MAINTAINING HIGH TOUCH IN A HIGH-TECH HEALTH FUTURE: Ethical and societal issues in multi-omics and digital health for end-of-life care in people with neurological conditions

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TRANSLATION AND IMPLEMENTATION

• Clinical utility and impact on care provided, especially on advance care planning and access to EoL resources
• Prognostic accuracy and effect on disease outlook
• Evidence (sample size and study design) needed before implementation in hospital and community settings
• Intrusiveness, privacy, and security concerns
• Communication of findings to the person and caregivers

EQUITY, DIVERSITY, AND INCLUSION

• Motivations for and drivers of technology development
• Gender, racial/ethnic, and socio-economic diversity of sample sources and study participants
• Integration of these modalities in diverse settings, such as rural areas and under-resourced hospitals

IMPACT ON END-OF-LIFE CARE

• Role of the physician in interpreting findings
• Responsibilities of family and caregivers in monitoring health status and providing care
• High-tech technologies may impact the high-touch and warmth provided in end-of-life care
• Excessive quantification (measuring well vs living well)

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