NATIONAL QUALITY BOARD

5 October 2022 09:00 to 11:00

Virtual Meeting

MINUTES

PRESENT		
Steve Powis (Chair)	Sean O'Kelly (Chair)	
Adam McMordie (for William Vineall)	Aidan Fowler	Anna Severwright
Chris McCann (for Louise Ansari)	Colin Brown (for Susan Hopkins)	Gail Allsopp
Jamie Waterall	Kate Terroni	Mark Radford
Lorna Squires (for Ruth May)	Vin Diwakar	Yvonne Doyle
IN ATTENDANCE		
Anne Worrall-Davies	Carl Shaw	Cathy Hassell
Deborah Ivanova	Genevieve Cameron	Georgina Dean
Jane Docherty	Kathryn Lupton	Luisa Banks
Marie Cox	Marina Soltan	Neil Cunningham
Rosie Benneyworth	Tim Gardner	
Danny McDonnell (secretariat)	Dominique Black (Secretariat)	Fiona Butterfield (Secretariat)
APOLOGIES		
Clenton Farquharson	Louise Ansari	Lyn Romeo
Ruth May	Susan Hopkins	William Vineall
Shera Chok		

AGENDA

1. Welcome & Minutes of Previous Meeting.
2. a) LeDeR Annual Report
   b) Who I am matters – Experiences of being in hospital for people with a learning disability and autistic people. CQC report.

3. Mortality Review Working Group
4. Public Perceptions of Health and Social Care, The Health Foundation Report
5. Any Other Business

1. Welcome & Minutes from Previous Meeting

1.1 STEVE POWIS (Chair) opened the fourth National Quality Board (NQB) of 2022. SEAN O'KELLEY was welcomed as the new co-chair of NQB.

1.2 Attendees and apologies were noted as above.

1.3 The following changes to membership were noted:

- Viv Bennett has retired – Jamie Waterall is attending the NQB from OHID
- Rosie Benneyworth, Interim Chief Executive of HSIB is attending NQB in an observational capacity.

1.4 The minutes of the meeting on 21 June 2022 were approved and agreed as a true and accurate record. The minutes will be published in due course, alongside the associated agenda.

2. a) LeDeR Annual Report

2.1 LUISA STEWART and CARL SHAW (expert by experience) provided the NQB with an overview of the findings from the LeDeR annual report 2021. This is the seventh LeDeR Annual Report for LeDeR, the update provided to the NQB is in the context of previous LeDeR reports and aims to share learning.

2.2 CARL SHAW explained that assumptions must not be made based on a diagnosis; everyone is different, and everyone must be treated as an individual.

2.3 ANNE WORRALL-DAVIES informed NQB that LeDeR now has seven years of data, having been first piloted in 2015 and nationwide by 2017. There have been 14,500 completed reviews with local system learning, the reviews have important individual value especially to families and loved ones.

2.4 Evidence is consistent, national meta-analysis has shown the same information about causes of premature mortality; patients with a Learning Disability or autism diagnosis are frequently not receiving the care they need to live long healthy lives. It was noted that a Learning Disability is not in itself a life limiting condition.

2.5 The 2021 annual report demonstrates that 49% of deaths were avoidable, compared to 22% of avoidable deaths seen in the general population. Reasonable adjustments are not being made and information is not easily

accessible. Covid-19 had a disproportionate impact on people with a learning disability, with 35% excess deaths, compared to 14% excess deaths in the general population in 2020.

2.6 LeDeR has led to improvements such as improved access to vaccines and the reasonable adjustment digital flag to allow provision of reasonable adjustment needs. Practical actions by the LeDeR programme include work on sepsis, soft signs deterioration, a deterioration toolkit being rolled out and funded work across the Midlands region for deterioration in supported living. The programme has developed toolkits on acute care, preventing and identifying pneumonia and are working on sleep apnoea toolkit.

2.7 NQB was asked to :

- Consider how the NQB can support the next steps work to impact on health inequalities around circulatory diseases, cancer, and epilepsy?

- Consider how the NQB can provide leadership in our engagement with the Royal Colleges to support a change in behaviour among mainstream clinical staff towards people with a learning disability and autistic people?

2.8 JAMIE WATERHOUSE offered to work alongside the LeDeR team in conjunction with the OHID *All Our Health* public health training programme, which aims to increase the public health impact of all and includes a Learning Disability training resource through a public health lens. Work can be done in partnership to finesse and develop for launch.

Learning Disability should be at the heart of prevention work and this needs to be included with social care as well, with increased access to blood pressure testing as an example.

2.9 GAIL ALLSOPP asked if it would it be helpful to have guidance that improved the diagnosis of Learning Disability and should NICE consider this? The presenters agreed that this is a live issue in the LeDeR programme and improving diagnosis would be valuable.

The Royal College of General Practice have a Learning Disability group linked into Midlands training work.

2.10 ANNA SEVERWRIGHT added that it was great to hear from another expert by experience and would encourage NQB to bring lived experts to future meetings. NQB could play a role in modelling and encouraging the wider system to do the same. In relation to access to health advice, the system is bad at dealing with difference; we expect people to interact with the system in a set way, this culture needs to change, including the language and messaging.

2.11 MARINA SOLTAN stated that community acquired pneumonia is an important point, patients with a Learning Disability who attend an acute respiratory centre put of hours can face colleagues who struggle to communicate with them and the service struggles to meet their needs.

Clinical risk scores do not take into account Learning Disabilities. MARINA is looking at this work currently and keen to link up.

2b) Who I am matters – Experiences of being in hospital for people with a learning disability ad autistic people. CQC report.

2.12 KATE TERRONI introduced the item *Who I am matters – Experiences of being in hospital for people with a learning disability and autistic people, CQC report.* DEBBIE IVANOVA stated that the report shares information we already know, things that aren't changing quickly enough. The report will be published on 3 November 2022. There is huge inequality in accessing care and the quality of care that people receive. The work started with Oliver McGowan's LeDeR review.

2.13 MARIE COX presented the findings from the report to the NQB by theme. The themes are not to be considered in isolation, but all make up peoples' experiences. The report is set out as a series of statements or challenges, none of this is new.

2.14 NQB was asked to consider:

- How can NQB accelerate changes and improvement in this area?
- Why do people with a Learning Disability and autism have poorer outcomes?

The health system needs to be more proactive, information such as hospital passports and flags could help, as well as developing community relationships and discussing at annual health checks.

2.15 VINDIWAKAR shared with NQB a story in relation to a patient whose care should have been better and questioned if we fully understand the root causes of the experiences being described in the report? Lack of staff training if often cited but training does not always solve the problem. If training and shared care records were the solution, we would have solved these problems. We need to think about causes and impacts in a very different way.

2.16 ANNA SEVERWRIGHT commented on coproduction, when anything is changing, redesigning services, there must be a wider range of voices in designing and inputting into that. This may need to be done differently for people with a Learning Disability. This may take longer but the service will work effectively for more people. It is important to actively ask Learning Disability patients how they found a service, the feedback service is often not accessible.

2.17 AIDAN FOWLER confirmed that the Serious Incident framework has now been superseded by the Patient Safety and Incident Response Framework, which changes the way we support and encourage organisations to investigate incidents, all based on learning and a themed approach. PSIRF

moves away from root cause analysis, looking in a more holistic way at underlying principles to change and avoid things happening again in the future. PSIRF involves patients, relatives and carers in a way that hasn't always happened previously.

2.18 NQB agreed to receive an update on progress for LeDeR and experiences of care for patients with a Learning Disability and autism in Spring 2023.

3. Mortality Review Working Group

3.1 CATHY HASSELL updated the NQB on the work of the Mortality Review Working Group. In April 2022 the NQB asked for better joined up work designed to understand death and death in an NHS setting. Learning from Deaths (LfD) of people in the care of providers can improve future care. This work builds on the former DHSC LfD programme and guidance.

3.2 The aim is to join up the already ongoing work to understand deaths and help people to care for patients, learn and prevent premature mortality.

3.3 The initial work scopes out what is already in place and what can add value to the existing work. The scoping found no shortage of work at national, regional, or local level. However, there could be better visibility of what is already in place, which is key. The recommendation from the scoping work is to establish this group to join up and identify themes and gaps and learning.

3.4 The working group will be chaired by AIDAN FOWLER, NHSE National Director of Patient Safety, and will meet quarterly reporting into the NQB.

3.5 AIDAN FOWLER stated that the scale of this work considers deaths that are scrutinised coronially or via a medical examiner, half of those deaths occur in hospital, half in the community. Most of these deaths are expected and there are no flaws in care. There is a need to understand to ensure that all the existing information is brought together, learning will overlap and needs to result in action and beneficial change. The working group will not propose new data collections but will aim to optimise use of the data already in existence.

3.6 NQB provided agreement for the working group proposal, endorsed the establishment of a working group, to secure Patient and Public representation, and endorsed the proposal to develop policy.

4. Public Perceptions of Health and Social Care, The Health Foundation Report

4.1 TIM GARDNER introduced to the NQB The Health Foundation Report *Public Perceptions of health and social care, what the government should know.* The Health Foundation is an independent charity with a mission to improve health and health care for people of the UK via a range of means including

funding, academic research, supporting frontline imp programmes, in house research policy and analytics.

4.2 GENEVIEVE CAMERON shared the headline findings from most recent survey, which was developed in partnership with Ipsos. This is the second survey and midpoint in a 2 year programme of research into public perceptions.

4.3 The survey captures whole public experience and views on standards of the quality of NHS and social care, tracks views on changes to standards of care over time, and expectations of future changes. Perception of quality is relatively preserved despite the pressures seen and must not be taken for granted.

4.4 YVONNE DOYLE asked if the NQB has access to and an understanding of why people in disadvantaged areas have a worsened perception of services? Is this simply life experience as a whole or specific to the quality of healthcare in these areas? NQB agreed it was an important area to consider.

4.5 JAMIE WATERALL raised triangulating the many areas of data of public perceptions and considering the impact of those. Increased costs of living may impact on perception, NQB agreed to consider what can be done to understand this further.

4.6 CHRIS MCCANN informed NQB the Healthwatch survey shows concerns regarding patient access; additional burdens to access are seen in deprived areas, for example accessing services online, challenges in relation to travelling to services, this may impact on how these communities perceive quality of care.

4.7 Of the 2,000 people surveyed, approximately half had contact with a GP, much smaller numbers had visited an outpatient setting or A&E.

4.8 Prevention is really important as well as patient access. English speaking is a barrier and impacts on experience. The Index of multiple deprivation domain, the health and disability deprivation domain, maybe worth looking at in context.

5. Any Other Business

5.1 No other business was raised. The next NQB meeting is 21 November 2022.

6. Actions:

Actions
NQB agreed to consider why people in disadvantaged areas have a worsened perception of services.
NQB agreed to consider what can be done further to understand how the increased cost of living may impact on public perception of healthcare quality.