

Supplement 1: Code families, codes and quotations¹

Code Family 1: Criteria for screening

Codes (19): [criteria for screening: false positive is a reason to start w/ few conditions] [criteria for screening: early detection and effective treatment, severity] [criteria for screening: false positive caused delay in reporting and community lack of trust] [criteria for screening: good essay, reliability] [criteria for screening: importance of quick dx and confirmatory testing] [criteria for screening: international] [criteria for screening: low % false positive] [criteria for screening: move from prevalence to severity and psychological stress] [criteria for screening: move from treatment to counselling] [criteria for screening: pilot study] [criteria for screening: rarity of conditions complicates justification] [criteria for screening: specificity and sensitivity] [criteria for screening: different panels to different populations] [criteria for screening: donors' interests] [prevalence: important to epidemiologists] [prevalence: high/knowledge about justify/affects the screening panel] [prevalence: purpose of screening] [purpose of screening dx and treatment] [treatability: of conditions detected]

Quotation(s): 64

Code Family 2: Decision/policy making issues

Codes (36): [centralization of program: in favor] [centralization of program: not for follow up] [centralization of program: against] [centralization of program: the opposite] [cut-off levels: changes in order to detect certain variants] [cut off levels: technical issue?] [Cut off levels: differences between states/countries] [Decision making process: philosophical aspect neglected] [Decision making process: towards implementation] [Evolution of program ambiguity: decision making re implementation] [Evolution of program ambiguity: panel of conditions] [evolution of program ambiguity: reporting of results] [evolution of program ambiguity: American consultation] [Evolution of program ambiguity: decision making mechanism re implementation] [evolution of program ambiguity: of schedule] [evolution of program: ad hoc committees] [evolution of program: adding conditions gradually] [evolution of program: advocacy groups are

¹ The number of codes classified under each family appears in round brackets; the codes classified under each family appear in square brackets, total number of quotations appears at the end of the code family

not active in NBS] [evolution of program: history] [evolution of program: no sufficient evidence base for justification by ad. com] [evolution of program: advisory committee role and consistency] [evolution of program: biochemistry and DNA banking] [expansion: bottom up] [expansion: need for] [expansion: timing] [mechanism for determination of conditions in panel] [pilot testing: details about] [pilot testing: is unnecessary] [pilot testing: was unethical] [pilot testing: hard to go back] [pilot testing: reasons to stop] [public interest more important than the individual] [storage of bloodspots for quality control] [storage of bloodspots: for future medical treatment of the newborn] [storage of bloodspots: future use only for NBS research purposes] [storage of bloodspots: on identifiable bloodspots]

Quotation(s): 192

Code Family 3: ELSI & Cultural, economical, and political issues

Codes (40): [benefit to society] [benefit to society: not in rare conditions] [benefit to society: public awareness of genetic disorders] [benefit to the baby] [benefit to the family] [benefit to the family: reproductive decision making] [benefit: broadening the concept] [comparison to vaccination] [cultural aspect: awareness in prenatal vs. no interest in post-natal] [cultural aspect: deliberate non planning] [cultural aspect: donation for a state in war situation, limited resources] [cultural aspect: less formality, direct contact] [cultural aspect: setting up the booth...] [cultural aspect: hardship of life in Israel] [economical aspect: use of money for other purposes] [economical aspect: screening is cost effective] [education for professionals] [evolution of program ambiguity: panel of conditions] [evolution of program ambiguity: reporting of results] [evolution of program ambiguity: of schedule] [expansion: need for] [IC: currently no requirement] [IC: is not a realistic requirement] [IC: it depends on us when we are ready to provide the public with knowledge] [IC: less strict than U.S.] [IC: liability] [IC: opting out] [IC: the program will require it when it is time] [IC: when should we obtain it?] [IC: who should obtain it?] [legal aspect National Health Insurance Law & health basket] [pilot testing: was unethical] [political aspect: need for consultants for the screening directorship] [political aspect: need for collaboration] [political aspect: resentment of interviewee] [program temporality] [social aspect: NBS improves equity] [social issues: stigmatization] [technology: drives policy] [uncertainty of results]

Quotation(s): 210

Code Family 4: Exchange of knowledge issues

Codes (12): [American influence] [American influence: criticism of] [American influence: paternalism] [centralization of program: against] [evolution of program ambiguity: reporting of results] [evolution of program: advocacy groups are not active in NBS] [international experience] [international experience: we are following] [international experience: we should follow] [public awareness: gene-environment interaction] [public awareness: neonatal vs. prenatal] [public interest more important than the individual]

Quotation(s): 94

Code Family 5: Routinization of new technology

Codes (15): [expansion: bottom up] [expansion: need for] [expansion: timing] [mechanism for determination of conditions in panel] [pilot testing: details about] [pilot testing: is unnecessary] [pilot testing: hard to go back] [pilot testing: reasons to stop] [program functioning: disorganization] [technologies used by the Israeli program] [technology: drives policy] [technology: routinization of new technologies] [upgrading system] [upgrading the system: computation and website] [upgrading the system: non identifiable barcode]

Quotation(s): 93

Code Family 6: Uniqueness and Challenges of program

Codes (21): [challenges of program: adapting the screening to the state and data] [challenges of program: avoiding over treatment] [challenges of program: dealing with uncertainty by international experience] [challenges of program: handling false positive] [challenges of program: maximal treatment and minimal parental stress] [challenges of program: no metabolic specialty] [challenges of program: uniform panel] [challenges of program: follow up after detection] [challenges of program: higher standard of ethics] [challenges of program: need for consultation to deal w/ uncertainty] [challenges of program: need for resources] [challenges of program: resources for follow up] [challenges of program: no complicated questions as opposed to personalized medicine] [challenges of program: locating patients] [uniqueness of program: gaps between the center and periphery] [uniqueness of program: heterogenic communities] [uniqueness of program: quick delivery of bloodspots] [uniqueness of program: small country single lab] [uniqueness of program: tailored to different regions/communities] [uniqueness of

program: highest number of Metabolists/geneticists/pediatricians] [uniqueness of program: no responsible pediatrician for newborn]

Quotation(s): 57