



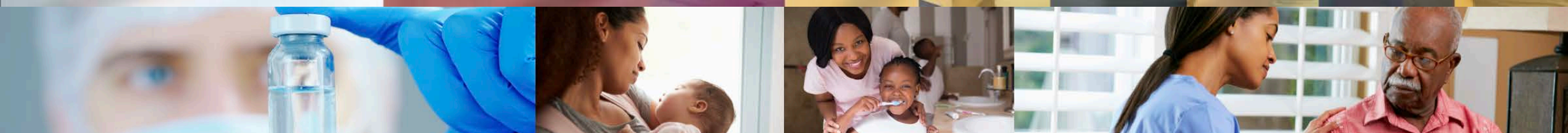
Maryland Cancer Registry

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Mission and Vision

MISSION

The mission of the Prevention and Health Promotion Administration is to protect, promote and improve the health and well-being of all Marylanders and their families through provision of public health leadership and through community-based public health efforts in partnership with local health departments, providers, community based organizations, and public and private sector agencies, giving special attention to at-risk and vulnerable populations.

VISION

The Prevention and Health Promotion Administration envisions a future in which all Marylanders and their families enjoy optimal health and well-being.



Objectives

- Describe the purpose and background of the Maryland Cancer Registry (MCR)
- Review the MCR data collection process
- Identify how MCR data are utilized

Maryland Cancer Registry (MCR)

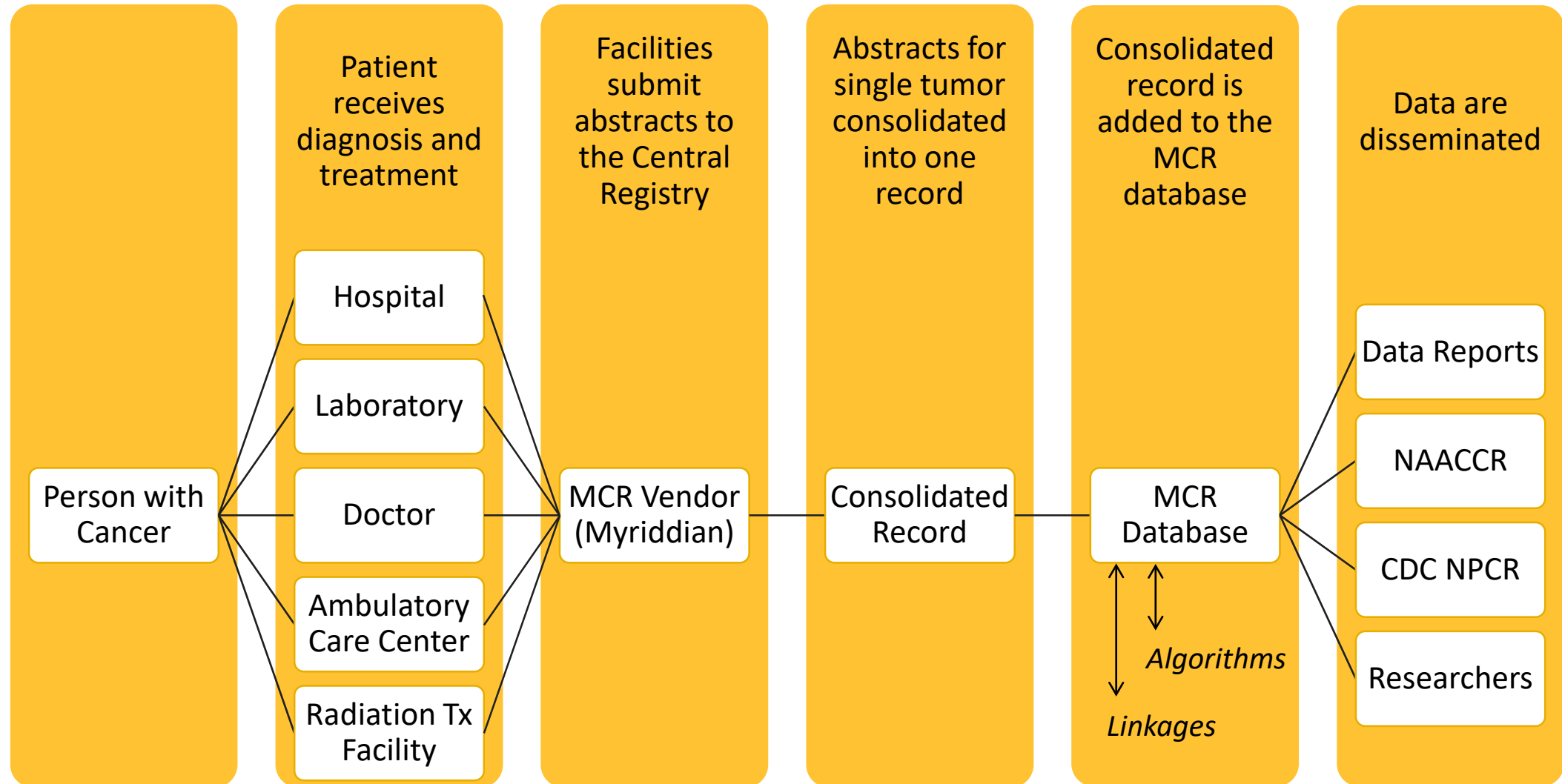
Data Collection and Processing



MCR History

- Officially began in 1993
 - Law - Maryland Health-General Article, §§18-203 and 18-204
 - Regulation – Code of Maryland Regulations (COMAR) 10.14.01
- Includes all new cases of reportable tumors diagnosed and/or treated in Maryland:
 - Malignant or in situ cancers (all types of cancer except basal and squamous cancer of the non-genital skin)
 - Benign and borderline brain and central nervous system tumors

Reporting Process





Reporting Process (cont.)

- 100+ cases per year → report electronically
 - Web Plus direct data entry
 - Cancer registry program (NAACCR file)
 - Through own program
- <100 cases per year → report on paper with path report attached
- Reports submitted 6 to 9 months after initial diagnosis or treatment of a cancer patient



Tumor Abstract/Report

- Information reported varies by reporter type, but may include:
 - Demographics
 - Histology
 - Date of diagnosis
 - Cancer site (location)
 - Grade
 - Stage
 - Treatment
- Common language from North American Association of Central Cancer Registries (NAACCR) and other national standard setters



Data Processing

- MCR completes case finding:
 - Linkage with Breast and Cervical Cancer Program
 - Linkage with the Colorectal Cancer Program
 - Disease index review for hospitals
 - Death certificate follow-back
 - Interstate data exchange
 - Linkage with Indian Health Service (every 5 years)

Data Processing (cont.)

- MCR cleans the data:
 - Unknown race lookup
 - Lab-only follow-back
 - Linkage with Social Security Death Index
 - Linkage with National Death Index
 - Geocoding
 - De-duplication
 - NAPIIA and NHIA Algorithm
 - Submission edits
- Data submitted annually to CDC, National Program of Cancer Registries (NPCR) and NAACCR

NPCR National Data Quality Standard:

- ✓ Reported within 23-24 months
- ✓ 95% data completeness
- ✓ 3% or fewer death certificate-only cases
- ✓ 1/1000 or fewer unresolved duplication rate
- ✓ 3% or fewer records missing age
- ✓ 3% or fewer records missing sex
- ✓ 5% or fewer records missing race
- ✓ 3% or fewer records missing county
- ✓ 99% pass CDC standard edit set

NAACCR Gold Certification:

- ✓ Reported within 23 months
- ✓ 95% data completeness
- ✓ 3% or fewer death certificate-only cases
- ✓ 1/1000 or fewer unresolved duplication rate
- ✓ 2% or fewer records missing age
- ✓ 2% or fewer records missing sex
- ✓ 2% or fewer records missing county
- ✓ 100% pass CDC standard edit set



Maryland Cancer Registry (MCR)

How Are MCR Data Used?



Data Limitations

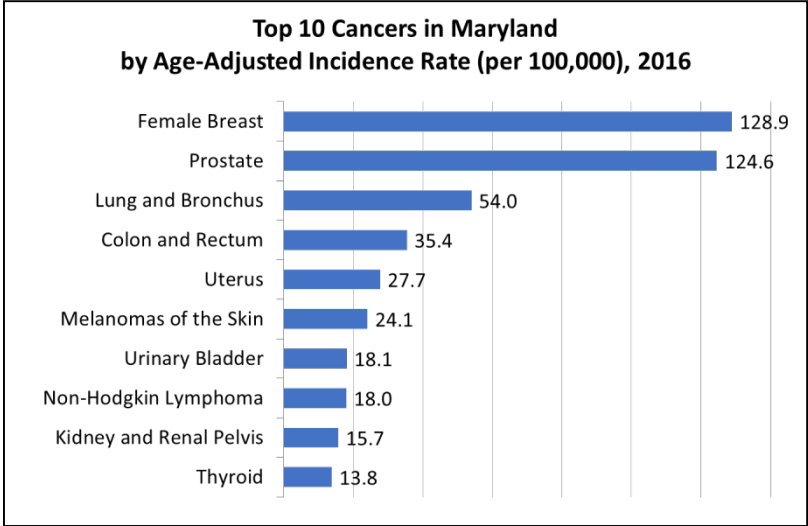
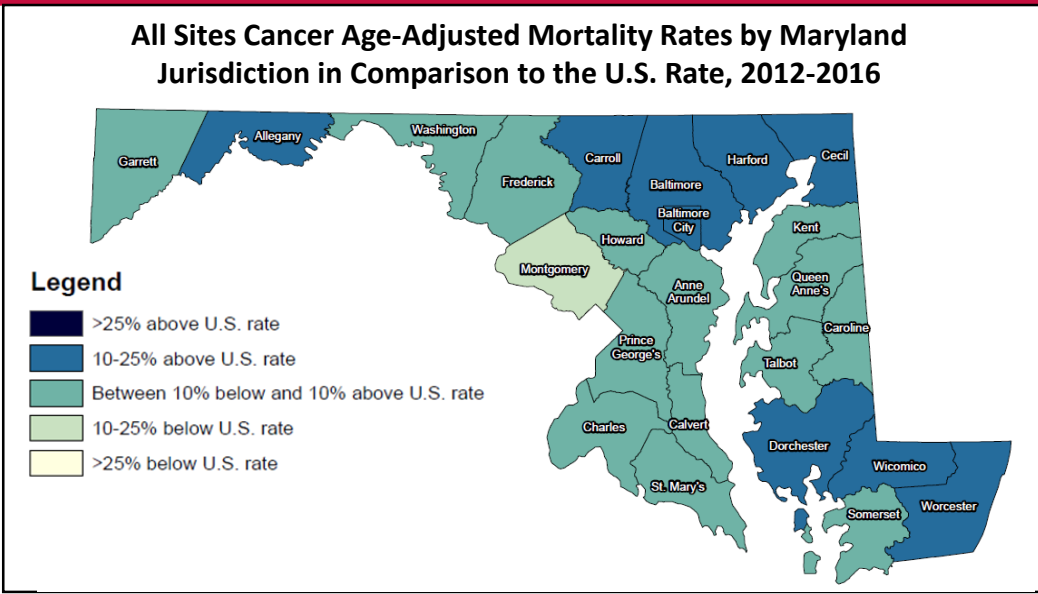
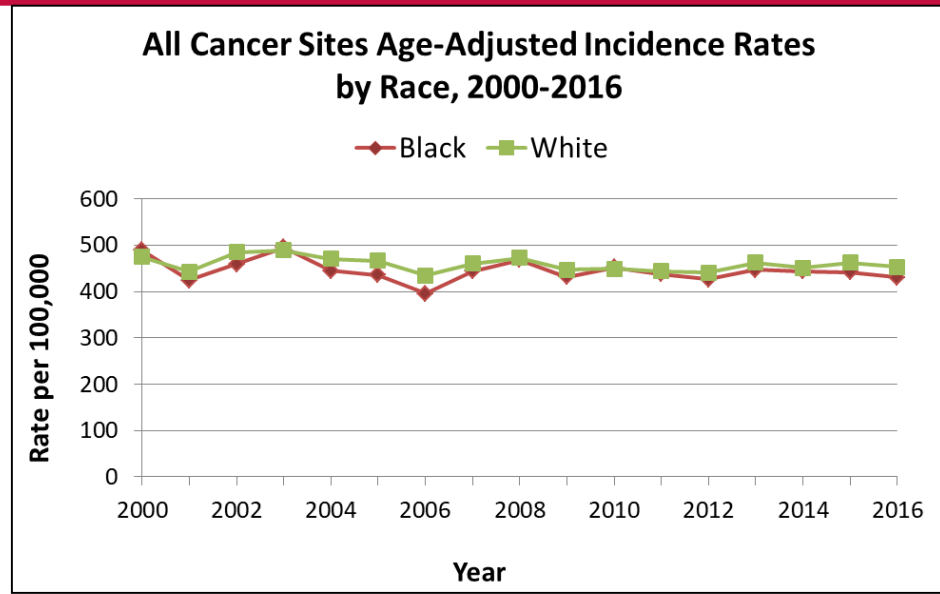
- Data collection and processing results in at least 2-year data lag
- Data may not be appropriate for all questions/hypotheses
- Changes in reporting standards over time
 - Fields become obsolete, change, or are added
 - Coding of a field changes over time
- Data are missing or inaccurately reported
 - Cases not reported to the MCR
 - Data in two fields may conflict within one tumor record
 - Data from two reporters may conflict (e.g., one hospital says no radiation; radiation facility says radiation given)



MCR Data Availability

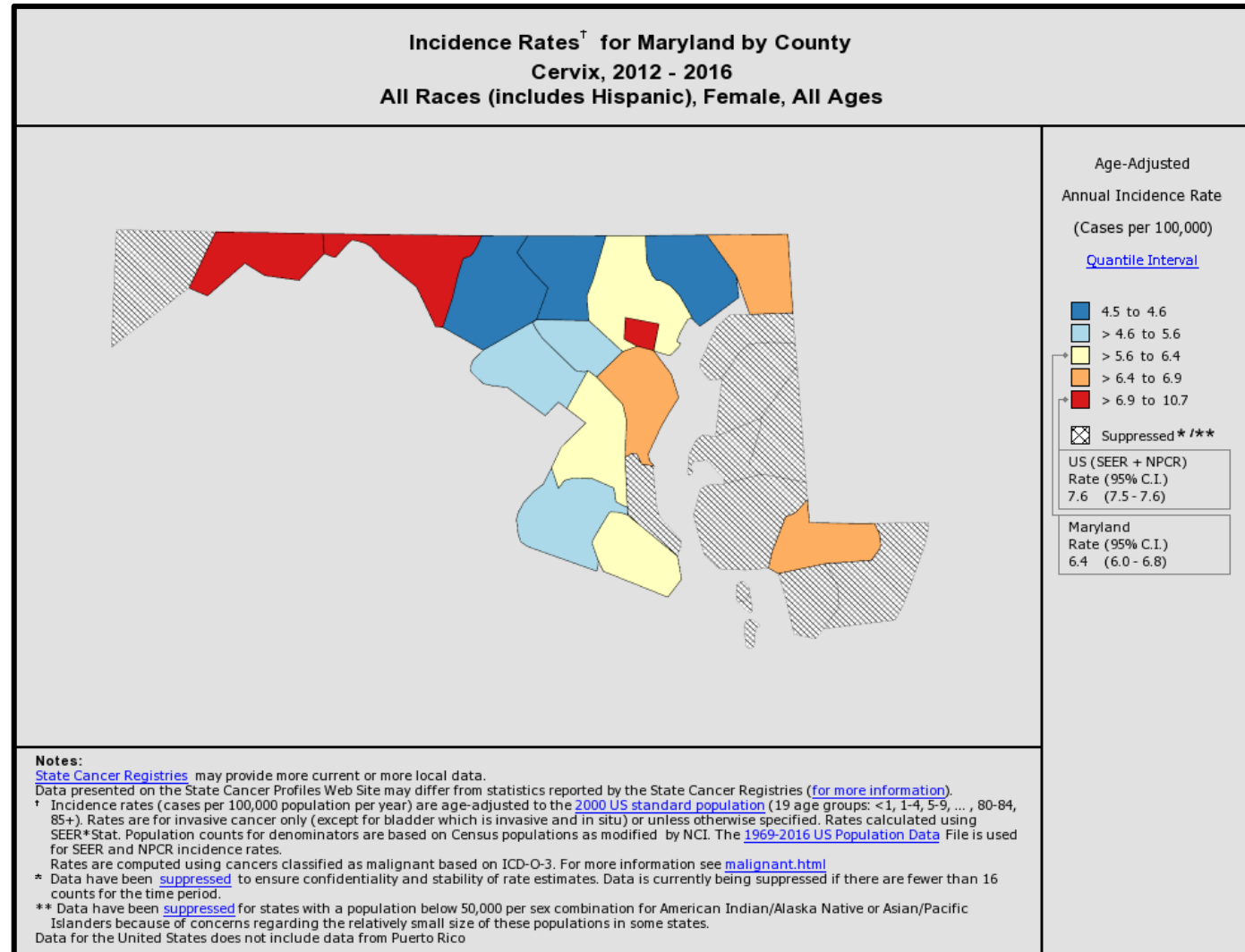
- Center for Cancer Prevention and Control publishes annual reports:
 - Cigarette Restitution Fund Cancer Report
 - Incidence and Mortality Report
- MCR Epidemiologists respond to data requests from researchers, hospitals, local health departments, and other stakeholders
- Requests may require:
 - Data Request Form
 - Detailed research proposal
 - IRB approval
 - Data Use Agreement
 - Confidentiality Agreement

1. Monitor incidence, disparities, and trends



2. Inform public health programs and policies

- Allegany County increased focus on cervical cancer screening due to high incidence
- Queen Anne's County requested number of oral cancers by age to consider adding oral cancer screening in their county program



3. Inform health services planning

- Catchment area
 - Hospital requested county-level cancer counts to assess market share
 - Cancer Center requested age at diagnosis for nine types of cancer in catchment area for strategic planning and reporting
- Treatment options
 - Hospital asked for colon and ovarian cancer counts to assess need for a Hyperthermic Intraperitoneal Chemotherapy facility
- Patient follow-up
 - Hospital requested death information for persons treated in the hospital

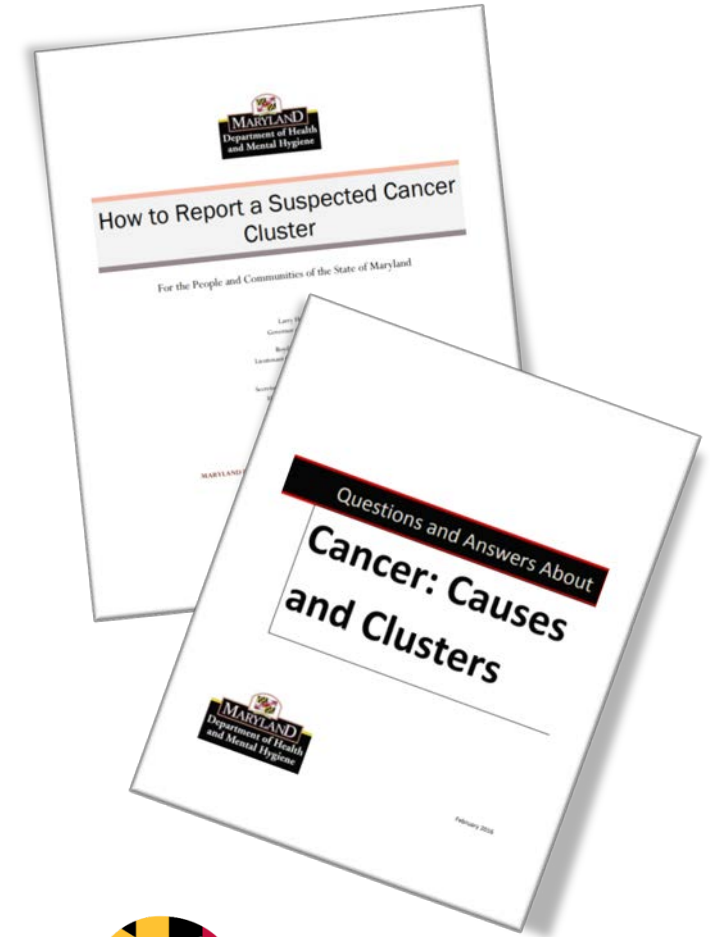


4. Determine funding allocations

- Describe cancer burden and need for public health funding
- Maryland Health-General Article, §13-1108, Cigarette Restitution Fund-Cancer Prevention, Education, Screening and Treatment Program funding is allocated to local jurisdictions and includes:
 - A base amount of funding
 - Allocation based on incidence count for targeted cancers in the jurisdiction
 - Allocation based on death count for targeted cancers in the jurisdiction

5. Investigate potential cancer clusters

- MDH Environmental Health Bureau and MCR
- Investigation process
 - Request information
 - Identify cases in the MCR
 - Analyze data (e.g. rates; standardized incidence ratios, SaTScan)
- Response letter
 - Statement of concern
 - Environmental assessment (e.g. possible exposures)
 - Data analyses, including tables and maps
 - Findings and recommendations
- Limitations (e.g. workplace history, prior residences, etc.)
- <https://phpa.health.maryland.gov/cancer/Pages/Cancer-Clusters.aspx>





6. Conduct research

- Line-listed data at the tumor level
 - Receive data based on specific parameters (e.g. type of cancer, age range, diagnosis year, etc.) of research study
- Linkage for cohort studies
 - Researchers send data to the MCR to be matched
 - Examples:
 - Registry Linkage and Cohort Study of Cancer Risks in US Radiologic Technologists
 - Black Women Health Study: A Follow-up Study for Causes of Cancer in Black Women

6. Conduct research (cont.)



- Patient contact studies use MCR data to identify eligible population for follow up research
 - Maryland is an “opt in” state
 - Used to improve survivorship care and educate cancer survivors
 - Central registry in Oregon sent letters to 2,801 people diagnosed with breast or ovarian cancer that may be hereditary explaining benefits of genetic counseling
 - MCR mailed about 3,200 letters for The Pathways to Wellness (PTW) Study to assess group programs for young breast cancer survivors



Thank you!

- MDH, Center for Cancer Prevention and Control and the MCR team
- Myriddian, LLC (MCR Quality Assurance and Data Management vendor)
- Reporting Facilities
 - Hospitals
 - Laboratories
 - Radiation facilities
 - Physicians
 - Other states



Questions?

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Maryland
DEPARTMENT OF HEALTH

Prevention and Health Promotion Administration

<https://phpa.health.Maryland.gov>