**Development of the Rare Renal Disease Registry (RaDaR)**

In 2008, some BAPN members, led by Moin Saleem (Bristol) in collaboration with the UK Renal Registry, acquired MRC funding to pilot a rare disease registry initially focused on glomerular disease in children. The aim was to model a generic system for all rare diseases, which would help end the proliferation of standalone databases and drug company- funded registries.

At the same time a UK rare renal disease strategy was being developed by an RA/BAPN working party[[1]](#footnote-1) . The strategy addressed the need to provide expert care for people with rare kidney diseases, as well as promulgating research. A particular clinical challenge was the care of rare disorders of children who with improvements in clinical care were npw surviving into adulthood[[2]](#footnote-2). The strategy also established the principles for a rare renal disease registry (RaDaR). Patient consent would be required for entry into the registry to be compliant with national data protection regulations. Rare Disease Groups (including clinicians, researchers, patients and carers) would be established for each rare disease (or for a group of related diseases). These groups would be responsible for developing disease-specific data fields; for providing expert information for patients and carers, as well as health professionals; and for initiating relevant research projects.

RaDaR was established with additional funding from Kidney Research UK and British Kidney Patients Association[[3]](#footnote-3). Its development has been overseen by the RA Rare Disease Committee chaired initially by Mark Taylor, followed by Detlef Bockenhauer (GOS) and since 2018 by Danny Gale (Royal Free). Great care was taken to ensure its sound governance, in particular with regard to privacy and data protection. For organisational and governance reasons it remains within RA[[4]](#footnote-4), alongside the Registry , sharing aspects of its technical platform. From 2016 it has been funded within the capitation fee which also supports the Registry and PatientView.

In 2021, there are 29 Rare Disease Groups. Patient recruitment into RaDaR has been consistently rapid (26,000 patients from 2021) although Rare Disease Groups have proved variable in their progress at developing relevant research, a critical metric of success.

1. Rare Kidney Diseases: An Integrated Strategy for Patients in the U.K (2010) <https://renal.org/wp-content/UK_Rare_Kidney_Disease_Strategy>. The RA/BAPN Working Party had multiprofessional, as well as patient and carer representation, and was co-chaired by Mark Taylor (Birmingham) for BAPN, and John Feehally (Leicester) for RA.

 [. It pre-dated a national strategy for rare diseases published by the Department of Health in 2012.](https://renal.org/wp-content/UK_Rare_Kidney_Disease_Strategy%20.%20This%20strategy%20pre-dated%20a%20national%20strategy%20for%20rare%20diseases%20pbulished%20bu%20te%20Dpeartmetn%20of%20Helath%20in%202012.%20in%20co-chaired%20by%20%20Mark%20Taylor%20%28Birmingham%29%20and%20John%20Feehally%20%28Leicester%29played%20a%20key%20role%20in%20the%20development%20of%20RaDaR%2C%20which%20was%20underpinned%20by%20a%20UK%20Rare%20Renal%20Disease%20Strategy%20which%20had%20been%20developed%20by%20an%20RA/BAPN%20working%20party%20which%20had%20multiporfessional%2C%20as%20well%20as%20patient%20and%20carer%20representation.%20%20%20%20)  [↑](#footnote-ref-1)
2. An exemplar is cystinosis. In 2010 there were fewer than 150 adults living with cystinosis most receiving RRT. How should they have access to disease-specific expertise while for practical reasons, receiving most of their care in their local renal unit? [↑](#footnote-ref-2)
3. Now Kidney Care UK [↑](#footnote-ref-3)
4. https://renal.org/rare-renal/radar [↑](#footnote-ref-4)