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European ME Alliance Statement
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Agenda Item 10: Roadmap for action on artificial intelligence in health in the WHO European Region 2026-2033

Honourable Chair, distinguished delegates,

For people living with Myalgic Encephalomyelitis (ME), sometimes referred to as ME/CFS, this roadmap provides an important test of whether AI will reduce health inequalities or risk perpetuating them.

People with ME have experienced decades of under-recognition, diagnostic delay, inadequate research and inappropriate or harmful approaches to care.

An AI algorithm based on incorrect data and biases can therefore make an invisible patient even more invisible.

For this reason, the European ME Alliance urges **WHO and Member States to ensure that four essential safeguards are effectively implemented** within the roadmap, particularly for people with complex and historically under-recognised conditions.

First, data equity. Data gaps, under-representation and bias must be actively identified and addressed for conditions such as ME, with safeguards to prevent historical diagnostic errors and inappropriate care practices from being reproduced in AI systems.

Second, patient participation. People living with these conditions must be meaningfully involved in the design, development, validation and evaluation of AI systems that may affect their care.

Third, human rights and human oversight. AI must support, not replace, independent clinical judgement. No person should be denied appropriate assessment, treatment or care solely because an algorithm fails to recognise a complex or poorly understood condition.

Fourth, transparency and accountability. Patients must be informed when AI is used in decisions about their care and have access to understandable explanations, effective mechanisms to challenge decisions, and meaningful human review.

We are asking WHO and Member States to ensure that innovation does not reproduce yesterday's inequalities with tomorrow's technology.

If AI is to serve everyone, it must also serve those whom health systems have historically failed to see, including people with ME.

Thank you.

European ME Alliance website: https://www.europeanmealliance.org/emea-news-whoe-RCP76.shtml