



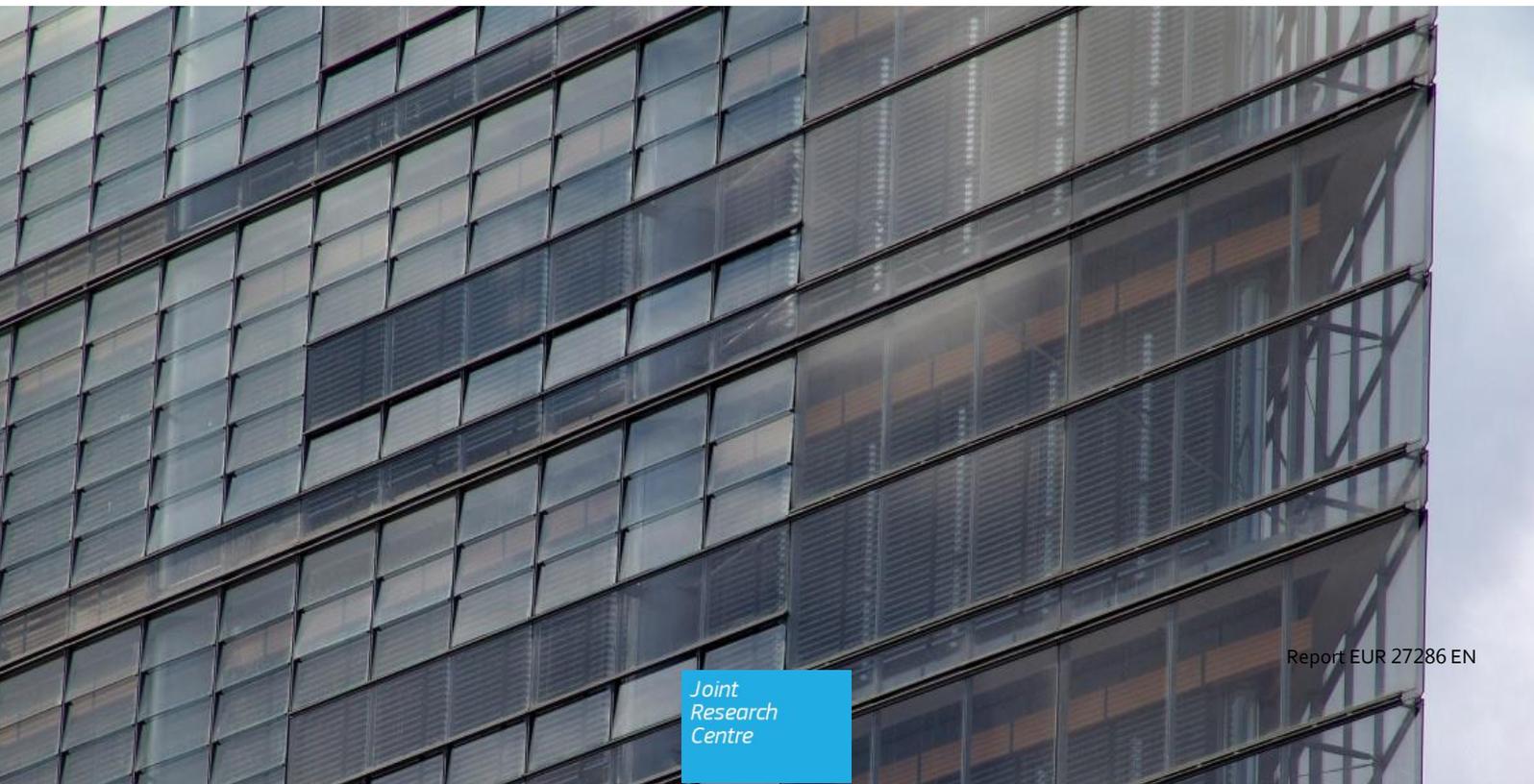
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# Institutional trust: beyond transparency

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Abstract

The report presents reflections, thoughts and results from two workshops held at JRC premises in 2014: the first was "Digital memories: Ethical perspectives" ( 16th-17th January 2014) and the second "Open Data in health" (18th November 2014). The cases presented in the workshop cover different area of citizen involvement: health, can be perceived as more immediate.

The reflection on how digital changes habits and access to data health was supported, in the workshops, by national authorities', journalists' and citizen participation experiences and cases.

The memories and its management, with and after the evolution and the widespread diffusion of the digital technologies, was presented by librarians, archivists and experts of institutions of memories taking in consideration digital native and not document and archives.

Both sectors, health and memories, are traditionally institutionally managed and the administration was for centuries not delegate to others than public institutions.

With the advent of Open Access, Open Data and an ever more pervasive digital diffusion institutions should faces the changes and the suggestion from citizen. Crucial is to be aware on how the digital changes the access and the management in these areas and how power relations are modified and enriched in the net(works).

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*“Trust is a peculiar resource. It is built rather than depleted with use”*

Anonymous



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# Summary

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# 1. Introduction: trust, ethics and institutions in the digital realm

## 1.1 On trust

The concept of trust has several meanings and definitions. Rosseau et al. (1998) identified trust as “a psychological state comprising the intention to accept vulnerability based upon positive expectations of behaviour of another”, whereas Lewicki and Tomlison (2003) described trust as “an individual belief in, and willingness to act on the basis of the words, actions, and decisions of another”. Lewis and Weigert called trust a highly complex and multi-dimensional phenomenon. These definitions bring us to a knowledge-based conception of trust, in which trust depends on information and experience. Giving the fact that it is difficult to be knowledgeable about who “another” is in the cyberspace (Dutton et al., 2013), in the throes of going digital we cannot avoid making ourselves vulnerable to many others.

The impossibility of directly check other individuals’ actions in cyberspace has brought a diminishment of interpersonal trust on one hand, and the need for reassuring institutional trust on the other, as a direct consequence of trusting virtual entities, instead of people.

“A person trusting an institution, then, is making herself vulnerable to the actions of others guided by the institution as a consequence of what she knows about the regularities [or irregularities] of institutional behaviour and about the behavioural incentives [or obligations] as set by the institution” (Lahno, 2001).

Institutions are trusted because it is assumed that shared private information can remain “confidential” (Richards et al. 2014) and also because there is the overarching idea that the institution itself is trustworthy. However, a recent study discussed the high corruption levels in EU countries that ‘undermines the trust of citizens in democratic institutions and processes’ (COM(2014) 38 final) and ‘High profile scandals associated with corruption, misuse of public funds or unethical behaviour by politicians have contributed to public discontent and mistrust of the political system’, and to some extent also mistrust in institutions (Yeo, 2013). Nonetheless, institutional trust should not be grounded on individual behaviours (Ariansen, 2003), as individuals deeply impact institutions themselves, generating, as a consequence, a devastating loss of trust in institutions. In addition, the “digital” turn of institutional practice is emphasizing the sense of distance amongst institutions - as trusted agents - and citizenship. Hence, “as with individuals, the question of whether we can reasonably trust institutions reduces to the question of whether institutions can be trustworthy” (Hardin 1998). If institutions – and the people behind them – derailed from their institutionally grounded behavioural tracks, can we still rely on institutions? Are the guiding rules for institutions still effective?

Going digital therefore means loosening the prerequisites for ensuring trusted stable relationships, i.e., traditional bonds and or enduring interactions (Lahno, 2001). Consequently society needs to find other bonds that may support trust in the digital landscape. What forms can these have?

Internet mediated communications and transactions are supposed to increase interactivity with and transparency and accessibility of governments (Song, 2013) and institutions, which are elements that sustain trust between citizens and institutions. Interactivity has been particularly reinforced by making institutional services available online; yet, putting technologies at the service of institutions does not automatically map on trustworthy relationships – at most they are just maintained: ‘These interactions do not consume or produce trust. They just happen’ (Uslaner, 2001).

With the digital turn, trust is more than technologies ensuring privacy, secure transactions and digital signatures – certainly very important; but we argue that it is much more about engaging citizens in the debate about what makes an institution transparent, accountable and effectively responsive to citizens’ needs. Hitherto, governments and institutions seem to be mainly focused on communication - a one-way strategy - whereas citizens are demanding two-way communications, in ‘which individuals [could be] creators of content rather than just passive recipients (Welch *et al.*, 2004). Digital trust is also dependent on multi-generational, multi-regional, multi-cultural... interactions and social perspectives. Consequently, in order to nurture trust, multi-layered, technical and non-technical ways of interweaving the social digital fabric are required.

‘The citizen perception of trust is a cognitive [and subjective] reflection of the information and data obtained by the public regarding governmental [institutional] performance’ (Welch *et al.* 2004). In a setting where citizens have been used to democratic access and creation of information without any intermediation, this statement seems to us rather incomplete. We hypothesised that citizen approach to trust is also about the quality, veracity and accuracy of the data provided by governments, as well as the accessibility and preservation of data outside institutional walls. Moreover, it is also linked to practice of knowledge governance that reflects the multiplicity of sources and plurality of perspectives in knowledge production and assessment (for example, interpretations of historical and political accounts; scientific uncertainty in policy relevant science, etc.). Citizens’ expectations are no longer based on institutions acting according to rules that assume their privileged position, but rather on direct ways of making institutions accountable. Moreover, in an era of Open everything paradigm (Stelle, 2014), if such expectations are not met by institutions, society will organise in different ways as already demonstrated in recent times (for example, wikileaks is an expression of alternative ways to truth seeking) further eroding institutional trust.

We reckon that there is a misconception about transparency in the digital domain. A number of institutions have based their accountability strategy on opening data, because in their view this narrows down the information gap between citizens and governments. But, do citizens and institutions have the same ideas about how transparency, and consequently trust, need to be faced? What are the meanings of transparency and trust about in a digital context? Is files' opening enough to make an institution transparent, or should we look beyond transparency?

In the present report we would like to explore how meaningful transparency and co-production could restore trust in institutions. On one hand, the traditional belief that institutional processes are designed in the most suitable way for serving citizens could be checked by a meaningful transparency. We argue that meaningful transparency means providing citizenry with tools and knowledge that make them capable of making institutions accountable towards all citizens. On the other hand, co-production and hands-on initiatives, directly checked and experienced by citizens should be promoted, in order to open ‘a path previously restricted by economic cost and industrial organization to small numbers of

professional producers of information, knowledge and cultural to large numbers of ordinary people, enabling them to contribute to the public good in a particular domain' (Blenker & Nissebaum, 2006).

From our perspective, the focus should move beyond updated institutional administrative practices to real transparency and wide accessibility, in Alter's words:

'How then can governments start to win back the trust of their citizens? First, we need to improve the measurement of trust and generate data to help policymakers understand the expectations of citizens. Second, we must address *big trust*, the ability of government to reassure citizens that it is taking care of the things that are beyond the control of individuals, though in a fully accountable, transparent, fashion. Government has to demonstrate that it can *govern for the future* and *govern for the unexpected*. Third, we need to build fairness in policymaking. This has at least two dimensions: first, prevent undue influence in policymaking by addressing the challenges posed by political financing and lobbying, and second, make policymaking and implementation processes more inclusive through information, and consultation with the public' (Alter, *Op. Cit*)<sup>1</sup>

## 1.2 Knowledge, knowledge production, and trust

Trust has been related to knowledge, and especially to scientific knowledge, in different ways and for different reasons. The most traditional, and somehow idealised, vision of science proposed by sociologist Robert Merton (Merton, 1968) was built on the assumption that the communality of knowledge amongst scientists—their creating and sharing scientific knowledge—is connected to their trustworthiness. Indeed, the practice of scientific work by scientists is depicted at the same time as the source for their correct ethical attitudes (the ethos of science) and the reason for being trusted by society.

The self-referential character of the scientific community towards society as the official validator of knowledge and as an undisputed ethical model have started been challenged with the emergence of risks and uncertainties—especially when science and technology are used to validate public decisions. Decisions adopted under conditions of uncertainties require the reliability and independency of experts involved in assessing those risks.

The emergence of risks and uncertainties that result from the social implementation of science brought to light a dual need. In the first place, the necessity to broaden consultation with scientists, wherever divergences of opinion emerge vis-à-vis the possible occurrence of potentially harmful events. In the second place, the need to directly involve citizens and sharing knowledge and decisions affecting society.

Trust has, therefore, switched from a taken-for-granted property of scientific knowledge-making to a goal that scientific and political institutions have to actively and accountably pursue in their relations with society. Trust has thus become the benchmark concept for citizens' attitudes vis-à-vis the

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<sup>1</sup> Alter, R. Building up trust. The Huffington Post <[http://www.huffingtonpost.com/oeed/building-up-trust\\_b\\_5263999.html](http://www.huffingtonpost.com/oeed/building-up-trust_b_5263999.html)> [Last accessed: 28.09.2014]

knowledge which informs public policies. The limited possibility of accessing information, of finding visibility and transparency in experts' procedural choices, of checking their credentials and possible conflicts of interest, of knowing and comparing different opinions, of controlling the content and form of technical and scientific decisions are elements of the problem.

Since the 1990s, the changes which have taken place in the relationship between science and society have left a profound mark on institutional arrangements and on all the rights which are linked to the social contract.

The digital revolution has certainly introduced unheard components to the relations between trust and knowledge, allowing new communities and new forms of collaborative production of knowledge to take place. This is why both the digital collecting, maintenance, and transmission of (past and present) memories as well as the institutional policies for open data appear to be interesting phenomena in generating trust.

### 1.3 The organisation of this report

The report presents reflections, thoughts and results from two workshops held at JRC premises in 2014: the first was "Digital memories: Ethical perspectives" ( 16th-17th January 2014) and the second "Open Data in health: how knowledge may generate trust" (18th November 2014). Why do we offer these two cases, what they contribute to the discourse of trust in institutions...

The cases presented in the workshop cover two different areas of citizen involvement: health, can be perceived as more immediate.

The reflection on how digital changes habits and access to data health was supported, in the workshops, by national authorities', journalists' and citizen participation experiences and cases.

The memories and its management, with and after the evolution and the widespread diffusion of the digital technologies, was presented by librarians, archivists and experts of institutions of memories taking in consideration digital native and not document and archives.

Traditionally both sectors, health and memories, are institutionally managed and, for centuries, their administration has been the privilege of public institutions.

With the advent of Open Access, Open Data and an even more pervasive digital diffusion institutions should faces the changes and the suggestion from citizen. Crucial is to be aware on how the digital changes the access and the management in these areas and how power relations are modified and enriched in the net(works). Today we have to front many new "knowledge objects" and entities, continuously transforming the established/traditional cycle of knowledge production, as we had known it for long time.

There is a crucial passage from single knowledge to a plural one. Once the production was or could be plural but the assessment and the governance was preeminently, if not exclusively, hierarchically and from the top managed, nowadays we are in context that has many facets, and the management is not

more delegable and delegated to a single institution. The knowledge and its management can be multidirectional and participative.

Normative and regulative questions arise and the definition of what is subject and or object in this evolving moment in the area of health and memories was one of the questions guiding us in the development of the workshop and of the report.

Health and memories: one more tangible, one more theoretical are taken as examples of two fields in which institution and citizen can have an active role in the process of developing and consolidating trust.

The reflections and the recommendations arising from the workshops are presented after a short introduction of the workshops themselves, followed by suggestions for further readings.

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## 2. Institutions of memory and Open data in health as relevant cases for building digital trust

*“the preservation of that cultural content rightly should be viewed as a matter of public trust, something that transcends individual or particular interests or ownership and that demands public resources and public policies to protect it” (Smith, 2007)*

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In the process of European integration, trusted relations between institutions and citizens have been highlighted as a key-element in establishing reliable conditions for citizens when dealing with institutions. The passage from primarily direct and human-based relations to mostly digitalised interactions has even increased the need for trust, not only as to the technical aspects of security measures (e.g. protection of data in the web), but also as to normative issues of transparency, accountability, openness, accessibility, etc. . ‘Trust in the digital environment relies on new methods for establishing and authenticating identity, and managing information in a way that supports security and privacy as well as sharing and access’ (Duranti & Rogers, 2012). Here, the expression building trust refers to the process of identifying and implementing the necessary requirements to frame and maintain confident digital interactions: this process needs some dedicated reflections and actions and should be shaped as a continued iterated process.

In such an important issue as the social making of history, it is quite relevant to find new attitudes towards memory like the ones *“of historians initially preferring digital collections created by trusted entities. Historians use digital collections by authentic institutions, such as the Library of Congress, and higher education institutions, earlier in the analyzing period, and their use of digital collections created by individuals or small nonprofit organizations occurs later”* (Sinn & Soares, 2014). Institutions of memory - as trusted institutions for preserving memories - are being displaced by other stakeholders. In the cases section, after our research, we are going to deep in what are the main factors involved, but it

is fair to anticipate that the lack of a corpus regarding ethical issues in institutions of memory is triggering some concerns about their trustworthiness. That is why at JRC we found interesting to approach the improvement of citizens' trust towards institutions, taking institutions of memory as a case of study.

The focus of this endeavour is on institutional and corporate digital historic identities vis-à-vis the impact of institutional compliance with privacy rules on the institutional image through time; ultimately, we want to seek to improve the conditions for conciliation between privacy rights and archiving obligations. Indeed, since the origins of the state under the rule of the law, different rights and obligations define and shape the moving boundaries separating and connecting private citizens and public institutions. As for more than a century privacy has been framed as the set of values aimed at preserving and protecting the intimacy and autonomy of individuals' lives, and is currently a fundamental right in many legal systems, public institutions are entitled and obliged to gather and preserve history and collective memories. Institutional memory has a long-standing tradition in terms of creating, maintaining and guaranteeing organisational identity, stability of relationships, trust and accountability, both within institutions themselves and towards citizens. These duties have been strengthened through the historical experiences of authoritarian regimes which erase institutional historical memory and through the transition towards e-government, where institutions primarily interact with citizens through the Web. Moreover, their ethical dimensions — if not a real citizens' right to institutional memory — have become apparent, as matters of personal identity and reputation and protection of family relations, as well as a commitment towards future generations, are involved.

Indeed, these practices aiming at keeping track and trace of institutional history can be seen as part of an institutional ethics, at least as conceived in the European context, namely how institutions 'should' — in all legal systems — behave in articulating, assessing and implementing values and moral principles related to their practices, procedures and policies. In the digital age, as institutions increasingly relate to, and interact with, citizens/users through the Web, and their Web self-representation already expresses not only a different channel of communication, but their metonymic image as a whole, institutional memory has become a relevant issue for ICT ethics. Moreover, other ethical concerns arise because new 'mechanical' players such as research engines are self-attributing the mission that was traditionally performed by human agents in those institutions.

In this context, we argue that values such as accountability, credibility, transparency, respect for identities and human agency should be also taken into account through the maintenance of institutional Web histories. Do we need a right to institutional Web history in order to ensure responsible, reliable, accountable and documented storytelling about our pasts? Time has passed since we first saw our lives going digital and we are witnessing some symptoms of urgency with regards to memory practice, in particular some undiscussed trends and transpositions from other realms that affect the practice of institutional memory; for example, private Web archiving practices, arbitrary deletion of websites or parts of them within institutions or just poor or labyrinth-like access to past sites, algorithmisation and automation of memory-keeping and access, discussions about the private and public value of memory, etc.

All these observations made it timely to take institutions of memory as a case of study.

*“Institutions can only persist because there are people who trust in them and because they do so in mutual understanding” (Lahno, 2001)*

A second relevant case as to highlight some current requirements in building digital trust is Open Data.

As already explained earlier in this report, since the origins of the scientific method and of the State under the rule of the law, knowledge, and knowledge production and exchange, have been depicted as essential elements of trustworthy institutions and of trusted public decision-making. As said, this connection between knowledge and trust has been fundamental in establishing the ethics and integrity of science within the scientific communities. In knowledge and technology-based societies the creation and sharing of knowledge represents a major path towards generating and maintaining trusted relations between institutions and citizens. In this context Open Data reveals a special relevance.

Before becoming a matter of institutional concern, open data was rooted in the practice of the scientific community. Researchers were the first who perceived the benefit of openness and of sharing of data. Already in the mid-20<sup>th</sup> century, in his classical portrait of the normative character of the scientific community, sociologist Robert Merton was supporting the idea of common good applied to knowledge and showing the benefits of open scientific data (and the need for an absence of intellectual property rights in research) (Merton, 1968) .

Open Data is, according to a widely accepted definition, data that can be freely used, reused and redistributed by anyone—subject only, at most, to the requirement to attribute and share alike. And, indeed, the very meaning of Open Data lies at the interface between epistemology and democratic theory.

The revised EU Directive 2013/37/EU on the re-use of public-sector information emphasises the "vast, diverse, and valuable pool of resources that can benefit the knowledge economy," especially in terms of development of new services based on novel ways of combining and applying such information – with the goals of stimulating economic growth and promoting social engagement.

However, even though Open Data have been framed by European institutions mostly as new field for economic development, the creation, use and reuse of data by citizens also represents a great opportunity to test and improve trust in institutional digital interactions.

On the one hand, from an epistemological perspective, the open character (especially) of science has been framed and proposed as both an indicator and an evidence itself of valid knowledge; on the other hand, from a political point of view, this openness has been associated to the democratic connotation of the society based on this kind of knowledge.

Indeed, the very meaning of Open Data lies at the interface between epistemology and democratic theory. Due to its potential for sharing knowledge and knowledge production, Open Data can play a unique role as to the task of shaping trusted digital relations. The concept refers to a deeply value-laden

vision of the human cognitive endeavor, namely the ideal of the universal and boundless sharing of knowledge; moreover, it is a phenomenon radically rooted in, and generated by, digital technologies.

Openness in Open Data, as the feature highlighting the correct approach to both epistemic and democratic systems, is shared by other "open" movements such as open source and open access. All these trends share a normative structure as to the relations between science and society. These are: availability and access, reuse and redistribution, and universal participation.<sup>2</sup>

First, data must be available as a whole, and at no more than a reasonable reproduction cost, preferably by downloading over the Internet. Also, the data must also be available in a convenient and modifiable form. Second, data must be provided under terms that permit reuse and redistribution including the intermixing with other datasets. Third, everyone must be able to use, reuse and redistribute. For example, 'non-commercial' restrictions that would prevent 'commercial' use, or restrictions of use for certain purposes (e.g. only in education), should not be allowed.

Health and health data add an interesting perspective to the topic of Open Data for several reasons. Health is a highly political domain, not only in terms of social welfare allocations, but also for its connections to the environment, environmental politics, and industrial policies. Environment and health are connected domains where knowledge production by citizens (citizen science) has often complemented, when not confronted, official knowledge. Moreover, significant changes are happening in how scientists and citizens relate and become "partners" in performing research (e.g. in genomic research). Finally, health is the domain where citizens are more willing to be directly engaged through the Internet and ICT devices.

It is definitely interesting to see how, through several web-mediated initiatives, health data have become a way for citizens and researchers to argue against certain legal regulations and restraints, and to introduce new rights. This is the case, for instance, of genetic information as public, and not just medical, knowledge (and the fight against limitations for for Direct-to-Consumer tests) (Vayena, 2014) as well as of access to raw genetic data as a new (moral) individual right (Lunshof *et al.*, 2014).

Even though Open Data have been framed by European institutions mostly as new field for economic development, the creation, use and reuse of data, and especially health data, by citizens also represents a great opportunity to test and improve trust in institutional digital interactions.

This is the rationale for looking at trust through the case of Open Data in health.

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<sup>2</sup> <http://opendatahandbook.org/en/what-is-open-data> [Last accessed: 02.12.2014]

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## 2.1. Case of study 1: Institutions of memory

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### 2.1.1. Overview and background

With the pervasiveness of ICT and progressive hybridisation of our online and offline lives, institutional archives (institutions of memory) are also undergoing a continuous and fast process of adaptation. First, institutions of memory have been urged to modify their working and preservation procedures to allow digital documents to enter the archive. During the 2000s, the spreading of social networks and the massive participation of citizens as active content creators for the Web raised new issues for the governance of the institutions of memory. Besides complex technical problems, which are mainly due to the abundance of digital information and its apparently easy and costless retrieval, some ethical issues have emerged.

Firstly, digital memories generated outside an institution seem to be expected to form part of institutional memories, not just for contextualising purposes, but to

enhance understanding about the archival materials. In a wider sense, the expectation is that ordinary people, previously underrepresented, form part of the constitution and preservation of history, despite loosening up archival procedures and received notions of quality. Given the open and free access to huge amounts of information, disintermediation is a real threat that puts the authenticity, accuracy and veracity of digital documents under suspicion. So, some concepts, such as access to trustworthy information, provenance and unbroken custody, should be revisited.

*Archives, as preservers of historic identities, need sustainable and stable models that ensure the digital safeguarding of documents, both paper and digital, without losing their trustworthiness.*

*Digital memories: ethical perspectives. Summary report, 2014*

Access to trustworthy information is considered a crucial element for institutional accountability. The rediscovery of the concept of provenance for guaranteeing digital documents' integrity is paramount to

*The truthfulness of records is based on the overarching idea that they are under the control of a trusted authority, which ensures the integrity of the system, its accuracy and reliability; but what makes existing institutions trustworthy and how can this be reinforced?*

*Digital memories: ethical perspectives. Summary report, 2014*

ensuring trustfulness with institutions of memory. Moreover, the idea of the 'unbroken custody' — i.e. 'a traceable and uninterrupted line of care, control and usually possession of a body of records from creation to preservation that can serve as a means of protecting the authenticity of the record'<sup>3</sup>— needs a clearer definition of rules in the digital context. Who ensures the quality of institutional memories? What quality criteria are needed in a world of overlapping and redundant memory functions?

Secondly, in a society that considers and uses corporate search engine results (from commercial companies, such as Google, Yahoo and Bing) instead of using the material stored and accessible from institutions of memory, it is possible to have a parallel development of biased memories: the (legitimated according to the tradition) ones generated by institutions of memory and the ones generated by people and the algorithms corporations use (legitimated by — not necessarily known — different societal mechanisms). Moreover, corporations in the form of search engines have self-assigned uninvited functions in memory preservation, as is well expressed by Google's mission statement: 'Google's mission is to organise the world's information and make it universally accessible and useful'<sup>4</sup>.

In that hybridised (i.e. coexistence and co-production of different endeavours of memory preservation with different agendas and different actors) and multi-layered space, what will govern memories? Their secrecy, confidentiality or free availability? With which criteria will they be preserved? Can intellectual property of digitally born documents be ethically and clearly established? And how should the institutional ethical duty to preserve memories be framed? The social practice of memory — understood as a source of knowledge — inevitably changes the (co-)production of knowledge.

*Letting citizens participate in contents' selection, in a kind of participatory archiving, will increase the dialogue between citizens and institutions in order to improve institutions' of memory trustworthiness*

*Digital memories: ethical perspectives. Summary report, 2014*

Our third question regards the process of remembering as a function of memory. Since we think everything can be found, collected, organised, etc. using ICT, we make little effort to remember. We can better retrace how to look for information or where we put it than the information itself. Our tendency

<sup>3</sup> InterPares 2 project: terminology database ([http://www.interpares.org/ip2/ip2\\_terminology\\_db.cfm](http://www.interpares.org/ip2/ip2_terminology_db.cfm)). [Last accessed: 28.3.2014]

<sup>4</sup> <https://www.google.com/about>

to rely on ICT is accelerating de-skilling, de-learning and forgetting mechanisms, which also leads us to the use of the Internet as an infinite archive.

And, last but not least, will the paradoxical character of digital information simultaneously being ephemeral and lasting provoke an irremediable loss of collective memory? In addition, destroying traces or purposefully stopping their deletion through ICT technologies could constitute another way of biasing information, conscious that the fragmentation of historical sources is not related only to digital but it can be enhanced by it. It is argued that History — here capitalised to refer to the broad collection of all the relevant documented narratives that humankind is willing and responsible to preserve — needs to be written looking at the digital landscape and its wide spectrum of points of view. In order to do so, a debate among institutions should be generated to see if traditional institutions of memory can cope with this new digital framework, or if a new kind of ‘participatory archive’ should be developed.

As an important pillar for knowledge, cultural heritage and history, these open questions about digital memory aim to shed light on how the ‘digital’ has changed the concept of memory (of remembering and forgetting) and the changing role that institutions of memory need to play in this challenging context of memory governance and ethics.

Despite having been developed within scholarly literature, institutional ethics has not significantly impacted institutional behaviours. As institutional and corporate entities are composed of individuals, ethics codes have primarily looked at, and established norms for, individuals and individual behaviours, as institutions and corporations are made up of people. However, institutional ethics has also addressed issues related to institutions as ‘moral subjects’ — super-individual entities expressing special forms of behaviour. When dealing with institutions as subjects, the mission and vision of the institution should be consistent with its operations and management, and these should be integrated with ethical goals — which, in contemporary societies, should include democratic goals. At the individual level, this should imply not only that those who are associated with the institution behave ethically in implementing institutional duties, but also that these duties strengthen their ethical behaviours as individuals.

If these principles traditionally apply to institutions, the impact of ICT on the institutional management of memories and its ethical problems require further investigation and reframing of rights. ICT introduces essential differences between individuals and institutions. In the EU context, there is no still

*So there could be a way of providing a trustful context for these documents, by allowing to the archives to be custodians of non-institutionalised archival initiatives. Archives could apply the knowledge acquired over time to embrace these initiatives in order to give them more reliability.*

*Digital memories: ethical perspectives. Summary report, 2014*

*Citizenship is demanding more transparency in order to regain trust in institutions, but ethical issues are not equally visible in all institutions of memory*

*Digital memories: ethical perspectives. Summary report, 2014*

universal right to be forgotten<sup>5</sup>. When institutional memories involve individual behaviours, the distinction between the private and public sphere can be blurred. How far can (and how much need is there for) historical memory (to) legitimately override an individual right to forgetfulness? How should the line be drawn? And who will draw it?

Rethinking institutional behaviours, reconnecting individuals and institutions and building trust in managing memories in a multi-stakeholder pervasive ICT context is just at the beginning.

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<sup>5</sup> A proposal to reform the EU data protection regulation is in its final stages ([http://europa.eu/rapid/press-release\\_MEMO-14-186\\_it.htm](http://europa.eu/rapid/press-release_MEMO-14-186_it.htm))

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## 2.1.2. Recommendations

From the literature review and experts' discussion and findings of the workshop (see earlier section), a number of recommendations for the practice of memory preservation of current Institutions of Memory are offered here that speak to practice, policy and further research:

### 2.1.2.1. Recommendations for practice:

In the era of pervasive Internet access and intense on-line activity, citizens' expectations about free access to authentic documents are increasing. Trust in Institutions of Memory relies on acknowledging that the practice of archival is being democratised and there is a growing number of loci for 'un-official' versions of facts.

#### Recommendations:

**2.1.2.1.1.** Institutions of Memory have a central role in **explaining the distinction between the information stored in Institutions of Memory – historical evidence and legacy - and the information that flows unverified in the Internet.** Hence, **it is the duty of traditional practice to raise awareness of demarcations and spell out qualities of traditional practice itself.** Taking for granted that citizenry can in general make a difference based on transparency and reputation criteria is no longer a valid assumption.

**2.1.2.1.2.** In the digital environment, Institutions of Memory should take advantage of their skilled experience and play the role of **third trusted parties** to store materials and make them available.

**2.1.2.1.3.** In order to verify trustworthiness in a digital context and clarifying the aforementioned distinction to users, Institutions of Memory should **reformulate traditional and fundamental archival procedures** taking into account the digital context, where multiple actors and multiple sources co-exist; these procedures should themselves be widely discussed with the users.

**2.1.2.1.4.** Institutions of Memory are putting great effort in digitisation; however, the rapid increase of digitally born documents makes them hard to manage. In that context, digital information created by institutions is not always preserved as it is expected. So, the recommendation is to **encourage proper institutional websites archiving.**

**2.1.2.1.5.** Since the archived records only become memory when they are registered by *Institutions of Memory*, **inclusive procedures when creating standards** and policies are required, in order to foster an extensive participation of countries.

2.1.2.1.6. In order to meet citizens' Right to access to documents and also meeting what is expressed in the article regarding Freedom of expression and information <sup>6</sup>, public engagement in the social construction of memory should be promoted by the Institutions of Memory, namely by providing **friendly and effective tools** to facilitate access, creation and reuse of the records they contain.

#### 2.1.2.2. Recommendations for policy on digital memory governance:

As discussed at the workshop, the multi-actor, multiple values, multi-usages, multi-media and emerging norms require a co-produced approach to memory governance. Hence, in here a number of recommendations are suggested.

#### Recommendations:

2.1.2.2.1. Provided that hybrid and sustainable funding models are found, it is paramount **to promote a close collaboration among all parties implied** (industry, institutions, governments, and citizens); it is recommended that **ethics specifications are the main criteria when defining business models for collaborative preservation initiatives and establish each partner's scope and responsibility.**<sup>7</sup>

2.1.2.2.2. Not all the issues are equally visible and defined in Institutions of Memory. 'In several Member States no clear and comprehensive policies are on the preservation of digital content' (European Commission Recommendation, 2011). **Harmonised and coordinated policies regarding digital preservation should be encouraged by the EU**, in order to promote an equal construction of European Memory. Indeed, **besides harmonizing existing legal provisions, those policies should be proactively informed and driven by ethical considerations.**

2.1.2.2.3. Preserving processes are expensive and could be unequal, in order to facilitate content creators to have their content preserved, Institutions could **provide incentives and recommendations for creators of digital content to make content born-archival** and therefore ensuring their preservation.

#### 3. Recommendations on further research:

A great deal of the issues discussed in relation to the research questions proposed was not settled. Furthermore, those research questions have created further ones. Hence in here we briefly allude to research questions that need further examination with regards to the project TRUDI.

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<sup>6</sup> As stated in the European Chart of Fundamental Rights, article 42 Right of access to documents and article 11 Freedom of expression and information (OJEC C364, 18-12-2000) Retrieved from: [http://www.europarl.europa.eu/charter/pdf/text\\_en.pdf](http://www.europarl.europa.eu/charter/pdf/text_en.pdf) [Last accessed:4.4.2014]

<sup>7</sup> For instance, in Commission Recommendation of 27 October 2011 on digitization and online accessibility of cultural material and digital preservation (OJEU L 283/39 29-10-2011), general guidelines for public-private partnerships models for digitization are given. These guidelines do not mention anything about ethical criteria to take into consideration when establishing this kind of collaboration. Retrieved from: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:283:0039:0045:EN:PDF> [Last accessed: 4.4.2014]

## Recommendations:

**2.1.2.3.1.** Not just policies are needed, but knowledge. There are some issues that could be solved with adequate policies and discussions, but there are others that will need another approach to archival practices. Experts in the workshop agreed that they do not have yet enough knowledge regarding digital environment (legal and technical) and there is a need to understand how everything is intertwined in a digital world. Hence, a **dialogue among all relevant actors should be initiated in order to provide a wide multi-perspective shared ground** for developing further timely and appropriate policies in this arena.

**2.1.2.3.2.** The archival profession has developed its code of ethics, but experts at the workshop thought that every actor involved in building memories need an ethical approach to data. Those **ethical principles must be considered as shared societal values and they need to be further investigated**, as the discussion of ethics of archiving is not a settled issue.

**2.1.2.3.3.** Experts of the workshop put a lot of emphasis on the importance of Institutions of Memory, but not so much in memory in Institutions themselves. **Institutions should refocus the act of preserving memories from administrative practices to the knowledge sphere.** The process of creating organisational knowledge and ensuring the maintenance of its traces inside their daily organisational practices by all the actors involved, should also be considered as part of the institutional memories to be preserved. But this is clearly a subject of further research and will be further enquired by TRUDI, as this is at the heart of developing trustworthy relationships with the entities that are responsible for digitalisation of knowledge.

Finally, history and historical legacy and in general knowledge and values to be left to future generations need to delve not just in institutions, but also on citizens. Moreover, there is a need to ensure that policy and technology take those values into account in the ICT design and deployment phases. What memory is and which roles Institutions of Memory are playing in a digital landscape should be widely discussed in order to properly frame ethical and legal concerns and eventually offer recommendations for policymaking.

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## 2.2. Case of study 2: open data in health sector

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### 2.2.1. Overview and background

Knowledge, and knowledge production and exchange, have been traditionally shown as relevant components of trust and as ways to create relevant bonds within communities. As said, this connection between knowledge and trust has been crucial in establishing the ethics and integrity of science within the scientific communities. In knowledge and technology-based societies the creation and sharing of knowledge represents a major path towards generating and maintaining trusted relations between institutions and citizens.

Open Data reveals a special relevance in this context. The philosophy behind open data has been long established within the scientific community, especially as portrayed in the Mertonian tradition of science (Merton, 1968); however, the term "open data" itself is recent and gained popularity with the rise of the Internet.

As already mentioned, according to a definition which is also subtended to the EU policies and legislation,<sup>8</sup> Open Data is data that can be freely used, reused and redistributed by anyone—subject only, at most, to the requirement to attribute and share alike.

*Due to its potential for sharing knowledge and knowledge production, Open Data can play a unique role as to the task of shaping trusted digital relations*

Indeed, the concept refers to a deeply value-laden vision of the human cognitive endeavour, namely the ideal of the universal and boundless sharing of knowledge; moreover, it is a phenomenon

radically rooted in, and generated by, digital technologies.

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<sup>8</sup> See Directive 2003/98/EC of the European Parliament and of the Council of 17 November 2003 on the re-use of public sector information, and Directive 2013/37/EU of the European Parliament and of the Council of 26 June 2013 amending Directive 2003/98/EC on the re-use of public sector information on the re-use of public sector information. See also: Communication from the Commission to the Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, Towards a thriving data-driven economy, COM(2014) 442 final, Brussels, 2.7.2014.

Open Data has several applications in the domain of state reforms and e-government. Health represents a major sector where citizens are willing to become more knowledgeable and empowered in order to make better informed, autonomous, and personalized decisions. At the same time, even though citizens' interactions with health-related institutions—and with institutions in general—are increasingly mediated by digital technologies, often citizens cannot easily

*A full agreement about how Open Data should be normatively defined and what health data means does not exist. While the EU is still completing a normative framework for Open Data, a harmonised vision of it is not*

process and reuse health-related information because of the high skills and technological means required. In this respect, the assumption that trust can be simply strengthened by opening up the health data sector cannot be taken for granted: relations amongst knowledge, trust, and technologies have to be better explored and rethought.

Indeed, despite the potential for Open Data to contribute to re-founding institutional trust, several issues still need to be clarified and addressed.

Gaps in national legislations and, lack of standardization in Open Data requirements, quality, and availability are undermining its value in enabling institutional trust. Also, the focus and the relevance of

*Moreover, in order to fully exploit Open Data as a source for trust, two further elements are crucial, namely that the necessary security measures are set up, and that adequate learning and skills are provided to citizens to empower them.*

Open Data have been primarily associated with its economic and commercial value, while its role in re-establishing citizens' trust towards institutions—beyond the rhetoric of mere transparency—has not been adequately investigated. For instance, the fact that the existing policies and

laws on Privacy and Open Data are often in conflict, not only diminishes the effectiveness of public action, but can also instigate distrust.

The issues and questions that the workshop aimed to explore were the following. What is the state-of-the-art on Open Data in the European policies and legal documents? Is Open Data mostly perceived as an economic opportunity? Is its civic dimension adequately highlighted? Are Open Data policies and initiatives addressing and meeting citizens' needs properly? Which trade-offs are currently existing between Open Data and Privacy? Does the current situation actually reflect citizens' readiness to engage in the governance of their health data? Is open "raw" data enough for building trust amongst institutions and citizens? How technical security measures can—if they can— help overcome these tensions? What is needed to adequately empower citizens in using Open Data in the health sector?

*Amongst these, data related to health seems to possess a privileged role in connecting knowledge and trust between institutions and citizens.*

The workshop encompassed three sessions, each asking a different set of questions, namely:

- 1 - What is the current state-of-the-art on Open Data? What does Open Data in health mean?

- 2 - European policies on Privacy and Open Data: conflicting or complementary?
- 3 - Existing portals for Open Data, institutional duties, citizens' expectation: which roles for whom?  
Which role for the media?

In each session—chaired by a European Commission officer with expertise in the related field—different visions on Open Data, from the institutional, the academic/research, and the civil society perspectives were illustrated.

The first set of questions, mostly related to the meaning and implications of Open Data in the relations between institutions and citizens. The issues were explored through the illustration of two cases of open data. In its presentation Rob Hagendijk (Amsterdam University, NL) described the socio-technical imaginaries related to the data on rare diseases and the relevance of the European normative framework for rare diseases as the adequate and trusted scale for collecting and sharing health information. Indeed, despite their manifested anti-Europe feelings, citizens in the Netherland expressed the need for a Europeanization of knowledge about rare diseases, thus revealing that an important element of trust exists towards EU institutions.

The Research director of the French Ministry of Health, Franck von Lennep, illustrated the French open database in the health sector and the Report on Open Data en Santé published by the Commission on Open Data (July 2014). Even though the commitment of the French administration towards Open Data in health started 10 years ago, the Report represents the beginning of a new policy plan aimed at implementing the idea of “*démocratie sanitaire*” within the context of renewed trusted relations between institutions and citizens in the State under the rule of the law (*Etat de droit*).

The second session addressed the controversial relations between privacy and Open Data through two complementary presentations, given by Manuel Garcia Sanchez, from the Spanish Authority for Data Protection, and by Magnus Stenbeck, epidemiologist from the Swedish Karolinska Institute. Sanchez expressed concern towards the impact that Open Data can have on privacy, showing how these impacts are still largely unknown and unpredictable. In Sanchez's opinion, a culture of privacy should be disseminated amongst researchers, while several technical and non-technical measures should be adopted in order to cope with uncertainties and threats posed by unleashed data. Stenbeck illustrated the longstanding Swedish policy in support of collecting health data through registries, and argued that the proposed European Regulation has the potential to threaten this public health framework.

Besides their different perspectives as data protection officer and epidemiologist, however, both speakers agreed that Open Data should come together with privacy. Indeed, even though the new proposed Regulation on data protection seems to pose some challenges to registries on health and diseases (especially in the field of tumour registries), privacy should find its place within the concept and practice of Open Data.

Finally, the third session primarily focused on the role of the media in improving Open Data usability for citizens and therefore in empowering them. Antonia Rana (scientific officer at the JRC) presented an articulated and detailed analysis of Open Data primarily from the perspective of their quality, showing how the quality aspects may be crucial in connecting knowledge and trust. Also, Rana explored some existing portals on Open Data, comparing them in terms of usability by citizens.

Rosy Battaglia (also on behalf of Guido Romeo, both data journalists) touched on several issues related to how usable Open Data can play a relevant role for citizens as tools to protect their health and the environment.

Following the presentations, the Chairs started and moderated the discussion, allowing participants to the workshop to express their views. The Workshop aimed at drafting some suggestions and recommendations to be offered to the European Commission.

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## 2.2.2. Recommendations

This section summarises reflections and recommendations emerged and shared through the discussions by participants. They reflect the division in three Groups organised around the three thematic sessions of the Workshop.

The discussion in Group 1 focused on how to create more trust between civil society, industry, and the government.

Group 2 focused on the seemingly conflicting policies of Open Data and privacy, and on the need to overcome the existing gaps.

Group 3 focused on the different roles that social structures other than institutions, especially the media, should perform to improve usability of Open Data by citizens.

Some recommendations remain intentionally overlapping, thus revealing and highlighting the connectedness of the different issues. These overlaps have been here signalled through cross-references.

### 2.2.2.1. General recommendations on Open Data in health and trust

#### 2.2.2.1.1. A clear and harmonized definition of “Open Data” and the accompanying Open Standards (see 3.1)

Reference to Open Data should be made only when some minimal requirements for Open Standards<sup>9</sup> are met and when the data conforms to “the” Open Data definition (see 2.2.2.2.1, 2.2.2.2.2 and 2.2.2.3.1).

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<sup>9</sup> UK Cabinet Office, Open Standards Principles, September 2013, Available at <https://www.gov.uk/government/publications/open-standards-principles/open-standards-principles#open-standard-definition> (Last accessed: 10 December 2014).

As said, according to the definition adopted by the EU, but representing a shared broad understanding of Open Data, this is “data that can be freely used, reused and redistributed by anyone—subject only, at most, to the requirement to attribute and share alike.” However, several official documents have characterized Open Data in a precise and detailed way. According to the UK White Paper on Open Data (2013), for instance, Open Data, namely “(q)ualitative or quantitative statements or numbers that are assumed to be factual, and not the product of analysis and interpretation,”<sup>10</sup> is precisely classified depending on their degree of openness and has to meet certain requirements. The classification follows Tim Berners Lee’s system of quality stars, where the optimal situation is defined by the assignment of five stars: openly licensed, openly accessible, structured, open format, URIs for entities, linked.

As to standards, Open Data has to be accessible at no more than the cost of reproduction; be in a digital, machine readable format for interoperation with other data; and be free of restriction on use or redistribution. Common standards are essential in order to achieve the main goal of Open Data. Indeed, not all data in the public sector is standardised in quality and is equally accessible; and “(a) lack of common standards is a barrier that can make it difficult for users to scrutinise activity or generate added value.”<sup>11</sup> According to this vision of the roles and responsibilities of institutions, citizens should not be exposed to increased, unjustified costs due to the specific digital choices made by institutions.

#### 2.2.2.1.2. Need for an open governance of Open Data and the need for an inclusive process (see 2.2.2.3.2)

The process for generating data should be as inclusive as possible, encompassing different narratives and all relevant actors, researchers, government and industry, but citizens (patients) and data journalists as well. Data can be very complicated to be collected, summarised and interpreted, and experts may not be aware of what health data are needed by citizens: focus groups, hackathons, surveys, etc. may be used to find this out.

This open engagement is likely to raise awareness and self-reflexivity about the role of Open Data in changing the way certain interactions (e.g., doctor/patient relations) are now taking place. The fact that data is open to everybody has a strong meaning as to a radical democratization of medicine—what the French document on Open Data in Health has called “démocratie sanitaire.”<sup>12</sup>

#### 2.2.2.1.3. Knowledge and data should derive from a legitimate process

Attention to the process through which data are produced has been stressed as a major factor in building trust. Knowledge may generate trust when knowledge appears legitimate not just by reference

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<sup>10</sup> HM Government, Open Data. White Paper. Unleashing the Potential. Presented to Parliament by the Minister of State for the Cabinet Office and Paymaster General by Command of Her Majesty, June 2012, 7.

<sup>11</sup> UK Cabinet Office, Open Standards Principles, September 2013, cit.

<sup>12</sup> Ministère des Affaires Sociales et de la Santé, Commission open data en santé, Rapport, 9 juillet 2014. Available at: [http://www.drees.sante.gouv.fr/IMG/pdf/rapport\\_final\\_commission\\_open\\_data-2.pdf](http://www.drees.sante.gouv.fr/IMG/pdf/rapport_final_commission_open_data-2.pdf) (Last accessed: 11 December 2014).

to its being scientifically valid, but because it is produced through a fair, democratic and inclusive process.

Building legitimacy also requires transparency of the process making the assumptions underlying an Open Data project explicit and readily accessible. Disease registries should be built with more attention to an inclusive, democratic process, namely a process where different voices are taken into account and that remains transparent through all its phases.

Moreover, trust and the legitimacy of the process are enhanced through multiple correlated data coming from different sources. Indeed, in this way institutions no longer have a privileged position in producing valid knowledge to be used in decision-making, but they become part of an increased transparent process of both knowledge production and trust production (see 3.6).

#### 2.2.2.1.4 Open Data and open source

In order to transparently achieve the goal of openness in data, open source software may become a necessary requirement. This is software where the rights are granted to access and modify the source code, and to use, reuse and redistribute the software, with no royalty or other costs.

As some documents have made clear, Open Data, Open Standards, and in some cases also Open Source should be seen as component of the same process towards transparency and shared production of knowledge.

#### 2.2.2.1.5. Provide the data and then proceed to improve them

It is not always necessary to have ideal conditions: provide the data first, and learning will follow.

Release the data, give room to the utilization and the debate, and allow interpretations unfold,<sup>13</sup> while providing mechanisms for oversight and alertness in order to prevent potential negative outcomes (see 2.2.2.2.2 and 2.2.2.2.3).

Indeed, release of data should be preceded by a careful and detailed impact analysis.<sup>14</sup>

This does not mean (see 2.2.2.1.6) that the quality of data is not relevant: on the contrary, the goal must focus on achieving the five star ranking— data should be curated in terms of formats and accessibility, without cleaning it, i.e. original data.

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<sup>13</sup> This recommendation remained controversial as some participants disagreed with it. They proposed instead to integrate the recommendation with the following statement: “Premature dispatch of not validated data can undermine any subsequent analysis and interpretation, the latter also prone to bias, confounding and uncertainty like any other process of inference from raw data. The need for a prompt release of data and a direct use and interpretation of it should be always confronted with the specific situation and context, in particular considering the level of complexity of the data itself and the fact that proposed hypotheses have to be tested through the data.”

<sup>14</sup> It needs to be taken into account that, once a dataset is release, little control remains in the hands of the data owner.

Go beyond discussion of principles and discuss the specific technical as well as social and normative solutions—with experts, civil society representatives, etc. to reach an accepted compromise solution and also to build legitimacy.

Even though it is not clear in advance what society wants to know, and whether citizens are interested in the “open” data or are they looking for “open” answers, the unfolding of the process will clarify these issues.

#### 2.2.2.1.6. Data, metadata, and quality

On the data portal, include explanation of how the data had been produced (metadata) so as to make it easier to use/interpret it correctly.

Quality assurance shall be pursued at each level of the data life cycle: production, registration, storage, distribution, analysis, interpretation, and shall be applied to metadata as well. Example of quality assurance in the field of cancer registration can be shared in other fields. Quality assurance of data and the usability of the platform should benefit of adequate investments (see 2.2.2.3.3 and 2.2.2.3.5).

#### 2.2.2.1.7. Create participatory and inclusive platforms where the process of generating data becomes transparent and empower users/citizens with “rights in design” (see 2.2.2.3.1, 2.2.2.3.3. and 2.2.2.3.5)

Data (and, more broadly, knowledge) should be shared through participatory and collaborative platforms after having brought together all relevant stakeholders. The notion of a digital platform refers to both the software and hardware of a site for the provision of Open Data and the promotion of the active role for stakeholders. It may include social media and citizens online communities.

Moreover, the process should also take into account how individuals are empowered. Citizens should be entitled to having “rights in design,” namely they should be given the right to influence and/or control some features of digital architectures and to decide how they want to interact with a system (e.g. access to raw data). Multiple user interfaces or pathways should be provided for data sets, as well as different levels of aggregation or disaggregation.

#### 2.2.2.1.8. Make platforms user-friendly

It is important to ensure the quality/user-friendliness of the platform itself. Ultimately, society cares about data especially in relation to the new answers to problems that data can make possible. However, it is essential that those who use the data can provide their own interpretations and can communicate them. The same data may be interpreted in different ways (for instance, different people may have a different approach to the choice of confidence intervals and therefore to inference).

To this end, involve and engage all parties, from scientists to journalists to industry.

Explain technical solutions; explain that full anonymisation may not always be a possible, adequate or desirable solution (see 2.2.2.2.1).

2.2.2.1.9. Need to (re)define the research needs: what the society wants to be addressed (even though citizens may not be aware of their preferences when simply asked)

Attention should be paid more to applied, specific knowledge and data related to citizens' needs. Digital platforms should provide space for citizens' needs and agendas, not only for researchers' interests. Citizens should be allowed to add personal stories to the platforms.

2.2.2.1.10. Sensitive vs. Open Data

Open Data systems need to compromise in order to achieve legitimacy. Indeed, the individual providing the data may have a different understanding of her data in terms of privacy than a scientist looking at them (see 2.2.2.2.1).

Explain that some data become useless once they are anonymized. If Open Data are not used then they are useless, if they are used then the ultimate goal can be questioned.

Find compromises on anonymisation to always ensure the usefulness of Open Data. Adoption of technical and by-design measures when dealing with sensitive records (e.g. medical information) can help ensure research aims while granting full respect of individual rights enshrined in the EU legal framework.<sup>15</sup>

2.2.2.1.11. Post-research traceability

Keep track of research studies (and research hypotheses behind them) which are performed through Open Data. Explain how the data was produced to use it better; assure that the analysis, interpretation and reporting will be done responsibly and in a competent and quality-assured way.

As to research data, scientists should be committed towards the effort of preparing the data to be released for sharing, of documenting the research process, and making it publicly available.

2.2.2.1.12. Pay attention to the relevance of (different) scales in Open Data

While some public issues can be better discussed and shared at local/national level (cultural features specific to a national health system), other topics, such as rare diseases, seem to require a wider scale, especially at the European level.

Scale is also relevant in the issue of aggregation vs. disaggregation. This should always be an option built into any data system. Important aspects can easily get lost in aggregation or can be harder to see in disaggregation.

2.2.2.1.13. Open Data requires a different understanding and framing of owning

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<sup>15</sup> A variety of views were expressed as to how prioritize needs and how compromise on privacy, and the recommendation remained controversial.

In the context of Open Data the concept of “belonging” can often be found to refer to the free use of data instead of the expression “property rights.” This broader approach to “to whom data belongs” requires a deeper understanding and a normative framework.

There is also the need to address technological dimensions of Open Data – attention to e-commerce and the need for incentives for Open Data (to improve trust of people providing their data and allowing them full control of their data).

## 2.2.2.2. Recommendations on making Open Data and privacy complementary

### 2.2.2.2.1. Provide Open Data “with” privacy (see 2.2.2.1.8 and 2.2.2.1.10)

Open Data and privacy are not and should not be presented as opposing, conflicting issues. Indeed, they should be seen as complementary and a culture of complementarity, as well as mechanisms for this end, should be set in place. A culture of Open Data and privacy should be supported, disseminated and implemented, while individual and community rights should be balanced.

Provide traceability information about data use and modification.

There should not be a dichotomy between consent and no consent. However, is informed consent necessary in every case? And what about transparency?

There is the need to facilitate the consent process (especially to take into account the aspect of evolving needs of data, e.g. for epidemiological use), without overburdening the research work.

A graduated consent mechanism should also be made possible in order to ease the research work while ensuring usefulness of the data. Moreover, building research on trust by individuals also has an impact on data quality and, consequently, on increasing the added value of data. The cancer registry example is one of the cases in which new methods need to be developed, as cases missing for lack of consent or other reasons might compromise the usefulness of the registry.

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### 2.2.2.2.2. Need for a distinction between public and Open Data (see 2.2.2.1.1)

Some documents have clearly distinguished public data and Open Data. Open Data in the public sector refers to data made available to citizens in open forms; public data has been defined as “anonymized, non-core reference data on which public services are run and assessed, on which policy decisions are based, or which is collected or generated in the course of public service delivery.”<sup>16</sup>

However, terminologies are not univocal,<sup>17</sup> and a clarification is needed, not only in general (see 2.2.2.1.1), but specifically in the health domain.

### 2.2.2.2.3 Freedom of reuse and privacy

According to Open Data philosophy and policy, users should be free to use the data for whatever purpose or not. Even though this open approach belongs to the theory of Open Data, this is not always the case in practice.

With reference to privacy and data protection, some possible criteria for distinctions can be proposed: personal information; high consequence/impact; risk-based approach.

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<sup>16</sup> HM Government, Open Data. White Paper, cit., p.8.

<sup>17</sup> See V. Mayer-Schonberger, K. Cukier. 2013. *Big data: a revolution that will transform how we live, work and think*. London: John Murray.

Moreover, should we collect all possible data we think we need—allowing an “appetite for data”—or not? Is there room for some “restricted use” in Open Data? Is this still Open Data? Publicly available doesn’t mean unrestrained (e.g. authentication procedures) (see 2.2.2.1.5).

#### 2.2.2.2.4. Provide data together with preventive measures ensuring security and integrity (see 2.2.2.1.5)

Transparency and traceability of data—for example, by providing logs of modifications and use—as well as integrity of data, from source to use and application of data, should be provided.

Integrity is connected to the quality of data: for instance, when you know that data is going to be published, you can try to influence it.

Think about preventative measures (e.g. incentives for anonymisation), and think preventatively about potential purposes – e.g. anticipating the consequences of misuses? What type of license? Who will enforce it?

A risk-based approach is needed to security of data, especially for data controllers – important for providers and users of data to understand their responsibilities.

### 2.2.2.3. Recommendations on the different roles for institutions and the media

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#### 2.2.2.3.1. Open Data needs to be underpinned by Freedom of Information legislation(s) and practices to make public institutions remaining accountable through time (see 2.2.2.1.1)

Freedom of information laws (FOI laws) are aimed to provide access by the general public to data held by national governments. They establish an individual "right-to-know" towards government-held information. However, not all European States have adopted and/or implemented legislative acts to grant their citizens FOI laws. Also, what is the enforceability of the existing FOI laws? Which rights do citizens have to contest the full compliance of governments?

#### 2.2.2.3.2. Joint commissions with different stakeholders should be established to identify priorities/topics/areas/data to be published (see 2.2.2.1.2)

Tensions still exist between what public institutions decide to publish and what the public needs/wants. Moreover, the gaps should be filled between data and information (and how to proceed from the former to the latter).

Forms of partnerships and training are needed (e.g. joint projects with journalists, statistical methodology specialists, NGOs for data analysis and to get to new questions).

Digital technologies could also help in finding out which information is more requested in order to speed the process of making it available (typically, health, environment, and government). However, this cannot be the only driver in delivering data sets.

#### 2.2.2.3.3. Ensuring everybody the opportunity to comment and to see the comments is important

The need also exists for feedbacks from users—and not just from data producers— about the quality and usability of data.

#### 2.2.2.3.4. Data should be made available in different formats in order to ensure communication

Different audiences require publication in different formats: both specialists and non-experts may require raw data, but processed information—explaining who processed the data and how it has been processed— should be made also available to citizens.

Often open portals are quite sophisticated from the technical point of view, but they are not user-friendly. Explanatory tools and tutorials should be prepared to help users.

#### 2.2.2.3.5. Trust also depends on the quality of data and on the process for data production (see 2.2.2.1.6)

Trust is also dependent on qualities such as certification, reputation, and monitoring performed both by publics and specialists.

As to institutions, building and maintaining trust depends on a variety of factors in generating, preserving, and delivering data. The level of skill revealed by institutions in dealing with knowledge and technologies is an essential component of their being trusted by citizens.

#### 2.2.2.3.6 (Data) journalists should be also be accountable and act in a transparent way to remain accountable as a trusted vigilant party in assessing the quality of institutional data

As data journalists may become a trusted party in analyzing institutional behavior and performance, and in providing feed-backs to citizens, requirements of accountability and transparency also apply to them (see 2.2.2.1.3).

### 3. General recommendations for rethinking and strengthening institutional trust

“Whatever matters to humans beings, trust is the atmosphere where they thrives.” (Bok, 1978)

"It is not possible to demand the trust of others; trust can only be offered and accepted"  
(Luhmann, 1979)

Protecting common goods by means of collectively built technological means represents a process where the democratization of power goes hand in hand with building social engagement, commitment, and trust. If participatory procedures have been defined by STS scholar Sheila Jasanoff as “technologies of humility” (Jasanoff, 2003), DIY technologies can be seen from this perspective—namely the democratization of science policy-making—as “technologies of trust.” Indeed, as some participants noted, practices of “making together” also involve spending time together, getting to know each other, and also learning from each other in a process that can often generate trust amongst those who share the experience.

Trust between citizens and institutions of memory nowadays is twofold. Citizens must trust institutions, but also institutions must trust citizens in order to make them participants

“Citizen History is an experiment in finding out what happens if we trust our visitors enough to allow them to bring their diverse perspectives and boundless enthusiasm into the research work of the museum and share our authority” [...] “This will require a high degree of trust on the part of the museum—but so far, our most dedicated citizen historians have proven themselves to be accurate and thorough, in other words, trustworthy users and guardians of the memory of the students who signed the album”<sup>25</sup>

Citizens participation for forming the archive “it is easy to see that someone being trusted by a friend, or any other person, can be motivated by this very fact actually to act in trusty worthy ways” (Lahno, 2001) In participatory archives, the most extreme way of letting people build a collection, trustworthiness is also fundamental (Huvila, 2008). “...its trustworthiness can be considerably less dependent on an individual authority or an authority of an individual academic group or viewpoint than in a traditional archive”. In fact the reliability of the records depends more on the participants, their records and the descriptions they provide.

In the recent times very big changes happened in the knowledge production.

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<sup>25</sup> <http://futureofmuseums.blogspot.it/2011/07/more-crowdsourced-scholarship-citizen.html> [Last accessed: 01.12.2014]

The context in which was traditionally situated was transformed and enriched by the advent of digital technologies. The transformation involves the actors, the process and the places.

The widespread diffusion on new media, systems and technologies enables a wider participation and make essential to consider new viewpoints.

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