IG Ethics and Social Aspects of Data
25 September 2015- Working Session 9
Report made by Mersiha Mahmić-Kaknjo

Co-chairs: Kalpana Shankar and Candice Lanius

Introduction – Kalpana Shankar

Short introduction of all participants. Short introduction of the IG.

Kalpana Shankar and Corey Jackson were working on project called "Data Sharing and Ethics in Sharing Citizen Science" through summer. Corey will present the results, and try to translate it into deliverables of this IG.

"Data Sharing and Ethics in Sharing Citizen Science"- Corey Jackson

Citizen science is defined as "scientific work undertaken by members of the general public, often in collaboration with or under the direction of professional science and scientific institutions."

There are 6 types of data.

Most of the science is constraint by the way we can process them.

Data sharing and ethics issues are important in citizen science.

It is not clear who owns data and how data can be used, much is up to the individual scientist. Sharing correlates to success of citizen science.

There are many regulations, institutions, review boards relevant to data sharing. Effective regulations are: e- privacy directive (EU), Information act (US), Right to information act (AU).

When it comes to citizens as collaborators in science, ESAD group is important. There are many cases where citizens made some important discoveries.

There are some obvious biases in this study: Corey is himself a citizen science researcher, US based, and actively participating in one such project.

The sample was not too big - 15 projects - from: astronomy, marine biology, ornithology, etc. In total, 20 documents were discovered, 2 documents had no documents on ethics.

Research Q1: How do they communicate policies? There were 9 different types of documents used for the surveyed projects; the most important were on privacy, user agreements, etc. People talk about content ownership, permitted uses, trademarks, user-generated content; license to use, policy was an important issue too.

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Communicating policies looked (most of them) like a bunch of lawyers made the documents; there was a lack of specifity in area of data sharing. On the other hand, ethic documents seem to be well represented.

Research Q2: What was the policy content? There are 9 documents mentioning data, 10 mentioning ethics or privacy, number of mentions 76 and 118 respectively.

Content of policies: language on privacy and ethics almost sufficient, ethics issue insufficient.

There is a need to formulate something like checklists for the citizens' science.

Next steps in this research would be: refine sampling, develop checklists.

Q: Were the issues such as ethical dimensions or Belmont principles considered?
A: IRBs provided sufficient information. There were 2 types of data: data on the researchers' contribution, and the data on the researchers themselves.

Q: Who owns the data?
A (Corey): That is a difficult question, domain-specific. There are some cases where it is clear who owns data.

Q: What about ownership of data in Europe?
A: There were different standards on data sharing, that is where this IG could help.
A: Funder of the study has right to own data.
A: Patients are the owners of data in health-care.

Q: Where is differentiating between ethics and legality. What are the ethical issues?
A (Kalpana): When IG was formed; someone said this IG was not needed, because there is already a group on legal issues. There is a big difference between the ethics and legality. IGs at RDA have to produce deliverables; the basic idea was Corey's project could be translated into deliverables of this IG.

Q: Ethics are contextual, knowing little could be dangerous. There are some important issues rising from this: Where that data is going to live, there is a temporal dimension of this. What happens when citizen discover endangered species, do you want to have this info shared? There are also many dimensions to be considered concerning this issue. What resources are available to people needed to make ethical decisions on their discoveries. What the anticipated use is?
A (Kalpana): We do not agree. Data should be shared. There are some special situations where risks are bigger than benefits, but these are just exceptions.

Q: We are running to support system, new dimensions of ethical, legal, technical issue, we interviewed researchers, librarians. Interesting deliverable would be to release some good case studies in different disciplines. Why are you doing the research? Where there are no good policies?
A (Kalpana): Checklists would not be appropriate, since they are not complex enough.

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Q (Karmela): How does research integrity part fit in? There are gaps between policies, practices and the real world. In Canada there is some regulation on ethics. There could be no researcher integrity if the data were not shared. How does the scientist science differ from citizen science?
A: Practical issues about what is implemented are the most important.

Q: In Australia importance of citizen science is absolutely paramount, it is mandatory to get good data from committed citizens; this question has to be tackled, since the territory is so huge. The way to approach the communities is very important. If we do not deal with that, we will lose important data.
A: It would be interesting to hear the experiences from the other part of the world.

Q: Interesting that studies picked have no personal data. Did the IRBs have the competence?
A: No, there were not collecting personal data, and the IRBs were not always competent.

Q: Who are the checklists are for? Policy makers?
A (Kalpana): Guidance for research ethics committees would be welcomed. This is too much activity for a voluntary project. There are so many issues we could not tackle, because there was a lack of resources.

Q (Freyja): I am working on teaching game developers to create ethical games. It is not a classical checklist, but provides some guidance. It is more a document where steps were considered, then a checklist. Such guidance could be helpful in this case, more than a checklist.

Q (Candice): Another potential deliverable could be tackling the issue of how we were taught ethics, offering curriculum for ethics.
Q (Karmela): Scandals seem to fuel up ethics issue. We have to have ethics where it is really needed, not all over the place.

Q: DataONE should be explored.

Q: People jump over the ethical parts little too quickly. Do we know what ethical and legal parts are?
A: It was only a small part of issue tackled.

Q: Maybe Corey's research could be distributed.
A: We should certainly put some stuff in wiki; having annotated bibliography on ethics would be useful.

Q: Who is the audience for what this group creates. Researcher, librarians? Libriarians would benefit from such short overviews of ethical issues. On the other hand, case studies could help researchers.

Q: Are others interested in ethical collection of data (social media), outsourcing data collections? A lot of attention was raised about laboratories using animals.
A: There is a desire to open RDA to more commercial players.

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Next steps – Wrap up – Kalpana Shankar

It is difficult to give deliverables when people work voluntarily.

1. Corey's study will continue, it will be expanded with more sites of interest and deeper analysis. There is a need of some policy of data sharing - guidance – to be developed (not to be called a checklist).

2. Deliverable: Develop Case studies/use cases on Citizens working with scientists.

3. Deliverable: Annotated wiki bibliography will be developed.

4. Deliverable: Produce some educational material.

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