Exclusive: NHS England delays treatment choices after legal threat

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NHS England has cancelled key meetings at which it was due to decide whether to fund a series of treatments for serious conditions following a threat of judicial review, HSJ has learned.

The organisation’s first specialised services “prioritisation round” meetings were due to take place tomorrow and on Thursday, at which its clinical priorities advisory group was due to consider cases for funding drugs and treatments previously put forward by clinicians on its specialised commissioning clinical reference groups.

However, CPAG members were informed on Friday last week that the “prioritisation round” meetings had been postponed.

HSJ has seen a solicitor’s letter which was sent to NHS England challenging a scorecard it was proposing to use at the meetings to compare the merits of different treatments. The letter threatened to take a judicial review if the meetings went ahead. NHS England has confirmed the reason for the cancellation and delay was doubt about its “approach to prioritisation and specialised commissioning”.

Known as a “letter before action”, sent by legal firm Leigh Day and Co, it argued its client and others with rare diseases would be disadvantaged by the application of the scorecard.

HSJ understands the scorecard gives more weight to treatments that can benefit the most patients for the smallest unit cost, and also scores treatments based on the strength of the available evidence.

However, these criteria could disadvantage patients with rare diseases where, due to small patient populations, it is sometimes not possible to conduct randomised control trials, and companies tend to charge more for treatments to ensure they get a return on their investment.

The letter for action was sent on behalf of a 10-year-old boy who suffers from Morquio (or MPS IVA), an ultra rare disease affecting just 88 children and young adults in England at present. The condition means the boy has grown to just over a metre in height but his internal organs have continued to grow at a normal rate causing complications which required surgery when he was a
young child. He has been treated with an enzyme replacement therapy elosulfase alfa (Vimizim) on a clinical trial since 2009. The drug was due to be considered by CPAG this week.

However, his parents and the MPS Society supporting them feared the application of the scorecard would see him and other children denied access to the drug.

The letter to NHS England said: “[The parents] anticipate a marked deterioration in his condition if the drug therapy is discontinued and say that it would be heart breaking to witness this after seeing [their child] make such strides. They accept, however, the constraints of the NHS and are simply seeking to ensure that the drug is not denied to their son as a result of an unfair, bias process [which] would be additionally devastating.”

Leigh Day, acting under an emergency grant of public funding, claimed the scorecard was unlawful as there had been no consultation on its use, or policy or guidance on how it should be used.

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Concern about the scorecard has been growing among a number of patient groups. In addition, HSJ has spoken to individuals who were present at meetings of NHS England’s specialised commissioning programme of care boards in late October, where it was used to rank treatments ahead of the CPAG meeting.

They complained it was not clear what was meant by the criteria, such as what was meant by health inequalities, and that the process was rushed with some treatments being given as little as 10 minutes consideration.

NHS England’s letter in response to Leigh Day, sent on Friday, said the body “was itself considering the appropriate approach to prioritisation and specialist commissioning”.

It said: “As part of that consideration it has concluded that further work remains to be done, and that the CPAG meeting scheduled for next week should be deferred.”

The letter continued: “The next step is for NHS England to consider in December the decision making process(es) to be used in specialised commissioning and how treatments should be prioritised… The use of a scorecard may be retained or jettisoned entirely, and if retained the form of the scorecard may be varied.

“The position of rare conditions and ‘orphan’ illnesses will be considered. Before making a decision on the process(es) to be used, NHS England will carry out a public involvement exercise on its proposals.”