



RaDaR

Rare Disease Registry

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Radar Administrator

Background

- Limited medical expertise on rare kidney diseases
- Radar aims to create an online database of patient information to share best practice guidelines
- Managed by a dedicated Rare Disease Group of experts in each condition
- May lead to future research studies on new treatments or ways of diagnosis

Data Capture

| | | | |
|---------------|---|---|--|
| Surname | <input type="text" value="Mouse"/> | NHS Number | <input type="text" value="123 4567 8900"/> |
| First Name | <input type="text" value="Mickey"/> | Add Id | <input type="text" value=""/> <input type="button" value="Add"/> <input type="text" value="Choose One"/> |
| Alias Name | <input type="text"/> | Hospital Number | <input type="text" value="X0000001"/> |
| Date of Birth | <input type="text" value="01-01-2000"/> <input type="button" value="17"/> <i>Help</i> | Renal Unit | <input type="text" value="B'Ham - Paeds"/> |
| Sex | <input type="text" value="Male"/> | RRT Modality | HD <input type="radio"/> PD <input type="radio"/> Tx <input type="radio"/> none <input type="radio"/> |
| Ethnic Group | <input type="text" value="Irish (NMO)"/> | Renal Diagnosis | <input type="text" value="Hyperoxaluria"/> |
| Address | <input type="text" value="1 Main Street"/> <input type="text" value="Disneyland"/> <input type="text"/> <input type="text"/> | Date of Diagnosis | <input type="text" value="01-01-2000"/> <input type="button" value="17"/> <i>Help</i> |
| Postcode | <input type="text" value="D1 234"/> | Responsible Consultant | <input type="text" value="Dr Sally HULTON"/> |
| Email address | <input type="text" value="mickey@mouse.co.uk"/> | Other relevant Clinician and contact info | <input type="text"/> |
| Phone 1 | <input type="text" value="0123 456 7890"/> | Consent (RaDaR only) | <input checked="" type="checkbox"/> Consent Forms |
| Phone 2 | <input type="text"/> | Comments | <input type="text" value="Consented in clinic by MD 01/01/2013. Data entered 02/01/2013."/> |
| Mobile | <input type="text" value="0987 654 3210"/> | | |

Information Security

- Data is encrypted and password protected
- Participants provided with a secure log-in to access and check your own information
- Identifiable data only available to your doctor so they can contact you if needed
- Members of the Rare Disease group will only see anonymised data – numbers rather than names

To take part...

- If your child is treated at BCH:
 - Collect an information sheet
 - Sign the consent form
 - Hand back to me
- If you or your child are currently treated elsewhere:
 - Collect an information sheet
 - Take to your doctor at your next appointment
 - Ask them to register you

RareRenal.org

- Patient and doctor information on rare kidney diseases
- Written by Rare Disease Groups and managed by the Renal Association
- Feedback on PH Information sheet
 - Language and layout
 - Information provided
- Comments/suggestions to melanie.dillon@renalregistry.nhs.uk