**Supplementary table 1**: Results of the hierarchical literature review displaying number and proportion of existing rheumatoid arthritis (RA) cohorts and registers items collecting specific items and instruments.

|  |  |  |  |
| --- | --- | --- | --- |
| **ITEM** | **n of cohorts /total n of cohorts (%)** | **INSTRUMENTS** | **n of cohorts /total n of cohorts (%)** |
| AGE | 67/67 (100%) |  |  |
| GENDER | 67/67 (100%) |  |  |
| MARITAL STATUS | 14/67 (20.9%) |  |  |
| SOCIO-ECONOMIC STATUS | 40/67 (59.7%) | Level of education | 26/40 (65%) |
| Employment status | 22/40 (55%) |
| Area of residence (zip code,..) | 8/40 (20%) |
| Years of education | 6/40 (15%) |
| Income level | 3/40 (7.5%) |
| Social class (high/middle/low) | 2/40 (5%) |
| FAMILY HISTORY | 7/67 (10.4%) |  |  |
| ETHNICITY | 14/67 (20.9%) | Race | 8/14 (57.1%) |
| Country of origin / place of birth | 5/14 (35.7%) |
| Spoken language | 1/14 (7.1%) |
| DIAGNOSIS OF RA | 43/67 (64.2%) | 1987 ACR criteria | 35/43 (81.4%) |
| Clinical diagnosis | 20/43 (46.5%) |
| 2010 ACR/EULAR criteria | 11/43 (25.6%) |
| DISEASE DURATION | 62/67 (92.5%) |  |  |
| SYMPTOM DURATION | 17/67 (25.4%) |  |  |
| SMOKING | 45/67 (67.2%) | Smoking current/previous/never | 32/45 (71.1%) |
| Smoking Y/N | 15/45 (33.3%) |
| Pack-years | 12/45 (26.7%) |
| Smoking duration / how long | 8/45 (17.8%) |
| Cigarettes per day | 7/45 (15.6%) |
| Duration of non-smoking | 3/45 (6.7%) |
| Smoking never/ever | 3/45 (6.7%) |
| Smoking start and stop date | 1/45 (2.2%) |
| BODY MASS INDEX | 31/67 (46.3%) |  |  |
| ALCOHOL INTAKE | 8/67 (11.9 %) |  |  |
| COMPOSITE SCORE OF DISEASE ACTIVITY | 61/67 (91%) | Disease activity Score 28 joints (DAS28) | 60/61 (98.4%) |
| Clinical disease activity index (CDAI) | 20/61 (32.8%) |
| Simplified disease activity index (SDAI) | 17/61 (27.9%) |
| ACR-response criteria | 10/61 (16.4%) |
| EULAR response criteria | 7/61 (11.5%) |
| DAS44 | 5/61 (8.2%) |
| RITCHIE | 5/61 (8.2%) |
| RA disease activity index (RADAI) | 2/61 (3.3%) |
| routine assessment of patient index data 3 (RAPID-3) | 1/61 (1.6%) |
| Thompson Index | 1/61 (1.6%) |
| SWOLLEN / TENDER JOINT COUNT (SJC/TJC) | 58/67 (86.6%) | SJC28/TJC28 | 53/58 (91.4%) |
| SJC66/TJC68 | 13/58 (22.4%) |
| SJC44/TJC44 | 6/58 (10.3%) |
| SJC32/TJC32 | 4/58 (6.9%) |
| SJC46 /TJC46 | 2/58 (3.4%) |
| SJC59/TJC59 | 1/58 (1.7%) |
| PATIENT GLOBAL OF DISEASE ACTIVITY(PTGA) | 52/67 (77.6%) | Visual analogue scale PtGA | 48/52 (92.3%) |
| Numeric rating scale PtGA | 5/52 (9.6%) |
| PtGA Global Health | 26/52 (50%) |
| PtGA disease activity related to arthritis | 15/52 (28.8%) |
| Disease activity last week | 7/52 (13.5%) |
| Disease activity today | 1/52 (1.9%) |
| EVALUATOR GLOBAL OF DISEASE ACTIVITY (EGA) | 34/67 (50.7%) | Visual analogue scale EGA | 25/34 (73.5%) |
| Numeric rating scale EGA | 9/34 (26.5%) |
| EGA disease activity related to arthritis | 17/34 (50%) |
| EGA Global Health | 5/34 (14.7%) |
| PAIN | 48/67 (71.6%) | Visual analogue scale pain | 44/48 (91.7%) |
| Numeric rating scale pain | 6/48 (12.5%) |
| Overall pain | 11/48 (22.9%) |
| Pain related to arthritis | 10/48 (20.8%) |
| FATIGUE | 28/67 (41.8%) | Visual analogue scale fatigue | 19/28 (67.9%) |
| Numeric rating scale fatigue | 5/28 (17.9%) |
| Visual analogue scale fatigue from SF-36 | 5/28 (17.9%) |
| Checklist individual strength (CIS) fatigue | 1/28 (3.6%) |
| Profile of fatigue and discomfort (PROFAD) | 1/28 (3.6%) |
| MORNING STIFFNESS | 16/67 (23.9%) |  |  |
| EXTRA-ARTICULAR MANIFESTATION (EAM) | 31/67 (46.3%) | EAM Y/N | 31/31 (100%) |
| Type of EAM | 23/31 (74.2%) |
| PHYSICAL FUNCTION | 54/67 (80.6%) | Health Assessment Questionnaire | 51/54 (94.4%) |
| Short Form-36 Physical Component Score | 16/54 (29.6%) |
| Funktionsfragebogen Hannover (FFbH) | 3/54 (5.6%) |
| Signals of Functional Impairment (SOFI) | 1/54 (1.9%) |
| HEALTH RELATED QUALITY OF LIFE (HRQOL) | 36/67 (53.7%) | Short Form-36 (SF-36) | 22/36 (61.1%) |
| EuroQol-5D (EQ-5D) | 17/36 (47.2%) |
| RA Quality of life (RAQoL) | 4/36 (11.1%) |
| Arthritis impact measurement scale AIMS (1 or 2) | 3/36 (8.3%) |
| Short Form-6D | 2/36 (5.6%) |
| Short Form-12 | 1/36 (2.8%) |
| Rheumatoid Arthritis impact of disease (RAID) | 1/36 (2.8%) |
| WORK PRODUCTIVITY | 10/67 (14.9%) |  |  |
| JOINT SURGERY | 27/67 (40.3%) | Type of surgery | 17/27 (63%) |
| Localisation of surgery | 17/27 (63%) |
| Date of surgery | 11/27 (40.7%) |
| GRIP STRENGTH | 4/67 (6%) |  |  |
| ACUTE PHASE REACTANS | 58/67 (86.6%) | C-reactive protein | 58/58 (100%) |
| Erythrocyte sedimentation rate | 51/58 (87.9%) |
| SEROLOGY | 60/67 (89.6%) | Rheumatoid factor (RF) | 59/60 (98.3%) |
| Anti-CCP Antibodies (ACPA) | 49/60 (81.7%) |
| RF titre | 18/60 (30%) |
| ACPA titre | 20/60 (33.3%) |
| CURRENT Disease modifying anti-rheumatic drug (DMARD) | 63/67 (94%) | Type of DMARD | 60/63 (95.2%) |
| Dose of DMARD | 41/63 (65.1%) |
| Start date | 35/63 (55.6%) |
| Stop date | 34/63 (54%) |
| Frequency DMARD | 31/63 (49.2%) |
| Duration of DMARD | 28/63 (44.4%) |
| Route of administration | 21/63 (33.3%) |
| DMARD HISTORY | 41/67 (61.2%) | Reason for discontinuation | 32/41 (78%) |
| Type of previous DMARD | 29/41 (70.7%) |
| Number of previous DMARDs | 22/41 (53.7%) |
| Duration of previous DMARD therapy | 12/41 (29.3%) |
| Dose of previous DMARD | 7/41 (17.1%) |
| GLUCOCORTICOIDS | 53/67 (79.1%) | Glucocorticoid Y/N | 48/53 (90.6%) |
| Glucocorticoid dose | 38/53 (71.7%) |
| Route of administration | 22/53 (41.5%) |
| Duration of therapy | 19/53 (35.8%) |
| Cumulative dose | 1/53 (1.9%) |
| Start and stop date | 1/53 (1.9%) |
| Non-steroidal Anti-inflammatory drugs (NSAIDS | 43/67 (64.2%) | NSAIDs Y/N | 41/43 (95.3%) |
| Type of NSAID | 25/43 (58.1%) |
| Frequency NSAID use | 16/43 (37.2%) |
| NSAID dose | 15/43 (34.9%) |
| Duration of NSAID use | 11/43 (25.6%) |
| ADVERSE EVENTS | 40/67 (59.7%) | Any adverse event | 30/40 (75%) |
| Serious adverse events | 30/40 (75%) |
| Description of severity | 6/40 (15%) |
| Recorded hospitalisation | 3/40 (7.5%) |
| STRUCTURAL DAMAGE | 30/67 (44.8%) | Erosions Y/N | 23/30 (76.7%) |
| Sharp van der Heijde Score | 15/30 (50%) |
| Larsen Score | 9/30 (30%) |
| Rau Ratingen Score | 2/30 (6.6%) |
| ULTRASOUND JOINT | 9/67 (13.4%) |  |  |
| MRI JOINTS | 4/67 (6%) |  |  |
| CHEST X-RAY | 8/67 (11.9%) |  |  |
| COMORBIDITIES | 43/67 (64.2%) | Type of comorbidity | 42/43 (97.7%) |
| Charlson Comorbidity Index | 4/43 (9.3%) |
| Cardiovascular disease | 33/43 (76.7%) |
| Cancer | 32/43 (74.4%) |
| Hypertension | 31/43 (72.1%) |
| Diabetes mellitus | 30/43 (69.8%) |
| Pulmonary disease (COPD, Asthma,..) | 30/43 (69.8%) |
| Hyperlipidemia | 22/43 (51.2%) |
| Depression | 21/43 (48.8%) |
| Osteoporosis | 19/43 (44.2%) |
| Cerebrovascular disease (stroke,..) | 14/43 (32.6%) |
| Liver disease | 12/43 (27.9%) |
| Tuberculosis | 11/43 (25.6%) |
| Chronic Kidney disease | 10/43 (23.3%) |
| Thyroid disorder | 8/43 (18.6%) |
| Gastrointestinal disorder (ulcer,..) | 5/43 (11.6%) |
| Neurologic disorder | 4/43 (9.3%) |
| Anemia / Cytopenia/ | 3/43 (7%) |
| Viral infections (Hep, HIV) | 3/43 (7%) |
| VACCINATION | 1/67 (1.5%) |  |  |
| TREATMENT NOT RELATED TO RA | 20/67 (29.8%) |  |  |

**Supplementary Table 2.** Summary of initial list of tentative items and the outcome of each step from literature review (column a) until final voting round (column e)..

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Items** | **a) Proportion of publications reporting on item** | **% of participants who favoured INCLUSION** | | | |
| **b) in expert group survey** | **c) at first face-to-face meeting** | **d) in working group ratification survey** | **e) at second face-to-face meeting** |
| **Age** | 100 | 95 | 100 | 100 | 100† |
| **Gender** | 100 | 96 | 95 | 100 | 100† |
| **Marital status** | 21 | 31 | 6 | 0 | 0† |
| **Socio-economic status** | 60 | 67 | 53\* | 30 | 0† |
| **Family history** | 10 | 79 | 26 | 9 | 0† |
| **Ethnicity** | 21 | 69 | 5\* | 30 | 0† |
| **Diagnosis of RA** | 64 | 100 | 95 | 100 | 100† |
| **Disease duration** | 93 | 97 | 100 | 100 | 100† |
| **Symptom duration** | 25 | 86 | 16\* | 22 | 0† |
| **Diet** | AD | 27 | 0 | 0 | 0† |
| **Physical exercise** | AD | 57 | 5 | 4 | 0† |
| **Smoking** | 67 | 89 | 89 | 100 | 100† |
| **Body mass index** | 46 | 65 | 80\* | 83 | 100† |
| **Alcohol intake** | 12 | 47 | 11 | 9 | 0† |
| **Composite score** | 91 | 100 | 95 | 91 | 100† |
| **Tender joint count** | 87 | 100 | 94 | 100 | 100† |
| **Swollen joint count** | 87 | 100 | 94 | 100 | 100† |
| **Patient global** | 78 | 99 | 94 | 100 | 100† |
| **Evaluator global** | 51 | 97 | 74 | 83 | 100† |
| **Pain** | 72 | 96 | 90 | 96 | 100† |
| **Fatigue** | 42 | 81 | 40\* | 52 | 41 |
| **Morning stiffness** | 24 | 81 | 0\* | 0 | 0† |
| **Extra-articular manifestation** | 46 | 86 | 37\* | 26 | 0† |
| **Physical function** | 81 | 99 | 79 | 96 | 100† |
| **Health related quality of life** | 54 | 95 | 50\* | 48 | 88 |
| **Work productivity** | 6 | 82 | 20 | 0 | 0† |
| **Sexual life** | AD | 46 | 5 | 0 | 0† |
| **Joint surgery** | 40 | 82 | 61\* | 61 | 0† |
| **Grip strength** | 6 | 57 | 0\* | 0 | 0† |
| **Acute phase reactants** | 87 | 99 | 100 | 100 | 100† |
| **Serology** | 90 | 97 | 100 | 96 | 100† |
| **Current DMARD** | 94 | 99 | 100 | 100 | 100† |
| **DMARD history** | 61 | 97 | 100\* | 91 | 100† |
| **Glucocorticoids** | 79 | 99 | 90 | 100 | 100† |
| **NSAIDS** | 64 | 90 | 33\* | 13 | 0† |
| **Adverse events** | 60 | 81 | 26\* | 30 | 0† |
| **Structural damage by X-ray** | 45 | 92 | 74\* | 74 | 100† |
| **Ultrasound** | 13 | 66 | 5 | 0 | 0† |
| **MRI of joints** | 6 | 49 | 6 | 4 | 0† |
| **Chest X-Ray** | 12 | 63 | 11 | 4 | 0† |
| **Comorbidities** | 93 | 93 | 100 | 87 | 100† |
| **Vaccination** | 2 | 68 | 11 | 9 | 0† |
| **Treatment not related to RA** | AD | 63 | 5 | 17 | 0† |
| **Physiotherapy** | AD | 63 | 5 | 0 | 0† |
| **Occupational therapy** | AD | 64 | 0 | 0 | 0† |
| **Psychological/emotional therapy** | AD | 61 | 0 | 0 | 0† |
| **Podiatry** | AD | 51 | 0 | 0 | 0† |

Abbreviations: AD = added to the list by the steering/working group; DMARD disease modifying antirheumatic drug; NSAID non-steroidal anti-inflammatory drug; RA rheumatoid arthritis;

\*after second voting round;

†voting on total set;

Items with no consensus (<70% voted YES or NO) are shown in grey; items >70% voted YES (inclusion) in green; >70% voted NO (exclusion) in red;

**Supplementary Table 3.**

Comments and points raised during discussion at the two face-to-face meetings, for individual items

|  |  |
| --- | --- |
| **ICLUDED ITEMS** | **COMMENTS** |
| 1) Age | Included after first round of voting at first face to face meeting |
| 2) Gender | Included after first round of voting at first face to face meeting |
| 3) Disease duration | Included after first round of voting at first face to face meeting |
| 4) Diagnosis of RA | Diagnosis by clinician is the least common denominator of existing cohorts; In inception cohorts also aim for 2010 ACR/EULAR criteria; semantic difference as 1987/2010 are classification not diagnostic criteria!; components of 2010 ACR/EULAR criteria (such as 66/68 JC) not part of MCD therefore can not recommend to 2010 ACR/EULAR criteria; feasibility issue; for established RA cohort no additional value, |
| 5) Body mass index (BMI) | PRO: Important for drug dosing /drug efficacy; weight related to comorbidities  CON: Difficult to assess in daily practice; self-reported too vague; Preferably report height and weight, not BMI; Patient partner felt embarrassed about stigma |
| 6) Smoking | Included after first round of voting at first face to face meeting |
| 7) Tender joints | At least use 28 joint count; if 66/68 joints are collected, require Mannequin to calculate CDAI/ SDAI/ DAS28 |
| 8) Swollen joints |
| 9) Patient global | Included after first round of voting at first face to face meeting; Interim work to identify best wording will be carried out(9) |
| 10) Evaluator global | Included after first round of voting at first face to face meeting |
| 11) Pain | Reference period 'today' too short time period to capture pain (fluctuate; might be influenced by exertion to get to clinic today) Research agenda to assess difference between TODAY and LAST WEEK |
| 12) Physical function | Instruments that can be converted into HAQ are acceptable too (i.e. Funktionsfragebogen Hannover FFbH) |
| 13) Health related quality of life (HRQoL) | Only if EQ-5D free of use; if not HRQoL would only be optional; EULAR initiative to provide free licensing ongoing |
| 14) Composite Scores | Due to interdependency of items CDAI, SDAI, DAS28, EULAR and ACR response criteria can be calculated by content of minimum core dataset; ACR/EULAR remission criteria (10) can be calculated as well |
| 15) Acute phase reactants | Standard of care should be both; If to choose 51% vote for CRP as it is important to calculate ACR/EULAR remission criteria(10); 6% for ESR |
| 16) Serology | Standard of care to capture both, realize cost factor and national limitations; 0% want to capture RF only; if both (RF AND ACPA) is not available recommended to collect SEROPOSITIVITY (RF and/or ACPA) |
|
| 17) Structural Damage X-ray | PRO: 1) Gives an idea of severe disease.; 2) Baseline indicator of erosions; 3 )important to understand the potential of devastation of the disease; 4) Important and easy;  CON: 1) poor sensitivity to change; 2) neither reliable nor valid when assessed without complicated Scoring system; 3) difficult to assess  reference 'RA typical erosions as defined according to van der Heijde et al (11) |
| 18) DMARD History | By collecting NAME of previous DMARD(s) one will be able to extract NUMBER of previous DMARDs and TYPE of DMARD (bDMARD, sDMARD, tsDMARD); reason for discontinuation should be collected if possible;  PRO: Important to predict response; should be reported in daily practice  CON: not easy to capture from historical cohorts; recall bias |
| 19) Ongoing / most recent DMARD | Define most recent DMARD within last 3 months;  other possible instruments to consider: dose of DMARD (65%); Frequency of DMARD use (59%), route of administration (47%) |
| 20) Glucocorticoids | PRO: relevant for side effects/ measure for disease severity  CON: no standardized way to assess it  agreement was reached via online survey after the 2nd F2F meeting |
| 21) Comorbidities | PRO: Major confounder in many outcomes; Relevant to side effects/treatment approaches and risks; polypharmacy;  CON: limitation of feasibility  Six domains according to the EULAR initiative on reporting comorbidities (8):   * cardiovascular disease (ischaemic cardiovascular disease including myocardial infarction, pectoris angina or a stent; stroke or transient ischemic attack; heart failure; lower limb peripheral arterial disease) * malignancies (breast cancer, prostate cancer, cervix cancer, uterus cancer, lung cancer, colon cancer, non-melanoma skin cancer, melanoma, pancreas cancer, brain cancer, metastasis without known origin; Hodgkin or Non-Hodgkin’s disease or any other cancer) * infections (bacterial including latent or active tuberculosis, viral, fungal or parasitic) * gastrointestinal disease (gastroscopy-proven peptic ulcer) * osteoporosis (osteoporotic fracture) * depression (formally diagnosed depression)   agreement was reached via online survey after the 2nd F2F meeting |
| **EXCLUDED ITEMS** | **COMMENTS** |
| 1) Marital status | Excluded after first round of voting at first face to face meeting |
| 2) Family history | Excluded after first round of voting at first face to face meeting; |
| 3) Socioeconomic status | Keep it on research agenda  PRO: Important confounder; powerful predictor for outcomes, level education important in terms of self-management/patient education (literacy),  CON: Comparability limited, feasibility of instrument is driving choice, instruments not clear, if country is known it is sufficient, also rural vs city areas important |
| 4) Ethnicity | PRO: risk on certain diseases/ adverse events might be larger in certain ethnic groups  CON: not core; Not feasible because not allowed in France (on national level); no standardized tool |
| 5) Symptom duration | PRO: important for predicting RA (first swelling); to define "start" of the disease, important for physical function; important for interpretation of different disease phases;  CON: patient's perspective of symptom duration can be complex and attributed to events that may not be relevant to the disease presentation; Not relevant for longstanding/established RA |
| 6) Diet | CON: not feasibly in daily practice; no easy tools to assess (long questionnaires) |
| 7) Physical exercise | Excluded after first round of voting at first face to face meeting |
| 8) Alcohol intake | Excluded after first round of voting at first face to face meeting |
| 9) Fatigue | PRO: very important to patients, and often refractory to interventions, not decisive for treatment but poorly understood; included in OMERACT core outcome set;  CON: dependent on too many other factors unrelated to RA disease activity; Captured by Patient global; NOT included after 4 rounds of voting never reached cut-off of 60% |
| 10) Morning Stiffness | PRO: important for patients; Relevant for clinical practice for deciding on inflammation; second voting round as it was emphasized by patient partners to be important;  CON: For research purposes less relevant (not sensitive to change), important for diagnosis, not for established RA; no good psychometric property for research existing |
| 11) Extra-articular manifestation | PRO: Reflect disease burden, important to have a complete history of the patient, important for clinical decision making  CON: On global level difficult to interpreter and to collect; limited additional benefit for research; never used for research |
| 12) Work productivity | Excluded after first round of voting at first face to face meeting; |
| 13) Sexual life | Excluded after first round of voting at first face to face meeting; |
| 14) Joint Surgery | PRO: Important for practice and informative for research (gives summary of past severity), marker end of stage joint destruction, long term outcome  CON: difficult to collect in patients with several surgeries; recall bias, many surgeries not related to RA; no standardized tool available; no additional benefit; not core; |
| 15) Grip strength | PRO: important to patients; second voting round as it was emphasized by patient partners to be important;  CON: Not used in clinical practice or for research |
| 16) NSAIDs | PRO: important as related pain; disease activity; association of (co)morbidity and NSAID  CON: Poorly collected in established cohorts, not used in research, patients do not know, difficult to collect |
| 17) Adverse events (AE) | PRO: Crucial regarding drug safety, often reason why registers were developed;  CON: interrelated with comorbidities; Defining concept is very difficult; not feasible to collect, concern about validation what is measured  May consider AE as ‘research agenda’ for instruments and collaborative methods |
| 18) Ultrasound | Important but not core; excluded after first round of voting at first face to face meeting; |
| 19) MRI joints | Excluded after first round of voting at first face to face meeting; |
| 20) Chest x-ray | Excluded after first round of voting at first face to face meeting; |
| 21) Vaccination | CON: Time consuming and most patients do not have information available; |
| 22) Treatment unrelated to RA | PRO: important information when prescribing RA personalised treatment; impact on management and adverse events;  CON: interdependency with comorbidities; not feasible |
| 23) Physio-Therapy | Excluded after first round of voting at first face to face meeting; |
| 24) Occupational Therapy | Excluded after first round of voting at first face to face meeting; |
| 25) Psychological / Emotional Therapy | Excluded after first round of voting at first face to face meeting; |
| 26) Podiatry | Excluded after first round of voting at first face to face meeting; |