Response to Better Health, Better Care – A discussion document

By the National Rheumatoid Arthritis Society

Introduction

The National Rheumatoid Arthritis Society is the only patient-led organisation specifically focussing on the needs of people with Rheumatoid Arthritis (RA) in the UK. There are approximately half a million people with RA in the UK, including approximately 52,000 adults with RA and some 1000 children under the age of 16 with the juvenile form of the disease (Juvenile Idiopathic Arthritis) in Scotland.

We welcome the opportunity to contribute to the discussion document, Better Health, Better Care and also that the Scottish government and NHS Scotland have confirmed their commitment to working with the voluntary sector to better reflect and respond to the individual needs of people with long term conditions such as RA.

NRAS is an active member of the Long Term Conditions Alliance Scotland and we have members and volunteers across Scotland as well as Scottish Medical and Allied Health Professional Advisors who all work in partnership with us to represent and support the needs of people with RA and JIA in Scotland.

Our Response

Whilst we enthusiastically welcome all the new opportunities to enhance anticipatory care outlined in your Framework for Discussion, our response will focus on our area of interest in relation to this paper – Long Term Conditions – and specifically on rheumatoid arthritis.

We know that early referral to a consultant rheumatologist to get a diagnosis, rapid introduction of disease modifying therapy (window of opportunity) and tight control of the disease, particularly in the very early stages, produces better long term outcomes $^{1,2,3,4}$.
We know from our contacts with people with RA in Scotland and from our interaction with rheumatology health professionals that early diagnosis, prompt initiation of DMARD therapy and tight management of disease is not always being achieved in our current models of care. The reasons for this are many and complex, however when considering new models of care with the possibility of a greater proportion of care being delivered in the community, the question is how can we work with primary care clinicians to ensure that comprehensive care can be delivered in a viable way that maintains the expertise that patients really need to improve their long term outcomes and enable them to live a productive and satisfying quality of life.

NRAS is not against a greater level of care being delivered in the community but the emphasis must be that the patient receives the right care at the right time from the right health professional (i.e. one who has the expertise to manage not only the basic day to day reviews but is able to identify individuals who require changes in treatment or aggressive management to improve long term outcomes, rather than applying a general holding approach to care – which in the end will result in poor long term outcomes for many patients).

When considering service re-design, the unique circumstances of inflammatory arthritis patients need to be properly understood by the commissioning organizations, some of whom seem to us to be demonstrating a lack understanding about appropriate treatment pathways for patients with inflammatory arthritis and how their needs fit into their approach to achieving new ways of service delivery.

Patients require specialist expertise to manage a wide range of needs relating to this complex disease (including assessment of cardiovascular risk and other co-morbidities on an annual basis). Additionally, although it is recognised that GP's with a Special Interest play a vital and important role in rheumatology services, there are few in Scotland and they have limited, if any, specialist nurse or allied healthcare professional expertise that matches that currently provided within specialist units. In many areas successful models of local shared care protocols have been developed with GPs generally providing a ‘monitoring’ service for regular blood tests although this is not the case in all areas.

If we look at how care of other long term conditions has been organized in Scotland we can see some good examples of where long term conditions such as diabetes and heart disease have been very successfully managed in primary care. The reason for this success is because the disease area has been made a national priority by government and legislation has been introduced along with the necessary funding to ensure implementation. Extensive training of primary care health professionals has also been at the heart of these initiatives.

If one considers for a moment, inflammatory autoimmune diseases of which rheumatoid is the most common, no such national priority, legislation,
funding or training has taken place and yet, in spite of GPs not wishing to suddenly find themselves treating a group of patients they don’t have the expertise or knowledge to treat, reforms are going in that direction with all long term conditions, irrespective of the fact that they do not all require or have the same level of resource. GPs and primary health care teams are being asked to do an ever increasing amount of work which seems to be unachievable and unsustainable.

Community expertise in Long Term Conditions
What are the benefits?

| Asthma Disease Pro-Active Management | Cardiac Disease Management | Diabetes Pro-Active Management | Inflammatory Arthritis
| Annual review/recall resulting in | Regular monitoring & prescribing resulting in | Recognition of co-morbidities risk resulting in | No Nurse Training resulting in
| Define risk groups | Define risk groups | Define risk groups | Minimal Data Collected
| Better outcomes | Costs to prescribing recognized | Treatment for co-morbidities (cholesterol etc.) access to services | Fail to recognize co-morbidity/risk/needs

We need to ask: What can primary care currently do for rheumatoid arthritis? How can they pro-actively support people with RA and deal with their problems and queries when they need advice and/or treatment for flares and/or side effects, or for example, if they get an infection when on immunosuppressive drugs? There are currently no incentives to encourage GPs to extend their knowledge and expertise for this specific group of patients. With increasing use of the new biologic therapies, we also need to ask how will they monitor/counsel and advise patients on Anti-TNF or other biologic therapy.
We hope that this response will make clear that whilst we welcome the opportunity and challenge which new forms of service delivery bring, especially where we can improve on what is currently happening, it is extremely important that the needs of people with specific diseases such as RA will be understood in the whole context of long term conditions where there is a huge difference between treating a 70 year old with osteoarthritis and a 20 year old with RA who needs rapid access to specialist care, support to remain in work and likely access over time to a range of biologic therapies.

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References