UK Renal Registry – exciting developments

Renal Association

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Developments at the UKRR

• Faster and wider reporting of audit data
  – New format annual report
  – Data portal
  – Patient summary of annual report

• Increased transparency to data held and streamlined process to access data
  – Data completeness exercise
  – Research ready datasets
  – New website
  – New data application process
Annual report

• **Key changes**
  – Timeliness – slicker standardised process
  – Align more closely to Renal Association guidelines
  – Fewer chapters and consistent format
  – Reduced commentary – thank you to previous contributors

• **Forthcoming changes**
  – Add an HHD chapter
  – Update access to transplant chapter

• **New opportunities and outputs**
  – Patient summary
  – Publications – diabetes, ethnicity, AKI, HES adjusted survival
  – Explore CKD data
  – AKI annual report
  – Portal
Patient summary – infographics

75% dialysed for 4–5 hours per session

95% dialysed 3 times per week

Just under 26,000 adults were on haemodialysis at the end of 2017 - around 4 in 10 of all those on treatments for kidney failure

Developed in collaboration with RA Patient Council
Completeness of UKRR data

• Dataset 4.2 is a list of all the data items we are permitted to collect
• A small subset are used in the annual report
• What about the rest?
• Data completeness exercise (data portal)
• Positive outcomes
  – more data items for guidelines/targets
  – renal centres can identify gaps in data
  – prioritise collection
  – increase visibility of data for audit/research use
Audit/research ready datasets

• Aspirational aim – the data completeness exercise is the first step
• Maximise use of registry data both internally and externally
• New research director and new RA research strategy coming – we’ll wait for those before progressing
Accessing UKRR data

• Background – we have to have a HRA approved process to release data for audit and research purposes – s251 and REC permissions

• Current process works but is onerous and lengthy

• We want to make it easier for people to use UKRR held data while remaining IG compliant – if someone has an idea we want it to be quicker for them to find out if it’s feasible and also to be handed the data