

West Midlands Cerebral Palsy and Spasticity Network meeting

Ricoh Arena, Phoenix Way, Coventry CV6 6GE

18th November 2015

Evaluation Feedback

Were the printed learning aims/objectives of the course met?

Yes - 57

No – 2

Not sure - 5

Didn't receive learning outcomes x 5

Was there any bias or conflict of interest evident in the course?

YES - 6

NO - 58

~ Use of Botox x 2

~ Differing opinions on the use of Botox

~ Some bias in presentation on Botox, feels like there was lack of pro toxin evidence presented, plus lack of detail/critique re studies

~ Surgery / PT

~ Seemed very orthopaedically / surgically leaned

~ Inviting Botox / Ibsen to sponsor & then slating Botox!

Were the speakers/instructors knowledgeable?

YES - 65

NO - 0

What have been the best things about this event?

~ The talk on evidence of current practice in the use of botulinum toxin x 10

~ Current evidence on Botox & its effectiveness especially in comparison to serial casting

~ Evidence for Botox or not

~ CPIPS x 15

~ CPIP discussion – very informative – will be very useful for postural management – objective

~ CPIPS talk – would be great to have this in the West Midlands

~ CPIPS talk very inspiring

~ CPIPS explanation & possible development

~ Data collection & working together

~ Evidence & current practice about Baclofen

~ Discussion about further research x 3

~ Up to date research evidence

~ Information on CCG/Commissioning

~ Mark Gaston's talk in particular was very inspiring – I hope we can take integrated data collection forward. Realising that my concerns are shared across the region, mainly around lack of consistency – data collection in this group

~ Discussion around therapy provision post SDR x 2

~ Open discussion re. management across the region

~ Networking x 9

- ~ Great to Network with the consultants, other physios & professionals & share ideas x 3
- ~ Quality talks, relevant, discussion & networking
- ~ Inter/multi-disciplinary discussions
- ~ Opportunity for discussion
- ~ Discussions & sharing of practice x 2
- ~ Clearer understanding of current practice in the West Midlands
- ~ Local issues on CP
- ~ Hearing the work others are doing
- ~ Good multidisciplinary working
- ~ Good information
- ~ Really good team day!
- ~ Relaxed atmosphere so people contributing & open discussion
- ~ Informal good opportunity to discuss, network & chat to colleagues x 2
- ~ Becoming aware of how everyone else is working
- ~ Venue, timing, content
- ~ Speakers, venue, catering x 3
- ~ Interesting discussions x 3
- ~ All interesting & well presented & stimulating
- ~ The variety of topics covered
- ~ Friendly medical representatives
- ~ Interesting trade stands x 2
- ~ Some new information
- ~ Presentations & discussion especially evidence in current practice
- ~ Perspectives & practice from elsewhere in the UK x 2
- ~ Everything as I found all talks have ↑my knowledge, views, confidence, what is out there & where to seek help
- ~ It was very positive to see a broad spectrum of specialties from across the region with an obvious enthusiasm to improve care/systems
- ~ Good turn out
- ~ Well organised, good venue, good speakers – well-chosen topics

What would you have liked to be different?

+ve

- ~ Nothing x 8
- ~ More meetings - possibly 2 per year
- ~ Nothing just more of these days!
- ~ After Marks talk it would have been good to meet in geographical groups to discuss taking CIPPS forward
- ~ Focus on strategy & solutions
- ~ Practical discussions – Rx approaches – more of
- ~ More discussion re relevant research funding
- ~ More paediatricians, neonatologists contributing
- ~ Very much orthopaedic as CP is a complex condition & community paed's play a very important role
- ~ How do we go about getting a RCT started? Some questions unanswered in this section
- ~ More information & discussion around treatment for upper limb with a functional focus x 2
- ~ Guidelines for Occupational Therapists
- ~ Advice on how to present new therapy treatment approaches to commissioners i.e. business plans for funding
- ~ More evidence around SDR
- ~ To discuss further what our individual consultants feel about different Rx options & how that impacts on our children
- ~ To know who our Commissioners are & for them to be aware of regional problems

-ve

- ~ Information on times/location sent out a bit earlier
- ~ Sound system – very difficult to hear some of the speakers & air con noisy x 4
- ~ More microphones
- ~ Better food
- ~ Not at the Ricoh, took 2 ½ hours to get there

general

- ~ Access to slides ahead of event
- ~ Handouts
- ~ Shorter breaks, earlier finish
- ~ Central venue e.g. Birmingham
- ~ People speaking in audience to state who they were & their profession x 3
- ~ Name badges x 2
- ~ More therapy based sponsors
- ~ Hard to fit into a day but more gaps to speak to different people (realise it's not just a networking day!)
- ~ I'm not sure I gained that much from research question session in terms of answers but it did open up my mind to look for research opportunities
- ~ Needed more understanding on Commissioning
- ~ More therapy led presentations
- ~ Involvement & opinion of Community Paediatrician
- ~ I think future events would benefit from having some parent/carer or young person input, e.g. a topic from their perspective etc.

Which aspects of this event have been relevant to your personal CPD?

- ~ All x 23
- ~ All content, very informative, good pace, good for all levels & professionals
- ~ All as it can all be "tapped" used in my everyday practise & ↑ quality of workmanship
- ~ Most of it x 2
- ~ I'm new in role as spasticity lead so excellent for networking & guidance
- ~ CIPIS x 16
- ~ Botox x 15
- ~ Baclofen x 5
- ~ ITB x 3
- ~ EBP
- ~ Research x 5
- ~ SDR & therapy x 4
- ~ Commissioning x 2
- ~ Spasticity management
- ~ Attending a MDT networking meeting. Improving communication & team working
- ~ Outcome measures
- ~ Getting other professional perspectives
- ~ Sharing of ideas

Please indicate how useful you found each session:

Programme	Very good	Good	Satisfactory	Less than satisfactory
Introduction <i>Steve Cooke, Consultant Paediatric Orthopaedic Surgeon & Ram Vadivelu, Consultant Paediatric Orthopaedic Surgeon</i>	38	21		
Evidence and current practice in the use of botulinum toxin <i>Emma Shears, Consultant Paediatric Orthopaedic Surgeon</i>	54	4	2	
Update on the use of intrathecal baclofen in cerebral palsy <i>Steve Cooke, Consultant Paediatric Orthopaedic Surgeon</i>	43	18		
Commissioning for specialist services Rob Freeman, Consultant Paediatric Orthopaedic Surgeon	25	34	5	
Cerebral Palsy Integrated Pathways Mark Gaston, Consultant Paediatric Orthopaedic Surgeon	48	13		
Discussion regarding the potential for clinical research what are the questions we want to answer? <i>Facilitated by Andy Metcalfe & Simon Gates, Assoc Profs</i>	14	32	7	
Discussion regarding the potential for clinical research continuation of above and discussion about starting randomised trials across the West Midlands <i>Facilitated by Andy Metcalfe & Simon Gates, Associate Professors</i>	12	29	14	1
Plans for the introduction of CPIP in the West Midlands Group Discussion	22	14	2	
Post Intervention Physiotherapy <i>Anna Fry, Clinical Lead Physiotherapist</i>	22	27	5	
Open forum for discussion of difficult cases or for further talk about topics raised during the day <i>Facilitated by Steve Cooke, Consultant Paediatric Orthopaedic Surgeon</i>	17	13	5	

What would you like more of?

- ~ All good, well balanced
- ~ Literature reviews
- ~ Opinion into the use of Botox in light of Emma Shear's presentation
- ~ Discussion around evidence & use of other treatment options for CP
- ~ Discussion re. types of orthosis used in CP & how orthotist judge this without gait analysis
- ~ Orthotics opinion
- ~ More discussion / video etc. of treatment following SDR x 2
- ~ Discussion about moving CPIP forward & tackling lack of uniformity
- ~ Wider discussion relating to muscle relevant drugs i.e. ethanol injection, dantrolene, diazepam & current evidence of use for patients with CP
- ~ Standards of care in CP – very generic I know but clear that there is disparity across
- ~ Microphones
- ~ Attendance by Neurologists, Orthotists, Neonatologists
- ~ Occupational Therapy & treatment for CP
- ~ Research & evidence based practice on function in activities of daily living & fine motor
- ~ Evidence based practice
- ~ Therapy input
- ~ Patient representative
- ~ Patient/child & parents perspectives/experiences

- ~ For research pick say the HTA and agree what precisely the standardised treatment would be as slightly different treatment & demand greater increase in power to determine if there is an effective multicentre studies. So that for 5 years a standardised data collection
- ~ Case studies / discussion x 111
- ~ Therapy related discussions
- ~ Evidence of Rx's used
- ~ More open discussions
- ~ Email circulation list for discussion in between events
- ~ Sharing each Trusts practices
- ~ More standardised physio spasticity management
- ~ Audits / research outcomes
- ~ Any area in paediatrics as I find it all relevant to my work & understanding
- ~ Working together – be clear how we improve services
- ~ consider as a network meeting other than medical professionals invited, but overall excellent programme for both paediatricians & orthopaedics
- ~ Metabolic born disease
- ~ New classifications
- ~ Radiology – more about when to do & when to repeat, when to get 2nd opinion
- ~ Different patterns etc.
- ~ Regional protocols
- ~ New drug treatments
- ~ Care strategies, therapy, medication etc.
- ~ Other interventions i.e. Behavioural
- ~ Group discussion/brain storming was a great way for individuals from different specialties to network and discuss topics, being able to see from different perspectives.
- ~ Parent/carer or young person involvement – having the perspective of patients and their carers is integral to true partnership working and co-design of services. It also gives useful insight into being on the receiving end of services to enable changes of practice where necessary. Overall making for more holistic /patient-centred care.
- ~ Input from/attendance by neonatologists would be good as many early diagnosis of CP are picked up by them, or even may be flagged up whilst babies are in NICU.
- ~ Market place of third sector organisations that may be useful to professionals for their own knowledge and to be able to signpost patients to.
- ~ Discussion about the validity of foreign/non-NHS therapies as a supplement to regular therapy models (physio) would be interesting. Such as: conductive education, polish spider suit therapy, hyperbaric therapy, brainwave etc.
- ~ Contact details for various specialist centre or therapists if people are willing
- ~ Afternoon Tea with cake

What would you like less of?

- ~ Breaks – total of 2 hours is not needed x4
- ~ Less air con – it was cold
- ~ Less noise from extractors
- ~ Not hearing properly / more roaming mics
- ~ Research discussions
- ~ Not just surgery – thought it was too orthopaedic / surgery biased
- ~ Personal experiences
- ~ Less jargon – more accessible for newly qualified – consideration to all levels/knowledge of audience

Any other comments / suggestions for future topics/events?

comments

- ~ Good balance
- ~ Very enjoyable day
- ~ Excellent event – thank you
- ~ Very interesting & very informative – Many thanks
- ~ Great to get away from day-to-day with most of the team – lots of discussion
- ~ A very good & interesting day! Good range of presentations
- ~ Many thanks for arranging – facilitating a very informative day – enjoyable too!
- ~ ‘Barney’ made travel difficult
 - ~ Please give more notice for next year – some colleagues have commented it was too short for them to cancel clinics
- ~ Everything excellent

suggestions

- ~ Ask the team from Leicestershire to come & talk
- ~ Further investigation into Botox vs serial casting & who does serial casting as appears to be different some places physio other Drs/consultants
- ~ Spasticity pathways & make clearer what best pathway is, as in B’ham some CP provide Baclofen i.e. Heartlands & see consultant paediatrician + physio, others to orthopaedic consultant for Botox & also consultant paediatrician deals with Baclofen & doesn’t all communicate well. ?? What other areas do
- ~ Improved communication →Health professionals across the board & best way to do this
- ~ Transition into adult services
- ~ More discussion around SDR
- ~ Discussion around other interventions used in spasticity / mis-imbalance e.g. lycra / FES / orthotics
- ~ Types of orthotics in CP – evidence based practise
- ~ Epidemiology of CP in the West Midlands for planning future services & research direction
- ~ More case studies
- ~ Passive stretches
- ~ Constraint induced movement therapy
- ~ Upper limb & treatment outcomes
- ~ Orthotics
- ~ Trying to gain an understanding across the board of what physiotherapy involves & getting parents, children & other MDT members to understand this doesn’t have to be provided by a PT. Handling over self-management earlier – will this improve transition from paed to adult services in terms of expectations

General Feedback	Excellent	Good	Satisfactory	Fair	Poor
Venue	47	15			
Location	44	14	1	2	
Catering	42	17	1	1	
Event Administration	36	18	6	1	1

Number of delegates: 67

Number of evaluation forms returned: 65 (97% return)

Collated from Evaluation forms by Lesley Hines, Partners in Paediatrics