Model of Care for Rheumatology in Ireland

National Clinical Programme for Rheumatology

RHEUMATOLOGY

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

ROYAL
COLLEGE OF
PHYSICIANS
OF IRELAND

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Patient Support Group

Arthritis Ireland

Abbreviations

ADL	Activities of Daily Living
ADON	Assistant Director of Nursing
ANP	Advanced Nurse Practitioner
AS	Ankylosing Spondylitis
CAG	Clinical Advisory Group
cDMARDs	Conventional Disease Modifying Anti-Rheumatic Drugs
CHO	Community Healthcare Organisations
CNS	Clinical Nurse Specialist
CPD	Continued Professional Development
CSPD	Clinical Strategy and Programmes Division
CT	Computed Tomography
DNA	Did Not Attend
DXA	Dexa Scan
ED	Emergency Department
GIM	General Internal Medicine
GP	General Practitioner
HSCP	Health and Social Care Professionals
HSE	Health Services Executive
ICF	International Classification of Functioning, Disability and Health
ICGP	Irish College of General Practitioners
JIA	Juvenile Idiopathic Arthritis
KPI	Key Performance Indicators
MDT	Multidisciplinary Team
MRI	Magnetic Resonance Image
MSD	Musculoskeletal Disease
MSK	Musculoskeletal
OLCHC	Our Lady's Children's Hospital Crumlin
OPD	Outpatient Department
PDP	Personal Development Planning
PsA	Psoriatic Arthritis
RA	Rheumatoid Arthritis
RCPI	Royal College of Physicians of Ireland
RhCN	Rheumatology Clinical Network
RMDU	Rheumatic and MSK Diseases unit
SMI	Self-Management Intervention
SpA	Spondyloarthropathy
TBPM	Team Based Performance Management
WTE	Whole Time Equivalent

Glossary

Health and Social Care Professionals (HSCPs): The HSCP Act 2005 has given statutory basis to the regulation of 12 professions listed below. Any other health and social care profession deemed appropriate by the Minister for Health may be added in the future.

Clinical Biochemists	Dieticians	Medical Scientists
Occupational Therapists	Orthoptists	Podiatrists
Physiotherapists	Psychologists	Radiographers
Social Care Workers	Social Workers	Speech and Language Therapists

Clinical Networks are linked groups of professionals and organisations from primary, secondary and tertiary care, working in a coordinated manner, unconstrained by professional and health board boundaries, to ensure equitable provision of high quality, clinically effective services

Community Healthcare Organisations (CHOs) are the new structures in which health care will be provided in the community. There are nine CHOs to deliver an integrated model of care. This will facilitate a move towards a more integrated health care system, improving services for the public by providing better and easier access to services, services that are close to where people live, more local decision making and services in which people can have confidence.

Performance Indicators are data points used to measure inputs, activities, outputs or outcomes, and are used to monitor the progress of the programme being reviewed.

Interdisciplinary Team Working uses holistic, collaborative and patient focused approach. Effective joint goal setting and review is the cornerstone of the IDTs process.

Multidisciplinary Team (MDT) Working involves professionals working independently in order to achieve discipline specific goals, individual team members may not communicate directly with all other team members in care planning

Whole Time Equivalent (WTE) is the equivalent number of combined part time and full-time staff basis e.g. two staff members both working half time are equivalent to one whole time post.

Clinical Leads Foreword

The delivery of care to patients with rheumatic and musculoskeletal (MSK) disorders in Ireland is limited largely by the deficiencies in resources that are currently available in community, primary and secondary care. Delivery is also hampered by the absence on clear guidelines for management and the lack of opportunity to develop integrated care pathways across primary and secondary care. Whilst the care delivered in Irish Healthcare is of high quality, the above deficiencies have led to significant difficulties in accessing care resulting in lengthy delays for assessment, diagnosis and treatment.

In this Rheumatic and MSK disorders model of care document, we outline a model which aims to ensure that the rheumatology patient is seen and assessed and treated by the right person, in the right place and in the timeliest manner. Based on international best practice, we set out both personnel and infrastructure requirements and we propose an integrated organisational structure, based on the hospital networks, which aims to ensure that all patients in Ireland will receive the same standards of quality care wherever they present within these networks.

The model of care outlined is both ambitious and achievable.

While some of the costs involved could be met through identifying inefficiencies within the system, it is without doubt that investment, both in staffing and in infrastructure, will be required to facilitate the implementation of this model of care and in shaping future rheumatology services.

The model also establishes the foundation on which the National Clinical Programme Clinical Advisory Group will develop Care Pathways as outlined in Section 4.

The Rheumatology community together with our patients will work closely with all other stakeholders, including hospital network managers and CHO managers, to ensure that equity in delivery of the model across all 6 hospital networks and 9 CHOs is achieved.

David Kane

Professor David Kane (2015 – current)

Professor Oliver FitzGerald (2010 – 2015)

Executive Summary

Rheumatic and Musculoskeletal disorders (RMDs) are a group of more than 200 different conditions that affect 1 in 4 people of all ages, equivalent to 1.2 million Irish citizens (www.eular.org). It is estimated that 2% of the EU GDP is spent on direct medical care of RMDs. RMDs are the leading cause of disability in Ireland. RMDs cause the single greatest socioeconomic cost of any disease group due to lost productivity from long-term work absence and due to the payment of disability benefits.

There will be a dramatic increase in the prevalence of RMDs in the next decade due to an increasing and ageing population. RMDs impede the ability of people to remain economically and socially active when becoming older. The social and economic impact of RMDs will be accentuated by the necessity to maintain the larger, ageing Irish population in work to a later age.

Many RMDs, such as rheumatoid arthritis, have seen major advances in specialist Rheumatology treatment in the past decade, effective in preventing joint damage and patient disability. The need to develop Rheumatology services for the provision of better care for all patients with RMDs in Ireland is recognised by the Health Service Executive (HSE). In 2010, a National Clinical Programme for Rheumatology (NCPR) was established with the overarching aim of: "Adopting a chronic disease model of care so as to facilitate a right person, right place, first time approach to patients with RMDs."

The NCPR has now produced this model of care for development of Rheumatology services for the management of Rheumatic and Musculoskeletal Diseases in Ireland (Appendix 5). The model of care notes that Ireland has one of the lowest ratios of rheumatologists to population in the EU and when implemented will bring service provision for RMDs in line with evidence-based practice and international standards of care.

The model of care envisages expansion of Rheumatology services in a hub-and-spoke model of tertiary centres operating within 6 rheumatology networks coterminous with the new hospital groups and integrated with primary care services through Community Healthcare Organisations (CHOs). Given that 1 in 4 Irish people suffer from RMDs the Rheumatology Model of Care seeks to deliver both specialist services in a tertiary setting and to promote and assist the development and delivery of primary care services for patients with RMDs in co-ordination with the Primary Care Division and National Clinical Advisor and Group Lead for Primary Care. This will provide co-ordinated care and uniform standards of service delivery for patient across the networks and across primary, secondary and tertiary care which is supported by the development of clear referral protocols, pathways and therapeutic standards. When implemented, this will bring service provision for RMDs in line with evidence-based practice and best international standards of care.

1. Introduction and Background

As the demographic profile in Ireland changes, with increased life expectancy and rising numbers of the population moving into the middle and older age groups, it is expected that the incidence of chronic rheumatological conditions such as arthritis will increase. At the same time, new medical therapies are radically changing the approach to disease management and are significantly affecting clinical outcome. With the introduction of improved therapeutic strategies with cDMARDs and new therapies such as biological medications for inflammatory arthritis, lasting disease remission is the new therapeutic goal (Emery et al., 2008). Preservation of work status, maintenance of quality of life and prevention of joint damage and disability are additional benefits of successful treatment. In rheumatoid arthritis (RA) and other inflammatory rheumatologic conditions, the time has come for goal-directed management like treating RA to an agreed target. This involves monitoring patients closely and titrating medication in order to achieve the agreed goal of clinical remission or low disease activity usually within the first 6 months of diagnosis, thus reducing costs significantly (Smolen et al., 2010). It is the implementation of this new standard of care, which challenges us all.

A previous HSE working group on Arthritis and Allied conditions, convened in 2009*, documented current service provision, examined existing international models of care and undertook a gap analysis of what might be required in order to provide a first-class rheumatology service in Ireland. A report stemming from this work was presented to Dr Barry White when he took up his position as Director of the Clinical Strategy and Programmes Division (CSPD) within the HSE in 2009. Responding to this report, dir. White set up a the NCPR with the clear goal of implementing changes within the delivery of care to rheumatology patients which would improve the quality of the service, access to the service and also address aspects of cost.

The rheumatic and MSK disorders model of care is a key component of the work of the NCPR and will greatly help to define future service improvements.

*not published but all documents available from the NCPR

1.1 Overarching Aim of the Programme

To develop a chronic disease model of care to facilitate a right person, right place, first time approach to patients with rheumatic and MSK disorders.

Programme Objectives

Quality

- To monitor and reduce mortality associated with rheumatic and MSK disorders with the aid of a rheumatology national register
- To improve both short-term and long-term outcome measures (e.g. disease activity scores) in patients with rheumatic and MSK diseases using a Treat to Target approach.
- To reduce physical, psychological and work disability related to rheumatic and MSK diseases and improve self-management

Access

Primary care:

- Ensure engagement regarding rheumatology services within the full national roll out of primary care teams and appropriate clinical infrastructure
- To reduce the overall numbers of patients referred to/requiring routine follow up rheumatology Outpatient Department (OPD) appointments by developing primary care services integrated assessment teams as appropriate

Secondary Care:

- To reduce waiting lists for all rheumatology referrals to <6 months within 1 year
- To reduce waiting lists for all rheumatology referrals to <3 months within 2 years
- Allow fast tracking of early inflammatory arthritis and systemic disease in order to reduce waiting times for such urgent referrals to <2 weeks within 1 year

Integration between Primary care and Secondary Care:

- Develop integrated clinics/consultations between primary and secondary care services managing people with rheumatic and MSK diseases as close to their home as possible
- To develop national referral guidelines for all patients with MSK disease within 1 year

Value

- To identify potential efficiencies and savings within the system e.g. use of Biosimilars, dose reduction strategies, etc.
- To reduce MSK-related work disability by ensuring appropriate timely interventions by an MDT
- By ensuring timely access to services, to reduce the impact of rheumatic disease-related joint damage (e.g. reduced requirement for joint replacement surgery)

  - Identify and treat patients at risk for osteoporosis, to significantly reduce low-trauma fracture occurrence and consequent morbidity and mortality
  - Evaluate the use of biologic medications with the aim of maximising cost effectiveness of hi-tech expenditure

1.2 Programme Solutions

Quality Solutions

- Establish Rheumatology Clinical Networks (RhCNs) that are underpinned by robust clinical and corporate governance structures
- Develop performance indicators that support the implementation of model of care
- Develop/agree/implement national clinical guidelines, standards of practice, care pathways with all partners that move from prevention and self-care through to hospital care and ensure that the use of primary and secondary care is appropriate to patients' needs
- Care pathways to include detailed and agreed clinical audit measures and all services must engage in clinical audit
- To agree and implement disease specific and patient focused quality outcome measures
- To enhance and develop self-management and patient education programmes that are tailored to particular levels of complexity and risk e.g. those developed by Arthritis Ireland
- To further develop "fracture-liaison" programmes so as to ensure that patients with osteoporosis are identified and treated in a timely manner
- A national arthritis registry to be established
- To utilise the International Classification of Functioning, Disability and Health (ICF) as a framework to develop these measures. Activity and participation outcomes to be measured in tandem with outcomes that focus on body structure and function

Quality Solutions: Education and Research

- To develop an accredited Continued Professional Development (CPD) programme in the assessment and treatment of MSK conditions for all disciplines. This programme to include e-learning modules
- To promote service-related and translational research programmes related to rheumatic diseases
- Develop and agree an integrated competency framework for each discipline working in rheumatology services across primary, secondary and tertiary services
- To review and develop, in partnership with the Higher Education Authority and Universities, MSK training programmes in the undergraduate courses in all the relevant disciplines

Access Solutions

- Provide access to a Multidisciplinary Team (MDT) at community level which will enable individual and population-based self-management support, education, optimal clinical and social care in the most appropriate setting, education, avoidance of complications, improved outcomes and optimal quality of life
- Facilitate care across the chronic disease spectrum e.g. a falls clinic in primary care can be used to identify those at risk of osteoporosis and could also be used for health promotion in patients at risk
- Increase consultant rheumatology time by 40% within 1 year – this to be achieved by taking all rheumatology consultants off General Internal Medicine (GIM) call and by appointing new consultant rheumatologists.
- Develop and increase extended scope role in nursing, occupational therapy pharmacy and physiotherapy and to enhance multidisciplinary/interdisciplinary management
- Provide full MDT access to all dedicated rheumatology services, only one third of the recommended nurse specialists, occupational therapists and physiotherapists are in post nationally. An integrated workforce planning exercise needs to be completed on MDT staffing levels requirements in implementing the proposed model of care. Secondary care services to have an outreach component
- Developing educational programmes and liaising with community MDTs will facilitate optimal management of MSK conditions in the community and avoid "inappropriate" referrals
- To examine the possibility of integrated care protocols for patients on biologic therapies

Value Solutions

- To develop and agree evidence-based national guidelines for use of biologic therapies, including biosimilars, in a cost-effective manner in conjunction with the Medicines Management Programme
- To develop cost effective (e.g. community based, protocolised, etc.) infusion programmes which will provide economies of scale and substantial savings (vial sharing savings of €100,000/yr/100 patients treated or savings associated with use of biosimilars)
- To review usage of drugs within the General Medical Scheme, in particular those where efficacy is unproven
- To work with the OPD programme to ensure that all patients seen at OPDs are appropriately referred and have all the pre-assessment work-up completed prior to attending outpatient clinics in secondary care
- To reduce the 'did not attend' (DNA) rate to 12% as per National OPD performance improvement programme

- To liaise with Department of Social Welfare and to reduce MSK work-related disability costs (estimated €350m/year) by 10% in 2 years
- By introducing/rolling out an effective fracture-liaison programme including a falls risk assessment, to substantially increase the numbers of patients with fractures assessed to 90% within 1 year

2. Rheumatic and Musculoskeletal disorders

2.1 Definitions and Epidemiology

Rheumatic and MSK disorders are a group of conditions which may result in damage to the muscles, bones and joints of the body. In most cases, these are chronic conditions that cannot be cured. Arthritis is the leading cause of disability in people aged 55 years and over and hence is the greatest cause of health service usage (Vos et al., 2015). Over 1 in 5 people have some form of arthritis (Arthritis Ireland, 2015a) and the condition accounts for over 30% of all general practitioner (GP) visits (Bevan et al., 2009a). A recent report from the Central Statistics Office (2008) confirmed that chronic back pain is the second commonest condition among adults after hypertension. The Institute of Public Health MSK briefing document in September 2012 found that 169,000 adults (5.1% of the population) had rheumatoid arthritis in the previous 12 months, which had been clinically diagnosed.

The policy framework for the management of chronic diseases from the Department of Health and Children (DoHC) defines chronic diseases as long-term conditions, lasting more than 6 months, are non-communicable, involve some functional impairment or disability and are usually incurable (HSE, 2008b). This definition includes arthritis and allied conditions. In table 1, you will find the most common forms of arthritis and allied conditions and each has a different cause, incidence and prevalence.

Table 1. Rheumatic and Musculoskeletal disorders

Osteoarthritis and Regional MSK pain	One of the ten most disabling diseases in developed countries with 500,000 people affected in Ireland. Affects 18% women and 10% men over 60 years (Woolf & Pfleger, 2003) – rates for asymptomatic osteoarthritis much higher. 80% of people with arthritis have limitations in movement. 25% cannot perform the ADL. In Europe nearly ¼ of adults are affected by longstanding Musculoskeletal problems that limit everyday activity (Department of Health (UK), 2006). It is estimated that 30% of all GP consultations are about MSK complaints (Department of Health (UK), 2006)

Rheumatoid Arthritis	Affects 1 in 100 people; 40,000 people in Ireland have RA. 70% of people with RA cannot work outside of home due to their disease, costing the state €1.6 billion (Bevan et al., 2009a) Only 27% of 732 patients with RA surveyed over 5 years in the UK were in paid employment (Young et al., 2000) Early intervention can significantly improve outcome.
Spondyloarthropathy (SpA)	SpA includes a number of related diseases such as ankylosing spondylitis (AS) (recently re-named Axial SpA) and psoriatic arthritis (PsA). AS is an inflammatory condition predominantly affecting the spine. Over 44,000 people in Ireland are affected: 2-3 times more common in males (Bevan et al., 2009a). Typically earlier onset than RA and associated with the skin rash psoriasis, PsA affects 0.25% of population; 10,000 people in Ireland affected. Often poor outcome with progression despite therapy. Joint damage and deformity can be severe in some cases.
Osteoporosis	Present in 15% of Caucasians aged 50-59 years and 70% of those over 80 years. It is estimated that 300,000 people in Ireland have Osteoporosis. 1 in 5 men and 1 in 2 women over the age of 50 will develop a fracture due to osteoporosis in their lifetime (Irish Osteoporosis Society) The most serious is hip fracture, fatal for 20% of patients, permanent disability for 50% (Stafford et al., 2004).
Systemic Rheumatic Disease: Connective Tissue Disease and Vasculitis	Relatively uncommon; Estimated 2,000 people in Ireland affected. Multisystem diseases with high morbidity and frequently requiring acute hospital intervention. Specialist care can improve outcomes and quality of life.

Juvenile Idiopathic Arthritis (JIA)	A group of disorders of unknown origin characterised by joint pain, swelling and stiffness in children less than 16 years of age. Many present between 1-3 years at a crucial time of development and growth and occurring more commonly in females (Hoffart et al., 2010) Affects 1,200 children in Ireland (Arthritis Ireland, 2016) who require specialist care within months of diagnosis, so as to prevent permanent joint damage and growth retardation.
Fibromyalgia	One of the most common reasons for patients to visit a GP is widespread MSK pain attributed to abnormal pain processing (Department of Health, 2006) Poorly understood: prevalence 2% in women, aged 20-55. Multidisciplinary intervention, education and self-management strategies are recommended (Braun et al., 2011)
Hypermobility Syndrome	Hypermobility means that one can move some or all of their joints more than most people can. It's often known as being double-jointed and can be referred to as joint hyperlaxity. Hypermobile joints are very common, and most people won't have any problems. However, a minority of people with hypermobile joints experience pain or other symptoms. There are a number of different syndromes e.g. Ehlers Danlos syndrome where patients present with significant complications (Arthritis Research UK, 2015).
Acute Monoarthritis / Gout	A frequent emergency department presentation, management can be hampered by the broad range of causative pathologies and non-specific nature of clinical presentation (Siva et al., 2003). Sepsis and crystal-associated (e.g. gout) are common causes. Gout is the commonest inflammatory arthritis and prevalence is increasing with 1 in 40 of the UK population now affected (Kuo et al, 2014)

2.2 The need for a population health approach

In addition to practical resource driven issues, the model of care will only succeed if a population health approach is taken to the prevention and management of rheumatic and MSK disorders. There are those who have an undiagnosed arthritis who require early diagnosis, secondary prevention and appropriate management. Figure 1, which applies to all chronic conditions, shows the segmentation of complexity (levels 1-3) as it relates to rheumatic and MSK disorders. It is important to appreciate that these three levels are not distinct cohorts of patients; people in each level can improve or deteriorate and move between levels.

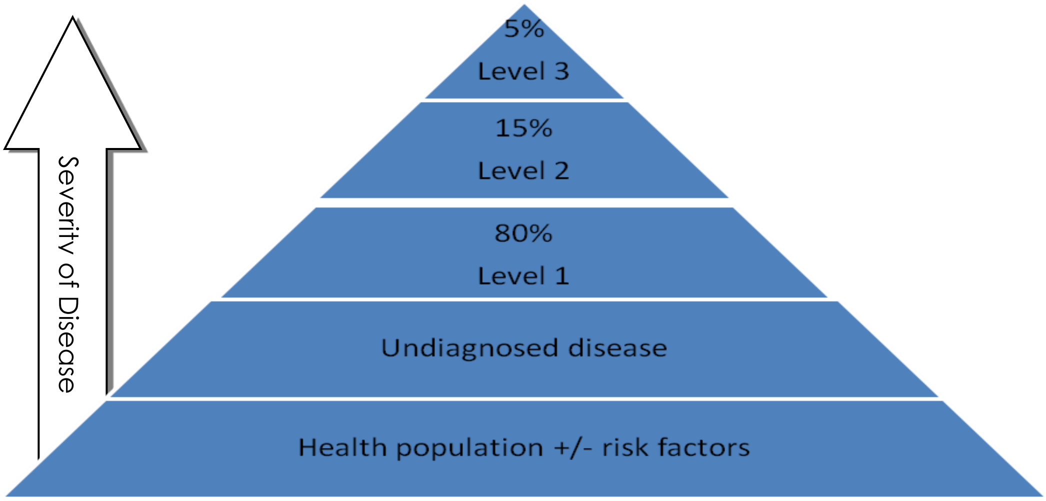

Figure 1. Population Health approach as it relates to MSK health (Taylor, 2007, HSE, 2008b, Minnock et al., 2012)

Level 1

Individuals who have rheumatic and MSK disorders which is well controlled by the patients themselves. It is assisted by self-management participation and as required primary care support (approximately 70-80% of patients).

Level 2

Individuals with more complex illness. They may have one or more chronic illness of varying severity but are not at risk of hospitalisation if they are well managed in the community (approximately 15-20% of patients). These patients can be monitored by self-management participation and identified via achievement or non-achievement of specific treatment goals.

Level 3

Individuals with complex conditions, often with complications. They require specialist care, intensive intervention and are at high risk of hospitalisation (Approximately 5-7% of patients).

3. Model of Care

People with rheumatic and MSK disorders may often experience pain, disability, reduction in societal participation and altered quality of life (Badley, 1995). Timely access to appropriate health care and related services is crucial to minimising this impact. Patients with rheumatic and MSK disorders require the input of MDT rheumatology services, and many different models of care are proposed internationally.

Two major documents were reviewed by the NCPR working group:

- European Action Towards Better MSK Health (European Bone and Joint Health Strategies Project, 2004)
- The MSK Service Framework (Department of Health (UK), 2006).

3.1 Rationale for Model Selection

The Model of Care should:

- Be patient-centred and provide better outcomes for people with rheumatic and MSK disorders through a more actively managed patient pathway
- Reflect the need to develop services at community, hospital level and integration between the two. A key challenge is to develop and agree integrated care protocols at the interface between services
- Be applicable to the existing Irish health and social care system and consistent with recent healthcare strategic initiatives (Department of Health and Children, 2001, HSE, 2008a, Department of Health, 2012, Department of Health, 2013a, Department of Health, 2013b)
- Allow for the development of generic care pathways and for the development of evidence–based care pathways for specific conditions (e.g. JIA).
- Emphasise community models of care, reducing the requirement for hospitalisation.
- Adopt a holistic approach which will address psychological and social needs as well as physical needs.
- Meet the NCPR objectives.

The NHS MSK Services Framework (DOH (UK), 2006) is the most adaptable model to an Irish setting. This view is based on the overarching concept emphasised in the framework which is excellence of care provided through a wide range of advice, support, diagnosis, treatment and rehabilitation interventions.

3.2 Key Elements of Model of Care

For the well population the goal is:

- To protect, promote and improve the health of the population to enable people to lead healthier and fulfilled lives with optimised quality of life.
- To reduce risk factors related to rheumatic and MSK disorders – osteoporosis prevention, prevention and treatment of obesity, prevention and early treatment of joint injury/damage.

For those who have developed rheumatic and MSK disorders the goal is:

- To provide individual and population-based early diagnostics, self-management support, education, optimal clinical and social care in the most appropriate setting.
- To achieve stable control of condition, avoidance of complications, improved outcome and improve quality of life.

For those whose rheumatic and MSK disorders have deteriorated the goal is:

- To provide individual and population-based groups with the knowledge to recognise their deterioration, with ease of access to the most appropriate service and to appropriate clinical and social care in the most appropriate setting.
- To achieve stable control of the condition, timely surgery if required, rehabilitation and palliative care support where appropriate, in order to ensure best outcomes and best quality of life.

Other essential elements of the model of care:

- RhCNs will operate across the 6 hospital groupings but implementation requires a significant increase in rheumatology staffing as envisaged under this model of care (Table 2).
- RhCNs are linked groups of health professionals and organisations from primary, integrated, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and organisational boundaries, to ensure equitable provision of high quality, clinically effective services. As the governance and operations of the hospital groupings further develop and consolidate, rheumatology services should be planned at a group or network level (Table 2). The challenge for each network will be to provide equity of access across the network from primary care, through level 2 and level 3 hospitals.
- Prevention and Self-Management – further develop self-management programmes with close links to primary care.

- Primary Care – MSK conditions account for a large and increasing proportion of consultations in primary care. Therefore, the model of care advocates that the primary care MDT provides assessment, diagnosis and treatment, as well as give advice to adults and children on healthy lifestyles to help prevent rheumatic and MSK disorders. This will be done in conjunction with the management of other chronic diseases in primary care and in conjunction with partners like Arthritis Ireland and the Irish Osteoporosis Society and other relevant patient support organisations. There needs to be a reinforcement of self-management as a crucial aid to treatment; and also screening for complications (e.g. osteoporosis, cardiovascular disease). The early referral of patients with more complex needs should be facilitated and the development of shared care protocols for some of these conditions will encourage management of chronic conditions as close to home as possible.
- Integrated Care – maximise services between primary and secondary care through review of stable patients by experienced health care professionals including drug monitoring clinics, reinforcements of self-management principles, group education, GP with a special Interest in Rheumatology(GPSI), Advanced Nurse Practitioner (ANP)/Clinical Nurse Specialist (CNS) led community clinics, Therapy–led (Occupational Therapy and Physiotherapy) clinics with access to specialist assessment, treatment and management.
- Secondary Care – clinics for patients with complex disease requiring multi-disciplinary co-ordinated care; provision of early intervention clinics for both new patients and for those requiring urgent consultant reviews.
- Tertiary Care – the development of rheumatology rehabilitation with day case and inpatient models of care tailored to patient needs.
- Existing rheumatology rehabilitation facilities will be incorporated into RhCNs, but they will also provide a tertiary care focus for patients with complex rehabilitation needs. These centres should develop a network or national resource function. Suitable patients for these services could be identified through care pathways and non-achievement of specified treatment goals.

4. Care Pathway development

In order to achieve the above objectives, the NCPR will plan and develop care pathways in the following broad areas of rheumatology in order of priority:

1. Osteoarthritis/Regional MSK pain (upper limb, lower limb and spinal groupings)
2. Rheumatoid Arthritis
3. Spondyloarthropathy
4. Osteoporosis
5. Systemic rheumatic disease: Connective Tissue Disease/Vasculitis
6. JIA
7. Gout
8. Fibromyalgia & Hypermobility syndromes
9. Methotrexate prescribing and monitoring

Other pathways will be developed by NCPR in priority of service need (see Table 2 below).

Table 2. Rheumatology Musculoskeletal Medical and Long-term Conditions Framework

	Domains				
	Inflammatory Arthritis / Disease	**Diagnostics and Pain Management**	**Auto-immune Rheumatic Disease**	**Bone Conditions**	**Rare Conditions**
Pathways	Rheumatoid Arthritis	Osteoarthritis	Systemic Lupus Erythematosus	Osteoporosis	Hereditary Recurrent Fevers
	Spondylo-arthropathy	Fibromyalgia	Sjogren's Syndrome	Paget's Disease of Bone	Sarcoidosis
	Reactive / Septic Arthritis	Inflammatory Regional Pain (e.g. back, limb)	Myositis	Regional bone disorder	Relapsing Polychondritis
	Gout / Crystal Arthritis	Mechanical regional pain (e.g. back, limb)	Systemic scleroderma	Osteomalacia	Amyloidosis
	Polymyalgia Rheumatica	Hypermobility Syndromes	Vasculitis	Other Metabolic Bone Disease	Rare Arthropathies

5. Rheumatology Clinical Networks

These are linked groups of health professionals and organisations (including patient representatives) from primary, integrated, secondary and tertiary care. This proposed model of care supports the delivery of a seamless, responsive and flexible system of patient care, provided by any and all partners in a collaborative MDT working for and with the patient. The work of the RhCN will direct the implementation, evaluation and modification of this model of care. Central to this work is how the system produces productive integration and interactions between an informed, activated patient and a prepared, proactive team producing improved outcomes.

Working together it is envisaged that the development of RhCN nationally will:

- Ensure one standard of care is delivered across all regions.
- Enable availability of a spectrum of rheumatology services to the patient ranging from primary prevention services, self-management and primary care services, including scheduled GP visits to underpin good practice models of care for the patient's specific illnesses.
- Develop secondary care services to include specialist clinics, shared care systems and appropriate services for complex rheumatology patients.
- Enable patient care plans to be developed on an integrated care basis between clinicians in primary and secondary care as appropriate to the patient's needs. Patients with stable needs will be cared for in primary care settings. Those with more complex disease will require increased levels of specialist care. This includes supporting the development of therapy-led clinics.
- Empower many patients to manage their own conditions through the provision of patient self-management programmes and education tailored to their particular level of complexity or risk.
- Mobilise the support of community and voluntary services to provide support to rheumatology patients in their own communities.
- Rely on communication, co-operation and integration of hospital and primary care.

5.1 Structure of Rheumatology Clinical Networks

The NCPR is proposing 6 RhCNs based on hospital group configuration, there may be more than one rheumatology centre in each network (Table 3).

Table 3. Rheumatology Clinical Networks Configuration

Hospital Group / Rheumatology Clinical Network	Hospitals with Rheumatology Services	Hospitals without Rheumatology Services	Specialist Hospitals	CHO Area
Dublin North East	• Beaumont • Connolly	• OLOL Drogheda • Cavan • Louth • Monaghan	Rotunda	7,8,9
Dublin Midlands	• St James's • AMNCH/Naas • Tullamore	• Midlands-Portlaoise	Coombe	7, 8
Dublin East	• Mater • St. Vincent's • Navan • Cappagh • Our Lady's Hospice and Care Services	• Mullingar • St. Luke's, Kilkenny • Wexford General • St Columcille's • St Michaels, Dun Laoghaire	National Maternity Royal eye and ear	5,6,7,9
South/ South West	• CUH • UHW • Kerry • SIVUH	• South Tipperary* • Bantry • Mallow • Mercy	Lourdes Orthopaedic CUMH	3,4
West/ North West	• UHG/Merlin park • Sligo • Manorhamilton	• Mayo general • Letterkenny • Portiuncula • Roscommon (e-clinic only)		1, 2
Mid-West	• Limerick / Nenagh • Mid-West Orthopaedic Hospital	• Ennis General • St. John's Limerick	Mid-West Maternity Hospital	3

*Rheumatology clinic but not provided by rheumatologist

The RhCN will be under the governance of the NCPR in conjunction with the acute hospital and primary care division and will support and guide the work of each regional network.

Membership of the steering group will include representation from all relevant stakeholders including a nominated network representative from each RhCN.

The leadership and management function of the RhCN will be delivered through the sessional commitment of an appointed RhCN Clinical Lead and RhCN Manager in each RhCN. All professionals involved with care delivery are de facto members of the network.

5.2 Clinical and Corporate Governance

The RhCN will be underpinned by a robust programme of clinical governance where those who deliver the services are empowered and accountable, proactive and visible in the management of their service. They will assist in the specification of the appropriate clinical standards and performance indicators.

Each RhCN will require a clinical and corporate governance structure and the work of each clinical network will be integrated at a national level. These RhCN will support local service providers to improve performance by implementing standards that demonstrably improve the safety and quality of care. The RhCNs will report to the National Steering Committee, established by the CSPD programme in conjunction with Acute Hospital Division, and chaired by the NCPR lead. This committee would report to the CSPD programme and to the Acute Hospital division.

Leadership

A national expert Clinical Advisory Group (CAG) would influence and inform service planning, service delivery and monitoring at both local and national levels.

RhCN lead clinicians will be chosen from the network and must exhibit clinical authority, ability to inspire the interdisciplinary team and to work in partnership across professional boundaries. The lead Rheumatologist of the network will need time allocated away from clinical work to lead the network. Appropriate remuneration will be required to fund backfill of the lead clinician’s post. The supporting team will include a Network Manager who would apply programme management skills to ensure the delivery of high quality, safe effective person-centred care.

RhCN accreditation

RhCNs would be subject to a process of endorsement and quality assurance by the HSE, in particular the national quality standards for safer better healthcare, and or other quality standards as deemed appropriate.

Core principles and elements of RhCNs

Accountability to deliver quality, safe and reliable healthcare in line with HIQA and HSE standards. Targets will be agreed with each site which will be reported on a continuous basis with regular review.

Clarity about its management arrangements including, a Lead Clinician appointment. Each network will produce an annual report to the HSE which will be publicly available.

Monitoring and review Key Performance Indicators (KPIs) will be developed jointly by the RhCN lead in conjunction with the NCPR.

Multidisciplinary working will be delivered with clearly defined roles and responsibilities.

Capacity planning in each RhCN will define and make clinical priorities and identify and implement cost saving initiatives. The RhCN will plan and manage resources within their region to provide optimum services.

Communications within the RhCN will ensure systems are in place to provide clear communication and consultation with all stakeholders in planning, design and delivery of services.

Clinical effectiveness and audit will be core to each RhCN collecting and reporting high quality information on clinical effectiveness and outcomes.

Service user involvement both formal and informal will be facilitated at all points on the continuum of care and feedback will inform services.

Risk management will be core to each RhCN making sure that mechanisms are in place to develop implement and monitor patient safety across the networks. This will be inclusive of robust incident management, effective risk registers and complaints ensuring that these are managed effectively and in line with relevant policies.

Education and training within the RhCN will ensure that all professionals involved in the network are participating in appropriate appraisal systems that assess competence to carry out roles. Systems will be developed to ensure consistent policies on training, competencies and CPD. Educational and training opportunities will be exploited in particular through exchanges among clinicians working across the rehabilitation continuum in community and primary care, and in hospital/specialist centres.

Cost effectiveness within each RhCN will optimise productivity and reduce service variation and monitor opportunities for achieving value for money healthcare delivery.

5.3 Critical Success Factors for Implementation and Functioning of RhCN

- Deficits in rheumatology manpower and infrastructure need to be addressed to allow implementation of this model.
- Further engagement in the development and roll out of Primary Care Teams
- Commitment to partnership working to develop guidelines for prevention, assessment, treatment and care for patients based on evidence-based practice and evolution of same through audit, evaluation and outcome measurement.
- Collaboration of existing rheumatology units where more than one exists within a clinical network and link with emerging academic health centres to provide a more comprehensive service. The development of sub-specialisation can also be considered as appropriate. This can be mapped in a coherent fashion once the Hospital Groupings are further developed.
- Establish a national arthritis registry and link to clinical database. The establishment of a national registry linked to a database will provide important service-and clinical-related data which in turn will be critical in further service planning and delivery.
- Together with the National Clinical Programme for Trauma and Orthopaedic Surgery (NCPTOS), establish a national joint replacement registry and audit service. A national joint registry will collect information on joint implants to provide evidence of their long-term effectiveness. It will lead to monitoring of performance of these new joints and faster identification of those joint replacements that perform less well. This database of information about artificial joints will also monitor how well individual hospitals perform in this area of healthcare. Funding through a levy on joint implant sales could be considered.
- Development of national laboratory test centre/partnership with centres for highly specialised testing e.g. muscle biopsies (neuropathology).
- Development of appropriate audit and research strategies underpinned by evidence and structured education (to include mandatory and desirable education for all groups involved). This will ensure competence in the workforce and support CPD. Education where possible, should be offered in flexible blended options to maximise uptake.
- Developing agreements that facilitate care coordination across organisations
- Linking Patients to Outside Resources
- Partnerships with CHOs

Current challenges relate to:

- The early stage of service integration and re-design in our health services.
- While progress is being made, there remains significant under-development of primary care teams.

- There is also under-development of specialist posts and hospital services in this clinical field. This leads to inequity of access to resources and to a lack of national clinical protocols and care pathways in primary, shared and hospital settings.
- There is also a need for further development of information sharing and communication technology between all stakeholders, particularly at the interface between primary and secondary care.
- Education and training of health care professionals regarding arthritis and allied conditions is a priority across under-graduate and post-graduate levels
- All the proposed improvements to staffing and infrastructure are being suggested in a most challenging economic environment

5.4 Community Health Organisations (CHOs)

For this RhCN model to work it is important that facilities for patients with rheumatic and MSK disorders be developed in primary care centres, adequate for the population served and to include individual, group and gym clinic spaces. Currently, there is considerable inequity of access to community services such as occupational therapy, physiotherapy and podiatry. At national level, a plan is required for how many MSK Occupational Therapists and Physiotherapists need to be in place per head of population in order to ensure equity of access for patients with MSK conditions. The NCPR will advocate and assist with this work in conjunction with the chronic disease integrated programme. This must include sufficient space for individual group and gym work. At present, although some primary care teams have an occupational therapist or a physiotherapist on the team, these professionals have limited scope to provide services to deal with MSK conditions as they have no access to the above facilities, GPs are therefore forced to refer patients to secondary care for these services.

The GP, Community Occupational Therapist, Community Physiotherapist, Practice Nurse and Public Health Nurse can facilitate self-management programmes, as well as individual assessment and treatment sessions. GPs and Practice Nurses can be involved in agreed integrated care pathways with secondary care for patients with more complex conditions. It is envisaged that in the future, specialist staff from the rheumatology centres will undertake outreach joint sessions in these centres with their primary care colleagues.

Many patients with osteoarthritis, regional MSK pain, osteoporosis or fibromyalgia can be assessed and treated in primary care by an MDT to include the GP, Community Occupational Therapist, Community Physiotherapist, Public Health Nursing and Social Work Services, if the proper infrastructure is in place. The treatment plan of care will be developed together with specialists within the rheumatology centre according to evidence-based practice guidelines.

5.5 Self-Management Programmes

Public and patient involvement in healthcare delivery must be a key element of the model of care thus engaging in a population level of health promotion and prevention including education and empowerment (DoHC, 2006, Taylor, 2007, HSE, 2008).

The systematic management of long term conditions with patient/user involvement and education on self-management can decrease emergency attendances and inpatient admissions leading to less demand for services (Arthritis Ireland, 2013). Lorig et al (1993) found that education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs.

Self-management, a widely used term in health education encompassing health promotion, empowerment and patient education, can be defined as follows:

Self-management facilitates “the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition”. (Barlow et al., 2002)

Self-management interventions (SMI) include educational, behavioural and cognitive approaches to influencing health knowledge, attitudes, beliefs and behaviours so as to promote independence, maintain or adjust life roles, and address the psychological impact of disease (Iversen et al., 2010). SMI goals are to support the persons' efforts to:

- Understand the nature of their illness and its treatments
- Identify emerging health problems in the early stages
- Adhere to self-care practices
- Make needed changes in their health habits
- Improve coping with the mental and physical demands of their illness given their unique economic cultural and social circumstances.
- Know when and where to seek assistance with their arthritis management.

5.5.1 Arthritis self-management in Ireland

Currently there is a wide spectrum of different types of SMIs occurring at various settings (Table 4) including:

(a) day to day individual education and structured group self-management programmes provided by HSCPs in secondary and primary care, and

(b) Arthritis Ireland self-management programmes delivered by trained patient educators in the community. Arthritis Ireland has developed a robust national infrastructure for the delivery of patient-led self-management programmes (also available online since 2015). Since 2006 over 5000 people have completed these community-based programmes.

An Arthritis Ireland study of course participants 2006-2011 showed a 34% reduction in GP visits after 1 year, fewer Emergency Department (ED) visits, fewer overnight stays and less visits to healthcare clinics. Due to limited capacity, these programmes are not meeting current needs, and there is a severe deficiency at a primary care level with geographical location of the person with arthritis a major influence on access.

Table 4. Type and location of current arthritis self-management programmes in Ireland

Secondary Care	Primary Care
HSCP, Pharmacy and Nurse-Led Education Programmes: Work Instability Programmes Amplified MDT Pain Management Programmes AS Classes Osteoporosis Education Programmes Lifestyle management inc. Joint Protection and Fatigue Management Programmes Musculoskeletal Health Medication Management	HSCP, Pharmacy and Nurse-Led (where available) Education Programmes: OA Knee Classes Back Classes Hydrotherapy Classes Clinical Pilates Classes Development of Joint Protection and Fatigue Management Programmes Medication Management
Specified and Condition-Specific Individual Education	Home/Community Based Individual Interventions Joint Specific Exercise Programmes
	Arthritis Ireland Led Programmes: Arthritis Self-Management Programme Break the Pain Cycle workshops AI Branch Organised Walking Groups AI Branch Organised Adapted Exercise classes

5.5.2 Delivery of a Self-Management Programme

An action plan is required to ensure that SMIs are planned and delivered in an integrated manner across the RhCNs and that patients get access to the most appropriate SMIs at all levels of the model of care. There is a recognition that self-management programmes should be delivered in a primary care setting and a SMI continuum should exist from primary to secondary/tertiary care where more specialist intervention can be provided.

This implementation plan should review the efficacy of various models, outline the staffing requirements and training needs, and contain proposals for the number of programmes to be delivered per annum in each clinical network. Self-management programmes need to be incorporated into the clinical pathways for the various rheumatic and musculoskeletal disorders.

6. Vocational Rehabilitation

Multiple international studies have shown that unemployment is generally harmful to physical and mental health and that work is associated with well-being (Waddell and Burton, 2006). However, very high rates of work disability have been identified in people with arthritis (Bevan et al., 2009b, Burton et al., 2006, Verstappen et al., 2004, Boonen et al., 2004, Dadoniene et al., 2004). Every third person with RA becomes work disabled (Bevan et al., 2009b) and as many as 40% of people with RA leave the workforce completely within five years of diagnosis. Survey data showed that 70% of Irish people with RA were unable to work due to arthritis (Arthritis Ireland, 2008).

Unemployment rates in AS are three times higher than in the general population (Boonen et al., 2001). A job loss rate of 46% has been identified among people with fibromyalgia and up to 15% of all working days in a calendar year are lost due to sick leave by employees with fibromyalgia (Al-Allaf, 2007, White et al., 2008)

The annual cost of lost productive time due to RA and other forms of arthritis in Ireland has been estimated as €1.6 billion (Bevan et al., 2009a). There is clearly a high level of unmet vocational need among Irish people with arthritis and there are very significant healthcare and welfare costs associated with work disability in this group.

A strong evidence base exists to support self-management and vocational rehabilitation interventions for reducing work disability (Waddell et al., 2008, College of Occupational Therapists, 2003, Bevan et al., 2009b, Macedo et al., 2009, van Duijn and Burdorf, 2008, Vlieland et al., 2009, Lacaille et al., 2008, Backman et al., 2008, Palmer et al., 2012, Li-Tsang et al., 2008, COST B13 Working Group, 2004, Williams et al., 2007).

Vocational Rehabilitation (VR) may be described as "a process to overcome the barriers an individual face when accessing, remaining or returning to work following injury, illness or impairment. This process includes the procedures in place to support the individual and or/employer or others (e.g. family and carers), including help to access the VR and to practically manage the delivery of VR" (Department for Work and Pensions (UK), 2004).

It is essential that all adolescents, young adults and people with work instability and disability have access to VR. Currently however, VR services for this population in Ireland are extremely limited and under-resourced. Arthritis Ireland previously offered group education programs to people with arthritis in relation to work but available evidence clearly indicates the need for individualised interventions including contact with employers and workplaces for successful vocational outcomes. The HSE occupational therapy services in acute hospitals and primary care offer extremely limited, primarily advice based, work related services to this group currently due to limited resources.

The "Fit for work" coalition - established in 2011 - is a task force comprising representatives of the health and business sectors that aims to reduce workplace absenteeism and improve the lives of people living with MSK disease. It is envisaged that VR programmes will be developed as an outcome of the "fit for work coalition".

The University of Limerick in conjunction with Arthritis Ireland secured funding through the Disability Activation Project supported by the European Social Fund and the Department of Social Protection to run individualised, occupational therapy led vocational rehabilitation programs for people with Arthritis in the Border, Western and Midland counties. The program is called 'Working with Arthritis: Strategies and Solutions', aimed to overcome the barriers people with arthritis face when accessing, remaining in, or returning to work. The program is being evaluated in terms of work outcomes, psychosocial outcomes and an economic evaluation will be completed.

Musculoskeletal diseases are the leading cause of temporary workplace disability accounting for 7 million lost days in absenteeism each year, amounting to over €750m in costs to the economy. (Bevan 2009). Fit For Work (FFW) Ireland is calling for the development of a national early intervention policy and infrastructure to support employers to intervene at an early stage in order to offset long term absence. This would include a number of measures including the appointment of occupational health "Case Managers" to provide a central link between the employer, the employee and their GP. In its basic form, where an Occupational Health Nurse contacts the employee after 4 weeks absence, it is estimated that this intervention would result in net savings of €89m (or 10%) at a cost of €3m. The introduction of an enhanced case management service involving additional support resources such as physiotherapy, counselling and occupational therapy, would result in estimated net savings of €178m (or 20%) at a cost of €12m.

FFW Ireland proposes that the Department of Social Protection implement a case management pilot. The chosen region would cover approximately 10,000 cases of people currently on Illness Benefit. 3 nurses and 3 administrators would be employed at a cost of €375k, with an external agency managing the pilot. The establishment of such a pilot would give the Department a clear indication of the measurable savings to the exchequer and could provide the case for its wider implication in Ireland.

To address the work needs of arthritis patients a number of short/medium term actions are required:

1. The adoption of an early intervention policy in employee absence
2. Introduce a fit note following an Irish College of General Practitioners (ICGP) review of sickness certification
3. Set up some Irish pilot employers through IBEC to prove a case for early intervention.

In 2011, over €77m was paid out by the Department of Social Protection and evidence from UK would show that 4-5% savings off this bill could be made by a formal national intervention policy.

In the long term:

1. Appointment of Clinical Specialist Occupational Therapists to lead the development of a nationwide community based vocational rehabilitation service for adolescents and people of working age with arthritis and allied health conditions based on the current best available evidence.
2. The development of vocational rehabilitation services nationwide.
3. Development of a comprehensive education program for MDT working with people with arthritis on vocational rehabilitation is required.

7. RhCN Service Delivery requirements

7.1 RhCN requirements

In most cases, there will be more than one rheumatology centre in each hospital grouping. An RhCN centre will ideally be based in a hospital where there is ready access to the range of sub-specialities. Given the similar nature of the patients (i.e. those with disabilities) and of the conditions treated (e.g. osteoarthritis) resulting in similar spatial and staff requirements, a close and functional relationship with orthopaedics where possible should be considered. In some regions, the rheumatology centre might be based across 2 sites e.g. Sligo/Manorhamilton. The following describes standards related to both facilities and staffing, which each centre would require in order to function effectively. It is recognised that the standards in most cases are such that considerable investment into rheumatology services will be required in order for all centres to achieve the necessary standards. This will only be achieved once the requirements are clearly delineated and an implementation plan over several years developed.

7.2 Facilities and Staffing

In order to function adequately each RhCN (each RhCN may have more than one centre delivering care) should have:

- Adequately designed facilities for service provision
    - Designated outpatient facilities including examination rooms (1 for each staff member attending clinic), treatment rooms and day room/rest room for patients
    - Designated day-case rehabilitation facilities including gym space, hydrotherapy facilities, activities of daily living (ADL) and hand therapy clinical space, individual treatment rooms and access to group space.
    - Office accommodation for staff members
    - Rapid access from Primary and Secondary care facilities and from Emergency Dept/AMU
    - Access to internet/email/fax/telephone and to Video consultation
- Access to adequate dedicated rheumatology beds for:
    - Day infusion (2 beds per 100,000),
    - 5-day admissions (1 bed per 100,000)
    - 7-day admissions (1 bed per 100,000)
    - 5 Day / Day case assessment and rehabilitation beds (2 beds per 100,000)
- Access to specialist laboratory and diagnostic imaging services
    - Basic laboratory testing at all centres including immunology (e.g. ANA/ENA/RF/CCP/ANCA)
    - Plain X-Ray, musculoskeletal ultrasound, CT scanning, DXA scanning, MRI imaging
    - A Musculoskeletal Radiologist

To affect the change proposed in this model of care, it is vital that manpower issues are addressed in the first instance as follows:

- Plan for a phased expansion of Consultant numbers initially up to a minimum 1 per 100,000 population in each region. An ideal ratio according to WHO and BSR would be 1:79,000 (assuming no GIM commitment).
- For the Paediatric Rheumatology population, there is a need to appoint 3.9 WTE additional Consultants specialising in paediatric rheumatology based at Our Lady's Children's Hospital Crumlin (OLCHC) and Temple Street Children's University Hospital with a view to the integration and relocation of the two centres to the new National Children's Hospital. Where possible, new posts developed should focus purely on rheumatology (no GIM component).
- Reduce GIM component for current posts to maximise care of patients with rheumatic disease.
- Co-ordinate rheumatic patients requiring admission through A&E by organising direct admission under the rheumatology team/urgent review clinics.
- Increase specialist registrar numbers – the number of posts will depend on the number of new Consultant appointments each year.
- Anticipated for every 100,000 of a population*:
    - 1.0 WTE Rheumatology CNS
    - 1.0 WTE MSK Clinical Specialist Physiotherapist (Advance Practice Therapist who functions to assess MSK patients as first contact practitioners)
    - 1.0 WTE Senior Physiotherapist
    - 1.0 WTE Extended Scope Occupational Therapy practitioner.
    - 1.0 WTE Senior Occupational Therapist
- Ensure for every 300,000 of the population there is access to:
    - ANP
    - Clinical Specialist Physiotherapist
    - Clinical Specialist Occupational Therapist
    - Dedicated Pharmacist
    - Dedicated Psychologist
    - Dedicated Podiatrist
    - WTE Dedicated Medical Social Worker
    - WTE Dedicated Senior Dietician

*Health and Social care professionals & nursing should have an outreach component. It is essential that there is an appropriate skill mix in the clinical networks

Within each RhCN integrated workforce needs will be continually assessed and job descriptions developed to reflect where care can best be delivered for the patient. Cross service provisions need to be considered, for example ANPs/CNSs and HSCP specialists could work between a rheumatology centre and primary care team (e.g. joint appointment) thus creating continuity of care for the patient, maximising exposure of specialist care at community level and creating opportunities for education and support of non-specialist colleagues.

7.3. Secondary Hospital Care

Secondary Hospitals which are part of the rheumatology network but not one of the rheumatology centres should provide adequate facilities for dedicated rheumatology outpatient assessment. Patients should expect to receive a similar standard of care in a secondary hospital as they would receive in a rheumatology centre. Access to all ancillary services however may not be available. Patients will have access to a specialist-delivered opinion, plain X-ray and phlebotomy but may have to travel for sub-speciality referral or specialised investigations e.g. MRI.

7.4. Tertiary Rheumatic and Musculoskeletal Diseases Units

Patients with complex illness, in particular those requiring lengthy periods of in-patient, day-patient or a continuum of in- or day-patient MDT rehabilitation should have access – ideally local - to specialised MDT treatment such as already exists in Rheumatic and MSK Diseases unit (RMDU) at Our Lady's Hospice & Care Services Harold's Cross, Dublin; Croom Hospital Limerick and Manorhamilton, Leitrim. It is recommended that the existing facilities are retained and developed. Where practical the RMDU's should provide tertiary care access for patients with more complex rehabilitation needs who do not have access to such facilities within their network. The Model of care for the RMDU already established at Our Lady's Hospice & Care Services Harold's Cross, Dublin is included in Appendix 2.

All RMDU's should develop academic links in order:

- To develop and pilot innovative ways of providing evidence-based best care to rheumatic disease patients at both community and secondary care levels. Following success in pilot studies, these innovative approaches can be extended nationally.
- To develop programmes of MDT education for all professions in modular format to complement existing programmes e.g. UCD Graduate Diploma in Rheumatology Nursing at Our Lady's Harold's Cross, in response to the educational requirements identified through the needs analysis.
- To conduct front-line clinical and patient-centred research which will improve our understanding of rheumatic disease pathogenesis and treatments.

8. Paediatric Rheumatology

The National Centre for Paediatric Rheumatology was established in 2006 in OLCHC with the appointment of Ireland's first paediatric rheumatologist. Prior to this appointment, there was a monthly rheumatology clinic in OLCHC under the care of a general paediatrician, with complex and severe cases being sent overseas to units in the United Kingdom (UK). A second consultant paediatric rheumatologist was recruited in October 2012 (NCPPN, 2015).

Demand for this national service has grown dramatically year on year, patient numbers have increased by almost 400% since 2006. The specialty of rheumatology continues to one of the most rapidly growing services within Ireland's largest tertiary children's hospital and now accounts for the highest number medical day care patients per year (NCPPN, 2015).

A weekly rheumatology clinic in Children's University Hospital, Temple Street, was established during the 1990's. The service was initially provided by a general paediatrician and since 2008 by a consultant paediatric rheumatologist who is employed on a part time basis as a general paediatrician.

It is estimated that in excess of 2,200 outpatients were seen by the National Centre for Paediatric Rheumatology by the end of 2014. The service is largely outpatient or day ward-delivered with only 80-90 inpatient admissions per year in OLCHC. There are patients waiting in excess of two years for a new appointment in OLCHC. (NCPPN, 2015)

Table 5. Conditions recognised and actively managed by the paediatric rheumatology service

JIA	Oligoarticular JIA Polyarticular JIA (RF negative/positive) Systemic JIA Enthesitis-related JIA Psoriatic JIA Undifferentiated JIA
CTD	Juvenile dermatomyositis (JDM) Systemic lupus erythematosus Mixed connective tissue diseases (MCTD) Scleroderma – systemic and localised/linear morphoea Sjogren's syndrome Overlap CTD

Vasculitis	Systemic vasculitis Polyarteritis nodosa Undifferentiated systemic vasculitis GPA/Wegner's Disease Behcet's syndrome Atypical Kawasaki disease Atypical Henoch Schonlein purpura Takayasu's arteritis/GCA Hypocomplementemic vasculitis or hypersensitivity vasculitis Cerebral vasculitis Post-infectious vasculitis
Systemic autoinflammatory disorders	Periodic fever syndromes (HIDS, PFAPA, CINCA,MWS,FCUS, FMF, TRAPS) Chronic recurrent multifocal osteomyelitis DIRA CANDLE syndrome
Reactive (post-infective) arthritis	Lyme disease with arthritis Post-streptococcal arthritis Post-infectious arthritis Relapsing polychondritis
Patients requiring immunosuppressant therapy	(under guidance of Rheumatology) Uveitis – idiopathic, other Lymphoproliferative disease
Other arthritis associated with systemic disease	Cystic fibrosis-related arthropathy Inflammatory bowl-related arthropathies Anti-phospholipid syndromes Osteoporosis (Idiopathic/Iatrogenic)

Genetic syndromes associated with stiff joints, arthralgia, arthritis	Skeletal dysplasia CACP Down's arthropathy/arthritis
Metabolic disorders with arthropathy	Mucopolysaccarodosis Hurlers
Non-inflammatory disorders	Benign hypermobility and hypermobility related to underlying syndromes (Ehlers Danlos Syndrome, Marfan's syndrome, Larsen's syndrome, Sticklers etc.) Pain amplification syndrome / chronic pain syndrome Reflex sympathetic dystrophy and complex regional pain syndromes Cold-induced injury Over use syndromes Erythromelalgia
Joint disease associated with other medical conditions	Complex, immunodeficiency, neoplasm, infectious disease, endocrine disorders, genetic, post-transplantation, and arthritis associated with birth defects

The National Clinical Programme for Paediatrics and Neonatology (NCPPN) has developed a model of care document detailing the proposed hub and spoke design, including the required staffing and infrastructure to facilitate successful implementation.

A national arthritis registry should also be developed with an associated clinical database. These initiatives will provide core data regarding arthritis and allied conditions which will in turn inform service planning and delivery for many years to come.

'Hub and spoke' model of care http://www.hse.ie/eng/about/Who/clinical/natclinprog/listofprogrammes.html)

Paediatric rheumatology is an ideal service in which to replicate this successful model of care. Given that the vast majority of patients have a chronic illness and many require the expertise of the unit for a considerable portion if not all of their childhood, this model develops local expertise and reduces travel for the patient to the national centre. The geographical spread of patients attending the NCPR is greatest from counties Cork, Donegal and Limerick outside the Greater Dublin area (see Figure 2). This model of care has been implemented in many units within the National Health Service (NHS) in the UK. Scotland, a country with a very similar population (over 5 million) and an even more fragmented geographical area, has a very integrated model of care from a large paediatric unit in Glasgow. It provides a network of outreach clinics from the hub unit, with clearly defined care pathways.

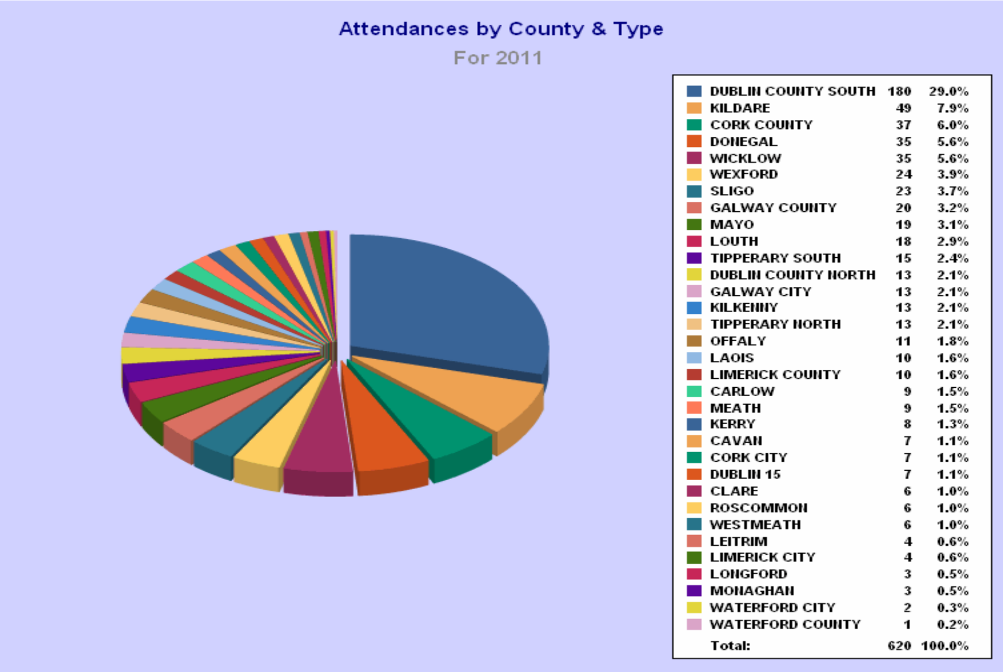

Figure 2. Rheumatology outpatient attendances by county 2011

A network would promote service delivery at the most local point of contact supported by agreed clinical standards and a service model. It will facilitate effective service interfaces and support good practice in a multidisciplinary approach.

- National referral process – a single referral document, available online to all clinicians and primary care providers, will be completed and sent by post or online
- Referrals triaged as urgent, soon or routine
- Referrals triaged on age (general clinic or teen transition clinic)
- Point of referral identified, if outside greater Dublin area linked with outreach clinic minimum of twice yearly, initial assessment to occur in NCPR
- Non-inflammatory conditions are assessed in hub unit or outreach clinic. All non-inflammatory conditions will be followed up locally if required.

It is proposed that the hub centre will provide an outreach clinic on a quarterly basis to the following areas:

a. Cork
b. Limerick
c. West/Northwest - Galway

This clinic will be attended by a paediatric rheumatologist with a local physician (either a consultant general paediatrician or an adult rheumatologist). Ideally, both will be in attendance as this would allow for replication of the already successfully award-winning model of care provided by the combined Crumlin/SVUH Transition Clinic in Dublin. As the outreach service develops, a separate transition clinic quarterly in each of the centres is expected to be needed. A local adult rheumatologist link in each outreach hospital will be required to ensure successful implementation of this model of care.

There will be a robust system for information sharing across a pathway of care and shared care guidelines and protocols to deliver good practice.

Outpatient care in the hub centre (new children's hospital) will remain unchanged with four-weekly outpatient clinics. There will be a requirement for further development of formal transition services across the greater Dublin area in addition to the SVUH Transition Clinic. Inpatient and day ward services will be provided in a dedicated paediatric clinical area within the new children's hospital (plans in process). A dedicated biologic and infusion suite will be part of this.

MDT care/input:

- Physio triaged non-inflammatory clinics (specialist physiotherapist)
- Nurse-led OPDs – biologic assessment and pre- injections
- Nurse-administered joint injections
- MDT-led non-inflammatory care programme
- Clinical specialist physiotherapy and occupational therapy triaged non-inflammatory clinics
- Physiotherapy – administered joint injections

9. Governance

The approach to clinical governance for the NCPR will be in line with the Code of Governance for the HSE. Clinical governance means corporate governance for clinical performance, built on the model of the Chief Executive Office, working in partnership with the Clinical Directors, Directors of Nursing/Midwifery and Service/Professional Leads. Clinical governance is about people receiving the right care, at the right time, from the right person in a safe, honest, open and caring environment. Effective governance arrangements recognise the interdependencies between corporate, financial and clinical governance across the service and integrates them to deliver high quality, safe and effective healthcare. Effective governance and accountability can be achieved by embedding leadership and operational management at a corporate and clinical level. This is underpinned by 6 key steps (Figure 2):

- Agree the measurable safety, quality, access and cost objectives you want to achieve which are in line with HSE national priorities.
- Ensure there is a documented standardised pathway in place, which is supported by standard clinical decision making and regulatory requirements.
- Ensure that all parties involved in the pathway have total clarity of their accountability roles, responsibilities and governance arrangements.
- Ensure there is a balanced set of metrics in place to track the performance of the pathway.
- Ensure there is an effective meeting held regularly, where those who are managing the pathway identify variance in its operational performance and log actions to be taken to improve the outcome for the patient.
- Where the reason for the variance is unclear or the action to address variance is significant then ideally there should be some skilled local project and process improvement resource available to guide the clinicians through the change process (may need external support or oversight).

The NCPR has embedded these principles by adopting a leadership and accountability framework that envisages every clinician and administrator working in the programme having clear roles and responsibilities. The structure of the programme is summarised in figure 3, where the patient is pivotal to clinical and corporate governance strategy development. It embraces clinical effectiveness, clinical audit, research and development, clinical indicators, integrated pathways, risk management, and organisational development.

The governance structure consists of two supervisory groups (sections 9.1 and 9.2).

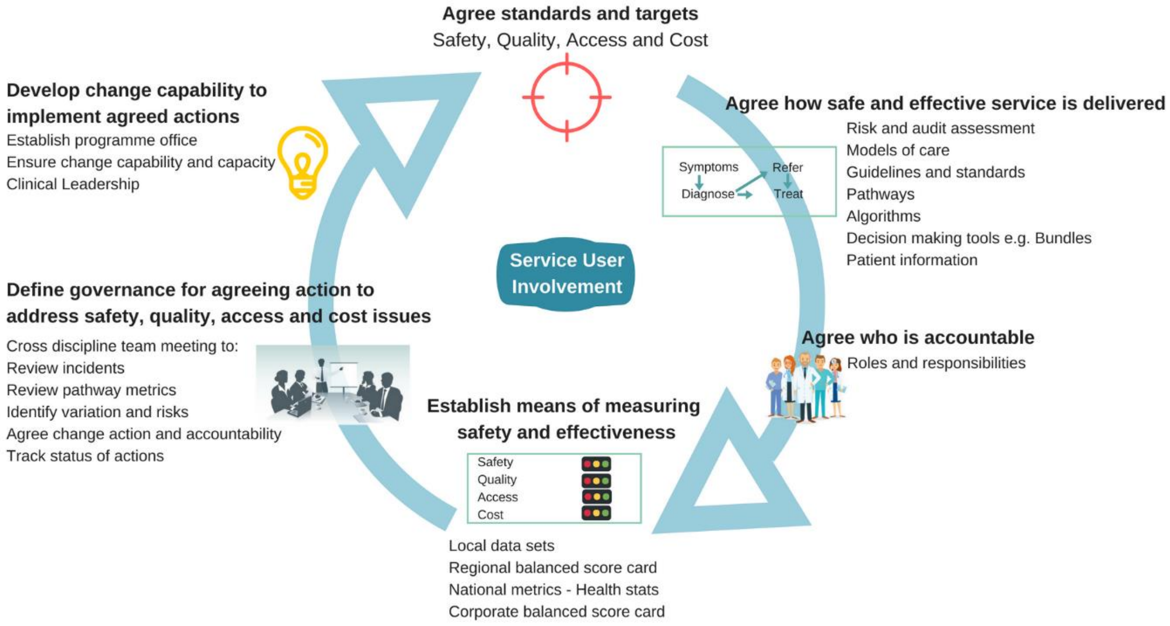

Figure 3. The embedding of Clinical Operational Management

9.1 Project group

The project group was convened in June 2010. The project group consists of: a National Clinical Lead who is a Consultant Rheumatologist, a General Practitioner Co-Lead, a Nursing Lead, a Physiotherapy Lead, an Occupational Therapy Lead, a Public Health Specialist, a Primary Care Practice Nurse Co-ordinator, at least 1 Patient Representative and a Rheumatologist representing each of the 6 HSE Hospital Groups. This group meets at least once monthly to plan, implement and continuously evaluate the programme.

9.2 Clinical Advisory Group

The clinical advisory group was first convened in June 2010. This group consists of Consultant Rheumatologists (Adult and Paediatric) and the president of the Irish Society for Rheumatology who is the Chairperson.

9.3 Roles and Responsibilities

1. The **National Clinical Lead** for the NCPR will be a consultant rheumatologist working in one of the regional centres. He or she will be accountable to the National Programme Director for Clinical Strategy and Programmes, the Clinical Advisory Group for the NCPR, the CEO and board of the HSE. He or she will be responsible for delivery of programme goals, quarterly reporting of national KPIs (section 9.5), national audit results, continuous improvement including reporting and managing adverse events and complaints.
2. The **Regional Rheumatology Leads** are the lead clinicians for rheumatology in each of the 6 Hospital Groups. He or she reports to the National Clinical Lead. He or she will be responsible for quarterly reporting of KPIs and audit outcomes for the region which they

represent. They will also be responsible for continuous improvement and managing adverse events and complaints within their region.

3. The **National Nursing Lead** is a nurse with background in specialist rheumatology nursing. He or she is accountable to the National Clinical Lead and to the National Nursing Directorate. He or she will represent nursing on the programme. For example, make recommendations in association with the other nurse specialists or recommend performance management and monitoring training of CNS, ANP and other nurses in outpatients and inpatient rheumatology settings.
4. The **Consultant Rheumatologists** will be accountable to the regional lead regarding rheumatology care only. He or she will be responsible for delivery of programme goals.
5. The **HSCP Leads representing Dietetics, Medical Social Worker, Occupational Therapy, Physiotherapy, Podiatry and Pharmacy** have a background in specialist rheumatology care and they represent one of the HSCP groups on the programme. They should lease with their specialist therapist colleagues to ensure adequate representation and make recommendations for example related to performance management and monitoring training of HSCP specialists in outpatient and inpatient rheumatology settings.
6. The **Rheumatology MDT** consisting of Dietician, Clinical Specialist Occupational Therapist, Staff and Senior Occupational Therapists, Clinical Specialist physiotherapist in MSK triage, senior and staff grade resources from Physiotherapy, Pharmacist and Podiatrist are clinically accountable within their own professions. However, in certain aspects of care they may be accountable to the patients-named consultant (e.g. adhering to weight bearing status). They are professionally accountable to their respective line managers e.g. Occupational Therapist Manager or Physiotherapist Manager in their health care setting. He or she will be (1) responsible for the local delivery of high quality, safe and risk adverse rheumatology care in the health care setting; (2) responsible for the safe, efficient and effective management of patient information both paper and electronic; and (3) is accountable for attaining the competencies and performance targets as set out by the quality care programme.
7. The rheumatology **ANPs and CNSs** are clinically accountable to the patient's named consultant rheumatologist. They are professionally accountable to the Director of Nursing in their health care setting. He or she will be (1) responsible for the local delivery of high quality rheumatology care in the health care setting; (2) responsible for the safe, efficient and effective management of patient information both paper and electronic; and (3) accountable for attaining the competencies and performance targets as set out by the clinical care programme.
8. The **General Practitioner** is accountable to the Irish College of General Practitioners and the HSE. The GP is responsible for the general management of rheumatology patients in the community, and for maintaining contact with their regional

rheumatology centre. GPSI is a GP with a special interest who manages rheumatology patients both within the Rheumatology service and the community.

9. The **Professional Development Co-ordinator for Practice Nurses** is accountable to the HSE and will link with the practice nurses privately employed in general practice with regard to their responsibility in the management of rheumatology patients under the care of the GP

9.4 Training

A. Medical

There is currently a specialist registrar training programme in rheumatology structured through the Royal College of Physicians in Ireland (RCPI). This 5-year programme which includes GIM training is co-ordinated by a National Specialty Trainer who is appointed by RCPI. A core rheumatology training curriculum has been agreed. Specialist Registrar trainees are evaluated continuously by their local hospital trainer and by a committee established by RCPI on a yearly basis.

B. Physiotherapy

The CPR (Chartered Physiotherapists in Rheumatology) group which is a special interest group of the Irish Society of Chartered Physiotherapists (ISCP) promotes, organises and provides ongoing CPD training and education specific to physiotherapy in rheumatology. It also acts as an information resource to physiotherapists nationally and provides external training to other disciplines and patient groups. There are also both Senior and Staff grade physiotherapy national competency framework documents.

C. MSK Clinical Specialist physiotherapists (Advanced Practice)

The HSE HSCP Leadership, Education and Development Unit funded Advanced Physiotherapy Musculoskeletal training in 2010/2011.

The objective of the training was to give physiotherapists the additional knowledge and skills to support professional development working at an advanced level in a consultant led outpatient clinics. Thirty-three applicants completed the course, coming from each of the four HSE regions. Refer to Appendix 4 for details of training programme. Further training days will be planned in coming years to address training needs.

Modular programmes can be developed to address the education needs of role extension including referral for radiological investigations, blood tests and administration of injections. These can be delivered to the care providers in blocks e.g. Mandatory training days. This development would be in conjunction with the ISCP and HSE HSCP Leadership, Education and Development Unit.

It is planned to establish groups that would be affiliated to the RhCN for the purposes of delivering specific areas of CPD. The ISCP has an Advanced Practice Physiotherapy network through which the national programme will liaise to ensure that upcoming training requirements for this group are met. Local arrangements are in place in each centre to maintain individual competency levels for working at an advanced level, succession planning and developing other skills that may be required e.g. injection therapy.

D. Nursing

Professional accountability of nurses and midwives is clearly defined by the Scope of Nursing and Midwifery Practice Framework. Each nurse and midwife are individually accountable for his/her professional practice including appropriate delegation.

Non-rheumatology specialist nurses will have access to a short rheumatology educational programme to assist them in the care and timely referral of rheumatology patients to the appropriate specialist HCP.

Defined competencies using a competency framework will allow staff nurses develop into CNS's and work toward Advance Nurse Practitioner over a predetermined period of time. For nurses interested in developing their specialty roles, there is a recognised Post Graduate Rheumatology Diploma established by UCD and facilitated at Our Lady's Hospice and Care Services. All new rheumatology CNS's and ANP's will be expected to become registered nurse prescribers.

A rheumatology nurse job description, personal development Plan, the competency framework with supported mentorship; benchmarking and extensive clinical experience will enable the novice rheumatology nurse over time to practice at an advanced level.

E. Occupational Therapy

The professional accountability of occupational therapists is clearly defined in the code of ethics from the National Association of Occupational Therapists of Ireland (AOTI). The Rheumatic MSK Disorders and Chronic Pain Advisory group to AOTI has developed protocols for splinting for various diagnoses. In addition, this group are currently developing a competency document for Occupational therapy grades working in rheumatology, in primary and secondary care settings. A handbook for Occupational Therapists on Vocational Rehabilitation for clients with chronic pain and musculoskeletal disorders in Ireland has been published. AOTI in conjunction with the advisory group provide rheumatology education and training courses for primary care occupational therapists. Members of this subgroup were involved in the development of a handbook titled 'Vocational Rehabilitation for clients with chronic pain and musculoskeletal disorders in Ireland' in 2012. This publication details the valuable role OT contributes to this field. There is excellent potential to expand the role of occupational therapists into advanced practitioner and clinical specialist roles. The value of occupational therapy led clinics is well recognised in the UK, particularly in the speciality of hands and upper rehabilitation (Ellis et al., 2001, Lee–Rose et al., 2009, Storey et al., 2008).

F. Nutrition and Dietetics

Professional accountability of dieticians is defined in the Irish Nutrition Dietetic Institute Code of Professional Practice. The protection of title is pending through state registration.

G. Podiatry

Professional accountability of Podiatrists is clearly defined in the International Federation of Podiatrists (Fédération Internationale Podologues (FIP)) code of practice document. There are both Basic and Senior Grade podiatrist national competency framework documents.

Podiatrists receive extensive training in the diagnosis and treatment of MSK and rheumatological disorders affecting the lower limb during the BSc. (Hones.) Podiatry programme at NUI Galway. This is complemented with pharmacology training, injection therapy training as well as complementary therapies such as acupuncture. Undergraduate training also encompasses the management of tissue viability problems and therefore podiatrists are ideally suited to manage the vascular, dermatological and neurological manifestations of rheumatological disorders that are often compounded by foot deformity.

It is anticipated that postgraduate training in extension of the role of the podiatrist will commence in September 2015. This training will include referral for radiological and haematological investigations, use of diagnostic ultrasound and the provision of specialist footwear and orthoses.

H. Pharmacy

Professional accountability for pharmacists is governed by legislation which is overseen by the Pharmaceutical Society of Ireland. Furthermore, many Hospital Pharmacists hold post graduate qualifications in Clinical and Hospital Pharmacy. CPD is a requirement for registration and practice as a pharmacist and is led by the Irish Institute of Pharmacy.

9.5 Key Performance Indicators, Audit and Research

Regular prospective audit will be central to the programme in order to justify funding and demonstrate improved outcomes in quality and access. The Rheumatology Electronic Patient Record, which will be updated at every clinical encounter, will contain the data required for generating KPIs. Special arrangements for audit of telephone and electronic communication will be made and the HIPE data base will be used to understand outcomes in hospitalised patients. Initial KPIs have been submitted to the directorate and include:

1. % improvement in wait time for OPD access for urgent patients
2. % improvement in wait time for OPD access for routine patients.
3. Gap between supply (number of patients seen) and demand (number of referrals received) per month/year.

The MSK physiotherapy initiative has 4 KPIs collected by the programme (Appendix 3).

The KPIs chosen are specific, measurable and feasible in that for the most part they use existing data. They have considered the domains of 'structure, process and outcome' with particular emphasis on quality and access. The process will involve establishing a baseline, tracking changes and reporting on improvements or areas which require intervention. The KPIs also provide criteria and standards for clinical and organisational audit.

Governance will be addressed at two levels to ensure an effective performance monitoring system:

- Scientific governance of the KPIs within the overall Clinical programmes with technical oversight of the selection of indicators; updating based on evidence; agreement of data definitions; ensuring robust analysis; etc. and
- Reporting structure for sign off on KPIs, and for implementing processes for data collection, analysis and reporting.

The National KPIs will be reviewed in the context of the Corporate and Service Plan within the Department of Health. Data collation, analysis and reporting processes will be developed with the Directorate of Corporate Planning and Control Processes (CPCP). The KPIs will also be reported in conjunction with current monitoring HSE frameworks i.e. Healthstat. In addition, KPIs will also be reviewed in the context of the outcomes from the development of the care pathways. In September 2010, HIQA published 'Guidance on developing KPIs and minimum data sets to monitor health care quality' (HIQA, 2010) based on an analysis of evidence from an extensive literature review. This document has been used to inform the NCPR on indicator development.

9.6 Education and Research

The strong commitment to education and research in all rheumatology departments nationally is clearly evident. This model is predicated on clinical rheumatology service development being supported by ongoing education and research to innovate and improved services. Output as measured by publications, grant support and higher degrees is considerable given the small number of centres and individuals involved. This is all the more impressive when the absence of any protected academic time is factored in.

The University sector is a vital component of the proposed RhCNs. Recognising this, Arthritis Ireland has funded the development of an Academic Rheumatology Centre linked initially to both UCD and TCD. This initiative includes the appointment of Chairs in Rheumatology at both universities together with lecturer and administrative support. The centre is facilitating meaningful engagement and collaboration with other universities and rheumatology departments at UCC, UCHG, UL, etc. A research nurse network is being established nationally. Enhanced education and research relating to arthritis is an essential component of service delivery and the following actions are proposed:

a) Develop a core curriculum for undergraduates agreed by all universities and across all disciplines
b) Develop and extend post-graduate degree/diploma courses for specialists in the area of rheumatology, support and mentoring to enable extended scope of practice for health and social care professionals.
c) Develop multidisciplinary short courses possibly via blended learning to maximise the provision of education to non-rheumatology specialists e.g. primary care teams, MDTs, GP training/Immersion and practice nurses study days.
d) There is a need to expand the delivery of graded education programmes focussed on arthritis and related conditions for all Health and Social Care service providers, especially those dealing with marginalised groups or in residential settings e.g. The FETAC level 5 Health Care Support Certificate module entitled -Rheumatic Conditions Care Support programme. Our Lady's Hospice and Care Services Harold's Cross received FETAC approval in 2008 to deliver this module. These programmes can range from basic awareness programmes to CPD programmes.
e) Develop education opportunities focusing on disease prevention in conjunction with groups such as Arthritis Ireland.
f) Education requirements to be focused on needs of specific groups e.g. SPR's, nursing and HSCPs. Post-graduate programmes also need to develop suitable programme for primary care.

The Rheumatology MSK Clinical programme successfully received funding via a joint initiative between the Health Research Board, the Health Service Executive and the Royal College of Physicians. The project, "Supporting Work Participation through Early Intervention in Patients with Regional Musculoskeletal Pain", aims to develop an early integrated care intervention to improve work retention/participation, improve functional status, and increase health related quality of life for people with musculoskeletal diseases (MSDs).

9.7 Risk Management

The HSE has in place structured systems to identify report, investigate and address incidents that arise in the delivery of healthcare services. There are protocols are in place, that are adhered to nationally so as to ensure that any incidents of harm are investigated locally, any issues are identified, and actions taken to ensure that risk is minimised. Staff members employed by the HSE have been trained to ensure that all local investigations follow the agreed HSE's Investigation Procedure.

For rheumatology, systems will be in place to ensure adherence to good standards, including ethical standards and systems for making and dealing with complaints. This will happen in line with HSE's Quality and Patient Safety Directorate, which oversees the quality of services and the adherence to standards, so as to ensure that patient safety is protected. With robust investigation of adverse incidents, learning is identified and shared across the system. Clinical decision-making support tools in the form of Integrated Care Pathways, Standard Operating Procedures and Management Operating Procedures have been developed by the programme to ensure that care given is standardised and evidence based.

Information governance including how data will be protected and how information will be disseminated throughout the system will be developed in line with the overall Clinical programmes. The forthcoming Health Information Bill will address issues around data.

Many of the drugs used in Rheumatology carry specific risks for patient harm, in terms of both clinical complications and medication error. In addition to the management of such incidents via the HSE's established systems, there is a need to monitor for and report adverse outcome associated with medication use to the Hospital Pharmacy Association.

9.8 Performance Management

The NCPR recommends team-based performance management (TBPM) as a mechanism for managing performance across each RhCN.

TBPM:

- Provides greater clarity on roles and purposes
- Enables better communication and participation within and among teams
- Increases motivation by providing a structure within which staff can contribute to the service goals
- Provides a means for identifying and addressing learning and development needs

Each of the RhCNs will be expected to perform and function as a team. Personal Development Planning (PDP) is a continuous development process that enables people to make the best use of their skills and helps advance both the individuals plans and the goals of the organisation. The Rheumatology teams are expected to develop PDP's and to discuss them with their line managers and regional lead on a regular basis.

These teams are expected to comply with local and national disciplinary and grievance policies when poor performance requires review.

10. Potential Impact

10.1 Value

It is suggested that the NCPR can significantly contribute to cost savings. These savings can in turn be re-invested in the NCPR ensuring that programme developments are cost-neutral.

Potential areas of savings include:

1. Rational use of biologic therapies

The cost of these treatments is significant (approx. €125m/year), but this cost must be balanced against the long-term benefits including quality of life indicators. The clinical efficacy of these treatments has been proven in both randomised controlled trials and long-term observational studies. Additional evidence from national Irish data between 1995 – 2010 shows a reduction in the number of hospital bed days for RA, and a reduction in the number of RA patients requiring elective orthopaedic procedures both closely correlating with an increase in TNF prescribing during the same period. Further significant cost savings can be made with elimination of wastage and dose-reduction policies. In order to achieve this, the following steps will be required:

   a) Development of web-based high-tech prescription authorisation system which will in addition provide accurate data on biologic usage
   b) Unifying hospital-delivered and high-tech delivered drug budgets to allow for community delivered infusion programmes, policies for safe vial-sharing and cost savings (€100,000/year/100 patients treated)
   c) Consideration of use of Biosimilars and the development of dose reduction policies for patients with stable rheumatic disease.

2. Early intervention strategies for individuals out of work because of MSK-related issues would improve patient’s physical, emotional and vocational outcomes while saving considerable expense for the exchequer. The introduction of a “Fit Note” instead of a “Sick Certificate” would help put the focus on what the individual is able to do and thus facilitate an early return to the workplace (Work Foundation Research, 2012).
3. Identification and treatment of patients with osteoporosis who are at risk of fracture. The introduction of fracture–liaison programmes, including a falls risk assessment, to substantially increase the number of patients with low trauma fractures assessed and treated.

10.2 Information Technology

To deliver on the full potential that the clinical care programmes offer, will require significant information and knowledge management, and technology to support and enable these changes.

Of note, the Fair Care plan that sets out the healthcare programme of the latest administration makes explicit reference to the need to set aside such investment so “IT follows the Patient”.

The results of a HSE survey on the priorities of the national clinical programmes leads indicated that an "Integrated Electronic Patient Record" was their number one clinical services support need identified in 2012.

Several of the key elements of the IT solutions required have already been outlined within the HSE ICT Strategy (HSE, 2011), while many of the key challenges related to the rollout of an Electronic Patient Record are documented within the HIQA roadmap for an eHealth platform and national EHR (HIQA, 2011).

An exploration of the fit between the National Clinical Programmes ICT needs and related options for such support will need to be undertaken.

10.3 Implementation Timeline

As one of the national programmes in clinical care, the National Clinical Programme for Rheumatology is considered along with other specialities involved in providing care to those with chronic disease. As there is a major focus on care-delivery at outpatient level, the NCPR will liaise closely with the outpatient function within the HSE. Additionally

The NCPR is surveying and visiting each site nationally to conduct a gap analysis to allow for the development of an informed implementation plan, which will follow in the near future.

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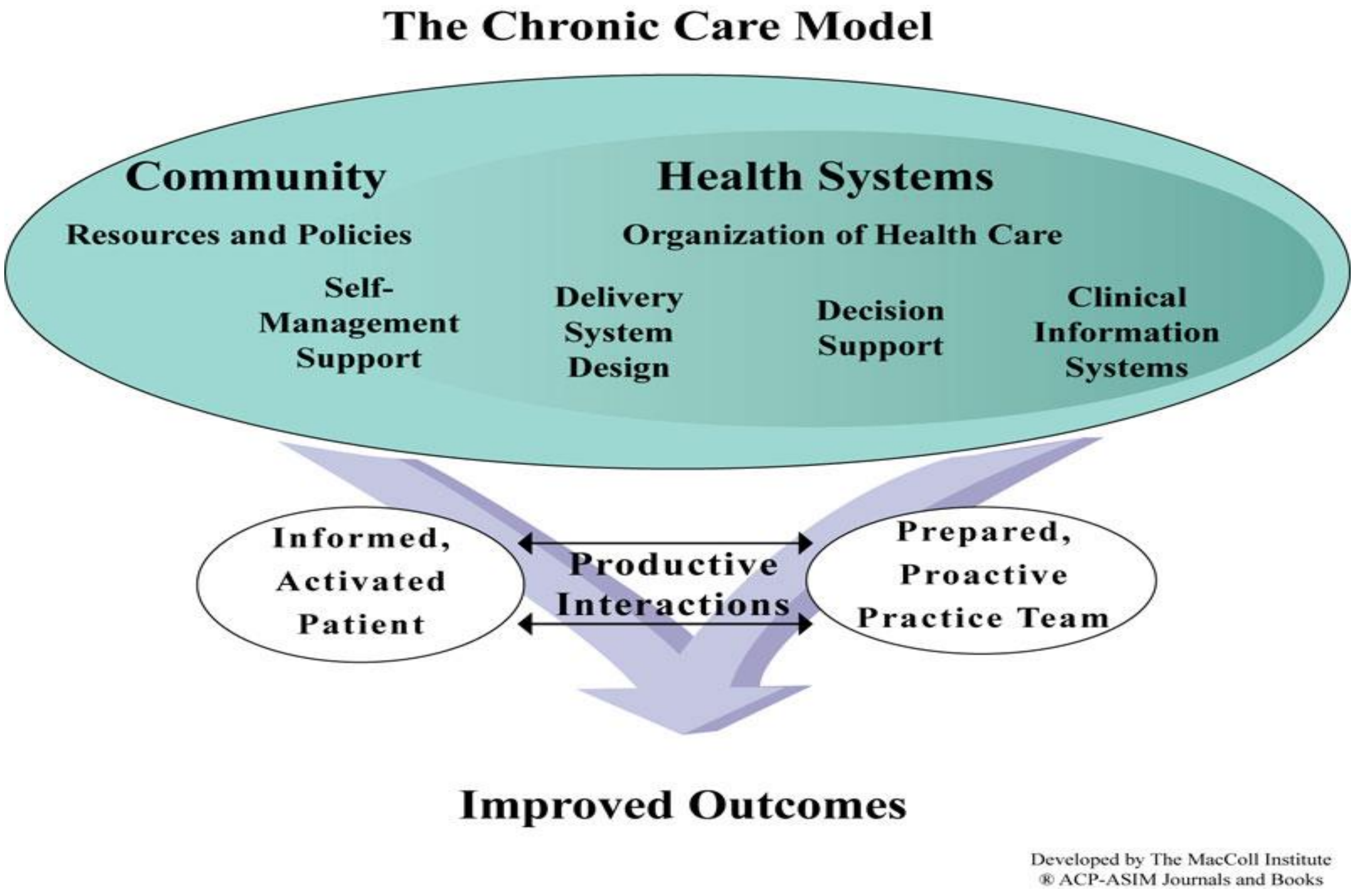
Appendix 1

Chronic Care Model (Wagner, 1998)



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Appendix 2

Rheumatic Musculoskeletal Disease Unit, Our Lady's Hospice and Care Services – A Tertiary Referral Rheumatology Facility

The rheumatic and musculoskeletal disease unit (RMDU) at Our Lady's Hospice and Care Service (OLH&CS) is dedicated to the treatment of patients with chronic rheumatologic conditions who require medical management, specialist care and rehabilitation. The RMDU is located within OLH&CS complex where high quality of care, support, accommodation and facilities are provided by expert MDTs, support services and volunteers. Clinical expertise is shared across all care services on site to enhance pain and symptom management and quality of life for all patients.

As is recognised internationally with all chronic disease groups, 30-40% of rheumatology patients' care needs are inappropriately met through standard outpatient care (Minnock et al., 2012c) adding to the personal, societal, health and social care burden of chronic rheumatic diseases (Department of Health, 2006, Taylor, 2007a, Health Service Executive, 2008, Minnock et al., 2012a). The RMDU patient population predominately comprises those categorised as: -

i) High risk patients requiring care management (Level 2), that is, a period of focused multidisciplinary assessment and monitoring), and

ii) Highly complex patients requiring case management (Level 3), that is, long term care co-ordination. These are service needs identified in chronic disease model of care (Department of Health, 2006, Minnock et al., 2012c) (Figure 3).

Care Delivery Model's Three-Pronged Approach

The key to the successful care of people with long-term conditions which include musculoskeletal conditions such as osteoarthritis and rheumatoid arthritis comprises: -

Level 1: Supported self-care

Collaboratively helping individuals and their carers to develop the knowledge, skills and confidence to care for themselves and their condition effectively; this approach, includes health promotion.

Level 2: Care management

Providing people who have a complex single need or multiple conditions with responsive specialist services, using multidisciplinary teams and disease-specific protocols and pathways.

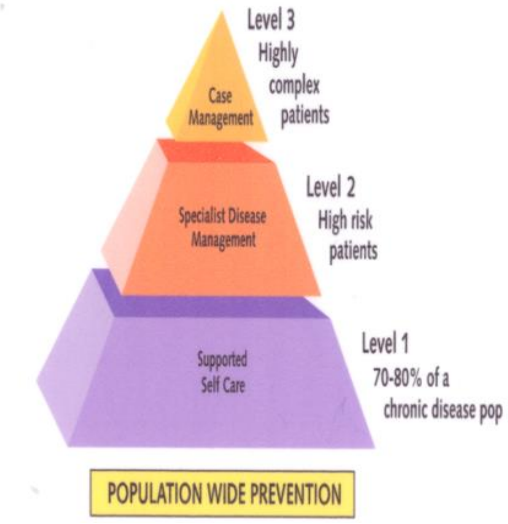

Figure 4. Chronic Disease Pyramid of Care Model

Level 3: Case management

Identifying the most vulnerable people, those with highly complex multiple long-term conditions and using a case management approach to anticipate, co-ordinate and join up health and social care.

The **overarching goal** of the dedicated RMDU at OLH&CS is to improve symptom control, function and wellbeing in patients who are experiencing significant physical, emotional or vocational disability in order to enhance healthcare outcome and to minimise the personal, societal health and social care burden of chronic rheumatic and musculoskeletal diseases.

The essence of the RMDU is specialist **interdisciplinary team care** (IDTC) grounded in a **biopsychosocial** (BPS) **model of care** (Engel, 1977). This incorporates multidisciplinary assessment, diagnosis, treatment, rehabilitation and on-going disease management provided on an In-Patient, Day-Patient care according to the medical and functional/psychosocial requirements of the patient (Minnock et al., 2012b); Outpatient care is also provided to select patients with most complex needs (Taylor, 2007a, Minnock et al., 2012c) as a health quality initiative in order to maximise patient outcome, optimise healthcare resource utilisation i.e. reducing acute hospital attendance and admission need.

Onsite **team expertise** comprises consultant rheumatologists, paediatric rheumatologist and specialist registrars, generalist, specialist and advanced nursing expertise, incorporating intravenous infusion services, nurse prescribing and joint injections; occupational therapists, clinical specialist occupational therapist, incorporating vocational rehabilitation; physiotherapists, aquatic physiotherapists; medical social worker and liaison psychiatry incorporating psychotherapy interventions; dedicated clinical pharmacist; podiatry and orthotic services; phlebotomy and radiography.

The **multiple admission pathways** reflect both the regional and national profile of RMDU and includes referrals from St Vincent's Healthcare Group, Our Lady's Children's Hospital, Crumlin, Cappagh National Orthopaedic Hospital, patients referred from St. James's Hospital and Tallaght Hospital (15% in 2012), and referrals from other rheumatology centres nationally).

Local evaluation of service need, utilisation and patient outcome

In one survey conducted on 91 in-patients during 2011 the likelihood of requiring the following additional healthcare services if not treated at RMDU was reported, more visits than usual to GP (n=75), to consultant rheumatologist (n=61), to an accident and emergency department (n=29), to consultant orthopaedic surgeon (n=21), to public health nurse (n=19), and overnight hospital admission (n=16), 99% of respondents reported deriving benefit from RMDU in terms of managing and coping with their condition. This survey confirmed that patients with chronic rheumatic disorders have limited access to appropriate interdisciplinary healthcare within their locality (Minnock et al., 2012a).

It is recognised within that with chronic disease care models that those patients with more complex care needs exert a disproportionate drain on healthcare resources as they require specialist care, intensive intervention and are at high risk of hospitalisation (Taylor, 2007, Health Service Executive, 2008). A local audit to quantify and identify patients whose healthcare needs are more suited to single or multidisciplinary outpatient care at RMDU as opposed to standard outpatient care (OPD) found this to be in the region of 5% of the service population (Minnock et al., 2012c).

To evaluate health status prior to initiation and following completion of IDCP's at RMDU, during a 3-month period in 2012, 59 patients completed seven internationally recognised core outcome measures in rheumatic diseases. A statistically significant improvement in health outcome was found on programme completion in relation to early morning stiffness duration (p≤0.037); pain (VAS p≤0.0001); global health status (VAS p≤0.002); fatigue level (p≤0.027), fatigue effect (p≤0.005). Mean health assessment questionnaire) (HAQ) score at initiation (1.52) and completion (1.49) represented mild/moderate overall functional impairment. A statistically significant improvement in life activities (p≤0.001) was demonstrated (Minnock et al., 2012b).

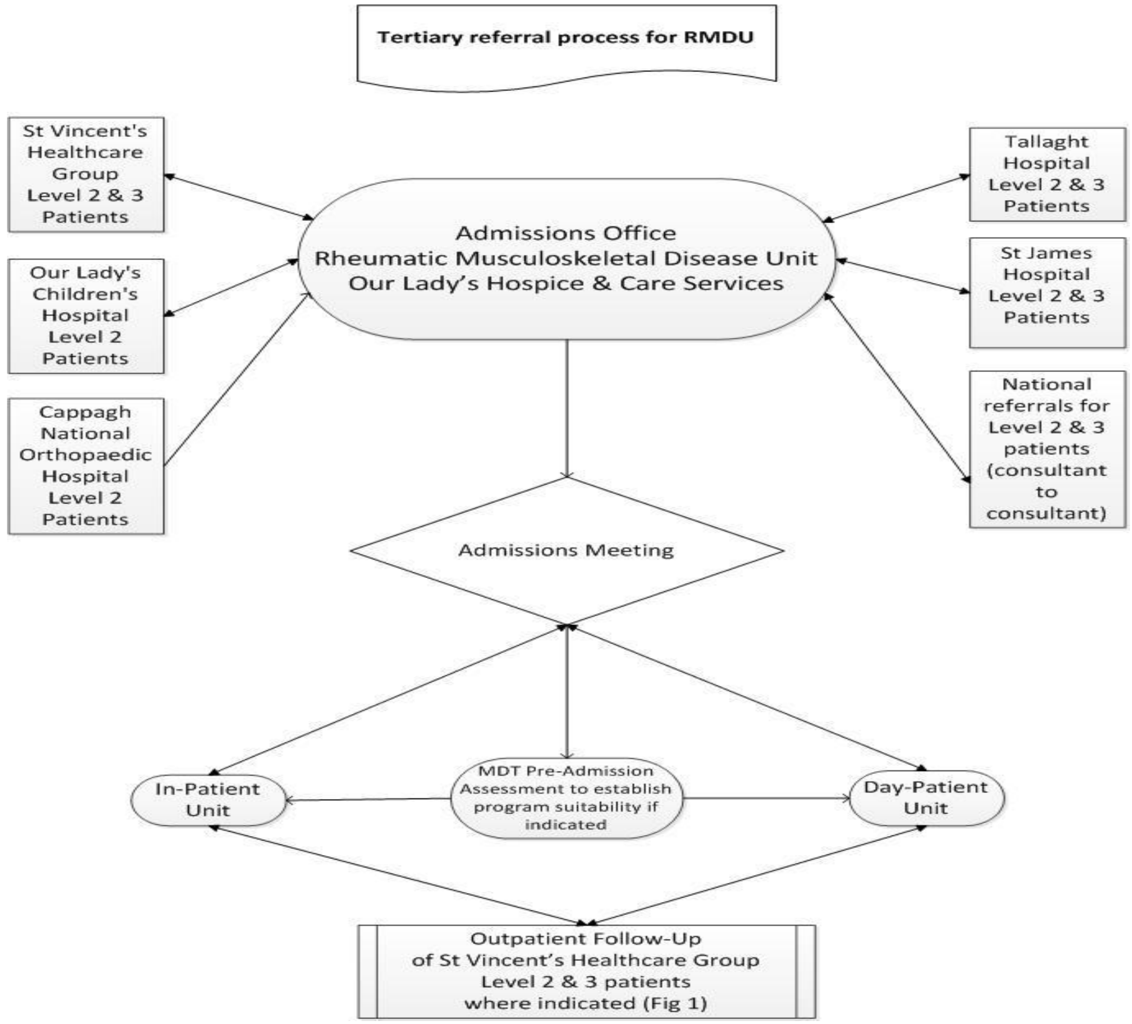

Figure 5.Tertiary referral pathways to RMDU, OLH&CS

Interdisciplinary Care Programmes

Inpatient and/or Day-Patient (Full Day/Half Day/Sessional)

Programmes of care provided for patients with rheumatologic conditions (i.e. widespread generalised inflammatory arthritis or osteoarthritis or connective tissue disorder include:

I. Disease management and re-conditioning programme
II. Pain management programme
III. Medication management programme (pre-treatment screening/review/IV infusion)
IV. Young adult with rheumatic disease (YARD) programme
V. Upper and lower limb joint replacement/reconstruction post-operative programme
VI. Degenerative spinal /vertebral insufficiency fracture rehabilitation programme
VII. Spondyloarthropathy education and management programme

Outpatient Care

Follow-up outpatient care is also provided to select patients whose healthcare needs are more suited to single or multidisciplinary outpatient care at OLH&CS as opposed to standard outpatient care within the acute healthcare setting (OPD); this patient population includes:

I. High risk patients requiring care management i.e. until treatment targets reached such as disease remission, when then referred for standard OPD follow-up (Level 2, Figure 1), and
II. Highly complex patients requiring case management through care co-ordination (estimate 30% service patient population) (Level 3, Figure 1) (Minnock et al., 2012c, Health Service Executive, 2008),
III. Patients requiring fertility & pregnancy related healthcare.

Group Education Programmes

I. Inflammatory arthritis
II. TNFi treatment
III. Bone Health
IV. Back care
V. Living well with arthritis (pacing and joint protection)
VI. Managing stress in everyday life
VII. Relaxation

Education and Research

Educational Suite Onsite & in partnership with UCD & TCD

I. Graduate Diploma in Rheumatology Nursing
II. Pathophysiology of Rheumatic Diseases, (Professional Certificate)
III. Management of Age Related Bone and Joint Disorders (Professional Certificate)

IV. Management of Intra-articular & Soft tissue injection techniques (Professional Certificate)
V. Rheumatology for Healthcare Professionals (3-day programme) (Introduction)
VI. GP trainee immersion day (onsite multidisciplinary delivery)
VII. Musculoskeletal Assessment for Health Professionals: Blended Learning: On-line & workshop
VIII. Undergraduate nursing, occupational therapy, physiotherapy and pharmacy student placements
IX. FETAC (Health Care Assistants) (Care Skills Module).

Translational Research

The RMDU Translational Research programme integrates the rheumatology group with researchers in molecular and cellular biology, psycho-immunology and cancer across the ERC, the Conway Institute, UCD and TCD. The Rheumatology Research group includes Principal Investigators - Prof Douglas Veale, Dr Ursula Fearon, Dr Eamonn Molloy, Prof Gerry Wilson, and Prof Oliver FitzGerald with a primary clinical focus on early, inflammatory arthritis and giant cell arteritis, and a scientific focus on mechanisms of angiogenesis, inflammation, biomarkers, epigenetics and genetics.

Supporting Patients with chronic rheumatologic conditions:

The Rheumatic and Musculoskeletal Diseases Unit at OLH & CS is recommended as the model of care for a rheumatology tertiary referral centre expertly positioned to support development of all rheumatology services nationally. In keeping with international statistics in relation to population management for chronic conditions (Taylor, 2007b), and further substantiated by a local study (Minnock et al., 2012c), it can be stated that between 3-5% of patients within all rheumatology services nationally (estimated 1500-2500 patients) experience more complex care needs as they have significant physical, emotional or vocational disability. Ideally, these patients should participate in the multidisciplinary assessment and treatment programme at an RMDU in order to enhance healthcare outcome and minimise overall disease burden.

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Appendix 3

Key Performance indicators of the National MSK Physiotherapy Triage Initiative

KPI 1	
Title	Number of new MSK Orthopaedic and Rheumatology attendances seen by MSK Physiotherapist
Description	New Outpatient- attendance by a patient at a hospital clinic, for a planned consultation, who has NOT been seen previously as an outpatient with the same condition (same consultant referral) within the previous 12 months
Rationale	This indicator is a key access indicator. All MSK physiotherapists should be seeing a minimum number of patients per year in order to meet demand. The number of outpatients to be seen per hospital per year can then be calculated.
Target	Combined target of orthopaedic and rheumatology patients: target combined orthopaedic and rheumatology = 80 per MSK physiotherapist per month and 1000 new patients per MSK physio per year
Reporting	KPI will be reported monthly to clinicalprogrammeadmin@rcpi.ie

KPI 2	
Title	New:Return attendance ratio
Description	The ratio of the number of new patients seen in an Orthopaedic/Rheumatology outpatient clinic over a certain time period to the number of return outpatients seen in that clinic over the same time period. Return patients are those who re-attend after their initial new appointment for a review appointment associated with the one referral
Rationale	This is an access indicator. A high number of return appointments will limit the number of possible new appointments
Target	10:1 new:return (minimum tolerated)
Reporting	KPI will be reported monthly to clinicalprogrammeadmin@rcpi.ie

KPI 3	
Title	Referrals triaged as appropriate for MSK physiotherapist shall be seen by an MSK physiotherapist within 3 months of receipt of referral at hospital centre
Description	Percentage of referrals seen this month that have been seen within 3 months of receipt of referral
Rationale	This is an access indicator and is line with the SDU technical guidance on OPD wait times 2015
Target	70% of referrals have been seen by an MSK physiotherapist within 3 months of receipt of referral
Reporting	KPI will be reported monthly to clinicalprogrammeadmin@rcpi.ie

KPI 4	
Title	Percentage DNA rate for New patient appointments across orthopaedics and rheumatology
Description	Percentage of new patients who did not attend their first appointment in both orthopaedics and rheumatology in the previous month
Rationale	This is an access indicator and is in line with the National OPD performance improvement guidelines for DNAs in 2015
Target	12% DNA rate as per national OPD performance improvement programme
Reporting	KPI will be reported monthly to clinicalprogrammeadmin@rcpi.ie

Appendix 4

Advanced Physiotherapy Musculoskeletal Training for Physiotherapists

Objective

The Advanced Physiotherapy Musculoskeletal Training for Physiotherapists course was provided following identification of this need as a strategic priority in 2010. The objective of the training was to give physiotherapists the knowledge and skills to practice at an advanced level in a consultant – led clinic. The programme aimed to replicate the theory-based training available to physiotherapists in the UK, undertaking similar roles and to instruct physiotherapists in the process required to establish and maintain their competency as a physiotherapist working in a consultant led clinic.

Sponsor

The training programme proposal was approved and funded by the HSE Health and Social Care Professions (H&SCP) Leadership, Education and Development (2010) in response to a call for strategic priority continuing professional development (CPD) funding-disciplinary specific from the ISCP.

Training Course

The training was scheduled over 12 days, in general 4 blocks of 3 days between September 2010 and December 2010.

Expert musculoskeletal clinicians who have established very successful physiotherapy led musculoskeletal advanced practice roles in the UK were invited to deliver the training. A large number of Irish based medical consultants were involved in the candidate training.

The programme content was modelled on existing masters-level programmes available in the United Kingdom (UK). The training programme was structured in a similar manner to a Higher Education Institution (HEI) Module.

The key components of the training included:

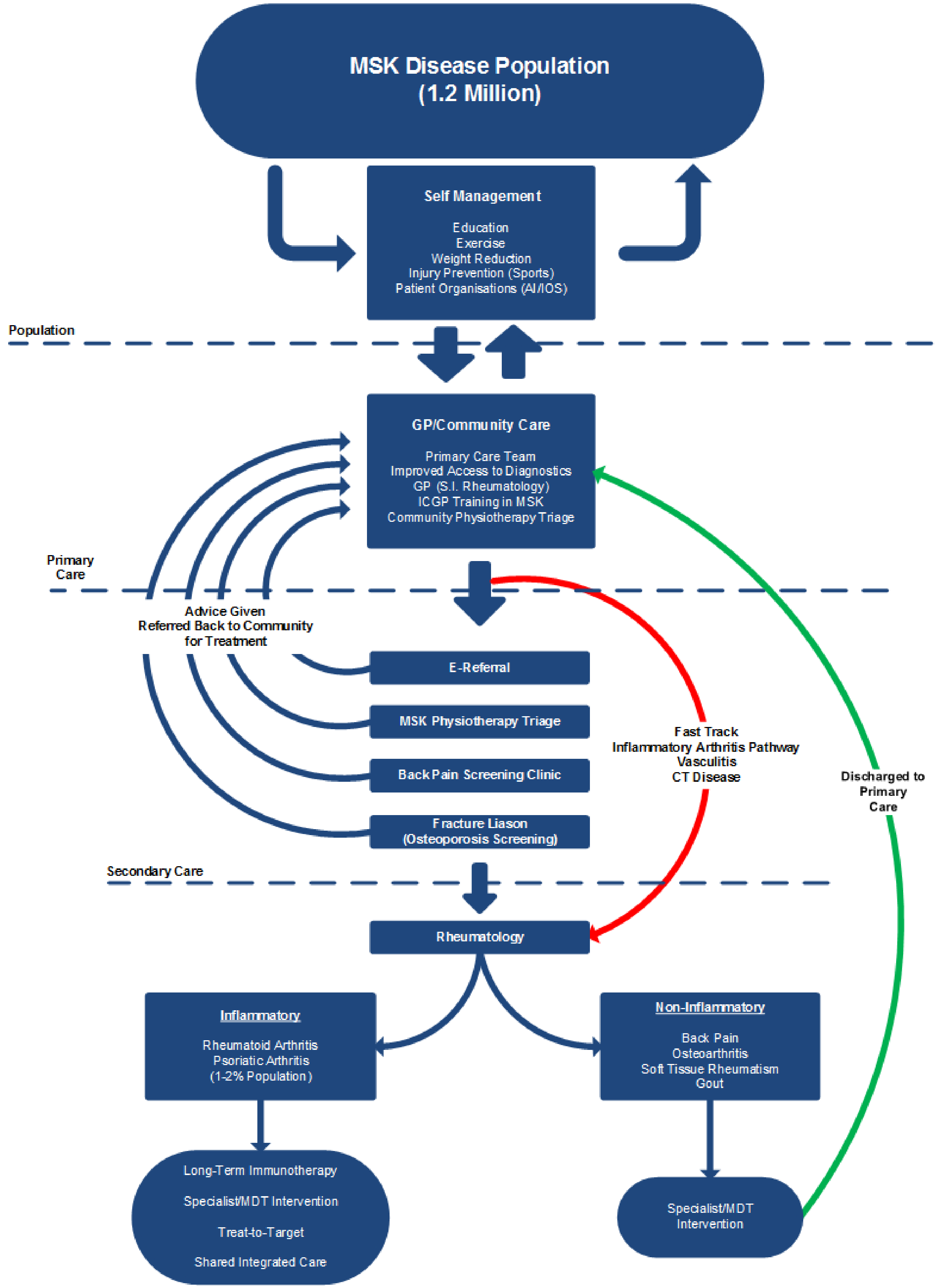
- Advanced Clinical examination skills,
- Clinical Decision making in Musculoskeletal Patients
- Requesting and Interpreting Blood Tests
- Assessment and screening for vascular pathologies, neurological disorders and endocrine disorders in Musculoskeletal patients
- Pharmacology and Pain
- The role of the Advanced Physiotherapy Practitioner
- Establishing and maintaining clinical competency
- Successful models of Musculoskeletal Clinics
- Developing and Structuring Musculoskeletal Clinics
- Leadership and Management Skills
- Medico-legal implications of working in an advanced practice role

Geographical distribution of the successful candidates

HSE Region	Number of Representatives	Location
HSE Dublin Mid-Leinster	9	AMNCH, Tallaght x 3 Midlands General Hospital, Portlaoise x 1 St. Vincent's University Hospital x 2 St. James Hospital x 3
HSE Dublin North East	13	Beaumont Hospital x 3 Cappagh Hospital x 1 Cavan Hospital x 1 Connolly Hospital x 2 Mater Misericordiae University Hospital x 3 Monaghan Hospital x 1 Navan Hospital x 1 Our Lady of Lourdes Hospital Drogheda x1
HSE West	5	Galway University Hospitals x 2 Letterkenny General x 1 Mayo General Hospital x 1 Sligo General x 1
HSE South	6	Cork University Hospital x 2 Cork Orthopaedic Hospital x 2 Waterford Regional Hospital x 2

Appendix 5

Rheumatology Model of Care Flow



RHEUMATOLOGY

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