Involving Fathers in Ante-natal Screening for Sickle Cell Disorders: Improving Informed Decision Making

Recommendations from the Project for Clinical Commissioning Groups and Specialist Commissioning

- Be aware that sickle cell is a leading genetic condition in England. Obtain up-to date figures from NHS England. For example at the time of writing 1 in 450 ‘White-British’ newborns carries a sickle cell-relevant gene, 1 in 1850 of all births in the UK is a child with sickle cell disorder and 1 in 70 is a sickle cell or thalassaemia carrier.

- Health care professionals, such as midwives and genetic counsellors, feel their resources and time are being stretched and that the focus is more on delivering targets than ensuring proper and appropriate care. They would like more support to ensure good care for mothers and recognition of the difficulties they face in providing this. If fathers are encouraged to engage with ante-natal care, especially if genetic testing of men becomes part of antenatal or primary care, planning for the future needs of this group is essential. Practitioners would also like more advice and support on how best to engage with fathers.

- Consider making resources available to support GPs who offer sickle cell screening in primary care, or consider commissioning voluntary groups to undertake this provision.

- More education and awareness about sickle cell is needed. This does not necessarily mean providing clinical information or ensuring that genetic education is provided in schools. Parents require information linking the social consequences of decision making with clinical material. Information also needs to be more readily accessible (such as translated accounts, using social media and ‘apps’ and more community resources) and in some cases specifically geared towards men.

- Involve the local voluntary and community services to ensure that outreach includes fathers. Voluntary sector providers have an excellent track record of engaging with local communities and are often more trusted than NHS provision.

- Ensure that patients, carriers and voluntary organisations for sickle cell are involved in Clinical Commissioning Groups as well as Specialist Commissioning. Consider setting up a taskforce to ensure this and make sure community members with a good knowledge of sickle cell are included.

- Ensure that services are inclusive of fathers and that they are welcomed across the board (from ante-natal care to more specialist provision). This would also achieve equity and reduce inequalities.

- Ensure the provision of specialist services, as well as counselling, for fathers and families affected by carrier status.

A copy of the final report and resources can be found at:

http://www.york.ac.uk/media/healthsciences/documents/research/public-health/23116_A4_report%20v3.pdf

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