NEW YORK STATE OF OPPORTUNITY. Department of Health

Quality of Care Program Mortality Review

September, 2017

Overview

- Discussions about mortality review have occurred in the NYS Quality of Care Advisory Committee for over seven years with input from national experts.

- A review of mortality among people with HIV is to be included in the 2018 review of care provided in 2017

- A subcommittee, comprised of members of the QAC and CAC, has been meeting since April to develop the review process

Scope of Review

- Mortality review will include:
  - Reporting of deaths among PLWH in an organization (includes deaths on site and deaths of established patients)
  - Identification of deaths attributable to HIV and analysis of specific causes of death
    - Emphasis placed on identifying modifiable factors associated with deaths of PLWH
    - Facilities will submit a plan for addressing these factors
    - Special focus will be given to access to care/care coordination issues, including access to specialty care, that may have contributed to death
- The average number of reviews per site will be approximately 9 (range 0-66*) based on preliminary 2016 eHIVQUAL results on number of decedents/site

*An HIV program reporting on other hospital departments, including ED, in their organization

Coding Causes of Death in HIV (CoDe)

- Developed by the University of Copenhagen to standardize approach to collecting data on cause of death and reviewing deaths.

- Mortality Subcommittee CoDe Subgroup has adapted the CoDe chart abstraction tool and instructions for using the tool for use in NYS
  - Adaptations of the CoDe tool by the San Francisco Department of Public Health have also been considered

New York State Mortality Data Collection From

*Date of death: ___–___– ___ (MM/DD/YYYY)

1. Active Patient: ☐ Yes ☐ No

2. Died at Institution: ☐ Yes ☐ No
If no, facility of death _____

3. a. Patient's zip code_____ b. Zip code of facility where patient is active _____
c. Zip code of facility where patient died (if different) _____

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Section 1: Background Demographics

A. Year of birth (yyyy) _ _ _ _ **B.** Year of HIV diagnosis (yyyy) _ _ _ _

C. Sex assigned at birth: ☐ male ☐ female ☐ intersex ☐ unknown

D. Current gender identity: ☐ male ☐ female ☐ trans male ☐ trans female

☐ gender non-conforming/non-binary ☐ other ☐ unknown

E. Race and ethnicity: ☐ Asian ☐ Black, non-Hispanic ☐ Hispanic ☐ Native American/Alaskan Native

☐ Native Hawaiian/Pacific Islander ☐ White, non-Hispanic ☐ Other (please specify_____)

☐ unknown

F. Country of Birth: ☐ U.S. ☐ Other (please specify_____) ☐ unknown

G. Preferred Language: ☐ English ☐ French or Creole ☐ Spanish ☐ ASL

☐ Other (please specify_____) ☐ unknown

Background Demographics Cont.

H. Risk: ☐ MSM ☐ IDU ☐ MSM-IDU ☐ Heterosexual ☐ Heterosexual-IDU ☐ Perinatal

☐ Not reported ☐ Other_____ ☐ unknown

I. Height (cm):___

J. Weight (kg) : ___
(most recent before death)
Date / /
(MM/DD/YYYY weight measured)

Weight (kg) : ___
(1 year prior to death)
Date :___–___–___
(MM/DD/YYYY weight measured)

K. Insurance at time of death (select all that apply)

☐ Private Managed Care or Commercial Coverage
☐ Medicaid Managed Care; plan name:_____
☐ Medicare
☐ HIV SNP; plan name: _____
☐ Medicaid
☐ Uninsured
☐ ADAP Plus
☐ Unknown
☐ ADAP

Section 2: Data Sources

Facility 1: _____

A. Hospital files ☐ Yes, complete ☐ Yes, incomplete ☐ No
If incomplete, what is missing? _____

B. Outpatient clinic chart ☐ Yes, complete ☐ Yes, incomplete ☐ No
If incomplete, what is missing? _____

Facility 2 (if applicable): _____

A. Hospital files ☐ Yes, complete ☐ Yes, incomplete ☐ No
If incomplete, what is missing? _____

B. Outpatient clinic chart ☐ Yes, complete ☐ Yes, incomplete ☐ No
If incomplete, what is missing? _____

Facility 3 (if applicable): _____

A. Hospital files ☐ Yes, complete ☐ Yes, incomplete ☐ No
If incomplete, what is missing? _____

B. Outpatient clinic chart ☐ Yes, complete ☐ Yes, incomplete ☐ No
If incomplete, what is missing? _____

Other Data Sources

C. Autopsy report ☐ Yes, complete ☐ Yes, incomplete ☐ No

D. Registry ☐ **G.** Patient's medical provider ☐

E. Obituary ☐ **H.** Nursing home ☐

F. Patient's relatives or partner ☐ **I.** RHIO ☐ (please specify _____)

J. Community-based care management org ☐ **K.** Other ☐ (please specify _____)

Section 3: Risk Factors

A. Ongoing risk factors:

1. Cigarette smoking

a. Current (within last 6 months) ☐ Yes ☐ No ☐ Unknown

b. Past (6 -12 months) ☐ Yes ☐ No ☐ Unknown

c. Past (> 12 months) ☐ Yes ☐ No ☐ Unknown

d. Never ☐ Yes ☐ No ☐ Unknown

2. Excessive alcohol consumption

a. Current (within last 6 months) ☐ Yes ☐ No ☐ Unknown

b. Past (6 -12 months) ☐ Yes ☐ No ☐ Unknown

c. Past (> 12 months) ☐ Yes ☐ No ☐ Unknown

d. Never ☐ Yes ☐ No ☐ Unknown

3. Active substance use

a. Current (within last 6 months) ☐ Yes ☐ No ☐ Unknown

b. Past (6 -12 months) ☐ Yes ☐ No ☐ Unknown

c. Past (> 12 months) ☐ Yes ☐ No ☐ Unknown

d. Never ☐ Yes ☐ No ☐ Unknown

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Risk Factors Cont.

3.1 If substance use occurred in the past 6 months, route (select all that apply)

☐ IDU ☐ Sniffing ☐ Ingestion ☐ Skin Popping ☐ Smoking ☐ Unknown

3.2 If substance use occurred, circle all of the types of drugs used, in the past 6 months, regardless of route of administration

1. Amphetamines 2. Benzodiazepines 3. Cocaine/crack
4. Crystal methamphetamine 5. Ecstasy 6. Hallucinogens (PCP, LSD, other)
7. Heroin 8. Inhalants (glue, nitrous oxide)
9. Ketamine 10. Prescription opioids (Vicodin, Codeine)
6. Other substance(s) _____

4. Opioid Use Disorder Treatment (methadone, buprenorphine or naltrexone)

a. Current (within last 6 months) ☐ Yes ☐ No ☐ Unknown

b. Past (6 months or more) ☐ Yes ☐ No ☐ Unknown

c. Never ☐ Yes ☐ No ☐ Unknown

Risk Factors Cont.

5. Living situation in 12 months prior to death (select all that apply and identify the most recent with an asterisks)
   a. Stable Permanent Housing ☐
   b. Temporary Housing ☐
   c. Unstable Housing ☐
   d. Homeless ☐
   e. Unknown ☐
6. Incarcerated within 12 months prior to death ☐ Yes ☐ No ☐ Unknown
7. Ever received hospice care ☐ Yes ☐ No ☐ Unknown
8. Experienced challenges accessing care due to transportation barriers in the 12 months prior to death

☐ Yes ☐ No ☐ Unknown

Section 4: Co-morbidities

A. Ongoing chronic conditions:

1. Hypertension ☐ Yes ☐ No ☐ Unknown

- Controlled ☐ Yes ☐ No ☐ Unknown
- Blood pressure closest to time of death in an outpatient setting _____ Date ____/___/_____ MM/ DD/ YYYY

2. Diabetes mellitus ☐ Yes ☐ No ☐ Unknown

- Controlled ☐ Yes ☐ No ☐ Unknown
- Hemoglobin A1c closest to time of death in an outpatient setting _____ Date ____/___/_____ MM/ DD/ YYYY

3. Dyslipidemia ☐ Yes ☐ No ☐ Unknown

- Controlled ☐ Yes ☐ No ☐ Unknown

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Co-morbidities Cont.

B. Cardiovascular disease
(*myocardial infarction, stroke, invasive cardiovascular procedure, angina, arrhythmia, or peripheral arterial disease)*

a. Current ☐

b. Past (resolved) ☐

c. No indication from medical record or provider ☐

C. History of depression

a. Within past 12 months ☐

b. Ever ☐

c. No indication from medical record or provider: ☐

- Evidence of having received clinical care or medication for depression: ☐Yes ☐No ☐Unknown

D. Bipolar Disorder ☐Yes ☐No ☐Unknown

- Evidence of having received clinical care or medication for Bipolar Disorder:

☐Yes ☐No ☐Unknown

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Co-morbidities Cont.

E. PTSD ☐ Yes ☐ No ☐ Unknown

- Evidence of having received clinical care or medication for PTSD: ☐ Yes ☐ No ☐ Unknown

F. Anxiety Disorder ☐ Yes ☐ No ☐ Unknown

- Evidence of having received clinical care or medication for Anxiety Disorder:

  ☐ Yes ☐ No ☐ Unknown

G. Neurocognitive Disorder ☐ Yes ☐ No ☐ Unknown

H. Suicide Attempt or Ideation

a. Within past 12 months ☐

b. Ever ☐

c. No indication from medical record or provider ☐

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Co-morbidities Cont.

I. Liver disease:

1. Chronic elevation of liver transaminases ☐Yes ☐No ☐Unknown

2. Chronic HBV infection ☐Yes ☐No ☐Unknown

3. Chronic-HCV infection ever* ☐Yes ☐No ☐Unknown

- Cured ☐Yes ☐No ☐Unknown
- If yes, date of sustained virologic response (SVR) ____/___/_____
  MM/ DD/ YYYY

*If decedent had been cured but was re-infected at time of death, please indicate hepatitis C infection in section 7 part C

4. HDV infection ☐Yes ☐No ☐Unknown

5. History of previous liver decompensation ☐Yes ☐No ☐Unknown

6. Clinical signs of liver failure in the 4 weeks before death ☐Yes ☐No ☐Unknown

7. Liver fibrosis staging available (ever) ☐Yes ☐No ☐Unknown

If Yes, please indicate:

- The date of most recent biopsy/ non-invasive fibrosis testing/Fibroscan ___/___/____
  MM/ DD/ YYYY
- The stage of fibrosis (0-4): |__| and/or Fibroscan results: _____ kPa

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Co-morbidities Cont.

J. Non-AIDS defining cancer ☐Yes ☐No ☐Unknown

If yes specify:

i. Type_____

ii. Date of diagnosis ____/___/_____
MM/ DD/ YYYY

K. Chronic Kidney Disease ☐Yes ☐No ☐Unknown

- Stage: _____
- Chronic hemodialysis ☐Yes ☐No ☐Unknown

L: Opportunistic Illnesses and Date of Diagnosis

Illness	Date (MM/YYYY)

Section 5: ART and laboratory values prior to death

A. Has the patient EVER received ART ☐ Yes ☐ No ☐ Unknown

If YES, when was ART started (in months before death):

☐ ≤ 1 month before ☐ ≤ 3 months before ☐ ≤ 6 months before ☐ More than 6 months before

B. Did the patient receive ART at the time of death? ☐ Yes ☐ No ☐ Unknown

- ***If No***, Date of stopping __ __ – __ __ – __ __ __ __ **(MM/DD/YYYY)**

C. Laboratory values (please complete all fields where data is available)

Laboratory values	Time	Value	Unit	Date MM/DD/YYY
HIV RNA	1. Most recent at time of stopping ART		Copies/mL	__ __ - __ __ - __ __ __ __
	2 Most recent prior to death.		Copies/mL	__ __ - __ __ - __ __ __ __
CD4+ cell count	1. Most recent prior to last stopping ART		Cells/mm3	__ __ - __ __ - __ __ __ __
	2. Most recent prior to death		Cells/mm3	__ __ - __ __ - __ __ __ __
	3. Nadir CD4 count		Cells/mm3	__ __ - __ __ - __ __ __ __
Hemoglobin	Most recent prior to death		/	__ __ - __ __ - __ __ __ __

Section 6: Hospitalizations in the 12 months prior to death

Name of hospital	Date of hospitalization (MM/DD/YYYY)	Primary and secondary discharge diagnoses

Section 7: Cause of death

A. Was the death sudden? ☐ Yes ☐ No ☐ Unknown

B. Was the death unexpected? ☐ Yes ☐ No ☐ Unknown

C. Please complete the table below by recording all illnesses and conditions (acute and chronic) or injuries that the patient had at the time of death

Illness / Condition / Injury (text)	**Date of onset** MM/DD/YY	**Certainty of diagnosis[a]**		
		Definite	Likely	Possible
1.	____-____-____	☐	☐	☐
2.	____-____-____	☐	☐	☐
3.	____-____-____	☐	☐	☐
4.	____-____-____	☐	☐	☐
5.	____-____-____	☐	☐	☐
6.	____-____-____	☐	☐	☐
7.	____-____-____	☐	☐	☐
8.	____-____-____	☐	☐	☐
9.	____-____-____	☐	☐	☐

[a]**Certainty of Diagnosis: Definite**=95-100% certainty, **Likely**=80-95% certainty, **Possible**=50-80% certainty

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Cause of death Cont.

D. Brief narrative of the sequence of events leading to death (please include means of diagnosis of illnesses):

E. In summary, the causal relation between the conditions leading to death was (complete this section with the corresponding number from table C above):

1. Condition that directly caused death (immediate cause): _____

2. Due to or as a consequence of: _____

3. Due to or as a consequence of: _____

4. Condition that initiated the train of morbid events (the underlying condition) _____

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Cause of death Cont.

F. Was the death related to immunodeficiency?

Was the underlying or contributing cause of death a CDC C disease or Hodgkin's Lymphoma?

☐ Yes ☐ No ☐ Unknown

*If **No,** do you consider the death to be related to immunodeficiency? (Please refer to the algorithm in the instructions)*

☐ Yes, definitively

☐ Yes, likely

☐ Yes, possibly

☐ No, assumed not

☐ No, definitely not

Comments:

Section 8: Post-mortem/Autopsy

A. Has autopsy been performed: ☐ Yes ☐ No ☐ Unknown

B. Did the autopsy reveal any evidence of substance use at time of death?

☐ Yes, with the agent: _____ ☐ No ☐ Unknown

Please include the full autopsy and toxicology reports if available and provide a brief summary of the findings from the autopsy report.

Post-mortem/Autopsy

C. Has a verbal autopsy been performed? ☐ Yes ☐ No ☐ Unknown

Please include the verbal autopsy report, if available, and provide a brief summary of the findings from the verbal autopsy

Section 9: Adverse effects of medical treatment

A. Was the death considered to be related to a medical treatment? ☐ Yes ☐ No ☐ Possibly

B. The suspected relation was to: ☐ Antiretroviral treatment ☐ Other medical treatment

Please provide a brief narrative of the suspected association including the name of the medication and the date of starting:

Sign-off

Completed by: Name (in print) _____

Position: ☐ Physician ☐ Nurse ☐ Other, describe _____

Directly involved in the medical care of the patient around the time of death? ☐ Yes ☐ No

Date (MM/DD/YYYY):__ __ - __ __ - __ __ __ __ **Signature:** _____

Reviewed by (if applicable): Name (in print) _____

Position: ☐ Physician ☐ Nurse ☐ Other, describe _____

Directly involved in the medical care of the patient around the time of death? ☐ Yes ☐ No

Date (MM/DD/YYYY):__ __ - __ __ - __ __ __ __ **Signature:** _____

The data abstraction can be performed by anyone at the facility with access to the patient's medical records, but the form must be reviewed by a clinician, if not completed by one to begin with.

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Next Steps

- Methodology, Analysis and Access to Care subgroups will meet and discuss further aspects of the review process and data analysis
- Full guidance on the Mortality Review will be completed in early December, with sufficient time for distribution by mid-month.
- Webinars on the Mortality Review will be hosted in late December or early January

Questions and comments can be direct to Leah Hollander (leah.hollander@health.ny.gov)