

SWIMS NEWS



ISSUE 1 / September 2005

Welcome!

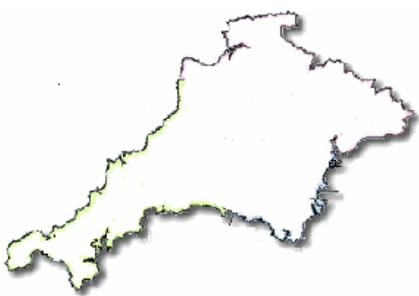
Welcome to the first issue of **SWIMS NEWS!** The SWIMS Project has now been running for one year and we have issued this Newsletter to keep you informed of the progress of the project and to highlight issues which may be of interest to you.

Who are we?

The SWIMS Project team is based at the Tamar Science Park, adjacent to Derriford Hospital in Plymouth. We are part of a wider research community at the Peninsula Medical School, working to improve the knowledge of disease processes and treatments.

A reminder about what the SWIMS Project is all about

What is the SWIMS Project? Studies which gather information about how a disease begins and then changes over time are known as *natural history studies*.



The SWIMS Project is a natural history study of MS in the South West peninsula, aiming to gather vital information about MS *from the point of view of those with MS*. The project commenced in August 2004 and is expected to run for ten years.

Why is this research being done? In order to develop better treatments for MS, a detailed understanding of how MS affects those with the condition is required. In other words, researchers will only be able to assess the usefulness of new treatments (especially those aimed at changing the course of the disease) if there is a good understanding of how MS progresses over time.

What does the project involve? The SWIMS Project takes a fresh approach to MS natural history studies by asking people with MS themselves about changes in their MS over time, rather than relying on an examination of the patient by a doctor. This is achieved using questionnaire booklets which are designed to be completed by participants and which cover a range of issues relating to MS and the impact of MS on everyday life. The advantage of using patient-focused information is that a much more detailed and meaningful picture of MS can be built up. This is *not* a clinical trial, and the project does *not* involve any extra visits to the GP or hospital.

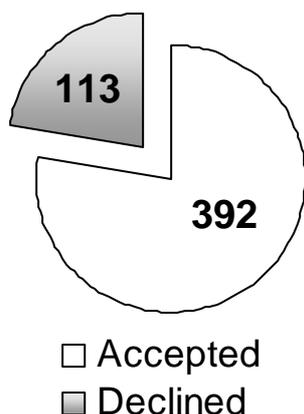
Why do this research in the South West? The project is a geographical natural history study, meaning that the study is performed within a defined population, i.e. the residents of Devon and Cornwall. This is an ideal area in which to perform natural history studies because it's such a nice place to live people don't move away much! This makes staying in contact with the MS population over a long time more achievable. Another advantage is that people living in towns and in the country are both well represented, making it easier to apply the findings to the MS population in other areas of the UK.

SWIMS progress - the beginning...

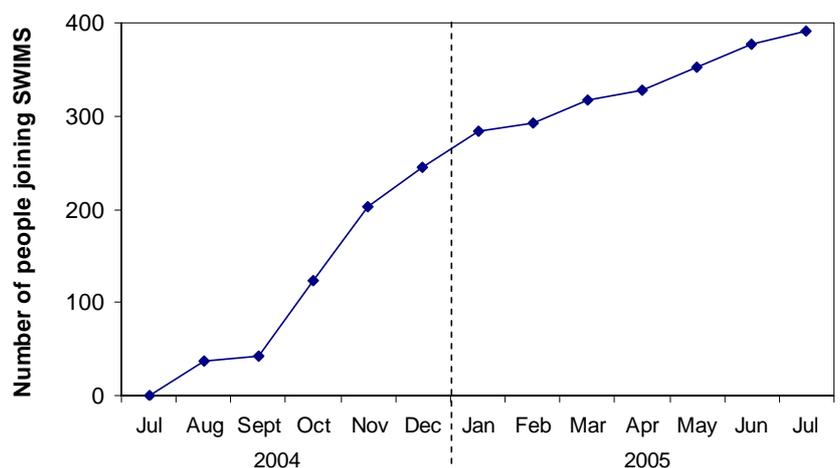
We commenced the project in August 2004. Between August 2004 and July 2005, over 500 people with MS have been invited to join the SWIMS project. As shown below, about three quarters of you were happy to participate, and we thank you all for taking the time and effort to help us.

Number of participants

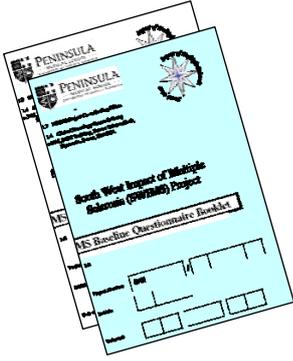
(July 2005)



Cumulative Recruitment



SWIMS progress - where are we now?



Of all the questionnaires that have been sent out to participants, **over 90%** have been completed and returned to us. This is a **FANTASTIC** response rate and, again, we are grateful for your contribution.

Your questionnaires are already generating useful data on how MS impacts on everyday life. As a starting point we have analysed data from the first 200 questionnaires that we received back from SWIMS participants. We found that on average MS was diagnosed about **4 years** after the first symptom appeared (although this ranged from 1 month to 35 years), and that **half** of the participants had experienced at least one relapse during the previous year. The most commonly reported symptom was **fatigue** followed by **poor balance** and **muscle weakness**.

We have been able to do a detailed analysis of how well some of the rating scales used in MS perform. For example, we've found that the "*Fatigue Impact Scale*" does not actually measure fatigue in MS very well, whereas the "*General Health Questionnaire*" provides a good way of rating the general wellbeing of people with MS. Later this year we will be presenting these findings at MS conferences in Torquay and Thessaloniki, Greece.

Future plans

- To give us a more complete picture of the impact of MS on everyday life, we want to ensure that we involve as many people with MS as possible. The more participants we have on board the better, so we have submitted a request to the Research Ethics Committees for permission to expand the project to Cornwall and the rest of Devon.

Perhaps you could also help us boost numbers by mentioning the SWIMS Project to other people you think might be interested in taking part?

- It is very important that we understand why people may NOT want to take part in this project, and this is something that we would like to investigate in the future. Once we have identified the reasons that might prevent people from taking part in the project, we will try to address these issues. In this way we hope to improve the design of the SWIMS Project, and our other questionnaire-based studies.

Just a reminder!



SWIMS Project Questionnaire Booklets are sent to you every 6 months. The first booklet is the longest. You will be pleased to know the rest are shorter and, in due course, we may be able to reduce the length of these further.

New appointment

Tracey Jones-Hughes will take over as project coordinator from Wendy Ingram, who will shortly be starting maternity leave. For your information, we have listed the people you may have contact with during the course of the project.

Professor John Zajicek

Principal Investigator for Plymouth area

Dr Jeremy Hobart

Principal Investigator for Torbay area

Dr Wendy Ingram

Dr Tracey Jones-Hughes

Project Coordinator

Suzi Reilly

Senior Research Nurse

Sue Varley and Mark Warner

Data Team

Jane Vickery

Neurology Trials Coordinator

If you have any comments on the project or on **SWIMS NEWS** please do not hesitate to contact us.

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