

**NORTH EAST QUALITY OBSERVATORY SERVICE
(NATIONAL COLLABORATING CENTRE
FOR INDICATOR DEVELOPMENT)**

FOR

**NATIONAL INSTITUTE FOR HEALTH AND CARE
EXCELLENCE**

INDICATOR DEVELOPMENT PROGRAMME

Feedback report on piloted indicators

Topic area: Familial hypercholesterolaemia

Pilot period: 13th December 2018 – 31st March 2019

IAC meeting date: 5th June 2019

Output: Recommendations for NICE indicator menu

Contents

Summary of recommendations	3
Indicator 1 Assessment of patients aged 29 years and under with a high total cholesterol	3
Indicator 2 Assessment of patients aged 30 years and older with a high total cholesterol	4
Indicator 3 Referral of patients with a clinical diagnosis of familial hypercholesterolaemia	6
Background	7
Practice recruitment	7
Assessment of feasibility, reliability and acceptability	8
Feasibility and reliability	8
Acceptability	8
Topic feedback	8
Indicator-level feedback	10
Assessment of implementation	12
Assessment of piloting achievement	12
Practices' views on implementation issues and impact	13
Training requirements	13
Workload, resource utilisation and costs	14
Changes in practice organisation	14
Other feedback on implementation issues	15
Barriers to implementation	16
Assessment of exception reporting (or future Personalised Care Adjustment)	18
Assessment of overlap with and/or impact on existing QOF indicators or local schemes	18
Other overall views on implementation of the indicators (including unintended consequences)	18
Suggested amendments to indicator wording	19
Appendix A: Practice recruitment	20
Appendix B: Indicator development	21
Appendix C: Acceptability and implementation recommendations	22

Summary of recommendations

Indicator 1: Assessment of patients aged 29 years and under with a high total cholesterol

The percentage of people aged 29 years and under, with a total cholesterol concentration greater than 7.5 mmol/l that are assessed against the Simon Broome or Dutch Lipid Clinic Network (DLCN) criteria

Acceptability assessment

The findings from the survey and the interviews were not consistent for this indicator. 78% of survey respondents agreed that this indicator would improve the quality of care. However, the views from the majority of interviewees were not supportive of inclusion, mainly due to their perception of the suitability of an indicator that would only yield small patient numbers.

Implementation assessment

Minor problems with implementation.

Issues to be resolved prior to implementation

Issue	Detail	Mitigating activity
Workload in identifying people with raised cholesterol was heavy (small number of practices)	Reviewing searches of cholesterol levels to find patients	Automatic searches / protocols / flags could be set up in the systems
Data quality issues relating to existing clinical system coding	Patient identification is reliant on correct coding by practices of existing cholesterol levels (and pre-diagnosed familial hypercholesterolaemia) Recording of family history is also a useful prompt for cholesterol measurement but may be poorly coded	Prompts to ask about family history at registration of new patients and other opportunities
Completion of diagnostic tools	Two practices reported that they were unable to fully complete the tools due to a lack of knowledge from the patient	Advance information for patients prior to a consultation to discuss a high cholesterol level

Item 3c (ii)

Issue	Detail	Mitigating activity
The two tools produced different results	One practice reported different results from the two tools for the same patient	As the Dutch Lipid Clinic Network criteria are harder to apply in practice, to consider promoting the Simon Broome criteria? Practice training for the chosen tool(s).
Awareness of reasons for early diagnosis of FH	Some views suggested a lower awareness of importance of high cholesterol in younger people, and the potential impact on years of life saved for individuals if FH detected and treated	Awareness raising

Indicator 2: Assessment of patients aged 30 years and older with a high total cholesterol

The percentage of people aged 30 years and older with a total cholesterol concentration greater than 9.0 mmol/l that are assessed against the Simon Broome or Dutch Lipid Clinic Network (DLCN) criteria.

Acceptability assessment

84% of survey respondents agreed that this indicator would improve the quality of care. The views from the majority of interviewees were supportive of inclusion.

Implementation assessment

Minor problems with implementation.

Item 3c (ii)

Issues to be resolved prior to implementation

Issue	Detail	Mitigating activity
Workload in identifying people with raised cholesterol was heavy (small number of practices)	Reviewing searches of cholesterol levels to find patients	Automatic searches / protocols / flags could be set up in the systems
Data quality issues relating to existing clinical system coding	<p>Patient identification is reliant on correct coding by practices of existing cholesterol levels (and pre-diagnosed familial hypercholesterolaemia)</p> <p>Recording of family history is also a useful prompt for cholesterol measurement but may be poorly coded</p>	Prompts to ask about family history at registration of new patients and other opportunities
Completion of diagnostic tools	Two practices reported that they were unable to fully complete the tools due to a lack of knowledge from the patient	Advance information for patients prior to a consultation to discuss a high cholesterol level
The two tools produced different results	One practice reported different results from the two tools for the same patient	<p>As the Dutch Lipid Clinic Network criteria are harder to apply in practice, to consider promoting the Simon Broome criteria?</p> <p>Practice training for the chosen tool(s).</p>

Item 3c (ii)

Indicator 3: Referral of patients with a clinical diagnosis of familial hypercholesterolaemia

The proportion of people with a clinical diagnosis of familial hypercholesterolaemia (FH) referred for specialist assessment.

Acceptability assessment

72% of survey respondents agreed that this indicator would improve the quality of care. The views from the majority of interviewees were supportive of inclusion.

Implementation assessment

Minor problems with implementation.

Issues to be resolved prior to implementation

Issue	Detail	Mitigating activity
Onward referral to services – capacity	Some concerns that services may be overwhelmed (although also noted that numbers were small)	Commissioners to resolve.

Background

As part of the NICE indicator development process, all clinical and health improvement indicators for general practice proposed for inclusion in the NICE Indicator Menu are piloted, using an agreed methodology, in a representative sample of GP practices across England.

The aim of piloting is to test whether indicators work in practice, have any unintended consequences and are fit for purpose.

A list of piloted indicators for this topic is shown in Appendix B.

Practice recruitment

Number of practices recruited	30
Number of practices withdrawing	4
Final number of practices in the pilot	26
Number of practices participating in feedback	25

Feedback was obtained via interviews and survey, and it was possible for individuals to participate in both the survey and the interviews. The table below indicates the participation for the pilot overall and also shows the number of practices taking part in interviews for this topic in particular.

Feedback participation by role and method

Staff role	Survey	Interview	Interviews for FH topic
GP	14	18	10
Practice Manager	13	15	8
Other senior management	3	4	1
Admin staff (including finance, IT, performance)	2		
Number of participants	32 (25 practices)	37 (25 practices)	19 (14 practices)

Assessment of feasibility, reliability and acceptability

Feasibility and reliability

It was possible to develop Business Rules to support this topic and all indicators within it.

Practices also noted in their responses that clinical system protocols could be developed or flags used to identify patients, but that this relied on the correct clinical codes being used, or the information being recorded in the first place (particularly about family history).

Acceptability

Topic feedback

There was reasonable agreement from the survey respondents (69%, 22/32) that the topic of familial hypercholesterolaemia (FH) represents what is important to patients, families and carers, with 2 respondents disagreeing. There was also a common view that this represents what is important to clinical staff (66%, 21), with 8 people (25%) being unsure and the remaining 3 disagreeing (mainly linked to the later points about small numbers of patients).

“Patients with family history of high cholesterol are definitely keen to know what their own results are”. (GP, survey)

“The familial hyperlipidaemia is something that is significant at a single loci in time for the family”. (GP, survey)

“FHC (familial hypercholesterolaemia) - not enough patients”. (GP, survey)

Just over half of the survey respondents were supportive of the indicators being financially incentivised (56%, 18); however a more positive view was obtained from the interviews, with 11 of the 14 practices (79%) being in favour of this.

There were mixed opinions in terms of the indicators being suitable for quality improvement (without incentivisation). Only 41% of those responding to the survey (13 participants) were in favour of this, with 10 people (31%) not supportive and the remaining 9 being unsure.

Item 3c (ii)

A range of comments were provided during the interviews with regard to this topic, with three practices stating that it was useful to have a prompt on the topic as they may not have specifically looked at it in practice before and could see the benefits for some patients. Two practices (2/14, 14%) thought the patients should be picked up through 'good medical practice' without the need for an indicator.

"I think it's a really good prompt for the GPs to actually do something because I think they are so busy that actually it's those sorts of patients that sometimes fall through the net to be quite honest". (Practice manager, interview)

"I think from the hypercholesterolaemia point of view if anyone wasn't doing it they would be in trouble in the sense that they aren't giving patients justice". (GP, interview).

Three practices currently identified patients through NHS Health Checks or via cholesterol screening of patients with conditions included in QOF, such as diabetes or coronary heart disease, and a further two practices thought that large scale screening for high cholesterol in the under 40 years old population would be challenging (if this was required to increase the numbers identified with high cholesterol). Another GP did not think the indicators would improve quality of care, suggesting that a standardised questionnaire would be useful to pick up on relevant risk factors as screening through blood tests was impractical.

One practice noted that there were few patients aged under 40 years with a cholesterol already recorded but that they would capture information about family history with new patient registrations, and another practice said that patients would self-present for a cholesterol check if they had a family history of FH.

"I think we already have that as part of our diabetes and coronary heart disease screening on QOF anyway. They do look at cholesterol levels. I think that one is quite significant because it does make a difference to people's outcomes at the end of the day. I would agree that it would be a significant thing to do". (GP, interview)

Four survey respondents (4/32, 12.5%) stated that there were existing schemes relating to FH in their local area, with one of these declaring that the pilot had had a positive impact (described below) and the remaining three (9%) stating no impact.

Item 3c (ii)

Seven of the 14 practices interviewed (50%) were undertaking specific work relating to FH, with one practice providing further details relating to their local incentive scheme. They described their FH clinic which was set up specifically to actively look for people with potential FH, mainly relating to those aged 30 years and over but also those who were younger than this on an opportunistic basis. Six practices (6/14, 43%) were already aware of the clinical diagnosis and onward referral recommendations as set out in the [NICE clinical guideline \(CG71\) relating to identification and management of FH](#), which were mainly applicable to newly registered patients.

Indicator-level feedback

The views of survey respondents in terms of the impact on quality of care for patients were obtained for each of the three familial hypercholesterolaemia indicators.

The majority of respondents (78%, 25) agreed that the assessment of patients aged 29 years and under with a high total cholesterol would make the quality of care for patients better, and this was the view of 84% of respondents with regard to the second FH indicator (relating to assessment of patients aged 30 years and over).

“Easy to get accurate levels with blood tests and patients tend to be well motivated to get advice and help for this - even it means simply taking a tablet”. (GP, survey)

However, the general view from practices was that it was difficult to find patients with a high total cholesterol in either of the two age groups included in the indicators who had not already been identified through their family history, but this was particularly the case with those aged 29 years or under.

“We've actually got quite a young population but we don't tend to do regular blood tests unless they request them”. (GP, interview)

To note that the indicators being piloted only require application of the diagnostic criteria to patients who have already been identified with a high cholesterol, and are not aimed at promoting population screening with cholesterol testing.

For those aged 29 years or under, most practices thought that a very high cholesterol value was very rare and that the relatively small patient numbers relating to this clinical topic could mean that practices either received payment for a relatively limited amount of work or possibly would not remember to implement it.

Item 3c (ii)

“If they're 22 (years old) you might not bother, saying, “Oh, don't worry about it, we'll worry when they're 40.” But if it came back enormous, like, you know, formal, “This is hyperlipidaemia 9”, around 9 or something ridiculous, then it makes sense”. (GP, interview)

“Hypercholesterolaemia searches did not produce a high population. New patients were screened at new patient health check opportunistically. We will be discussing in a clinical meeting to establish if the Partners would like to continue to offer checks and referral if positive for quality of patient care”. (Practice senior manager, survey)

“...In terms of indicator development, it's a good indicator but there's not much work to do so I'd agree with that. Overall, in terms of effectiveness, you probably find other areas that will probably be more fruitful..... You could potentially say everyone under 29 have your cholesterol checked but then you're screening everybody, aren't you?... So if there is a family history and there's risk, we know those patients, we screen them anyway”. (GP, interview)

“I think it would only affect a very small number, wouldn't it? I mean we're in quite an educated area and people do tend to present themselves, 'There's a strong family history of cholesterol. I'd like mine checking’”. (Practice manager, interview)

“...It would be great for a GP to be paid to do that but I think if I'm taking my provider hat off, I think it's going to be payment for not doing a lot”. (GP, interview)

Almost 72% of respondents (23/32) agreed that referral of patients with a clinical diagnosis of FH for specialist assessment could make the quality of care for patients better. However, some interview comments suggested that any patients with a clinical diagnosis would already have been referred.

“However, most patients have already been recognised and referred appropriately already without prompt”. (GP, survey)

Assessment of implementation:

Assessment of piloting achievement

The baseline extraction covers a 12 month time period and the final extraction a 4 month time period.

Item 3c (ii)

Indicator 1: Assessment of patients aged 29 years and under with a high total cholesterol

% patients aged 29 or under with a high total cholesterol assessed for FH	Baseline	Final
Practices	26	26
Practice population	321,651	321,815
Generated (<=29 + 7.5+)	25	68
Excluded: existing FH diagnosis before cholesterol	0	0
Excluded: previous referral	1	0
Excluded: diagnosed without assessment	0	0
Denominator	24	68
Numerator	0	0
Percentage	0.00%	0.00%

Indicator 2: Assessment of patients aged 30 years and older with a high total cholesterol

% patients aged 30 years and older with a high total cholesterol assessed for FH	Baseline	Final
Practices	26	26
Practice population	321,651	321,815
Generated (>30 + 9+)	888	833
Excluded: existing FH diagnosis before cholesterol	3	1
Excluded: previous referral	8	4
Excluded: diagnosed without assessment	8	3
Denominator	869	825
Numerator	0	1
Percentage	0.00%	0.12%

Item 3c (ii)

Indicator 3: Referral of patients with a diagnosis of familial hypercholesterolaemia

% patients with a clinical diagnosis of FH referred for specialist assessment	Baseline	Final
Practices	26	26
Practice population	321,651	321,815
Generated (FH)	4	19
Excluded: existing FH diagnosis	4	6
Excluded: previous referral	0	2
Denominator	0	11
Numerator	0	3
Percentage	0.00%	27.27%

Practices' views on implementation issues and impact

Training requirements

When asked if they thought it would be advisable to undertake additional training, if the topic of familial hypercholesterolaemia was introduced nationally, 53% of the survey respondents (17/32) said yes, with a further 25% (8) stating that no further training was required, and the remaining 7 respondents (22%) were unsure.

This view was also reflected in the interviews, with four practices (4/14, 29%) requesting awareness raising and training; however one practice stated they would be happy if adequate guidance was available.

"I think with anything new there will always need to be some awareness raising, if not training. I think that goes without saying". (Practice manager, interview)

"Potentially would need reminding of e.g. Simon Broome criteria for FH". (GP, survey)

"The hypercholesterolemia assessment takes education to know what to ask". (GP, survey)

"...A bit of education around who might benefit from being screened would be useful". (GP, interview)

"Familial Hypercholesterolaemia just requires reading around subject if knowledge lacking". (GP, survey)

Workload, resource utilisation and costs

With regard to additional clinical workload during the pilot, 56% (18/32) of survey respondents considered there to be no extra or acceptable extra workload during the pilot. Eleven respondents (34%) were unsure and the remaining 3 (9%, 3/32) stated that the clinical workload was heavy. For the 3 respondents who reported heavy workload, it was stated that both GP (3/3) and non-GP (1/3) clinical roles were affected, involving additional time to review hypercholesterolaemia searches.

Almost 69% (22/32 survey respondents) considered there to be no extra or acceptable extra administrative workload during the pilot. Seven respondents (22%) were unsure and the remaining 3 (9%, 3/32) stated that the administrative workload was heavy.

The general view from practices was that a standard length appointment with a GP or practice nurse was sufficient for a relevant discussion with the patient including advice, family history and health promotion relating to FH.

“...They’ll probably fit into a normal appointment slot because you don’t need the patient here once you’ve taken the history to fill in the rest of the criteria. So maybe just a little bit of admin time after the patient leaves but I don’t feel like you need the patient here to complete the indicator”. (GP, interview)

Changes in practice organisation

In terms of set up and preparation for the pilot, practices noted that clinical system protocols could be developed or flags used to identify patients, but there is reliance on the correct clinical codes being used, or the information being recorded in the first place.

“...The family history part is always very poorly coded unless you’ve specifically gone in and asked it in an NHS health check”. (GP, interview)

“...When you’re coding things such as family history, everyone does it in different ways. Some practices might put it in a completely different component of the system as to what you do and we will need to formulate these registers. I think there does need to probably be a phase of quality improvement or some sort of project work before these indicators go live just so you’re getting accurate data really...” (Practice senior manager, interview)

Item 3c (ii)

“...If somebody had gone through this process, like we had done the primary person, then once we’ve gone off to genetics normally, then, we’re fed back, you know, “Oh my God, you need to get your cholesterol done for all the children.” So then we have the children come back in saying, “I need to have my cholesterol doing,” and we said, “What the hell is this?” So it’s normally from genetics perspective where we actually will get our prompts rather than from us doing the blood tests”. (GP, interview)

One practice explained how they had prompted questions about family history during the pilot.

“I tweaked the templates sent out and I put in the family history questions in there to try and bring that all together because it’s something that we don’t do terribly well as a rule. It is on our new patient questionnaires but if I’m honest, it’s recorded with variable efficacy. So I think that’s an area that most practices would have to scrub up on. It’s not something that’s particularly well recorded in primary care, is my feeling”. (Practice manager, interview)

Two practices provided suggestions regarding the automated identification of patients with high cholesterol within the clinical system, with a third practice providing a note of caution regarding excessive use of clinical system prompts.

“Retrospective search used during pilot. During QOF year suggest prompt if cholesterol level > (greater than) defined level so clinician assesses at the time”. (GP, survey)

“Protocols in clinical system to check and highlight where issues were”. (Practice manager, survey)

“I think that the risk with all of these prompts is, in the clinical system you can have half a page of prompts and after a while clinicians become anaesthetised to them and actually ignore them all”. (Practice manager, interview)

Other feedback on implementation issues

Two practices described their approach to implementing these indicators during the pilot period.

“We did start that as part of a health promotion for a little bit..... We did set that up with the nurse so yes, it may have affected appointment times. So it’s not just the doctor who deals

Item 3c (ii)

with it. We get them to see the nurse as well to give them initial advice and all the health promotion type of thing because we shift them off to the lipid clinic". (GP, interview)

"In reality once we have done the blood tests and have chatted to them, in order to save us the time of seeing them back in the clinic we tend to communicate a fair bit electronically. We would do phone calls, text messages and talk to them to get them to phone us rather than getting them to come back.... Once you have done the blood pressure, weight, height etc. the QRISK and the JBS3 is automatically worked out for us (by EMIS). We have got a good text message service where if it was just high but their QRISK wasn't high we can just attach a link to their text message where they can open up the link and watch their diet and stuff like that automatically.... We are notifying them of the results but we are also advising them of where they can go to help themselves". (GP, interview)

One practice stated that they would refer a patient with a suspected diagnosis to the lipid clinic for further tests and that they were not encouraged to make the clinical diagnosis, instead recording the patient as 'serum lipids are high' (but still commencing treatment) until the lipid clinic confirmed the clinical diagnosis.

Another practice stated that it would be useful to run indicators from this topic alongside pre-diabetes screening in primary care or that it could be included in one of their existing GP federation schemes to perform blood pressure checks in those aged 30 to 39 years old.

Barriers to implementation

Two practices (2/14, 14%) raised concerns regarding the ability to fully complete the diagnostic tools (Simon Broome or Dutch Lipid Clinic Network criteria) due to a lack of family history knowledge provided by the patient.

"We found in our practice that the referrals were already being undertaken and when questioning patients to complete the tool for the pilot many did not understand the family history questions or have the information necessary to enable the GP to complete the tool". (Practice manager, survey)

Item 3c (ii)

Three practices (3/14, 21%) reported issues they had experienced with completion of the tools.

“The two tools suggested for FH produced different answers for the same patient and the same data added. These would need to be verified”. (Practice senior manager, survey)

“But it was useful having a link to the Simon Broome and Dutch criteria. My colleagues noticed that with...I think it was Simon Broome, it's quite specific, you have to have a non-LDL level, no, an LDL level, which we couldn't figure out if that was the same as a non-HDL level or... so we couldn't fill that one in, progress any further with that criteria. With the Dutch criteria, it was almost... not specific enough because you're either eligible or not eligible to complete the rest of that... we just had a bit of trouble filling in those criteria”. (GP, interview)

“The familial cholesterol area showed that the practice was referring appropriate people to secondary care and that many patients contacted did not understand the questions being assessed on the scoring tool”. (Practice manager, survey)

With regard to onward referral to a specialist clinic following a clinical diagnosis of FH in primary care, practices raised concerns regarding information relating to the correct referral pathway and also the capacity of the lipid clinic services.

“I've been researching this stuff, trying to find out how to write a template. And I've been doing it, and every time I see one of these mildly-raised cholesterols, I can't remember what on earth I'm going to do. Every single time. And I'm using the templates and I can't remember. So I think it's going to be really, really hard to do”. (GP, interview)

“Our CCG has invested an awful lot of time and effort on something called Clinical Support Information. It's on an intranet system...It has the pathway. It's quite clear what people have to do for certain conditions.... Whatever you come up with will have to be built into other people's systems as well. You can't just say refer them to a clinic. It's like where is the clinic? Who runs the clinic? It will involve secondary care in the planning and organisation of that as well so you've got to be mindful. It's not just here's some training on how to do something. It's what is the impact on the ground on the local services”. (Practice manager, interview)

“The hospitals would need to have capacity to see patients if we refer them.” (Practice senior manager, survey)

“Do we have resources outside of primary care to deal with it, is my question, I mean in the lipid clinics. There is only a few of them around, isn't there?” (GP, interview)

Item 3c (ii)

One practice raised concerns regarding the potential incentivisation of these indicators, as the FH diagnosis pathway involves different providers of care and different roles and responsibilities, to ensure there was no negative impact on the income to the practice. Another practice also wanted to ensure that this work would be appropriately funded if the indicators became part of a contract.

“..It's also about the impact on primary care and whether that's going to be adequately funded through the additional indicators, so how many points and what is the value thereof and how much are we going to construct GP/nurse follow-up plan, pursuing this pathway. If it is to be introduced, there just needs to be adequate remuneration within it”. (Practice manager, interview)

Assessment of exception reporting (or future Personalised Care Adjustment)

Given the short time period available for the pilot, we are unable to comment upon likely levels of exception reporting.

Assessment of overlap with and/or impact on existing QOF indicators or local schemes

It is possible that there are various schemes and services already in existence in local areas which overlap with the requirements of these indicators.

Other overall views on implementation of the indicators (including unintended consequences)

Four of the 32 survey respondents (12.5%) reported positive things that they didn't expect to experience during the pilot, with three of these providing further details on their experience.

“Most patients from retrospective search had already been identified and referred appropriately to lipid clinic”. (GP, survey)

“We found young patients who we didn't know might have FH”. (Practice senior manager, survey)

Item 3c (ii)

“Certainly made me learn about hyperlipidaemia”. (GP, survey)

Two of the survey respondents (6%) stated that there were negative things that they didn't expect to experience, with one practice providing further details.

“The hyperlipidaemia requires additional codes to say why you don't do things. The hyperlipidaemia for instance if you have abnormal bloods you don't have a way to say awaiting a review for diabetes or hypothyroid. (GP, survey)

Suggested amendments to indicator wording

No amendment to indicator wording are suggested in response to the pilot.

Appendix A: Practice recruitment

A sample of 30 GP practices from across England was recruited by the NCCID to participate in the indicator pilot for 2018/19. Practices were to be representative of England in terms of the range of practice list sizes ([NHS Digital QOF 2016/17](#)) and level of deprivation ([Public Health England Index of Multiple Deprivation \[IMD\] 2015](#)). An additional aim was that there was practice coverage with regard to three of the four principal clinical system suppliers.

There were 4 of the 30 practices who subsequently withdrew from the pilot, one just prior to the commencement of the pilot, two practices mid-pilot and one close to the end. One of the remaining practices underwent a merger just prior to the start of the pilot which resulted in a change in the stratum for this practice due to the practice population more than doubling in size.

Final practice numbers in each stratum of practice list size and level of deprivation participating in the pilot are shown in the table below. When compared to the distribution of practices initially planned to target (in order to be fully representative of practices in England on these dimensions), there is over-recruitment in one stratum (large list size, least deprived) and under (no) recruitment in one stratum (small list size, least deprived); however, in this case, there is a practice categorised with medium list size and low deprivation where the list size (5,518 registered patients) is close to the lower end of the range.

Broadly speaking, based on this and other background data available to characterise the pilot practices, they appear to be fairly representative of GP practices in England.

Table 1: Participating pilot practice numbers by stratum

List size	IMD score			Total
	Least	Medium	Most	
Large	8	2	4	14
Medium	3	4	2	9
Small	0	2	1	3
Total	11	8	7	26

Appendix B: Indicator development

The NICE Indicator Advisory Committee (IAC) in June 2017 considered a review, undertaken by NICE and supported by Public Health England, of the care pathway relating to [FH in the context of NICE guidance](#) and [NICE quality standards](#), which included proposed areas for potential indicator development.

IAC agreed to proceed to piloting and consultation on indicators focused on assessment for a clinical diagnosis of FH for patients with a high cholesterol, and referral of patients with a clinical diagnosis of FH for specialist assessment as detailed below.

Indicator wording as piloted

Indicator 1: Assessment of patients aged 29 years and under with a high total cholesterol

The percentage of people aged 29 years and under, with a total cholesterol concentration greater than 7.5 mmol/l that are assessed against the Simon Broome or Dutch Lipid Clinic Network (DLCN) criteria

Indicator 2: Assessment of patients aged 30 years and older with a high total cholesterol

The percentage of people aged 30 years and older with a total cholesterol concentration greater than 9.0 mmol/l that are assessed against the Simon Broome or Dutch Lipid Clinic Network (DLCN) criteria.

Indicator 3: Referral of patients with a diagnosis of familial hypercholesterolaemia

The proportion of people with a clinical diagnosis of familial hypercholesterolaemia (FH) referred for specialist assessment.

Appendix C: Acceptability and implementation recommendations

Acceptability recommendations

In order to provide recommendation to the Indicator Advisory Committee, the degree of acceptability of the indicators to practices is assessed and reported in the 'Summary of Indicators' section as follows:

- a) A summary of the percentage (of respondents to the survey) responding to the survey questions which relate to whether indicators within the topic should be financially incentivised and their impact on the quality of care for patients;
- b) Relevant indicator- specific comments reported descriptively.

Implementation recommendations

Implementation recommendations in the 'Summary of Indicators' section are based on a judgement of the findings reported by pilot practices relating to workload, training, set up and preparation, taken from surveys and interviews/focus groups. A narrative overview of the ease of implementation from these findings, forms the basis of the implementation category used for the recommendations in the topic reports.

The implementation categories are:

- No problems (with implementation)
- Minor problems (resolvable)
- Major problems (potentially resolvable)
- Major problems (not resolvable)