



Implementing a patient-led service for chronic conditions

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Many chronic conditions with fluctuating levels of disease activity are traditionally managed by lifelong regular medical reviews. However, this means appointments do not always coincide with patient need, while the volume of reviews makes it difficult to respond quickly to requests for help. Research in rheumatoid arthritis suggests that hospital-initiated reviews can be replaced by patient-initiated reviews, supported by nurse-led initiatives.

Rheumatoid arthritis is a chronic disease with unpredictable repeated episodes of synovitis and joint pain, leading to joint destruction, disability, pain and fatigue. Daily unpredictability causes distress and helplessness, putting stress on relationships as roles and dependency change (Newman et al, 1996; Ryan, 1996; Perry, 1991).

Patients need the skills to manage their condition and helping them to develop these is a key nursing intervention. Other interventions by the multidisciplinary team include reducing pain, swelling and deformity, preserving function and maximising coping and self-management. Pharmaceutical interventions include anti-inflammatory drugs and disease modifying anti-rheumatic drugs.

Traditionally, patients are managed by routine medical reviews, initiated by the rheumatologist every 3-6 months. However, as the appointment is determined months in advance, patients are often reviewed when they are well.

Also, because of the number of rheumatoid arthritis patients being routinely reviewed, urgent requests for help in times of increased disease activity are difficult to accommodate. A patient experiencing a flare-up of their rheumatoid arthritis may therefore have to wait several

months for an appointment, while at the same time 35 per cent of routine medical reviews are deemed unnecessary by rheumatologists (Hehir et al, 2001).

Empowerment and facilitating patients' ability to self-manage are prime nursing functions and are known to be associated with improved outcome in rheumatoid arthritis, while patient self-management is a government objective (Department of Health, 2001; Ryan, 1999; Lorig et al, 1993). The development of rheumatology nurse specialists and consultant nurses, nurse-led telephone helplines and a randomised controlled trial (RCT) of nurse-led management indicate the potential for nurse-led care in rheumatoid arthritis (McCabe et al, 2000; Hill et al, 1994; Phelan et al, 1992).

A six-year RCT undertaken by the team tested patient-initiated review against traditional regular reviews initiated by rheumatologists (Hewlett et al, 2005). In the new direct-access system (DAS), regular rheumatologist-initiated reviews were replaced by patient-initiated reviews, accessed through a telephone helpline run by the rheumatology nurse specialists.

Decisions on the need for a medical appointment are made collaboratively by the patient and the rheumatology nurse specialists, and medical reviews are provided within 10 working days. Occupational therapy, physiotherapy or nurse reviews can also be

BOX 1. STEERING GROUP MEMBERS

Service role	Project role
Consultant nurse (SH)*	Project leader
Rheumatology nurse (DP)	Project nurse
Rheumatology nurse specialist (ST)	Manage helpline and reviews
Consultant rheumatologist (JK)*	Medical advice/collaboration
Clinic coordinator (WH)	Appointment bookings
Senior secretary (AB)	Administrative liaison
Patient representative (RN, SB, MU)*	Advice (education, literature)
*Previously involved in the RCT	

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requested via the helpline. The RCT showed that patient-initiated reviews reduce unnecessary medical reviews and make more efficient use of limited resources, while maintaining patients' physical and psychological status.

The RCT data also showed that patients and GPs were more confident about and satisfied with the patient-initiated review system, compared with routine follow-up. Given this evidence it was decided to implement a DAS as the normal clinical service for 700–800 patients with rheumatoid arthritis in the Bristol Royal Infirmary Rheumatology Centre. Results from RCTs need to be implemented within the context of local issues, therefore two important changes were made to adapt the RCT into clinical practice. The two-yearly research review was replaced by a rheumatology nurse specialist (RNS) review for any patient who does not request an appointment within two years, and an education session would be provided for patients entering the DAS system.

Implementation of research is notoriously difficult (Glasziou and Haynes, 2005) and in this case it clearly involved major changes in the working practices of the nurses, rheumatologists and administrative support staff and challenged beliefs about traditional practice. Such a major undertaking is best supported by having staff dedicated to manage the complex changes, so an application was made to the Foundation of Nursing Studies for a nurse to manage the implementation. The aim was to develop a robust DAS system and enrol approximately 400 patients, after which the smaller number of patients becoming eligible to enter the DAS as they reach two years' disease duration would be manageable within existing nursing resources.

Project management

Implementation addressed four areas:

- Setting up the clinic system;
- Designing a patient education session to prepare patients for the DAS;
- Establishing the helpline;
- Establishing the RNS review for patients who have not had a medical review for 24 months.

The implementation of any new service needs to involve the whole team in order to ensure all necessary issues are addressed and to enhance feelings of ownership. It is important therefore to ensure the steering group incorporates appropriate stakeholders (Box 1). Other team members were invited to specific meetings as necessary, for example the IT manager to assist with a new computer booking system and the hospital manager to discuss waiting lists. Meetings were initially monthly, reducing in frequency as implementation progressed, while the project manager and project nurse met weekly. All team members were invited

to contribute to all meetings and were given the opportunity to discuss any difficulties in their areas. Three months of organisation were necessary before patients could be enrolled in the DAS system.

Setting up the clinic system

The rheumatologist raises the subject of the DAS at the end of patients' routine medical consultations, records this in their notes and indicates that they are to enter the DAS on the standard outpatient request slip. Patients hand this slip to the clinic coordinator who amends the computer follow-up to the DAS, and enters their next appointment on to a two-year pending list. Patients are given an initial information sheet explaining the system, and booked into a DAS patient education session. The clinic coordinator offers them an immediate opportunity to discuss the DAS further with the clinic nursing staff. A GP information sheet and guidelines on managing rheumatoid arthritis are enclosed with the consultant's clinic letter.

Initially 2–3 slots on a routine clinic list were converted for use as DAS appointments (the appointments ran for 20 minutes). As more patients entered the DAS system these slots became oversubscribed and it became more difficult to meet the 10-working-day deadline. Additional clinic slots were then converted to the DAS. When the first consultant had converted two complete clinic lists to the DAS per week, most of his rheumatoid arthritis patients had been enrolled, and enrolment commenced for the next consultant.

Two major issues needed early consideration. First, medical staff's annual leave and public holidays had a major effect on our ability to provide appointments within 10 working days, particularly over Easter and spring bank holidays, which fall close together. In order to overcome this, one or two routine clinic lists needed to be temporarily used for DAS patients, but as routine clinics were booked six weeks in advance, this had to be planned at least 2–3 months ahead.

Another problem was that routine clinic lists often contained several slots allocated to new patients but when clinics were converted to the DAS, those slots were inadvertently lost and later had to be urgently reinstated.

Patient education session

The steering committee felt that patients joining the DAS required a specific educational intervention before entering the system. Based on 20 years' experience of patient self-management programmes in rheumatoid arthritis and in consultation with the patients on the steering group, the team designed a 90-minute session with four key objectives (Box 2, p30). An overview on the role of the rheumatology nurse specialist is also given as well as a short session on recognising and managing an

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BOX 2. DAS EDUCATION PROGRAMME'S OBJECTIVES AND OUTCOMES

Objective	Outcome (the patient will:)
Understand how the DAS operates and what to expect	Know some of the history of the DAS Know how the DAS system operates Know the helpline is available 9am-5pm, Monday to Friday Know they will be offered an appointment within 10 working days if required
Understand when and how to request an appointment with the nurse or doctor	Recognise the obvious and less obvious reasons why they may request a clinic appointment Understand how they request an appointment with rheumatology nurse specialist or doctor Understand that the DAS is not an emergency service, and when they should contact their GP or A&E Know they or their GP can use the helpline
Be able to use the telephone helpline	Know the helpline number Understand that the helpline is confidential and will only be heard by the rheumatology nurse specialist Understand that the helpline is not answered throughout the day and they will need to leave a message Know they must leave the date, time, full name, date of birth, contact number and a short message
Feel confident about using the DAS	Feel confident about using the telephone helpline and know how to request an appointment Be assured that they will be seen if they request an appointment Be aware that if they have not attended an outpatient appointment for 24 months they will automatically be followed up

inflammatory flare of rheumatoid arthritis. At the end of the session, patients are given a comprehensive DAS information leaflet, a business card with the helpline details and a prompt card on how to use the helpline (some patients are unaccustomed to answerphones and do not leave messages or forget to leave their name). The steering group patients attended the pilot education session and provided important feedback on the presentations and literature, which were acted upon.

The nurse-led education session is delivered to groups of 5-8 patients with partners or friends if desired. It is held two days a week in the patient education room within the rheumatology centre. Occasional early-evening sessions are held for patients who cannot attend during the day. Patients who decline to attend a session are contacted by the project nurse who explains that it is a prerequisite for joining the DAS or given a clinic appointment with the rheumatology nurse specialist who goes through the information on a one-to-one basis.

Establishing the helpline

The steering committee agreed a protocol for managing the helpline using published research and guidance (McCabe et al, 2000; RCN, 1999; Telephone Helpline Guidelines Group, 1995). The RCT data showed that the helpline nurse changed the outcome of the helpline calls in 26 per cent of cases, so it is

essential that the point of contact is clinical rather than clerical (Mitchell et al, 2004). Access to a recent letter sent to the patient from the clinic is useful to help the rheumatology nurse specialists to respond to calls, and it was agreed that these could be obtained immediately from the secretaries when a patient calls (accessing patient's notes takes 1-3 days).

The helpline is permanently connected to an answerphone/voicemail. Calls are checked each morning and evening (Monday to Friday, 9am-5pm) and returned within 24 hours. Other units may wish to consider out-of-hours responses if they have an inpatient ward. The answerphone system enables the rheumatology nurse specialist to plan when to return calls, allowing her to give patients her full attention, rather than having calls constantly interrupting the working day. It also enables her to consult members of the multidisciplinary team or review the patient's clinic letter before returning the call. The rheumatology nurse specialist records the nature of the call, any actions taken or advice given and the record sheet is photocopied for the patient's notes, ready for when they are subsequently seen in clinic. The helpline is situated in the rheumatology nurse specialist's office to provide privacy and medical and secretarial staff are situated nearby. With 420 patients on the DAS, the calls account for approximately two clinic sessions per week of the rheumatology nurse specialists' time.

Format of the nurse specialist review

Patients who do not request a medical appointment for two years are recalled for a rheumatology nurse specialist review. To ensure these patients are identified, on joining the DAS system patients are given a two-year 'pending' appointment, which is rescheduled each time they attend the clinic so the two years is always from the latest appointment.

The aims of the review are to:

- Check the patient's condition is well controlled;
- Review health status and function;
- Review medication, monitoring and side-effects;
- Ensure the patient can manage inflammatory flares;
- Refer the patient to other members of the multidisciplinary team as appropriate;
- Support the patient in managing and coping with a chronic illness;
- Ensure the patient understands the DAS system.

The project nurse and rheumatology nurse specialist discussed the review format with all members of the multidisciplinary team and the resulting review form guides the hour-long consultation. However, the rheumatology nurse specialist uses her judgement to move beyond the specified format if necessary.

Audit

Helpline calls over a six-month period were audited (n=382). The bulk of these related to inflammatory arthritis flares (45 per cent), drugs (32 per cent) and general advice (24 per cent), but many patients had more than one question. Only 62 per cent of the calls resulted in an appointment with the rheumatologist. Other patients were either given an appointment with their GP or the clinic's occupational therapist, rheumatology nurse specialist or physiotherapist, while some decided, in collaboration with the rheumatology nurse specialist, that they did not need an appointment (26 per cent). Clearly the helpline is being used for more than just requests for appointments with a rheumatologist, and it would not be appropriate for it to be run by a clerical member of the team.

Rheumatology nurse specialist two-year review appointments were audited (n=30). The rheumatology nurse specialist made no referrals for 16 of the 30 patients, while seven were referred to the rheumatologist, five to physiotherapy, five to X-ray, four to occupational therapy, four to podiatry and one to the self-management programme. Only three patients needed a reminder about accessing the DAS system more readily. Compared with 30 consecutive rheumatoid arthritis patients reviewed by the other rheumatology nurse specialists during routine outpatient visits, the data does not suggest that DAS patients coming for a two-year review are in greater need than those being regularly reviewed.

Waiting times for 40 consecutive requests for DAS

appointments were audited and only five were found to be outside the target of 10 working days. Of these, two patients chose a later day for their own convenience and one was due to clinics being cancelled over Christmas.

Implementation in other units

Members of the steering committee believe that a new system is best implemented by appointing a project nurse to drive the process. Some staff will be resistant to change and the system requires many professionals to change their practices and challenge their own beliefs about the need for routine review. It also challenges the confidence of patients about easy access to the system in times of need, when their previous experience has been that such access is difficult to organise and accompanied by long delays. The appointment of a project nurse was the key element in engendering a sense of ownership, teamwork and commitment and in reducing the workload caused by implementation for the rest of the team. The involvement of patient partners was crucial for their practical, common sense approach and ability to liaise with our patient advisory group.

Conclusion

Over two years 420 patients have been enrolled and the system is running efficiently. The seconded project manager has returned to her normal post in the rheumatology unit but continues to provide the DAS education sessions and act as a DAS troubleshooter. Patients continue to be enrolled into the DAS on a rolling basis, and this is managed within the existing nursing staff complement.

The implementation of the DAS has combined evidence-based practice with the introduction of nurse-led services, education, helplines and reviews. The system utilises the skills of the nurse as a patient assessor and adviser providing a vital point of contact for the patient, reducing unnecessary appointments and fast-tracking urgent ones. Some patients report that they manage problems for longer as they know rapid help is available through the DAS and that they feel more empowered. Such perceived benefits need exploring using qualitative research methodology.

Patient-initiated review is a system that could be tested in a number of other chronic diseases, both within rheumatology, such as psoriatic arthritis, and other specialties where control is currently primarily held by the hospital medical team, such as inflammatory bowel disease. The DAS ensures timely care during episodes of urgent need, such as a flare-up of the disease, and reduces the number of routine but unnecessary reviews, thus reducing NHS costs. Implementation of such a radical change requires commitment, teamwork and enthusiasm, as well as a dedicated project nurse, but the benefits for patients and staff are significant. ■

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