

# Understanding Ethics and Human Rights in Smart Information Systems

A Multi Case Study Approach

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**Abstract**: Smart information systems (SIS), systems based in machine learning approaches to artificial intelligence using big data analytics are high profile examples of emerging technologies that have the potential to significantly affect most aspects of personal and societal life in industrialised societies. They are the subject of much scientific research but also of large amount of philosophical and sociological studies. A key question they raise relates to ethical questions they may raise which can involve questions of human rights.

The majority of these reflective approaches to SIS are based on anecdotal evidence or conceptual considerations. There is little research investigating the actual ethical issues these technologies raise in their real-world environments. Rigorous empirical research tends to focus on particular technologies or application examples. While such research can produce interesting insights, it is

not sufficient to give a broader overview of these technologies. One reason is that the technologies and components involved as well as the applications of such SIS vary greatly.

One way of overcoming this limited view of ethics and human rights of SIS that is based on rigorous empirical research while providing a broad overview of technologies is to undertake a set of parallel case studies that provides simultaneous insights into a range of technologies. This paper outlines the rational and principles according to which such a multiple case study can be undertaken. It describes the process of selection of cases and development of the methodology as represented by a case study protocol. It provides the rationale and methodological underpinning for the set of 10 case studies that are published in the same special section of the ORBIT journal.

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# Introduction: Ethics and Human Rights Concerns of Smart Information Systems

In 2016 the Executive Office of the President of the United States published two reports covering possible consequences of the large-scale introduction of artificial intelligence (AI) into the US society and economy (Executive Office of the President, 2016a, 2016b). Similar reports were published around the world, for example by the UK House of Commons (House of Commons Science and Technology Committee, 2016), followed by the House of Lords (HoL, 2018), European Parliament (European Parliament, 2017) and many other legislative and governmental bodies. The reason why artificial intelligence attracts such a large amount of policy attention is that there are expectations that the integration of AI into economic and social processes is likely to have disruptive consequences and that policymakers will be called upon to react appropriately to the changes caused by AI. This is the currently accepted view and can be seen as political orthodoxy. AI is expected to change whole industries and bring huge economic benefits. At the same time, there are worries that AI will have significant ethical implications, may

cause mass unemployment, discriminate against minority, disempower people and skew political processes.

While this description can be seen as the conventional wisdom of the day, it is typically not clear what it is based on and whether there is empirical evidence to support the benefits or the costs of AI. The power of the narrative is undeniable, but it is often difficult to assess where it originates and at which stage of this development we can reasonably assume to be. This lack of empirical is problematic, in particular for policymakers who are called upon to regulate the new technology but typically without a strong empirical basis on which policies can be based. While this state of affairs may be impossible to overcome completely, partly due to the complexity and mercurial nature of AI and partly because of the fundamental uncertainty of the future which is being legislated, it is nevertheless important to improve the evidence base of policy in this area. This editorial paper therefore sets out to provide the basis for the collection of such empirical evidence. It provides the shared conceptual and methodological basis of the 10 case studies that are published alongside this paper and should be read in conjunction with these individual case studies.

This editorial provides an example of how the much-applied case study approach can be made useful to gain a broader overview of topic as broad as that of ethical and human rights implications of SIS. By providing a detailed account of the development and implementation of the case study approach, the paper provides an example for similar wide-ranging case study work.

Following this introduction, the paper briefly defines the concept of SIS and justifies the choice of this term. It then explains the choice of the case study approach. The majority of the paper then describes the approach taken to identify suitable case study topics and the development of the methodology as summarised in the case study protocol. The paper ends with a discussion of lessons learned and an outlook of next steps.

# **Smart Information Systems**

In this paper we use the term smart information systems or SIS to refer to a set of technologies and techniques that in current discourse are often referred to as artificial intelligence, machine learning, big data analysis and others. We do this to ensure that it is clear that we are not claiming to refer to a particular branch of these technologies but are more interested in their combination with other technologies and in particular in their

social implications. The term AI is currently used widely and most of the policy-oriented publications that were cited earlier use some definition, such as

"Technologies with the ability to perform tasks that would otherwise require human intelligence, such as visual perception, speech recognition, and language translation"

There is, however, general agreement that there is no general agreement on an exact scientific definition of AI. As a recent study of AI on a global level by Elsevier (2018) has shown that the term AI covers a large number of existing fields of research but that in various domains (science, media, policy, education) there is little to no overlap in the use of the term. A typical strategy that policy-oriented reports use to define AI more narrowly is to highlight similar and related terms and current trends. It is probably uncontroversial to say that the current use of AI refers to a 'narrow' view of AI, which means that it aims at specific applications without suggesting that AI has general reasoning capabilities similar to humans (also known as 'general' AI). This narrow AI typically makes use of machine learning, more specifically based on neural networks and often deep neural networks. This type of technology can be characterised as a type of statistical analysis of data that is very good at pattern recognition in large data sets. It has come to prominence in recent years, even though the fundamentals of the technology and the algorithms have been around for decades, because the performance of affordable computers has increased dramatically at the same time, as the amounts of data collected for scientific, economic or administrative purposes has exploded. This led to a wide availability of large amounts of data (or 'big data') that was capable of being analysed through machine learning, which has led to impressive results.

We have decided to use the term SIS, following Stahl and Wright (2018), to indicate that we are not interested in a particular technology or data type. Instead, we are interested in the ethical, social and human rights aspects of these technologies. We therefore chose the term 'information systems', as this denotes a field that focuses on the use of information technology in organisations (typically, but not exclusively businesses) and aims to bring together technical and social expertise to understand the role of technology but also to provide lessons for effective practice (Avgerou and McGrath, 2007). We are not interested in any type of information system, but specifically those systems that relate to AI, which is why we chose the term 'smart information systems'. We hope that this

<sup>&</sup>lt;sup>1</sup> Department for Business, Energy and Industrial Strategy, *Industrial Strategy: Building a Britain fit for the future* (November 2017), p 37:

https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/664563/industrial-strategy-white-paper-web-ready-version.pdf, cited according to (HoL, 2018, p. 14)

choice narrows the field of investigation sufficiently to allow us to cover it sufficiently, while at the same time being open enough to cover phenomena of interest.

The subject area of SIS is clearly broad. Our interest is in providing empirical evidence that can inform policy development. The next question we considered is therefore which methodological approach would allow for an adequate coverage of SIS.

# The Multiple Case Study Approach to SIS

The motivation behind the research leading to this paper was to better understand the ethical and human rights aspects of SIS. Research in this area has grown exponentially in recent times, leading not only to the policy discourse referred to earlier, but also to a number of monographs (Mayer-Schonberger and Cukier, 2013; O'Neil, 2016), academic publications (Floridi et al., 2018; Mittelstadt and Floridi, 2016; Winfield and Jirotka, 2018) and contributions from companies and other organisations. Our starting point was the observation that, despite the high level of activity in this field, there is very little systematic empirical investigation of the nature and consequences of these technologies in their social environment. Our research question is therefore: how can ethical and human rights aspects of SIS be investigated?

There are of course numerous ways of doing such research that could include large-scale surveys, the analysis of existing data sets, including national statistics, literature analysis and many more. For our purposes it is important to collect data that not only provides an insight into the phenomenon in question but also that the outcomes can be communicated to an interested audience, including to policymakers. In addition, the research area is such that there is a large amount of literature on what might constitute ethical or human rights issues of SIS, but the phenomenon of interest for our investigation is how these are instantiated in practice. Part of the research is therefore to remain vigilant for gaps in the literature and use the research to produce additional insights which are not widely discussed yet.

For these reasons we decided to use a case study approach. Case studies are a well-established methodology in social and organisational studies (Eisenhardt, 1989; Yin, 2003a, 2003b). in our study the purpose of the cases was not so much the testing of hypotheses but the exploration of new phenomena with a view to contributing to policy development. We therefore decided to pursue case studies employing an interpretive paradigm (Klein and Myers, 1999; Myers and Walsham, 1998; Walsham, 1995). The clear downside of this approach is that cases only produce punctual insights, which was counter to our aim of contributing to a better understanding across the broad range of SIS. We therefore decided to undertake a set of 10 parallel case studies that would allow us to ORBIT Journal DOI: https://doi.org/10.29297/orbit.v2i1.102

shed light on a range of technologies as well as ethical issues and human rights. The following sections explain in more detail how we developed this idea and turned it into a practical method.

#### **Background: Developing Criteria**

The study was undertaken in the context of an EU-funded project (SHERPA, <a href="www.project-sherpa.eu">www.project-sherpa.eu</a>) which determined some of the boundary conditions of the research. It meant that the case studies had to be conducted by a diverse and distributed team of partners with different backgrounds and areas of expertise and that they had to be done in a rather tight time frame of eight months.

The process of case study development began in March 2018. Having successfully won the SHERPA contract, attention turned to understanding what would be involved in the case study process. It was decided that a number of criteria needed to be established early on to ensure the successful development and production of ten high-quality case studies. The work package leader (the University of Twente (UT)) created a process to distinguish the different types of case studies that should be carried out. This included a broad literature study of the main ethical issues in Big Data and artificial intelligence (AI), to determine possible concerns to be uncovered and addressed in the case studies, and the creation of an example case study for consortium partners to follow.

Several brainstorming sessions occurred at UT between March and April 2018 regarding the means of distinguishing the different case studies to effectively cover a broad reach of areas and ethical issues surrounding the use of SIS in practice (see Fig 1). One approach considered was to distinguish case studies by means of technical classification, and particularly by reference architecture. Hence case studies could have been distinguished along the lines of relational versus non-relational, batch processing versus real-time processing, or data type, to list a few examples. A 2<sup>nd</sup> means of distinguishing case studies considered was by 'user type'. Hence case studies could have been distinguished by whether the user was an individual, a business, an individual within a business, or a process application. The 3<sup>rd</sup> means of distinguishing the case studies was by application domain. This focused on the field in which the SIS would be applied. Hence distinguishing features might include whether the application was a social network, a business system, or a part of the Internet-of-Things (IoT).

<sup>&</sup>lt;sup>2</sup> See <a href="https://www.ibm.com/developerworks/library/bd-archpatterns1/">https://www.ibm.com/developerworks/library/bd-archpatterns1/</a>
<a href="https://www.saama.com/blog/design-big-data-architecture-6-easy-steps/">https://www.saama.com/blog/design-big-data-architecture-6-easy-steps/</a>
<a href="https://www.saama.com/blog/design-big-data-ar

<sup>&</sup>lt;u>ahttp://www1.unece.org/stat/platform/display/bigdata/Classification+of+Types+of+Big+Data</u>

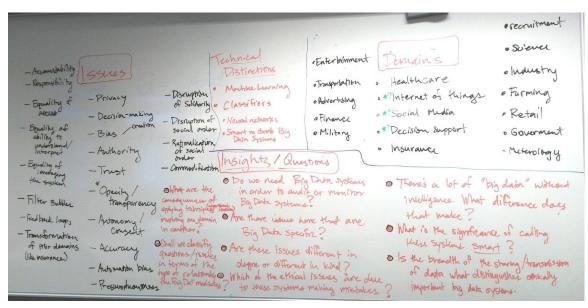


Fig. 1. Image of Brainstorming at University of Twente

Following further discussion, it was agreed that at the very least, case studies should include employees, consumers, citizens, and governments. The final set of case studies was then determined to encompass both targets and application domains, at least one case per type of data user, and a distribution of cases over the different technical categories. However, it was acknowledged that this would lead to an ideal situation, and one which may need to be tempered with the availability of willing case study participants. It was decided to establish a list of different social domains using and integrating SIS, with the attempt of covering a wide number of these areas within the case studies. The final agreed list of application domains can be seen in Table 1.

Having agreed the ideal list of application domains, attention turned to gaining a broad understanding of ethical issues currently faced across these domains. A literature review was carried out which approached both concerns with Big Data and AI in general and at the application level. It was sent to partners to understand the many ethical issues surrounding SIS. Finally, a review of the technologies employed in Big Data and AI was also carried out, so that partners were provided with technical knowledge and understanding of SIS before conducting domain specific research for their case studies and also preparation for their interviews with experts in those areas.

Alongside the literature review, UT carried out a review of the applications of SIS, along with a review of potential consortium partners who may be suitable for working on

https://www.ap-institute.com/big-data-articles/how-is-big-data-used-in-practice-10-use-cases-everyone-should-read

certain social domains from their expertise, research areas, and interests (prior to the May 1<sup>st</sup> launch date). Furthermore, UT also conducted a broad domain analysis of SIS applications. Through a combination of desktop research and personal contact lists, UT identified a number of organisations from the 16 social domains that use and integrate SIS in Europe. This list was distributed to SHERPA consortium partners as a suggestion of organisations to use for their case studies. Finally, an example case study was developed on Google DeepMind and the Royal Free Trust and was shared in May 2018.

Social Domains
Banking and securities
Healthcare
Insurance
Retail and wholesale trade
Science
Education
Energy and utilities
Manufacturing and natural resources
Agriculture
Communications, media and entertainment
Transportation
Employee monitoring and administration
Government
Law enforcement and justice
Sustainable development
Defence and national security

 Table 1: Social Domains Identified

# **Preparation of Case Study Research**

The next phase of the case study research started in May 2018 when partners involved in the cases met and discussed what the case studies should look like. Partners needed to understand the potential domain interests across the consortium. It was also discussed if partners had contacts in those domains or could think of organisations that would be suitable case study participants.

At the launch event the example case study was presented, alongside the application domains. There was considerable discussion as to which domains partners should focus on. The launch presented an opportunity to connect with different partners and understand respective interests. One of the objectives at the launch event was to correlate partner interests and connections with the application domain criteria which had been developed in advance.

Once the application domains had been agreed, a further decision was taken about whether certain application domains should be used as case studies (see Table 2). It is important to point out that in parallel to the case study research the consortium also developed a set of scenarios. These are not subject to this paper and will be described elsewhere. They are important to reference, however, as they form part of the attempt to gain a general overview of the field. This means that some of the topics or technologies of interest that were not covered by the case studies were allocated to the scenarios (see Table 3). The main difference between case studies and scenarios is that case studies refer to current technologies that are being used, whereas scenarios are likely future technologies that are not yet used or at least not on a large scale. There was a discussion of which domains would fit better as a case study or scenario. For example, defence and national security was determined to be better suited as a scenario. By contrast, cyber security, in which one of the consortium partners was a dedicated expert, was deemed to be more suitable as a case study. The initial agreement also covered the amount of time that could be spent on each case study and the process of collaboration which included a weekly teleconference.

Some of the case studies try to provide a broad analysis of a particular domain, most of the case studies delved into a specific area or topic within their domain of choice in order to provide a more detailed and interesting case study. For example, some case studies focused on one organisation to provide a broad overview of some SIS issues in that domain, such as: BASF for agriculture (CS03) and Liander for energy (CS07). Other case studies focused on a particular category within that domain to provide a more nuanced examination of SIS in that area, such as: a municipality for the government case study (CS02); smart cities as an aim within the Sustainable Development Goals (CS04); a large scientific research project (CS05); health insurance (CS06); and a supply-chain management risk prevention company (CS10).

Some of the case studies focused on specific applications, technologies, or departments within their domain of research: Internet-of-Things for employee monitoring (CS01); customer relations management in retail (CS09); and the use of SIS in cybersecurity department of a telecommunications provider (CS08). Overall, the case studies cover a wide range of areas, domains, specialisations, technologies, and approaches in the use and implementation of SIS, but were still able to provide cohesion and scientific rigour by following the case study protocol we completed before the case studies commenced.

No.	Case Study Social Domain
CS01	Employee monitoring and administration
CS02	Government
CS03	Agriculture
CS04	Sustainable development
CS05	Science
CS06	Insurance
CS07	Energy and utilities
CS08	Communications, media and entertainment

CS09	Retail and wholesale trade
CS10	Manufacturing and natural resources

**Table 2**: Case Study Division

No.	Scenario Social Domain
SC01	Healthcare
SC02	Defence & National Security
SC03	Education
SC04	Transportation
SC05	Law Enforcement and Justice

Table 3: Scenario Division

## **Developing Case Study Protocol**

Having agreed on the topics of the cases to be developed and the attribution of work, the next step was to agree on the detailed methodology and steps to be taken. Following common academic nomenclature, we called this the 'case study protocol' (Yin, 2003a). The case study protocol was created to guarantee consistency of approach and timeliness of the case studies.

A compromise needed to be agreed between an ideal number of interviewees, the ability to find willing participants, and the time constraints of the work package. In the end, a minimum number of one interviewee was agreed upon – if that individual was knowledgeable on both the technical and ethical use of SIS – with a recognition that two or more interviewees would be better. The case study protocol was officially agreed on 16<sup>th</sup> August 2018, outlining a specific breakdown of tasks and deadlines to ensure successful completion of 10 case studies by January 31<sup>st</sup> (see Table 4). Following the finalisation of the protocol, a promising case study was identified to be used as a pilot (agriculture case study). This pilot served as the template to ensure consistency of style and format, as well as common approaches to content. In addition, case study authors were required to upload interview transcripts to NVivo for analysis.

A final consideration was the need for ethics approval by research ethics committees at participating universities. The project lead (UT) submitted the case study protocol to the

<sup>&</sup>lt;sup>5</sup> Deadlines for each component of the case study needed to grapple with the long summer break, the Christmas holidays, and a relatively short amount of time in January to finalise the case studies. Taken together, this meant that interviewees needed to be identified and contacted prior to mid-July in order to be sure of interviews conducted in September. The September deadline was important in order to have a first draft of the case study ready for the end of October, which could then be peer-reviewed at UT by the end of November. This would allow for approximately 3 weeks to respond to the peer-review process by each author, before passing the case study to the Quality Assurance Officer in January, still allowing time for final edits before the end of the month.

<sup>&</sup>lt;sup>6</sup> NVivo is qualitative data analysis software from QSR International.

University's research ethics committee in July 2018, and received a favourable response within 2 weeks. This allowed for the case studies to be carried out by UT with full ethical approval, as well as case studies by non-university partners. The other universities needed to gain ethics approval from their own research ethics committees. Given that research ethics approval is required prior to interviews taking place, it was important that the research ethics process was completed by the end of July 2018. A significant aspect of gaining ethics approval was the development of a consent form and information sheet as part of the case study protocol, which could be used by partners prior to conducting interviews (see Appendix B.1 and B.2).

Deadline	Task
27/06/2018	Identify partner's Principal Investigator/POC and Co-Investigator/Deputy POC for
	case study
13/07/2018	<ol> <li>Get ethics board approval for study (if available)</li> </ol>
	2. Identify interviewees (interviewee should have good technical knowledge
	about the structure and use of SIS in the organisation)
	3. Approach contact(s) - explain purpose of study, nature of study, likely
	questions, arrange interview date/time
20/07/2018	Confirm agreement with organization(s) to participate in case studies in writing
03/08/2018	Carry out preliminary background research on organisation and its use of SIS
31/08/2018	<ol> <li>Complete Case Study Protocol Template for organisation</li> </ol>
	2. Carry out detailed background research on organisation's use of SIS
07/09/2018	Obtain written informed consent from interviewees
21/09/2018	Conduct interview(s)
28/09/2018	Transcribe interviews
	2. Upload transcriptions and other data to repository
12/10/2018	Conduct preliminary analysis (see guide for final report, below)
26/10/2018	<ol> <li>Write up draft report using template</li> </ol>
	2. Send draft report to interviewee(s) for validation (i.e. check our view that
	what they said is the same as their views on what they were saying). Allow
	for 2 weeks turnaround.
09/11/2018	Send agreed draft report to UT
30/11/2018	Discuss draft report with UT
21/12/2018	Write up final report using template and send to UT and the QA officer
14/01/2019	Discuss final revisions with QA officer
31/01/2019	UT to undertake cross-case analysis and compile final report
T 11 4 D	

**Table 4:** Research Plan

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<sup>&</sup>lt;sup>7</sup> In addition, in July, the authors of the case studies in WP1.1 were also approached by the leader of WP 2.2, who wished to use the information and interviewees from WP 1.1 as part of the stakeholder analysis process in WP 2. Some concern was raised among the authors that this might lead to volunteers for the interviews becoming overburdened with requests for information from the SHERPA project. However, it was decided that the transcripts of the interviews, published in a secure online server accessible to the leader of WP 2.2 would be sufficient for the purposes of the later work package.

Having agreed on the principles of collaboration, we now describe execution of the case study research. The full case study protocol that guided this work is available in Appendix A.

# **Conducting Case Studies**

Conducting the case studies involved carrying out background research, both generic regarding the application domain, identifying interviewees, and research on the organisation(s) that they belong to, and conducting the interviews. These stages lasted from June 2018 (the beginning of general background research) until October 2018. The project lead rigorously kept track of partners' progress, through an Excel Matrix, throughout this process to ensure deadlines were met (see Fig 2).

					13/7/2018	13/7/2018	20/7/2018	20/7/2018	3/8/2018	31/8/2018	31/8/2018	7/9/2018	21/9/2018	28/9/2018
No	Case Study	Partner	POC	dPOC	IRB Approval	Interviewee(s) Approached			Preliminary Background Research Completed		Detailed Background Research Completed	Written Informed Consent from Interviewee(s) Obtained	Interview(s) Conducted	Interview(s) Transcribed and uploaded
1	Employee Monitoring (IoT)	UCLanCY & AHR	Josephina	Andreas	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х
2	Government (municipalities)	UT	Mark	Kevin	Х	Х	Х	Х	Х	Х	Х	Х	Х	Х
3	Agriculture (agribusiness)	UT	Mark	Kevin	Х	Х	Х	X	Х	Х	Х	X	Х	Х
4	Sustainable Development (smart cities)	UT/EBS	Mark	Anya	х	х	х	х	х	х	х	х	х	х
5	Science (Human Brain Project)	DMU	Tilimbe	Bernd	Х	Х	Х	X	Х	Х	Х	Х	Х	Х
6	Insurance (Health)	EUREC	Natalija	Lisa	-	Х	Х	Х	Х	Х	Х	Х	Х	Х
7	Energy (Smart Grid)	TRI	Tally	Rowena	-	х	Х	X	х	х	Х	х	Х	Х
8	CRM (Telecoms)	UT/F-SEC	Kevin	Alexey	-	Х	Х	Х	х	х	Х	Х	Х	Х
9	Telecoms (Cybersecurity)	UT/F-SEC	Kevin	Alexey	-	Х	Х	Х	Х	Х	Х	Х	Х	Х
10	Manufacturing (SCM)	DMU	Tilimbe	Bernd	Х	х	Х	X	Х	Х	Х	x	Х	х

Fig 2: Case Study Progress

# **General Background Research**

For each case study, existing as it did in its own application domain, general background research needed to be carried out. This came in addition to the more general research on ethical issues in Big Data carried out prior to the start of the project. For each case study, the author investigated articles on ethics and legal issues for the particular application domain across a range of media. These included academic journals, trade journals, and Internet searches. In the process of the background research, both primary and secondary interview candidates were identified and contacted. Once initial contact had been established, permission for an interview was sought, alongside sending the potential interviewee the case study protocol, an information sheet, and a consent form (see Appendix B.1 and B.2).

# Specific Background Research

Once interested persons had been identified and confirmed to be interviewed, more targeted background research could be conducted. This research focused on the particular company or organisation to which the interviewee belonged. The specific background

research enabled the case study author to gain a fuller understanding of the issues faced by the organisation which was to form a part of the case study and to be informed of likely issues during the interview. It also meant that the interviewer could incorporate questions retrieved from their background research into the interview, rather than solely following the research questions from the case study protocol.

#### **Conducting Interviews**

Where possible, interviews were conducted at the place of work of the interviewee, so that they felt comfortable and were not inconvenienced by travel. Provision had been made for interviews to be held over Skype or by phone, in instances where an interviewee was too far away, or they opted to do it remotely. The interviewer(s) provided the information sheet and consent form to the participant days or weeks before the interview, and also prior to the commencement of the interview itself. These were explained to the interviewee before they signed the consent form.

One issue which was not discussed in advance, and from which the case studies would have benefited, was an interview methodology. Several of the case study authors had little or no experience in conducting social science interviews. As a result, some case studies were based on an interview following the precise questions found in the case study protocol, while other case studies took a more open interview style, covering many topics but in a less dogmatic way than indicated in the protocol. Furthermore, some interviews were carried out on a strictly one-on-one basis, while others were conducted in a workshop format involving one or two interviewers and up to three interviewees (for example, the telecommunications case study).

Over time, a high degree of flexibility was also required: Organisation who had nominally agreed to be interviewed pulled out (social media case study); some application domains were very difficult to find willing interviewees (energy case study); while some domains even proved to be impossible to find participants (banking & finance). These challenges were countered by changing organisations to those who were willing to be interviewed or changing the domain area entirely.

#### Reflection

Following each interview, the case study author scanned and uploaded a copy of the signed consent form to a central secure location on our website. UT ensured that all documents were uploaded by the partners and that it was clear what the interviewees had consented to in their agreement. Notes from each interview were consolidated, and a

thank you email sent to each interviewee. They were also informed that they would receive a first draft of the report once it was complete.

# **Reporting on Case Studies**

The reporting process on the case studies began in October 2018. This consisted of having each interview transcribed and analysed in NVivo. Following this, a draft of the full case study was composed and sent to the interviewee for confirmation. The draft was then sent to WP 1.1 leader (UT) for peer-review. The review document was then returned to the initial author, who had until the end of December to return a final draft. This draft was then submitted for the QA process in January 2019, which resulted in further edits being required from each case study author by mid-January. Finally, the final version was sent to the deliverable coordinator in the last week of January. This enabled the writing of the final report by the deadline of 31 January 2019 (see Fig 3).

					12/10/2018	26/10/2018	26/10/2018	31/10/2018	9/11/2018	30/11/2018	21/12/2018	31/1/2019
No	Case Study	Partner	POC	dPOC	Preliminary Analysis Conducted (at NVivo workshop)	Draft Report Written	Draft Report Sent to Interviewee(s)	Coding in Nvivo Complete	Draft Report Sent to UT	Draft Report Discussed with UT	Final Report Sent to UT	Final Report Written by UT
1	Employee Monitoring (IoT)	UCLanCY & AHR	Josephina	Andreas	Х	Х	X	Х	Х	Х	Х	Х
2	Government (municipalities)	UT	Mark	Kevin	Х	Х	Х	Х	Х	Х	Х	Х
3	Agriculture (agribusiness)	UT	Mark	Kevin	Х	Х	Х	Х	Х	Х	Х	Х
4	Sustainable Development (smart cities)	UT/EBS	Mark	Anya	х	х	х	х	х	х	х	x
5	Science (Human Brain Project)	DMU	Tilimbe	Bernd	Х	Х	х	Х	Х	Х	Х	Х
6	Insurance (Health)	EUREC	Natalija	Lisa	Х	Х	Х	Х	Х	Х	Х	Х
7	Energy (Smart Grid)	TRI	Tally	Rowena	Х	Х	Х	X	Х	Х	Х	Х
8	CRM (Telecoms)	UT/F-SEC	Kevin	Alexey	Х	Х	Х	Х	Х	Х	Х	Х
9	Tele coms (Cybersecurity)	UT/F-SEC	Kevin	Alexey	Х	Х	Х	Х	Х	Х	Х	Х
10	Manufacturing (SCM)	DMU	Tilimbe	Bemd	х	Х	х	Х	х	Х	Х	х

Fig 3: Progress chart

# **Transcription**

While each partner was responsible for the transcription of their interview(s), a transcription service was identified which could transcribe the interviews quickly and at a very competitive price. This company was recommended by several of the partners within the consortium and had a strong track-record in the industry. The structure of these transcriptions also allowed partners to analyse their data in a more consistent way in NVivo.

# **Data Analysis using NVivo**

It was decided to follow normal qualitative data analysis procedures (Charmaz, 2006; Miles and Huberman, 1994). The starting point were the ethical and human rights issues identified in the literature review. In order to remain open to new issues, all data concerning a case study would be analysed using these nodes, but allowing case study ORBIT Journal DOI: https://doi.org/10.29297/orbit.v2i1.102

authors to add and amend these. In order to ensure that this would be done consistently, the consortium decided to make use of a well-known qualitative data analysis tool, NVivo server 10. However, not all case study authors were familiar with interpretive and qualitative data analysis or the analysis tool. Therefore, a workshop was arranged for the 2<sup>nd</sup> week of October to introduce case study authors to NVivo and provide a focused period of time for the transcribed interviews to be analysed. The workshop environment meant that the methodology for using NVivo (such as whether to encode concepts or precise phraseology) could be discussed and agreed as a group. Prior to the workshop, comprehensive notes on the use of NVivo were compiled and sent to case study authors.

The NVivo workshop proved to be a strong success, with most of the nodes for the case study analysis being created over the two-day period. There were some technical issues with the system which were ultimately overcome.

#### Writing, Reviewing and Editing Drafts

Following the NVivo workshop, case study authors had 3 weeks to compile the first draft of their case study. This essentially involved pulling together background research and the interview to identify what the main ethical issues facing that particular organisation had been, and whether the interview had raised ethical issues which had not been identified in the literature

Most case study authors were able to submit a first draft of their report by the first week of November. At this stage, each case study was returned to the interviewee for approval. This was to ensure that the interviewee agreed on the content of the interview as presented. However, most interviewees were extremely busy and did not respond to the case study author. Given that the case studies had already received consent in advance of the interview, it was decided that interviewee confirmation of the case study was good to have but not essential, as it could have led to indefinite delays on the finalisation of each case study. However, it was also agreed to anonymise the interviewee unless there was a specific written consent by the interviewee to include their names in the final document.

Following its submission to the project leader, each case study was subject to peer review by two academics at the University. The peer review process looked at a number of issues, including quality of content, quality of English, and consistency of style across all of the case studies. When the case study had been reviewed it was returned to the author for appropriate edits. On occasion, it proved more time efficient for the peer reviewers to make stylistic changes themselves and for the author to confirm using track changes. The revised version was returned by mid-December.

The QA process took place in January and performed the function of a third peer review and highlighted further issues which had not been recognised previously. Once each case study had been reviewed by the QA process it was returned to its originating author for final edits before being sent on to the leader of the case study task and the project coordinator. The task leader then combined all of the case studies into a single deliverable for submission to the European Commission by 31<sup>st</sup> January 2019, and the project coordinator conducted final edits before submitting them to the project workbook and the ORBIT Journal.

One question uncovered by the QA process concerned the intended audience of the case study which had ramifications for their formatting. On the one hand, the intended audience was the European Commission, and through them practitioners who would be looking at the case studies as a means of understanding ethical issues within their own particular application domain. On the other hand, the case studies had been carried out in a rigorous manner such that they were suitable for publication in a social science journal. This meant that for each case study there were 2 intended audiences: academic and non-academic. It was decided that the case studies should be accessible for both academic and non-academic audiences. In order to entice non-academic readers to engage with the cases and to render them more accessible, the authors were encouraged to use visual elements and limit the length of the text. As a result, the cases published in this special issue of the ORBIT journal are more visually diverse than is normally the case for academic journals, including the ORBIT journal itself.

#### Conclusion

This paper describes the development of 10 case studies of ethical and human rights issues in SIS, thus making an important contribution to the larger discussion of AI and big data. These SIS case studies bring the first large-scale empirically-grounded analysis of what is happening across a number of sectors in Europe, such as government, health care, cybersecurity, telecommunications and insurance. A number of key challenges were faced in the design and development of the 10 case, but along with this quite a few lessons have been learnt. This concluding section will look first at the challenges faced and then lessons learnt, which should be taken as recommendations for future case study management and development.

# Challenges

There were a number of challenges faced throughout the project. Contributing to many of these was the lack of experience of many of the case study authors. Of the 10 case studies, 6 were carried out by authors with little or no social science

experience/background. This meant that these authors had to be trained in data collection (interviews) as well as data analysis principles and techniques.

A second challenge was the lack of time available to develop the case studies. It was agreed at an early stage that the case studies would be stronger with more interviewees. However, the realities of the time constraints provided with the work package meant that it was difficult to do this.

The third challenge was the time assigned to partners for writing the case studies. For some partners, this proved to be too demanding, and there was some shuffling of PMs between partners to focus efforts on a handful of.

A fourth challenge was that some partners dropped out of the process owing to red tape issues within their organisations. In yet other cases, no partners were found within the application domain at all. This was particularly true of the banking and securities sector, in which a case study had been envisioned to focus on the use of SIS in trading of securities

Technical problems with the NVivo software formed a fifth challenge. As servers on which NVivo was hosted were migrated, crucial information was lost, leading to work having to be duplicated. Most of the information was regained from backups, but this delayed the work.

The sixth challenge was the focus on intended audience. The case studies had been conducted with a primarily academic audience in mind, with a view to the publication of the case studies in a special issue of an academic journal. However, it was decided to make the case studies attractive and approachable for non-academics, and so included elements that an academic paper would not necessarily concern itself with, such as pictures, charts, and tables.

Challenge	Explanation
Experience	Lack of social science experience among some of the case study authors
Time	Lack of time for more interviews within organisations and additional organisations
Planning	Insufficient time allocated to some case study authors
Participation	Difficulty identifying, confirming, and liaising with case study participants
Technical	NVivo software crashing, incompatibility with Apple computers
Audience	Contradictory intended audiences

**Table 9**: Challenges encountered during the case study research

# Insights

The initial step of drafting the case study protocol, while not ideal, went a long way to shaping expectations and providing consistency for the case studies. This consistency was aided further by the identification of a pilot case study at a very early stage in the process. Although this meant that the author of the pilot case study had to work harder than others in terms of keeping ahead of the pack, it did mean that consistency could be achieved more effectively.

The weekly case study Skype calls were also crucial to the successful completion of the case studies to a high standard within the time allotted. These are both provided a sense of team coherence and avoided case study authors feeling neglected or ignored. They also introduced an element of accountability on a regular basis which meant that few case studies fell behind, because each author knew that they had to give an account about their progress on a weekly basis.

The data analysis workshop was another notable success within the project. In conjunction with the weekly Skype calls, this led to the case study authors meeting in person for the first time as a group. It allowed for collective discussion on methodology and approach, and ensured that the majority of the case studies were all at a suitable point of progress by mid-October 2018.

Finally, the project leader was supportive throughout the process of the development, writing, and reviewing of the case studies. He attended a significant number of the weekly Skype calls, making himself available for clarification purposes. He provided encouragement and support, rather than attempting to be disciplinarian. He was understanding towards the partners with no social science experience and was very accommodating to reviewing the case studies. This was very much appreciated by the case study authors and provided the effective guidance required for high-quality case study reports.

# **Next Steps**

This account of the case study research has formed the basis of all case studies that are published in the same special section of the ORBIT journal. One central reason for providing this account is that it removes the onus from the individual case studies to report on methodology, leaving them free to focus on the substantive findings. The individual 10 case studies that were originally included in the project deliverable are published as separate papers, following a final round of review.

The special section stops here and provides the full cases. The obvious next step that will be reported elsewhere is the analysis across the 10 cases. This multiple case study exercise was conducted to collect insights across the broad range of SIS and a cross-case ORBIT Journal DOI: https://doi.org/10.29297/orbit.v2i1.102

analysis is called for, to extract what those broader insights are. This work is under way and will be made available in an appropriate venue in due course.

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# **Appendices**

# **Appendix A: Case Study Protocol**

We used exploratory case studies to uncover ethical issues which arise through the use of SIS across a number of different types of organisations. From the individual case studies, we will take a cross-case analysis to build a matrix of ethical issues experienced by different organisations. The primary research question was: How do organisations perceive ethical concerns related to SIS and in what ways do the organisations deal with them?

We believed that there would be discrepancies between how companies deal with the ethical considerations related to the SIS they employ. While some companies would search for the ethical considerations and deal with them well, some would search for them and deal with them poorly, others would search for them and not find any (even though they are present), while a fourth group would not search for them at all. We wanted to gain evidence from of each of these cases to address the empirical plausibility of the research question.

#### **Epistemology**

Researchers need to decide on the research approach that most accurately addresses their research questions. Epistemology is a viewpoint about the nature of enquiry, the kind of knowledge discovered or produced, and the kind of strategies that are consistent with this (Becker and Niehaves, 2007). Our research sought to understand the ethical and human rights issues arising from SIS from the perspective of those developing it. Our case studies adopted an interpretivist approach, which allowed for both rigour and flexibility (Walsham 1995). It enabled researchers to empathise with research participants and seek to elicit insights, rather than an objective truth. This allowed us to understand 'reality' as the blending of the various (and sometimes conflicting) perspectives which coexist in social contexts, the common threads that connect the different perspectives and the value systems that give rise to the seeming contradictions and disagreements around the topics discussed. Whether one sees this reality as static (social constructivism) or dynamic (social constructionism) was also a point of consideration, as they both belong in the same "family" approach where methodological flexibility is as important a value as rigour.

With interpretivist approaches, it is often difficult for novice researchers to maintain consistency and coherence, as is for untrained evaluators to assess its rigour. Explicating

the methods, protocols and procedures to be followed, as well as the reaching a common understanding of the semantics that underlie the research is of paramount importance. Hence, the following section explains in detail the methodology employed for the collection and analysis of the research material and their synthesis with the view to theorise around the ethical and human rights issues arising from SIS.

#### Methodology

The methodology that was used to answer the research question would be through qualitative case studies (Yin, 2015, 2003). As such the case study is defined by the interest in individual cases, which are the object of the research (Stake, 2005). The cases that were used in the SHERPA project were contemporary and complex functioning units, investigated in their natural context. The essence of using a case study methodology is that it allows for triangulation in coming up with a matrix of ethical issues experienced by different cases. Also, the qualitative case study methodology was ideal because of the descriptive and exploratory nature of the research which is dominated by 'how' and 'what' questions in gaining insights on the ethical issues that result from SIS and how they are dealt within respective cases.

We looked for diverse examples of SIS use which will highlight both common issues and anomalous issues across the cases. Each case study is exploratory, aiming to uncover the insights of organisational representatives on the matter and possibly the position of their organisation as a result. The case studies adopted an interpretivist approach, which allows for rigour in the methodology, but also for the required flexibility (Walsham 1995). The unit of analysis for each case study was the use of SIS in the organisations (cases) investigated, be these corporate, governmental, NGO, project or other. We examined the cases from multiple lenses and levels of analysis (Rowley, 2002) in order to provide a holistic understanding across organisational levels, disciplines and technology domains.

#### **Data Collection**

In order to explore how different cases or organisations perceive ethical concerns related to SIS and in what ways they deal with them, the following types of data sources were used:

- Documents (e.g. organisation website and publications, company records, project documents and memoranda, illustrative materials (newsletters, publications that form part of the history), archival records) (see Table 5)
- Interviews (at least 2, open-ended, semi-structured, questions below face-to-face is best, otherwise telephone/Skype) to be transcribed (see Table 6)

There was a minimum of one interview per case study from different professional disciplines (i.e. a business representative and an IT representative). It was important to address the interview questions to those most able to answer them (e.g. a Chief Technical Officer - CTO). However, in most cases, it was also valuable to speak to a Policy Advisor or others at the organisation who can address the impact of the technology on society. In some cases, the CTO was in a position to address all of the questions sufficiently (e.g. the government case study). Beyond the interview(s), supporting/supplementary information was required to develop a contextual understanding of the case study and lend credence to (or criticise) the responses of the interviewee.

Number	Research Question
1	In which sector is the organisation located (e.g. industry, government, NGO, etc.)?
2	What is the name of the organisation?
3	What is the geographic scope of the organisation?
4	What is the name of the interviewee?
5	What is the interviewee's role within the organisation?

**Table 5:** Desk Research Questions

No	Research Question
1	What involvement has the interviewee had with SIS within the organisation?
2	What type of SIS is the organisation using? (e.g. IBM Watson, Google Deepmind)
3	What is the field of application of the SIS (e.g. administration, healthcare, retail)
4	Does the SIS work as intended or are there problems with its operation?
5	What are the innovative elements introduced by the SIS (e.g. what has the technology enabled within the organisation?)
6	What is the level of maturity of the SIS? (i.e. has the technology been used for long at the organisation? Is it a recent development or an established approach?)
7	How does the SIS interact with other technologies within the organisation?
8	<ul> <li>What are the parameters/inputs used to inform the SIS? (e.g. which sorts of data are input, how is the data understood within the algorithm?)</li> <li>Does the SIS collect and/or use data which identifies or can be used to identify a living person (personal data)?</li> <li>Does the SIS collect personal data without the consent of the person to whom those data relate?</li> </ul>
9	What are the principles informing the algorithm used in the SIS (e.g. does the algorithm assume that people walk in similar ways, does it assume that loitering involves not moving outside a particular radius in a particular time frame?)  • Does the SIS classify people into groups? If so, how are these groups determined?  • Does the SIS identify abnormal behaviour? If so, what is abnormal behaviour to the SIS?

10	Are there policies in place governing the use of the SIS?
11	How transparent is the technology to administrators within the organisation, to users within
	the organisation?
12	Who are the stakeholders in the organisation?
13	What has been the impact of the SIS on stakeholders?
14	How transparent is the technology to people outside the organisation?
15	Are those stakeholders engaged with the SIS? (e.g. are those affected aware of the SIS, do
	they have any say in its operation?)
	If so, what is the nature of this engagement? (focus groups, feedback, etc.)
16	In what way are stakeholders impacted by the SIS? (e.g. what is the societal impact: are
	there issues of inequality, fairness, safety, filter bubbles, etc.?)
17	What are the costs of using the SIS to stakeholders? (e.g. potential loss of privacy, loss of
	potential to sell information, potential loss of reputation)
18	What is the expected longevity of this impact? (e.g. is this expected to be temporary or
	long-term?)
19	What has been the impact of the SIS on stakeholders?
20	Are those stakeholders engaged with the SIS? (e.g. are those affected aware of the SIS, do
	they have any say in its operation?)
21	If so, what is the nature of this engagement? (focus groups, feedback, etc.)
22	In what way are stakeholders impacted by the SIS? (e.g. what is the societal impact: are
	there issues of inequality, fairness, safety, filter bubbles, etc.?)
23	What are the costs of using the SIS to stakeholders? (e.g. potential loss of privacy, loss of
	potential to sell information, potential loss of reputation)
24	What is the expected longevity of this impact? (e.g. is this expected to be temporary or
	long-term?)

**Table 6**: Interview Research Questions

#### Recording and management of data

The interviews were recorded using a suitable tool that allowed access in a broadly accessible format (e.g. mp3). All interviews were transcribed by the researcher or by a reputable third-party company (UKTranscription). The individual undertaking the interview had to confirm and validate the transcription. Once the interview data has been analysed, the researcher deleted the audio recordings. All data including the interview transcripts were stored and logged in secure group repository (WordPress and NVivo). The audio files were deleted, once the analysis of the interview was completed.

#### Data analysis

The collected data was analysed using a thematic analysis technique. In using a thematic analysis, we were able to highlight, expose, explore, and record patterns within the collected data. The themes are patterns across data sets that are important to describe several ethical issues which arise through the use of SIS across a number of different

types of organisations. In addition, NVivo was used as a tool for the data analysis. UT will also engage in a cross-case analysis of the ten different case studies, which will draw together ethical issues arising in the ten case studies. This will then form the backbone for the ethical analysis in WP1.4.

#### **Guide for Final Report**

Each case study culminated in a final report consisting of an analysis and identification of core ethical issues that arise in the case study. The issues included likely and unlikely ethical concerns (see Table 7). For consistent reporting across the 10 case studies, a template for the final report was provided (see Appendix C).

Ethical Issue	Question Example	<b> </b> √
Privacy	Does the use of the technology raise concerns that people's privacy might be at risk or endangered?	
Personal Data	Does the technology or its use presume a particular group or person "own" the data? If so, who?	
Security	Does the technology use personally-identifying data? If so, is this data stored and treated securely?	
Inclusion of stakeholders	Are people affected by the technology involved in any way with its use or implementation? Do they have an opportunity to have a say in how the technology impacts them?	
Consent of stakeholders	Have people affected by the technology been given an opportunity to consent to that technology existing or having the impact that it does on their lives?	
Loss of employment	Does the use of the technology put people's jobs at risk, either directly or indirectly?	
Autonomy/agency	Does the use of the technology impact in any way on people's freedom to choose how to live their lives?	
Discrimination	Can/does the technology or its use lead to discriminating behaviour in any way? Does the technology draw on data sets that are representative of those stakeholders affected by the technology?	
Potential for military/criminal/ nefarious use	Could the technology be used for military, criminal or other ends which were not envisaged or intended by its developers?	
Trust	Does the technology impact people's trust in organisations, other people, or the technology itself?	
Power asymmetries	Can or does the technology exacerbate existing power asymmetries by, for instance, giving a large amount of power to those already holding power over other people?	
Inequality	Can or does the technology reduce inequalities in society or exacerbate them?	
Fairness	Is the technology fair in the way in which it treats those affected by it?  Are there unfair practices which arise in relation to the technology?	

Justice	Does the technology or its use raise a feeling of injustice on the part of	
	one or more groups affected?	
Freedom	Does the technology or its use raise questions regarding freedom of	
	speech, censorship, or freedom of assembly?	
Sustainability	Is the technology or its use sustainable, or does it draw on limited	
	natural resources in some way?	
Environmental	Does the technology have any impact on the environment, and if so	
impact	what?	

**Table 7:** Checklist of Ethical Issues

#### **Outline of narrative**

The final report took a narrative structure. In constructing the final report, partners addressed the hypothesis to avoid drowning in the data (there were many aspects arising in the course of the research which were not strictly pertinent to the ethical issues in the case study). The analysis rested on all of the relevant evidence, rather than "cherry picking" certain aspects. For instance, it may be possible to see a privacy violation occurring, but the organisation in question may have also recognised this and taken steps to resolve it. In such cases, both the potential violation and the mitigation were noted. This was not intended to be a comprehensive report on everything uncovered in the course of the research, but a report on the ethical issues. Ultimately, "the goal of the report is to describe the study in such a comprehensive manner as to enable the reader to feel as if they had been an active participant in the research and can determine whether or not the study findings could be applied to their own situation. It is important that the researcher describes the context within which the phenomenon is occurring as well as the phenomenon itself." (Baxter & Jack 2008, p555).

#### **Potential Issues**

We identified a number of potential issues that were to be addressed during the interviews, qualitative analysis and writing up of the reports (see Table 8).

Issue	Explanation of Issue			
Unbounded	We are interested in ethical issues arising from the use of SIS in organisations.			
	Hence, we want information relating to the use of SIS and ethical issues that the			
	organisation has recognised and either dealt with or chosen to ignore			
Incomparable	It is extremely important that the case studies be comparable. We are therefore			
	adopting a positivist framework and using this case study protocol to inform the			
	design of every case study to ensure comparability. This will be supplemented by			
	bi-weekly meetings to discuss progress and share experiences. "The rigour off			
	case studies should therefore be judged by the same criteria [as any other			
	empirical, scientific method] of internal validity, external validity, construct			
	validity, and reliability" (Yin 1992 p124)			

Contact does	Raw data is highly valuable in these case studies to allow for developed analysis.
not have	However, it is accepted that this may not be available (or shareable with us). In
access to	those cases, focus will be placed on issues faced and dealt with (or not as
relevant	applicable) by the organisation.
material	
Understanding	All case studies will be preceded by the principal investigator conducting
issues	background reading of Yin (1992), Mittelstadt et al (2014) and Macnish (2010) to
	gain an understanding of the purpose of the case study (Yin 1992), the range of
	issues currently identified in use of algorithms (Mittelstadt et al 2014) and an
	example of how analysis of an algorithm's parameters can lead to ethical
	concerns (Macnish 2010).

**Table 8:** Potential Issues

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# Appendix B: Ethics Approval

# **B.1 Consent Form**

Issue	Respondent's initials			
I have read the information presented in the information letter about the case study				
I have had the opportunity to ask any questions related to this study, and				
received satisfactory answers to my questions, and any additional details I wanted.				
I am also aware that excerpts from the interview may be included in				
publications to come from this research. Quotations will be kept anonymous				
unless I give specific permission to the contrary (below).				
I give permission for my name to be associated with excerpts from the				
interview which may be included in publications to come from this research.				
I give permission for my organisation to be identified in any final publications				
produced by SHERPA.				
I give permission for the interview to be recorded using audio recording				
equipment. (if necessary).				
I understand that relevant sections of the data collected during the study may				
be looked at by individuals from or a project partner from SHERPA. I give				
permission for these individuals to have access to my responses.				
I understand that the audio recording may be given to a transcription service				
company to transcribe. I give permission for these organisations to have				
access to my audio files for transcription purposes				
With full knowledge of all foregoing, I agree to participate in this study.				
I agree to being contacted again by the researchers if my responses give rise to interesting findings or cross references.				
□ No □ Yes				
If yes, my preferred method of being contacted is:				
☐ Telephone:				

☐ Email:						
☐ Other:						
Participant		Consent				
Name		taken by				
Participant		Signature				
Participant Signature						
Date		Date				

#### **B.2 Consent Form Information Sheet**

SHERPA - Shaping the ethical dimensions of smart information systems (SIS) – a European perspective

Task 1.1 – Case Studies

Please take some time to read this information and ask questions if anything is unclear.

Contact details can be found at the end of this document.

#### What is the purpose of this study?

This study aims to develop a case study for the SHERPA project regarding ethical issues arising in the use of artificial intelligence and big data (Smart Information Systems - SIS). This information will be used to develop an analysis of these ethical issues and, thereafter, a workbook on the responsible development of SIS. The information gained from these interviews will identify potential gaps in understanding and reinforce comprehension of well-known issues.

#### Who is organising this research?

The research for this study is being undertaken by

A Research Ethics Committee has reviewed and approved this research.

#### Why have I been chosen?

The project aims to develop 10 case studies from a number of different contexts. These will include business, government, insurance, agriculture and banking. The aim is to develop a broad understanding of ethical issues spanning these contexts, recognizing

similarities and differences. You have been chosen as a member of one of these contexts with a good understanding of the use of SIS within your own particular context.

#### Do I have to take part?

Participation in this study is voluntary and you may ask any questions before agreeing to participate. If you agree to participate, you will be asked to sign a consent form. However, at any time, you are free to withdraw from the study and if you choose to withdraw, we will not ask you to give any reasons.

#### What will happen to me if I take part?

If you agree to take part in this study we will interview you in person, or by phone/Skype, regarding your experience with SIS.

We may ask you to participate in a follow-up interview, though participation in this is optional.

#### What are the possible benefits of participating?

The study aims to develop an understanding of ethical issues, the purpose of which is to inform the SHERPA project proposals for the responsible development of SIS. In addition to helping the SHERPA project, advanced ethical analysis will be carried out on the case study to which you contribute, which may raise issues that your organisation would like to know about and take steps to remedy.

#### What are the possible risks of taking part?

There are no risks in taking part in this study. At any time during the interview you can choose to withdraw. You may also choose to withdraw your data from being used in the project at any time until 1 January 2019.

#### How will my interview be used?

The case studies will combine quantitative and qualitative elements and will be designed and analysed by SHERPA project partners who have experience in ethical analysis. The recording of the interview may be transcribed by parties outside of the consortium. If this happens, the transcription company will delete the recording and transcription after the transcription is approved. On the consent form we will ask you to confirm that you are happy for the SHERPA consortium to use and quote from your interview. Any such use will be anonymous unless you indicate otherwise on the consent form. Information which

will identify your organisation will also be kept out of publications unless otherwise indicated on the consent form.

#### What will happen to the results of the project?

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be identified in any reports or publications and your name and other personal information will be anonymised unless you indicate otherwise on the consent form.

#### What happens to the interviews collected during the study?

The interviews will be transcribed by the interviewers or a designated, approved third-party agency. If we use a third-party transcription service, we will ensure that there is a signed data processing agreement in place. The audio files will be deleted, once the analysis of the interview is complete.

#### What happens at the end of the project?

You may request a summary of the research findings by contacting Kevin Macnish, University of Twente (<u>k.macnish@utwente.nl</u>).

#### What about use of the data in future research?

If you agree to participate in this project, the research may be used by other researchers and regulatory authorities for future research.

#### Who is funding the research?

This research is funded by the European Commission] under grant no. 786641.

#### What should I do if I have any concerns or complaints?

If you have any concerns about the project, please speak to the researcher, who should acknowledge your concerns within ten (10) working days and give you an indication of how your concern will be addressed. If you remain unhappy or wish to make a formal complaint, please contact Kevin Macnish, <u>k.macnish@utwente.nl</u>.

#### **Fair Processing Statement**

This information which you supply and that which may be collected a part of the project will be entered into a filing system or database and will only be accessed by the researcher and supervisor involved in the project. The information will be retained by the researcher's institution and will only be used for the purpose of research, statistical and

audit and possibly commercial purposes. By supplying this information you are consenting to us storing your information for the purposes above. The information will be processed by use in accordance with the provisions of the Data Protection Act 1998. No identifiable data will be published.

# **Appendix C Template for Final Report**

Length: 7500 - 9000 words

#### Structure:

1. Introduction -300 - 500 words

#### Introduce

- A. The topic and describe the aim of the report
- B. Any case-specific research question(s),
- C. Methods (to the extent different from the general approach advocated for the case studies) and
- D. Outline of the remainder of the report.
- 2. Background review: ethical issues in the application domain you are discussing (e.g. SIS in health care) 1500 2500 words

(Literature review)

- A. Description of the domain and its use of SIS (i.e. how SIS is currently being used in healthcare)
- B. Survey of ethics literature of SIS in the domain you will discuss, as well as own identification of ethical issues [Do this is a systematic way that gives an overview of ethical issues that have been identified and discusses each]
- C. Conclusion

- 3. Introduction to the case study and descriptive analysis 2000 2500 words (Empirical research, interviews, literature study presented in journalistic style)

  Description of the setting:
- A. description of the organisation(s) and individual(s) interviewed interview questions 1-6,
- B. of the SIS systems(s) being used by the organization(s) interview question 7,
- C. the aims of the organization(s) in using these systems interview question 8,
- D. does the system work as intended or are there issues with its operation interview question 9,
- E. identify some general (non-ethical) impacts that the system has (had) on the organization interview questions 10-12.
- F. the way in which the system(s) work interview questions 13-14,
- G. the policies governing the system(s) use interview questions 15-16,
- H. who are stakeholders and what is the impact on them interview questions 17-24
- 4. Ethical issues -2000 2500 words
- A. Identify benefits and harms of the system from the point of view of stakeholders.
- B. Identify ethical issues with the system(s),
- a. That are the result of the design and normal operation of the system, and
- b. The particular uses and responses to it or its impact by stakeholders. (These can be ethical issues recognized by stakeholders or not recognized.)
- c. Discuss the extent to which these are recognized by stakeholders and any remedial measures that have been taken already (laws, policies, initiatives, redesigns, etc.).
- d. Draw upon the information gathered during the interviews; literature study; and research about the case

5. Conclusion 500 - 1000 words

Summary of findings.

- A. What have we learned from the case study?
- B. What are possible ways in which the ethical issues can be mitigated?
- C. What further investigations should be done?