Guidance for NHS Regional Genetics centres about patients who have had Direct to Consumer genetic tests*.

Background:

Companies that offer genetic tests Direct to Consumer (known as DTC tests) are increasing their marketing activities in the UK and over the Internet. This may encourage more people to access genetic testing directly, rather than though an NHS healthcare provider. As a result, NHS patients may present to their GP or other NHS professionals requesting help with the interpretation of results, further genetic testing (for themselves, a partner or other family members), or access to screening or other medical services. The NHS will only provide follow up for DTC genetic testing results, and incur the associated costs, when the results are clinically significant.

Principles:

1. Genetic tests that are clinically indicated, and of proven clinical validity and utility, can be requested by a wide range of health care professional across the NHS. Staff in regional genetics centres are available to discuss the indications for genetic testing and to help ensure that the right samples are taken and sent to an accredited laboratory for analysis.
2. Individuals who access DTC tests privately, through personal choice, should be aware that the mutation screen performed may be completely inappropriate for their particular situation. If they have a medical history or family history which suggests that genetic testing is indicated then they should be advised to request this via the NHS. DTC labs often only screen for a very limited number of mutations in individual genes, which means that the negative predictive value of such a test result is negligible (in other words, a negative result may not reduce their risk of having a mutation at all if the mutation in their family is not tested for).
3. NHS genetic test reports are written using a standard, internationally recognised nomenclature and both scientists and clinicians are able to help non geneticists and patients interpret these reports. NHS staff should not interpret reports from non accredited labs that have not been written using the recognised nomenclature as this may lead to errors of interpretation.
4. If a patient who has had a DTC test is reported to have a pathogenic mutation in a gene for which NHS testing is offered (e.g. *BRCA*) then it is appropriate to see them in an NHS genetics clinic in order to discuss the result and future management (for them and their relatives).
5. If a patient wants to discuss a DTC result for which NHS genetic testing is not usually offered (e.g. predisposition variants, paternity tests and ancestry information) then they should be prepared to pay privately for that consultation and for any additional screening/testing that they request.

Conclusion:

NHS service providers have a responsibility to provide high quality, cost-efficient care for patients who are entitled to receive it, and for whom there is a valid indication for them to be seen; but they must ensure that the NHS does not incur unwarranted costs as a consequence of performing additional clinical/laboratory work that would not normally form part of their responsibilities.

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