Cedar Campus

Data Partner Priorities and Data Integration Recommendations

Prepared by: The Drexel University Cedar Campus Evaluation Team in consultation with the PHMC R&E Group for PHMC Public Health Campus Stakeholders

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Summary

A critical component of an evaluation of a place-based, co-location initiative like the PHMC Public Health Campus on Cedar ("Cedar Campus") is to integrate and align data collected by individual programs in order to compile and share collective outcomes. The evaluation team met separately with data leaders of the individual Cedar Campus programs to gather information about their existing data systems, evaluation priorities, and data-sharing concerns. Representatives from Cedar Campus service providers then participated in an "all partners" meeting in September 2024. The purpose of this meeting was to discuss priorities and opportunities for incorporating data across their respective administrative systems in order to inform a shared evaluation of the campus as a whole. The following report summarizes data sharing priorities and concerns emerging from this meeting as well as recommendations for collecting and analyzing data in a shared evaluation.

A major focus of this meeting was to identify which measures would be most useful to partners for providing evidence of Cedar Campus improved care linkage and patient outcomes.

The measurement priorities that participants identified included metrics related to:

1. Public perceptions/patient experience, with a focus on understanding how to increase engagement with services and programming at Cedar. Partners indicated a desire to understand whether/how use of Cedar services proliferated through patient social networks (i.e. families, households, word of mouth).
2. Service needs, related to both clinical and informational/ educational services.
3. Service access/utilization, including a comment that access to care metrics should be prioritized.
4. Referrals to services and use of multiple services.
5. Patient outcomes, including reduced inpatient readmissions for conditions related to other services available at Cedar Campus.
6. Use of space, as an important area of data collection with a need to understand how spaces at Cedar are currently being used versus how spaces there could best serve the community.

The most frequently mentioned data priority areas included:

1. Referrals to services
2. Use of multiple services
3. Patient outcomes

Partners also shared expected challenges related to data collection and sharing at Cedar Campus. These included:

1. Ensuring the data collected accurately reflects what we want to measure (e.g., "referrals don't always translate to a patient attending the appointment or having the need met," and so we should/could track referral completion).
2. Programming needs to be responsive and accessible in order to be useful. Repairing community relations was also indicated as an important challenge to contend with. Given the reputation of the facilities Cedar replaced, new systems, policies, and practices are needed to gain the community's trust. Consistent patient, and

community member input is essential for responsive programming and rebuilding trust.

3. Finally, data-related logistical challenges include navigating between institutions' different systems, specific measures used, and data sharing processes, as well as the extended timelines often required.

Proposed Measures

Based on these responses, we recommend prioritizing one or more of the following types of measures in the table below. These are measures that 1) correspond to frequently mentioned priorities as prioritized by service providers, and 2) are likely to be available in a similar way in multiple institutions' existing data systems. We also note which types of measures are likely to be simpler or more complex to calculate. As mentioned in the meeting, some measures, such as public perceptions and community needs, are being collected through surveys and interviews. These will need to continue to be collected on a regular basis for continual input and the ability to detect changes in perceptions and experiences with Cedar Campus over time. (*see page 3*)

Measure	Difficulty	Calculations	Goal
Total number of visits in a defined time period	Simplest to calculate	Aggregate visits across providers and programs	Increase over time? Or more optimal distribution, such as lower proportion ED and higher proportion outpatient?
		Visits by program	Increase over time? Increase over time for some programs and decrease for others?
		Visits by patient location/ neighborhood (e.g., zip code)	Increase in number of visits from patients living in neighborhoods surrounding Cedar Campus
Number of return visits and readmissions in a defined time period	More difficult to calculate because return visits by individual patients have to be calculated, as opposed to just total counts of visits	Return visits to outpatient clinics * Can be overall or by program	Increase over time
		Return visits to ED or CRC, inpatient readmissions * Can be overall, by program, by diagnosis type	Decrease over time
Number of referrals made to providers within Cedar Campus in a defined time period	May be more difficult to calculate, since it requires tracking which services and providers were available on campus at a given time	Aggregate total referrals across programs	Increase over time
		Referrals by program * May prioritize certain service(s), such as referrals made from ED and CRC	Increase over time
Use of multiple services by the same patient or family	More difficult to calculate, since it requires identifying the same patient (or family) across multiple providers' data systems	Total number of patients/families using multiple services * A less comprehensive version of this measure is also being collected in surveys	Increase over time

Recommendations and Opportunities for Data Partner Collaboration

In order to utilize the proposed measures above, infrastructure must be put in place to support interorganizational collaboration and coordinated data collection efforts. Using ***Common Data Elements (CDEs)*** and/or developing an ***Integrated Data System (IDS)*** are opportunities for Cedar data partners to collaboratively engage in data collection efforts.

Using ***Common Data Elements (CDEs)*** refers to standardizing data across systems to facilitate combining and comparing them. For Cedar Campus data partners, using CDEs may include:

- Agreeing on how to define measures already being collected. Possible examples are developing a specific definition that all providers will apply to their medical record systems to identify patients living in the neighborhoods surrounding Cedar Campus, or developing a specific definition that all providers will use to identify referrals being made to other Cedar Campus providers.
- Agreeing to add additional measures that align between providers. A possible example is developing a specific question to incorporate into patient satisfaction surveys that asks about the use of multiple services or programs at Cedar Campus.

Developing an ***Integrated Data System (IDS)*** refers to a type of data sharing where individual records can be linked across providers. This may not be feasible in the short term but, if implemented in the longer term, could have great benefits for service provision and coordination.

Additional information and resources about CDEs and IDS can be found below.

Using Common Data Elements (CDEs)

- What are CDEs?
    - CDE: standardized, precisely defined questions paired with a set of specific allowable responses, used systematically across different sites, studies, or clinical trials to ensure consistent data collection. Common Data Elements: Standardizing Data Collection
- Why would CDEs be helpful to data partners of the PHMC Public Health Campus on Cedar?
    - Reduce the time and cost needed to develop data collection tools
    - Promote standardized, consistent, and universal data collection
    - Improve data quality
    - Facilitate data sharing
    - Improve opportunities for meta-analysis and comparison of results from different studies
    - (Project Overview | NINDS Common Data Elements)
- Process for CDE utilization:
    - Create a CDE Working Group with representation across Cedar data partners.
    - Build consensus on the overall goals of Cedar Campus and the cross-program analytical goals, as well as their accompanying activities and deliverables.
    - Identify/develop CDEs that each provider can collect (see steps below).
    - Complete all necessary documentation including the creation of codebooks, templates and forms, guidance documents, training materials, etc.

    - Ensure the adoption, use, and regular sharing/reporting of CDEs.
- How are CDEs identified?
    - Utilize or adapt existing CDEs from existing repositories such as the NIH CDE repository, the PHENotypes and eXposures (PhenX Toolkit), the Rapid Acceleration of Diagnostics-Underserved Populations (RADx-UP), or existing EHR fields such as ICD-10 codes, and others.
    - CDEs can also be created (calculated) using pre-existing data using a standardized approach that ensures comparability across multiple datasets, research sites or studies.
- How are CDEs developed?
    - Determine constructs or data needed to demonstrate achievement of goals as a basis for identification of calculated measures or required standardized questions and responses.
    - Select standardized questions and responses for each construct
    - Select and use a standardized defining software to define and code selected questions and responses to transform to a CDE

Resources related to CDE identification and development

- Common Data Elements: Standardizing Data Collection
- Data Element Search

Establishing an Integrated Data System (IDS)

- What is an IDS?
    - An integrated data system (IDS) periodically links individual-level administrative data from multiple public service agencies and contracted service providers, creating a rich picture of individual service needs, participation and outcomes over time.
- Why would an IDS be helpful to data partners of the PHMC Public Health Campus on Cedar?
    - Integrated data systems (IDS) are well suited to serve as the backbone for research and evaluation of multi-system initiatives that are serving the same client/patient population and/or catchment community.
    - Rapid and lower-cost data collection and analysis (since data do not need to be re-linked for each project).
    - The ability to identify shared populations across services, as well as pre-service exposures and post-service outcomes for these populations.
    - The ability to use comparative designs with novel control groups to evaluate interventions and programs.
- Process for the establishment of an IDS:
    - Develop processes to ensure data security, data privacy, and legal compliance through a combination of institutional review board (IRB) review and data use agreements (DUAs).
    - DUAs governing the IDS must allow for periodic data transfers to update the IDS and allow for multiple potential uses of the data, including stipulating when and

    how organizations will have the opportunity to review data products before dissemination.
        - Potential uses include service monitoring and improvement, program evaluation, grant applications, advocacy, and research. Rules governing IDS use may vary depending on the use and/or on the user.
    - Determine an appropriate IDS governance structure and protocols related to legal agreements, technology and data security, and data standards.
        - Relevant stakeholders include current and potential service providers, other potential data providers (e.g., City of Philadelphia), data users, patients and caregivers, and community members.
    - Develop a sustainability plan including staffing, technological, and funding needs.

Resources related to data sharing and IDS establishment

- https://aisp.upenn.edu/about-data-sharing/
- https://aisp.upenn.edu/wp-content/uploads/2020/06/AISP-Intro-.pdf
- aecf-usingIDStoimprovecasemanagement-2017.pdf