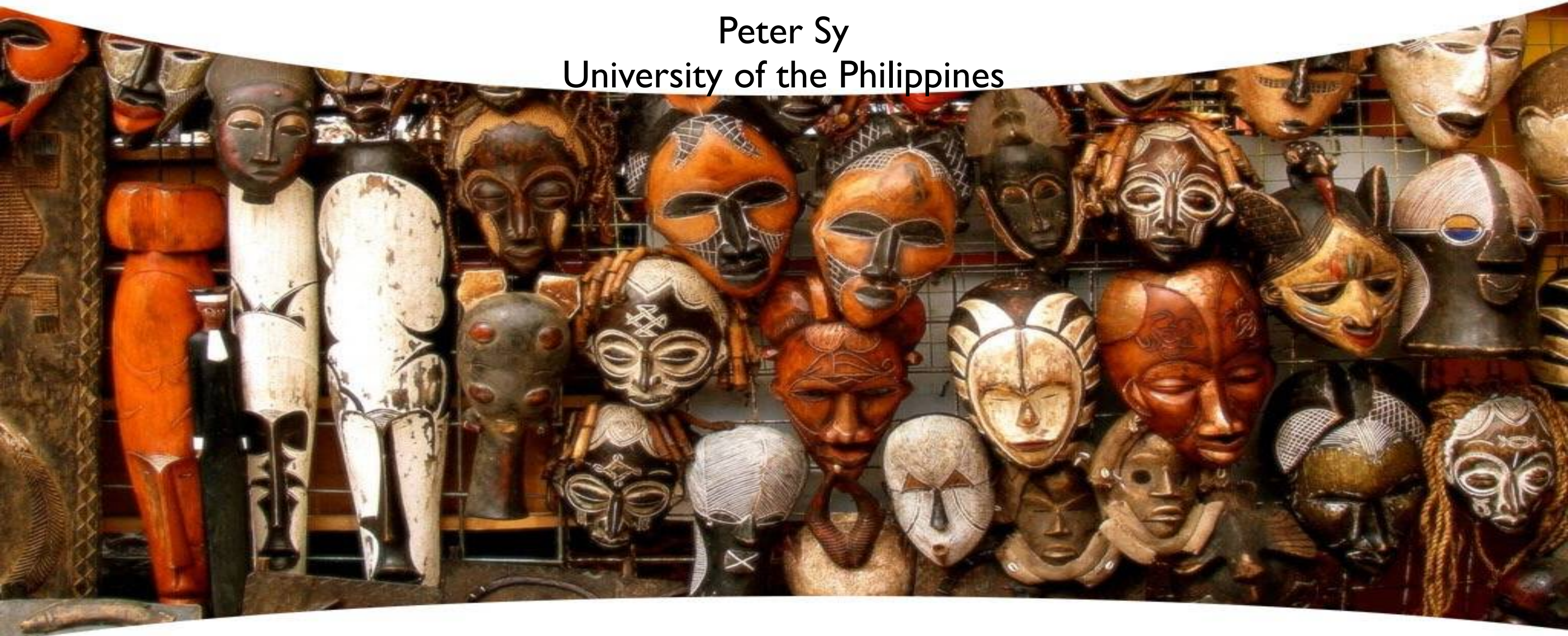


Data Privacy in Health Research and Clinical Practice

Peter Sy

University of the Philippines



Privacy defined

- Privacy - the right to be let alone (Warren & Brandeis, 1890)
- Decisional Privacy - pertains to personal and family decisions about life, death, and reproduction that **protect citizens from state intrusions**

Privacy defined

- Informational Privacy - "the claim of individuals, groups, or institutions to determine for themselves **when, how, and to what extent information** about themselves is communicated to others" (Alan Westin, 1967)

Privacy Regulation

- RA 10173: Data Privacy Act of 2012
 - patterned after EU's Data Protection Directive 95/46/EC
- Implementing Rules and Regulations of RA 10173
- policy: protect right to privacy and support free flow of information



Res Reg, comparative

- EU: “The processing of personal data for archiving purposes in the public interest, **scientific** or historical research purposes or statistical purposes should be **subject to appropriate safeguards** for the rights and freedoms of the data subject pursuant to this Regulation.” (sec 156, General Data Protection Regulation 2016/679 - 27 April 2016)
- “Where personal data are processed for scientific **research purposes**, this Regulation should also apply to that processing” (sec 159)

Definitions

- Personal information - any information from which the identity of an individual is apparent or can be reasonably and directly ascertained by the entity holding the information, or when put together with other information would directly and certainly **identify** an individual



WORLD

India scans a billion irises in interest of national security

Alice MacGregor

Wed 16 Mar 2016 12.33pm



The Indian government is proposing legislation which would allow federal agencies access to its enormous biometric database – which last week reached a rough total of one billion citizen records.

67% 3:58 PM
www.cnet.com/news

Facebook's newest privacy problem: 'Faceprint' data
A court case moves forward over whether the social network is breaking the law for not asking your explicit permission for scanning and storing your facial features.

Thomas Trutschel, Photothek via Getty Images

by **Katie Collins** / @katiecollins
May 6, 2016 8:05 AM PDT / Updated: May 6, 2016 1:19 PM PDT



Facebook knows you so well these days that

99% 11:17 PM
theguardian

home > tech UK world sport all

Internet

Face recognition app taking Russia by storm may bring end to public anonymity

FindFace compares photos to profile pictures on social network Vkontakte and works out identities with 70% reliability



Findface has amassed 500,000 users in the short time since the launch Photograph: Getty Images

Shaun Walker in Moscow

99% 11:15 PM

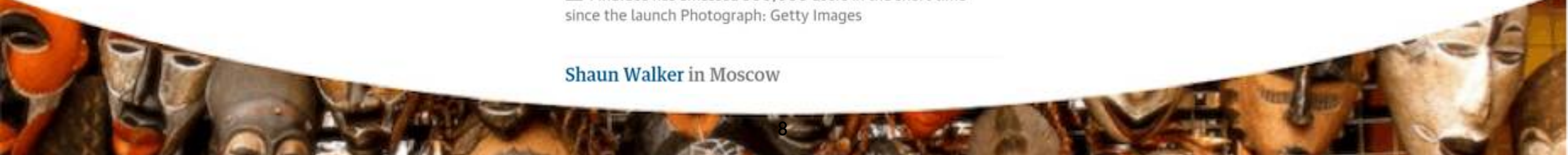
Try Newsweek for only \$1.25 per week

TECH & SCIENCE
PORN STARS AND SEX WORKERS TARGETED WITH FACIAL RECOGNITION APP

BY **ANTHONY CUTHBERTSON** ON 4/29/16 AT 6:23 AM



A campaign in Russia is targeting sex workers



Definitions

- Sensitive personal information -
 - (1) about an individual's race, ethnic origin, marital status, age, color, and religious, philosophical or political affiliations;
 - (2) About an individual's health, education, genetic or sexual life of a person, or to any proceeding for any offense committed or alleged to have been committed by such person, the disposal of such proceedings, or the sentence of any court in such proceedings;



Kuwait has become the first country to make DNA testing mandatory for all residents

Those who refuse risk prison time.

FIONA MACDONALD 13 JUL 2015




In a controversial move, Kuwait has passed a law making it mandatory for all its 1.3 million citizens and 2.9 million foreign residents to have their DNA entered onto a national database.

Definitions

- Sensitive personal information -
 - (3) Issued by government agencies peculiar to an individual which includes, but not limited to, social security numbers, previous or current health records, licenses or its denials, suspension or revocation, and tax returns; and
 - (4) Specifically established by an executive order or an act of Congress to be kept classified.

 **TAKE US WITH YOU EVERY MONTH** 

Researchers intentionally leak details of 70,000 OkCupid profiles

By [Meredith Placko](#) May. 16, 2016 1:44 pm  [mplacko](#)

0 shares    



Another day, another data breach. If there is one surefire bet in the world of internet security, it's that your personal information will end up out in the ether for anyone to view.

Target Article

Is Deidentification Sufficient to Protect Health Privacy in Research?

Mark A. Rothstein, University of Louisville School of Medicine

The revolution in health information technology has enabled the compilation and use of large data sets of health records for genomic and other research. Extensive collections of health records, especially those linked with biolog-

level of protection to deidentified information without unduly burdening research.

DEFINING “DEIDENTIFIED” INFORMATION

Science News

from research organizations

Posting 'anonymized' research data may pose threats to patient privacy

Date: May 16, 2016

Source: Wolters Kluwer Health: Lippincott Williams and Wilkins

Summary: Many healthcare journals encourage researchers to post their original data online, in the interest of research openness. But open sharing of research databases can place private patient information at risk, according to a special topic paper.

Share:



FULL STORY

Many healthcare journals encourage researchers to post their original data online, in the interest of research openness. But open sharing of research databases can place private patient information at risk, according to a special topic paper in *Anesthesia & Analgesia*.



Definitions

- Personal information controller - person or organization who controls the collection, holding, processing or use of personal information, including a person or organization who instructs another person or organization to collect, hold, process, use, transfer or disclose personal information on his or her behalf



Definitions

- Personal information processor - any natural or juridical person to whom a personal information controller may outsource the processing of personal data pertaining to a data subject
- Processing - any operation performed upon personal information including, but not limited to, the collection, recording, organization, storage, updating or modification, retrieval, consultation, use, consolidation, blocking, erasure or destruction of data.

Definitions

- Data subject - “an individual whose personal information is processed”
- Consent of the data subject - “any freely given, specific, informed indication of will, whereby the data subject agrees to the collection and processing of personal information about and/or relating to him or her.”



Consent

- informed of
 - purpose, nature and extent of processing, including intention to process personal data for scientific, statistical or research purpose
 - period that consent is deemed effective or instructions on how consent can be withdrawn
- rights as data subject



Consent

- evidenced by written, electronic or recorded means
- may also be given on behalf of the data subject by a lawful representative or an agent specifically authorized by the data subject to do so

Guardian sustainable business
children's rights and business

Could children one day sue parents for posting baby pics on Facebook?

Pictures once kept hidden in family photo albums are now being shared with the world, and children may not appreciate it in the future



Privacy Principles

- I. Transparency: Be informed of whether personal information is being processed; of purpose, scope & method of info processing; to whom personal information might be disclosed; data retention limit
- - in regard to policies and practices relating to the management of personal information in the research project

Privacy Principles

- I. **Transparency**: Be informed of whether personal information is being processed; of purpose, scope & method of info processing; to whom personal information might be disclosed; data retention limit
- - in regard to policies and practices relating to the management of personal information in the research project

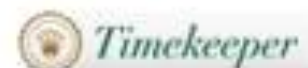
Special report: Technology and politics ▾

Living with technology

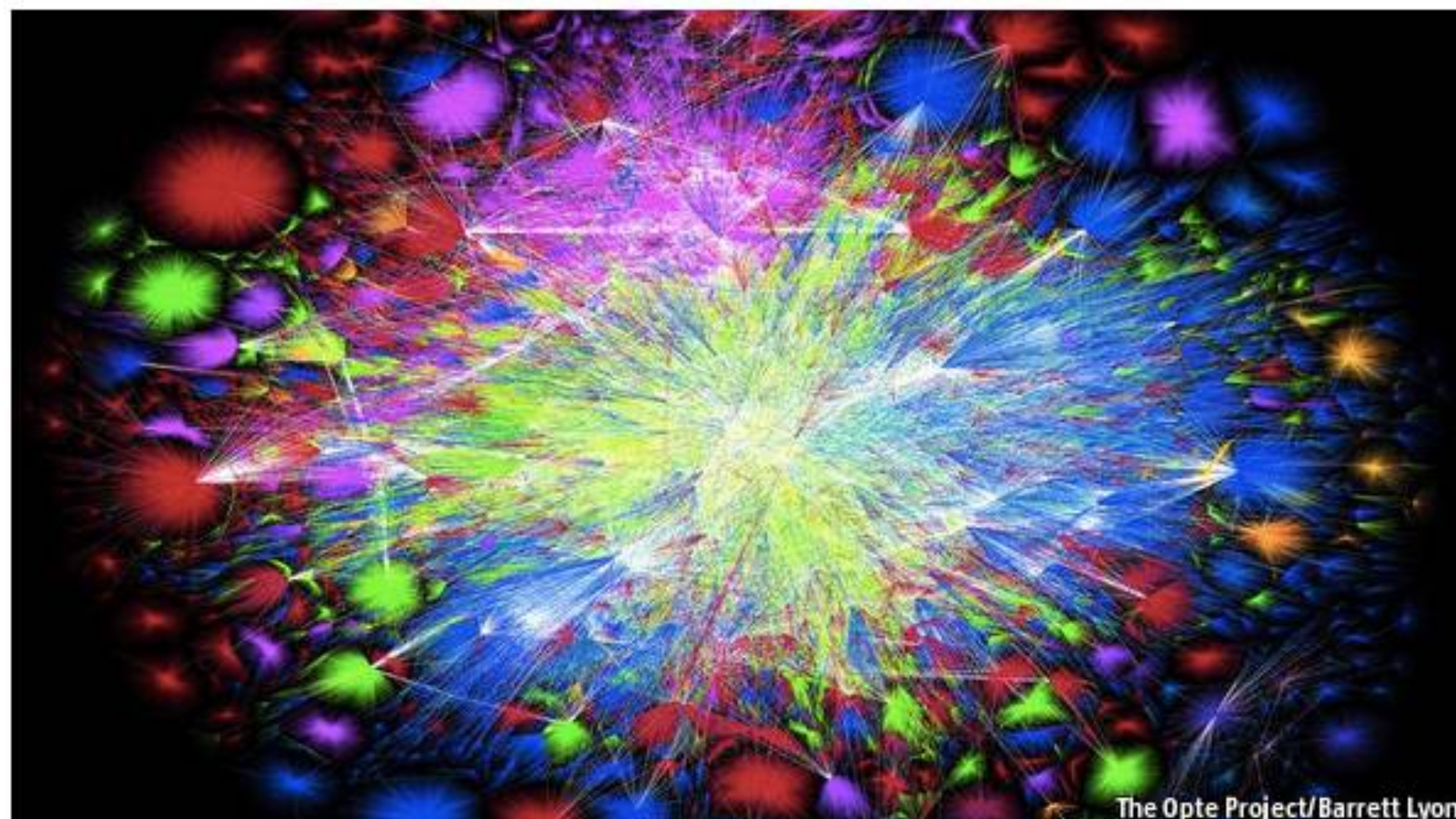
The data republic

To safeguard democracy, the use of data should be made as transparent as possible

Mar 26th 2016 | [From the print edition](#)



630



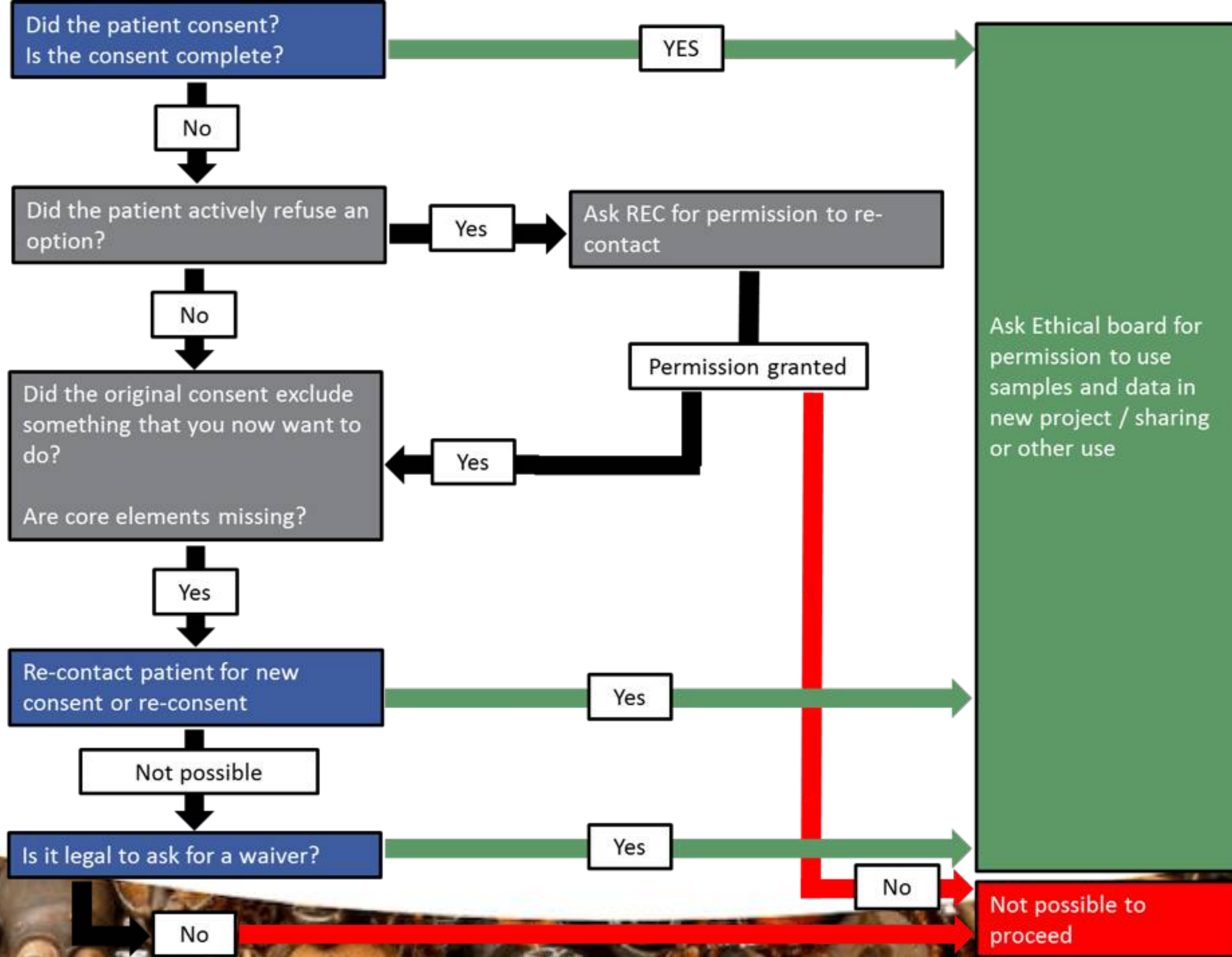
The Opte Project/Barrett Lyon

Privacy Principles

- 2. Legitimate Purpose - clear purpose for which personal information is collected at or before the time the information is collected

Privacy Principles

- 3. Consent - “freely given, specific, informed indication of will, whereby the data subject agrees to the collection and processing of personal information” (Sec 3b)
- Consent - from data or research subjects for the collection, use, or disclosure of personal information



Privacy Principles

- Consent - may be necessary but not sufficient to protect their rights



Science Head quarters

Facebook fiasco: was Cornell's study of 'emotional contagion' an ethics breach?

A covert experiment to influence the emotions of more than 600,000 people. A major scientific journal behaving like a rabbit in the headlights. A university in a PR tailspin



Privacy Principles

- 4. Proportionality: Personal information must be “adequate and not excessive in relation to the purposes for which they are collected and processed” (Sec 11d)

Privacy Principles

- 5. Accountability - designation of specific individual or individuals who are accountable for the organization's privacy compliance

hai doc reply asap may gf po ako.5yrs na kami 21 na sya.din.
2yrs+ na po sya walang regla.hndi pa sya na bubunts normal
Ing namn dugo nya sa katawn nya.sabi din nya.parihu dn cla ng
mama nya dati at unti nya.mga pinsan din.tumataba dn po sya
ngayun!tumataba dn balakang nya at pos,un.may napansin dn
po ako sa loob ng V nya na parag matigas na bilog.dati wla po
akong nahihipu ganun.ayaw dn nyang magpa check,up.anu
dapat ipa inum sakanya para mag regla na sya?salamat

Yesterday at 3:41 PM · Like · Reply



Magandang Aron

Dok Bru

www.dokbruendocrine-witch.net

Endocrine Witch
Personal Blog

0 Comments · 0 Likes · 0 Shares

Timeline · About · Photos · Likes · More

0 Add Your Facts

Privacy Principles

- 6. Access - be informed of the existence, use, and disclosure of personal information; be given access to that information; to amend info as appropriate (Sec 11c, 16b,8)

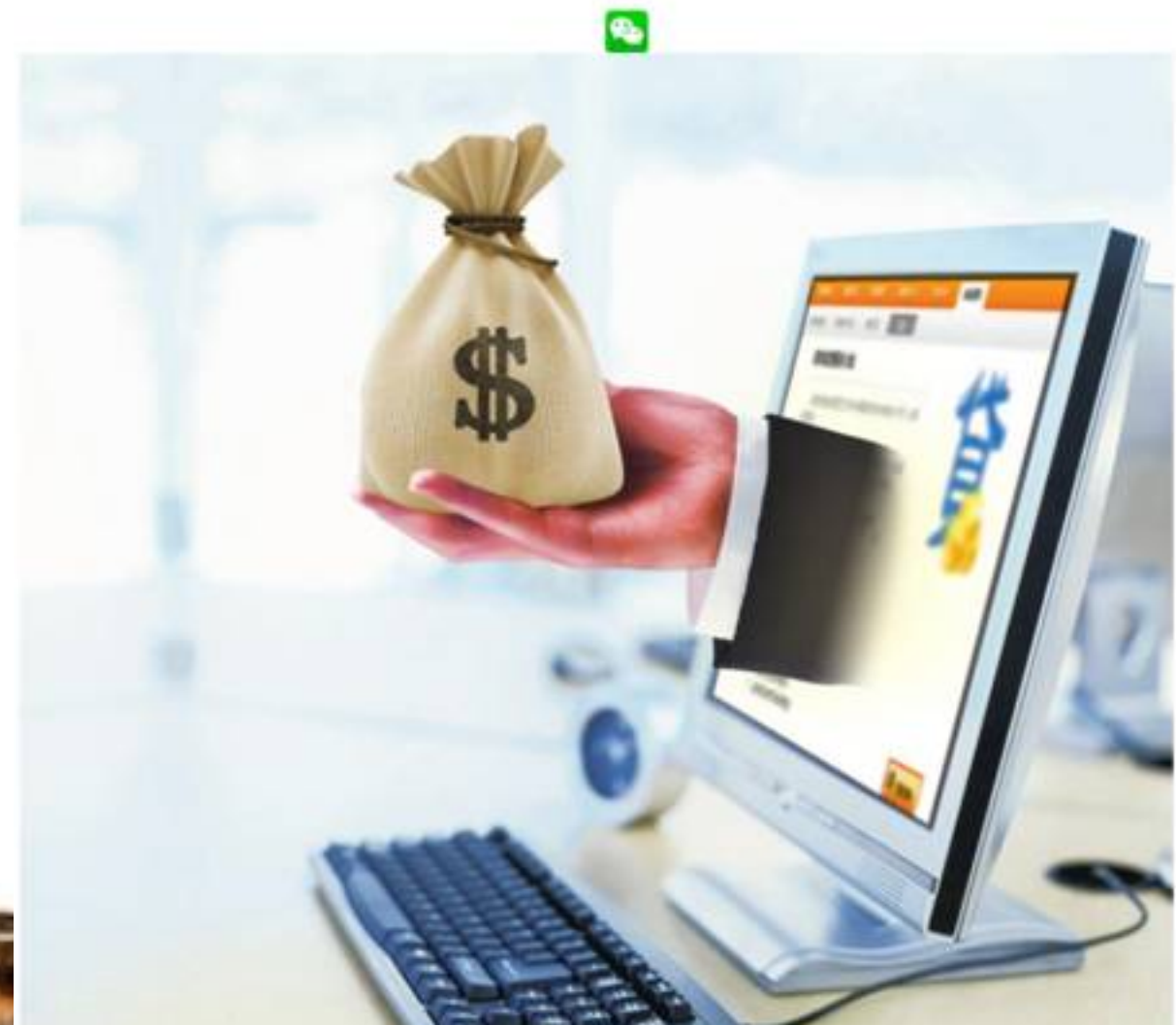
Privacy Principles

- 7. Limited Use, Disclosure and Retention - no use or disclosure for purposes other than those for which it was collected, except with the consent or by law. Info retention only as long as necessary.

English >>

Nude pics as IOU: a new, risky online loan among Chinese university students

(People's Daily Online) 13:32, June 14, 2016



Privacy Principles

- 8. Accuracy, completeness, up-to-date for the purposes for which it is to be used

Privacy Principles

- 9. Safeguards - security safeguards appropriate to the sensitivity of the information

the security ledger



INTERNET OF THINGS ▼

CONNECTED CARS

THREATS ▼

THOUGHT LEADERSHIP ▼

PODCASTS

VIDEO

You are here: [Home](#) » [Companies](#) » [Anthem Healthcare](#) » Doctors Still In the Dark After Electronics Records Hack Exposes Data on 4 Million

Doctors Still In the Dark After Electronics Records Hack Exposes Data on 4 Million

POSTED BY: PAUL JULY 31, 2015 16:34 0 COMMENTS



A **hack** of the Indiana firm Medical Informatics Engineering has exposed medical information on millions of Americans, including 1.5 million in Indiana.

Privacy Principles

- 10. Challenge and Compliance - making clear to research or data subjects the processes for privacy challenge, incident reporting, and compliance

end

