MEDICAL EXAMINATIONS FOR NON HEALTH PURPOSES

EUROPEAN STANDARDS
FOCUS PRESENTATION

- RELEVANT COUNCIL OF EUROPE HUMAN RIGHTS STANDARDS
- MEDICAL EXAMINATION/HEALTH ASSESSMENT PRIVATE INSURANCE / EMPLOYMENT
- TESTS FOR DETECTING LATENT SERIOUS INCURABLE DISEASE (NON)GENETICS)
- PREDICTIVE GENETIC TESTING (INCLUDES PREDISPOSITION,SUSCEPTIBILITY)
- USE OF EXSTING GENETIC INFORMATION
LAY OUT PRESENTATION

• PERTINENT TEXTS COUNCIL OF EUROPE
• BASIC ASSUMPTIONS
• HUMAN RIGHTS INVOLVED: INDIVIDUAL, SOCIAL
• NON DISCRIMINATION PRINCIPLE
• CASE LAW
• WHY COMMON EUROPEAN STANDARDS AS A MATTER OF URGENCY

HENRIETTE ROSCAM ABBING
COUNCIL OF EUROPE > 20 YEARS ACTIVITY

• NEW MEDICAL TECHNOLOGICAL POSSIBILITIES (EARLY DETECTION, PROGNOSTIC, SUSCEPTIBILITY)

• POSSIBLE ADVERSE EFFECTS OF USE MEDICAL EXAMINATION FOR NON HEALTH PURPOSE
PERTINENT COUNCIL OF EUROPE RECOMMENDATIONS

• REC 89/14 HIV-HEALTHCARE-SOCIAL SETTINGS
• R(92)3 GENETIC TESTING FOR HEALTHCARE PURPOSES
• R(97)5 PROTECTION MEDICAL DATA
• R(2010) 13 AUTOMATED PROCESSING IN CONTEXT PROFILING
• 2000 REPORT MEDICAL EXAMINATIONS PRECEDING EMPLOYMENT/INSURANCE

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PERTINENT TEXTS COUNCIL EUROPE CORE STANDARDS

EMPLOYMENT: MEDICAL EXAMINATION ONLY IF JOB RELATED HEALTH REQUIREMENTS, NO PREDICTIVE RISK ASSESSMENT, NO COMMUNICATION TEST RESULTS

INSURANCE: (SOCIAL FUNCTION)
- NO PREDICTIVE TESTING
- UNDER FIXED LEVEL NO COMMUNICATION EXISTING GENETIC INFORMATION (TO COUNTER ADVERSE SELECTION)

PRIVACY: COLLECTION/PROCESSING/USE GENETIC DATA ONLY FOR HEALTH/SCIENTIFIC RESEARCH; PREDICTIVE: ONLY OVERRIDING INTEREST

AUTOMATED PROCESSING IN CONTEXT PROFILING: NO SENSITIVE (GENETIC, HEALTH) DATA UNLESS LAWFUL PURPOSES/APPROPRIATE SAFEGUARDS
ART. 12: PREDICTIVE GENETIC TESTS ONLY FOR HEALTH OR SCIENTIFIC PURPOSES LINKED TO HEALTH PURPOSES

“BECAUSE THERE IS AN APPARENT RISKS THAT USE IS MADE OF GENETIC TESTING POSSIBILITIES OUTSIDE HEALTHCARE, FOR INSTANCE IN THE CASE OF MEDICAL EXAMINATION PRIOR TO EMPLOYMENT OR AN INSURACNE CONTRACT, IT IS OF IMPORTANCE TO CLEARLY DISTINGUISH BETWEEN HEALTH PURPOSE FOR THE BENEFIT OF THE INDIVIDUAL ON THE ONE HAND AND THIRD PARTIES’ INTERESTS, WHICH MAY BE COMMERCIAL, ON THE OTHER HAND.” (ER)
OVIEDO CONVENTION

• ART. 26.1: EXCEPTIONALLY GENETIC PREDICTIVE TEST: PUBLIC SAFETY, PREVENTION CRIME PROTECTION PUBLIC HEALTH, RIGHTS FREEDOMS OTHERS (PRESCRIBED BY LAW/ NECESSARY)

• PROTOCOL GENETIC TESTING(2000): SCOPE LIMITED TO HEALTH/ SCIENTIFIC PURPOSES: LITTLE SIGNIFICANCE FOR MEDICAL EXAMINATIONS FOR NON- HEALTH RELATED PURPOSES
BASIC ASSUMPTIONS

- MEDICAL TECHNOLOGY INSTRUMENT FOR DISTRIBUTION SOCIAL GOODS
- WORK/PRIVATE INSURANCES CONDITIONS FOR SUBSISTENCE
- ELEMENT OF COMPULSION: TOUCHES UPON RESPECT DIGNITY – PRIVATE LIFE – NON-DISCRIMINATION
- NEGATIVE IMPACT ON USE HEALTHCARE SERVICES
- BALANCE JUSTIFIED NEEDS INDIVIDUAL /INTERESTS INSURANCE COMPANIES TO PREVENT ADVERSE SELECTION
- HEALTH ASSESSMENT IN THE BENEFIT OF THE EMPLOYEE NOT FOR THE FINANCIAL HEALTH OF THE UNDERTAKING.
- SELECTION JOB-CANDIDATE NO REPLACEMENT DUTY EMPLOYER TO ENSURE HEALTHY WORKING CONDITIONS
PRINCIPLES MEDICAL EXAMINATION

• MEDICAL EXAMINATION/OBJECTIVES SHOULD BE JUSTIFIED
• WHAT IS ASKED AND EXAMINED SHOULD BE
  ➢ RELEVANT
  ➢ NECESSARY
  ➢ PROPORTIONAL
• INFORMATION COLLECTED SHOULD ONLY BE USED FOR THE OBJECTIVES
INDIVIDUAL HUMAN RIGHTS
RIGHT TO PROTECTION PRIVATE LIFE

PHYSICAL INTEGRITY, INFORMATIONAL PRIVACY:
RIGHT NOT TO KNOW /DATA CONFIDENTIALITY

-ECHR: RIGHT TO PRIVATE LIFE, ART. 8
-OVIEDO: FREE INFORMED CONSENT (ART 5),
PRIVATE LIFE (ART. 10), PREDICTIVE TESTS
ONLY FOR HEALTH/SCIENCIFIC RESEARCH (ART. 12)

-EU CHARTER FUNDAMENTAL RIGHTS: PHYSICAL
/MENTAL INTEGRITY (ART. 3),PRIVATE LIFE (ART.10),
DATA PROTECTION (ART. 8)
SOCIAL HUMAN RIGHTS
ADEQUATE MEANS FOR SUBSISTENCE

• EUROPEAN SOCIAL CHARTER (ESC): RIGHT TO WORK, SAFE/HEALTHY WORKING CONDITIONS, HEALTH PROTECTION, SOCIAL SECURITY, SOCIAL/MEDICAL ASSISTANCE, PROTECTION AGAINST POVERTY/SOCIAL EXCLUSION, HOUSING, SOCIAL WELFARE SERVICES ETC.
SOCIAL HUMAN RIGHTS

• OVIEDO CONVENTION: EQUITABLE ACCESS TO HEALTH CARE, ART. 3 (ART.12-NO PREDICTIVE GENETIC TESTS EXTRA GUARANTEE)

• EU CHARTER FUNDAMENTAL RIGHTS: SOCIAL SECURITY/SOCIAL ASSISTANCE, HEALTH CARE, ACCESS TO SERVICES OF GENERAL ECONOMIC INTEREST, HIGH LEVEL CONSUMER PROTECTION
PROHIBITION OF DISCRIMINATION

a. ESC: ART. E, INCLUDES HEALTH
b. ECHR: ART14, HEALTH NOT MENTIONED/NOT EXCLUDED. CRITERIA: RELEVANCE, LEGITIMACY AIM, PROPORTIONALITY
c. ECHR/PROTOCOL NR 12: GENERAL PROHIBITION (STATES OBLIGATIONS): “RELATIONS IN THE PUBLIC SPHERE NORMALLY REGULATED BY LAW, FOR WHICH THE STATE HAS CERTAIN RESPONSIBILITY eg. ARBITRARY DENIAL OF ACCESS TO WORK OR TO SERVICES WHICH PRIVATE PERSONS MAKE AVAILABLE TO THE PUBLIC, SUCH AS MEDICAL CARE."
d. OVIEDO CONVENTION: ART. 11: GENETIC HERITAGE
e. EU CHARTER F.R.: ART. 21, GENETIC TRAITS, HEALTH NOT MENTIONED, BUT NOT EXCLUDED; HORIZONTAL WORKING
ENFORCEMENT HUMAN RIGHTS INSTRUMENTS

- **EUROPEAN CONVENTION HUMAN RIGHTS:**
  EUROPEAN COURT OF HUMAN RIGHTS (EcrtHR):

- **OVIEDO CONVENTION:**
  EcrtHR USES OVIEDO CONVENTION AS RELEVANT SOURCE

- EcrtHR ALSO DEALS WITH SOCIAL ASPECTS:
  “THERE IS NO WATER-TIGHT DIVISION SEPARATING THE SPHERE OF ECONOMIC AND SOCIAL RIGHTS FROM THE FIELD COVERED BY THE CONVENTION; WHILE THE LATTER SETS FORTH WHAT ARE ESSENTIAL CIVIL AND POLITICAL RIGHTS, MANY OF THEM HAVE IMPLICATIONS OF A SOCIAL OR ECONOMIC NATURE” (Arey v. IRELAND, 9-10-1979). THESE RELATE INTER ALIA TO SOCIAL WELFARE”.

- (ADHERENCE EU TO ECHR)
EcrtHR: EXAMPLES INDIVIDUAL/SOCIAL RIGHTS

- PAYMENT FOR MEDICAL TREATMENT: RIGHT TO LIFE
- SOCIAL WELFARE, GUARANTEE OF MINIMUM STANDARD OF LIVING: PROHIBITION DEGRADING TREATMENT
- ACCESS TO PERSONAL MEDICAL RECORDS
- DISCLOSURE MEDICAL FILES: RIGHT TO PRIVATE LIFE
- DEATH IN A MEDICO-LEGAL INSTITUTION: RIGHT TO (PRIVATE) LIFE, PROHIBITION OF INHUMAN TREATMENT, DISCRIMINATION
EUROPEAN SOCIAL CHARTER ENFORCEMENT

• COUNTRY REPORTS

• COLLECTIVE COMPLAINT PROCEDURE;
  = MEDECINS DU MONDE INTERNATIONAL VS FRANCE: eg. HOUSING, SOCIAL PROTECTION AND HEALTHCARE, DISCRIMINATION (ROMA)
  = ASSOCIATION OF CARE GIVING RELATIVES AND FRIENDS: RIGHT ELDERLY PERSONS TO SOCIAL PROTECTION (DRASTIC INCREASE LONG TERM CARE CHARGES)
EU CHARTER FUNDAMENTAL RIGHTS

• APPLIES TO EU INSTITUTIONS
• APPLIES TO MEMBER STATES WHEN IMPLEMENTING EU LAW
• ENFORCEMENT VIA EUROPEAN COURT JUSTICE
• WHEN EU ADHERES TO ECHR: CHARTER TAKES PRECEDENCE ONLY WHEN MORE AMPLE PROTECTION
LAND MARK JUDGEMENT EcrtHR
DISCRIMINATION HIV)

IMPORTANT CITATIONS IN RELATION TO HIV/AIDS - UN DOCUMENTS:
- ELIMINATION OF ALL DISCRIMINATIONS/ENSURING FULL ENJOYMENT
HUMAN RIGHTS, INCLUDING ACCESS TO HEALTHCARE, EMPLOYMENT,
SOCIAL AND HEALTH SERVICES, PRIVACY AND CONFIDENTIALITY
- "OTHER STATUS INCLUDES HEALTH
- PHYSICAL DISABILITY/VARIOUS HEALTH IMPAIRMENTS FALL WITHIN
SCOPE ART 14 ECHR
- EUROPEAN CONSENSUS COMMON STANDARD ADDITIONAL
/POSSIBLE RELEVANT CONSIDERATION INTERPRETATION
ECH/NARROW MARGIN APPRECIATION MEMBER STATE
(APPL 2700/10, JUDGEMENT 10-3-2011, DEF: 15-9-2011)

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MEDICAL EXAMINATION SELECTION INSTRUMENT FOR SOCIAL GOODS

• ADVANCES IN (PREDICTIVE) TECHNOLOGY eg. FULL GENOME SEQUENCING, PHARMACOGENETICS

• PRESENT ECONOMIC/FINANCIAL CRISIS EUROPE

• HIGH LEVEL OF UNEMPLOYEMENT

• DECREASE SOCIAL SECURITY/WELFARE BENEFITS

• INCREASE SOCIAL FUNCTION PRIVATE INSURANCE

• UNEMPLOYMENT: EMPLOYERS MORE PLAYFIELD TO SINGLE OUT HEALTHY CANDIDATES
MEDICAL EXAMINATIONS - SELECTION INSTRUMENT FOR SOCIAL GOODS

• PUBLIC HEALTH CONSEQUENCES:
  + THRESHOLD TO ACCESS HEALTH CARE OUT OF FEAR TO HAVE TO DISCLOSE TEST RESULTS FOR THE PURPOSE OF EMPLOYMENT /INSURANCE
  + IDEM, HINDRANCE TO PARTICIPATE IN SCIENTIFIC RESEARCH
WHY STANDARDS?

- LESS PUBLIC SAFETY NET/SCARCITY SOCIAL GOODS MAKES CITICENS DEPENDENT ON PRIVATE SECTOR
- USE MEDICINE FOR DISTRIBUTION SOCIAL GOODS A REAL THREAT FOR INDIVIDUALS
- CALLS FOR GUARANTEES ACCESSIBLITY BASIC SERVICES (POSITIVE DUTY STATE)

HENRIETTE ROSCAM ABBING
WHY EUROPEAN STANDARDS?

DIVERGENT POLICIES/REGULATIONS

- DISTORTIONS INTERNAL MARKET
- EXTENSIVE CROSS BORDER MOVEMENTS: SERVICES, HEALTHCARE, EMPLOYMENT
- DIFFERENT LEVEL CONSUMER PROTECTION
- DIFFERENT LEVEL HUMAN RIGHTS PROTECTION
- CROSS BORDER ELECTRONIC HEALTH DATA

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WHY EUROPEAN STANDARDS?

WHEN THE SOCIAL STRUCTURE FAILS TO MEET BASIC SOCIAL NEEDS, EUROPEAN STANDARDS FOR COLLECTION/USE SENSITIVE INFORMATION FOR INSURANCE AND EMPLOYMENT URGENTLY NEEDED IN ORDER TO STOP /PREVENT

- SOCIAL EXCLUSION
- DISPROPORTIONAL INTERFERENCE INDIVIDUAL HUMAN RIGHTS
OBJECTIVES EUROPEAN STANDARDS

• IMPROVE LEGAL POSITION PERSON SUBJECTED TO MEDICAL EXAMINATION

• PREVENT UNLIMITED USE MEDICAL KNOWLEDGE

• GUARANTEE PARTICIPATION IN SOCIAL ATTAINMENTS
EUROPEAN COMMITMENTS:


• 2011 STATEMENT CONFERENCE 50TH ANNIVERSARY ESC: NEED TO REINFORCE SOLIDARITY IN EUROPE, SO THAT THE AIM OF IMPROVING ECONOMIC COMPETITIVENESS IS ACCOMPANIED BY A GROWING RESPECT FOR FUNDAMENTAL SOCIAL STANDARDS.

• OBJECTIVE EC TREATY: ATTAINMENT HIGH LEVEL OF EMPLOYMENT AND SOCIAL PROTECTION, RAISING THE STANDARD OF LIVING AND THE QUALITY OF LIFE, ECONOMIC AND SOCIAL COHESION AND SOLIDARITY AND THE FREE MOVEMENT OF PERSONS.