Ensuring high standards of British Society for Rheumatology clinical guidelines: Reflections from the coalface

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Ensuring high standards of British Society for Rheumatology clinical guidelines: Reflections from the coalface

By Sarah Mackie, Alexander Allen, Elizabeth MacPhie, Ian Giles

Clinical guideline development by the standards audit guidelines working group (SAGWG) is one of the most valued activities of the British Society for Rheumatology (BSR). In this article, based on a <u>webinar</u>, we reflect on our experiences of involvement in guidelines from working group membership to leadership of SAGWG to explain the process and highlight reasons why anyone can and should get involved. This editorial represents the opinion of the authors and not necessarily of NHS, NIHR, or Department of Health.

Why should I get involved in guideline development?

Continual expansion of research publications means that practising evidence-based medicine often requires more than a simple PubMed search. Clinical guidelines are developed following a systematic review process to summarise the best available evidence underpinning our everyday clinical practice. Recommendations are made on how best to optimise patient care based on the quality of this evidence. In this regard BSR guidelines are intended as an aid to clinical judgement and do not provide the answers to every clinical question that ultimately depends on an individual patient's condition, circumstances and wishes alongside the clinical assessment of their multi-disciplinary team.

BSR endorsement of a guideline guarantees that a robust process was followed in its development. BSR guidelines are accredited by National Institute for Health and Care Excellence (NICE) which ensures that the highest standards are followed. As well as creating something of value to the rheumatology community, getting involved in this process provides opportunities for professional development and networking. One way to get involved is to join the SAGWG committee that oversees production of all BSR guidelines. To immerse yourself fully however, in the guideline process then you should join or form a working group.

Forming a guideline working group

The first step in the process is to propose a topic to the BSR that if accepted will then require formation of a working group. The guideline proposal may be triggered by a major new development in clinical practice (e.g. a new imaging technique or licensed drug); or may represent an area of clinical uncertainty where despite a body of evidence, there is a lack of consensus and practical guidance for the clinician.

Composition of working group membership is important to ensure diversity of experience and all group members must be prepared to make a meaningful contribution, as consensus agreement is required within the group. Patient representation is essential, often through initial patient and public engagement work to help formulate questions and then agree final recommendations. It is important to have representation from clinicians and multiple allied health professionals (including nursing, physiotherapy, occupational therapy and others) to ensure all relevant aspects of the topic are covered. Including other specialists is essential to ensure relevance to other disciplines. International representation may be useful for global relevance.

The process itself

The BSR has developed a guidelines protocol as a helpful practical guide to ensure each guideline will conform to the quality standards set by the BSR.(1) The technical part of the guideline development process is based on the GRADE process, which is well-documented online.(2, 3) The BSR now provides support for the systematic literature review component, which will be very beneficial to future guideline groups. The first step however, is to carry out a broad scoping exercise including stakeholder engagement. For rapidly-evolving areas of clinical practice, or where there is variation in practice, this scoping process is crucial to uncover potential pushback from audience members who may face challenges in implementing the recommendations with their currently available resources. Often, a guideline working group will discover that a particular word, phrase or idea is understood differently by people working outside their sub-speciality, and rewording may be needed. The better the initial scoping, the fewer surprises there will be when the draft guideline goes out to peer review and stakeholder consultation. During this final writing phase the guideline may need to go through multiple iterations to ensure it will be as useful as possible to the target audiences.

A challenging but rewarding process

Guideline development is very time-consuming, but the more you put into it, the more you get out of it. For those of us who have been involved in guideline writing, the systematic approach to evidence synthesis and the need to produce a balanced guideline relevant to the whole target audience inevitably results in a deeper understanding of the clinical topic and the current controversies and evidence gaps. The finished product is clear evidence of the attention to detail and perhaps more importantly attention to people that is required. Guideline leads need to ensure that all group members have an equal voice and that everybody is willing to update their beliefs when presented with new information. The process of exploring diverse perspectives within a mutually respectful process can often form the basis for future collaborative work based on the shared understanding that has developed during the guideline process.

A similar process is followed by EULAR-endorsed recommendations (4) and ACR Clinical Practice Guidelines.(5) They all contain multi-specialist, allied healthcare professional and lay input using systematic literature review and GRADE methodology to derive evidence and thus generate recommendations or points to consider. A key difference however is that BSR guidelines have been awarded National Institute for Health and Care Excellence (NICE) accreditation, following an assessment by NICE of the BSR guideline process to confirm that critically evaluated high quality processes are being followed. This NICE accreditation allows health and social care professionals working in the NHS to identify the most trusted sources of guidance and thus improve patient outcomes through providing robust evidence using NICE quality standards.

The importance of dissemination

Ultimately, guidelines have little impact unless people read and act upon them. Traditional academic outputs such as conference presentations and publications are important for ensuring credibility. Guidelines can also be disseminated via the medical press, social media, podcasts and patient organisations. For the GCA guideline, patient representatives from PMRGCAuk and PMR GCA Scotland, one of whom was a guideline co-author, led on co-writing a <u>lay summary</u> to distil the essence of the guideline to patients and general practitioners (GP).(6) Similarly, <u>lay</u> (7) and <u>GP</u> (8) summaries exist for the pregnancy guidelines. Ultimately the true test of a guideline is whether it improves the quality and safety

of clinical care that can be evaluated by means of audit and quality improvement projects at a local, regional or national level.

The pace of research is continuously accelerating. More than ever, we need clinical guidelines to inform our practice. The most valuable asset for involvement in clinical guidelines is real-world experience, either as a patient or as a member of the multidisciplinary rheumatology team. The process offers many opportunities for personal and professional development and it is deeply rewarding to see the finished product read, cited and used.

- 1. British Society for Rheumatology. Creating Clinical Guidelines: Our Protocol v.5.1 Revised on behalf of SAGWG. October 2019.
- 2. GRADE Working Group. The Grading of Recommendations Assessment, Development and Evaluation (GRADE) Working Group website 2011 [updated 10/1/2011. Available from: http://www.gradeworkinggroup.org/.
- 3. Schünemann H BJ, Guyatt G, Oxman A (editors). GRADE handbook for grading quality of evidence and strength of recommendations. Updated October 2013: GRADE Working Group; 2013. Available from: guidelinedevelopment.org/handbook.
- 4. van der Heijde D, Aletaha D, Carmona L, Edwards CJ, Kvien TK, Kouloumas M, et al. 2014 Update of the EULAR standardised operating procedures for EULAR-endorsed recommendations. Annals of the Rheumatic Diseases. 2015;74(1):8.
- 5. American College of Rheumatology. Policy and Procedure Manual for Clinical Practice Guidelines. January 2015: https://www.rheumatology.org/Portals/0/Files/ACR%20Guideline%20Manual Appendicesupdated%202015.pdf.
- 6. Mackie S, Slater K, Neill L. The 2020 British Society for Rheumatology guideline on diagnosis and treatment of giant cell arteritis: highlights for patients PMR-GCA Scotland. 2020. Available from https://pmrgcascotland.com/wp-content/uploads/2020/08/BSR-GCA-guideline-2020-highlights-for-patients-2020-08-20.pdf.
- 7. Flint JD, Giles I. Taking medication for rheumatological diseases whilst pregnant or breastfeeding: Guidance published. Atlas of Science. April 24, 2016. Available from https://atlasofscience.org/taking-medication-for-rheumatological-diseases-whilst-pregnant-or-breastfeeding-guidance-published/#more-12550.
- 8. Giles I. Rheumatic diseases: new guidance aids prescribing of drugs in pregnancy. Guidelines in practice. 10 March, 2016. Available from https://www.guidelinesinpractice.co.uk/musculoskeletal-and-joints-/rheumatic-diseases-new-guidance-aids-prescribing-of-drugs-in-pregnancy/352721.article.