‘EXCEPTIONAL TIMES’

The Coronavirus Pandemic and the Renal Association – 2020

The First Hundred Days

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Introduction

The coronavirus (COVID-19) pandemic provoked an unprecedented and rapid reshaping of all health and social care in the UK (and of course worldwide). The pandemic has been widely discussed and the way it has been dealt with in the UK will continue to be scrutinised.

The specific aim of this narrative is to review and evaluate the early response of the UK kidney care community to the pandemic, and in particular the role played by the Renal Association (RA).

There is a wider context which is well beyond the scope of this commentary. The whole NHS response to the COVID-19 pandemic in the first half of 2020 was framed by 'once in a generation' circumstances. There was an outpouring of respect from public and politicians alike for the remarkable work being done by the NHS. There was recognition that all people were still receiving extraordinary care from the NHS despite the pressures of the pandemic. This meant a refreshing lack of criticism of the NHS, and a lack of unreasonable expectation. There also emerged a very different planning environment in which requests for service redesign were no longer met by demands for voluminous business plans against the expectation that decisions would be slow, and funds would quite probably be insufficient. For a period of time whatever innovative and effective changes were required were encouraged, with the presumption that resources would be made available.

It proved to be an extraordinary time of change, which required unprecedented and rapid changes in the UK's model of kidney care. Changes which were nationally led, but locally coordinated and delivered. Whether unique or a foretaste for future crises, it certainly opened an opportunity for lasting changes in the delivery of kidney care in the UK which if grasped could be for the long term benefit of patient, carers and healthcare professionals.

This narrative was commissioned and completed 'in the heat of battle' in June 2020, when there was 'real and present danger' for renal healthcare workers, and for those with new and established kidney disease whose care became bound up in a maelstrom of change and challenge. Later reflection will undoubtedly refine our view of the lessons and opportunities which have emerged, and how they have been grasped. But it is presented here unedited,

as written in June 2020, without the false wisdom of hindsight. Here is a description of what happened, a timeline of when things happened, and contemporary opinion on why and how things happened.

As RA archivist and a retired nephrologist I had time to observe things dispassionately, free from the heavy burdens of clinical care and professional leadership which were carried by the key figures in this narrative. I have discussed with a number of those leaders in order to be sure I am correctly reflecting facts and dates, and also to get some sense of how it has felt to be involved at the centre of this remarkable upheaval. Nevertheless this narrative and the judgments within it are entirely mine, and I apologise for any inaccuracies or solecisms.

Timeline

A cluster of viral pneumonia cases of unknown cause in Wuhan was reported at the end of December 2019 to the WHO by health authorities in China. This was identified as a novel coronavirus infection, soon styled COVID-19. WHO declared the outbreak as a Public Health Emergency of International Concern on 30 January 2020, and then as a Pandemic on 11 March 2020.

When concerns about COVID-19 were focused in Wuhan, China the likely course of events in the UK remained uncertain. Once the epidemic had reached Western Europe (with its first epicentre in Lombardy, Italy[1]) it was clear to RA leaders that a substantial COVID-19 epidemic was unavoidable in the UK with very major implications for the clinical work of the UK kidney care community.

The first UK death attributed to COVID-19 infection was on 7 March 2020, which I have arbitrarily fixed as Day 0 to track the pace of work in the subsequent weeks, which is shown in a timeline in Appendix 1.

This narrative covers a period of one hundred days: from day -14 (21st February 2020) to day 86 (1st June 2020). During the first phase (80 days or so) the RA response to the COVID-19 pandemic was intense and transformative, taking place in an unprecedented NHS environment of risk and change, new problems arising almost daily.

[1] The first case was reported in Lombardy on 31 January 2020, and the first death on 22 February 2020.

In a second phase (20 days or so) the work remained intense and demanding, but the pressing innovations had been made and patterns of work established.

This narrative has been signed off on day 86, and will not be re-edited with the aid of the retrospectoscope.

Organising the Renal Association Response

The RA President (Graham Lipkin) recalls his first discussion with RA Clinical Vice President (Paul Cockwell) on day -14 (21 February). From that discussion there rapidly developed a deep and broad RA response to the pandemic and its implications for kidney care. It was immediately clear that a response involving the whole kidney community was required. The approach of these RA leaders was inclusive, involving the other organisations representing both professionals and patients in the kidney community – including British Renal Society (BRS), Kidney Care UK, the National Kidney Federation (NKF), and Kidney Research UK. From the start RA assumed the overall leadership role with the agreement of the other organisations. Fortunately Lipkin, Cockwell, and Indranil Dasgupta (RA Secretary) all worked in the same city, indeed the same trust[2], facilitating the very frequent exchanges between them which were needed as the scale of the challenge emerged.

Other RA leaders playing key roles included Katie Vinen (King's) (chair, Clinical Services Committee) and James Medcalf (Leicester) (medical director, UK Renal Registry (UKRR)). Many, many more played their leadership part – both within RA and locally, where renal unit clinical directors in particular had demanding responsibilities. It would be impossible to name all such individuals in this narrative and invidious to identify some but not others. I have therefore chosen to name only a very small number in senior leadership positions. But the contribution of all RA members in their varied roles has been crucial and is highly respected.

The highly committed professional staff of RA and UKRR also played a crucial role. Ron Cullen, the CEO, bringing to bear his considerable experience of senior NHS management.

[2] Lipkin and Cockwell at Queen Elizabeth Hospital, Dasgupta at Heartlands Hospital; both part of University Hospitals Birmingham NHS Foundation Trust. Murmurings in less anxious times that the RA leadership might have become too 'Birmingham-centric' now seemed irrelevant.

A COVID-19 Renal Guidance Group was quickly established chaired by the RA Clinical Vice-President. It included representatives of all organisations in the kidney community[3]. Terms of reference were agreed. There were weekly conference calls of the group also attended by a number of renal unit clinical directors. These calls, sometimes with up to forty attendees required skilled chairing to deliver effective communication and decision making.

Communications

A strategic plan of this range and complexity, in which most elements of the landscape were changing, required an effective communications strategy, which was led by the RA Secretary. The basis for good communications was the effectiveness of the COVID-19 Renal Guidance Group in disseminating information and plans to all the represented organisations. In particular the work of NKF and Kidney Care UK was important in ensuring that prompt accessible information reached patients. Important advice and guidance was posted on the RA website, with e-blasts to the membership. An e-mail address, COVID-19@renal.org was established as a portal for questions and concerns, and for sharing relevant documents. Messages reaching COVID-19@renal.org which required responses were directed to the appropriate leader on a daily basis by the RA secretariat.

Information for patients was mostly written by RA members, and appropriate language then assured by review provided by Kidney Care UK. There were soon 45 pieces of information posted covering the implications of COVD-19 for the whole range of kidney patients. They were much valued - thousands of hits soon accumulated.

Early identification of the major issues

A rapid review of the scope of the problem led to guidance for RA members and the community published on Day 4[4] (Appendix 2). This offered information, advice, and the promise of continuing national advocacy. The increased risks of viral infection and AKI in

[3] As well as RA, BRS, NKF, KCUK, this also included representatives of BRS affiliates (including Association of Renal Technicians, Renal Pharmacy Group, Renal Nutrition Specialist Group), and NHS England Clinical Reference Group (CRG) for kidney care

[4] COVID-19: challenges for renal services https://renal.org/covid-19/ra-resources-renal-professionals/covid-19-challenges-renal-services/

those with pre-existing CKD disease was first described[5], and then the review concentrated on expected challenges to service delivery. It anticipated very heavy clinical load due to the pandemic which seemed likely to overwhelm existing critical care and acute medical services. It anticipated tensions between these demands and the need for renal units to provide continuing care to many, including those from wider geographical areas than the local communities served by their hospitals. COVID-19 patients not requiring critical care would need to be cohorted in areas with resources for dialysis. Care delivery would be challenged by staff infection rates and continuation of home dialysis by carer illness. Transplantation and face to face outpatient activity should be suspended. But it was in-centre HD which provided the greatest clinical and logistical challenges – including unavoidable exposure of staff to infected patients who need regular treatment leading to staff shortages, difficulty cohorting infected patients when attending for dialysis, risks to supplies, and to hospital transport.
This guidance, and perhaps most importantly the comprehensive and practical check list which accompanied it[6] provided the basis for local planning and care delivery.

Patterns of work changed substantially for almost all clinician RA members. Many consultants and SpRs were reassigned to the acute general medical service, and familiar long daily hours were replaced by shift patterns, for example 12 hours on, 12 hours off; 4 days on, 4 days off. SpRs out of programme doing research were all recalled to clinical work. These became uncertain times for trainees, and to mitigate some of their concerns the chair of the RA SpR Club was sensibly made a regular member of COVD-19 Renal Guidance Group.

The challenge of in-centre HD

Recognition of the unique challenges of providing in-centre HD during the pandemic led to further recommendations for renal clinical directors from the COVID-19 Renal Guidance

[5] Based on the best available international review of COVID-19 and kidney: Naicker S et al. The Novel Coronavirus 2019 epidemic and kidneys. Kidney Int 2020; 97: 824

[6] Checklist for renal services in respect of the COVID-19 pandemic. https://renal.org/covid-19/ra-resources-renal-professionals/checklist-renal-services-respect-covid-19-pandemic/

Group published on day 11[7](Appendix 2), which itemised practical steps needed to secure the care of HD patients by mitigating risks to transport and staffing, rapid screening of suspected COVID-19 cases, providing cohorted dialysis facilities to separate those who became COVID-19 positive, and securing arrangements for in-patient care and transfer of HD patients admitted urgently elsewhere.

The day 11 recommendations also confirmed that a regional infrastructure within NHS England was being established to support renal services, ensuring that trusts with renal services in a region would have to work closely together in this period to deliver the service change required.

The Challenge of AKI

The high incidence of AKI in those with severe COVID-19 infection rapidly became apparent. Although not identified in early reports from Wuhan, data from Italy and early UK experience identified by ICNARC[8] indicated that 25-30% of ventilated patients developed AKI requiring renal replacement therapy[9]. RA and the Intensive Care Society worked closely and openly throughout to help address the many implications of this. Work with the Head of Specialist Commissioning for NHS England resulted in guidance[10] published on day 39.

From the time the AKI issue was appreciated the RA President initiated discussions with the Intensive Care Society and the National Clinical Director for Critical Care; discussions which were consistently collegial and effective. Intensive care units were finding their staffing increasingly stretched. Established patterns of recent years in which AKI in the critical care setting was managed almost exclusively by intensivists and their teams with little nephrology input were becoming unsustainable. One aspect of the problem was mitigated

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[7] Recommendations to all renal clinical directors (on chronic dialysis) https://renal.org/recommendations-renal-clinical-directors/

[8] ICNARC, Intensive Care Audit & Research Centre

[9] This incidence changed little as more extensive data were reported by ICNARC

[10] NHS England specialty guides: Clinical guide for renal replacement therapy options in critical care during the coronavirus pandemic. https://www.england.nhs.uk/coronavirus/publication/specialty-guides/

by considerable numbers of nephrologists received rapid training in ventilator skills and worked as intensivists throughout the crisis.

Major concerns soon grew about lack of machines to deliver continuous extracorporeal RRT in the ICU setting, and lack of consumables including lines, filters and filtration fluid[11]). Urgent discussions involving the RA President, intensive care leaders, the Head of NHS Specialised commissioning for England and NHS Procurement made clear that available CVVH machines fell far short of the number required to meet expected demand, nor could the existing supply chain be ramped up to meet that demand. The Renal Pharmacy Group worked hard on novel approaches to filtration fluid production, although ultimately their proposals could not meet MHRA[12] requirements. There was a return to the use of intermittent HD in ICUs, renal unit technicians (supported by the Association of Renal Technologists) worked rapidly to establish reverse osmosis capacity in critical care units. Intermittent HD was soon providing 20% of all critical care RRT.

Another option, for many years little used in the UK for AKI in adults, was peritoneal dialysis (PD). King's College Hospital, London – among those meeting the heaviest COVID-19 burden – was one hospital where extracorporeal RRT capacity was exhausted, and deployment of acute PD became a necessity in ICU. Concerns that prone management for respiratory support would be a major barrier for PD compromising catheter usage with leakage and drainage problems did not materialise. King's Kidney Care rapidly produced a clinical protocol to support acute PD.[13]

A further issue reflected the growing demand for ICU beds as COVID-19 case numbers rapidly grew. ICUs understandably sought to focus their efforts on those with greatest chance of recovery, eschewing admission of those with significant comorbidities. There were occasional reports that otherwise fit ESKD patients were being denied ICU admission

[11] Not only were filters and line in short supply, their useful longevity was being compromised by the prothrombotic effects of COVID-19, despite assiduous attention to anticoagulant protocols.
[12] MHRA, Medicines & Healthcare products Regulatory Agency
[13] KCH Renal Covid Acute PD on ICU Protocol. Elaine Bowes, Hugh Cairns, Clare Sharpe for King's Kidney Care. https://renal.org/wp-content/uploads/2020/04/KCH-Renal-Covid-Acute-PD-on-ICU-protocol-final.pdf

(a strategy for which there was no good evidence); an issue addressed in a message to RA members from the President on day 36 [14] (Appendix 2).

Kidney transplantation

RA had early discussions with NHS Blood & Transplant (NHSBT)[15] proposing the need for a policy statement, as soon as it became clear that kidney transplant would effectively cease during the severest part of the pandemic. Among several factors were the inevitable reduction in deceased donors as ICUs were overwhelmed, concerns about virus transmission with donated organs, risk of virus infection in more heavily immunosuppressed patients early after transplant, and the 'crowding out' of renal surgery by other clinical priorities.

Guidance on the management of transplant recipients with suspected or proven COVID-19 infections was published jointly on day 18 by RA and British Transplantation Society (BTS)[16] with an update on day 49.

Recommendations for those who are immunosuppressed

Advice on risk stratification for both transplant and non-transplant patients receiving immunosuppression was led by the Royal College of Physicians (RCP) and, to ensure consistency, was coordinated with the various specialist societies whose members care for patients with autoimmune disease. A small RA working group of adult and paediatric nephrologists contributed. It was published on day 16 (the day robust 'lockdown' was established in the UK)[17] . More detailed advice for kidney patients followed on day 20 with

[14] Urgent patient issues: patient shielding, AKI & equitable access to ITU. https://renal.org/urgent-patient-issues-patient-shielding-aki-equitable-access-itu/

[15] NHS Blood & Transplant, the UK-wide 'arm's length' body overseeing organ donation and transplantation, as well as blood transfusion.

[16] BTS- RA guidance on the management of transplant recipients diagnosed with or suspeBTS- RA guidance on the management of transplant recipients diagnosed with or suspected of having COVID19 https://bts.org.uk/wp-content/uploads/2020/03/Clinical_management_transplant_recipients.pdf

[17] Stratified risk for prolonged self-isolation for adults and children who are receiving immunosuppression for disease of their native kidneys https://renal.org/stratified-risk-prolonged-self-isolation-adults-children-receiving-immunosuppression-disease-native-kidneys/

an update day 25[18]. All this advice included a frank reminder that there was no evidence base and that pragmatic guidance was being offered to assist consistent identification of the most vulnerable.

‘Shielding’ for Kidney Patients

The developing vocabulary of the crisis soon made ‘shielding’ a familiar concept. NHS England published a list of patient groups requiring shielding, estimated to be 1.5 million people in England. This included transplant recipients, and others with immune disease taking regular immunosuppressive medication.

The government shielding recommendations however contained a critical omission – dialysis patients were not mentioned. The resolution of this issue provides a reminder of the truism that ‘back channels’ based on personal relationships can outflank ‘official channels’. A letter pointing out this important omission sent from the kidney community to the Chief Medical Officer for England[19] and the Secretary of State for Health[20] produced a polite response but no action. A conversation between Donal O’Donoghue (nephrologist, RA Past-president, RCP Registrar) and Stephen Powis (nephrologist and Medical Director, NHS England) produced immediate action, and a message from RA to clinical directors asked that lists of dialysis patients be submitted to trust COVID-19 leads within 24 hours.

Prioritisation of RA Advice

As outlined above, a swathe of guidance and broad recommendations covering major areas of kidney care (AKI, CKD, dialysis, transplant, and immunosuppression) had been rapidly produced.
A number of highly specific guidelines were also produced, responding to clinician and patient concerns. Rapid publication of some of these reflected the effectiveness of RA Rare

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[18] Guidance for clinicians with patients receiving immunosuppression treatment for autoimmune conditions of their native kidneys during COVID-19. https://renal.org/guidance-clinicians-patients-receiving-immunosuppression-treatment-autoimmune-conditions-native-kidneys-covid-19/
[19] Professor Chris Whitty
[20] Matt Hancock, MP

Disease Groups (RDGs)[21] , whose small and tight-knit expert groups could be fleet-footed in guideline production and peer review.

Understandably there was anxiety among those with kidney disease who were pregnant as the pandemic grew, and the Pregnancy and CKD RDG was able to publish guidance by day 16[22].

Advice was also urgently needed for patients with tuberous sclerosis complex and their physicians, since a substantial proportion of patients are being treated with mTOR inhibitors[23] in line with evidence-based clinical guidelines. Guidance on the management of this issue was published by the Tuberous Sclerosis Complex RDG by day 18[24].

Ramadan in 2020 began on day 47, ending on day 77. Specific guidance for kidney patients on fasting during the COVID-19 pandemic was published on day 47 [25].

The time-honoured tradition of eating and drinking during dialysis also came under scrutiny because of theoretical risks of transmission when face masks are removed, and because some countries had already issued edicts, unsupported by evidence, that this practice should cease. These concerns were sufficient to require the production of a guideline by the Renal Nutrition Group largely based on common sense[26].

Guideline work was also required in response to outside pressures and 'noise'. An example was advice about treatment with RAS (renin-angiotensin system) blockers. From mid-February there was media interest creating uncertainty and anxiety among the many patients (including those with kidney disease) taking RAS blockers as prolonged therapy for blood pressure control or protection of kidney function. In the somewhat febrile atmosphere of the time, baseless advice to stop RAS blockers began to circulate[27]. A cluster

[21] Rare Disease Groups, covering twenty disease areas, are a key operational element of the RA Rare Renal Disease strategy. https://rarerenal.org/rare-disease-groups/

[22] Recommendations for women with kidney disease who are currently pregnant, or considering pregnancy, during the COVID-19 pandemic. https://renal.org/wp-content/uploads/2020/03/COVID-Pregnancy-Kidney.pdf

[23] mTOR (mammalian target of rapamycin) inhibitors, including sirolimus and everolimus

[24] Advice to specialists caring for patients with Tuberous Sclerosis Complex (TSC) in the UK. https://renal.org/attention-specialists-caring-patients-tuberous-sclerosis-complex-tsc-uk/

[25] Rapid review guidance for patients intending to fast during the COVID-19 pandemic – CKD, transplants, diabetes and occupational health advice.

[26] Eating or drinking during hospital or satellite unit based haemodialysis and COVID-19

[27] The author, for example, who had for a decade been taking an ACE inhibitor for hypertension, was strongly advised at a social gathering in early March by a respiratory physician colleague, to stop the ACE inhibitor … 'just in case'.

of preliminary reports suggested that use of RAS blocker use may be a risk factor for severe COVID-19 infection, although perhaps only a 'marker' of risk due to the co-morbidities treated with these agents including hypertension and diabetic kidney disease. Coronaviruses had been shown to gain entry to cells by utilizing ACE2, although emerging basic science was providing biological plausibility for both benefit and harm from RAS blockade. Both the emerging epidemiology and the preliminary basic science received undue media exposure. Existing guidance on circumstances in which those at very high risk of AKI should temporarily stop RAS blockers also needed to be affirmed. Position statements on these issues for professionals and patients on this issue therefore became an urgent and time-consuming priority, and became the first clinical guideline published by RA during the epidemic, on day 8[28] [29].

UK Renal Registry

The UK Renal Registry (UKRR) played a key role in the collection and analysis of novel data about COVID-19 infection. The timing for the introduction of this substantial additional work into UKRR's programme was perhaps unfortunate since the UKRR/RA offices had only just completed a move to new premises in north Bristol, leaving Southmead Hospital where UKRR has been based for 25 years.

From day-1 the UKRR medical director initiated discussions also involving the RA Clinical Vice-President, and the RA Director of Informatics Research (Dorothea Nitsch, LSTMH[30]), and began planning for regular data collection on RRT patients with COVID-19 infection. UKRR staff rapidly established the simplest possible digital data collection tool (requiring only NHS number, date of birth, RRT modality, and date of positive COVID-19 test). RRT modalities were classified as centre HD, home HD, PD, transplant, and undialysed CKD. Renal units were requested to return these data by Thursday 5pm each week, and they were immediately cross-checked with the Personal Demographic Service of NHS Digital to ensure duplicates were excluded and to establish which patients were still alive, UKRR sending a report to the units within 24 hours. Data collection was launched on day 17, and

[28] The RA position statement on COVID-19 and ACE Inhibitor/Angiotensin Receptor Blocker use. https://renal.org/covid-19/ra-resources-renal-professionals/renal-association-uk-position-statement-covid-19-ace-inhibitorangiotensin-receptor-blocker-use/

[29] In due course more substantial observational data did not sustain these concerns - Williams B, Zhang Y. Lancet 2020;395:1671.

[30] LSTMH, London School of Tropical Medicine & Hygiene

twenty units first returned data the same week. By day 30 weeks most units were returning data, and at day 60 there was virtually complete coverage – 50 of 51 units in England[31], and all units in Scotland (via the Scottish Renal Registry), Wales and Northern Ireland. UKRR assembled weekly reports which were immediately available to clinical directors[32]. There were inevitable limitations in very recent data, due for example to lag in event reporting the Personal Demographic Service. But with every week the data became stronger, and the analyses more robust. The denominator for these initial analyses was the cohort on RRT on 31 Dec 2018.

The first analyses from these data were presented by Medcalf at a RA webinar on day 67 , and posted on day 72[33].Important findings were an apparent increase in infection risk and mortality in these on in-centre HD compared to other modalities (though differing testing strategies represented a significant confounder). Higher infection risk and worse outcome were also seen in Black and South Asian ethnicities, but these ethnicities were overrepresented in the regions with highest case numbers (London and West Midlands).

An initial analysis linking the UKRR data with transplant wait list status held by NHSBT was published on day 68[34]. Among the findings was preliminary evidence that COVID-19 infection risk and mortality were substantially lower among in-centre HD patients wait-listed for transplantation compared to in-centre HD patients as a whole.

NHSBT in parallel had established its own data collection with a much more extensive dataset than UKRR's minimalist model (which only required NHS number, modality, and date of COVID-19 positive swab). This double reporting inevitably placed further demands on busy renal unit staff, and it was reassuring that UKKR data returns continued to be prompt and complete.

For the next phase of data analysis, all renal units were also asked to expedite their 2019 Q4 returns and did so without exception by day 75. This meant that the cohort receiving RRT on 31 Dec 2019 could now be followed prospectively.

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[31] The one centre not providing data at day 65, stated that no COVID-19 cases had yet been identified at that centre
[32] Reports became fortnightly from day 69.
[33] https://renal.org/covid-19/data/
[34] Analysis performed on combined dataset of NHSBT & UKRR. https://renal.org/wp-content/uploads/2020/05/Analysis-performed-on-combined-data-set-of-NHSBT-and-the-UKRR-v2_AC-v3.pdf

The power of analyses involving kidney patient data held by UKRR comes in significant part from linkage with other datasets, for example data collected by ICNARC[35] as well as COVD-19 testing results held by Public Health England. Obtaining permissions for such linkages has been a considerable frustration for UKRR in the robust information governance environment over recent years; even uncontentious proposals have been viewed as significant variations on UKRR's permission for its routine work through section 251 of the Health and Social Care Act.. The process of application for linkage permission has been time-consuming and sluggish (waits for uncontentious decisions could typically be at least 8 weeks). Happily the COVID-19 crisis provoked the Secretary of State to relax the permission process from March to September 2020 to facilitate time-critical COVID-19 work, and the decision timeline almost immediately shortened to two weeks.

There was understandable enthusiasm for other data collections on COVID-19 infection in kidney patients. Organisations within and outside the UK (including for example both ERA-EDTA and ISN) initiated data collections and sought support from UK nephrologists. It was important to remind those considering contributing to such international efforts that the UK has tight health information governance framework with significant penalties for breaches. RA guidance on this matter was published on day 27.[36]

Planned linkages between UKRR and other agencies were approved from 1st June 2020, so valuable new analysis can now be expected. For example, UKRR had been collecting data for several years on AKI cases identified in clinical laboratories by serum creatinine measurements (some 900,000 clinical records each year). Linkage to Public Health England will enable identification of the proportion of AKI cases associated with COVID-19 positivity.

UKRR has delivered an important stream of information to support the kidney community's approach to the COVID-19 pandemic. It was able to do so because it built on existing trusted systems for data collection. It was also able to do so because of a concerted effort by many of its staff led by Retha Steenkamp, UKRR Head of Operations. For the best part of six weeks, much UKRR's routine work was interrupted or displaced by the COVID-19 work.

[35] ICNARC, Intensive Care National Audit and Research Centre

[36] RA guideline statement on planned/ongoing data collections and information governance in the context of the COVID-19 outbreak. https://renal.org/wp-content/uploads/2020/04/RA-guideline-statement-on-COVID-19-data-collection-and-IG-3.pdf

Despite this, UKRR published its annual report and also a planned AKI report on time in May 2020 – a remarkable achievement.

Partnerships within the kidney community

The coherence of the kidney community was a striking feature of its COVID-19 response. Among the organisations within that community there have over the years been occasional tensions when areas of responsibility and influence were being parsed; but these were all set aside. The many tasks were allocated without rancour, and with no exception the required work accepted and delivered with high energy and timeliness. An important factor in this success was undoubtedly the early establishment of the COVID-19 Renal Guidance Group and the work of its very effective chair, the RA Clinical VP.

Although not directly involved in clinical care, Kidney Research UK (KRUK) made an important contribution to the effort, chiefly through Charlie Tomson[37], KRUK trustee and chair of their Research Strategy Committee.

Partnerships with national professional bodies

RA had important interactions with a number of other national professional bodies with distinct or broader interests. RA's work with the Intensive Care Society was highly effective in facing down the growing crisis in provision of critical care RRT (see above, AKI, page 7). UKRR built productive data sharing with ICNARC.

Royal College of Physicians

RA was playing a leading role the reorganisation and transformation of kidney care. Some major issues, more wide reaching across the NHS, were best left to others. The Royal College of Physicians (RCP) became an effective and authoritative voice – notably in emphasising and documenting the enormous burden being borne by acute medical services (and respiratory medicine in particular) and highlighting the challenges for junior doctors. Sufficient supply of personal protective equipment (PPE) was a continuing problem for renal units, as for other areas of health and social care. While renal unit clinical directors engaged vigorously with local procurement systems to ensure suitable prioritisation, the national

[37] Tomson, as well as his current roles at KRUK, was well placed to grasp the breadth of the challenges, as an RA past President, and past chair of URKR

debate on the insufficiency of PPE was led by RCP. RCP also led the call for an effective COVID-19 testing strategy. RCP led the development of COVID-19 clinical specialty guidelines.

Partnership with national NHS bodies

NHS England & the NHS in the devolved nations

RA worked directly with NHS England on specific major challenges in service delivery, primarily through the NHS England specialty commissioning team. The dominant issues were the service delivery adaptations needed to sustain in-centre HD and the severe concerns about AKI management. RA leaders also supported key clinicians involved in parallel discussions within the devolved nations. Healthcare commissioners from Scotland, Wales and Northern Ireland attended the weekly calls of the COVID-19 Renal Guidance Group.

NICE

NICE (National Institute for Health & Care Excellence) was energetically supportive of the kidney community. This was undoubtedly assisted by the role at NICE of Kevin Harris (past RA Clinical Vice President)[38]. Rapid guidelines were produced out with the usual time-consuming NICE guideline process. In a short time NICE COVID-19 rapid guidelines emerged on dialysis service delivery[39], AKI[40], and CKD[41]. These NICE rapid guidelines were valuable in validating approaches to clinical care, setting them within NHS processes, and repetitively cross-referring to other government guidance related to COVID-19. However they added little to the pragmatic plans and processes already put forward and implemented by RA and renal units. Furthermore the 'consultation' process required by NICE sometimes generated additional, apparently urgent, work for RA. For example the NICE dialysis service delivery guideline had to be reviewed and critiqued by RA within a five hour window.

Media involvement

[38] Harris in 2020 is programme director and clinical advisor for the Interventional Procedures Programme at NICE
[39] https://www.nice.org.uk/guidance/ng160
[40] https://www.nice.org.uk/guidance/ng175
[41] https://www.nice.org.uk/guidance/ng176

For the most part RA and the rest of kidney community were able to get through their demanding work without much media interest. Only when the shortage of RRT equipment for AKI in critical care received wide attention was the RA President requested to appear on national television. With happy timing, he and other RA trustees had recently received media training, and the interview was completed without controversy,

UK Kidney Week 2020

UK Kidney Week (UKKW) 2020 was due to take place in Birmingham 24th-26th June 2020. Inevitably it had to be cancelled; the decision was taken in March by mutual agreement of RA, BRS and the meeting secretariat. At first the meeting venue declined to refund any of the paid deposit, which would have resulted in a major financial challenge for both RA and BRS, but happily a successful negotiation eventually resulted in only a small fraction of that deposit being retained.

Conclusion

RA and the kidney community should be proud of what was achieved in the first hundred days of the COVID-19 pandemic in the UK. While the whole kidney community, patients and professionals alike had much insecurity and uncertainty to bear, a number of senior RA leaders bore formidable burdens of responsibility and decision making , requiring continuous working for weeks on end, alongside the ongoing clinical and management which more than filled their normal working week. When asked how they coped, their responses were typified by one who described it as 'busy but not impossible'. Time demands were to some extent mitigated by fewer clinics and lack of travel. Other mitigating factors included the sense that the overwhelmingly high demand phase must be time-limited, once major structural and organisational changes in clinical care had been agreed, and the widespread sense of collaborative 'can do' energy which typified the kidney communities response to RA leadership.

RA's leadership in the first hundred days of the COVID-19 epidemic in the UK was very effective, characterised by high energy, clarity of thinking and communication, and efficiency of execution. Their leadership style proved collegial and empowering. Brave and

far-reaching decisions were made which enabled risks to new and existing people with kidney disease to be minimised. Although inevitably substantial loss of life could not be prevented.

Following these hundred days the most pressing part of the crisis was past: case numbers and deaths fell. Novel patterns of clinical work became familiar, opportunities to restart furloughed clinical work (notably kidney transplantation) could now be considered.

Beyond that RA and the community must ask if 'things will never be the same again'. Before the pandemic major rethinking of traditional patterns of clinical care delivery was underway based on the work of the Getting It Right First Time (GIRFT) programme, whose leaders - the RA President and Will McKane (Sheffield) had visited each renal unit in England to review their approaches to all aspects of service delivery[42]. A renal transformation programme was emerging from that. As challenges related to COVID-19 begin to settle, there is a risk that energy for such transformation is dampened, whereas the disruptive effects of these hundred days and those days that follow needs to be the stimulus to ensure the radical overhaul of kidney care that will benefit patients and professional alike.

John Feehally

June 2020

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[42] The first time that the RA President had visited each unit since RA President John Feehally visited all UK units in 2004-2006

Appendix 1.

Timeline of publication of COVID-19 crisis including publication of key documents relevant to kidney care

2020	Day		Advice & guidance published by RA	Main authorship	Relevant national guidance
22 Feb	*-16*	*First Lombardy death*			
6 March	*-1*		COVID-19@renal.org launched as RA point of contact		
7 March	*0*	*First UK death*			
9 March	*2*		COVID-19: challenges for renal services	RA - anon	
12 March	*5*	*Twenty UK deaths*	Checklist for renal services in respect of the COVID-19 pandemic	RA - anon	
15 March	*8*		The Renal Association, UK position statement on COVID-19 and ACE Inhibitor/Angiotensin Receptor Blocker use	RA - anon	
15 March	*8*		RA UK position statement for patients: novel coronavirus infection and the use of blood pressure medications	RA - anon	
18 March	*11*		Recommendations to all renal clinical directors (on chronic dialysis)	COVID-19 Renal Guidance Group	
20 March	*13*				NICE COVID-19 rapid guideline: dialysis service delivery [NG160] - anon
23 March	*16*	*UK 'lockdown'*	Stratified risk for prolonged self-isolation for adults and children who are receiving immunosuppression for disease of their native kidneys	RCP – with RA addition	
23 March	*16*		Recommendations for women with kidney disease who are currently pregnant, or considering pregnancy, during the COVID-19 pandemic	Pregnancy & Kidney Disease RDG: Matt Hall (Nottingham) Kate Bramham (King's) Liz Lightstone (Imperial) Graham Lipkin (RA President)	
23 March	*16*		Commentary on the NICE COVID-19 rapid guideline: dialysis service delivery	Michael Robson (Guy's) James Burton (Leicester) Sharlene Greenwood (King's) Marteen Taal (Derby)	
25 March	*18*		Updated: Guidance on the management of transplant recipients diagnosed with or suspected of having COVID19	(updated again on April 25 – day 49)	
25 March	*18*		Advice to specialists caring for patients with Tuberous Sclerosis Complex (TSC) in the UK	Tuberous sclerosis RDG Chris Kingswood (Brighton) Nicholas Annear (St. George's) Daniel Gale (UCL) Graham Lipkin (RA President)	
27 March	*20*		Guidance for clinicians with patients receiving immunosuppression treatment for autoimmune conditions of	RA – anon	

			their native kidneys during COVID-19		
2 April	*26*		COVID-19: Checklist and Guidance for management of Peritoneal Dialysis Programmes	Simon Davies (Stoke) Mark Lambie (Stoke) Martin Wilkie (Sheffield) (with input from other multiprofessional clinicians)	
3 April	*27*		Data collections and information governance in the context of the COVID-19 outbreak	James Medcalf (Medical director UKRR) Dorothea Nitsch (RA director of informatics research) Neil Sheerin (RA Academic VP) Tom Gray (RA data protection officer)	
8 April	*32*	*UK death rate peaks*			
12 April	*36*		Urgent patient issues: patient shielding, AKI & equitable access to ITU	RA President, Clinical VP, CSC chair	
15 April	*39*				NHS England specialty guides: Clinical guide for renal replacement therapy options in critical care during the coronavirus pandemic
21 April	*45*		KCH Renal COVID Acute PD on ICU Protocol	Elaine Bowes Hugh Cairns, Clare Sharpe	
22 April	*46*		Statement on COVID-19 related acute kidney injury and intensive care capacity	RA, BRS, Kidney Care UK, NKF	
24 April	*48*		Ramadan: guidance for patients intending to fast during the COVID-19 pandemic	Shafi Malik (Coventry)	
25 April	*49*		Updated: Guidance on the management of transplant recipients diagnosed with or suspected of having COVID19	RA-BTS: anon	
4 May	*58*		Eating or drinking during hospital or satellite unit based haemodialysis and COVID-19	Renal Nutrition Group of the British Dietetic Association with the support of BRS, RA, Kidney Care UK, NKF	
6 May	*60*				NICE: COVID-19 rapid guideline: acute kidney injury in hospital [NG175] - anon
13 May	*67*		RA Webinar COVID-19 & Kidney Patients: The UK Experience	Indranil Dasgupta (Birmingham) Chris Laing (UCL) Claire Sharpe (King's) Gareth Jones (Royal Free) James Medcalf (UKRR) Thomas	

				Hiemstra (Cambridge)	
14 May	*68*		Analysis performed on combined dataset of NHSBT and UKRR	UKRR	
15 May	*69*	*Beginning of 'lockdown' easing in England*			COVID-19 rapid guideline: chronic kidney disease [NG176] -anon
18 May	*72*		COVID-19 surveillance report for renal centres in the UK – up to 6 May 2020	UKRR	
18 May	*72*		Nephrology societies call for ensuring optimal care to patients with kidney diseases during the COVID-19 pandemic	RA co-signatory with ISN and 12 other international and national nephrology organisations	
1 June	*86*				

Appendix 2. Selected RA Guidance for Members

Here are shown four of the most substantial messages from the RA President and other senior leaders during the first hundred days .

9th MARCH 2020 (Day 2)

COVID-19: challenges for renal services

a) Risks to patients with kidney disease

In conventional influenza infection, patients at increased risk of complications are considered to be: those aged 65 years or older; long stay residential care home residents; and those with: chronic respiratory diseases; chronic heart disease; chronic kidney disease, nephrotic syndrome and established renal failure; chronic liver disease; diabetes, and immuno-compromised patients.

The particular complications associated with high morbidity and mortality are pneumonitis and secondary bacterial pneumonia. COVID-19 virus infection may also be associated with worsening in the clinical condition of patients with a range of existing medical conditions, such as heart failure, diabetes, coronary heart disease, asthma and chronic obstructive pulmonary disease (COPD).

Patients with pre-existing CKD will be at increased risk of AKI through pyrexia, poor fluid intake from anorexia and sore throat, diarrhoea, and NSAIDs used by patients for treatment of myalgias and headaches. Thus patients with kidney disease, many of whom have the above listed comorbidities or risk factors, are likely to be more at risk of serious morbidity and mortality during a pandemic. This will result in additional and perhaps disproportionate pressure on renal units where the skills for caring for these patients are concentrated.

A review of COVID-19 and kidney disease can be read here.

b) Staffing issues

Up to 50% of the workforce may require time off work at some stage over the entire period of a pandemic. Staff absence from work will be not just due to personal infection, but also to provide care for dependants (whether ill relatives, or children as a result of likely school closures), family bereavement, other psychosocial impacts, fear of infection and/or practical difficulties in getting to work. At the peak of a pandemic, between 15% and 20% of staff may be absent at any one time.

All hospital doctors, whatever their base specialty, are likely to be involved in the care of patients with influenza. Nephrologists (because they have general skills) will need to be prepared to help out in other clinical areas where possible.

As elective in-patient and non-urgent out-patient activity will be cancelled during a pandemic, new working patterns and responsibilities will need to be brought in to place to cope with the demands of the acute in-patient workload.

Modelling suggests that small organisational units (5 to 15 staff) or small teams within larger organisational units are likely to suffer higher percentages of staff absences – up to 30–35% over a two to three-week period at the local peak. This may have a significant impact on the running of satellite dialysis units.

Flexible (and extended) working rotas will be needed to cover staff shortages and emergency workload. A pandemic will put staff under considerable pressure and there are likely to be conflicts between staff's professional and/or contractual obligations, personal or family responsibilities and concerns about risks.

There are potential legal issues that may impinge on Trusts' pandemic plans. These range from regulatory matters through to concerns about staff undertaking unfamiliar roles, and Trusts/specialties temporarily providing levels of treatment which differ from those recommended in the usual protocols.

c) In-patients

Estimates suggest that existing hospital capacity may only meet 20% to 25% of the expected demand at the peak of a pandemic wave. Proportionate admission thresholds based on clinical management guidelines will therefore need to be agreed and progressively applied across specialties within trusts. Consistency and equity in the application of such thresholds will be an important factor in gaining public understanding and maintaining confidence. Common understanding and interpretation of those guidelines by health professionals at the primary, secondary and social care interfaces are particularly important. Renal service beds will be in great demand.

Patients who are receiving dialysis treatment are more at risk of getting influenza infection and, when infected, of suffering a more severe clinical course. Unless they need ventilatory support, the inpatient care of such patients will need to be in an area where dialysis equipment and the appropriately trained staff are located. Tension may develop between demands on the hospital trust to care for its local DGH population and of the renal unit to provide care for a wider catchment area will be significantly more acute than usual.

d) Haemodialysis

Challenges to the ongoing provision of maintenance out-patient haemodialysis for patients in established renal failure include:

- Staff shortages affecting the main unit and satellite units
- Difficulty cohorting infected patients when attending for dialysis
- Unavoidable exposure of staff to infected patients who need regular treatment
- Risks to hospital transport
- Risk to supplies and their delivery
- Carer illness implications for patients on home dialysis programmes

- Possible shortage of technicians

e) Peritoneal dialysis

Patients who are receiving peritoneal dialysis (PD) treatment have the relative advantage over patients who are receiving unit or satellite based haemodialysis treatment of not needing to attend hospital regularly. This will reduce their exposure to infection. However the specific risks they face are:

- Uncertainly over delivery of PD supplies.
- Nursing and medical support
- Increased risk of infection through reduced immunity

It will also be difficult to maintain a service that can commence new patients on PD, mainly through a lack of nurses to provide the intensive training required.

f) Transplantation programs

It is unlikely that there will be the human and hospital resources during a pandemic for living or deceased donor kidney transplant programs to operate. Given the multiple personnel involved in successfully organising and seeing through a renal transplant, the pressures on the hospital facilities (particularly beds and critical care), and the enhanced risk of infection acquired in the peri-procedural period, it is likely that transplant programs will need to be temporarily suspended.

g) Out-patients

All non-urgent out-patient activity will need to be cancelled for a period that could be between two and five months, depending on the behaviour of the pandemic locally. The need to provide the emergency inpatient care for influenza and non-influenza cases will be overwhelming, and staff who are able to attend for work, and facilities, will be triaged to life-saving work on the wards.

However each specialty has a complement of patients under long term out-patient care who require ongoing careful supervision to avoid serious complications of their condition or its treatment. Some new referrals will still be necessary for those needing urgent out-patient assessment and management. The challenge will be to ensure the availability of such urgent care.

18th MARCH 2020 (day 11)

Recommendations on chronic dialysis treatment to renal unit clinical directors

We are writing with recommendations to all renal clinical directors on advisory management and provision of chronic dialysis treatment to address safety issues in this pandemic. Please could you share this with renal service matrons and operational managers. The advice comes from the COVID-19 Renal Guidance Group with representation from all professional and patient bodies responsible for kidney disease care.

Many renal services are addressing crucial areas for the safe care of renal patients in this time, and you will be aware of this within your organisations. We are advising all renal services to consider the following.

1. **Some patients with end-stage renal failure who require transport to attend for in centre or satellite unit dialysis may be at immediate risk. Some dialysis transport providers are indicating that they will not transport patients who have symptoms that could be due to COVID-19 or who have confirmed COVID-19.** Dialysis units should have a register of all patients who are reliant on transport provision and a plan to mitigate this eventuality. These patients could be supported by: (i) alerting patients that where possible friends and family should bring them in for dialysis sessions (ii) assessing if there are any volunteer structures that can work to provide support for dialysis patient transport in this period (iii) potentially working with local St John's Ambulance or other emergency contingency providers.

2. **Rapid screening of all dialysis patients with suspected COVID-19.** Dialysis treatment is a time-critical treatment. Patients receiving in-centre dialysis are not effectively able to self-isolate due the need to attend regular dialysis to stay alive. Dialysis units could potentially be viewed as "closed communities" where there is an increased risk of outbreak within each unit. We are receiving reports from colleagues in other countries of patients dying as a consequence of being isolated whilst waiting for screening or results from screening. There are reports from clinical colleagues in UK renal services of dialysis patients being placed at risk through being isolated and dialysis being delayed. This puts UK patients who receive dialysis treatment at risk of death through cardiac arrest secondary to hyperkalaemia. All dialysis patients who develop symptoms suggestive of COVID-19 should be screened urgently with a rapid test turn-around time. Dialysis treatments should not be delayed as a consequence of waiting for results of screening for COVID-19.

3. **Dialysis services should be configured to provide** (i) dedicated (cohort) dialysis facilities patients who are COVID-19 +ve (ii) dedicated facilities for patients who require isolation as consequence of contact or a consequence of awaiting test results (iii) safe treatment to all other dialysis patients in this period.

4. **All dialysis patients who are admitted to a hospital that does not have dialysis facilities and are not requiring ITU care are urgently transferred to their base hospital for in-centre dialysis treatment.**

5. **Enter discussion with independent sector providers of dialysis regarding flexible staffing arrangements and the need for agreed joint polices on management of infected and suspected patients.**

The group wishes to hear of units unable to implement these recommendations in their organisation. Please let us know on COVID-19@renal.org

We will support through advocating nationally for you.

A regional infrastructure to support NHSE structures is being established to support renal services; Trusts with renal services in a region will have to work closely together in this period to deliver the service change required.

12th APRIL 2020 (Day 36)

Urgent patient issues: patient shielding, AKI & equitable access to ITU

There are 3 key patient issues that I need to bring to your urgent attention.

Kidney patient shielding status

Deadline 5pm Monday 13th. All dialysis and transplant recipients and those receiving IS for immunological kidney disease (IKD) can benefit from this (some have included those in advanced kidney care). The central approach has missed many of our patients (circa 50%). Your Trust has a list of those patients on the central list. **Your Trust lead for COVID19 needs to send a list of ALL RENAL TRANSPLANT, DIALYSIS & THOSE ON IS FOR IMMUNOLOGICAL KD to ensure none are missed. The lists will likely be on hand to you of your patients-please forward to your Trust COVID lead. I recognise the ridiculous deadline – hope a day later will still be accepted**

Acute kidney injury – COVID19

Modelling of peak ITU activity indicates around 1200-1500 patients at same time across England (AKI in 26% ventilated and 3% non-ventilated ITU patients). Estimates of peak ITU activity has been lowered. The RA has worked with NHSE to develop COVID19 AKI prevention guidance for physicians and ITU management which will publish within 2 days. **The key message is to maintain euvolaemic NOT overly dry.** The latter approach will increase AKI further and severely challenge available capacity. Even at current prediction patient numbers are challenging to machine availability and consumables. Renal services are an important part of this working with ICU partners-will circulate links to guidance ASAP.

- **Talk now to your ITU leads to plan for peak AKI capacity**
- **CVVH protocols to enable minimum 3 patients/machine over 48h**
- **Review CVVH anticoagulation protocol to address with pro-thrombotic state and save filters**
- **Link to Regional Renal Emergency ODN leads who will discuss with ITU ODN on regional basis**
- **Where appropriate and renal nurse staffing allows, consider Int HD support to ITU and allow early discharge. Renal advice and nursing and technical support will be required**

Equitable access to ITU for patients with ESKD (dialysis and transplant)

The early phase has created a battle mentality in ITUs. We are aware of several patients declined for ventilation across the UK purely on the basis of ESKD co-morbidity which of course is inappropriate and not evidence based. NICE has produced urgent guidance on critical care admission criteria based on CFS. ESKD survival in general on ITU is similar to the general population. **The RA has produced ethical guidance to compliment RCP and NICE . ESKD and COVID19 alone is NOT A CONTRAINDICATION TO ITU admission.** Please challenge where appropriate and refer to local Trust Ethics Groups where needed.

We are proud to be part of our renal community who have already taken such a proactive approach and key leadership roles across many Trusts and nationally in this crisis.

22nd APRIL 2020 (Day 46)

Statement on COVID-19 related acute kidney injury and intensive care capacity – RA, BRS, Kidney Care UK, NKF

Acute kidney Injury (AKI) refers to sudden failure of kidney function. In patients with a COVID-19 infection that requires treatment on an intensive care unit (ICU), over 25% of patients on ventilators develop severe AKI and require dialysis support.

Severe AKI on the ICU is usually treated by passing the patient's blood through a machine that works 24/7 to remove the excess fluid and toxins that accumulate in the body when the kidneys are not producing sufficient urine. The treatment requires sophisticated machines that need sterile tubing sets and bags of fluids that contain the essential electrolytes that are removed along with the toxins and need to be replaced.

There is now a critical national shortage of the material required for the usual treatment in ICU. There are major efforts underway with all providers to source more tubing sets and fluid bags.

Kidney professionals across the UK are working with the NHS to try to ensure that patients on ICU who need treatment for AKI can receive it. We are working in regional renal and critical care NHS networks that have been set up to help deliver treatment for patients with kidney disease. This ensures that hospitals are helping each other in a coordinated way by sharing capacity and equipment. Kidney specialists are also working with ICU specialists to ensure that ICUs are supported to be able to manage patients with severe AKI.

An alternative to the usual ICU treatment is the shorter, more efficient, treatment that is currently used by many thousands of people in the UK who attend a dialysis unit two or three times a week or treat themselves at home. This 'intermittent' treatment is very widely used so we do not expect to have shortage of the tubing sets or fluids. It does however, require the installation of additional equipment and staff training to be able to deliver it in ICUs.

Some ICUs are already set up to deliver this treatment and are doing so, whilst others are adapting their structure to be able to do so. Staff from dialysis units are training their colleagues in ICUs to be able to deliver intermittent treatment. We are encouraging ICUs that can use intermittent treatment to do so where possible. We are also encouraging, where possible, the movement of patients from an ICU that may be affected by shortages in sterile tubing sets and bags of fluids to ICUs that can provide intermittent treatment. This is to allow the limited supply of these consumables to be used

where patients are too unwell to transfer. In some centres, successful introduction of peritoneal dialysis on ICUs has provided additional support for the kidneys.

We wish to reassure patients on long term dialysis that this urgent situation is due to the huge increase in the number of patients in ICUs with acute kidney injury. We do not anticipate any issues with supplies of the material needed for long-term haemodialysis or peritoneal dialysis.

We are profoundly concerned about the shortage of consumables for treating AKI in ICUs and will do our best to ensure that all patients who need treatment will be able to receive this when it is needed.

This statement is supported by the UK kidney professional and patient organisations.