RaDaR Training - Data Quality Refresher
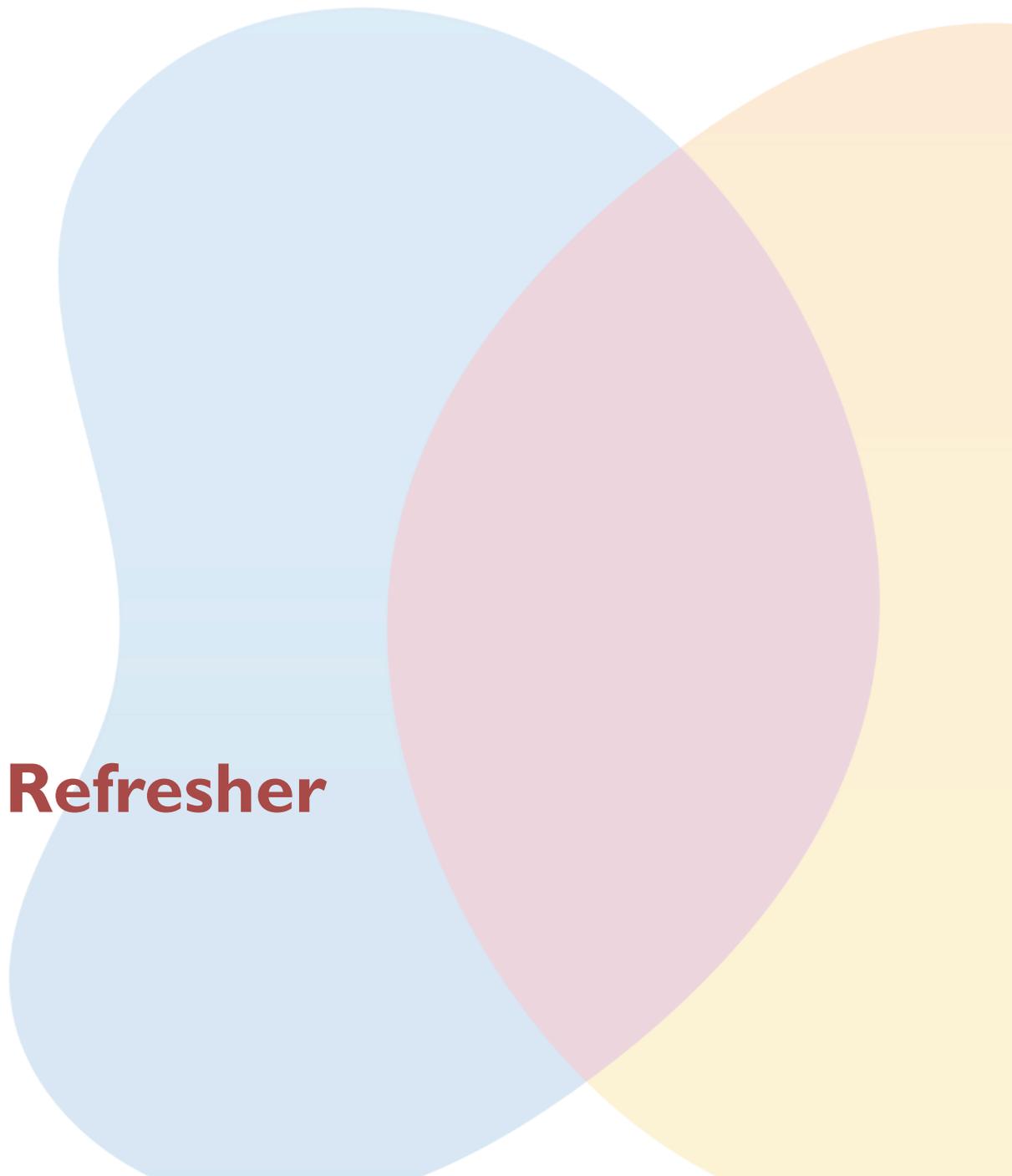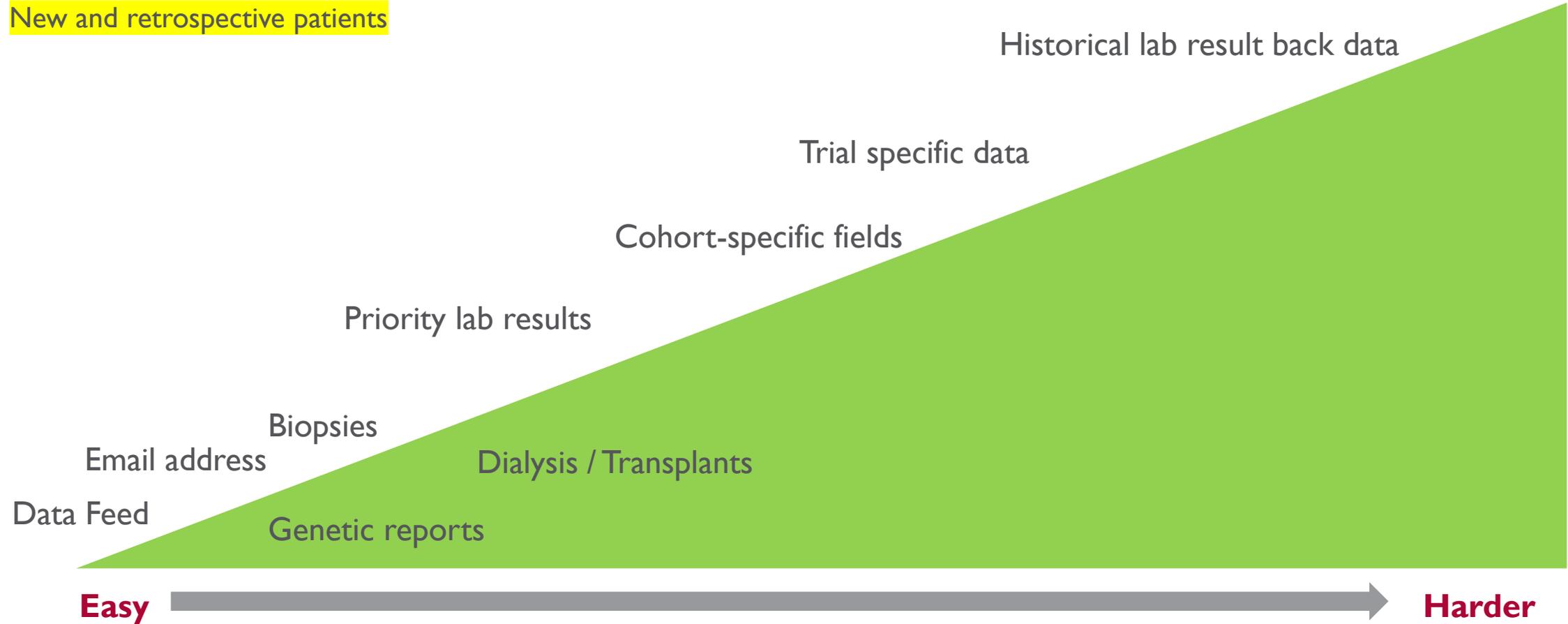
We need your help to improve the data quality (DQ) for research

- Training materials: https://ukkidney.org/rare-renal/recruitment
- Data is valuable for rare disease patients ; better data - research becomes more powerful!
- Stats: 180 recruited patients in last month, 79% have **no** data feed, 77% have **no** pathology report, 18% have **no** email
- Be data sleuths / investigators - feedback queries
- External Link to DQ info: https://www.gov.uk/government/news/meet-the-data-quality-dimensions
- Accuracy (transcription errors, units of measure)
- Completeness (temporal, native and transplant biopsies)
- Timeliness (up-to-date, update deceased patients (DoD) on RaDaR, email)
- Validity (things that look incorrect, males with female conditions)
- Anonymisation (remove patient identifiable data in reports)

Triangle of data collection difficulty!

New and retrospective patients

Historical lab result back data

Trial specific data

Cohort-specific fields

Priority lab results

Biopsies

Email address

Dialysis / Transplants

Data Feed

Genetic reports

Easy → **Harder**

Data Checklist

- Data feed – provides follow-up data
- Priority lab results at time of diagnosis (or 90 days either side)
    - Serum Creatinine, eGFR, uACR, uPCR
- Evidence to support the diagnosis – biopsy (pathology) report ; genetic report ; clinical picture ; biochemistry
    - Biopsy priority cohorts:
    - Membranoproliferative Glomerulonephritis (MPGN)
    - IgA Nephropathy native AND transplant biopsies
    - Alport Syndrome biopsies and electron microscopy (EM) biopsy reports (latter is more relevant here)
    - Membranous Nephropathy (MN) biopsies
    - Nephrotic Syndrome (INS)
- Email address – newsletters, questionnaires, identification for trials
- Pathways/ Endpoints – DoD, All Dialysis sessions / all Transplants
- Cohort specific fields – ask
- Cohort specific guidance available
- Where have patients transferred from and moved to? If patient sites not already in RaDaR, please let us know.
- Checks apply to new patients in RaDaR and retrospective
- Completeness reports will be available to target gaps