**Lynch UK network research meeting kick off meeting (23rd November 2021).**

Lynch syndrome is the commonest familial cancer syndrome, affecting 1 in 150 to 400 individuals in the general population and contributing to ±3.5% of all colorectal and endometrial cancers. Personal and/or a family history of these gastrointestinal and extra-intestinal malignancies can be used to identify at-risk individuals, but is limited in efficacy and so systematic testing of incident cases has been introduced in the UK, as per NICE Diagnostics Guidance DG27 & DG42.

The identification and surveillance of Lynch syndrome patients is currently being evaluated: NICE has recently published guidelines mandating the histopathologic examination of all endometrial cancers for MMR defects (DG42), and major societies are evaluating data regarding efficacy and cost-effectiveness of a gene-tailored approach to surveillance intensity. Analysing the impact of these changes on the service requires a collaborative approach between endoscopists, surgeons, pathologists, clinical geneticists and allied healthcare professionals. However, in contrast to surrounding nations, the UK does not currently have a Lynch syndrome research working group wherein such issues can be critically evaluated for immediate patient or future research benefit.

The purpose of this online meeting was to survey ideas towards harmonising care and research for this patient population across the UK and kickstart the Lynch syndrome network. During the afternoon we first heard from international speakers Prof Christoph Engel (University of Leipzig, Germany) and Prof Monique van Leerdam (Netherlands Cancer Institute, Amsterdam) about some of the successes and also challenges of existing Lynch syndrome patient registries in Germany and the Netherlands, respectively. We also had short presentations from Prof Emma Crosbie and Dr Kevin Monahan on the current UK landscape with regards to patient registries and clinical trials focusing on Lynch syndrome patients. Six researchers presented ongoing studies, both clinical and pre-clinical, in short Dragon’s Den-styled pitches to the audiences for an opportunity to win a £500 research prize. The audience voted Dr Neil Ryan (University of Bristol) and Ms Ottilie Swinyard (Queen Mary University London) as the winners. After a short tea break, the meeting continued in three break-out sessions to discuss opportunities towards a Lynch syndrome patient registry, clinical trials and biobanking. These break-out sessions really reflected the tremendous enthusiasm within the community. Many ideas were put forward which are currently being brought together and will soon be circulated amongst meeting participants through a dedicated newsletter.

This first meeting drew close to 100 participants from a diverse background of clinical geneticists, surgeons, endoscopists, pathologists, epidemiologists and basic scientists. We were fortunate to also have the participation and support of Lynch syndrome UK and Lynch syndrome Ireland patient advocates for which we are very grateful. This first meeting generated many excellent ideas which will be put to our meeting participants. We also look forward to collaborating with our international partners in Germany and the Netherlands in this regard.

We look back on a highly successful and inspiring kick-off event. Future meetings will be announced soon. We have put out a call for those interested in taking up roles to move our budding initiative forward. Finally, we gratefully acknowledge the Pathological Society for sponsoring this meeting, as well as the research prizes, through Open Scheme funding. This allowed us to host the meeting through the Royal College of Pathology which also badged our meeting.

Marnix Jansen, 9th December 2021