**Neuroendocrine Cancer UK: Patient Survey re PERT: opened May – July 2024**

Total responses = 148 within 1 month: 100% completion rate (all questions answered)

From all regions of UK :84% England / 8% Scotland / 5% Wales / 3% Northern Ireland

**Type of neuroendocrine cancer (by primary site):**

44% Pancreatic / Duodenal: 38% Small Bowel: 4% Lung: 3% CUP (unknown primary): 11% Other

**Pre-shortage usual PERT supply:**

85% take Creon 25,000iu / 9% Nutrizym 22 / 3% Creon 10,000iu / 3% other preparation

35% take up to 10 capsules/day: 45% up to 20/day: 15% up to 40/day:

5% take less than 10 or more than 40

For 83% GP prescribes and 85% obtain supply from local pharmacy

62% usually receive 1 month supply at a time: 27% usually receive 2-3 months’

Stock usually held at home before re-filling prescription:

8% < 1wk / 50% 1-2 weeks / 34% 1 month / 8% > 1 month

**Over last 3-6 months -** **have you experienced any difficulties with your USUAL PERT prescription / supply (brand and dose)?**

No = 9.5% / Yes - once = 23% / **Yes - more than once = 67.5%**

**Reason**: 3% no prescription / 23% restricted stock / **74% told no stock**

**Alternatives:** 61% offered an alternative BUT ~50% of those had difficulty obtaining it

**38% have run out completely on 1 or more occasion.**

**Have you ever reduced your USUAL dosage to avoid running out?** 34% No / **66% Yes**

* I have tried to reduce dose ... but found steattorhea returned
* Not yet however I am considering reducing my food intake and the dose to try and see if I can manage this
* Reduce or miss days when I know I'm at home..
* I have no pancreas . . .I can’t

**Have you ever gone without eating or reduced your food intake?** 58% No / **42% Yes**

* I'm now regularly missing meals and reducing amounts
* Altered diet to further reduce any fat - but struggling to maintain weight
* Not yet but I am now at this stage because if I can’t get any I’ll have to
* Avoidance of food is the only manageable way to continue
* I have reduced meal sizes and stopped taking Creon outside of main meals
* **20% have gone without eating on more than 1 occasion**

**Has this affected your well-being in any way?** 34% No / **65.5% Yes**

* Physically: increased symptoms – due to missed or reduced dose. Weight loss.
* Mentally: increased anxiety / stress – a) supply / filling prescription

 b) impact on health and daily life