



PRIVACY COMMITTEE – 2014 REPORT

Dr. J. Stoffman (Chair)
Dr. S. Cloutier
Dr. M. Steele
Dr. A. Tinmouth
Dr. L. Jardine

The Committee did not have the opportunity to meet by teleconference over the past year. The major development has been progress with the privacy governance and framework being developed by Rachel St. John and Pamela Snively from AccessPrivacy, now with Osler Hoskin and Harcourt LLP:

Overall things are going well, and they have essentially completed the data gathering component of the project. Thanks to all the centers who were involved in speaking and meeting with Rachel and Pamela, particularly the Hamilton center and Arun and Aicha. What was clear from this process was that the definitive redevelopment of the CHARMS database has not yet been decided upon. As such, it is not possible at this time to prepare an inclusive privacy governance and impact assessment for a system which is continuing to evolve in its function and deliverables.

Privacy legislation in the different provinces has not contemplated the kind of data sharing that is taking place in CHARMS (the law is silent on the situation), and as such it is difficult to approach it in a way that will be legislatively compliant. A solution would be to properly anonymize the data, while maintaining its use to the AHCDC [Given our limited population base and small sample sizes, the EXID coupled with the other data points being requested (DOB and gender) render the data identifiable at law]. They have spoken with an academic expert in Ontario who has developed a software solution to address similar issues of anonymization that may be useful in our situation. These were fruitful discussions, and this may provide a potential long-term solution.

While the redevelopment of CHARMS continues, AccessPrivacy will develop a privacy framework that will satisfy our current activities, with the recognition that it will need to be adjusted and fine-tuned when the new database is ready for implementation. The policies and processes are currently in progress, and we will continue to receive regular updates. They are fully aware of the urgency of this process, and are working towards a quick but effective resolution.

J. Stoffman
Chair, Privacy Committee