

The History of the UK Paediatric Renal Registry

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Introduction

- The UK Renal Registry (UKRR) hosts a paediatric registry, which reports demographic, biochemical and outcomes data on all renal replacement therapy (RRT) patients under 18 years managed in UK paediatric centres.
- The paediatric registry was formed in 1995 and is entering its 20th year.

Aims

- We aim to describe the history and development of this registry, including challenges faced and its role today.

Methods

- All UKRR reports were reviewed to establish timelines. Dr Malcolm Lewis (ML, a paediatric nephrologist who wrote the original database and remains an active subcommittee member) was interviewed to capture the processes and his reflections.

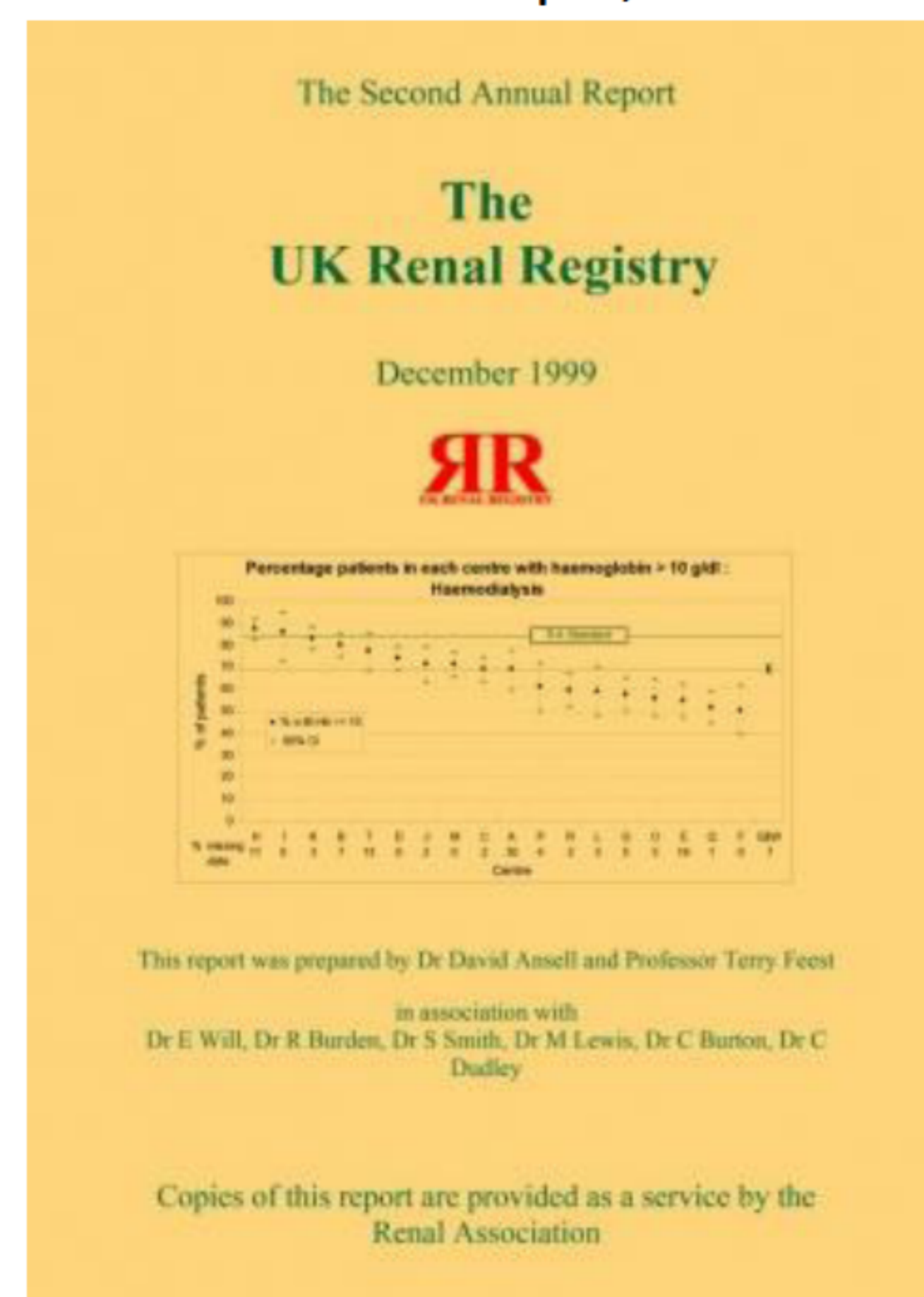
Timeline

- **1994**
ML creates a local clinical database in Filemaker.
- **1995**
A two year pilot project with the British Association for Paediatric Nephrology (BAPN) and the UKRR begins with support from the Renal Association. This led to ML creating a dataset and database that would collect paediatric data, supported by the BAPN. Data items for adults were adapted, expanded to incorporate growth and a consensus opinion was reached on coding for diagnoses, from European and international classification systems. Participation was mandated in England through the NHS National Service Specification. Roche Pharmaceuticals contributed £5000 funding, which was used to buy computer equipment and support travel to the 13 paediatric centres, shown in **Figure 1**. Ongoing costs were funded by a capitation fee.

Figure 1.
Locations of the 13 UK Paediatric Nephrology centres.



Figure 2.
UKRR Second Annual Report, 1999



- **1996**
Annual data collection begins. Initially all information technology support was done by both ML and Manchester Children's Hospital renal data manager, Jo Shaw, with data collection shared with local clinical teams. Initial data extraction was onto floppy disk and sent via post, which was usually faster than electronic transfer by modem!

- **1997**

The BAPN creates an Audit and Registry Subcommittee. Committee chairs are listed in **Box 1**.

- **1999**

Publication of the first paediatric report, presented as a chapter of the second adult report, shown in **Figure 2**.

- **2000**

Anticipated short term reversion from electronic to paper based data returns.

- **2007**

2006 UKRR annual report published as a supplement in *NDT*, with three paediatric chapters comprising demography, growth and anaemia.

- **2009**

Merger with UK Renal Registry and relocation to Bristol to support integration with the adult registry. Extracts from clinical systems were imported into the original database facilitated by local data managers and central informaticians. A change in census date to conform with adult and European registries was also agreed. The current format of two paediatric chapters reporting demography and biochemistry was adopted, with UKRR registrars now involved in data analysis and report writing.

- **2013**

100% electronic data returns achieved.

- **2014**

Appointment of the British Kidney Patient Association funded, Kidney Research UK managed Tony Wing Clinical Research Fellow with the aim of bringing the adult and paediatric registries closer together.

Box 1.
BAPN Audit and Registry Committee Chair
1997 – Dr Alan Watson
2000 – Dr Jane Tizard
2004 – Dr Chris Reid
2007 – Dr Jonathon Evans
2008 – Dr Carol Inward
2012 – Dr Manish Sinha

Discussion

The leading challenges still faced are those of:

- integrating the adult and paediatric databases to facilitate accurate reporting of data for 16-18 year olds
- moving from annual to quarterly returns
- improving completeness
- harmonising smooth data extraction from the variety of bespoke clinical systems.

In the future, developments in data storage and processing are likely to lead to exponential increases in the amount of data items held, with the potential for real time collection of blood results, and scope to expand collection to include acute kidney injury and chronic kidney disease. In Europe, the sequelae of the European Union Data Protection Reform may impact on the current operations of disease specific registers and these effects remain to be seen.

Conclusions

- **The timeline presented demonstrates that enthusiasm, technology, funding and collaboration were the key components of this registry. The process has evolved from the input of a single individual with UKRR backing to a more integrated approach with formal systems for better data management and statistical resources, greater information security and an overall more supported registry.**
- **The paediatric registry's value over time has become providing demographic data and biochemical data comprehensively on each UK paediatric RRT patient and allows benchmarking and comparison to national guidance and standards. It also provides data on trends since 1998, as well as being a research resource and basis for service planning and evaluation.**

References

1. <https://www.renalreg.org/publications-reports/>
2. The British Association for Paediatric Nephrology: The first thirty years 1973-2003. Richard H R White