

NORFOLK HEALTH OVERVIEW AND SCRUTINY COMMITTEE
Minutes of the meeting held at County Hall
on 18 January 2024

Members Present:

Cllr Jeanette McMullen	Great Yarmouth Borough Council
Cllr Brenda Jones	Norfolk County Council
Cllr Pallavi Devulapalli	Borough Council of King's Lynn and West Norfolk
Cllr Robert Kybird	Breckland District Council
Cllr Peter Prinsley	Norwich City Council
Cllr Richard Price	Norfolk County Council
Cllr Robert Savage	Norfolk County Council
Cllr Fran Whymark	Norfolk County Council

Co-opted Member (non voting):

Cllr Edward Back	Suffolk Health Scrutiny Committee
Cllr Edward Thompson	Suffolk Health Scrutiny Committee

Substitute Members Present

Cllr Holiday substituting for Cllr Boyle

Also Present:

Tricia D'Orsi	Executive Director of Nursing, Integrated Care Board (ICB)
Ian Riley	Executive Director for Digital and Data, Norfolk, and Waveney Integrated Care Board
Geoff Connell	Director of Digital Services, Norfolk County Council
Gary O'Hare	Governance and Safety Advisor, Norfolk, and Suffolk NHS Foundation Trust
Dr Andrew Kelso	Medical Director, NHS Suffolk and North East Essex ICB Board
Alex Stewart	Chief Executive Officer, Healthwatch Norfolk
Peter Randall	Democratic Support and Scrutiny Manager
Dr Liz Chandler	Scrutiny & Research Officer
Maisie Coldman	Trainee Committee Officer

1 Apologies for Absence

- 1.1 Apologies for absence were received from Cllr Boyle (substituted by Cllr Holiday), Cllr Shires, Cllr Kybird, Cllr Cork, Cllr Dark and Cllr Bambridge.

2. Minutes

- 2.1 The minutes of the previous meeting held on 9 November were agreed as an accurate record of the meeting.

3. Declarations of Interest

3.1 There were no declarations of interest.

4. Urgent Business

4.1 There were no items of urgent business.

5. Chair's Announcements

5.1 There were no Chair's announcements.

6. Norfolk and Waveney Integrated Care Board Digital Transformation Strategy

6.1 Ian Riley, Executive Director for Digital and Data, Norfolk, and Waveney Integrated Care Board (N&WICB), introduced the N&WICB Digital Transformation Strategy. The full version of the Digital Transformation Strategy was available on the N&WICB website. The committee heard that the Digital Transformation Strategy was developed in line with the national Digital Strategy, with key priorities being the implementation of Electronic Patient Records (EPR) in the three acute hospitals, the sharing of identifiable and anonymous data safely and, digital literacy. Norfolk and Waveney had low benchmarking compared to the rest of the county concerning digital maturity.

6.2 Geoff Connell, Director of Digital Services, Norfolk County Council (NCC), added that the Digital Transformation Strategy was an example of cross-organisation collaborative working between the N&WICB and NCC.

6.3 The committee received the annexed report (6) from Dr Liz Chandler, Scrutiny and Research Officer, that noted information to aid the examination of Norfolk and Waveney Integrated Care Board's (N&WICB) Digital Transformation Strategy.

6.4 The following discussion points and clarifications were offered:

- It was confirmed that the procurement process for the development of the EPR software had occurred and that MEDITECH had been awarded the contract. Members were reassured that the procurement process was robust and that providers had to meet certain standards.
- MEDITECH had been commissioned to develop the EPR software across acute hospitals. It was acknowledged that no system would be without bugs but that there was confidence that MEDITECH would be able to identify and remove bugs if they were ever to occur. Providers have a clear business continuity plan in the event of system issues. Additionally, the ability of patients to access their records would strengthen resilience if the system were to go down.
- The EPR would have an associated portal that would allow the patient to access their records and interact with clinicians. The NHS App over time would incorporate parts of the care record.
- Members of the committee heard that it would be against GDPR guidelines to sell patients' data. Reassurance was offered that it was not the intention to sell patient data. Strong governance arrangements and pathways for accountability reduce the likelihood of this further. Additionally, data controllers can withdraw access to data if it was to be used inappropriately.

- Following a question about the safeguards to protect patient data, it was confirmed that data was anonymised. A patient would only be identifiable by a number that would link patient records across the system together.
- A member asked if the data that was held by the system would be useful if there was a health crisis, such as a pandemic. In response, it was shared that the non-identifiable data was a powerful tool for analysis. If from the non-identifiable data patients of interest were identified, this would be passed on to the practice.
- Members raised concerns from within their communities over the secureness of the data. In reply, it was noted that the EPR would be more secure than paper records which were currently being used. Authorised access would be required to see the documents and there were plans to grant different levels of access to patient records. It was hoped that the EPR would offer assurance to patients that their records were being stored and accessed appropriately.
- There was a need to better understand residents' thoughts about where they want their data to go / what they would like it to be used for. A Citizens' Summit in London highlighted that citizens were against their data being sold but would be comfortable for it to be used to aid medical research. A member questioned if a more nuanced system of consent was required so that patients could indicate their preferences. The system of consent was set nationally, and work was being carried out to see how this could be more nuanced.
- There was a general feeling that the patient would have more control over their data as they would be able to access and contribute towards it. There was a future ambition that patients would be notified when their records have been accessed.
- A member shared anecdotal evidence of their frustrations about having to sign into multiple software packages to carry out their clinician work. In response to this, the committee heard that a benefit of the EPR that was being worked towards would be a single sign on so that all systems that are used can be accessed via one software.
- The committee heard that the data hub aspect of the Share Care Record (SCR) would bring data from multiple care settings into one place, including the notification of death. Having access to a larger pool of data across multiple care settings would allow for the bigger picture to be established when doing mortality reviews.
- There are nine SCR providers across the country. Currently, the SCR is local but national work and conversations was occurring to consider how they could be joined up.
- It was confirmed that patients can opt out of the SCR.
- There was a general concern amongst members about cyber security and the need to ensure that the systems are robust. The committee heard that the responsibility to ensure safe practices was all data controllers and that more funding was being directed towards cyber security than ever before.
- In response to a member's question about the inclusion of frontline staff in the development and design of new systems, the committee heard that that was a

clinical design authority in which staff help to shape the systems and service. It was regarded as important to understand the issues from the perspective of staff.

- It was noted by officers that cultural change within care settings was an important aspect of the Digital Transformation Strategy. Work was being carried out, which included workstreams on focus areas, to support staff to understand and use the systems.
- The implantation of the EPR and the SCR would allow for the Integrated Care System to follow through on its commitment that patients only share their story once.

6.5 The Chair concluded the discussion, highlighting that whilst the importance of moving towards the systems was noted, there needed to be reassurance that the system was robust, had the necessary safeguards in place, and would undergo auditing processes. Patients' ability to access their records and data was important and the conversations around consent to make it more nuanced were required nationally.

6.6 Summary of actions:

- To recommend that the EPR and SCR make use of robust software and that suitable auditing takes place.

7. Norfolk and Suffolk NHS Foundation Trust (NSFT) Mortality Recording and Reporting Review

7.1 Gary O'Hare, Governance and Safety Advisor, Norfolk, and Suffolk NHS Foundation Trust, introduced the committee to the Norfolk and Suffolk NHS Foundation Trust (NSFT) Mortality Recording and Reporting Review report. This was the first joint report between NSFT and N&WICB and it was hoped that this would signify their determination to work in collaboration. Key points of the report were highlighted to the committee. They heard that work had been done to develop an electronic record system, that there was a diverse focus group with appropriate representation, and that the report would also clarify how deaths would be categorised.

7.2 Dr Andrew Kelso, Medical Director at NHS Suffolk and Northeast Essex ICB Board described that Suffolk and Northeast Essex ICB had supported NSFT to improve mortality recording and learning. The co-produced work carried out offered valuable insight into the unique needs of bereaved relatives.

7.3 Tricia D'Orsi, Executive Director of Nursing, N&WICB, highlighted that there was a commitment to ensure that the Norfolk Health Overview and Scrutiny Committee (HOSC) would be kept up to date on the collaborative work occurring between N&WICB and NSFT.

7.4 The committee receive the annexed report (6) from Dr Liz Chandler, Scrutiny and Research Officer, that noted information to aid the examination of the Norfolk and Suffolk NHS Foundation Trust (NSFT) Mortality Recording and Reporting Review.

7.5 The following discussion points and clarifications were offered:

- A member asked for clarification about which deaths would be captured within the new electronic record system. It was confirmed that in-patients would be

automatically recorded irrespective of whether their death was related to mental health or not. It would also record the deaths of patients discharged from the hospital/community hospital within 6 months before their death. Multiple sources would be used to collect this information such as the NHS Spine, primary health care, and bereavement officers. Once the death had automatically been picked up, it would be triaged and reviewed with the assumption that learning would be shared.

- Action 16 related to an external verification of the accuracy of NSFT data and how it was being recorded, this would be carried out by an external consultancy team. A member questioned why this action had not been carried out. In reply, it was noted that the delay was due to the scope of the auditing process needing to be established, this would include colleagues' involvement. This would be dependent on seeing how the new system operates. NSFT wanted to be assured that the right data was being collected and that the appropriate access and categorisation were occurring before an auditor was appointed. Members were reassured that this would be sourced and that the expected time frame was March/April 2024.
- The committee heard that the Grant Thornton co-produced action plan that HOSC had requested to have sight of within one month of the 14 September 2023 meeting, was still waiting to be signed off by the ICB and NSFT. Members of the committee shared their frustrations regarding the delay in receiving the Grant Thornton co-produced action plan and were keen to establish a timeline for when this might be expected. Healthwatch Norfolk added that this frustration was also felt by bereaved relatives involved in co-producing the action plan. In response to this, officers highlighted the desire to produce a plan that understood and accounted for all the issues.
- The Grant Thornton co-produced action plan would be overseen by the Learning from Deaths Action Plan Management Group which had recently been established. The Grant Thornton co-produced action plan was one aspect of the work that was happening.
- It was confirmed that the Grant Thornton co-produced action plan was developed in conjunction with the Forever Gone: Losing Count of Patient Deaths report. A member felt that this report needed to be acknowledged within the terms of reference of the Deaths Action Plan Management Group.
- It was raised that the report included a lot of action but no evidence of outcomes. In reply, it was suggested that NSFT return to HOSC to note the outcomes and direction of travel, concerning mortality recording and reporting.
- The communication between HOSC, N&WICB, and NSFT was highlighted as poor. There was generally a desire to see the recording and reporting of mortality data improve but that communication was a barrier. Cllr Jones was the link between HOSC and NSFT, she shared her difficulties with this relationship. In response, Gary O'Hare offered to meet Cllr Jones with himself and Caroline Donovan, the Chief Executive of NSFT, to ensure that the link with HOSC was being utilised.
- In reply to a question about whether the bereaved relatives working on the co-produced action plan were comfortable with the delay, the committee heard that the bereaved relatives, who are the authors of the Forever Gone: Losing Count of Patient Deaths report, were not currently engaging in the system as they were

disappointed in the way it was working. The offer for them to be part of the newly established Deaths Action Plan Management Group remained.

- The role of medical examiners was shared with the committee, and they were notified that in April 2024 there would be a change to extend their current role to include the certification of death that community doctors carry out. Medical examiners are asked to look out for particular circumstances, such as mental health-related deaths, and to notify partners when they occur. The medical examiner can act as a contact and source of the notification of death. NSFT's electronic recording system was needed to ensure that there was the right connection with the medical examiners.
- There was an emphasis on the opportunities to learn and not necessarily looking at processes/issues in isolation. National work on mental health data reporting was occurring, it was felt that this was an opportunity to make the system better and to bring it in line with the national direction.

7.6 The Chair shared with the Committee a statement (Appendix A) written by Caroline Aldridge, Anne Humphrys and Cllr Emma Corlett, the authors of Forever Gone: Losing Count of Patients Deaths report.

7.7 The following comments were made in response to the statement:

- Tricia D'Orsi responded that time was needed to reflect on the statement given so that all the issues could be understood and addressed. The relationship between Caroline Aldridge and Anne Humphrys was noted as valuable. Dr Andrew Kelso echoed this response.
- Gary O'Hare reiterated his offer to meet with Caroline Aldridge, Anne Humphrys and Cllr Emma Corlett.
- Members noted how poignant and moving the statement was.
- The motion that was agreed at the 14 September 2023 meeting to call for a Statutory Public Inquiry was in progress but had been delayed. A letter to the Secretary of State would be sent imminently.
- Members of HOSC felt that it would be valuable to reach out to Caroline Aldridge, Anne Humphrys and Cllr Emma Corlett to better understand their experience.

7.8 Chair concluded the discussion, noting the importance for HOSC and residents of Norfolk and Waveney to fix the issue with mortality recording and reporting. The general feeling from the committee was that HOSC wants NSFT to succeed and that the mental health services that they provide need to work for the people who require them. The need for prompt information sharing between organisations was vital as was ensuring that the electronic record system was robust and working in line with its intentions. Data did need to be accurate and recorded appropriately and audits would be essential to ensuring that this was the case.

7.9 Summary of actions:

- The committee would receive the Grant Thornton co-produced action plan as soon as it was available

- The Forever Gone: Losing Count of Patient Deaths report would be included in the terms of reference of the Deaths Action Plan Management Group
- The offer by NSFT for the authors of the Forever Gone: Losing Count of Patients Deaths report would to re-engage with the mortality work would be made to the authors
- NSFT will return to HOSC in May with an update on progress and vision for NSFT.

8. Proposed Forward Work Programme 2023/24

- 8.1 The Committee received a report from Peter Randall, Democratic Support and Scrutiny Manager, which set out the current forward work programme and briefing details. The Committee **agreed** the details for both briefings and future meetings.
- 8.2 Cllr Price suggested that the proposed closure of Blakeney Surgery, part of Holt Medical Practice, be considered. Cllr Holiday provided the committee with additional context highlighting that the service supports over 2000 residents. During the COVID-19 pandemic the practice withdrew from clinical services and there, from what could be established by the member, was no formal governance process followed. It was asked if this could be considered, that the ICB find the formal governance process that was followed, and that N&WICB pause the decision to close the practice.
- Tricia D’Orsi noted that it was not within her gift to decide to pause the close of Blakeney Surgery. She would take back the request for further information and would be happy to bring it back to the committee.
- 8.3 Cllr Jones suggested that malnutrition and poverty in Norfolk and Waveney be looked at following data that suggest that Norfolk and Waveney have the highest rates of malnutrition in the county. Tricia D’Orsi suggested that this could be arranged in collaboration with the Public Health team at NCC.

Fran Whymark Chair Health and Overview Scrutiny Committee

The meeting ended at 12:31



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Statement from the co-authors of Forever Gone: Losing Count of Patient Deaths to Norfolk Health Overview and Scrutiny Committee - 17th January 2024

After we attended Norfolk HOSC to discuss the Grant Thornton audit and Forever Gone, we left the meeting full of hope and galvanised to work with the system as a result of the robust recommendations from HOSC. These demonstrated an understanding of the seriousness of the situation and a need for urgent and decisive action. HOSC recognised the need to hold the system to account because losing count of the deaths due to inadequate mortality data, and therefore the inability to learn from it to prevent other deaths, had happened in plain sight. Regretfully, we have stepped away from the mortality work because of the behaviours, actions, and inaction, of the Norfolk and Suffolk systems. This includes the failure of both ICBs to hold NSFT to account and the utter disdain shown by senior officers across the system for the HOSC recommendations and bereaved families.

When we presented Forever Gone at the public board meetings of both ICBS and NSFT in July and August 2023, the Chairs stated our report should hold equal weight with the Grant Thornton audit and that recommendations from both reports must be addressed. All three Boards ratified recommendations that included working with bereaved families to develop an action plan. Unanimously, we were apologised to and promised the system was committed to working with us in order to learn and change. The Chair of the Norfolk and Waveney ICB apologised publicly because *"...too many people had not received the care they needed and that too many people have died"*. She went on to say that it was important to listen to people like us because we *"... had been saying for years that the data is not consistent or accurate, and that should have been listened to much earlier..."* because we *"were in essence right"*. Sadly, all were empty apologies and promises. There is clearly no intention from the system to address our findings. We are still not being listened to, we are not convinced the data is good enough yet, and too many people are still dying.

The ICBs asked HOSC for an extension to enable a detailed plan with timings to be submitted on November 9th 2023. No plan was submitted then or since. A detailed plan was made by the collaborative mortality group and agreed by all parties including NSFT. It was agreed that any coproduction with bereaved families should be undertaken independently of NSFT with the ICBs to lead the work. This was vetoed by NSFT at the last-minute, thus evidencing both ICBs failure to fulfil their commitments to HOSC and bereaved families. All parties involved in the Mortality Task Group were made fully aware of our concerns in a resignation letter from Caroline Aldridge. Therefore, the report from NSFT is disingenuous because it gives the impression that genuine co-production has taken place and that bereaved people's wishes have been listened to and will be incorporated into any plan.

Sadly, the behaviours of many officers in the Mortality Task Group added to the harm we have already experienced. We cannot articulate strongly enough how damaging it is to be invited to get involved with promises of genuine collaboration, in the hope that this time things will be different, only to be disregarded, and for the system to close ranks and return to the status quo. It is not ethical or morally justifiable to use bereaved people in such tokenistic or disempowering ways.

There have been 9 CEOs in the last decade without demonstrable change in the culture, behaviours, or death rates. HOSC have tried many times to hold NSFT to account resulting in NSFT repeatedly apologising for providing misinformation or inaction. This shows a resistance to scrutiny which has been reflected in the mortality work where NSFT have frustrated attempts to look at the data on deaths and be open and transparent about the work they are doing. The culture has not changed since Rob Behrens, Parliamentary and Health Service Ombudsman, stated when interviewed for Newsnight *"Patient Safety is not held in as high esteem as the reputation of the trust."*

The reality is that too many people continue to be Forever Gone. Too many families wake up each day with a well of grief that is never going to run dry. These families are left making futile and painful attempts to make things better and are having their grief paraded by a system that simply wants them to go away. The ICBs seem to have abdicated their responsibility to oversee NSFT. It now falls to those with statutory powers, like HOSC and the Secretary of State, to use the power we do not hold and follow this through. Those who are Forever Gone and their families are counting on you not to let them down.

STATEMENT ENDS

Possible Questions

We feel there are fundamental questions that HOSC might want to ask on behalf of bereaved families:

- Can NSFT say with confidence that everyone who has died under their care and management have been counted and they could answer with certainty whether someone's loved one has been included in their figures?
- Can the ICBs and NSFT say why they have not followed HOSC's recommendations and submitted a co-produced plan?
- Can the ICBs and NSFT produce a copy of the plan made by the Mortality Task Group in 2023 and show how they will use this for the basis for a new plan given the main thrust is for NSFT not to lead on this work?
- When can HOSC expect the promised co-produced plan with supporting evidence of bereaved families' views on it?
- How does NSFT plan to honour the commitments made to learn from Forever Gone given that we have had to withdraw for our own wellbeing and there is no mention of it in the terms of reference for their new group?
- How do the ICBs plan to honour the commitments made to learn from Forever Gone?
- When can the outstanding points from the Grant Thornton plan, which are critical to producing accurate mortality data, be complete? When will the re-audit take place to verify improvement?
- How long will it be before the mortality data can answer important questions raised by Grant Thornton and Forever Gone, such as 'how many people died following discharge?' or the level of detail required to identify patterns?

Additional information

We said at the time of writing *Forever Gone* that if this did not change things and made services safer, then nothing would. Sadly, we have drawn the conclusion that no matter what we, and other bereaved families do, the system will not change because the system itself does not want to.

We remain very concerned about NSFT's plans to bring the coproduction with bereaved families in-house. We certainly have felt at times bullied, gaslighted, excluded and belittled. We know that other bereaved people have experienced retraumatising from trying to work with the trust. Repeatedly, they have demonstrated they do not have the organisational maturity, grief literacy, or humility to work in psychological safe ways with traumatically bereaved people.

The ICBs have not demonstrated the ability to work healthily with bereaved people either, or to hold NSFT to account, and it has been very disappointing to see how quickly things have reverted.

The behaviours we observed and experienced in the Mortality Task Group include:

- The Chairs and CEOs agreeing that officers who attended this group would be decision-makers and, therefore, there would be no hold up to the work and no one organisation or person had the veto in relation to this work. They reneged on this when NSFT vetoed things.
- At the suggestion of the ICB Chairs and with everyone's agreement, Caroline was appointed Co-Chair. This was dropped without explanation when Caroline refused to co-sign a misleading statement to HOSC. This is gaslighting.
- Attendance was poor particularly from NSFT who repeatedly did not provide information or feedback asked for by the group. Their engagement and input in meetings was minimal.
- Caroline did the greater majority of the work to formulate the groups wishes into drafts, re-drafts of the plan and a schedule. The wider group had neither the time nor seemingly the inclination to move beyond ruminating about what co-production entailed.
- The group seemed to struggle to differentiate co-production with service-users/carers and bereaved families. We met with both Healthwatches to explain the expertise they would need to do this work with traumatically bereaved people.
- The mortality task group seems to be a classic example of the 'pit of inaction'. We observed the toxic power relationships and culture at NSFT, and between the ICBs and NSFT, surface and undermine this work.

People have been harmed by mental health related bereavements and the processes that follow, some have been further harmed by attempting to work with the system to support positive change, and, critically, people will be harmed if the system recruits and uses traumatically bereaved people without a radical shift in behaviours.

We are involved with a large network of bereaved people the majority of whom refuse to engage with NSFT. We are concerned that our withdrawal means NSFT have a very small pool of bereaved families to engage in their new Mortality Group. That group is big and has a largely corporate membership which many would find intimidating. Unless NSFT are able to recruit (and safely support) bereaved people with an understanding of and willingness to scrutinise mortality data, and who are not too traumatised or vulnerable, the co-production will be tokenistic at best.

Over the last 9 years, we have tried so many different ways (carrot and stick) to provoke positive change and prevent deaths. No doubt, NSFT will ask for time for their new CEO to fix things. Newly in post, she vetoed the coproduced plan and then drafted in an out of area associate to lead on NSFT's mortality work. Frankly, we have lost faith that given the entrenched issues relating to mortality at NSFT and the current state of services and the wider system it is possible to address the underlying rot. There has been plenty of talk with repeated rhetoric and promises but little action. If our efforts to prevent deaths are futile then all we can do is to focus on supporting those who are bereaved because of mental illness. Hence our decision to withdraw.