

All-Party Parliamentary Group on Vulnerable Groups to Pandemics

Focus on Respiratory Patients Meeting

Minutes of the meeting held on 22 April 2021, 15:00 – 16:30

Attendees

Virendra Sharma MP (Chair), Paul Beresford MP, Lord Mendelsohn, Sarah Woolnough (Asthma UK and the British Lung Foundation), Natalie Goodchild (patient representative), Professor Daniel Peckham (Professor of Respiratory Medicine at St James Hospital, Leeds), Carol Stonham (the Primary Care Respiratory Society), Andy Gregory (Vertex Pharmaceuticals), Michele Salter (Sickle Cell Society), Bridgit Sam Bailey (Positive Ageing in London), Charlotte Martin (Leukaemia Care), Susan Walsh (Primary Immunodeficiency UK), Adam Croom (Asthma UK and the British Lung Foundation), Lee Pryce, Lynsey Beswick (Cystic Fibrosis UK), Nick Woodcock (PulmonX), Rosemary Shapcott, Sarah McFayden (Asthma UK and the British Lung Foundation), Scott Lawson, Sangeeta Thave (Office of Virendra Sharma).

Apologies

- Jim Shannon MP

Event Report

1. Welcome and introduction – Virendra Sharma MP

The Chair welcomed participants to the meeting on care for respiratory patients to discuss issues in the care and treatment of respiratory patients throughout the COVID-19 pandemic.

The Chair welcomed the continued activity of the APPG and introduced the running order of the guest speakers and the key topics for discussion, namely the disruption of care and barriers in access to care, and the key requirements for improving care going forward.

The Chair introduced Sarah Woolnough, Chief Executive Officer of Asthma UK and the British Lung Foundation, to share insights on the main issues respiratory patients faced throughout the pandemic and the key changes needed to improve their care.

2. Sarah Woolnough, CEO of Asthma UK / the British Lung Foundation

Sarah Woolnough noted a key role that charities played throughout the pandemic, highlighting that calls to the charity helpline had increased by 500%.

Woolnough emphasised that lung disease is the UK's biggest killer and that one in five will develop a lung condition which is why lung conditions are a big driver of winter pressure on the NHS, but suggested that despite this, lung disease is rarely a political priority and underdiagnosis throughout the pandemic meant that the number of patients with lung disease will be even higher than it currently stands. Woolnough thus welcomed the focus on respiratory conditions and the importance of the ongoing APPG inquiry.

Woolnough set out the four main ways respiratory patients have been affected by the pandemic: the disruption in access to care and the 70% decline in urgent referrals; the low prioritisation of

younger people with less severe asthma for vaccination; anxiety and a lack of support while shielding; and prejudice around mask exemption for lung disease patients.

Woolnough concluded a call for a national plan to restore levels of care for respiratory patients, and a support package for shielding patients for future pandemics, highlighting the importance of improved communication between charities, patients and the Government.

3. Professor Daniel Peckham, Professor of Respiratory Medicine, St James's Hospital, Leeds

Ms Woolnough gave way to Professor Daniel Peckham, Professor of Respiratory Medicine at St James's Hospital, Leeds. Professor Peckham focussed on the care of cystic fibrosis patients through COVID-19, giving an overview of the prevalence, effects and treatment of cystic fibrosis.

Professor Peckham then laid out some of the positives and negatives he had witnessed throughout the pandemic for cystic fibrosis patients and the changes in treatment. Professor Peckham noted the acute impact COVID-19-related disruption has had on transplantation and access to care in general as a key negative, as well as a lack in data access and difficulty reaching some patients across the local community.

Professor Peckham then noted the positives he had seen, such as the diminishing 'red tape' associated with healthcare allowing new modes of treatment to be brought to patients faster and the utility of new digital technologies in maintaining contact with patients.

Professor Peckham noted three key areas of focus for improving care in the coming months and years: first, the importance of community care and creating partnerships with patients; the importance of developing a better data system with more up to date data across the NHS; and the need for outpatient-centred care with highly effective drugs.

4. Natalie Goodchild – Patient Testimony

The Chair introduced Natalie Goodchild, a patient representative with cystic fibrosis. Goodchild briefly noted the key daily requirements a patient with cystic fibrosis has to mitigate the risk of their health deteriorating such as daily therapy, exercise and maintaining a good diet.

Goodchild raised with concern the negative impact shielding had had on her, limiting opportunities for exercise – key for her in managing the disease –and the issues she had had with food deliveries, most notably the limited number of items allowed in food deliveries that she relied on.

Goodchild went on to note the positives that had come out of care for cystic fibrosis patients throughout the pandemic. Most specifically Goodchild noted the positive impact access to Kaftrio and other new drugs had had on managing her condition. Goodchild highlighted the normalisation of mask-wearing and health and sanitary protocols, self-awareness of symptomology and new virtual clinics as positive changes.

5. Carol Stonham, Executive Chair, Primary Care Respiratory Society

The Chair then introduced Carol Stonham, Executive Chair of the Primary Care Respiratory Society. Stonham focussed her speech on the out of hospital care offered throughout COVID-19.

Stonham noted that although there has been an impression that primary care has not been offered throughout the pandemic, it has – just in new and different methods. Stonham did note, however, that diagnostic tests were often on hold, with a backlog now built up.

Although a reduced number of x-rays and diagnostic tests were completed, Stonham highlighted the lack of presentation from patients as a key issue, noting that fear of COVID-19 or confusion around symptoms often made patients reluctant to seek help.

Stonham did note the effectiveness of at-home pulmonary rehabilitation classes and the new technologies that were used, but highlighted the need to consider individual patients' needs and the risk that technology-centred care will only widen the digital divide in society. Stonham extended this concern with a thought on the workforce, noting the great work they have done, but highlighting the possibility of losing much of the workforce following COVID-19.

Stonham concluded her speech by welcoming the successful vaccine programme, the general reduction in seasonal influenza, and the success of at-home care, but echoed her earlier calls for a patient-focussed recovery programme and not a one-size-fits-all approach with the appropriate funding to address the backlog of diagnostic care that is needed.

6. Discussion

The Chair then opened the discussion questioning whether patients with respiratory conditions had been treated as seriously as patients with other diseases such as cancer. Woolnough noted the lack of data available for respiratory conditions in comparison to cancer and stressed the importance of improving data collation. Woolnough highlighted the importance of a respiratory recovery plan just as there is for cancer.

Professor Peckham noted the effect that shutting down care had on respiratory services, and that red tape may have had an unequal effect across diseases, while Stonham pointed to the lack of clear communication from the government as a key issue, with guidance for conditions such as asthma left to the discretion of each clinician.

Lord Mendelsohn stated that the Joint Committee on Vaccination and Immunisation (JCVI) had given politically skewed guidance on vaccination, and questioned the guest speakers as to whether respiratory patients would be sufficiently protected by vaccination.

Peckham noted that much of that information was not yet known and that efficacy would only be proven over time, but did note immunosuppressed patients may struggle more through limited methods of treating underlying respiratory diseases. Woolnough highlighted the need for better prioritisation and suggested that better understanding and definitions of asthma may have led to a more effective vaccination programme. Woolnough also noted the impact that air pollution has on respiratory patients as a key factor that was not considered.

Lord Mendelsohn further noted the impact that 'Long Covid' has had and will continue to have and asked whether there was any evidence this would disproportionately affect respiratory patients. Each of the speakers noted that ongoing studies would determine the scope of the effects of Long Covid but that the information was not yet known. Stonham did note that there was no proof that isolation worsens effects of Long Covid but did highlight the effect it had on mental health and general health as issues that must be considered. This point was echoed too by Sarah Woolnough.

The Chair passed over to the Secretariat to close the webinar; the Secretariat closed noting that the key lessons include the need for a national platform for respiratory, a new understanding of the importance of home-care solutions, and the need for a national recovery plan.