

## **All-Party Parliamentary Group on Vulnerable Groups to Pandemics**

### **Meeting on Persistent Vulnerability: Long-term Protection of Cancer and Immunocompromised Patients**

**Minutes of the meeting held on 21 July 2021, 15:00-16:00**

#### **1. Introduction from Chair – Lord Mendelsohn**

The Chair welcomed attendees to the meeting, noting the risk of the unlocking of most public health measures two days prior to the webinar.

The lifting of nearly all mandated public health measures has been met with concern across patient communities, with many people with underlying conditions with low antibodies and limited protection to the virus despite courses of a Covid-19 vaccine.

The Chair noted cancer patients, particularly those undergoing treatment or in the convalescence period, are at greatest risk of severe morbidity and mortality.

The Chair noted the importance of proactively monitoring the health of immune-suppressed people and research into and understanding of protective therapies, and additional courses of vaccination.

#### **2. Blood Cancer UK presentation**

The Chair welcomed Helen Rowntree, Director of Services, Research and Engagement, Blood Cancer UK, to present on the protection of blood cancer and immunocompromised patients through Covid-19.

##### **Blood cancer patient vulnerability**

Ms Rowntree noted there are 230,000 patients with blood cancer in the UK and an estimated 500,000 immunocompromised patients. Covid-19 infection has been found to behave differently in people with blood cancer, and people remain particularly vulnerable to Covid-19 with lifting restrictions and rising circulation of the virus.

Rowntree noted many people with blood cancer have weakened immune systems and do not mount a strong antibody response to the vaccine – a study released in the spring of 2021 found 58% of blood cancer patients developed an antibody response after two doses of a Covid-19 vaccine, compared with 97% of healthy adults. The quality of the response in immunocompetent patients who did mount an immune response was found to be questionable. Among chronic lymphocytic leukaemia (CLL) patients, the immune response was less than 40% of that in healthy adults.

##### **Patient charity supportive role**

80% of blood cancer patients have reported the pandemic has impacted their mental wellbeing, and since the announcement of the full relaxation of restrictions, Rowntree noted the charity has reported a 250% increase in calls to their support line, with the Government's advisory, rather than prescriptive, guidance undermining patient safety.

Rowntree noted a Blood Cancer UK survey found 80% of respondents had not received appropriate information from their healthcare team on their ongoing health protection, though Rowntree noted the charity is well-placed for further support of and communication to patients as restrictions remain unlocked.

### **3. UK Coronavirus Cancer Monitoring Project presentation**

The Chair welcomed Dr Lennard Lee, Co-Executive Lead of the UK Coronavirus Cancer Monitoring Project (UKCCMP), a consortium set up on 18 March 2020 to “safeguard, protect and monitor” patients living with and recovering from cancer during Covid-19. The project involves patient groups including Blood Cancer UK and MacMillan Cancer Support, professional bodies including the Association of Cancer Physicians, academic bodies including the University of Birmingham, and clinicians.

#### **UKCCMP findings**

Early in the pandemic, Dr Lee noted members of the UKCCMP found many patients were not coming forward with suspected cancer, resulting in chemotherapy treatments, by time-to-treatment, being drastically reduced in the early phases of the pandemic, even before the imposition of lockdown measures on 23 March 2020.

Dr Lee noted the UKCCMP found patients with blood cancers are more likely to get Covid-19 and require more intensive treatment, with the susceptibility to Covid-19 in patients with leukaemia nearly three times higher compared with the overall cancer population.

A UKCCMP study found no observable harm from recent anti-cancer treatment in Covid-19 mortality rates, with the ITU admission rate low in a study of cancer patients with Covid-19.

#### **UKCCMP recommendations and next steps**

Dr Lee concluded to note understanding vaccine efficacy is important – national data sets are available and should be analysed to understand the risk in the vulnerable. Dr Lee called for planning and strategising to support improved access to testing, treatment and new modes of condition management, concluding that new shielding guidance and a long-term health protection plan should be formulated.

The project will next issue a survey to individuals involved in the project, analyse national datasets on vaccine efficacy to understand cancer patients’ risk, and support antibody testing, treatment and research to identify and reduce risk.

### **4. Kidney transplant patient testimony**

Dr Lee gave way to Hal Cohen, a double kidney transplant patient, to share testimony on his experience through Covid-19.

Cohen noted he had accepted shielding on a personal level, but noted the broad impact on persistently vulnerable transplant patients, and noted many immunocompromised people seek further direct protection through vaccination or other health interventions.

Cohen addressed the risks posed to immunocompromised patients through the recent unlocking of public health measures, calling for people to have awareness from their

employers of their vulnerability; and the risk of masks now only being encouraged rather than mandated, calling for non-restrictive mitigations such as mandated mask-wearing to be reintroduced.

Cohen suggested Covid-19-vulnerable people need to be supported with funding for and access to trial treatments, such as a third dose, a vaccine 'mix and match' and prophylaxis. Cohen further called for expedited approvals, including through emergency use, for proven treatments such as monoclonal antibodies.

The Chair indicated, after a fourth or fifth vaccine, CEV people may get protection, calling for a CEV strategy including a booster regime to be considered.

## **5. CLL patient testimony**

The Chair introduced Nick York, a CLL patient and Patient Advocacy Healthcare Liaison Officer at Leukaemia Care. CLL is a treatable but incurable blood cancer of the b cells – those providing people with immunity.

York noted he is now on continuous therapy that further impacts his ability to mount a response to vaccinations. In lieu York suggested targeted monoclonals may provide protection.

York suggested that, through Covid-19 and with the lifting of restrictions, it has felt like being diagnosed with cancer of the immunity all over again, with a 'new set of rules' on vulnerability, and that the current phase of the pandemic is presenting the greatest mental health impact across his whole cancer journey.

Like Cohen, York stressed mandated, rather than advisory, government guidance on mitigations such as mask-wearing gave reassurances to shielders. This was echoed by many webinar attendees, arguing prescriptive shielding guidance elicited a positive mental health impact in most shielders, contrary to government communication on shielding.

The Chair suggested further research is needed on the efficacy of alternative therapies to vaccines, such as targeted monoclonals.

## **6. Clinical oncologist presentation**

The Chair introduced Professor Alison Birtle, Consultant Oncologist at the Rosemere Cancer Centre, Lancashire Teaching Hospitals. Professor Birtle noted her personal experience in shielding through the first lockdown, with her and other shielding clinicians finding difficulties in setting up virtual ward-rounds without support.

### **Treatment prioritisation**

Professor Birtle noted with systemic therapy prioritisation, different centres prioritised cancer treatments differently based on their respective professional opinion and available staff.

In her centre, priority treatment was based on chance of success and chance of cure – curative treatment with at least a 50% chance of cure to treatment at relapse of cancer was prioritised. Chemotherapy prior to bladder removal was stopped due to the 5% survival advantage felt to be lower than risk. More radiotherapy than surgery was prescribed for bladder cancer, with a small amount of surgery paused as benign work was paused.

## **Cancer care in Covid-19 waves**

Professor Birtle noted in the first lockdown there was no backlog to tackle, with lots of work paused, meaning services were initially not as affected by isolating or shielding staff as in the spring and summer of 2021.

The broad initial aim was to communicate with and support patients, and minimise face-to-face contact; this was supported by NICE guidance issued on 20 March 2020 prescribing cutting non-essential face-to-face follow-up consultations following the delivery of systemic anticancer treatments.

Professor Birtle noted the results of a Cancer52 survey finding 26% of patients had appointments delayed or moved, with 8% reporting appointments had been cancelled with no alternative offered. 12% found appointments had continued as usual.

## **Patient monitoring and communication through Covid-19**

Professor Birtle noted that, of those receiving regular surveillance to monitor cancer, including blood tests or scans, 14% still await appointments, while 25% indicated tests and scans had been attended as usual.

46% had relied on online forums for information on their cancer, 43% were in contact with their hospital cancer team, 18% with their GP, 45% had used government or NHS websites, and 35% used charity websites or helplines, with patient groups demonstrating clear communicative value through the pandemic.

A key recommendation from the survey for improved care through Covid-19 included increased clarity on the scheduling of care and treatment, with a key positive change to care options the rise in telephone and video consultations and communication on care.

## **Covid-19 surge study**

Professor Birtle presented key findings from a Covid-19 surge study – a 24% chance of mortality was found after 30 days for patients undergoing surgery with perioperative Covid-19 infection.

Risk factors included male sex, age over 70, a cancer diagnosis, the need for emergency surgery, and whether major surgery was required.

The key conclusion from the study was that post-op complications and mortality is higher than pre-Covid-19, meaning surgery should have been postponed and non-operative management used.

## **2021 issues and recommendations in urological surgery**

Professor Birtle reported issues faced this year in urological surgery include the Covid-19 catch up and staff isolations. Advantages include extra PPE for staff and no surgeries being paused.

Professor Birtle stressed the need for defined surgical pathways, green Covid-19 sites, and a seven-week delay to elective surgery through contraction of Covid-19.

Professor Birtle called for vaccination before chemotherapy or radiotherapy; lateral flows twice weekly; and for all precautions to be taken around care. Professor Birtle stressed the importance of maintaining cancer treatment, with worse outcomes found without treatment.

## **Attendees**

*Lord Mendelsohn, Helen Rowntree (Blood Cancer UK), Dr Lennard Lee (UKCCMP), Hal Cohen, Nick York, Professor Alison Birtle, Michael Tilby (UKCCMP), Anne MacDowell (Fight Bladder Cancer), David McIntosh (Plasma Action UK), Bridgit Sam-Bailey (London Older People's Strategies Group), Louise Wright (Action Pulmonary Fibrosis), Susan Walsh (Immunodeficiency UK), Debra Montague (ALK Positive), Yasmin Sheikh (Anthony Nolan), Fiona Loud (Kidney Care UK), Kit Greenop (RPP Group), Gaelan Komen (RPP Group), Charles Waller (RPP Group), Ciaran Johnston (RPP Group).*

*Louise Tarrant, Carole Waldon, Linda Fraser, Mike Dicks, Kay Price, Lucy Hardiman, Christine Fraser, Lorraine Arnold, Melanie Salsbury, Sana Gilfillan, Lynda Starkie, Jo Dalton, Philippa Willitts, Miranda Scanlon, Robyn Noble, Vix Woodthorpe, Sally Hayton, Warren Beardall, Colette Lambe, Laura Broughton, Sandie Gilbert, Janine Wright, Phoebe Collins, Andrew Gregory, David Innes, Sonya Pettigrew, Shirley Dodds, Lynne Grant, Michiel Van Zanten, Leanne Howis, Debbie Lambert, Alison Preston, Sue Carr, Linda Nephi-Williams, David Yates, Claire Vine, Alistair Wilson, Zoe Smith, Michael Carr, Elizabeth Evans, Rebecca Doughty, Ben Kind, Simon Johnes, Julie Thomas, Lisa Forrest, Elis Amlsct, Janet Barnes, Anna Turville, Maureen Harris, Rachel Harris, Jessica Rose, Chris Brewer, Helen Harrison, Ismay Inkson, Sarah Spoor, Xanthe Verney, Deborah Daniels, Gill Allan, Ella Guthrie, Maria Linfield, Maria Clark, Sey Afolabi, Lisa Safiullah, Ann Pearce, Agela Robertson, Geraldine Hills, Catherine Winget, Matthew Stypulskowski, Eleanor Huish, Elizabeth Silva, Suze Kirkham, Naomi John, Alison Allam, Jemma Lough, Emmg Kelly, Sarah Carpenter, Siobhan Gee, Rosalind Conway, Rowena Lawrence-Thorn, Liza Benny, Lucy Hatherell, Denise Knowles, Claire Mayes, Carly Webb, Sarah Hayward, Josh Niderost, Rachel Moxey, Janine Dixon-Wilkinson, Malcolm Rhodes, Ian Cooper, S Chiu, Celia Anderson, Navpreet Singh, Julia Trewick, Eileen Purves, Teresa Pennington, Richard Honeyman, Rebecca Grandison, Graham Lavender, Mick Williams, Boryana Nankova, Kate Wakley, Victoria Caine, Gail Wiegman, Charlotte Cardus, Lynsey Beswick, Mark Hughes, Nicola Hutchinson, Kerry Andrews, Susan Fineman, Lisa Wilson, Keith Hoddy, Karen Rockell, Elizabeth White, Ann Howarth, Justine Cornforth, Tessa Bindloss, Stella Silverstein, Jess Briggs, Daisy Evans, Snehasish Guha, Tatiana Conrad, Kate Robinson, Abi Howgego, Anthea Malik, Andrea Barrett, Andrew Tran, Maria Ionescu, Beverley Satchell, Philip Cross, Frances Daly, Martin Little, John Bennell, Claudia Miron, Anna James, Joanne Ollerton, Deb Gompert, Emma Kinloch, Jess Sellers, Lynne Jones, Patricia Lindskog, Susan Watson, Lisa Clark, Karen Maycock, Gemma Fuller, Elizabeth Johnston-Yong, Cameron Millar, Helen Kerrigan, Alison Crockford, Callum Tempest, Tom Rhodes, Naomi Waterman, Sanjeev Johal, Rosie Smith, Charlotte Martin, Marie Lauder, Bernie Divin, Carl Broadbridge, Heather Graham, Hazel Sims, Carole Carter, Catherine Vassallo, Clare Saunders, Pete Clapham, Samantha Sharp, Teresa Pennington, Olivia Holcombe, Kathryn Tee, Francesca Haydon, Kira Draper, Yvonne Olive, Colin White, Stephanie Sinclair, Catharine Hall, Maria Wysocki-Jones, Laura Cameron, Nicola Whatley, James Hargrave, Rahcel Sykes, Angela Peake, Yvonne Aryitey, Wendy Longman, Tina Norris, Victoria Waite, Sarah Todd, Chris Painting, Geraldine Springett, Lucinda Jefferson, Maureen Gibson, Amanda McCauley, Kathryn Head, Hilary Henery, Julie Addis-Fuller, Lou Gillett, Rebecca*

*Bateman, Tracy Humphrys, Tina Dowell-Lucas, Norah Grant, Carol Olley, Eleanor Matthews,  
Louise McLellan, Avril Griffiths, Sarah Roberts, Sally Hall.*