

Consensus best practice recommendations for scleroderma – a UKSSG initiative

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The **UK Scleroderma Study Group (UKSSG)** has worked with patients, doctors, pharmacists and allied healthcare professionals to develop a series of consensus best practice recommendations for management of important clinical manifestations of systemic sclerosis (SSc).

These recommendations have been developed multidisciplinary working groups focusing on major aspects of SSc. Our goal was to develop a set of practical recommendations that incorporate current best practice from the UK scleroderma centres. In this way modern expert approaches to key aspects of SSc can be shared and clinicians dealing with SSc cases can have guidance about investigation and treatment. These recommendations have as their target secondary care centres that are involved in managing SSc but might share care with specialist scleroderma centres such as those that contributed to the recommendations. This will include rheumatologists and organ-based specialists and a key part of each recommendation was involvement of appropriate non rheumatology medical specialists. A list of the members of the consensus best practice groups is included on this web-page. An important aim of this project is to ensure that all UK scleroderma patients receive best practice management and we hope that access to specific therapies will become more equitable. This will have clear direct benefit to patients as it will ensure that good practice is highlighted and poor practices are abandoned. The scope of each topic will include investigation as well as treatment, and so provide a real framework for safe and effective management of SSc. There will also be benefit to the NHS if treatments are as far as possible harmonised across centres and are evidence-based.

These best practice approaches take account of and complement other initiatives in this area, such as the published **EULAR scleroderma treatment recommendations¹** and **BSR Treatment Guidelines** for scleroderma that are being currently under development. The recommendations are down-loadable as pdf documents and generally there are two parts to each – a series of simple schematics and a glossary to explain the schematic in more detail and provide relevant source references for information. It is planned that some of these recommendations will be published as separate manuscripts and citations for these publications will be included as they emerge.

References:

- Kowal-Bielecka O et al. **Ann Rheum Dis.** 2009; 68: 620-8.

Overview of UKSSG recommendations for management of SSc

- **Digital vasculopathy in SSc** - Working group chaired by Ariane Herrick (Manchester, UK)
- **Gastrointestinal tract manifestations** – Working group chaired by Chris Denton (London, UK)
- **Interstitial lung disease** - in conjunction with Royal Brompton Hospital – Bridget Griffiths (Newcastle, UK)
- **Cardiac scleroderma** – Maya Buch (Leeds, UK)
- **Pulmonary hypertension** – to link with current UK PH Centre recommendations Gerry Coghlan (London, UK)

- **Renal complications** – Chris Denton (London, UK)

List of UKSSG members and centres

To be added

Working group members for each recommendation: - to be completed

- **Digital vasculopathy** – Prof Ariane Herrick, Prof Chris Denton, Dr Voon Ong,
- **Gastrointestinal tract** – Dr Charles Murray, Dr Voon Ong, Prof Chris Denton, Prof Ariane Herrick, Dr Simon Lal, ...
- **Interstitial lung disease** – Dr Bridget Griffiths, Dr Voon Ong, Prof Chris Denton, Dr Elizabeth Renzoni, Prof Athol Wells, Dr James Lowden
- **Cardiac scleroderma** – Dr Maya Buch, Dr Gerry Coghlan, Dr Voon Ong
- **Renal complications** – Prof Chris Denton, Dr Bernadette Lynch, Dr Aine Burns, Dr Mark Harber
- **Pulmonary hypertension** – Dr Gerry Coghlan, Dr David Kiely, Dr Benji Schreiber

Add SSc Soc and RSA, pharmacist, specialist nurse,