

**PROJECT NAME:**

Management of patients with Neuroendocrine Tumours (NETs) in Wales with care closer to home utilising patient reported outcomes to facilitate the appropriate delivery of care.

**JOINT WORKING PROJECT SUMMARY:**

The aim of this project is to establish and implement a patient reported outcome measure (PROM) online solution for patients with NETs which is an all Wales service, based on the functional and technical requirements set out in Cardiff and Vale University Health Board (CAVUHB) PROMs specification.

The twenty-month project will have six phases:

- A baseline service evaluation of current NET patient care for patients at CAVUHB in South Wales.
- Deployment of an online PROMS solution based on national standards.
- Implementation of an online PROMs solution enabling patient activation and self-management.
- Integration into CAVUHB's internal applications.
- Full integration to patient management.
- Review the pathway and outcomes, repeat service evaluation and submit a sustainable service business case together with final report.

**Anticipated benefits to the NHS:**

- Aligns with NHS vision of providing care closer to home and also with national NHS policy and the Value Based Healthcare scheme;
- Less reliance by patients on hospital care thereby releasing capacity and contributing to a greener environment;
- This project will promote integrated access between patient reported outcomes and clinical data enabling more efficient provision of care;
- Reduction in our carbon footprint as patients can be managed closer to home;
- Improves the digital maturity of CAVUHB.

**Anticipated benefits to patients:**

- Clinical staff and patients will be able to identify physical and mental wellbeing needs to provide focused intervention, treating symptoms and promoting well-being earlier leading to more effective management and improved quality of life;
- With more patient engagement and integrated access with remote consultations, patients will be able to self-manage some of their symptoms, nutrition and well-being, and prevention of need for emergency care;
- With care closer to the home, patients will have less time, cost and carbon spent on travel with healthcare alongside a patient and carer financial cost-saving;
- Patients' confidence in the service will improve with a visibly modernised service over a devolved nation;
- Promotes patient self-management and further encourages independent management, facilitated by a user-friendly interface;
- Once national infrastructure is in place, patient PROMs can be viewed by any clinician in any Health Board in Wales (including primary care) that a patient attends; the interim measure is the patient (where digitally enabled) will be able to show their PROM record to other University Health Board until fully integrated architecture is achieved.

**Benefits to Ipsen:**

- Opportunity to work collaboratively with a European NET Centre of Excellence specialist centre and also support country-wide project;
- Patients may receive appropriate Ipsen products where clinically indicated in accordance with local and national clinical guidelines;
- Collaborating on a significant service development project, aligning to Ipsen's strategic pillar of becoming a partner;
- Demonstrates Ipsen's commitment to oncology;
- Gain further insight into self-management and care at home and align with strategic objectives. And explore the opportunity to share outcomes further in NHS;
- Ability for Ipsen to share learnings and outputs of this project with other centres to improve patient outcomes and patient activation.

**PROJECT START DATE & DURATION: September 2022 (27 months).**

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