

Sister Study Vulvar Cancer Outcomes (any behavior)<sup>1</sup> and Characteristics: Data Release 9.1<sup>2</sup>

|   | N         | % of cohort       |
|---|-----------|-------------------|
| <b>Total Cases<sup>3</sup></b>            | <b>56</b> | <b>0.1</b>        |
| <b>Timing, Behavior, and Site</b>         | <b>N</b>  | <b>% of cases</b> |
| Baseline                                  | 20        | 35.7              |
| Invasive                                  | 17        | 30.4              |
| Labium majus                              | 2         | 3.6               |
| Overlapping sites                         | 1         | 1.8               |
| Unknown <sup>4</sup>                      | 14        | 25.0              |
| <i>In situ</i> - Vulva                    | 3         | 5.4               |
| Unknown timing <sup>5</sup>               | 2         | 3.6               |
| Invasive - Unknown <sup>4</sup>           | 1         | 1.8               |
| <i>In situ</i> - Vulva                    | 1         | 1.8               |
| Incident                                  | 34        | 60.7              |
| Invasive                                  | 22        | 39.3              |
| Labium majus                              | 2         | 3.6               |
| Labium minus                              | 1         | 1.8               |
| Overlapping sites                         | 1         | 1.8               |
| Unknown <sup>4</sup>                      | 18        | 32.1              |
| <i>In situ</i> - Vulva                    | 12        | 21.4              |
| <b>Incident</b>                           | <b>34</b> |                   |
| <b>Race/Ethnicity<sup>6</sup></b>         |           |                   |
| Non-Hispanic White                        | 31        | 91.2              |
| Non-Hispanic Black                        | 1         | 2.9               |
| Hispanic                                  | 0         | 0.0               |
| Other                                     | 2         | 5.9               |
| <b>Age (in years) at Diagnosis</b>        |           |                   |
| Under 50                                  | 2         | 5.9               |
| 50-64                                     | 19        | 55.9              |
| 65 and older                              | 13        | 38.2              |
| <b>Diagnosis Confirmation<sup>7</sup></b> |           |                   |
| Medical                                   | 25        | 73.5              |
| NDI Plus or death certificate only        | 0         | 0.0               |
| None                                      | 9         | 26.5              |

| Characteristic                        | N         | %    |
|---------------------------------------|-----------|------|
| <b>Incident – Medically Confirmed</b> | <b>25</b> |      |
| <b>Stage at Diagnosis<sup>8</sup></b> |           |      |
| 0                                     | 11        | 45.8 |
| I                                     | 12        | 50.0 |
| II                                    | 0         | 0.0  |
| III                                   | 1         | 4.2  |
| IV                                    | 0         | 0.0  |
| Missing, cannot stage                 | 1         |      |

<sup>1</sup> Cancer events are defined by the following ICD10 cancer codes: invasive vulva (C51) and *in situ* vulva (D07.1). Other ICD10 cancer codes that may be used when vulva is indicated as one of the favored primary sites: invasive female genital organ (C57.9), invasive pelvis (C76.3), invasive unspecified site (C80), *in situ* female genital organ (D07.30), uncertain behavior of female genital organ (D39.8, D39.9), unspecified behavior of genitourinary organ (D49.59).

<sup>2</sup> Data release 9.1 includes outcomes from follow-up phases that closed on or before 9/30/2019

<sup>3</sup> Excludes cancer diagnoses where vulvar site of origin could not be ruled out, but it is not the favored site [n=5]

<sup>4</sup> Unknown site includes vulvar - not specified

<sup>5</sup> Unknown timing represents cases that are unknown if diagnosis at or prior to baseline vs. post-baseline (i.e. incident case)

<sup>6</sup> Race/ethnicity: precedence given to Hispanic ethnicity first, then Black race, then other race, then White race

<sup>7</sup> Medical confirmation of reported vulvar cancer is generally from pathology report but may include other medical documentation; National Death Index (NDI) Plus or death certificate confirmation is specific to cases that do not have medical confirmation

<sup>8</sup> Stage at diagnosis is only available for cases with medical confirmation