Research Ethics and Public Trust, Preconditions for Continued Growth of Internet Mediated Research

Public Confidence in Internet Mediate Research

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Abstract: In this paper we argue for the position that responsible safeguards for privacy and ethical treatment of human data are of vital importance to retain the public confidence and trust that is necessary for the development and future success of internet mediated research (IMR). We support our position based on the high level of popular and media attention that is currently directed at IMR, which in combination with the relative uncertainties that still exist around the ethics of various IMR methods, raises the risk that IMR might succumb to a public backlash of similar proportions to the controversy that hit genetically modified (GM) crops in Europe. Based on the lessons that came out of the GM crops controversy we discuss the ethics requirements and challenges that must be met in order to retain the public trust in IMR. We end our argument by briefly reviewing a couple of examples of "privacy protecting architectures" that are being developed for IMR.

1 INTRODUCTION

The position we argue for in this paper is that responsible safeguards for privacy and ethical treatment of human data are of vital importance to retain the public confidence and trust that is necessary for the development and future success of Internet Mediated Research (IMR).

Data derived from observations of human behaviour and communication is intimate and personal, no matter how or where the data was collected. Furthermore, since such data is provided by human participants who are ultimately free to choose if they want to contribute to research studies, or not, the ability to perform such IMR critically depends on the level of trust that people have in the IMR research community. If people understand how their data is being used and can feel confident about the benefits that the analysis of this data can offer to themselves and society in general, then they will not only willingly contribute their data but may even choose to actively participate in further studies such as citizen science projects.

The recent flood of media stories about leaks, hacks and misuse of personal data is eroding people's trust in the concept of social media analysis to the extent that they may soon rise up in a revolt against all forms of IMR. Without transparency of methods, clear ethics guidelines and technical safeguards against (inadvertent) invasions of privacy, public opinion could call for a boycott on IMR similar to the backlash against genetically manipulated crops that was triggered in the EU in the 1990s (Carr and Levidow, 2000).

The argument for our position is structured as follows: First we will set the scene by highlighting the level to which IMR is currently "in the public eye". Next we draw upon the experiences from the GM crops controversies in order to learn some "lessons from history". This is followed by a discussion of the "Ethical requirements and challenges for IMR" and a brief look at some "privacy protecting architectures for IMR" that are being developed. Finally we conclude by summarizing the position of this paper and the arguments we have presented.

2 IN THE PUBLIC EYE

Following in the wake of the explosion in popularity and size of social media services over the last decade, IMR including web-based questionnaires, social media analysis and web analytics has rapidly risen to become one of the most publically visible forms of social science. For better or for worse, this 'fame' is for one part due to reflected glory from association with flashy technology companies like Google, Facebook and Twitter that are constantly in the news, and for another part the result of anticipated influence of quantitative data about human behaviour generated by IMR on government and corporate policy development. By producing and accessing databases that are orders of magnitude larger than traditional data sources (Dragland, 2013), and doing so at speeds that can approach (near) real-time processing of events, IMR is allowing new types of quantitative and statistical analysis that are promising to revolutionize social science. Both of these developments have drawn the attention of corporate, governmental and international institutions interested in "evidence based policy" (Wilsdon, 2014). Even the UN is looking to this data revolution as an essential part of the global development agenda after the 2015 millennium development goals (MDGs) (Independent Expert Advisory Group, 2014).

All of this fame and fortune (i.e. grant funding) however carries with it a price tag in the form of heightened public scrutiny, especially with regards to the ethical conduct of the research (Booth, 2014; BBC News, 2014) and possible failures to ensure privacy protections (Barbaro and Zeller, 2006; Narayanan and Shmatikov, 2009).

3 LESSONS FROM HISTORY: GM CROPS

In this section we look at one of the more controversial episodes in the recent history of the relationship between science and the general public, namely the European GM crops controversy of the 1990s. The case of the GM crops controversy is, in our view, especially relevant since it also involved research that, in the public eye, was strongly associated with corporate interests and also strongly hinged on the trust relationship between scientists and the public.

In the 1990s the introduction of genetically modified crops in Europe triggered a public backlash against GM foods and biosciences in general (Carr and Levidow, 2000). The cause of this controversy has since been attributed to a combination of issues relating to public trust in regulatory institutions, scientists and industry (Frewer et al. 2004).

At the start of the 1990s, European regulators discussed the issue of GM foods almost exclusively as an issue of risks to the environment and human health. The regulators failed to address people's fears that unintended effects are unpredictable and thus unknown to science (Miles and Frewer, 2001) or to adequately address the potentially transformative nature of the technology on societal and social structures, thus producing an erosion of public trust in these institutions. This potentially transformative impact of society is a concern we can also find in the current scare stories about the 'death of privacy' due to social media mining (Andrews, 2014; Jayson, 2014).

By failing to take due account of what was driving public concern, the motives of those developing the regulatory framework appeared suspect. By appearing unconcerned with public and environmental welfare the legitimacy of the regulatory framework, and regulatory agencies with responsibility for developing that framework, was jeopardized. We do not believe that IMR has reached this stage of public distrust yet.

The initial response to the public resistance to GM crops was to dismiss many of the public fears about GM crops as irrational and to attempt to gain public acceptance by educating people with facts and information. By the second half of the 1990s this strategy had proven itself to be ineffective (Biotechnology and the European Public Concerted Action Group, 1998) and was replaced by a shift towards participatory strategies. The main driver behind these strategies was the belief that in order to ensure societally accountable development of technologies, e.g. genetically modified foods, there must be a larger public involvement in debates and decisions. Belief in this strategy was supported by empirical research on the success of technological innovations which repeatedly showed that early involvement of end-users in the development process significantly increase the likelihood of market success (Cooper and Kleinschmidt, 1987; Dwyer and Mellor, 1991; Wheelwright and Clark, 1992).

Ideally the participatory process proactively engages in a debate with the citizens prior to the development of technologies (and products) using a variety of tools designed to engender active involvement of the public. Such a debate not only

reassures the public that their concerns are being respected, but also produces a better understanding of the public concerns, allowing them to be more effectively introduced into risk assessment and risk management practices.

In terms of lessons that could be learnt for the introduction of new technologies in society, the GM crops controversy clearly illustrated the importance of maintaining the public trust, and the difficulties in regain that trust once it has been lost.

The controversy also demonstrated how, in a democratic society where choice exists, people refuse to consume (literally or figuratively) what they associate with some negative attribute.

In part as a response to the lasting aftereffects of GM foods controversy on the biosciences in Europe, the EU is now pushing for a much stronger emphasis on Responsible Research and Innovation (RRI). Under the RRI agenda (Sutcliffe, 2011) the aim is to:

- deliberately focus research and innovation to achieve a social or environmental benefit;
- have consistent, ongoing involvement of society, from beginning to end of the innovation process, including the public & non-governmental groups, who are themselves mindful of the public good;
- assess and effectively prioritise social, ethical and environmental impacts, risks and opportunities, both now and in the future, alongside the technical and commercial;
- develop oversight mechanisms that are better able to anticipate and manage problems and opportunities and which are also able to adapt and respond quickly to changing knowledge and circumstances;
- make openness and transparency an integral component of the research and innovation process.

One element of this new approach to research and innovation has been an increased interest in participatory procedures to involve the public in the decision making process in some way.

When considering how such participatory procedures might be applied to IMR it is important to acknowledge that social media users are likely to have higher expectations about the level of personal involvement in decision making than the general population in the 1990s. For users who are used to constantly expressing their opinions about the things they find online, be it via comment boxes or 'like' buttons, participatory engagement with IMR policies requires an ability to voice an opinion on the perceived value (acceptability) of individual IMR projects.

4 ETHICS REQUIREMENTS AND CHALLENGES FOR IMR

Ethics guidelines and institutional review boards play an important role in establishing an environment of trust, where the public knows what kind of research practices they can expect, and researchers can gain confidence in their methods by knowing who to turn to for an objective evaluation.

The Code of Human Research Ethics (British Psychological Society, 2013) outlines four main principles underpinning the ethical conduct of research: 1. Respect for the autonomy and dignity of persons; 2. Scientific value; 3. Social responsibility; and 4. Maximising benefits and minimising harm.
For IMR the following issues often pose particular challenges when evaluating the ethics of a (proposed) study:

1. public-private domain distinction online;
2. confidentiality and security of online data;
3. procedures for obtaining valid consent;
4. procedures for ensuring withdrawal rights and debriefing;
5. implications for scientific value and potential harm.

4.1 Public-private Domain Distinction

When dealing with potential data derived from online sources, e.g. discussions on user-groups or social networks, the extent to which this should be considered as being in the public or private domain is often problematic. From a strictly legal perspective only documents that are not protected by copyright law should be classed as being 'in the public domain'. Regardless of the legal distinctions between public and private interaction domains, however, when confronted with data that was clearly derived from specific online communications (e.g. a Twitter post), the data will always be experienced as intimate and personal by the person who posted it. In order for people to feel comfortable with research on such data therefore, requires that they have a high level of trust in the researchers.

4.2 Confidentiality and Online Security

Anonymization is one of the most basic steps for maintaining confidentiality, showing respect and thus gaining the trust of research participants. The

need to protect the anonymity of participants is even more pressing in IMR on social media posts where access to the raw data, i.e. the on-line posts, cannot be controlled by the researcher. At the same time, the wealth of secondary information sources that can be mined in connection to any hint at the identity of a participant is making it increasingly easy to de-anonymize research data. The classic example of this is of course the de-anonymization of users in the AOL Search Log by journalists of the New York Times in 2006 (Barbaro and Zeller, 2006).

4.3 Valid Consent

Valid consent fundamentally deals with respect for the autonomy and dignity of persons. In order for valid consent to take place it is vital that the participant is fully aware and has a true understanding of that which is being consented to. This is why, for instance, research involving children requires consent from their legal guardian. In many respects, the requirement for valid consent represents a core value of any democratic society, and yet it is probably the principle that is most frequently violated on-line. An illustrative example of this was the statement in the controversial 2014 Kramer et al. publication on IMR using Facebook, in which they asserted that participants had provided consent for the study since "it was consistent with Facebook's Data Use Policy, to which all users agree prior to creating an account on Facebook, constituting informed consent for this research" (Kramer et al., 2014). The Data Use Policy however, even if it was actually read by a Facebook user, does not provide any information about the nature of the specific Kramer et al study. The requirements for full awareness and true understanding of the matter that was being consented to was therefore clearly violated in this study.

More in general however, any IMR study that uses already available social network posts is confronted with the problem of obtaining true valid consent from the authors of those posts. While this clearly presents a technical and potentially labour intensive challenge, the advantage of consistently making the extra effort of obtaining valid consent will go a long way towards establishing a conscientious and trustworthy reputation.

4.4 Withdrawal and Debriefing

The right to withdraw and the provision of adequate debriefing are both closely linked to valid consent. Since the act of participation often provides a deeper understanding of the true nature of a study the right to withdraw supports the validity of the consent provided by the participants who remain in the study. The same is true of the debriefing, especially for research where the nature of the study requires that the participants must be naïve to the true purpose of the task/manipulations. One of the challenges for IMR is the indirect or remote interaction with participants which includes the possibility of participants disappearing from the study (e.g. closing a web browser page of an on-line questionnaire) without communicating if they wish their data to be removed and without paying attention to debriefing information.

4.5 Scientific Value and Potential Harm

Beyond issues relating to the execution of research, a key element to evaluating the ethics of research proposals is to establish if the study is likely to produce results that are of scientific and/or social value or if there are risks of potential harm. The importance of dealing with these questions in a thorough and transparent manner, and the potential for a public backlash when this process is lacking, was highlighted by the failure of the biosciences community to clearly establish the rigor of their ethics procedure in the case of GM foods. More recently, controversies over social responsibility of IMR studies are threatening to become a recurring theme with stories like "Facebook reveals news feed experiment to control emotions" (Booth, 2014) and "OKCupid experiments with 'bad' dating matches" (BBC News, 2014) being picked up in the popular media. In order to counter this trend and retain public confidence it is important to consider the probable societal impact and response that a study is likely to produce and weight this against the anticipated scientific value.

5 PRIVACY PROTECTING ARCHITECTURES FOR IMR

In order to encourage compliance with ethical research protocols it is important to make this compliance as easy as possible by providing tools that are intrinsically privacy-respecting. This is especially true for IMR where much of the research is being done by corporations or other groups that lack structures like the university ethical review boards. Three such tools are:

1. The PRISONER (Privacy-Respecting Infras- tructure for Social Online Network Experimental Research) architecture by Hutton et al. (2012)
2. The Dataware system by Mortier et al. (2013)
3. The Ma3tch (autonomous anonymous analysis) technology.

PRISONER (Hutton et al, 2012) is an architecture that was developed for conducting social network experiments that preserve participant privacy. The core element of the architecture is the workflow manager unit that passes all data through a data sanitiser before they are analysed or presented to participants. The data sanitiser applies the appropriate privacy-preserving transformations, that are indicated by a privacy policy file.

Dataware (Mortier et al 2013) is a set of technologies that were designed to enable people to regain control over the digital data that is constantly being created by and about them. Dataware provides mechanisms for collating data that is held in multiple locations (e.g. social media networks, loyalty cards or banks) and making it available for processing by third-parties, while retaining control over the access to the data.

Ma3tch (Kroon, 2013) was originally built to enable Financial Intelligence Units from various countries to achieve virtual information integration without infringing upon security, confidentiality, privacy and/or data protection regulations. The Ma3tch uses a 'privacy by design' framework that is based on distributed agents to facilitate decentralized but integrated information access, processing and analysis. Relevant information and knowledge that is distributed between autonomous organizations is automatically detected and applied throughout the network as soon as it emerges. Crucially the sensitive raw data is never shared, only anonymized standardized information is shared.

Each of these tools presents a different approach to the problem of privacy preserving data handling, and while much work is yet to be done, they do at least provide examples to show that IMR can be done without risking violations of privacy and human dignity. As such, development of these tools, and others like them, provides a clear signal that there is no excuse for breaking the codes of ethical research conduct. They also provide beacons of research integrity to raise confidence and trust from the public.

6 CONCLUSIONS

Based on the high level of popular and media attention currently directed at anything related to social media or the internet, IMR is currently receiving a greater level of media scrutiny than most other types of research. In combination with the uncertainties that still exist around various aspects of IMR ethics, this media attention carries the risk for IMR of triggering a controversy and public backlash similar to the one that hit GM crops in Europe in the 1990s. In order to avoid such a controversy it is essential to retain the confidence and trust of the public which, in the light of the "Snowden revelations", depends heavily on the use of responsible safeguards for privacy and ethical treatment of human data.

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