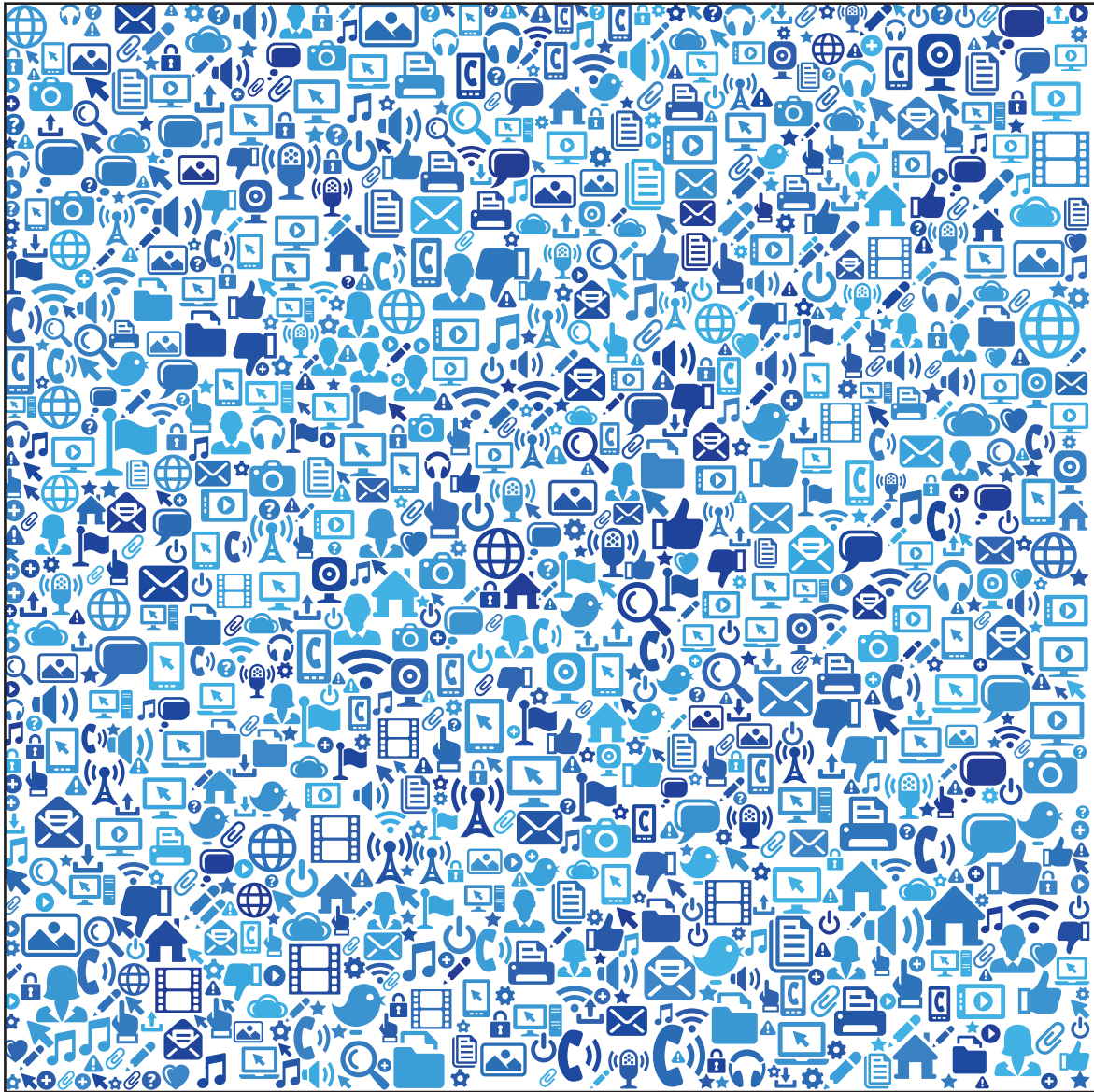


MARCH 2016 VOLUME 14 ISSUE 1

# PAIN NEWS

A PUBLICATION OF THE BRITISH PAIN SOCIETY



**Social media for professionals in Pain Medicine**

**Impact of dysmenorrhea**

**The diagnosis – shades of grey**

**The tyranny of hidden waiting list**

ISSN 2050-4497



THE BRITISH PAIN SOCIETY





**THE BRITISH PAIN SOCIETY**  
An alliance of professionals advancing the understanding and management of pain for the benefit of patients

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THE BRITISH PAIN SOCIETY  
**PAIN NEWS**

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PAIN NEWS MARCH 2016

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The Editor welcomes contributions including letters, short clinical reports and news of interest to members, including notice of meetings.

**Next submission deadline : 31 March 2016**

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<https://www.britishpainsociety.org/for-members/pain-news/>

For adult patients with an inadequate response to laxative(s)<sup>1</sup>

# TREAT OPIOID-INDUCED CONSTIPATION AT ITS SOURCE<sup>1</sup>

Introducing MOVENTIG, the first once-daily tablet that  
targets the effect of opioids on the mu-receptors in  
the bowel but not the brain<sup>1</sup>

MOVENTIG is a peripherally-acting mu-opioid receptor  
antagonist (PAMORA), not a laxative<sup>1</sup>

MOVENTIG can be used with a variety of opioids, allowing  
for tailored and flexible choice of opioid dose<sup>2</sup>

See NICE tag 345<sup>3</sup>  
[www.nice.org.uk/guidance/ta345](http://www.nice.org.uk/guidance/ta345)

MOVENTIG is indicated for the treatment of opioid-induced constipation  
(OIC) in adult patients who have had an inadequate response to laxative(s)\*<sup>1</sup>

▼ This medicinal product is subject to additional monitoring. This will allow quick identification of new safety information. Healthcare professionals are asked to report any suspected adverse reactions. See section 4.8 of the SmPC for how to report adverse reactions.

#### PRESCRIBING INFORMATION

**Moventig 12.5mg and 25mg film-coated tablets**▼ (naloxegol oxalate)

**Consult Summary of Product Characteristics before prescribing.**

**Use:** Adults: treatment of opioid-induced constipation (OIC) in adult patients who have had an inadequate response to laxative(s). For definition of inadequate response to laxative(s), refer to section 5.1 of SmPC.

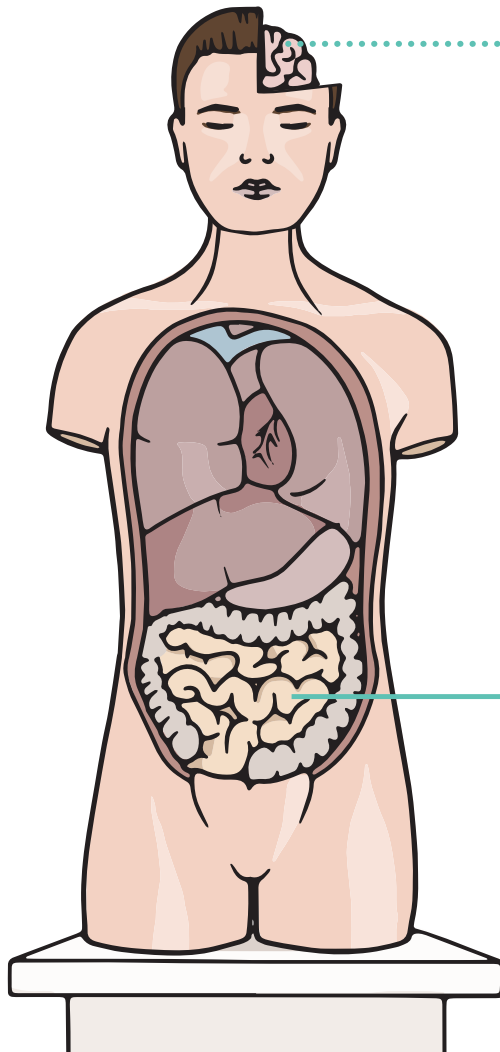
**Presentation:** 12.5mg or 25mg naloxegol film-coated tablet.

**Dosage and administration:** Recommended 25mg once daily. Take on empty stomach at least 30 minutes prior to first meal of day or 2 hours after first meal of day. **Elderly patients (≥65 years):** No adjustment recommended. **Renal impairment:** Moderate to severe renal impairment starting dose 12.5mg. Discontinue if side effects impact tolerability. Increase to 25mg if well tolerated. No adjustment required for mild renal impairment. **Hepatic impairment:** No adjustment required in mild to moderate impairment. Use in severe hepatic impairment not recommended. **Moderate CYP3A4 inhibitors:** Starting dose 12.5mg, can be increased to 25mg if well tolerated. No adjustment required for weak CYP3A4 inhibitors. **Cancer-related pain:** No adjustment required. **Paediatric population (<18 years):** Safety and efficacy not yet established.

**Contraindications:** Hypersensitivity to active substance or any of the excipients or any other opioid antagonist. Patients with known or suspected gastrointestinal (GI) obstruction or patients at increased risk of recurrent obstruction. Patients with underlying cancer who are at heightened risk of GI perforation, such as those with underlying malignancies of gastrointestinal tract or peritoneum, recurrent or advanced ovarian cancer, vascular endothelial growth factor (VEGF) inhibitor treatment. Concomitant use with strong CYP3A4 inhibitors (e.g. clarithromycin, ketoconazole, itraconazole or telithromycin; protease inhibitors such as ritonavir, indinavir or saquinavir; grapefruit juice when consumed in large quantities).

**Warnings and precautions:** Use with caution in patients with any condition which might result in impaired integrity of the gastrointestinal tract wall. Advise patient to discontinue therapy and promptly notify physician if unusually severe or persistent abdominal pain develops. Use with caution in patients with clinically important disruptions to the blood brain barrier with observation for potential CNS effects. Discontinue if evidence of opioid-mediated interference with analgesia or opioid withdrawal syndrome occurs. Use with caution in patients taking methadone. Cases of opioid withdrawal syndrome have been reported in the naloxegol clinical programme (DSM-5). If opioid withdrawal syndrome is suspected the patient should discontinue Moventig and contact their physician. Use with caution in patients 6 months following myocardial infarction, symptomatic congestive heart failure, overt cardiovascular (CV) disease or patients with a QT interval of ≥500msec. Use with caution in OIC patients with cancer-related pain.

**Drug interactions: Strong CYP3A4 inducers:** Concomitant use not recommended.



MOVENTIG treats opioid-induced constipation (OIC) at its source in the bowel...  
 ...with minimal impact on opioid-mediated analgesic effects on the central nervous system (CNS)

NEW oral once-daily  
**moventig**<sup>®</sup>  
 naloxegol

*Treat at the Source*

**P-gp inhibitors:** Dosing recommendations for Moventig when co-administered with medicinal products causing both P-gp and CYP3A4 inhibition should be based on CYP3A4 inhibitor status – strong, moderate or weak.

**Fertility, pregnancy and lactation:** Not recommended during pregnancy or breast-feeding. The effect of naloxegol on fertility in humans has not been studied.

**Undesirable events:** Consult SmPC for full list of side effects. *Very Common:* Abdominal pain, diarrhoea. *Common:* Nasopharyngitis, headache, flatulence, nausea, vomiting, hyperhidrosis. *Uncommon:* Opioid withdrawal syndrome.

**Legal category:** POM.

**Marketing authorisation number:** Moventig 12.5mg film-coated tablets 30 EU/1/14/962/001; Moventig 25mg film-coated tablets 30 EU/1/14/962/005.

**Basic NHS cost:** Moventig 12.5mg film-coated tablets 30; £55.20; Moventig 25mg film-coated tablets 30; £55.20.

**Marketing Authorisation holder:** AstraZeneca AB, SE-151 85 Södertälje, Sweden.

**Further information is available from:** AstraZeneca UK Ltd., 600 Capability Green, Luton, LU1 3LU, UK. Moventig is a trade mark of the AstraZeneca group of companies.

**Date of preparation:** 08/2015. PAI 15 0001

Adverse events should be reported. Reporting forms and information can be found at [www.mhra.gov.uk/yellowcard](http://www.mhra.gov.uk/yellowcard). Adverse events should also be reported to AstraZeneca on 0800 783 0033.

\*Definition of laxative inadequate responder (LIR): In the two weeks prior to first study visit patients had to have reported concurrent OIC symptoms of at least moderate severity while taking at least one laxative class for a minimum of four days during the pre-study period.<sup>1</sup>

In a 52-week safety study, there were no important unexpected differences in safety and tolerability findings between patients who received MOVENTIG 25mg and patients receiving usual care (i.e. laxative regimen decided by clinician).<sup>1†</sup> There is limited clinical experience with the use of MOVENTIG in OIC patients with cancer-related pain. Therefore, caution should be used when prescribing MOVENTIG to such patients<sup>1</sup>

<sup>†</sup>KODIAC 8 (n=804) was a phase 3, 52-week, multi-centre, open-label, randomised, parallel group study of MOVENTIG vs usual care in the treatment of OIC in patients with non-cancer pain. The primary objective was to assess long-term safety and tolerability for MOVENTIG 25mg and to compare with usual care treatment using descriptive statistics.<sup>1</sup>

**References**

1. MOVENTIG Summary of Product Characteristics. Last accessed August 2015.
2. AstraZeneca UK Ltd Data on File MOV-012-AUG15.
3. NICE technology appraisal guidance [TA345]. Published July 2015. Available at: [www.nice.org.uk/guidance/ta345/chapter/1-Guidance](http://www.nice.org.uk/guidance/ta345/chapter/1-Guidance) Last accessed September 2015.

Date of preparation: October 2015. 891,207.011



# British Pain Society Calendar of Events

To attend any of the below events, simply book online at:

[www.britishpainsociety.org/mediacentre/events/](http://www.britishpainsociety.org/mediacentre/events/)



THE BRITISH PAIN SOCIETY

## 2016

### Annual Scientific Meeting

Tuesday 10<sup>th</sup> – Thursday 12<sup>th</sup> May 2016

Harrogate

The multidisciplinary nature of the Society's is pivotal to the continuing success of its Annual Scientific Meeting, which has attracted an average of over 600 healthcare professionals to its previous five Meetings. This multidisciplinary nature is reflected throughout the scientific programme, with lecture, workshop and seminar topics chosen specifically to be of interest to all participants, whatever their speciality. Further information can be found on: <https://www.britishpainsociety.org/2016-asm/>

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### The Power of the Mind in Pain

#### Philosophy & Ethics SIG Annual Meeting

27<sup>th</sup> to 30<sup>th</sup> June 2016

Rydall Hall, Cumbria

This meeting promises to be a most stimulating conference considering the power of the human mind in pain. There will be a number of speakers looking at a wide range of subjects including spirituality, hypnosis, healing, the placebo effect and other mind-body connections.

It will be held at Rydal Hall near Ambleside in the Lake District and during the conference there will be time to explore the gardens and grounds of the hall as well as the beautiful surrounding lakes and hills.

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### Pain in Children Study Day

13<sup>th</sup> July 2016

Churchill House, London

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### Interventional Pain Medicine SIG Annual Meeting

16<sup>th</sup> September 2016

Manchester Airport

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### Patient Liaison Committee Annual Seminar

3<sup>rd</sup> November 2016

Churchill House, London

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### Headache SIG Annual Meeting

16<sup>th</sup> November 2016

Churchill House, London

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Further details for all our meetings can be found on our events listing page:

[www.britishpainsociety.org/mediacentre/events/](http://www.britishpainsociety.org/mediacentre/events/)



Dr Arasu Rayen *Editor*  
 pns.rayen@gmail.com



Recently, after my consultation, myself and one of my patients were discussing about advancement in technology and how

much the technology has changed the world, especially in the field of communication. He told me that in 1970s, if he wanted to talk to family members abroad, he had to book a long distance call at the Post Office at a particular time. Fast-forward 30 years, you can Skype or Facetime from anywhere in the world to anyone of your nearest and dearest. So many VOIP (Voice over Internet Protocol) apps, instant messaging, social media and video chat apps are available at our disposal on our smartphones. These not only help us to keep in touch with our nearest and dearest but they are also great for anyone to propagate ideas,

news, information and so on instantaneously across the world. This unique property is so useful in our professional life. In this issue of *Pain News*, Damien Smith, Stephen Humble and Arun Bhaskar are elaborating for us professionals in Pain Medicine, on the importance of keeping up with the explosion of the social media phenomenon. They provide us with a simple introduction to social media and Twitter. Please read this interesting article. They are planning to write at least two more articles in future on this subject, so watch this space.

As ever, this edition of *Pain News* is packed with lot of news items, articles on professional perspectives and informing practice. There are three articles on Paediatric Pain Management – a news item on the Paediatric Pain Symposium, an article by Thanthullu Vasu on their Paediatric Pain Service and another article by Matthew Jay on the Paediatric Chronic Pain Network (Informing Practice). They are not only useful for everyone who deals with paediatric pain, but also for anyone of

us. There are three articles on tyranny of diagnosis in the Professional Perspectives section (which are transcripts of the talk given at the Philosophy & Ethics Special Interest Group (SIG) meeting). They are interesting and thought provoking.

Although I am writing this editorial in January, by the time you read this, we must be very close to the change of season. Winter is fading away (hopefully!). Spring is on the horizon and the time to move your clocks forward is just a few weeks away. Similar to the seasons, we are having change in the British Pain Society (BPS) as well. In May, William Campbell, who has been our President for the past 3 years, will be stepping down, and Andrew Baranowski will be taking over the helm of BPS. The President's message in this issue of *Pain News* will be William's last one. He has been steering the BPS through difficult times. He was always very supportive of *Pain News*, the editorial board and its autonomy. I thank him wholeheartedly for this and wish him well.

# Dr William Campbell



THE BRITISH PAIN SOCIETY

Pain News

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SAGE



This will be my final message as President, since Dr Andrew Baranowski will be the President of the Society by the time you receive the next issue of *Pain News* in June. A lot of my activities on

behalf of the British Pain Society (BPS) has been a continuum of work initiated by my successor Professor Richard Langford, such as e-Learning in Pain, establishing the new BPS website and completing the Quality Framework for Pain.

Of course, these activities are the result of team work, frequently valued with input from organisations outside the BPS, such as the Pain Consortium (comprising representation from the Chronic Pain Policy Coalition (CPPC), Faculty of Pain Medicine (FPM) Royal College of Anaesthetists, the Clinical Lead for Pain, Royal College of General Practitioners (RCGP) and the BPS). The Pain Consortium started during my term of office, so that the four organisations could report on the development of their respective work streams (generated by the Pain Summit of 2011).

- Problematic/complex pain (FPM)
- Awareness campaign (CPPC)
- Commissioning guidance (RCGP)
- Epidemiology of chronic pain (BPS)

The Pain Consortium is in a good position to challenge pain issues that have arisen nationally, since the

Consortium represents the vast majority of healthcare professionals and patients within the United Kingdom.

## Pain Summit (2011) – work stream D; Epidemiology of Chronic Pain

The work stream D from the Pain Summit of 2011 has been a massive task, taken on by Professor Gary Macfarlane 2 years ago. The work was divided into three themes – Data sources (what is currently available and can this be used in the future?), Terminology (terms used and recorded in routine clinical practice) and Health measures (which measures to be used within all healthcare settings). All but the terminology threads of this work have been completed. We are trying to make sure that the terminology used is in keeping with international and national plans both now and for the future, so it is not only important to get this correct but also the resulting data from this should be a very powerful tool within the BPS armoury for the future.

## The BPS website

I must encourage you all to populate the BPS website, especially those who are leads within facets of the BPS, such as Special Interest Group (SIG) Chairs. Some have already carried out a great job, but we need the others to do likewise for the benefit of SIG members and potential members.

## European Pain Federation EFIC

For both the International Association for the Study of Pain and the European Pain

Federation EFIC (we are a chapter of both), this is the ‘Year against joint pain’. As a result, many of the educational components of pain organisations will have a joint pain theme. This is such a common problem, especially with advancing age and consumes so much in medicines, reduced mobility and resulting co-morbidities. EFIC launched its ‘European Year Against Pain (EYAP)’ in Brussels during January to highlight this issue.

## Elections

You will shortly receive notification of the Council elections by email and in your inbox within the BPS website, after you log in. Please do vote. It only takes a few moments, yet your vote may ensure that your discipline within the healthcare disciplines of pain has a voice on the Council. If you do not vote, it will not happen!

## Surveys

Over the past few years, we have made changes to the Annual Scientific Meetings following on from delegate feedback. Naturally, we cannot please everyone, but the feedback informs us on the Council of changes that may suit you. We then make a change, check via feedback in the following year and make other small changes – audit.

Last summer, we also carried out surveys of current and recently lapsed members to establish your wants and needs of the BPS. As you will see later, this has been most enlightening for us.



Dr William Campbell

### **PAIN Less Campaign**

On our Strategy Day of December 2013, we considered that two areas needed addressing:

The Society's income and how to avoid using our reserves

How we could improve membership benefits and numbers

The membership will be addressed shortly, but a considerable amount of work on this is currently underway. With regard to the Society's cash flow, we have sufficient regular income from the membership to carry out basic or core activities, including staff wages, rent, key Committee meetings and our two publications *British Journal of Pain* and *Pain News*. All additional activity requires identifiable funding in advance.

As I mentioned in the March 2015 and September 2015 issues of *Pain News*, we have introduced efficiency savings and carried out an office staff restructure early in 2015. Dr Baranowski identified the looming problem and took measures to address it as Honorary Treasurer.

This has now evolved into what we call the PAIN Less Campaign, being led and guided by Dr Paul Wilkinson along with Andrew Baranowski. There is also a significant input from our CEO Jenny Nicholas and a dedicated working group, as well as external advice on marketing and fundraising. Key messages have been agreed that will support the combination of a public awareness campaign, in addition to looking for additional income.

Members of the Society will be requested to support and be involved at the very core of this campaign over the coming months. The idea being to achieve local as well as national awareness of the effects of pain on the individual, as well as their relatives, friends and society. National Awareness involves a combination of a public

awareness campaign, in addition to looking for additional income.

The project is very well underway and additional information will be available on the BPS website in due course.

### **Undergraduate Pain Education: a practical guide to implementing a pain curriculum into health professional education in the United Kingdom**

Although this is a new BPS publication, it has taken several years of work by Professor Nick Allcock and his team. It will shortly be available on the BPS website under publications and should ideally be read in conjunction with the FPM Core Standards for Pain Management Services in the United Kingdom, below.

### **Core Standards for Pain Management Services in the United Kingdom**

An additional publication affecting all healthcare professionals involved in pain management has been launched by the FPM and endorsed by the BPS. There was a major contribution from the BPS and the document can be seen at <https://www.rcoa.ac.uk/document-store/core-standards-pain-management-services-the-uk>

This should be read in conjunction with the BPS document above and vice versa.

### **Opioid Aware**

Opioid Aware: a resource for patients and healthcare professionals to support prescribing of opioid medicines for pain. The work of this Public Health England document was carried out via the FPM Royal College of Anaesthetists and endorsed by the BPS. This resource replaces previous BPS publications on this subject (see

<https://www.rcoa.ac.uk/faculty-of-pain-medicine/opioids-aware>). Although the BPS was one of many stakeholders, this document was very largely the work of Professor Roger Knaggs and Dr Cathy Stannard, and they are to be congratulated on such a valuable resource.

### **Farewell**

As mentioned at the beginning of this message, the majority of the work carried out by the Council is to raise the awareness of pain nationally and improve the availability of educational material via the Annual Scientific Meetings, Study Days, SIGs of the Society as well as through the *British Journal of Pain*. Both elected and co-opted Council carry out a considerable amount of this work, but credit must be given to others within the BPS who quietly work away at matters of national pain importance, including those working within the Clinical Reference Group – Specialised Pain Services, epidemiology of pain and pain training, to mention but a few. This is an uphill struggle with reduced resources, yet so many members give up much of their time on this quest. I applaud you all for your ongoing endeavours (you know who you are – there are too many to mention here).

As I say farewell, I wish to acknowledge the outstanding contributions made by all of the BPS Council, in particular the secretariat, led by our Chief Executive Officer – Jenny Nicholas, our Honorary Secretary – Martin Johnson, Interim Honorary Treasurer – John Goddard and of course our incoming President – Andrew Baranowski in whom I have every confidence for the future well-being of the BPS.

With warm regards to you all  
William





## Dr Martin Johnson



THE BRITISH PAIN SOCIETY

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SAGE



Like William, this will be my last *Pain News* column (as Honorary Secretary). We prepare our dispatch a good 2 months in advance of publication date –

indeed my first column was written in January 2013. Thus, it is now January 2016 as I write and, as usual, it is pouring with rain – I do hope that none of you have been flooded out in the major events in Scotland and North England – if you were flooded, I do hope your household is now on the road to recovery.

### Personal thoughts

I do apologise that my last column did not appear in the December 2015 edition. In late October 2015, my father (who had been diagnosed with cancer in 2009) became acutely unwell. I thus began the balancing act of home, work and constantly travelling between London and Yorkshire. Eventually, my father was under the care of fantastic ‘hospice at home’ team and passed away in early December. Why do I mention this personal event? First, because I wish to thank all my friends and colleagues within the British Pain Society (BPS) who have passed on their

messages of support and sympathy. Also, during the final weeks of my father’s illness, I admit I felt stressed and this started to permeate all aspects of my life. I began to question if I was doing any good in the pain world, or if I was, was it to the detriment of my family (in terms of work load). One event focused my mind again – when my dad was admitted to hospital, he was very confused – when I first saw him (12 hours after admission), he was even more confused. I gently asked the nurse if his analgesics had been given/assessed (they had not – the one negative part of otherwise impeccable care). As soon as his pain was under control, he was much better. Afterwards, I realised THIS is why I fight for systems and processes around pain control that make a difference to the lives of many, including their family. As the oldest of the pain-related national organisations in the United Kingdom, the BPS has a very central role to play in making that difference.

### Changes

The last 3 years have been difficult as the effects of the recession bit into the Society combined with changing methods in the National Health Service (NHS) and no new drugs in the field of pain management. This all combines to reduce membership, attendance at the Annual Scientific Meeting (ASM) and the BPS income. Do you remember when entire pain management departments used to close so that everyone could attend the ASM – we would have to

resuscitate several managers in the NHS if that happened now!

When I wrote my first column 3 years ago, our membership stood at 1,443 – it is now 1,280, an 11% drop. No specific reason has been identified – the reasons for falling income above could equally apply to membership. Roger has written a brief summary of the recent membership survey elsewhere in this edition of *Pain News*. Sadly, only 28% of members took part in the survey – though two-thirds of those who took part were either satisfied or very satisfied with their membership. Many members say that they are unaware of the inner workings of the Society or cannot influence the workings (which some described as a closed shop) and yet last year’s Council vote attracted several candidates not usually involved in the general running of the BPS – sadly, despite the new electronic voting system, the voting turnout was still low.

The Council has recently voted to engage the services of a membership consultant – an initial meeting with her showed that she had many positive ideas for the Society.

On another positive note, I am pleased that our latest Special Interest Group (SIG) – the Headache SIG – had a very successful first meeting with 98 attendees on 25 November 2015.

### Website

I hope everyone is taking advantage of the facilities within the new BPS website. Do not forget to set your own email preferences about receiving meeting

announcements and reminders and also about receiving general BPS and Pain updates on dNews .

### Coding

Everyone should be aware of the continuing discussion about coding pain. However, General Practice in Scotland has successfully applied to the UK Health and Social Care Information Centre for a Read Code for Chronic Pain. The new Read code was released in October 2015 and can be used across the UK General Practice.

### Thanks

I was asked by Richard Langford to take over the role of Honorary Secretary, from my predecessor Professor Pat Schofield, slightly earlier than normal, due to Pat wishing to concentrate on her phenomenal work with pain management in the elderly. I thus commenced my role in October 2012. I thus wish to thank our past President, Richard, and our present President William for all of their hard work and support. There is no doubt our treasurers have the worst job on the Executive, especially when funds are

From the Honorary Secretary

Dr Martin Johnson

dropping, therefore I have to give a big thank you to John, then Andrew (and back to John) for all of their dedication to duty – likewise all members of the Council. To Jenny and team, you are simply the best – the BPS would not exist without you. May I wish Roger the best of luck as he takes up the reins of Hon Secretary along with Andrew and Heather in the Executive.

Dear reader, of course there are others with who the BPS simply would not exist – *you* and the rest of our members – keep paying the subs!

SMi presents the 16th annual

# Pain Therapeutics

Capturing the latest developments and innovations to accelerate market access

HOLIDAY INN KENSINGTON FORUM, LONDON, UK

23RD - 24TH  
**MAY**  
2016

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- Dr Steven Kamerling, Therapeutic Area Head for Pain & Inflammation, Zoetis
- Dr Stephen Doberstein, Senior Vice President and Chief Scientific Officer, Nektar Pharmaceuticals

**FEATURED SPEAKERS**

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- Dr Richard Butt, Senior Director, Research Project Leader, Clinical Research, Pfizer
- Dr Ozgur Sancak, Global Medical Science Lead – Pain, RB
- Dr Thomas Christoph, Senior Director, Head of Pain Pharmacology, Grunenthal GmbH
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- Dr Catherine Stehman-Breen, VP Clinical Sciences, Regeneron

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WEDNESDAY 25TH MAY 2016, HOLIDAY INN KENSINGTON FORUM, LONDON, UK

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# Spotlight - Felicia Cox

*The width and breadth of BPS membership is testimony to the diversity within the organisation and in the pain world. The Editorial Board would like to acknowledge this richness by shining a spotlight on some of our members. In this edition, we speak to Felicia Cox at Royal Brompton & Harefield NHS Foundation Trust.*



Felicia Cox

**1. What is your professional background and what attracted you to the world of pain?**

This reminds me of the question posed by Mrs Merton to

Debbie McGee – What first attracted you to the millionaire Paul Daniels? I am a Registered Nurse and qualified in Australia. I worked for almost 10 years in perioperative practice before being offered the opportunity to set up an acute pain service using an audit and education. I was supervised during this year's long project by Dee Burrows who will be known to many members. This project was in response to the publication of *Pain after surgery*. Things have progressed significantly since then. Thanks to Kate Seers that we have so many enthusiastic, dedicated and well-educated nurse specialists working in pain.

**2. What brought you in contact with the BPS?**

To be honest, I cannot really remember, but it may have been peer pressure from colleagues in the now-defunct Faculty of Specialists. Victor, Christine, Gordon and Neal to name a few.

**3. Apart from being a member, do you contribute in any other way to the work of the BPS?**

I do have a life outside of pain, but I am kept pretty busy with pain-related work and projects. I am co-opted to Council as I am the current Editor of the *British Journal of Pain* (BJP) (and also represent the Royal College of Nursing (RCN) as I am the chair of the RCN Pain and Palliative Care Forum which has over 14,000 members). The BPS gets value for money as I also sit on the Communications Committee and regularly host events at the Annual Scientific Meeting (ASM).

**4. Are there any further developments you would like to see happening within and through the BPS?**

To survive, we need to offer something unique (and cost effective) to all disciplines, and we need to constantly adapt. We need more disciplines represented at Council – this means more members putting themselves forward for elections.

**5. What do you feel is the role of the wider BPS membership?**

Where do I start? 1. Ensure Council are aware of innovations and challenges in clinical practice by getting in touch, by writing for *Pain News* and why not consider a letter to the Editor of the BJP? 2. Get

involved. Come up with some ideas for study days and events.

**6. If you were President of the BPS for a day, what would you do?**

I would nominate 1 day of the year as National Pain Day and hog the media spotlight by performing a live duet with perhaps Bono (post back surgery) in front a flash mob that I had organised on Twitter.

**7. What are you known for professionally?**

In addition to my refined sense of humour, and ability to chat with anyone, I would like to think that I am a finisher of tasks. No obstacle is too great to surmount. I hope no one mentions static! On a more sensible note, I facilitated the development of the BJP from a stand-alone publisher to the support and opportunities that the global publisher SAGE offers. I am delighted that in 2016, I will be the first nurse member of the International Association for the Study of Pain (IASP) Clinical Updates in pain advisory board. I am looking forward to that challenge.

**8. What are you most passionate about professionally?**

Interdisciplinary working and since being on the sharp end of a bone marrow aspiration needle 10 years ago raising the profile of procedural

pain. Also ensuring equity of care for people with a learning disability.

**9. What do you have a knack for?**

Getting things done.

**10. What would be impossible for you to give up?**

Too many vices to mention.

**11. How do you want to be remembered?**

I came, I saw, I networked!

**12. Any life achievements you are particularly proud of?**

Being awarded Honorary Membership of the BPS alongside

Nick Allcock was the highlight of 2015.

**13. Anything else you would like to tell people about yourself?**

I think I have said enough.



**Follow the Society on twitter**

Please follow the Society on twitter **@BritishPainSoc**

We will be sharing relevant information and updates from the Society.

## Upcoming council elections



You will shortly receive notification of the Council elections by email and in your inbox within the BPS website, after you log in. Please do vote. It only takes a few moments, yet your vote may ensure that

your discipline within the healthcare disciplines of pain has a voice on the Council. If you do not vote, it will not happen!

# Inaugural Headache Special Interest Group meeting

Sarah Love-Jones *Treasurer of the Headache Special Interest Group*



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The most recently formed Special Interest Group (SIG) of the British Pain Society (BPS) – the Headache SIG which was founded at the Annual Scientific Meeting (ASM) of the BPS in Glasgow in April 2015 – held its first meeting at Churchill House on 25 November 2015. This was a resounding success with 98 delegates registering and attending the meeting. This is one of the largest attendances at a SIG inaugural meeting on record.

The meeting was the brainchild of the dynamic Dr Vivek Mehta (Chair of the Headache SIG), who successfully created an informative and exciting programme of lectures. The day was kicked off with the 'Pathophysiology of migraine' by Dr Farooq Maniyar, Consultant Neurologist, who enlightened us on some of the mechanisms. This was followed by 'Diagnosis of headache' by Dr Anish Bahra, Consultant Neurologist and Secretary of the Headache SIG, who very cleverly summarised her 20 years of experience to give us a simple method of

categorising the normally daunting subject headache diagnoses. Dr Simon Ash, Consultant Orthodontist, informed us about 'Dental pain – a cause of headache?' which included a practical exercise where we assessed the bite of the person sitting next to us in the lecture theatre, looking for lateral displacement of bite, which can be a cause of headache. The first session concluded with Dr Serge Nikolic, Consultant Pain Physician, informing us of 'How much of headache is Cervicogenic?' which is a significant cause of headache.

The second session of the day was 'Psychological Aspects' with a well delivered patient story of what it was like to finally get a diagnosis and live with chronic facial pain. This was followed by Dr Clare Daniel, who presented on the aspects of 'Psychology of Headache'.

After lunch, Dr Fayyaz Ahmed, Consultant Neurologist, updated us on the National Institute for Health and Care Excellence (NICE)-accredited procedures including Botox for migraine and

Occipital Nerve Stimulation for intractable chronic migraine. Dr Kevin Shields, Consultant Neurologist, informed us about the practical use of Nerve Blocks and Botulinum toxin for headache and migraine. More practical aspects of 'Neuro-stimulation for Headache' was well covered by Dr Giorgio Lambro, Consultant Neurologist, and finally, Dr Rigmor Jensen from the Danish Headache Centre updated us on 'Emerging techniques' including the new Sphenopalatine Ganglion Stimulation for cluster headache.

The day was a great success in terms of education and networking with a true multidisciplinary audience of Pain Physicians, Neurologists, Dentists, Oral surgeons, Psychologist, Nurses, Osteopaths, Rehabilitation and Physiotherapists.

Plans are in progress to have a joint meeting next year with the British Association for the Study of Headache (BASH), so we look forward to another great meeting in 2017.

## Faculty of Pain Medicine - Upcoming Events at the Royal College of Anaesthetists, London

### **Musculoskeletal System Examination for Diagnosing Pain Problems**

**Wednesday 15th June 2016.** £175, £140 for trainees/nurses

<http://www.rcoa.ac.uk/education-and-events/fpm-musculoskeletal-system-examination-diagnosing-pain-problems>

Lectures and workshops include:

- The role of clinical examination
- Lumbar spine and pelvis examination
- Hips and knee examination
- Ankle and foot examination
- Cervical and thoracic spine examination
- Wrist, hand and elbow examination
- Shoulder examination

### **Faculty of Pain Medicine 9th Annual Meeting**

**Friday 2nd December 2016.**

Further details available soon at:

<http://www.rcoa.ac.uk/faculty-of-pain-medicine/news-and-events>

### **Pain in Secure Environments**

Pain in Secure Environments is a one day course run by the Faculty of Pain Medicine and is endorsed by Public Health England. The course has been developed to meet the workforce training requirements for those professionals working within Secure Environments.

**Monday 11th April 2016,** Near Lichfield, Staffordshire

<http://www.hawkesyardestate.com/conferences.aspx>

**Monday 9th May 2016,** Royal College of Anaesthetists, Holborn, London

The course fee is £250. For further information and future courses, please see:

<http://www.rcoa.ac.uk/faculty-of-pain-medicine/pain-in-secure-environments>



# 11th Paediatric Pain Symposium – bridging the gaps: the humanities and sciences in pain

Polly Louise Langdon *PhD Candidate, University of Southampton*

Great Ormond Street Hospital's (GOSH) 11th Paediatric Pain Symposium (PPS) took place in London on 10 and 11 December 2015. The PPS is a multidisciplinary event, providing a forum for researchers and healthcare professionals to present and discuss their work in paediatric pain. The 11th PPS included 38 presenters and 95 delegates from various professional backgrounds, including paediatric nurses, anaesthetists and paediatricians. The content of the symposium reflected the biopsychosocial model of pain, the GOSH Pain Service's philosophy of clinical care. Day 1 presentations reflected the symposium's theme by combining humanities and sciences in paediatric pain research. On Day 2, the focus moved to evidence-based clinical care. Each day delegates were able to attend two of four running workshops tailored to the day's theme.

## Day 1 presentations and workshops

Day 1 kicked off with a session on the biopsychosocial understanding of chronic post-operative pain (CPP). After a brief introduction about the prevalence of post-operative pain and its biomedical predictors by Suellen Walker, Reader in Paediatric Anaesthesia and Pain Medicine, UCL, Sandrine Géranton, Senior Research Fellow, UCL presented evidence from animal studies to support her hypothesis that the predisposition to

develop chronic pain can be recognised as a molecular signature, set in the dorsal horn of the spinal cord by epigenetic mechanisms. Following this, Christina Liossi, Senior Lecturer in Health Psychology, University of Southampton, critically reviewed the literature of the psychological predictors of CPP and demonstrated how clinical, statistical and methodological considerations are inextricably related in understanding that literature. After lunch, a panel comprising Dilini Rajapakse, Consultant in Paediatric Palliative Care, Sophie Pownall, Solicitor and Hugo Wellesley, Consultants in Paediatric Anaesthesia, presented the audience with an ethical dilemma relating to the care of a fictitious patient. The question raised was 'can a 13-year old boy with cancer decide to opt for palliative care instead of experimental curative cancer treatment in contrast to his parents' wishes?' and the presenters discussed ethical and legal issues related to the case.

As a trainee Health Psychologist, I attended the workshops that I deemed most relevant to my discipline. The first workshop, titled 'Pain management and the social determinants of health', led by Matthew Jay, Data Administrator, GOSH, Beverly Sokel, Clinical Psychologist, GOSH, and Nick Wright from the Camden Citizen's Advice Bureau at GOSH focused on the social aspects of paediatric chronic pain, including family financial difficulties, parental divorce and childcare and how they influence chronic

pain and its management. The second workshop, 'Chronic pain mechanisms', led by Orla Moriarty, Research Fellow, UCL, and Richard Howard, Consultant in Paediatric Anaesthesia & Pain Medicine, GOSH, discussed the epidemiology, neural connexions and mechanisms thought to underlie symptoms and behaviours seen in patients with chronic pain. By reviewing both animal and human research, they demonstrated how the subjective experience of pain, including its site, intensity, quality, unpleasantness and associated suffering result from interactions between multiple inputs, including sensory, physiological, affective, sociocultural, behavioural and cognitive, with a large distributed brain network being accessed during nociceptive processing.

The first day of the PPS closed with a very interesting lecture by Professor Joanna Bourke, Historian from Birbeck College, University of London. Joanna's recital of the history of paediatric pain elicited thoughts about how spectacularly far paediatric pain research and clinical practice has progressed throughout the centuries.

## Day 2 presentations and workshops

The second day started with an excellent presentation on pain in neurodisability: mechanisms and management by Charlie Fairhurst, Consultant in Paediatric Neurodisability, and Susie Turner, Clinical



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## 11th Paediatric Pain Symposium – bridging the gaps: the humanities and sciences in pain

Specialist Paediatric Physiotherapist from Evelina London Children's Hospital, and continued with an emotive presentation about pain stories from Professor Bernie Carter, University of Central Lancashire.

After lunch, Kevin McCarthy, Consultant in Paediatric Anaesthesia & Pain Medicine, talked about new approaches to multimodal analgesia, including interesting new research findings for the use of intravenous vitamin C in reducing post-operative pain.

Following this, Mark and Ben Thomas, Consultants in Paediatric Anaesthesia & Pain Medicine, GOSH and Chelsea & Westminster Hospital, respectively, gave very interactive presentations about Internet resources specific to paediatric pain. Ben encouraged live tweeting of the symposium and showed delegates how to use [#goshpainsymp](#) to promote the event.

Dilini Rajapakse, Consultant in Paediatric Palliative Care, and Christina Lioffi hosted a workshop on priorities in paediatric palliative care research. In a highly interactive workshop, they discussed research questions that arise from day-to-day practice, highlighted barriers and challenges to doing research in this clinical speciality, and looked for solutions. They discussed the importance of research collaboration and methods, for identifying and achieving consensus regarding research priorities in this field, and presented the 'Top 10' research priorities identified by the National Institute for Health Research Clinical Studies Group for Pain and Palliative Care in Children and Young people. More information about each of the priorities, including current systematic reviews and



*Pain forum and multidisciplinary panel discussion at the end of the final day of the Symposium. From left to right: Ishani Perera, Jude Middleton, Kevin McCarthy, Christina Lioffi and Mark Thomas.*

ongoing trials, if any, are on the UK Database of Uncertainties about the Effects of Treatments (UK DUETs): <http://www.library.nhs.uk/duets/SearchResults.aspx?catID=14528&tabID=296&>

The final workshop that I attended was about pain assessment in children led by Becky Saul, Lecturer Practitioner and Clinical Nurse Specialist in Pain, GOSH. Becky gave an in-depth discussion on techniques and tools used for assessing acute and chronic pain and explained the importance of using validated and developmentally appropriate pain assessment tools. Also, the key is to use these tools regularly, to record scores clearly, and to use them to inform clinical decision-making. The workshop was broken up with a video task where delegates were asked to assess a neonatal patient's pain level and discuss, as a group, the appropriate course for action.

I feel I need to highlight the excellent workshop run by Sue Maillard and Ishani

Perera, Physiotherapists, GOSH, and Glyn Williams, Consultant in Paediatric Anaesthesia & Pain Medicine, GOSH, in which the presenters discussed the mechanisms that lead to Complex Regional Pain Syndrome (CRPS), how it is diagnosed and how to identify and effectively manage this rare condition. They also presented data on the characteristics and outcomes of a cohort of children with CRPS seen at GOSH and discussed recent research in this field.

The symposium concluded with a multidisciplinary panel discussion where members of the panel answered questions from the audience about different aspects of paediatric pain.

### Further information and next event

For those of you who were unable to attend this year's PPS, if you are a clinician interested in learning more about managing paediatric pain, you can access a series of modules about Paediatric Pain launched on Compass (the education portal on the RCPCH website: <http://rcpch.learningpool.com/>). Alternatively, if you have a research idea that you would like to take forward and you need feedback and support, you can get in touch with the Institute for Health Research Clinical Studies Group for Pain and Palliative Care in Children and Young people: <https://www.crn.nihr.ac.uk/>

The 12th PPS will be held in December 2016. Anyone interested should take a look at the website – <http://www.gosh.nhs.uk/paincontrol-noticeboard> – for more information.



# Northern Ireland Pain Summit 2015

**Pamela Ball** *Chair, The Pain Alliance of Northern Ireland*

**John O'Hanlon** *Convenor, Northern Ireland Pain Society*



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The first Northern Ireland (NI) Pain Summit was held in May 2012 and so 2015 seemed like as good time to reflect on the progress that has been made in improving services for those who live with long-term pain, to celebrate the successes and to prioritise future work. To this end, the Pain Alliance of Northern Ireland and the Patient and Client Council (PCC, the voice of the patient in health and social care (HSC) in NI) held the second NI Pain Summit on 18 November 2015. This brought together patients, carers (and their supporting organisations), healthcare professionals (HCPs), key HSC providers, commissioners, civil servants and Members of the Legislative Assembly (MLA) to review the progress made since the NI Pain Summit 2012 in the following areas:

- Raising awareness of the extent of the problem of people living with chronic pain;
- Commissioning services across all healthcare sectors;
- Education at undergraduate and postgraduate levels for HCPs.

We also wished to identify areas where provision of services and training/ education require investment and continue to develop consensus around the interventions and service models which offer the best strategies for people with long-term pain. Given the financial and other constraints on our health service, not least the fact that we now face another radical restructuring of HSC

organisations, we wanted to engage HSC and third sector organisations, leading providers and commissioners in prioritising actions to achieve this.

## What has been achieved since the first NI Pain Summit?

At the 2012 Summit, the Minister for Health, Social Services and Public Safety, Edwin Poots MLA, announced that chronic pain was considered to be a long-term condition and standards and the strategic direction for services would come within the Department's Long-Term Condition Strategy, a major advance. Prior to this, the Department had only suggested that chronic pain be considered as an entity in its own right. Chronic pain is now set within the long-term condition funding stream.

The PCC's survey of the experiences of people living with chronic pain and their experiences of the services provided for them (*The Painful Truth*) was published in February 2014. This reflected the views and experiences of over 2,500 sufferers and made ten recommendations to the Minister, seven of which were accepted in whole or in part. The Minister reiterated his acceptance that chronic pain is a long-term condition in its own right, and among other actions, crucially directed the HSC Board and the Public Health Agency (PHA) to carry out a scoping exercise of the pain services across primary and secondary care. This was completed early in 2015 and identified the paucity of service in the community and the patchy nature of

secondary care services, with no service currently having the resource to offer a comprehensive range of care. All five HSC Trusts offer some service, and all services offer some elements of care that are very good, but there is considerable variation in the resource between Trusts.

A Chronic Pain Forum has now been established by the joint commissioners (PHA and Health and Social Care Board (HSCB)) and involves clinicians from all professional groups (including both physical and mental health), patients, carers, voluntary sector organisations, general practitioners (GPs) and Local Commissioning Groups. Although it is early days, this group has submitted a 5-Year Plan to the Department of Health (at the request of the Assembly Health Committee) setting out how investment in the service might be used to meet the demands placed upon it. It has also made a significant contribution to the pathway for pain management within the Integrated Care Partnerships. Other strands of work include how technologies might best be used to improve patient care.

In terms of the outcomes in chronic pain education, the Medical School (Queen's University, Belfast) has examined its curriculum to identify where and when pain education is covered and as a result has reinstated teaching in chronic pain management in the form of attending a pain clinic, writing a commentary about the experience and an introductory lecture. The majority of GPs and many physiotherapists have had training in supporting patients in pain



self-management using the Pain Toolkit. GPs and Community Pharmacists have received additional training on analgesics and non-pharmacological pain management, and podiatrists have had training in the chronic pain management as the new diabetic care pathway identified the need for their knowledge of the management of neuropathic pain to be enhanced.

### How did the 2015 Summit meet its aims?

First, in raising awareness of the burden of chronic pain, a lady living with complex regional pain syndrome and two young people with severe arthritis spoke most eloquently about the impact of pain on their ability to work and schooling and how it affects their activity, mood and relationships with family and friends. They identified where healthcare and voluntary services had, and had not, helped them and reflected on how acceptance of their pain and the limitations that it placed on them was key to their ability to cope. Both the Chair of the NI Assembly Health Committee and the Deputy Chief Medical Officer related how the patient stories published in *The Painful Truth* had such an impact in ensuring that chronic pain has become a priority both for the NI Assembly and Department and their willingness to support change and development of services. The Chief Executive and the Chair of the PCC stated their commitment to continuing to support



*From left to right: Dr Pamela Bell, Chair PANI; Professor Maureen Edmunson, Chair PCC; Ms Maeve McLaughlin MLA, Chair, NI Assembly Health Social Services and Public Safety Committee; Mrs Louise Skelly, Operations Director, PCC and service user Norma Johnston.*

patients and patient groups through continuing their involvement with the Chronic Pain Forum and continuing to blog about it. At their workshop on the afternoon of the event, a number of patients spoke most movingly about the burden of pain in their lives.

In terms of the size of the problem, Dr Kathryn Martin, Lecturer in Epidemiology at the University of Aberdeen, presented the epidemiology of a variety of chronic pain conditions and alerted us to the likelihood of increasing demand as our population of elderly people increases. The British Pain Society's work in supporting patients with chronic pain was ably presented by the President, highlighting not only the work of the Patient Liaison Committee but also how its other activities (alone and in partnership with other agencies) impact the services delivered to patients. We were fortunate to have Pain Concern's Airing Pain Team record interviews with speakers and delegates so we will reach a much wider audience.

The Director of Commissioning at the HSCB presented the results of the PHA scoping study and outlined the vision for future services/pathways of service development. He recognised that even with the adoption of new ways of delivering the service and early

supported self-management, considerable investment is required in secondary care pain services as well. Current capacity is only half of what is required. The Convenor of the NI Pain Society and a local GP presented their own vision of the need for services to change. Always keen to learn from the experiences of other health economies, we invited Professor Blair Smith, Lead Clinician for Chronic Pain in Scotland, and Mrs Sue Jenkins, Acting Senior Lecturer, Section of Anaesthetics, Intensive Care and Pain Medicine, Cardiff University, to present the developmental work that has been carried out in Scotland and Wales, respectively. It is clear that both regions are somewhat ahead of NI in terms of work already undertaken to improve services, but that many of the problems they encountered are very similar to our own. One of the specific challenges facing NI will be determining how to build on the progress already achieved throughout the forthcoming restructuring.

In an afternoon workshop, the PHA and HSCB leads of the Chronic Pain Forum explored what good pain management service provision should look like. They concluded that public awareness needs to be raised through an advertising campaign using a celebrity or through a popular TV series. Information needs to be easy to find (pain patients sometimes struggle to concentrate) authoritatively collated and concise. With the diagnostic process often protracted or delayed, interim access to management options is essential to avoid lack of information 'while waiting'. Group settings are good for sharing not just socially but also of information on how to manage conditions and navigate healthcare systems. Local access to exercise through pain management-aware active community coaches and other locally available options like relaxation and alternative therapies is hugely important. Helplines (e.g. Pain Concern)

## Northern Ireland Pain Summit 2015



*Organisers and sponsors from left to right: Mrs Lorna Reilly, Rosemont; Dr Pamela Bell, PANI; Mrs Coirle Butler, Napp; Mrs Louise Skelly, PCC; Mrs Joanne Mc Kissick, PCC; Dr William Campbell, BPS and Mr Ian Little, Grunenthal.*

or prompt access to a key worker is essential, especially during flare ups to avoid help seeking in ill-equipped settings (A&E departments or out-of-hours GP services). HSC professionals (e.g. GPs) with special interest need to share knowledge with colleagues to increase their capacity and avoid deskilling.

Education of HCPs, patients and the public is a topic that arises very regularly at meetings with patient groups. In this workshop, we reviewed the additional educational activity (regular and sporadic) undertaken by HCPs since the 2012 Summit, identified that nurses had received less additional postgraduate training and drew up plans to address this. Education for GPs in Training (GP Registrars) was also felt to be deficient, and the NI Medical and Dental Training Agency will be approached to determine the level of training already placed and to see how this might be enhanced. Education (and support) for those running Community Groups, for those living with chronic pain, could enhance the quality of support that they offer and encourage attendance at events. The content and availability of courses to meet this need should be scoped.

### What of the future?

Clearly, we remain on a journey and are far from our ultimate goal. The road to improvement in pain services remains a

difficult one, potentially becoming steeper and more treacherous during the restructuring of the health service. The fact that some of the seed of work undertaken will fall on stony ground is assured.

We need to continue to raise awareness of the good work being undertaken and not just highlight the deficiencies. This message was repeated in most of the conversations that took place during breakout times at the summit.

However, there are some positives, in particular, the way in which the Chronic Pain Forum has brought together all stakeholders, with patients, carers and the voluntary sector having an equal part in the processes of service redesign with clinicians and all HSC organisations. Not tokenism but real engagement – every voice heard. We are also encouraged by the support of the NI Assembly Health Committee and the Chief and Deputy Chief Medical Officer and the commitment of the PCC in continuing the work. They will need to shine the light of strategic thinking on the road ahead.



# The Clulow Award 2015

Sam Eldabe *Chair, Science and Research Committee*

In 2001, Mildred B Clulow bequeathed a legacy to the British Pain Society (BPS) to fund research into the causes and cure of pain. The Society created a research grant award named the Mildred B Clulow Award. In 2011, a further legacy was bequeathed from Elaine Clulow. The award was subsequently renamed the Clulow Award to reflect the new donation. The BPS invites competitive applications for a research grant within any field of pain research with costs of up to £50,000 every 2 years.

For the 2015 round, the BPS Science and Research Committee received nine very high-quality proposals. The proposals spanned a wide breadth of pain research and included a pilot randomised clinical trial of pulsed radiofrequency (RF) and trigger point injections in chronic abdominal wall pain, an observational study to analyse opioid utilisation and patients' characteristics in

Wales, a qualitative evaluation of a research-based film about adult experiences of pain in chronic pain education, a proposal for the application of stratified medicine to aid diagnosis and management of patients with orofacial pain. A primary care pain management proposal aimed to explore the value of a piloting a navigator tool, to improve the patient and healthcare professional consultation focussing on self-management of chronic pain. The dominant sector remained basic science and translational work with proposals focussing on basic science of complex regional pain syndrome (CRPS), chemotherapy-induced painful neuropathy and HIV-associated sensory neuropathy.

Following initial scrutiny by members of the BPS Science and Research Committee, proposals were scored on a number of domains (members declaring conflict of interest did not score or

comment on proposals where they were conflicted). The top four scoring proposals were further discussed at a special committee meeting.

The committee unanimously agreed to award the funding to Dr Ilona Obara for her proposal titled: mTORC1 and the regulation of opioid analgesic efficacy in chronic pain: a translational approach. Ilona Obara is a lecturer in pharmacology at Durham University. Ilona's proposal builds on her previous work and aims to investigate how the enzyme known as the 'mammalian target of rapamycin complex 1', or mTORC1, changes the levels of neuropathic pain in mice when morphine is administered solely or together with metformin, a drug that inhibits mTORC1 and is widely clinically available.

The BPS wishes Ilona every success in her research. I will aim to keep you updated on the progress of her research.



# Membership survey 2015

Roger Knaggs *Honorary Secretary Elect*

Many thanks to the British Pain Society (BPS) members who took time to complete the survey that was distributed last summer. This was the first time that the Council had the opportunity and resources to ask members for their views and opinions of the Society and the value of their membership.

Overall, there were 355 responses, around 28% of the Society's membership. Most responses were received from members in clinical practice (79.0%), with a smaller number from retired members (7.6%) and those involved in education (6.9%) and clinical research (5.5%). Although the majority of responses were from anaesthetists (50.2%), other professions included nursing (21.4%), psychology (5.9%), physiotherapy (3.3%) and general practice (3.3%), reflecting our multi-professional membership.

Around two-thirds of those who responded were either satisfied or very

satisfied with their membership. The main reasons for joining were as follows: to be part of multidisciplinary community (80%), for professional development (65.4%), to support mission of advancing pain management and the understanding of pain (46.9%) and for networking opportunities (45.4%). While the reasons for remaining a member were similar for joining, there were a few differences in priority, particularly receiving *Pain News* and the *British Journal of Pain* that was a more frequent reason why people remain members. Attending the Annual Scientific Meeting, original publications and guidelines, networking opportunities, topical news and opinion and advocacy for availability and development of pain services nationally were seen as the most valued services of the Society.

The questionnaire produced a wealth of information on a range of different

topics. Key messages have been used in assisting on priority decisions over the next few years. Many members expressed a view that they were not aware of the workings of the Society, and we hope that the recent development of regular 'push emails' will keep you informed of activities. Another innovation was the recent regional study day on neuropathic pain that was held in Liverpool. In addition, we are reviewing our membership strategy, and you will hear more about this as this work develops.

At the same time, we took the opportunity to contact former members to ask why they had not taken the opportunity to renew their membership. For some, it was the recent change to online payment, but for many, it was retirement or moving out of the specialty of pain management.

Watch out for another opportunity to let us know your opinion later in 2016.

The British Pain Society is nothing without you, its members, and we appreciate your continuing involvement and support. We recognise that, for many members, in recent years, the decision to pay the membership fee for a non-compulsory professional society has been more challenging so we will continue to look closely at our fees and we will take care to limit any increases. We hope that you will continue to encourage your colleagues to join us.

May we also remind you that The British Pain Society is a registered charity and we welcome funds received from legacies and through sponsorship. As we know from the numbers who have joined fun runs at previous ASMs, many of our members are actively engaged in sporting activities. So, if you are signing up for any marathons, half-marathons, triathlons, swims or tiddlywinks contests, please consider nominating The Society as your chosen charity.



Thank you for supporting the BPS!



# Pain Message in Parliament

'UK Pain Messages', a fact sheet about chronic pain and its impact on patients and the society was launched by representatives from the organisations involved at a Parliamentary meeting held in the House of Commons, on

18 November 2015. The Pain Consortium – comprising the leads from the Faculty of Pain Medicine, the Royal College of General Practitioners, the British Pain Society and the Chronic Pain Policy Coalition - have come

together, with input from Pain UK, to gain a consensus relating to these facts and figures, highlighting the burden of Chronic Pain in the United Kingdom. Following are the pictures from the launch event.

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**EVENTS**

18 November 2015

**Events Round-up: 18 November**

Energy Secretary **Amber Rudd** speaks at the **Institute of Civil Engineers** in London on UK energy policy (10:30am). Announcements will include Government plans to close coal power stations by 2025

Business Secretary **Sajid Javid** delivers the keynote speech at a conference hosted by **Ernst and Young** and the **Premier League** on the impact of the Premier League on the UK economy (11:25am)

Foreign Secretary **Philip Hammond** meets with the Cypriot President **Nicos Anastasiades** and Foreign Minister **Ioannis Kasoulidis** in Cyprus

Minister for Preventing Abuse **Karen Bradley** and shadow health minister **Luciana Berger** speak at an event hosted by **Digital-Trust** in Portcullis House on the threat of digital crime. Plaid Cymru home affairs spokesperson **Liz Saville-Roberts MP** and co-chair of the All-Party Parliamentary Group on Digital Crime **Cheryl Gillan MP** chair the event

Culture Minister **Ed Vaizey** speaks at the **Intel Security** summit in London (11:30am)

Northern Powerhouse Minister **James Wharton** speaks at the **Institute of Economic Development's** annual conference in London on what the Northern Powerhouse means for UK economic growth (11:00am)

Education Minister **Sam Gyimah** attends a **Place2Be** head teachers' conference and joins a boat trip as part of the Government's **Your Life** campaign on STEM subjects

Policing Minister **Mike Penning** makes speech via videolink to the **Security Industry Authority** annual conference

Shadow education secretary **Lucy Powell** speaks in London at a **National Union of Teachers** event (10:30am)

Shadow health minister **Andrew Gwynne** takes part in a panel discussion on overcoming obesity at **Food Matters Live**

House of Commons Education Committee chair **Nell Carmichael** delivers the keynote address at a **Reform** policy dinner (7:00pm)

National Infrastructure Commission chair **Lord Adonis**, **Lord Adebowale**, Conservative London mayoral candidate **Zac Goldsmith MP**, Labour London mayoral candidate **Sadiq Khan MP** and Deputy London Mayor for **Policing and Planning** **Edward Lester** speak at **The London Conference**

**Lord Luce** speaks at a **Chronic Pain Policy Coalition** event in Parliament on how to improve the lives of people with chronic pain

Other Private Secretary to the Queen **Lord Gavin** speaks at a lecture on the power of the Crown in Parliament at Westminster Abbey (1:15pm)

Scottish Health Secretary **Shona Robison** visits Queen Elizabeth University Hospital in Glasgow to mark European Antibiotic Awareness Day (11:15am)

Scottish Social Justice Secretary **Alex Neil** makes an announcement in Edinburgh on human rights (9:30am) and announces that the Scottish Government has exceeded its affordable homes target

Welsh shadow minister for social services **Dr Altaf Hussain** makes an announcement on delayed transfers of care

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## Pain Message in Parliament



We published the 'UK Pain Messages' in December 2015 edition of *Pain News*. *Pain News* is pleased to publish it again in this edition. You may want to send these documents to your local Member of Parliament, CCGs contacts, Health and Wellbeing Board or any other health authority/individual to raise awareness of Chronic Pain.

## UK Pain Messages

There are a large number of messages used for Chronic Pain by a variety of organisations. The aim of the UK Pain Messages is to define and gain consensus and consistency over the facts and figures used when highlighting the burden of Chronic Pain in the UK. These messages, separately in the public domain, have been approved by the following organisations/individuals: Faculty of Pain Medicine, Royal College of General Practitioners' Chronic Pain Lead, British Pain Society, Chronic Pain Policy Coalition and importantly patients via Pain UK.

- The Department of Health recognises chronic pain as a long-term condition in its own right and as a component of other long-term conditions.<sup>1</sup>
- It is estimated that 14 million people live with chronic pain in England alone. In 2011, 31% of men and 37% of women reported persistent pain. Of these, 25% (or one in four – 3.5 million) said that their pain had kept them from usual activities (including work) on at least 14 days in the previous three months.<sup>2</sup>
- A person living with pain will have a very poor quality of life – much worse than other conditions, and as bad as significant neurological diseases such as Parkinson's.<sup>2</sup>
- Low back pain is ranked highest out of 291 conditions studied by the Global Burden of Disease study, ranking number one for years lost to disability worldwide. In fact four of the top 12 disabling conditions globally are persistent pain conditions (low-back and neck pain, migraine, arthritis, other musculoskeletal conditions).<sup>3</sup>
- 41% of people who attended pain clinics report that their pain has prevented them from working, and 13% have had to reduce their hours.<sup>4</sup>
- 66% of people attending A&E seeking help with pain had more than three visits to a healthcare professional in the preceding six months.<sup>4</sup>
- The 2008 Chief Medical Officer report states that 25% of pain sufferers lose their jobs; 16% of sufferers feel their chronic pain is so bad that they sometimes want to die.<sup>5</sup>
- Men and women in the lowest income households are more likely to report chronic pain (42%), compared to those in the highest quintile (27%).<sup>2</sup>
- Severe chronic pain is associated with increased risk of mortality, independent of socio-demographic factors.<sup>6</sup>
- Attending specialist pain services improves quality of life (in total, 56% of providers reported post-treatment improvement in EQ5D-3L score, and 76% reported improvement specifically in pain-related quality of life).<sup>4</sup>



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# Opioids Aware: A resource for patients and healthcare professionals to support prescribing of opioid medicines for pain

Roger Knaggs *Associate Professor in Clinical Pharmacy Practice School of Pharmacy University of Nottingham*

*Opioids Aware* is a tool that all those that manage patients with pain should be very familiar with.

There has been a sharp and sustained increase in the prescription of opioid painkillers in recent years. The latest figures from 2014 record that 22.75 million prescriptions were written in England with a total cost of nearly £305 million to the National Health Service (NHS). Similar rises in prescribing in the United States and elsewhere have been accompanied by increases in harms related to these drugs including addiction, unintentional overdose and death. Opioid painkiller problems in the United Kingdom have not reached the epidemic proportions seen in the United States, but we know that over 5% of adults in England and Wales have used opioid medicines that were not prescribed for them in the past year. Almost all the increase in opioid prescribing has been for treatment for

long-term pain; however, opioid medicines are often ineffective for many patients with these conditions.

In the United Kingdom and other countries, guidelines for prescribers on the use of opioids have been available, but awareness of guidelines and their use has been disappointing. Rather than simply update the previous British Pain Society's publication 'Opioids in Persistent Pain: Good Practice', a new resource, *Opioids Aware*, has been developed for all healthcare professionals, patients and their carers to support safe and rational use of opioid medicines.

The resource has been developed by healthcare professionals and policy groups. In addition to major contributions from the British Pain Society and Faculty of Pain Medicine, several other medical royal colleges, the Royal Pharmaceutical Society, the Public Health England, NHS England, the National Institute for Health

and Care Excellence (NICE), the Care Quality Commission (CQC) and the NHS Business Services Authority have helped to ensure that *Opioids Aware* is relevant for everyone involved in the decision to prescribe and take opioid medicines.

Perhaps, the most important message to prescribers is that if medicines (of any sort) do not work for the patient, they should be stopped. This is clearly not happening in the case of opioids, and patients and prescribers often make the decision to try increasingly high doses. This is almost never helpful and substantially increases the risk of harm from opioids.

*Opioids Aware* is a web-based resource, funded by Public Health England and hosted by the Faculty of Pain Medicine, Royal College of Anaesthetists and can be found at [www.fpm.ac.uk/faculty-of-pain-medicine/opioids-aware](http://www.fpm.ac.uk/faculty-of-pain-medicine/opioids-aware)





# Social media for professionals in Pain Medicine – an introduction and Twitter

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*Social media, noun:*

Websites and applications that enable users to create and share content or to participate in social networking.

*Social networking, noun:*

The use of dedicated websites and applications to interact with other users, or to find people with similar interests to one's own. (Google definitions)

## Introduction

When we see or hear phrases like social media or social networking, applications such as Twitter, Facebook and Instagram might come to mind for most of us. But for millennia, we have found effective ways to interact with others who have similar interests to our own across vast distances. Therefore, social media in one form or another has been around for a very long time. Indeed, there are claims that the first postal service originated in Persia between 1700 BC and 500 BC. However, the first well-documented state-run service was the *Cursus Publicus*, which was set up by Emperor Augustus (64 BC–AD 14), which enabled communication across the Roman Empire. The need to form social networks is not a new phenomenon, but the tools used for this process have changed over time.

Telegraph	1792
First successful telephone transmission	1876
Marconi patented radio	1896
Email	1966
Wikipedia	2001
Facebook	2004
YouTube	2005
Twitter	2006 <sup>1</sup>

## Reaching 50 million users

Telephone took 75 years to reach 50 million users compared to Internet which took only 4 years. Compare these to the reach of angry birds which took only 35 days to reach 50 million users.<sup>2</sup>

Radio, telephone and television required raw materials, construction and labour to have the infrastructure and then



distribution and sales to reach the 50 million mark. In contrast, once the infrastructure of the Internet was in place, interactive websites such as Google, Facebook and Twitter could harness the Cambrian Explosion of technology and applications that constitute a significant part of the global community. 'The strengths of social media are the interactivity, connectedness, participation, openness, conversation and sense of community that it fosters'.<sup>3</sup>

Over the coming issues of *Pain News*, we will introduce social media and some of its current applications and discuss how it can be utilised to further communication and knowledge relevant to Pain Medicine.

## Twitter

### What is it?

Twitter was founded in March 2006 and was launched in July 2006 by Evan Williams, Noah Glass, Jack Dorsey and Biz Stone. Many use it to share news, jokes or message whatever is on their mind. Users are limited to using a maximum of 140 characters to convey their message. Every second there are (on average) 6,000 tweets (messages) that correspond to 360,000 tweets per minute, 500 million tweets per day and a whopping 200 billion tweets per year!

Looking at those numbers, you would be right to think ‘how can I be heard among all that Twitter noise?’ The power of Twitter may be illustrated as follows: one of the authors (D.S.) attended the Peterhouse Medicolegal conference in Cambridge, United Kingdom, on September 2015. In one of the afternoon lectures, there was an excellent slide on cortical remapping post amputation (Figure 1). The slide was tweeted by one of the authors to 150 followers. It was retweeted by a follower in the United Kingdom who has 7,000 followers and then retweeted by them and so on. Within 45 minutes, it was read and retweeted by people in Athens, Amsterdam, Utrecht, Izmir and London. It was then seen and ‘liked’ by people in Buenos Aires and Melbourne. Within a very short period of time, within an hour, the tweet had gone around the world and was seen over 1,500 times.

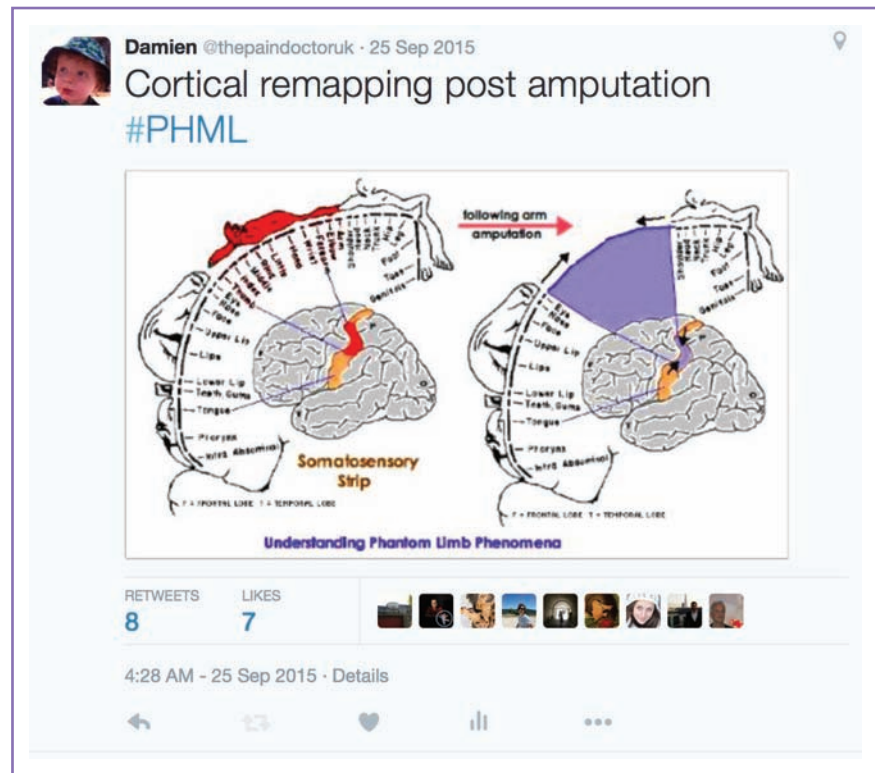
The rapid mode of communication and dissemination of information is also the reason that Twitter has been involved in

controversy and censorship. It has been used as a mode of communication during political and civil unrests, used in protests and revolutions including the ‘Arab Spring’. Currently, it is completely blocked and unusable in Iran, China and North Korea and has been previously banned in Turkey, Iraq and Egypt. Most people all over the world, young and old alike, are using smart phones and are familiar with smart-phone technology.

Due to its instant networking, it is now increasingly being used in emergencies and during major incidents. In March 2012, the UK Government produced a document giving tips on how to use social media in emergencies. During the recent flooding in the United Kingdom, the environment agency was sending regular updates with flood warnings and alerts, this was then mirrored by the Twitter traffic in the corresponding areas using hashtags (#) mentioning the word #flood (Figure 2).<sup>4</sup>

### How do I use Twitter?

Once you sign up using an email address, you can create your own Twitter profile or persona. Search for someone who you know or anyone who you may find interesting. You then ‘follow’ these people or organisations. You can look at who your friends and colleagues follow to get some ideas. You will then receive a constantly updated 24-hour Twitter feed onto your homepage from everyone you follow and things they have tweeted, retweeted or liked. If you do not like what someone is saying or they Tweet too much, then you can politely mute them from your homepage (temporarily or permanently) without having to ‘Unfollow’ them. Twitter could be described as a very noisy party with many of people talking at the same time, but you can control whom you listen to or interact with.



Twitter definitions

Twitter	The brand name of a social media service and website where user can post messages which are 140 characters long
Tweet	A message sent on Twitter up to 140 characters
Retweet	The act of sharing another user's tweet to your following
Twitterati	Keen or frequent users of Twitter
Liked	Liking a tweet indicates that you appreciate it and also save it on your homepage so that you can access it quickly later on
Follower	Another Twitter user who has followed you to receive your tweets in their timeline
#	Denotes something that is happening and you can see what everyone is saying about it (e.g. #BritishPainASM2015, #Flood, #FOAM)
@	denotes a person or organisation that you can follow (e.g. @BritishPainSoc)
Trending	A topic or hashtag that is popular on twitter at that moment
Troll	Internet slang for an unpleasant person who starts arguments or upsets people with inflammatory or offensive comments

When can I use it?

Twitter is a great tool to use at conferences. It is possible to see what is happening in satellite sessions and to share pictures and links of papers being discussed and feel that sense of participation, conversation and community. Before the conference, the organisers can create a # related to the meeting, for example, #BritishpainASM2015 and #IASPCongress2016. Delegates can use this #name during the conference to share information from the lectures:

- Pictures from the lecture;
- Links to papers that have been quoted;
- Take notes;
- Share comments with others;
- Send questions to speakers;
- Information from the exhibition hall.

Delegates may tweet the contents of the lecture, workshop or poster, and this is a positive way of sharing and summarising the salient educational messages. In this way, Tweets can even be accepted during the appraisal and revalidation process as proof of attending the meeting and of reflective practice.

How can I get my voice heard?

Pain Medicine may not be the largest specialty in the United Kingdom, but with simple measures, it is possible to communicate its message effectively to patients and the general population. With approximately 200 pain clinics in the United Kingdom, we should make our voices heard. This can be illustrated by looking at some analytics from Twitter. The number of people that organisations follow and the number of tweets sent may be considered to reflect how large an audience or population can be reached and also the potential impact on that audience (Table 1).

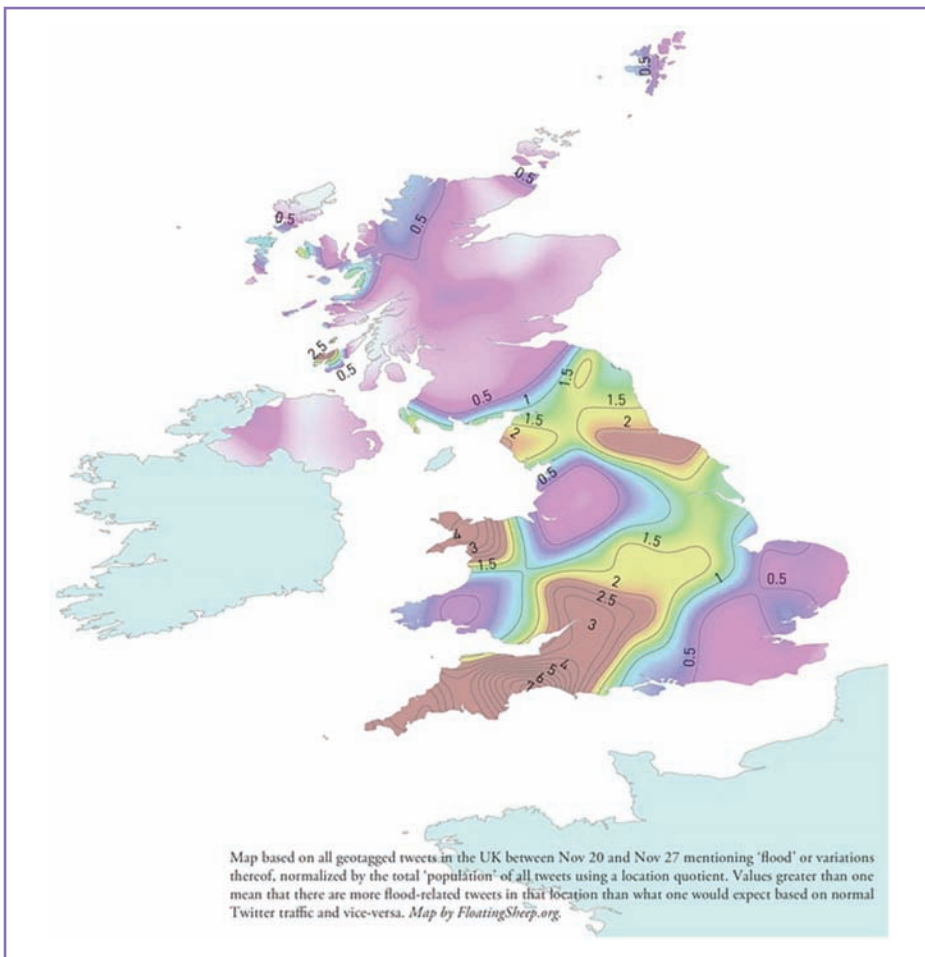


Table 1. Twitter analytics using Twitonomy Metrics for pain, anaesthetic and medical organisations (figures used from 9 January 2016)

	@ BritishPainSoc	@ EFIC_org	@ IASPPAIN	@ rcoanews	@ aagbi	@ TheBMA	@ FOAM_ Highlights	#FOAMed
Followers	1,227	451	3,301	7,737	6,726	64,972	14,903	
Following	168	329	75	26	4,039	2,200	105	
Tweets/day	0.17	0.7	0.1	0.5	3.7	13.8	2.8	~1,000
User Mentions	98 (0.5)	108 (0.3)	40 (0.1)	99 (0.1)	1,275 (0.4)	1,373 (0.4)	578 (0.1)	
Retweets	26%	38%	4%	11%	43%	29%	15%	

Table 2. Twitter analytics using Twitonomy Metrics for individuals (data from 9 January 2016)

	@EricTopol	@pascalmeier74	@traumagasdoc	@ButNHS
Followers	78.3K	45.6K	9,446	51.6K
Following	347	50K	1,650	4.5K
Tweets/day	6.1	16.8	14.7	25
User Mentions	4,216 (1.3)	2,576 (0.8)	3,456 (1.08)	376 (0.1)
Retweets	94.8%	33%	26.5%	13%

The International Association for the Study of Pain (IASP), European Federation of IASP Chapters (EFIC), British Pain Society and Royal College of Anaesthetists (RCOA) all send less than one tweet per day. This means that the number of people reached will be severely limited. The British Medical Association (BMA) and the Association of Anaesthetists of Great Britain and Ireland (AAGBI) send more than one tweet per day and follow over 2,000 people giving them a larger audience and therefore significant impact. Indeed, there are approximately 15 million people on Twitter in the United Kingdom alone,<sup>5</sup> and it is very popular among journalists.

But you do not have to be a large organisation to be heard (see Table 2).

When we compare these figures with the ones mentioned previously, it is clear to see that pain organisations have

plenty of scope to improve their presence on Twitter and on Social Media in general, which will lead to an enhanced impact. Social media such as Twitter and Facebook may be used in a highly effective manner specifically for clinical education and continuing professional development. An excellent example of this is #FOAMed (Free Open Access Meducation). This will be explored further in the next article on Social Media to be published in the next edition of *Pain News*.

### Conclusion

Social media may be considered as a natural evolution of our desire to interact with each other. News is disseminated as it happens often by people involved or around where it is happening using social media; there is no delay in getting the information out unlike conventional

printed press, radio or TV. There is an untapped opportunity for professionals working in pain clinics to become interconnected with each other and the outside world. This may lead to an advancement of knowledge through greater sharing which has the potential to enhance patient care. At the same time, there is also a chance to raise the profile for Pain as a specialty and ultimately improve public awareness, and perhaps even help to safeguard the specialty through the current (and future) climate of financial austerity.

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# The diagnosis: shades of grey – healing the disease or the diseased?

Suan Khoo *Professor in Oral Pathology & Oral Medicine, University of Malaysia*

This article is the transcript of the lecture given by the author at 2015 Philosophy and Ethics SIG meeting at Launde Abbey

I am in a privileged situation. I do something, oral pathology, very objectively: I look down a microscope and it is 'yes' or 'no' with no shades of grey. I see patients in the clinic with lumps and bumps which is again very objective. But, a large part of what I deal with is orofacial pain and I spend a lot of time talking with patients – perhaps not more than three in a 4-hour clinic.

## Temporomandibular joint disorders

This is a very non-homogenous group including myofascial pain, arthrogenic pain from a true joint disorder such as disc displacement, or from degenerative osteoarthritis. I also see neuropathic pain such as trigeminal neuralgia, or secondary to interventions such as extractions or root canal treatment, and what is known as burning mouth syndrome, and a few neurovascular disorders such as facial migraine which we do not treat, but diagnose and refer.

I did my PhD in biopsychosocial aspects of temporomandibular disorders (TMD). Quite a lot of the patients do have depressive or anxiety disorders together with TMD, which makes it complicated when you treat them. I always tell the general practitioners (GPs) or the students that it is a thing I cannot deal with quickly because by the time the patients reach me they have acquired many layers that I have to undo. Incidentally, I am also a sufferer myself, I have temporomandibular joint disorder.

We tell students and trainees that their first priority is to make the diagnosis and

make sure they are not missing any serious pathology and decide if they want to treat or refer. But, we have to be careful to avoid just putting people in compartments, thinking we have got it right and dishing out the prescriptions. When it becomes apparent that you have no effective treatment for them, you realise that you will have to spend time with them. Time is a very expensive commodity, but there is no other way. Students find this difficult to grasp.

Most of my patients come because of pain; anxiety is usually only a secondary issue. It is difficult to get Asian patients to talk about their pain. They just want something done. They will tell you where the pain is, but will only talk *about* it if you ask them. The patients I now see in the private hospital are more able to verbalise their problems than the ones I used to see in the public hospital, but also seem to spend more time ruminating about it than the latter who tend to be more stoic.

I have suffered from TMD since my dental school days, more than 30 years ago. I treated it initially with diazepam with some success; but, I came to recognise that that I was taking more and more and more of it, especially at times of stress. I tried splints and everything else. But for the last 20 years, I have hardly used anything. I am not desperate and am not in pain every day, but I have learnt to regard it as a warning signal that I should slow down. I can relate to many of the stressors involved in combining career and family that my patients tell me about, and this helps me



a lot in managing them; but I have learnt not to intrude. At the beginning, I thought I was doing them a favour by giving them a year of appointments and encouraging them to pour things out. But then I realised that they might not want to see me again because they are very embarrassed because they have told me so much. But sometimes they do break down – maybe what I have said triggers something – and they unload everything on me.

The old approach to TMD was very biomedical, trying to find out what was wrong with the patient's muscles or joints and trying to fix it. For instance with occlusal rehabilitation (correction of bite abnormality by dentistry or jaw surgery) which is irreversible and we do not advocate any more. Now, we have Dworkin's dual axis classification with physical characteristics on Axis 1 and psychological factors on Axis 2, and I find that the kind of descriptive diagnosis this provides is more useful than a label. I do not now even believe TMD is often much to do with the dental apparatus at all. But I have to be careful what I teach trainees about this, or they may tell patients 'it's just

## The diagnosis: shades of grey – healing the disease or the diseased?



stress' – the most overstated diagnosis – don't we all have stress? So, I take pains to make trainees and patients understand that it is not just stress alone, but at the same time help them to recognise the stressors, which may be quite minor everyday things bugging them, which tend to aggravate their problems.

I still have to assess the physical disabilities of the jaw from which I can get an Axis I diagnosis and classify them as suffering from a muscle disorder, a disc displacement or a joint condition. Whereas 10 or 15 years ago it was all lumped together simply as TMD disorder we have come to realise that every patient is different. Assessment of pain is no longer on a simple 0–10VAS; we assess functional limitation due to pain. With regard to psychological distress, we are not trying to diagnose depression or anxiety, but rather getting a feel that something is going on. We may want to refer them, but most of the patients I see do not want to see a psychiatrist. But about 2% of the patients I see are suicidal, and those I have to refer.

I use a simple questionnaire to assess psychosocial functioning. I try to show

trainees how to use the biopsychosocial model to see that the ways in which patients manifest and appraise their pain are individual. As society is becoming more affluent, I am seeing more people who want to talk, but in our medical culture, we are not used to listening which can be regarded as wasting time in a busy clinic or GP surgery.

### Neuropathic pain

I see a group of patients with burning or shooting pain which can be trigeminal neuralgia, but it is very often related to trauma. Some have had implants. The damage is done, and the brain pathways have changed and very often the management is only supportive. Occasionally, I can pick up from the cone beam computerised tomography (CT) scan that there has been damage to the alveolar nerve either from local injections. This is always a danger when you take out a wisdom tooth or place an implant, and sometimes, the CT scan shows that the canal is breached proving trauma. This is avoidable and the question of litigation arises. What should I tell the patient? Should they sue? This is a growing problem as more people are trained in physical interventions. Patients come with a mouthful of root canal treatments which may not have been done properly. There are already plastic changes in the brain and once again treatment is mainly supportive.

Patients, mainly peri-menopausal women, with burning mouth syndrome (a controversial and poorly understood problem) tell you that their whole mouth is on fire. This kind of expression is something that we have learned from the West and is not Asian at all. English words to describe pain that we learn from textbooks such as lancinating and pricking may mean little to Asian patients. This, and trying to use numerical pain scores, illustrates the difficulty of getting into numbers, words and symbols that you are familiar with but may mean little, or something different, to us.

### Illness, suffering and culture

In Asia, to be ill means really ill, in bed or in hospital. Anything less such as chronic pain is little expressed and people carry on, they may have to work, stoically and do not talk about suffering unless it is very severe. But our society is changing. I probably suffer like a Westerner: I cannot stand pain; my tolerance is very low. Illness is only one of many possible forms in which suffering can appear in any culture. Suffering induces an individual to try to understand what is happening, by seeking the help of a doctor to legitimise it as the result of disease.

How do we read people's suffering? Just because someone does not verbalise it does not mean they are not in pain. Of our three main ethnic groups in Malaysia, Indians are much more verbal and expressive when in pain and are regarded as having low-pain thresholds, but this is really just a matter of culture.

There is a lot of respect for doctors among Asians and people do not like to question them even though they may disagree with them. The problem then arises when the doctor cannot pinpoint what is wrong and they do not have a diagnosis to legitimise their problems and their suffering.

### Buddhism, mindfulness and meditation

I come from a Buddhist background. I have been brought up thinking about questions about me, the I and the ego, such as who is experiencing pain?

What is the *me* that is suffering? When relieving pain of the other, who is 'the other'?

When pain is 'relieved', who finds relief? These are very philosophical concepts to bring into a scientific culture, but Western society has begun to embrace Buddhism. I sometimes try to detach myself from pain through my practice of mindfulness, which stems from Buddhism. I try to use my own experience to help patients, for instance,

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encouraging them to think of activities (other than work) which will distract them from their pain, and to try to introduce them to mindfulness and meditation. I tend not to use these words as people are very conservative in matters of religion, so I suggest that at times of stress, they just have to sit in a quiet corner and concentrate on their breathing, if only for 1 minute, and if they can do this, they can begin to detach themselves from their pain and spend less time ruminating about it.

My patients have taught me a lot. In their quest for healing, patients are engaged in a continuous search for new doctors and new information, looking for something to give them some hope of the possibility of healing. Trainees tend to learn everything in black and white and like labels such as psychogenic pain, but I have been trying to get them to try to understand what patients are searching for. Some may go too far and respond with empathic distress, and I have to remind them that they have to remain professional or they may add to the patients' problems. I encourage them to look at themselves and what is going on in their own minds and examine their own actions.

### Listening

The physician healer creates a safe environment for patients to reveal their stories by encouraging storytelling. He must bely intentions to heal and suspend personal views and values so he can enter the patient's world without bias. He can help them to ascribe meaning to their illnesses and to move on to a new narrative that increases the ability to respond to the changes wrought by the illness. I have to keep reminding myself to listen properly. Sometimes we listen, just enough to make the diagnosis, trying to filter out the significant symptoms. We are so keen to get down quickly to when-why-exacerbating features and so on that we are continually interrupting. But instead

of plaguing someone with pesky questions, we should be listening attentively and analytically as if he were a character in a play giving a soliloquy.

### Objectivity and shades of grey

We use tools such as the Brief Pain Inventory and Beck's Depression Inventory in both research and in clinical practice to try to be as objective as possible, but I am not sure that something like the 'faces' (emoticons expressing severity of pain) in the Universal Pain Assessment Tool is very helpful in our culture. Nothing beats listening to the patient. Assessment and treatment of diseases and disorders are more or less universally accepted, but it is the cultural context that presents shades of grey. Our people are not very forthright with their opinions; in Asia, especially Korea, Japan and China, the ideas of harmony and balance of Yin and Yang and striving for the least disruption possible are prevalent. We try not to draw attention to our problems. My parents are in pain and are not happy about it, but do not talk about it.

### Diagnosis and suffering

Whether or not the diagnosis is apparent, we are often tempted either to endorse someone's suffering or to alleviate their anxiety by giving them a minimal diagnosis. We are reluctant to mention death. This goes against the objectivity of my oral pathology training and again involves compartmentalisation. I tell them 'I do not really know but I do not think it is cancer but let us monitor you ...' But this may not do the patient justice. The information you give depends on what the patient wants to know and why she wants to know it. We deal with so many shades of grey. We sometimes do not know who is playing the bigger role: the clinician or the patient. If you are dictated to by what the patient wants all the time, we who are supposed to be medically trained have no choice but to collaborate.

To receive a diagnosis that places one's suffering in a medical context can be both a confirmation and a disappointment for the patient. It does at least give them access to some treatments. But if these fail, then what ...? The patient possibly acknowledges with gratitude the diagnosis she has received from the doctor, but this does not account for the fact that she never recovers. Diagnosis has elicited recognition from the medical establishment for her ailments and part, but not all, of her suffering. The remainder remains to be dealt with: she still has to live with it. Medical recognition of suffering involves acknowledging, and even sharing, patients' feelings of helplessness. When we do not have a diagnosis, or really know what we are treating, and at best are relieving only part of their distress, the patient needs to be aware that we do not know – but confident that we will continue supporting them.

Advances in medical technology infuse a hope that medicine is able to alleviate pain and suffering. In order to gain these benefits, patients as well as medical professionals, must interpret somatic or psychological suffering and disturbances in terms of medical diagnoses. The diagnosis becomes an emblem for hope while at the same time turning suffering into something medically and socially legitimate. Is it then our task to bring hope through diagnosis?

*The change from expert-doer to servant-accompanier requires that physicians attend to how they are with patients as much as what they do for them.*

HM Adler

*The most powerful therapeutic tool you'll ever have is your own personality.*

David Sackett



# The tyranny of the hidden waiting list: bureaucratic management of referrals and unmet patient needs

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This article is the transcript of the lecture given by the author at 2015 Philosophy and Ethics SIG meeting at Launde Abbey

We keep hearing about the conflict of values between managerial imperatives and patient needs. Instead of the patients we *are* seeing, I want to draw attention to the patients we are *not* seeing and who are experiencing ‘The undulations of hope and despair ...’ (Ernest Brown.)

There is tension between the interests of individual patients and those of the population. It has even been suggested that we could deal with bigger numbers and get rid of waiting lists by only running groups, with no individual assessment. We are always trying to reconcile the demand from service managers with the needs of the patient in front of you or the despairing patient in front of the general practitioner (GP) desperate to come to the pain clinic.

The political background we are working with in New Zealand has involved copying bits of the things that have not worked in Britain, Australia and America. We have been given the triple aim ‘to improve Quality, Equity and Best Value from the Resources’.

Last year, I discovered quite by accident that some weeks earlier, a manager realised that there were a whole lot of patients who would not be seen within the recommended time frame of 4 months, so they had to be returned to their GP, or in other words ‘dumped’. There was no record of the number sent back. The GPs were sent letters saying

‘Please reassess if they still need to be seen in the pain clinic. We will give you US\$45 to see them’ (Note: in New Zealand, people pay to see their GP). They started to trickle back, but in the meantime, more new people had been added to the waiting list, so we are now seeing people after 8 months. So that was not very helpful.

Measures designed to ensure fair and consistent care designed for surgery (for acute care), which are supposed to ‘reduce the barriers to access’, are inappropriate for long-term care and pain clinics. How can you deal with the experience of chronic pain with the ‘alternation of hope and despair’ and the guilt and these complex things with a priority list? How can you put it into numbers? We are supposed to give patients a ‘Clinical Score’ from 1 to 5 based on measures of pain, disability and ability to work and so on which will be used (by management) to give them a Priority Ranking *for surgery*. We are being told we should not worry about our patients’ social problems and so on, so we can ‘mitigate risk’. Yet scoring tools ‘should not be used to deny access but to facilitate it’.

Strategies we are advised to use instead include the following:

- Communication (a weasel word!);
- Integrated care pathways;
- Improving the ratio between specialist

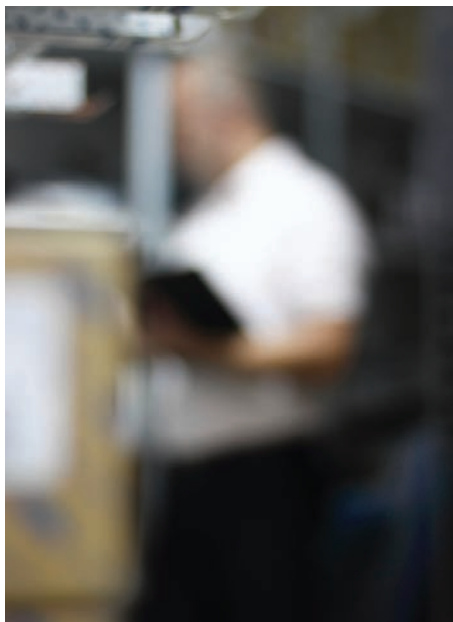


and follow-up appointments (meaning we should aim to see a patient once, cure them and send them away. I have rarely been able to work like that regularly, apart from the occasional patient);

- ‘Whole system thinking’ (I think that probably came from the National Health Service (NHS));
- Support the GPs (that at least is good);
- Pop-up clinics (for people who do not need the whole thing);
- Specialists in the community (what you call GPs with a Special Interest or ‘Gypsies’);
- Non-contact first specialist appointment: where the specialist writes an investigation and care plan for the GP without seeing the patient. This apparently works for neurologists, but despite it not saving any money in the long run, our



The tyranny of the hidden waiting list: bureaucratic management of referrals and unmet patient needs



measure their functional capacity and cannot measure their experience.

### Waiting lists

If waiting lists do have a purpose, is it deterrence, delay or deflection? I think it is denial – *exclusion*. I get the feeling that our patients do not matter because pain is not a life-threatening disease. It is not glamorous – we do not have an Angelina Jolie publicising us. When you see the amount of money that has gone into chronic pain compared with palliative care, we seem to be falling behind. Who decides what is important about whether or not and which patient should be seen soonest?

I am asking for help. I get so tired with feeling that managers' actions are unethical. How do I come to terms with that without getting angry and being rude to them? How can I manage patients more efficiently so I can see more? How can I teach GPs so they do not say things like 'you will end up in a wheelchair'.

### Points for discussion

If you are a patient and a member of the sharp-elbowed middle classes and know how to work the system and the complaint procedures and so on, you can force your way in, but this seems very unfair.

Our responsibility is to do the best for the patients we do see and not beat ourselves up about a system we may not like, but we are not in a position to change. Maybe that is defeatist, but if

we behave to high ethical and moral standards and try to be exemplars of what good care might be, that will filter through in other ways.

We are trying to prioritise different kinds of pain depending on what we can do to help. We see neuropathic pain early and work with the physios and spinal surgeons on musculoskeletal pain. But chronic widespread pain should not be coming into a medicalised service, and we need to develop something completely new and different for that involving social prescribing and support.

How can patients be mobilised? Patients with common conditions can belong to big and powerful groups like Diabetes Care, and cancer charities can raise huge funds, but there is very little public awareness of chronic pain.

There are 14 million people in the United Kingdom living with chronic pain, and in a city, the size of Sheffield, 29,000 people are in pain, but only a 1,000 get to see the pain service.

One cannot set oneself up against a mammoth organisation, but we can tilt at it. If we use the media and get stories into the *Daily Mail* ('I was suffering because I could not get to the pain clinic') or the Internet, whether it is right giving a patient the number of their local MP or someone at the BBC – to empower them to go out and pursue the matter. But we within the system are pretty hamstrung.

managers want us to introduce it into the pain clinic;

- Collaboration, evaluation and so on – none of which actually happen;
- Alternative providers (including our nurses) that is good.

All this is supposed to lead to better job satisfaction. It is presented with a 'can do' attitude, so if it does not work, it is the clinician's fault. It has been described as the 'imposition of spurious rationality into an irrational process'.

We do need some rationing, but although 'society needs numbers, patients need care', they are not integers (Peter Moskovitz). We give them priority scores for when they are allowed to come and see us, but we can only



# The Tyranny of Diagnosis?

Jeremy Swayne *Retired GP*

This article is the transcript of the lecture given by the author at 2015 Philosophy and Ethics SIG meeting at Launde Abbey

The question we set out to explore and challenge in the conference with this title was taken directly from a paper by Rosenberg<sup>1</sup>: 'The Tyranny of Diagnosis: Specific Entities and Individual Experience', and I will set the scene with a digest of his arguments and depict the many aspects of the therapeutic encounter that the word 'diagnosis' evokes in a mind map, a 'landscape of diagnosis'.

These quotations from Rosenberg's paper exemplify his theme:

*Diagnosis has always played a pivotal role in medical practice, but in the past two centuries, that role has been reconfigured and has become more central as medicine ... has become increasingly technical, specialized, and bureaucratized.*

*This modern history of diagnosis is inextricably related to disease specificity, the notion that disease can and should be thought of as entities existing outside the unique manifestations of illness in particular men and women.*

*... diagnosis, prognosis, and treatment have been linked ever more tightly to specific, agreed-upon disease categories.*

*Everywhere we see specific disease concepts being used to manage deviance, rationalize health policies, plan healthcare, and structure specialty relationships within the medical profession. And I have not even mentioned the countless*



*instances in which clinical interventions and expectations have altered the trajectory of individual lives.*

*In other words, diagnosis has become the servant, the slave even, of the disease-based model of medicine.*

He goes on to describe disease and its specific categories and entities in a variety of guises:

- As a social phenomenon;
- As a 'narrative' – in terms of the natural history;
- A necessary tool for managing and transcending the subjective, local and idiosyncratic, the incoherence and arbitrariness of human experience; the elusive relationship between the individual and the collective; thus facilitating the progress of scientific medicine;
- As the basis of protocols and guidelines for clinical care, institutional decisions and research;
- As a justification for the dominance of the hospital in medical education;

- As a convenient mechanistic language for accommodating difficult clinical problems;
- As permitting an 'iatrogenesis of nosology' through the invention of protodiseases; often defined by surrogate measures such as cholesterol levels or bone density;
- As a bureaucratic and administrative necessity;
- As an excuse for ignoring the social determinants of illness and the suffering of the person;
- As a smokescreen obscuring medicine's moral, technical and market identities.

Diagnosis, says Rosenberg, is 'a key to the repertoire of passwords that give access to the institutional software that manages contemporary medicine. It helps to make experience machine readable'. It is what Barry et al.<sup>2</sup> called the 'biomedical filter'.

In the process of diagnosis, 'the patient is necessarily objectified and recreated into a structure of linked pathological concepts and institutionalised social power'.

Diagnosis labels, defines and predicts and in so doing helps constitute and legitimate both the reality it discerns and the authority of the medical system to manage it. In doing so, it provides culturally agreed meanings for individual experience, and by this means, replaces uncertainties – for better or worse – by a structured narrative.

Diagnosis, says Rosenberg, is an age-old ritual that holds both doctor and patient hostage. (In which) a continuing narrative is condensed into a discrete



act. Agreed-upon disease pictures, often configured by what can be measured and evaluated against statistical norms, are points on a spectrum that do no justice to the infinite variety of men and women in it, rather like the observations of the blind man in the fable who is asked to describe an elephant by feeling its trunk.

Within this managerial context, the practitioner's role is inevitably compromised and ambiguous. How does one ensure clinical flexibility and an appropriate measure of practitioner autonomy in such a system?

At the end of the paper, Rosenberg changes tack. Having noted earlier the long-standing disquiet about treating diseases and not people and a tendency to denigrate the physician's holistic and intuitive clinical skills, he turns to the distinction between the disease and the illness, which he refers to as 'the incoherence and arbitrariness of human experience, that needs to be assimilated into the larger shared context of institutions, meanings and relationships in which we all exist as social beings'.

We are always the sum of our illness and our disease, and there is an

inevitably elusive relationship between the individual experience of the one and the collective context of the other. Just as disease entities and the diagnostic imperatives they evoke can be fragmenting and alienating in terms of an individual's relationship to that larger society, they can also be understood, Rosenberg suggests, in a social system sense, as holistic and integrative.

That may be true. But it is an uncomfortably totalitarian view of medicine's role. It smacks of Heath's<sup>3</sup> vision of clinicians and health services ushering people in increasing numbers across the border from the Kingdom of the well into the Kingdom of the sick driven by 'detaching notions of disease from the experience of suffering, broadening the definitions of diseases, turning risk factors into diseases (the 'protodiseases', generated by Rosenberg's 'iatrogenesis of nosology') and most potent of all, fear'. Is that true? Is that what we are doing?

In Fitzpatrick's<sup>4</sup> book, *The Tyranny of Health*, he writes 'When health becomes the goal of human endeavour it acquires an oppressive influence over the life of the individual. If people's lives are ruled by measures they believe may help to prolong their existence, the quality of their lives is diminished'. Is that really what is happening?

The 'iatrogenesis of nosology', through the invention of protodiseases, is illustrated by the story of a healthy man who was treated for a high cholesterol and developed a constellation of distressing mental and physical symptoms which resolves when he stopped taking statins.

One reason, says Spiro,<sup>5</sup> why doctors over-treat and over-study, and do not always talk with or listen to, their patients, is because they are too busy looking at organs and laboratory findings.

'Technology is overused', says Spiro, 'because doctors expect to find an answer to every problem if they only look hard enough with the right instruments'.

As McCormick<sup>6</sup> wrote 'Our patients deserve of us accurate diagnosis and appropriate treatment. But when accurate diagnosis is impossible and appropriate treatment unavailable we delude both them and ourselves by using diagnostic labels and prescribing specific treatments'.

Nevertheless, in his essay, 'Diagnosis is treatment', Brody<sup>7</sup> points out that a virtue of diagnosis, involving as it must be a human relationship between physician and patient, is 'that it explains symptoms, encourages expressions of care, provides a mantle for distress that society will accept, and implies the possibility of gaining control over it'.

So, diagnosis is an indispensable and multifaceted process at the heart of the therapeutic encounter. The implication of Rosenberg's paper, and perhaps our task at this conference, is that we seek to redress the balance between its biomechanical, biosocial and biopolitical dimensions and its role in promoting human healing.

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# Leicester paediatric chronic pain service

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Chronic persistent pain in children is unrecognised and undertreated; it is a public health concern of major significance.<sup>1</sup> Persistent pain in children does not just affect the child or their family, but it is a significant financial burden to the UK economy.<sup>2</sup> It was estimated that the total cost of a parent's lost time alone is approximately £8,000 annually, while the direct costs were £4,431 annually.<sup>3</sup> Unfortunately, access to multidisciplinary paediatric pain clinics in our country is limited or in some places non-existent.

Persistent pain in children where there is no identifiable cause leads to significant functional impairment. In majority of the children presenting to our clinic, pain is not easily linked to a known cause or a well-understood pathology.

Some of the common conditions presenting to our paediatric chronic pain clinic include the following:

- Functional abdominal pain;
- Chronic widespread pain, including spectrum of functional pain disorders;
- Headaches;
- Hypermobility and joint pains;
- Bone pain, complex regional pain syndrome (CRPS) and post-orthopaedic surgical pain;
- Variety of other pain conditions.

In the last 12 months, our service saw 80 chronic pain children; majority of them were between 12 and 16 years though the age range was between 4 and 18 years. Girls accounted for 76% of our patients. Orthopaedics were the main referrers (56.4%), while other specialties

included paediatric consultants (15.4%), rheumatologists (18%), urology, gynaecology, neurosurgeons and others. At least one-quarter of our patients came from outside our neighbouring counties; this explains the need for these services nationwide (Figures 1–5).

Children with persistent pain present a variety of other problems including sleep problems, problems with school/college attendance, restriction of physical activities, problems with social development and emotional problems. The most important indication for a referral to a tertiary paediatric clinic should be that the child has significant functional and/or emotional impairment, which affects their school/college attendance; furthermore, these children will present high levels of pain-related anxiety.

Chronic pain in children affects the family; there is evidence to show increased levels of personal strain in family.<sup>4</sup> Fifteen percent of parents with suffering children reported career restriction.<sup>5</sup> It is not only the mothers but even research in fathers has shown evidence for presence of frustration and helplessness.<sup>6</sup> Eccleston has shown that there is clinically significant parental anxiety and stress prior to treatment.<sup>7</sup> Even siblings reported high anxiety and depression.<sup>8</sup>

Our multidisciplinary clinic aims to restore the social integration of the child; one of the most important tasks in this regard is to improve the school/college attendance. Our team strongly believes that the child needs the school

environment for optimal social development. Studies have unfortunately shown that chronic pain causes more school absences.<sup>9</sup> These children are unable to take part in sports and other extracurricular activities also. Social integration could be really stressful after long absences; education of school staff to pace this could be vital in the recovery.<sup>10</sup>

Children suffering with chronic pain develop maladaptive behaviours and could catastrophise about pain. Parental attention and secondary gains could be explored in detail in a multidisciplinary clinic. Most of these children also have sleep problems, and our clinic specialises in dealing and managing this condition. Sleep problems predict quality of life and recovery in children with chronic pain.<sup>11</sup>

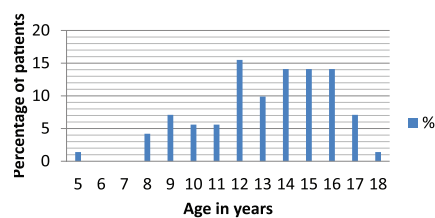
The most vital treatment that these children receive from our clinic is education of the pain mechanism; we use a variety of metaphors and analogies to improve the knowledge of chronic pain and need for management strategies.<sup>12,13</sup> Rehabilitative approach<sup>7,14</sup> and cognitive reassurance<sup>15</sup> has high level of evidence with regard to outcome from chronic pain in children. The strongest evidence for recovery is from psychological interventions.<sup>16</sup>

We use the adolescent Pain Toolkit with all our patients,<sup>17</sup> and we use video clips to educate these children on the pathophysiology of chronic persistent pain.<sup>18</sup> Adherence to recommendations in a paediatric pain programme has been found to be high for physiotherapy.<sup>19</sup> We use breathing and relaxation exercises, transcutaneous

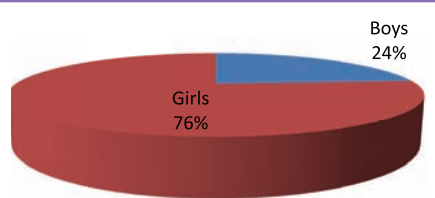
## Professional perspectives

### Leicester paediatric chronic pain service

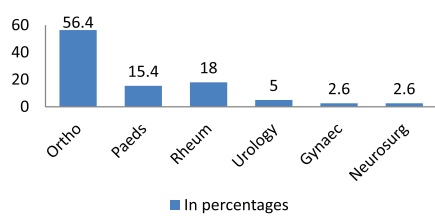
**Figure 1.** Demographics of patients – age



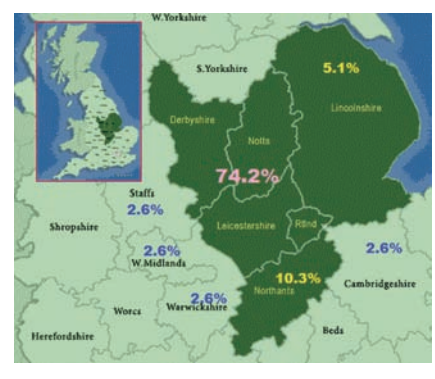
**Figure 2.** Demographics of patients – sex



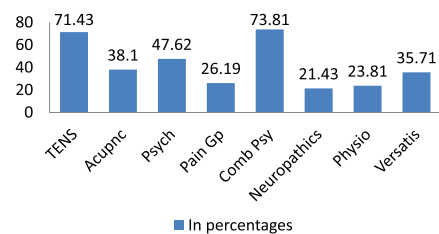
**Figure 3.** Referrals from specialties



**Figure 4.** Geographical areas of referrals



**Figure 5.** Treatments given in Leicester service



electrical nerve stimulation (TENS) machine (71.43% of our patients) and acupuncture (38.1%) in many of our patients as a means of pain education and rehabilitation.

We offer individual psychological sessions (47.62%) as well as running a pain management group (26.19%). This group runs on Wednesdays after school and runs for 6 weeks (90 minutes session). Our outcomes with this group have been very encouraging. Medications have not yielded huge success in children with chronic pain.<sup>20–22</sup> Evidence is not high for medication use, and we restrict this in our group of patients. However, if need to use medication, the dosages include the following:

- Amitriptyline – start at 0.1 mg/kg/day;
- Gabapentin – start at 5 mg/kg tds increasing to maximum of 30 mg/kg/day;
- Pregabalin – 1:6 ratio to gabapentin;
- Opioids – significantly restricted role in chronic pain.

However, we have used topical 5% lignocaine plasters in 35.71% of our patients, and our results have been very promising. Out of the 80 patients, 21.13% were discharged and 19.72% were given open appointment. We improved the school attendance in majority of our patients and are planning for further research in this field.

### Case example 1

A 10-year-old girl presented to the paediatric gastroenterology team with abdominal pain. She was diagnosed with positive Epstein-Barr virelogy and chronic fatigue syndrome. She became wheelchair bound for 14 months and used crutches to move at home. She had seen variety of specialists including surgeons and orthopaedicians. She had various investigations including ultrasound, X-rays and blood tests. She was referred by the orthopaedic team for knee pain, but when she came to clinic, her ankle pain was the worst. She was also admitted by the paediatric rheumatology team and had intensive rehabilitation for joint hypermobility.

A detailed history of this young girl was taken; she was recently diagnosed with depression and was started on sertraline and was under the community psychologist. She had missed more than 4 months of school, and we liaised with the school nurse to look at a partial timetable. She missed most of the social life and her sleep pattern was totally chaotic. She had delayed initiation of sleep with day-time tiredness. Her family history uncovered her mother's chronic pain issues as well as the fact that three of her siblings had chronic pain issues. Detailed examination was also done.

Significant time was spent on educating the pathophysiology of chronic pain to this child and family. The Pain Toolkit was used to explain the strategies for chronic pain management. 'Understanding chronic pain' video clip was used. Detailed plans were made to improve sleep hygiene. TENS machine and acupuncture trials were made. She was also prescribed topical 5% lignocaine plasters for localised ankle pain. She was booked for individual psychology sessions, and a back-up plan of a gabapentin trial was advised to the GP. TENS and psychology helped her significantly. She did not need the medication trial. Her school attendance

improved significantly in the next few months.

### Case example 2

A 14-year-old girl presented with abdominal pain of 15-month duration. She had multiple hospital admissions and was referred to us by the Paediatric Gastroenterologist. She had multiple endoscopies, ultrasound, X-rays and blood tests. She had seen four paediatricians and one private paediatric consultant before.

The history of this girl elaborated that her parents were separated a year ago and she was the only child. She was a high-performing child in the swimming clubs and had stopped this activity due to pain. She had also stopped horse riding. She had missed 60% of her school attendance and had sought special education needs, help and support. As she was not coping well, liaison paediatric psychology referral had been made. Her only social media contact was in North America, and we liaised with how to improve her sleep keeping this vital contact.

Pain education was the most important part of her comprehensive treatment plan. TENS and acupuncture trials were made. She was also given a trial of amitriptyline medication. Sleep hygiene was vital part of our discussions. Her pain-coping strategies improved significantly with our multidisciplinary treatment plan.

### Case example 3

An eight year old girl was admitted as an in-patient with a four week history of left knee pain, which was investigated

extensively by the orthopaedic team. Her pain progressed to cause widespread allodynia needing two hospital admissions. Blood tests, X-rays, ultrasound and magnetic resonance imaging (MRI) were all negative; even a bone-marrow biopsy was done due to her acute presentation which was negative. She was not weight bearing, and the rheumatologists had started a course of steroids. She was already on opioids and amitriptyline.

This child had presented a year ago, with significant jaw pain, to a private pain clinician. She also suffered with chronic urticaria. She was also on gabapentin and phenergan. Stress and tiredness clearly worsened her pain. She was a very active child undertaking various activities before including dance, gymnastics, swimming, piano lessons and was part of school choir. She had already tried physiotherapy and TENS machine without much benefit.

Her parents were anxious and education was focused not only on the child but also on her parents, regarding the chronic pain management strategies. Distraction techniques including breathing and relaxation strategies were used. The Pain Toolkit was used, and knee desensitisation techniques including massage, creams and hot showers were advised. Advice on posture and core muscle strength was part of our plan. We increased her gabapentin appropriately and added topical 5% lignocaine plasters. We advised individual psychology sessions and she did prefer this route. Melatonin was added by the paediatric team for sleep improvement. Medication helped her allodynia, and the knee pain settled in few weeks time.

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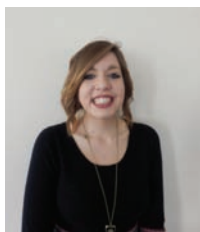


# The impact of dysmenorrhoea on adolescent girls' health-related quality of life

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Adolescent dysmenorrhoea is highly prevalent, with up to 93% of girls aged 12–18 years reporting some form of menstrual-related pain.<sup>5</sup> Although

prevalence rates are high, many young girls with dysmenorrhoea do not present to health care professionals (HCPs). For example, in one study, just 29% of adolescents reporting severe menstrual pain had sought medical help.<sup>1</sup> In addition, many adolescents with dysmenorrhoea are often solely using various ineffective, non-pharmacological methods to relieve their symptoms.<sup>6</sup> The combination of under-reporting to HCPs and reliance on ineffective self-management methods indicates that dysmenorrhoea is overall poorly managed in the adolescent population.

Although adolescent dysmenorrhoea is highly prevalent, poorly managed and characterised by unpleasant symptoms, no reviews had previously investigated its impact on health-related quality of life (HRQoL). Therefore, we carried out a systematic review of studies investigating the impact of dysmenorrhoea on adolescents' HRQoL. This article provides a brief overview of the review

methods and key findings and concludes with a brief discussion of the limitations of current literature and implications of findings for future research.

## Review methodology

Following the PRISMA guidelines (Preferred Reporting Items for Systematic Reviews and Meta-Analyses), studies were identified through a three-stage search of CINAHL, MEDLINE, EMBASE and PsychINFO electronic databases for articles available in English language between 1960 and 2015. Studies were included in the review if they investigated the impact of adolescent ( $\leq 18$  years) dysmenorrhoea ( $\geq 3$  menstrual cycles) on HRQoL, or any of its domains, that is, physical, emotional, social and school functioning. Although research in this area is still in its infancy, 42 studies were deemed eligible for review.

## Findings

Overall, the prevalence of menstrual pain, among adolescent populations, ranged from moderate, 25%,<sup>7</sup> to high, 93%.<sup>5</sup> In addition to pain, adolescents reported a wide variety of accompanying menstrual symptoms (e.g. cold sweats, headaches, vomiting, syncope, fainting, sweating, fluid retention and abdominal bloating). However, no studies reported the

## Adolescent dysmenorrhoea

Dysmenorrhoea, commonly known as period pain, is the most common gynaecological complaint of adolescent girls<sup>1</sup> and is characterised primarily by recurrent, crampy, lower abdominal pain during menstruation.<sup>2</sup> Other unpleasant symptoms associated with dysmenorrhoea include nausea, vomiting, loss of appetite, headaches, backache, diarrhoea, flushing and sleeplessness.<sup>3</sup> Dysmenorrhoea can be categorised as primary or secondary, with primary dysmenorrhoea being the most common type found in adolescents.<sup>1</sup> Individuals are diagnosed with primary dysmenorrhoea when they experience symptoms without any pelvic abnormalities and have a normal ovulatory cycle.<sup>4</sup> In contrast, secondary dysmenorrhoea (seen in approximately 10% of dysmenorrhoeic adolescents) is associated with pelvic abnormalities such as pelvic inflammatory disease and endometriosis.<sup>3</sup>

## The impact of dysmenorrhoea on adolescent girls' health-related quality of life



incidence of *all* possible accompanying symptoms within a sample.

Dysmenorrhoea was associated with impaired psychological functioning. Specifically, adolescents reported feeling that their pain had a negative impact on their emotional well-being,<sup>8</sup> feeling unhappy and nervous while menstruating,<sup>9,10</sup> and generally feeling negative emotions about menstrual experiences.<sup>11</sup> In addition, dysmenorrheic adolescents reported increased levels of anxiety,<sup>12–14</sup> neuroticism,<sup>12</sup> depression,<sup>13–16</sup> impaired concentration,<sup>13</sup> mood changes<sup>11</sup> and distress associated with bodily sensations.<sup>14,17</sup>

Adolescents reported that their activities of daily living (ADL) were negatively affected by dysmenorrhoea, including limiting adolescents' ability to engage in usual activities,<sup>18,19,20–23</sup> carry out daily chores,<sup>19,24</sup> engage in sports/exercise regimens,<sup>5,19,20,23–26</sup> carry out casual paid work,<sup>5</sup> sleep,<sup>18</sup> concentrate while reading<sup>18</sup> and engage in recreational activities.<sup>27,28</sup> Dysmenorrhoea was associated with

adolescents being less active during menstruation<sup>29,30</sup> including being unable to lift heavy objects<sup>9</sup> and staying in bed while menstruating.<sup>22,23,30</sup> It also had a negative impact on adolescents' social relationships with both family members and peers.<sup>5,13,31</sup> Dysmenorrhoea limited adolescents' engagement in social activities<sup>24,25,30,32</sup> and in some cases resulted in adolescents feeling that they had become reclusive/shy during menstruation.<sup>10</sup>

Research indicates that menstrual pain can limit aspects of adolescents' academic performance. Specifically, dysmenorrhoea is associated with a lack of focus on school content and missing exams.<sup>31,32</sup> Dysmenorrhoea can negatively impact adolescents' exam performance,<sup>31</sup> class participation,<sup>24</sup> ability to carry out homework,<sup>19,24</sup> school grade,<sup>33</sup> school activities<sup>20</sup> and school work.<sup>5</sup> Finally, the most reported impact of dysmenorrhoea investigated by the included studies was school absenteeism. Between 1%<sup>34</sup> and 51%<sup>35</sup> of dysmenorrheic adolescents reported menstrual pain-related school absence. Of those that reported the days of school missed due to dysmenorrhoea, absenteeism ranged from individual missed classes<sup>24</sup> to 7 full school days.<sup>10</sup> Not surprisingly, adolescents generally reported that the impact of dysmenorrhoea on their HRQoL increased with pain severity.<sup>5,24</sup>

### Discussion

Overall, adolescents reported that dysmenorrhoea had a negative impact on every aspect of their HRQoL. Specifically, dysmenorrhoea affected psychological functioning, ADL, social relationships and activities, academic performance and school attendance. In addition, associations between dysmenorrhoea and impaired HRQoL were positively related to menstrual pain severity.

From a biopsychosocial perspective, the relationship between dysmenorrhoea

and HRQoL can be best conceptualised as bi-directional. Although dysmenorrhoea can affect HRQoL, psychological and social factors also influence the overall experience of menstrual pain.<sup>36–38</sup> For example, associations between dysmenorrhoea and heightened levels of anxiety could be interpreted as a direct result of experiencing monthly menstrual pain. However, anxiety has been found to increase activity within the parahippocampal network in the brain resulting in increased pain perception.<sup>39</sup> Therefore, anxiety experienced among dysmenorrheic girls may also contribute to adolescents' pain experience.

Several common limitations within the existing literature should be taken into consideration while interpreting these conclusions. Most studies included in the systematic review ( $n=26$ ) were conducted in non-Western cultural settings. As menstrual attitudes and beliefs are culturally and socially constructed,<sup>39–41</sup> there is a need for up-to-date research of adolescent dysmenorrhoea within Western cultures. Also, previous research has not compared HRQoL outcomes among adolescents with primary and secondary dysmenorrhoea. Most studies do not report whether participants had any underlying pelvic pathology. Of those that did,<sup>5,11,13,21,42</sup> there was no comparison between how primary or secondary dysmenorrhoea impacted HRQoL. Therefore, additional concerns associated with the pelvic pathologies of secondary dysmenorrhoea, such as endometriosis which is associated with infertility,<sup>43</sup> were not taken into account.

Finally, it should be noted that very few studies reported the use of validated tools to measure all outcomes. Specifically, many studies did not report the use of validated pain severity scales (e.g. the Visual Analog Scale (VAS) and Numerical Rating Scale (NRS)) or HRQoL outcomes.<sup>19</sup> Due to the lack of scientifically valid and reliable measures



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used, it is difficult to draw reliable conclusions and establish the impact of dysmenorrhoea on all domains of HRQoL.

Future research could benefit from using validated and reliable measures to investigate the impact of dysmenorrhoea on all aspects of adolescent HRQoL. Improving the understanding of how dysmenorrhoea affects the lives of adolescents may help adolescents, their parents and HCPs to manage the pain and improve the quality-of-life outcomes in this population.


To conclude, current evidence indicates that adolescent dysmenorrhoea can have a profound, negative impact on many aspects of adolescent HRQoL, including psychological, physical, social and school functioning and well-being. The limitations in the literature to date highlight the necessity for further research in this area and give an indication of the ways in which research can move forward to develop a better understanding of adolescent dysmenorrhoea and improve pain management and quality-of-life outcomes.

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# The Paediatric Chronic Pain Network: working together to improve children's pain management

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**Glyn Williams** *Consultant in Paediatric Anaesthesia and Pain Management, Great Ormond Street Hospital Foundation Trust*



## Background

The provision of services for children and young people with chronic pain has been criticised as inadequate.<sup>1</sup>

There are a small number of highly specialised paediatric pain management services in the United Kingdom, but the resource does not match the demand, and waiting times for assessment and treatment are often very long. The majority of chronic pain in children is therefore managed in primary and secondary care.

In many cases, this is an appropriate model of care, provided the healthcare staff involved feel they have the necessary knowledge, skill, resource and support. The tertiary centres then being able to provide care for the more complex or refractory cases and act as a mechanism of support and advice for local healthcare providers.

A number of strategies have recently been put in place around chronic pain in children to promote education, strategies for evidence-based clinical care and support for healthcare professionals. Both E-Learning for Health (<http://www.e-lfh.org.uk/>) and Compass (the education portal on the Royal College of Paediatrics



and Child Health (RCPCH) website: <http://rcpch.learningpool.com/>) have launched a series of modules about

Paediatric Pain. A recent article has also suggested clear referral and management pathways as an aid to early recognition and intervention using a multi-disciplinary biopsychosocial formulation.<sup>2</sup>

In addition to these, the Pain Control Service at Great Ormond Street Hospital has established the Paediatric Chronic Pain Network (PCPN) and set up a Clinician Telephone Support Service (CTSS) with a view to collaborating with and supporting other professionals involved with treating chronic pain in children.

## PCPN

In setting up the PCPN, the aim was to provide a forum for all interested healthcare workers involved in Paediatric Chronic Pain to meet, interact, learn and share experience. We hope to provide information and education for care providers and referrers, promote quality improvement and identify research and development opportunities.

The first meeting took place in November 2014 and there have been two further since. The meetings are programmed for half a day (validated for 2.5 CPD points by the RCPCH) and have involved a mixture of informative talks and case presentations with plenty of time for discussion, opinion and networking.

The most recent meeting was held at the Institute of Child Health in November 2015. About 40 healthcare professionals joined us to discuss the physiology, diagnosis and management of neuropathic pain in children and the management of complex cases outside specialist units. There was a wide multi-disciplinary mix among the delegates with representation from paediatrics, anaesthetics, physiotherapy, psychology, rheumatology, nursing and integrated and complementary medicine.

Feedback for the meetings from delegates has been consistently very positive. The format and content have been well received with the aims of the PCPN being met. It has been very clear from these meetings the difficulties we all face in the treatment of Chronic Pain in Children, the strong collective desire to improve services and outcomes and the importance we all place in collaboration.

## Future plans

We aim to continue with twice yearly meetings of the PCPN, the next one being due in March/April 2016. The

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programmes for these meetings will continue to be set by the suggestions and requirements of the whole group.

We also hope to increase numbers and develop the scope of the network beyond the regular meetings. We have recently formalised the group, and we are inviting colleagues to join as members. This will hopefully allow us to develop consensus management and referral pathways and guidelines, drive quality improvement and promote research.

More information about the PCPN, future meetings, resources from previous events and how to get in touch can be found at [www.gosh.nhs.uk/pcpn](http://www.gosh.nhs.uk/pcpn)

### Clinical Telephone Support Service (CTSS)

The CTSS is available for clinicians who would like to consult with us before making a referral. We are able, through this service, to advise on optimising and continuing local

management and on the appropriateness of referrals to us. More details and how to access the service can be found on our website: [www.gosh.nhs.uk/chronicpain-refer](http://www.gosh.nhs.uk/chronicpain-refer)

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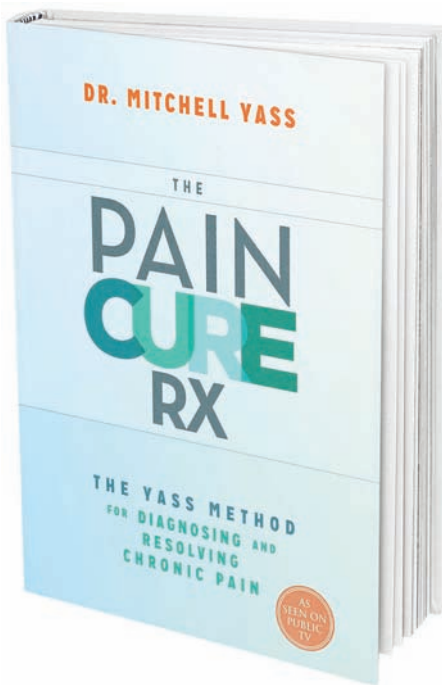
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## Book review – *The Pain Cure*

Michael Yass



**Review by: Paul Rees *Physiotherapist, Sandwell and West Birmingham Hospitals NHS Trust***

*The Pain Cure* is intended as a self-management tool for those people who are affected by persistent pain. Within this book, Mitchell Yass advocates his approach to managing persistent pain which he refers to as 'The Yass Method'. The Yass Method is introduced as a concept for assessment leading to diagnosing and resolving chronic pain. Mitchell Yass has a Bachelor's degree and a Doctorate in Physical Therapy. Based upon his experience, Yass has developed a book, '*The Pain Cure*', to challenge conventional thinking on pain. His argument is around the inconsistency in the pain that people experience versus

modern forms of diagnosis such as magnetic resonance imaging (MRI) scanning. Yass disputes the concept of diagnosis solely by MRI scanning by highlighting inconsistencies in the pain people experience with differing MRI presentations. For example, people reporting high levels of pain when there are only minimal changes noted with investigation. Yass proposes that the majority of persistent pain is muscular in origin rather than structural. He believes that inconsistencies in people's pain experience with similar structural change seen with conventional investigation support this hypothesis.

The book takes the reader through the process of self-examination, diagnosis and treatment of education and exercise. The proposed clinical assessment combines range of movement testing, muscle testing, flexibility assessment, palpation, gait evaluation, postural assessment and balance testing. In addition, he asks readers to consider the pattern of symptoms in terms of the activities that make it better and the factors which contribute to the symptom aggravation.

From the assessment, Yass provides a reasoned guide to a number of common musculoskeletal conditions to enable readers to gain further insight to their pain problems. Finally, Yass guides the reader through special tests to confirm or refute possible diagnoses that are made through MRI scanning.

Part II of the book is concerned with resolving pain. This section of the book provides a number of musculoskeletal pain presentations with a number of associated tests to attempt to differentiate between them. Once a diagnosis has been achieved, the reader

is then directed to the exercise section of the book where a variety of joint specific exercises can be found to address the problem.

Yass's theory of an over reliance on imaging in the assessment and diagnosis of musculoskeletal pain is supported by a number of authors which include Brinjikji et al. They identified numerous spinal changes on MRI in patients who were asymptomatic. Unfortunately, this ideology fails to engage fully with conventional understanding of chronic or persistent pain management. Yass suggests that weakness is predominately the problem for the majority of patients who experience persistent pain. It could be argued that weakness maybe a component of a persistent pain problem rather than the sole underlying cause.

Exclusively discussing the physical aspects of a person's persistent pain fails to fully appreciate and understand the role of other factors such as psychology and social situation. It is widely accepted that both of these can act as a contributing factors to the development of persistent pain. The Yass Method fails to directly acknowledge and address potential psychological components that are synonymous with long-term pain presentations. Within the narrative, Yass does provides the reader with an improved understanding of common musculoskeletal diagnoses that they may have been given by health professionals along with guidance about future expectations. It could be argued that by providing the reader with such information, the book could indirectly facilitate a modest reduction in anxiety felt by the reader; however, the book fails to deal with these issues specifically.



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This book does help the reader to gain a greater understanding of their musculoskeletal conditions and provide them with direction for self-management. While the book may provide some relief, the title '*The Pain Cure*' remains an ambiguous term. It is widely understood and accepted that there is no cure for chronic or persistent pain. The Yass Method may help patients with persistent pain to improve their strength which may in turn have an effect on a patient's function. The word 'cure' may suggest to

the reader that there is a point where they may become pain free. While this may be true for some musculoskeletal conditions, for persistent pain problems, this title may be misleading and provide the reader with false expectations with regard to an outcome.

The Yass Method, therefore, shows a polarised understanding of the components of persistent or chronic pain. This fails to provide the reader with a truly holistic insight into assessment, diagnosis and guidance to self-

management treatment of persistent pain. Failure to acknowledge psychological components such as mood, anxiety and avoidance behaviours compromises the effectiveness of this book as a self-help guide for patients. Although Yass advocates a self-management approach, the use of the word 'cure' in the title has the potential to provide patients with an unrealistic expectation of what can be achieved through engagement with this book.

## Word Search

M P R I A T Z Y I P O A L P Y E	ADOLESCENT
U C D A D E N O M S E A K N X E	ANXIETY
A Y E H D N S W X H K X I E J W	DIAGNOSIS
H D H P A I E A R S R S E T E T	DISEASE
W C O R C T D R E U Q R G W E C	DYSMENORRHEA
X A Y L H L O J W S R I K O N S	ETHICS
H T I I E N P A E D I A T R I C	FAMILY
I I C T E S L Q I S A D H K A A	HEALTH
J S T M I P C A O D K Y E I R B	NETWORKING
K M S K Y N G E E Y W C A N T G	PAEDIATRIC
N Y C Y O N G L N B A U L G R V	RESEARCH
D P J A O Q T M Z T Y M T P I F	TRAINEE
B Y H S A N X I E T Y M H Y O Z	TYRANNY
K Q I H C R A E S E R H S Q U H	WAITING
C S F X R B K T I Y Y L I M A F	
Q N Z L W W W D B P A U X D N K	

## New Members



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### New Members ratified since October 2015

Name	Current Post	Place of Work
Dr Ananth Balasubramaniam	Advanced Pain Trainee	Clatterbridge Hospital
Mrs Yvonne Barnicoat	Clinical Nurse Specialist in Chronic Pain Management	Littlemoor Health Centre, Dorset Community Pain Service
Mr Neill Bartlett	Pain Management Programme Psychology Lead	Broomfield Hospital, Chelmsford
Dr Hannah Dawe	ST6 Anaesthetics/ Higher Pain	Ashford and St Peter's NHS Trust
Dr Martin Dunbar	Consultant Clinical Psychologist	Pain Management Programme East CHCP, Glasgow
Dr Adrian Head-Rapson	Consultant Anaesthetist	Ormskirk District and General Hospital
Dr Peter Keogh	Advanced Pain Trainee	The Royal London Hospital
Dr Min Liu	Anaesthetics ST5	University Hospital Lewisham
Dr Maureen Tilford	Self employed hypnotherapist	Norwich

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# Mike Gregory – obituary (1957 to 2015)

Dr John Orton

Dr Paul Cook

Dr R Krishnamoorthy



Michael A Gregory was born on 15 March 1957 and died on 23 November 2015. He

leaves behind his wife and three children.

Mike Gregory was educated at Barts and did his higher professional training in Northwest region in the 1980s. Like quite a few of us in Manchester, he spent a year abroad at the Prince of Wales Hospital in Sha Tin, Hong Kong (Chinese University of Hong Kong). Here, with Tony Gin (now Professor), he co-authored a paper on the use of propofol infusions to provide anaesthesia for caesarian sections. This was probably the first published record of this use. Back in the United Kingdom, he joined the Anaesthetic Department at the Royal Oldham Hospital in 1990 where he specialised in Obstetric Anaesthesia and Acute and Chronic Pain Management.

He soon established the first patient-controlled analgesia (PCA)-based acute pain service in the Northwest in a characteristically laid back but effective managerial style.

He was an early adopter of TIVA and participated in Zeneca's phase 3 clinical trials on TCI.

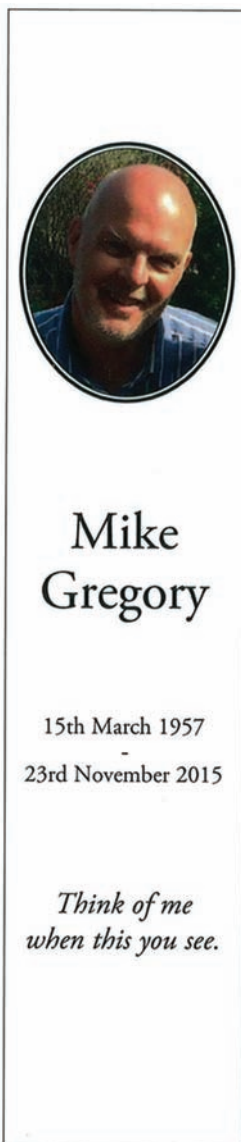
He had multiple management roles including that of clinical director.

He later became a full-time consultant in chronic pain. Mike undertook several industry-led research projects in connection with chronic pain. He was the principal investigator for many national clinical trials and few multi-centre international trials. He sat on the drugs and therapeutics committee, research and eight other committees during his role as a consultant in pain medicine in the Pennine Acute Hospitals NHS Trust. He chaired the Northwest Pain Group for 4 years and supported all the academic activities of the group both directly and indirectly until few weeks before his death.

Mike was an avid reader both fiction and medical – deeply knowledgeable in his field. He was adept at enjoying life to the full. He lectured widely and was supportive to the staff who worked with him and deeply generous.

A good man, an experienced guide, excellent trainer, believed that maximal treatment options and multi-disciplinary care should be available for all chronic pain patients and one of the most profitable consultants for the trust known for his efficient way of working.

He is greatly missed by the patients, department, management of the trust, the North West Pain Group and the pain management community of the North West. Dr Kershaw's hospice would also miss Mike as he was involved in providing valuable input to this hospice in his own time.





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The Philosophy & Ethics Special Interest Group of the British Pain Society

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[meetings@britishpainsociety.org](mailto:meetings@britishpainsociety.org)