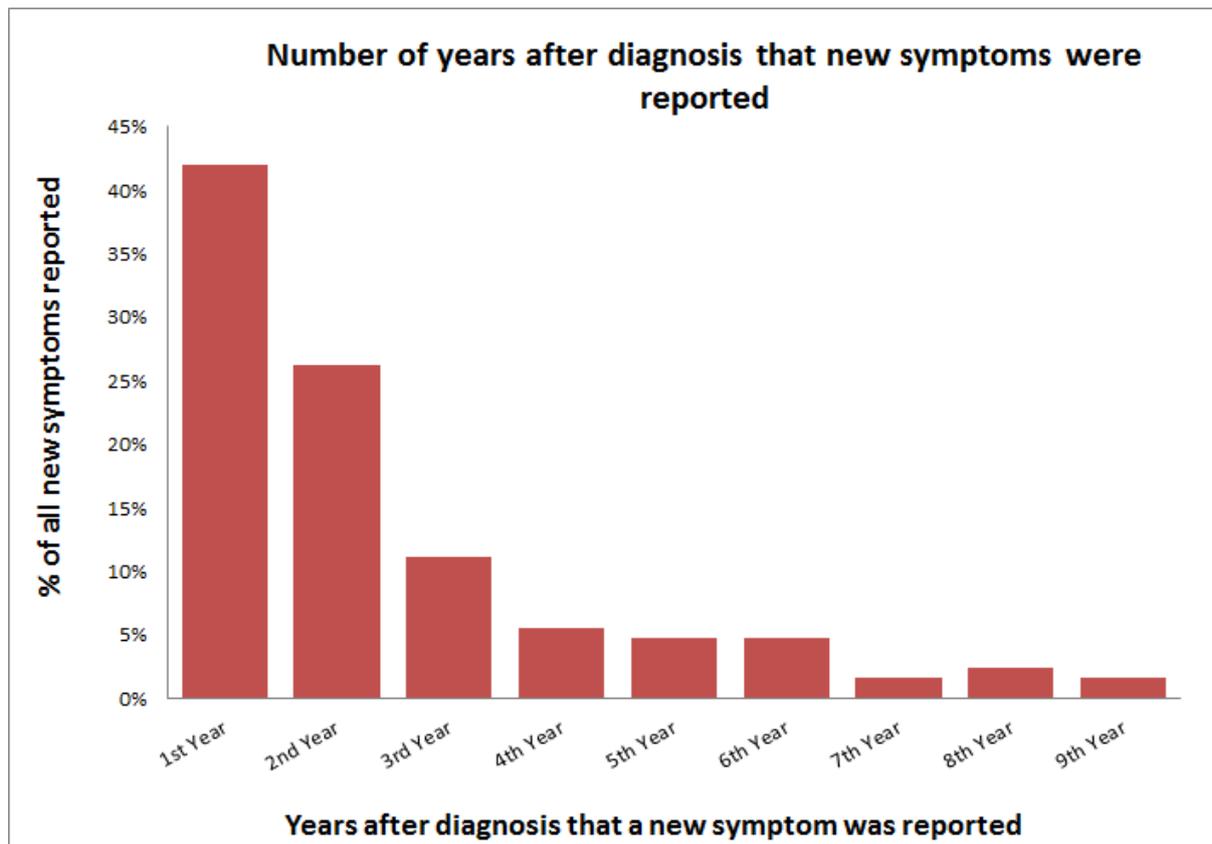
We have now recruited 144 participants with CIS to the SWIMS project, 30% of whom are male and 70% female. The average age of CIS participants is 46 but participant ages range from early 20s to late 60s.

Since 2004, nearly 600 booklets have been sent out to CIS participants and 82% of these have been completed and returned. This is a fantastic response—thank you!

Approximately one quarter of CIS participants complete their booklets online. Online booklet completion helps to keep the costs of running SWIMS low but for some reason booklets are not completed as often by online participants as they are by postal participants! If you are finding that you don't remember to complete online booklets please let us know if there is anything we can do to help.

In our last newsletter we told you about the symptoms people with CIS experienced when they were diagnosed: the most commonly reported symptoms were numbness and pins and needles (or tingling); the least commonly reported was double vision.

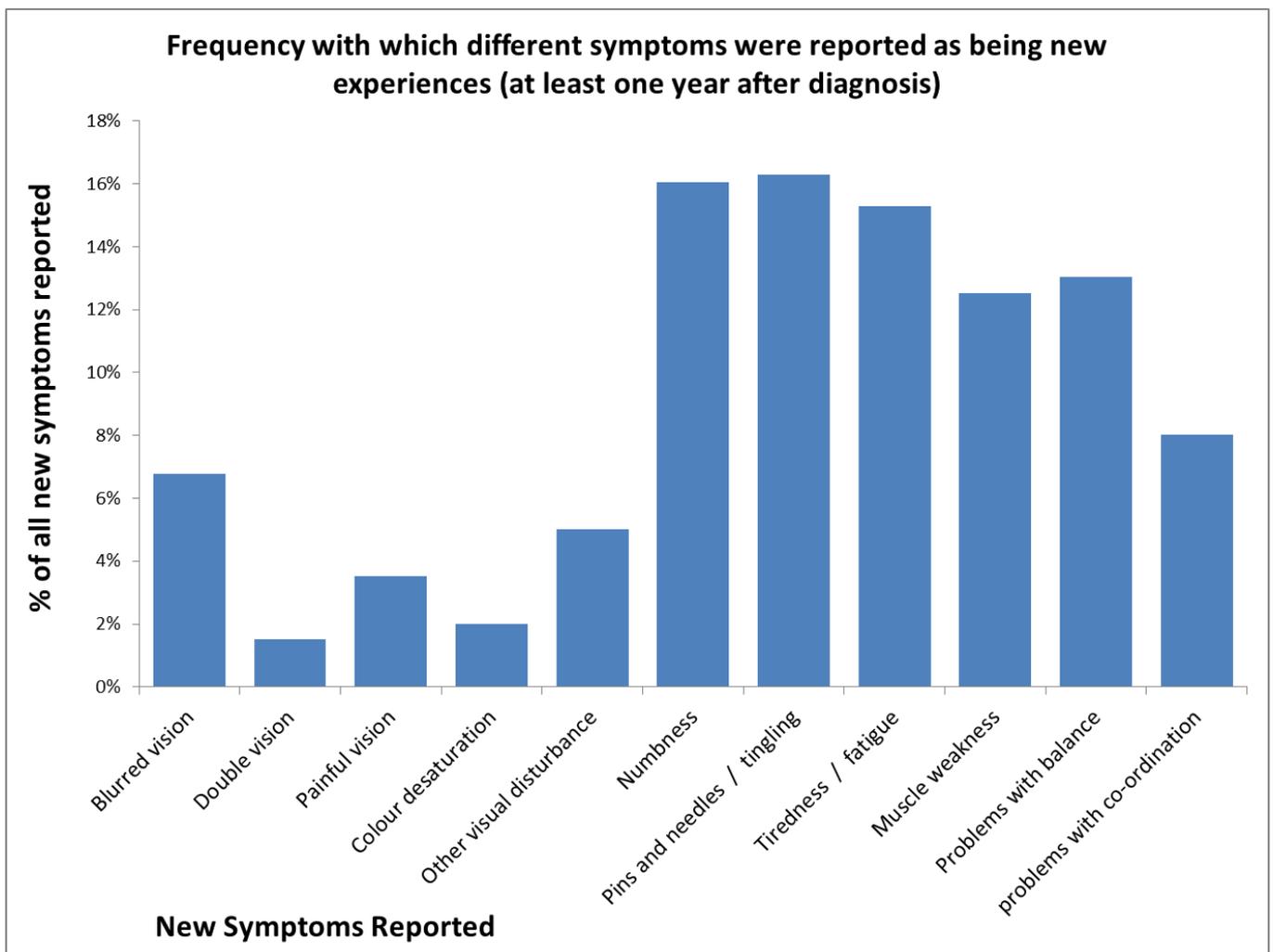
We have now looked at what you have told us about the occurrence of new symptoms: 66% of all CIS participants have reported experiencing at least one new symptom following diagnosis. Most people reported the new symptoms during the first two years after diagnosis although some new symptoms were reported up to 9 years after diagnosis.



Of those people reporting new symptoms, most (63%) only reported new symptoms in one particular year although a few individuals reported new symptoms occurring in five different years. Most reported between one to three new symptoms but a small group reported that they had experienced all of the listed symptoms.

Some people also reported new symptoms that were not included on the list including: headaches and pain and strange sensations such as crawling on skin.

The most frequently reported new symptoms were the same ones that were most often reported at diagnosis: Numbness and pins and needles closely followed by fatigue.



As we collect more information over the next few years we will be able to analyse the data properly and look for patterns that help to explain why different people have different experiences.

Future Organisation of SWIMS: SWIMS and the MS Register



SWIMS started 10 years ago with the aim of improving understanding of what it feels like to have CIS or MS. Participants have provided an amazing amount of information and many people have contributed to SWIMS for a long time but, we need to keep collecting more long-term information.

The MS Society has funded SWIMS for many years and also funds a project called the UK MS Register. Like SWIMS, the Register aims to advance understanding of CIS and MS and thus improve the treatment options for people with these conditions. Together, we have been discussing how SWIMS and the Register could collect information more efficiently and safely share some of their information with other researchers, including:

- sharing some of the costs of running SWIMS with the Register e.g. storing data securely at the MS Register (in Swansea) instead of here in Plymouth;
- improving our online booklets; and
- providing smaller SWIMS booklets to people in both projects because some questions are asked by both studies.



The UK MS Register collects data across the UK from people with MS and in future will start to collect information from people with CIS as well.

The Register has access to advanced computing techniques to securely collect, store and, in some cases, to link datasets.

The Register also supports researchers who wish to recruit and collect data for clinical trials and observational studies like SWIMS.

What does the Register do with the data?

As well as collecting information from their own participants the Register acts as a safe archive of other data. New electronic datasets can be added and sometimes may be linked to existing Register Data. Researchers can ask for access to combined data held by the Register in order to answer specific questions. No identifiable information is released, which means that the data are anonymous.

Plymouth, Truro and Exeter are due to become a clinical centres for the MS Register

Recently, neurologists at most hospitals in the South West have started working with the Register. This means that many MS patients will be asked by their neurologist to consider joining the MS Register and may also be asked to join SWIMS.

Since both projects collect similar information it is sensible to look at ways of working together.

More information about the Register can be found at:



<http://www.ukmsregister.org/Portal/Home>

email: contact@ukmsregister.org



[facebook.com/UKMSRegister](https://www.facebook.com/UKMSRegister)



Telephone: **01792 606354**



**UK MS Register, Institute of Life Science 2, College of Medicine,
Swansea University, Swansea, SA2 8PP**

How does this affect existing CIS participants in SWIMS?

We are looking at ways to:

- improve the security and efficiency of our data management by moving data to the Register;
- use the Register's technical expertise to improve SWIMS online questionnaires;
- link hospital data about a participant's CIS with information from SWIMS booklets e.g. collecting MRI scans results using methods developed by the Register; and
- ask participants if they are interested in helping other, different studies about CIS.

Your opinions matter to us and if you have any suggestions, comments or queries about the proposals, please do contact us



Email: swimsproject@plymouth.ac.uk



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



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Plymouth Science Park, Plymouth, PL6 8BX**

SWIMS Questionnaire Booklets

Every booklet is valuable

We know that completing our booklets takes time but we really do need everyone's help to collect as much data as possible. We genuinely 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 provide 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 and will stop sending them to you.

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 but we really do value your contribution: your information is crucial to helping us understand the impact of CIS and why a few people with CIS will later be diagnosed with MS.

SWIMS Public and Participant Involvement (PPI) Group

In Spring 2014, twenty people agreed to join our new Participant and Public Involvement Group to help shape the SWIMS Project in future. During 2015 they helped us to decide which analyses should be given the highest priority. We hope that in 2016 this new PPI Group will help us consider plans for SWIMS to work with the UK MS Register.

The SWIMS PPI Group is open to anyone who is interested in CIS/MS and the SWIMS Project. From time to time we ask members for their opinions and may in future invite them to attend discussions. There is however, no commitment for members to remain in the group or participate in activities.

If you, or anyone you know, would like to be involved please contact the SWIMS office for more details.

Contact the SWIMS Team



Email: swimsproject@plymouth.ac.uk



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



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To visit our website go to:

http://research.psmd.plymouth.ac.uk/cnrg/swims_newsletters.php