Resource impact summary report

Resource impact
Published: 22 May 2024

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NICE has recommended setmelanotide as an option for treating obesity and hyperphagia in genetically confirmed Bardet-Biedl syndrome (BBS) in people aged 6 years and over, only if they are aged between 6 and 17 years when treatment starts. These people can continue having setmelanotide as adults until they need to stop. Setmelanotide is only recommended if the company provides it according to the commercial arrangement.

The eligible population for setmelanotide is around 150 per year in 2024/25 rising to around 160 per year in 2028/29 after adjusting for expected population growth.

Around 15% of people's disease will not respond to treatment with setmelanotide and they will stop treatment after 14 weeks and a further 1% will discontinue treatment each year.

By year 5, around 5 people per year will begin treatment with setmelanotide and around 140 people will be continuing treatment from previous years once the market share of setmelanotide reaches 90% as shown in table 1.

Table 1 new, continuing, and total number treated with setmelanotide by year

	2024/25	2025/26	2026/27	2027/28	2028/29
Eligible population for setmelanotide	176	178	179	181	183
Market share for setmelanotide	33%	66%	90%	90%	90%
People starting treatment with setmelanotide	58	68	55	11	5
People who continue treatment beyond 14 weeks (responders)	50	58	47	9	4
People whose symptoms do not respond to setmelanotide and stop treatment after 14 weeks.	8	10	8	2	1
People continuing treatment with setmelanotide	0	49	106	152	160
Total people treated with setmelanotide	58	117	161	163	165

Setmelanotide is self-administered by subcutaneous injection and is assumed in the resource impact template to be given as 2.5 mg daily following a 2-week period of dose titration where the dose is given as 1 mg daily for a week then 2 mg daily for a week.

There is a simple discount patient access scheme for setmelanotide. NHS organisations can get details on the Commercial Access and Pricing (CAP) Portal.

Services for people with BBS are commissioned by NHS England. Providers are specialised Bardet-Biedl clinics.

The payment mechanism for the technology is determined by the responsible commissioner and depends on the technology being classified as high cost.