

Grampian Renal Observatory

Briefing Paper 1401

Aberdeen Applied Renal Research Collaboration

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Building a platform for improving renal care: Grampian Renal Observatory

Background

The increasing availability of electronically collected health and care information creates opportunities to improve health surveillance, plan services and optimise patient care, tailoring it to individual need.

Chronic kidney disease (CKD) is common, affecting ~10% of the adult population, an estimated 500,000 people in Scotland. In those over 65 years, more than 50% have evidence of CKD. With substantial uncertainty about the significance to health, who was at greatest risk and how best to optimise care, CKD made an excellent model for assessing the feasibility and showcasing the potential benefits of linking health records in Scotland.

Aims

With relatively modest investment from a project grant from the CSO (CZH/4/656), NHS Scotland research support through NHS Grampian endowments, and NHS renal endowment funding we aimed to:

- Establish if relevant clinical records could be extracted and linked to create a research platform
- Test the potential value of the platform by conducting:
 - A series of validation projects.
 - Primary epidemiological research to address clinical research priorities.
 - The platform development within the evolving Grampian Data Safe Haven (DaSH) infrastructure to assess the feasibility of continuing to build the resource for future research.

This paper provides a brief overview of the results of this work and lists the current publications and outputs.

Methods

The Grampian DaSH architecture and processes were developed using the Grampian Renal Observatory as a pilot. At the core is a 10 year extract of regional laboratory biochemistry data of relevant test results assessing kidney function (~4 million records for around 400,000 adults).



Key results and lessons

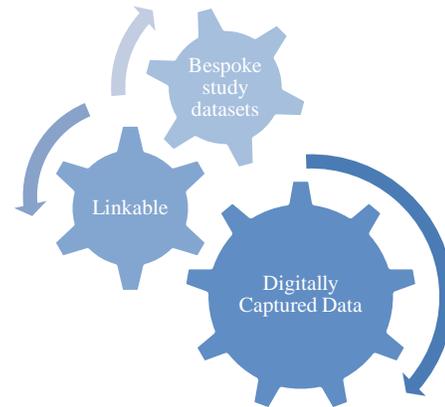
Establishing a platform makes 'research ready' linkable extracts of data from biochemistry, hospital episode (SMR01), death registry and the Scottish Renal Registry from which bespoke study specific datasets can be constructed.

- Demonstrated feasibility and value of data linkage in Scotland.
- Enabled validation of processes, data and methods identifying the critical importance of metadata relating to, for example, laboratory assay and calibration procedures and highlighting the strengths and limitations of hospital episode data versus case note review.
- Showcased the ability to address clinical priorities for research in a timely and cost effective fashion.
- Demonstrated the ability to use routine data to develop toolkits to understand illness and outcomes, support service planning and stratify patients based on health risk.

CKD epidemiology collaboration providing data for meta-analysis. This work led to the US Food and Drug Administration and pharmaceutical industry developments of new clinical trial endpoints. We have been approached by potential research collaborators in Scotland, UK and internationally to develop a range of research programmes using the Grampian Renal Observatory.

Conclusion

Increased digital capture of data and the architecture to link data from different sources to create bespoke study datasets provides a valuable approach to improve health surveillance, service planning and patient care.



References and outputs

- A Marks et al.** Chronic Kidney Disease – where next (predicting outcomes and planning care pathways)? *EMJ Neph.* (accepted for publication).
- M Soo et al.** Approaches to ascertaining comorbidity information: validation of routine hospital episode data with clinician-based case note review. *BMC Res Notes.* 2014, 7:253
- A Marks et al.** Definitions of progression in chronic kidney disease—predictors and relationship to renal replacement therapy in a population cohort with 6 years follow-up. *Nephrol Dial Transplant.* 2014, 29:333
- D Nitsch et al.** Associations of estimated glomerular filtration rate and albuminuria with mortality and renal failure by sex: a meta-analysis. *BMJ* 2013, 346:f324
- A Marks et al.** Chronic kidney disease, a useful trigger for proactive primary care? Mortality results from a large U.K. cohort. *Fam Pract.* 2013, 30:282
- S Hallan et al.** Age and the Association of Kidney Measures with Mortality and End-Stage Renal Disease. *JAMA* 2012, 308:2349

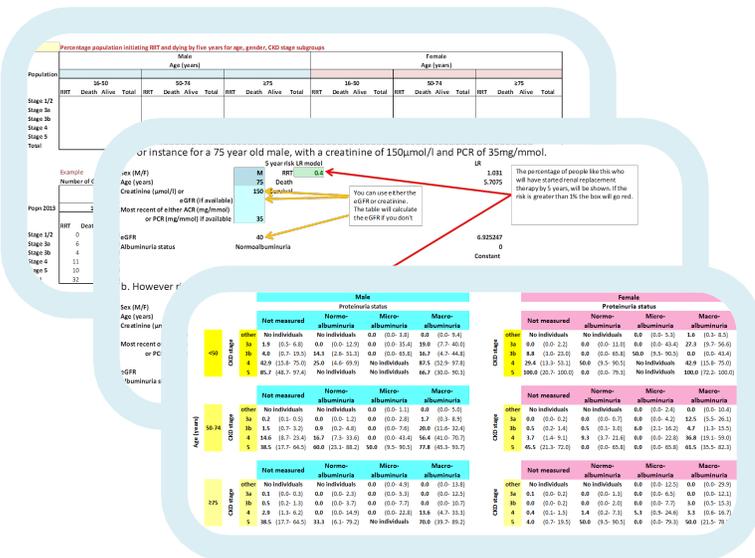
- Challenged the development of the local safe haven architecture to the satisfaction of local custodians and ethics committees.

The programme of work has enabled participation as one of only three UK centers in an international

Acknowledgements

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