RHEUMATOLOGY SERVICES FOR NORTHERN NHS HIGHLAND

Report by Dr Malcolm Steven and Dr John Harvie, Consultant Rheumatologists’, Gill McVicar, General Manager, Mid Highland CHP and Alison Mackay, Project Manager on behalf of Elaine Mead, Chief Operating Officer

The Board is asked to:

- Note the proposals to redesign NHS Highland rheumatology services.
- Approve the direction of rheumatology services for NHS Highland.
- Endorse the proposed redesign process.

1. Summary

A review of NHS Highland rheumatology service was initiated in 2008 to cope with pressures resulting from new national standards of care including rapid access to specialist care for patients with suspected rheumatoid arthritis, to safely administer new ‘biologic’ treatments and to meet new waiting time targets.

The review identified deficiencies and recommends the initial steps to develop a hub and spoke service emphasising quality and safety while encouraging self management, equity of access to appropriate levels of care and where appropriate to deliver care closer to patients’ homes.

In NHS Highland

The key recommendations are:

- The continued availability of a seven day inpatient facility at Highland Rheumatology Unit and access to medical beds at Raigmore Hospital for complex cases.

- Establishment of a rheumatology day case/infusion service in a reduced complement of beds at the Highland Rheumatology Unit, Dingwall and a multi-specialty infusion service at Raigmore, with plans to set up further units across Highland where there is a recognised need.

- To extend specialist multi-disciplinary care at Raigmore and peripheral out patient clinics

- To develop structured education and training for arthritis patients and their families

- To offer education and clinical skills training to clinicians in the primary care and community teams with a view to extending their role in the management of patients with chronic arthritis.

- Integrated care pathways are being explored and developed to support appropriate and timely referrals
2. Introduction

This paper will provide a background and rationale for the review of whole system Rheumatology services in NHS Highland set in the context of national policy, the Quality Strategy, NHS Highland Strategic Framework and Professional Guidelines. It will then propose a direction of travel for Highland Rheumatology services and outline the next steps in the process.

Inflammatory Arthritis is the term used to describe a range of auto immune conditions which include rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis and juvenile idiopathic arthritis. It is progressive and the pattern and progression varies from individual to individual. It is characterised by pain which can be disabling, stiffness, reduced joint function and reduced mobility. The disease is also systemic and can therefore also affect the whole body, including heart, lungs and eyes.

The National Institute for Clinical Excellence (NICE) estimate that approximately 400,000 people suffer from Rheumatoid Arthritis in the UK, with about 12,000 new cases a year.

A review of NHS Highland rheumatology service was initiated in 2008 to cope with pressures resulting from new national standards of care including rapid access to specialist care for patients with suspected rheumatoid arthritis, to safely administer new 'biologic' treatments and to meet new waiting time targets. The key drivers for the review are contained in Appendix 1.

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3. Background

The National Perspective

National Policy Direction

- Services should be as close to patient’s homes as possible and be as specialised as necessary
- Patients with rheumatoid conditions should be identified very early in their condition and be seen by a Consultant for assessment and treatment planning
- Multi professional integrated care should be available and supported by care pathways
- There should be a reduction in avoidable hospital admissions and in length of stay
- Independence and self management for patients should be supported and maintained
- Education and training for patients and staff should be facilitated

There is a requirement to ensure that care is better integrated, responsive and of high quality. ‘Better Health, Better Care calls for the NHS in Scotland to

“Help people to sustain and improve their health, especially in disadvantaged communities, ensuring better, local and faster access to health care.”

The Long Term Condition Strategy highlights the following key action points

- Improve patient experience
- Build capacity to support self management
- Improve staff knowledge, skills and access to training
- Systematic, integrated multi agency approach
Local and faster access  
Improved networks  
Improved information systems

Rheumatoid arthritis was identified at national level as a priority condition for action by community health partnerships as part of long term conditions strategies.

NHS Scotland’s Quality Strategy highlights the requirements for:
- Caring and compassionate staff and services
- Clear communication and explanation about conditions and treatment
- Effective collaboration between clinicians, patients and others
- A clean and safe care environment
- Continuity of care
- Clinical excellence

NHS Scotland has put new emphasis on management of patients with a long term condition to ensure integrated, responsive and high quality care. (HDL 2007 (Feb 2007), Delivering for Health: Rehabilitation Framework 2007 and Better Health, Better Care 2007, Quality Framework 2010). With increasing emphasis on self management and where possible providing care near patients’ homes. National professional and patient bodies have released a number of rheumatology standards of care (NICE 2009, ARMA 2004, National Audit Office 2009, PHIS 2007, SIGN 2010 and House of Commons Committee of Public Accounts 2010). To meet these aims for Highland rheumatology patients a review and redesign of the service was undertaken.

National guidelines above set minimal standards of care for early identification and referral of patients with rheumatoid arthritis and more serious forms of disease for specialist and multi-disciplinary management and for increasingly intensive treatment involving powerful new drugs. Simultaneously and as an exemplar of ‘long term conditions’, guidelines encourage more self-management and more local primary/community care for patients with stable arthritis whilst ensuring a responsive, integrated service allowing fast access back to specialist care for patients experiencing disease flares or complications of their disease or treatment. Services must therefore meet both standards of care and access issues encompassed in ‘Shifting the balance’ and management of long term conditions.

Rheumatoid arthritis was identified at national level as a priority condition for action by community health partnerships in NHS Highland as part of their strategy for long term conditions with the difficult but essential provision of high quality and safe rehabilitation and re-enablement services to local communities across Highland.

Rheumatology is the medical speciality providing diagnosis and care for patients with a variety of bone and joint conditions including more complex inflammatory conditions such as rheumatoid arthritis, as well as a number of rarer auto-immune conditions such as Systemic Lupus Erythematosus along with metabolic bone diseases. Musculoskeletal problems are the third commonest causes of patients attending General Practice, with the highest onward referral rate to specialist services (orthopaedics and rheumatology) and is the major user of physiotherapy and occupational therapy in primary and secondary care. Despite this clinicians in primary care and the community have been shown to lack the necessary training to manage a variety of rheumatological problems.

Nationally, rheumatology like other specialty services, are evolving from significant inpatient resources supported by outpatients to the widespread development of day case facilities. The rheumatology department in NHS Highland is led by two consultants supported by two part-time Specialist Doctors, two specialist out-patient nurses and specialist Allied Health Professionals. Currently the service is delivered from the Highland Rheumatology Unit (HRU) Dingwall from a small number of medical beds at Raigmore and at outpatient clinics in Raigmore, Nairn, Dingwall, Golspie, Fort William, Broadford, Portree, Thurso and Wick.
The 14 bed HRU provides assessment and multidisciplinary specialist management of patients with newly diagnosed inflammatory arthritis or flares of the condition and intensive rehabilitation of those patients and of those with more chronic problems or following orthopaedic surgery. They can receive individualised care including twice daily physiotherapy and specialist AHP care including hydrotherapy at the adjacent, charitably managed Puffin Pool in an effective inter-agency partnership.

The Dingwall X-Ray Department offers rapid access imaging and has become the regional centre for a direct access service for DEXA scanning of patients suspected of having osteoporosis. Over the years an informal service has evolved at HRU for outpatients and day cases presenting for urgent assessment of flares, delivery of joint injections and assessing suspected complications of their disease or treatment. Patients with more complex disease who have potentially serious disease of the heart, lungs, liver, kidneys and nervous system are managed in beds at Raigmore Hospital by the Consultant Rheumatologists to access specialist imaging, cross specialty opinions, and more invasive treatments.

Rheumatology
National professional and patient bodies such as NICE 2009, ARMA 2004, National Audit Office 2009, PHIS 2007, SIGN 2010 and House of Commons Committee of Public Accounts 2010, set minimal standards of care for early identification and referral of patients with rheumatoid arthritis and more serious forms of disease for specialist and multi-disciplinary management and for increasingly intensive treatment involving powerful new drugs. Simultaneously and as an exemplar of ‘long term conditions’, guidelines encourage more self-management and more local primary /community care for patients with stable arthritis whilst ensuring a responsive, integrated service allowing fast access back to specialist care for patients experiencing disease flares or complications of their disease or treatment. Services must therefore meet both standards of care and access issues encompassed in ‘Shifting the balance’ and management of long term conditions.

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The Review
This speciality was identified by NHS Highland as a priority for review and work has been ongoing for several years to identify the patient flow issues, challenges and potential solutions.

Two workshops involving patients, GPs’ and representatives of all relevant clinical disciplines and management in primary and secondary care were held in 2009 and an independent consultant with rheumatology expertise was appointed and presented a report in spring 2009 which confirmed that the service was delivering a high quality rheumatology service but was stretched by the advent of more stringent clinical standards and by new waiting list targets whilst sustaining a regional service through peripheral clinics and suggested options for change. Due to the long term absence of the independent consultant, the report was never finalised and published as such but it is available on the NHS Highland website.

Summary of Independent Review
- Increase clinical manpower to nationally recommended targets ( 1 Consultant per 85,000 )
- Optimise number and role of specialist nurses
- Review the use of the Highland Rheumatology Unit to allow increased day-care and one stop clinics and review inpatient and bed demand acknowledging the effect on bed use in Raigmore.
- Appointing administrative support to free up clinician time
Summary of the workshop – Key areas of concern
While acknowledging the clinical areas some concerns were expressed on the report and the financial implications at a time of financial stringency but acknowledged a number of areas requiring further consideration:

- Lack of clinical capacity
- Highland Rheumatology Unit activity and efficiency
- Lack of administrative support
- Out patient activity and efficiency
- Outreach services
- Reviewing the Infusion Service. Delivery by specialist nurses precludes wider use of their skills
- Lack of education and training in the community/primary care

The Vision for NHS Highland is:-
Our vision is therefore to provide quality care at all times; to support people and communities to maximise their own health; to develop precision driven services so that when people need our care they experience timely, focused, effective services that minimises the duration and frequency of contact; and to ensure that every health pound spent delivers maximum health gain.

The NHS Highland Strategic Framework incorporates the principles of the Quality Strategy and highlights the following characteristics

- promoting good health, self care and independence
- high quality, integrated, equitable, needs and evidence-based, and cost-effective
- increasingly community-based with hospital beds preserved for the most acutely ill and those with specialist needs
- integrated with, and complementary to, local authority, voluntary and independent sector care
- run by healthy, flexible, well-motivated and well-trained staff working to their maximum potential and capability
- using modern, flexible, efficient, green assets to maximum effect
- with zero wastage and inefficiency across all services and no unnecessary overheads

The Review of Highland Rheumatology Services has been in process for approximately two years and is seeking to ensure that the professional guidance, Quality Strategy and Vision for NHS Highland are reflected in the recommendations.

Training Questionnaire
A questionnaire was distributed to primary care and community clinicians to assess their degree of training and practical skills and their requirements and recommendations for a service redesign. The great majority reported a minimum level of training usually at undergraduate level with little formal access to postgraduate updates or clinical skills sessions. Practitioners requested better structured access to the rheumatology team including availability of guidelines for referral and treatment and easier phone contact. Several highlighted the difficulty in getting expedited appointments for established patients experiencing flares or problems with medication.

Proposals
The themes identified from workshop and questionnaire included

- Inpatient Services – a review of specialist unit (HRU) use including links with Raigmore, medical cover, length of stay, admission criteria.
• Out patient and local service development – a review of new to return ratios, potential for increasing specialist nurses and AHP involvement at central and peripheral clinics. Investigating increased involvement of primary care and community clinicians in routine follow up. Appendix 2 proposed new out-patient referral pathway.

• Education and training – self care management and support education for patients and carers, learning needs of extended primary and community care teams, education and training for specialist staff.

Three subgroups were established to progress these aspects of work and their feedback but progress has been slow and compromised by concerns about a loss of a 7 day inpatient service as part of Board wide measures to optimise bed use. As a compromise four beds were shut but were re-opened pending the outcome of the review.

More recently a small group has prioritised the initial steps which would allow the progress of the priority areas and these are brought to the Board for consideration. More work on the demand and capacity and a consolidated management continues under a newly appointed project manager reporting to the Chief Operating Officer.

More comprehensive information on the service is attached as Appendices and the independent report is available on NHS Highland website at: http://www.nhshighland.scot.nhs.uk/hottopics/pages/rheumatiologydraftreport.aspx

Implementation
Action Plan suggests a recommended direction of travel for the redesign of rheumatology services.

The plan picks up on the key 3 components
1. Creating clinical capacity
2. Developing day case/infusion services
3. Development of more locally driven services
4. Education ,training and raising awareness

IN SUMMARY

In Patient Services
Despite all of the above, it is inevitable that some patients will continue to require acute care or specialised rehabilitation that will necessitate hospital admission. This inpatient care will be provided in the Highland Rheumatology Unit in Dingwall, which will continue to act as a Hub for the service for 7 days per week. Some patients require the more acute setting in Raigmore Hospital at times due to ease of access to Consultants and diagnostic services.

Out Patient Services
Outpatient Clinics will continue to be provided in a range of settings across Highland. Day Case services will initially be developed in Highland Rheumatology Unit where there is access to specialist staff. In addition, a biologic infusion service will be developed in HRU as well as peripheral sites beginning with Belford Hospital. In HRU, this will necessitate the reduction of beds to 10 in order to free up a 4 bedded bay to equip as an infusion unit.

It is hoped that the development of the new infusion units will free up specialist nurses to contribute to most of the above services, again reducing consultant workload.

Education and Training
There is a need for awareness raising and education for patients and carers, generalist staff and specialist staff. Supporting patients in self care and self management of their condition is a key plank of national and Highland policies and learning packages and web based...
information is being developed. GPs and other generalist community staff although keen to be involved have expressed the need for updating and in some cases more detailed training on rheumatoid conditions, early detection and intervention and the new drugs that are in use. The sub group that has explored this are now working with Remote and Rural Healthcare Education Alliance, to develop training packages and educational resources.

Implementation

A Project Manager has been appointed to steer the implementation of the action plan. A Redesign team will continue to work with her and will advise on the specialist aspects of the plan’s implementation. Work has been done to scope the alterations required to establish an infusion unit in HRU and alterations can begin in the near future. Staff in HRU will be supported to develop skills and competencies required to operate an infusion unit. Staff in Belford Hospital have already begun to offer this service for patients in there area and links with the Rural Physician have been established.

Communication and Engagement Plan – Appendix 3

The purpose of the communication plan is to define all interested parties and the means and frequency of communication between them and the redesign team.

The first step will be a meeting of the Friends of HRU hosted by the Consultants on 2nd December. A press release will be drafted to ensure that the wider public is aware of the immediate changes that are planned. In addition, the original working group will be invited to an event in January to ensure that they have the opportunity to hear the outcomes of their early work and to comment on the Action Plan.

4. Contribution to Board Objectives

The Strategy and action plan will support the Board’s commitment to the delivery of national standards of high quality care, and support self management and community expertise by creating day case services and enhancing peripheral clinics with a view to preventing and reducing hospital admissions and thus shifting the balance of care nearer to the patients’ homes.

5. Governance Implications

Staff Governance
Education, training and development of hospital and community staff are a major component of the Action Plan. The Rheumatology Unit along with NES has prioritised specific training needs in relation to rheumatology and funding is being sought to deliver appropriate clinical skills training and good access to specialist opinion and support.

Patient and Public Involvement
Involvement of patient groups from National Rheumatoid Arthritis Society (NRAS) Arthritis Care and Joint Potential, as well as patients and Friends of the Rheumatology Unit will continue to influence any decision-making.

Clinical Governance
Infusions- All HRU nursing staff are receiving training and shadowing to support infusion therapy. There must be a clinician on site when infusions are undertaken. A defibrillator requires to be purchased. These will all be addressed through the action plan.

Training standards and governance will be required in respect of community and primary care staff.
6. **Financial Impact**

No new resource has been identified to allow for service expansion and therefore redesign of existing services and a change in the way we deliver care and treatments has been explored initially. However it has been recognised that the rheumatology service is a Highland wide resource and funding some of the service improvements will have to be viewed on an invest to save basis and funding seen as a Board wide responsibility.

The continuing increase in expensive nationally approved new biologic drugs will require budgetary planning. In the long term the prevention of disability should realise reduced NHS and societal costs but may not be realised for some years. It is also anticipated that improved access to specialist care at an early stage, multidisciplinary input and instilling self management principles may lead to a long term reduction in pharmacy spend.

Any resource implication will be addressed through the risk register.

7. **Impact Assessment**

The Rheumatology Review will strongly embrace the equality and equity for all patients. The action plan and any developments or initiatives will be assessed, to ensure equality and diversity issues have been addressed.

Dr M Steven & Dr J Harvie
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26 November 2010
MAIN DRIVERS FOR THE REVIEW - ESTIMATED SERVICE DEMAND

- There are about 47,000 patients living with a musculoskeletal condition in Highland, with only about 800 new patients per year being referred to secondary care. This is likely to increase as the population is ageing and living longer with chronic conditions (as seen from the increased referral rate as from April 2010). (National Institute for Clinical Excellence (NICE) estimate that approximately 400,000 people suffer from rheumatoid arthritis in the UK with about 12000 new cases a year) There are approximately 200,000 people in the UK who have ankylosing spondylitis. For psoriatic arthritis estimates vary, between 84,000 and 177,000. Inflammatory arthritis affects thousands of children, as well as adults. Around 12,000 children under 16 are affected by juvenile idiopathic arthritis (JIA). It is one of the commonest causes of physical disability that begins during childhood. As such we would expect approximately 3500 patients in the Highland area to have an inflammatory joint disease. (verified by PH) Unfortunately no sources have been provided in relation to the above facts and under time constraints only the following has been accomplished:

- Evidence based clinical guidelines advise earlier access to specialist care to allow treatment to prevent long term ill health and costly disability.

- Shifting the balance of care policies aim to care for more people closer to home through multi-professional teams with less reliance on specialist care and inpatient stays while ensuring appropriate access to secondary care for flares and specialist monitoring to ensure that standards of care are maintained. However the House of Commons Committee of Public accounts recognised that GPs receive on average only two hours of teaching on musculoskeletal conditions during their training, including minimal coverage of inflammatory arthritis and there was inconsistency of specific multidisciplinary services.

- The Scottish Government’s Rehabilitation Framework. At present the specialist rehab practitioners, physiotherapists and occupational therapists are based in Dingwall and patients travel to them. Although clinics are held in a wide range of peripheral sites and are attended by physicians, nurses supported by community work being provided by occupational therapists. A better trained and supported clinical network may allow patients to access some of their care locally.

- Equity of access. Services need to be accessible to patients wherever they live in Highland, and whether they are new or existing patients. The existing network of peripheral clinics don’t fully represent local burden of disease but are limited by current manpower

- New drug therapies. The existing service has similarly been stressed by the arrival of new ‘Biologic’ drugs for patients. These new drugs which substantially improve quality of life and prevent long term disability are very expensive and are staff intensive in their safe use. Strategies are needed for funding and using them safely as recommended by NICE and SMC.

- Waiting times targets. The services need to be configured in such a way as to achieve the 18 week referral to treatment target allowing for the ability to prioritise urgent cases at physician’s discretion.

- Require to demonstrate efficiency and value for money.
A POSSIBLE OUTPATIENT PATHWAY

- **New rheumatoid arthritis referrals** will be treated intensively initially by rheumatology consultant and multidisciplinary team with many clinics thereafter led by the multidisciplinary team with emphasis on instilling self management. As patients come under control the interval between appointments can be spaced ultimately leading to an annual consultant visit and annual nurse review.

- **Slow Stream Arthritis referrals.** With less severe disease will have less intensive consultant involvement with an earlier institution of specialist nurse annual review.

- **Established patients** will be seen regularly by a member of the team. Protocols for intermediate review in the community / primary care will be developed which allow rapid re-referral to the specialist team

- **CT Patient and rare condition referrals** shall be seen at the consultant clinic – no change

- **Ankylosing spondylitis patients**, after diagnosis should have the opportunity to attend physiotherapy led clinics.

- **Biologic patients** will be seen as day cases and outpatients with substantial input from specialist nurses to lead education on self administration of therapy, screening for contraindications and the required monitoring of continued efficacy.

- **Infusion units** for biologic patients receiving intravenous therapies will be developed at HRU and Raigmore. The staffing required to extend access of infusion therapies to other medical disciplines may free up specialist rheumatology nurses to contribute to most of the above services,

- **Flare up patient referral** will be seen at the drop in Day Services Unit and seen by the multi-disciplinary team and/or consultant.
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