

**RaDaR Patient Representative and Rare Disease Group Lead Meeting**

**Monday 2<sup>nd</sup> September 2019**

**10am – 3.30pm**

Resource for London, 356 Holloway Road, London, N7 6PA

**10.00am - Registration and coffee**

**10.30am - Welcome and introductions** (Danny Gale, Rare Disease Committee Chair)

**10.35am - Current status of RaDaR** (Melanie Dillon, RaDaR Operations Officer)

**10.40am - Ethics and re-consent** (Kate Bramham, Rare Diseases Committee Deputy Chair)

**10.45am - Current and future research** (Rare Disease Group Leads)

ADPKD (Dick Sandford)

MPGN/C3G/DDD WGS (Danny Gale)

NephroS/NURTuRE (Moin Saleem)

PREDICT (Kate Bramham)

**11.45am - Other research initiatives**

ERKNET (Tess Harris)

NIHR BioResource (Kathy Stirrups)

NCARDS (Mary Bythell)

NHS Digital (Jackie Shears)

**12.30pm – 1.15pm Lunch**

**1.15pm - Patient Council and information resources** (Fiona Loud, Kidney Care Policy Director)

**1.30pm - Kidney Research UK support** (Pete Storey, KRUUK Rare Disease Programme Lead)

### Split session

**1.45pm - Patient Representatives Discussion Session**

Joined by Fiona Loud (Kidney Care UK), Sarah Harwood & Pete Storey (Kidney Research UK)

**Suggested topics:**

1. How to gather and communicate patient-led research priorities
2. Patient engagement in rare disease groups

**Clinicians Data Masterclass**

Fiona Braddon, RaDaR Clinical Informatics Manager

**How to apply for and use a RaDaR data download**

**2.45pm - Patient Representatives feedback** (Sarah Harwood, Kidney Research UK)

**3.00pm - Summary and next steps** (Danny Gale, Rare Disease Committee Chair)