Privacy, Discoverability, Openness, and Publicity



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Why are these issues relevant to us?

Often as computer scientists & engineers we focus on selecting the best *technology*, but forget about the social aspects

This includes issues of:

Privacy

 This may make the difference between people wanting to use the system or not

We will come to Discoverability, Openness, and Publicity over the course of the talk.

Swedish Constitution

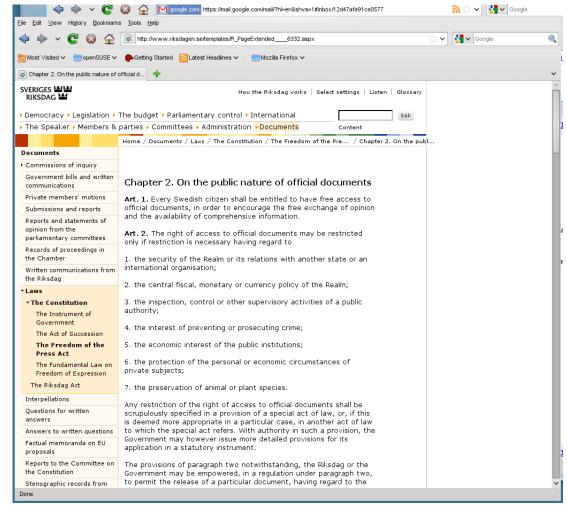
Four fundamental laws:

- The Instrument of Government
- The Act of Succession
- The Freedom of the Press Act
- The Fundamental Law on Freedom of Expression

"The fundamental laws take precendence over all other laws. This means that other laws may never conflict with the provisions of the fundamental laws."

http://www.riksdagen.se/templates/r_page____6357.aspx

The Freedom of the Press Act (Sweden)



Derives from Freedom of Information Act ("offentlighhetsprincipen" – "principle of publicity") introduced as the Freedom of Press Act ("Tryckfrihetsordningen") in 1766 which included: freedom of both writing and publishing ("skrif- och tryckfrihet")

http://www.riksdagen.se/templates/R_PageExtended____6332.aspx

Chapter 2. On the public nature of official documents

Art. 1. Every Swedish citizen shall be entitled to have free access to official documents, in order to encourage the free exchange of opinion and the availability of comprehensive information.

The Freedom of the Press Act (continued) – 7 restricted areas

Art. 2. The right of access to official documents may be restricted **only** if restriction is necessary having regard to

- 1. the security of the Realm or its relations with another state or an international organisation;
- 2. the central fiscal, monetary or currency policy of the Realm;
- 3. the inspection, control or other supervisory activities of a public authority;
- 4. the interest of preventing or prosecuting crime;
- 5. the economic interest of the public institutions;
- 6. the protection of the personal or economic circumstances of private subjects;
- 7. the preservation of animal or plant species.

Note: changes in **font face** or color added by GQMJr

The Freedom of the Press Act

(continued)— restrictions circumscribed

Any restriction of the right of access to official documents shall be scrupulously specified in a provision of a special act of law, or, if this is deemed more appropriate in a particular case, in another act of law to which the special act refers. With authority in such a provision, the Government may however issue more detailed provisions for its application in a statutory instrument.

EU context wrt "public" documents

European Union Directive 2003/98/EC

http://www.epsiplatform.eu/content/download/3234/34944/file/English_I_34520031231en00900096.pdf

Article 3: General principle

"Member States shall ensure that, where the re-use of documents held by public sector bodies is allowed, these documents shall be re-usable for commercial or non-commercial purposes in accordance with the conditions set out in Chapters III and IV. Where possible, documents shall be made available through electronic means."

wrt = with respect to

EU context wrt "public" documents

European Union Directive 2003/98/EC

http://www.epsiplatform.eu/content/download/3234/34944/file/English | 34520031231en00900096.pdf

Directive begins with a long "Whereas:"

- (2) The evolution towards an information and knowledge society influences the life of every citizen in the Community, *inter alia*[†], by enabling them to gain new ways of accessing and acquiring knowledge.
- (3) Digital content plays an important role in this evolution. Content production has given rise to rapid job creation in recent years and continues to do so. Most of these jobs are created in small emerging companies.
- (5) One of the principal aims of the establishment of an internal market is the creation of conditions conducive to the development of Community-wide services. Public sector information is an important primary material for digital content products and services and will become an even more important content resource with the development of wireless content services. Broad cross-border geographical coverage will also be essential in this context. Wider possibilities of re-using public sector information should *inter alia* allow European companies to exploit its potential and contribute to economic growth and job creation.

† "among other things" indicating only an example

European Union Directive 2003/98/EC (continued)

- (12) The time limit for replying to requests for re-use should be reasonable and in line with the equivalent time for requests to access the document under the relevant access regimes. Reasonable time limits throughout the Union will stimulate the creation of new aggregated information products and services at pan-European level. Once a request for re-use has been granted, public sector bodies should make the documents available in a timeframe that allows their full economic potential to be exploited. This is particularly important for dynamic content (e.g. traffic data), the economic value of which depends on the immediate availability of the information and of regular updates. Should a licence be used, the timely availability of documents may be a part of the terms of the licence.
- (13) The possibilities for re-use can be improved by limiting the need to digitise paper-based documents or to process digital files to make them mutually compatible. Therefore, public sector bodies should make documents available in any pre-existing format or language, through electronic means where possible and appropriate. Public sector bodies should view requests for extracts from existing documents favourably when to grant such a request would involve only a simple operation. Public sector bodies should not, however, be obliged to provide an extract from a document where this involves disproportionate effort. To facilitate re-use, public sector bodies should make their own documents available in a format which, as far as possible and appropriate, is not dependent on the use of specific software. Where possible and appropriate, public sector bodies should take into account the possibilities for the re-use of documents by and for people with disabilities.

. . .

(15) Ensuring that the conditions for re-use of public sector documents are clear and publicly available is a precondition for the development of a Community-wide information market. Therefore all applicable conditions for the re-use of the documents should be made clear to the potential re-users. Member States should encourage the creation of indices accessible on line, where appropriate, of available documents so as to promote and facilitate requests for re-use. Applicants for re-use of documents should be informed of available means of redress relating to decisions or practices affecting them. This will be particularly important for SMEs which may not be familiar with interactions with public sector bodies from other Member States and corresponding means of redress.

European Union Directive 2003/98/EC (continued)

- (16) Making public all generally available documents held by the public sector concerning not only the political process but also the legal and administrative process is a fundamental instrument for extending the right to knowledge, which is a basic principle of democracy. This objective is applicable to institutions at every level, be it local, national or international.
- (17) In some cases the re-use of documents will take place without a licence being agreed. In other cases a licence will be issued imposing conditions on the re-use by the licensee dealing with issues such as liability, the proper use of documents, guaranteeing non-alteration and the acknowledgement of source. If public sector bodies license documents for re-use, the licence conditions should be fair and transparent. Standard licences that are available online may also play an important role in this respect. Therefore Member States should provide for the availability of standard licences.
- (20) Public sector bodies should respect competition rules when establishing the principles for re-use of documents avoiding as far as possible exclusive agreements between themselves and private partners. However, in order to provide a service of general economic interest, an exclusive right to re-use specific public sector documents may sometimes be necessary. This may be the case if no commercial publisher would publish the information without such an exclusive right.
- (21) This Directive should be implemented and applied in full compliance with the principles relating to the **protection of** personal data in accordance with Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and of the free movement of such data (1).
- (22) The intellectual property rights of third parties are not affected by this Directive. For the avoidance of doubt, the term 'intellectual property rights' refers to copyright and related rights only (including *sui generis* forms of protection). This Directive does not apply to documents covered by industrial property rights, such as patents, registered designs and trademarks. The Directive does not affect the existence or ownership of intellectual property rights of public sector bodies, nor does it limit the exercise of these rights in any way beyond the boundaries set by this Directive. The obligations imposed by this Directive should apply only insofar as they are compatible with the provisions of international agreements on the protection of intellectual property rights, in particular the Berne Convention for the Protection of Literary and Artistic Works (the Berne Convention) and the Agreement on Trade-Related Aspects of Intellectual Property Rights (the TRIPS Agreement). Public sector bodies should, however, exercise their copyright in a way that facilitates re-use.

Swedish context wrt "public" documents

~20% of labor force in the public sector down from a much higher fraction, due to privitization

Taxes are ~50% of GDP

European Union Directive 2003/98/EC - Public Sector Information (PSI) \Rightarrow Swedish law, Lag 2010:566 "to promote the development of an information market by facilitating re-use by individuals of documents supplied by the authorities on conditions that cannot be used to restrict competition."

http://www.epsiplatform.eu/news/news/sweden_italy_new_psi_laws

Interestingly:

- Programs are **not** considered documents (under §6 of 2010:566)
- Documents of educational or research institutions or cultural institutions are not covered under this law (under §3 of 2010:566)
- Does not apply to documents whose rights are owned by a third party (under §5 of 2010:566)
- Fees for using documents can **not** exceed the cost of collection, production, reproduction, dissemination, and "a reasonable return on investment" (under §7 of 2010:566)

Finnish context wrt "public" documents

Act on the Openness of Government Activities of 1999

http://www.finlex.fi/en/laki/kaannokset/1999/en19990621.pdf

- Authorities must respond to requests for access
- Authorities must also provide and promote information openness
 - Requirement for good information management

Chapter 1 — General provisions

Section 1 — *Principle of openness*

- (1) Official documents shall be in the public domain, unless specifically otherwise provided in this Act or another Act.
- (2) There are specific provisions that apply to the right to attend Parliamentary plenary sessions, meetings of municipal councils and other municipal bodies, court hearings and meetings of ecclesiastical bodies.

Section 2 — Scope of application

This Act contains provisions on the right of access to official documents in the public domain, officials' duty of non-disclosure, document secrecy and any other restrictions of access that are necessary for the protection of public or private interests, as well as on the duties of the authorities for the achievement of the objectives of this Act.

Section 3 — Objectives

The objectives of the right of access and the duties of the authorities provided in this Act are to promote openness and good practice on information management in government, and to provide private individuals and corporations with an opportunity to monitor the exercise of public authority and the use of public resources, to freely form an opinion, to influence the exercise of public authority, and to protect their rights and interests.

Art. 3. Document is understood to mean any written or pictorial matter or recording which may be read, listened to, or otherwise comprehended only using technical aids. A document is official if it is held by a public authority, and if it can be deemed under Article 6 or 7 to have been received or drawn up by such an authority.

- A recording under paragraph one is deemed to be held by a public authority, if it is available to the
 authority using technical aids, which the authority itself employs, for communication in such form that it
 may be read, listened to, or otherwise comprehended. A compilation of information taken from material
 recorded for automatic data processing is however regarded as being held by the authority only if the
 authority can make it available using routine means.
- A compilation of information taken from material recorded for automatic data processing is **not** however regarded as being held by the authority if the compilation contains personal information and the authority is not authorised in law, or under a statutory instrument, to make the compilation available. Personal information is understood to mean any information which can be referred back directly or indirectly to a private person.

⇒ Format does not matter, but personal information is protected

Art. 4. A letter or other communication which is directed in person to an official at a public authority is deemed to be an official document if it refers to a case or other matter falling within the authority's purview, and if it is not intended for the addressee solely in his capacity as incumbent of another position.

⇒ Most E-mail is public!

Art. 5. The Riksdag and any local government assembly vested with decisionmaking powers is equated with a public authority for the purposes of this Chapter.

⇒ Legistlative assemblies are not exempted

Art. 6. A document is deemed to have been received by a public authority when it has arrived at the authority or is in the hands of a competent official. A recording under Article 3, paragraph one, is instead deemed to have been received by the authority when it has been made available to the authority by another in the manner indicated in Article 3, paragraph two. Competition documents, tenders and other such documents which it has been advertised shall be delivered under sealed cover are deemed not to have been received before the time appointed for their opening.

Measures taken solely as part of the technical processing or technical storage of a document which a public authority has made available shall not be construed to mean that the document has been received by that authority.

⇒ Most physical mail is public!

Art. 7. A document is deemed to have been drawn up by a public authority when it has been dispatched. A document which has not been dispatched is deemed to have been drawn up when the matter to which it relates has been finally settled by the authority, or, if the document does not relate to a specific matter, when it has been finally checked and approved by the authority, or has otherwise received final form.

The provisions of paragraph one notwithstanding, a document of the nature referred to below is deemed to have been drawn up

- 1. in the case of a day book, ledger, and such register or other list as is kept on an ongoing basis, when the document has been made ready for notation or entry;
- 2. in the case of a court ruling and other decision which shall be pronounced or dispatched under relevant provisions of law, and records and other documents insofar as they relate to such a decision, when the decision has been pronounced or dispatched;
- 3. in the case of other records and comparable memoranda held by a public authority, when the document has been finally checked and approved by the authority or has otherwise received final form, but not the records of Riksdag committees, auditors of local authorities, official commissions of inquiry or local authorities where they relate to a matter dealt with solely in order to prepare the matter for decision.

⇒ defines when it becomes "official"

Art. 8. If a body which forms part of, or is associated with, a public authority or other similar organisation for the public administration has transferred a document to another body within the same organisation, or has produced a document for the purpose of transferring it in this manner, the document is not deemed thereby to have been received or drawn up, other than if the bodies concerned act as independent entities in relation one to the other.

Art. 9. Neither shall a memorandum which has been prepared at a public authority, but which has not been dispatched, be deemed to be an official document at that authority after the time at which it would be deemed to have been drawn up under Article 7, unless it has been accepted for filing and registration. Memorandum is understood to mean any aide memoire or other note or record produced solely for the preparation or oral presentation of a matter, but not such part of it as contributes factual information to the matter.

Preliminary outlines or drafts of decisions or written communications of a public authority and other like documents which have not been dispatched are not deemed to be official documents unless they have been accepted for filing and registration.

⇒ "Working document" exemption

Art. 10. A document held by a public authority solely for the purpose of technical processing or technical storage on behalf of another is not deemed to be an official document held by that authority.

⇒ For "storage only" exemption

Art. 11. The following documents are not deemed to be official documents:

- 1. letters, telegrams, and other such documents delivered to or drawn up by a public authority solely for the purpose of forwarding a communication;
- 2. notices or other documents delivered to or drawn up by a public authority solely for the purpose of publication in a periodical published under the auspices of the authority;
- 3. printed matter, recordings of sound or pictures, or other documents forming part of a library or deposited by a private person in a public archive solely for the purpose of care and safe keeping, or for research and study purposes, and private letters, written matter or recordings otherwise transferred to a public authority solely for the purposes referred to above;
- 4. recordings of the contents of documents under point 3, if such recordings are held by a public authority, where the original document would not be deemed to be an official document.

The provisions of paragraph one, point 3, concerning documents forming part of a library do not apply to recordings held in databases to which a public authority has access under an agreement with another public authority, if the recording is an official document held by that authority.

⇒ Exempt documents

Art. 12. An official document to which the public has access shall be made available on request forthwith, or as soon as possible, at the place where it is held, and free of charge, to any person wishing to examine it, in such form that it can be read, listened to, or otherwise comprehended. A document may also be copied, reproduced, or used for sound transmission. If a document cannot be made available without disclosure of such part of it as constitutes classified material, the rest of the document shall be made available to the applicant in the form of a transcript or copy.

A public authority is under no obligation to make a document available at the place where it is held, if this presents serious difficulty. Nor is there any such obligation in respect of a recording under Article 3, paragraph one, if the applicant can have access to the recording at a public authority in the vicinity, without serious inconvenience.

Art. 13. A person who wishes to examine an official document is also entitled to obtain a transcript or copy of the document, or such part thereof as may be released, in return for a fixed fee. A public authority is however under no obligation to release material recorded for automatic data processing in any form other than a printout except insofar as follows from an act of law. Nor is a public authority under any obligation to provide copies of maps, drawings, pictures, or recordings under Article 3, paragraph one, other than in the manner indicated above, if this would present difficulty and the document can be made available at the place where it is held.

Requests for transcripts or copies of official documents shall be dealt with promptly.

Art. 14. A request to examine an official document is made to the public authority which holds the document.

The request is examined and approval granted by the authority indicated in paragraph one. Where special grounds so warrant, it may however be laid down in a provision under Article 2, paragraph two, that in applying this rule, examination and approval shall rest with another public authority. In the case of a document of central significance for the security of the Realm, it may also be laid down in a statutory instrument that only a particular authority shall be entitled to examine and approve questions relating to release. In the aforementioned cases, the request shall be referred to the competent authority forthwith.

No public authority is permitted to inquire into a person's identity on account of a request to examine an official document, or inquire into the purpose of his request, except insofar as such inquiry is necessary to enable the authority to judge whether there is any obstacle to release of the document.

⇒ Privacy of the **requestor** and their **purpose**

Art. 15. Should anyone other than the Riksdag or the Government reject a request to examine an official document, or release such a document with a proviso restricting the applicant's right to disclose its contents or otherwise dispose over it, the applicant may appeal against the decision. An appeal against a decision by a minister shall be lodged with the Government, and an appeal against a decision by another authority shall be lodged with a court of law.

The act referred to in Article 2 shall set out in greater detail how an appeal against a decision under paragraph one shall be lodged. Such an appeal shall always be examined promptly.

Special provisions apply to the right to appeal against decisions by authorities under the Riksdag.

⇒ Right to appeal a request that is denied

Art. 16. A note concerning obstacles to the release of an official document may be made only on a document covered by a provision under Article 2, paragraph two. Such a note shall refer to the relevant provision.

⇒ Right to know grounds for denial

Art. 17. It may be laid down in law that the Government, or a local government assembly vested with decision-making powers, may determine that official documents relating to the activities of a public authority which are to be taken over by a private body may be transferred into the safe keeping of that body, if it requires the documents for its work, without the documents ceasing thereby to be official. Such a body shall be equated with a public authority in respect of documents so transferred when applying Articles 12 to 16.

It may also be laid down in law that the Government may determine that official documents may be transferred to the Church of Sweden, or any part of its organisation, for safe keeping, without the documents ceasing thereby to be official. This applies to documents received or drawn up no later than 31 December 1999 by

- 1. public authorities which no longer exist and which performed tasks relating to the activities of the Church of Sweden; or
- 2. decision-making assemblies of the Church of Sweden.

In applying Articles 12 to 16, the Church of Sweden and any part of its organisation shall be equated with a public authority in respect of documents so transferred.

⇒ Right to access continues **even** if the documents are transferred to private body

Art. 18. Basic rules concerning the storage of official documents, weeding and other disposal of such documents are laid down in law.

⇒ Can dispose of documents, but must follow defined procedure

Does this only concern government produced documents?

Sarbanes-Oxley, Health Insurance Portability and Accountability Act (HIPAA), FRA-lagen, ...

- Significant data retention and access requirements
- Authentication and logging of who key corporate officials talk to in order to ensure compliance with blackout periods
- Authentication and logging of who access a patient's medical records
- Call detail records to be retained
- ISPs retaining URLs accessed per subscriber

• ...

Personal Data Act (PUL): 29 April 1998

The purpose of this Act is to protect people against the violation of their personal integrity by processing of personal data.

Term	Meaning
Processing (of personal data)	Any operation or set of operations which is taken as regards personal data, whether or not it occurs by automatic means, for example collection, recording, organisation, storage, adaptation or alteration, retrieval, gathering, use, disclosure by transmission, dissemination or otherwise making information available, alignment or combination, blocking, erasure or destruction.
Personal data	All kinds of information that directly or indirectly may be referable to a natural person who is alive.

PUL = Personuppgiftslag

PUL §5: Processing of personal data subject to the act

This Act applies to such processing of personal data as is wholly or partly automated.

The Act also applies to other processing of personal data, if the data is included in or is intended to form part of a structured collection of personal data that is available for searching or compilation according to specific criteria.

⇒ Processing or **Processable** personal data

PUL §6: Exemption of private processing of personal data

This Act does **not** apply to such processing of personal data that a natural person performs in the course of activities of a purely private nature.

⇒ Keeping private records is OK

PUL §7: Relationship to freedom of the press and freedom of expression

The provisions of this Act are not applied to the extent that they would contravene the provisions concerning the freedom of the press and freedom of expression contained in the Freedom of the Press Act or the Fundamental Law on Freedom of Expression.

The provisions of Sections 9–29 and 33–44 and also Section 45, first paragraph, and Sections 47–49 shall not be applied to such processing of personal data as occurs exclusively for journalistic purposes or artistic or literary expression.

⇒ Fundamental laws have priority

PUL §8: Relationship to the principle of public access to official documents

The provisions of this Act are not applied to the extent that they would limit an authority's obligation under Chapter 2 of the Freedom of the Press Act to provide personal data.

Nor do the provisions prevent an authority from archiving or saving official documents or that archive material is taken care of by an archive authority. The provisions of Section 9, fourth paragraph, do not apply to the use by an authority of personal data in official documents.

⇒ Private data can be archived/stored in official documents

PUL §9: Fundamental **requirements** for processing of personal data

The controller of personal data shall ensure that

- a) personal data is processed only if it is lawful,
- b) personal data is always processed in a correct manner and in accordance with good practice,
- c) personal data is only collected for specific, explicitly stated and justified purposes,
- d) personal data is **not processed** for any purpose that is incompatible with that for which the information is collected,
- e) the personal data that is processed is **adequate** and **relevant** in relation to the purposes of the processing,
- no more personal data is processed than is necessary having regard to the purposes of the processing,
- g) the personal data that is processed is correct and, if it is necessary, up to date,
- h) all reasonable measures are taken to correct, block or erase such personal data as is incorrect or incomplete having regard to the purposes of the processing, and
- i) personal data is not kept for a longer period than that as is necessary having regard to the purpose of the processing.

PUL §9 requirements - continued

However, as regards the first paragraph, d), the processing of personal data for historical, statistic or scientific purposes shall not be regarded as incompatible with the purposes for which the information was collected.

Personal data may be kept for historical, statistic or scientific purposes for a longer time than that stated in the first paragraph i). However, personal data may **not** in such cases **be kept for a longer period than is necessary** for these purposes.

Personal data that is processed for historical, statistical or scientific purposes may be used in order to take measures as regards the person registered only if the person registered has given his/her **consent** or there is **extraordinary reason** having regard to the **vital interests** of the registered person.

⇒ Long terms records have constrained used (the importance of **forgetting**)

PUL §10: When processing of personal data is permitted

Personal data may be processed **only** if the registered person has **given** his/her **consent** to the processing **or** if the processing is **necessary** in order

- a) to enable the **performance of a contract** with the registered person or to enable measures that the registered person has requested to be taken before a contract is entered into,
- b) that the controller of personal data should be able to comply with a **legal obligation**,
- c) that the vital interests of the registered person should be protected,
- d) that a work task of **public interest** should be performed,
- e) that the controller of personal data or a third party to whom the personal data is provided should be able to perform a work task in conjunction with the **exercise of official authority**, or
- f) that a purpose that concerns a **legitimate interest** of the controller of personal data or of such a third party to whom personal data is provided should be able to be satisfied, if this interest is of greater weight than the interest of the registered person in protection against violation of personal integrity.

PUL §11: Direct Marketing

Personal data may not be processed for purposes concerning direct marketing, if the registered person gives notice in writing to the controller of personal data that he/she opposes such processing.

⇒ Direct marketing can be limited

PUL §12: Revocation of consent

In those cases where processing of personal data is only permitted when the registered person has provided his/her consent under Section 10, 15 or 34, the registered person is entitled **to revoke at any time consent** that has been given. Further personal data about the registered person may not subsequently be processed.

A registered person is not entitled, beyond that provided by the first paragraph and Section 11, to oppose such processing of personal data as is permitted under this Act.

⇒ Can revoke consent, but can not block all processing (only some)

PUL §13: Prohibition of processing of sensitive personal data

It is prohibited to process personal data that reveals

- a) race or ethnic origin,
- b) political opinions,
- c) religious or philosophical beliefs, or
- d) membership of a trade union.

It is also prohibited to process such personal data as concerns health or sex life.

Information of the kind referred to in the first and second paragraphs is designated as *sensitive personal data* in this Act.

⇒ Definition of **sensitive** personal data

PUL §14: Exemptions from the prohibition of processing of sensitive personal data

Despite the prohibition of Section 13 it is permitted to process sensitive personal data in those cases stated in Sections 15–19.

In Section 10 there are provisions concerning the cases in which processing of personal data is **not permitted in any case whatsoever**.

§15: Consent or publicising

Sensitive personal data may be processed if the registered person has given his/her explicit consent to processing or in a clear manner publicised the information.

⇒ Sensitive personal data **exemptions**

PUL §16: Necessary processing

Sensitive personal data may be processed if the processing is necessary in order that

- a) the controller of personal data should be able to **comply** with his/her **duties** or **exercise** his/her **rights** within employment law,
- b) the **vital interests** of the registered person or some other person should be able to be protected and the registered person cannot provide his/her consent, or
- c) legal claims should be able to be established, exercised or defended.

Information that is processed on the basis of the first paragraph a) may be disclosed to a third party only if there is within employment law an obligation for the controller of personal data to do so or the registered person has explicitly consented to the provision.

⇒ "necessary" processing **exemptions**

PUL §17: Non-profit organizations

Non-profit organisations with political, philosophical, religious or trade union objects may within the framework of their operations process sensitive personal data concerning the members of the organisation and such other persons who by reason of the objects of the organisation have regular contact with it. However, sensitive personal data may be provided to a third party only if the registered person explicitly consents to it.

⇒ Non-profit organization exemptions

PUL §18: Health and hospital care

Sensitive personal data may be processed for health and hospital care purposes, provided the processing is necessary for

- a) preventive medicine and health care,
- b) medical diagnosis,
- c) health care or treatment, or
- d) management of health and hospital care services.

A person who is **professionally operational** within the health care sector **and** is **subject to a duty of confidentiality** may also process sensitive personal data that is subject to the duty of confidentiality. This also applies to the person who is subject to a similar duty of confidentiality and who has received sensitive personal data from the operation within the health care sector.

⇒ Health care exemptions

PUL §19: Research and statistics

Sensitive personal data may be processed for research and statistics purposes, provided the processing is necessary in the manner stated in Section 10 and provided the interest of society in the research or statistics project within which the processing is included is manifestly greater than the risk of improper violation of the personal integrity of the individual that the processing may involve.

If the processing has been approved by a research ethics committee, the prerequisites under the first paragraph shall be deemed satisfied. Research ethics committee means such special body for consideration of research ethics issues that has representatives for both the public and the research and that is linked to a university or a university college or to some other instance that to a very substantial extent funds research.

Personal data may be provided to be used in such projects referred to in the first paragraph, unless otherwise provided by the rules on secrecy and confidentiality.

⇒ Research & public interest **exemptions**

PUL continued

§20: Authorization to prescribe further exemptions

§21: Information concerning legal offences, etc.

⇒ only public authorities can keep this info

PUL §22: Processing of personal identity numbers

Information about personal identity numbers or classification numbers may, in the absence of consent, **only** be dealt with **when** it is **clearly justified** having regard to

- a) the purpose of the processing,
- b) the importance of a secure identification, or
- c) some other noteworthy reason.

⇒ Special protection for ID numbers

Information to the registered person

- Information that should be provided voluntarily: PUL §23 and §24
- Information that **must** be provided voluntarily: PUL §25
- Information that shall be provided upon application: PUL §26
- Exemptions from the obligation to provide information in the case of secrecy and duty of confidentiality: PUL §27
- Rectification (PUL §28)
- Automated decisions (PUL §29)

⇒ Providing information (concerning that person) to a person

Security in processing

§30: Persons who process personal data

§31: Security Measures

The controller of personal data shall implement appropriate technical and organisational measures to protect the personal data that is processed. The measures shall provide a level of security that is **appropriate** having regard to

- a) the technical possibilities available,
- b) what it would cost to implement the measures,
- c) the special risks that exist with processing of personal data, and
- d) how sensitive the personal data processed really is.

If the controller of personal data engages a personal data assistant, the controller of personal data shall ensure for him/herself that the personal data assistant can implement the security measures that must be taken and ensure that the personal data assistant actually takes the measures.

Transfer of personal data to a third country

§33: Prohibition of transfer of personal data to a third country

§34 and §35: Exeptions of the prohibition of transfer of personal data to a third country

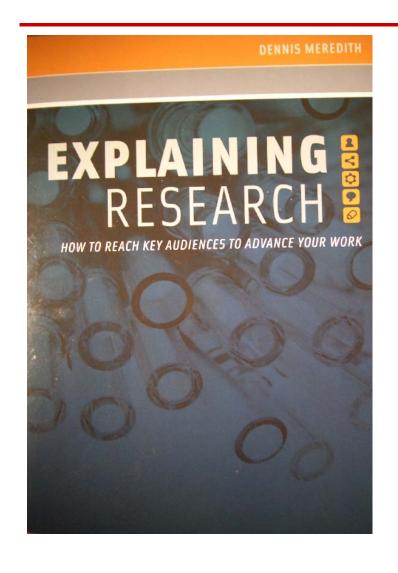
- ⇒ Of major importance for cloud computing:
 - Where is your computation running?
 - How can you know?

PUL continued

Note: The remaining sections of the act are primarily administrative: description of penalties, damages, appeals, etc.

Open by default

Promoting ones work



Dennis Meredith, Explaining Research: How to reach key audience to advance your work, Oxford University Press, 2010, ISBN 978-0-19-973205-0

Press releases, Video news releases, ...

⇒ **Actively** promoting your work will require more work

Explaining your research is a professional responsibility and frequently a necessity

- For *academic* researchers publishing your results is often critical for employment, promotion, tenure, getting funding for more research, ...
- For *industrial* researchers publishing your results is often critical for employment, promotion, getting funding for more research, ...

Essential for:

- the evaluation of your ideas by your peers
- influencing others
- success in your research & career

What is the purpose of your writing, web page, blog, video, ...?

- Knowing the purpose (or purposes) will help you achieve your goal
- What is the outcome you want?

Synergy as a strategy

⇒ The combined impact of all of your communications should be more than just their sum.

Who is your audience? Who are your audiences?

- Peers, colleagues, potential collaborators, potential students, ...
- Your boss, administrators, ...
- Funding agencies & foundations, private donors, ...
- Legislators, regulators, ...
- Your friends & enemies
- The general public

When writing – always think of your audience

- You want to communicate your research
- You want to explain your research
- You want to engage your reader
- You want to educate your reader

The last three are harder when you have a lay audience or persons who are outside the immediate field.

⇒ Do **not** assume that your reader is one of your peers.

What does your audience already know? What do they want to know?

- Assess what your intended audience already knows – so that you know what you can assume that they know, enabling you to focus on what they do not (yet) know.
- Keeping in mind your purpose/goals include what the audience needs to know
- Try to answer the most likely questions

⇒ Find the right balance for your audience between **too little** and **too much.**

What is the appropriate tone?

 If the document/result is formal, then the tone should be formal

• • •

 If the document/result is informal, then the tone should be informal

Most of your academic and professional writing is going to be **formal**, hence:

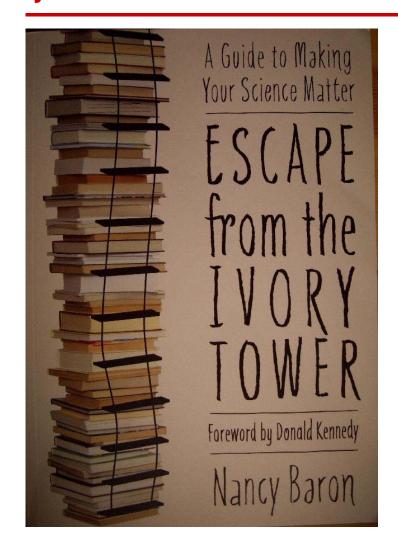
- Avoid wiriting in the first person
- Avoid contractions & slang
- Cite your sources in order to support your argument(s)

Further resources

- http://explainingresearch.com/ web site for book
- http://researchexplainer.com/ Dennis Meredith's blog
- http://explainingresearch.com/working-with-
 pios 360.html Working with Public Information

 Officers suppliment to the book

Promoting ones work – communicating with journalists



Nancy Baron, Escape from the Ivory Tower: A Guide to Making Your Science Matter, Island Press, 2010, ISBN 978-1-59726-664-2

Connecting science, journalism, and policy

The 4th section of the book: "Becoming an Agent of Change"

⇒ Being proactive

Focus: Environmental science

Making problems open & giving prizes

Open Innovation Network	URL
Challenge.gov	www.challenge.gov
Grand Challenges in Global Health	www.gradchallenges.org
Idea Connection	www.ideaconection.com
InoCentive	www2.innocentive.com
NineSigma	www.ninesigma.com
OmniCompete	www.omnicompete.com
Scientists without Borders	www.scientistswithoutborders.org
The X Prize Foundation	www.xprize.org

Adrienne J. Burke, Science & Prizes: How open innovation networks can help solve scientific puzzles, The New York Academy of Sciences Magazine, Winter 2011, pp. 17-21.

Conclusions

- Open/Public/Official is getting more open
- Privacy is becoming more circumscribed
- Have to work hard to make the things you want to keep private stay private, while there are lots of means (if you want) to make information more public
- Once information is public, it will probably not be forgotten!
- Scott McNealy, CEO of Sun Microsystems, in 1999 stated: "You Have Zero Privacy Anyway. Get Over It"
 - Is this true?
 - Will it become more or less true?
 - What choices will you make in your life and work that realize this?

References

- 1. The World's First Freedom of Information Act: Anders Chydenius' Legacy Today, Anders Chydenius Foundation, Publication 2, Kokkola, Finland, 2006, ISBN 952-99519-2-2, http://www.scribd.com/doc/5885744/The-Worlds-First-Freedom-of-Information-Act-SwedenFinland-1766
- 2. U. S. Freedom of Information Act (FOIA), Public Law, 89-554, 80Stat. 383, 1966, Amended 1996, 2002, 2007
- 3. The Freedom of the Press Act, SFS 1949:105, 1949, http://www.riksdagen.se/templates/R Page 6313.aspx
- 4. The Fundamental Law on Freedom of Expression, SFS 1991:1469, 1991, http://www.riksdagen.se/templates/R Page 6316.aspx
- 5. Public Sector Information (PSI), European Union Directive 2003/98/EC, http://www.epsiplatform.eu/content/download/3234/34944/file/English 1 34520031231en00900096.pdf
- 6. Lag (2010:566) om vidareutnyttjande av handlingar från den offentliga förvaltningen, SFS 2010:566, Socialdepartementet, Utfärdad: 2010-06-03, Ändrad: t.o.m. SFS 2010:1494, http://62.95.69.3/SFSdoc/10/100566.PDF
- 7. Sarbanes–Oxley Act of 2002, <u>Public Law 107-204</u>, 116 <u>Stat.</u> 745, enacted July 30, 2002, http://www.gpo.gov/fdsys/pkg/PLAW-107publ204/content-detail.html
- 8. Health Insurance Portability and Accountability Act (HIPAA) of 1996, Public Law 104-191, 1996
- 9. Lag (2008:717) om signalspaning i försvarsunderrättelseverksamhet, Försvarsdepartementet, Utfärdad 2008-07-10, Ändring infördt.o.m. SFS 2009:967 (FRA-lagen)
- 10. Lag (2009:967) om ändring i lagen (2008:717) om signalspaning i försvarsunderrättelseverksamhet, http://62.95.69.3/SFSdoc/09/090967.PDF
- 11. Personuppgiftslag (1998:204), Justitiedepartementet L6, Utfärdad 1998-04-29, Ändring införd t.o.m. SFS 2010:1969
- 12. Dennis Meredith, *Explaining Research: How to reach key audience to advance your work*, Oxford University Press, 2010, ISBN 978-0-19-973205-0
- 13. Nancy Baron, Escape from the Ivory Tower: A Guide to Making Your Science Matter, Island Press, 2010, ISBN 978-1-59726-664-2
- 14. Adrienne J. Burke, Science & Prizes: How open innovation networks can help solve scientific puzzles, The New York Academy of Sciences Magazine, Winter 2011, pp. 17-21.

¿Questions?