Welcome

Welcome to the second 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 also encourage you to give us some feedback to help ensure there is something for everyone in the newsletter and to really start to build up a project community.

Project Update

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

The Royal Cornwall Hospitals NHS Trust
Doncaster & Bassetlaw Hospitals NHS Foundation Trust
Wirral University Teaching Hospital
Countess of Chester Hospital NHS Foundation Trust

NHS Lanarkshire & Monklands Hospital, Airdrie are just getting ready to go having had some IT system challenges to overcome.

The next wave of sites to start in the New Year are:

Newcastle and Northumbria
Liverpool and Aintree
Southend
Newry, Northern Ireland
Ulster, Northern Ireland

Our support pack of materials which is made available to all sites has been updated. The pack includes our Laboratory Information Guide, letter/factsheet to be issued to surrounding GP practices and CCGs and both written and YouTube Guide to interpreting eGFR graphs. This is sent to sites in the months leading up to their start date. This is followed by a competency assessment pack including 30 sample graphs and marking sheet which all members of the lab team who will be involved in assessing the graphs, need to pass before commencing live reporting.

We are also finalising a document to be adapted and used locally to help build the business case with your CCG and SCN to enable you to sustain the project beyond the first year of funding. This will be supplemented by a simple infographic highlighting some of the key facts and figures and which will include some powerful patient stories. We will share these with you as soon as they are finalised as it is important that this development work begins in earnest.

A huge vote of thanks to Martin Cassidy, QI Lead at the East Midlands Network who has developed this infographic and together with his team and their experiences setting up the parallel initiative across the East Midlands Strategic Clinical Network, is a great asset to the overall ASSIST-CKD project.

Qualitative Evaluation

An evaluation of the set-up phase of the project was undertaken by Dr Nicola Thomas, Associate Professor in Kidney Care at London South Bank University and member of the ASSIST-CKD project team. This involved telephone interviews with nine members of the project team, and included questions such as what worked; what would you have done differently; and what are the key learning points for the next phase? A number of themes have now been discussed within the team and in order to capitalise on the learning, the following actions have been/are being initiated:

Project Supported by:
**ASSIST-CKD**
A programme to spread eGFR graph surveillance for the early identification, support and treatment of people with progressive chronic kidney disease

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**Newsletter**

- Find out who is important at each Trust site and link them together
- Identify the ‘language’ that each group (IT, lab, renal team, commissioners) speaks and find out how to ‘hook them in’
- Every site is different with different structures and cultures
- More time is needed to prepare sites
- Flow chart with milestones for each site has now been developed
- ‘Issue logs’ have been created, so outstanding issues have ongoing review.

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**Learning Event**

30th November 2015, Birmingham.

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Thank you to everyone who attended the event in Birmingham last month. We had nearly 50 people from the various sites involved, the project team, Renal Registry, The Health Foundation, Public Health England and others. This was our first major networking opportunity and a chance for the sites not yet started to get a better understanding of the realities of the process from the people who have already begun the project. We were able to show some excellent examples as a direct result of this project, of patients who have already been identified as at high risk, and their GP has now been alerted that they need to get specialist advice as soon as possible.

The project was put into context extremely well by Dr Hugh Rayner who has been running the programme in Birmingham for a number of years and showed some powerful statistics on how patients have benefited locally. The day was rounded off with a powerful talk from Rob Finnegan, a member of the Patient Project Team who brought home the realities of living with kidney failure and being on dialysis to demonstrate how applicable and relevant to the real world ASSIST-CKD is going to be.

Please do send back your feedback forms to help us plan for the next meeting on **May 23rd**, again in Birmingham. The event was accredited by the Royal College of Physicians and Pathologists as well as by the Institute of Biomedical Scientists. Do contact us if you need a certificate of attendance.

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**An Update from the Patient Project Team**

What does good look like for people with kidney disease? – how will we know if we’ve succeeded? It’s not only about graphs but positive patient outcomes. How can the ASSIST-CKD intervention lead to better quality of care?

As with any quality improvement project, Patient & Public Involvement (PPI) is a critical element and the Patient Project Team (PPT) was set up to support the project to make sure that it is centred on the needs of people with progressive kidney disease.

We have recruited a nationwide team who not only have personal experience of kidney disease and its impact but also bring their wider commercial expertise to ensure the project’s success. Members of the PPT have been assigned to all of the project’s work streams ensuring that the patient perspective is strongly represented in all activities.

**What does that involve?**

- Comment on content and optimum delivery of all patient-facing communications.
- Work locally and nationally to get buy in and implementation of intervention with GPs & CCGs.
- Use the patient and carer voice to influence the commissioning process.
- Support the design and delivery of Qualitative and Quantitative evaluation.
- Help promote the project through media channels and patient groups.
- Represent the operations team at national or local meetings.
- Making sure the project brings benefits to patients for whom it really matters.

PPT member, Rob Finnigan, was lucky enough to receive a transplant 12 years ago and has first-hand experience of the physical, lifestyle and psychological implications of kidney disease. He is particularly supporting the communications work stream.

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**Kidney Research UK**
Funding research to save lives
Our IT program, being in a different format from that used in Birmingham did cause some issues, but we reported everything back and made some suggestions to the ASSIST-CKD team, and so we were extremely pleased to hear at the workshop in November this has helped to create version 2, or the “Cornwall version” of the software as it now been described. Hopefully for those coming on-board from now, you will have a smoother start.

An eGFR report from a patient in Cornwall

We were keen to share details on ASSIST-CKD with a wider audience; after all it’s lovely to start something new, innovative and beneficial to the population, and to be the first pilot site in the UK. We held a talk for the laboratory staff and wrote an article for the directorate newsletter.

We also had two features in our own Lab Med News for primary care - an initial summary of the project explaining graph-reports would soon be coming out, then another incorporating an FAQ section covering some of the questions we had received from GPs.
To address some of the queries coming into the renal team by phone and email, we were able to modify the information provided on the graph-reports too. With support from the hospital communications team we even appeared, together with Dr Steve Dickinson (Renal), on our local radio station, Pirate FM, talking about CKD and the potential impact of the ASSIST-CKD project on our patients.

So our advice and tips?

- Be prepared for the first two weeks to be slow, but don’t worry you’ll speed up and streamline.
- Get a good printer as initially the number of newly reported patients will be high.
- Before creating the Word document reports (via ‘Print All List’ button), order them alphabetically by GP location (by clicking on the ‘location’ tab at the top of the list) - it makes it easier to pack for posting.
- While the Word document of graphs is being created you can monitor progress by looking above & left of the patient list at ‘Processing Patient x of x’, and when finished ‘Report Created’.
- Create an Excel spreadsheet log showing the number of patients to review & number reported and the time taken to do the review, create the Word document reports & print, sort and post them. This information can feed into the business case to help sustain the project beyond the first year of funding.
- DO contact the ASSIST-CKD team! They will listen and help you any way they can.

GOOD LUCK!

Contact the Team

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We will soon be circulating a spreadsheet with email contact details of laboratory teams at each participating site to help further build the project community and to enable you to share ideas and best practice. Do please let Rowena know if you would rather not include your details – assist@kidneyresearchuk.org

Please let us know if 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).

If you have any ideas or suggestions for the newsletter, please do get in touch by emailing angelalumsdon@kidneyresearchuk.org.

In the meantime, may we wish you all a very Merry Christmas from the Project Team

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