

Lymphoma Action: lymphoma and COVID-19 webinar

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Transcript of webinar

Host

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Expert Panel

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Transcript

Stephen: Thank you to everybody who registered and submitted questions. We're delighted to welcome people from the UK and overseas as well. We've got a lot to get through, but I want to remind people that the answers given in this webinar are specific to the UK.

So again, thank you for joining. My name is Steven Scowcroft and I'm the Director of Operations and External Affairs at Lymphoma Action. We provide information, support and we enable people to have access to treatment and care through various activities, and particularly help to facilitate the voice of people affected by lymphoma.

It's with great pleasure that we are able to put on this webinar today with a really good panel of haematology consultants from around the UK. I'd like to hand over to each of their panel members to introduce themselves and then we'll get on with the questions.

Graham: My name is Graham Collins. I'm a haematology consultant and the lymphoma lead in Oxford.

Wendy: I'm Wendy Osborne and I'm a haematology consultant in Newcastle.

Robert: Robert Marcus, consultant haematologist in London

Stephen: So that's our panel today. And again, thank you very much on behalf of Lymphoma Action and all of the participants for being with us today.

I just wanted to give an overview really of the current landscape and where we find ourselves now, seven weeks in from lockdown and a few weeks more than that from when COVID-19 was first around. We knew seven weeks ago that government indicated people affected by blood cancers to be in an extremely high-risk group: people with lymphoma, along with leukaemia and myeloma. People in this group were being urged to shield. We had to learn about shielding, self-isolating and social distancing.

I think it's fair to say that although there is limited evidence, we've been able to take a very cautious and pragmatic approach to the situation. Lymphoma Action works very closely with whole range of their lymphoma specialists, like those we've got on the panel today, in order to get a consensus of opinion. We're taking the information that is available, trying to consolidate that, and add clarity, and make it easier to understand. But it is a rapidly changing environment as well. So it has been a challenge but we've been able to generate guidance, with our medical

advisory panel and group of lymphoma consultants, to try and answer these questions. What we will cover today is what we know now, but this may change over time, and we will update this as more evidence and more experience is gained.

Stephen: Our first questions is around lymphoma and COVID-19. What is the link?

Graham: Why are people with lymphoma at risk? Well, I think there's two main reasons really. And the first is that when I see a new patient with lymphoma and I'm explaining to them what lymphoma is, I normally don't say to them 'It's a blood cancer' because often their blood tests are normal. But I do say to them that it's quite well regarded as a cancer of the immune system. So it actually primarily affects the immune system: that's the organ that it's derived from. Lymphocytes are part of our adaptive immune response. So perhaps it's not surprising that even in patients who haven't had treatment for lymphoma, there is often a degree of lowered immunity (so immunosuppression). And we do sometimes even see that in blood tests with a low lymphocyte count or low antibody levels, sometimes even before treatment. But then of course we start treatment in some people – not everybody, but in many people they do get treatment – and that treatment itself is immune suppressive.

Chemotherapy lowers the immune system in a very acute way very quickly, and we talk about neutropenia (when the neutrophils are low) where people are at risk of all sorts of infections. But even when chemotherapy is finished we often use antibody therapies as part of the treatment and these can produce a longer-lasting milder suppression of the immune system. So it normally suppresses lymphocytes: if your lymphocyte count is low it may predispose you to viral infections, but they're annoying and not dangerous. But now of course we have a virus which isn't just annoying, it is potentially dangerous. So for those two reasons, really lymphoma patients in particular (over and above for example breast cancer or bowel cancer patients) we think probably are at higher risk.

Although I should say, and you'll hear this time and time again from us, the data on how much lymphoma patients are at risk is quite thin: we have very little evidence base at the moment to go on with a lot of this.

Wendy: I agree with Graham's point, that there are so many unknowns at the moment about COVID-19. Obviously, we didn't even know of its existence until a few months ago and we are presuming that our patients are at risk because we know that they are at risk of other infections. And so therefore it would make sense that they are going to be more at risk of this new coronavirus.

I think that the thing that we're very interested in, and why we are collecting all the UK data of every cancer patient who contracts and develops COVID-19, is that we know that a lot of the complications are about their immune response to the virus. And it may be that because some of our patients have a dampened immune response because of the treatment and because of the underlying lymphoma, that that isn't the case. So the jury is out: we need to collect the data, but at the moment we are being cautious and suggesting that our patients are at increased risk.

Is there any specific difference across different types of lymphoma? Obviously different people have different types of lymphoma, whether it's Hodgkin lymphoma, non-Hodgkin, high-grade, low-grade, B or T cell. Is there any difference around the different types of lymphoma?

Robert: I think there are differences because the immune system would be affected differently in different subtypes. We know that patients with low grade lymphoma, small lymphocytic lymphoma, follicular lymphoma and marginal zone lymphoma may have abnormalities of the immune system before they start treatment. We know that patients with low grade lymphomas may get longer term therapies than patients with high-grade lymphomas. And of course, although we can suppress low-grade lymphomas for longer periods, many patients do eventually relapse, which suggests that there are some lymphoma cells still remaining which may affect the immune system.

Whereas patients with high-grade lymphoma, say diffuse large b-cell lymphoma, are often cured of their disease with primary therapy, which is completed within six months.

We also don't know precisely whether or not patients with Hodgkin lymphoma may be affected differently, because of the chemotherapy they may receive. So I think we are learning all the time and the precautionary principle is the one we should follow here, which is that we are concerned that patients with, or who have had treatment for lymphoma, maybe at increased risk of greater complications and therefore we think that those patients should regard themselves as a little bit more vulnerable.

Stephen: People are interested to know whether there are people who had lymphoma have also had COVID-19 as well, and have they recovered, what was their experience? What do we know now, seven weeks in?

Graham: There have been some very brief reports published in the literature. There was a group of only about 19 patients that was published from China not that long ago. This was a group of patients who had all sorts of cancers, not just lymphoma. And it was quite concerning that their mortality rates were quite high, and this is where a lot of the anxiety does come from quite understandably. There have been subsequent publications. There was another publication specifically from Wuhan quite recently looking at patients with haematological cancers. And again, they reported quite high rates of mortality. But, when you read the paper, these patients – even before they had coronavirus – were in-patients in hospital. So they were very high risk; some of them were even on ITU (intensive care) for other reasons. So although they had very high mortality, how much of that was the fact they were just sick already, and how much of it was the fact that they specifically had a haematological cancer? So it's very mixed at the moment.

I'm sure we've all had patients now in this country who've had coronavirus. And most hospitals, mine included and I know Wendy's too, have been collecting the data from patients. We know who've had it, and even that's quite hard to tease apart because the only people really who have been tested are those who are in hospital. So we do know that from our own experience, lymphoma patients who were admitted to hospital and then tested positive, about a third of them sadly did succumb to the virus and did die, and about two-thirds of them recovered.

But of course, there will be a whole load of other patients with lymphoma who did get the virus but who never ended up in hospital. So please don't hear me say that a third of patients with lymphoma who get coronavirus will die. That's not the case. It will be lower than. Quite how much lower we're not sure. How many patients at home who get coronavirus will need admission, we just don't know - because the testing hasn't really been there yet.

Stephen: The next question is around shielding. We've learnt a lot about shielding, what are high clinical risk groups, what does shielding mean and what are you able to do when shielding. So how do you shield in the current environment?

Graham: I hope Wendy can chip it because she's done a lot of the thinking around shielding.

The whole concept of shielding comes from the fact that we feel that there is a high-risk group – in this case lymphoma patients – and we want to minimise exposure as much as possible. And as I'm sure most people on the call know far better than me, at least in terms of personal experience, that involves really not leaving the house and trying to minimise contact with other people as much as possible. That's the sort of concept of shielding and it really comes from a public health perspective of minimising this sort of transfer rate.

Now, the big question is who needs to shield? And the principal has been that the government – where essentially the shielding advice comes from – is being very cautious and that's understandable because it is obviously a serious virus with potentially serious outcomes. And the advice that the government has given is that anybody with a blood cancer – and lymphoma would fall under that – should shield irrespective of the stage of their disease.

Now, that's a rather woolly statement and as lymphoma doctors we've been discussing with our colleagues around the country what that means and how we should interpret that. I'll be completely honest that we haven't particularly come up with a consistent consensus there. I think pretty much all of us feel that for low-grade lymphomas, as Robert said really, we don't regard people as ever being cured and we would assume that there is an impact on the immune system even if people have never had treatment or if they had treatment 10 years ago and have never relapsed. So I think pretty much everybody is recommending shielding for every patient who has a low-grade lymphoma either now or in the past, whether or not they've needed treatment.

More contentious are those people who've had a high-grade lymphoma and have been treated with, for example R-CHOP 10 years ago, and so we would regard them as cured. They don't have a blood cancer *now* so should they shield? It's really difficult to say; people vary. It's very difficult and it does involve a discussion with your clinical team really as to how suitable shielding is for your particular circumstances.

Stephen: Robert - how would you respond to that?

Robert: I think it's very much individual. I think that low-grade lymphomas patients who've not had therapy, patients who are on treatment or had recent therapy - I think there's no doubt in my view that the risks there are increased.

But I think when it comes to high-grade lymphomas, you've got to also layer that on to comorbidity of the patient. So for example, if you're 65, male and you weigh 90 kilos and you had R-CHOP chemotherapy and you've got a little bit of heart failure and you've also got diabetes, that's a very different category from a patient 20 years younger, female weighing 50 kilos, who runs a marathon every couple of weeks and is blood sugar, blood cholesterol, and blood pressure normal.

I think you have to layer the lymphoma onto the comorbidities of the patient. And you may find that there are independent comorbidities, which means that patients do have to shield, and that lymphoma or previous therapy for lymphoma is one extra factor. And we need to look at context.

We also don't know for example, whether or not Hodgkin lymphoma differs from diffuse large B-cell, and whether if you had, for example, bleomycin that may make your lungs a little bit weaker in the long term, and get increased complications.

My view is that I think that one has to be cautious. At the same time, one has to keep in mind the fact that there's family, there's children's school, there's teenagers going in and out, you may need to work, you may not be able to be furloughed.

I think that all has to be taken to the risk:benefit ratio, and ought to be taken into account when making these recommendations, which should be individual.

We can give overall advice about certain categories of lymphoma, like patients on chemotherapy who've had recent treatment, or low-grade lymphomas where we know that there's an element of immunosuppression there. When it comes to high-grade lymphomas which might have been cured, or Hodgkin lymphoma, then we have to take into account all the other factors such as age, gender, weight, and the need that people have to go out and work and where they're working.

So, I think one can't give blanket advice. I think that we would like to be able to say we can offer individualised advice to our patients, given the background of what's happening.

Wendy: I'm sure that Graham and Robert covered it because I know that even between the three of us, we've had lots of emails about how to get that balance right between being cautious enough that we're not going to miss people, and being too cautious in the sense of this having such a big impact on people's lives. So, I think that's something that we're learning as we move forward: collecting the data and just trying to be pragmatic at the moment when we don't have any data to back us up with our opinion.

Stephen: I think generally from some of the networks that we are involved with as Lymphoma Action, we have a regular call with the NHS and number of other cancer charities. And in terms of shielding it has been a regular topic there. Particularly around the letters that are going out, the different stages that people receive letters, the different Trust's putting them out at different times. I think it's probably fair to say that most of the letters will have gone out, but if people feel that they should have received a letter and haven't, then the message is to talk to your clinical team or talk to your GP. There is still a mechanism for getting on the list, in terms

of having a letter, and also what that means in terms of spots at supermarkets and access to additional support through your local authority or local area.

Obviously with shielding, people have now been shielding for up to seven weeks. People are very keen to find out what will happen next. They also know that the recommendation is to shield for 12 weeks, but what will happen beyond that? I'm not sure that we know the answer to that right now, but that is something we've been working with the consulting community to provide that information on our website, and as Lymphoma Action we will continue to do so once more information is available on unlocking from lockdown and what the impact of that is on people shielding and their families.

Stephen: We've had some specific questions about whether masks and gloves are helpful, not only from a kind of recovery but also in within the shielding situation. People are being asked to shield themselves away from their own family in their own home. So does this actually help?

Robert: Gloves have got to be used properly. There's no point in actually putting on a pair of gloves that isn't intrinsically protective, unless you're actually taking them off appropriately after exposure. And others - medical students – are taught exactly how to put gloves on, how to take them off, for surgical procedures. So, there's no point putting a pair of gloves on, touching the doorknob which the postman has touched, and then touching your face. You've got to be aware that gloves are protective for you *only* if you put them on and take them off properly

Masks are very contentious. I hear the briefings, as you've heard, and it may well be that you're actually inhaling less in a confined space. And if you have COVID yourself, you're less likely to spray other people. In terms of *your* protection, my interpretation of the data that's coming through is that in confined spaces, especially if you're in close proximity – and there's evidence now that a meter is more likely to transmit than two meters. And of course, duration of exposure is important too. My sense is that certainly many European countries that have enclosed spaces (shops, public transport etc), the mask may be valuable.

But again you have to put it on and take it off properly. There's little point in having a mask on for two or three hours, and then taking it off with your hands covering the mask, and then touching your face afterwards. So I think the techniques of using the mask have to be taught as well as gloves.

Stephen: We've talked about shielding and the practicalities of shielding, but actually that's a really difficult thing to do. And so, **how can someone look after their well-being, particularly in this shielding situation? Do you have any advice for how to deal with the emotional impact?**

Robert: It's the least precise area. I think some of us are suffering more than others – those with children at school, those who can't work, those who have got family members with other illnesses – are obviously more affected.

You layer on to everything that everyone is suffering from in terms of restriction. You layer on to that the presence of lymphoma – be it the presence of lymphoma requiring shielding because you've got the disease and you can't go out because of the risks of it if you did get the

infection at is was severe – and also the questions regarding follow-up, further scans and chemotherapy.

We would hope that patients who require therapy are getting it, and we hope also that patients who require the appropriate follow-up, are either getting that by video conference or by direct face-to-face consultation. I don't think I can give any expertise in looking after one's emotional wellbeing over and above what you see in the various charitable websites and various advice columns.

It's difficult because you're finding the confinement difficult; most of us are staying in a lot more of the time, we're not going to football matches, pubs, concerts, theatres. Those of us who find any consolation in religious ceremony would find it very difficult because collectivity informs a lot of the religious rituals that we follow, and certainly some people can find consolation in contemplation. But the lack of personal contact means that it's more difficult.

Now, I think we're better off perhaps than they were a generation ago because we have got this kind of link, but I think that it's very difficult to give any concrete advice.

I think that being in the home for a lot of the time means that you may look around you. Those who like reading books perhaps, can set themselves the goals of the books they've always wanted to read. Those of a practical bent may say that I'd like to build the furniture I want to build; listen to the music I want to listen to.

I think we all have to accept though that this should, on the one hand, be finite- and that the level of extreme lockdown is going to be limited. But I think it may have a long-term effect on social interaction and the presence of the virus in the community – whether or not herd immunity, vaccination, effective therapies, come through I think it is going to have a long-term effect on the way we interact with our family, and more importantly with strangers, with distancing.

I've been listening to some online concerts from the Wigmore Hall and I cannot imagine the time when 500 people are going to sit next to each other and actually listen to someone playing a piano. So I think that we're going to have to accept there are going to be big differences in the way those interactions take place.

In terms of my own expertise in emotional well-being, I can't give you specific advice, but I think that we have to try and adapt ourselves to a new situation and look at our home life as perhaps more central to what we do than we did before. Now that's easy if you've got a nice home and a garden, but if you're confined to a small flat and you've got a large family around, and you can't get out, that's much more difficult. I'm sorry I can't be more specific than that, but I hope that's helpful.

Wendy: So for a lot of the patients that I speak to, the biggest impact on their mental health is their anxiety about how we are looking after their lymphoma. So a lot of patients are ringing our specialist nurse anxious because we've changed some treatment approaches, which I know that we're going to come on the discuss in the next section. I think the thing that I would want to stress is that all of the decisions that we've made, we've looked at that risk:benefit balance and we feel as medical professionals that the change in practice is for the best interest of each

of our individual patients. And it will be adjusted patient by patient. We are literally discussing these patients one by one to make sure that we feel that the risk of COVID-19 outweighs the risk of that, whether that be an outpatient appointment. If we feel we need to see our patients in clinic we are still doing it. But if we feel that we can get the best care by a telephone consultation, that's what we're doing. So, I think that reassurance that we are thinking carefully to try and reduce the stress, because no one likes change - particularly if you're in the middle of a lymphoma treatment or on a follow-up for lymphoma treatment.

Graham: Well, I've taken up the guitar during the lockdown. So it's good for my emotional well-being; I'm not sure about my family though. No, I don't have anything to add. Like Robert said, we've all got our anecdotal ways of doing it, but I don't feel any more expert to advise in that respect.

Stephen: Just reiterating from a Lymphoma Action point of view, we obviously have information about that on the website in our COVID-19 area. But also, we have ways that people can engage through our now-virtual support groups (where we had some support groups before), and you can give our helpline a call and they are there to help to deal with some of the questions or the challenges that individuals might be having.

Robert: I think the interaction - I mean the video interaction – between patients and doctors and nurses is obviously not as intimate or as easy. But I think we also have to face the possibility that we are going to see our patients and we're going to be in masks and the patients will be in masks and the signals that we pick up from each other are going to have to be very different. And that maybe, if not a long-term certainly a medium-term consequence of this, that our ability to both signal and pick up signals from each other will be affected in the medium and long term and we have to be aware of that.

Lymphoma and treatment – what do changes in treatment mean?

Stephen: A lot of people have been seeing some differences to their treatments, not being able to go to hospital, not be able to access appointments and so on. **Can you address questions around why is my treatment being changed or stopped, is it because of the cancer, the lymphoma, or is it because people are more interested in COVID-19, or just that the doctors aren't there in the hospital?**

Graham: Those are very good questions. And as Wendy said, it's quite clearly a source of anxiety and concern and we really 'get' that. I mean, it's very distressing when plans have changed.

I think early on in the pandemic, none of us really knew what impact it would have on our ability to deliver the service. So, we did make plans, partly based on what happens when we have no chemotherapy nurses: either they're looking after COVID patients or they're self-isolating. So that was a concern and it depends where you are around the country as to how much the epidemic has hit your local area.

In Oxford we've been reasonably hit, but thankfully we have maintained our staffing levels to such an extent that we can deliver the treatment we feel should be given. We have changed

some treatment regimes, but that's not based on our capacity but based on what we feel would be safer for patients.

Robert's already alluded to this risk:benefit ratio: every decision we make in medicine is based on the benefit versus the risk. And if the benefit is very high and the risk is very low, then it makes sense to do it. And if the risk is very high and the benefit is very low, it makes sense *not* to do it. The benefit here is pretty static because we've been using these treatments for a while, but the risk is changing a lot.

So if you've got, for example, a high-grade lymphoma like diffuse large b-cell lymphoma, the benefit of chemotherapy is very very high because we aim to cure two-thirds to three-quarters of people. The risk has gone up because we're worried that people who could contract COVID-19 would be higher risk on chemo, but the benefit still outweighs the risk. So pretty much every centre I know around the country is still giving high-grade lymphoma treatment, and Hodgkin lymphoma treatment, at the right doses etc.

It's much more nuanced for other types of treatment particularly when you think about low-grade. So think about maintenance for example, which is a very common form of treatment that does have a benefit to many patients: it prolongs remissions, but it hasn't been shown to increase life expectancy – it doesn't increase cure. So there is a benefit - I don't deny that, but it's much more modest than the benefit of R-CHOP for diffuse large B-cell lymphoma. Whereas the risk of it: there has always been a slight risk of maintenance, but it's gone from there to there [indicates slight increase with hand]. In the past we knew maintenance increased your risk of infections to a modest amount, now the risk of getting COVID-19 is probably a consideration and may be raised by being on maintenance.

So NICE has actually issued guidance nationally, which I would agree with, to say that for now while we're in at peak still of COVID-19, we at least pause giving maintenance treatments because the risk is outweighing the benefits. So it's not – I would emphasise – largely a capacity issue, it's more of a safety issue.

Wendy: I agree with that. At the beginning we weren't sure we had; to look at both capacity and what's best for the patient. And I think now as *so many* changes have been made with hospital services and a lot of elective work stopping, our capacity is much less of a concern. And so our decisions and changes in treatment have been felt to be, and hope to be, in the patient's best interest.

We know that from the start of this anyone over the age of 70 has been asked to be shielded. On top of that those patients with a low-grade lymphoma have another reason to shield. So we don't want to be bringing them up to the hospital for infusion of drugs which A) may lower their immunities further, but B) also may expose them to the novel coronavirus.

We're hoping that we're able to explain these changes to patients. We're hoping because there's been a UK-wide approach – which is obviously NICE endorsed – that patients throughout the country don't feel that different things are being done in different geographical areas. This risk:benefit for changing treatment has really been – hopefully – in the patient's best interests.

Stephen: Another question is around **people who perhaps have had treatment start and are now waiting to see if the treatment that had started before COVID-19 will happen.** Or they are waiting to see if they are in remission but needing to have blood tests to check that, or a telephone appointment. Is that likely to happen in the GP surgery or hospital?

Robert: I think in terms of what Graham and Wendy were saying about curative therapies: I'm sure we should continue with Hodgkin and diffuse large B-cell lymphoma. And I think it's correct that we need to address the issue of low-grade disease. And we now take the view that watch and wait – or observations – for most patients with low-grade lymphoma, we say 'if the glands are bothering you, if there's a large gland in the axilla or the neck' and we'd say, well it's time to think about therapy.

But actually, we push the threshold and so, as long as that's not causing any problems swallowing, as long as that mass under the arm isn't actually stopping you moving your arm, we should delay treatment a bit. So, I think that our thresholds are changing and watch and wait might be a little bit longer before we start therapy given the current environment.

And I agree about maintenance therapy: I think maintenance therapy might decrease your immunity, but it doesn't improve survival, although it may keep you free of disease for longer. We just don't know how long the virus is going to be prevalent for, so how long you're going to be immunosuppressed.

We also need to address the intensity of therapy as well. If you have low-grade lymphoma, would you want a more intensive or less intensive approach? And, again, without going into too much detail, we know that drugs such as bendamustine are more effective than lower intensity regimens, but they may affect your immunity more. We've done this and I know that Graham Collins has published a paper on this as well. So we've got to weight-up the risks again, risks and benefits, where you are in the country and whether you've got pre-existing lung disease or where there's a high prevalence in your area.

In terms of follow-up investigations, I think that once patients have responded to therapy it would be very attractive to get the scan done to confirm remission status. But I think a delay of three or four weeks – in the absence of symptoms – is very rarely going to have any impact on whether or not you actually offer further treatment or how you classify the patient.

I also think that in terms of maintenance therapy, you might find you can give subcutaneous maintenance treatment and that means that patients don't need to leave home. At the same time, that is going to be immunosuppressive, and we have again to weigh up the risks of the treatment and the benefits. So I think that's all got to be weighed up.

In terms of blood counts, once they've recovered from treatment, although we do do routine blood counts, how necessary they are is not absolutely certain. And once you've recovered from your final course of chemotherapy, most patient's white cell counts and haemoglobins and platelets do come up. So the routine blood count may be less important than we think it is.

I think it's only the patients who've got symptoms of lymphoma that will actually need the face to face or the video conference.

Stephen: From our experience of the conversations with the NHS, certainly over this period of time they've been trying to get to a position where they've got cancer-specific pathways, particularly for surgery but also for chemotherapy delivery. Hospitals – as well as ones dealing with COVID-19, are trying to separate patients in order to continue with the routine treatments as much as possible. This situation is probably going to stay with us for the foreseeable future, as we come to terms with what the new normal is, living with COVID-19 as well as living with lymphoma.

Stephen: the impact of COVID-19: what does that mean for my lymphoma – particularly for someone who's not had lymphoma for a while? Is it more likely that they'll relapse or what is the impact?

Wendy: I think this is difficult because there's still a lot of unknowns. We've had patients who have had treatment for lymphoma and recovered from COVID-19. There are lots of different types of lymphoma as well as lots of different types of treatment.

I think my biggest concern would be my patients who were already on treatment who the COVID-19 infection causes delay in their primary treatment, particularly if they've a high-grade lymphoma. So this is the group that obviously – as we've just discussed – where we don't want to stop treatment. We feel that that benefit of treatment still outweighs the COVID risk. However, that's the biggest risk group, for me, where they're going to then need a delay in treatment.

But other patients, we don't know: that's why we're advising the shielding group. That's why we're advising to limit hospital follow-ups and possible unnecessary blood tests. But we don't want to cause fear: there are patients who have had COVID-19 after really intensive chemotherapy who have recovered OK.

So it's that balance of just being sensible, pragmatic and cautious, but not going into a panic that everybody with lymphoma who gets COVID is going to have big problems because I don't think that's true.

Graham: I completely agree with Wendy. But just to add that there's no obvious link that I can imagine of how, you know, if you're stable with let's say low-grade lymphoma or if you've just had high grade lymphoma, if you get COVID, is it likely to bring the lymphoma back again? It's impossible to say for sure, but I think it's unlikely because we've had other coronaviruses around for a long time, and we've had other respiratory – serious respiratory – viruses around for a long time like flu, and there's never really been a suggestion that being infected with one of those viruses increases your risk of relapse. There is a story of viruses in lymphoma, but it's more things like glandular fever viruses in people who are immunosuppressed. So I would be generally quite reassured that I can't see that there would be a link between infection and increased risk of bad outcomes from the lymphoma.

Robert: I'd also add that we've all seen patients with lymphomas who have got low volume lymphadenopathy – so small lymph glands – who get a viral infection and the lymph glands really start growing. And the worry then is 'is this the lymphoma taking off', but actually it's the lymph gland responds to virus.

We don't know that will happen with COVID. We mustn't assume that if lymph glands start to grow in response to infection; that it's actually the lymphoma. It may well be the lymph glands are actually responding to the presence of the virus. We've all seen patients where they had viral infections and lymph gland have grown and three months later the lymph glands have shrunk again.

So I think we mustn't jump to the conclusion *necessarily* that even if the lymph glands start to grow, it means that the lymphoma is progressing. It might just be this is the way that the patient with lymphoma responds to viral infections.

Stephen: So as you've outlined there 'I have some symptoms; they could be my lymphoma, but they could also be COVID-19. What do I do? I'm too scared to go to the GP or too scared to go to the hospital, but I'm worried.' What would your advice be?

Robert: I would advise you go to the GP and go to the hospital because most general practice now are practicing appropriate screening. They're letting one or two patients in at a time and many clinics are actually taking temperatures of patients before they go in. So I think that going to visit your GP is much less risky than staying at home with those symptoms. They could be COVID symptoms in which case they're going to need treating; they're going to need screening. And if they are lymphoma symptoms, once again, your own team needs to know about that. I think if you're concerned that these are the same symptoms you had before when you had your lymphoma – if you've got your sweats, fevers and weight loss back – or you had a lymphoma which presented with cough and you've got cough again, then I think contact your local team, contact your named nurse – your CNS - or the consultant team, and actually ask for their advice.

Do not delay in seeking advice whether or not this is infection or it's lymphoma, it's important to actually have that discussion, to be seen, and to be appropriately managed. So I would not delay and I think that now most hospitals and most general practices are taking appropriate precautions to try and reduce to an absolute minimum the possibility of cross-infection.

Wendy: I completely agree. I think that this is really important. We know that our new patient referral rates are down and our emergency intakes are down. Actually one of my biggest concerns for patients is that they aren't coming in. So our patients on active treatment – if they've got neutropenic sepsis – we still need them to ring and come in as they always would have done before.

I completely agree that if any of our patients who would normally ring us with what they felt was a lymphoma-related problem they still need to ring us. Then we would still most likely see them. Because this goes back to that risk:benefit balance and it's really important that we're not missing problems, missing new counts of lymphoma, because everybody is staying at home, which is important, but it's really important that they also contact us.

So we're putting this out on our Trust's Twitter feeds because we're worried about how our numbers have actually come down significantly for emergency admissions.

Robert: A&E attendances are going down and down, and I know from indirect close family member's experience of going to A&E, actually the place has been empty where it probably

shouldn't have been. So I think the risks of going to A&E, or your general practitioner or some emergency care centre, are actually less than they were because fewer people are going. The steps are being taken to maintain distancing, and maintaining a level of reduction of possibility of cross infection. So I think anyone who's concerned they might have either COVID with lymphoma, or that lymphoma's coming back must contact their general practitioner or treating team.

Stephen: For my healthcare professionals: when should I contact you or when will you be contacting me again? We often hear this on the helpline that people don't want to be bothering their medical team particularly at a time when we're being told to protect the NHS. Aren't they too busy to worry about me and my particular lymphoma? What is the advice?

Graham: I do often hear this. But you've got to realise we are here to treat patients. That is our job. So if we're busy that's fine, you know, that means we're treating patients and it means *you* should also ring if you've got a problem. So, I would echo really what Wendy and Robert said: that that is our job, that's why we're here.

Hospitals around the country are managing to keep the capacity going for haematological malignancies and other cancer treatments and absolutely you should contact us in the normal way if you've got any concerns or queries, do please just ring up.

With us, we always recommend going through our specialist nurses; other hospitals may have other routes, but please do it in the normal way. Don't delay: you know, we are open for business.

And when will we contact you? Well, I very much hope that routine follow-ups will be taking place. Yes, they'll probably be very different in terms of the context in which they're done. We're having almost exclusive telephone clinics now and we've just introduced this 'Attend Anywhere', which is a video consultation platform. But we are still seeing some patients face to face when that's appropriate: when we need to examine people. When we have a new diagnosis we usually see patients face to face: we feel that's a bit more appropriate or we certainly give the option to see them face to face.

We should be contacting you in the normal way and if we're not, then again chase us, do ring up.

Another slight concern I've got is, because our method of practice is changing - we're changing the way we do things - the ball can sometimes be dropped. With the best will in the world, follow-up appointments might not be made because we're just not in the routine of making them because we're doing things in a different way. So do chase us please *please* don't sit at home thinking we're too busy to be contacted.

Stephen: Thank you, that's really good advice.

Stephen: We had a couple of questions from earlier experiences particularly with the GP versus the consultant in the hospital: one saying one thing and the other saying something different. What should people do in that situation? I know you've reiterated about trying to

be persistent to get an answer or to get an appointment. But where do you see that challenge?

Wendy: I think that because there often cannot be such a clear message when everybody's got slightly different stories, different lymphomas, different treatments, and we haven't got the data behind us, and people are interpreting the Public Health England data slightly differently. I've certainly spoken with GPs directly and I think that if there's not any clarity then we see GPs all the time and we can try and work out what the best advice is for the patient now.

What we're trying to do is to have overriding pragmatic advice so that not everybody is having to have individual discussions with their GP or their consultants. But if there are difficult individual situations, then I think that the hospital consultant can discuss that with the GP to come up with the answer. And I'm sure that this advice will be updated as we have more data behind it: the Government are updating things all the time for information with lymphoma professionals.

Stephen: One to leave people with and particularly I know is poignant at this moment, is around vaccines or what will happen as we start to ease restrictions. So, **when is a vaccine being developed, and how suitable would it be for people with lymphoma: will they be prioritised perhaps?**

Wendy: I think this is the million-dollar question, isn't it? When will it be developed? The answer is I don't know. I know that there's lots of work going on. I think there's quite a lot in Oxford, is that right Graham? So I would hope that it would be suitable for people with lymphoma; we prioritise them for other vaccines. We know, as we discussed at the very start of this webinar, that we are fearful that our lymphoma patients are at slight increased risk because of their lower immunity. And therefore we would hope that that highest risk group – or perceived high-risk group – would be prioritized for a vaccine.

I don't know the time scale for these, and I don't know any more than that. I don't know if Graham or Robert know more?

Graham: There are two major trials going on at the moment one based around Oxford; one at Imperial in London. And I think the issue is, we just don't know if they're going to work. And if they do, then hopefully we may, *may*, be starting the initial sort of delivery of vaccine as an off-trial way, in nine month's time. But to do it on a big scale will take longer than, that because it takes a while to scale these things up, but there's so many things that have to fall into place for that to happen that it may just not happen for a lot longer than that. So it's very difficult and, whilst I absolutely echo Wendy's sentiments, I would really hope that cancer patients in general would be prioritised.

What we don't know is, if a vaccine works in a normal healthy volunteer if you like, is it going to work in somebody who's got lymphoma or being treated for lymphoma? That's not *necessarily* the case. There are other vaccines that we know don't work so well in patients who've had treatment that suppresses the immune system. So there is going to need to be some specific research around cancer patients – lymphoma patients particularly – receiving these vaccines, as to how effective they are.

Robert: I think that's right. I think we don't know for example, if you have the vaccine and then get your lymphoma therapy, which may contain antibody which reduce your immune cells, will you still be immune afterwards? We know from stem cell transplant, for example, we have to re-vaccinate patients after that to restore their immunity to childhood illnesses, and the same may be the case here. So although vaccination may protect patients with lymphoma who've had therapy, it won't necessarily protect those going into treatment or on maintenance. We have to be very very cautious in assuming that everything will go back to normal in terms of treatment if vaccination is effective.

Graham: Can I just add that I don't want to sound all doom and gloom because you know, imagine that the vaccine doesn't work at all in lymphoma patients: if it works in everyone else then we get that herd immunity. So it's really good to have a vaccine even if it doesn't specifically work well in lymphoma patients.

Stephen: On that note I'm going to draw the webinar to a close today. Thank you very much to everybody who's joined us. I hope that we've been able to answer the majority of people's questions. Thank you again to our expert panel – to Wendy, Robert and Graham – for giving your time today.

This transcript is intended to be read alongside viewing the video of this webinar at lymphoma-action.org.uk/lymphoma-and-covid-19-videos.

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