

PID Forum: Understanding AI's ability to transform PID healthcare

27 January 2025

PID FORUM

Understanding AI's ability to transform PID healthcare

AN IPOPI EVENT

Hosted by MEP András Kulja (EPP, Hungary)

27 Jan 2025
16.00 - 18.00
EUROPEAN PARLIAMENT
SPINELLI 5E3



The illustration depicts a network of healthcare professionals and medical technology. A central AI chip icon is connected to various icons representing medicine, research, and digital health. Figures of doctors and nurses are shown interacting with these elements, symbolizing the integration of AI into healthcare.



EVENT PROGRAMME

- 16:00** *Networking coffee*
- 16:30** *Welcome address*
- 16:45** *Setting the scene: AI & PIDs*
- 16:55** *The European perspective on AI*
- 17:15** *Exemplifying AI: Practical Opportunities & challenges for PIDs*
- 17:35** *Open panel discussion*
- 17:50** *Closing statements*



Social media: *@ipoppi_info*

Hashtag:

- *#PIDForum*



Welcome Address

MEP András Kulja
(EPP, Hungary)



Setting the Scene

Martine Pergent

President, IPOPI



Understanding AI's ability to transform PID healthcare Setting the scene

Martine Pergent,
IPOPI President

IPOPI PID Forum

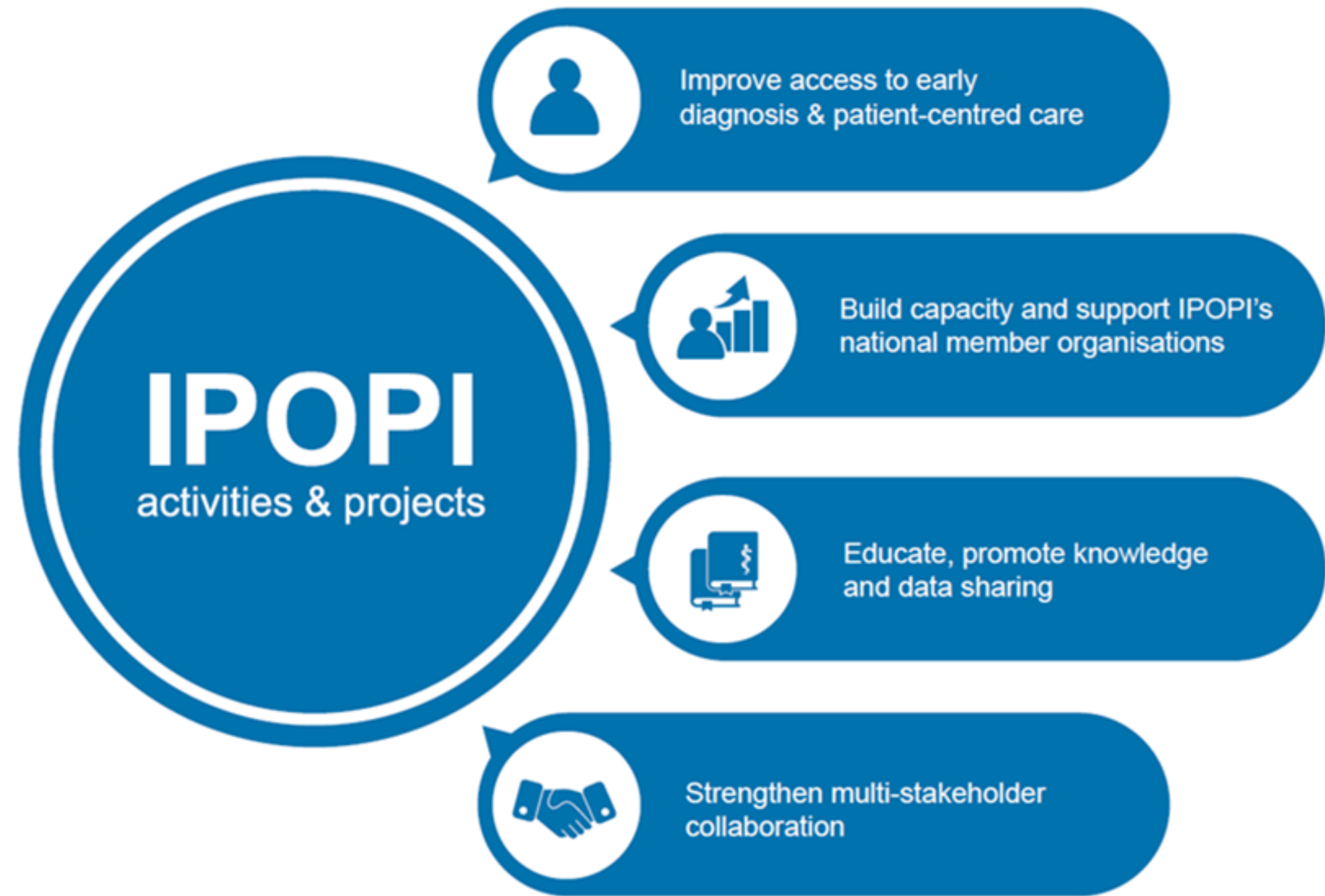
Understanding AI's ability to transform PID healthcare
27 January 2025, European Parliament, Brussels

Introduction to IPOPI

The association of national patient organisations dedicated to improving:

- Awareness
- Access to early diagnosis
- Access to care

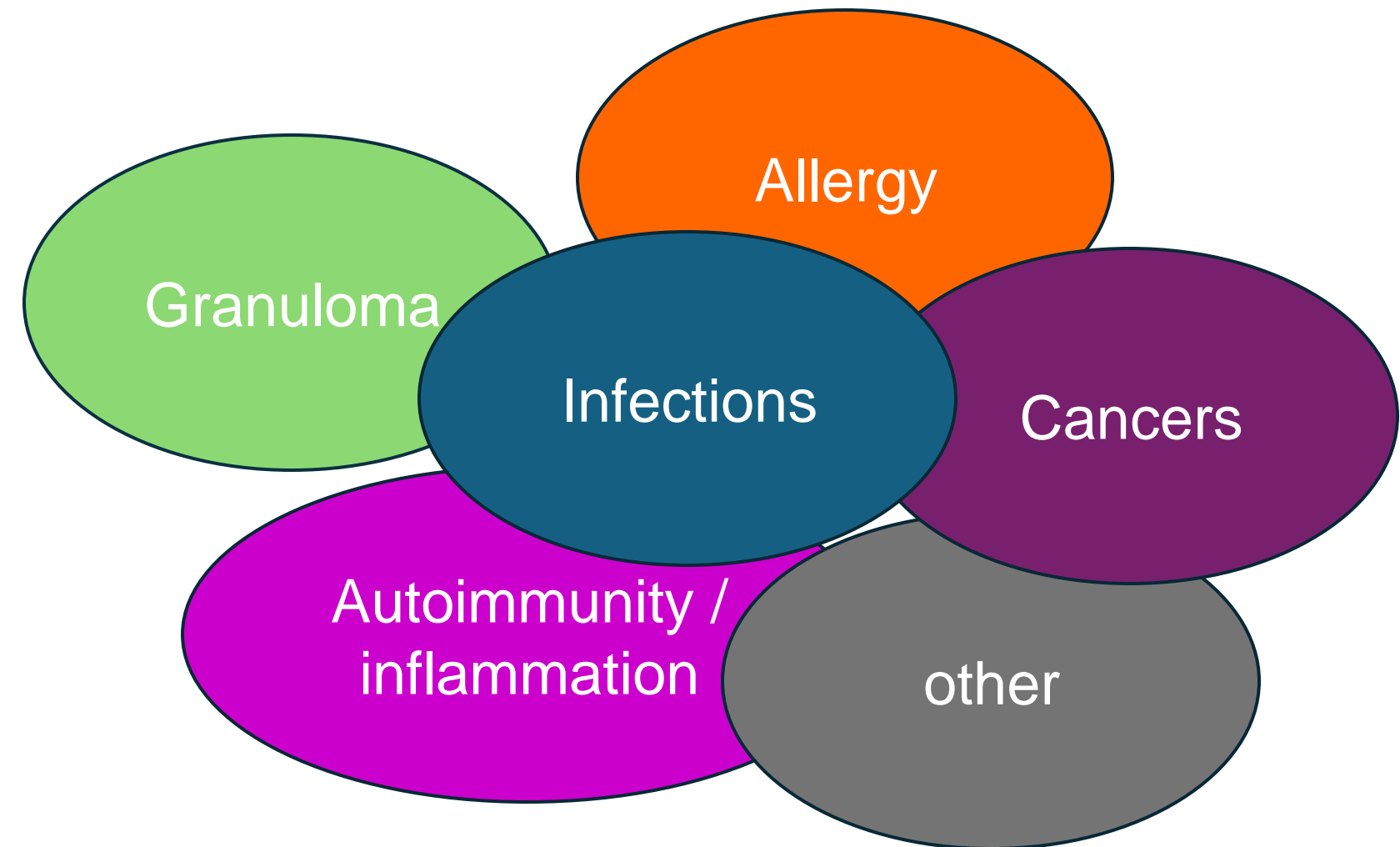
For patients living with primary immunodeficiencies (PIDs) worldwide



What are Primary Immunodeficiencies (PIDs)?

- 550+ different genetic rare and chronic diseases
- The immune system does not work properly or at all
- Affect children and adults
- Clinical presentations are variable
- In many cases, delay in diagnosis
- Different treatment options, depending on the PID

- Patients with PIDs can have:



Introduction

30%

of world's data
volume =
healthcare data

26s

New medical
article

3.900

Publications per
year for a
dermatologist

Imaging data =

90%

of all healthcare data.
Critical for clinical analysis and
medical intervention

3%

of healthcare data
is used to
generate actual
insights

1/1.000.000

Risk of harm when flying

1/300

Risk of harm in healthcare

Global shortage of HC professionals

Today: **7M**

2030: **10M**

WHO expect to grow by 2030

World's population is aging

By 2050

More people aged 60+ than children under 15

In 2000

More people aged 60+ than children under 5



Artificial intelligence

AI: the potential for making healthcare more human

Opportunities
Gains

Threats
Risks

AI to take care of / speed up the routine so that healthcare professionals can deliver the extraordinary

How's AI inspiring when applied to our field?

Diagnosis

Management
of the disease

Predictive,
modelling AI

Research

Data

Genetic
analysis

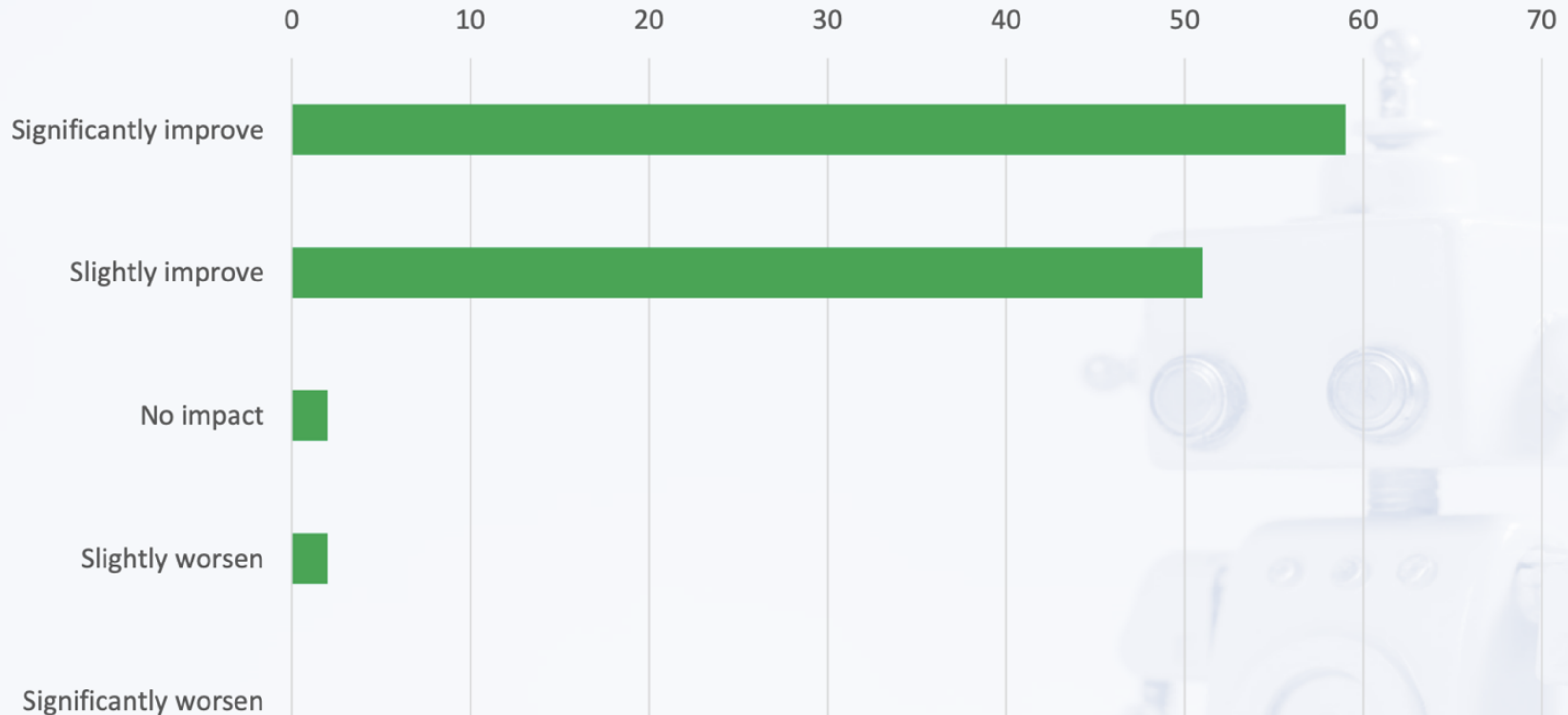
Drug
discovery,
development,
repurposing

Remote
monitoring

Professional
education and
training

Patients' perspectives

To what extent do you believe AI can improve patient outcomes in the coming years?



Survey conducted by EPF in Spring 2023 – 146 respondents – 12 languages - Most represented disease area: cancer. Followed by rare diseases

Patients' perspectives: key challenges

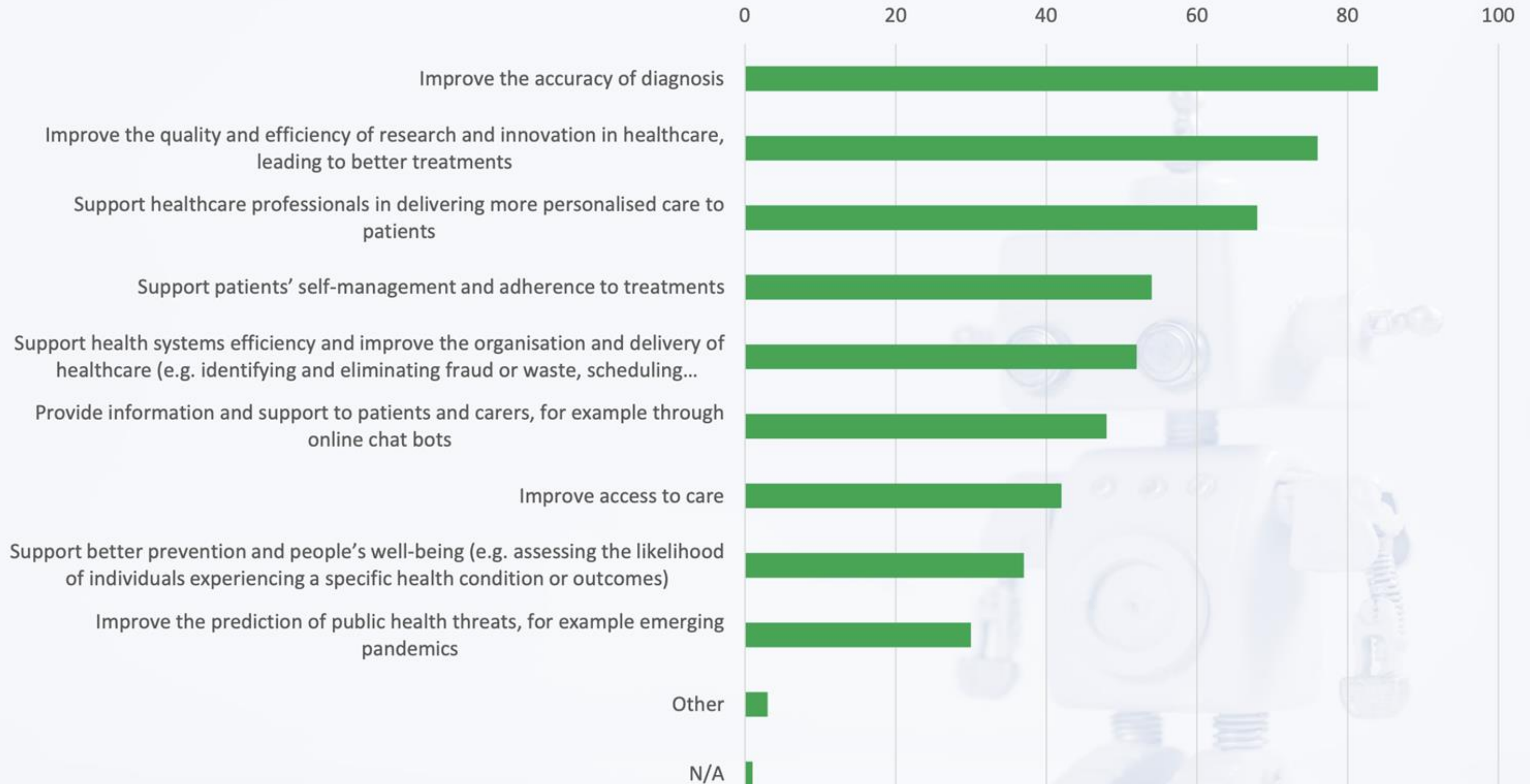
For your organisation, what are the main worries concerning AI in healthcare?



Overall
Sufficient level of trust in AI solutions, BUT strongly dependent on levels of human autonomy (human oversight needed) & respect of ethical consideration

Patients' perspectives: most interesting applications for AI in Health

In your opinion, what are the most interesting applications for AI in health?



Source [EPF](#)

AI regulation: WHO

World Health Organisation – 6 ethical principles for AI in health



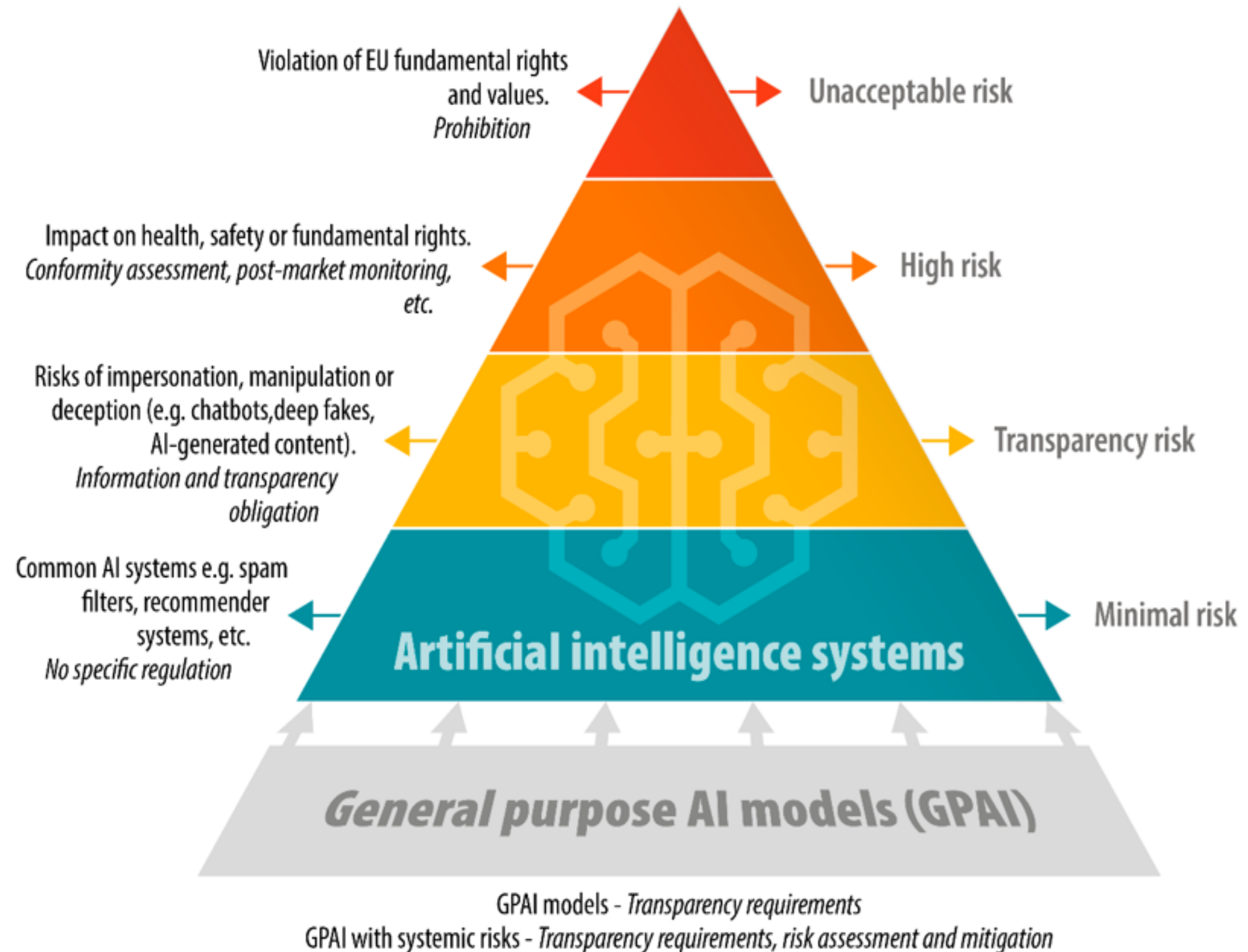
1. Protect autonomy
2. Promote human well-being, safety and public interest
3. Ensure transparency, “explainability” and intelligibility
4. Foster responsibility and accountability
5. Ensure inclusiveness and equity
6. Promote AI that is responsive and sustainable

AI regulation: EU



EU – EU AI Act

Foster trustworthy AI in Europe and beyond, by ensuring that AI systems respect fundamental rights, safety and ethical principles and by addressing risks of very powerful and impactful AI models



U.S. Department of Health and Human Services (HHS)

HHS Artificial Intelligence Strategic Plan

- **Vision:**
to be a global leader in innovating and adopting responsible AI to achieve unparalleled advances in the health and well-being of all Americans.
- **Overarching objective:**
to set in motion a coordinated public-private approach to improving the quality, safety, efficiency, accessibility, equitability, and outcomes in health and human services through the innovative, safe, and responsible use of AI.
- **4 Key goals**



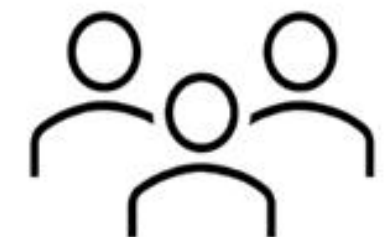
Catalyzing health AI innovation and adoption to unlock new ways to improve people's lives



Promoting trustworthy AI development and ethical and responsible use to avoid potential harm



Democratizing AI technologies and resources to promote access



Cultivating AI-empowered workforces and organization cultures to effectively and safely use AI

AI development in the world

Many countries have plans and/or regulate the use of AI...

- EU countries – most of them have developed comprehensive strategies to advance artificial intelligence research & development
- USA – National AI Initiative, AI in Government Act –HHS strategic plan
- China – New Generation Artificial Intelligence Development Plan
- South Korea - AI National Strategy
- Canada – Artificial Intelligence Action Plan
- Japan – AI Ethics Guidelines
- Singapore – AI for the Public Good
- United Arab Emirates – AI Strategy

...Showing the need for further harmonisation.

Challenges at stake in AI development in health

•Investment

- Significant funding is required to develop AI tools tailored to rare diseases and PIDs.
- International investments, especially in Europe, including joint public-private projects.

•Collaboration

- Need for cross-border collaboration on principles, standards, interoperability, and data sharing

•Regulatory Framework

- Balance smart regulations with competitiveness for Europe.

•Ethics

- Patient Privacy and Data Security
- AI systems may reflect biases in the data used to train them
- Informed Consent Patients on data use

•Technical Challenges

- Reliability: AI tools must ensure prompt, accurate, consistent and interpretable results.
- Data Quality and Integration: Many healthcare systems lack standardised, high-quality data.
- Transparency and Explainability: AI models often operate as "black boxes" >Trust? .

>>> **Harmonisation**



Paving the way for potential solutions

- **Cooperation and harmonisation**
 - Encourage cooperation and synergies to enable economies of scale and facilitate innovation, while harmonizing regulations at EU level
- **Robust governance**
 - Establish frameworks to guide ethical use and ensure accountability
- **Inclusive design**
 - Engage with diverse stakeholders to create systems that adapt to different populations
- **Education and awareness**
 - Equip healthcare professionals & patients with knowledge about AI potential and limitations

Thank you for your attention!

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The European Perspective on AI

Tatjana Evas, Legal and Policy Officer on Artificial Intelligence Regulation and Compliance, DG CNECT A3, European Commission



The European Perspective on AI

Nooshin Amirifar, Account Manager

Electrotechnology – Standardization, CEN & CENELEC



Panel: Exemplifying AI: Practical Opportunities And Challenges For PIDS

- ***Johan Prévot, Executive Director, IPOPI***
- ***Dr. Helen Leavis, Internist and Associate Professor, UMC Utrecht***
- ***Dr. Jacques Rivière, Paediatric Immunologist, Vall d'Hebron University Hospital***
- ***Martine Pergent, President, IPOPI***



Open Floor Discussion



Closing Statement

MEP András Kulja
(EPP, Hungary)

**THANK YOU FOR
ATTENDING**

THE PID FORUM!

Stay tuned for more...

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