There is lots of information about the SUMS study on the website below which is regularly updated:

https://www.plymouth.ac.uk/research/sums

We also have a twitter account! @SUMSstudy
We are tweeting regular updates and photos to raise awareness of the study – follow us to find out more!

Study summary

To date, 105 people have finished the study; this includes 46 completed final assessments and 8 withdrawals in the South West, and 49 completed final assessments and 2 withdrawals in East Anglia. Our final participants are due to finish by the end of December 2017, when analysis of the results will begin.

The SUMS study is investigating whether regular use of a standing frame at home is beneficial to people with progressive MS. It has recruited participants from all of the Healthcare Trusts in Devon, Cornwall and Norfolk and Suffolk. This study provides therapists and people with MS the opportunity to find out how standing frames might impact on a range of issues that are known to be important to people with progressive MS, such as movement, function, bladder and bowel control, and quality of life. Understanding this is important so that people with MS can make informed judgements as to whether they wish to participate in a standing programme, and so that therapists, commissioners, and policy makers can understand the benefits that this may bring to patients. We look forward to continuing our assessments with the people involved in the study over the coming months, and will keep you updated via our website, twitter and future newsletters.
How do we share data with participants?

People with multiple sclerosis involved in the SUMS study, have asked us whether it is possible to see the results of their assessments at the end of the study. This isn’t something we routinely do, but it has made us think about whether we should. We hope to work with a group of people with MS to hear their views. This will be an informal discussion group that will be held at the Peninsula Allied Health Centre, although we are happy to organise this at a second venue (South West or East Anglia) if there are lots of volunteers. The group will meet on Thursday 12th October 2017 at 10.30am for approximately 90 minutes. Travel expenses will be paid and we will make sure we bring some nice refreshments!

If you would like to share your views, please contact us by email at neuroresearch@plymouth.ac.uk or leave a message on our answerphone 01752 587599.

Raising awareness

We are continuing to raise awareness of the SUMS study through talks as part of some of the MS information days for people with MS and their carers throughout the South West.

<table>
<thead>
<tr>
<th>MS Information Days in Devon and Cornwall</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hear from local specialists including</strong></td>
</tr>
<tr>
<td>Neurologists</td>
</tr>
<tr>
<td>Physiotherapists</td>
</tr>
<tr>
<td>Therapists</td>
</tr>
<tr>
<td><strong>Find out what you can do to help yourself</strong></td>
</tr>
<tr>
<td><strong>Find out about local research/services:</strong></td>
</tr>
<tr>
<td>What is happening in your region?</td>
</tr>
<tr>
<td>SWIMS &amp; the UK MS Register: how the projects are changing and what that means for you</td>
</tr>
</tbody>
</table>

**Where**
- Barnstaple: Roundswell Community Centre
- St Austell: Merlin Centre

**When**
- Saturday 9 Sept 2017
  - 11:00 – 16:00
- Saturday 11 Nov 2017
  - 10:00 – 16:00

**Book a space**
- Tel: 01752 315246
- 0800 015 3430 (free from most landlines)
- email: swimsproject@plymouth.ac.uk

**Places are free and lunch/refreshments provided**
Information for Health Professionals

Wendy is talking about posture and positioning at the MS Trust Conference in November 2017. Check out the MS Trust website for further information about this fantastic conference; including information on applying for a bursary to help with funding.
https://www.mstrust.org.uk/event/ms-trust-2017-conference-0

In June we presented our SUMS poster at the European Neurological Convention, EdExcel in London and at the Plymouth University School of Health Professions research conference.

Any problems?

It is really important to address any issues such as backache or knee pain when using the standing frame; often simple adjustments can make all the difference. Check out the information leaflets we have available on our website for helpful hints and tips on achieving a comfortable position.
https://www.plymouth.ac.uk/research/sums

What height?

We have had a few therapists ask about the correct height of frame to order for people. Please download our helpful guide via this link;

Meet the Team

If you would like any further information about the study, please get in contact with us.

South West Contact Details

Jenny Freeman
Tel. 01752 587599 or 01752 588835
Email. SUMSstudy@plymouth.ac.uk
or jenny.freeman@plymouth.ac.uk
Post: Jenny Freeman, Peninsula Allied Health Centre
Plymouth University, Derriford Rd, Plymouth PL6 8BH

Rachel Dennett

Carol Lunn

Norfolk and Suffolk Contact Details

Wendy Hendrie
Tel: (01603) 488561
Email: mscentrenorwich.wendyhendrie@gmail.com
Post: Wendy Hendrie, MS Centre Norwich, Delft Way, Norwich NR6 6BB

Stephen Hooley

Newsletter September 2017