

# 36. Development of a Patient Reported Experience Measure (PREM) for interdisciplinary care in systemic diseases with skin manifestations (skin IMIDs)

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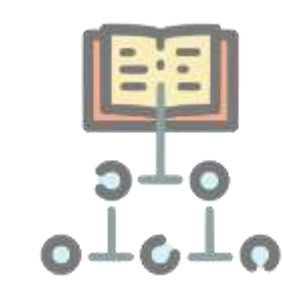
## Introduction

**Background:** Medical outcomes of systemic diseases with skin manifestations (immunomediated inflammatory diseases, or IMIDs, such as connective tissue diseases), require rapid diagnosis and tailored treatment of various organ systems. Due to modern immunomodulatory treatments, this requires collaboration between different disciplines. However, interdisciplinary care (IC) encounters challenges, such as fragmented care pathways, insufficient communication, etc. Also, patient experiences strongly influence adherence and in consequence medical outcomes.

The **objective** of this research was to pinpoint the key elements essential for gauging a patient's encounter with interdisciplinary care. Patient reported experience measures (PREMs) are user-friendly tools to monitor the quality of care and identify improvement areas. Here we aimed to create a succinct questionnaire for patient-experiences and needs in IC of skin IMIDs.



## Methods



- Pubmed-based literature review
- Elaborating a longlist with potential relevant items

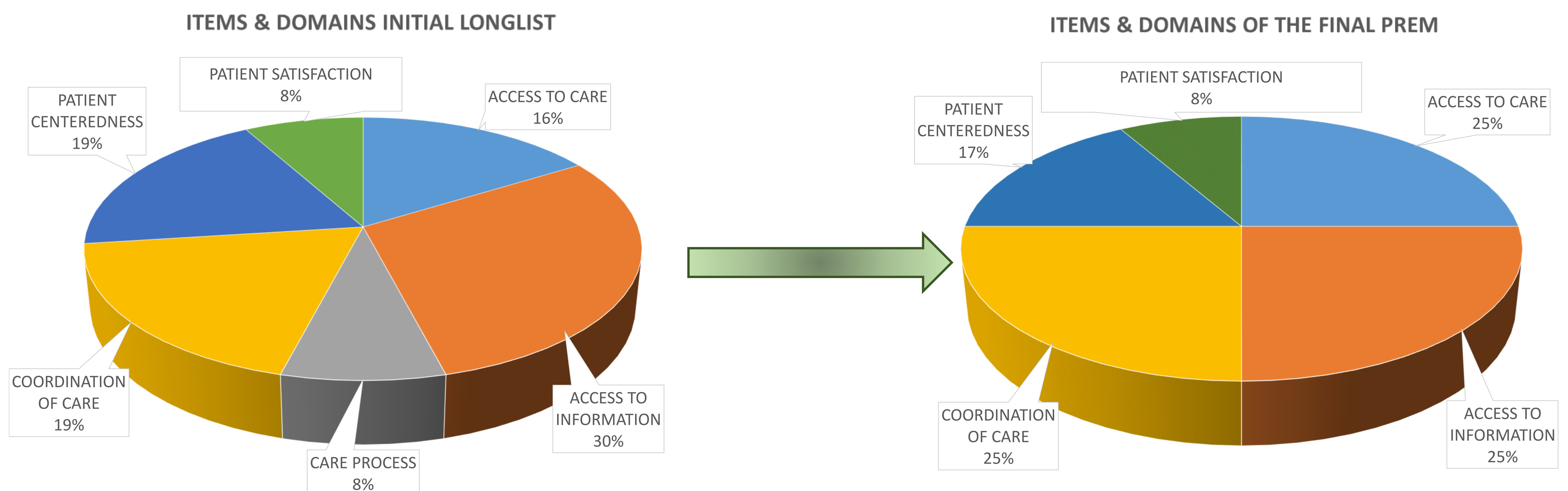
- Participant recruitment at University Hospital Brussels, Belgium
- 13 semi-structured interviews until saturation of mentioned items

- Two modified Delphi-approach focus groups with patients and care providers

- Formulating statements and final questionnaire
- E-mail rounds: consensus final PREM

## Results

### Evolution of domains and items during process



### Patient demographics

N = 16

<b>Diagnosis</b>	Psoriasis	3
	Lupus	3
	Behçet's disease	1
	Type II diseases	2
	Sarcoidosis	2
	Systemic sclerosis	1
	Dermatomyositis	2
	Hidradenitis suppurativa	1
	Non-diagnosed	1
	<b>Sex</b>	Female
Male		7
<b>Age</b>	Average age	47
<b>Time since diagnosis</b>	< 1 year	6
	> 1 year	10

### PREM for IC in skin IMIDs

Statements to be rated by a 5 point-Likert-scale

1. Waiting time between making this appointment and the appointment itself was acceptable
2. Waiting time between appointments with services within our hospital was acceptable
3. There is a clear point of contact in case of an urgent question
4. I was actively listened to/enough attention was paid to my story
5. I had sufficient participation regarding my treatment
6. My preferences regarding my care plan were taken into account (scheduling examinations, referrals, etc.)
7. It is clear which health care providers are involved in my care plan
8. I feel that my medical record is adequately known by the health care providers
9. I feel that there is adequate discussion between caregivers
10. I feel that caregivers are aligned about my care plan
11. I was adequately explained my treatment (medication and/or other therapies such as UV therapy, etc.)
12. It is clear who takes on the coordinating role
13. My care plan was adequately explained and is clear
14. The general practitioner was adequately informed about my care plan
15. I am satisfied with the interdisciplinary care

## Conclusion

The shift in domains from literature search to the final PREM underlines the high importance of access to information, coordination of care, access to care, patient centeredness and patient satisfaction when treating patients in an interdisciplinary setting with skin IMIDs.