Oregon Library Association Intellectual Freedom Committee Tuesday Topic, December 2018



Welcome to Tuesday Topics, a monthly series covering topics with intellectual freedom implications for libraries of all types. Each message is prepared by a member of OLA's Intellectual Freedom Committee or a guest writer. Questions can be directed to the author of the topic or to the <u>IFC committee</u>.

DNA Kits, Genealogy, and Privacy

Home DNA test kits are a <u>hot commodity</u> this holiday season. People are eager to learn more about their ancestry and family heritage, as well as genetic health risks and traits.

But there have been <u>concerns</u> raised over the privacy of these kits. For one, law enforcement agencies have been using genetic databases in combination with genealogical information to locate suspects. While this can lead to the <u>identification of criminals</u>, it has also led to <u>mistaken arrests</u> and concerns over what else this information might be used for in the hands of law enforcement agencies.

Another area of concern is health information. A <u>recent study</u> demonstrated that supposedly anonymous data from a public research project could be identified through a genetic database. Others worry that, despite the <u>Genetic Information Nondiscrimination Act</u>, there is not enough being done to protect people from medical discrimination based on genetics. [FYI, here are <u>Oregon's laws on the subject</u>.]

Of course, <u>issues of privacy are not new to genealogy</u>. But perhaps this is a good time of year for those of us in libraries to reflect on how we address privacy concerns in genealogy at our libraries. As Lisa Hoover wrote on the <u>ALA Intellectual Freedom Blog</u>, "Being aware of the potential privacy concerns will allow us to make sure genealogical research continues to be fun and safe for patrons – and their family members."

One thing to consider is whether your library includes discussions of privacy in genealogy programming and instruction. If not, think about including issues such as reading and understanding privacy policies (and the fact that they can legally change at any time); avoiding using family data in passwords or security questions; reading all of the terms and conditions before taking a DNA test; avoiding public disclosure of information about living people; and how to delete your DNA from genetics companies.

Another item to contemplate is whether your library includes a note on your website suggesting patrons read the terms and conditions and privacy policy of genealogy databases before using. Here is an <u>example from New York Public Library</u>. Along the same lines, think about whether you point out these things when working with a patron, before taking them to the resource.

So the next time a patron approaches the desk and asks for information on DNA test kits, what will you tell them? And just what *will* you say to that relative who asks you yet again this year to upload your information to their family tree? Perhaps it's time for a discussion about <u>how their decisions can impact</u> <u>other relatives as well</u>.

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