



## **'Worried sick' – the impact of COVID-19 on people living with kidney disease in Wales: Findings from a patient survey**

### **Background**

The COVID-19 pandemic has had a profound impact for people living with kidney disease. During the pandemic Kidney Care UK, Kidney Wales, Paul Popham Fund, Renal Support Wales have been working with the Welsh Clinical Renal Network and Wales Kidney Research Unit to produce a newsletter to provide patients with up to date information on the guidelines and services available to them. Following on from the Kidney Care UK, Worried Sick patient survey that was carried out across the whole of the UK the team were keen to carry out a Welsh specific patient survey.

All three charities have had to adapt their services during this time and have seen a huge increase in the requests from kidney patients and their families, illustrating the challenges they face and their urgent need for information, advice and support. At the very beginning of the pandemic there was a lot of confusion over shielding advice, initially only a minority of people with kidney disease in Wales were classed as extremely vulnerable by the government despite their renal teams believing different. This meant that many struggled initially to gain access to much needed services. The three charities in Wales worked together to campaign to the Welsh Government. This resulted in a change in those being identified as extremely vulnerable, meaning most people with kidney disease at stage 5 plus should then have been able to access services and support.

There are about 10,000 people with CKD in Wales in the extremely vulnerable shielding group including those with transplants, those on dialysis and those with specific types of kidney disease requiring immunosuppressants. People on dialysis are at particular risk as they must go to hospital for their life-maintaining treatment three times a week. We set up an online survey to better understand the concerns, anxieties and unmet needs of people living with kidney disease.

The survey demonstrates that a quarter of patients reported disruption to their care, including surgery or appointments being cancelled, or inability to have blood tests or check-ups and three quarters of patients reporting that their mental health has been affected.

We greatly appreciate the care the NHS has given to kidney patients during the pandemic, but it is essential that the Government, NHS and other key organisations such as local authorities and supermarkets learn now from the experience of the first pandemic wave, to improve resilience and communications for the future, whether or not there is a second wave of COVID-19.



**Kidney Care UK, Kidney Wales, Paul Popham Fund Renal Support Wales is calling for:**

1. Government to set out an evidenced plan for the future, which reassures kidney patients that they have not been forgotten, assures them that healthcare services are safe, and gives those who need to continue to self-isolate as lockdown eases for the rest of the population hope of a way back to some kind of normality over time.
2. Kidney patients to be prioritised and given personalised advice as the NHS works to return services to pre COVID operation, ensuring all patients with CKD, including those who are at risk of progressing, are contacted to check and monitor their condition and offer them support, including transplantation, to help them delay further, potentially serious, deterioration in kidney function.
3. A clear plan to provide kidney patients with mental health support and an acknowledgement from Government, of the need to address this urgently.
4. Government commitment to provide simple, direct, accurate and timely communications to patients and the charities that support them, now more than ever.
5. Systems to be improved so that all kidney patients receive accurate written guidance from Government and the NHS to enable them to protect themselves and access critical services.
6. Improvements to the Government portal, other online systems and non-digital systems to ensure that all patients are able to access healthcare and essential supplies, such as food and medicines, and financial support, in the event of a local lockdown or when they need to self-isolate .

**Methodology**

The online survey was open from 13<sup>th</sup> July to 7<sup>th</sup> August 2020. It was advertised on Kidney Care UK, Kidney Wales and Paul Popham Fund, Renal Support Wales social and media networks. The full list of questions is included in the appendix. The majority of respondents were female 67% and 33% male, live in South West Wales (Swansea Bay University Health Board) 35%, live in Mid to South East Wales (Cardiff & Vale Health Board) 40%, live in North Wales (Betsi Cadwaladr Health Board) 24%, aged 0-15 7%, 16 to 30 15%, 31 to 60 63%, 61+ 15%, the majority were transplant recipients 53%, 32% CKD stage 5, 11% CKD stage 3-4 2% AKI, 2% stated other and White British 100%. More demographic detail is available in the appendix.



## Key Findings

### **1. Nearly half of Patients did not feel confident to shield to the expected level**

While the majority felt confident to shield to the expected level (59%), 41% still were not fully confident to shield to the expected level.

There are over 1300 people with kidney disease dialysing in hospital or a clinical centre. At the start of lockdown and the shielding journey it was very difficult to get PPE for clinical teams and patients. During this period there was a lot of confusion around whether people on dialysis should have been shielding and whether patients should wear a mask or not while dialysing, with some being told they could not eat during dialysis treatments. This was quickly rectified. With a lot of confusing messages, PPE not readily available, anxiety about going to appointments, it is not surprising 41% of respondents were not fully confident to shield to the expected level.

- 13% of respondents were dialysing in hospital or unit based, of which:
  - 37% fairly confident to shield to the expected level
  - 5% not feeling confident at all to shield to the expected level.

### **2. Nearly half found it difficult to access government support**

While 38% found government support helpful and easy to access 48% found it difficult to access with 28% finding it very unhelpful.

As mentioned above, there was a lot of confusion initially whether dialysis patients should be shielding or not. Kidney Care UK, Kidney Wales and the Paul Popham Fund campaigned for this to be turned around. When Welsh Government confirmed that people with kidney disease (CKD stage 5) were classed as extremely vulnerable the process of informing those patients was not straight forward. Renal Hospital Teams were tasked with informing the patients GP's who to send shielding letters to.

- 27% of respondents were informed by their GP to shield, of which:
  - 16% received a letter
  - 11% informed verbally

Some hospital teams also choose to inform patients themselves to ensure their patients received their letter:

- 13% received a letter from their hospital teams.

5% of respondents were not told to shield and 3% said they had received conflicting advice – this is not surprising.

As well as the confusion over who was classed as extremely vulnerable and how and when they would receive their shielding letter it was then difficult to access services. Shielding patients had to contact their local council to access services, each council had a different process.

- 20% found local government helpful but difficult to access
- 15% not helpful but easy to access



- 13% not helpful and difficult to access and
- 15% were not able to access government support at all.

This is concerning when over half of respondents wanted and still want support with food and medical deliveries.

- 31% need help with food deliveries
- 28% with medical deliveries
- 15% need help with emotional support
- 10% found it difficult to access PPE
- 5% need financial and transport support

As a result of these difficulties nearly a quarter found it difficult getting food delivered to them. 22% found it difficult to get food delivered - Out of the 22% some may not have had the support of family and friends and some units said they helped patients order food as they were unsure how to order on-line and/or book priority slots.

Kidney Care UK, Kidney Wales and the Paul Popham Fund are working together to supply units with devices and user guides so that patients can access on-line services.

This would have been easier if they knew that there were services out there to support them however over a half did not know there were volunteering services out there to help them or that they were eligible or how to contact them:

- 33% did not know there were services out there to help them
- 22% did not know they were eligible
- 22% did not know how to contact them

### 3. **Three quarters of patients felt lonely / anxious or isolated**

Nearly half had serious concerns how lonely anxious or isolated they felt – 43%

While under a quarter said they did not have serious concerns there were still over a quarter who had some concerns.

A diagnosis of chronic kidney disease (CKD) can be devastating, for patients and their loved one, affecting mental as well as physical health. The COVID-19 pandemic has magnified this, and patients are understandably anxious about many different issues, from their risk of contracting COVID-19, to what they or their families need to do to shield, to their risk if they have to attend hospital for necessary treatment, to how they will access support. As time goes on, patients have more questions and worries for the future, both the impact for them and for loved ones:

Over a quarter were fairly or seriously concerned that a household has had to continue going out to work. Even though patients were shielding 28% were fairly to seriously concerned that a family member had to go to work to avoid losing their income. Worries about family members returning to school or work once lockdown had finished was a common theme, with people worried about whether they could continue to successfully shield as lockdown was eased further and people are expected to return to work or education.



4. **Nearly a quarter struggled financially**

24% seriously struggled financially

This is not surprising when most people with kidney disease had to shield. With employers also struggling during this time, having to decide whether to furlough staff or not. If patients were lucky, they would have been asked to work from home and if well enough this would be the perfect solution. It is unknown how many patients were working at the time, how many were furloughed or made redundant or whether their employers collapsed during the pandemic. It is also unknown how many patients are not working. What we do know is that calls to all charities to discuss PIP and gain advice on employment increased.

- 6% reported that they took leave / time off from work
- 4% were unable to take leave / time off from work

5. **A quarter had their treatment affected by Coronavirus**

25% had surgery or an appointment cancelled. With a further 25% either not being able to have check-ups and blood tests or found it more difficult to get advice about health worries from their GP or hospital team.

1,000 people reach kidney failure every year and regular monitoring of people with kidney disease is essential. This can help delay progression of the disease and potentially the need for burdensome and expensive dialysis. Many kidney patients in the moderate to advanced stages of kidney disease will have had monitoring appointments cancelled during the COVID-19 outbreak. There are serious implications of failing to spot major progression in kidney disease to both the individual and NHS services.

It is not surprising that just under a quarter felt anxious that appointments were cancelled 20% felt fairly serious or seriously anxious or unwell due to cancelled / postponed / delayed treatments

6. **100% of patients wanted up to date advice on Covid-19 and shielding**

- 67% on Covid-19
- 33% on Shielding



Appendix 1:

## Full list of survey questions

### Demographic questions

1. How old are you?  
0 - 15 / 16 - 30 / 31 - 45 / 46 - 60 / 61 - 75 / 75+
  
2. What is your gender?  
Male / Female / Non-binary / Other / Prefer not to say
  
3. 3. Where do you live?
  - Blaenau Gwent
  - Bridgend
  - Caerphilly
  - Cardiff
  - Carmarthenshire
  - Ceredigion
  - Conwy
  - Denbighshire
  - Flintshire
  - Gwynedd
  - Isle of Anglesey
  - Merthyr Tydfil
  - Monmouthshire
  - Neath Port Talbot
  - Newport
  - Pembrokeshire
  - Powys
  - Rhondda Cynon Taf
  - Swansea
  - Torfaen
  - Vale of Glamorgan
  - Wrexham
  
4. Which race / ethnicity best describes you?
  - White/ White British
  - Black / African / Caribbean / Black British
  - Asian / Asian British
  - Mixed / Multiple ethnic groups
  - Prefer not to say
  - Other



5. What is your kidney condition/treatment?

Please tick all that apply

- Chronic Kidney Disease stage 3-4
- Chronic Kidney Disease stage 5
- Acute kidney injury (AKI)
- Kidney Cancer
- Dialysis at a unit or hospital
- Home Haemodialysis
- Peritoneal Dialysis
- Transplant

**Coronavirus support questions**

1. Have you been told that you should shield by any of the following \*tick all that apply\*?

- An official Government letter
- A text message from the Government
- A letter from your GP
- A letter from your hospital team
- I have been told verbally by my GP or hospital doctor
- I have not been told to shield
- I have received conflicting advice

2. Have you changed your lifestyle in order to shield to the recommended level by any of the following methods: (options will be yes / no / not applicable)?

- Staying at home
- Taking leave / time off from work
- Working from home
- Having food and medical supplies delivered
- Family members co-isolating
- Using personal protective equipment (PPE) when attending appointments (e.g. facemasks / gloves)

3. How confident are you that you are able to shield to the recommended level?

Very confident / Fairly confident / Not at all confident

4. Have you attempted to / signed up to receive additional support from the Government?

For example, with shopping and prescription delivery?

- Yes, I've signed up
- I've tried to sign up but have not been able to
- No, I haven't signed up because I don't need the support
- No, I haven't signed up because I'm not eligible for support because I'm not shielding
- I didn't know I could sign up
- I'm not sure



5. What has your experience been of the Government's additional support?
- Very helpful and easy to access
  - Very helpful but difficult to access
  - Not helpful but easy to access
  - Not helpful and difficult to access
  - I was unable to access the Government's additional support
6. What support did you/do you want help with?
- Food deliveries
  - Medication delivery
  - Transport to dialysis or other hospital appointments
  - Access to personal protective equipment for dialysis appointments (e.g. facemasks / gloves)
  - Financial support
  - Emotional or mental health support
  - Other (please specify)
6. Would you like to make any further comments on your experience of the Government's additional support?
7. Have you had difficulty getting food delivered to you?
- Yes Page
  - No
  - No, because I do not need to shield and can go to the shops
  - No, because I have a family member to go to the shop for me
  - No, because I have a priority access delivery slot from a supermarket
  - No, because a voluntary organisation is helping me with shopping
  - Have you contacted a volunteer organisation to help with food deliveries?
  - Yes, and they have been able to help
  - Yes, but they've not been able to help
  - No, I didn't know about them
  - No, I didn't think I'd be eligible
  - No, I didn't know how to contact them
  - No, I didn't know they could help with shopping
  - No, I prefer to do my own shopping
8. Which volunteer organisation did you contact?
- NHS Volunteers
  - COVID mutual aid
  - A local voluntary group
  - Other



9. Has coronavirus affected the treatment and support you receive from the NHS? \*tick all that apply\*

- I have had surgery or other appointments cancelled
- My dialysis programme has been altered / reduced
- I have found it difficult to get to my dialysis appointments
- I have not been able to have blood tests or check ups
- It has been more difficult to get advice about any health worries from my GP or hospital team
- It has not impacted the treatment I receive
- I have not been able to have a transplant
- Other

10. What have been the other impacts of coronavirus? \*please circle 1 – 5, where 1 means this has not affected me and 5 means this has been a very serious concern\*

- I feel anxious / lonely / isolated
- A member of my household has had to continue going out to work, even though I am shielding, to avoid losing their income
- I have struggled to get food
- I have struggled to get medicine delivered
- I feel anxious or unwell due to cancelled / postponed / delayed treatment
- I've struggled financially
- Other

11. Do you think you've had coronavirus symptoms?

- Yes, and I've been tested
- Yes, but I've not been tested
- No, I haven't had symptoms
- Not sure

### Charity Support Questions

1. Have you referred to Kidney Care UK information on COVID-19?
  - a. Yes, via website guidance
  - b. Yes, via telephone
  - c. No, I have not needed it
  - d. No, I did not know it was available
2. Have you found Kidney Care UK information helpful?  
Scale of very unhelpful – very helpful (1 to 5 stars)



3. What more information would you like from Kidney Care UK?
  - a. Mental health support
  - b. Dietary advice
  - c. Exercise support
  - d. Details of how to contact support services
  - e. Signpost to sources of further information (e.g. money advice service or Government support)
4. Have you accessed any of the following services provided by the Paul Popham Fund, Renal Support Wales?
  - a. Yes, I have contacted their telephone support service – Careline
  - b. Yes, I have accessed one of their Kidney Café Support Groups on-line
  - c. Yes, I have attended a virtual Kidney Café Support Group Meeting
  - d. Yes, I have accessed their Counselling Service
  - e. Yes, I have accessed their Peer Support Service and spoke to a Peer Mentor
  - f. No, I have not needed it
  - g. No, I did not know it was available
5. What support did you need?
  - a. Latest advice on COVID-19
  - b. Guidance on Shielding
  - c. Emotional or mental health support
  - d. Financial support
  - e. Medical assistance
  - f. To talk to a supportive voice
  - g. Other (please specify)
6. Did you find the support you received from Paul Popham Fund, Renal Support Wales, helpful?  
Scale of very unhelpful – very helpful (1 to 5 stars)
7. Have you accessed information and support from Kidney Wales? Please tick all that apply
  - a. Yes, via telephone
  - b. Yes, via email
  - c. Yes, via website
  - d. Yes, via social media (including the Kidney Wales Facebook Group)
  - e. Yes, by participating in Facebook Live Q&A sessions
  - f. No, I have not needed it
  - g. No, I did not know it was available
8. Did you find the support you received from Kidney Wales helpful?  
Scale of very unhelpful – very helpful (1 to 5 stars)
9. Have you received and read the Collaborative Newsletter produced by Kidney Care UK, Kidney Wales, Paul Popham Fund and the Welsh Clinical Renal Network – COVID-19 Update?
  - a. Yes, I have read all issues
  - b. Yes, I have read issue one
  - c. Yes, I have read issue two
  - d. Yes, I have read issue 3
  - e. Yes, I have read issue 4
  - f. No, I did not know it was available
  - g. No, I did not need advice or support



10. Did you find the Newsletter Helpful?

Scale of very unhelpful – very helpful (1 to 5 stars)

11. What information would you like to see in the Newsletter?

- a. Mental health support
- b. Dietary advice
- c. Exercise support
- d. Details of how to contact support service
- e. Signpost to sources of further information (e.g. money advice service or Government support)
- f. Patient stories
- g. Other (please specify)

12. Would you like the Newsletter to continue after the Covid-19 pandemic?

Yes / No / I am not sure