The call for RA stories received a fantastic response from the public and the reading panel had a tough job in selecting the contributions which would feature in the published volume. Once the successful contributions were chosen, Arthritis Ireland proceeded to design a book, which could be sold in the book trade and online.

Results: In September 2019, Arthritis Ireland published *My RA Story: Personal accounts of living with rheumatoid arthritis*. Launched in the National Library of Ireland by Sinead Moriarty, the 46 contributions touched upon themes of pain, fatigue, emotional impact, disability, surgery, education, career, family, goal-setting, self-management, connecting with others, hope, etc.

The contributors came from people who were living with RA for over 40 years, as well as from those who were more recently diagnosed.

The book is a hugely valuable contribution to health literature. Arthritis Ireland now plans to make the book available for sale internationally, through Amazon and other retail channels, as well as promoting it more extensively in rheumatology clinics.

In October, one of the contributors was interviewed on national television about her RA story, as part of a feature on World Arthritis Day.

Conclusion: This campaign gave people living with RA a platform to write about and share about their condition. Fronted by an RA champion with significant name recognition and an enormous audience in her own right, best-selling author, Sinéad Moriarty, the book, *My RA Story*. Crucially, the book is a valuable resource for people who are newly diagnosed with the disease and uncertain of what the future holds.

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PARE0004

PATIENT PERSPECTIVE ON THE EFFICACY AND RISKS OF GLUCOCORTICOIDS IN RHEUMATOID ARTHRITIS – AN INTERNATIONAL SURVEY OF 1344 PATIENTS

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Background: The Glucocorticoid Low-dose Outcome in Rheumatoid Arthritis Study (GLORIA) is an international investigator-initiated pragmatic randomized trial designed to study the effects of low-dose glucocorticoids (GCs) in elderly patients with Rheumatoid Arthritis (RA).

The research team is also committed to promote a better understanding of the risks and benefits of these drugs among health professionals and patients. In order to achieve these goals, it is important to assess the current ideas and concerns of patients regarding GCs.

Objectives: To evaluate the current patient perspective on the efficacy and risks of GCs in RA patients who are or have been treated with GCs.

Methods: Patients with RA completed an online survey (with 5 closed questions regarding efficacy and safety) presented in their native language. RA patients were recruited through a variety of patient organizations representing three continents. Patients were invited to participate through national patient organizations. In the USA, patients were also invited to participate through MediGuard.org. Participants were asked for their level of agreement on a 5-point Likert scale.

Results: 1344 RA patients with exposure to GCs, from Brazil, USA, UK, Portugal, Netherlands, Germany and 24 other countries** participated: 89% female, mean age (SD) 52 (14) years and mean disease duration 13 (11) years. The majority of participants (84%) had ≥10 years of education. The duration of GCs exposure was 1.6 (4.2) years. The majority of participants had read articles or pamphlets on the benefits or harms of GC therapy.

Regarding GCs efficacy (table 1), high levels of endorsement were found: about 2/3 of patients considered that GCs as very useful in their case, more than half considered that GCs were effective even at low doses, and agreed that GC improved RA symptoms within days.

Regarding safety (table 1), 1/3 of the participants reported having suffered some form of serious adverse events (AEs) due to GCs, and 9% perceived this as "life-threatening. Adverse events had a serious impact on quality of life, according to about 1/3 of the respondents.

Conclusion: Patients with RA exposed to GC report a strong conviction that GCs are very useful and effective for the treatment of their RA, even at low doses. This is accompanied by an important prevalence of serious AEs. Understanding the patient perspective can improve shared decision-making between patient and rheumatologist.

References: **Funding statement:** This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 634886.

Table 1 – Results of the surveys, across different countries, concerning patient perspective on the efficacy and risks of glucocorticoids in patients with RA.

	All	Brazil	USA	UK	Portugal	Germany	NL	Others**
GCs are or have been very useful to me								
Agree	58	64	56	62	42	51	66	54
Slightly agree	20	20	21	11	12	30	10	18
Neutral	6	4	8	7	5	6	6	10
Slightly disagree	3	4	5	1	4	0	3	3
Disagree	4	3	7	3	1	4	3	3
Missing	9	6	1	15	25	9	9	12
At a GC dose of 5 mg/day:								
Are very effective in the control of signs and symptoms of RA								
Agree	41	48	42	40	31	28	46	38
Slightly agree	25	25	15	20	28	45	20	12
Neutral	12	11	24	8	12	12	16	12
Slightly disagree	5	7	6	6	4	6	4	4
Disagree	6	4	7	6	1	4	5	7
Missing	12	6	3	19	25	9	9	15
Improve RA symptoms within days								
Agree	41	45	44	37	34	37	44	39
Slightly agree	23	23	19	19	20	33	23	24
Neutral	12	12	18	8	13	8	12	9
Slightly disagree	6	6	7	7	7	0	6	7
Disagree	8	8	8	10	1	3	5	7
Missing	11	6	3	19	25	9	9	15
I have suffered very SAEs due to GCs								
Agree	29	40	44	13	15	18	18	29
Slightly agree	3	9	9	9	9	0	32	18
Neutral	14	15	12	15	17	4	7	11
Slightly disagree	1	0	0	0	0	0	7	2
Disagree	44	40	43	56	43	58	27	41
Missing	9	6	1	15	25	9	9	12
N (% of total)								
	432 (100)	184 (24)	211 (49)					117 (27)
How serious do you consider these SAEs								
Life threatening	9	NA	55	32	NA	NA	NA	13
Serious impact in my QoL	36	NA	39	38	NA	NA	NA	23
Minor impact in my QoL	27	NA	28	52	NA	NA	NA	17
Mild and well tolerated	29	NA	18	50	NA	NA	NA	32

Numbers indicate %.

**Others (% of total): Italy 1.9%; Spain 1.7%; Romania and Canada, each one 1.4%; Belgium 0.6%; France, Australia and Venezuela, each one with 0.2%; Algeria, Angola, Argentina, Belize, Cyprus, India, Ireland, Japan, Mauritius, Mexico, Mozambique, Moldova, Nicaragua, Norway, Sweden and Switzerland each one with 0.1%.

*The Portuguese, Germany and Deutschland version as well as the English survey through MediGuard.org, didn't have this question due to legal constraints (% of answers per frequency category).

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PARE0005

INTEGRATED REFERRAL OF NEWLY DIAGNOSED RHEUMATOID ARTHRITIS PATIENT TO EDUCATION AND SUPPORT RESOURCES DELIVERED BY PATIENT LED ORGANISATION

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Background: NRAS follows best practice, evidence-based standards in all we do. Whilst huge strides have been made in the diagnosis and treatment of RA, the impact on quality of life can be significant and for many this disease remains hard to come to terms with. NRAS services and resources can improve the outcomes of people with RA/Adult JIA through a framework of supported self-management resources tailored to individual need. It is particularly important to provide the right support at the beginning of a person's journey with RA, when unhelpful health beliefs, anxiety and incorrect information can influence how someone responds to prescribed

medication and treatment thus impeding their ability to achieve the best outcomes. We know, for example, that many people do not take their medication as prescribed which reduces their chances of achieving remission or low disease activity state.

Objectives: To demonstrate that by referring patients online as part of a quality improvement programme to NRAS Right Start Service, we can show improved outcomes for patients with early RA when measured by the MSKHQ. Referred patients will benefit by: a) Better understanding what RA is; b) knowing how it can affect them; c) getting the right support; d) feeling more in control; receiving a tailored pack of information that meets their personal needs; e) be able to talk to a like-minded person who has lived with RA. It's a 4 step process which starts with the health professional referring their patient to NRAS on line. NICE Quality Standard 3 states that "Adults with rheumatoid arthritis are given opportunities throughout the course of their disease to take part in educational activities that support self-management." Our service enables health professionals to meet their responsibilities against this national quality standard.

Methods: In preparation for the introduction of this service at BSR congress 2019, an audit of the NRAS helpline service was undertaken at the end of 2018 and remains on going. Currently we have 224 responses which have been analysed against specific criteria. An Advisory Board comprising 7 clinicians, from different hospitals was appointed to work with NRAS on this important research.

Results: In the helpline audit, when asked 'how concerned are you about your disease?', alarmingly, 78% of those surveyed scored their level of concern about their disease at 7 or higher out of 10, while only 8% scored it at 5 or below. When asked about the emotional effects of their RA, 62% scored it as 7 or more where 10 was the worst possible impact. 94% of survey respondents said that they would definitely or very likely recommend NRAS and its services to another person. These results led to the development of New2RA Right Start launched in 2019, whereby health professionals across the UK can refer their patients directly to NRAS via a consented online referral which is fully GDPR compliant. To date (31st Jan, 2020), we have made calls to 101 patients, from 24 referring hospitals of which 55 have been successfully completed, 34 have had information sent through the post although our helpline team were unable to speak to them, and 12 remain open. Data analysis on the service is being carried out by King's College Hospital London, comparing the results of patients who have been referred to Right Start within the national audit who have completed a baseline and 3 month follow up MSKHQ and patients in the audit who have not participated in Right Start.

Conclusion: Anecdotal, we have had a tremendous response to this service from both patients and referring health professionals. We await data from King's on the above figures, which we will have within the next 2 months and further data, should this abstract be accepted, will be available prior to June 2020. Right Start enables health professionals to comply with QS3 above, of the NICE Quality Standards in RA, one of the key standards against which they are being audited in the NEIAA national audit. Once data and write up in a peer review journal has been published we plan to roll this service out to people with more established disease.

References:

[1] To be done, not included in word count.

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SATURDAY, 06 JUNE 2020

Work and rehabilitation

PARE0006

WORK PRODUCTIVITY LOSS IN PATIENTS WITH INFLAMMATORY ARTHRITIS

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Background: Limited data exist of work productivity loss in patients with Rheumatoid Arthritis (RA), Psoriatic Arthritis (PsA) and Spondyloarthritis (axSpA).

Objectives: The objective of this research was to assess productivity loss and absenteeism in patients with RA, PsA and axSpA.

Methods: The study was designed as a cross-sectional study aimed to collect patient-reported outcomes from patients with RA, PsA and axSpA in Denmark via a nurse administered questionnaires and patient journals. Patients ≥18 years with RA, PsA or axSpA were consecutively recruited for the study over a 6-month period via routine visits to outpatient rheumatology clinics. Descriptive statistics were analyzed using SAS.

Results: Of 488 respondents, 62% were women and mean age was 53.5 years (RA:57.4; PsA:52.6; axSpA:43.6). Average time since diagnosis was 11-15 years, however, for PsA and axSpA most patients answered 6-10 and 0-5 years, respectively. 280 (57%) answered that they had a job and completed the WPAI questionnaire (RA: 149 (51%); PsA: 48 (56%); axSpA: 83 (75%)). Average work hours was 31.9 in the last week (RA:31.2; PsA:33; axSpA:32.4). Average missed work hours were 4.3 in the last 7 days ((RA:4.0; PsA:4.2; axSpA:4.8), of which 32% was missed due to their inflammatory arthritis (RA:30%; PsA:38%; axSpA:32%). Mean absenteeism was highest for patients with PsA (mean=6.8; SD=17.7) followed by patients with axSpA (mean=5.4; SD=15.1) and with RA (mean=3.4; SD=12.2). Mean productivity loss was 20.5 (SD=23.8) for patients with RA, 27.6 (SD=25.8) for PsA and 26.3 (SD=25.8) for axSpA

Conclusion: We found that patients with PsA or axSpA miss more hours of work compared with patients with RA and when they are at work they have a higher absenteeism/lower productivity. This even though that both the group of patients with PsA and the axSpA were younger and had lived less time with their diagnosed disease compared with the group with RA.

Disclosure of Interests: Trine Pilgaard Shareholder of: Pfizer, Employee of: Pfizer, Bente Appel Esbensen: None declared, Sandra Elkjaer Stallknecht Consultant of: Pfizer

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SATURDAY, 06 JUNE 2020

RMD research

PARE0007

PATIENT AND PUBLIC INVOLVEMENT IN CLINICAL TRIAL DESIGN

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Background: Patient and public involvement (PPI) is gaining increasing recognition as important in ensuring research is relevant and acceptable to participants. Rheuma Tolerance for Cure (RTCure) is a 5 year international collaboration between academia and industry; focusing on earlier detection and prevention of rheumatoid arthritis (RA) through the use of immune-tolerising treatments.

Objectives: To bring lived experience and insight into scientific discussions; and to evolve collaboration between lay representatives and academia/industry.

Methods: 9 Patient Research Partners (PRPs) from 5 European countries were recruited via the EULAR PARE Network and institutions within the RTCure Consortium (8 PRPs with RA and 1 'at risk'). They were asked to enter into a legal agreement with the Consortium. PRPs participated in teleconferences (TCs) and were invited to attend face-to-face (F2F) meetings at least annually. Requests for input/feedback were sent from researchers to PRPs via the project's Patient Engagement Expert [SK].

Results: PRP involvement has given researchers and industry partners a new perspective on patient priorities, and focused thought on the ethics of recruitment for