

RaDaR: The Next Ten Years

Wednesday 28th February

**Seminar Room 1, Education Centre at the Queen Elizabeth Hospital
Birmingham, Mindelsohn Way, Edgbaston, Birmingham, B15 2GW.**

09.30	1.	Registrations and refreshments from 9.30am
10.00	2.	Welcome and introductions (Detlef Bockenbauer, Rare Disease Committee Chair)
10.20	3.	Current status of RaDaR (Melanie Dillon, RaDaR Operations Manager)
10.40	4.	Future plans - Where does RaDaR go in the next ten years? (Detlef)
11.00	BREAK	
11.15	5.	Group discussions – breakout groups
		<p>Key question: How do you see RaDaR being used?</p> <ul style="list-style-type: none"> • What are the big research questions you want answered? • What are the expectations that this will drive patient benefit? • How is the data to be used? • How do you think RaDaR can support this? <p>Group joins to share discussions and findings in plenary.</p>
12.45	LUNCH	
13.30	6.	<p>Explore existing examples of research undertaken utilising RaDaR (Detlef to chair)</p> <ul style="list-style-type: none"> • Liz Colby NURTURE • Paul Brenchley MN Research • Michael Randles Alports Syndrome Research
14.00	7.	Supporting patient groups - the Kidney Research UK model (Sarah Harwood & Tracey Murray, Kidney Research UK)
14.30	8.	Supporting patients and families with rare diseases (Fiona Loud, Kidney Care UK)
14.45	9.	Summary and next steps (Detlef)
15.00	10.	Lab tour (optional)/Rare Disease Group Lead Meeting