**Multiple long-term conditions (multi-morbidity) in people with Intellectual Disability**

**30 November 2023**

# Multiple long-term conditions (multi-morbidity) in people with Intellectual Disability

Chaired by Dr Deepa Bagepalli Krishnan

Speakers:

Alix Glazier, an expert by experience

Sarah Rabbitte, LD nurse, Leicestershire Partnership NHS Trust

Dr Gemma Lewin, Speciality trainee, Leicestershire Partnership NHS Trust

Dr Amala Jesu, Clinical Director, Leicestershire Partnership NHS Trust

Dr Satheesh Gangadharan, Consultant Psychiatrist, Leicestershire Partnership NHS Trust

# RCPsych Dean's Grand Rounds

**Patient experience**

Alix Glazier, an expert by experience

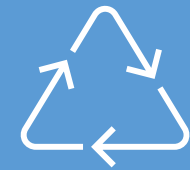Sarah Rabbitte, LD nurse, Leicestershire Partnership NHS Trust

**Academic evidence**

Dr Gemma Lewin, Speciality trainee, Leicestershire Partnership NHS Trust

**What does data tell us?**

Dr Amala Jesu, Clinical Director, Leicestershire Partnership NHS Trust

**Local initiatives to drive change**

Dr Satheesh Gangadharan, Consultant Psychiatrist, Leicestershire Partnership NHS Trust

Questions

Questions +panel discussion

# Multiple long-term conditions (MLTC) in people with intellectual disability (ID)

# Evidence base

**Dr. Gemma Lewin**

# Multiple long-term conditions

- Two or more co-existing conditions in an individual
- 1 in 3 adults globally, increasing significantly with age and level of socioeconomic deprivation
- Associated with premature death, poor quality of life, increased health service utilisation
- One of the most significant challenges faced by global healthcare
- Primer published in Nature (Skou et al., 2022)
  - Little is known about the prevention of MLTC
  - Little evidence exists to support any specific approach to the management of MLTC

# What can be taken from existing research in the general population?

A systematic review of 566 studies on MLTC noted that >50% considered the occurrence of only 8 common conditions, and 21.5% of studies did not consider any mental health condition (Ho et al., 2021) *The Lancet Public Health*.

A modified Delphi study produced a consensus on conditions that should be included for future MLTC research. Intellectual disability was not considered (Ho et al., 2022) *BMJ Medicine*.

Intellectual disability was initially absent from national guidance for MLTC and is now present in definition alone (NICE). There is no specific guidance that has been curated for people with ID and MLTC.

# MLTC in ID

A population based cross-sectional analysis observing primary health care data for >1.4 million adults in Scotland. >8000 (0.54%) had a diagnosis of ID. (Cooper et al, 2015) *Published in BMC Family Practice*

- **A call for guidance tailored to people with intellectual disability**
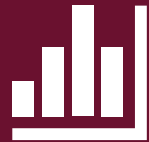
**68.2%** had MLTC

Significantly likely to have a **greater number of conditions**

**Similar across all socioeconomic levels**

**Increases with age.** People with ID have **similar prevalence of MLTC at age 20-25 as the general population age 50-54**.

MLTC prevalence **increased in females.**

The **profile of health conditions differs to the general population.**

# ID and MLTC clusters

- Clusters are co-occurring long term conditions
  - Further understanding about the nature of MLTC in ID
  - Determine whether there are links between co-occurring MLTC
  - Identify subgroups of individuals that may benefit from focussed prevention strategies

**Only 15% (n=3) of studies reported on clusters**

**40% of studies focused on people with specific chromosomal conditions or subgroups of people with intellectual disability**

**55% of studies focused on people with a defined severity of intellectual disability**

# A note on psychiatric disorders

- Age standardised **prevalence of MTLC 38.8% compared to 29.6% in general population** (Filipčić et al., 2018) *Journal of Psychosomatic Research*

- Meta-analysis and call to action for SMI and multiple long-term conditions: **Pooled OR 1.84** (95% CI 1.33 to 2.54) (Pizzol et al., 2023) *BMJ Mental Health*

- Risk factors include increasing age, sex (female) and level of deprivation

- Consideration of challenges: multidimensional and complex

- Little cluster analysis available, results between studies vary and no consensus achieved

# Management for MLTC in ID

The multimorbidity concept

Multi-specialty communication (across departments, primary/secondary/tertiary, between health and social care)

Integrated care and review of care coordination

Further understanding of MLTC and cluster analysis

Considerations for intellectual disability

Person centred "me being me"

# Population level challenges

## Dr. Amala Jesu

# Analysis of GP data April 2023

**4,925 people on the LD register with a GP based in LLR**

- 2,100 (42.6%) registered with a GP in Leicester City
- 2,690 (54.6%) registered with a GP in Leicestershire
- 135 (2.7%) registered with a GP in Rutland
- There are more men (59.0%) than women (41.0%) registered with LD

**1,110 people (22.5%) live in the 20% most deprived neighbourhoods of England**

**This compares to 13.4% of the non-LD population**

**Significantly more people with LD live in 20% most deprived areas than people without LD**

- (The Aristotle system pulls data from GP, hospital and prescribing records)

# Health conditions & LD (national picture)

## Common health conditions for people with LD include:

- Mental health problems (8.4 times more common) – Bipolar, depression and SMI
- Epilepsy (estimated prevalence 22%)
- Being underweight or overweight (6.4% underweight and 37.5% obese, both higher than comparator populations)
- Dementia (4.3% aged 55-64 and 5.9% for 65-74 in 2017/18, 0.3% and 1.1% in comparator group)

## Top 5 groupings for cause of death:

- Covid 19,
- Circulatory diseases (heart failure, hypertension & lipid disorder)
- Respiratory diseases (COPD and asthma)
- Cancers
- Nervous system diseases

- Source: LeDeR National programme
- Source: Mencap HI overview

# Health conditions and LD (Local data)

The proportion of people with a health condition is significantly higher in the LD population than the non-LD population for 9 conditions

The proportion of people with a condition is significantly lower in the LD population than the non-LD population for 2 conditions (hypertension and COPD)

There is no statistical difference in the proportion of LD and non-LD populations with 4 conditions

# Health conditions and LD (Local data)

| Confidence level | LD population | | Non-LD population | | |
|---|---|---|---|---|---|
| 95.0% | No. (LD popn) | % (LD popn) | No. (non-LD) | % (non-LD) | Significance compared to NON LD pop |
| Whole population | 4,925 | 100.0 | 1,152,220 | 100.0 | |
| Bipolar | 110 | 2.2 | 3,865 | 0.3 | Higher |
| Depression | 310 | 6.3 | 43,960 | 3.8 | Higher |
| Obesity | 220 | 4.5 | 34,725 | 3.0 | Higher |
| Dementia | 75 | 1.5 | 8,740 | 0.8 | Higher |
| Heart failure | 75 | 1.5 | 16,380 | 1.4 | Similar |
| Hypertension | 590 | 12.0 | 173,945 | 15.1 | Lower |
| Lipid disorder | 305 | 6.2 | 69,415 | 6.0 | Similar |
| Asthma | 775 | 15.7 | 138,595 | 12.0 | Higher |
| COPD | 50 | 1.0 | 20,330 | 1.8 | Lower |
| Hypothyroid | 400 | 8.1 | 40,600 | 3.5 | Higher |
| Diabetes | 550 | 11.2 | 82,230 | 7.1 | Higher |
| Renal | 150 | 3.0 | 36,805 | 3.2 | Similar |
| Osteoporosis | 80 | 1.6 | 18,270 | 1.6 | Similar |
| ASD | 235 | 4.8 | 2,030 | 0.2 | Higher |
| SMI Register | 335 | 6.8 | 9170 | 0.8 | Higher |

# Health conditions and LD (Local data)

The most prevalent condition for people with LD is asthma (775 people, 15.7% of the LD population)
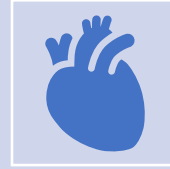
This is followed by hypertension (590 people, 12.0%) and diabetes (550 people, 11.2%)

The conditions with the biggest difference between people with LD and those without are:

Severe Mental Illness (SMI) where 6.8% of the LD population are on the SMI register compared to 0.8% of the non-LD population

Hypothyroidism (8.1% of the LD population and 3.5% of non-LD) which is the same rate as a study of GP records nationally in 2017/18 for the LD population*

ASD (4.8% of the LD population and 0.2% of the non-LD), nationally ASD was found for 30.7% of the LD population in 2021-22**

* Source: PHE, Health inequalities, Thyroid disorders
**Source: NHS digital, Health and care of people with LD, experimental stats 2021-22

# Health conditions and LD (Local data)

**1,930 (39.2%) people with LD have 5 or more chronic conditions, over 4 times more than the non-LD population**

This compares to 9.7% of the non-LD population and is a significantly higher rate in the LD population

**300 people (6.1%) with LD are at a risk of emergency hospital admission, over 4 times higher than the non-LD population**

This compares to 1.5% of the non-LD population and is a significantly higher risk in the LD population

# Collaborative working - LDA

Partnership between Local authorities, NHS providers and commissioners since autumn 2020 to transform services

LLR is now second in the whole of the Midlands (and in the top ten in England) in terms of the number of annual health checks completed

Introduction of the LDA Health Inequalities group and a subgroup focusing on learning around the deteriorating person

LeDeR has been influential and a focal point in steering these groups with the learning into action

# Data-driven Machine-learning Aided Stratification and Management of Multiple Long-term Conditions in Adults with Intellectual Disabilities

**Satheesh Gangadharan**
**Consultant Psychiatrist**

**Thomas Jun**
**Professor of Socio-technical design**

# Summary Description - DECODE

**WP1:** **Data** mining, preparation and **bias mitigation**

Year 2000 onwards

CPRD (48,167 adults)

SAIL (27,700 adults)
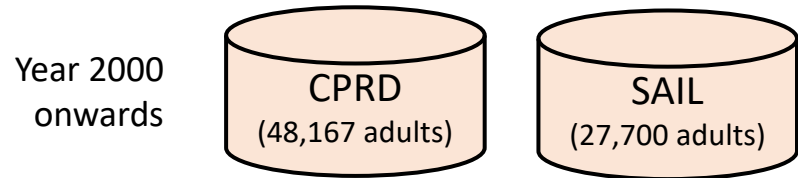
**Primary care**: visits, signs, symptoms, test results, diagnoses, and prescribed medicine/treatment

**Secondary care:** referrals to specific treatments

**Social aspects:** referrals to home environment and education

**Outcomes**: additional conditions, discharge and mortality

CODES   READ   ICD-10   BNF   (W)IMD

**WP2: AI** applications

- MLTC **cluster** identification: **2-3 dominant** clusters
- Identification of combinations of **risk factor**
- MLTC **trajectory** development
- Conflict investigation of **multiple guidelines**
- **AI outputs**

Cluster analysis          Trajectory analysis
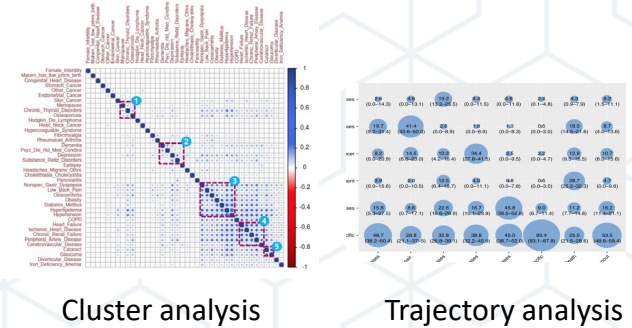
**WP4:** Developing a **model of effective care coordination**

- Actionable insights from AI
- Lived experience
- Professional expertise
- Service providers/commissioners
- Policy experts
- Innovators
- → Feasibility, ethical/legal concern and **implementation plans**
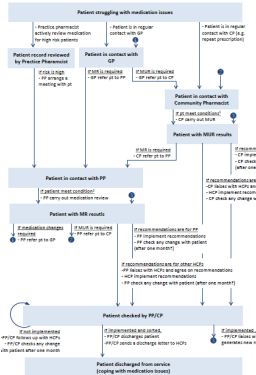
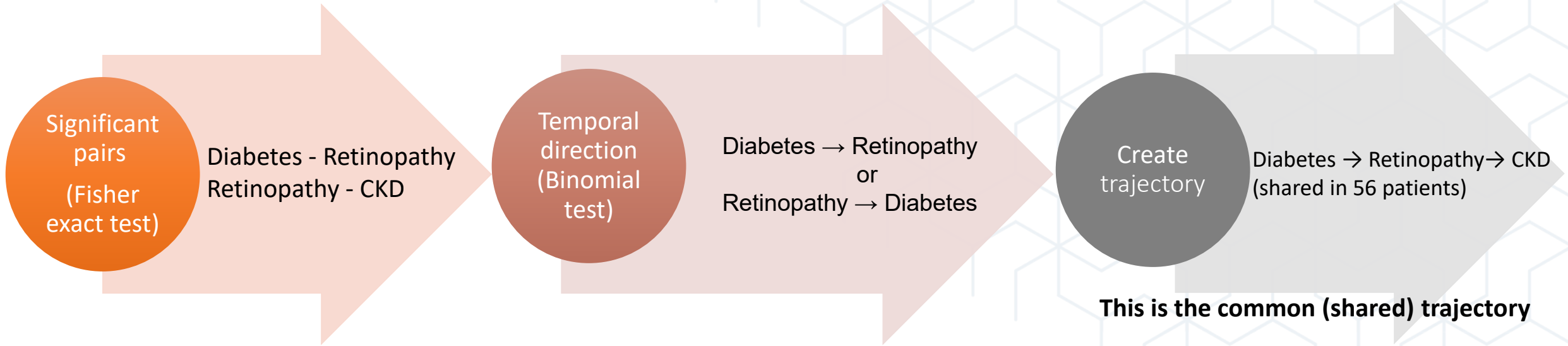**WP3:** Design of meaningful **visualisation** of AI outputs

Health and social care professionals

People with ID and carers
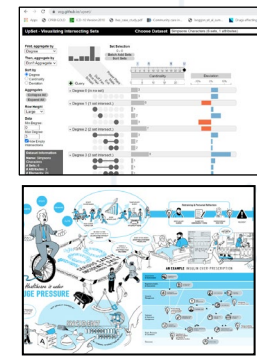
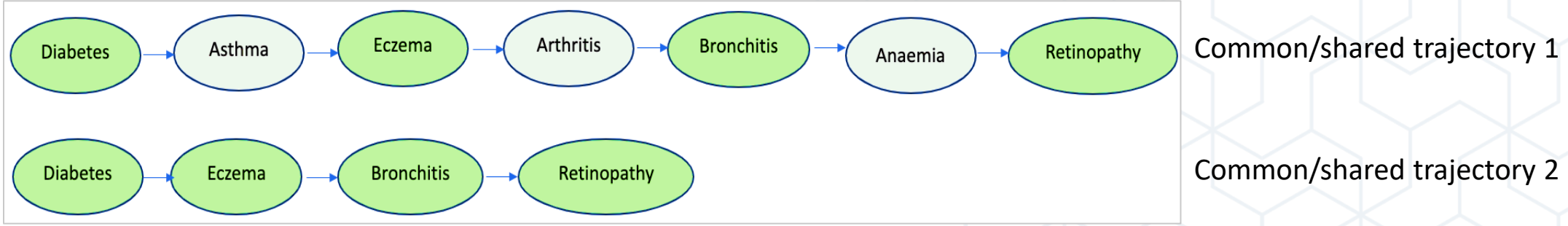**Interactive** data **visualisations**

Accessible **visual narratives**

# Identifying Common Long-Term Condition Trajectories

Identify which conditions are likely to co-occur and their temporal direction.
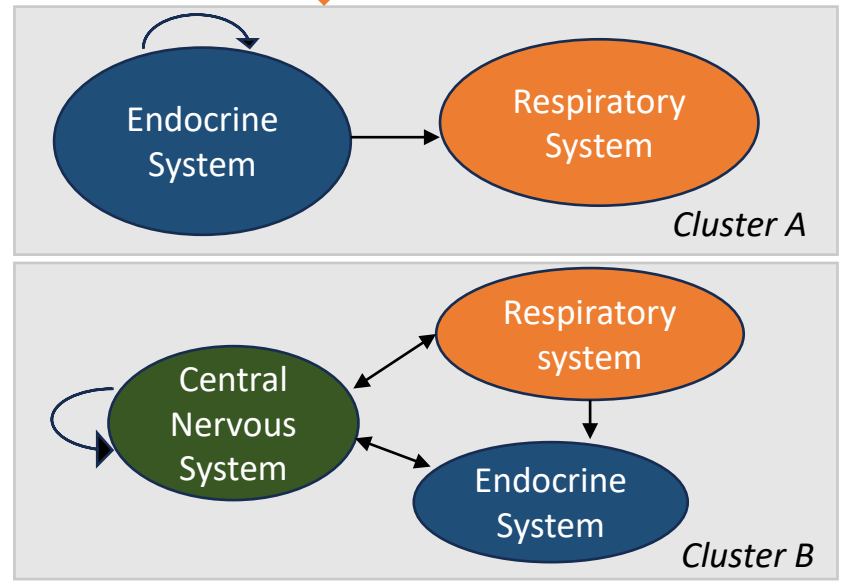
**Significant pairs (Fisher exact test)** → Diabetes - Retinopathy
Retinopathy - CKD

**Temporal direction (Binomial test)** → Diabetes → Retinopathy
or
Retinopathy → Diabetes

**Create trajectory** → Diabetes → Retinopathy→ CKD
(shared in 56 patients)

**This is the common (shared) trajectory**

We get different trajectories of different lengths, which we need to cluster based on the similar patterns they share.

# Identifying Common Long-Term Condition Trajectories

Diabetes → Asthma → Eczema → Arthritis → Bronchitis → Anaemia → Retinopathy

Common/shared trajectory 1

Diabetes → Eczema → Bronchitis → Retinopathy

Common/shared trajectory 2

**Dynamic Time Warping**

Group trajectories by similar diagnostic patterns over time

Endocrine System → Respiratory System

*Cluster A*

Central Nervous System ↔ Respiratory system → Endocrine System

*Cluster B*

**Why Dynamic Time Warping?**
- Unsupervised ML clustering algorithm
- Identifies shared disease patterns across **varying trajectory lengths**
- Clusters reveal the co-occurrence of conditions and their probable **chronological order**

- Healthcare providers can understand disease progression.
- Given a patient's profile we can identify the trajectories closest to their profile over time.

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# Objectives

- Capture requirements of professionals for the design of a dashboard

- Formative evaluation of the dashboard as this develops over time.



# Research Methodology
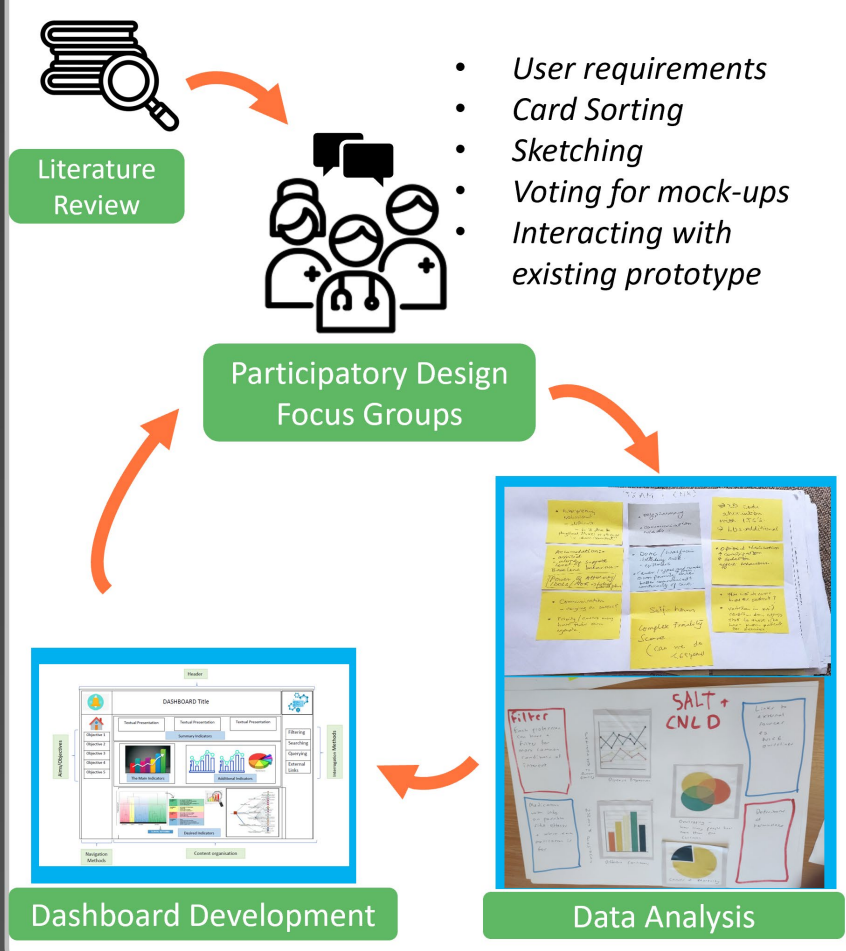
Literature Review

- *User requirements*
- *Card Sorting*
- *Sketching*
- *Voting for mock-ups*
- *Interacting with existing prototype*

Participatory Design Focus Groups

Dashboard Development

Data Analysis

# Results



DECODE Dashboard Prototype

# People with Intellectual Disability

Data Visualisation



Data Physicalization



Data Storytelling Components

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