Minimum Data Set

Recommended data set for DNA

Minimum data set (data without asterisks should be provided to users)	Recommended data set
• **Identification of depositor*.** • **Identification of number of the family*.** • **Identification of number of the patient/participant*.** • Identification of number of the biospecimen. • Consent/approval by a Human Research Ethics Committee (Y/N) (include HREC Approval Reference Number). • Gender and age of patient/participant. • Pathology of family with Online Mendelian Inheritance in Man number (i.e. a database with represents a catalogue of human genes and genetic disorders). • Status of the biospecimen (eg affective, non-affected, indication of suspected diagnosis). • Date, year and month of the collected material. • Nature of the biospecimen where DNA was extracted from (e.g. affected, non-affected). • Preservation or storage conditions. • Quantity of biospecimen: ○ For DNA: concentration of µg/µl and number of µl.	• Consent. • Family tree. • Samples from relatives available. • Form of supply. • Maximum delay for delivery (linked to the nature of a given biospecimen). • Karyotype. • Quantity of families and subjects available for the specific disease. • Detailed information of treatment/medications. • Information on disease outcome. • Associated clinical data (eg laboratory parameters, imaging data, molecular data. • Information on life style. • Information of family history. • DNA finger printing or another method of authentication. • Hazard status.

Data set for tissues and isolated cells

Minimum Data Set (data without asterisks should be provided to users)	Recommended data set
• **Identification of depositor*.** • **Identification of number of the patient/participant*.** • Identification of number of the biospecimen. • Consent/approval by a Human Research Ethics Committee (Y/N) (include HREC Approval Reference Number). • Gender and age of patient/participant. • Disease diagnosis. • Status of the biospecimen (eg affective, non-affected, indication of suspected diagnosis, indication of grade of tumour). • Origin of the biospecimen (organ and tissue). • Date, year and month of the collected material. • Hazard status. • Nature of the biospecimen (eg tissue, slide, cells and pellet). • Documentation on processing method (eg chemical preservation). • Preservation or storage conditions (eg liquid nitrogen, -80^{o}C, room temperature).	• Consent. • Details of diagnosis. • Related biospecimen (eg DNA and biopsy) • Quantity or concentration available. • Characteristics of the sample (eg sample composition, content of tumour cells). • Delay of freezing. • Form of supply. • Maximum delay for delivery (linked to the nature of a given biospecimen). • Information on treatment/medications. • Information on disease outcome. • Associated clinical data (eg laboratory parameters, imaging data, molecular data. • Information on life style. • Information of family history. • DNA finger printing or another method of authentication.

Data set for cell cultures (cell line, primary cultured cells and transformed cells)

Minimum Data Set	Recommended data set
• Identification of depositor. • Identification of number of the biospecimen. • Consent/approval by a Human Research Ethics Committee (Y/N) • Gender and age of patient/participant • Disease diagnosis. • Type of cell line (cell line, primary cultured cells, transformed cells). • Origin of the biospecimen (organ and tissue). • Date, year and month of the collected material. • Hazard status. • Nature of the cells (eg epithelia, fibroblast, lymphocyte). • Culture condition (medium and subculture routine). • Preservation or storage conditions (eg liquid nitrogen, -80^{o}C, room temperature).	• Consent. • Details of diagnosis and outcome of disease. • Characterisation of cells (doubling time, tumourigenicity, karyotype etc.) • Related biospecimen (eg tissue, serum, DNA) • Quantity or concentration available. • Number of passage. • Form of supply. • Maximum delay for delivery (linked to the nature of a given biospecimen). • Detailed information on treatment. • Morphology and growth characteristics. • Reference paper (for cells lines). • DNA finger printing or another method of authentication.