

## CONFERENCE ABSTRACT

### An integrated model for Haemophilia care nationally

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Haemophilia and von Willebrands disease are inherited bleeding disorders which affect 2,111 people in Ireland. Haemophilia care is highly organised and integrated with formal collaboration between the doctors and health care teams, the patient organisation and the HSE. Haemophilia care is centred around three comprehensive care centres who provide the full range of multidisciplinary services required. These centres are certified under a European certification process. There are also secondary centres who provide a less comprehensive service. There is a national register of all patients with these inherited bleeding disorders and agreed national treatment protocols. There is a statutory National Haemophilia Council which recommends policy and priorities to the Department of Health and the HSE. The NHC includes the directors of the 3 comprehensive centres, a director of a secondary centre, a specialist nurse, a dentist, the Irish Haemophilia Society, the HSE and the Department of Health. The Council monitors the development and implementation of care nationally and sets out the priorities for development of services on a national basis. The Council organises audits of the centres on a regular basis by an external peer team. These audits over the past nine years have resulted in the identification of deficiencies and measurable improvement in the infrastructure and service to patients. Use of technology to monitor treatment is very advanced and includes an electronic patient record system, a smartphone app to monitor use of coagulation factor concentrates in the home by patients, an alert system for severe bleeding episodes and the current development of a patient portal under the HSE Lighthouse project. The system also includes tracking and tracing of every vial of medication in each hospital and patients home to allow for optimal clinical management, ability to recall products if required on safety grounds and allow for rotation of stock between hospitals to minimise waste. The patient population are very well informed and understand the requirement to attend expert comprehensive centres regularly and for any surgical procedure. A high level of ongoing collaboration exists between the patient organisation and the clinical teams at the centres both collectively through the Council and individually. Education of patients on home infusion, new products and treatment developments is jointly undertaken by the clinical teams and the Society. New technological innovations always include a patient panel to ensure the practicality of solutions being proposed.

Gannon; Patient perspectives on functional recovery and physical activity following curative treatment for oesophageal cancer.

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**Keywords:** haemophilia; comprehensive care; partnership; technology

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