14th International Donor Registry Conference & WMDA Meetings

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Dr James Robinson

Modelling an international donor recruitment strategy in a collaborative pilot study between a UK and Indian donor registry

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Finding a match for a donor

We match patients and donors based on their HLA genes

Finding a match is dependent on finding a donor with a compatible HLA type to the patient

This is made more difficult by the variation in the HLA genes

- The HLA region is the most variable in the human genome
  - Allele variation
  - Haplotype variation

- Diversity and variation can be linked with race/ethnicity/ancestry and/or geographical distribution

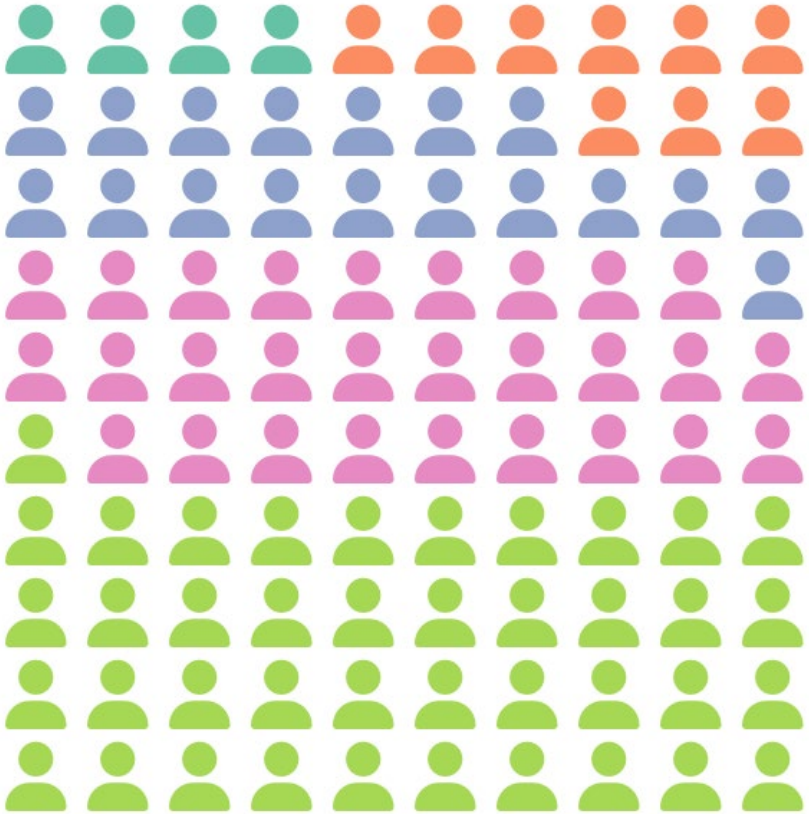
UK Register Diversity

Anthony Nolan has a register with donors from different ethnicities

	AN	UK
White British	83.2%	74.7%
Asian	5.6%	7.0%
Black	3.0%	4.0%
African	0.6%	2.5%
African Caribbean	2.4%	1.0%

Ethnicity	AN register (July 2023)	%
White British/Irish	737,149	83.2
South Asian	49,419	5.6
India	14,280	1.6
Pakistan	6,866	0.8
Bangladesh	1,696	0.2
African	5,517	0.6
African-Caribbean	21,474	2.4
Jewish	10,490	1.2
East Asian	4,628	0.5
Middle Eastern	2,103	0.2
European	16,312	1.8
Central/Southern European	7,719	0.9
Eastern European	5,641	0.6
Mediterranean	2,952	0.3
Other/Unknown	38,887	4.4

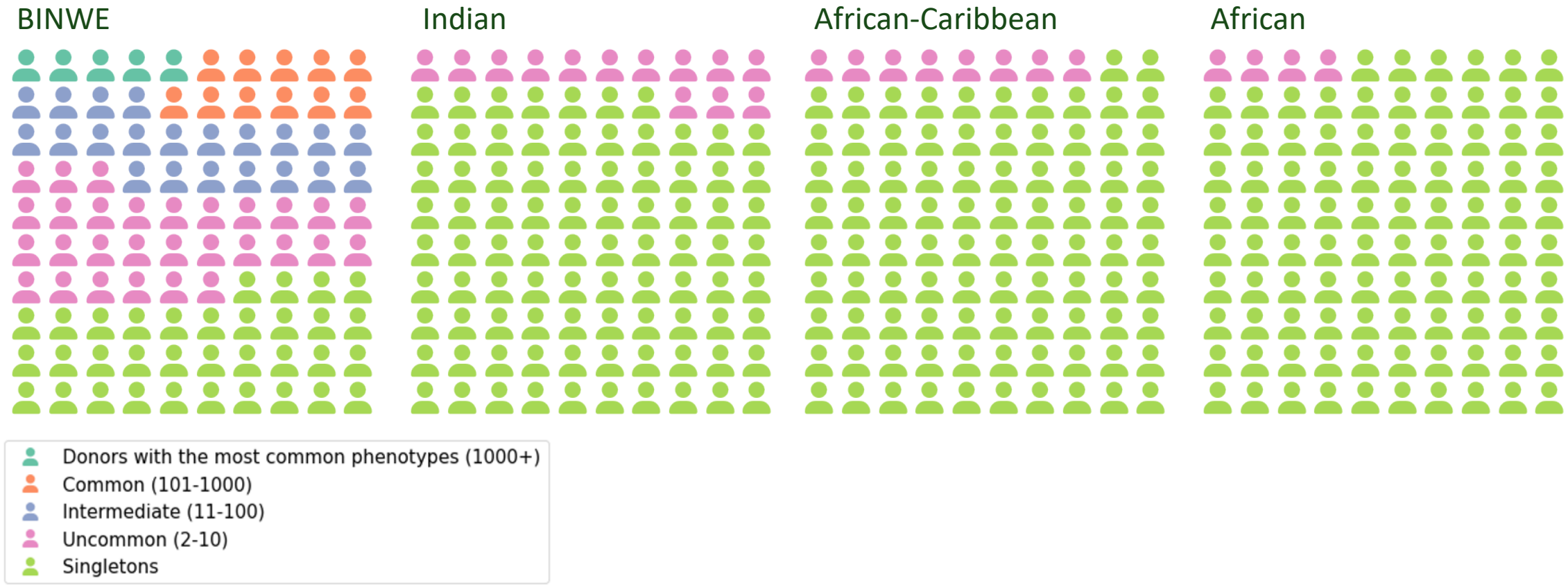
Types of Donor Phenotypes



- Donors with the most common phenotypes (1000+)
- Common (101-1000)
- Intermediate (11-100)
- Uncommon (2-10)
- Singletons

358,630 singletons out of 443,379 distinct phenotypes from 875,759 donors

Recruiting 100 donors



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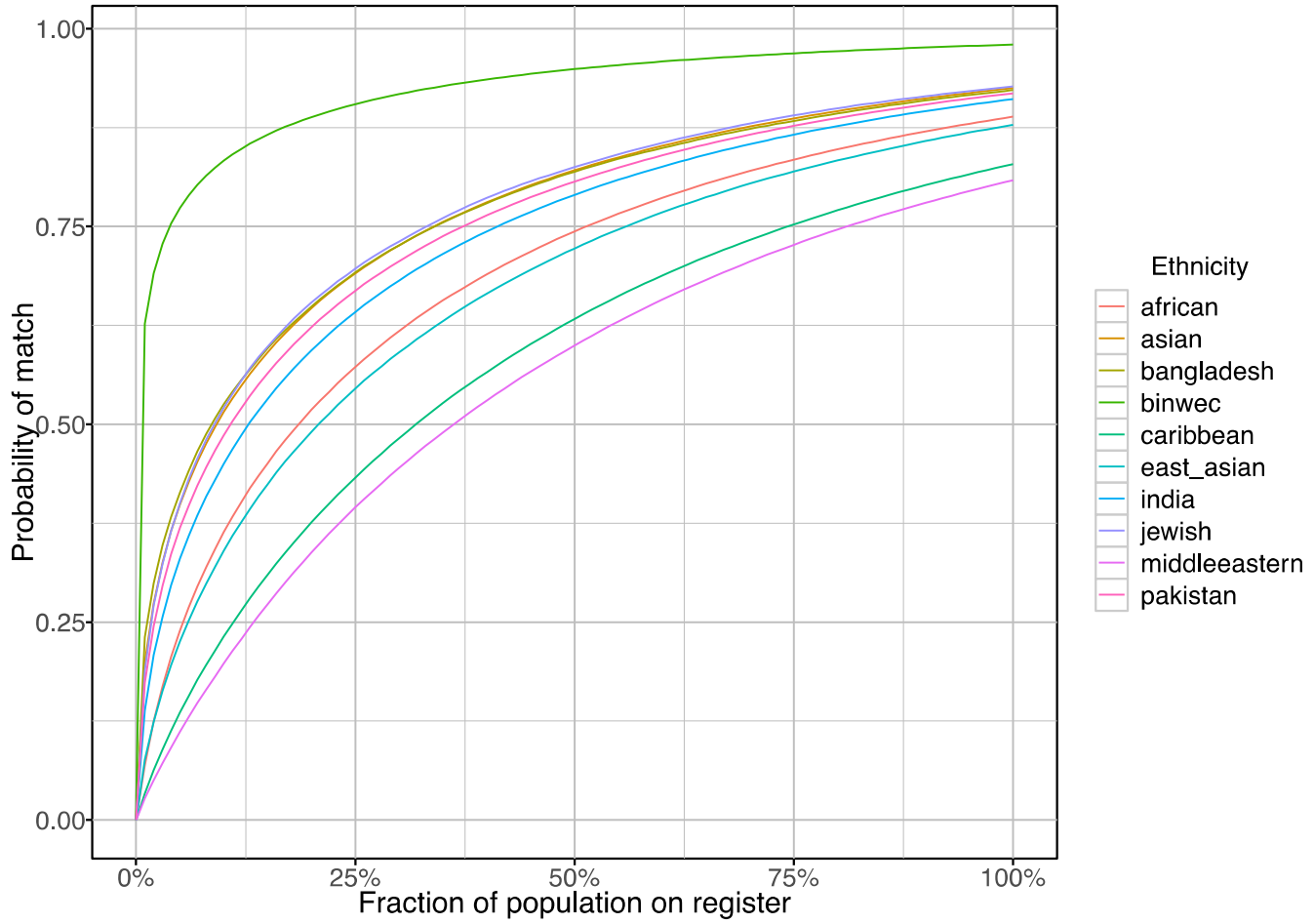
Diversity and Matching

- The chance of finding a match increases with more donors
- But there will always be unique individuals
- Even if you had everyone in the world on a register you would still not find a match for everyone
- The curves differ due to the level of diversity within the different groups



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The DATRI Project

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- Donor recruitment efforts in the UK have diversified the AN register.
- However, previous work indicates that the UK population from ethnic minority groups alone cannot deliver the diversity of HLA types needed.
- The British Asian population is the largest ethnic minority population in the UK, and there is an established register in a relevant country: DATRI, which is based in Chennai, India.
- We are collaborating with DATRI in a pilot study to investigate whether the directed recruitment of donors outside of the UK could benefit ethnic minority patients in the UK.
  - NIHR Funded project (**NIHR205433**)

FUNDED BY NIHR | National Institute for Health and Care Research

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Aims

- Calculate HLA allele, haplotype, and phenotype frequencies from the DATRI register using our in-house tools and use these to build models that will inform recruitment strategy decisions.
- Understand the HLA diversity in the DATRI Register, the wider Indian population and relationships to the UK Asian population.
- Model likely demand for British Asian patients and matching on both Anthony Nolan and DATRI register.
- Identify common phenotypes within the Indian population to guide the enrichment of donors who are most likely to be selected for patients.
- To recruit 10,000 new donors to the DATRI register based on this analysis.

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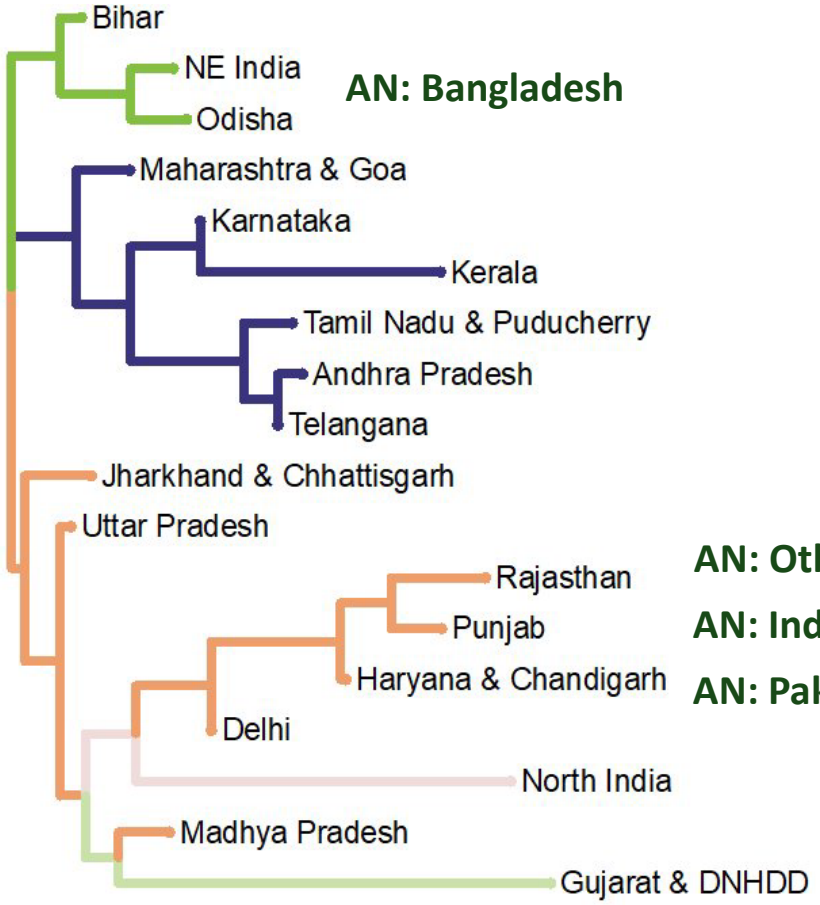
Clustering donors

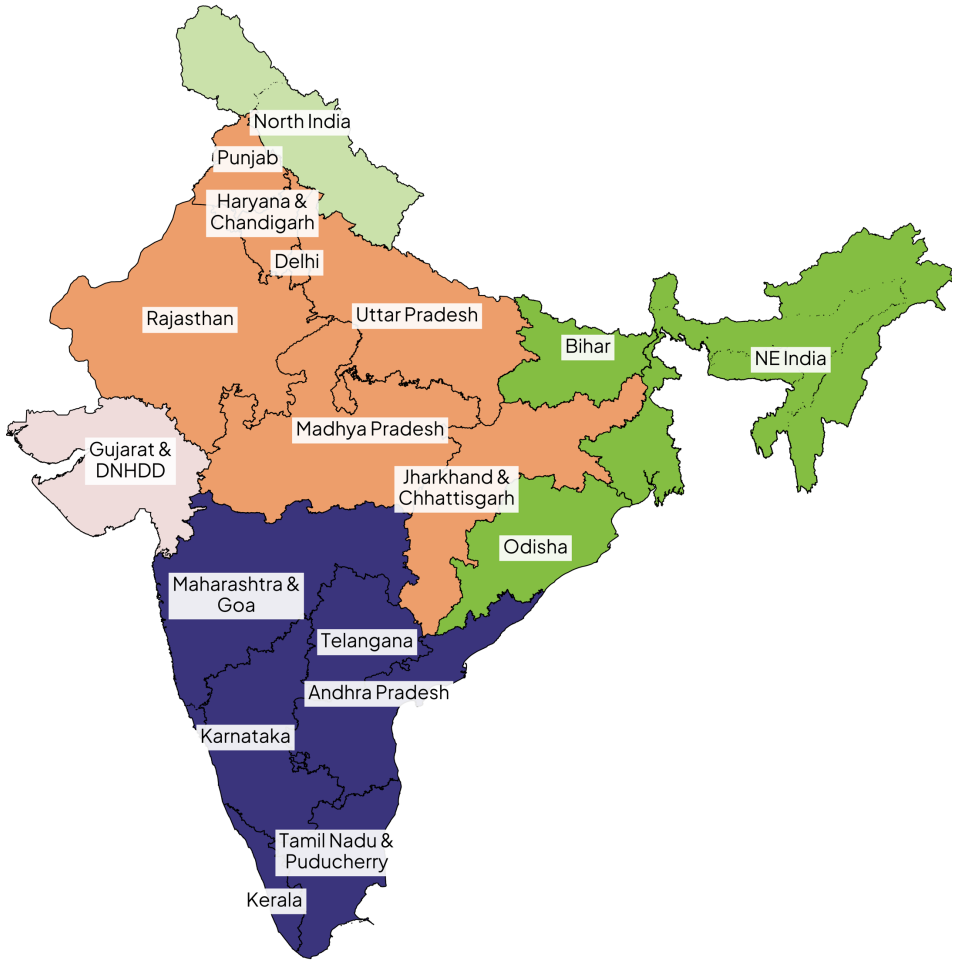


AN: Bangladesh

AN: Other South Asian

AN: India

AN: Pakistan



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Patient Matches

- Generated multiple patient cohorts based on ~1 year of patient searches (2,332 patients), simulated 100 times.
- Simulated recruiting 10,000 donors from each region
- Modelled the number of potential patient matches to new donors by region

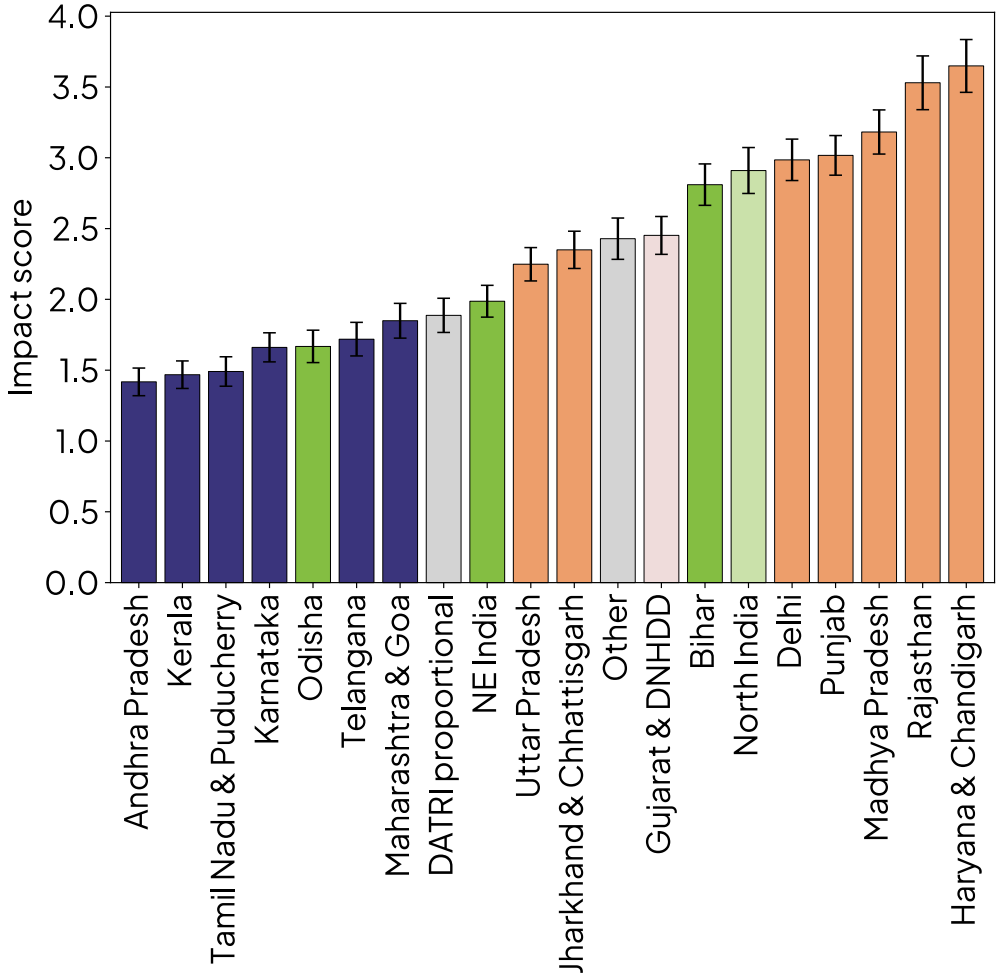
Modelled patient ethnicity	Number of patients	Percent
White British/Irish	2006	86%
South Asian	163	7%
Other	163	7%

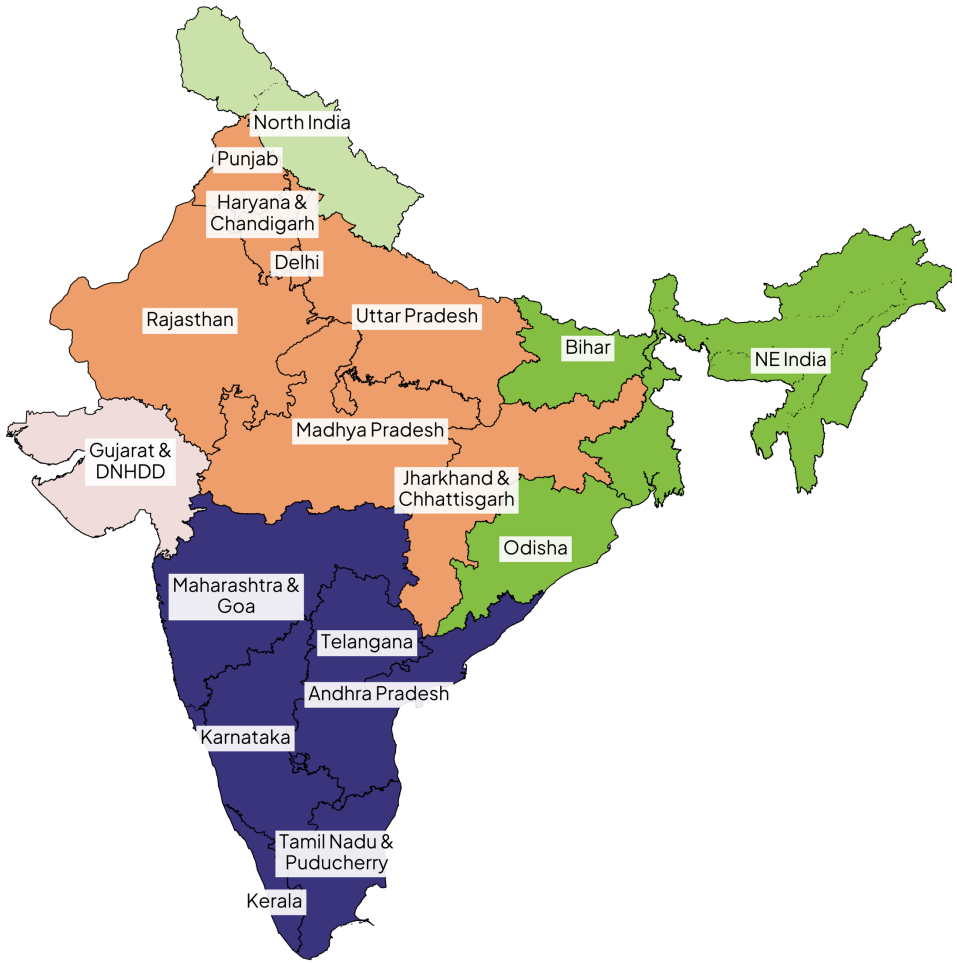
Patient Matches

- Not all matches have the same impact
- Some patients already have over 100 matches
  - Is the impact of these matches less?
- Converted matches to a reward score
  - Decreasing reward if patient already has matches
  - Further decreases the more matches a patient already has
- Re-scored the model of patient matches

Previous matches	Impact score for one additional match
0	1
1-5	0.5-0.8
6-10	0.1-0.3
11+	<0.1

Patient Matches





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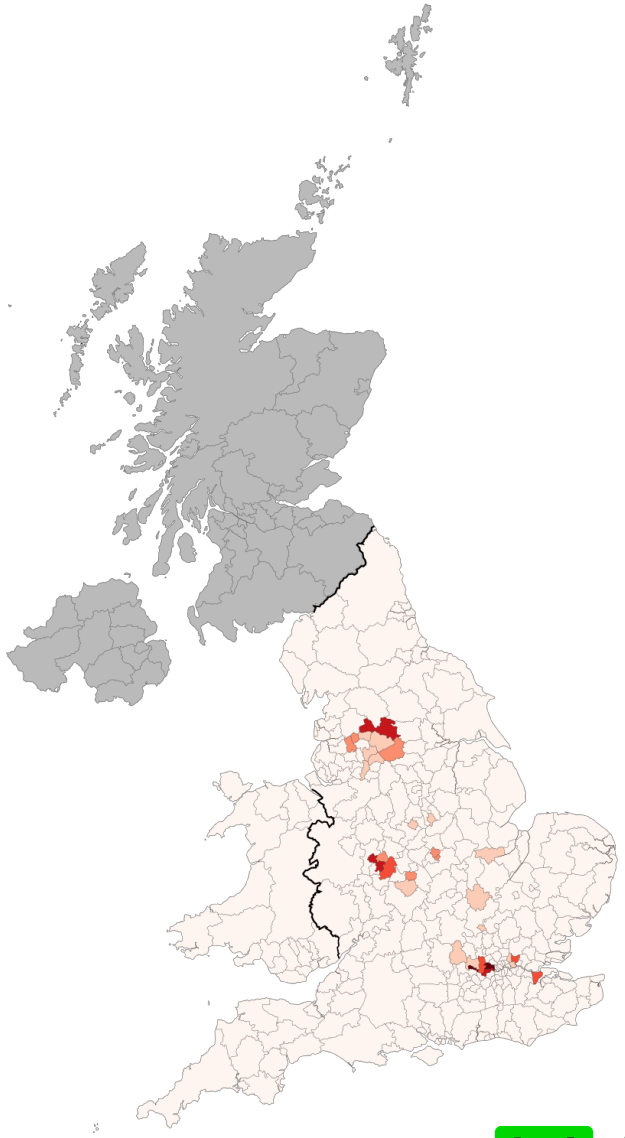
Patient Matches

Top ten languages spoken in England and Wales, excluding English (English or Welsh in Wales), from the 2021 Census.

1) Polish (612,000)
2) Romanian (291,000)
3) **Punjabi (291,000)**
4) **Urdu (270,000)**
5) Portuguese (225,000)
6) Spanish (215,000)
7) Arabic (204,000)
8) **Bengali (199,000)**
9) **Gujarati (189,000)**
10) Italian (160,000)



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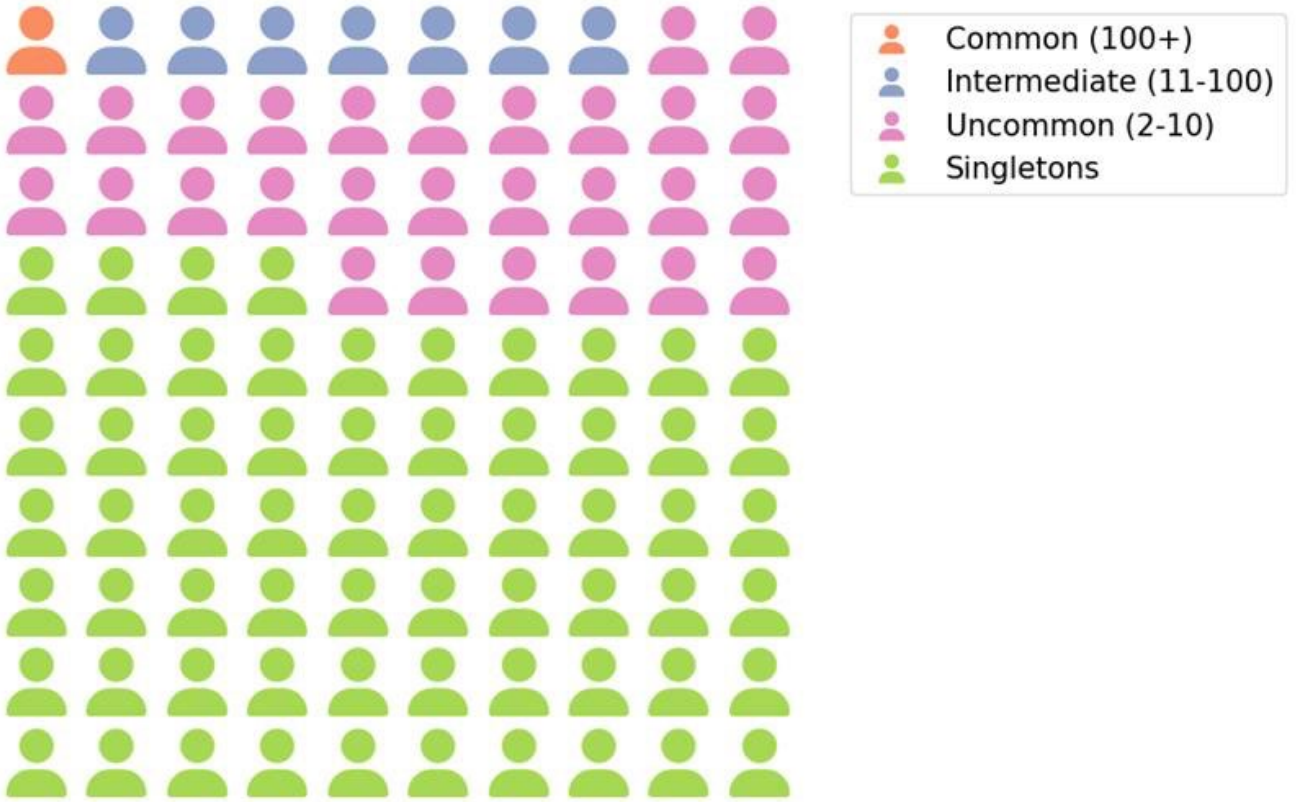
Analysis of new donors

DATRI have recruited and typed 3,162 new donors in the first year

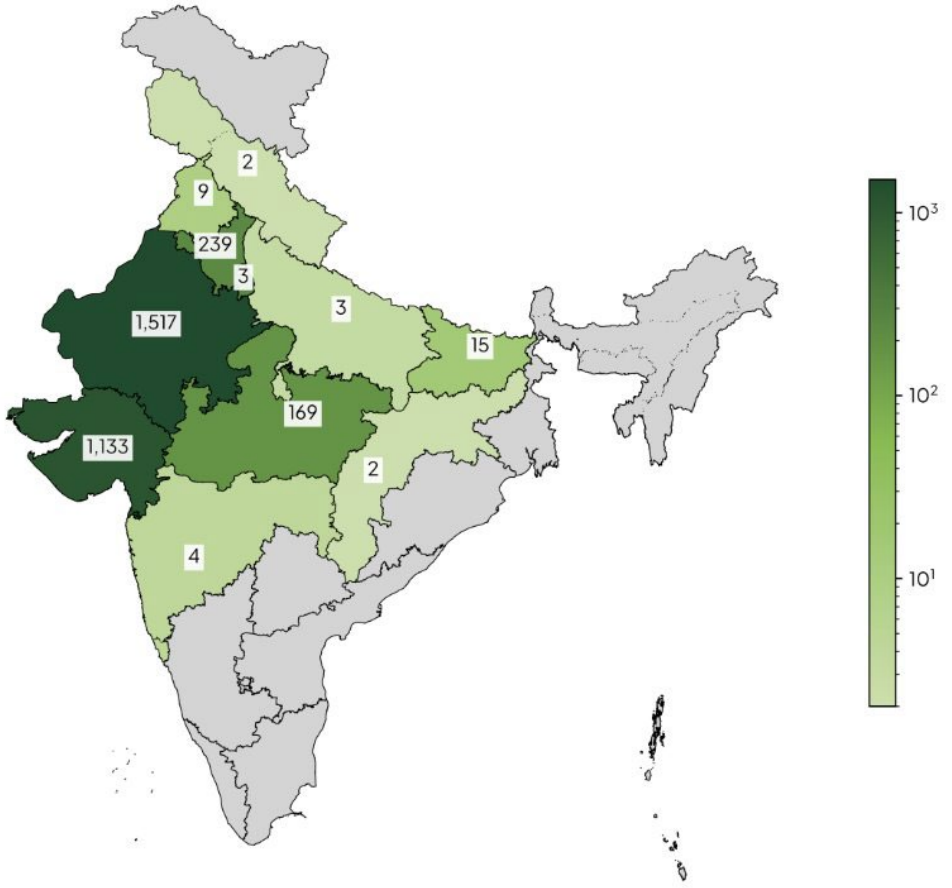
- 67% of these donors have phenotypes that are new to the DATRI register.
    - 41 phenotypes (84 donors) are not only new but seen in more than one donor

- 11% of donors have phenotypes that were previously singletons on the register



Year 1 impact

	Unique patients	Total matches	10/10 matches	Patients with agreed donors	Donated
Domestic	259	355	59	7	2
Rest of the world	168	313	13	1	--
Anthony Nolan	58	119	4	--	--
Total	**427**	**668**	**72**	**8**	**2**



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What next for this pilot?

- DATRI will continue recruitment of donors
- Bioinformatics team will analyse impact of DATRI recruitment
- Bioinformatics team will provide DATRI with demographic analysis of HLA types
    - Improve recruitment of donors for local population

- DATRI is a pilot, so where next?
    - Where else could this model work?
    - Additional funding from NIHR or Oversees Development Fund?
- Could this model be used for other UK patients?

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Questions