

PERT shortage update and Q&A

29th April 2025





12.00 – 1.30pm

Via Zoom Webinar

#PCUKStudyDay

Key findings from charity patient surveys

Charity patient survey findings

				
Difficulty getting PERT prescriptions on more than one occasion	82%	68%	89%	n/a
Altering diet and/or dosage of PERT	80%	66% reduced dosage 42% stopped/reduced eating	38% (27% went without PERT)	37% (8% went without PERT)
Increased stress/anxiety and/or affected their wellbeing	51%	66%	87%	80%
Issues with symptom management	80% said symptom management was more difficult. Common symptom: bloating, wind, diarrhoea. 27% of people experienced weight loss.	n/a	Common symptoms: diarrhoea and bloating. 52% reduced quality of life. 23% poor control of their diabetes.	Nearly 40% significant or severe impact on their health. 55% experienced digestive issues. 20% losing weight.

Comments

"It's bad enough knowing you are dying. **I don't need to be stressing and ringing around** for what should be readily available. "

"One pharmacy gave me 100 and told me to come back in a month to get another 100. **I need the best part of 100 a week to control symptoms.**"

"I'm trying not to eat certain meals or reduce my fat content to save Creon. **But I keep being told I need to eat well so I can have my (cancer) treatment** ...what do I do?"

"I am **missing out on having lunch**, but being diabetic and having no pancreas, this is causing multiple problems."

"If I can't get my Creon **I can't work, and I'll lose my job and my house.**"