NHS
Central and South
Genomics

Equality, Diversity and Inclusion Strategy

Content

Introduction

The Central and South Genomic Medicine Service (CAS GMS) want to ensure there is equal access to and uptake of NHS genomic medicine across population groups.

Equity of access is crucial for ensuring that all members of society have an equal opportunity to access testing and feel able to fully understand what that testing entails as well as its potential outcomes. Diverse communities often face systemic and structural barriers that limit their access to vital resources. These barriers can stem from factors such as socioeconomic status, race, ethnicity, gender, disability, and geographic location. These inequities result in disparities in education, healthcare, economic opportunities, and overall quality of life.

This strategy is needed to address these disparities head-on and create a more just and inclusive society by recognising and addressing the complex intersection of various identities such as race, gender, socio economic status and disability among others. By removing obstacles and creating tailored solutions, our strategy seeks to foster social cohesion, reduce inequality, and empower individuals from all backgrounds to achieve their full potential. Through collaborative efforts and evidence-based strategies, we aspire to create lasting change and a more equitable future for everyone.

It will take time and sustained action to remove the barriers to access and uptake that exist for some population groups however within the next 3-5 years, we expect to have fostered a dialogue that supports action planned to remove barriers rather than have reached a level playing field across population groups.

Background

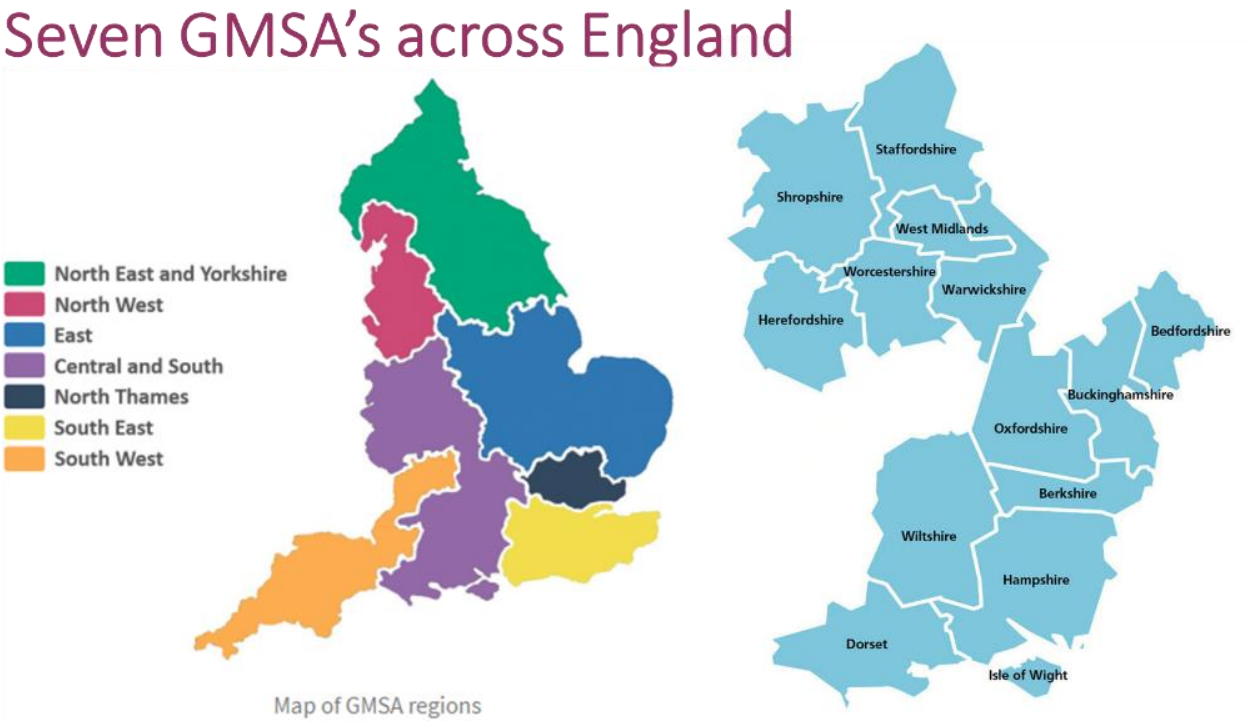
Equity and diversity in genomic medicine are important to Central and South Genomic Medicine Service Alliance (CAS GMSA). Commissioned by NHSE, one of our deliverables is to ensure that there is equity of access to genomic testing. Our equality, diversity and inclusion strategy builds upon genomics achievements from the 100,000 Genomes Project (Investigators, 2021) and pledges to address inequalities for our people, patients and communities with meaningful action. The strategy will be an ongoing process that requires dedication and collaboration.

This draft strategy outlines our plans over the next 5 years to ensure fair and inclusive access to genetic and genomics information, testing and healthcare services across the diverse population of the Central and South regions. By addressing the disparities in genomics research, data and testing we aim to improve health outcomes for all individuals. This applies regardless of age, disability, gender identity and reassignment, pregnancy and maternity, race (ethnicity, nationality, national origin, skin colour), religion or belief, sex, sexual orientation and socio-demographic factors.

The strategy will be informed and developed through collaborative efforts involving key stakeholders i.e. healthcare providers, CAS GMSA Patient and Public Involvement panel (PPI), patients groups, community groups, religious organisations and charities to align closely with the Accelerating Genomic Medicine in the NHS Strategy (NHS England, 2022)

Seven Genomic Laboratory Hubs (GLHs) were established in October 2018 by NHSE, and in 2020 the Genomic Medicine Service Alliances (GMSA's) were formed, aligned to the GLH geographies. Central and South Genomic Medicine Service Alliance (CAS GMSA) hosted by University Hospitals Birmingham NHS Foundation Trust is the regional alliance responsible for developing stakeholder partnerships and delivering the NHS England national genomics strategy.

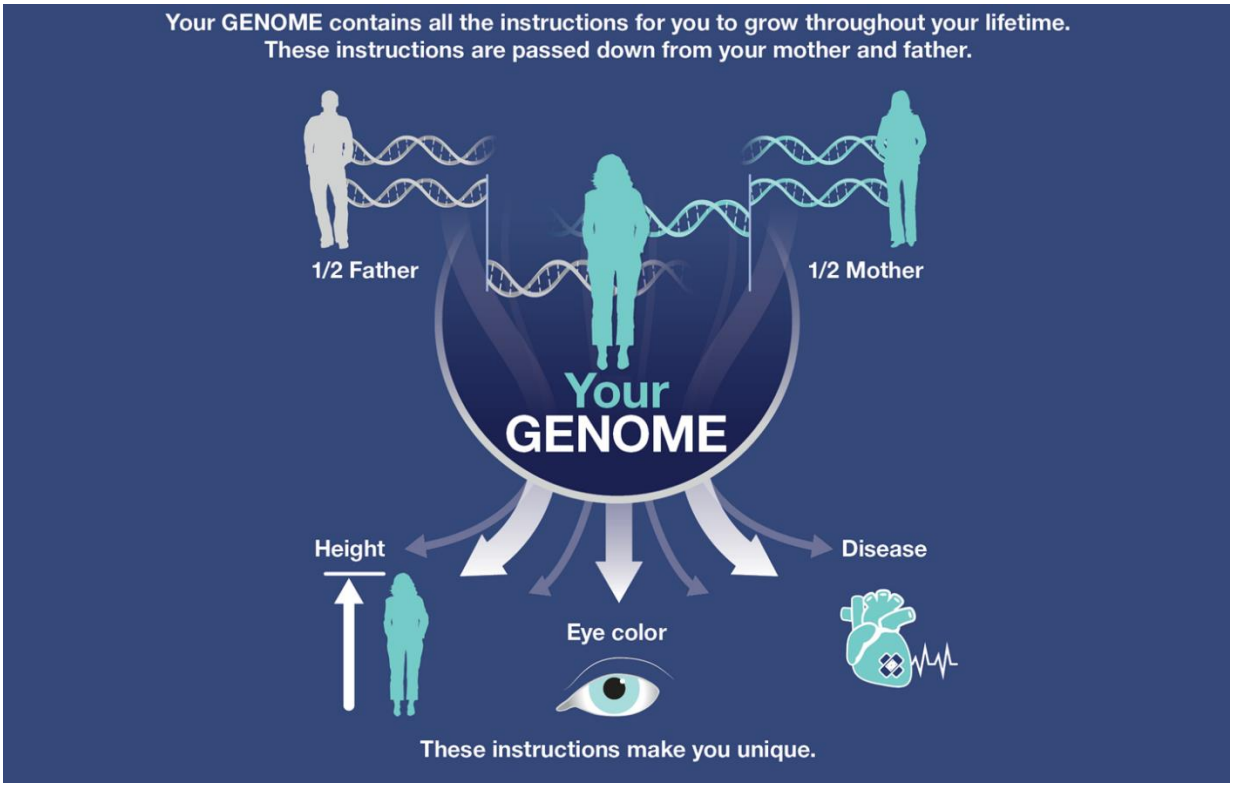
CAS GMSA serves a population of approx. 10 million people. CAS covers 41 NHS trusts from the West Midlands through central England to the south coast with clinical genetics centres based in Birmingham, Oxford, and Southampton. Our vision is to deliver equitable access to genomic based diagnostics and therapeutics across the NHS by developing clinical pathways for delivery, with a particular focus on under-represented and under-served populations and primary care as well as developing the workforce to embed genomics in all relevant areas of clinical practice (NHS England, 2018).



What is genomics?

Genomics is the study of an individual's entire genetic makeup, including all their genes and DNA. We all share 99.9% of our DNA and we all have differences in our genome. These variations can be caused by a variety of factors, including our ancestry and ethnicity, and the smallest difference can have large implications for the way we diagnose, treat, and manage health conditions. Alongside ethical reasons, there is a scientific necessity to improve diversity in genomic research (2019).

80% of people in research studies are of European ethnicity. This overrepresentation of a 'Eurocentric' population in genomic databases has resulted in misdiagnoses, poor understanding of conditions and inconsistent delivery of care. In addition, there is also higher levels of mistrust amongst excluded/underrepresented communities on the collection and use of their genetic data. As a result, genomic medicine does not always benefit all people equally (Genomics England, 2023).



Genome.gov

What is Equality, Diversity and Inclusion (EDI)

Equality is about treating individuals fairly and ensuring that they have the same opportunities to fulfil their potential.

Equity involves providing resources according to the individual needs of populations to achieve their highest state of health.

Diversity means recognising, respecting and valuing difference and includes individuals and groups with varying backgrounds, experiences, perceptions, values, and beliefs. It is important to understand, value, and respect those differences.

Inclusion strives for an environment that offers affirmation, celebration, and appreciation of different approaches, styles, perspectives, and experiences. Inclusion recognises and values the differences we each bring and where everyone can be their true selves in a safe and trusted environment. Inclusion enables equitable access to services, opportunities, resources and can contribute to an organisation's success.

EDI is essential to improve quality of care for patients and staff with the aim of providing a positive patient experience. Getting EDI right for patients is important so that individuals receive appropriate services in relation to their needs, patients can access information about the services provided and are able to participate and contribute to the development of services that meet the needs of our diverse communities.

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CAS GMSA is committed to creating an inclusive environment by striving to support a workforce which is valued and whose diversity reflects the communities it serves. We believe that this commitment will lead to improved services for patients and greater equality in opportunities for staff.

Evidence suggests there are sectors of the population which are underrepresented and underserved in currently available genomic testing. It is important to explore and discover why that is, with the aim of ensuring everybody can make an informed decision regarding genomic testing and research.

We will ensure that patients, the public and health care professionals in the region will have access to information and testing regardless of background, ethnicity, disability or socioeconomic factors.

Our Priorities

CAS GMSA is dedicated to ensuring that health and genomic research is reflective of the true diversity of the region's population. Equitable representation is essential for producing meaningful and applicable outcomes that benefit everyone.

With a focus on equity amongst all groups of people for genomic testing, the development of this strategy and action plan will be implemented by the GMSA to ensure that every message and action is inclusive, accessible and representative of diverse perspectives.

Four key priorities have been identified

Key Priority 1- Engagement with people, communities, healthcare providers and policymakers.

Aims:

1. Foster collaboration and partnership and keep key stakeholders informed and engaged
2. To increase and sustain engagement with community groups to gain and maintain long term trust in genomics

Objectives:

I. Working with partners including voluntary, community, faith and social enterprise organisations, NHS bodies such as Cancer Alliances and NHS EDI networks, raise awareness of this strategy and genomic medicine
II. Promote open dialogue, transparency and meaningful engagement to drive positive change and increase access for all individuals in genomic medicine.
III. Co-produce culturally sensitive educational materials that explain the benefits and importance of genomics testing, addressing concerns raised through engaging with people and communities.
IV. Identify opportunities for disseminating information in communities through trusted leaders utilising existing spaces i.e., GP surgeries, community halls, places of faith.
V. Ensure that resources and opportunities are distributed fairly across the region without causing unintended negative consequences.

Key Priority 2 • Data collection to identify and address health inequalities in genomic medicine.

Aims:

1. Collaborate with key stakeholders and experts – professional and those with lived experience - to implement targeted initiatives to identify understand and dismantle barriers to equitable genomic health.
2. Collect, analyse and utilise data based on patient and staff feedback, to identify gaps in population health and reduce health inequalities and prioritise implementation strategies.
3. Increase access to testing for all, particularly in underrepresented groups.

Objectives:

I. Engage with professionals and experts with lived experience to understand barriers to equitable access to genomic medicine.
II. Develop and implement data collection plans to track disparities in access to genomic medicine.
III. Analyse patient and staff feedback data to identify gaps in population health and prioritise strategies for implementation.
IV. Prioritise the use of 'data and digital' tools to develop insights aimed at reducing health inequalities in genomic medicine.
V. Target and address disparities by focusing on ethnicity and demographic data collection.

Key Priority 3 • Workforce Review to achieve a diverse genomic workforce.

Aims:

1. Collaboration with key stakeholders i.e., healthcare providers, to support and review workplace practices for diversity and inclusion.
2. Prioritise EDI and cultural competency training for genomic service teams to reflect the population and cultivate a workforce that is representative of the diverse community covered by CAS GMSA.

Objectives

I. Engage with healthcare providers to assess and support workplace practices that promote diversity and inclusion.
II. Cultivate a workforce that represents the diversity of the region to drive innovation and ensure equitable benefits from genomic advancements.
III. Promote inclusivity in genomics education and training to ensure a representative workforce through a geographically equitable genetic/genomic service.

Key Priority 4 • Research Diversity and Inclusion

Aims:

1. Ensure health and genomic research reflects the diversity of the region's population.
2. Promote equitable representation to produce meaningful and applicable outcomes.
3. Increase diversity in genomic /genetic healthcare practice and among genomic research participants.

Objectives:

I. Implement strategies to increase diversity in research participant recruitment.
II. Support initiative that address barriers to participation in health and genomic research.
III. Advocate for inclusive research practices at both national and regional levels.
IV. Foster collaboration to promote diversity and inclusion in research projects.
V. Recognise achievements and contributions from diverse stakeholders e.g., Patients/experts with lived experience

Engagement			
Aim	**Objective**	**Action**	**Timeline**
1.1 **1.2**	**1.I** **1.II** **1.III** **1.IV** **I.V**	Build upon and increase trust in the genomic medicine service as well as increase understanding of and benefits from genomic medicine.	Ongoing
		Share the GMSA commitment to genomics EDI with the public through various communication channels. This includes promoting diversity in genomics research findings and medical relevance and benefits for all communities.	
		Look to create joint initiatives or projects with charities and EDI Leads that address shared goals and foster collaboration.	
		Review governance and effectiveness of CAS GMSA Genomics EDI network.	
		Collaborate with other institutions that have implemented successful genomic EDI strategies.	
		Establish partnerships with community and faith organisations.	
		Co-production and development of culturally sensitive educational materials that explain the benefits and importance of genomics testing, addressing common concerns and misconceptions. To increase understanding of genomics.	
		Collaborate with community leaders, religious organisations, PPI groups, healthcare providers, local organisations and translation services to disseminate	

		information and promote awareness about genomics testing.	
		Organise workshops, webinars, and community events to provide information and answer questions about genomics testing in a culturally appropriate manner, to engage, build trust and create trusting and collaborative partnerships.	
		Offer training sessions that highlight the importance of diversity in genomics practice and research.	
Data			
Aim	**Objective**	**Action**	**TimeLine**
2.1 **2.2** **2.3**	**2.I** **2.II** **2.III** **2.IV** **2.V**	Existing data is incomplete and not representative of the region and accurate data is required to assess the current state and provide a baseline upon which to focus activity and measure improvement in addressing genomic health inequalities. A comprehensive assessment of the current practices related to genomics end to end pathways, research and implementation will be undertaken.	Ongoing
		Analyse existing genomic testing data to identify barriers to engagement and gaps in data collection e.g., ethnicity and demographic data - this can have direct bearing on outcomes or genetic diagnosis.	
		Co-produce and conduct surveys/research with diverse communities and organisations to gather data on barriers and challenges faced by different groups.	

		Regularly report on the results of these efforts to demonstrate accountability and transparency.	
Workforce			
Aim	**Objective**	**Action**	**Timeline**
3.1 **3.2**	**3.I** **3.II** **3.III**	Support stakeholders i.e. tertiary, primary and secondary care organisations with targeted recruitment efforts, mentorships and contribute to supportive work environments.	Ongoing
		Utilise local opportunities/events to promote careers in genomics aimed at encouraging recruitment of a more representative workforce	
		Support stakeholders in the creation and implementation of strategies to attract and retain diverse talent in genomics practice, research, and related fields.	
		Support and collaborate with stakeholders in embedding a sense of belonging, improvements to recruitment, promotion and diversity.	
		Collaborating with clinical genetics services across the region to ensure genetic counsellors and clinical staff are culturally competent and sensitive to the unique needs and values of diverse populations through training and shared practice.	
		Provide resources to help patients and health care professionals navigate the complexities of genomic testing, including assistance with informed consent, result interpretation, and decision-making.	
		Collaborate with and support NHS organisations to incorporate genomics	

		related information into unconscious bias and inclusion training in their mandatory, equality and diversity, education and training.	
		Share best practice and learning to collectively advance the field in an inclusive and equitable manner.	
Research			
Aim	**Objective**	**Action**	**Timeline**
4.1 **4.2** **4.3**	**4.I** **4.II** **4.III** **4.IV** **4.V**	Alongside our research directors and in partnership with relevant charities and EDI leads collaborate with genomic research institutions e.g., Biomedical Research Centre (BRC), National Institute for Health and Care Research (NIHR) and laboratories where there is potential for specific research, which targets and identifies populations that have been historically underrepresented, to support the diversity of their sample collections	Ongoing
		Advocate for inclusive research practices that prioritise equitable representation in studies related to genomics. It is essential that research and clinical trials reflect our diverse population to provide benefits to all patients. It is fair that people from different backgrounds, with different needs have the opportunity to take part in research which may be of benefit, and which may be relevant.	
		Increased transparency about genomic research, ensure that patients and public are involved in the design and communication of research and increase the diversity of people taking part in	

		research will help to earn their confidence.	
		Collaborate with research institutions and laboratories to develop and validate genomic testing panels that are specifically tailored to diverse populations.	

Together with our partners and stakeholders regular reviews will be undertaken to ensure the actions planned and in place are being achieved with the desired outcomes of equity and equality in all areas of genomics and if required appropriate agreed upon adjustments will be made.

Appendix

Health Equality Assessment Tool

Project/Programme initiation document

EDI Key Stats and contacts

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