RaDaR: The Next Ten Years

Wednesday 28th February 2018

Event Report

Introduction

We were delighted to host over 25 patient representatives, Rare Disease Group Leads, site staff, and charity supporters, who braved the snow to help us celebrate RaDaR's achievements to date and consider where we go in the next ten years.

Presentations

The presentations from the day were circulated to attendees and are also available online at www.RareRenal.org or by request from Melanie.Dillon@renalregistry.nhs.uk

Group discussion

Attendees were split into five mixed groups of patient and clinicians, and ask to discuss the key question **How do you see RaDaR being used?**

Several discussion prompts were given and the key responses from the groups are listed below:

What are the big research questions you want answered?

- Long term prognosis
- Prevalence statistics – by region, age group etc
- Natural history of the condition
- Treatment optimisation – precision medicine
- Effectiveness of genetic testing methods
- Optimal renal imaging strategy
- Mental health/support issues

What are the expectations that this will drive patient benefit?

- Quality of life outcomes and how patients are affected
- Long term outcomes and epidemiology data to give to patients at diagnosis
- How do you as a patient compare to the wider cohort
- Liaise with Patient Council
- Patient-driven research
- Promote patient contact – with clinicians and each other
- Increase patient activation in their own care and wider research

How is the data to be used?

- Links with bio banks
- Merge datasets with those from other studies/registries
- Link with clinical trials
- Patient entered data via online consent
- International linkages
- Short-term – 6-12 month – pharma projects
- Support development of best practice treatment guidelines
- Linkage with HES and ONS datasets for long-term follow-up

How do you think RaDaR can support this?

- Family linkages
- Identification of eligible patients for new treatments
- Links with the 100,000 Genome Study
- As a two-way information source rather than just putting information in with none coming out
- Flag levels of data completeness/quality with clinicians/patients
- Tell patients what is being done with their data, why and how it (may) help to develop a treatment/cure for their condition
- Share findings
- More disease-specific fields

<u>Key learning points from the day</u>

RaDaR has come a long way in its first (almost) ten years. Recruitment has seen a major surge in recent years and the expansion to cover more conditions and sites makes it a potentially extremely valuable research tool.

This would not be possible with the generous support of our charity funders **– Kidney Research UK, Kidney Care UK** and **the PKD Charity** – and the enthusiasm of our patient representatives and Rare Disease Group Leads.

The two key priorities going forward are:

1. Re-consenting existing patients onto the new study documents. This is vital for data linkage and direct patient contact.

2. Improved patient communication. RaDaR needs to do more to keep patients involved in what is going on.

Thank you all for coming and for your on-going support of RaDaR.