

Nurse PI: Putting Rare Renal Diseases on the RaDaR

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The majority of patients with rare diseases are still without effective treatment and research opportunities for such patients are limited (European Commission website, accessed 14/7/16). To combat this, Rare Disease UK (2011) has recommended that 'support should be given to develop and sustain systems for data collection and disease registries for patients with rare diseases'.

A novel approach to achieve this is to employ a senior research nurse (SRN) as principal investigator (PI) as they are in an ideal position through links with research networks and collaborating research facilities.



Glasgow Clinical Research Facility (GCRF) SRN Hayley King used her experience in research and renal nursing to become PI for the National Registry of Rare Kidney Diseases (RaDaR) for adults in Greater Glasgow and Clyde.

RaDaR is an initiative designed to collate information from patients with rare kidney diseases and therefore encourage future research. Becoming a SRN PI for this registry required a significant time commitment for the SRN and collaboration with colleagues.



Hayley used her expertise to teach and involve the renal research nurse team in screening, identifying, recruiting, and consenting patients to the registry. This required commitment and organisation as recruitment occurs in all renal clinics throughout GG&C. As an extended SRN role it also required support from GCRF renal doctors and managers.



The SRN PI role has been successful, recruiting over 400 patients to date. This will increase opportunities for patients with rare diseases to become involved in research and raise their awareness of support networks, in turn, improving our understanding of rare diseases.



Becoming the first nurse PI in GCRF was, however, challenging due to the time commitment and reservations from colleagues who viewed the PI role as a medical position. Explaining the benefits for patients, gaining administration support and demonstrating a boost to recruitment helped to alleviate concerns.



The role of the SRN PI has enabled patients that otherwise may not have had this opportunity to be involved in research. The SRN PI is a position that GCRF endeavours to support in the future and currently several more SRNs are becoming PIs across a variety of specialties.

References:

European Commission website, accessed 14/7/16

<http://ec.europa.eu/research/health/index.cfm?pg=area&areaname=rare>

Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy (2011) Rare Disease UK

<http://www.rare-disease.org.uk/documents/RD-UK-Strategy-Report.pdf>

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