

DEVELOPING A WEBSITE RESOURCE THROUGH QUALITATIVE RESEARCH INTO EXPERIENCES OF SYSTEMIC VASCULITIS AND UK HEALTHCARE

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BACKGROUND

- People searching online can find it difficult to know what they can trust
- Few personal experience websites are generated through rigorous research

AIM

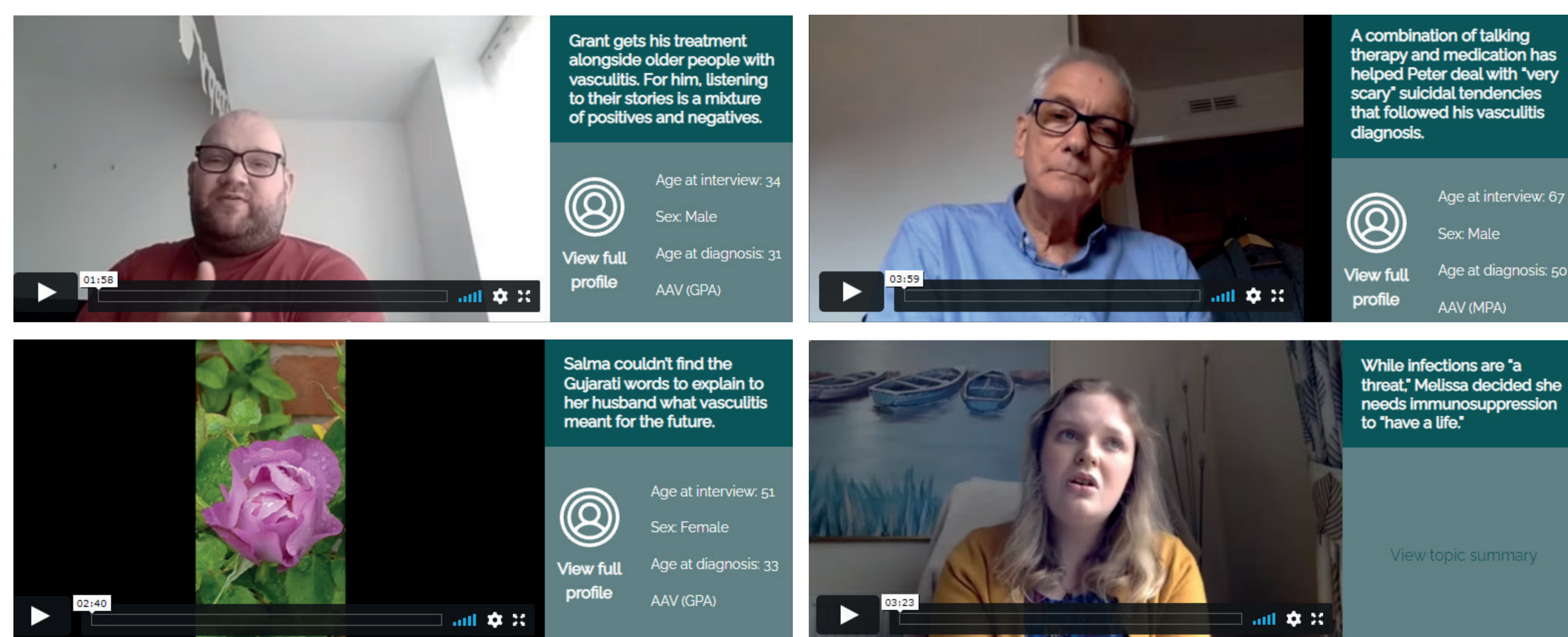
To create a trusted, balanced web resource for patients and professionals about people's experiences of systemic vasculitis and UK healthcare

METHODS

- 32 in-depth qualitative video (or audio) interviews (UK wide)
- Maximum variation sample
- Narrative interview style and thematic analysis

RESULTS

Vasculitis resource and short 'catalyst' film designed to help staff and patients think about how they could improve care locally (available at www.healthtalk.org)



Signpost people living with systemic vasculitis to the healthtalk.org resource to help them:

- **Feel connected** to others
- **Compare and contrast** their experiences
- Think about **uncertainties and decisions**

> Daily life with vasculitis

- Living day-to-day with systemic vasculitis
- Living with the emotional impact of systemic vasculitis
- Living with the practical impacts of systemic vasculitis
- Living with the financial impact of systemic vasculitis
- Explaining systemic vasculitis to other people

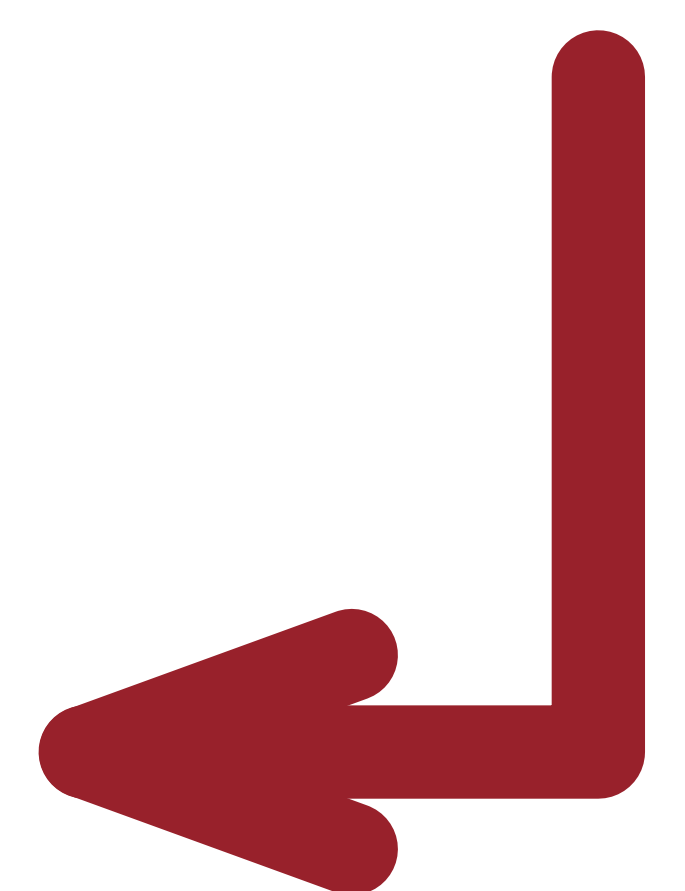
> Treating vasculitis

- Treating systemic vasculitis
- Managing systemic vasculitis flares and seeking help
- The damage that systemic vasculitis does to the body
- Making decisions about increasing, reducing or changing systemic vasculitis medication
- Side effects of steroids and other systemic vasculitis medication

> People's Profiles

- Aged 20-29
- Aged 30-39
- Aged 40-49
- Aged 50-59
- Aged 60-69
- Aged 70+

Explore the resource for professional development



Use the 20-minute film as a 'catalyst' e.g. to get patients and NHS staff talking together about how you can jointly **improve people's experiences** of your service



Charlie feels sad that his doctors were 'hands off' while he was having chemotherapy.

For further information on the VOICES study, see

