Spring/Summer 2013

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The use of Functional Electrical Stimulation in neurorehabilitation

Audit of the use of the Goal Attainment Scale

Sharing good practice: **Critical appraisal: what it is and why do we need it?**

National conference 2013

JOURNAL OF THE **ASSOCIATION OF CHARTERED PHYSIOTHERAPISTS IN NEUROLOGY**

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ACPIN'S AIMS

1. To promote and facilitate collaborative interaction between ACPIN members across all fields of practice including clinical, research and education.

2. To promote evidence informed practice and continuing professional development of ACPIN members by assisting in the exchange and dissemination of knowledge and ideas within the area of neurology.

3. To provide encouragement and support for members to participate in good quality research (with a diversity of methodologies) and evaluation of practice at all levels.

4. To maintain and continue to develop a reciprocal communication process with the Chartered Society of Physiotherapy on all issues related to neurology.

5. To foster and encourage collaborative working between ACPIN, other professional groups, related organisations ie third sector, government departments and members of the public.

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Forethought

From the Chair

Dr Gita Ramdharry
Senior Lecturer, St George's School of Rehabilitation Science, Faculty of Health and Social Care Sciences, St George's University, London, and Kingston University

As the dust settles after another ACPIN national conference, I've taken time to reflect on the words of our learned speakers.

On the first day we heard an excellent range of talks around the topic of community rehabilitation. Services, exercise, falls and patient involvement. A strong, key message was repeated about not just listening to the words of our patients, but making their thoughts, opinions and experiences at the centre of what we do. We heard great examples of how this has been done well in both research and service contexts. I certainly took away some valuable tips and lessons.

The second day focused on people with multiple sclerosis. We heard about opportunities, with exciting drug developments, rehabilitation research and inspiring accounts of sports participation. We also became aware of the challenges. Variations in local services, commissioning priorities and threats to disability benefits are already impacting. We are well placed to advocate for people with MS as individuals, but also as an organisation.

ACPIN is already planning ways to support members to have a say in local decisions and are also contributing to key national guidelines that future decisions on service provision may be based. Now is a crucial time for our individual and collective voices to be heard. Let us do what physiotherapists do best: speak up and get involved.

Change is in the air

A few words from the exiting ACPIN President

Dr Margaret Mayston
Senior Teaching Fellow, Division of Biosciences, Faculty of Life Sciences, University College London

It is officially the first day of spring. Spring not only signals change but it is also one of my favourite times of year – when possible I try and experience spring in this hemisphere and then a second one in September in the southern hemisphere. It is of course also the time of year when the ACPIN Conference and AGM takes place, including the change of executive and president (every four years).

It is hard to believe that I have been the ACPIN President for four years. One of the great things about the four year term of office is that the President has the pleasure of working with three different Chair people. All have displayed the range of '6-hat behaviours' that I talked about in my inaugural talk (de Bono 2004). I have seen three changes of Chair from the Jo Tuckey/Cherry Kilbride cooperative, followed by Siobhan MacAuley to the current Chair, Gita Ramdharry – each with their own dedicated and inspiring style of leadership, and each contributing to the further work of ACPIN. Each Chair has been presented with a challenge, risen to it and come out positively, ably supported by the terrific team of dedicated executive committee members and regional representatives. All do this work in their own time and with great enthusiasm. In these last four years there have been changes in the structure of ACPIN and CSP annual conferences, the professional networks, to say nothing of changes in the NHS and the down-banding of some therapists – there have been high times and not so high times.

As ACPIN goes from strength to strength, it seems it is well placed to meet the current vision of the CSP which is mindful of the need to develop a vision for the future. A few of these objectives are about leading and securing delivery of physiotherapy practice to make it fit for the future as well as expanding opportunities for physiotherapy to provide quality patient services across the UK. With its on-going programme of national and regional meetings, courses and lectures ACPIN is already in their stride as far as meeting these objectives is concerned.

It has been an immense privilege to work with this dedicated group of neurophysiotherapists and I will miss the spirited and informative meetings of the executive and regional representatives. I know that my successor Dr Fiona Jones will make a significant and valuable contribution to the future work of ACPIN over the next four years. Fiona is an excellent therapist, researcher, teacher and wonderfully warm person, who has made and will continue to make important contributions to the future work of ACPIN and neurophysiotherapy. I look forward to continuing to support ACPIN from the perimeter. It is also a time of personal change for me as I alter my work-life balance and explore more of what life can offer and what different contributions can be made. So back to the theme of spring – for both professional and personal reflection: spring cleaning (a review and reflection on what to leave behind and what to take into the future), emergence of new, and possibly the resurgence of dormant things (perhaps taking on new challenges and activities, and revisiting past ones) but most of all it is a celebration of colour and life. ACPIN as a group and ACPIN's conference logo this year is both of those things. Thank you all.

Five thoughts

from the incoming ACPIN President

Dr Fiona Jones
Reader in Rehabilitation, School of Rehabilitation Science, Faculty of Health and Social Care Sciences, St George's University, London, and Kingston University

Well, I am now the new president of ACPIN and still feeling immensely proud to have been asked. This is just a very brief reflection and summary of the address I made at our recent national conference. I promise to try and write something more riveting and thought provoking in subsequent issues. I hope I haven't set myself up for a fall now!

As homework for my presentation I decided I needed inspiration and did what many of us do when faced with a blank PowerPoint slide, and (after doing some on-line shopping) I searched the internet. I looked for inspiration from our previous ACPIN presidents and as I searched I became in awe of the successes and achievements of all of them; Sue Edwards – described by many as the 'mother of neuro', Sue Mawston, Margaret Mayston and Ray Tallis. I stopped looking when I read that Professor Tallis had been described as a 'polymath'; the fact that I had to look up what this meant did not really help my pursuit for inspiration. Eventually I settled on five thoughts as I had been given five minutes to speak by Gita, our Chair. This time restriction did help me and I am a firm believer in 'less can be more' sometimes. I recognised that the audience of ACPIN members may not necessarily know who I am, so I indulged myself a bit and spoke about the areas that had informed my practice, research and thinking.

The first thought that came to mind was the work of John Kitwood. His research on personhood and dementia has been pivotal to what I believe should inform the interactions with those people we are privileged to work alongside. He describes personhood as 'a standing or status bestowed upon one human being by others, in the context of relationship and social being. It implies recognition and respect and trust'. His work in dementia has been the inspiration for training and service development by the Alzheimer's Society and also informed strategy in dementia care across the UK. We could learn a lot from looking at his work in dementia; it will help us to retain our focus on 'the person' when we work with people with other neurological conditions.

My second thought was NICE as it had been finding a lot of space in my thoughts. Some of us were involved in a consultation on the revised *Stroke Rehabilitation Guidelines*, and to cut a long story short, it has been a difficult process. But it is so important that ACPIN makes its voice heard in these consultations. NICE guidance will be used to inform the new NHS commissioning Board which will in turn influence commissioning decisions in the new CCGs. So it is vital that we all get involved in these consultations if asked. We all know that most of NICE guidance is informed by the findings of randomised controlled trials and I can't help but suggest you have a look on the 'bad science' website for an alternative overview on research http://www.badscience.net/

Goal setting is a huge topic, and maybe one for a future debate but just to say that I spoke about my continuing aversion to SMART goals. When searching this area I came across another acronym I liked better 'DUMB'- which stands for Dangerously Unattainable Monstrously Big Goals. Intuitively I prefer this acronym, maybe because we have all set them, usually on January 1st. A good friend and colleague of mine told me she does it every time she takes a size 12 into the changing room, knowing full well

The new ACPIN President, Dr Fiona Jones.

she is a size 14! Joking aside I urge you to have a look at some of the research by Dr William Levack from Otago University in New Zealand. In one of his recent studies he explored goal setting in stroke rehabilitation. He identified the concept of 'privileged goals', which are those given greater priority by professionals, and not necessarily aligning to the person's own values or goals. William is coming to the UK this autumn and will be running a workshop supported by London ACPIN.

It could have been because I had two dogs at my feet when I was preparing my presentation – who knows? But my fourth thought was 'dogs', or more specifically the benefit they can bring for us in terms of participation and social interaction. I am ever more convinced that dogs are good for us – although I realise not everyone will share this view. But public health is a real growth area and rehabilitation providers are going to need to know their local population and deliver services that promote activity, participation and well-being (a tenuous link between dogs and rehabilitation I know). Nevertheless the new health and well-being boards will aim to bring together everyone from NHS commissioning groups to adult social care specialists, children's trusts and public health professionals to design local strategies for improving health and social care integration. More and more we are going to have to look beyond the medical model for our answers to public health problems. I think this is an exciting time for physiotherapists and we shouldn't be concerned about working with other exercise professionals, fitness instructors and the voluntary sector to devise new and creative ways to promote health and well-being. That brings me to a final thought about the potential benefits that can be had when we collaborate. My new interest is in 'co-production' which involves sharing our service design and delivery with different groups and in particular those people who are users of our services. There is a never-ending rhetoric in the press and government policy about the challenges faced as people live longer with a greater number of long-term conditions. But this also gives tremendous scope and opportunity for collaboration with service users and to use our specialist skills and experiences in Neurorehabilitation alongside different sectors and colleagues.

I am really looking forward to my tenure of president, and hope you will contact me with ideas and topics for future discussion. Enjoy the spring – when it comes!

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The use of Functional Electrical Stimulation in neurorehabilitation

experience in private practice

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Functional Electrical Stimulation (FES) is a well-established rehabilitation technique that involves using controlled pulses of electrical current to stimulate intact peripheral nerves. This can create muscle contractions in paralysed or weak muscles in clients presenting with upper motor neurone injuries in order to perform a functional activity.

We are a team of neurological FES specialist physiotherapists working in a private practice in Wimbledon Village. Our ethos is to help, enable, empower and enhance functional ability to maximise patients' potential. The majority of our clients have sustained a traumatic brain or spinal cord injury or have transverse myelitis(TM), multiple sclerosis(MS) or cerebral palsy(CP).

At Neurolink Physiotherapy, conventional neurophysiotherapy modalities are combined with innovative and pioneering technology. We pride ourselves on having a holistic approach to each client's rehabilitation, accessing greater client potential than using single modalities in isolation.

In 2005, we started to incorporate FES into our practice, initially using the Odstock Microstim unit, two-channel stimulator and the foot drop stimulator. However, we wanted to explore FES options that could recruit more than two muscle groups simultaneously for clients presenting with bilateral arm/leg paralysis or weakness and options for clients with upper motor neurone injuries.

In 2006, we started working with the Restorative Therapy equipment, namely the RT300 FES leg system. The clinical evidence emphasizes the use of this treatment for the spinal cord injury population, for both chronic and on-going rehabilitation, to promote recovery and as a means to prevent secondary complications associated with this pathology. An assessment, treatment and review service was offered for clients who purchased their own RT300 leg bikes.

A client using the RT300 Leg FES System.

In March 2011, we started to use the Stiwell Med 4 FES system for home programmes and clinical treatment sessions if more than two channels/muscle groups needed to be stimulated simultaneously or if the client would benefit from the use of EMG triggered stimulation.

A client using the Stiwell Med 4 FES system.

In September 2011, we expanded our clinical services to provide a wider range of FES treatments options which include the RT200, an elliptical arm and leg FES system and the RT600, a stand and stepping FES system.

BACKGROUND

There is a body of evidence to support the use of patterned FES cycling in rehabilitation. Some of the findings are outlined below.

1. Maintenance of musculature

Evidence has shown that clients presenting with spinal cord injuries require three 30 minute FES cycling sessions per week for optimal results to build muscle mass (Scold *et al.*, 2002). Scremin *et al* (1999) concluded that leg muscle volume increased 10% after six months of FES training in motor-complete tetraplegic spinal cord patients.

2. Maintenance of bone density

Frotzler *et al* (2008) concluded that high-volume FES-induced cycle training for five sessions a week of 60 minutes each could partially reverse bone loss and thus may reduce fracture risk. Trabecular and total bone mineral density (BMD) as well as the total cross sectional area in the distal femoral epiphysis increased significantly but no changes were seen at the tibia.

3. Muscle strength and cardiovascular training

Bremner *et al* (1992) showed that a programme of stimulation-induced lower limb exercise increased the exercise tolerance of all patients, as determined by a progressive increase in exercise time, cycling rate and exercise load. Increases in thigh muscle area and joint range of motion were recorded and all incomplete subjects reported an improvement in functional capabilities and general well-being.

4. Prevention of skin breakdown

Vanoncini *et al* (2010) concluded that stimulation of the erector spinae, on one side of the spine only, can induce a trunk rotation on the sagittal plane, which causes a change in the pressure distribution. The authors concluded that electrical stimulation of the trunk extensors can be a useful tool for pressure sore prevention.

5. Glucose tolerance

Griffin *et al* (2009) concluded that 30 minutes of FES cycling per day, three times a week, for 10 weeks significantly improved lean muscle mass, cycling power, work capacity, endurance, glucose tolerance, insulin levels, inflammatory measures, and motor and sensory neurological function. There were no significant differences in bone or adipose tissue.

6. Spasticity

Clients need to have three sessions of FES cycling weekly for a period of six to eight weeks before a reduction in spasticity is observed. Spasticity within the first few weeks increases and may have an impact on clients' functional ability eg transfers. (Krause *et al* 2008). However, an earlier paper showed that there was a significant reduction of spasticity after each stimulation session and concluded that stimulation could be another potential treatment modality for MS patients, especially those with a high score in the expanded disability status scale (Krause *et al* 2007).

7. CNS remyelination

McDonald *et al* (2002) concluded that patterned neural activity might help correct the dysmyelination and demyelination that contributes to functional deficits after SCI. Remyelination of axons that were stripped after injury requires optimal electrical activity in the nerve. The strongest evidence comes from the peripheral nervous system. Recovery in the adult CNS might also involve the production of new neural cells, particularly oligodendrocytes needed for remyelination. Although this mechanism of cell renewal is not well understood, recent work from several laboratories has shown that running can boost the production and survival of new brain cells.

CLINICAL EXPERIENCE

At our practice we offer all of these advanced FES technologies in a clinical rehabilitation setting. We have noticed how our clients with MS, TM and TBI have benefitted from using the RT200 arm and leg elliptical trainer alongside weekly neurophysiotherapy. The bike has enabled us to focus on stimulating and strengthening weak muscles in the upper limb (in particular those that can help reduce shoulder subluxation), core and lower limb simultaneously in a timed sequence for clients with a hemiparesis. This has provided cognitive stimulation during cycling as clients have to aim for a 50:50 balance between the affected and unaffected side. We have observed the increased cardiovascular benefits in clients presenting with MS, TM, TBI and spinal cord injury. For our ambulatory clients, we use the ten metre time walk, video analysis, modified Ashworth scale and the Berg Balance scale as our outcome measures. For wheelchair dependant clients we use the data and graphs available online through restorative therapy, the pulse oxymeter data available on the bike during each session, thigh measurements to determine muscle bulk gained and the modified Ashworth scale.

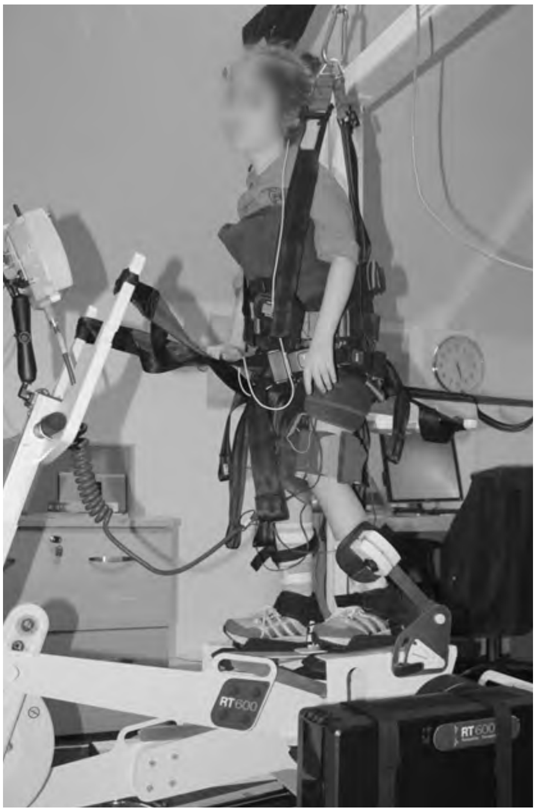
Our MS clients have reported that they have felt the benefits of the FES therapy for up to five days post treatment. Comparatively, these same clients have reported that the benefits of neurophysiotherapy alone were only felt for two to three days post treatment. They reported finding FES less fatiguing then neurophysiotherapy and feeling more re-energized afterwards.

The RT600 is currently the only stand and stepping FES system in the world. We are the first private clinic in the UK using this system with our clients on a daily basis. The system

A client using the RT200 Arm and Leg Elliptical FES System.

A client using the H200 Bioness Hand device.

combines partial weight bearing with standing and or stepping and FES. Over the past year we have been using this technology with clients who present with complete and incomplete paraplegia and tetraplegia including children over four years of age.



A client using the RT600 Stand and Stepping FES System.

As this is a new system, the evidence is currently being formulated; however we have observed and clients have reported that they have noticed improvements in their sitting and standing upper body balance.

We have recorded significant improvements using the RT600 demonstrating an increased weight bearing capacity in clients with a complete spinal cord injury. The lower limb weight bearing percentage range (scored out of 100% with 100% being full weight bearing) has increased from 15% to 40% over a period of six to nine months for clients. This has been achieved from once to twice weekly sessions lasting up to 60 minutes of standing and stepping. Additionally this trend also translates to our clients with incomplete spinal cord injuries; the percentage increase of weight bearing capacity ranging from 45% to 90% over a period of three to six months. Similarly this outcome was achieved from once or twice weekly sessions lasting up to 60 minutes of standing and stepping.

Our assessment and review of our clients using the RT600 once weekly have concluded that clients with incomplete SCI and TBI have had an increase in concentric and eccentric muscle control. This has been observed during walking and sitting down from a standing position post session.

We have also observed that clients with incomplete spinal cord injury and TM using the RT600 once weekly for 30-45 minutes have gained improvements in static and dynamic sitting balance as well as static standing balance and tolerance of standing.

The RT bikes use FES within a motorised pattern of movement and the evidence has shown that this is more beneficial than electrical stimulation provided in a static position. It is thought that the patterned movement might tap into central pattern generators although minimal research evidence is available to support this hypothesis.

In June 2012, we expanded our FES clinical range to include the Bioness H200 wireless hand FES device and the L300 foot drop wireless FES device which we incorporate and use in our assessment and treatment sessions with our clients..

The wireless L300 foot drop system and the wireless L300 Plus thigh system can be used in conjunction with the client's physiotherapy home and clinic sessions. The new L300 Plus system facilitates the stimulation of the weak thigh muscles in addition to using the L300 cuff to stimulate tibialis anterior. The timing of the stimulation is sequenced to the client's gait pattern.

The use of the L300 Plus components in neurophysiotherapy sessions has created opportunities for us to safely mobilise clients with some movement in their affected leg and to facilitate gait in clients presenting with hemiplegia sooner than conventional neurophysiotherapy. This has also helped clients to be able to tap into

A client walking using the Bioness L300 Plus system.

the motor and sensory feedback that the FES provides during standing and stepping.

Previously, clients with lower motor neurone lesions would not benefit from the standard FES set up. The evidence on the effectiveness of FES in lower motor neurone injuries was reported by K Hern *et al* (2010) in the RISE Project where they concluded that stimulation of denervated muscles is an effective home therapy that results in the rescue of muscle mass and tetanic contractibility. This is the next generation of FES treatment that we are starting to explore in order to provide a more holistic service for our clients presenting with lower motor neurone injuries.

Since June 2012, we have used the RT 300 leg bike with clients with lower motor neurone injury with a larger pulse width, and in November 2012 we introduced home electrical stimulation programmes with larger pulse widths using the Stiwell 4 units to stimulate the muscle instead of the peripheral nerve. Whilst there is minimal evidence for use of electrical stimulation in lower motor neurone injuries, analysis has shown that the stimulation has resulted in increasing muscle bulk therefore reducing the risk of skin breakdown and pressure ulcers. As no protocols and guidelines have been developed yet for lower motor neurone stimulation, we have implemented this treatment approach cautiously and with guidance from neuromodulation and FES specialists. To date we have observed positive gains made by our clients and will continue to collate clinical data. In the future, we would like to undertake a clinical study exploring whether functional electrical stimulation combined with a body weight support and stepping using the RT600 can increase bone density in the femur in complete spinal cord injury.

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An audit of the use of the Goal Attainment Scale

in patients seen by the community neuro team in Warrington

To assess that all patients seen between August 2011 and August 2012 by the community neuro team, if suitable for rehabilitation, have a holistic goal set by a member of the rehabilitation team. This is done by using the Goal Attainment Scale (GAS) as an outcome measure (Turner-Stokes 2009). The audit indicates those patients who have achieved their goal, those who have not and the reasons for not achieving.

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REASON FOR CARRYING OUT THE AUDIT

Measuring the effectiveness of community-based rehabilitation can often be challenging. Standardised outcome measures are difficult to apply due to the desired outcome from treatment being dependent on the patient's lifestyle and level of disability (Hurn *et al* 2006).

The *National Clinical Guideline for Stroke* (2008) recommends that those clients who are suitable for rehabilitation have a holistic goal set by the physiotherapist, occupational therapist and the team as a whole. The guidelines recommend the following:

- patients should participate in the process of setting goals
- goals should be meaningful and relevant
- both short-term and long-term targets should be included
- outcomes should be specific, time-bound and measurable
- family members should be included where appropriate

The guidelines state that goals can be used to guide and inform therapy and treatment. One way of quantifying treatment that meets these recommendations is through Goal Attainment Scaling. This audit reflects the results of an audit of the use of the Goal Attainment Scale (GAS) as an outcome measure within the community neuro team in Warrington.

Therapists within the community neuro team in Warrington use the GAS (*Appendix 1*) to record SMART goals for each patient. GAS is a tool used to quantify the attainment (or otherwise) of goals set (Turner-Stokes 2009). Each goal is patient led and is therefore patient centred. GAS is used to score the effectiveness of treatment, evaluate patient progress and is scored in a standardised way. Each goal is tailored to the patient's needs and the levels within the goal are set according to the patient's current and expected performance. Achievement of each goal is measured on a five-point scale ranging from -2 to +2, with a review date set to ensure the patient is meeting expected performance. Within the team the baseline of the patients seen was set at level -2 and Level 0 as the level the patient was expected to achieve. Levels +1 and +2 were interpreted as better than the expected outcome (Turner-Stokes 2010).

METHOD

Each goal that was completed for the patient was recorded using the goal sheet (*Appendix 1*). In order to record the information for the audit a GAS summary sheet was designed (*Appendix 2*) which summarises the information from the goal sheets. All patients referred to the community neuro team during the period between August 2011 and August 2012 were included in the audit. The audit was completed at quarterly intervals and included patients with a variety of neurological conditions such as MS, Parkinson's disease and stroke. During the screening of referrals, all patients were coded as either stroke or neuro. Each patient was assessed by a physiotherapist or occupational therapist, or both, as to whether on-going treatment was indicated and, if applicable, a goal was set after the second visit. Goals were discussed between the therapist, patient and carer as appropriate to ensure a patient-centred approach. For

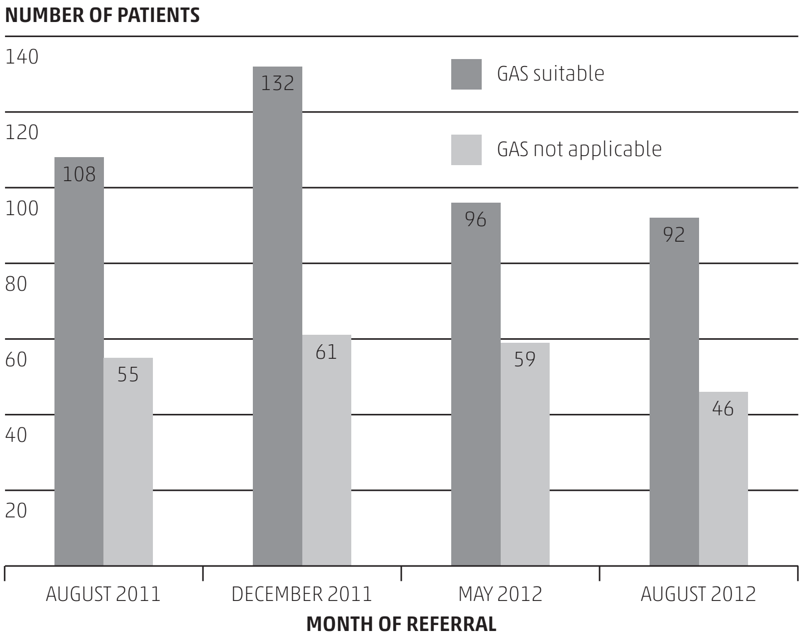

FIGURE 1

REASON FOR NON-TREATMENT	NUMBER OF PATIENTS
Admission to hospital	24
Inappropriate referral	27
Declined therapy	11

TABLE 1

those patients for whom further input from the service was not indicated, data and reasons why treatment was not appropriate was recorded. The category of stroke (*Appendix 2*) was determined by the Hospital team and only applied for those patients discharged from hospital with a stroke. At the review date, it was determined whether the patient had achieved their expected outcome, and needed a new goal set or whether they had reached a plateau in their potential and further goal setting was not applicable. For those patients who did not achieve level 0, codes were allocated which gave the reason why the goal was not achieved (*Appendix 2*). All data from the GAS summary sheet was inputted by a therapist within the team using a tool developed in Microsoft Access, designed by the clinical audit specialist. Once the data was inserted onto the electronic tool, the clinical audit specialist was informed and then analysed the data. The method for analysis of the data included:

- completion of a query in the access-based audit tool
- export of the data to Excel where further analysis was conducted using Pivot Tables
- analysis of data for all patients included in the audit period
- use of a comparison table, comparing each audit period

The clinical audit specialist then forwarded the results to the community neuro team for further interpretation and drawing of conclusions.

RESULTS

The following data was obtained from the audit:

- number of patients suitable for rehabilitation and goal planning
- diagnosis of those treated
- numbers of goals achieved and reasons if not achieved
- levels of achieved goals
- number of goals per patient

Patients were assessed as to their suitability for rehab and if further treatment was applicable (*Figure 1*).

The most common reason why GAS was not appropriate was due to on-going treatment not being indicated. Other reasons are shown in *Table 1*.

Referred patients were categorised as either Neuro diagnosis or stroke/TIA if a hospital discharge. Those patients who had an old stroke and were referred by a GP or other secondary care provider were counted separately. (*Figure 2*).

The number of goals set against the number of goals achieved level 0, +1 and +2 is summarised in *Table 2*.

A further summary of the number of goals set and the level achieved, including those that achieved below 0, can be seen in *Figure 3*.

Within the group that achieved below 0, the main reason was that the goal set was suitable but not achievable for the patient; this accounted for 47 patients. Other reasons for not achieving goals were non-compliance with treatment or the goal (29 patients). Two patients had a goal set that was not suitable for them resulting in another goal being set and 13 patients were too unwell for treatment or admitted to hospital.

To break down the goals further, the number of goals per patient was also audited. The results are seen in *Figure 4* (overleaf).

IMPLICATION FOR PRACTICE

Since implementation of GAS, the team has made many changes to its practice. The team meet regularly to discuss goals so that an MDT approach is taken and to ensure goals were suitable for each individual patient. This can often mean joint goal setting between occupational therapists and physiotherapists as well as individual goals from each professional. The rehab assistant and assistant practitioner within the team also write goals, therefore maximising the number of suitable goals per patient. By having a discussion within the MDT about the patient's goals, it helps to minimise inappropriate goal setting resulting in a poor outcome. By having a positive outcome and achieving level 0, this indicates that the team are successfully identifying the task the patient wants to work on and achieve. It also indicates the effectiveness of the service. To ensure more goals are set, prompts are given at weekly team meetings to ensure staff are reviewing patients and setting new goals when appropriate.

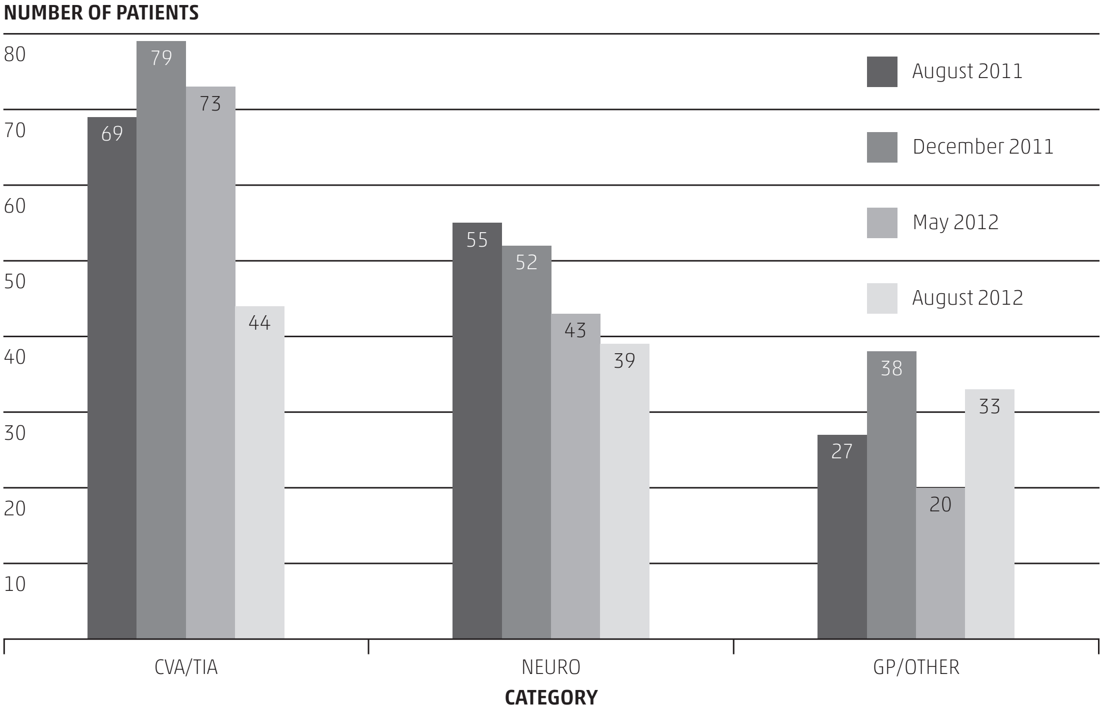

FIGURE 2

	AUGUST 2011	DECEMBER 2011	MAY 2012	AUGUST 2012
Set	169	176	152	144
Achieved	137	155	129	121

TABLE 2

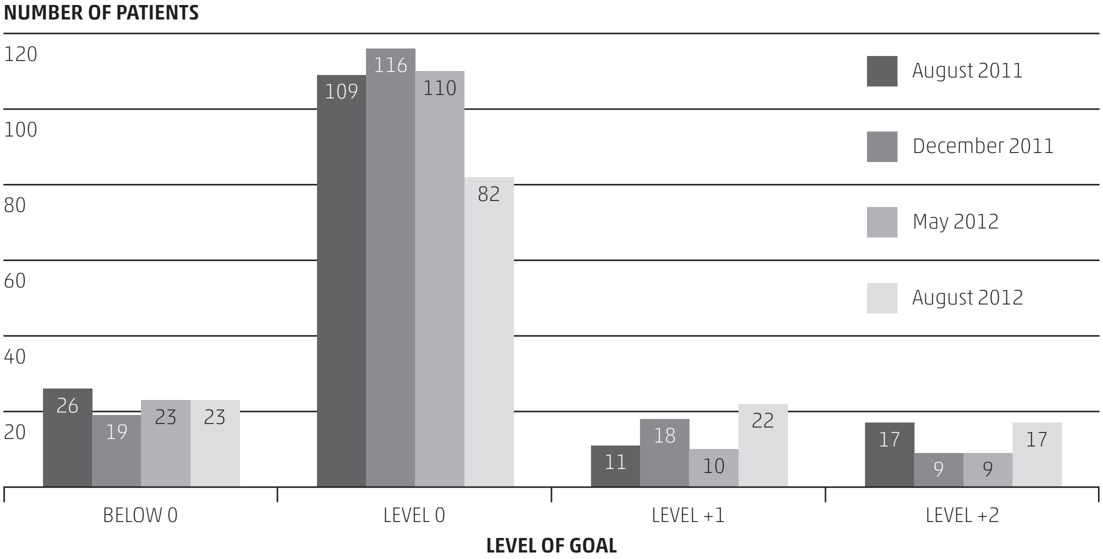

FIGURE 3

DISCUSSION

The Goal Attainment Scaling method allows for patient involvement and can ultimately lead to an improved outcome. By involving the patient from the start of their treatment it can encourage them to reach their goals and also allows for sharing of information and for more realistic goals to be set.

On initial assessment the therapist identifies whether rehabilitation is suitable. If more than two sessions are delivered, then rehab is deemed appropriate and a goal must be set. However, there are a large number of people for which goal setting is not appropriate. As the results indicate this can be due to many reasons; however, the audit indicated that this was mainly due to on-going treatment not being suitable for the patient. This can often be due to the fact that the patient's problems at the time of referral

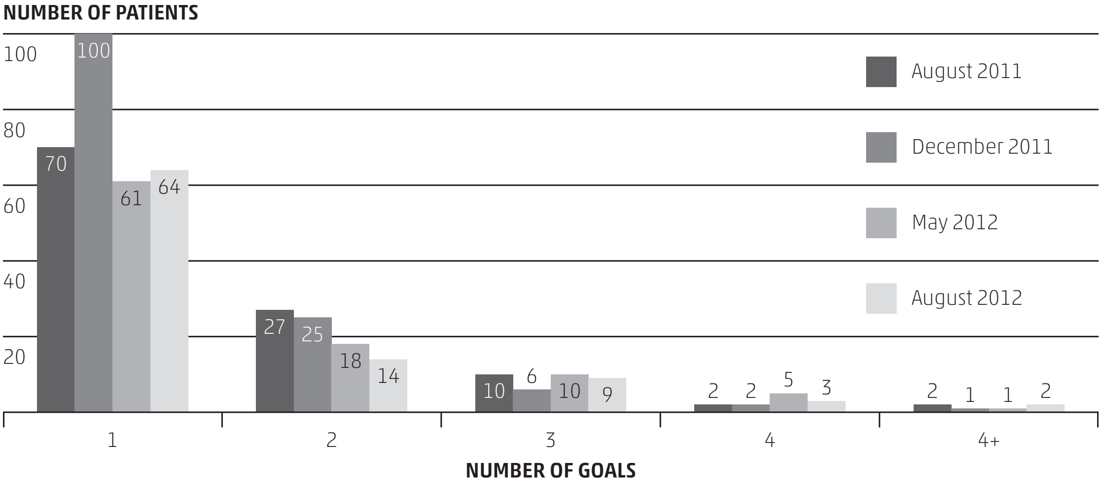

FIGURE 4

have resolved when the therapy assessment is undertaken. All patients who were suitable for rehabilitation had a goal set. The majority of patients achieved their set goal by achieving level 0. However, a large portion of goals were set but did not achieve level 0. Although this may be seen as a negative, GAS can also identify when patients have reached their rehabilitation potential and may be a good indicator for discharge.

This audit demonstrates that the GAS measures a clinically meaningful change in activity/participation in patients undergoing rehabilitation for disability caused by stroke or other neurological conditions. In such a diverse population of neurological problems, it provides a more sensitive measure of specific change than other measurement tools. It also allows for the comparison of outcomes whilst retaining individualised treatment goals. The Goal Attainment Scale displays evidence of being consistently more responsive when compared to more traditionally used outcome measures such as the FIM and the Brunel scale (Turner-Stokes 2009). Although all three measures showed statistically significant change, GAS captures more gains beyond the FIM and Brunel (Khan *et al* 2008). It can be a valuable adjunct to outcome measurement; however, it should still be used alongside other standardised assessment tools to ensure a comprehensive assessment.

GAS promotes collaborative goal setting between the patient and therapist (Hurn *et al* 2006). Should the goals that are set by the patient be considered unrealistic by the rehabilitation team, attempts are made to determine more achievable short-term goals that provide the basis for complex goals further into therapy. Within the neurological field, there is an identified need for a wider uptake of patient-determined goals to adequately focus on activities that have a meaningful outcome for the patient. It is hoped that by using patient-centred goals, favourable outcomes in mood, participation and perception of health-related quality of life will also be improved (Hurn *et al* 2006). The additional involvement of carers in the rehabilitation process may also lead to favorable patient outcomes, as well as reducing the emergence of carer burden.

CONCLUSION

Goal setting using GAS is a valuable tool in providing goals that are meaningful and relevant to the patient. It acts as a guide to inform treatment and can also be used to evaluate the outcome of therapy. It can be used as an indicator when therapy is no longer appropriate or of benefit to the patient and can be useful to indicate the rate of change. However, goal setting should always be used in conjunction with other standardised measures to ensure a comprehensive approach.

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APPENDIX 1

Goal sheet

Name:			
DOB:			
NHS number:			
Goal number:			
Goal level:	**Body function**	**Activity**	**Participation**
Date set:			
Review date:			
Achieved on:			

Problem identified:

+2
+1
0
-1
-2

Action Plan	By who	How often	By when

Patient signature	
Therapist signature	
Therapist name	

APPENDIX 2

Goal summary sheet

Name:	
DOB:	
NHS number:	

☐ GAS applicable
☐ Ongoing treatment not indicated
☐ Inappropriate referral
☐ Admitted to hospital
☐ Patient died
☐ Patient declined treatment

Stroke	**GP**	**Other**	**Not stated**

☐ Stroke cat 1
☐ Stroke cat 2
☐ Stroke cat 3
☐ Stroke cat 4
☐ Stroke cat 5
☐ TIA
☐ MND
☐ Parkinsons
☐ Neuro other

No	Level achieved	Code (if score is less than 0)

Code	Reason for not achieving level 0
1	Non-compliance with treatment/GAS
2	GAS set was not suitable
3	GAS set suitable but not achievable
4	Medically unwell for treatment
5	Admitted to hospital

Sharing good practice

Critical appraisal, what is it and why do we need it?

Reflections on a process

Monica Busse
Cardiff University

How does one decide the best possible intervention for a patient, particularly someone with a unique presentation or even a rare disease? Often, clinical guidelines (NICE 2011), which are evidence-based recommendations on the appropriate treatment and care of people with specific diseases and conditions, will be the first port of call for clinicians. They usually include systematically developed statements that are intended to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances (Woolf *et al* 1999).

Guidelines, however, are also dependant on rigorous development and subject to the same quality standards as individual research reports (Shaneyfelt *et al* 1999). Amongst a range of key quality indicators, guidelines should have a clear scope and purpose, whereby overarching objectives, health question and target population are clearly described. There should be a demonstrable, rigorous and systematic approach to selecting the evidence, so that the methods for formulating the recommendations are clear. To this end, The AGREE II Instrument (retrieved January 2013 from www.agreetrust.org) is a generic tool designed primarily to help guideline developers and users assess the methodological quality of guidelines. AGREE II can be used to assess the quality of guidelines, provide a methodological strategy for their development, and inform the content and delivery of information. But what should a clinician do if there are no accessible or acceptable clinical guidelines?

I was faced with exactly this issue seven years ago when I first began work with people with Huntington's Disease (HD). HD is a neurodegenerative disease that results in a disorder of movement, cognition and behaviour. The prevalence ranges from 6-14 per 100,000 (Walker FO 2007), which in comparison to stroke, Parkinson's disease and multiple sclerosis, can be considered a fairly rare disease. I recall one of the first times that I met a patient with HD. It was very clear to me that this person presented with impairments and related functional problems including being at significant risk for falls. Clearly, this was a clinical presentation that could be amenable to a structured physiotherapy intervention, but I was not aware of guidelines or indeed any large bodies of evidence defining the mobility deficits or the possible approaches that should be considered.

This interaction prompted me to look in the literature for evidence in support of physiotherapy for this population. I structured the review using a PICO approach. The PICO approach is very useful in helping to define your research question in that you define the **population** under investigation, the **intervention** of interest, what you would consider to be eligible **comparators** and what **outcomes** would be expected. Using a PICO approach facilitates a clearly defined search strategy and is an important component of the critical appraisal process. The PICO approach helps to create well focused questions and to define the inclusion criteria that then leads to a structured literature search.

Once I had identified literature that met my inclusion criteria, I needed to decide whether the studies that I had identified were of a sufficient quality. I also needed to be confident that the articles identified were from reliable sources, such as recognised scientific journals, and hence could be considered relatively unbiased. This was where my ability to critically appraise what I was reading became important. Based on my judgement of the literature, I could then decide what action, if any, could be implemented in my specific context.

Critical appraisal is the process of carefully and systematically examining research to judge its trustworthiness, and its value and relevance in a particular context (Burls A 2009). In order to be confident in appraising the literature, an understanding of different study designs is necessary. For example, studies can be either qualitative or quantitative in nature, both of which have advantages and disadvantages. Qualitative studies, such as participant observation, focus groups or interviews, are important in gathering information about perceptions, problems, beliefs and experiences. Quantitative studies, such as case control, cohort or randomised controlled trials provide numerical explanations for set observations. Systematic reviews and meta-analyses are secondary appraisals of primary studies that aim to synthesise the range of studies conducted on a specific topic.

Once you have determined the design, the Critical Appraisal Skills Programme (www.casp-uk.net (accessed January 2012) provides a range of checklists that can be used to aid the critique. For systematic reviews, the PRISMA statement is very helpful (www.prisma-statement.org (accessed January 2012)) and for randomised controlled trials the CONSORT statement should be visited (www.consort-statement.org (accessed January 2012)). Both of these are not critical appraisal tools, but rather standards that researchers need to adhere to when conducting and reporting trials, reviews and meta-analyses. A working knowledge of these statements is therefore advantageous to the critical appraisal process. Another extremely useful resource is the well-known, *How to read a paper* series by Trisha Greenhalgh (www.bmj.com/about-bmj/resources-readers/publications/how-read-paper (accessed January

2012). This series is exceptionally good as it gives a clear step-by-step approach to assessing different designs and includes understandable statistical guidance.

My literature review and critique conducted in 2006 (Busse and Rosser 2007) identified limited relevant studies pertaining to physiotherapy in HD, and resulted in the formation of a working group funded by the European Huntington's Disease Network. This group subsequently worked to review, critique and publish guidelines for physiotherapy using much of the process described above (Quinn and Busse 2007). Given that most physiotherapists do not frequently see people with HD, these guidelines provide a synthesis of the available evidence and expert guidance, to promote best practice in this relatively rare disease. These guidelines are now utilized by physiotherapists and other healthcare professionals throughout the EU, and have helped to promote the utilization of physiotherapy and exercise as an intervention strategy.

Finally, there are a few additional considerations that clinicians may want to consider when reviewing studies reporting interventions. In order for an intervention to be applicable in clinical practice, it needs to be feasible and safe. Information on location, supervision, adherence/ retention and adverse events (Busse *et al* 2012) should be provided in research reports of feasibility studies. Clearly if an intervention is not feasible in the real world, even if producing excellent clinical results, this is not going to be implemented in practice. In summary, critical appraisal is not only essential for researchers but is a core skill that any clinician should develop to both support their day to day working practice and to justify the important role that physiotherapists have when working with neurological patients.

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Setting the trend

A course in self-management

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The Bradford Specialist Multiple Sclerosis (MS) Team consists of a nurse, physiotherapist, occupational therapist and consultant neurologist with a specialist interest in MS. The team has a caseload of approximately 650 people with MS in a mainly urban setting. We sit within the acute trust but are able to offer an outpatient and domiciliary service, seeing the patient wherever best meets their needs. We work very much as an MDT and often case-manage patients to provide coordinated and timely care.

This article describes a Living with MS self-management course which was established by the physiotherapist and nurse in 2008. Since then, we have run six courses, inviting approximately 400 people with MS. With the addition of an occupational therapist to the team in 2009, and in response to feedback, the course has evolved to better meet the needs of patients. The course was initially directed at our newly diagnosed patients. After completing several courses, we recognised the potential value of rolling this out to our wider caseload and focusing on 'self-management'.

Rationale

The course initially had a purely educational approach, as we perceived this to be the primary need of newly diagnosed patients. As a team, we made the assumption that all our patients implicitly understood the concept of self-management; however this was not evident in practice. We found that patients were not confident in knowing when and who to contact for advice regarding their MS. We therefore identified the need for self-management and health promotion to be formalised.

The benefits of a group format were that it was an efficient use of our time; it allowed us to educate and involve friends and family members and it also provided the opportunity for peer support. Many said it was the first time they had met someone else with MS and allowed them to share their own experiences of living with the condition. It also allowed informal carer support from the team, but also from other carers.

Aims of the course

- encourage active involvement and participation in health management
- empower patients to make decisions and work in collaboration with the MS team
- educate and improve knowledge for both patients and families
- be deliberate and explicit about self-management
- explain the responsibility of the patient in managing their condition
- enhance patient ability to take action appropriately

	Welcome and drinks 10mins	**Part 1 Teaching and Discussion** 40mins	**Break** 20mins	**Part 2 Exercise/activity taster session** 40mins
Week 1		**What is self-management** MS Team		**Exercise and MS** MS specialist physiotherapist
Week 2		**Fatigue and MS** MS specialist occupational therapist		**Tai Chi** Tai Chi instructor
Week 3		**Diet and MS** Dietician		**Pilates** Physiotherapist
Week 4		**Complementary therapies** Massage, Reiki, Alexander Technique, Reflexology, Acupuncture, Relaxation, Aromatherapy		
Week 5		**Work and MS** MS specialist occupational therapist		**Kickboxing** Kickboxing instructor
Week 6		**Group dinner** optional		

FIGURE 1

- improve patient understanding of the roles of different health care professionals
- encourage and facilitate a healthy lifestyle
- allow peer support
- facilitate adjustment to diagnosis and/or a progression of MS

Whilst this group allows us to be direct about self-management, it is not the only time that we use this approach. It does provide a good starting point for understanding living with MS but often, further intervention is necessary. This approach may form part of our one-to-one sessions, other group sessions and MS Clinics. We have found some patients are more accepting of self-management than others and for some it takes time to understand this approach in living with a long-term condition.

Course format

The course lasts for six weeks for two hours in an evening (6.00pm-8.00pm – see *Figure 1*). It is held at a local, accessible community centre and is funded by the local MS Society branch. The branch also volunteers help to host and contribute their experience to the evenings.

Patients are invited by post and if they decline or are unable to attend, are asked again up to three times. One of the reasons we do this is to allow for the varying time needed by some to make their first steps towards accepting their condition, meeting others with MS and talking about their experiences.

We invite double the capacity of the venue because we have learnt from previous groups that it ensures a good number of attendees and allows for a drop-out rate.

The group is delivered by the MS Team along with others who generously give up their time. Help was sourced from professionals with an interest in MS and we provided them with feedback and evidence for their continuing professional development portfolios. Complementary therapists and exercise instructors were found via Cancer Network and other regulatory bodies.

For each session there is selection of relevant literature for patients to take away. This is to reinforce what they have heard during the sessions. We also provide details of local exercise groups and services to facilitate patient participation beyond the group.

Impact of the Course:

The course has set the trend for the patient's journey and their relationship with the MS team by:

- having a flexible and informal approach in a community setting
- being locally relevant
- 'normalising' living with MS
- increasing appropriate self-referrals
- increasing peer support and friendships
- providing a point of reference for the future
- improving understanding of the MDT roles and who to approach for help
- demonstrating the MDT approach and collaborative working
- creating an interest and desire to access the team for support

Patient feedback

We asked for feedback at the end of each session with anonymous questionnaires. This included a numerical rating scale and comments. This feedback helped us to review and adapt the group accordingly. *Figures 2 and 3* are the combined results of feedback from our last three groups.

Comments from patient feedback:

'It just opened my eyes. I can now see that I can carry on my life as normal- as normal can be for me.'

'I now have a more positive outlook on current matters and possibly more rational thought!'

'It has given me the impetus and motivation to get out of the house and I now think more positively, eat healthily and exercise.'

'It's helped me not to feel guilty and have more understanding of fatigue and how to deal with it.'

'Very informative and allowed me to bring up issues I wouldn't bring up normally.'

'It has been useful to know my legal rights at work and where to get support.'

'It's helped me to think more positively and accept the condition, giving me a much needed reminder that, despite MS, I must get on with life.'

HOW USEFUL WAS THE SESSION? (VAS OUT OF 10)

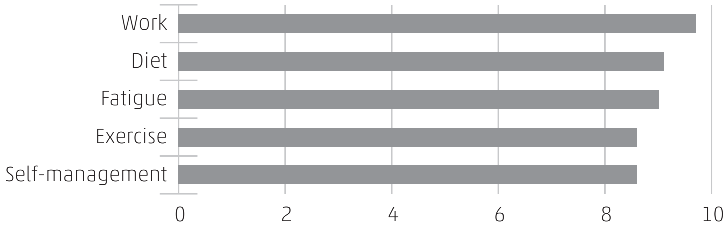

FIGURE 2

HOW ENJOYABLE WAS THE TASTER SESSION? (VAS OUT OF 10)

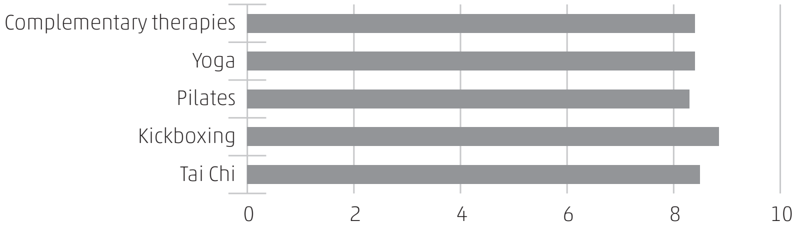

FIGURE 3

Conclusion:

This course demonstrates a model of good practice, which is in-line with national guidelines and reflected in our patient feedback. It is constantly evolving in response to feedback to ensure we continue to meet patients' needs.

Our team philosophy is to be flexible, approachable, honest and knowledgeable. This, combined with the fact that we really enjoy running the course, contributes to its effectiveness and success.

Looking forward, we are now in a position where a large percentage of our patients have attended the course. We will continue to offer this course to all newly diagnosed patients and we are reviewing how else we can support our patients on their journey of living with MS. This year we plan to run an additional course/session with a different format and timing, but with similar content.

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The effect of a short course of physiotherapy intervention on a patient with Huntington's disease

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Huntington's disease is a neurodegenerative condition with a range of physical, cognitive and psychological symptoms that lead to complex social care needs over a long period of time.

Anecdotal evidence would suggest patients are not referred routinely for physiotherapy and there is currently minimal evidence supporting physiotherapy input to this patient population. (Busse *et al* 2008 and Quinn *et al* 2010). This, together with the complex presentation of overlying cognitive and psychological symptoms, may in part explain why the physical problems of this population are rarely addressed by community or hospital-based physiotherapy. The community-based HD team within Aneurin Bevin Health Board (ABHB), which includes a physiotherapist, was set up in 2010 with the purpose of improving uptake to services previously not routinely accessed by this patient population and allowing patients and their families a greater choice in how their care can be delivered.

The patient

Peter has been known to the community HD team since 2010. He is a 44-year-old male, symptomatic since 2006. He lives in an Independent Living Scheme home with five other residents with physical disabilities and is supported by carers over a 24-hour period. He has no family support. Peter's current care package consists of supervision and some assistance for ADL and outside visits. He is independently mobile both inside and outside, able to negotiate all terrains, steps and stairs, and access cars and buses unaided. He undertakes no domestic tasks. In line with the Huntington's disease classification he is considered to be at stage II-III of the disease process with a total functional capacity scale of 8 .(See *Tables 2 and 3* in *Appendix*).

His current medication is:

- Mirtazapine 30mg od
- Olanzapine 5 mg od
- Paracetamol 500mg od

Peter presented with physical symptoms more prevalent in lower limbs and trunk. The movement patterns are well managed; however staff caring for Peter felt they were beginning to cause a more noticeable interference, and they had concerns with regard to his safety when walking. This was noted as a decrease in ability to stand safely, with more frequent falls and a decrease in walking speed and distance. Peter did not have any concerns himself but had recently stopped attending a local gym because he was finding it too hard. He reported no significant fear of falling. Also of note was Peter's alcohol intake of eight units a night.

Physiotherapy advice was sought at this time by the patient's key carer. As well as his physical symptoms, due to effects of the Huntington's disease process, Peter demonstrates a decreased ability to follow instructions, poor insight, low motivation to change, perseverance of thought and task, occasional irritability, irrational behaviour and decreased communication skills. He could not identify problems, contribute to goal planning nor maintain a home-based exercise regime even with the support of his carers. A falls log could not be used as Peter fell mostly when in his room and was therefore not witnessed by his carers. It was agreed by all parties that attendance at a local outpatient department might be successful in identifying whether physiotherapy could improve the patient's walking ability.

Neurophysiotherapy assessment:

Peter presented with dystonic plantarflexion/inversion patterning distally within his lower limbs. He had a decreased step length, with increased width between the feet causing him difficulty in achieving forward propulsion of the body over an extended lower limb and he did not achieve weight transference from heel strike to toe off. He struggled to maintain quiet stance within a reasonable step width and was unable to achieve or maintain tandem stand without support. His posture of stance was one of mild flexion of trunk, hips and knees with an anteriorly-tilted pelvis. This moved his centre of gravity more posteriorly, therefore adding to the difficulty of achieving forward or anterior translation efficiently. Peter was also unable to achieve single leg stance for longer than three seconds without support.

Peter displayed good strength through full range within his lower limbs although flexion patterns interrupted sustained hip and knee extension. He had adequate core stability with only minimal interference from a dystonic anterior tilting pelvis. He was however less stable on his left trunk/hip with a more pronounced dystonic foot.

Peter had retained good processing skills and proprioceptive awareness. He could follow simple verbal instructions and modify movements. He was able to give feedback of different sensations following a change even with his communication difficulties. He responded positively and appropriately to being handled.

Peter demonstrated an ability to learn and move from volitional to automatic movement.

OUTCOME MEASURE	PRE TREATMENT	POST TREATMENT
Timed 10m walk	12.8 seconds 20 steps	10.4 seconds 15 steps
Single leg stance (within Berg Balance test)	3 seconds	5 seconds
Falls efficacy scale Total score greater than 70 indicates a fear of falling	20	41

TABLE 1

Therapy aims

1. To improve gait pattern by improving stride length and therefore speed over timed distance.
2. To enable Peter to continue to access his environment safely and appropriately to his disease progression for as long as possible.
3. To prepare Peter for changes to his physical ability in the future.
4. To ensure patient and staff are able to manage his falls.

Treatment goals

1. To identify if improved stability at left hip/trunk decreases the amplitude and/or effect of the dystonic left foot on stance, step standing and during gait.
2. To identify if improved stability at left foot decreases the amplitude and/or effect of the dystonia within the left foot.
3. To identify if the use of visual cueing helps achieve improved step length and width.
4. To identify if use of an appropriate walking aid and or orthosis enhances any aspect of the walking pattern and familiarise patient with its use.
5. To ensure patient has a means of getting up from a fall.

Outcome measures

1. Timed 10m walk (Watson M 2002)
2. Falls Efficacy Scale. (Tinetti M *et al* 1990)
3. Shortened Berg Balance Scale (Rao AK *et al* 2009, Chou *et al* 2006)

Long-term goals

1. Improve timed 10m walk speed by two seconds and reduce step number by five.
2. Improve single leg stance from three seconds to ten seconds.
3. Improve ability to repeat sequence of on/off floor with or without verbal prompts.

Results

See *Table 1* above.

Discussion

Peter achieved two out of the three long-term goals; however his method of on/off the floor had to be adapted as he was unable to follow all sequences of backward chaining. The third goal of increased single leg stance was achieved but by less than predicted. All goals were jointly agreed with both Peter and his lead carer and documented using the Goal Attainment Scale (GAS). This works really well in this patient population as standardised outcomes may not change significantly and patients can find it difficult to identify their own goals. Peter had no concerns about falls prior to treatment or in his reduced ability to walk any distance, or a desire to reduce falls yet these were all identified by care staff and therapist as problems. This lack of insight and reduced awareness of his problems if not recognised may lead to non compliance with a home exercise regime and or a quick discharge in a busy department.

Peter was compliant with intervention and really enjoyed each session. Staff found it easier to get him out of bed on the day of therapy as there was a reason to get up. Falls reduction was not targeted as it could not be reliably measured. Peter fell mostly when alone in his room during the evenings and early mornings and was therefore unwitnessed and unrecorded. It is doubtful that a reduction in falls would be an attainable goal in this instance.

Validated outcomes measures are a starting point but in this population they may not be the best indicator of change whereas use of the GAS allows more individualised and sensitive goal setting. The timed ten metre walk did reflect a positive change in step length via the number of steps and, in this case, speed. However reducing speed may be the preferred outcome in some patients that have a tendency to rush. A measured change in gait pattern despite the interference of involuntary movements could suggest that Peter had gained an improved mechanism for dealing with the effects of involuntary movement patterns. Similarly the shortened Berg balance test omits those tests that require good cognitive function and are unnecessarily challenging with involuntary movements; yet still includes some common functional tasks and has been validated against the original 14 item test in stroke (Chou *et al* 2006). Peter was able to follow the verbal instructions on all seven items.

It was not appropriate to use Peter's perspective regarding falls as an outcome as no problems were identified. The Falls Efficacy Scale has proven difficult to score accurately as the scale is weighted to confidence in falls rather than likelihood of falls. Its abstract nature can also cause some patients difficulty. It was interesting to note in this case that Peter had minimal concerns with regard falls in the initial assessment, yet identified a decreased confidence in his ability post treatment. A different carer accompanied Peter on each occasion, therefore no outcomes could be identified from the carers. This could be explored in the future via carer burden or proxy reporting.

Compliance was improved in this instance with department attendance; Peter was usually difficult to rouse in the morning and took a long time to get up and breakfasted. However he had a reason to get up and achieved this in six out of seven appointments. Previous attempts to engage with this patient within his home had been unsuccessful. However, other patients may not tolerate busy outpatient departments. It is not yet known what the long-term effects are of this intervention but Peter demonstrated carry over on a weekly basis which allowed progression of therapy intervention. Peter has an excellent support team working with him on a daily basis and they appreciated having something to engage the patient with and ideas to maintain the effects at home.

Barriers to successful treatment in this population need to be explored further. Lack of evidence-based treatment should not prohibit intervention; however in order to ensure patients with Huntington's disease are not labelled uncooperative and unmotivated on initial assessment, physiotherapists should seek a basic understanding of the disease manifestation and presenting signs. As well as physiotherapists unfamiliar with this condition, some of the reasons for lack of successful treatment at traditional physiotherapy departments could include lack of insight by the patient, social isolation and embarrassment to be seen outside of familiar environment. There may also be apathy or ignorance from the patient's family regarding the benefits of undertaking physiotherapy, as many will have lived with Huntington's disease through at least one other generation.

Take home message

There is scope for physiotherapy intervention within this disease process and this can be achieved through specific and goal-orientated treatment. A degree of understanding of the effects of the multitude of both physical and non-physical symptoms and a flexible delivery system are needed if successful outcomes are to become more commonplace. Case study reports are an ideal way of exploring the effects on an individual basis.

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APPENDIX

Tables to calculate Total Functional Capacity and disease stage. Adapted from Shoulson I and Fahn S (1979) in *Physiotherapy guidance document* EHDN working group 2009.

OCCUPATION	FINANCE	DOMESTIC TASKS	ACTIVITIES OF DAILY LIVING	CARE LEVEL
3 Normal	3 Normal	2 Normal	3 Normal	2 Home
2 Reduced capacity for work	2 Slight assistance	2 Normal	3 Normal	2 Home
1 Marginal work only	1 Major assistance	1 Impaired	2 Minimal impairment	2 Home
0 Unable to work	0 Unable	0 Unable	1 Gross tasks only	1 Chronic care facility
0 Unable to work	0 Unable	0 Unable	0 Unable	0 Skilled nursing care

TABLE 2

STAGE OF DISEASE	TOTAL FUNCTIONAL CAPACITY SCORE
Stage I presymptomatic	11-13
Stage II early	7-10
Stage III mid	3-6
Stage IV late	1-2
Stage V end	0

TABLE 3

Focus on

Private practice

Anita Wade-Moulton
Burscough Neuro Physiotherapy

Having qualified in Bradford in 1982 under the very respected and traditional Principal Margaret Hollis and then Pete Young in the final two years, (after her retirement), private practice was never a consideration as my career path.

It was clear soon after qualifying that my passion lay in the treatment of neurological disorders. Working under the inspirational Val Steele in Bradford gave me the freedom to explore my skills and helped my self-development in this field through courses and service development.

Experience in Leeds and then Fazakerley Hospitals further helped my scope of experience in neurology. I still had no intention of becoming a private practitioner although throughout this time I had seen occasional neurological private patients, usually at the request of friends or family.

And then despite reaching a respectable high level in the NHS the change started to happen. The chain of events began with an unexpected pregnancy! Both I and my husband were overjoyed but it was clear that I didn't want to return to full-time work. Unfortunately at that time job share was in its infancy and that was not an option.

During a brief spell in part time NHS work, enquiries from colleagues started to come in asking if I was interested in seeing private patients with stroke and who suffered with neurological problems – so then it evolved – the private practitioner!

It is a steep learning curve working in the environment where patients do not need motivating and where they actively seek out physiotherapy rather than being told they must have it. The challenges to us as neurophysiotherapists are enormous; from problem solving in the very complex disabled patient, to improving the gait and walking speed of a very high level functioning patient at the other extreme. Patients range from those who normally are considered not to require further physiotherapy because they are independent (but not working at their normal level), to those with problems too complex to effect a change in the short window of physiotherapy available. We have patients where all the problems are very evident but we have to ask the questions: 'Where do we start?' and 'How long will it take to make small changes?' For the high-level patient we have to delve deep to find out which components of movement are missing and how to work this patient so he is functioning at an even higher level nearer to normal. And then we have the patients who we know that with the appropriate physiotherapy input, will be able to stand, transfer and not need to be hoisted, but can they afford the amount of physiotherapy needed to affect this progress? All challenges in different ways.

Working in private practice is still about the passion to problem solve and help improve the patient's quality of life. It is about the patient having goals they aspire to in order to make what might seem small but important changes in their lives; for instance being able to weight bear during transfers so they do not require hoisting, to get on/off a toilet, to be able to get in and out of a car, to be able to use the arm to dress, or to be able to walk on uneven ground to enable them to take a short walk in the countryside with their wife and dog – just to mention a few.

Patient-centred goals and outcomes are and always have been the necessity and driving force in most private practices, now summarised in the 'buzz word' PROMS – Patient Recorded Outcome Measures, which we are all encouraged to adopt. Why does it feel like the wheel is being reinvented again?

Undoubtedly there are differences for the physiotherapist in private practice and the physiotherapist working in the NHS. This often starts with the patients; many have been discharged from the NHS, not necessarily because they have reached their full potential, but because it is not possible with the current limited resources for them to continue. These patients have actively sought out private physiotherapy so in the main they are well motivated, which has a massive impact on recovery. Some patients are at the very acute stage of recovery, some are years down the line, and others require maintenance physiotherapy, without which there would be a decline in their condition and function.

Wherever possible we work alongside the NHS at the patient's request, in keeping with the CSP guidelines. (Unfortunately not all areas adopt this approach). This mutual working can work very well, requiring good communication between all parties in a non-threatening enthusiastic manner which should only benefit the patients' outcomes and experience.

It is true that patients usually have to fund their own treatment to achieve their potential and this is one of the difficult areas for us in private practice. I think most physiotherapists are uncomfortable 'charging' patients but in today's climate of patient choice and limited resources, if we are able to offer a skilled reasoned dynamic service which enables the patient to achieve their goals, it is filling a gap and should be a service that compliments the NHS. Many patients have had very good input from the NHS physiotherapists and continued progress and support is part of the service we can give to patients.

All in all, private practice can be very rewarding indeed, but as always there is a downside.

For a start, you abandon the comfort of a regular income, pension, paid holidays etc for an awful lot of lying awake at night worrying, "Will I get enough patients to be able to pay the bills this month and put food on the table?" Next comes the worry, "Am I doing everything required by CSP and HPC?" It's not just about treating patients (that would be lovely); you need to keep abreast of all the latest developments in data protection, note keeping, outcome measures etc whether working as a lone practitioner or in a practice. The numerous policies on patient audit, complaints procedures, accident and incidents and lone practice need to be considered and add to the workload of the private physiotherapist. Legal requirements are much more evident than 25 years ago as are the demands of patients, reflecting a change in the balance of power. In all it is a good thing that the level of competence, honesty, and integrity that is paramount in our physiotherapy services can now be investigated and questioned should a patient be dissatisfied with our services. The HPC is quite rightly very active in supporting patients to expect this high level of care.

Then you need to be able to go above the normal CPD requirements as you will want to keep on the cutting edge of your particular field of expertise. Things move on very quickly and working out on your own it is possible to start to lag behind in current treatment and knowledge. Peer support groups and keeping up with recent developments in our field is essential if we are to provide a top quality service to our patients.

Overall if you are dedicated it is possible to have an excellent career in private practice. The hours worked are often long, unpredictable and involve 'non-paid work' such as communication with others in the team, dealing with patient enquiries, talking to relatives, travelling, report writing or just plain paper work! The advantage is that this may be *at* the time you choose and *where* you choose!

One final thought – many presume that private patients are all wealthy and drive expensive cars – this could not be further from the truth; most of our patients are just ordinary folk who may have saved for a rainy day then suddenly it was pouring. Some food for thought if you are thinking or have already started your journey into private practice.

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The life of a PhD student

Anonymous

Last time I explained how the long hours spent working on a PhD are filled. I also explained how I had to pass my first year viva to achieve doctoral progression. I passed – so here I am again!

I thought it was important to explain in this entry what the type of support structures are that I rely on to continue on this incessant journey. These are my personal views and I am sure if you ask others in the same position they find other (and no doubt better ways) to gain help and support.

Before I set out on my PhD, my supervisor asked what seemed, at the time, a slightly strange question. Is your partner supportive of you doing this? It is only now that I am halfway through the three years that I see how significant a question this was.

I will come back to that most important aspect of support from the family, but first, I want to introduce the support mechanisms available for the PhD itself. All PhD students have a designated lead supervisor and either a second supervisor or advisor, depending on the University. This team of two to three people provide the main academic support but I have found personally that it is peer support that is more useful on a day to day basis. You also don't feel quite so foolish asking silly questions. We have an excellent post-doctoral research associate who is always able to provide clear direction and other PhD students who are good to discuss and share problems with.

As I have described before, the clinical trial means I am at the hospital more than the university, so I am not able to use this support network as much as I would like. It has been great, therefore, to find an orthotist at the Trust doing his PhD part-time. We have been able to meet up at regular intervals to discuss frustrations and also throw around ideas, and this has been mutually advantageous. Also at the hospital are colleagues who have supported me through the frustrating years trying to get the research off the ground and who continue to provide great encouragement.

Finally though, I come back to the family. Your family will provide the most important of support networks. My wife is the foundation on which I depend to allow me to try and achieve my objectives. I have to be honest and say I feel like I am being extremely selfish at times. I think I have to be to maintain resoluteness and be steadfast to the work but I do not like myself for it.

My wife is truly the best support I could wish for. She is completely understanding in knowing how much I want this and how hard I have worked to get to this point. She is also aware of how hard I need to keep working to achieve my goals but also knows exactly when I need to stop work and take a break. She says that I helped her through her years at university so it is only payback but I know I am hugely indebted to her already for her support.

To add to the busyness, we now have an amazing wee baby boy who was born during my PhD. While sleep deprivation does not help with the concentration, he certainly provides the ability to relax me with a single grin. Importantly he also ensures I keep a perspective on my work. We have developed a good routine where my wife feeds him and then I take over and get him ready for bed. We then take it in turns to get him off to sleep. This lets me do some more work.

There are so many people who I depend on for support so although it is a very personal pursuit it feels more like a team effort at times. Looking back I now know exactly why my supervisor asked if my partner was supportive. The added stresses and increased workload mean that you need someone who is both accommodating and encouraging and I am lucky to have such a person.

expanding minds and networks

ACPIN national conference & AGM

1st–2nd March 2013
The Hilton Hotel Northampton

Lecture abstracts

Evaluation of community rehabilitation service delivery

in long-term neurological conditions

Dr Diana Jackson PhD MSc MCSP
Senior research fellow, Cicely Saunders Institute of Palliative Care, King's College, London

Following in-patient rehabilitation, people with complex neurological disability require on-going community-based rehabilitation and social support to consolidate gains and maximise integration.

We aimed to register and follow-up a cohort of patients discharged from London in-patient neurorehabilitation units for one year, and investigate the community services they were referred to.

Patients/carers completed postal questionnaires at discharge and twice more at 6/12 intervals. Measures of impairment, dependency and community integration were included. A new tool, The Needs and Provision Complexity Scale (NPCS), was used to compare needs for health/social services (NPCS-needs) against services received (NPCS-gets) in five domains. Community services accessed by patients were mapped and surveyed to determine their configuration and perceived barriers to service utilisation.

428/499 of discharged patients were registered – 63% male, 65% aged 36-65, with LTNCs (50% strokes, 24% other ABIs, 9% spinal, 6% neuropathy, 5% progressive, 6% other). Most (79%) were discharged home and largely referred to CRTs. Only 31% consistently returned questionnaires. At 6/12 post discharge, needs for medical and nursing care were relatively well met, but there was significant under-provision of on-going community rehabilitation, equipment and social support. Neither demographic variables nor diagnosis predicted how much rehabilitation/support patients received post-discharge. Paradoxically, integration improved more in those with unmet needs, who were least disabled, but did not change in more disabled patients whose rehabilitation needs were met.

Given the scarcity of community rehabilitation services, therapy teams may focus their efforts on patients with the greatest needs for support, but for whom community re-integration is more challenging. Further investment in services to support community-based social integration is needed.

Dr Diana Jackson trained as a physiotherapist and worked in a variety of hospital settings before specialising in neurological rehabilitation. A desire to understand more about the effectiveness of interventions and after care for people with acquired brain injuries and their families prompted an interest in research. An MSc in Rehabilitation Studies at Southampton University, followed by a PhD, led her towards health services research. She is now a senior research fellow at the Cicely Saunders Institute of Palliative Care, King's College London. The Institute brings together academics, healthcare professionals, community organisations, patients and carers in one centre and acts as the hub for a network of international research. Diana's research interests include pain assessment, evaluating interventions for people with acquired brain injuries, community rehabilitation and understanding the needs and experiences of carers of adults with a range of long term neurological conditions.

Exercises at home for people
with Huntington's disease

Dr Monica Busse PhD MSc MCSP
Senior lecturer, Department of Physiotherapy, Cardiff University

Huntington's disease (HD) is an autosomal- dominant neurodegenerative disorder, caused by a mutation of the Huntington gene. It results in severe motor dysfunction, cognitive decline and behavioural changes over an extended period of time. Chorea and dystonia are distinctive features of the disease, and function is directly impaired through loss of motor skills including gait and postural control.

Onset of symptoms is generally between ages 40-60, and to date there is no treatment to prevent, delay or slow the disease process, although there are ongoing international efforts to identify possible targets and interventions.

The benefits of physical activity and exercise are well documented in healthy individuals, and can have positive social effects and impact on health, fitness, functionality and psychological wellbeing. Positive effects of exercise have also been seen in a range of people with Long Term Neurological Conditions (LTNCs), such as Parkinson's disease (PD) and multiple sclerosis. While studies in support of exercise in people with HD are lacking, there is growing recognition of the potential that exercise may have in symptom management and disease modification.

Sustaining regular exercise can be a challenge for individuals with and without chronic health conditions. Engaging in such behaviour is further complicated in people with HD by the triad of motor, cognitive and behavioural symptoms that are experienced over time. Most notably, behavioural symptoms including depression, apathy, irritability and cognitive impairments (such as difficulties in organisation, planning, dual-tasking and adapting to new routines) can limit physical activity behaviour. Other barriers, including poor physical health, transportation issues, other time conflicts, social stigma, external demands and lack of motivation, have been reported in healthy and aging populations.

Results from a series of different community-based exercise interventions, that have been conducted by the Cardiff Physiotherapy Group, will be presented in this session with a view to informing delivery of home-based interventions in neurodegenerative diseases like HD. Such community-based interventions that are both person and environment specific are critical to support and encourage people with HD to adopt lifestyle changes. Indeed, our interventions specifically focus not only on exercise prescription and motor control based interventions, but on the social support requirements of physical activity interventions in neurodegenerative disease, where cognitive and behavioural challenges are common.

Monica Busse is a senior lecturer in the Department of Physiotherapy, Cardiff University and Huntington's disease senior research fellow in the Brain Repair Group, Cardiff University. Her research to date has mainly focused on developing evidence and guidelines for targeted physical interventions in long-term neurological conditions such as Huntington's disease (HD). She is a co-lead facilitator (with Dr Lori Quinn) of the European Huntington's Disease Network (EHDN) Physiotherapy Working Group and leads the Cardiff Huntington's Disease Physiotherapy Group, which has been working to develop research studies that provide evidence to support best practice for physiotherapists working with HD.

Community stroke services in Tower Hamlets:
service users showing us the way forward

Tess Baird Bsc (Hons) OT Msc Neurorehabilitation
Clinical lead for neurology, Royal London Hospital, London

Engaging service users and their families in feedback on their experiences is recognized as good practice (Department of Health 2006). At Barts and the Royal London Stroke Service it is central to how we shape current and future service for the people of Tower Hamlets.

Different models of service user engagement will be reviewed, along with practical examples of how we have used our Stroke Reference Group to improve pathway communication and develop relationships with external and voluntary agencies. Finally, how they have helped us develop and embed a self-management philosophy across the stroke pathway will be discussed.

Department of Health (2006) *Our health, our care, our say: a new direction for community services* White paper www.dh.gov.uk/en/Publicationsandstatistics/ Publications/ PublicationsPolicyAndGuidance/ DH_4127453.

Tess Baird has worked in the field of neurology, specifically stroke, for 16 years since graduating as an occupational therapist from Oxford Brookes University in 1995. She has worked across London in both inpatient and community stroke teams. She is currently the clinical lead for neurology at Royal London Hospital and is the rehabilitation lead for the Bart's Health Stroke Pathway. She is the Chair for the Stroke Forum for College of Occupational Therapist Specialist Section in Neurology (SSNP) and is part of the training staff for Bridges stroke self-management programme. She completed her MSc in Neurorehabilitation in 2005 which is where her interest in goal setting and engaging service users developed through her research on 'Goal setting: the patient's perspective.'

Action for Rehabilitation from Neurological Injury (ARNI)

what is it, does it work and what could it mean for physios?

Dr Meriel Norris PhD MSc PGCert (LTHE)
Physiotherapy lecturer, Brunel University, London

Evidence suggests that functional recovery post stroke can continue beyond six months (Demain *et al* 2006, Hendricks *et al* 2002).

Yet most rehabilitation services are extremely limited at this point with current access to community-based therapies, in particular physiotherapy being described by stroke survivors as being too brief and time limited to promote best recovery (The Stroke Association 2012, Winchcombe 2012). Subsequently, the need to develop strategies for accessing further rehabilitation beyond the current NHS pathways is evident. In some areas of the UK ARNI is being proposed/implemented to meet this gap.

ARNI was created by a stroke survivor who believed he had unmet goals at the point of discharge from formal therapy. Through study of the evidence base, martial arts and experimentation, the founder has created a functional training programme that intends not only to address physical problems but also looks at critical psychological aspects such as motivation, self-monitoring and the creation and delivery of ambitious goals.

ARNI is currently being delivered privately but also increasingly commissioned by local authorities to support the long-term recovery of stroke survivors. As such it has the potential to be a useful adjunct to physiotherapy. However, the evidence supporting the programme runs behind its implementation. Following an introduction to ARNI, the evidence on its efficacy to date will be presented, with some final comments on what this could all mean for physiotherapists.

Hendricks HT, van Limbeek J, Geurts AC, Zwarts MJ (2002) *Motor recovery after stroke: A systematic review of the literature* ***Archive of Physical Medicine and Rehabilitation*** 83(11) pp1629-1637.

Demain S, Wiles R, Roberts L, McPherson K (2006) *Recovery plateau following stroke: fact or fiction?* ***Disability Rehabilitation*** 28(13-14) pp815-821.

The Stroke Association (2012) *Struggling to recover* London.

Winchcombe M (2012) *A life more ordinary – findings from the Long-Term Neurological Conditions Research Initiative* ***Department of Health*** (http://www.ltnc.org.uk/download_files/final%20reports/ALMO_for_web.pdf)

Dr Meriel Norris graduated as a physiotherapist in 1995. She has worked for several years in the NHS predominantly in the field of stroke. After some years working in India she undertook an MA in Medical Anthropology. She completed her PhD at Brunel University in 2009, where she currently works as a lecturer within the physiotherapy division. For the past three years Meriel has been working in a collaborative group investigating the efficacy and acceptability of the ARNI approach.

A balancing act

the assessment and rehabilitation of older adult fallers, including dance mat exercises

Dr Matt Liston MCSP
Trial manager, Faculty of Health and Social Care Sciences, St George's, Univeristy of London/Kingston University London

Approximately one third of adults over the age of 65 fall annually, approximately half of which experience two or more falls per annum.

People that fall can experience a multitude of injuries post fall including contusions, fractures and increased mortality, and can experience wide ranging effects on well-being including reduced balance confidence, fear of falling and social isolation.

A number of studies have identified risk factors for falling including impairments in somatosensory function, impaired visual function, reduced muscle strength, increased postural sway and reduced dual tasking ability. Vestibular function is not commonly assessed or treated in older adult fallers, although recent evidence suggests this may be worthwhile. The first part of this talk will discuss some current evidence regarding vestibular dysfunction in older adults and fallers.

The physical rehabilitation of fallers typically consists of a programme containing strengthening and balance exercises and gait training. However, few programmes address vestibular function. Customised multi-sensory rehabilitation (MSR) has been shown to be effective for individuals with known vestibular dysfunction, yet the efficacy of these programmes in older adult fallers has not been fully assessed. The current evidence for MSR will be discussed alongside novel approaches to therapy.

The use of choice stepping reaction time protocols has been identified as a novel approach to assessment and rehabilitation of fallers, especially since gaming systems are becoming cheaper and with higher resolution sensors. The final part of this talk will discuss the possibilities for using dance mats for the assessment and rehabilitation of fallers.

Dr Matt Liston began his research career designing artificial muscle systems in the Department of Mechanical Engineering, University of Bath after qualifying as a zoologist from the University of Reading in 2000. Following this Matt retrained as a physiotherapist, graduating from King's College London and went on to join the Centre for Human and Aerospace Physiological Sciences at KCL to pursue his PhD. Matt completed his PhD entitled 'Advances in the assessment and rehabilitation of older adult fallers' in 2012. His thesis investigated balance function, assessment of falls risk and effects of multi-sensory rehabilitation in older adults and older adult fallers. In February 2012 Matt took up a post with Dr Fiona Jones at the Faculty of Health and Social Care Sciences, St George's/Kingston University of London as trial manager for the SESAME trial. SESAME is a study investigating the acceptability and feasibility of providing a self-management programme for individuals that have had a stroke.

Workshop sessions

Option 1

Independent prescribing

Davina Richardson

BSc Physiotherapy MSc Neurosciences

This conference has given us the opportunity to discuss the opportunities with the introduction of independent prescribing rights and ongoing utilisation of other medicines management frameworks to benefit the patients we work with.

The aims of this session are:

1. To review information and signpost to useful websites and sources of information to increase knowledge of the following frameworks relating to medicines management.
    - legal frameworks
    - competency frameworks
    - education frameworks
2. To provide examples and discussion of where physiotherapy medicines management models have been set up and utilised to improve patient care.
3. To explore practical implications of becoming a prescriber and getting more involved in medicines management.

The learning objectives are:

1. To be able to access useful resources to help understand the process of becoming a group of professionals with prescribing rights.
2. To be able to identify appropriate training needs as an individual.
3. To be able to assess if prescribing rights are right for you in your current role or future roles.

Davina Richardson is currently employed as the clinical lead therapist neurosciences at Imperial College Healthcare NHS Trust in London. She leads a team of physiotherapists and occupational therapists supporting the needs of patients presenting with neurological impairments across various clinical areas within the Trust including neurosurgery, neurology, neuro-oncology, major trauma, general medicine and private patient services. Following an interest in supporting the management of spasticity with appropriate medicines she became a member of the Medicines Management committee at the Chartered Society of Physiotherapy in 2000 and more recently the Allied Health representative on the Imperial College Health Care NHS Trust non-medical prescribing committee.

Option 2

Any Qualified Provider, prime vendor model contract

Claire Strickland FCSP

This workshop will seek to equip participants with a greater understanding about contracting models being used within the NHS and should help you to answer the following questions:

- Do you know how your service is funded?
- Do you know what contracting model is being used?
- Why does this matter to you and your patients?

Claire Strickland has been head of the Physiotherapy Practice Unit at the Chartered Society of Physiotherapy (CSP) since February 2011. Prior to this she worked in the National Health Service (NHS) for 30 years as manager and neuroscience lead clinician within the Barts and the London NHS Trust. She gained commissioning experience as a member of the Professional Executive Committee (PEC) in Tower Hamlets PCT, leading on cross-agency neuroscience pathway redesign.

Option 3

Outcome measures

Steve Tolan MCSP

The CSP have identified (based on the Department of Health's methodology for PROM use) that the preferred method is: Generic PROM plus condition specific PROM plus PREM.

The Department of Health (in the next 12 to 18 months) intends to bring in EQ-5D as a standard generic PROM across specialities. The reason for this is that it is simple, provides comparability across specialities and can be used to generate Quality Adjusted Life Years (QALYs). This should be paired with a disease-specific PROM for added sensitivity. Finally, the patient's experience is vital to capture where possible, since this is the 'other side of the coin' to patient outcome.

This workshop will:

- Try to build some consensus on identifying relevant outcome measures in stroke and MS and/or
- Prioritise which conditions should be given closer consideration

Steve Tolan has been a professional adviser at the Chartered Society of Physiotherapy (CSP) since 2011. He is part of the CSP's Health Informatics project team which includes topics such as outcome measurement, electronic patient records, telehealth and commissioning models. He has been engaged in the promotion of the EQ-5D tool within the AHP services, currently represents the CSP on the National Allied Health Professional Informatics Strategic Task Force (NAHPIST) and is a reference group member on the joint Department of Health and Arthritis Research UK MSK PROM programme.

Update on disease-modifying therapies

for people with multiple sclerosis

Prof Carolyn Young MD FRCP
Consultant neurologist and honorary professor of neurology, Walton Centre for Neurology and Neurosurgery

Professor Young provided an update on medical therapeutic and disease-modifying interventions for multiple sclerosis.

Professor Carolyn Young is a consultant neurologist at the Walton Centre for Neurology and Neurosurgery, which is a supra-regional centre responsible for neurological services for a population of over three million people in the northwest of England and in north Wales. She has a specialist interest in disabling neurological disorders, particularly multiple sclerosis and motor neurone disease. Since appointment as a specialist in 1992, she has founded services in multiple sclerosis and motor neurone disease. She has also developed neurological rehabilitation, having previously been sole consultant for a 16 bedded inpatient neurological rehabilitation unit. Professor Young has been principal investigator for over 50 trials in multiple sclerosis and several trials in motor neurone disease. She has written over 100 papers in multiple sclerosis, brain injury, motor neurone disease and rehabilitation. She has co-authored several British guidelines, for the Association of British Neurologists and others. These guidelines have provided national NHS guidance on management of motor neurone disease including NIV, prescription of beta interferons and glatiramer acetate for MS, and spasticity treatment. Professor Young has participated in the NICE assessment process for beta interferon, glatiramer acetate, natalizumab, fingolimod, riluzole and NIV in motor neurone disease. She is also honorary professor of neurology at the University of Liverpool, and on the UK Specialist Register for Neurology and the European Board of Physical Medicine and Rehabilitation.

Falls in people with multiple sclerosis:

risk factors and management opportunities

Hilary Gunn
Lecturer in Physiotherapy, School of Health Professions, Plymouth University

Falls are a significant issue for people with multiple sclerosis (MS) and are associated with serious emotional and physical consequences.

Rehabilitation professionals play an integral role in falls management; their ability to accurately identify contributing factors is essential to evaluate risk and develop appropriate management strategies. However, the current evidence base is limited and specific risk factors have not yet been identified to inform the development of targeted falls interventions in people with MS.

In this presentation, the evidence base for the risk factors for falls in MS will be discussed, including the findings of our recently published systematic review[1] and data from our own Primary research study[2]. This prospective cohort study included 150 people with MS recruited via a local MS database. People with different MS disease types, ranging from 3.5 to 6.5 on the Expanded Disability Status Scale (EDSS) were eligible for inclusion. Predictor variables included the short form Physiological Profile Assessment plus measures of spasticity, ataxia, dual task interference, falls confidence, cognition, vestibular and autonomic disturbance. The primary outcome variable was falls frequency measured prospectively over a three month period, using a self-reported falls diary.

The results of our work to date have enabled us to highlight some of the key issues that may be pertinent, both to identify those particularly at risk of falls, and to form the basis of a management intervention. Our ultimate aim is to develop a falls intervention specifically tailored to the needs of people with MS, and some of the opportunities and challenges associated with this will be discussed in this presentation.

1 Gunn H, Newell P, Haas B, Marsden JF, Freeman J (2012) *Identification of risk factors for falls in multiple sclerosis: a systematic review and meta-analysis* ***Physical Therapy*** December 13.

2 Gunn H, Creanor S, Haas B, Marsden J, Freeman J *Risk-factors for falls in multiple sclerosis: an observational study* (In submission).

Hilary Gunn is a physiotherapy lecturer at Plymouth University, Devon. She graduated from Queen Elizabeth School of Physiotherapy, Birmingham in 1990, and achieved an MSc in 2005. Clinically, Hilary specialised in adult neurology, working in acute, rehabilitation and community settings. She also worked extensively with older people with multiple pathology, developing an interest in falls management from this time. Her current teaching and research activities combine these interests, and she is now working towards a PhD focusing on the management of falls in people with MS.

Development of the updated multiple sclerosis NICE guidelines

Laura J Weir
Head of Policy and Campaigns for the MS Society

Laura Weir focused on how the MS Society is working with the National Institute for Health and Clinical Excellence to develop the MS clinical guideline.

In particular, she looked at what will be in the guideline, what has not made it into the guideline, what the implications might be, and what our hopes are for the future. She also gave a preview of some of the MS Society's funded care and services research where this is of relevance to the professionals in the audience..

Laura Weir is Head of Policy and Campaigns for the UK MS Society, with responsibility for devising and managing political and parliamentary campaigns.

During Laura's six years with the MS Society, amongst other things, she has worked with NICE to develop a campaigns guide for access to a NICE approved treatment for MS, has been instrumental in obtaining a commitment from NICE to update the clinical guideline for MS changing the way the Institute reviews its guidelines and has worked alongside volunteers campaigning for access to treatments locally. Most recently, Laura gave oral evidence during the NICE appraisal for the first pill for MS.

She was elected to Chair Patients Involved in NICE (PIN) in July 2011. PIN is now a coalition of over 80 organisations committed to enabling patient groups to engage productively with NICE. Independent from NICE and the pharmaceutical industry, the group uses its combined knowledge, experience and direct contact with patients from a wide range of conditions, to ensure NICE puts patients, carers, and patient groups at the centre of all of its work. Laura recently gave evidence to the Health Select Committee as part of it's inquiry into the work of NICE.

PIN acts as a critical friend and a respected and equal partner in developing and shaping aspects of NICE's work, as well as providing a forum for enabling patient groups to engage productively with NICE. Through PIN, Laura has worked with the Institute to establish a series of free workshops for patients groups to learn more about the work of NICE and to understand how they can contribute and shape NICE guidance being developed.

Laura has also recently become a board member on the NICE Implementation Collaborative (NIC), a group established to drive implementation of NICE guidance where there is slow or inconsistent uptake across the NHS.

Laura has a degree in Politics from the University of York and an MSc in Public Policy from University College London. In 2012, her team won 'In House Team of the Year Award' at the National Public Affairs News Awards.

Being active with multiple sclerosis

Tim Worner

Tim is by no means a professional speaker but has a passion and pride for the activities he does, rarely at a competitive level, but just to enjoy and challenge himself and his MS and sometimes to prove to others he can do it.

Since Tim's diagnosis over ten years ago and taking ill health retirement, he has found a whole new life, taking up many new activities and returning to some that he did many years ago when much younger. Tim finds they are such a benefit to his well-being that he encourages others, showing many things are still possible regardless of disability.

This enthusiasm very much includes sharing information with all health professionals so that they can pass onto their patients his mantra of 'One life: live it!'

Tim Worner lives in Poole, Dorset with his wife, Shirley. Tim was a supermarket manager until he took ill health retirement over ten years ago. Since then he has taken up many activities and been involved with many things in connection with MS. He is a member of UK MS Society, a member of the FACETS trial steering group, a former Chair of the Bournemouth and District Branch of the MS Society, where he currently oversees services such as physiotherapy, counselling and the Citizens Advice Bureau and has introduced many new services, increasing membership, especially to younger PWMS. He also liaises with the health professionals at the Poole MS team on behalf of the branch and its members. Last year at MS Life in Manchester he ran the activity zone, including two presentations with Jane Petty, the lead physiotherapist for the MS Society, and did a workshop on fatigue. Last year, also with Jane Petty, he did a 'keep active' workshop at a 'living with MS day' held by the MS Society in Harrogate. He has set up and runs a group called MateS aimed at younger and newly diagnosed people. This group has been running for about six years and is part of Bournemouth MS branch. He is also area organiser for Sportability. He has also appeared on a Mr Motivator DVD! Tim is a member of two gun clubs of which he is a range officer at both and committee member at one. He also enjoys horse riding, sailing and dog walking.

Vocation and participation

for people with multiple sclerosis

Gail Townsend

Occupational Therapist, Neuro-rehabilitation Services, Buckinghamshire PCT

Participation in vocational and other meaningful activities help us identify who we are and where we fit in our world.

Multiple sclerosis (MS) presents many ongoing challenges to participation in paid employment and other valued roles. People with MS are often required to redefine their roles and make adjustments, not just once but whenever their condition changes. Paid employment is only one aspect of vocation, but its value to the individual and society mean that it can often be the main focus.

Maintenance of an existing work role, or staying with an existing employer is seen as the best option for people with MS. However when paid employment is no longer possible it is vital that people with MS are supported to find other roles and occupations that give meaning and structure to their lives.

Gail Townsend has been working as an occupational therapist for 30 years and is currently working as an occupational therapist in a community neurological rehabilitation service in Buckinghamshire, working with people with all neurological conditions. Her MPhil (2009) is based on her research into developing support for people with MS who wished to remain in work. The At Work with MS Toolkit which was developed from the research is available on the MS Trust website.

Panel discussion

Commissioning MS services:

who wants what and why?

with **Jakko Brouwers**, **Oliver Krouwel**, **Louise Rogerson** and **Tim Worner**

Jakko Brouwers MSc MCSP

Jakko trained and qualified as a physiotherapist in the Netherlands. From qualification onwards he has been specialising in neurorehabilitation. In 2005 he completed his MSc in Neuroscience Physiotherapy at Cardiff University. He has worked in a wide variety of settings in the UK and abroad which includes the Bath Head Injury Unit and Rookwood Hospital (Welsh Regional Spinal Cord Injury and Specialist Neuro Rehabilitation Unit). He is currently the superintendent physiotherapist for specialist rehabilitation at Rookwood Hospital and has worked in this post since 2002. In this role, he provides clinical and operational leadership to the Spinal Cord Injury (SCI) and Acquired Brain Injury (ABI) physiotherapy teams. He is the therapy lead for neurosciences in Wales. Due to his role in developing the pathway for neuroscience patients in Wales, he is currently seconded to the innovation and improvement team at the Cardiff and Vale University Health Board, where he manages a range of service improvement projects. This secondment is due to end in May 2013.

Oliver Krouwel

Oliver completed his undergraduate degree in Applied Sports Science and Coaching at The College of St Mark and St John in Plymouth in 2002. He then undertook a Post Graduate Certificate in Education and enjoyed three years teaching in a secondary school in Swindon. Olly started his physiotherapy career by completing the MSc Rehabilitation Science at Brighton University in 2008. After completing his junior rotations with Croydon NHS trust and publishing his research in manual therapy, he moved to Burrswood Christian Hospital and has developed into the lead outpatient physiotherapist.

Louise Rogerson

Louise qualified from the University of East London in 1995, and subsequently worked at the Royal London and Bart's Hospital Trust before moving to specialise in neurology at Homerton Hospital, and then Wythenshawe Hospital in Manchester. In 2003 Louise took up a role in a private clinic, and also carried out published research with Dr Sarah Tyson into the use of walking aids after stroke. In 2005 Louise took up a post within South Manchester PCT working as a service improvement manager; establishing and maintaining tier two interface services including musculoskeletal, gynaecology, falls, and pain management.

In 2007 Louise commenced a role as scheduled care commissioner at Trafford PCT where she has remained ever since. Her current role as service reform lead for clinical pathways includes the review and development of a wide range of services. The areas covered include stroke, neurology, cancer, palliative care, cardiovascular disease, and musculoskeletal services. Projects of note include the introduction of a low level pain management service in the community combining iPAD CBT with physiotherapy intervention, and the development of a tablet interface to capture Advance Plans for patients in care homes which can be shared directly with GPs and the wider health community.

Louise has maintained her private practice neurophysiotherapy since 1999. Her current caseload is dominated by patients with Parkinson's Disease, and she has enjoyed learning from long-term relationships with a number of patients, boosting her understanding of this complex disease and its impact on quality of life. Louise was a member of the ACPIN executive committee for 10 years, resigning in 2010.

Louise is looking forward to taking up a new role as a performance improvement manager with the newly formed CCGs across Trafford, South and Central Manchester. In addition, she is working with a local company to develop software to improve physiotherapy documentation, capture of outcomes, and increase access to modern technologies within telehealth to boost carryover of treatment programmes.

Tim Worner
See biography on page 28.

Poster presentation winner

A day in the life of people with multiple sclerosis

an exercise and physical activity based study

Andrea Stennett
Centre for Research in Rehabilitation, Brunel University, London

Multiple sclerosis (MS) is a chronic disabling disease of the central nervous system. Recent figures show that approximately 100,000 people are living with MS in the United Kingdom (MS Society 2009). People with MS (pwMS) suffer from a wide range of impairments and are less physically active than the average population (Motl *et al* 2005).

There is no cure for MS, therefore keeping people physically active is one way of managing the symptoms of the disease (Petajan *et al* 1996, Rimmer *et al* 2000). However, there is evidence to suggest that adherence is a major problem in this population (Kayes *et al* 2011, Beckerman 2010). This poses an ongoing challenge for physiotherapists to keep people with MS physically active. As such, this highlights a developmental need to establish a wide range of activities that clinicians can draw on to keep people with MS engaged in physical activities.

Therefore, the main aim of this study is to develop a professionally guided exercise and physical activity programme by using the views and priorities of people living in the community with MS.

Keywords: Multiple Sclerosis, Exercise, Physical Activity

Right: Andrea Stennet receiving her prize for best poster presentation from Gita Ramdharry, ACPIN Chair.

AGM 2013

Apologies
Jane Petty Research Officer

Minutes of the 2012 AGM
Accepted and voted as an accurate account

President's addresses
These can be found on pages 2-4 of this edition of *Syn'apse*

- **Outgoing president** (Dr Margaret Mayston)
- **In-coming president** (Dr Fiona Jones)

Chair's address
Dr Gita Ramdharry

Treasurer's report
Jo Kileff

Election of Executive Committee members

Honorary secretary
Adine Adonis
Proposer: Chris Manning
Seconded: Sandy Chamber
Vote carried

Honorary treasurer
Chris Manning
Proposer: Fiona Jones
Seconded: Lisa Knight
Vote carried

New committee members
Lisa Bunn
Proposer: Adine Adonis
Seconded: Chris Manning
Vote carried

Nikki Guck
Proposer: Sandy Chamber
Seconded: Anne Roger

Fran Brander
Proposer: Anne Roger
Seconded: Lorraine Azam

AOB
None

The meeting closed at 1.00pm

Chair's address

Dr Gita Ramdharry
Senior Lecturer, St George's School of Rehabilitation Science, Faculty of Health and Social Care Sciences, St George's University, London, and Kingston University

Taking over from Siobhan MacAuley last year was a nerve-wracking time. The handover took place at one of the best ACPIN conferences I have ever attended, which made me realise how high my predecessor had set the bar. Thanks very much, Siobhan!

This year we have been settling into the new CSP governance system for the professional networks and we are part of the neuroscience alliance along with ACPIVR. There are two alliance link people at the CSP , Imogen Scott-Plummer and Rebecca Middleton, and it's proving a useful relationship, aiding communication and discussion. We are still developing how this will function.

One of our other big changes this year is our foray into social media. We now have a Facebook page and Twitter feed. We have nearly 350 'likes' on Facebook and have nearly 200 followers on Twitter. This seems to be proving to be a very useful form of communication with members, but it also enables us to link in with other bodies such as the INPTA (International Neurological Physical Therapy Association) and the Society for Rehabilitation Research. All useful connections.

Dr Fiona Jones has stepped down as our representative on the UK stroke forum and we would like to thank Fiona for all of her hard work over the years on behalf of ACPIN. Michelle Price is taking over this position. Michelle is a consultant physiotherapist in stroke and neurorehabilitation in Wales. We're very grateful to her for taking on this role and we are sure her extensive knowledge and experience will make her an excellent representative of our network.

The joint ACPIN/SNPP splinting guidelines are still being worked on and thanks go to all of you who responded to the call by Dr Cherry Kilbride to participate in the Delphi study. The second wave of that study will happen later this month.

ACPIN has also been involved as a stakeholder in guideline consultations from NICE. Most recently, Jane Petty responded to the MS consultation on our behalf and a team of members produced a response to the recent stroke rehabilitation guideline consultation. This is a role ACPIN are being asked to be involved with more and more, and we are thinking of ways to efficiently and effectively respond to consultations. We really need the views of members to help us to provide informed responses so we would urge you to give us your feedback when the calls come out on iCSP, Facebook and Twitter.

One of ACPIN's aims is to support research activity of our members. We are encouraged by the posters and *Syn'aps*e articles that are sent to us. For some time we have had a research bursary that members can apply for of £1,000. We have had very few enquiries for this money and we would like to encourage members to access this funding to support research costs. £1,000 can cover costs such as patient travel, postage, transcription costs etc.

Syn'apse continues to be a successful publication for our network and we are continually on the lookout for articles and features. This year, we awarded two prizes for the best original research and the best practice development articles. The prize was a free place at this conference. Congratulations to Webster, Longbottom and Jones for their paper on Parkinson's disease and also to Rebecca Bradshaw for her paper on CIMT.

After the success of last year's conference, this year's event was a daunting task. Numbers are a little down this year which we think might reflect difficulties members are having getting funding and leave for CPD. We'd be interested on your feedback and insights on this. But despite this, we still strive to make it a successful event for those of you who have joined us today. ACPIN is grateful to the Hilton Northampton for their excellent organisation and Kevin Wade of kwgraphicdesign who produces our conference materials. The Executive Committee and regional representatives have worked hard to come up with ideas and support for the conference. I'd particularly like to thank three people who have worked tirelessly to make it come together: Nikki Guck who organised the exhibitors and sponsors, Chris Manning who developed the programme and liaised with speakers, and Lorraine Azam who dealt with all of the registration, bookings and liaison with the Hilton.

We also have a few sad farewells today. After ten years serving on the committee, we must say goodbye to Anne Rodger and Jo Kileff. Anne has been our honorary secretary for several years and her calm, patient wisdom and experience will be greatly missed. Jo has had the treat of delivering wonderful financial news to us year after year. Our healthy bank balance has, I'm sure, been in part due to her excellent commitment to the treasurer role. Thank you both.

Treasurer's report

Jo Kileff

I will now present a summary of the financial accounts for national ACPIN for the year end 31st December 2012.

The total income (*Figure 1*) was £100,444. This was an increase on last year's income and was mainly due to an increase in income from the March conference, and an increase in our membership. Bank interest remains low and one of our priorities this year has to be to find a suitable place to keep our money, whilst keeping it accessible.

Expenditure (*Figure 2*) for 2012 was planned to and has risen significantly compared to 2011. This was mainly due to two reasons: more conference expenses, with a two-day residential course rather than a single day, and included more audio visual services, including the videoing, and naturally therefore more costs have been incurred. We have secondly paid £10,000 up-front towards some new splinting guidelines, which are being put together in association with NANOT, and we eagerly await the findings. Other costs have small variations between years, but nothing significant.

Figure 3 divides the course income and expenditure up for the conference that ACPIN held this time last year, March 2012. The conference was planned to run at a loss, with low course fees in order to put some money back into the membership. You will see that the course was run at a significant loss.

The balance sheet (*Figure 4*) on the 31st December 2012 showed a small profit of £6,187 and we carry forward reserves of £153,135 into 2013. We have explored and continue to explore ways of feeding this money back into the growing membership. We are heavily subsidising this course again this year and will continue to run our courses at a very low rate, whilst we have the money to do so. We are investigating other ideas to allow regions to benefit. If, as previously, anyone has any suggestions of projects that ACPIN could get involved in that would benefit all members, do speak to one of the committee.

Copies of Accounts 2012

Full copies of the ACPIN accounts for 2012 are available on request.

Vote for Accountants

Vote carried to retain the current accountants for 2013: Langers, 8–10 Gatley Road, Cheadle,Cheshire, SK8 1PY.

INCOME

	2012	2011
	£	£
Course fees	26,133	13,150
Membership	69,015	60,608
Capitation	3,890	5,864
Database	1,343	899
Bank interest	63	59
Total	**100,444**	**80,580**

FIGURE 1

EXPENDITURE

	2012	2011
	£	£
Conference	40,595	12,198
Syn'apse	11,196	8,374
Travel	8,427	9,727
Administration	6,731	3,818
Research	545	0
Capitation	13,045	11,710
Computer costs	188	6,275
UK Stroke Forum	372	457
Splint Guidelines	10,000	0
Accounts, bank, gifts, sundry	3,158	1,472
Total	**94,257**	**54,031**

FIGURE 2

COURSES

2012	INCOME	EXPEND
	£	£
March national conference	26,133	40,595

FIGURE 3

RESERVES

	£
Reserves brought forward	146,947
Surplus/deficit	6,187
Reserves carried forward	153, 135

FIGURE 4

Delegate's report

Stuart McDarby
Manchester Regional Representative

When I first saw the agenda for this year's conference and AGM, my first question was: how will this help my practice? As a physiotherapist based primarily in stroke rehabilitation inpatients, I could perhaps be forgiven for having some preconceptions regarding the two-day programme. I'm pleased to say any concerns were soon laid to rest!

Day one's programme was based around community rehabilitation and featured lectures on service delivery with long-term conditions; exercises for Huntington's disease patients; community stroke service development; a project to enable patients who have been discharged from services to access further rehabilitation over a longer period and a trial looking at rehabilitation for older adult fallers. The ACPIN AGM was in the middle of the day and Friday closed with a choice of workshops. I attended an outcome measures session led by Steve Tolan from the CSP and, like the rest of the day, found it worthwhile and informative.

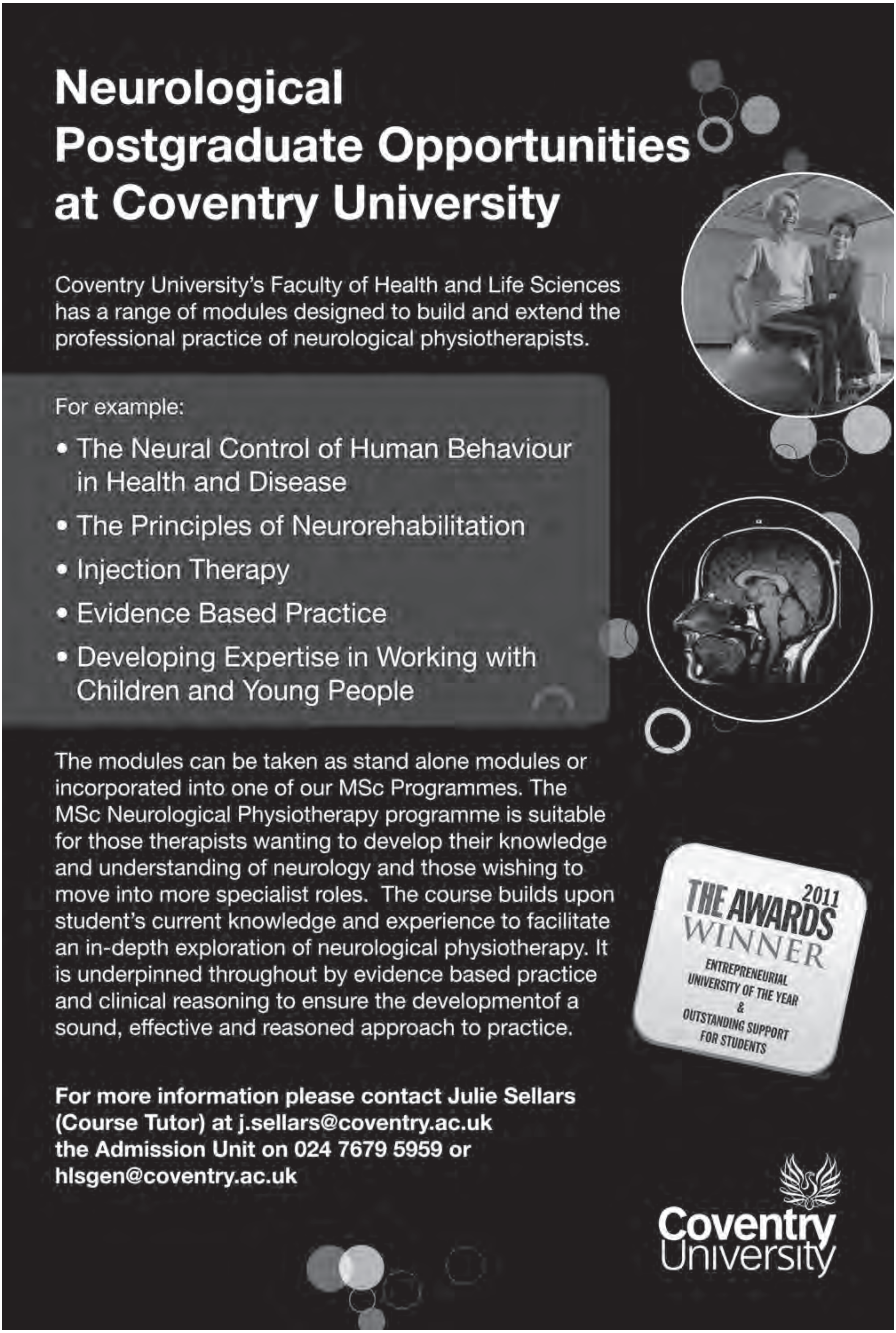
The second day (Saturday) was themed 'Recent advances in Multiple Sclerosis' and, appropriately enough, opened with an engaging lecture on Disease Modifying Therapies in MS by Professor Carolyn Young of The Walton Centre. The sessions that followed included a study on falls in people with MS; the input of the MS Society in developing the new NICE guidelines for MS; an entertaining talk by MS campaigner Tim Worner in remaining active with multiple sclerosis and a perspective on Vocation and Participation with MS. The last session was a panel discussion which prompted a number of interesting points around commissioning services for long-term conditions and how these are likely to be planned in the future.

The conference always provides the opportunity for networking (it was in the title of this year's AGM!) and the consensus amongst those I spoke to was that this year's programme was stimulating and relevant. The speakers presented their projects and studies regarding design, methodology and results in a way that was translatable to current practice. It was possible to draw clear parallels with other long-term conditions and patient populations, especially in the work around falls and developing services. The speakers, as at previous ACPIN events, were well chosen and gave excellent, engaging lectures. It is always useful to hear the perspectives of patients and patient groups and both Tim and Laura spoke with humour and warmth about their work and experiences. The different sessions were chaired by ACPIN committee members and there was opportunity to ask questions, along with keeping the programme flowing! Perhaps most interesting were the points made around commissioning services and how the Department of Health is likely to look at this in the future. As a profession that is heavily involved with care across the whole patient journey and one that has such a strong influence, these discussions are becoming increasingly critical.

As in previous years, the conference benefitted from the excellent facilities at the Hilton Hotel. It is easy to see why this venue remains the popular choice for the AGM. The room space and catering is always to a high standard and the staff friendly and helpful. Friday night also saw the traditional dinner dance with the triumphant return of 'Huggy flares'!

Overall the conference and AGM was a really positive experience. It was good to see physiotherapists from different areas, both clinically and geographically, and staff from both NHS and private healthcare. Quality CPD and study leave are often difficult topics for people and events like this remain valuable and important to us as therapists. I would encourage any members to consider attending next year's AGM/conference.

As I mentioned at the start, I was a little sceptical about the overall pertinence of the course to my practice, but my fears were soon assuaged and I had plenty to reflect on during my drive back to the North West!


THE AWARDS 2011
WINNER
ENTREPRENEURIAL UNIVERSITY OF THE YEAR
&
OUTSTANDING SUPPORT FOR STUDENTS

5 minutes with...

Tom Edwards

Interviewed by **Adele Griffiths**

Can you tell us a bit about yourself?
I am a retired schoolmaster living in the South Wales valleys with my wife who is still working. I enjoy walking with friends and fishing in the mountain lakes. In mid 2012, I was diagnosed with Motor Neurone Disease which has predominately affected my left arm and hand (I am right-handed). I am no longer able to walk long distances but am still independent walking although I occasionally catch my toe.

What has your experience of physiotherapy been like?
At my initial physiotherapy assessment I was quite dismissive of the need to attend physiotherapy and could not really see what benefit I could derive. I agreed to come to a couple of sessions to work on some exercises at home. However, once I found the initial intervention beneficial, I became keen to attend and have continued to attend one to two times a month.

How do you cope with the physical difficulties of having MND?
I am fiercely independent and too proud to ask my family for help with the many day-to-day tasks that have become so much more difficult. Rather than ask for help I spend a long time wrestling with each problem until I solve it.

What about the psychological aspects?
I seem these days to be experiencing mood swings – often times from mountain top to pit bottom! Never before had I considered myself to be moody. I am showing a reluctance to praise my wife and family for their efforts on my behalf – I seem to be taking too much for granted!

I am a very lucky person from the point of view that I have a dozen or more superb "best friends". These have all rallied around with phone calls, visits, trips out for meals and general taxi-ing about. Some of these friends are lifelong and others younger and more able. It gives me great comfort to realize that there is nothing they would not do for me. I know also that I would do the same for them if they were in my shoes.

Do you have any tips or advice for other MND sufferers?
Knowing how pleased I feel on discovering some little tactic that helps me in my condition, I cannot but wonder if Stone Age or Iron Age man did feel elation at the discovery of fire, stone and flint tools and weapons etc. I really hope that he did.

Tom's top solutions include:
- Pull holes to buttons rather than buttons to holes.
- Pass string through zip holes to give you leverage on the zip.
- Use kitchen units to press against to pull zips – to give the tension required.
- Use a rubber pad to help with jars.
- Use a pliers handle through the ring pulls of tins to aid leverage.
- Use sharp scissors to cut meat and sausages.
- Use a melamine placemat to hold paper for writing.
- Use a bulldog clip to hold back cheque book stubs whilst writing a cheque.
- Use a rubber cushion to improve height position and comfort on dining chairs.
- Establish a butter-spreading pattern on toast.
- Work out your movement patterns for dressing/undressing: use easy-to-handle clothes.
- Keep doing crosswords and word searches to keep your brain active.
- Do the exercises given to you by your physio!
- Know your limitations – in stamina and movement.

Tom also shared some of the equipment he has found particularly helpful
- Long-handled shoe horn.
- Footwear with Velcro fastenings.
- Cushion–bottomed tray.
- Rubber pad for jar tops.
- Deckchair [from Nauticalia] for holding books to read.
- Thermos mug – keeps drinks hot and has a useful carrying handle so that you can hook it onto your belt.
- Automatic fly fishing reel by Vivarelli – handles a loose fly line which is impossible to manage with my left hand.
- Camera which can be managed with one hand – Panasonic Lunix TZ 20 – brilliant – allows me to photograph my exercises and my new grandchild.

News

WFNR launches award to mark brain awareness week

To support Brain Awareness Week (11–17 March 2013), The World Federation for Neurorehabilitation (WFNR) has launched the WFNR Franz Gerstenbrand Award for clinicians, researchers and allied health professionals to recognise and reward a neurorehabilitation project that has benefitted patients.

'We're delighted to announce this Award, worth £3000, during Brain Awareness Week to highlight our work in neurorehabilitation,' said Stephanie Clarke, WFNR President. The annual, single prize will be awarded as either a travel bursary to a clinical conference, professional development course or research project.

Named after Professor Franz Gerstenbrand, in recognition of his continuous contributions to neurorehabilitation, the award is open to WFNR members and non-members worldwide.

Entries can come from any aspect of neurorehabilitation and examples include a patient or clinic management initiative, research project, best practice development or the use of a new technological development. A panel of four or five judges, led by the WFNR President, will review the entries.

For further details and details on how to apply, visit www.wfnr.co.uk

The WFNR was established in 1996. It is a multidisciplinary organisation based in the UK and open to any professional with an interest in neurological rehabilitation. The organisation exists to act as a forum of communication between those with an interest in the subject. The WFNR now has over 4,000 members worldwide with National Societies in various countries affiliated to the WFNR. In addition, there are over 25 Special Interest Groups formed for topics as diverse as mild brain injury, robotics and telerehabilitation.

ACPIN membership

Sandy Chambers MSc MCSP SRP
ACPIN Honorary Membership Secretary
Email: memsec@acpin.org

The new ACPIN membership software is up and running! Thank you to all who have been brave and signed into the system to set up their new memberships or renewals or who have just had a look. And a BIG thanks to those who ran into problems and worked with me to get them solved. Though there are still some parts that are not complete and not all bugs are out, as of writing this, we are definitely on our way.

The new system, when complete, will allow members to see their details and edit them in real time, if needed, without needing to contact anyone and wait for a response. You will also be able to see your payment history and details. Additionally, the entire system will be much more automated from the administrative end, saving time and money – very important to all volunteer organisations! As a bonus, we hope that everyone will find this new system easy to manage and negotiate.

In part due to the online system, we began 2013 with over 2,400 registered members. I expect that success to continue and to grow as our added efficiency keeps ACPIN one of the best value-for-money Professional Network groups in the CSP.

Please feel free to contact me with any questions or suggestions you have about our membership system.

ACPIN email

Regional representatives can now be contacted via dedicated ACPIN email addresses (see page 56) – usually the region name followed by '@acpin.net'

For regional representatives your region's email account can be accessed via the ACPIN website using the 'ACPIN email' login button on the homepage and entering the account name and password (obtainable from the ACPIN secretary). This also applies to Executive Committee members.

The advantage of using these email accounts is twofold: firstly, when a representative leaves post, emails do not have to be forwarded to the new representative and secondly the account can be accessed via a web browser on any computer which has an internet link.

Visit the ACPIN website

to apply for or to renew your membership, find out what is happening in your region, download past presentations from ACPIN conferences and much more!

www.acpin.net

Neurology programme at Physiotherapy UK 2013

Below is the programme for the neurology strand at this year's Physiotherapy UK.

It is on Friday 11th and Saturday 12th October 2013 at the International Convention Centre in Birmingham.
Book early and save money. Confirm your bookings by May 18th and get two days for the price of one.* See website for full details www.physiotherapyuk.org.uk

FRIDAY 11 OCTOBER
A cabinet of curiosities: shaping physiotherapy through opportunity
Dr Emma Stokes

Grasping opportunities – maximising influence
Lesley Mercer TUC President

2013 *NICE guidelines for stroke rehabilitation*
Sandy Chambers MCSP NICE GDG

Navigating change and making an impact: the way forward
Dr Fiona Jones FCSP President ACPIN (pictured left)

Enhancing quality of life for people with long-term conditions
Jill Lockhart MCSP NHS Improving Quality

Focused symposium: strategies for implementing the guidelines
Dr Gita Ramdharry MCSP Chair ACPIN
Debbie Neal MCSP Consultant physiotherapist
Louise Rogerson MCSP Commissioner
Jill Lockhart MCSP NHS Improving Quality

SATURDAY 12 OCTOBER

Applying the 2013 *European Guideline for Physiotherapy in Parkinson's* to UK Practice
Dr Anna Jones MCSP (pictured left)
Fiona Lindop MCSP
Bhanu Ramaswamy MCSP

Neuro poster presentations

Improving physical function beyond physiotherapy – the evidence and the scope of partnership working
Suma Surendranath MCSP Parkinson's UK
Professor Lynn Rochester MCSP PhD

The Francis report
Dr Helena Johnson MCSP Chair of Council CSP

***The Francis report* – still worried?**
Catherine McLoughlin CBE Independent management consultant

Consultation and the organisation
Karen Middleton CBE Chief Health Professions Officer, NHS Commissioning Board

* Full members only. Other discounts applicable to other member groups.

Physiotherapy UK
CONFERENCE & TRADE EXHIBITION 2013

Reviews

Reviews of research articles, books, courses and equipment in *Syn'apse* are offered by regional ACPIN groups or individuals in response to requests from the ACPIN committee. In the spirit of an extension of the ERA (evaluating research articles) project they are offered as information for members and as an opportunity for some members to hone their reviewing skills. Editing is kept to a minimum and the reviews reflect the opinions of the authors only. We give the authors of the original book or paper the opportunity to respond. We hope these reviews will encourage members to read the original article and not simply take the views of the reviewers at face value.

Physiotherapy UK 2012

Dr Jacqueline Crosbie
ACPIN Northern Ireland regional representative

It had been around 15 years since I had attended the UK national CSP meeting. So when the opportunity of going on behalf of ACPIN came along, I was keen to go. The event has morphed from the CSP Congress into Physiotherapy UK, which I think is a good move and brings a different perception of the event and helps to make the CSP brand more cohesive.

The last time I had been to this event it was held in the Birmingham NEC. In 2012 it was held in the city of Liverpool. This was another plus point for me as I had never had the chance to visit Liverpool. It was going to be great to visit the city so strongly associated with the Swinging Sixties, the Beatles, football and many other aspects of popular culture.

I was impressed by both the city and the Physiotherapy UK event. Around 800 delegates gathered from 12-13 October, and around 80 clinical experts gave us the benefit of their knowledge and experiences. The conference followed the three main therapeutic themes of neurology, cardiorespiratory and musculoskeletal and also added the theme of health care issues. I think this was useful as we like to hear about the most up-to-date research in our clinical area but do not necessarily then think about how it will translate and fit with current policy developments and the organisation of health care.

Take-home messages

Exercise is the key. This would not be new to physiotherapists; in fact Plato wrote that 'lack of activity destroys the good condition of every human being'. The overwhelming evidence from research is that the promotion of, and encouragement to engage in, physical activity is vital for the health of the general population and for those with physical disabilities. Professor Helen Dawes, Oxford Brookes University, drew attention to some of the issues around the exercise response and recovery in people who have neurological conditions. It is thought that around 1.5 hours per week of moderate to vigorous exercise are needed to have health benefits in the general population. There is no evidence of harm to those with neurological conditions when engaging in such levels of activity. However, exercise levels remain low in the general population and may be even lower in those with neurological problems.

There was a glimmer of hope to offer, in that studies have shown that as little as one x 20 minute session of light exercise has shown a measurable effect on mobility and well-being in people with Multiple Sclerosis (MS). Taking exercise of higher intensity may increase the health benefits but conversely can also reduce the person's tolerance. People with MS may also have a delayed heart rate response to exercise which can normalise over time and is trainable with exercise. An overriding reason people with MS stop exercising are the lower limb symptoms they can experience when physically exerting themselves. These are not well tolerated but can improve as the person's strength and fitness improve. This information should be helpful when therapists are trying to get patients to engage in exercise programmes.

The National Sentinel Stroke Audit recommends that stroke patients should receive at least 45 minutes of rehabilitation per day whilst in a stroke unit. Professor Avril Drummond, Nottingham University, explained that in the main this does not happen across the NHS and for lots of reasons. However, other European countries were further ahead at delivering this as a minimum. There was generally a need for better use of resources and a reorganisation of ways of delivering rehabilitation.

Highs and lows

A particular high point was the speech from Katie Piper, a burns survivor, who gave the 2012 Founder's Lecture. She was attacked and had acid thrown in her face when she was 24 years old. She had been a model and TV presenter at the time and she told the story of her recovery. She sustained severe burns to her face, and thorax and was also left blind in one eye. She was inspirational as she spoke about her decision to survive and turn her life around. She underwent specialist rehabilitation and had much praise for the physiotherapists who delivered this. The day of her speech was her birthday and the audience responded with a chorus of 'Happy Birthday'. The CSP donated £6,000 to the Katie Piper Foundation following the event.

For me, a low point was the presentation about personal health budgets given by Stuart Lane from the Department of Health. I had hoped to hear that the scheme had been successful in allowing people with disabilities to manage the financial help they receive from central government at a local level, and to purchase services relevant to them. The method has been piloted from 2009 in several areas in England and Wales. There were some success stories from users, but my impression was that the system was costly and difficult for some users to work with.

Things I didn't know

'A deep breath can move the median nerve.' Jane Greening revealed this in her presentation on the specifics of non-specific arm pain (NSAP). She explained a number of mechanical factors that are present in NSAP, eg during shoulder and arm movements the first rib should elevate to allow the median nerve to slide and this does not happen in people with NSAP. Also, wrist movement should cause the median nerve to slide at the level of the joint but again this does not happen in cases of NSAP. Inflammation changes the water content of nerve tissue and this seems to happen profusely in NSAP.

Most entertaining session

This was a session on the Angel Taxonomy, which turned out to be a method of categorising patients and care across the NHS. The presenter was very funny and witty in the delivery of what could have been an uninspiring topic, changing it into one that everyone at his session wanted to hear more about. Essentially he told the story of how a method of managing complex care had been developed in Wales, producing a common language that was meaningful to health care staff and enabled them to organise health and social care services in a more targeted and efficient way. He probably could earn a better living as a stand-up comedian, and was very practical and common sense focused. I'd encourage people to find out more by looking at www.complexcare-wales.org

Practical tips for clinical practice

How to use cueing effectively for people with Parkinson's disease was a really good practical workshop given by Professor Lynn Rochester, Newcastle University. The types of cues to use at the various stages of the disease were explained, ie breaking down tasks and attentional cues for people with Hoehn and Yahr stage I-II; external or visual cues with stage II-II; and increasing help from carers to provide external cues in stage III-IV. It was also suggested that cues have a hierarchy of introduction: start with attentional cues (such as thinking or vocalising cue words out loud), then auditory, then visual and ultimately if necessary enlist help of carers to provide external cues. Smart phones and MP3 players use technology to provide audible and variable speed metronome counts or musical cues. Another practical suggestion was the side stepping strategy to help a person to move around the kitchen or living room. Cues are unlikely to be useful to someone with significant cognitive deficits or who lives in a very chaotic environment. The person's ability to dual task may also need to be assessed and taken into account as the individuals cognitive reserve can get used up very quickly.

Prizes

A *Dragon's Den*-style competition offered a prize of up to £5,000 from the CSP Charitable Trust for innovative physiotherapy projects. Dr Kathleen Reilly, a research physiotherapist from the Nuffield Orthopaedic Centre, won £1,000 to fund the creation of a prototype anti-pronation sock. The 'dragons' were Dr Karen Barker, clinical director of the musculoskeletal directorate at Nuffield, Dr Lesley Holdsworth, director of NHS 24, Sammy Margo, a CSP spokesperson in private practice, and Professor Graham Smith, a rehabilitation and sports injury consultant.

Overall, I thoroughly enjoyed the whole event and appreciated having the chance to represent ACPIN at the professional networks stands, alongside the trade exhibition. Happy to help again next year if you need someone!

International Neuroscience Physical Therapy Association (INPA) update

Ralph Hammond MCSP
ACPIN south west

The International Neuroscience Physical Therapy Association (INPA) represents national groups of physical therapists with a specialist interest in neurology and neuroscience.

INPA aims to support national organizations and individual physical therapists with an interest in advancing the scope and practice of neurological physical therapy by supporting and facilitating research, evidence-based practice, clinical specialization, knowledge exchange, inter-professional and international collaboration and promotion of partnerships with clients and carers.

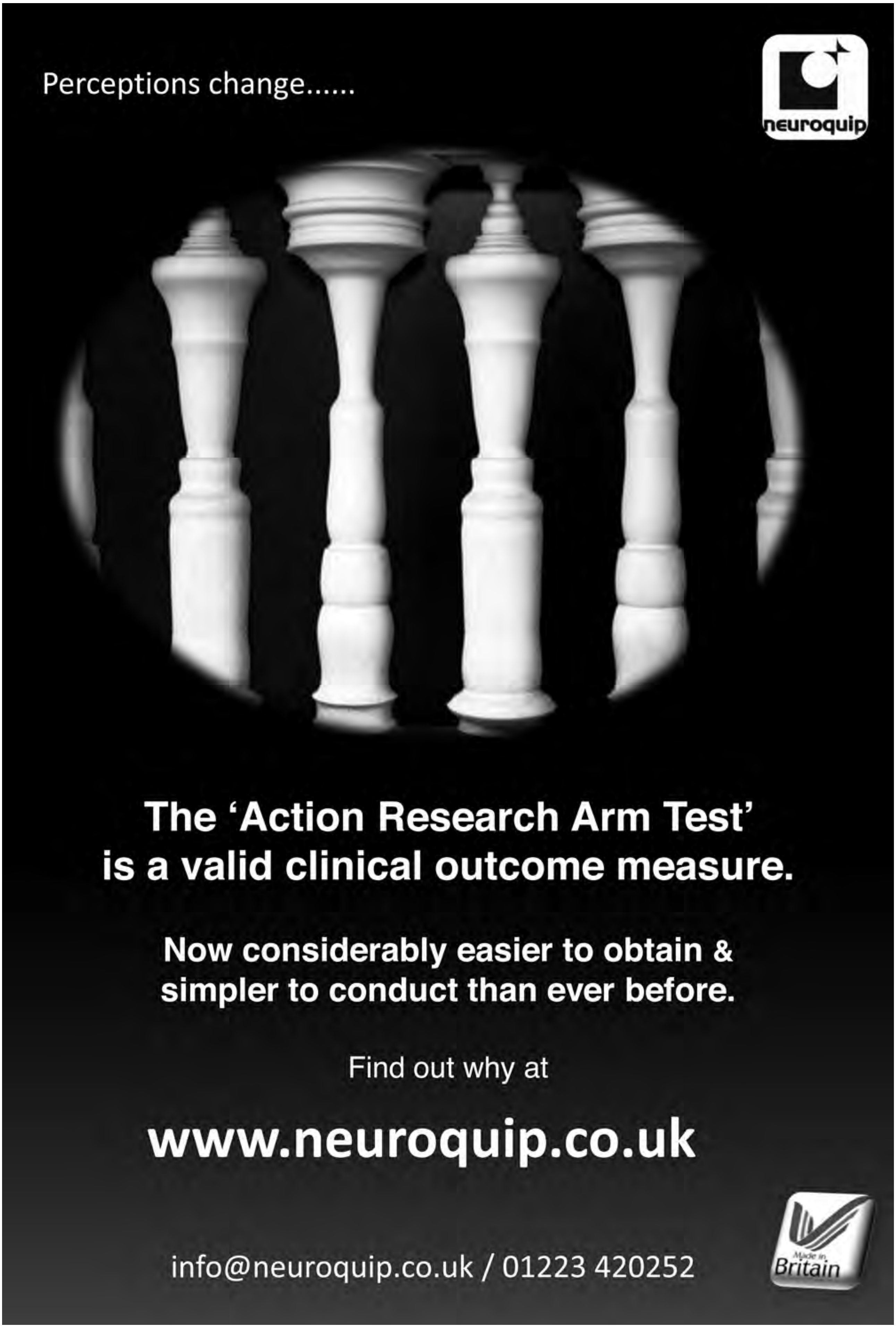
The vision of INPA is a global interest group of neuroscience physical therapists committed to excellence in neuroscience physical therapy in clinical practice, research and education. The collaboration is the recognized international voice for neuroscience physical therapy.

In March 2013, Ralph Hammond, the ACPIN representative to INPA, attended a two-day training event hosted and delivered by the WCPT secretariat. WCPT is the World Confederation for Physical Therapy. Founded in 1951, the World Confederation for Physical Therapy (WCPT) is the sole international voice for physical therapy, representing more than 350,000 physical therapists worldwide through its 106 member organisations. The confederation operates as a non-profit organisation and is registered as a charity in the UK (www.wcpt.org).

The aims of the two days were to:

1. Understand WCPT's strategic plan and its implications for subgroups
2. Share knowledge and experiences to address a range of practical issues
3. Consider responsibilities, expectations and management of the subgroup – WCPT relationship
4. Understand WCPT brand identity and its communications and marketing strategy and how this relates to subgroups
5. Identify opportunities for collaborative working
6. Develop a forward work plan
7. Develop an action plan to take back to subgroup executive committees

These were two excellent days. There was time to share experiences, ideas and knowledge about how to develop INPA. Ralph will be feeding back to the INPA executive committee the action plan he developed over the course of the event. ACPIN members, who want to know more about INPA, please go to its Facebook page.



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Resources of interest

ElearnSCI.org

An international web-based teaching resource for Spinal Cord Injury

Recognising the need to disseminate information about comprehensive management of Spinal Cord Injury (SCI), the International Spinal Cord Society (ISCoS) took the initiative to develop elearnSCI.org, a web-based teaching and educational resource.

elearnSCI.org specifically addresses the current lack of professional development opportunities for medical and paramedical professionals involved in SCI Management due to the limited access of up-to-date SCI training and learning materials/resources. The content has been developed by 332 leading SCI professionals and educationalists from around the world and reflects realities in both high and low resource settings. The content has been informed by the most up-to-date SCI research and as such will be of relevance to students, those new to the field of SCI and to SCI practitioners everywhere. The Asian Spinal Cord Network (ASCoN), Indian Spinal Injuries Centre (ISIC), Livability and the Lifetime Care and Support Scheme have partnered with ISCoS to develop this resource, with financial support from Access to Health Care.

The aim of this resource is to provide comprehensive information on SCI management to students and clinicians from all medical and paramedical disciplines involved in SCI care. The educational resource comprises seven modules each consisting of various sub-modules. The 'Overview for the whole team' module provides basic information of SCI Management for all disciplines involved in Spinal Injury Management. Five other modules cater to the needs of various disciplines ie doctors, nurses, physiotherapists, occupational therapists/assistive technologists, and psychologists/social workers/peer counsellors. It is recommended that users go through the first module, 'Overview for the whole team' before they access their discipline-specific modules. The seventh module provides information on various aspects pertaining to the prevention of SCI.

Each sub-module covers a specific component of SCI management and includes:

- a presentation giving an overview of the topic
- activity-based learning exercises
- references
- self-assessment questions

The project was approved in October 2010 during the ISCoS Annual Scientific Meeting in New Delhi and work began immediately thereafter. 332 experts of ISCoS and various affiliated societies from 36 countries have been involved in compiling the resource through 28 subcommittees, each working on a particular sub-module. This widespread participation has given it a global perspective. The consensus document for each sub-module has been reviewed by the Education Committee and Scientific Committee of ISCoS. An Editorial Committee comprising 23 experts met in New Delhi in April 2012 to review and edit the sub-modules. Editorial work continued online thereafter.

The web platform for hosting the educational resource has been developed at New Delhi by Grapes Software. This company was shortlisted after a detailed process of evaluation of various interested applicants. The web platform is underpinned by a sophisticated interface to enable ISCoS administrators to be largely independent of ongoing IT support on completion of the project. The interface enables the administrators to upload, move, copy and change the content of any screen and all interactive activities. This feature was considered important for the long-term viability of the project.

elearnSCI.org was launched during the International Spinal Cord Society's 51st Annual Scientific Meeting in London on 4th September 2012 but will continue to evolve in the coming years.

ElearnSCI.org is an initiative of the Education Committee of the International Spinal Cord Society (ISCoS).

Modules

This module is intended as an introduction to the **basic principles of SCI management** appropriate for all members of the multidisciplinary team. It covers topics such as prehospital care, acute medical care, management of vertebral lesion, management of bladder/bowel, management of complications, psychological support, comprehensive rehabilitation and the role of different health professionals.

How to use this Website?

This website is for medical and paramedical professionals working in the field of spinal cord injuries. It contains learning modules for the whole team as well as for doctors, nurses, physiotherapists, occupational therapists, assistive technologists, social workers, psychologists and peer counsellors. The modules are intended for medical and paramedical students and junior clinicians. Others who have yet not assimilated sufficient knowledge on comprehensive management.

Message from President ISCOS

The eLearning project of ISCoS is born out of the Society's objectives to advise, encourage, guide and support the efforts of those responsible for the care of patients with spinal cord injury and to support the efforts of those responsible for the education and training of medical professionals and professionals allied to nursing. The aim is to improve their knowledge and skills to benefit individuals with spinal cord injury.

About elearnSCI.org

Recognising the need to disseminate information about comprehensive management of Spinal Cord Injury (SCI), the International Spinal Cord Society (ISCoS) took the initiative to develop elearnSCI.org, a web-based teaching and educational resource. elearnSCI.org specifically addresses the current lack of professional development opportunities for medical and paramedical professionals involved in SCI Management due to the limited access of up-to-date SCI training and learning materials/resources.

Audio-Visual on elearnSCI.org

Website to be best viewed in IE8, IE9, Mozilla 15.0.1 and above, Chrome 21.0, Safari 4.0.3

Vision

As the authority on the management of spinal cord injuries, ISCoS will aspire to promote free and easy access to relevant educational resources on 'Comprehensive Management of Spinal Cord Injuries' amongst health professionals involved in SCI management and also amongst people living with spinal cord injury, their families, health care providers, policy makers and the community in general.

Mission

The mission of elearnSCI.org is to improve the quality of lives of people living with spinal cord injury by disseminating awareness about spinal cord injury prevention and comprehensive management globally.

brainaid.com

Meet PEAT. A life-changing Android™ app for people with cognitive challenges. PEAT helps individuals with executive function disorders complete more real-world tasks, improving their quality of life and independence.

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mindMender Traffic Controller

www.mikezachry.com/projects/mindmender/traffic-controller/

Subscribe to this page to stay in the loop about the mindMender Traffic Controller iPad game to exercise and improve upper extremity and eye-hand coordination.

CSP resources

Learning information services maintains a current awareness page on the CSP website (www.csp.org.uk/professional-union/library/current-awareness) about how to ensure that you keep fully up to date with the latest developments. The page tells you about other current awareness services, journal alerts, database alerts, RSS feeds and much more.

The current awareness page mentions a service called CASH – Current Awareness Service for Health – this is a superb service offered by the NHS Improvement Network. You can chose a specialist area/s that you want to be kept updated on, and results can be emailed to you (or sent via RSS – the choice is yours). If you want a general overview of what is happening in all the specialist areas, then you can chose the CASH full newsfeed, and/or the Daily Health Bulletin (a daily round-up of all the latest health news stories and hot topics, including reports and guidelines from the Department of Health and NICE).

The CASH website is a fantastic source of information and is well worth a look.

Current awareness

Keeping up to date with information is often referred to as 'current awareness'. This guide lists four common ways to do this.

1: Journal alerts

2: Topic alerts

3: Web information

4: RSS feeds

Regional reports

East Anglia

Nicola Alexander

2012 saw our membership numbers continuing to grow and a strong committee. We have welcomed Paul Chapman into the role of secretary while Anna Colbear has taken a break for maternity leave.

Last year's programme was well received and well attended. In the autumn we ran two successful courses: a locomotion weekend taught by Bobath tutor, Helen Lindfield at Ipswich Hospital, and a Spinal Cord Injury course tutored by Debbie Hill at Norwich Community Hospital. Unfortunately, the Spinal Cord Injury course was not filled, but all attendees provided very positive feedback.

The 2013 programme to date has included a motor relearning course by Gemma Alder at Ipswich Hospital. Gemma's humour and enthusiasm made the day very enjoyable. We were certainly all provided with enough reading material for the next few months!

The rest of the 2013 programme at time of writing is:

- May 2013 AGM and MS lecture at UEA
- 28th August 2013 – Connective tissue and fascia course at Addenbrookes
- autumn – Exploring cognition – venue and date tbc

We hope that the 2013 programme is as successful as last year's; we endeavour to provide a programme that caters for the whole of the membership, so if you have any course ideas, or are able to provide alternative venues, please get in touch. Look forward to seeing you this year.

Kent

Nikki Guck

I would like this time to thank the membership in Kent ACPIN for their support in the last year; we have more than doubled our numbers and far exceeded our wildest dreams in such a short space of time. We hope this is as a result of our committed team delivering brilliant study days and the drive of the professional networks to provide excellent evidence-based education which is impacting on everyday practice.

As a committee we fully understand the struggles for study leave and the prices of courses so we have tried hard to ensure that they are delivered at an affordable cost, but meet the needs of the membership.

In November 2012, we were able to provide a brilliant two-day Aquatic therapy course in adult neurology delivered by Dr Heather Epps. The course was a mix of theory and practical and we were able to tailor it to meet the needs of the delegates, successfully using clients to demonstrate the techniques. The feedback was brilliant and we may be able to follow up with another advanced practical component in the near future if required.

Unfortunately, in December 2012, we had to delay our Christmas lecture, but plans are afoot to deliver the kinesiology study day in June 2013.

As we go to print we have been able to provide an excellent ataxia study day in conjunction with our AGM in March 2013, delivered by Professor John Marsden and Dr Lisa Bunn from Plymouth University. The response to the course was fantastic and we are thankful to both John and Lisa for delivering a brilliant thought-provoking day.

We have a 'save-a-date' for your diaries for 11th May 2013, when Professor John Rothwell will be providing Kent ACPIN with a study day on 'The Basal Ganglia and movement control with implications on clinical practice'. Professor Rothwell has provided us with fantastic study days in the past and we are grateful for his support to the education and development of the neurotherapists in Kent.

Our programme is always unfolding and there are plans for a stroke study day later in 2013; we hope to use the excellent knowledge of local clinicians and new innovative practice. All new dates will be notified to the membership, and advertised on the website.

As a committee we would like to send our heartfelt thanks to two committee members that are stepping down. Chris and Morag have provided tireless commitment to Kent ACPIN and we wish them success in their future ventures. Additionally, we would like wish Hannah every success and luck with the upcoming months and the birth of her new baby. We shall see you back on the committee later in the year.

As the region covers a large geographical area, we as a committee are always keen to hear from members that wish to join us, especially as we have lost three members from the committee. It is very sociable, as well as being a good time to network and discuss changes that are occurring in the ever-changing NHS and private sectors.

We are always also looking for members to send us ideas for future courses and evening lectures. Please do not hesitate to contact either myself or anyone on the committee on kent@acpin.net – we look forward to hearing from you.

London

Andrea Shipley

London ACPIN is, as ever, expanding and events continue to be well attended.

Sadly this year we have to say goodbye to our regional representative of the last few years, Andrea Stennett. Andrea has had to relinquish her London representative role that she has performed so efficiently and despite trying to shake off the responsibilities sooner, the Committee have resisted this move until now. She has represented us well and we would like to take this opportunity to say 'big thanks'. I have the unenviable task of taking her seat, trying to fill her shoes and trying to represent us as steadfastly as she has done. Thankfully Andrea has agreed (despite her hectic schedule) to stay on the committee, so we do not lose her wise input completely.

The name of your new regional representative is Andrea Shipley (yes a little confusing, often catching out the current committee members!) and I am here to serve you, or at least offer you representation as best I can.

So let's cut to the chase: this year we have a most magnificent programme that I feel I can safely say offers something for everyone.

We kicked off in February with Liz Dewar's evening presentation on 'The principals of exercise prescription in neurology' and had the AGM on the same night.

In March, Mindy Levin devoted a Saturday to teach us the latest on 'Motor control and motor learning in neurology rehabilitation'.

On June 15th we will have our half day research update. Topics will be confirmed nearer to the time.

We will have our cheese and wine evening on September 12th with a lecture by Catriona Neville on the management of facial palsy.

Finishing the year off on October 26th we have a day with New Zealand's expert on goal setting, Dr William Levack

All this, if not free, then at a complete bargain rate for ACPIN members. We look forward to seeing you in 2013.

Manchester

Stuart McDarby

2012 was a successful year for Manchester ACPIN, where we provided a combination of evening lectures and, supported by Yorkshire and Merseyside ACPIN, ran a well received two-day course in September.

The two-day balance course was led by internationally renowned tutors Anne Shumway-Cook and Marjorie Woollacott and was undoubtedly the highlight of the year. Feedback was overwhelmingly positive and attendees left with valuable ideas and information.

The committee wishes to thank all those speakers who have helped us provide a programme and venues in 2012 and we look forward to working with you again in future!

From a committee perspective, we have welcomed a new member in Lindsay Suddell, whilst the other core members of the team remain intact. These are: Claire (Chair); Helen (treasurer); Anna (Secretary); Stuart (regional representative); Lorraine (national executive committee) and members Dani and Lindsay.

Claire is to step down from her position as Chair at the March AGM and we wish to thank her for her invaluable help and contribution over recent years. Motherhood duties permitting, we hope she continues to play a part!

We are putting together a programme for 2013 which we hope our members will find exciting and interesting, as well as relevant to current physiotherapy practice. In March we had our AGM and an evening lecture which we encouraged all our members to attend. Other courses planned for this year include: upper limb function, spinal cord injury and functional disorders – as always we will provide full details nearer the time.

Thanks again to all our members and we look forward to seeing you in 2013!

Merseyside

Anita Wade-Moulton

Our membership stands at 60 and at present these are our executive committee and committee members

- President – Sharon Williams
- Chairperson – Jenny Wynne
- Secretary – Heather Linnane
- Treasurer – Jo Haworth standing down – nominated Sami Bartley
- Membership Secretary – Jackie Isaacs
- Regional representative – Anita Wade-Moulton
- Yahoo Internet account – Sami Bartley
- Committee Member – Caroline Child

Unfortunately due to unforeseen circumstances the November course organized with Clare Fraser (Bobath tutor) and 'The shoulder' lecture had to be cancelled at rather short notice. There have been a few changes within the committee over the last year and hopefully we are now starting to pull things together after the past 'rocky' year.

Thank you to all who sent back the 'Survey Monkey' which helped the committee in reviewing what members in Merseyside ACPIN want from their local ACPIN and helped us in planning for the next twelve months.

We have lots of exciting topics to cover, with a combination of lectures and workshops to be organized at varying times (evenings, Saturday mornings and weekends) so hopefully there will be something to suit everyone. The difficulty now is pinning down the people to deliver these on a particular date!

We will email members as soon as specific dates and times are organized for the proposed programme. The following are planned but dates still have to be confirmed:

- May – Fatigue management
- June – half day Vestibular workshop
- August – Functional psychology
- October – MS lecture
- June/November – Bobath weekend course

As ever we are always looking for new committee members to join the team to help in planning and keeping the Merseyside ACPIN fresh and bringing new ideas forward.

Northern Ireland

Dr Jacqueline Crosbie

The 2012-13 ACPIN programme for Northern Ireland has so far run from October 2012 to January 2013, with monthly evening lectures. We opened the year with a talk on the management of incontinence in people with disability, from Martina Daly, a local incontinence management nurse. In November, we had a session focusing on the neuropsychology aspects of falls, from Shelley McKeown, a clinical psychologist. For this year's sessions we have altered the time of the evening lectures, moving from 7:30 to 6:00 pm. We hope to attract members and colleagues to come along 'after work' rather than going home and coming back into Belfast again. We shall see if this boosts the numbers of regular attendees as this can fluctuate from month to month.

In February 2013, we hosted a demonstration session of a sleep system by Hugh Kerr, from Moorings Mediquip followed by our AGM. NI ACPIN is planning to run two courses in 2013. The first will be on upper limb rehabilitation from Catherine Cornell scheduled for 3rd and 4th May. We are also planning a Parkinson's disease study day, hopefully taken by Fiona Lindop.

In June 2011, the minister for Health, Social Services and Public Health in Northern Ireland announced that a review of the provision of health and social care was to be undertaken. The main conclusion was that there was an unassailable need for change and so there has been an ongoing series of seminars run by the NI DHSS&PH to disseminate the findings of the review and to promote a new model for the provision of health and social care services in NI.

The job situation in NI for newly qualified physiotherapists continues to remain difficult with financial restrictions placed on filling vacant posts. Attending ACPIN meetings continues to be a good way for those who are still seeking employment to maintain clinical knowledge and to network.

Our past chair Anne-Marie O'Kane was successful in gaining a promotion and has returned to employment in Belfast so she has resumed the position as chair for this year. There has been no other change to the NI elected officers.

- Chair – Anne-Marie O'Kane
- Secretary – Carla McGuigan
- Treasurer – Sarah McConnell
- Regional representative – Dr Jacqueline Crosbie

Northern

Anne Wood

2012/2013 has been a busy year for Northern ACPIN committee with a baby boom within the committee adding an extra challenge to our organisational skills. Following the success of our launch of 'Best in practice' evening lectures in 2011/2012, it was decided to continue this theme into 2012/2013. Recent topics have included: Motor neurone disease, acute head injuries and movement disorders. In February 2012 the evening lecture, 'The Bobath Concept, its place in contemporary neurorehabilitation' was led by Paul Johnson and in March the topic was 'Functional disorders' led by Jason Price, a neuropsychologist. We are currently formulating further 'Best in practice' lectures for the coming year.

Northern ACPIN also ran a 'Casting in neurology' practical workshop in June 2012 and the course 'Motor relearning: a problem-solving approach, theoretical and practical applications in neurophysiotherapy for stroke in August 2012. We have managed to book Sue Raine, Bobath tutor for a course in June 2013 (topic to be determined) and are planning to run courses in vestibular rehabilitation and acupuncture in neurology later in the year.

We welcome any ideas for courses, lectures or events for the future and are very keen to receive any members who would like to join our friendly committee.

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Oxford

Claire Guy

From our committee to all Oxford members – welcome to our report for the spring edition of *Syn'apse*. Our evening lectures remain the mainstay for Oxford ACPIN with regular attendance over 20 and although the venue tends to be Oxford, we will hope to be sharing these more widely. Please let the committee know your preference on venue location.

The autumn programme was successful: Clare Park, SLT talking on dysphagia; Professor Derick Wade, on the minimally aware state and four Spinal Injury 'stations' at Stoke Mandeville demonstrating different level of SCI functional outcomes.

The spring programme started with Professor Helen Dawes who stole the attendance record with a talk around latest research results for exercise and MS, and once again made this information accessible and transferable to the clinic setting.

Pat Postill spoke on 'Posture management unwrapped' and shared the wealth of her experience in finding posture solutions for complex disability and Stana Bojanic was once again a welcomed AGM speaker – 'Spinal cord anatomy and infarct'. Other planned talks are the 'Painful shoulder' with Jo Pierce; FES with Natalie Wallace; a patient's story, as he prepares for a marathon following a significant traumatic brain injury and a talk on functional outcomes following Spinal Cord Injury with two staff from the NSIC, Stoke Mandeville. There will also be a talk on brain imaging.

Two courses are planned: vestibular rehabilitation in May 2013 and an Ataxia course in November with Sue Armstrong. Please look at *Frontline*, where most of the meetings are advertised, to check out the venue, and also on the ACPIN website on our regional page. If in doubt, please contact me on the address below.

A big thank you to our members for your commitment at lectures. Keep any ideas coming to us; you can contact me on oxford@acpin.net

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Scotland

Gillian Crighton

We have another busy year planned for ACPIN Scotland. We started off on the 25th of April with the MS study day in Perth, followed by an Apraxia study day and AGM on the 18th May in Dundee. A goal-setting day is planned for the 18th October in Perth and a balance course towards the end of the year.

We are really keen for new committee members, meeting around four times a year in Perth. If you are interested in joining our committee or wish to find out more about what we do please contact me on scotland@acpin.net

If you would like to share any academic work, useful websites or the results of your projects with other ACPIN members please contact me, or alternatively you could write an article for *Syn'apse*.

Suggested website: www.physiotherapyexercises.com. This is a really useful site to download individualised patient exercise programmes. It is free and easy to use.

South Trent

Laura Mitton

The last few months have seen South Trent ACPIN hosting a number of evening lectures including an insight into 'Movement science' at Kings Mill Hospital which was well attended. In November a clinical psychology lecture 'A life plan interrupted' was hosted in Leicester which received very positive feedback.

The coming year looks busy for South Trent including evening lectures in March by the Wii Star research team and an insight into stem cell research. In April we held a 'journal club' reviewing research concerning Pusher Syndrome and in June we are hosting a weekend course looking at the head, neck and thorax led by Sue Raine.

Other courses include a morning workshop on spasticity and a day course on low tone (dates TBC). If you require any further information please do not hesitate to contact the regional representative Laura Mitton on southtrent@acpin.net. We are always looking for new committee members and welcome any new ideas from any of our members.

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South West

Helen Madden

South West ACPIN continues to be active within the region with our membership currently approximately 200 members. We successfully held a raffle in 2012 with a prize of two places at national ACPIN conference with the prize gratefully accepted by two of our members (one based in Bristol and one based in Devon). We plan to continue with the raffle in 2013 and further details of the terms and conditions are on our webpage.

Our committee are currently based in Bristol with a subgroup in Devon, and we potentially might also have a subgroup forming in Cornwall this year. Our committee numbers have unfortunately dwindled in numbers in 2012 due to people going on maternity leave or people moving out of the area. So if you are interested in getting involved in ACPIN in the South West then please get in touch, as there are likely to be people on the committee near you who you can connect with, whether you are based in Bristol, Devon or Cornwall.

Courses organised over the last six months have been held in various locations including Barnstaple, Cullompton, Somerset and Bristol and have included a motor learning study day, gait training evening lecture, orthotics evening lecture, BBTA problem-solving workshop in optimising functional environments in the community and our AGM in March which included various neurology lectures. We are currently planning our courses in 2013 and will be in touch with our members via email and the ACPIN south west regional page with further details once confirmed. Places for courses will only be confirmed once a completed application form and payment has been received by the course organiser.

Please get in touch with us if you wish to find out more information about being on the committee, or ideas/suggestions for future courses or venues at southwest@acpin.net

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Surrey and Borders

Emma Jones

Surrey and Borders ACPIN Committee has seen a number of changes over recent months. A number of long-standing members have resigned due to other commitments. We have been extremely grateful for their contribution and experience within the committee and their involvement will be missed. The Chair, Regional Representative, Secretary and Treasurer remain unchanged. We currently have a committee of ten.

We have a continued strong membership of over 120 members and we have been well supported with attendance at both our evening lectures and study days.

This year we have also introduced a bursary scheme in order to support our members with further study – if you are interested in applying, details of the bursary and an application form can be found on the ACPIN website under our Surrey and Borders region.

Our AGM and first evening lecture of the year was on February 25th at Guildford, with Professor Helen Dawes speaking on exercise in neurology. This was an informative and interesting start to the 2013 programme, providing an update on research being undertaken at Oxford Brookes University.

On the 23rd April we had an evening lecture on EMG triggered FES at Frimley Park Hospital. Futher events include:

- June 2013 – evening lecture – ‘Physiotherapy at end of life’
- September 2013 – Study day TBA
- November 2013 – evening lecture – ‘Update on Life CIT trial’ with Sebastien Pollett

On-going events with be forwarded to Surrey and Borders ACPIN members by email. They will also be advertised in *Frontline*, on the iCSP website and on the ACPIN website as well as Facebook and Twitter, so keep your eyes peeled!

Please do not hesitate to contact me with any queries or suggestions for future programmes on surrey@acpin.net

We look forward to seeing you all at future events!

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Wales

Adele Griffiths

Following the successful balance course hosted in Cardiff in September 2012, Wales ACPIN hosted a WebEx event in December open to all course delegates when the course tutors Anne Shumway Cooke and Marjorie Woollacott joined us to listen to delegates’ experiences of putting what they had learned into practice. This was an excellent opportunity for reflection and the tutors reminded delegates of ways to progress exercises and suggested how to solve difficulties. Delegates also received a postcard from ACPIN in the New Year which had been filled in during the course with resolutions of how to change practice.

2013 opened with a well-attended WebEx presentation by Richard Pawsey and Adele Griffiths discussing physiotherapy roles in spasticity management clinics.

The winter training day and AGM was held in Port Talbot hospital and focused upon exercise in MS. The programme included contributions from a patient with a very positive exercise experience, an MS Society Trustee with an outstanding approach to living and working with MS and updates on disease modification and exercise from Lynne Watson, Specialist MS Physio for Swansea and West Wales (ABMU). There were no new appointments at the AGM. The membership of ACPIN Wales is now over 100.

At the national ACPIN conference in March Jakko Brouwers and Reji Abraham demonstrated the use of Webex to the reps from the other regions.

Other events planned for 2013 are:

- a hydrotherapy study day
- a lecture on rehabilitation technology
- a WebEx to the regional representatives demonstrating WebEx
- a WebEx feedback on national ACPIN conference
- a WebEx debate about the use of passive stretching in long-term management
- a WebEx journal club with Cardiff University School of Healthcare Studies

You can email us at wales@acpin.net for membership advice and to register for courses or a WebEx.

All members of Wales ACPIN are welcome to attend committee meetings.

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Wessex

Lindsay O’Connor

Since our last update the regional committee for Wessex has continued to be supported by a number of core members, but as always we would welcome new members wishing to join - please contact wessex@acpin.net for further information. We have recently noticed a lack of committee members from the west of our region, for example Bournemouth and Poole, and are really keen to gain any new committee members from the area so we can best represent the region.

The end of last year saw a successful programme of events. In September we hosted a study day on understanding and treating pusher behaviour led by specialist physiotherapist Gemma Alder;participants felt this was a really good day with lots of clinically relevant content. Our evening lecture in October focused on vestibular rehabilitation from two perspectives: specialist physiotherapist Julie Bluck explored the evidence base for vestibular rehabilitation post acoustic neuroma surgery and clinical specialist physiotherapist Adrian Yeoman discussed the signs and management of peripheral or central vertigo. Both speakers received excellent feedback on the content and presentation of their talks. Our final event of 2012, held in November, was a study morning exploring the aetiology and treatment of functional disorders. This included presentations and a group panel discussion from consultant neurologist Dr Sean Slaught, consultant liaison psychiatrist Dr Janet Butler and highly specialist physiotherapist Glenn Nielsen. The morning proved to be extremely popular with excellent attendance and the broad range of speakers and opportunity for questions sparked several interesting and thought-provoking discussions between the presenters and attendees.

Our first event of 2013, in February, was an evening lecture on living with a spinal cord injury led by Peter Hutchings of the Spinal Injuries Association. This follows on from his successful talk last summer and we are excited to continue working with Peter, who is an excellent presenter and resource to us as therapists. In March we held an evening lecture updating on current local research, which was followed by our AGM. The schedule for the rest of the year has yet to be finalised and we welcome new committee members wishing to assist with the planning and running of these future events. Currently we aim to run a revision of the gait study day which unfortunately had to be postponed last year, and are planning some interesting events exploring: minimal awareness, functional strength training and neuro-oncology. We are also exploring the options for a larger event to be run in 2014, which we hope will mirror the success of our previous conference on spasticity.

Please get in touch with any comments or suggestions; we always welcome your input in order to represent members of the Wessex region as best as possible.

West Midlands

Cameron Lindsay

Our November disease specific event was on neuromuscular diseases and brought together clinical specialists in neurology and respiratory as well as a consultant neurologist to cover a wide range of topics on the area, with a particularly interesting question and answer session at the end.

In early February we had a functional upper limb electrical stimulation event with the chance to try two products out. This was well attended and feedback was positive.

At the end of March our AGM was planned to be a regional update on Early Supported Discharge for stroke. However, given that this remains so disjointed, and changes continue on a regular basis, it was felt we should postpone this until the whole process has settled down. This meant that we had a roundup of current local neuro rehabilitation trials being led by physiotherapists within the region prior to our AGM. A member of the Stroke Research Network presented a brief outline of the networks remit, before Trudy Pelton presented results of the GRABIT study and the protocol of the Visual Cue Training (VCT) study, and Cameron Lindsay presented some preliminary findings from the EUBoSS study.

At the end of April we were very pleased to welcome Paulette Van Vliet for two study days looking at training reach-to-grasp following stroke and feedback and practice to enhance neuroplasticity and motor learning after stroke. These were particularly well attended and as always feedback was excellent.

Planned for the autumn and winter we have a neuroplasticity and cognitive reserve course, and an evening looking at functional patients.

The committee would finally like to thank Caroline Graham for continuing as the Chair for West Midlands ACPIN.

Yorkshire

Kirstie Elliot

Now that the Christmas break is over the committee are busy sorting out another varied programme for the year. So far we have held a very popular ‘Strategies to deepen clinical reasoning in neurological rehabilitation’ evening lecture, as well as a study day on vestibular rehab and another on Parkinson’s disease, led by Bhanu Ramaswamy.

Our AGM this year will be on spasticity and its management. Setting a date has proved tricky but should be resolved soon. Please ensure your contact details on the website are up to date to ensure we have the correct email address for you.

In April we will be running two movement science based courses ‘Easy to follow training for reach-to-grasp’ and ‘Putting feedback and practice into action with stroke patients’. These will be led by Prof Paulette van Vliet who is travelling over from Australia. Numbers are limited on this course and will be prioritised to Yorkshire ACPIN members.

We are also looking to host master classes with Mary Lynch-Ellerington for those that have completed the basic three-week course at least and details re this will be following soon. Evening lectures in the pipeline include gait analysis, mental capacity act and DOLs and gait research/outcome measure.

Yorkshire ACPIN continues to try to provide a varied lecture programme including trying to access other venues which is not always easy. If people know of speakers who would be willing to provide an evening lecture or day course in an area of Yorkshire not well covered we would be more than happy to help arrange this.

Please contact us on yorkshire@acpin.net if you have any questions, queries or suggestions.

Writing for Syn'apse

***Syn'apse* is the official peer-reviewed journal of the Association of Chartered Physiotherapists in Neurology (ACPIN). *Syn'apse* aims to provide a forum for publications that are interesting, informative and encourage debate in neurological physiotherapy and associated areas.**

***Syn'apse* is pleased to accept submitted manuscripts from all grades and experience of staff including students. We particularly wish to encourage 'novice' writers considering publication for the first time and ACPIN provides support and guidance as required. All submissions will be acknowledged within two working weeks of receipt.**

Examples of articles for submission:

Case Reports

Synapse is pleased to accept case reports that provide information on interesting or unusual patients which may encourage other practitioners to reflect on their own practice and clinical reasoning. It is recognised that case studies are usually written up retrospectively. The maximum length is 3,000 words and the following structure is suggested:

Title – this should be concise and reflect the key content of the case report.

Introduction – this sets the scene giving background to the topic, and why you consider this case to be important, for example what is new or different about it? A brief overview of the literature or the incorporation of a few references is useful so people can situate the case study against what already is known.

The patient – give a concise description of the patient and condition that shows the key physiotherapeutic, biomedical and psychosocial features. Give the patient a name, but not their own name. Photographs of the patient will need to be accompanied by explicit permission for them to be used. Only relevant information to the patients' problem should be included.

Intervention/method – Describe what you did, how the patient progressed and the outcome. Aims, treatment, outcomes, clinical reasoning and the patient's level of satisfaction should be addressed. Indications of time scales need to be considered.

Implications for practice – Discuss the knowledge gained, linking back to the aims/purpose, and to published research findings. Consider insights for treatment of similar patients, and potential for application to other conditions.

Summary – List the main lessons to be drawn from this example. Limitations should be clearly stated, and suggestions made for clinical practice.

References – the Harvard style of referencing should be followed (please see *Preparation of editorial material* below).

Original research papers

These should not exceed 4,000 words and papers should include the following headings:

- **Abstract** – (maximum of 300 words)
- **Introduction**
- **Method** – to include design, participants, materials and procedure
- **Results**
- **Discussion**
- **Conclusion** – including implications for practice
- **References**

Abstracts of thesis and dissertations

Abstracts from research (undergraduate and postgraduate) projects, presentations or posters will be welcomed. They should be up to 500 words, and broadly follow the conventional format: introduction, purpose, method, result, discussion, conclusion.

Audit report

A report which contains examination of the method, results, analysis, conclusions of audit relating to neurology and physiotherapy, using any method or design. This could include a Service Development Quality Assurance report of changes in service delivery aimed at improving quality. These should be up to 2,000 words.

Sharing good practice

This *Syn'apse* feature aims to spread the word amongst ACPIN members about innovative practice or service developments. The original format for this piece started as a question and answer session, covering the salient points of the topic, along with a contact name of the author for readers to pursue if they wish. Questions were loosely framed around the following aspects (this would be for an audit)

- What was the initiating force?
- How did you go about it?
- What measurements did you use?
- What resources did you need?
- What did you learn about the process?
- How has it changed your service?

However recent editions have moved away from this format, and provide a fuller picture of their topic eg *Introducing a management pack for stroke patients in nursing homes* (Dearlove H Autumn 2007), *An in-service development education programme working across three different hospitals* (Fisher J Spring 2006), *A therapy led bed service at a community hospital* (Ramaswamy B Autumn 2008) and *Establishing an early supported discharge team for stroke* (Dunkerley A Spring 2008).

Product news

A short appraisal of up to 500 words, used to bring new or redesigned equipment to the notice of readers. This may include a description of a mechanical or technical device used in assessment, treatment management or education to include specifications and summary evaluation. Please note, ACPIN and *Syn'apse* take no responsibility for these products, it is not an endorsement of the product.

Reviews

Course, book or journal reviews relevant to neurophysiotherapy are always welcome. Word count should be around 500. This section should reflect the wealth of events and lectures held by the ACPIN Regions every year.

OTHER REGULAR FEATURES

Focus on...

This is a flexible space in *Syn'apse* that features a range of topics and serves to offer different perspectives on subjects. Examples have been a stroke survivor's own account, an insight into physiotherapy behind the Paralympics and the topics of research, evidence and clinical measurement.

Five minutes with...

This is the newest feature for *Syn'apse*, where an ACPIN member takes 'five minutes' to interview well-known professionals about their views and influences on topics of interest to neurophysiotherapists. We are always keen to receive suggestions of individuals who would be suitable to feature.

PREPARATION OF EDITORIAL MATERIAL

Copies should be produced in Microsoft Word. Wherever possible diagrams and tables should be produced in electronic form, eg excel, and the software used clearly identified.

The first page should include:

- The title of the article
- The name of the author(s)
- A complete name and address for correspondence
- Professional and academic qualifications for all authors and their current positions

For original research papers, a brief note about each author that indicates their contribution and a summary of any funds supporting their work.

All **articles should be well organised and written in simple, clear, correct English**. The positions of tables and charts or photographs should be appropriately titled and numbered consecutively in the text.

All **photographs or line drawings** should be at least 1,400 x 2,000 pixels at 72dpi.

All **abbreviations** must be explained.

References should be listed alphabetically, in the Harvard style. (see www.shef.ac.uk/ library/libdocs/hsl-dvc1.pdf) eg:

Pearson MJT et al (2009) *Validity and inter-rater reliability of the Lindop Parkinson's Disease Mobility Assessment: a preliminary study* **Physiotherapy** (95) pp126-133.

If the article mentions an **outcome measure**, appropriate information about it should be included, describing measuring properties and where it may be obtained.

Permissions and ethical certification; either provide written permission from patients, parents or guardians to publish photographs of recognisable individuals, or obscure facial features. For reports of research involving people, written confirmation of informed consent is required.

SUBMISSION OF ARTICLES

An electronic and hard copy of each article should be sent with a covering letter from the principal author stating the type of article being submitted, releasing copyright, confirming that appropriate permissions have been obtained, or stating what reprinting permissions are needed.

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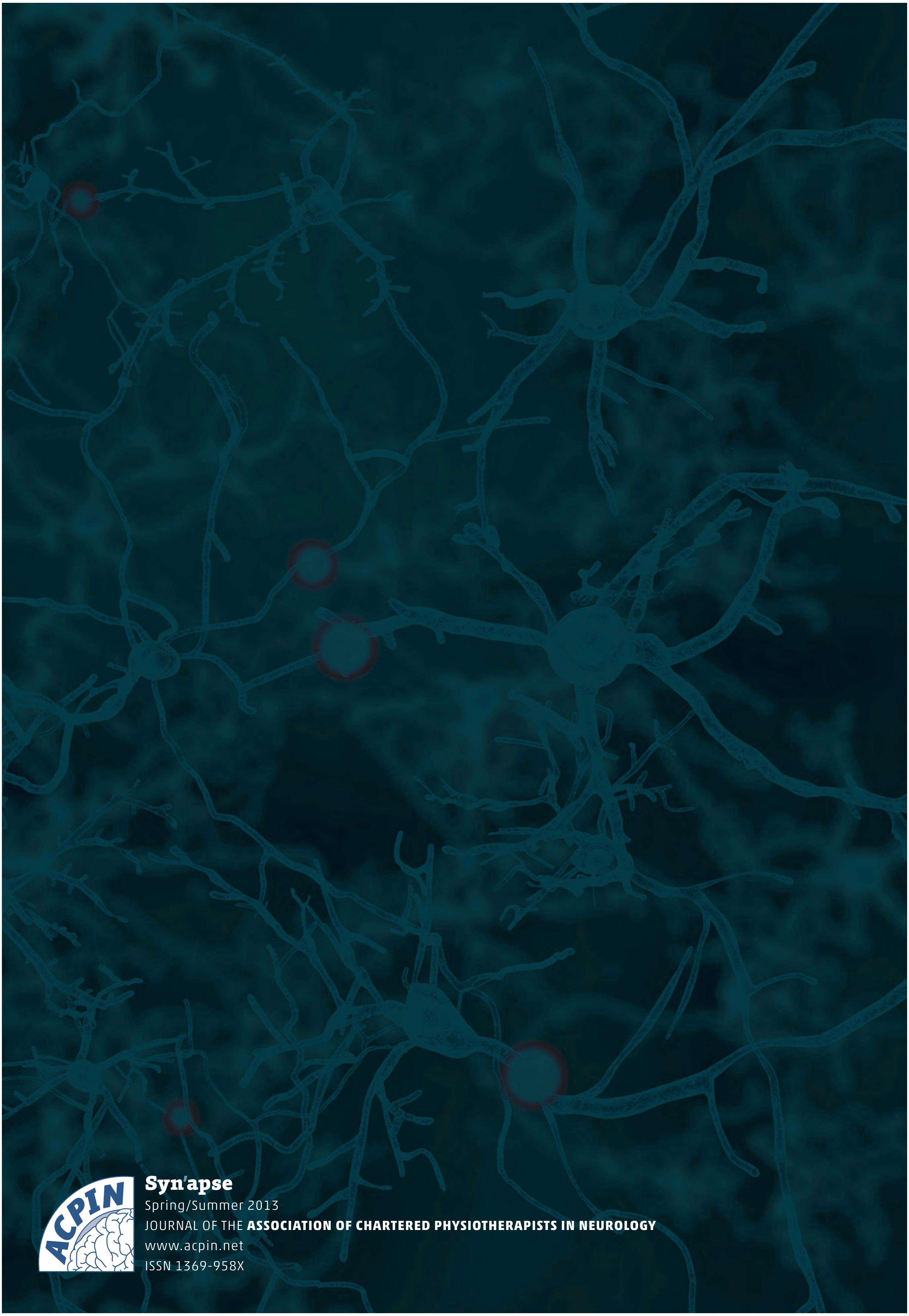

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