Patient Explainer: Personal Data

“Data” is a term used to describe information that can be collected about a person when s/he is receiving treatment for drug-resistant tuberculosis. This information can be used in several ways. For example, it can be used by health care providers to determine what type of treatment is best. It can be used by clinics to know how to contact a person with test results. It can be used by people wanting to learn more about the way a drug works. Data about you belongs to you, and whenever it is to be shared with anyone, you should be aware of what is being shared, how it will be shared, and why it will be shared. That way, you can decide whether or not you agree to it.

Some data can be used to specifically identify who you are. This would include your full name, your address, or your phone number. Some data cannot be specifically used to identify you, such as how tall you are or what color your eyes are. It is important to make sure that data that could be used to identify you are protected in all circumstances.

In order to determine if one of the compassionate use drugs might be able to help treat your TB, your doctor, other health care providers, and the company that makes the drug will need to have access to some data about you. You do not need to provide any information to continue receiving TB treatment, but without data about your medical condition, health care providers may not be able to determine if the compassionate use drug might be able to help you.

While your own doctor will have information that could easily identify you (such as your full name, date of birth, and address), information about your medical condition can be shared in a protected way with others involved in the decision making and follow up of you while on the compassionate use drug. For example, your own doctor can provide your age, weight, lab test results, and other types of results to other health care providers and the drug company using only your initials. This is sometimes called “pseudonymized data”. Usually, this data is linked given a specific code number. A few people involved in your care may have a “key” in which the code number is linked to your full name, address, and/or phone number (or other information that could identify you). Sometimes, some of the data will be shared without any code number or key or anyway to link it back to information that could identify you. This is called “anonymized data”.

Most countries and companies have very specific rules that specify how data about you can be used, and you may be asked to sign a form stating that you understand this prior to being considered for a compassionate use drug. Remember, you have control over what data is shared about you.

Some words that may come up in the form about how your data will be used and protected are described in more details below.

- **Anonymized**: No information that could be used to identify you is provided and there is no key or code linking the shared information to information that could be used to identify you.

- **Code**: A group of numbers, letters, or a combination of numbers and letters which is assigned to you so that people cannot identify who you are.

- **Data**: Information.

- **Data transfer**: When information is shared between different groups of people. For compassionate use, this is only done with pseudonymized or anonymized data, unless specific permission is obtained.

- **Disclose**: To tell or share information with someone.

- **Identifying data**: Information about you that could be used by people to specifically know who you are, such as your full name, your address, and/or your telephone number.

- **Key**: A list of code numbers with links to identifying data.

- **Lodge a complaint**: To let someone know you have concerns about how your data are being used.

- **Personal data**: Information about you, including health information.

- **Portability**: Sending or transferring data from one place to another.

- **Pseudonymized**: A code number (or letters) are used to share the information about you and the shared information cannot identify you. However, there is a list that a few people have access to in which the code is linked to information that could identify you.

- **Rectification**: The process of correcting data or making it more clearly reflect the real information.

- **Restriction of processing**: To stop or limit how data are being used.

- **Retention**: How long data kept for.

- **Right to object**: The ability to ask to stop the use of your data.

- **Supervisory authority**: The group appointed by the government in your location who make the rules about how data can be used.

- **Withdrawing consent**: Removing the prior permission you gave to use your data.

Finally, if you reach out directly to the drug company that is making the compassionate use drug to report a problem, then they may need to collect information that could be used to identify you. If you go through your own health care provider, s/he will usually be able to share your code number with you so that you do not have to share identifying information with the company. You are free to share any information you like with the company, but that information could possibly be used to identify you, so it is important to consider this carefully.