

Racial politics and the measurement of health inequalities



Professor Julia Lynch

Michael Tu and Mamaswatsi

Kopeka

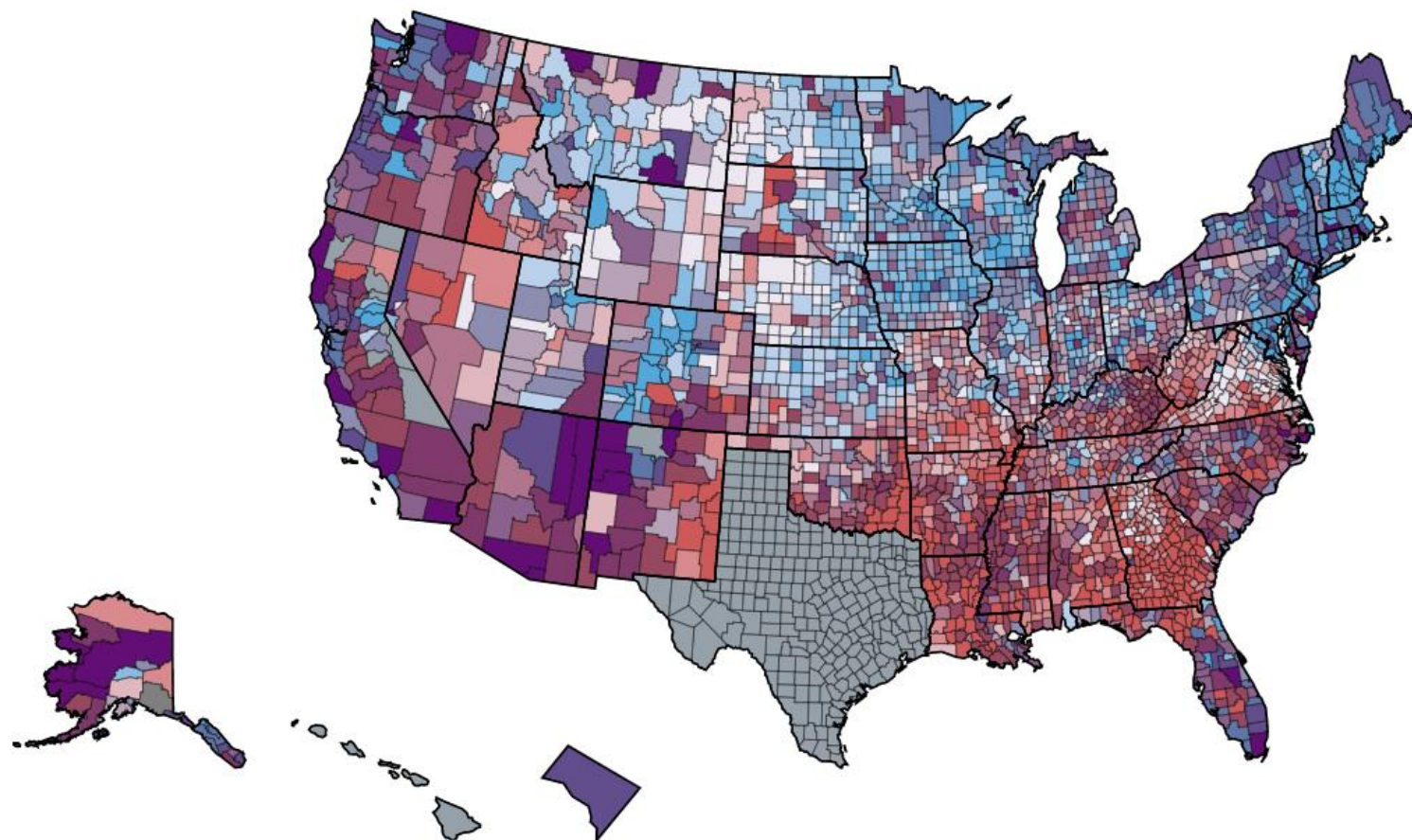


Presentation Outline

PART 1	Introduction
PART 2	France
PART 3	United Kingdom
PART 4	Tying it together
PART 5	Conclusion and Next Steps

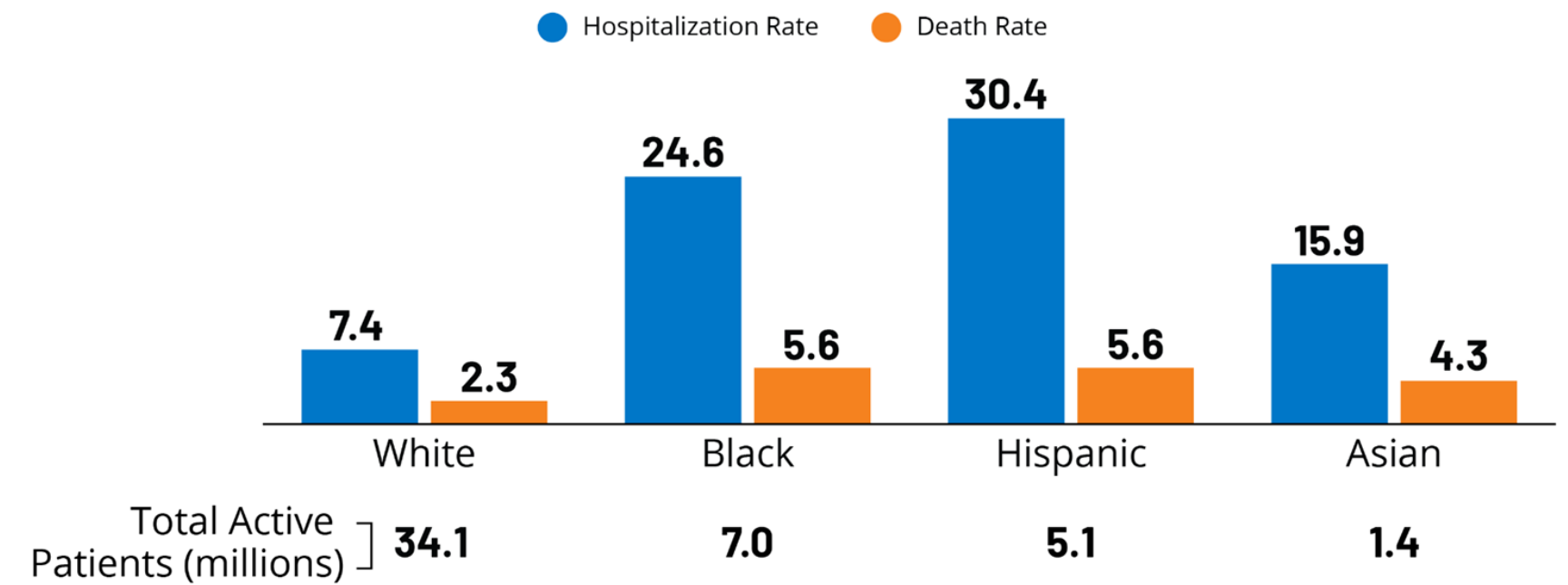


Percent of Population Fully Vaccinated by Social Vulnerability Index (SVI)



COVID-19 Hospitalization and Death Rates among Active Epic Patients by Race/Ethnicity

Rate per 10,000, as of July 2020



Introduction:

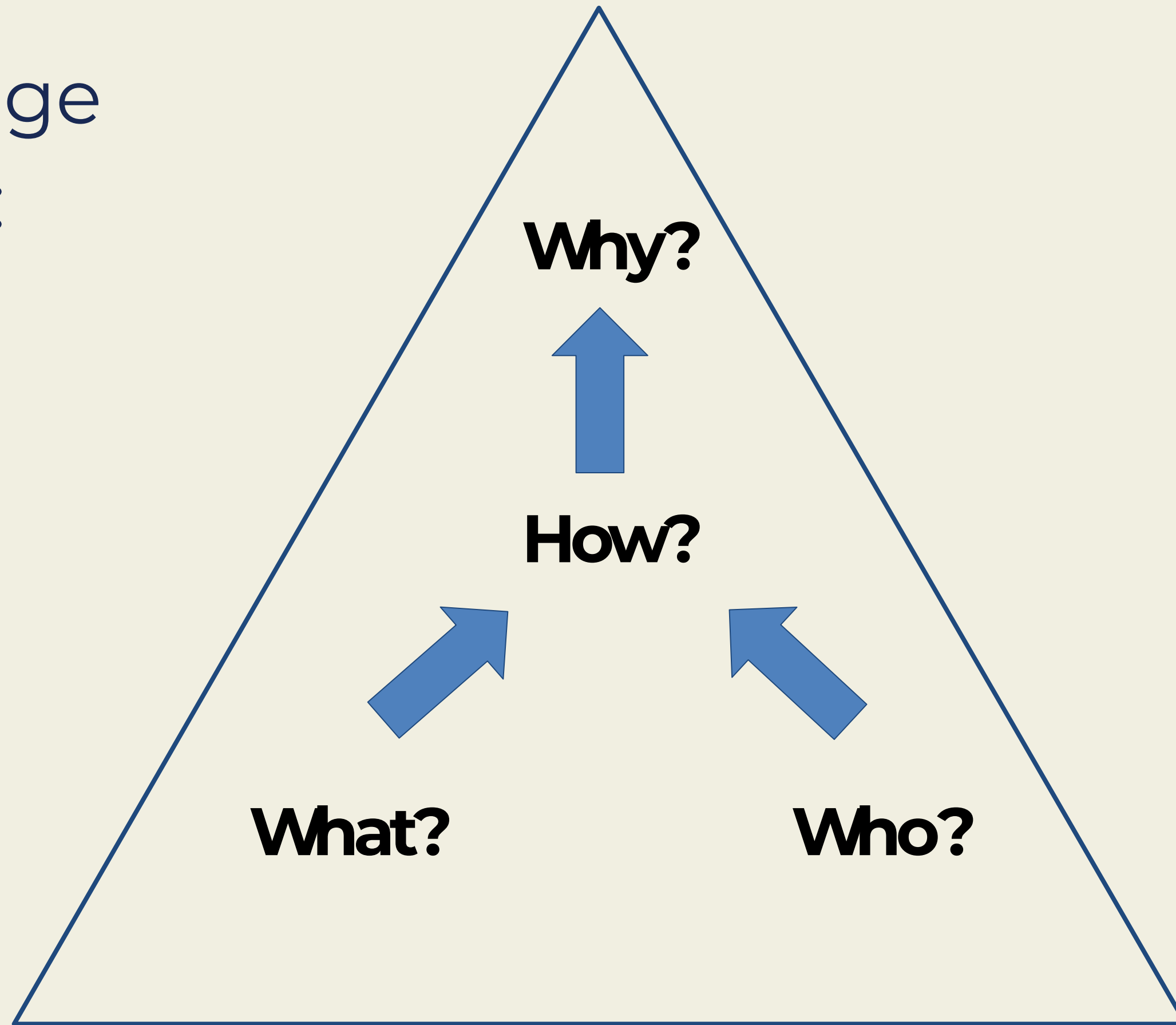
- The study of public health is the examination of population through the usage of statistics and data
- Most of these data are not “naturally occurring”
- We choose what data to collect, what questions to ask



Why do we have the data that we have?



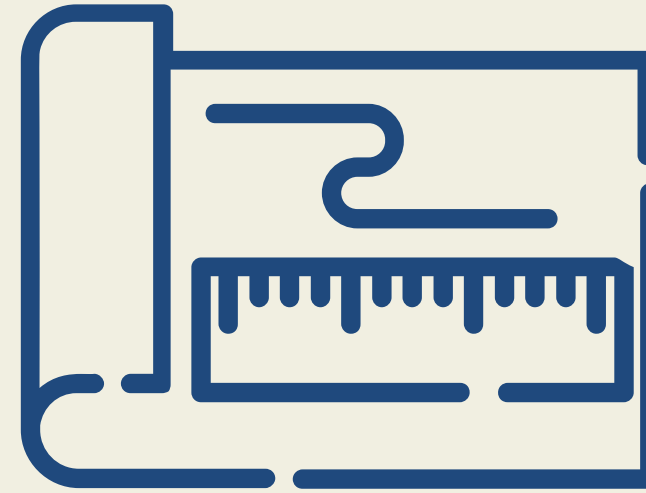
Knowledge Pyramid:



First Steps on This Journey:

- I. Basic History
- II. Timing of Changes
- III. Sociodemographic Data
- IV. How changes occur
- V. Context
- VI. Data Transmittal
- VII. Motivations

Eventually moved away from this stricter research framework but all questions developed around figuring these things out



4 major questions to answer:

1. DEATH REGISTRATION

- a. What sociodemographic information about those who are registered as having died is available to central government officials, from the time that death registration began until the present day?

1. RECORD LINKAGE

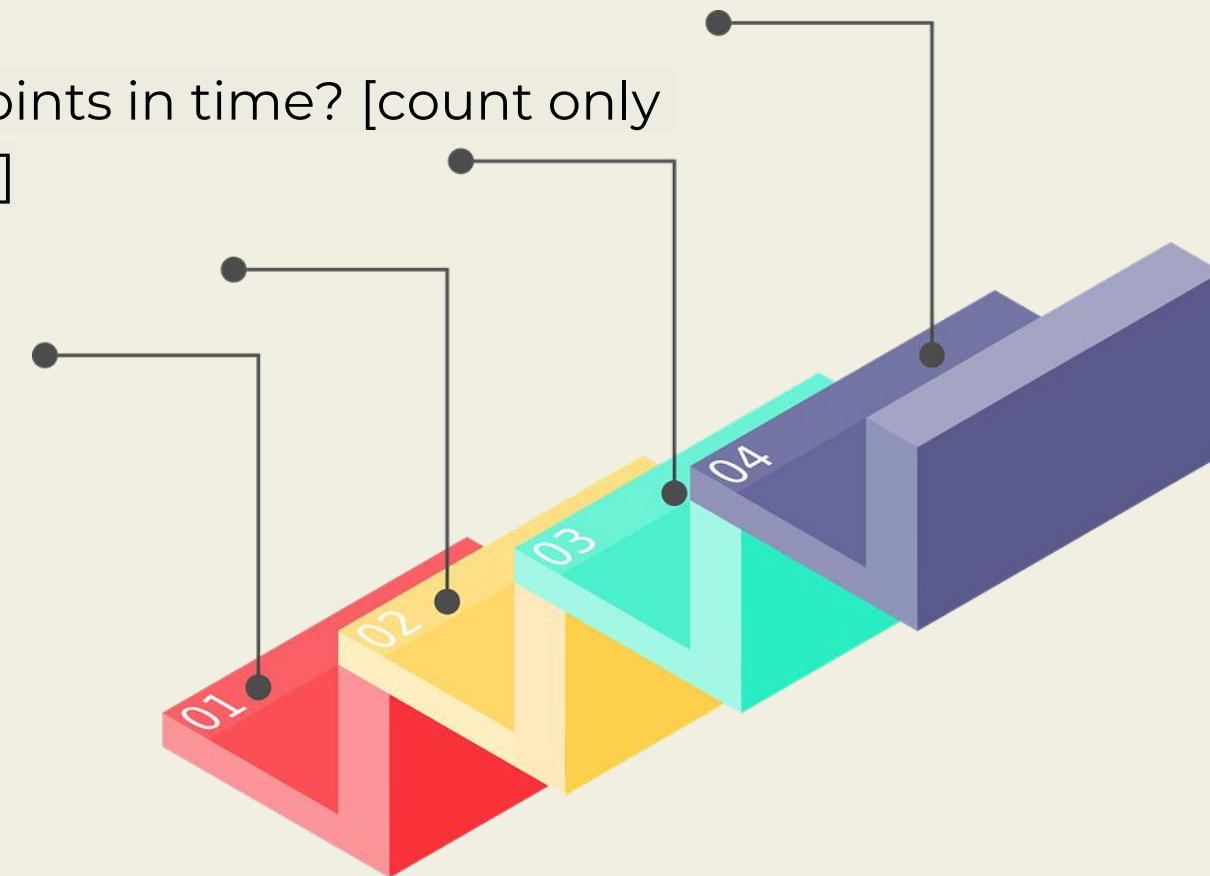
- a. Can researchers and government officials LINK records of deaths to other sources of sociodemographic information (e.g. the census, social security administration data).

1. USE OF SOCIODEMOGRAPHIC DATA

- a. What do governments do with the sociodemographic information they have about the deceased, and how does this change over time?

1. OTHER SOURCES OF HEALTH DATA

- a. What other sources of health data are available in your country, at what points in time? [count only surveys and cohort studies that are funded/used by government agencies]
 - i. Notifiable events registries
 - ii. Disease registries
 - iii. Regular health surveys
 - iv. Cohort studies

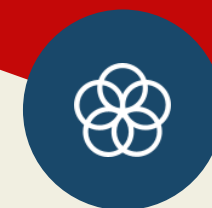




JUNE: DEATH CERTIFICATES



JULY: RECORD LINKAGE



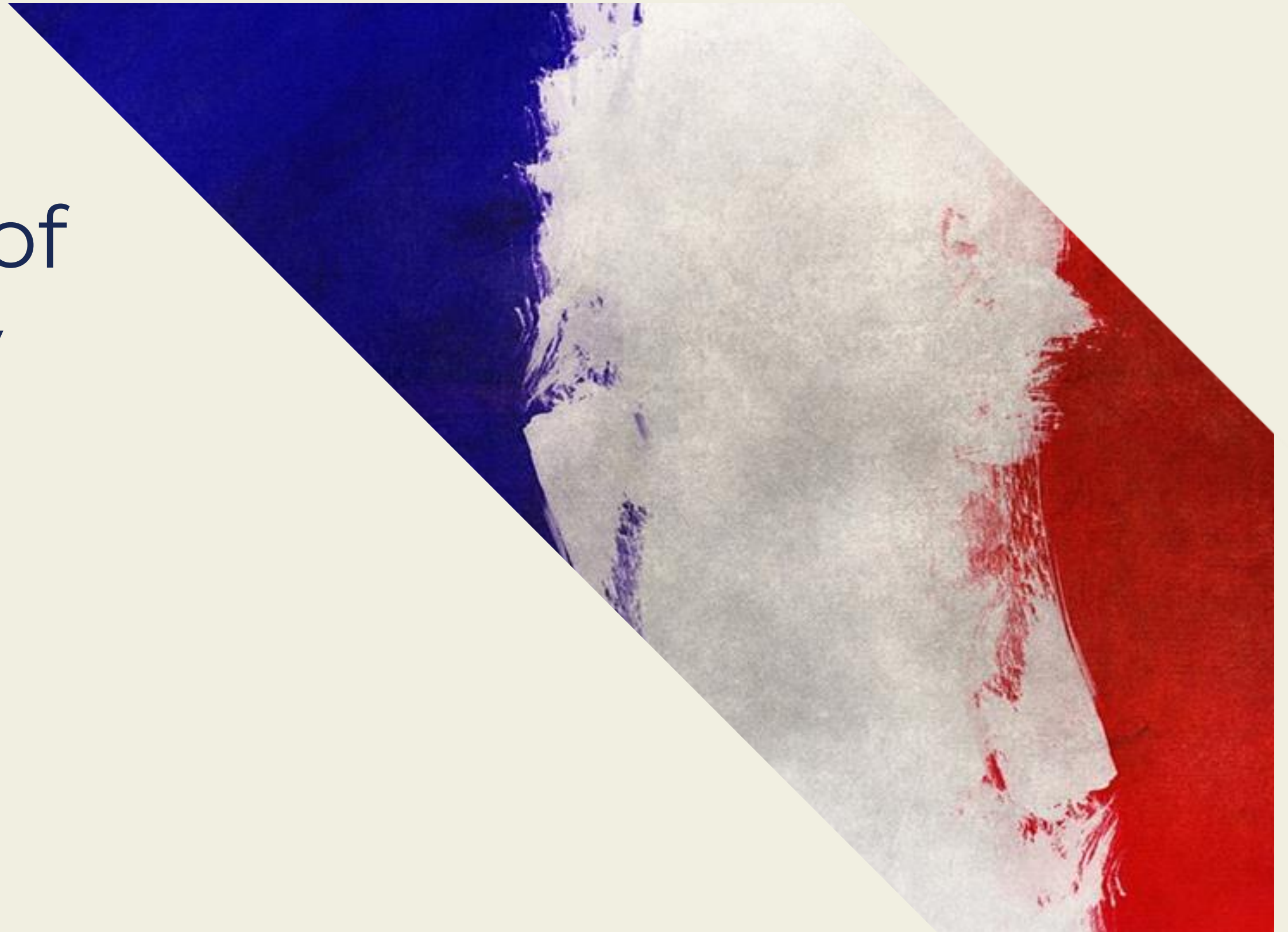
AUGUST:

FILLING IN THE GAPS



FRANCE:

Universalism of Days Gone By



France at a Glance



Inserm



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- Power center in Europe
- Hub of Enlightenment
- Strong republican tradition
- History of laïcité (secularism)
- Expansive bureaucracy and civil registration
- Unitary state

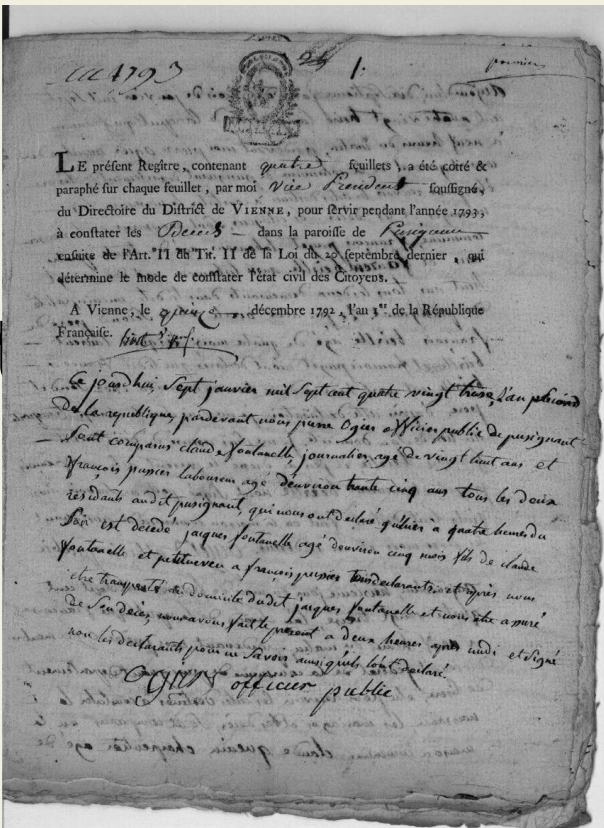
The French Death Certificate - What

- Well Documented History

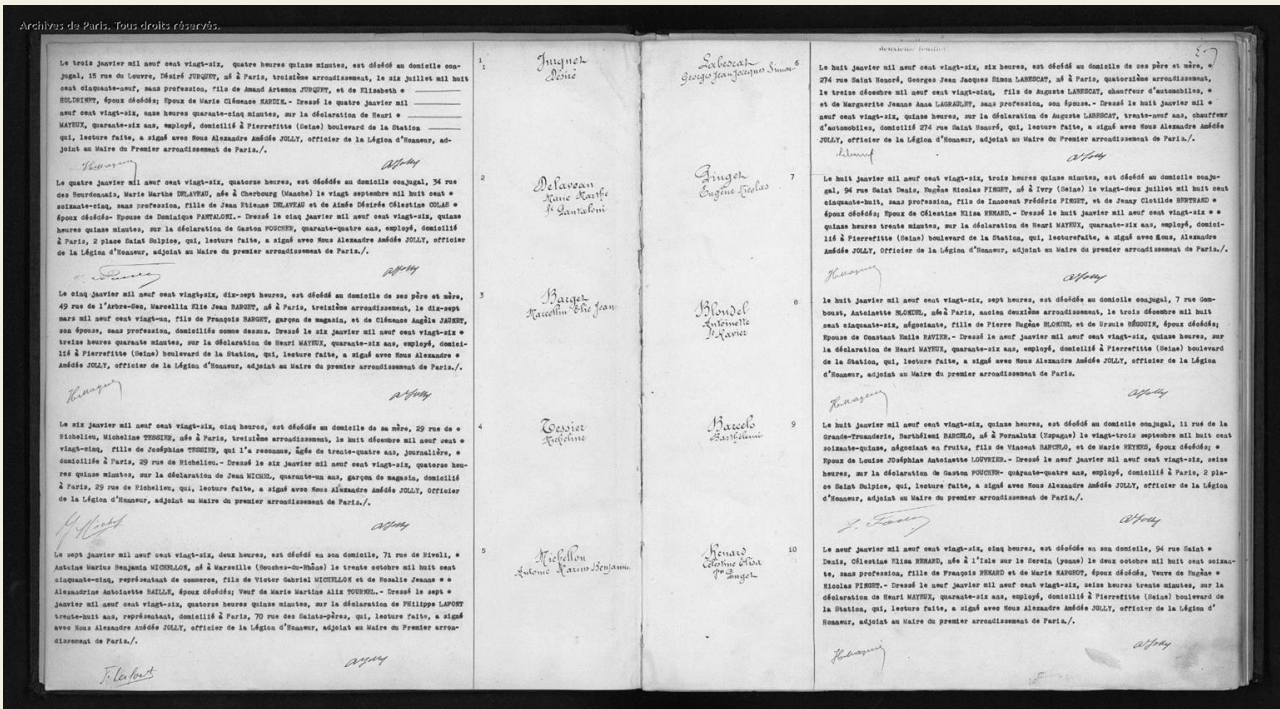
- Continuous production and preservation
- Important SEP data tracked:

- Birthplace
- Living Address
- Profession

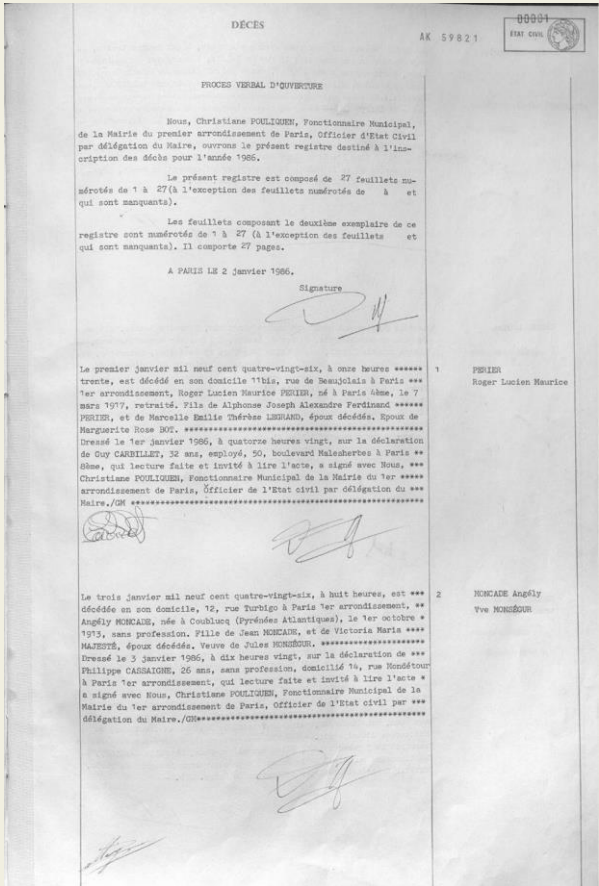
- Of both decedent and parents



1793 - Civil Registration from the Department of the Rhone



1926 - Civil Registration from Paris



1986 - Civil Registration from Paris

Different diction, but vital information is largely the **same!**

The French Death Certificate - Who / How



- INSEE responsible for high-level collection and processing
- Municipalities keep a comprehensive record, send bulletin to INSEE
- Complex Circuit of Data Transmission

The bulletins used by the INSEE to collect mortality data from municipalities

DEPARTEMENT _____ RÉPUBLIQUE FRANÇAISE ANNÉE 19____

ARRONDISSEMENT _____ N° de l'acte : _____

Commune _____ N° d'ordre du décès : _____

Décès survenu le _____ du mois de _____ 19__ à _____ heures du _____ (quatin au soir)

1. Sexe : masculin ☐ féminin ☐

2. Date et lieu de naissance : Né le _____ du mois de _____ 1____, à _____, département de _____

3. État civil : Célibataire ☐ Marié ☐ Veuf ☐ Divorcé ☐ *Si l'adulte :* ☐ *Si l'enfant de moins de cinq ans :* ☐ *Si le décès était marié :* ☐ *Si l'enfant a moins d'un an :* ☐

4. Si le décès était marié : Nombre d'enfants vivants ou morts issus du mariage (mort-nés non compris) _____ Mode d'alimentation : ☐ Au sein ☐ Au biberon ☐ Par allaitement mixte

5. Profession du décédé (1) _____ Patron (1) ☐ Employé (1) ☐ Ouvrier (1) ☐

6. Si le décès est un enfant : Profession du père (1) _____ Patron (1) ☐ Employé (1) ☐ Ouvrier (1) ☐

7. Maladie ou accident cause de mort : _____ aiguë ☐ chronique ☐

8. Le décès a-t-il été constaté par un médecin ? ☐ Oui ☐ Non

Le Déclarant : _____ Le Maire, ou le Préposé de l'état civil, Vu : _____ Le Médecin de l'état civil,

Après délassage, adresser l'avis de décès à l'INSEE et le bulletin de décès à l'ARS.

RÉPUBLIQUE FRANÇAISE
INSTITUT NATIONAL DE LA STATISTIQUE ET DES ÉTUDES ÉCONOMIQUES
BULLETIN DE DÉCÈS
Ce bulletin doit être adressé à l'Agence Régionale de Santé

7

A. IDENTIFICATION DE LA COMMUNE

Code département ☐ Code commune (1) ☐

Libellé de la commune _____

N° de l'arrondissement _____

Section (2) _____

Type de registre ☐ Unique ☐ U ☐ Autre ☐ A ☐ — préciser _____

N° de l'acte ☐ N° d'ordre de l'avis de décès ☐

B. RENSEIGNEMENTS RELATIFS AU DÉFUNT

Date du décès _____ jour, mois, année _____

Sexe ☐ Masculin ☐ M ☐ Féminin ☐ F

Né(e) le _____ jour, mois, année _____

À _____ Libellé de la commune _____

N° de l'arrondissement _____ Département (3) ☐

Outre-mer (3) _____

Pays pour l'étranger (3) _____

Activité Profession ☐ Retraité(e) ☐ 1 ☐ Inactif(ve) ☐ 2 ☐ Actif(ve) ☐ 3 ☐ — préciser profession et situation professionnelle

Situation professionnelle (4) ☐ Salarié(e) de l'État ou des collectivités territoriales ☐ 1 ☐ Autre salarié(e) ☐ 2 ☐ À son compte ☐ 3

Nationalité ☐ Française ☐ 1 ☐ Étrangère ☐ 2 ☐ — préciser le pays _____

Domicile Libellé de la commune _____

N° de l'arrondissement _____ Département (3) ☐

Outre-mer (3) _____

Pays pour l'étranger (3) _____

État matrimonial au moment du décès ☐ Célibataire ☐ 1 ☐ Marié(e) ☐ 2 ☐ Veuf(ve) ☐ 3 ☐ Divorcé(e) ☐ 4

C. RENSEIGNEMENTS RELATIFS AU DÉCÈS

Lieu du décès ☐ Logement ☐ 1 ☐ Hospice, maison de retraite ☐ 4 ☐

☐ Établissement hospitalier ☐ 2 ☐ Voie ou lieu public ☐ 5 ☐

☐ Clinique privée ☐ 3 ☐ Autre ☐ 6 ☐

Le certificat médical confidentiel de décès a-t-il été fourni ? OUI ☐ O NON ☐ N

Le présent bulletin est à compléter par le médecin ou le préposé de l'état civil, en application de la loi n° 51-711 du 7 juin 1951 relative à l'organisation de la statistique.

Volet administratif : à compléter par le médecin ou le préposé de l'état civil, en application de la loi n° 51-711 du 7 juin 1951 relative à l'organisation de la statistique.

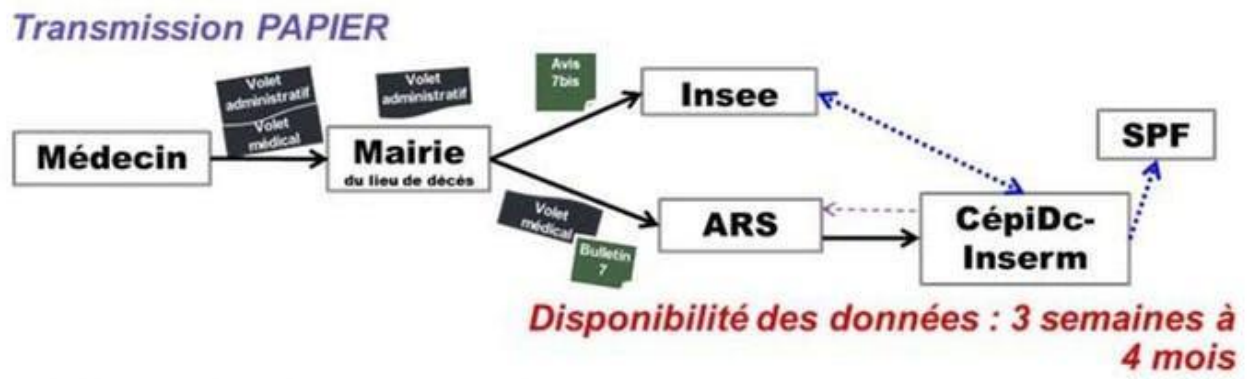
Volet médical : à compléter par le médecin ou le préposé de l'état civil, en application de la loi n° 51-711 du 7 juin 1951 relative à l'organisation de la statistique.

En application de la loi n° 51-711 du 7 juin 1951 relative à l'organisation de la statistique, les réponses à ce questionnaire sont protégées par le secret statistique et doivent être fournies à la seule fin de l'enquête.

La loi n° 75-17 du 6 janvier 1975 relative à l'informatique, aux fichiers et aux bases, s'applique aux données recueillies à la présente enquête. Elle garantit aux personnes concernées un droit d'accès et de rectification pour les données les concernant. Ces données sont destinées à être traitées par des ordinateurs de grande capacité.

Fait le _____ (date de création du bulletin)
Cachet de la mairie et signature de l'officier de l'état civil.

Figure 7. Cheminement des informations sur la cause de décès en 2020. Le cas d'une transmission papier (Source : Cepidc)



The French Death Certificate - Why

- More important question is it does **NOT** have certain things
 - This branched off into questions about privacy
 - Many codified proscriptions
- Deeper questions about universalism and racism



Race?



Ethnicity?

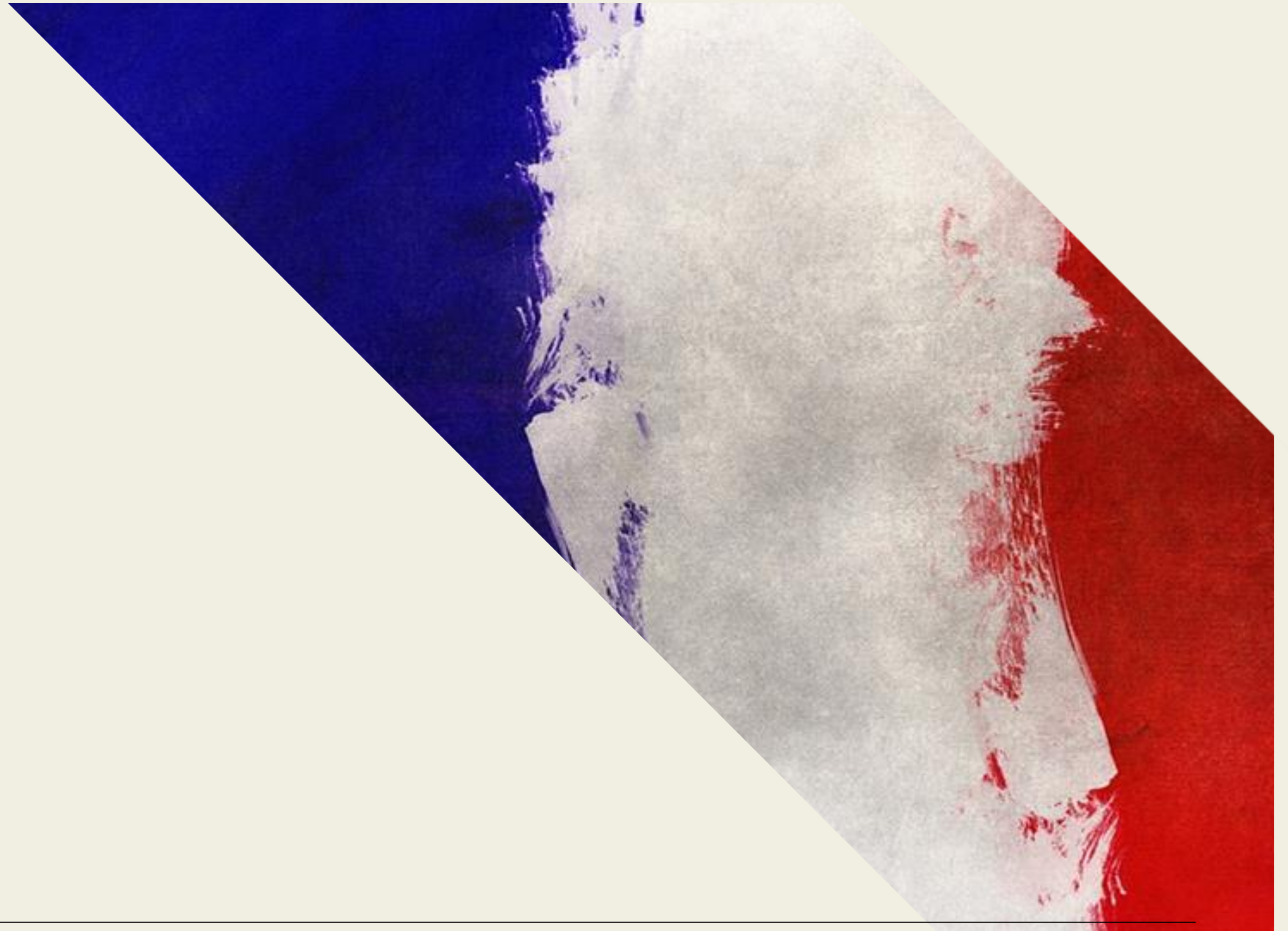


**Religion,
etc.?**





FRANCE: Privacy Law



French Privacy Law - Origins and Secularism

French Third Republic (1870-1940)



Secularism
Laïcité



French Privacy Law - WW2 and the Vichy Era

French Identity Card
from Vichy Era

Préfecture de _____

Carte d'Identité N° 5527

Nom Eyffus
Prénoms Gilbert David May
Profession _____
Né le 7 sept. 1916
à Paris
Nationalité française
Département _____
Domicile avenue de l'Alphonse Paris 16^e
act. 8 rue du Général Foy Paris

Empreintes Digitales : _____

SIGNALEMENT :

Taille <u>1.70</u>	Nez { Dos <u>rect.</u> Base _____
Cheveux <u>bruns</u>	Dimension _____
Moustache _____	Forme du visage <u>oval</u>
Yeux <u>bleus</u>	Teint <u>mat</u>
Signes particuliers _____	

Signature du Titulaire, _____

Le Commissaire de Police, _____

13 FRANCS

Loi du 11-12-42

Vichy France
(1940-1944)



French Privacy Law - The 1978 Law

“Like Snowden + Watergate”



Art. 31. — Il est interdit de mettre ou conserver en mémoire informatisée, sauf accord exprès de l'intéressé, des données nominatives qui, directement ou indirectement, font apparaître les origines raciales ou les opinions politiques, philosophiques ou religieuses ou les appartenances syndicales des personnes.

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French Privacy Law - The Modern Idea of “Race” and the Research Landscape



“Race”



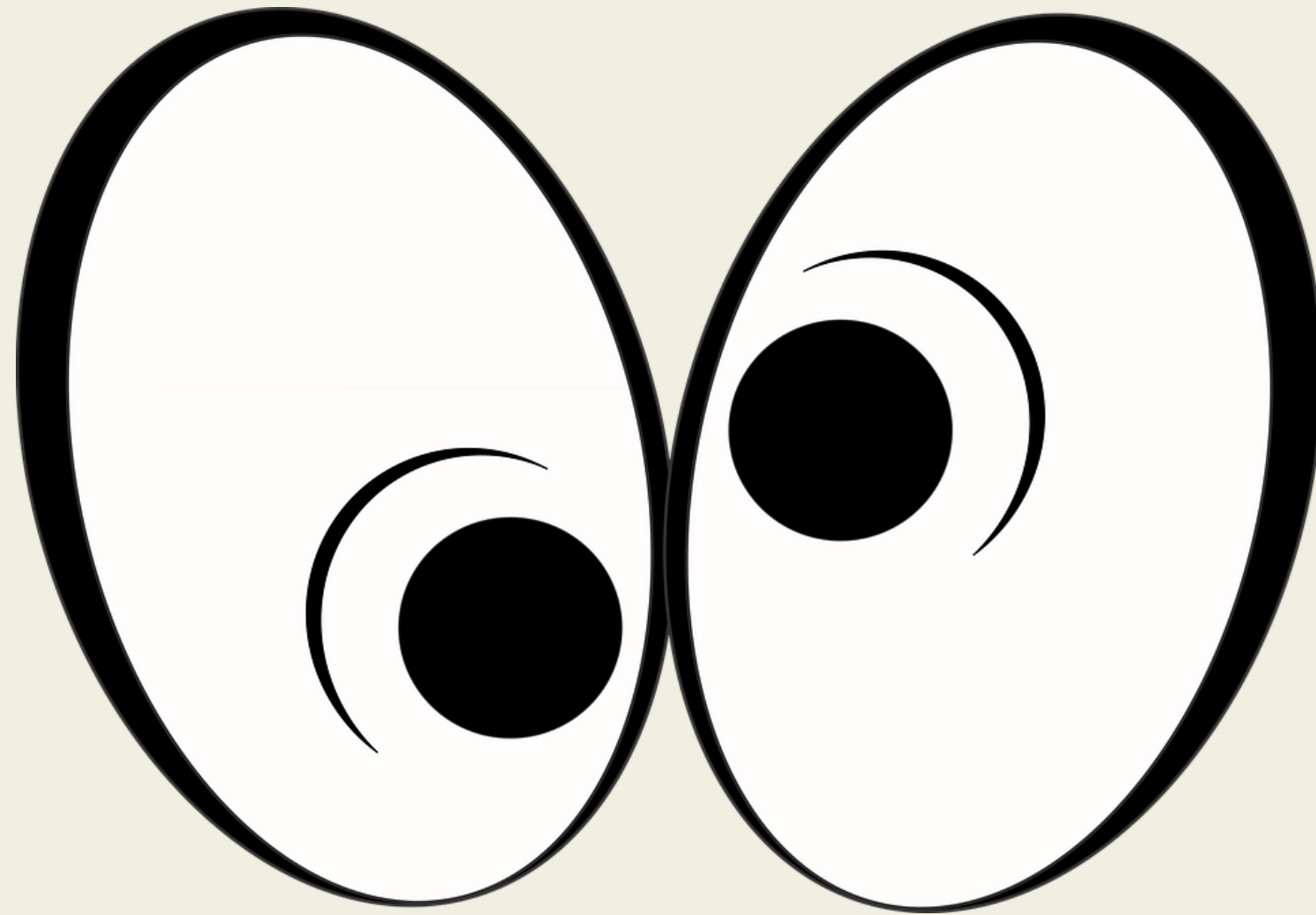
UNITED KINGDOM: Debating Ethnicity




 Q: What's the most challenging part of a crying infant?



 Hopefully you said: I don't know why they are crying, because they can't say the reason



 But... that does not mean there is no valid reason behind their screams, does it?





A blue rectangular sign with rounded corners is mounted on a grey, textured wall. The sign features a white arrow pointing to the left and the word "Ignorance" in white, bold, sans-serif capital letters. The sign is secured with four small, dark screws. In the bottom left corner, there is a small, circular inset showing a portion of the Union Jack flag.





Scotland:
In 1854, Lord Elcho's bill of registration was passed, and the national government in Scotland started collecting information on marriages, births, and deaths in January 1855.

England and Wales:
In 1836, England and Wales passed a civil registration act, which was effective starting the 1st July 1837, through which they would record marriages, births and deaths.

1854. BIRTHS in the District of St Nicholas in the Burgh of Merdeen

	(1.)	(2.)	(3.)	(4.)	(5.)	(6.)	(7.)	
	No.	Surname, and Name (if given). Name, when given or altered in Baptism, or otherwise, after Registration of Birth.	When and Where Born, with Hour of Birth.	Sex.	Name, Surname, and Rank or Profession of Father.	Name, and Maiden Surname of Mother.	Signature, Qualification, and Residence of Informant, if out of the House in which the Birth occurred.	When and Where Registered, and Signature of Registrar.
20. In our Action relating to the paternity of a child named Donald Smith born December 23 1856 at the instance of Agnes Smith residing at Commerce Street of Aberdeen against Donald Ross residing in Upper Kirkcaldy of Aberdeen the Sheriff of Aberdeen on the 15 th day of August 1859 found that the said child was the illegitimate child of the parties aforesaid August 23 1859 J. B. D. Reg. Gen.		<u>Smith</u>	<u>1856</u>		<u>Mr Donald Ross</u>	<u>Agnes</u>	<u>Agnes Smith</u>	<u>1857</u>
		<u>Donald</u>	<u>December</u>		<u>residing in</u>	<u>Smith</u>	<u>Matther</u>	<u>January 8th</u>
			<u>Twenty third</u>		<u>Upper Kirkcaldy</u>	<u>Domestic</u>	<u>Present</u>	<u>A. Thorden</u>
			<u>6 1/2 30m A.M.</u>		<u>of Aberdeen</u>	<u>Servant</u>		<u>John Wall</u>
			<u>30 Commerce</u>		<u>Illegitimate</u>			<u>Registrar</u>
			<u>Street</u>					
		<u>Merdeen</u>						

CERTIFIED COPY OF AN ENTRY OF DEATH

Given at the GENERAL REGISTER OFFICE,
SOMERSET HOUSE, LONDON.

Application Number P.A.3,32571/54/9

REGISTRATION DISTRICT BRADFORD YORKSHIRE

1866 DEATH in the Sub-district of 141a in the County of York

(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)
When and where died	Name and surname	Sex	Age	Occupation	Cause of death	Signature, description, and residence of informant	When registered	Signature of registrar
Twentysventh June 1866 Stony Lane Eccleshill	John McLlland	Male	55 Years	Groom and Gardener	Phtisis Pulmonalis 4 months Certified	x the mark of Sarah Lee Present at death Stony Lane Eccleshill	Twentyninth June 1866	Matthew Balne Registrar

CERTIFIED to be a true copy of an entry in the certified copy of a Register of Deaths in the District above mentioned.
Given at the GENERAL REGISTER OFFICE, SOMERSET HOUSE, LONDON, under the Seal of the said Office, the 19th day of October 19 64

A 466892

CAUTION:—Any person who (1) falsifies any of the particulars on this certificate, or (2) uses a falsified certificate as true, knowing it to be false, is liable to prosecution.

Reproduced with the kind permission of the Registrar General for Scotland

United Kingdom: Debating Ethnicity



News

Scotland introduces record of ethnicity on death certificates

BMJ 2012 ; 344 doi: <https://doi-org.proxy.library.upenn.edu/10.1136/bmj.e475> (Published 17 January 2012)
Cite this as: *BMJ* 2012;344:e475

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Bryan Christie
[Author affiliations](#) ▾

Scotland has become the first UK country—and one of the first in the world—to record ethnic origin on death certificates. The data will be used to learn more about important health differences between different groups.

Opinion | **Sport** | **Culture** | **Lifestyle**

[Americas](#) [Asia](#) [Australia](#) [Middle East](#) [Africa](#) [Inequality](#) [Global development](#)

🕒 This article is more than **9 months old**

England to require ethnicity on death certificates to help tackle Covid-19

Government plans measures to help understand why minorities are more vulnerable



Commission on Race and Ethnic Disparities



- Published in March 2021
- Key takeaways:
 - There is no evidence of the blocking of ethnic minority advancement into professional-managerial positions in Britain
 - The Review found no evidence of systemic or institutional racism, but instead pointed to complex factors***
 - Concluded that most of the increased risk of infection and death from covid-19 among people from ethnic minorities was explained by **socioeconomic factors** and that inequalities in outcomes “are driven by risk of infection, as opposed to ethnicity alone being a risk factor.”
BMJ

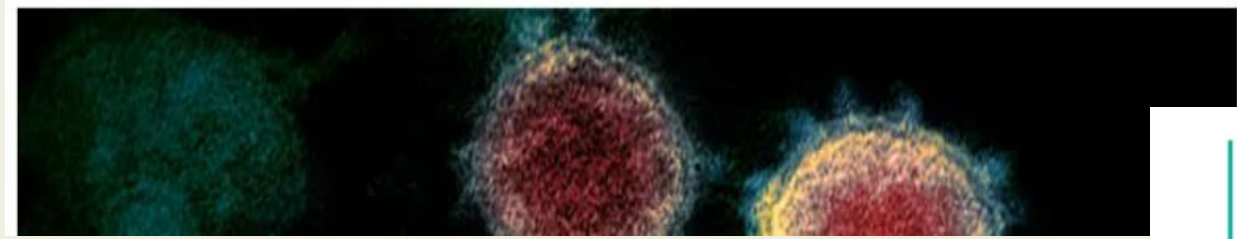


What have researchers done?

Black people four times more likely to die from Covid-19, ONS finds

Official figures show that wide disparity not just due to health and economic differences

- [Coronavirus - latest updates](#)
- [See all our coronavirus coverage](#)



Protecting and improving the nation's health

Disparities in the risk and outcomes of COVID-19

Disparities in the risk and outcomes from COVID-19

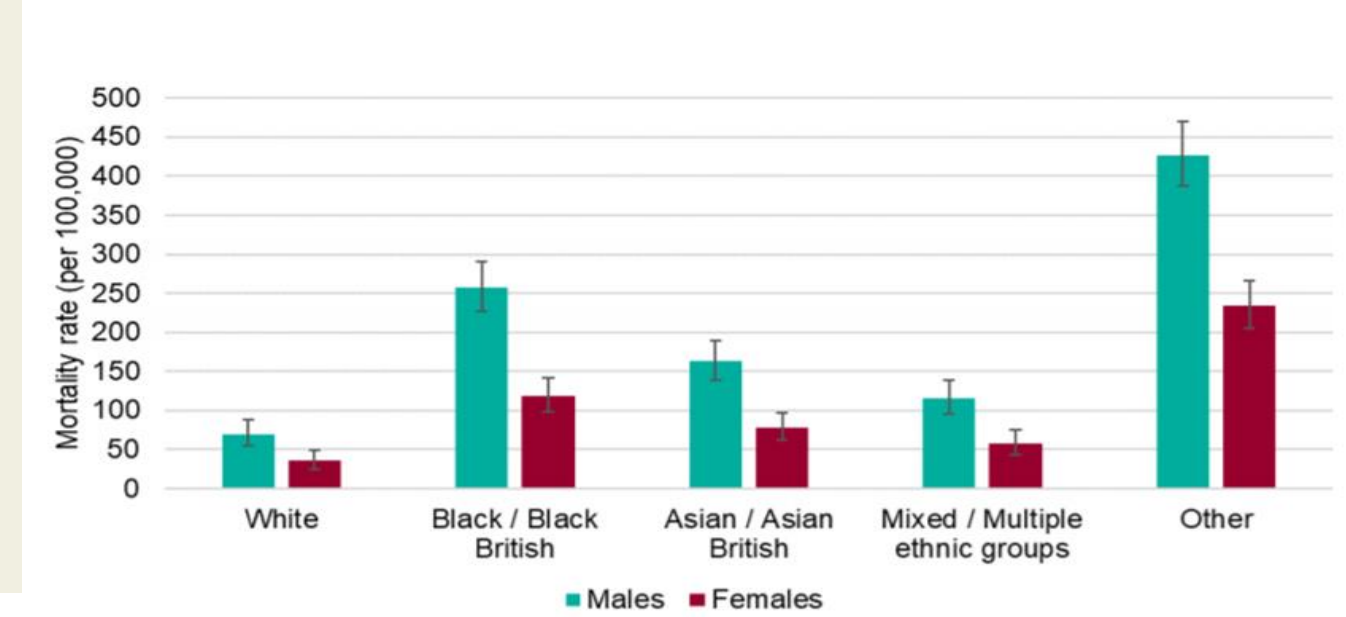


Figure 4.5. Age standardised mortality rates in laboratory confirmed COVID-19 cases by ethnicity and sex, as of 13 May, England. Source: Public Health England: COVID-19 Specific Mortality Surveillance System.



Tying it all together

France:

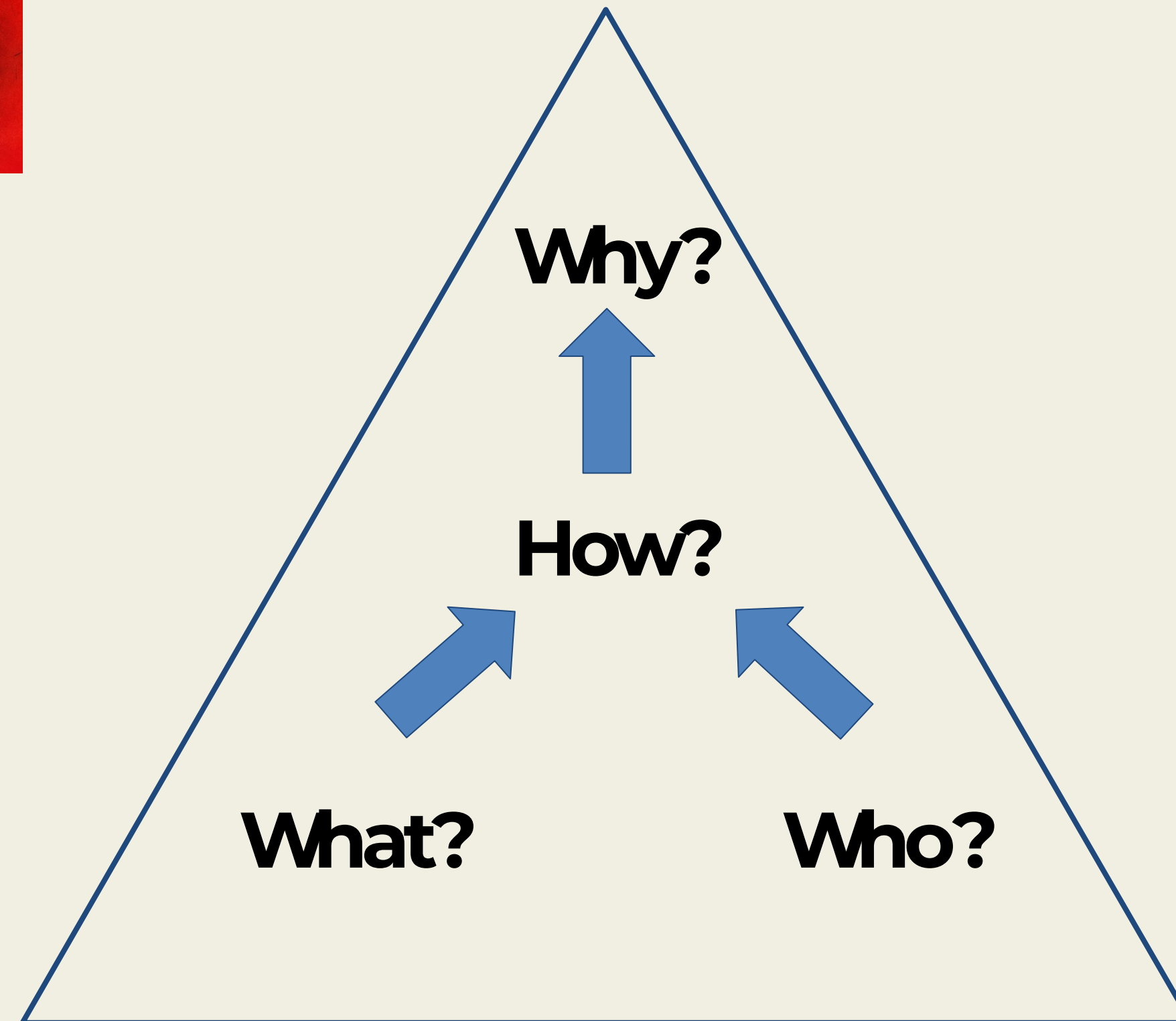


Why? Ideals of republicanism and universalism. Lack of a widespread reckoning with concept of race. Inertia.

How? Complex circuit of data transmission through many government agencies

Who? Collected at the municipal level, processed and centralized at national level

What? Long history of relatively unchanging data



UK:

Why? The view of an equal Britain “unlike the United States”, within a racially just and **equal** (note, not equitable) system

How? Nationalized system of data collection through vital statistics, census, and episodic reports

Who? Collected by the Office of National Statistics, at the national level

What? Absence of ethnicity and race data in death certificates and mortality data, despite a detailed account of socioeconomic data and occupation

EPISTEMIC VIOLENCE

Epistemic Violence: “I have thus defined epistemic violence as **a forced delegitimation, sanctioning and repression** [...] of certain **possibilities of knowing**, going hand in hand with an attempted enforcement [...] of other possibilities of knowing.”

Sebastian Garbe 2013, Institute of Sociology at the Justus-Liebig University in Giessen



EPISTEMIC DILEMMA

- How do we collect data on ethnic and racial health disparities? and Mortality?
 - Clearly not death certificates
 - Census records (?)
- What words are used to describe these classifications? What is the historical and sociopolitical context of these classifications?
 - Any problems with the classifications?





Different Countries, Different Approaches



**RÉPUBLIQUE
FRANÇAISE**

*Liberté
Égalité
Fraternité*

Citizenship

AND BELONGING:

WHAT IS

Britishness ?

Next Steps



OTHER SOURCES OF
INFORMATION



CONTEXT



CROSS-NATIONAL COMPARISONS

Acknowledgements



PHARMACEUTICALS IN INDIA: AVAILABLE BUT NOT AFFORDABLE

ANDREW BELTRAN, OMAR HUSNI, MAMASWATSI KOPEKA, KARISHMA
LACHHWANI, MIGUEL MEDRANO-PIEDRA, KRISTEN SMITH, MICHAEL TU

JULY 22, 2021



2021 SUMR Research Symposium

12:00pm – 5:30pm ET | August 16, 2021 – August 20, 2021

Penn LDI Summer Undergraduate Minority Research Scholar
Program