Sharing personal cancer genome data: a patient and researcher experience

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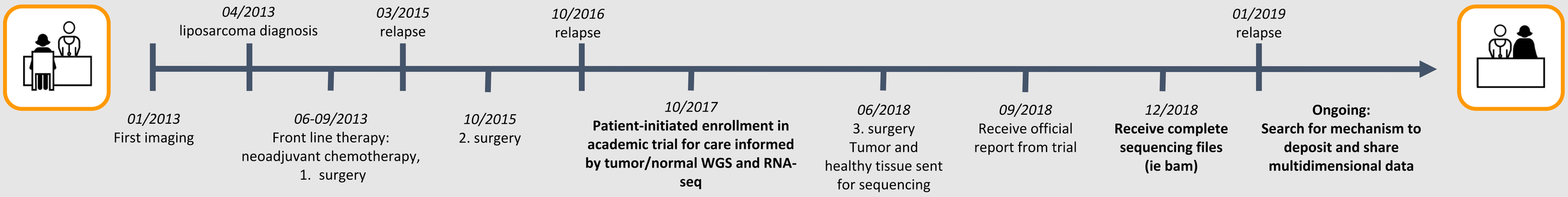
Once a patient with cancer obtains their own raw genomic sequencing data, what can they do with it? Where can they put the data such that it is findable and accessible by others? What rights do they have concerning ownership and control of data access? Can we envision a system in which patients are not only objects, but also partners in OMICS research?

Timeline



The Patient's perspective

- Can I only opt out of research programs/trials or also actively contribute to making research on my disease move faster? Instead of simply consenting to data-sharing, can I catalyze it?
- Willing to take on risks to make things go faster: "I have only one life"
- As a scientist, I know data is only useful if it is both broadly accessible and also findable. Can I deposit my data on platforms that scientists know and use? Do scientists have to go through time-consuming administrative work to retrieve the data?
- Do I have to allow completely open access or can/should some controls be implemented - in particular with respect to for-profit organizations?
- Interested in research focused on the individual patient - no time to wait for the assembly of a cohort, which can take years in case of a rare disease

The Researcher's perspective

- Am I allowed to accept and work on this data? Is the timescale of research compatible with that of a patient with a life-threatening disease?
- FS is a scientist and clearly well informed on risks and limitations, how do I guarantee this for other patients? Is consent different than for initial sequencing?
- Am I allowed to deposit it in platforms like EGA or dbGaP? Do I have the time to always get back to the patient (for updates, data sharing with collaborators…)?
- Do I need to formally collaborate with original sequencing institution? Is it different for sequencing performed in a research context or academic trial versus health-care system/standard of care/for-profit organizations?
- Can a cohort be achieved, in particular for rare diseases? Limits of personalized medicine: general principles need to be discovered for the system to remain sustainable

The repository we are looking for

- data is easy to find and access, but patient can control access
- able to integrate and link multidimensional data originating from the same patient: genomics, proteomics, but also medical records, imaging - anything the patient is willing to contribute over time
- patient remains part of the process: is informed on a regular basis about how data is used, how patient data is positioned with respect to the group analyzed
- patient can agree to be contacted
- sustainable and perennial

Suggestions? Please contact us!!

GDPR: privacy and portability

- EU GDPR (applied since May 2018) is multifaceted but, in our experience, current implementation is heavily focused on protecting privacy, which inherently limits data-sharing even by motivated patients and scientists. But can one size fit all, i.e. should the same laws be applied to situations as different as data on social media and health data of an incurable patient?
- EU GDPR also protects a right to data *portability.* Nonetheless, our experience shows that portability is not straightforward - even when both patient and data generator agree to it.
- In France, there is a constitutional right to protection of health. For diseases with no functioning therapy, is delaying actions which would work towards achieving this protection legitimate and sustainable?

Moving forward

- Important to distinguish question of whether and when to return data from what a patient can do with it once it's returned.
- Patient should have full rights for controlling sharing of their data once they receive it.
- Mechanisms to facilitate patient liberated data are particularly important when it is generated through healthcare system, as opposed to research.
- Functioning system should expect heterogeneity - in terms of diagnoses, assays, geography, etc
- Can patients and researchers team up to create an (if possible international) data repository? Who will fund it?

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