Acknowledgements: We gratefully acknowledge Prof. Uwe Haberkorn (University Hospital Heidelberg and DKFZ, Heidelberg, Germany) and iTheranostics Inc. (Dulles, VA, USA) for providing the precursor FAPI-04.

Disclosure of Interests: Christina Bergmann: None declared, Jörg H.W. Distler Speakers bureau: Actelion, Anamar, ARXX, Pharma, Boehringer Ingelheim, Celgene, Galapagos, GSK, Inventiva, JB Therapeutics, and UCB, Grant/research support from: Anamar, Active Biotech, Array Biopharma, ARXX, aTyr, BMS, Bayer Pharma, Boehringer Ingelheim, Celgene, Galapagos, GSK, Inventiva, Novartis, Sanofi-Aventis, RedX, UCB, Christoph Treutlein: None declared, Koray Tascilar Speakers bureau: Gilead sciences GmbH, Pfizer Turkey, UCB Turkey, Anna-Theresa Mueller: None declared, Armin Atzinger: None declared, Alexandru-Emil Matei: None declared, Johannes Knitzka: None declared, Andrea-Hermina Györfi: None declared, Anja Lueck: None declared, Clara Dees: None declared, Alina Soare: None declared, Andreas Ramming: None declared, Verena Schönnau: None declared, Oliver Distler Speakers bureau: Arxx Therapeutics, Baecon Discovery, Blade Therapeutics, Bayer, Böhringer Ingelheim, Catenion, Competitive Drug Development International Ltd, Corbuspharma, CSL Behring, ChemomAb, Horizon Pharmaceuticals, Ergonex, Galaapagos NV, Glenmark Pharmaceuticals, GSK, Inventiva, Italfarmaco, IQvia, Kymera, Lilly, Medac, Medscape, MSD, Novartis, Pfizer, Roche, Sanofi, Taget Bio Science, UCB, Grant/research support from: Bayer, Böhringer Ingelheim, Mitsubishi Tanabe Pharma, Olaf Prante: None declared, Philipp Ritt: None declared, Theresa Ida Goetz: None declared, Markus Koehner: None declared, Michael Cordes: None declared, Tobias Baerle: None declared, Torsten Kuwert Speakers bureau: Honoraria for occasional lectures by Siemens Healthineers, Grant/research support from: Research grant to the Clinic of Nuclear Medicine by this entity covering projects in the field of SPECT/CT, Georg Schett: None declared, Christian Schmidkonz: None declared
DOI: 10.1136/annrheumdis-2021-eular.114

OP0273

THE SCLERODERMA CLINICAL TRIALS CONSORTIUM DAMAGE INDEX (SCTC-DI) IN A SYSTEMIC SCLEROSIS COHORT WITH 10-YEARS FOLLOW-UP

M. G. Lazzaroni¹, M. Breda¹, F. Franceschini¹, P. Airò¹. ¹ASST Spedali Civili di Brescia, University of Brescia, Rheumatology and Clinical Immunology Unit, Department of Clinical and Experimental Sciences, Brescia, Italy

Background: Systemic Sclerosis (SSc) is characterized by increased mortality and organ damage accrual. A composite SSc Damage Index was recently developed by the Scleroderma Clinical Trials Consortium (SCTC-DI) and was demonstrated as a predictor of mortality both in the Australian derivation cohort and in the Canadian validation cohort.

Objectives: To evaluate in a single centre cohort of SSc patients with 10-years follow-up: (1) the evolution of organ damage over time; (2) factors associated with the development and accrual of organ damage.

Methods: A retrospective analysis was performed on patients prospectively followed in our centre from 1989 to 2019. Organ damage was evaluated with SCTC-DI (0-55 scale; moderate damage >5, severe damage >12) and comorbidities with Charlson Comorbidity Index (CCI, which includes the age of the patient). Patients were included when a follow-up of at least 10 years was available together with SCTC-DI at the diagnosis (baseline, T0), 1 year (T1), 5 years (T5) and 10 years (T10) after the diagnosis. Univariable and multivariable analysis (logistic regression) were performed when appropriated.

Results: 253 SSc patients were included (female 93%; Caucasians: 99%; median age at diagnosis: 52 years (IQR: 43-60); diffuse cutaneous subset: 15%; anti-centromere (ACA)+ 55%; anti-Topoisomerase 1+20%; anti-RNA polymerase III+: 4%; ever smokers: 28%). Median interval between the first SSc symptom other than Raynaud's phenomenon and the diagnosis was 1 year. SCTC-DI progressively increased from diagnosis to T10 ($p<0.0001$; Kruskal-Wallis test). Moderate damage (score:6-12) was observed in 22 patients at T0 (8.7%), in 30 at T1 (11.9%), in 45 at T5 (17.7%) and in 73 at T10 (28.9%). None of the patients had severe damage (score:13-55) at T0 and T1, while it was present in 6 at T5 (2.4%) and in 13 at T10 (5.1%).

At T0 no difference in SCTC-DI scores was observed when comparing different subgroups according to gender (female vs. male), disease subsets (diffuse vs. limited) and autoantibodies (ACA- vs. ACA+). At T1, SCTC-DI score was higher in patients with diffuse vs. limited cutaneous subset, and ACA- vs. ACA+ ($p<0.0001$ for both).

Multivariable analysis demonstrated that a moderate or severe organ damage (SCTC-DI score >5) at 5 years was positively associated with diffuse cutaneous involvement ($p=0.009$, OR 4.55, 1.46-14.1), SCTC-DI at T0 ($p=0.015$, OR 1.34, 1.06-1.70) and at T1 ($p<0.0001$, OR 1.65, 1.30-2.07), and negatively associated with ACA+ ($p=0.024$, OR 0.32, 0.12-0.86), while CCI and male sex showed no association. At 10 years SCTC-DI>5 was associated with diffuse cutaneous involvement ($p=0.013$, OR 4.30, 1.36-13.7), SCTC-DI at T5 ($p<0.0001$, OR 1.67, 1.38-2.01), while SCTC-DI at T0, CCI, male sex and ACA+ had no association. Among 253 patients, 90 (36%) died after >10 years of follow-up. In non-survivors, as compared to survivors, SCTC-DI score was significantly higher at the baseline (T0) and during the entire follow-up ($p<0.0001$ for every timepoint).

Conclusion: At the end of 10-years follow-up (T10), 35% of patients in our cohort had moderate or severe organ damage (SCTC-DI score>5). Diffuse cutaneous involvement was associated with higher SCTC-DI scores at different time points (T5 and T10). Organ damage, quantified by SCTC-DI at different time points, was confirmed as a factor associated with mortality in patients who reached more than 10 years of follow-up.

REFERENCES:

[1] Ferdowsi N, et al. Ann Rheum Dis. 2019;78:807-16.

Disclosure of Interests: None declared

DOI: 10.1136/annrheumdis-2021-eular.582

PARE Abstract session

OP0274-PARE

EVALUATION OF PATIENT SATISFACTION FOR TELEHEALTH (PHONE AND VIDEO) IN RHEUMATOLOGY OUTPATIENTS DURING COVID-19 PANDEMIC

Y. Oh^{1,2}, A. Hennessey^{1,2}, L. Young^{1,2}, D. Yates^{1,2}, C. Barrett^{1,2}. ¹Redcliffe Hospital, Rheumatology, Redcliffe, Australia; ²The University of Queensland, Medicine, Saint Lucia, Australia

Background: Telehealth via phone (TPhone) or video conference (TVideo) in rheumatology has been a topic of interest for many years. Its use was rapidly expanded due to the international public health emergency of coronavirus disease-19 (COVID-19) outbreak in 2020. Australian Medicare Benefits Schedule (MBS) swiftly enabled temporary MBS telehealth items on 13 March 2020, currently extended until 31 March 2021¹. In the early phase of the COVID-19 pandemic, Antony et al. conducted a single-centre public survey to assess patient perception of rheumatology telehealth. Their results showed that 98.4% of patients consider telehealth acceptable during the pandemic². It is unclear, however, whether this positive perception persists after patients experience a telehealth. In addition, a survey data in 2019 suggested more than half of Australian rheumatologists work in private practice³. Therefore, inclusion of private patients will better represent patient perception of telehealth.

Objectives: The aim of this study was to evaluate patient satisfaction with telehealth during the COVID-19 pandemic. This would determine its feasibility to be integrated in future rheumatology outpatient model.

Methods: A questionnaire containing 30 questions was sent to rheumatology patients who attended telehealth appointments at a level 2 public hospital and a local private clinic between April and May 2020. The questionnaires aimed to obtain information on baseline demographics (sex, age, public or private patient, employment status, visual or auditory impairment), appointment details (TPhone or TVideo, usual arrangement for face-to-face (F2F) appointment, cost effectiveness) and appointment satisfaction using a 5-point Likert scale. Descriptive statistical analysis was conducted.

Results: The questionnaire was sent to 1452 patients, of which 494 patients responded (34%). Female predominance (77.1%) and a higher proportion of TPhone (79.1%) was seen in the respondents. A majority of patients were existing patients known to the services (90.9%). More than 70% of responses indicated overall satisfaction in specialist care via telehealth, and 88.7% perceived this suitable during a pandemic. Of all respondents, 21.7% were prescribed new medication, and the majority of these patients were confident in taking the new medication after the telehealth appointment. Future acceptability for TPhone was significantly lower in private patients compared to public patients ($p=0.01$). Sub-group analysis revealed that higher telehealth satisfaction was associated with needing to take time off work to attend face-to-face appointment ($p=0.02$), perception of cost effectiveness ($p<0.001$) and TVideo ($p=0.03$).

Conclusion: This is the first study which included both public and private rheumatology patients to evaluate patient satisfaction for telehealth during the COVID-19 pandemic. Overall high level of satisfaction was seen in telehealth most notably associated with its cost effectiveness. A higher percentage of patients who had TVideo compared to TPhone were receptive to future telehealth via TVideo, supportive of the importance of visual cues. This in turn will have significant administrative and technological burdens to coordinate in comparison to a F2F or TPhone review. This qualitative study provides valuable insight of patient perception of telehealth, which has the potential to compliment the traditional rheumatology outpatient model of care following the pandemic.

REFERENCES:

[1] COVID-19 Temporary MBS Telehealth Services 2020 [Available from: <http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Factsheet-TempBB>].

[2] Antony A, Connelly K, De Silva T, Eades L, Tillett W, Ayoub S, et al. Perspectives of Patients With Rheumatic Diseases in the Early Phase of COVID-19. Arthritis Care & Research. 2020;72(9):1189-95.

[3] Association AR. Workforce Survey Executive Summary 2019 2019 [Available from: <https://rheumatology.org.au/members/documents/WorkforceSurveyExecutiveSummary-websiteMay2019.pdf>].

Acknowledgements: University of Queensland Nursing staff at Redcliffe Hospital and Administration officers at Redcliffe & Northside Rheumatology

Disclosure of Interests: None declared

DOI: 10.1136/annrheumdis-2021-eular.2885

OP0275-PARE THE UNACCEPTABLE DELAY TO DIAGNOSIS IN AXIAL SPONDYLOARTHRITIS; DEVELOPING A CALL TO ACTION FOR A GLOBAL HEALTHCARE CHALLENGE

W. Gerhart¹, M. T. Duruöz², J. Lowe³, D. Webb⁴, L. Wermeskog⁵, J. Davies⁶, R. Howard⁷, M. Mallinson⁸, C. L. Koehn⁹. ¹Canadian Spondylitis Association, Director, Toronto, Canada; ²Marmara University School of Medicine, PMR Department, Istanbul, Turkey; ³Axialspondyloarthritis International Federation, Projects, London, United Kingdom; ⁴National Axialspondyloarthritis Society, Director, London, United Kingdom; ⁵Spafo Norge Spondyloartrittforbundet, Director, Oslo, Norway; ⁶Axialspondyloarthritis International Federation, Executive, London, United Kingdom; ⁷Spondylitis Association of America, Executive, Los Angeles, United States of America; ⁸Axialspondyloarthritis International Federation, Volunteering, London, United Kingdom; ⁹Arthritis Consumer Experts, Director, Vancouver, Canada

Background: The current delay to diagnosis from symptom onset represents one of the greatest challenges in axial spondyloarthritis (axSpA). Research shows an average global delay of almost 7 years¹ – and as long as 15 years in some cases² – during which time the condition can progress considerably and lead to irreversible damage. Data indicates that women wait longer than men for a diagnosis³, and there has been very limited progress in reducing the time to axSpA diagnosis. The axSpA diagnosis delay has a hugely detrimental impact on an individual's quality of life. Because the disease frequently has early onset¹, individuals are left with untreated or incorrectly-treated symptoms at a formative period in their life course, whilst they await their diagnosis.

Objectives: The Axial Spondyloarthritis International Federation (ASIF) set out to coordinate a comprehensive evidence-based global review of the factors influencing the current axSpA diagnosis delay and to produce a definitive report that shines a light on these barriers, as well as providing a resource that can ultimately empower a range of international stakeholders to reduce this delay.

Methods: A full literature review was carried out to identify relevant available global evidence exploring the axSpA diagnosis delay. In autumn 2020 ASIF held two virtual global forum events, involving patients and patient group representatives, researchers, rheumatologists and other healthcare professionals, to methodically explore key diagnosis challenges across different healthcare systems and the opportunities for addressing these. Break-out discussions were held and participants were asked to identify the personal and societal effects of the diagnostic delay; the reasons it occurs; and initiatives to tackle the challenge. Alongside key stakeholder testimonies, best practices from around the world were also identified. 92 stakeholders participated in the events; they represented patients and healthcare professionals from 23 countries across five continents.

Results: The findings from these activities were incorporated within a new 'Delay to Diagnosis' report, which for the first time definitively sets out the lived realities from a global perspective of the axSpA diagnosis delay. The report identified important commonalities across different countries and healthcare systems contributing to the current average global 7-year diagnosis delay, including:

- Poor awareness of axSpA, particularly in primary care services
- Complexities in diagnosing the disease
- Poorly defined referral pathways
- Insufficient patient access to rheumatologists and appropriate diagnostics

The report also highlights the significant impact this delay has on individuals and wider society, providing a foundation for future advocacy work. A series of recommendations have also been identified, the implementation of which will help to instigate tangible progress in reducing the current delay.

Conclusion: Despite longstanding challenges, there are now clear opportunities for transforming how axSpA is diagnosed around the world. This message needs to be heard and acted upon urgently by all those involved in the management and delivery of axSpA care. The future programme of work for ASIF's Delay to Diagnosis project will respond to these findings and be centred around supporting axSpA patient associations globally to take this call to action forward throughout 2021 and beyond.

REFERENCES:

- [1] Zhao et al; Diagnostic delay in axial spondyloarthritis: a systematic review and meta-analysis; *Rheumatology*, 2021
- [2] Garrido-Cumbrera, M., Poddubnyy, D., Gossec, L. et al. The European Map of Axial Spondyloarthritis: Capturing the Patient Perspective—An Analysis of 2846 Patients Across 13 Countries. *Curr Rheumatol Rep* 21, 19 (2019)
- [3] Jovani et al; Understanding How the Diagnostic Delay of Spondyloarthritis Differs Between Women and Men: A Systematic Review and Metaanalysis; *The Journal of Rheumatology* December 2016

Disclosure of Interests: Wendy Gerhart Employee of: I was employed by Janssen Canada from 1992 - 2017, Mehmet Tuncay Duruöz: None declared, Jo Lowe Grant/research support from: No financial grants received individually. However, my role as Project Manager at ASIF is currently funded partially by UCB Global and partially by Novartis Global, Dale Webb Speakers bureau: Janssen and Novartis, Grant/research support from: Individually, no. But NASS receives grants from AbbVie, Biogen, Eli Lilly, Janssen, Novartis and UCB, Lil-lann Wermeskog Grant/research support from: Individually, no. But Spafo Norge receives a small amount of funding for ongoing projects from Novartis., Jo Davies Grant/research support from: Individually, no. However, ASIF are currently funded by UCB, Lilly, Boehringer Ingelheim, Janssen and Novartis; this funding partially covers staff salaries as well as a range of projects, the content and outputs of which are not influenced by the funders., Richard Howard Shareholder of: AbbVie, Amgen, Bristol-Myers Squibb, GSK, Johnson & Johnson, Eli Lilly, Merck, Novartis, Pfizer, and Teva. I own <20 shares of any one stock and these stocks represent <4% of personal investments, Consultant of: Yes, GSK, Novartis - but then donated to Spondylitis Association of America, Grant/research support from: I have not personally received financial grants. SAA has received financial support from AbbVie, Amgen, BI, J&J, Lilly, Novartis, Pfizer, UCB., Michael Mallinson Consultant of: No. But, for full disclosure: I have received honoraria in the past, for participating in patient advisory board activities, from Abbvie, Novartis, Pfizer and UCB., Cheryl L Koehn Grant/research support from: OUR ORGANIZATION, ARTHRITIS CONSUMER EXPERTS, HAS. I HAVE NOT AS AN INDIVIDUAL. HERE IS OUR PUBLICLY AVAILABLE DISCLOSURE ON ALL ONLINE AND PRINT MATERIALS, PRESENTATIONS, MEETINGS, GOVERNMENT CONSULTATIONS:

<https://jointhealth.org/about-principles.cfm?locale=en-CA>

Over the past 12 months, ACE received grants-in-aid from: Arthritis Research Canada, Amgen Canada, Canadian Institutes of Health Research, Canadian Rheumatology Association, Eli Lilly Canada, Hoffman-La Roche Canada Ltd., Knowledge Translation Canada, Merck Canada, Novartis Canada, Pfizer Canada, Sandoz Canada, Sanofi Canada, St. Paul's Hospital (Vancouver), UCB Canada, and the University of British Columbia.

DOI: 10.1136/annrheumdis-2021-eular.2368

OP0276-PARE CREATING POLITICAL LEVERS TO IMPROVE AXIAL SPONDYLOARTHRITIS CARE

J. Hamilton¹, D. Webb², S. Whalley³. ¹National Axial Spondyloarthritis Society, Head of Policy & Health Services, London, United Kingdom; ²National Axial Spondyloarthritis Society, CEO, London, United Kingdom; ³M&F Health, Health Communications, London, United Kingdom

Background: Research carried out in 2016 by NASS showed that the range and quality of axial spondyloarthritis (axial SpA) services generally offered around the UK were variable¹. The publication by the regulator, the National Institute for Health and Care Excellence (NICE), of a Guideline for Spondyloarthritis (NG65) in 2017² and the corresponding Quality Standard (QS170) in 2018³, for the first time provided national guidance and standards of services that should be available for people with axial SpA. National oversight of the implementation of these however was missing.

Objectives: NASS worked with Parliamentarians to establish the All-Party Parliamentary Group for Axial Spondyloarthritis in January 2019. We gave it a very specific objective - to oversee the implementation of NH65 and QS170. The group seeks to improve axial SpA services in England whilst raising awareness of the condition at a parliamentary level, working closely with NASS.

Methods: The group is a unique forum in the UK, bringing together patients, clinicians, researchers, policy makers, national bodies and parliamentarians. The group has met five times covering a range of topics including the delay to diagnosis, the uptake of NG65 and hydrotherapy.

In 2019 the group carried out a national inquiry into the standards of axial SpA services in the UK, developing a ten-question quality framework, based largely on the NICE Guideline recommendations and Quality Standard. In July 2020 a meeting was convened to discuss the impact of COVID-19 on axial SpA services. The meeting presented research carried out by NASS and M&F Health with patients and clinicians respectively.

Results: The results of the national inquiry for England were published in January 2020⁴. The inquiry found that large discrepancies remain in the provision of axial SpA services. Only 21% of local commissioning bodies have an inflammatory back pain pathway, and less than half of NHS providers have a specialist axial SpA clinic.

The results of COVID survey shows significant impacts on the health of axial SpA patients and on the availability and modality of rheumatology services. The APPG later published a report with a set of recommendations⁵, creating minimum service specifications for axial SpA services during crisis periods such as the recent pandemic, as well as service recovery. Comment on this research was also published in *The Lancet Rheumatology*⁶.