

Working together to improve rheumatology services

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From the inception of the NHS in 1948 until the late 1990s, treatment for inflammatory rheumatic diseases had been limited. With the advances in science and technology, early diagnosis is often now possible and a variety of new, but invariably expensive, therapies have been developed with substantial health improvements for patients. The NHS is currently going through a period of major reforms which will affect rheumatology practice and medicine as a whole. Improved links between primary and secondary care will be crucial to these changes and more effective collaboration should lead to better patient outcomes.

What have been the most recent developments?

Inflammatory arthritis used to be an incurable and progressive disease. Vasculitis was invariably fatal and having osteoporosis often meant fractures and pain. The treatment of rheumatic diseases, however, has radically changed in the last five years. The specialty has been transformed by a better understanding of disease pathogenesis leading to the development of new drugs based upon the targeting of key cytokines such as tumour necrosis factor alpha (TNF-alpha) now known to be closely involved in disease development. There have also been major advances in technological imaging such as power Doppler ultrasound and magnetic resonance imaging (MRI) while the ability to carry out research and self-education has been made easier with the advent of the internet and databases such as PubMed. Information is now readily accessible and dissemination of information between clinicians via email and the web has also enabled patients to educate themselves about their own conditions.

The therapeutic armamentarium has grown substantially for rheumatologists. TNF-alpha antagonists and B cell depletion therapy are two such advances. Others, such as anti-CTLA4Ig and anti-B lymphocyte stimulating antibodies, are also on the horizon but these all require increased financial resources. It may be that early treatment of rheumatoid arthritis for example, albeit with expensive drugs, could lead to an overall reduction in expenditure with less inpatient treatment, for joint replacement surgery for example, and more importantly less time off work and improved self-esteem for patients.

How has service organisation changed and how will it change in the future? Many departments have limited access to inpatients beds. As an alternative, patients are often treated in day-case units. Given that rheumatologists look after patients with inflammatory and multi-system diseases there will always be a need for access to beds in secondary and tertiary care hospitals. Clinical nurse specialists and general practitioners with special interests (GPwSIs) have helped to absorb some of the workload but not without additional financial costs.¹

The patient lobby is important in highlighting the importance of good quality care in rheumatology and this has been facilitated through organisations such as the National Rheumatoid Arthritis Society (NRAS) and the Arthritis and Musculoskeletal Alliance (ARMA). Patients now have much higher expectations of the quality of healthcare they receive and wish to be involved in decision making about their treatment but these reasonable expectations require longer consultation times.

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Conference programme

■ What have been the developments in the last five years?

Dr Andrew Bamji, Queen Mary's Hospital, Sidcup

■ Introducing the standards of care

Professor David Scott, Norfolk and Norwich University Hospital

■ The view from patients with rheumatoid arthritis

Ailsa Bosworth, National Rheumatoid Arthritis Society

■ Personal experience and view from BackCare helpline

Helen Montgomery, BackCare

■ View from a primary care trust

Andrew Parker, Brent Teaching Primary Care Trust
Dr Madhukar Patel, Brent Teaching Primary Care Trust

■ View from a clinician on innovation in services

Dr John Halsey, Royal Lancaster Infirmary

■ How health policy is developing

Professor Julian Le Grand, London School of Economics

■ The view from the Department of Health

Gary Belfield, Department of Health

■ Debate and questions from the floor

Panel: Professor David Scott, Ailsa Bosworth, Dr John Halsey

■ Summing up and agenda setting for the future

Professor David Isenberg, President, British Society for Rheumatology

What are the potential problems to be faced in the years to come? Change is often difficult to accept. Working to targets, for example, could have an adverse impact on clinical practice with patients prioritised according to how long they have been on a waiting list rather than on their clinical need. This issue frequently makes clinicians feel deprofessionalised and demoralised.

Introducing the standards of care

Rheumatology is now established as a major specialty. There is, however, no National Service Framework (NSF) for musculoskeletal disease and one is not likely but the Department of Health (DH) is about to launch a national musculoskeletal health strategy. In addition ARMA has produced its own 'NSF' known as 'Standards of Care' (SoC),² which has set out a number of key principles from the concept of patient-centred services and patient pathways to the key role of the multidisciplinary team and understanding the holistic needs of patients. The first documents set standards for the management of inflammatory arthritis, osteoarthritis and back pain and were published in November 2004. They provide an excellent framework on which to base audit and improve local patient care. The second wave will include autoimmune rheumatic diseases, bone disease and regional musculoskeletal pain and will be published in 2006/7.

The view from patients with rheumatoid arthritis

Clinicians and policy makers can learn a great deal from patients and patient groups, especially those with long-term conditions. Although we are heading towards, as the government want, a more patient-led NHS, patients and clinicians alike would prefer to see a patient-centred rather than patient-led service. Patients, rightly, want to be treated promptly by the most appropriate person, to be involved in decision-making and to rely on and trust their team. A number of features need improvement to make disease management easier: prompt referral and diagnosis, rapid access when needed to a range of services, eg when the disease is flaring, annual reviews, better pain control, adequate cardiovascular assessment, and more holistic care. Patients often feel demoralised when they cannot quickly access an appropriate healthcare professional when their disease becomes active, or at least obtain telephone advice perhaps from a clinical nurse specialist. One reason that patients are not promptly referred by their GPs is the difficulty of recognising the onset of inflammatory arthropathies. There is a need to improve rheumatology teaching at medical school and for doctors in-training in general.

Process mapping (what happens to a patient with a particular disease from first contact with a GP) can help to reveal problems in the patient pathway where the patient may have contact with large numbers of professionals involved in their care and can help to identify the bottlenecks. One key area of concern is that patients do not feel adequately cared for when admitted to non-rheumatology beds where nurses may not understand their individual needs.

Personal experience and the view from BackCare helpline

Patients are frustrated by the slow process from first contact with the GP to reaching a diagnosis and receiving treatment in secondary care. One such complaint relates to back pain where patients, following a visit to a consultant, must then wait for scans, results and further referrals before receiving treatment. Patients get disheartened by this process which in turn leads to problems with employers, family and friends, secondary depression and pain amplification. This scenario led to the development of BackCare helpline which has provided excellent advice for back pain sufferers, although patients usually feel dispirited by the time they call. In an ideal world, GPs could refer these patients to a musculoskeletal coordinator at the primary care trust (PCT) who would decide the most appropriate local professional for the patient to see and arrange rapid diagnostics followed by a treatment plan, perhaps at a one-stop clinic. This idealised outcome is still some way off and one concern is that this may lead to over-investigation of back pain, which often requires simple assessment rather than expensive investigation.

View from a primary care trust

New systems are now in place with regard to practice-based commissioning (PBC) of services, flow of funds (payment by results (PBR)) and Choose and Book (CAB) – a shift in ethos in giving patients a greater choice of NHS hospitals and independent treatment centres from which to obtain treatment. The aims of CAB and the planned use of primary triage systems may not, however, be compatible. In addition CAB, and to some extent PBR, should drive up standards but what will happen to 'less popular' departments and hospitals? Will their income dry up? Primary care trusts such as Brent are evaluating musculoskeletal care pathways to ensure a seamless and integrated service for patients and this involves preventing inappropriate referrals to secondary care and utilising other professionals such as GPwSIs and physiotherapists. Education is essential if this is going to work as GPwSIs will need to achieve and maintain agreed levels of competency.

View from a clinician on innovation in services

Communication within a department and between primary and secondary care is important in order to provide a highly effective service. Department away days are an effective way of bringing the team together and planning for the year ahead, with participants from primary and secondary care, managers and patients. Developing community-based disease-modifying anti-rheumatic drug monitoring is popular and convenient with patients. This is usually undertaken by practice nurses who, for example, work to agreed British Society for Rheumatology monitoring guidelines. One major innovation has been the advent of a consultant-led electronic advice service for GPs, which in just one pilot has led to a 63% reduction in secondary care referrals. Various patient pathway models have been created

to facilitate rapid, efficient and appropriate referral of patients, whereby the triage of patients to an appropriate clinic is actually run by a GPwSI, an extended scope practitioner and perhaps a manager. Successful examples include ones developed in Bangor³ and Stoke.⁴ Service innovation will play a key part in improving standards with the help of inter-unit idea sharing.

How health policy is developing

Two of the driving forces behind the current NHS reforms are the renowned long waiting lists and over-crowding in accident and emergency departments, and the concept of the state monopoly of provision. The norm for patients would be referral to their local hospital, and if they received a poor service, apart from complaining or moving to the private sector, they could do little else. This problem led to the controversial introduction of hospital targets, which in turn led to rewards for those which successfully met them and penalties for those that did not. In the short term, they have led to, for example, shorter waiting times for outpatient appointments but in the long-term they distort activity figures and obstruct clinical decision-making, leading to demoralisation.

In principle, patient choice sounds attractive as for some it will lead to a greater sense of control. A significant number of patients, however, will not be able to comply with the choices proposed. A patient in a rural area is unlikely to opt for a hospital 60 miles away when one is only five miles from home. Also, do GPs during a seven-minute consultation have time to discuss all the options and make the booking?

Hospitals may have a perverse incentive to over-investigate and over-treat as a result of PBR as this would be financially beneficial. It is said that PBC will help to control this but again there are risks – what will happen to hospitals, for example, that under-provide?

The view from the Department of Health

The DH is trying to shift the balance of power in the NHS from the top downwards, ie from the government to the patient and

local community. Shifting services to the community is a government priority and is the subject of the recent White Paper, *Better services and more choice, on your doorstep*.⁵ The DH and the Royal College of Physicians are undertaking pilot studies to assess the effect of moving dermatology and rheumatology services out to primary care at two sites; the results will be published in about 18 months. One of the priorities is to increase the status of musculoskeletal services with PCTs since these disorders account for 60% of long-term sickness and 44 million GP consultations per annum.

Summary

The fast-moving changes in the NHS, particularly with respect to patients with chronic diseases, are a challenge and will have major financial and practical costs. For these changes to be successful the potential threat posed by PBR, PBC and CAB for smaller acute hospitals needs to be evaluated. Most importantly, bridging the primary and secondary care interface will be essential for the 'new' NHS to be successful. The shape of rheumatology in the future is also likely to depend on the national musculoskeletal strategy due to be published in the coming weeks.

References

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- 5 Department of Health. *Better services and more choice, on your doorstep*. London: DH, 2006.