

CQC review of investigations into deaths in NHS trusts

Expert Advisory Group notes

Tuesday 21 February, 2.00pm – 5.00pm

Welcome and introductions:

Mike Richards (MR) opened the meeting.

Session one: Media evaluation of report launch

James Hedges (JH) presented an evaluation of the media activity surrounding the launch of the report in December. Key points included:

- The story was widely covered by national press and trade media.
- It received more coverage than State of Care, CQC's annual flagship publication.
- Web analytics indicate that online engagement with the report and associated web content was strong. This includes 1,559 downloads of the full report over the first four days following publication.

Feedback from the group included:

- At a local level, the report was useful in asserting the importance of family involvement.
- The report had an impact not only on the NHS but also in discussing the issues with safeguarding boards and health and wellbeing boards.
- There should have been a stronger emphasis on people with learning disabilities and mental health needs, both in the media coverage and the report itself.
- CQC's media work should have involved more direct contact with families.
- Families and carers do not feel informed of subsequent developments. **Action: CQC to publish update on progress since the report's publication.**

Engagement with Department of Health Learning from deaths implementation programme

Session two: Work programme overview

- Tim Jones (TJ), Head of Patient Safety at the Department of Health, presented an overview of the eight workstreams that make up the programme, which are based on the recommendations in the report.

- The new guidance for NHS trusts (workstream 2) will be presented to the National Quality Board on 1 March and then launched by the Secretary of State at the NHS Improvement conference on 21 March.

Session three: Discussion on the draft guidance on learning from deaths

TJ asked the group for feedback on the draft guidance, which had been circulated in advance. He stressed that the draft is very much a working document and they are looking for lots of feedback – both before and after publication, as there will be opportunities for ongoing comment and discussion following its release.

The key factor will be to make sure NHS trusts have information to enable them to collect data from 1 April but the content will continue to be developed with input from stakeholders.

The main points from the group were:

Family and carer involvement

- The current draft doesn't yet meet the needs of families and carers:
 - Families and carers don't know what to expect from deaths investigations.
 - Format: this document is too long and difficult to navigate. The guidance should also start with the principles or expectations for the involvement of families and carers – this should be the approach of all guidance, tools or methods that are developed during the delivery of all workstreams for the learning from deaths programme.
 - It is not clear what scope is applied to determine which deaths are investigated. This will limit how this can be explained to families, carers and staff working in services. It is particularly important that it offers clarity on patients with a learning disability or mental health condition.
 - The Structured Judgement Review process will always be flawed unless it automatically involves families and carers and, from the start, recognises the problems of relying solely on notes taken by the clinical teams.
 - Families and carers should always be asked if they had any concerns. This simple step can often clarify whether or not an investigation is needed, and can shorten the process considerably. Speaking to families and carers is important not for the sake of meeting a standard or satisfying an expectation, but to find out what may have gone wrong with the person's care. It is

important that services understand the vital information that families and carers can provide.

- Duty of Candour should be reinforced by the guidance document and make sure the standards for sharing information support staff to do the right thing. To effectively support this, the NHS Litigation Authority should also be invited to comment on the document.
- The guidance should include the appointment of a family liaison officer at the very beginning and the family and carers should be made aware of who this is.
- Continued engagement of the Expert Advisory Group was felt to be critical to the guidance, allowing the standards to capture the developments in thinking and approach that had taken place since last May. Examples of this include not referring to deaths as incidents or incidents as deaths. Members of the group felt this document should be focused on mortality only (used against all deaths), while other documents should be responsible for incidents.
- MR stated that the guidance could not be signed off by the National Quality Board until it covers family and carer involvement.
- There was concern raised that the timescales involved mean families and carers are not being involved in the development of the guidance and this needs to be urgently considered by the DH team.

Implementation

- The Sustainability and Transformation Plans (STPs) should be considered as they could play a useful role in how local systems look at how the care someone received was joined up.
- It was felt there is a great deal of work to do to make sure NHS clinical commissioning groups are properly implementing the tools they already have in existing guidance (the Serious Incident Framework produced by NHS England in 2015) and looking at what they can do to support the implementation of the new guidance. However, because of the large number of CCGs (over 200) and the level of technical expertise needed, this will be a difficult task for national roll out. It was suggested that it might be better to combine into fewer, larger groups for the purpose – refer back to NHS England?
- Any referral into a review process should include asking families and carers if they had any concerns about the care that was delivered. This cannot be the only criterion (see Solent example below). However, it may be critical to identifying concerns at an

early stage. The guidance states there is a need for mortality reviews. Solent NHS Trust has a set of criteria for these:

- Did the family have any concerns?
 - Did the GP have concerns?
 - Did the clinicians have concerns?
 - Did the risk team have concerns?
 - A mortality review is triggered if any one of these criteria is met.
- The guidance will rely on there being a large enough group of skilled investigators. This is one of the workstreams for the programme and Healthcare Safety Investigation Branch (HSIB) will be leading on improving skills and training for investigators.
 - To deliver genuine change, you need an active change implementation process.
 - This is 'no-brainer efficiency': this learning is part of the day job and it is vital to providing preventative care before a patient dies. Need to have an honest discussion about the resources needed – it will tie up resources but lack of money cannot be an excuse.
 - RCA isn't always appropriate for deaths investigations and narrative reviews should be an accepted alternative, especially in mental health and learning disability deaths. This was acknowledged and there are commitments to review the serious incident framework to strengthen its implementation.
 - The application of the guidance needs to extend beyond the NHS and TJ confirmed it will apply to all NHS-funded care but there may be a phased approach to delivery. This position will be reviewed again and it will form part of discussions with the NQB. MR asked that this be stated explicitly in the guidance to ensure this is very clear and to avoid any confusion for services and the public.
 - The Structured Judgement Review process will require trusts to regularly publish what they have learned. This will not be a league table, as the data will not be comparable between trusts, or over time within a trust.

Other comments

- The guidance needs to engage with primary care and adult social care. We need to be clearer about when the roll out of new guidance to primary care and adult social care will take place, as 40% of deaths occur outside hospital.
- The focus should be on learning, not on outcomes (i.e. how avoidable a death is). There are two types of learning:

- i. personal/team
- ii. learning for the wider system.

Different mechanisms are needed for each.

- The language being used is still a problem, with no consistent terminology. There was acknowledgement that different people have different reasons for carrying out a review or investigation, which has an effect on the language used. Use of 'avoidability' etc is problematic as it immediately puts people on their guard. Use of 'incidents' is problematic – deaths are not 'incidents'.
- **Action: members of the EAG were asked to email their comments on the framework to deathsreview@cgc.org.uk.**
 - Challenge: none of the EAG members are families or carers. To ensure families are involved in developing the framework, it should be published online for comment.
 - Family involvement shouldn't be an afterthought. It should take the form of a formal consultation and not rely on ad hoc conversations.
 - Can the document be prefaced with a clear statement that family engagement from the earliest stages is crucial; the best way of doing this hasn't yet been agreed and is open to innovative practice, but providers need to understand the principle?
 - Feedback from the group was invited as soon as possible, before a discussion by the National Quality Board on 1 March.
- While the guidance is still in development, there is a clear expectation that trusts will act on it now.

Session four: Mapping the processes for learning from deaths

Leigh Sandals (LS) from Delivery Associates presented a draft process map for discussion, which sets out outcomes, processes and who is involved in learning from deaths. This draft was an initial starting point for discussion and was based on the draft framework.

Feedback from the room:

- Families don't appear on the process map in any obvious way – they should be at the heart of the process.
- Andrew Walker (North London Coroner) can advise on the role of coroner – the coroner's role is an important one.
- The inclusion of the dashboard is risky – we need to be careful not to drive a punitive performance management system.

- In parts of the country where the LeDeR methodology has been rolled out, learning disability deaths should be reviewed using the LeDeR methodology, otherwise they are reviewed using structured judgement review.
 - This depends on people with learning disabilities being identified when they come into contact with care services.
- Access to information between services is crucial to reaching accurate conclusions.
 - NHS Digital plays an important role in this.
 - Finding out when a person has died, and which services the person has been in contact with, should be automated and could use their NHS number.
- Can we have one set of guidance for acute trusts and one for MH trusts?
 - MR: we need all parts of the system to work together. Having more than one set of guidance risks fragmentation. However, the guidance may contain sections for specific services.
 - By not starting with the patient and the family, we create fragmentation.
- Thematic analysis is a key part of the learning exercise – we need narrative, not just numbers.
- A picture of the process map, showing contributions from the group, is at the end of these notes.

Session five: Workstream 8 – strengthening CQC’s assessment of learning from deaths

CQC is working on how to turn learning from the review into a tool our inspectors can use.

We can learn from:

- The methodology we used when we carried out our site visits for the review.
- Previous methodologies (not reinventing the wheel).
- Sharing this work as we progress, so we can use feedback to help us to improve it.
- The tool will be part of our inspection framework under ‘well-led’.
- Questions on which we’d welcome feedback include:
 - What would be the triggers for inspector review/focus?
 - When should we apply this?
 - Who should we be talking to when we inspect?
 - Should we be doing this everywhere? Or just on focussed inspections?

We will pilot this in our ‘well-led’ inspections in May/June.

Training for CQC inspectors will be crucial.

We also welcome thoughts and ideas on how we can better engage with families.

Session six: Evaluation of the review and lessons learned

Kim Forrester asked the group to comment on:

- What worked well over the course of the review.
- What could have been better.
- What key messages should be passed to the project team responsible for CQC's review of child and adolescent mental health services (CAMHS), which is setting up its own EAG.

Feedback from the group included:

- The review has pushed quality up the agenda.
- EAG members' comments were listened to and changes were made as a result.
- CQC has been on a journey with the EAG. It's important this isn't lost as new people join the group.
- The EAG should continue to meet occasionally (possibly annually, or more frequently?) to review progress.
- Many people brought a personal point of view to the work.
- CQC had people out in the field, who were able to see how serious the problems are.
- The EAG was an environment that welcomed openness, which included live tweeting during meetings.
- The longevity of the EAG and its diversity were two of its strengths.
- There are some groups that weren't represented on the EAG:
 - The Royal College of Psychiatrists
 - Adult Safeguarding Boards
 - Individual families and carers.
- The review embraced social media, which was often important for driving improvement.
- CQC could have been clearer about payments and expenses – this is a potential barrier to involving families and carers.
- If CQC wants to include children and young people in its forthcoming review of child and adolescent mental health, it's important to give thought to the format in which information is presented.

