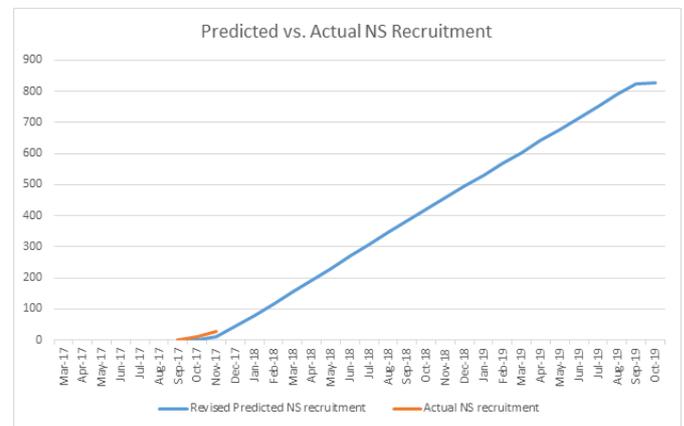
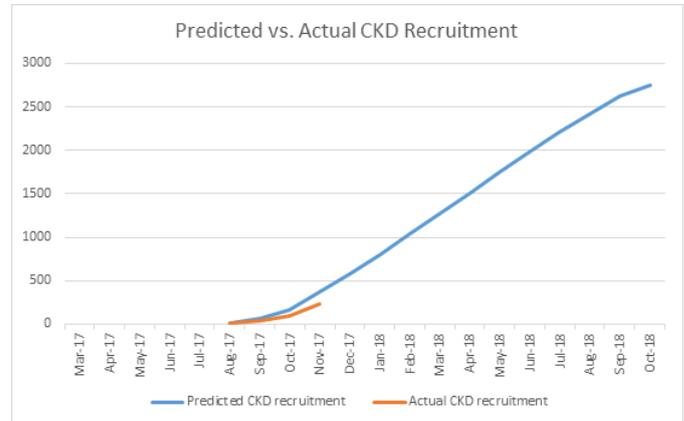


Newsletter

Welcome to the first edition of the **NURTURE** newsletter. We are aiming to produce an update every quarter to share the progress, good news and ideas that we hope will make this programme a success for us all.

Of the 13 sites participating in NURTURE, nearly all have now recruited their first patient. Recruitment currently stands at **276/3000 CKD** and **49/800 NS** patients (as of 18/12/17). As you can see from the graphs, CKD recruitment is under target at this early stage, so please contact us if you have any issues that we can help resolve with you. Sites have reported that sample processing does become easier with practice! We will be sending out site-specific recruitment graphs very soon, so you can monitor your progress on recruitment and biopsies.

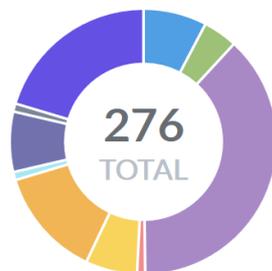
We want to thank all of the research teams at sites for your contribution to date. **NURTURE** is a very ambitious project which will benefit many patients, and you are helping to make it happen!



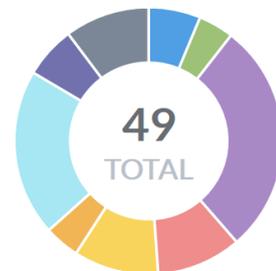
NURTURE Recruitment

For up-to-date recruitment figures, please visit the **NURTURE website** (www.nurturebiobank.org). The website also displays details of the cohorts in the 'dynamic data' section of the website and the latest news about the project in the 'news' section.

Nurture - CKD Recruitment



Nurture - INS Recruitment



Data correct 18.12.17

In collaboration with



Supported by



Inspired by patients.
Driven by science.



NURTuRE recruitment/in clinic tips

- Questionnaires can be posted to patients before visit, to bring with them on the clinic visit day. This can be done **BEFORE** the consent form is signed by the patient, but not given to the nurse until it has been signed. Please ensure during the visit that the questionnaire is fully completed.
- The alcohol question in the background questionnaire asks for alcohol units/week. If the patient responds in average per month, please divide their answer by 4 for a weekly average.
- Routine blood/urine results collected within one week of the visit are valid and **do not need to be repeated**. However, please ensure that all blood/urine results are recorded... if missing, please carry these out during the research visit.

Patient stories

We are keen to work with your site as the project progresses to give the opportunity for local patients to become ambassadors of **NURTuRE**. One of the first patients to be recruited in Derby tells her story:

Skevy's story

Derbyshire mum Skevy Piponides was diagnosed with stage 3 CKD seven years ago and hopes her involvement in the **NURTuRE** study could eventually shed a light on the cause of her chronic kidney disease.

“My case continues to baffle doctors. I had no prior symptoms or problems but, after a bout of mild dizzy spells, tests revealed that I had the kidney of an average 80-year-old, in terms of condition and function.

No one can explain how this has happened, but the NURTuRE biobank may help to finally get to the bottom of this mystery and shed further light on the causes of other kidney conditions. I've never been part of a research study before but, if my involvement can help other people like me, then that would be fantastic.”



Skevy and her daughters, Florentina and Andrea

NURTuRE investigators meeting

Thank you to those who attended the investigator meeting in Birmingham last month where we came together to share learnings and troubleshoot any issues that you may be facing with the **NURTuRE** project. A few of the top tips and suggestions that arose:

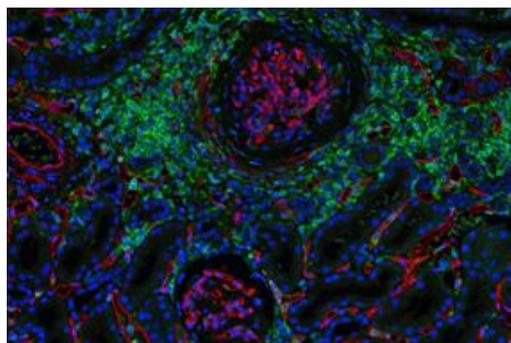
Biopsy samples

The biopsy quota for **NURTuRE** is 15-20% of total recruited patients (more would be fantastic). The biopsies will be analysed by Birmingham University, who can scan in the images for a digital copy of the biopsy slide, allowing researchers access to images and analysis alongside RaDaR data and sample analysis. Tips for increasing the percentage of patients with a biopsy include:

- Screening biopsy meetings and lists to target patients specifically having biopsies.
- Speaking to patients about **NURTuRE** at the biopsy visit.

REMEMBER!

Ask nurses to keep track of patients who have had a biopsy, and remind them that the biopsy reports should be uploaded onto RaDaR under the pathology tab.



Multiplex staining for endothelial cells (red) and leukocytes (green)

Relapse/Remission Samples

Please remember the importance of collecting relapse and corresponding remission samples for Nephrotic Syndrome patients – the samples are most valuable as close to relapse as possible (i.e. within 24 hours of starting steroids). However, the relapse samples are still valuable for as long as the patient remains nephrotic, so please do collect these even if this is longer than 24 hours after the relapse occurred. **Tips for collecting relapse/remission samples are:**

- Communicate the importance of returning during relapse with patient at the initial visit. Give patient a card with the contact details (e.g. telephone number, secure email) of who to contact in case of relapse. Contact Liz (liz.colby@bristol.ac.uk) if you need a copy of these cards.
- Look at the ward admissions list, and create an alert on the system to contact the Research Nurse.

RaDaR

- **DON'T FORGET** to input the diagnosis of the patient into RaDaR. Avoid assigning 'CKD' as the diagnosis, and ask a consultant for a clinical diagnosis in the absence of a biopsy diagnosis.
- **DON'T FORGET** to complete the renal disease progression section at the bottom of the primary diagnosis tab on RaDaR.
- Make sure you look at local Patient View feed to determine which routine results are not fed through. Contact Fiona Braddon (Fiona.braddon@nhs.net) to see if this can be updated. Please also contact Fiona to have your local nurse team add patients onto **Patient View** (covered by RaDaR consent for the NS study, but please check local practice).
- For patient medications – use the date of visit and manually type in the medications of the patient for that day.
- **Remember to complete the Primary Renal Diagnosis box in RaDaR** – if you don't know the diagnosis, please ask your PI or other clinician – try to avoid using CKD as the PRD unless the cause is genuinely unknown.

******SOP update******

Please ensure that the PAXgene tubes are stored UPRIGHT in the freezers! This is to reduce the risk of leakage of the samples.

Helping to profile NURTuRE

Working with all of our partners and supporting organisations, it is important to raise the profile of the NURTuRE project within the renal community locally, nationally and further afield.

We sent out a press release to launch the project back in the summer and since then have also featured NURTuRE in **Kidney Research UK's Update Magazine** (https://issuu.com/kidney_research_uk/docs/update_autumn_nov_2017_issue_14_fin) as well as in the July issue of the **Journal of Kidney Care** (www.magonlinelibrary.com/doi/10.12968/jokc.2017.2.4.222).

Do take the opportunity to have a read.



MRC Stratified Medicine News

We are very pleased to announce the success of a major grant application to the Medical Research Council, for a project entitled: **NURTuRE – changing the landscape of renal medicine to foster a unified approach to stratified medicine.**

This £3.1 million project will use the valuable samples and clinical data collected in the **NURTuRE-NS (NephroS)** and **NURTuRE-CKD** registry, and generate new data and methods that will allow us to redefine the diagnostic categories of nephrotic syndrome. This will help to provide individualised diagnostic tests and new therapies and will be based on deep analysis of patient DNA, blood and biopsy samples provided within this study. The four-year project is boosted by in-kind industry partner contributions and the continued involvement of Kidney Research UK and the UK Renal Registry. We look forward to keeping you updated on this project, and for the enthusiasm of **NURTuRE** sites to continue with the recruitment over the next two years.

Project Leads include Moin Saleem, Gavin Welsh, Rachel Lennon, Ania Koziell, Phil Kalra, Colin Campbell, Elaine Davies, Retha Steenkamp.

Wishing you all a restful Christmas break and a Happy New Year!
The NURTuRE team

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