

NEWSLETTER

REGIONAL LYNCH SYNDROME EXPERT NETWORK

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Fourth Lynch Syndrome Expert Network meeting

We are pleased to share a summary of the fourth regional Lynch Syndrome Expert Network meeting held on 18th October 2024. This virtual event attracted a diverse group of attendees and provided valuable insights into the latest advancements in Lynch Syndrome research, clinical care, and training initiatives.

National Updates on Lynch Syndrome Testing

Kevin Monahan, Consultant Gastroenterologist and Clinical Director for the Lynch Syndrome and Family Cancer Clinic at St Mark's Centre for Familial Intestinal Cancer, presented a comprehensive update on national projects. He highlighted the significant increase in tumour testing for colorectal and endometrial cancers from 2019 to 2022. Monahan also discussed the successful transition to a mainstreaming model, where local cancer teams conduct genetic testing, resulting in reduced patient wait times. He shared that nearly 11,000 individuals with Lynch syndrome have been identified, although delays in genetic report delivery remain a concern.

Mainstreaming Pathway & Regional Collaboration

The meeting focused on the mainstreaming pathway, endorsed by NHS England, which provides a more integrated approach to diagnosing Lynch syndrome. Monahan described the regional network of cancer alliances and multidisciplinary teams (MDTs) that collaborate weekly to address complex cases. Additionally, Laura Monje-Garcia

provided details on upcoming workshops on gynaecology and colorectal cancer and highlighted the NHS Learning Hub transition of online training resources for healthcare professionals involved in genetic testing.

Genetic Testing and Clinical Contributions

Claire Brooks, Principal Clinical Scientist at North-West Thames Regional Genetics Laboratory, discussed the inherited cancer testing process, specifically focusing on germline analysis for Lynch syndrome.

Dharmisha Chauhan, Lead Genomic Pharmacist at North Thames GMSA, called for improved aspirin uptake among Lynch syndrome patients, suggesting a pilot program to monitor its impact in primary care.

Terri McVeigh and Yasmin Clinch from the Royal Marsden NHS Foundation Trust presented on molecular testing for dMMR cancers and provided a comprehensive overview of the clinical genomics lab services at RMH.

Active Trials and Clinical Updates

Kai Keen Shiu, Consultant Medical Oncologist UCLH Gastrointestinal Oncology Service, Cancer of Unknown Primary Service Honorary Associate Professor reflected on active trials and eligibility criteria for recruitment like the Prism which is now open, and referrals are being accepted at UCLH.

Education and Training Initiatives

Angela Brady, Consultant Clinical Geneticist at North-West Thames Regional Genetics Service, shared an update on education and training programs. These included genomics education sessions, the Primary Care Education Programme, and a Genomics Question Time.

Lynch Surveillance Hub at UCLH

James Harris, Programme Manager NHS North Central London Cancer alliance & Lucy McLaughlin Head of cancer commissioning North

Central London presented and update on Lynch Surveillance Hub at UCLH and answered all the questions about the hub and modelling done so far.

Gynaecological Perspective on Lynch Syndrome

Rachel Perfect, Gynae Lynch Nurse Specialist, and Ashwin Kalra, Clinical Research Fellow at Barts Health, shared findings related to Lynch syndrome from a gynaecological standpoint. Rachel presented data on genetic testing for Lynch syndrome in gynaecological cancers, and Ashwin discussed the endometrial mainstreaming teaching programme and the Detect 2 study.

Closing Remarks

The meeting concluded with final thoughts from Dr Kevin Monahan, emphasising the ongoing efforts to improve patient care, genetic testing, and training resources for healthcare professionals.

We remain committed to advancing the diagnosis, treatment, and care of individuals with Lynch syndrome through collaboration, research, and education.

Lynch Syndrome Patient Information Evening

The Lynch Syndrome Patient Information Evening was held on Wednesday, 16th October, from 16:45 to 19:00, with **460 participants** attending the online event. This year's programme highlights included Dr Neil Ryan, who discussed gynae-oncology cancer risk, Dr David Church, the lead for the LynchVax vaccine project, and Dr Kevin Monahan, who provided an update on ongoing trials and the bowel screening programme. In addition, the ever-popular Consultants Q&A panel was featured, offering attendees the opportunity to connect and ask questions in a friendly and supportive environment. There were also numerous requests for a recorded video of the session from those who were unable to attend.

Lynch Syndrome Lunch and Learn Sessions – October 2024

In October 2024, we hosted two educational Lunch and Learn sessions focused on Lynch Syndrome and its relation to colorectal and endometrial cancers.

Lynch Syndrome Lunch and Learn Endometrial Cancer – October 24, 2024

The endometrial cancer session, led by Ashwin Kalra, was attended by **45 participants**. Attendees gained a deeper understanding of the connection between Lynch Syndrome and endometrial cancer, with expert guidance on prevention, diagnosis, and treatment options.

Lynch Syndrome Lunch and Learn Colorectal Cancer – October 25, 2024

The colorectal cancer session, led by Dr Kevin Monahan and Laura Monje-Garcia, was attended by **56 participants**. The session provided valuable insights into the genetic factors of Lynch Syndrome and its impact on colorectal cancer, offering practical knowledge to better understand and manage the condition.

Both sessions received positive feedback from participants, who described the sessions as insightful and very informative. Attendees appreciated the expert-led discussions, which provided valuable knowledge on the genetic aspects of Lynch Syndrome and its implications for cancer risk.