



AGENDA

Patient Information Seminar

St George's Kidney Patients Association

September 7th 2020, 5:30pm – 6:30pm
Online Zoom meeting,

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

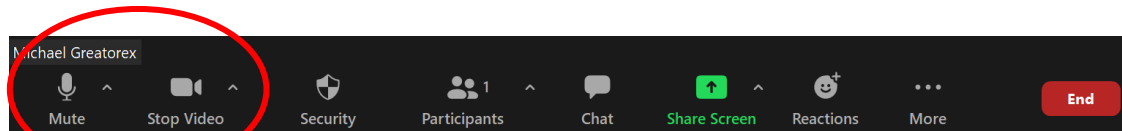


Agenda

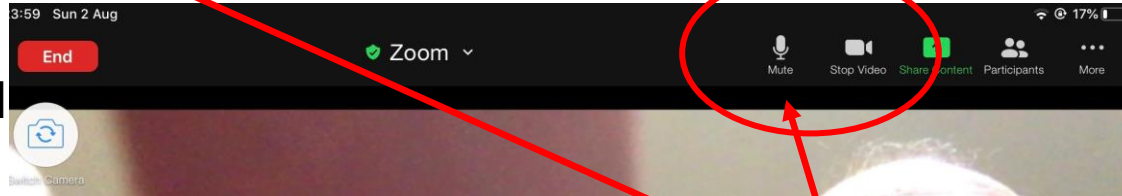
- **Welcome, introduction & brief explanation of Zoom & the meeting format**
 - **Michael Greatorex - Chairman SGKPA**
- **PatientView – Michael Greatorex & Patrick Reynolds**
- **The Renal Diet – Helena Jackson**
- **Question & Answer session**
 - **Patrick Reynolds – IT Lead, Renal Unit**
 - **Helena Jackson – Lead Dietician, Renal Unit**
 - **Dr Joyce Popoola – Consultant, Renal Transplantation**
- **Feedback Survey & Meeting Close** (1 minute – Online / Multiple choice)
- **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

PC



iPad



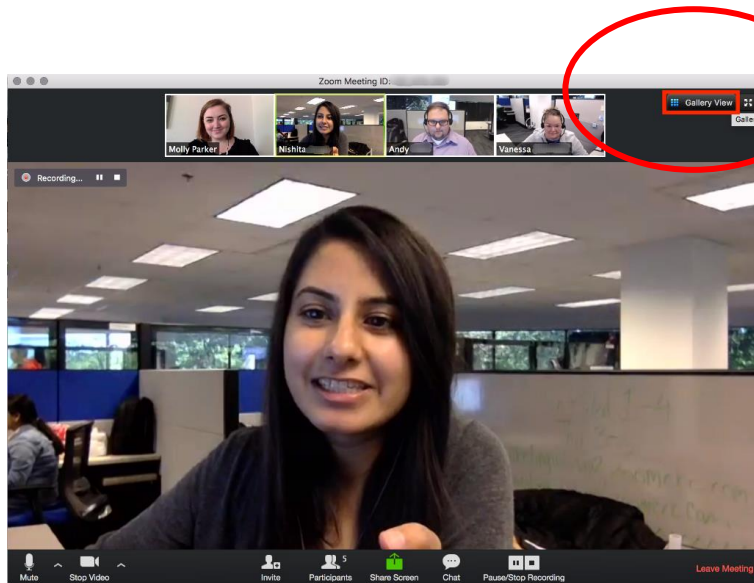
Android



- 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 your view but for this meeting the best view will be Active Speaker.



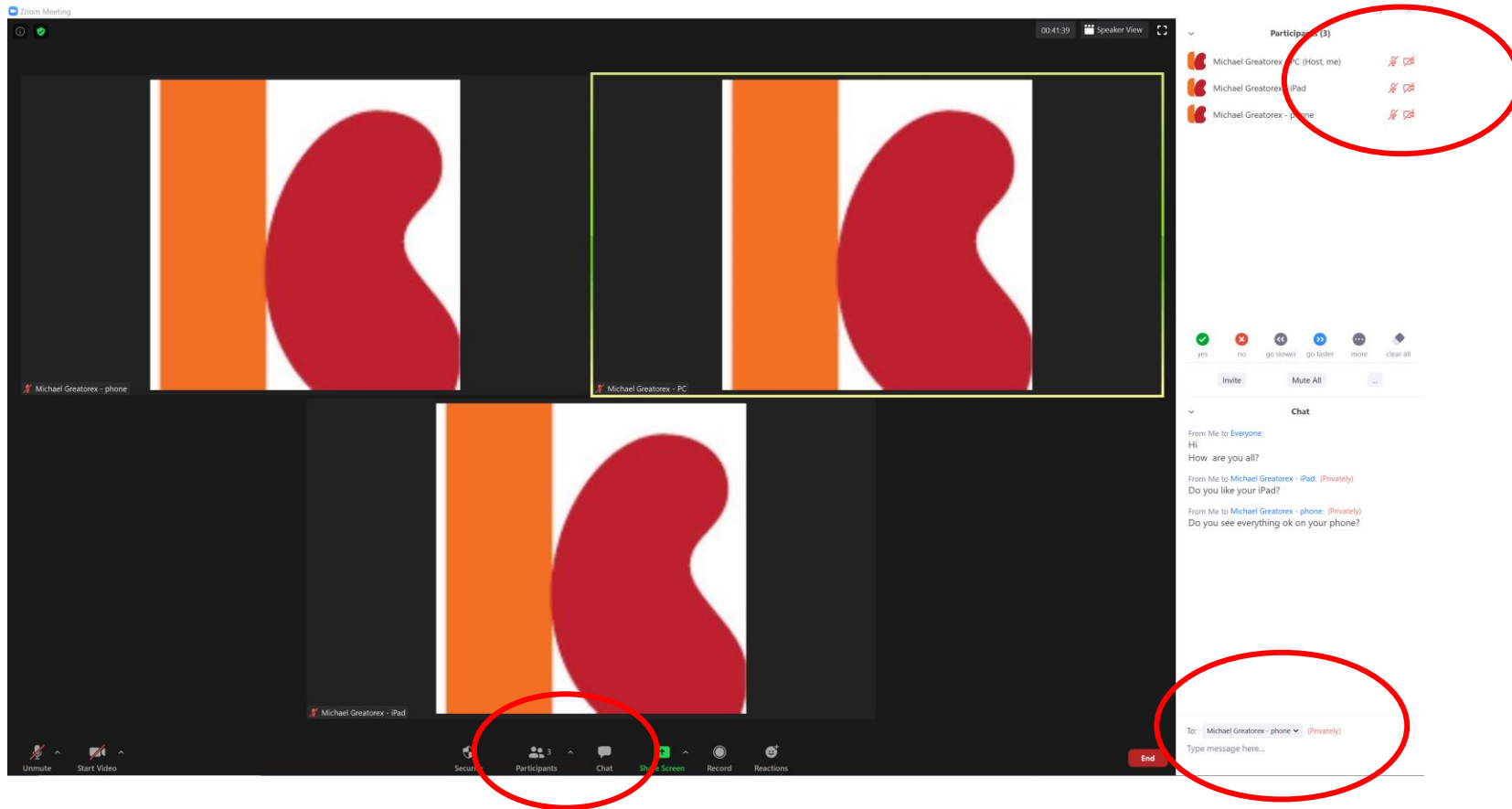
Active Speaker View



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

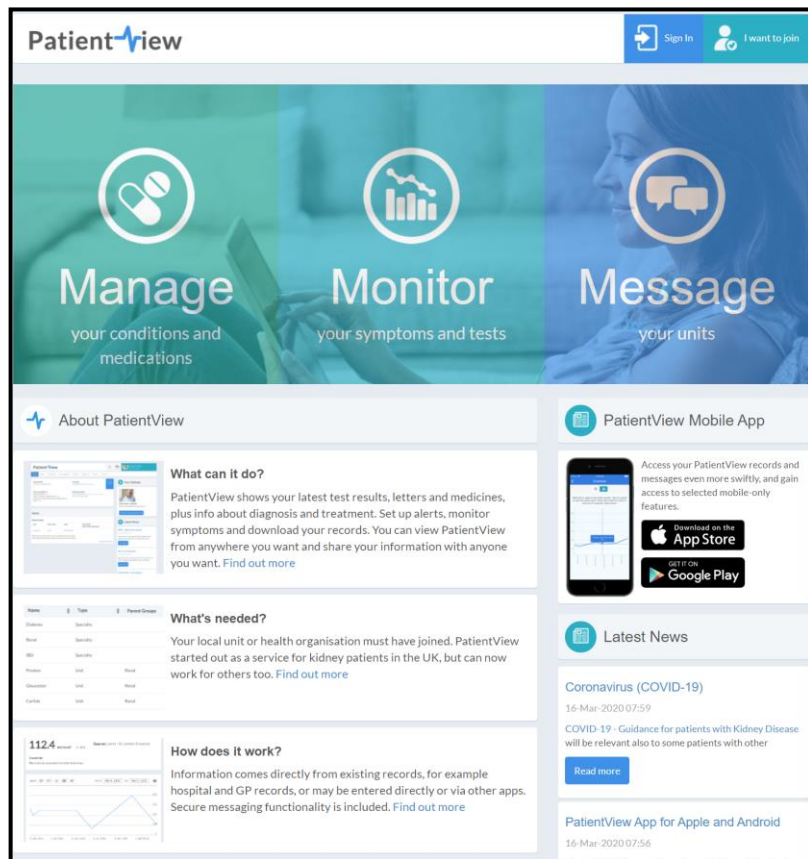
- Please keep your device on MUTE unless you are speaking.
- Avoid talking at the same time as others where possible.
- Remember that some people will be joining by phone so can see anything.
- Please use the raise hand 🖐️ feature (to speak yourself), the chat facility, a text message or email to ask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



PatientView

- Overview of the system
- How as a patient I use it
- Questions

Patientview – Access to your blood results and more – www.patientview.org



What can it do?

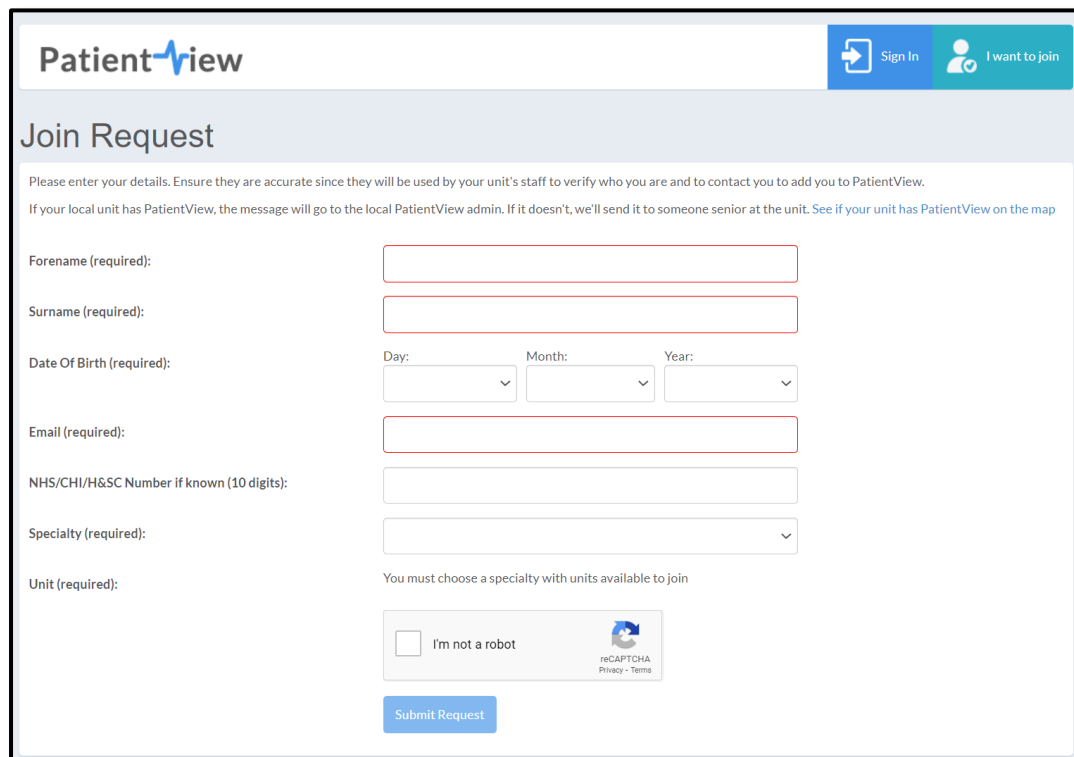
PatientView shows your latest

- Test results,
- Letters (Not St George's) & medicines
- Information about diagnosis & treatment.
- Set up alerts (for new blood results)
- Monitor symptoms
- Download your records.

You can view PatientView from **anywhere** you want including on mobiles and share your information with anyone you want.

Patientview – How to register

(www.patientview.org/#/request)



The screenshot shows the PatientView registration page. At the top, there's a header with the PatientView logo and two buttons: 'Sign In' and 'I want to join'. Below the header is a section titled 'Join Request'. A paragraph of text explains that details entered will be used for verification and contact. Another paragraph states that if the local unit has PatientView, the message will go to the local admin, otherwise to a senior staff member. A link is provided to see if the unit has PatientView on the map. The form fields include: Forename (required), Surname (required), Date Of Birth (required) with Day, Month, and Year dropdowns, Email (required), NHS/CHI/H&SC Number if known (10 digits), Specialty (required) with a dropdown, and Unit (required) with a note to choose a specialty with available units. At the bottom, there's a checkbox for 'I'm not a robot', a reCAPTCHA logo, and a 'Submit Request' button.

PatientView Sign In I want to join

Join Request

Please enter your details. Ensure they are accurate since they will be used by your unit's staff to verify who you are and to contact you to add you to PatientView.

If your local unit has PatientView, the message will go to the local PatientView admin. If it doesn't, we'll send it to someone senior at the unit. [See if your unit has PatientView on the map](#)

Forename (required):

Surname (required):


Date Of Birth (required): Day: Month: Year:

Email (required):

NHS/CHI/H&SC Number if known (10 digits):

Specialty (required):

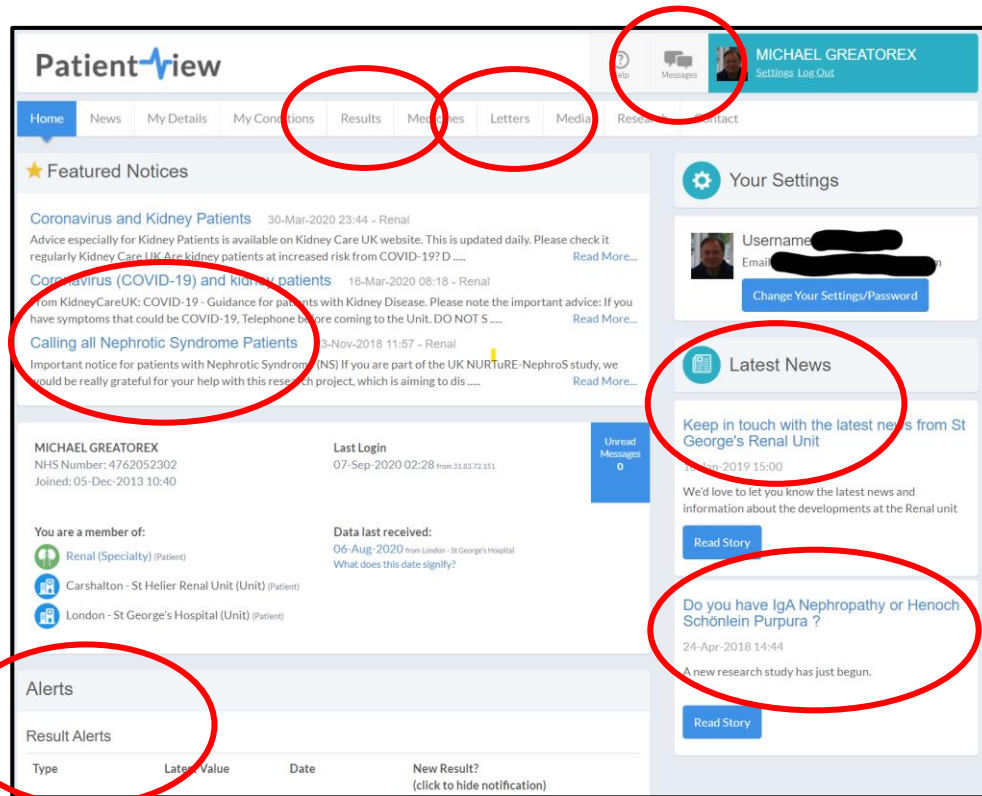
Unit (required): You must choose a specialty with units available to join

☐ I'm not a robot  reCAPTCHA Privacy - Terms

[Submit Request](#)

- Process now simpler & online, just fill in form
- Authorisation should take 24-48 hours
- You have to "Opt-in" and can "Opt-out" at any time
- The service was designed for renal patients but now available to other units.
- It is available to patients, but also relatives, carers and GPs if authorised.

Home page contains notices, news, alerts and links to all other functions



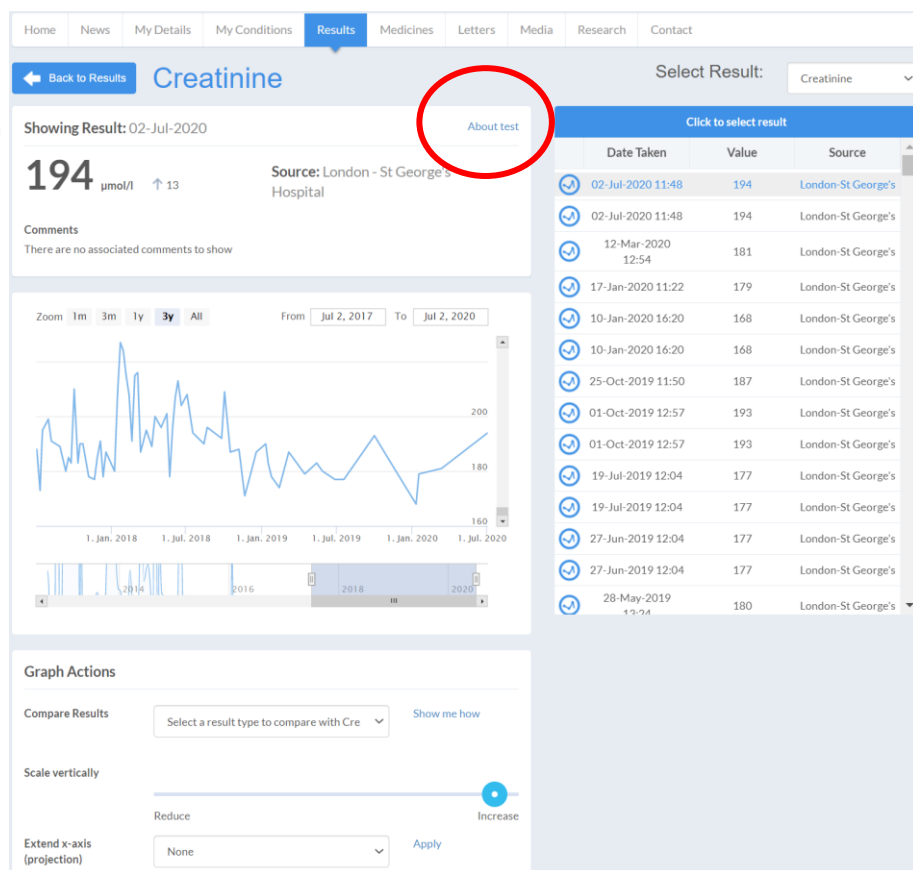
- Results is the key tab
- No "Letters" for St George's
- Alerts - chosen by YOU (at bottom of screen)
- News from St George's on the RHS (right hand side)
- Research project advisories also shown here
- Secure messaging (top of screen)

Patientview – Access your latest & historical blood results, understand & graph them

The screenshot shows the Patientview website interface. At the top, a navigation bar includes links for Home, News, My Details, My Conditions, Results, Medicines, Letters, Media, Research, and Contact. The 'Results' tab is highlighted with a red circle and labeled '5.'. Below the navigation bar, there are buttons for 'Table View', 'Export' (circled in red), 'Diagnostics', and 'Enter Your Own Results' (circled in red and labeled '4.'). The main content area displays a list of test results under the heading 'Showing Panel: Latest'. A 'Latest' tab is selected and labeled '1.'. Below this, there are eight test result cards arranged in a 2x4 grid. Each card shows the test name, a large numerical result, the source (London - St George's Hospital), the showing result date (02-Jul-2020), and a 'View Chart' button. The tests shown are Urea (11.9 mmol/l), Creatinine (194 µmol/l), Ca (2.39 mmol/l), eGFR (<REQ> ml/min/1.73m2), Phos (1.12 mmol/l), AdjCa (2.37 mmol/l), Potassium (4.7 mmol/l), and Hb (139 g/l). The 'View Chart' button for the Creatinine test is circled in red and labeled '2.'. The 'About test' link for the Ca test is circled in red and labeled '3.'. The 'Export' button is circled in red and labeled '5.'. The 'Enter Your Own Results' button is circled in red and labeled '4.'.

1. This tab shows the **latest** results.
2. "View Chart" shows both table of previous results & graphs
3. "About test" describes the test range & more
4. You can enter your own results
5. You can download them too (**Export** a file in CSV format)

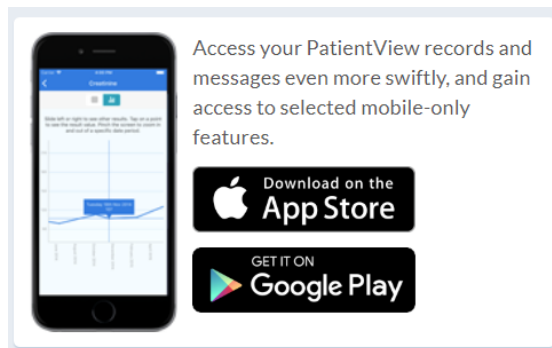
Patientview – Access to your blood results and letters



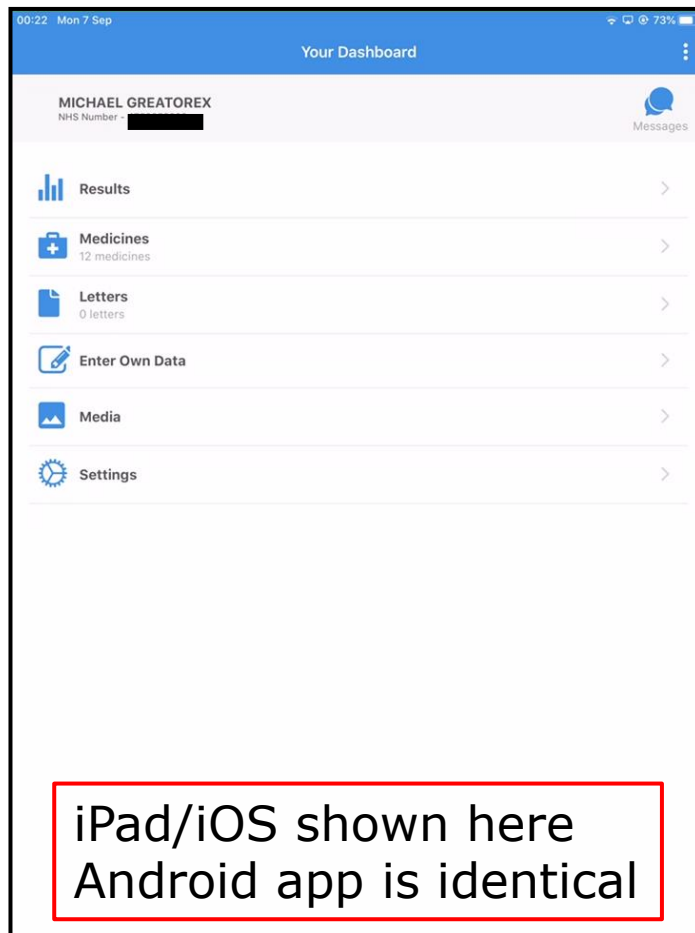
- You can track the progress of a test result over time.
- For example, this graph shows how this person's kidney function has progressed over the last 3 years.
- The about button explains the result and the normal range.
- A user guide with a number of videos is available to help learn what the system can do
<http://help.patientview.org/patientview2/>

Different ways to access PatientView

- You can access PatientView from a web browsers (as shown in the previous pages)
- Or you can download the App from Apple or Google stores.



The PatientView App



- Similar functionality to browser
 - No news, conditions, hospital contacts, research links, home dialysis treatment data upload.
 - But does have **notifications** and media upload.
 - And a different layout of results and more powerful graphing
- Key is results are download to the device and are viewable **offline**.
- It supports biometric logon (fingerprint and retinal)
- More developments coming: e.g. BPM from photo & Nephrotic Syndrome diary.

How to make the most of PatientView - Patient uses

- View specific results – e.g. the next day (depending on cut-off)
- Track your changing condition, such as
 - A specific health issue e.g anaemia
 - An improving/declining transplant function
- Use as a part of taking control of your own health
 - Providing your own measures (weight BPM, glucose, pulse, home dialysis results etc)
 - Informing & preparing yourself prior to clinic appointments
- Sharing information
 - Unify GP & renal unit test results
 - Unifying renal unit information if you move units
 - Show GP your latest results at an appointment
 - Let relative (or GP) see or have access to PatientView & your results



Question & Answer session

- **OBJECTIVE: Answer as many questions that you have about PatientView, diet, clinic & general COVID-19 questions.**
- **Patrick Reynolds – IT Lead, Renal Unit**
- **Helena Jackson – Lead Dietician, Renal Unit**
- **Dr Joyce Popoola – Consultant, Renal Transplantation**

Combined Questions (1/4)

Area	Questions
PatientView	<ul style="list-style-type: none">• Comment - great to have eGFR and other results available usually on the same day as the blood test albeit at 2am. Very helpful although it's frustrating that users cannot enter their diagnosis and following up the abbreviations is a bit cumbersome. Printing out results is useful too when one finds out how to do it.• I am under both Renal and Gastroenterology teams. But I can only access the results for Renal. How can I access the others?• PatientView - how easy is it to export a list of results so they can be sent to doctor if they don't have access to the data. (with minimal manipulation)

Combined Questions (2/4)

Area	Questions
Diet	<ul style="list-style-type: none">Adjusting to, in my case a low Potassium diet, is challenging bearing in mind ones normal diet and preferences. There are a few strange suggestions as to what one can eat on the printout I was given: eg doughnuts and Whatsits! I've found looking up levels for certain fruit and vegetable items on the internet quite helpful but time consuming and hard to compare potassium amounts in say 10gms of one type of fruit relative to another. A list would be most helpful. I've found contradictory advice regarding using ready meals which I do occasionally make use of.I am with my primary care team nearing eighty years of age diagnosed with CKD 3 (to be due for re-monitoring) and age-related macular disease which may be turning from the dry kind into wet AMD. I try to follow the wholefood plant-based nutrient-rich food plan advised by Michael Greger MD (author of How not to Die and How not to Diet with a corresponding free Daily Dozen app supplemented by a blog). I am not on medication apart from Hylo-Tear without preservative for dry eye syndrome.<ol style="list-style-type: none">Is it preferable to use flaxseed oil instead of flaxseeds or, for that matter, to split the daily dose of 1 tbsp of flaxseeds between the seeds and the oil. Flaxseeds are advised for another condition, as are for general health four walnut halves and two Brazil nuts a day.Lycopene, lutein and zeaxanthin are recommended to halt progression of AMD. I prefer food such as kale to supplements but as tomatoes and spinach are somewhat contra-indicated in kidney disease I wonder if it is better to use supplements for these nutrients rather than food.Is there a renal vegan vitamin/mineral combination on the UK market which will be helpful and not detrimental to also retaining my residual eyesight? The US based ones don't seem to be available on the UK market.I hardly eat meat now but do eat high protein yoghurts/nuts in diet. Should I be taking iron supplements? Can iron be low if HB1a1c is ok?Is the clinic continuing to do regular checks on iron and cholesterol levels?

Combined Questions (3/4)

Area	Questions
Clinic & Medical questions	<ul style="list-style-type: none">• Can we have a general Covid update on whatever is happening at St. Georges please. Any new changes to the system/appointments etc• How often should I expect to see a consultant as an AKC patient? Since my first visit to the nurse led AKC clinic almost 2 years ago, I have not seen my consultant, nor a Dr apart from one clinic visit to Queen Mary's hospital. I don't find 2 years acceptable although I have no idea what other patients are. Although my eGFR continues to slowly decline, usually it is considered 'stable'. I have a potential transplant donor and we have both undergone work-up tests, but now due to my age/Covid, I am currently considered 'too high a risk'. All very upsetting and worrying. I'm probably one of the older patients with CKD.• The transplant team are making greater use of email which I applaud, however it is beginning to show a level of disorganisation with information getting forgotten, and questions raised lost in translation. In the last meeting Dr Popoola said the use of email was being reviewed, can the team update us on progress, advise how information shared this way is being monitored to ensure effective replies, and how we as patients are being reviewed given face to face visits and regular blood tests are becoming less and less likely?• Just like to know when I can expect a copy of my blood tests. They were done at Queen Mary's hospital on the 7th of August. As I've been in for over a month and been in hospital both my GP and I would like to see the blood tests. Also I had an telephone appointment with Dr Popoola but waited all day but no call. Is this what happens now?• It would be good to still keep a telephone appointment, even though we will not be seeing the consultants face to face for now. Could we have a phone conversation set up to replace the face to face please? Bloods may look fine, but it would be reassuring to have that scheduled meeting in place for any other questions that may be linked, and for reassurance.

Combined Questions (4/4)

Area	Questions
Clinic & Medical questions (continued)	<ul style="list-style-type: none">• Do foods such as Soya or hormone treatments (for example HRT) affect progression of kidney cysts?• I have read that people at higher-risk from coronavirus - presumably including renal patients - might be some of the first to be offered a vaccine, if and when one becomes available. Do we know if it is being tested on any renal or immunosuppressed patients in the current trials or if there are any plans to do this?• Some of us want to visit relatives we haven't seen since before lockdown, or start new relationships: what's the advice on displays of affection such as hugging?• Do you have tips on how to maintain both physical and mental good health in the coming winter months.• Again on the colder, wetter months, how to safely meet with immediate family when garden meetings are not practical!• Does the clinical team have any advice, over and above national guidelines, to help kidney patients decide whether (or not) to travel by public transport?• Why does Colliers Wood have no sheets and pillow case and patients have to lie on damp plastic?



Feedback survey

- This should take you approximately 1 -2 minutes 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!

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