

# Patient View

## Establishing trust in AI methods and promoting understanding

Julien Delaye, EURORDIS



© The HTx Consortium 2019-2023. This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement N° 825162.

# Demystifying AI for Patients and Society

- Important to explain/vulgarise what AI in health is
- AI is often depicted in a threatening or funny way in pop culture, but:
  - AI is not solely Chat GPT
  - AI is not solely an episode of Black Mirror
  - AI is not solely a rendition of Freddy Mercury singing My Heart Will Go On on Tik Tok
  - AI is not solely a tool to create images
  - AI is not solely there to build self-sufficient robots
- In health, AI entails wearables, personalised health apps and assistance, enhanced methods for personalised approaches and optimised drug development, research, surveillance, HTA methods and tools, etc.



# AI and Data Analysis/Evidence Generation

- AI should address and improve data quality and strengthen analysis, while protecting patient confidentiality, safety of storage
- It is vital to know and display whether HTx research has shown that AI can analyse more easily health medical records and provide evidence, in the absence of other real-world data such as well-structured databases or registries
- Strong added value for methods and multiple uses of AI in healthcare



# AI and Prevalence of Diseases

- The use and reliability of AI depends on data and logically increases when more data are available
- The question is, what happens when faced with rare and mostly ultra-rare conditions?
  - E.g. comparison between Diabetes type 1 (8.4 million people worldwide in 2021), Multiple Sclerosis (2.8 million worldwide in 2020) and Fibrodysplasia Ossificans Progressiva (FOP) (1/2.000.000 people worldwide in 2018)
- If data is scarce, could we still foresee the use of AI one way or another?



# AI Technology Errors vs Human Errors

- Is there research / knowledge on how society in general and patients in particular react differently when an error is made by a human versus an AI technology?
  - E.g. Shared-decision-making or predictive tools based on AI: if the method is not correct, and a decision is made that can harm the patient, then the person in question might protest more than if the decision would have been made by a human based on his/her own medical knowledge without AI.
- [EPF](#) states that AI tools should only be designed to support and complement human skills, and never assume decision-making powers.



# AI and Governance

- AI results can be provided by industry, academia, health technology assessment bodies, regulatory authorities, payers and commissioning authorities. None of them are really neutral.
- When end users, patients in particular, have doubt on results stemming from AI analysis, where can they ask how reliable the analysis was? Which scientific authority plays the role of neutral, independent, objective referee who can assess the adequacy of the method used?
- Transparency and accountability are also key elements in ensuring that patients accept and trust AI methods and solutions



# Conclusion

- Great potential benefits thanks to AI in healthcare (from diagnosis, outcome prediction, to quality and efficiency of research and innovation, surveillance, and HTA)
- But important gaps seem to remain or at least remain unclear and should be addressed
- Demystifying = Building trust
- It is possible that we are only at the very beginning of what AI could do but an ethical and fair approach is necessary, as well as education, trainings and digital literacy, and solid governance
- Patient toolkit on the HTx website







## HTx Patient Toolbox

### Facing challenges in HTA

Policies and Real-World Data (RWD)

### Choosing the best treatment for you

Developing prediction models

### Using the right PROMs for you

Using the PROMs app

Using the PROMs SELECT app



© The HTx Consortium 2019-2023. This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement N° 825162.



Thank you!

Julien.delaye@Eurordis.org



© The HTx Consortium 2019-2023. This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement N° 825162.