

# The eGFR3 Study Newsletter

## Nov 2022

### New Partnership with Flinders University (Darwin)

Congratulations to Dr Jaqui Hughes, leader of the eGFR3 Study, on her appointment to Clinical Research Professor of Aboriginal and Torres Strait Islander Health Advancement at Flinders University, Darwin. Prof Jaqui Hughes and the eGFR3 study team recently moved from Menzies School of Health Research to Flinders University, Darwin. The eGFR3 Study continues to work in close partnership with Chief Investigators from our partnering institutions, Flinders University, Menzies School of Health Research, University of Queensland, South Australia Health and Medical Research Institute, St Vincent's Hospital, Northern Territory Health, and James Cook University.

During 2022 and 2023, eGFR3 Study Chief Investigators Sian Graham (Menzies), who co-chairs Aboriginal and Torres Strait Islander Community Governance Group, Phillip Mills (JCU), also a member Aboriginal and Torres Strait Islander Community Governance Group and Jaqui Hughes, eGFR3 Study leader (Flinders) will visit communities to reconfirm support for this research and talk about how the Study is progressing.



**Photo:** eGFR3 Study Aboriginal and Torres Strait Islander Community Governance Group: From left, Elsie Seriat, Natalie Hunter, Sian Graham, Helen Fejo-Frith, Phillip Mills. Not present: Janella Isaacs

### Annual Aboriginal and Torres Strait Islander Community Governance Group Workshop

The 2022 workshop was held in Darwin at Club Tropical Resort. The Community Governance Group provide recommendations to the Investigators about the how the study should continue in communities. This workshop provided the opportunity for 3 days of sharing and decision making, discussion about the best way to conduct this research and what community kidney health action looks like.



**Photo:** Thank you to Uncle Richie Fejo and Larrakia Nation for providing a heart-warming Welcome to Country. Uncle Richie is the Senior Larrakia Elder on Campus at Flinders University and a proud Larrakia Elder and welcomed all workshop delegates to the unceded Larrakia Country.

### Shared Governance

One aim of the eGFR3 Study is to describe the process and outcomes of a shared governance model. This includes research investigators, clinicians and community members working together to develop and analyse information, then decide how to share this information with communities in ways that are culturally acceptable.

A strength of the eGFR3 Study is the Aboriginal and Torres Strait Islander Leadership Group. This group of Investigators works in tandem with the governance groups and provide guidance for all the Governance Groups.

## Data Sovereignty

The eGFR3 Study is finding good ways to ensure that information (data) known about eGFR participants is kept safe and secure, and under Indigenous control. At the workshop in August, a guest speaker from Terri Janke Company lead discussion about data sovereignty. With this knowledge, the Aboriginal and Torres Strait Islander Community Governance Group provided recommendations to the Researchers to describe how these sovereignty principles are applied to the eGFR3 Study.

The Community Governance Group also reviewed the participant consent form to ensure all options for data use, storage and destruction are offered to all participants. These changes require ethical approval before implementation.



**Photo:** Chief Investigator Associate Professor Odette Pearson seeks input from the community researchers about best methodology



**Photo:** eGFR3 Study Aboriginal and Torres Strait Islander Community Governance Group working together at the August 2022 Meeting



**Photo:** Helen Fejo-Frith

## Community Based Researchers

Nine Community Based Researchers are working with the eGFR3 Study. They continue training in community to do research the right way. The eGFR3 induction program takes approximately 20 hours over several weeks and provides learning opportunities to satisfy requirements towards Certificate II Community Health Research credentialing. With this training, Community Researchers will assist with data collection, make sense of the findings, write reports, and translate the results into community action. Community researchers will retain these skills to work with community and other research projects when opportunities arise.

## Beyond 2022

Community Based Researchers, and the Community Governance Group recommend the Research team to visit in their communities. The purpose of these visits is to confirm and develop relationships, reconfirm that kidney health is still a priority and explore the best way to work with community to continue research into kidney health. Each community will have the opportunity to reassess priorities since the last eGFR Kidney Study and since COVID interrupted health care. In November 2022, we are planning to visit with community Elders and groups in Thursday Island and visit to support Community Based Researchers in Galiwin'ku and Wurrimiyanga. We look forward to meeting you soon.

**Principal Chief Investigator Professor Jaqui Hughes,**  
**eGFR Study Manager Diana Mosca**  
**Clinical Research Officer Andrea Porteous**

Flinders Rural and Remote Health

P 8920 0212 | M: 0439 476 888 | E: | [egfr@flinders.edu.au](mailto:egfr@flinders.edu.au)