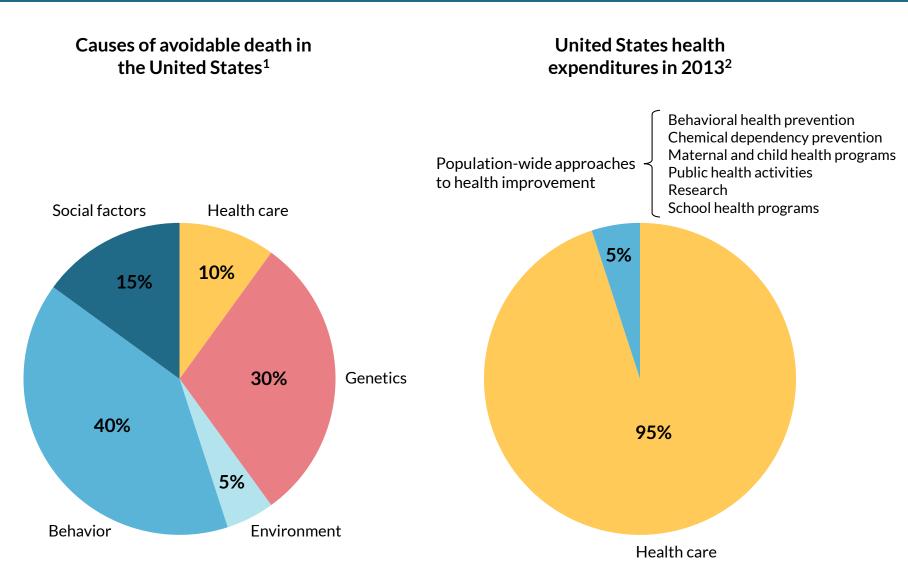
Initial recommendations to the Interim Leadership Council on data sharing and integration in King County

Performance Measurement Workgroup



Background

Health extends far beyond health care.



¹ McGinnis et al., The case for more active policy attention to health promotion. Health Affairs 2002; 21(2):78-93.

² Centers for Medicare & Medicaid Services, Office of the Actuary. National health expenditures, by source of funds and type of expenditure. 2013.

In King County, there is a broad understanding that health begins where we live, learn, work and play.

This is embodied in the Accountable Community of Health.

King County Accountable Community of Health (ACH)

AWARENESS



Due to the complex nature of the upstream drivers of poor health and disparities (i.e. where we live, learn, work and play), we must work across sectors, agencies and communities in order to improve heath and promote equity

VISION



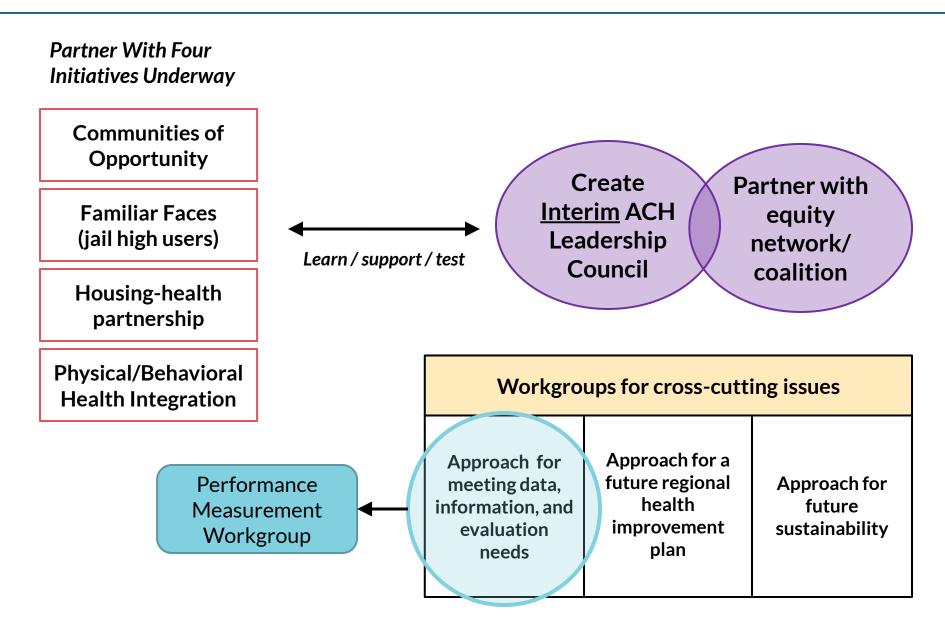
Building healthier communities through a collaborative regional approach focusing on social determinants of health, clinical-community linkages, and whole person care

GOAL

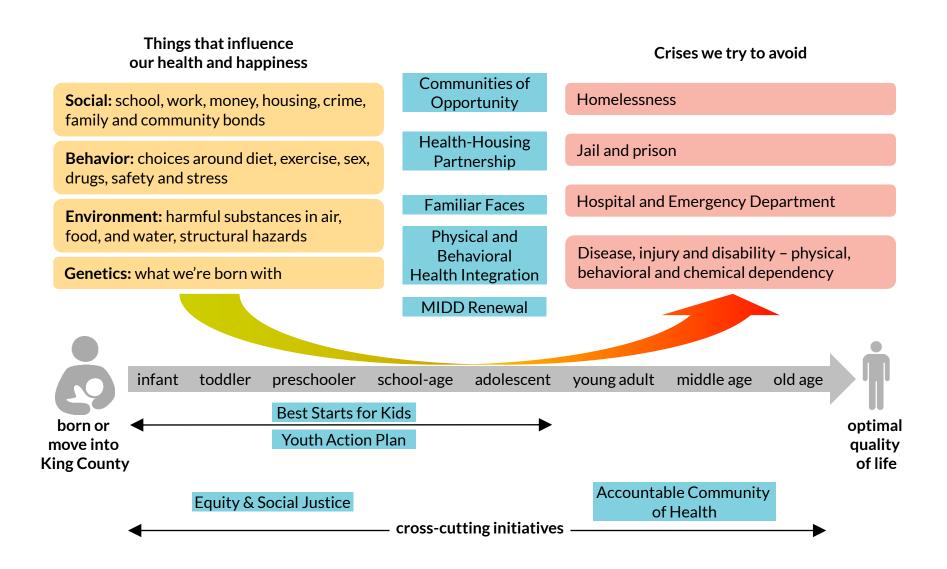


Better health and better quality of care at a lower cost = the Triple Aim

King County Accountable Community of Health Plan for 2015



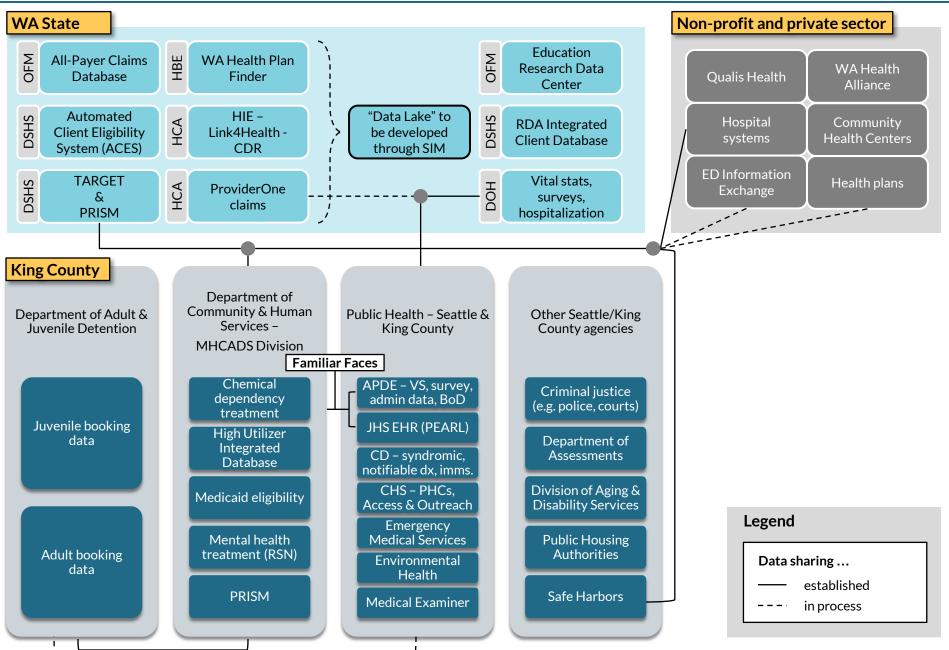
In King County, ACH-backed, Health & Human Services Transformation initiatives are working across sectors throughout the life course



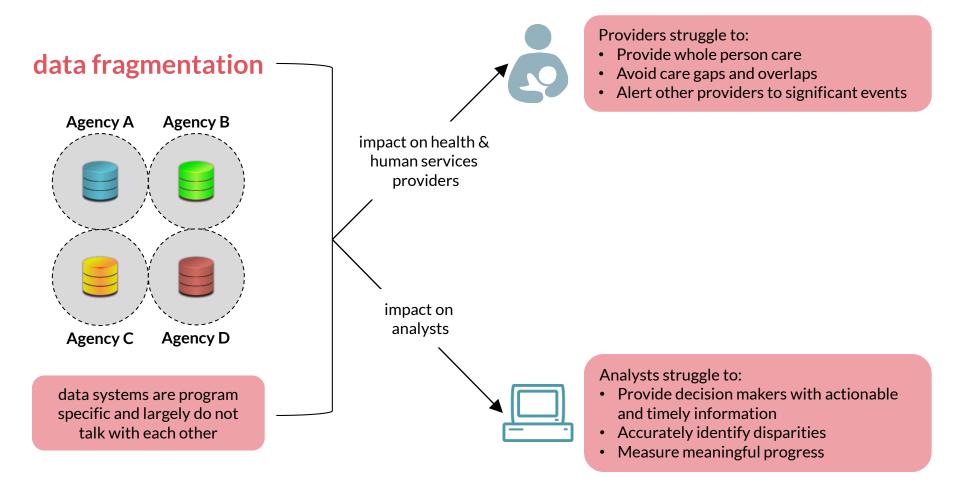
There is great promise in this growing collaborative approach to promote heathy individuals and communities.

To know if we are making progress, these initiatives need cross sector data, but substantial barriers stand in the way.

Landscape of selected King County data assets to support ACH-backed initiatives



Impact of data fragmentation on health and human services transformation



ACH-backed initiatives are struggling to share and integrate cross sector data

Vision

Data needs

community features

	Communities of Opportunity	Housing-Health Partnership	Familiar Faces	Physical/Behavioral Health Integration
,	All children, adults, and communities in King County are healthy, have quality/ affordable homes, thrive economically, and feel a part of a community	Build the evidence base to support housing and health linked services as a key strategy for eliminating health inequities and for achieving the Triple Aim	Improve health and social outcomes, while reducing costs, for individuals in King County with complex health and social needs, and high use of services and supports	Integrate physical health, behavioral health, and chemical dependency treatment services by January 2020
	diabetes & hypertension	Medicaid claims data	jail involvement	behavioral health treatment
	housing cost burden	PHA resident data	emergency service use	chem. dependency treatment
	home ownership	electronic health records	preventable hospitalization	physical health claims
_	housing condition	behavioral health treatment	diabetes & hypertension	electronic health records
	employment rate	chem. dependency treatment	healthy weight	
	academic performance	academic performance	housing stability	
	youth with adult to talk to	jail involvement	mental distress	
	adults with emotional support		substance use	
	community connections		employment	
	mental distress		living wage	
	food security, food deserts		poverty level	
	living wage		quality of life	
	workforce participation		satisfaction with care	Legend
	job placement		per capita cost	Access to data
	business ownership, stability		courts, arrests, warrants	established
	business displacement			in process
	housing displacement			absent
	foreclosures			

Identify requirements for sharing data in King County Develop a value proposition for shared data Performance Measurement Workgroup will provide guidance to the ACH Explore alignment with other ACHs Leadership Council and support data and and the state around metrics. evaluation needs of cross sector initiatives access to data, and interoperability Support data needs of King County cross sector initiatives Recommend future role, home and structure of PMW in 2016

• Leverage technical staff and data systems that are in place Backbone function • Ensure administrative/operational support to move the PMW forward Shared data needed to understand the whole picture Shared data/measurement • Mutual benefit to shared data for all stakeholder groups • Build common vision for shared and integrated data in King County Common agenda • Align with state/other ACHs to avoid duplication and promote consistency Mutually reinforcing Consider both qualitative and quantitative data activities • No one agency holds all the data to evaluate the full Triple Aim **Continuous** • Use learning and rapid feedback to continually readjust 5 communication & Flexible PMW membership and scope under guidance of Leadership Council phased approach

¹Collective Impact Forum (FSG), Guide to Evaluating Collective Impact, 2014. ²Public Health Seattle & King County, Collaborating for a Healthier King County: A Path Forward for Accountable Community Health Design in King County, Washington; December 2014.

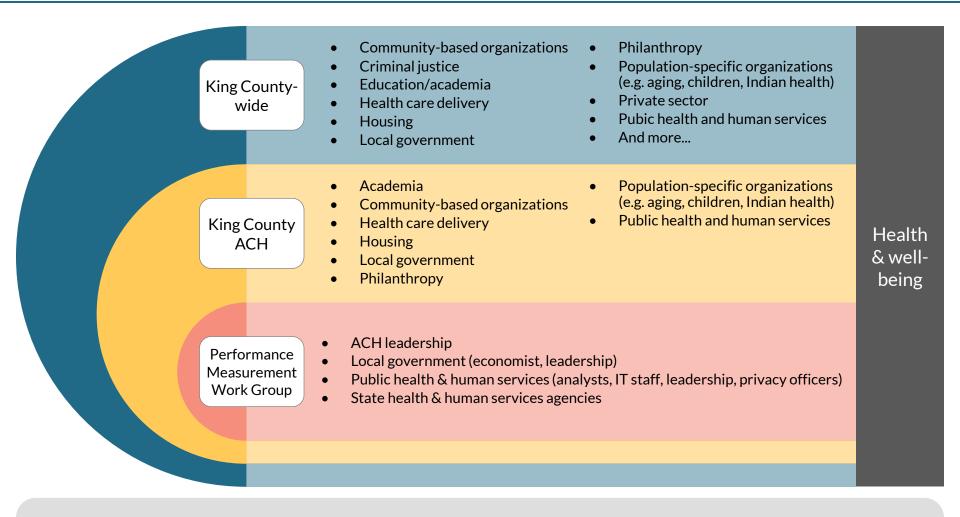
E Q U

PMW membership, December 2015

Member	Role	Organization	Rationale	
Mary Jane Alexander & Rene Franzen	Privacy officers	PHSKC & DCHS	Data sharing must protect individual confidentiality and follow regulations	
Jeff Duchin & Maria Yang	Health Officer, Medical Director	PHSKC & DCHS	Perspective on individual- and population-level use of health and human services data	
Tracy Hilliard	Director of Data Integrity	City of Seattle	City of Seattle is a key partner in transformation initiatives and has a role in administering HMIS	
Jutta Joesch	Health Care Economist	Executive's Office King County	Reducing health care costs is one element of the Triple Aim	
Eli Kern	Epidemiologist, APDE	PHSKC	To serve as technical lead to the PMW	
Kathy Lofy	State Health Officer	DOH	Promote alignment with Analytics, Interoperability & Measurement work of Healthier Washington	
David Mancuso	Director, Research & Data Analysis	DSHS		
Laura Pennington	Performance Measures Program Manager	Office of Health Innovation & Reform, HCA		
Marguerite Ro, Co-Lead	Chief, APDE Chief, CDIP	PHSKC	DCHS and PHSKC are two primary providers of health & human services information	
Caitlin Safford	Manager, External Relations	Coordinated Care	Critical link with the Interim Leadership Council, to which the PMW is accountable	
Debra Srebnik	Analyst, MHCADSD	DCHS	DCHS and PHSKC are two primary providers of health and human services information	
Amina Suchoski, Co-Lead	Vice President, Business Development	United Healthcare	Critical link with the Interim Leadership Council, to which the PMW is accountable	
Lee Thornhill	Social Research Scientist, APDE	PHSKC	To provide backbone support to the PMW	

Initial recommendations to the Interim Leadership Council on data sharing and integration in King County

With many sectors and organizations contributing to health & well-being in King County, relationship building is an essential but time-consuming step in moving towards data integration



- PMW currently a subset of areas contributing to health and well-being in King County
- PMW also a subset of health and non-health data creators, data consumers & data enablers in King County
- In its first 6 months, PMW has focused primarily on developing relationships and a common understanding around data sharing & integration across this subset of organizations

Step		When	Status
1	 Barriers to and potential solutions to data sharing & integration discussed during 4 PMW meetings, with focus on four ACH-backed initiatives¹ Discussion, feedback and questions gathered during these 4 meetings formed the basis for developing initial PMW recommendations on data sharing & integration 	Jun-Sep 2015	Done
2	PMW technical lead & backbone staff work with voluntary PMW subgroup (DCHS analyst, DCHS privacy officer, King County health care economist) under guidance of PMW coleads to develop initial, draft PMW recommendations	Sep-Oct 2015	Done
3	 Initial draft recommendations presented to full PMW membership Feedback gathered and used to refine recommendations for PMW voting and approval 	Oct-Dec 2015	Done
4	PMW votes on and prioritizes recommendations	Dec 2015	Pending
5	 PMW-approved recommendations presented to King County ACH ILC for review ILC-approved recommendations used to form 2016 PMW work plan 	Jan 2016	Pending

¹Communities of Opportunity, Familiar Faces, Housing-health partnership, Physical/Behavioral Health Integration

How do we move from data fragmentation to data integration?

- Following 8 steps describe one potential pathway towards data integration
- An iterative process steps may be omitted or deferred as needed
- In 2015, PMW has focused primarily on steps 1-5

Link and analyze cross agency data **Value** Embrace the idea that all parties Leverage for operations, assessment, and/or proposition benefit from data sharing shared data evaluation Plan integrated, real-time, client-Plan to Common Learn to speak common language level database for care for data privacy, sharing & security language integrate coordination and evaluation 3 Use traditional & innovative Develop or build upon an existing Safeguard methods (e.g. contracts) to permit **Integrate** data integration solution and protect shared & stored data Leverage Leverage integrated database for Share one-time or routine data **Share** integrated operations, assessment, and/or extracts per established contracts evaluation data

Ongoing monitoring of process, outcomes and impacts of data sharing and integration

1. Define and disseminate the added value of data sharing and integration in King County

Need: Lack of a common understanding for how shared data can benefit community health in King County inhibits the relationship and trust building that is essential for sharing cross agency health and non-health data

Recommendation

Working with communication staff, develop and disseminate effective messaging for how data sharing and integration can be used to protect and promote community health in King County, including working towards equity and social justice

Details & deliverables

- "Communication staff" to be identified through King County ACH ILC, may include in-kind staff time from organizations participating in King County ACH
- Target audiences for messaging may include three broad groups data creators (e.g. government agencies, health plans), data consumers (both technical and non-technical, including the public), and data enablers (e.g. privacy officers, IT professionals)
- Form group of 2-3 communications staff, supported by PMW member/staff, to develop communications work plan, to include:
 - Overall and specific goals, target audience(s), and specific deliverable(s) of communication plan
 - Delegated roles, responsibilities & timeline for producing and disseminating deliverable(s)
- Key messages may include:
 - Validate importance of protecting health and non-health information and preventing unintended information disclosure
 - Raise awareness of successful local data integration projects and their benefits to King County residents

Required resources

Communications staff time, PMW member/staff time, potential costs for dissemination (e.g. report production)

Focus

King County government

King County ACH

King County-wide

2. Build and monitor trust in data sharing

Need: Data is shared across agencies at the speed of trust, and building and sustaining trust is an active and resource-intensive process

Recommendation

Develop and implement a work plan for building, monitoring, and sustaining trust around sharing of health and non-health data between organizations represented on the King County ACH, other ACHs, and with selected state agencies

Details

- Initial health and non-health data priorities to reflect data needs of King County ACH-backed initiatives
- Work plan to be developed by PMW members/staff, to include:
 - Identification of specific health and non-health data sources to be included
 - Assessment of factors driving current lack of trust in data sharing between ACH members, ACHs, and state agencies
 - Development and implementation of 1-2 initiatives for addressing these factors
 - Method for monitoring changes in organization-level trust over time
 - Roles, responsibilities and timeline
- **Deliverable:** Baseline report summarizing barriers to trust, proposed approach for building trust, and monitoring approach
- **Deliverable:** Quarterly monitoring of organization-level trust with brief progress reports over 1-2 year period

Required resources

PMW member/staff time

Focus

King County government

King County ACH

King County-wide

3. Align data privacy and sharing practices across King County ACH members

Need: Variability in regulations governing data privacy and inconsistent interpretation of these regulations are major barriers to cross agency integration of health & non-health data in King County

Recommendation

Align privacy officers across King County ACH members through monthly ACH-endorsed meetings

Details

- King County ACH members to identify privacy officers to attend meetings
- Meetings to be supported by PMW member/staff (if needed)
- Privacy officers to develop work plan, to potentially include:
 - Develop unified interpretation for what is legally defensible for electronic sharing of protected health and non-health information
 - Establish clarity on data privacy and sharing definitions, including sharing of data for non-treatment requirements, and standards for creating deidentified and limited data sets
 - Reach agreement on common best practices for secure storage of protected health and non-health data
 - Assess variation in patient consent forms across King County ACH members, and make recommendations for standardization
 - Roles, responsibilities and timeline
- **Deliverable:** Guidance document to summarize recommendations for aligned data privacy and sharing practices, to be used by King County ACH members

Required resources

Privacy office staff time, PMW members/staff time

Focus

King County government

King County ACH

King County-wide

4. Identify opportunities for data alignment across 5 Managed Care Organizations (MCOs)

Need: Given MCOs' statewide presence, robust ACH engagement, and role as a producer and consumer of health & non-health data, data alignment across MCOs may support building shared data in the ACH context

Recommendation

Identify and pursue opportunities for data alignment across 5 MCOs, including which new data sources have common value, and how to define a mutually beneficial data sharing relationship between MCOs and other King County ACH members

Details

- Plan for 4-8 meetings (initially monthly) in 2016 for MCO staff to discuss opportunities for alignment of data priorities and perspectives with each other, and with other ACH members
- Meetings to be supported by PMW member/staff
- Purpose of meetings is exploratory, and thus meetings may work towards a proposal for how MCOs can best align their data assets and priorities with each other and with other ACH members
- MCOs may opt to focus discussion on existing initiatives with MCO involvement and data needs, such as care coordination initiatives (e.g. Familiar Faces)
- MCOs may decide to include other ACHs and/or state agencies given their statewide role in both health care and ACHs
- **Deliverable:** Proposal for initiative(s) to support MCO data alignment

Required resources

MCO staff time, PMW members/staff time

Focus

King County government

King County ACH

King County-wide

5. Seek alignment in data sharing and privacy guidelines with WA state agencies

Need: As state agencies develop their own unified interpretation of data privacy regulations, ensuring King County alignment will help to prevent additional data fragmentation in the future

Recommendation

Request inclusion of King County ACH representation in meetings convened by the Health Care Authority as partners in state efforts to address common issues and barriers for electronic sharing of protected health information, including efforts to develop a unified interpretation for what is legally defensible in the collection, sharing and use of that information

Details

- Privacy officers from King County ACH members to work with HCA staff to determine ideal timeline and approach to include King County ACH and other ACHs in state-level work to unify data sharing practices for protected health information (PHI)
- Identify opportunities to expand work to include other health (e.g. behavioral health, chemical dependency) and non-health (e.g. housing) data sources

Required resources

Privacy officer staff time

Focus

King County government

King County ACH

King County-wide

6. Identify opportunities for accelerating data sharing procedures in King County government

Need: The time consuming and resource-intensive nature of data sharing agreements is a major barrier to timely and meaningful data sharing among King County government agencies

Recommendation

Investigate factors that drive timeframes for implementing health and non-health data sharing contracts among King County government agencies, including how earlier engagement with privacy and legal officers may accelerate this process, and how collaboration between data analysts, program managers, and privacy/legal officers can be increased

Details

- Assign to a PMW subgroup to focus on King County government data sharing and integration challenges
- Data sharing timeline barriers and opportunities for improvement to be identified through series of subgroup meetings in 2016, and categorized according to themes (e.g. motivational, economic, political, legal, technical, ethical)
- Deliverable: PMW report to summarize factors driving data sharing timelines among King County government agencies, and opportunities for improvement, to be submitted to King County ACH ILC in 2016 (timeline to be decided)

Required resources

Privacy officer and PMW member/staff time

Focus

King County government

King County ACH

King County-wide

7. Support data sharing needs of the King County Health & Human Services Transformation Plan (HHSTP)

Need: Due to data fragmentation, King County HHSTP initiatives are struggling to share and integrate cross sector data needed for care coordination and program evaluation

Recommendation

Identify initiative-specific and cross-cutting barriers and potential solutions to meeting the data needs of HHSTP initiatives

Details

- Assign to a PMW subgroup to focus on King County government data sharing and integration challenges
- Assess effectiveness of limited project-specific data sharing contracts versus broad in scope contracts, the ability to add data elements without modifications to contracts, and steps to move towards global cross agency data sharing contracts
- **Deliverable:** Create data sharing contract templates for sharing of i) protected, identifiable data between King County government agencies, ii) protected, identifiable King County government data with external partners, iii) limited King County government data sets with external partners, and iv) deidentified King County government data with external partners
- **Deliverable:** Develop Release of Information (ROI) form to allow individuals to provide consent for use of health (behavioral, chemical dependency, physical diagnosis and treatment), housing, criminal justice and other social services data to identify them for recruitment in interventions or programs
- **Deliverable:** Develop bidirectional data sharing contract to allow PHSKC/DCHS to receive identifiable Public Housing Authority (PHA) 50058 form data, and PHSKC/DCHS to share back an individual-level, linked, limited (or de-identified) dataset containing booking, jail health, behavioral health treatment, chemical dependency treatment, permanent supportive housing, homelessness, and Medicaid claims data for PHA evaluation purposes

Required resources

PMW member/staff time

Focus

King County government

King County ACH

King County-wide

8. Expand PMW work to include additional health and non-health sectors

Need: PMW currently represents only a small subset of areas/organizations contributing to health and well-being in King County

Recommendation

Investigate options for data sharing with additional sectors relevant to health and social well-being, including education, court and arrest data, tax/wealth data, and Electronic Health Records

Details

- Plan to discuss during PMW meetings in 2016
- Purpose of discussion is exploratory, and thus may work towards a proposal for how to prioritize and invite additional sectors to work with the PMW on data sharing challenges
- PMW may opt to focus discussion on existing King County ACH initiatives with cross sector data needs, such as Communities of Opportunity & Familiar Faces
- **Deliverable:** Proposal for process to prioritize and invite additional sectors for PMW work on data sharing, to be submitted to King County ACH ILC in 2016 (timeline to be decided)

Required resources

PMW member/staff time

Focus

King County government

King County ACH

King County-wide

9. Continue to build and maintain shared DCHS/PHSKC database for HHSTP initiatives

Need: To support the cross agency data needs of HHSTP initiatives, additional work is needed to build and maintain an existing DCHS/PHSKC shared database

Recommendation

To support HHSTP initiatives, continue to develop and maintain a secure DCHS/PHSKC SQL server space for storage, linkage, and extraction of shared datasets (e.g. claims data, jail booking data)

Details

- Assign to a PMW subgroup to focus on King County government data sharing and integration challenges
- Identify resources needed to support KCIT to incorporate Medicaid claims data into shared DCHS/PHSKC SQL server
- Identify annual resources needed to support KCIT to maintain SQL server
- Deliverable: Medicaid claims data added to shared SQL server
- **Deliverable:** Linked booking-claims data extracts available for use by DCHS/PHSKC analysts for HHSTP purposes
- **Deliverable:** SQL server maintained over time by KCIT

Required resources

PMW member/staff time, funding to support KCIT to build and maintain database

Focus

King County government

King County ACH

King County-wide

10. Plan for how King County ACH can benefit from new & existing state-level data assets

Need: Though substantial federal dollars are being invested in state-level health and non-health data assets, there is a lack of clarity as to how ACHs will benefit from these critical resources

Recommendation

Request that state health and human services agencies provide a plan and timeline for how the King County ACH will benefit from state data assets (including reporting, data extracts, access to raw data) developed through Healthier Washington and other efforts (e.g. Clinical Data Repository, AIM Infrastructure/Data Lake, All-Payer Claims Database, etc.)

Details

- Request specifics from HCA, DOH, and DSHS as to how King County ACH will be supported by state-level data assets, to include:
 - Reporting of summary health and non-health information (e.g. WA Health Alliance, Providence CORE, Link4Health)
 - Access to routine, periodic data extracts for care coordination and detailed analysis (e.g. PRISM)
 - Access to raw/underlying data for care coordination and detailed analysis (e.g. EHR data submitted to CDR)
 - Timeline for King County ACH access to various data assets
- **Deliverable:** Detailed plan and timeline developed by HCA, DOH, and DSHS to specify how and when King County ACH can expect to access assorted state-level data assets

Required resources

PMW member/staff time, state agency staff time

Focus

King County government

King County ACH

King County-wide

11. Accelerate meaningful use of new administrative health and non-health data sources

Need: Rather than reinvent the wheel, King County government agencies could leverage lessons learned and existing tools from state agencies to accelerate the meaningful use of administrative data for care coordination and program evaluation

Recommendation

To accelerate the meaningful use of new administrative data sets (e.g. claims) by King County government agencies, namely DCHS and PHSKC, request that state data stewards share lessons learned, including relevant software programs and code that can be used to add value to raw data

Details

- Research and Data Analysis (RDA) Division of DSHS has long history of using administrative health and social services data sources to support care coordination and evaluation of publically funded services (e.g. PRISM)
- DCHS and PHSKC were recently granted access to King County Medicaid claims data for the purpose of public health surveillance
- RDA sharing of lessons learned and programming code for adding value to raw claims data would help to accelerate the DCHS/PHSKC learning curve
- **Deliverable:** Relevant lessons learned and programming code for processing and analyzing ProviderOne claims and eligibility data shared with DCHS and PHSKC analysts

Required resources

RDA staff time, DCHS/PHSKC analyst time

Focus

King County government

King County ACH

King County-wide

12. Identify opportunities for data alignment across ACHs

Need: Given that health knows no borders, efforts are needed now to promote data alignment across Washington's ACHs

Recommendation

Identify and pursue opportunities for data alignment across ACHs, including data sharing standards, inter-ACH data sharing agreements, and common outcome measures across ACH-backed health and well-being initiatives

Details

- Use PMW meetings in 2016 to identify ideal approach for addressing data alignment across ACHs, such as using existing avenues (e.g. ACH Development Council, RWJ PHSSR grant) versus new approaches (e.g. new cross-ACH work group)
- **Deliverable:** Use the identified approach to build alignment across a range of cross-ACH data issues, including:
 - Align health and non-health data standards and practices on privacy and sharing, ROI forms, secure storage, etc. across ACHs
 - Develop program-specific and/or broad in scope cross-ACH data sharing agreements to support statewide care coordination and evaluation of health and human services transformation (e.g. claims data, behavioral health treatment data, housing data)
 - Align metrics and evaluation methodology across related ACH-backed health and well-being initiatives (e.g. care coordination initiatives in King County and North Sound ACHs)

Required resources

PMW member/staff time, external ACH member/staff time

Focus

King County government

King County ACH

King County-wide

13. Investigate options for an integrated data system in King County government

Need: To support the cross agency data needs of HHSTP initiatives, work is needed to outline a plan for building an integrated data system to support care coordination and program evaluation

Recommendation

Investigate options for DCHS and PHSKC to work with KCIT to build a real-time, integrated data system that allows health and human service providers to coordinate care across sectors (i.e. single care plan), including identifying the costs and logistics associated with different approaches to data integration, and how existing IT infrastructure and data sharing contracts can be best leveraged to support this goal

Details

- Assign to a PMW subgroup to focus on King County government data sharing and integration challenges
- In 2016, the PMW will work with KCIT to investigate options for building an integrated data system to support care coordination needs of HHSTP initiatives, beginning with the Familiar Faces initiative and Physical/Behavioral Health Integration in King County
- "Real-time" implies that the integrated data system would make use of data that is updated on a daily/weekly/monthly basis to support effective care coordination
- **Deliverable:** Proposal for KCIT-backed integrated data system to support care coordination needs of HHSTP initiatives

Required resources

KCIT staff time, DCHS/PHSKC analyst time, PMW member/staff time

Focus

King County government

King County ACH

King County-wide

14. Identify options for data steward(s) to serve the King County ACH

Need: Uniting health and non-health data under the King County ACH to drive health and human services transformation is a grand and novel vision, and the decision for selecting a data steward(s) should be given careful attention

Recommendation

As more health and non-health data are shared and integrated under the King County ACH and HHSTP, identify options for where these data can be stored with efficiency, security, and accountability

Details

- Use PMW meetings in 2016 to select an approach for how to identify desirable characteristics for data steward(s) to serve the King County ACH
- Data steward(s) must be able to receive, process, store, and extract relevant health and non-health data with efficiency, security and accountability
- Additionally, data steward(s) must have sufficiently broad legal and technological safeguards to support this role

Required resources

PMW member/staff time

Focus

King County government

King County ACH

King County-wide

Prioritizing PMW work for 2016

	Recommendation	High/medium/low priority	2016 quarter for completion
1	Define & disseminate added value of data sharing/integration in King County		
2	Build and monitor trust in data sharing		
3	Align data privacy and sharing practices across King County ACH members		
4	Identify opportunities for data alignment across 5 MCOs		
5	Seek alignment in data sharing and privacy guidelines with WA state agencies		
6	Accelerate data sharing procedures in King County government		
7	Support data sharing needs of the King County HHSTP		
8	Expand PMW work to include additional health and non-health sectors		
9	Continue to build shared DCHS/PHSKC database for HHSTP initiatives		
10	Plan for how King County ACH can benefit from state-level data assets		
11	Accelerate meaningful use of new administrative data sources		
12	Identify opportunities for data alignment across ACHs		
13	Investigate options for an integrated data system in King County government		
14	Identify options for data steward(s) to serve the King County ACH		

Next steps

- PMW-approved recommendations will be presented to ILC for approval in early 2016
- ILC-approved recommendations will be used to form 2016 PMW work plan:
 - Need to develop detailed work plan and timeline for 2016
 - Need to designate roles and responsibilities for 2016 work plan
 - Need to identify any additional staffing/resource needs of PMW for 2016 work

You can learn more about the Performance Measurement Work Group here

FOR MORE INFORMATION, CONTACT:

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Definitions of key data sharing & integration concepts - 1

Alignment - position of agreement or alliance

Analyst – in the health & human services context, a person who uses health and non-health data for agency operations (e.g. coordination of mental health services) and/or program monitoring & evaluation

Care coordination – deliberate organization of client care activities between two or more participants (including the patient) involved in a client's care to facilitate the appropriate delivery of health and human services; typically requires exchange of information among participants responsible for different aspects of care

Client-level data – also called individual-level data, a data set that contains information about individual clients; data can be either identifiable (e.g. names) or non-identifiable (e.g. health outcome)

Community health – public health approach aimed at maximizing health and wellbeing and minimizing disparities in a given community, which can be defined either geographically (e.g. city) or demographically (e.g. race/ethnicity)

Cross agency data – two or more data sources that are maintained at two or more separate agencies or organizations, but collectively provide information on a single population or community

Data consumer – entity or individual that uses data for a specific purpose

Data creator – entity or individual that produces data for a specific purpose

Data element – individual piece of information in a data set, such as "date of birth"

Data enabler – entity or individual that need neither produce nor consume data, but provides an essential service that supports data creation and/or data consumption (e.g. IT professional)

Data extract – subset of data from a larger database or data system (e.g. birth certificates for King County residents born in 2010)

Data integration – linkage of client-level data from different agencies for a specific purpose

Data lake – unstructured repository where databases are stored, but not linked or related to each other

Data linkage – combining two or more separate data sets to provide fuller information on a single population or community (e.g. combining birth certificates with infant hospitalization records)

Data privacy – IT approach that forms the ability of an organization to determine what electronic data can be shared with third parties

Data security – protecting electronic data from corruption and unauthorized access

Data sharing – sharing of individual- or aggregate-level data between 2 or more entities

Data sharing agreement - a formal, legal contract between 2 or more entities documenting how data will be shared, used, and protected

Data steward - entity responsible for management of electronic data

Data storage – archiving electronic data for use by a computer or device

Data warehouse – type of integrated data system where all data are routinely and automatically linked and stored in a central repository

Deidentified data set – data set for which an individual's identity cannot be determined through the information contained

Distributed database system – type of integrated data system where databases remain at each agency; users can access each database separately

Equity – all people have full and equal access to opportunities that enable them to attain their full potential

Definitions of key data sharing & integration concepts – 2

Evaluation – in the health & human services context, the use of qualitative and/or quantitative data and methods to determine of the results or impact of a program or policy

Federated database system - type of integrated data system where databases remain at each agency, but users can access all data together; also can be used to build logical data warehouse

Health data – data related to physical health, behavioral health, and/or chemical dependency, including risk factors, health status, and utilization and cost of health services

Interoperability - ability to electronically interoperate - or mix - different data sets

Legally defensible - capable of being defended, protected or justified through the legal process

Limited data set - limited set of identifiable patient information as defined in the Privacy Regulations issued under the Health Insurance Portability and Accountability Act (HIPAA)

Memorandum of understanding - see "data sharing agreement"

Monitoring - in the health & human services context, observing and checking the progress or quality of a program or policy over time

Non-health data - data related to determinants of health, but excluding health and health care status or outcomes; includes data on education. criminal justice, employment, demographics, housing, community assets, and other human services

Open data – data that can be freely used, re-used and redistributed by anyone - subject only, at most, to the requirement to attribute and share

Privacy officer – person designated by an organization that routinely handles protected health & non-health information, to develop, implement, and oversee the organization's compliance with regulations governing data privacy and security

Protected [health/non-health] information - data for which privacy and security are governed by local, state and/or federal regulations

Public health & human services - referring to local government agencies that collectively provide a range of services including assessment & evaluation, policy development, physical health, behavioral health and chemical dependency services, disease surveillance, population health (e.g. vaccination), and housing and other human services

Raw data - data that has not been subjected to processing or any other manipulation; also referred to as primary data

Real-time data – data that is updated and available for use on a daily, weekly, or monthly basis

Release of information - statement signed by a client authorizing an entity to provide information about the client's situation to designated third parties for a specific purpose; also referred to as a patient consent form

Social justice - all aspects of justice, including legal, political and economic, and requires the fair distribution of public goods, institutional resources and life opportunities for all people

SQL server – Microsoft product used to manage and store information; also referred to as a "relational database management system"

Unintended information disclosure - malicious or accidental disclosure of confidential or sensitive information to an untrusted environment (e.g. accidental data disclosure, data breach, data spill, data leak)