**Supplementary Table 1:** MEDLINE search strategy

Search date: March 2, 2017

Database(s): Ovid MEDLINE: Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE® Daily and Ovid MEDLINE® 1946-Present
Limits: English language, 2000 - Current

**Search Strategy:**

|  |  |
| --- | --- |
| **#** | **Searches** |
| 1 | socioeconomic factors/ or sociology, medical/ or public opinion/ or personal satisfaction/ or social perception/ or exp attitude to health/ or exp community participation/ or consumer behavior/ or (((public or consumer? or patient? or citizen? or user? or end-user? or individual? or personal or (interest adj2 group?)) adj4 (need? or perspective$ or priorit$ or empowerment or engag$ or value$ or particip$ or demand? or input? or experience? or choice? or opinion$ or attitude? or advocac$ or panel? or referendum? or survey or co-creat$ or co-construct$ or centered or oriented)) or "participatory perspective?" or patient-facing or patient-related or social or societ$ or sociolog$ or socioeconomic$ or socio-economic$ or ("social constructivist" adj4 technology) or (living adj3 (quality$ or standard?)) or inequalit$ or techno-anthropolog$ or sociotechn$ or (socio-technical adj2 (perspective$ or practice?)) or (technolog$ adj2 mediat$ adj2 relation$) or (("Human Factor?" or HF) adj2 method?)).tw. |
| 2 | jurisprudence/ or legislation as topic/ or liability, legal/ or intellectual property/ or confidentiality/ or guidelines as topic/ or lj.fs. or (legal cases or legislation or guideline?).pt. or (law? or justice or jurisprudence or legal or "regulatory requirement?" or contract? or legislation or "government? regulat$" or judicial$ or juridic$ or medicolegal or (legal adj2 (brief? or case?)) or ordinance? or regulation? or accountability$ or negligence? or liabilit$ or "intellectual propert$" or privacy or confidential$ or "personally identifiable information").tw. |
| 3 | exp ethics/ or exp ethics, professional/ or exp human rights/ or exp informed consent/ or exp patient rights/ or prejudice/ or morale/ or morals/ or religion/ or disclosure/ or self disclosure/ or mandatory programs/ or exp anthropology/ or exp psychology/ or "religion and medicine"/ or commodification/ or dehumanization/ or health care rationing/ or health services accessibility/ or health equity/ or proxy/ or social values/ or truth disclosure/ or altruism/ or decision making/ or decision making, organizational/ or "compassionate use trials"/ or e.sb. or eh.fs. or px.fs. or es.fs. or (((ethic$ or bioethic$) adj3 (issue? or situation?? or value? or aspect? or research or principle? or privacy or biomedic$ or health care or healthcare or clinical or code? or directive? or analys$ or review? or consultation? or consultant? or committee? or institutional or organizational or hospital? or professional or medical or dental or nursing or pharmac$ or assessment-model or assessment? or judgment? or evaluation? or estimate? or governance or responsib$ or attitude? or "public opinion?")) or (right? adj3 (human? or "wom$n's" or reproducti$ or patient? or "patient's" or "patients'" or treatment? or die or death)) or (moral? adj3 (polic$ or complicit$)) or (natural adj3 law?) or (interest? adj3 conflict?) or (consent adj3 inform$) or prejudice$ or moral? or religion? or inequalit$ or (interest adj2 group?) or disclosure? or "self disclosure?" or ethic$ or bioethic$ or (social adj2 justice) or metaethics or casuistry or anthropolog$ or psycholog$ or sts or "science and technology studies" or "science, technology and society").tw. |
| 4 | (ELSI or ELSIs or "ethical-legal-social issues" or (ethical adj2 legal adj2 social adj2 issues)).tw. |
| 5 | quality of life/ or exp health status/ or ((qualit$ adj2 (life or ("activities of daily" adj (life or living)))) or (health-related adj3 (qualit$ adj2 life)) or HRQL or HRQOL or "quality-of-life weights" or "well being" or wellbeing or wellness or "subjective well-being" or (health adj2 (level or status or good)) or healthiness or (functional adj2 (ability$ or assessment))).tw. |
| 6 | utilit$.tw. |
| 7 | 5 and 6 |
| 8 | patient preference/ or exp patient satisfaction/ or ((health adj2 utilit$) or (patient adj preference?) or (preference adj2 measure?) or preference-based or "preference elicitation" or "patient reported outcomes").tw. |
| 9 | social values/ or social norms/ or value of life/ or ((value? adj2 (social or orientation?)) or (life adj2 (valuation or value?) adj2 economic) or (norm? adj2 (social or societal))).tw. |
| 10 | 1 or 2 or 3 or 4 or 7 or 8 or 9 |
| 11 | \*technology assessment, biomedical/es, lj, mt, og, ut or (((assessment? or appraisal? or overview? or review or diffusion) adj2 (technolog$ or drug? or medicine? or vaccine? or treatment? or pharmaceutical? or device? or therapeutic$)) or HTA?).tw. or (health adj2 technology assessment).jw. |
| 12 | 10 and 11 |
| 13 | limit 12 to (english language and yr="2000 -Current") |

Supplementary Table 2: Examples of consolidation of ideas from the literature and brainstorming session

|  |  |
| --- | --- |
| Ideas from the literature and brainstorming | Consolidated items |
|  |  |
| out-of-pocket cost | additional financial costs to patients or family |
| financial costs to patients |  |
| financial worries |  |
| financial reimbursement |  |
| additional costs to patients or family |  |
|  |  |
| physician-patient trust | physician-patient relationship |
| physician-patient relationship |  |
| prefer face-to-face contact |  |
| interaction/relationship with health care provider |  |
|  |  |
|  |  |
| the technology itself may be a burden | ease of use; usability |
| patients' motivation & ease of use of technology |  |
| usability = effectiveness, efficiency, satisfaction |  |
| learnability = easy to learn |  |
| convenience |  |
| ease of use, easy to access |  |
| complexity and burden of technology or treatment |  |
|  |  |
| religious, social, cultural convictions | cultural beliefs and norms |
| religious beliefs |  |
| social norms |  |
|  |  |
| discrimination concerning test results (employment, insurance) | discrimination because of genetic test results |
| discrimination by employers, insurance, schools |  |
| social stigmatization related to genetic test results |  |
| discrimination based on test results |  |
| insurance companies are against genetic anti-discrimination because they do not want to insure genetic hi-risk patients |  |
| employers are concerned that workers will sue them for not providing insurance coverage or not hiring them |  |
| genetic test discrimination |  |

Supplementary Table 3: Characteristics of study participants

|  |  |  |  |
| --- | --- | --- | --- |
| Characteristic |  | Frequency | % |
| Type of work (more than one answer was permitted) | academic | 15 | 20.55 |
|  | clinician | 4 | 5.48 |
|  | researcher | 26 | 35.62 |
|  | patient advocate | 1 | 1.37 |
|  | student | 8 | 10.96 |
|  | public sector worker | 1 | 1.37 |
|  | government employee | 2 | 2.74 |
|  | industry employee | 1 | 1.37 |
|  | nursing | 0 | 0 |
|  | public health | 2 | 2.74 |
|  | health care | 7 | 9.59 |
|  | other | 6 | 8.22 |
|  |  |  |  |
| Gender | Female | 24 | 63.16 |
|  | Male | 14 | 36.84 |
|  |  |  |  |
| Age | 40 years of age and younger | 17 | 44.74 |
|  | 41 to 55 years of age | 17 | 44.74 |
|  | 56 to 65 years of age | 3 | 7.89 |
|  | 66 years of age or older | 1 | 2.63 |
|  |  |  |  |
| Area of expertise (more than one answer was permitted) | Ethics or bioethics | 3 | 4.84 |
|  | Health technology assessment | 26 | 41.94 |
|  | Economics or health economics | 18 | 29.03 |
|  | Medicine | 6 | 9.68 |
|  | Law or legal issues | 0 | 0 |
|  | Social science | 6 | 9.68 |
|  | other | 3 | 4.84 |