

Future

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Annual Meeting for the Danish
HNPCC registry

Daily operation and organisation

- Strengthen collaboration with medical disciplines.
 - Better reporting back
 - Easier reporting to registry
- LOVD reporting – assist
- Biobank: Frozen blood, tumor material
- Restructure organisation of registry
 - Support clinical care and research in smaller patient groups
 - Need for new roles, curators?
- Development of patient information

Research direction

- Surveillance optimisation
 - Colonoscopic: Lars Lindberg
 - Gynecological: Zohreh Ketabi
- Tumorbiology – Prof. Mef Nilbert, Christina Therkildsen
- Immune therapy – Christina Therkildsen
- Compliance / adherence – Helle Vendel Petersen
- Endoscopic optimisation:
- Risk epidemiology, disease burden estimation in Lynch syndrome. Therkildsen/Nilbert/Ladelund

In short

- Hold on to multi disciplinary data collection and use
- Hold on to core organisation with steering committee and scientific committee.
- Focus on small family/patient groups
- Rethink professionals roles in daily operation
- Do research, more and better!!