Co-Chairs: Ms. Luizilda de Oliveira and David Poms

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## District of Columbia Health Information Exchange Policy Board

# Recommendations on Data Governance and Sustainability for the DC Community Resource Inventory (CRI)

### I. SUMMARY

HIE Policy Board Community Resource Inventory subcommittee proposes five recommendations related to data governance and sustainability for the Community Resource Inventory (CRI). The DC CRI aims to consolidate information on community-based resources available to beneficiaries in the District of Columbia and to establish direct connections to stakeholders that address health-related social needs. The Department of Health Care Finance (DHCF) will serve as the anchor institution for the DC CRI with shared oversight responsibility with relevant Health and Human Services agencies as applicable. The recommendations also incorporate essential aspects such as data standards, regular maintenance and management of resource information, and continued governance of the DC CRI to ensure that all relevant data are provided in a publicly accessible manner. Finally, the recommendations also aim to enhance collaboration and shared maintenance among data stewards for public benefit.

# II. PROBLEM STATEMENT

In the subcommittee's work, several members and other relevant DC HIE stakeholders underscored the importance of a shared resource directory that can facilitate and augment their work to address health-related social needs and improve health equity. However, establishing this shared resource requires a structure that allows for categorization of community-based resources, reliable verification of information provided, an inclusion/exclusion policy, the development of operational workflows, and cooperative data maintenance mechanisms. Furthermore, the continued operation of the CRI requires overall oversight and day-to-day monitoring, to both ensure that community resource data are accurate and to enable CRI lookup capabilities within the screening and referral functions developed through the DC Community Resource Information Exchange (CoRIE) initiative.

To address these issues, the subcommittee reviewed the feasibility of several governance and sustainability models. This was done by reviewing the DC Positive Accountable Community Transformation (PACT) CRI Action Team's testing and evaluation strategies for each model considered. The subcommittee also evaluated the CRI Action Team's recommendations which included discussions on standardized data terminologies, best practices related to data provision and cooperative management, and policy levers to support the operation of the CRI. The CRI subcommittee proposes three (3) recommendations on data governance for the DC CRI to best address the use, exchange, and governance of CRI data.

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## III. SUBCOMMITTEE GOAL AND ACTIVITY

This activity can be added under the subcommittee's overall goal to develop recommendations for consideration by the HIE Policy Board that are related to the use, exchange, sustainability, and governance of community resource directory data through the District HIE infrastructure.

### IV. DISCUSSION

The HIE Community Resource Inventory (CRI) subcommittee proposes the following recommendations:

**Recommendation #1**: The DC CRI should be composed of registered and designated CRI entities that participate in a collaborative, federated network, share data management responsibilities, and bidirectionally exchange resource data.

- Establish a District-wide Community Resource Inventory as a data utility a regulated public private partnership with sufficient staff capacity and funding to ensure open, publicly-accessible, accurate, and up-to-date community resources and services.
- District agencies that provide, accredit, or fund community-based programs or human services should keep an up-to-date record of those programs, make it available in a standardized data format to the DC CRI, and establish policies to ensure the reliability of this information, in coordination with the HIE Policy Board.

**Recommendation #2:** DC government agencies should consider requiring participation in the CRI from service providers, third party referral providers, and associated software vendors that receive public funds for care coordination.

**Recommendation #3**: The DC HIE Policy Board should ensure a subcommittee, workgroup, and/or technical evaluation panel that is committed to continued research and deliberation on ongoing resource data governance challenges that may arise over time. Such a subcommittee or workgroup would be tasked with ensuring that the assets of the DC CRI remain reliably maintained, usefully curated, and openly accessible to all DC stakeholders, and that the rules pertaining to the management and use of the CRI continue to be set by a participation of designated representatives.

As part of drafting these recommendations, the CRI subcommittee worked to establish several key themes, culminating in the above listed recommendations.

• Exploring Rulemaking to Govern CRI Functions: The subcommittee discussed the possibility of rulemaking to establish a registration and designation process, similar to the DC HIE Final Rule, that allows for an entity to ensure that the DC CRI has a core set of resource information that is publicly available. The subcommittee agreed that the use of registered and designated entities may provide the foundation for an effective public-private partnership to further care coordination and to better address health-related social needs. Additionally, the subcommittee discussed a proposal for DHCF to request

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Outcomes Based Certification for the DC CRI to request continued funding for the CRI beyond fiscal year 2025.

- <u>Adopting a Governance Model</u>: The subcommittee deliberated on the benefits of several data governance models and determined that a data utility model best fits the function of the DC CRI. This model enables a single 'source of truth' for all participating organizations. The model reduces duplicative effort across organizations that may not have the capacity to independently verify and update resource information, while simultaneously increasing the reliability and use of the DC CRI. The subcommittee also discussed how participating resource stewards can share responsibility for the maintenance of records and work in a collaborative approach for mutual benefit. Individual data stewards are also responsible for creating and maintaining a canonical registry within their respective organizations that lists out community resource information in a standardized format that they share with the DC CRI. Additionally, the subcommittee concluded that the definition of a 'data utility' must align with exiting definitions used by DHCF and the DC HIE.
- <u>Establishing Standards for Bi-directional Data Exchange</u>: In order to ensure up-to-date listing of community resource information, the subcommittee recognized the need to clearly define the mutual exchange of community resource data that is expected by entities that are participating in the CRI. As a result, a visual representation of the data flow was developed. This is located in <u>Figure 1</u>. The subcommittee underscored the importance of collaboration with data stewards, both as a mechanism to yield higher quality data and to reduce burden. The subcommittee highlighted that several data stewards have expertise in specific social need domains (such as housing or food), which may be leveraged to provide the most accurate data for public benefit. Additionally, the model reduces costs and burden on organizations as they can receive updated resource information from other data stewards who have different expertise. Furthermore, creating a structure for shared maintenance empowers data stewards as 'partners' who will assume responsibility for the resource information provided in their specific domain. This bi-directional exchange acts as a mutual benefit, which in turn serves as an incentive for data stewards to participate in the DC CRI.

The subcommittee also discussed data sharing mechanisms and concluded that while data may be best shared via an API, a bi-directional exchange may also be achieved if data stewards shared community resource information in other file formats (such as CSV) depending on the technical capabilities of the organization. The subcommittee highlighted the importance of outlining requirements, such as a minimum set of information for each community resource, to enable the exchange of data in a standardized format.

<u>Determining Staffing Required for CRI Functions</u>: To ensure that resources are regularly updated, the subcommittee discussed staffing recommendations. The subcommittee voted on and approved staffing strategies that best addressed the areas where data is produced in the data flow as shown in <u>Figure 1</u>. This includes Quality Assurance Specialists (who will perform verification and maintenance of the resource records available on the DC CRI on a bi-annual basis at a minimum), a Data Partnerships Manager (who will work with cross-sector entities such as vendors, governmental agencies, and other

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aggregators to both ensure that the CRI is receiving high-quality resource information and to sustain continued partnership with these entities), and a Data Collaborative Manager (who will curate records available in the DC CRI to ensure cross-sector alignment related to resource taxonomies, clinical terminologies, and program-related metadata).

• Policy Levers to Ensure High-Quality Data: The subcommittee emphasized that the creation of a shared, publicly available resource inventory presents a unique opportunity to accumulate community resource information from disparate sources in a standardized format. This includes community resources that are provided, accredited, or funded by the District. The subcommittee discussed the use of a 'Service Register' – defined as an official list of all of services provided by an organization – as a best practice and policy solution for District agencies, with the added benefit of connecting beneficiaries to needed resources. Additionally, to best support care coordination efforts as identified in Goal #4 of the District's 10 Strategic Goals for Health IT and HIE, the subcommittee underscored the importance of mandating participation in the CRI by any publicly-funded service providers, third-party referral providers, and software vendors. This may include contract language that requires organizations to submit information in a standardized format to the DC CRI. Such a policy would also align with Recommendation #2 as outlined in the 2022 State Medicaid Health IT Plan (SMHP) Update. A future action is securing inter-governmental collaboration on the DC CRI with new rulemaking or MOUs as needed.

Furthermore, the subcommittee leadership also discussed several questions related to oversight and monitoring. The subcommittee concluded that DHCF should serve as the anchor institution for the DC CRI, with shared oversight by related-HHS agencies as required. To ensure that future data governance challenges are appropriately addressed, the subcommittee underscored the importance of a dedicated subcommittee or workgroup that can ensure that DC CRI continues to be responsive to the needs of beneficiaries. The subcommittee further highlighted that the workgroup should include members who are representative of all DC CRI stakeholders.

#### V. RECOMMENDATION(S) FOR BOARD ACTION:

The Community Resource Inventory (CRI) subcommittee proposes that the DC HIE Policy Board approve the recommendations on CRI data governance and sustainability.

The subcommittee recommends that the Board assign the role of executing Recommendation #3 to the CRI subcommittee. These functions include, but are not limited to, the following: (1) Providing feedback and updates to any draft regulations; (2) Ensuring DC CRI data are maintained in accordance with nationally recognized standards (with guidance from DHCF) by providing oversight the data maintained by the DC CRI; and (3) Collaborating with other HIE Policy Board subcommittees to engage HIE stakeholders to increase the use of the DC CRI for social needs referrals.

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Figure 1: DC CRI Data Exchange Diagram

#### The DC CRI requires community participation to ensure records for programs and services offered are up-to-date

