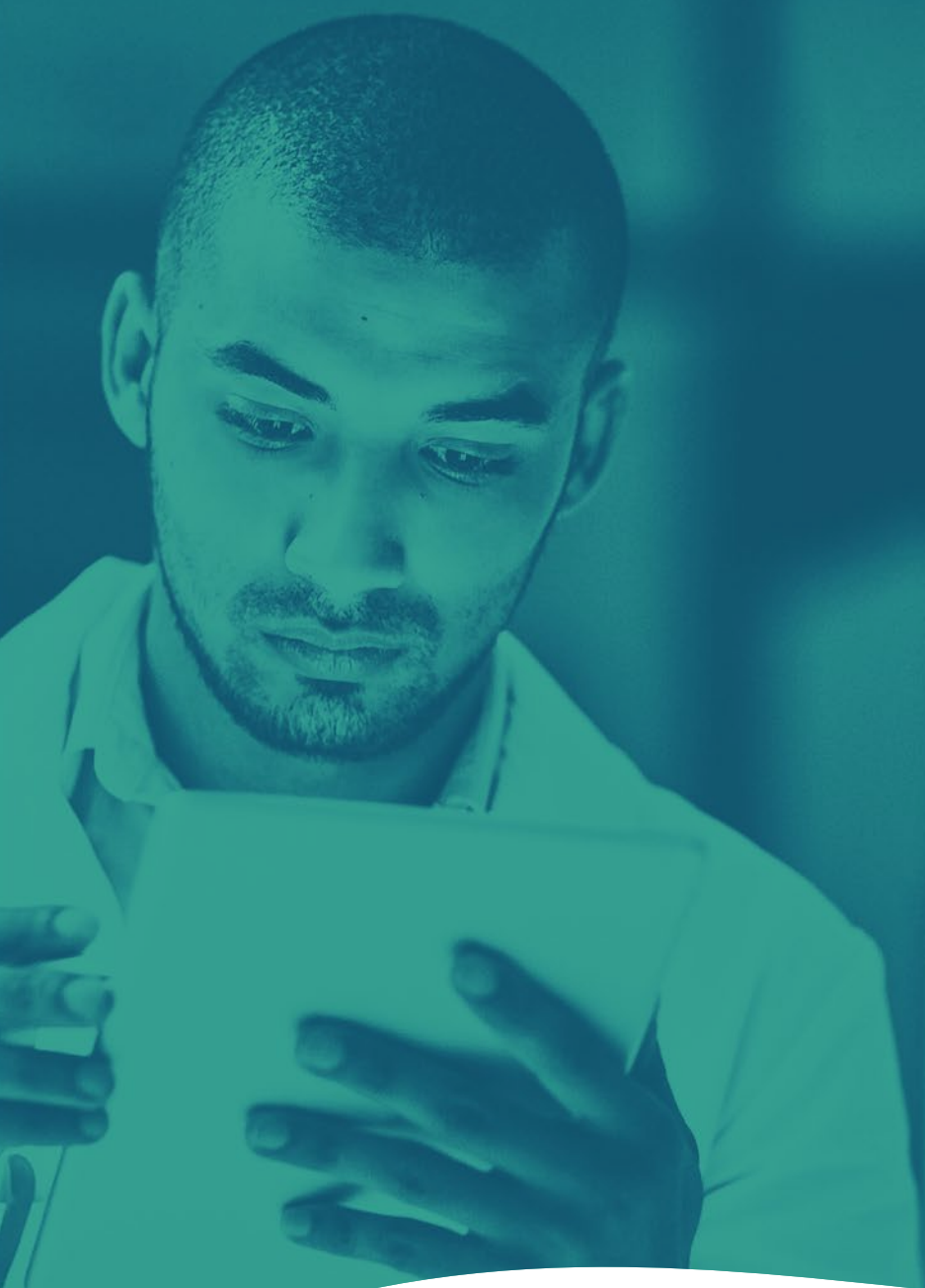


# UK RENAL RESEARCH STRATEGY PROGRESS REPORT



2016

2017

2018

2019



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## The purpose of this progress report

Welcome to the UK Renal Research Strategy Progress Report 2019.

This report aims to examine whether progress has been made against the four aims and 13 recommendations set out in the first UK Renal Research Strategy, published in 2016.

It records the opinions and experiences of key representatives from the UK kidney community, three years on from the launch of the Strategy.

Those consulted included representatives from renal organisations, clinical study groups and patient groups, together with researchers based at UK universities and hospitals.

Feedback was also sought from other non-renal interested groups, including representatives from heart and diabetes charities and national research organisations.

**In the following pages you will find respondents' summarised views on:**

- What has happened in the UK Kidney environment since 2016.
- Where progress has been made.
- Why progress has stalled in some areas.
- What themes and issues are of importance to the kidney community.
- How further progress can potentially be made through a number of suggested ways forward.

# Executive summary

The first UK Renal Research Strategy was published in 2016 to highlight areas where it was believed investment and collaborative efforts would have maximum impact to benefit the health and welfare of kidney patients and those at risk of kidney disease.

This strategy was also a 'first of its kind' in terms of the way it was developed through community collaboration to devise a broad based set of ambitions that were not focused on a single outcome or theme.

This approach was widely heralded and admired, which facilitated the opportunity to raise the profile of the kidney research agenda within and beyond the kidney community.

The strategy stated that "concerted action from many parties over the next five to ten years will be needed to realise these aims." So, three years on from the launch of the strategy, a progress review was undertaken.

Views were sought from representatives from across the UK kidney community, and from representatives from key non-renal organisations. Feedback was gathered during three main phases:



• **Phase 1** – Where telephone interviews were held with all eight co-authors of the original strategy document, using a set list of questions.

• **Phase 2a** – Where the same set of questions were emailed out to 40 members of the wider kidney community (including Clinical Study Group/Network leads, organisational leads and patients), followed by a second set of follow-up questions, based on anonymised emerging themes and issues from phase 1.



• **Phase 2b** – Where social media was used during UK Kidney Week, together with post-event e-newsletters to elicit wider views. However, no-one responded to this invitation.

• **Phase 3** – Where the same original questions, adapted where appropriate, were used to seek views from non-renal stakeholders via email. Six organisations were approached and responses were received from:

- Diabetes UK
- Juvenile Diabetes Research Fund
- British Heart Foundation
- National Institute of Health Research
- Daphne Jackson Trust



Overall, the viewpoints suggest that progress has been made against the aims and recommendations and many examples of progress are given. However, progress is seen as patchy – with some areas faring far better than others. Opinions over rates of progress also differ considerably.

The feedback has highlighted the challenge of tracking progress across such a diverse audience and keeping the strategy alive and relevant. But we hope that the many suggested ways forward contained in this review, which have come from all parts of the kidney community, will help to update people about the varied work and initiatives that have been completed, are ongoing or are in the pipeline.

This 2019 review of the strategy gives the kidney community the opportunity to further the aims and recommendations beyond what has been achieved so far and ensure that, together, we can maximise our research efforts to benefit the health and welfare of kidney patients and those at risk of kidney disease.

# Strategic Aim 1

Increase engagement of professionals, patients and the public with kidney research.

## Recommendation 1:

Develop a culture where every person with a renal disorder<sup>1</sup> accessing any type of renal service (or their families and carers, where appropriate) is offered the opportunity to participate in research.



## Feedback overview:

There is a general feeling that progress is patchy. Some units and trusts are far better than others at getting people involved with research and so, in those areas, there are more opportunities and slow, steady progress is occurring, but there is no consistency nationwide. There is also a feeling that this recommendation can only be truly progressed if there is a significant increase in the number of research trials available. Some examples of partial and good progress with patient involvement were cited, especially in the area of rare kidney diseases, for example:

- NURTuRE<sup>2</sup> – the first kidney biobank for chronic kidney disease (CKD) and idiopathic nephrotic syndrome (INS) covering England, Scotland and Wales.
- RaDaR<sup>3</sup> – the National Registry of Rare Kidney Diseases.
- NephroS<sup>4</sup> – the National Study of Nephrotic Syndrome.
- QUOD<sup>5</sup> – the UK Quality in Organ Donation programme, a national biobank resource focused on donated organ, tissue and blood samples.
- Commercial aHUS<sup>6</sup> and ADPKD<sup>7</sup> studies – where kidney patients were involved in the clinical development of new drugs and the repurposing of an existing drug to treat the rare diseases Atypical Haemolytic Uremic Syndrome (aHUS) and autosomal dominant polycystic kidney disease (ADPKD).

But many still feel that a culture change is needed to ensure that real progress is made across the board.

## Suggested ways forward:

- Share best practice models and roll them out.
- Continue to develop and encourage the widespread adoption of ‘Consent for Consent’ and ‘Consent for Contact’ policies (linking patient registries to a user-friendly portal to increase the number of patients who can register an interest in research by simply registering once).
- Use the establishment of RaDaR to generate participation in research into rare diseases.
- Support and encourage healthcare professionals to bring up the issue of patient involvement in research in routine consultations.
- Use learnings from the cancer community to help make patient involvement in kidney research feel like the norm.



“ A few large trials have taken place but it’s still the exception, rather than the rule for kidney patients to be invited to take part in research. ”

“ There are now more opportunities for patients to get involved but there is no consistency. ”

<sup>1</sup> The terms ‘kidney’ and ‘renal’ are used interchangeably throughout, as are ‘nephrology’ and ‘renal medicine’

<sup>2</sup> <https://www.nurturebiobank.org/>

<sup>3</sup> <https://rarerenal.org/radar-registry/>

<sup>4</sup> <https://rarerenal.org/clinician-information/nephrotic-syndrome-clinician-information/nephros-study/>

<sup>5</sup> <http://www.quod.org.uk/>

<sup>6</sup> <https://kidneyresearchuk.org/2019/04/16/eculizumab-a-new-drug-to-treat-ahus/>

<sup>7</sup> <https://kidneyresearchuk.org/2019/06/21/new-drug-compound-could-tackle-major-life-limiting-kidney-disease-adpkd/>

## Recommendation 2:

Increase and promote equitable access to research for minority groups with kidney disorders, including children and those from Black, Asian and Minority Ethnic (BAME) backgrounds.




### Feedback overview:

Some respondents believe that some progress has been made, especially with children. Examples of progress here included:

- The merger of Kids Kidney Research with Kidney Research UK.
- The RADaR registry of rare diseases and some of the clinical studies highlighted in Recommendation 1.

However, the majority feeling is that far more work still needs to be done with BAME communities – and BAME communities must be involved in finding ways to progress this recommendation.

Some examples of progress were given, for example:

- Kidney Research UK's report on health inequalities<sup>8</sup> – which highlights the urgent need to reach and better engage with communities at greater risk of developing kidney disease.
- Guy's and St Thomas' Gen Africa<sup>9</sup> project – which is examining the relationship between genetics and kidney problems in some black people with HIV. 
- Culture CKD<sup>10</sup> – a study investigating cultural influences on physical activity and exercise beliefs in people with CKD.
- KQUIP<sup>11</sup> – a national initiative to help improve kidney services.
- King's College Hospital's work around the rehabilitation needs of BAME groups<sup>12</sup>.

But there is still a general perception that not enough has been done to progress this recommendation.

“I haven't seen many good examples of clinical research studies that have taken specific actions to increase recruitment from these minority groups.”

### Suggested ways forward:

- Seek opportunities for more cross working with adult clinical study groups to see if any studies could also be applicable to under 18s.
- Implement the recommendations of the Kidney Research UK Report on Health Inequalities.
- Encourage renal centres serving populations with high ethnic diversity to develop their own strategies to communicate with and encourage these populations to engage. These strategies could then be used to develop a national model of best approaches.
- Use Kidney Research UK's peer educator model to signpost poorly-reached communities to research opportunities.
- Develop a shared translation resource to open up research to more people.
- Remember to engage the elderly population too – the Prepare for Kidney Care<sup>13</sup> study can give valuable information when counselling older people in their decision-making about dialysis.

<sup>8</sup> <https://kidneyresearchuk.org/2019/03/13/report-reveals-disparities-in-kidney-health-across-the-uk/>

<sup>9</sup> <https://www.guysandstthomas.nhs.uk/research/studies/hiv.aspx#na>

<sup>10</sup> <https://kidneyresearchuk.org/research/research-networks/clinical-study-groups/exercise-and-lifestyle-clinical-study-group/>

<sup>11</sup> <https://www.thinkkidneys.nhs.uk/kquip/>

<sup>12</sup> <https://www.kcl.ac.uk/scwru/res/capacity/bme>

<sup>13</sup> <http://www.bristol.ac.uk/population-health-sciences/projects/prepare-kc-trial/>

### Recommendation 3:

Create a national kidney biobank for collection and storage of biological samples from every kidney patient, to provide a strategic resource for fundamental and translational research.

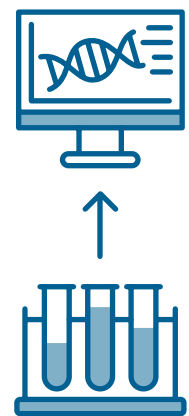


### Feedback overview:

The NURTuRE biobank is seen by many as an example of substantial progress and a catalyst to progress in other areas. It is credited for leading to the establishment of other biobanks, (such as the NURTuRE+, RaDaR, QUOD and QUOD Expand biorepositories) and also helping to raise the profile of kidney research with patients. However, some feel that this progress still only relates to a minority of patients. There is a desire to see the creation of a national biobank for all renal disorders but people are still unsure how this could be funded in practice. Another point raised was the need to think about how best to use data once it has been collected.

### Suggested ways forward:

- Increase the number of research studies that utilise data from the new kidney biobanks.
- Make more use of the general UK biobank for renal studies.
- Continue to explore ways to provide long-term funding for a national kidney biobank.



“NURTuRE has raised the profile of research for many patients. It has led to people being more amenable to be approached for other studies.”

“NURTuRE is a good first step but we are still lagging behind cutting edge genomics/proteomics compared to cancer.”

## Recommendation 4:

To complete the research loop, better communicate the outcome of all kidney research to patients and the public in accessible language that they can understand.



### Feedback overview:

There are mixed feelings around progress made towards this recommendation. Some people feel the community is getting better at sharing information with the public through its:

- Increased use of social media, infographics and video.
- Information events such as Kidney Research UK's Patient Information Days and Fellows Day and the national Pint of Science<sup>14</sup> initiative.
- Charity and organisational communications and news sharing with the national media.
- High quality information for patients and families such as the InfoKID<sup>15</sup> website and Kidney Care UK's *Kidney Matters*<sup>16</sup> magazine.

However, others feel that the renal community is still lagging far behind the cancer, heart and diabetes communities in this area.

There is a strong feeling that renal research needs to greatly improve the way it communicates with patients, for example making it compulsory to write good quality lay summaries and ensuring that patients are informed of research findings. But others point out that some people need support to do this, possibly through training on how to write for a lay audience, advice on where to send the lay summaries for maximum effect and actually being given time in the 'working day' to focus on patient involvement.

“The increased use of social media is a very positive step forward. This has revolutionised how people can get information and speak directly to researchers.”

### Suggested ways forward:

- Offer more kidney stories to the national media.
- Produce more blogs with lay summaries when papers come out.
- Ensure that all research participants automatically receive an update of results when they are published – in lay terms.
- Increase awareness of the support available to help researchers produce better lay communications of their research outcomes. For example, Kidney Research UK now runs workshops to show researchers how to write lay summaries and clearly communicate their work.
- Ensure that research charities and funding bodies emphasise that a good quality lay summary is a mandatory part of a grant application.
- Explore ways to share information about research to all kidney patients, especially those who are not part of a specific kidney disease group who may only be seen during clinic visits.
- Highlight kidney research work to other healthcare professionals (not involved in research) through a simple poster. Encourage them to share this information with their patients, and help to signpost patients who may then want to get involved with research projects.



“Sometimes researchers would like to do more public engagement work but increased workloads and a lack of time prevents them from doing what they want to do.”

<sup>14</sup><https://pintofscience.co.uk/>

<sup>15</sup><https://www.infokid.org.uk/>

<sup>16</sup><https://www.kidneycareuk.org/about-kidney-health/kidney-matters/>

# Strategic Aim 2

Capitalise on the full spectrum of research approaches to ensure a well-balanced portfolio that includes underlying mechanisms, prevention, treatment and impact.

## Recommendation 5:

Preserve support and funding of laboratory science, because new fundamental discoveries are the key to future improvements in health.



## Feedback overview:

There is a general feeling that Kidney Research UK is playing a key role in ensuring that funding is available for laboratory science but the short-term nature of some funding and a general lack of funds (possibly made worse by Brexit) is a serious risk to progress here. Other issues raised included the need to retain the expertise of established renal researchers and the need to emphasise how laboratory science can impact patient care. Examples of success and progress given included:

- Research work around the kidney disease IgA Nephropathy (IgAN)<sup>17</sup>.
- Investigations into the molecular profile of single cells<sup>18</sup> (cell omics).
- The repurposing and roll out of the drug Eculizumab to help prevent kidney failure in people with aHUS (highlighted in Recommendation 1)<sup>19</sup>.
- Personal awards for paediatric renal researchers involved in laboratory science.

“Stable long-term funding for laboratory science is provided by Kidney Research UK, the Wellcome Trust and the Medical Research Council. More is needed but the amount available has increased over the past 3–5 years.”

“This is an area where I think progress is more limited and this may largely relate to funding. Partnerships between charities may increase access to new funding streams.”

“We need to shout about basic science discoveries more and demonstrate how they impact patient care.”

## Suggested ways forward:

- Continue to seek long-term funding for discovery science, possibly through partnerships and new funding streams.
- Increase the promotion of basic science discoveries and clearly demonstrate how they impact patient care.
- Investigate better ways to ensure the continuity of research expertise in laboratories by giving established researchers more support and job security.
- Consider developing some ‘long-thin’ projects (with the same total spend but over a much longer period) to help programmes of research that are by their nature long-term.



<sup>17</sup> <https://www2.le.ac.uk/colleges/medbiopsych/events/past-events/27-march-2018-professor-jon-barratt>

<sup>18</sup> <http://www.med.cam.ac.uk/clatworthy/>

<sup>19</sup> <https://youtu.be/k3TejdM1W6w>



## Recommendation 6:

Increase the number and quality of clinical trials, to address evidence gaps and measure and determine best practice/treatment.



### Feedback overview:

There is a general feeling that progress has been made here, especially since the establishment of the UK Clinical Trials Network<sup>20</sup> and Clinical Study Groups. Many examples of successful, ongoing and planned local and national clinical trials were given, including:

- PIVOTAL<sup>21</sup> – a pioneering clinical trial investigating the optimum amount of intravenous iron that can be given to patients on dialysis.
- MinTAC<sup>22</sup> – a study comparing the effectiveness of steroid drugs for the treatment of minimal change disease in nephrotic syndrome.
- PEDAL<sup>23,24</sup> – a study examining the benefits of exercise for people on haemodialysis.
- Several major studies<sup>25</sup> aimed at improving the outlook and quality of care for children with renal conditions such as PREDNOS 1 and 2 and HOT-KID.
- STOP-ACEi<sup>26</sup> – a study investigating whether stopping treatment with ACEi, ARB or a combination of both drugs, compared with continuing on these treatments, improves or stabilises renal function in patients with progressive stage 4 or 5 CKD.
- CREDENCE<sup>27</sup> – a landmark trial studying a new treatment for people with both Type 2 diabetes and CKD.
- SIMPLIFIED<sup>28,29</sup> – a trial testing whether treatment of dialysis patients with natural vitamin D improves survival rates and quality of life.

- ATTACK<sup>30</sup> – a study to discover whether people with CKD should take a daily low-dose aspirin tablet to reduce the risk of a first heart attack or stroke.

But there was also a feeling that, although progress is happening, there is still a need to greatly increase the number of kidney patients taking part in clinical trials.

Many cited the expense of running clinical trials and felt that more funding is needed from industry, national funding bodies and other funding streams in order to increase the number of trials available to patients. Some also feared that Brexit could adversely affect industry's desire to invest in UK trials.

### Suggested ways forward:

- Secure more funding for clinical trials from industry and funding bodies like the National Institute for Health Research.
- Lobby for a more equitable share of research funding from national bodies (in order to bring renal more in line with funding for other conditions such as cancer and heart disease).
- Promote the importance of large and small trials with funders – especially in the case of rare diseases where patient numbers in trials will always be low.
- Strengthen links with the UK Renal Fibrosis Network and the UK Renal Imaging Network in order to promote more clinical trials.
- Work towards making it the norm to approach patients to take part in trials at the time of diagnosis.

<sup>20</sup> <https://www.ukcrn.org/research-infrastructure/clinical-research-networks/uk-clinical-research-network-ukcrn/>

<sup>21</sup> <https://kidneyresearchuk.org/2019/01/29/iron-trial-results-pave-the-way-for-improved-haemodialysis/>

<sup>22</sup> <http://www.ukkw.org.uk/wp-content/uploads/2019/08/O334.pdf>

<sup>23</sup> <https://clinicaltrials.gov/ct2/show/NCT02222402>

<sup>24</sup> <https://kidneyresearchuk.org/research/research-networks/clinical-study-groups/exercise-and-lifestyle-clinical-study-group/>

<sup>25</sup> <https://kidneyresearchuk.org/research/research-networks/clinical-study-groups/paediatric-nephrology-clinical-study-group/>

<sup>26</sup> <https://www.birmingham.ac.uk/research/activity/mds/trials/bctu/trials/index.aspx>

<sup>27</sup> <https://kidneyresearchuk.org/2019/06/19/diabetic-drug-trial-follow-on-results-reveal-promising-outcomes-for-diabetic-kidney-patients/>

<sup>28</sup> <http://cctu.medschl.cam.ac.uk/Trials/Simplified/Simplified.htm>

<sup>29</sup> <https://kidneyresearchuk.org/research/research-networks/uk-renal-trials-network/>

<sup>30</sup> <https://www.southampton.ac.uk/attack-trial/about/about-attack.page>

### Recommendation 7:

Embed commitment to robust and appropriate patient-focused and patient-led qualitative research, to allow improvements in quality of care, health, quality of life and patient empowerment.



#### Feedback overview:

Perceptions of progress were mixed for this recommendation. Many felt that there was now an increased awareness of the importance of patient-focused and patient-led research. Examples of progress included:

- The Speak Study<sup>31</sup> – the first national survey of young adults on kidney replacement therapies to investigate the impact of permanent kidney failure of the lives of young people in the UK.
- The establishment of a National Institute for Health Research supported Kidney Patient Involvement Network within the UK Kidney Research Consortium.
- Patient surveys conducted by organisations including Kidney Care UK and Kidney Research UK which help to identify issues of importance to patients.
- The Kidney Patient Report Experience Measure (PREM<sup>32</sup>) – a national annual survey of kidney patients.
- The SONG initiative<sup>33</sup> – an international initiative with aims to establish a set of core outcomes and outcome measures across the spectrum of kidney disease for trials and other forms of research.
- The ASK trial<sup>34,35</sup> – which is looking at why people from certain social backgrounds are disadvantaged in terms of finding living kidney donors.

However, this view is countered by a belief that a lot more still needs to be done to truly involve patients – especially in the area of quality of life studies. Some also felt that it was still difficult to get qualitative research funded and published and that qualitative research is still regarded as a second-class form of research in some areas.

“I think the whole kidney community has bought into patient-focused and qualitative research in a way that we hadn't five years ago.”

“I'm aware of some good examples of qualitative research and of patient input into the design of studies, though there's more work to be done.”

“There's an increasing awareness of patient-led/patient-focused qualitative research and the need to address issues that are important to patients rather than of interest to clinicians/researchers.”

#### Suggested ways forward:

- Devise workshops which focus on qualitative methods.
- Develop research training and mentoring for multidisciplinary team members.
- Further develop patient-led research hubs, such as that in Cambridge.
- Widen engagement with patients to get more people involved with research and a greater range of opinions around research ideas.



<sup>31</sup> <https://www.renalreg.org/projects/speak/>

<sup>32</sup> <https://www.renalreg.org/projects/prem/>

<sup>33</sup> <https://songinitiative.org/>

<sup>34</sup> <https://bmjopen.bmj.com/content/6/3/e010605>

<sup>35</sup> <https://kidneyresearchuk.org/research/research-networks/clinical-study-groups/transplantation-clinical-study-group/>

## Recommendation 8:

Build the evidence base (improvement science) that will reduce unwarranted variation in practice and increase equitable access for patients to the best available treatment.



### Feedback overview:

There is a general feeling that progress is happening here; with one view expressed feeling that the renal community has almost led the way in this field of research. The KQUIP initiative (highlighted in Recommendation 2) and the associated Think Kidneys<sup>36</sup> awareness raising campaign were cited frequently as good examples of a programme that was responding to the recommendation. Other initiatives highlighted included:

- ASSIST CKD<sup>37</sup> – a project which aims to provide better and safer patient care by identifying people with CKD who are at the greatest risk of disease progression through the monitoring of kidney function (eGFR) graphs over time.
- Share HD<sup>38,39</sup> – a project which aim is to help people on haemodialysis become more independent and confident in taking responsibility for their own treatment.
- Tackling AKI study<sup>40</sup> – which was designed to improve outcomes for patients with acute kidney injury by improving diagnosis, increasing awareness and improving basic elements of patient care.
- The PITHIA trial<sup>41</sup> – which aims to evaluate pre-implantation kidney biopsies as a tool to help increase the number and quality of kidneys transplanted.
- The new workforce planning document established by the British Renal Society's rehabilitation network.
- Exercise studies including PEDAL and CYCLE-HD<sup>42</sup> and studies<sup>43</sup> using large amounts of anonymised patient data.

However, others felt that far more work is still needed in this area, especially around the issue of health inequality.

### Suggested ways forward:

- Develop collaborations between the Lifestyle & Exercise Clinical Study Group and other Clinical Studies Groups to capitalise upon expertise across the board.
- Devise ways to determine when a particular intervention has been shown clearly enough to be effective in order to move from conventional research to quality improvement/implementation research.
- Continue to address kidney health inequalities by finding ways to implement the recommendations of Kidney Research UK's Report on Health Inequalities (highlighted in Recommendation 2).
- Continue to lobby government, industry and national funding bodies to push renal improvement science further up the national agenda.
- Develop evidence-based formal recommendations and guidance for standard practice for practitioners. The current development of Exercise and Lifestyle Guidelines should help with this.



“I think the ATTOM<sup>44</sup> study will be a game changing study in terms of equity of access to transplantation and identifying and ironing out variation of practice.”

<sup>36</sup><https://www.thinkkidneys.nhs.uk/>

<sup>37</sup><https://assist-ckd.org/>

<sup>38</sup><https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5702083/>

<sup>39</sup><https://kidneyresearchuk.org/2019/01/23/empowering-patients-through-shared-haemodialysis-care/>

<sup>40</sup><https://www.health.org.uk/improvement-projects/tackling-acute-kidney-injury-a-multi-centre-quality-improvement-project>

<sup>41</sup><http://www.pithia.org.uk>

<sup>42</sup><https://kidneyresearchuk.org/research/research-networks/clinical-study-groups/exercise-and-lifestyle-clinical-study-group/>

<sup>43</sup><https://www.magonlinelibrary.com/doi/abs/10.12968/jokc.2018.3.4.252>

<sup>44</sup><https://www.odt.nhs.uk/odt-structures-and-standards/research/current-odt-research/attom-study/>

# Strategic Aim 3

Support the research training and career development of all contributors to renal research, to build sustainable research capability and capacity.

## Recommendation 9:

Increase resources and mentorship to develop and maintain research skills among all health professionals, to ensure high quality multi-disciplinary renal research.



## Recommendation 10:

Improve support, training and career paths for non-clinical renal scientists in the academic sector.



## Feedback overview:

Respondents tended to combine their views around Recommendations 9 and 10. Generally, people feel that some progress has been made but there is a need to ensure that research opportunities are open to the whole renal workforce and that regional variations are reduced. Kidney Research UK is praised for investing significant efforts in supporting researchers through its fellowship programmes for allied health professionals and clinical PhD students and events like Fellows Day. Other examples of progress given included:

- The Medical Research Council's 'New Investigator Research Grants'.
- New routes to assist allied health professionals, developed by the National Institute for Health Research, to help them progress along clinical research and academic paths.
- Kidney Research UK's decision to re-name its non-clinical fellowships to ensure consistency with other funding charities.

However, there is a strong view that issues including funding shortages, a lack of time, employment infrastructure, a lack of job security and short-term grants, continue to pose a significant challenge to recruiting and retaining new researchers – and retaining the expertise of experienced researchers.

“I would suggest that Recommendation 10 be extended to include not just renal scientists but also look at wider issues of support, training and career pathway across the board.”

## Suggested ways forward:

- Develop a UK-wide mentorship programme to ensure that all areas offer the same access to support for clinical and non-clinical research staff and students. Make it automatic for fellows to receive an independent mentor and ensure that mentors are given adequate training and time to take on this role. Possibly explore the creation of a Renal Association-sponsored mentor scheme with a mentorship portal with clinical academics from renal medicine grouped into areas of interest for people to make contact.
- Examine ways to increase opportunities for basic scientists to become tenured.
- Develop a small personal bridging grant programme (circa £3,000 to £5,000) for post-doctoral researcher to apply for.
- Simplify career grant options and market them more vigorously.
- Develop research training programmes for the whole research workforce, including nurses, allied health professionals and multidisciplinary team members. Possibly devise a research module based on existing online nursing training modules.
- Link strategic research themes with career support to steer rising stars into priority fields such as health inequalities and prevention.
- Include research training and paid study leave in the curriculum for healthcare professionals caring for patients with kidney disease.
- Find ways to enable and encourage people to stay in a research career, rather than doing a project and then returning to clinical work.
- Improve job security for research staff and address issues around gender gaps and challenges in research parity when aligned with maternity leave.

“ I think progress is being made, and Kidney Research UK is a big and important player here. ”

“ Kidney Research UK has introduced more fellowship opportunities. Collaboration with the Daphne Jackson Trust, and the Chief Scientist’s Office Scotland are examples. Kidney Research UK’s Allied Health Professional fellowships are part of the programme. ”

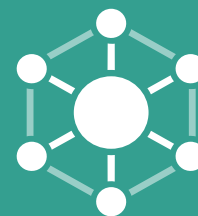


# Strategic Aim 4

Create a more open research culture to maximise cross-disciplinary and collaborative research.

## Recommendation 11:

Strengthen formal partnerships across disciplines, patient groups, professional bodies and charities aligned with kidney disease, particularly in diabetes and cardiovascular disease.



## Feedback overview:

There is a general feeling that good progress is being made towards this recommendation in all areas, especially around building good foundations with the diabetes and heart communities. Specific examples of progress given included:

- The UK Renal Imaging Network and UK Clinical Trials Network becoming part of the UK Kidney Research Consortium.



- The establishment of the Kidney Patient Involvement Network<sup>45</sup> – a partnership of voluntary, charity and professional organisations and academics from the University of Salford.

- More examples of research being led by or involving multidisciplinary team members.
- The development of pockets of formal partnerships between patients, clinicians, scientists and industry which are often disease specific. For example, Alports, Nephrotic Syndrome, complement, ADPKD and CKD.
- Closer working links with NHS Blood and Transplant, the Research, Innovation, Technology and Advisory Group (RINTAG) and the British Transplant Society.
- The joint statement between Kidney Research UK and diabetes UK<sup>46</sup> – a public statement to highlight the seriousness of kidney disease in people with diabetes and joint intent to address this problem together.
- Kidney Research UK meetings with Diabetes UK and the British Heart Foundation.
- Meetings held with diabetes and renal Clinical Study Groups.



- The Multi-morbidity Joint Conference<sup>47</sup> held on 1 July 2019 – which was a one-day conference, organised by the Renal Association, Kidney Research UK, the National Institute for Health Research and the Royal College of Physicians, to stimulate discussion and ideas in addressing multi-morbidity (co-occurring diseases).

But some question whether this work is sustainable and expandable and feel that the other disease charities should be doing more to help forge relationships. There is also a sense that partnerships need to lead to research funding or studies which will benefit kidney patients.

## Suggested ways forward:

- Organise network meetings and forums (with renal and non-renal) to allow for a greater discussion and transparency of clinical work and research currently being undertaken.
- Highlight the clinical areas of interest groups in order to disseminate relevant information and research, as well as clinical questions.
- Continue to develop relationships with Diabetes UK.
- Increase efforts to collaborate with the British Heart Foundation and other members of the heart community in order to link renal to the cardiovascular aspect of the NHS plan.
- Convert partnerships with Diabetes UK and the British Heart Foundation into research funding or studies which benefit patients with kidney disease.
- Come together with the diabetes community to progress the work of the CREDENCE trial (highlighted in Recommendation 6) by seeking urgent NICE approval for the use of new drugs.

<sup>45</sup> <https://kpin.org.uk/about-us/>

<sup>46</sup> <https://www.kidneyresearchuk.org/about-us/kidney-research-uk-and-diabetes-uk-joint-statement>

<sup>47</sup> <https://renal.org/multi-morbidity-joint-conference-monday-1-july-2019-rcp-london/>

## Recommendation 12:

Build closer research links with industry to identify new therapeutic targets, develop collaborative clinical trials and increase research funding opportunities.



### Feedback overview:

There is a feeling that links with industry have definitely improved and there is now an increased recognition of the need to work together. Examples of good progress cited included:

- The development of the PIVOTAL iron trial (highlighted in Recommendation 6) and the NURTuRE biobank (highlighted in Recommendation 6).
- The repurposing of the drug Eculizumab<sup>48</sup> to help prevent kidney failure in people with aHUS (highlighted in Recommendations 1 and 5).
- Joint working with the Glasgow-based biotech company Mironid<sup>49</sup> to develop a new class of drugs to treat ADPKD (highlighted in Recommendation 1).
- The role played by Kidney Research UK in establishing a model for kidney collaboration by facilitating links between industry, academia, medicine, patients and grant funders.
- Improvements to recruitment to industry-funded studies.
- Frequent and closer interaction with industry on account of the National Institute for Health Research's commercial portfolio.



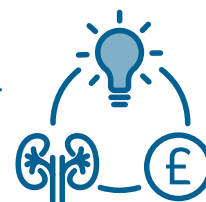
But some people feel that issues such as intellectual property rights still need to be clarified with industry and that industry's perceived preference for therapeutic and pharmacological research may mean that it is less inclined to support qualitative research involving multidisciplinary team expertise. There is also a fear that progress may be hampered due to time, funding and staffing issues and an NHS move (in some areas) towards cheaper generic, unbranded medicine.

“I think this is something that we are definitely mindful of and actively seeking to do and I think that people are comfortable with the concept.”

“There is an increasing recognition of the need for industry, academia and the health service to work together, though there are barriers.”

### Suggested ways forward:

- Develop a better understanding of the industry perspective around issues such as institutional delays on contracts and risk averse legal teams.
- Clarify issues such as ownership of Intellectual Property (IP) rights and the commercialisation of discoveries.
- Seek new ways to fund research nurses to help increase recruitment to industry-funded studies.
- Devise ways to reduce the variability of clinical study group links with industry.
- Consider ways to address the issue of increased generic medication use whilst still developing wider links with industry.

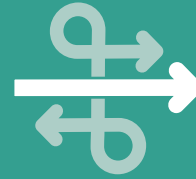


<sup>48</sup> <https://kidneyresearchuk.org/2019/04/16/eculizumab-a-new-drug-to-treat-ahus/>

<sup>49</sup> <https://kidneyresearchuk.org/2019/06/21/new-drug-compound-could-tackle-major-life-limiting-kidney-disease-adpkd/>

### Recommendation 13:

Work collectively towards a simpler, faster and more responsive pathway to ethical and regulatory approval, particularly for low-risk projects.



### Feedback overview:

There is a feeling that much more still needs to be done here. A small minority of people have experienced some improvements but possibly as a result of ongoing improvements, such as recent reforms to ethics and regulatory approval, rather than as a direct result of the renal strategy. However, for the majority processes still remain complex and time-consuming. There are still many examples of studies starting late. There is a strong belief that progress is beyond the power of the renal community alone and that change will only happen if there is 'buy-in' from the government and national health services, local trusts and universities.

### Suggested ways forward:

- Urge trusts and universities to align Research and Development department practices and reduce internal delays by properly resourcing legal and contracting teams.
- Consider a joint approach with other research organisations to lobby government to develop an overarching blanket agreement that would be applicable to all trusts.

“Recent reforms to ethics and regulatory approval processes have resulted in a much more rapid approvals process. Internal delays within Trust and University research and development departments as well as legal and contracting departments seem to be a more important source of delays to initiating research projects at present.”

“The Health Research Authority has improved the set up and governance of studies but there are still many examples of studies starting late. More improvements to streamline these processes are necessary otherwise there is a risk to the UK's share of involvement in commercial clinical trials.”



“ Meeting this strategy and ensuring the recommendations are delivered cannot be achieved by one organisation in isolation. Forging partnerships across the breadth of the community is essential and we look forward to seeing our partnership go from strength to strength. ”



# Overarching opinions on the Strategy as a whole

Respondents were also asked a series of questions about the Strategy as a whole which covered the following topics:

## Pace of progress

Overall feedback suggests that some progress is being made towards all four aims, but individual opinions over the rate of progress differ considerably. For example, one view expressed may feel that substantial progress has been made in a particular area while another may believe that there has been little to no progress made at all.

Some believe that it is impossible to gauge whether progress is being made and to what extent because of a lack of measurable data and targets (which is examined in more detail in the green sections). However, one view expressed argues that the Strategy should be seen as a roadmap rather than a fixed plan with set timescales and felt it could be difficult, in practice, to agree and implement targets for such a diverse group.

Many feel that timeframes for progress will vary depending on the nature and extent of work needed to realise specific aims and the amount of control the renal community has over

change, therefore some 'cultural' changes will inevitably take longer. Some also fear that Brexit could significantly delay progress in some areas, such as the recruitment and retention of some members of the renal research workforce and European funding and partnership opportunities.



There is a general desire to regularly check on progress towards all four aims in order to ensure continued momentum and enable flexibility to respond to any future developments or changing priorities.

## Data gaps

Many people felt they were unable to accurately gauge if progress was being made or not due to:

- A lack of baseline data around patient involvement in research (Recommendation 1).
- An absence of measurable data to show if the strategic aims are being fulfilled or not.

There was a feeling that smart objectives should now be developed to make it clear what success and progress should look like.

“I think a lot of progress will be made in five years but it's not clear from the strategy document what success looks like.”

“In terms of culture, patient engagement and collaboration, I think we are already making progress and within five years we will have made more progress. But there's no smart objective to say 'by how much progress'.”

“It's very difficult to track all the work that is being done, particularly if it's being funded by a different funding body.”

## Target setting

Many respondents were in favour of target setting in some form. Suggestions around the form the targets could take included:

- A simple rag rated system.
- SMART objectives.
- Only introducing objectives where applicable.
- Having a set of clear outcomes for every recommendation.



However, it was also pointed out that unrealistic targets could demotivate people; especially as the success of the strategy was based on the good will of volunteers, and that progression could require an additional funding/time commitment which may not exist.

“We now need a clear outcome or expectation for each recommendation – we need to be clear about what percentage of progress is regarded as being successful and we need to be able to revisit this expectation to make sure it’s enough.”

“I think effective delivery of the strategy is dependent on setting clear targets even if these need to be incremental towards the overall goals otherwise there is a danger that the strategy becomes a ‘nice idea’ that made no difference.”

“I think it is possible to set realistic but challenging targets. However, there is also a risk of getting this wrong and unrealistic targets tend to be demotivating.”

## Suggested ways forward:

- Devise ways to collect data (including baseline data) to help measure rates of progress.
- Consider measuring changes in the ‘ways forward’ that were suggested for each of the recommendations in the Strategy – and possibly do the same for the ‘ways forward’ suggested in this review report.
- Produce a revised strategy in 2021 with a series of specific and measurable (SMART) objectives or a simple RAG-rates system to clearly identify areas with different rates of progress.
- Devise short and long term targets with measurable outcomes, for example aiming for a 5% year on year increase in number of patients participating in studies.
- Regularly review ongoing work to help identify:
  - Where improvements are happening.
  - Areas which may need more focus.
  - Any recommendations which may need to be reconsidered if there is little to no evidence of progress.
- Create an oversight committee to help ensure progress and delivery against the Strategy.

“The strategy should be a long term project which is refreshed every five years. A five year timescale is important to create a sense of urgency that will drive progress. But it should be acknowledged that some aims will require longer than five years to achieve and may need to continue across several revisions of the strategy.”



“It is important to milestone progress of the strategy at regular intervals.”

“To lengthen the timeframe may risk reducing the pace of development. It may be better to have a formal review at five years and a new five year strategy. This may keep some of the existing recommendations and introduce new ones.”

## Overarching opinions on the Strategy as a whole continued

### Areas needing more focus

Three popular themes emerged from this question:

- Communication – improving and expanding patient engagement (especially with BAME communities).
- Recruiting, training and retaining the kidney research workforce.
- Big data – maximising the use of the large quantities of health service data stored in UK databases.

One view expressed highlighted funding as an overarching focus, another suggested a push for collaborative efforts to fund multi-centred studies and another felt there was a need to find out who was doing what in order to gauge which areas need more focus.



### Suggested ways forward:

- Produce a brief and clearly written kidney research summary report, perhaps on an annual basis, to help inform patients, the public and the rest of the research community about ongoing studies and research findings.
- Devise ways to raise the profile of kidney research to the wider academic community.
- Seek funding to ensure continuity in expertise in research environments, especially in laboratories and institutions where core funding for important technical support is not provided.
- Establish a “big data” network within the UK Kidney Research Consortium and seek guidance from the UK Renal Registry about the best ways to use and handle very large datasets.
- Hold talks with NHS Digital to help make it easier for investigators to access data from multiple databases.

“If we cannot increase resources and mentorship to develop and maintain research skills among all professionals, particularly allied health professionals and doctors in training and non-clinical renal scientists, then all other aspects of the strategy will fail.”

“I don’t feel we’re good as a community at sharing the outcomes of research in a language which ordinary people can understand at a local level (in hospitals) or at a national level – unless there’s a big breakthrough.”

“We need more focus on the use of “big data” resources to maximise the use of the excellent data resources available in the UK.”

### Issues missing from the original Strategy

The Strategy is seen as being a very comprehensive document but, in response to this question, Brexit and the use of big data and technological advances were highlighted. People also mentioned the following issues:



- The impact of multi-morbidity and how best to treat patients with co-existing diseases, aligning renal with the NHS England plan.
- The need for international cooperation and collaboration.
- The introduction of deemed consent for organ donation in England in 2020.
- The psychosocial aspects of kidney disease.
- Disease prevention.
- Raising the profile of kidney research within the academic community.
- Overcoming the lack of time for healthcare workers to do research.

Another suggestion was to ensure that examples of progress achieved are included in all strategy updates.

### Suggested ways forward:

- Ensure that these issues are considered and adequately covered in the next version of the Strategy.

“It’s not difficult to see that you could engage people from diabetes, people from cardiovascular and cancer etc with kidney specialists – you just have to think outside the box a little bit and start thinking about how you can get these people into the room and how you can start talking to them. You could do that quite easily and that wouldn’t cost a lot of money.”

## The biggest priority or opportunity, three years on from the launch of the Strategy

Many suggestions were offered by respondents. The most popular were:

- Developing collaborations within and beyond the renal community (Recommendation 11).
- Developing the renal research workforce – recruiting, training, mentoring and retaining researchers and making sure that research is embedded in all the workforce (Recommendations 9 and 10).

People also suggested:

- Securing more funding for research.
- Increasing the number of patients involved with research, especially from BAME communities.
- The need for more baseline and ongoing data to measure progress towards the Strategy aims (especially in the case of Recommendations 1-3).
- Harnessing new technology.
- Collecting more patient data by establishing more biobanks and using data already collected in existing banks.
- Research advances (such as quality of life improvements, work to stop kidney scarring, identifying the tipping point before which kidney diseases can be reversed and improving survival rates by studying dialysis and transplantation outcomes).
- Communication and accountability (sharing information about progress and taking responsibility for progressing certain areas).

One view expressed also felt it was now time to strip back and simplify the strategy.

### Suggested ways forward:

- The UK Renal Research Consortium should consider surveying units about capacity and barriers in order find ways to improve research infrastructure in individual sites.

## Whether the renal community should forge ahead with developing greater links with diabetes and cardiovascular communities

Generally views expressed support this suggestion but a few felt that this should not become the sole focus of the Strategy, fearing that it could cause other parts of the Strategy to stagnate and possibly lessen the kidney research community’s ability to stand out from other ‘higher-profile’ diseases.

“This is important but shouldn’t be a sole focus. We need to equally ensure that nephrology gains standing in its own right.”



## Whether the renal community should forge ahead in another area instead

A range of answers were given to this question (and many suggestions were offered as an addition rather than as an alternative to forging ahead with diabetes and heart collaborations). These included:

- Focusing on tackling health inequalities, disease prevention and early diagnosis, mental health and quality of life improvements.
- Getting more patients involved in all aspects of research.
- Securing more funding for research.
- Focusing on workforce development.
- Clarifying how best to take the Strategy forward (by setting targets and agreeing accountability).

The need to remain flexible in order to react to potential changes in the renal landscape was also stressed.

# Key themes and issues that emerged

During the process of gathering feedback, the following themes and issues emerged, which often cut across all of the aims and recommendations:

## Communication

A lack of knowledge about progress made towards aims and recommendations and a desire to improve communication within the renal community.

“The challenge (for all of us) is that people have information overload. The main issue is: are the right messages getting to the right people at the right time (e.g. opportunities and support structures)?”

All responses to the Strategy review were based on personal experiences and perceptions. Some people felt well informed about progress being made and activities undertaken as a whole while others felt their knowledge is restricted to their own areas.

The majority view cited a need to get more information about overall progress – possibly through annual reporting, together with a regular newsletter written in lay terms.

## Suggested ways forward:

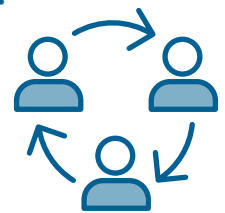
- Devise initiatives to increase and improve interactions between different research fields, possibly through the support of the Renal Association and Kidney Research UK.
- Introduce annual reporting of Strategy progress as a fixed item during UK Kidney Week.

## Accountability

Many people feel it is now time for groups or individuals to take responsibility for progressing certain areas of the Strategy. However, others question how this would work when progress is based on good will and voluntary self-drive and motivation. Some feel that progress can only be made if the community works together and fear that ‘sectioning off’ responsibility could lead to people losing interest in areas that they are not responsible for. Other questions raised included: who would do what, where would they get the time to do this extra work, who would support them and what would happen if accountability was not delivered?

## Suggested ways forward:

- Explore the possibility of setting up broad-based strategy working groups to champion specific projects or recommendations, whilst ensuring that the community works together to bring about change.
- Encourage individuals in leadership positions to strongly endorse research involving kidney patients, take a personal interest in recruitment for clinical studies and encourage others to follow their example.
- Encourage younger members of the renal research workforce to see the Strategy as something that involves them and relies on their support and input.
- Seek funding to ensure that individuals are given the time and financial support to take on these additional voluntary roles.



“I think somebody or a group should now be saying: ‘I am going to champion this particular project/recommendation’ and then they should do that.”

## Potential risks to progress

When asked to pinpoint potential risk areas people cited a range of issues including:

- Time and funding shortages.
- Restrictive career structures.
- A lack of opportunity to get involved with research.
- Problems around getting widespread patient involvement with research – especially in BAME communities.
- Worsening bureaucracy.



“ Only a small proportion of patients with kidney disease have the opportunity to contribute to research and renal services are getting squeezed. So capacity and breadth is a definite risk. ”

“ Everything that we want to achieve requires funding and time. ”

## Suggested ways forward:

- Continue to innovate, share good practice, seek out new partnerships and influence decision-makers to help make improvements in all the areas highlighted.

## Threats

Four interlinked threats to progress were regularly highlighted throughout the consultation process:

- A lack of time.
- A lack of money.
- Problematic and restrictive work practices, career progress and employment infrastructures.
- Brexit.

## Suggested ways forward:

- Lobby trusts and the NHS as a whole to embed protected time to do research in job descriptions for all clinical staff.
- Encourage more kidney scientists and clinicians to join grant review panels.
- Encourage universities to properly fund and support established researchers who want to continue their work in the laboratory, rather than follow an academic career path.
- Ensure continuity in the lab environment by embedding non-clinical grants or studentships in an overall culture of investing in the preservation of expertise.
- Continue to pressure funding bodies to move away from the culture of awarding short-term grants.
- Work with universities and other higher education institutions to encourage them to reduce the financial constraints of their academic models and so retain more young and established non-clinical kidney scientists.
- Establish a comprehensive network of kidney research nurses and allied health professionals at every renal unit and create training programmes and career pathways that make a career in kidney research attractive to them.
- Develop more charity partnerships to help increase access to new funding streams.
- Build and share models for research that work in tandem with clinical services. Learn from those units who recruit well to studies – in terms of their methods, culture and organisation.



“ Increasing NHS workloads mean that clinicians often don't get the time to encourage more patients to get involved with research – and don't even have the time to do any research themselves. ”

# External viewpoints

## Feedback was also received from representatives from the following organisations:

- Diabetes UK
- Juvenile Diabetes Research Fund
- British Heart Foundation
- National Institute of Health Research
- Daphne Jackson Trust

Their views highlighted a desire to build closer collaborations, share good practice and work together as part of a wider group to address barriers and issues that are common to all.

## Strategic Aim 1: Recommendation 1-4

### Feedback overview:

There is a general feeling that progress has been made in some areas, for example:

- The NURTuRE Biobank
- Kidney Research UK's involvement in the Quality in Organ Donation (QUOD) initiative and the expanded Medical Research Council programme
- Improved research communications – especially through Kidney Research UK's website, email newsletters and social media channels

However, some feel that widening patient access to research is restricted by the limited number of clinical trials available and hindered by communication challenges around making people aware of research opportunities.

Specifically regarding the diabetic patient population, one organisation said they had not seen a marked increase in engagement in kidney research over recent years among people with Type 1 diabetes – but wondered whether this was due to the relatively young age of their supporters and a possible feeling that potential kidney complications were a long way in the future for them.



They also felt that industrial investment was being held back because of a lack of a biomarker to show how kidney complications could be prevented or slowed down in

early diabetes. Although they warned against the risk of oversimplifying the prevention message in co-morbidities because some conditions that can lead to kidney damage cannot be prevented.

## Suggested collaborative ways forward:

- Using the new National Institute for Health Research 'Be Part of Research'<sup>50</sup> clinical trials website and potential links to the NHS App to help to target research trials and programmes to potential participants. This could be done by adding reciprocal links on kidney charity/organisation websites and the 'Be Part of Research' website.
- Forging greater collaborations with all research engagement organisations to help share expertise around increasing equitable access to research and reduce costs.
- Replicating the British Heart Foundation's series of subject-driven reviews/reports and work to improve how they present locations, themes and outcomes of their research funding through their public-facing channels.
- Working together on the issue of governance requirements by taking part in the Health Research Authority's consultation on transparency in research.



## Strategic Aim 2: Recommendation 5-8

### Feedback overview:

The well-established kidney Clinical Study Groups is seen as a clear example of progress but the finite nature of funding for trials was cited as a threat – which affects research into all conditions. Some respondents said they were certainly more aware of kidney projects happening in the UK. However, there was still a feeling (from one respondent) that more needed to be done to put qualitative research on an equal footing with more traditional research as it could benefit people living with a wide range of conditions.

Another respondent cited the importance of working with other groups, including government organisations, to help advance this strategic aim.

## Suggested collaborative ways forward:

- Link with wider trial registries to help increase the number and quality of clinical trials.

<sup>50</sup> <https://bepartofresearch.nihr.ac.uk/>



## Strategic Aim 3: Recommendation 9-10

### Feedback overview:

Kidney Research UK's annual Fellows Day was cited as a very good way of bringing future research leaders together and showcasing their work. There is also a strong feeling that closer collaborations (such as joint communications, sharing and adopting new ideas and techniques and sharing resources already in place) could help to develop and retain a wider research workforce.

### Suggested collaborative ways forward:

- Seek constructive feedback on ensuring that the language and configuration of funding schemes is tailored to be inclusive to the widest possible audience of healthcare professionals.
- Issue joint communications about sponsorship opportunities for researchers.

## Strategic Aim 4: Recommendation 11-13

### Feedback overview:

There is overwhelming support for the continuation and further development of collaborative working. Several examples of progress were given including joint initiatives between Kidney Research UK and Diabetes UK, the Juvenile Diabetes Research Fund, the Daphne Jackson Trust and the British Heart Foundation. Other examples of ongoing work were also given, including:

- Looking into the possibility of jointly engaging with patient groups, rather than organisations individually approaching the same people.
- Looking at ways to share content across organisations rather than duplicating information.

### Overarching opinions on the Strategy as a whole

The non-renal respondents also gave their feedback to the following questions:



#### Pace of progress:

There is a general feeling that a long-term vision and short-term targets (e.g. five years) is the best way forward to ensure progress and be flexible enough to respond to changing needs and priorities.

#### Areas needing more focus:

Only two respondents answered this question. They highlighted the need to fund more research, engage more people with kidney disorders in the research and ensure it is translated into practice as quickly as possible. They also suggested the continuation and expansion of joint working and partnerships.

#### Issues missing from original strategy:

Respondents suggested a range of topics which they felt were missing from the original strategy document. These included:

- The mental health and wellbeing of people living with kidney conditions.
- The need for an increased emphasis on equality, diversity and inclusion throughout the strategy.
- The growing importance of big data.
- A greater transparency in research delivery which, they felt, had now led to the development of better resources and tools.



One respondent felt that the landscape had changed since the publication of the Strategy and cited a number of key reports and plans that should now be considered. These included:

- The National Institute for Health Research's Future of Health report<sup>51</sup>.
- The NHS Long Term Plan<sup>52</sup>.
- The Accelerated Access Collaborative<sup>53</sup>.
- The Department of Health and Social Care and NHS England's Twelve actions to support and apply research in the NHS<sup>54</sup>.

#### The biggest priority or opportunity, three years on from the launch of the Strategy:

Greater collaboration was the most popular answer to this question. There is a strong feeling that this will speed up progress and, in some cases, will be the only way to tackle major barriers. One respondent also suggested focusing on big data in order to help predict the risk of disease development and progression.

### Shared themes

A number of themes and issues were raised by the non-renal respondents – all of which echoed the views of the kidney community:

- **Target setting** – there were queries over how success was being measured and monitored.
- **Communication** – there is a desire for more information about progress being made and especially in relation to improvement science and qualitative research.
- **Threats** – the same key threats were highlighted:
  - A lack of money for research.
  - Difficulties around developing and retaining a research workforce.
  - Inconsistencies in practice and service.



<sup>51</sup> [https://www.rds-eastmidlands.nihr.ac.uk/resources/RAND\\_RR2147.pdf](https://www.rds-eastmidlands.nihr.ac.uk/resources/RAND_RR2147.pdf)

<sup>52</sup> <https://www.england.nhs.uk/long-term-plan/>

<sup>53</sup> <https://www.nice.org.uk/aac>

<sup>54</sup> <https://www.england.nhs.uk/publication/12-actions-to-support-and-apply-research-in-the-nhs/>

# Conclusion

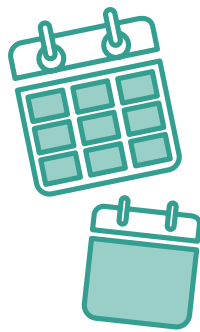
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We hope that you have enjoyed reading this progress report and we hope that the feedback obtained and summarised reflects some of your own views around progress against the UK Renal Research Strategy.

The aim of the review was to gather opinions from across our community, reignite the drive to realise our ambitions and ensure the ongoing relevance of the strategy in a changing renal landscape.

Progress relies on the good will and continued self-motivation of individuals who are dedicated to improving the health and quality of life of kidney patients and those at risk of kidney disease.

Change is undoubtedly happening but timeframes will vary considerably. But by continuing to work together, sharing ideas and experiences and working with other partners we can gather momentum, despite the many challenges we face.



What's clear is the need to find workable ways to measure progress so that an accurate review and regular assessment of the strategic aims and recommendations can be done.

So there will need to be consideration of the findings summarised in this report, and a plan of action developed based on the views with suggested ways forward for certain organisations and individuals.

## Acknowledgment

We would like to acknowledge the people who gave their time to be interviewed and those who provided their feedback without whom this progress report could not have been achieved. And to Kidney Research UK who commissioned an independent consultant to undertake and write this progress report.

# Abbreviations and acronyms

**ADPKD** Autosomal Dominant Polycystic Kidney Disease

**aHUS** Atypical Haemolytic Uremic Syndrome

**ASK** **Access to living-donor Kidney transplantation** – a trial which is looking at why people from certain social backgrounds are disadvantaged in terms of finding living kidney donors.

**ATTOM** **Access to Transplantation and Transplant Outcome Measures** – a study which aims to improve equity of access to kidney and pancreas transplantation across the UK and optimise organ allocation to maximise the benefit, including cost-effectiveness, from kidney and kidney-pancreas transplantation.

**BAME** Black, Asian and Minority Ethnic

**CKD** Chronic Kidney Disease

**IgAN** IgA Nephropathy

**INS** Idiopathic Nephrotic Syndrome

**KQulp** **Kidney Quality Improvement Partnership** – a national initiative to help improve kidney services.

**NephroS** The **National Study of Nephrotic Syndrome**

**NURTuRE** The **National Unified Renal Translational Research Enterprise** – the first and unique kidney biobank for chronic kidney disease (CKD) and idiopathic nephrotic syndrome (INS) covering England, Scotland and Wales.

**PIVOTAL** **Proactive IV irOn Therapy in haemodiALysis patients** – a pioneering clinical trial investigating the optimum amount of intravenous iron that can be given to patients on dialysis.

**PREM** **Patient Report Experience Measure** – a national annual survey of kidney patients.

**QUOD** **Quality in Organ Donation** – a national biobank resource focused on donated organ, tissue and blood samples.

**RaDaR** The **National Registry of Rare Kidney Diseases** is a Renal Association initiative designed to pull together information from patients with certain rare kidney diseases.

**SONG** **Standardised Outcomes in Nephrology** – an international initiative with aims to establish a set of core outcomes and outcome measures across the spectrum of kidney disease for trials and other forms of research.

**SPEAK** **Surveying People Experiencing young Adult Kidney failure** – the first national survey of young adults on kidney replacement therapies to investigate the impact of permanent kidney failure of the lives of young people in the UK.



## Thank you

We are grateful to all the individuals who gave up their time to provide feedback for the UK Renal Research Strategy Progress Report 2019.

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