Supplementary file 2 EQPERA Data collection template

Enrollment and interview logistics (t_1 and t_2)

Respondent ID ID number

Date of birth dd/mm/yyyy

Gender man, woman, X

Respondents' place of residence postal code, location

Responsible recruiter function, name, contact details

Rheumatology center name, location

Type of rheumatology center academic hospital, general hospital, private practice

Treating rheumatologist name
Date of diagnosis dd/mm/yyyy

Symptom duration in months, [date of diagnosis - date of symptom

onset]

Disease duration in months; calculated with date of diagnosis Comorbidity no severe comorbidities present [yes/no]

Date of RA treatment initiation dd/mm/yyyy

Months of treatment experience at t_1 date interview t_1 - date treatment initiation = between

3-6 months

Initial treatment the local treatment protocol for early RA: free text,

no details on dosages

Initial treatment allocated according to clinical yes/no

prognostic factors

Step-down strategy yes/no (as initial treatment strategy)
MTX-only step-up yes/no (as initial treatment strategy)
MTX + early bridging glucocorticoids yes/no (as initial treatment strategy)

o glucocorticoids starting dose <30mg/day yes/no
 o glucocorticoids starting dose ≥30mg/day yes/no

Early combination therapy classical DMARDs yes/no (as initial treatment strategy)

with glucocorticoids

number of DMARDs included number
 glucocorticoids starting dose <30mg/day yes/no
 glucocorticoids starting dose ≥30mg/day yes/no

Early combination therapy classical DMARDs yes/no (as initial treatment strategy)

without glucocorticoids

number of DMARDs included number

Biologicals as a first hit yes/no (as initial treatment strategy)

Responder to initial treatment (at moment of t_1 yes/no

recruitment)

Patient obliged or deciding to discontinue RA yes/no

treatment (at moment of t_1 recruitment; e.g., because of safety reasons, patient's

decision)

Reason to not recruit patient free text or N/A (not applicable)

Date of study invitation dd/mm/yyyy (sharing of invitation letter)

Reason in case not interested in study (if free text

shared)

Invitation for t_1 by phone (if interested) dd/mm/yyyy (first contact between patient and

researchers)

Verbal consent for t₁ after phone call yes/no

Contact details patient address/phone number/email

Patient-preferred contact method by phone or email Date and timing of individual interview t_1 dd/mm/yyyy; hour

Location of individual interview t₁ home or rheumatology practice/clinic

Reminder for t_1 sent dd/mm/yyyy Reason in case interview t_1 was cancelled (if free text

Respondent gave written informed consent *t*₁

Interviewer t₁ name yes/no

Interviewer is involved as participant's health

professional in daily practice

 t_1 respondent gave consent at t_1 to be yes/no

contacted again for second part of study (t2)

Reason in case not interested in t_2 (at t_1)

participation (if shared)

'Feeling uncomfortable to talk in group', 'Fear for seeing other patients', 'Not interested in the story

yes/no

of other patients', 'Other'

date focus group - date treatment start= at least 1 Months of treatment experience at t₂

year (between 12-18 months) after treatment

'Not interested to share own experiences in group',

initiation

dd/mm/yyyy

free text

Invitation letter t2 sent by post dd/mm/yyyy (by researchers) Invitation for t_2 by phone dd/mm/yyyy (by researchers)

Verbal consent for t2 after phone call yes/no If not interested in group interview, interested yes/no

in individual interview instead?

Reason in case not interested in t₂ (if shared)

'Not interested to share own experiences in group',

'Feeling uncomfortable to talk in group', 'Fear for seeing other patients', 'Not interested in the story

of other patients', 'Other'

home or rheumatology practice/clinic

Date and timing of focus group t₂ dd/mm/yyyy; hour

clinical or non-clinical setting Location of focus group t₂

If applicable: Date and timing of individual dd/mm/yyyy; hour

interview to

If applicable: Location of individual interview t2

Reminder for t₂ sent (focus group or individual

interview)

Reason in case focus group (or individual

interview) t2 was cancelled (if shared)

Respondent gave written informed consent t2

ves/no Moderator t2 name Observer(s) t₂ name(s) If applicable: Interviewer t₂ name Are the (interviewers/) moderators/observers yes/no

involved as health professionals in the

participants' daily clinical care

Socio-demographic data: patient-reported t_1

Date of birth dd/mm/yyyy Gender man, woman, X Educational level t1 low, moderate, high

Currently employed t ₁	yes/no
Employment status t ₁	employed, not employed, retired,
	housewife/houseman, student
Marital status t ₁	single, together unmarried, married, widower,
	other
Living status t ₁	alone, with partner and/or kids, with other
	persons

Socio-demographic data: patient-reported t ₂	
Currently employed t ₂	yes/no
Employment status t_2	employed, not employed, retired, housewife/houseman, student
Marital status t ₂	single, together unmarried, married, widower, other
Living status t_2	alone, with partner and/or kids, with other persons
Clinical data: patient-reported data t ₁	
VAS general health t ₁	100-mm visual analogue scale from best (0/100) to worst (100/100)
VAS pain t ₁	100-mm visual analogue scale from best (0/100) to worst (100/100)
VAS fatigue t ₁	100-mm visual analogue scale from best (0/100) to worst (100/100)
Key words in preparation of t_1 interview	Key words describing:
	- the impact of RA on their life
	 which outcomes of their illness and treatment they considered most important
Clinical data: patient-reported data t ₂	
VAS general health t ₂	100-mm visual analogue scale from best (0/100) to worst (100/100)
VAS pain t ₂	100-mm visual analogue scale from best (0/100) to worst (100/100)
VAS fatigue t ₂	100-mm visual analogue scale from best (0/100) to worst (100/100)
Key words in preparation of \emph{t}_2 focus group	Key words describing which outcomes of their

Clinical data: health professional-reported data t_1 and t_2 (to be extracted from database/patient file)

(/interview)

, p,	
Date of diagnosis	dd/mm/yyyy
Symptom duration	in months, [date of diagnosis - date of symptom onset]
Disease duration	in months; calculated with date of diagnosis
Comorbidity	no severe comorbidities present [yes/no]
Start of treatment	dd/mm/yyyy
Months of treatment experience at t_1	date interview t_1 - date treatment start = between 3-6 months
Months of treatment experience at t2	date focus group t_2 - date treatment start = at least 1 year

important

illness and treatment they considered most

Initial treatment the local treatment protocol for early RA, free text,

no details on dosages

Initial treatment allocated according to clinical yes/no

prognostic factors

Step-down strategy yes/no (as initial treatment strategy)
MTX-only step-up yes/no (as initial treatment strategy)
MTX + early bridging glucocorticoids yes/no (as initial treatment strategy)

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Early combination therapy classical DMARDs yes/no (as initial treatment strategy)

with glucocorticoids

o number of DMARDs included number
o glucocorticoids starting dose <30mg/day yes/no
o glucocorticoids starting dose ≥30mg/day yes/no

Early combination therapy classical DMARDs yes/no (as initial treatment strategy)

without glucocorticoids

number of DMARDs included number

Biologicals as a first hit yes/no (as initial treatment strategy)

Treatment failure in the first year yes/no Treatment failure after 1 year yes/no Patient who discontinued treatment (t₁ or t₂; e.g., yes/no

because of safety reasons, patient's decision)

Note. RA: Rheumatoid Arthritis; MTX: Methotrexate; DMARDs: Disease-Modifying Anti-Rheumatic Drugs; VAS: Visual Analog Scale; t_1 : time point 1= 3-6 months after start of the initial treatment for early rheumatoid arthritis; t_2 : time point 2= 12-18 months after start of the initial treatment for early rheumatoid arthritis.