

The myClinicalOutcomes website: providing real-time, patient-level PROMs data

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The national patient reported outcome measures (PROMs) programme has been under way since April 2009, yet the true value of capturing and utilising these metrics has yet to be realised. The current system needs to evolve and should deliver real-time, patient-level benefits for more procedures, bringing long-term monitoring into routine clinical practice. The myClinicalOutcomes website is a low-cost, straightforward web-based system that could improve the current situation.

At the time of writing, the most recently available PROMs data have only just been published for the year April 2010 to March 2011. It is late October. The data do not provide any insight into how I am performing as a surgeon or how my patients have benefited from any intervention, let alone more detailed insight such as how the case mix, procedure choice or the passage of time affects the reported outcome. Indeed, as a surgeon, my only role when such data are published is in helping others understand why the face-value conclusions, drawn without the benefit of a critical statistical eye, aren't reasonable. In this case, the only valid conclusion is that, despite (anecdotally) operating on less-straightforward patients than the regional private and NHS benchmarks, there is actually no statistical difference in the comparison of our performance as a department. In short, I feel we could be doing more with this kind of data.

Kathy McLean, Chair of the NHS Clinical Advice and Leadership Future Forum, has aired concerns: *'Many [clinicians] highlighted inadequacies in the current system relating to the accessibility and use of data about health outcomes. Clinicians said they wanted to have better access to accurate data about health outcomes so that they could benchmark outcomes and improve services. They wanted to see data collected and used to support evidence-based practice and evidence-based commissioning. Many pointed out that these data also need to be transparent and widely available, especially to enable patients to make informed choices about their care.'*

Furthermore, as the National Programme for IT, which imposed centrally chosen

systems on trusts, is dismantled, there is a shift in emphasis in favour of the new GP commissioners and local providers choosing systems that better meet their specific needs. Katie Davis, Managing Director of NHS Informatics, recently said that the NHS cannot work with a 'one size fits all' approach to systems: *'We need to be able to recognise where there is a special local need for services that are different'*. These views are very much in line with the recommendations of the Department of Health's 'Information Revolution' white paper, intended to support such localism in the pursuit of quality, albeit in the hope that such changes will pay for themselves. While the RCS supports the 'provision of good-quality data' there is 'particular concern [that] no central funding will be made available to support delivery and implementation'.

Following an outcomes-focused research fellowship at the University of British Columbia in 2009, as a new consultant, I began to investigate systems that might combine the collection of outcomes for research purposes with use in routine clinical practice. Finding no suitable and cost-effective systems, I designed and built my own. The result, www.myClinicalOutcomes.co.uk, has now launched and is, and must remain, a free resource for NHS surgeons and patients to use, seeking private funding from partners outside the NHS to support ongoing development. Currently applicable to all orthopaedic subspecialties covering all procedures, as well as the procedures covered by the national PROMs programme, we are building the site to cover all other suitable surgical procedures.



Figure 1
The myClinicalOutcomes
Homepage
(www.myclinicaloutcomes.co.uk)

received by patients and surgeons alike, with managers and board members keen to use the information as evidence for the productivity and quality of care delivered in the department. Early indications are that most patients successfully engage with the site, although those less used to the internet may need a prompt or the assistance of a friend or family member. Currently, approximately 82% of adults in the UK have internet access and although this is lower in many typical 'patient' demographics, availability and skills are growing in all groups. Those without access or the ability or support to use such new systems simply continue to be cared for using traditional means.

The system is currently under trial across all orthopaedic subspecialties at the Royal Cornwall Hospital and Duchy Hospital, in association with Isis Innovation, who license the Oxford scores. Patients are directed to the site with a brief prompt in all routine correspondence at all stages of treatment. On registering brief details, they are asked to complete both condition-specific and generic well-being scores. With their consent, this information is made immediately available to their surgeon, with entered operation details validated by the surgeon before being stored to their account.

Patients are subsequently emailed every three months to remind them to take further assessments. They receive

concise, tailored feedback for each score completed and their progress is charted. Scores completed at home, or on clinic systems, can then be reviewed by the surgeon at either a high-level 'dashboard' overview, or a 'drilled-down' individual response level. Patients with unexpectedly low or rapidly deteriorating scores, or any that drop out of the system and do not respond to reminder emails, are flagged for attention. All patient-identifiable data are double encrypted and stored on secure servers that meet NHS standards and the Information Commissioner's Office has been satisfied by the robust security standards and procedures in place.

The trial of the system is being well

The system has received the attention of local GPs who are taking the initiative in the new commissioning landscape and are writing its use into new commissioning guidelines. The aim is to support timely referral to secondary care and to support high-quality follow-up shared by the GP and surgeon. As a result of this, as well as adding specific GP access, additional specialties and making it easier for clinicians to access and visualise their own patients' data, we continue to work with patient groups such as Arthritis Care to ensure the site remains useful to patients throughout their care pathway. In the future, it is our intention that the system be made widely available for use as required by local commissioning, managerial and clinical needs.

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