

The Specialised Healthcare Alliance spring survey results

Introduction

In May 2018 the Specialised Healthcare Alliance (SHCA) ran a survey to gather views on the processes for assessing treatments for rare and complex conditions. Given the wide range of experiences amongst the Alliance's members and corporate supporters the survey included questions on the following:

- NHS England's prioritisation process
- NICE's assessment processes, including the highly specialised technology evaluations and single technology appraisals for specialised conditions
- The Individual Funding Request (IFR) process

This briefing includes the headline findings from the survey, as well as specific comments from respondents on each of the processes listed above. In total, the survey received 43 responses, 90 per cent of which were from patient organisations or charities.

Headline findings

The survey revealed some common themes and concerns:

- Greater flexibility for rare disease treatments was identified as the most important area in which reforms should be made to the prioritisation process, NICE Single Technology Appraisal and IFR process
- There was widespread support for a formal mechanism to give higher priority to rare disease treatments. For instance, one respondent commented, "*such patients are already disadvantaged due to lack of experience of clinicians resulting in long diagnostic delays and lack of support by allied healthcare professionals. Sometimes such treatments are their only hope of obtaining any quality of life.*"
- NICE's processes for evaluation are considered significantly more transparent than those of NHS England, with nearly 60% of respondents finding the prioritisation process not very or not at all transparent, compared to just over 30% when asked about the NICE HTA process. One respondent noted "*if allowed to select an evaluator with NHSE & NICE as competitors, NICE would win every time.*"

NHS England's prioritisation process

Respondents recognised the improvements recently made to the NHS England prioritisation process. However, there was consensus that more could be done to improve transparency of the process, decision-taking and communication with stakeholders.

In discussing the lack of transparency, one respondent remarked, "*the video is a good first step, but there are still not nearly enough details in the public domain about how decisions*

are made." Another respondent noted, "*without actual minutes and notes of the scoring system it is impossible to know what was actually considered.*"

Only 15% considered it very easy to access information on the prioritisation process and no respondents said they completely understood what evidence is valued by NHS England. Of those that had made a submission to the prioritisation process, over 50% felt their contribution was either undervalued or not valued at all. Ultimately, no respondents felt very confident in the decisions being taken and nearly 10% were not confident at all.

NICE's highly specialised technology evaluations (HST) and single technology appraisal (STA) process

Although seen as more transparent than NHS England's prioritisation processes, there was frustration among respondents regarding the division between the HST and STA processes and concern as to how the budget impact test and lower cost-effectiveness threshold might affect access to treatments.

One respondent commented that "*unfortunately the majority of treatments for rare diseases fall somewhere between the QALY threshold of an STA and an HST, too specialised for STA appraisals but not rare enough for HST.*" Nearly 70% of respondents were either not very confident or not confident at all in the suitability of the STA process for treatments of rare diseases and no respondents were very confident in its suitability.

Likewise, there were significant concerns regarding the budget impact test and lower cost-effectiveness threshold. All respondents had some level of concern that the budget impact test could limit patients' access to medicines and 95% of respondents were either very concerned or somewhat concerned regarding the impact of a lower cost-effectiveness threshold for all NICE appraisals on patients' access to medicines, in line with proposals in a recent Government consultation.

Individual Funding Request (IFR) process

Unlike the progress made by NHS England's prioritisation processes, no respondents thought the IFR process was becoming easier over time for patients to access treatments. Over 60% of respondents noted it was challenging or very challenging to access information on IFRs, all respondents commented it was either challenging or very challenging to access treatment through IFR and no respondents felt very confident in IFR decisions.

Conclusion

The SHCA is committed to working collaboratively to improve these processes for patients with rare and complex conditions. To this end, the SHCA would welcome the opportunity to discuss the survey findings with representatives from NHS England, NICE and the Department of Health and Social Care and share ideas on how some of these concerns raised in this survey could be addressed.

About the SHCA

The Specialised Healthcare Alliance is a coalition of patient-related groups and corporate supporters with a strong record of campaigning on behalf of people with rare and complex conditions in need of specialised care.

SHCA, June 2018