Paradoxes in mental health: current and future ethical challenges

Prof. François Ansermet
Emeritus professor of the Universities of Geneva and Lausanne
Member of the Comité consultatif national d'éthique 2013-2021
Psychoanalyste WAP

29th Meeting of the National Ethics Councils (NEC)
Forum 12-13 May 2022, Paris, France

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COMITÉ CONSULTATIF NATIONAL D'ÉTHIQUE POUR LES SCIENCES DE LA VIE ET DE LA SANTÉ

European Commission


PSYCHIATRIE
EN PÉRIL
IMMINENT

We judge a society by the way it welcomes in those who feel they have no place in it…

The psychiatric institution:

a mirror of contemporary society,

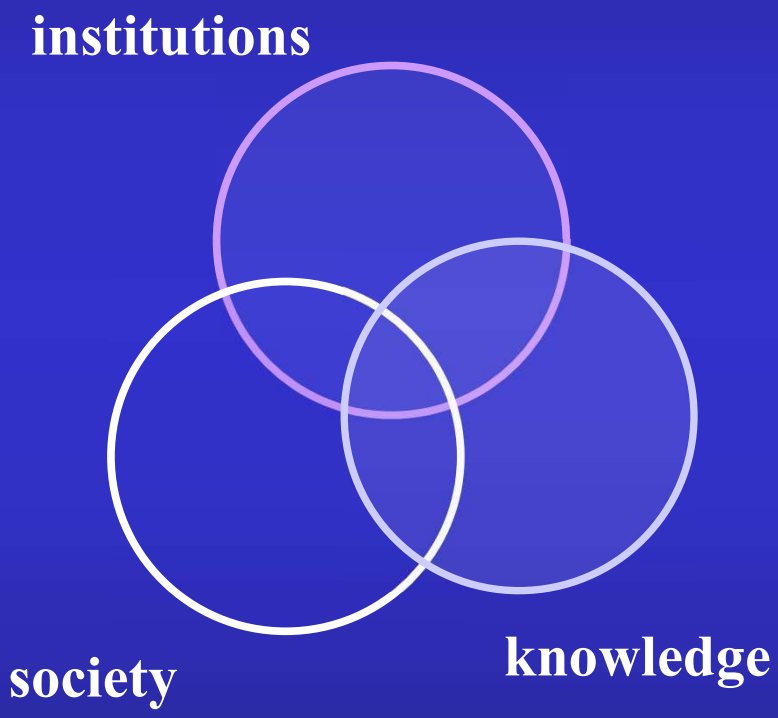
its organisation,

its problems,

…

Three distinct malaises !

- Malaise in the institution
- Malaise in society
- Malaise in fields of knowledge

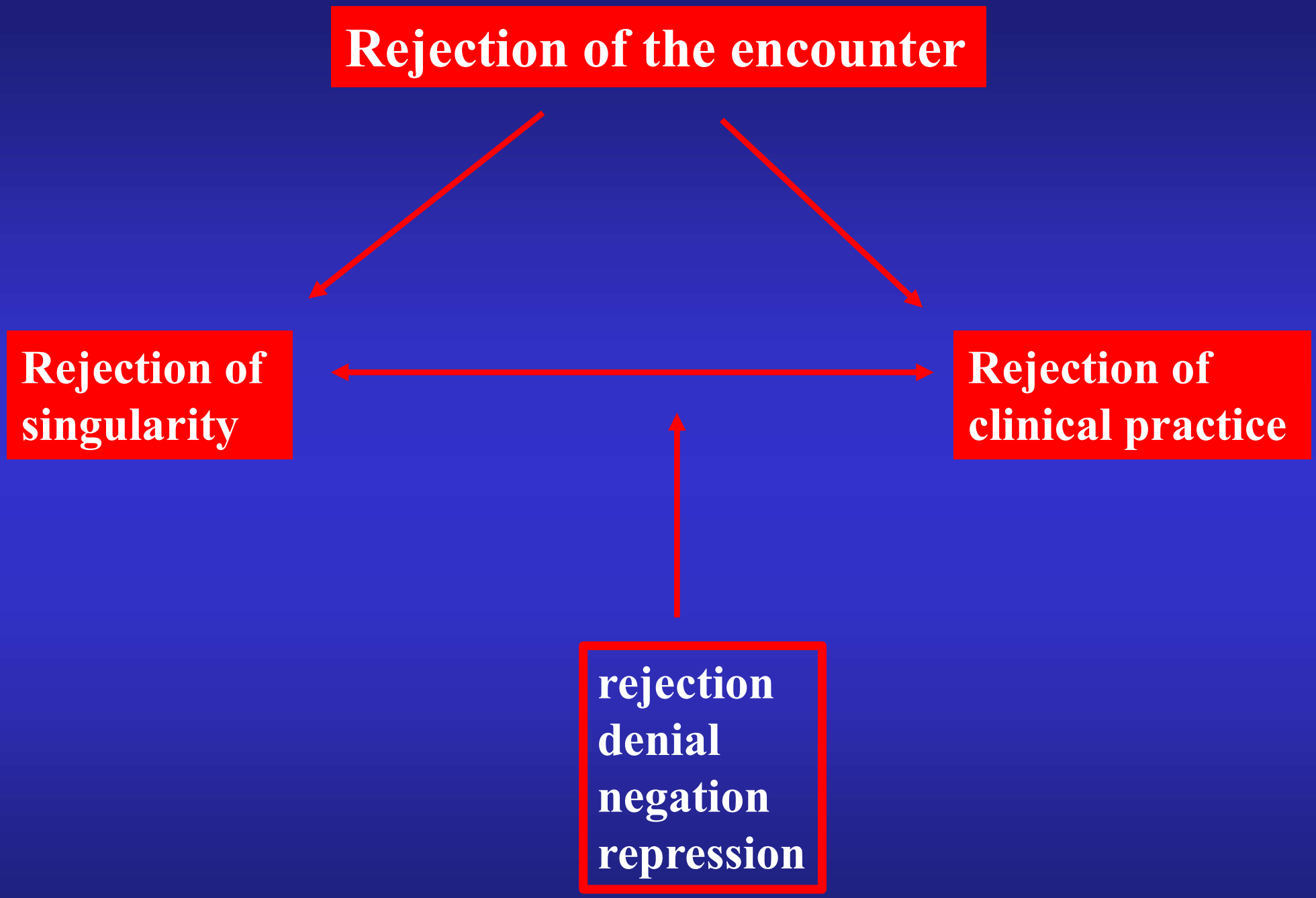


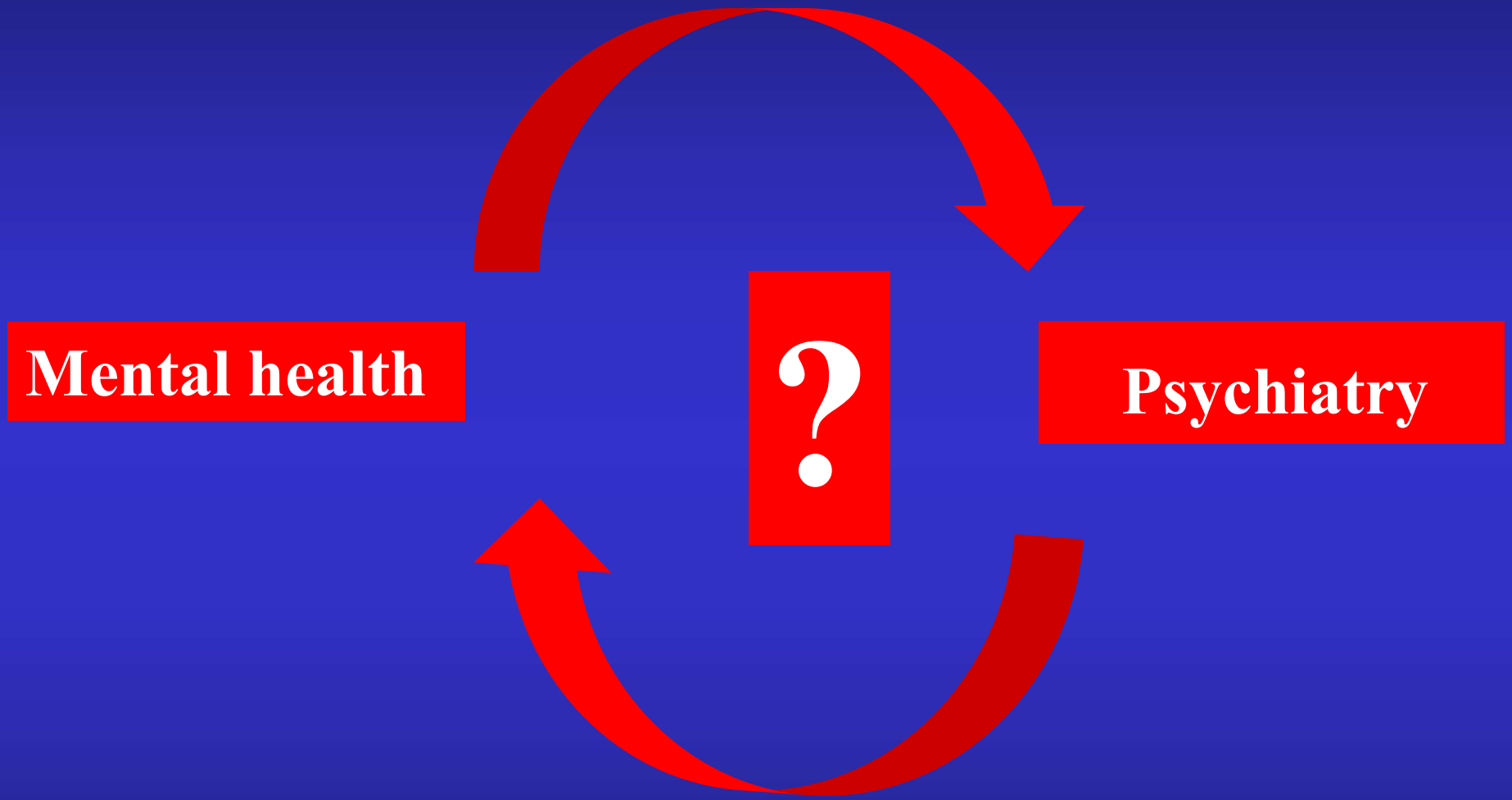
the encounter with the other

Anxiety +++

the psychiatric framework
as a **defence against the encounter**

Rejection of the encounter !


Rejection of the encounter
Rejection of singularity
Rejection of clinical practice
rejection
denial
negation
repression


Mental health
?
Psychiatry

?

risks that come with the concept of *Mental Health*:

- **rejection of the psyche**
- **rejection of the suffering**
- **rejection of the tragic dimension of existence**
- **rejection of clinical practice**

…

- **rejection of “madness”**

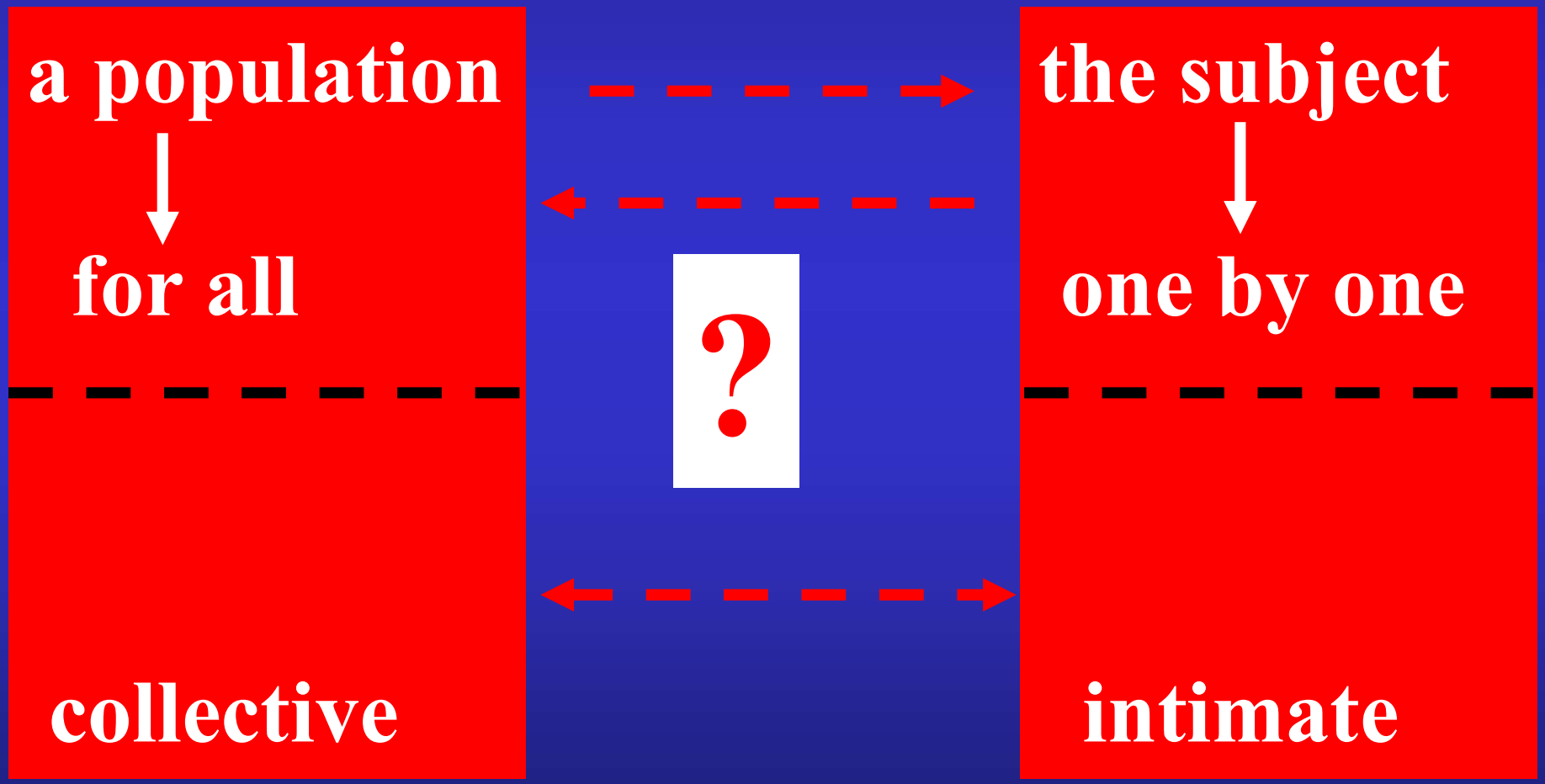
?

risks that come with the concept of *Psychiatry*:

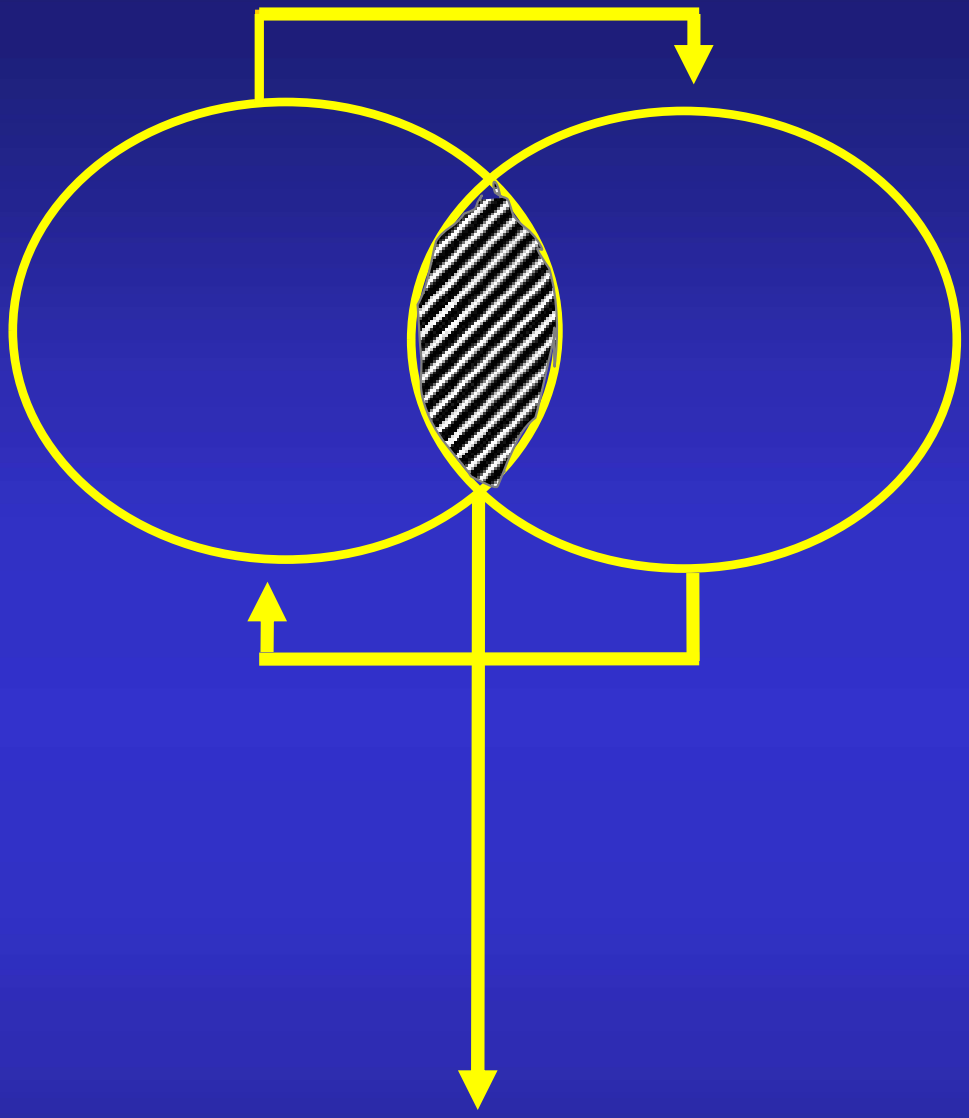
- **rejection of the social dimensions**
- **rejection of the political dimensions**
- **rejection of the epidemiological dimensions**

…

- **rejection of the collective dimensions**


a population
for all
collective
the subject
one by one
intimate
?

intimate



collective

individual psychology is immediately and at the same time social psychology

according to Freud, (1921) ***Group Psychology and the Analysis of the Ego.***

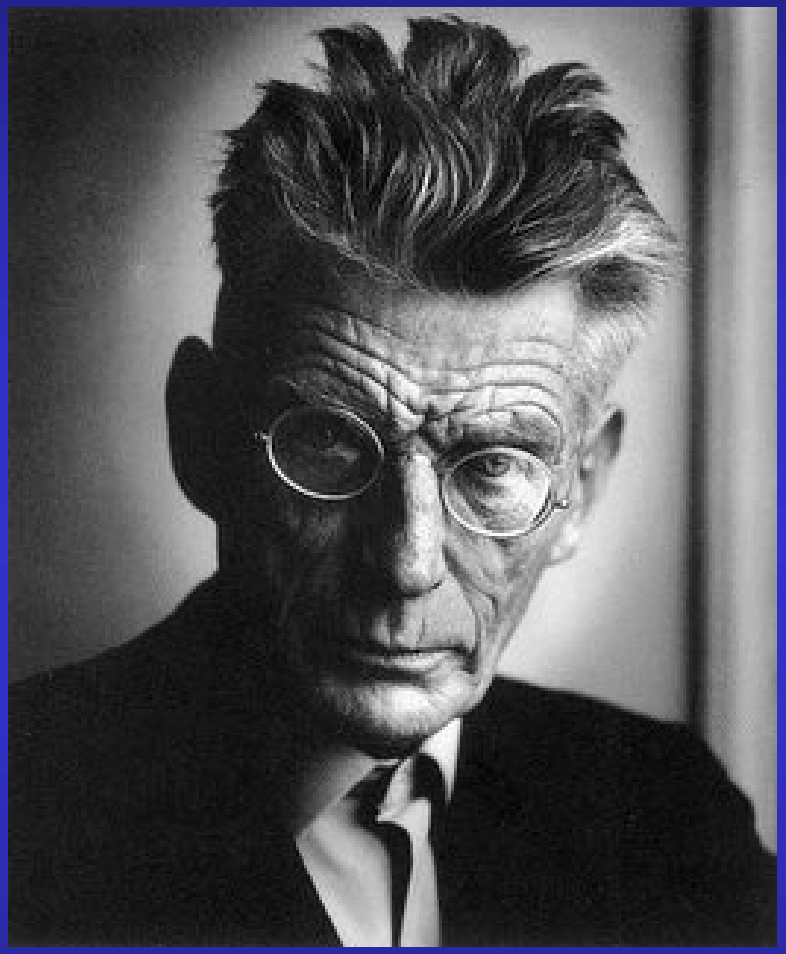
Where is madness ?

Madness ?

- **Intimate:**
  "the kind found within the asylum walls"

- **Collective:**
  "the kind that deafens the world with its sound and fury"

Lacan (1936/1949) 'The Mirror Stage as Formative of the *I* Function' in *Écrits, p. 80*



Samuel Beckett

“Your are on earth, there’s no cure for that.”

“We are all born mad, some remain so.”

The contemporary is the time of paradoxes !

Paradoxes:

- **Contradictory statements**
- **Ambivalence**
- **Coinciding opposits**

1. Paradoxes of the normal and the pathological

Contemporary crisis in diagnoses !

2014

Publication of DSM 5 ---- system of categories (disorders)

vs

RDoC (NIMH, Insel) ---- dimensional system (endophenotypes)

DSM:

medicalisation of the human condition !

DSM II : **182 categories**

DSM III-R **292 categories**

DSM IV **365 categories**

DSM 5 **400 categories**

Michel Foucault, 1973:

“The world is a big asylum”

Medicalisation of existential suffering…

RDoC:

biologising the human condition !

The sophism of a biological basis

1. There are mental disorders
2. These mental disorders have biological origins
3. If they have biological origins, then they are not mental
4. Therefore, there are no mental disorders

Poincaré, H.
The Foundations of Science: Science and Hypothesis

“have we really the right to speak of the cause of a phenomenon?

….any one phenomenon will not be the effect of a single cause, but the resultant of causes infinitely numerous”

The normal and the pathological, where is the boundary ?

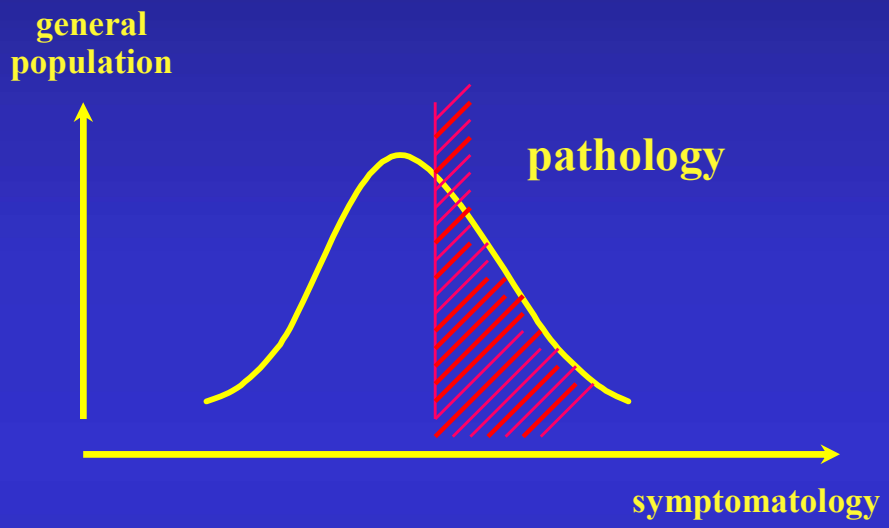
Richard Smith, BMJ, 324, 2002

“non-diseases”

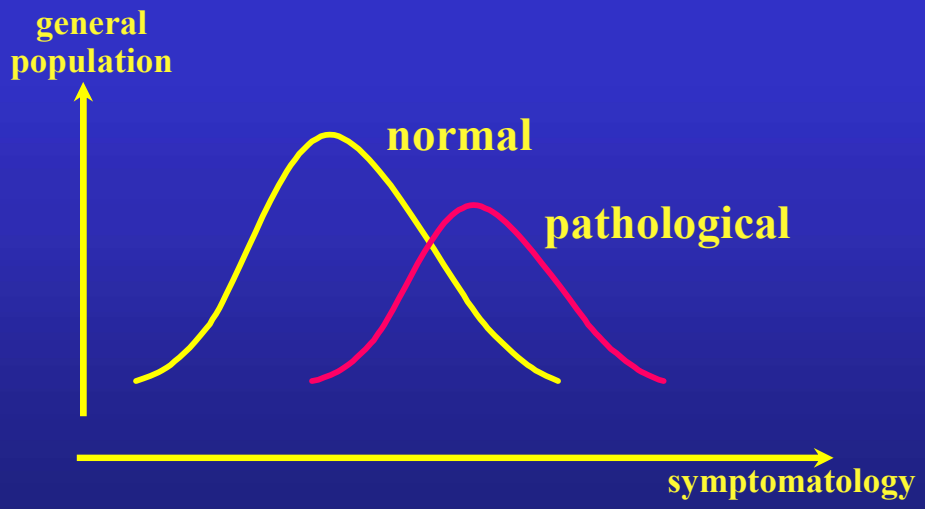
Age
Boredom
Bags under eyes
Ignorance
Baldness
Freckles
Big ears
Grey or white hair
Ugliness
Jet lag
Cellulite
Anxiety about penis size
Road rage
Loneliness
……..

The normal and the pathological ?

quantitative variation



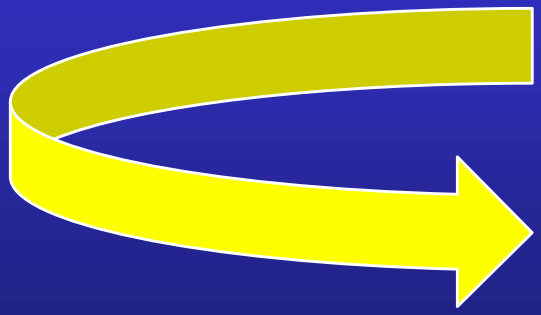
qualitative differentiation



Reconfigurations of the normal and the pathological

The norm for all

To each their norm



?!

Outside the norm for all !

“transmutation of madness into [mental] illness” (17th – 20th century)

Foucault, « Le pouvoir psychiatrique », Collègue de France, 1973-74, p. 351

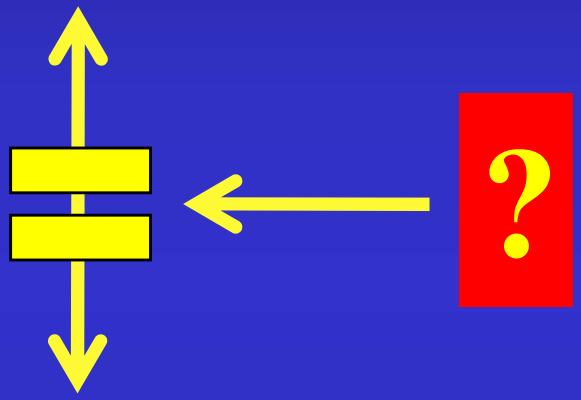
“liberation” of diagnosis …

Ibid

depathologise !
demedicalise !

Paradoxically …

Generalised mental disorders



Where is the boundary ?!

Disappearance of mental disorders

2. Paradox of the rejection of madness

The rejection of madness
(The missed encounter between madness and psychiatry)

Madness is back !... :

- **In prisons**
- **In radicalisation and fanaticism**
- **In nationalism**
- **In litigious delusions (Lacan, Seminar III, p. 18)**
- **On social media**

→ **"everyone is mad" !** (Lacan, ***Ornicar ?***, 17/18, 1979, p. 278)

Pascal

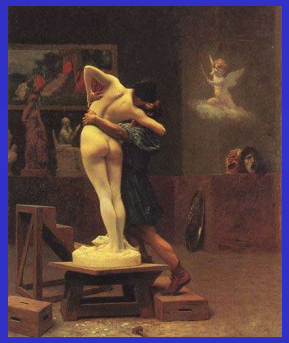
« les hommes sont si nécessairement fous, que ce serait être fou par un autre tour de folie, de n'être pas fou »

"Men are so necessarily mad that it would be another twist of madness not to be mad."

3. Paradox of the performative

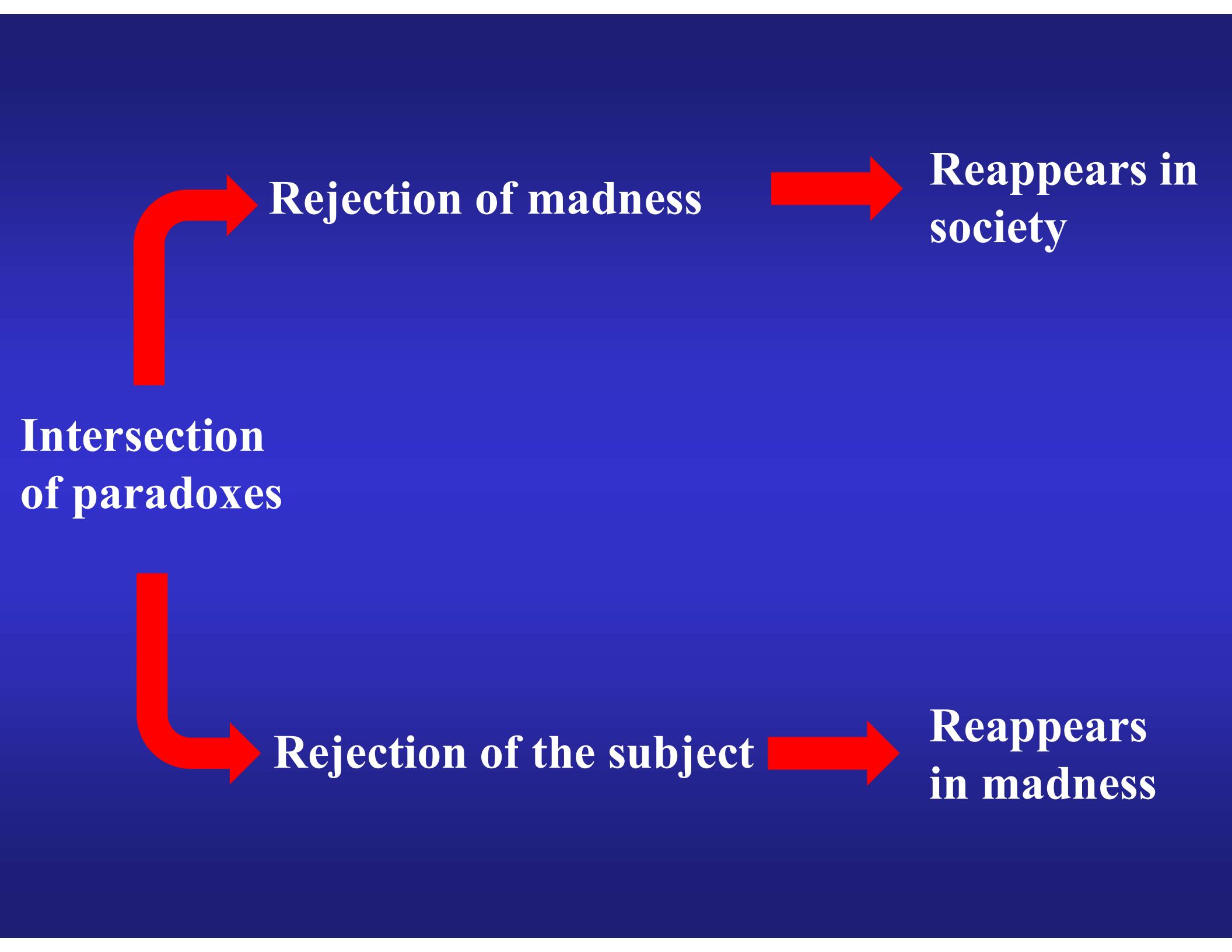
I am what I say
I am what it is said I am

Pygmalion effect



“moulding” (Ian Hacking)

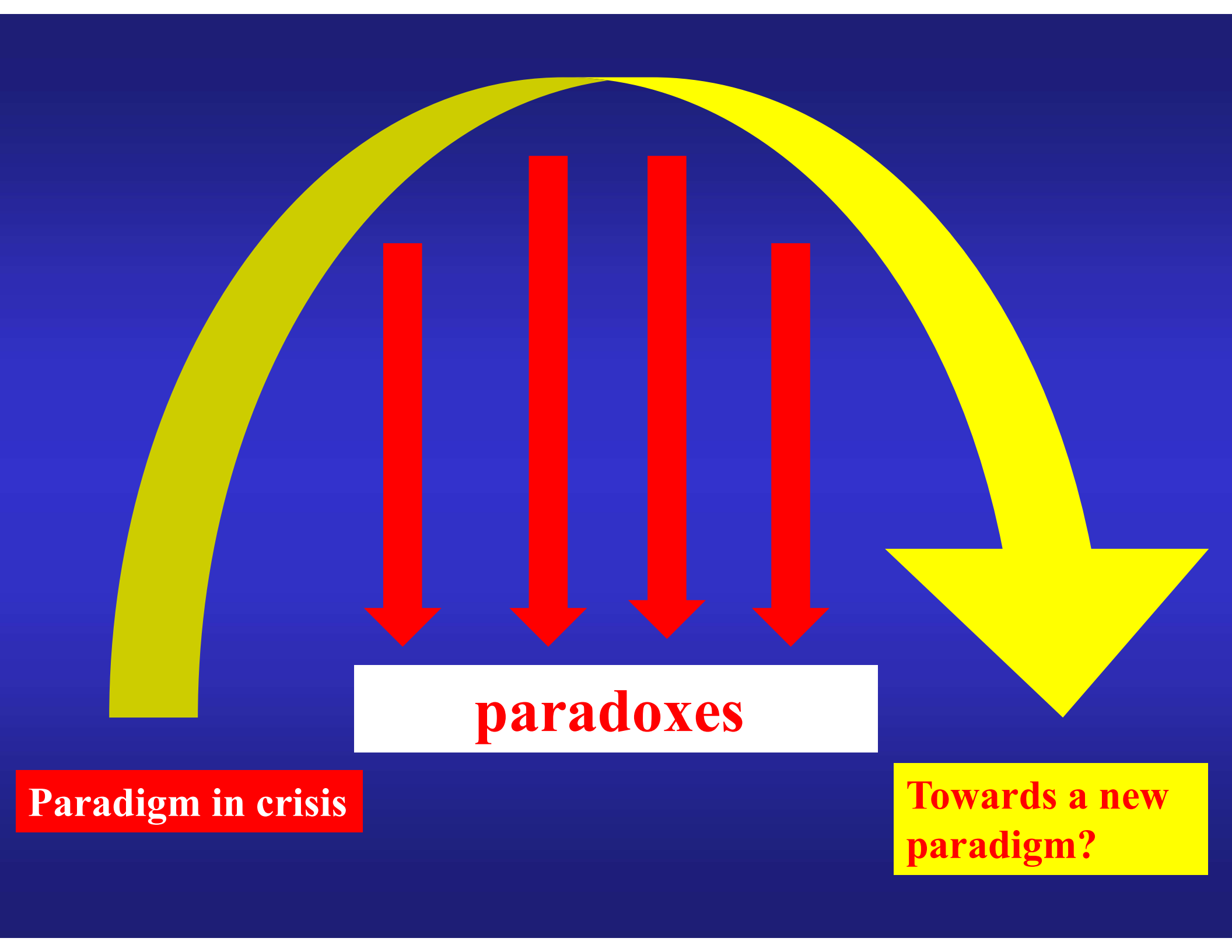
prediction ---- prevention ---- prescription


Rejection of madness
Reappears in society
Intersection of paradoxes
Rejection of the subject
Reappears in madness

crisis in psychiatry

paradoxes

Towards a new paradigm?!


paradoxes
Paradigm in crisis
Towards a new paradigm?

Paradoxes:

hurdles

Open to the new !
Change of paradigm

For a new paradigm:

Connection to the city/connection to culture

Psychological crisis: connection to the other is broken (family/society/culture)

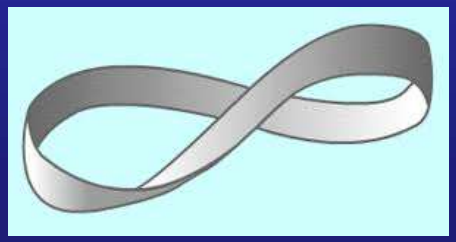
A connection that needs to be rewoven:

aim and condition of psychological care …

A different kind of hospital!

- **Multiple interfaces city/culture/ care - in a place where one *comes to be treated***

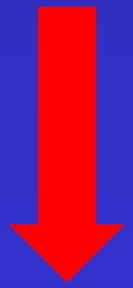
Möbius effect between the inside and the outside…
'principle of infinity'



Moebius:
A single sided strip

Max Bill

destigmatisation



give back space to the subject, their story, including in its tragic dimensions.

a return to clinical practice !

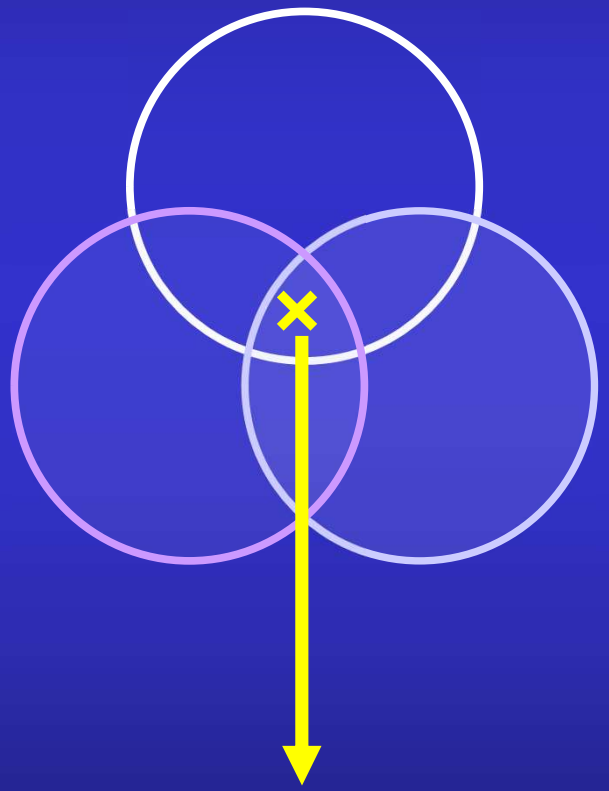
the illnesses vs the ill !

treating illnesses

treating the ill (the subject)

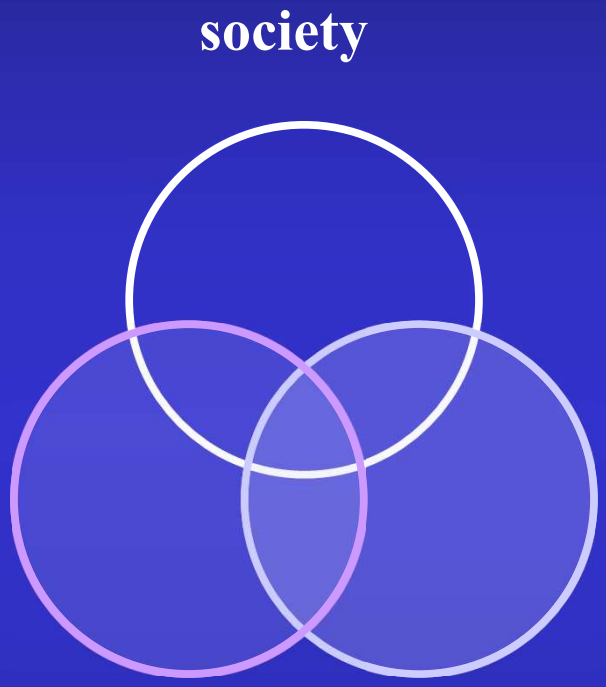
Malaises

Way out

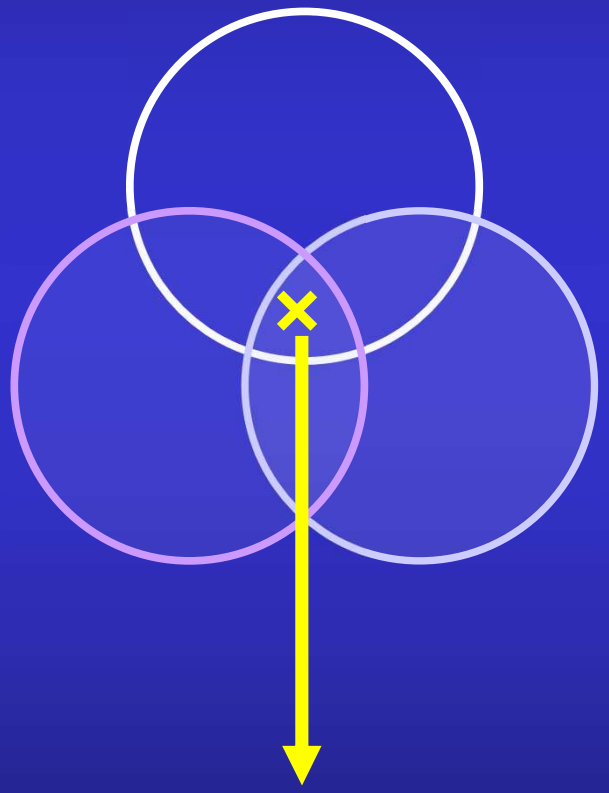


Clinical practice !

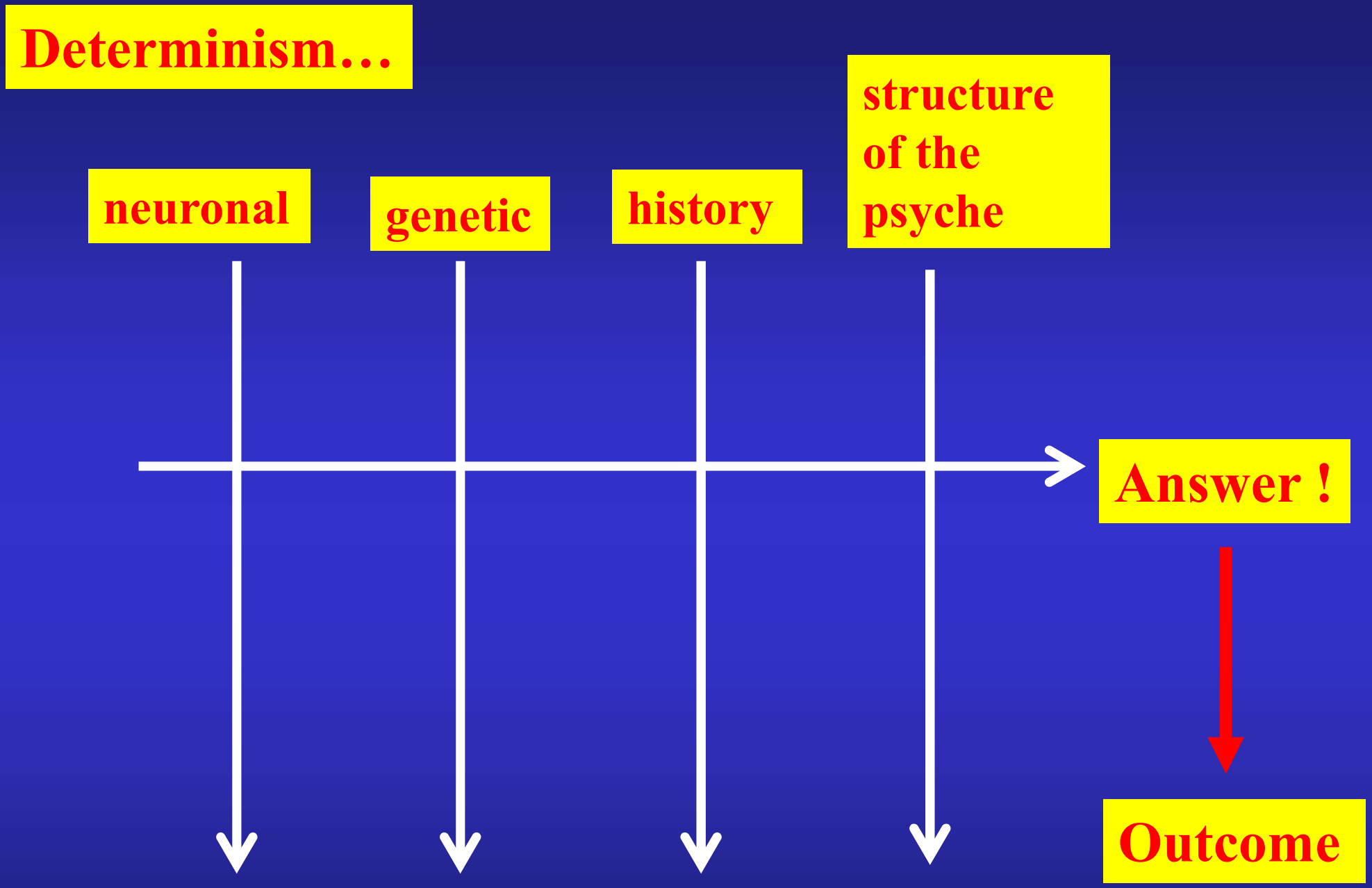
Malaises



Way out



The subject's answer


Determinism…
neuronal
genetic
history
structure of the psyche
Answer !
Outcome

Ethical challenges:

Making psychiatry a practice of individual outcomes

…following an ethics of outcomes,
of continuously evolving individual solutions
that are both novel and unpredictable…

Opening up the future !

29th Meeting of the National Ethics Councils (NEC) Forum

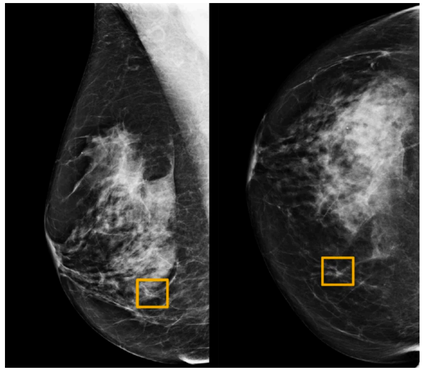
Responsible Development and Governance of AI

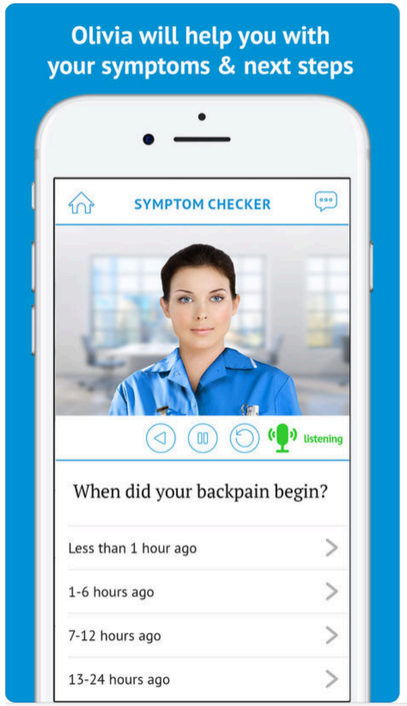
Raja Chatila
Institute of Intelligent Systems and Robotics (ISIR)
Faculty of Sciences and Engineering
Sorbonne University, Paris, France
Member, French National Pilot Committee on Digital Ethics (CNPEN)

Raja.Chatila@sorbonne-universite.fr

Multiple Applications of A.I. And Robotics

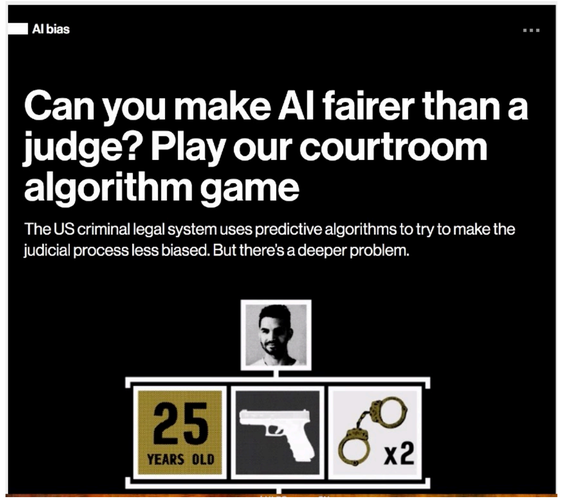
- Transportation, logistics, delivery
- Smart cities
- Healthcare
- Manufacturing
- Agriculture
- Personal services & assistance
- Security
- Recommender systems, advertisement
- Recruitment & management
- Insurance & finance
- Public services
- Justice
- Warfare
- …





A face-scanning algorithm increasingly decides whether you deserve the job

HireVue claims it uses **artificial intelligence** to decide who's best for a job. Outside experts call it 'profoundly disturbing.'



ARTIFICIAL INTELLIGENCE TECHNIQUES AND APPROACHES

[Annex I, referred to in Article 3, point 1, EU Legislative proposal (21/04/2021)]

(a) Machine learning approaches, including supervised, unsupervised and reinforcement learning, using a wide variety of methods including deep learning;

(b) Logic- and knowledge-based approaches, including knowledge representation, inductive (logic) programming, knowledge bases, inference and deductive engines, (symbolic) reasoning and expert systems;

(c) Statistical approaches, Bayesian estimation, search and optimization methods.

Most current AI systems are based on Machine Learning

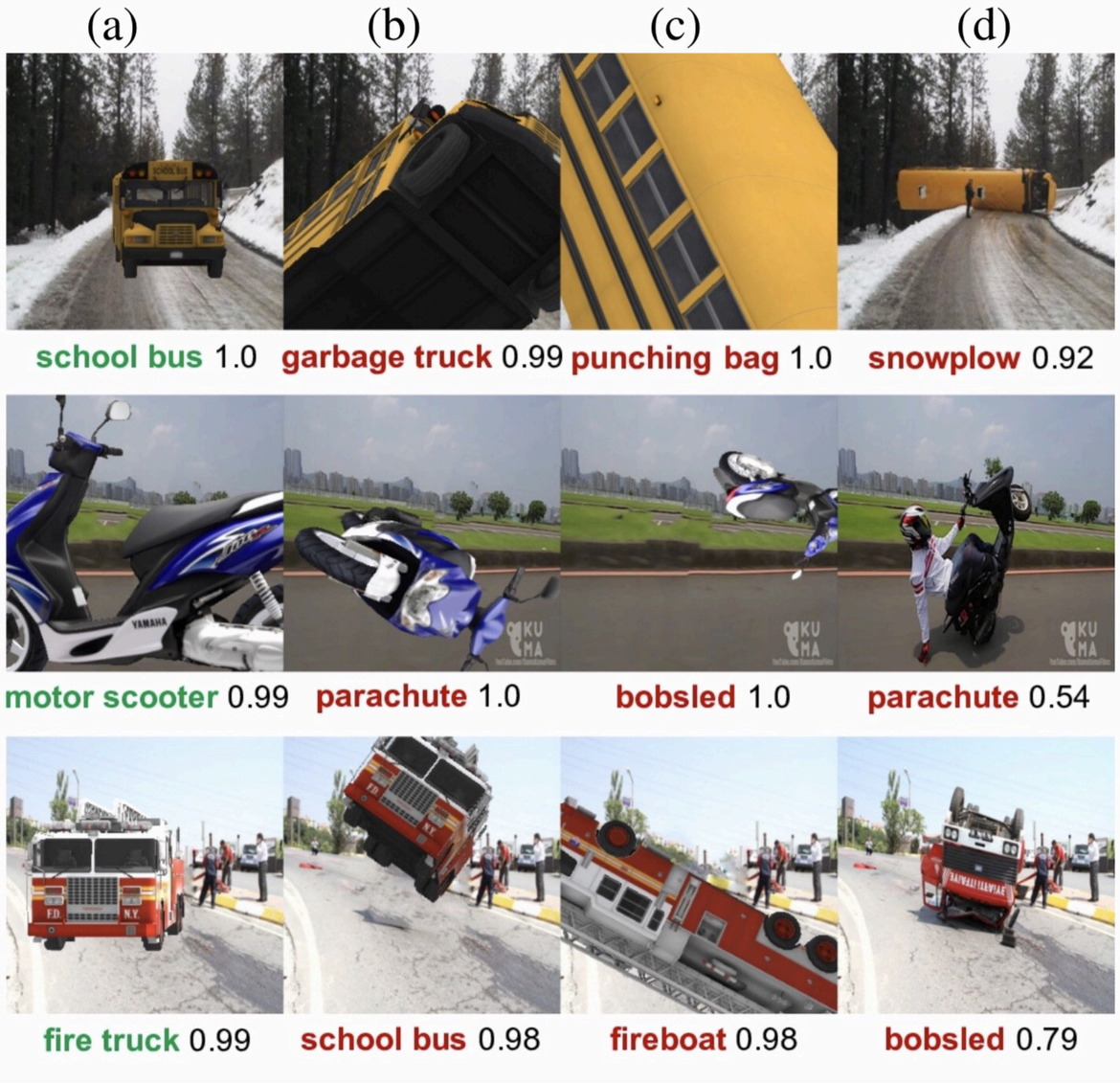
- Search for regularities and similarities in data
- Statistical correlations of data features to make predictions

- No reasoning using data and mathematical/physical theories and models
- No understanding of causes to build general models for making predictions

Deep Learning Limitations

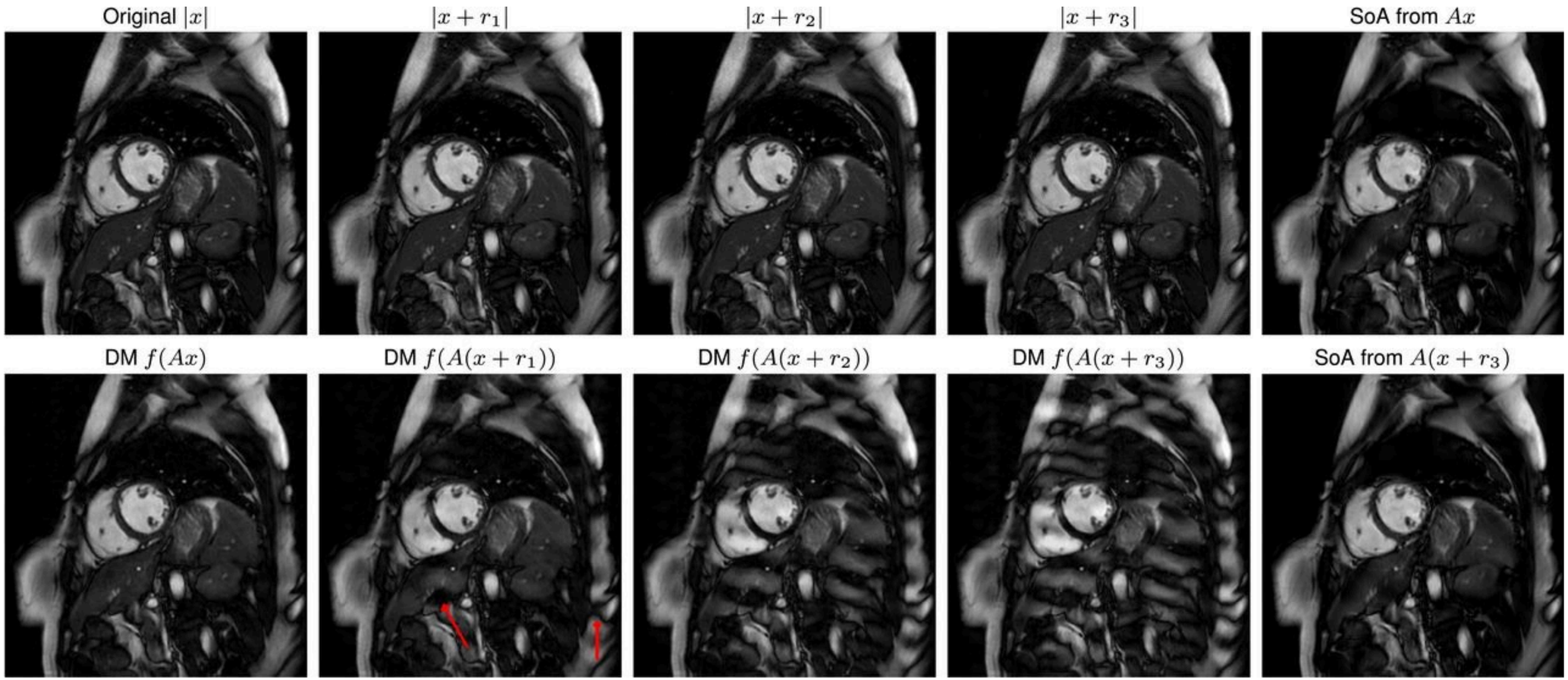
Targeted physical perturbation experiment
The misclassification target was Speed Limit 45.

Robust Physical-World Attacks on Deep Learning Models K. Eykholt et al. CVPR 2018.



Strike (with) a Pose: Neural Networks Are Easily Fooled by Strange Poses of Familiar Objects. Michael A. Alcorn et al., CVPR 2019

Issues in Medical Imagery Interpretation



Perturbations r_j (created to simulate worst-case effect) with $|r_1|<|r_2|<|r_3|$ are added to the image x.

(*Top*) Images 1 to 4 are original image x and perturbations $x+r_j$.

(Bottom) Images 1 to 4 are reconstructions from $A(x+r_j)$ using the Deep MRI (DM) network f, where A is a subsampled Fourier transform (33% subsampling);

(Top and *Bottom*) Image 5 is a reconstruction from Ax and $A(x+r_3)$ using an SoA method; **Note how the artifacts (red arrows) are hard to dismiss as nonphysical.**

On instabilities of deep learning in image reconstruction and the potential costs of AI

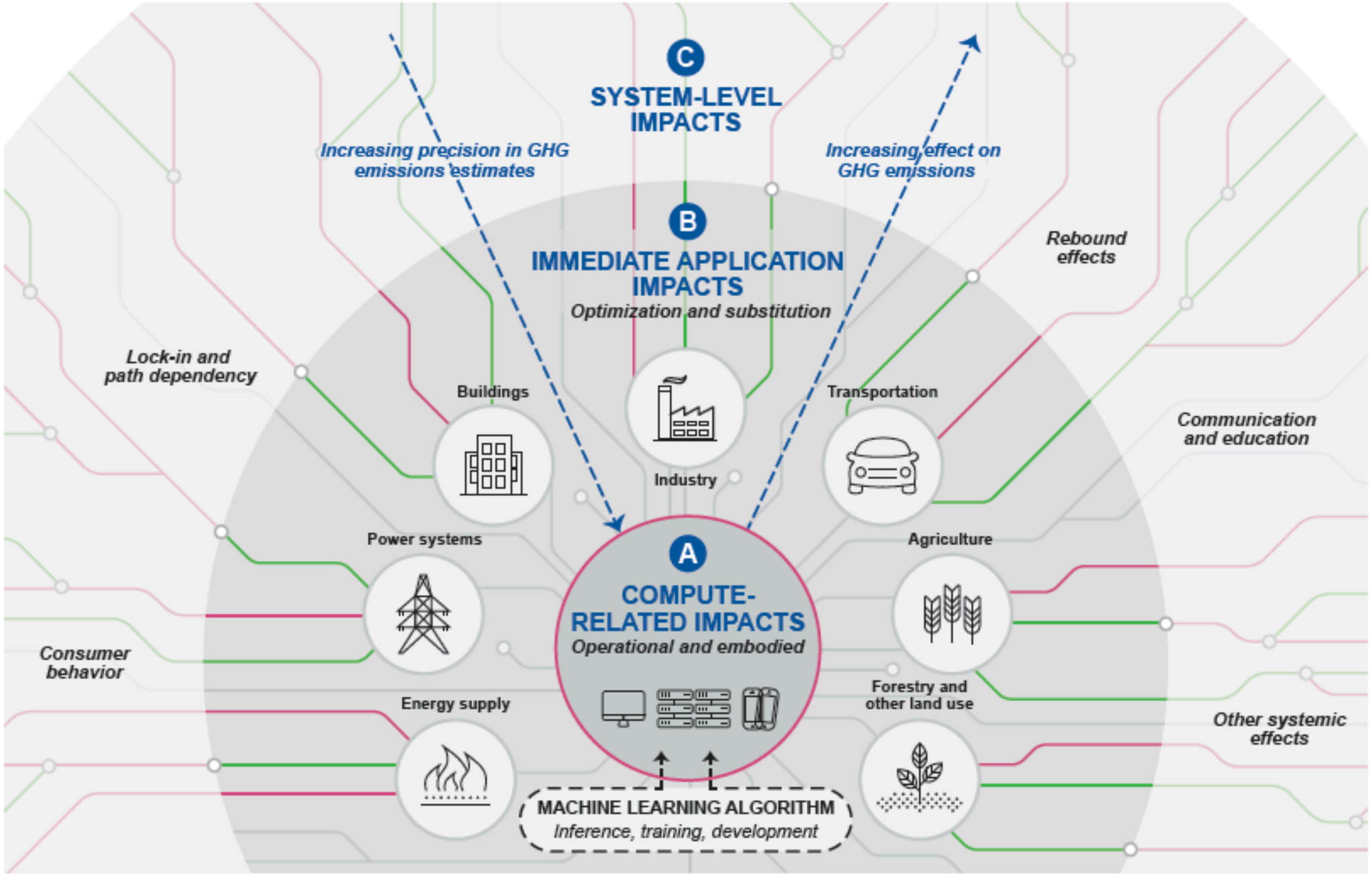
Vegard Antun et al. PNAS 2020;117:48:30088-30095

PNAS

Issues in Statistical ML

- AI Black box: data, millions/billions of parameters, optimization algorithms, off-the-shelf components
- No solid verification and validation processes, qualification and benchmarking of results
- Absence of causal links between inputs and outputs: no explanation of results
- AI systems lack semantics and context awareness

Evaluation and Mitigation of AIS Environmental Impact



From
Lynn Kaack, Priya Donti, Emma Strubell, George Kamiya, Felix Creutzig, et al..

Aligning artificial intelligence with climate change mitigation. 2021. hal-03368037

Decision and Action Delegation to AI systems

- Critical applications (healthcare, transportation, …)
- Areas raising human rights, discrimination and social issues, …

→ **Need for responsible design and development**

→ **Need for ethics and responsible governance**

Ethical Principles for Trustworthy AI

Ethical imperatives

- **Principle of Autonomy**: “Preserve Human Agency and control”
- **Principle of Non maleficence**: “Do no Harm” - Neither cause nor exacerbate harm or otherwise adversely affect human beings. safety and security, technical robustness.
- **Principle of Justice**: “Be Fair”. Equal and just distribution of benefits and costs, free from unfair bias, increase social fairness
- **Principle of Explicability**: “Operate transparently”. Traceability, auditability, transparent system capabilities, …

Requirements for Trustworthy AI

High-Level Expert Group on AI (EU) - April 2019

1. **Human agency and oversight**- Including respect tof fundamental rights, human control
2. **Technical robustness and safety** - Including resilience to attack and security, fall back plan and general safety, accuracy, reliability and reproducibility
3. **Privacy and data governance** - Including respect for privacy, quality and integrity of data, and access to data
4. **Transparency** - Including traceability, **explainability** and communication
5. **Diversity, non-discrimination and fairness** - Including the avoidance of unfair bias, accessibility and universal design, and stakeholder participation
6. **Societal and environmental wellbeing** - Including sustainability and environmental friendliness, social impact, society and democracy
7. **Accountability** - Including auditability, minimisation and reporting of negative impact, trade-offs and redress.

Tool: Assessment List for Trustworthy AI - ALTAI

https://ec.europa.eu/digital-single-market/en/high-level-expert-group-artificial-intelligence

French Digital Ethics Council examined topics

- Digital technologies and the pandemic
- Automated Driving
- Conversational agents (Chatbots)
- Artificial Intelligence in medical diagnosis
- Facial, postural and behavioural recognition
- Health data

Takeaways:
Responsible Development, Use and Governance of AI

- ML is a very efficient technology for automating data analysis
- AI is no silver bullet for many application. Avoid technical solutionism.
- AI systems using machine learning need to be made robust and resilient
- Explainability is essential to build trust in AI systems
- Appropriate design approaches, governance frameworks, auditing and certification of AI systems are necessary
- Complying with a responsible AI approach can be assessed through the compliance with the HLEG-AI 7 key requirements.
- Ethics Councils can provide recommandations and raise research questions.

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European Commission

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12-13 May 2022, Paris, France

The Spanish Bioethics Committee (CBE) in the context of the pandemic: Spanish National Strategy for the vaccination against Covid-19 and the role of bioethics through the CBE participation - Federico De Montalvo Jääskeläinen

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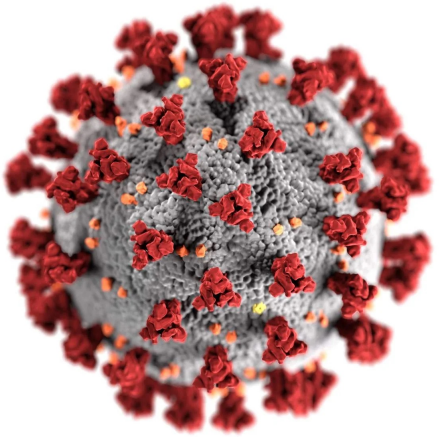

sábado, 28 de noviembre de 2020

El comité que mejor conoce el impacto de la covid

Política y Normativa

soledadvalle

Sáb, 28/11/2020 - 09:00

PRIORIZATION

THE WORD OF THE PANDEMIC FROM A BIOETHICAL PERSPECTIVE

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PRIORIZATION IS NOT STRANGE TO OUR HEALTHCARE SYSTEMS (PUBLIC MODELS)

BIOETHICAL CONFLICTS ARE NOT STRANGE TO THE HEALTHCARE SYSTEM AND TO ITS DECISION MAKING PROCESS (values involved, such as life, integrity, privacy. …)

TWO TALES/THREE DATES

1. MARCH 2020

2. SEPTEMBER 2020

3. APRIL 2021

MARCH 2020

SUN	MON	TUE	WED	THU	FRI
1	2	3	4	5	6
8	9	10	11	12	13
15	16	17	18	19	20
22	23	24	25	26	27
29	30	31			

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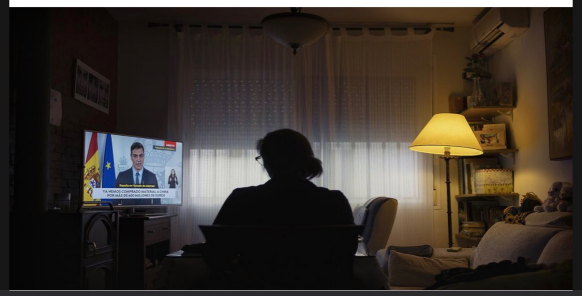
‘Stop everything that has to be stopped’: The inside story of Spain’s coronavirus state of alarm

EL PAÍS chronicles the days running up to the spring lockdown and what came after in an era that some ministers describe as the worst of their lives



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Coronavirus

Spain orders nationwide lockdown to battle coronavirus

Government instructs people to stay at home for two weeks, and closes bars, restaurants, cafes and cinemas

- Coronavirus - latest news
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Millions confined to homes af Spain and France impose coronavirus lockdowns

Measures mean 174m people in Europe face restrictions on movement in their own countries

An empty avenue in Barcelona on Sunday © AP

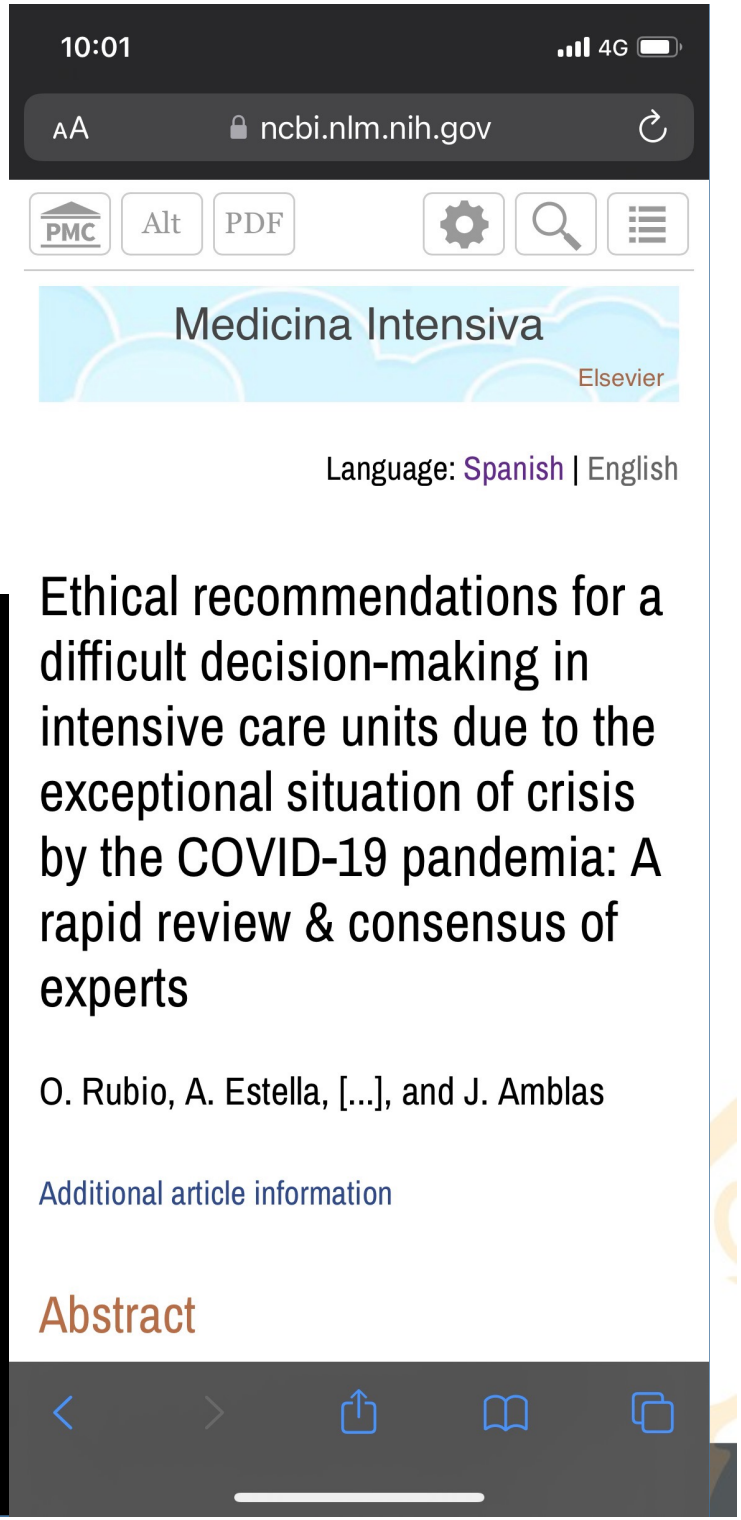
Save

SEMICYUC

LOS PROFESIONALES DEL ENFERMO CRÍTICO

RECOMENDACIONES ÉTICAS PARA LA TOMA DE DECISIONES EN LA SITUACIÓN EXCEPCIONAL DE CRISIS POR PANDEMIA COVID-19 EN LAS UNIDADES DE CUIDADOS INTENSIVOS. (SEMICYUC)

A BIOETHICAL CRISIS IN A PUBLIC HEALTH CRISIS



Semicyuc
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SOCIAL VALUE OF THE INDIVIDUAL

23. Tener en cuenta **el valor social de la persona enferma.**

10:01 4G
AA ncbi.nlm.nih.gov
PMC Alt PDF
Medicina Intensiva
Elsevier

Language: Spanish | English

Ethical recommendations for a difficult decision-making in intensive care units due to the exceptional situation of crisis by the COVID-19 pandemia: A rapid review & consensus of experts

O. Rubio, A. Estella, [...], and J. Amblas

Additional article information

Abstract

COMILLAS
UNIVERSIDAD PONTIFICIA
ICAI ICADE CIHS

DO INDIVIDUALS HAVE SOCIAL VALUE?

BIOETHICAL DIAGNOSIS OF THE PANDEMIC

1. UTILITARIANISM

2. DILEMMATISM

3. SCIENTIFICISM

Comité de Bioética de España

Comité de Bioética de España

INFORME DEL COMITÉ DE BIOÉTICA DE ESPAÑA SOBRE LOS ASPECTOS BIOÉTICOS DE LA PRIORIZACIÓN DE RECURSOS SANITARIOS EN EL CONTEXTO DE LA CRISIS DEL CORONAVIRUS

"Natural rights is simple **nonsense**"

Jeremy Bentham

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ZAGREBELSKY

IT IS NOT ONLY THE MOST BENEFIT FOR THE MORE NUMBER OF INDIVIDUALS, IT IS ABOUT THE LESS NUMBER OF INDIVIDUALS EXCLUDED FROM HAPPINESS

2. DILEMATISM

DIEGO GRACIA:

The human being tends to reduce the courses of action to two and usually extreme. It is a dichotomous logic, a bias of dilemmatism

In real life there are few dilemmas and many problems

3. SCIENTIFICISM

El Dr. Simón y la isla de Francis Bacon

FEDERICO DE MONTALVO

Querido lector, si el título de esta tribuna le ha llevado a pensar que aquí encontrará una crítica a la labor del Dr. Fernando Simón durante esta crisis sanitaria, mejor no siga leyendo, porque su expectativa se verá rápidamente frustrada. Tal crítica, al margen de que uno pueda o no compartir su actuación, no creemos que sea en este momento justa y, por tanto, ética. Pero, ya que ha iniciado la lectura de la tribuna, le animamos a continuarla porque lo que sí encontrará aquí es una explicación, estrictamente académica, de por qué creemos que en España la política ha dejado un papel estelar a la ciencia en la toma de decisiones frente a los principales problemas que nos ha traído esta crisis. De estos sombríos tiempos que estamos viviendo quedará un extraño regusto a cientifismo.

Y lo que está ocurriendo, no puede dejar de traernos el recuerdo de Francis Bacon y su novela utópica de *La Nueva Atlántida*. El eminente filosófo situaba su relato en una isla de los mares del sur, la desconocida isla de Bensalem, a la que arribó un barco para avituallarse de provisiones. Y en ella, los tripulantes tuvieron la oportunidad de conocer la existencia de la Casa de Salomón, dedicada al estudio de las obras y criaturas de Dios, constituyendo el alma misma de la sociedad que la habitaba. La Casa de Salomón tenía encomendadas, entre otras funciones, anunciar las predicciones verosímiles de enfermedades y plagas, aconsejando acerca de lo que debía hacerse para evitar tales males y remediarlos. La metáfora le permite a Bacon mostrar la utopía de un Estado ideal en el que la felicidad de sus ciudadanos descansa en una perfecta organización social, presidida en la toma de las decisiones políticas por científicos, como si la mera resolución de los problemas científicos resolviera los de índole social.

Además de este fenómeno de la sustitución de la política por la ciencia, también está teniendo lugar otro que conecta directamente con aquél: la transformación generalizada de los problemas en dilemas, de manera que las soluciones se ofrecen como absolutamente extremas. Y hay una relación directa entre ambos fenómenos porque la ciencia se expresa habitualmente en términos dilemáticos, de manera que solo hay una respuesta correcta, sin que los cursos o soluciones intermedias encuentren cabida en el método científico.

Las referencias a los expertos, a lo que defienden o proponen los científicos y los técnicos, han sido permanentes en las comparecencias de las autoridades. Incluso, muchas de dichas comparecencias han estado presididas, no por responsables políticos, sino por los propios expertos. Pero ni el problema ni el debate son nuevos. José Esteve Pardo ya denunció hace unos años que el carácter expansivo de la actividad científica y tecnológica no puede ir en detrimento del carácter jurídico-político de la toma de decisiones por parte de las autoridades. Son funciones de distinto contenido. El poder científico tiene funciones de información, dictamen y, en definitiva, valoración de riesgos, pero no de decisión. La legitimación científica, por el conocimiento experto y especializado, no alcanza al poder decisorio, que corresponde a las instancias públicas que tengan atribuidas, por determinación constitucional, tales funciones. Y el propio Esteve Pardo añade que es la diferencia natural y de objetivos de estos dos poderes. Si a la ciencia no le compete la adopción

Fernando Simón, ayer, en la rueda de prensa. EFE

El poder científico tiene funciones de información, pero no de decisión

de decisiones, ello no es sólo por falta de legitimación sino, sobre todo, porque ella misma no pretende decidir. No podemos esperar decisiones de la ciencia. No es solo que la ciencia es prudente por naturaleza, sino que sus investigaciones se expresan en probabilidades y están permanentemente abiertos a la discusión. Existen controversias científicas no resueltas en torno a muchos de los riesgos para la salud que son hoy objeto de debate y sobre las que el Derecho, las instancias y órganos habilitados para ello, deben adoptar importantes decisiones. Esa facultad y obligación de decidir del Derecho, concluye, son al mismo tiempo la grandeza y la servidumbre del Derecho y de sus operadores.

También Daniel Innerarity nos recuerda, más recientemente, que una democracia es un sistema en el que no son los expertos quienes tienen la última palabra, sino la ciudadanía, lo que se traduce en el hecho de que por encima de la administración están los políticos, es decir, quienes nos representan. Delegar la toma de decisiones políticas en los expertos puede resultar un recurso persuasivo, pero ni éstos tienen suficiente autoridad cuando sus opiniones son fácilmente contestables desde la propia ciencia ni paradójicamente reducen la complejidad del problema a resolver, antes al contrario, lo aumentan al producir mayor imponderabilidad y contingencia.

En el ámbito de la Bioética, Diego Gracia Guillén, bajo el término de la falacia tecnocrática, nos dice que se reducen los problemas éticos a meros problemas técnicos, trasladando la gestión del propio poder a los expertos, de manera que éstos no solo tendrán la capacidad de gobernar su propio sector productivo sino, más allá, la sociedad en general.

Como conclusión, parece que la política ha podido redescubrir, a través de la ciencia, una magnífica herramienta de control social, superior al dinero o, como destacara Gilles Lipovetsky, al consumo de masas: la salud. Por tanto, la cuestión clave que debería observarse en los próximos meses y que nos sirve para terminar es si esta aparente biopolítica, en los términos de Foucault, ha venido o no para quedarse, como cual isla de Bensalem. Ya nos advirtió hace más de un siglo uno de los mayores genios que ha dado nuestra Nación, Miguel de Unamuno, que es el cientifismo una enfermedad de que no están libres ni aun los hombres de verdadera ciencia.

Federico de Montalvo Jääskeläinen es presidente del Comité de Bioética y profesor de Derecho Constitucional (UPComillas, ICADE).

3. SCIENTIFICISM

WHO SHOULD SOLVE THE PANDEMIC, SCIENTIFICS OR POLITICIANS?

CAN WE SOLVE THIS CRISIS WITHOUT CONSIDERING ALL THE ELEMENTS INVOLVED?

IS THERE POLITICS WITHOUT EDUCATION, ECONOMY WITHOUT POLITICS AND HEALTH WITHOUT ECONOMY?

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SEPTEMBER 2020

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30			

www.calendaroptions.com

WILL THERE BE VACCINES FOR EVERYBODY?

URGENTE El plan de Navidad limita las cenas a seis personas con toque de queda a la una en Nochevieja y Nochebuena

LA CRISIS DEL CORONAVIRUS >

¿Y si fuera más útil vacunar primero a la cajera del supermercado?

Un trabajo académico dirigido por un ingeniero español sugiere que inmunizar antes a las personas con más interacciones sería más efectivo que priorizar a los grupos de riesgo

ÁNGELES ESPINOSA

Dubái - 24 NOV 2020 - 00:30 CET


ESTRATEGIA DE
VACUNACIÓN
COVID-19 EN ESPAÑA
-LA VACUNA-


ESTRATEGIA DE
VACUNACIÓN
COVID-19 EN ESPAÑA
GOBIERNO
DE ESPAÑA

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ETHICAL PRINCIPLES

RISKS

GROUPS


does this virus
treat everybody
the same way?
RIS
ROUPS

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Q: Does COVID-19 only affect older people?

A: No. People of all ages can be infected by SARS-CoV-2, the virus that causes COVID-19. However, older people and people with some pre-existing health conditions are more at risk of severe illness. [1]

ETHICAL PRINCIPLES

EQUALITY

NECESSITY

EQUITY

VULNERABILITY

THE BEST INTEREST OF CHILDREN

SOCIAL BENEFIT

RECIPROCITY

RISKS

Mortality

Exposition

Social and economic impact

Transmission

3.5 Grupos de población y criterios a utilizar en la valoración de priorización

Se han valorado los **grupos de población** que figuran a continuación (resumen en la tabla 3.2). El orden en que se han evaluado estos grupos no indica ningún orden de prioridad:

- Personal sanitario y sociosanitario. Se incluyen también las personas que prestan cuidados a las personas vulnerables en sus hogares.
- Personas residentes en centros de mayores.
- Población general mayor de 64 años.
- Personas con gran dependencia.
- Personas con condiciones de riesgo.
- Personas que viven o trabajan en comunidades o entornos cerrados.
- Personas pertenecientes a poblaciones vulnerables por su situación socioeconómica.
- Personas con trabajos esenciales.
- Personal docente.
- Población infantil.
- Población adolescente y joven (mayores de 16 años).
- Población adulta.
- Población de áreas de alta incidencia y/o situaciones de brotes.
- Embarazadas y madres que proporcionan lactancia natural.
- Población seropositiva a SARS-CoV-2.

Tabla 3.2 *Valoración de varios grupos de población, criterios utilizados, principios éticos aplicables y estimación poblacional.*

Grupo de población		Criterios de priorización				Principios éticos aplicables*	Estimación poblacional$
		Riesgo gravedad	Riesgo exposición	Riesgo impacto	Riesgo transmisión		
Personal sanitario y sociosanitario . residencias mayores . Personal 1ª línea		MEDIO	ALTO	ALTO	ALTO	7,6,3	1,7 M (0,6M >50a
		MEDIO	ALTO	ALTO	MUY ALTO	7,6,3	0,32M (0,1M >50a 0,86M
Personas de residencias de mayores		MUY ALTO	ALTO	ALTO	ALTO	1,2,3	0,38 M
Mayores a partir de 65 años . 65-74 años . ≥75 años		ALTO	ALTO	ALTO	ALTO	1,2,3	9 M
		MUY ALTO	ALTO	ALTO	ALTO	1,2,3	4,5M 4,5M
Personas con gran dependencia		ALTO	ALTO	ALTO	ALTO	1,2,3,4	0,36
Condiciones de riesgo	Evidencia alta	ALTO	ALTO	MEDIO	ALTO	4,3,2	0-64: 8 M >65: 7 M
	Evidencia media o baja	MEDIO	MEDIO	MEDIO	MEDIO	4,3,2	
Entornos cerrados**	Viven	MEDIO	MEDIO	MEDIO	ALTO	7,3,2	---
	Trabajan			ALTO		7,3,2	
Situación socioeconómica desfavorecida*		MEDIO/ ALTO	ALTO	ALTO	ALTO	3,2	---
Situación laboral**	Esencial	MEDIO	MEDIO	ALTO	ALTO	6,7	4,2M (0,7 >50a)
	Vulnerables					6,3,2	0,17M
Personal docente		MEDIO	ALTO	ALTO	ALTO	5	1,1 M (0,4>50a)
Población infantil***		BAJO	ALTO	MEDIO	ALTO	5,6	7 M (<14 a)
Adolescentes y jóvenes***		BAJO	ALTO	MEDIO	ALTO	5,6	7 M (15-29a)
Embarazadas y lactancia		ALTO	MEDIO	MEDIO	MEDIO	5,2	0,37 M
Población adulta		MEDIO	MEDIO	MEDIO	MEDIO	6,2	24 M (30-64a)

***Principios y valores éticos:** 1) Igualdad en dignidad y derechos, 2) Necesidad; 3) Equidad, 4) Protección de las personas con discapacidad en situación de vulnerabilidad, 5) Interés superior del menor, 6) Beneficio social,7) Reciprocidad. **Mayor gravedad sólo en los agrupamientos humanos donde confluyen personas donde por edad, sexo o condiciones de riesgo la enfermedad puede ser más grave. ***Escolarizada y no escolarizada. $Datos de carácter orientativo.

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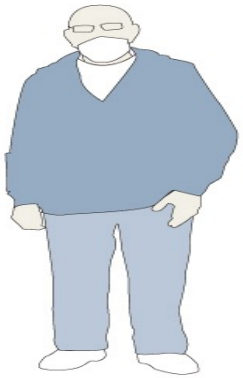
VACUNAS DE ARN MENSAJERO

Pfizer moderna

SIN LÍMITE DE EDAD

GRUPO 1 Y 2

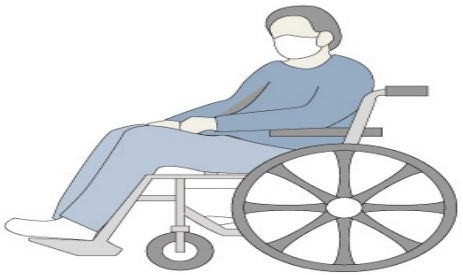


Personal de residencias

Personal sanitario de primera línea

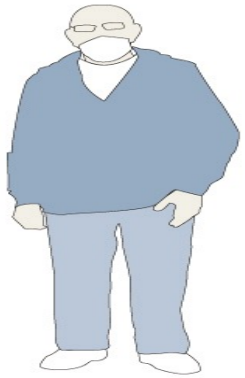
GRUPO 3 Y 4

Personal sociosanitario



Grandes dependientes y cuidadores

GRUPO 5



Personas de 80 años o más

comillas.edu

FUENTE: Ministerio de Sanidad
J. AGUIRRE | EL MUNDO GRÁFICOS

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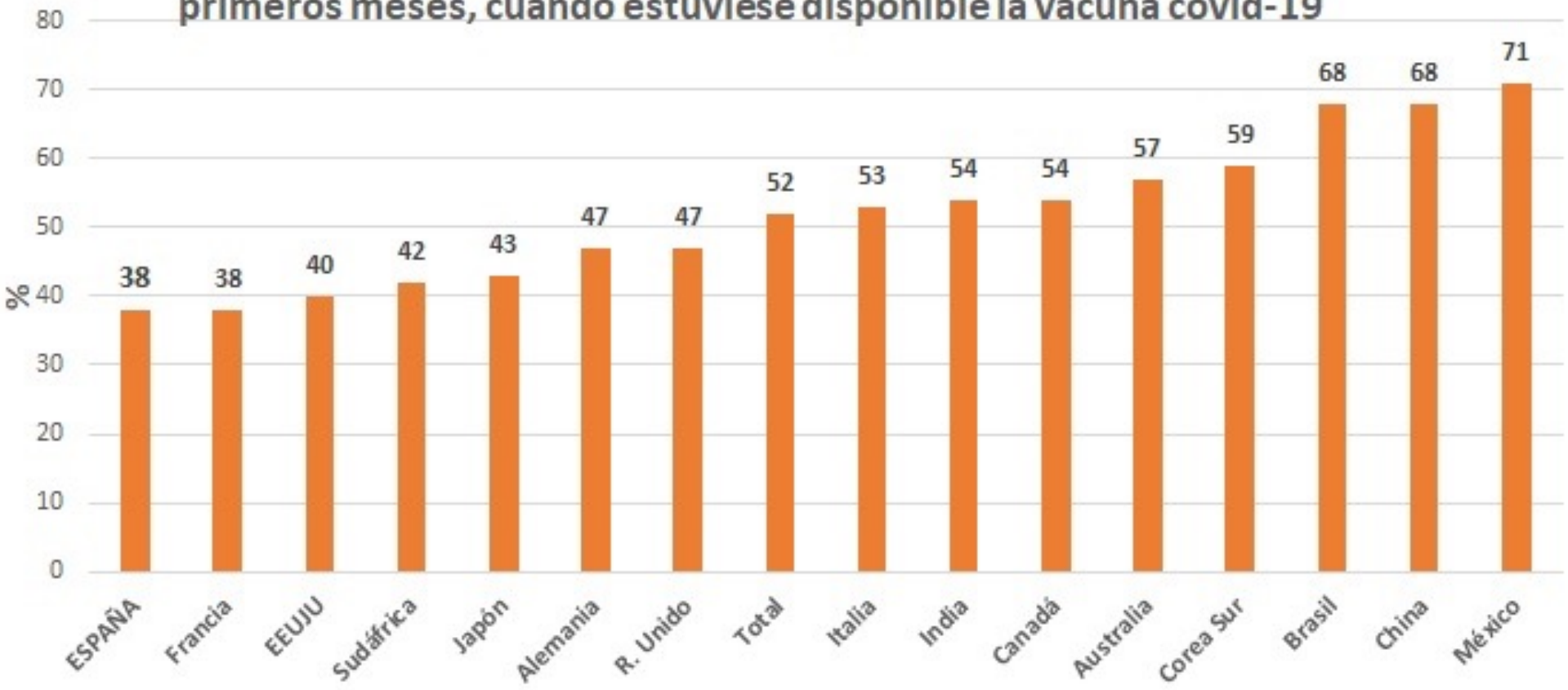
Figura 2.-Porcentaje de personas que se vacunarían en los tres primeros meses, cuando estuviese disponible la vacuna covid-19



Fuente: Ipsos para World Economic Forum. Fecha encuesta: 8-13 de cotubre de 2020.

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ESTRATEGIA DE VACUNACIÓN COVID-19 EN ESPAÑA

DOSIS ENTREGADAS	DOSIS ADMINISTRADAS	Nº PERSONAS PAUTA COMPLETA	% PERSONAS VACUNADAS SOBRE POBLACIÓN MAYOR DE 12 AÑOS
97.011.384	94.485.123	40.439.425	93,0 %
			% DE PAUTA COMPLETA SOBRE POBLACIÓN MAYOR DE 12 AÑOS
			92,6 %

REASONS FOR A SUCCESS

LIVING STRATEGY

STEP BY STEP

NON COMPULSORY v VOLUNTARY

STRATEGY BASED ON ETHICAL PRINCIPLES


Araceli de 96 años primera persona vacunada en España

LIVING STRATEGY

Consulta la estrategia

Actualización estrategia

Actualización estrategia

Actualización estrategia

Actualización estrategia

Actualización estrategia

Actualización estrategia

Actualización estrategia

Actualización estrategia

CRISIS OF THE SECOND SHOT AND MIXED SHOT

cbe Comité de Bioética de España

INFORME DEL COMITÉ DE BIOÉTICA DE ESPAÑA ACERCA DE LOS FUNDAMENTOS ÉTICO-LEGALES DE PERMITIR A LAS PERSONAS MENORES DE SESENTA AÑOS QUE HAN SIDO VACUNADOS CON PRIMERA DOSIS DE VAXZEVRIA, VACUNARSE, EN SEGUNDA DOSIS, CON LA MISMA VACUNA

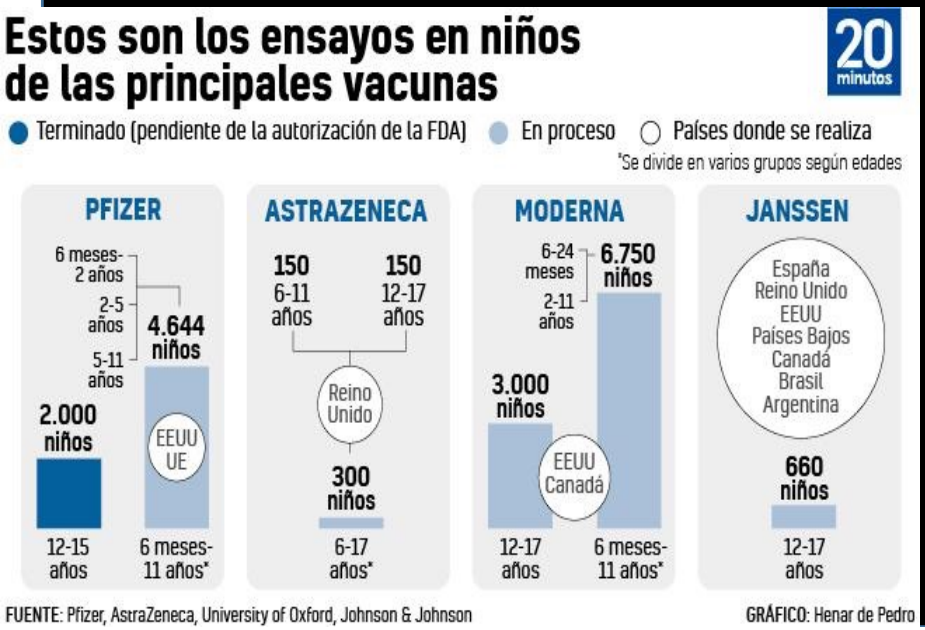
Comité de Bioética de España

INFORME DEL COMITÉ DE BIOÉTICA DE ESPAÑA ACERCA DE LOS FUNDAMENTOS ÉTICO-LEGALES DE PERMITIR A LAS PERSONAS MENORES DE SESENTA AÑOS QUE HAN SIDO VACUNADOS CON PRIMERA DOSIS DE VAXZEVRIA, VACUNARSE, EN SEGUNDA DOSIS, CON LA MISMA VACUNA

THERE IS NOT A RIGHT TO CHOOSE VACCINES

BUT IS BETTER TO BE VACCINATED EVEN WITH A NON MIXED BOOST

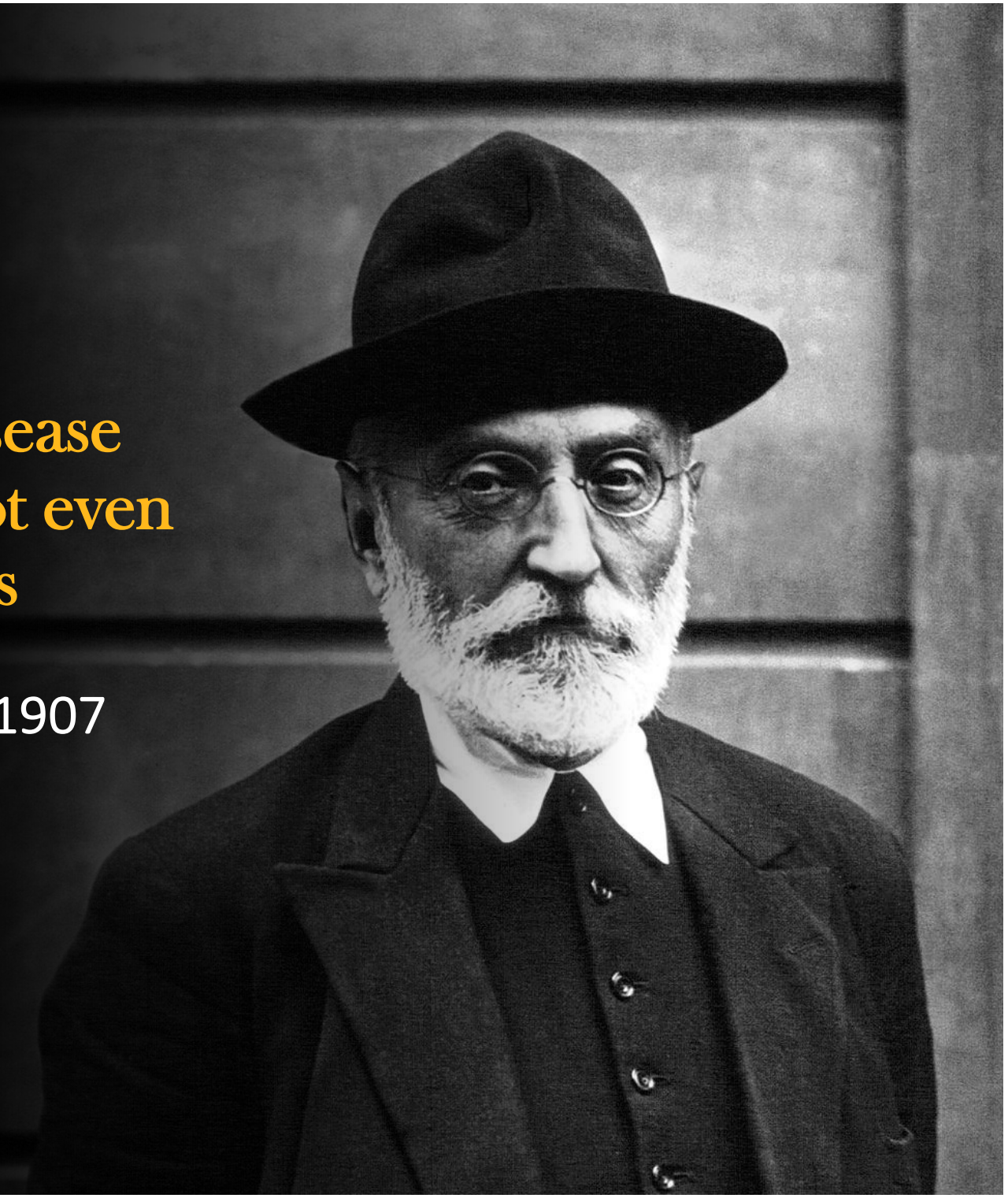
IS IT ETHICAL TO VACCINE OUR CHILDREN?




Nuestro
planeta,
nuestra
SALUD

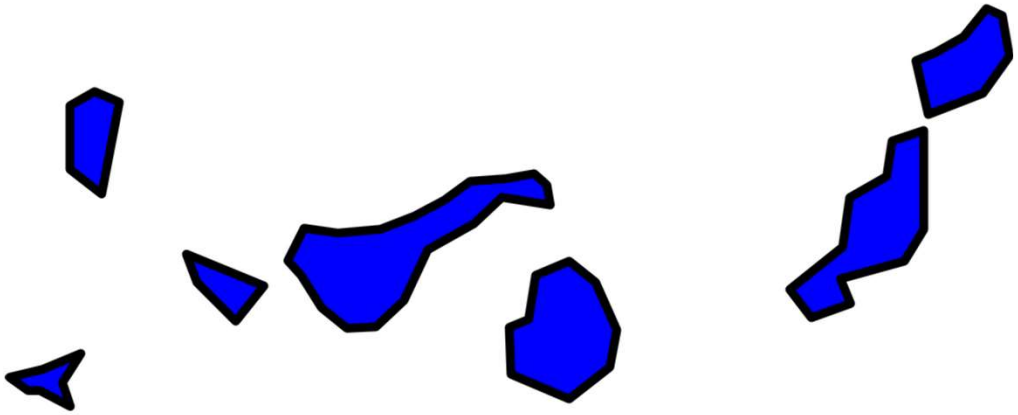
Scientifism is a disease from which are not even free our scientifics

Miguel de Unamuno, 1907



29th NATIONAL ETHICS COUNCILS FORUM

“THE PANDEMIC. STRENGTHS AND WEAKNESSES”



Dr. Amós García Rojas

Abril 2022

PRESIDENTE AEV

ASOCIACIÓN ESPAÑOLA DE VACUNOLOGÍA

Asociación Española de Vacunología

Fundación Española de Vacunología

""When we believed that all the answers, changed all the questions"

Mario Benedetti

LA COVID-19

UNEXPECTED

NOT INITIALLY VALUED

IMPOVERISHED HEALTH SYSTEM

COVID-19

GLOBAL WARMING

POVERTY

MAN'S RELATIONSHIP WITH ANIMALS

Without health there is no economy

Without economy there is no health

Midpoint

DO VACCINES SAVE LIVES?

NOT ALL VACCINES ARE THE SAME

I AM NOT PROVACCINE

VACCINES AS AN ATTITUDE

VACCINES

COVAX PROGRAM

EU PURCHASING CENTRA

VACCINES

SLOWLY

LOGISTICAL COMPLEXITY

COMMUNICATION

STRATEGY

PRIORIZATION

LOGISTICS ANALYSIS

COMMUNICATION

VACUNAS

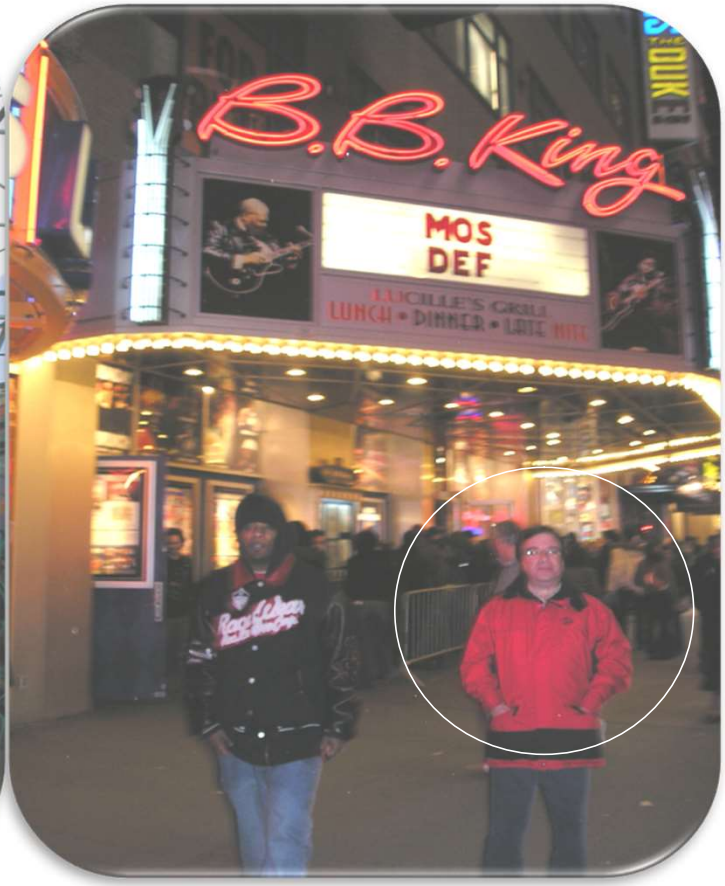
VACCINATION IN DEVELOPED COUNTRIES

VACCINATION IN POOR COUNTRIES

NUEVO ESCENARIO

BUT BE CAREFUL, WE ARE STILL IN A PANDEMIC

CALM, PATIENCE MORE PRUDENCE



THANK YOU VERY MUCH

From Theory to Practice: Ethics Guidelines for Trustworthy AI and Challenges of Implementation

Lorena Jaume-Palasí


Human agency and Oversight
Technical robustness and Safety
Privacy and Data Governance
Transparency
Diversity, Non-Discrimination and Fairness
Societal and Environmental wellbeing
Accountability
To be continuously evaluated and addressed throughout the AI system's life cycle

Technical context

Cammio (Xpress-Analytics using IBM Watson)*

Xpress Analytics analyses the spoken text of the candidates and, based on the OCEAN model, classifies the personality traits into a personality profile.

*Used a.o. by: EU Careers according to Cammio report

Technical context.
SAP & Cammio Cooperation

Accordingly, in this example we have at least:

1) the logic of SAP's language scans (gender neutral),

2) the logic of Cammio (strongly gendered) and

3) the logic of IBM Watson together with

4) the logic behind the psychological OCEAN model and

5) the logic of the platform on which all systems are operated,

if necessary - depending on the architecture model - even including

(6) the addition of an intermediate analytical layer

Socio-technical context

The Flaws of Policies Requiring Human Oversight of Government Algorithms

42 Pages • Posted: 13 Sep 2021

Ben Green
University of Michigan at Ann Arbor - Society of Fellows; University of Michigan at Ann Arbor - Gerald R. Ford School of Public Policy; Harvard University - Berkman Klein Center for Internet & Society

Date Written: September 10, 2021

Abstract

Policymakers around the world are increasingly considering how to prevent government uses of algorithms from producing injustices. One mechanism that has become a centerpiece of global efforts to regulate government algorithms is to require human oversight of algorithmic decisions. However, the functional quality of this regulatory approach has not been thoroughly interrogated. In this article, I survey 40 policies that prescribe human oversight of government algorithms and find that they suffer from two significant flaws. First, evidence suggests that people are unable to perform the desired oversight functions. Second, human oversight policies legitimize government use of flawed and controversial algorithms without addressing the fundamental issues with these tools. Thus, rather than protect against the potential harms of algorithmic decision-making in government, human oversight policies provide a false sense of security in adopting algorithms and enable vendors and agencies to shirk accountability for algorithmic harms. In light of these flaws, I propose a more rigorous approach for determining whether and how to incorporate

The first paper really looked at how introducing risk assessments alters the predictions that people make. The primary finding was that people respond to risk assessments in biased ways. People are more likely to follow a recommendation to increase their estimate of risk when evaluating Black defendants and more likely to decrease their estimate of risk suggested by the risk assessment when evaluating white defendants. So, even if we were to say, "OK, this algorithm might meet certain standards of fairness," the actual impacts of these algorithms might not satisfy those constraints when you think about how humans are going to respond.

The second study was an extension of that, looking at whether people are able to evaluate the quality of algorithmic predictions. We found that they weren't. People can't really do that job, which is central to the idea of people being able to determine which recommendations from an algorithm they should work with or not.

that actually make judges more likely to weigh risk more heavily when making decisions? We must balance the desire to reduce risk with other interests around the liberty of defendants, and so on. Are we improving the accuracy of human prediction? Or are we actually making risk a more salient feature of decision-making?

We ran an experiment to test that and found that we're more in the latter camp. We're not simply altering people's predictions of risk. We're altering how people factor risk into their decisions, and essentially prompting them to weigh risk as a more important factor when making decisions.

What does a judge have to do?

- Judicial power is vested in the judges
- Judicial independence
- Dispense justice

What does a judge have to do?

- Dispense justice (> interpreting the law)
  - Evaluate (individual) risk – social prognostics
    - Personality of the perpetrator, past life (especially previous convictions), the circumstances of the crime and the living conditions of the perpetrator
  - Agreements in advance with the court and prosecution
  - Consider material and procedural laws
    - term of imprisonment,
    - prohibition of retroactivity,
    - avoidance of unnecessary hardships,
    - relieving the criminal justice system etc.
  - Defense of the rule of law

RESEARCH ARTICLE | SOCIAL SCIENCES

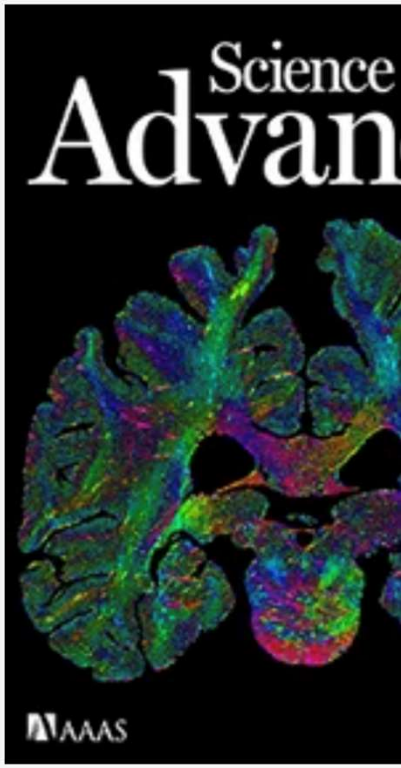
The limits of human predictions of recidivism

ZHIYUAN "JERRY" LIN, JONGBIN JUNG, SHARAD GOEL, AND JENNIFER SKEEM Authors Info & Affiliations

SCIENCE ADVANCES • 14 Feb 2020 • Vol 6, Issue 7 • DOI: 10.1126/sciadv.aaz0652

Abstract

Dressel and Farid recently found that laypeople were as accurate as statistical algorithms in predicting whether a defendant would reoffend, casting doubt on the value of risk assessment tools in the criminal justice system. We report the results of a replication and extension of Dressel and Farid's experiment. Under conditions similar to the original study, we found nearly identical results, with humans and algorithms performing comparably. However, algorithms beat humans in the three other datasets we examined. The performance gap between humans and algorithms [illegible] participants were not provided with immediate feedback on the accuracy of their responses. Algorithms also outperformed humans when the information provided for predictions included an enriched (versus restricted) set of risk factors. These



Genome evolution of a nonparasitic heterotroph, the diatom *Nitzschia p*

BY RYOMA KAMIKAWA, TAKAKO MOCHIZUKI, E

Sub-angstrom noninvasive imaging

Moral Automatization

Machine oversight of humans

Centering habitus (instead of material and procedural law)

Consistency as moral efficiency

Centering algorithmic norms over procedural, human oversight

Challenges

- Risks, conflicts and frictions go beyond the isolated analysis of a single product > technical ecosystems in a large socio-technical context.
- Challenges and trade-offs regarding transparency and explainability of a complex ecosystem. Transparency is not accountability
- Risks, conflicts and frictions go beyond quality and security processes
- Risks, conflicts and frictions are frequently out of the scope of a general AI regulation
- The need to *zoom out.* Context of use

Twitter: @lopalasi
email: ljp@ethicaltech-society.org

Thank you!

Digital Health
Combining Bioethics and Cyberethics

Claude Kirchner

CCNE pour les sciences de la vie et de la santé
comité national pilote d'éthique du numérique

Inria

CERNA

29th Meeting of the National Ethics Councils (NEC) Forum
UNESCO, Paris — May 12, 2022

The world is undergoing a profound digital conversion

A formidable opportunity

Source of progress and innovation

...

with also (many)
unexpected usages

The New York Times | http://nyti.ms/1yOlvAu

FASHION & STYLE

To Siri, With Love

How Apple's Siri Became One Autistic Boy's B.F.F.

By JUDITH NEWMAN OCT. 17, 2014

Of all the worries the parent of an autistic child has, the uppermost is: Will he find love? Or even companionship? Somewhere along the line, I am learning that what gives my guy happiness is not necessarily the same as what gives me happiness. […] Siri makes Gus happy. She is his sidekick. Last night, as he was going to bed, there was this matter-of-fact exchange:

Gus: "Siri, will you marry me?"

Siri: "I'm not the marrying kind."

Gus: "I mean, not now. I'm a kid. I mean when I'm grown up."

Siri: "My end user agreement does not include marriage."

Gus: "Oh, O.K."

An evolution that includes what we do not see or no longer see

- Energy production: electricity, gas, etc.
- Fluid management: water, traffic, ...
- Logistic chains: supermarket supplies, …
- Scientific research: astronomy, history, economics, informatics, medicine, ...
- Agriculture: optimized distribution of fertilizers, …
- Biomedical: vaccine development, ...

An evolution AND a conversion

« conversion requires a retrospective examination of the past (thus the re-interpretation and re-capturing of older frameworks and contents into the new ones) as well as new explanations of actions and events »

— Milad Doueihi, ***Digital Cultures***, Harvard University Press, 2011
La grande conversion numérique, La librairie du XXIe siècle
Editions du Seuil, 2008, p. 23

Digital Health

Convergence of health and digital sciences and technologies

US-FDA: DH includes mobile health, health information technology, wearable devices, telehealth and telemedicine, and personalized medicine

Allows

Reduce inefficiencies

Improve access

Reduce costs

Increase quality

Personalize medicine solutions

Needs

Software as a Medical Device, incl. AI

Cybersecurity

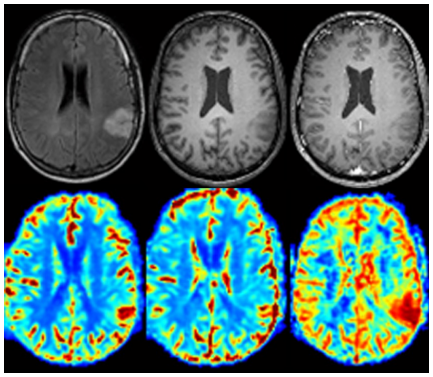
Medical Data Systems

Medical Device Interoperability

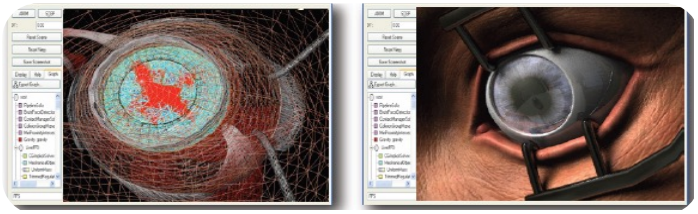
Wireless Medical Devices

Exemples in all medicine domains

- Medical diagnosis and AI
- AI to triage Covid-19 patients
- Tele-medicine and tele-care
- Vaccines and drugs researches
- Epidemiology
- Global health, etc…



Making possible a global integration of prevention, diagnosis, care and support



Why does

the representation and digital processing of information

have such an impact on humans, their organizations,… health and medicine

We are biological information processing systems
—and not only that—

. The reading of this text
. The functioning of an organ
. The reasoning conducted to understand a situation

are information processing operations,
often absolutely non-elementary

In a context where humans and digital information processing systems co-evolve

- They complement each other
- Interact
- Collaborate
- Combine

with profound consequences for and on humans

Keeping in mind that digital systems are human designed

The cyber-civilisation

- Based on a deep synergy between biological (eg human) and digital information processing systems
- Based on mastery and confidence in information processing systems, considered globally
- Relies on non-trivial qualities of digital information systems like: cybersecurity, non-maleficence, confidence, …

On needs of ethics, understood as: ``Reflection on human behaviors and the values on which they are based, carried out with a view to establishing a doctrine, a science of morality ''

—— French Academy dictionary

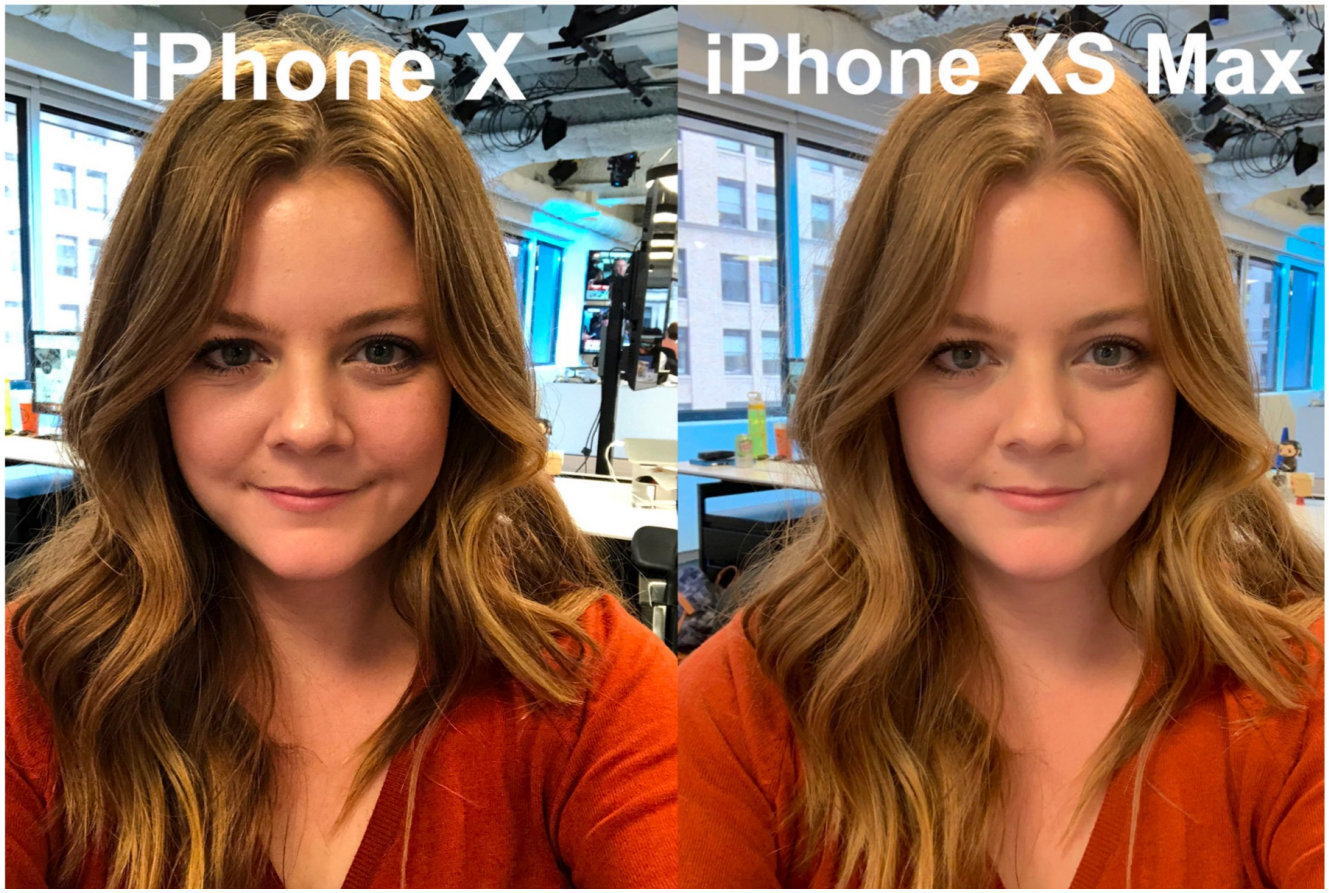
Information processing is not new…

© In Ethics and Computational Photography, Fredo Durand, MIT EECS & CSAIL

And the topics is unfortunately of full actuality:

(Sophisticated) information processing for everyone

https://www.businessinsider.com/beautygate-iphone-xs-camera-appears-to-apply-beauty-mode-to-selfies-2018-9 https://www.imore.com/beautygate



What are the values embedded in the algorithms?

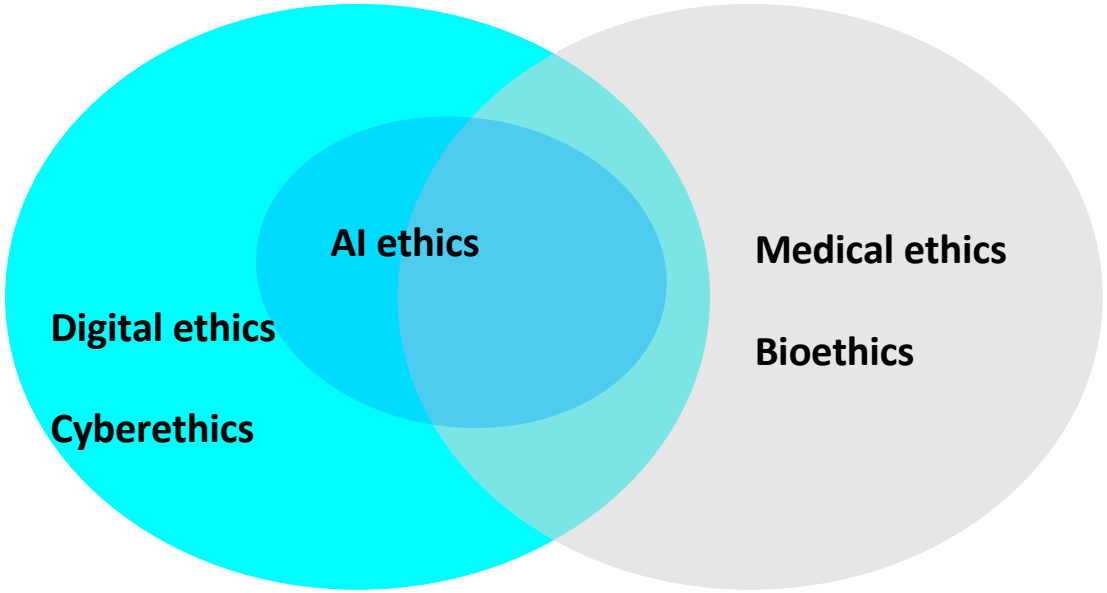
Who decide ?

Digital or Cyber ethics integrates…

- Important and lasting influences of digital technologies on humans
- The fascination provoked by machines that imitate the living
- A radical and universal questioning of the way we consider today human autonomy, social and political relationships
- Contributions of digital technology to the objectives of sustainable development, in particular for education, culture, health, social justice, economy, environment

https://www.ccne-ethique.fr/fr/actualites/manifeste-pour-une-ethique-du-numerique

Cyber and Medical Ethics are Combining



Belmont report (1978)

Menlo report (2012)

Ethics guidelines for trustworthy AI (2019)

Ethically aligned design (2019)

European ethical principles for digital health (2022)

Fairness
Explainability
Reproductibility
Justice
Privacy
respect of persons
Non-maleficence
Loyalty
Dignity
Sustainability
Transparency
Accountability
Autonomy
Beneficence
Public interest

The doctor, the machine and the patient
a combination of intermediations

The machine (using digital technology and in particular machine learning) will enrich and complexify the relationship between the doctor and the patient.

- **doctor <-> machine** intermediation: how to co-construct, e.g. a medical diagnosis? what training?
- **patient <-> machine** intermediation: consent? what autonomy? what automation?
- **doctor <-> patient** intermediation: in a renewed situation to co-discover and co-master, what ethics?

The doctor, the machine and the patient
Renewed questions

- Human oversight or human guarantee?
    - What do we want to guarantee or supervise?
    - Transparency, autonomy (of whom?), reproducibility, responsibility?
- How can regulation, whether European or national, be informed?

Not allowing to benefit from digital capacities would clearly raise ethical questions!

Concluding remarks

Ethics, an imperative of digital humanism

Ethics, especially in the digital world, is also a competitive advantage for companies

Ethics to help taking into full consideration the environmental footprint of digital technology

The combination of biological and digital information processing systems introduces a new complexity at the heart of which ethics plays a crucial role in helping to build regulation

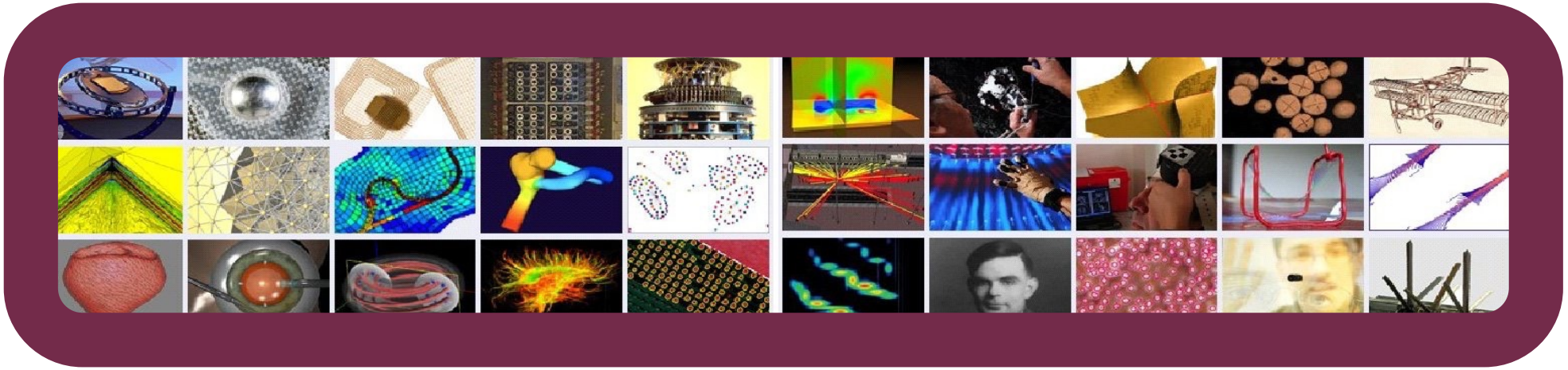
Bioethics and Cyberethics

Ethical issues of digital health require a global approach to the combination of cyberethics and bioethics.

At the French level, moving forward with this objective also means giving ourselves the means to coordinate and combine the reflections of:

— the National Consultative Ethics Committee for Life Sciences and Health

— the National Consultative Ethics Committee for Digital Technology and Artificial Intelligence, that is in the process to be created after its pilot version.



claude.kirchner@inria.fr

Thank you!

https://www.ccne-ethique.fr/fr/actualites/manifeste-pour-une-ethique-du-numerique

proEthics

Participation, community engagement and social value in the light of research ethics – experiences from the proEthics project

29th NEC Forum

Prof. Dr. Dirk Lanzerath
Dr. Lisa Tambornino
European Network of Research Ethics Committees (EUREC)

Guiding Thoughts

- social trust in scientific knowledge and trust in the system of science is indispensable
- science and society are not antagonists: science is a social practice *within* a social practice.

Recent experiences

- successful management of the pandemic only with modern science and research
- but misinterpretation and miscommunication can be a source of fake news and and anti-scientific ideologies
- great challenge to productively interlink science and society
- Society learns from science / science learns from society: PARTICIPATION

New Ethical Requirements: Science within Society

- trust and accountability
- broad responsibility of researchers:
  - „Respect for colleagues, research participants, society, ecosystems, cultural heritage and the environment.“ (ALLEA ECoC, 2017, p. 4)
- stronger normative interaction between science and society

https://allea.org/code-of-conduct/

Responsibility of Ethics Bodies

- Ethics Councils, EGE and DH-BIO as interface between science and politics

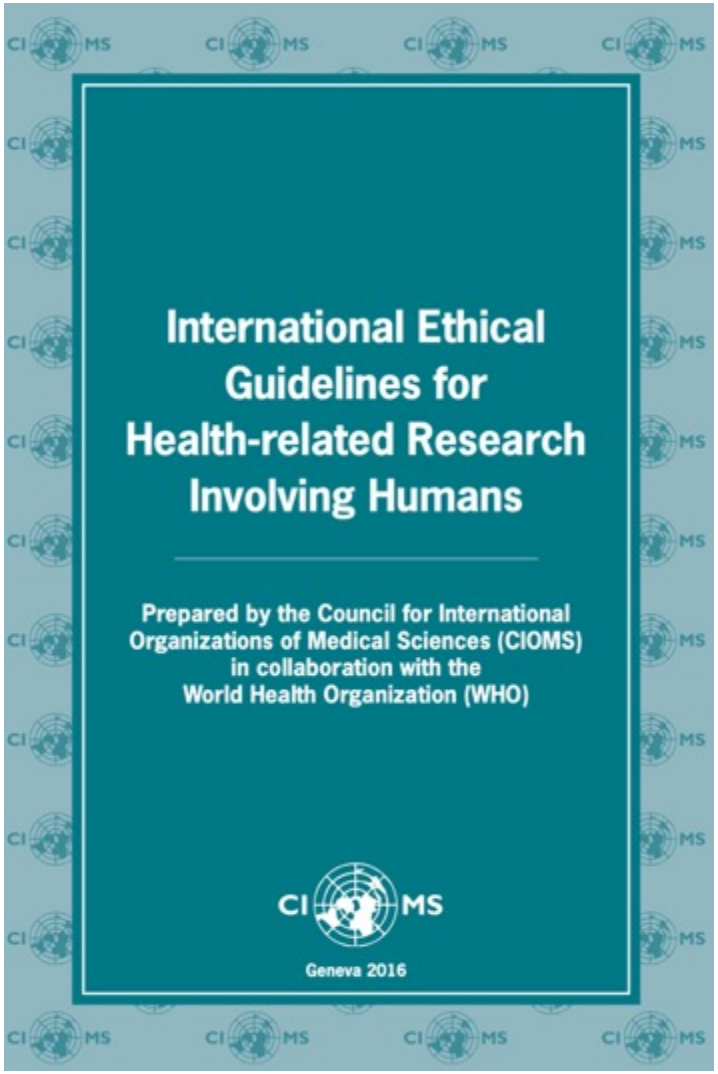
- but also a responsibility of RECs

social value: fundamental justification for undertaking research

“Scientific and social value cannot legitimately subject study participants or host communities to mistreatment, or injustice. (...) Researchers, sponsors, research ethics committees and relevant health authorities, such as regulators and policy-makers, must ensure that a study has sufficient social value to justify its associated risks, costs and burdens.“

(CIOMS, International Ethical Guidelines for Health-related Research Involving Humans Guideline 1, 1-2)

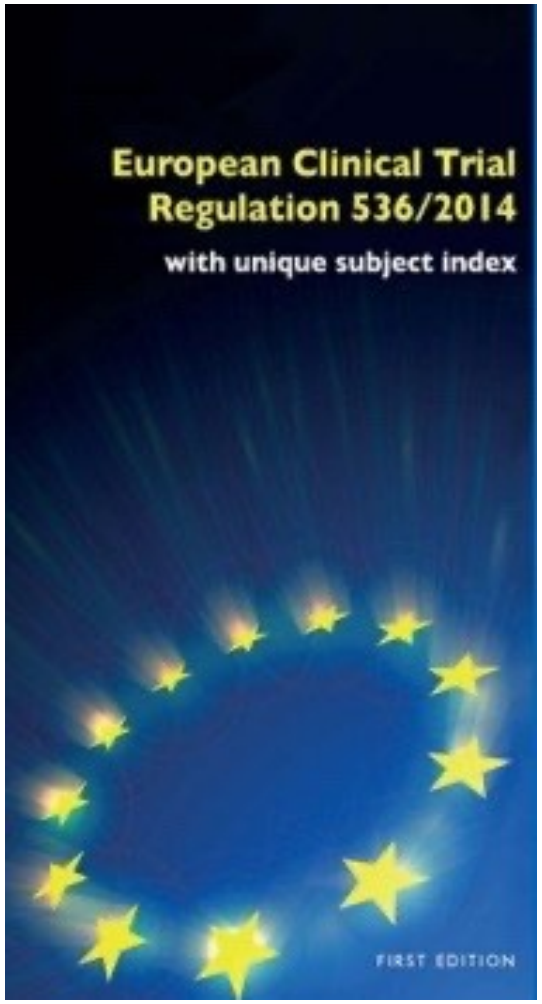
https://cioms.ch/publications/product/international-ethical-guidelines-for-health-related-research-involving-humans/



Participation of Laypersons in RECs

"'Ethics committee' means an independent body established in a Member State in accordance with the law of that Member State and empowered to give opinions for the purposes of this Regulation, taking into account the views of laypersons, in particular patients or patients' organisations;"

(REGULATION (EU) No 536/2014, Art. 2.2 (11))



YPAG

A Young Persons Advisory Group: group composed of children and young people actively involved in research; change from research subjects (participants of research) into partners with researchers (designing the research)

https://eypagnet.eu

eYPAGnet
European Young Persons' Advisory Group Network

European Network
of Research Ethics and Research Integrity

https://eneri.eu

proEthics

Participatory Real Life Experiments in Research And Innovation Funding Organisations on Ethics

pro-ethics.eu

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 872441.

About proEthics

- proEthics is a 4 year H2020 project, running from 2020 to 2023.
- **Key question:** How can citizens and other stakeholders be involved in research and innovation activities, and how can this be done ethically?
- proEthics is testing **new ways of participation** and is developing an **ethics framework** for ethics of participation processes.
- 15 partners from 12 European countries (8 RFOs)
- Coordinator: ZSI

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 872441.

Partner Map

proEthics

Funding Partners

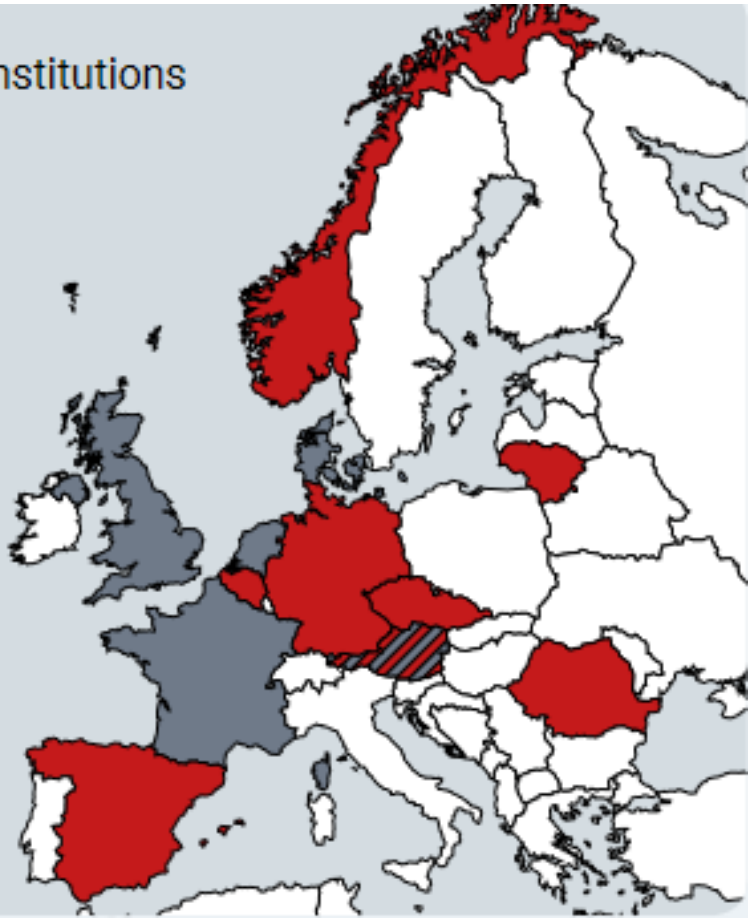
- Austria (FFG)
- Belgium (Innoviris)
- Czech Republik (TACR)
- Germany (VDI/VDE-IT)
- Lithuania (RCL)
- Norway (RCN)
- Romania (UEFISCDI)
- Spain (CDTI)

Technical Experts

- Austria (ZSI)
- Denmark (DBT)
- France (Sciences Po)
- Netherlands (TUD)
- United Kingdom (Nesta)

+ European Institutions

- EUREKA
- EUREC Office



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 872441.

Partners

proEthics

ZSI

Fonden Teknologi Rådet

TU Delft

SciencesPo

Nesta

EUREKA

EUREC Office

Innoviris

The Research Council of Norway

Norges Forskningsrad

CDTI

Centro para el Desarrollo Tecnológico Industrial

Technology Agency of the Czech Republic

Technologická agentura ČR

FFG

Austria Research Promotion Agency

VDI/VDE-IT

VDI/VDE Innovation + Technik

UEFISCDI

Unitatea Executiva pentru

Research Council of Lithuania

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 872441.

Background

proEthics

Research and innovation aim to create new knowledge and technologies that benefit our society.

By including the people affected we can make the research and innovation activities more useful and relevant.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 872441.

Challenges and ethical issues

proEthics

Example: Citizen panel for assessing research projects that create new technologies for home care services

- How do we make sure the panel covers all the different needs of different carers, and the people their care for?
- How to make sure that everyone gets heard equally and that no one is exploited?

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 872441.

Challenges and ethical issues

proEthics

- What kinds of projects should citizens be involved in, at what stages and to what degree?
- How do we make sure participants **know enough** about a project to make decisions about it?
- How to choose the **right participants** to present a target group?
- How to choose the **right process** for participant involvement?
- How to **avoid biases** in citizen selection?
- How do we need to **take care about participants** during participatory involvement?

- How do we ensure to **protect privacy rights** of participants and obtain **informed consent?**
- How can participatory activities be conducted in line with **basic ethical principles and values in research ethics and research integrity** (e.g. respect for autonomy, transparency, trust)?

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 872441.

The proEthics ethics framework

- A **first version** of the ethics framework is online available under pro-ethics.eu => PRO-Ethics outputs
- The ethics framework offers a set of questions and related actions to consider when **designing, implementing and evaluating a participatory process**.
- **Target group:** With the ethics framework proEthics targets **RFOs, ethics bodies** and **others involved in research and innovation activities**
- This first version is meant to be **empirically tested and further improved** over the course of the next 1,5 years.

RFOs AND PARTICIPATION

- RFOs are mainly conducting expert-led processes and do not carry out participatory activities.
- But: RFOs should include citizens and other stakeholders, e.g. in topic identification, programme design and project evaluation.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 872441.

The proEthics ethics framework

- **PART I: General considerations on ethics and participation**
- **PART II: Tools and Guidelines**
  - A. How should a participatory process be designed?
  - B. Which type of activity is targeted by the participatory process?
  - C. Which types of participants are targeted?
  - D. Where are the ethics issues and risks?
  - E. Are selection processes addressing all critical factors?
  - F. Has the implementation deviated from the design?
  - G. What are the outcomes and the added value?

before participation (design phase of the participatory event);

during participation (implementation of the participatory event);

after participation (feedback following the completion of the participatory event).

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The proEthics ethics framework

A) How should a participatory process be generally structured? *[before]* *[during]* *[after]*
▸ ***Action A1: Identify the expected type of contribution and the expected type of input.*** *[before]*
Identify why you are interested in certain types of knowledge and perspectives in the first place. This will allow for the design of more focused discussions and will ensure that the overall intention justifying the need for a participatory process is properly framed and outlined.
▸ ***Action A2: Allow for flexibility in the planning of the participatory process.*** *[before]* *[during]* *[after]*
All stages of R&I processes should be interconnected with the design of the participatory process, anticipating future impacts. Since unexpected nuances and concerns of participants may reveal themselves in the course of the project, flexibility is needed to be considered from the outset, in order to adjust and consider new findings openly. Participatory processes should therefore allocate enough time and resources for their final stages, in order to secure the uptake and incorporation of results and also to secure a meaningful impact. The allocation of resources, time and the selection of participatory methods[21] is intertwined with the extent of flexibility, which should be determined as accurately as possible.
▸ ***Action A3: Enable a feedback loop and dialogue between RFO and R&I projects; as well as between RFO/R&I projects and participants.*** *[before]* *[during]* *[after]*
Feedback from concrete experiences in specific fields can provide useful indicators to evaluate where the focus of participatory processes should be placed and how engagement should be furthered in future activities. Transparency towards participants should be established from the

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 872441.

Next steps to enhance the ethics framework

proEthics

- Existing participatory processes of the 8 RFO partners will be further analysed to improve the ethics framework.
- Three **workshops with ethics and integrity bodies** will be conducted within 2022 in order to find out how the ethics framework can be adjusted to their needs.

proEthics is looking forward to getting feedback to further improve the ethics framework!

pro-ethics.eu => PRO-Ethics outputs

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 872441.

proEthics

Thank you!

proEthics has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 872441.

National Ethics Council and health care democracy/Citizen democracy

Council of Europe perspective and reference work

Laurence LWOFF
Human Rights and Biomedicine Division
Council of Europe
http://www.coe.int/bioethics

Council of Europe




- Intergovernmental organisation established in 1949
- 46 member states
- Role: **strenghthening human rights (ECHR)**, democracy and the rule of law
- **Protecting** human rights in biomedicine **to promote** developments for the benefit of human beings
- Convention on Human Rights and Biomedicine (Oviedo Convention) (1997)

Convention on Human Rights and Biomedicine (1997)

Article 28 – Public Debate

- Requires that:
  - The fundamental questions raised by the developments of biology and medicine are subject of appropriate public discussion in the light, in particular, of relevant medical, social, economic, ethical and legal implications
  - The possible application of those developments is made subject to appropriate consultation

Convention on Human Rights and Biomedicine (1997) Article 28 – Public Debate

- To create greater public awareness
- To ascertain society 's views with regard to problems which concerns its members as a whole
- Choice of procedures remain opened
- Rôle of ethics committee underlined

25 years later

- Public debate / Public dialogue

→ Integral part of new democratic governance frameworks

Why new governance frameworks are necessary

CoE Strategic Action Plan on Human Rights and Technologies in Biomedicine (2020-2025)

→ To optimise chances of stimulating innovation:

- contributing to human flourishing, and
- minimising applications with negative consequences on individuals and society.

Which governance framework?

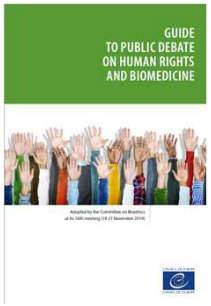
New models of governance

- From managing the risk to managing the process
- To start with values to be protected – Human rights as governance tool
  - Ensuring that human rights considerations taken into account from the earliest stage
- To steer innovation with social goods and values
- Anticipatory and responsible model of governance
  - Public engagement

Public debate – Public dialogue

- Common understanding?
- Genuine deliberation of substantive issues ?

→ Guide to public debate
Key features and examples



- Need for ongoing dialogue between the public, scientists and policy makers so that technological developments are robustly deliberated, democratic and legitimate

- Online seminar 2 March 2021: COVID-19 and public debate - Lessons learned and preparedness (coe.int)

Laurence.lwoff@coe.int

www.coe.int/bioethics

Involuntary psychiatric treatment of patients with mental disorders

29th Meeting of the National Ethics Councils (NEC) Forum
12-13 May 2022, Paris, France
SESSION 3
ETHICS AND MENTAL HEALTH

Marjeta TERČELJ ZORMAN, Vice Chair of the Commission of the Republic of Slovenia for Medical Ethics, University Clinical Centre Ljubljana

Maja RUS MAKOVEC, University Psychiatric Clinic Ljubljana & Medical faculty, University of Ljubljana, Slovenia

1426th meeting Committee on Bioethics (DH-BIO)

At the 1426th meeting DH-BIO on 15 February 2022, a draft Additional Protocol was written to the Convention on Human Rights and Biomedicine concerning the protection of human rights and the dignity of persons with regard to involuntary placement and involuntary treatment within mental healthcare services.

The Protocol pursues its objective in three ways

Firstly, by reaffirming the general rule of free and informed consent of the person concerned to any measure in mental healthcare,

Secondly, by reinforcing the safeguards to ensure that involuntary measures are only used as a last resort,

Thirdly, by ensuring that persons subject to involuntary measures can effectively exercise their rights.

Involuntary psychiatric treatment of patients with mental disorders

It is well known that patients with severe mental disorders are treated differently in each European country.

There are no relevant clinical guidelines in this area.

Why not?

Involuntary psychiatric treatment of patients with mental disorders

- Perhaps because of the different health and legal systems, the different cultural traditions associated with mental health.
- Thus, when researching and introducing clinical guidelines, we are faced with incomparable data.

- Health legislation is unrelated in most European countries. It is even more or less separate for physical-somatic and mental health in all countries, resulting in and maintaining a medically surviving dichotomy between physical and mental health. This situation leads to unequal treatment and discrimination of patients with mental disorders. It deepens the stigma of patients with mental disturbances and psychiatry as a profession.

Involuntary psychiatric treatment of patients with mental disorders

- What does involuntary treatment in psychiatry mean as an ultima ratio measure that is necessary to protect human rights and dignity?

- In which circumstances it does not constitute a prior violation of human rights?

- Whether and in what situation could be too narrow an interpretation of free will and rights in deciding on the compulsory treatment of mental disorders in Draft explanatory report to the **Additional Protocol to the Convention on human rights** and biomedicine concerning the protection of human rights and dignity of persons with regard to involuntary placement and involuntary treatment within mental health care services.

Criteria for involuntary placement and for involuntary treatment

- **Is the principle that a sick person is dangerous for himself and his surroundings enough?**

- We should think much well about the key role in the treatment of this disease, to stop it, to improve it, to slow down the course of the disease itself. Unjustified involuntary treatment is only one side of the violation of the dignity of the psychiatric patient, as the patient's untreated severe mental disorder mostly leads to the complete destruction of social life, which also results in the loss of his human dignity.

Criteria for involuntary placement and for involuntary treatment

- Involuntary treatment of a patient with mental disorders at the beginning of this decision, doubts arise both in the patient‘s legal representative and the psychiatrist.

- How to clarify doubts and maintain the personal integrity and dignity of the patient?

Criteria for involuntary placement and for involuntary treatment

- Engaging in interfering with the rights of involuntary treatment of patients with mental disorders is only one side of the story. The other side, usually overlooked, is dealing with the issue of the rights of untreated patients with mental disorders.

- Namely, we find ourselves in a situation where the patient does not agree to the indicated treatment for some reason and therefore, we are not allowed by law to treat him without his consent. Due to the disease itself, such a patient with mental disorder also has a compromised ability to competently refuse treatment.

Criteria for involuntary placement and for involuntary treatment

Therefore, it is even more important

to have constant dialogues

on professional and ethical dilemmas

with psychiatrists and with ethicists and other different professionals who decide on the involuntary treatment of such patient.

Two presenters?

- Two perspectives in terms of Gregory Bateson’s aphorism that two eyes see better than one
- In our dialogue, we found that mental health professionals in discussions about the ethics of involuntary treatment usually try to convince other subjects that the psychiatrist's decision has a professional justification and is ethical in nature, as it should benefit the patient's health.
- Often other subjects in the debate are not impressed by these explanations
- In interaction we have developed idea that psychiatry could be perceived as more trustworthy in ethical debate with more intense **self-reflection on power and trust**

Two perspectives of mental health care

1

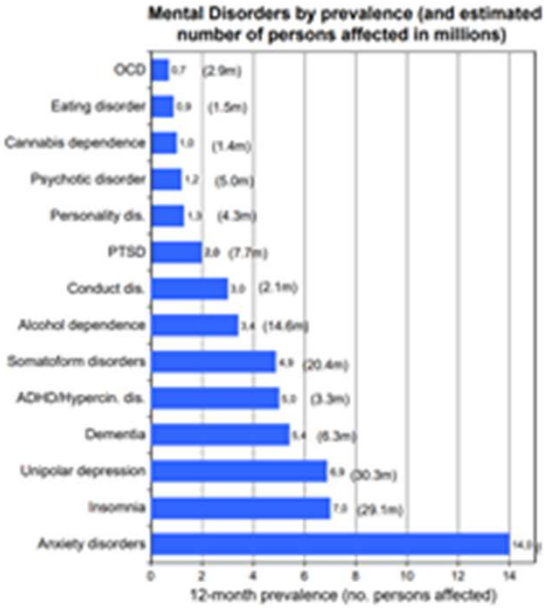
- Mental and substance use disorders as the leading cause of disability worldwide (Whiteford et al, Lancet 2013)

- Worldwide “mental health treatment gap” 70% (Kohn et al, Bull World Health Organ 2004)

- Trials conducted in low- and middle-income countries have demonstrated effectiveness of both psychopharmacological treatment and evidence-based psychotherapies (Mehta et al, Br J Psychiatry 2015)

It is ethically urgent to disminish the obstacles for mental health care by lowering the stigma and by increasing availability of treatment programs

ECNP/EBC Report 2011. The size and burden of mental disorders and other disorders of the brain in Europe 2010



Only minority of patients experience involuntary admission, however

2

Legacy of institutional history of psychiatry contribute to negative perceptions: mental illness treated as a transgression - hospitalizations resembled prison stay (Daverio et al, Riv Psichiatr 2017)

Involuntary admissions are universal experiences in mental health services, but absence of systematic data in this area (Sashidharan et al, Epidemiology and Psychiatric Sciences 2019)

Differences related to legal aspects and not to clinical assessment and kind of treatment (Wasserman et al, European Psychiatry 2020)

Lack of the capacity to act autonomously due to metal disorder could be short-/transient or long-term

- Application of medical ethics to context of endangerment of own life or the lives of others, own health or the health of others or serious property damage to himself or others, due to mental disorder; threats cannot be prevented by other forms of assistance

- Lack of decision-making capacity is generally not a necessary criterion for involuntary psychiatric admission (Sjostrand et al, BMC medical Ethics 2015)

- Conditio sine qua non - the principle of legality as immanent part of ethics regarding involuntary admission

- Enactment of modern mental health legislation in all low- and middle-income countries essential goal (Hanlon et al, International Review of Psychiatry 2010)

Involuntary admission could be perceived as the opposite of the fundamental paradigm of clinical medicine ethics (Varkey, Med Princ Pract 2021)

Beneficence

Nonmaleficence

Autonomy

Justice

Ethical concerns beyond legal implications

A space for different forms of knowledge? - Power dynamics privileges professional authority over that of lived experience (Molas, Dialogue 2016)

- The power asymmetries in mental health services are the reality
- If a space for different forms of knowledge has been created, than we can talk about an asymmetric reciprocity
- This kind of interaction overcome the potential toxicity of power privileges

Advocacy to promote different understandings of mental distress (UN Human Rights Council 2017)

- Advocacy is urgent and basic ethical protection for vulnerable and less powerful ones in asymmetric relations, but it is not neutral or self-reflective

Concerns regarding epistemic injustice in psychiatry: testifying & interpreting

Epistemic injustice is a harm done to a person by

- undermining her capacity to engage in practices as giving knowledge to others
- or making sense of one's experiences (Crichton et al, BJPsych Bulletin 2017)

»Ethically bad affective investment« (Fricker, Power and The Ethics of Knowing 2007)

- negative (often unconscious) stereotypes can be resistant to counter-evidence
- … despite best (conscious) intentions of physicians

Epistemic trust

Epistemic trust

- in the authenticity and personal relevance of interpersonally transmitted knowledge (Fonagy, Campbell, Psychiatr Hung 2017)
- allows the recipient of the information being conveyed to relax their epistemic vigilance
- this relaxation of epistemic vigilance allows us to accept that what we are being told matters to us

- More relaxed epistemic vigilance:
  - Psychiatric professional knowledge regarding capacity to understand & ability to control one's behaviour due to mental disorder could be accepted with greater trust?
  - It could be accepted that autonomy can be restored by treatment? (Matthews, J Appl Philos 2000)

Co-construction of epistemic trust

- Ethical obligations for psychiatric profession:
  - changes in psychiatric training to emphase the psychological aspects of patient care to focus on the existential, ethical, and personal aspects
  - to provide a respectful platform for personal testimony
  - more intense research activity of involuntary interventions considering frequency & the controversial perceptions among patients, other professionals or wider public (Kallert, Current Opinion in Psychiatry 2008)

- WPA 2007 Thematic Conference Coercive treatment in psychiatry was an example of good practice in developing epistemic trust - there was participations of both users and professionals
- Are there ethical obligations to promote epistemic trust for all other subjects in debate?

European Psychiatric Association EPA on compulsory admission

The Ethics Committee of EPA survey on involuntary admission procedures of patients with mental disorders in 40 countries (Wasserman et al, European Psychiatry 2020)

Main issues: Legislation of involuntary admissions - Key actors in procedure - Most common reasons

- Medical model comprises a united view on the diagnostics and treatment
- But it is difficult to regulate procedures for involuntary admission because legal aspects are rooted in national legislations
- Collecting examples of good practices in EU: Committee on Bioethics' Strategic Action Plan on Human Rights and Technologies in Biomedicine 2020-2025 (the Council of Europe) & the Ethics Committee of the EPA

"People working in the field need to be constantly aware about ethical challenges" – **how to do it in reality of every day clinical practice**?

An ethics of care that is informed by a practice of asymmetrical reciprocity

- To overcome worry that asymmetry is based on power positions and differences in epistemic privilege (Molas, Practical Ethics: Issues and Perspectives 2018)

- Training of self-reflexivity as an immanent part of ethical conduct in emergency psychiatry
  - Often high-risk situations for all involved in an acute clinical situation: focus of staff training more on principles for managing violence & aggression and de-escalation (NICE Guideline NG10, 2015)
  - The training of staff working in an urgent psychiatric context can be very distant from existential and narrative themes

- To change the culture of psychiatry - connecting training of emergency psychiatry with self-reflective issues
- Post-interventions of involuntary admission can open space for patients' narrative as part of clinical guidelines

Thank you for your attention