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# Enhancing with The Patient Experience Library

Dr Nicole Thomas

## ABSTRACT

Dementia research within disadvantaged populations lacks sufficient evidence, limiting research design. Patient and public engagement activities can bridge this gap. However, practical constraints may hinder comprehensive inclusion, sometimes resulting in tokenism, a sentiment echoed by the affected populations. The ComPHAD project, "Community Approaches to Public Health and Dementia Research," aims to co-develop a sustainable platform to understand the primary care, public health and social care needs for dementia, with a focus on poorly represented communities.



The Patient Experience Library, housing over 60,000 documents replete with healthcare narratives, serves as a valuable resource. ComPHAD leveraged the Patient Experience Library for a review of grey literature, encompassing government reports and community organisation publications. This offered access to diverse narratives to fill the current gap in evidence.

We conducted a comprehensive search on dementia and marginalised communities using the Patient Experience Library repository. Reports were assessed by two researchers using a traffic light system. Reported factors which impact healthcare access and potential research engagement were categorised using the socioecological model of Alzheimer's which helped to inform topics for preliminary workshops.

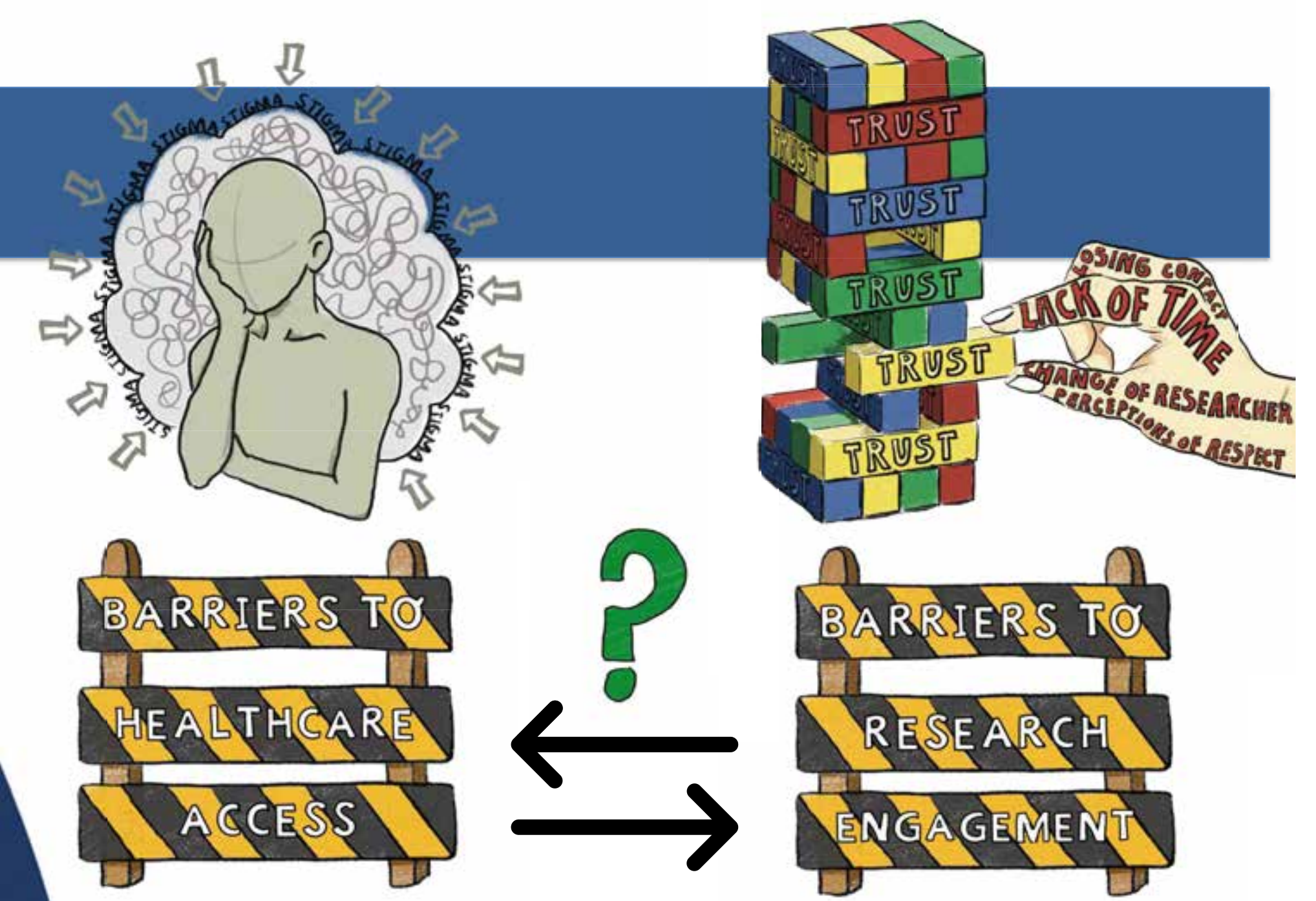
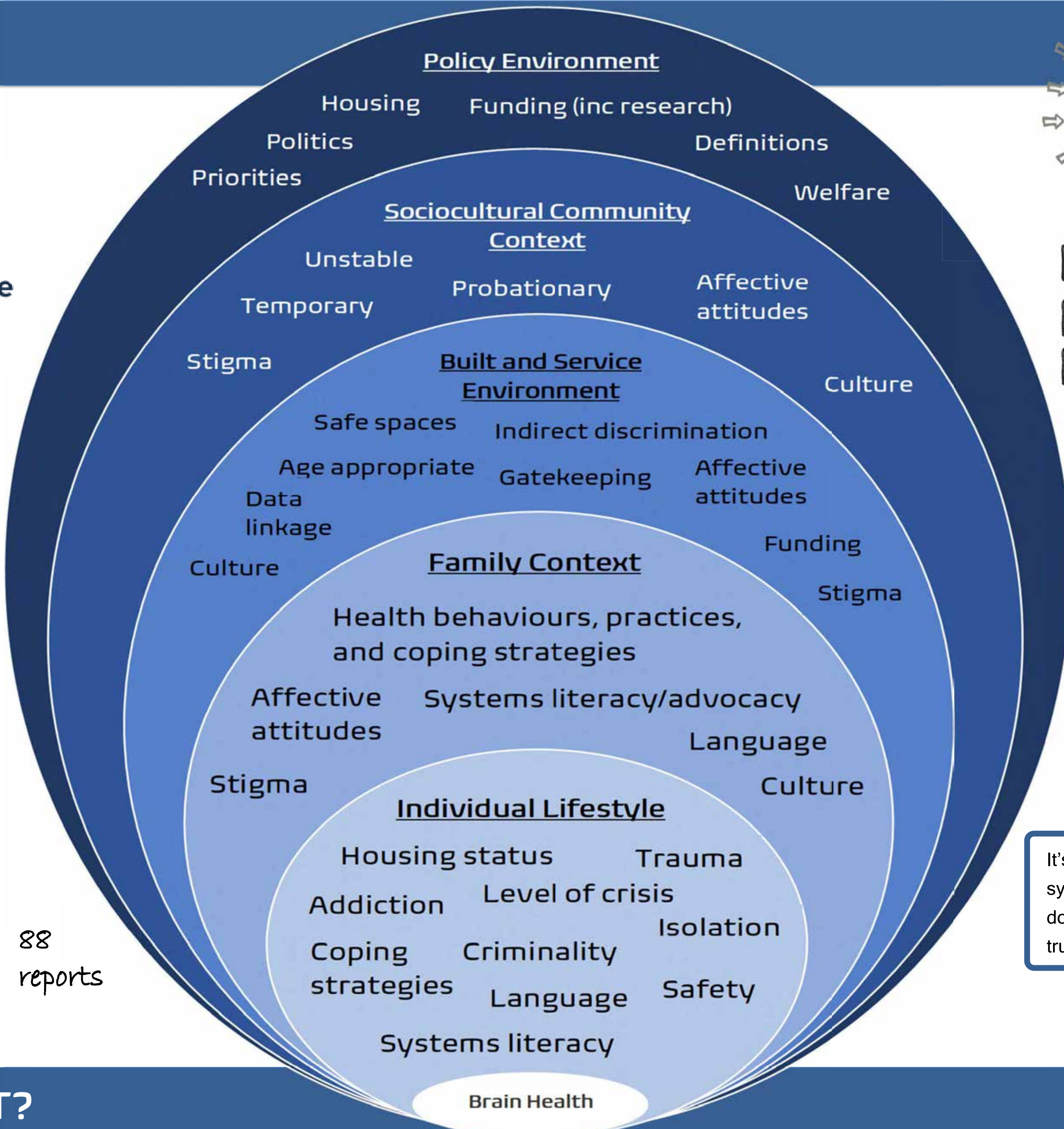
## FINDINGS



**Patient Experience Library**

638 reports  
↓ *First screening*  
161 reports  
↓ *Second screening*  
88 reports

Gov't	Healthwatch
23	40
Charities	Other
14	2



We don't feel safe when we're being questioned

We have to learn the language of all the systems as well as the spoken language

It's hard to trust a system when it doesn't appear to trust us

I was taught to not make a fuss or share problems outside the family

## WHAT NEXT?

- 1 Co-development of a 'Lived Experience Approach'
- 2 Co-development of a 'brand' and logo
- 3 Community mapping of 'friendly places'
- 4 Co-development of community KT methods

