



Think Kidneys National AKI Programme

Review and Evaluation Report



Think Kidneys is a national programme led by
NHS England in partnership with UK Renal Registry

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1. Foreword

I am delighted to present this report which evaluates the work of the Think Kidneys Acute Kidney Injury (AKI) Programme on behalf of the Programme Board. The suffering of AKI to individuals and the consequent increased cost to the health economy is well documented, and the NHS is the first health care system in the world to address this global challenge at a national level.

It is now four years since the National Patient Safety team, now part of NHS Improvement, decided to prioritise a programme of work to improve the management of AKI and the benefits of this work are being felt across almost every part of the NHS. In those four years, the AKI programme has created the platform for significant improvement in the management of AKI at a local level as well as raising awareness with staff and the public on the importance of keeping kidneys healthy.

The initial ambition for the Think Kidneys AKI national programme was to:

- Establish the data flows to allow successful audit and quality improvement
- Provide clinicians and patients with the education, information and access to and about acute kidney injury to inform individual care
- Support commissioners and organisational leads in driving and championing the need to improve acute kidney injury care.

While the AKI programme was never intended to be a panacea or magic bullet for AKI, it has without doubt raised awareness of AKI across every sector of the NHS and beyond and has improved systems and delivery of care.

As this has been a national programme undertaken in conjunction with NHS England and later NHS Improvement, it has benefited from a national CQUIN, two Patient Safety Alerts and collaboration with the Patient Safety Collaboratives.

Renal disease, and particularly AKI, cannot be separated from many other health conditions – long term conditions such as coronary heart disease or diabetes and dementia all increase the individual's risk, as well as acute episodes in hospital, and for all of us, the ageing process. The success of the programme, not only in what it has delivered but also in the way it has worked, should be celebrated. The challenge now for the NHS is to maintain the momentum gained by the development of these resources so that AKI continues to be in the forefront of people's minds when they are addressing safety within their organisations.

I want to thank everyone for their commitment and enthusiasm to the programme. I recognise that for many their time devoted to working on the programme has been competing with demanding clinical work and other important priorities.

I am pleased this report provides a summary and early evaluation of the impact and success of the programme. This report is not able to quantify lives saved; bed days saved, or pain and suffering reduced as a result of the resources, technological advances and improved measurement and reporting capability brought about by the programme. However, the evidence we do have demonstrates that the programme

has had wide reach. Working across England the programme has raised levels of awareness of AKI, educated people and, most importantly, improved safety for patients and increased efficiency in the face of continuing financial constraint.

One of the outstanding characteristics of the programme has been its range. Working with primary and community care, especially the work with GPs and their teams and the care home sector, has been a successful factor of the programme and demonstrates clearly that patient safety is the responsibility of everyone working to provide health and social care, regardless of position.

I hope you enjoy reading this report. Further information about the programme can be found at www.thinkkidneys.nhs.uk and this website will be updated and maintained as an important part of the legacy of this successful programme of improvement work.

Please accept my best wishes,



Dr Mike Durkin
NHS National Director of Patient Safety
NHS Improvement

2. Welcome and Introduction

Welcome to the final report of the National Acute Kidney Injury programme, Think Kidneys. Working as a partnership between NHS England and the UK Renal Registry the programme was established to reduce the burden that acute kidney injury brings to individuals and the healthcare system.

In 2013, World Kidney Day (WKD) focussed on AKI – common, harmful and potentially treatable – linked to more than 100,000 deaths per year and complicating illness for 20% of emergency admissions. At an event held to support WKD I talked about the evidence which showed there were failures in recognising AKI, missed opportunities to treat AKI and potentially avoidable deaths associated with AKI.

Several challenges were laid out. There was a need to improve preventative strategies – ensuring appropriate hydration, modifying drugs and understanding who was at risk. We need to enhance early diagnosis, using simple biochemical measures to generate warning results and provide simple and reliable guidance on treatment. The role of education of the NHS workforce and of the public and patients is vital to raising awareness of the critical role of the kidneys in health and illness. And on a system level, we must ensure commissioners and the NHS enable the system to be ‘kidney aware.’

Talking at that event, I said ‘To achieve sustained improvement we need to prioritise AKI as a major health issue. We need to reduce the harm that AKI results in. It needs the same systematic approach applied that has resulted in such an improvement in MRSA across the NHS.’

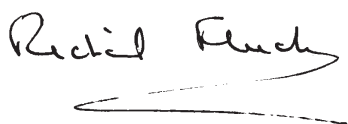
One year later, Think Kidneys was established. It is perhaps unique in the degree of collaboration between stakeholders and NHS structures, and in this we should include the distinctive contribution made by patient representative members on both the Board and the Workstreams. In just three years our work has dramatically increased the profile of AKI across the health care system. For example, it has deployed NHS Safety Alerts to mandate a national algorithm to improve detection of AKI. AKI was highlighted as a priority in the NHS Five Year Forward View and a national incentive scheme was mandated to improve communication between primary and secondary care. A national public awareness campaign was successful in raising the profile of kidney health. Advice and resources have been developed to support education of patients and professionals in all sectors of healthcare. Clinical management resources, again across professions and sectors, have been produced and are in use across the country. Finally, the engine for improvement, data on AKI is now flowing into the UK Renal Registry. Patient stories, experience and advice has been critical to driving the narrative.

So, this report is of use to anyone involved in healthcare. For commissioners and policy makers it provides the arguments for a focus on AKI as well as an example of sustainable change through partnership. For all professionals, be they working in a care home, a community pharmacy, and ITU or an admissions ward, AKI is relevant to them and better kidney care will improve outcomes for the people they look after. Principally for the public and patients this is for them, demonstrating that the NHS as a system can improve and has improved their care.

I need to thank so many people. There are literally hundreds of people who have been directly or indirectly involved in this work. They have been generous with their time, committed in their focus and awe inspiring in their intellect. A list of people involved in the Workstreams is on our website and

particular thanks are due to the chairs and co-chairs. The operational team at the UK Renal Registry, led by Karen Thomas have kept driving us forward. I have learnt so much about communication from the team that gave us the brand 'Think Kidneys', a name that people can identify with and is such a powerful message. Mike Durkin, now at NHS Improvement, and Martin McShane, formerly at NHS England, gave the programme the space and permission to get on and do it. Finally, the biggest thanks to Joan Russell and Ron Cullen, who formed that cabinet of ideas and leadership that has given us such a successful programme.

The NHS remains under huge pressure, managing what seem like impossible demands. There remains much to be done and the programme will continue albeit with a focus on data and improvement. But Think Kidneys would not have been achievable in any other healthcare system across the world and on such scale. It is something that we should be proud of as others look to us for solutions to the global healthcare problem that is AKI – common, harmful, treatable.



Richard Fluck

Former National Clinical Director (Renal), NHS England

Clinical Co-Chair Internal Medicine Programme of Care at NHS England

Consultant Nephrologist Derby Teaching Hospitals NHS Foundation Trust

3. The Case for the National Think Kidneys AKI Programme

AKI has been recognised as a global health issue and safety challenge for many years. The statistics support this and are a dramatic driver for change, pointing to the need to do things differently. Despite that challenge, the NHS is the first health system in the world to attempt to tackle AKI with a system-wide approach.

Well documented statistics speak for themselves in respect of AKI in the UK.

- Up to 100,000 deaths each year in hospital are associated with AKI¹
- Up to 30% of those deaths could be prevented with the right treatment and care¹
- It is estimated that 1 in 5 people admitted to hospital as an emergency has AKI²
- Around 65% of AKI starts in the community³
- Office of National Statistics for 2016 show there are almost 12 million people in the UK aged 65 or over - and all regions of the country are seeing a faster growth in those aged 65 and over than in younger age groups⁴. People of greater age are more at risk of AKI than the younger population
- 15 million people in the UK live with a long term condition which are more prevalent in older people⁵. This places them at greater risk of AKI
- The annual cost of AKI-related inpatient care in England is estimated at £1.02 billion, just over 1% of the NHS budget⁶.

Within the United Kingdom several policy publications resulted in response to the challenge of AKI. The National Institute for Health and Clinical Excellence (NICE) published guidelines on the clinical management of AKI in 2013 at which time they stated

"The National Institute for Health and Care Excellence (NICE) has published a new guideline which promises to save thousands of lives and hundreds of millions of pounds each year. Evidence suggests a lack of education about the condition among healthcare workers. The NICE guideline aims to raise awareness and recommends that AKI is tackled by people working in health across all specialties, not just renal units, from chief executives to healthcare assistants.... Early detection of AKI is a key priority and will prevent the patient's condition becoming critical... Small improvements in care have the potential to save thousands of lives each year."

AKI is also recognised as an international challenge. The International Society of Nephrology's '0 by 25'⁷ campaign recognises the need to raise awareness of AKI and improve care, through timely diagnosis and treatment.

The Think Kidneys programme was established to address the need identified by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) and NICE. Think Kidneys has responded by raising awareness of AKI, improving access to education, developing effective resources and sharing best practice across the NHS and beyond.

4. Why AKI is a Patient Safety Priority - the National Perspective from NHS Improvement

AKI is a sudden reduction in kidney function. It is not a physical injury to the kidney and often occurs without symptoms. In England over half a million people sustain AKI every year with AKI affecting 5-15% of all hospital admissions². As well as being common, AKI is harmful, associated with 40,000 excess deaths per annum of which up to a third may be preventable¹. AKI is costly to the health care system with estimates of between £0.5-1 billion excess cost per annum. Globally it is recognised as a major patient safety challenge for health care⁶.

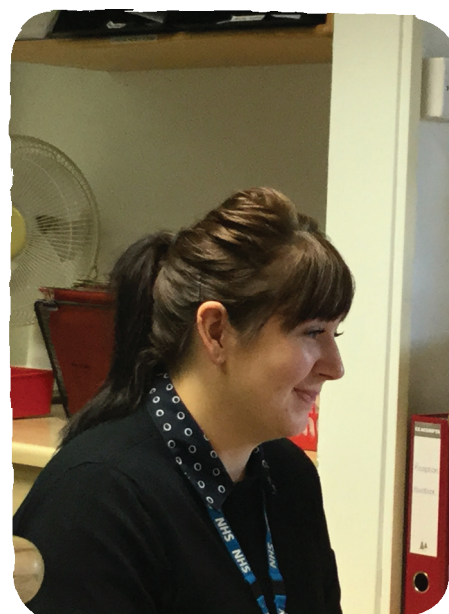
Evidence exists that care processes can be improved to provide better outcomes. The 2009 National Confidential Enquiry into Patient Outcome and Death (NCEPOD) Report demonstrated that a significant component of harm arises from poor standards of AKI care with limited access to specialist care and guidance. There was delayed diagnosis of AKI resulting in lack of treatment¹. Studies are beginning to emerge showing that improvements in basic care lead to better patient outcomes.

The Patient Safety Team of NHS Improvement (formerly NHS England) has provided patient safety leadership to the AKI programme. Working in partnership with the NHS England National Clinical Director for Renal and the UK Renal Registry this has provided the opportunity to improve in an area in which the level of avoidable harm is well recognised.

The Think Kidneys programme provided the opportunity for national support to this work through the development of patient safety alerts, commissioning levers – CQUIN and system levers – and Clinical Pathology Accreditation assessment. More recently the programme has achieved public and media recognition for the resources produced, the patient safety alerts and the public campaign. Through NHS England, and now NHS Improvement, Patient Safety engaged with all key stakeholders in relation to this work. For example, Patient Safety Alerts were approved by the NHS England Patient Safety Steering Group and supported by relevant Patient Safety Experts Groups (PSEG). Membership of the expert groups included relevant professional organisations, clinical experts, commissioners, the Care Quality Commission and patient representatives. The Steering Group included chairs of the seven PSEGS, senior leads from NHS England and other national organisations. (The PSEGS were disbanded in 2016 and at the time of writing a new partnership model is in development).

Think Kidneys also reported to the Patient Safety Steering Group and collaborative work led to the following outputs;

- Patient Safety Alert† – standardising the early detection of AKI, published June 2014
- Patient Safety Alert – sharing and signposting to Think Kidneys resources, published August 2016
- A national Commissioning for Quality and Innovation (CQUIN) payments scheme was developed for 2015/16 – and a local CQUIN for 2016/17 († more information on patient safety alerts can be found here on NHS Improvement's website)



1. National Patient Safety Alert - *Standardising the early detection of AKI*

This alert, issued in June 2014, identified actions to support the implementation of the nationally agreed AKI algorithm into laboratory information management systems. This in turn provides the framework to ensure that a timely and consistent approach to the detection and diagnosis of patients with AKI can be taken across the NHS. The alert also identified the requirement for warning stage test results identified by the algorithm, to be sent to a central point (the UK Renal Registry) for national monitoring purposes. Pathology laboratories were required to switch on the alert for secondary care in March 2015 and for primary care in April 2016.

2. National Patient Safety Alert - *Resources to support the care of patients with Acute Kidney Injury*

This Alert was issued in August 2016 to continue to raise awareness of AKI and to signpost clinicians from all care settings, including GPs and community pharmacists, to the resources developed by Think Kidneys. Following this alert the Think Kidneys website saw a dramatic increase in visits and download numbers.

3. Introducing the National CQUIN

In turn, Think Kidneys and NHS Patient Safety influenced the Five Year Forward View. Improving AKI was one of the priorities for operational delivery in NHS England's Five Year Forward View (into Action) in 2015/16 where it states:

'...NHS England has identified tackling sepsis and acute kidney injury as two specific clinical priorities for improving patient outcomes for 2015/16. Over a five year timeframe, improving care in these areas would have the biggest potential impact in reducing premature mortality. Sepsis and acute kidney injury will therefore form the basis of new national indicators for the 2015/16 commissioning for quality and innovation (CQUIN) incentive framework.'

The CQUIN scheme was intended to deliver clinical quality improvements and drive transformational change. Their intended impact was to reduce inequalities in access to services, improve the experience and outcomes for patients accessing the service.

The AKI CQUIN was designed to improve the recovery of individuals with AKI and to ensure appropriate follow up to minimise short and long term consequences. It was originally planned to run over three years but was retired as a national CQUIN after 12 months. It remains available as a local scheme.

The change required was that the discharge summary includes each of four key items:

1. The stage of AKI (a key aspect of AKI diagnosis) and primary diagnosis;
2. Evidence of medicines review having been undertaken (a key aspect of AKI treatment)
3. The type of tests required on discharge; for monitoring (a key aspect of post discharge care);
4. The frequency of tests required on discharge for monitoring (a key aspect of post discharge care).

The data source for the CQUIN was the discharge summaries of patients identified with AKI. The data sample presented here is taken from laboratory Information management systems' CQUIN Elements: discharge summary items on AKI

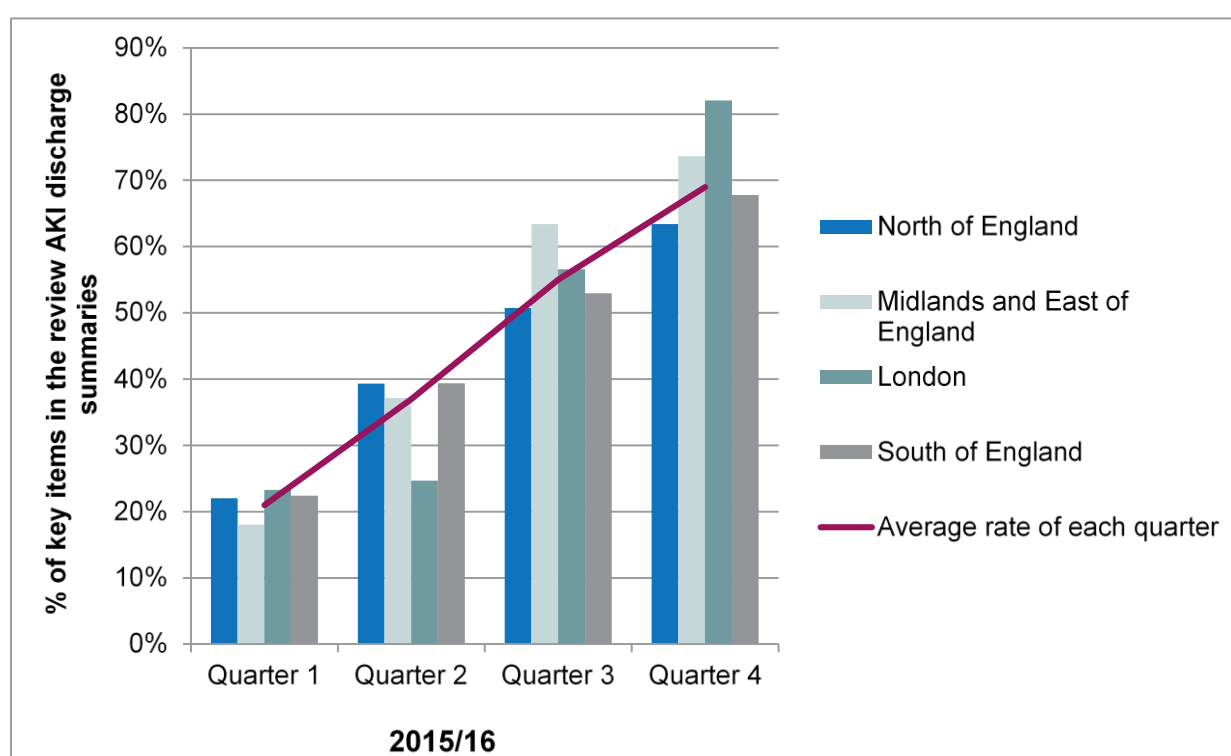
- Stage of AKI (a key aspect of AKI diagnosis)
- Evidence of medicines review having been undertaken (a key aspect of AKI treatment)

- Type of blood tests required on discharge for monitoring (a key aspect of post discharge care)
- Frequency of blood tests required on discharge for monitoring (a key aspect of post discharge care)

In 2015/16 data from over 29,000 episodes of AKI provided data for the CQUIN compliance.

The impact of the CQUIN can be seen in the chart below. Across the year of operation of the CQUIN, organisations and regions rapidly improved the quality of information within records of individuals who had had an episode of AKI. This implied better in-hospital recognition and treatment and improved follow up within primary and secondary care.

Figure 1: Proportion of completed key items assessed in AKI patients' discharge summaries by region (Quarter 1 2015/16 to Quarter 4 2015/16, England)



In summary using national levers has given purpose and momentum to the work of Think Kidneys. It supported the use of commissioning tools to improve detection and treatment through the patient safety alerts and the CQUIN.



Your kidneys are amazing

They filter your blood 40 times a day through 140 miles of tubes and a million filters.

They produce 1.5 litres of urine a day to get rid of toxins and waste products from your body.

You can help your kidneys to work better by staying hydrated.

‘THINK KIDNEYS’

Visit www.thinkkidneys.nhs.uk
Or talk to your GP or pharmacist to find out more

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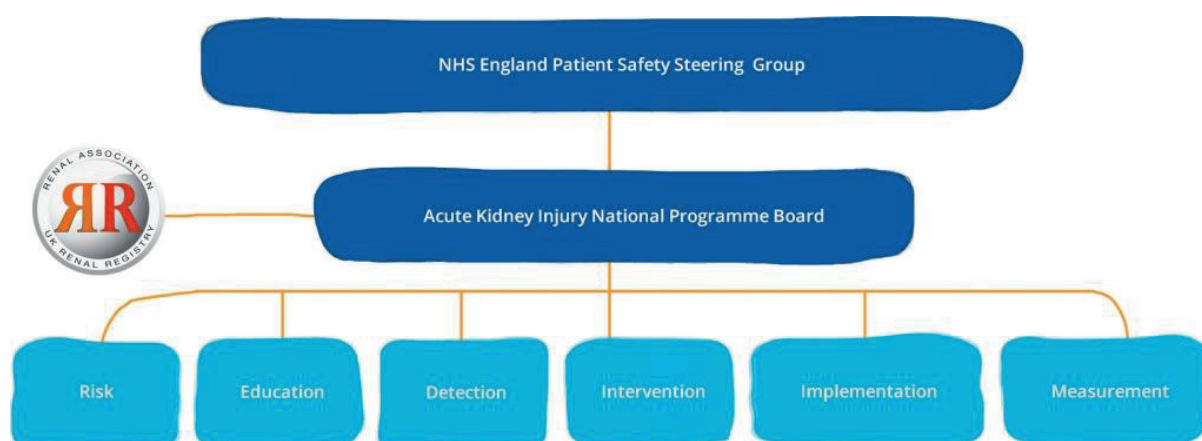
5. Programme Overview - How Think Kidneys Worked

With the implementation of the Health and Social Care Act (2012), in April 2013 NHS England came into being. With it were a new set of National Clinical Directors (NCDs), including a post for Renal Disease. AKI had been identified as a high priority. The NCD brought together the UK Renal Registry, NHS England Patient Safety and other stakeholders to develop and implement work to improve outcomes for people with AKI. That initial scope was defined across three broad areas. First, to establish measurement across the system to facilitate sustainable improvement. Second, through education and guidance, improve care for the individual with timely detection, treatment and recovery. Third, to support commissioners and organisations in global improvements of AKI as part of improving safety, following the Berwick Review into Patient Safety⁸ and Francis Public Inquiry⁹.

The Think Kidneys Programme Board first met in October 2013. NHS England and the UK Renal Registry established membership of the Board and representatives of stakeholder organisations and individuals with appropriate expertise were invited to join. The Board was formalised with terms of reference to ensure accountability and good governance practice were in place for the life of the programme.

The Board established the structure for the programme identifying the Workstreams that were required and the key priorities and areas of work were agreed, as well as the interfaces between the workstreams. Chairs and Co-Chairs for each Workstream were identified with the aim that membership would grow as people registered their interest in working in specific subject areas. Recruitment to the areas of work was intended to be inclusive and broad in range – patients, social care and allied health care professionals as well as clinicians from primary and secondary care were invited to join the work.

Fig 2 – Think Kidneys Programme Structure



A Programme Manager was appointed in December 2013 whose remit was to expand the membership of the six Workstreams, and to develop the scope and start the work to identify the potential outputs needed to meet the original objectives and aims of the programme. This work continued until the launch and design event, following which priorities were agreed and action plans developed to ensure delivery on the original ambitions.

The Think Kidneys team is large in number, taking advantage of the skills, knowledge and experience of people interested in the impact and challenge of AKI from across all sectors and professions of the NHS. Bringing together such a diverse group of people to deliver the Think Kidneys AKI programme was a challenge. But Richard Fluck and the Programme Board's flexible leadership style provided guidance and direction as well as the freedom for those undertaking the work to get on with the task in hand. The ambition was to allow the work to develop whilst providing a clear overall strategic direction and that approach may explain the richness and depth of the output.

Trying to spread the message through my Trust was so much easier to do through this campaign and availability of website - trying to get own pharmacy department then mental health prescribers on board with the key messages was possible by signposting to website.

(anon evaluation survey)

The programme has proved that geography and physical location are no barrier for people working well together, sharing their ideas and experiences to deliver. Ranging from the North East to the South West, with an invitation to representatives in the devolved nations to participate, team members worked virtually and met infrequently. It is testament to individuals' commitment and passion for the subject of managing AKI that resulted in most of the members contributing to the programme in their own time when the day job still had to be done. It's this drive to see improvement for patients that makes the programme as well as the NHS, unique. The patient representatives who were involved in all areas of work must also be recognised for their commitment and valuable contribution to the programme.

When asked, what's been the best thing about working on the Think Kidneys programme, by far the most common response has been "working with the people involved". This has been because of the diversity of the professionals and patients represented on the team and recognises the benefits this has brought, and because everyone has been so enthusiastic about the work.

Project Management

Managing a huge range of multidisciplinary team members, primary care colleagues, care home managers, commissioners and patients takes skill, commitment and leadership. The small programme team has worked hard to successfully keep the Workstreams on track, on time and on budget.

Programme Board meetings have been held quarterly and for the first year or so the Workstreams met, in the most part by teleconference, monthly. The Workstreams were required to log their activities and progress, next steps and any challenges they were facing. A central risk register was maintained and reviewed quarterly along with the budget in line with good practice and governance requirements.



Communication and Engagement

Communication and an identity, or branding, emerged as an important issue early on. Recognising that need, expertise from Brand Ethos and Taylor Made supported this important aspect in the formative stages. The name 'Think Kidneys' was created with the involvement of renal staff from two trusts. Recognising that what was required was a name that was simple, easy to remember and from which a brand or marque could be developed, it was a straightforward and well supported decision. With a name and a brand, plans to design the website commenced, considering the user journey and requirements. The Think Kidneys website was built in a unique way – in five days. Working together, a facilitator, the developers, a researcher, programme experts and a writer met a very tight deadline to go live on 1 November 2014. The website has been well received and the original aim for it to become the online 'go to' place for all matters AKI is a reality with almost 200,000 page views in two years. Both the brand and the web resource will be one of the important legacies of this work.

Communication has been an important element of our work as we aimed to reach as many in the renal community and beyond as possible. Using existing networks, social media, individual connections, the media and other specific channels we targeted messages about our offer to people working across health and social care. Our aim has been to make the Think Kidneys resources easy to find, easy to access, consistent, appropriate and timely. We believe our strong brand has helped us to do this and it is now being used to support other kidney improvement initiatives.

6. The Workstream and Working Group Reports

The Development of the Algorithm

The original need to develop an alert system for AKI can be traced to the AKI Consensus meeting held in 2012 at the Royal College of Physicians of Edinburgh (RCPE). The RCPE has a tradition of holding multi-professional meetings to discuss how to tackle important clinical problems. The output of such meetings are consensus statements that outline actions that participants agree will make significant progress towards achieving improved patient care. The consensus statement from this meeting was:

'Identification of AKI in both primary and secondary care should be facilitated through introduction of e-alert systems. At present systems are being developed ad hoc. A national group should be established to develop agreed standards for e alert systems recognising the need for some system dependent local flexibility. Components of the system should include an agreed definition of AKI based on the KDIGO classification and a standardised methodology for derivation of baseline serum creatinine. We recommend use of an enzymatic serum creatinine assay with an IDMS Traceable calibration to enable standardisation.'

Members of The Association for Clinical Biochemistry and Laboratory Medicine (ACB) suggested to its Council Executive that the ACB should take these ideas forward by assembling stakeholders and developing a plan of action. The chair of the ACB scientific committee was asked to co-ordinate this.

Once stakeholders were together it became clear that the new NHS England NCD for Renal was planning a national programme -Think Kidneys. This national programme would tackle the changes that needed to be made to patient care following the publication of the NCEPOD report which revealed missed opportunities to detect and treat AKI. Accordingly, the National Clinical Director was invited to nominate renal physicians who would become leading members of the multi-professional group charged with designing the algorithm. The other invited stakeholders were clinical biochemists who had attended and contributed to the Edinburgh consensus statements and representatives of the Laboratory Information Management Systems (LIMS). This latter group were crucial to the adoption of a system that would rely on electronic reports from pathology information systems to draw attention to patients who had already developed AKI, or whose serum creatinine changes suggested that they could be in the early stages of AKI.

The algorithm design meeting took place in July 2013. An intense day's work resulted in an agreed algorithm in diagrammatic form, an agreement from the LIMS suppliers that the algorithm could be incorporated into their software, and that they were willing to do it as part of their software development programme within an agreed time limit. The algorithm was to be a standardised national implementation. Furthermore, the algorithm would reside in the LIMS rather than in any other information system to allow uniform reporting of AKI via the existing pathology test reporting systems.

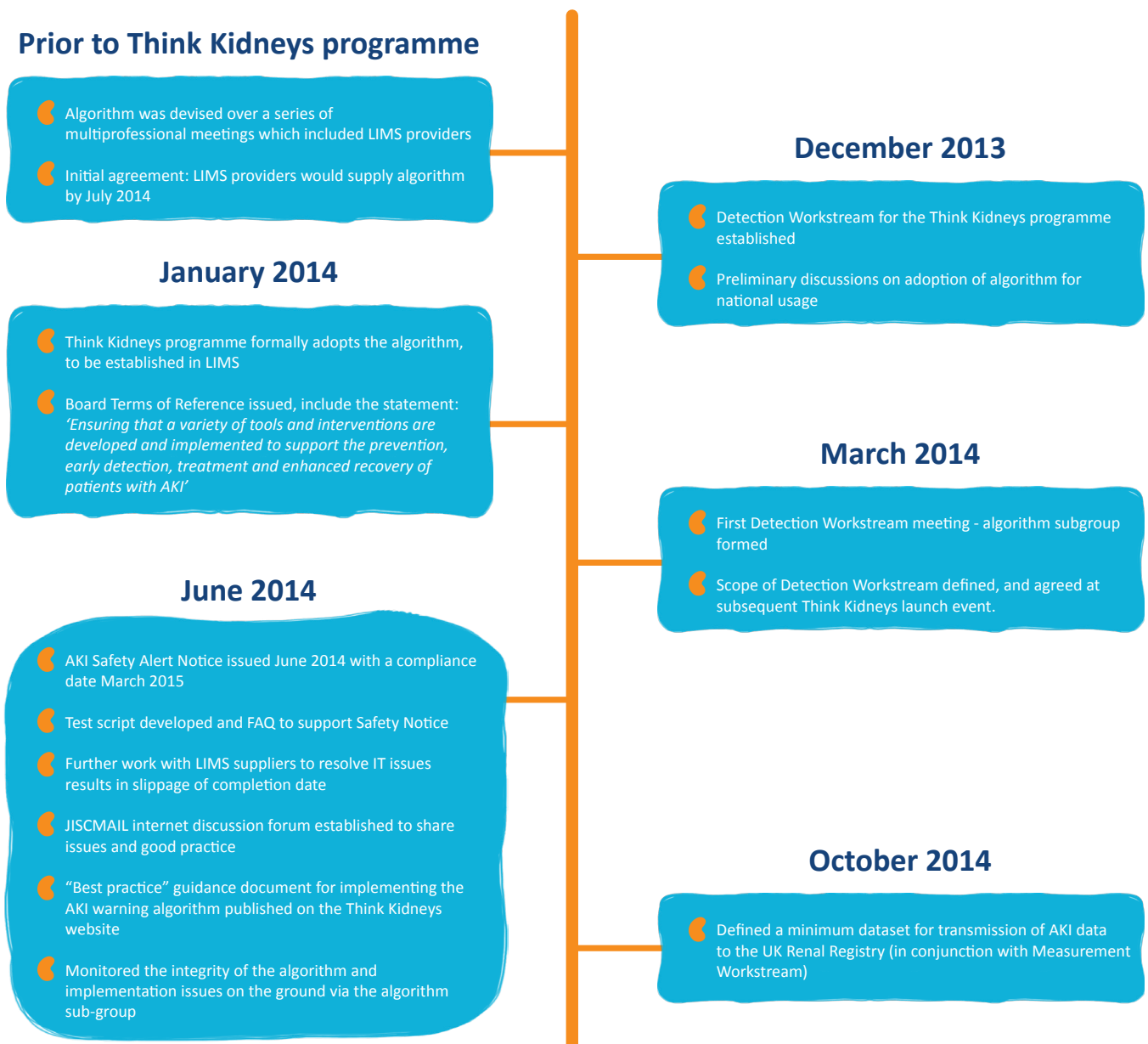
A Think Kidneys Detection Workstream was brought together in 2014 incorporating renal physicians and clinical biochemists from the original algorithm design group. This group continued to meet until January 2017 to handle enquiries from Trusts and suggestions for refining the algorithm as well as providing a source of expertise and advice for the other Think Kidneys Workstreams.

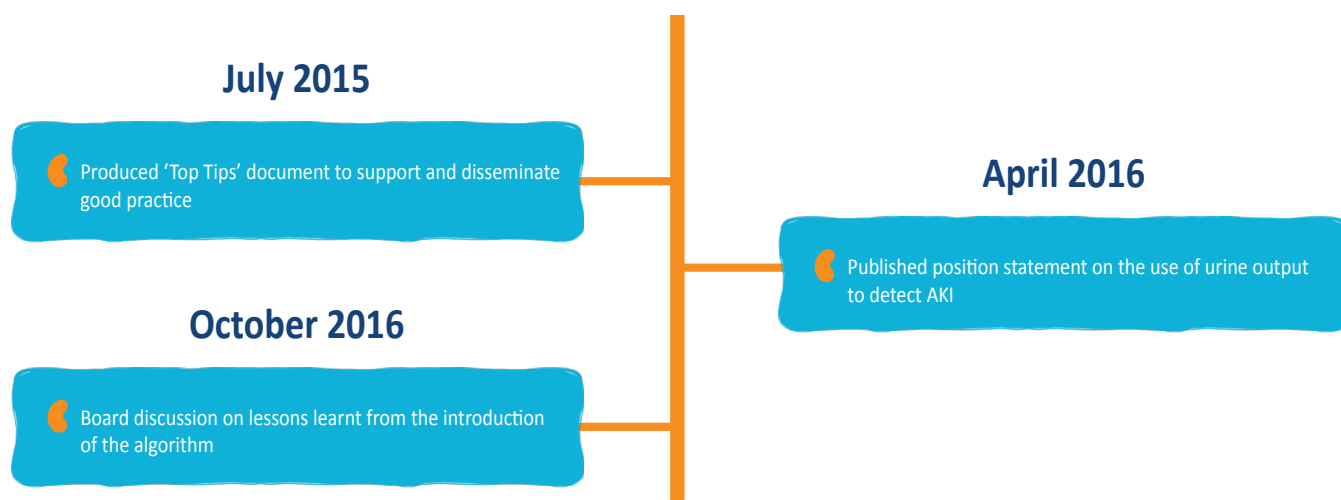
Detection Workstream

The development of the algorithm was the starting point for the Think Kidneys programme. Without the algorithm and the ability to detect and report AKI results the changes in practice and behaviour to improve patient safety would not have been possible.

The Detection Workstream recognised from the outset the importance of collaboration and a multi-disciplinary approach to the work. An effective working relationship with pathology laboratories' Local Information Management Supplier (LIMS) companies was developed. This resulted in the LIMS willingness to deliver and roll out innovative software developments for AKI detection. We also established a relationship with the Health and Social Care Information Centre and delivered the Read code for the AKI warning stage test result. Others stakeholders included the Medicines Healthcare Regulatory Agency and GPs with whom we had high level discussions to support the primary care phase for roll out of the AKI warning stage test result.

Below is a timeline of activities which details the sequence of work and events which developed the algorithm and spread its implementation across the NHS path lab information systems. Of importance was the message that the AKI warning stage test result required clinical interpretation.





I am impressed with the ambition of the programme and the extent to which these ambitions have been achieved
(anon evaluation survey)

Intervention Workstream

The Intervention Workstream recognised that improving detection rates and identification of AKI meant that both primary and secondary care clinicians needed easy access to comprehensive advice on how to care for patients with AKI. The Intervention Workstream developed the tools to enable clinicians to Think Kidneys.

The aim was to provide advice which describes actions that clinicians should take to reduce harm to patients with AKI, both in the community, primary care, secondary care, and critical care, together with those patients receiving renal support.

Guidance was produced for the follow-up management of patients who had experienced an episode of AKI. These included

- when to re-start drug treatment e.g. ACEI, ARB, diuretics
- adjustment of medications such as insulin, oral hypoglycemic agents, to prevent further complications
- long-term follow-up of patients, given risk of CKD and further AKI

Information was developed to empower patients, care givers and pharmacists to stop ACEIs, ARBs and diuretics during a period of acute illness. Tools were developed for primary care clinicians, including GPs, practice nurses, pharmacists, and for secondary care clinicians, including junior and senior doctors in all specialties; specialist nurses; pharmacists. The online resources were all developed for the Think Kidneys website.

Dr Blakeman led on the development of a consensus on responding to AKI warning stage test results in primary care, which started to be received in many areas in April 2016. This work has now been published: Blakeman et al: *Development of guidance on the timeliness in response to acute kidney injury warning stage test results for adults in primary care: an appropriateness ratings evaluation*. BMJ Open 2016; 6:e012865. Drs Tomson and Blakeman contributed to a systematic review, now in press in BMJ Open, entitled “What are the risks and benefits of temporarily discontinuing medications to prevent acute kidney injury” – work co-ordinated by the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care West (Bristol CLAHRC).

Outputs of the Intervention Workstream

Guidelines for Medicines Optimisation in Patients with AKI	Points to note and factors to consider in the medicines management of patients either with, or at risk of AKI
Discharge summary minimum data content for AKI	Recommended minimum data content for discharge summaries for patients whose hospital admission included an episode of AKI
Sick Day Guidance Statement	An Interim Position Statement from the Think Kidneys Board on ‘Sick day’ guidance in patients at risk of AKI
Primary Care Guidance	<p>Acute Kidney Injury in Primary Care video – As warning stage test results for AKI are received in primary care, why is this important and what difference will it make?</p> <p>Changes in kidney function during ACEI ARB diuretic treatment in primary care – information on changes in kidney function during diuretic treatment</p> <p>Quick Guide to Potentially Problematic Drugs and Actions to Take in Primary Care – which medications may need to be avoided or used with caution during an AKI episode</p> <p>Recommended Response Times to AKI Warning Stage Test Results for Adults in Primary Care – at-a-glance resource explains what actions to take when, when to treat or when to refer</p> <p>Recognising and Responding to AKI in Primary Care – understanding cause, possible medication factors, fluid volume status and options for review</p> <p>When to re-start drugs stopped during AKI – when or if to re-start ACEI, ARB, diuretics etc. after an episode of AKI</p> <p>Responding to AKI Warning Stage Test Results in Primary Care – highlighting key factors to consider when responding to results for adults in primary care, covering the stages of AKI, history of acute illness, co-morbidities and risk factors</p>
Nutrition Guide	Overview of nutritional considerations in the treatment of adult patients with AKI in hospital
Minimum Care Bundle for Patients with AKI in Hospital	Details recommended minimum requirements of a care bundle for patients with AKI in hospital

The most successful element of the Intervention Workstream's work is the package of advice for primary care clinicians. To date, much of the advice on management of AKI has focused on secondary care; indeed, much of the research evidence comes from intensive care settings. Developing guidance for primary care entailed engagement with primary clinicians using the UCLA RAND Consensus Process and then subsequent meetings with clinicians in the North East and South West (Bristol). The primary care advice has been accessed by many primary care clinicians and the resource web pages are the second most popular on the website, with over 25,000 downloads and page views. The Medicines Optimisation Guide has been the most accessed resource on the website with over 7,550 views and downloads.

The greatest challenge for the Intervention Workstream has been the calibration of the advice – ensuring that an appropriate response to an AKI warning stage test result would occur with high reliability, while ensuring that we do not set expectations unrealistically high. This was particularly important when advising on the appropriate response to AKI warning stage test results in primary care – a setting in which immediate clinical assessment of patients whose test results trigger an AKI warning stage test result can be very difficult and disruptive.

Risk Workstream

AKI is a risky business and the Risk Workstream set out to raise awareness of the risk of AKI across the healthcare community.

The Workstream developed resources which are available on the Think Kidneys website and include

Communities at risk of developing acute kidney injury	Publication detailing those most at risk of AKI
STOP AKI cards pilot project	Credit card sized handouts with guidance for patients at risk of AKI (not yet publicly available)
How to Keep Your Kidneys Safe	Handout for patients – information leaflet on the risk of AKI, produced in collaboration with the Education Workstream, the BKPA and RCGP
Secondary Care AKI Risk Matrix and Prevention Care Bundle	Concise matrix providing guidance on risk factors and events
An AKI Quality Standard/AKI Risk workstream resources matrix	Expected completion date of early 2017 this guidance will map NICE Quality Standards for AKI with the relevant Think Kidneys Resources
Acute Kidney Injury Patient Leaflet	Patient information leaflet for people who have had an episode of AKI, produced in collaboration with the Education Workstream and the British Kidney Patient Association.

The Risk Workstream worked with a range of people to develop the offer for the NHS. These included a range of healthcare professionals - clinicians, pharmacist, dietician as well as patients, hospital administrators and policy makers.

The most successful and enjoyable event was a face to face meeting in London that led to the development of the risk matrix and was a catalyst for a joint meeting of the Education, Risk and Intervention Workstreams. At this event the very important primary care resource – the STOP card was developed, which is being piloted in a number of areas at the time of writing.

The AKI warning stage test result has proved an important driver to improving the recognition of patients with AKI in primary and secondary care. The Risk Workstream has supported its implementation but considered how to evaluate when individuals may be at risk, reinforcing the fact that patients are at risk of AKI in many communities.

The concept of risk has evolved following the publication of the NICE guidance in 2013. Individuals may have fixed risk related to factors such as age or other illnesses, modifiable risk factors such as medications or clinical procedures. That inherent risk is then enhanced by a trigger event such as infection. Better understanding of the interplay between these factors will in time improve risk prediction and improve preventative strategies.

Implementation Workstream

The Implementation Workstream was established to explore how commissioning tools and levers might be developed to ensure the best treatment and management of AKI across primary and acute care in a range of associated community health and care settings and services. In other words, how a healthcare system might approach AKI.

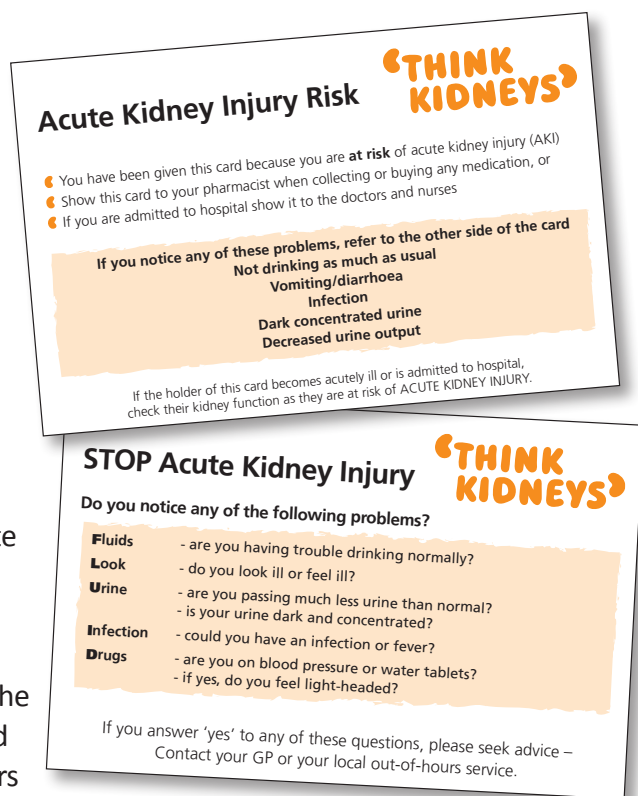
The goal was to investigate changes that might be made via such levers and the efficacy of these changes on patients' health, to reduce harm, and ultimately death associated with AKI.

The Workstream started with the Southern Derbyshire Clinical Commissioning Group (SDCCG) Pathfinder project, which was originally set up by the Dialysis Clinical Reference Group NHS England, and which was then formally linked to the Implementation Workstream's work. Other CCG areas working on AKI at the same time was also considered as their work developed, for example Salford CCG.

The Pathfinder project was initially led by Nesta Hawker, Senior Accountable Commissioner and Regional Programme of Care Manager Internal Medicine (North), NHS England and involved many people and organisations in the work including CCG staff, secondary care health and care professionals (including people working in acute settings, with and without renal units) and all staff who may meet patients.

The Workstream sought to explore the following -

- How to develop tools and new ways of working to reduce the incidence of AKI and provide evidence that they are effective and really work
- How to collect and analyse baseline data
- How to develop commissioning tools in the form of CQUINs and enhanced service agreements.



The ambition was that this work would show -

- reduction in preventable AKI, resulting in reduced mortality and complications for patients
- reduction in length of stay, including critical care and re-admissions to hospital
- reduction in the number of patients requiring long term dialysis as a result of chronic kidney failure, exacerbated by acute kidney injury
- an improvement in prognoses for patients
- an effective care pathway, developed by and agreed with commissioners and providers for AKI pathways.

The Workstream delivered and tested a range of resources, nationally for the programme and locally for the Pathfinder project. Some resources are duplicated as they were adapted for local use.

Table 1

National resources developed
Care Bundles linking treatment to risk assessment results - contributing to local and national CQUIN development
Staff education and awareness activity across all stakeholder audiences
Primary Care Guidance to support AKI Warning Stage Test Results/Patient Safety Alerts re AKI – resources were locally and nationally developed
Primary Care and Nurse Practitioner Forum content on AKI education
Sick Day Guidance in a variety of formats
Care Home education and awareness sessions
Care Home Pathways
Commissioner related ‘toolkit’ resources and case studies
Local resources developed
Electronic Risk Assessment Tools for acute admissions - contributing to local and national CQUINs targets
Enhanced Discharge Summaries including enhanced information about AKI - contributing to local and national CQUINs
Medicines optimisation and reconciliation procedures, contributing to local and national CQUINs and prescribing quality schemes
Online GP surveys to assess knowledge and awareness in Primary Care, both before the work and subsequently
Peer review and Academic Detailing procedures and consultant led session proformas
Locally Commissioned Service Specifications for Primary Care
Pharmacy awareness and education sessions
Care Home education and awareness sessions
Care Home Pathways



Are you unwell?

When you have diarrhoea and vomiting you may have trouble taking enough fluid to stay hydrated. This could put your kidneys at risk.

Check with your GP or pharmacist about taking your regular medicines.

Keep your kidneys safe

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Visit www.thinkkidneys.nhs.uk
Or talk to your GP or pharmacist to find out more



‘THINK KIDNEYS’



Think Kidneys is a national programme led by NHS England in partnership with UK Renal Registry

Working together

The Implementation Workstream met to discuss the scope of the work and subsequent progress across the CCG areas involved at development sessions, one for secondary care and one for primary care. A wide range of stakeholders were invited to their share experiences and ideas.

The Workstream collated information from all the CCGs involved – Southern Derbyshire, Salford, Wessex and the Patient Safety Collaborative Cluster for AKI. Discussions fed into the Programme Board.

Between meetings group members communicated regularly and directly and via email which helped to build trust and share experiences.



In Southern Derbyshire, the Pathfinder Steering Group met monthly to test commissioning tools, and to support mechanisms and educational awareness raising activities in very practical ways across all health and care settings. Enthusiasm for the project was maintained by utilising a project manager to coordinate the Steering Group. A project manager at the acute trust ensured a high-level focus for the acute activity. Initially it was important to understand commissioning timescales to enable activity to take place at pace. Regular gatherings and discussion of intelligence gave us real time commentary on progress and allowed a dynamic improvement cycle to emerge and carry the work forward.

Successes of the Implementation Workstream include

- Development of the National CQUIN
- Primary Care Locally Commissioned Services Framework involving 56 general practices in Southern Derbyshire
- Prescribing Quality in Prescribing Scheme
- Increased awareness of AKI, its risks, prevention, management and treatment across all health and care setting – a follow up survey told us that there was an improvement in knowledge and self-reported confidence in dealing with AKI.
- Early indications which suggest that Southern Derbyshire has achieved a 2.4% reduction in crude mortality rates from AKI over the last two years.

A key challenge for the implementation work was timing. Working alongside the other Workstreams, the Implementation Workstream tested their outputs for national roll out. However, in practice timing dictated that local areas were developing and testing their own interventions as well as looking at other outputs, and so national standardised roll out of improvements was harder to achieve.

A further challenge was communication links with CCGs which were not directly involved in the project; it was sometimes difficult to communicate with them about their engagement with the project or more specific interventions, and the potential for the work.

Ruth Briggs, patient representative on the Southern Derbyshire Pathfinder Steering Group has provided probably the best overview of the work –

“It seems to me that the AKI programme gave an opportunity for a diverse group of staff across the SDCCG area to focus on a significant issue that mattered to them, and to work together to improve diagnosis and treatment of a relatively common condition - AKI.

Through our activity, the awareness and understanding of many health professionals and health care workers and patients has been enhanced, and there is now an improved likelihood of AKI prevention, detection patient engagement and treatment as a result.

Our collaboration contributed to this and helped develop effective methodologies and an energy for engagement that those of us privileged to be involved all witnessed. Of itself this has driven raised standards and raised expectations, has informed, encouraged and supported work done by other teams nationally, and to my mind has no doubt informed practice in a multitude of small and perhaps less obvious ways. I think that this was perhaps best evidenced in the patients note book, in the care homes training and in the very positive reception the wider training and awareness has had across all sectors of the health and care system we have touched.”

Measurement Workstream

The Measurement Workstream worked to develop a national database of all episodes of AKI treated by the NHS in England, held at the UK Renal Registry - the Master Patient Index (MPI). This will allow the NHS to accurately measure the scale and severity of AKI, with information about recovery from AKI as well as mortality.

Importantly, the Measurement Workstream has designed an analysis plan to give a complete picture about AKI in England; how incidence and outcomes vary across populations, geographies and hospitals, where patients are treated and where AKI is first detected, and how renal function before an episode of AKI affects outcomes. The Workstream has been supported by the UKRR in its aim of collecting data from all NHS trusts in England, creating a portal at the UKRR for data receipt and working with NHS laboratories to ensure that data can be transferred seamlessly from laboratory information management systems to the MPI. We are progressing links with other NHS databases (e.g. Hospital Episode Statistics) which increases the value of the information collected in the MPI. In the future, the MPI will be a valuable tool for quality improvement and research to improve outcomes for NHS patients who have AKI and is a great legacy from the Think Kidneys programme.

The following summary details the progress of the Measurement Workstream over the past two years and defines the work for phase two.

Following the Patient Safety Alert in June 2014 pathology laboratories were required to implement the new algorithm for the detection of AKI warning stage test results into their laboratory information management systems by March 2015, and to report their results to the UK Renal Registry.

“People think, oh, a heart attack that’s a big thing...but kidneys I don’t think are any different. You have something like this and your kidneys fail – your body is failing”

AKI Patient – Andrew Quill

The Measurement Workstream was established to develop the collection and analysis of data from the labs and to

- establish a data set to be collected automatically
- develop systems to publish demographic information demonstrating the size of the AKI problem
- understand demographic information requirements to demonstrate the size of the ‘at risk’ group
- understand the consequences of measuring incidence of acute kidney injury and its impact on individuals, organisations and communities.

Results to date

To date over 1,200,00 AKI warning stage test results have been reported in 390,960 individuals (table 2, data until December 2016). Data completeness was high in laboratories reporting with 84 laboratories returning data to date.

Table 2 AKI Warning Stage Test Results reported to UK Renal Registry up to December 2016

Total number of labs: 84	
Total number of AKI Warning Stage test results: 1,273,714	
Total number of patients: 390,960	
Data Item	% Complete
NHS no	99.1
Sex	99.9
DOB	99.9
CCG/Post code	97.2

Key statistic

- Amongst all AKI warning stage test results, AKI warning stage 1 was most common in both adult and paediatric patients (77.9% and 78.4% respectively).

Demographics

The peak AKI warning stage test result was defined as the highest AKI stage reached within 30-days of the first AKI warning stage test result.

Key statistic

- The median age of adult patients with all stages of AKI warning was broadly similar (AKI-1 = 74.8 years, AKI-2 = 75.5 years and AKI-3 = 73.9 years, table 3).

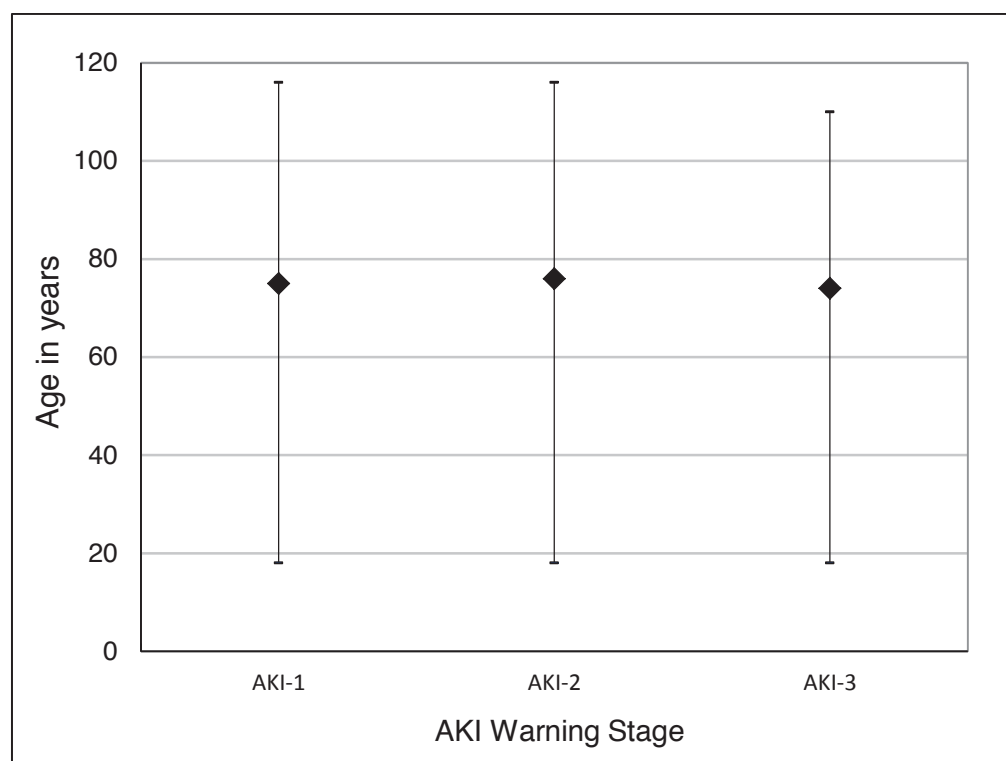
Table 3 number of patients, median age and gender by AKI warning stage

	AKI Warning Stage		
	1	2	3
Number	297,258	50,191	33,878
Age (median)	74.8	75.5	73.9
Gender (% Male)	45.0	47.1	46.5

All AKI warning stage test results are less common in males.

Paediatric data collection is still in development. This reflects that the eGFR for paediatric patients with AKI was less reported due to laboratories not having access to key information e.g. the weight/height of paediatric in-patients.

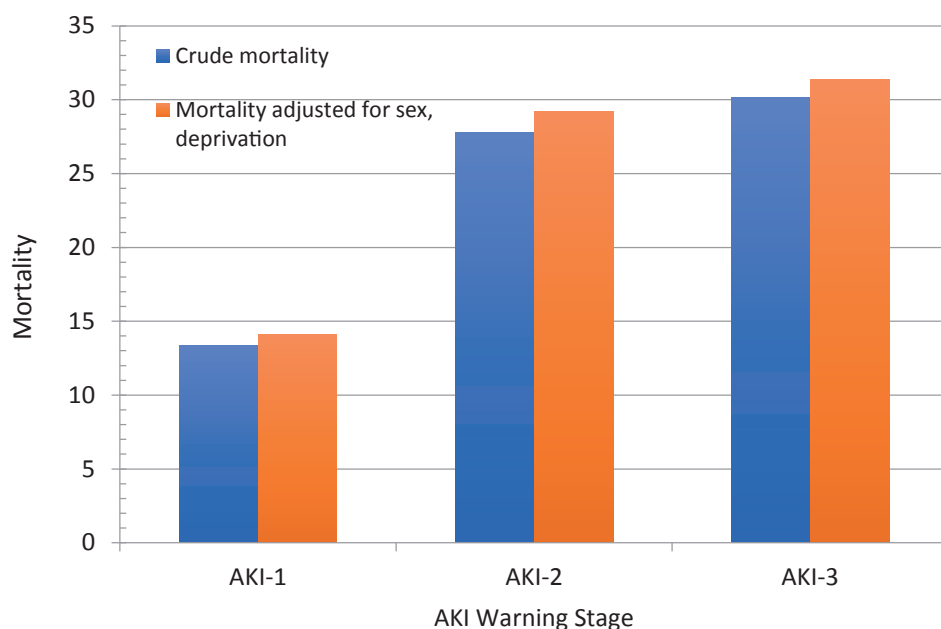
Fig 3 Median age (bars representing the total age range) in each AKI Warning Stage test result for adult patients



Mortality at 30 days after first AKI Warning Stage test result

Mortality at 30 days after first AKI warning stage test result (figure 2) was related to the AKI warning stage of the individual. Across all ages, mortality 30 days after first AKI warning stage test result was lowest for AKI warning stage 1 (13.3%), increasing to 27.8% for AKI warning stage 2 and 30.2% for AKI warning stage 3.

Fig 4 Mortality 30 days after first AKI Warning Stage Test result by AKI Warning Stage



Data by Clinical Commissioning Group

The incidence of AKI was estimated using the CCG population and number of AKI patients that was submitted for the CCG to the UK Renal Registry. As not all laboratories are currently submitting AKI data to the UKRR, the AKI incidence may not reflect total incidence at CCG level and thus the estimated incidence of AKI was used to estimate the coverage of AKI at CCG level. CCGs with an estimated AKI coverage of <3.5 cases of AKI per 1,000 of the CCG population were assumed not to be fully covered, and mortality rates are not shown for these CCGs. Patients whose information did not include their postcode have been deleted from the CCG mortality analysis.

There was wide variation in crude mortality (unadjusted for case-mix) for all AKI warning stages between CCGs, ranging from 10.5% to 23.9%, with the average mortality across all CCGs at 19.2%.

This means that about one in five AKI patients died within 30 days from the first AKI warning stage test result. The crude 30 day mortality rates are available and will gradually be shared with CCGs once the laboratories covering their population are providing data to the UK Renal Registry.

Further work on the data

Over the coming months (early 2017) the aim will be work with the labs to increase the number of labs reporting AKI warning stage test results. In tandem we aim to increase the quality of data being submitted and we will feedback to labs about data and how well they are doing.

Further analysis of the data will be developed, particularly using links with other datasets such as hospital episode statistics and the Intensive Care National Audit and Research Centre. We will continue to develop reporting at national, regional and individual unit level to enable effective comparators to drive improvement.

Education Workstream

The aim of the Education Workstream was to

- ensure education for AKI is prioritised and appropriately resourced across primary and secondary care
- work towards the development of a public awareness campaign.

Working with many stakeholders – RCGP, HEE, GMC, RCP and other Royal Colleges, CPPE, RPS, Trusts, patients, universities and others, the Workstream identified and then signposted NHS staff to current effective and endorsed resources for training on the presentation, management and treatment of AKI on the Think Kidneys website. The Workstream engaged with healthcare education providers on the delivery of AKI education.

Our aim was to make the Think Kidneys website the 'go to' place for educational resources and links to resources for all healthcare professionals regardless of sector in which they are working. New resources developed by the Workstream members included an AKI specific online module for GPs endorsed and accessed through the Royal College of General Practitioners website, information and feature articles in the nursing press. We worked with the Centre for Pharmacy Postgraduate Education to develop their learning campaign for Autumn 2015. Uptake was good and the resources well received (see page 30).

Linking people with existing proven educational resources demonstrates the NHS's ability to share and learn from high quality materials. Many of the educational resources on the Think Kidneys website have been developed in-house by NHS organisations with the aim of increasing awareness and understanding of the risk, prevention, detection, management and treatment of AKI. Sharing in this way prevents reinventing the wheel and is ultimately cost effective.

Most of the Education Workstream's work was undertaken by individuals or small working groups and we met virtually and occasionally face to face. We found this to be the most effective way to progress our work, playing to the skills and strengths of team members.

A sub-group of the Workstream came together to develop a public campaign. This was not officially part of the original plan for Think Kidneys, but when a survey of the public, as part of early communications activity told us that only 50% of the population know that their kidneys make urine, the Board felt we had a responsibility to respond to this challenge. While we initially thought we could educate the public about the risk



and impact of AKI, we realised this would be too complex a topic and that we had to start with simple messages about the importance of kidneys for health.

The campaign comprised a set of five thought provoking posters with very clear messages, which were produced for use across the NHS. Four of the posters were endorsed by the Royal Pharmaceutical Society for display in pharmacies. Twenty thousand posters are now on display across the NHS. An animated infographic was also created for the website and is displayed in GP practices and hospital clinics across the country. A media campaign followed which was kick-started by a 30-minute focus on Radio 2's Jeremy Vine show, supported by GP Dr Sarah Jarvis. Targeting specific media outlets, the campaign reached around 20 million people and won the Campaign of the Year Award at the Health Business Awards in November 2016.

Challenges for the Education Workstream were primarily around the low baseline of understanding of AKI across the NHS and among the public. Calibrating complex professional and public messages was also taxing but because of the wide range of people engaged in our work with special skills and experience, we were able to succeed in delivering on our plans. Co-ordinating our work with the outputs of the other Workstreams was also complicated at times. However, these challenges were overcome over time and as Co-Chairs of the Education Workstream we are delighted with all our work, believing as we do that we have contributed to real change and improvement in the care of people at risk of, or with, AKI.

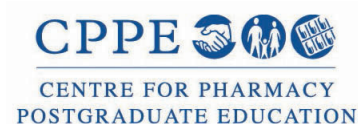
Think Kidneys and CPPE Pharmacy Campaign

During autumn 2015 the Centre for Pharmacy Postgraduate Education ran a national campaign, designed with the Think Kidneys team, to engage the pharmacy professions with this high priority area. This covered 65,000 registered pharmacy professionals across England.

A six-week programme of activities was developed, which sought to progressively engage different members of the team and culminated in every member of the team being asked to make a public commitment to the change that they were going to make. The outcomes and impact were shared in time for World Kidney Day 2016.

Our campaign of learning started with two animations which explored the difference that could have been made in community or hospital settings if the pharmacy team had remembered to 'Think Kidneys' with their patients. Despite being simple, the animations had a big impact and requests were made from other NHS teams to embed these on their websites.

The campaign moved on to an 'All About Kidneys' knowledge challenge. This was a 10 question quiz hosted on the CPPE website which tested people's knowledge of kidney disease. It linked them to key sources of learning or information to provide them with the evidence for the different responses.



The quiz has been transferred to a Medicines Quiz App to continue to stimulate learning on the topic as a legacy from the campaign.

The third stage was to distribute an open learning programme to all registered pharmacy professionals across England. This was launched at the Pharmacy Show in Birmingham – using a live periscope feed to enable access for those who couldn't attend the conference. Educational articles were also written for the Clinical Pharmacist Journal to support the programme.

The next stage was to support team members with applying the learning to their own practice, with articles specifically for pharmacy technicians in two separate journals highlighting their role in supporting people at risk of developing AKI. Engagement with the wider pharmacy support team comprised a podcast and a poster challenge - encouraging them to develop posters (for staff or customers) with their key messages and intended changes. A Twitter chat was also held for pharmacists.

The final challenge was for people to share their commitment to making a difference for their customers. Our colleagues at the Think Kidney programme developed a web page to capture people's pledges and we got back in touch with people in early 2016 to find out how they got on. We were fortunate to work with the NHS Specialist Pharmacy Services in developing a national audit for hydration messages, which all community pharmacies in England are encouraged to participate in and feed in their results at a national level.

These resources are available at www.cppe.ac.uk/aki to view.

Jim Mackey – CEO of NHS Improvement, response to an email sharing that the alert was in HSI and that there would be Sky News coverage on AKI - *"This is exactly the sort of thing we need to be doing, relentlessly and thoughtfully. Well done."*

Working Groups providing guidance for Care Homes, People Working with Children, and Mental Health Professionals

Care Homes Working Group

Understanding the increased risk of AKI in the frail elderly person, and that two thirds of AKI starts in the community, it was recognised that care homes' staff have the potential to help prevent, treat and support the management of AKI. Around 430,000 people live in care homes in the UK, cared for by around half a million staff, so how could awareness of AKI be improved and how can it be prevented?

At the start of the programme an Ipsos Mori survey was undertaken. We wanted to find out what people know about their kidneys and the results were published - 'Understanding what the public know about their kidneys and what they do'. The most surprising finding was that only 50% of the general public know that their kidneys make urine, let alone how to keep them healthy and safe. This fact was the impetus for the public campaign and the response from care homes has been to use the posters to raise awareness with their residents, staff, family members and visitors, of the important messages around hydration and potential harm from some drugs during times of acute illness.

Care homes, most of which are privately owned, have not traditionally worked closely with the NHS on improvement initiatives or to develop new ways of working, so we asked them how we could do

it. In July 2015 we invited 100 people – nurses, health care assistants, managers, owners, experts and commissioners to join us for a workshop to explore the scale of the problem and what was required.

Following the workshop, at which we viewed the evidence and learned from Essex County Council about their pilot with care homes, we asked for volunteers to form a working group. A representative mix of people from different professional backgrounds worked together to develop a package of resources for care homes to help tackle AKI. Comprising short (10 minute) training and awareness raising sessions, the resource was piloted and subsequently made available on the Think Kidneys website. A practical guide for staff to use as an aide memoire to help identify and manage people with AKI is in development.

While initially focussing on AKI, the training also looks at hydration and the impact of poor hydration and what can be done to improve fluid intake. Some of the care homes involved have worked with the residents and their families to make sure they also understand the importance of hydration and the problems that can ensue if insufficient fluids are consumed. Several care homes have added the AKI awareness sessions to their mandatory staff training.

“As a former nurse from a nursing home and a member of the in-house quality team at Birmingham Crosscity CCG, I was keen to be involved in the Think Kidneys initiative. We have good links to nursing homes in our region and see the problems associated with dehydration and Acute Kidney Injury.

It is really important for care homes to be aware of the importance of keeping residents properly hydrated. Dehydration carries with it the associated risks of confusion, UTIs, falls, AKI and multiple organ failure. The CCG is responsible for carrying out quality audits at nursing homes in our region and we have now included a number of recommendations aimed at helping nursing homes to prevent, diagnose and manage AKI more effectively.

We suggest that each nursing home should have nominated hydration champions whose role is to ensure that residents have a sufficient intake of fluids. We recommend recording fluid intake on a nursing chart so that care homes can identify hydration problems before they become chronic. If a resident declines fluids for three consecutive days, there needs to be a clear escalation route involving the GP. If no further proactive measures are appropriate at this point to increase fluid intake, we recommend initiating end of life discussions.”

Paula Cashmore, Birmingham Cross City CCG

Paediatric Working Group - Caring for children at risk of, or with AKI

Consultant paediatric nephrologists, who are members of the British Association of Paediatric Nephrologists, came together with pharmacist colleagues to create the paediatric working group. Resources developed are for people working in primary and secondary care regarding the detection and management of AKI in children.



Certain children are at greater risk of AKI either because of pre-existing disease or risk factors, or because they fall into an acute high-risk scenario. These children should have their serum creatinine

measured and steps should be taken to prevent AKI by monitoring kidney function, maintaining adequate hydration and by minimising harm. The guidance helps to identify those at risk and includes a recommended set of age related reference ranges for creatinine. Children's creatinine changes with age, and depends on how big they are and how much muscle mass they have. So, the interpretation of a creatinine value must bear this in mind.

Resources developed include:

- Guidance for clinicians managing children at risk of, or with, acute kidney injury
- Managing children with acute kidney injury in primary care
- Keeping your Kidneys Safe – a leaflet for young people
- Keeping your Child's Kidneys Safe - for parents / carers of children who are taking medicines that may reduce how well the kidneys work, particularly if your child is dehydrated.

Mental Health Working Group

Consultant psychiatrists worked with members of the Think Kidneys team to develop guidance for colleagues in mental health environments, whose patients have, or are at risk of, AKI. This reflects the need for a multidisciplinary approach to identify mental health patients at risk of AKI. As it may be a secondary illness, AKI could be spotted by anyone from the team - the health care assistant who notices the cup of tea that hasn't been touched, to the consultant appraising the patient's medication. Multidisciplinary training in the identification and management of AKI in mental health settings should ideally be routine.

With respect to psychiatry, there are times when patients lack the drive or motivation to care for themselves, such as in severe depressive illness. In some cases the person lacks the ability to care for themselves, such as in dementia. This self-neglect can lead to dehydration and consequent AKI. Dehydration may also occur associated with laxative or diuretic abuse in anorexia nervosa. The logistical challenges of performing blood tests in mental health units and the relative rarity of the need to keep fluid charts on patients in psychiatric units (compared to those admitted to acute general wards) means that vigilance by the multidisciplinary team and escalation protocols in the instance of clinical concerns regarding hydration must be robust.

In the guidance developed by the team, information highlights some potential areas for concern for patients with specific mental health issues.

The group adapted the Primary Care Tables 1 and 2 to fit in a mental health setting, and this is available on the website, together with the guidance:

- Guidance for Mental Health professionals on the management of AKI
- Recommended response times to AKI Warning Stage Test Results for Adults in Mental Health Facilities – Table 1
- Recognising and Responding to Acute Kidney Injury in Mental Health Facilities – Table 2.



Are you taking the piss?

Do you know how hard your kidneys work?

They use a quarter of your energy to remove toxins and make urine. And they have to work even harder if you don't drink enough to stay hydrated. It's no laughing matter.

Find out more about keeping them healthy at thinkkidneys.nhs.uk or nhschoices.nhs.uk

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Or talk to your GP or pharmacist to find out more

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Think Kidneys is a national programme led by NHS England in partnership with UK Renal Registry

7. Conclusions

Evaluation and Impact

Evaluating the Think Kidneys programme in its entirety is not easy. The programme has involved so many individuals, teams and organisations that without allowing them the space to have their say about what they've achieved, we are likely to omit some of our impact. That said, this is an overview to evaluate the major objectives of the programme and some of the unanticipated work that developed as a consequence of our activities.



- Creating a workable and efficient algorithm for the pathology laboratory software suppliers to implement into lab information systems, was the driver for the two national safety alerts and the CQUIN. The result is the hard data the UK Renal Registry is receiving from labs and the consequent analysis of that data. And the softer result is that more accurate results enable faster responses in treatment and management and better patient outcomes and experiences.
- The programme was funded to set up a national data collection system for AKI. That has been achieved and we now have monthly data on warning stage test results being submitted to the UK Renal Registry from 70% of pathology labs. This is creating the largest Master Patient Index on AKI in the world and will drive improvement and development.

As part of efforts to evaluate the programme, in Autumn 2016 a short survey of seven questions was sent to various contacts asking them to complete it and pass it on to their teams and others. A total of 220 people responded from across all sectors and professions in the NHS as well as patients. 68% of respondents were from secondary care, 20% primary care and 12% social care, patients or 'others'. 70% of respondents had heard of Think Kidneys and 50% had visited the website at least once.

Five broad themes emerged from the responses received about the usefulness of the resources.

1. Educational resources: the Think Kidneys publications were well received and used.

Awareness raising material for healthcare professionals
The videos were helpful to use in teaching

2. Best practice guidance: guidance was recognised as practical and helpful.

The patient perspective of service, their individual stories and how shared learning with other health care providers can improve across the UK
Practical guidance on how to look after patients with AKI and following AKI

3. Implementation: the tools from Think Kidneys supported organisations in developing their service.

Increased awareness of the recognition and management of AKI
Found it all really helpful in setting up an AKI service in the trust



4. Patient literature: support for patient information.

Documentation provided for non-specialist colleagues / primary care and patients / families

Lots of information suitable for patients

5. The brand: a point of focus and a place to go to for stories, guidance and advice

All the guidance has been useful. The website has probably been most useful

- From feedback, it's clear people are using the tools and resources developed. Visits to the Think Kidney website have continued to increase and since its launch in November 2015 there have been almost 150,000 visits and 200,000 page views. Documents have been downloaded from the site too, the most popular being
 - Recommended Response Times to AKI Warning Stage Test Results in Adults in Primary Care
 - Guidelines for Medicines Optimisation in Patients with AKI, and
 - Recognising and Responding to AKI in Primary Care.
- All the Workstreams achieved their principle objectives. Many achieved more.
- The programme has been inclusive involving primary and secondary care, paediatrics, social care in the community and in care homes, pharmacy, mental health and commissioners. At the time of writing we are developing resources for ambulance trusts and community services.
- The programme has supported improvement work on a local, regional and national basis and one of its main legacies is that it will continue to be an engine for driving improvement.

- Think Kidneys has supported other projects in AKI. These include Tackling AKI, funded by the Health Foundation and the Patient Safety Collaboratives established by NHS England Patient Safety team. This included an AKI cluster of nine Academic Health Science Networks. The Centre for Postgraduate Pharmacy Education led a campaign in 2015 on AKI to raise awareness in both the community and in hospitals. The STARSurg Collaborative launched the 'Outcomes After Kidney injury in Surgery (OAKS): protocol for a multicentre, observational cohort study of acute kidney injury following major gastrointestinal and liver surgery'.
- The UK Renal Registry will continue to support the Think Kidneys AKI website and programme and ensure that the information is regularly reviewed and updated. Reports on AKI will be a regular responsibility of the UK Renal Registry.
- Think Kidneys has published case studies about improvement work on AKI from around the UK. These have been well received and are a great way of sharing how services have developed so that people can learn from each other. The case studies, and also personal stories of people who have experienced AKI, can be found on the website at www.thinkkidneys.nhs.uk
- The well recognised Think Kidneys brand was developed for the programme and has been powerful with all our audiences and effective as a call to action for the NHS. Key to its success is that it was created involving input from a range of stakeholders.
- The public campaign to raise awareness of the importance of kidneys for health and life has reached over 20 million people in England. This was done through
 - Display of 20,000 posters in patient areas across the NHS
 - BBC Radio 2 – Jeremy Vine Show, Sarah Jarvis and Board patient representative Michael Wise, 7,000,000 listeners. The producer reported that they had never had such a response to their health section of the programme before on social media.
 - Sky News all day report on hourly bulletins following the publication of the second alert – viewer numbers are 4 million per day
 - Feature article in The Mail on Sunday - 9 million readers
 - BBC Midlands – Graham Torrington Show with Michael Wise, Board Patient Representative – 9,000,000
 - OK magazine – 3.1 million readers
- Using the media trade and others we have reached many of our stakeholders with articles and features on the Think Kidneys programme in the following publications
 - Journal of General Practice Nursing
 - Health Care Public Health
 - BMJ
 - Dietetics Today
 - Renal Association News
 - Nursing Times
 - Journal of the Royal College of Nursing
 - Practice Management
 - Journal of Practice Nursing
 - Journal of Community Nursing
- Social media has been actively used to broadcast key messages and there are over 1,500 followers on Twitter. Over 2,000 messages have been 'tweeted' about our work as well as supporting others' activity.

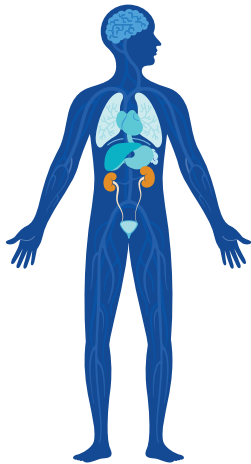
(Almost) everything you need to know about your kidneys



Most people have two kidneys
They are about the size of your clenched fist, they each weigh around 150g and are shaped like kidney beans



They sit in your lower back under the bottom ribs
Only 50% of the population know that kidneys produce urine



They filter your blood every minute of the day
Your blood goes through the kidneys 40 times in 24 hours. There are 140 miles of tubes and a million filters in your kidneys



They are the hardest working organs in your body
They use 25% of the blood from every heartbeat

What causes kidney problems?

One of the most common causes of kidney disease is diabetes. But there are many others including genetic and inflammatory conditions, blockages of urine flow and high blood pressure that can be a cause and/or consequence of kidney problems.

About 1 in 10 people has some form of Chronic Kidney Disease (CKD). CKD is a long term loss of kidney function which can be harmful. Not all CKD gets worse but it can lead to kidney failure. CKD also increases the risk of heart attack or stroke and increases the risk of acute kidney injury.

Acute Kidney Injury (AKI) is serious and can occur when a person is unwell. AKI is a quick reduction in kidney function. Finding AKI in the early stages is very important as it can make other health problems more difficult to treat.

Of emergency admissions to hospital 1 in 5 people have AKI. AKI can occur after major surgery or with heart problems. Up to 100,000 deaths in hospital in the UK each year are associated with AKI. It causes harm and suffering and costs a lot.

Why you need to think kidneys



If you are worried about your kidneys visit your GP and find out if screening is necessary



Always 'Think Kidneys' when visiting your GP as CKD and AKI often show few symptoms



Your kidneys are remarkable and can look after you at just 10% functionality



AKI often gets better and can even recover fully as the underlying problems are treated

What do your kidneys do?



Make urine
Regulate salt and water in your body, making about 3-4 pints of urine each day



Remove waste products from your blood



Produce hormones
Regulate your blood pressure



Create erythropoietin to control the production of red blood cells



Activate Vitamin D

Keep bones healthy



Clean your blood
Remove many drugs that some people take for other conditions

What are the symptoms of kidney problems?

In the early stages of kidney disease there are often no symptoms. There may be no pain or reduction in urine output. Kidney problems are found by a simple blood or urine test so we recommend that people at risk of CKD or AKI are tested regularly to spot problems as soon as possible.

Symptoms of more serious kidney problems can include:
• Tiredness • Frequent headaches • Loss of appetite • Sleep problems • Itchy skin • Nausea or vomiting • Swelling or numbing of the hands or feet • Passing urine more (especially at night) or less often than usual • Darkening / lightening of the skin • Muscle cramps

How to keep your kidneys healthy



Don't smoke



Keep your weight down



Exercise regularly



Drink alcohol in moderation



Eat a healthy diet including fresh fruit, vegetables and fish



Reduce your intake of salt, processed foods and soft drinks

If you take regular medication ask your pharmacist how it may affect your kidneys

Kidney disease is serious. It's harmful and changes lives. Protect your kidneys as if your life depended on it: because it does! Find out how to keep your kidneys healthy and safe www.thinkkidneys.nhs.uk

You can become a donor and help save a life by signing up at: www.organdonation.nhs.uk

Your kidneys are amazing. They work so hard for you. Look after them and Think Kidneys

‘THINK KIDNEYS’

‘THINK KIDNEYS’

NHS



Think Kidneys is a national programme led by NHS England in partnership with UK Renal Registry

Think Kidneys Legacy and the Future

The National AKI Think Kidneys programme was established with limited objectives though it was clear from early in the project that a longer-term view was needed. Improvement in care may require strategic direction but for it to work the work needs to be owned by the professionals and patients in their day to day lives.

This has been achieved. In three years, the understanding of AKI in England within the NHS has been transformed. Think Kidneys is a powerful example of the NHS change model in action, with a strong focus on a shared vision, can bring about improvement in the outcomes for people who have AKI.



The direct legacy of the programme is three-fold.

First, the UK Renal Registry is now the custodian of the largest database of episodes of acute kidney injury in the world. Over 70% of laboratories in England return data on a regular basis to the Registry. This Master Patient Index provides a rich picture of the extent and impact of AKI on the population and as the back bone of systematic improvement it will enable and support the improvements to come.

Second, it has utilised and supported several system-wide initiatives. The two national patient safety alerts have been effective and had a long-lasting impact. The national CQUIN only ran for one year but demonstrated benefit in a short time (see section 4 for detail). It is a matter of regret the CQUIN did not continue for the planned three years although many local health economies continued the work. AKI became a separate theme within the Patient Safety Collaboratives, with its own cluster and several high profile national projects for improvement have been funded in support for more work – for example, Tackling AKI sponsored by the Health Foundation and the Google Deepmind work.

Third, it has created the now recognisable brand ‘Think Kidneys’ under which the resources have been developed and made available. Those resources are broad in their nature, allowing individual teams to adjust, develop and improve the services and care they provide and they are key to jump starting improvement work. A new application for smart phones and tablets is launched at the review event at the end of February 2017. Under the umbrella of the UK Renal Registry, the Think Kidneys brand has supported two other important initiatives – Transforming Participation in CKD and the Kidney Quality Improvement Partnership (KQIP). Using the brand we developed an award winning public campaign on kidney health – recognising that the public fail to understand the value of healthy kidneys for their wellbeing. The reason everyone needs to “Think Kidneys”.

*One of the most successful clinical programmes that I have been associated with.
A great achievement with a legacy of improved clinical and public awareness
(anon evaluation survey)*

There is also an intangible legacy around the inclusive nature of the work. A huge number of people gave their time to make this programme work. The topic was grasped and owned with enthusiasm and commitment by many people outside the tight boundaries of the nephrological world. Patients and carers were involved from the start, leading and shaping the work. The depth and breadth of advice and engagement has been a huge success, covering social care, primary care, secondary and specialised care, across ages and between interests. Going to a meeting on mental health and hearing about AKI or a nursing home and listening to how they look after their residents’ kidneys is a marker of how AKI is becoming part of ‘normal business’. The support and efforts from primary care are a further example of the wide engagement that this work has achieved.

The future

Looking forward, Think Kidneys will continue. It will move from being a joint endeavour between the UK Renal Registry, NHS England and NHS Improvement to being run by the Registry. NHS England and NHS Improvement will continue to maintain links through the new board structure and via the Renal Clinical Reference Group and the Patient Safety team. While still providing the important outward facing presence the emphasis will change to one of supporting the continued improvement needed around AKI.

The Think Kidneys AKI project was supported by NHS funding and there is a need to continue to support the functions around the activity within the Registry. This will come in the form of a proportion of the current capitation fee that renal centres pay to the Registry from income generated from clinical activity. In turn, the costs of the capitation will be included more explicitly within the reference cost returns that determine current reimbursement.

Data collection, linkage, analysis and publication

The largest area of work that will develop over the next two years will be around data. Currently, the UK Renal Registry receives data direct from biochemistry laboratories on episodes of AKI as defined by the national algorithm. That will continue and the hard work and support of biochemists and the lab teams has been essential to the success of this work. There is a recognition that while the labs have worked hard to implement the changes required further support will be needed from the Registry in the future to help reduce the burden on labs and to feedback on data collection issues. Much of that is around the practicalities of the data returns and ensuring the labs are aware of the high value of the work they do in sending through this data.

These data on AKI then need to be linked to other data sources. The UK Renal Registry continues to work with NHS Digital to ensure it has appropriate permissions to access and link other relevant data to this Master Patient Index.

Running in parallel with these efforts, the Registry team will begin the process of analysis and interpretation. The Think Kidneys team will have an important role in leading that work providing the necessary expertise. From that, one of the early responsibilities for Think Kidneys is to develop a publication plan – what reports are needed, how often and to whom they need to be distributed. There will be a need to make the data available to others in support of external work. Organisations, from NHS England down to providers, will need to access their own data reports.

These data then allow the Think Kidneys programme to continue to support improvement around AKI. Key links have been established with the Patient Safety Collaboratives and Tackling AKI. The Kidney Quality Improvement Partnership also sits within the Think Kidneys portfolio and will be supporting improvement learning across renal providers. The ambition is to provide projects with data support to allow them to evidence change.

Think Kidneys will also then act as a repository of good practice. Working with the Kidney Quality Improvement Partnership (KQIP) and using the Think Kidneys brand, examples of improvement work will be made available and disseminated for other teams to use or adapt. Such projects will also then inform revision to the guidance packages that currently sit on the Think Kidneys website. One important area to keep under review is the AKI laboratory algorithm. A group will be established to review the performance of the system and, in the light of evidence, recommend any changes. These will be considered carefully, accepting the complexity involved in implementing any changes.

Think Kidneys will continue to work with NHS England and NHS Improvement. AKI remains an important global healthcare issue. Whilst there are areas of good practice there is still the need to provide leadership and a focus to foster improvement, to distribute excellence and to sustain change. For example, Think Kidneys has been working with NICE in producing quality standards across primary and secondary care.

The functions of the new Think Kidneys can be summarised as evidence production, collaboration and improvement. The project now moves to the next phase – a phase where this work acts as the support to local and regional initiatives in tackling AKI. Its legacy has been to establish a strong structure of leadership, evidence, guidance and communication which will act as the foundations for the work yet to come.

“The only way to be sure is to go out and test your ideas and programmes, and to realise that you will often be wrong. But that is not a bad thing. It leads to progress.”

Matthew Syed, Black Box Thinking





Is your child unwell?

A child with diarrhoea and vomiting often can't take enough fluid to maintain hydration. This puts their kidneys at risk.

Speak to your doctor or pharmacist before giving them ibuprofen.

Keep their kidneys safe

'THINK KIDNEYS'

Visit www.thinkkidneys.nhs.uk
Or talk to your GP or pharmacist to find out more

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NHS England in partnership with UK Renal Registry

8. Appendices

Think Kidneys Products, Publications and Outputs

General Resources

- Think Kidneys Leaflet – Information on the NHS campaign to improve the care of people at risk of, or with, acute kidney injury
- Rising to the Challenge and Tackling Acute Kidney Injury Poster – Poster on the Think Kidneys Campaign
- Understanding what the public know about their kidneys – Report of low awareness and understanding of kidneys, their function and how to keep them healthy

Patient Information Leaflets

- How to Keep Your Kidneys Safe – Information leaflet for patients at risk of AKI
- How to Keep Your Kidneys Safe – Easy print information leaflet for patients at risk of AKI
- Acute Kidney Injury Patient Leaflet – Information leaflet for patients who have had AKI
- Acute Kidney Injury Patient Leaflet – Easy print information leaflet for patients who have had AKI
- Keeping your Kidneys Safe – a leaflet for young people
- Keeping your Child's Kidneys Safe – for parents / carers of children

Resources for Primary Care

Introduction to AKI

- Acute Kidney Injury in Primary Care video – As warning stage test results for AKI are received in primary care, why is this important and what difference will it make?

Quick Guides

- Changes in kidney function during ACEI ARB diuretic treatment in primary care – information on changes in kidney function during diuretic treatment
- Quick Guide to Potentially Problematic Drugs and Actions to Take in Primary Care – Which medications may need to be avoided or used with caution during an AKI episode
- Recommended Response Times to AKI Warning Stage Test Results for Adults in Primary Care – This at-a-glance resource explains what actions to take when, when to treat or when to refer
- Recognising and Responding to AKI in Primary Care – Understanding cause, possible medication factors, fluid volume status and options for review
- When to restart drugs stopped during AKI – When or if to re-start ACEI, ARB, diuretics and other antihypertensive drugs after an episode of Acute Kidney Injury

Detailed Resources

- Communities at risk of developing acute kidney injury – publication detailing those most at risk of AKI

- Responding to AKI Warning Stage Test Results in Primary Care – Highlighting key factors to consider when responding to results for adults in primary care, covering for example the stages of AKI, history of acute illness, co-morbidities and risk factors

Other Resources

- Responding to AKI Warning Stage Test Results in Primary Care Poster – Poster highlighting Think Kidney's Primary Care Resources
- Why measure? The importance of data – background to the patient safety alert for AKI and prevalence

Resources for Secondary Care

Detailed Resources

- Secondary Care AKI Risk Matrix and Prevention Care Bundle
- AKI Injury Warning Algorithm Best Practice Guidance – Guidance to help with the installation, testing and introduction of AKI detection in clinical practice
- Audit Measures – Recommendations for Secondary Care AKI Management process audit measures
- Creating the Renal Registry text file in WinPath – creating the file for the Registry
- Discharge summary minimum data content for AKI – recommended minimum data content for discharge summaries for patients whose hospital admission included an episode of AKI
- Minimum Care Bundle for Patients with AKI in Hospital – Recommended minimum requirements of a care bundle for patients with AKI in hospital
- Nutrition Guide – Overview of nutritional considerations in the treatment of adult patients with AKI in hospital
- Sick Day Guidance Statement – An Interim Position Statement from the Think Kidneys Board on 'Sick day' guidance in patients at risk of AKI
- Top Tips For Best Practice in AKI Reporting – AKI episode reporting advice
- Top Tips 2 for Best Practice in AKI Reporting – additional advice
- Transmitting AKI Warning Stage Data to the UK Renal Registry – Best practice guidance on transmitting AKI warning data to the UK

Mental Health

- Guidance for mental health professionals on the management of acute kidney injury – Guidance on the multi-disciplinary approach required to identify, manage, prevent and treat mental health patients at risk of or with AKI
- Recognising and Responding to Acute Kidney Injury for Adults in Mental Health facilities – Understanding cause, possible medication factors, fluid volume status and options for review
- Recommended response times to AKI Warning Stage Test Results for Adults in Mental Health facilities – This at-a-glance resource explains what actions to take when, when to treat or when to refer

Paediatrics

- Guidance for clinicians managing children at risk of, or with, acute kidney injury – This guidance is intended for doctors, nurses and allied healthcare professionals looking after children.

Pharmacists

- Guidelines for Medicines optimisation in patients with AKI – Points to note and factors to consider in the medicines management of patients either with, or at risk of AKI
- Pharmacists Thinking Kidneys Leaflet – Working with pharmacists to raise awareness of AKI, helping to avoid it where possible and improve treatment and care

Details of other Think Kidneys programmes

The strength of the Think Kidneys brand and its wide recognition among the renal community and beyond influenced the decision to brand two subsequent major renal community improvement initiatives under the Think Kidneys banner.

The first is the **Transforming Participation in Chronic Kidney Disease** programme which is working with 16 renal units to examine how patient activation can have an impact on a person's health and help them to live their best life. Using already established surveys –

- CSPAM – Clinical Support for Patient Activation Measures
- PAM – Patient Activation Measure
- PROM – Patient Reported Outcome Measures, and
- PREM – Patient Reported Experience Measures in collaboration with the BKPA

The aim of the programme is to determine how to change the nature of the conversations and behaviours of clinicians and patients to ensure patients get the support they need to become more involved in their care, decisions about their care and how to achieve their life goals.

Rachel Gair is the Programme Facilitator and can be contacted at Rachel.Gair@renalregistry.nhs.uk
You can also find out more about the programme at www.thinkkidneys.nhs.uk/ckd

The Kidney Quality Improvement Partnership – (KQIP) is an initiative launched in June 2016 to develop, support and share improvement in kidney services to improve people's health and add value. Working to make quality improvement a way of life for everyone working in renal care, KQIP will work to support and showcase national, regional and local improvement effort.

KQIP is a dynamic network of kidney health professionals, patients and carers who are committed to developing, supporting and sharing quality improvement in kidney services to enhance outcomes and quality of life for patients with kidney disease.

KQIP's aim is to improve the lives of adults and children affected by kidney disease by supporting healthcare professionals, kidney units, renal networks and commissioners across the UK to achieve the highest quality of care for patients.

KQIP builds on rather than replaces existing quality improvement structures. It will do this by helping kidney services to embed quality improvement into daily practice, understanding and reducing unwarranted variation in care, and spreading and sharing good practice.

For more information contact James.McCann@renalregistry.nhs.uk and you can find out more at www.thinkkidneys.nhs.uk/kquip



Does your urine look like this?



If so, you need to drink more to keep your kidneys safe.
Healthy pee is 1 to 3, 4 to 8 you must hydrate.

Find out more at www.thinkkidneys.nhs.uk

**‘THINK
KIDNEYS’**

Visit www.thinkkidneys.nhs.uk
Or talk to your GP or pharmacist to find out more

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Acknowledgements

This report would not be complete without acknowledging the work of many people. More than one hundred people have been involved in the programme in the last three years. Some have worked on specialist areas and other across the spectrum of the outputs we have delivered. I speak on my own behalf and that of my fellow sponsors when I say that we have been most impressed by the unstinting dedication and commitment of everyone.

Tight deadlines and sometimes seemingly impossible turnaround times have too often been the order of the day, and this has been on top of significant day jobs. But we have met them and we should all share in the fact that the success of the programme is entirely down to the people involved.

I would like to thank everyone for your commitment, dedication, challenge, expertise and time. The programme has achieved all it set out to do and more. And we should all be very proud of what we have done.

Thank you

A handwritten signature in black ink that reads "Ron Cullen". The letters are cursive and fluid, with the first name "Ron" and last name "Cullen" clearly distinguishable.

Ron Cullen

CEO UK Renal Registry

