Who Owns a Patient's Clinical Data?

I've personally struggled with this concept for a long time. When i thought about it, the options i would come up seemed to be only 3:

1. Vendors: those who develop the systems that providers use to collect and store clinical data retrieved from patients.
2. Providers: the doctors who provide medical care also by collecting and storing patient's data in systems developed by the vendors.
3. Patients.

At the end, i came to the realization that, even though each one of these parties can have influence on the data itself, none of them are the actual owners of the data: clinical data is a human heritage and should be accessible to everyone.

And here's why none of the above options really convinced me.

Vendors

I have heard some stories where a product vendor holds the doctor hostage of clinical data: the doctor might not pay for the vendor's services any longer and the vendor, instead of simply interrupting its actual services, it also decides not to allow access to the clinical data to the doctor any more. My initial reaction to that has always been "hey, that's not ethical: the vendor's don't own that data, it's the practice's (or doctor's) data!". Yes, i feel strongly against this behavior.

Providers

Maybe doctors own the data they collect. After all, they have put in the investment of purchasing the hardware and finding the patients and actually collecting the data. But even this never felt quite complete, because what happens when the provider retires and doesn't really do anything with the data they collected? Should all that data get lost with him or her? Decades of hard work gone to waste? That doesn't seem quite right either.

Patients

So if the patient owns the data, then they would have to be the ones ultimately responsible for it's integrity and safety. Certainly they could allow others to take care of it for them, however it could be hard to make sure that the entire medical record remains "in one piece". What if the patient accidentally or purposely deletes parts of the medical record?

So after a lot of struggle with this, i decided to tackle the problem starting from first principles. And i came up with this list:

- Everyone wants to suffer less.
- Illness, pain and death are most commonly associated with suffering.
- Humanity is striving to reduce its diseases, physical pains and to elongate its lifetime.
- Medicine has provided ways to fight diseases, reduce pains and increase life expectancy.
- Improvements in the medical field require lots of scientific research.
- Scientific research requires lots of clinical data.

If the above points hold true, then it follows that there is a direct correlation between human suffering and clinical data. Which means that

> **Lots of Clinical Data Help Humanity Suffer Less**
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> So at this point it became pretty apparent to me that clinical data is a human's heritage and should be therefore available to anyone for research or patient's care purposes, provided the datum consumer is not ill-intended.

Certainly patient and provider should have a say as to who should have access to which part's of the data, and if the data should be able to identify the patient or not. In some cases, it is best if the patient is not aware of some opinions, thoughts or discoveries of the medical provider yet. Similarly, a patient might not want to fully trust a specific medical provider or for some other reason want to just give access to a partial subset of his or her clinical data to a provider. However these configurable permissions should not stop the data from being anonymously, globally and forever available. Besides, isn't this what humanity has always wanted? The ability to just walk into any medical provider's office without anything more than an ID, and allow them to access our medical records in order to provide medical care for us?

What remains now is figuring out a technology that can allow for all this to work. Up until 2008, the software we at our disposal was not able to provide a functional, reliable, secure, scalable solution to the problem. However, the invention of the Bitcoin has introduced the new concept of the blockchain, a technology which theoretically has all the physical capabilities to make the above concept become real. Now, just the fact that the technology is there, doesn't mean the problem has been solved: after all, we also currently have the technology to colonize Mars. That doesn't mean we can colonize Mars without putting in some serious work. And serious work is required in the medical field as well, before we can manage to make this technology become widespread.