MEETING OF THE Quality Committee 2 November 2023			
Report Title: Audit of deaths GIC 1 April 2022- 31 March 2023			**Agenda No.:** 11
Report Author and Job Title:	[redacted]	**Lead Executive Director:**	Dr Chris Abbott, CMO
Appendices:	Appendix 1: Audit of Deaths GIC Waiting List and Open Cases 1 April 2022-31March 2023		
Executive Summary:			
Action Required:	Approval ☐ Discussion ☒ Information ☒ Assurance ☐		
Situation:	Report of an audit of deaths in Adult Gender Clinic: 1 April 2022-31 March 2023. Patient deaths can be considered in 3 cohorts: 1. Active/open cases 2. On waiting list 3. Patients discharged before death i.e., case closed. Deaths of patients on waiting list and of those open to the Adult Gender Clinic are reported on the Quality Portal. Deaths of patients discharged before death were not included in this audit. An audit of deaths that occurred within 6 months of discharge needs to be completed. It has been difficult to find out cause of death for many patients but this information is needed to better understand mortality in this cohort of patients, to look at areas requiring further scrutiny and action, to highlight improvements that should be made particularly if this relates to patient care and to share learning for the service. Two audits of deaths of patients attending Adult Gender Clinic were reported in April 2023. In this report data is presented for 1 year – 1 April 2022-31 March 2023 Total number of deaths: [redacted]		
Background:	Reports/audits of deaths in the Trust Adult Gender Services were previously discussed at Trust Board in April 2023. Recent (April 2023, October 2023) (and forthcoming) inquests of patients on Adult Gender Clinic waiting list have again highlighted concerns about length of waiting list and relationship to suicide/unnatural death. The Trust has been issued with a Prevention of Future Deaths Order (April 2023) and is expected to receive a further PFD in October 2023.		

	There are differing views both internally and externally, about responsibility for patients on the waiting list and for the need to undertake harm reviews. This report is an audit of deaths for the year ending 31 March 2023. The audit is of two cohorts – those on GIC waiting list during that period and those open to the service who died during the year to end March 2023. One of the ongoing difficulties has been finding out cause of death both in the active (open) patient cohort and in those on the waiting list. There has been additional effort to ascertain cause of death for the cohort reported here. Previous audits suggest that the cause of death in the age group 18-25 years is more likely to be unnatural and that older patients (over 50) are more likely to die from medical causes. The findings in this audit are in keeping with previous audits.
Assessment:	Further details on the deaths of [redacted] patients are presented below. The available data continues to tentatively suggest that the cause of death in younger patients on waiting list and open to service is more likely to be unnatural/suicide. Available data for deaths of both open cases and those on waiting list suggests there is a need to pay greater attention to physical co-morbidities. Several patients died of cancer. This may be in keeping with the general population profile but needs further scrutiny including if there is any link with prescription of cross sex hormones (not clearly evident) There may be an assumption that deaths are more likely on the waiting list. This may not be correct. It is not possible to benchmark data against general population data. Links need to be made with other adult gender services nationally to share information.
Key recommendation(s):	Comments and queries are presented in the report below. The Quality Committee is asked to consider the findings and the issues raised in this report.

Implications:				
Strategic Objectives:				
☒ Improve delivery of high-quality clinical services which make a significant difference to the	☐ Be a great & safe place to work, train & learn for everyone. A place where we can all thrive and feel	☐ Develop & deliver a strategy & financial plan that supports medium & long-term organisational	☐ Be an effective, integrated partner within the ICS & nationally, supporting improvements in	☐ Ensure we are well-led & effectively governed.

lives of the people & communities we serve.	proud in a culture of inclusivity, compassion & collaboration.	sustainability & aligns with the ICS.	population health & care & reducing health inequalities.	

Relevant CQC Domain:	Safe ☒	Effective ☒	Caring ☒	Responsive ☒	Well-led ☒
Link to the Risk Register:	BAF ☐	CRR ☐	ORR ☐		
	Risk Ref and Title:				
Legal and Regulatory Implications:	Yes ☐	No ☐			
	There may be legal and regulatory implications related to deaths (PFD, Regulation 28) rather than this report.				
Resource Implications:	Yes ☒	No ☐			
	There are resources implications arising from this report in terms of continuing to support 1. similar audits, 2 supporting inquests, 3 legal advice.				
Equality, Diversity, and Inclusion (EDI) implications:	Yes ☒	No ☐			
	Very long waiting lists preclude easy access to the service.				
Freedom of Information (FOI) status:	☐ This report is disclosable under the FOI Act.	☐This paper is exempt from publication under the FOI Act which allows for the application of various exemptions to information where the public authority has applied a valid public interest test.			
Assurance:					
Assurance Route - Previously Considered by:	ELT				
Reports require an assurance rating to guide the discussion:	☐ Limited Assurance: There are significant gaps in assurance or action plans	☒ Partial Assurance: There are gaps in assurance	☐ Adequate Assurance: There are no gaps in assurance	☐ Not applicable: No assurance is required	

Deaths in Adult Gender Service

Background: Investigation of Patient Deaths at TPNHSFT

- Informatics run reports x3 per week against the Demographic Batch Service.
- Deaths of patients on open case load or on waiting list are notified to relevant services.
- Death should be logged on Quality Portal.
- Decision made at Incident Panel (or before) as to the type of investigation that should follow
- Most of the work on mortality is in relation to deaths in Adult Gender Services
- Currently only 2-3 clinicians in the Trust are trained to undertake serious incident investigations

Background (cont)

- Over the last 12-18 months, the workload to complete mortality reviews and concise reports has been dependent on a very small number of clinicians and the patient safety administrator.
- Separate Incident Panels focusing only on deaths in GIC were held for several months to work through all reports. This work continues.
- This work was happening alongside procurement for replacement of Quality Portal and work to ensure Trust is compliant with the Patient Safety Incident Response Framework(PSIRF)
- The Care Notes outage August 2022- December 2022 had a significant impact.
- There have been multiple changes in personnel supporting the patient safety function.

Wider GIC context

Month – end of	Waiting list end of	Case load at end of	Total no of referrals to 31 March
March 2018	3516	4652	3039
March 2019	5258	5325	3628
March 2020	6867	5926	3407
March 2021	8660	6098	2994
March 2022	11145	5772	4085
March 2023	12551	5742	3433

Ascertaining cause of death – Adult Gender Clinic

- Patients come from a very wide geographical area.
- Very large number of referrals, patient on waiting list, open cases
- Once patient death is known , letters are sent to GPs and Coroners Officers requesting information. Repeated follow up phone calls (x3 sometimes x4, then stop)
- In many instances efforts to find out information continues over several months
- Contact with other services if patient also known to that service
- Previous liaison with London Region Medical Examiner's Office
- Recent direct contact with National Medical Examiner
- Direct contact with General Register Office (registry of deaths)
- Families are not usually contacted to find out cause of death.

General Register Office

- The certified entry in the Register of Deaths is a public document and the only central repository of information.
- Anyone can apply to GRO and pay for individual death certificate.
- Although the Register of Deaths is a public document the Trust Caldicott Guardian has some concerns about requesting a large amount of information in this way i.e.. Duty of confidentiality to patients even after death and following a patient's known wishes after their death.
- Cumbersome to request information for potentially large number of deceased patients.

- General Register Office - GOV.UK (www.gov.uk)

National and Regional Medical Examiner

- There is no central database to identify patients via Medical Examiners
- If medical examiners have been involved in cases, at a local level, the local ME office may be able to help provided the numbers of cases are not large .
- The challenge arises because medical examiners may not have been involved as some cases go direct to coroners or may occur in the community (where medical examiners have been extending to over the last few months only).

- NHS England » The national medical examiner system

Deaths in Adult Gender Service

- The information on deaths of patients logged on Quality Portal since 2018 and connected to the Adult Gender Services has previously been reviewed – reported in April 2023
- Separately there was an audit of [redacted] deaths (non sequential, covering 2020-2022) of patients connected to the Adult Gender Service – also reported in April 2023
- The audit presented here focuses on data for the year-1 April 2022-31 March 2023.
- The main emphasis of this audit was to ascertain causes of death

Audit of Deaths GIC Waiting List and Open Cases 1 April 2022-31 March 2023

Waiting list 1 April 2022-31 March 2023

- Number of deaths GIC waiting list n=[redacted]
- Cause/likely cause of death now known in [redacted]
- Age cohorts:

71-80 yrs: [redacted] ≤5

61-70 yrs: [redacted] ≤5

51-60 yrs: [redacted] ≤5

41-50 yrs: [redacted] ≤5

31-40 yrs: [redacted] ≤5

21-30 yrs: [redacted] ≤5

20 yrs or under [redacted] ≤5

Explanatory Notes:

We have masked low numbers as the symbol '≤5', which indicates where numbers are equal to or less then 5. It is the NHS Digital standard not to provide data where the numbers are smaller than 5 as this may lead to identification of individuals.

Disclosure of this type of personal data, or identifiable personal data would thus be unfair, breaching the Duty of Confidentiality to patients, even after death

Cause of Death – waiting list

Deceased on w/l	Age at death	Cause of Death
Trans female	[redacted]	[redacted]
Trans female	[redacted]	
Male	[redacted]	
Male	[redacted]	
Trans female	[redacted]	
Trans female	[redacted]	
Trans female	[redacted]	
Trans female	[redacted]	
Trans female	[redacted]	
Trans female	[redacted]	

Waiting list : Co-morbidity

- Significant physical co-morbidities in age group over 50 years especially Respiratory Disease and Cardiovascular Disease
- Psychiatric co-morbidities more evident in younger age cohort < 50 years and particularly under 40 yrs.
- ASD [redacted] patients [redacted] under 30 years) Redacted number is equal to or less than five)

Open cases 1 April 2022-31 March 2023

- Number of deaths GIC open case list n=[redacted], [redacted]patients had not yet been seen and [redacted] case should have been closed . Cause of death known in [redacted]
- Age at death range 24-70 years
- Age cohorts:

61-70 yrs:[redacted] ≤5

51-60 yrs : 6

41-50 yrs :[redacted] ≤5

31-40 yrs:[redacted] ≤5

21-30 yrs:[redacted] ≤5

Explanatory Notes:
We have masked low numbers as the symbol '≤5', which indicates where numbers are equal to or less then 5. It is the NHS Digital standard not to provide data where the numbers are smaller than 5 as this may lead to identification of individuals.
Disclosure of this type of personal data, or identifiable personal data would thus be unfair, breaching the Duty of Confidentiality to patients, even after death

Cause of death and co-morbidities– open cases

Deceased – open cases	Age at death	Cause of Death	Co-morbidity
Trans male	[redacted]		
Trans male			
Trans female			
Trans female			
Trans male			
Trans female			
Trans female			
Trans female			
Trans female			
Trans male			
Trans female			

Cause of death and co-morbidities–

- Of open cases - [redacted] cases need further review as cause of death has only recently come to be known.
- Raw data presented , unable to relate findings to population data.
- Questions :

1. Is the suicide rate/rate of unnatural deaths higher/the same as in the general population in patients on the waiting list and attending the Adult Gender Clinic and/or is the rate higher in certain cohorts compared to that age group in the general population.
2. Is the cause of death as suspected suicide/unnatural death more prevalent on waiting list? Need to compare with other years. Is being on the waiting list a risk in its own right? . Is the presence of physical and psychiatric co-morbidities the same/higher than general population age matched.
3. Is there any increase in deaths from cardiovascular disease or certain malignancies related to use of cross sex hormones?
4. How are patients on the waiting list accessing adequate physical care particularly if they have transitioned
5. What are the causes of death in the 18-24 year old age group or wider younger age group– up to 30 years?

And are these the right questions?

Recommendations

- Available data for deaths of both open cases and those on waiting list suggests there is a need to pay greater attention to physical co-morbidities . There should be a review of what is recorded and how physical health and mental health comorbidities are integrated into overall narrative (noted as an issue in previous audit especially around mental health)
- Triangulate findings from this audit with other GIC reports
- Present audit findings to GIC Executive
- Review and approve current (draft) SOP on reporting and logging deaths in light of the findings of this audit.
- Consider requesting death certificates on a cohort of patients from waiting list and open cases to further support the questions raised in this and the previous audits.
- Sharing of information on causes of death in patients attending/on waiting list for Adult Gender Clinic needs to be done across gender services
- An audit of deaths that occurred within 6 months of discharge needs to be completed.
- Information is available on total number of deaths from 2017 (when Adult Gender Clinic transferred to TPNHSFT) – 3 cohorts (deceased case closed, deceased on waiting list, deceased open). This data should be reviewed.

Conclusion

- Some progress has been made in ascertaining cause of death but the process of finding out is very time consuming and not sustainable. Internally more adept systems are needed to support this work