

Box 1.: Suggested required core data set for family health history representation in the electronic health record [3]

Individual

Identification: individual and relatives

Age

Date of death/age at death, cause of death

Ethnicity/race

Biological sex, identification of biological parents

Multiple birth status, consanguinity, adoptive status

Disorders: context-specific, taking account of intended end user and life stage of patient

Research identifier placeholder (if part of data bank/research protocol)

Relevant genetic/genomic test results

Data field for “unknown”: to denote that question was asked but answer not known

Approximate dates/ages for data fields

Sensitive fields

“Certainty of data”

Integration with other electronic/personal health record elements

Ability to define data sharing status

Family

Data representation: to allow generation of pedigree using standardized graphical nomenclature

Relatives: a minimum of 1st and 2nd degree relatives

Box , Wilson BJ; supplement material

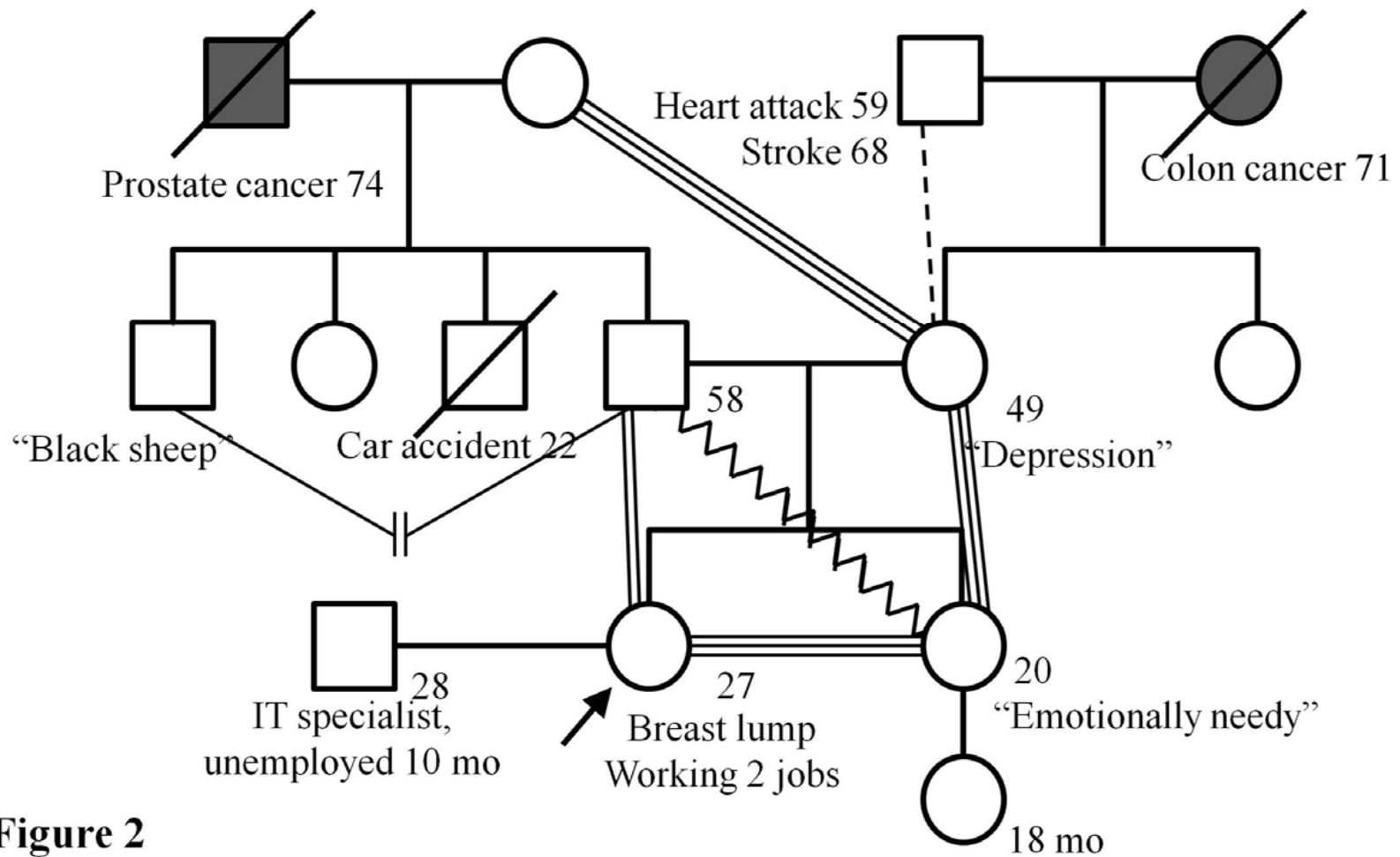


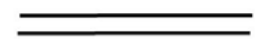
Figure 2

Figure 2, Wilson BJ

Legend



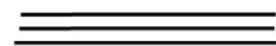
Cancer diagnoses



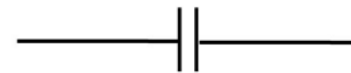
Close



Conflictual or poor



Very close



Estranged or cut off



Distant

Figure 2:

Example of family systems genogram, with explanation of lines drawn to represent nature of relationships [42]

Figure 2 legend and heading, Wilson BJ (Supplementary Material)