St Helens and Knowsley Teaching Hospitals NHS Trust

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Subject:	Information retrieval request for Lynch Syndrome screening study

REQUEST

In the UK it is estimated that 175,000 people have Lynch , a hereditary form of colorectal cancer. Diagnosis through genetic testing is crucial for determining the treatment, informing relatives and starting colonoscopic surveillance to reduce cancer incidence and mortality in patients with LS and their relatives. There are two guidelines based on molecular tumour characteristics to select suspected patients for further genetic testing. In 2014 the Royal College of Pathologists (RCPath) recommended all new patients with colorectal cancer below age 50 to be screened for Lynch syndrome via immunohistochemistry testing (IHC). Furthermore, they stated that the molecular test should be performed at the time of diagnosis, called routine screening. In 2017 NICE guidelines became available recommending universal tumor screening via IHC or microsatellite instability (MSI) testing, irrespective of clinical assessment, age or family history.

The charity organization Bowel Cancer UK investigated the implementation of routine tumour screening. At the end of 2014, mid-2016 and 2018 they carried out a Freedom of Information (FOI) request to several hospitals in the UK to evaluate the RCPath dataset implementation. **Because a qualitative study will be conducted in Amsterdam, that builds on this earlier FOI request study performed by Bowel Cancer UK, we hope that you could send us the FOI request answers you gave to Bowel Cancer UK in 2014, 2016 and the most recent 2018 of your hospital trust by email?** In the attachment the questions from the FOI requests are listed.
The study that will be conducted by the VU University Medical Center in Amsterdam will investigate the experiences of medical specialists with the implementation of recent guidelines regarding universal LS tumour screening in colorectal cancer. Participants will share their experiences through an interview conducted by telephone. As researchers we are especially interested in possible barriers and facilitators to implementation and the collaboration between genetic and non-genetic specialties. This study aims to contribute to the FOI request study performed by Bowel Cancer UK through exploring reasons for the relatively low number of hospital trusts carrying out

molecular testing at the time of diagnosis and the existence of different pathways.

RESPONSE

Under section 21 of the Freedom of Information Act St Helens & Knowsley Teaching Hospitals Trust do not have to provide information to the applicant which is easily accessible by other means. This information you require can be viewed via the Trusts new publication Scheme at –

http://www.sthk.nhs.uk/about/Documents/FOI/2015/Request%20response%20122020616.pdf