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LYNCH SYNDROME AND APPLICATION OF THE RCPATH COLORECTAL CANCER DATASET IN THE UNITED KINGDOM

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Introduction: Lynch syndrome is estimated to cause over 1,000 cases of colorectal cancer in the UK every year. Individuals that have Lynch syndrome have a lifetime risk of developing colorectal cancer or other Lynch associated cancers of >35%. Yet fewer than 5% of individuals with the condition have been diagnosed in the UK. The Royal College of Pathologists (RCPATH) cancer dataset (July 2014) mandates the use of immunohistochemistry or other testing for molecular features of Lynch syndrome in colorectal cancer or Lynch associated cancer patients under the age of 50, at the time of diagnosis. Performing this type of screening test for Lynch syndrome identifies those at greater risk of recurrence as well as family members at extended risk through early cascade testing.

Method: The strategy was developed by Bowel Cancer UK with advice from the Medical Advisory Board of the charity. We identified all NHS hospital trusts in England, health boards in Scotland and Wales and health and social care trusts in Northern Ireland. A freedom of information (FOI) request was submitted to each of these bodies in which a number of questions were asked to establish whether they were implementing the RCPATH core dataset requirement, with regard to mismatch repair (MMR) testing for Lynch syndrome. As this was an FOI request respondents were required to respond within 20 working days.

Results: In England, 78% of trusts responded, 100% responded in Scotland and Northern Ireland; one health board in Wales did not respond. In England and Scotland 50% of hospital trusts and health boards currently do not follow the RCPATH cancer dataset. 4 health boards in Wales do not, and all health and social care trusts in Northern Ireland stated they perform MMR testing to identify suspected Lynch syndrome patients. In England only 28 of those that did not perform testing stated they were intending to implement the dataset and two in Wales. Scotland is in the process of developing a nationally agreed protocol for implementation of the dataset. We found that among trusts and health boards that do test for Lynch syndrome many do not yet have in place a systematic reflex service, as mandated by RCPATH.

Conclusion: Our findings show that the RCPATH dataset may have already had some impact on the application of MMR testing for Lynch syndrome in patients diagnosed under the age of 50. However there is considerable variation in approach. We recommend that: England and Wales carry out a nationwide initiative to look at ways of delivering a consistent approach to reflex testing for Lynch syndrome; that all CCGs commission to reflect the RCPATH cancer dataset thus ensuring providers are compliant with the dataset.

Disclosure of Interest: None Declared