EQUALITY, DIVERSITY AND INCLUSION

Our EDI strategy

PARKINSON'S UK
CHANGE ATTITUDES.
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Contents

Why is an EDI strategy important?

Parkinson's UK is here for everyone in the Parkinson's community.

Parkinson's doesn't discriminate. Anyone can get it.

Despite this, evidence suggests where you live, your income, ethnicity or gender can impact when you're diagnosed and the support and services you can access.[1] We want to change that. We can and must do more.

We want to remove barriers so that everyone in our community can access the right support and services, tailored to their needs.

And by having a diverse network of people involved with research, we're more likely to make breakthroughs that change the lives of people with Parkinson's. To do this, we also need to have a diverse and inclusive workforce that reflects the community we serve.

Our strategy summary

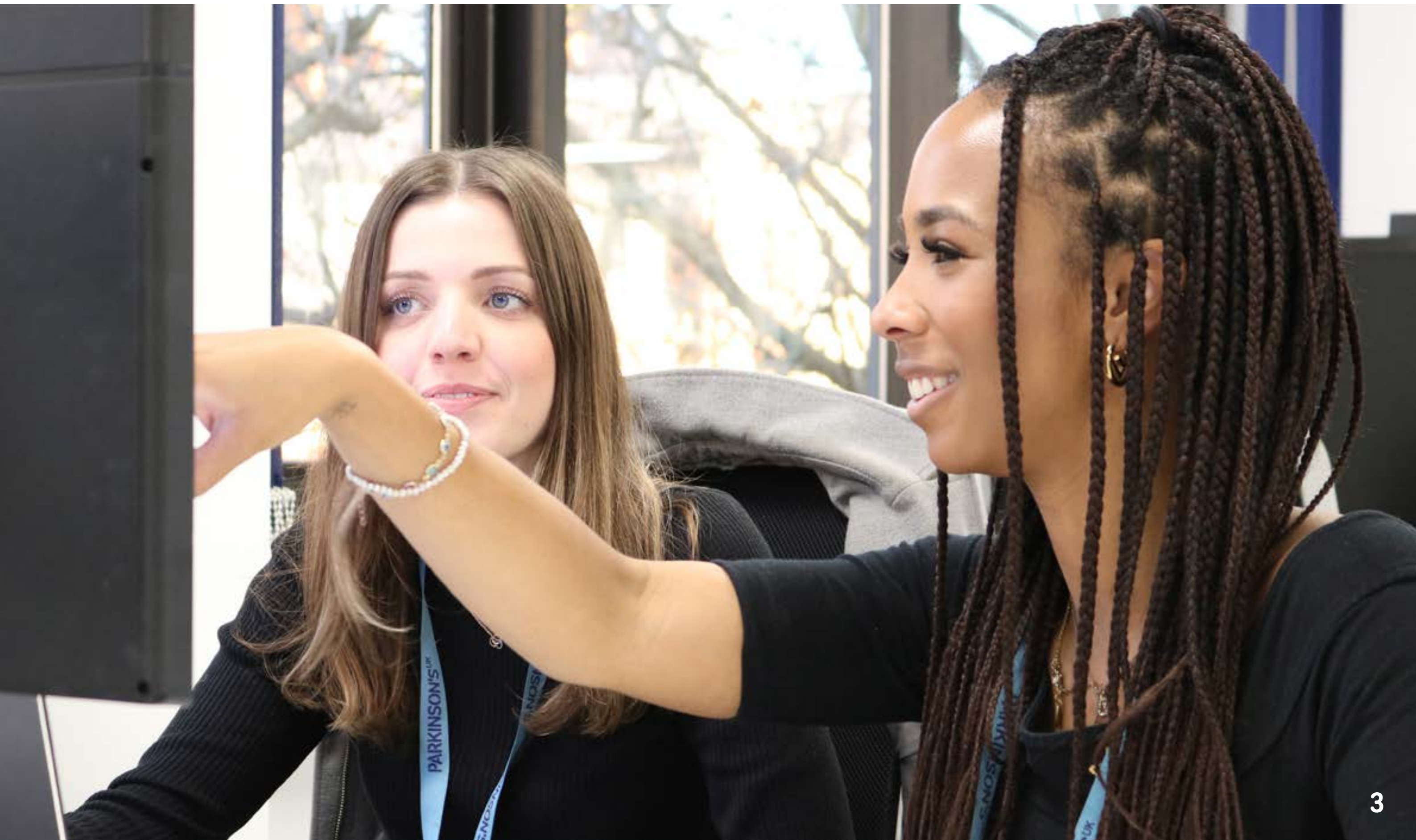
We want equity for everyone who lives with Parkinson's, and the people in their lives, in the UK. That means everyone in the community has access to the same opportunities and support regardless of their background or where they live. So that we're able to deliver real change, we've established priority areas for action based on what will have the biggest impact.

We've set out 3 equality, diversity and inclusion ambitions:

- Engage people from all socioeconomic backgrounds.
- Race equality in the research and support we offer the Parkinson's community.
- Attract, develop and progress our diverse talent across all protected characteristics.

These 3 ambitions are tied together by our overarching goal: to understand and address the needs of the whole Parkinson's community.

We've set solid aims over a set timescale so that we can measure, evaluate and be held accountable for our progress.



Our overarching goal

Understand and address the needs of the whole Parkinson's community.

Where we are now

Over the last few years, we've recognised the importance of equality, diversity and inclusion and started to make progress in creating a more diverse and inclusive culture at the organisation.

A diversity working group

We've built a diversity working group to highlight gaps that need to be addressed by our EDI strategy. The group has gathered insight which will shape how we reach more communities.

The Parkinson's UK People strategy

We launched the Parkinson's UK People strategy which identifies equality, diversity and inclusion as key areas for development for our workforce (staff and volunteers). It will guide us to create a diverse, inclusive environment which respects the individual, creates a sense of belonging and a culture of valuing and supporting each other.

We've still got a lot to do

While we've made significant steps towards creating a more diverse culture at the organisation, we recognise there's still a lot of work for us to do. We know we haven't consistently led an approach to equality, particularly with our volunteer and wider community, before now. This has made it difficult to hold ourselves accountable or measure progress.

Up until now, working towards a more diverse and inclusive culture has relied on the enthusiasm and commitment of individuals.

We know staff and volunteers at Parkinson's UK are passionate about inclusion, and recognise the importance of a diverse workforce. But we don't currently have a whole organisation approach to equality, diversity and inclusion. This strategy will be embedded in our work, culture and values. By having it in place, we'll have a collective approach to equality, diversity and inclusion. We'll be able to measure and evaluate our progress as we go and adapt when needed.

Where we want to be by 2024

By 2024 we'll:

- Have a mandate for a clear, collective approach to supporting equality, diversity and inclusion in the organisation, including in the Board of Trustees' own practise[2], approved by the board
- Have recruited an EDI Resource Lead who will be driving forward actions and governance to guide embedding equality, diversity and inclusion in our ways of working
- Be monitoring, troubleshooting and delivering against agreed measures of success and baseline measures (data recorded before any action has been taken, to compare data after to demonstrate improvement, which will be retained in line with GDPR)
- Continue to publish data on the number of employees who tell us they're disabled in line with company law.

Because our overarching goal in this strategy is to get the right approach, governance and investment in roles and ways of working, we don't have targets for after 2024. After 2024, our success will be measured by our progress in our other 3 ambitions.

How we'll get there

To reach this goal, the board will approve a mandate to deliver our EDI strategy, including establishing roles to drive forward the strategy, agreeing targets and a clear equality, diversity and inclusion roadmap based on the ambitions and goals set out in this strategy.

Core work and projects will be reviewed so that the ambitions in this strategy are planned into their delivery.

Our first ambition

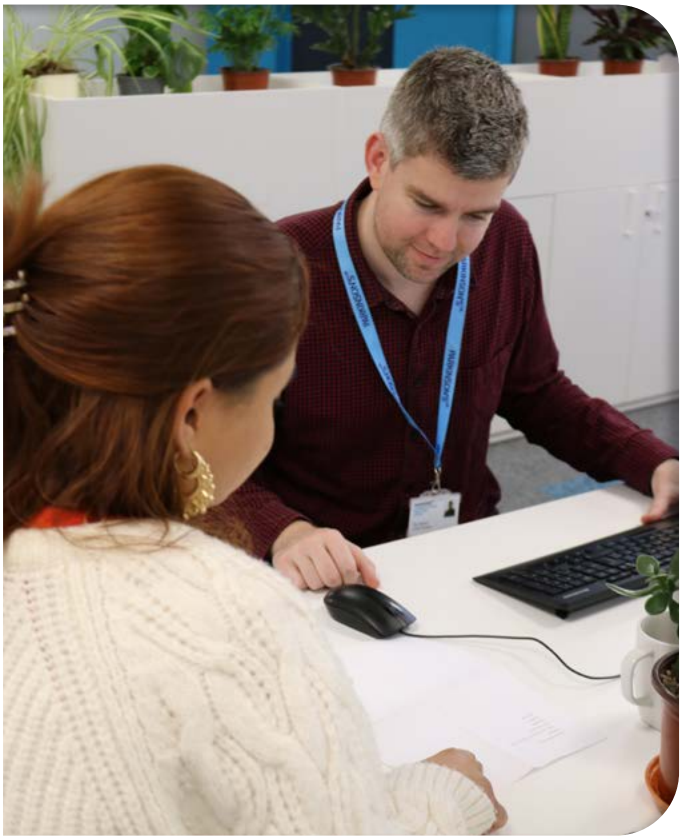
Engage people from all socioeconomic backgrounds.

Where we are now

We know anyone can get Parkinson's. And evidence suggests where you live and your income impacts the support you're able to access[3].

Currently, we don't have much data on the socioeconomic status of people being supported by our services. However, we know people living in socioeconomically deprived areas are less likely to connect with Parkinson's UK[4]. From insight into other areas, it's reasonable to assume this pattern is across all services.

We know that to reach people from diverse socioeconomic backgrounds, we need a better understanding of how income, background or geography might affect access to services and support, as well as how able they are to influence and shape services.



Where we want to be by 2024

By 2024 we'll:

- be using specific insights to inform core work and make sure our equality, inclusion and diversity values are embedded in the delivery of projects
- be using baseline measures to assess whether we're reaching people from different socioeconomic backgrounds and adapt according to findings
- have an 'engagement journey' for people living with Parkinson's and the people who love and care for them. This will map what people need and when taking into account the differences in experience for people depending on their socioeconomic background. It will help us continue to adapt so that we can make sure the whole community has access to the opportunities to get involved with the organisation, as well as access to the information and support they need.

Where we want to be by 2026

By 2026, we want people with Parkinson's, and the people who love and care for them, to have access to tailored support regardless of their socioeconomic background.

How we'll get there

To reach this ambition, we'll gather more insights into socioeconomic status and Parkinson's. This insight will be used in our core and project work to make sure socioeconomic factors are considered in our engagement and support of the Parkinson's community.

We'll work across the Association of Medical Research Charities (AMRC) to collaborate with other charities that are leading on understanding and addressing barriers to accessing services and support. And we'll collaborate with organisations to identify opportunities for local partnerships to engage communities.

Our second ambition

Race equality in the research and support we offer the Parkinson's community.

Where we are now

So that we can deliver the best support and make breakthroughs in Parkinson's research, we need to listen to and involve everyone affected by the condition. This isn't currently the case.

We know that 97% of people currently interested in research are white British. And that responses to Parkinson's treatment can be different depending on your ethnic background. That's why we need to be more representative of the Parkinson's community in our research.

As well as barriers in research, we know that our services aren't reaching minority ethnic communities. Only 4.7% of people engaged with the charity identify as minority ethnic, but we've estimated 7.6% of people with Parkinson's in the UK are from minority ethnic backgrounds[5].

Where we want to be by 2024

By 2024 we'll:

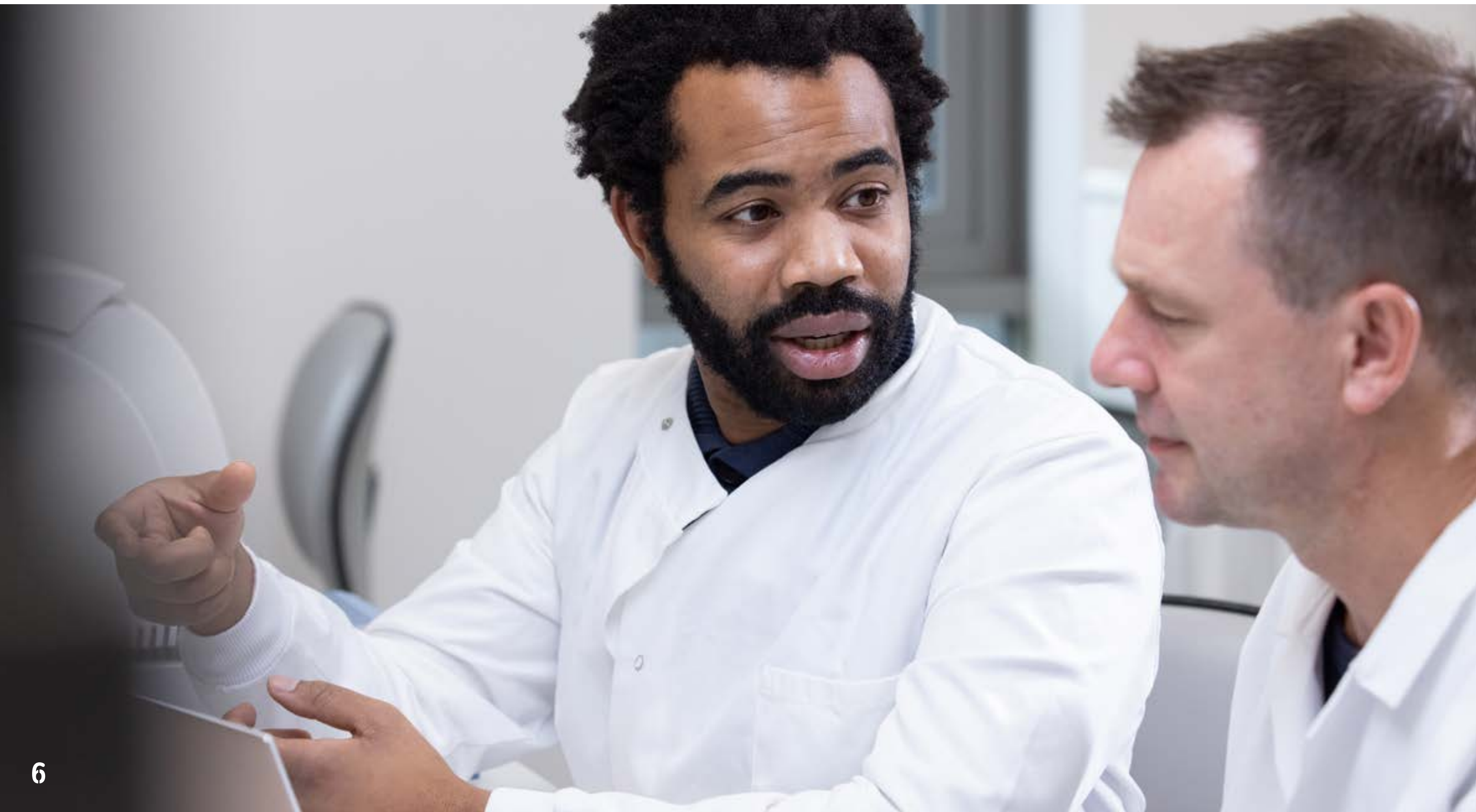
- have a collective approach to locally engaging ethnically diverse communities
- have data on how and when minority ethnic groups would find support most helpful
- use set targets to monitor and take action to address barriers minority ethnic groups face in terms of Parkinson's support and opportunities to get involved with Parkinson's UK through research, volunteering and other activities.

Where we want to be by 2026

By 2026, we'll have a clear understanding of the background of people living with Parkinson's in all four nations. The demographic of people accessing Parkinson's UK's services and support will be representative of the demographics across the community.

How we'll get there

To reach this ambition, we'll use baseline data to monitor whether we're engaging minority ethnic groups in research. And we'll establish a nationwide approach to locally engaging minority ethnic communities.



Our third ambition

Attract, develop and progress our diverse talent across all protected characteristics.

Where we are now

We know that to be there for everyone living with Parkinson's, and those who love and care for them, we need a diverse workforce (staff and volunteers), that represents people from all protected characteristics.

We've started to make good progress on this. In the last year (2021), 20% of job appointments have been made to people from ethnic minority backgrounds. And people from minority ethnic backgrounds make up 8% of our leadership roles.

However, there's still work to do. We're lacking in data and insight for our volunteer base. We have data on around 25% of our volunteers. Of those that we have data for, 91% identify as white. Our volunteer base is also predominantly over 65 years old and female.

9% of our workforce have told us they have a disability compared to 20% of the working UK population[6].

Where we want to be by 2024

By 2024 we'll:

- we'll have invested in recruitment resources, campaigns and processes to reach more diverse communities in our volunteer and staff recruitment
- occupational requirement exemptions will be established if positive action is taken in recruitment
- staff and volunteers will have access to a learning programme on being inclusive in all aspects of their role, such as management.

Where we want to be by 2026

By 2026, we want to reflect the demographics of the UK population in our workforce. We'll have a particular focus on specific areas:

- The number of people living with Parkinson's and people living with disabilities who work at the charity will reflect the working age population.
- At least 14% of our workforce will be from a minority ethnic background, to reflect the demographic of the UK.

We'll have data on the protected characteristics for around 50% of our volunteers, and use the insight to work with our volunteers towards an inclusive and diverse volunteer base.

Equality, diversity and inclusion training will be a priority for all staff. Managers will drive this.

We want staff and volunteers to feel Parkinson's UK is an inclusive and supportive place to work. We'll track this through the People Pulse Survey (a survey of our workforce).

How we'll get there

To meet this ambition, we'll engage more volunteers to get insight into protected characteristics so that we can identify where we can do more to have a more diverse volunteer base.

We'll implement positive action in recruitment, which means providing support to people from underrepresented groups to help them overcome disadvantages when they're competing with other applicants. We'll focus on supporting people living with Parkinson's, people living with disabilities and people from a minority ethnic background.

We'll develop an EDI training programme. And staff's roles and responsibilities will be adjusted to include the priorities of the EDI strategy.

Our promise

This EDI strategy is our public commitment and investment to change for people with Parkinson's, and the people who love and care for them.

Led by our board and CEO, we will work collectively to address the needs of the whole Parkinson's community.

Our Executive Leadership team, People Committee and board will measure and monitor our progress so that we can take accountability and adapt where needed.

And equality, diversity and inclusion will be embedded in everything we do and the values we hold as an organisation.

References

[1] Evidence across dementia related conditions. Hypothesis that this would correlate with Parkinson's condition based on insight from four nations' social deprivation analysis.

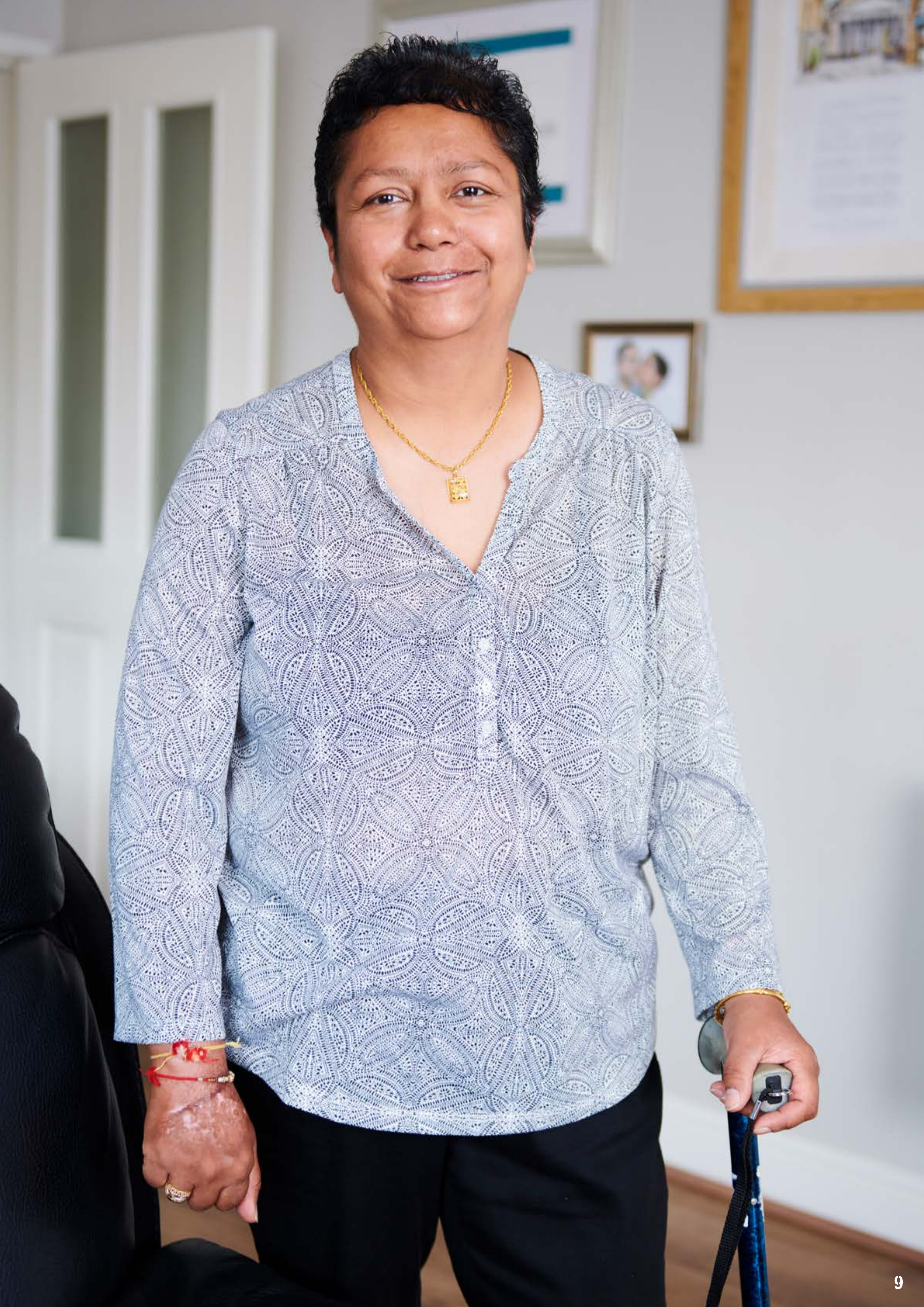
[2] Charity Governance Code Principle 6: Equality, diversity and inclusion

[3] Evidence across dementia related conditions. Hypothesis that this would correlate with Parkinson's condition based on insight from four nations' social deprivation analysis.

[4] Cathal Doyle - Healthcare data June 2022

[5] https://www.parkinsons.org.uk/news/our-response-report-commission-race-and-ethnic-disparities

[6] https://researchbriefings.files.parliament.uk/documents/CBP-7540/CBP-7540.pdf



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Improving life for everyone
affected by Parkinson’s.
Together we’ll find a cure.

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