

## Supplemental material 7: Minimal dataset for patient registry for adult CNO

**Generic data elements:** consent, date of birth, sex at birth, current gender, country at birth, country of residence, follow-up status, date of death if applicable, first contact with centre, clinician responsible, date of first clinical manifestations, how diagnosis was reached, date of diagnosis, biobank samples available for research.

Of note: The form is filled out at initial referral, and subsequently during follow-up with either periodic consultation depending on local protocols (minimally every 2 years), or with a major treatment switch or change in clinical picture. The data system should capture differences between the initial form and follow-up forms as representing changes in clinical course and management (e.g. new additional features, treatment switches). The form may be potentially be supplemented with patient reported outcomes (PROs) and patient reported outcome measures (PROMs), which can be filled out by the patient directly. PROMs relevant to CNO include, among others, Brief Pain Inventory Short Form and EQ-5D.

### Data elements for condition specific module for adult CNO

Variable	Response type & options	Comments
Type of imaging performed	Checkbox - Magnetic Resonance Imaging (local) - Magnetic Resonance Imaging (total body) - Computed Tomography (local) - Computed Tomography (total body) - ( <sup>99m</sup> Tc]Tc-HDP SPECT/CT - PET/CT (if checked; specify tracer in free text) - Plain X-ray	Automatically deduces whether total body imaging has been performed
Localization of CNO bone lesions	Checkbox Total-body skeleton image with zoom-in possibility in typical regions such as: - Clavicles (left/right) - Ribs (left/right, including level) - Sternum - Spine (including vertebral level) - Mandible (left/right) - Ilium (left/right) - Other (specify)	Automatically yields total number of bone lesions

Radiologic activity of CNO bone lesions	Severe/moderate/mild/none	Defined by bone marrow oedema or increased radiotracer uptake, will be assessed by central review of images
Skeletal damage (erosions hyperostosis, ankylosis, soft tissue ossification) due to CNO	Yes/no, if yes, checkbox for specification	Exact definitions of erosions, hyperostosis, ankylosis and soft tissue ossification including typical localizations given in field instruction.
Bone biopsy performed	Radio buttons Yes/no	
Additional features (history or current)	Checkbox - Arthritis - Sacro-iliitis - Enthesitis - Dactylitis - Palmoplantar pustulosis - Psoriasis - Hidradenitis suppurativa - Severe acne - Uveitis - Inflammatory bowel disease	
Other auto-inflammatory features (history or current)	Radio buttons Yes/no, if yes, free-text specification	
Smoking habit	Dropdown Past/current/never	
Work participation	Full absence from (paid) work due to CNO/partial absence from (paid) work due to CNO/no absence from (paid) work due to CNO	
Positive family history (1 <sup>st</sup> degree relatives) for autoinflammatory/autoimmune disease	Radio buttons Yes/no	List of autoinflammatory/autoimmune diseases is provided.
Bone pain at CNO lesion site	Radio buttons Yes/no, if yes, specify Numerical Rating Scale (NRS) for pain if available	
Focal inflammatory signs at physical examination	Radio buttons Yes/no	E.g. erythema, warmth, soft tissue swelling

Erythrocyte sedimentation rate	Numeric (mm/h)	
C-reactive protein	Numeric (mg/L)	
Treatment history for CNO or CNO-related symptoms	Checkbox - NSAID/COXIB - csDMARD - Bisphosphonates (IV) - Bisphosphonates (oral) - TNFi - Other biologic DMARD - Glucocorticoids (systemic) - Glucocorticoids (intra-articular) - Opioids - Surgery - Physical therapy - Other (free text)	Include treatment for osteitis AND treatment for additional features, if present.
Current treatment for CNO	Checkbox - NSAID/COXIB - csDMARD - Bisphosphonates - TNFi - Other biologic DMARD - Glucocorticoids (systemic) - Glucocorticoids (intra-articular) - Opioids - Surgery - Physical therapy - Other (free text)  All that all selected prompt a follow-up question for type, administration route, and dose	Include treatment for osteitis AND treatment for additional features, if present.
Indication for current treatment	Checkbox - Bone pain at CNO lesion site - To improve functioning or quality of life - Prevention of complications	Complications may include: vertebral collapse Structural skeletal damage secondary to inflammation may include: erosions, hyperostosis, ankylosis, soft tissue ossification

	- Prevention of structural skeletal damage secondary to inflammation - Additional features (if selected, specify which based on previous entry)	
Adverse effects of current treatment	Free text	