

# ASSIST-CKD

A programme to spread eGFR graph surveillance for the early identification, support and treatment of people with progressive chronic kidney disease

# Newsletter

Issue 3  
April 2016

## Welcome

Welcome to the third ASSIST-CKD project newsletter designed to update you all with the project's progress, share hints and tips from participating sites and keep you informed on how the project is being promoted through conferences and publications.

We would really welcome your feedback to help ensure there is something for everyone in the newsletter and to start to build up a project community.

## Project Update

Four of the first wave sites are now reporting on eGFR graphs having started last Autumn.

1. Royal Cornwall Hospital, Truro
2. Monklands Hospital, Airdrie (about to start having had some IT system challenges to overcome)
3. Arrowe Park Hospital, Wirral and Countess of Chester Hospital
4. Doncaster & Bassetlaw Hospital

The next wave of sites about to start are:

5. Liverpool, Aintree and Southport
6. Newcastle and Northumbria
7. Southern Trust, Newry, Northern Ireland
8. Westcliffe on Sea, Southend
9. South Eastern Trust, Ulster, Northern Ireland

with the following sites due to get underway this summer:

10. Northern Trust, Antrim, Northern Ireland
11. Wrexham, North Wales
12. Bangor, North Wales
13. Epsom & St Helier, Carshalton

Our final wave, to start in January 2017, includes a 4<sup>th</sup> site in Northern Ireland which is indicative of the tremendous support and interest here.

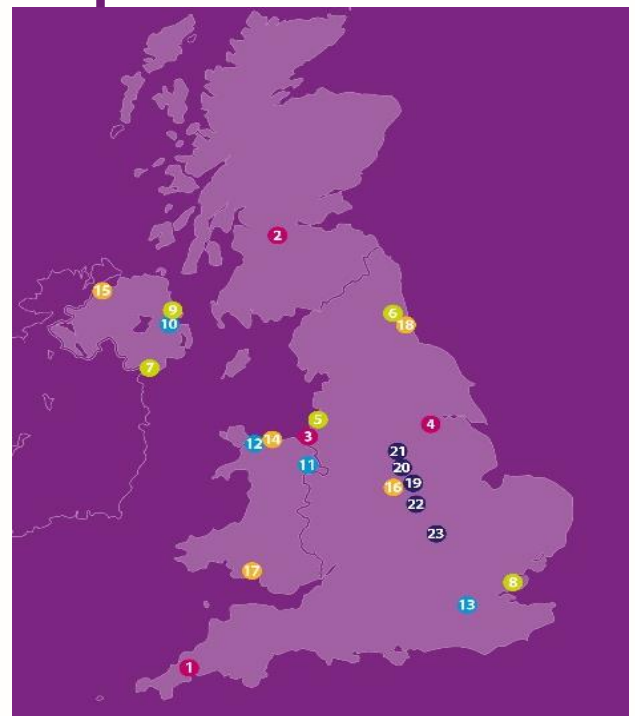
14. Glan Clwyd, North Wales
15. Western Trust, Derry, Northern Ireland
16. Derby
17. Swansea, South Wales
18. Sunderland

Diane Corrigan, Consultant in Public Health Medicine at the Public Health Agency, Northern Ireland said:

"In Northern Ireland, through the efforts of GPs and hospital clinical teams, we have made significant progress in reducing end stage kidney disease incidence from its peak of 140pmp in 2005.

One of the secondary care actions was to introduce a mandatory Acute Kidney Injury (AKI) awareness programme for junior doctors and an e-alert system to detect those at risk of AKI in hospital and primary care. It is therefore very timely that we now focus on enhancing the recognition of CKD progression in the community setting. At a recent meeting of the regional commissioner & provider Nephrology and Transplantation Group, we were very supportive of colleagues in the 4 Trusts involved in the ASSIST-CKD project. We look forward to a time when eGFR graph surveillance is embedded in clinical practice, leading to improved outcomes in people with progressive kidney disease through earlier intervention."

## Map of site locations



Project Supported by:



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## Qualitative Evaluation

Dr Nicki Thomas who leads the qualitative evaluation workstream for the ASSIST-CKD project, has confirmed that this process has just commenced with the wave one sites. The aim is to understand the experiences of those directly involved in the project, including laboratory staff, clinicians in renal units and primary care staff. One-to-one semi-structured interviews (either face-to-face or by telephone) with laboratory staff in each Trust has started, with questions being asked such as "tell me your overall experiences of being involved with the eGFR project; what specifically has worked/not worked; how far has the training equipped you to undertake this new role; have you any recommendations for other labs who will be developing the system in the future? "

In addition secondary care staff involved in the intervention will be interviewed, with questions focusing on the practicalities of the intervention, barriers and enablers of adoption and sustainability. GPs will be asked for their feedback via an electronic questionnaire which is being piloted in the phase one sites. We understand that some sites have also directly contacted their own GPs for feedback.

At a later stage, a full economic evaluation in a limited number of sites is planned.

## An Update from the Patient Project Team

It is well known that having patients and the wider public involved at most stages of healthcare has a number of benefits. The active involvement of patients in ASSIST-CKD via the Patient Project Team is key to the research partnership, aiming for changes to service delivery and patient outcomes as the project evolves.

Team member, Susan Gianstefani attended the NHS Health Check conference in March, to promote the important message about CKD as part of the NHS Health Check programme to delegates who were mostly representatives from councils, responsible for local implementation. Several key contacts were identified and useful feedback collected. Rob Finnigan attended the project's Evaluation Advisory Group meeting and has also helped to identify key contacts within local kidney patient groups and NHS Trust media teams at our participating sites, to inform our strategy for promoting the project locally to maximum effect.

Putting together a cohesive business case to local commissioners to ensure ongoing funding is key to the principles of ASSIST-CKD being adopted within routine practice beyond the project itself. Amjid Ali, has used his unique insight and experience to help with the model produced. He also spoke at the event in Bristol referred to later in the newsletter, and received some very positive feedback to his talk.

The group are keen to build on and continue to work alongside the healthcare professionals to aid success of the ASSIST-CKD project.

*Tracey Rose*, PPT Lead.

## PPT Member Profile

Amjid Ali, was on dialysis for over 23 years before receiving a living related kidney donation in May 2011. Amjid is a management consultant working across a number of private, public and voluntary sector organisations having retired from his career in banking, where he was responsible for setting up and leading the Islamic Financial Services Division in the UK for HSBC Bank.

He works in partnership with NHSBT as the project lead, 'Transplantation within the framework of Shariah (Islamic Law)'- a pioneering initiative to engage Muslim faith leaders and community influencers to increase awareness and engagement amongst the diverse Muslim communities in the UK.

He also chairs and sits on a number of Strategic Advisory Boards providing guidance on matters relating to diversity and inclusion, community engagement and sustainability. With his background, Amjid has had extremely valuable input into the development of the project business case.



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## Our new Project Manager Awareness and profiling

Lesley Woolnough joined us in March, although she worked with Kidney Research UK a few years back on our health inequalities programmes. Lesley has 20 years senior, healthcare experience in the charity and industry sectors and is a key opinion leader in patient/public advocacy, engagement and bladder and bowel incontinence care. She has been a driving force in improving healthcare outcomes for people suffering with continence conditions, helping found the All Party Working Group for Continence Care; and has successfully led and delivered a number of projects in the pharmaceutical outsourcing sector. With an extensive network of clinical and policy decision makers built through successful partnerships, she will be a valuable member of the operational team.



Of course we are very grateful to Jo Moore for her support as project manager through the first year of the ASSIST-CKD project, and she has been helping with transition as Lesley takes over the role.

## **NEW** Learning Event Mon 13<sup>th</sup> June 2016, Birmingham.

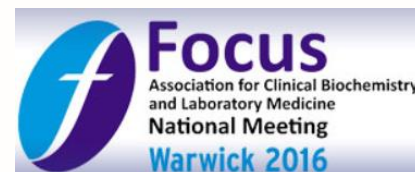
**Please note the change of date for our second learning event.** A number of key individuals were unable to attend on 23<sup>rd</sup> May due to NHS pressures on staff time and clinical demands of the real world so having made this decision we hope that more of our sites will be able to take part. Nearly 50 people attended our first event in November and we want this second event to be as successful. It is an important networking opportunity and a chance for the sites not yet started to get a better understanding of the process from those who have already begun the project. This programme will have more emphasis on interactive, parallel workshops with themes such as implementation and IT for those sites yet to start, data collection, evaluation and business case development, and the importance of the patient voice.

There will be something for everyone and plenty of opportunities for questions and discussion, and we hope to see representation from all of our sites. We are seeking accreditation from the Royal Colleges of Physicians and Pathologists as well as the Institute of Biomedical Science. More details attached.

We recently attended two meetings organised by the **South West Strategic Clinical Network**, ably assisted by the Cornwall site and 2 members of our Patient Project Team. Rachel Levenson, Cardiovascular Programme Manager at the SWSCN commented:

*"We were delighted to include presentations from the ASSIST-CKD team at 2 recent renal education events for primary care at Lifton, Devon and Bristol, attended by over 50 GPs. There is much talk about the power of the patient voice and the potential value to patients was reinforced by 2 patients talking about their experiences which will be remembered by all those who attended. Commissioners are interested to see the results of the project as it is rolled out across the initial pilot sites to inform introduction of the project across the South West".*

Anna Barton and Angela Mallard from The Royal Cornwall Hospital are also presenting a poster at the annual FOCUS conference in Warwick this week.



We were also invited to attend The Health Foundation Annual reception in March which focused on 'Scaling up', to talk about the project and had a small stand with posters and flyers for delegates to find out more.



Nicki Thomas (mentioned earlier) has also been invited to present an update on the project at this year's UK Kidney Week hosted by the Renal Association and British Renal Society, in Birmingham in June.

Please let us know if you have any ideas on where we can talk about the project (locally, regionally or nationally), or if you would like us to send you any project materials (for example for your local CCG, Trust Management, or Kidney Patient Association).





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## The Business Case

We have now finalised a document to be adapted and used locally to help build the business case with your commissioners to enable you to sustain the project beyond the first year of funding. This has been sent out already to our first wave sites. Cornwall have now submitted theirs and we await an update on progress.

The document details the prospective outcomes and expected benefits through this project, for commissioners, individual GPs and of course, for patients. It describes example costs and potential savings for a 300,000 population.

It is complemented by a simple infographic highlighting some of the key facts and figures to support the case. The first version of the infographic is available but we are further enhancing it and will share with you as soon as it is available.

In making an approach, sites could consider asking for funding in their CCGs 5-year planning rounds. The funding requested will still be modest and this will also allow time for the intervention to bed in and potentially influence take-on rates of dialysis.

## East Midlands Update

The East Midlands Clinical Network, partner to the national Assist-CKD Programme, continues to support the implementation of the eGFR surveillance programme across the East Midlands.

Following initial meetings involving commissioning managers, consultant nephrologists, GPs, clinical scientists and pathology IT for each pathology laboratory in the region, commissioner and provider support has been confirmed to progress with the implementation of this programme. With support from the ASSIST-CKD team, pathology IT colleagues have addressed technical issues and are scheduling time to install the software.

### Contacts

**Lesley Woolnough:** Project Manager  
E: [lesleywoolnough@kidneyresearchuk.org](mailto:lesleywoolnough@kidneyresearchuk.org)  
T: 0776 5838 071

**Rowena Sampson:** Project Administrator  
E: [assist@kidneyresearchuk.org](mailto:assist@kidneyresearchuk.org)

**[www.kidneyresearchuk.org](http://www.kidneyresearchuk.org)**

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Martin Cassidy and his colleagues at the Network are committed to the implementation of the eGFR surveillance programme, working with University Hospitals of Nottingham, Sherwood Forest Hospital, Chesterfield Royal Hospital, University Hospitals of Leicester, Kettering General Hospital, and Northampton General Hospitals, and are aiming for implementation by the end of June 2016.

## Contacting the Team

**Dr Hugh Gallagher,** Clinical Project Lead  
[Hugh.Gallagher@esth.nhs.uk](mailto:Hugh.Gallagher@esth.nhs.uk)



**Michael Nation**  
Project Lead  
[michaelnation@kidneyresearchuk.org](mailto:michaelnation@kidneyresearchuk.org)

**Lesley Woolnough,** Project Manager  
[lesleywoolnough@kidneyresearchuk.org](mailto:lesleywoolnough@kidneyresearchuk.org)



**Rowena Sampson**  
Project Administrator  
[assist@kidneyresearchuk.org](mailto:assist@kidneyresearchuk.org)  
01733 367 834 or 07771 992 558

We would welcome any ideas or suggestions you may have for the newsletter, or if you want to contribute to the next edition (July) please do get in touch by emailing [angelalumsdon@kidneyresearchuk.org](mailto:angelalumsdon@kidneyresearchuk.org)

