# RaDaR – how it all started

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Tomorrow’s World, 7 July 1965

2008

# Why is Rare Disease a problem?
# - The patient perspective

- Patients with rare disease often consider themselves forgotten or lost
- European Council in 2009 described patients with rare disease as particularly isolated and vulnerable
- Features common to them all include:
    - the considerable hurdles to receiving optimal care
    - the difficulty obtaining a diagnosis
    - delay in time from presentation to review by an expert
    - lack of available therapy
    - lack of clinical research
    - lack of support and information sources

**Requires a patient database, as a crucial starting point**

# The initial vision

- A sustainable long-term clinical database for all rare kidney diseases, open to all UK renal centres
- Ability to link with other databases, including international registries
- A central portal for professional and patient advice, and for the latest research in rare diseases

MRC Medical Research Council

- A MRC focused grant call was issued in 2008, for focused cohort building

- Application submitted from Bristol, with Mark Taylor (Birmingham Children's Hospital) as a co-investigator

- Proposal was for 2 pilot cohorts – Paediatric SRNS and MPGN
- Aim was for 500 patients

- Successfully awarded, with project commencement in 2009

# Initial progress

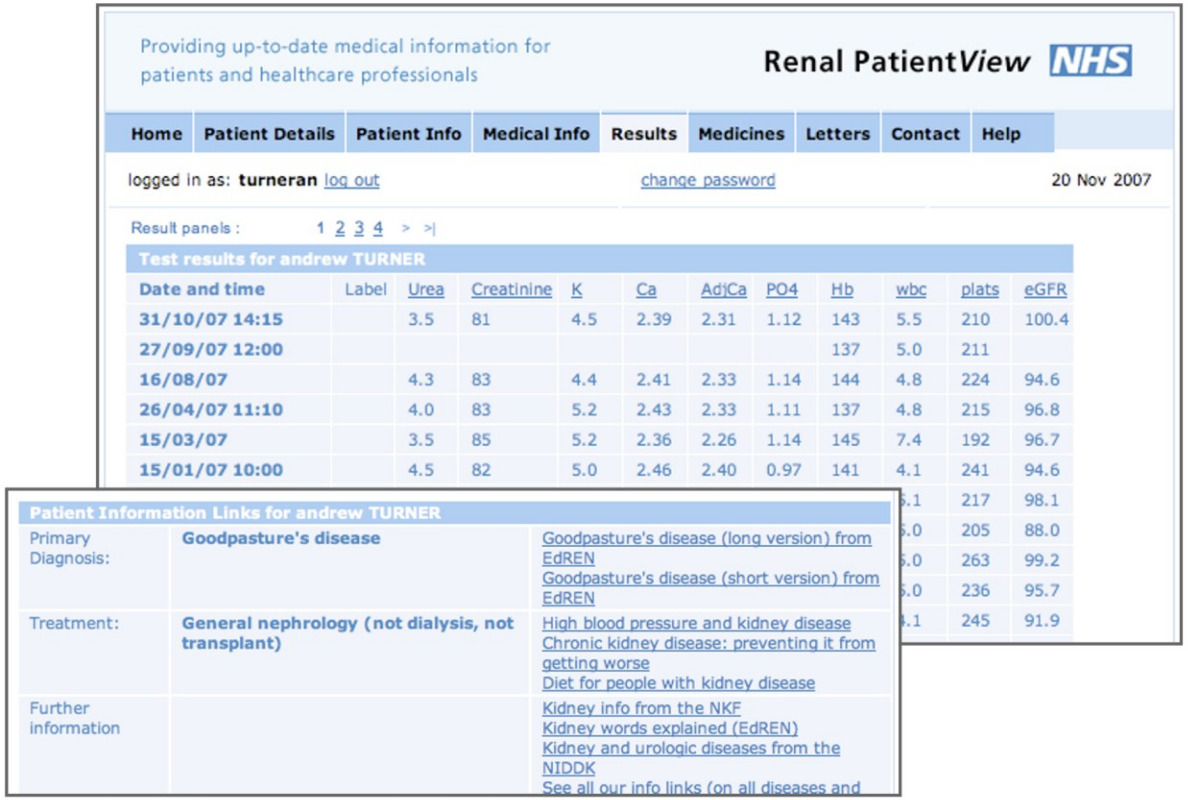
A small group was formed, Myself, Hugh McCarthy, Fiona Braddon, Mark Taylor, Neil Turner, Fiona Karet - to establish:

1. Data field definitions
2. Employed a web developer, integrate access with UKRR
3. Governance structure and Rare Disease Group definitions
4. Flow of different types of data (Type 1 and Type 2 data)
5. Other aspects, e.g. logo, communications strategy, acronym (RaDaR)

We met regularly at the UKRR

Providing up-to-date medical information for patients and healthcare professionals

Renal PatientView NHS



Providing up-to-date medical information for patients and healthcare professionals

Renal PatientView NHS

logged in as: **turneran** log out

change password

20 Nov 2007

Result panels : 1 2 3 4 > >|

**Test results for andrew TURNER**

| Date and time | Label | Urea | Creatinine | K | Ca | AdjCa | PO4 | Hb | wbc | plats | eGFR |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **31/10/07 14:15** | | 3.5 | 81 | 4.5 | 2.39 | 2.31 | 1.12 | 143 | 5.5 | 210 | 100.4 |
| **27/09/07 12:00** | | | | | | | | 137 | 5.0 | 211 | |
| **16/08/07** | | 4.3 | 83 | 4.4 | 2.41 | 2.33 | 1.14 | 144 | 4.8 | 224 | 94.6 |
| **26/04/07 11:10** | | 4.0 | 83 | 5.2 | 2.43 | 2.33 | 1.11 | 137 | 4.8 | 215 | 96.8 |
| **15/03/07** | | 3.5 | 85 | 5.2 | 2.36 | 2.26 | 1.14 | 145 | 7.4 | 192 | 96.7 |
| **15/01/07 10:00** | | 4.5 | 82 | 5.0 | 2.46 | 2.40 | 0.97 | 141 | 4.1 | 241 | 94.6 |
| | | | | | | | | | .1 | 217 | 98.1 |
| | | | | | | | | | .0 | 205 | 88.0 |
| | | | | | | | | | .0 | 263 | 99.2 |
| | | | | | | | | | .0 | 236 | 95.7 |
| | | | | | | | | | .1 | 245 | 91.9 |

**Patient Information Links for andrew TURNER**

| | | |
|---|---|---|
| Primary Diagnosis: | **Goodpasture's disease** | Goodpasture's disease (long version) from EdREN<br>Goodpasture's disease (short version) from EdREN |
| Treatment: | **General nephrology (not dialysis, not transplant)** | High blood pressure and kidney disease<br>Chronic kidney disease: preventing it from getting worse<br>Diet for people with kidney disease |
| Further information | | Kidney info from the NKF<br>Kidney words explained (EdREN)<br>Kidney and urologic diseases from the NIDDK<br>See all our info links (on all diseases and |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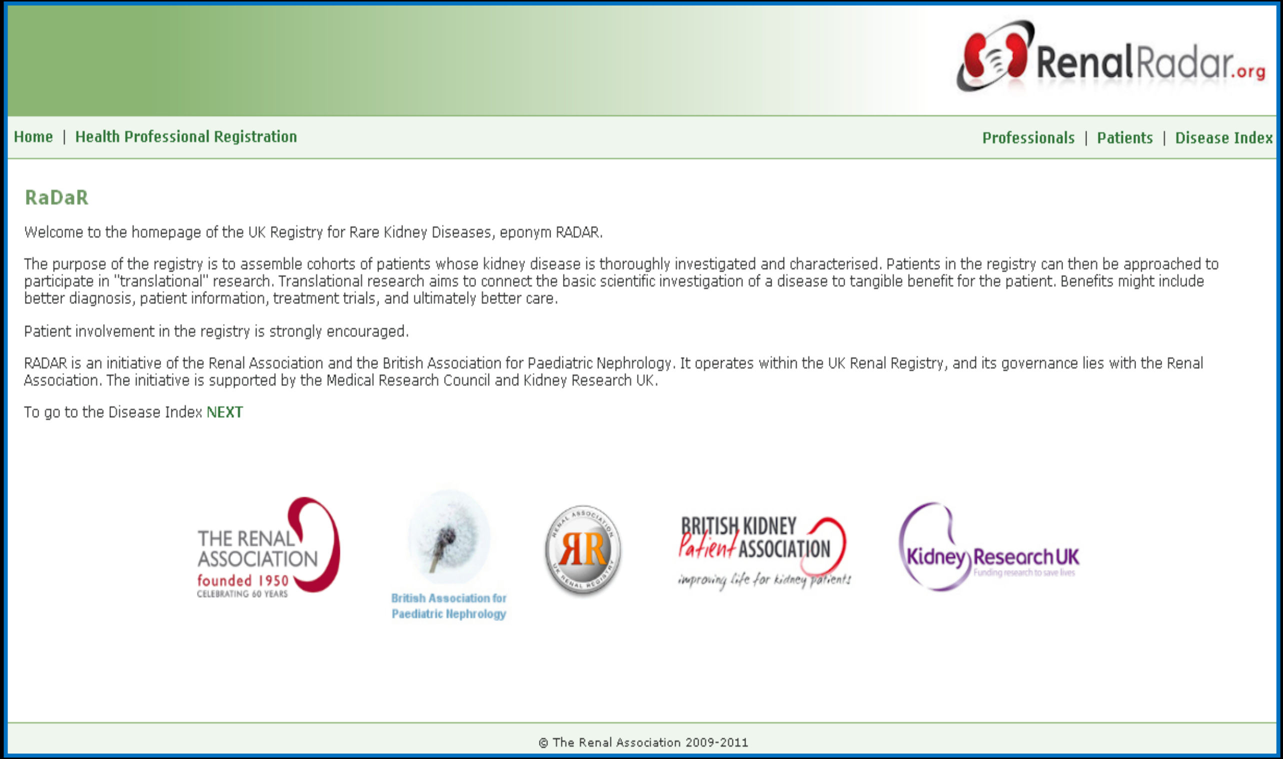
IN A PERFECT WORLD, NO ONE WOULD BE ABLE TO USE ANYTHING.

# The National Registry of Rare Renal Disease

RenalRadar.org

RareRenal
Information on rare kidney diseases

- ➢A database fronted by a website.
- ➢Developed utilising the IT infrastructure of the UK Renal Registry.
- ➢Designed to build national cohorts of patients with rare kidney disease to enable multi-faceted and innovative research.
- ➢Now links with Renal Patient View



**RaDaR**

Welcome to the homepage of the UK Registry for Rare Kidney Diseases, eponym RADAR.

The purpose of the registry is to assemble cohorts of patients whose kidney disease is thoroughly investigated and characterised. Patients in the registry can then be approached to participate in "translational" research. Translational research aims to connect the basic scientific investigation of a disease to tangible benefit for the patient. Benefits might include better diagnosis, patient information, treatment trials, and ultimately better care.

Patient involvement in the registry is strongly encouraged.

RADAR is an initiative of the Renal Association and the British Association for Paediatric Nephrology. It operates within the UK Renal Registry, and its governance lies with the Renal Association. The initiative is supported by the Medical Research Council and Kidney Research UK.

To go to the Disease Index NEXT

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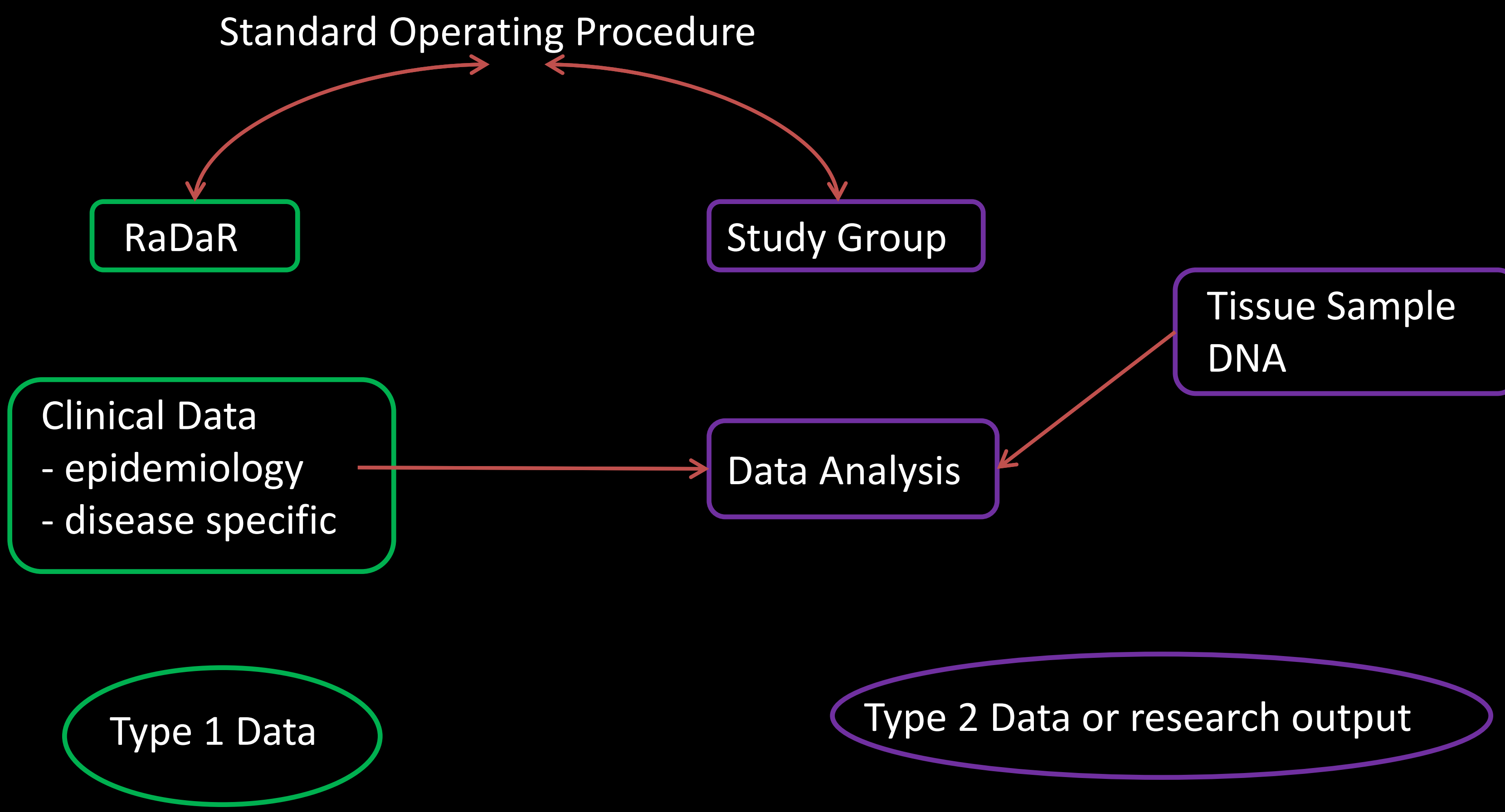
The first two projects utilising this registry:
•Steroid Resistant Nephrotic Syndrome
•MembranoProliferative GlomeruloNephritis

# RaDaR – a registry with the capability to create disease specific studies



Standard Operating Procedure

RaDaR

Study Group

Tissue Sample
DNA

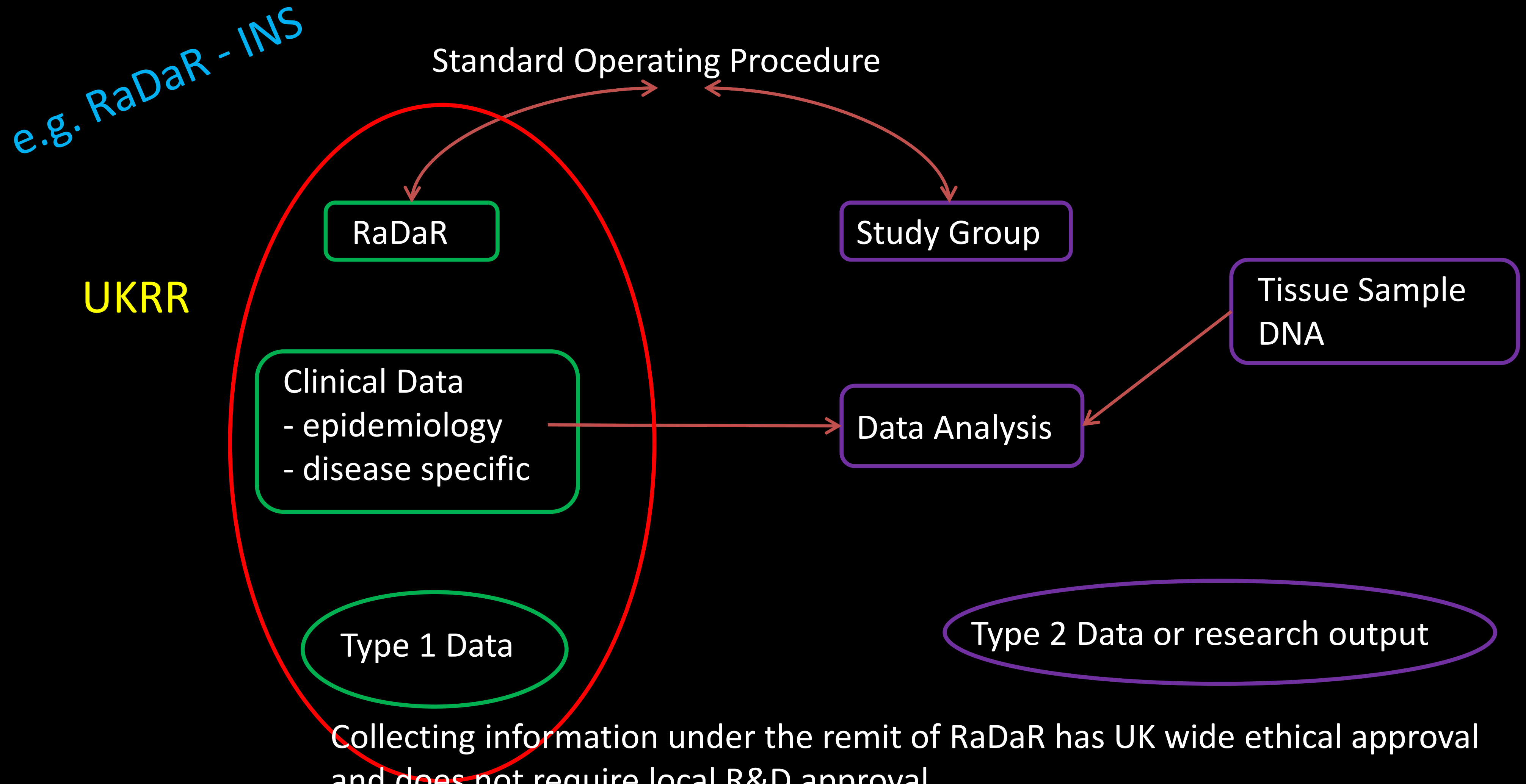
Clinical Data
- epidemiology
- disease specific

Data Analysis

Type 1 Data

Type 2 Data or research output

# RaDaR – a registry with the capability to create disease specific studies



e.g. RaDaR - INS

Standard Operating Procedure

RaDaR

Study Group

UKRR

Tissue Sample
DNA

Clinical Data
- epidemiology
- disease specific

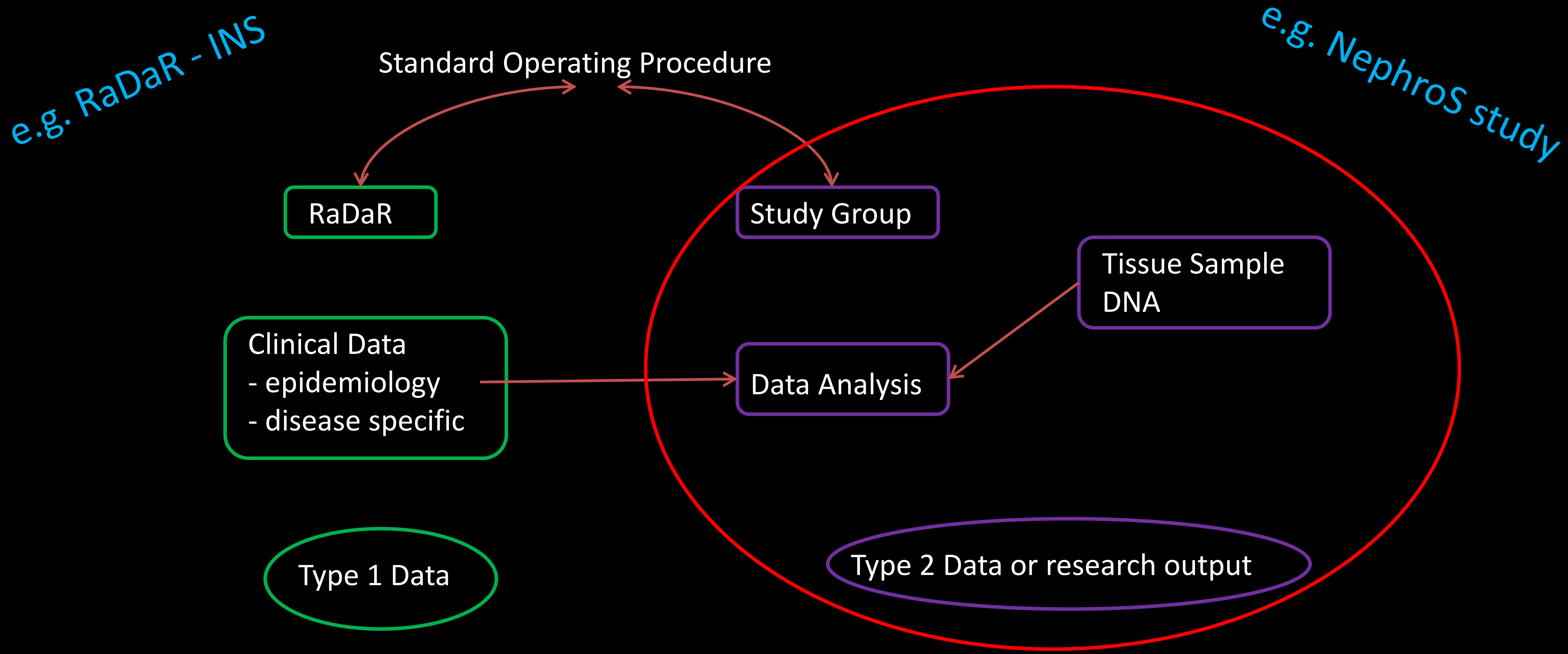
Data Analysis

Type 1 Data

Type 2 Data or research output

Collecting information under the remit of RaDaR has UK wide ethical approval and does not require local R&D approval

# RaDaR – a registry with the capability to create disease specific studies



e.g. RaDaR - INS

Standard Operating Procedure

e.g. Nephros study

RaDaR

Study Group

Tissue Sample
DNA

Clinical Data
- epidemiology
- disease specific

Data Analysis

Type 1 Data

Type 2 Data or research output

Study groups need separate ethical approval to undertake detailed studies

# UK Renal Rare Disease Registry

RenalRadar.org

RareRenal
Information on rare kidney diseases

- INFRASTRUCTURE – secure web based – clinician and patient logins
- EDUCATION –
- Information for Clinicians
  - Up to date literature/research reviews
  - Management and diagnostic protocols written by expert groups

- Information for Patients
  - Information on the disease in lay terms, tests involved, medications often used and current research

- All information available on the website
  - Patient data
  - Latest research
  - Patient forums

# Capability and roll-out of RADAR

- COMPREHENSIVE to cover all of UK (60 million population)
  - Enrolled all 13 UK Pediatric Nephrology Centres (first wave)
  - Next enrolled all UK Adult Nephrology Centres
  - Links in place to upload data continuously from UK renal IT systems

# The bigger picture

- Plenty of registries have come and gone, depending on the enthusiasm of the clinicians

- RADAR needs to be built into a wider strategy for Rare Disease, that is well governed and sustainable

Tomorrow’s World, 7 July 1965