Enhancing Physical Activity and Quality of Life in People with Severe Physical Disability: Could Standing Frame Programmes Help?

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RESEARCH WITH PLYMOUTH UNIVERSITY

SUMS
STANDING UP IN PEOPLE WITH MULTIPLE SCLEROSIS

Outline of talk

- Related to people with MS
- Why increase physical activity?
- What's the evidence for standing programmes?
- Our research: The SUMS Study

Could Standing Frame Programmes Help?

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Lowered physical activity level

Physical activity and multiple sclerosis: a meta

Robert W Motl, Edward McAuley and*
Department of Kinesiology, University of

Using meta

Key words
bliographies of the
m 13 studies with 2360 MS
eighted mean ES was heterogenous,
measures of physical activity, nondiseased
s. The cumulative evidence suggests that individuals
ulations.

The cumulative evidence suggests that people with MS are less physically active than non- diseased populations.

Inactivity worse when:

- using objective versus self report measures
- progressive > relapse remit

Mult. S

Cavanagh et al 2011 , Sandroff et al 2012, Rietberg et al 2014

ACRM
AMERICAN CONGRESS OF REHABILITATION MEDICINE

Archives of Physical Medicine and Rehabilitation

journal homepage: www.archives-pmr.org

Archives of Physical Medicine and Rehabilitation 2013;94:1829-36

SPECIAL COMMUNICATION

Development of Evidence-Informed Physical Activity Guidelines for Adults With Multiple Sclerosis

Amy E. Latimer-Cheung, PhD,[a] Kathleen A. Martin Ginis, PhD,[b] Audrey L. Hicks, PhD,[b] Robert W. Motl, PhD,[c] Lara A. Pilutti, PhD,[b,c] Mary Duggan,[d] Garry Wheeler, PhD,[e] Ravin Persad, BASc,[f] Karen M. Smith, MD[g,h]

Canadian Physical Activity Guidelines and Canadian Sedentary Behaviour Guidelines

www.csep.ca/guidelines

Use the links below to download or order the Canadian Physical Activity Guidelines and Canadian Sedentary Behaviour Guidelines info sheets and related resources. For more information and background on the Canadian Physical Activity Guidelines and Canadian Sedentary Behaviour Guidelines, please visit the Background Information page.

Link to page: Canadian Physical Activity Guidelines for Adults with Multiple Sclerosis

Canadian Physical Activity Guidelines for Adults with Multiple Sclerosis

Guidelines Info Sheet	UPDATED! September 2013 Guidelines for MS Toolkit	UPDATED! September 2013 Toolkit Insert
SUMMARY OF THE Canadian Physical Activity Guidelines	MSGETFIT TOOLKIT	MSGETFIT TOOLKIT

NICE National Institute for Health and Care Excellence

Multiple sclerosis

management of multiple sclerosis in primary and secondary care

Issued: October 2014

NICE clinical guideline 186

Freeman&Gear/MSTrust/2015

Guideline Recommendations:
for people with mild to moderate MS

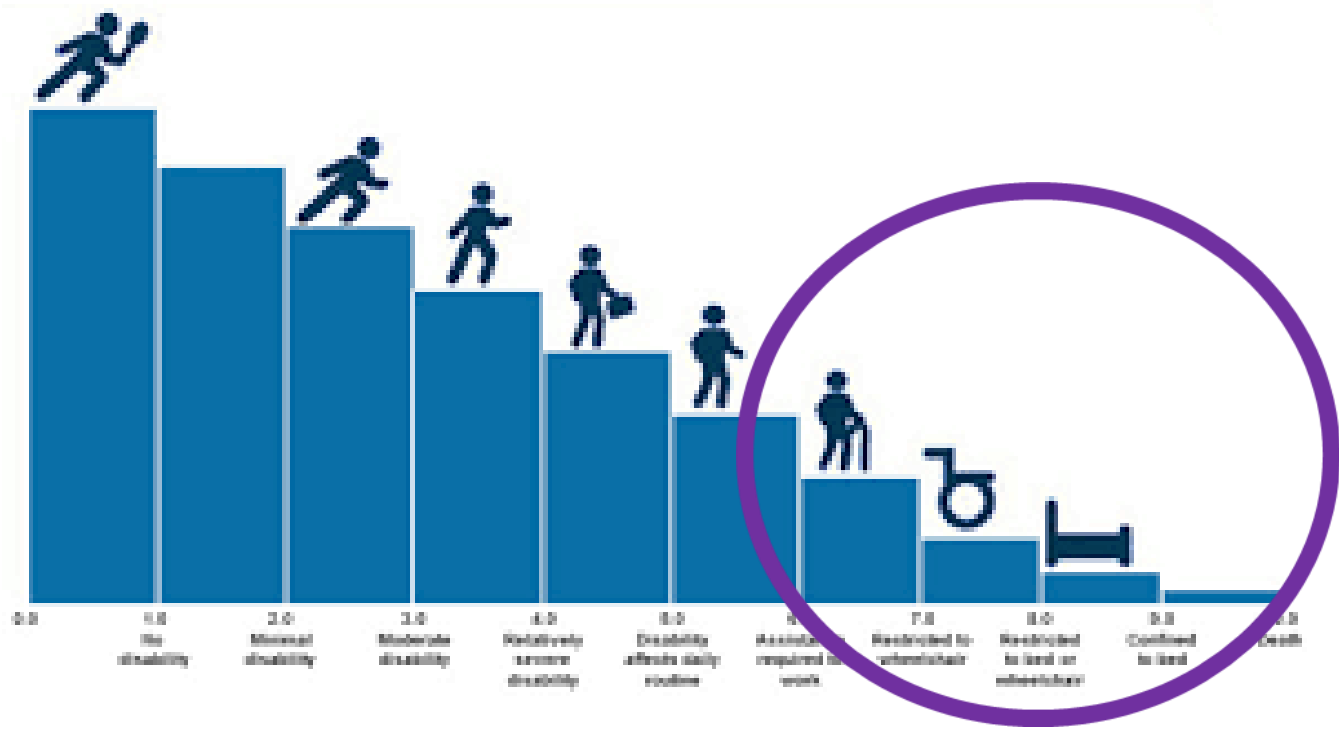
Resistance Exercise:
2x/week
moderate intensity (60-80% 1RM,
10 – 15 repetitions, 1-3 sets) minimum 8 weeks

Aerobic Exercise:
2-3/week
mod intensity (60-80% max HR) 30 minutes
minimum 4 weeks

Natural History of MS

An estimated:

- 66% move to a progressive phase within 8 years
- 50% are unable to walk unaided in 15 years
- 25% will become dependent on a wheelchair:
  - Difficulty changing positions
  - Maintaining activity levels



Relative dearth of evidence in those with: progressive forms of MS severe disability (> EDSS 6.5)

Progressive multiple sclerosis 2

Treatment of progressive multiple sclerosis: what works, what does not, and what is needed

Anthony Feinstein, Jenny Freeman, Albert C Lo

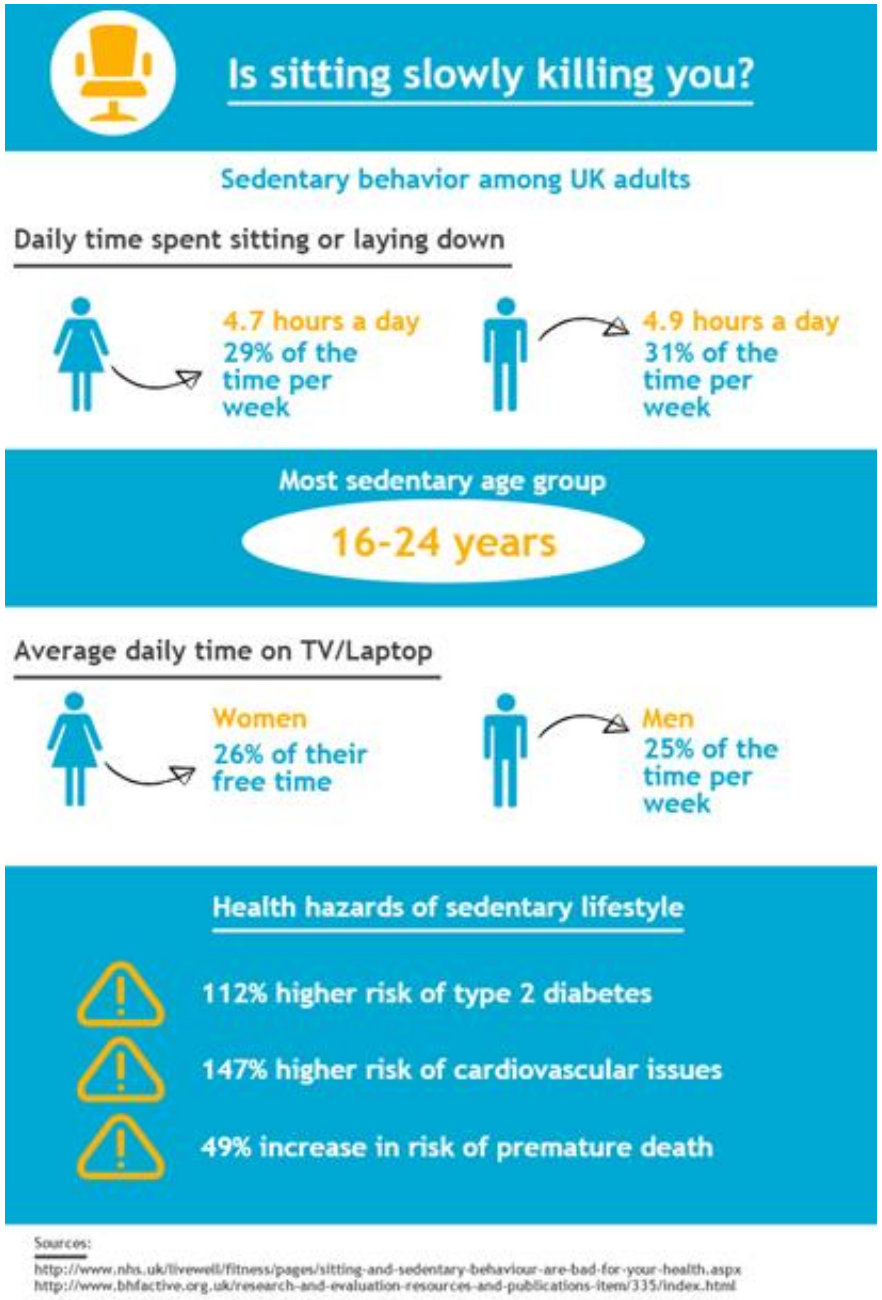
Lancet Neurol 2015; 14: 194–207

See Comment pages 132 and 133

This is the second in a Series of three papers about progressive multiple sclerosis

Sunnybrook Health Sciences Centre, University of Toronto, Toronto, ON, Canada (Prof A Feinstein MD); Faculty of Health and Human Sciences, Plymouth University, Plymouth, UK (J Freeman PhD);

Disease-modifying drugs have mostly failed as treatments for progressive multiple sclerosis. Management of the disease therefore solely aims to minimise symptoms and, if possible, improve function. The degree to which this approach is based on empirical data derived from studies of progressive disease or whether treatment decisions are based on what is known about relapsing-remitting disease remains unclear. Symptoms rated as important by patients with multiple sclerosis include balance and mobility impairments, weakness, reduced cardiovascular fitness, ataxia, fatigue, bladder dysfunction, spasticity, pain, cognitive deficits, depression, and pseudobulbar affect; a comprehensive literature search shows a notable paucity of studies devoted solely to these symptoms in progressive multiple sclerosis, which translates to few proven therapeutic options in the clinic. A new strategy that can be used in future rehabilitation trials is therefore needed, with the adoption of approaches that look beyond single interventions to concurrent, potentially synergistic, treatments that maximise what remains of neural plasticity in patients with progressive multiple sclerosis.



Regardless of time spent in formal exercise, spending prolonged periods in sitting can contribute to premature morbidity and mortality

In people with MS ….

↑ incidence of:

- Osteoporosis (Cosman 1998, Dobson 2013), and associated fractures (Bhattacharya 2014)
- Depression (Zorzon et al 2001)
- Fatigue (Petajan & White 1999)
- Cardiovascular diseases (Bronnum-Hansen 2004, Jadidi 2013, Motl 2011)

There is:

- ↓ aerobic capacity (maximal O2 consumption) (Mostert et al 2002)
- ↓ muscle activation, mass and strength (Dalgas 2008)
- conflicting info re ↑ resting HR, ↑ diastolic blood pressure (Anema et al 1991, Pepin et al 1996)

Co-morbidities are higher in those in the progressive phase of the disease (Marrie 2010, 2013 2015; Simpson 2014)

Impact of prolonged sitting in MS

25% of people with MS spend much of their day sitting

↓

2° complications (potentially reversible)

Physical problems

Weakness, pain, spasms, muscle / joint stiffness, constipation, chest infections

Psychosocial problems

Depression
Lower self esteem
Self identity issues

↓ quality of life [5]

Significant economic costs:

- ~ 15% of pwMS develop pressure sores (costs of a single sore range from £1,064 (grade 1) to £24,214 (grade 4)[6].
- Average cost per wheelchair dependent patient is 4–5 times > ambulatory patient[7].
- Significant ↑ in emergency hospital admissions in people with progressive neurological disability, including MS.

Managing these issues is a key goal of therapists:

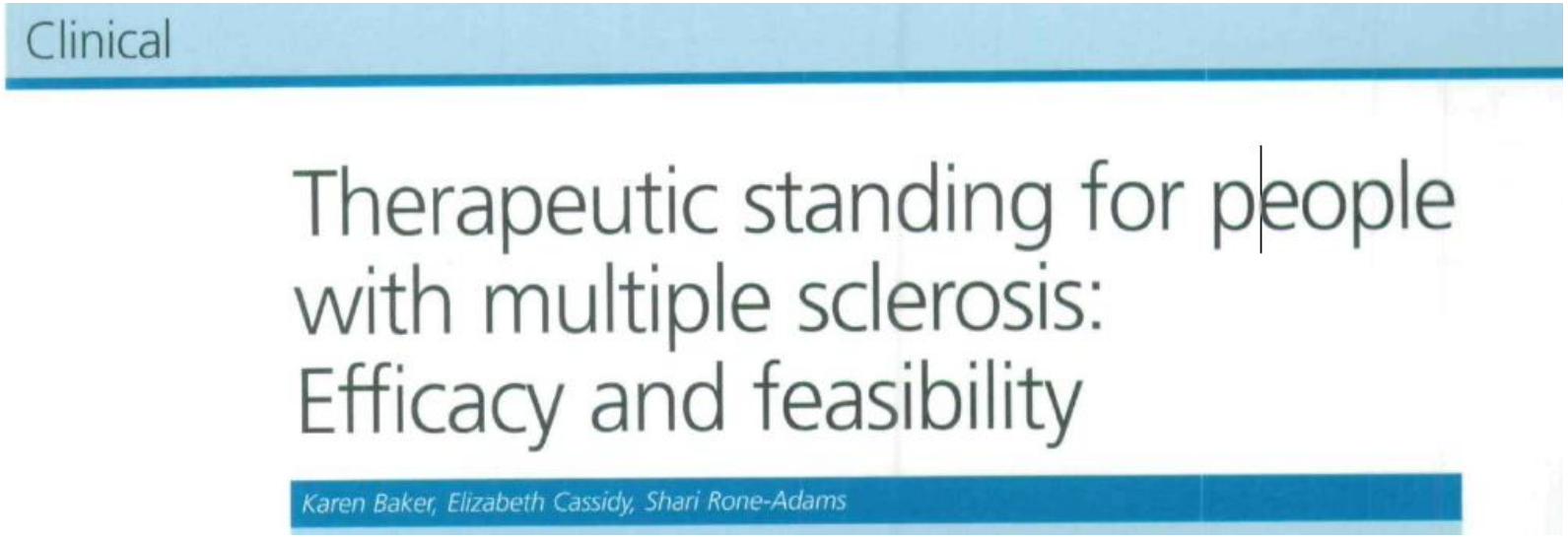
But….

- How difficult is it to achieve this in people who have precarious balance / difficulty walking to go to local gyms or exercise classes?
- Do you struggle with designing exercise programmes to suit their needs?
- How easy is it for people to undertake the exercises you prescribe them?
- Do they/ their carers struggle undertaking them regularly and over the long term?
- How much time is spent sitting down?
- …..even when they are exercising!

Effective self-management strategies are needed……. but challenging

Could use of a standing frame programme within a self-management programme at home be a potential option for addressing this?

What's the evidence? (1)


Clinical

Therapeutic standing for people with multiple sclerosis: Efficacy and feasibility

Karen Baker, Elizabeth Cassidy, Shari Rone-Adams

Baker et al (2007) Int J Ther Rehabil 14(3):104-9
Pilot cross-over pilot RCT
Home based standing 30 min/daily/3weeks versus exercise programme
Participants: n=6, >EDSS7.0, 2° progressive MS
Outcomes: spasticity, spasms, range of motion LL joints (0.3.6. weeks)
Results: in standing groups sig ↑ hip and ankle ROM ($p<0.05$) ; trend ↓ spasticity and spasms

What's the evidence? (2)

Disability and Rehabilitation
An international, multidisciplinary journal

http://informahealthcare.com/dre
ISSN 0963-8288 print/ISSN 1464-5165 online

Disabil Rehabil, Early Online: 1–8
 DOI: 10.3109/09638288.2014.957790

informa
healthcare

RESEARCH PAPER

A pilot mixed methods investigation of the use of Oswestry standing frames in the homes of nine people with severe multiple sclerosis

W. A. Hendrie[1], M. J. Watson[2], and M. A. McArthur[2]

[1]MS Centre, Iceni Court, Norwich, UK and [2]School of Allied Health Professionals, University of East Anglia, Norwich, UK

- Mixed-methods approach:
- 9 in-depth single case studies (ABC design)
- 6 women, 3 men; Using wheelchair as predominant means of mobility ; Able to be assisted into standing position
- Regular standing over 1 year, 30 minutes/ 3x weekly
- Stat. sig. improvements in strength, ADL, spasms ($p<0.05$) (but not pain, bowel frequency)
- Subjective improvements in continence, clonus and fall rate

Hendrie et al 2014: Qualitative component

Phenomenological perspective: lived experience of standing

In-depth interviews at three time points with 9 participants (n=27) over the year

Overarching findings:

The programme reinstated a sense of belonging and optimism by restoring important life roles, a sense of achievement and feelings of normality

Regaining Skills

"You feel as if you are doing something to make it better, you are more in control" (John)

Changed Body, Changed Mind

"When you are sitting you get shorter and shorter…but when you stand up you feel proud and great again…" (Frances)

Relationship Roles

"I know I can't go out much now, suddenly I can go up and I'm part of it anyway" (Louise)

Optimism for the Future

"When you stand and achieve things, the feel-good factor overspills emotionally and you start to feel good about other things, so you start to plan other things….." (Sue)

What's the evidence (3)

Disability and Rehabilitation: Assistive Technology, 2012; Early Online: 1–9

ISSN 1748-3107 print/ISSN 1748-3115 online
DOI: 10.3109/17483107.2012.678031

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ORIGINAL RESEARCH

On an equal footing: adults' accounts of the experience of using assistive devices for standing

Birgitta Nordström[1,2], Annika Näslund[2] & Lilly Ekenberg[1]

Aim: to illuminate the meaning that standing holds for persons who use standing devices
Approach: phenomenological/hermeneutical; in-depth interviews n = 15 (7 progr; ? n = MS)
All had been using standing devices (tilt tables, standing frames, standing wheelchairs) > 1yr
Overarching findings :

- the upright body position opens up an opportunity for connection to the outside world.
- has both physical and psychological benefits
- may be something that unites the body and self.

Alters the Person's Sense of Self

Standing creates the sensation of having a living body

It gives a feeling of the body being in training & standing, to do what one could for one's body.

"…but it becomes another thing, then I am not as insignificant… I become more like others, it is more normal."

Augments the Person's Availability to the Outside World

Standing opened up the sensation of independence and provided the opportunity to look at the world with new eyes.

'Oh is it here, at this height, that it all happens,' where I was before… nowadays you see everything from below. All of a sudden I was a normal person!

Strengthens Social Interplay

"I think that collaboration works better when one is standing up; it is obvious, when one is lying down… you can't collaborate…"

Changes a Person's Motivation and their Expectations over Time

Standing was a way to ensure that one's body would be able to cope with what the future would bring.

What's the evidence? (4)

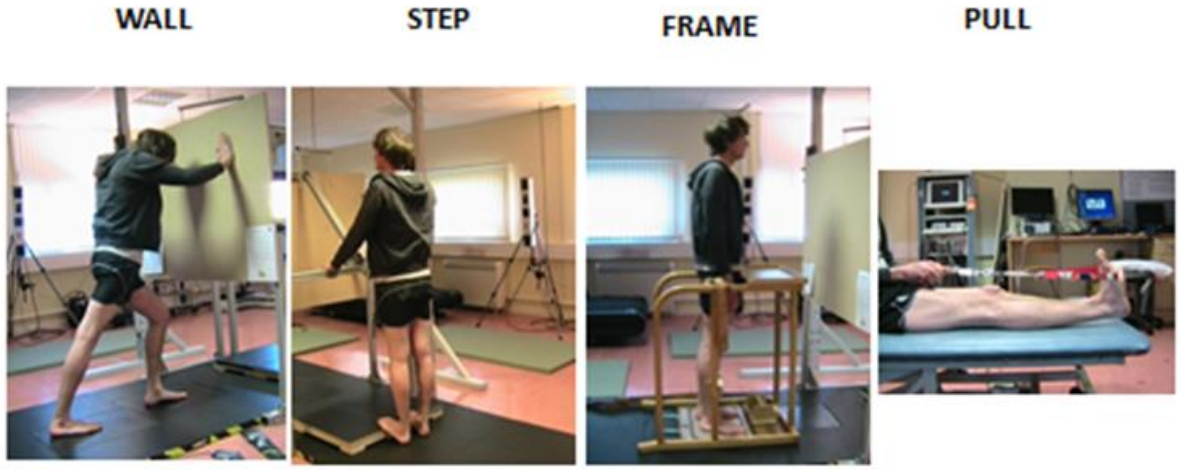
80% of pwMS have ↑ in muscle stiffness due to passive stiffness and/or spasticity.

<u>Methods</u>

- Lab-based study
- Joint position measured using 3D motion analysis
- Applied force by torque transducers.
- Slow (5o/s) & fast (170o/s) stretches applied via a motor to measure stiffness

Results: duration and magnitude of force required to ↓ stiffness in hypertonic LL muscles was only achieved in supported standing position with greater disability

Investigating 4 different Stretches



27 pwMS (EDSS 4.5-7.0) were compared to 15 age and gender matched controls.

Marsden, Ofori and Freeman 2013[9]

What's the evidence? (5)

The effect of supported standing in adults with upper motor neurone disorders: a systematic review

Meredith Newman and Karen Barker

Clinical Rehabilitation
26(12) 1059–1077

DOI: 10.1177/0269215512443373
cre.sagepub.com
SAGE

Static frames and tilt tables

Methodology:

- 17 RCT's (SCI, ABI, PD, CP, Stroke, MS)
- n = 540 participants, 73% non-ambulant
- One pilot RCT in MS (Baker [2007])

Newman et al 2012 : What were the effects of standing?

Outcome	Number of studies / 17	Improved Outcome
Spasticity	9/17	7/9
Range of Movement	7/17	5/7 *
Bowel function	7/17	5/5
Bladder function	4/17	4/4
Spasms	4/17	3/4
Weakness	2/17	2/2
Activities Daily Living	2/17	2/2
Posture	2/17	2/2
Respiration	2/17	2/2
Pressure Ulcers	2/17	2/2: 17% & 37% improved
Pain	1/17	32% improved

Conclusions: more robust evidence is required

SuMS
Standing Up in Multiple Sclerosis

A multi-centre randomised controlled trial to assess the effectiveness and cost effectiveness of a home-based self-management standing frame programme plus usual care versus usual care in people with progressive MS who have severely impaired balance and mobility.

Investigators: J Freeman (CI), W Hendrie, L Jarrett, A Barton,
S Creanor, A Hawton, J Marsden, J Zajicek

NHS
National Institute for Health Research

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STANDING UP IN PEOPLE WITH MULTIPLE SCLEROSIS

Aims of SUMS study

Primary aim

- to assess the clinical and cost effectiveness of the home-based standing frame programme plus usual care versus usual care

Secondary aim

- to qualitatively explore the impact of this programme from the perspective of the person with MS and their carer

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STANDING UP IN PEOPLE WITH MULTIPLE SCLEROSIS

Objectives of SUMS study

1. Assess clinical effectiveness in improving motor function (primary outcome) and quality of life.

2. Assess clinical effectiveness in improving balance, muscle strength, joint and muscle range, painful spasms, respiratory, bladder and bowel function, number of falls (secondary outcomes).

3. Establish cost effectiveness

4. Explore the subjective experience of using a standing frame within the home (pwMS and carer perspective).

SUMS Trial Design

- Pragmatic multi-centre RCT with blinded outcome assessment and full economic evaluation.

- 3 year study
- 140 people with progressive MS
- Standing programme over 20 weeks plus 16 week follow up
- Blinded assessments by research therapist at local centres: 0, 20, 36 weeks
- Audio diaries 20 people throughout study

Participant information sheet given to participant

Telephone screening to:
- Check entry criteria
- Arrange an appointment for assessment

Week 1
-Opportunity to ask questions
-Consent
-60 minute baseline assessment by independent assessor
-Random Allocation to intervention/ usual care group

Weeks 1 – 20
Standing Frame Group
-Standing Frame ordered and delivered
-Two NHS physio. sessions set up the standing programme
- Standing 3x weekly for 30 minutes (20 weeks)
- 6 telephone calls by physiotherapist to check progress
- Monitoring of adverse events
- Audio diaries (sub set)

Weeks 1 – 20
Usual Care Group
-Continue with usual physiotherapy and healthcare
- Monitoring of adverse events

Week 20
60 minute baseline assessment by independent assessor
Continue with usual care / standing programme

Week 36
60 minute baseline assessment by independent assessor
End of study

Fidelity Checking

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8 Study Centres

1. Torbay and Southern Devon Health and Care Trust
2. Northern Devon Trust
3. Livewell South West (nee Plymouth Community Health)
4. Royal Devon and Exeter NHS Trust
5. Cornwall Partnership NHS Foundation Trust (CFT) (nee Peninsula Community Health
6. Norfolk Community Health and Care Trust
7. Suffolk Community Health and Care Trust
8. East Coast Community Health Care CIC

Each site has on average seven teams involved in delivering physiotherapy within the community

SUMS: Where are we now?

As of 14.5.16
55 participants :

- 28 South west
- 27 East Anglia

SUMS Study Web-site
www.plymouth.ac.uk/research/sums

If you know of any other people with MS who may be interested in participating in this study, please do let us know.

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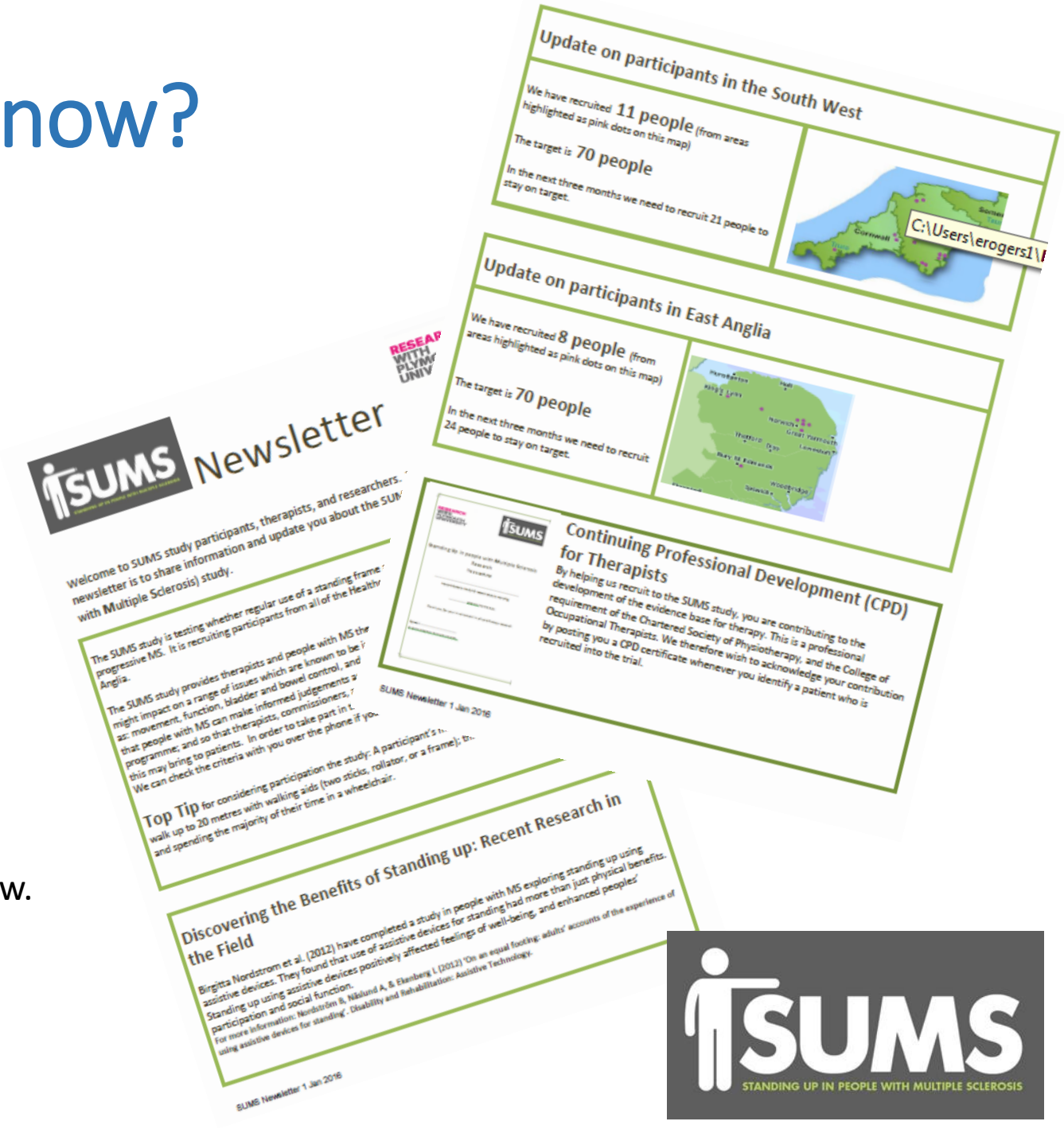

Summary

- People with progressive MS generally lead sedentary lives, and find it difficult to increase their activity levels. As physio's it can be very challenging supporting them to change this.
- Preliminary evidence suggests supported standing:
  - help to confirm and build a person's trust in his/her body and self
  - may have positive physical outcomes for people with progressive MS who have severely impaired balance and mobility
- No evidence to date looks at cost effectiveness
- Watch this space for more definitive evidence (2018) on the SUMS Study Web-site www.plymouth.ac.uk/research/sums

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Thank you for listening: any questions?

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