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PAIN NEWS

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THE BRITISH PAIN SOCIETY

**Management of pain in people with dementia
in the hospital**

Some ethical dilemmas

Virtuous patient

Patient reported outcome measures



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THE BRITISH PAIN SOCIETY
PAIN NEWS

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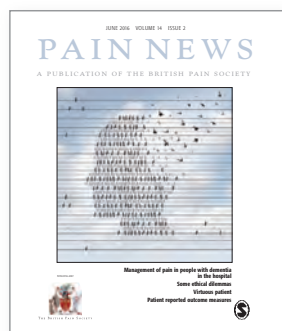
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THE BRITISH PAIN SOCIETY

2016

The Power of the Mind in Pain

Philosophy & Ethics SIG Annual Meeting

27th to 30th 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.

Pain in Children Study Day

13th July 2016

Churchill House, London

The morning lectures have a focus on common pain problems within paediatrics - headaches and joint pains, in addition to expert insight on the provision of pain management programmes. In the afternoon, delegates can choose to attend three workshops on areas of assessment, measurement and management of pain, beyond straight-forward simple analgesia.

Interventional Pain Medicine SIG Annual Meeting

16th September 2016

Manchester Airport

Patient Liaison Committee Annual Seminar

3rd November 2016

Churchill House, London

Headache SIG Annual Meeting

16th November 2016

Churchill House, London

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

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Dr Arasu Rayen *Editor*

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Change is in the air. By the time you receive this issue we will have a new President, Honorary Secretary and Honorary Treasurer.

Andrew

Baranowski, a Pain Management Consultant, is our new President. Andrew has a wealth of knowledge about the BPS as he had previous been an Executive Officer - as Honorary Treasurer. He has vision and mission to lead BPS forward. Roger Knaggs, our incoming Honorary Secretary, is a Professor in pharmacology and has served on the BPS council in various positions. Heather Cameron, a Physiotherapist, will be our Honorary Treasurer. Heather has also served on the council for some years. As you can see from the executive posts, BPS is truly a multidisciplinary Society with a mission of 'enabling best pain management for all' and vision of 'stop suffering from pain' (please see the President's message).

Arun, Damien and Stephen have written their second article on Social Media. After giving us the history, basics and background information about social media in their previous article, they are giving a compelling case in their second article in this issue, for us to look into and get involved in social media to benefit in our professional life. Thank you to the team for enlightening us about social media and the likes of FOAM (FOAM - Free Open Access Meducation – Medical education for anyone, anywhere, anytime) and SMACC (The Social Media and Critical Care Conference).

Journal of Observational Pain Medicine (JoOPM – <http://www.joopm.com/index.php?journal=joopm&page=issue&op=current>) is an initiative by Raj Munglani, one of our Pain Management Consultants, to have an online-only, open-access journal for professionals in Pain Medicine. This is a free-to-access (open-access) journal with articles on pain management practice.

Dementia is a growing problem in our society. With increasing longevity and expanding population of elderly patients, prevalence of dementia in hospital patients is found to be nearly 40%. Pain severity assessment and

management in this group of patients is extremely difficult. In this issue of *Pain News*, Professor Closs writes in her article 'Management of pain in people with dementia in hospital: time for a change of approach', about meta-review of the observational pain instruments available and an observational study of four site hospital wards. She concludes that we need a different approach for assessment and management of pain in this group of patients. Her team has also devised an electronic tool to track pain assessment, intensity and career input in a chronological visual format.

We all remember what a prom is in our personal life. What is a PROM in NHS? It is Patient-Reported Outcome Measures. NHS England states that PROM will help to measure and improve the quality of care it provides (<http://www.nhs.uk/NHSEngland/thenhs/records/proms/Pages/aboutproms.aspx>). In this issue, Holmes et al.'s article on PROM deals with a question: PROM - what could they mean for your clinical practice?

Summer is upon us and it is time for outdoor activities; I'm off for a bike ride. See you in the next issue which will include reports from the 2016 ASM.

Social media for professionals in Pain Medicine – part 2: the good, the bad and the ugly

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Social media has become a revolutionary global phenomenon in the 21st century. It is hard to comprehend the explosive increase in the use of technology to interact with friends and family on a daily (or often minute-to-minute) basis. For the modern generation, it is as hard to imagine a world before social media, as it is to imagine a world before the aeroplane in the latter half of the last century. Despite, or even perhaps due to the huge popularity of the likes of Twitter, Facebook and YouTube for recreational communication, the educational and professional use of social media has been relatively slow to become accepted and integrated by mainstream healthcare professionals. It is easy to see why social media has been overlooked as a huge number of the general population simply use it to share photos of pets/dinners/holidays or play monotonous games that involve catapulting disgruntled birds or crushing sugary confectionary. However, this is now changing as more and more professionals are embracing the potential of these technologies to overcome the deficits of traditional ways of communicating up to date knowledge such as in scientific journals, textbooks and conferences. It has been suggested that it can take on average up to 17 years before research findings become integrated into routine clinical practice;¹ lack of awareness and lack of familiarity are key factors in this long drawn process. Social media is an excellent way



to disseminate information rapidly to a large number of people in your profession and beyond. Journal articles as well as photographs and comments can be shared instantaneously across the globe using platforms such as Twitter and Facebook. In this way, social media can assist with lifelong learning and the promotion of new research and new ideas via enhanced interaction with your peers and experts across the globe.

Proliferation

The pervasiveness of social media has proliferated exponentially over the last decade to the point where it can take far more effort to avoid it than to engage with it. This is especially true for the likes of Google Plus, Facebook and YouTube to mention but a few. Indeed, it is no longer considered the future of social interaction, it is now the present and is an accepted standard. Perhaps some of the best and most practical contemporary examples of

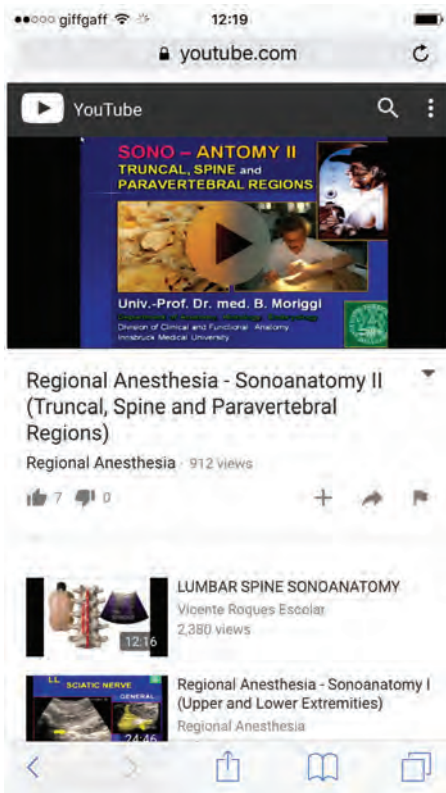


social media for medical education are videos on YouTube providing practical demonstrations of interventional techniques and the TED talks (Technology, Entertainment, Design), which share ideas across a broad spectrum encompassing science, education, business and healthcare. Google Groups allows health professionals to interact within private or invitation-only communities within which colleagues can discuss the latest clinical developments, the politics of healthcare or interesting/challenging clinical cases. A notable example of this being the UK-based Pain Consultants' Google Group, which has over 500 members to date.

Whether you like it or not

Whether you like it or not patients already use search engines and social media to find out background information before choosing where to go for healthcare, who

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to consult and as source material for questions that they may raise during the clinical consultation. At some point in time, every institution will have a disgruntled patient or employee that may well post negative comments on the web. If this polarised view of your workplace is the first or the only thing that is in the public domain for all to see, it does not reflect well on you and your institution, whether the criticism is deserved or not. It's not possible to control the Internet, but it is beneficial to put out positive content relevant to you and your place of work. Therefore, burying your head in the sand or contemplating the merits of becoming a modern-day Luddite is not a sensible approach. With that being said, it is worth considering that anything you communicate via social media may ultimately reach the public domain, whether it was intended initially or not. Indeed, many businesses and celebrities actively encourage information about themselves or their products to 'go viral' as a way of maximising exposure of self-promotion. As health professionals it is advisable to follow professional guidelines such as those of the GMC² as well as

rules suggested by colleagues with experience in this area (Mandrola text box). However, it is also worth considering the modern-day proverb: 'If you are not at the table, you are on the menu'. Specifically, if you have no Internet presence, it is easy for someone else to literally take over your persona on the Internet and set up false accounts on Google Plus and LinkedIn and in this way 'steal' your personality and digital footprint for their own monetary or professional gains.

GMC's guidance on Doctors' use of social media²

- Treat colleagues fairly and with respect
- Your conduct must justify your patients' trust in you and the public's trust in the profession
- You must maintain patient confidentiality. You should remember when using social media that communications intended for friends or family may become more widely available. The standards expected of doctors do not change when communicating on social media rather than face to face or through other traditional media.
- Identifying yourself as a doctor is good practice
- When advertising your services, you must make sure the information you publish is factual and can be checked, and does not exploit patients' vulnerability or lack of medical knowledge
- Doctors are accountable for their actions and decisions in other aspects of their professional lives
- You should be open about any conflict of interest and declare any financial or commercial interests in healthcare organisations or pharmaceutical and biomedical companies
- Social media can provide a valuable forum for airing and debating different viewpoints, and we don't want to stop doctors exchanging views freely and frankly.
- Doctors' use of social media can benefit patient care by engaging people in public health and policy

discussions; establishing national and international professional networks; and facilitating patients' access to information about health and services.

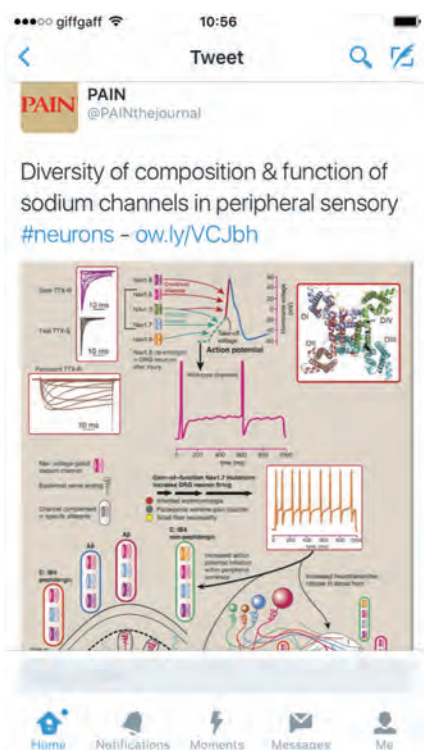
John Mandrola's 10 rules for social media (abbreviated):³

1. Do not fear social media – lack of patient education is a significant problem.
2. Never post anything when angry (or neurologically impaired).
3. Strive for accuracy.
4. When in doubt, pause (sleep on it. Re-read. Remember the permanency of digital media).
5. Don't post anything that can identify a patient. Changing details of the case is not enough. Avoid terms like, 'this morning' or 'today'. Don't underestimate privacy.
6. Ask permission: if you want to write about a specific case, get permission from the patient.
7. Be respectful: don't say anything online that you wouldn't say in person. Put yourself in their shoes.
8. Assume beneficence: social media tempts one to toss stones. Resist that urge.
9. Be careful 'friending' patients online.
10. Educate yourself and ask questions.

Game changer

For many serious clinicians, social media such as Twitter and LinkedIn can appear at first and even at second glance, as both prosaic and frivolous. However, while these websites can be used to fritter away countless hours, they also have an inherent potential to communicate educational material in an efficient manner. For example, it is possible to follow journals such as *PAIN*, *Anaesthesia* and *the British Journal of Anaesthesia* on Twitter and receive regular tweets with web links related to recent papers that

Social media for professionals in Pain Medicine – part 2: the good, the bad and the ugly



they have published. In this way, new clinical developments may be absorbed and assimilated with minimal effort in moments of downtime, such as on the train during the daily commute or during a long case in the operating theatre, when we may not have remembered to bring the paper journal. LinkedIn and YouTube may also be used in a similar vein to disseminate information and raise awareness of events such as Annual Scientific meetings (see World Congress on Pain image). As discussed in the previous article, conference delegates can share information live in real time to colleagues across the world via Twitter. In contrast, Facebook is arguably better suited to private and recreational use. However, there are numerous self-help groups with Facebook pages where patients can share their thoughts and experiences of their medical conditions, including chronic pain. Thus, social media may be seen as a game changer for contemporary clinicians and may go some way to facilitate us all keeping up to date in a time efficient manner and also help us with revalidation; of specific relevance to this is the concept of #FOAM.



#FOAM

- If you want to know how we practiced medicine 5 years ago, read a textbook.
- If you want to know how we practiced medicine 2 years ago, read a journal.
- If you want to know how we practice medicine now, go to a (good) conference.
- If you want to know how we will practice medicine in the future, listen in the hallways and use FOAM.
- From International Emergency Medicine (EM) Education Efforts and E-Learning by Joe Lex, 2012.⁴

FOAM stands for Free Open Access Meducation.⁴ The concept was formalised in Dublin, Ireland, over a now legendary pint of Guinness, hence the reference to foam. The vision was to create an online community focused around medical education relevant to EM that was free from journal paywalls and the influence of big pharmaceutical

industry. FOAM aims to bring the educators and learners together and make learning a more dynamic and active process in order to share the latest knowledge and developments. It enables people to take their presentations and papers that lie dormant on their hard drives and make them available to any colleagues that need them. This is particularly relevant in this scandalous era where high-profile scientific journals preside over an often maligned system characterised by steep publication charges, expensive paywalls and opaque peer review. Currently, authors (and reviewers) give up their valuable time and research for free, while corporations control and limit the distribution of knowledge and thus make themselves large profits. In stark contrast, FOAM may be considered as a collection of evolving, collaborative and interactive open access medical education resources with the aim of making the world a better place using all available media platforms. At present, EM is leading the field in this area, but there is huge scope for Pain Medicine to embrace this opportunity.

SMACC

In 2013, the first SMACC (Social Media and Critical Care) conference was held in Sydney, Australia. It had no formal backing from any college, society or university, but attracted 700 delegates from the FOAM community. In 3 years and after several meetings, SMACC Dublin June 2016 has capped its numbers at 2000 and has already been sold out. These conferences aim to give delegates a say in all aspects of the meeting and to provide short, engaging and inspiring educational talks that will be recorded and then released as free podcasts. The SMACC experience is being acknowledged as not just about academia, but also about fostering a real sense of community. The Pain world has not yet embraced social media to this extent, though the Pain Research Forum has provided a place for members of the research community to engage and interact with each other.

The good, the bad and the ugly Benefits

Social media provides an excellent and unrestricted opportunity to facilitate continuing education and lifelong learning. Users can share up-to-the-minute knowledge instantaneously and also discuss it directly with colleagues and potentially even with experts in the field across the globe. The nature of most forms of social media is such that it encourages brevity and the sharing of focused information in an easily accessible manner. At present and also for the foreseeable future, there is no sign of paywalls or financial restrictions on its use. Social media websites can provide a pragmatic way to navigate the vast array of resources including textbooks, journals and websites in the field in which you work. In addition, knowledge from conferences across the globe can be shared freely or at a relatively minimal cost, thus allowing much greater interaction and dissemination of information. This could also be associated with some positive environmental effects by reducing the carbon footprint, given the polluting effects of long distance travel and also the expenses incurred. If handled in a sensible way, social media platforms may also offer good opportunities to interact with the general public and the society in general, including your local community and potentially even your patients. In general terms, however, it is not advisable to befriend patients online.

Pitfalls

Social media can take up a lot of your time and it is easy to get distracted into looking at recreational sites and pretend

to be working. Social media users may also come across as rude and narcissistic by giving the impression that they are ignoring other people and instead focusing on an LCD screen. However, perhaps of more concern is that online discussion of clinical anecdotes risks inadvertent breaches of confidentiality through the release of poorly disguised descriptions or by discussing very recent cases. On another cautionary note, direct conversations with patients themselves may inadvertently expose personal health information and thereby violate patient confidentiality. The relatively unrestricted nature of social media may be a double-edged sword and your comments can be misappropriated or even taken out of context and used to portray a distorted or misleading caricature of the person or the situation.

Trolls

Trolls are people who post offensive or inflammatory messages that may even seek to bully or harass other users. They can flood platforms with huge numbers of irrelevant or nonsensical messages, and can vandalise a website. They may post under numerous aliases and can send spam for financial gain or simply personal amusement. Trolls themselves are often considered to be lonely social misfits with dark personality traits such as those observed in antisocial or psychopathic personality disorder. The standard advice is to ignore Trolls – that is, ‘Don’t feed the Troll’; this seems entirely sensible, given that it would be unrealistic to reason with a sadistic psychopath in person.

Where do we go from here?

Twenty five years ago, except for a handful of visionaries behind the social media revolution, no one could predict or fathom the extent to which things have developed to its current stage. Predicting the future has never been an easy business, but that hasn’t stopped people from trying. Various theories abound, including the complete immersion of humanity into a high-tech dystopia featuring the endless use of smart technologies such as virtual reality glasses, holograms, self-driving cars and sentient robots. Meanwhile, multinational corporations gain a stranglehold on media and all countries and all cultures gradually coalesce into a globalised monoculture. Wearable technology of the kind popularised by Inspector Gadget will track and anticipate our every movement. Or perhaps it won’t. Perhaps, 25 years from now social media will seem as anachronistic as Betamax or the Telegram.

Acknowledgement

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



Some ethical dilemmas in public health: how can we value life and health fairly?

Peter Bennett *Head of Analysis, Health Protection, Department of Health*

This article is a transcript of the talks given in Philosophy and Ethics meeting of 2015 in Launde Abbey

Introduction

I head a small analytical team in the Department of Health that looks at interventions in public health. These range from vaccination and screening programmes, to emergency preparedness, to 'lifestyle' risks such as smoking, drinking and obesity. Working at a population level makes ethical dilemmas to do with specific individuals less obvious. But what does concern us is whether the health budget is being used as 'effectively' as possible. And that question cannot be framed without an ethical dimension. Although we often talk about costs, the only costs that matter here are *opportunity costs* – what else you could have done with the same resources. How should we make such choices? There are some technical issues, but the big questions are at heart a matter of ethics. And if the whole system fails to work as well as it could, the bottom line is that a whole lot of individuals suffer the consequences, whether or not we see who they are.

Valuing life

I want to introduce you to a world of measurement and quantification, which may be mysterious and distasteful to some. Whether or not it remains distasteful, I hope to make it slightly less mysterious. You may have some

acquaintance with the concept of a quality-adjusted life year (QALY). I want to share some ethical dimensions involved in using a metric like that to prioritise resources and highlight some dilemmas.

I am *not* going to discuss uncertainty about the effectiveness of interventions. That's a huge, but different, topic. This talk is about the other bit of the equation: even if you *know* how much good to public health something is going to do: how do you value that? How do you put a monetary value on peoples' health and wellbeing? It's tempting to shy away from such a question. But economists have grappled with it – and I believe that it has to be faced if we are tasked with doing the most possible good with limited resource.

To go back a step, how do you value a life – for example, if you have the opportunity to reduce road deaths? One way is simply to value lost earnings. Looking at transport safety, this was how it used to be done. The fundamental problem here is that a life is valued only 'instrumentally' – what it's worth on the market. This has some pernicious consequences. A good lawyer might be able to argue for some vast sum for the death of a financial high-flier or a future brain surgeon, but what about ordinary Joe Soap who does nothing very



remarkable – how much was he worth? You also had to find reasons to avoid giving a negative worth to people past retirement age

The conceptual breakthrough came when economists argued that to value a reduction in risk, you should ask the people whose lives are at risk. Hence the current concept of 'willingness to pay'. You ask the population: suppose you have a safety measure which could reduce your risk of accidental death by, say, one in a million. How much would you be prepared to pay for that? You don't know who is the one person who would otherwise be killed – but it *could be you*. So, you find out what people answer – and the egalitarian bit is that you then take the average. In terms of public policy, we are blind as to whether the actual life lost or saved is a millionaire or a pauper. For the United Kingdom, the answer – the 'value of a statistical life' – used to be

Some ethical dilemmas in public health: how can we value life and health fairly?

about £1 million: over the years, it's crept up to a bit over £2m. That's the figure used in cost-benefit analysis for transport schemes.

Quality of life

If we are interested not just in life but length and quality of life, we need to know how people would *compare* a year of life in 'perfect' health (or as good as you could imagine it to be) and various other health states. There are various ways of defining health states, but it is usually done at present using a metric called EQ-5D. This has five dimensions: mobility; self-care; ability to carry on your usual activities; pain and discomfort and anxiety and depression.

To cut a long story short, further surveys use so-called 'standard gambles' and other means to find out how strongly people would prefer to be in one state compared with another. Putting the results together gives willingness to pay for a QALY. And what *that* gives you is a common currency. So, if you want to measure how much good would be done with an immunisation programme or a measure to discourage smoking, or introducing a new drug, (and National Institute for Health and Care Excellence (NICE) uses a similar method) you work out how many QALYs are gained, at what cost. In at least one version of a perfectly rational world, Government would put all the things it could do into a rank order of QALYs gained per £ spent, then tick them all off from the top and keep going down until it ran out of money. Then, you would have done as much good as it was possible to do.

So, maybe the aim of health policy should simply be to 'maximise the number of QALYs for the population'. But there are some value judgements underlying this. One is the principle that everyone's QALYs are of equal worth: there is no denying that this *is* a value judgement, even if we regard it as

benign. QALY maximisation based on population averages also fails to allow for individual variability in preferences. Mrs Smith might be prepared to stand a huge amount of pain because she wants to survive, perhaps to see her grandchildren grow up, whereas Mr Jones has had enough suffering. The doctor with an individual patient can at least have that conversation. If all you have in front of you is a population, an average may be the best available measure. But it is far from perfect.

There is another ethical controversy about 'ageism': the older we get, the fewer QALYs we have to lose. Speaking personally, I accept that saving my life aged 20 would have been more worthwhile than saving it now. Otherwise, the last 43 years of my life have been entirely worthless! But, debate about QALYs being 'unfair to the old' rumbles on. One can also question the validity of asking people hypothetical questions – for example, to imagine what it would be like to go from full mobility to wheelchair, and then value that. (There is a nice saying that nothing in life is quite as important as you think it is while you are thinking about it.) An alternative suggestion is to use the judgement of people who are in the state that you are trying to value. That sounds reasonable enough, but has problems too. In general, pain and discomfort gets less weight than if you value it in advance – perhaps because people adapt to the state they are in. Now there's a dilemma: should one value reduction in pain less because people are adaptable? Or is that ethically perverse?

More fundamentally, 'QALYs maximisation' can be criticised as *too* individualistic. We may have gone from the Dark Ages of only valuing somebody according to their earnings, but is it right to ignore wider societal costs and benefits? If we can improve someone's health, not only will they need less care themselves (that's in the model already) but they may also become able to

provide more care to others, for example, to other members of the family. Or they may become well enough to get employment (and start paying taxes). How much of this should we include? This is an area of active debate. You can take the narrower view that our job is to maximise health, given a constrained budget. That tends to be NICE's view, whereas the Department tries to start from the ideal of cost-benefit analysis that includes all the societal factors.

Valuing QALYs

Having said all that, how much is a QALY actually worth? It depends, as ever, on how you ask the question! The Willingness-to-Pay research suggests a societal valuation of about £60,000 – more than most people earn in a year. But can we collectively afford to pay that rate? Looking cost-effectiveness within a limited budget, at what price does the National Health Service (NHS) actually 'purchase' QALYs? This is where you get to lower thresholds – for example, NICE's guideline of £20,000–£30,000 per QALY for new drugs. Indeed, the latest research suggests that the NHS currently purchases QALYs at about £15,000 each. So, if you approve (say) a new vaccination programme, however wonderful the benefits, you really ought to be getting QALYs at £15,000 *and no more*. Otherwise, you may be displacing other activity that is doing more good. You don't know exactly what it is you are displacing – and thereby hangs a difficulty. If you *don't* implement the programme, you know who the losers are; if you *do* implement it above a cost-effective price, the analysis says that you must be causing harm to others, somewhere in the system. But in general, the losers are hidden. You maintain the impression of having done good.

So, health administrators 'ought not' to pay more than about £15,000 per QALY for NHS programmes, all things being equal. But other things are never

Some ethical dilemmas in public health: how can we value life and health fairly?

equal. There is evidence to suggest that if you want to follow society's preferences, people weight QALYs more highly for more severe conditions. They will also want you to weight harm to children more highly – even *after* allowing that they have more QALYs to lose. How should one respond to these pressures? There is no single, ethical answer.

Further dilemmas

I will finish with a couple of specific dilemmas. The first concerns avoidance of harm. For example, if you inadvertently give a blood transfusion that carries an infection, you actually harm someone; you don't just fail to do them good. How should you value *that*? Suppose you can predict what the health consequences will be. You can estimate the QALY loss. How much should you (as a decision maker) be prepared to pay to avoid losing those QALYs? The dilemma again is that if you pay a high price for 'safety' from a fixed budget, the QALY loss elsewhere may be much higher. Nevertheless, there is quite a bit of research showing that you ask how much people would be willing to *accept* in return for an increase in risk rather than how much they would pay to have it

reduced, you get a much higher value. So, when should this bigger 'willingness to accept' value for avoidance of harm be used, rather than willingness to pay? This is clearly an ethical question. At present, we think that that the higher value should be used if the harm caused would violate an entitlement (and getting uninfected blood may be such a case). But, in other contexts, for example, reconfiguration of services, there are almost always *some* losers, even if the system is better overall. And if you value these losses more highly than the gains, this will not be best for the population as a whole. But this leaves a lot of grey areas. What are the limits of sheer bad luck?

My final dilemma concerns valuation of lives in poor health. Is a QALY the right measure, or should all lives count equally? Consider a hypothetical choice. Under Policy A, you expect to save the lives of 100 people who would live on average another 40 years. With Policy B (for the sake of argument, costing exactly the same), you would expect to save 100 people who would live on average 1 year. In this extreme example, I suspect that we would have little difficulty in choosing Policy A; even if the people benefitting under policy B are elderly and those

under A are healthy young adults, the choice does not feel unacceptably 'ageist'. But a more difficult choice occurs if the two groups differ not in expected longevity but in quality of life. Policy A would save the lives of 100 people who would on average live in fair health for another 10 years (Let's say 0.8 QALYs). Policy B would save the lives of 100 people expected to live for another 10 years in poor health (say 0.4 QALYs.) Do you reckon everybody's life is worth the same, or do you choose so as to maximise QALY gains? That gets you in to all sorts of equity issues. Does preferring A to B discriminate against the disabled? And if we decide to ignore the QALY calculation and just count lives saved, suppose then we have Policy C which would improve the quality of life for 100 people from 0.4 to 0.8. If you believe that A and B are of equal value, the nonsensical implication is that C must be worth nothing! How do you manage to count the lives of people as 'equal in value' without devaluing things that you could do to improve their quality of life? And how do make those things add up: not only morally but somehow, in our world, arithmetically?

I will leave you with that little conundrum.



Reconceptualising patient-reported outcome measures: what could they mean for your clinical practice?

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Patient-reported outcome measures are increasingly being used to collect patient outcomes on a routine basis in healthcare. This article will overview how patient-reported outcome measures were developed, their current use in clinical practice and will discuss the impact they may have when used within treatment of non-malignant pain.

What are patient-reported outcome measures?

'Patient-reported outcome measures' (commonly abbreviated to PROMs) is an umbrella term for standardised instruments and questionnaires collecting data on patients' perceptions and views about their health. When completed, they typically produce a numerical score.^{1–7}

PROMs can be used to measure constructs of health, health status, quality of life and quality of care, as well as the processes, structures and outcomes of care.^{5,8,9} PROMs capture patient views, feelings and subjective experiences unlike traditional methods such as biophysical measures.¹⁰

The development of PROMs were initially devised for use within health research, especially randomised-controlled clinical trials (RCTs).¹¹ Traditionally, health has been measured using negative end-points, such as mortality, or through assessing biological factors, these are an objective approach of measurement to quantify health.¹² However, it was acknowledged that these traditional measures may not provide a comprehensive record of patient experience of illness and treatment,

highlighting a need for progression to other outcome measures.^{13,14} Although the quantification of biological features is associated with patient experience, non-biological factors are also important aspects of patient outcomes, as well as playing a fundamental role in influencing patient outcomes.¹⁴ This led to the development of general health measures to be used within RCTs that assessed and quantified the many facets to health and illness.¹²

Why use PROMs in clinical practice?

The use of outcome measures was incorporated into clinical practice as patients' subjective views were deemed as valuable information to evaluate healthcare as well as assessing the efficacy of conventional medical treatment.^{11,15} In the early 1990s, PROMs were used in three main ways within clinical practice, to increase knowledge over disease trajectories, evaluate the effectiveness of treatment on individual patients and assess the quality of the care provided.¹¹ These outcomes were thought to be intrinsically linked to processes of providing quality healthcare, and so PROMs were used to inform clinicians about health management and aid the

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development of treatment plans.^{11,16}

The National Institute for Clinical Excellence (NICE) stated that the collection of patient views may enable realistic interpretations of the evidence during appraisal of medical, surgical and therapeutic technologies, diagnostic techniques, pharmaceuticals and health promotion activities.¹⁷ PROM data were suggested to provide an insight into the effectiveness, appropriateness and acceptability of the technology, as well as the impact of a health technology on patients' physical or psychological symptoms, disability, functioning and overall quality of life. A report in 2005 by Appleby and Devlin³ for the Kings Fund acknowledged a shift from measuring healthcare to examining quality and performance from the perspective of the patient, recognising that patient views are vital to their care. Within the National Health Service (NHS), routine measurement was suggested to have two main uses: to provide information on health of patients and any health gains from treatment and additionally could be useful in allocating resources, priority setting and future planning of the NHS.³

The NHS created a report in 2008, highlighting the importance of using PROMs to measure patient's perspective of effectiveness of care.¹ In 2009, a new Standard NHS Contract for Acute Services was introduced, in accordance with this guidance, all licensed providers of Unilateral Hip replacements, Unilateral Knee replacements, Groin Hernia Surgery or Varicose Vein Surgery funded by the NHS are expected to invite patients to

complete a pre-operative and post-operative PROMs questionnaire. Thus, from origins in clinical research by 2009, PROMs had become part of routine clinical practice in parts of the NHS.

What impact do PROMs have in clinical practice?

The use of PROMs in clinical practice has triggered research to identify what impact(s) this new practice might have on the process of care and subsequent patient outcomes.

An early review, conducted by Greenhalgh and Meadows,¹⁸ aimed to assess current evidence by examining RCTs exploring the use of PROMs in routine clinical practice. The authors found a limited amount of evidence suggesting that using PROMs may positively influence the detection of psychological problems and facilitate communication between clinicians and patients.¹⁸

A number of other reviews have since assessed the impact of using PROMs in clinical practice, examining evidence from controlled trials and RCTs. As a result of claims that PROMs could provide additional information to clinicians and improve patients care, Espallargues and Valderas¹⁹ conducted a systematic review assessing the effectiveness of providing feedback on PROMs to clinicians. The review included 21 RCTs examining the provision of patients' health status to clinicians. The authors concluded that the impact of providing feedback on PROMs to clinicians was unclear but that PROM use may modify elements of the healthcare provided through increased diagnosis of conditions and use of health services.¹⁹

Reviews have also focused on specific areas of healthcare settings or conditions. Many empirical studies have focused on oncology and the impact of adopting PROMs for patients, clinicians and healthcare organisations. A recent review examined whether the use of PROMs in active anticancer treatment was associated with patient outcomes, health

service outcomes and processes of care.²⁰ The review included RCTs and non-randomised studies where PROM data were sent to clinicians or patients to improve patient care. The results were narratively synthesised and effect sizes estimated for some outcomes. Use of PROMs in oncology settings was found to be associated with increased supportive care, improved symptom control and patient satisfaction.²⁰ However, the reviewers concluded that there were limited significant findings with small effect sizes and additional research was needed.

An additional area of interest has been the use of PROMs within psychiatric settings. Gilbody et al.²¹ conducted a review to assess how measuring health-related quality of life (HRQoL) could improve the quality of psychological care in psychiatric and non-psychiatric settings, and for those with common mental disorders. RCTs and quasi-randomised trials were included in the review and results pooled using a random effects model. The reviewers concluded that there was limited evidence to support the use of PROMs in clinical practice in these settings, with no overall difference in treatment outcome and limited evidence suggesting improvement in patient satisfaction.²¹

Another review examined qualitative research on clinicians' experiences of using PROMs.⁸ Authors used thematic analysis to synthesise 16 studies. The analysis raised issues on the practicalities of collecting data, clinicians' values of PROM data and how clinicians made sense of the information provided. Additionally, one theme stated that some clinicians viewed PROMs to have the potential to impact on the processes of care, such as influencing communication, shared decision-making and planning care.⁸

Why use PROMs in the treatment of non-malignant pain?

Recently, we conducted a systematic review on implementing PROMs in

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clinical practice in non-malignant pain, such as rheumatoid arthritis, back pain and surgical pain, aiming to identify the potential impact(s) of implementing PROMs in routine clinical practice on the process and outcome of healthcare for non-malignant pain. The systematic review identified 13 eligible studies. The synthesis of results suggested that PROMs may be included in the initial consultation to assess patients, and for decision-making regarding the patients care. During the course of the patient's treatment, PROMs can be used to track the progress of a patient, evaluate the current treatment and change the course of care if required. The use of PROMs is also thought to influence the therapeutic relationship between patient and clinician. Post-treatment, PROMs may also have a direct influence on other outcomes, such as pain and patient satisfaction. Due to the weaknesses in quality of studies, and a lack of generalisability, it is not currently possible to provide a comprehensive understanding of how PROMs have an impact in clinical practice for pain. The empirical literature to date produces a general picture of the potential impact PROMs may have throughout the treatment process.

Furthermore, theoretical literature suggests that PROMs initiate several processes which may influence outcomes. PROMs can be used to assess the impact of disease, injury or specific symptoms from the patient's perspective.²² This may increase clinician knowledge surrounding patients' pain and the impact it may have. PROMs are thought to provide data for discussion and facilitate communication between the patient and clinician.^{11,18,23} The measures can enable patients to communicate any needs or concerns they may have. This enables clinicians to identify any patient education need and prescribe specific support and tailored education or counselling. In this respect, the identification of problems may reduce

the number of questions to be asked by the clinician, shortening the patient history examination and leaving more time for treatment or discussion of treatment options. However, there is also the potential for PROMs to have adverse effects; asking patients to regularly monitor and report on their pain could lead to hypervigilance and increase avoidance behaviours, negatively impacting quality of life.

PROMs may additionally facilitate the provision of individualised patient-centered care.¹⁸ Data available from PROMs enable both the clinician and patient to identify and prioritise key patient issues, with PROMs providing information on what is the most troublesome or the biggest priority for treatment. Additionally, improved communication may further lead to greater patient satisfaction.^{18,19,23}

PROMs are also used to monitor treatment response.¹⁹ PROM scores provide the means to assess the effect of treatment, understand patients' progress and identify if the treatment plan is appropriate. Identification of problems, monitoring of changes and discussion of treatment options through PROMs data can assist clinicians' decisions surrounding changing treatment or providing additional treatment.^{4,18,19,22} Clinicians may change treatment, prescribe drugs, change or reduce medication, order further tests or provide additional advice on self-management. Through enhanced communication, individualised tailored advice and increased patient satisfaction, patients' self-efficacy may improve, increasing the likelihood of behaviour change, adherence to treatment or enhancing their ability to self-manage their health.²²

Conclusion

PROMs may potentially affect the process and outcomes of patient care when used in the treatment of non-malignant pain. The research base evaluating the use of

PROMs in routine clinical practice is relatively new with an underdeveloped theoretical basis for their use. Overall, the research suggests that PROMs may lead to improvements clinically and psychologically for patients. However, as the findings across studies are not consistent and the mechanisms through which PROMs operate have not been established, further research in this area is needed.

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