

“Cancer Genetic Testing from a Socio-Philosophical Perspective”

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Background

Institutional:

ESRC Genomics Policy & Research Forum

Personal:

Academic Background & Role at the Forum

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ESRC Genomics Policy & Research Forum Workshop “The Evaluation of Genetic Services”

- Explored ways in which to assess the value and usefulness of genetics services in health care

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Overview

Medical background

- 1) Cancer genetics
- 2) Cancer genetic testing

Socio-philosophical reflection

- 1) Nature of genetic information
- 2) Impact on clinician-patient relationship
- 3) Challenges for confidentiality & consent

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Cancer Genetics

- 1) Cancer taxonomy
- 2) Prediction of individual's level of risk
- 3) Selection of treatment

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Cancer Genetic Testing

- relatively rare cancer syndromes caused by single gene defects
- subset of common cancers which are due to & follow inheritance patterns of single gene defects but where environmental factors influence the development of disease
- majority of common cancers caused by complex interactions between several gene variants and environmental factors – will facilitate life style changes to lower the risk

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Nature of Genetic Information

- 1) Sensitive
- 2) Familial
- 3) Emotive
- 4) Mythic
- 5) ...

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Sensitive

- Medical data is sensitive and to be handled confidentially.
- “Non-obvious” genetic data is considered particularly sensitive (O’Neill, 2003).

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Familial & Intergenerational

- Genetic data is not strictly individual.
- The process of obtaining data is experienced on an individual level yet genetic variations are shared by related individuals.

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Emotive

- Genetic data is fraught with worries, fears, hopes & expectations.

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Mythic

- Amongst 'lay' rather than 'expert' communities, genetic data has reached an almost mythic status as explanatory concept of disease.

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The Role of Practitioner/ Geneticist/ Counsellor

- The clinician deals not only with the patient, but with his/her families of past/present/future.
- The intergenerational context affects the clinical encounter via emotions –social tensions or emotional support (Petersen, 2003).
- The clinician is the gatekeeper of complex expert knowledge.

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The Role of the Patient

- The patient *seeks* genetic information where he/she consents to genetic testing.
- The patient tries to *understand* the information provided. For a variety of reasons this can be difficult.
- The clinician/health care system needs to respond to the patient's expertise (Petersen, 2003).

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Challenge for Ethical Practice of Confidentiality

Principle of confidentiality applies to the handling of all medical information.

“Non-obvious” genetic data (O’Neill, 2003) is particularly sensitive and should be obtained, & handled with great confidentiality.

- Is confidentiality an absolute imperative?

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Challenge for Ethical Practice of Informed Consent

Informed consent applies to all medical treatment to prevent coercion and deceit.

- How can individual consent be obtained in the context of genetic data and its intergenerational aspect?
- Should legislation deal with genetic testing?

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