mycophenolate mofetil, cyclophosphamide, and stem cell transplantation. In the first round, patients were asked to indicate which information on the benefits and harms is essential for making a treatment decision; they could also add new items. In the second and third rounds, patients were asked to prioritize the items. After the third round, a live, online panel discussion was held in order to reach consensus. Consensus was defined as $\geq 75\%$ agreement among panel members.

Results: Of the 36 patients invited, 67% (n=24) completed the first, 69% (n=25) the second and 75% (n=27) the third round. In the third round, median age of participants was 51 years (IQR 18), median disease duration was 4 years (IQR 5), 52% was female. Most patients had completed either an intermediate education level (59%) or high level of education (30%). Patients were or had been treated with mycophenolate mofetil (67%), methotrexate (44%), cyclophosphamide (41%), autologous stem cell transplantation (26%), rituximab (4%). Seven percent of patients were treatment-naïve. After the third round, eight patients joined the online panel discussion to reach final consensus. The panel reached consensus on seven benefits (prolonged progression-free survival, improved quality of life, improved daily functioning, improved pulmonary function, improved skin thickness, improved mobility and reduced fatigue) and four adverse events (treatment-related mortality, viral infections, cardiac damage, increased risk of cancer) as key themes for the decision making process (Table 1).

Conclusion: This study identified essential aspects of the four main treatment options for dcSSc. Our results can be used to develop effective patient information.

Table 1. Agreement on benefits and harms that should be addressed

Benefits	Agreement	Harms	Agreement
Improved pulmonary function	100%	Viral infections	88%
Improved skin thickness	100%	Cardiac damage	88%
Improved mobility	100%	Increased risk of cancer	88%
Prolonged progression-free survival	95%*	Treatment-related mortality	79%*
Improved quality of life	77%*	Flare or relapse of disease	63%
Improved daily functioning	77%*	Temporary increase in fatigue	25%
Reduced fatigue	75%	Temporary negative impact	25%
		on social activities	
Improved hand function	25%	Nausea	25%
Improved mood	25%	Other autoimmune disease	13%
Improved cardiac function	13%	Hormonal imbalance	13%
Improved oesophageal function	7%	Concentration difficulty	13%
		Diarrhea	13%
		Erectile dysfunction	13%
		Depression	13%
		Infertility	13%
		Hair loss	13%

*Items on which consensus was reached in round 3

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AB0915-PARE DEVELOPMENT AND USABILITY OF A WEB-BASED PATIENT-TAILORED TOOL TO SUPPORT ADHERENCE TO URATE-LOWERING THERAPY IN GOUT PATIENTS

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Background: Adherence to prescribed urate-lowering therapy (ULT) among gout patients is considered to be among the poorest of all chronic conditions. eHealth programs can be a possible opportunity to foster ULT adherence.

Objectives: This study describes the development and usability evaluation of a web-based tool to support ULT adherence among gout patients, specifically designed for a complement to usual care.

Methods: The Integrated Change (I-Change) model was used as theoretical basis for the development. The model combines various socio-cognitive theories and differentiates between three phases: a pre-motivational, a motivational, and a post-motivational phase. In practice, the I-Change gout tool contains three sessions, following the three phases of the I-Change model. Patients receive tailored feedback based on their answers in the form of animated videos and text messages after each session, and are prompted to set specific goals and action plans for their ULT adherence. The content and development of the I-Change gout tool was determined along an iterative process within a steering group of clinicians and researchers, supported by patient interviews and gout specific literature related to key aspects of medication adherence behavior. A cross-sectional

mixed methods design was used to test usability of the support tool consisting of a think aloud method and a usability questionnaire.

Results: The steering group decided on the content of the three sessions of the I-Change gout tool. Depending on the intention to change ULT adherence behavior patients were navigated through the I-Change gout tool, patients with a low intention go through all 3 sessions and patients with a high intention go through the pre- and post-motivational session (figure 1). In total, the I-Change gout tool contains three sessions with 80 questions, 66 tailored textual feedback messages, and 40 tailored animated videos.

Figure 1. Flowchart of the computer-tailored I-Change gout tool for urate-lowering therapy adherence.

Twenty gout patients and seven healthcare professionals participated in the usability tests. The program end score rating for the gout tool was on average 8.4 ± 0.9 (range 6-10) for patients and 7.7 ± 1.0 (range 6-9) for healthcare professionals. Furthermore, participants reported a high intention to use and/or recommend the program in the future. Yet, participants identified some issues for further improvement of the systems user-friendliness by addressing barriers (e.g. more explicitly navigation) and weaknesses (e.g. technical and health literacy). The I-Change gout tool was updated according suggestions of improvements of the participants.

Conclusion: This study provides initial support for the usability by patients and healthcare professionals of a ULT adherence I-Change gout tool. Further studies need to be conducted to assess its efficacy and (cost-) effectiveness in daily practice.

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AB0916-PARE KNOWLEDGE OF DISEASE, DIAGNOSIS, ADHERENCE AND IMPACT OF RESEARCH IN PATIENTS WITH INFLAMMATORY ARTHRITIS

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Background: The diagnosis and treatment of inflammatory arthritis has been transformed largely by the development of drugs that target specific molecules of the immune system. However, these changes have increased the complexity of the mechanisms of disease, its treatment and patients understanding. Patient education is needed in this area to facilitate decision making and to facilitate strong patient-partnerships in research.

Objectives: The aim of this study was to examine the level of understanding of inflammatory arthritis patients and the need for strong patient-partnership in research.

Methods: An online anonymous survey addressed questions about diagnosis, routine tests, medications and how they work, medication adherence, disease flare, heredity, pregnancy, and patient involvement in research.

Results: There were 1,873 respondents, 1416 of which had inflammatory arthritis (IA)-RA (65.8%) and PsA (34.2%). They were predominantly female (RA 86%,

PsA 85 %), aged 55±13 and 50±12. Less than 35% of patients had an understanding of diagnostic tests, what was measured and the implication for disease, with 75.5% also concerned about heredity. There was a high level of understanding of how specific medications treat inflammatory arthritis (72.9%). Adherence was also very high (>87%), with the main reasons for stopping medication without the advice of their clinician, 'feeling better' and 'side effects' however a significant proportion of patients (69.9%) reported a disease-flare following cessation of medication. Patients of childbearing age (69%) were also concerned that inflammatory arthritis reduced their chances of getting pregnant, with only 8% believing arthritis medications were safe to take during pregnancy. Finally, only 9% of patients had ever been asked to participate in a research study.

Conclusion: This study demonstrates a need for the development of stronger patient-partnerships with clinicians and researchers in relation to patient education and engagement with research, to create a platform where patients can have meaningful input and involvement in future research studies.

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AB0917-PARE KNOWLEDGE ON SYSTEMIC LUPUS ERYTHEMATOSUS (SLE) AND ITS MANAGEMENT AMONG SLE PATIENTS ATTENDING RHEUMATOLOGY CLINIC AT NATIONAL HOSPITAL OF SRI LANKA

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Background: Systemic Lupus Erythematosus (SLE) is a chronic relapsing and remitting multi-system involving autoimmune condition mainly affecting females of reproductive years. As any other chronic disease needing long term treatment and follow up, proper patient education and high level of patients' knowledge on their own diagnosis is mandatory for the optimum management. It is proven that poor patient awareness has led to poor compliance and catastrophic relapses. There were no Sri Lankan study to assess patients' knowledge on SLE and its management.

Objectives: To describe the demographic data, any exposure to patient education and to assess knowledge about their own diagnosis and its management among a group of already diagnosed patients with SLE attending rheumatology clinic in National Hospital of Sri Lanka.

Methods: A cross sectional descriptive study was carried out with convenience sampling and data were collected using interviewer administered questionnaire. All already diagnosed patients with Systemic Lupus Erythematosus attending the Rheumatology clinic during the data collection period were invited to participate in the study and total of 45 were enrolled with 100% response rate.

Results: Overall 45 participants were in the study and all were females. The mean age was 37 (±12.53) years and the average disease duration was 62 months. Considering the exposure to patient education 89.87% had at least one type of patient education and 10.1% had none. A significant proportion (84.4%) was aware about their own diagnosis and 82.2% was able to correctly mention their current medication. Overall knowledge about the disease and its management was moderate (68.7%) among this study population according to our scoring system. However, they had a poor knowledge (45%) relating to pregnancy and contraception.

Conclusion: The above study describes important demographic data, exposure to patient education and patients' knowledge about their own disease in population of Systemic Lupus Erythematosus patients attending National Hospital of Sri Lanka. Their overall knowledge regarding SLE, its management and complications were at a moderate level and awareness regarding pregnancy and contraception in a SLE patient was at a lower level. Therefore, clinicians should pay more attention in to patient education when managing conditions like SLE as it directly affect the patients' compliance and overall disease outcome.

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AB0918-PARE FAMILY PLANNING AND RMDs: A SURVEY

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Background: It is well known and universally acknowledged that RMDs are not related to old age, as those who are affected by these illness between 30 and 45 years old are a big number, perhaps the biggest one. Therefore, family planning and pregnancy are topics even more actual and their management is certainly one of the biggest source of distress and troubles in people affected by RMDs and their spouses.

Objectives: to define and deeply understand the problem's dimension, ANMAR made a survey according to the CAPIRE Observatory.

Methods: an pposite questionnaire was given to patients waiting for a rheumatological consultation, during 6 months in 2020.

Results: Over 300 women with an RMD fulfilled the questionnaire:

7 on 10 women are trying to become pregnant

51% of them did not notice it to their Rheumatologist.

57% of them has been already pregnant.

Conclusion: In Italy, women with RMDs are over 3.5 millions and the a lot of them are women of childbearing potential.

As therapies actually used are really effective, but may induce side effects on the reproductive system, it is absolutely needed to inform the Rheumatologist about the intent to procreate and to have suggestions about the correct choice of contraception models.

Communication between patient and Rheumatologist must be improved, even in this important topic.

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AB0919-PARE WHAT DO OLD PEOPLE THINK OF THEIR RHEUMATOID ARTHRITIS TREATMENTS?

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Background: Managing chronic diseases such as rheumatoid arthritis (RA) is a challenge on a daily basis for rheumatologists and convincing our patients to properly take their medication may be difficult especially with elderly. First step comes with our patients' education and suppressing misbeliefs and misconceptions.

Objectives: To study beliefs of elderly RA patients on DMARDs and see what they really think of their treatments.

Methods: A cross-sectional study was conducted in a rheumatology clinic over a period of 4 months. Patients over the age of 65 having RA and being treated with conventional DMARDs or biologics were questioned about their medication. The belief about medicines questionnaire (BMQ) was used to assess different beliefs. It is a validated questionnaire of 18 items. Patients responded freely to each item using a Likert scale. The clinician later collected the data and 4 scores were calculated (concern (c), necessity (n), overuse and harm), thus classifying patients on 4 different groups as follows: accepting if n≥ 15 and c<15, ambivalent n≥ 15 and c≥15, indifferent if n< 15 and c <15 and skeptical if n<15 and c≥ 15.