

SWIMS Participant and Public Involvement (PPI) Group

In Spring 2014 fourteen people generously agreed to join our new Participant and Public Involvement Group to help shape the SWIMS Project in future.

Our aim in 2014 was to find out which research questions were considered to be important to the Group. Whilst not everyone agreed on the exact order of importance, this is how the Group ranked the possible research questions.

Priority (1=highest)	Proposed research questions
1	Can we use the information collected for SWIMS to provide guidance on when to seriously consider taking disease modifying treatments ?
2	Which groups of questions in the SWIMS booklets are most useful to show that someone has worsened?
3	Which questions in the SWIMS booklets are most useful to model disease
4	Are there groups of symptoms that indicate a worse prognosis?
5	Can we predict someone's likely health state in a few years time or do we need to collect more data (same for longer or different data)?
6	Do changes in an individual's answers to questions in the SWIMS booklets reflect mood or the disease course?
7	Do we have to ask so many questions in the booklets, or can some be used as proxies for others?

The Group also told us their opinions on MS research more generally. The most popular ideas were:

- Researching non-pharmacological treatments for MS and alternative therapies (e.g. acupuncture, cognitive behaviour therapy, functional electrical stimulation).
- Improving treatment of common MS symptoms, especially fatigue.
- More research and information on Vitamin D.
- Finding a treatment for progressive MS .

During 2015 we hope the PPI Group will help us consider plans for long-term funding to support SWIMS. This will include looking at ways for SWIMS to work much more closely with a project called the UK MS Register—a plan that is discussed on the next few pages.

The SWIMS PPI Group is open to anyone who is interested in MS and the SWIMS Project. If you, or anyone you know, would like to be involved please contact the SWIMS office (SWIMS contact details are on page 6).

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 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 been a loyal supporter of SWIMS for many years. Ultimately we all want to advance understanding of MS and through this improve the treatment options for people with the condition. Together with the MS Society we have been discussing how we could collect information more efficiently and how we could safely share some of that information with other researchers.

We now have an opportunity to work more closely with another research project funded by the MS Society: **the UK MS Register**. It will take several months to fully explore the practicalities and implications of such a partnership but potentially it may mean that:

- Information provided by SWIMS participants would be stored on secure servers at the MS Register in Swansea (instead of at the University of Plymouth);
- the cost of funding the SWIMS Project would be reduced by sharing some costs with the Register;
- participants who take part in both projects would probably be able to complete smaller booklets because some questions are common to both projects.
- The online questionnaires will be improved.

We are talking to the MS Register team and in particular are focusing on data security and sharing data.



The UK MS Register is funded by the MS Society and collects data across the UK to help understand the impact of MS on people with the condition, on social care and on the NHS.

The Register has access to advanced computing techniques to securely collect, store and link datasets, and this is a powerful tool for researchers. The Register also provides a support service for researchers who wish to recruit people and collect data for clinical trials and other studies. For example, researchers in Glasgow were able to test a new questionnaire about self-catheterisation very quickly using this service.

Future Organisation of SWIMS: What is the MS Register?

What do UK MS Register participants do?

The Register is open to anyone in the UK over the age of 18 with a confirmed diagnosis of MS. Participants complete regular online questionnaires and some are also asked to allow their clinical information to be collected. Over 10,000 people have so far completed online questionnaires. From time to time, the Register may contact participants and invite them to participate in other research projects.

What does the Register do with the data?

As well as collecting information from participants the Register is designed to act as a safe archive of other data. New electronic datasets can be added and may be linked in a secure way to existing Register data. Researchers can apply to analyse combined data held by the Register in order to answer specific questions about MS. No identifiable information is released, which means that the data is anonymous.

Plymouth is due to become a clinical centre for the MS Register

During 2015, neurologists at Derriford Hospital are planning to start working with the MS Register. This means that, with the patient's consent, neurologists will contribute clinical information (e.g. MRI data) to the Register. The Register already works with several clinical sites around the country. By standardising the information collected across different clinical centres, a valuable pool of information will be available to researchers, and this is a great development for MS research in the UK.

People attending MS clinics at Derriford Hospital are therefore likely to be asked to join both SWIMS and the Register. Since we know that some similar information is collected for both projects it seems sensible to look at ways of sharing that information between the two projects where appropriate.

More information about the UK MS 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 participants in SWIMS?

Discussions with the MS Society and the Register are in the early stages and it will take us some time to discuss all the practical options that are available.

Your opinion matters to us. At the end of this newsletter we have included a survey to obtain feedback from SWIMS participants. This survey is entirely optional and any responses will be used for guidance only.

Later in the year we should be able to provide you with more details. If you have any queries about the proposals please do not hesitate to contact us:



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



email: swimsproject@plymouth.ac.uk



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ITTC Building 1,
Plymouth Science Park,
Plymouth,
PL6 8BX

Messages from the SWIMS Team:

Every booklet counts!

Although we know that it can take quite a bit of time and effort to complete SWIMS booklets we really do need everyone's help to collect as much information as possible. Our recent review of the information we have collected so far shows us that we really do need to collect more so that the results represent everyone with MS and can accurately reflect the long-term effects of MS.

If you have stopped returning booklets recently please consider completing the next one; we 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.

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

Online questionnaires: frequently asked questions

Why do I get an “Internal Server Error 500” message when I get to the end of the booklet?

Each year a few participants encounter an error message when they submit the final page of their online booklets, usually stating an “Internal server problem.” We are trying to fix this problem but please rest assured that no information has been lost.

The information from each page is saved to our system once you click on “Submit” at the end of that page. The computer then navigates to a new page. At the end of the booklet, you should be taken to a “Thank You” page but it appears that this link does not always work. We apologise for this and for the concern it has caused. Please ignore the error message and be reassured that all information has been saved.

Why do I get an error message when entering dates?

This problem often occurs on the questions about relapses. Most dates can only be entered in the format: mm/yyyy — the month (as a number) followed by the year.

e.g. 20th September 2009 would be entered as 09/2009

If you type in too many numbers by including a day, an “Internal Server” message will appear. Just go back and then type in the date again in the correct format.

Why does the “Forgotten Password” link not work?

Usually people only have problems with this link if they have changed their email address and forgotten to tell us. We send your password to the email address that you have provided, so please make sure we have the most current email address for you.



Oculomotor Pilot Therapy for Improving Movement of the EYES in Multiple Sclerosis

Do you have Progressive Multiple Sclerosis and difficulties with tremor and in-coordination?

Researchers based at Plymouth University are investigating whether a home based program of eye movement training can improve people's control of their arm, walking and balancing.

Problems with the control of eye movements, inco-ordination and balance are common in people with progressive MS. This work will look at how these may be linked and, by participating in a month long course, how people with MS could manage their balance and inco-ordination by 're-training' eye movement. The work could lead to a new, effective way of managing the symptoms of progressive MS.

The study is one of 22 projects that have been funded in nine countries across the world by the Progressive MS Alliance which is an international collaboration committed to finding effective ways of treating progressive forms of the condition.

Professor Jonathan Marsden, Professor and Chair in Rehabilitation at Plymouth University's Faculty of Health & Human Sciences, will lead this one year study.

If you would like further information on this study please contact Professor Jon Marsden:



Email: Jonathan.marsden@plymouth.ac.uk



Telephone: 01752 587 590



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Plymouth, PL6 8BH



Standing at home with the help of a standing frame:

Is this a useful intervention for people with progressive multiple sclerosis?



Do you find yourself spending much of your day sitting down, either because of difficulties with your standing balance, or other issues such as weakness, spasms or fatigue? All of these symptoms can make standing for any length of time very challenging.

Researchers at Plymouth University are undertaking a study which will involve people with progressive MS from across the South West and East Anglia, to see whether using a standing frame at home may help people with standing balance and walking difficulties improve their health and well being. The study is looking for 70 volunteers living in the South West to participate in this study.

To be able to participate, at best you will be able to walk up to 20 metres using 2 sticks, elbow crutches or a walking frame. If you are not able to stand up by yourself it is still likely that you can still participate in this study.

You will need to have the agreement of someone, such as a family member, who is happy to help you get into the standing frame if this is too difficult for you to achieve by yourself.

Finally you will need to be able to keep the frame in your home so that you can stand in it three times a week.

The Chief Investigator is Dr Jenny Freeman (Associate Professor in Physiotherapy and Rehabilitation) and the Study Co-ordinator is Esther Fox at Plymouth University.

If you are interested in this study, or have any questions you would like to ask about it, please contact Esther Fox:



Telephone: 01752 588835



Email: SUMSstudy@plymouth.ac.uk



WEBPaMS: Web-Based Physiotherapy for People Affected by MS

Do you find it difficult to exercise regularly even though you know that exercising can help you stay as fit and active as possible?

Do issues such as availability of transport, living in a rural location, being at work or struggling with fatigue make it difficult to access exercise opportunities?

Would a home-based exercise programme individually designed for you by a physiotherapist help you to exercise regularly?

Researchers based at Plymouth University are undertaking a multi-centre research study, funded by the MS Society, in England and Scotland. This study will investigate the effectiveness of two different types of exercise programme to help you to continue to exercise in the long term. The two programmes are an internet-based exercise programme and a standard written exercise programme.

The study is looking for 30 volunteers with MS living in the South West. To be eligible to take part you should be known to a Plymouth Neurologist, have access to the internet and email, not already be taking part in exercise more than once a week and have some difficulty with your walking.

If you would like to find out more about the study or are interested in taking part we would like to hear from you.

Please contact Rachel Dennett (Research Physiotherapist):



Telephone: 01752 587571



E-mail: rachel.dennett@plymouth.ac.uk

New studies seeking recruits: Research at Exeter



The MS Research team at the Royal Devon and Exeter Hospital comprises Dr Timothy Harrower and nurses Sarah Irvine and Gail Hayes. The team works closely with Lou Jarrett, Clinical Nurse Specialist, to make sure patients get the best possible treatment available for them.

At Exeter we remain extremely active and have a wide variety of studies running e.g.

- We are successfully recruiting patients to a **Fampridine** study.
- **Tecfidera** is now available on prescription and we have a long term observation study looking at the effectiveness of this drug.

We are also hoping later this year to start up a study for those with **primary progressive MS** and another one for those with **secondary progressive MS**.

As before we would like to thank all our patients for their time and energy and the whole neurology team for their commitment to provide high quality research.

Please do contact either Sarah Irvine or Gail Hayes if you would like further information:



Telephone: **01392 406979**

New studies seeking recruits: Research at Plymouth



Research nurses Marie Roy and Ali Anderson at Derriford are currently recruiting people with both **Relapsing Remitting MS** and **Progressive forms of MS** for trials and would welcome enquiries from anyone interested.



Usually clinics are held at either Derriford Hospital or the Plymouth Science Park (near the hospital) and travel expenses are reimbursed.

Marie and Ali are always keen to hear from people interested in taking part in local MS research and, with permission, will keep a record of those who might be interested. This allows them to quickly identify those who wish to be notified about new trials recruiting people with MS.

If you are interested in taking part in trials at Derriford Hospital please contact Marie:



Telephone: **01752 431247**



Email: plh-tr.N7Research@nhs.net

SWIMS Project , Room N16, ITTC Building, Plymouth Science Park, Plymouth, PL6 8BX
Telephone: **0800 015 3430** (*free from most landlines*) or **01752 315246**
email: swimsproject@plymouth.ac.uk

SURVEY—PLEASE DETACH

What do you think about the SWIMS Project and MS Register working together ?

We would like to find out what you think of SWIMS working with the UK MS Register in future.

You do not have to answer any of these questions but we would be grateful for any ideas you would like to share with us. This survey is anonymous and does not commit you to any of the proposed changes.

If you do want to respond please complete the survey and return it in the enclosed FREEPOST envelope, or call the SWIMS office (10am-3pm) on 0800 015 3430, or email swimsproject@plymouth.ac.uk with your comments.

1 Would you be happy for the data collected by SWIMS to be moved from the University of Plymouth to the University of Swansea? (The data will be stored in a secure location)

Yes

No

Any comments?

2. Would you be happy for the MS Register to manage SWIMS data on behalf of the SWIMS team? *i.e. making sure that the booklets are sent out on time, that the data is entered correctly and that everyone's records are up to date. The SWIMS team in Plymouth team will still be available for queries as usual.*

Yes

No

Any comments?

3. Would you be interested in joining both SWIMS and the UK MS Register?

Yes No

If YES would you be happy for:

(a) the projects to share personal information? *e.g. names, addresses, to minimise the amount of correspondence you receive?*

Yes No

(b) the projects to share your answers when the same questionnaires are used by both projects? *(so that both studies do not have to ask you the same questions?)*

Yes No

Any comments?

4. Should we be actively contacting SWIMS participants and telling them about new MS research projects and clinical trials that are looking for recruits, if they are eligible?

Yes No

Any comments?

5. Is it reasonable for information from questionnaires to be combined with information obtained from health records elsewhere (e.g. MRI results, hospital admissions for relapses)?

Yes No

Any comments?

6. Some people have withdrawn from SWIMS and can no longer be contacted. Is it reasonable for information they have provided in questionnaires to be combined with information obtained from health records elsewhere (e.g. MRI results, hospital admissions for relapses)?

Yes No

Any Comments?

7. Should other MS researchers be able to use anonymous SWIMS data in their own studies of MS? (i.e. excluding anything that could be used to identify you)

Yes No

Any comments?

8. How should the SWIMS team keep people informed about proposed changes?

(Tick all that apply)

via the SWIMS newsletter
(approx. twice per year)

via a separate letter to each participant

via email

at a meeting in your local area

Other?

9. Would you be interested in joining a group to discuss what changes should be made to SWIMS?

Yes

No

(If Yes, please contact the SWIMS team)

Any comments?

Is there any other information that you think we should be providing or any other comments you would like to make?

Please return in the FREEPOST envelope

THANK YOU