

- Recognise from the outset that the impact of the crisis will fall hardest on those who already face discrimination and inequality, including Black, Asian and other minority ethnic groups, disabled people, carers, women and gender minority populations and those living in areas of high deprivation, and that these inequalities will affect some people in combination
- Maintain the principles and values of patient choice, shared decision making and voice, so that services are shaped by patients, disabled people and others who most need them
- Ensure there are fully resourced services available to help people maintain people's mental wellbeing, to treat mental ill health, and to ensure that no one is left isolated
- Ensure carers get the support they need, including emotional support, to continue to care for their loved ones
- Provide clear, concise and timely communication, updated regularly, about the impact of the crisis on support and services, what is available in the interim, and when and how services may begin to restart
- Ensure access needs are respected and met, including providing materials in different formats and languages, including signing, descriptions, captioning and transcription for all official visual content, and that people are able to access support offline if they do not have access to the internet
- Maintain compassionate end-of-life and bereavement support services, with clear communication between staff, patients and others, and the opportunity to be with friends and family members at the end of life unless totally impossible.

## Introduction

The COVID-19 pandemic, beginning globally in 2019 and stretching well into 2020 so far, has radically reshaped many of the services we had previously taken for granted. The official period of 'lockdown', begun in March 2020, saw some support and activities familiar to day-to-day life suspended completely. Even at the time of writing, as lockdown is eased across most – but not all – of the United Kingdom, many businesses remain closed, services remain limited and futures remain uncertain.

During lockdown, communities have celebrated the NHS and the people who work for it en masse. We know that frontline health and care workers have continued to put their own health at risk during this pandemic, to deliver what services they can. However, we also know there have been considerable challenges.

The Patients Association wanted to get a better understanding of how patients, disabled people and others have been experiencing those services during the pandemic. We wanted to know about both the experience of health and care services, and the experience of daily life – the things that make a difference to our wellbeing.

To do this, we produced a survey, open to all, covering issues relating to healthcare for both COVID-19 and pre-existing conditions, how aspects of government support were working, and whether people felt they were getting all the support they needed. This included support at the end of life and after bereavement, for some.