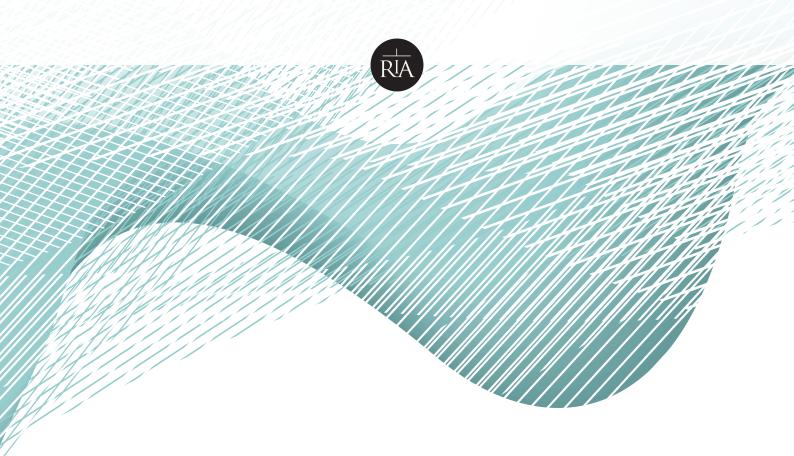


Expert Opinion Piece: Engineering and Computer Science Committee
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Context

Big Data is a frontier with significant implications for citizens, governments and business. There is growing public unease about the pace of growth in Big Data and lack of transparency about its use. Data use by public and private entities raises important questions about ownership, privacy, individual rights and societal progress.

There is a fundamental tension that exists between data, its uses, and its users. Citizens have legitimate concerns that data collected by third parties, relating to their actions, beliefs, preferences or intentions, may be used without their (informed) consent. They fear that its misuse may have a detrimental impact on their interests, intentionally or not, because third parties can use their data as well.

Data protection legislation and the complications that could potentially arise are a growing source of unease for researchers. In 2013 Science Europe, a non-profit organisation representing more than 50 major research-funding and research-performing organisations throughout Europe, published an opinion paper: The Benefits of Personal Data Processing for Medical Sciences in the Context of Protection of Patient Privacy and Safety. This paper warned of the devastating implications of amendments, if passed, to the European Commission's proposal for a General Data Protection Regulation. The Commission's proposals contain a number of provisions and exemptions crucial to facilitating vital medical and health research within a framework of protection of individual rights to privacy. So far discussion about the protection of individuals in the data age has focused on privacy. Legislation and political discourse has largely been limited to this one aspect of the ethical issues that arise in a Big Data age.

Big Data poses significant ethical challenges. The field is constantly changing. Data ethics theory spans disciplines that have traditionally had little or nothing to do with one another. Collaboration across areas such as data science, ethics, law and philosophy is not easy, and comprehensive expertise in all of these fields is a lot to ask. Current efforts at such collaboration need to be recognised and appreciated and should be encouraged and strengthened by good practitioners. Those dealing in data research are frequently aware that vested interests (often, although not always, commercial) may favour a model where ethics is dealt with as issues arise – or even after the technology has been developed. Practitioners are increasingly aware this model is backwards.

We cannot allow technology to drive thinking on data ethics. When it comes to data, we should define the rights of all stakeholders before we put the technology into use. We cannot afford to wait until the technology is in place. The field of data ethics is more developed in some spheres than in others. The Insight Centre for Data Analytics in Ireland wants to progress the discussion in the data science field and facilitate the cross-disciplinary discussion that needs to happen. Legislation alone is unlikely to be nimble or encompassing enough to protect individuals and their data. We need to define the rights and wrongs of data collection and use.

Tim Berners-Lee, the creator of the world wide web, has suggested the development of a Magna Carta, a bill of rights for European citizens, for the web. Recently, the Insight Centre has proposed a Magna Carta for Data. There is a case for broadening this idea beyond the web, as there are many forms of data that are not web accessible but have societal and personal relevance. Individuals should be entitled to certain guarantees in terms of their data, but the internet age has made an individual's rights regarding data difficult to legislate for. The legal protections currently in place are accessible only to those with adequate resources to negotiate them. Therefore, an agreed set of principles, which the Magna Carta for Data sets out to define, would help resolve such issues with current and future legislation.

A Magna Carta for Data

A Magna Carta for Data, akin to the Universal Declaration of Human Rights, could be adopted by nations and industry. It would lay out a set of principles to provide assurances to individuals that, when they click the Terms and Conditions button, they are signing up to fair and agreed set of principles that observes their rights as well as those of the vendor.

Data needs a Magna Carta because data has value. It is a major currency. We cannot limit a Magna Carta for Data to data on the internet. People's rights regarding their data should be universal no matter how the data is collected or stored. A Magna Carta should be a living and evolving document. Technology develops rapidly; a Magna Carta for Data should be capable of adapting if necessary. It should acknowledge the potential value of data and the benefits for society in the use of Big Data. Whether and how we balance the value of data versus the rights of the individual is something that needs careful consideration. Data is a valuable currency in research, industry and society. It potentially holds the key to better, safer, more efficient societal systems and much more besides. However, a balance is needed. The temptation is ever present for industry and others to exploit the data of individuals for profit and yet, without the trust and cooperation of the originators of that data, any sustainable system of research would be impossible.

If we do not acknowledge and examine the different interests involved, the rights of the individual will be swept away in this data gold rush. We believe that we must ask the difficult questions. And we believe firmly that the individual, not the value of their data, must be at the centre of any discourse about a Magna Carta for Data.

This idea has been well received at a European level. Policy makers, while still focused on privacy and data protection issues rather than the general concept of data ethics, are nonetheless aware of the shortcomings of legislation and the need for something more. What is still unclear is the form such a document would take, and indeed what would be in it. It would be a living, evolving document, but what exactly it would entail is yet to be decided.

One positive step is to bring experts from different disciplines together, as is being done in some cases. There are pockets of expertise in different fields and our first step is to listen and learn. Such efforts should be encouraged and facilitated.

We can balance the needs and rights of individuals in the Big Data age, but collaboration and cooperation is key. A Magna Carta for Data would go some way to providing assurance to citizens that they can share their data without making themselves vulnerable to abuse.

Without trust and buy-in from citizens, we will never fully realise the possibilities of Big Data. Citizens who are not confident in those who wish to use their data will withdraw it. In many ways Big Data research and use is a partnership, but it is one that must have the generator of the data at its heart. We must develop a bill of rights for data use.

Process for Developing the Magana Carta for Data

The Magna Carta for Data is an ambitious and powerful concept that will have significant impact in a variety of domains where personal data must be dealt with. Therefore, the Magna Carta for Data must be developed through as broad a consultation process as possible, bringing together key stakeholders and experts, along with input from officials in Brussels in relation to the new European General Data Protection Regulation that comes into full effect in 2018.

In addition, opportunities for developing new technologies to support the implementation and deployment of the Magna Carta for Data, as well as putting data owners in full control of their data, must be created and nurtured. Therefore, it is important that the Magna Carta for Data becomes a priority for national and international research and development funding agencies, and that representatives of these organisations are also involved in the development of the Magna Carta for Data.

Professor Barry O'Sullivan is the Director of the Insight Centre for Data Analytics at University College Cork and leads the centre's strategic policy engagements in Europe. He can be contacted at barry.osullivan@insight-centre.org



Royal Irish Academy 19 Dawson Street Dublin 2 D02 HH58

info@ria.ie 00 353 (0) 1 676 2570

www.ria.ie