EVENT REPORT

PID Forum: Understanding AI's Ability to Transform PID Healthcare

27 January 2025

On 27 January 2025, the International Patient Organisation for Primary Immunodeficiencies (IPOPI) organised a PID Forum titled 'Understanding AI's ability to transform PID healthcare'. The event took place in the European Parliament in Brussels (Belgium) and was hosted by Member of the European Parliament **MEP András Kulja** (EPP, Hungary).

Leire Solis, Health Policy and Advocacy Director of IPOPI, acted as a moderator and opened the event by emphasising the need to discuss AI's impact on healthcare, particularly in the context of the EU AI Act. The Forum explored both opportunities and concerns, such as bias, inequality, and misinformation, and how to ensure vulnerable individuals, like PID patients, can be supported by and protected from AI.

Welcome Address

In his opening statement, **MEP András Kulja** (EPP, Hungary), a medical doctor, highlighted AI's potential to transform care for primary immunodeficiencies (PIDs) and rare disease treatment. He stated that the European Parliament should ensure patient voices are heard and painted a grim picture of current challenges in Hungary such as healthcare shortages, high preventable death rates and low life expectancy.

He described how AI is already revolutionising healthcare, from advanced diagnostics to personalised treatment plans and operational efficiencies in

hospitals. Turning to mental health, Dr Kulja highlighted how AI can also enhance mental health through virtual companions. According to him, AI offers hope, particularly for rare diseases, by enabling faster diagnosis, identifying treatment patterns, and driving new drug discoveries. However, MEP Kulja also warned of the dangers of AI, namely spreading misinformation and amplifying biases. As a doctor who used social media to increase medical literacy and build trust in medical science, he emphasised the need to ensure algorithm transparency.

Setting The Scene

Martine Pergent, President of IPOPI, introduced the audience to IPOPI's work and reviewed the findings of a learning expedition she conducted on the role of AI in healthcare. PIDs recoup over 550 different conditions, she noted, and AI has the potential to achieve a faster and more accurate diagnosis, improve disease management, create predictive modelling, drive new drug discovery or repurposing and enable remote monitoring. She highlighted that only 3% of available healthcare data is being used, a major opportunity for AI-driven advancements. Despite AI's potential, she stressed the need for human oversight, as ethical considerations remain critical and steps need to be taken to ensure AI models are transparent and patient data is secure. She pointed out that greater European and global collaboration was needed to harmonise regulations, enhance interoperability, and encourage smart regulation to allow responsible innovation. Finally, she concluded that cooperation, ethical governance and inclusive design would be key to AI's successful integration into healthcare.

The European Perspective on AI

Martin Ulrich, Senior Policy Officer of the European Commission's AI Office, addressed the AI Act and some of the general misconceptions surrounding the EU's view on AI. He emphasised that the European Commission recognises the immense potential of AI, particularly in healthcare, where it could improve diagnosis, surgery, and drug development, ultimately leading to significant public health benefits.

He explained that the AI Act aimed to mitigate risks without stifling innovation, using a tiered risk-based framework that balanced restrictions with the need for high standards in high-risk applications. Mr Ulrich said that the AI Act sought to create a unified European AI market, avoiding fragmented national regulations that could hinder data-sharing and innovation. He stressed that beyond regulation, the EU remained committed to AI promotion, investment, and collaboration with industry stakeholders. The newly established AI Office would oversee both regulatory and promotional (including investments) efforts, ensuring a balanced approach.

Nooshin Amirifar, Team leader and Account Manager at European Committee for Standardisation (CEN) and the European Committee for Electrotechnical Standardisation (CENELEC), discussed the critical role of creating standards in AI regulation. She explained that CEN and CENELEC are officially tasked by the European Commission to develop European standards across various sectors, among which are AI, cybersecurity and healthcare. These standards ensure a harmonised approach across Europe and often have global ramifications as they are often mimicked by other countries across the globe. She explained that AI standardisation efforts had started years ago with a focus group created to map industry needs and establish a common language for AI developers and users. CEN and CENELEC are collaborating closely with the European Commission to provide a series of standards in response to the requirements of high-risk AI systems of EU AU Act, before they become mandatory in August 2026. She also emphasised the importance of inclusivity by engaging a broad range of stakeholders from industry, research and NGOs.

Panel Discussion – Exemplifying AI: Practical opportunity and challenges for PIDS

Johan Prévot, Executive Director of IPOPI, introduced the RareFind AI project, which will use AI to reduce diagnostic delays for patients with primary immunodeficiencies. He explained that patients with PID often endure a diagnostic odyssey, consulting multiple specialists before receiving a definitive diagnosis. He elaborated on the project's goal to identify previously undiagnosed PID patients by analysing hospital patient data stored across various

hospital departments. The algorithm will help connect the dots between the different data and allow for the identification and referral to an immunologist of individuals at high risk of having PID. One of the main challenges, he noted, is calibrating the sensitivity of the algorithm, given the vast number of symptoms facing PID patients. Additionally, he stated that other challenges include securing agreements with hospitals for data access and ensuring the tool's effectiveness to achieve sound referrals and avoid overwhelming immunologists. The project is currently in a pilot phase in France, with plans to expand to other countries in the future.

Dr Helen Leavis, Internist and Associate Professor at UMC Utrecht, discussed the two projects she is working on: one focused on the early detection of primary antibody deficiencies and the other on secondary healthcare. She explained that the first project, aimed at primary healthcare, uses AI to analyse structural data and blood tests to detect antibody deficiencies across the Netherlands, provide this analysis to General Practitioners and then have patients referred to specialised care. The cost-effective project has now been validated in the Netherlands and the UK. Currently, the focus is on obtaining more funding to refine their model to reduce unnecessary referrals and fully automise it. They are also working on obtaining a CE certification. The second project focuses on secondary healthcare, developing a more advanced model using detailed data from hospitals. Dr Leavis informed the audience that ensuring the data's accuracy – due to hospitals using different systems and storing data in different ways – is the biggest challenge to creating a comprehensive AI system. She also highlighted other challenges such as ethical concerns, reluctance to burden potential patients and the high costs of CE certification.

Dr Jacques Rivière, Paediatric Immunologist at Vall d'Hebron University Hospital in Barcelona, shared insights from an eight-year-long project called the 'PIDCAP project', focused on improving the early detection of PIDs in primary care. His project aims to reduce the diagnostic delay, which can last 4-7 years depending on where you are in Europe, often leading to permanent damage by the time patients are diagnosed. His team developed an algorithm for detecting PIDs in primary care settings. The PIDCAP algorithm

detects around 30% of patients in the hospital cohort, which is considered a good balance between identifying cases and preventing alert fatigue. Additionally, his team is also working on a secondary immune deficiency project to support primary immune deficiency efforts, using data from more common conditions to improve their models. The main challenges the two projects face, he explained, include the poor quality and inconsistency of medical data, as doctors are not trained to input data in a standardised way and most hospitals use different digital infrastructures. He called for more harmonised data and highlighted initiatives like open EHR that could aid in creating better patient archetypes.

Martine Pergent, President of IPOPI, summarised the key takeaways from the panel discussion. Cooperation, she stated, was essential to involve both AI developers, health stakeholders, patient groups and physicians, including those in primary care. She found that access to properly stored and harmonised data was crucial. She concluded that transparency, sensitivity and reliability of algorithms needed to be carefully considered, with an emphasis on developing them collaboratively. Ethical concerns, such as secure data and patient protection, must be balanced with the benefit that comes from AI case uses, in addition to education of healthcare professionals and anxiety from ethical boards towards AI use creating many false positives or negatives. She also explained that education was key to ensuring healthcare professionals are prepared to use and understand the benefits of new tools and innovation in the healthcare sector. Lastly, she highlighted the challenge of financing and the need for more investment.

Open Floor Discussion

The panel discussion was followed by an open floor discussion which saw several patient representatives from across Europe take the floor to highlight their concerns and challenges.

Dr Eva Varga, Vice President of the Hungarian PID patient organisation HOPI, noted the systemic failures in Hungary's healthcare system, particularly the rapid decline in the number of general practitioners. She emphasised the human element in healthcare and the

unique relationship a long-time family doctor has with a patient. While acknowledging AI's speed and ability to process more information, she believes it should be used as a tool to complement, not replace, the human factor.

David Jiménez González, board member of the Spanish PID patient organisation AEDIP, explained that he initially was concerned about the use of AI in healthcare, but his views shifted after learning more about projects like those from Dr Rivière and Dr Leavis. He shared the case of a patient, Daniel, who was diagnosed late, and how AI could have helped avoid complications.

Otilia Stanga, IPOPI board member and chair of the Romanian PID patient organisation ARPID, was very excited about AI's potential in shaping the future of healthcare. However, she highlights that countries like Romania are still struggling with digitalisation, with many hospitals still relying on paper patient charts. She stresses the importance of not letting the gap between countries widen and recognising the different speeds and challenges each country faces.

Helena Hjertonsson and Atakan Yesil, representatives of the pharmaceutical company Takeda, weighed in with their own experience with AI. They shared insights on the company's deployment of AI to improve the identification of viral pathogens in plasma, which traditionally required manual microscopes. This AI-driven process aims to increase accuracy and improve the safety of plasma, showcasing the potential for AI to transform fundamental processes.

Closing Statements

In his closing remarks, **MEP András Kulja** (EPP, Hungary), expressed his gratitude to all participants, colleagues, and guests for their contributions to the discussion on the impact of AI on the PID community. As an MEP and a surgeon, he acknowledged the importance of understanding different layers of various topics. He highlighted the challenges of being a medical doctor with broad responsibilities, especially in a field outside his speciality, and appreciated the opportunity to learn more through the event.