

**British Society for Genetic Medicine Parliamentary Briefing on Cousin Marriages
January 2nd 2025**

Marriage (Prohibited Degrees of Relationship) Bill 2nd Reading January 17th 2025

Who we are

The British Society for Genetic Medicine (BSGM) is an independent body which provides a forum for professionals involved in genetics and genomics as a clinical service and in research. We support the promotion and advancement of genetic and genomic science in clinical and research practice for the public benefit. BSGM has always taken an active role in considering social, ethical and legal issues.

Why we have written this Parliamentary Briefing

We are staunch supporters of women's freedom and rights including the right to make informed reproductive choices. Alongside this, the reduction of inequalities in and barriers to accessing healthcare faced by minority groups and marginalised communities is one of our key priorities.

We are therefore concerned about the proposed Bill to prohibit the marriage of first cousins in the UK which was introduced on December 10th 2024 (ref 1). Our specific concerns are that it:

- is based on misunderstandings about the risks associated with first cousin marriages
- will adversely affect the provision of health care for women and children in communities where cousin marriage is common
- will foster distrust within those communities
- does not recognise the benefits of cousin marriages which people experience, e.g. strengthening of family bonds and care arrangements within the extended family
- appears to conflate cousin marriages with forced marriages and so-called honour killings

We have written this briefing to:

- clarify the facts about the risks associated with first cousin marriages
- emphasise the importance of awareness raising about inherited and rare conditions by engaging and supporting marginalised individuals and communities and for improved access to genetic counselling and testing
- highlight that there is a risk of further discrimination against, and stigmatisation of, couples in cousin marriages and the communities in which these are common practice

Factors that increase the chance of babies being born with genetic conditions or congenital anomalies

Blood relatives are more likely to carry the same genetic variants than people who are unrelated to each other. As a result, there is a higher chance of parents who are first cousins having a baby with an autosomal recessive genetic condition ([Autosomal recessive inheritance - Genomics Education Programme](#)):

- parents who are unrelated have a 2-3% chance of having a baby with a genetic condition or congenital anomaly
- parents who are first cousins have a 4-6% chance of having a baby with a genetic condition or congenital anomaly; most of the increased chance is due to recessively inherited genetic conditions

This means most (94-96%) babies born to parents who are first cousins do **not** have a genetic condition or congenital anomaly.

Many other factors increase the chance of babies being born with genetic conditions or congenital anomalies and are legal in the UK, for example:

- use of assisted reproductive technology
- father's age (35 years or older)
- mother's age (19 years or younger and 35 years or older)
- smoking (including vaping)
- drinking alcohol
- prescription drugs

Engagement, discrimination and stigmatisation

The consequences of discrimination against and stigmatisation of couples in cousin marriages and their communities include:

- negatively affecting engagement with genetic risk information and with clinical services because of an emphasis on cousin marriage rather than on recessive inheritance (ref 2)
- alienation of communities that are singled out, resulting in them not accepting research findings that associate cousin marriages with negative health outcomes (ref 3)

Various initiatives have focused on raising awareness about inherited conditions and improving access to genetic counselling and testing in communities in which first cousin marriages are common. These highlight that:

- such information is valued and empowers individuals/couples to make informed choices about marriage and reproduction (ref 4)
- there is a desire for accurate and understandable information (ref 5)

Improving genetic literacy is critical to empower people to make informed decisions; underlying this is the need to establish and maintain trust at community level (ref 6). Co-developing and co-designing services to increase awareness and make services and information accessible to support minority groups and marginalised communities is also important (ref 7). These

strategies may alleviate some of consequences of discrimination and stigmatisation outlined above.

Conclusion

Misunderstandings and misinformation about cousin marriages have a negative impact for minority groups and marginalised communities, risking an increase in social tensions and further alienation. This would exacerbate social and health inequity and have an adverse societal and economic impact.

BSGM welcomes conversations that utilise our expertise in genetic and genomic medicine for the benefit of our patients and communities across the UK. We and our members work with patient groups, the NHS across the four nations, the government and the devolved administrations to identify ways to improve our health care system for all communities.

We expect individuals and organisations across health care, academia and government to work together in progressing the UK Equality Act, 2010. We support the ongoing work of the Race and Health Observatory to see a reduction of healthcare inequalities. This will bring health and economic benefits to the population and will promote unity between and within communities.

References

1. [Marriage \(Prohibited Degrees of Relationship\) Bill - Hansard - UK Parliament](#) accessed 11/12/2024
2. Darr A et al, Addressing key issues in the consanguinity-related risk of autosomal recessive disorders in consanguineous communities: lessons from a qualitative study of British Pakistanis, *Journal of Community Genetics* (2016), 7, 65–79
3. Ajaz M et al, UK Pakistani views on the adverse health risks associated with consanguineous marriages. *Journal of Community Genetics* (2015) 6:331-342
4. Khan N et al, Developing and evaluating a culturally appropriate genetic service for consanguineous South Asian families. *Journal of Community Genetics* (2010) 1:73-81
5. Darr A et al, Examining the family-centred approach to genetic testing and counselling among UK Pakistanis: a community perspective. *Journal of Community Genetics* (2013) 4:49-57
6. Salway S et al, Responding to the increased genetic risk associated with customary consanguineous marriage among minority ethnic populations: lessons from local innovations in England. *Journal of Community Genetics* (2016) 7:215-228
7. Cupp MA et al Exploring perceptions of consanguineous unions with women from an East London community: analysis of discussion groups. *Journal of Community Genetics* (2020) 11:225-234

Contact details

British Society for Genetic Medicine
1 Naoroji Street
Islington
London
WC1X 0GB

Email: comms@bsgm.org.uk

Tel: 020 3925 3675