

Identifying and Serving Children with **Health Complexity**: Spotlight of Efforts to Develop and Pilot the Kaiser Permanente Northwest Pediatric Care Together™ Program

March 2019 Summary



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Introduction/ Background: The purpose of this summary is to provide an overview of a collaborative effort between the Oregon Pediatric Improvement Partnership (OPIP) and Kaiser Permanente Northwest (KPNW) to better address children’s health complexity. Health complexity takes into account medical and social factors that impact a child’s health, health care access, and ability to engage in recommended treatments and services. The [Oregon Pediatric Improvement Partnership \(OPIP\)](#) is a statewide organization focused on improving the health of children and youth in Oregon. [KPNW](#) is a closed health system serving over 100,000 pediatric members from Eugene Oregon, to Southwest Washington, both publicly- and privately-insured.

Over the last five years, OPIP received two grants supporting consultation and support to KPNW in their efforts to build, pilot, and evaluate a complex health management program focused on children with health complexity. This funding included a subcontract from the state’s Title V agency ([the Oregon Center for Children and Youth with Special Health Needs](#)) Systems of Services for CYSHCN grant and the [Lucile Packard Foundation for Children’s Health](#). Through these efforts, OPIP provided technical assistance to KPNW to support the development of their complex care management program (called Pediatric Care Together™ or PCT™) by supplying references, conceptualizing the health complexity methods to apply, and creating tools for KPNW consideration. The underlying construct is based on the concept of using health complexity information to identify patients who may benefit from supplemental supports often not provided by a conventional medical home team or by an exceptional needs care coordination team. This complex care management program would also identify the right team members to provide these supports. In addition, the assigned team supporting these patients would need to perform detailed assessments of the children and families in order to determine the levels of support they would benefit from, figure out ways to share and track the plan, as well as evaluate the effectiveness of the program.

Within KPNW, these elements and tools were explored, refined, customized, and built by KPNW leadership and the PCT™ Operations team. KPNW then piloted the model in one site, located at the Mt Scott pediatric clinic, and has subsequently spread the model to one other site. Joyce Liu, MD the Medicaid Medical Director for Kaiser Permanente Northwest has been the lead champion, advocate, and developer of the KPNW specific components of this model. Dr Liu has also led efforts to share aspects of the model across other Kaiser Permanente regions.

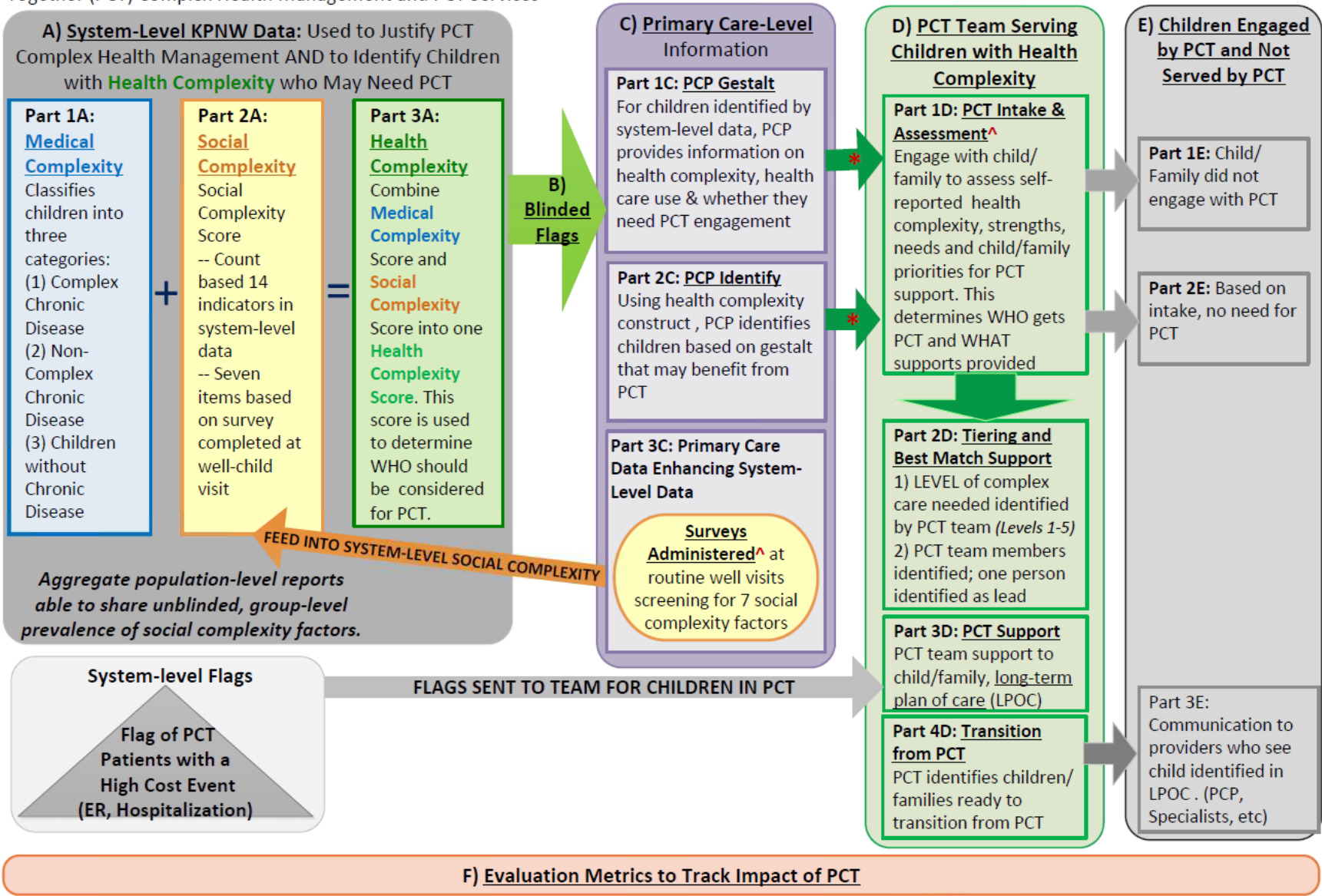
This summary provides a description of the key elements and learnings as of **March 2019**. With KPNW’s ongoing commitment to this work, the PCT™ program will likely evolve and expand to other sites. Therefore, the summary may not accurately reflect the improvements made to the program in the future.

Although every health system has unique features that necessitate individual considerations in building a complex care management program, the purpose of this brief is to share learnings gathered. We believe there is much to learn from the process, and we will describe and share these models and lessons in this brief.

Structure of This Summary Brief Anchored to Figure 1 and Hyperlinks to Specific Sections:

Figure 1 provides a high-level overview of the key components of the system-level and primary care-level methods used to identify children for PCT™, and also the specific components of the PCT™ program itself. **Within this visual are hyperlinks** to the specific **sections of this summary** that provide more detail. **On March 14th, OPIP and KPNW will be hosting a [webinar](#) to answer questions about the overview provided, and to share key learnings about success, barriers, and ongoing opportunities.**

Figure 1. Overview of **System-Level** and **Primary Care-Level** Methods Within KPNW to Identify Children with Health Complexity and Assign Pediatric Care Together (PCT) Complex Health Management and PCT Services



* Only children confirmed or identified PCP move to Part 1D for PCT engagement.

[^]Unblinded, at family's disclosure, child-level information obtained through assessment is what is used by PCT team.



A) System-Level KPNW Data: Used to Justify PCT Complex Health Management AND to Identify Children with **Health Complexity** who May Need PCT

A key component of the work was defining the target population for the efforts. The system-level data were critical to the following:

1. **Quantifying the need** for the Pediatric Care Together™ program, and the **investment of resources requested**; to develop a **shared understanding about the level of health complexity within the KPNW population**.
2. **Identifying potential pilot sites** for the PCT™ program based on locations with high rates.
3. **Identifying children who would benefit from further assessments** to understand whether the PCT™ program would be beneficial
4. **Identifying populations** that can be used to evaluate the impact of the PCT™ program.

The target population chosen for this work was children with high levels of **health complexity**, meaning they had significant **medical** and **social complexity**.

1A Medical Complexity: Medical complexity was operationalized through the use of the [Pediatric Medical Complexity Algorithm \(PMCA\)](#), with a priority focus on children identified with “complex chronic disease” OR children with “non-complex chronic disease”. Due to the depth and breadth of KPNW internal data, they chose to use the strictest version of the PMCA algorithm and used a three-year look back period at services and diagnoses.

2A Social Complexity. We anchored our efforts to the definition of social complexity defined by The [Center of Excellence on Quality of Care Measures for Children with Complex Needs \(COE4CCN\)](#) as “A set of co-occurring individual, family or community characteristics that can have a direct impact on health outcomes or an indirect impact by affecting a child’s access to care and/or a family’s ability to engage in recommended medical and mental health treatments”. The [COE4CCN identified 18 factors](#) that either in past literature or through their own studies were correlated with worse health outcomes or higher health care costs.

Based on those factors, KPNW then examined specific indicators that existed or could be collected using system-level data available for all children. **Figure 2** provides an overview of the specific factors identified. With guidance from OPIP, KPNW created a [summary count](#) of the number social complexity indicators for each child. **Section C** of this summary brief provides more detail on the new items that were added to surveys administered at well-child visits to enhance the robustness of the system-level data, and address gaps in the system-level data.

At a population-level and for groups of children in KPNW, the prevalence of specific factors was examined and considered for resource allocation. At a child-level the global complexity count is a **blinded count** that indicates how many of the factors appeared for the child, but not which specific factors. When shared and presented, these data were often shown by whether the child had 3 or more of the factors.

Figure 2: KPNW System-Level Data on Social Complexity

System-Level Data Currently Available in Searchable Fields:

- 1. Poverty**
 - Medicaid
 - Subsidized exchange
 - Children’s Health Program
 - Medical Financial Assistance
- 2. Limited English proficiency**
 - Translator need
- 3. Parent mental health service need**
 - State claims for Medicaid patients
 - Parent mental health Diagnosis in KP System
 - Parent ADDM Diagnosis in KP system
- 4. Child welfare system involvement**
 - Foster care kids are tracked
 - Exceptional Needs Care Coordinator
- 5. Child mental health service need**
 - Services or Diagnosis in KP system
 - Teen screened positive on PHQ-9 or GAD7
- 6. Child substance abuse treatment need**
 - Services or Diagnosis in KP system
 - CRAFFT screening results

New Social Complexity Data Asked About in Patient Surveys at Well-Visits (Started In February 2018)

- 1. Poverty (2 Items)**
 - Insecure housing
 - Food Insecurity
- 3. Limited English proficiency**
- 4. Death of a loved one**
- 5. Domestic violence and family stress**
- 6. School absenteeism (truancy)**
- 7. Child involvement with law enforcement- juvenile or criminal justice**



3A Health Complexity: The indicators of **medical and social complexity** were then combined, at a child-level, to ascertain overall health complexity. The specific medical complexity identified by the PMCA (complex, chronic; non-complex chronic) and their level of social complexity (number of factors identified, if 3 or more were identified) were considered. OPIP led the development, in partnership with Oregon Health Authority and with significant input from various stakeholders including KPNW, of a nine-part Health Complexity Categorical Variable shown in **Figure 3**.

Figure 3: Health Complexity Categorical Variable

MEDICAL COMPLEXITY (3 Categories)	SOCIAL COMPLEXITY		
	3 or More Indicators	1-2 Indicators	None in System-Level Data
HIGH Medical Complexity (Chronic, Complex PMCA=1)	#1 <i>(Chronic, Complex medical complexity and 3 or more social complexity indicators)</i>	#2	#3
MODERATE Medical Complexity (Non-Complex, Chronic PMCA=2)	#4	#5	#6
NO MEDICAL COMPLEXITY (PMCA=3)	#7	#8	#9 <i>(No medical complexity and no social complexity indicators)</i>

Developed by the Oregon Pediatric Improvement Partnership

B) Blinded Flags

The system-level data could then be used, at a child-level, to identify children for whom the primary care provider could provide context, knowledge, and information about whether the child/family may benefit from outreach and assessment from the PCT™ team. As noted earlier, KPNW has over 100,000 pediatric patients, and it was therefore determined to not be feasible to do a detailed and robust assessment of all children by the primary care provider. The system-level data was helpful in identifying a subset of kids or parents who had already accessed services that in the literature are correlated with higher health care costs and worse health outcomes.

Selecting which kids identified by the health system data for the primary care provider has been an evolving process within the PCT™ development and pilots. Key factors taken into consideration included the bandwidth of the PCT™ team, available PCT™ staffing for assessments (e.g. whether there is social work and nursing support) and the magnitude and number of children identified by site and for the specific primary care providers to whom blinded flags would be sent. Currently, as of March 2019, KPNW is prioritizing children who have complex or non-complex medical conditions and 3 or more social risk factors (#1, #4, and #7 in the health complexity diagram in Figure 3). As more nursing staff are available within the PCT™ team, then all kids with chronic conditions and any social factor will be included (#2 and #5).

Then, once a group of children is identified, a list of children was then shared with the primary care team to allow them to provide additional context about the child and whether they may benefit from PCT™ team engagement. All providers within the pilot primary care sites first received training on Trauma Informed Care and on Adverse Childhood Events by members of the local PCT team or the advisory team.

NO SPECIFIC INFORMATION ABOUT THE SPECIFIC INDICATORS ARE SHARED WITH THE PCP, OR WITH THE PCT™ TEAM. The list of patients was a list of children identified with higher levels of health complexity.

Over the course of implementation of the PCT™ pilot program, different criteria have been used to determine which children are flagged and identified. Specific methodology has depended on the number of children identified within each of the nine-part quadrants of health complexity, the capacity of the PCT™ team, current staffing (e.g. social worker vs. nursing staff will lead assessment), and the number of children identified for specific provider teams for assessments.

C) Primary Care-Level Information

The work within KPNW prioritized a focus on children who are primarily seen within a primary care setting. Therefore, the partnership with, and engagement of the primary care team about their knowledge of the child and family, and the degree to which they think there may be a fit with the PCT™ program was critical. The primary care team also provided assistance and support in connecting children and families to PCT™. Below are three essential components led by the PCP team.

1C Primary Care Provider Gestalt: For children identified by system-level data, PCP provides information on health complexity, health care use & whether they need PCT™ engagement

Time and again during the course of this work, the primary care providers/teams were seen as essential for their knowledge of and input on their patients. PCPs have a personal view of their patients' strengths, resiliency, and challenges that may support or contrast the system-level data, and the value of this PCP gestalt is paramount to this process. It is crucial for PCPs to review the list of patients identified by system-level data as having health complexity and provide additional information on strengths and resiliency, health complexity, health care use, and whether the patient/family needs PCT™ engagement.

Within the pilot sites, for children identified by the system-level data, a list of patients was sent to the primary care team serving them and general feedback and input was requested. KPNW providers found that they were able to provide input on other risk factors that were not always apparent in system-level information and give important insight on care coordination needs for their patients. Only children for whom the primary care provider indicated potential value of PCT™ engagement were then passed to the PCT™ staff. Over the course of the pilot, the PCT™ staff found that the most effective model for engaging the family was to have the PCP introduce the staff in a visit. For children who weren't seen at the identifying visit, team members would try to be present at the next visit to allow for a warm handoff. If the child did not have a visit scheduled, then outreach was conducted.

Part 2C: PCP Identify Using health complexity construct, PCP identifies children based on gestalt that may benefit from PCT™

One enlightening aspect of this project was the construct of health complexity being incorporated into how providers thought about families and how best to use the PCT™ program to have staffing and supports to serve children with high health complexity. We found that by having an awareness of health complexity and thinking about their patients using this construct, providers then began to identify patients for the PCT™ that had not been identified in the system-level data. This step of soliciting PCP input and identifying individual patients based on provider knowledge and insight was an important part of the PCT™ process.

3C. Primary Care Data Enhancing System-Level Data

One limitation of system-level data is that it will miss risk factors not available in the available databases. To enhance and supplement the social complexity information that is available, the front line can gather more information directly from families. As the importance of social determinants of health becomes more and more apparent, front line providers are starting to proactively gather data about challenges such as food insecurity and school truancy, and collecting this information in a standardized way would be ideal.

In KPNW, social complexity questions were incorporated into patient surveys collected during well visits to add to the level of social complexity for individual patients. **Figure 4** provides an overview of the seven questions, that were added to these well-child visits surveys and for which trackable data was collected and fed into the system-level data focused on social complexity.

Figure 4: Social Complexity Data Asked in Patient Surveys at Well-Visits

1. **Poverty**
 - Insecure housing: In the last 12 months were there times when your family couldn't buy enough food?
 - Food Insecurity: In the past year did you struggle to pay the mortgage, rent, or utility bills? Or, did you have to stay with other people because you could not pay these bills?
2. **Limited English proficiency:** Medical conversations can be hard to understand. Do you want an interpreter for future doctor visits? If yes, what language?
3. **Death of a loved one:** Has your child been affected by the death of a loved one?
4. **School absenteeism (truancy):** During the past 12 months, did your child miss > 18 days of school? Or average > 2 days of missed school per month?
5. **Involvement with law enforcement- juvenile or criminal justice:** Has a family member spent time in jail?

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D) PCT Team Serving Children with Health Complexity

This section provides an overview of the specific tools and strategies that are then used by the PCT[©] team within the pilot sites of KPNW, and provides links to compendiums and resources provided by OPIP that were considered and used as starting point templates and fodder.

Note about the Staff within the PCT[™] Team: In the current model, the PCT[™] teams are located at the pilot primary care sites and meet weekly. The team includes staff that have dedicated time for PCT[™] that includes a social worker, pediatrician, nurse, and navigator.

Part 1D: PCT[™] Intake & Assessment: Engage with child/family to assess self-reported health complexity, strengths, needs and child/family priorities for PCT[™] support. This determines WHO gets PCT[™] and WHAT supports are provided.

As was noted before, the PCT[™] team receives blinded system-level flags based and information provided by the primary care team about the child and family. The first and most critical step of the PCT[™] team is to outreach and engage with the child and family. This engagement includes sharing about why the child and family was contacted, what the PCT[™] can provide in terms of supports, and **obtaining an understanding about the child or family priorities for support.** Again, the primary care provider is a critical partner in engaging the family and explaining why they thought PCT[™] would be helpful.

To support KPNW in developing the PCT[™] tools and assessments, OPIP developed a compendium of resources and tools that were reviewed and considered by the KPNW leadership and PCT[™]. These tools can be found here: <http://www.oregon-pip.org/resources/ComplexCareResources.html>. OPIP also brought in national experts to speak about their models of care coordination and findings from their efforts including Richard Antonelli, MD and Rita Mangione-Smith, MD, MPH.

After numerous meetings with the KPNW team, a framework for assessing patients to be on-boarded to PCT[™] was provided by OPIP to KPNW and included major categories to consider, specific questions to ask, and detailed information to gather during the intake assessment process. KPNW reviewed and provided input on this framework and used it to guide their onboarding process. It was quickly learned

that due to the extensive amount of information ideally gathered and the nature of some of the assessment questions, the intake could take multiple visits and would require some individualization of the process by a skilled person. For this reason, a majority of the children were onboarded by the social worker on the PCT™ team.

Many **lessons were learned, and key considerations** included:

- a. **Age-specific Tool:** The assessment tool needs to take into account the age of the child, in particular focusing on the age-appropriateness of the questions, health goals, care coordination needs, and developmental or behavioral assessment. Age will also determine whether the child should have input in the assessment, and whether some questions should be asked to patient alone (preferably the case for adolescents). Options to address this include creating different assessment tools for different age groups or using labeling schemes within the assessment tool that indicate which items should be gathered for which age groups and which questions should be asked directly to patient.
- b. **Intake Person:** Depending on the patient's type of complexity and potential needs, it may be appropriate to have different members of the team perform specific portions of the assessment. For example, for a patient who is very medically complex, a nurse or other medical personnel may be the most appropriate person to gather most of the intake assessment. For a patient who has significant social complexity, a social worker or behavioral health provider may be the most appropriate person to gather the intake assessment. There could also be some combination of team members performing the assessment.
- c. **Other Sources:** The primary care provider, specialists, therapists, and school team may be important sources of information for the intake. It is important to conduct a thorough chart review and consider obtaining Release of Information for other sources (school, other providers).

Below is a **summary of important components to consider** in the creation of an intake assessment tool, organized by family- and child-specific questions.

Family Factors to Assess for in the Intake Process:

- Demographics, including all those in household, contact preferences, language preference
- Concerns, regarding **child, family functioning**
- Family history, including medical, mental health, substance use
- Strengths, including supports, religion, resiliency
- Challenges, including health of parents/siblings, **accessing care, housing, transportation, food insecurity, finance, child care, DV, substance use, impact of child's health on parent's ability to work**
- Recent significant events, including change in home environment (someone moving in or out), change or loss of housing, divorce, incarceration, sickness or loss of family member, change in job, change in school
- **Relationship with child**
- **Resource needs**
- Goals for child's health and goals for PCT™ support.

Child Factors to Assess for in the Intake Process:

- Medical history, including diagnoses, concerns, medications, treatment, equipment needs, questions, care team
- **Medical goals and barriers**

- **Development**
 - Age 0-5: feeding, sleeping, developmental milestones, behavior, social-emotional regulation/mental health
 - Age 6-11: school/learning, behavior, social, sleep, eating, mental health
 - Age 12-18: school/learning, social, sleep, eating, self-care, substance use, mental health
- **Mental health**, including concerns, diagnoses, treatment, self-harm and suicidality, screening if needed
- **Substance abuse**, including past and present, treatment, effect on family/individual, screening if needed
- **Education/School**, including strengths, challenges, supports, goals
- **Child's report** of concerns, strengths, challenges, recent significant events, relationship with family, resource needs, goals (see above for Family)

Another important consideration in developing an intake and assessment tool is to determine what factors will be collected in a standardized way and at standardized intervals (at baseline, periodically) in order to track, assess, and evaluate the impact of the complex health management program. As will be described in **Section F – Evaluation Metrics**, a critical source of data about the impact of the program on health and health outcomes is clinical provider assessments of a child and family's health and child/family report. The baseline assessment is a critical time period to collect this data in fields that are trackable for the population served by the complex health management program; the family and child factors **bolded** above are ones to consider collecting in a standardized fashion so they can be used for tracking impact and outcome.

2D Tiering and Best Match Support

Only children/families who engage in the PCT™ assesment and who are identified as a best match for the program are “enrolled” in the PCT™ program and receive supports.

A Pediatric Care Together Intensity Stratification tool (**Figure 5**) was created by KPNW to determine and track the patient's level of complexity, need for care, general functioning, and preventable utilization as a means for allocating resources and determining the intensity of outreach. This tiering system is also meant to take into account the patient's level of engagement with PCT™ and improvement in their medical and social needs as the patient progresses through the PCT™ program, helping to track the impact of PCT™ and to determine when the patient is ready to graduate from the program. There will be cases where the level of engagement remains low, or may differ between patient and family, and the barriers to engagement will be collected and examined. Extensive discussions were held regarding when a patient is considered “on-boarded” to PCT™, as this impacts when the team should initiate services and support, and also determines when the team starts to gather outcome data to assess the impact of PCT. The KPNW team decided that once a patient has an engagement score of 3 (which corresponds to tier 3 of intensity stratification), they would be considered officially in PCT.

That being said, this an area where there is ongoing development work and focus within KPNW. They are considering the potential value of developing an engagement tool that is separate from a stratification tool.

Figure 5: Pediatric Care Together Intensity Stratification ¹

Key	0	Tier 1	Tier 2	Tier 3	Tier 4	Tier 5
Description	Graduated No preventable ER or hospital visits in last 6 months. Patient has independently maintained needed medical and community supports for past 6 months and adhering to treatment plans	<ul style="list-style-type: none"> Complex medical & Social risk factors Monitoring for independence 	<ul style="list-style-type: none"> Complex med & Social risk factors Stable with services Member actively outreaches to us if needed and learning how to navigate the medical and community care system 	<ul style="list-style-type: none"> Complex medical and social risk factors Improving but continues with some unmet social or medical needs. Engaging in needed supports but vulnerable. Has rapport with team as long as outreach continues. 	<ul style="list-style-type: none"> Complex medical and social risk factors Behaviors or complex medical needs having significant impact on member and family functionality (work, home, school) Beginning engagement in medical and social support systems: attending >50% of recommended care Or Preventable ER or hospital 1x / 3 mo Building rapport with PCT 	<ul style="list-style-type: none"> Complex medical & social risk factors More than 3 unmet social or medical needs May need higher level of care Behaviors or complex medical needs having significant impact on member and family functionality (work, home, school) Or Preventable ER or hospital 1x per month OR Poor adherence to plan of care
Outreach Intensity / Frequency		1x / 3-4 mos.	1x / 1-2 months	1x / 2 weeks +/-Community visits	1x / week Community visits	2x / week or more Community visits
Engagement tiering?						E=engaged C=contemplate NR=not ready

¹ Assumptions:

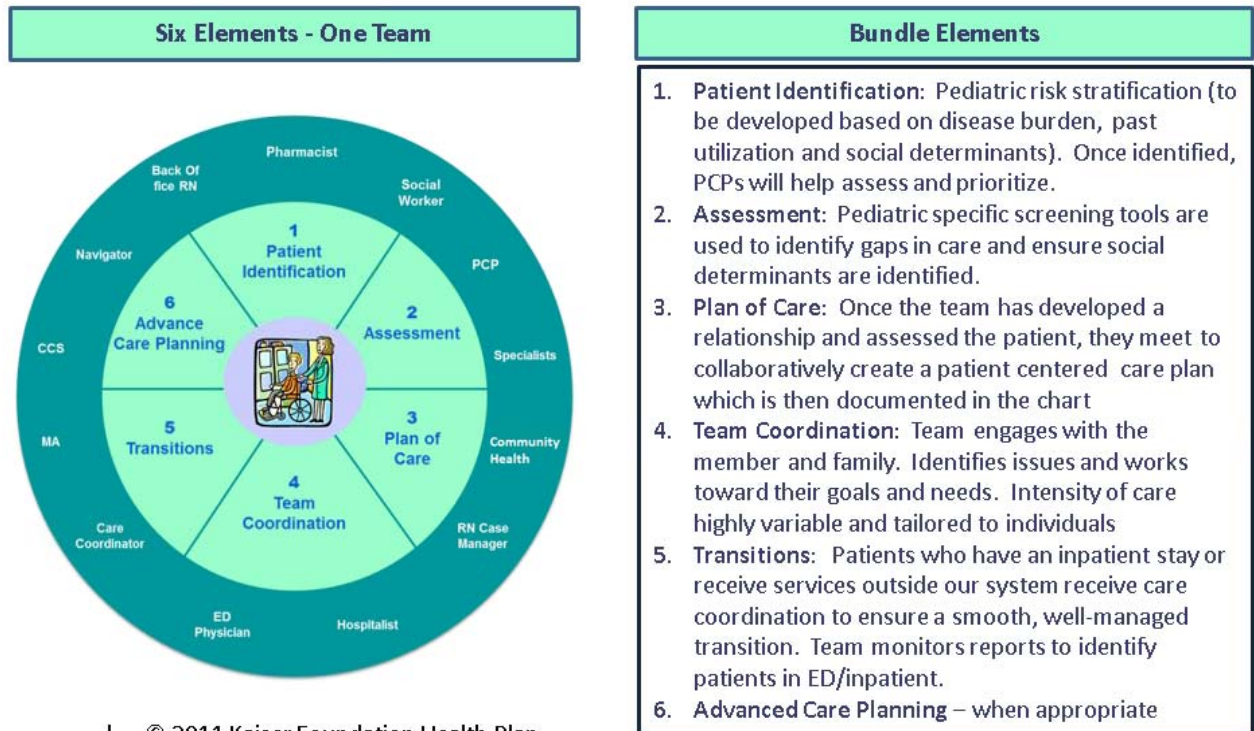
- Most PCT patients will meet tier 5 criteria upon entry. Tier 5 lists the failure to engage in needed preventative services as on par with ER overuse. Our experience has taught us that teens and families mistrustful of the health care system build trust and engage better with initial face to face visits.
- Expect patients move down the tiering system as they actively engage in needed services and independently navigate the medical system for their own care.
- Some patients may move back up on the tiering system if they develop a new diagnosis or a new social risk factor.
- Pediatrics represents a unique population in that early intervention may help mitigate long term health consequences from adverse childhood events (ACES).

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3D PCT© Support

The Pediatric Care Together™ model was meant to provide standardized complex care management for children. PCT™ pulled together a care team consisting of different care providers, coordinators, clinic and community supports, and navigators to perform elements of complex care management, including identifying children in need of additional supports, assessing for specific gaps in their care, creating a patient-centered care plan, coordinating team efforts, and managing transitions within the health system. As a patient’s needs are identified, a best match team is created to address those needs, with the hope of maximizing quality of life and health while decreasing healthcare cost and utilization. **Figure 6** provides an outline of the key components of the PCT™ model.

Figure 6: Pediatric Care Together© Model



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OPIP provided KPNW with resources and tools for developing a shared plan of care: <http://www.oregon-pip.org/resources/ComplexCareResources.html> . KPNW 's electronic record is in Epic. Therefore, the care plan they had to use had to fit within an EPIC EHR. KPNW utilized and leveraged the **EPIC Longitudinal Plan of Care (LPOC)**. KPNW created specific sections and specific categories within the LPOC to map to the goals of the PCT™ program and based on extensive input from the PCT™ team. **Figure 7** on the following page provides an overview and outline of KPNW's LPOC™ within EPIC and the key sections they created and found of the highest value. This includes where they documented the patient's story in the Care Coordination Note (CCN), the patient's support system and living situation, the patient's goals, the patient's care team, and the care team's plans and goals. The LPOC allows for communication among PCT™ team members, but also allows for sharing of crucial and relevant clinical information with subspecialists, emergency room staff, or other healthcare team members. There is an additional section "Below the Line" that allows for any personal information that the patient may share to be documented but stay in a confidential part of the electronic record.

Figure 7: KPNW's EPIC-Based Longitudinal Plan of Care (LPOC)™

The screenshot displays the EPIC-based Longitudinal Plan of Care (LPOC) for a patient named Cody KPNW. The interface is organized into several key sections:

- What's Important to Know About Me (PCCN):** Contains patient story, top preferences, and parent concerns.
- Steps I can Take to Achieve What's Important to Me (Goals):** Lists clinical goals such as medication compliance and emergency room visits.
- My Health Team:** Lists providers including a General Family Practice doctor and a Nurse Practitioner.
- My Contact Information (Demographics):** Provides contact details for the patient and guardians.
- My Family and Friends (Update under Demographics):** Lists family members like the mother, father, and grandfather.
- My Home (Living Situation):** States the patient lives at home with parents.
- Additional information about Me:** Includes a problem list (e.g., Diarrhea, Adjustment Disorder), recent ER/hospital visits, legal documents, and a list of visits with dates, providers, and departments.
- My Calls & Emails:** Lists communication history with various providers.

Blue callout boxes highlight specific features:

- Patient Story (PCCR):** Points to the 'What's Important to Know About Me' section.
- Patient Goals:** Points to the 'Steps I can Take to Achieve What's Important to Me' section.
- Add yourself to the Care Team:** Points to the 'My Health Team' section.
- My Plan:** Points to the 'Plan to avoid health emergencies' section.
- Patient's Support System & Living Situation:** Points to the 'My Family and Friends' and 'My Home' sections.
- Problem List and Overview Notes:** Points to the 'My Problem List' section.
- Legal Documents Driving My Care:** Points to the 'My Legal Documents' section.
- My Visits (CV & TAV) & My Calls & Emails:** Points to the 'My Visits' and 'My Calls & Emails' sections.

A key component of PCT™ support is **periodic clinical assessments and collection of child/family reported health status**. These routine and periodic measurements are critical to gauge and track the

impact of the services provided. At times this proved cumbersome and difficult within the PCT™ pilot implementation. KPNW is now developing clear expectations, timelines, and feasible methods by which the data can be collected as part of the PCT™ supports.

4D Transition from PCT™

An important component of a complex care model is determining when and how patients will be transitioned from the program. While not formalized in KPNW yet, a couple of key important considerations have been gathered to date from the pilot work:

- Document and track **when a child/family is no longer receiving support** that this can be accounted for when evaluating the impact of the support.
- **Quantify and clarify what level of engagement** with the complex team counts as continued engagement vs. lack of engagement.
- **Documentation** should be made as to whether the **complex care management team transitioned the child/family off OR whether the child/family chose to leave the support** as this will be helpful in understanding and evaluating efforts.
- Develop a **transition plan to the “health team”** identified in the LPOC that is not part of the complex care program.
- Develop a **clear communication plan for the child/family about this transition**, what to expect, and who they can go to for questions.
- Collect **health assessment and patient/family reported health outcomes data at the time the child is transitioned out of the program**. This is critical for evaluation.

E) Children Engaged by PCT and Not Served by PCT

Throughout the PCT™ pilot implementation there were children who were identified as potential candidates for the PCT™ team to engage or who the PCT™ worked with and who did not continue to receive services. While learnings are still being gathered, below are insights that have been gathered that may be valuable for others to consider as they implement a complex health management program.

Part 1E: Child/Family did not engage with PCT™

- Not all children identified by the system-level data and then confirmed by the primary care team were able to be engaged by the PCT™ team. Some of these children had not accessed primary care, but instead had accessed urgent or emergency care settings and were not willing to connect with the primary care or PCT™ team. Other children or families did not return phone calls or engage when offers of support were provided.
- Children who had high levels of medical complexity were flagged for ongoing monitoring and to assess for further opportunities for supports.
- The primary care and PCT™ team also received notifications if these children accesses high cost services such as an emergency room and conducted subsequent outreach and engagement.

Part 2E: Based on intake, no need for PCT™

- The PCT™ detailed assessments of the child and family strengths, goals and needs ultimately determine whether the PCT™ team and services are a best match. If a child is assessed and not identified for PCT™, closed loop communication is made to the primary care provider team.

Part 3E: Communication to providers who see child identified in LPOC . (PCP, Specialists, etc.)

- A key component of the KPNW LPOC™ is identification of the health care team that cares for the child and family.
- When a child is transitioned out of the PCT™ program, it is noted within the LPOC and the health care team identified is notified.
- Within the KPNW pilots, a goal was to transition a child out of PCT™ after a year of team-based services. There have been a number of learnings gathered about the feasibility of set timelines and children that were and were not able to transition from PCT™ services that will be shared on the March 14th webinar.

F) Evaluation Metrics to Track Impact of PCT

One of the key objectives in building KPNW's PCT™ program was to gauge and describe the impact of the complex care program on enrolled patients. In an extensive literature review of other pediatric complex care models, it is clear that demonstrating the benefit of complex care management is very difficult and complex, especially with regard to pediatric populations. And yet, the ability to demonstrate some positive impact of such a program is key to sustaining the efforts and supporting the resource pool needed.

OPIP developed an **evaluation metrics framework** to assess the program's impact and provided it to KPNW leadership for review and implementation. This framework, **described in further detail in Figure 8**, was developed after discussion with several local and national thought leaders in the field, and outlined detailed categories of information to be gathered from standardized fields in the EMR and/or from assessments collected by the PCT™ team at routine time periods. These categories were divided into:

- 1) **Utilization of medical services**— Assessment of medical services used, separated into utilization/costs we hope to reduce (acute services listed at the top) and preventative/recommended services that were felt to be protective (listed below). These protective recommended services **could** increase costs, but will very likely improve health overall and could ultimately decrease acute care costs down the road.
- 2) **General functioning** – Assessment of how the patient and family are functioning, both medically (disability, health, quality of life) and socially (school/work functioning, social risk factors, mental health).
- 3) **Patient/parent report of care experience** – Assessment of family experience as it relates to access and quality of care management, care of personal life, and family empowerment, using validated survey questions.

Within **Figure 8**, the items in bold are specific areas of the PCT™ intake and assessment that should be collected in a way that will allow for evaluation and assessment. The specific survey items proposed to

KPNW to collect patient and parent report can be found on the OPIP website here: https://oregon-pip.org/projects/Packard_Kaiser.html. The development of a standard way to collect this data is now in progress, with a goal of being able to track individual patients over time and to gauge the impact of the PCT™ Program on health care utilization, general functioning/quality of life, and health care experience, as well as to compare cohorts of patients with similar complexity in sites with and without complex care management. **Items in bold are items that would need to be collected as part of the PCT© intake and assessment or transition.**

Figure 8: OPIP Proposal to KPNW for the Categories for Evaluating the PCT™ Program		
<i>Utilization of Medical Services</i>	<i>General Functioning</i>	<i>Patient/Parent report</i>
<p>1. Acute services used- The PCT program hopes to REDUCE the use of these services for PCT patients. These variables can be collected via system-level data in the EHR, and will include:</p> <ul style="list-style-type: none"> • ER visits • Urgent care clinic visit • Hospital admission (bed days) • PICU admission (bed days) • Hospital readmission (within 30 days) • No Show/Canceled Appointments <p>2. Preventative/recommended services used- The PCT program hopes to INCREASE access of appropriate services for PCT patients. By and large these variables can be collected via system-level data available. Variables will include:</p> <ul style="list-style-type: none"> • Well child care visits • Immunizations (up-to-date) • Routine follow-up (i.e. med check, weight check) • Tracking of completed referrals (specialists, services-OT/PT/speech) • Tracking filled prescriptions • Mental health services • Substance abuse services 	<p>Methodological Considerations: Assessments in general functioning will take into account certain patient characteristics (age, medical vs social complexity). The variables may be gathered from EHR, system-level data, team assessments or asked directly to the family. Identified variables include:</p> <ul style="list-style-type: none"> • Medical functioning (team-assessed/family input) • Quality of health assessment (team-assessed/family input) • School functioning (Onboarding) <ul style="list-style-type: none"> ○ Includes absentee rate ○ Has IEP/504 if appropriate ○ School needs addressed ○ Behavioral health plan if appropriate • Work functioning (Onboarding) <ul style="list-style-type: none"> ○ Includes missed days • Adherence to treatment goals (team-assessed, shared plan of care) • Tracking KPNW PCT tiering system (team assessed) • Tracking of Overall Health Complexity Score (System-level data) • Tracking of disease-specific measures (if applicable): BMI, HgbA1c, ACT, TRACK, ASQ, PHQ-9, CRAFFT, Vanderbilt 	<p>Methodological Considerations: This will be a set of 10 questions to be administered at time of onboarding and periodically during and after complex care management to assess family experience. Questions will include assessments of at least the following variables:</p> <ul style="list-style-type: none"> • Access to care and care management services • Quality of care and care management services • Care of personal life • Family empowerment • Open-ended feedback for complex care management