

Participatory AI in Endocrinology: Supporting Shared Decision-Making Through Multimodal Sensing

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Summary: Endocrine disorders require continuous interpretation of physiological, behavioral, and biopsychosocial information. We present a human centered multimodal sensing framework developed at Adhera Health to better understand the needs of people living with chronic conditions including obesity, diabetes, and growth disorders. The framework integrates wearable derived signals, patient reported outcomes, behavioral interaction patterns, and patient generated language to support contextualized care and shared decision making between patients, caregivers, and clinicians. Combining approaches from Artificial Intelligence and Human Computer Interaction, this work establishes the foundation for the ENDOTRAIN project on multimodal AI systems for adrenal insufficiency management in the context of the PhD project DC7.

Keywords: multimodal sensing, biopsychosocial data, endocrine disorders, human centered AI, shared decision making

Background

Endocrine disorders such as obesity, diabetes, growth disorders, and adrenal disorders require continuous longitudinal management involving heterogeneous physiological and contextual information. While wearable and mobile sensing technologies have significantly expanded the availability of patient-generated health data, many systems remain limited in their ability to integrate psychosocial context, behavioral patterns, and psychosocial data into clinically meaningful use cases, including also the shared decision making between patients and clinicians in the context of self-management and patient education. Chronic endocrine conditions are strongly influenced by stress, symptom perception, caregiver dynamics, treatment burden, and lifestyle adaptation, motivating biopsychosocial approaches to digital health solutions. This is particularly evident in adrenal disorders where the hormone of cortisol is also affected by aspects such as stress, sleep and other factors.

Adhera Health Platform

The initiative will leverage the Adhera Caring platform, a digital health platform designed to support the creation of longitudinal, multimodal cohorts in chronic conditions through continuous patient engagement and real-world data capture. The platform combines longitudinal real-world data collection capabilities with participant engagement and self-management support functionalities that facilitate continuous follow-up and contextual understanding of the treatment experience in real-world settings. The platform

supports the collection of active and passive patient-generated health data, patient-reported outcomes, behavioral and psychosocial measures, treatment experience data, engagement metrics, and contextual family-level information over time.

Unlike traditional patient-centric approaches, the Adhera Caring platform incorporates a family-centered framework that enables the capture of household routines, family support dynamics, caregiver perspectives, and shared lifestyle factors that may influence treatment persistence and long-term obesity management. This approach is particularly relevant in obesity and obesity-related comorbidities, where health behaviors and treatment experiences are often shaped within the family environment.

The Adhera Caring platform has been successfully deployed across multiple chronic conditions, including type 1 diabetes [1], type 2 diabetes [2], growth hormone disorders [3,4], and obesity [5], and is currently being expanded to additional therapeutic areas and chronic disease populations.

Open Research Challenges

Current approaches in endocrine digital health increasingly rely on multimodal data combining wearable derived physiological time series, structured clinical variables, patient reported outcomes, behavioral interaction patterns, and biopsychosocial dimensions relevant to chronic disease management. However, major research gaps remain regarding how Artificial Intelligence systems and Digital Twin approaches can

transform heterogeneous multimodal data into representations that are clinically meaningful, trusted, and useful for both patients and clinicians in the context of daily life with chronic conditions.

Existing AI driven approaches often focus on prediction accuracy while providing limited understanding of how biopsychosocial context, lived experience, emotional burden, treatment routines, and family dynamics influence self management and clinical decision making. In endocrine disorders such as adrenal insufficiency, clinically relevant events are strongly affected by stress, behavioral adaptation, symptom interpretation, and contextual factors that are difficult to capture through isolated physiological measurements alone.

Another important challenge relates to trust, explainability, and usability of AI supported Digital Twin systems. Current approaches often conceptualize trust as an individual user attribute, while chronic disease management is inherently collaborative and involves multiple stakeholders including patients, caregivers, clinicians, and increasingly AI systems and AI Agents. There is limited knowledge regarding how trust should be managed when AI generated outputs are interpreted differently by different actors. For example, an AI recommendation may be trusted by clinicians but not by patients, particularly when the recommendation affects daily life, self-management routines, emotional wellbeing, or lifestyle adaptations. In such contexts, shared decision making becomes critical, requiring AI systems that not only provide technically accurate outputs, but also support negotiation, communication, contextualization, and alignment between stakeholders.

These challenges introduce important opportunities at the intersection of Artificial Intelligence, Human Computer Interaction, and Computer Supported Cooperative Work. Understanding how humans interact, negotiate, and build trust with AI mediated representations remains an open research question, particularly in chronic endocrine care where decision making is continuous, longitudinal, and highly contextual.

Expected Results in Endotrain

Prior deployments of multimodal digital health interventions at Adhera Health in obesity, diabetes, and growth disorders demonstrated the feasibility of integrating physiological, behavioral, and biopsychosocial information into longitudinal endocrine care pathways. Participatory studies highlighted the relevance of contextual factors including emotional burden, treatment routines, family dynamics, symptom interpretation, and

behavioral adaptation for understanding the needs of people living with chronic conditions. Building on this foundation, the Adhera Health DC7 subproject within ENDOTRAIN is expected to contribute to the development and evaluation of multimodal Artificial Intelligence systems capable of integrating wearable derived physiological time series, structured clinical data, patient reported outcomes, biopsychosocial measures, and patient generated natural language reports in adrenal insufficiency. The project will explore multimodal fusion strategies for combining heterogeneous data modalities into contextualized patient representations supporting personalized care and shared decision making between patients, caregivers, and clinicians. The DC7 project will also contribute Human Computer Interaction methodologies for transforming multimodal biopsychosocial data into interpretable visual and language-based representations that facilitate shared decision making and improve communication around complex endocrine conditions.

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