

Rt Hon Wes Streeting
Secretary of State for Health and Social Care
39 Victoria Street
London
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Dear Secretary of State,

Congratulations again on your appointment as the Secretary of State for Health and Social Care and the Labour party's successful election into government.

Many thanks for your call to me in the first hours of your appointment, we were delighted and reassured by the importance you are giving to patient experience and patient voice by placing them at the centre of your plans for change. On that note, I am very pleased we have been invited to contribute to Lord Darzi's expert advisory group for his rapid investigation into NHS performance. We will of course endeavour to support the review in any way we can to ensure the experience of patients and unpaid carers sits at the heart.

National Voices Members

I am writing this letter to you on behalf of our members at National Voices. As you know, we are a coalition of over 200 health and care charities, focused on patient experience and health inequalities felt across the system. As a collective we felt your assessment of the NHS as "broken" was both accurate and refreshing as it has voiced what many of the people we advocate for have felt over the last few years, as they have increasingly struggled to access the health and care they need. The COVID-19 pandemic compounded existing inequalities, exacerbated existing issues with NHS performance and had a profound impact on people's mental health. Now four years on, we are still feeling the effects, from those living with Long Covid to the millions of people who are waiting a long time to receive the healthcare they need. Below is a list of burning topics our members are keen for us to discuss with you, now you are in your new role. We would be delighted to meet with you and your advisors to help find equitable solutions to this mix of short and medium term concerns.

1. Building back equitably

Access remains very difficult, and we recognise the importance Labour has placed on cutting NHS waiting times by making it one of its five national missions. At National Voices we are increasingly concerned about access to care for those facing health inequalities. For example, a recent [Nuffield Trust report](#) found "systematic inequality where people in poorer areas get worse access to planned

care than richer counterparts – for example, the most deprived tenth receive 20% fewer hip replacements than the English average”. Our own unpublished research shows that Integrated Care Systems (ICSs) have cut the money they offer to patients through the transport reimbursement scheme by 25% since 2019-20 and 2023-24, making it harder for people with disabilities to travel to health and care appointments in a way that works for them.

Many of the barriers faced are concerned with the failure to get the basics right – for example, letters arriving after appointments, a lack of choice over appointment times to fit in with zero-hour contracts or caring needs, and translators not being booked when needed.

We are reassured that reducing the gap in healthy life expectancy is central to your plans and we are looking for bridging solutions ahead of the ten-year NHS reform plan to ensure health inequalities in all its forms are addressed through this approach. As we look to address systemic inequalities, we must also see a clear way forward for mental health care to achieve parity with physical health care.

Similarly, Labour’s ‘Fit For the Future’ fund to double the number of CT and MRI scanners is much needed, allowing the NHS to catch cancer and other conditions earlier, saving lives. We have encouraged a joined-up approach to diagnosis demonstrated through clear intentions to implement a ten-year Strategic Diagnostics Plan. [Our vision for improving patient experience of diagnosis](#), outlines our recommendations to improve patients’ diagnosis experiences and support people to better self-manage their long-term conditions.

2. Medication shortages

Medication shortages have been a growing problem in the last couple of years, many underpinned by global issues. However, in recent months some shortages have slipped into crisis, with some life-preserving medication just not available to patients. As just one example, [Pancreatic Enzyme Replacement Therapy \(PERT\) taken by people who are pancreatic insufficient](#), is now widely unavailable with some hospitals restricting their own supply to inpatients only, people driving hours to collect some medication they have tracked down online, and in some cases eating drastically less and not leaving the house due to the severe impact of this medication not being available. The shortage is due to continue until 2026 and it is understood that the UK is struggling with supply more than European counterparts.

While we understand DHSC is working hard to alleviate the impact of these medication shortages, the current workarounds have failed and patients and pharmacies, already struggling with funding settlements, are left to solve a problem much larger than themselves. The Royal Pharmaceutical Society has recognised that many solutions are unfairly impacting people who do not have access to cars and, as a charity, we are uncomfortable with digital solutions to allow people to ‘hunt down’ stock as it leaves those digitally excluded without vital drugs. We have already written to the Minister of State for Secondary Care to flag this issue and we are willing to help your team review medication shortages as a matter of urgency to explore any extraordinary measures the government can make in the short term and in the medium-term to rebuild relations with global pharmaceutical companies

so we avoid such crises in the future.

3. Digital exclusion

While many of your manifesto plans were welcomed, we are concerned that the impact of digital exclusion has not been as widely understood and mitigated for in policy plans. For example, in line with [our work addressing inequalities in research](#), we welcome Labour's intentions to make clinical trials more accessible, but are concerned about the focus on using the NHS App as the primary method to access opportunities. Current estimates suggest [8.5 million people lack basic digital skills, and 1.5 million people don't have a smartphone, tablet or laptop](#), and would therefore find themselves at a disadvantage. The Hewitt Review raised some simple solutions to exclusion that could be built into policy, for example allowing access to iPads in community health centres to widen access to those who cannot afford to use them otherwise.

4. Cost of living

While we appreciate the policies outlined in the wider manifesto regarding the cost of living crisis, we urge the Labour party to bring in additional interim measures to support individuals with long-term conditions and/or disabilities whose health has been directly impacted by ongoing financial struggles.

This concern was mirrored by the Prime Minister in his previous role as leader of the opposition, during a 2022 [Prime Minister's Questions](#), as he shared Phoenix's story. Phoenix is on kidney dialysis at home and is reliant on a dialysis machine to survive. As a person with a long-term condition, requiring dialysis at a great cost, Phoenix said that he felt he was being priced out of existence.

Phoenix's situation is not unique and the issues he experiences do not only apply to people relying on dialysis. In our conversations with members, we have increasingly been hearing about [how the cost of living crisis is affecting many different groups](#) of people living with health conditions and disability.

Many health conditions require the use of personal powered equipment enabling people to remain safe, independent, and in some cases, alive, and many of these conditions are excluded from any reimbursement policy, meaning that individuals have to [face these unavoidable costs themselves](#).

We are grateful that Sir Keir Starmer drew attention to our work in this area and this important issue.

The cost of living crisis will only be exacerbated with winter pressures; in the winter of 2022 alone, the number of people not fulfilling prescriptions due to costs almost doubled in December, which could create unwarranted demand on unplanned hospital admissions. Acting on this issue, which will only become more pertinent as Labour approach their first winter in government, presents the party with a vital opportunity to demonstrate how they will support individuals with long-term conditions and/or disabilities.

5. Primary care

DHSC and NHS England have made great strides in improving access to primary care, and we are pleased to see many of our asks in [Our Vision for Primary Care](#), developed in conjunction with our members and people with lived experience, have started to be implemented. However, the shift to online booking comes with its own concerns which are not being reviewed or monitored and the burden on both patients with long-term conditions and unpaid carers is rising as they are too often left to manage the interplay between primary and secondary care.

We were pleased that [much of our manifesto calls around getting the basics right](#) in primary care were reflected in your own manifesto but feel more can be done around out of hours access, continuity of care and support for those with long-term conditions. We would welcome the opportunity to discuss some practical, equitable solutions to help give patients choice and control over who they see, when and how.

We hope this letter reflects some of the challenges you are already dealing with and is taken in the spirit of practical solution-finding in which it is sent.

We look forward to working with you over your tenure to ensure the voice, experience and needs of patients are central to both NHS recovery and its future development.

With kind regards,

Jacob Lant
Chief Executive
National Voices



With the support of 110 National Voices member charities, as follows:

Mark Linehan, CEO, **Abbey Community Association**

Bradley Price, Director of Policy and Public Affairs, **Action for Pulmonary Fibrosis**

Philippa Sharman, Communications & Research Manager, **Addison's Disease Self-Help Group**

Vivienne Evans OBE, Chief Executive, **Adfam**

Caroline Abrahams, Charity Director, **Age UK**

Simone Miles, Chief Executive, **Allergy UK**

Noha Al Afifi, Interim CEO, **Arthritis Action**

Sue Brown, CEO, **Arthritis and Musculoskeletal Alliance**

Lisa McNeil, Chair, **Aspergillosis Trust**

Sarah Sleet, CEO, **Asthma + Lung UK**

Tony Thornburn OBE, Chair, **Behcet's UK**

Maggie Gilbert, Coordinator, **Better Living CIO**

Helen Rowntree, Chief Executive, **Blood Cancer UK**

Tess Linton, Chief Executive, **Borderline Support UK CIC**

Manveet Basra, Associate Director, Public Health, Inclusion and Awareness, **Breast Cancer Now**

Anna Schurer, Chair, **British Dupuytren's Society**

Sarah Mistry, Chief Executive, **British Geriatrics Society**

Sasha Daly, Interim CEO, **Cancer52**

Joel Rose, Chief Executive, **Cardiomyopathy UK**

Helen Walker, Chief Executive, **Carers UK**

Percy Akudo, Head of Strategy, **Caribbean & African Health Network (CAHN)**

Andy Bell, Chief Executive, **Centre for Mental Health**

Leigh Andrews, Head of Speech and Language Therapy, **Change Communication**

Anne Fox, CEO, **Clinks**

Suzi Henderson, CEO, **Cloverleaf Advocacy**

Helen Paisley, Chief Executive, **Community Dental Services CIC**

Marianne Radcliffe, Chief Executive Officer, **Crohn's & Colitis UK**

Dr Robin Dover, Chair of Trustees, **Cyclical Vomiting Syndrome Association UK**

Andy Pike, Head of Policy, Campaigns and Public Affairs, **Dementia UK**

Helen Kirrane, Head of Policy, Campaigns & Mobilisation, **Diabetes UK**

Kamran Mallick, CEO, **Disability Rights UK**

Victoria Wareham, Director of Operations and Development, **Dystonia UK**

Susan Adey Rankin, Chair, **East Staffordshire Patient Engagement Group**

Diana Perry, CEO & Founder, **Ectodermal Dysplasia Society**

Emma Cox, Chief Executive, **Endometriosis UK**

Alison Fuller, Director of Health Improvement and Influencing, **Epilepsy Action**

Shizana Arshad, Equally Well UK Lead, **Equally Well UK**

Judith Potts, Founder, **Esme's Umbrella**

Vicky Thomson, Chief Executive, **Every-One**

Sarah Mann, CEO, **Friends, Families and Travellers**

David Ralph, CEO/Chair, **Furness Mental Health Trust (FMHT)**

John Grumitt, CEO, **Future Care Capital**

Rich Collins, Chief Executive, **GAIN (Guillain-Barré and Associated Inflammatory Neuropathies)**

Capt Cat S Burton FRAeS, Chair, **GIRES**

Michael Chandler, CEO, **Groundswell**

Gemma Griffiths, Chief Officer, **Help2Change CIC**

Gabriela Matouskova, CEO, **Hope 4 The Community CIC**

Roger Smith, Trustee & Chair, **Hounslow Borough Respiratory Support Group**

Mo Peskett, Chair, **ICUsteps**

Richard Beesley, Founder & Director, **Juvenile Arthritis Research**

Paul Bristow, Chief Executive, **Kidney Care UK**

Portia Roberts-Popham, Executive Director, **Locorum Ltd**

Jeremy Rossman, Trustee, **Long Covid Kids**

Natalie Rogers, Founding Trustee, **Long Covid Support**

Ondine Sherwood, Co Founder, **LongCovidSOS**

Caroline Olshewsky, CEO, **Lupus UK**

Karen Friett, Chief Executive, **Lymphoedema Support Network**

Gemma Peters, Chief Executive, **Macmillan Cancer Support**

Ed Holloway, CEO, **Macular Society**

Sam Royston, Executive Director of Policy and Research, **Marie Curie**

Mark Rowland, Chief Executive, **Mental Health Foundation**

Dr Sarah Hughes, Chief Executive, **Mind**

Alex Massey, Head of Campaigns, Policy and Public Affairs, **MND Association**

Dr Sarah Rawlings, Executive Director of Research and External Affairs, **MS Society**

Dr Hina J Shahid, Chair & GP, **Muslim Doctors Association & Allied Health Professionals CIC**

Dr Sophie Castell, Chief Executive, **Myeloma UK**

Dr Dale Webb, CEO, **National Axial Spondyloarthritis Society**

Clare Jacklin, CEO, **National Rheumatoid Arthritis Society**

Mandy Crandale, Chief Executive Officer, **National Survivor User Network**

Dr Raven Bowen, CEO, **National Ugly Mugs**

Maddy Desforges OBE, CEO, **NAVCA (National Association for Voluntary and Community Action)**

James Inman, Founder, **neurobetter**

Patrick Mayne, Coordinator, **Northern Cancer Voices**

Dympna Cunnane, CEO, **Our Time**

Jo Betterton, Trustee, **Pain UK CIO**

Diana Jupp, Chief Executive, **Pancreatic Cancer UK**

Juliet Tizzard, Director of External Relations, **Parkinson's UK**

Sophie Randall, Director, **Patient Information Forum**

Mohammad Ismail Wasway, Managing Director, **PatientsCann UK**

Silvia Petretti, CEO, **Positively UK**

Charlotte Howden, CEO, **Pregnancy Sickness Support**

Chiara De Biase, Director of Health Services, Equity & Improvement, **Prostate Cancer UK**

Susan Oliver, Chair and Trustee, **Pseudomyxoma Survivor**

Harriet Oppenheimer, Chief Executive, **RNID**

Sue Farrington, Chief Executive, **Scleroderma & Raynaud's UK**

Ian Boyd, CEO, **Self Help UK**

Ceinwen Giles, Co-CEO, **Shine Cancer Support**

Kirit Mistry, Founder & Health Inequalities Lead, **South Asian Health Action**

Ian Joslin, Trustee/Treasurer, **Stickler Syndrome UK**

Juliet Bouverie OBE, Chief Executive Officer, **Stroke Association**

Shuranjeet Singh, Director, **Taraki Wellbeing**

Liz Gill, Co-CEO, **The British Porphyria Association**

Rachel Halford, CEO, **The Hepatitis C Trust**

Natalie Diana Busari, Senior Director, **The Nerve of My Multiple Sclerosis CIC**

Georgina Carr, Chief Executive, **The Neurological Alliance**

Sarah Massie, Director of Programmes, **The Point of Care Foundation**

Louise Sellar, Director, **The Thyroid Trust**

Eamonn Dunne, Partnerships & Projects Development Manager, **Thomas Pocklington Trust**

Lyn Mynott, CEO, **Thyroid UK**

Sue Thomas, Trustee, **Time To Talk Mental Health UK**

Andy Fletcher, Chief Executive Officer, **Together for Short Lives**

Julie Bass, Chief Executive, **Turning Point**

Sue Dimmock, Chair, **UKPIPS (UK Primary Immune-deficiency Patient Support)**

Chloe Hayward, Executive Director, **United Kingdom Acquired Brain Injury Forum**

Samantha Sherratt, Transformation Director, **Urostomy Association**

Helen James, Founder, **VCSE Nutriri**

Deborah Alsina, Chief Executive Officer, **Versus Arthritis**

Leslie Billy, Chief Executive, **Viewpoint**

Dr Stewart Manning, Chairman, **Yorkshire Cancer Community**

Chris Lewis, COO, **Your SimPal**