DIGITAL NETWORKING FOR ACQUIRED HEMOPHILIA A: A REGION-WIDE CARE PATHWAY FROM DIAGNOSIS TO FOLLOW-UP

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Background and Aims. Acquired Hemophilia A (AHA) is a rare, potentially life-threatening bleeding disorder caused by autoantibodies against factor VIII. It mainly affects older adults and is often associated with delayed diagnosis and fragmented care, particularly outside expert centers. The aim of this project was to develop a region-wide digital care pathway connecting peripheral services with the Regional Reference Hemophilia Center of the Policlinico Universitario Paolo Giaccone in Palermo, to accelerate diagnosis, support treatment decisions, and improve follow-up of patients with AHA.

Materials and Methods. A secure digital health platform was developed to link emergency departments, hematology units, laboratories, community pharmacies, and general practitioners with the reference center. The platform supports rapid teleconsultations for suspected AHA, centralized interpretation of coagulation tests, including FVIII activity and inhibitor evaluation, and shared decision-making on haemostatic and immunosuppressive treatment. During follow-up, clinicians can update symptoms, bleeding events, therapies, and laboratory results in real time, allowing specialists to remotely adjust treatment and monitor associated conditions. Access is role-based and data protection measures comply with privacy requirements.

Results. Development began on 6 December 2023 and the platform became fully operational across the region in February 2025. Four physicians from four community hospitals were onboarded, including two from emergency departments and two from hematology units. During the first six months, twelve expert consultations were requested for suspected AHA. Two confirmed AHA patients were managed end-to-end through the shared pathway, one from the emergency setting and one from a hematology unit. After discharge, general practitioners entered regular clinical and laboratory updates, reviewed by the reference center. In both cases, treatment was tailored remotely and complete remission was achieved. Structured follow-up also enabled timely surveillance and led to the diagnosis of an early-stage cancer in one patient.

Conclusions. A digitally connected care network can bring rare-disease expertise closer to patients, even when specialist knowledge is centralized. In AHA, this model may shorten time to diagnosis, align therapeutic decisions, and ensure safe monitoring after discharge, including surveillance for associated malignancy. This approach could be extended to other rare diseases, improving equity of access, continuity of care, and real-world evidence collection within the Italian National Health System.