

The patient journey of SSc-ILD in Europe: an integrated analysis of healthcare professional and patient perspectives

6th Systemic Sclerosis World Congress, July 12-14, 2020

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Speaker disclosures

- Anna-Maria Hoffmann-Vold has received research funding and/or consulting fees or other remuneration from Actelion, Boehringer Ingelheim, Bayer, Roche, MSD and GSK.

Introduction and aims

- SSc is a rare, multiorgan disease; ILD is frequently present^{1,2}
- Little is known about patients perspectives

The aim is to analyse patient journeys, experiences and needs of SSc patients with and without ILD and healthcare professionals from 8 European countries in order to identify unmet needs in the care and management of SSc patients.

Methods

- Qualitative, semi-structured, in-depth, individual interviews^{3,4} were conducted using four sets of around 70 research questions, adjusted to the interviewees profile (specialist, patient, patient organisation, caregiver)
- Focus of the interviews were unmet needs along three phases of the patient pathway:
 - pre-diagnosis (first symptoms, first line consultation, referral)
 - diagnosis (tests, consultations)
 - post-diagnosis (consultations, treatment, quality of life, patient support)

Interviewed health care professionals and patients



Health Care Professionals Perspective

95 European-based HCPs with experience in SSc-ILD care

42 rheumatologists

6 dermatologists

2 cardiologists

7 nurses

23 pulmonologists

6 internists

3 radiologists

1GP

5 paramedics

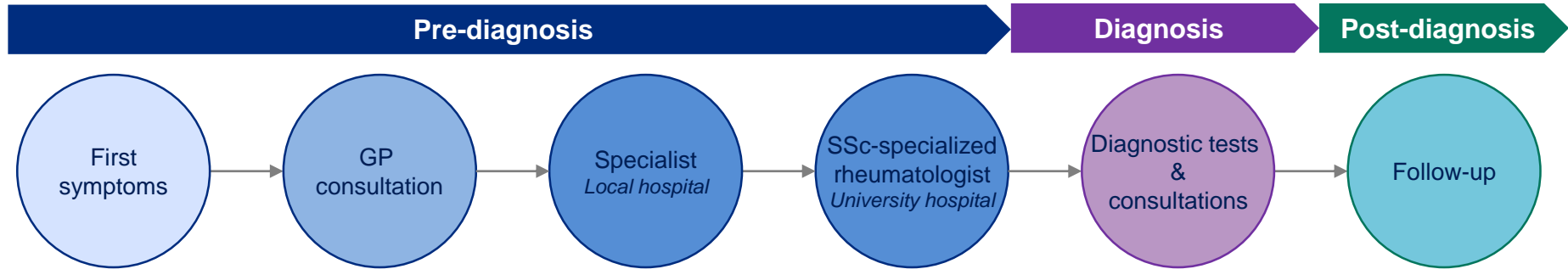


Patient Perspective

42 Patients, 3 patient organisation representatives and 4 caregivers

Participating countries: Belgium, Denmark, Finland, Greece, Netherlands, Norway, Portugal and Sweden

SSc (-ILD) patient pathway




Common unmet needs along the SSc patient pathway - identified by HCPs and patients (in pre-diagnosis phase)

Pre-diagnosis

Diagnosis

Post-diagnosis

- 
- Lack of knowledge of patients regarding first SSc symptoms
 - Insufficient knowledge of GP regarding SSc
 - Low awareness of specialists regarding SSc



- Lack of clear referral structure

Common unmet needs along the SSc patient pathway - identified by HCPs and patients (in diagnosis phase)



- Lack of awareness regarding ILD



- Lack of national care path
- Lack of specialised nurses



- Difficulties to remember information from the diagnosis consultation
- Patients' confusion when receiving the diagnosis

Common unmet needs along the SSc patient pathway - identified by HCPs and patients (in post-diagnosis phase)

Pre-diagnosis

Diagnosis

Post-diagnosis



- Lack of treatment options
- Lack of clear & positive information
- Lack of paramedical care
- Lack of psychological support

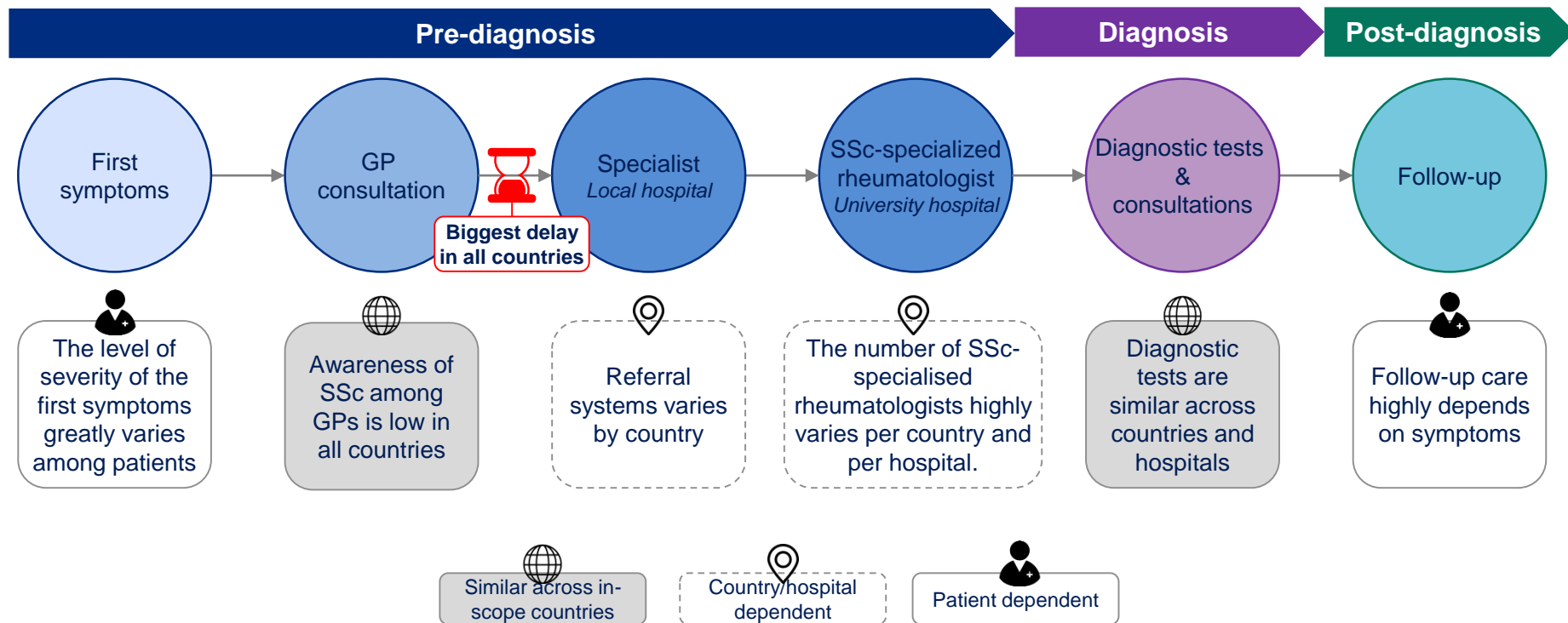


- Lack of multidisciplinary collaboration among specialists



- Difficulties to meet other SSc patients for patients that live in remote areas
- Difficulty to explain the disease others

SSc patient pathway in the 8 included countries



Conclusion

Main unmet needs

- Delayed referral and diagnosis
- Lack of a clear referral structure
- Insufficient support for patients and caregivers



Possible strategies and solutions

- Education of general public, general practitioners, and physicians in community hospitals to ensure earlier recognition of symptoms and timely diagnosis
- Establish national pathways of care for SSc patients providing a clear referral framework
- Provide clear and reliable sources of information to help patients communicate with HCPs, family and friends. Offer patient educational sessions

Acknowledgements and other disclosures

- This qualitative research was conducted by Alcimed and funded by Boehringer Ingelheim International GmbH (BI).
- The authors meet criteria for authorship as recommended by the International Committee of Medical Journal Editors (ICMJE).
- The authors did not receive payment for the development of the presentation.
- Writing and editorial support was provided by Alcimed, which was contracted and funded by Boehringer Ingelheim.
- BI was given the opportunity to review the presentation for medical and scientific accuracy as well as intellectual property considerations.