DNA DATA SHARING AND PRIVACY CHALLENGES

Sara Huston Katsanis

August 17, 2017

Rapid DNA Forum

"OF COURSE I VALUE MY PRIVACY...THAT'S WHY I ONLY SHARE MY PERSONAL INFORMATION WITH 700 OF MY CLOSEST FRIENDS!"

Citizens define what is private

1. Iris/retina scan
2. Fingerprint scan
3. DNA
4. Passport details
5. Date of birth
6. Bank account details
7. Credit ratings
8. Salary/compensation
9. Performance at work
10. Mobile phone details
11. Residential address
12. Family details
13. Medical records
14. Debit/credit card details
15. Income tax details


SAY
'AHHH'!
WARRANTLESS
DNA
COLLECTION
OK!
WWW.CARTOONaDAY.COM

Electronic Frontier Foundation's spotlight (and FOIAs)

Rapid DNA: Coming Soon to a Police Department or Immigration Office Near You

BY JENNIFER LYNCH | JANUARY 6, 2013

EFF Sues Justice Department for Records About FBI's Plans for Rapid DNA

PRESS RELEASE | AUGUST 17, 2015

Maryland v King oral arguments

MR. DREEBEN: You are not wrong, Justice Kagan, but the future is very close to where there will be ra
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And, as I suggested, with the advent of rapid DNA, it's not that it is unconstitutional before rapid DNA, but rapid DNA will permit DNA identification to repl
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MS. WINFREE: On the question of rapid DNA, the FBI estimates that we're about 18 to 24 months away from that world, and I would cite the National District Attorneys Association's amicus brief on page 20 where it discusses the -- that this is not science fiction. So we are very, very close to that.

THE SUPREME COURT RULES DNA CAN BE TAKEN AFTER ARREST.

www.investors.com/cartoons

Maryland v King – Scalia's dissent

The Court also accepts uncritically the Government's representation at oral argument that it is developing devices that will be able to test DNA in mere minutes. At most, this demonstrates that it may one day be possible to design a program that uses DNA for a purpose other than crime-solving—not that Maryland has in fact designed such a program today. And that is the main point, which the Court's discussion of the brave new world of instant DNA analysis should not obscure. The issue before us is not whether DNA can *some day* be used for identification; nor even whether it can *today* be used for identification; but whether it *was used for identification here*.

Universal DNA database fosters population equity

Kuwait's mass DNA database is a huge attack on genetic privacy

The Gulf State will soon be the first nation to force all residents and visitors to hand over DNA, risking its reputation and more, warns geneticist **Olaf Rieß**

DAILY NEWS 21 October 2016

Kuwait to change law forcing all citizens to provide DNA samples

New Scientist Sep 13, 2016 Yasser Al-Zayyat/AFP/Getty Images

What's so special about genetic information anyway?

- Is a **DNA profile** the same as a fingerprint?
  - …maybe, maybe not…

- A **DNA sample** contains information that can predict
  - disease propensities
  - psychological predispositions
  - medical information
  - biological relationships
  - ancestry or ethnic data

- A **DNA sample/profile** may contain information the DNA source may not know, may not wish to know, and/or may not wish others to know
  - "Right not to know"

History of avoiding sensitive genetic information in forensics

- Criminal scientific applications demand due process and respect for Constitutional rights of the “innocent until proven guilty”
- Law enforcement is under scrutiny for civil rights violations
- DNA Advisory Board specifically chose CODIS markers not associated with medical traits, physical traits, and ancestral geographic origins
  - … but mostly because this means they are biologically neutral and will have higher mutation rates in each generation, making them diverse markers

Public perceptions (and misconceptions?)

- Police will use what they can to catch criminals
- Public fears lack of privacy from government
- “Police may plant my DNA at a crime scene”

- DNA sample is not distinguished from DNA profile
- DNA marker is not distinguished from DNA marker genotype

- DNA offender samples are not distinguished from DNA evidence samples
- DNA used in court for conviction are not distinguished from investigative uses

JOURNAL OF FORENSIC SCIENCES

J Forensic Sci, 2012
doi: 10.1111/j.1556-4029.2012.02253.x
Available online at: onlinelibrary.wiley.com

TECHNICAL NOTE

CRIMINALISTICS; JURISPRUDENCE

Sara H. Katsanis,[1] *M.S. and Jennifer K. Wagner,*[2] *J.D., Ph.D.*

Characterization of the Standard and Recommended CODIS Markers*

	CODIS Marker	Gene Name	Disorder(s) Caused by Gene Mutations	Number of (#) Phenotypes Associated Within 1 kb	Predicted DNA Elements
1	D18S51	*BCL2* (B-cell CLL/lymphoma 2)	Leukemia/lymphoma, B-cell	11	ELAV1 binding site
2	FGA	*FGA* (fibrinogen alpha chain)	Congenital afibrinogenemia; hereditary renal amyloidosis; dysfibrinogenemia (alpha type)	17	PABPC1 binding site
3	D21S11	None		1	None
4	D8S1179	None		17	None
5	VWA*	*VWF* (von Willebrand factor)	Von Willebrand disease	12	ELAV1 binding site
6	D13S317	None		5	None
7	D16S539	None		8	None
8	D7S820	*SEMA3A* (sema domain, immunoglobulin domain, short basic domain, secreted (semaphorin) 3A)		8	CELF1, ELAV1 and PABPC1 binding site
9	TH01	*TH* (tyrosine hydroxylase)	Segawa syndrome, recessive	18	ELAVL1, PABPC1 and SLBP binding site
10	D3S1358	*LARS2* (leucyl-t mitochondria)			
11	D5S818	None			
12	CSF1PO	*CSF1R* (colony receptor)			tor; g site
13	D2S1338	None			
14	D19S433	*C19orf2* (uncha			sitivity site; SLBP binding site
15	D1S1656	*CAPN9* (calpain 9)		10	PABPC1 binding site
16	D12S391*	None		6	None
17	D2S441	None		6	None
18	D10S1248	None		6	DNase I hypersensitivity site
19	Penta E	EST: BG210743 (uncharacterized EST)		8	None
20	DYS391	None		1	None
21	TPOX	*TPO* (thyroid peroxidase)	Thyroid dyshormonogenesis 2A	5	PABPC1 and SLBP binding site
22	D22S1045	*IL2RB* (interleukin 2 receptor, beta)		11	None
23	SE33	None		9	None
24	Penta D	*HSF2BP* (heat shock factor 2-binding protein)		6	PABPC1 and SLBP binding site

"…even for CODIS marker genotypes statistically associated with biomedically relevant phenotypes, statistical association is not synonymous with positive or negative predictive value."

Markers are shown in their relative rank according to Hares (1).
*VWA and D12S391 are colocated on 12p13 within 6 Mb.

Report

Current Biology

Individual Identifiability Predicts Population Identifiability in Forensic Microsatellite Markers

Highlights

- Ancestry information is compared for the CODIS forensic markers and non-CODIS loci
- The CODIS markers have ancestry information comparable to random marker sets

Authors

Bridget F.B. Algee-Hewitt, Michael D. Edge, Jaehee Kim, Jun Z. Li, Noah A. Rosenberg

Current Biology *26*, 935–942, April 4, 2016 ©2016

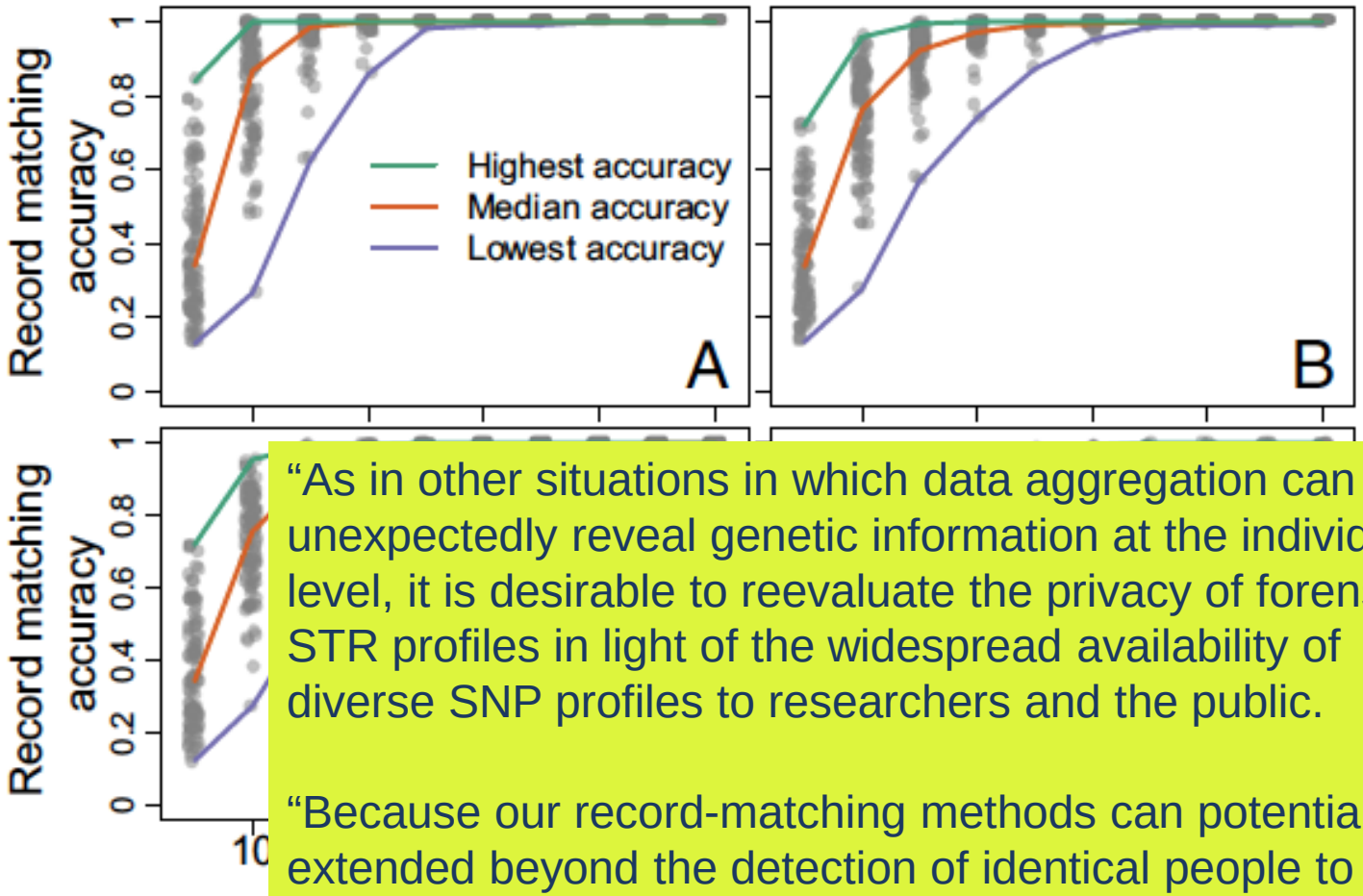
PNAS

Linkage disequilibrium matches forensic genetic records to disjoint genomic marker sets

Michael D. Edge[a], Bridget F. B. Algee-Hewitt[a], Trevor J. Pemberton[b], Jun Z. Li[c], and Noah A. Rosenberg[a,1]

[a]Department of Biology, Stanford University, Stanford, CA 94305; [b]Department of Biochemistry and Medical Genetics, University of Manitoba, Winnipeg, MB, Canada R3E0J9; and [c]Department of Human Genetics, University of Michigan, Ann Arbor, MI 48109

www.pnas.org/cgi/doi/10.1073/pnas.1619944114



"As in other situations in which data aggregation can unexpectedly reveal genetic information at the individual level, it is desirable to reevaluate the privacy of forensic STR profiles in light of the widespread availability of diverse SNP profiles to researchers and the public.

"Because our record-matching methods can potentially be extended beyond the detection of identical people to the detection of relatives—matching a SNP profile of an individual to an STR profile of a relative—we expect that privacy considerations will extend to this scenario as well."

Fig. 4. Record
number of loci,
Fig. 1; results are shown horizontally jittered. (*A*) One-to-one matching. (*B*) One-to-many matching selecting the STR profile that best matches a query SNP profile. (*C*) One-to-many matching selecting the SNP profile that best matches a query STR profile. (*D*) Needle-in-haystack matching.

Human genetic identification applications

Crime Solving

- Homicides
- Sexual assaults
- Property crimes

Remains Identification

- Military
- Missing persons
- Mass fatalities

Human Trafficking

- International missing persons database
- Domestic non-criminal public database

Tolerance for privacy risks probably vary based on the application

Criminal Investigatio

- Matches to a database
- Familial searching
- Molecular photo-fitting

Citizenship

- Verify relationship of immigrant applicant
- Detection of adoption fraud

Personal Use

- Civil investigations (e.g., custody, inheritance)
- Relationship testing
- Genealogy research
- Infidelity

Lessons from public biobanks and medical genomics research

- Informed consent as a transparency mechanism is a foundation for privacy protections
- Laws and federal rule-making can restrict research and prevent translation of science
  - e.g., Human Subjects Common Rule
- Government transparency reassures public
  - e.g., Million Veterans program
- Altruism is alive and well

What data is to be shared? With whom?

- DNA sample sharing? Or DNA profile sharing?
- Personally-identifiable data with a profile? Or de-identified genetic profiles?
- Between criminal justice agencies for crime-solving? For terrorism? For mass disaster?
- From criminal justice agency to immigration agency? Or from immigration agency to criminal justice agency?
- Across borders?

Inherent privacy benefits of Rapid DNA approach

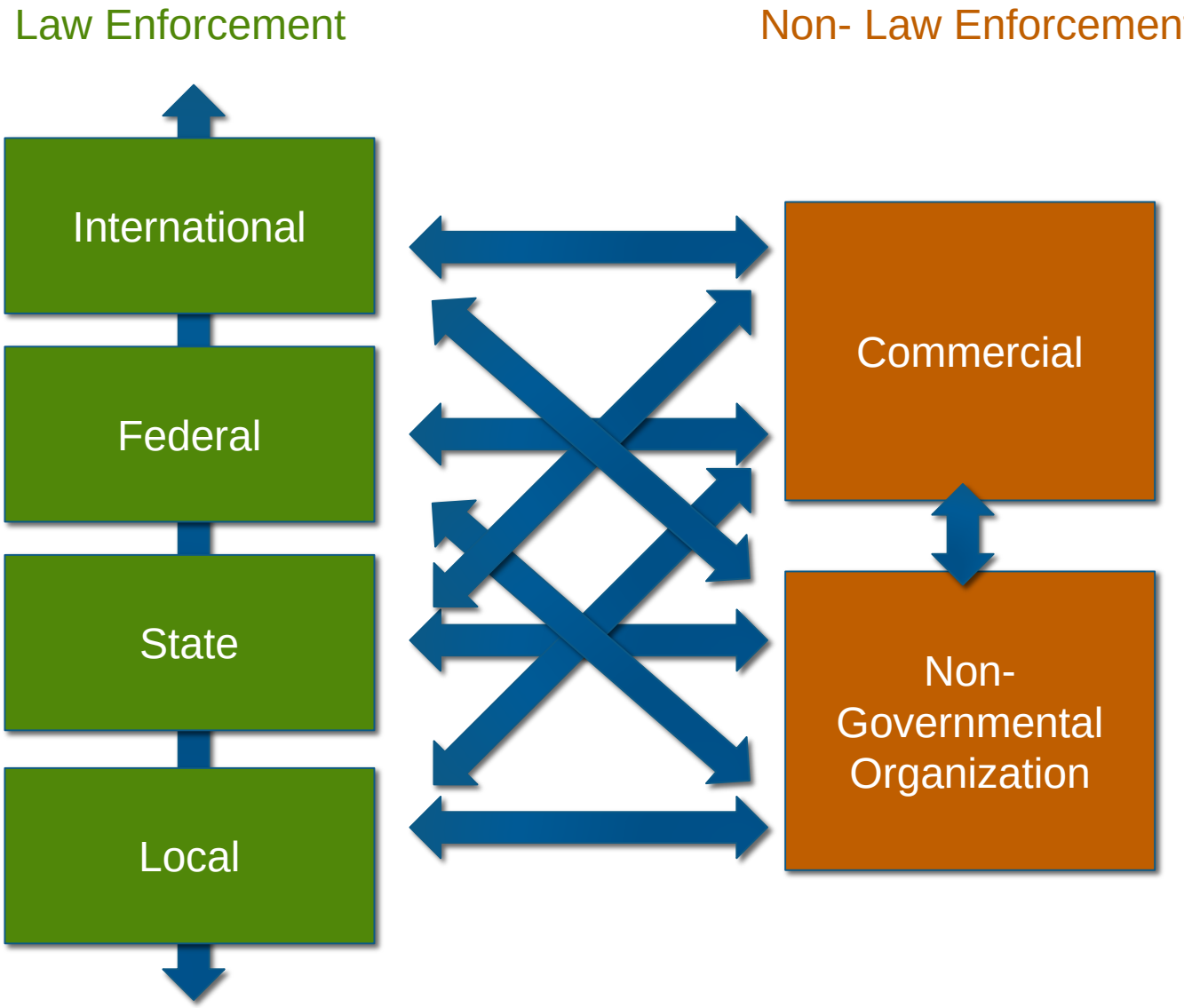
- Fewer eyes/hands, lower risk of mishandling and inadvertent privacy intrusion
- Consumption / destruction of sample swab by design
- Optional connectivity to databases
- Option to “search and release” during detention – both the person of interest and the sample

“Family” is a social construct, not a biological one






DNA data-sharing rules will vary



Privacy Act of 1974

(a) The Congress finds that –

(1) the privacy of an individual is directly affected by the collection, maintenance, use, and dissemination of personal information by Federal agencies;

(2) the increasing use of computers and sophisticated information technology, while essential to the efficient operations of the Government, has greatly magnified the harm to individual privacy that can occur from any collection, maintenance, use, or dissemination of personal information;

(3) the opportunities for an individual to secure employment, insurance, and credit, and his right to due process, and other legal protections are endangered by the misuse of certain information systems;

(4) the right to privacy is a personal and fundamental right protected by the Constitution of the United States; and

(5) in order to protect the privacy of individuals identified in information systems maintained by Federal agencies, it is necessary and proper for the Congress to regulate the collection, maintenance, use, and dissemination of information by such

https://www.justice.gov/opcl/privacy-act-1974

Relevant bits of the Privacy Act in a nutshell…

- does not apply to non-US citizens / legal residents
  - “The term “individual” means a citizen of the United States or an alien lawfully admitted for permanent residence.” (§3(a)(2))
- excludes “matches” for criminal justice purposes
  - §3(a)(8)(B)
- restricts sharing of data across agencies and outside of agencies
  - §3(e)(1) and §3(e)(10)
- requires consent of the individual
  - §3(e)(3)

NDIS & the Privacy Act (61 FR 37495)

- Individuals covered by the NDIS law:
  - Convicted offenders
  - Missing persons and their close biological relatives
  - Victims
  - DNA lab personnel

- The law does not cover the DNA sample itself, only the DNA profile and the personally identifiable information associated with it

NDIS & the Privacy Act (61 FR 37495)

- Permits direct disclosures of NDIS records to Federal, State and local criminal justice agencies who participate in NDIS

- Permits secondary or indirect disclosures of DNA records…
  - To criminal justice agencies for law enforcement ID purposes
  - In judicial proceedings
  - For criminal defense purposes
  - For a population statistics or research, if personally identifiable information is removed

Fair Information Practice Principles for Rapid DNA

Privacy Impact Assessment
for the

Rapid DNA System

DHS/S&T/PIA-024

February 8, 2013

Contact Point
Christopher Miles
Science and Technology Directorate
Department of Homeland Security
(202) 254-6642

1. Transparency
2. Choice/consent for individual participation
3. Purpose specification
4. Data minimization
5. Use limitation
6. Data quality and integrity
7. Security
8. Accountability and auditing

Sara's thoughts on Rapid DNA uses outside of NDIS

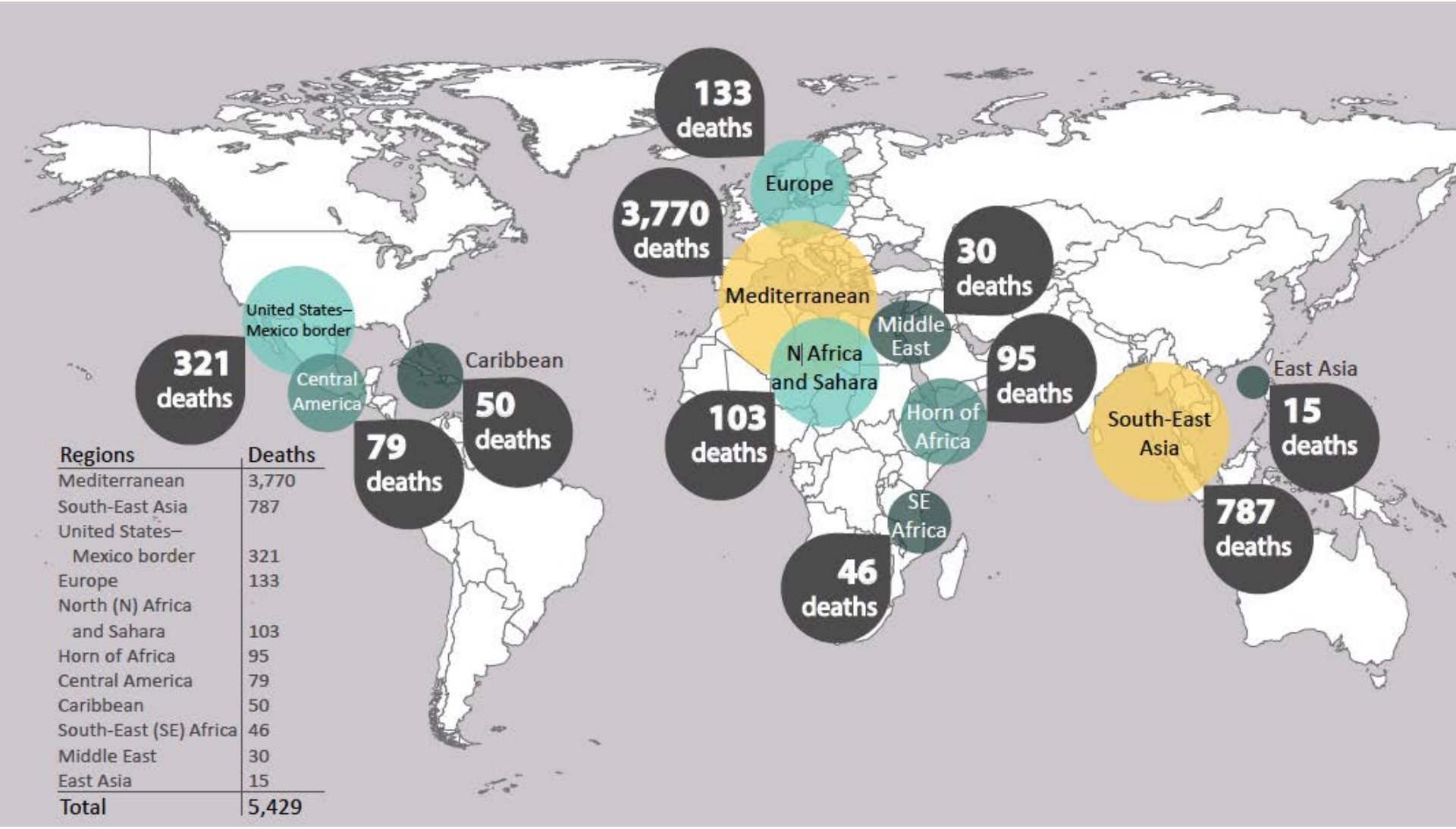
- DNA collected by US agencies ***not*** for NDIS would be subject to the Privacy Act, unless exempted for criminal justice or for terrorism surveillance under the Patriot Act

- The protections of the Privacy Act do not cover foreign persons (except legal residents)

- DNA collected by private organizations outside of a government agency is NOT subject to the Privacy Act

- *Questions remaining…*
  - Would DNA collected and then discarded by an agency be considered a data record?
  - If Rapid DNA applications are entirely managed by private entities, what privacy protections are needed? What data could be shared with government agencies?
  - What protections are needed for collection of foreign persons' DNA?

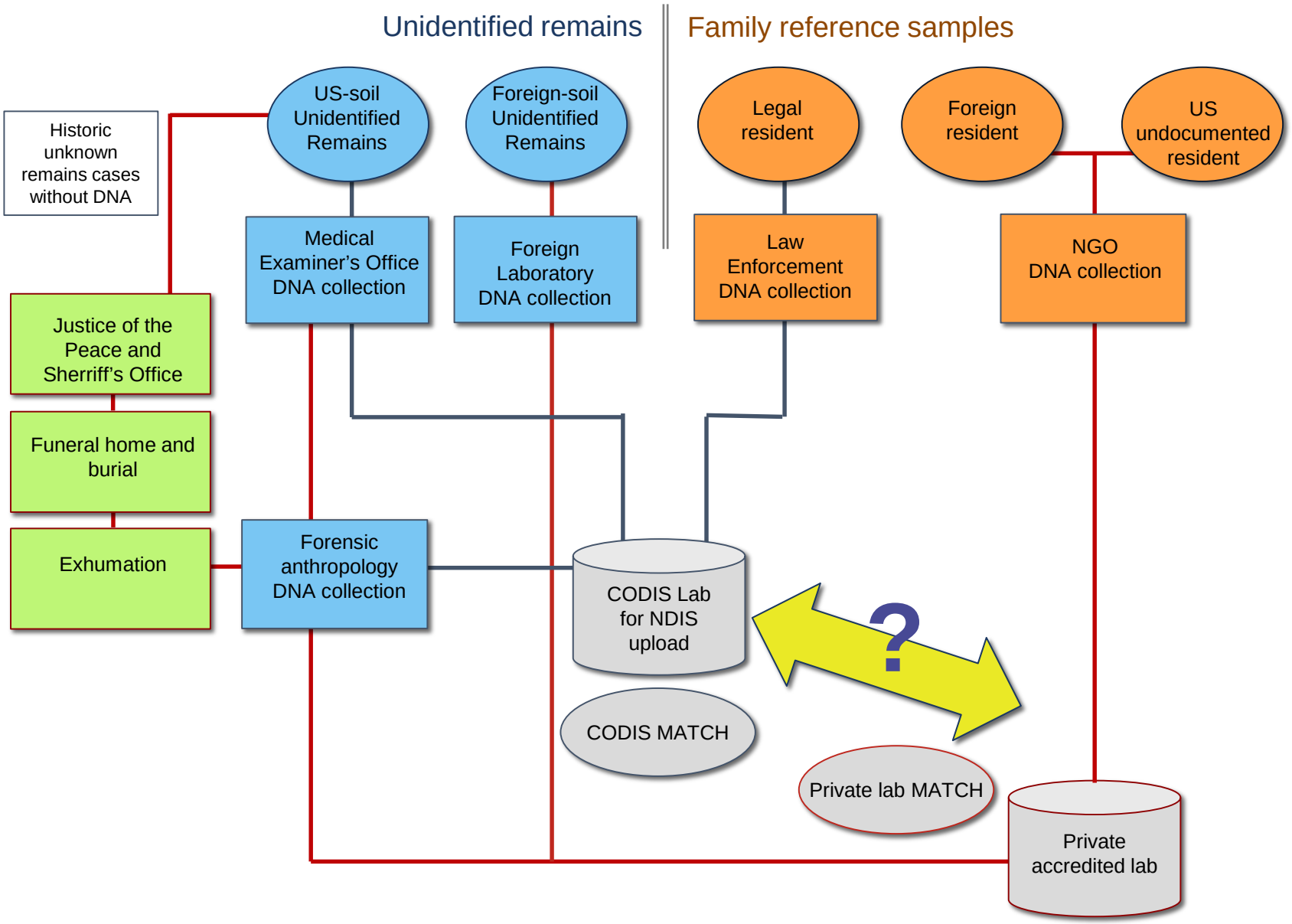
Migrant border-related deaths around the world, 2015



Regions	Deaths
Mediterranean	3,770
South-East Asia	787
United States–Mexico border	321
Europe	133
North (N) Africa and Sahara	103
Horn of Africa	95
Central America	79
Caribbean	50
South-East (SE) Africa	46
Middle East	30
East Asia	15
Total	5,429

Source: *Fatal Journeys 2* International Organization for Migration Report 2016

DNA collection for missing migrant investigations



What is needed to move science forward?

- Legal infrastructure to permit use of technology
  - (while minimizing privacy intrusions)
- Improved public-private partnerships
  - (along with accountability guidelines)
- Public dialogue to minimize misconceptions
  - (while respecting alternative perspectives)
- Better forums to translate science to the public
  - (not just through crime TV shows and juries)
- Courage to apply new technologies
  - (while researching the gaps and challenges)

THANK YOU

sara.katsanis@duke.edu

Duke Students

Alexa Barrett ‘15
Lindsey Snyder ‘18
Victoria Grant ‘19
Richard Phillips ‘17

Collaborators

Jennifer Wagner, Geisinger Health
Seth Faith, NCSU
Amy Mundorff, UT-Knoxville
Thomas Parsons, ICMP
Carlos Bustamante, Stanford
Amanda Flaim, Michigan SU

Advisors

Nita Farahany
Bob Cook-Deegan
Robin Kirk
Suzanne Shanahan

Duke SCIENCE & SOCIETY