Ethique et big data

Cambo les Bains, 27/09/2018

- Big data et consentement ‘libre et éclairé’
- Big data et big science

Questions autour du consentement 'libre et éclairé': 2 exemples

- L'expérimentation sans consentement: « Experimental evidence of massive scale emotional contagion through social networks » (*PNAS*, 17/06/2014)
- Tous présumés consentants: le projet 'care.data' du National Health Service (England)

Experimental evidence of massive scale emotional contagion through social networks

- Les auteurs: ADI Kramer (Core Data Science Team, Facebook Inc); JE Guillory et JT Hancock (Departements of Communication and Information Science, Cornell Univ)
- L'hypothèse de la recherche: il est possible de modifier les émotions exprimées par les utilisateurs de Facebook selon que l'on filtre leur 'News feed' pour privilégier l'expression d'émotions positives ou négatives
- Le critère de jugement: le nombre de mots 'positifs' ou 'négatifs' d'après le Linguistic Inquiry and Word Count Software

Experimental evidence of massive scale emotional contagion through social networks

- Le plan expérimental:
  - ≈ 600 000 utilisateurs de Facebook répartis en 4 groupes de 150 000 sujets
  - 2 groupes 'témoins' et 2 groupes exposés au filtrage, l'un en 'positif' et l'autre en 'négatif'
  - Vérification de la comparabilité des groupes pré exposition
  - Exposition au filtrage pendant une semaine (janvier 2012)
  - Comparaison avant-après des émotions exprimées par les sujets exposés et par les témoins
- Résultats: c.f. le titre de l'article ……

Le débat d'éthique autour de cette étude

- 'Editorial expression of concern' du *PNAS*, publié en même temps que l'article
- Editorial : Protecting human research participants in the age of big data (ST Fiske et RM Hauser, *PNAS*, September 2014**)**

Editorial expression of concern (IM Verma, PNAS, juin 2014)

- ''Questions have been raised about the principles of informed consent and opportunity to opt out in connection with the research of this paper. The authors noted in their paper ''*The work was consistent with Facebook's Data Use Policy, to which all users agree prior to creating an account on Facebook constituting informed consent for this research.* ''. When the authors prepared their paper for publication in PNAS, they stated that ''*Because this experiment was conducted by Facebook , Inc. for internal purposes, the Cornell University IRB determined that the project did not fall under Cornell's Human Research Protection Program*.''
- ……
- It is nevertheless a matter of concern that the collection of the data by Facebook may have involved practices that were not fully consistent with the principles of obtaining informed consent and alllowing participants to opt out.

Protecting human research participants in the age of big data (ST Fiske et RM Hauser, *PNAS*, September 2014**)**

- 'In commerce and on the Internet, experimentation is ubiquitous and invisible, and there is no protection for human participants beyond typically unread use agreements.'
- 'One might well wonder why academic research is more subject to ethical review than that of business enterprises.'
- 'It is time for a forward revision of the 'Common Rule' that will maintain adherence to the principles of the Belmont report of 1978: respect for persons, benificience and justice.'
- 'The National Research Council, supported by the National Science Foundation and a number of private organizations and foundations, prepares a consensus report on revision of the 'Common Rule'.'

- Revised Common Rule:
  - Applicable depuis Juillet 2018
  - L'étude 'Facebook' pourrait-elle être réalisée en septembre 2018?

Le projet 'care.data' du National Health Service (NHS) England (2013)

- NHS England has described the *care.data* service as: '...a new, modern data system for the NHS in England. Known as *care. data*, its purpose will be to provide timely, accurate information to citizens, clinicians and commissioners about the treatments and care provided by the NHS. The aims of the care.data programme are sixfold:
- To support patients' choice
- To advance customer services
- To promote greater transparency
- To improve outcomes
- To increase accountability
- To drive economic growth by making England the default
- location for world-class health services research.

- **B B C** NEWS, Février 2014
  - **Care.data: How did it go so wrong?**
- **«** The government decides to shut down its troubled care.data programme …… » (From Computer.weekly, 6 juillet 2016)

The social licence for research: why 'care.data' ran into trouble (Carter et al, J Med Ethics, (January 2015) (1)

- The tenor of the arguments (of the Academy of Medical Sciences (AMS)) was that the proper solution to the challenges surrounding use of routine medical data for research purposes might then be one of adjusting the regulatory environment to accomodate what the public would support.
- ……. The core of the AMS argument was that **the social licence** for the use of medical records for research was more permissive than the operation of the regulatory environment allowed.
- 'Social licence to operate': expectations of the society regarding the conduct and activities of corporations that go beyond the requirements of formal regulation.

The social licence for research: why 'care.data' ran into trouble (Carter et al, J Med Ethics, January 2015) (2)

- 'Social licence to operate': expectations of the society regarding the conduct and activities of corporations that go beyond the requirements of formal regulation.
- Legal authority does not necessarily command social legitimacy.
- What the social licence emphasises is the possible need for those undertaking activities likely to provoke public disquiet to go 'beyond compliance' with legal requirements.

Juin 2016: Recommandations du National Data Guardian for Health and Care

- Data security review
  - Consent and opt-out
    - The Secretary of State for Health asked the National Data Guardian (Dame Fiona Caldicott) to develop a consent/ opt-out model which makes it absolutely clear to patients/users of care when health and social care information about them will be used and in what circumstances they can opt out.

Recommandations du National Data Guardian
Mise en application par le Department of Health

- Reco 11: There should be a new consent/opt-out model to allow people to opt-out of their personal confidential data being used for purposes beyond their direct care. This would apply unless there is a mandatory legal requirement or an overriding public interest.
- Reco 15: People should continue to be able to give their explicit consent, for example to be involved in research.

- ***By December 2018, people will be able to access a digital service to help them understand who has accessed their summary care record. By March 2020, people will be able to use online services to see how their personal confidential data collected by NHS Digital has been used for purposes other than their direct care.***

Pour une utilisation éthique du big data en santé, deux impératifs font consensus:

- **Trustworthiness** (loyauté, véracité, crédibilité, …): the identification and realization of the conditions foundational to establishing and maintaining repeated and reproducible trust in another person, system, or practice**.**
- **Accountability** (‘rendre des comptes’)

Big data, big science?

- Science et éthique des grands consortia (From Dove and Özdemir, *Laws*, 2015)
  - If the traditional (and albeit mythic) role of both science and bioethics was to **'speak truth to power**', the modern role of consortia science and ethics is to '**propagate power as truth**'
  - **Extrem centrism** is observed in the shadow efforts of key actors to sustain epistemic silence within larger group.
- Bénéfices et risques de l'association big data – open access