Objectives: We created a proposal for a Gold Standard time to diagnosis for axial SpA and a national implementation plan (4) through consensus development with patients, healthcare professionals and professional bodies.

Methods: A.A scoping literature review identifying where delays occur, from first symptom onset to diagnosis by a rheumatologist, and potential solutions. From this, a summary report / draft plan was produced for consultation

B.A national consultation survey to elicit views on the proposals from clinicians, healthcare professionals, professional societies and patients

C.Structured feedback to written proposals via e-consultation with clinicians and patients

D.A consensus development workshop to finalise the Gold Standard and implementation plan.

Results: The literature review identified four delays:

1. People do not know axial SpA may be a cause of their chronic back pain
2. Primary care practitioners may not recognise features of axial SpA
3. People may be referred to non-rheumatologists who may not recognise axial SpA promptly
4. Rheumatology and radiology teams may not optimally request or interpret investigations.

202 participants responded to the summary report (74% patients, 21% healthcare professionals, 5% professional societies). All supported the principles behind the gold standard time to diagnosis. Qualitative analysis confirmed agreement with the proposed solutions, underscoring the importance of education and visibility for axial SpA within primary care and increased public awareness. Additional proposals were suggested, including a tool in primary care to run audits on IT systems.

40 clinicians contributed to the e-consultation and 55 clinicians, policy makers, social marketing experts, health journalists and patients attended the consensus workshop. Consensus was reached on a gold standard time to diagnosis of one year, and the principles, key components and phasing of the implementation plan. This included: public awareness about axial SpA symptoms; a primary care clinical champions programme; creating a referral pathway from primary care direct to rheumatology; a secondary care service educational programme.

Conclusion: There is consensus from UK axial SpA clinicians, patients and professional societies on the need for a Gold Standard time to diagnosis of axial SpA of one year, so that patients can live happy, healthy and productive lives.

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POS0060-PARE RHEUMATOID ARTHRITIS IN NORWAY: A SURVEY-BASED PATIENT EXPERIENCE

C. P. Fjellstad¹, M. Hägg², M. Kautonen³, R. Mandla⁴. ¹Norsk Revmatikerforbund, PAG, Oslo, Norway; ²Nordic Healthcare Group Oy, Research, Helsinki, Finland; ³Nordic Healthcare Group Oy, Service Design, Helsinki, Finland; ⁴Pfizer, Medical Affairs, Oslo, Norway

Background: The Norwegian Association of Rheumatologists has established a national procedure for management of rheumatoid arthritis (RA) in Norway.¹ The

purpose of the procedure is to support equal and evidence-based diagnosis, care and follow-up of RA patients¹. It serves as guidance to all responsible of RA patient health care. The procedure includes recognized themes in rheumatic care.^{2,3} The impact of the procedure on RA care in Norway is, however, unknown.

Objectives: To understand the patient experience through evaluating how the national procedure for RA is being followed from the patient viewpoint. To identify gaps and areas of improvement to align the national procedure and patient experience.

Methods: Members of patient organization Norwegian Rheumatism Association were invited to answer a survey on demographic and disease-specific variables, perceived health and quality of care. The survey was supported by service design patient interviews (N=14). The invitations for interviews were sent through many initiatives for a representative population.

Results: The observational RA cohort constituted of N=374. The patients were on average satisfied with shared decision-making, care and follow-ups: 71 % felt their illness was under control. Patients in centralized areas were more satisfied with well-being. Diagnosis times have shortened from on average 1.7 to 1.5 year in 10 years. Patients, especially those working, were dissatisfied with rehab support. 30 % of patients felt cooperation of primary and secondary care was not satisfactory and 32 % were worried for future treatment.

Table 1 shows the differences in awareness of comorbidities and regular vaccination need. Where applicable, the table also shows the percentage of patients screened. The results show that patients are aware of risks, but are not being screened for the conditions. Younger patients (< 50 years) with symptoms for less than five years were generally less aware.

Table 1. Awareness of comorbidity and regular vaccination need

	Comorbidities						Regular vaccine need
	Heart disease	Lung disease	Osteoporosis				
	Awareness	Screened	Awareness	Screened	Awareness	Screened	Awareness
Overall (# of patients)	70 % (239/342)	34 % (115/342)	37 % (127/342)	25 % (87/342)	58 % (201/344)	41 % (141/343)	56 % (191/344)
Age							
Under 50 yrs	67 % (42/63)	24 % (15/63)	39 % (24/62)	27 % (17/63)	46 % (29/63)	19 % (12/63)	51 % (32/63)
Over 50 yrs	71 % (197/279)	36 % (100/279)	37 % (103/280)	25 % (70/279)	61 % (172/281)	46 % (129/280)	57 % (159/281)
Disease onset							
Under 5 yrs	56 % (27/48)	19 % (9/48)	29 % (14/48)	20 % (10/49)	51 % (25/49)	21 % (10/48)	59 % (29/49)
Over 5 yrs	72 % (212/294)	36 % (106/294)	38 % (113/294)	26 % (77/293)	59 % (176/295)	44 % (131/295)	55 % (162/295)

The education of patients about regular vaccines (e.g. influenza and pneumonia) could be improved. Only 56 % were aware of the need for these vaccines due to RA. When asked specifically, 73 % of patients had received an influenza vaccine and 48 % pneumonia vaccine.

Conclusion: This survey examines quality of care, shared decision-making, disease awareness and planning and provides a gap analysis of patient experience and national procedure. The results show that national procedure in RA is being followed from the patient viewpoint. Patients are satisfied with care, but information on preventive care (e.g. vaccination and comorbidity awareness and screenings) could be strengthened. This could improve planning of care and the outlook, particularly for young patients.

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