Slough Genetic Risk Equity Project

Presented by: Lindsay Maida

Project Background

The project derived from within the Equity & Equality Guidance for LMNS' and is referred to in the Three-Year Delivery Plan, to address one of the leading causes of mortality and morbidity in neonates.

The national support offer applies the principles of proportionate universalism to support high need areas with funding for genetic literacy programmes, workforce and clinically led national support.

Consanguineous marriages are respected and widely practiced

- Sociocultural factors include: maintenance of family structure and property, ease of marital arrangements, financial advantages.

Pakistan consistently shows the highest prevalence of consanguinity – target population for this project.

Over 90% of babies born to consanguineous parents are healthy.

Aims of this work:

a. Improve access to genomics services for underserved groups
b. Give families the opportunity to make informed reproductive decisions

Slough Context

Large Pakistani population in Slough

- Nearly 50% of Asian or Asian British Slough residents identify as Pakistani [1]
- 9.1% of total residents report Pakistan as place of birth [2]

Experience poorer health outcomes (language barriers, unemployment)

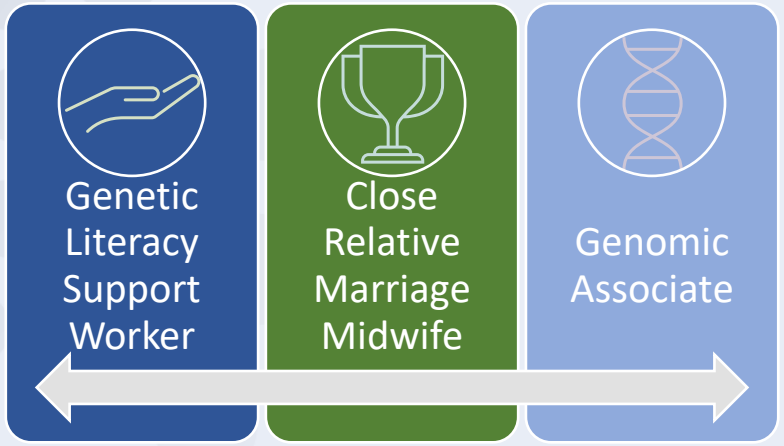
Often living in multigenerational households

Maintain close-knit family ties with extended family

Decisions often not made by individual alone

- Influence of family members and clinicians

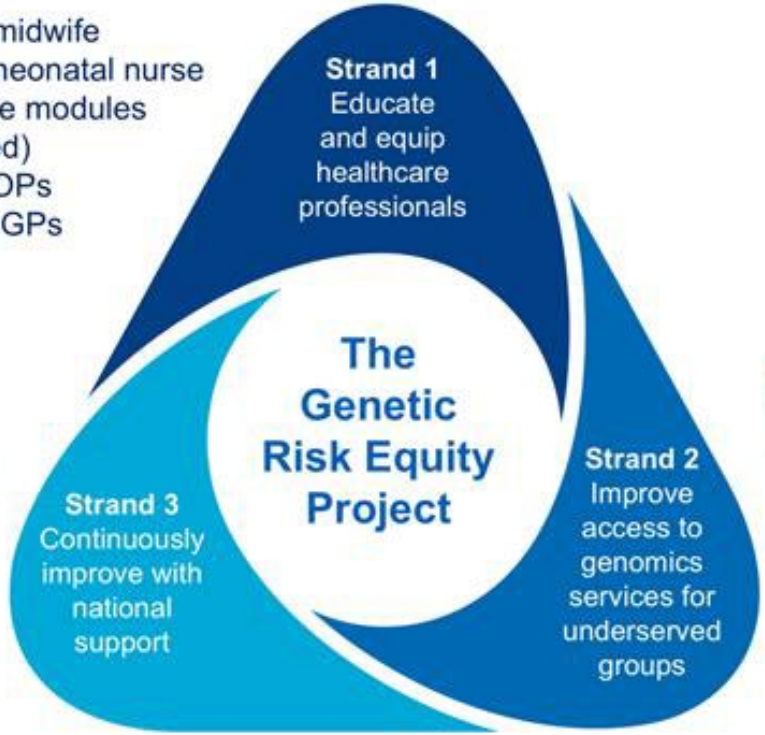
[1] Frimley Local Insights Tool 2020 (Frimley Health and Care Integrated Care System)
[2] ONS Census 2021 - Slough



The 3 strands of Culturally Competent Genetic Services

NHS

- Close relative marriage midwife
- Close relative marriage neonatal nurse
- e-Learning for Healthcare modules
- MSDS guidance (updated)
- NCMD guidance for CDOPs
- Referral decision aid for GPs



- Clinical leadership from Naz Khan RN HV MSc
- Expert reference group
- Community of practice
- Highlight reports
- Metrics
- Evaluation

Genomics associates in Regional Genetic Services

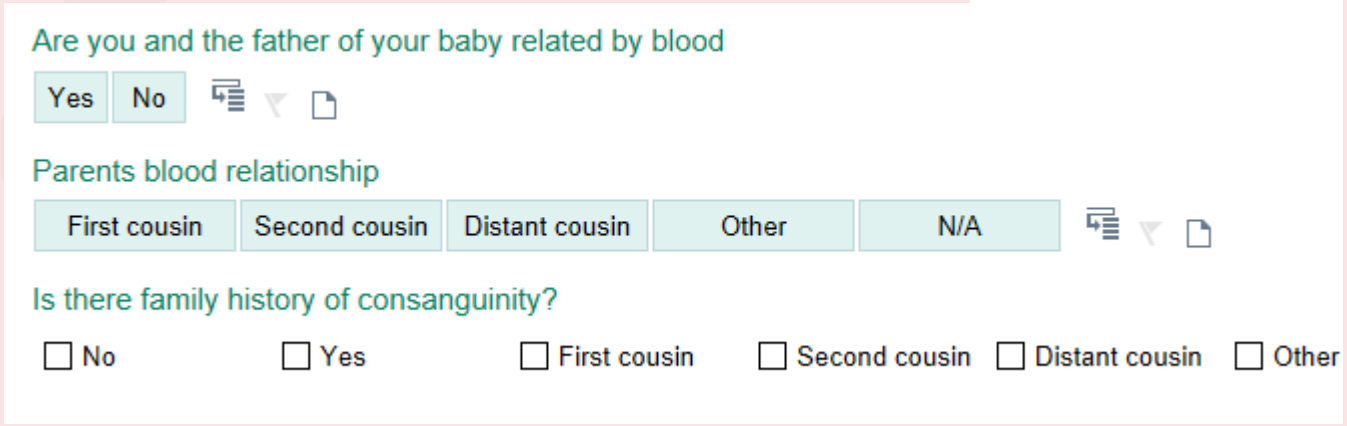
- Engage families once referred to the service
- Follow up non-attenders and support family conversations
- Cascade screening in extended families

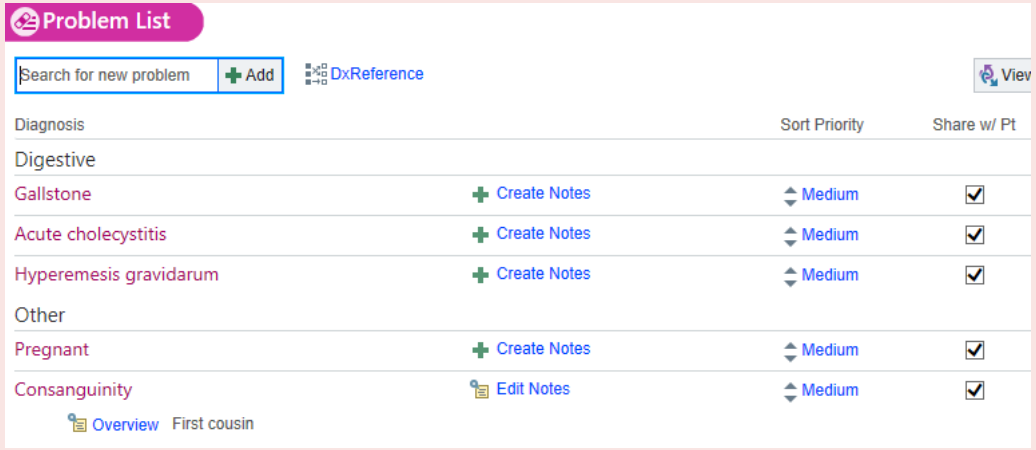
Data Collection

Clinic Management Information System (CMIS)

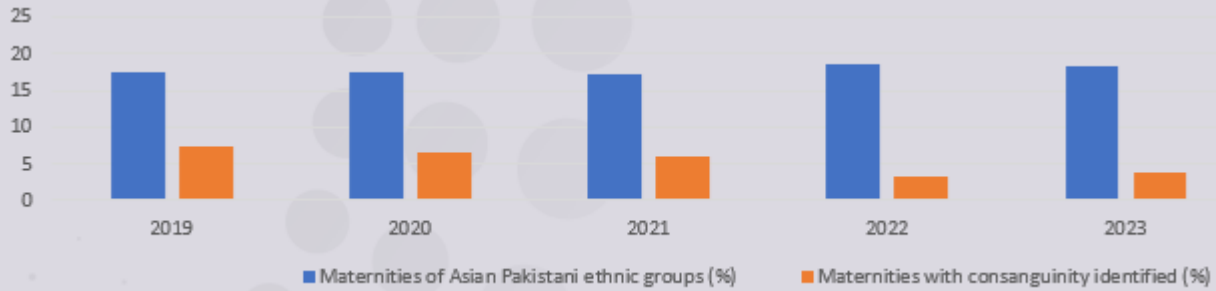
Previously used until June 2022

Frimley Epic EPR

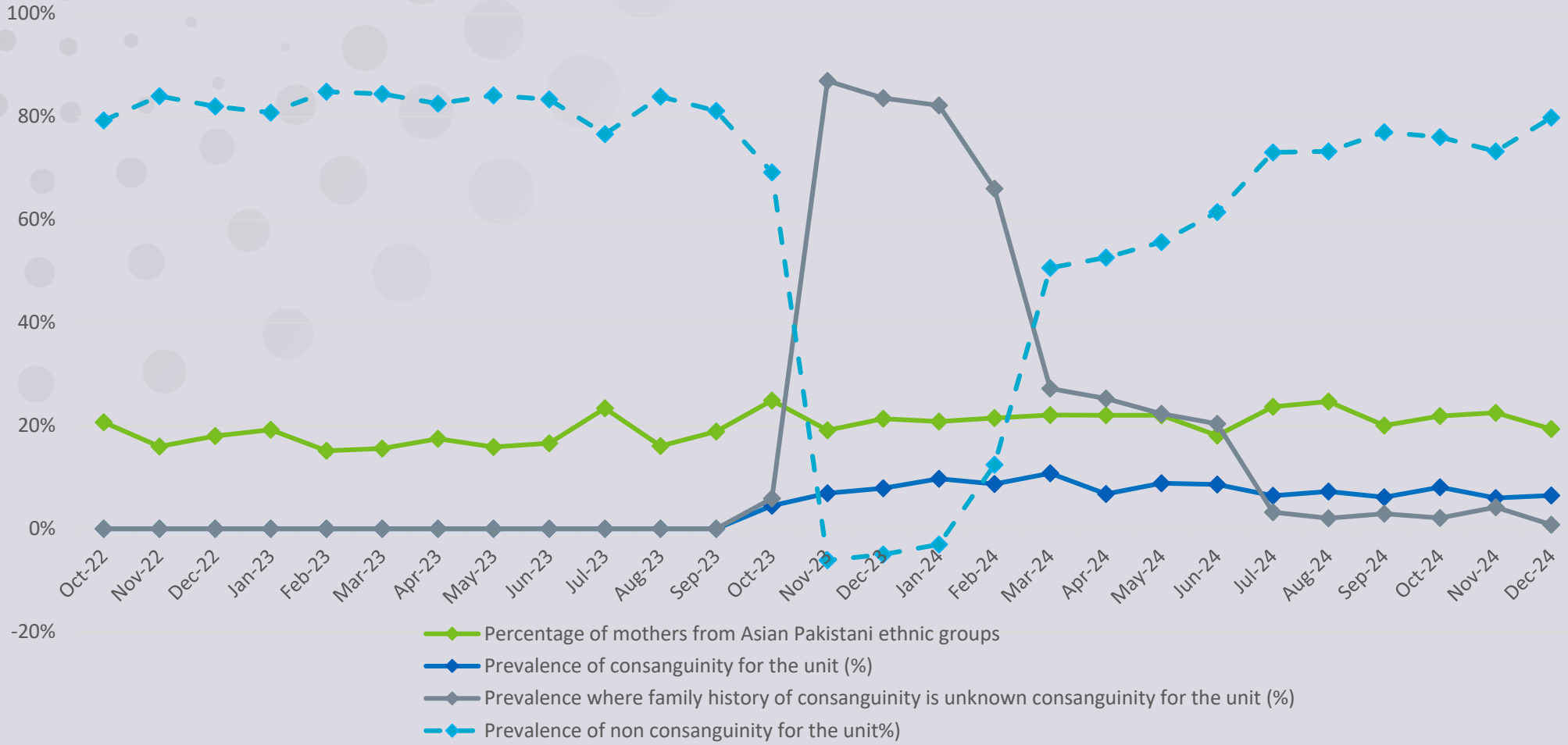




% Maternities of Asian Pakistani ethnic groups and maternities with consanguinity identified, 2019-2023



MSDS Submitted Data: % Maternities of Asian Pakistani ethnic groups and maternities with consanguinity identified, 2019-Feb 2024



Measuring Success

Increase in number of referrals to Oxford Centre for Genomic Medicine

Decrease in unknown consanguinity status data

Decreased timeframe in initiating referrals to Oxford Centre for Genomic Medicine

Positive feedback from service users through experience survey

90% e-learning access rate amongst midwives

Increased knowledge in genetics by clinical and non-clinical staff, as assessed through Close Relative Marriage and Genetics Awareness survey