patients' concerns regarding family planning and pregnancy (FPP) were inadequately or inconsistently addressed.¹

Objectives: To investigate the general level of information on FPP and the potential concerns among Danish patients with CIDs.

Methods: An online survey to identify FPP issues was designed, and CID patients aged 18–50 years (yrs) were included. Respondents were recruited through patient organisations providing their members with a link to the questionnaire. In addition to demographics, information relating to time of diagnosis, treatments received, pregnancies, and course of disease were collected along with access to and concerns regarding FPP. Descriptive statistics were applied.

Results: Eligible patients included 368 with rheumatological diagnoses (RA, PsA, JIA, nr-axSpA, or AS; 304 [83%] female, mean age: 40 yrs; 64 [17%] male, mean age: 42 yrs) and 95 with dermatological diagnoses (PSO or PsA; 64 [67%] female, mean age: 37 yrs; 31 [33%] male, mean age: 42 yrs). Among the rheumatic patients, 43% of females and 53% of males were currently receiving systemic treatment and 37% of females and 22% of males had received >3 different systemic treatments (other than painkillers and non-steroidal anti-inflammatory drugs [NSAIDs]). Lack of access to FPP information was consistent across age groups, but higher in those with dermatological diagnoses (Table).

In total, 68% of patients with rheumatological and 73% with dermatological diagnoses had biological children and among these 18% and 23% of patients, respectively, indicated their disease had affected how many children they had or planned to have. The most frequent concerns among patients with rheumatological diagnoses were the potential physical impact of a pregnancy, disease worsening, heredity and being able to take care of the child (19, 16, 16 and 13%, respectively), whilst disease worsening and heredity (12 and 16%, respectively) were the most frequent concerns in those with dermatological diagnoses. Many patients experienced disease worsening during or after pregnancy (rheumatologic diagnoses: 16% and 34%; dermatologic: 20% and 59%, respectively).

Conclusion: Danish CID patients of reproductive age have concerns related both to their disease and to FPP, which affect their decisions around family planning. The majority of patients responding to this survey reported limited access to information about FPP, pointing to a need for healthcare professionals to provide standardised family planning information.

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Table. Proportion of patients with rheumatological or dermatological diagnoses who reported having little or no access to FPP information, stratified by age

Age	Rheumatological diagnosis N (%)	Dermatological diagnosis N (%)
18–29 yrs	19 (49)	14 (74)
30–39 yrs	61 (58)	16 (73)
40–50 yrs	134 (60)	34 (63)

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RMD research

PARE0025

“RA - DON'T GIVE UP” - LIFE WITH RHEUMATOID ARTHRITIS FROM PATIENTS' PERSPECTIVE

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Background: Rheumatoid arthritis (RA) as chronic and progressing to disability disease decreases a quality of life of every person suffering from it. Knowledge about this influence from patient perspective is important to limit burden of RA and organize appropriate care for patients.

Objectives: RA has input on every area of individual and social lives. Recognition of patients' situation in daily life, professional life, participation in treatment, taking life decision gives possibilities to better understanding of diseases and starting activities to change lives with RA. Aim of research was to learn attitudes, knowledge and experiences of people living with RA.

Methods: The study was initiated by KnowPR in partnership with Polish Rheuma Federation “REF”. Main researcher was Tomasz Sobierajski PhD., sociologist from Warsaw University. The first stage of the study was a workshop with patients with RA organized by REF. It was brainstorming to identify main problems, appropriate understand life with RA and discussion on questionnaire. After small pilot study on questionnaire, research was made by CAWI technique. Questionnaire had been linked on professional websites, facebook, Twitter, health forums. The data had been completed during one month - January 2019.

Results of survey were presented in booklet with comments. Opinions introducing results were done from persons represented patronages of project: minister of patient rights, president of Polish Society for Rheumatology, national consultant in rheumatology, directors of National Institute of Geriatrics, Rheumatology and Rehabilitation. Publication was enriched by stories of people with RA living full lives. Publication was launched during press conference and disseminated in hard copies and on-line with free access.

Results: In survey took part 619 respondents with RA - mostly women (90%). The biggest group of respondents (34%) was in age 46-60 years old. Duration of disease was different - from few months to more than 40 years. More than half of respondents are suffering from RA more than 10 years. Disease influences of every life area. Only 38% of respondents participate in decision about their treatment and took it together with rheumatologist. There are different opinions about way of taking medication. There are not differences among age groups and duration of disease in this. Majority of patients suffer from pain (73%), from limited abilities (68%) and from permanent fatigue (69%) in everyday lives. Rheumatologist has the biggest confidence among patients like a source of information about disease (73%). Other health professionals have lower confidence (35-40%). Majority of respondents (68%) note his knowledge about diseases like rather good and better. Respondents didn't connected their decision of having a child with disease how it has been before (59%). Part of respondents had to change or resign of professional work (30%). Part of them resigned from social life and hobbies before disease. In opinion of 57% of respondents RA changed totally their lives (57%).

Conclusion: Results of survey was used like a tool in lobbying for accessibility in newest treatment in RA. Further recognize of quality of life in RA is needed. Interviews of focus groups and individuals are planned.

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Disclosure of Interests: None declared

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PARE0026

WHICH PATIENT-REPORTED OUTCOMES DO RHEUMATOLOGY PATIENTS FIND IMPORTANT TO TRACK DIGITALLY? A REAL-WORLD LONGITUDINAL STUDY IN ARTHRITISPOWER

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Background: Development of a standardized approach to assess key elements of disease activity in rheumatology clinical trials has been the goal of Outcome Measures in Rheumatology Clinical Trials (OMERACT), American College of