Roundtable Discussion on the Forthcoming Nice Quality Standard on FASD

Side Event Following the Greater Manchester Alcohol Exposed Pregnancies Launch
17 May 2019 - 3:00-4:30 pm

Summary/Report[1]

Key points

- A NICE quality standard on FASD will be produced in the coming year. It will identify the five most important things for improving care in this area, based on the Scottish SIGN guidelines. Each of these five points will include a statement and one or more measures that are achievable and it will include ways to assess the progress.

- A NICE quality standard has 'weight' in ways that NICE guidance does not. As set out in the Health and Social Care Act, once a quality standard is produced, it is a requirement that commissioners have due regard for the content of a quality standard.

- This quality standard will be based on the Scottish SIGN guidance and any other existing NICE guidance on related topics (for example pregnancy, etc).

- The process involves opportunities for significant consultation on the five points (September/October 2019) and then again on the draft quality standard (March/April 2020).

- The committee will be comprised of and chaired by some standing committee members from NICE who will not have specific expertise in the issue area. Other committee members will be publicly recruited for roles specific to this quality standard.

- Quality standards are reviewed internally by NICE annually and as progress is demonstrated the standards will be changed to reflect areas for further improvement.

- Further informal meetings like this one might be held to consider what can be done to maximise the impact of a NICE quality standard on FASD. It was noted that this is a profound change and will need to be backed by resources and cross-governmental coordination.

- In parallel, the multi-year process for NICE guidance on FASD should be started now, exploring a joint referral from the Department of Health and NHS England. This would be to allow England to follow its own long-term approach, to eventually fill in some gaps in the SIGN guidance for the specific needs of England and Wales and/or to address issues that are not included in SIGN (post-diagnostic care and issues relating to adults with FASD).

- Establishing an intercollegiate and agency group for FASD training, based on the domestic violence group that grew from the work done on a quality standard for domestic violence is a possible next step.

- The importance of stakeholder engagement throughout the process was highlighted, including in identifying the five most important areas for improving quality of services and then later commenting on the second phase of the consultation.

[1] The discussion was co-chaired by Dr Raja Mukherjee and Sandra Butcher and held according to Chatham House Rules, meaning that the substance of discussion can be reported out but without attribution to anyone in the room. No attempt was made to achieve any sort of consensus. Sandra Butcher, NOFAS-UK served as rapporteur: sandra.butcher@nofas-uk.org.

Introduction

On 17 May 2019, an informal roundtable discussion took place involving 15 people, including policy makers, health care professionals and clinicians, academics and stakeholders. The meeting took place in the margins of the launch of the Greater Manchester Alcohol Exposed Pregnancies Programme[2]. It also followed a 9 May 2019 meeting of the All-Party Parliamentary Group on FASD focused on findings of a new report from NOFAS-UK, based on Freedom of Information requests to all CCGs and NHS Trusts, "Crisis of Commissioning: CCGs Are Failing Government Policy on FASD." At the 9 May APPG meeting, the Department of Health released the following announcement:

> *"Department of Health and Social Care have got confirmation that NICE will be developing a Quality Standard on FASD based on the Scottish SIGN guidelines. NICE, working with key stakeholders will develop a work programme to help them deliver this over the coming months. This is welcome news as a step to help improve diagnostics and the clinical pathway in England on FASD."*[3]

On 16 May NICE published its timeline for the new Quality Standard on FASD.[4]

As a NICE quality standard on FASD is quite a significant change that will have impact on many levels[5], NOFAS-UK organised this informal roundtable discussion to collect ideas for concrete next steps and items for further discussions. This report outlines a general understanding of the process.

NHS providers, commissioners, practitioners and regulators use Quality Standards to:

- identify gaps and areas for improvement
- measure the quality of care
- understand how to improve care
- demonstrate you provide quality care
- commission high-quality services

Additional insights on how to use Quality Standards is available on the NICE website here.

The concept of NICE quality standards is different from NICE guidelines. NICE guidelines look at original evidence and interpret and make recommendations for practice. Quality standards by contrast highlight a small number up to five key areas for quality improvement. Quality standards tend to be used for people commissioning and/or leading services to improve quality.

To have a quality standard there has to be an existing guideline and recommendation to draw upon. Since SIGN guidelines on FASD now exist and SIGN is accredited by NICE, therefore NICE can do a quality standard. In general, this is positive, but the process is restricted to what is already in the guideline (and other existing NICE guidelines).

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[2] The Greater Manchester programme is in Phase 1, which continues through March 2021. The programme sits under the population health prevention umbrella. Phase 2 is under discussion and starting in April 2021 Phase 2 will include diagnosis and support. The new NICE Quality Standard on FASD may help facilitate the work already underway in Manchester.

[3] The announcement and the NOFAS-UK report were the subject of a BMJ report here: Jacqui Wise, "NICE plans new standard for fetal alcohol disorders," BMJ 2019;365:l2186, https://www.bmj.com/content/365/bmj.l2186

[4] https://www.nice.org.uk/guidance/indevelopment/gid-qs10139

[5] The Welsh Government has an agreement with NICE and follows NICE Quality Standards: http://www.wales.nhs.uk/governance-emanual/nice-guidance. Northern Ireland reviews NICE guidance annually and "where found to be applicable" it is "endorsed by the DoH for implementation in the HSC": https://www.health-ni.gov.uk/topics/safety-and-quality-standards/national-institute-health-and-care-excellence-nice?fbclid=IwAR1XcYU5ApHfSsmRdg7wTa0iyNwyt65zPtr_ICzSZxlNbBbs-S9-IELICmo

The benefit of a quality standard versus a guideline is that guidelines are not mandated. The Health and Social Care Act set out quality standards[6]. Once a quality standard is produced, it is a requirement that commissioners have due regard for the content of a quality standard. It has 'weight'. While it is not a pass/fail measure, they are expected to demonstrate improvement and they work with the Care Quality Commission on this.

A quality standard on FASD may help in the English context to address some of the challenges involved with the CCGs system and what some have called a 'post-code lottery' with regard to commissioning of FASD services.

Each quality standard identifies the five most important things for improving care. They include a statement and one or more measures that are achievable and include ways to assess the progress. Beneath that there is text about what the statement means, how commissioners and providers should interpret that.

Determining the five most important things needed to improve care is a challenging process that involves significant opportunities for input. Identifying these five things can be the 'hardest part' of the whole process.

While it is tied to the existing guidelines, it's possible that the accompanying information can include or allude to some additional information even if not directly in the guidelines. For example, sometimes if the committee feels it's important to deal with an issue but no recommendations yet exist on supporting how to do that, they can identify it as important but indicate there is as of yet no way to deal with that particular issue.

There will be at least one measurable action per theme.[7] Also, in a situation where things might be different according to age (for example what is needed for a 2-1/2 year old might be different than for a 14-year old), this potentially could be dealt with by a statement with different measures broken down by age.

A quality standard takes 10 months generally and there is flexibility within their annual work programme. This new quality standard on FASD has been negotiated into this year's work programme. In contrast the process for NICE guidelines can take 2-3 years.

Each year NICE looks at every quality standard and sees what evidence exists that things are starting to improve. If improvement is shown, they get the committee back together to determine what is next. NICE internally assesses whether there is any evidence that progress has been made against each statement. In nine out of ten cases, for the first two years there is no progress, followed by a high proportion of cases where progress starts to be seen.

The committee composition

NICE will look at the guideline, what it covers and will identify a range of roles that need to be on the committee. Committee members will be recruited on that basis. Those roles will be publicly advertised by NICE and others.

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[6] http://www.legislation.gov.uk/ukpga/2012/7/notes/division/5/8/2

[7] The NICE quality standard on autism is here as an example (though this is further down the line than an initial quality standard on FASD will be, they are based on how to improve the situation that exists here and now. https://www.nice.org.uk/guidance/qs51. The first quality statement for autism is: "People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral."

NICE has three standing committees. One will take the topic of FASD, so the committee will by design include a number of standing members, complimented by these other specialist roles. Standing members include those from across health and social care as well as lay members. By design, standing members have no expertise in the topic, but having been through the process they know how to work with specialists to develop priorities.

The chair of the committee also by design will not have an interest in or expertise in the area.

- Once the recruitment phase is open, people with related expertise should respond to that recruitment call.

Process

Topic engagement is the first phase. All stakeholders will be asked what they think are the five most important things to improve the quality of care in this area. It is a public exercise and anyone can respond. NICE will record all responses and also will identify key organisations and stakeholders. They also will look at what data, surveys, activities exist. (It's possible to register as a stakeholder here[8].)

That list goes to the committee for a half-day meeting to identify the five areas of consensus. The statements and measures will be based on this. Once the committee agrees, this then goes out for formal consultations, including to stakeholders.

The second committee meeting determines what to change based on feedback from the consultation process.

There will be approximately 20 people In the room. The committee dates are fixed for years in advance at NICE. Stakeholders will be on the committee.

Provisional schedule for the quality standard on FASD:

Topic engagement	02 September 2019 - 08 October 2019
Prioritisation meeting	10 December 2019
Quality standard consultation	05 March 2020 - 02 April 2020
Post-consultation meeting	12 May 2020
Expected publication	31 July 2020

What is means to have a NICE quality standard based on Scottish SIGN guidance

In this case the guidance upon which the quality standard on FASD will be based will remain the Scottish SIGN guidance, with no ability to influence that content.

Where there is a difference specifically between the Scottish and English systems, this will be addressed on a case by case basis.
If there are other existing NICE guidance that relate to the topic – for example on things like prevention, preconception, providing early information on alcohol in pregnancy - these can be included in this quality standard even if they are not in SIGN.

Some concerns about applicability of SIGN for the English context were discussed. This is a partial list, it was not a main focus of this discussion given time constraints.

[8] https://www.nice.org.uk/guidance/indevelopment/gid-qs10139

- SIGN guidance is based on Scotland, which has a different health care system. They are centrally funded and this will be different in England given the CCG structure.
- SIGN drew heavily on Canadian guidelines and as a result some developments in other places were not included.
- SIGN doesn't address awareness raising.
- NDPAE in DSM5 is not mentioned, this was provided as an example of the need to signpost some developments in the field that are coming.
- Post-diagnostic support is not fully covered in SIGN.
- Adult services are not included in SIGN.

Initiating a separate process of NICE guidance on FASD

It's possible in the meantime to put in motion the full process for a NICE guidance based on the English situation – either on issues directly covered by SIGN or perhaps for those issues that are not fully covered, for example adults diagnosis and support or post-diagnostic support more broadly. This is something the group generally thought should be further explored.

- The multi-year process for NICE guidance on FASD should be started now, exploring a joint referral from the Department of Health and NHS England. This would be to allow England to follow its own long-term approach, to eventually fill in some gaps in the SIGN guidance for the specific needs of England and Wales and/or to address issues that are not included in SIGN (post-diagnostic care and issues relating to adults with FASD).

While some participants noted the limitations of the process being based on Scottish SIGN guidance there was general agreement that having NICE quality standard on FASD can significantly change the landscape. It is encouraging to note that these quality standards are constantly reviewed and that as progress begins to filter through the system, they can become further strengthened.

Hypothetical examples were discussed. This was not the main focus of the discussion, these are given here to help highlight the range of things possible (so long as they link with the Scottish SIGN guidelines and any possible related existing NICE guidance). Not all of these examples are formulated in language that would necessarily fit exactly with the NICE format.

- Someone with suspected FASD must be seen within 6 months for diagnostic assessment.
    - All local areas should develop pathways for access to diagnosis
    - Where local services do not yet exist ensure relationships and referral pathways with more specialist clinics exist

- Everyone who is diagnosed with FASD should be able to access support (with some sort of measurable action here).

- A thorough alcohol screening to be conducted for all pregnant women

    - The results should be included in the child's notes. Discussion focused on the need to ensure attention is paid to the way this might be done as there is as yet no standard system (red book versus online records).
    - Perhaps it might trigger mandatory exams for the child at key time intervals
    - Perhaps this might trigger mandatory action for follow up with the woman after birth for future pregnancy planning

It was noted that the NICE quality standard process can have follow-on effects where there is specific interest driving things forward. NICE does work with the Royal Colleges regarding quality standards, but that is a different action. An example was discussed about a quality standard on domestic violence[9] where Professor Gene Feder took an interest in training and formed an "Inter-Collegiate and Agency National DVA Forum" to address training issues specifically. This approach may well be important to FASD. It needs GP, Psychology, PAed, SALT, OT, PSychaitry and more.

- Establishing an intercollegiate and agency group for FASD training, based on the domestic violence group that grew from the work done on a quality standard for domestic violence is a possible next step.

- The importance was noted of helping stakeholders (adults and young people with FASD, birth mothers and others parenting/caring for those with FASD) understand the strengths and limitations of this process and highlighting the areas where their engagement can help inform the process, particularly in the first phase of consultation in identifying the five most important areas for improving quality of services and then later commenting on the second phase of the consultation.

The bigger picture – what might it look like in a year's time

It was noted that it is important to ensure consideration of the broader impact of a NICE quality standard on FASD and the need for forward planning. As this quality standard will be a reality in a year's time, what implications does this have for cross-governmental coordination, for ensuring there is access to training on a wide scale (and ensuring the quality of that training), how to help educate CCGs and other healthcare policy makers on the issues and how to meaningfully move forward, how to promote lessons learned from 'vanguard sites' or areas of best practice, how to address FASD in a systemic way as things move toward Sustainable Transformation Partnerships (STPs) and integrated systems of care, etc.

- Creative thinking needs to start now to maximise the many ways in which case studies and good practice can be promoted following a NICE quality standard. Some of these can be included on the NICE website.

- Resources will be needed and budgeting should begin. It was noted in other countries where similar standards exist (Canada, Australia, USA, Scotland), they were backed by significant resources from governments. For example Australia invested AUS$20 Million into the process of FASD development which has moved the field forward in those areas.

It was noted that the Department of Health is preparing a report on FASD that is not constrained to the SIGN guidance and it was hoped that some of the broader questions will be laid out in that report. The situation regarding addressing the needs of adults with FASD and also post-diagnostic care integrated across systems need particular attention. (For example, those assessing Education, Health and Care plans, those involved with foster and adoptions systems and those assessing benefits will need to understand the import of this.)

Conclusion

A NICE Quality Standard doesn't mean things on the ground will change instantly. It will take time. But like a huge ship turning direction - this will be the signal from the top that it's time to change

[9] https://www.nice.org.uk/guidance/qs116

course, that things are pointing in new directions and people will be held accountable for improving the quality of care in this area.

FASD is an area gaining momentum and it was noted that the wide range of policy makers, researchers, practitioners and clinicians, and stakeholders involved with the process are enthusiastic to pick up and maximise the impact of the NICE quality standard. This is the beginning of the process. Further meetings can be held to consider what can be done to maximise the impact of a NICE quality standard on FASD. All participants appreciated the opportunity to discuss the process and possibilities at this informal meeting and look forward to continued positive engagement on this issue.

Roundtable participants
(Individuals participated in their personal capacities, affiliations are listed only for background)

Nick Baillie, NICE
Jo Buckard, Red Balloon Training
Sandra Butcher, NOFAS-UK
Penny Cook, Salford University
Paula Headen, Midwife, PAHNT
Kate Fleming, University of Liverpool
Amanda Fletcher, Midwife, Royal Oldham Hospital
Jill Gillmore, FASD Northwest
Mark Gilmore, FASD Northwest
Susan McGrail, FASD Northwest
Jen Michaels, PAHNT
Raja Mukherjee, National FASD Clinic
Rachael Nielsen, Alcohol Exposed Pregnancies Programme, Greater Manchester
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