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.

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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 ≤7.5mg/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