

USING PATIENT ONLINE IN INFLAMMATORY ARTHRITIS

RCGP, 2018

Purpose of this document

This guidance is for GPs and practice nurses caring for patients with inflammatory arthritis. The aim is to describe how access to GP online services contributes to person-centered care in this context and to present the case for recommending online record access to patients with inflammatory arthritis.

It describes how you can help them make use of GP online services to access information about their healthcare to improve their ability to understand and self-manage their condition and help to coordinate their care. It also describes how patients can make use of online access to see test results and other health information to prepare for consultations and empower them to be more engaged in their own care.

This guidance does not seek to cover aspects of shared care but its aim is to help the patient become more engaged and informed by utilising online services. Therefore, for clinical management please refer to your local shared care agreement and NICE guidelines.²

Inflammatory Arthritis in the UK

Rheumatoid arthritis (RA) is a chronic, progressive autoimmune disease associated with inflammation principally of synovial joints that affects over 400,000 people in the UK. Psoriatic arthritis is a similar autoimmune condition, which affects up to 156,000 people in England and Wales.¹ This guidance focuses on these two conditions but the principles can be applied to any inflammatory arthritis.

The life expectancy of people with RA is 5-10 years less than the general population. About 50% of this early mortality is due to cardiovascular disease. RA also causes significant morbidity. Approximately one third of people have to give up work because of the disease within two years of onset. The total cost of RA in the UK, including indirect costs and work-related disability, has been estimated at between £3.8-4.75 billion per year.²

Early hospital referral is usually indicated and confirmation of the diagnosis and initiation and supervision of disease-modifying antirheumatic drugs (DMARDs) are usually the role of secondary care. Around 95% of patients will be on at least one of these medications and will require regular and careful monitoring. Once stabilised on treatment, patients on DMARDs need frequent monitoring for adverse effects. This is usually carried out in primary care, in line with local shared care agreements.² The primary care team are responsible for on-going prescribing of DMARDs

and regular, reviews (usually annual) which are part of the Quality and Outcomes Framework in England at the time of writing.³

The role of Patient Online in inflammatory arthritis care

The role of Patient Online is a supportive one in inflammatory arthritis. Inflammatory arthritis can be very complex and vary significantly from patient to patient. Some patients may need frequent visits to the hospital, numerous bloods tests, scans and investigations; for some the condition may be stable and hospital and general practice attendances may be infrequent. This variation in the condition requires individualised care for every patient and Patient Online can aid each patient.

With online record access patients can have key information about their health at their fingertips. With detailed coded record access, they can read their latest test results and look at trends if the Patient Online system they use has that functionality. GPs in England have a contractual requirement to make this offer and provide this to patients. Practices can also offer access to the full medical record but this is optional. It gives access clinical correspondence and consultation notes.

Online access to book and cancel appointments and order repeat prescriptions is a benefit to all patients with inflammatory arthritis. They can

all benefit from record access as well, particularly those patients who have complex disease or co-morbidities and may struggle to keep up to date with or understand their health needs and healthcare.

Detailed coded record

Experience has shown that the first thing that patients do when they get Patient Online record access is to check the accuracy of their record. Knowing that the information their GP holds about them and makes available to others is accurate, can help the patient feel confident that those making vital decisions about their care are well-informed and there is no need for the patient to keep explaining their history. This is particularly important when patients have complex conditions such as RA, where shared care is common and the accuracy of prescribing records and adverse drug reactions is essential.

They may find information that they disagree with. They may also want to add something to the record, such as a missing allergy or adverse drug reaction. It helps to make it clear to all patients when they apply for record access that the practice is willing and ready to discuss their reaction to the record and receive requests for changes. The practice is not obliged to change the record or add data at the patient's request, but it is reasonable to make a note of the patient's opinion in their record if a patient request is denied.

There is more information on data quality in the toolkit. There is also advice on how to manage data which may upset or harm the patient, or data that

is confidential information about a third party.

Health literacy

It can be time consuming to help patients improve their health literacy. Using tried and trusted techniques such as "chunk and check" and "teach back" to explain important terms in the record can help. Patients can use their detailed coded record as a list of terms to learn about and understand their condition. By encouraging patients to engage with their own health record, they are more likely to become inquisitive and engaged with their diagnoses, investigations and treatments that they identify within the record itself. This also allows them to engage with other aspects of their health not directly related to their inflammatory arthritis.⁴

Latest blood test results

Blood tests are used to monitor side effects of DMARDs and disease activity to help identify flares of their condition. Many patients like to monitor their latest blood test results. Responsibility for recall, taking the blood samples and ensuring that actions required by the results are carried out lies with health care professionals, in line with an agreed local shared care agreement, but the test results for DMARD monitoring are few and easy to explain to a patient. Providing a paper list of the results that require action helps (see table below) and patients often learn to interpret their test results.

There is more information in the Explaining Test Results guidance and a patient leaflet explaining Abnormal Test Results in the toolkit.

DMARD monitoring test abnormalities requiring action
White cell count below $3.5 \times 10^9 / l$
Neutrophils below $1.6 \times 10^9 / l$
Unexplained eosinophils above $0.5 \times 10^9 / l$
Platelet count below $140 \times 10^9 / l$
Mean cell volume above 105 f/l
Creatinine rising more than 30% over 12 months and/or calculated GFR below 60 ml/min/1.73 m ²
ALT and/or AST above 100 U/
Unexplained reduction in albumin to less than 30 g/l

Table 1: Laboratory Abnormalities requiring action⁵

Trends in blood test results

Both the British Society of Rheumatology and NICE suggest that trends in test results in inflammatory arthritis are as important as the latest absolute value.^{5,2} as well as responding to absolute values in laboratory tests, it is also relevant to observe trends in results. A gradual decrease in white blood cells or gradual derangement of liver function tests, while still within the normal reference ranges, may be significant. Although not all Patient Online systems have the functionality to display result trends, they do allow patients to copy their results and watch for trends that may indicate a problem. This can improve the patient's self confidence in their understanding of their condition and treatment and confidence in their health professionals. It can help them to prepare for consultations and engage more effectively with secondary and primary care during a flare. A recent study has also shown that patients tend to present less frequently to primary care and secondary care generally when they have access to their own health records and results.⁶

GP2GP

When patients move and change practice all their coded blood test results from their previous practice remain available through Patient Online as long as the record from their old practice is transferred by GP2GP. The patient can use their smartphone or tablet to access their Patient Online account and share their results at the hospital. This is better than using a hospital computer which may record their Patient Online log in details and is becoming easier with the advent of public wifi in the NHS.⁷

There is more about the impact of changing practice on the detailed coded record available to patients via Patient Online in the Detailed Coded Record guidance in the toolkit.

Person-Centred Care and Patient Online

Patients are interested in more than their blood test for monitoring their disease and treatment. Box 1 shows a summary of the information that a patient with inflammatory arthritis may be particularly interested in. Patient Online record access allows patients to review their health information and identify the thing that matters to them about their inflammatory arthritis and related risk factors. Being in possession of information before the consultation helps them

Box 1: Summary of information relating to inflammatory arthritis

Detailed coded record

- Diagnoses and problem lists
- Complications of the arthritis or its treatment
- Major procedures and investigations related to the arthritis
- Lifestyle records: exercise, smoking and alcohol consumption
- Employment and disability details
- Examination results: height, weight, body mass index, blood pressure, joints
- Test results: Full blood count, inflammatory markers, lipid profile, blood glucose, urine albumin-creatinine ratio and renal function
- Codes relevant to management of the arthritis including last review dates and personal preferences
- Codes relating to other risk factors, e.g. cardiovascular risk
- Records of health promotion activities, such as screening and immunisations
- Allergies and adverse reactions
- Current and past prescribed medication

Full medical record

- Relevant referrals and hospital reports and letters, including radiology reports
- Consultation notes and full care plans

Information for patients with RA on test results and care plans

1. [Laboratory tests used in the diagnosis and monitoring of rheumatoid arthritis](#)
2. [Cardiovascular risk and RA](#)
3. [UK Lab Tests Online UK](#)

focus on what matters to them, ensure that they discuss them with their health professional, take a more active part in making decisions about their care and remember advice that they are given.

It may be that time has to be spent explaining the information that they have seen in their records but the time is well spent in boosting their health literacy.⁴

The RCGP Person-Centred Care Network recommend a proactive care planning model (also referred to as Collaborative Care and Support Planning and Primary Care Support Planning).⁴ Its aim is to give people with long-term conditions more control of their health by allowing them to focus on what's important to

them. The core aim is to transform the current fragmented 'tick box' review into a constructive and meaningful interaction between those with technical expertise (health professionals) and those with lived experience (patients) allowing the interaction to focus on what matters to them. The model is illustrated in Figure 1 and represents an iterative approach to care.

The model proposes that patients bring their experience and reflection on their self-management of their arthritis and co-morbidities, including information from self-assessment tools such as the DAS28, and interaction with healthcare services to the consultation. The patient is able to use their reflections about them to prepare for a review consultation. They can think about their priorities and decide what they want to achieve in the consultation.

For patients with inflammatory arthritis or any long-term condition, Patient Online can add another dimension to their preparation. Prior knowledge of test results enables patients to focus on the results that present a problem. The clinician does not have to go through the blood results in detail. With less new information to absorb patients find it easier to remember the key information and advice given to them. This empowers them to participate more fully in decisions about their care and take greater

ownership of their long-term condition.

The next step is to record the consultation. If all the important facts, decisions, plans and targets agreed during the consultation are coded, the patient with online access can review at any time. They may use the information as an aide memoire, as encouragement to improve their self-management of their arthritis and in future consultations in the practice or at the hospital.

In summary, from a patient online perspective, the consultation review takes the same form as that shown in Figure 2. The initial GP consultation may signpost the patient to Patient Online, agree a number of objectives or targets, and update the coded record with data relevant to that review. The patient can then view their coded record at any time, view previous results or other coded information. They are then able to make comparisons and analyse trends in their results. If a patient sees particularly concerning results or is having a flare, they can discuss this directly with the specialist team.

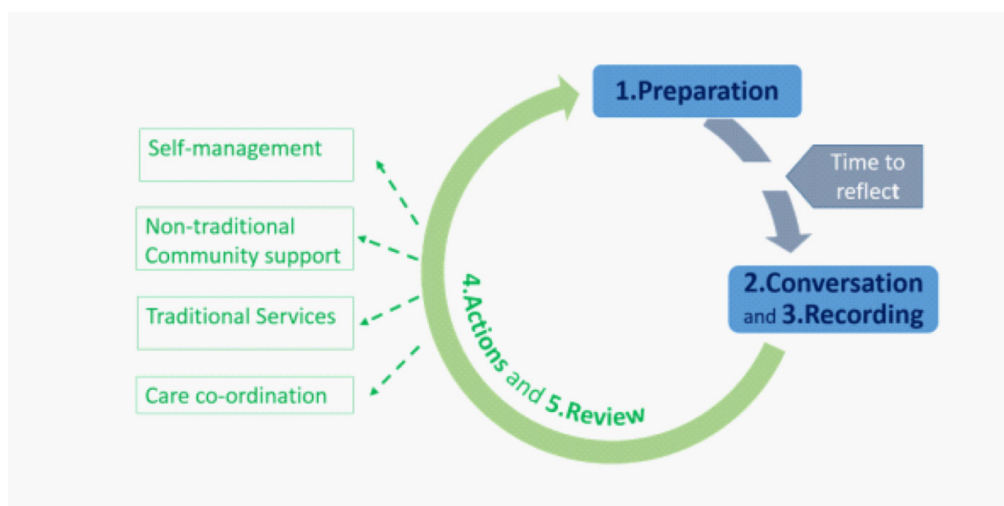


Figure 1: Person-centred consultation

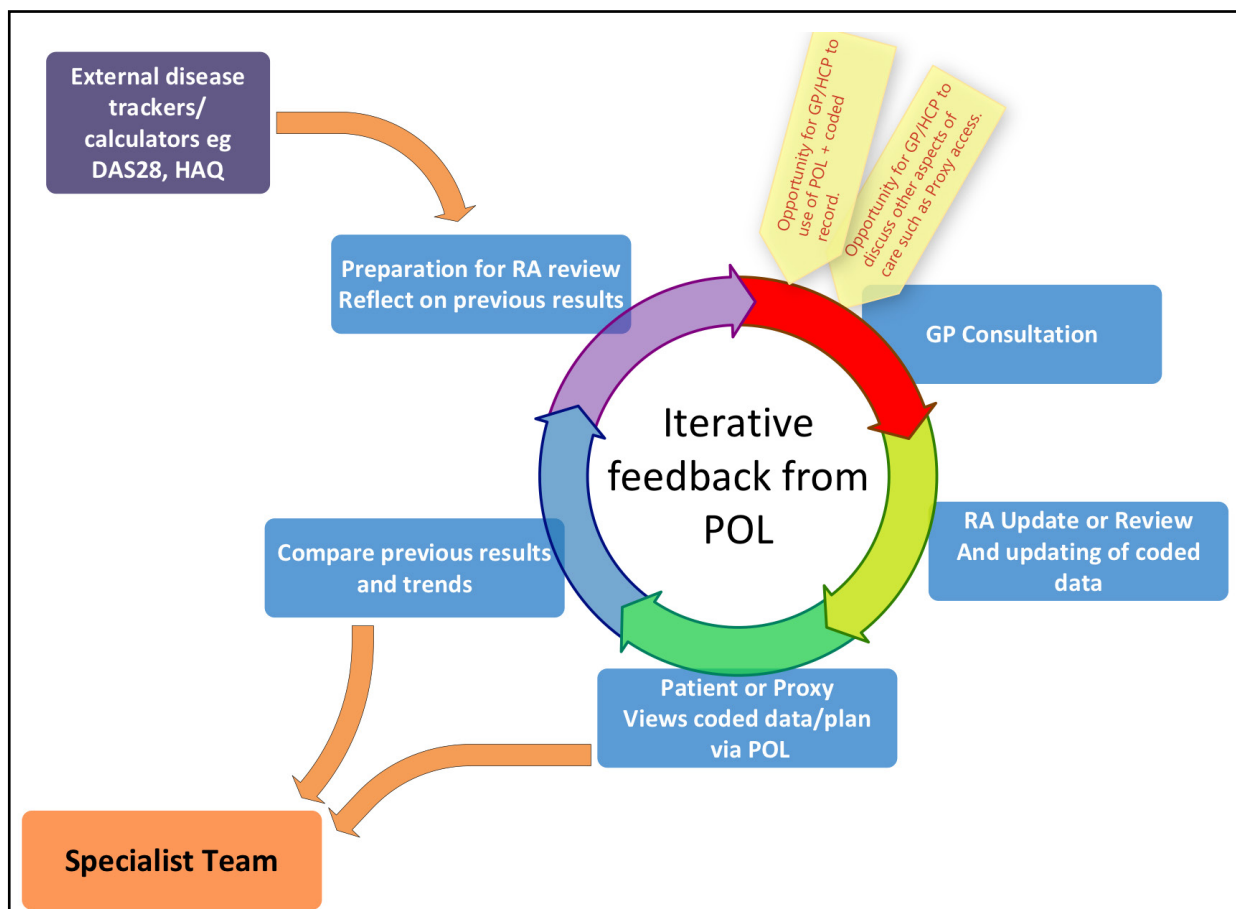


Figure 2: Patient Online iterative review process

Summary

This document has shown how Patient Online record access can be useful in inflammatory arthritis to patients, the practice and hospital specialists. It supports person-centered care through iterative feedback of health information to the patient.

Clinical Scenario

Andrew Dawson is a 61-year-old man who takes methotrexate for rheumatoid arthritis. He has a background of hypertension and chronic kidney disease.

He has to have regular blood tests because he takes methotrexate and he would like to have online access to his detailed coded record to monitor the results of the tests. He thinks that he would find it reassuring to have all the latest results available at any time and to keep an eye on the results so that he knows when to contact the practice or his rheumatology team.

This is an opportunity for the practice to recommend the other benefits of Patient Online, while making sure that he understands how to protect his online access to maintain his privacy and access his detailed coded record. To monitor his methotrexate, it is important that Andrew look at the CRP, ESR, white cell, neutrophil, eosinophil and platelet counts, MCV, AST or ALT, creatinine and eGFR. To help him understand the meaning of the test, he can be directed to resources such as [Lab Tests Online UK](#) or the [National Rheumatoid Arthritis Society](#).

Over the next couple of months, Andrew continues to monitor his condition and appears to be developing a flare so contacts his rheumatology specialist team who direct him to have blood tests carried out at his practice. His GP contacts him to let him know that his inflammatory markers are raised and to contact his specialist team. His team is out of area and so Andrew uses Patient Online to print his recent results to take with him to his rheumatology appointment.

Note: Whilst it can be useful to patients to have online access test results used to assess flares of their arthritis, this should not change the usual care of flares (specified in local shared care plans and/or NICE guidelines.²

Nearly a year later Andrew is due for his annual review and has had a repeat set of bloods taken including cholesterol. He has not had any problems with his rheumatoid arthritis for nearly 12 months and it's now well controlled. He looks through his record before the appointment with his GP for his review. The review then takes place as previously outlined. Andrew looks through his coded data, understands that his arthritis is stable, but notices that his cholesterol is rising. This prompts a discussion with his GP at the review regarding his cardiovascular risks and a statin is then introduced. The process is summarised in Figure 3.

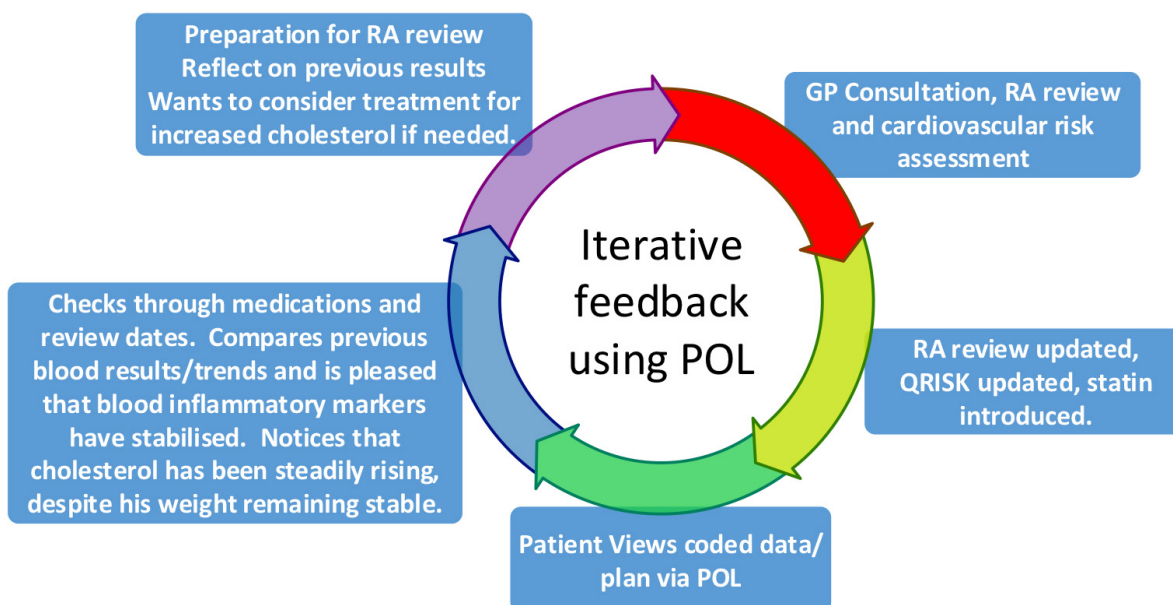


Figure 3: Clinical scenario

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