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ABOUT THE NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (NIAR)
ABOUT THE NATIONAL INFLAMMATORY ARTHRITIS Registry (NIAR)

Introduction

Rheumatoid Arthritis (RA), the most common form of inflammatory arthritis is estimated to affect about 1% of the population. Of unknown aetiology, it typically affects many joints, causing acute inflammation, in most cases leading to joint erosions and joint damage (1). The NIAR, initiated in 2008, was set up with the aim of obtaining information about patients with Rheumatoid Arthritis. Information about patients with the other inflammatory arthritides will be collected in the future.

Objectives

1. To determine the incidence and prevalence of RA in Malaysia.
2. To obtain demographic data.
3. To determine the disease expression in terms of clinical manifestations.
4. To study the management of patients.
5. To assess patients’ outcome, studying patients’ disease activity, extent of disability, economic impact and mortality rate.

Inclusion Criteria

Patients enrolled into the registry are patients with established Rheumatoid Arthritis, diagnosed by a rheumatologist.

Instrument

A structured Case Report Form (CRF) [Appendix I] is used for data collection. The CRF was designed and reviewed by a technical committee. Prior to the launch of the registry, copies of the CRFs were distributed to doctors from the various hospitals involved. A trial run was done and feedback given to the committee before the final CRF was used for data collection. Training sessions were also conducted at the hospitals involved.

Patients’ outcome is assessed three times - at months 0, 6 and 12.

Data Flow Process

The registry is coordinated centrally at the Clinical Research Centre (CRC) based at Hospital Selayang. Each hospital has an appointed clinic and registry nurse. The database is available online via password access.

Patients attending their regular clinic appointments were identified. Verbal consent was obtained from patients using the Patient Confidentiality Information form [Appendix II]. Demographic information was obtained from the patient or carer. Joint count assessments
were then performed by the assessing doctor while other information necessary to fill into
the CRF was obtained from patients’ medical records. The registry nurse then entered the
information into the online database. The next outcome date was then determined and this
was coordinated with patients’ scheduled clinic visit.

![Data Flow Process]

**Figure 1: Data Flow Process**

**Progress**

The NIAR was launched officially on 18th December 2008. After a trial run, the first patient
was enrolled into the registry on 21st April 2009. The online database was started on 22nd
May 2009. As of 31st August 2010, 1000 patients have been enrolled into the registry.
DISTRIBUTION OF CASES ACCORDING TO HOSPITAL

National Inflammatory Arthritis Registry (NIAR)
1. DISTRIBUTION OF CASES ACCORDING TO HOSPITAL

Three hospitals were chosen for the pilot project, namely Hospital Selayang, Hospital Tuanku Jaafar, Seremban and Hospital Putrajaya. These hospitals were selected as they are the largest rheumatology centres in the MOH. The distribution of cases are as follows:

- **Hospital Putrajaya**: 202 (20.2%)
- **Hospital Tuanku Jaafar, Seremban**: 364 (36.4%)
- **Hospital Selayang**: 434 (43.4%)

*Figure 2: Distribution of cases according to hospital*
DEMOGRAPHICS

National Inflammatory Arthritis Registry (NIAR)
2. DEMOGRAPHICS

2.1 GENDER DISTRIBUTION

The gender distribution showed a female preponderance at 87.4% (n=874) compared to males 12.6% males (n=126). The male to female ratio was approximately 7:1.

2.2 AGE DISTRIBUTION

Figure 3: Gender distribution

Figure 4: Age Distribution
Currently, data has only been collected for adult patients with Rheumatoid Arthritis, defined as those above 12 years old.

The mean age was 52.57 years with the youngest patient being 18 years and the oldest 87 years.

More than half of the patients were in the 41-60 age group categories.

### 2.3 ETHNIC GROUP

The Malays being the largest ethnic group in Malaysia made up 43.2% of the patients in the registry. The Indians who are the smallest of the 3 major ethnic groups in Malaysia made up 30.4% followed by the Chinese at 24.1%. The other ethnic groups and foreigners comprised 2.3% of the patients.

![Distribution of ethnic groups](image)

Comparing these figures with the 2004 Malaysian Census, the Indians are over-represented since they constitute only 7.1% of the Malaysian population (2). The under-representation of the other ethnic groups in the registry may be explained by the fact that none of the hospitals in Sabah or Sarawak were included in this pilot project.
2.4 SOCIO-ECONOMIC STATUS

2.4.1 PROFESSIONAL VS NON-PROFESSIONAL

The majority of patients were from the lower socio-economic group. Nearly 90% were non-professionals.

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Malaysian Census 2004</th>
<th>NIAR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Malay</td>
<td>50.4%</td>
<td>43.2%</td>
</tr>
<tr>
<td>Chinese</td>
<td>23.7%</td>
<td>24.1%</td>
</tr>
<tr>
<td>Indian</td>
<td>7.1%</td>
<td>30.4%</td>
</tr>
<tr>
<td>Other</td>
<td>18.8%</td>
<td>2.3%</td>
</tr>
</tbody>
</table>

Table 1: Comparison of ethnic groups with Malaysian Census 2004

Figure 6: Distribution of professional and non-professional groups
2.4.2 INCOME GROUP

![Monthly income distribution graph]

Two-thirds of patients had a monthly income of less than RM3000.

2.4.3 PERSONAL MEDICAL INSURANCE

![Insurance distribution graph]

Two-thirds of patients did not have any medical insurance.
CHARACTERISTICS OF PATIENTS

National Inflammatory Arthritis Registry (NIAR)
### 3. CHARACTERISTICS OF PATIENTS

#### 3.1 NUMBER OF PATIENTS FULFILLING AMERICAN COLLEGE OF RHEUMATOLOGY (ACR) CRITERIA

The traditional definition for Rheumatoid Arthritis has been defined as patients fulfilling 4 or more of the 7 criteria listed in the 1987 ACR criteria (Table 2) (3). This criteria has been revised in the new ACR-EULAR criteria published in 2010 (4).

<table>
<thead>
<tr>
<th>ACR criteria</th>
<th>% of patients fulfilling criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥ 3 joints arthritis</td>
<td>94.4</td>
</tr>
<tr>
<td>Symmetrical arthritis</td>
<td>92.8</td>
</tr>
<tr>
<td>Arthritis in a wrist, MCP or PIP joint</td>
<td>70.5</td>
</tr>
<tr>
<td>Morning stiffness &gt; 1 hour</td>
<td>70.5</td>
</tr>
<tr>
<td>Positive rheumatoid factor</td>
<td>68.5</td>
</tr>
<tr>
<td>Erosions or osteopenia on hand or wrist radiograph</td>
<td>41.0</td>
</tr>
<tr>
<td>Rheumatoid factor</td>
<td>6.1</td>
</tr>
</tbody>
</table>

* symptoms present for at least 6 weeks

Table 2: 1987 ACR criteria for Rheumatoid Arthritis

The proportion of patients fulfilling each criterion is shown in Table 3.
The percentage of patients fulfilling the 1987 ACR criteria is shown in Figure 9. 78.3% fulfill the ACR criteria definition for Rheumatoid Arthritis however a significant proportion fulfill less than 4 of the criteria.

![Pie chart showing percentage of patients fulfilling ACR criteria](image)

**Figure 9: Percentage of patients fulfilling ACR criteria**

### 3.2 DURATION OF DISEASE BEFORE DIAGNOSIS

Almost half of the patients were diagnosed late, that is more than a year after the onset of symptoms. However, a significant proportion of patients were diagnosed between 1 to 6 months from symptom onset.

![Bar chart showing duration of disease before diagnosis](image)

**Figure 10: Distribution of patients according to duration of disease before diagnosis**
Comparing professionals and non-professionals, it would appear that more professionals are diagnosed earlier, that is less than 6 months from disease onset. However, even amongst the professionals, about 40% were diagnosed more than a year from the onset of symptoms.

![Bar chart showing duration of disease before diagnosis comparing professionals and non-professionals.](chart)

**Figure 11:** Duration of disease before diagnosis comparing professionals and non-professionals

### 3.3 ASSOCIATED MEDICAL PROBLEMS

#### 3.3.1 MEDICAL CO-MORBIDITIES

Among the medical conditions, hypertension was the commonest co-morbidity with a prevalence of 36.2%. This is slightly lower than the national prevalence of 42.6% of hypertension in adults above 30 years of age (5). Next was hyperlipidaemia at 25.5% followed by diabetes at 16.1%. The National Health and Morbidity Survey in 2006 found that the prevalence of diabetes is 12% (6). 6.1% of patients had been diagnosed to have osteoporosis. Peptic ulcer disease and ischaemic heart disease were each reported in 3.9% of the patients.

The other medical conditions with the reported figures are listed in Table 4.
3.3.2 MALIGNANCIES

16 cases of malignancies were reported. The highest malignancy reported was breast cancer. The other malignancies to find out what the other malignancies are 4 other malignancies includes - kidney, brain, thyroid & colon cancer

3.4 EXTRAARTICULAR MANIFESTATIONS

There are a number of extraarticular manifestations associated with Rheumatoid Arthritis. The commonest one seen in this patient cohort was keratoconjunctivitis sicca followed by lung fibrosis and anaemia due to rheumatoid arthritis.
patients had rheumatoid nodules. The percentages of patients with each extraarticular manifestations are listed below.

<table>
<thead>
<tr>
<th>Manifestation</th>
<th>Numbers</th>
<th>Percentage %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keratoconjunctivitis sicca</td>
<td>226</td>
<td>22.6</td>
</tr>
<tr>
<td>Interstitial lung disease</td>
<td>61</td>
<td>6.1</td>
</tr>
<tr>
<td>Anaemia (due to RA disease activity)</td>
<td>37</td>
<td>3.7</td>
</tr>
<tr>
<td>Rheumatoid nodules</td>
<td>61</td>
<td>6.1</td>
</tr>
<tr>
<td>Eye inflammation</td>
<td>8</td>
<td>0.8</td>
</tr>
<tr>
<td>Fever</td>
<td>5</td>
<td>0.5</td>
</tr>
<tr>
<td>Raynaud’s</td>
<td>4</td>
<td>0.4</td>
</tr>
<tr>
<td>Entrapment neuropathy</td>
<td>4</td>
<td>0.4</td>
</tr>
<tr>
<td>Atlanto-axial subluxation</td>
<td>4</td>
<td>0.4</td>
</tr>
<tr>
<td>Cutaneous vasculitis</td>
<td>3</td>
<td>0.3</td>
</tr>
<tr>
<td>Mononeuropathy</td>
<td>2</td>
<td>0.2</td>
</tr>
<tr>
<td>Polyneuropathy</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>Felty’s syndrome</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>Cervical myelopathy</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>Pleural effusion</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Pericarditis/effusion</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Amyloidosis</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lymphadenopathy</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Others</td>
<td>9</td>
<td>0.9</td>
</tr>
</tbody>
</table>

Table 5: Extraarticular manifestations

3.5 DISEASE STATUS AT 1ST NOTIFICATION

The DAS28 score is used to assess patient’s disease activity. The DAS28 score is calculated based on the number of swollen and tender joints (only 28 joints are assessed), general health assessment using a patient visual analogue scale and either ESR or CRP. Patients are then categorized into either having low (DAS28 2.6 to 3.2), moderate (DAS28 >3.2 to 5.1) or high (DAS28 >5.1) disease activity states or in remission (DAS29 <2.6). Those whose DAS28 scores cannot be obtained for various reasons were classified as unknown. Nearly half of the patients in this cohort were in the moderate and high disease categories.
Figure 13: Disease status at 1st notification

Disease activity based on
DAS28 ESR/CRP score

- Remission: 13.9
- Low disease activity: 16.5
- Moderate disease activity: 31.5
- High disease activity: 16
- Unknown: 22.1
DISEASE BURDEN

National Inflammatory Arthritis Registry (NIAR)
4. DISEASE BURDEN

4.1 WORK STATUS

![Work status and reasons for unemployment](image)

Figure 14: Work status and reasons for unemployment

8% of patients were unemployed but significantly, nearly 52% of those who were unemployed attributed this to their disease. 32% of patients were home-makers.

4.2 DAYS OF SICK LEAVE TAKEN DUE TO ARTHRITIS IN THE PAST 3 MONTHS

![Days of sick leave taken due to arthritis in the past 3 months](image)

Figure 15: Days of sick leave taken due to arthritis in the past 3 months

Out of the 338 patients who were employed, 81 patients took between 1 to 14 days of sick leave due to arthritis. 3 patients took between 15 to 30 days of sick leave and 1 patient took sick between 46 to 60 days. None took more than 60 days of sick leave.
STANDARD OF CARE

National Inflammatory Arthritis Registry (NIAR)
5. STANDARD OF CARE

5.1 TIME TO INITIATION OF DMARDS AFTER DIAGNOSIS

A large proportion of patients were started on Disease Modifying Anti-Rheumatic Drugs (DMARDS) soon after the diagnosis was made. This is in accordance with current treatment recommendations.

![Figure 16: Time to initiation of DMARDS after diagnosis](image)

Comparing professionals and non-professionals, there does not appear to be much difference in terms of when treatment was started.

![Figure 17: Time to initiation of DMARDS after diagnosis comparing professionals and non-professionals](image)
5.2 TYPES OF DMARDS USED

Methotrexate (MTX) being the anchor drug in the treatment of Rheumatoid Arthritis was used in 86.6% of patients. This was followed by sulphasalazine (SSZ) at 69.5% and hydroxychloroquine (HCQ) at 34.6%. The use of Leflunomide was 24.1%. The other less commonly used drugs for example cyclosporine, penicillamine, azathioprine and cyclophosphamide were used in 2.7% of the patients.

![Figure 18: Types of DMARDS used](image)

5.3 USE OF COMBINATION DMARDS

697 of patients were on combination DMARDS. The distribution of patients using the various combination DMARDS are shown in the figure below.

![Figure 19: Combination DMARDS used](image)
5.4 USE OF BIOLOGICS

The use of the TNF inhibitors comprising Infliximab, Etanercept and Adalimumab was 3.9% in this patient cohort.

5.5 USE OF ORAL STEROIDS

Short courses of oral steroids is sometimes used as bridging therapy. The use of steroids in this patient population was 38.2%.

5.6 USE OF NSAIDS/COX2 INHIBITORS

Non steroidal anti-inflammatory drugs (NSAIDS) is used as analgesic therapy. If NSAIDS are contraindicated, patients can be prescribed cyclo-oxygenase 2 inhibitors (COX2 INHIBITORS). About 62% of patients had been on NSAIDS/COX2 INHIBITORS.

5.7 SURGERY

4% of patients have undergone arthroplasty. Surgical interventions such as arthrodesis, spinal surgery and synovectomy are not commonly performed. Surgeries not directly related to rheumatoid arthritis for example appendicectomy or caesearean sections are categorized into other.

![Figure 20: Surgical interventions](image-url)
DISCUSSION

National Inflammatory Arthritis Registry (NIAR)
DISCUSSION

This is a pilot project involving only three hospitals from the Ministry of Health. In order to better reflect the demographics, characteristics, standard of care and patient outcomes in the general population, there is a need to recruit patients from more centres including those from private and university hospitals.

There is over-representation of Indians in this registry perhaps due to sampling bias because of the areas covered by the three hospitals. Not surprisingly, many of the patients are non-professionals and from the lower socio-economic group since the three hospitals are public hospitals. These patients do not have medical insurance cover and need financial aid from the government.

A significant proportion of patients do not fulfill the ACR criteria for rheumatoid arthritis. This confirms the fact that the criteria should not be used as the sole criterion for diagnosis since many patients do not fulfill the criteria at disease onset especially those who present early in the course of the disease.

Alarmingly, many patients are still diagnosed late. This may result in increased disease burden. Nevertheless, the results from the registry show that there are a significant proportion who are diagnosed less than six months from disease onset. It may be that patients who were diagnosed late were those who were diagnosed in the earlier years whereas there may be a trend now towards earlier diagnosis. However, this would require further study.

A significant number of patients have medical co-morbidities. The prevalence of the various diseases in this patient cohort are similar to the prevalence rates of the Malaysian adult population. Patients with rheumatoid arthritis are at risk of osteoporosis due to the disease itself as well as due to steroid use. The prevalence of osteoporosis in this cohort was reported as 6.7%. This is markedly below the reported prevalence of 22% (7). This might be due to under-reporting or that patients have been not adequately screened. Patients with rheumatoid arthritis are also at increased risk of malignancies. Of the malignancies, the incidence of lymphoma has been reported to be two-fold higher than expected (8). However, there were no cases of lymphoma in this patient cohort.

In terms of patient outcome, many patients are still in the moderate to high disease activity categories. The reasons for this need to be ascertained. It may be that more aggressive treatment strategies need to be instituted. The cost-effectiveness of biologics also need to be determined in relation to this.

Among the unemployed patients, more than half of the patients claim that this is due to their disease. Of note, 32% of patients are home-makers. It would be interesting to find out whether the decision to be a home-maker was influenced by their disease.

The majority of patients were started on treatment soon after the diagnosis was made. This is in accordance with current treatment guidelines (9).
CONCLUSIONS AND RECOMMENDATIONS

National Inflammatory Arthritis Registry (NIAR)
CONCLUSIONS AND RECOMMENDATIONS

Thus far, several interesting results have been obtained from the registry. The data confirm that rheumatoid arthritis has significant socio-economic impact to the society. Therefore, policies need to be implemented to reduce the financial burden to patients and to society as a whole. There is also a need to raise awareness among the general public regarding the disease and primary care physicians need to refer early so that patients can be treated appropriately. Clinicians also need to be aware that patients with rheumatoid arthritis have co-morbidities and need to be treated holistically.

The NIAR data offers much potential for research and hopefully, this will serve as an impetus for research and the implementation of policies for the benefit of patients.
REFERENCES

National Inflammatory Arthritis Registry (NIAR)
REFERENCES


(2) Malaysian census 2004


**REGISTRI INFLAMASI ARTHRITIS MALAYSIA**
**NATIONAL INFLAMMATORY ARTHRITIS Registry (NIAR)**

**MAKLUMAT KERAHSIAAN PESAKIT**

- Niar telah ditubuhkan untuk memantau rawatan bagi pesakit Reumatoid serta kesannya.
- Tujuannya adalah untuk meningkatkan taraf penjagaan pesakit.
- Klinik Reumatologi ini turut menyertai registri ini.
- Dalam tempoh penjagaan dan rawatan, kami akan mengumpul maklumat peribadi dan klinikal anda. Ini bertujuan untuk mengurus dan merancang penjagaan kesihatan anda. Maklumat ini berguna untuk menilai kualiti penjagaan yang disediakan serta membantu menaiktaraf perkhidmatan kami.
- Adalah mustahak untuk anda mengetahui bahawa maklumat peribadi dan klinikal anda akan digunakan bagi tujuan ini. NIAR mengamalkan polisi kerahsiaan maklumat pesakit mengikuti taraf keselamatan pawai keselamatan dan antarabangsa. Tiada maklumat peribadi yang mengenalpasti pesakit akan didedahkan.
- Anda berhak untuk tidak berkongsi maklumat anda dengan NIAR. Sila berunding dengan doktor anda untuk maklumat lanjut mengenai registri ini sekiiranya anda mempunyai sebarang keraguan.
- Kerjasama dan sumbangan anda amat dihargai.

**INFORMATION ON PATIENT CONFIDENTIALITY**

- NIAR was started to monitor treatment for Rheumatoid Arthritis and its outcomes.
- The aim is to improve patient care.
- This Rheumatology Clinic participates in NIAR.
- In the course of your care, we collect information about you and your treatment. We use this mainly to plan and manage your care. Some of the information will also be used to measure the quality of care we provide and to carry out work aimed at improving our care and services.
- It is important that you know that your data is being used in this way. NIAR observes strict policies and practices to assure confidentiality that comply with both national and international security standards. No information is published which identifies individual patients.
- You have the right not to share your information with NIAR. Please ask your doctor for more information if you have any doubts on NIAR.
- We appreciate your cooperation and understanding.

Untuk maklumat lanjut, sila hubungi NIAR di:
For further information, please contact NIAR at:

No Telephone/Phone No : 03-61203233 ext 4169/4181
No Fax/Fax No : 03-6120781
Laman Web/Website : https://app.acrm.org.my/NIAR
**NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (NIAR-RA)
NOTIFICATION FORM**

**SECTION 1: PATIENT DETAILS & DEMOGRAPHICS**

1. **Name:**
   - MyKad/ MyKid: -
   - OR Old IC: -
   - Other ID document No: -
   - Specify document type (if others): -

2. **Address:**
   - Postcode: -
   - Town/Cty: -
   - State: Johor Darul Ta'zim -
   - Kedah Darul Aman -
   - Kelantan Darul Naim -
   - Melaka -
   - Negri Sembilan Darul Khusus -
   - Pahang Darul Makmur -
   - Perak Darul Ridzuan -
   - Perlis Indera Kayangan -
   - Pulau Pinang -
   - Sabah -
   - Sarawak -
   - Selangor Darul Ehsan -
   - Terengganu Darul Iman -
   - Wilayah Persekutuan Kuala Lumpur -
   - Wilayah Persekutuan Labuan, Sabah -
   - Wilayah Persekutuan Putrajaya, Selangor -
   - Not applicable - Foreign:

3. **Date of Notification:**
   - (dd/mm/yyyy):

4. **Contact number:**
   - Homephone: -
   - OR H/P: -

5. **Gender:**
   - Male:
   - Female:

6. **Date of Birth:**
   - (dd/mm/yyyy):
   - Estimated/presumed year of birth:

7. **Ethnic group:**
   - Other Malaysian, specify:
   - Foreigner, specify country:
   - Male:
   - Female:
   - Melaka -
   - Bidayuh -
   - Chinese -
   - Orang Asli -
   - Indian -
   - Kadazan Dusun -
   - Bajau -
   - Orang Ulu -

**SECTION 2: NEXT OF KIN, EDUCATION, OCCUPATION**

1. **Next of kin:**
   - Name:
   - Contact no.: Telephone:
   - Relationship:

2. **Education level:**
   - No formal education:
   - Primary:
   - Secondary:
   - Tertiary:
   - Unknown:

3. **Current occupation:**
   - Legislators, senior officials, managers:
   - Technicians, associate professionals:
   - Service workers, shop and market sales workers:
   - Craft and related trades workers:
   - Elementary occupations:
   - Professionals:
   - Clerical workers:
   - Skilled agricultural, fishery workers:
   - Plant and machine operators and assemblers:
   - Homemaker:
   - Others, specify:

4. **Date of last employment:**
   - (dd/mm/yyyy):
   - Reason:
     - Due to disease:
     - Due to family circumstances:
     - Unknown:

5. **Household income (RM):**
   - Less than RM1500:
   - RM1500 - RM3000:
   - RM3001 - RM6000:
   - Above RM7000:
   - No income:
   - On social welfare:

6. **Days of sick leave taken due to inflammatory arthritides for the past 3 months:**
   - Unknown:

7. **Has personal medical insurance?**
   - Yes:
   - No:
   - Unknown:

**SECTION 3: DIAGNOSIS**

1. **Diagnosis:**
   - Rheumatoid Arthritis:
   - Psoriatic Arthritis:
   - Other inflammatory arthritides:
   - Ankylosing Spondylitis:
   - Juvenile Idiopathic Arthritis (Irrespective of pattern):
   - Male/female:

---

*Diagnosis = Rheumatoid Arthritis, kindly proceed to complete this form from Page 1 to 4.

[Version 1.5 last updated on 28/07/2009 (based on 11/09/2005 meeting) * exclusively FAQs]
NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (NIAR-RA)

<table>
<thead>
<tr>
<th>Joint Assessment (1/2)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>JOINTS</strong></td>
</tr>
<tr>
<td>Temporomandibular</td>
</tr>
<tr>
<td>Sternoclavicular</td>
</tr>
<tr>
<td>Acromioclavicular</td>
</tr>
<tr>
<td>Shoulder</td>
</tr>
<tr>
<td>Elbow</td>
</tr>
<tr>
<td>Wrist</td>
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<tr>
<td>MCP1</td>
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<td>MCP2</td>
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<tr>
<td>MCP3</td>
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<tr>
<td>DIP5</td>
</tr>
<tr>
<td><strong>Swelling</strong></td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Joint Assessment (2/2)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>JOINTS</strong></td>
</tr>
<tr>
<td>Hip</td>
</tr>
<tr>
<td>Knee</td>
</tr>
<tr>
<td>Ankle</td>
</tr>
<tr>
<td>Tarsus/Mid Tarsal</td>
</tr>
<tr>
<td>MTP1</td>
</tr>
<tr>
<td>MTP2</td>
</tr>
<tr>
<td>MTP3</td>
</tr>
<tr>
<td>MTP4</td>
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<td>IP1</td>
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<tr>
<td>PIP4</td>
</tr>
<tr>
<td>PIP5</td>
</tr>
<tr>
<td><strong>Swelling</strong></td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
</tbody>
</table>

**For Clinic Use Only:**
- **ID:**
- **Centre:**

**SECTION 1: JOINT ASSESSMENT**

1. **Date of Assessment:**
   - / / (dd/mm/yyyy)

2. **Joint Evaluation - Upper Extremities**
   - **RIGHT SIDE**
     - Not Evaluable: Yes
     - Tenderness: Yes
     - Swelling: Yes
   - **JOINTS**
     - Temporomandibular
     - Sternoclavicular
     - Acromioclavicular
     - Shoulder
     - Elbow
     - Wrist
     - MCP1
     - MCP2
     - MCP3
     - MCP4
     - MCP5
     - IP1
     - PIP2
     - PIP3
     - PIP4
     - PIP5
   - **Swelling**
     - Yes
     - No

3. **Joint Evaluation - Lower Extremities**
   - **RIGHT SIDE**
     - Not Evaluable: Yes
     - Tenderness: Yes
     - Swelling: Yes
   - **JOINTS**
     - Hip
     - Knee
     - Ankle
     - Tarsus/Mid Tarsal
     - MTP1
     - MTP2
     - MTP3
     - MTP4
     - MTP5
     - IP1
     - PIP2
     - PIP3
     - PIP4
     - PIP5
   - **Swelling**
     - Yes
     - No

4. **ACR functional status:**
   - Normal (I)
   - Limited in daily activities (II)
   - Limited in vocational/vocational activities (III)

5. **Radiographic erosion at assessment:**
   - Yes
   - No
   - Not available / Not Done

*mandatory fields*
### NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (NIAR-RA)

#### JOINT ASSESSMENT (2/2)

**Preliminary Report: April 2009 - August 2010**

**National Inflammatory Arthritis Registry (NIAR)**

#### SECTION 2: INVESTIGATIONS (AT NOTIFICATION)

<table>
<thead>
<tr>
<th>Blood test</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. ESR:</td>
<td>(mm/hr)</td>
</tr>
<tr>
<td>2. CRP:</td>
<td>(mg/L)</td>
</tr>
<tr>
<td>3. Anti CCP:</td>
<td>Positive</td>
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</tbody>
</table>

**SECTION 3: RA ACTIVITY**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. General health assessment</td>
<td>(mmHg)</td>
</tr>
<tr>
<td>2. Physician’s global assessment of RA Activity</td>
<td>(mmHg)</td>
</tr>
</tbody>
</table>

**SECTION 4: DAS 28 ESR CALCULATION**

<table>
<thead>
<tr>
<th>Clinical Variable</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tender joint count</td>
<td>(count)</td>
</tr>
<tr>
<td>2. Swollen joint count</td>
<td>(count)</td>
</tr>
<tr>
<td>3. ESR</td>
<td>(mm/hr)</td>
</tr>
<tr>
<td>4. General Health Assessment</td>
<td>(mmHg)</td>
</tr>
<tr>
<td>5. DAS 28 Score</td>
<td>(Auto calculate)</td>
</tr>
</tbody>
</table>

(Notes: Formula for DAS 28 ESR calculation: $0.56 	imes \sqrt{(Tender Joint Count) + 0.28 	imes \sqrt{(Swollen Joint Count)} + 0.70 	imes \ln(ESR)} + 0.614 \times General Health Assessment$)

**SECTION 5: DAS 28 CRP CALCULATION**

<table>
<thead>
<tr>
<th>Clinical Variable</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tender joint count</td>
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<td>3. CRP</td>
<td>(mg/L)</td>
</tr>
<tr>
<td>4. General Health Assessment</td>
<td>(mmHg)</td>
</tr>
<tr>
<td>5. DAS 28 Score</td>
<td>(Auto calculate)</td>
</tr>
</tbody>
</table>

(Notes: Formula for DAS 28 CRP calculation: $0.56 	imes \sqrt{(Tender Joint Count) + 0.28 	imes \sqrt{(Swollen Joint Count)} + 0.38 \times \ln(CRP) + 0.614 \times General Health Assessment + 0.94}$)

General Health Assessment = disease activity on a 100 mm VAS
## NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (NIAR-RA)

### TREATMENT

**SECTION 8: TREATMENT**

1. Was there any new medication administered?:
   - Yes
   - No
   - Not applicable

<table>
<thead>
<tr>
<th>Drug</th>
<th>1. Steroids PO</th>
<th>Azathioprine</th>
<th>Cyclophosphamide</th>
<th>Cyclophosphamide</th>
<th>Ciclosporine</th>
<th>CCQ Inh</th>
<th>Opioid</th>
<th>Others, specify:</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Steroids IM</td>
<td>Hydrcychloroquine (HCQ)</td>
<td>Infliximab</td>
<td>Etanercept</td>
<td>Adalimumab</td>
<td>Rituximab</td>
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<td>Leflunomide</td>
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<td>Mycophenolate</td>
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<td></td>
<td>SSZ</td>
<td>Cyclosporine</td>
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<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

**SECTION 7: OTHER THERAPY**

1. Complementary medicine:
   - Yes
   - No
2. Acupuncture:
   - Yes
   - No

**SECTION 8: SURGERY**

1. Arthroplasty:
   - Yes
   - No
2. Arthrodesis:
   - Yes
   - No
3. Spinal surgery:
   - Yes
   - No
4. Synovecetomy:
   - Yes
   - No
5. Other surgery, specify:
   - Yes
   - No

**SECTION 9: ADMISSION TO HOSPITAL**

<table>
<thead>
<tr>
<th>No.</th>
<th>Date of Admission (dd/mm/yyyy)</th>
<th>Date of Discharge (dd/mm/yyyy)</th>
<th>Duration (days)</th>
<th>Reason for Admission</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>RA flare infections</td>
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<td>Cardiovascular</td>
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<td>Drug-related</td>
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<tr>
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<td></td>
<td></td>
<td>Others, specify:</td>
</tr>
</tbody>
</table>

*mandatory fields*
### NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (NIAR-RA) OUTCOME

**Instruction:** If check boxes are provided, check one box only. If radio buttons are provided, check one box only.

1. **Date of Assessment:**
   - 
   - 
   - 
   - 
   - (dd/mm/yyyy)
   - Not applicable

2. **Estimated date of next follow up:**
   - (dd/mm/yyyy)

### SECTION 1: PATIENT STATUS

1. **Patient Status:**
   - Alive
   - Death
   - Remission (< 2.6)
   - Moderate disease activity (>3.2 to 5.1)
   - Low disease activity (2.6 to 3.2)
   - Unknown
   - High disease activity (>5.1)

   **i) Date of death:**
   - (dd/mm/yyyy)

   **ii) Primary cause of death:**
   - RA related
   - Non RA related
   - Other causes
   - Unknown

   **Transfer to a new centre**

   **i) Date of transfer:**
   - (dd/mm/yyyy)

   **ii) Centre:**
   - Centre Code:

   **iii) Name of new centre:**

   **Reason:**

   **Lost to follow up**

---

Finalized Version 1.1 last updated on 23/09/2009 (based on 11/08/09 meeting)  
Mandatory fields

ADD page for subsequent follow up months:

ADD Outcome page, 2, 3 and 4
## NATIONAL INFLAMMATORY ARTHRITIS REGISTRY (NIAR-RA) WORKSHEET

**For Office Use only:**  
ID:  
Centre:  

### Instructions:  
1. Where check boxes are provided, check (☑) one or more boxes. Where radio buttons are provided, check (☑) one box only.  
2. Kindly ensure that the horizontal line of the VAS scales are 100 mm in length.

### I. Patient Name:  

| NRIC Number: |

### II. Centre Code:  

| Or Reporting centre name: |

### III. Follow up month:  

| 1st Notification (Month 0) | Month 6 | Month 12 |

(Please enter the VAS measurement from the worksheet into section 3: RA Activity (Page 3))

### 1. Date of Measurement:  

| (DD/MM/YY)  |

### 2. RA Activity  

**General Health Assessment**:  

| “How do you feel today?”  | 100 (very bad) |

| 0 (very well) | 100 (very bad) |

| Measurement (mm) |

**Physician’s global assessment of RA activity**:  

| 0 (very well) | 100 (very bad) |

**Measurement (mm)**