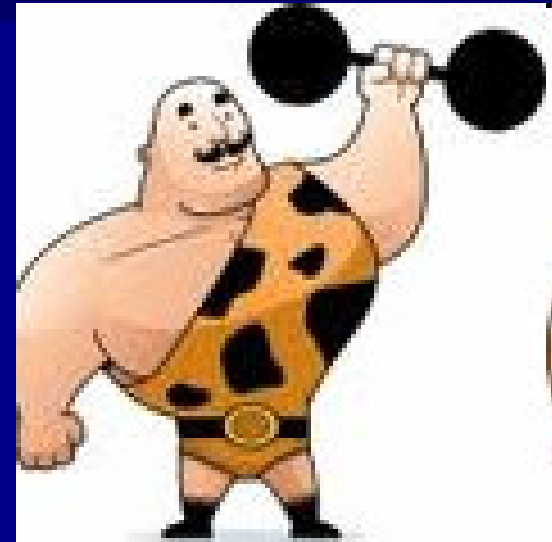


Using routine data for recruitment and follow-up in large-scale clinical studies

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Who?

- HPS (Randomised 20,000)
- SEARCH (Randomised 12,000)
- ASCEND (Randomised over 10,000)
- THRIVE (Randomised 25,000, 8,000 in the UK)
- BIOBANK (Recruited 500,000)



UK BIOBANK

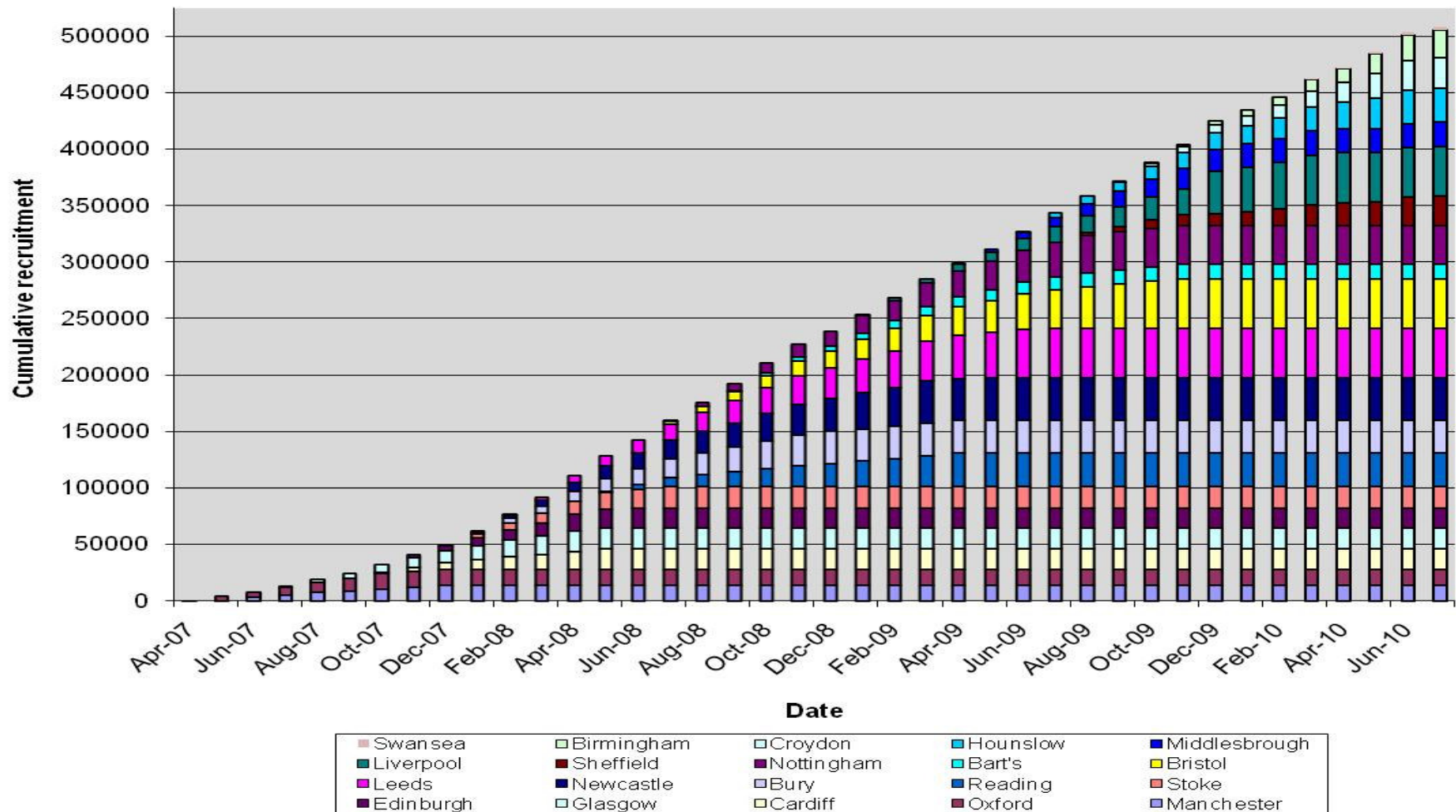
- Prospective trial.
- Aim to recruit 500,000 across ~20 sites.
- Inclusion criteria: age 40-70
- Sent ~9M invites to people within the catchment area of an assessment centre.

→ Automation Essential

UKB Process

- Acquire data
- Clean data, allocate to assessment centre.
- Invite to fill centre.
- Other stuff...

UKB Recruitment



THRIVE

- Study in patients with heart related problems.
- Randomised 25,000 (8,000 in UK).
- Many assessment centres.
- Recruitment via local datasets.

- → Dealt with over 170 individual data cleaning exercises. No two trusts the same.

ASCEND

- Study in diabetics.
- Postal – no assessment centres.
- Recruitment via multiple routes.

- → Lack of central access makes this study very hard.

Long Term Follow-Up?

- It could be worse...



Long Term Follow Up

- Death Registries
- Cancer Registries
- HES Data
- Other data sources

- → Importance of unique identifiers

Current THRIVE Follow-Up Processes

- Via the patient (not always reliable)
- Via the local site/nurse (can be problematic...)
- Some registries

- Not as practical for UKB or ASCEND.

Conclusion

- Existing registries can be very useful in Long Term Follow-Up and recruitment
 - Cheaper
 - Easier
 - Less intrusive
 - More comprehensive

And we're done...

- Questions?