General Election 2015

10 things the next Government can do to help people with rheumatoid arthritis
About us

The National Rheumatoid Arthritis Society (NRAS) is ‘the voice’ of people affected by Rheumatoid Arthritis (RA) across the whole of the UK. Founded in 2001, we are the only UK charity devoted specifically to RA, and in July 2014 we launched a new service for families, children, young people and adults affected by Juvenile Idiopathic Arthritis (JIA).

RA is a chronic, progressive and disabling disease where the immune system attacks the synovial lining to the joints and other organs. If left untreated, the joint can lose its shape and alignment, cause bone erosion and ultimately lead to destruction of the joint and permanent disability. It is a systemic disease, which means it can also affect internal organs of the body such as the heart, eyes and lungs.

The purpose of this manifesto

It is part of NRAS’s core charitable aims to campaign for improvements to public services for people with RA.

In the run up to the General Election, and beyond, we want to strike up a conversation with policymakers, our members and the wider public about opportunities that exist to further improve RA services.

This manifesto has been designed as an aide-memoire to help inform discussions between the charity’s supporters and policymakers. You can help us to spread our message by doing the following:

- Contact your local parliamentary candidates using our template letter: www.nras.org.uk/2015manifesto
- Attend constituency meetings with your parliamentary candidates to discuss this manifesto and give them a print out of this document.

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1. Early Diagnosis

There is a ‘window of opportunity’ for people with RA. Those diagnosed and started on optimal treatment within 12 weeks of symptom onset are more likely to achieve remission and minimise joint damage. Yet most are not diagnosed and treated in time.

Poor public awareness and a lack of GP knowledge are the two biggest factors contributing to late diagnosis. People with symptoms tend to wait months before going to see their GP and then visit their GP several times before being referred to a specialist for diagnosis.

Whilst serious problems remain, levels of GP education about RA have improved over the last 20 years. Meanwhile, major research conducted in the UK between 1995 and 2005 suggested that public awareness of RA had not improved over the last decade.

More recently, the National Audit Office, the UK Public Accounts Committee and the King’s Fund health thinktank, have all produced reports confirming that poor public awareness is a major problem and calling for further action to be taken.

The problem is so severe that the National Clinical Director for Musculoskeletal Conditions says, “poor public awareness is now the number one challenge to improving clinical outcomes for RA.” Public Health England has just commissioned a pilot, which needs to go further.

Early diagnosis also benefits society. The National Audit Office says that doubling the proportion of RA patients that receive optimal treatment within the 12 week ‘window’, from current levels of 10% to 20%, could generate economic gains of £31 million over 5 years.

We call on the next Government to introduce a national public awareness campaign and double early diagnosis rates within 5 years.
2. Clinical Commissioning Group Outcome Indicator

The Clinical Commissioning Group Outcomes Indicator Set (CCG OIS) is an important policy framework that examines the quality of local services commissioned by Clinical Commissioning Groups (CCGs) in England.

The CCG OIS contains performance indicators, which contribute to the aims of the 5 domains of the NHS Outcomes Framework (another NHS quality framework), and can be derived from NICE Quality Standards.

These indicators matter because they help CCGs and Health and Wellbeing Boards to identify local priorities and to demonstrate progress made by local commissioners against agreed outcomes.

A NICE Quality Standard for RA was published in June 2013 and 5 potential RA indicators were considered by NICE’s CCG OIS Committee in October 2013, but none were put forward for testing.

The potential indicators discussed included: the proportion of people with RA attending rheumatology units within 3 weeks of referral; the proportion receiving combination therapy within 6 weeks of referral; and the proportion with a Disease Activity Score (DAS) of 2.6 or under.

NICE’s CCG OIS Committee justified its decision by saying it believed these indicators were covered by incentives, such as the Best Practice Tariff for Early Inflammatory Arthritis (BPT), or that data was only available locally, or that it was not possible to measure wider quality.

This is a missed opportunity to align incentives in the CCG OIS with the Best Practice Tariff on Early Inflammatory Arthritis and focus the attention of commissioners on helping people with RA achieve DAS remission.

We call on the next Government to devise a CCG Outcome Indicator for RA that is synchronous with the NICE RA Quality Standard.
3. Commissioning for Quality & Innovation Payment

Commissioning for Quality & Innovation payment (CQUIN) payments are a form of NHS financial incentive that enable commissioners to reward local healthcare providers who achieve agreed healthcare goals in England.

This type of lever is supposed to incentivise providers to deliver quality and innovation improvements beyond the basic requirements set out in the NHS Standard Contract. Under the rules, commissioners can pay a provider up to 2.5% of the contract’s value.

A Halifax Summit on RA, held in November 2012 with local experts, noted insufficient incentives for local health services to tackle RA. Participants felt a CQUIN examining Disease Activity Scores (DAS) might address this problem.


In April 2014, the Royal National Hospital for Rheumatic Diseases NHS Foundation Trust became one of the first healthcare providers to enter into a CQUIN for RA self management programmes.

However, these developments are the exception to the rule, because no best practice CQUIN for RA or Inflammatory Arthritis has been devised.

A coherent incentives framework could be created by aligning CQUIN payments with NICE Quality Standard measures and the Best Practice Tariff on Early Inflammatory Arthritis.

We call on the next Government to create a template Commissioning for Quality & Innovation (CQUIN) payment for Inflammatory Arthritis.
4. Best Practice Tariff

Best Practice Tariffs (BPTs) are another form of financial incentive aimed at encouraging best practice across NHS services in England.

When creating a BPT, the Department of Health (DH) tries to structure and price it to incentivise high quality and cost effective care.

The DH first introduced BPTs in 2010/11 and continues to support their use. The range of BPTs has grown over time and a BPT for Early Inflammatory Arthritis (EIA) was introduced in April 2013.

There are 3 levels of payment: level 1 - for patients referred to rheumatology services with suspected EIA, which is ruled out; level 2 - for patients referred to rheumatology services with suspected EIA, which is confirmed and appropriate treatment is initiated; level 3 – for patients who proceed to biologic therapies within the first year of diagnosis.

The BPT matches the NICE Quality Standard, which stipulates that time between GP referral to specialist diagnosis should be no more than 3 weeks and that DMARD treatment should start within 6 weeks of referral.

Providers can choose not to implement the BPT, but are supposed to be no worse off financially if they do. If they choose not to then the provider will continue to be paid the agreed price for first and follow up attendances.

Audit Commission evidence suggests BPTs can lead to service improvements, particularly if paired with public reporting. However, this does not routinely happen at the moment. We need comparative data to judge the BPT’s effectiveness and enable improvements.

We call on the next Government to review the Best Practice Tariff on Early Inflammatory Arthritis and make public reporting compulsory.
RHEUMATOID ARTHRITIS IN NUMBERS

580,000 people affected in England

3 x more common in women than men

26,000 new cases of RA per year

Each year RA costs the NHS £560m
5. Strategic Clinical Network

Strategic Clinical Networks (SCN) exist to bring together commissioners, providers and service users to help improve commissioning, encourage innovation and reduce variation in services.

SCNs are hosted and funded by network support teams at NHS England, which cover 12 geographical areas. SCNs are supposed to cover conditions or groups of patients that fulfil 9 assessment criteria, such as the belief that improvements can be best achieved through an integrated, whole system approach.

The first 4 SCNs were announced in July 2012 and cover: Cancer; Cardiovascular Disease (including cardiac, stroke, diabetes and renal disease); Maternity and Children’s Services; and Mental Health, Dementia and Neurological Conditions.

Shockingly, Musculoskeletal (MSK) disorders are not covered by any of these SCNs. This is despite the fact that MSK accounts for more than £5bn of NHS spend each year, with the latest Global Burden of Disease study ranking MSK as the single biggest cause of disability in the UK.

To try and bridge the gap, with limited support from DH and NHS England, the Arthritis and Musculoskeletal Alliance (ARMA), is trying to develop MSK Clinical Networks (MCN) by identifying good practice within the sector and using this to inform the design of future MCNs.

The ARMA project is innovative, but to enable widespread and long lasting change, the MSK community believes that further ongoing central funding, support and evaluation is required which could best be provided through creating a dedicated SCN for MSK.

We call on the next Government to create a Strategic Clinical Network for MSK disorders.
6. Joint Strategic Needs Assessments

Musculoskeletal (MSK) disorders pose a significant, growing risk to the health of the UK population, which requires urgent action.

Each year 7.5 million working days are lost due to MSK and by 2030 the number of people living with arthritis is expected to increase by over 50% amongst the over 65s.

However, despite these obvious impacts there is comparatively little data published about MSK disorders within local authority joint strategic need assessments (JSNAs), which are the main strategic documents that assess and predict future local health needs.

In 2011, the Chief Medical Officer for England went on record as saying that, “national data on the full extent and impact of some musculoskeletal diseases are often difficult to obtain.”

The suggested JSNA core dataset produced for local authorities by the Association of Public Health Observatories contains just 1 measure for MSK – admissions for hip and knee replacement.

In addition, neither the Local Government Group’s Joint Strategic Needs Assessment: Data Inventory guide, nor Public Health England’s new Data and Knowledge Gateway contain datasets on MSK.

The lack of data about the health burden posed by MSK and the lack of agreed outcome measures are causing it to be overlooked by local authorities when they undertake strategic health planning. This needs to stop.

We call on the next Government to develop an MSK core dataset for JSNAs and issue new guidance on coverage of MSK within JSNAs.
RHEUMATOID ARTHRITIS IN NUMBERS

RA costs the wider economy £4.75bn per year

Sickness absence and worklessness due to RA costs £1.8bn a year

40% of people with RA lose their job within 5 years of diagnosis

Doubling early diagnosis could save £31m in productivity over 5 years
7. Self Management

Long term conditions (LTCs) account for 50% of all GP appointments and it is estimated that around 70% of the total health and care spend in England is attributed to caring for people with LTCs.

At the same time, we have an ageing population, with the proportion of the population over the age of 65 in England increasing due to rising life expectancy. This in turn is leading to an increase in the number of people living with 1 or more long term conditions.

Patients with LTCs have a small amount of scheduled time to spend with their healthcare professionals during the course of a year. To maximise clinical outcomes it makes sense to consider how patients look after themselves (self manage) during their daily lives.

Self management is defined as ‘involving (the person with the disease) engaging in activities that protect or promote health, monitoring and managing the symptoms and signs of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes’.

Evidence suggests that patients who effectively self manage have better health outcomes and use less healthcare - with noticeably fewer unscheduled, expensive hospital admissions. Research by Self Management UK concluded it can generate cost savings of £1,800 per patient per year.

We believe that all patients with a LTC should have the right to receive self management support to help optimise their health outcomes. However, the NHS Constitution is the principle document setting out these patient rights and there is currently no reference to self management within it.

We call on the next Government to make access to self management support a fundamental right within the NHS Constitution
8. Prescription Charges

Many people with long term medical conditions still have to pay for the prescriptions they need to stay well. Whilst RA treatment is free, people with RA frequently need prescriptions for associated health problems.

The NHS list of medical exemptions to prescription charges in England was drawn up in 1968. Since then, people with some conditions, such as epilepsy and diabetes, have received all of their prescriptions free of charge. Since 2009, cancer patients also have free prescriptions.

Meanwhile, people with autoimmune diseases such as RA still have to pay the same charges as everyone else for many of their prescriptions.

A 2013 survey by the Prescription Charges Coalition of 4,000 people with long term conditions in England found that people are sometimes having to choose between paying for food, clothing, bills or their prescriptions.

Some people are stopping or rationing their medicines because of an outdated and arbitrary system. Charging is also short sighted as it makes it more difficult for people to manage their conditions effectively, leading to more severe health problems and extra costs to the NHS.

We call on the next Government to include RA within the list of medical exemptions to prescription charges
9. Progressive Conditions

The Employment and Support Allowance (ESA) is the primary welfare benefit for people who are ill or disabled that require financial support because they cannot work, or need support to return to work.

To get access to the benefit, claimants have to undergo a Work Capability Assessment (WCA) and are then placed in the Work-Related Activity Group (WRAG), the Support Group, or are found fit to work.

ESA matters because many people with RA are diagnosed whilst of working age and need support. Indeed, over a quarter of people with RA stop working within 1 year of diagnosis and over half within 6 years.

A diagnosis of RA does not automatically mean someone cannot work, but work disability usually increases with disease duration. ESA claims are thus often a last resort, when symptoms have become too severe.

Currently, the WCA makes no allowance for people with ‘progressive conditions’, i.e. people who have a condition that is incurable and that is likely to only get worse over time.

NRAS research found that around 44% of new claimants with RA were placed in the WRAG between 2008 and 2013 and expected to take steps towards employment, with only 25% put in the Support Group.

This means people with RA are often needlessly reassessed, which incurs unnecessary costs to the tax payer and emotional distress to the claimant.

The Work and Pensions Select Committee also noted problems and called for reduced reassessments for claimants with progressive conditions and fewer WRAG placements for those whose prognosis is unlikely to improve.

We call on the next Government to publish progressive conditions guidance to cover Support Group access and reduced reassessment
10. The 20 Metre Rule

The Personal Independence Payment (PIP) has replaced the Disability Living Allowance (DLA) as the welfare benefit for working age people who need help with the costs of long term ill-health or disability.

The benefit is split into 2 parts: a daily living component and a mobility component. To qualify for either component claimants must be assessed.

People with RA are likely to want to claim the PIP higher rate mobility component, because 90% have a foot pathology that restricts mobility and may result in foot operations, ankle fusions, and hip replacements.

However, the eligibility criteria to gain access to higher rate mobility component has been reduced from 50 metres under DLA to 20 metres within PIP. This means that if a claimant is able to stand and move more than 20 metres, with or without an aid, they will no longer be eligible.

NRAS is very concerned about the restricted eligibility criteria for the PIP higher rate mobility component. As RA is a fluctuating condition, the new criterion makes it less likely that RA claimants will get the right support.

Many people with RA will lose support received under DLA, including access to the Motability scheme, which gives access to an adapted vehicle to travel around. NRAS research suggests 34% of RA claimants with a current vehicle will have to give up work if they lose the higher rate.

No clinical justification has been provided for this change. 50 metres is established as a standard distance in other disability guidelines, such as building regulations. Ability to mobilise over 50 metres or less also remains the eligibility criteria for the Employment and Support Allowance.

We call on the next Government to change the Personal Independence Payment’s unfair 20 metre rule back to 50 metres.
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