the FORM

Section I: Ressources Questionnaire
(has URL)
— use boolean for Ys/No response.

- It's my choice for my child / person under my care
  to have genomic testing. (Ys / No).
  I [. . . . .] (parent's guardian / name); (ressource, Patient)
- Understand that my child's / the person under my care's)
  DNA will be tested by: (ressource, relatedPerson
                                    (observatio
  - Panel   - Exome   - Genome.   4 ress: valueSet / observah
- To look for changes in genes that may be associated with:
  [. . . . .] (condition or Clinical Indicat) — ressource: observation /
                                                          valueSet!

- About the test

- If provide consent to share my child's / person under my
  care's sample, genomic data, and related health informate
  for: Ressource: consent.
  - general research use   Ys / No
  - health / medical / biomedical research   Ys / No
  - research involving the following areas:
    specified disease [. . . . .]
  - future use is limited to research involving a
    particular gender [. . . .] or - male - female
      (Ys / No)   if Ys } - other: [. . . . .].
  - future use is limited to pediatric research.   yes / No.
    future use is limited involving a specific population. Ys / No.
               to research
      if Ys ; . . . .
    - future use is limited to data generated form
      sample collected after the following consent form date Ys / No

- I have had enough time to consider the informat*
in this consent form and have;

(consent): provision, actor, period, part of, based on: ...

  - had the opportunity to discuss genomic testing
  and its implicat* with a health professional. **Yes**/No
  - Been given access to information about
  genomic Testing.   **Yes**/No
  - Been able to ask questions until I am satisfied
  with the answers.   **Yes**/No
  - Been offered a copy of this consent form.   **Yes**/No

      Binary
      (handle info* sharing)

- I provide consent to have genomic testing
as summarised in these forms;

ressource/
Patient {

Child's name (patient)   Date of Birth   Parent's / Guardian's ID.

Parent's/Guardian's   Email/Address.
name (related
     Person)

}

Health Professional name   Health Professional ID.   ] Ressource:
                                                             - Practicioner
                                                             - Health Care Service

- The following individual can be given my child's / the
person under my care's results if I am unable
to be contacted:

contac
  • Contact name: ...   ] ressource/Observat*
                                     (related person)
  • " number: ...
  • relat* to the patient:

Section II: Research study. (ressource: locatz)
  - organization

- I confirm that i (ressource: consent).
  ↳ attribut: provision (can capture Yes or No)

- I've read this information statement and I understand its contents. Yes/No

- I understand what my child and I have to do in the study. Yes/No

- I understand the risks my child could face because of their involvement in this study. Yes/No

- I voluntarily consent for myself and/or my child to take part in this study. Yes/No

- I've had an opportunity to ask question about the study and I'm satisfied with the answers I've received.

- I understand that this study has been approved by a suitable human research.

- I understand I'll receive a copy of this informate statement and consent form. ↳ ressource: Binary

+ signature (ressource: generate Definition
              (extension attribut).