



Title	Hereditary Nonpolyposis Colorectal Cancer in Denmark – A Health Technology Assessment
Agency	DACEHTA, Danish Centre for Health Technology Assessment National Board of Health, 67 Islands Brygge, DK-2300 Copenhagen S, Denmark; Tel: +45 72 22 74 00, Fax: +45 72 22 74 07; www.dacehta.dk
Reference	2007; 7(3). ISBN 97887-7676-450-0. Full text report in Danish and English summary available at www.sst.dk/publ/Publ2007/MTV/HNPCC/HNPCC.pdf

Aim

To review the present situation for patients suspected of having hereditary colorectal carcinoma (CRC) and to provide recommendations for the future.

Conclusions and results

- Families with hereditary CRC (HNPCC) are identified primarily in surgical departments, and HNPCC patients/families are registered at every contact with the healthcare system.
- HNPCC families are also at increased risk for other types of cancer – most frequently, eg, in the uterus, stomach, small intestine, bile tract, upper urinary tract, and brain.
- Notions of individual autonomy and bodily integrity represent core values in established medical ethics. These values are challenged by the concept of prevention (the societal wish to save lives), which in concert with the establishment of the family tree in genetic counseling makes information to family members a concrete possibility.

In conclusion, the fraction of colorectal cancer caused by hereditary factors is unknown. The well-known syndromes of familial adenomatous polyposis (FAP) and hereditary nonpolyposis colorectal cancer (HNPCC) comprise 5% of all patients with colorectal carcinoma. It is estimated that hereditary factors are involved in up to 35% of all cases with CRC, although neither biological mechanisms nor heredity are known. HNPCC is by far the most frequent hereditary syndrome causing CRC.

Recommendations

The recommendations include:

- To establish a national classification system of HNPCC diagnoses as a common database
- To establish nationally uniform guidelines for informed consent to genetic counseling

- To establish higher integration of the different medical specialties: surgery, pathology, clinical genetics, and clinical biochemistry
- To advise families with an increased frequency of stomach or urinary tract cancer to follow a more intensive control program, including gastroscopy.

Methods

Registries have been reviewed and data have been compiled.