Privacy Implications: Case statement review


Introduction

1. Reads both very broad and very specific at the same time. Is the intent of the group to focus only on human subjects? Perhaps an "IRB for data" focus? (I think this may be addressed in the full statement, but it is not in agreement with the webpage?)

2. Consider restating the scoping statement, "as well as related datasets that have the potential to be combined in a way that can expose private information," to more clearly define and limit the potential datasets this group may be targeting.

3. The last sentence of the scope is very confusing. I am having difficulty separating the privacy of "data sharing" as it relates to repositories from the statement that the group is not interested in data publishing or data management related to same? Is the implication that there should be another WG focused on privacy as it relates only to "ethical, legal and data publishing issues surrounding research data sharing"?

4. Would encourage removal of the term "scientific", as oral history data sets frequently contain information of the type referenced here.

Objectives

1. Should various policy statements not also be reviewed along with legal frameworks?

2. It appears that the group intends to focus only on human subject data, maybe modify the group name to reflect this focus?

3. The objectives represent a shift away from the case statement language. The group is encouraged to clarify the scope.
   a. Where the introduction mentions a goal of appropriate management, the objectives address the goals in terms of legalities.
   b. Where the introduction refers to privacy-related concerns, the objectives focus on legal framework impact on data sharing.
c. The objectives do not mention the metadata development, listed as a goal within the introduction.

Participation

1. This group should consider requesting direct participation from the Legal Interoperability group, given the evident crossovers in goals, etc.

Outcomes

#1:
A. Is the expectation that this outcome will be more restrictive than current laws in each country? If not, would it be a restatement of existing laws?
B. Would encourage the group to develop this framework so that it is easy to consume as part of online training or training-resource websites.
C. Would encourage the group to consider the opportunities for integrating this framework into current education efforts for RDM.

#2:
A. This is much needed. Where do you plan on publishing these definitions? RDA-DFT term collection tool (TeD-T)? Other?
B. Many of these definitions of key vectors will be drawn from current law, where each political entity will have their particular perspective on the term. How will useful definitions be derived from these sources in a responsible manner?

#3:
A. Change "situations" to "example scenarios".
B. Allow yourselves some room, change “an outline” to “a presentation;” it may be that an outline is not the most useful format.
C. Would encourage the group to consider these as a set of practical implementations, and in that vein, consider developing them out as practical policy statements, based on the work done by the RDA-Practical Policy group.

#4:
A. This is much needed.
B. What is the easily consumable format & how will it be kept up-to-date?
C. How will the information (and metadata) deal with "XXX is a key vector, but country 1 ignores it and country 2 adds vector YYY, which is not considered a key vector"?

#5:
A. Consider this should be a superset or extension of an existing metadata standard and not a duplication.

#6:
A. Who is the intended audience for this campaign? Would encourage the group to include funders, institutions, scholarly organizations, and publishers in addition to researchers
and repositories as parties that may be interested in adopting or adapting the framework as requirements or policies.

Mechanisms & Coordination

No comment.