



Citation for published version:

Hughes, M, Baker, A, Farrington, S & Pauling, JD 2018, 'Patient organisation-led initiatives can play an important role in raising awareness about Raynaud's phenomenon and encourage earlier healthcare utilisation for high-risk groups', *Annals of the Rheumatic Diseases*. <https://doi.org/10.1136/annrheumdis-2018-214161>

DOI:

[10.1136/annrheumdis-2018-214161](https://doi.org/10.1136/annrheumdis-2018-214161)

Publication date:

2018

Document Version

Peer reviewed version

[Link to publication](#)

This is the authors' accepted manuscript of a letter published in final form in *Annals of the Rheumatic Diseases*. The Version of Record is available via: <http://dx.doi.org/10.1136/annrheumdis-2018-214161>. (C) The Authors, 2018. Published by BMJ.

University of Bath

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Patient organisations can play an important role in raising awareness about Raynaud's phenomenon and encourage earlier healthcare utilisation for high risk groups

Michael Hughes^{1,2} Amy Baker³, Sue Farrington³, & John D Pauling^{4,5}

1. Department of Rheumatology, Royal Hallamshire Hospital, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK
2. Centre for Musculoskeletal Research, The University of Manchester, Salford Royal NHS Foundation Trust, Manchester Academic Health Science Centre, Manchester, UK
3. Scleroderma and Raynaud's UK, 18 - 20 Bride Lane, London, UK.
4. Royal National Hospital for Rheumatic Diseases (at Royal United Hospitals), Bath, UK
5. Department of Pharmacy and Pharmacology, University of Bath, Bath, UK

Corresponding Author:

Dr John D Pauling BMedSci BMBS PhD FRCP

Senior Lecturer & Consultant Rheumatologist,

Royal National Hospital for Rheumatic Diseases,

Upper Borough Walls,

Bath, BA1 1RL

Tel: (0044) 1225 473 468

Fax: (0044) 1225 473 452

JohnPauling@nhs.net

Word count 600/600

Sources of support: Scleroderma and Raynaud's UK

Competing Interests: None declared

Raynaud's phenomenon (RP) manifests as episodic vasospasm of the extremities (hands and feet) in response to cold exposure. RP can be primary (idiopathic) or secondary to underlying disease such as systemic sclerosis (SSc). Attacks of RP are often associated with digital colour changes reflecting local tissue perfusion and oxygenation. RP results in pain, numbness, impaired function and reduced quality of life [1, 2]. The obliterative vasculopathy of SSc can result in digital ulceration. Diagnostic delay of secondary RP remains a major unmet need. The average time between the onset of RP and the emergence of the first non-RP symptom in women with limited cutaneous SSc is >5 years [3]. This contributes to delay in diagnosis; with >25% of women not diagnosed with SSc for >10 years after RP symptoms first emerged[4].

Against this background, Scleroderma Raynaud's UK (SRUK) developed a "Raynaud's test" for their website (<https://www.sruk.co.uk/raynauds/raynauds-test/>). Visitors answer 5 questions (derived from expert consensus RP classification criteria [5, 6]) to determine if RP was likely and whether medical assessment might be necessary (Table).

No identifiable information is collected. Algorithms provide respondents with statements indicating "This is unlikely to be Raynaud's" or that "You may have Raynaud's". All participants are encouraged to seek medical advice if they experience painful or frequent symptoms, or have other concerns. All participants answering "yes" to question 5 (irrespective of other responses) are given recommendations to be assessed by their primary care physician (Table).

We examined anonymised data from 18840 respondents from 43 countries who completed the "Raynaud's test" between 22/06/2017 and 21/06/2018. We have no information on who completed the test or how they acted on the information supplied in response to their answers. The figures are solely presented to provide some impression of the possible demographics of those completing the test. RP was deemed "unlikely" in 1138 (6%). The majority of respondents were informed they "may have Raynaud's" (14140, 75%). The remaining 3562 respondents (19%) were also informed they may have Raynaud's, but given additional advice to seek medical attention having reported the development of digital ischaemic lesions (yes to question 5). Accepting the inevitable selection bias accompanying positioning the test on the SRUK website, the considerable proportion of respondents reporting features that might represent SRP was of interest and it is hoped may have

encouraged some respondents to seek medical attention when they had not previously done so.

Utilisation of our Raynaud's test highlights the large number of people visiting patient organisation websites for information and the potential of patient organisations to encourage involvement of people in their own healthcare. Our findings also highlight the global reach of "National" web-based patient organisations. The internet has provided the general public with a readily available tool for the self-investigation of new experiences/symptoms that might indicate the presence of disease. Carefully designed tools of this nature can positively influence health utilisation by providing reassurance to people interested to learn about RP and encouraging earlier medical assessment of people at risk of potentially life-threatening disease such as SSc. This type of interaction between healthcare professionals, patient organisations and the public is at the heart of important initiatives such as the EULAR 'Don't Delay, Connect Today!' campaign, that is seeking to raise awareness around the importance of early diagnosis [7]. The diagnostic potential of mobile health technology is fast becoming an important tool for influencing patient referral processes and can be particularly valuable for people living in remote areas. We must, however, be alert to the dangers of diagnostic inaccuracy and incorporate appropriate safeguards that signpost people to seek healthcare assessment of intrusive or potentially serious symptomatology [8].

Acknowledgements

The authors wish to thank Professor Ariane Herrick for her help devising questions and responses comprising the "Raynaud's Test".

References

1. Pauling, J.D., et al., *A multi-national qualitative research study exploring the patient experience of Raynaud's phenomenon in systemic sclerosis*. Arthritis Care Res (Hoboken), 2017: p. ePublished ahead of print.
2. Pauling, J.D., et al., *The patient experience of Raynaud's phenomenon in systemic sclerosis*. Rheumatology (Oxford), 2018.
3. Walker, U.A., et al., *Clinical risk assessment of organ manifestations in systemic sclerosis: a report from the EULAR Scleroderma Trials And Research group database*. Ann Rheum Dis, 2007. **66**(6): p. 754-63.

4. Delisle, V.C., et al., *Sex and time to diagnosis in systemic sclerosis: an updated analysis of 1,129 patients from the Canadian scleroderma research group registry*. Clin Exp Rheumatol, 2014. **32**(6 Suppl 86): p. S-10-4.
5. Brennan, P., et al., *Validity and reliability of three methods used in the diagnosis of Raynaud's phenomenon. The UK Scleroderma Study Group*. Br J Rheumatol, 1993. **32**(5): p. 357-61.
6. Maverakis, E., et al., *International consensus criteria for the diagnosis of Raynaud's phenomenon*. J Autoimmun, 2014. **48-49**: p. 60-5.
7. 'Don't Delay, Connect Today'. EULAR Campaign 2017/18 [Accessed 23rd August 2018]; Available from: https://www.eular.org/what_we_do_dont_delay_connect_today_2017.cfm.
8. Wolf, J.A., et al., *Diagnostic inaccuracy of smartphone applications for melanoma detection*. JAMA Dermatol, 2013. **149**(4): p. 422-6.

Table 1: The questions and responses comprising the online SRUK 'Raynaud's Test'

Questions (Q) comprising the Raynaud's Test	
Question 1	Are your fingers sensitive to the cold?
Question 2	Do your fingers change colour in response to temperature change or stressful situations? (white, blue, red and purple)
Question 3	Do you get numbness or pain in the affected area when they change colour?
Question 4	Do you feel stinging or throbbing when the affected area warms up?
Question 5	Have you ever developed any sores/ulcers on your fingers or toes?
Responses provided to visitors depending on their answers to questions 1-5	
No to Q1-5 OR Yes to Q1 but no to Q2-5	<p>This is unlikely to be Raynaud's however if you experience painful or frequent symptoms, or are concerned, then it may be worthwhile visiting a GP</p> <p>You may be over sensitive to the cold and so to reduce your symptoms try to keep warm. Take a look at our information below to support you with keeping warm and avoiding smoking. If you would like to know more information about Raynaud's then why not have a look at the further information below. Raynaud's is a common condition affecting around 1 in 6 people. In people who have Raynaud's, the small blood vessels in the extremities are over-sensitive to changes in temperature or stress</p>

	<p>causing a Raynaud's attack Raynaud's symptoms generally affect the fingers and toes, but all extremities can be involved, including the ears</p>
<p>Yes to Q1, Yes to one of Q2-4, and No to Q5</p>	<p>You may have Raynaud's</p> <p>Raynaud's is a common condition affecting around 1 in 6 people. In people who have Raynaud's, the small blood vessels in the extremities are over-sensitive to changes in temperature or stress. This causes a Raynaud's attack where the fingers change colour typically white, blue, or red. Raynaud's symptoms generally affect the fingers and toes, but all extremities can be involved, including the ears, nose, lips, tongue and nipples. If you are experiencing painful or frequent symptoms then it is worthwhile visiting your GP to discuss the situation, including management techniques and possible treatment options.</p>
<p>Yes to Q5, irrespective of the answers provided to Q1-4</p>	<p>You may have Raynaud's</p> <p>Raynaud's is a common condition affecting around 1 in 6 people. In people who have Raynaud's, the small blood vessels in the extremities are over-sensitive to changes in temperature or stress. This causes a Raynaud's attack where the fingers change colour typically white, blue, or red. Raynaud's symptoms generally affect the fingers and toes, but all extremities can be involved, including the ears, nose, lips, tongue and nipples.</p> <p>The majority of people with Raynaud's symptoms have "Primary Raynaud's phenomenon" which can be intrusive but should not cause any lasting damage to the fingers. Primary Raynaud's often starts during adolescence. A minority of people experiencing Raynaud's have an underlying health condition causing these symptoms. We use the term "Secondary Raynaud's phenomenon" when this is the case. This can be more serious and we have tests available to help identify people who might have secondary Raynaud's.</p> <p>If you have developed sores or ulcers on your fingers or toes then we would recommend an assessment at your GP surgery to rule out an underlying health problem.</p> <p>If you are experiencing painful or frequent symptoms then it is worthwhile visiting your GP to discuss the situation, including management techniques and possible treatment options.</p>