CANCER REGISTRY ADVISORY COMMITTEE

MEETING MINUTES
February 10, 2025

Attendees	Affiliation
Robin Yabroff (*Chairperson*)	American Cancer Society
Clement Adebamowo	University of MD/School of Medicine
Nicole Fowler	Tumor Registry Association of MD
Norma Kanarek	JHSPH (Retired)
Clifford Mitchell	MDH/Environmental Health Bureau
Monique E. Wilson	MDH/Environmental Health Bureau
MCR Staff	
Benjamin Leo	MDH/PHPA/CCPC
Afaq Ahmad	MDH/PHPA/CCPC
Jennifer Hayes	MDH/PHPA/CCPC
Delores Rich	MDH/PHPA/CCPC
Myriddian Staff	
Vijay Medithi	Myriddian, LLC
Jason Myers	Myriddian, LLC
Guests	
Ilan Kokotek	JH Preventive Medicine

Call to order/Introductions:

- All attendees introduced themselves and shared their respective affiliations.
- The committee welcomed Benjamin Leo, Program Manager for the Maryland Cancer Registry

Approval of Minutes (September 12, 2024):

- The minutes from the September 12, 2024 meeting were approved.

Maryland Cancer Registry (MCR) Updates*:*

- *Announcement:* Tyler Adamson, former Epidemiology Team Manager, is no longer with the Center for Cancer Prevention and Control. Attendees were encouraged to check their email boxes for any responses they may be waiting to receive from Tyler. If it is MCR related, the request should be re-sent to Ben Leo. If it is something related to epidemiology, it can be forward to Ben and it will be forwarded to appropriate staff.

- *MCR Incidence & Mortality Report – 2021* – The 2021 Incidence and Mortality report is completed and currently being reviewed internally for edits. An announcement will be made when the report is posted.
- *Data Requests/Data Release Review* –
    - Request for data must be submitted to the MDH, Maryland Cance Registry and data request forms can be found at: https://health.maryland.gov/phpa/cancer/SiteAssets/Pages/mcr_data/MCRDataRequestFormMDH-page%201.pdf .
    - Aggregate data is considered to be any data released that does not have a count between one and five. Included are counts such cancers, county, race, ethnicity, gender, etc.
    - Rates provided by MCR are derived from this data. The data can be released without IRB approval and is usually a quick turn around.
    - Line listed data is used by studies that require linkages or other line listed data for analysis. These studies must go through the IRB and an agreement process
    - In addition, facilities are entitled to receive their own data back if needed and can request death information. The data request form for facilities requesting death information can be found at: https://health.maryland.gov/phpa/cancer/Pages/mcr_reporter.aspx
    - There is a standing approval for county health officers to receive data if agreements are up to date with the current health officer.
        - *Q: What percentage of completion do you have to have for the MCR to release data to county health officers?*
        - *A: They could receive the January 29 download up to 2022 as of today. 2023 will be available next year. The MCR is only permitted to release "complete data."*

- *Deficient Facilities Update* -
    - Tremendous progress has been made as a result of all the hard word of the MCR and Myriddian staffs.
    - More than 90% of the 12-month data is in and the gap between when things are due, and the collection of accurate data is closing significantly.

Fast Healthcare Interoperability Resources (FHIR):

Introduction to FHIR

- FHIR (Fast Healthcare Interoperability Resources) is a standard for exchanging healthcare information electronically.
- Developed by HL7 International to improve interoperability between systems.
- Designed to be flexible, scalable, and suitable for electronic Health information exchange and various healthcare applications.
- Leverages contemporary web technologies like JSON and XML• Provides a modern, web-based approach to data exchange.
- Enables seamless integration between electronic health records (EHRs), mobile apps, cloud services, and other platforms.
- Reduces data silos and enhances coordination of care.

Core Benefits of FHIR

- Interoperability: Standardized data formats and APIs improve system compatibility.
- Efficiency: Reduces duplication of data entry, minimizing errors.
- Data Accessibility: Enables real-time data access for clinicians and researchers.
- Data Consistency: Provides Standard data models and terminologies
- Patient-Centric Care: Supports personalized treatment plans and patient engagement.
- Innovation: New application and services. Mobile health apps and telehealth.

Key Use Cases of FHIR

- Clinical decision support systems.
- Population health management.
- Remote patient monitoring and telemedicine.
- Public health reporting and research data collection. FHIR Role in Cancer Registration• Streamlines data collection and reporting for cancer registries.
- Enhances real-time surveillance and early detection efforts.
- Facilitates integration of genomic, clinical, and treatment data.
- Improves research capabilities and population health insights.

Future Potential of FHIR

- Integration with AI and machine learning for predictive analytics.
- Expanded use in value-based care models and public health.
- Enabling global health data exchange and real-time surveillance.
- Supporting precision medicine initiatives.

Challenges and Considerations

- Data Security and Privacy: Ensuring that patient data remains protected against breaches and unauthorized access.
- Integration with Legacy Systems: Many hospitals rely on older EHRs that may not be easily compatible with FHIR.
- Cost of Implementation: Investment in technology, training, and compliance efforts.
- Data Governance and Ownership: Determining who controls, accesses, and modifies patient data in a shared ecosystem remains a challenge.
- Lack of Standardization in Implementation: Variability in how different vendors and organizations implement FHIR can still lead to inconsistencies.
- Regulatory and Compliance Barriers: Ensuring that FHIR-based exchanges meet HIPAA, GDPR, and other global data protection laws can be complex.
- Limited Expertise and Training: Healthcare professionals and IT teams may require extensive training to effectively use and implement FHIR solutions.

Competitors & Alternatives

- HL7 v2 & v3: Older standards that preceded FHIR but are still widely used.
- CDA (Clinical Document Architecture): Commonly used for document-based data exchange.
- IHE (Integrating the Healthcare Enterprise) Profiles: Frameworks for specific clinical workflows.

- OpenEHR: Open-source standard for clinical data management.
- DICOM: Standard for medical imaging interoperability.
- Proprietary APIs from EHR Vendors: Solutions from Epic, Cerner, and other EHR providers.
- Google Cloud Healthcare API: Supports FHIR but also integrates HL7v2 and DICOM, enabling cloud-based healthcare data exchange and AI-driven analytics.
- OMOP (Observational Medical Outcomes Partnership): A Common Data Model (CDM) for research and large-scale observational studies.

What is the FHIR Pilot?

- Innovative Technology
- A public health reporting technology developed in partnership with CDC that uses Health Level 7 (HL7), FHIR® standard protocol as data model for data exchange
- Technical Pilot Study
- Test applied technology mandated by the Cures Act
- Test capability for enhanced clinical data collection for research and federal reporting requirements
- Anticipated Benefits
- Encourages use of modernized healthcare data exchange and technology for timeliness
- Reduces burden on data senders/receivers, meeting new requirements of the Cures Act
- Allows near real-time data reporting, standardized transfer, and use of elect

Why Participate in the Cancer Surveillance Data FHIR® Pilot ?

- Current reporting tools, processes, and technology are outdated, difficult to implement
- Cancer case reporting often requires labor-intensive manual processes
- Automated capture of cancer cases and treatment information from EHRs can provide data faster for research and public health
- The pilot utilizes advanced FHIR® healthcare data standard, which complies with provider mandates stated in the 21st Century Cures Act.
- Reliable, adaptable data exchange to reduce burden, time, and effort for data informed action
- The pilot Will assess:
    - technical implementation, interoperability
    - clinical reporting cancer data capabilities10

Goals of the Cancer Surveillance Data FHIR® Pilot

- Complete implementation and testing of the Central Cancer Registry Reporting (CCRR) Implementation Guide (IG) in clinical settings.
- Leverage open application programming interfaces (APIs) (e.g., FHIR® R4, Bulk FHIR®) for standards-based data exchange.
- Prove capability to send cancer defined data to data receivers via FHIR®.
- Refine documentation of the systems and software involved in the pilot, for burden reduction for providers and future reporting.
- Further inform the development of the relevant IGs.
- Assess data findings for value added research to cancer care population.

Myriddian Updates:

MCR NAACCR and NPCR Data Submission 2024

24 Month Data Submission: November 2024

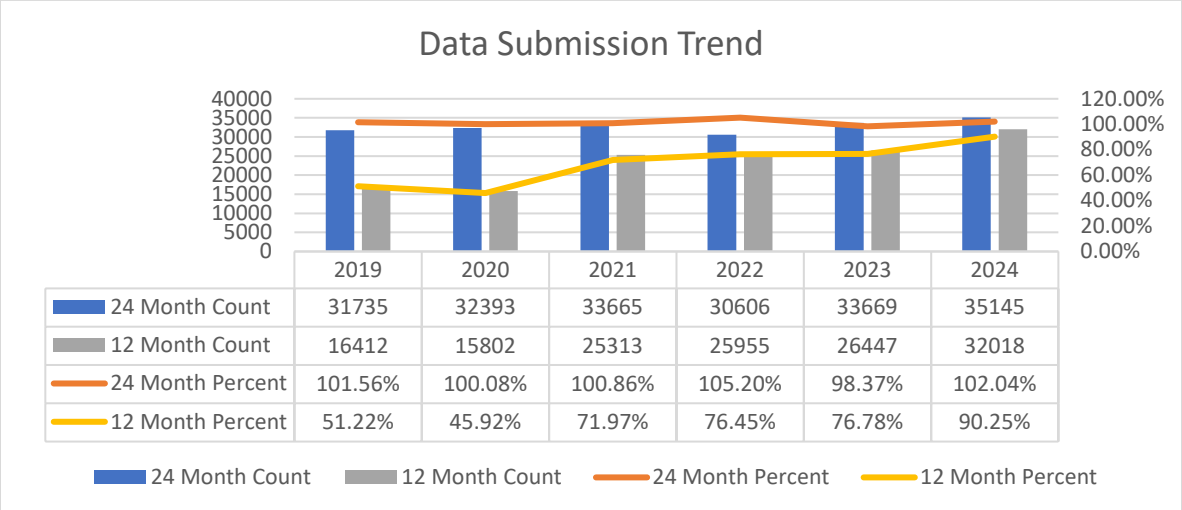
2022 Dx year cases:	Total Records:	40,172
	Total Malignant:	34,536
	Total Incidence Count:	35,145
	Total Expected Count:	34,443
	Completeness Percentage:	102.04%

12 Month Data Submission: December 2024

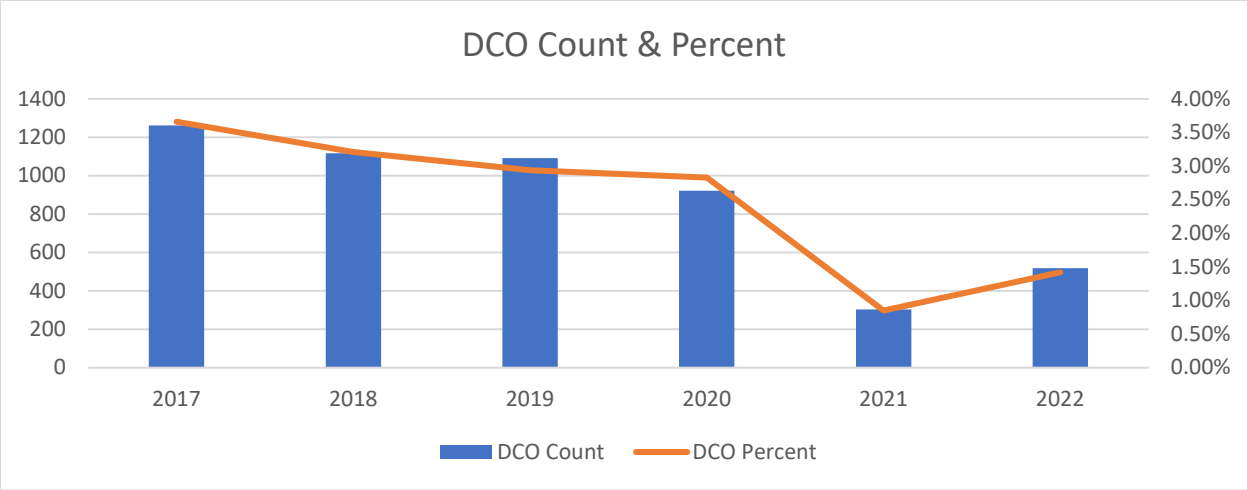
2023 Dx year cases:	Total Records:	36,271
	Total Malignant:	30,821
	Total Incidence Count:	32,018
	Total Expected Count:	36,020
	Completeness Percentage:	90.25%

* MCR Estimation with 3% increase from prior year

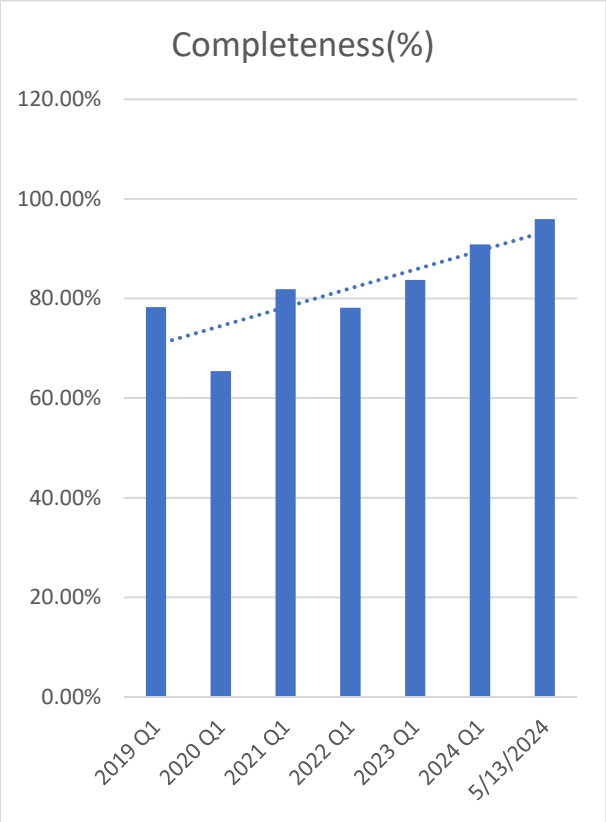
MCR NAACCR and NPCR Data Submission 2024

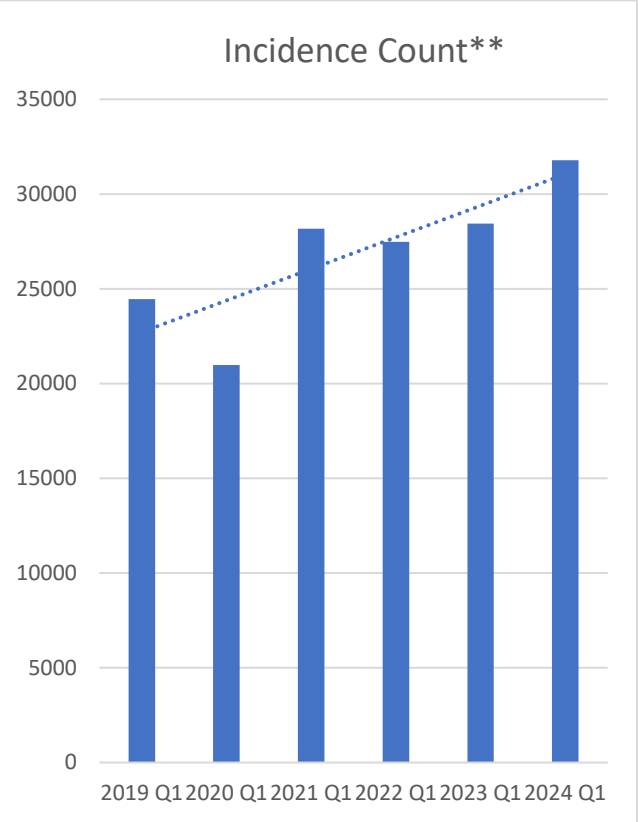


	2019	2020	2021	2022	2023	2024
24 Month Count	31735	32393	33665	30606	33669	35145
12 Month Count	16412	15802	25313	25955	26447	32018
24 Month Percent	101.56%	100.08%	100.86%	105.20%	98.37%	102.04%
12 Month Percent	51.22%	45.92%	71.97%	76.45%	76.78%	90.25%



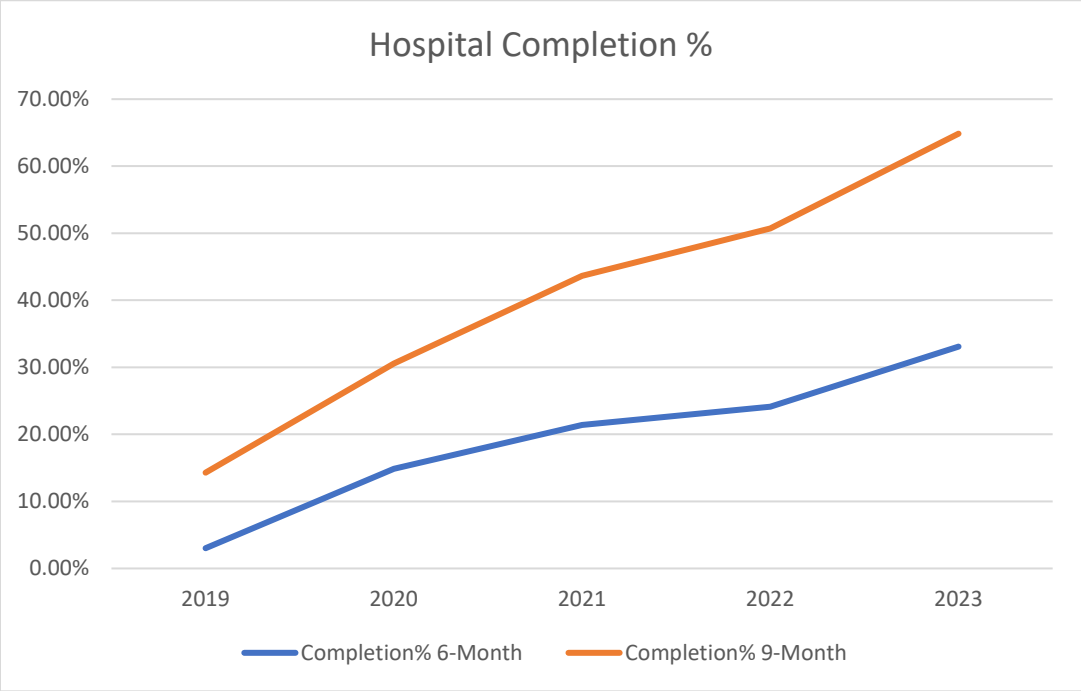
MCR Data Collection Progress





Hospital Case Completeness Progress

Diagnosis Year	Completion% 6-Month	Completion% 9-Month
2019	3.02%	14.29%
2020	14.86%	30.57%
2021	21.39%	43.64%
2022	24.13%	50.73%
2023*	33.09%	64.85%



Modified Records

- Myriddian is moving forward with the modified records
- Hospital Vendor Group helped finalize the list of modified record variables
- If any of the trigger variables are updated in the registry database, it would generate an M-Record for that abstract.
- Myriddian will limit the "M" records to 2018 and newer diagnosis years
- "A" Record must have been previously transmitted.
- Working with vendors to limit the burden on the facilities
- Vendors to set up the process for their clients over the next 2-3 months
- Myriddian will begin testing in Feb/March timeframe
- Annual request in Spring 2025

Closing/Next Meeting
The next meeting will be held on ***Monday, May 12 at 9:30 am.***

Additional Reference LINKS from Meeting Discussion

Advancing Cancer Care through FHIR-Based Reporting: Updates from USCDI+ Cancer

https://www.healthit.gov/buzz-blog/interoperability/advancing-cancer-care-through-fhir-based-reporting-updates-from-uscdi-cancer

Enabling-21-century-applications-for Cancer Surveillance through Enhanced Registries and Beyond

https://nap.nationalacademies.org/catalog/28676/enabling-21st-century-applications-for-cancer-surveillance-through-enhanced-registries-and-beyond?utm_source=linkedin&utm_medium=social&utm_campaign=NASEM_share_intent