

A patient reported outcome measure for Giant Cell Arteritis

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**Joanna Robson
Consultant Senior Lecturer in Rheumatology
UHBristol
University of the West of England, Bristol**

What is Giant Cell Arteritis?

- Headache
- Scalp tenderness
- Visual loss
- Jaw or tongue pain
- Systemic: malaise, fever, weight loss, fatigue and depression
- Thoracic aortic aneurysm in 15%

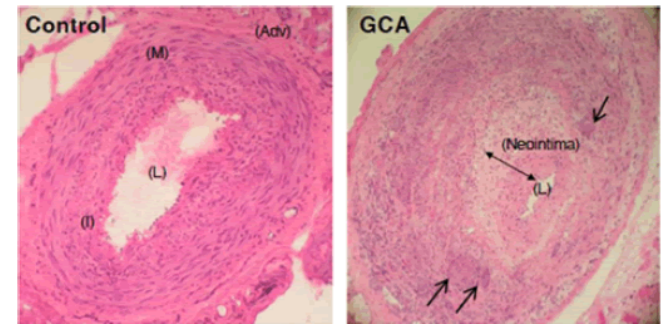
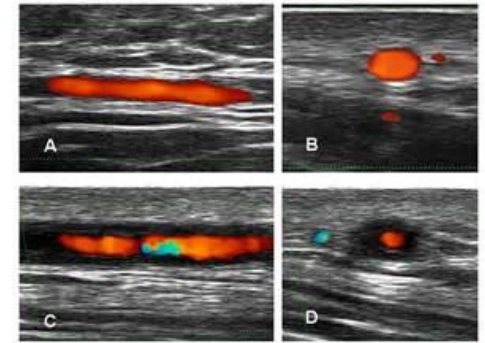
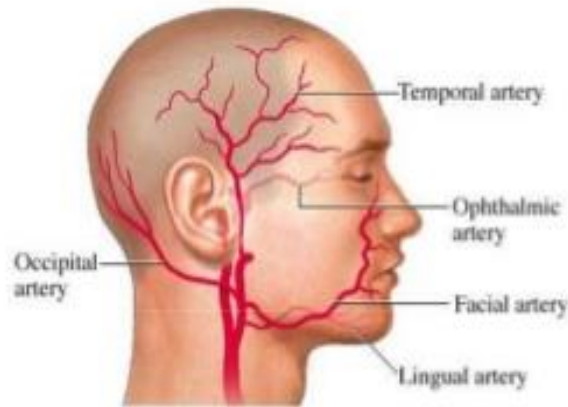
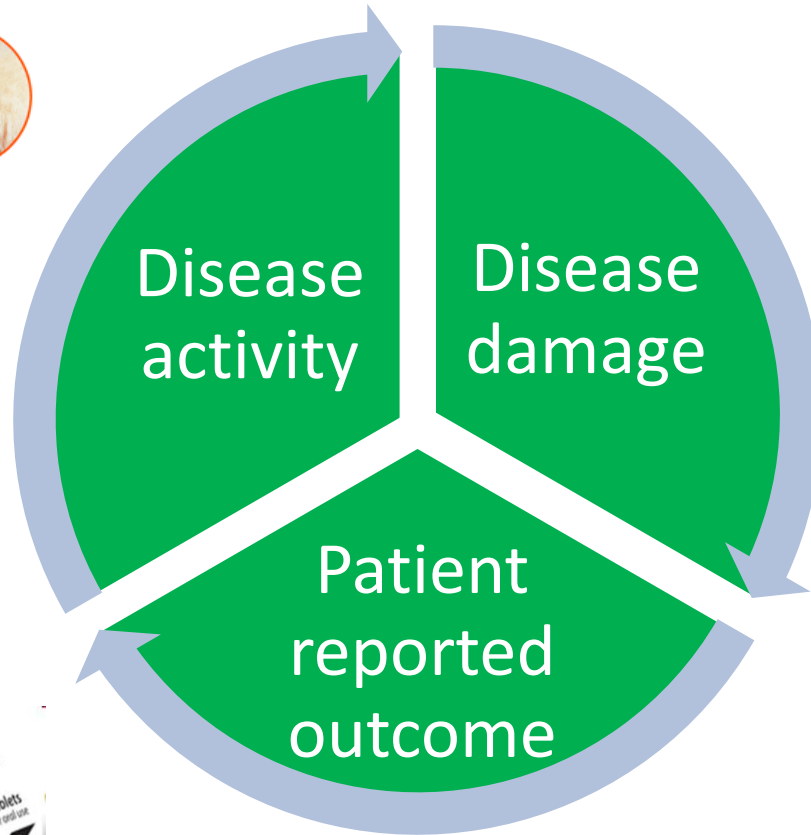
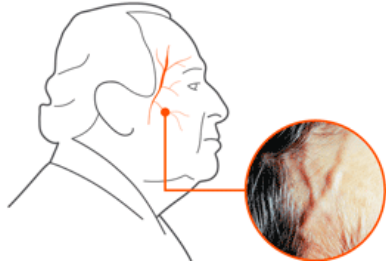


Figure 1: Normal temporal artery biopsy (left) as opposed to a temporal artery biopsy from a patient with giant-cell arteritis (right) disclosing typical transmural mononuclear cell infiltration, internal elastic lamina breakdown and intimal hyperplasia. Double head arrow remarks the thickened intima and single head arrows indicate the presence of giant-cells. Haematoxylin-eosin staining. L: lumen; I: intima; M: media; Adv: adventitia.

Outcomes in GCA and PMR



Difficulties with everyday life

Due to having vasculitis or its treatment, how difficult have you found the following activities, in general, during the past 4 weeks?

Please ✓ **only one box** for each statement.

	No difficulty	A little difficult	Moderately difficult	Extremely difficult	I could not do this
12. Walking around shops for <u>at least</u> an hour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Walking up a flight of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Doing the physical activities that you wanted to (such as walking, sports, or fitness classes)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Washing and drying yourself, or getting dressed, <u>without help</u> from another person	<input type="checkbox"/>	<input type="checkbox"/>			
16. Getting enough good sleep	<input type="checkbox"/>	<input type="checkbox"/>			

Patient reported outcome measures PROMs

Social and emotional impact

Due to having vasculitis or its treatment, how often have the following applied to you, in general, during the past 4 weeks?

Please ✓ **only one box** for each statement.

	None of the time	Rarely	Sometimes	Often	All of the time
17. I have felt concerned about my weight (weight gain or weight loss)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I have felt upset or frustrated because I have been unable to work or do my everyday tasks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Project aims

- Investigate health related quality of life in relation to GCA and its treatment
- Development of a PROM for patients with GCA for use as an outcome measure in clinical studies (e.g. randomised controlled trials).

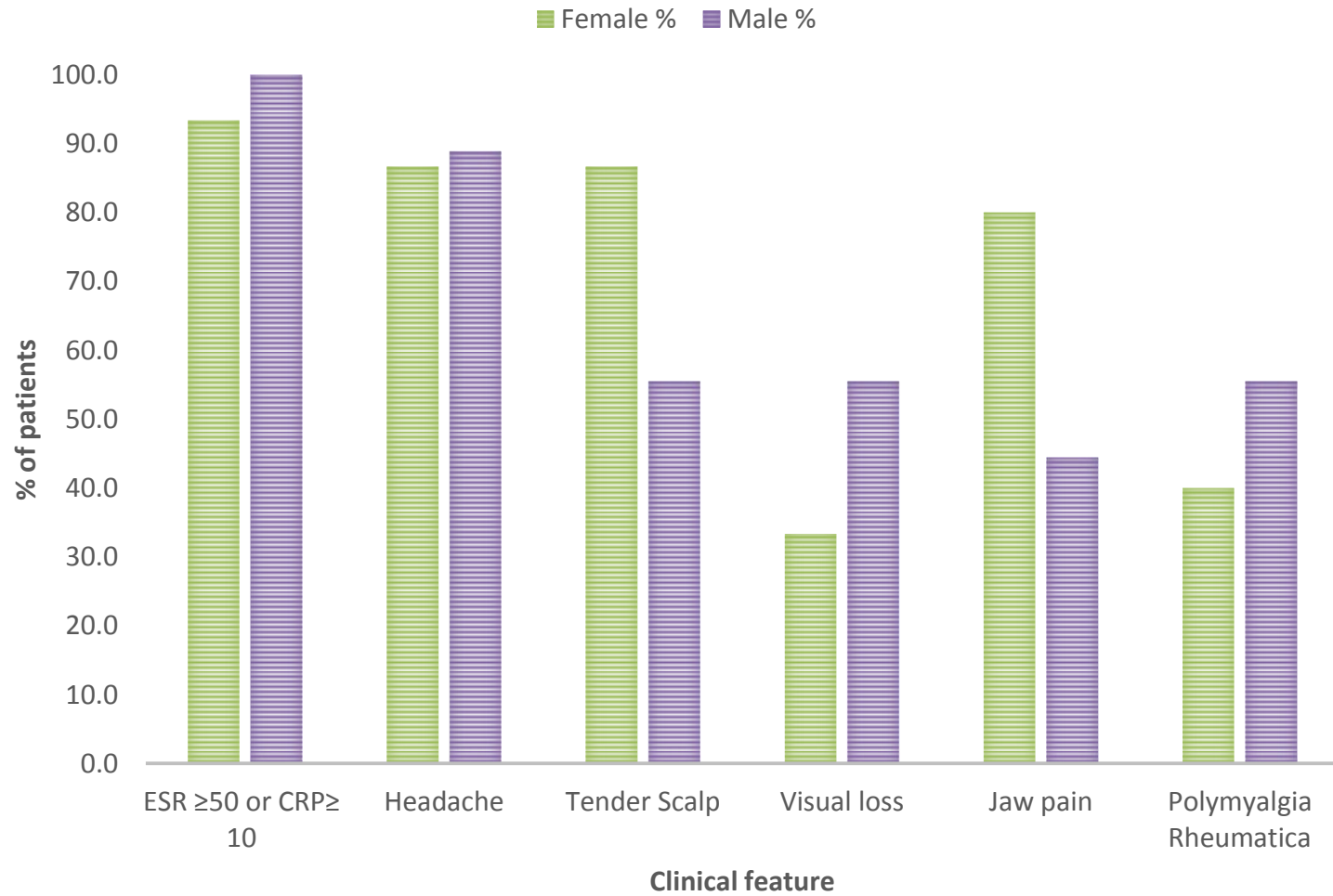
Methods

- Steering committee: qualitative and clinical researchers, patient partners, methodologists.
- In-depth qualitative interviews with patients with GCA to identify themes of importance
- Purposive sampling to include range of disease phenotypes (blindness, aortitis) and demographics
- Rheumatology and Ophthalmology
- Interviews transcribed - Inductive analysis.

Results

Demographics		University Hospitals Bristol (n=13)	Bath (n=6)	North Bristol (n=4)	Weston (n=1)	Total (n=24)
Sex, n (%)						
	Male	3 (23.1)	4 (66.7)	1 (25.0)	1 (100)	9 (37.5)
	Female	10 (76.9)	2 (33.3)	3 (75.0)	0 (0)	15 (62.5)
Age, n (%)						
	<70 yrs	3 (12.5)	1 (4.2)	0 (0)	0 (0)	4 (16.7)
	≥70 yrs	10 (77.5)	5 (95.8)	4 (100)	1 (100)	20 (83.3)
	Mean	76	74	77	72	75
Diagnostic test, n (%) *						
	Biopsy	12 (92.3)	3 (50.0)	4 (100)	1 (100)	20 (83.3)
	Ultra/S	0 (0)	4 (66.7)	0 (0)	0 (0)	4 (16.7)
	CTA	1 (7.7)	0 (0)	1 (25)	0 (0)	2 (8.3)
	PET	0 (0)	1 (16.7)	1 (25)	0 (0)	2 (8.3)
Time from diagnosis, n (%)						
	<1 year	9 (72.2)	0 (0)	2 (50.0)	1 (100)	12 (50.0)
	≥1 year	4 (27.8)	6 (100)	2 (50.0)	0 (0)	12 (50.0)

GCA PATIENT CLINICAL FEATURES



Activities of Daily Living (ADLs) and Function

Symptoms

Psychological impact

Participation

Impact on global health and health perception

Beneficial support and treatment

Comorbidities and secondary conditions

Diagnosis

Disease progress and steroid reduction process

Activities of Daily Living (ADLs) and Function

Symptoms

Psychological impact

Participation

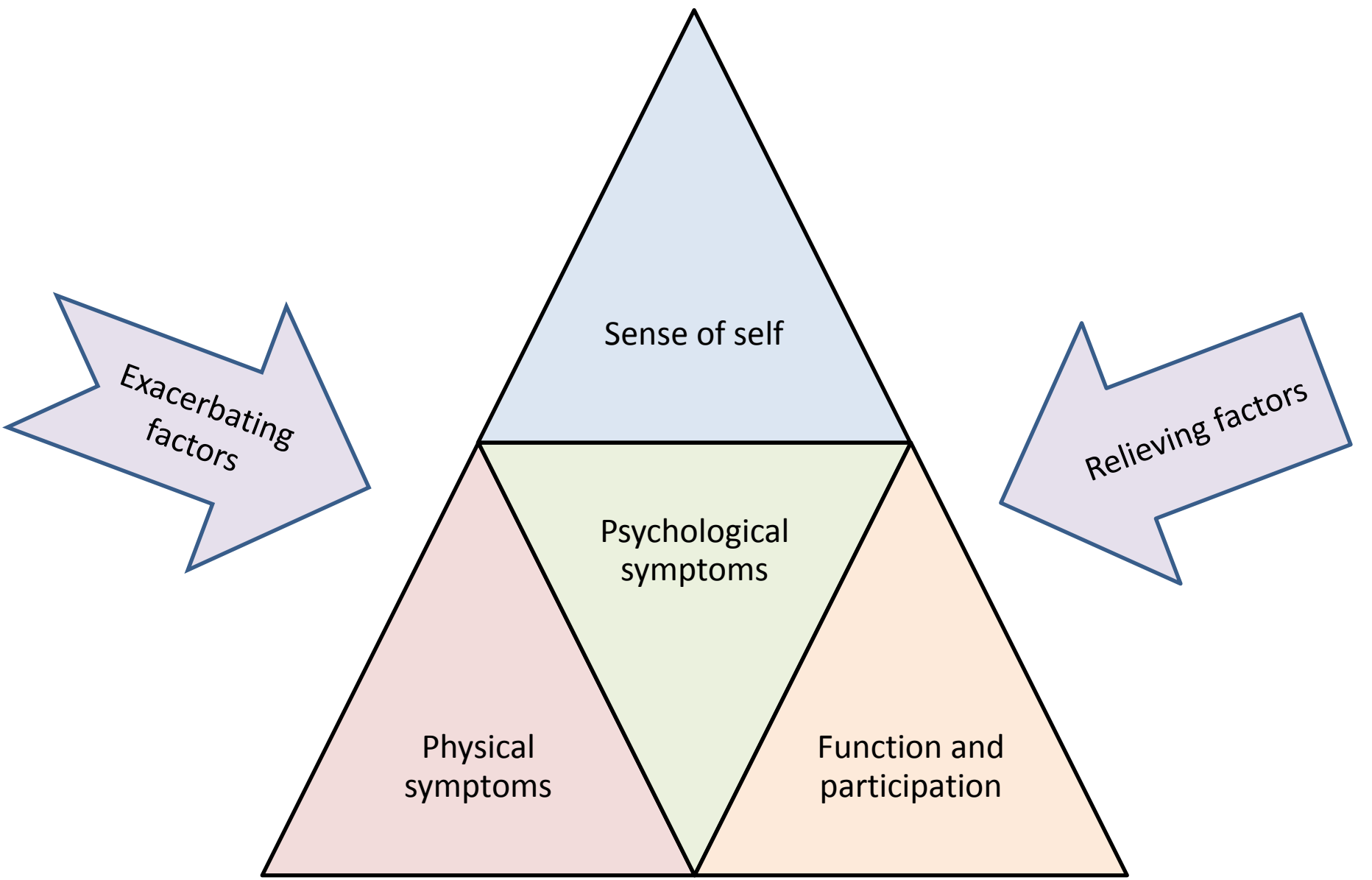
Impact on global health and health perception

Beneficial support and treatment

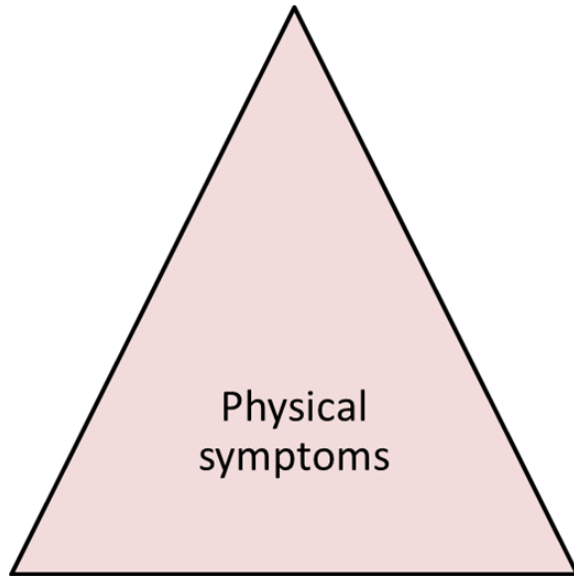
Comorbidities and secondary conditions

Diagnosis

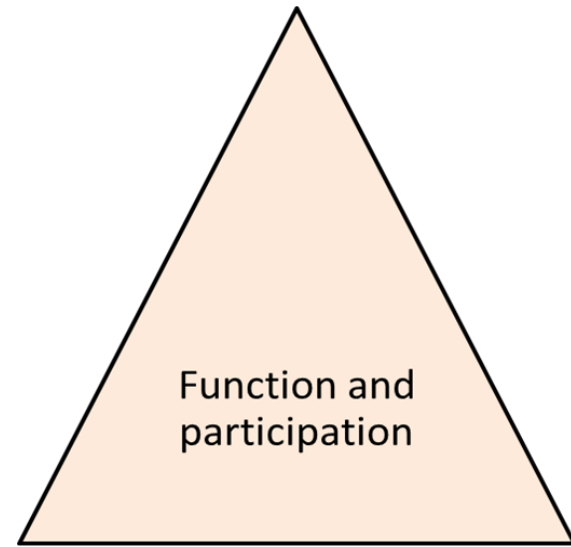
Disease progress and steroid reduction process



Initial conceptual framework for the GCA PROM: incorporating symptoms and impact of GCA and its treatment

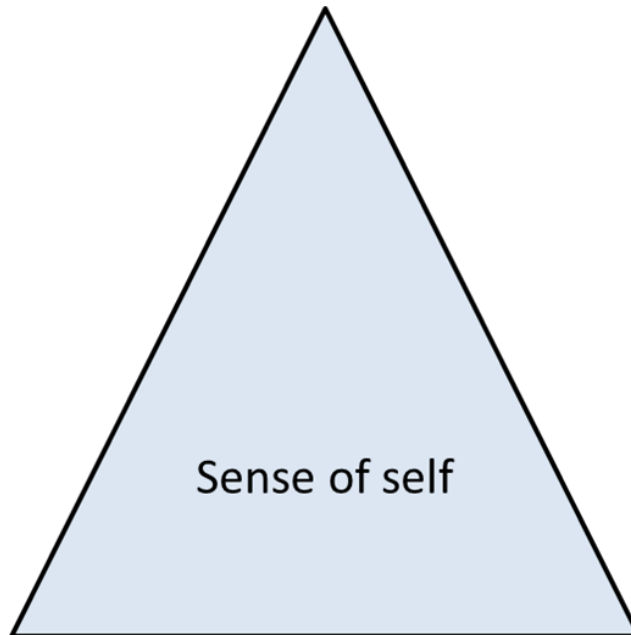
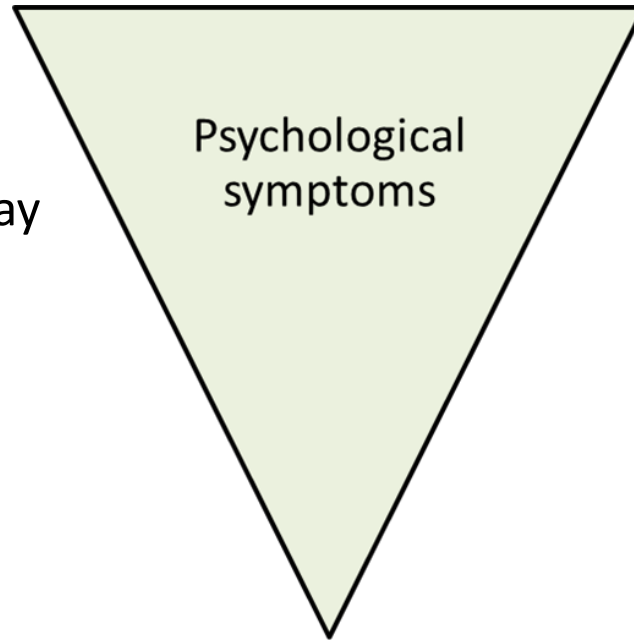


- Headache
- Scalp sensitivity
- Muscle pain and stiffness
- Getting going in the morning
- Breathing problems and chest pain
- Unsteadiness
- Visual symptoms
- Change in physical appearance
- Gastric symptoms
- Flu-like symptoms
- Weight loss and gain
- Ear, nose and throat pain



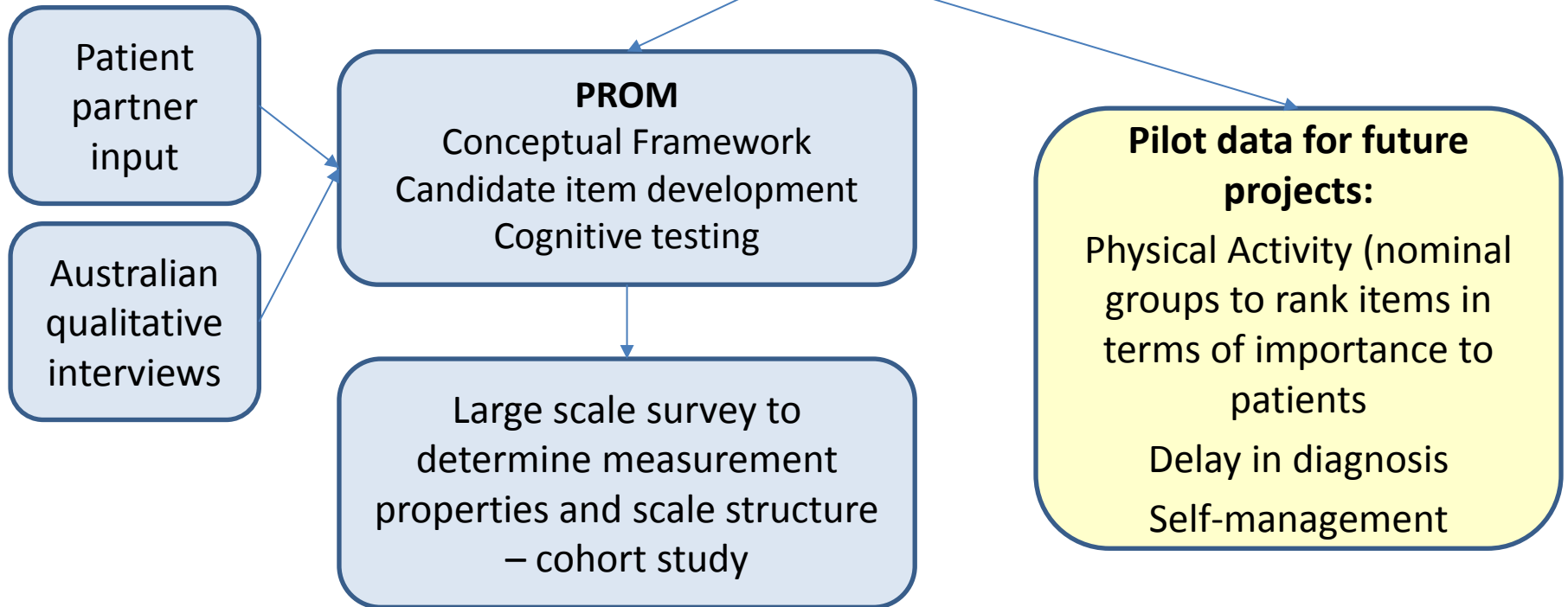
- Driving
- Essential household tasks
- Lower limb function-hips and knees
- Shopping
- Upper limb function-shoulders
- Visual function
- Walking/ personal mobility
- Family and caring roles
- Hobbies at home/ physical and social
- Work- paid and voluntary

- Anger
- Brain fog and concentration
- Coping and getting through the day
- Energy, tiredness and fatigue
- Psychological side effects
- Worry, anxiety, stress
- Hypervigilance



- Loss of normality
- “Ruled by steroids”
- Adaptation to medications
- Impact on travel
- Loss of confidence in ones own body especially mobility/ stability

Underpinning qualitative paper detailing health related quality of life in Giant Cell Arteritis and areas of interest to patients



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