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Establishment of data security, big data, seamless flow of data from the national registry to the international registry

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Data security is the nightmare of every CEO and every politician, a breach can bring the end to seemingly invincible multinational companies and to governments. Data that used to be safely and physically locked behind guarded doors to safe rooms is now sitting on a cloud somewhere, ready to be downloaded for any malignant purpose. However data is critical to success in health care at many levels.

Consider the World Marrow Donor program. If you are a potential recipient you need to be able to test you HLA typing result against all of the 40 or so million people registered to the bone marrow donor registries around the world. That check for potential donors needs to be in 'real time' and as fast as possible. What that means for you if you are a potential donors is that some critical information about you – your country of residence, age, sex, blood group, CMV and other viral test results and you HLA typing data, as well perhaps as weight – must be available all over the world. You must also be uniquely traceable from that data.

Consider also the Global Observatory on Organ Donation and Transplantation managed by the Spanish ONT and held by the World Health Organisation. Between 100,000 and 150,000 people are transplanted each year in the countries registering data and limited data such as which organ was transplanted and what gender the donor and recipient were is conveyed to the central database.

If we consider national registries we look to the SRTR in the US, ANZDATA in Australia and New Zealand for examples of registries that carry much more granular data on individuals that have been transplanted or are on waiting lists to be transplanted. These registries have different ways of retrieving data – from transplant units with voluntary or compulsory data entry.

Each of these examples has to resolve a number of data security issues to function successfully and securely:

1. Consent for having and holding individuals' data

2. Data retention and back up security
3. Data access 'cyber security'
4. Data integrity and completeness
5. Data analysis security
6. Data downloads and uploads

In order to flow data from a national registry to an international registry there are many barriers that relate both to security and to elements of privacy as well as national interest and reputation. What will data be used for? Who can be exposed by the presentation of data? Once data leaves a jurisdiction the level of control available on that data diminishes dramatically and that leads to a great reluctance to transfer data.

While the barriers are substantial, there are mechanisms to allow for successful achievement of major international goals without insurmountable opposition.