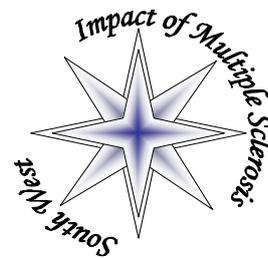


# SWIMS News



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

## Spring 2012 Progress Report

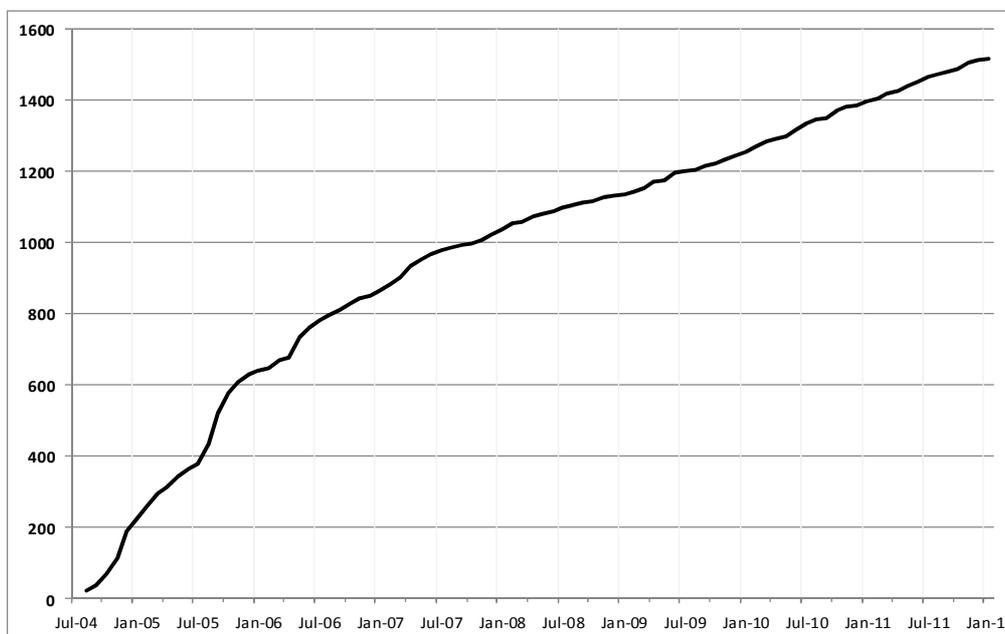
“The SWIMS Project will do three things. It will enable us to (1) understand what it is like to have MS or CIS, (2) improve the way that changes in MS symptoms and disability are measured—a vital step forward for the testing of new and emerging treatments for MS, and (3) predict what will happen to individuals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

**We would like to welcome those of you who have recently joined the project. There has been a surge of new recruits from North Devon lately and we are delighted that you have decided to take part!**

By the end of January 2012 over 1,500 people with MS or CIS had consented to take part (shown below). Some of you have now completed over seven years, which is very much appreciated so we thank you for your contribution to date.

In this issue we include more of your frequently asked questions. Also we have some information about a new clinical trial in secondary progressive MS that is taking place in our department, and currently recruiting volunteers to take part. In addition there’s a summary of some other research projects taking place in Devon and Cornwall that might interest you.

Lastly we have some news about changes to our institution.



## Your frequently asked questions

### *SWIMS is for people who have relapses and I don't, so it's not relevant to me.*

The first five pages of the questionnaire booklet are indeed about relapses. If you do not have relapses you can let us know by answering 'no' to the very first question in the booklet — 'Have you had any relapses in the last 6 months?' We would like to stress that this is not just a project for people who are experiencing relapses. **Everyone with a diagnosis of clinically isolated syndrome or MS is very important to this research, regardless of the type of MS.** From page 6 onwards in the questionnaire booklet there are questions that do not focus on relapses.

### *Why do you ask the same questions each time, in each questionnaire?*

One of the aims of SWIMS is to track changes in MS over time (changes due to relapses or due to general progression). 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.

There's no doubt that for some of you 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.

In an ideal world the questions would be tailored to individual participants. We would leave out any questions that we are 100% certain do not apply to an individual (based on previous answers) but we are not in a position to offer this format at the moment.

## Research Opportunities in Devon and Cornwall

**We know that taking part in SWIMS takes up some of your valuable time and energy; however, we are letting you know about studies that are taking place in case you are interested in participating in additional research.**

### *Clinical Neurology Research Group, Peninsula College of Medicine and Dentistry*

We are now recruiting to a clinical trial for people with **secondary progressive MS**. The trial medication is intravenous, with half the participants receiving a placebo. The treatment will happen at Derriford Hospital, Plymouth, plus clinics at the Tamar Science Park, Plymouth. We can't say whether you will be eligible to take part until we have done various tests and taken blood samples from you. However, to be considered for participation you will:

- be aged 18-58 inclusive
- have had secondary progressive MS for two years or more
- be able to walk (with or without sticks/crutches)
- not have been treated with Tysabri or Campath



If you would like further information about this study, or you would like to register your interest in taking part in clinical trials for people with MS, please contact Marie Roy (research nurse) on **01752 315261** or [marie.roy@nhs.net](mailto:marie.roy@nhs.net).

## Research Opportunities continued

### Balance and Mobility Study

Esther Fox (physiotherapist) is currently running a multi-centre clinical trial investigating different types of physiotherapy exercise for people with mobility and balance difficulties. Esther is looking for people who are experiencing mild to moderate difficulties with balance and mobility, and who are not currently participating in another clinical trial, to take part. If you are aged **over 18 years**, are **able to walk independently with or without a walking aid** such as a stick, and **have not had a relapse within the past three months** you may be eligible to participate in this study. For this research, **it does not matter what type of MS** you have.

The study will require your involvement for 16 weeks in total. You will participate in one-to-one exercise sessions with a physiotherapist over a 12 week period, during which time you will also be asked to undertake a home exercise programme. Over this time you will also be required to undergo three assessment sessions, involving tests of your balance and mobility. Your travel expenses for attending these sessions will be reimbursed.

If you would like further information please feel free to call Esther Fox on **01752 587599** or email [esther.fox@plymouth.ac.uk](mailto:esther.fox@plymouth.ac.uk)

### Falls in MS Project

This project is being run by Hilary Gunn (physiotherapist), and aims to identify the risk factors associated with falls in all types of MS. We have had an excellent response to our request for participants, and only need 15 more volunteers to reach our target of 150 people! Anyone who is **able to walk without assistance from another person** is eligible to participate, **regardless of whether you fall or not**.

Participating in the project involves attending a hospital **local to you** on a one-off basis for an assessment, followed by recording any falls you may have in a simple diary for twelve weeks. We are really keen to reach our 150 participant target, so please feel free to contact Hilary if you are interested in getting involved.

Hilary can be contacted on **01752 588825**, or email [hilary.gunn100@plymouth.ac.uk](mailto:hilary.gunn100@plymouth.ac.uk).

**PHYSIOTHERAPY  
WITH  
PLYMOUTH  
UNIVERSITY**

## *A word about our institution*

You may be aware that the Peninsula College of Medicine and Dentistry (from which the SWIMS Project is run) is a joint college between the Universities of Exeter and Plymouth. Well, this is set to change. You might have heard on the local news that each of the two universities will have its own medical school, and the joint college will no longer exist.

These changes will not affect the running of the SWIMS Project at all. SWIMS remains a study of 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.

The medical school at the University of Plymouth is to be called 'Plymouth University Peninsula Schools of Medicine and Dentistry', whereas the medical school at the University of Exeter will be the 'University of Exeter Medical School'.

The SWIMS Project team will remain at our current location in Plymouth, attached to the University of Plymouth, and as such your questionnaires will eventually display a new 'Plymouth' logo.

If you have any questions about this matter, or any other SWIMS-related issue then please do contact us. We will be happy to discuss things with you.

**WITH  
PLYMOUTH  
UNIVERSITY  
PENINSULA**  
SCHOOLS OF MEDICINE & DENTISTRY

---

**SWIMS Project Coordinating Office, Room N16, ITTC Building, Tamar Science Park, Plymouth, PL6 8BX**

Email: [swimsproject@pms.ac.uk](mailto:swimsproject@pms.ac.uk)

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

To visit our website go to [www.pcmd.ac.uk/cnrg](http://www.pcmd.ac.uk/cnrg)

