Appendix One

Retrospective Review of all Patients who died as an In-Patient with a known diagnosis of Learning / Intellectual Disability (LD) SFH 2018-19

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Introduction

The National Policy for 'Learning from Deaths' has been implement across the NHS. Key patient groups of specific need and possible vulnerability were identified in this policy and must have close scrutiny including those with Learning / Intellectual Disability. There is an expectation that all patients with these diagnoses are prospectively and proactively reviewed and then reported through the internal mechanisms of the Trust. This is especially important if there may be poor care and excess harm that might have led or contributed to a complaint, serious incident and or external scrutiny e.g. investigation and inquest by the Coroner Service. External review through the LeDeR programme is also part of the current national and local standard. This report reviews in part the status and learning from the Nottinghamshire programme.

As part of the good governance of the Mortality Surveillance Group (MSG) there was a retrospective planned review of these patients because of the inconsistent reporting to MSG of the number of deaths and the quality of the patients care.

This is an interim report from an ongoing review. It begins to test 4 questions:

1. What did the Trust know about these patients already?
2. Are there potential gaps in the governance of the Trust?
3. What risks and opportunities for improvement does this mean?
4. How is information being shared to those that were close to the patient?

Method
Data pertaining to all the patients with these diagnosis thought to have died in this period (April 2018 - April 2019) was received by the Trust lead clinician for mortality from the clinical nurse specialist for patients with LD. Mortality Reporting Data for these patients was then accessed and reviewed by this clinician and summary outcomes of the mortality were reviewed with steps 1 Initial Review ,step 2 Structured Judgement Review and step 3 (Avoidability Assessment) recorded. Any relevant text comments were also recorded.

Planned meetings with the Legal Department, Governance Support Unit and Specialist Teams (such as Sepsis CNS and Resuscitation Team) were conducted to establish the relevant information they had and acted on these cases. Data Quality review was the performed with the help of the senior information analyst using the prescribed codes to look for missed cases of these patients who might have died in our in-patient care.

With the following Learning Disability codes :	
F70 - Mild mental retardation	F73 - Profound mental retardation
F71 - Moderate mental retardation	F79 - Unspecified mental retardation
F72 - Severe mental retardation	F81 - Specific developmental disorders of scholastic skills
Q90 - Downs syndrome	

Results

Patients identified:
Initially 13 patients were identified with no new cases being offered by the specialist teams. 1 death occurred soon after discharge and therefore was not part of the standard in-patient review system but would be available to the LeDeR programme. 12 patients died in Kings Mill Hospital.

It is noted that the close working relationship of the Governance Support Unit and the Legal Service Department who meet weekly to identify, discuss cases and update processes.

Outcomes

Step 1-		11 / 12 (92%) cases achieved an initial review.

Step 2 -		7/12 (58%) cases achieved the SJR of which there were none assessed as poor or very poor care.

Step 3 –		5 cases there was no excess avoidability risk. 3 were implied but not confirmed by Step 2 was no excess avoidability risk .The remaining cases it was not known.

General Surgery
The cases reviewed from this department only saw fit to do the initial review; there should have been at least a SJR due to the positive trigger in the tool.

Respiratory Medicine
This department seems to have cared for a number of these patients. The compliance to achieve reviews was less than required. Case 10 which pending inquest appears to relate to a respiratory consultant with a low rate of compliance for electronic review submissions.

LeDeR Review

Case Data pending, general performance static given below.

Legal / Coroner

There were 3 cases already known to have triggered legal and safeguarding process.

Comments

Pneumonia / Aspiration Pneumonia, Sepsis and Bowel problems seem not unsurprisingly more common to be cited in the diagnosis or mechanism of death.
There was little easily to find evidence of out of hospital advance care planning for the end of life care, this it must be stated is a biased or skewed simple. There was good practice noted in hospital of the end of life care provided however. In one case (6) the GP to not engage in such planning despite the requests of the care providers. Not all the patients had comments supplied by the LD CNS but for those that did there was a variable compliance in the quality of the core documentation standards.

Data Quality
5 extra cases have been identified by the information team that require review to establish if they are truly missed cases or not. See appendix 1 for additional information.

Proposed Conclusions
This interim report supports further discussion by the Trust about the good practice that has been seen and potential areas for improvement both in clinical care and clinical governance.

1. What did the Trust know about these patients already?
2. Are there potential gaps in the governance of the Trust?
3. What risks and opportunities for improvement does this mean?

- There has been an apparent increase in the mortality reviews recorded on the electronic review system
- There were examples of good clinical care when some cases were considered.
- There were good examples of governance from the specialists teams involved with working across teams and there is already a body of information to easily access.
- At first glance the clinical care and outcomes don’t trigger excess risk or identify adverse outcomes.
- At first glance the Trust seems to know which patients have died, where and what from.
- A particular case (2) demonstrated the openness of 2 senior and experienced consultants to perform a joint review of a case where pre-hospital care seemed to have a very significant causal effect on outcome. This case will also be subject to Coronial review.

But

- Data Quality checks have potentially highlighted 5 further cases (found through clinical coding searches) that need further review to establish if they truly represent missed cases. If they are missed cases why did we not know about them?
- The compliance to Mortality Review is below the expected standard where all should receive at least an initial review and SJR. Review of the MSG minutes demonstrates these cases are not routinely shared or discussed at MSG via the divisions.
- When reviews are completed there seems to variation in the quality and extent of the process, ranging from detailed reviews by some to only initial screens by others. This tends to add doubt to the consistency of the assessment of the SJR and AA.
- There are clearly cases which require further review and challenge including at MSG. This includes case 12 where the Resuscitation Officer had flagged the case to the Sepsis CNS because the sepsis led to a cardiac arrest and the Resuscitation Officer had highlighted possible elements of sub-optimal care.

- Not all reviewers follow the correct stepped approach when performing this task and progress to SJR and AA.
- The review process becomes more subjective and is open to significant (unintentional) bias without more challenge. This is potentially exaggerated where there is a failure of the clinical teams to engage with the wider multi-disciplinary and specialist teams. This statement needs to be tempered because the review could not look at the quality of the M+M discussion in specialities or divisions.
- Not all the patients had comments supplied by the LD CNS but for those that did there was a variable compliance in the quality of the core documentation standards e.g. Care Planning and DNA CPR and MCA related decisions.
- LeDeR completion in Nottinghamshire is in significant delay (up to 18 months for some cases) and the Trust cannot rely on timely information from this process to aid learning and improvement.

4. How is information being shared to those that were close to the patient?
   Unfortunately this review process can't reliably answer this question at present. This level of information is not routinely shared at MSG and not recorded in the e-MRT. Further attempts will take place through discussion with the Patient Experience Team to highlight any on involvement.

Formulation of Recommendations

Care must be taken with this initial report as further information is being sort to complete the review. Recommendations must come from Mortality Surveillance Group. Key Areas to consider

- Increasing awareness of clinical risks and management of common causes for admission and deterioration (aspiration / pneumonia, sepsis, epilepsy, bowel problems)
- Clinical documentation standards
- Individual, Teams, Services and Divisions reporting requirements and compliance
- Specialist clinical teams' involvement and case identification list includes but not exclusively: LD, Safeguarding, Sepsis, IPC, EoL, and Resuscitation.
- Improved coordination, information sharing and registration of cases and themes through governance teams (GSU, Legal) reporting to MSG
- Feedback from learning and accountability especially to those close to the patient
- Links and reporting via the future Medical Examiner Service

Summary Table of Cases

Case	Team / Ward	Step 1 (Initial Review)	Step 2 (SJR)	Step 3 (AA)	LeDeR Review	Serious Incident	Legal / Coroner Action	Comments
1	Resp	✓	✓ GC	✓ NA		no	none	1a. Pneumonia (CAP) LD front of house care plan behind alert card. Good external MDT working conducted by LD nurse. Good communications between teams. DoLs paperwork complete. LD care plan completed DNACPR incomplete Support provider unwilling to support rapid discharge until funding had been firmly agreed, resulting in him dying in the hospital setting.
2	Geri	✓	✓ GC	✓ ?		no	Yes Safeguarding	Pre-admission factor determined outcome making the AA a difficult question to answer. This case was presented to the Trust Clinical lead by the Clinical Chair for joint review, discussion and moderation.
3	Resp	⊖	⊖	⊖		no	none	Death shortly after discharge, SJR therefore not done Recognised as EOL and fast tracked home on the 16th July. Saw by LD specialist and specialist palliative care nurse both giving a clear plan om 22/6. Regular input of LD nurse Pain well managed. LD care plan fully completed DoLs in situ but applied for 2 weeks after admission and not fully completed.

								AND in place however not marked as for being applicable across all areas. Reviewing notes suggests this could have been seen as a deteriorating patient and could have been supported in the community on the GSF No MCA paperwork in situ
4	Resp	✓	✓ GC	✓ PN		no	none	1a. Asp Pneumonia 2. Epilepsy LD care pathway in situ. Eol plans in place. AND Not discussed with family Paperwork states lacking in capacity but no 2 stage test for medical decisions. Nursing 2 stage tests have no plan of care
5	EAU	✓	✓ GC	✗		no	None (referred <24h) MCCD issued	1a. Lung Cancer Last days of life plan in place. DNACPR present. Not discussed with anyone, no MCA to determine capacity for this. No advance care plan. Previous discharged 10days earlier, notes suggest he was a potentially deteriorating patient but not placed on GSF.

6	24	✓	✓ GC	✓ NA		no	none	GP didn’t engage in ACP EoL despite request
7	ED/EAU	✓	✓ EC	✓ PNL		no	yes – in progress Safeguarding S42	Pre-admission factor determined outcome
8	G / Surg	✓	✗	✗		no	none	1a. Asp Pneumonia 1b. Stoma Obstruction
9	G / Surg	✓	✗	✗		no	none	1a. Bowel Ischaemia
10	Resp/ 24	✗	✗	✗		yes	yes – in progress	Potential Inquest
11	Geri	✓	✗	✗		no	none	1a. Asp Pneumonia 2. Dementia, Epilepsy, Downs S
12	EAU	✓	✓ AC	✓ PN		no	none	Attempted CPR. Further check for Sepsis Standards, concerning comment on SJR and information from Resus and Sepsis teams
13	Resp	✓	✓ GC	✗		no	none	Pre-admission factor Presented with Sepsis

Key
EC Excellent care **GC** Good Care **AC** Adequate Care **PC** Poor Care **VPC** Very Poor Care
NA Not Avoidable (Definitely) **PN** Probably / Possibly / Unlikely Not Avoidable

Appendix 1
5 cases were identified by the information team, each of these cases were looked through Medway, alerts, and System1 to clarify the presence of a definite diagnosis of LD / IDD. None were already known and registered with the Trust with this diagnosis and alert flag. 3 cases were not strongly supported by system1 record for diagnosis. 2 cases might have this diagnosis, received annual LD checks. 100% of cases received at least an initial review 2 of which were deemed not to trigger an SJR (excellent or good care) and were 3 SJR and of which 2 received an AA (both not avoidable factors)

Case	LD?	Team / Ward	Step 1 (Initial Review)	Step 2 (SJR)	Step 3 (AA)	LeDeR Review	Comments
1	Not on register No formal diagnosis	Resp	✓	✗	✗		No known by team to LD – therefore no SJR 1a. Bronchopneumonia 1b. CCF 2. AKI, Diabetes
2	Not on register No formal diagnosis	G/Surg	✓	✓ EC	✗		No known by team to LD – therefore no SJR 1a. aspiration pneumonia 1b. Pseudo-obstruction 1c. Frailty 2. MS Quadriplegia
3	Not on register No formal diagnosis	EAU	✓	✗	✗		No SJR 1a. Bronchopneumonia LD in MCCD 2. though
4	Not on register	EAU	✓	✓ EC	✓ Def Not Avoidable		1a. septic shock 1b. bowel ischaemia No narrative to support SJR
5	Not on register Annual check Probable diagnosis No formal diagnosis	ICCU	✓	✓ GC	✓ Def Not Avoidable		Post cardiac arrest. No specific cause entered on MRT, admitted to ICCU and then withdrawal of care