

Designing more inclusive clinical research

What people with lived experience changed in my Lewy body dementia study

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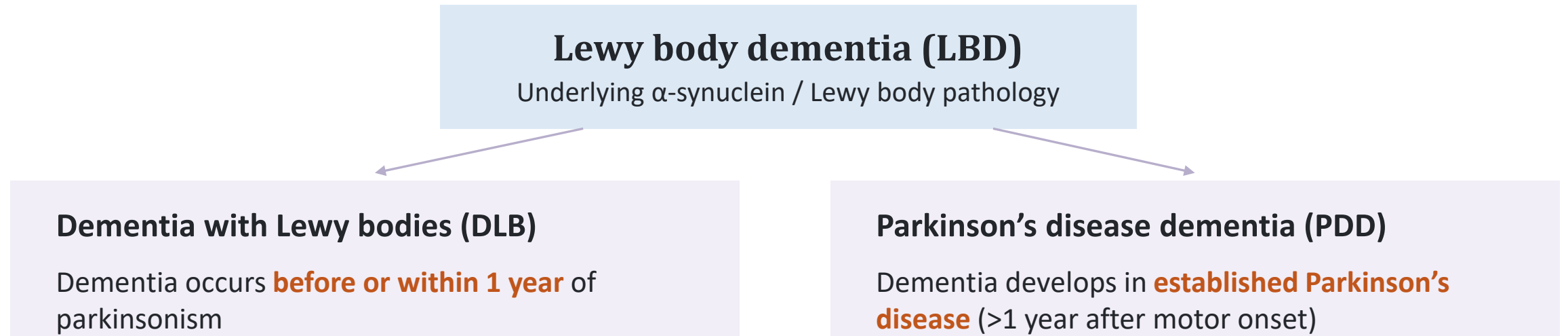
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Lewy body dementia: one pathology, two clinical syndromes



Marked clinical and pathological heterogeneity

Parkinsonism

Cognitive fluctuations

Visual hallucinations

REM sleep behaviour disorder

Variable Alzheimer's and vascular co-pathology

Increasingly characterised using biomarkers

DaT-SPECT → Nigrostriatal dopaminergic dysfunction

Blood and CSF AD biomarkers → Co-pathology (e.g. p-tau, A β)

α -synuclein SAA → Direct evidence of misfolded α -synuclein

The evidence base is strikingly unrepresentative

- Only **9 LBD studies** have examined ethnoracial differences
- Very few compared **clinical phenotype** across groups
- Almost **no comparative biomarker evidence** in LBD



>90%

of participants in identified LBD clinical trials were described as non-Hispanic White

Ethnicity was often not reported at all

Limited representation constrains the generalisability of LBD evidence.

My fellowship: understanding LBD in underrepresented populations

Planned cohort

People with LBD 90



30 minoritised ethnic 60 White European

Controls 40



Four questions

- Cerebral small vessel disease
- White-matter integrity
- Fluid biomarkers and co-pathology
- Clinical change over 18 months

What taking part involves

Clinical and cognitive assessment → MRI brain scan → Blood, with optional CSF → Follow-up at 18 months

A research protocol is also a participant journey

What the protocol says

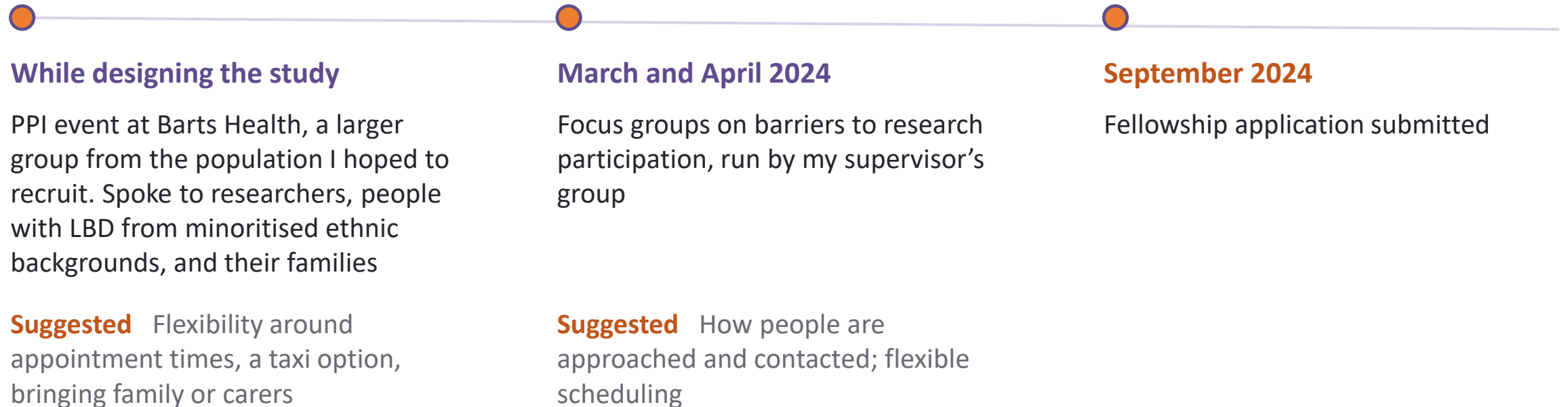
-  Clinical and cognitive assessment
-  MRI brain scan
-  Blood test
-  Optional lumbar puncture
-  Follow-up at 18 months

What the day looks like to the person taking part

- Getting to central London
- Up to six hours at a research centre
- Fitting around symptoms and medication
- Often bringing a family member or carer, sometimes more than one
- Demanding thinking and memory tests
- Coming back 18 months later

We involved people before the study design was fixed

Participant involvement, before the fellowship was submitted



These discussions informed the fellowship design and application

What makes clinical research easier or harder to take part in?

Focus groups with 17 people with Parkinson's and carers from Black communities in the UK

Trust

What is research for, and who ultimately benefits?

Concern about being experimented on: "guinea pig"

Stigma and privacy

Taking part can disclose a diagnosis someone has chosen not to share

Low awareness: "not a Black disease"

Accessibility

Time of day and travel to the venue

Medication schedules and fluctuating symptoms

Much of this is modifiable by researchers

People wanted to take part and we looked for ways to address the issues they raised.

Turning lived experience into study design

Meaningful involvement should be evident in the protocol

What we heard

What went into the study

Fixed appointment times are hard



Flexible booking where possible, built around the person

Getting there is a barrier



Taxis where needed; travel and lunch covered

Family and carers matter



Carers welcome, and their travel reimbursed

Contact preferences differ



Phone, email, text or paper

Planned to keep listening a phone call after every visit, and two funded focus groups to review participant materials

Also built in: no blanket exclusion based on language; multilingual communication where possible; interpreter and translated-information support where needed; visits can be split over shorter days; validated language versions and culturally appropriate cognitive measures where possible

Connecting with people

Broadening both community and clinical routes into the study



Clinical and research routes

Queen Square clinics and registry

Barts Health and Queen Mary

Imperial and other London centres

Community engagement mosques and faith centres, Parkinson's UK Lewisham, a Chinese community event in Islington and a health convention at Neasden Temple

If we want to connect with people, we need to make the effort to go to them and into their communities.

From recruitment challenge to growing momentum

7

participants from minoritised ethnic backgrounds recruited during August 2026 alone

At least one participant a week

the rate I am now recruiting

Where the study is now

People with LBD 8 of 30



from minoritised ethnic backgrounds

Controls 7 of 20



from minoritised ethnic backgrounds

What I have learnt from talking to people

1

Make it personal

Go into communities, talk to people directly, and show that you are genuinely interested in involving them.

2

Accessibility is often practical

Appointment times, transport, food, whether a carer can come, and how long the visit lasts.

3

Underrepresentation is not unwillingness

People told us they wanted to take part. How research is offered, and how people reach it, matters enormously.

One group cannot speak for a whole community, and broad ethnic categories hide real differences.

These observations are consistent with wider UK evidence on research familiarity, language, trust, community-based recruitment and reciprocity.

Five things I have learnt for future studies

1

Map the participant journey

What are you actually asking someone to do?

2

Involve people before the protocol is fixed

Do not try to anticipate the barriers on your own.

3

Factor in funds to support participation

Transport, shorter visits and carer costs need to be in the budget.

4

Measure where people are lost

Not only who consents, but who was eligible and who was approached.

5

Build in a feedback loop

Recruitment is information. Be ready to change delivery.

PPI was most useful when it led to changes in the protocol.

Thank you

Questions welcome

The people living with Lewy body dementia and Parkinson's, and their families and carers, who gave their time to the study and to the involvement work and everyone who has taken part.

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