

Participant information

Record ID	1
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Deltager	<input checked="" type="checkbox"/> ja

Response was added on 2021-11-12 09:32:35.

General registry information

What is the status of your registry? running and including patients

Coverage

Please estimate how many (percentage) of the eligible spondyloarthritis patients in your country, that are registered 70

Please estimate how many (percentage) of the eligible psoriatic arthritis patients in your country, that are registered 60

How did you obtain the coverage estimate above? (Tick all that apply) other

Please specify estimation - the registry is mandatory, but the entry is not strictly enforced by the National health insurance, 2. only patients with axSpA and PsA are followed, i.e., the patients with reactive, enteropathic, undifferentiated SpA are not...

Which institutions/organisations can include patients in your registry? (Tick all that apply) departments of rheumatology at hospitals departments of rheumatology at university hospitals

Please give an estimate of how many departments of rheumatology at hospitals (not including university hospitals) that include patients in your registry 6

Please give an estimate of how many departments of rheumatology at university hospitals that include patients in your registry 2

When is the data registered? (Tick all that apply) at pre-specified registry visits

What is the schedule for pre-specified registry visits? 0, 12, 24, 36, 48, 72, 96,... q24wks- during the pandemic, the week 36 was often omitted, and after week 48, a visit per year is what we aim for now.

Is it possible to register visits outside of the pre-specified visit schedule, eg. if a patient has a flare? yes

Ethics

Is approval from a local ethics committee needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply)

- yes
 comment

Comment

we have an umbrella ethics committee approval for effectiveness and safety analyses

Do patients need to sign informed consent to be included in your registry?
(Tick all that apply)

- yes
 comment

Comment

the patients sign an informed consent and data release form

Are any additional local approvals needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply)

- no

Funding

How is the registry funded?
(Tick all that apply)

- from research grants
 industry

Please estimate the percentage of funds coming from research grants

20
((0-100%))

Please estimate the percentage of funds coming from industry, eg. pharmaceutical company

80
((0-100%))

The percentages add correctly up to a 100%

What is the basis of participation by a clinic/department/office in the registry?
(Tick all that apply)

- mandatory

Is the clinic/department/office financially compensated for registration?

- no

Inclusion criteria

What event triggers the inclusion of a patient into the registry?
(Tick all that apply)

- other

Please specify

first bDMARD/tsDMARD treatment initiation

Which criteria do you base the inclusion on?
(Tick all that apply)

- diagnosis
 treatment

Is a minimum age required for inclusion?

- yes, 18 years or above

Which diagnoses are included in your registry? (Tick all that apply)	<input checked="" type="checkbox"/> ankylosing spondylitis (AS) <input checked="" type="checkbox"/> non-radiographic axial spondyloarthritis (nr-axSpA) <input checked="" type="checkbox"/> psoriatic arthritis (PsA) <input checked="" type="checkbox"/> rheumatoid arthritis
Which year did inclusion of AS patients begin?	2010
Which year did inclusion of nr-axSpA patients begin?	2015
Which year did inclusion of PsA patients begin?	2010
Do patients need to be treated with biological DMARDs (including targeted synthetic DMARDs) to be included in the registry?	<input checked="" type="radio"/> yes
Have the inclusion criteria changed over time?	<input checked="" type="radio"/> no
General comments	the inclusion criteria did not change, but the eligibility criteria for starting bDMARDs did... They are less strict than they used to be. nr-ax-SpA can be identified from the classification criteria

Response was added on 2021-11-12 09:37:19.

Data management

What are the options for data entry? (Tick all that apply)	<input checked="" type="checkbox"/> electronic
Are the data fields in your registry interactive, such that invalid or unprobable data is flagged when entered (edit checks) (Tick all that apply)	<input checked="" type="checkbox"/> yes <input checked="" type="checkbox"/> comment
Since when (year) has the data fields been interactive?	2008
Comment	validation is not perfect
Please describe any other data validation procedures that you may use	we rarely send out discrepancy queries
How does your registry retain data management services? (Tick all that apply)	<input checked="" type="checkbox"/> external company <input checked="" type="checkbox"/> a researcher/administrative personal does data management beside other duties
Which is the background of your data manager(s)? (Tick all that apply)	<input checked="" type="checkbox"/> clinical
Which are the most commonly used data analysis software/programming languages in your organization? (Tick all that apply)	<input checked="" type="checkbox"/> R <input checked="" type="checkbox"/> excel
How is the data stored in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> a relational database framework (like SQL)
Which are the main data formats used for raw data extractions? (Tick all that apply)	<input checked="" type="checkbox"/> r-derived format
Where is your data collection platform hosted? (Tick all that apply)	<input checked="" type="checkbox"/> external company
Who maintains your data collection platform? (Tick all that apply)	<input checked="" type="checkbox"/> external company
How frequently is the database updated with the latest information? (Tick all that apply)	<input checked="" type="checkbox"/> real-time
Is linkage to other databases or registries possible?	<input type="checkbox"/> no

General comments

linkage is doable as patients are identified in the database using the health insurance number, but there is no interactive linkage.

Response was added on 2021-11-12 09:39:12.

Demography

Please indicate which of the following variables are collected in your registry
(Tick all that apply)

- age (year of birth)
 sex
 weight
 height

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Weight	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Height	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Diagnosis

How is a diagnosis registered?
(Tick all that apply)

- classification criteria
 other diagnostic categories

Specify which diagnostic categories

RA, PsA, axSpA

Do you register
(Tick all that apply)

- date for diagnosis

Do you register
(Tick all that apply)

- not registered

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Day/month/year of diagnosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Which classification criteria are registered?
(Tick all that apply)

- ASAS
 New York
 CASPAR

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ASAS	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
New York	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CASPAR	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In which patients can you register ASAS? both

Do you register individual ASAS classification items?
(Tick all that apply) yes

Do you register individual New York classification items?
(Tick all that apply) yes

Do you register individual CASPAR classification items?
(Tick all that apply) yes

Response was added on 2021-11-12 09:48:38.

Axial spondyloarthritis

Which disease status characteristics can be registered in axSpA patients?
(Tick all that apply)

- swollen joint count
 tender joint count
 enthesitis
 physician global
 other

Please specify

patient global

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 28
 other

Please specify

+25 ACJ, SCJ, DIP1-5, ankle, MTP1-5

Do you register specific location of swollen joints?
(Tick all that apply)

- yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- other

Please specify

+26 ACJ, SCJ, DIP1-5, ankle, MTP1-5, hip

Do you register specific location of tender joints?
(Tick all that apply)

- yes

Enthesitis

Do you register specific location of enthesitis?
(Tick all that apply)

yes

Which locations are registered?
(Tick all that apply)

- achilles tendon insertion
- 1st costochondral joint
- 7th costochondral joint
- posterior superior iliac spine
- anterior superior iliac spine
- iliac crests
- 5th lumbar spinous process

Please indicate which specific indices that are used,
if applicable

MASES

Physician Global

Please write the wording of the question regarding
physician global

Physician global disease activity assessment -
grade on a scale 0-10 (0-no activity, 10- high
disease activity)
(translate into english if possible)

Coxitis

Do you assess coxitis? If yes, please indicate how it
is assessed

no

Response was added on 2021-11-12 09:51:43.

Psoriatic arthritis

Which disease status characteristics can be registered in PsA patients?
(Tick all that apply)

- swollen joint count
 tender joint count
 enthesitis
 physician Global
 other

Please specify

patient global, BASDAI, BASFI

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician Global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 28
 Other

Please specify

+25 ACJ, SCJ, DIP1-5, ankle, MTP1-5

Do you register specific location of swollen joints?
(Tick all that apply)

- yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 28
 Other

Please specify

+26 ACJ, SCJ, DIP1-5, ankle, MTP1-5, hip

Entesitis

Do you register specific location of enthesitis?
(Tick all that apply)

yes

Which locations are registered?
(Tick all that apply)

- achilles tendon insertion
- 1st costochondral joint
- 7th costochondral joint
- posterior superior iliac spine
- anterior superior iliac spine
- iliac crests
- 5th lumbar spinous process

Please indicate which specific indices that are used,
if applicable

MASES

Physician global

Please write the wording of the question regarding
physician global

Physician global disease activity (0-10)
(Translate into english if possible)

Coxitis

Do you assess coxitis? If yes, please indicate how it
is assessed

Ask the patient if he/she has hip (groin) pain

Response was added on 2021-11-12 09:56:56.

Medication

Which therapies are registered in your registry?
(Tick all that apply)

- biological dmards (bDMARDs), including targeted synthetic dmards (JAK)
- conventional synthetic dmards (csDMARDs)
- glucocorticoids
- NSAIDs
- medication for comorbidity

bDMARDs

Which year did bDMARD registration begin? 2008

Is it mandatory to register bDMARD therapy? yes

csDMARDs

Which year did csDMARD registration begin? 2008

Is it mandatory to register csDMARD therapy? yes

Glucocorticoids

Which year did glucocorticoid registration begin? 2008

Is it mandatory to register glucocorticoid therapy? yes

Is the mode of administration registered?
(Tick all that apply) not registered

NSAIDs

Which year did NSAID registration begin? 2008

Is it mandatory to register NSAID therapy? no

Medicaton for comorbidities

What types of medical therapy for comorbidities are registered?

all medications used at the time of visit can be entered

What information regarding ONGOING medications is registered?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	frequency	administration mode
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NSAIDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
medication for comorbidity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Time points for registration (ONGOING medications)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
NSAIDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
medication for comorbidity	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

What information regarding PAST medications is registered at inclusion in registry?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	name of drug
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
glucocorticoids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
NSAIDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Discontinuation reasons

What are the possible reasons for discontinuation of a bDMARD?
(Tick all that apply)

- lack of efficacy
- adverse events
- remission
- lost to follow-up

Is it possible to register multiple reasons for discontinuation?

no

Does your registry link to prescription database or other external data sources on prescriptions on a regular basis as input to registry?
(Tick all that apply)

no

Response was added on 2021-11-12 10:07:02.

Patient reported outcomes

Which patient reported outcomes (PROs) are registered in axSpA and/or PsA patients?
(Tick all that apply)

- BASDAI
 BASFI
 pain
 global disease
 HAQ

Are any of the PROs registered in either axSpA or PsA only?

yes

Which PROs are registered uniquely in either axSpA or PsA?

BASDAI and BASFI are mandatory only for axSpA

Mode of registration

What are the options for registration of PROs?
(Tick all that apply)

paper forms

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
BASDAI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASFI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Global disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
HAQ	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

BASDAI

Are the individual BASDAI components registered?

yes

BASFI

Are the individual BASFI components registered?

yes

Pain, fatigue and global assessments

Please write the wording of the question relating to pain

How severe was the pain in the past week?
(please translate into english if possible)

Please write the wording of the question relating to global assessment of disease

How does your disease affect you today?
(please translate into english if possible)

HAQ

Are the individual HAQ items registered?

yes

Which HAQ versions may be used in your registry?
(Tick all that apply)

improved HAQ

Response was added on 2021-11-12 10:08:21.

Laboratory

Which laboratory test can be registered?
(Tick all that apply)

- ESR
- CRP
- hemoglobin
- ALAT
- creatinine
- HLA-B27

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ESR	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CRP	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Hemoglobin	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
ALAT	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Creatinine	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

How are laboratory test results registered?
(Tick all that apply)

- entered by health care staff

Response was added on 2021-11-12 10:09:48.

Imaging

Which imaging modalities can be registered?
(Tick all that apply)

- Magnetic Resonance Imaging (MRI)
 X-ray

Information on each image

	date of examination	full image report	image file	scoring system	+/- progression	other
What information on each MRI exam is registered?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What information on each x-ray exam is registered?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

MRI

Which anatomical regions can be registered?
(Tick all that apply)

- sacroiliac joint MRI

X-ray

Which anatomical regions can be registered?
(Tick all that apply)

- sacroiliac joint radiographs

General comments

latest imaging can be recorded at inclusion into the registry, there is no follow-up

Response was added on 2021-11-12 10:13:42.

Comorbidities

Which extraarticular manifestations and comorbid conditions are registered?
(Tick all that apply)

- uveitis
- psoriasis
- inflammatory bowel disease (IBD)
- ischemic heart disease (IHD)
- cerebrovascular disease (CVD)
- hypertension
- diabetes (DM)
- dyslipidemia
- osteoporosis
- chronic kidney insufficiency (CKI)
- chronic liver disease, eg. hepatitis, cirrhosis
- solid cancer
- hematological cancer
- depression
- tuberculosis (TB)
- other

Please specify

thyroid disease, demyelinating disease, epilepsy,
asthma, COPD, peptic ulcer disease,

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
uveitis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IBD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IHD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CVD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hypertension	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
DM	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CKI	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
depression	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
TB	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

other

Mode of registration - how are comorbid conditions registered?

	patient-reported	by health-staff	linkage from other registry
uveitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
depression	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
TB	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
other	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Do you use ICD-10 codes for registration? no

General comments patient reported comorbidities are checked against available medical records.

Response was added on 2021-11-12 10:15:48.

Lifestyle

Which lifestyle parameters are registered?
(Tick all that apply) smoking

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Smoking	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Smoking

How is smoking status characterised?
(Tick all that apply) current
 former
 never

Do you register a start date?
(Tick all that apply) no date is registered

Do you register a stop date for former smokers? No

How is average number of smoked cigarettes registered?
(Tick all that apply) number of daily cigarettes

General comments We record
years of smoking
cigs smoked per day
years abstaining from smoking at inclusion into the
registry, so we can deduce the year of starting and
stopping in smokers and ex-smokers

Response was added on 2021-11-12 10:17:22.

Safety

Can you register adverse events in your registry?
(Tick all that apply) yes, directly into registry

Is it mandatory to register adverse events through
your registry? yes

Which adverse events are registered in your registry?
(Tick all that apply) non-serious adverse events
 serious adverse events?

Information on adverse events

	date of event	MeddRA	ICD10-code	outcome	other
Non serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (non serious AE) picked from a list, entered as free text

Please specify (serious AE) picked from a list, entered as free text

Participant information

Record ID	2
Name	Karin Laas
Registry	ESRBTR (Estonia)
E-mail	karin.laas@itk.ee
Deltager	<input checked="" type="checkbox"/> ja

Response was added on 2021-11-04 14:55:21.

General registry information

What is the status of your registry? running and including patients

Coverage

Please estimate how many (percentage) of the eligible spondyloarthritis patients in your country, that are registered 95

Please estimate how many (percentage) of the eligible psoriatic arthritis patients in your country, that are registered 95

How did you obtain the coverage estimate above? (Tick all that apply) by prior study of coverage

Which institutions/organisations can include patients in your registry? (Tick all that apply) departments of rheumatology at hospitals departments of rheumatology at university hospitals

Please give an estimate of how many departments of rheumatology at hospitals (not including university hospitals) that include patients in your registry 3

Please give an estimate of how many departments of rheumatology at university hospitals that include patients in your registry 1

When is the data registered? (Tick all that apply) at routine visits

Are all routine visits registered in your registry - or only some? only some visits

Ethics

Is approval from a local ethics committee needed for a study on de-identified data (eg. a EuroSpA upload)? (Tick all that apply) no

Do patients need to sign informed consent to be included in your registry? (Tick all that apply) no

Are any additional local approvals needed for a study on de-identified data (eg. a EuroSpA upload)? (Tick all that apply) no

Funding	
How is the registry funded? (Tick all that apply)	<input checked="" type="checkbox"/> industry
Please estimate the percentage of funds coming from industry, eg. pharmaceutical company	100 ((0-100%))
The percentages add correctly up to a 100%	
What is the basis of participation by a clinic/department/office in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> mandatory
Is the clinic/department/office financially compensated for registration?	<input type="checkbox"/> yes
Inclusion criteria	
What event triggers the inclusion of a patient into the registry? (Tick all that apply)	<input checked="" type="checkbox"/> new treatment
Which criteria do you base the inclusion on? (Tick all that apply)	<input checked="" type="checkbox"/> diagnosis <input checked="" type="checkbox"/> treatment
Is a minimum age required for inclusion?	<input checked="" type="checkbox"/> yes, 18 years or above
Which diagnoses are included in your registry? (Tick all that apply)	<input checked="" type="checkbox"/> ankylosing spondylitis (AS) <input checked="" type="checkbox"/> non-radiographic axial spondyloarthritis (nr-axSpA) <input checked="" type="checkbox"/> psoriatic arthritis (PsA) <input checked="" type="checkbox"/> rheumatoid arthritis <input checked="" type="checkbox"/> other
Which year did inclusion of AS patients begin?	2013
Which year did inclusion of nr-axSpA patients begin?	2013
Which year did inclusion of PsA patients begin?	2013
Which other diagnoses are included?	Juvenile idiopathic arthritis
Do patients need to be treated with biological DMARDs (including targeted synthetic DMARDs) to be included in the registry?	<input type="checkbox"/> yes
Have the inclusion criteria changed over time?	<input type="checkbox"/> no

Response was added on 2021-11-08 19:59:33.

Data management

What are the options for data entry? (Tick all that apply)	<input checked="" type="checkbox"/> electronic
Are the data fields in your registry interactive, such that invalid or unprobable data is flagged when entered (edit checks) (Tick all that apply)	<input checked="" type="checkbox"/> yes
Since when (year) has the data fields been interactive?	2013
How does your registry retain data management services? (Tick all that apply)	<input checked="" type="checkbox"/> person employed as data manager
Which is the background of your data manager(s)? (Tick all that apply)	<input checked="" type="checkbox"/> data science/biostatistician/technical
Which are the most commonly used data analysis software/programming languages in your organization? (Tick all that apply)	<input checked="" type="checkbox"/> stata
How is the data stored in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> a relational database framework (like SQL)
Which are the main data formats used for raw data extractions? (Tick all that apply)	<input checked="" type="checkbox"/> simple text files, eg. csv, tsv
Where is your data collection platform hosted? (Tick all that apply)	<input checked="" type="checkbox"/> by a hospital IT-administration
Who maintains your data collection platform? (Tick all that apply)	<input checked="" type="checkbox"/> hospital IT-administrator
How frequently is the database updated with the latest information? (Tick all that apply)	<input checked="" type="checkbox"/> real-time
Is linkage to other databases or registries possible?	<input type="checkbox"/> yes
Which registries can be linked to? (Tick all that apply)	<input checked="" type="checkbox"/> mortality registry <input checked="" type="checkbox"/> electronic medical records

Response was added on 2021-11-08 20:01:21.

Demography

Please indicate which of the following variables are collected in your registry
(Tick all that apply)

- age (year of birth)
 sex
 weight
 height
 death

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Weight	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Height	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How is vital status registered
(Tick all that apply)

- by healthstaff, manually

Diagnosis

How is a diagnosis registered?
(Tick all that apply)

- through ICD-10 codes

Do you register
(Tick all that apply)

- year of diagnosis

Do you register
(Tick all that apply)

- not registered

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Day/month/year of diagnosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Which classification criteria are registered?
(Tick all that apply)

- ASAS
 CASPAR

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ASAS	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CASPAR	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In which patients can you register ASAS?

AxSpA

Do you register individual ASAS classification items?
(Tick all that apply)

no

Do you register individual CASPAR classification items?
(Tick all that apply)

no

Response was added on 2021-11-08 20:01:26.

Axial spondyloarthritis

Which disease status characteristics can be registered in axSpA patients?
(Tick all that apply)

- swollen joint count
 tender joint count
 physician global

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 66

Do you register specific location of swollen joints?
(Tick all that apply)

- no, just joint counts

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 68

Do you register specific location of tender joints?
(Tick all that apply)

- no, just joint counts

Physician Global

Please write the wording of the question regarding physician global

Physicians assessment of disease activity
(translate into english if possible)

Coxitis

Do you assess coxitis? If yes, please indicate how it is assessed

No

Response was added on 2021-11-08 20:01:30.

Psoriatic arthritis

Which disease status characteristics can be registered in PsA patients?
(Tick all that apply)

- swollen joint count
 tender joint count
 physician Global

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician Global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 28
 66

Do you register specific location of swollen joints?
(Tick all that apply)

- no, just joint counts

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 28
 68

Do you register specific location of tender joints?
(Tick all that apply)

- no, just joint counts

Physician global

Please write the wording of the question regarding physician global

Physicians assessment of disease activity
(Translate into english if possible)

Coxitis

Do you assess coxitis? If yes, please indicate how it is assessed

No

Response was added on 2021-11-08 20:01:35.

MedicationWhich therapies are registered in your registry?
(Tick all that apply)

- biological dmards (bDMARDs), including targeted synthetic dmards (JAK)
- conventional synthetic dmards (csDMARDs)
- glucocorticoids

bDMARDs

Which year did bDMARD registration begin? 2013

Is it mandatory to register bDMARD therapy? yes**csDMARDs**

Which year did csDMARD registration begin? 2013

Is it mandatory to register csDMARD therapy? yes**Glucocorticoids**

Which year did glucocorticoid registration begin? 2013

Is it mandatory to register glucocorticoid therapy? yesIs the mode of administration registered?
(Tick all that apply)

- oral
- intraarticular

Are specific locations of injected joints registered? no**What information regarding ONGOING medications is registered?**

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	frequency	administration mode
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
glucocorticoids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Time points for registration (ONGOING medications)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

What information regarding PAST medications is registered at inclusion in registry?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	name of drug
bDMARDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Discontinuation reasons

What are the possible reasons for discontinuation of a bDMARD?
(Tick all that apply)

- lack of efficacy
- adverse events
- remission
- pregnancy wish
- infection
- lost to follow-up
- death

Is it possible to register multiple reasons for discontinuation?

no

Does your registry link to prescription database or other external data sources on prescriptions on a regular basis as input to registry?
(Tick all that apply)

no

Response was added on 2021-11-08 20:01:39.

Patient reported outcomes

Which patient reported outcomes (PROs) are registered in axSpA and/or PsA patients?
(Tick all that apply)

- BASDAI
 pain
 global disease
 HAQ

Are any of the PROs registered in either axSpA or PsA only?

- no, all PROs are registered in both diagnoses

Mode of registration

What are the options for registration of PROs?
(Tick all that apply)

- paper forms

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
BASDAI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Global disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
HAQ	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

BASDAI

Are the individual BASDAI components registered?

- no, only the composite score

Pain, fatigue and global assessments

Please write the wording of the question relating to pain

patients global assessment of pain
(please translate into english if possible)

Please write the wording of the question relating to global assessment of disease

patients global assessment of disease activity
(please translate into english if possible)

HAQ

Are the individual HAQ items registered?

no

Which HAQ versions may be used in your registry?
(Tick all that apply)

stanford HAQ DI without adjustment for use of aids
and devices

Response was added on 2021-11-08 20:01:43.

Laboratory

Which laboratory test can be registered?
(Tick all that apply)

- ESR
- CRP
- HLA-B27
- IgM-RF

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ESR	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CRP	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

How are laboratory test results registered?
(Tick all that apply)

- entered by health care staff

Response was added on 2021-11-08 20:01:57.

Comorbidities

Which extraarticular manifestations and comorbid conditions are registered?
(Tick all that apply)

- uveitis
- psoriasis
- inflammatory bowel disease (IBD)
- ischemic heart disease (IHD)
- cerebrovascular disease (CVD)
- hypertension
- diabetes (DM)
- dyslipidemia
- osteoporosis
- chronic kidney insufficiency (CKI)
- chronic liver disease, eg. hepatitis, cirrhosis
- solid cancer
- hematological cancer
- depression
- tuberculosis (TB)
- fibromyalgia

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
uveitis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IBD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IHD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CVD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hypertension	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
DM	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CKI	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
depression	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
TB	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
fibromyalgia	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Mode of registration - how are comorbid conditions registered?

	patient-reported	by health-staff	linkage from other registry
uveitis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
depression	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
TB	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
fibromyalgia	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Do you use ICD-10 codes for registration?

 no

Response was added on 2021-11-08 20:02:07.

Safety

Can you register adverse events in your registry?
(Tick all that apply) yes, directly into registry

Is it mandatory to register adverse events through
your registry? yes

Which adverse events are registered in your registry?
(Tick all that apply) non-serious adverse events
 serious adverse events?

Information on adverse events

	date of event	MeddRA	ICD10-code	outcome	other
Non serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (non serious AE) drop down menu and free text.

Please specify (serious AE) drop down menu same as for nSAE

Participant information

Record ID	4
Name	Almut Scherer
Registry	SCQM
E-mail	almut.scherer@scqm.ch
Deltager	<input checked="" type="checkbox"/> ja

Response was added on 2021-12-17 14:06:20.

General registry information

What is the status of your registry? running and including patients

Coverage

Please estimate how many (percentage) of the eligible spondyloarthritis patients in your country, that are registered 10

Please estimate how many (percentage) of the eligible psoriatic arthritis patients in your country, that are registered 10

How did you obtain the coverage estimate above? (Tick all that apply) other

Please specify These are crude estimates. Based on <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4470267/pdf/nihms407401.pdf> we assume prevalence of 1%. With a population of 8.7Mio we expect 87'000 cases. We have recorded 5'000 axSpA patients since 2005, which is about 5%. With incidence, our estimates are higher.

Which institutions/organisations can include patients in your registry? (Tick all that apply) private rheumatology practices departments of rheumatology at hospitals departments of rheumatology at university hospitals

Please give an estimate of how many private rheumatology practices that include patients in your registry 50

Please give an estimate of how many departments of rheumatology at hospitals (not including university hospitals) that include patients in your registry 15

Please give an estimate of how many departments of rheumatology at university hospitals that include patients in your registry 5

When is the data registered? (Tick all that apply) at routine visits

Are all routine visits registered in your registry - or only some? only some visits

Ethics

Is approval from a local ethics committee needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply)

- yes
 no
 comment

Comment

For anonymized data, it should not be needed, but it depends a bit on the cantonal ethics committee, how they handle this.

Do patients need to sign informed consent to be included in your registry?
(Tick all that apply)

- yes

Are any additional local approvals needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply)

- yes

Please specify which additional approvals are needed

Approval from SCQM for research use of data

Funding

How is the registry funded?
(Tick all that apply)

- industry
 other

Please estimate the percentage of funds coming from industry, eg. pharmaceutical company

90
((0-100%))

Please specify which other sources

Other foundations, Swiss Society of Rheumatology

Please estimate the percentage of funds coming from other sources

10
((0-100%))

The percentages add correctly up to a 100%

What is the basis of participation by a clinic/department/office in the registry?
(Tick all that apply)

- voluntary

Is the clinic/department/office financially compensated for registration?

- no

Inclusion criteria

What event triggers the inclusion of a patient into the registry?
(Tick all that apply)

- new diagnosis
 new treatment
 other

Please specify

A patient can be included at any time-point during the patient journey

Which criteria do you base the inclusion on?
(Tick all that apply)

- diagnosis
 other

Is a minimum age required for inclusion?

- no

Which diagnoses are included in your registry? (Tick all that apply)	<input checked="" type="checkbox"/> ankylosing spondylitis (AS) <input checked="" type="checkbox"/> non-radiographic axial spondyloarthritis (nr-axSpA) <input checked="" type="checkbox"/> psoriatic arthritis (PsA) <input checked="" type="checkbox"/> rheumatoid arthritis
Which year did inclusion of AS patients begin?	2005
Which year did inclusion of nr-axSpA patients begin?	2005
Which year did inclusion of PsA patients begin?	2006
Please specify which additional inclusion criteria	Patient needs to speak one of the official country languages (DE, FR or IT)
Have the inclusion criteria changed over time?	<input checked="" type="radio"/> no

Response was added on 2021-12-17 14:06:24.

Data management

What are the options for data entry? (Tick all that apply)	<input checked="" type="checkbox"/> paper based <input checked="" type="checkbox"/> electronic
Are the data fields in your registry interactive, such that invalid or unprobable data is flagged when entered (edit checks) (Tick all that apply)	<input checked="" type="checkbox"/> yes
Since when (year) has the data fields been interactive?	2009
Please describe any other data validation procedures that you may use	obligatory fields exist, such as start dates of drugs, with a minimal level of information of YYYY
How does your registry retain data management services? (Tick all that apply)	<input checked="" type="checkbox"/> a researcher/administrative personal does data management beside other duties
Which is the background of your data manager(s)? (Tick all that apply)	<input checked="" type="checkbox"/> data science/biostatistician/technical
Which are the most commonly used data analysis software/programming languages in your organization? (Tick all that apply)	<input checked="" type="checkbox"/> R <input checked="" type="checkbox"/> python
How is the data stored in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> a relational database framework (like SQL)
Which are the main data formats used for raw data extractions? (Tick all that apply)	<input checked="" type="checkbox"/> simple text files, eg. csv, tsv
Where is your data collection platform hosted? (Tick all that apply)	<input checked="" type="checkbox"/> external company
Who maintains your data collection platform? (Tick all that apply)	<input checked="" type="checkbox"/> external company
How frequently is the database updated with the latest information? (Tick all that apply)	<input checked="" type="checkbox"/> monthly <input checked="" type="checkbox"/> other
Please specify	daily snapshot that are not saved for maintenance, monthly permanent snapshot
Is linkage to other databases or registries possible?	<input type="checkbox"/> no

General comments

Linkage to other registries is, in principle possible, but it there is no unique identifier that is available across registries, so one has to do linkage e.g. with privacy preserving linkage or similarity linkage based on names or dob. Linkage has to be done for each research project separately and ethics approval is needed for this.

Response was added on 2021-12-17 14:06:29.

Demography

Please indicate which of the following variables are collected in your registry (Tick all that apply)

- age (year of birth)
- sex
- weight
- height
- death

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Weight	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Height	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

How is vital status registered (Tick all that apply)

- by healthstaff, manually
- other

Please specify

There is no fixed time interval for vital status registration. Therefore, death is an outcome that is very difficult to study with our data.

Diagnosis

How is a diagnosis registered? (Tick all that apply)

- classification criteria
- other diagnostic categories

Specify which diagnostic categories

clinical diagnosis by the rheumatologist

Do you register (Tick all that apply)

- date for diagnosis
- month of diagnosis
- year of diagnosis

Do you register (Tick all that apply)

- date for symptom onset
- month of symptom onset
- year of symptom onset

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Day/month/year of diagnosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Day/month/year of symptom onset

Which classification criteria are registered?
(Tick all that apply)

- ASAS
 New York
 CASPAR

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ASAS	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
New York	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CASPAR	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

In which patients can you register ASAS? AxSpA

Do you register individual ASAS classification items?
(Tick all that apply) yes

Do you register individual New York classification items?
(Tick all that apply) yes

Do you register individual CASPAR classification items?
(Tick all that apply) yes

Response was added on 2021-12-17 14:06:32.

Axial spondyloarthritis

Which disease status characteristics can be registered in axSpA patients?
(Tick all that apply)

- swollen joint count
- tender joint count
- enthesitis
- dactylitis
- physician global
- BASMI

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Dactylitis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASMI	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 28
- 44
- 66

Do you register specific location of swollen joints?
(Tick all that apply)

- yes
- comments

Please specify

44 is recommended but doctor can switch to 28 or 66/68

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 28
- 44
- 68

Do you register specific location of tender joints?
(Tick all that apply)

- yes
- comments

Comments

tender joints were not collected in DB2 btw 2005 and 2020. From Jan 2021 onwards, it is part of the questionnaire

Enthesitis

Do you register specific location of enthesitis?
(Tick all that apply)

yes

Which locations are registered?
(Tick all that apply)

- achilles tendon insertion
 plantar fascia insertion
 1st costochondral joint
 7th costochondral joint
 posterior superior iliac spine
 anterior superior iliac spine
 iliac crests
 5th lumbar spinous process

Please indicate which specific indices that are used,
if applicable

MASES +

Dactylitis

How is dactylitis assessed?
(Tick all that apply)

other

Other

dactylitis in the past 12 months? If so, was it detected clinically, in the MRI or in the Xray/CT or via sonography?

Physician Global

Please write the wording of the question regarding physician global

Global estimate of the disease activity by the physician (from context it is clear that it is about day of visit)
(translate into english if possible)

BASMI

Are the individual BASMI components registered?

yes

Do you register the individual BASMI measurements (cm, degrees)?

yes

Which BASMI scale is used?

3-point

Coxitis

Do you assess coxitis? If yes, please indicate how it is assessed

yes, coxitis in the past 12 months? If so, was it detected clinically, in the MRI or in the Xray/CT or via sonography?

General comment

About the visit structure:

We used the column: Follow-up visit to indicate what we collect at yearly controls and the column "at treatment change" to indicate what we collect in intermediate controls.

Yearly controls are very broad and cover many subjects. Intermediate controls focus on medication, disease activity, safety.

Visits at treatment changes are recommended by the swiss society of rheumatology but the system (database) does not trigger reminders for e.g. a 3-6 months follow-up visit after start of a b/tsDMARD.

Regarding BASMI: Our BASMI is three point. This means that we apply two thresholds per variable to split them into low, middle and high and only calculate the score on the three.

We collect tragus to wall rather than occiput to wall and adjust for the tragus vs occiput by just using different thresholds. Ours are 3 and 18. The literature for the tragus shows stuff like 19 and 31 for that

Response was added on 2021-12-17 14:06:36.

Psoriatic arthritis

Which disease status characteristics can be registered in PsA patients?
(Tick all that apply)

- swollen joint count
- tender joint count
- enthesitis
- dactylitis
- skin
- nails
- physician Global
- BASMI
- other

Please specify

HAQ

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Dactylitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Skin	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Nails	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician Global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASMI	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 28
- 44
- 66

Do you register specific location of swollen joints?
(Tick all that apply)

- yes
- comments

Comment

66 is recommended

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 28
 44
 68

Do you register specific location of tender joints?
(Tick all that apply)

- yes
 comments

comments

68 is recommended

Entesitis

Do you register specific location of enthesitis?
(Tick all that apply)

- yes

Which locations are registered?
(Tick all that apply)

- achilles tendon insertion
 plantar fascia insertion
 1st costochondral joint
 7th costochondral joint
 posterior superior iliac spine
 anterior superior iliac spine
 iliac crests
 5th lumbar spinous process

Please indicate which specific indices that are used,
if applicable

MASES +

Dactylitis

How is dactylitis assessed?
(Tick all that apply)

- other

Other

dactylisit in the past 12 months? If so, was it detected clinically, in the MRI or in the Xray/CT or via sonography?

Skin

Which instruments are used for registering skin involvement in PsA?
(Tick all that apply)

- other

Other

7 scale question: none, almost none, light, light to moderate, moderate, moderate to severe, severe

Nails

Which instruments are used for registering nail involvement in PsA?
(Tick all that apply)

other

Other

3 types of nail problems: (none), oil points, pitted nails, onycholysis

Physician global

Please write the wording of the question regarding physician global

Global estimate of the disease activity by the physician (from context clear that it is at the visit)
(Translate into english if possible)

BASMI

Are the individual BASMI components registered?

yes

Do you register the individual BASMI measurements (cm, degrees)?

yes

Which BASMI scale is used?

3-point

Coxitis

Do you assess coxitis? If yes, please indicate how it is assessed

yes, coxitis in the past 12 months? If so, was it detected clinically, in the MRI or in the Xray/CT or via sonography?

Response was added on 2021-12-17 14:06:38.

Medication

Which therapies are registered in your registry?
(Tick all that apply)

- biological dmards (bDMARDs), including targeted synthetic dmards (JAK)
 conventional synthetic dmards (csDMARDs)
 glucocorticoids
 NSAIDs

bDMARDs

Which year did bDMARD registration begin? 2005

Is it mandatory to register bDMARD therapy? no

csDMARDs

Which year did csDMARD registration begin? 2005

Is it mandatory to register csDMARD therapy? no

Glucocorticoids

Which year did glucocorticoid registration begin? 2005

Is it mandatory to register glucocorticoid therapy? no

Is the mode of administration registered?
(Tick all that apply)

- oral
 intraarticular

Are specific locations of injected joints registered? no

NSAIDs

Which year did NSAID registration begin? 2005

Is it mandatory to register NSAID therapy? no

What information regarding ONGOING medications is registered?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	frequency	administration mode
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Time points for registration (ONGOING medications)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
NSAIDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

What information regarding PAST medications is registered at inclusion in registry?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	name of drug
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Discontinuation reasons

What are the possible reasons for discontinuation of a bDMARD? (Tick all that apply)

- lack of efficacy
- adverse events
- remission
- other

Please specify from 2021 on, there is more detailed reasons for discontinuation

Is it possible to register multiple reasons for discontinuation? yes

How is it decided which is the primary reason for discontinuation? up to the investigator

Does your registry link to prescription database or other external data sources on prescriptions on a regular basis as input to registry? (Tick all that apply) no

Response was added on 2021-12-17 14:06:41.

Patient reported outcomes

Which patient reported outcomes (PROs) are registered in axSpA and/or PsA patients?
(Tick all that apply)

- BASDAI
- BASFI
- pain
- nightly pain
- fatigue
- global disease
- HAQ
- EQ-5D
- other

Please specify

SF12, DLQI skin quality of life, HAQ, ASAS-HI since Nov 2018, GPAQ exercise score since Oct 2021

Are any of the PROs registered in either axSpA or PsA only?

yes

Which PROs are registered uniquely in either axSpA or PsA?

BASDAI and BASFI in axSpA only, DLQI and HAQ in PsA only

Mode of registration

What are the options for registration of PROs?
(Tick all that apply)

- paper forms
- on screen in waiting room
- through website/app

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
BASDAI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASFI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Nightly pain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Global disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
HAQ	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
EQ-5D	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

BASDAI

Are the individual BASDAI components registered? yes

BASFI

Are the individual BASFI components registered? yes

Pain, fatigue and global assessments

Please write the wording of the question relating to pain

Wie würden Sie die Stärke Ihrer Schmerzen insgesamt in den letzten 7 Tagen einschätzen? How would you rate your overall pain in the past 7 days?
(please translate into english if possible)

Please write the wording of the question relating to nightly pain

Wie würden Sie die Stärke Ihrer Schmerzen in der Nacht insgesamt in den letzten 7 Tagen einschätzen? How would you rate your overall pain in the night in the past 7 days?
(please translate into english if possible)

Please write the wording of the question relating to fatigue

BASDAI-1 Wie würden Sie Ihre allgemeine Müdigkeit und Erschöpfung durchschnittlich in den letzten 7 Tagen beschreiben? How would you rate your overall tiredness and fatigue on average in the past 7 days?
(please translate into english if possible)

Please write the wording of the question relating to global assessment of disease

Wie aktiv ist Ihre Krankheit heute? How active is your disease today?
(please translate into english if possible)

HAQ

Are the individual HAQ items registered? yes

Which HAQ versions may be used in your registry?
(Tick all that apply)

stanford HAQ DI with adjustment for use of aids and devices

EQ-5D

Are the individual EQ-5D items registered? yes

Which EQ-5D version is used?

3L

Which algorithm is used?

'European index', see DOI 10.1007/s10198-003-0182-5

Response was added on 2021-12-17 14:06:43.

Laboratory

Which laboratory test can be registered?
(Tick all that apply)

- ESR
- CRP
- hemoglobin
- ALAT
- creatinine
- HLA-B27
- IgM-RF
- stored samples available for later analyses (biobank)

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ESR	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CRP	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Hemoglobin	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
ALAT	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Creatinine	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Stored samples available for later analyses (biobank)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Biobank

Which sample types are collected?
(Tick all that apply)

- serum
- other

Please specify

Blood for DNA

How are laboratory test results registered?
(Tick all that apply)

- entered by health care staff

Response was added on 2021-12-17 14:06:45.

Imaging

Which imaging modalities can be registered?
(Tick all that apply) X-ray

	date of examination	full image report	image file	scoring system	+/- progression	other
What information on each x-ray exam is registered?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

X-ray

Which anatomical regions can be registered?
(Tick all that apply) spine radiographs
 sacroiliac joint radiographs
 hands and feet

Which scoring system? We perform mNY ISG scoring and (in context of research project) MSASSS spine score

Frequency of image registration

Please comment on the frequency of registration of the various image modalities, eg. at specified time points, as needed, in connection with research projects or other.

Images are recommended in time intervals of two years

Response was added on 2021-12-17 14:06:48.

Comorbidities

Which extraarticular manifestations and comorbid conditions are registered?
(Tick all that apply)

- uveitis
- psoriasis
- inflammatory bowel disease (IBD)
- ischemic heart disease (IHD)
- cerebrovascular disease (CVD)
- hypertension
- diabetes (DM)
- dyslipidemia
- osteoporosis
- chronic kidney insufficiency (CKI)
- chronic liver disease, eg. hepatitis, cirrhosis
- solid cancer
- hematological cancer
- depression
- tuberculosis (TB)
- fibromyalgia
- other

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
uveitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
depression	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
TB	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
fibromyalgia	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
other	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (other)

Up to 2016, we collected a list of comorbidities, that was shown and adapted at each visit. Since 2016, we have a health issue system with categories and sub-categories and within these, a text field for diagnosis. Events can be entered with full or partial date. All already known comorbs and events are shown at each visit with the question to confirm or adapt (add events).

Mode of registration - how are comorbid conditions registered?

	patient-reported	by health-staff	linkage from other registry
uveitis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
depression	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
TB	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
fibromyalgia	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
other	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Do you use ICD-10 codes for registration? no

Response was added on 2021-12-17 14:06:50.

Lifestyle

Which lifestyle parameters are registered?
(Tick all that apply)

- smoking
 alcohol consumption
 physical activity
 other

Please specify

work status etc

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Smoking	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Alcohol	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physical activity	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Smoking

How is smoking status characterised?
(Tick all that apply)

- current
 former
 never

Do you register a start date?
(Tick all that apply)

- no date is registered

Do you register a stop date for former smokers?

- No

How is average number of smoked cigarettes registered?
(Tick all that apply)

- other

Please specify

Psa has questions for the two questions to calculate pack-years. axSpa has no further details

Alcohol

How is alcohol consumption quantified?
(Tick all that apply)

- other

Please specify

none, rarely, daily, more than daily

Physical activity

How is physical activity defined?
(Tick all that apply)

other definition

Please specify

Now full GPAQ. Old PSA version tracked none vs less than 1h/w vs 1 to 2 h/w vs more for activities with sweating or elevated heart rate, Old axSpa just ask for exercises per week

How is physical activity quantified?
(Tick all that apply)

other

Please specify

See 'Please specify' above

Response was added on 2021-12-17 14:08:02.

Safety

Can you register adverse events in your registry?
(Tick all that apply) yes, directly into registry

Is it mandatory to register adverse events through
your registry? no

Which adverse events are registered in your registry?
(Tick all that apply) non-serious adverse events
 serious adverse events?

Information on adverse events

	date of event	MeddRA	ICD10-code	outcome	other
Non serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (non serious AE) diagnosis of AE, suspected drug, life threatening, hospitalization, and some other questions from the swissmedic adverse event reporting form

Please specify (serious AE) as with non-serious.

General comments Information on date of event can be in the format yyyy, mm/yyyy or full date OR is in some cases unspecified. Therefore, we often are dealing with an interval information on the occurrence / start of the event.

Participant information

Record ID	5
Name	Ana Rodrigues
Registry	Reuma.pt
E-mail	anamfrodrigues@gmail.com
Deltager	<input checked="" type="checkbox"/> ja

Response was added on 2022-01-19 18:14:16.

General registry information

What is the status of your registry? running and including patients

Coverage

Please estimate how many (percentage) of the eligible spondyloarthritis patients in your country, that are registered 10

Please estimate how many (percentage) of the eligible psoriatic arthritis patients in your country, that are registered 15

How did you obtain the coverage estimate above? (Tick all that apply) other

Please specify comparison of the estimated prevalence of these disease in Portugal with the patient registered

Which institutions/organisations can include patients in your registry? (Tick all that apply) private rheumatology practices
 departments of rheumatology at hospitals
 departments of rheumatology at university hospitals

Please give an estimate of how many private rheumatology practices that include patients in your registry 75%

Please give an estimate of how many departments of rheumatology at hospitals (not including university hospitals) that include patients in your registry 98%

Please give an estimate of how many departments of rheumatology at university hospitals that include patients in your registry 100%

When is the data registered? (Tick all that apply) at routine visits

Are all routine visits registered in your registry - or only some? all visits

Ethics

Is approval from a local ethics committee needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply) no

Do patients need to sign informed consent to be included in your registry?
(Tick all that apply) yes

Are any additional local approvals needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply) no

Funding

How is the registry funded?
(Tick all that apply) from research grants
 industry

Please estimate the percentage of funds coming from research grants 15
((0-100%))

Please estimate the percentage of funds coming from industry, eg. pharmaceutical company 85
((0-100%))

The percentages add correctly up to a 100%

What is the basis of participation by a clinic/department/office in the registry?
(Tick all that apply) voluntary

Is the clinic/department/office financially compensated for registration? no

Inclusion criteria

What event triggers the inclusion of a patient into the registry?
(Tick all that apply) new diagnosis
 new treatment

Which criteria do you base the inclusion on?
(Tick all that apply) diagnosis

Is a minimum age required for inclusion? no

Which diagnoses are included in your registry?
(Tick all that apply) ankylosing spondylitis (AS)
 non-radiographic axial spondyloarthritis (nr-axSpA)
 psoriatic arthritis (PsA)
 rheumatoid arthritis
 other

Which year did inclusion of AS patients begin? 2009

Which year did inclusion of nr-axSpA patients begin? NA

Which year did inclusion of PsA patients begin?	2009
Which other diagnoses are included?	systemic vasculitis; Idiopathic juvenil arthritis; myositis; systemic Lupus erythematosus;s sjogren
Have the inclusion criteria changed over time?	<input checked="" type="checkbox"/> no

Response was added on 2022-01-19 18:40:55.

Data management

What are the options for data entry? (Tick all that apply)	<input checked="" type="checkbox"/> electronic
Are the data fields in your registry interactive, such that invalid or unprobable data is flagged when entered (edit checks) (Tick all that apply)	<input checked="" type="checkbox"/> yes
Since when (year) has the data fields been interactive?	2012
Please describe any other data validation procedures that you may use	manually
How does your registry retain data management services? (Tick all that apply)	<input checked="" type="checkbox"/> person employed as data manager
Which is the background of your data manager(s)? (Tick all that apply)	<input checked="" type="checkbox"/> data science/biostatistician/technical
How is the data stored in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> a relational database framework (like SQL)
Which are the main data formats used for raw data extractions? (Tick all that apply)	<input checked="" type="checkbox"/> excel
Where is your data collection platform hosted? (Tick all that apply)	<input checked="" type="checkbox"/> external company
Who maintains your data collection platform? (Tick all that apply)	<input checked="" type="checkbox"/> data manager
How frequently is the database updated with the latest information? (Tick all that apply)	<input checked="" type="checkbox"/> real-time
Is linkage to other databases or registries possible?	<input type="checkbox"/> no

Response was added on 2022-01-19 18:55:36.

Demography

Please indicate which of the following variables are collected in your registry (Tick all that apply)

- age (year of birth)
- sex
- ethnicity
- weight
- height
- death

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Weight	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Height	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

How is vital status registered (Tick all that apply)

- by healthstaff, manually

Diagnosis

How is a diagnosis registered? (Tick all that apply)

- classification criteria
- other diagnostic categories

Specify which diagnostic categories

expert opinion

Do you register (Tick all that apply)

- date for diagnosis
- month of diagnosis
- year of diagnosis

Do you register (Tick all that apply)

- date for symptom onset
- month of symptom onset
- year of symptom onset

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Day/month/year of diagnosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Day/month/year of symptom onset	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (diagnosis)

we can always registry this information at any time of the follow-up

Please specify (symptom onset)

we can always registry this information at any time of the follow-up

Which classification criteria are registered?
(Tick all that apply)

- ASAS
 New York
 CASPAR

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ASAS	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
New York	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
CASPAR	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (ASAS)

we can always registry this information at any time of the follow-up

Please specify (New York)

we can always registry this information at any time of the follow-up

Please specify (CASPAR)

we can always registry this information at any time of the follow-up

In which patients can you register ASAS?

AxSpA

Do you register individual ASAS classification items?
(Tick all that apply)

yes

Do you register individual New York classification items?
(Tick all that apply)

yes

Do you register individual CASPAR classification items?
(Tick all that apply)

yes

Response was added on 2022-01-19 19:17:46.

Axial spondyloarthritis

Which disease status characteristics can be registered in axSpA patients?
(Tick all that apply)

- swollen joint count
- tender joint count
- enthesitis
- physician global
- BASMI
- other

Please specify

ASDAS

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASMI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

66

Do you register specific location of swollen joints?
(Tick all that apply)

yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

68

Do you register specific location of tender joints?
(Tick all that apply)

yes

Enthesitis

Do you register specific location of enthesitis?
(Tick all that apply) yes

Which locations are registered?
(Tick all that apply) all of the below

Please indicate which specific indices that are used,
if applicable SPARCC and MACES

Physician Global

Please write the wording of the question regarding
physician global Disease activity according to physician opinion
(0-100 mm)
(translate into english if possible)

BASMI

Are the individual BASMI components registered? yes

Do you register the individual BASMI measurements (cm,
degrees)? yes

Which BASMI scale is used? 11-point

Coxitis

Do you assess coxitis? If yes, please indicate how it
is assessed no

Response was added on 2022-01-19 19:23:00.

Psoriatic arthritis

Which disease status characteristics can be registered in PsA patients?
(Tick all that apply)

- swollen joint count
- tender joint count
- enthesitis
- dactylitis
- skin

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Dactylitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Skin	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

66

Do you register specific location of swollen joints?
(Tick all that apply)

yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

68

Do you register specific location of tender joints?
(Tick all that apply)

yes

Entesitis

Do you register specific location of entesitis?
(Tick all that apply)

yes

Which locations are registered?
(Tick all that apply)

all of the below

Please indicate which specific indices that are used, if applicable

SPARCC ; MASES

Dactylitis

How is dactylitis assessed?
(Tick all that apply)

- as part of classification criteria
 as a count

Skin

Which instruments are used for registering skin
involvement in PsA?
(Tick all that apply)

- PASI

Coxitis

Do you assess coxitis? If yes, please indicate how it
is assessed

no

Response was added on 2022-01-19 20:04:03.

Medication

Which therapies are registered in your registry?
(Tick all that apply)

- biological dmards (bDMARDs), including targeted synthetic dmards (JAK)
- conventional synthetic dmards (csDMARDs)
- glucocorticoids
- NSAIDs
- medication for comorbidity

bDMARDs

Which year did bDMARD registration begin? 2009

Is it mandatory to register bDMARD therapy? no

csDMARDs

Which year did csDMARD registration begin? 2009

Is it mandatory to register csDMARD therapy? no

Glucocorticoids

Which year did glucocorticoid registration begin? 2009

Is it mandatory to register glucocorticoid therapy? no

Is the mode of administration registered?
(Tick all that apply)

- oral
- intramuscular
- intraarticular

Are specific locations of injected joints registered? no

NSAIDs

Which year did NSAID registration begin? 2009

Is it mandatory to register NSAID therapy? no

Medicaton for comorbidities

What types of medical therapy for comorbidities are registered?

it is possible to register any treatment for chronic non communicable disease but is underreported

What information regarding ONGOING medications is registered?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	frequency	administration mode
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
NSAIDs	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
medication for comorbidity	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Time points for registration (ONGOING medications)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
NSAIDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
medication for comorbidity	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What information regarding PAST medications is registered at inclusion in registry?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	name of drug
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
NSAIDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Discontinuation reasons

What are the possible reasons for discontinuation of a bDMARD?
(Tick all that apply)

- lack of efficacy
- adverse events
- remission
- pregnancy wish
- infection
- surgery
- death

Is it possible to register multiple reasons for discontinuation?

no

Does your registry link to prescription database or other external data sources on prescriptions on a regular basis as input to registry?
(Tick all that apply)

no

Response was added on 2022-01-20 12:45:29.

Patient reported outcomes

Which patient reported outcomes (PROs) are registered in axSpA and/or PsA patients?
(Tick all that apply)

- BASDAI
- BASFI
- pain
- nightly pain
- fatigue
- global disease
- HAQ
- EQ-5D

Are any of the PROs registered in either axSpA or PsA only?

- no, all PROs are registered in both diagnoses

Mode of registration

What are the options for registration of PROs?
(Tick all that apply)

- through interview with health-staff
- on screen in waiting room
- through website/app

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
BASDAI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASFI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Nightly pain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Global disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
HAQ	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
EQ-5D	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

BASDAI

Are the individual BASDAI components registered?

- yes

BASFI

Are the individual BASFI components registered? yes

Pain, fatigue and global assessments

Please write the wording of the question relating to pain

Please indicate the level of pain that you felt in your spine at any moment (day or night) during last week
(please translate into english if possible)

Please write the wording of the question relating to nightly pain

Please indicate the level of pain that you felt in your spine during the night during last week
(please translate into english if possible)

Please write the wording of the question relating to fatigue

FACIT questionnaire
(please translate into english if possible)

Please write the wording of the question relating to global assessment of disease

considering the way the disease disturbs you, how do you feel during the last week?
(please translate into english if possible)

HAQ

Are the individual HAQ items registered? yes

Which HAQ versions may be used in your registry?
(Tick all that apply)

stanford HAQ DI with adjustment for use of aids and devices

EQ-5D

Are the individual EQ-5D items registered? yes

Which EQ-5D version is used?

eq-5d-3l

Which algorithm is used?

the portuguese validated algorithm

General comments

EQ-5D Portuguese population norms.
Ferreira LN, Ferreira PL, Pereira LN, Oppe M.
Qual Life Res. 2014 Mar;23(2):425-30. doi:
10.1007/s11136-013-0488-4. Epub 2013 Aug 3.
PMID: 23912856

Response was added on 2022-01-20 12:46:39.

Laboratory

Which laboratory test can be registered?
(Tick all that apply)

- ESR
- CRP
- hemoglobin
- ALAT
- creatinine
- Hba1c
- cholesterol
- HLA-B27
- IgM-RF
- stored samples available for later analyses (biobank)

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ESR	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CRP	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Hemoglobin	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
ALAT	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Creatinine	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Hba1c	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Cholesterol	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Stored samples available for later analyses (biobank)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Cholesterol

Which specific cholesterol types are registered?
(Tick all that apply)

- total cholesterol
- LDL
- HDL
- triglycerid

Biobank

Which sample types are collected?
(Tick all that apply)

- whole-blood
- serum
- plasma
- joint fluid

How are laboratory test results registered?
(Tick all that apply)

- electronically tranfered from lab system
- entered by health care staff

Response was added on 2022-01-20 12:55:55.

ImagingWhich imaging modalities can be registered?
(Tick all that apply)

- Magnetic Resonance Imaging (MRI)
- X-ray
- DXA
- Ultrasound (US)
- Computer Tomography (CT)

Information on each image

	date of examination	full image report	image file	scoring system	+/- progression	other
What information on each MRI exam is registered?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What information on each x-ray exam is registered?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What information on each DXA exam is registered?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What information on each US exam is registered?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What information on each CT exam is registered?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

MRIWhich anatomical regions can be registered?
(Tick all that apply)

- spine MRI
- other

Please specify

peripheral joints

X-rayWhich anatomical regions can be registered?
(Tick all that apply)

- spine radiographs
- hands and feet

DEXAWhich anatomical regions can be registered?
(Tick all that apply)

- lumbar spine
- femoral neck
- wrist

Ultrasound

Please indicate which anatomical regions that can be registered all

CT

Please indicate which anatomical regions that can be registered? joints, spine, pelvic

Frequency of image registration

Please comment on the frequency of registration of the various image modalities, eg. at specified time points, as needed, in connection with research projects or other.

Although Reuma.pt has the ability to register all imaging, the researchers do not register this information on reuma.pt

General comments

Imaging is not regularly register in Reuma.pt

Response was added on 2022-01-20 13:26:17.

Comorbidities

Which extraarticular manifestations and comorbid conditions are registered?
(Tick all that apply)

- uveitis
- psoriasis
- inflammatory bowel disease (IBD)
- ischemic heart disease (IHD)
- cerebrovascular disease (CVD)
- hypertension
- diabetes (DM)
- dyslipidemia
- osteoporosis
- chronic kidney insufficiency (CKI)
- chronic liver disease, eg. hepatitis, cirrhosis
- solid cancer
- hematological cancer
- depression
- tuberculosis (TB)
- fibromyalgia

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
uveitis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
depression	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
TB	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
fibromyalgia	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Mode of registration - how are comorbid conditions registered?

	patient-reported	by health-staff	linkage from other registry
uveitis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
depression	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
TB	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
fibromyalgia	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Do you use ICD-10 codes for registration?

 no

Response was added on 2022-01-20 13:29:51.

Lifestyle

Which lifestyle parameters are registered?
(Tick all that apply)

- smoking
 alcohol consumption

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Smoking	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Smoking

How is smoking status characterised?
(Tick all that apply)

- current
 former
 never

Do you register a start date?
(Tick all that apply)

- no date is registered

Do you register a stop date for former smokers?

- yes

How is average number of smoked cigarettes registered?
(Tick all that apply)

- other

Please specify

pack-day and number of years

Alcohol

How is alcohol consumption quantified?
(Tick all that apply)

- other

Please specify

number of units/day

Response was added on 2022-01-20 13:30:12.

Safety

Can you register adverse events in your registry?
(Tick all that apply) yes, directly into registry

Is it mandatory to register adverse events through
your registry? no

Which adverse events are registered in your registry?
(Tick all that apply) non-serious adverse events
 serious adverse events?

Information on adverse events

	date of event	MeddRA	ICD10-code	outcome	other
Non serious AE	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Serious AE	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Participant information

Record ID	6
Name	Dan Nordstrøm
Registry	ROB-FIN
E-mail	Dan.Nordstrom@hus.fi
Deltager	<input checked="" type="checkbox"/> ja

Response was added on 2021-11-24 13:09:13.

General registry information

What is the status of your registry? running and including patients

Coverage

Please estimate how many (percentage) of the eligible spondyloarthritis patients in your country, that are registered 60

Please estimate how many (percentage) of the eligible psoriatic arthritis patients in your country, that are registered 60

How did you obtain the coverage estimate above? (Tick all that apply) by prior study of coverage

Which institutions/organisations can include patients in your registry? (Tick all that apply) departments of rheumatology at hospitals departments of rheumatology at university hospitals

Please give an estimate of how many departments of rheumatology at hospitals (not including university hospitals) that include patients in your registry 10

Please give an estimate of how many departments of rheumatology at university hospitals that include patients in your registry 5

When is the data registered? (Tick all that apply) at routine visits

Are all routine visits registered in your registry - or only some? all visits

Ethics

Is approval from a local ethics committee needed for a study on de-identified data (eg. a EuroSpA upload)? (Tick all that apply) no comment

Comment Based on permit from Finnish Institute for Health and Welfare

Do patients need to sign informed consent to be included in your registry? (Tick all that apply) no

Are any additional local approvals needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply) yes

Please specify which additional approvals are needed Permit from Social and Health Data permit Authority
FINDATA

Funding

How is the registry funded?
(Tick all that apply) from research grants
 industry

Please estimate the percentage of funds coming from research grants 80
((0-100%))

Please estimate the percentage of funds coming from industry, eg. pharmaceutical company 20
((0-100%))

The percentages add correctly up to a 100%

What is the basis of participation by a clinic/department/office in the registry?
(Tick all that apply) voluntary

Is the clinic/department/office financially compensated for registration? no

Inclusion criteria

What event triggers the inclusion of a patient into the registry?
(Tick all that apply) new diagnosis
 new treatment

Which criteria do you base the inclusion on?
(Tick all that apply) diagnosis

Is a minimum age required for inclusion? yes, 18 years or above

Which diagnoses are included in your registry?
(Tick all that apply) ankylosing spondylitis (AS)
 non-radiographic axial spondyloarthritis (nr-axSpA)
 psoriatic arthritis (PsA)
 rheumatoid arthritis

Which year did inclusion of AS patients begin? 2000

Which year did inclusion of nr-axSpA patients begin? 2013

Which year did inclusion of PsA patients begin? 2000

Have the inclusion criteria changed over time? yes

How and when did inclusion criteria change? ASAS and CASpar criteria entered in 2020

Response was added on 2021-11-24 13:09:21.

Data management

What are the options for data entry? (Tick all that apply)	<input checked="" type="checkbox"/> electronic
Are the data fields in your registry interactive, such that invalid or unprobable data is flagged when entered (edit checks) (Tick all that apply)	<input checked="" type="checkbox"/> no
How does your registry retain data management services? (Tick all that apply)	<input checked="" type="checkbox"/> person employed as data manager <input checked="" type="checkbox"/> a researcher/administrative personal does data management beside other duties
Which is the background of your data manager(s)? (Tick all that apply)	<input checked="" type="checkbox"/> data science/biostatistician/technical
Which are the most commonly used data analysis software/programming languages in your organization? (Tick all that apply)	<input checked="" type="checkbox"/> R
How is the data stored in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> other
Please specify	R-derived format
Which are the main data formats used for raw data extractions? (Tick all that apply)	<input checked="" type="checkbox"/> r-derived format
Where is your data collection platform hosted? (Tick all that apply)	<input checked="" type="checkbox"/> at a hospital in a rheumatology department
Who maintains your data collection platform? (Tick all that apply)	<input checked="" type="checkbox"/> data manager
How frequently is the database updated with the latest information? (Tick all that apply)	<input checked="" type="checkbox"/> other
Please specify	On demand from each center.
Is linkage to other databases or registries possible?	<input checked="" type="checkbox"/> yes
Which registries can be linked to? (Tick all that apply)	<input checked="" type="checkbox"/> mortality registry <input checked="" type="checkbox"/> prescription registry <input checked="" type="checkbox"/> comorbidity <input checked="" type="checkbox"/> electronic medical records

Response was added on 2021-11-24 13:10:32.

Demography

Please indicate which of the following variables are collected in your registry
(Tick all that apply)

- age (year of birth)
 sex
 weight
 height

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Weight	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Height	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Diagnosis

How is a diagnosis registered?
(Tick all that apply)

- through ICD-10 codes
 classification criteria

Do you register
(Tick all that apply)

- month of diagnosis

Do you register
(Tick all that apply)

- month of symptom onset

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Day/month/year of diagnosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day/month/year of symptom onset	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Which classification criteria are registered?
(Tick all that apply)

- ASAS
 New York
 CASPAR

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ASAS	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
New York	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CASPAR	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In which patients can you register ASAS? AxSpA

Do you register individual ASAS classification items?
(Tick all that apply) yes

Do you register individual New York classification items?
(Tick all that apply) yes

Do you register individual CASPAR classification items?
(Tick all that apply) yes

Response was added on 2021-12-14 17:04:39.

Axial spondyloarthritis

Which disease status characteristics can be registered in axSpA patients?
(Tick all that apply)

- swollen joint count
 tender joint count
 enthesitis
 physician global
 BASMI
 other

Please specify

BASDAI, BASFI

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 66
 other

Please specify

79 optional

Do you register specific location of swollen joints?
(Tick all that apply)

- yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 68
 other

Please specify

79 optional

Do you register specific location of tender joints?
(Tick all that apply)

- yes

Enthesitis

Do you register specific location of enthesitis?
(Tick all that apply) yes

Which locations are registered?
(Tick all that apply)

- medial femoral condyle
- achilles tendon insertion
- lateral epicondyle
- 1st costochondral joint
- 7th costochondral joint
- posterior superior iliac spine
- anterior superior iliac spine
- iliac crests
- 5th lumbar spinous process

Please indicate which specific indices that are used,
if applicable MASES, LEI

Physician Global

Please write the wording of the question regarding
physician global physicians evaluation of activity of disease
(translate into english if possible)

BASMI

Are the individual BASMI components registered? yes

Do you register the individual BASMI measurements (cm,
degrees)? yes

Coxitis

Do you assess coxitis? If yes, please indicate how it
is assessed no

General comment Schober, chest-expansion, forward-lateral bends,
head to wall measures, head rotations

Response was added on 2021-12-14 17:10:25.

Psoriatic arthritis

Which disease status characteristics can be registered in PsA patients?
(Tick all that apply)

- swollen joint count
 tender joint count
 enthesitis
 skin
 physician Global

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Skin	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician Global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 66
 Other

Please specify

79 optional

Do you register specific location of swollen joints?
(Tick all that apply)

- yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 68
 Other

Please specify

79 optional

Do you register specific location of tender joints?
(Tick all that apply)

- yes

Entesitis

Do you register specific location of enthesitis?
(Tick all that apply) yes

Which locations are registered?
(Tick all that apply)

- medial femoral condyle
- achilles tendon insertion
- lateral epicondyle
- greater tochanter
- 1st costochondral joint
- 7th costochondral joint
- posterior superior iliac spine
- anterior superior iliac spine
- iliac crests
- 5th lumbar spinous process

Please indicate which specific indices that are used,
if applicable MASES, LEI

Skin

Which instruments are used for registering skin
involvement in PsA?
(Tick all that apply) body surface area %

Physician global

Please write the wording of the question regarding
physician global physicians evaluation of disease activity
(Translate into english if possible)

Coxitis

Do you assess coxitis? If yes, please indicate how it
is assessed no

General comment head to wall, forward-lateral bends, chest
expansion, Schober, if applicable/symptoms

Response was added on 2021-12-14 17:18:11.

Medication

Which therapies are registered in your registry?
(Tick all that apply)

- biological dmards (bDMARDs), including targeted synthetic dmards (JAK)
 conventional synthetic dmards (csDMARDs)
 glucocorticoids

bDMARDs

Which year did bDMARD registration begin? 2000

Is it mandatory to register bDMARD therapy? no

csDMARDs

Which year did csDMARD registration begin? 2008

Is it mandatory to register csDMARD therapy? no

Glucocorticoids

Which year did glucocorticoid registration begin? 2000

Is it mandatory to register glucocorticoid therapy? no

Is the mode of administration registered?
(Tick all that apply)

- oral

What information regarding ONGOING medications is registered?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	frequency	administration mode
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Time points for registration (ONGOING medications)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

What information regarding PAST medications is registered at inclusion in registry?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	name of drug
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Discontinuation reasons

What are the possible reasons for discontinuation of a bDMARD?
(Tick all that apply)

- lack of efficacy
- adverse events
- remission
- other

Please specify

SAE, skinreaction, bloodreaction

Is it possible to register multiple reasons for discontinuation?

no

Does your registry link to prescription database or other external data sources on prescriptions on a regular basis as input to registry?
(Tick all that apply)

- yes, for bDMARDS
- yes, for csDMARDS
- yes, for glucocorticoids

Response was added on 2021-12-14 17:32:19.

Patient reported outcomes

Which patient reported outcomes (PROs) are registered in axSpA and/or PsA patients? (Tick all that apply)

- BASDAI
- BASFI
- pain
- fatigue
- global disease
- HAQ
- other

Please specify

15D equaling EQ-5D

Are any of the PROs registered in either axSpA or PsA only?

- no, all PROs are registered in both diagnoses

Mode of registration

What are the options for registration of PROs? (Tick all that apply)

- on screen in waiting room
- through website/app

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
BASDAI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASFI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Global disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
HAQ	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

BASDAI

Are the individual BASDAI components registered?

- yes

BASFI

Are the individual BASFI components registered?

- yes

Pain, fatigue and global assessments

Please write the wording of the question relating to pain

how much pain have you been experiencing
(please translate into english if possible)

Please write the wording of the question relating to fatigue

how much fatigue have you been experiencing during last week
(please translate into english if possible)

Please write the wording of the question relating to global assessment of disease

how are you doing regarding your joint disease
(please translate into english if possible)

HAQ

Are the individual HAQ items registered?

yes

Which HAQ versions may be used in your registry?
(Tick all that apply)

stanford HAQ DI with adjustment for use of aids and devices

Response was added on 2021-12-14 17:34:18.

Laboratory

Which laboratory test can be registered?
(Tick all that apply)

- CRP
 HLA-B27
 IgM-RF

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
CRP	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

How are laboratory test results registered?
(Tick all that apply)

- electronically tranfered from lab system
 entered by health care staff

General comments

CCP-ab

Response was added on 2021-12-14 17:35:16.

General comments

mention of SI.tis either on X-ray or MRI

Response was added on 2021-12-14 17:38:03.

Comorbidities

Which extraarticular manifestations and comorbid conditions are registered?
(Tick all that apply)

- uveitis
 psoriasis
 inflammatory bowel disease (IBD)
 chronic liver disease, eg. hepatitis, cirrhosis
 tuberculosis (TB)

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
uveitis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IBD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
TB	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (chronic liver disease)

evaluated on demand

Please specify (TB)

evaluated on demand

Mode of registration - how are comorbid conditions registered?

	patient-reported	by health-staff	linkage from other registry
uveitis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
TB	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Do you use ICD-10 codes for registration?

 yes

General comments

other co-morbidities might be manually entered if relevant

Response was added on 2021-12-14 17:41:23.

Lifestyle

Which lifestyle parameters are registered?
(Tick all that apply) smoking

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Smoking	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Smoking

How is smoking status characterised?
(Tick all that apply) current
 former
 never

Do you register a start date?
(Tick all that apply) for current smokers
 for former smokers

Do you register a stop date for former smokers? yes

How is average number of smoked cigarettes registered?
(Tick all that apply) not registered

Response was added on 2021-12-14 17:43:28.

Safety

Can you register adverse events in your registry?
(Tick all that apply) yes, directly into registry

Is it mandatory to register adverse events through
your registry? no

Which adverse events are registered in your registry?
(Tick all that apply) non-serious adverse events
 serious adverse events?
 other

Other all relevant

Information on adverse events

	date of event	MeddRA	ICD10-code	outcome	other
Non serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Participant information

Record ID	7
Name	Tore Kvien
Registry	NOR-DMARD
E-mail	t.k.a.kvien@medisin.uio.no
Deltager	<input checked="" type="checkbox"/> ja

Response was added on 2021-12-08 14:06:08.

General registry information

What is the status of your registry? running and including patients

Coverage

Please estimate how many (percentage) of the eligible spondyloarthritis patients in your country, that are registered 25

Please estimate how many (percentage) of the eligible psoriatic arthritis patients in your country, that are registered 25

How did you obtain the coverage estimate above? (Tick all that apply) other

Please specify Based on population

Which institutions/organisations can include patients in your registry? (Tick all that apply) departments of rheumatology at hospitals

Please give an estimate of how many departments of rheumatology at hospitals (not including university hospitals) that include patients in your registry 4

When is the data registered? (Tick all that apply) at pre-specified registry visits

What is the schedule for pre-specified registry visits? 0, 3, 6, 9, 12, 18, 24 - then every 6 months

Is it possible to register visits outside of the pre-specified visit schedule, eg. if a patient has a flare? no

Ethics

Is approval from a local ethics committee needed for a study on de-identified data (eg. a EuroSpA upload)? (Tick all that apply) comment

Comment The informed consent includes information about data sharing

Do patients need to sign informed consent to be included in your registry?
(Tick all that apply) yes

Are any additional local approvals needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply) no

Funding

How is the registry funded?
(Tick all that apply) from research grants
 industry

Please estimate the percentage of funds coming from research grants 20
((0-100%))

Please estimate the percentage of funds coming from industry, eg. pharmaceutical company 80
((0-100%))

The percentages add correctly up to a 100%

What is the basis of participation by a clinic/department/office in the registry?
(Tick all that apply) voluntary

Is the clinic/department/office financially compensated for registration? no

Inclusion criteria

What event triggers the inclusion of a patient into the registry?
(Tick all that apply) new treatment

Which criteria do you base the inclusion on?
(Tick all that apply) diagnosis
 treatment

Is a minimum age required for inclusion? yes, 18 years or above

Which diagnoses are included in your registry?
(Tick all that apply) ankylosing spondylitis (AS)
 non-radiographic axial spondyloarthritis (nr-axSpA)
 psoriatic arthritis (PsA)
 rheumatoid arthritis
 other

Which year did inclusion of AS patients begin? 2000

Which year did inclusion of nr-axSpA patients begin? 2010

Which year did inclusion of PsA patients begin? 2000

Which other diagnoses are included? All arthritides receiving csDMARDs (until 2012) and bDMARDs (from 2000)ed

Do patients need to be treated with biological DMARDs (including targeted synthetic DMARDs) to be included in the registry?

yes

Have the inclusion criteria changed over time?

yes

How and when did inclusion criteria change?

All DMARDs from 2000, only bDMARDs and tsDMARDs from 2012

Response was added on 2021-12-08 14:09:57.

Data management

What are the options for data entry? (Tick all that apply)	<input checked="" type="checkbox"/> electronic
Are the data fields in your registry interactive, such that invalid or unprobable data is flagged when entered (edit checks) (Tick all that apply)	<input checked="" type="checkbox"/> comment
Comment	Interactive to some extent
Please describe any other data validation procedures that you may use	Summary statistics
How does your registry retain data management services? (Tick all that apply)	<input checked="" type="checkbox"/> person employed as data manager
Which is the background of your data manager(s)? (Tick all that apply)	<input checked="" type="checkbox"/> data science/biostatistician/technical
Which are the most commonly used data analysis software/programming languages in your organization? (Tick all that apply)	<input checked="" type="checkbox"/> R <input checked="" type="checkbox"/> stata <input checked="" type="checkbox"/> SPSS
How is the data stored in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> a relational database framework (like SQL)
Which are the main data formats used for raw data extractions? (Tick all that apply)	<input checked="" type="checkbox"/> excel
Where is your data collection platform hosted? (Tick all that apply)	<input checked="" type="checkbox"/> at a hospital in a rheumatology department
Who maintains your data collection platform? (Tick all that apply)	<input checked="" type="checkbox"/> data manager
How frequently is the database updated with the latest information? (Tick all that apply)	<input checked="" type="checkbox"/> monthly
Is linkage to other databases or registries possible?	<input type="checkbox"/> yes
Which registries can be linked to? (Tick all that apply)	<input checked="" type="checkbox"/> mortality registry <input checked="" type="checkbox"/> prescription registry <input checked="" type="checkbox"/> comorbidity

Response was added on 2021-12-08 14:12:34.

Demography

Please indicate which of the following variables are collected in your registry (Tick all that apply)

- age (year of birth)
 sex
 weight
 height

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Weight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Height	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (weight)

To be included with next update in protocol

Please specify (height)

To be included with next update in protocol

Diagnosis

How is a diagnosis registered? (Tick all that apply)

- through ICD-10 codes

Do you register (Tick all that apply)

- date for diagnosis

Do you register (Tick all that apply)

- not registered

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Day/month/year of diagnosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Which classification criteria are registered? (Tick all that apply)

- ASAS
 CASPAR

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ASAS	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CASPAR	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In which patients can you register ASAS?

AxSpA

Do you register individual ASAS classification items?
(Tick all that apply)

yes

Do you register individual CASPAR classification items?
(Tick all that apply)

yes

Response was added on 2021-12-08 14:20:30.

Axial spondyloarthritis

Which disease status characteristics can be registered in axSpA patients?
(Tick all that apply)

- swollen joint count
 tender joint count
 physician global
 other

Please specify

BASDAI and ASDAS

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- other

Please specify

28 plus 4 (foot and ankle)

Do you register specific location of swollen joints?
(Tick all that apply)

- yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- other

Please specify

same as for swollen joints

Do you register specific location of tender joints?
(Tick all that apply)

- yes

Physician Global

Please write the wording of the question regarding physician global

Hvordan vil du beskrive pasientens sykdomsaktivitet? VAS 0-100 fra "ingen aktivitet" til "svært aktiv"
(translate into english if possible)

Coxitis

Do you assess coxitis? If yes, please indicate how it is assessed

No

Response was added on 2021-12-08 14:22:10.

Psoriatic arthritis

Which disease status characteristics can be registered in PsA patients?
(Tick all that apply)

- swollen joint count
 tender joint count
 physician Global
 other

Please specify

DAPSA based on 28 joints

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician Global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- Other

Please specify

28 + 4 as for AS

Do you register specific location of swollen joints?
(Tick all that apply)

- yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- Other

Please specify

28 + 4

Do you register specific location of tender joints?
(Tick all that apply)

- yes

Physician global

Please write the wording of the question regarding physician global

Hvordan vil du beskrive pasientens sykdomsaktivitet? VAS 0-100 fra "ingen aktivitet" til "svært aktiv"
(Translate into english if possible)

Coxitis

Do you assess coxitis? If yes, please indicate how it is assessed

No

Response was added on 2021-12-08 14:25:47.

Medication

Which therapies are registered in your registry?
(Tick all that apply)

biological dmards (bDMARDs), including targeted synthetic dmards (JAK)
 conventional synthetic dmards (csDMARDs)
 glucocorticoids

bDMARDs

Which year did bDMARD registration begin? 2000

Is it mandatory to register bDMARD therapy? other

Please specify In principle yes, but some patients do not approve participation and some clinicians forget

csDMARDs

Which year did csDMARD registration begin? 2000

Is it mandatory to register csDMARD therapy? other

Please specify since 2012 only registered when in combination with bdmard

Is it mandatory to register glucocorticoid therapy? no

Is the mode of administration registered?
(Tick all that apply)

oral
 intramuscular
 intraarticular

Are specific locations of injected joints registered? yes

What information regarding ONGOING medications is registered?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	frequency	administration mode
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Time points for registration (ONGOING medications)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

What information regarding PAST medications is registered at inclusion in registry?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	name of drug
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
glucocorticoids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Discontinuation reasons

What are the possible reasons for discontinuation of a bDMARD?
(Tick all that apply)

- lack of efficacy
- adverse events
- remission
- lost to follow-up
- death
- other

Please specify

Specified as text

Is it possible to register multiple reasons for discontinuation?

yes

How is it decided which is the primary reason for discontinuation?

Uncertain

Does your registry link to prescription database or other external data sources on prescriptions on a regular basis as input to registry?
(Tick all that apply)

no

General comments

Linkage to prescriptions can be done for validation purposes

Response was added on 2021-12-08 14:28:39.

Patient reported outcomes

Which patient reported outcomes (PROs) are registered in axSpA and/or PsA patients?
(Tick all that apply)

- BASDAI
 pain
 fatigue
 global disease
 EQ-5D
 patient acceptable symptom state (PASS)
 other

Please specify

MHAQ

Are any of the PROs registered in either axSpA or PsA only?

- no, all PROs are registered in both diagnoses

Mode of registration

What are the options for registration of PROs?
(Tick all that apply)

- on screen in waiting room
 through website/app

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
BASDAI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Global disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
EQ-5D	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
PASS	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

BASDAI

Are the individual BASDAI components registered?

- yes

Pain, fatigue and global assessments

Please write the wording of the question relating to pain

"Hvor mye smerte har du hatt den siste uken?" VAS fra "Ingen smerter" til "Uutholdelige smerter" (please translate into english if possible)

Please write the wording of the question relating to fatigue

"I hvilken grad har en følelse av uvanlig tretthet eller utmattelse vært et problem for deg den siste uken?" VAS fra "Tretthet er ikke noe problem" til "Tretthet er et stort problem" (please translate into english if possible)

Please write the wording of the question relating to global assessment of disease

"Vi ber deg vennligst vurdere aktiviteten i din revmatiske sykdom i løpet av den siste uken. Når du tar alle symptomene med i betraktning, hvordan synes du tilstanden er?" VAS fra "Bra, ingen symptomer" til "Svært dårlig"
(please translate into english if possible)

EQ-5D

Are the individual EQ-5D items registered?

yes

Which EQ-5D version is used?

3 response options

Which algorithm is used?

I think it is the British

Patient acceptable symptom state (PASS)

Please write the wording of the question relating to PASS

Tenk gjennom hvordan din revmatiske sykdom har påvirket deg den siste uken. Hvis du de neste månedene vil forbli som du var i løpet av den siste uken, vil det være akseptabelt eller uakseptabelt for deg? (Akseptabelt - Uakseptabelt)
(please translate into english if possible)

General comments

PASS udgår i forbindelse med næste protokoll oppdatering.

Response was added on 2021-12-08 14:29:23.

Laboratory

Which laboratory test can be registered?
(Tick all that apply)

- ESR
- CRP
- HLA-B27
- IgM-RF
- stored samples available for later analyses (biobank)

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ESR	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CRP	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Stored samples available for later analyses (biobank)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Biobank

Which sample types are collected?
(Tick all that apply)

- whole-blood
- serum

How are laboratory test results registered?
(Tick all that apply)

- entered by health care staff

Response was added on 2021-12-08 14:30:05.

Frequency of image registration

Please comment on the frequency of registration of the various image modalities, eg. at specified time points, as needed, in connection with research projects or other.

Not entered into NOR-DMARD

Response was added on 2021-12-08 14:31:13.

Comorbidities

Which extraarticular manifestations and comorbid conditions are registered?
(Tick all that apply)

- ischemic heart disease (IHD)
- cerebrovascular disease (CVD)
- hypertension
- diabetes (DM)
- chronic kidney insufficiency (CKI)
- chronic liver disease, eg. hepatitis, cirrhosis
- solid cancer
- hematological cancer
- depression
- other

Please specify

hypertension, angina pectoris, myocardial infarction, cardiac failure, previous percutaneous coronary intervention (PCI) or bypass operation, intermittent claudication, cerebral haemorrhage/ischemic stroke/transient ischemic attack (TIA), asthma/bronchitis/chronic lung disease, allergy/eczema, chronic back pain, cancer, neurologic disease, diabetes, hypothyroidism, mental illness, alcohol and/or narcotic substance abuse, renal disease, liver disease, gastrointestinal disease including ulcer, anaemia or other haematological disorder, and about occurrence of early coronary vascular disease (CVD)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
IHD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
depression	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
other	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	patient-reported	by health-staff	linkage from other registry	
IHD	<input checked="" type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
CVD	<input checked="" type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
hypertension	<input checked="" type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>

DM	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CKI	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
depression	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
other	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you use ICD-10 codes for registration?

no

General comments

Via go-treat it

Response was added on 2021-12-08 14:31:47.

Lifestyle

Which lifestyle parameters are registered?
(Tick all that apply) smoking

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Smoking	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Smoking

How is smoking status characterised?
(Tick all that apply) current
 former
 never

Do you register a start date?
(Tick all that apply) no date is registered

Do you register a stop date for former smokers? No

How is average number of smoked cigarettes registered?
(Tick all that apply) not registered

Response was added on 2021-12-08 14:32:28.

Safety

Can you register adverse events in your registry?
(Tick all that apply) yes, directly into registry

Is it mandatory to register adverse events through
your registry? yes

Which adverse events are registered in your registry?
(Tick all that apply) non-serious adverse events
 serious adverse events?

Information on adverse events

	date of event	MeddRA	ICD10-code	outcome	other
Non serious AE	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Serious AE	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

General comments With next protocol update, only SAEs will be recorded.

Participant information

Record ID	8
Name	Pasoon Hellamand
Registry	ARC
E-mail	p.hellamand@amsterdamumc.nl
Deltager	<input checked="" type="checkbox"/> ja

Response was added on 2022-01-11 13:08:22.

General registry information

What is the status of your registry? running, but closed for inclusion

Coverage

Please estimate how many (percentage) of the eligible spondyloarthritis patients in your country, that are registered 0

Please estimate how many (percentage) of the eligible psoriatic arthritis patients in your country, that are registered 0

How did you obtain the coverage estimate above? (Tick all that apply) other

Please specify One study (van der linden, 1984) has found a prevalence of 0.10% for AS patients in the NL. Assuming 17.5 million population, this amounts to 17500 AS patients. Calculation $((100/17500)*100\%) = 0.5\%$ The amount of patients with AS were ~3000 (=2957).

Which institutions/organisations can include patients in your registry? (Tick all that apply) departments of rheumatology at university hospitals

Please give an estimate of how many departments of rheumatology at university hospitals that include patients in your registry 1

When is the data registered? (Tick all that apply) at routine visits

Are all routine visits registered in your registry - or only some? all visits

Ethics

Is approval from a local ethics committee needed for a study on de-identified data (eg. a EuroSpA upload)? (Tick all that apply) yes comment

Comment We added in the PIF an option to give permission to share data with researchers abroad. So only patients that have ticked this option are uploaded to EuroSpA.

Do patients need to sign informed consent to be included in your registry?
(Tick all that apply) yes

Are any additional local approvals needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply) no

What is the basis of participation by a clinic/department/office in the registry?
(Tick all that apply) voluntary

Is the clinic/department/office financially compensated for registration? no

Inclusion criteria

What event triggers the inclusion of a patient into the registry?
(Tick all that apply) other

Please specify

In our registry any patient with axSpA regardless of treatment stage can be included in the registry. We have an outpatient clinic where all patients who had a visited were asked to join the study.

Which criteria do you base the inclusion on?
(Tick all that apply) diagnosis

Is a minimum age required for inclusion? yes, 18 years or above

Which diagnoses are included in your registry?
(Tick all that apply) ankylosing spondylitis (AS)
 non-radiographic axial spondyloarthritis (nr-axSpA)

Which year did inclusion of AS patients begin? 2019

Which year did inclusion of nr-axSpA patients begin? 2019

Have the inclusion criteria changed over time? no

General comments The answer to question one is 0.5% but it does not let me answer this.

Response was added on 2022-01-11 11:14:00.

Data management

What are the options for data entry? (Tick all that apply)	<input checked="" type="checkbox"/> paper based <input checked="" type="checkbox"/> electronic
Are the data fields in your registry interactive, such that invalid or unprobable data is flagged when entered (edit checks) (Tick all that apply)	<input checked="" type="checkbox"/> yes
Since when (year) has the data fields been interactive?	2019
How does your registry retain data management services? (Tick all that apply)	<input checked="" type="checkbox"/> a researcher/administrative personal does data management beside other duties
Which is the background of your data manager(s)? (Tick all that apply)	<input checked="" type="checkbox"/> clinical
Which are the most commonly used data analysis software/programming languages in your organization? (Tick all that apply)	<input checked="" type="checkbox"/> R <input checked="" type="checkbox"/> other
Please specify	Google spreadsheet, I don't use excel.
How is the data stored in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> a relational database framework (like SQL)
Which are the main data formats used for raw data extractions? (Tick all that apply)	<input checked="" type="checkbox"/> simple text files, eg. csv, tsv
Where is your data collection platform hosted? (Tick all that apply)	<input checked="" type="checkbox"/> external company
Who maintains your data collection platform? (Tick all that apply)	<input checked="" type="checkbox"/> data manager <input checked="" type="checkbox"/> researcher/epidemiologist
How frequently is the database updated with the latest information? (Tick all that apply)	<input checked="" type="checkbox"/> weekly <input checked="" type="checkbox"/> monthly
Is linkage to other databases or registries possible?	<input type="checkbox"/> no

Response was added on 2022-01-11 11:18:49.

Demography

Please indicate which of the following variables are collected in your registry
(Tick all that apply)

- age (year of birth)
 sex
 weight
 height
 death

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Weight	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Height	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How is vital status registered
(Tick all that apply)

- by healthstaff, manually

Diagnosis

How is a diagnosis registered?
(Tick all that apply)

- other diagnostic categories

Specify which diagnostic categories

Diagnosis is made by the treating rheumatologist. It does not always have to be ASAS+ and/or NY+, but usually it is.

Do you register
(Tick all that apply)

- date for diagnosis
 month of diagnosis
 year of diagnosis

Do you register
(Tick all that apply)

- year of symptom onset

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Day/month/year of diagnosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day/month/year of symptom onset	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Which classification criteria are registered?
(Tick all that apply)

- ASAS
 New York

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ASAS	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
New York	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In which patients can you register ASAS?

AxSpA

Do you register individual ASAS classification items?
(Tick all that apply)

yes

Do you register individual New York classification items?
(Tick all that apply)

no

Response was added on 2022-01-11 11:32:50.

Axial spondyloarthritis

Which disease status characteristics can be registered in axSpA patients?
(Tick all that apply)

- swollen joint count
- tender joint count
- enthesitis
- physician global
- BASMI

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASMI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 28
- 44

Do you register specific location of swollen joints?
(Tick all that apply)

- yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 28
- 44

Do you register specific location of tender joints?
(Tick all that apply)

- yes

Enthesitis

Do you register specific location of enthesitis?
(Tick all that apply)

- yes

Which locations are registered?
(Tick all that apply)

- achilles tendon insertion
- 1st costochondral joint
- 7th costochondral joint
- posterior superior iliac spine
- anterior superior iliac spine
- iliac crests
- 5th lumbar spinous process

Please indicate which specific indices that are used, if applicable

MASES criteria

Physician Global

Please write the wording of the question regarding physician global

How active was your disease on average during the last week (scale 0-10); 0 = not active; 10 = very active
(translate into english if possible)

BASMI

Are the individual BASMI components registered?

yes

Do you register the individual BASMI measurements (cm, degrees)?

yes

Which BASMI scale is used?

3-point

Coxitis

Do you assess coxitis? If yes, please indicate how it is assessed

Only if the patient has complaints, not regularly.

General comment

For the BASMI we have the continuous values (so we could calculate linear) and we have the 3-point scale.

Response was added on 2022-01-11 11:33:03.

General comment

We do not include PsA patients.

Response was added on 2022-01-11 11:36:37.

MedicationWhich therapies are registered in your registry?
(Tick all that apply)

- biological dmards (bDMARDs), including targeted synthetic dmards (JAK)
- conventional synthetic dmards (csDMARDs)
- glucocorticoids
- NSAIDs
- medication for comorbidity
- other

Please specify

all medications are registered

bDMARDs

Which year did bDMARD registration begin?

2019

Is it mandatory to register bDMARD therapy?

 yes**csDMARDs**

Which year did csDMARD registration begin?

2019

Is it mandatory to register csDMARD therapy?

 no**Glucocorticoids**

Which year did glucocorticoid registration begin?

2019

Is it mandatory to register glucocorticoid therapy?

 noIs the mode of administration registered?
(Tick all that apply) oral**NSAIDs**

Which year did NSAID registration begin?

2019

Is it mandatory to register NSAID therapy?

 no

Medication for comorbidities

What types of medical therapy for comorbidities are registered? all

What information regarding ONGOING medications is registered?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	frequency	administration mode
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
NSAIDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
medication for comorbidity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Time points for registration (ONGOING medications)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
NSAIDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
medication for comorbidity	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

What information regarding PAST medications is registered at inclusion in registry?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	name of drug
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Discontinuation reasons

What are the possible reasons for discontinuation of a bDMARD?
(Tick all that apply)

- lack of efficacy
- adverse events
- remission
- pregnancy wish
- death

Is it possible to register multiple reasons for discontinuation? no

Does your registry link to prescription database or other external data sources on prescriptions on a regular basis as input to registry?
(Tick all that apply) no

General comments Theoretically speaking we could easily get start & stop dates for all patients, however, we do not register them in our EDBC. Just for bDMARDs.

Response was added on 2022-01-11 12:44:54.

Patient reported outcomes

Which patient reported outcomes (PROs) are registered in axSpA and/or PsA patients?
(Tick all that apply)

- BASDAI
 BASFI
 nightly pain
 fatigue
 global disease
 EQ-5D
 other

Please specify

General health questionnaire, physical activity, intoxications,

Are any of the PROs registered in either axSpA or PsA only?

 yes

Which PROs are registered uniquely in either axSpA or PsA?

all in axspa

Mode of registration

What are the options for registration of PROs?
(Tick all that apply)

 paper forms**Time points for registration**

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
BASDAI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASFI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Global disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
EQ-5D	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

BASDAI

Are the individual BASDAI components registered?

 yes

BASFI

Are the individual BASFI components registered?

 yes

Please write the wording of the question relating to nightly pain

Howmuch backpain did you have during the night the last week?
(please translate into english if possible)

Please write the wording of the question relating to fatigue

How tired were you the last week?
(please translate into english if possible)

Please write the wording of the question relating to global assessment of disease

How active was your disease the last weeks?
(please translate into english if possible)**EQ-5D**

Are the individual EQ-5D items registered?

 yes

Which EQ-5D version is used?

The one with 5 options

Which algorithm is used?

I haven't created a composite score yet

General comments

We also have a global assessment of health:

To what extent did your disease affect your global health during the last week (also available last 6 months).

Response was added on 2022-01-11 12:47:43.

Laboratory

Which laboratory test can be registered?
(Tick all that apply)

- ESR
- CRP
- hemoglobin
- ALAT
- creatinine
- HLA-B27

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ESR	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CRP	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Hemoglobin	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
ALAT	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Creatinine	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

How are laboratory test results registered?
(Tick all that apply)

- entered by health care staff

General comments

We also have AF, gGT, thrombocytes, leukocytes

Response was added on 2022-01-11 12:48:48.

Frequency of image registration

Please comment on the frequency of registration of the various image modalities, eg. at specified time points, as needed, in connection with research projects or other.

X-rays done every 2 years in clinical practice.

Response was added on 2022-01-11 12:50:58.

Comorbidities

Which extraarticular manifestations and comorbid conditions are registered?
(Tick all that apply)

- uveitis
- psoriasis
- inflammatory bowel disease (IBD)
- ischemic heart disease (IHD)
- cerebrovascular disease (CVD)
- hypertension
- diabetes (DM)
- dyslipidemia
- osteoporosis
- chronic kidney insufficiency (CKI)
- chronic liver disease, eg. hepatitis, cirrhosis
- other

Please specify

We have something called "other" with blank field where researcher can enter any disease. E.g, surgery, cancer, etc.

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
uveitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
other	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Mode of registration - how are comorbid conditions registered?

	patient-reported	by health-staff	linkage from other registry
uveitis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

IHD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
other	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Do you use ICD-10 codes for registration?

no

Response was added on 2022-01-11 12:56:12.

LifestyleWhich lifestyle parameters are registered?
(Tick all that apply)

- smoking
 alcohol consumption
 physical activity

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Smoking	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Alcohol	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physical activity	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

SmokingHow is smoking status characterised?
(Tick all that apply)

- current
 other

Please specify

If someone is "no" smoker (could be never or former, no distinction is made)

Do you register a start date?
(Tick all that apply)

- no date is registered

Do you register a stop date for former smokers?

- No

How is average number of smoked cigarettes registered?
(Tick all that apply)

- number of daily cigarettes

AlcoholHow is alcohol consumption quantified?
(Tick all that apply)

- average number of units/week

Physical activityHow is physical activity defined?
(Tick all that apply)

- not defined

How is physical activity quantified?
(Tick all that apply)

- sessions per week
 sessions per month

General comments

For physical activities, if a patient has had fysio, sport, individual exercises, cycling, walking, working in garden or has "other" physical activity. We also report how many times per day or week. Howmany minutes every time.

Response was added on 2022-01-11 12:56:48.

Safety

Can you register adverse events in your registry?
(Tick all that apply) yes, directly into registry

Is it mandatory to register adverse events through
your registry? no

Which adverse events are registered in your registry?
(Tick all that apply) non-serious adverse events
 serious adverse events?

Information on adverse events

	date of event	MeddRA	ICD10-code	outcome	other
Non serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

General comments I dont know what MeddRA is.

Participant information

Record ID	9
Name	Florenzo Iannone
Registry	GISEA
E-mail	florenzo.iannone@uniba.it
Deltager	<input checked="" type="checkbox"/> ja

Response was added on 2022-01-16 08:55:31.

General registry information

What is the status of your registry? running and including patients

Coverage

Please estimate how many (percentage) of the eligible spondyloarthritis patients in your country, that are registered 15

Please estimate how many (percentage) of the eligible psoriatic arthritis patients in your country, that are registered 10

How did you obtain the coverage estimate above? (Tick all that apply) other

Please specify by the the estimated prevalence of the diseases

Which institutions/organisations can include patients in your registry? (Tick all that apply) departments of rheumatology at hospitals
 departments of rheumatology at university hospitals

Please give an estimate of how many departments of rheumatology at hospitals (not including university hospitals) that include patients in your registry 4

Please give an estimate of how many departments of rheumatology at university hospitals that include patients in your registry 13

When is the data registered? (Tick all that apply) at pre-specified registry visits

What is the schedule for pre-specified registry visits? 6 months

Is it possible to register visits outside of the pre-specified visit schedule, eg. if a patient has a flare? yes

Ethics

Is approval from a local ethics committee needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply)

comment

Comment

GISEA has been approved as whole. Further submission to IRB are needed in case of change of the data set already approved

Do patients need to sign informed consent to be included in your registry?
(Tick all that apply)

yes

Are any additional local approvals needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply)

yes

Please specify which additional approvals are needed

In case of new data to collect

Funding

How is the registry funded?
(Tick all that apply)

other

Please specify which other sources

Industry sponsorships for events and meetings arranged by GISEA.

Please estimate the percentage of funds coming from other sources

100
((0-100%))

The percentages add correctly up to a 100%

What is the basis of participation by a clinic/department/office in the registry?
(Tick all that apply)

voluntary

Is the clinic/department/office financially compensated for registration?

no

Inclusion criteria

What event triggers the inclusion of a patient into the registry?
(Tick all that apply)

new treatment
 other

Please specify

new treatment with bDMARDs or tsDMARDs

Which criteria do you base the inclusion on?
(Tick all that apply)

treatment

Is a minimum age required for inclusion?

no

Do patients need to be treated with biological DMARDs (including targeted synthetic DMARDs) to be included in the registry?

yes

Have the inclusion criteria changed over time?

no

Response was added on 2022-01-16 09:02:47.

Data management

What are the options for data entry? (Tick all that apply)	<input checked="" type="checkbox"/> electronic
Are the data fields in your registry interactive, such that invalid or unprobable data is flagged when entered (edit checks) (Tick all that apply)	<input checked="" type="checkbox"/> comment
Comment	We are discussing about flagging the missin of some key data
Please describe any other data validation procedures that you may use	Checking the inconsistency of data
How does your registry retain data management services? (Tick all that apply)	<input checked="" type="checkbox"/> external company
Which is the background of your data manager(s)? (Tick all that apply)	<input checked="" type="checkbox"/> data science/biostatistician/technical
Which are the most commonly used data analysis software/programming languages in your organization? (Tick all that apply)	<input checked="" type="checkbox"/> SPSS
How is the data stored in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> a relational database framework (like SQL)
Which are the main data formats used for raw data extractions? (Tick all that apply)	<input checked="" type="checkbox"/> simple text files, eg. csv, tsv
Where is your data collection platform hosted? (Tick all that apply)	<input checked="" type="checkbox"/> external company
Who maintains your data collection platform? (Tick all that apply)	<input checked="" type="checkbox"/> external company <input checked="" type="checkbox"/> data manager
How frequently is the database updated with the latest information? (Tick all that apply)	<input checked="" type="checkbox"/> monthly
Is linkage to other databases or registries possible?	<input type="checkbox"/> yes
Which registries can be linked to? (Tick all that apply)	<input checked="" type="checkbox"/> prescription registry

Response was added on 2022-01-16 09:04:23.

Demography

Please indicate which of the following variables are collected in your registry
(Tick all that apply)

- age (year of birth)
- sex
- ethnicity
- weight
- height
- death

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Weight	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Height	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How is vital status registered
(Tick all that apply)

- by healthstaff, manually

Diagnosis

How is a diagnosis registered?
(Tick all that apply)

- through ICD-10 codes
- classification criteria

Do you register
(Tick all that apply)

- date for diagnosis

Do you register
(Tick all that apply)

- date for symptom onset

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Day/month/year of diagnosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day/month/year of symptom onset	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Which classification criteria are registered?
(Tick all that apply)

- New York
- CASPAR

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
New York	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CASPAR	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you register individual New York classification items?
(Tick all that apply)

no

Do you register individual CASPAR classification items?
(Tick all that apply)

no

Response was added on 2022-01-16 10:31:20.

Axial spondyloarthritis

Which disease status characteristics can be registered in axSpA patients?
(Tick all that apply)

- swollen joint count
- tender joint count
- enthesitis
- dactylitis
- physician global
- other

Please specify

HAQ, VAS pain, BASDAI

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Dactylitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

66

Do you register specific location of swollen joints?
(Tick all that apply)

yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

68

Do you register specific location of tender joints?
(Tick all that apply)

yes

Enthesitis

Do you register specific location of enthesitis?
(Tick all that apply) no, only as a total count

Please indicate which specific indices that are used,
if applicable LEI

Dactylitis

How is dactylitis assessed?
(Tick all that apply) as a count

Physician Global

Please write the wording of the question regarding
physician global

The PhGA was collected on a 0-10 numerical rating scale by asking the physician's "overall assessment of the activity of the axSpA during the last 48 hours," with inactive disease and active disease as anchors (a higher score means higher disease activity)
(translate into english if possible)

Coxitis

Do you assess coxitis? If yes, please indicate how it
is assessed no

Response was added on 2022-01-16 10:33:21.

Psoriatic arthritis

Which disease status characteristics can be registered in PsA patients?
(Tick all that apply)

- swollen joint count
- tender joint count
- enthesitis
- dactylitis
- skin
- nails
- physician Global
- other

Please specify

VAS pain, HAQ

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Dactylitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Skin	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Nails	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physician Global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

66

Do you register specific location of swollen joints?
(Tick all that apply)

yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

68

Do you register specific location of tender joints?
(Tick all that apply)

yes

Entesitis

Do you register specific location of entesitis?
(Tick all that apply) no, only as a total count

Dactylitis

How is dactylitis assessed?
(Tick all that apply) as a count

Skin

Which instruments are used for registering skin involvement in PsA?
(Tick all that apply) PASI
 body surface area %

Nails

Which instruments are used for registering nail involvement in PsA?
(Tick all that apply) free text description

Physician global

Please write the wording of the question regarding physician global

The PhGA was collected on a 0-10 numerical rating scale by asking the physician's "overall assessment of the activity of the axSpA during the last 48 hours," with inactive disease and active disease as anchors (a higher score means higher disease activity)
(Translate into english if possible)

Coxitis

Do you assess coxitis? If yes, please indicate how it is assessed no

Response was added on 2022-01-16 10:37:52.

MedicationWhich therapies are registered in your registry?
(Tick all that apply)

- biological dmards (bDMARDs), including targeted synthetic dmards (JAK)
 conventional synthetic dmards (csDMARDs)
 glucocorticoids
 other

Please specify

csDMARDs are recorded only in pts taking bDMARD or tsDMARD

bDMARDs

Which year did bDMARD registration begin?

2010

Is it mandatory to register bDMARD therapy?

 yes**csDMARDs**

Which year did csDMARD registration begin?

2010

Is it mandatory to register csDMARD therapy?

 yes**Glucocorticoids**

Which year did glucocorticoid registration begin?

2010

Is it mandatory to register glucocorticoid therapy?

 noIs the mode of administration registered?
(Tick all that apply)

- oral
 intramuscular

What information regarding ONGOING medications is registered?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	frequency	administration mode
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Time points for registration (ONGOING medications)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What information regarding PAST medications is registered at inclusion in registry?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	name of drug
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Discontinuation reasons

What are the possible reasons for discontinuation of a bDMARD?
(Tick all that apply)

- lack of efficacy
- adverse events
- remission
- pregnancy wish
- infection
- lost to follow-up
- death

Is it possible to register multiple reasons for discontinuation?

no

Does your registry link to prescription database or other external data sources on prescriptions on a regular basis as input to registry?
(Tick all that apply)

no

Response was added on 2022-01-17 00:08:40.

Patient reported outcomes

Which patient reported outcomes (PROs) are registered in axSpA and/or PsA patients?
(Tick all that apply)

- BASDAI
 pain
 fatigue
 global disease
 HAQ

Are any of the PROs registered in either axSpA or PsA only?

- no, all PROs are registered in both diagnoses

Mode of registration

What are the options for registration of PROs?
(Tick all that apply)

- paper forms
 through interview with health-staff

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
BASDAI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Global disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
HAQ	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

BASDAI

Are the individual BASDAI components registered?

- yes

Pain, fatigue and global assessments

Please write the wording of the question relating to pain

"Numerical rating scale ranging from 0 (no pain) to 100 (worst imaginable pain) measuring actual back pain intensity
(please translate into english if possible)

Please write the wording of the question relating to fatigue

Numerical rating scale ranging from 0 (no tired at all) to 100 (extremely tired) measuring fatigue intensity during the last 24h"
(please translate into english if possible)

Please write the wording of the question relating to global assessment of disease

Considering all the ways your arthritis has affected you, how active do you feel your arthritis is today on a scale ranging from 0 to 100
(please translate into english if possible)

HAQ

Are the individual HAQ items registered?

yes

Which HAQ versions may be used in your registry?
(Tick all that apply)

stanford HAQ DI without adjustment for use of aids
and devices

Response was added on 2022-01-17 00:09:28.

Laboratory

Which laboratory test can be registered?
(Tick all that apply)

- ESR
- CRP
- hemoglobin
- creatinine
- HLA-B27
- IgM-RF

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ESR	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CRP	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Hemoglobin	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Creatinine	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

How are laboratory test results registered?
(Tick all that apply)

- entered by health care staff

Response was added on 2022-01-17 00:13:27.

Frequency of image registration

Please comment on the frequency of registration of the various image modalities, eg. at specified time points, as needed, in connection with research projects or other.

The register allows to upload images but it is not mandatory and therefore very few data are available

Response was added on 2022-01-17 00:14:51.

Comorbidities

Which extraarticular manifestations and comorbid conditions are registered?
(Tick all that apply)

- uveitis
- psoriasis
- inflammatory bowel disease (IBD)
- ischemic heart disease (IHD)
- cerebrovascular disease (CVD)
- hypertension
- diabetes (DM)
- dyslipidemia
- osteoporosis
- chronic kidney insufficiency (CKI)
- chronic liver disease, eg. hepatitis, cirrhosis
- solid cancer
- hematological cancer
- depression
- tuberculosis (TB)
- fibromyalgia

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
uveitis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
depression	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
TB	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
fibromyalgia	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Mode of registration - how are comorbid conditions registered?

	patient-reported	by health-staff	linkage from other registry
uveitis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
depression	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
TB	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
fibromyalgia	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Do you use ICD-10 codes for registration?

 yes

Response was added on 2022-01-17 00:15:49.

Lifestyle

Which lifestyle parameters are registered?
(Tick all that apply)

- smoking
 alcohol consumption

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Smoking	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Smoking

How is smoking status characterised?
(Tick all that apply)

- current
 former
 never

Do you register a start date?
(Tick all that apply)

- no date is registered

Do you register a stop date for former smokers?

- No

How is average number of smoked cigarettes registered?
(Tick all that apply)

- not registered

Alcohol

How is alcohol consumption quantified?
(Tick all that apply)

- other

Please specify

it is not quantified

Response was added on 2022-01-17 00:16:17.

Safety

Can you register adverse events in your registry?
(Tick all that apply) yes, directly into registry

Is it mandatory to register adverse events through
your registry? no

Which adverse events are registered in your registry?
(Tick all that apply) non-serious adverse events
 serious adverse events?

Information on adverse events

	date of event	MeddRA	ICD10-code	outcome	other
Non serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Participant information

Record ID	10
Name	Anne Gitte Loft
Registry	Danbio
E-mail	Anne.Gitte.Loft@auh.rm.dk
Deltager	<input checked="" type="checkbox"/> ja

Response was added on 2021-11-23 13:45:44.

General registry information

What is the status of your registry? running and including patients

Coverage

Please estimate how many (percentage) of the eligible spondyloarthritis patients in your country, that are registered 95

Please estimate how many (percentage) of the eligible psoriatic arthritis patients in your country, that are registered 85

How did you obtain the coverage estimate above? (Tick all that apply) other

Please specify best guess

Which institutions/organisations can include patients in your registry? (Tick all that apply) private rheumatology practices
 departments of rheumatology at hospitals
 departments of rheumatology at university hospitals

Please give an estimate of how many private rheumatology practices that include patients in your registry approx 25-30

Please give an estimate of how many departments of rheumatology at hospitals (not including university hospitals) that include patients in your registry approx 22

Please give an estimate of how many departments of rheumatology at university hospitals that include patients in your registry approx 3

When is the data registered? (Tick all that apply) at routine visits

Are all routine visits registered in your registry - or only some? only some visits

Ethics

Is approval from a local ethics committee needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply) no

Do patients need to sign informed consent to be included in your registry?
(Tick all that apply) no

Are any additional local approvals needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply) no

Funding

How is the registry funded?
(Tick all that apply) from public sector, eg. state or other
 industry

Please estimate the percentage of funds coming from public sector, eg. state or other 15
((0-100%))

Please estimate the percentage of funds coming from industry, eg. pharmaceutical company 85
((0-100%))

The percentages add correctly up to a 100%

What is the basis of participation by a clinic/department/office in the registry?
(Tick all that apply) mandatory
 voluntary
 other

Please specify mandatory for axspa og psa bdmard, voluntary for psa non bdmard

Is the clinic/department/office financially compensated for registration? no

Inclusion criteria

What event triggers the inclusion of a patient into the registry?
(Tick all that apply) new diagnosis

Which criteria do you base the inclusion on?
(Tick all that apply) diagnosis

Is a minimum age required for inclusion? no

Which diagnoses are included in your registry?
(Tick all that apply) ankylosing spondylitis (AS)
 non-radiographic axial spondyloarthritis (nr-axSpA)
 psoriatic arthritis (PsA)
 rheumatoid arthritis
 other

Which year did inclusion of AS patients begin? 2006

Which year did inclusion of nr-axSpA patients begin?	2009
Which year did inclusion of PsA patients begin?	2006
Which other diagnoses are included?	SLE, juvenil arthritis
Have the inclusion criteria changed over time?	<input checked="" type="checkbox"/> yes
How and when did inclusion criteria change?	2010
General comments	Mandatory to include newly diagnosed patients with SpA since 2010

Response was added on 2021-11-23 13:09:00.

Data management

What are the options for data entry? (Tick all that apply)	<input checked="" type="checkbox"/> electronic
Are the data fields in your registry interactive, such that invalid or unprobable data is flagged when entered (edit checks) (Tick all that apply)	<input checked="" type="checkbox"/> no <input checked="" type="checkbox"/> comment
Comment	Most fields not interactive/limited, e.g. CRP
Please describe any other data validation procedures that you may use	It is not possible to start a new bdmard before the prior is stopped. Patients can only be registered once nationwide.
How does your registry retain data management services? (Tick all that apply)	<input checked="" type="checkbox"/> external company
Which is the background of your data manager(s)? (Tick all that apply)	<input checked="" type="checkbox"/> data science/biostatistician/technical
Which are the most commonly used data analysis software/programming languages in your organization? (Tick all that apply)	<input checked="" type="checkbox"/> R <input checked="" type="checkbox"/> excel <input checked="" type="checkbox"/> python
How is the data stored in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> a relational database framework (like SQL)
Which are the main data formats used for raw data extractions? (Tick all that apply)	<input checked="" type="checkbox"/> r-derived format <input checked="" type="checkbox"/> SQL-output
Where is your data collection platform hosted? (Tick all that apply)	<input checked="" type="checkbox"/> external company
Who maintains your data collection platform? (Tick all that apply)	<input checked="" type="checkbox"/> external company
How frequently is the database updated with the latest information? (Tick all that apply)	<input checked="" type="checkbox"/> real-time <input checked="" type="checkbox"/> weekly <input checked="" type="checkbox"/> other
Please specify	Real time for patient reported outcomes, daily for death, weekly for group level data
Is linkage to other databases or registries possible?	<input checked="" type="checkbox"/> yes

Which registries can be linked to?
(Tick all that apply)

- mortality registry
- prescription registry
- comorbidity
- electronic medical records
- other

Please specify

soon real time integration with laboratory values
eg CRP becomes possible

General comments

Linkages requires approval from authorities and is
done on external datasets.
Mortality is by linkage daily in registry

Response was added on 2021-11-23 13:10:26.

Demography

Please indicate which of the following variables are collected in your registry (Tick all that apply)

- age (year of birth)
 sex
 weight
 height
 death

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Weight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Height	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (weight) Not done routinely

Please specify (height) Not done routinely

How is vital status registered (Tick all that apply) through regular linkage to national register

Diagnosis

How is a diagnosis registered? (Tick all that apply) through ICD-10 codes

Do you register (Tick all that apply) month of diagnosis
 year of diagnosis

Do you register (Tick all that apply) month of symptom onset
 year of symptom onset

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Day/month/year of diagnosis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Day/month/year of symptom onset	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Which classification criteria are registered? (Tick all that apply) ASAS
 New York
 CASPAR

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ASAS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
New York	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
CASPAR	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (ASAS) When it is considered relevant

Please specify (New York) When it is considered relevant

Please specify (CASPAR) When it is considered relevant

In which patients can you register ASAS? both

Do you register individual ASAS classification items?
(Tick all that apply) yes

Do you register individual New York classification items?
(Tick all that apply) yes

Do you register individual CASPAR classification items?
(Tick all that apply) yes

General comments Concerning registering of classification criteria
this is not always done - it depends on the
clinician

Response was added on 2021-11-23 13:11:10.

Axial spondyloarthritis

Which disease status characteristics can be registered in axSpA patients?
(Tick all that apply)

- swollen joint count
 tender joint count
 enthesitis
 physician global
 BASMI

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASMI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 28
 66

Do you register specific location of swollen joints?
(Tick all that apply)

- yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 28
 68

Do you register specific location of tender joints?
(Tick all that apply)

- yes

Enthesitis

Do you register specific location of enthesitis?
(Tick all that apply)

- yes

Which locations are registered? (Tick all that apply)	<input checked="" type="checkbox"/> achilles tendon insertion <input checked="" type="checkbox"/> plantar fascia insertion <input checked="" type="checkbox"/> patellar tendon insertion <input checked="" type="checkbox"/> quadriceps insertion <input checked="" type="checkbox"/> supraspinatus insertion <input checked="" type="checkbox"/> medial epicondyle <input checked="" type="checkbox"/> lateral epicondyle <input checked="" type="checkbox"/> greater tochanter
--	---

Please indicate which specific indices that are used, if applicable	SPARCC
---	--------

Physician Global

Please write the wording of the question regarding physician global	Physician evaluation of disease activity (translate into english if possible)
---	---

BASMI

Are the individual BASMI components registered?	<input checked="" type="checkbox"/> yes
---	---

Do you register the individual BASMI measurements (cm, degrees)?	<input checked="" type="checkbox"/> yes
--	---

Which BASMI scale is used?	<input checked="" type="checkbox"/> 3-point
----------------------------	---

Coxitis

Do you assess coxitis? If yes, please indicate how it is assessed	No - only pain in the hip joint is registered
---	---

General comment	Epecially enthesitis scores is not always registered - it depends on the physician. BASMI is measured at selected visits.
-----------------	---

Response was added on 2021-11-09 08:52:42.

Psoriatic arthritis

Which disease status characteristics can be registered in PsA patients?
(Tick all that apply)

- swollen joint count
- tender joint count
- enthesitis
- physician Global
- BASMI

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician Global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASMI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 28
- 66

Do you register specific location of swollen joints?
(Tick all that apply)

- yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 28
- 68

Do you register specific location of tender joints?
(Tick all that apply)

- yes

Entesitis

Do you register specific location of entesitis?
(Tick all that apply)

- yes

Which locations are registered? (Tick all that apply)	<input checked="" type="checkbox"/> achilles tendon insertion <input checked="" type="checkbox"/> plantar fascia insertion <input checked="" type="checkbox"/> patellar tendon insertion <input checked="" type="checkbox"/> quadriceps insertion <input checked="" type="checkbox"/> supraspinatus insertion <input checked="" type="checkbox"/> medial epicondyle <input checked="" type="checkbox"/> lateral epicondyle <input checked="" type="checkbox"/> greater tochanter
--	---

Please indicate which specific indices that are used, if applicable	SPARCC
---	--------

Physician global

Please write the wording of the question regarding physician global	Physician evaluation of disease activity (Translate into english if possible)
---	--

BASMI

Are the individual BASMI components registered?	<input checked="" type="checkbox"/> yes
---	---

Do you register the individual BASMI measurements (cm, degrees)?	<input checked="" type="checkbox"/> yes
--	---

Which BASMI scale is used?	<input checked="" type="checkbox"/> 3-point
----------------------------	---

Coxitis

Do you assess coxitis? If yes, please indicate how it is assessed	No - only tender/not tender hip joint is registered.
---	--

General comment	BASMI is normally only registered for patient with axial involvement. In many cases only 28 joints are registered - depending on the physioician
-----------------	---

Response was added on 2021-11-23 13:13:12.

Medication

Which therapies are registered in your registry?
(Tick all that apply)

- biological dmards (bDMARDs), including targeted synthetic dmards (JAK)
- conventional synthetic dmards (csDMARDs)
- glucocorticoids
- NSAIDs

bDMARDs

Which year did bDMARD registration begin? 2009

Is it mandatory to register bDMARD therapy? yes

csDMARDs

Which year did csDMARD registration begin? 2009

Is it mandatory to register csDMARD therapy? yes

Glucocorticoids

Which year did glucocorticoid registration begin? 2009

Is it mandatory to register glucocorticoid therapy? no

Is the mode of administration registered?
(Tick all that apply)

- oral
- intramuscular
- intraarticular

Are specific locations of injected joints registered? yes

NSAIDs

Which year did NSAID registration begin? 2012

Is it mandatory to register NSAID therapy? yes

What information regarding ONGOING medications is registered?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	frequency	administration mode
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
NSAIDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Time points for registration (ONGOING medications)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
bDMARDs	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
NSAIDs	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

What information regarding PAST medications is registered at inclusion in registry?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	name of drug
bDMARDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
glucocorticoids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
NSAIDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Discontinuation reasons

What are the possible reasons for discontinuation of a bDMARD?
(Tick all that apply)

- lack of efficacy
- adverse events
- remission
- pregnancy wish
- infection
- surgery
- cancer
- lost to follow-up
- death
- other

Please specify

project participation and no information given

Is it possible to register multiple reasons for discontinuation?

yes

How is it decided which is the primary reason for discontinuation?

That is it not possible to register

Does your registry link to prescription database or other external data sources on prescriptions on a regular basis as input to registry?
(Tick all that apply)

no

General comments

I general NSAIDs is registered for axSpA and axPsA. csDMARDs and prednisolone might not always be registered.

Response was added on 2021-11-23 13:44:37.

Patient reported outcomes

Which patient reported outcomes (PROs) are registered in axSpA and/or PsA patients?
(Tick all that apply)

- BASDAI
- BASFI
- pain
- fatigue
- global disease
- HAQ
- EQ-5D
- patient acceptable symptom state (PASS)
- external anchor question

Are any of the PROs registered in either axSpA or PsA only?

- no, all PROs are registered in both diagnoses

Mode of registration

What are the options for registration of PROs?
(Tick all that apply)

- paper forms
- on screen in waiting room
- through website/app

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
BASDAI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASFI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Global disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
HAQ	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
EQ-5D	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
PASS	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Anchor	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Please specify (EQ-5D)

annually

BASDAI

Are the individual BASDAI components registered? yes

BASFI

Are the individual BASFI components registered? yes

Pain, fatigue and global assessments

Please write the wording of the question relating to pain

Hvor mange gigtsmerter har du for tiden/ How much pain due to arthritis do you have at the moment (please translate into english if possible)

Please write the wording of the question relating to fatigue

Hvor træt er du for tiden/ how tired are you at the moment (please translate into english if possible)

Please write the wording of the question relating to global assessment of disease

Hvor meget påvirker gigten som helhed Deres tilværelse for tiden/How does the arthrits affect your overall life at the moment (please translate into english if possible)

HAQ

Are the individual HAQ items registered? yes

Which HAQ versions may be used in your registry? (Tick all that apply)

MD-HAQ

EQ-5D

Are the individual EQ-5D items registered? yes

Which EQ-5D version is used?

5L

Patient acceptable symptom state (PASS)

Please write the wording of the question relating to PASS

Tænk på alle de måder, som din gigt har påvirket dig de seneste 48 timer. Hvis du i de kommende måneder fortsatte med at have det, som du har haft det de seneste 48 timer, ville det så være acceptabelt for dig? (please translate into english if possible)

External anchor question

Please write the wording of the external anchor question

Since your last visit, has your arthritis become (please translate into english if possible)

How many response categories are used?

7

General comments

IT is intended to get all patient to answer the questions regarding PROs. however, some patients forget to do it before the visit, promise to do it afterwards - but forget about it

Response was added on 2021-11-09 09:13:19.

LaboratoryWhich laboratory test can be registered?
(Tick all that apply)

- CRP
- Hba1c
- cholesterol
- HLA-B27
- IgM-RF
- stored samples available for later analyses (biobank)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
CRP	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Hba1c	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Cholesterol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Stored samples available for later analyses (biobank)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (Hba1c)

at yearly visits

Please specify (cholesterol)

at yearly visits

Please specify (biobank)

typically at project visits

CholesterolWhich specific cholesterol types are registered?
(Tick all that apply)

- total cholesterol
- LDL
- HDL
- triglycerid

BiobankWhich sample types are collected?
(Tick all that apply)

- whole-blood
- serum
- plasma

How are laboratory test results registered?
(Tick all that apply)

- entered by health care staff

Response was added on 2021-11-09 09:20:58.

ImagingWhich imaging modalities can be registered?
(Tick all that apply)

- Magnetic Resonance Imaging (MRI)
- X-ray
- DXA
- Ultrasound (US)

Information on each image

	date of examination	full image report	image file	scoring system	+/- progression	other
What information on each MRI exam is registered?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
What information on each x-ray exam is registered?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
What information on each DXA exam is registered?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
What information on each US exam is registered?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (MRI)

SI-led: 4 graderinger, Columna: +/- inflammation.

Please specify (x-ray)

SI-led: +/- NY kriterier opfyldt, columna: +/-inflammation, hænder/fødder: erosion/ikke erosion

Please specify (US)

68 joints, b-mode 0-3 and doppler 0-3

MRIWhich anatomical regions can be registered?
(Tick all that apply)

- spine MRI
- sacroiliac joint MRI

X-rayWhich anatomical regions can be registered?
(Tick all that apply)

- spine radiographs
- sacroiliac joint radiographs
- hands and feet

DEXA

Which anatomical regions can be registered?
(Tick all that apply)

- lumbar spine
 femoral neck

Ultrasound

Please indicate which anatomical regions that can be registered

jaw, AC- and SC- shoulder, elbow, wrist, MCP, PIP, DIP hip, knee, foot, MTP and PIP

Frequency of image registration

Please comment on the frequency of registration of the various image modalities, eg. at specified time points, as needed, in connection with research projects or other.

MR at diagnosis, as needed and related to projects
X-ray SI-joints and spine at diagnosis, as needed and related to projects
X-ray hands and feet as needed

General comments

It is mandatory to registerer data of examination, precises results are not required

Response was added on 2021-11-23 13:16:23.

Comorbidities

Which extraarticular manifestations and comorbid conditions are registered?
(Tick all that apply)

- uveitis
- psoriasis
- inflammatory bowel disease (IBD)
- ischemic heart disease (IHD)
- cerebrovascular disease (CVD)
- hypertension
- diabetes (DM)
- dyslipidemia
- osteoporosis
- chronic liver disease, eg. hepatitis, cirrhosis
- depression
- tuberculosis (TB)
- other

Please specify

bronchitis, asthma, metabolic disease, gastric ulcer, DS, depression

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
uveitis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IBD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IHD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
CVD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
hypertension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
DM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
dyslipidemia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
osteoporosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
chronic liver disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
TB	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (IHD)

at annual status, given by the patient

Please specify (CVD)

at annual status, given by the patient

Please specify (hypertension)

at annual status, given by the patient

Please specify (DM)

at annual status, given by the patient

Please specify (dyslipidemia)	at annual status, given by the patient
Please specify (osteoporosis)	at annual status, given by the patient. DEXA scans are entered manually including BMD
Please specify (chronic liver disease)	at annual status, given by the patient
Please specify (depression)	EQ-5D
Please specify (other)	at annual status, given by the patient

Mode of registration - how are comorbid conditions registered?

	patient-reported	by health-staff	linkage from other registry
uveitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CVD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hypertension	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
DM	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
depression	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
TB	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
other	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you use ICD-10 codes for registration? no

General comments It is not mandatory to make annual registrations. Therefore, data are not collected for all patients

Response was added on 2021-11-23 13:17:44.

Lifestyle

Which lifestyle parameters are registered?
(Tick all that apply)

- smoking
 alcohol consumption
 physical activity

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Smoking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Alcohol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Physical activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (smoking)

Annual registration, by the patient

Please specify (alcohol)

Annual registration, by the patient

Please specify (physical activity)

Annual registration, by the patient

Smoking

How is smoking status characterised?
(Tick all that apply)

- current
 former
 never

Do you register a start date?
(Tick all that apply)

- for current smokers
 for former smokers

Do you register a stop date for former smokers?

- yes

How is average number of smoked cigarettes registered?
(Tick all that apply)

- number of daily cigarettes
 other

Please specify

number of pipe stops per day and number of cigars and cerutter per day

Alcohol

How is alcohol consumption quantified?
(Tick all that apply)

- average number of units/week
 other

Please specify

Også muligt at vælge binær variabel: over/under sundhedsstyrelsens anbefaling.

Physical activity

How is physical activity defined?
(Tick all that apply)

- not defined

How is physical activity quantified?
(Tick all that apply)

- sessions per week
 sessions per month

Response was added on 2021-11-09 09:29:28.

Safety

Can you register adverse events in your registry?
(Tick all that apply) yes, directly into registry

Is it mandatory to register adverse events through
your registry? no

Which adverse events are registered in your registry?
(Tick all that apply) non-serious adverse events
 serious adverse events?

Information on adverse events

	date of event	MeddRA	ICD10-code	outcome	other
Non serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Please specify (non serious AE)

In new treatments recently marketed

Participant information

Record ID	11
Name	Gary Macfarlane
Registry	BSRBR-AS
E-mail	epidemiology@abdn.ac.uk
Deltager	<input checked="" type="checkbox"/> ja

Response was added on 2021-11-23 15:12:39.

General registry information

What is the status of your registry? closed

Coverage

Please estimate how many (percentage) of the eligible spondyloarthritis patients in your country, that are registered 0

How did you obtain the coverage estimate above? (Tick all that apply) other

Please specify Our estimate is 0.5% This is based on the paper Hamilton et al (2015)

Which institutions/organisations can include patients in your registry? (Tick all that apply) departments of rheumatology at hospitals departments of rheumatology at university hospitals

Please give an estimate of how many departments of rheumatology at hospitals (not including university hospitals) that include patients in your registry 40

Please give an estimate of how many departments of rheumatology at university hospitals that include patients in your registry 40

When is the data registered? (Tick all that apply) at routine visits

Are all routine visits registered in your registry - or only some? all visits

Ethics

Is approval from a local ethics committee needed for a study on de-identified data (eg. a EuroSpA upload)? (Tick all that apply) no

Do patients need to sign informed consent to be included in your registry? (Tick all that apply) yes

Are any additional local approvals needed for a study on de-identified data (eg. a EuroSpA upload)? (Tick all that apply) yes

Please specify which additional approvals are needed

We are required to seek approval from the British Society for Rheumatology

Funding

How is the registry funded?
(Tick all that apply)

from research grants
 industry

Please estimate the percentage of funds coming from research grants

2
((0-100%))

Please estimate the percentage of funds coming from industry, eg. pharmaceutical company

98
((0-100%))

The percentages add correctly up to a 100%

What is the basis of participation by a clinic/department/office in the registry?
(Tick all that apply)

voluntary

Is the clinic/department/office financially compensated for registration?

other

Please specify

They are indirectly compensated: recruitment to research studies (such as registry) provides research nurse support

Inclusion criteria

What event triggers the inclusion of a patient into the registry?
(Tick all that apply)

new treatment
 other

Please specify

The treatment group are starting biologic therapy for the first time, the comparison group are those biologic naive and not starting such therapy.

Which criteria do you base the inclusion on?
(Tick all that apply)

age
 diagnosis
 treatment

Is a minimum age required for inclusion?

other age limit

Please specify the age limit applied

16 years or above

Which diagnoses are included in your registry?
(Tick all that apply)

ankylosing spondylitis (AS)
 non-radiographic axial spondyloarthritis (nr-axSpA)

Which year did inclusion of AS patients begin?

2012

Which year did inclusion of nr-axSpA patients begin?

2014

Do patients need to be treated with biological DMARDs (including targeted synthetic DMARDs) to be included in the registry?

no

Have the inclusion criteria changed over time?

yes

How and when did inclusion criteria change?

In 2014 patients who met clinical ASAS criteria only became eligible

Response was added on 2021-11-23 15:12:43.

Data management

What are the options for data entry? (Tick all that apply)	<input checked="" type="checkbox"/> paper based <input checked="" type="checkbox"/> electronic
Are the data fields in your registry interactive, such that invalid or unprobable data is flagged when entered (edit checks) (Tick all that apply)	<input checked="" type="checkbox"/> comment
Comment	Some fields (e.g. dates)
Please describe any other data validation procedures that you may use	We did have double data entry for a small proportion of questionnaires
How does your registry retain data management services? (Tick all that apply)	<input checked="" type="checkbox"/> a researcher/administrative personal does data management beside other duties
Which is the background of your data manager(s)? (Tick all that apply)	<input checked="" type="checkbox"/> other
Please specify	Administrator
Which are the most commonly used data analysis software/programming languages in your organization? (Tick all that apply)	<input checked="" type="checkbox"/> R <input checked="" type="checkbox"/> stata
How is the data stored in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> a relational database framework (like SQL) <input checked="" type="checkbox"/> other
Please specify	Stata
Which are the main data formats used for raw data extractions? (Tick all that apply)	<input checked="" type="checkbox"/> other
Other specify	Stata
Where is your data collection platform hosted? (Tick all that apply)	<input checked="" type="checkbox"/> other
Please specify	University
Who maintains your data collection platform? (Tick all that apply)	<input checked="" type="checkbox"/> data manager

How frequently is the database updated with the latest information?
(Tick all that apply)

other

Please specify

Data collection is complete

Is linkage to other databases or registries possible?

yes

Which registries can be linked to?
(Tick all that apply)

mortality registry
 prescription registry
 comorbidity

General comments

Mortality linkage is possible; Prescription and other morbidity registers are only available in Scotland. We are not linked at present and this would be a considerable amount of work and considerable cost.

Response was added on 2021-11-23 15:12:46.

Demography

Please indicate which of the following variables are collected in your registry (Tick all that apply)

- age (year of birth)
 sex
 weight
 height

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Weight	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Height	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Diagnosis

How is a diagnosis registered? (Tick all that apply)

- classification criteria

Do you register (Tick all that apply)

- other

Please specify

Year first seen by a rheumatologist

Do you register (Tick all that apply)

- year of symptom onset

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Day/month/year of diagnosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day/month/year of symptom onset	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Which classification criteria are registered? (Tick all that apply)

- ASAS
 New York

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ASAS	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
New York	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In which patients can you register ASAS?

AxSpA

Do you register individual ASAS classification items?
(Tick all that apply)

yes

Do you register individual New York classification items?
(Tick all that apply)

yes

General comments

Weight and Height are also available when commencing an eligible biologic drug

Response was added on 2021-11-23 15:12:53.

Axial spondyloarthritis

Which disease status characteristics can be registered in axSpA patients?
(Tick all that apply)

- swollen joint count
 tender joint count
 enthesitis
 BASMI

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASMI	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- other

Please specify

40

Do you register specific location of swollen joints?
(Tick all that apply)

- yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 44

Do you register specific location of tender joints?
(Tick all that apply)

- yes

Enthesitis

Do you register specific location of enthesitis?
(Tick all that apply)

- no

Please indicate which specific indices that are used, if applicable

N/A

BASMI

Are the individual BASMI components registered? yes

Do you register the individual BASMI measurements (cm, degrees)? no

Which BASMI scale is used? 11-point

Coxitis

Do you assess coxitis? If yes, please indicate how it is assessed No

Response was added on 2021-11-23 15:13:06.

Medication

Which therapies are registered in your registry?
(Tick all that apply)

- biological dmards (bDMARDs), including targeted synthetic dmards (JAK)
 NSAIDs

bDMARDs

Which year did bDMARD registration begin? 2012

Is it mandatory to register bDMARD therapy? no

NSAIDs

Which year did NSAID registration begin? 2012

Is it mandatory to register NSAID therapy? no

What information regarding ONGOING medications is registered?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	frequency	administration mode
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Time points for registration (ONGOING medications)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	name of drug
NSAIDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Discontinuation reasons

What are the possible reasons for discontinuation of a bDMARD?
(Tick all that apply)

- lack of efficacy
 adverse events
 remission
 pregnancy wish
 death
 other

Please specify

(1) Participant decision, (2) Financial (NHS level)

Is it possible to register multiple reasons for discontinuation?

no

Does your registry link to prescription database or other external data sources on prescriptions on a regular basis as input to registry?
(Tick all that apply)

no

Response was added on 2021-11-23 15:13:09.

Patient reported outcomes

Which patient reported outcomes (PROs) are registered in axSpA and/or PsA patients?
(Tick all that apply)

- BASDAI
- BASFI
- pain
- fatigue
- global disease
- EQ-5D
- other

Please specify

ACR 2011 fibromyalgia criteria

Are any of the PROs registered in either axSpA or PsA only?

yes

Which PROs are registered uniquely in either axSpA or PsA?

All above = axSpA only. (Our PsA data is not yet in EuroSpA.)

Mode of registration

What are the options for registration of PROs?
(Tick all that apply)

paper forms

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
BASDAI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASFI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Global disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
EQ-5D	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

BASDAI

Are the individual BASDAI components registered?

yes

BASFI

Are the individual BASFI components registered? yes

Pain, fatigue and global assessments

Please write the wording of the question relating to pain Various, including pain question in SF12, EQ5D, 100mm VAS (please translate into english if possible)

Please write the wording of the question relating to fatigue Chalder Fatigue Scale (please translate into english if possible)

Please write the wording of the question relating to global assessment of disease BAS-G (please translate into english if possible)

EQ-5D

Are the individual EQ-5D items registered? yes

Which EQ-5D version is used? 5L

Which algorithm is used? Crosswalk values available from: <https://euroqol.org/eq-5d-instruments/eq-5d-5l-about/valuation-standard-value-sets/crosswalk-index-value-calculator/> Based on: van Hout et al. Interim scoring for the EQ-5D-5L: Mapping the EQ-5D-5L to EQ-5D-3L value sets. Value in Health 2012; 15(5): 708-15.

Response was added on 2021-11-23 15:13:12.

Laboratory

Which laboratory test can be registered?
(Tick all that apply)

- ESR
- CRP
- HLA-B27

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ESR	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CRP	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

How are laboratory test results registered?
(Tick all that apply)

- entered by health care staff

General comments

Protocol required CRP or ESR.
For some participants there are both.

Response was added on 2021-11-23 15:13:15.

General comments

We have no images.
We have data at registration re:
~ Bilateral sacroiliitis (Gr2) or unilateral (Gr3)
on x-ray, and/or
~ Active inflammation on MRI suggestive of SpA;
but we have no images as part of the registry.

Response was added on 2021-11-23 15:13:18.

Comorbidities

Which extraarticular manifestations and comorbid conditions are registered?
(Tick all that apply)

- uveitis
- psoriasis
- inflammatory bowel disease (IBD)
- ischemic heart disease (IHD)
- cerebrovascular disease (CVD)
- hypertension
- diabetes (DM)
- osteoporosis
- chronic kidney insufficiency (CKI)
- chronic liver disease, eg. hepatitis, cirrhosis
- solid cancer
- hematological cancer
- depression
- tuberculosis (TB)
- fibromyalgia
- other

Please specify

Hip/Spine surgery

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
uveitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
depression	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
TB	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
fibromyalgia	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
other	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Mode of registration - how are comorbid conditions registered?

	patient-reported	by health-staff	linkage from other registry
uveitis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
depression	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
TB	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
fibromyalgia	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
other	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Do you use ICD-10 codes for registration?

 no

General comments

Comorbidities recorded at registration. If new event during following, may constitute an AE/SAE and addition data collection would take place.

Response was added on 2021-11-23 15:13:22.

Lifestyle

Which lifestyle parameters are registered?
(Tick all that apply)

- smoking
 alcohol consumption
 other

Please specify

Work, including WPAI:SHP

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Smoking	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Alcohol	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Smoking

How is smoking status characterised?
(Tick all that apply)

- current
 former
 never

Do you register a start date?
(Tick all that apply)

- no date is registered

Do you register a stop date for former smokers?

- No

How is average number of smoked cigarettes registered?
(Tick all that apply)

- number of daily cigarettes

Alcohol

How is alcohol consumption quantified?
(Tick all that apply)

- average number of units/week

General comments

Daily cigarettes only recorded in those with "daily or almost daily" tobacco use.
 Alcohol consumption only in those with "weekly, daily or almost daily" alcohol use.
 Data collection is PROM (questionnaire) at registration and at questionnaire follow-up.

Response was added on 2021-11-23 15:13:25.

Safety

Can you register adverse events in your registry?
(Tick all that apply)

yes, directly into registry

Is it mandatory to register adverse events through
your registry?

no

Which adverse events are registered in your registry?
(Tick all that apply)

non-serious adverse events

serious adverse events?

other

Other

Events of special interest (incident comorbidity
(see previous list) and/or pregnancy)

Information on adverse events

	date of event	MeddRA	ICD10-code	outcome	other
Non serious AE	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Serious AE	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Participant information

Record ID	12
Name	Daniela Di Giuseppe
Registry	ARTIS
E-mail	daniela.digiuseppe@ki.se
Deltager	<input checked="" type="checkbox"/> ja

Response was added on 2022-01-24 21:32:14.

General registry information

What is the status of your registry? running and including patients

Coverage

Please estimate how many (percentage) of the eligible spondyloarthritis patients in your country, that are registered 82

Please estimate how many (percentage) of the eligible psoriatic arthritis patients in your country, that are registered 76

How did you obtain the coverage estimate above? (Tick all that apply) by comparison with other national registries of therapy, diagnoses etc.

Which institutions/organisations can include patients in your registry? (Tick all that apply) private rheumatology practices
 departments of rheumatology at hospitals
 departments of rheumatology at university hospitals

Please give an estimate of how many private rheumatology practices that include patients in your registry 10

Please give an estimate of how many departments of rheumatology at hospitals (not including university hospitals) that include patients in your registry 31

Please give an estimate of how many departments of rheumatology at university hospitals that include patients in your registry 7

When is the data registered? (Tick all that apply) at routine visits

Are all routine visits registered in your registry - or only some? only some visits

Ethics

Is approval from a local ethics committee needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply) yes

Do patients need to sign informed consent to be included in your registry?
(Tick all that apply) no

Are any additional local approvals needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply) no

Funding

How is the registry funded?
(Tick all that apply) from public sector, eg. state or other
 industry

Please estimate the percentage of funds coming from public sector, eg. state or other 50
((0-100%))

Please estimate the percentage of funds coming from industry, eg. pharmaceutical company 50
((0-100%))

The percentages add correctly up to a 100%

What is the basis of participation by a clinic/department/office in the registry?
(Tick all that apply) voluntary

Is the clinic/department/office financially compensated for registration? no

Inclusion criteria

What event triggers the inclusion of a patient into the registry?
(Tick all that apply) new diagnosis
 new treatment

Which criteria do you base the inclusion on?
(Tick all that apply) diagnosis
 treatment
 disease activity

Is a minimum age required for inclusion? yes, 18 years or above

Which diagnoses are included in your registry?
(Tick all that apply) ankylosing spondylitis (AS)
 non-radiographic axial spondyloarthritis (nr-axSpA)
 psoriatic arthritis (PsA)
 rheumatoid arthritis
 other

Which year did inclusion of AS patients begin? 1999

Which year did inclusion of nr-axSpA patients begin? 1999

Which year did inclusion of PsA patients begin?	1999
Which other diagnoses are included?	All treated in rheumatology units
Do patients need to be treated with biological DMARDs (including targeted synthetic DMARDs) to be included in the registry?	<input checked="" type="checkbox"/> no
Please specify any disease activity inclusion criteria applied for patients with AS or nr-axSpA, eg. ASDAS, BASDAI, ASAS or other.	none
Please specify any disease activity inclusion criteria applied for patients with PsA, eg. DAS28 ,DAPSA28 or other.	none
Have the inclusion criteria changed over time?	<input checked="" type="checkbox"/> no
General comments	The coverage is only regarding b/tsDMARD patients, and it is based on a preliminary analyses done as part of a research project. The final numbers will probably be higher.

Response was added on 2022-01-24 21:32:19.

Data management

What are the options for data entry? (Tick all that apply)	<input checked="" type="checkbox"/> electronic
Are the data fields in your registry interactive, such that invalid or unprobable data is flagged when entered (edit checks) (Tick all that apply)	<input checked="" type="checkbox"/> yes
Since when (year) has the data fields been interactive?	2003
How does your registry retain data management services? (Tick all that apply)	<input checked="" type="checkbox"/> person employed as data manager
Which is the background of your data manager(s)? (Tick all that apply)	<input checked="" type="checkbox"/> data science/biostatistician/technical
Which are the most commonly used data analysis software/programming languages in your organization? (Tick all that apply)	<input checked="" type="checkbox"/> R <input checked="" type="checkbox"/> SAS <input checked="" type="checkbox"/> stata <input checked="" type="checkbox"/> excel <input checked="" type="checkbox"/> SPSS
How is the data stored in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> a relational database framework (like SQL)
Which are the main data formats used for raw data extractions? (Tick all that apply)	<input checked="" type="checkbox"/> excel <input checked="" type="checkbox"/> SAS-derived format
Where is your data collection platform hosted? (Tick all that apply)	<input checked="" type="checkbox"/> external company
Who maintains your data collection platform? (Tick all that apply)	<input checked="" type="checkbox"/> external company
How frequently is the database updated with the latest information? (Tick all that apply)	<input checked="" type="checkbox"/> real-time
Is linkage to other databases or registries possible?	<input type="checkbox"/> yes
Which registries can be linked to? (Tick all that apply)	<input checked="" type="checkbox"/> mortality registry <input checked="" type="checkbox"/> prescription registry <input checked="" type="checkbox"/> comorbidity

General comments

The linkage is possible, but only for researchers that have ethical permission. We at the register do not link our data to external registers, with the exception of the mortality register to update information on death date

Response was added on 2022-01-24 21:32:23.

Demography

Please indicate which of the following variables are collected in your registry (Tick all that apply)

- age (year of birth)
 sex
 weight
 height
 death

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Weight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Height	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (weight) rarely registered

Please specify (height) rarely registered

How is vital status registered (Tick all that apply) through regular linkage to national register

Diagnosis

How is a diagnosis registered? (Tick all that apply) through ICD-10 codes
 classification criteria

Do you register (Tick all that apply) date for diagnosis

Do you register (Tick all that apply) date for symptom onset

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Day/month/year of diagnosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day/month/year of symptom onset	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Which classification criteria are registered? (Tick all that apply) ASAS
 New York
 CASPAR

Time points for registration				
	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ASAS	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
New York	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
CASPAR	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Please specify (ASAS)		complemented or registered later if changed or incomplete		
Please specify (New York)		complemented or registered later if changed or incomplete		
Please specify (CASPAR)		complemented or registered later if changed or incomplete		
In which patients can you register ASAS?		<input checked="" type="checkbox"/> both		
Do you register individual ASAS classification items? (Tick all that apply)		<input checked="" type="checkbox"/> yes		
Do you register individual New York classification items? (Tick all that apply)		<input checked="" type="checkbox"/> yes		
Do you register individual CASPAR classification items? (Tick all that apply)		<input checked="" type="checkbox"/> yes		
General comments		The use of classification criteria is not mandatory		

Response was added on 2022-01-24 21:32:26.

Axial spondyloarthritis

Which disease status characteristics can be registered in axSpA patients?
(Tick all that apply)

- swollen joint count
- tender joint count
- enthesitis
- dactylitis
- physician global
- BASMI
- other

Please specify

Basdai, basfi

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Dactylitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASMI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 28
- 66

Do you register specific location of swollen joints?
(Tick all that apply)

- no, just joint counts

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 28
- 68

Do you register specific location of tender joints?
(Tick all that apply)

- no, just joint counts

Enthesitis

Do you register specific location of enthesitis?
(Tick all that apply) no, only as a total count

Please indicate which specific indices that are used,
if applicable Leeds

Dactylitis

How is dactylitis assessed?
(Tick all that apply) as a count

Physician Global

Please write the wording of the question regarding
physician global

Disease activity: Integers (mm) on a scale between
0 and 100, where 0 means the absence of disease
activity and 100 corresponds to the highest
possible disease activity.
(translate into english if possible)

BASMI

Are the individual BASMI components registered? yes

Do you register the individual BASMI measurements (cm,
degrees)? yes

Which BASMI scale is used? 11-point

Coxitis

Do you assess coxitis? If yes, please indicate how it
is assessed no

Response was added on 2022-01-24 21:32:30.

Psoriatic arthritis

Which disease status characteristics can be registered in PsA patients?
(Tick all that apply)

- swollen joint count
- tender joint count
- enthesitis
- dactylitis
- skin
- nails
- physician Global
- BASMI
- other

Please specify

dapsa, mda. BASMI only for pts with axial disease

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Dactylitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Skin	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Nails	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician Global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASMI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 28
- 66

Do you register specific location of swollen joints?
(Tick all that apply)

- no, just joint counts

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 28
- 68

Do you register specific location of tender joints?
(Tick all that apply)

- no, just joint counts

Entesitis

Do you register specific location of entesitis?
(Tick all that apply) no, only as a total count

Please indicate which specific indices that are used,
if applicable Leeds

Dactylitis

How is dactylitis assessed?
(Tick all that apply) as a count

Skin

Which instruments are used for registering skin
involvement in PsA?
(Tick all that apply) body surface area %

Nails

Which instruments are used for registering nail
involvement in PsA?
(Tick all that apply) other

Other yes/no variable

Physician global

Please write the wording of the question regarding
physician global Disease activity: Integers (mm) on a scale between
0 and 100, where 0 means the absence of disease
activity and 100 corresponds to the highest
possible disease activity.
(Translate into english if possible)

BASMI

Are the individual BASMI components registered? yes

Do you register the individual BASMI measurements (cm,
degrees)? yes

Which BASMI scale is used? 11-point

Coxitis

Do you assess coxitis? If yes, please indicate how it
is assessed no

Response was added on 2022-01-24 21:32:34.

MedicationWhich therapies are registered in your registry?
(Tick all that apply)

- biological dmards (bDMARDs), including targeted synthetic dmards (JAK)
 conventional synthetic dmards (csDMARDs)
 glucocorticoids
 NSAIDs

bDMARDs

Which year did bDMARD registration begin? 1995

Is it mandatory to register bDMARD therapy? no**csDMARDs**

Which year did csDMARD registration begin? 1995

Is it mandatory to register csDMARD therapy? no**Glucocorticoids**

Which year did glucocorticoid registration begin? 1995

Is it mandatory to register glucocorticoid therapy? noIs the mode of administration registered?
(Tick all that apply)

-
- oral

NSAIDs

Which year did NSAID registration begin? 1995

Is it mandatory to register NSAID therapy? no**What information regarding ONGOING medications is registered?**

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	frequency	administration mode
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
NSAIDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Time points for registration (ONGOING medications)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
NSAIDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

What information regarding PAST medications is registered at inclusion in registry?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	name of drug
bDMARDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
glucocorticoids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
NSAIDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Discontinuation reasons

What are the possible reasons for discontinuation of a bDMARD?
(Tick all that apply)

- lack of efficacy
- adverse events
- remission
- pregnancy wish
- surgery
- death
- other

Is it possible to register multiple reasons for discontinuation?

no

Does your registry link to prescription database or other external data sources on prescriptions on a regular basis as input to registry?
(Tick all that apply)

no

General comments

the information on dosage and administration mode are not mandatory, and not always reported

Response was added on 2022-01-24 21:32:38.

Patient reported outcomes

Which patient reported outcomes (PROs) are registered in axSpA and/or PsA patients?
(Tick all that apply)

- BASDAI
- BASFI
- pain
- fatigue
- global disease
- HAQ
- EQ-5D

Are any of the PROs registered in either axSpA or PsA only?

yes

Which PROs are registered uniquely in either axSpA or PsA?

basdai, basfi

Mode of registration

What are the options for registration of PROs?
(Tick all that apply)

- paper forms
- through interview with health-staff
- on screen in waiting room
- through website/app

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
BASDAI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASFI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Global disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
HAQ	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
EQ-5D	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

BASDAI

Are the individual BASDAI components registered?

yes

BASFI

Are the individual BASFI components registered? yes

Pain, fatigue and global assessments

Please write the wording of the question relating to pain

How much pain have you had in the last week due to your rheumatic disease?
(please translate into english if possible)

Please write the wording of the question relating to fatigue

How tired have you been in the last week due to your rheumatic disease?
(please translate into english if possible)

Please write the wording of the question relating to global assessment of disease

How have you felt in the last week, in general, given your rheumatic disease?
(please translate into english if possible)

HAQ

Are the individual HAQ items registered? yes

Which HAQ versions may be used in your registry?
(Tick all that apply)

stanford HAQ DI with adjustment for use of aids and devices

EQ-5D

Are the individual EQ-5D items registered? yes

Which EQ-5D version is used?

We use EQ5D 3L

Which algorithm is used?

The algorithm used is the standard algorithm for UK

Response was added on 2022-01-24 21:32:41.

Laboratory

Which laboratory test can be registered?
(Tick all that apply)

- ESR
- CRP

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ESR	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CRP	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

How are laboratory test results registered?
(Tick all that apply)

- entered by health care staff

Response was added on 2022-01-24 21:32:46.

Comorbidities

Which extraarticular manifestations and comorbid conditions are registered?
(Tick all that apply)

- uveitis
 psoriasis
 inflammatory bowel disease (IBD)

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
uveitis	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Mode of registration - how are comorbid conditions registered?

	patient-reported	by health-staff	linkage from other registry
uveitis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Do you use ICD-10 codes for registration? no

Response was added on 2022-01-24 21:32:49.

Lifestyle

Which lifestyle parameters are registered?
(Tick all that apply)

- smoking
 physical activity

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Smoking	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physical activity	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Smoking

How is smoking status characterised?
(Tick all that apply)

- current
 former
 never

Do you register a start date?
(Tick all that apply)

- no date is registered

Do you register a stop date for former smokers?

- No

How is average number of smoked cigarettes registered?
(Tick all that apply)

- not registered

Physical activity

How is physical activity defined?
(Tick all that apply)

- other definition

Please specify

How much time do you spend a regular week on physical exercise that causes you to become short of breath, such as running, gymnastics or ball sports?

How is physical activity quantified?
(Tick all that apply)

- other

Please specify

Time per week

General comments

We are using the national indicator questions decided by Socialstyrelsen (National Board of Health and Welfare). These include 3 questions; the one above + How much time do you spend a regular week doing everyday exercise, such as walking, cycling or gardening? Add up all the time (at least 10 minutes at a time). + How much do you sit during a normal day if you exclude sleep?. All answers as categorical time intervals

Response was added on 2022-01-24 21:32:52.

Safety

Can you register adverse events in your registry?
(Tick all that apply) yes, directly into registry

Is it mandatory to register adverse events through
your registry? no

Which adverse events are registered in your registry?
(Tick all that apply) non-serious adverse events
 serious adverse events?

Information on adverse events

	date of event	MeddRA	ICD10-code	outcome	other
Non serious AE	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Serious AE	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Participant information

Record ID	13
Name	Jacub Zàvada
Registry	ATTRA
E-mail	zavada@revma.cz
Deltager	<input checked="" type="checkbox"/> ja

Response was added on 2021-12-11 15:59:08.

General registry information

What is the status of your registry? running and including patients

Coverage

Please estimate how many (percentage) of the eligible spondyloarthritis patients in your country, that are registered 95

Please estimate how many (percentage) of the eligible psoriatic arthritis patients in your country, that are registered 95

How did you obtain the coverage estimate above? (Tick all that apply) by prior study of coverage

Which institutions/organisations can include patients in your registry? (Tick all that apply) private rheumatology practices
 departments of rheumatology at hospitals
 departments of rheumatology at university hospitals

Please give an estimate of how many private rheumatology practices that include patients in your registry 45

Please give an estimate of how many departments of rheumatology at hospitals (not including university hospitals) that include patients in your registry 9

Please give an estimate of how many departments of rheumatology at university hospitals that include patients in your registry 6

When is the data registered? (Tick all that apply) at pre-specified registry visits

What is the schedule for pre-specified registry visits? 0, 3, 6 months, then every 6 months. After 3 years, annually

Is it possible to register visits outside of the pre-specified visit schedule, eg. if a patient has a flare? yes

Ethics

Is approval from a local ethics committee needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply) no

Do patients need to sign informed consent to be included in your registry?
(Tick all that apply) yes

Are any additional local approvals needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply) no

Funding

How is the registry funded?
(Tick all that apply) from research grants
 industry

Please estimate the percentage of funds coming from research grants 5
((0-100%))

Please estimate the percentage of funds coming from industry, eg. pharmaceutical company 95
((0-100%))

The percentages add correctly up to a 100%

What is the basis of participation by a clinic/department/office in the registry?
(Tick all that apply) mandatory

Is the clinic/department/office financially compensated for registration? yes

Inclusion criteria

What event triggers the inclusion of a patient into the registry?
(Tick all that apply) new treatment

Which criteria do you base the inclusion on?
(Tick all that apply) diagnosis
 treatment

Is a minimum age required for inclusion? no

Which diagnoses are included in your registry?
(Tick all that apply) ankylosing spondylitis (AS)
 non-radiographic axial spondyloarthritis (nr-axSpA)
 psoriatic arthritis (PsA)
 rheumatoid arthritis
 other

Which year did inclusion of AS patients begin? 2002

Which year did inclusion of nr-axSpA patients begin? 2012

Which year did inclusion of PsA patients begin?	2002
Which other diagnoses are included?	JIA
Do patients need to be treated with biological DMARDs (including targeted synthetic DMARDs) to be included in the registry?	<input checked="" type="checkbox"/> yes
Have the inclusion criteria changed over time?	<input checked="" type="checkbox"/> no

Response was added on 2021-12-11 16:10:34.

Data management

What are the options for data entry? (Tick all that apply)	<input checked="" type="checkbox"/> paper based <input checked="" type="checkbox"/> electronic
Are the data fields in your registry interactive, such that invalid or unprobable data is flagged when entered (edit checks) (Tick all that apply)	<input checked="" type="checkbox"/> no
Please describe any other data validation procedures that you may use	users are being reminded to fill missing core data
How does your registry retain data management services? (Tick all that apply)	<input checked="" type="checkbox"/> person employed as data manager
Which is the background of your data manager(s)? (Tick all that apply)	<input checked="" type="checkbox"/> data science/biostatistician/technical
Which are the most commonly used data analysis software/programming languages in your organization? (Tick all that apply)	<input checked="" type="checkbox"/> excel <input checked="" type="checkbox"/> SPSS
How is the data stored in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> a relational database framework (like SQL)
Which are the main data formats used for raw data extractions? (Tick all that apply)	<input checked="" type="checkbox"/> excel <input checked="" type="checkbox"/> SQL-output <input checked="" type="checkbox"/> custom/composite format
Where is your data collection platform hosted? (Tick all that apply)	<input checked="" type="checkbox"/> other
Please specify	Institute of Biostatistics and Analyses
Who maintains your data collection platform? (Tick all that apply)	<input checked="" type="checkbox"/> data manager
How frequently is the database updated with the latest information? (Tick all that apply)	<input checked="" type="checkbox"/> real-time
Is linkage to other databases or registries possible?	<input type="checkbox"/> no

Response was added on 2021-12-11 16:22:14.

Demography

Please indicate which of the following variables are collected in your registry (Tick all that apply)

- age (year of birth)
 sex
 weight
 height
 death

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Weight	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Height	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How is vital status registered (Tick all that apply)

- by healthstaff, manually

Diagnosis

How is a diagnosis registered? (Tick all that apply)

- other diagnostic categories

Specify which diagnostic categories

physician diagnosis

Do you register (Tick all that apply)

- month of diagnosis
 year of diagnosis

Do you register (Tick all that apply)

- month of symptom onset
 year of symptom onset

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Day/month/year of diagnosis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day/month/year of symptom onset	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Which classification criteria are registered? (Tick all that apply)

- none

General comments

ATTRa collects most but not all items of classification criteria (ASAS/NY). In Psa we ask if pt fulfills some set of criteria (Moll Wright or CASPAR)

Response was added on 2021-12-11 16:29:15.

Axial spondyloarthritis

Which disease status characteristics can be registered in axSpA patients?
(Tick all that apply)

- swollen joint count
- enthesitis
- dactylitis
- physician global

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Dactylitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 44

Do you register specific location of swollen joints?
(Tick all that apply)

- yes

Enthesitis

Do you register specific location of enthesitis?
(Tick all that apply)

- yes

Which locations are registered?
(Tick all that apply)

- achilles tendon insertion
- plantar fascia insertion
- 1st costochondral joint
- 7th costochondral joint
- posterior superior iliac spine
- anterior superior iliac spine
- iliac crests
- 5th lumbar spinous process

Please indicate which specific indices that are used, if applicable

MASES

Dactylitis

How is dactylitis assessed?
(Tick all that apply)

as a count

Physician Global

Please write the wording of the question regarding
physician global

Global activity assessed by physician (VAS 0-100)
(translate into english if possible)

Coxitis

Do you assess coxitis? If yes, please indicate how it
is assessed

No

Response was added on 2021-12-11 16:37:05.

Psoriatic arthritis

Which disease status characteristics can be registered in PsA patients?
(Tick all that apply)

- swollen joint count
- tender joint count
- enthesitis
- dactylitis
- skin
- nails
- physician Global

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Dactylitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Skin	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Nails	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician Global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

66

Do you register specific location of swollen joints?
(Tick all that apply)

yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

68

Do you register specific location of tender joints?
(Tick all that apply)

yes

Entesitis

Do you register specific location of enthesitis?
(Tick all that apply) yes

Which locations are registered?
(Tick all that apply) achilles tendon insertion
 plantar fascia insertion

Dactylitis

How is dactylitis assessed?
(Tick all that apply) as a count

Skin

Which instruments are used for registering skin
involvement in PsA?
(Tick all that apply) other

Other psoriasis severity global assessment (0-5)

Nails

Which instruments are used for registering nail
involvement in PsA?
(Tick all that apply) other

Other semiquantitative (none/mild/moderate/severe)

Physician global

Please write the wording of the question regarding
physician global "physian global activity assesement (VAS 0-100)
(Translate into english if possible)

Coxitis

Do you assess coxitis? If yes, please indicate how it
is assessed via 66/68 joint count

Response was added on 2021-12-11 16:45:47.

Medication

Which therapies are registered in your registry?
(Tick all that apply)

- biological dmards (bDMARDs), including targeted synthetic dmards (JAK)
- conventional synthetic dmards (csDMARDs)
- glucocorticoids
- NSAIDs
- medication for comorbidity

bDMARDs

Which year did bDMARD registration begin? 2002

Is it mandatory to register bDMARD therapy? yes

csDMARDs

Which year did csDMARD registration begin? 2012

Is it mandatory to register csDMARD therapy? yes

Glucocorticoids

Which year did glucocorticoid registration begin? 2012

Is it mandatory to register glucocorticoid therapy? yes

Is the mode of administration registered?
(Tick all that apply) oral

NSAIDs

Which year did NSAID registration begin? 2012

Is it mandatory to register NSAID therapy? no

Medicaton for comorbidities

What types of medical therapy for comorbidities are registered?

selected groups (e.g. medication for hypertnesion, diabetes, depression..) and free string

What information regarding ONGOING medications is registered?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	frequency	administration mode
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Time points for registration (ONGOING medications)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
NSAIDs	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
medication for comorbidity	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

What information regarding PAST medications is registered at inclusion in registry?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	name of drug
bDMARDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
glucocorticoids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
NSAIDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Discontinuation reasons

What are the possible reasons for discontinuation of a bDMARD?
(Tick all that apply)

- lack of efficacy
- adverse events
- remission
- lost to follow-up
- death
- other

Is it possible to register multiple reasons for discontinuation?

no

Does your registry link to prescription database or other external data sources on prescriptions on a regular basis as input to registry?
(Tick all that apply)

no

Response was added on 2021-12-11 16:54:18.

Patient reported outcomes

Which patient reported outcomes (PROs) are registered in axSpA and/or PsA patients?
(Tick all that apply)

- BASDAI
- BASFI
- pain
- fatigue
- global disease
- HAQ
- EQ-5D
- other

Please specify

WPAI, SF36

Are any of the PROs registered in either axSpA or PsA only?

yes

Which PROs are registered uniquely in either axSpA or PsA?

BASDAI and BASFI only for AxSpA

Mode of registration

What are the options for registration of PROs?
(Tick all that apply)

- paper forms
- on screen in waiting room
- through website/app

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
BASDAI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASFI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Global disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
HAQ	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
EQ-5D	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

BASDAI

Are the individual BASDAI components registered? yes

BASFI

Are the individual BASFI components registered? yes

Pain, fatigue and global assessments

Please write the wording of the question relating to pain

How much pain has your illness caused you DURING THE PAST WEEK? Please indicate how unpleasant your pain was:
(please translate into english if possible)

Please write the wording of the question relating to fatigue

How much of a problem has unusual fatigue been for you DURING THE PAST WEEK?
(please translate into english if possible)

Please write the wording of the question relating to global assessment of disease

Please indicate below how you feel when you consider all the ways in which your illness now affects you
(please translate into english if possible)

HAQ

Are the individual HAQ items registered? yes

Which HAQ versions may be used in your registry?
(Tick all that apply)

- stanford HAQ DI with adjustment for use of aids and devices
- M-HAQ
- MD-HAQ

EQ-5D

Are the individual EQ-5D items registered? yes

Which EQ-5D version is used?

3L

Response was added on 2021-12-11 16:55:22.

Laboratory

Which laboratory test can be registered?
(Tick all that apply)

- ESR
- CRP
- HLA-B27
- IgM-RF

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ESR	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CRP	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

How are laboratory test results registered?
(Tick all that apply)

- entered by health care staff

Response was added on 2021-12-11 16:57:23.

Imaging

Which imaging modalities can be registered?
(Tick all that apply)

- Magnetic Resonance Imaging (MRI)
- X-ray

MRI

Which anatomical regions can be registered?
(Tick all that apply)

- sacroiliac joint MRI

X-ray

Which anatomical regions can be registered?
(Tick all that apply)

- spine radiographs
- sacroiliac joint radiographs

Frequency of image registration

Please comment on the frequency of registration of the various image modalities, eg. at specified time points, as needed, in connection with research projects or other.

at baseline we ask if MRI or XRAY was performed, and if erosive/osteoproliferative changes have been present

Response was added on 2021-12-11 16:59:15.

Comorbidities

Which extraarticular manifestations and comorbid conditions are registered?
(Tick all that apply)

- uveitis
- psoriasis
- inflammatory bowel disease (IBD)
- ischemic heart disease (IHD)
- cerebrovascular disease (CVD)
- hypertension
- diabetes (DM)
- dyslipidemia
- osteoporosis
- chronic kidney insufficiency (CKI)
- chronic liver disease, eg. hepatitis, cirrhosis
- solid cancer
- hematological cancer
- depression
- tuberculosis (TB)

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
uveitis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IHD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CVD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hypertension	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
DM	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CKI	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
depression	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
TB	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Mode of registration - how are comorbid conditions registered?

	patient-reported	by health-staff	linkage from other registry
uveitis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
depression	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
TB	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Do you use ICD-10 codes for registration?

 no

Response was added on 2021-12-11 17:00:47.

Lifestyle

Which lifestyle parameters are registered?
(Tick all that apply) smoking

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Smoking	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Smoking

How is smoking status characterised?
(Tick all that apply) current
 former
 never

Do you register a start date?
(Tick all that apply) no date is registered

Do you register a stop date for former smokers? No

How is average number of smoked cigarettes registered?
(Tick all that apply) number of daily cigarettes

Response was added on 2021-12-11 17:01:26.

Safety

Can you register adverse events in your registry?
(Tick all that apply) yes, directly into registry

Is it mandatory to register adverse events through
your registry? no

Which adverse events are registered in your registry?
(Tick all that apply) serious adverse events?

	date of event	MeddRA	ICD10-code	outcome	other
Serious AE	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Participant information

Record ID	14
Name	Gerður María Gröndal
Registry	ICEBIO
E-mail	gerdurgr@landspitali.is
Deltager	<input checked="" type="checkbox"/> ja

Response was added on 2021-12-17 16:03:11.

General registry information

What is the status of your registry? running and including patients

Coverage

Please estimate how many (percentage) of the eligible spondyloarthritis patients in your country, that are registered 95

Please estimate how many (percentage) of the eligible psoriatic arthritis patients in your country, that are registered 95

How did you obtain the coverage estimate above? (Tick all that apply) by comparison with other national registries of therapy, diagnoses etc.
 by prior study of coverage
 other

Please specify The number is 95% of those on biologics

Which institutions/organisations can include patients in your registry? (Tick all that apply) private rheumatology practices
 departments of rheumatology at hospitals
 departments of rheumatology at university hospitals

Please give an estimate of how many private rheumatology practices that include patients in your registry 7

Please give an estimate of how many departments of rheumatology at hospitals (not including university hospitals) that include patients in your registry 0

Please give an estimate of how many departments of rheumatology at university hospitals that include patients in your registry 1

When is the data registered? (Tick all that apply) at routine visits

Are all routine visits registered in your registry - or only some? only some visits

Ethics

Is approval from a local ethics committee needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply)

 yes

Do patients need to sign informed consent to be included in your registry?
(Tick all that apply)

 no
 comment

Comment

registry is part of their e-medical chart

Are any additional local approvals needed for a study on de-identified data (eg. a EuroSpA upload)?
(Tick all that apply)

 yes
 comment

Please specify which additional approvals are needed

Data protection authorities, Research committee of the Landspítali

Comment

see above

Funding

How is the registry funded?
(Tick all that apply)

 from public sector, eg. state or other

Please estimate the percentage of funds coming from public sector, eg. state or other

100
((0-100%))

The percentages add correctly up to a 100%

What is the basis of participation by a clinic/department/office in the registry?
(Tick all that apply)

 mandatory

Is the clinic/department/office financially compensated for registration?

 no**Inclusion criteria**

What event triggers the inclusion of a patient into the registry?
(Tick all that apply)

 new treatment
 other

Please specify

when starting biological treatment

Which criteria do you base the inclusion on?
(Tick all that apply)

 diagnosis
 treatment
 disease activity
 other

Is a minimum age required for inclusion?

 yes, 18 years or above

Which diagnoses are included in your registry? (Tick all that apply)	<input checked="" type="checkbox"/> ankylosing spondylitis (AS) <input checked="" type="checkbox"/> non-radiographic axial spondyloarthritis (nr-axSpA) <input checked="" type="checkbox"/> psoriatic arthritis (PsA) <input checked="" type="checkbox"/> rheumatoid arthritis <input checked="" type="checkbox"/> other
Which year did inclusion of AS patients begin?	2008
Which year did inclusion of nr-axSpA patients begin?	unknown
Which year did inclusion of PsA patients begin?	2008
Which other diagnoses are included?	RA, Arthritis uns, reactive arthritis
Do patients need to be treated with biological DMARDs (including targeted synthetic DMARDs) to be included in the registry?	<input checked="" type="radio"/> other
Which other treatment criteria are applied?	most are on biologics but not all
Please specify any disease activity inclusion criteria applied for patients with AS or nr-axSpA, eg. ASDAS, BASDAI, ASAS or other.	mostly for application of biological treatment
Please specify any disease activity inclusion criteria applied for patients with PsA, eg. DAS28, DAPSA28 or other.	DAS28CRP, BASDAI and/or ASDAS
Please specify which additional inclusion criteria	see above, in need of biologics
Have the inclusion criteria changed over time?	<input checked="" type="radio"/> no

Response was added on 2021-12-17 16:05:58.

Data management

What are the options for data entry?
(Tick all that apply)

- paper based
 electronic

Are the data fields in your registry interactive, such that invalid or unprobable data is flagged when entered (edit checks)
(Tick all that apply)

- no

How does your registry retain data management services?
(Tick all that apply)

- external company

Which is the background of your data manager(s)?
(Tick all that apply)

- data science/biostatistician/technical

Which are the most commonly used data analysis software/programming languages in your organization?
(Tick all that apply)

- R

How is the data stored in the registry?
(Tick all that apply)

- a relational database framework (like SQL)

Which are the main data formats used for raw data extractions?
(Tick all that apply)

- excel
 r-derived format

Where is your data collection platform hosted?
(Tick all that apply)

- external company

Who maintains your data collection platform?
(Tick all that apply)

- external company

How frequently is the database updated with the latest information?
(Tick all that apply)

- real-time

Is linkage to other databases or registries possible?

- yes

Which registries can be linked to?
(Tick all that apply)

- mortality registry
 prescription registry
 comorbidity
 electronic medical records

Response was added on 2021-12-17 16:09:02.

Demography

Please indicate which of the following variables are collected in your registry (Tick all that apply)

- age (year of birth)
 sex
 weight
 height

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Weight	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Height	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Diagnosis

How is a diagnosis registered? (Tick all that apply)

- through ICD-10 codes

Do you register (Tick all that apply)

- month of diagnosis
 year of diagnosis

Do you register (Tick all that apply)

- month of symptom onset
 year of symptom onset

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Day/month/year of diagnosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day/month/year of symptom onset	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Which classification criteria are registered? (Tick all that apply)

- ASAS
 New York
 CASPAR
 other

Please specify

diagnosis but not classification criteria is mandatory

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ASAS	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
New York	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CASPAR	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In which patients can you register ASAS? AxSpA

Do you register individual ASAS classification items?
(Tick all that apply) no

Do you register individual New York classification items?
(Tick all that apply) no

Do you register individual CASPAR classification items?
(Tick all that apply) no

Response was added on 2021-12-17 16:12:50.

Axial spondyloarthritis

Which disease status characteristics can be registered in axSpA patients?
(Tick all that apply)

- swollen joint count
- tender joint count
- enthesitis
- dactylitis
- physician global
- BASMI

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Dactylitis	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Physician global	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASMI	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Please specify (enthesitis)

not mandatory

Please specify (dactylitis)

not mandatory

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 28
- 66
- other

Please specify

66/68 is sometimes registered

Do you register specific location of swollen joints?
(Tick all that apply)

- yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 28
- 68

Do you register specific location of tender joints?
(Tick all that apply)

- yes

Enthesitis

Do you register specific location of enthesitis?
(Tick all that apply) other

Please specify not mandatory

Dactylitis

How is dactylitis assessed?
(Tick all that apply) other

Other not mandatory

Physician Global

Please write the wording of the question regarding
physician global VAS scale
(translate into english if possible)

BASMI

Are the individual BASMI components registered? yes

Do you register the individual BASMI measurements (cm,
degrees)? yes

Which BASMI scale is used? 3-point

Response was added on 2021-12-17 16:16:15.

Psoriatic arthritis

Which disease status characteristics can be registered in PsA patients?
(Tick all that apply)

- swollen joint count
- tender joint count
- enthesitis
- dactylitis
- physician Global
- BASMI

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Dactylitis	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Physician Global	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
BASMI	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (enthesitis)

not mandatory

Please specify (dactylitis)

not mandatory

Please specify (BASMI)

not mandatory

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 28
- 66

Do you register specific location of swollen joints?
(Tick all that apply)

- yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 28
- 68

Do you register specific location of tender joints?
(Tick all that apply)

- yes

Entesitis

Do you register specific location of enthesitis?
(Tick all that apply) no

Please indicate which specific indices that are used,
if applicable not mandatory

Dactylitis

How is dactylitis assessed?
(Tick all that apply) other

Other not mandatory (LL)

Physician global

Please write the wording of the question regarding
physician global VAS scale
(Translate into english if possible)

BASMI

Are the individual BASMI components registered? yes

Do you register the individual BASMI measurements (cm,
degrees)? yes

Which BASMI scale is used? 3-point

Coxitis

Do you assess coxitis? If yes, please indicate how it
is assessed no

Response was added on 2021-12-17 16:19:22.

MedicationWhich therapies are registered in your registry?
(Tick all that apply)

- biological dmards (bDMARDs), including targeted synthetic dmards (JAK)
- conventional synthetic dmards (csDMARDs)

bDMARDs

Which year did bDMARD registration begin? 2008

Is it mandatory to register bDMARD therapy? yes**csDMARDs**

Which year did csDMARD registration begin? 2008

Is it mandatory to register csDMARD therapy? no**What information regarding ONGOING medications is registered?**

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	frequency	administration mode
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Time points for registration (ONGOING medications)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (csDMARDs)

not mandatory to register csDMARDs

What information regarding PAST medications is registered at inclusion in registry?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	name of drug
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

csDMARDs

Discontinuation reasons

What are the possible reasons for discontinuation of a bDMARD?
(Tick all that apply)

- lack of efficacy
- adverse events
- remission
- pregnancy wish
- infection
- surgery
- cancer
- lost to follow-up
- death

Is it possible to register multiple reasons for discontinuation?

 yes

How is it decided which is the primary reason for discontinuation?

clinical judgement

Does your registry link to prescription database or other external data sources on prescriptions on a regular basis as input to registry?
(Tick all that apply)

 no

Response was added on 2021-12-17 16:23:01.

Patient reported outcomes

Which patient reported outcomes (PROs) are registered in axSpA and/or PsA patients?
(Tick all that apply)

- BASDAI
 pain
 fatigue
 global disease
 HAQ

Are any of the PROs registered in either axSpA or PsA only?

- no, all PROs are registered in both diagnoses

Mode of registration

What are the options for registration of PROs?
(Tick all that apply)

- paper forms
 on screen in waiting room

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
BASDAI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Global disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
HAQ	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

BASDAI

Are the individual BASDAI components registered?

- yes

Pain, fatigue and global assessments

Please write the wording of the question relating to pain

Put a mark on the line below (see example) to illustrate the pain due to your disease during the last week. No pain 0 _____ 100
 Unbearable pain
 (please translate into english if possible)

Please write the wording of the question relating to fatigue

Put a mark on the line below (see example) to illustrate your fatigue due to your disease during the last week. No fatigue 0 _____ 100
 Unbearable fatigue
 (please translate into english if possible)

Please write the wording of the question relating to global assessment of disease

Put a mark on the line below (see example) to illustrate the effect of disease activity on your health during the last week. No effect on health 0 _____ 100 Unbearable effect on health (please translate into english if possible)

HAQ

Are the individual HAQ items registered?

yes

Which HAQ versions may be used in your registry? (Tick all that apply)

stanford HAQ DI without adjustment for use of aids and devices

Response was added on 2021-12-17 16:23:28.

Laboratory

Which laboratory test can be registered?
(Tick all that apply)

- CRP
- HLA-B27
- IgM-RF

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
CRP	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

How are laboratory test results registered?
(Tick all that apply)

- entered by health care staff

Response was added on 2021-12-17 16:27:46.

Imaging

Which imaging modalities can be registered?
(Tick all that apply)

- Magnetic Resonance Imaging (MRI)
- X-ray
- Ultrasound (US)
- Computer Tomography (CT)

Information on each image

	date of examination	full image report	image file	scoring system	+/- progression	other
What information on each MRI exam is registered?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
What information on each x-ray exam is registered?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
What information on each US exam is registered?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
What information on each CT exam is registered?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (MRI)

not mandatory

Please specify (x-ray)

not mandatory

Please specify (US)

not mandatory

Please specify (CT)

not mandatory

MRI

Which anatomical regions can be registered?
(Tick all that apply)

- spine MRI
- sacroiliac joint MRI
- other

Please specify

not mandatory

X-ray

Which anatomical regions can be registered?
(Tick all that apply)

- spine radiographs
- sacroiliac joint radiographs
- hands and feet
- other

Please specify

not mandatory

Ultrasound

Please indicate which anatomical regions that can be registered

all joints, same as DANBIO

CT

Please indicate which anatomical regions that can be registered?

not done

Frequency of image registration

Please comment on the frequency of registration of the various image modalities, eg. at specified time points, as needed, in connection with research projects or other.

Clinical judgement, not mandatory

Response was added on 2021-12-17 16:28:55.

Comorbidities

Which extraarticular manifestations and comorbid conditions are registered?
(Tick all that apply)

none

Do you use ICD-10 codes for registration?

yes

General comments

Is it possible to make linkage with other registries incl comorbidities

Response was added on 2021-12-17 16:30:28.

Lifestyle

Which lifestyle parameters are registered?
(Tick all that apply)

smoking
 other

Please specify

not mandatory

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Smoking	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Smoking

How is smoking status characterised?
(Tick all that apply)

current
 former
 never

Do you register a start date?
(Tick all that apply)

for current smokers
 for former smokers

Do you register a stop date for former smokers?

yes

How is average number of smoked cigarettes registered?
(Tick all that apply)

number of daily cigarettes

General comments

Smoking is registered as in DANBIO

Response was added on 2021-12-17 16:31:24.

Safety

Can you register adverse events in your registry?
(Tick all that apply) yes, directly into registry
 only by linkage to relevant registries

Is it mandatory to register adverse events through your registry? yes

Which adverse events are registered in your registry?
(Tick all that apply) serious adverse events?

	date of event	MeddRA	ICD10-code	outcome	other
Serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Participant information

Record ID	15
Name	Catalin Codreanu
Registry	RRBR
E-mail	ccodreanu01@gmail.com
Deltager	<input checked="" type="checkbox"/> ja

Response was added on 2021-12-29 10:20:03.

General registry information

What is the status of your registry? running and including patients

Coverage

Please estimate how many (percentage) of the eligible spondyloarthritis patients in your country, that are registered 100

Please estimate how many (percentage) of the eligible psoriatic arthritis patients in your country, that are registered 100

How did you obtain the coverage estimate above? (Tick all that apply) other

Please specify In Romania, inclusion of patients treated with biologics in the Registry is mandatory. We estimate an almost 100% inclusion rate of patients on current biological treatment.

Which institutions/organisations can include patients in your registry? (Tick all that apply) private rheumatology practices
 departments of rheumatology at hospitals
 departments of rheumatology at university hospitals
 other

Please give an estimate of how many private rheumatology practices that include patients in your registry 5-10

Please give an estimate of how many departments of rheumatology at hospitals (not including university hospitals) that include patients in your registry 35

Please give an estimate of how many departments of rheumatology at university hospitals that include patients in your registry 15

Please specify In Romania, patients are included in the Registry by the treating physician, so number of departments is not relevant. We have 372 rheumatologists, 27 rehabilitation specialists and 18 internal medicine specialists including patients in the Registry.

When is the data registered? (Tick all that apply) at pre-specified registry visits

What is the schedule for pre-specified registry visits? usually each 6 months

Is it possible to register visits outside of the pre-specified visit schedule, eg. if a patient has a flare? yes

Ethics

Is approval from a local ethics committee needed for a study on de-identified data (eg. a EuroSpA upload)? (Tick all that apply) yes

Do patients need to sign informed consent to be included in your registry? (Tick all that apply) yes

Are any additional local approvals needed for a study on de-identified data (eg. a EuroSpA upload)? (Tick all that apply) yes

Please specify which additional approvals are needed Scientific Committee of the RRBR

Funding

How is the registry funded? (Tick all that apply) from research grants industry

Please estimate the percentage of funds coming from research grants 50 ((0-100%))

Please estimate the percentage of funds coming from industry, eg. pharmaceutical company 50 ((0-100%))

The percentages add correctly up to a 100%

What is the basis of participation by a clinic/department/office in the registry? (Tick all that apply) mandatory

Is the clinic/department/office financially compensated for registration? no

Inclusion criteria

What event triggers the inclusion of a patient into the registry? (Tick all that apply) new treatment

Which criteria do you base the inclusion on? (Tick all that apply) treatment

Is a minimum age required for inclusion? yes, 18 years or above

Do patients need to be treated with biological DMARDs (including targeted synthetic DMARDs) to be included in the registry?

yes

Have the inclusion criteria changed over time?

no

Response was added on 2021-12-29 10:20:23.

Data management

What are the options for data entry? (Tick all that apply)	<input checked="" type="checkbox"/> paper based <input checked="" type="checkbox"/> electronic
Are the data fields in your registry interactive, such that invalid or unprobable data is flagged when entered (edit checks) (Tick all that apply)	<input checked="" type="checkbox"/> yes
Since when (year) has the data fields been interactive?	2013
How does your registry retain data management services? (Tick all that apply)	<input checked="" type="checkbox"/> external company <input checked="" type="checkbox"/> person employed as data manager <input checked="" type="checkbox"/> a researcher/administrative personal does data management beside other duties
Which is the background of your data manager(s)? (Tick all that apply)	<input checked="" type="checkbox"/> clinical <input checked="" type="checkbox"/> data science/biostatistician/technical
Which are the most commonly used data analysis software/programming languages in your organization? (Tick all that apply)	<input checked="" type="checkbox"/> excel <input checked="" type="checkbox"/> SPSS <input checked="" type="checkbox"/> other
Please specify	Java
How is the data stored in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> a relational database framework (like SQL)
Which are the main data formats used for raw data extractions? (Tick all that apply)	<input checked="" type="checkbox"/> excel <input checked="" type="checkbox"/> SQL-output
Where is your data collection platform hosted? (Tick all that apply)	<input checked="" type="checkbox"/> external company
Who maintains your data collection platform? (Tick all that apply)	<input checked="" type="checkbox"/> external company
How frequently is the database updated with the latest information? (Tick all that apply)	<input checked="" type="checkbox"/> real-time
Is linkage to other databases or registries possible?	<input type="checkbox"/> yes
Which registries can be linked to? (Tick all that apply)	<input checked="" type="checkbox"/> prescription registry <input checked="" type="checkbox"/> electronic medical records

General comments

The registry can be linked to other databases, but the linkage is not active at present moment. Additional developments are needed.

Response was added on 2021-12-29 10:20:37.

Demography

Please indicate which of the following variables are collected in your registry
(Tick all that apply)

- age (year of birth)
 sex
 weight
 height
 death

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Weight	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Height	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How is vital status registered
(Tick all that apply)

- by healthstaff, manually

Diagnosis

How is a diagnosis registered?
(Tick all that apply)

- classification criteria

Do you register
(Tick all that apply)

- month of diagnosis
 year of diagnosis

Do you register
(Tick all that apply)

- month of symptom onset
 year of symptom onset

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Day/month/year of diagnosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day/month/year of symptom onset	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Which classification criteria are registered?
(Tick all that apply)

- ASAS
 New York
 CASPAR

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ASAS	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
New York	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CASPAR	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In which patients can you register ASAS? AxSpA

Do you register individual ASAS classification items?
(Tick all that apply) yes

Do you register individual New York classification items?
(Tick all that apply) yes

Do you register individual CASPAR classification items?
(Tick all that apply) yes

Response was added on 2021-12-29 10:20:49.

Axial spondyloarthritis

Which disease status characteristics can be registered in axSpA patients?
(Tick all that apply)

- swollen joint count
 tender joint count
 enthesitis
 dactylitis
 other

Please specify

BASDAI, ASDAS

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Dactylitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

66

Do you register specific location of swollen joints?
(Tick all that apply)

yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

68

Do you register specific location of tender joints?
(Tick all that apply)

yes

Enthesitis

Do you register specific location of enthesitis?
(Tick all that apply)

- no, only as a total count
 other

Please specify

enthesitis are registered as a total number and it is possible to describe the location (optional)

Dactylitis

How is dactylitis assessed?
(Tick all that apply)

as part of classification criteria

Coxitis

Do you assess coxitis? If yes, please indicate how it is assessed

Clinically, in the tender joint count and by imaging (x-ray/MRI)

Response was added on 2021-12-29 10:21:05.

Psoriatic arthritis

Which disease status characteristics can be registered in PsA patients?
(Tick all that apply)

- swollen joint count
- tender joint count
- enthesitis
- dactylitis
- skin
- physician Global
- other

Please specify

DAPSA

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Enthesitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Dactylitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Skin	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Physician Global	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

66

Do you register specific location of swollen joints?
(Tick all that apply)

yes

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

68

Do you register specific location of tender joints?
(Tick all that apply)

yes

Entesitis

Do you register specific location of enthesitis?
(Tick all that apply) yes

Which locations are registered?
(Tick all that apply) medial femoral condyle
 achilles tendon insertion
 supraspinatus insertion

Please indicate which specific indices that are used,
if applicable Leeds

Dactylitis

How is dactylitis assessed?
(Tick all that apply) as part of classification criteria
 as a count

Skin

Which instruments are used for registering skin
involvement in PsA?
(Tick all that apply) PASI

Physician global

Please write the wording of the question regarding
physician global

Please rate how much the disease is globally
affecting your patient, taking into account all the
aspects of the disease (e.g. psoriasis and
arthritis) over the past week
(Translate into english if possible)

Coxitis

Do you assess coxitis? If yes, please indicate how it
is assessed

Clinically in TJC and imaging (x-ray /MRI)

Response was added on 2021-12-29 10:21:21.

Medication

Which therapies are registered in your registry?
(Tick all that apply)

- biological dmards (bDMARDs), including targeted synthetic dmards (JAK)
- conventional synthetic dmards (csDMARDs)
- glucocorticoids
- NSAIDs
- medication for comorbidity

bDMARDs

Which year did bDMARD registration begin? 2013

Is it mandatory to register bDMARD therapy? yes

csDMARDs

Which year did csDMARD registration begin? 2013

Is it mandatory to register csDMARD therapy? yes

Glucocorticoids

Which year did glucocorticoid registration begin? 2013

Is it mandatory to register glucocorticoid therapy? no

Is the mode of administration registered?
(Tick all that apply) not registered

NSAIDs

Which year did NSAID registration begin? 2013

Is it mandatory to register NSAID therapy? yes

Medicaton for comorbidities

What types of medical therapy for comorbidities are registered? all

What information regarding ONGOING medications is registered?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	frequency	administration mode
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
NSAIDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Time points for registration (ONGOING medications)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
glucocorticoids	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
NSAIDs	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
medication for comorbidity	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

What information regarding PAST medications is registered at inclusion in registry?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	name of drug
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
csDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
NSAIDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Discontinuation reasons

What are the possible reasons for discontinuation of a bDMARD?
(Tick all that apply)

- lack of efficacy
- adverse events
- remission
- pregnancy wish
- infection
- surgery
- cancer
- lost to follow-up
- death

Is it possible to register multiple reasons for discontinuation?

no

Does your registry link to prescription database or other external data sources on prescriptions on a regular basis as input to registry?
(Tick all that apply)

no

General comments

Registration of glucocorticoids is done through categories (treatment since last visit, dosage over/under 7,5 mg daily) not actual doses. Treatment for comorbidity: yes/no but not mandatory. Past NSAIDs: only for AxSpA

Response was added on 2021-12-29 10:21:34.

Patient reported outcomes

Which patient reported outcomes (PROs) are registered in axSpA and/or PsA patients?
(Tick all that apply)

- BASDAI
 pain
 global disease
 HAQ
 EQ-5D

Are any of the PROs registered in either axSpA or PsA only?

yes

Which PROs are registered uniquely in either axSpA or PsA?

axSpA: BASDAI; PsA: pain score

Mode of registration

What are the options for registration of PROs?
(Tick all that apply)

paper forms

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
BASDAI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pain	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Global disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
HAQ	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
EQ-5D	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (HAQ)

optional anytime

Please specify (EQ-5D)

optional anytime

BASDAI

Are the individual BASDAI components registered?

yes

Pain, fatigue and global assessments

Please write the wording of the question relating to pain

Please rate the level of your joint pain related to PsA during the last week
(please translate into english if possible)

Please write the wording of the question relating to global assessment of disease

Please rate how much the disease is globally affecting you, taking into account all the aspects of the disease (e.g. psoriasis and arthritis) over the past week
(please translate into english if possible)

HAQ

Are the individual HAQ items registered?

no

Which HAQ versions may be used in your registry?
(Tick all that apply)

stanford HAQ DI with adjustment for use of aids and devices

EQ-5D

Are the individual EQ-5D items registered?

yes

Which EQ-5D version is used?

EQ-5D-3L

Which algorithm is used?

according to EuroQol

Response was added on 2021-12-29 10:21:42.

Laboratory

Which laboratory test can be registered?
(Tick all that apply)

- ESR
- CRP
- hemoglobin
- ALAT
- creatinine
- Hba1c
- cholesterol
- HLA-B27
- IgM-RF

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ESR	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CRP	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Hemoglobin	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
ALAT	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Creatinine	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Hba1c	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Cholesterol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (Hba1c)

optional anytime, when available

Please specify (cholesterol)

optional anytime, when available

Cholesterol

Which specific cholesterol types are registered?
(Tick all that apply)

- total cholesterol
- LDL
- HDL
- triglycerid

How are laboratory test results registered?
(Tick all that apply)

- entered by health care staff

Response was added on 2021-12-29 10:21:48.

ImagingWhich imaging modalities can be registered?
(Tick all that apply)

- Magnetic Resonance Imaging (MRI)
- X-ray
- DXA
- Ultrasound (US)

Information on each image

	date of examination	full image report	image file	scoring system	+/- progression	other
What information on each MRI exam is registered?	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What information on each x-ray exam is registered?	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What information on each DXA exam is registered?	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What information on each US exam is registered?	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

MRIWhich anatomical regions can be registered?
(Tick all that apply)

- spine MRI
- sacroiliac joint MRI

X-rayWhich anatomical regions can be registered?
(Tick all that apply)

- spine radiographs
- sacroiliac joint radiographs
- hands and feet

Which scoring system?

According to NY criteria for sakroileitis

DEXAWhich anatomical regions can be registered?
(Tick all that apply)

- lumbar spine
- femoral neck

Ultrasound

Please indicate which anatomical regions that can be registered

at enthesitis sites

Frequency of image registration

Please comment on the frequency of registration of the various image modalities, eg. at specified time points, as needed, in connection with research projects or other.

at start of biological treatment and afterwards, as clinically needed

Response was added on 2021-12-29 10:22:00.

Comorbidities

Which extraarticular manifestations and comorbid conditions are registered?
(Tick all that apply)

- uveitis
- psoriasis
- inflammatory bowel disease (IBD)
- ischemic heart disease (IHD)
- cerebrovascular disease (CVD)
- hypertension
- diabetes (DM)
- dyslipidemia
- osteoporosis
- chronic kidney insufficiency (CKI)
- chronic liver disease, eg. hepatitis, cirrhosis
- solid cancer
- hematological cancer
- depression
- tuberculosis (TB)
- fibromyalgia
- other

Please specify

any other

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
uveitis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
depression	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
TB	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

fibromyalgia	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
other	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Mode of registration - how are comorbid conditions registered?

	patient-reported	by health-staff	linkage from other registry
uveitis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
depression	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
TB	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
fibromyalgia	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
other	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Do you use ICD-10 codes for registration?

no

Response was added on 2021-12-29 10:22:09.

Lifestyle

Which lifestyle parameters are registered?
(Tick all that apply) smoking

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Smoking	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Smoking

How is smoking status characterised?
(Tick all that apply) current
 former
 never

Do you register a start date?
(Tick all that apply) no date is registered

Do you register a stop date for former smokers? No

How is average number of smoked cigarettes registered?
(Tick all that apply) number of daily cigarettes

Response was added on 2021-12-29 10:22:14.

Safety

Can you register adverse events in your registry?
(Tick all that apply) yes, directly into registry

Is it mandatory to register adverse events through
your registry? no

Which adverse events are registered in your registry?
(Tick all that apply) non-serious adverse events
 serious adverse events?

Information on adverse events

	date of event	MeddRA	ICD10-code	outcome	other
Non serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Serious AE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Participant information

Record ID	16
Name	Isabel Castrejon
Registry	BIOBADASER
E-mail	isabelcastrejonf@gmail.com
Deltager	<input checked="" type="checkbox"/> ja

Response was added on 2022-02-03 18:13:36.

General registry information

What is the status of your registry?	<input checked="" type="checkbox"/> running and including patients
Which institutions/organisations can include patients in your registry? (Tick all that apply)	<input checked="" type="checkbox"/> departments of rheumatology at university hospitals
Please give an estimate of how many departments of rheumatology at university hospitals that include patients in your registry	28
When is the data registered? (Tick all that apply)	<input checked="" type="checkbox"/> at routine visits
Are all routine visits registered in your registry - or only some?	<input checked="" type="checkbox"/> only some visits

Ethics

Is approval from a local ethics committee needed for a study on de-identified data (eg. a EuroSpA upload)? (Tick all that apply)	<input checked="" type="checkbox"/> yes
Do patients need to sign informed consent to be included in your registry? (Tick all that apply)	<input checked="" type="checkbox"/> yes
Are any additional local approvals needed for a study on de-identified data (eg. a EuroSpA upload)? (Tick all that apply)	<input checked="" type="checkbox"/> no

Funding

How is the registry funded? (Tick all that apply)	<input checked="" type="checkbox"/> from public sector, eg. state or other <input checked="" type="checkbox"/> industry
Please estimate the percentage of funds coming from public sector, eg. state or other	10 ((0-100%))
Please estimate the percentage of funds coming from industry, eg. pharmaceutical company	90 ((0-100%))
The percentages add correctly up to a 100%	
What is the basis of participation by a clinic/department/office in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> voluntary

Is the clinic/department/office financially compensated for registration? yes

Inclusion criteria

What event triggers the inclusion of a patient into the registry?
(Tick all that apply) new treatment

Which criteria do you base the inclusion on?
(Tick all that apply) treatment

Is a minimum age required for inclusion? yes, 18 years or above

Do patients need to be treated with biological DMARDs (including targeted synthetic DMARDs) to be included in the registry? yes

Have the inclusion criteria changed over time? no

General comments The financial compensation is to cover the data entry personnel at each centre.

Response was added on 2022-02-03 18:18:40.

Data management

What are the options for data entry? (Tick all that apply)	<input checked="" type="checkbox"/> electronic
Are the data fields in your registry interactive, such that invalid or unprobable data is flagged when entered (edit checks) (Tick all that apply)	<input checked="" type="checkbox"/> yes
Please describe any other data validation procedures that you may use	regular external monitoring
How does your registry retain data management services? (Tick all that apply)	<input checked="" type="checkbox"/> a researcher/administrative personal does data management beside other duties
Which is the background of your data manager(s)? (Tick all that apply)	<input checked="" type="checkbox"/> data science/biostatistician/technical
Which are the most commonly used data analysis software/programming languages in your organization? (Tick all that apply)	<input checked="" type="checkbox"/> stata
How is the data stored in the registry? (Tick all that apply)	<input checked="" type="checkbox"/> a relational database framework (like SQL)
Which are the main data formats used for raw data extractions? (Tick all that apply)	<input checked="" type="checkbox"/> excel
Where is your data collection platform hosted? (Tick all that apply)	<input checked="" type="checkbox"/> external company
Who maintains your data collection platform? (Tick all that apply)	<input checked="" type="checkbox"/> data manager <input checked="" type="checkbox"/> researcher/epidemiologist <input checked="" type="checkbox"/> other
Other	The Spanish Society of Rheumatology Research Foundation
How frequently is the database updated with the latest information? (Tick all that apply)	<input checked="" type="checkbox"/> real-time
Is linkage to other databases or registries possible?	<input type="checkbox"/> no
General comments	As far as I know we did not linked BIOBADASER to other registries it would be possible

Response was added on 2022-02-03 18:21:06.

Demography

Please indicate which of the following variables are collected in your registry
(Tick all that apply)

- age (year of birth)
- sex
- ethnicity
- weight
- height
- death

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Weight	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Height	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How is vital status registered?
(Tick all that apply)

- by healthstaff, manually

Diagnosis

How is a diagnosis registered?
(Tick all that apply)

- other diagnostic categories

Specify which diagnostic categories

according to clinical diagnosis

Do you register
(Tick all that apply)

- date for diagnosis
- other

Please specify

if exact date is not available an approximation

Do you register
(Tick all that apply)

- date for symptom onset

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Day/month/year of diagnosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day/month/year of symptom onset	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Which classification criteria are registered?
(Tick all that apply)

- none

Response was added on 2022-02-03 18:26:17.

Axial spondyloarthritis

Which disease status characteristics can be registered in axSpA patients?
(Tick all that apply)

- swollen joint count
 tender joint count

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (swollen joint count)

when change of therapy or at least once a year

Please specify (tender joint count)

same

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 28

Do you register specific location of swollen joints?
(Tick all that apply)

- no, just joint counts

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 28

Do you register specific location of tender joints?
(Tick all that apply)

- no, just joint counts

Coxitis

Do you assess coxitis? If yes, please indicate how it is assessed

no

Response was added on 2022-02-03 18:27:43.

Psoriatic arthritis

Which disease status characteristics can be registered in PsA patients?
(Tick all that apply)

- swollen joint count
 tender joint count
 other

Please specify

BASDAI and ASDAS-CRP if axial manifestations

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Swollen joint count	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Tender joint count	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Swollen joints

How many swollen joint counts can be registered?
(Tick all that apply)

- 28

Do you register specific location of swollen joints?
(Tick all that apply)

- no, just joint counts

Tender joints

How many tender joint counts can be registered?
(Tick all that apply)

- 28

Do you register specific location of tender joints?
(Tick all that apply)

- no, just joint counts

Coxitis

Do you assess coxitis? If yes, please indicate how it is assessed

no

Response was added on 2022-02-03 18:39:28.

Medication

Which therapies are registered in your registry?
(Tick all that apply)

- biological dmards (bDMARDs), including targeted synthetic dmards (JAK)
- conventional synthetic dmards (csDMARDs)
- glucocorticoids

bDMARDs

Which year did bDMARD registration begin? 2000

Is it mandatory to register bDMARD therapy? yes

csDMARDs

Which year did csDMARD registration begin? 2000

Is it mandatory to register csDMARD therapy? yes

Glucocorticoids

Which year did glucocorticoid registration begin? 2000

Is it mandatory to register glucocorticoid therapy? yes

Is the mode of administration registered?
(Tick all that apply)

- oral
- intraarticular

Are specific locations of injected joints registered? yes

What information regarding ONGOING medications is registered?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	frequency	administration mode
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Time points for registration (ONGOING medications)

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Please specify (bDMARDs)

one year follow-up

What information regarding PAST medications is registered at inclusion in registry?

	start date	stop date	temporary start and stop dates	discontinuation reasons	dosage	name of drug
bDMARDs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Discontinuation reasons

What are the possible reasons for discontinuation of a bDMARD?
(Tick all that apply)

- lack of efficacy
- adverse events
- remission
- pregnancy wish
- infection
- surgery
- cancer
- lost to follow-up
- death
- other

Please specify

Discontinuation for non-medical reasons

Is it possible to register multiple reasons for discontinuation?

 no

Does your registry link to prescription database or other external data sources on prescriptions on a regular basis as input to registry?
(Tick all that apply)

 no

Response was added on 2022-02-03 19:05:56.

Patient reported outcomes

Which patient reported outcomes (PROs) are registered in axSpA and/or PsA patients?
(Tick all that apply)

- BASDAI
 global disease

Are any of the PROs registered in either axSpA or PsA only?

- no, all PROs are registered in both diagnoses

Mode of registration

What are the options for registration of PROs?
(Tick all that apply)

- paper forms
 other

Please specify

Variable according to each clinic, mostly in paper or during clinical encounter by doctor

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
BASDAI	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Global disease	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

BASDAI

Are the individual BASDAI components registered?

- no, only the composite score

Please write the wording of the question relating to global assessment of disease

no specific wording, depending on each center (please translate into english if possible)

Response was added on 2022-02-03 19:11:36.

Laboratory

Which laboratory test can be registered?
(Tick all that apply)

- ESR
- CRP
- HLA-B27
- IgM-RF

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
ESR	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CRP	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

How are laboratory test results registered?
(Tick all that apply)

- entered by health care staff

Response was added on 2022-02-03 19:18:47.

Frequency of image registration

Please comment on the frequency of registration of the various image modalities, eg. at specified time points, as needed, in connection with research projects or other.

No image registration

Response was added on 2022-02-03 19:21:49.

Comorbidities

Which extraarticular manifestations and comorbid conditions are registered?
(Tick all that apply)

- uveitis
- psoriasis
- inflammatory bowel disease (IBD)
- ischemic heart disease (IHD)
- cerebrovascular disease (CVD)
- hypertension
- diabetes (DM)
- dyslipidemia
- osteoporosis
- chronic kidney insufficiency (CKI)
- chronic liver disease, eg. hepatitis, cirrhosis
- solid cancer
- hematological cancer
- depression
- tuberculosis (TB)
- fibromyalgia

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
uveitis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IBD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IHD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CVD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hypertension	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
DM	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CKI	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
depression	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
TB	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
fibromyalgia	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Mode of registration - how are comorbid conditions registered?

	patient-reported	by health-staff	linkage from other registry
uveitis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
psoriasis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IBD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
IHD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CVD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hypertension	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
DM	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
dyslipidemia	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
osteoporosis	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
CKI	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
chronic liver disease	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
solid cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
hematological cancer	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
depression	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
TB	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
fibromyalgia	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Do you use ICD-10 codes for registration?

 no

General comments

Charlson index with possibility to add additional comorbidities

Response was added on 2022-02-03 19:24:05.

Lifestyle

Which lifestyle parameters are registered?
(Tick all that apply) smoking

Time points for registration

	at inclusion in registry	at start/change of treatment	at follow-up visits	other
Smoking	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Smoking

How is smoking status characterised?
(Tick all that apply) current
 former
 never
 other

Please specify non-specified

Do you register a start date?
(Tick all that apply) for current smokers

Do you register a stop date for former smokers? No

How is average number of smoked cigarettes registered?
(Tick all that apply) not registered

Response was added on 2022-02-03 19:24:45.

Safety

Can you register adverse events in your registry?
(Tick all that apply) yes, directly into registry

Is it mandatory to register adverse events through
your registry? yes

Which adverse events are registered in your registry?
(Tick all that apply) non-serious adverse events
 serious adverse events?

Information on adverse events

	date of event	MeddRA	ICD10-code	outcome	other
Non serious AE	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Serious AE	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>