CLL Support webinar with Prof Adrian Bloor. Jan 20, 2022 **Q & A**	
"End of the Pandemic? Living with Covid & CLL/SLL as the New Normal"	
Question	**Answer**
6. my daughter works for the NHS. She tested positive on Monday 10 January 2022. She has not come out of her 10 day isolation but is still testing positive. How safe is it to meet up with her and can she come into our house? Thank you,	It's always difficult to be specific but at the Christie we allow staff to treat high risk patients 14 days after an infection assuming they don't have any symptoms. This can be earlier if they have negative test results. Some people have a positive test for quite some time after infection but are not infectious and we don't keep testing them. I hope this helps. Adrian
7. How do you obtain a priority PCR test and letter? I have contacted GP surgery, 119 and Hospital Haematology Department with no success.	This can be tricky and I am afraid I don't have a perfect answer. Priority tests are sent out centrally. Government website suggests calling 119 https://www.gov.uk/government/publications/pcr-home-testing-for-people-eligib for-new-covid-19-treatments which is what I would recommend and be persistent. If you cannot get a priority test and develop COVID symptoms then recommend getting a test through the normal process ASAP. If it is positive then call GP/119 to get referred to your local COVID Medicines Delivery Unit (CMDU); if this fails then your Consultant or CNS can also make a referral. You will however only be eligible for treatment for 5 days after a positive test
8. As a registered CEV patient with CLL, I have not received the letter and Priority PCR Test Kit. I've spoken to my GP, Haematology Team, 119, Leukaemia Care and nobody seems to be able to help. Could you tell me what has gone wrong and how do I get a Priority PCR Test Kit in case I need it to trigger the Antiviral Treatment.	See 7
9. My GP said do 119, went through that service and told they wouldn't be able to give me an appointment.	See 7

10. "For both the 4th Booster vaccine and the Covid treatments, some GPs and Haematology Departments seem to have a difference of opinion to the blood cancer charities, on who needs to be treated. Charities are saying that anyone with CLL should receive the 4th vaccines and have access to Covid treatments. However, GPs refer to the "Green Book", which uses the term "Severely immunocompromised" rather than "Any stage". Therefore, some GPs are classifying "watch and wait" as **NOT** "Severely immunocompromised" and are refusing vaccines and treatments on that basis. Who is correct? Should all CLL patient received a 4th Booster and Covid treatments regardless of stage. If so, who is going to correct the GPs understanding?" As evidence: I was refused a 4th Jab by my GP practice, my haematology departments said they didn't know about the booster or treatments and haven't got back to me after two weeks. NHS 119 would not send a "Priority PCR" testing kit because I didn't receive a letter regard the treatments.	Who gets 4th dose is open to interpretation as you suggest. All CLL patients are immunosuppressed to some extent however it depends on many factors including stage of disease, age, other medical problems, history of infections, immunoglobulin levels and any prior treatment. I think it's fair to say that people with very early stage disease might not be classed as being 'severely immunocompromised' but it's hard to generalise. My general practice is to refer patients for 4th vaccine however if you have been told you are not eligible then would suggest speaking to your consultant/GP or CNS.
11. I received priority test with no return box. rang 119 and they could only send normal kit. how do we get priority Octr test kits?	See 7
12. Many CLL people like me have NOT received a priority code PCR test and letter about new treatments. We have gone through a lot of stress and frustration by being pushed from GP to 119 back to GP to NHS England to consultant with no success.	I agree. The system isn't perfect but it is really challenging to roll this out. My advice is as for number 7.
13. An article in last week's Times newspaper, suggested that not all At Risk patients would be given antivirals if they become Covid positive, as some would form a control group. Is this true? If so, what are the decision criteria and who makes the decision? (the antivirals mentioned were molnupiravir and Paxlovid. - from Bernard Hopkins	CLL patients are on the list of those who would be considered to be at risk and eligible for COVID treatments including Paxlovid. I have not seen anything from NHS to suggest otherwise.
14. I was quite ill after my third vaccine including cellulitis from the injection site and am really nervous about having my 4th vaccine next week.	Understand your concerns and as with all things the decision to go ahead is based on balance of risks and benefits. Some people can have reactions to one dose and not to another and its not inevitable that you would have problems with 4th dose. I think this is one you need to speak to your team about to assess how high your risk of COVID infection is; for most CLL patients the benefits of 4th dose outweighs the risk
15. LFT tests are my passport to some sort of life. If the Government stop supplying them, will we be able to get them free like the rest of our meds?	I am sorry I don't know what is happening here

16. Do you know when the STATIC trial will begin?	First quarter of 2022 is when this is planned to open. It may take longer for this to open up in each site as some departments have had real issues with capacity and staffing due to COVID
17. If we use our priority PCR test, do we get a replacement?	Guidance says that replacements can be obtained through 119. Its important to only use the priority test if you have symptoms.
18. How do i get an anti body test to see if the vaccinations are working? Also do I need to keep having them?	This can be arranged through GP or hospital and in most centres is easy to arrange. It is likely that a high antibody level (?>250) is needed for immunity although antibody levels don't however precisely correlate and can change with time (either up or down). Increasingly I test my patients as it can help to know if the vaccine has produced a response although it can be hard to know what the results mean. At this point I have not been doing repeated tests unless the antibody levels are low and then I repeat to see if this improves with subsequent vaccination(s)
19. Now the general population of UK is getting back to normal with no face masks, etc.. where does this leave CLL/SLL in the short term?	I would suggest not rushing to drop precautions until we have seen the levels fall and what happens as things are relaxed. There is a common sense balance here and you need to look after yourself so would stick with masks, hand hygiene and avoiding crowds for now.
20. Although I am registered as a CLL patient with my Doctor I was not offered the third vaccination but was then offered the booster. I was not contacted about the availability of antivirals if I became infected. My GP says that these decisions are not made by the practice and that there are different definitions of vulnerability. Can you advise on this please?	As above system is not perfect. For vaccines, you need to be considered to be highly immunosuppressed to get 4th vaccine which is subjective (see 10) but all CLL patients are eligible for the new treatments (see 13). Not all CLL patients are however on the list of vulnerable patients and you might need to chase this.

21. As someone with Watch and Wait CLL for many years, how does the need for 4th vaccination work or not.	Hard to say - see also 10. I have not recommended 4th vaccine to some of my patients (young, early stage disease, lack of progression, good antibody levels and/or previous infection) but this is a decision taken on individual basis. For most I would recommend 4th dose but you should speak to your CLL team about this.
22. Does everyone on here know about the simple "Covid age test" to see what risk you are?	COVID age can be calculated as per https://alama.org.uk/covid-19-medical-risk-assessment/ **but please read the caveats as not all CLL patients are the same**
23. My GP surgery hasn't known about either the 3rd primary jab nor the Priority PCR kit and we've had to educate them on these. They have been very responsive for which we are grateful. how many GP surgeries	See above
24. I see many comments of people getting antibody tests. Antibodies are not the whole story, as I understand it. Is there a way of checking if T Cells have been affected positively by having the vaccine?	See above re antibody tests. It would be great if we could also measure T-cell response which is another really important measure of vaccine response but sadly no test available outside research at this stage.
25. Is there any personalised assessment which may give us a better indication of our own levels of immunosuppression as we move through our CLL	This is a good question however there is no tool which can be used to precisely answer this question. It's a clinical assessment made for each patient which can be subjective.
26. do you have any suggestions about travelling abroad? If you get Covid and need antiviral treatment, would that necessarily be available (eg in Italy)?	At this stage I would be taking things very carefully (see 19) and foreign travel might not be the best thing to do until we have seen better control and lower levels in the community. I don't know what would be available overseas.
27. I haven't had a letter re eligibility for COVid treatment either or a pcr test.	See above
28. I have had CLL for 6yrs - still on watch and wait. Need to lose weight and become fitter. What is your opinion on Exipure - food supplement to aid weight loss and would it be suitable for a CLL sufferer. Thanks - Lin M	I am sorry I don't have expertise on this. I am however a bit sceptical about supplements claiming to aid weight loss. Living well with CLL is really important but many claims made about supplements are not sadly backed up with good data.
29. so no presentation about the subject advertised?	Sorry!

30. I'm recovering from covid, it took me longer than most I think and I have been left with inflamed eyes-has anyone else had this?	I have not seen this but other patients may have experienced similar.
31. When is it going to end? I have been positive for 14 days. Not poorly as such but getting concerned. I am on venetoclax after 10 months on the obinitumazab / venetoclax regime	You might have positive tests for a long time - up to 3 months. This doesn't however necessarily mean you have an active infection or are infectious. I would be guided much more by symptoms and in patients who are well I don't test beyond 14 days.
32. I have had 3 covid jabs but show no antibodies because I'm on Ibrutinib. Should I bother to have a 4th jab. Richard	Yes as it might help although unfortunately I suspect it also won't produce a response. Helen Parry's study is trying to investigate if pausing ibrutinib helps vaccine response, but we don't know this for now
33. Re Approved study is it for only pts taking BTK3 inhibitors - what about pts taking on V&O	Is this with respect to the planned study in Birmingham? If so this is only for patients on BTKi. At this stage I would recommend that those on V+O continue with treatment
34. I was fortunate enough to receive anti-viral treatment (Molnupiravir) when I had Covid 2 weeks ago. Do the AV's have any effect on our ability to develop anti bodies or might they affect any antibodies I might have already had?	I am not aware of risk here
35. With the removal of covid measures, how safe will schools be for teachers with CLL (on W&W or on treatment)?	Really hard to say. As above, important to continue to take care and would recommend masks etc until we are clear COVID has really come under control. You need to speak to your medical team to assess risk and also the School who are obliged to make reasonable adjustments to protect you

36. Are there any studies re effectiveness of new treatment for COVID for CLL patients?	Not specifically although they have been tested in vulnerable patients. In the published papers patients had risk factors although only few had active cancer including CLL. The benefit in blood cancer patients is largely inferred but I suspect we will see more published over coming weeks and months in cancer patients specifically. If you would like to see the published papers (not especially user friendly I'm afraid) they are at https://www.nejm.org/doi/full/10.1056/NEJMoa2116044 and https://www.nejm.org/doi/full/10.1056/NEJMoa2107934
37. I also haven't received the PCR Antigen kit that should have arrived in the post. I contracted Covid in mid Nov and was symptom free. Are there any consequences to my health for not having had the Antigen treatment? Can the Antigen treatment be used more than once?	if you have had COVID and recovered then you should have some protection from repeat infection. The benefit from the new treatments might not be that great in as much as you have not had a severe infection although you would still be eligible to receive them if you picked up infection again
38. could Dr Bloor please give some tips as to what practical steps we could take to avoid catching covid given our vulnerability which goes a bit more beyond just saying 'be cautious'. At the moment we ask anyone we see inside to take a LFT before seeing us and wearing an FFP3 mask when attending something inside like a church service or a concert or travelling on an aircraft or train. Any other thoughts?	It's so hard to be specific and I wish I had a solution to keep everyone safe. think you are taking the right steps with masks and using LFT when people come to visit. Crowds in confined spaces are the highest risks for infection (read something that biggest risk is shopping) and these are the situations you need to be most careful with.
39. Even if you are wearing a protective mask, how likely is it you can still get infected through your eyes?	Unless someone coughs in your face the risk through eyes in general population is probably not that great. Visors seem to have the greatest benefit in health care workers exposed to high risk environments where there is lots of virus in the air.

40. Who is responsible for providing information to the NHS that a person is high risk and should get a letter and PCR test concerning eligibility for antivirals if Covid positive? Needless to say I am a CLL patient but have received no such letter or test!	In 2020, GP and hospitals were tasked with updating NHS about high risk patients. Now it should be picked up when your diagnosis is made (how it is coded which is stored centrally) but none of these systems is fool proof which means that many patients have never been listed. You can speak to GP/hospital if you are not on a list but can't guarantee this will work
41. I'm on Ibrutinib & have had several antibody tests. All have been negative. I've had 3 jabs. How do I get a T cell test.	Sorry this is not available outside research studies. Wish it was
42. Are there any known studies yet to determine the level of antibodies needed which provide the effective level of protection against Covid infection? I understand if a person is positive for antibodies this does not mean they are protected sufficiently.	Simple answer is no but evidence suggests that high levels may be needed. Using the most widespread assay anything over 0.8 is 'positive' but this may well not be protective. In general population, antibody levels are often high (>250 and sometimes into thousands) whereas in CLL patients they can be much lower. Gut feeling is that levels >250 are probably needed to give meaningful protection. This does however not take into account T-cell response which we can't easily measure.
43. For both the 4th Booster vaccine and the Covid treatments, some GPs and Haematology Departments seem to have a difference of opinion to the blood cancer charities, on who needs to be treated. Charities are saying that anyone with CLL should receive the 4th vaccines and have access to Covid treatments. However, GPs refer to the "Green Book", which uses the term "Severely immunocompromised" rather than "Any stage". Therefore, some GPs are classifying "watch and wait" as NOT "Severely immunocompromised" and are refusing vaccines and treatments on that basis. Who is correct? Should all CLL patient received a 4th Booster and Covid treatments regardless of stage.	See above
44. I have been on watch and wait since 2014. I used to have blood tests every 12 weeks at my GPS and see my cell consultant once a year now. This has all seemed to stop now since COVID and get a telephone appointment with my cell consultant or one of his colleagues once a year . I have to arrange getting my own blood tests etc and give my GP all the information on my COVId third jab etc as the surgery were not aware of it . I am starting to worry about my health now as I also suffer from arthritis. How do I go forward. ?	Many CLL patients on watch and wait can be safely monitored every 6-12 months. This does however mean that you might not get updates about treatment and COVID. I think it would be a good idea for you to try and make an appointment to talk this through with your team

45. I am 9 months into treatment with Obinatuzamab and Venetoclax and have had only mild side effects - aching joints and general fatigue. I have always been given full information and support with regard to the treatment and side effects.	Agree - this is my experience (not as a patient though)
46. How do I get a PCR kit and antiviral advice? I've tried everything!	See above
47. Question related to Kevin and mindfullness etc - can I ask what Kevin's work background was/is? (CBT techniques can be destructive for some, so support needs to be tailored to the individual. Some people need to find things to do that they can be a do, rather than thinking therapies. It all depends on the individual.)	One for Kevin
48. I would love to know what the correct SNOMED-CT coding should be on my file to identify me for new or early treatments. I'm w&w with CLL. Maybe not one for this session but possibly something he could reply to in follow-up	SNOMED code for CLL is 51092000. You would have to check with your health records dept to see what's on your file.
49. Nice to know about Aclara- it was mentioned when I started discussing treatment. But I was not eligible, so worth mentioning that not everyone will be able to have it if it is not on the funding list for their treatment history. Also ibrutinib seems to be working for me, but nice to have it as an option if needed. Ibru still a good drug but yes drawback is have to take it all the time. Small price to pay if it works.	Agree - ibrutinib is a good drug. Acalabrutinib appears to be as effective and fewer side effects and would now be my choice over ibrutinib but until fairly recently was quite restricted in availability. If ibrutinib is working and well tolerated would stick with it
50. I completed FCR in November, had 2 covid jabs before the start of treatment a 3rd 6 weeks after treatment. Is there any point having 4th jab in February as I have read that there isn't much point in having any jabs, flu or covid until 12 months after FCR?	Response after rituximab can be poor for 12 months but seems to get better after that. I would however press on with vaccination now to try and get protected. In addition, you may have responded pre-treatment and this does not necessarily go away when you have the treatment. The biggest problem is in people who have never been vaccinated where rituximab tends to prevent you responding
51. The low number of vulnerable people not becoming ill with Covid might be down to their, like me, taking severe precautions in their lives and basically shielding for nearly two years.	I agree. More vaccination and possibly lower risk of omicron also likely to contribute.
52. Has a survey been completed of CLL patients to determine the effects of COVID on us compared with non CLL patients?	There has been quite a lot of research which has looked at this and found that COVID outcomes were worse in CLL patients compared to people without. This is however mostly from earlier in the pandemic.

53. Covid has highlighted big differences in advice and services to people with CLL around the country. How can we try to make the access to vaccines, PCR tests, advice relating to CLL and covid etc more equitable?	Lobbying, patient empowerment, working with NHS and charities to try and make sure we don't have postcode variation.
54. I have CLL and after being diagnosed in 2018 my blood count increased month on month. I then need chemotherapy treatment FCR for 4 months. I was then in remission for 18 months. However my bloods have started to rise again. It is still very low but it concerns me that it may rise as quickly as it did the last time. What are my next options for treatment when needed.	Outside of a trial, options would be acalabrutinib, ibrutinib, venetoclax or venetoclax+rituximab. Of these I would use either Ven-R or acalabrutinib. Remission duration was quite short after FCR and would be important to assess for evidence of p53 deletion or mutation. The optimal treatment at relapse is not entirely clear. Venetoclax+Ritux offers the best chance of MRD negative remission and is only for 2 years but outcomes if you don't get to MRD negativity are not so good. On this basis there are some advocates of using acalabrutinib for high risk disease (with lower chance of getting to MRD negativity). on the basis that it is continuous therapy. You should also speak to your team about trials although there are no national studies currently open. A smaller trial open in a few centres run from UCLH is looking at role of ROR-1 bispecific antibody to consolidate response in patients who dont get an optimal response to treatment and if this is available nearby its somethign to consider depending on how you respond to your next treatment. All things to discuss with your team
55. Any news if/ when Evusheld, AstraZeneca's antibody treatment, for prophylactic use, might be available for immunocompromised patients.	Sorry I don't have any information on this. It was approved for limited use in US in December but I am not sure when it will be available in Europe or who will be eligible.

56. Is Monoclonal vaccines the answer? I am on the Provent trial, I know I had the vaccine and ended up with anti-S IgG level AU/ml of 3773.8 shortly. Intuitively I think this was due to MAB rather than the two standard vaccinations I had.	Good question and we don't know which vaccine is the best. Its good news that you got such a good response although impossible to say if this was down to vaccine or to the long acting antibody (AZD7442) which you may have received as part of the trial. I hope we will get access to this (Evusheld) although as for 55 I don't know when this might be released/available in the UK
57. Mine is not a question. Just to perhaps answer other people's queries. I ordered PCR test kits for myself and my husband and they should be delivered today. My CNS has arranged my 4th Vaccine and I have just had an invitation to go today.	Good news and glad it's working for you
58. I just explained to my Surgery that my CLL Nurse had advised I should have a 4th vaccine and they booked me in.	Mirrors my experience in that if you ask then generally you can get the vaccine or treatment.
59. Good to hear that you have ordered your PCR tests but that is not really the problem. The problem is getting the Priority kits which very few people have received or been promised. Currently the timescale in getting test results is such that it will not be quick enough in many cases to start the drugs which need to be taken very quickly after you start with your covid infection	Agree - timelines are tight if you have a test which is why its really important to try and pursue referral to CMDU as soon as you have a positive test.
60. Should partners of those who are extremely clinically vulnerable have a fourth vaccination if they are over 60 and have no underlying health conditions? Our GP has offered my 64 year old husband a 4th vaccination but I can't find any guidance to support this. I had my 4th vaccination yesterday.	I don't think this is necessary. Most people with a normal immune system will respond to 3 doses and 4th shouldn't be needed. It's also restricted to those with weakened immunity
61. Is Acalabrutinib simply a better version of Ibrutinib? I have been on the Flair trial (Ibrutinib and Venetoclax) for 2 years and I wondered if it would be possible to switch to Acalabrutinib and Venetoclax?	In a randomised trial for patients with high risk relapsed disease the efficacy of ibrutinib and acalabrutinib was similar but acala patients had fewer side effects. If I was starting someone on therapy and had the choice, I would choose acala however I would not switch someone who was responding well to alternative treatment. Would hold it back until it was required.

62. Is a booster after a third full vaccination against COvid the same as the fourth vaccination that you have been talking about?	Yes sorry if I wasn't clear. CLL patients should receive 3 primary doses and 4th dose as a booster. General population gets 2 primary doses and 3rd dose as a booster.
63. Are Haematology depts streamlining their admin by developing standard template clinical letters emphasising ongoing immunosuppression, for patients to request from the dept, to take to vaccination centres or GP to enable vaccination ?	Its mixed and I don't know what everyone is doing. We have sent out a text message to all haematology patients about access to COVID treatments and we also try to speak to patients about COVID when they come to clinic. We also have a COVID phoneline for our patients. It's really hard to cover everyone.
64. What is CMDU please?	Covid Medicine Delivery Unit - regional centres where you can access COVID treatments
65. what does cmdu mean please thank you	See above
66. Out of interest there is a full list of CMDU's online	CMDU directory: https://www.england.nhs.uk/coronavirus/publication/covid-medicine-delivery-ur directory/ In Scotland, the CMDU directory is available on the following link: https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19/coronavirus-covid-19-treatments I have had first-hand experience of using this and it worked well. Lines are usually open 9 – 5 daily.
67. mine is an answer to the question about PCR tests as I received mine yesterday. I rang the Test and Trace service and told them I had CLL and needed a PCR test to have at home in case i got COVID. I had no problem and was sent it.	I am glad this worked. I know it can be difficult to get the rapid tests.
68. 119 not does work for Rapid Test unless you have a letter	It appears that availability is inconsistent. I wish that wasn't the case
69. Yes 119 worked for me for a rapid test.	See 68
70. I tried 119 for a PCR but there was no appropriate menu option for this if you did not currently have symptoms. Do you say you do?	See 68

71. 119 Does Not Work re Priority PCR TEST	See 68
72. I am In Scotland and have a letter giving details of who to call to get priority Treatment if Covid positive however there has not been any mention of Priority PCR test kits etc. i assume its different from England	Yes, its different in Scotland and Wales. I am not sure if it works better outside England
73. 119 won't send out fast track PCR tests, only the standard ones. 119 advised to speak to my GP.. he had no idea had to get one !	Sadly GP or hospitals don't have access
74. will my recent covid skew my next blood tests due very soon?	It's possible it will push your lymphocyte count up or down but this can be taken into account when interpreting the result. Make sure your team knows you have had COVID.
75. Hello, thank you Prof Bloor, this is very helpful. Is it possible for someone to write down the names of the Covid antiviral treatments, I'm not sure how to spell them & am trying to write them down and failing! thank you	Molnupiravir is an oral antiviral. Sotrovimab is an intravenous neutralising antibody. Paxlovid is an oral antiviral which is not yet available but should be soon. CMDU determine who gets which drug which is currently dependent primarily on availability. Sotrovimab is considered first with molnupiravir if not possible (supply or beds to treat). This will be revised when paxlovid becomes available but the final policy on how this will be used is not yet available. For current drugs see https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2021/12/C1530_Interim-clinical-commission policy-neutralising-monoclonal-antibodies-or-antivirals-for-non-hospitali.pdf
76. If I'm not on "the list", who do I contact to ensure this?	See 68 and elsewhere. Should make sure your hospital has updated your records such that you CLL diagnosis has been recorded which is how 'the list' is generated.
77. Can I clarify is the 5 day window from start of symptoms or from positive result?	Both. You need to be within 5 days of onset of symptoms and also positive PCR. Current commissioning policy is found at https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2021/12/C1530_Interim-clinical-commission policy-neutralising-monoclonal-antibodies-or-antivirals-for-non-hospitali.pdf . See also 75

78. I was missed from PCR priority list because I see haemaologist privately (my GP thinks). After 90' on phone to 119 finally got one sent to my home within 24 hours.	See 68
79. I repeat, 119 did not help procure the Priority PCR test after 3 conversations	See 68
80. Has research been done for patients with CLL who receive early "anti virals" for COVID? Are the outcomes better for those have "anti virals" than those who dont take them?	We don't know this specifically as yet - see 36
81. my count is 104 and I'm slightly aneamic but not had any treatment yet, I caught covid and seemed to be recovering well so didn't have the antivirals, but then it kicked back in and I wish I'd had it as it lasted for another week and has left me very run down, so if I got it again I would definitely have the antivirals	Hopefully you will not get another infection having had COVID already but you would be eligible if this happened. I hope you get better
82. Further to my previous message i was told that if I did get Covid and did the PCR test they would organise a courier to pick it up from my home.	V glad this worked for you. Hasn't done for others - see 68
83. I contracted Covid just after Christmas after (I think) exposure on 23 December, starting to feel unwell on 26th Dec. I thought it was a cold and did not take a LFT until 28 Dec and completed a PCR test on the 29 Dec. I received a call from a NHS doctor in response on 2 January. I was told that the 5 day period for qualifying for the antivirals starts when symptoms first appear, NOT from the date of a positive LFT and that I was too late to qualify. I was also told that my symptoms appeared too minor to qualify. It took me nearly 2 weeks before I gave a negative LFT.	Yes sorry to hear this. The 5 day period is from both the onset of symptoms AND the date of a positive PCR. See also 77. LFT and PCR can stay positive for weeks after resolution of infection but doesn't necessarily mean you have an active infection or can pass it on. In general we don't test at the Christie beyond D14 but act on symptoms.
84. If LFT is positive but in the absence of being able to obtain PCR result back quickly within say 36 / 48 hrs, would Haematology depts support us being referred ed to CMDU on basis of positive LFT's , esp if 2 consecutive positive LFT's ?	I am sorry that current rules currently need a PCR. You could certainly ask your team but suspect it wouldn't work. Getting a PCR ASAP is really important.
85. Any news on prophylactics like Eversheld? Equivalent for people who haven't made antibodies as vaccines are for the masses.	Sorry no - not clear when Evusheld will be available in UK. See 55 and 56
86. Not a question, just a comment: my understanding is that general masks don't protect the wearer, but reduce the wearer's chance of spreading Covid. More specialist masks are the only ones that actually protect the wearer.	Protection from masks does work both ways but level of protection does depend on the type of mask and distance. See recent published review https://www.pnas.org/content/118/4/e2014564118 for more information

87. What about T cell response in CLL patients? Does it fall off like antibody response does?	T-cell response is also important post COVID vaccines. This is harder to measure than antibodies and has been less well studied. In CLL patients some will develop antibodies, some T-cells and s ome both (or neither) so cannot use one result as a surrogate for the other. Overall however both T-cell and antibody responses are less in CLL patients compared to those without CLL. We don't really know how durable the T-cell response is in CLL patients
88. 4th vaccine - same as first 3doses or different ?	Good question. Available data suggests that mRNA vaccines produce the best effect as booster with the biggest impact observed in those who received AZ vaccine for first two doses. As such I would currently recommend using either pfizer or moderna for doses 3 and 4; I dont think there is much to choose between these. If you have had pfizer already and had no response then I would still stick with mRNA vaccines although chance of responding to dose 4 if first 3 havent worked is not that great unfortunately. I have occasionally tried AZ vaccine in this context although there are no real data to indicate this works. See https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)02717-3/fulltext
89. Do you recommend a private Shingrix vaccination for us over 80's and if so where can we get one?	Anyone over 70 can get one through their GP on the NHS
90. I agree Venetoclax is a breeze to take, for me!	Glad to hear you doing well.
91. When will the long acting antibody combination EVUSHELD become available?	See 55 and 56
92. With the issues of various levels of response to vaccines, what is your opinion on monoclonal antibodies such as Evusheld - the AZ MAB combo that has been approved in the US but is apparently pending approval here	I think this could help but not something we have access to. See 55 and 56

93. I have asked time and again for antibody testing and have been told that with CLL I need to have a detailed test which is only done in major haematology centres. I am due to return to working in my local hospital and am anxious being vulnerable and working in a hospital where Covid patients will be.	This is widely available and is a simple test. I can only recommend persistence. As a caveat however it can be difficult to know what the results mean (positive does not equal immune, we don't know the optimal level for any protection and this only measures one aspect of response; T-cells might be equally or more important).
94. Are antibody level tests now being made routinely available to patients with blood cancers through their Haematology clinics ?	See 18,24,41,93
95. I have CLL diagnosed Aug 2018 employed 25 years - they are not playing ball	Need to speak to HR or seek legal advice on this
96. What's the future beyond Acalabrutinib & Venetoclax?	I think the future is likely to be with time limited combination therapies aimed to eradicate MRD. Optimal combination is however y to be determined. We will see more data emerging (eg from FLAIR) about this. Non covalent BTKi (eg pirtobrutiinb - LOXO305) also looks effective and will expect to see this coming into front line setting at some stage. I don't know if we have seen the end of FCR - still very effective for a subset of patients but likely to be surpassed by non chemo combinations. Beyond that bispecific antibodies look interesting in patients who have a suboptimal response. Place of CART therapy is uncertain at the moment. BTK/BCL2 degraders are intriguing in patients who become resistant to BTK inhibitors or venetoclax but at very early stage. What we need to be able to do is to personalise therapy to try and integrate molecular diagnostics to guide treatment but this is easier said than done. Expect to see us using more than p53 in the future.

97. I have had a second booster how safe is it to have one every three months	We don't know how often to vaccinate. At the moment repeat vaccination appears to be effective in boosting antibody levels for a lot of people (although not all CLL). There is nothing yet suggesting any significant safety concerns. I am sure we will see continued vaccination going forward but cant believe it will be every 3 months. Watch this space.
98. Are we likely to have access to Evusheld, the prophylactic, any time soon?	See 55 and 56
99. In the light of your comments about returning to work. I am a secondary teacher and I feel I should leave the profession to protect myself. Am I over-reacting? Currently on V&O	I cant really give a straight answer but would sit tight for now. I hope a we all do that COVID will come under some better control and everyone including CLL patients will be able to return to normality.
100. Is it ok to have the monoclonal vaccine if you're taking Hizentra ?	Yes vaccines are fine with IVIG
101. If I only have a couple more months on venetoclax, should I wait until I finish for 4th vaccine?	Hard call. The concerns about COVID are here now and gut feeling would be to get on with the vaccine and not delay.
102. The addition of risk of ventricular fibrillation leading to cardiac arrest to the Ibrutinib trial seems pretty serious. How should a patient on the Flair trial assess the increased risk?	Risk of AF is fairly high on ibrutinib - 10-15% in trials but some studies have suggested incidence up to 30-40%. It is generally relatively mild and most patients can continue on treatment (some with modified dose or other medication to control heart rate). It is more common in those who have heart disease or cardiac risk factors before starting treatment. Significant risks include age, high blood pressure, high cholesterol, smoking). More significant heart disease (eg ventricular arrhythmias) with risk of sudden cardiac death have also been reported and are much greater concern but thankfully much less common (1-2% of patients). In practice what this means is that I carefully consider cardiac risks in patients who have history of cardiac risk factors and woudl try to use an alternative if this is available.

103. Does every antibody test show if your antibodies are from the vaccine or from having contacted Covid. And does it matter which they test?	Spike protein antibodies are from infection and vaccine. Nucleocapsid antibodies are from infection only. If you want to know vaccine response, it is important to look at spike protein antibodies.
104. Do the vaccines make your white cell count higher? Does the vaccine affect your CLL?	Vaccines and other causes of inflammation can change the white count in CLL and cause lymph nodes to swell. Normally this just settles with follow up. There is no good evidence to show that vaccines make CLL worse.
105. Could you explain a little about when you see CAR-T treatment being used in future	T-cells in CLL patients don't work so well (called T-cell exhaustion) which means that CAR-T cells (made from the T-cells) are often less effective. This led to the ZUMA8 trial ending as they couldn't manufacture effective product. Exhaustion gets worse with advanced disease. As such I think CART cells will be placed increasingly in high risk patients (eg p53 deletion or failure to achieve MRD negativity following venetoclax) at earlier stage of disease. This is work in progress. Otherwise CD19 might not be the best target and some interesting trials looking at CART against ROR1 or using CAR-NK cells which are derived from donors and get around the T-cell exhaustion. its an area to watch and something that should be looked at in trials currently.

106. Thanks so much for all info Prof Bloor - super helpful. Any data as to how CLL patients (whatever stage) have reacted if catch Covid and get or don't get antiviral treatment?	Outcomes following COVID infection in CLL patients are not as good as for the general population although encouragingly are getting better (see tps://ashpublications.org/blood/article/138/18/1768/476453/COVID-1 patients-with-CLL-improved-survival) This mirrors the reduced mortality seen in the general population as a consequence of vaccines, population immunity, better treatment. Gut feeling is that the outcomes following omicron will also not be as bad as for delta although some of this is also due to the passage of time and the factors above. We dont know how good COVID treatments are in CLL as they have been mainly tested in patients with other risk factors (see 36) but expectation is th they will help
107. Any news on prophylactics like Eversheld? Equivalent for people who haven't made antibodies as vaccines are for the masses.	See 55 and 56
108. In the light of the Birmingham Study, suggesting that CLL patients on acalabrutinib only have 34% immunity after 2 vaccinations does Prof. Bloor have any particular suggestions for this group of patients?	Its all about risk and benefit. For someone on treatment who needs therapy I would continue but also continue to vaccinate as response can improve with time. This is an area that the STATIC trial will hope to look at (ie do we really need to continue treatment long term or can we stop), and also Helen Parry's trial looking at 3 week pause to hopefully help vaccines work better. If you have had an excellent response and wanted to consider pausing treatment this is something you would need to speak to your team about.
109. Is there a known problem of a Covid booster jab initiating autoimmune haemolytic anaemia. If this situation occurred, should a fourth booster jab be taken up. (This situation happened to me).	This has been reported (rarely). I would have significant reservations about safety of further vaccines although it can be hard to know if the haemolysis was driven by the vaccine or your CLL. Definitely one you need to speak to your haematologist about. I don't know if other vaccines would be any safer.

110. I would like to ask what CLLS thinks about **Enovid**, an Israeli barrier treatment which has been recommended.	Some data suggest this could work. It's unlikely to do any harm but has only been investigated in a small study so far.
111. Surviving Covid - I am on Watch and Wait, having CLL, but is my chances better surviving an attack of Covid as I do not need *active treatment* or does it depend on the type of Covid there is around, e.g. are my odds worse with Delta or Alpha than Omicron? What roughly would be my chances of survival with any kind of variant?	Risk of COVID depends on a number of risk factors including stage of CLL, vaccine response, any CLL or COVID treatment given, age, severity of infection and other COVID risk factors. The mortality following COVID in CLL patients is also reducing and we don't know what the relative risk is with omicron vs delta. See recent study in 105 but this is also subject to significant bias in that most patients were hospitalised and in this group the outcomes would be expected to be worse. We simply don't have great data about outcomes in patients who have COVID and are at home. I am sorry this is vague. Bottom line is continue to be careful, get vaccinated and try to get treatment if you get infection. **BUT** - things might be looking better than they did in 2020
112. I have CLL and on Watch and Wait. I am concerned that both my Haematologist and GP, especially the latter due to pressure of work, may not be up to scratch about the latest treatment for CLL patients who gets Covid. **Would it be acceptable to contact my Haematologist in the first instance, in the hope that he can help me if I contact Covid, rather than my GP?** I have spoken to my Haematologist's Support Nurse who seems to know less than I do, thus I am concerned about getting the most-up-to-date treatment if I was to come down with Covid, but also that the latest information on treatment for leukaemia patients is not getting through to all NHS staff.	You certainly can do however it all depends on how responsive your team are. If you get COVID then you need to get a referral to the CMDU ASAP who are gatekeepers of treatment.
113. New Covid treatments such as Regeneron.	Regeneron doesn't work for omicron so we use very little or none of i now. Treatments pre-hospital as above see 55,56. For patients in hospital we still use treatments such as dexamethasone and remdesivir but these are for those who are more unwell.
114. How do I get access to the new Covid treatments?	Covered elsewhere
115. What should I do if I test positive?	Covered elsewhere

116. Is there still a threat from the Delta variant?	Much less so. Delta outgrew alpha and omicron outgrew delta. There is still likely to be some delta but tiny numbers now and unlikely to re-emerge. We will almost certainly see different strains coming through but hope is that they will be less virulent (ie less serious disease) as seen for omicron.
117. What impact does Covid have on CLL patients?	Huge - I hope I have covered this in response to other questions
118. Are we entering a 'new normal' for CLL patients?	Let's hope so however it's still not the time to be completely relaxing. think we will know much more over the next few months and we do seem to be seeing some light at the end of the tunnel.
119. Many CLL patients on Ibrutinib and similar drugs have no antibodies despite vaccinations. As they can't know what sort of T-cell response they may have what is the best approach to living with the disease going forward please?	Common sense, try to reduce the risk where you can, get vaccinated and continue with sensible PPE such as masks. Crowds are the big issue where you breathe lots of other peoples air and something I would be careful with. We will have to see what happens with the further relaxation of restrictions and sadly for CLL patients we are not out of this yet.
120. In order to get community treatment, those of us with CLL who suspect we have Covid are currently asked to send in a PCR test result and if this proves positive, we are entitled to get help in the community, which presumably means somebody coming to our home with medication. However as the government is now accepting lateral flow tests instead of PCR tests for other purposes, is it possible that we will be able to report positive lateral flow tests to get community treatment?(we could, for example, take a photograph of the positive result?)	LFT might be accepted in the future although currently access to treatment for COVID needs a PCR.
121. I have no antibodies to 3 vaccines so very worried about high Covid cases and high transmissibility, what can you suggest to remedy the situation? I have no nurse specialist and consultant/secretary does not respond to messages, GP knows nothing about treatments.	You might consider seeking a second opinion. I am really sorry you feel so un-supported.
122. Are people on W&W vulnerable to a poor outcome with Covid? Are all people in all stages of CLL eligible for the 4th jab and Covid treatment? What are my chances of surviving covid? Is Delta still a threat?	I think I have covered these questions

CLL Specific Questions	
125. What are the latest treatments for CLL?	see 96
126. How many GP surgeries really understand CLL?	Its hard to say. From my experience it's really mixed. Try to get as much info as you need from your haematologist and CNS and ask CLLSA or other charities who provide support. If your GP can't answer your questions then you can ask for a referral.
127. How many GP surgeries are aware of the treatment pathway for immunosuppressed?	All should be but in practice I am not sure. It will get better with time a this all had to be rolled out very quickly.
128. Can someone with TP53 missing / IgVH unmutated expect MRD and if so what combination can possibly offer this?	Chances of getting MRD negativity appear much the same with p53 deletion and unmutated IGVH in the front line setting following treatment with Ven-O (https://ashpublications.org/blood/article/135/26/2402/452766/Prognc and-predictive-impact-of-genetic). The concern is where MRD remains positive leading to often quite sh remissions. This is an area that needs to be looked at in trials (eg using CART and bispecific antibodies). Suggest discussion with your haematologist
129. am on ibrutinib but no peg fed and can't take it	It's not licensed but there are some case reports showing that this can be done - https://ashpublications.org/blood/article/128/22/5371/99954/Use-of-Ibrutinib-Via-Nasogastric-NG-Tube-amp, https://pubmed.ncbi.nlm.nih.gov/30186643/) You would need to speak to your haematologist and pharmacist at hospital. I'm sorry but I have no personal experience with this.

130. What is the Static trial, I have not heard of it?	This is a trial to investigate outcomes for continuous BTK inhibitor therapy vs interruption of treatment and restarting on progression in patients who have had an excellent response to therapy. Its designed as a follow on to FLAIR although non FLAIR patients can be considered. It will be open hopefully in the first part of 2022 in around 80 centres (mostly those running FLAIR). Suggest discussion with your team
131. how does venetoclax and obinutuzumab compare to acalabrutnib for CLL treatment?	Both effective but different and no data to directly compare outcomes. Ven-O is for a year and has good chance of achieving MRD negativity but is somewhat more inconvenient (Obin is given on a drip and venetoclax needs careful dose escalation over first 5 weeks). Acala is oral and easier to take initially but long term therapy and unlikely to get to MRD negativity. Patient choice, presence of cardiac risk factors and local capacity are some of the factors taken into consideration. There is no clearly 'best' option and I use both.
132. Approaching second treatment. What are the options?	Mostly choice between BTKi (acala/ibrutinib) and Venetoclax+/-rituximab - see other responses where I think I have covered this. You should also speak to your team about any trials available
133. Stopped Ibrutinib after 8 cycles due to uncontrolled AFib. Had a 9 month break and started Acalabrutinib 5 weeks ago. Within 2 weeks started large bruising/bleeding. Dose reduced by half for the past 3 weeks but still bruising. How long can I expect bruising/bleeding to continue before I can return to full dose? Also add that I have ITP.	Bruising is common with all BTKi and will likely continue although in my experience most patients can tolerate it. I would not worry too much about getting onto full dose. Bruising is worse if other bleeding risks (eg low platelets, aspirin, anticoagulants). I have had to stop BTKi in some patients due to bruising and then would consider either observation (if CLL well controlled) or

134. is Loxo a BTK Inhibitor?	yes it’s called a non-covalent BTK inhibitor which relates to the way it binds to BTK. In trials this looks promising and think we will see more of this going forward.
135. Thanks for asking my earlier question. I'm guessing its not possible to switch from Ibrutinib to Acalabrutinib? (I'm also on Venetoclax on the Flair trial).	No I would not swap if you are responding well. This is also not possible in FLAIR
136. Re Acalabrutinib, could Prof Bloor speak about AF risk and how this manifests? I have been taking Acal since September and have started to experience bouts of palpitations.	Palpitations, shortness or breath, chest pain. You should seek medical attention about this.
137. Coming out of remission. What are the steps?	If no hard indication to treat (white cell doubling <6 months, Hb/platelets ok, no bulky/symptomatic nodes or spleen, no symptoms) then sit tight. Many patients can have quite a long time between early signs of progression and needing treatment. Its back to watch and wait. If you have more significant symptoms or evidence of disease then you need to speak to your team about options - see also 131,132