

Catalogue of socio-economic impact studies/projects
Under the Biomedical Disciplines Programme (1994-1998) - ELSA Projects

Contract N°: BMH4-CT96-1665

Duration: 36 Months

Starting date: 01.04.1996

Title:

Genetic screening and testing: towards Community policy on insurance, commercialisation and promoting public awareness
EUROSCREEN

Brief description:

EUROSCREEN is a continuation of earlier EU funded research on "Genetic screening: ethical and philosophical perspectives, with special reference to multifactorial diseases" and investigates three issues not covered in the earlier project but identified as arising out of it. The three issues from three related strands: the ethics of insurance, commercialisation and programmes for public education and raising awareness.

The project will be carried out by means of the reinforced concerted action focusing on a demonstration project - the piloting of a genetic information "shop" on a city high street in the north-west of England associated with targeted training seminars for young researchers from all over Europe, for the specific purposes of the concerted action. The demonstration phase is primarily in the public awareness strand but is also linked to the other two.

The insurance strand will seek to build on previous EU funded work on life insurance by investigating the conceptual and ethical basis of the institution of insurance, exploring the differences between health and life insurance, examining the extent to which genetic information constitutes a special case, and elucidating the implications for Community policy in the light of relevant Community directives.

The commercialisation strand will examine the extent to which commercialisation is occurring in different countries, explore the advantages and disadvantages of commercialisation, investigate the factors influencing the use of available tests, and examine the possible mechanisms for regulation in Europe.

The public awareness strand, in addition to piloting the Genetic Information shop will obtain information about debate-generating activities elsewhere e.g. in Denmark, explore the social factors influencing success, liaise with bodies such as consumer organisations and develop a series of training seminars at the centralised facility in Preston. The project is primarily philosophical but involves 20 researchers from 8 countries representing a variety of disciplines: Philosophy, Sociology, Law, Genetics, History of Medicine, Public Health Medicine. It seeks

to strengthen existing links of the group with industry, consumer organisations and public policy making.

Keywords:

Genetic screening, insurance, commercialisation, public awareness

Participants:

Prof. Ruth Chadwick (Coordinator)

Centre for Professional Ethics
University of Central Lancashire
Vernon Building
UK - Preston PR1 2H
Tel: + 44 1772 892541
Fax: + 44 1772 892942

Prof. Henk ten Have

Dept of Ethics, Philosophy and History of Medicine
Faculteit der Medische Wetenschappen
Katholieke Universiteit Nijmegen
PO Box 9101
NL - 6500 HB Nijmegen
Tel: + 31 80 61 53 20
Fax: +31 80540254

Prof. Jorgen Husted

Dept of Philosophy
Aarhus University
Bygning 328,
NDr Ringgade
DK - 8000 Aarhus C
Tel: + 4589421111
Fax: + 45 89 42 22 23

Dr Stuart Horner

Beth Shemesh
Spring Lane
Samlesbury
UK - Preston PR5 0UX
Tel: + 44 1772 877600

Dr Angus Clarke

Institute of Medical Genetics
University of Wales
College of Medicine
Heath Park
UK - Cardiff CF4 4XN

Tel: + 44 1222 744052
Fax: + 441222747603

Dr Domenico Coviello

Institute of Biology and Genetics
University of Genova
Viale Benedetto XV, 6
I - 16132 Genova
Tel: + 39 10 353 8980
Fax: + 39 10 353 8978

Drs. Kris Dierickx

Centrum voor Bio-Medische Ethiek en Recht
Katholieke Universiteit Leuven
Kapucijnenvoer 35
B - 3000 Leuven
Tel: + 32 16 33 69 51
Fax: + 32 16 33 69 52

Prof. Dr Gertrud Hauser

Institute of Histology and Embryology
University of Vienna
Schwarzspanierstrasse 17
A - 1090 Vienna
Tel: + 43 1 40 480 268
Fax: + 43 1 40480418

Dr Mairi Levitt

Centre for Professional Ethics
University of Central Lancashire
Vernon Building
UK - Preston PR1 2HE
Tel: + 44 1772 892541
Fax: + 44 1772 892942

Mr. Tony Mc Gleenan

Faculty and School of Law
The Queen's University of Belfast
21 University Square
IRL - Belfast BT7 1NN
Tel: + 44 1232 245133
Fax: + 44 1232 325590

Dr Darren Shickle

Centre for Applied Public Health Medicine
University of Wales
College of Medicine
Cathays Park
UK - Cardiff CF1 3NW
Tel: + 44 1222 231021
Fax: + 44 1222 238606

Dr Urban Wiesing

Institute for Theory and History
of Medicine
Westfälische Wilhelms
Universität Münster
Waldeyerstrasse 27
D - 48149 Münster
Tel: + 49 251 83 52 91
Fax: + 49 251 83 53 39

Mr. Veikko Launis

Dept of Philosophy
University of Turku
Hameenkatu 6
FIN - 20500 Turku
Tel: + 358 21 633 6338
Fax: + 358 21 633 6270

Prof. Heta Häyry

Dept of Practical Philosophy
University of Helsinki
Unioninkatu 40B, POB 24
FIN - 00014 Helsinki
Tel: + 358 0 44 24 24
Fax: + 358 0 191 7627

Dr Matti Hayry

Dept of Practical Philosophy
University of Helsinki
Unioninkatu 40B, POB 24
FIN- 00014 Helsinki,
Tel: + 358 0 44 24 24
Fax: + 358 0 191 7627

Drs. Rogeer Hoedemaekers

Dept of Ethics, Philosophy and
History of Medicine

Faculteit der Medische Wetenschappen

Katholieke Universiteit Nijmegen

PO Box 9101

NL - 6500 HB Nijmegen

Tel: + 31 80 61 53 20

Fax: + 31 80 54 02 54

Under the Biotechnology Programme (1994-1998) - ELSA Projects

Contract N°: BMH4-CT96-1665

Duration: 36 Months

Starting date: 01.04.1996

Title:

Genetic screening and testing: towards Community policy on insurance, commercialisation and promoting public awareness
EUROSCREEN

Brief description:

EUROSCREEN is a continuation of earlier EU funded research on "Genetic screening: ethical and philosophical perspectives, with special reference to multifactorial diseases" and investigates three issues not covered in the earlier project but identified as arising out of it. The three issues from three related strands: the ethics of insurance, commercialisation and programmes for public education and raising awareness.

The project will be carried out by means of the reinforced concerted action focusing on a demonstration project - the piloting of a genetic information "shop" on a city high street in the north-west of England associated with targeted training seminars for young researchers from all over Europe, for the specific purposes of the concerted action. The demonstration phase is primarily in the public awareness strand but is also linked to the other two.

The insurance strand will seek to build on previous EU funded work on life insurance by investigating the conceptual and ethical basis of the institution of insurance, exploring the differences between health and life insurance, examining the extent to which genetic information constitutes a special case, and elucidating the implications for Community policy in the light of relevant Community directives.

The commercialisation strand will examine the extent to which commercialisation is occurring in different countries, explore the advantages and disadvantages of commercialisation, investigate the factors influencing the use of available tests, and examine the possible mechanisms for regulation in Europe.

The public awareness strand, in addition to piloting the Genetic Information shop will obtain information about debate-generating activities elsewhere e.g. in Denmark, explore the social factors influencing success, liaise with bodies such as consumer organisations and develop a series of training seminars at the centralised facility in Preston. The project is primarily philosophical but involves 20 researchers from 8 countries representing a variety of disciplines: Philosophy, Sociology, Law, Genetics, History of Medicine, Public Health Medicine. It seeks to strengthen existing links of the group with industry, consumer organisations and public policy making.

Keywords:

Genetic screening, insurance, commercialisation, public awareness

Participants:**Prof. Ruth Chadwick (Coordinator)**

Centre for Professional Ethics
University of Central Lancashire
Vernon Building
UK - Preston PR1 2H
Tel: + 44 1772 892541
Fax: + 44 1772 892942

Prof. Henk ten Have

Dept of Ethics, Philosophy and History of Medicine
Faculteit der Medische Wetenschappen
Katholieke Universiteit Nijmegen
PO Box 9101
NL - 6500 HB Nijmegen
Tel: + 31 80 61 53 20
Fax: +31 80540254

Prof. Jorgen Husted

Dept of Philosophy, Aarhus University
Bygning 328
NDr Ringgade
DK - 8000 Aarhus C
Tel: + 4589421111
Fax: + 45 89 42 22 23

Dr Stuart Horner

Beth Shemesh
Spring Lane
Samlesbury
UK - Preston PR5 0UX
Tel: + 44 1772 877600

Dr Angus Clarke

Institute of Medical Genetics
University of Wales
College of Medicine
Heath Park
UK - Cardiff CF4 4XN
Tel: + 44 1222 744052
Fax: + 441222747603

Dr Domenico Coviello

Institute of Biology and Genetics
University of Genova
Viale Benedetto XV, 6
I - 16132 Genova
Tel: + 39 10 353 8980
Fax: + 39 10 353 8978

Drs. Kris Dierickx

Centrum voor Bio-Medische Ethiek
en Recht
Katholieke Universiteit Leuven
Kapucijnenvoer 35
B - 3000 Leuven
Tel: + 32 16 33 69 51
Fax: + 32 16 33 69 52

Prof. Dr Gertrud Hauser

Institute of Histology and Embryology
University of Vienna
Schwarzspanierstrasse 17
A - 1090 Vienna
Tel: + 43 1 40 480 268
Fax: + 43 1 40480418

Dr Mairi Levitt

Centre for Professional Ethics
University of Central Lancashire
Vernon Building
UK - Preston PR1 2HE
Tel: + 44 1772 892541
Fax: + 44 1772 892942

Mr. Tony Mc Gleenan

Faculty and School of Law
The Queen's University of Belfast
21 University Square
IRL - Belfast BT7 1NN
Tel: + 44 1232 245133
Fax: + 44 1232 325590

Dr Darren Shickle

Centre for Applied Public Health Medicine
University of Wales
College of Medicine
Cathays Park
UK - Cardiff CF1 3NW
Tel: + 44 1222 231021
Fax: + 44 1222 238606

Dr Urban Wiesing

Institute for Theory and History of Medicine
Westfälische Wilhelms
Universität Münster
Waldeyerstrasse 27
D - 48149 Münster
Tel: + 49 251 83 52 91
Fax: + 49 251 83 53 39

Mr. Veikko Launis

Dept of Philosophy
University of Turku
Hameenkatu 6
FIN - 20500 Turku
Tel: + 358 21 633 6338
Fax: + 358 21 633 6270

Prof. Heta Häyry

Dept of Practical Philosophy
University of Helsinki
Unioninkatu 40B, POB 24
FIN - 00014 Helsinki
Tel: + 358 0 44 24 24
Fax: + 358 0 191 7627

Dr Matti Hayry

Dept of Practical Philosophy
University of Helsinki
Unioninkatu 40B, POB 24
FIN- 00014 Helsinki,
Tel: + 358 0 44 24 24
Fax: + 358 0 191 7627

Drs. Rogeer Hoedemaekers

Dept of Ethics, Philosophy and History of Medicine

Faculteit der Medische Wetenschappen

Katholieke Universiteit Nijmegen

PO Box 9101

NL - 6500 HB Nijmegen

Tel: + 31 80 61 53 20

Fax: + 31 80 54 02 54