



# AGENDA

Patient update

St George's Kidney Patients Association

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August 3<sup>rd</sup> 2020, 5:30pm – 6:30pm

Online Zoom meeting,

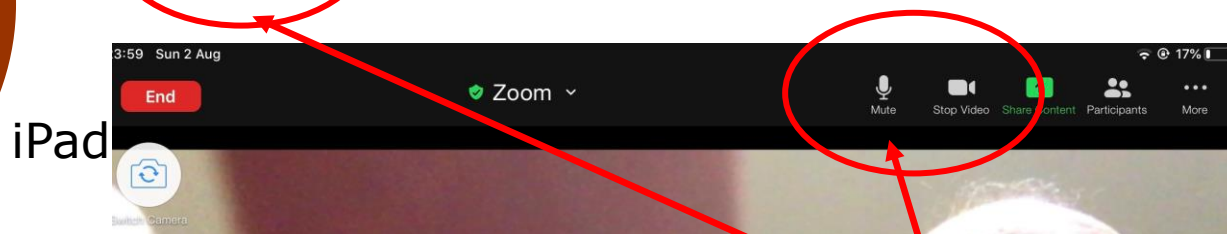
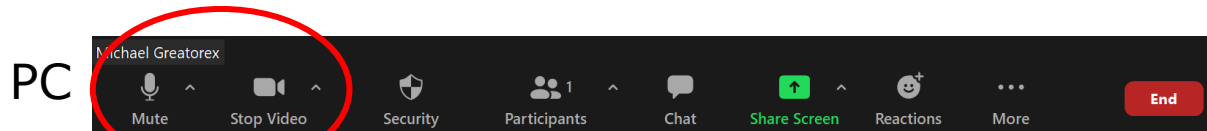
***Please with the register/join us at  
[www.sgkpa.org.uk](http://www.sgkpa.org.uk) to receive future  
invitations & news (if you haven't already)***

# Agenda

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- **Welcome & introduction to the meeting**
  - **Michael Greatorex - Chairman SGKPA**
  
- **Brief explanation of Zoom & the meeting format**
  - **Michael Greatorex - Chairman SGKPA**
  
- **Question & Answer session**
  - **Dr Debu Banerjee – Consultant & Clinical Lead, Renal Unit**
  - **Dr Joyce Popoola – Consultant, Renal Transplantation**
  - **Gulshan Vazir – Clinical Psychologist, Renal Unit**
  
- **Feedback Survey**      (1 minute – Online / Multiple choice)
  
- **Meeting Close**
  
- **After meeting**
  - **I will stay on afterwards if you would like me any leave further feedback to help us improve these sessions.**

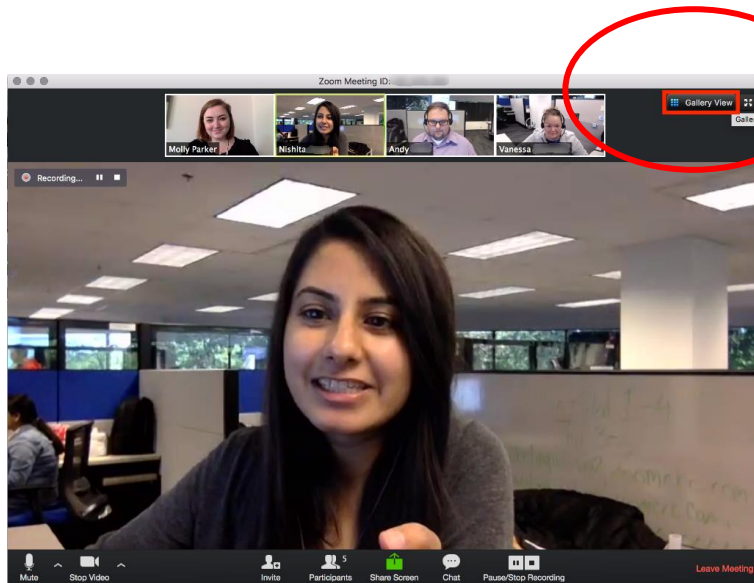
# Zoom controls – Familiarise yourself with these



- Controls vary by device and you need to tap/click to see them.
- Mute – Always keep MUTED unless you are speaking. (Mute using \*6 on a landline phone)
- Video – Your choice whether you use your video.

# Active Speaker View & Gallery

- You can change you view but for this meeting the best view will be Active Speaker.

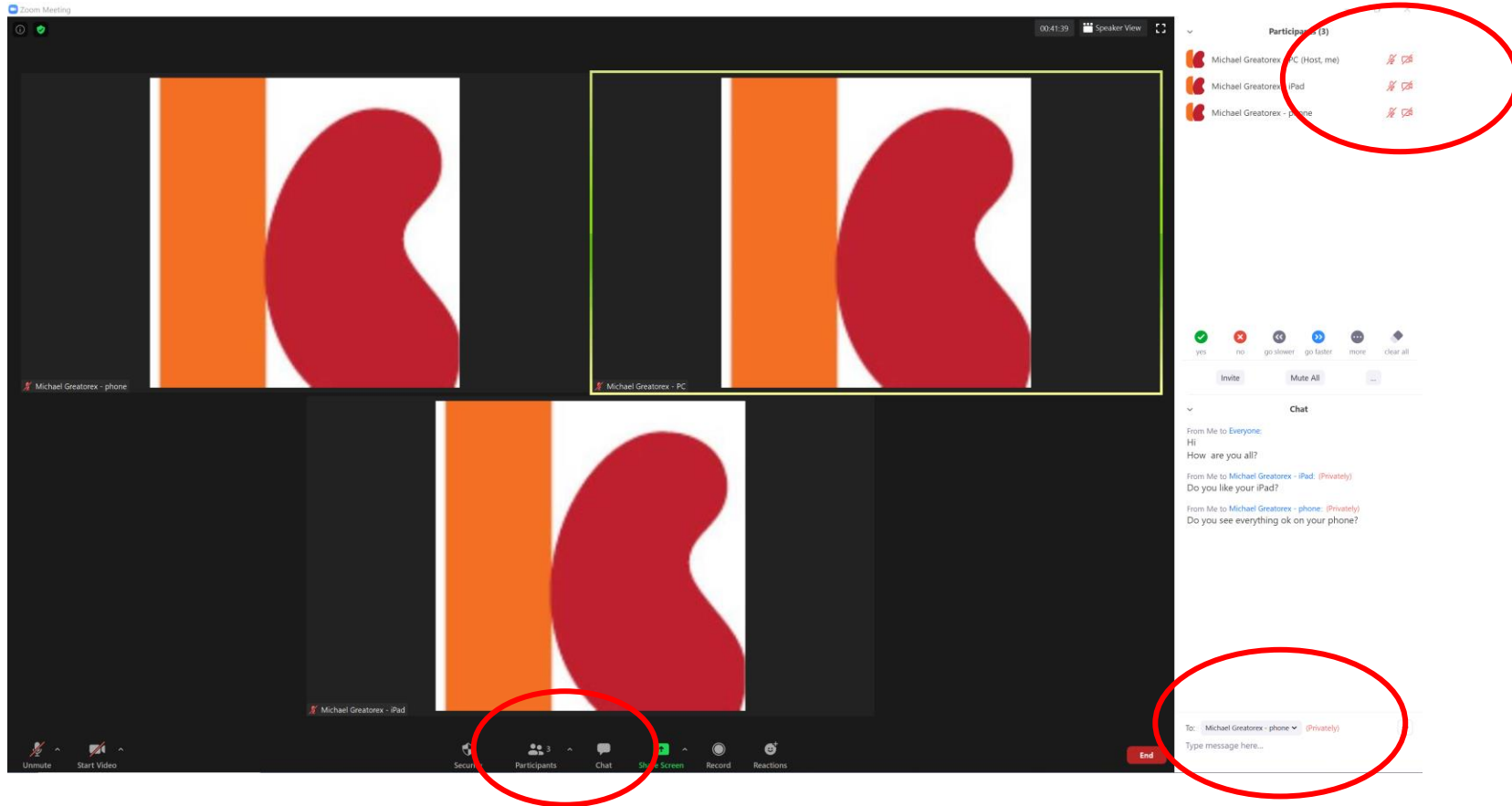


Active Speaker View



Gallery view

# Zoom controls – Optional Participant & chat screens on a PC or Mac



This is a PC View – Tablet/iPad will have a pop-up window and phones will switch to a new screen

# This Zoom meeting guidelines

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- Please keep your device on MUTE unless you are speaking.
- Avoid talking at the same time as others where possible.
- Remember that some people will be joining by phone so can see anything.
- Please use the raise hand 🙋 feature (to speak yourself), the chat facility, a text message or email to ask a question.

# Question & Answer session

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- **OBJECTIVE: Answer as many questions that you have about the current COVID-19 situation, new ways of working at the clinic and health/vaccine.**
- **Dr Debu Banerjee  
Consultant & Clinical Lead, Renal Unit**
- **Dr Joyce Popoola  
Consultant, Renal Transplantation**
- **Gulshan Vazir  
Clinical Psychologist, Renal Unit**

# Combined Questions (1/3)

Area	Questions
Post shielding advice	<ul style="list-style-type: none"> <li>• Should I be going back to work? ANSWER: It depends on the type of work you do. You think very carefully about a workplace that can't provide a safe environment. Where possible work from home. You should be following the government advice (via NHS website &amp; SGKPA) which will vary according to transmission rates in the community. Always wear a mask and wash hands frequently. Discuss measures in place with your employer. The clinical team can provide letters if required. (Letter applies to all subsequent work questions.)</li> <li>• Should I be using public transport? If not, how do I get to work?</li> <li>• How safe is public transport? I use a route of London overground and Jubilee line which is usually not very crowded and is all above ground. Are buses safer than trains? My family are anxious for me. (JM) ANSWER: Avoid public transport where possible (Working from home). If necessary, travel at quieter times. Wear a mask. Preferably walk, cycle, or use a car. Ask your employer for help if necessary.</li> <li>• If needing to come to St George's hospital for clinic appointments, are taxis COVID safe? I'm happy to drive to Queen Mary's where parking is easy for appointments. (MJ) ANSWER: Ask the firm. Most, if not all, firms are taking many precautions. Take the usual hand and mask precautions. Your own car will always be safer if you clean it.</li> <li>• Does the end of July date for shielding apply to me if there is no vaccine? ANSWER: Yes. You should continue to exercise significant caution.</li> <li>• Should I be able to go on holiday? ANSWER: Depends. Follow government guidance. Foreign holidays not recommended (flying). Villas better than hotels. UK better than overseas. Fast moving situation overseas. Track which countries are in the most risky situations (including capability of local healthcare systems). See <a href="https://www.worldometers.info/coronavirus/">https://www.worldometers.info/coronavirus/</a></li> <li>• Can my kids go back to school if I'm shielding? ANSWER: Yes if possible. It depends how well children can follow the safety measures put in place.</li> <li>• Which of my family and friends can I meet inside? Do we still have to socially distance? ANSWER: Depends on their situation. Exposure to other people and thus the virus.</li> <li>• Govt guidance now says we can visit family, go to shops, use public transport if we need to, visit hairdressers, go swimming etc. If we don't have to should we go? (NZ) ANSWER: Use your discretion and take precautions of masks, handwashing and social distancing.</li> <li>• I liked shielding as I had rules to follow but now I am not sure what to do safely. What can I do? Is it safe to meet people at a distance indoors? (JM) Social distancing, handwashing &amp; masks should be used. It is always better to meet outside rather than inside.</li> </ul>



# Combined Questions (2a/3)

Area	Questions
Clinic setup	<ul style="list-style-type: none"> <li>• What new measures are planned for dialysis? ANSWER: Thank you for all your understanding during the pandemic which has resulted in considerable disruption to you. The team will continue to move things around where there is a positive or suspected case.</li> <li>• What new measures are planned for transplant outpatients? ANSWER: Newly transplanted patients are seen in a different area to the longer term patients. More use of "virtual" appointments – come in for a blood test, results reviewed and in necessary a phone call and letter to your GP. Where necessary face-to-face appointments are still taking place but minimised to maintain social distancing. We expect everyone will wear a mask. You may also have temperature check and questions.</li> <li>• When will the transplant programme restart? (Live/deceased) ANSWER: The live donor programme began 3 weeks ago and the deceased donor programme started 10 days ago. We are proactively transplanting, slowly and staged programme so that people who are likely to require less post-operative hospitalisation are being transplanted in the first instance; avoiding longer stays at this point as there are more risks for long stay patients.</li> <li>• How will my visits to the transplant outpatients clinic work? Bloods taken, consultation etc. [ANSWER: see previous answer]</li> <li>• What measures are in place at St George's to keep us safe? (see above answers)</li> <li>• Can we park outside the clinic or do we have to go to the security lodge to have our parking tickets endorsed?</li> <li>• What's happening about the dialysis plans for the trailer?</li> </ul>

# Combined Questions (2b/3)

Area	Questions
Clinic setup	<ul style="list-style-type: none"><li>• Will the clinic provide updates to our GPs about our vulnerable status. Our GP reminded us that shielding had ended (felt a bit alarmed by that). What should we expect from our GP surgeries on an ongoing basis and how cautious do we need to be? How careful should we be with food and parcel deliveries? (ours still stay outside for 24hrs) (NZ)</li><li>• For those not yet on dialysis, how will our kidney function be monitored without blood tests which normally take place in face to face clinics? [ANSWER: Blood test can take place in the community or at hospital. Virtual appointment should still take place and if necessary face to face.]</li><li>• Why aren't masks compulsory at transplant clinic? I felt very unsafe at clinic the other day as the other patients were not wearing masks. All of us are vulnerable as we are immunocompromised and have been shielding. Why are masks not handed out at entrance to the clinic? I wear a mask whenever I leave the house for a walk. (JM) ANSWER: Masks are expected and handed out at the entrance to ST G by security guard. (Grosvenor Wing).</li></ul>

# Combined Questions (3a/3)

Area	Questions
Available help for you	<ul style="list-style-type: none"> <li>What help is available if I feel I need more well being support? ANSWER: Counselling still available in the community. In a crisis Samaritans available 24/7. Shout are available by text 85258 for young adults. Details in website article. SGKPA will publicise a user group of patients. If you want to talk to someone at the St George's psychology service, ask someone in the clinical team.</li> </ul>
Medical questions	<ul style="list-style-type: none"> <li>As a transplant patient I understand that I am more vulnerable if I catch the virus however I would like to know if I am also more vulnerable to catch the virus. (JS) {ANSWER: Yes to both}</li> <li>If we catch COVID what is the likelihood of hospitalisation? If we do catch COVID will we come into St Georges to be treated or to other emergency wards which may not be experienced in treating immunosuppressed patients? Is there specialist advice for treating transplant patients if they catch COVID due to their immunosuppression? (I'm concerned about going somewhere which does not know medical history) (NZ) ANSWER: where possible we will try to treat you as an outpatient. Cited an international patient, never admitted to hospital. If necessary we will. Signs are increasingly weak, worsening breathing and GP finds lowered O2 saturation. Separation of patients maintained between those testing positive, suspected &amp; negative.</li> <li>I recently spent 4 months in St George's with what can be only described as a very rough ride with Covid19. Does having COVID have any further negative effects on an all ready damaged renal system and will it prevent me having a kidney transplant in the future. ANSWER: For patients who developed CKD as a result of COVID you will be treated like any other patients and it does not preclude you from having a transplant.</li> <li>If you have not had a recent (last 4 months you should have one. You can have this in the community or at the hospital.)</li> </ul>

# Combined Questions (3b/3)

Area	Questions
Vaccine	<ul style="list-style-type: none"> <li>• What vaccines which are on trial, being developed will be suitable for immunosuppressed patients? Will the clinic be managing these directly for their patients if they get approved? (NZ) ANSWER: St George's following the progress of vaccines including those in UK, US, France, Russia &amp; China. Hope to proactive in trialling. Dexamethasone trial participation as an example. Vulnerable patients wouldn't be involved at an early stage but once proven safe and effective would be a priority.</li> <li>• Will a vaccine be suitable for transplant patients? Will we be at the front of the queue? (JM)</li> </ul>
Others	<ul style="list-style-type: none"> <li>• How badly affected have kidney patients been at St George's?</li> <li>• How many transplants patients contracted COVID 19 (St G / UK)? (SA) ANSWER: Patients have done very well. 1.5% nationally, ~2.5% in London although better in the suburbs. Worldwide, large portion of patients were not hospitalised. Further of hospitalised patients, large proportion only spent short time in hospital. Incidence in dialysis patients was higher.</li> <li>• Is there any additional monitoring or research being done into why black and Asians are disproportionately represented amongst kidney patients, other than the old assumptions around diabetes? For example I am not diabetic, my condition does not relate to another the factors often stereotypically aligned to BAME yet I am not aware of any research being undertaken or sponsored via St Georges into this are or treatments. If there is such how can we find out? ANSWER: Research is now underway. Factors include obesity, being male (especially older male), high exposure workplaces, diabetes, cardiovascular disease, respiratory disease, smoking, and use of high dose steroid (over 20/30mg). We will share information as it becomes known.</li> </ul>

# Additional questions asked on the call. 1/2

(from chat window)

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- Is it possible to check which type of masks we should be wearing if we are “extremely vulnerable” - I assume re-usable masks are sufficient and we don't need to have medical-grade disposable masks and that as long as nose/mouth covered that's the main thing and have been operating on that basis! Appreciate we may not get to this and fine if not - but great if so! [ANSWER – either as long as reusable masks are washed after each occasion]
- Can I invite friends to my house for a dinner party? Do we need to social distance indoors? Thanks [ANSWER – This depends – It is always better to meet in the garden rather than indoors. If not possible then if they are part of your official bubble, and are themselves careful, then yes. If not you should socially distance. ]
- For the visually impaired amongst us who live in a tactile world and where, as a blind person, it is hard to socially distance myself from others, will the unit write letters of explanation to employers/DWP to help them understand our additional risks? [ANSWER – Yes]
- Can you please reconfirm the name of the App to check COVID numbers please? [ANSWER – it was a website. The URL is <https://www.worldometers.info/coronavirus/> ]
- How often are dialysis patients tested for Covid 19? [ANSWER – As and when needed. There is no current evidence that regular testing helps. Patients are tested if they show symptoms or if another patient has tested positive]
- The few people without underlying conditions who became very ill seem to have done so because of an overreaction of their immune system. So if a transplant patient doesn't have any underlying conditions [diabetes or heart issues etc} can a suppressed system actually be a small positive. [ANSWER – There is no clinical evidence one way or other but Dr Banerjee speculated that low doses might.
- Can we send our daughter to school in Sept , she would be in reception. [ANSWER – key point is plan to attend but keep a close eye on things. Also whether you feel your daughter can follow instructions]
- Should I let my kids go to school in September? [ANSWER – see previous answer]
- Can I go to the dentist? [ANSWER – Definitely yes! It is a critical means of identifying potential issues and keeping you healthy]

**Edited for clarity, grammar & relevance**

# Additional questions asked on the call. 2/2

(from chat window)

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- Which family and friends can come inside the house? [ANSWER – See previous answer]
- Will it be possible to obtain a personalised risk assessment? [ANSWER – No although mention was made of a protocol (Alan Score?). Details to follow]
- Are you still intending to continue with the monitoring of (post-transplant) donor patients. [ANSWER – Yes. Key test is blood pressure. Other bloods can be done at GP too.]
- Do I need to have paper work with me when going to QMH for bloods? [ANSWER – New system changes means that your records should now be available on computer to doctors at QMH]
- If called for transplant we won't be able to self isolate in advance so how will you deal with this? [ANSWER – the test protocol was described. Questions, test within 4hrs, proceed if ok]
- Can my husband go back to bus driving (Spouse of patient) [ANSWER – Many precautions are being taking as they are high risk occupations. But please discuss with your consultant nephrologist]
- We may be alone but we are still spraying all of our food deliveries to get rid of any potential virus. Is this necessary?
- Can bloods be done at GP? [ANSWER: Yes, most except some specialised tests]
- I have had my blood test in the middle of July but have not yet had a video or call appointment. Is there a delay? Will I be contacted soon for the results? [ANSWER – if there is no issue, calls were often not made. Dr Popoola explained there had been delays as a result of getting the new ways of working up and running. They would also be setting up video calls if people on this call see the benefit. – See the survey results. Everyone who responded said yes (~18).]
- I had my blood test at the Nelson today and felt very uncomfortable. It was so busy and I had a 40 minute wait. Would it be possible to have an appointment time rather than have to do this?
- As a renal patient, should we have the flu jab? [ANSWER – Definitely yes!]

**Edited for clarity, grammar & relevance**



# Feedback survey

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- This should take you approximately 30-60 seconds and will give us
  - An understanding of how we've done on this call
  - The value and subject of any future meeting
  
- It will begin in a moment



# Thank you for coming!

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I will stay on afterwards if you would like me any leave further feedback to help us improve these sessions.



# Other feedback comments

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- The frustratingly long delays for letters to be sent out following clinic meetings so that my GP can issue medication changes. More use of Zoom meetings and email.? (MJ)
- I would be very interested to know why I have not received any emails or a single call from any of the renal doctors throughout the entire course of lockdown. I visited the hospital for bloods but have had no response or feedback. (SW)
- I have been a patient of XX for over 10 years but have never been told about or offered any medication or trials or treatments for my condition PKD, why is that? When I know of other with the same condition who have been offered all of the above.