KIDNEY HEALTH: DELIVERING EXCELLENCE
A progress report for 2017
The Kidney Health work has nurtured improved quality of healthcare for patients with renal disease by championing the potential of a collaborative approach between professionals and patients.

Dr Richard Baker: Chair, NHS England Clinical Reference Group for Renal Services; Consultant Nephrologist, Leeds Teaching Hospitals Trust
A VISION FOR FUTURE, BETTER, KIDNEY CARE

Welcome to the review of the Kidney Health: Delivering Excellence (KHDE) report that was published in October 2013. The KHDE report was produced in a close collaboration between kidney patients and clinicians, with input from primary care, allied professionals, commissioners and policymakers. The ultimate goal of the report was to bring about improvements that would benefit kidney patients. This progress review is based on a series of qualitative interviews with co-authors of the original report and key figures within the kidney community, together with a short stakeholder survey.

We hope that the KHDE ambitions are your ambitions too and that everyone reading this report will use them to promote better care, whether you are a patient, a doctor, a nurse, a member of our multi-professional teams, a commissioner or a provider of kidney services. Together we are stronger.

EXECUTIVE SUMMARY

The two National Service Frameworks (NSF) for Kidney Care produced in 2004 and 2005 provided a ten-year strategic guide for kidney professionals and policy makers. In 2012 the kidney community agreed to come together to create a vision for future kidney care. This vision was articulated in the 16 ambitions of the 2013 Kidney Health: Delivering Excellence report. The report reviewed progress against the NSF; it did not seek to specify what a service should look like, but instead it tackled the more fundamental matter of what a service should achieve from the patient perspective. The intention was that this would encourage national and local policymakers to decide how best to deliver the service, allowing for local conditions, and maintain the relevance of the ambitions in a changing NHS landscape.

This review summarises the progress made against the community’s ambitions. We believe that the Kidney Health report has been a positive force for change and shows clearly what we can achieve when we work together for a common goal. After its launch, a high level of awareness of the report was achieved at national level. It has had a significant impact and has led to, or influenced, a number of important initiatives that are contributing towards the delivery of many of its ambitions. However it is also clear that work needs to continue in order to achieve further improvements for kidney patients. Some areas in the report are largely unaddressed; others are the subject of initiatives at very early stages of development.

We have heard consistently that the messages of KHDE are as relevant now as in 2013. Secure in this knowledge, we look forward to working alongside stakeholders within the renal community and we call on all of them to continue to promote and realise our ambitions and, where necessary, challenge policymakers and the Government to deliver. The fact that the report was produced by patients and healthcare professionals is still as valid as ever. Given continuing support from the stakeholder organisations, we are confident that we will see further progress in our original ambitions over the next few years, together with an emphasis, reflected in an additional Kidney Health ambition, on promoting and enabling continuous quality improvement at all levels within our community.

Fiona Loud – Policy Director, British Kidney Patient Association
Hugh Gallagher – Consultant Nephrologist, St Helier Hospital
Joint Chairs, Kidney Health Partnership Board
THE KIDNEY HEALTH AMBITIONS

1. **Awareness**: People - both healthcare professionals and the general public - understand the factors that increase the risk of kidney disease, and action is taken to reduce these risks.

2. **Identification**: All people with kidney disease are correctly identified and monitored.

3. **Self-management**: All people with kidney disease are offered as much information as they would like in order to understand and manage their condition.

4. **Person-centred care**: Care is centred on the person, taking into account individual needs and preferences, quality of life, symptom burden and the presence of co-existing medical conditions.

5. **Acute Kidney Injury**: Avoidable harm related to acute kidney injury is prevented in all care settings.

6. **Preparation and Choice**: All people approaching end-stage renal disease, or moving from one type of treatment for end-stage renal disease to another, understand and are given sufficient time and support to prepare for a treatment that is suitable for them, chosen from the full range of options, including home dialysis therapies, transplantation and conservative care.

7. **Equity in Transplantation**: Listing for transplantation is based solely on clinical need and suitability, and is not influenced by ethnicity, socio-economic status, or where the potential transplant recipient lives.

8. **Increasing Transplantation**: The number of transplants, from both living and deceased donors, is increased such that all people likely to benefit from a transplant have the opportunity to receive one.

9. **Living well with a transplant**: A person who receives a transplant is enabled to manage their transplant and is supported to achieve the greatest possible benefit from it.

10. **Dialysis as a specialised service**: Dialysis care (including preparation for dialysis) continues to be commissioned as a service which is delivered against national standards, is nationally accountable, and is provided by kidney units with the capacity and workforce necessary for all patients to receive high quality dialysis using their chosen method.

11. **Lifestyle on dialysis**: People receive all of the information and education they require to engage fully in the planning and delivery of their dialysis, and are supported to minimise the detrimental impact of treatment on their lifestyle and to self-care if they wish.

12. **Care for children and young people**: All children and young people with chronic kidney disease have unrestricted access.

13. **Allied Services**: All people with kidney disease know about, and have access to, a specialist multi-professional team.
14. **Expert care in rare kidney diseases and in pregnancy:** All people with rare diseases affecting the kidney, and women with chronic kidney disease who are contemplating pregnancy, have unrestricted access to expert advice and care wherever they live and whenever it is needed.

15. **Research:** A research strategy for kidney disease is developed, supported by the funding required to design and conduct high quality studies, and used to further understanding of the mechanisms of disease and improve healthcare quality and outcomes.

16. **Conservative care:** All people who opt for conservative non-dialytic management of their kidney disease or choose to discontinue dialysis treatment are supported by a multi-professional team working closely together to ensure a smooth transition to palliative and end-of-life care.

17. **NEW Quality Improvement:** The kidney community promotes, encourages and supports continuous quality improvement and sharing of best practice by all healthcare workers to deliver better, safer, less variable and more efficient care.

‘Patients have been fully integrated as advisors at all stages of the Kidney Health programme. As a result, the outcomes and ambitions are based on improving the burden of treatment and not only looking at kidney disease itself. I’m particularly pleased that Ambition 17 has been added which focuses on improving quality and safety of patient care.’

*Tracey Rose, patient member of Kidney Health Partnership Board*
REVIEW FINDINGS

Our research strongly suggests that the KHDE report has had a significant and broad impact for the benefit of kidney patients.

There are two passages in the Executive Summary of the 2013 Kidney Health: Delivering Excellence report that describe clearly what the report set out to achieve:

‘Kidney Health: Delivering Excellence gives a voice to the ambitions of all those who understand and care about kidney services. It offers a view of kidney care from the whole kidney community, which means people affected by kidney disease and their families and carers as well as the many different groups of healthcare professionals who support and treat them.’

‘We do not presume to propose solutions. Our ambitions are independent of future changes in the structure of the NHS, whilst the solutions may not be. Our report sets the benchmark against which developments in NHS policy, structure, planning and operations can be measured by the kidney community. It must also be used by our community to justify and stimulate new initiatives to address the shortfalls we have identified.’

Following the publication of the 2013 report, a board was formed consisting of representatives from most of the organisations involved in kidney health, including kidney patients (the KHDE Partnership Board). This body continues to meet regularly with representatives from the delivery bodies (NHS England, NHS Blood and Transplant and Public Health England) to review implementation and discuss progress.

‘It championed the patient voice. It was picked up by a wide group of national and regional bodies and policymakers.’

Hugh Gallagher: Consultant Nephrologist, Epsom and St Helier NHS Trust

The KHDE Report was a stimulus that initiated or influenced numerous programmes from diverse bodies including NHS England, the Renal Registry and others. The report continues to guide and shape these initiatives as they develop. All of the interviewees for this progress report stated that they continue to refer to the report regularly. Full details of dissemination and exposure of the 2013 report can be found in Appendix 4.
The primary publicity for the 2013 report was extensive in the first 6 months and was sustained over a period of at least 12 months following the launch.

The report was created to be a stimulus for initiatives and discussion and was primarily aimed at national key opinion leaders, policymakers and organisations, including the organisations represented on the KHDE Board.

The results of the survey conducted as part of this progress report suggest that the report and the primary publicity were successful in reaching the main organisations in the kidney community.

The survey also indicated that KHDE may have been less effective in reaching some parts of the workforce and individual kidney patients.

The impact of KHDE is perhaps best illustrated by considering the number of important national and regional programmes that were initiated in response to the report or influenced by it.

- The Think Kidneys Acute Kidney Injury programme (1), a major initiative for the NHS England patient safety team, was significantly influenced by ambition 5, that ‘Avoidable harm related to acute kidney injury is prevented in all care settings’. Using the report as a strategic framework, the former National Clinical Director (NCD) was able to make the case for funding, resulting in a significant set of resources, a mandatory patient safety algorithm and an award-winning publicity campaign, supported by a programme team from the UK Renal Registry (UKRR).

- Transforming participation in Chronic Kidney Disease (2). The NCD also took the KHDE ambitions to the NHS England patient experience team, who provided the funding for a programme team run by the UKRR. The TP-CKD project was created to understand whether quality of life interventions can improve health outcomes, and directly reflects KHDE ambitions for kidney patients.

- The pan-London review of services delivered to kidney patients. This was led by Barts and the Royal London Renal Unit. Local patients selected the patient-centred care ambition (ambition 4) that ‘Care is centred on the person, taking into account individual needs and preferences, quality of life, symptom burden and the presence of co-existing medical conditions’ as the ambition in greatest need of progress. This powered a pan-London review of services from 2014-16, which is being used to generate local improvement and will be fed into the NW London Sustainability and Transformation Partnership plans.

- The National Renal Research Strategy (3) relates to ambition 15, and articulates a research strategy for kidney disease to unite the whole kidney professional and patient community and to provide information and evidence for funders, policymakers and those helping to create and support the next generation of researchers.

- The Kidney Quality Improvement Partnership (KQuiP) (4) is an inclusive national quality improvement initiative supported by kidney professional organisations, patient organisations, NHS England and the UK Renal Registry. It should be seen as a major opportunity to consolidate the role of the multi-professional kidney team.
We carried out an on-line survey in order to ascertain the full breadth of dissemination and adoption of findings for the purpose of this three-year review. 127 responses were received; 31% were from people (patients/carers) affected by kidney disease. We also conducted qualitative interviews with: the report’s co-authors; a senior Renal Nurse; the Chief Executive of the Renal Registry and the former Renal National Clinical Director. We presented and discussed the findings with the Kidney Health Delivering Excellence Partnership Board.

‘For the first time a strategic document looked at what patients really think and how they can impact on practice and outcomes.’

Fiona Loud : Policy Director, The British Kidney Patient Association

KEY MESSAGES:

85% of respondents said they thought drawing up ambitions in this way was important.

The ambitions considered to be most important were related to patient-centred care and self-management.

53% of respondents thought the document had had an influence on national policy in kidney care.

The interviewees were strongly of the opinion that the KHDE report had overall been an important force for change.

35% of survey respondents felt that the KHDE report had impacted significantly on the care received by patients at a local level.

Some patients and clinicians were unaware of the link between local delivery initiatives and the KHDE report.

All interviewees were strongly of the opinion that the report had both stimulated fresh initiatives and had been crucial in shaping other initiatives as they evolved.

Respondents to the survey were not convinced that improving kidney care is a current priority for the NHS, and felt more should be done to lobby policymakers.

Education and raising awareness of the messages in the report amongst healthcare professionals working “on the ground” was considered to be important.
PROGRESS AGAINST SPECIFIC AMBITIONS:

Increasing kidney transplantation was raised as important and in need of progress.

Raising awareness of the importance of looking after kidneys was also considered important; the perception was that some progress had been made here.

Acute Kidney Injury (AKI) was the ambition against which it was reported that the greatest amount of progress had been made.

It was felt that progress had been made against research ambition 15 with the creation of the UK Renal Research Strategy.

We received a small number of comments on rare diseases but are encouraged by the continued excellent progress of the RADAR rare disease database.

WHERE NEXT?

The kidney organisations who expressed an opinion remain committed to the ambitions in the KHDE report.

The report is considered still relevant.

The ambitions are seen as long-term goals for patients and professionals alike and need to remain in place, without major modification.

Some initiatives are still in development and are not yet visible at local level.

More work is needed in some specific areas; the survey indicates the three areas needing greatest input are self-management (45%), person-centred care (35%) and increasing transplantation (33%).

Our member organisations support continuing to raise the profile of Kidney Health across a wide range of communications channels.

Local Kidney Patient Associations, national patient charities and professional bodies have a role to play in this.

There was a strong view that significant progress can be made within the kidney community by patient and professional bodies continuing to take active ownership of individual ambitions.
‘It provided a framework within which everyone could work. There was probably a lot of work going on, but much of it was not coordinated and might not have been heading in a common direction. This report provided the direction and a framework within which to coordinate the work.’

**Ron Cullen: Chief Executive, The Renal Registry**

‘It has helped build closer relationships between patients and professionals by showing that they can come together to create a common view on what a service should be.’

**Richard Fluck: former National Clinical Director, Renal, NHS England and Consultant Nephrologist, Royal Derby Hospital**

**THE FUTURE**

- The findings support a need to drive the awareness and implementation of the report and in particular highlight the need for activities to raise awareness of the report with patients and professionals at a local level.
- We believe that all our stakeholders will be encouraged by the outcomes of the Kidney Health work so far, and will continue to devote focus and energy towards achieving our community’s ambitions.
- Effecting change in the medium to long term remains a key goal, and a consistent set of reference ambition statements will help in achieving this, particularly in a changing NHS environment.
The KHDE report now forms the strategic framework for a significant and increasing number of initiatives that are being developed by various organisations to address many of the report’s ambitions. Rather than making major changes at this stage, the emphasis should be on driving forward implementation work. In response to the feedback received we have added one new ambition to draw attention to the overarching importance of quality improvement to deliver better kidney care.

There are two other small changes to the ambitions. For ambition 6, Preparation and Choice, we have made clear that the list of treatments offered should include home therapies, transplantation and conservative care. For ambition 10, Dialysis as a Specialised Service, one phrase has been amended as highlighted: Dialysis care (including preparation for dialysis) continues to be commissioned as a service which is delivered against national standards and is nationally accountable, and is provided by kidney units with the capacity and workforce necessary for all patients to receive high quality dialysis using their chosen method.

It is not clear how dialysis services will be commissioned in the future. To date, dialysis has retained its specialised commissioning status (Ambition 10), but the best commissioning model in the long term has yet to be established. Any future solution must have buy-in from the whole community, which KHDE helps to bind together. The partnership between the kidney organisations and the delivery bodies that has grown out of the KHDE report should be seen as an opportunity for these structures to collaborate and help redesign the patient pathway. We have strengthened this ambition to demonstrate our commitment to a service which is delivered against national standards and is nationally accountable.

In the long term and with the loss of the Renal National Clinical Director role in NHS England, the galvanisation of MPs and Peers to understand and support renal services is more important than ever. There is a risk that by over-focusing on specific priority areas of medicine (e.g. diabetes) NHS England might fail to see the risks of denuding other areas. The evidence from our survey was that the renal community must do more in this area and that the KHDE Report could provide a focus for this. Not only does it continue to be an overarching strategic framework that guides and shapes new projects, ensuring that these meet the needs of patients, but it also paints a clear and concise picture of a major disease area that is interlinked with several others, most notably diabetes and cardiovascular disease.
CONCLUSIONS

1. The KHDE Report was well-publicised following its publication. It achieved a high level of visibility across national professional and patient organisations and national level policymakers.

2. The KHDE Report has not been as visible as we would have liked at local level amongst individual patients and professionals. This weakens its influence as an overarching strategy against which to measure the effectiveness of local and national initiatives to improve services. It also restricts the report’s role in driving and shaping local service design. This is an area that needs attention. Where the report was exposed at a local level at Barts and the Royal London Hospitals it had a major effect.

3. The KHDE Report had an important impact on kidney health policy at national level, resulting in numerous initiatives for patient benefit that have the stated aim of contributing towards the achievement of one or more ambitions. At this level, and for some ambitions, the report is therefore achieving its objectives.

4. The success of national initiatives such as the NHS England Acute Kidney Injury programme demonstrates that clear articulation of a vision shared by patients and professionals can be an effective means of encouraging national level policymakers to support and deliver major improvements in patient care.

5. It is essential to continue to press for active support from policymakers, in conjunction with national groups like the Clinical Reference Group, and especially through the kidney organisations working together.

6. The ambitions should largely remain as originally drafted in order to provide a clear and consistent strategic framework within which initiatives can be developed and their impact measured. We have recommended the inclusion of a new Quality Improvement ambition to make the point that continuous QI should be a core activity for all of us.

7. Following the completion of the Royal College of General Practitioners’ Kidney Care priority programme it is important to maintain the profile of kidney disease within primary care (5). We must both adapt and reach out to the Royal Colleges, Public Health England, existing National Clinical Directors, devolved nations and support new initiatives as they arise.
THE FOLLOWING RECOMMENDATIONS ARE MADE:

1. A continued role for the KDHE Partnership Board and a reaffirmation of its overarching responsibilities: to maintain oversight of progress against the ambitions; and to provide an interface with the delivery bodies, including the renal services Clinical Reference Group. Where relevant the KHDE Board should seek assurances from policymakers on accountability for specific ambitions, including the new Quality Improvement ambition.

2. The KHDE Board should develop a plan to raise awareness of the ambitions within the report, and consider a targeted campaign to engage with staff and patients at ground level.

3. The KHDE Board should continue to be sighted on progress, both overall (strategically) and in the individual initiatives within the kidney community that are addressing KHDE ambitions.

4. The KHDE Board should look carefully at the ambitions noted as having made less progress and evaluate whether forthcoming activities offer opportunity for improvement, and, if not, consider how progress might be made.

5. Efforts should also be made to maintain engagement with primary care, through the KHDE Board and its constituent organisations.

This report has been based on a sample of 127 responses in the on-line survey and five qualitative interviews. This provides limited coverage of the main target audiences and the depth of information is also limited. We recognise that the findings may be influenced by the interests and affiliations of the respondents.

In noting the conclusions and recommendations, the above should be taken into consideration and we have taken care not to over-interpret the results of the on-line survey. However, the quality of information and the consistency of the feedback from the responders go a long way towards compensating for the small sample size.

DECLARATION OF INTEREST

The interpretation of the survey results and initial drafting of the progress report has been prepared by Decideum Ltd. The main person carrying out this work was also the main adviser on policy and political matters to the Kidney Alliance and was involved in the development and authoring of the Kidney Health: Delivering Excellence report.

Acknowledgements

We are grateful to the following individuals for giving up their time to provide feedback during the qualitative interviews.

Ron Cullen Chief Executive, The National Renal Registry
Richard Fluck Former National Clinical Director, Renal, NHS England and Consultant Nephrologist, Royal Derby Hospital
Hugh Gallagher Consultant Nephrologist, Epsom and St Helier NHS Trust
Fiona Loud Policy Director, The British Kidney Patient Association
Breeda McManus Consultant Renal Nurse, St Bartholomew’s Hospital, London

We are equally grateful to all the people who responded to the on-line survey and to the members of the Kidney Health Partnership Board, including kidney patients, the British Kidney Patient Association, the National Kidney Federation, Kidney Research UK, the Polycystic Kidney Disease Charity, the Renal Association, the British Renal Society, UK Renal Registry, NHS England, NHS Blood and Transplant, Public Health England.
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<tr>
<th>AMBITION</th>
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<tr>
<td>Awareness: People - both healthcare professionals and the public understand the factors that increase the risk of kidney disease, and action is taken to reduce these risks.</td>
<td>Think Kidneys <a href="https://www.thinkkidneys.nhs.uk/campaign/">https://www.thinkkidneys.nhs.uk/campaign/</a></td>
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<td>Think Kidney Renal Registry AKI master patient index (in development) CKD Assist <a href="https://www.kidneyresearchuk.org/research/assist-ckd">https://www.kidneyresearchuk.org/research/assist-ckd</a></td>
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<td>The CVD Collaborative, managed by Public Health England</td>
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<td>Self-management: All people with kidney disease are offered as much information as they would like in order to understand and manage their condition.</td>
<td>The Think Kidneys Transforming Participation in CKD (TP-CKD) <a href="https://www.thinkkidneys.nhs.uk/ckd/">https://www.thinkkidneys.nhs.uk/ckd/</a></td>
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<td></td>
<td>Kidney Quality Improvement Partnership (KQUIP) <a href="https://www.thinkkidneys.nhs.uk/kquip/">https://www.thinkkidneys.nhs.uk/kquip/</a></td>
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<td>Renal Registry AKI database <a href="https://www.thinkkidneys.nhs.uk/aki/">https://www.thinkkidneys.nhs.uk/aki/</a></td>
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<td>Living well with a transplant: A person who receives a transplant is enabled to manage their transplant and is supported to achieve the greatest possible benefit from it.</td>
<td>The ATTOM Study <a href="https://www.renalreg.org/research/access-to-transplantation-and-transplant-outcome-measures-attom/">https://www.renalreg.org/research/access-to-transplantation-and-transplant-outcome-measures-attom/</a></td>
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<td>Dialysis as a specialised service: Dialysis care (including preparation for dialysis) continues to be commissioned as a specialised service, and is delivered by renal units with the capacity and workforce necessary for all patients to receive high quality dialysis using their chosen method.</td>
<td>2014 announcement from NHS England to maintain commissioning of dialysis as a specialised service and to explore alternative collaborative commissioning models through cooperation with kidney community representatives.</td>
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<td>AMBITION</td>
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https://www.thinkkidneys.nhs.uk/kquip/ |
| Care for children and young people: All children and young people with chronic kidney disease have unrestricted access to a service specifically designed to meet their needs. | Ready, Steady, Go  
| Allied Services: All people with kidney disease know about, and have access to, a specialist multi-professional team. | KQuIP |
| Expert care in rare kidney diseases and in pregnancy: All people with disease who are contemplating pregnancy have unrestricted access to expert advice and care wherever they live and whenever it is needed. | The RADAR database is developing well, with over 10,000 patients with rare diseases now registered  
http://rarerenal.org/radar-registry/ |
| Research: A research strategy for kidney disease is developed, supported by the funding required to design and conduct high quality studies, and used to further understanding of the mechanisms of disease and improve healthcare quality and outcomes. | The National Kidney Research Strategy.  
https://www.kidneyresearchuk.org/research/uk-renal-research-strategy |
| Conservative care: All people who opt for conservative non-dialytic management of their kidney disease or choose to discontinue dialysis treatment are supported by a multi-professional team working closely together to ensure a smooth transition to palliative and end-of-life care. | End of Life care strategy at NHS England  
https://www.gov.uk/government/policies/end-of-life-care |
APPENDIX 2: METHODOLOGY

The progress report looks at early progress against our ambitions, which largely occurred at a national level. For this reason, the sample group was kept relatively small and included people who were either involved in its publication or who were in the first line of recipients, and were expected to initiate its implementation.

The research consists of two components. The first component is an on-line survey conducted in April/May 2016. The survey received 127 responses. The respondents were from the following groups:

- 31% affected by kidney disease
- 21% kidney nurse
- 34% kidney doctor
- 8% allied healthcare
- 6% other

The second component is a series of five qualitative interviews, using the same overall discussion guide. This means each interview had broadly the same structure and similar questions were asked in each case.

THE RESULTS FROM THE INTERVIEWS AND THE SURVEY WERE COLLATED AND ANALYSED, IDENTIFYING COMMON THEMES WHERE POSSIBLE.

- 50% of respondents to the survey were very or somewhat familiar with the document. However, over a quarter (26%) had not heard of it. We do not know if this 26% came from within one or a small number of sectors of the kidney community.
- 85% of responders said they thought drawing up ambitions in this way was important.
- There was strong support for further awareness-raising support across a wide range of communications channels. Responders clearly thought that continuing to raise awareness of the ambitions is an important task for the kidney community.

IMPACT

- A little over half of respondents (53%) thought the document had had an influence on national policy in kidney care. However respondents were not convinced that improving kidney care is a current priority for NHS policymakers and felt more should be done to lobby policymakers in NHS England.
- The ambitions considered to be most important revolved around patient-centred care and self-management. Increasing kidney transplantation rates was specifically raised as important.
- Although over half of the respondents thought the report influenced national policy, significantly fewer (35%) thought the report had had an impact on their local care and only 4% thought the impact was major.
- By far the ambition against which progress had been made was AKI. It is also worth noting that responders thought significant progress had been made against the research ambition.
The following section gives more detail on some national projects that are taking forward the ambitions.

**Acute Kidney Injury (AKI)**
According to the interviewees, a major initiative within NHS England tackling acute kidney injury (AKI) was significantly influenced by the KHDE Report. Hundreds of people have been involved in developing and providing input into the compilation of this Registry database.

The national AKI programme includes seven work streams covering topics such as hydration, research, education and interventions. Many of these work streams link to other more general initiatives within the NHS. For example, the hydration work stream links to the NHS England Patient Safety Domain.

**Chronic Kidney Disease (CKD)**
The UK Renal Registry is starting to gather more complete data along the whole patient pathway, including primary and secondary care, driven by the KHDE Report and its ambitions.

**The Think Kidneys initiative**
This is another initiative run by the Renal Registry. It provides a web-based resource of information, education and training materials and tools aimed at patients, carers, health care professionals, researchers and commissioners. It started as an initiative relating to AKI but has now been broadened to cover AKI, CKD and quality improvement. Think Kidneys also publicises events relating to kidney care and provides a forum to promote the exchange of information, particularly between patients and carers.

**Patient Reported Outcome Measures**
Ambition 4 places emphasis on patient-centred care that takes account of individual needs. This prompted a successful application for funding the Transforming Participation in CKD programme, which includes work to develop Patient Reported Outcome Measures (PROMs).

**Patient activation**
Ambition 3 draws attention to self management and the need to ensure patients have as much information as they need to manage their own condition. This has been also tackled in the Transforming Participation programme through a set of ten pilots looking at patient activation in kidney care.

**Patient Reported Experience Measures**
The first PREM survey, developed by the BKPA and the UK Renal Registry, was launched in 2016, with 8,000 responses. The PREM is presently being evaluated and validated for future use to encourage action by renal units and create a greater understanding of how kidney patients experience their care.

**Quality improvement**
On a national level KQuP has recently been launched by the kidney community. It is an inclusive national quality improvement initiative supported by kidney professional organisations, patient organisations, NHS England and the UK Renal Registry. It should be seen as a major opportunity to consolidate the role of the multi-professional kidney team.
### APPENDIX 4 : PUBLICITY FOR THE 2013 REPORT

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<tr>
<th>PRIMARY PUBLICITY</th>
<th>SECONDARY PUBLICITY</th>
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<tr>
<td><strong>Direct distribution</strong></td>
<td>The former National Clinical Director, Renal used the report to hold discussions with other officials in NHS England, eventually resulting in a number of initiatives *see Impact section</td>
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<tr>
<td>The report was presented at the annual clinical directors meeting and sent to all clinical directors of renal units.</td>
<td>The Renal Advisory Group (RAG) accepted and adopted the recommendations</td>
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<td>Copies of the report were handed out at the National Kidney Federation kidney patient associations meeting in March 2014.</td>
<td>St Bartholomew’s Hospital organised two patient engagement events aimed at developing tools from the report. These events positioned patients to the fore and approached the ambitions from the patient perspective.</td>
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<tr>
<td>The report was published on the website of every organisation that endorsed it, that is seven of the main patient and professional organisations working in kidney care.</td>
<td>A patient Expo was held at St Bartholomew’s Hospital in May 2015. This started by talking about existing services and reviewing them in the light of the ambitions in the KHDE report.</td>
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<tr>
<td>A summary of the paper was published on the British Renal Society website.</td>
<td>Through St Bartholomew’s Hospital, the peer review aspects of the ambitions were fed directly into the Pan London scheme and so ambitions were used as quality standards in the scheme.</td>
</tr>
<tr>
<td><strong>Media and Parliamentary</strong></td>
<td>The Renal Registry took the report and discussed it widely through workshops and in particular with NHS England.</td>
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<tr>
<td>A parliamentary event was held to mark the launch at which the Parliamentary Under Secretary of State for Public Health, Jane Ellison MP, welcomed the report.</td>
<td>The Renal Registry used the KHDE Report as a strategic framework for the Registry’s programme of activities and this has led to a number of initiatives *see Impact section.</td>
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<td>A news release was drafted and distributed. This resulted in an article in the Daily Telegraph.</td>
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<td>An article was published by the National Association of Primary Care (NAPC).</td>
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<td>A series of syndicated local radio interviews was carried out</td>
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<td><strong>Conferences</strong></td>
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<td>At the British Renal Society spring conference in 2014, a small reminder card was placed in every delegate pack.</td>
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<tr>
<td>In the course of the 12 months following its publication, Fiona Loud of the BKPA, carried out numerous local and national presentations and the report was featured in Kidney Week in 2014.</td>
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<tr>
<td><strong>Local meetings</strong></td>
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<tr>
<td>Fiona Loud presented the report to patients and senior staff at a meeting at St Bartholomew’s Hospital.</td>
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<tr>
<td>A presentation was also given to the Yorkshire and Humberside Strategic Clinical Network and copies of the report were given to all members of the network.</td>
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</table>
1. https://www.thinkkidneys.nhs.uk/aki/
2. https://www.thinkkidneys.nhs.uk/ckd/
Kidney Health: Delivering Excellence

The Kidney Health Partnership Board

Enquiries to the authors via info@britishkidney-pa.co.uk or through the organisations below. Copies of the original Kidney Health: Delivering Excellence report are available on most of our websites e.g. www.britishrenal.org/quality-improvement-clinical-practice/kidneyhealth/

British Association for Paediatric Nephrology www.bapn.org.uk
British Kidney Patient Association www.britishkidney-pa.co.uk
British Renal Society www.britishrenal.org
British Transplant Society www.bts.org.uk
Kidney Research UK www.kidneyresearchuk.org
PKD Charity www.pkdcharity.org.uk
National Kidney Federation www.kidney.org
Renal Association www.renal.org
UK Renal Registry www.renalreg.org