

Focus group report: Familial hypercholesterolaemia

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Background

In April 2023, NICE held online focus groups with 9 members of the [NICE GP reference Panel](#) to provide feedback on draft indicators in development.

Composition of the focus groups is included in [Appendix 1](#). This report focuses on:

2022-130: The percentage of patients with a total cholesterol reading greater than 7.5 when aged 29 years or under, or greater than 9.0 when aged 30 years or over, who have been:

- diagnosed with secondary hyperlipidaemia or
- clinically assessed for familial hypercholesterolaemia or
- referred for assessment for familial hypercholesterolaemia or
- genetically diagnosed with familial hypercholesterolaemia.

Focus group purpose

To provide feedback on whether the indicators:

- have the potential to improve outcomes and address under- or over-treatment?
- would have unreasonable workload implications or burden of data collection?
- focus on actions within control of general practice?
- have any potential unintended consequences?

Feedback

Potential to improve outcomes

Attendees noted the potential benefits of identifying people who may need further assessment and increasing diagnosis rates of familial hypercholesterolaemia (FH). It was felt that this indicator may be acting as a safety net to ensure that high readings are acted upon appropriately.

There was support for reviewing more recent high readings, with less support for reviewing historical readings. Attendees noted the potential for the spurious results to be included for which the GP had already ruled out FH but not coded as such. It was also felt that historical results with no repeat high readings may not require further assessment.

It was questioned why the cholesterol threshold changed for people over 30 years old, and whether the indicator would check that the cholesterol reading was from a fasting sample.

Workload implications

For those readings that do indicate further assessment, attendees noted the workload implications for general practice would likely be highest in the first year of implementation. There was concern around the potential large number of patients that would be identified and uncertainty as to the accurateness of PCN Network DES data that showed approximately 60 patients per 10,000 would have a reading that match the indicator thresholds. Given the nature of FH, there may be pockets of high prevalence with some practices having more high readings recorded than others.

They also noted the resulting impact on secondary care and that family members would also need to be contacted and tested if FH was confirmed.

Attribution

No concerns were raised around attribution of responsibility.

Risks of unintended consequences

Some concerns were raised around the potential for the indicator to substantially increase waiting times for assessment in specialist services, especially in the first year of implementation. Patients and their families could be left with uncertainties and face substantial waiting times. It was also queried whether this could affect people's insurance quotes.

Stakeholder questioned whether the indicator aligned to the Accelerated Access Collaborative [lipid management pathway](#), and the potential to cause additional confusion if it did not.

Summary

Whilst there was some support for the potential to improve outcomes, the main concerns related to the potential for spurious or historical results to create additional workload with minimal clinical benefit.

Appendix 1: Focus group composition

Table 1: Attendee practice deprivation

Practice deprivation decile	Count of attendees
1-3	0
4-7	6
8-10	3

1 is the most deprived decile, 10 the least deprived decile.

Table 2: Attendee practice list size

Practice list size	Count of attendees
Less than 8000	2
8000 to 10999	2
More than 11000	5

National average list size 2021/22 = 9294

Table 3: Attendee practice QOF achievement 2021/22

Practice achievement	Count of attendees
Less than 580	3
580 to 620	2
More than 620	4

Total points available: 635 (national average practice achievement: 582)

Table 4: Attendee region

Region	Count of attendees
East of England	0
London	1
Midlands	1
North East and Yorkshire	4
North West	1
South East	1
South West	1