

Involving patients in healthcare improvement via Sensemaker

A Zoom for the Q Community led by:

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Polymyalgia rheumatica (PMR)



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(Cortico)steroids
treat inflammation

Side effects include:

- Anxiety
- Sleeplessness
- Weight gain

Clinical pathways for PMR

Diagnosed in primary care

May be referred to secondary care
(rheum)

Health inequalities

GIRFT: Better pathways needed

NHSEI: Outpatient Recovery and

Transformation > PIFU > Education

What patients told us

“Left to get on with it” / ignored

- Holistic approach, not just more drugs
- Support for managing steroid side effects (-> also relevant for other rheum patients)

Departmental feedback

- Access and Communication

What does this look like for us?

A rheumatology clinic + enquiry line

Limited capacity

Mismatch with demand

One year project: test out + evaluate
small improvements – PDSA

Steroid side effects Focus Group 1

Many different types of side effect

- Need to know what they are from the start
- Visible or invisible?
- Get better or get worse with time?
- "Coping" vs taking action to "manage and mitigate"?

Common sense model of self-regulation (Leventhal, 1970)

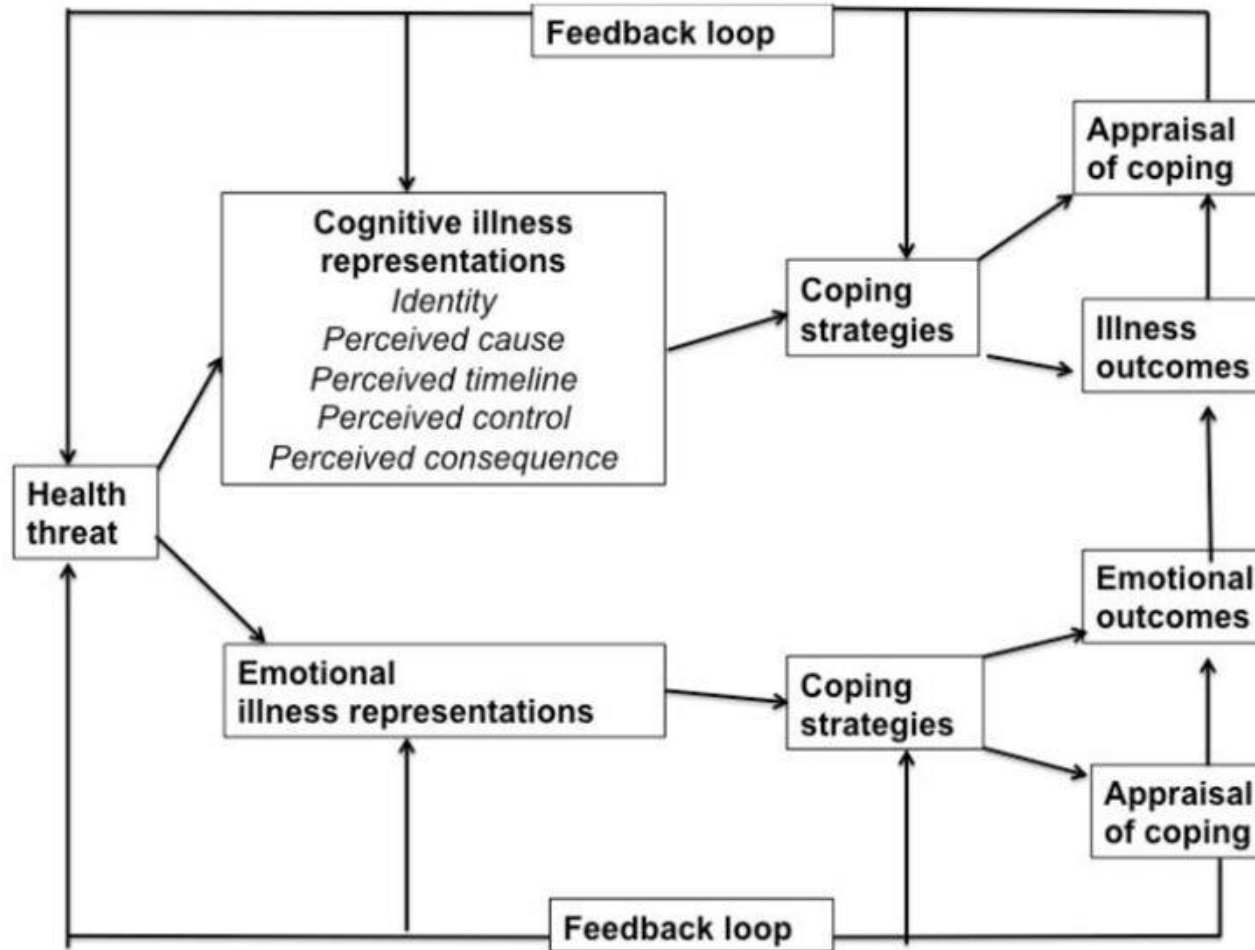


Figure adapted from Brandes & Mullan, 2014

Involving patients at scale

- Designed Sensemaker survey with our 2 patient partners
- Disseminated via online communities
- Diverse narratives – as expected for a side-effects project
- Sense-making sessions...

From sense-making to action

- Understanding is fundamental
 - “Education” over time
- Physical and mental health effects
 - “Anxious students don’t learn”
- The value of human connections
 - With a healthcare professional (talking)
 - With other patients (sharing)