

Is that okay if we reuse your health data?



Oh my! Looks like they want access to our health data!

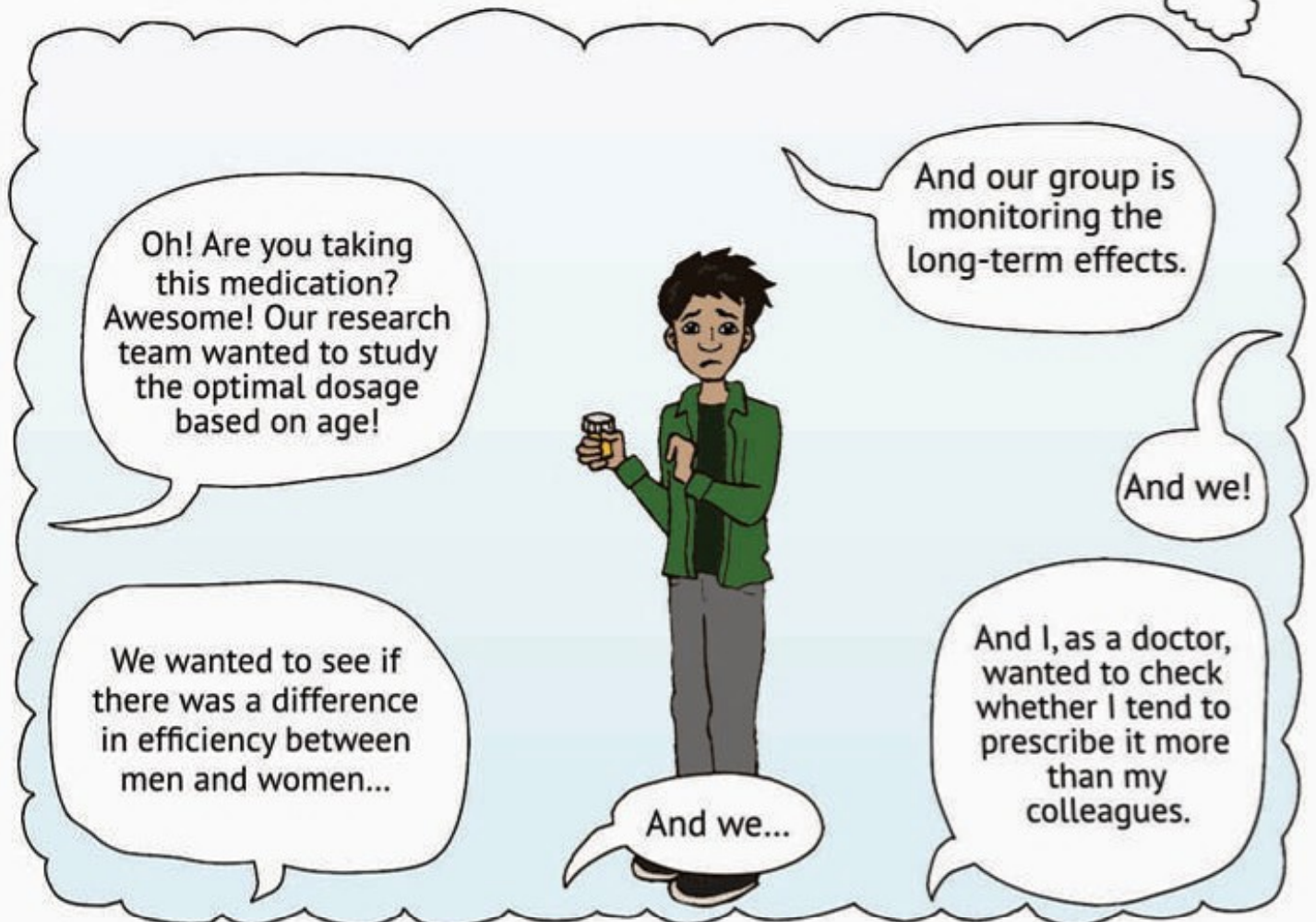
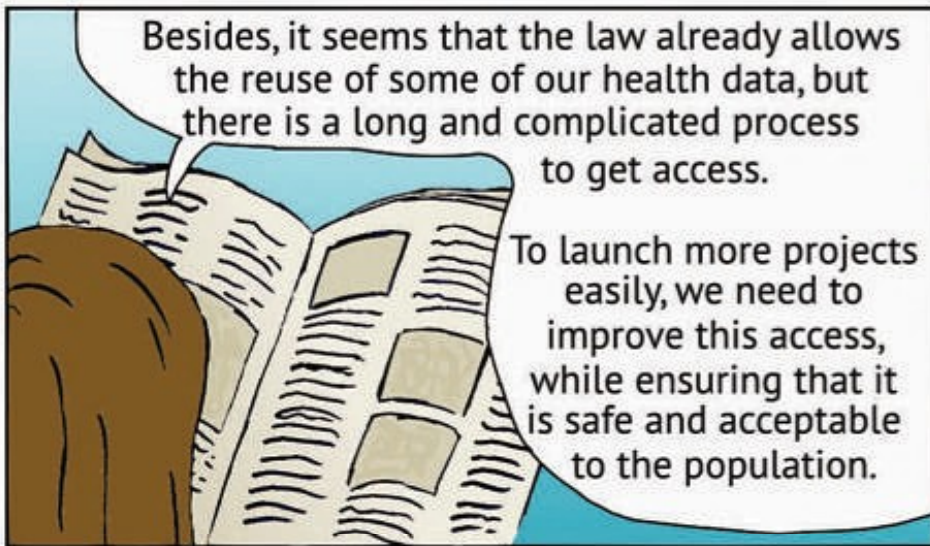
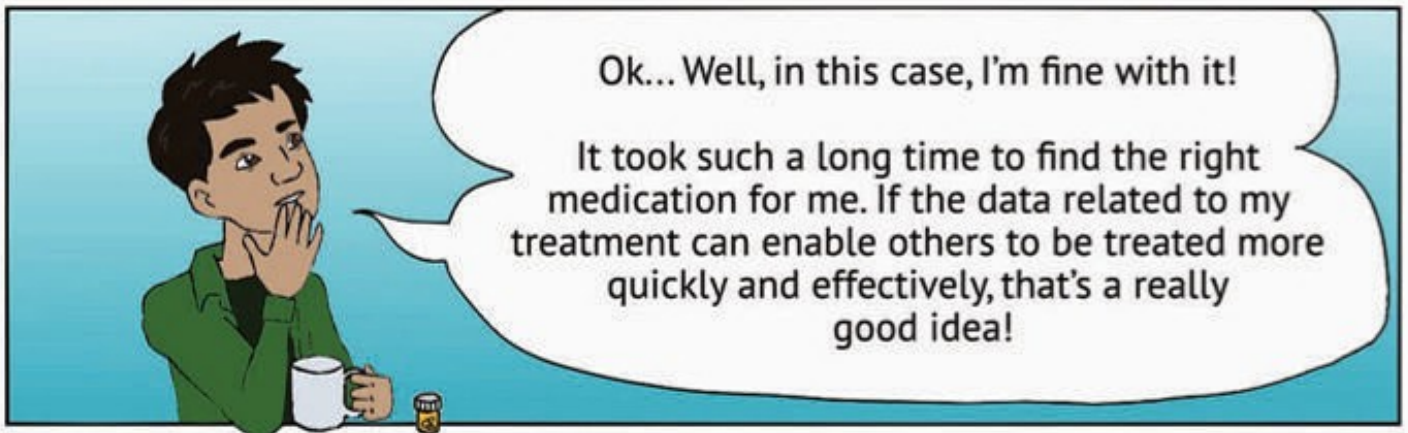
Everything that is generated when we go to the hospital, the clinic or the pharmacy... It could be reused after being used for care.



What!? It's private! And I don't want pharmaceutical companies to make a profit out of accessing my personal data, it's mine! And then, insurance companies might as well sneak into it?



Oh, wait! It says here that there would be a whole framework for this to be done in a safe and limited way. Basically, it's to enable research teams to make new discoveries and medical staff to improve their practices.



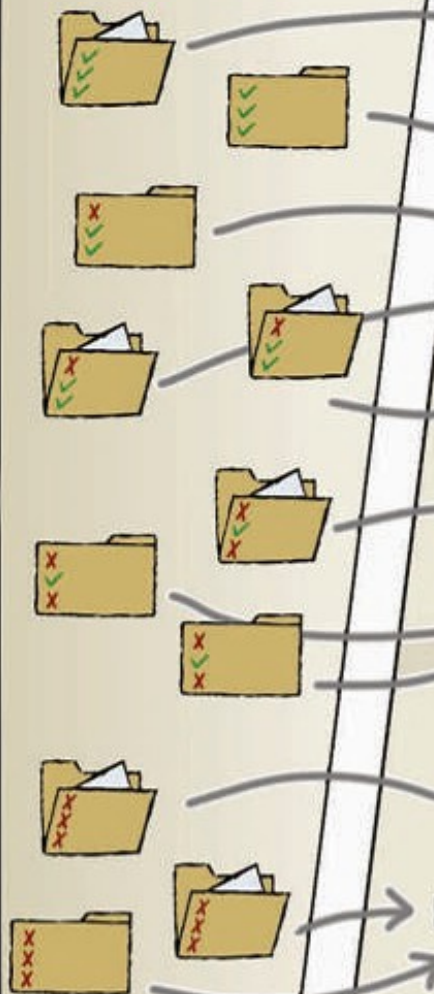
Yes and no. The CLARET research team at the *Université de Sherbrooke* is proposing a "meta-consent" model which is, in other words, a way to consent to several projects at once rather than one project at a time. This would be done via a portal. Look, it's explained here...



Characteristics are identified for all projects, such as: whether the data remains in Canada, whether the information is anonymized, or whether the use is not for profit...

Then, projects are grouped into families that share the same characteristics ...

On the portal, we can then indicate our consent for each family:



Green light - I agree to share my data for this family;



Yellow light - a priori, yes, but I want to be able to refuse certain projects of this family (opt-out);



Orange light - a priori, no, but I want to be able to accept certain projects of this family (opt-in);



Red light - none of the projects in this family can use my data.

In this way, everyone has full autonomy over the reuse of their health data.



The CLARET research team is also looking into the accessibility of the portal, to ensure that it reaches the full diversity of Quebec's population. The team also wants to integrate transparency tools, as people want to know how their data has been used and what the results are.

Oh, it's not related, but while I'm thinking about it: my mother would like us to go out to the movies every month, would you like to join us?



Hmmm...A priori, no, but let me know about each movie you choose, in case I want to go sometimes.



So it's an orange light of meta-consent, noted, hahaha!

For more information:
griis.ca/en/research/claret/

Translation of the popularized comic strip, scripted and illustrated by Dominique Wolfshagen

Thanks to the GRIIS members involved: Roxanne Dault, Frédérique Lévesque, Annabelle Cumyn, Jean-Frédéric Ménard, Maryse Couture and Jean-François Ethier. Thanks also to Karina Prévost and Denis Boutin, as well as to the Communication scientifique par la BD class (UdeS).

