

Discussion notes

Workshop 7 - Health in the age of “illness genes”

Workshop overview

On an almost daily basis we learn that a gene which increases the risk of us developing some form of cancer or decreases the likelihood of us getting diabetes or Alzheimer’s has been found. This workshop examined the way in which this information is communicated to the population and how, both as individuals and as a society, we make sense of it.

Chair:

Claudia Pagliari, Senior Lecturer in Primary Care at the University of Edinburgh

Presenters:

Robin Bunton, Professor of Sociology at the University of Teeside

Michael Fitzpatrick, General Practitioner, medical journalist and commentator

Harald Schmidt, Assistant Director of the Nuffield Council on Bioethics

Notes

- The session was opened with the comments:
 - How do genetics work and how is this understood?
 - How can the media be used to represent the work and progress that is made?
 - The understanding of this science can bring research and understanding from many disciplines together.
- Robin Bunton Presentation Discussion:
 - The vision of an idea or concept within research must not be confused with science and fact, either within this community or to the wider public.
 - Contemporary healthcare genetics is beginning to distance itself from the eugenics understanding of the past.
 - The timing of these debates are interesting with particular thought given to the ‘nature vs nurture’ debate. The effect of an individual’s genetic make-up may not have been as accepted in mid to late 20th century political and social thinking.
 - It is a hope that genomics could provide a more scientific input to these debates that wasn’t there previously.
- Michael Fitzpatrick Presentation Discussion:
 - It was suggested that linkages between communities and their relationships with doctors and nurses was stronger and more robust in provincial areas.

- Incentives for progress based in truth and science are often outweighed by where profit can be made.
 - Health is now tied up with notions of length and not quality which can be dangerous when considering maintaining good health.
 - A doctor is seen as a mediator between information and treatment but the workload this can generate can sometimes become unwieldy.
- Harald Schmidt Presentation discussion
 - Individuals seeking out information on the internet can often use their own judgement to assess whether the information is reliable and useful or untrustworthy.
 - Education is important for individuals to be able to make informed decisions.
 - Direct to consumer genetic testing firms market themselves in different ways, some as educational, some as fun, and some as serious providers of information.
 - It is imperative that those seeking information can frame what type of risk they are taking and adjust their behaviour and decisions accordingly.
 - The local GP can be seen as a gatekeeper and they must be empowered to work effectively in this role.
 - Individuals can also be empowered though contact and discussions with their GP, often in a more meaningful way than just seeking information on the internet.
- General Panel Discussion
 - The role of the GP was again reinforced but, as the patient is a consumer, if they demand referral then they will more than likely get it
 - There is now perhaps a growing scepticism that because GPs have to meet targets that they are not as reliable or trustworthy as they once were.
 - Self diagnosis and treatment is becoming a part of lifestyle management, not just singular occurrences.
 - There is a danger that people are putting too much emphasis on their body as the centre of their well being and when this lets them down there is no fallback to a mental strength.
 - Direct to consumer genetic testing can be something that is viewed for the wealthy.
 - There is a feeling that genetics has not yet influenced day-to-day medical practice.