Advice on data sharing for multi-site studies

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- New legislation – the EU General Data Protection Regulation (GDPR) – has significantly changed the approach to data
- Old approaches to data sharing are no longer feasible
- Significant work must occur within each organisation to identify what can and cannot be done with the data
- "Localising" data so it never leaves the "data controller" may be the simplest and most rigorous approach to running multi-site educational projects

At the beginning of our SMERC small grant project – involving four partners – we identified that data sharing would be a major challenge. In particular, the introduction of the GDPR caused substantial changes on what it means to be a "data controller" and when and how the controller can *transfer* data.

Importantly, analyses that are essential – even legally required – may not be *transferrable*. An institution may support the work, ethical approval has been granted for the work, and students support the research. But, without explicit consent regarding data transfer it may be impossible to have a colleague at another institution undertake the analysis. Projects of the type we have collaboratively run for years may now be impossible to carry out.

This also creates significant problems if you have a multi-site study with different areas of expertise. While not a serious problem if collecting small amounts of data where each participant can manually opt in to data transfers, it is a significant challenge for projects with large amounts of data.

It is possible to establish whether data transference is possible by consulting your institutional policies on data protection and GDPR. This should **always** be done before committing to a research project. You can find example guidance from two partners here:

https://www.ed.ac.uk/records-management/policy/data-protection

https://www.dundee.ac.uk/information-governance/dataprotection/

It is extensive, but most organisations will have a designated staff member to help. In general, we have found most of the projects educationalist want to do are permitted internally, but they are unable to transfer the data out of their institution for any purpose.

Localising data analysis

One solution is for a designated staff member to sign an honorary contract with each partner. The feasibility of this needs to be established in principle before the work begins. Then, the staff member can carry out the analysis on each system (ideally via a VPN, so there is no need to physically travel).

This means that there *is* no data transfer – and any de-anonymised or sensitive data never leaves the data controller. Once summary analyses are complete these can be exported.

There are several technical challenges. The staff member will need to be inducted (and so complete necessary IT training etc.) and receive access to the appropriate tools and systems. They will also need to abide by local policies while doing the work. Lastly, the process of creating honorary contracts may be onerous for some organisations.

While cumbersome, this is a significantly simpler approach than trying to post-hoc convert data into something which can be transferred. In some cases, a research project may have to be discontinued where it is impossible to transfer data – unless localisation is possible.

Conclusions

We recommend the localisation policy described above. However, this is based on our – apparently successful – application of it, and we cannot guarantee it is extendable to all partners. It is not legal advice, and where appropriate we recommend seeking legal advice from your organisation. More generally, adapting to the new and more complex environment of data sharing is likely to take time and this needs to be built into grant applications and project work.

If you have questions or suggestions, please get in touch as this is likely to be a developing process for all of us.

David Hope March 2019