




# Impact of the COVID-19 pandemic on treat-to-target strategies and physical consultations in >7000 patients with inflammatory arthritis

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## Abstract

**Objectives.** To explore the impact of the COVID-19 pandemic on treat-to-target strategies (disease activity, remission rates) and access to physical consultations in patients with inflammatory rheumatic disease, as well as to explore characteristics of patients with/without physical consultations in the clinic and the impact of early vs established disease.

**Methods.** Patients with RA, PsA or axial SpA (axSpA) prospectively followed in the nationwide DANBIO registry answered online questionnaires and reported patient-reported outcomes (PROs) in June and November 2020. Patient characteristics, disease activity and physical consultations in the clinic before and during the pandemic were identified in DANBIO [all patients and subgroups with early disease (disease duration  $\leq 2$  years)]. In individual patients, changes in PROs before and during the pandemic were calculated. Characteristics of patients with/without physical consultations were described (age, gender, education level, comorbidities, disease duration, treatment).

**Results.** We included 7836 patients (22% of eligible patients), 12% of which had early disease. PROs were stable before and during the pandemic, with median changes approximating zero, as well as in patients with early disease. Remission rates were stable. The relative decrease in the number of patients with physical consultations was 21–72%, which was highest in axSpA. Characteristics of patients with/without physical consultations were similar. Self-reported satisfaction with treatment options and access was >70%; the preferred contact form was physical consultation (66%).

**Conclusion.** In this nationwide study performed during the first 8 months of the pandemic, patient satisfaction was high and the PROs and remission rates remained stable despite the remarkable reduction in physical consultations, as well as in patients with early disease. Characteristics of patients with/without physical consultations appeared similar.

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#### Rheumatology key messages

- We investigated the impact of reallocated treatment access during the first 8 months of the COVID-19 pandemic.
- In 7836 patients with inflammatory rheumatic diseases, disease activity was stable despite a remarkable reduction in physical consultations.
- Characteristics of patients with physical consultations compared with those without were similar.

## Introduction

The coronavirus disease 2019 (COVID-19) pandemic has caused widespread reallocation of resources in the healthcare system [1, 2]. For patients with chronic inflammatory rheumatic diseases (IRDs), this has led to reduced access to physical (face-to-face) consultations, postponement of routine controls and increased use of phone consultations [3–6].

The impact of the ongoing pandemic and subsequent waves on the treat-to-target (T2T) strategy has only been scarcely described. A Swiss study performed during the first wave (until June 2020) reported no major changes in patient-reported outcomes (PROs) and flare rates in 666 patients with IRDs [RA, PsA, axial SpA (axSpA)] despite a 52% decrease in physical consultations, but did not include changes in disease activity and objective measures of disease activity (i.e. swollen joint counts) [3]. Evidence is needed regarding how a lack of joint assessments by the rheumatologist and other clinical examinations potentially violate the T2T strategy [1, 3]. This strategy requires frequent physical consultations early in the disease course in order to establish the diagnosis, evaluate treatment response, flare assessments, adjustment of medication [7, 8] and patient education [9]. The use of remote access consultations during the current pandemic is likely to fuel the discussion on how to optimally monitor patients with IRDs in routine care [3, 6, 7, 10]. Recent EULAR provisional recommendations suggest that in the context of COVID-19, physical consultations and monitoring could temporarily be postponed for up to 6 months or alternatively could be performed remotely when needed in patients with stable disease and treatment, but supportive data are lacking [11].

The first COVID-19 wave hit Denmark in March 2020, and after gradual reopening from mid-April, a second surge followed in late autumn 2020 with new restrictions (lockdown of public and private institutions etc.) from November onwards during the winter and spring. The DANBIO registry is well-established for prospective monitoring of patients with IRDs in routine care [12]. We have previously reported high levels of anxiety and self-isolation in patients followed in DANBIO during the first wave, but also high adherence to medication [13].

Thus, in patients with IRDs followed in the DANBIO registry, we aimed to investigate if the pandemic

affected the T2T strategy as evaluated by disease activity, including PROs and remission rates, and access to physical consultations during the first 8 months of the COVID-19 pandemic compared with before the pandemic. Furthermore, we explored differences between patients who showed up at the clinic and those who did not and patients with early vs established disease.

## Methods

The Danish nationwide quality registry, DANBIO, includes >95% of patients with IRDs treated with biologic DMARDs (bDMARDs) in routine care. Since 2005, patients newly diagnosed with RA as well as PsA, axSpA or other inflammatory diseases have been included, irrespective of treatment and disease duration [12]. It is recommended to monitor disease activity, outcomes (e.g. PROs), physician measures (global score and joint assessment) and CRP at least annually or when the medication is changed [12]. Until recently, self-entry of PROs has been performed via touchscreens in the waiting areas [14].

In the current study, patients in DANBIO were invited to participate in a voluntary questionnaire survey ('You and your rheumatic disease during times with coronavirus') if they fulfilled the following criteria:  $\geq 18$  years of age and one or more contact in DANBIO (at hospital or rheumatology specialist clinic in primary care) after 11 May 2019. In parallel, an online infrastructure allowing data entry of PROs and questionnaires from home by computer, tablet or smartphone was implemented as previously described [13]. Invitations were sent through eBoks, which is a national infrastructure available for electronic communication with 80–90% of Danish citizens (e-boks.com/Danmark/en).

Patients were invited to answer online questionnaires regarding current disease-specific PROs and health behaviours on two occasions: in June 2020 (18 May–1 July) and in November 2020 (5 October–16 November). Patients could participate in the second questionnaire irrespective of whether they had participated in the first. The questionnaires included the following items: current disease activity, consent to study participation, consent to access to patient files, background information (number of persons in household, education, occupational

status, comorbidities) and current impact of the pandemic on health behaviour (medication adherence) and contacts to the rheumatology clinic (Supplementary Fig. S1, available at *Rheumatology* online) [13].

For each patient, information from DANBIO regarding rheumatologic diagnosis, smoking status, use of DMARDs (at the latest visit before 11 March 2020), disease activity before (i.e. latest registration before 11 March 2020 and in the time interval 1 September 2019–1 February 2020) and during (time interval 1 September 2020–1 February 2021) the COVID-19 pandemic was retrieved. Similarly, information on glucocorticoid injections (intra-articular or intramuscular) and handling of patients with high disease activity (alerts) was included (only available for RA patients).

As an indicator of whether the T2T goal was achieved, we evaluated changes in PROs in individual patients and the proportion of patients in disease remission before and during the pandemic. Disease remission (yes/no) was defined as a 28-joint DAS (DAS28) <2.6 (RA, PsA) and an Ankylosing Spondylitis Disease Activity Score (ASDAS) <1.3 (axSpA).

Early disease was defined as a disease duration (i.e. number of years between year of diagnosis and year 2020) ≤2 years.

It is not registered in DANBIO whether outcomes and assessments are in connection with a physical consultation or if it is recorded by the patient from home. For the current study, we assumed that it was a physical consultation if there was an evaluation of swollen joint count in patients with RA or PsA or a physician global score in axSpA.

For a full overview of data collection, see [Supplementary Fig. S1](#), available at *Rheumatology* online, and the footnote in [Table 1](#). Patient partners were actively involved in all phases of the study.

## Statistics

Patient characteristics, disease activity and health behaviour are reported as numbers (including available data) and percentages or medians with interquartile ranges (IQRs) as appropriate. All data are reported as observed with no imputation of missing data.

Changes ( $\Delta$  values) in PROs before and during the COVID-19 pandemic were calculated according to two time intervals, namely between before and June 2020 and between before and November 2020. In individual patients, PROs [visual analogue scale (VAS) global score, VAS pain score, HAQ, European Quality of Life 5-Dimensions questionnaire (EQ-5D)] before was subtracted from a later time point and results presented as medians (IQRs). Absolute and relative changes in the proportion of patients with a physical contact before and during the pandemic were calculated. No statistical comparisons were made. Stratified analyses were performed including only patients with early disease. All data were analysed in R (version 3.6.1; R Foundation for Statistical Computing, Vienna, Austria).

## Ethics and data protection

Included patients gave electronic consent for study participation (secure log-in by unique personal identifier) before completing the questionnaire. The consent provided the researchers access to previous DANBIO registrations as part of the patient file. The project was approved by the regional data protection agency (P-2020-543, 14 May 2020).

## Results

Overall, 7836 patients (22% of eligible patients) answered questionnaires in both June and November and were included (12 789 patients answered questionnaire 1 and 14 758 answered questionnaire 2). Among included patients, 5270 (67%) had RA, 1221 (16%) had PsA, 936 (12%) had axSpA and 409 (5%) had another IRD. The median disease duration was 10 years and 787 (12%) patients had early disease ([Table 1](#)). Overall, 66% of patients had other comorbidities and 34% received treatment with a bDMARD ([Table 1](#)). Compared with the overall DANBIO population, included patients were less frequently <40 years of age and fewer had axSpA ([Supplementary Table S1](#), available at *Rheumatology* online).

### Disease activity and physical consultations

PROs appeared unchanged before and during the pandemic. Thus the median values for VAS patient global score, pain score, HAQ and EQ-5D were similar before the pandemic, in June and in November 2020 ([Table 2](#)). Furthermore, in individual patients, changes from before the pandemic to June and to November were close to zero (shown for changes in VAS global score between before the pandemic and November 2020; [Fig. 1](#)). Similarly, the percentages of patients reporting an acceptable symptom state (PASS = yes) and reporting unchanged, better or worse disease state (anchor) were very similar at the three time points ([Table 2](#)). From before the pandemic to November 2020, 11% of patients changed from scoring PASS = yes to PASS = no, 14% vice versa and 76% remained unchanged. Similar results were seen in stratified analyses only including the 787 patients with early disease ([Supplementary Table S2](#), available at *Rheumatology* online).

[Table 3](#) presents evaluator-based assessments at two 5 month intervals, i.e. 1 September 2019–1 February 2020 (before the pandemic) and 1 September 2020–1 February 2021 (during the pandemic). Overall, there was a relative decrease (10–72%) in the number of patients who received glucocorticoid injections, had registrations of CRP and physician global scores, and who had alerts due to active disease during the pandemic compared with before. Similarly, the number of patients with a physical consultation decreased from 67% to 53% in RA (relative decrease 21%), 65% to 47% in PsA (relative decrease 27%) and 37% to 10% in axSpA (relative decrease 72%). Overall, the median CRP and physician global score

**TABLE 1** Baseline characteristics of included patients at the time they replied to the first questionnaire, June 2020, stratified by diagnosis<sup>a</sup> (N = 7836)

Characteristics	RA (n = 5270)	PsA (n = 1221)	axSpA (n = 936)	Other (n = 409)	Total (N = 7836)	Available, n
Gender, n (%)	Female	657 (54)	418 (45)	282 (69)	5067 (65)	7836
Age, years, n (%)	≤39	123 (2)	49 (4)	41 (10)	328 (4)	7836
	40–69	3039 (58)	901 (73)	279 (68)	4917 (63)	
	≥70	2108 (40)	271 (22)	89 (22)	2591 (33)	
From the questionnaire: self-reported characteristics						
Lives alone, n (%)	1176 (22)	229 (19)	155 (17)	84 (20)	1644 (21)	7836
Highest education <sup>b</sup> , n (%)	Yes	2388 (46)	551 (46)	486 (53)	4024 (52)	7676
	Medium/long	1619 (31)	534 (44)	554 (60)	2905 (38)	7704
Current occupational status <sup>b</sup> , n (%)	Working	3205 (66)	804 (70)	527 (60)	4800 (66)	7275
Self-reported comorbidities <sup>c</sup> , n	≥1					
Information captured from DANBIO: patient and disease characteristics						
Smoking status, n (%) <sup>d</sup>	Current	813 (16)	175 (15)	161 (18)	1207 (15)	7361
	Previous/never	4146 (84)	966 (85)	727 (82)	6154 (75)	
Disease duration, years, n (%)	≤2	551 (12)	109 (11)	37 (13)	787 (12)	6805
	>2	4132 (88)	920 (89)	246 (87)	4132 (88)	
Current medication <sup>e</sup> , n (%)	bDMARD	1584 (30)	444 (36)	556 (59)	2681 (34)	7836
	csDMARD	4184 (79)	823 (67)	185 (20)	5438 (69)	7836

Percentages are according to patients with available data. <sup>a</sup>Diagnoses in DANBIO include RA (seropositive, seronegative, unspecified, juvenile arthritis), axSpA (AS, undifferentiated SpA, non-radiographic axSpA; PsA (PsA/arthritis), other (SLE, SS, chorioretinitis, reactive arthritis, 'other', missing)). <sup>b</sup>Categories include education: lower (blue collar, short courses, no education), medium/long (2–3 years+, 3–4 years+, >4 years+, other) and occupational status: working (student, full-time employee, part-time employee, flex job, self-employed, other), not working (unemployed, retired, sick-leave). <sup>c</sup>Comorbidities include eight items: lung disease/asthma, diabetes, heart disease, cancer, hypertension, obesity, psychiatric/depression, other. <sup>d</sup>According to the latest registration in DANBIO before 11 March 2020, excluding 419 patients who did not permit access to patient files. <sup>e</sup>bDMARD irrespective of concomitant conventional synthetic DMARD and vice versa. csDMARD, conventional synthetic DMARD.

**TABLE 2** PROs before<sup>a</sup> and during the pandemic (June and November 2020) in patients with inflammatory rheumatic disease (N = 7836)

Variable	Disease activity			Changes <sup>d</sup> from before the pandemic to	
	Before <sup>a</sup>	June 2020	November 2020	June 2020	November 2020
Patient VAS global, mm	30 (12–58)	28 (10–54)	29 (10–55)	–2 (–12–8)	–1 (–12–8)
Patient VAS pain, mm	27 (11–50)	28 (11–51)	29 (11–52)	0 (–9–9)	0 (–9–11)
HAQ	0.50 (0.13–1.0)	0.50 (0.13–1.00)	0.50 (0.13–1.00)	0.0 (–0.125–0.125)	0.0 (–0.125–0.125)
EQ-5D	0.80 (0.72–0.86)	0.80 (0.71–0.86)	0.80 (0.71–0.86)	0.0 (–0.08–0.03)	0.0 (–0.07–0.03)
PASS, yes <sup>e</sup> , %	73%	75%	76%	11%/13%/63%/14% <sup>f</sup>	11%/14%/63%/13% <sup>f</sup>
Anchor, n (%) <sup>b</sup>					
Much better	235 (4)	137 (2)	136 (2)	4%/6%/31%/59% <sup>g</sup>	4%/6%/32%/58% <sup>g</sup>
Little better	607 (9)	464 (6)	444 (6)		
Better	507 (8)	393 (5)	317 (4)		
Unchanged	3128 (48)	4021 (52)	4140 (53)		
Worse	607 (9)	873 (11)	770 (10)		
Little worse	1328 (20)	1706 (22)	1773 (23)		
Much worse	119 (2)	157 (2)	143 (2)		
Available, n					
Patient VAS global, mm	6908	7835	7833	6907	6905
Patient VAS pain, mm	6865	7835	7833	6864	6862
HAQ	6745	7813	7801	6722	6714
EQ-5D <sup>c</sup>	2011	7573	7681	1945	1975
PASS, yes	6491	7780	7760	6441	6431
Anchor	6531	7751	7723	6446	6418

Values are median (IQR) unless stated otherwise. Percentages are according to patients with available data. <sup>a</sup>Latest registration in DANBIO before March 2020. <sup>b</sup>How are you feeling today compared with the last time you went to the clinic? <sup>c</sup>Not mandatory in DANBIO (may be collected once yearly). <sup>d</sup>Presented as the difference between late minus early time point. <sup>e</sup>If you were to remain for the rest of your life as you were during the last 48h, would this be acceptable or unacceptable for you (yes/no)? <sup>f</sup>Proportion of patients answering the following combinations before and in June (or November): PASS yes–no/no–yes/yes–yes/no–no. <sup>g</sup>Proportion of patients answering before and June (or November): anchor worse–better/better–worse/unchanged–unchanged/other combinations.

remained unchanged before and during the pandemic and similar results were seen for the disease-specific outcomes, including DAS28, Clinical Disease Activity Index (CDAI), ASDAS and remission rates (Table 3). In the subgroup of patients with early disease, similar results were found, but the relative decrease in physical consultations for axSpA was smaller, 20% (Supplementary Table S3, available at *Rheumatology* online).

Answers to PASS at three time points (before the pandemic, in June 2020 and in November 2020) are shown in Supplementary Table S4, available at *Rheumatology* online. Across diagnoses, 271 patients (4%) changed from PASS=yes before the pandemic to PASS=no in both June and November, whereas for 9% of patients it was vice versa (no–yes–yes). Characteristics of patients who changed from PASS=yes to PASS=no in June and November appeared like that of other PASS combinations (Supplementary Table S4, available at *Rheumatology* online).

RA patients with or without a physical consultation had similar characteristics regarding age, gender, comorbidities and education (Table 4). For bDMARD-treated patients, there was a tendency towards more frequent physical consultations (Table 4).

More than half of the included patients had been in contact with the clinic during the 3 months preceding the

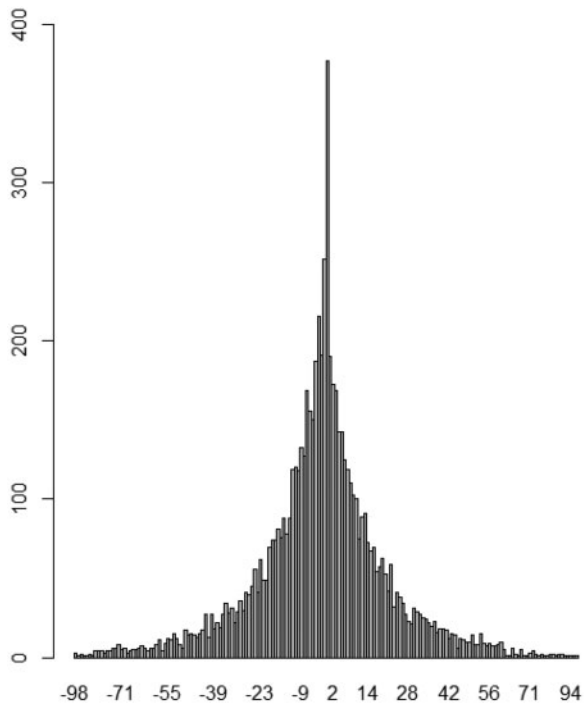
second questionnaire. Contacts were mainly physical consultations (42%) and/or telephone (34%), whereas video consultations and e-mails were rarely used (Table 5). Among the patients with contacts, 85% were satisfied (satisfied or very satisfied). Overall, 5–7% found access to the clinic and treatment options to be poorer compared with 1 year previously, whereas the majority found no difference. The preferred contact form was physical consultation (66%) followed by telephone consultation (18%) (Table 5). The same pattern was seen when assessing only patients with early disease (Table 5).

Overall, 6382 of 7836 patients (81%) reported being currently treated with DMARDs, and of those, 828 (13%) reported that the dose of at least one of their treatments had changed compared with before the pandemic. This was mainly due to changes in disease activity [740 patients (89%)], whereas 99 (1.5%) reported fear of COVID-19 to be the reason for the change (details not shown).

## Discussion

In this Danish nationwide study we included >7000 patients with IRDs who were prospectively followed in the nationwide DANBIO registry and who had replied to

**Fig. 1** Changes in patient VAS global in individual patients from before the pandemic to November 2020 ( $N = 6905$ )



x-axis: number of patients; y-axis: change in patient's global score (VAS 0–100 mm).

two online surveys during the first and second waves of the COVID-19 pandemic, a survey that included registration of disease-specific PROs. This information was then linked to the prospective registrations of disease activity by the rheumatologists (including joint counts, physician global score and CRP). Despite a significant reduction in physical consultations in the clinic compared with before the COVID-19 pandemic, the patients were overall highly satisfied with their access to treatment and consultations. PROs and disease activity were comparable to pre-pandemic levels. Very few patients changed DMARD treatment due to fear of COVID-19. Quite similar results were found for the 12% of patients with early disease (disease duration  $\leq 2$  years).

We demonstrated similar disease activity, including PROs before the pandemic and during the first and second waves with changes in median values of zero, and quartile ranges indicating no clinically relevant changes in the vast majority of patients. Remission rates were unchanged. Medication compliance was high and only a few patients reduced or withdrew DMARD treatment due to fear of COVID-19. This could be an explanatory factor for the observed stable disease activity. There was a major decrease in the number of physical consultations in the rheumatology clinic during the second wave, with an absolute decrease of 14–27% and a relative decrease of up to 72%, which was most pronounced in patients with axSpA, although fewer relative

changes were seen for axSpA patients with early disease (20%). We have no clear explanation for this, although age and gender distribution (younger, males) in axSpA could potentially have an impact. A study performed during the first wave in Switzerland showed a 52% decrease in physical consultations but stable disease activity and flare rates (as assessed by patient-reported disease activity) during the initial months of the pandemic [3]. That study did not explore potential differences between the patients with and without consultations. In our study we demonstrated that characteristics of RA patients (e.g. education level, social conditions and frailty/comorbid disease) with and without physical consultation appeared to be very similar, indicating that these factors did not impact access to treatment.

Our results are not fully in line with a EULAR-initiated survey among healthcare professionals that reported a negative impact of the pandemic on T2T strategies due to perceived postponement of treatment decisions and less likelihood to initiate a bDMARD or targeted synthetic DMARD [1]. However, important factors identified in this and other surveys include diagnostic delay and a shortage of DMARDs, including hydroxychloroquine or tocilizumab [1, 15], both of which were less relevant in our study, where the majority of patients had established disease (10 years disease duration) and a shortage of medicines has not played any major role during the pandemic in Denmark. In the current study, the T2T strategy was mainly evaluated as the proportion of patients in remission. Other outcomes such as erosive progression in RA, although relevant, would have required longer follow-up times.

Our results should be interpreted with caution: despite fewer physical consultations, we demonstrated no impact on disease activity and PROs and most patients were satisfied with the consultations and treatment options that they had been provided. However, 66% of patients preferred face-to-face consultations over phone contacts (which were only preferred by 18%). This illustrates that perhaps the most important aspect regarding patient-centred rheumatology care is accessibility and flexibility regarding the form of consultation: being face to face when needed, liaising needs and using telephone contacts or other remote solutions when suitable [1, 10, 11]. It was beyond the scope and design of the study to explore the feasibility of reallocating contact from physical to remote consultations. Thus information on phone contacts during the pandemic was self-reported by the patients and the corresponding information regarding pre-pandemic remote contacts was not available.

The pandemic has now lasted for  $>1$  year, with repeated lockdowns of societies worldwide. Previous studies have shown widespread disruption in the delivery of healthcare services, with poorer access to physical consultations and a switch towards remote care, including tele-health technologies (e.g. phone contacts) [16–19]. Important aspects of future studies are to explore its long-term impact. In the current study, mainly patients with long-standing disease and acceptable

**TABLE 3** Assessments, including physical consultations, before (1 September 2019–1 February 2020) and during (1 September 2020–1 February 2021) the pandemic and the change in the number of patients with assessments, stratified by diagnosis (N = 7417)

Characteristics	Assessment		Patients with assessment, n		Change in the number of patients with assessment, % <sup>d</sup>	
	Before	During	Before	During	Relative decrease	Absolute decrease
<b>RA (n = 4990)</b>						
Swollen joints (0–28), median (IQR)	0 (0–0)	0 (0–0)	3330	2637	21	14
Tender joints (0–28), median (IQR)	0 (0–2)	0 (0–1)	3331	2647	21	14
DAS28, median (IQR)	2.2 (1.7–3.1)	2.1 (1.6–2.8)	2965	2294	23	13
In remission (DAS28 < 2.6), %	65	69	2965	2294	23	13
CDAI, median (IQR)	4.3 (1.7–8.6)	4.2 (1.6–8.2)	3002	2375	21	13
CRP, mg/L, median (IQR)	3 (2–6)	3 (1–6)	3211	2740	15	9
Physician global score, mm, median (IQR)	5 (1–11)	5 (2–11)	3186	2556	20	13
Glucocorticoid injections, n (%) <sup>b</sup>	340 (7)	285 (6)	340	285	16	1
Patients with physical consultation, n (%) <sup>c</sup>	3330 (67)	2637 (53)	3330	2637	21	14
Alert, n (%) <sup>a</sup>			442	279	37	3
No further treatment available	8 (0)	3 (0)				
Awaiting further results	67 (1)	49 (1)				
Treatment intensified	291 (6)	169 (3)				
Patient do not wish change	23 (0)	20 (0)				
Other reason	53 (1)	38 (1)				
<b>PsA (n = 1151)</b>						
Swollen joints (0–28), median (IQR)	0 (0–0)	0 (0–0)	744	541	27	18
Tender joints (0–28), median (IQR)	0 (0–2)	0 (0–2)	746	546	27	17
DAS28, median (IQR)	2.3 (1.8–3.1)	2.2 (1.7–3.0)	648	473	27	15
In remission (DAS28 < 2.6), %	61%	62%	648	473	27	15
CDAI, median (IQR)	5.4 (2.3–9.8)	5.2 (2.2–9.6)	663	473	29	17
CRP, mg/L	3 (1–5)	3 (1–5)	727	588	19	12
Physician global score, mm, median (IQR)	5 (2–12)	6 (2–13)	727	537	26	17
Glucocorticoid injections <sup>b</sup> , n (%)	63 (5)	57 (5)	63	57	10	1
Patients with physical consultation, n (%) <sup>c</sup>	744 (65)	541 (47)	744	541	27	18
<b>axSpA (n = 890)</b>						
ASDAS, median (IQR)	2.2 (1.4–3.0)	1.9 (1.3–2.7)	529	478	10	6
In remission (ASDAS < 1.3), %	22	26	529	478	10	6
Physician global score, mm, median (IQR)	5 (1–8)	5 (1–10)	329	92	72	12
CRP, mg/L, median (IQR)	3 (1–6)	3 (1–4)	573	504	12	8
Patients with physical consultation, n (%) <sup>c</sup>	329 (37)	92 (10)	329	92	72	27

Excluding 419 patients (280 RA, 70 PsA, 46 axSpA, 23 other) who did not allow access to previous patient files, including previous DANBIO registrations. Included patients could contribute only one assessment/evaluation in the respective time intervals. <sup>a</sup>Action item in DANBIO for RA patients: actions performed in patients with one or more swollen joint and CDAI  $\geq 10.1$  and/or DAS28-CRP  $> 3.2$ . <sup>b</sup>Patients with at least one intra-articular or intramuscular injection in the time interval. <sup>c</sup>Patients with swollen joint count evaluation (RA/PsA) or physician global score (axSpA). <sup>d</sup>Relative decrease in the number of patients with assessment during the pandemic compared with before calculated as [(before – during)/before]  $\times 100\%$ . Absolute decrease is calculated as [(before – during)/N]  $\times 100\%$ .

**TABLE 4** Characteristics of RA patients with and without a physical consultation (swollen joint evaluation) before and during the pandemic ( $N = 4990$ )<sup>a</sup>

Characteristics	Before COVID-19 (1 September 2019–1 February 2020)		During COVID-19 (1 September 2020–1 February 2021)	
	Yes	No	Yes	No
Swollen joint evaluation Patients, <i>n</i>	3330	1660	2637	2353
Gender, female, <i>n/N</i> (%)	2341/3330 (70)	1144/1660 (69)	1858/2637 (70)	1627/2353 (68)
Age, years, median (IQR)	68 (59–74)	68 (59–74)	67 (59–66)	67 (60–74)
Other comorbidities, yes, <i>n/N</i> (%)	2041/3089 (66)	1003/1539 (65)	1574/2436 (65)	1470/2192 (67)
Longer education, <i>n/N</i> (%)	1536/3263 (47)	723/1623 (45)	1182/2583 (46)	1077/2303 (47)
Lives alone, yes, <i>n/N</i> (%)	729/3330 (22)	374/1660 (23)	577/2637 (22)	526/2353 (22)
Disease duration, $\leq 2$ years, <i>n/N</i> (%)	406/3134 (13)	145/1549 (9)	303/2486 (12)	248/2197 (11)
Current bDMARD, yes, <i>n/N</i> (%)	1111/3330 (33)	473/1660 (28)	902/2637 (34)	682/2353 (29)

<sup>a</sup>Excluding 280 RA patients who did not permit access to patient files.

symptom state participated (PASS=yes, 75%). In Denmark, it is recommended to monitor patients in DANBIO at least once a year [12]. A potential unwanted effect of the pandemic might be that some patients are not even seen annually in the clinic and evaluations are postponed or rely on remote consultations. This implies huge responsibilities on patients to be proactive and aware on when to approach their rheumatologist regarding problems related to disease control and treatment, an approach that seems to have failed in other disease entities, e.g. oncology [2, 20].

Furthermore, the face-to-face meeting may be an important entry point for correcting medication non-adherence and to handle difficult decisions regarding treatment changes. The latter may be of specific importance during a pandemic, where any treatment change often results in accentuated monitoring with blood samples, hand-outs of medication and clinical evaluations; all activities that are in contrast to in-home confinement [1].

The risk of selection bias is an important aspect that needs to be taken into consideration. The patients who participated in this questionnaire survey are not necessarily representative of the whole cohort. Thus the included 7838 in the study represented 22% of eligible patients. We have previously shown that mainly elderly patients did not have access to the eBoks system and could hence not be invited to participate [13]. Furthermore, compared with all eligible patients, included patients were less frequently young and fewer had axSpA. It could also be speculated whether participants in the survey were more often in disease remission, had higher education or had other capabilities or resources compared with patients who did not participate. It is also possible that included patients had a better understanding of their treatment options and were better at navigating the monitoring options available to them, resulting in higher satisfaction. However, we did not have data to explore this further. Due to lack of consent, information on disease activity in DANBIO could not be included from non-participants. Furthermore, our study mainly included

patients with long-standing disease, reflecting that this is the largest patient group in DANBIO. On the other hand, we found similar results in the subgroup of patients with early disease ( $\leq 2$  years disease duration). Nevertheless, our results may not be applicable to very recently diagnosed patients who would be likely to need closer follow-up and monitoring and have more medication changes.

The study was performed before the launching of COVID-19 vaccination programs and consequently it was not possible to explore the impact of vaccination.

The strengths of this study are the inclusion of a large prospective cohort of well-characterized patients who answered an extensive questionnaire at two time points during the pandemic. Combined with the prospective registrations in DANBIO, this allowed us to evaluate PROs and changes therein according to three time points (one before and two during the pandemic) and to identify concomitant registrations of treatment and objective measures of disease activity in the clinic before and during the pandemic.

In conclusion, this nationwide study including a large subgroup of >7000 patients with well-described IRDs and prospectively monitored in DANBIO showed—based on two extensive questionnaires and the collection of PROs—that despite a reduction in physical consultations, patient satisfaction with treatment access was high and the PROs were stable, as well as in patients with early disease.

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**TABLE 5** Access to treatment and patient satisfaction, based on questionnaire 2, November 2020, in all included patients and subgroup with early disease (disease duration  $\leq 2$  years)

Question	Answering options	All included patients (N = 7836)	Subgroup of patients with early disease (n = 787)
Contact with rheumatology clinic within the last 0–3 months <sup>a</sup> , n (%)	Physical consultation	3256 (42)	363 (46)
	Telephone <sup>c</sup>	2634 (34)	322 (41)
	E-mail	302 (4)	36 (5)
	Video consultation	24 0	3 0
	Other	480 (6)	33 (4)
	No contacts	2042 (26)	162 (21)
	Missing	185 (2)	15 (2)
Satisfaction with the contact, n (%) <sup>b</sup>	Very satisfied	3786 (67)	429 (70)
	Satisfied	989 (18)	91 (15)
	Neither-nor	293 (5)	44 (7)
	Unsatisfied	96 (2)	15 (2)
	Very unsatisfied	82 (1)	9 (1)
	Do not know	19 0	4 (1)
	Missing	344 (6)	18 (3)
Compared with last year, my access to rheumatology specialist is currently... n (%)	Better	250 (3)	47 (6)
	The same	5593 (71)	553 (70)
	Poorer	551 (7)	42 (5)
	Do not know	1061 (14)	104 (13)
	Not relevant	242 (3)	27 (3)
	Missing	139 (2)	14 (2)
	Compared with last year, my treatment options for arthritis are currently... n (%)	Better	287 (4)
The same		5856 (74)	564 (72)
Poorer		406 (5)	32 (4)
Do not know		893 (11)	90 (11)
Not relevant		217 (3)	27 (3)
Missing		177 (1)	17 (2)
Preferred contact form, n (%)		Physical consultation	5139 (66)
	Telephone	1428 (18)	126 (16)
	E-mail	195 (2)	25 (3)
	Video consultation	280 (4)	22 (3)
	Do not know	469 (6)	51 (6)
	Not relevant	192 (2)	18 (2)
	Missing	133 (2)	15 (2)

<sup>a</sup>More than one answer allowed per patient (percentages sum to  $>100\%$ ). <sup>b</sup>Percentages calculated for patients with one or more contact (for all included patients,  $N=5609$ ; for subgroup of patients with early disease,  $n=610$ ). <sup>c</sup>Not specified if physician or non-physician staff.

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## Dataavailability statement

All data relevant to the study are included in the article or uploaded as [supplementary information](#).

## Supplementary data

[Supplementary data](#) are available at *Rheumatology* online.

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