

Agenda IV: Use Case Scenarios

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Legal Requirements for DRC Review

- Per HPD Statute, in making recommendations, the DRC is required to consider one or more of the following:
 - whether the use of the data is consistent with the goals of the system,
 - whether it provides greater transparency regarding health care costs, utilization, quality, or equity, or
 - how the information may be used to inform policy decisions regarding the provision of quality health care, improving public health, reducing health disparities, advancing health coverage, or reducing health care costs.
- These considerations are broad and open to interpretation.
- There are no regulations or specific criteria the DRC must use.

Optional DRC Considerations

- Privacy:
 - Is reason or justification provided for all confidential or sensitive data elements requested?
 - Does the request satisfy minimum data necessary standards?
 - Does the requestor demonstrate ability to protect data privacy and security for requests that include direct personal identifiers?
- Anticompetitive Use & Commercialization of HPD Data:
 - Is there potential for anticompetitive use of the data?
 - Could the data be used for commercialization or marketing?

Optional DRC Considerations

- Results and Information Products:
 - Any concerns about the proposed objectives, methodologies, or potential limitations of the data?
 - What are the expected findings/outputs?
 - How will results be made available to policymakers or the public?
 - What level of aggregation will be applied to reports, presentations, and other information products intended for public dissemination?
 - How does the proposed project generate a public benefit for California?

- What is the state's involvement, if any?

Making Recommendations

- There are few statutory requirements, rules, or specific criteria
- Context is Key:
 - Who is requesting the data?
 - At what level of detail?
 - For what purpose, e.g., specific analysis needs/research questions?
 - Anticipated results?
 - How will results be shared or disseminated:
 - At what level of detail?
 - To what end?
- Requests will often raise unique questions and considerations

Use Case: Personally Identifiable Information (PII)

- For DRC Consideration:
 - Purpose: Is PII needed, why, how will it be used?
 - Direct Identifier uses:
 - Research linking data sources at the patient level
 - Treatment, payment, or health care operations
 - Health Oversight Agencies
 - Public Health Activities
 - Indirect Identifiers support many HPD uses:
 - Analysis of care patterns, adherence to standards, continuity of care
 - Geographic variation in cost, utilization, quality, access, equity, etc.
 - Is the request consistent with minimum data necessary standards?

Prevalence & Treatment of Asthma in Adolescent Patients

- Requestor – Researcher
- Type – Research Identifiable Data, all members under 18 with an asthma diagnosis or record of asthma related treatment
- Purpose: Understand geographic variation in adolescent asthma prevalence, use of services, and access to care. Identify areas of unmet need, support data driven decision making, inform policy.

Discussion Questions?

- Any concerns with this request fulfilling statutory mandates that the DRC is required to consider?
- What potential privacy concerns should be considered?
 - Is PII (direct or indirect) needed, and what would be the concerns and committee considerations?
- What potential anti-competitive or commercialization concerns should be considered?
- What could be some concerns with the analysis, results and information products?
 - Mode of data access/transmission, data limitations, data uses (example, linkages), methods that would be of concern, vulnerable populations, minimum data necessary, etc.
- What else would the DRC potentially have to consider?

Care Variation for Adults with Diabetes

- Requestor – Researcher, Advocacy Group
- Type – Standard Limited Dataset (SLD) for all members 18 and older with a diabetes diagnosis or record of diabetes related treatment. Direct Transmission of files request.
- Purpose: Understand geographic variation in adult diabetes prevalence, use of services, and access to care. Identify areas with high prevalence, relatively low service utilization, and where more providers and other resources may be needed.

Discussion Questions?

- Any concerns with this request fulfilling statutory mandates that the DRC is required to consider?
- What potential privacy concerns should be considered?
 - Is PII (direct or indirect) needed, and what would be the concerns and committee considerations?
- What potential anti-competitive or commercialization concerns should be considered?
- What could be some concerns with the analysis, results and information products?
 - Mode of data access/transmission, data limitations, data uses (example, linkages), methods that would be of concern, vulnerable populations, minimum data necessary, etc.
- What else would the DRC potentially have to consider?

Linking Disease Registry and HPD Data

- Requestor – Researcher
- Type – Research Identifiable Dataset for members with a relevant diagnosis or record of related treatment. Direct Transmission of files is requested.
- Purpose: Leverage combined disease registry and HPD data to create a more complete record of patient care and treatment costs. Compare the efficacy (match rates) of different matching algorithms. Publish and share findings with disease registries, state agencies, and the research community.

Discussion Questions?

- Any concerns with this request fulfilling statutory mandates that the DRC is required to consider?
- What potential privacy concerns should be considered?
 - Is PII (direct or indirect) needed, and what would be the concerns and committee considerations?
- What potential anti-competitive or commercialization concerns should be considered?
- What could be some concerns with the analysis, results and information products?
 - Mode of data access/transmission, data limitations, data uses (example, linkages), methods that would be of concern, vulnerable populations, minimum data necessary, etc.
- What else would the DRC potentially have to consider?