Genetic testing seeks co-ordinated approach in re-contacting patients

October 14 2014

GP with patient

A new study will be examining the implications of when and how NHS healthcare professionals re-contact patients with new genetic information that may impact their health or that of their family. The three year Economic and Social Research Council (ESRC) funded research will also explore issues of consent and how genetic information is stored.

Professor Susan Kelly from the University of Exeter is leading the project looking at how the NHS currently re-contacts patients; the legal context for this and the relevant guidelines; ethical issues, and expectations of both patients and professionals. The project involves partners from Cardiff University (Angus Clarke), the University of Southampton (Anneke Lucassen) and the Royal Devon and Exeter Hospital (Peter Turnpenny).

Professor Kelly explained:"The study will contribute to our understanding of implications of rapid innovation in genomics for patients, families and healthcare professionals. It will also provide evidence based recommendations regarding communication between healthcare professional and patients, potentially leading to the development of an ethical and professional framework regarding re-contacting patients."

She added: "The key questions we will be exploring are whether there is a professional duty or responsibility to re-contact patients for whom healthcare providers hold information deriving from genetic or genomic tests. These questions are pressing as these tests are used more widely in healthcare, by healthcare professionals outside clinical genetics, as genomics becomes 'mainstreamed'. We will be exploring professional and patient expectations concerning who, how and under what circumstances patients should be re-contacted in the light of new genetic information."

Genetic and genome testing is becoming increasingly relevant to specialist medical services outside of clinical genetics, as a means of using this new knowledge to influence peoples' health. For example, cardiologists, paediatrics and oncologists are ordering more tests as a result of the pace of innovation and improvements to genetic information available to them. The issue of re-contacting patients arises in relation to the development and improvement of diagnostic techniques, prognostic information, the availability of new or more refined genetic tests, or when new theories are developed.

The study will investigate the hypotheses that mainstreaming genomics in healthcare should be understood as a social as well as a technological process, and that professional subcultures across specialities will vary with regard to norms and expectations concerning re-contacting patients.

Clinical genetic services have developed practices around handling genetic information; as such knowledge is understood to raise familial, future disease risk and uncertainty concerns. The team of experts involved in the project hypothesise that there will be significant differences in how different medical specialties and healthcare providers handle the genetic information produced by such tests. It is not always clear who will inform patients of the results and potential impact of those results, or communicate new developments.

Professor Kelly explained:"Genetic services look at the patient and the family, rather than just the patient. Other healthcare providers have different professional styles and practices. GPs and consultants are used to seeing the patient in front of them and may deal directly with him or her as an individual. Genetic information may have implications for other family members and a wider range of healthcare providers will need to be familiar with these issues including when to re-contact someone in the light of new information."

Provided by University of Exeter

Citation: Genetic testing seeks co-ordinated approach in re-contacting patients (2014, October 14) retrieved 3 May 2024 from https://medicalxpress.com/news/2014-10-genetic-co-ordinated-approach-re-contacting-patients.html

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.