Involving Patients and Clinicians in Research on Frailty and AI

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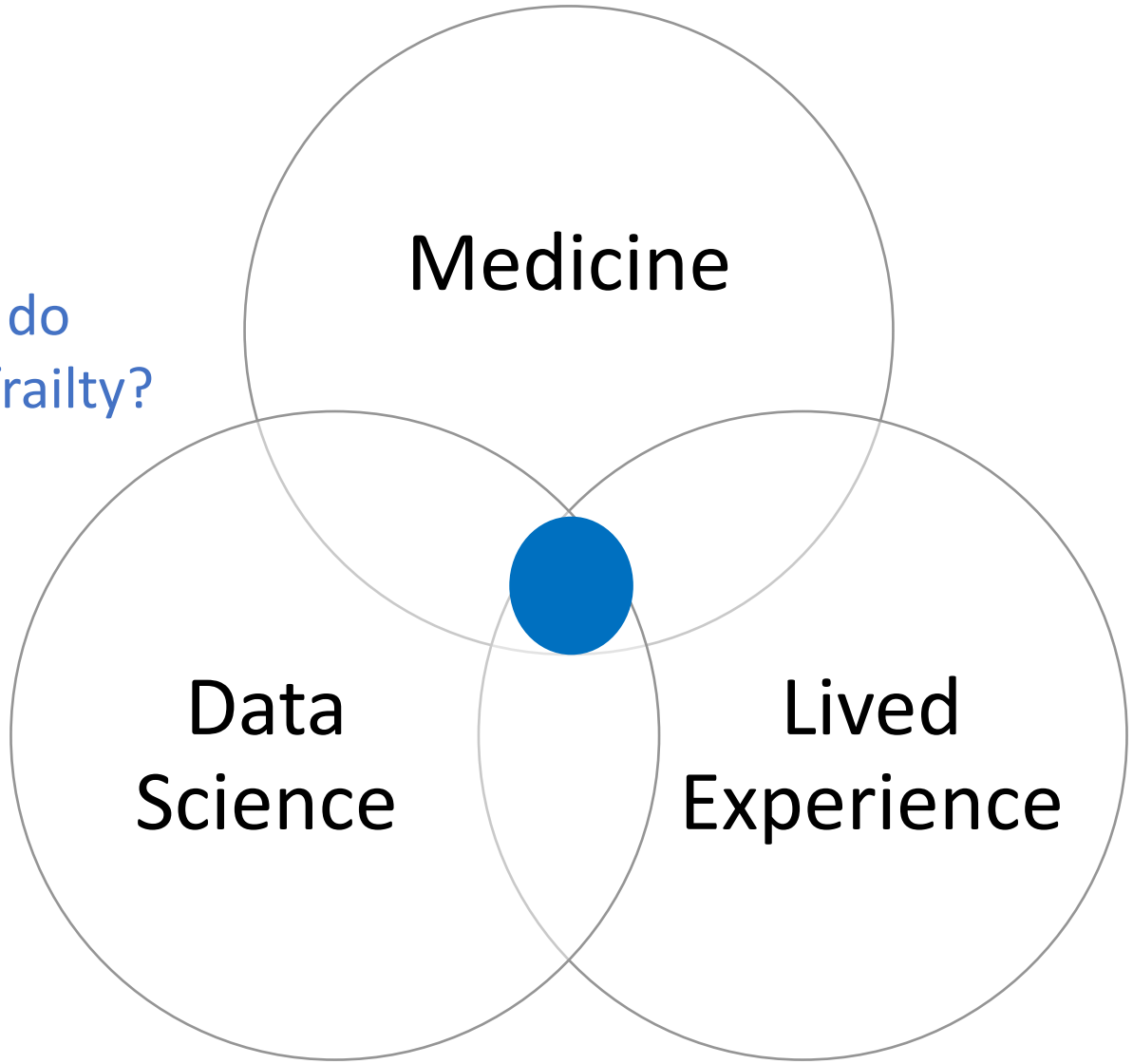
ACRC
Advanced Care Research Centre
Academy

THE UNIVERSITY of EDINBURGH

The Topic

PhD Project: What do data tell us about frailty?



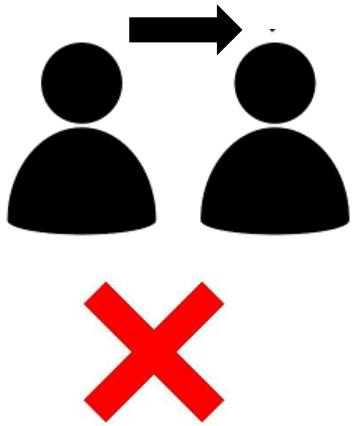
Some Communication Challenges

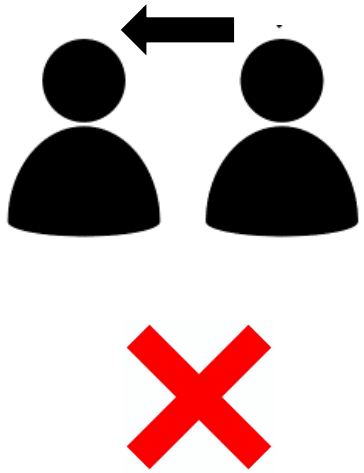
- Limited public awareness
- Low correlation between perceptions and the medical literature
- Negative connotations / stigma
- Existing content on frailty of a predominantly **technical** nature and aimed at healthcare professionals
- **Extremely limited online information resources** on frailty for the general public

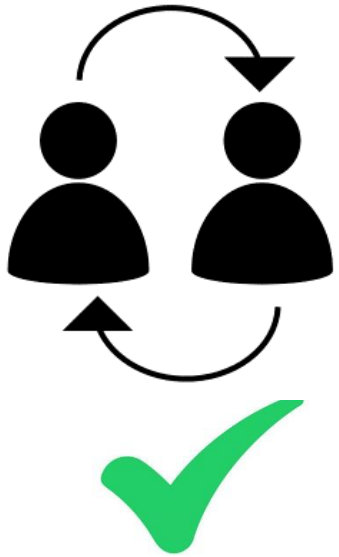
Perceptions among older people and informal carers

Age UK and the British Geriatrics Society (2015). Frailty: Language and Perceptions

Patient and Public Involvement (PPI)







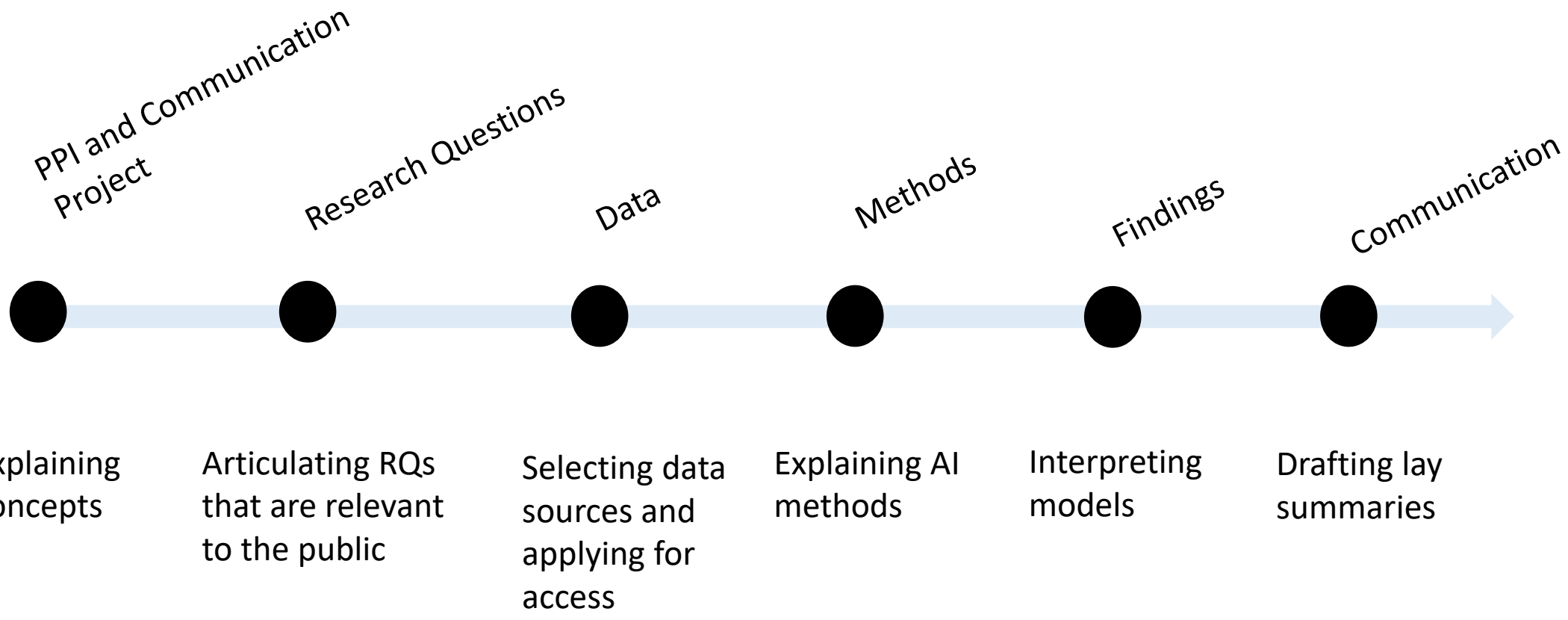
NHS Health Research Authority

"Public involvement in research means research that is done 'with' or 'by' the public, not 'to', 'about' or 'for' them. It means that patients or other people with relevant experience contribution to how research is designed, conducted and disseminated"

Including Patients and Clinicians in the Team

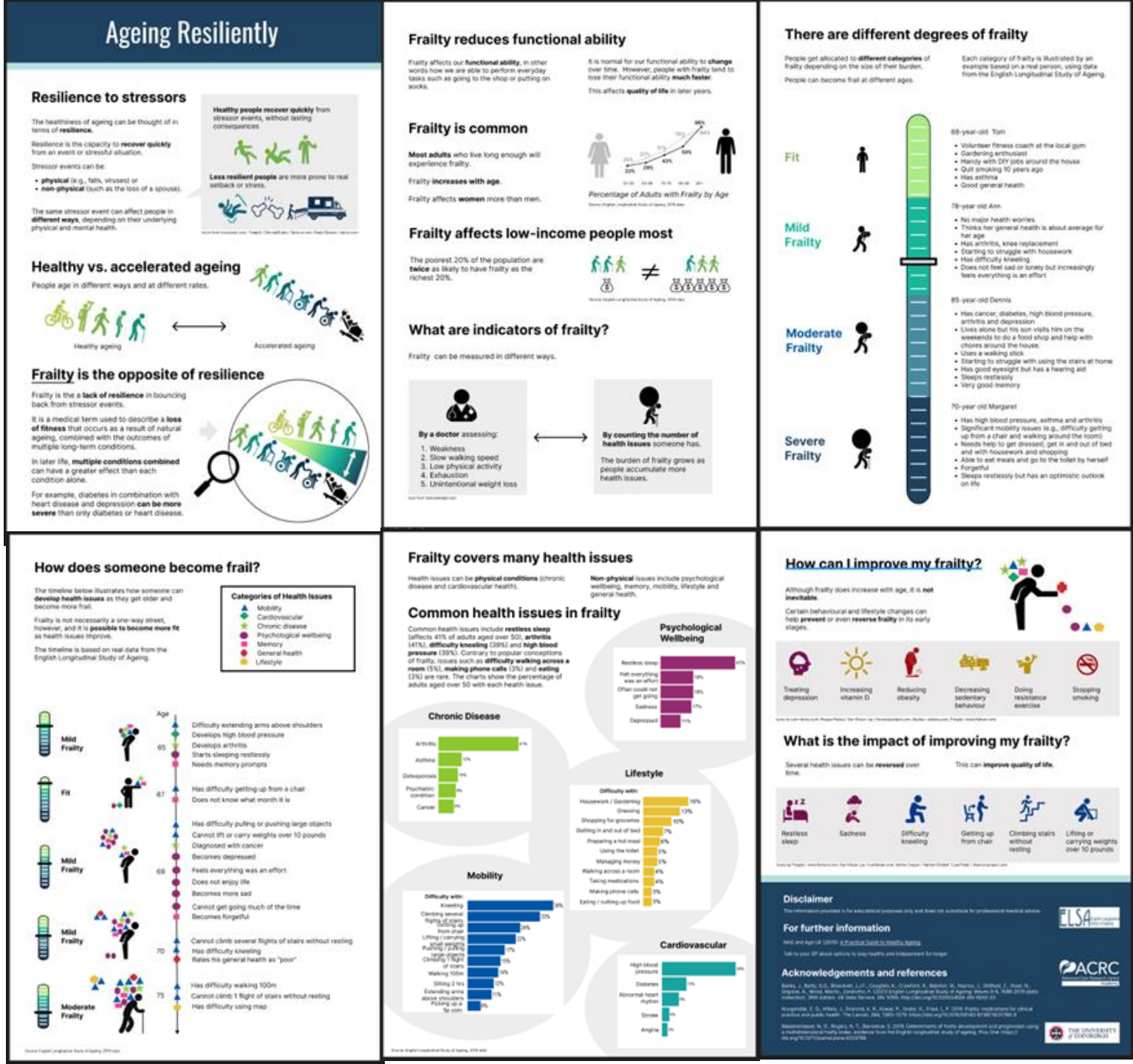
- Lara Johnson, PhD Student
- Dr Sohan Seth, Lead Data Scientist
- Dr Atul Anand, Consultant Geriatrician
- Professor Alan Marshall, Social Research on Inequality
- Professor Bruce Guthrie, GP
- PPI Group of lay people in later life

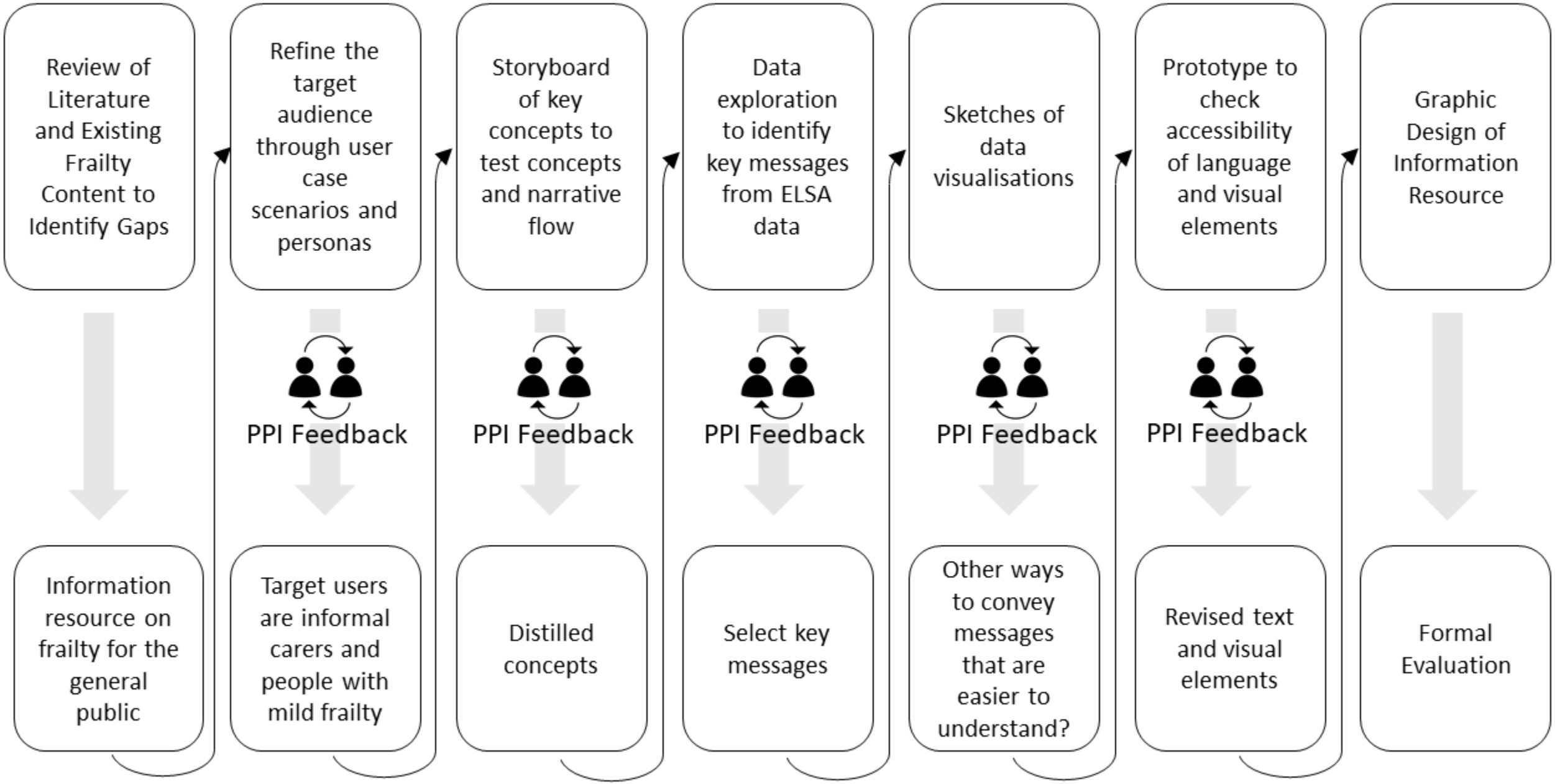
Embedding PPI in the Project Timeline



Frailty Information Resource

- **Co-designed with members of the public** to ensure relevance and accessibility
- All key messages **grounded in data**
- **Visual elements** used to enhance text-based content




Review of Literature and Existing Frailty Content to Identify Gaps
Refine the target audience through user case scenarios and personas
Storyboard of key concepts to test concepts and narrative flow
Data exploration to identify key messages from ELSA data
Sketches of data visualisations
Prototype to check accessibility of language and visual elements
Graphic Design of Information Resource
PPI Feedback
PPI Feedback
PPI Feedback
PPI Feedback
PPI Feedback
Information resource on frailty for the general public
Target users are informal carers and people with mild frailty
Distilled concepts
Select key messages
Other ways to convey messages that are easier to understand?
Revised text and visual elements
Formal Evaluation

Outreach

Wed 08/11/2023 17:46

Coull, Andrew <Andrew.Coull@nhslothian.scot.nhs.uk>

Frailty info

To Lara Johnson

Hi Lara

I hope you are well. I wanted to give you an update on the frailty work and the positive impact of the poster / leaflet and get your 'permission' for wider sharing.

We made the leaflet into a massive poster which is in all the community hospitals and day hospitals.

We use the leaflet in conversations with our patients when discussing frailty with them and their families.

I have referenced the leaflet in talks to GPs and on RefHelp (GP referral system for GPs for all specialities) and hope to send out to all Lothian GPs when we aim to encourage them to use the Clinical Frailty scale.

So...absolutely brilliant and very far reaching!

Are you okay with me sharing with GPs and as a resource on Ref Help?

Best wishes

Andrew

Background – The Clinical Context

Frailty reflects a state of **increased vulnerability** to adverse health outcomes for individuals of the same chronological age

- Counts the number of health deficits someone has
- The burden of frailty grows as people accumulate more health deficits
- Can be quantified in a frailty index
- Uses pre-existing data

Rockwood, K., & Howlett, S. E. (2018). Fifteen years of progress in understanding frailty and health in aging. *BMC medicine*, *16*(1), 1-4.

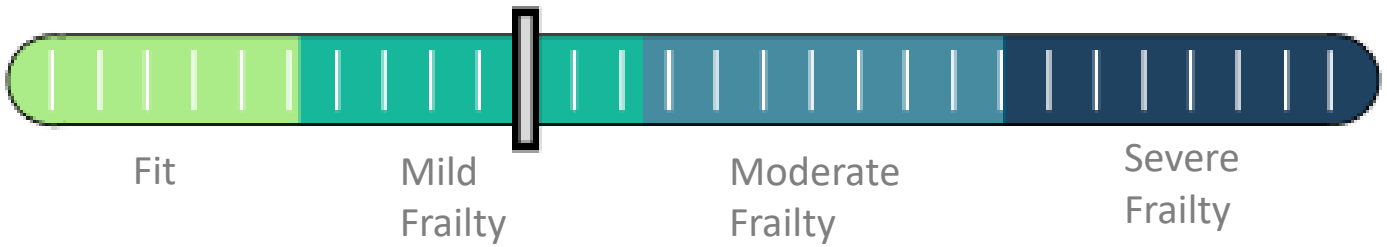
How a Frailty Index Works

Gather data from electronic health records

Calculate frailty scores

$$\text{Frailty Index} = \frac{\text{Number of health deficits}}{\text{Number of health deficits measured}}$$

Categorise patients



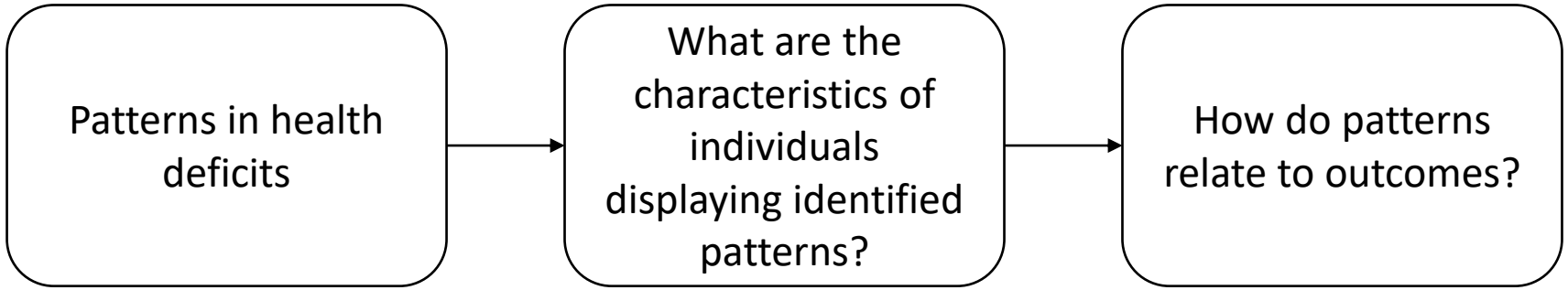
Make clinical decisions

Additional GP appointments, polypharmacy reviews, referrals, treatment

Clegg, A., Bates, C., Young, J., Ryan, R., Nichols, L., Ann Teale, E., ... & Marshall, T. (2016). Development and validation of an electronic frailty index using routine primary care electronic health record data. Age and ageing, 45(3), 353-360.

Research Questions

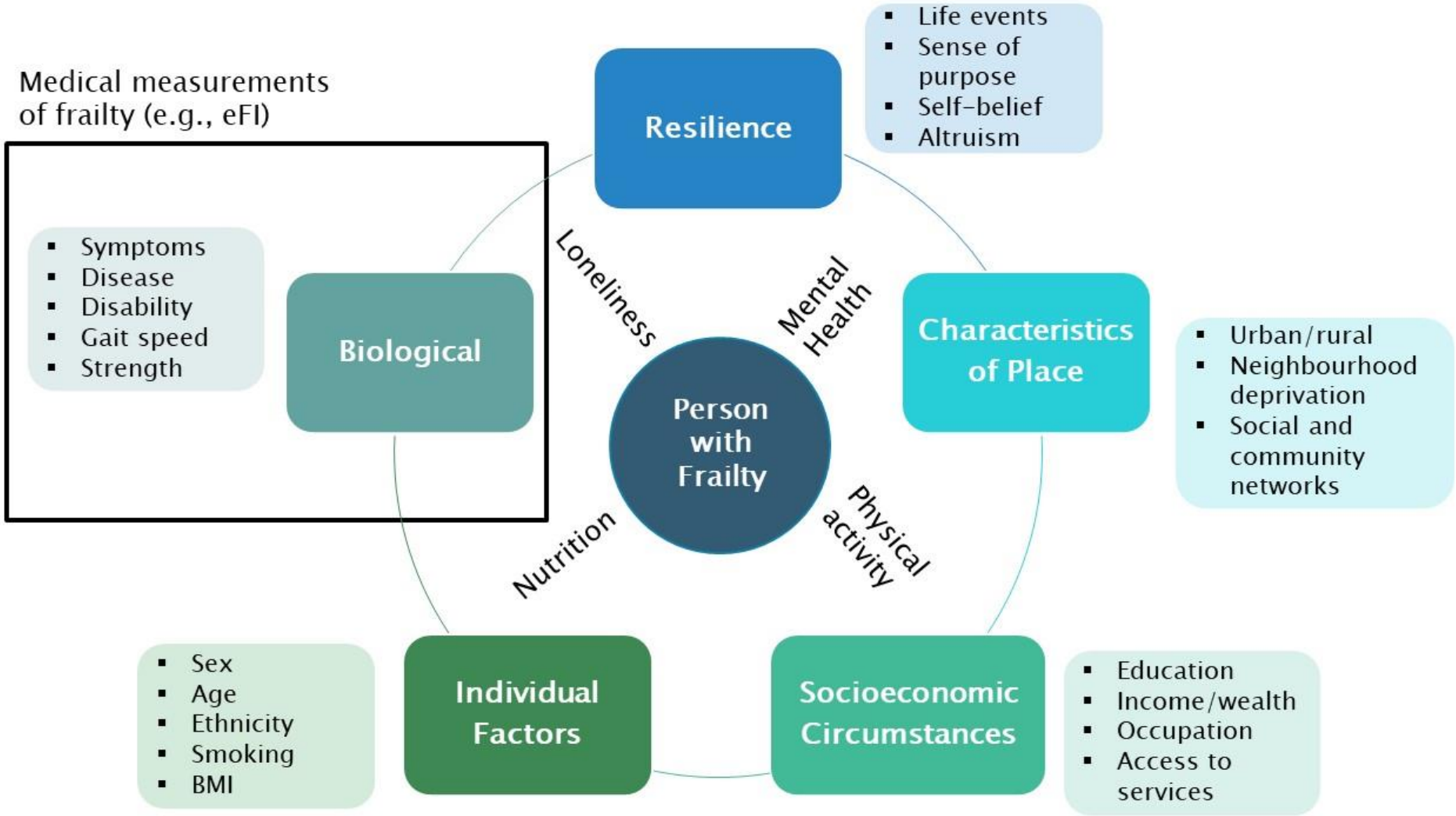
Aim: Identify subtypes of frailty



Do findings replicate in survey data and EHR?

Do findings make sense to patients and clinicians?

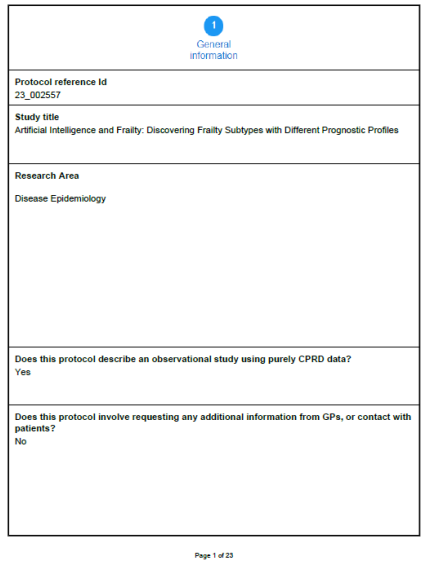
Viewing Frailty Holistically



Holistic model of frailty (adapted from Hale, Shah & Clegg, 2019)

Choosing the Data Sources

PPI Input on Detailed Protocol



Medicines & Healthcare products Regulatory Agency

CPRD

1 General information

Protocol reference Id
23_002557

Study title
Artificial Intelligence and Frailty: Discovering Frailty Subtypes with Different Prognostic Profiles

Research Area

Disease Epidemiology

Does this protocol describe an observational study using purely CPRD data?
Yes

Does this protocol involve requesting any additional information from GPs, or contact with patients?
No

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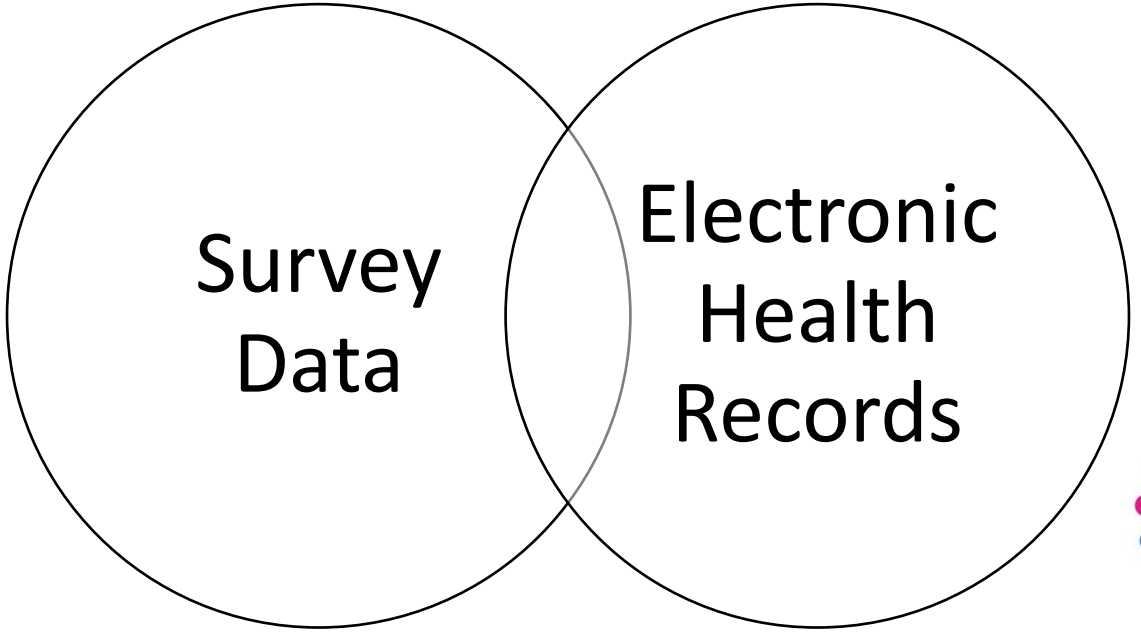


ELSA English Longitudinal Study of Ageing

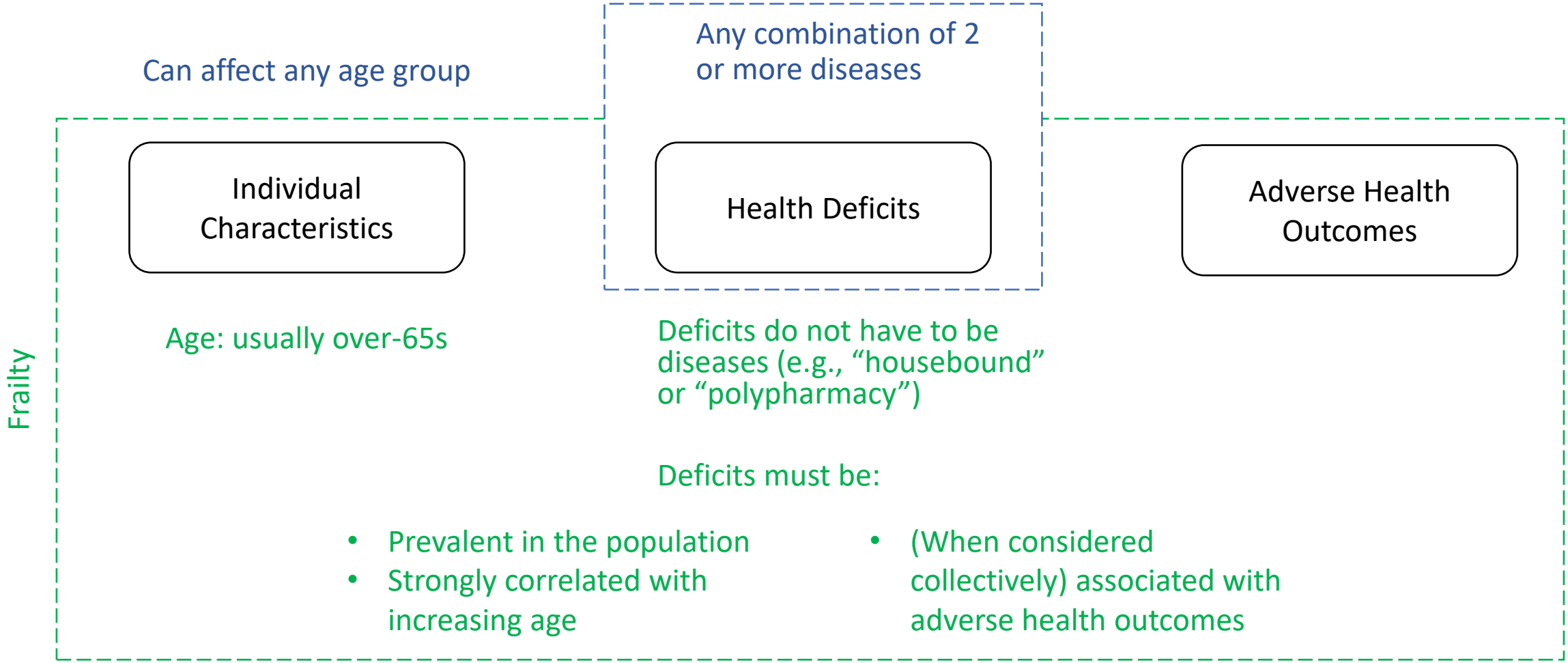
- N ~ 10,000 community-dwelling adults aged 50+ in England
- 2002-2019

CPRD MORE DIMENSIONS TO DATA

Clinical Practice Research Datalink

- N ~ 3.5m patients aged 50+ in England registered with a GP > 1 year
- 2010-2019

Distinguishing frailty from multimorbidity



Searle SD, MitnitskiA, GahbauerEA, Gill TM and Rockwood K. A standard procedure for creating a frailty index. BMC Geriatr. 2008;8:24.

Selecting the Variables of Interest

Independent Variables / Predictors

Individual Characteristics

- Sex
- Age
- *Place*
- *Socioeconomic information*

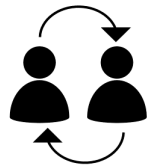
Health Deficits

- Health conditions
- *Mobility*
- *Activities of daily living*

Outcome Variables

Adverse Health Outcomes

- Mortality from any cause
- Unscheduled hospital admissions
- Falls
- Hip fractures



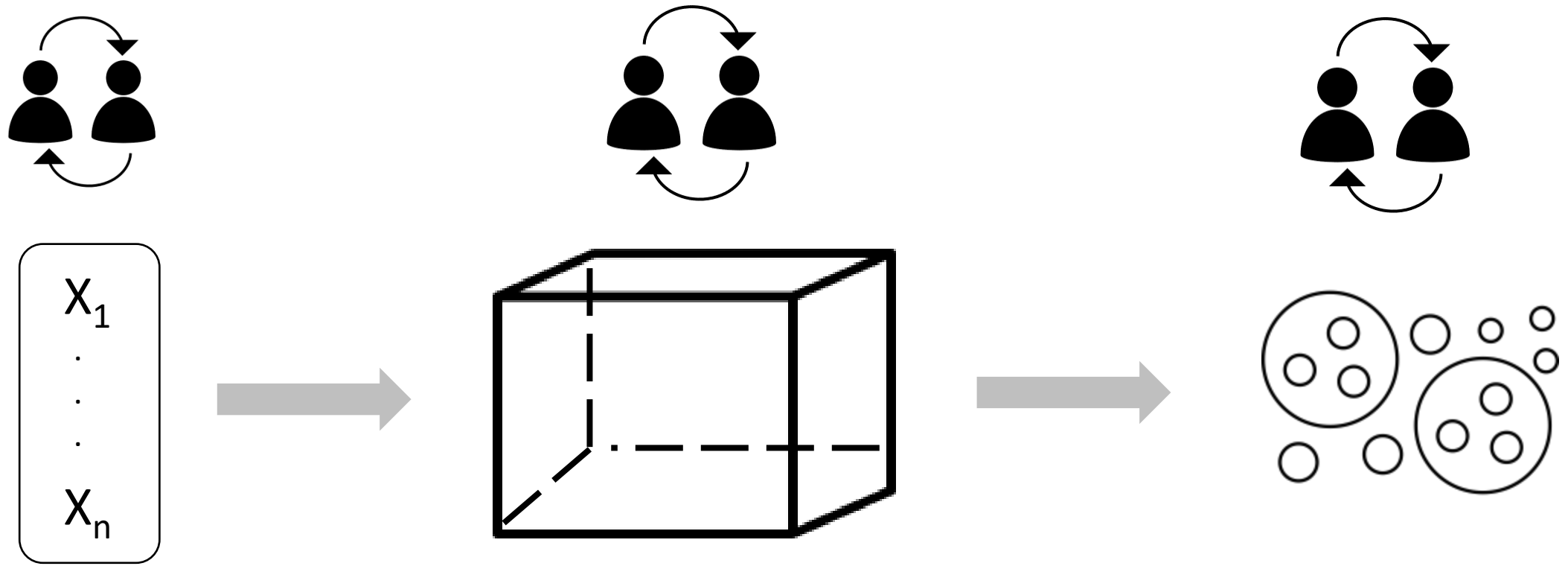
- *CASP-19 Quality of Life*
- *Whether receives care*

Defining the Study Population

Respondents aged 65+ in Wave 9 (2018-2019) with missing data < 20 deficits

	Men		Women		Total	
	N	**%**	**N**	**%**	**N**	**%**
N	2156	43.4%	2815	56.6%	4971	
Age (Years)						
65-69	563	26.1%	731	26.0%	1294	26.0%
70-79	1052	48.8%	1293	45.9%	2345	47.2%
80-89	483	22.4%	670	23.8%	1153	23.2%
90+	58	2.7%	121	4.3%	179	3.6%
Number of Deficits						
0	122	5.7%	108	3.8%	230	4.6%
1-5	1145	53.1%	1178	41.8%	2323	46.7%
6-10	464	21.5%	679	24.1%	1143	23.0%
11-15	200	9.3%	376	13.4%	576	11.6%
16+	225	10.4%	474	16.8%	699	14.1%
Number of Deficits, mean (SD)	6.56 (6.29)		8.54 (7.31)		7.68 (6.96)	
Frailty index score, mean (SD)	0.113 (0.109)		0.147 (0.126)		0.132 (0.119)	
CASP-19 score, mean (SD)	42.80 (7.90)		42.50 (8.27)		42.64 (8.11)	

Using Interpretable Methods



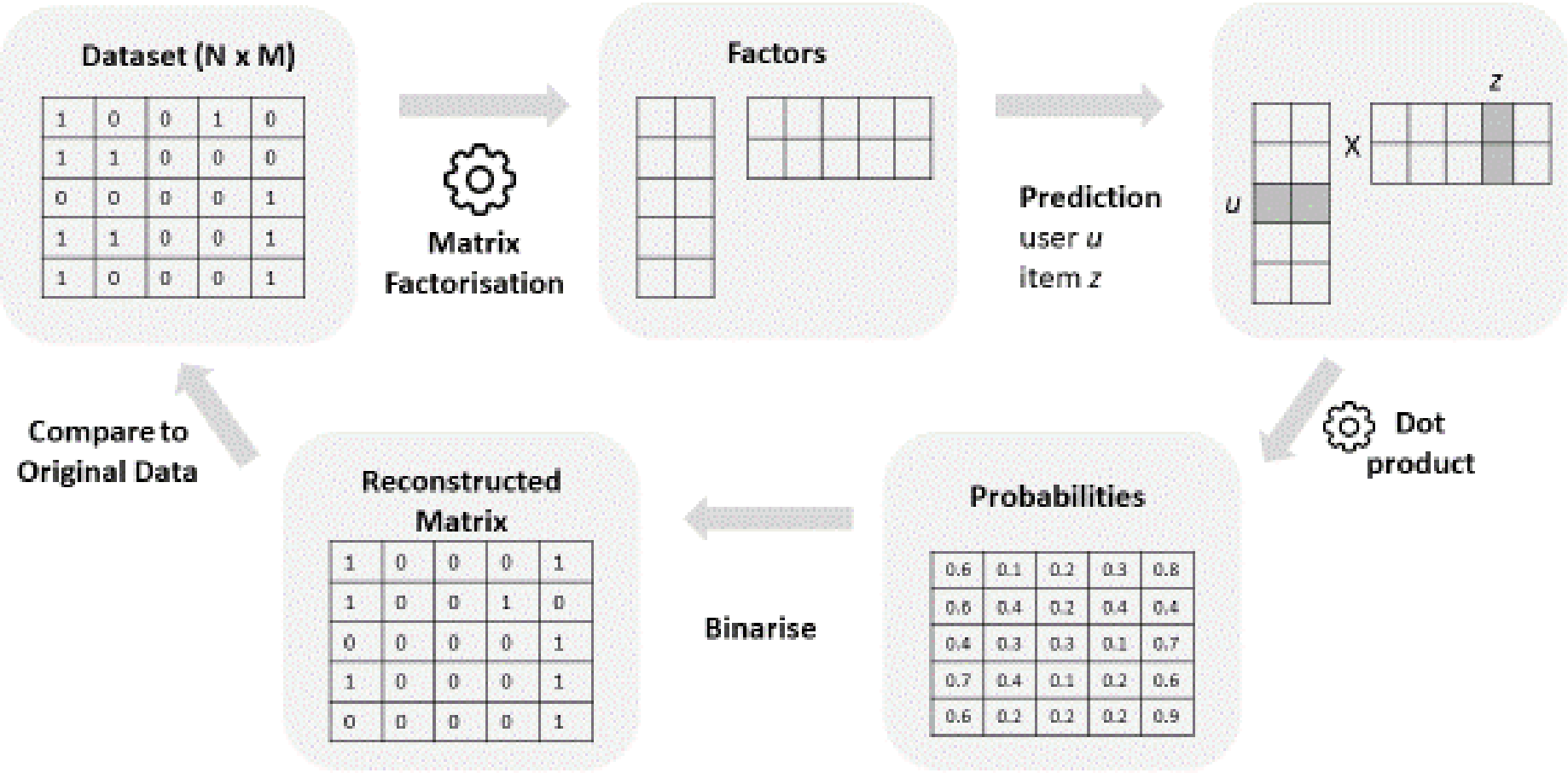
Data

Model

Findings

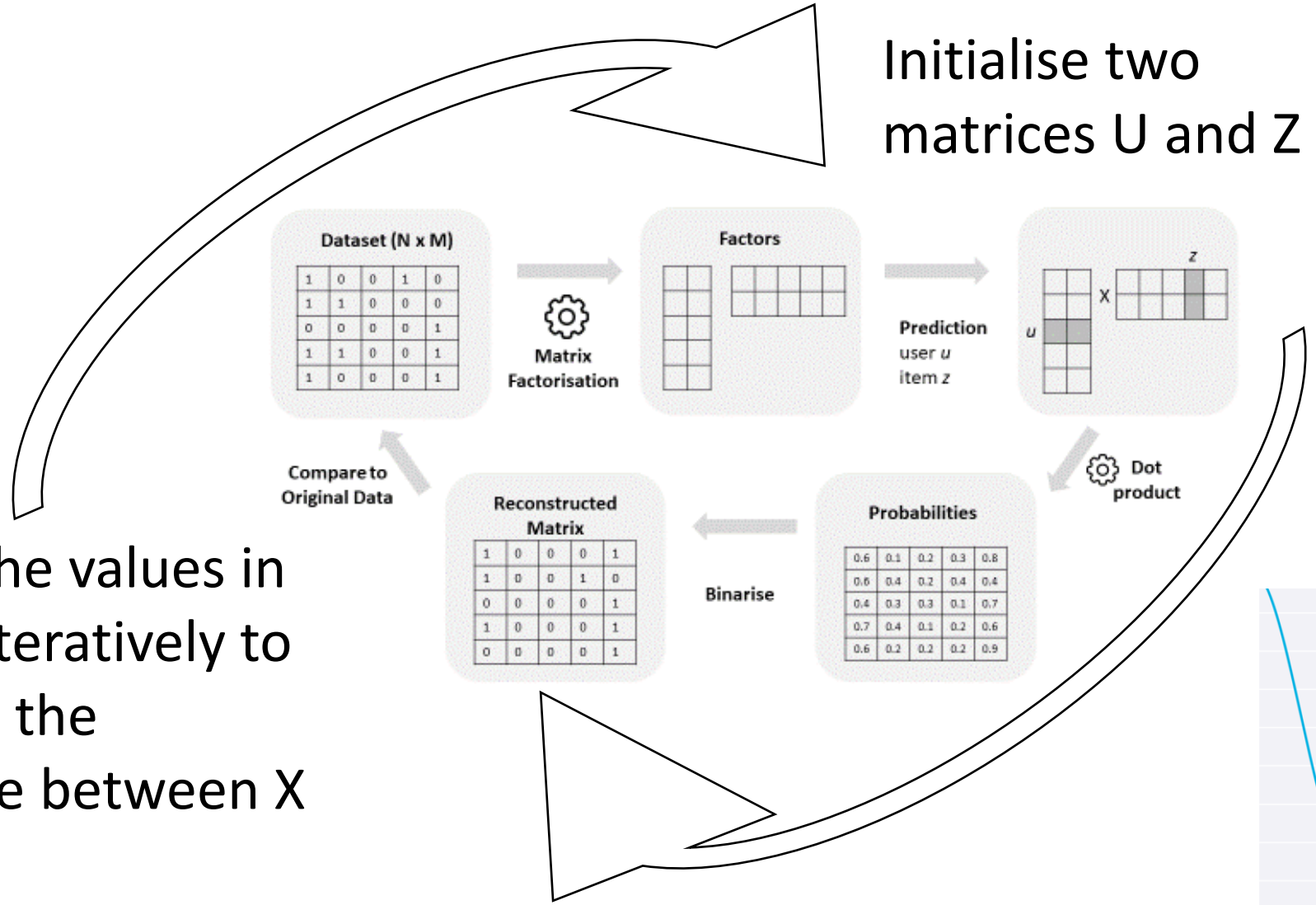
Boolean Matrix Factorisation (BMF)

Identifies groups of patients and groups of deficits



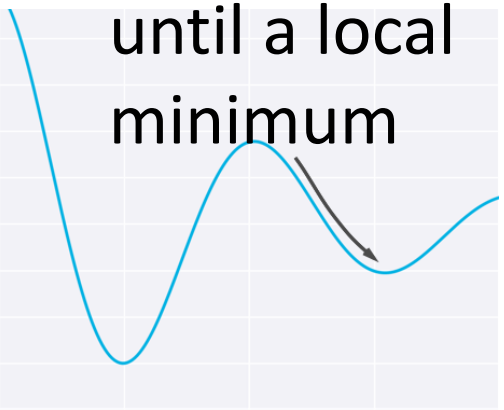
Iteration with Expectation Maximisation

Initialise two matrices U and Z



Update the values in U and Z iteratively to minimise the difference between X and U*Z

Converges until a local minimum



Model Evaluation and Selection

Reconstruction Error

$$\mathrm{err} = \left|\widehat{X} - X\right| / \left(NM\right)$$

Interpretability

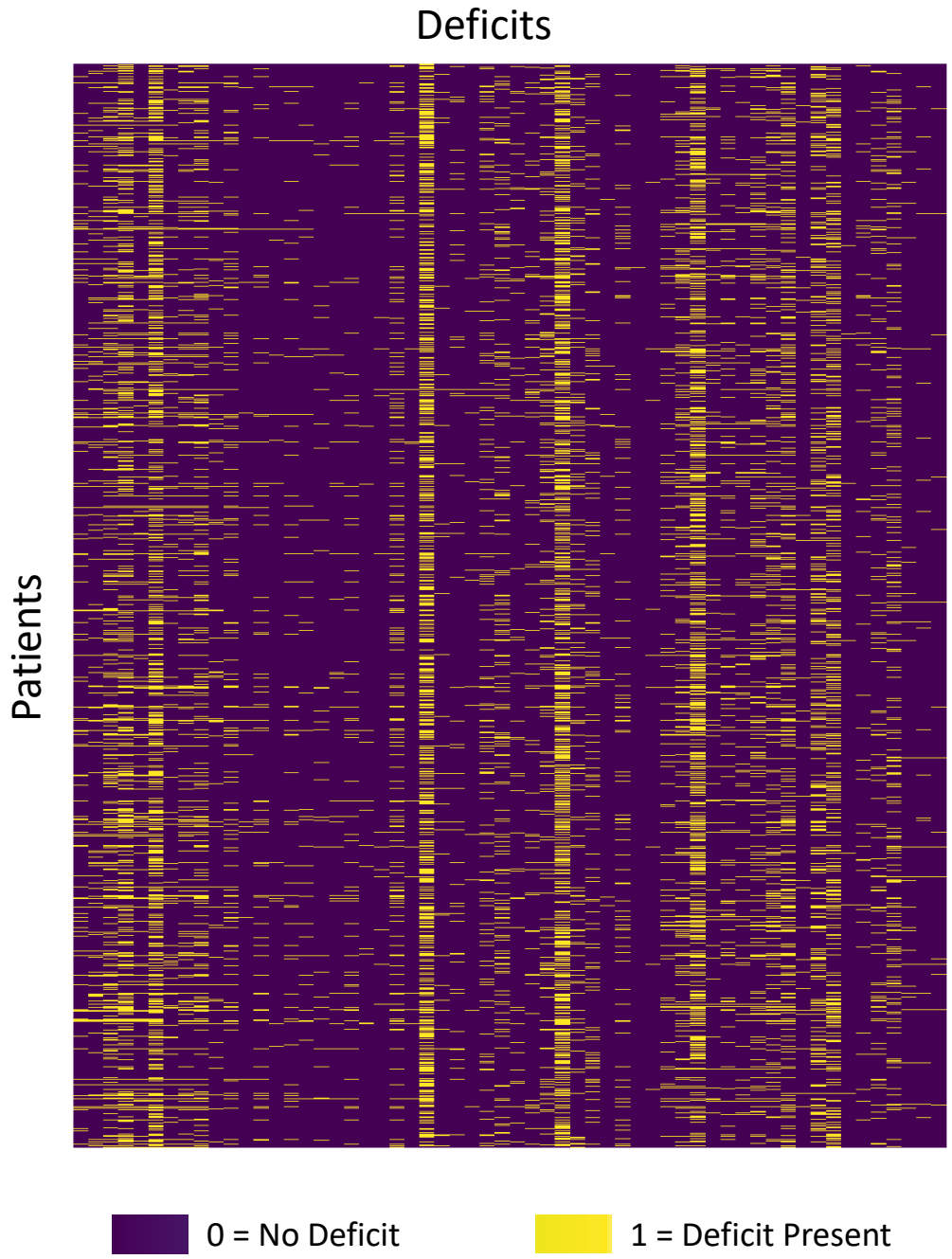
Do factors make sense to doctors and patients?

Prediction accuracy

Do factors better predict outcomes?

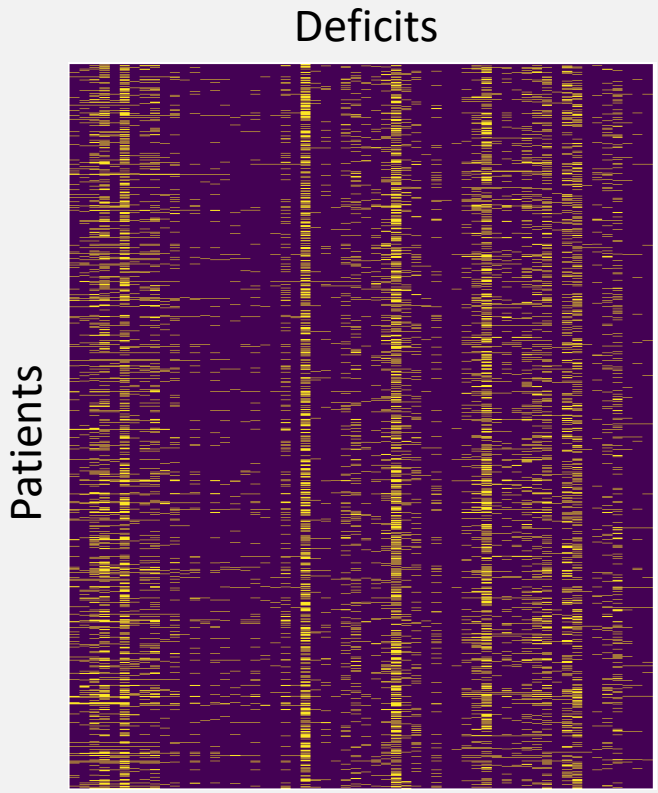
Visualising the Data

	Chronic Disease	Cardiovascular	Activities of Daily Living	Mobility	Psychological	Memory
ID	Arthritis	Heart-attack	Difficulty managing money	Difficulty walking	Depressed	Does not remember the year
Patient1	■					
Patient2	■		■	■		
Patient3		■				
Patient4	■		■			■
Patient5					■	



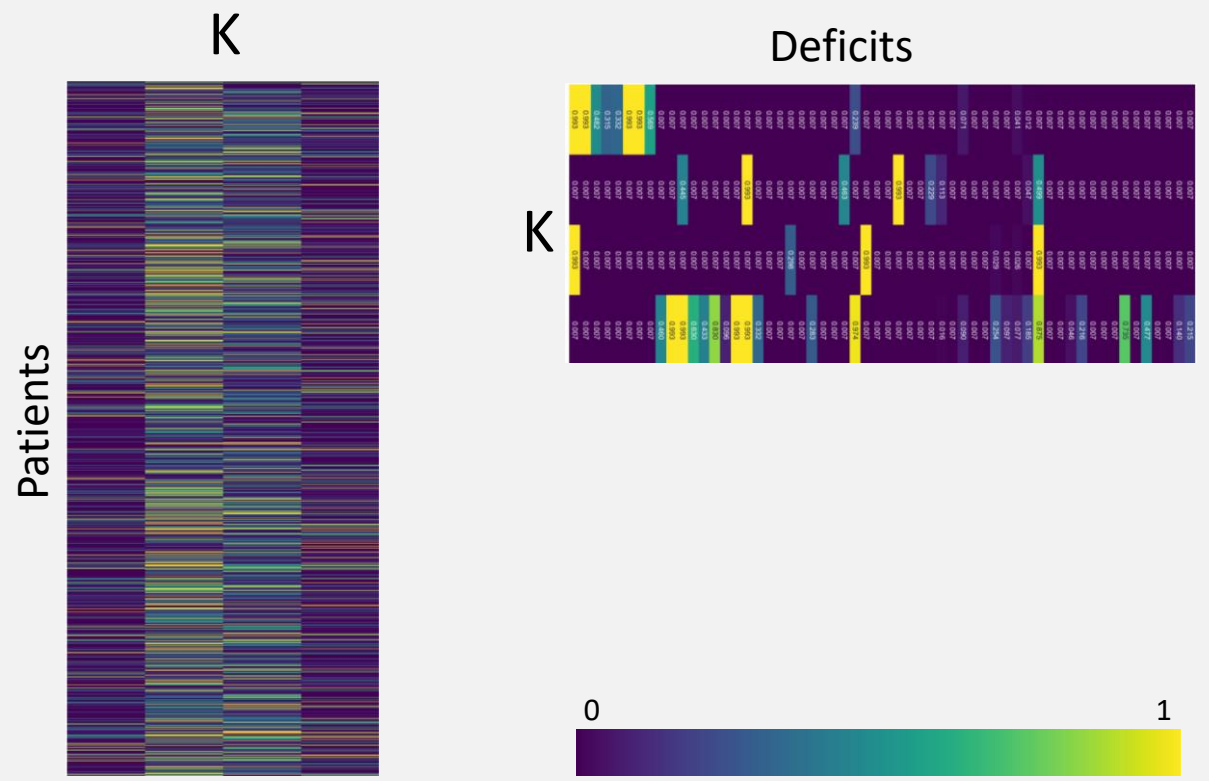
Decomposing into Latent Factors

Original Data

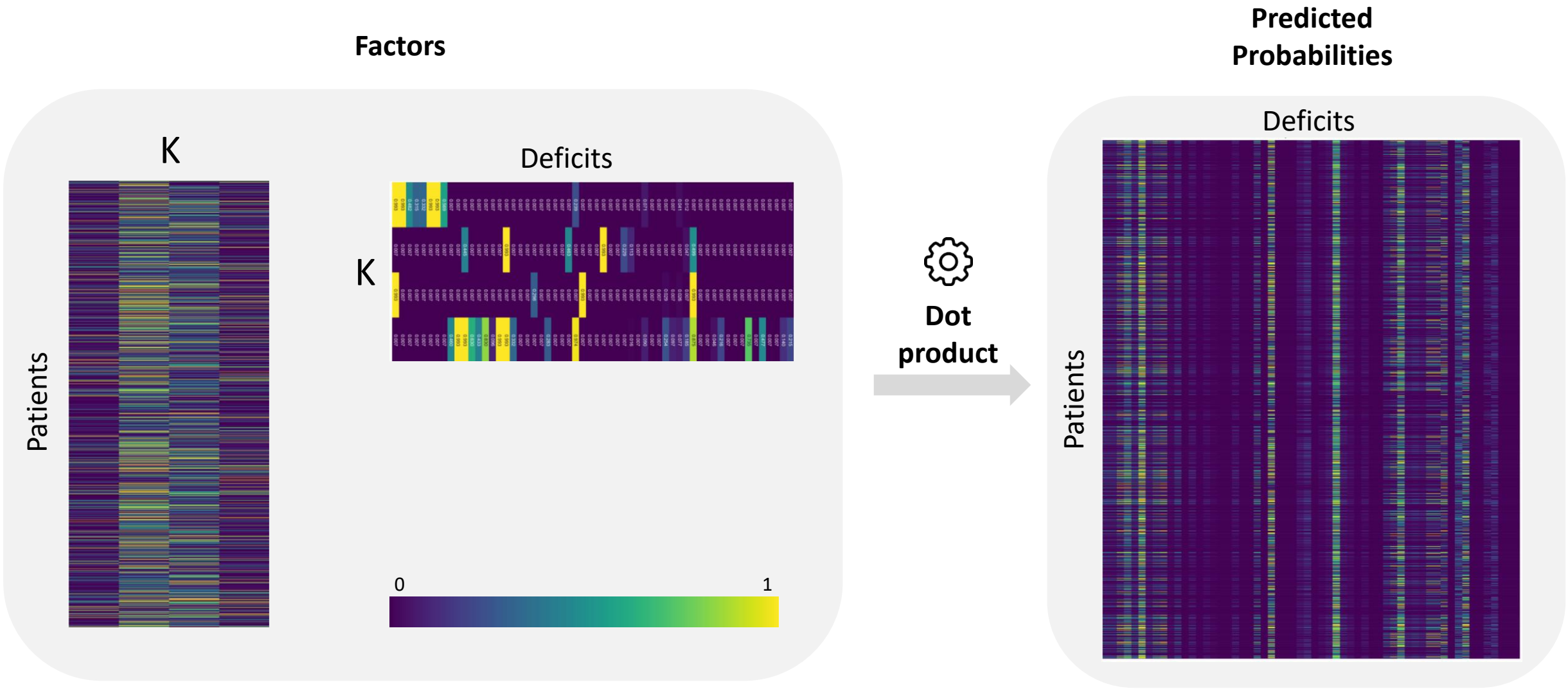


Matrix Factorisation

Factors

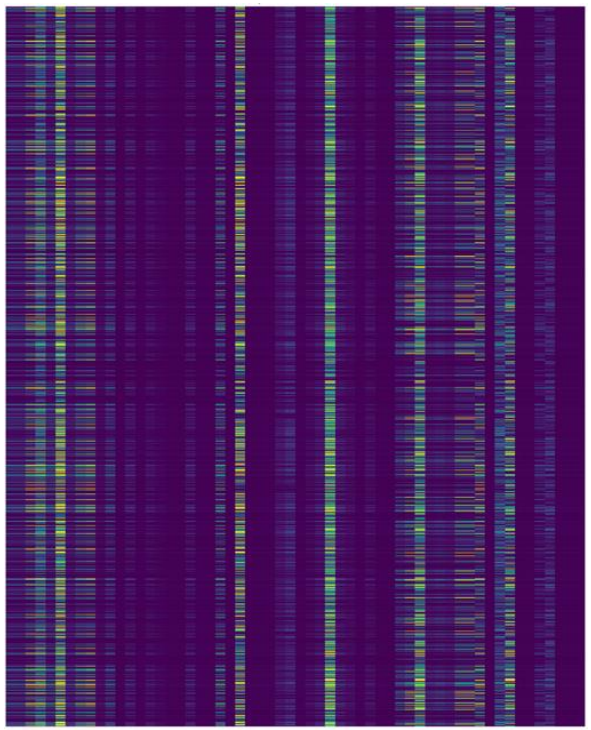


Predicting Probabilities



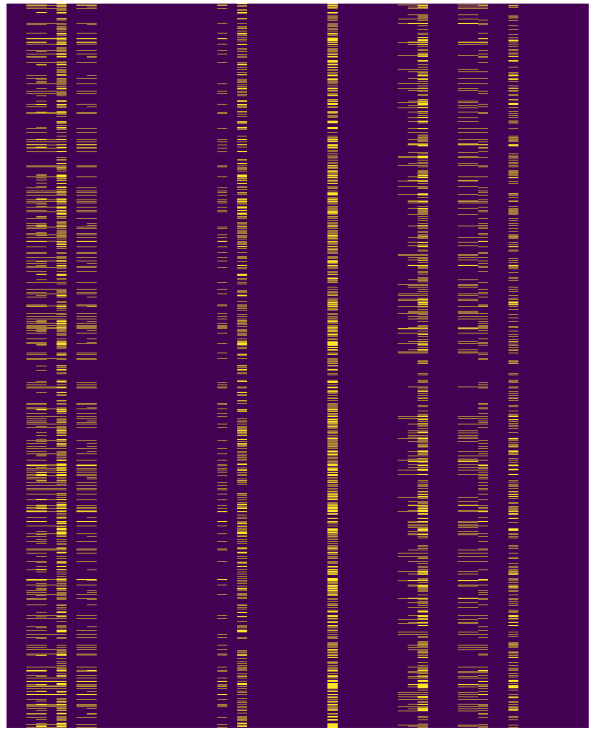
Reconstructing the Data

Predicted Probabilities



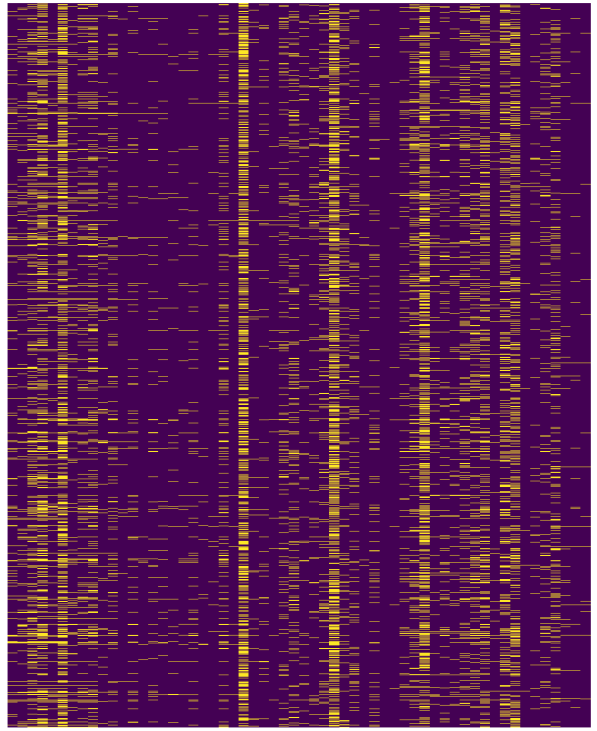
Binarise

Reconstructed Matrix (K = 4)



Compare to Original Data

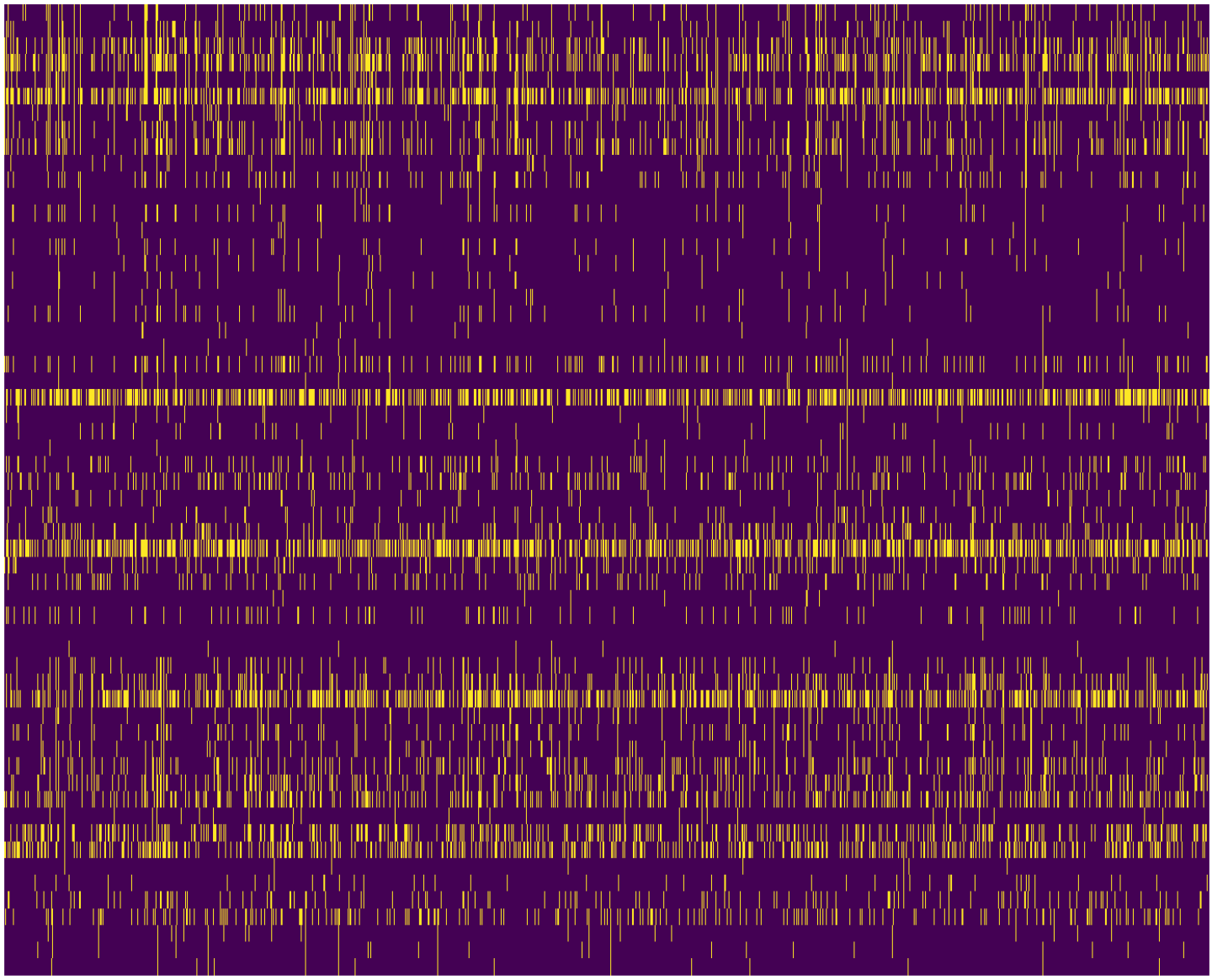
Original Data

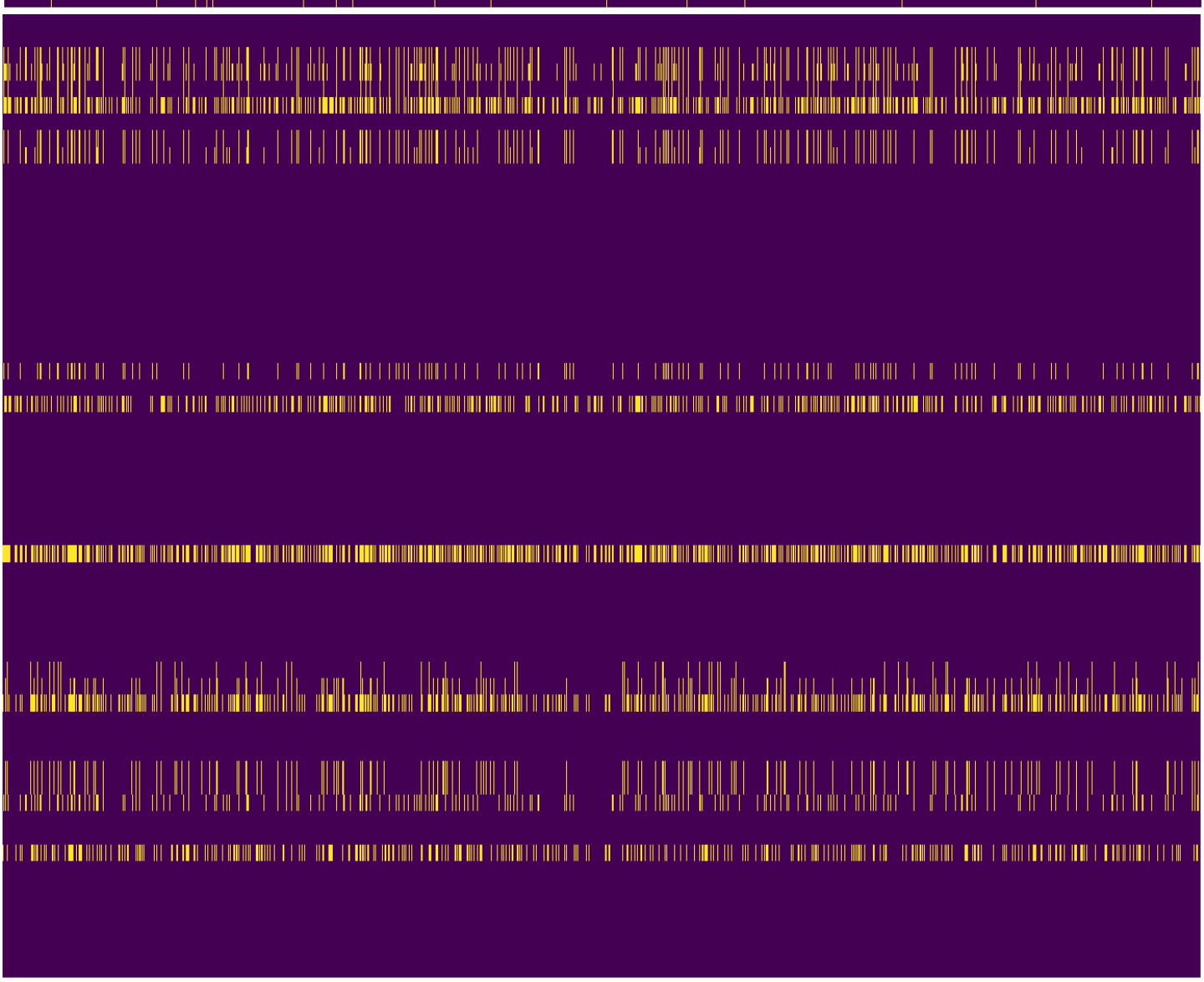


0 = No Deficit

1 = Deficit Present

Original Data

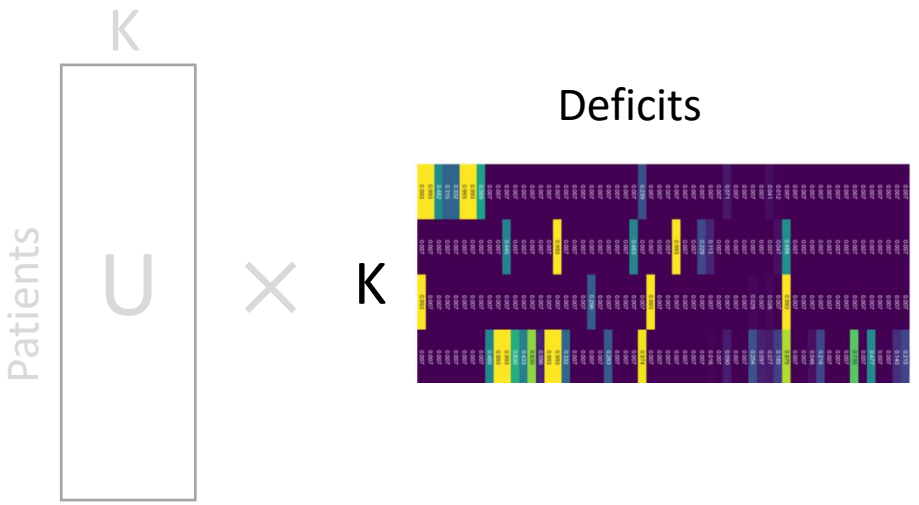




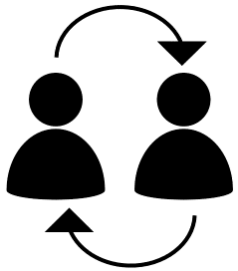
Reconstructed Matrix (K = 4)

Interpretability

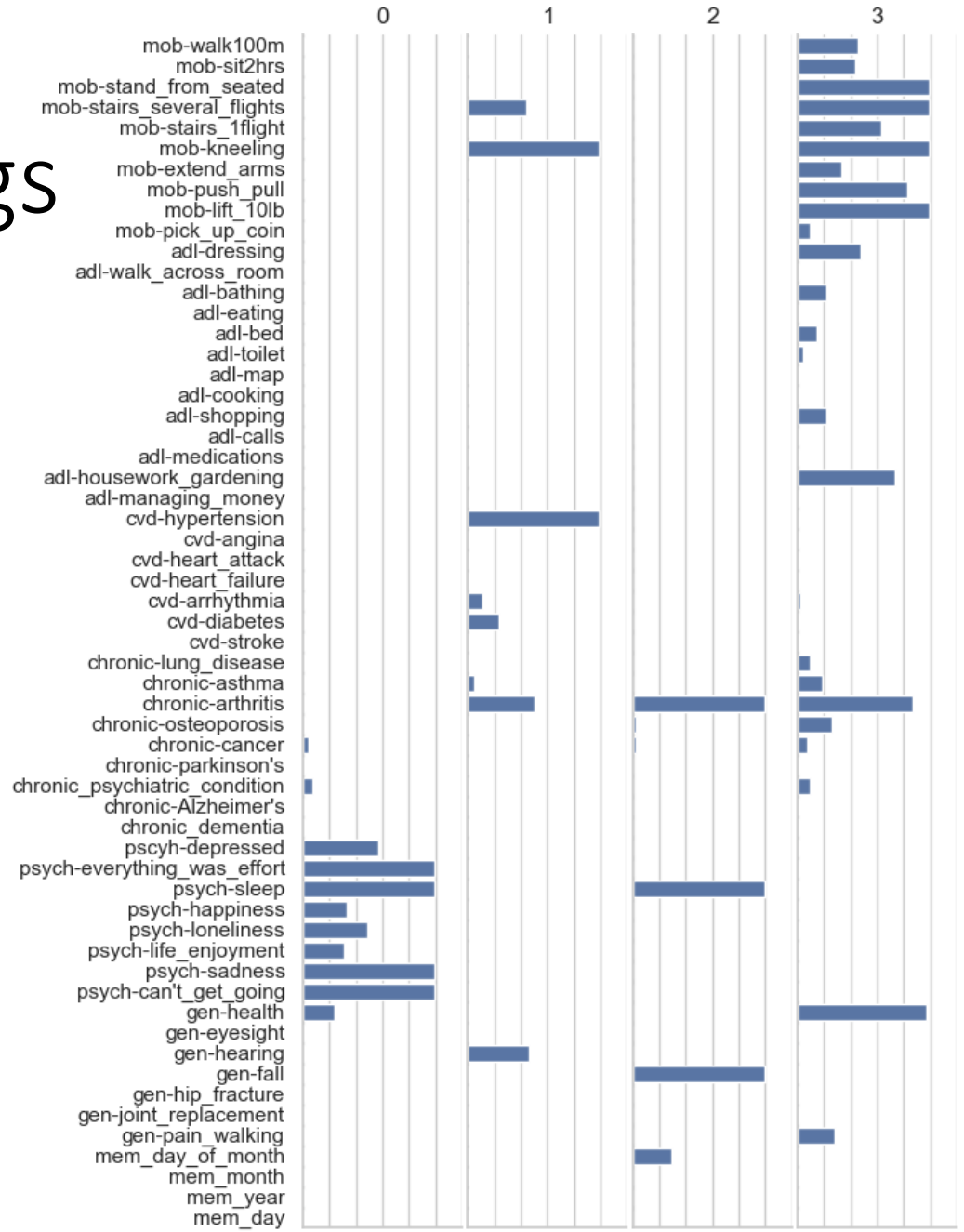
- Saliency of factor loadings (> |0.20|)
- Factors with a minimum of three salient deficit loadings
- Deficits load highly onto one factor
- Parsimony (simpler model with fewer parameters)
- Theoretical meaningfulness

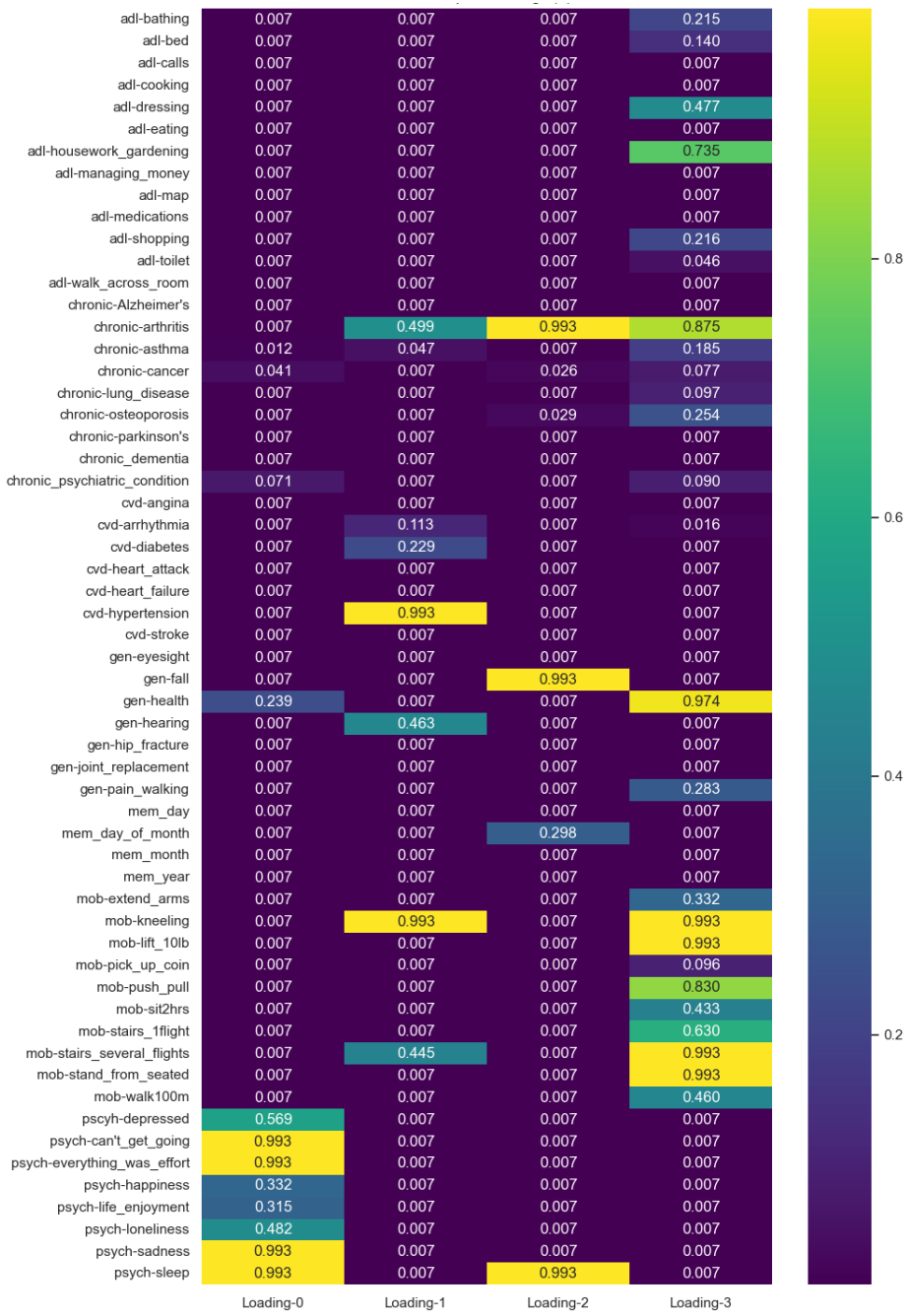


Deficit Loadings



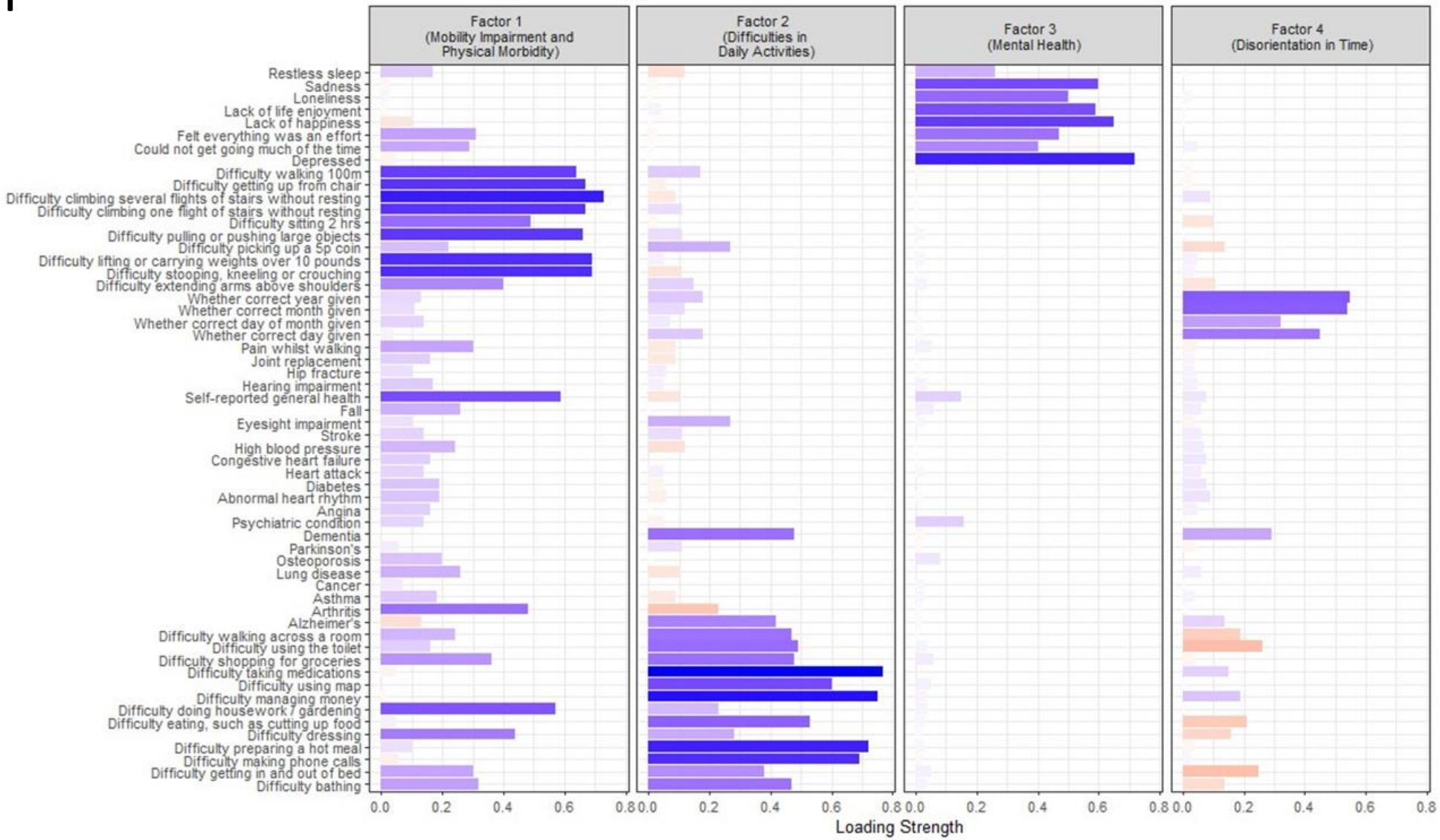
Feedback from PPI mentor and clinicians





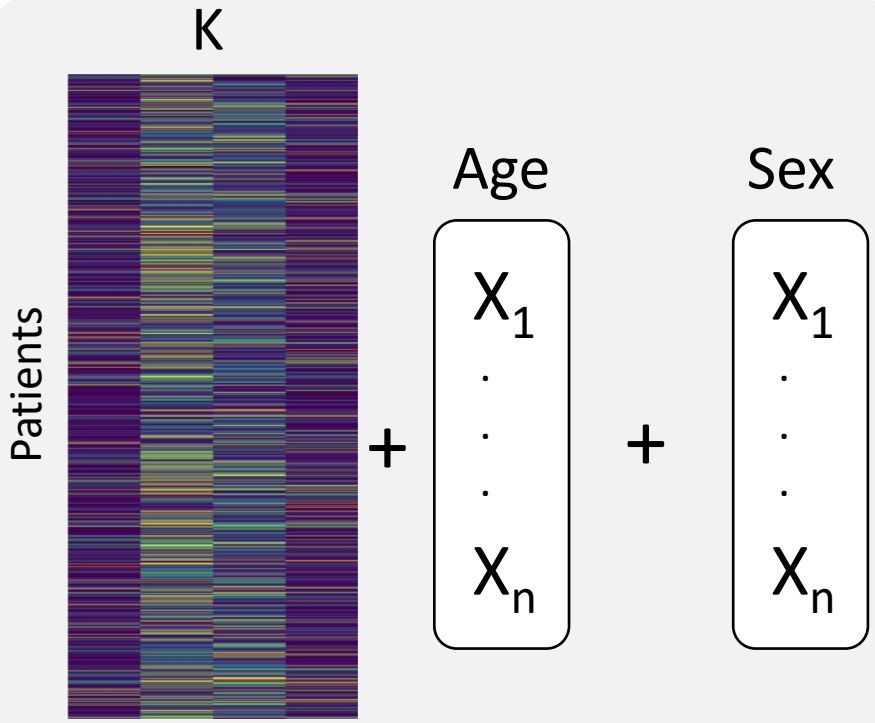
Four subtypes of frailty?

1. Mobility Impairment and Physical Morbidity
2. Difficulties in Daily Activities
3. Mental Health
4. Disorientation in Time

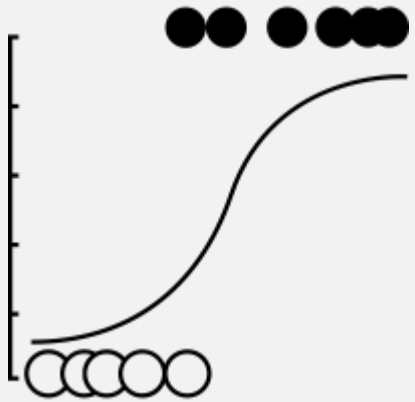


Predicting care needs

Boolean Matrix Factorisation



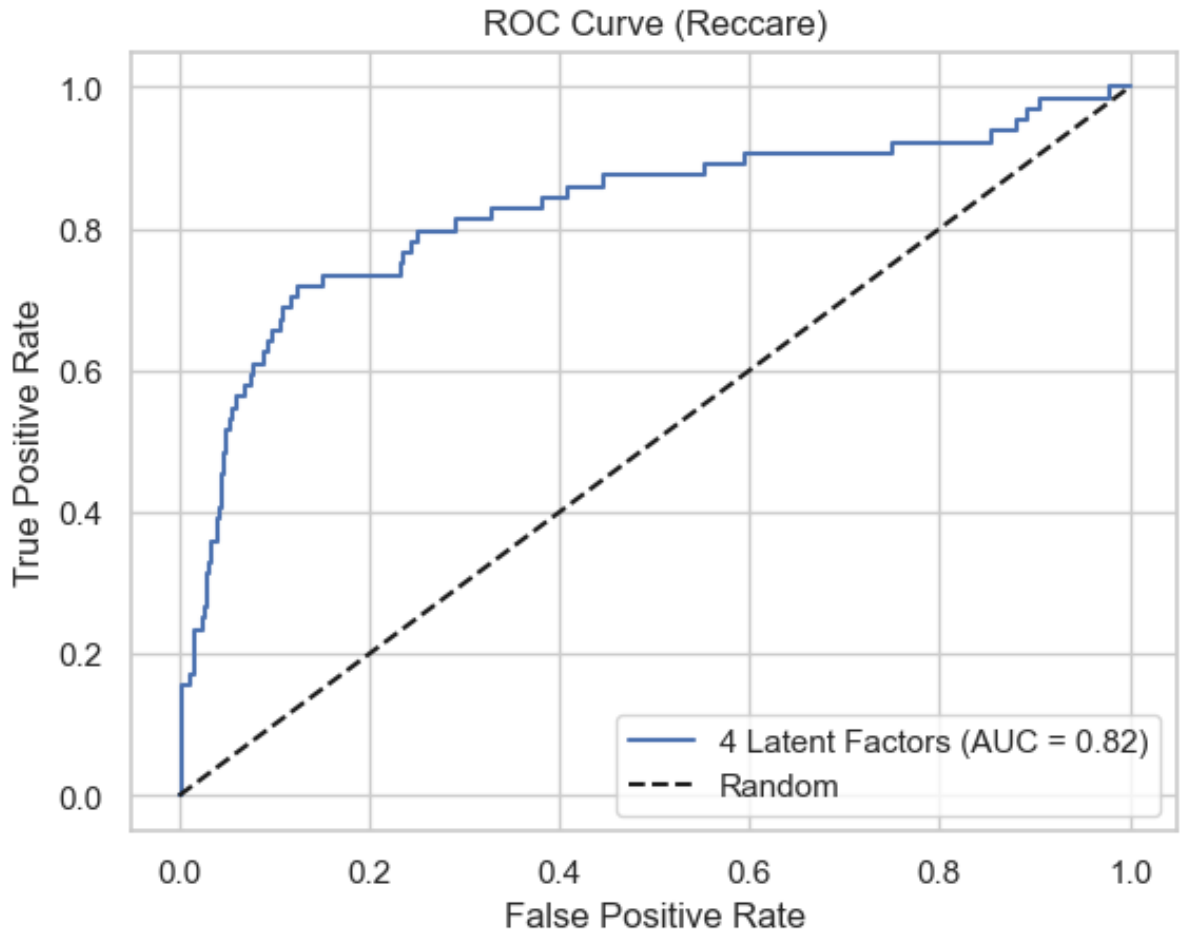
Logistic Regression



Receives care

Does not receive care

Test Accuracy: 91.3%



Future Work

- Methodological contribution for sparse data > improve outcomes prediction
- Investigating the relationship between the factors and patients' individual characteristics
- Replicating in electronic health records (CPRD)

Patients and Clinicians involved through:

- Inclusion in the research team
- Guiding the research direction
- Evaluating and selecting model
- Interpreting results
- Outreach

Thank you!

Questions?

LinkedIn

Lara.johnson@ed.ac.uk