



International Society for Gastrointestinal Hereditary Tumours
The Polyposis Registry
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National Institute for Health and Care Excellence
10 Spring Gardens
London SW1A 2BU, UK

18th July 2018

Dear Sir

**Re: NICE Guideline NG85
Pancreatic cancer in adults: diagnosis and management**

We refer to the recommendations set out in section 5.4.7 of this guideline, for 'people with inherited high risk of pancreatic cancer'.

The Council of the International Society for Gastrointestinal Hereditary Tumours (InSiGHT) notes with concern the NICE recommendation advocating pancreatic screening for those with Lynch syndrome.

Council unanimously dissents from this recommendation. It is our view that the evidence base to support this recommendation is lacking and carries with it a risk of harm. We call on NICE to retract the recommendation to allow wider consultation and to ensure that any such recommendation conforms to the WHO criteria for the introduction of screening.

We are also wish to highlight that it is premature to recommend this screening for those with Peutz-Jeghers syndrome outside of ethically approved research protocols; evidence of benefit over harms is not yet established which should be part of informed consent if such screening is undertaken.

Yours faithfully

A handwritten signature in blue ink, appearing to read 'Susan Parry'.

Dr Susan Parry
Chair, InSiGHT
Clinical Director of the New Zealand Familial Gastrointestinal Cancer Service.

on behalf of Council:

Professor Maurizio Genuardi
Director of the Institute of Medical Genomics at the Catholic University, Rome.

Professor Tom Weber
Chief of Surgery, Department of Veterans Affairs New York Harbor Healthcare System;
Past President of the Collaborative Group of the Americas for Hereditary Colorectal Cancer.

Professor Finlay Macrae
Head of Colorectal Medicine and Genetics, The Royal Melbourne Hospital, Melbourne, Australia.

Professor James Church
Director of the Sanford R Weiss Center for Hereditary Colorectal Neoplasia, Cleveland Clinic,
Cleveland, Ohio, USA; Founder, Collaborative Group of the Americas for Inherited Colorectal Cancer.

Dr Gabriel Capella
Director of the Hereditary Cancer Program at the Catalan Institute of Oncology, Spain.

Dr Ian Frayling
Consultant in Genetic Pathology in Cardiff, Wales.

Professor Nicoline Hoogerbrugge
Professor in Hereditary Cancer, Radboud University Medical Center, Nijmegen, The Netherlands.

Dr Andrew Latchford
Consultant Gastroenterologist and Assistant Director of the St Mark's Hospital Polyposis Registry,
Harrow, UK.

Professor Patrick Lynch
Professor of Medicine, Department of Gastroenterology, University of Texas MD Anderson Cancer
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Professor Allan Spigelman
Professor of Surgery, University of New South Wales; Director of St Vincent's Hereditary Cancer
Clinic, Sydney, Australia.





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