Seronegative arthropathies
Stakeholder scoping workshop

2 May 2014, Manchester

The stakeholder scoping workshop is held in addition to the formal consultation on the scope which is taking place from the 20 May to the 18 June 2014.

The objectives of the scoping workshop were to:

- obtain feedback on the specified population and key clinical issues included in the first draft of the scope
- seek views on the composition of the Guideline Development Group (GDG)
- encourage applications for GDG membership.

The scoping group presented a summary of the guideline development process, the role and importance of patient representatives, the process for GDG recruitment and proposed constituency for this group, and the scope. The GDG Chair then facilitated a structured discussion with the group based around pre-defined questions relating to the draft scope. Comments received have been summarised below. These are not necessarily the views of NICE, nor are they the collective view of everyone at the workshop.

Population

Does ‘seronegative’ need to be in title?

- Term redundant and has a negative perception
- Agreed it should be removed

Is there value in including children in this guideline?

- Agreed focus should be on the adult population
- Considered children to be a small population group
- Including children would complicate the guideline
- Should be a separate guideline as children are not small adults
- Definitely not the same condition, presents differently

- Agreed what was important was to consider patients 16 to 18 years of age to ensure transition to adult services successful and diagnosis and patient information not lost

General

- Suggestion to replace undifferentiated spondyloarthropathy with non-radiographic axial spondylitis

Care pathway

Are there specific patient experiences of care we need to cover – for example delaying diagnosis?

- Patients with Ankylosing spondylitis experience fatigue, mental health issues and find it difficult to access secondary care when condition flares (and primary care not able to give advice)
- Psoriatic arthritis considered a subgroup largely underdiagnosed
- Delayed diagnosis a big issue in this area
- If do not get an initial diagnosis right may end up treating the wrong 'condition'.
- Important to talk to other teams to ensure correct diagnosis made and therefore treatment provided

Should we consider diagnosis and treatment in terms of presenting symptoms (axial or peripheral or mixed) or should we focus on the 5 conditions (ie symptom-based management vs condition-based management)?

- Majority agreed symptom-based approach was the most appropriate
- Acknowledged most evidence would be based on the condition but outcome measures could be axial or peripheral

Should we look at the whole pathway or focus on Primary Care where the majority of diagnosis and management takes place?

- Primary Care not the focus but important to improve education and understanding of condition

- Management in Secondary Care but recognition of symptoms often happens in Primary Care so a quick referral for diagnosis is key
- Historical cohort without a diagnosis and seen rarely in Primary Care that should be ‘re-confirmed’

Newly diagnosed vs established disease – is this like RA where management is different for both?

- Should include both
- Newly diagnosed may be more active and need more support and information.
- Treatment same for all

Are the outcomes listed in the scope appropriate? Does the research evidence reflect what happens in clinical practice?

- Agreed that ‘fatigue’ should be included as a separate outcome. Acknowledged evidence on this only recently been collected
- Stiffness is important but hard to perceive
- Anti-inflammatory response has to include ACR response and BASDAI
- Pain definitely should be a separate outcome
- Global indices should be expanded
- Suggestion that outcome measures should start from a disease activity point of view. Would make the list shorter and more focussed
- Co-morbidities would fit under ‘on-going review’

Are the any equality or equity issues - under-diagnosis by gender, ethnicity?

- Women are underdiagnosed as can have Ankylosing spondylitis without damage showing on X-rays
- Treatment same for both genders same once diagnosis made

Having discussed all of the above what are your key issues to be covered?

- Early recognition and timely diagnosis
- Raised awareness and education

- Importance of multidisciplinary teams and 'joined-up thinking' about treatment across the disease
- Fatigue and flare management.
- Access to treatment
- Treatment of non-radiographic axial spondylitis
- Guidance on what tests should be used
- Sequencing of treatment in Secondary Care
- Clarity on where early imaging comes from, quality of imaging and development of imaging technology

Have we go the GDG composition right?

GDG

- *2 x GP (1 x with specialist interest)*
- *1 x Specialist Physiotherapist (Ankylosing spondylitis)*
- *2 x Adult Rheumatologist (already recruited)*
- *1 x Paediatric Rheumatologist*
- *1 x Psychologist*
- *3 x Lay/Carer Members (including a carer for a child)*

Co-opted experts

- *1 x Specialist Surgeon*
- *1 x Pharmacist*
- *1 x Topic Expert for each of the 5 disease areas (eg a Dermatologist)*

Suggested composition from the group:

GDG

- 2 x GP (1 x with specialist interest)
- 1 x Specialist Physiotherapist (Ankylosing spondylitis)
- 3 x Adult Rheumatologist (1 x with specialist interest in Ankylosing spondylitis)
- 3 x Lay/Carer Members
    - 1 x experience of axial symptoms
    - 1 x experience of peripheral symptoms
    - 1 x carer of a patient with severe disease
- 1 x Specialist Rheumatologist Nurse

Co-opted experts

- 1x Specialist Surgeon
- 2 x Radiologist (with specialist interest in MRI, X-ray, ultra-sound or PET)
- 1 x Adolescent Rheumatologist (specialist in transitioning from services)
- 1 x Lay Member (with experience of transitioning from JIA to adult services)

- 1 x Gastroenterologist
- 1 x Ophthalmologist
- 1 x Dermatologist

- Remove Paediatric Rheumatologist if children are not to be covered
- Pharmacist to be a full time member of the GDG?
- Psychologist to be a co-opted expert?