



**SCLERODERMA
& RAYNAUD'S UK**

The PIF TICK-

The application and assessment process

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Information and Support Services Manager

OUR VISION

A world where no one
has their lives limited
by Scleroderma or
Raynaud's

OUR GOALS

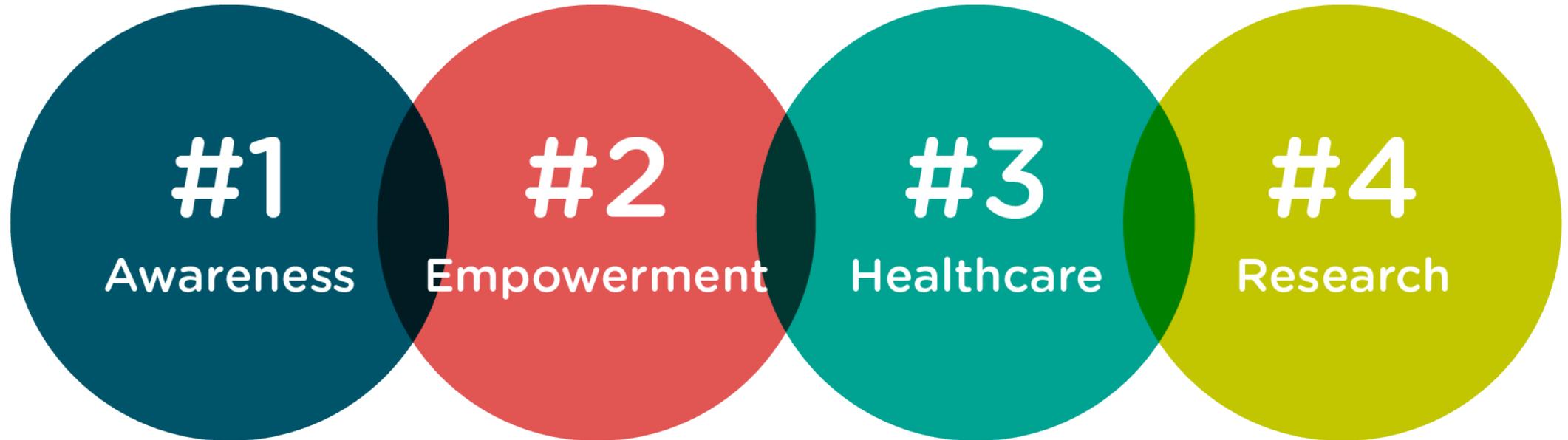


A cure for Scleroderma & Raynauds is found



The impact of Scleroderma & Raynaud's on people's lives is minimised

ACHIEVING OUR GOALS



WITH OUR COMMUNITY WE HAVE

AWARENESS

Delivered 8 Campaigns
Web Users up 300% to 418,000

50,000 + people taken online
Raynaud's Test

Raynaud's featured on BBC TV
for first time – reached 8.7m
people

EMPOWERMENT

Helpline takes on average
1,000 calls a year

Our information is in over 35
clinics and growing

85% report increased
confidence to self manage

HEALTHCARE

Co-founded RAIRDA
- alliance for rare rheumatic
conditions

Produced 'State of Nation'
report based on 2,389
responses

Worked with NHS Choices to
improve info on Raynaud's &
Scleroderma

RESEARCH

Invested 1.5 million in
Research

Established Patient Research
Panel

Est partnerships with MRC,
WSF, EPSRC & Insilico

SRUK Information and Support Services

Information and Support Services

Information

- Booklets
- Factsheets
- SRUK Magazine
- Website
- Digital
- Blogs
- Podcast

Support

- Helpline
- Support Groups
- Discussion Forum
- Regional Conferences

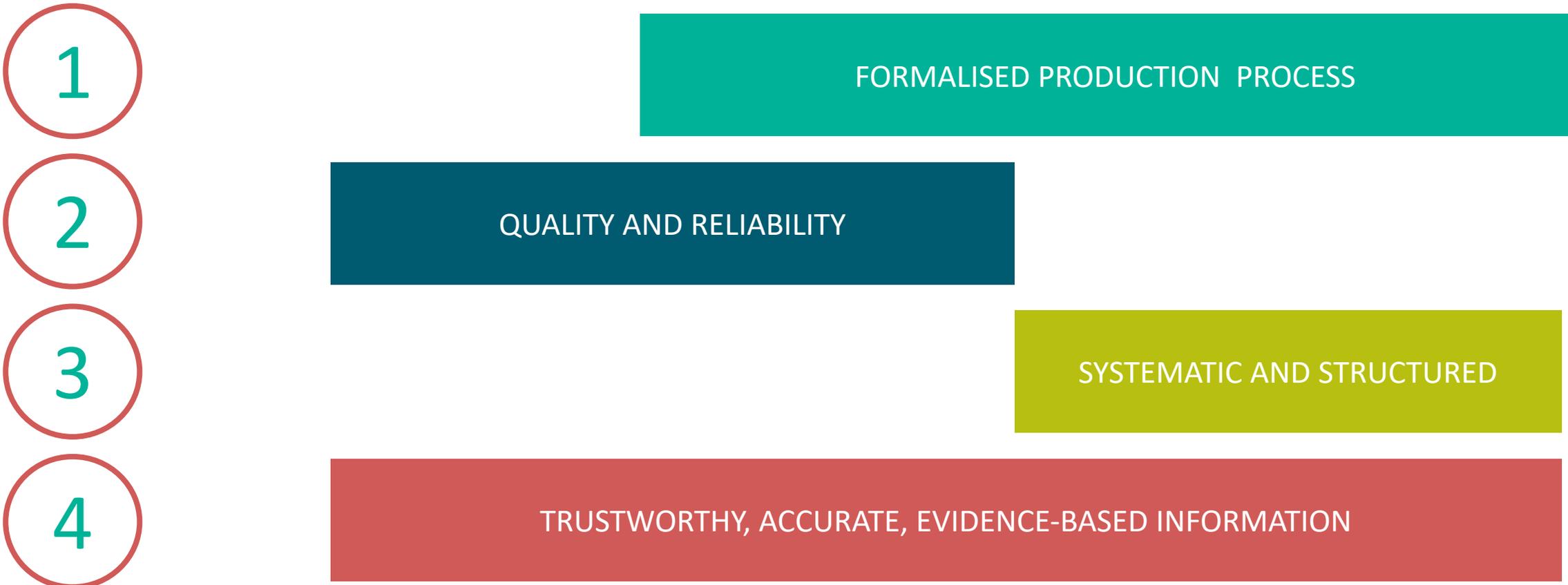


**Trusted
Information
Creator**



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Why we joined the PIF TICK



Benefits of joining the scheme

- Support from PIF – continuous improvement
- Benefits to our members and community– the ‘gold standard’ for information on Scleroderma and Raynaud’s in Rheumatology clinics
- Benefits to patients – good quality, trustworthy, evidence based health information.

The Application Process

- Mapping of PIF Quality Mark Criteria against current SRUK Information Production Process
- Tailor relevant sections of production process to meet PIF Quality Mark criteria form to meet minimum and desired criteria
- Criteria form is well laid out, clear and concise
- 2 hours to complete form
- Support is always available!!



Document

Assessment - What was it like?

- Submitted PIF Quality Mark Criteria Form along with supporting documents as evidence:
- Sensible criteria set at the right level
- Conducted via video conference
- Flexible and tailored approach – to the requirements of the individual organisation
- Took 2 hours
- Excellent support from Dan.

Next steps

- Action Plan to complete
- 12 months to implement actions
- Assessment in 1 year.



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THANK YOU

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