Cancer Webinar, 11th June 2020: Key Themes and Q&A

Healthwatch in Sussex is the independent champion for people who use health and social care services in Sussex.

Our job is to make sure that those who run local health and social care services understand and act on what really matters to people. We listen to what people like about services and what could be improved. We share what people tell us with those with the power to make change happen. We encourage services to involve people in decisions that affect them. We also help people find the information they need about services in their area.

Healthwatch in Sussex would like to thank all those who responded to the survey.

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1. Context

Healthwatch Brighton and Hove together with Healthwatch East Sussex and Healthwatch West Sussex (under the name of "Healthwatch in Sussex") responded to patient concerns and feedback about the lack of information about cancer services during the COVID-19 lockdown. A webinar was coordinated between the three local Healthwatch and Sussex Health and Care Partnership on Thursday 11th June between 5pm - 6pm. Publicity was sent out via the three local Healthwatch using mailing lists and social media. The media were also engaged via Healthwatch Brighton and Hove.

A total of one hundred people registered and 64% of these attended the webinar itself. Approximately one third (36%) were not in attendance due to personal reasons or technical difficulties with using the online platform and were instead offered access to the recording of the webinar. The registrants represented the general public, cancer patients and family and friends of cancer patients (totalling 43%) and health and social care professionals (57%).

A panel of three clinical experts provided information on cancer services and support services available across the county:

- Dr Mathew Thomas, Cancer GP lead for East Sussex;
- Dr Richard Simcock, consultant oncologist at the Sussex Cancer Centre and
- Scarlett Jinman-Dunt, a former oncology nurse now working for Macmillan.

The panel shared presentations with participants (see Annex X) and responded to a number of questions submitted both in advance and during the webinar. Dr Mathew Thomas took the place of our original panellist, Dr Alex Mancey-Barratt, who was unable to take place in the webinar (due to a family bereavement). The two GPs worked together on the final presentation slides that Dr Thomas presented.

The following summary presents:

- Key themes that emerged from the webinar
- Questions asked before and during the webinar by registrants together with the responses given by the presenters.
- The full transcript of the event.

For further information on cancer services during Covid-19 as well as the recording of the webinar itself and a copy of the powerpoint slides during the webinar, please visit: https://www.healthwatchbrightonandhove.co.uk/find-services/local-services/cancer-services-during-covid-19/

2. Key Themes

- **Cancer Screenings are currently limited:** Cervical screening is being risk-stratified and patients are being individually written to; Breast and Bowel screenings are in the process of resuming soon to clear the pre-COVID waiting list of patients testing positive for bowel and once suitable locations for breast screening are assured of being COVID-safe.

- **Availability of tests:** Endoscopies and colonoscopies for example, are available but there are some delays. The NHS are using locations such as the Montifiore Hospital in Brighton. A 14-day isolation period is required by patients beforehand to protect the clean hub.

- **GP Access:** GPs have remained open but are using remote communication with patients such as telephone and video consultations in line with lockdown. Patients are urged NOT to hold back from contacting their GP especially with a cancer-related concern such as a lump. The sooner the better to either eliminate the possibility of cancer or to begin treatment in the case of positive diagnosis.

- **Patients have not been lost in the system:** Patients undergoing treatment at the point of lockdown have not been forgotten, but the focus on handling corona virus patients has created some delays. Rehabilitation services have re-started for patients recovering from COVID to ensure they are ready to begin cancer treatment again.

- **Patient fears around hospital visits:** Patients SHOULD ATTEND hospital appointments. Patients coming to hospital are being seen in COVID-treated areas and away from A&E to avoid potential contact with COVID patients. Hospital staff are using PPE and ensuring the space is as safe as possible.

- **Movement towards managed self-care:** Cancer specialists have encouraged the movement towards less unnecessary appointments where patients are able to manage their condition at home, knowing they can contact their specialist at any time if needed. This movement has developed system-wide due to the COVID lockdown.

- **Cancer Shielding has lifted:** Cancer specialists agree that the messaging around shielding was confusing but that as hard as this was, shielding was appropriate in the context of lockdown. Likewise, it is appropriate for these restrictions to be lifted slightly now. In reality, 90% of oncology appointments remain by telephone and video.

- **COVID-19 during cancer treatment:** Figures now show that catching COVID-19 while undergoing cancer treatment is not as risky as specialists at first predicted.

- **Referrals are down:** Referrals to hospital doctors have halved since COVID-19 due to patient fears at having contact with medical staff or from concern about not wanting to bother medical staff who are prioritising COVID patients. Clinicians fear an influx once restrictions are lifted. The Macmillan Horizon Centre in Brighton and the Citizens advice bureau in West Sussex have noticed similar downturns in the number of patients being referred for their Macmillan funded welfare rights service and have similar concerns post-lockdown.

- **New lockdown methods are here to stay:** Methods used during the lockdown period such as telephone and video consultations with GP and hospital staff, are likely to continue in the future. While not negating the use of face-to-face contact, remote methods are useful and a positive move forward. Likewise, the use of PPE for staff (e.g. gloves, aprons) and patients being screened for COVID-19 and some isolation periods before treatment will remain.

- **Support services still available:** Services available prior to lockdown, are still available, now using remote methods such as telephone support and online sessions to reach patients. For example, the Macmillan Horizon Centre, Olive Tree, the Fountain Centre, Centre of Queen Victoria and Age Concern. Further information on all services can be found on individual websites as well as the Healthwatch website at: https://www.healthwatchbrightonandhove.co.uk/find-services/local-services/cancer-services-during-covid-19/

3. Questions raised by registrants of the webinar and responses provided by the presenter panel.

1. **‘I was diagnosed with a very low blood count in January and was on the fast track for investigations for possible gut cancer when the lock down came in and my endoscopy was postponed. How long will I have to wait to have the test and what will happen. I now have a lot of stomach pain.’ Another question asked about ‘colonoscopies and when these will be resumed.’**

Response by clinicians: Dr Richard Simcock “I know that colonoscopy was one of the services that was struggling most before anyone had even heard of COVID, and it is doubly difficult now. If there was one part of the hospital machinery that needed the most investment to help cope with a COVID surge, it's colonoscopy, but I'm afraid I don't have the answer to when it's going to get back up. What I would say is, what can we do differently and smarter and better and what has COVID taught us? Matthew may have a point to make on this but it has meant that fit testing, as part of our colon screening, has had a real boost because of COVID as a safer way to screen patients for colon disease.”

2. **Are they doing colonoscopies at the Montefiore Hospital in Brighton?**

Response by clinicians: Dr Richard Simcock “Yes, they are, and the follow-up question to that is will a 14-day isolation be required? Anyone visiting a clean hub will be asked to isolate for 14 days beforehand, because clean hubs only work if uninfected people come into them, so we have to do everything we can to keep them clean, so all patients will be asked to isolate for 14 days before entering a clean hub.”

3. **‘I have breast cancer and I am on medication. I have been called in for a mammogram. I have been strictly socially isolating and I am really worried about picking up Covid. Is it safe?’**

Response by clinicians: Dr Richard Simcock “I am absolutely sympathetic to that view. Citizens who have been at home very carefully shielding and not going out and about are then invited to leave their home and come into a healthcare establishment to be seen by a radiographer who is working with other radiographers. I can see why it's a concern. We have done everything that we can to make those procedures as safe as possible. All staff are in PPE, patients are able to have PPE, for example if you come to the mammographic screening unit at the Park Centre, you'll be screened for COVID symptoms before you arrive and you'll be offered PPE. All the staff will be wearing PPE and there is a clean-down, anyone who has had a mammogram will know it's an up close and personal physical test,

and all of that equipment is cleaned down afterwards. Nonetheless, if any individual felt that they did not wish to take that risk, they just contact us and we'll put them back on a rolling list to be called back at a later date.

Dr Mathew Thomas "Before referral to the hospital, there are various calculators around. GPs will use your gender, your ethnicity, your age, your illnesses, to work out what are the risks for you personally. Then, of course, have you been asked to shield at home. Having looked at all that, and if you are worried, he will discuss that with you, and he will discuss the issues around risk and around the risk of the cancer itself, and then you can decide that this is the right time for you to be sent to hospital."

4. **'I have been feeling sick and lost my appetite for the last couple of months and lost a bit of weight, feeling tired. I don't want to bother the GP as I know they are busy and the last information I had was that they were not seeing patients face to face. Are GPs 'open' now?'**

Response from clinicians: Dr Matthew Thomas "No, we didn't close. We simply transferred to trying to prioritise who we talk to and when and how. So, no, please don't have that feeling at all. Everyone who has a concern about cancer needs to contact us. We are open, we will deal with it, it's just that we will use technology that we have not used before."

5. **'I have lump in my breast from last year when I had a mammogram which said it was not cancer. Its getting bigger but not hurting. Should I go to my doctor. What would happen?'**

Response from clinicians: Dr Matthew Thomas "Yes. I would say go to your doctor. We understand anxiety is high, and justifiably so. If you are concerned, we are there. And your GP will know you, so he will know whether you're not the sort of person that normally worries and you've come back, and therefore that's a red flag to him, so please don't worry about any of that. We're doing the first contact over the telephone so you can talk this through with him before he actually brings you in, but no, all my colleagues would not have any problem if you phoned up and said 'I am concerned'."

6. **'Lack of referrals for people living or potentially living with Cancer for the benefits service provided by Citizen Advice' not receiving near enough same referrals 50% (20-30 - 10/15). PP and diagnosis in the people's pack but overwhelmed. Referrals through the hospital Macmillan support worker. Worried about the capacity to cope when floodgates open. 90% benefits. Furloughed or out of work and increase in employment issues to benefits.**

Response from clinicians: Dr Richard Simcock "We are sympathetic to this concern. Part of the next phase in our planning, and the thing that is occupying us

now is how do we begin to plan for the surge that is undoubtedly coming? In the last few weeks, the number of new patients I have seen in my clinic has been half what I would normally expect. The cancer wait times data for March saw 26,000 fewer patients seen in hospital based on referrals by their GP with suspected cancer, and we can only expect that to contain a large number of undiagnosed cancers which will be coming our way, I hope sooner rather than later so the next phase is to plan to accommodate those."

7. **I recently was informed by a member of the public following surgery for breast cancer, that they were told that all normal follow up appointments were now not happening and that the next time they would be seen would be following a mammogram in 12 months' time. They are understandably concerned by this. Given that referrals for cancer have been at an all-time low during the pandemic and are still not back at normal levels, why would this be? Surely patients will be needing more reassurance during this time than normal, not less?**

Response from clinicians: Dr Richard Simcock "I remember working for someone who told me that doctor's never change. All that doctors do is they die or retire and then they are replaced by new doctors who then change. That's the only way we get change in the health service. I don't know if that's true. But, one of the things that we've been trying to change around breast cancer follow-up, is moving towards what is called managed self-care. Knowing that actually a hospital visit for a woman who is well informed and has a phone number that she can ring and expect an answer is just as good as being seen regularly in hospital. Not everyone was willing to engage in that but COVID has enabled that change to happen system-wide quite quickly. So, it has enabled some changes that we have been wanting to make for some time. It's just important that we support it with the information that patients need to manage their care appropriately."

8. **During COVID-19 there have been changes made to the way that cancer services have been delivered. To what extent are these changes likely to stay permanent i.e. after the COVID-19 lockdown?**

Response from clinicians: Dr Richard Simcock "Well, I suddenly realised that people didn't necessarily want to spend an hour driving to Brighton, finding parking, and sitting for 45 minutes in my waiting room, just to talk to me for 5 minutes when they could have done it on the telephone. That was a lightbulb moment for me, and of course the adoption of telephone and video has been something that we will definitely hold on to. I would like to see a future where we offer patients follow-up and then we give them a choice. When it comes round to their appointment we just say would you like that to be a tele-health follow-up or would you like it to be in-person and we can flex the system accordingly. We know that coming to hospital is incredibly disruptive for patients. They have to take time off from work, they have to arrange childcare, they've got to pay for parking, and if they can do it all over a telephone in the comfort of their own home then all the better. I've also noticed that when people are at home when I do a tele-

consultation, they ask me more difficult questions. I think being in their own environment makes them more comfortable so maybe that's a good thing too."

9. **When can patients expect to hear about continuing outstanding treatment (example someone had one more treatment and this was stopped when pandemic hit and they have not heard anything since)?**

Response from clinicians: Dr Mathew Thomas "I wanted to just reassure everyone that, if you feel that you're in the system, that something's happened and you don't quite know what's going to happen now, whether you'll be delayed, that the hospitals are holding a list. They look at that list very regularly to make sure that people are prioritised and that they are kept an eye on, so you're not missed out, you're not lost."

10. **I am a carer for my husband who has refractory follicular Lymphoma. He was in hospital for 5 weeks with Covid 19-he had just started a drug trial before this at The Royal Marsden. It is crucial to get him well enough to restart his trial treatment but there does not appear to be any rehabilitation to assist with regaining full breathing capacity or any after care at all. GP surgeries are telling people to call 111 with any queries about Covid 19. What is happening in respect of this and what is the role of GP surgeries in Covid recovery.**

Response from clinicians: Dr Mathew Thomas "GPs have a role in prevention, screening, early diagnosis, and living well with and beyond cancer, and these are the people that you actually know in the community. I know it's really tempting to say, 'I want to bring my problem to my GP, but I'm really not sure about going on to have an endoscopy or have a CT scan, or have anything else done,' but actually we're doing everything we can to make the space safer, or as safe as possible, for you, so it's really important to engage if we actually do refer you."

Rehabilitation services have re-started. I suggest you speak to your GP who will know about what is available locally. These services will prioritise patients and try to treat them in a 'Covid-safe' way. Only the initial diagnosis of Covid-19 is being given to 111 now. GPs have a significant role in directing patients to the appropriate service in the Covid Recovery phase we are now in.

11. **The Independent have published an article (see below) saying hospitals are not equipped to deal with screenings including those associated with cancer. What do the speakers think about this?**

NHS on life support: Patients face diagnosis delays as hospitals struggle with surge in screenings
Hospitals are not equipped to deal with the surge in screenings and tests as the health service restarts care – leaving patients facing delays in diagnosis and treatment for conditions including cancer, according to medical leaders.

Read in The Independent: https://apple.news/ADyCFeH1_RoKBuCbelmFEkA

Response from clinicians: Dr Mathew Thomas "In terms of screening, there are three national screening projects generally, the cervical screening is initially being risk-stratified. Letters are now being sent, so we are starting to ask people to come in for them, but please wait for your letter or wait for your practice to call you.

"In terms of bowel and breast, they've both been paused, partly so that the backlog can be cleared of those who were testing positive in the bowel situation, and then for breast, you know that obviously a lot of the breast screening is done in vans which have to be cleaned, so those issues are currently being worked through, but that is hopefully likely to be started soon."

12. **Please can we have your comments about the removal of some cancer patients from 'shielding'. Can you find out what the rules are now please? When treatment was removed, we were told it was for our own good as we were at grave risk of getting the virus. So why are some now told they no longer have to shield? Please can you clarify?**

Response from clinicians: Dr Richard Simcock "I think the new guidance around shielding was badly announced, but the announcement itself was correct. What I'm seeing in my clinic is a large number of patients now who are experiencing enormous emotional and psychological distress from the impact of shielding. I'm very pleased to see those shielding restrictions very slightly lifted, and I think that's a safe thing to do in the context of this data. I don't think that the messaging has gone out that the shielding restriction lifting is consistent with the data. What are we doing now? I'd say this is a fluid situation. First of all, our out-patient practice has changed enormously. 90% of my consultations now are either by video chat, we're using the NHS Attend Anywhere platform. I've just been piloting that with three other oncologists over the last week, I have to say video is a huge leap forward over telephone."

13. **What percentage of patients are asked to come to an examination in a COVID-safe setting following the initial consultation?**

Response from clinicians: Dr Richard Simcock "For most of our follow-ups, we are able to do by telephone. I am maybe seeing 1 or 2 patients off the list, that's about 10%, if the patient is concerned that they have a lump, or they are requesting examination we'll bring them into clinic. We have, in the last few weeks, asked all of our new patients to come to clinic because we felt that was an important moment to establish a connection and do a baseline examination."

14. **If there is another spike on COVID in the winter months, will the response and effect on cancer effects be the same or may things be handled differently?**

Response from clinicians: Dr Richard Simcock "I think it will be similar but not the same. Never have I been more impressed with the NHS's resilience and flexibility, the ability of colleagues to flex the way they work across every part of the hospital has been extraordinary, and it's been very difficult to learn a lot of this stuff. But, now everyone is a dab hand on telephone consultations, video, we have pathways, we have red and green channels, we have infection-control procedures and everything is getting slicker and quicker. So, if it does hit us hard again, the impact will be there but it will be less acute than it has been this time."

Dr Matthew Thomas "I completely agree with Richard. I think we geared up to deal with the spike and the spike flattened, so in primary care we have stepped up the total triage, as we call it, so that's telephone calls and video consultations from 5% about 6 months ago, to 98% today. So, it won't be the same, we will cope with it better than it has been previously."

15. **Can we hear more about the data on proven diagnosis of COVID shown in Richard's slides?**

Response from clinicians: Dr Richard Simcock "In a large number of patients, even despite having proven COVID, they were able to continue to their original cancer plan. If people are interested to see the data, it's published every Wednesday and if you go to Google and type in UK cancer COVID monitoring project, you can sign up and you can see that week's data in your inbox."

Follow-up question: Just to clarify then that the data presented refers to cancer treatment plans changed due to confirmed COVID diagnosis rather than changed as a result of risk of COVID? This is not my experience.... In gynae, I feel that treatment plans have been changed due to risk and concern regarding managing patients if they go on to develop complications and/or COVID For example: not using Avastin or delaying surgery due to anticipated ITU requirements... Thank you for clarification.

Response from clinicians: Dr Richard Simcock "The data I presented was for cancer plans changed because the patient had proven covid - not due to risk of covid."

16. **Is there regional variation in screening, testing and isolating?**

Response from clinicians: Dr Richard Simcock "The testing guidance changes all the time, you have to be pretty quick. By the time you've read the 27-page document, a new one is out. But the new guidance today, in terms of our cancer patients, is that testing policies should be determined locally, based on the background prevalence of the virus. So, if you have a large number of infected people in the locality, your testing policy is going to be different compared to an area where there's a very low background rate. The principle is any patient who is coming for a long course of radiotherapy, or chemotherapy or cancer surgery can expect to be tested prior to that treatment starting."

17. **As a lung cancer patient. will we have access to Covid antibodies tests?**

Response from clinicians: Dr Richard Simcock "Antibody testing is complicated - there is reluctance to roll it out because we still don't know whether a person with antibodies should change their behaviours (and they probably shouldn't)."

18. **Will patients be required to isolate for 14 days pre-colonoscopy appointments? Also will this isolation delay pathways?**

Response from clinicians: Dr Richard Simcock "Yes they will. At the moment, the 14 day isn't lengthening pathways very much because we have fewer referrals and so are able to see patients much more quickly than usual."

19. **We were told that rather than Haywards Heath, a cancer hub would be organised at Sussex (Brighton). We were also told that private hospitals would be used to reduce lists, have either of these happened?**

Response from clinicians: Dr Richard Simcock "We are enormously grateful to the Macmillan horizon centre who have donated their space to us to use for clinic capacity. That in turn has allowed us to turn the outpatient service in the Sussex cancer centre to the haematology day unit. That in turn has allowed us to turn the haematology day unit into acute oncology unit, so patients with acute cancer

problems can be seen outside of the A&E space, by dedicated oncology professionals.

"[…]Also there is the Montefiore private hospital at Hove; Some head and neck and breast surgery going on at Queen Victoria hospital, East Grinstead. Flexing the private capacity that the NHS has bought sensibly, I don't think we are anywhere up to speed yet, getting those patients through that pathway is much slower, but we are starting to claw that back."

20. **A patient has been shielding prior to breast cancer surgery. Can her husband go out of the house or will this jeopardise her surgery?**

Response from clinicians: Dr Mathew Thomas "Yes. However, he needs to follow strict social distancing rules – I would suggest sticking to 2m despite any upcoming changes in this distance for the general public – and he also needs to follow the following guidance:

- spend as little time as possible in shared rooms, for example, the kitchen and sitting areas
- open windows to let fresh air into shared spaces
- keep 2 metres (3 steps) away from the person who's at high risk – avoid sharing a bed, if possible
- use separate towels, including hand towels and tea towels
- clean cutlery, dishes and pans thoroughly
- clean a shared bathroom each time you use it, for example, by wiping the surfaces you have touched
- clean objects and surfaces you touch often (such as door handles, kettles and phones) using your usual cleaning products."

21. **What consultation with the general public would the speakers like to see before any changes are made permanently post-COVID-19 lockdown?**

Response from clinicians: Dr Mathew Thomas "I would expect some reflection, which will include the patient voice, when the circulating virus drops to very low levels. In General Practice, I know my colleagues can continue to work in this 'total triage' way in the future. However, they also value face to face patient contact so this may change by mutual consent at some point. I feel that it is now recognized that there is so much that does not require more than a telephone call or email so this will remain. Fortunately, every healthcare working environment has a patient voice: Healthwatch, PPGs, PALS, GP Patient surveys etc, so I see these as feeding back on how this is working for patients."

Appendix 1: Full Transcript of the Webinar

Geoffrey Bowden (Chair): There has been a 60% drop compared to last year of being assessed of cancer following a referral, and that is massive. At the end of this event today, those of you who have registered will be sent an opportunity to give some feedback. It really is important for us to have that, especially as the Sussex Cancer Board will be meeting next week. It hasn't met for a while, and lived experience is on the agenda, so we want to be able to feedback to that board some of the things that have been said during this webinar. We've assembled a great panel for you, which reflects the patient journey from the GP through to the oncologists and the nurse.

Without further ado, I would like to hand over to Dr Mathew Thomas, who is the Cancer Treatment Lead GP for East Sussex. He has collaborated with Dr Alex Manson-Barrett, who is unable to attend due to a family bereavement. He will be followed by Dr Richard Simcock, Brighton and Sussex University Hospital Trust, who is a Macmillan consultant, and to complete is Scarlett Jinman-Dunt, formerly an oncology nurse, now Information and Support Services Manager at Macmillan Horizon Centre, Brighton. I'd like to handover now to Dr Mathew Thomas. The presentation you are going to see from our three panelists will be available on all local Sussex Healthwatch websites, and a recording of this event will also be available. My colleague will be creating a summary of the key points, which will be circulated to everyone who has registered, and put up on the websites as well. Over to you, Mathew.

Dr Mathew Thomas: Thank you, Geoffrey. As you know, I'm a GP, and at the moment we are all aware that cancer is a priority, and it's a real priority. We know that 50% of us will have a cancer diagnosis during our lifetimes. Most of them are treatable, so 50% of patients survive 10 years from diagnosis, and those figures are taken from 2010, so we know they are much better than that. In some cases, like breast, it's 75%, and again, that data is quite old, it's better than that. Prostate cancer is 78%. Coming forward early and being diagnosed early and being treated early is what we need to be doing. GPs have a role in prevention, screening, early diagnosis, and living well with and beyond cancer, and these are the people that you actually know in the community.

Just to give you a little bit of background, there is something called the 2-week-wait rule, which you may have heard of. It was brought in in 2005, and the NHS agreed criteria for urgent referrals for cancer, essentially to improve the diagnosis and make sure patients are seen early and treated early, and to reduce missed cancers. It's based on the recognition of certain symptoms and signs. Symptoms are what you tell us, and signs are what we find when we examine you. In those days, it was a 5% risk of having cancer. If we thought that you had the symptoms or signs, we would then refer you for urgent assessment and investigation. There's a target set, and that's what the 2 weeks is about. The target is that the patient, the

referral, leaves our building within 24 hours of you talking to us, and the first appointment with a secondary care specialist is within 2 weeks, and hence 2 week wait. There is also a treatment target, so that the time from leaving us to having your first treatment should you get cancer, or be diagnosed rather with cancer, is 62 days. This was subsequently refined in 2015. We had 5% before, so the threshold dropped to 3%. That's a 3% risk of having cancer, based on what you tell us and what we find when we examine you. Now, the aim is to diagnose, or indeed to exclude, cancer, for those who don't have it, within 28 days from the first referral by the GP.

How are things changing in 2020 because of COVID-19? Actually, the 2-week-wait pathways are still open. We all know what's happened, but I want to reassure you that the pathways are still there and they're still open. We and the hospital want you to come to us and to report any worrying symptoms, and we don't want you to sit on things, because that won't help you or the health service to treat you.

The first contact, you may have noticed, with your GP is by telephone these days, or a video link, and then there might actually be face-to-face contact, depending on whether that's required for an examination. We do that in, what we call, a COVID-protected place. We've organised ourselves so that there is as low a chance of being exposed to COVID-19 as possible. We've got new technologies in place to try and aid all of this, so there is an app that goes with smartphones that looks at skin lesions, for example. These are all new things that we've rapidly put in place. We've also got to think about the risk of cancer versus catching COVID-19. I know that's a worry for everyone. GPs will have their own experience of what's going on locally, and of looking at you and understanding what your needs and what's going on in the background for you, in terms of your age and other illnesses. All of that has to happen now. What happens after we refer you? Again, first contact is likely to be by a phone or a video link from the hospital, and then they decide with you what subsequent investigations will occur. Some of these have had to be adjusted, partly because it's risky for you and partly because it's risky for the staff, so things like endoscopies have had to be changed. We call it risk stratification, so it's to get people dealt with urgently first, and with as little risk to them and the clinicians doing the investigation as possible. A lot of it is undertaken in low-risk sites away from the main hospital units, and so again, that's to make it what we call a COVID-protected environment.

If we decide to refer for possible cancer, it's important to accept and keep those appointments. I know it's really tempting to say, 'I want to bring my problem to my GP, but I'm really not sure about going on to have an endoscopy or have a CT scan, or have anything else done,' but actually we're doing everything we can to make the space safer, or as safe as possible, for you, so it's really important to engage if we actually do refer you. I wanted to just reassure everyone that, if you feel that you're in the system, that something's happened and you don't quite know what's going to happen now, whether you'll be delayed, that the hospitals are holding a list. They look at that list very regularly to make sure that people are prioritised

and that they are kept an eye on, so you're not missed out, you're not lost. In terms of screening, there are three national screening projects generally, the cervical screening is initially being risk-stratified. Letters are now being sent, so we are starting to ask people to come in for them, but please wait for your letter or wait for your practice to call you.

In terms of bowel and breast, they've both been paused, partly so that the backlog can be cleared of those who were testing positive in the bowel situation, and then for breast, you know that obviously a lot of the breast is done in vans which have to be cleaned, so those issues are currently being worked through, but that is hopefully likely to be started soon. I thought I'd give you a couple of examples very quickly of the sort of thing you might expect.
We've got here a 72-year-old Asian lady with poorly controlled type 2 diabetes, and a body mass index of more than 30, who's noticed that she's got loose stools. That's the thing that's brought her to us for a few weeks. The first thing that will happen is that she is likely to call her GP practice, who will say, 'Yes, we'll take your details and the doctor will call you back later today.' The doctor will indeed call back, and he will discuss symptoms and a plan of investigation with her. He will possibly request her to attend in person, in the green, in inverted commas, part of the surgery, the protected part, because he might need to examine her abdominally. At that examination, both the GP and, as of now, the patient is being asked to wear a mask. The GP obviously wears more protective equipment than that, so gloves and a pinny. The GP will check all of the contact details and then will make an electronic referral, and give the patient a letter to explain what this is all about with a contact number on it, should there be any delays. The patient in this situation, because it's loose stools and because it's a concern about the bowels, may well be given a stool sample test to look for blood. That's quite important, that's a new thing, it's been introduced to try and help stratify the people we need to look at first. Then there's the all-important thing, the concern about risk. People have asked this quite a lot. 'What are my risks if I go to hospital?' There are various calculators around, and GPs will use your gender, your ethnicity, your age, your illnesses, and that's why I put all of that in this example, to work out what are the risks for you personally. Then, of course, have you been asked to shield at home. Having looked at all that, and if you are worried, he will discuss that with you, and he will discuss the issues around risk and around the risk of the cancer itself, and then you can decide that this is the right time for you to be sent to hospital.

For the vast majority of people, it is the right time to be referred. You will then be phoned by the hospital probably within 3 to 4 working days by one of the hospital clerks to book you into a slot for a telephone consultation, and that will be had with the consultant. Then, in this case, the likelihood is the patient would be asked to attend for some sort of examination, either a CT or a colonoscopy. Again, they would ask you to isolate for 14 days prior to the procedure. I think you will get the impression that we're doing everything we can to make the risk as low as possible for you, should you go to hospital. When you arrive at hospital, obviously

you're going to be wearing a mask, everyone's going to be wearing protective equipment, so again, everything is being done to protect you.

I'm just going to run through this very quickly. This is a 55-year-old white man with high blood pressure and a BMI, body mass index, of over 30, noticing a new mole that's changed in size and shape in the past few months, and is itchy. Again, the gentleman would call the practice, be called back by one of the GPs, but in this case, the new piece of technology would come into play. We would either use a new app that the patient would download on their mobile phone, and they would be able to take a photograph of their mole and send that to the hospital directly, if it's through that app, or on their mobile phone to the GP practice, who would then decide whether that needs to be sent on. With moles, it's obviously sensible to look at them, and that's why this new piece of technology will be used. The likelihood is that the referral will go ahead in the way we've just discussed with the lady, and the GP may well ask either that lady or this gentleman to have a blood test at the same time as that referral goes, and this would be done as an urgent case, so that there's enough information for the hospital to make better decisions at their end. Again, they'll have that discussion about risk. In this case, actually it's overwhelmingly sensible for him to be referred to hospital, because this could well be a melanoma, so skin cancer, so it's worth being referred. Again, the same applies, telephone call from the hospital, they will review those photographs, and if they think it's something that needs to be removed and looked at under a microscope, they will obviously organise that. Again, some of those investigations are done in what we are calling a COVID-protected environment, so there are various units around the area where that is the case. These are some of the problems that we've come across.

It's about who you contact if things aren't going well. If your symptoms have changed or have worsened, then if you've been referred, then there are usually telephone numbers on the referral letter, and there is also a hospital telephone number that can be called to let them know that your symptoms have worsened, however you can also go back to your GP and say, 'I haven't heard anything, my symptoms are getting worse.' If there's a delay in your first hospital appointment, again there's a telephone number at the bottom of that patient letter that you got when you were referred by your GP. In terms of a delay in your first or subsequent investigations in hospital, then again it's the hospital that would be the sensible place to call. Both Brighton and ESHT, that's East Sussex Hospital Trust, Eastbourne and Conquest, have dedicated numbers that you can call, and you will be given those numbers. If there's a delay in your first or subsequent treatment, again, it's the hospital that you would need to call. They are set up for this, this has been thought through, and they are available to talk to you. It may not be instantly, you may have to put your name on an answer machine, but they will call you back very quickly. Treatment side effects, again that's the hospital. Worrying hospital letters, to be honest, as a GP, patients get hospital letters and they do get worried, and the person they know and they want to ask an opinion of is often their GP. GPs won't mind if you do that, but again, the numbers we've talked about

are there, and the hospital is also happy to take those calls. Thank you.

Geoffrey Bowden (Chair): If I can now ask our oncologist, Richard Simcock, to take on the presentation to the next stage.

Dr Richard Simcock: Thank you, and thanks for the opportunity to discuss this with everyone. Geoffrey talked about lived experience of this, and I thought I'd just start with my own lived experience. Sussex has a little bit of notoriety in the COVID story, because the first non-Chinese patient to get COVID in the UK was infamous super-spreader Steve, who contracted COVID virus in Malaysia, in Singapore, and then came to this ski chalet on the right. He was on a ski trip with six of my best friends, and it was only by dint of a rota mishap that I wasn't on the same ski trip, unfortunately. One of the people on that ski trip then returned to England and stayed in my house for a week, so my first experience of COVID was to be put in quarantine for 2 weeks whilst people in hazmat suits came to collect the infected person from my house and take them off to St Thomas' Hospital to be isolated for 2 weeks. At that time, there were 8 infected people in the UK, and 6 of them were close friends of mine. I was in close contact with all of them. I should say, I have some small amount of sympathy for the politicians who didn't get to it quickly enough, because despite being very intimately involved with the very first steps of COVID in this country, neither did I. As we started to understand that COVID was going to be a problem towards the end of February and early March, we started to gather in our individual departments and tried to understand what the impacts were going to be. That required some capacity and demand planning, and some disaster planning, which relied on some metrics which we simply didn't have. We had our knowns, we knew what the expected cancer caseload was going to be, and we understood what our current operational capacity was. We already knew we had workforce shortages, and we already knew we had the longest cancer waiting times list that we'd had for some good many years prior to Christmas. What we didn't know was what the infection rate was going to be, the now infamous R rate. We didn't understand risk stratification, we didn't understand what COVID was going to do to the risk of having a cancer treatment, and I'll explain a little bit more about that in a moment. We didn't know what it was going to do to our own staffing levels, we didn't know how many of our own staff were going to be off and how we were going to be able to run units if we had a 5%, 10%, 20%, 40% sickness rate.

Then, to quote Donald Rumsfeld pictured here, there were 'unknown unknowns'. We had no idea what the PPE supply was going to be, and at that stage no-one was really talking about testing capacity, or how that was going to be ramped up, or how testing policies were going to be introduced. Our initial disaster planning, capability planning, was based on a number of known metrics, but a huge number of unknown metrics, and I think that goes some way to explaining why these systems are in constant flex. In our own department, in the cancer centre, we have 2 calls a week, Monday and Friday, where we gather intelligence and say, 'How does the land lie this week, and how do we need to change our services for

next week?' The one piece of data we had early in the piece was this data from Wuhan, which was terrifying. It was a small amount of data looking at the outcomes of patients with COVID, and looking at how that translated in terms of co-morbidities. What we were particularly interested in is how did patients who had cancer, or patients who previously had had cancer, fare if they had had COVID.

If you look at the bar chart on the left, you'll see patients, all of these patients who had either invasive ventilation in pink, or may have died, blue patients had a clinical indication for invasive, so may not have actually been ventilated, but may have been indicated. You'll see that patients who had no cancer from the Wuhan group, if we look at just the blue bars, about 15% indication for ventilation or ventilation and death, a prior history of cancer led to a rate of about 40%, and patients who currently had cancer, 75% of those patients were either dying of COVID or requiring ventilation. That was an absolutely terrifying figure for us, and informed a lot of what we did next in terms of planning how we would move forward with chemotherapy treatments. When we give treatments, every treatment that we offer to a patient should be based on a risk-benefit discussion, which is individualised to that patient. In common practice, in evidence-based medicine, we will have a clear idea of what the benefits are, and those benefits are known to us through clinical trials, from practical experience, and from our own data. We also understand what the risks are in our normal situation, but what COVID had done had suddenly put a big question mark over risk. We suddenly didn't know what the risks of chemotherapy might be. In my practice as a breast cancer oncologist, if I treat a woman with adjuvant breast cancer chemotherapy, I will consent to that patient that she has about a 1 in 8 chance of requiring hospital admission for antibiotics during therapy, she has about a 1 in 200 chance of needing those antibiotics on intensive care unit, and she has about 1 in 1,000 chance of dying, despite antibiotics and intensive care, of infection.

That is a very low risk, it's a risk we're hugely attentive to, and we are able to mitigate most of that risk and treat patients safely. We were looking at a situation where a treatment that might have a benefit of 3% or 4% absolute survival advantage might be more than doubly outweighed by a risk of mortality during COVID. That informed a lot of the discussions that happened early on in the piece about us reducing the amount of chemotherapy we were giving, reducing the amount of radiotherapy we were doing, and reducing the amount of surgery we were doing, because we were extremely concerned that the risks of those procedures during COVID might greatly outweigh any benefits. At the same time, we deliver chemotherapy exceptionally safely, because if a patient is unwell with a fever, they ring our unit up, they're triaged immediately to A&E, they get a blood test done within an hour and antibiotics within an hour, and we were expecting a scenario where that A&E service was totally overwhelmed by COVID, and that those support and safety netting systems may not be in place. We also knew that surgery may not be able to take place because of a demand on ventilators to ventilate patients with COVID, so it simply wasn't possible to anesthetize patients

on management HDU, and we knew that the radiology services that we use to stage and assess our treatment were not going to be available because they were redeployed. We also knew our own staff were going to be redeployed, and indeed, I spent 2 weeks myself as a care of the elderly consultant on COVID wards, where I wasn't seeing my own cancer patients. That was the initial aspect. I have to say, the situation has improved, and what we now have which we didn't have 2 months ago is better data.

The data I've got on the screen for you here is from the UK Cancer COVID Monitoring Project. This is a voluntary reporting project, which all the oncologists in Sussex have signed up for, and any patient who has a diagnosis of cancer at any stage, and also has a proven diagnosis of COVID, we are asked to submit their clinic data and outcomes to a database which is held by the University of Birmingham. The University of Birmingham have now collected 1,300 cases, the first 900 cases were reported in The Lancet 2 weeks ago, and what that data shows us is that, in this much larger data set than the data set we saw from China, cancer does not seem to be a significant predictor of poor outcome from COVID. The bar charts on the left show you outcomes from COVID. Red is patients who've died of their COVID infection, and purple is patients who are discharged home.

The bar on the left is people who've had chemotherapy within the previous 4 weeks, just over 400 of those patients, and the remainder are patients who did not have chemotherapy in the previous 4 weeks. Our expectation and our bias was that patients on chemotherapy, if they got COVID, we would have expected them to do badly with COVID, and we might have expected them to have a higher mortality. That has not been the experience from these first 1,300 patients in the UK, nor, must I say, has it been the experience of the first 900 patients that have also been now published from the USA. You can see that a COVID diagnosis did prompt clinicians to change the cancer plan. The graph on the left shows whether or not the treatment plan was interrupted because of COVID, over 59% that wasn't the case, but in 40% of cases of the patient got COVID, it was felt necessary to change their treatment plan, and there may be long-term implications of that. I think we can draw 2 conclusions from that. The best thing we can do for our cancer patients is make sure they don't get COVID in the first place, but the second thing we can be more reassured about is that getting COVID during cancer chemotherapy is a bad thing, but it's certainly not as bad as we first anticipated. In that context, I think the new guidance around shielding was badly announced, but the announcement itself was correct. What I'm seeing in my clinic is a large number of patients now who are experiencing enormous emotional and psychological distress from the impact of shielding. I'm very pleased to see those shielding restrictions very slightly lifted, and I think that's a safe thing to do in the context of this data. I don't think that the messaging has gone out that the shielding restriction lifting is consistent with the data. What are we doing now? I'd say this is a fluid situation. First of all, our out-patient practice has changed enormously. 90% of my consultations now are either by video chat, we're using the NHS Attend Anywhere platform. I've just been piloting that with three other oncologists over the last

week, I have to say video is a huge leap forward over telephone.

We are enormously grateful to the Macmillan horizon centre who have donated their space to us to use for clinic capacity. That in turn has allowed us to turn the outpatient service in the Sussex cancer centre to the haematology day unit. That in turn has allowed us to turn the haematology day unit into acute oncology unit, so patients with acute cancer problems can be seen outside of the A&E space, by dedicated oncology professionals. Through a change in rota, we now have 24/7 acute oncology consultant-led advice. From 9 in the morning to 9 at night there is a consultant presence. We are managing to maintain our outpatient activity at normal levels for follow-ups and we are doing face to face, when I am sat in Eastbourne outpatients just now where I have done a clinic and all of the new patients I've seen today, I've seen with appropriate PPE and the patients have been wearing a mask as well if necessary. So, outpatient services are running well. Diagnostic services are now getting back up to speed, we had a massive backlog of scans with the help of our radiology colleagues we have been able to go through that scanning list and decide scans, with the time been and gone do we still need them? Do we still need to do them? Some scans we've agreed that we can do without and make assessments in other ways, and we are now starting to claw back the shortfall. I think one of the unsung heroes for me in the hospitals are the radiologists who worked exceptionally hard to scan all the COVID patients and they've not been able to take their foot off the gas for 1 second because now we're hammering them with cancer workload. Surgery had a slow start but surgery has now been decanted in the main to clean surgical hubs. So, cancer units where we can deliver cancer surgery down a green, non-COVID pathway where patients are screened prior to treatment, isolated prior to surgery, and we can give their cancer surgery away from the main hospital, and then gynaecological and colorectal surgery and breast surgery at the Montefiore private hospital at Hove, some head and neck and breast surgery going on at Queen Victoria hospital, East Grinstead, and flexing the private capacity that the NHS has bought sensibly, I don't think we are anywhere up to speed yet, getting those patients through that pathway is much slower, but we are starting to claw that back.

Chemotherapy, well, for reasons I explained, we gave a lot less chemotherapy, that seemed the right thing to do at the time, we are now going back to pre-COVID levels of activity but delivering that in a cautious and careful way, we have made some cautious adjustments to protocol. Radiotherapy, likewise, we've adopted some what we call hypo-fractionated policies, so breast radiotherapy that previously was given over 15 sessions, we now know can safely be given over 5 sessions, and just today the NHS England gave us a small hope in saying that we might now be able to commission stereotactic radio surgery which is a good and safe alternative to lung cancer surgery and some other cancer surgeries. So, starting to claw back normal activity in all areas and also doing some modified activity in a COVID time.

Next and last slide, please. So, where do we go from here? We are now adapting to a new normal. That picture on the right is Liz, one of our therapy radiographers, and if you come to our department now, that's what you'll be greeted by, healthcare workers in gloves, apron and masks. You will be symptom screened for COVID at every visit, have you had a fever? Have you been living with anyone with a fever? And you will be tested for COVID prior to starting a new course of therapy. That way, we hope to keep our departments clean of COVID so we have red pathways in place so that if a patient became infected or we found out a patient was infected with COVID whilst treatment on our machine, we've got isolation and streamline pathways so we can carry on business as usually and maintain the pathways without disrupting them. The next phase in our planning, and the thing that is occupying us now is how do we begin to plan for the surge that is undoubtedly coming? In the last few weeks the number of new patients I have seen in my clinic has been half what I would normally expect. The cancer wait times data for March saw 26,000 fewer patients seen in hospital based on referrals by their GP with suspected cancer, and we can only expect that to contain a large number of undiagnosed cancers which will be coming our way, I hope sooner rather than later so the next phase is to plan to accommodate those. Thank you very much.

Geoffrey Bowden (Chair): Thank you, Richard. Over to you, Scarlett.

Scarlett Dunt: Hi everyone, my name is Scarlett and I am going to be quickly going through some of the services that Macmillan are currently offering in the area and nationwide. So, I will mainly be focusing on the Horizon Centre in Brighton, but information centres across the area, such as the Olive Tree, the Fountain Centre and the Centre of Queen Victoria are also offering similar support, as are Age Concern in both East and West Sussex. I have sent Michelle the East and West Sussex Macmillan leaflets which have more information and are available on the Healthwatch website. All the information I talk about regarding our services can also be found on our website. So, since going into lockdown and handing the centre over to the Trust, we have tried to move as many of our services as possible to either phone or virtual sessions. One of the first services that we moved across to phone support was the counselling services, so all these appointments are now over the phone for both existing and new clients. The service is still taking referrals, and Cathy, who runs the service is still doing assessments of new clients. Today we also ran our first mindful half hour session, which runs once a week to replace the mindful half hour that we used to run in the Centre. We have also moved all of our welfare benefit services across to the phone, again this service is still taking new referrals, whether that is self referrals from clients themselves or referrals from healthcare professionals. I really want to raise awareness about these services, and the fact that they are still running because we have seen a decrease in the number of people accessing welfare benefits. Also, citizens advice in both East and West Sussex are still open and running. We've also started introducing some information and support phone calls. We have a group of 4 experienced information and support volunteers who have been matched with

clients, and they phone them as often as they like. These volunteers offer information and support advice that is relevant to the client's need.

We are hoping that this service will help to bridge the gap for people who would usually come into the centre and speak to one of our volunteers in person. We have started running a number of virtual support using Microsoft Teams, one of the first sessions we started running is a session called Horizon Connect, which we run on a Monday, Wednesday and Friday. This is a virtual group session in which people can talk to others who are in a similar position to themselves. They can share how they are feeling, provide peer support and practical hints and tips whether that's regarding lockdown, diagnosis or treatment. It is not a structured session and it is open to anyone no matter their diagnosis or current treatment. It's also open to relatives and loved ones of people who have a cancer diagnosis. We have also started running some managing anxiety sessions on a Thursday. These sessions cover how to prevent anxiety building and what to do if you're experiencing anxiety and some coping strategies.
We felt that this was a really important session to offer as we know people are feeling really anxious at the moment about the current situation.

We also run some virtual group sessions such as Pilates, breathing workshop, yoga and some cookery workshops. We have also recently started running 1 to 1 sessions for acupressure. Some of our partners across the area have also moved a lot of their services online as well, such as Look Good, Feel Better, who used to come into the centre to run their group workshops. They have added resources and tutorials onto their website and have also started running live workshops. All the information about their services can be found on their website. Also, brighter outlook who used to come into the centre and run their exercise classes are still providing support for people living with and beyond cancer. Again, they are still accepting new referrals and you can self-refer through their website, either by filling in a form, or emailing the team directly. They have started running weekly Zoom exercises, and during lockdown have run 39 sessions, of which 92 clients have participated in. They also have video tutorials on their YouTube page including some seated sessions.

So, this table (on the slide) quickly shows the number of supported contacts we've had with clients throughout the month of May, using the different platforms that I have just mentioned. I will quickly go through some of the services that Macmillan are offering nationwide. So, their helpline is still open, and it's open 7 days a week, 8 until 8, and this offers important information and support. This can range from anything around questions about diagnosis, treatment, finances or anything to do with cancer, recently as well Macmillan have launched a new service, a phone buddy service, and this service matches someone with cancer with a volunteer who understands what they are going through, and then the volunteer can give them a weekly call. Volunteer buddies provide a listening ear and can provide information about other Macmillan services. Macmillan have also set up an online coronavirus hub on their website, and it's an up to date source of

information for people living with cancer. It includes short films from cancer care consultants, podcasts and answers to common questions about coronavirus. The Macmillan online community is still up and running and can be accessed through the website, and this is a space where thousands of people from across the globe can connect and give each other invaluable, emotional and peer support.

Finally, recently Macmillan have launched their forgotten C campaign. This has been brought about because throughout lockdown, Macmillan have been gaining insight into cancer services, and are being told that people aren't getting the timely support they need, and some vital appointments have been postponed, cancelled or changed as we heard earlier. There's also been a drop in the number of people who are being diagnosed and there are some concerns that this might be a ticking time bomb for a surgical diagnosis when lockdown is lifted. The campaign was recently launched nationwide to try and raise awareness around these issues. Macmillan are also pushing for clarity for people who are classed as extremely vulnerable. What happens now with them coming out of shielding, because there is still quiet a lot of mixed messaging and uncertainty around this. That's the end of my presentation.

Geoffrey Bowden (Chair): Thank you, Scarlett. Howard has asked a question about what percentage of patients that are asked to come to an examination in a COVID-safe setting following the initial consultation?

Dr Richard Simcock: For most of our follow-ups, we are able to do by telephone. I am maybe seeing 1 or 2 patients off the list, that's about 10%, if the patient is concerned that they have a lump, or they are requesting examination we'll bring them into clinic. We have, in the last few weeks, asked all of our new patients to come to clinic because we felt that was an important moment to establish a connection and do a baseline examination."

Geoffrey Bowden (Chair): Elaine asks when colonoscopies and endoscopies are set to be resumed. Any update?

Dr Richard Simcock: So, I don't know the answer to that. I know that colonoscopy was one of the services that was struggling most before anyone had even heard of COVID, and it is doubly difficult now. If there was one part of the hospital machinery that needed the most investment to help cope with a COVID surge, it's colonoscopy, but I'm afraid I don't have the answer to when it's going to get back up. What I would say is, what can we do differently and smarter and better and what has COVID taught us? Matthew may have a point to make on this but it has meant that fit testing, as part of our colon screening, has had a real boost because of COVID as a safer way to screen patients for colon disease.

Geoffrey Bowden (Chair): We were told that private hospitals would be roped in. I think you covered that?

Dr Richard Simcock: I did. The Montefiore Spa in Brighton is now essentially an NHS cancer surgery hospital.

Geoffrey Bowden (Chair): If there is another spike on COVID in the winter months, will the response and effect on cancer effects be the same or may things be handled differently?

Dr Richard Simcock: Well, I think it will be similar but not the same. Never have I been more impressed with the NHS's resilience and flexibility, the ability of colleagues to flex the way they work across every part of the hospital has been extraordinary, and it's been very difficult to learn a lot of this stuff. But, now everyone is a dab hand on telephone consultations, video, we have pathways, we have red and green channels, we have infection-control procedures and everything is getting slicker and quicker. So, if it does hit us hard again, the impact will be there but it will be less acute than it has been this time.

Geoffrey Bowden (Chair): Matthew?

Dr Matthew Thomas: I completely agree with Richard. I think we geared up to deal with the spike and the spike flattened, so in primary care we have stepped up the total triage, as we call it, so that's telephone calls and video consultations from 5% about 6 months ago, to 98% today. So, it won't be the same, we will cope with it better than it has been previously.

Geoffrey Bowden (Chair): Is it risk or diagnosed with COVID?

Dr Richard Simcock: Those graphs were specifically about patients who had a proven diagnosis of COVID. In a large number of patients, even despite having proven COVID, they were able to continue to their original cancer plan. If people are interested to see the data, it's published every Wednesday and if you go to Google and type in UK cancer COVID monitoring project, you can sign up and you can see that week's data in your inbox.

Geoffrey Bowden (Chair): Does anyone on our panel know whether there is regional variations in screening, testing and isolating?

Dr Richard Simcock: The testing guidance changes all the time, you have to be pretty quick. By the time you've read the 27-page document, a new one is out. But the new guidance today, in terms of our cancer patients, is that testing policies should be determined locally, based on the background prevalence of the virus. So, if you have a large number of infected people in the locality, your testing policy is going to be different compared to an area where there's a very low background rate. The principle is any patient who is coming for a long course of radiotherapy, or chemotherapy or cancer surgery can expect to be tested prior to that treatment starting.

Geoffrey Bowden (Chair): Are they doing colonoscopies at the Montefiore?

Dr Richard Simcock: Yes, they are, and the follow-up question to that is will a 14-day isolation be required? Anyone visiting a clean hub will be asked to isolate for 14 days beforehand, because clean hubs only work if uninfected people come into them, so we have to do everything we can to keep them clean, so all patients will be asked to isolate for 14 days before entering a clean hub.

Geoffrey Bowden (Chair): We have another female patient asking how long will it be before the test will happen as she thinks she has symptoms?

Dr Richard Simcock: Well, I don't know, perhaps I'll pass that back to Matthew, because I might ask her to go back to talk to her GP again to be re-assessed, because it might be that she needs her GP to advocate on her behalf for another pathway.

Geoffrey Bowden (Chair): Matthew?

Dr Matthew Thomas: Yes, well I think there are 2 ways to bring this back to our attention. The GP is one way to do it, however the GP will have already made the referral, and the patient prognosis is in the process of being investigated, the telephone number that she will have been given to call back if her symptoms worsen, and patients certainly are given those telephone numbers should be used. Please don't worry about using that. If your symptoms are worsening, then use either that telephone number or contact your GP again.

Geoffrey Bowden (Chair): Pat is 72, she is on medication and has been called in for a mammogram. She would like some reassurance whether it is safe to go in and have a mammogram.

Dr Richard Simcock: I am absolutely sympathetic to that view. Citizens who have been at home very carefully shielding and not going out and about are then invited to leave their home and come into a healthcare establishment to be seen by a radiographer who is working with other radiographers. I can see why it's a concern. We have done everything that we can to make those procedures as safe as possible. All staff are in PPE, patients are able to have PPE, for example if you come to the mammographic screening unit at the Park Centre, you'll be screened for COVID symptoms before you arrive and you'll be offered PPE. All the staff will be wearing PPE and there is a clean-down, anyone who has had a mammogram will know it's an up close and personal physical test, and all of that equipment is cleaned down afterwards. Nonetheless, if any individual felt that they did not wish to take that risk, they just contact us and we'll put them back on a rolling list to be called back at a later date.

Geoffrey Bowden (Chair): People don't want to bother their GP. John says he has been feeling sick and lost his appetite and has lost weight. He had heard they

weren't seeing patients. Are GPs open now?

Dr Matthew Thomas: No, we didn't close. We simply transferred to trying to prioritise who we talk to and when and how. So, no, please don't have that feeling at all. Everyone who has a concern about cancer needs to contact us. We are open, we will deal with it, it's just that we will use technology that we have not used before.

Geoffrey Bowden (Chair): The same goes to Emma who has a lump on her breast. Should she go to her doctor?

Dr Matthew Thomas: Yes. I would say go to your doctor. We understand anxiety is high, and justifiably so. If you are concerned, we are there. And your GP will know you, so he will know whether you're not the sort of person that normally worries and you've come back, and therefore that's a red flag to him, so please don't worry about any of that. We're doing the first contact over the telephone so you can talk this through with him before he actually brings you in, but no, all my colleagues would not have any problem if you phoned up and said 'I am concerned'.

Geoffrey Bowden (Chair): A member of the public was told that follow-up appointments were now not happening, they are concerned by this. Why would this be?

Dr Richard Simcock: I remember working for someone who told me that doctor's never change. All that doctors do is they die or retire and then they are replaced by new doctors who then change. That's the only way we get change in the health service. I don't know if that's true. But, one of the things that we've been trying to change around breast cancer follow-up, is moving towards what is called managed self-care. Knowing that actually a hospital visit for a woman who is well informed and has a phone number that she can ring and expect an answer is just as good as being seen regularly in hospital. Not everyone was willing to engage in that but COVID has enabled that change to happen system-wide quite quickly. So, it has enabled some changes that we have been wanting to make for some time. It's just important that we support it with the information that patients need to manage their care appropriately.

Geoffrey Bowden (Chair): Some of your presentations indicated that things will never go back to the way they were before. To what extent are these changes likely to stay permanent?

Dr Richard Simcock: Well, I suddenly realised that people didn't necessarily want to spend an hour driving to Brighton, finding parking, and sitting for 45 minutes in my waiting room, just to talk to me for 5 minutes when they could have done it on the telephone. That was a lightbulb moment for me, and of course the adoption of telephone and video has been something that we will definitely hold on to. I would like to see a future where we offer patients follow-up and then we give them a

choice. When it comes round to their appointment we just say would you like that to be a tele-health follow-up or would you like it to be in-person and we can flex the system accordingly. We know that coming to hospital is incredibly disruptive for patients. They have to take time off from work, they have to arrange childcare, they've got to pay for parking, and if they can do it all over a telephone in the comfort of their own home then all the better. I've also noticed that when people are at home when I do a tele-consultation, they ask me more difficult questions. I think being in their own environment makes them more comfortable so maybe that's a good thing too.

Geoffrey Bowden (Chair): The presentation will be available on our websites. Thank you everyone for tuning in. Thank you.