# Supplements

# part A: Search Strategy

We present the search in Medline as an example.

|  |  |
| --- | --- |
| **#** | **Search strategy** |
| 1 | (sociocultur$ or socio-cultur$ or sozio-kulturell$).ab,ti,ot.  |
| 2 | (society and (differen$ or disparit$)).ti,ab.  |
| 3 | societal.ti,ab.  |
| 4 | mainstream$.ti,ab.  |
| 5 | communit$.ti,ab.  |
| 6 | Social Perception/ or Social Values/  |
| 7 | Social Sciences/ or Sociology, Medical/  |
| 8 | Sociological aspects.ti,ab.  |
| 9 | (Attitude/ or attitude$.ti,ab.) and (differen$ or disparit$).ti,ab.  |
| 10 | (attitude$ and (differen$ or disparit$)).ti,ab.  |
| 11 | Public Opinion/  |
| 12 | Prejudice/ or prejudic$.ti,ab.  |
| 13 | (social norm$ or cultural norm$ or social moral$ or cultural moral$).ti,ab.  |
| 14 | (cultural belief$ or cultural ideas).ti,ab.  |
| 15 | Social Change/  |
| 16 | (social and (differen$ or disparit$)).ti,ab.  |
| 17 | socioeconomic factors/ or socio-economic.ti,ab.  |
| 18 | (inequalit$ or equity).ti,ab.  |
| 19 | social status.ti,ab.  |
| 20 | Health Services Accessibility/ and (differen$ or disparit$).ti,ab.  |
| 21 | social support/ |
| 22 | social support.ti,ab.  |
| 23 | social class/  |
| 24 | social meaning$.ti,ab.  |
| 25 | culture/ or cultural characteristics/  |
| 26 | (cultur$ and (differen$ or disparit$)).ti,ab.  |
| 27 | (cultural aspects or Cross-cultural aspects).ti,ab.  |
| 28 | Ethnic Groups/ or Anthropology/ or ethnicity.ti,ab. or ethnolog$.ti,ab.  |
| 29 | ethnic identity.ti,ab.  |
| 30 | Health Services, Indigenous/  |
| 31 | Gender Identity/ or (gender studies or women's studies or gender gap or gender role).ti,ab.  |
| 32 | ethic$.ti,ab.  |
| 33 | Morals/  |
| 34 | Religion/  |
| 35 | conscience.ti,ab.  |
| 36 | (human rights/ or Civil rights/ or Social Justice/ or Freedom/ or personal autonomy/ or Decision Making/ or Patient Rights/) and (different$ or disparit$).ti,ab.  |
| 37 | (freedom of choice or patient self-determination).ti,ab.  |
| 38 | patient participation/ or Consumer participation/  |
| 39 | (civil or citizen).ti,ab.  |
| 40 | Attitude to Health/  |
| 41 | Health Knowledge, Attitudes, Practice/  |
| 42 | "Patient Acceptance of Health Care"/ or adherence.ti,ab.  |
| 43 | psychosocial.ti,ab.  |
| 44 | behaviour.ti,ab.  |
| 45 | (applicab$ and (differen$ or disparities)).ti,ab.  |
| 46 | "power (psychology)"/  |
| 47 | or/1-44 |
| 48 | Technology Assessment, Biomedical/ |
| 49 | Technology, Medical/ |
| 50 | medical technology assessment.ti,ab. |
| 51 | health technology assessment.ti,ab. |
| 52 | technol$ assess$.ti,ab. |
| 53 | hta.ti,ab. |
| 54 | mta.ti,ab. |
| 55 | (evaluation adj5 technology).ti,ab. |
| 56 | or/48-55 |
| 57 | 47 and 56 |
| 60 | Social Support/ |
| 61 | social support.ti,ab. |
| 62 | 60 or 61 |
| 63 | 56 and 62 |
|  |  |

# Supplements

# part B

# Supplementary Table 1: Checklists

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Author****(year)** | **Country** | **Health technology** | **Objective/Topic** | **HTA- context** | **Application** | **Target group** | **Items of checklist/questionnaire** |
| (1) Office of Technology Assessment (OTA) (1976)(2) Banta (1993) | USA | No particular technology | To present a list of questions to explore the implications of introducing a new technology | YesYes | No application identified | HTA developers | 6 questions (with sub-questions) concerning social impact:What are the implications of the medical technology for the- Patient,- Patient’s family,- Society,- Medical-care system,- Legal and political system,- Economic system? |
| (3) Oortwijn et al. (1996) | Nether­lands | No particular technology | Development of a checklist for the evaluation of the societal relevance of research proposals with regard to new and existing medical technologies/8 investigational medicine proposals | Yes | Checklist was tested by the authors | HTA developers  | 10 indicators (with 25 criteria) concerning societal criteria:- Epidemiological criteria- Quality of life- Cost-of illness- Frequency of use- Efficacy- Costs- Controversy- Susceptibility of physicians to new knowledge- Indication region- Ethical & social implications |
| (4) Hofman (2005)(5) Droste et al. (2011)(6) Hofmann (2013) | Norway | No technology assessed in the first publication, but applications are provided in the two later publications. Hofmann (2013) focuses on ethical issues related to bariatric surgery in children and adolescents.Droste et al. (2011) applies the checklist in a systematic review on ethical issues of autologous stem cell transplantation (ASCT) in breast cancer. | To develop a procedure to integrate moral issues in HTA. | YesYesYes | Checklist was applied. | Potential target groups are HTA developers  | Items 33 questions concerning moral aspects related e.g. to stakeholders, technology, methodological choices, technology assessment For the socio-cultural assessment esp. the following points are of interest:* Medicalization
* Discrimination
* (social) responsibility of parents and stakeholders deciding on a child/adolescent
* Stigma of obesity
* Feelings of guilt and shame related to obesity
* Surgery as a medical solution for social problems (of unsound attitudes and discrimation)
* Social status
* Social economic status and race (disadvantaged children) – challenges norms for equality re access of treatment
* Professional and economic interest of stakeholders
* Social construction of obesity
* Normative (moral) aspects of obesity
* Social life participation of obese/treated children
* Psychosocial effects (especially because the target group)
* Restriction of life-style choices
* Autonomy
 |
| (7) EUnetHTA (2008a)(8) EUnetHTA(2008b)(9) EUnetHTA (2008c)(10) EUnetHTA (2008d)(11) Pasternack et al. (2009)(12) Saarni et al. (2011) | Europe | Multislice computed tomography (MSCT) coronary angiography (9, 11) Drug eluting stents (10, 11) Medical and surgical interventions (7) Diagnostic technologies (8) Obesity surgery (12)  | To describe the kind of research methodology which is typically used or should be used | YesYesYesYesYesYes | Checklist was applied. | HTA developers | 7 items with sub-questions: - Access to health care- Support- Working life- Economy of a citizen- Family life- Social relations- Attitudes and self-conception |
| (13) Gerhardus (2008) | Germany | No technology assessed | Suggestion for a list of questions  | Yes | No application | HTA developers | 9 questions concerning different themes:* Societal perspectives, values, attitudes
* Cultural context
* Status, behavior and acceptance of and power between groups
* Self-determination
* Social inequality
 |
| (14) Culyer & Bombard (2012)  | Canada | No technology assessed | Provides a list of questions to help decision makers become aware of equity considerations, that can also be relevant as socio-cultural aspects. The list is intended to be applied when planning an HTA and to structure discussions, evidence collection and decisions during the assessment process. | Yes | No application identified. | High-level decision makers, HTA-agencies | The checklist/framework presents the following topics operationalized in sub-questions:* Equity Versus Equality
* Domains of Equity
* Legal Obligations
* Embedded Inequity
* Implicit Stereotyping
* Institutional Bias
* Contexts, Behaviors, and Circumstances
* Processes in HTA
* Hidden Opportunity Costs
* Processes in the Delivery of Care
* Special Claims
* Cumulative Effects
 |
| (15) Littlejohns et al. (2012) | Denmark | No technology assessed | To explore the concordance of the social values framework developed by Clark and Weale (2011) (a checklist to pragmatically assess social values) to publicly available data and HTA-decision protocols. | Yes | Application to decision protocols of HTA-agencies.  | Not specified | Items:* Social values related to accountability
* Social values related to transparency
* Social values of decision making, of participation in decision making and priority setting
* Social values in clinical effectiveness (quality of benefits provided for patients)
* Social values in cost effectiveness
* Justice/equity or treatment different target groups of patients and solidarity in access of treatment
* Autonomy: treating individual preferences
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# Supplementary Table 2: Literature reviews

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Author (year)** | **Country** | **Health technology** | **Objective/topic** | **HTA-context** | **Systematic review** | **Sources**  | **Included studies** |
| (16) Hardon (1992) | Great Britain | Contraceptive technologies | To provide contribution to the argumentation of four different contraceptive technologies by discussing nature of their development and evaluation process.  | Yes | No | Different material on Depo Provera, Norplant, the contraceptive vaccine and an abortion pill  | Review of studies that assess the acceptability of Norplant |
| (17) Engelking (1995) | USA | Genetic screening, treatment options in oncology | To provide an overview of the socio-political, bioethical, psychological issues of genetic screening, treatment options in oncology emerging in the USA. | No | No | Review of "professional articles", texts, proceedings, government and lay publications | No information provided on how the analysed publications were chosen and how many were included in this study |
| (18) Donaldson & Currie (2000) | Canada | Studies involving the contracting out of surgical services by a public funder to a private provider of care and other procedures (e.g. gynaecology services (Caesarean section), treatment for chronic renal failure (transplantation, peritoneal dialysis),magnetic resonance imaging (MRI),surgical services | To conduct a systematic review on private surgical services and different access to medical care | No | No | Online bibliographic databases, review of reference lists, publications recommended by researchers of the field, internet searches | Studies of relevance to contracting out of surgical services and studies of relevance to contracting out of other medical procedures and studies comparing profit versus not-for-profit care  |
| (19) Stemerding & van Berkel (2001) | Netherlands | Maternal serum screening for Down syndrome | To analyse and evaluate the process in which maternal serum screening for Down syndrome, neural tube defects has been introduced in Dutch maternity care. | Yes | No | Dutch medical journals, reports of the government, and the political and cultural debate | No information provided on inclusion criteria and numbers of included publications  |
| (20) Garcia et al. (2002) | United Kingdom | Ultrasound screening | A review of women’s views of ultrasound screening was commissioned as part of a larger study of the clinical and economic aspects of routine antenatal ultrasound use | No | No | Online bibliographic databases, review of reference lists, publications cited by other experts in the field | Studies of women’s views about antenatal screening and diagnosis, pregnancy ultrasound |
| (21) Jennett et al. (2003) | Canada | Telehealth in geriatrics, paediatrics, first nations, home care, mental health, radiology, renal dialysis, rural/remote health service, rehabilitation | To review the socio-economic impact of telehealth  | No | Yes | Online bibliographic databases, internet sources (e.g. websites of key organizations and the government), journals and conference proceedings, communication with experts in the field | Studies on telehealth - in pediatrics- in geriatrics - in first nations - in home care - in mental health - in radiology - in renal dialysis - in rural/remote health service - in rehabilitation  |
| (22) Kmet et al. (2004) | Canada | Genetic testing for cancer susceptibility | To review the literature addressing the social, legal, ethical issues related to genetic testing for cancer susceptibility | No | Yes | Online bibliographic databases, searches of key government and organization websites, internet searches, bibliographies in primary research articles | Studies assessing awareness of cancer susceptibility, genes/ genetic testing for cancer, interest in genetic testing for cancer susceptibility. The uptake of genetic testing for cancer susceptibility, knowledge of breast/ovarian cancer genetics, perceptions on risks and benefits, psychological implications, economic studies. |
| (23) Kotwal (2004) | India | Injection practices | To review the literature on injection practices.  | No | No | No databases are explicitly mentioned  | Studies to review the present injection practices with various determinants and aspects of injection safety are divided in categories with different focus: formal health facilities, informal health facilities, community setting, national reviewsUnsafe injection practices are divided into three sub-categories regarding to the risk of transmission of: Hepatitis B Virus, Hepatitis C Virus, Human Immunodeficiency Virus  |
| (24) d´Agincourt-Canning & Baird (2006) | Canada | Genetic testing for hereditary cancers | To review gender aspects and research outcomes in relation to genetic testing for hereditary cancers | No | No | No databases explicitly mentioned.  | Literature on genetic testing with a focus on gender issues and the following key topics: * Division between sex and gender and their impact on health
* Influence of gender on uptake, interest and impact of genetic testing
* Influence of gender differences on (social and ethical) implications of genetic tests
 |
| (25) Michelle (2007) | New Zealand | (In-)fertility, in vitro fertilization (IVF), sperm and egg donation, surrogacy, PGD, human cloning and stem cell research  | To identify the issues of emerging reproductive and biogenetic technologies and their proposed regulation. | No | No | New Zealand’s mostly circulated newspapers and magazines during two time periods, search of two electronic databases (Index New Zealand and Newztext Plus) | Newspaper and magazine articles were included to identify the technologies that were featured and how extensively, their ascribed applications and implications, and the degree of favorable representation |
| (26) Street et al. (2008) | Australia | Retinal photography | To examine community perspectives (acceptability, social impact and potential uptake) of retinal photography to detect diabetic retinopathy | Yes | No | Online bibliographic databases, google scholar and the Australian Indigenous Health Info-Net, weblogs | Studies assessing perspectives of people living with diabetes or acceptance or uptake of screening or therapy associated with diabetes management |
| (27) Greil et al. (2010) | USA | Infertility treatment via IVF | To present a summary of published studies on social and psychological aspects related to infertility treatment via IVF. | No | No | Review of the scientific literature on the socio-psychological impact of infertility (databases not stated) | Studies that assess socio-psychological impact of infertility. Identified issues are presented with examples |
| (28) Racine et al. (2010) | USA/Canada | Technological innovations in neuroscience | To examine how technological innovations in neuroscience that create interfaces between science and society are presented in print media. | No | Yes | Literature research was conducted using the “guided news” function of the LexisNexisAcademic database. Limitations were set on publishing date between 1995 and 2004 in US and UK-English. | Articles featuring neurotechnology (Positron Emission Tomography and/or Single Photon Emission Computerized Tomography, EEG, neurostimulation techniques, for functional Magnetic Resonance Imaging, and for neurogenetics) were included |
| (29) Munn & Jordan (2011) | Australia | Magnetic Resonance Imaging (MRI) and Computed Tomog-raphy (CT) | To synthesize the existent evidence on patient experiences of high technology medical imaging. | No | Yes | Studies were identified in 16 medical and allied health databases. An initial search in Medline and CINAHL followed by analysis of the text words contained in title and abstract and index terms of the article. 2nd search included all these key words and included (Medline, CINHAL, AMED, Ingenta Connect, Embase, PsychINFO, Sociological Abstracts, Web of Science, SCOPUS, grey literature, Mednar, Intute, Google Scholar, Current Contents, Dissertation Abstracts). 3rd the reference lists of all included articles were screened. | Studies addressing patients’ experiences of high technology medical imaging were included and summarized into 33 categories, which were synthesized to 11 ways of experiencing imaging with MRI and CT scanners. |
| (30) Sobo et al. (2011) | USA | No technology assessed. | The study aims at identifying cultural artefacts, that are created by the Medical Travel Agencies (MTAs) and support the trend of medical traveling in the US.  | No | No | Searchenginewatch.com was consulted for the latest search engine rankings released by comScore  | Websites of Medical Travel Agencies (MTAs) that promote medical services for US customers in abroad markets.  |
| (31) Gallacher et al. (2013) | UK/ USA | Treatment burdens of three chronic conditions: stroke, heart failure and diabetes | To describe/discuss used methods and developed instruments to conduct qualitative systematic reviews of treatment burdens  | No | Yes | Qualitative studies in peer reviewed journals addressing patients experiences were identified through different databases (Scopus, CINAHL, Embase, Medline & PsycINFO, reference, footnote and citation searching). The search was conducted for English publications and from published from the year 2000.  | Studies addressing the experiences and treatment burden of patients with one of the three chronical conditions: stroke, heart failure and diabetes |

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# Supplementary Table 3: Stakeholder participatory approaches

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Author****(year), (citation)** | **Country** | **Health technology** | **Objective/topic** | **HTA-context** | **Participants and method** |
| (32) Batavia & Hammer (1990) | USA | Assistive devices in mobility and sensory impairments | To identify and prioritize the factors used by long-term users in assessing their assistive devices in mobility and sensory impairments | No | Participants: long-term users of assistive devices (panel of Consumer Experts with Mobility Impairment and panel of Consumer Experts with Sensory Impairment)Method: - A modified form of the Delphi method was used. - At each meeting all three stages of the Delphi Method were conducted (stage 1: responses to mailed survey questionnaire, specified issues were reviewed, analyzed and compiled in a list of mutually exclusive issues; stage 2: participants ranked issues identified in stage one and were asked to rank the issues in order of importance; stage 3: respondents were provided with the aggregated rankings of the group from stage two and asked to complete one final rank-ordering of the issues)  |
| (33) Fox (1996)(34) Institute of Medicine (1996) | USA | Xenotransplantation | The workshop focused on three major topics on xenotransplantation: the science base, the public health risks of infectious disease transmission, ethical and public policy issues (including the views of patients and their families). | NoNo | Participants: - 43 speakers and presenters (patients, families, advocates, physicians, surgeons, veterinarians, clinical researchers, molecular and cellular biologists, immunologists, bioethicists, social scientists, science, medicine, media writers, health policy analysts among others) and more than 200 workshop attendees- Expert committee consisting of experts of different medical backgrounds, social sciences, history, ethics, law, health services researchMethod:Two day workshop organized by the Institute of Medicine (IOM) Council on Health Care Technology; a committee of 13 persons prepared the workshop and used the results as a principal source of background |
| (35) TA-SWISS (2000)(36) Bütschi & Mosimann (2001) | Switzerland | Transplantation medicine | To perform a platform designed to get the population involved in the political decision-making process with respect to controversial issues under discussion in society concerning transplantation medicine. | YesNo | Participants:- randomly chosen 10000 citizen received an invitation to apply- of these a group of 28 volunteers was chosen (as balanced as possible concerning age, gender, occupation and region)- the hole process was supported by a mediator, an interpreter and a steering group consisting of an ethicist, scientists, politiciansMethod: - prior to the meeting: 11 fact sheets were prepared as information material for the citizen- 2 preparatory weekends: first weekend: input of three guest speakers on medical, ethical and legal aspects, second weekend: to define questions that should be discussed, to choose experts answering these questions- Workshop “PubliForum” over 3 days: day one and two: oral presentations, discussion of the questions, day three: citizen were divided into 6 working groups where the information of the experts was summarized, their own position was generated, own suggestions to improve the current situation were derived, results were again discussed in the whole group and finalised in a document |
| (37) Reuzel et al. (2001) | Netherlands | Pediatric cochlear implantation | Evaluation of pediatric cochlear implantation should be “participatory”, with persons involved participating, not just as research subjects, but as active agents who determine the evaluation’s course and outcomes.  | Yes | Participants- 51 stakeholders (otorhinolaryngologists, parents of deaf children, decision-makers, teachers, pedagogues, representatives of deaf organizations, etc.)Methods:- Interactive evaluation- 3 cycles of individual interviews: participants discussed their claims, issues, and concerns with the evaluator- participants remained anonymous to each other |
| (38) Rey (2003) | Switzerland | IVF | Increased inclusion of citizens in the decision-making process. The “publifocus” tool should explore a broad range of opinions of citizen concerning IVF. | Yes | Participants:- randomly chosen 6000 citizens received an invitation to apply- of these a group of volunteers was chosen (as balanced as possible concerning age, gender, occupation, parental status and region)Method:- reading materials in advance of the forum - Meeting “Publifocus”: 4 discussion rounds each lasting for 4 hours (1 group affected by IVF, others differed regarding sociodemographic characteristics)- 6 to 12 participants per discussion round |
| (39) Avard et al. (2007) | Canada | Newborn Screening (NBS) | To address emerging ethical and social issues related to NBS with Tandem mass spectrometry | No | Participants- policymakers, patient advocates, clinicians, representatives from provincial NBS programs and governmental and non-governmental organizations - academics studying law, ethics, sociology, and evidence-based medicineMethod: - Workshop during a Symposium organized by the Garrod Association: The participants received a summary of the discussion and understood the workshop’s goal was to provide a basis for further discussion |
| (40) Thomas (2007) | New Zealand | Xenotransplantation | To examine the cultural, ethical and spiritual dimensions of xenotransplantation | No | Participants:- people or groups of the Bioethics Council’s database and other who found out about the event from the internet and the mediaMethod:A series of two-stage meetings- a discussion document was circulated to participants beforehand- eight reconvening events (16 sessions) across the country, two of them in a cultural Māori environment and one in a bicultural environment- one member of the Bioethics Council attended each event and gave a brief introduction to xenotransplantation- work in small groups during the sessions- additionally there was a web-based discussion forum and the possibility to make written submissions on xenotransplantation |
| (41) Potter et al. (2009) | Canada | Prenatal/ preconceptional and newborn screening | To explore both guidance and current practice regarding the consideration of ethical, legal, social issues in HTA for prenatal/ preconceptional and newborn screening (typically maternal blood tests, ultrasound) tests on couples to determine whether they are carriers of a recessively inherited genetic conditionchromosomal abnormalities such as Down syndrome. | No | Participants:- 28 participants: HTA producers, policy decision-makers or advisors at the provincial and federal level, representatives from disease-specific consumer/family/patient organizations, health professionals, and researchersMethod:- knowledge synthesis study- environmental scan - literature scan - systematic review - workshop to discuss ethical, legal, and social issues (series of 6 presentations)- participants discussed and debated the issues surrounding approaches to integrating ELSIs in HTA for prenatal/preconceptional and newborn screening |
| (42) Nakagawa et al. (2010) | Japan | Nanotechnologies (NT) | The study aims at assessing the feasibility of a problem structuring method using social implications of nanotechnologies (NT) in Japan as an example.  | No | Methods:* using the problem structuring method to investigate the variety of perceptions on social implications of NT
* creation of hypothetical “cognitive maps” as visualizing technique for each stakeholder
* interviews with key stakeholders applying the cognitive maps
* revision and validation of cognitive maps
* identification of stakeholder specific issues
* reflections of relevance of the different issues needs to be done interactive communication between stakeholders
* identification of an agreed list of social issues
 |
| (43) Boenink et al. (2011) | The Netherlands | Technologies for early diagnosis of Alzheimer disease | New technologies for early diagnosis of Alzheimer disease will influence societal views of the disease and the process of ageing. The study aims at presenting an approach for implementing these socio-cultural images in the assessment of the emerging diagnostic technologies. | Yes | Participants:No application. Method suggestion.Method:Sociotechnical scenarios to be used in stakeholder discussions including e.g., patients, clinicians, relatives, the elderly, caregivers, and policy makers, industry, guideline developers are suggested. Focus groups are suggested to elicit stakeholder responses. It is suggested that several group meetings with different homogeneous stakeholder groups be conducted.  |
| (44) Danner et al. (2011) | Germany | No technology assessed. | The objective of this study is to introduce the analytic hierarchy process (AHP) – an MCDA-technique - as a preference elicitation method in HTA, that can help to quantify patient preferences for treatment endpoints. | Yes | Participants:* patients with previously diagnosed major depression (currently in remission)
* professionals involved in the care of patients with depression (e.g. psychiatrists, physiotherapists) working in private practice or hospitals and other specialized physicians

Methods:* patients and professionals participated in moderated AHP workshops and were requested to compare pairs of treatment endpoints related to antidepressant treatment and to score them using radio-controlled key pads
 |
| (45) Niemeijer et al. (2013)  | The Netherlands | Surveillance technology in residential care | To investigate the professionals’ and ethicists’ views on surveillance technology in residential care for people with intellectual disability.  | No | Participants:* 15 participants (2 ID physicians, 2 developmental psychopathologists, 2 ethicists (academics), 4 personal coaches and 5 support workers (professional carers)

Methods:* concept mapping method by Trochim (a cumputerassisted procedure consisting of five subsequent steps: 1)brainstorming, 2)prioritizing, 3)clustering, 4)processing, 5)analysis
* participants perform step 1 to step 3
 |

# Supplementary Table 4a: Primary data collection methods – surveys

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Author (year)** | **Country** | **Health Technology** | **Objective/topic** | **HTA-context** | **Participants and method** |
| (46) Roeder & Whitler (1986) | USA | Artificial heart technology | To assess public knowledge and opinion on artificial heart technology | No | Participants- statewide survey of Kentuckians conducted by the University of Kentucky Survey Research Center- the sample of 846 adults was selected using random-digit dialingMethod:public opinion survey in Kentucky |
| (47) Singer (1993) | USA | Genetic testing/ fetal diagnosis | To report attitudes toward genetic testing/ fetal diagnosis | No | Participants- citizens; no explicit description of participantsMethod:- cross-sectional national US-survey- general Social Survey, an omnibus face-to-face data collection instrument  |
| (48) Bowman & Saunders (1994) | Australia | Oocyte and embryo donation and assisted reproduction after menopause | To assess community attitudes towards ethical and social issues on oocyte and embryo donation and assisted reproduction after menopause | No | Participants- Australian men and women aged 18 years and olderMethod:* survey
 |
| (49) Ubel & Loewenstein (1995) | USA | Prognosis and retransplantation status in distri-bution of scarce transplantable livers | To measure relative importance people place on prognosis and retransplantation status in distribution of scarce transplantable livers | No | Participants- people attending the annual flower show of the Pittsburgh Botanical Gardens were surveyed.Method:- survey- those volunteering to fill out the survey were randomly assigned to receive one of two surveys |
| (50) Cox et al. (1996) | Canada | Coronary artery bypass surgery | To assess the impact of delaying coronary artery bypass surgery | No | Participants- prospective observational study of all residents of Nova Scotia and Prince Edward Island accepted for bypass surgery- consecutive nonemergency patientsMethod:* interviewer administered questionnaire
 |
| (51) Middleton et al. (1998) | United Kingdom | Genetic testing or deafness | To describe the attitudes that a group of culturally and non-culturally deaf people have regarding genetic testing for deafness | No | Participants- participants at the conference on the "Deaf nation" at University of Central LancashireMethod:- structured self-administered questionnaire- a questionnaire was put on every seat in a large auditorium before one of the main presentations |
| (52) Dissanayake et al. (2002) | Sri Lanka | New reproductive and genetic technologies | To explore perspectives towards new reproductive and genetic technologies from an Asian view | No | Participants- 36 physicians who were attending a course preparing them for the Master of Surgery (Obstetrics and Gynecology)Method:- questionnaire survey- physicians were asked to fill out a questionnaire at the end of their training course |
| (53) Lehmann et al. (2002) | USA | Genetic testing for breast and ovarian cancer | To determine the attitudes of Jewish women towards the potential social consequences of testing for breast and ovarian cancer | No | Participants- a subset of respondents to a 1995 demographic survey of 1200 Jewish families in the Boston metropolitan area- women between the ages of 18 and 70 reporting having at least one parent of Jewish descentMethod:- telephone survey- interviews were conducted from a central interviewing facility at the Center for Survey Research (CSR), University of Massachusetts, Boston using computer assisted telephone interviewing software- an average interview lasted 34 minutes |
| (54) Yogev et al. (2003) | Israel | Assisted reproduction and adoption | Examine the attitudes of gynecologists in Israel towards assisted reproduction and adoption in the context of changing social norms | No | Participants- gynecologists actively working in hospital departments and outpatient clinics in urban centers in Israel Method:- anonymous questionnaire |
| (55) Doukas et al. (2004) | USA | Genetic testing for prostate cancer | To determine the values, beliefs, attitudes influencing the intention of men to undergo or defer genetic testing for prostate cancer | No | Participants- healthy outpatient males with no present or past history of prostate cancer living in the Philadelphia Metropolitan area- patients physicians screened the list of eligible men Method:- computer assisted telephone interviewing, n = 400 men |
| (56) Kaplan et al. (2004) | Israel | Assisted reproduction technologies | To evaluate attitudes of gynecologists towards social aspects of assisted reproduction technologies | No | Participants- gynecologists actively employed in gynecological departments and outpatient clinics in urban centers in IsraelMethod:- 10-item questionnaire distributed by e-mail |
| (57) Bardia et al. (2004) | India | Sex determination methods | To assess social issues towards sex determination methods | No | Participants- 79 grandmothers in 3 villages- 81 pregnant women attending the antenatal clinic of the CRHSP hospital at Ballabgarh Method: - close-ended interview- face-to-face interview using a pre-tested, close-ended interview schedule  |
| (58) Calnan et al. (2005) | England, Wales | Multiple technologies: * New vaccine on Meningitis
* Heart transplant
* Human cloning
* Male pill
* Genetic screening for cystic fibrosis
* Stem cells
* Impaired speech and mobility
* Gene therapy
* Human ageing process
 | To explore public attitudes, to see the extent to which they reflect concerns regarding several topics  | No | Participants- random sample of 2777 people on the electoral register, aged 18 and above in England and Wales Method:- postal questionnaire- the questionnaire was pre-piloted in face-to-face interviews and in a pilot postal survey |
| (59) Dahl et al. (2006) | USA | Preconception sex selection via sperm separation | To ascertain demand and preferences for preconception sex selection via sperm separation | No | Participants- a sample of 1.197 men and women between the ages of 18 and 45 throughout the United StatesMethod:- a previously validated questionnaire- self-administered, web-based survey |
| (60) Missmer & Jain (2007) | USA | Sex selection for nonmedical reasons | To compare and contrast previous observations of patients’ preferences for sex selection for nonmedical reasons, the method and sex they would choose, as well as to quantify the relations between these choices and their demographic and socioeconomic characteristics | No | Participants- consecutive women who presented to the UIC Fertility Center for infertility careMethod:- questionnaire consisting of 24 questions sent by mail with a cover letter and postage paid return envelope- the questionnaire was pilot tested- one month after the initial mailing, a second mailing was sent to non-respondents |
| (61) Papaharitou et al. (2007) | Greece | Assisted reproduction | To assess attitudes towards various aspects of assisted reproduction, to detect differences due to occupational status | No | Participants- certified midwifes (CM) from the Graduate Registry of all CMs from the Midwifery department of the Highes Technological Institute of Thessaloniki (HTIT)- midwifery students (SM) from the 4-year program at the Midwifery department of the HTIT- female students from different fields of study - women from the general populationMethod:- self-administered questionnaire with 59 different variables divided into three sections |
| (62) Quinonez & Locker (2007) | Canada | Dental health care and oral diseases | To assess opinions on publicly financed dental health care and oral diseases | No | Participants- representative sample of Canadians >18yrsMethod:- cross-sectional and retrospective telephone interview survey- 17-item questionnaire  |
| (63) Wüstner & Heinze (2007) | Germany, Japan | Preimplantation genetic diagnosis | To learn about what young Germans and Japanese think about preimplantation genetic diagnosis | No | Participants - German students at the University of Augsburg, questionnaires were given out at places where students met and spent time- Japanese students at three different campuses in TokyoMethod:- comparative survey  |
| (64) Subramanian & Selvaraj (2009) | India | Prenatal diagnostic techniques (PNDT) | To assess social patterning in the proportion of sexes among infants before and after the implementation of the Pre-Natal Diagnostic Techniques (PNDT) Act | No | Participants- a nationally representative sample of households with infants Method:- time series data for five most recent years: 2004/05, 1999/00, 1993/94, 1987/88 and 1983- multivariable regression analysis- the outcome was log odds of having a male infant - household income, parental education, social caste, a variable representing periods before and after the implementation of the PNDT Act and state of residence were the main predictors of interest |
| (65) Poynten et al. (2010) | Australia | Pre-exposure prophylaxis (PREP) to HIV | To explore the awareness of rectal microbicides, the use of pre-exposure prophylaxis (PREP) and the willingness to participate in biomedical HIV prevention in a cohort of HIV-negative gay men | No | Participants:* 1427 HIV-negative homosexually active men in Sydney, Australia
* inclusion criteria: aged 18 years or older, tested HIV-negative, had sexual contact with at least one man in the past five years and lived in Sydney or had regular contact with gay events and venues in Sydney.

Method:* community-based cohort study
* annual structured face-to-face interviews (quantitative analysis)
* quantitative data on sexual behavior, about awareness of rectal microbicides, use of PREP and the willingness to participate in trials of such products.
 |
| (66) van der Roest et al. (2010) | The Netherlands | Dementia specific Digital Interactive Social Chart (DEM-Disc) | To evaluate the DEMentia specific Digital Interactive Social Chart (DEM-Disc) - an online based platform supporting informal caregivers caring for persons with dementia. | No | Participants:* informal carers of people with dementia familiar with computers and internet, and living in Amsterdam

Method:* pretest–posttest control group design
* informal carers in the control group could access DEM-DISC at home during a two month period
* structured questionnaires on caregiver characteristics using the Caregiver Management Style (CMS) Questionnaire, the General Health Questionnaire 28 (GHQ-28), the Centre for Epidemiologic Studies Depression scale (CES-D)
* occurrence of neuropsychiatric symptoms (Neuropsychiatric Inventory (NPI)) and Cognitive Functioning Mini-Mental State Examination (MMSE) was applied
* needs assessment: Camberwell Assessment of Need for the Elderly
* care and welfare use was measured (use of services list)
* experienced burden by informal carers [Short Sense of Competence Questionnaire (SSCQ)]
* carers perceived self-efficacy : Pearlin Mastery Scale (PMS)
* quality of life: Quality of Life Alzheimer’s Disease scale (QoL-AD)
* user friendliness and Usefulness and the satisfaction with DEM-DISC were measured by the USE Questionaire
 |
| (67) Vazquez et al. (2010) | USA | Implantable cardioverter defibrillator (ICD) | Based on the assumption that female ICD patients have higher rates of psychological distress, the study aims at testing the effectiveness of a female specific psychosocial group intervention on disease-specific quality of life outcomes in outpatient | No | Participants:* 29 women (>18 years) with implanted ICD
* outpatients from cardiovascular clinic at Shands Hospital at the University of Florida

Method:* randomized distribution to intervention (n=14) or wait list control (n=15)
* questionnaire including individual psychological batteries at baseline and at one month follow up measuring shock anxiety (Florida Shock Anxiety Survey (FSAS) and device acceptance (Florida Patient Acceptance Survey)
 |
| (68) Partridge et al. (2011) | Australia | Life extension technologies | To explore Australians’ attitudes towards the development and use of life-extending technologies and their attitudes to ethical, social and personal implications referring to life extension. | No | Participants:* 605 Australian adults, randomly selected from a database of active landline telephone numbers maintained by the University of Queensland Social Research (UQSRC)
* database contained information on the State of the landline only

Method:* survey using the Computer Assisted Telephone Interview (CATI)
* using a scenario/ vignette presenting views on life extension, followed by statements about the topic. Participants were asked to agree or disagree.
* the survey development was informed by earlier studies using focus groups and qualitative interviews.
 |
| (69) Suresh et al. (2011) | India | pandemic influenza (H1N1) vaccination | To assess students’ knowledge, attitude and acceptance of H1N1 vaccination during the post-pandemic period in India 2009. | No | Participants:* university students of Vellore Institute of Technology in India (802 respondents)
* convenience sample

Method:* cross-sectional study
* questionnaire with multiple choice and Likert scale type questions (duration 20 min)
* study started one month of initiation of the vaccination program
 |
| (70) Clover et al. (2012) | Ireland | Progenitor cellsin tissue-engineered products | To investigate patients’ willingness to accept tissue-engineered skin products derived from a variety of sources. The results were used to develop an ethical guideline. | No | Participants:* 279 patients attending plastic surgery/burns outpatient and medical outpatient clinics
* patients had acute burns, diabetes or Parkinson disease

Method:* questionnaire addressing a) willingness to have treatment with progenitor cells and b) the acceptance of the different cell sources for the treatment of various diseases
 |
| (71) Fex et al. (2012) | Sweden | Advanced medical technology use at home | To describe factors influencing the self-care agency and perceived health of persons using advanced medical technology at home. | No | Participants:* 180 adults performing homebased self-care involving long-term oxygen, a ventilator and peritoneal- or hemodialysis
* convenience sampling

Method:* questionnaire addressed perceived health and the daily life with medical technology. It includes Swedish versions of self-care agency scale and a 13-item version of the sense of coherence (SOC)-scale by Antonovksy
 |
| (72) Montague & Asan (2012) | USA | Health technologies in general | To investigate factors influencing patients trust into health technologies | No | Participants:* 101 obstetric patients who used the electronic fetal monitor while giving birth

Method:* online-survey
* questionnaire, containing 80 questions, measures patients’ trust in (1) their providers, (2) the technology, and (3) how their providers used the technology
 |
| (73) Rauscher et al. (2012) | USA | Mammography screening services | To determine potentially differences in accessing breast imagining between non-Hispanic white, non-Hispanic black, and Hispanic women and by women with and without private insurance. | No | Participants:* 43 screening facilities in Chicago (staff members directly involved in daily screening practice) completed the survey

Method:* a mammography facility survey for the metropolitan region of Chicago was conducted
* survey with 35 questions examining three measures of mammography quality: access to academic medical centers, access to radiologist who specializes in breast imaging and access to digital mammography
* analysis of the facility characteristic by patients’ race/ethnicity and private insurance
 |
| (74) Stormo et al. (2012) | Bolivia | Visual inspection with acetic acid (VIA) and cryotherapy for the prevention of cervical cancer | Exploring attitudes of Bolivian health professionals towards new technologies for cervical cancer prevention focusing on visual inspection with acetic acid (VIA) and cryotherapy for the prevention of cervical cancer. | No | Participants* 7 nurses and 35 physicians participating in five-day workshops on VIA and cryotherapy

Method:* application of two questionnaires assessing attitudes towards alternative methods of cervical cancer screening and the treatment of precancerous lesions
* 1st questionnaire (30 min) applied in the first workshop: multiple choice questions (current cervical cancer screening practices, perceived barriers to the early detection of cervical cancer, and attitudes of physicians toward the role of nurses in the provision of VIA and cryotherapy services)
* 2nd questionnaire (30 min) applied in the last workshop: multiple choice & open ended questions (acceptability of VIA and cryotherapy, perceived barriers for the implementation of these procedures using a single-visit screen-and-treat approach, and acceptability and familiarity with HPV testing and HPV vaccination
 |
| (75) Walker et al. (2012) | USA | Use of internet and mobile technologies for in-formation reception | The study aims at providing an overview of postpartum women’s access, perceived skill, confidence, and use of internet and mobile technologies; their views about receiving health information about postpartum weight and parenting; and potential influence of race/ethnicity or income level. | No | Participants:* 145 white/Anglo, African American or Hispanic new mothers of higher and lower income
* county in central Texas
* stratified random sample from the Center for Health Statistics, Texas Department of State Health Services (DSHS)

Method:* cross-sectional questionnaire (“Mothers’ Health Survey: Health & Parenting Information & How You Want”) mailed in English or Spanish
* addressing mothers’ internet and technology use (based on a blueprint with guiding conceptual definitions (Waltz, Strickland & Lenz, 2005) and the Teen tech survey (TTS: Budd, Schwarz, Elliott, & Haire-Joshu, 2009)
 |
| (76) Monthuy-Blanc et al. (2013) | Canada | Telemental health (psychotherapy delivered via videoconferencing). | To assess the role of mental health service providers’ attitudes and perceptions of telemental health (psychotherapy delivered via videoconferencing). | No | Participants:* 205 mental health service providers non-familiar with the use of telepsychotherapy to provide psychotherapy (working on 32 First Nation reserves in Quebec)

Method:* application of the Telepsychotherapy Acceptance Questionnaire, containing the Technology acceptance model (TAM)
 |
| (77) Wilson et al. (2013) | USA | Implantable Cardioverter Defibrillators (ICD) | The study aims at identifying factors influencing the patients’ acceptance of ICD and to prove for racial and gender differences. | No | Participants:* 101 ICD-patients (mean age= 65+/- 12.8 years; 34% female and 42% African American) - a collective seen in a cardiology clinic (between January and August 2010)

Methods:* Florida Patient Acceptance Survey (FPAS): 18 items to examine the acceptance of devices in pacemaker, ICD and implantable atrial defibrillator patients. The height of the score represents the acceptance.
* Florida Shock Anxiety Scale (FSAS): 10 items where respondents rate on a five point Likert scale (range from 1 to 5).
* ENRICHD Social Support Instrument: 7 items that assess four defining attributes of social support (emotional, instrumental, informational and appraisal).
* Hospital Anxiety and Depression Scale (HADS)
* Hoge Religiosity Scale
 |

# Supplementary Table 4b: Primary data collection methods – Focus groups

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Author (year)** | **Country** | **Health Technology** | **Objective/topic** | **HTA-context** | **Participants and method** |
| (78) Kerr et al. (1998a)(79) Kerr et al. (1998b) | Scotland | Genetics | To explore lay expertise on genetics | NoNo | Participants* mixture of lay people from community and support groups in central Scotland

Focus groups* 20 focus groups in two stages: first stage five groups with on average 6 participants, in the second stage seven groups with on average 4 participants
* first type of group: without having direct experience of a genetic or health related concern
* second type of group: had experiences of an illness or behaviour that may be related to genetics
* third type of group: direct experience of a genetic health concern
 |
| (80) Doukas et al. (2000) | USA | Genetic testing for prostate cancer risk | To determine key values, beliefs, attitudes that influence a man’s intention to undergo or defer against genetic testing for prostate cancer risk. | No | Participants* men from the general population aged 18-70 years excluding men who have or have had cancer
* recruitment through a firm specialized in focus groups and through advertisements in local newspapers and local churches, markets and restaurants

Focus groups* development of a discussion guide with 35 probe and broad open-ended questions
* 12 focus groups with a total of 90 participants
* educational video at the beginning of each focus group
 |
| (81) Kinney et al. (2001) | USA | Genetic testing for hereditary colorectal carcinoma (CRC) | To obtain insights into attitudes, beliefs, and informational needs about genetic testing for hereditary colorectal carcinoma (CRC). | No | Participants* 18 years or older, had either CRC or at least 1 first-degree relative (FDR) with the disease, had access to transportation and lived within approximately 60 miles of cancer center involved
* recruitment of CRC participants: patient lists at the University of North Carolina Lineberger Comprehensive Cancer Center, members of local CRC or ostomy support groups, through the media
* recruitment of FDR-participants: local community through the media, physician referral, referral by family members with CRC

Focus groups* each group with about 5-10 participants
* A one page written statement about genetic testing was distributed and read aloud by the moderator shortly after the focus group commenced
 |
| (82) Nigenda et al. (2003) | Cuba, Thailand, Saudi Arabia, Argentina | Antenatal care protocol | To collect information, besides other aspects, on the opinions about the new antenatal care protocol.  | No | Participants* women participating in a randomized controlled trial set up by the WHO in Cuba, Thailand, Saudi Arabia and Argentina: pregnant women who had completed two visits based on the traditional or modified protocol

Focus groups* 24 focus group discussions with 164 pregnant women
* Focus groups were carried out away from the health centers, in libraries, parks or women's houses, except in Saudi Arabia.
* They were carried out one year after the beginning of the trial and conducted by social/health researchers with experience in the application of these methodologies.
 |
| (83) Demiris et al. (2004) | USA | ‘Smart home’ technologies | To assess the perceptions and expectations of seniors with regard to technology installed and operated in their homes | No | Participants* an invitation to participate in the focus groups was posted at several locations within a Continuing Care Retirement Community in Columbia, Missouri
* a total of 15 older adults over the age of 65 participated

Focus groups* focus groups took place in three sessions and each lasted approximately 1 hour
* number of participants varied between 4 to 6
* the questionnaire was reviewed by team consisting of instrument development researchers and health care providers.
 |
| (84) Felt et al. (2008) | Austria | Organ transplantation and postnatal genetic testing | To explore lay peoples’ visions and versions of government, governance and participation, and how technologies (organ transplantation and post-natal genetic testing) are embedded in society | No | Participants * recruitment by mailing flyers to private households in Vienna’s (Austria) districts inhabited by people from different social backgrounds. Further, specific institutions, such as self-help groups, clinics, general practitioners and religious institutions were targeted

Focus groups* 2 focus groups with affected people
* 3 focus groups with non-affected people
* duration: 2 hours
 |
| (85) Lee et al. (2008) | Denmark | Dialysis | To explore patients’ views i.e. experiences with different dialysis modalities and key issues related to patients’ choice of modality | Yes | Participants* patient participants (27 patients and 18 relatives) were recruited through dialysis centres throughout Denmark and comprised dialysis patients above 18 years of age

Focus groups* as a part of a larger health technology assessment
* six focus group interviews with dialysis patients and relatives
 |
| (86) Hasegawa et al. (2011) | USA | Newborn screening (NBS) | To assess parental knowledge of NBS and their attitudes to NBS for untreatable.  | No | Participants:* 114 mothers (18-49 years) of at least one child not older than ten years with normal NBS results

Focus groups* 17 semi-structured focus groups held in Alaska, California, Hawaii and Washington (two hours duration)
* an introductory part at the beginning of the focus group was used to ensure participants’ have a similar knowledge of NBS
* verbal transcripts were analyzed using a theme oriented approach
* information about examples of untreatable disorders presenting in infancy were presented (Duchenne muscular dystrophy (DMD), ApoE susceptibility testing for Alzheimer Disease (for predisposition testing) and a range of questions was asked for each condition including the questionwhether or not parents would screen their newborn
* application of “long table analysis method” as qualitative method for analysis
 |
| (87) Coletti et al. (2012) | USA | Medication for atten-tion-deficit/ hyperactivity disorder (ADHD) | To investigate parental input on initiating medication for attention-deficit/ hyperactivity disorder (ADHD) to be used in the development of a provider delivered intervention to improve adherence to stimulations. | No | Participants:* parents or legal guardians of children aged 5 to 12 years, diagnosed with ADHD and with a recommendation for stimulant treatment
* purposive sampling
* heterogeneous groups

Focus groups* questionnaire on demographic information and child’s treatment history
* focus groups (2 hours duration) guided by a semi-structured interview guide
* verbally transcribed
* analysis applying an inductive strategy following Grounded Theory (Strauss & Corbin) and a deductive strategy applying an adapted version of the Unified Theory of Behavior Change to organize and understand parent accounts
 |

# Supplementary Table 4c: Primary data collection methods – Individual qualitative interviews

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Author, (year)** | **Country** | **Health Technology** | **Objective/topic** | **HTA-context** | **Participants and method** |
| (88) Burke & Nagle (1993) | Canada | Critical care environments | To identify the perceptions of critical care environments as held by patients’ significant others | No | Participants* 9 spouses of patients admitted to one of two critical care units

Methods* open ended interviews (from 25 minutes to 1 hour)
 |
| (89) Markens et al. (1999) | USA | Maternal alpha-fetoprotein (AFP) screening | To analyse how a group of women who refuse the offer of Maternal alpha-fetoprotein (AFP) screening account for their decision, to compare their explanations with those of women who took the test | No | Participants* Data came from 5 branches of a Southern Californian health maintenance organization (HMO).
* a random sample of 595 obstetrical patient charts - the first 25 women between the ages of 18 and 35 recruited in the sample who had refused AFP screening were interviewed
* women of diverse ethnic, social class and religious backgrounds
* all interviews took place after the 24th week of pregnancy
* limited to women who were at no known risk for bearing a child with a birth defect

Methods* lengthy face-to-face interviews
 |
| (90) Chapman (2002) | United Kingdom | Reproductive and testing technology for cystic fibrosis (CF) and Huntington’s disease (HD) | To present data on subjective perceptions of health and quality of life concerning reproductive and testing technology for cystic fibrosis (CF) and Huntington’s disease (HD) | No | Participants* individuals recruited from two regional centres, one for adult CF patients and the other for people living with HD
* 31 individuals with CF, 21 HD gene-positive individuals

Methods* semi-structured interview (average 50-60 minutes)
* Participants were introduced to a body chart, where they were asked to conceptualise their bodies from different perspectives.
* The interview schedule was tested in a short pilot study.
 |
| (91) Adair et al. (2009) | Canada | Predictive genetic testing (adult onset hereditary diseases, e.g. breast cancer, colon cancer, Huntington’s disease) | To explore perspectives on resource allocation for predictive genetic testing and associated ethical, legal and social issues | No | Participants* senior lab directors and clinicians at publically funded Canadian predictive genetic testing facilities
* participants were drawn from British Columbia, Alberta, Manitoba, Ontario, Quebec and Nova Scotia
* given the community sampled was identified as being relatively small and challenging to access, purposive sampling coupled with snowball sampling methodologies were utilized

Methods* 16 semi-structured interviews
 |
| (92) Underwood et al. (2009) | Australia | Strong life extension | To elicit researchers’ professional and personal attitudes towards strong life extension and the social and ethical issues that may arise.  | No | Participants- Australian and international researchers in scientific fields that are relevant to ageing- international researchers were recruited at an international conference on ageing- 14 researchers (five international researchers, and nine Australian researchers) Methods- semi-structured and in-depth interviews- ranging in length from a minimum of 10 min to a maximum of 76 min (average 36.5 min) |
| (93) Salter et al. (2011) | UK | Predictive medicine | To investigate women’s experiences when diagnosed as ‘at risk’ of chronic conditions such as osteoporosis and to reflect on consequences of implementing predictive medicine. | No | Participants:* 30 women, 73 to 85 years, living in Norfolk & Suffolk (UK), diagnosed as “at risk” for osteoporosis by screening for osteoporosis, but not formally diagnosed with osteoporosis
* the ATOM-study builds on participants of the SCOOP-trial – aiming at testing the effectiveness of a osteoporosis screening programme
* recruited within 6 months after the “of-risk”-labelling
* purposive sampling

Methods:* in-depth interviews (average duration 74 min)
* interview guide containing questions regarding e.g., use of preventive medicine, meaning and the risk-of-illness experience; knowledge, understanding and the embodiment of fracture risk status; and, social implications of biomedicine, attitudes to ageing, relationships with healthcare professionals
* coding approach for data analysis
 |
| (94) Xu et al. (2011) | USA | treatment of prostate cancer | To explore how black and white Americans decide about the treatment of prostate cancer. | No | Participants:* patients, black and white Americans in Detroit, Michigan, younger than 75, who had a treatment consultation with a urologist and/or radiation oncologist and were recently diagnosed with localized prostate cancer
* purposive sampling
* exclusion criteria: Patients who were not given a treatment choice and aren’t able to communicate in English.

Methods:* semi-structured interviews (duration: 60 to 120 min) using an interview guide based on the Health Belief Model (HBM) and the Cognitive-Social Health Informing Processing (C-SHIP) Model
* after transcription, coding and analysis, the gathered themes and patterns were compared across the participants.
* clinical factors were provided by the referral physician
* immersion/crystallization analysis technique based on theoretical preconceptions
* validation of the results through interviewees
 |
| (95) Wylie et al. (2012) | USA | Web-based screening and referral system called “The Online Advocate” (TOA) | To test a web-based screening and referral system called “The Online Advocate” (TOA) with the purpose of guiding young adults through social and health supporting services.  | No | Participants* convenience sampling from an urban hospital-based Adolescent/Young Adult Program at the Children’s Hospital Boston
* the first 50 participants using the TOA in this context also took part in the interview study
* inclusion criteria were: ability to read and to speak English, aged 15–25 years, able to give consent

Methods:* semi-structured interview
* application of the cognitive interviewing method to explore
* participants’ reactions on TOA
* theme-oriented coding approach
 |

# Supplementary Table 4d: Primary data collection methods – registries, data bases and health records

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Author (year)** | **Country** | **Health Technology** | **Objective/topic** | **HTA-context** | **Source of data and method** |
| (96) Raftery et al. (2005) | United Kingdom | No technology assessed | Assessment of potential use of routine databases in HTAs.No technology assessed | Yes | Source of data:* key literature sources, references from within those sources and a network of people with experience of routine databases

Methods:* development of a list of routine health databases which have potential for HTA through a combination of use
* assessment of the validity of the databases
* costs of databases were established from annual reports
* 272 databases identified, 62 databases are identified as having some potential use in any of three kinds of HTA
 |
| (97) Stern et al. (2005) | USA | Paediatric cochlear implant | To assess whether cochlear implant technology is provided to children with severe to profound sensorineural hearing loss in proportion to their racial/ethnic or SES.To compare data provided by a national health care database with data provided by cochlear implant manufacturers | No | Source of data* the Kids' Inpatient Database (KID) from the HCUP, a collaboration of private and state resources sponsored by the Agency for Health Care Research and Quality (AHRQ): random sample of 80% of non-newborn paediatric discharge records from 22 states, these records include two million paediatric discharges from 2521 acute care community, academic, and specialty hospitals in the United States
* information was also obtained from the two companies producing U.S. Food and Drug Administration - approved cochlear implants in 1997 and used to determine whether the data obtained from the Health Care and Utilization Project/ Kids’ Inpatient Database were representative of the national cohort of implanted children
* 124 participants of the KIDs study with cochlear implants were included in the analysis.

Methods:* logistic regression analysis was carried out to compare implanted children of different racial/ethnic backgrounds
 |
| (98) Price (2010) | USA | Human Papilloma Viruses (HPV) Tests | To explore professional speciality and patient characteristics related with the use of HPV DNA screening and to investigate issues of service provision in underserved populations. | No | Participants:* cervical cancer screening test claims for 415,239 female beneficiaries ages 21 to 64, enrolled in Medicaid for 12 months

Methods:* retrospective longitudinal study (for the period 2001- 2006) using Florida Medicaid administrative claims data
* empirical quantitative research of cervical cancer screening test claims (i.e. register data)
* the main outcome measure: Overall and appropriate use of HPV DNA tests. Socio-cultural relevant explanatory variables: patients age, race/ethnicity, district, provider specialty.
 |

# Supplementary Table 4e: Primary data collection methods – Methods combinations

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Author, (year)** | **Country** | **Health Technology** | **Objective/topic** | **HTA-context** | **Methods** |
| (99) Bellucci et al. (1998) | Switzerland | Xenotransplantation | The objective was to provide a qualitative evaluation of current discussion on xeno­transplantation of cells and organs. | Yes | Methods: * in-depth interviews: 18 Swiss experts from different fields (industry, medicine, law, patient association, social/critical organisations), approximately 2-hour personal interviews
* comprehensive written questionnaire: 5 experts in the fields of ethics, philosophy, theology
* shorter written opinions: 147 organizations, institutes, companies, and individuals for whom the topic of xenotransplantation could be relevant
 |
| (100) TA-SWISS (2001) | Switzerland | Ultrasound screening (US) | To explore how US is accepted, judged, experienced in men and women whose child received a sonographic diagnosis on fetal development disorder. | Yes | Methods:* prospective study: addressing 128 pregnant women and their spouses, first survey prior to the ultrasound screening: face-to-face interview and a questionnaire, second survey 12 days after the US, when participants had already received the feedback: interview by phone and a postal questionnaire, third survey 4 weeks postnatal or after the abortion: postal questionnaire
 |
| (101) Shepherd et al. (2007) | United Kingdom | New genetic technologies | To examine public attitudes towards new genetic technologies (therapeutic or reproductive human cloning for organ transplant, treatment for Parkinson's Disease, being in good health and wanting to live longer) | No | data presented are a part of a large study on attitudes to genomics which comprised several separate elementsMethods:* survey: nationally representative sample of approximately 2500 adults aged 18 and above, self-completion items on the British Social Attitudes Survey, an annual survey of social and political attitudes in the UK
* experimental vignette study: 368 adult members of the British general public, baseline questionnaire, randomly assigned to receive one of four vignettes, participants completed follow-up questions described in the vignette
* focus group study: 8 groups with members of the general public who had no particular involvement or investment in genomics-related issues recruited by a fieldwork agency to reflect the demographic profile of the populations, 2 groups with people affected by genetic Disease recruited through the Clinical Genetics Department of a London hospital, two moderators using an interview schedule
* media analyses: qualitative analysis of genomics-related newspaper articles from six UK newspapers
 |
| (102) Monahan & Fisher (2010)  | USA | Implantableradio-frequency identification devices (RFID) | To evaluate social and ethical issues related with the use of RFID in a hospital.  | No | Methods:* observations of staff’s conversation with each other and with patients during site visits in hospitals
* informal conversations with hospital staff
* 76 semi-structured interviews with hospital staff
* 12 interviews with RFID company vendors from 7 companies working with the 23 hospitals
* 1 interview with a patient
* analysis by multi-staged coding
 |
| (103) Coveney et al. (2011) | UK | Neurotechnologies | To investigate the social and ethical context and discourses of the use of neurotechnologies to regulate sleep and enhance cognition in the UK. Modafinil is used as a case study. | No | Methods:* 1st phase, 77 UK news articles and 2nd phase, 40 semi-structured qualitative in-depth interviews (face-to-face or phone)
* analysis by applying an analytical framework informed by Science and Technology Studies
* Grounded Theory for analysing the interviews
* discourse analysis (framework and metaphors) applied in the media analysis
* results of the discourse analysis fed into the interviews (as a kind of scenario development)
 |
| (104) Milligan et al. (2011) | UK | Telecare | To investigate the way telecare changes the way older peoples’ care experiences at home. | No | Methods:* 8 ethnographic interviews with telecare users
* 10 interviews with 10 key actors from social care
* 8 panel discussions incl. 8-10 participants (duration: 3-5h)
* observation of telecare installations/ telecare monitoring centres/ telecare promotional events
* thematic analysis
 |
| (105) Sockolow et al. (2011)(106) Sockolow et al. (2012) | USA | Electronic health records | To assess an interdisciplinary team of clinicians’ satisfaction with electronic health records (EHR). | NoNo | Methods:* two time periods (prior and after EHR implementation)
* evidence-based framework (Health Information Technology Research-based Evaluation Framework (HITREF)) guided assessment of clinician satisfaction (two time periods; 11 and 17 months after EHR implementation)

Methods:* clinician satisfaction survey – application of the survey described in Sockolow et al. 2011
* observation of clinicians
* follow-up interview with clinicians
 |
| (107) Youl et al. (2011) | Australia | No specific technology | The study aims at understanding associations between breast cancer recurrence in Australian women, survival and psychosocial outcomes with a focus on individual and rural factors.  | No | Methods:* longitudinal study design
* structured telephone interview (CATI) and self-administered questionnaire at two times post diagnosis, both aiming at collecting qualitative and quantitative data
* medical information from registries and national and hospital databases
* area-level data accessed through national bureau of statistics
 |
| (108) Trudel et al. (2012) | Canada | Information technologies’ performance in health care systems | To investigate the influence of the concept of mindfulness on the success or failure of information technologies’ performance in health care systems.  | No | Methods:* observations
* informal interviews during observations of the physicians using PACS
* 12 semi structured in-depth interviews (average duration: 60min)
* analysis of hospital documents (annual reports, internal newsletters, press releases etc.)
* reconstructing of case narrative and comparative coding approach
* triangulation of the different data sources
* validation of case study reports
 |
| (109) Rijken et al. (2012) | Thailand | Routine obstetric ultrasound | To investigate perspectives on routine obstetric ultrasound in a displaced Burmese patient population for the improvement of health promotion instruments.  | No | Methods* 30 observations
* 19 interviews based on observation results
* 7 focus group discussions
* quantitative survey based on the interview and focus group results
 |
| (110) Ripat & Woodgate (2012) | Canada | Assistive technologies (AT) | The study aims at understanding how AT contribute to participation from the perspective of individuals with spinal cord injuries as well as at revising the definition of AT. | No | Methods:* Grounded Theory approach
* in-depth interviews with 19 adults with a spinal cord injury
* Photovoice (Wang and Burris, 1997) to capture the insider perspective of the participants on the concept of participation (participants were ask to take pictures in their own surroundings)
* participants chose photos and brought them to a second interview
* coding approach
* triangulation of all data resources
 |
| (111) Rosenberg et al. (2012) | Sweden | Supporting technical devices | To explore the perspective of significant others of people diagnosed with Dementia on supporting technical devices. | No | Methods:* Grounded Theory approach
* 8 interviews
* 5 sessions with 3 different focus discussions building up on the conducted interviews
* coding approach following GT, focused coding of the interviews after analyzing the focus group data
 |
| (112) Pottinger & Palmer (2013) | Jamaica | IVF | To compare parents who were assisted by IVF/ICSI with parents who conceived spontaneously (SC) for differences in parenting anxiety, perceived burden of having a child and parenting styles as well as the cognitive and social-adaptive development of the children. | No | Methods:* semi structured interviews and cognitive tests were conducted
* for parents: a) The Parenting Style Quiz, a 30-item self-report questionnaire measuring beliefs and practices, b) the Impact on Family Scale, a 24-item scale measuring the impact of an event on four components of family life, c) the Dyadic Adjustment Scale, which is a 7-item instrument measuring marital or partner adjustment
* for children: the Vineland Social and Adaptive Scales, Interview Edition and a standardized cognitive test (The McCarthy test of Children’s Abilities) – containing a range of puzzles, toys, and game-like activities
 |

# Supplementary Table 5: Combined methodological approaches

The two checklist applications presented in table 1 combine different methodological approaches. To ensure a good overview we decided to list studies and the related applications together. However, the checklist applications need to also to be taken into account in the fifth group.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Author,(year) | Country | Health Technology | Objective/topic | HTA-context  | Source of data and method |
| (113) Kelty (1978) | USA | No explicit technology | To analyse value-laden problems and policies.To elicit public attitudes towards advances in biomedical and behavioural research and technology and to suggest alternative policies to deal with them. | Yes | Methods: * policy study: national panel of consultants (120 panellists), modified Delphi method, 3 structured inquiries by mail, anonymity was protected
* national opinion survey: random sample of 1679 US adults and the panellists, structured questionnaire
* colloquium of scientists and scholars: case-study-method to capture historical and sociological perspective, participants explored the social impact of advances and examined existing legal and institutional constraints and incentives governing the introduction of new technologies into medical practice.
 |
| (114) Canadian Public Health Association (2001)(115) Einsiedel & Ross (2002) | Canada | Xenotransplantation | The views of Canadians will help to guide the future development of government policy on xenotransplantation. | NoNo | Participants: - randomly chosen 2500 citizens received an invitation to apply- of these a group of 20 volunteers for each fora was chosen (regarding gender, age, mother tongue, urban/rural location, occupation)Method:- Canadian public consultation consisting of National telephone survey, web-based questionnaire, stakeholder survey, other input- Meeting “Citizen forums” over 2 days: - consultations in 6 regions- at each forum 15-23 citizens- expert panel presentation- reading materials before the forum, “orientation dinner”- first day: experts representing a variety of viewpoints on xenotransplantation would give a presentation, second day: citizen panel discussions without experts in small groups and in the plenary with the facilitator, development of key recommendations |
| (121) Neven (2010) | The Netherlands | A robot intended to enhance the health of elders | The study investigates interactions between robots (iRo) – developed to enhance the health of elder people at home, elder test users and robot designers. It aims at collecting information about definitions of health, ideas about ageing, and related images of shaping the technology. | No | Methods:* 2 qualitative semi-structured in-depth interviews with researchers
* observation of test users of iRo
* literature review (for iRo-researchers and fieldwork in peoples home)
* literature review: analysis of images of users in research documentations and publications on iRo produced by the research team
 |
| (122) Bombard et al. (2011)(123) Abelson et al. (2013) | Canada | No specific technology | The study’s objectives are 1) to elicit citizens’ social and ethical values related and 2) to test the feasibility of participatory approaches in HTA. | YesYes | Methods:* 14 citizens were randomly identified and build the Citizens’ Reference Panel on Health Technologies with the objective to provide ethical and social recommendations
* using a mixed methods approach discussions between panellists were transcribed and analysed using Content Analysis
* panellists additionally answered a questionnaire addressing the importance of values and their stability prior to and after the meeting
* data and results from the qualitative and quantitative part were combined and sent to the panellist for validation and for weighting the importance of the identified values
 |
| (124) Hogarth et al. (2012) | USA | HPV testing, the pap smear and the molecularisation of cervical cancer screening | To extend the concept of molecularisation in the context of screening programs using the DNA-based molecular testing for human papillomavirus as a case study.  | No | Methods:* exploratory literature searches to reveal key stakeholders (sources including e.g., patents, statutory filings by companies, scientific literature and news sources)
* identification of interviewees by using the results of the literature search
* 12 semi-structured interviews (duration: 40-150 min)
* triangulation of the data and results from the different sources
 |
| (125) Chidzambwa (2013) | UK | Telecare | The study aims at providing information about dealing with social aspects when designing telecare. | No | Methods:* four study phases: 1. Literature Review, 2. Pilot study, results of phase 1 and 2 were used in phase 3 the development of the framework, 4. validation
* 1. Literature review: more than 200 articles to understand the context of telecare
* 2. Pilot study and validation: collection of primary data to understand design and implementation process from a user perspective; methods applied: 14 observations, 10 semi-structured interviews (duration: 40min-1h)
* Delphi Study for the validation of the framework using 2 different questionnaires
 |

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