opening and closing of the bottle. This is termed Medication Event Monitoring System (MEMS). To our knowledge, there is no standard method to summarise and analyse the adherence data from MEMS.

Methods: A literature search was conducted in July 2017 in the databases PubMed, Embase and Cochrane. Search terms were related to the following MESH search terms: medication (non)adherence/compliance, medication persistence, chronic disease/illness, chronically ill, medical electronics, treatment, (drug) therapy, data analysis, statistical study.

Results: We identified 1493 articles, and immediately excluded 1127 off-topic articles and 48 double entries after screening of title and abstract. In the end, 207 articles were included.

The mean age of the patients in the studies was 52 (SD 46) years. A total of 62 different health conditions were studied. Most patients had HIV (29%) or heart failure (10%). The MEMS cap was used for a median of 3 months (IQR: 4; range: 1 week-24 months).

Outcome measures: Most studies computed an adherence score, expressed as the percentage of days on which the correct dose of medication was taken. The threshold to mark people as adherent was most frequently (38 studies) set at 80% (range 67%–95%). Timing compliance (i.e. the percentage of doses taken at the appropriate time) and dose compliance (i.e. the percentage of correct doses taken on each day) were also calculated in several studies (in 14% and 23%, respectively). In addition, a few studies (4%) calculated 'drug holidays', i.e. periods of a certain number of days on which the medication bottle was not opened, followed by a bottle opening.

Statistical analyses: Multilevel modelling and slopes in combination with one-sample t-tests were used to examine adherence patterns over time.

Ten studies assessed an intervention to improve adherence. Generalised Estimating Equation (GEE) model (n=4), ANOVA, McNemar's exact test, multilevel modelling, a summary analysis (details not reported), T-test or Wilcoxon test were used to compare the differences in adherence before and after an intervention.

Conclusions: Apart from the adherence score threshold, often set at 80% of days with correct medication dosing, we found that many different outcome measures and methods were used for the analysis of MEMS data, pointing to a lack of standardisation. Apparently, there is no consensus on the best outcome measures and a lack of validation studies that compare different methods to analyse MEMS data.

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Disclosure of Interest: None declared

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FRI0601 THE NATURE AND EXTENT OF DATA ITEMS COLLECTED ACROSS EUROPEAN PREGNANCY REGISTERS – FIRST RESULTS OF THE EUROPEAN NETWORK OF PREGNANCY REGISTERS IN RHEUMATOLOGY (EUNEP)

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Background: There is a high unmet need of robust data on the outcomes of pregnancies and drug safety in various inflammatory rheumatic diseases (IRD). The aims of the European Network of Pregnancy Registers in Rheumatology (EuNeP) are to bring together experts who run pregnancy registers, to define a core data set and to perform concerted data analyses.

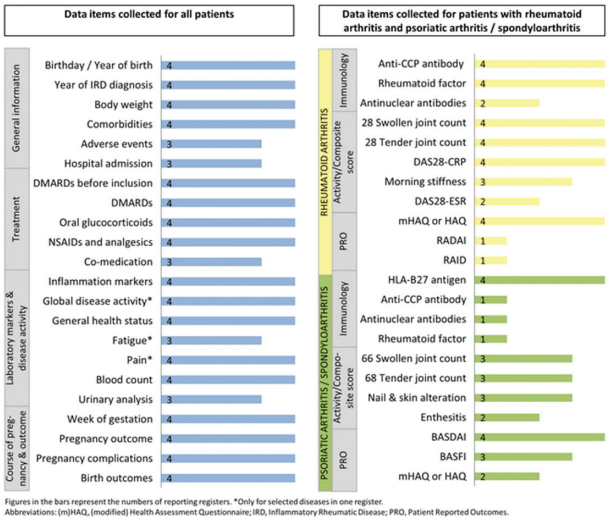
Objectives: To describe data items collected in existing multicentre European pregnancy registers in rheumatology.

Methods: A comprehensive survey on details of the registers was performed encompassing patient enrolment, inclusion criteria, demographics, disease specific and general outcomes, medical treatment, course and outcome of pregnancy and outcomes of the child. Free text answers were possible for all questions. Questionnaires were sent to the principle investigator(s) of the participating studies. The completed questionnaires were reviewed, and responses were evaluated descriptively. Only data items collected during pregnancy are shown.

Results: The following registers are involved in the collaboration: EGR2 (France), RePreg (Switzerland), REVNATUS (Norway) and Rhekiss (Germany). All registers collect data prospectively and nationwide. Patients can be included before pregnancy (child wish) or during pregnancy in all registers, and in RePreg also up to week 8 postpartal. Enrolment during pregnancy is possible up to gestation week 12 or thereafter in some specific cases (EGR2), week 20 (Rhekiss) or during complete pregnancy (RePreg and REVNATUS). All registers capture data via IT-based systems, REVNATUS documented on paper until 2016. During pregnancy, data is reported once every trimester by physicians and patients. Current figures, baseline characteristics and included IRD are presented in the table. Most of the data items that are independent of the underlying IRD are collected by all registers (figure 1). However, there are differences in the way data is collected and in the level of details.

	EGR2	RePreg	REVNATUS	Rhekiss
No. of enrolled patients	879	64	513*	777
No. of observed pregnancies	780	32	287	595
No. of completed pregnancies	446	6	266	344
No. of participating units	66	16	13	91
Year of register start	2014	2017	2006[IT 2016]	2015
Patient age (yrs), mean (SD)	32.1 (4.8)	33.6 (4.0)	30.8 (4.8)	32.4 (4.2)
Patient disease duration (yrs), mean (SD)	7.3 (6.1)	11.0 (7.4)	6.5 (6.8)	11.2 (81.7)
Diagnoses, N (%)				
RA	60 (6.9)	23 (35.9)	139 (27.1)	225 (29.0)
PsA	0**	11 (17.2)	44 (8.6)	66 (8.5)
SpA	55 (6.3)	24 (37.5)	107 (20.9)	101 (13.0)
JIA	-	-	78 (15.2)	43 (5.5)
Systemic lupus erythematosus	238 (27.4)	-	67 (13.1)	162 (20.8)
Other connective tissue diseases	371 (42.6)	-	36 (7.0)	129 (16.6)
Other IRDs	146 (16.8)	6 (9.4)	42 (8.2)	51 (6.6)

*Only patients enrolled in the IT-System are considered. ** PsA patients are included as peripheral SpA.



Figures in the bars represent the numbers of reporting registers. *Only for selected diseases in one register.
Abbreviations: (m)HAQ, (modified) Health Assessment Questionnaire; IRD, Inflammatory Rheumatic Disease; PRO, Patient Reported Outcomes.

Abstract FRI0601 – Figure 1. Figures in the bars represent the numbers of reporting registers.

Conclusions: Although the registers in this collaboration have similar designs, we found considerable differences in data items collected. In particular, the level of details of documented data and the information on disease-specific characteristics varied. Harmonisation of data collected in pregnancy registers would facilitate collaborative analysis.

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FRI0602 EULAR 'POINTS TO CONSIDER' FOR THE CONDUCTION OF WORKFORCE REQUIREMENT STUDIES IN RHEUMATOLOGY

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Background: EULAR has developed several recommendations and strategies for early referral, diagnosis and treatment of rheumatic diseases. These strategies, however, can only be implemented if sufficient manpower is available. An estimation of how many rheumatologists are needed to meet current and future population needs must be provided in order to counsel health care planners and decision makers. Current methods used for forecasting manpower are disparate, as are the variables incorporated into workforce projection models. Consequently, projections for the need of rheumatologists may vary by a factor of five between studies.([1]

Table. EULAR points to consider for the conduction of workforce requirement studies in rheumatology

No	Recommendation	LoA	LoE*
1	Workforce models should integrate supply, demand and needs of the respective geopolitical entity (e.g. municipality, region, state, country), and should express results as full time equivalents and as number of rheumatologists.	9.5 (0.9) 95%≥8	5
2	Workforce models should provide projections over a period of 5-15 years.	9.1 (1.1) 90%≥8	5
3	Workforce models should not assume a current balance between supply and need.	9.6 (0.7) 100%≥8	5
4	Workforce models should, where possible, rely on several data sources and include uncertainty analyses.	9.8 (0.4) 100%≥8	5
5	Workforce models should be regularly updated; updates should include an analysis of the actual performance (i.e. prediction validity) of the previous model.	9.5 (0.6) 100%≥8	5
6	Workforce needs for patient care should be based on the prevalence and referral rates of diseases managed by rheumatologists as well as on an estimation of time needed per patient.	9.7 (0.7) 100%≥8	5
7	Workforce needs for patient care should consider current and future demographics, sociocultural characteristics of the population and disease patterns.	9.5 (0.9) 95%≥8	5
8	Workforce needs and supply should consider work outside rheumatology patient care (e.g. administrative tasks, research, teaching, non-rheumatologic disease management), as well as patient care performed by other health professionals in rheumatology.	9.4 (0.9) 95%≥8	5
9	Workforce supply should account for demographic composition of rheumatologists, the number of rheumatologists entering and leaving the workforce, and generational attitudes of rheumatologists towards scope of practice and work-life balance.	9.1 (2.3) 85%≥8	5
10	Workforce models should consider the effects of medical developments, including new technologies, medications, artificial intelligence and e-health, on demand and supply.	9.4 (1.1) 85%≥8	5

Numbers in column 'LoA' indicate the mean and SD (in parentheses) of the LoA, as well as the percentage of task force members with an agreement ≥8.
LoA, Level of agreement, LoE, level of evidence according to Oxford Centre for Evidence-Based Medicine 2011 levels of evidence
*study design does not correspond to any of the levels of the OCEBM

Objectives: The aim of this project was to develop EULAR points to consider on the methodology of future workforce calculation models for rheumatologists in order to produce reliable, standardised and realistic estimates.
Methods: The EULAR Standardised Operating Procedures were followed. A systematic literature review (SLR) was conducted to retrieve workforce models in rheumatology and other specialities. The task force consisted of 20 experts (rheumatologists, health professionals and representatives from PARE) from 11 EULAR countries and the USA. Points to consider were based on expert opinion informed by the SLR, followed by group discussions with consensus obtained through informal voting. The level of agreement with the recommendations was voted anonymously.
Results: A total of 10 points to consider were formulated (table 1). The task force recommends models integrating supply (=workforce available to rheumatology), demand (=health services requested by the population) and needs (=health services that are considered appropriate to serve the population). Projections of workforce requirements should consider all factors relevant for current and future workload in and outside rheumatology patient care. Forecasts of workforce supply should consider demography and attrition of rheumatologists, as well as the effects of new developments in health care.
Conclusions: These are the first EULAR points to consider providing guidance on the methodology and the parameters to be applied in future national and international workforce requirement studies in rheumatology.

REFERENCE:
[1] Dejaco C, et al. Arthritis Care Res 2016.

Disclosure of Interest: None declared
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FRI0603 THE POTENTIAL USES OF AN INFODEMIOLOGY APPROACH FOR HEALTH-CARE SERVICES IN RHEUMATOLOGY

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Background: Infodemiology can help achieve the patient-centred care model. It is the science of determinants and distribution of information on electronic media. It can provide data to develop, collect, and evaluate metrics and indicators for information and communication patterns that are related to epidemiologic data or are useful for public health, policy making or even clinical practice. Google Trends (GTr) and Google AdWords (GAd) are two useful tools to assess demand-based infodemiology indicators. Its use is scanty in rheumatology.
Objectives: To illustrate the potential use of GTr and GAd, we present three case-studies: A) What search terms related to rheumatology are typed by people in Mexico (MX), the United States of America (USA), and Canada (CAN)? B) What is the search volume for specific DMARDs typed by people in MX, USA, and CAN?, and C) What is the positioning of the search term "arthritis" compared with two non-rheumatic diseases ("hepatitis C", "breast cancer") among MX, USA, and CAN?
Methods: GTr output is a relative search volume (the biggest volume is transformed to 100 and the rest are given as a proportion of it) and GAd output is the average number of searches per unit of time. We ran 3 different queries (MX, USA, CAN) for each case-study using GTr and GAd for years 2015–2017. Results were exported to a database for further analysis. Search volumes were adjusted per country's population and expressed as crude rates (searches per million; spm) when appropriate.
Results: To look for information on "rheumatology" people used 298 (MX), 654 (USA), and 637 (CAN) associated terms. "Arthritis" had 656, 550, and 548 associated terms in MX, USA, and CAN, respectively. For "arthritis treatment" there were 635, 569, and 569 associated terms in MX, USA, and CAN, respectively. Regarding DMARDs, there were 1,053 million searches during this period: methotrexate (28.5%), adalimumab (15.6%), rituximab (10.4%), and infliximab and etanercept (8.6% each). However, for every b- or tsDMARD search, there were fourteen (USA, CAN) to fifty-eight (MX) "turmeric" searches for the "treatment of arthritis". In 2015, search volume for "arthritis" was 120, 638, and 668 spm in MX, USA, and CAN, respectively. For 2016 and, 2017 figures remained similar for MX and CAN, but showed a 12% increase for the USA. In MX, "hepatitis C" had 114 spm in 2015, with a 32% increase by 2017. The USA and CAN had 1131 and 648 spm in 2015, with a 5% increase and an 8% decrease by 2017, respectively. For "breast cancer", search rates were 4 times higher than for "arthritis" for the three years in MX, with an average increase of 250% each October, concurrent with public awareness campaigns. In the USA and CAN, search volume was 36% and 56% less than that for "arthritis", with a 57% and 33% increase each October, respectively.
Conclusions: Infodemiology can have an added value to traditional research designs. It can serve for diverse purposes, such as assessing the penetration and impact of public awareness campaigns, patients' perceived needs, the appearance of new remedies, the positioning of diseases, disease-related cultural differences in ethnic groups, people perceptions on specific health-care systems, etc.
Disclosure of Interest: None declared
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FRI0604

TRENDS OF INFORMED CONSENT FORMS FOR INDUSTRY-SPONSORED CLINICAL TRIALS IN RHEUMATOLOGY OVER A 17-YEAR PERIOD: READABILITY, AND ASSESSMENT OF PATIENTS' HEALTH LITERACYAND PERCEPTIONS

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Background: The therapeutic arsenal in rheumatology has improved drastically during the last 20 years with the availability of biological and synthetic disease-modifying antirheumatic drugs. All these drugs required randomised controlled trials (RCTs) with thousands of rheumatic patients. All these patients went through the informed consent process and signed corresponding informed consent forms (ICFs).
Objectives: To assess trends in the length and readability of ICFs for industry-sponsored RCTs over a 17 year period. Additionally, to assess the health literacy (HL) and perceptions on ICFs among participants of current RCTs.
Methods: The grammatical readability (GR) of six pre-defined ICF sections (global, introduction, methods, risks/benefits, rights/responsibilities, and voluntary participation statement) of pivotal ICFs from industry-sponsored RCTs conducted at an outpatient rheumatology clinic during a 17 year period was assessed by using the INFLESZ instrument. Differences in GR were assessed by company, by disease and by study phase (95% CI of the mean and proportions; statistical significance assumed if no overlap), and by the years ICFs were written (1999—2005, 2006—2010, and 2011—2016; Kruskal-Wallis test). HL of patients was assessed with the SALHSA (inadequate, adequate) and S-TOFHLA (inadequate, marginal, adequate) instruments. Differences by age and schooling were determined by one-way ANOVA. Patient's perceptions and opinions on the ICF were assessed using a structured, self-reported, in-office questionnaire on an independent patient sample that had signed a pivotal ICF in the past 6 months.
Results: Thirty-nine ICFs about 22 drugs (18 biological or targeted synthetic DMARDs; 13 currently available on the market) from 13 pharmaceutical companies were analysed. The global mean readability was 57±3 (95% CI 56–58), and all ICFs were categorised as either "somewhat difficult to read" or "average". Readability remained at these levels without significant changes from 1999 to 2016. The "somewhat difficult" reading score was significantly more frequent in the "rights and responsibilities" and in the "informed consent statement" sections ($p<0.001$). The mean length of the ICFs written between 1999 and 2005 was 13±5 pages, with a significant increase thereafter (22±8 pages, $p<0.01$). Depending on the instrument, of 95 patients participating in the HL assessment, between 18% and 44% had limited HL. Of 90 patients participating in the perceptions questionnaire, 84% reported understanding the ICF well. However, 2%–57% misunderstood basic concepts, including the study drug name, randomization and placebo.
Conclusions: It seems that the considerable progress that has been made in medical research methods over time has not produced improvements in the process of informed consent in the industry-sponsored RCTs. The disparity between the readability of ICFs with patients' HL and their comprehension of ICFs continues, even after decades of attempts of regulatory agencies and numerous published suggestions.
Disclosure of Interest: None declared
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FRI0605

THE DEVELOPMENT PROCESS OF MOBILE HEALTH APPLICATIONS FOR SELF-MANAGEMENT IN PATIENTS WITH RHEUMATIC AND MUSCULOSKELETAL DISEASES IS HETEROGENEOUS AND OFTEN INCOMPLETE: RESULTS OF A SYSTEMATIC LITERATURE REVIEW

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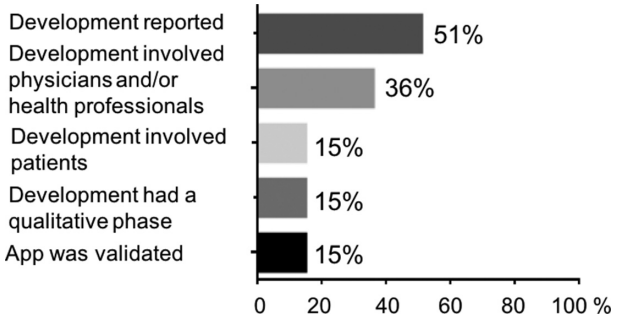
Background: Mobile health (mHealth) is exponentially growing in the current era, providing new potential and transforming the face of healthcare delivery. While the increasing availability of applications (apps) may enable people with rheumatic and musculoskeletal diseases (RMDs) to better self-manage their health, there is a general lack of evidence on ways to ensure appropriate development and evaluation of apps.
Objectives: To obtain an overview of existing mHealth apps for self-management in patients with RMDs, regarding content and development methods in particular, through a systematic literature review.
Methods: A search was performed up to December 2017 using EMBASE, Pubmed, Cochrane library, Web of Science and Psychinfo databases, with relevant key words and MeSH terms addressing three key domains: RMDs, self-management and mHealth. Double screening was performed on 15% of all abstracts against agreed inclusion criteria. For each publication relevant to an app for RMDs, the content, the aims, the target population of the apps and their development strategies were noted. The analysis was descriptive.
Results: Of 562 abstracts, 57 full text were screened. 39 articles were included in the analysis. 13 articles referred to an app linked to a connected device. Most of the apps targeted rheumatoid arthritis patients (n=11), juvenile idiopathic arthritis (n=7) and osteoarthritis (n=8). The development process of the app was poorly described in 19/39 (48.7%) of the studies (figure 1). Only 6/39 (15.4%) included patients, and 14/39 (35.9%) included health professionals or physicians in the development of such apps. Moreover, a qualitative phase occurred in only 6/39 (15.4%) of the cases. The app was tested and evaluated by physicians in 6/39 (15.4%). Patients were more frequently involved in app evaluation (29/39, 74.4%) but mostly indirectly through their adherence to the app. Only few of the apps published on were commercially available (5/39, 12.8%), 4/5 are free. One app is currently under development.



Abstract FRI0605 – Figure 1. Description of the development process of the apps in the 39 articles.

Conclusions: The development process of most apps was poorly described and potentially not satisfying in many studies. Despite patient willingness to use mHealth apps for self-management of their RMDs, a strong effort needs to be made to provide a standard and ensure quality and safety of newly-developed apps. This work will further inform EULAR points to consider for development, evaluation and implementation of mobile health applications for self-management of RMDs by patients.
Disclosure of Interest: None declared
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FRI0606

THE LIFT STUDY'S DIRECT-TO-PATIENT DESIGN PROVIDES RELIABLE SELF-REPORTED DATA FROM LUPUS PATIENTS

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Background: Direct-to Patient (D2P) clinical studies that rely upon social media, mobile connectivity, wearables, self-collected patient samples, and patient reported outcome data have the potential to revolutionise health research by enabling population-scale studies without the cost and complexity of traditional multi-site trials. D2P studies are particularly interesting for longitudinal studies where the burden of participants travelling to a central site is high; however, the quality and reliability of patient reported outcome data is unclear[1].
Objectives: The study evaluated the accuracy of self-reported data from a subset of patients in a 1000+participant D2P lupus study (www.theliftstudy.com) by comparing patient-reported data to medical records as well as genomic testing of individuals using participant-collected fingerstick blood samples.
Methods: The study was reviewed and approved by a central IRB (WIRB; Puyallup, WA). Subjects were recruited online across the U.S using social media. Electronically consented participants with self-reported lupus were asked to complete online surveys about their disease and drug history as well as provide medical record review (MRR) consent. A third party firm was employed for MRR and an independent physician summarised the following information: 1) participant age 2) confirmation of lupus 3) current lupus medications and 4) current steroid medications.