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# Developing a CKD Registry in Primary Care: Provider Attitudes and Input

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#### **Abstract**

**Background.**—Chronic disease registries have been successful at promoting delivery of guideline-concordant primary care for diabetes and hypertension but not for chronic kidney disease (CKD). To understand whether a registry could be designed to improve CKD management in primary care, we explored primary care provider (PCP) attitudes about the benefits (or lack thereof) of a CKD registry compared to other chronic diseases and the key facilitators of successfully implementing a CKD registry in safety-net primary care.

Study Design: Semistructured interview study.

**Setting & Participants.**—We conducted and recorded semi-structured, one-hour interviews with medical directors and quality improvement champions from safety-net adult primary care clinics in San Francisco.

**Analytic Approach.**—Recordings were transcribed and analyzed using a grounded theory approach until thematic saturation was achieved.

**Results.**—Twenty primary care providers were interviewed. Four themes relevant to the development of a successful CKD registry for safety-net primary care were identified: (1) provider beliefs that a CKD registry could aid in the delivery of team-based, high-quality CKD care; (2) clinic workflow re-design and staffing are key facilitators to successful implementation of a CKD registry; (3) unique complexities of CKD, such as varying etiologies, may limit the use of a CKD registry by non-physicians; and (4) a CKD registry is aligned with current primary care priorities and health care delivery strategies.

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**Limitations.**—Small sample size and reliance on clinician leaders within one health care delivery system.

**Conclusions.**—A CKD registry directed at the entire health care team, with the functionality to track, standardize and enhance CKD care through decision support, has potential to improve the management of CKD in safety-net primary care settings. These data directly informed the development of a CKD registry in these settings in San Francisco.

#### Keywords

CKD registry; primary care; safety-net; health IT; decision support; CKD awareness; chronic disease management; guideline implementation

Chronic kidney disease (CKD) is common, affecting at least 20 million Americans. The prevalence of CKD is expected to increase given the aging population and increasing burden of other chronic diseases associated with CKD, including diabetes, obesity, and hypertension. In 2009, costs for CKD patients who received Medicare benefits exceeded \$41 billion and in 2010 costs for Medicare patients with end-stage renal disease were \$32.9 billion. The expected increases in CKD prevalence and costs highlight the need for interventions that can halt this predicted trend. Early implementation of evidence-based CKD care can help prevent disease progression and associated complications. Innovative ways to increase early recognition of CKD and initiation of guideline-concordant therapies to slow CKD decline are thus important, particularly in public health care settings, where individuals at highest risk of CKD progression (e.g., racial/ethnic minorities, those with limited financial resources) receive their health care. A, 5

Primary care providers (PCPs) deliver most CKD care in the United States. Wide variation in recognition and management of CKD among PCPs results in suboptimal delivery of guideline-concordant CKD care. To address this issue, several groups have studied interventions to improve the quality of CKD care delivered in primary care settings.  $^{10-12}$  Drawz and colleagues  $^{10}$  examined the impact of making available a CKD registry on PCP adherence to guideline-concordant CKD care. Manns  $et\ al^{11}$  studied the effect of guideline prompts that accompanied estimated glomerular filtration rate (eGFR) laboratory results on patient receipt of angiotensin-converting enzyme (ACE) inhibitors or angiotensin receptor blockers (ARBs). Abdel-kader  $et\ al^{12}$  looked at the effect of point-of-care electronic alerts on nephrology referral rates for patients with an eGFR <45 ml/min/1.73 m<sup>2</sup>. While the latter study was underpowered, none of these interventions were associated with improved delivery of CKD care.

Disease registries are information platforms that support care management efforts for patients with chronic diseases. <sup>13</sup> Often embedded within electronic health records (EHRs), they capture and track patient-level data, allowing health care teams to proactively manage patients at point-of-care or via outreach. Registries have successfully promoted the delivery of guideline-concordant primary care for diabetes and hypertension. <sup>14-16</sup> With the minimal intervention effect of CKD registries in the aforementioned trials, we wanted to better understand whether a CKD registry could be designed to improve primary care management of CKD in public healthcare delivery systems, where there is limited access to specialty care. Our objectives with this study were two-fold: (1) to explore PCP attitudes and beliefs about the benefits (or lack thereof) of a CKD registry compared to other chronic disease registries, and (2) determine the key facilitators of successfully implementing a CKD registry in safety-net primary care.

#### Methods

We conducted semi-structured interviews of PCPs in the San Francisco Community Health Network, an integrated, but geographically dispersed, health care delivery system for San Francisco's indigent patients. The Network consists of Federally Qualified Health Centers, community-based organizations that provide comprehensive primary and preventive care to persons regardless of ability to pay, health insurance status or citizenship. We approached medical directors and clinician leaders of all 12 community-oriented and hospital-based adult Federally Qualified Health Centers within the Network via email and invited them to participate in the study. We also asked them for names of colleagues who had experience working in quality improvement. We invited those individuals to participate via email as well. All recruited providers serve a racially/ethnically diverse (28% Hispanic, 20% African American, 31% Asian, and 17% Caucasian), poor (approximately one-half are uninsured; 40% live at or below 200% of poverty level) and medically complex population, of whom approximately 11% have CKD. We chose primary care medical directors and providers with experience in performance improvement because of their ability to integrate both individual patient and health care system concerns and their knowledge about clinic priorities.

Interviews were conducted by one investigator (D.S.T.) between February and May 2012, to ensure consistency. At the beginning of each interview, PCPs reported basic demographic data. Interviews consisted of 8 questions that covered the following topics: barriers and challenges in managing patients with CKD in the Network, use (or lack thereof) of a CKD registry as an adjunct to CKD care, and key components of a CKD registry that would promote optimal functioning in a safety-net primary care setting (Box 1). Each conversation lasted one hour and was digitally recorded and professionally transcribed verbatim. Written, informed consent was obtained by participating providers. The study was approved by the Committee of Human Research at the University of California San Francisco.

Our analysis was guided by a modified grounded theory approach for discovering themes in qualitative data. <sup>17, 18</sup> While we developed a preliminary set of analytical codes prior to the first interview, the coding scheme was extensively refined during data collection and analysis. Two investigators (D.M., D.S.T.) coded the first 2 transcripts together, using paragraph-by-paragraph review and resolving disagreements via consensus. Few disagreements arose and a high level of consensus was achieved after reviewing two transcripts; given the scope of this study, we elected to forgo a formal calculation of intercoder reliability. Subsequent transcripts were coded separately by the two investigators. The two investigators met regularly to review new data and to discuss, re-group, and re-classify codes as appropriate according to new data. Through review and discussion of coded results, we identified emergent themes. After analyzing 14 interviews, no major new themes were emerging, and after conducting an additional 6 interviews we determined that we had reached thematic saturation and ceased data collection.

## Results

#### Study Participants and Themes

Of the 21 clinicians invited for an interview, 20 (95%) agreed to participate. Nineteen (95%) of participating providers were physicians and 1 was a nurse practitioner; 70% were women and 50% had greater than 15 years of clinical experience. All participants had experience using disease registries, as they were either clinic directors (n=11) or designated clinic quality improvement champions (n=9). (Table 1)

We analyzed transcripts resulting from 20 different interviews. We identified four themes relevant to the development of a successful CKD registry for safety-net primary care: (1)

provider beliefs about how a CKD registry could aid in the provision of high-quality CKD care; (2) facilitators of successful implementation of such a registry; (3) unique complexities of CKD that may limit the benefit of a CKD registry; and (4) alignment of a CKD registry with current primary care priorities vis-a-vis new primary care delivery strategies. Each of these themes appeared repeatedly in the data.

#### CKD Registries Can Help Providers Give High-Quality CKD Care

Most PCPs stated that a CKD registry with an emphasis on panel management would be useful, particularly to identify individuals with CKD and track those who fall out of care. One participant expressed such thoughts regarding patients who don't routinely adhere to their clinic visits.

"Right now I'm worried about who my patients with CKD are. I'm sure there are some people that haven't been in [for] a year or two. ... if I had a list of my patients – [I'd] look and see who's been in, who hasn't, and have volunteers call them and book appointments."

Study participants also believed that a CKD registry could help panel managers identify patients with more rapidly progressive kidney disease by examining trends in CKD progression over time.

Providers also acknowledged the benefits of focused point-of-care alerts, specifically those pertaining to basic quality metrics such as blood pressure (BP) control and overdue critical laboratory results. Practically speaking, many PCPs noted that incorporating automatic alerts with simple BP treatment algorithms could enable primary care clinics to standardize care for all CKD patients across providers with varying levels of training and comfort levels with CKD treatment. This would "prompt people, even if they're not fully educated about CKD, to make sure that they do a pretty comprehensive job of managing the disease." Prevalence of ACEi use and CKD-associated healthcare maintenance items, such as immunizations, was recommended in quarterly reports to aid with panel management, rather than at point of care. Additionally, easy access to referral and treatment guidelines and best practices pertinent to CKD management were considered key to a successful CKD registry for panel management, particularly in a safety-net setting, where specialty resources are limited.

"I think there's certainly a lot less that we as primaries have access to, in terms of in our setting. ... [We're] struggling with what is an appropriate referral. I feel like people are uncomfortable with their management right now that they just kind of haphazardly send people to renal clinic."

#### Facilitators of Successful Implementation of a CKD Registry

All PCPs and clinician leaders have competing priorities with respect to chronic disease management. Study participants acknowledged this and asserted that one facilitator to successful implementation of a CKD registry was the understanding that CKD was a priority condition, which merited health care system re-design to support clinician behavior change.

"Each clinic is going to have to consider the relative importance or priority of that particular registry relative to others, or if it's competing with other quality improvement priorities. It is a reality that needs to be considered."

Once CKD was considered a priority, employing non-physician health care providers to deal with the increased workload that would accompany implementation of the CKD registry was considered essential. Some tasks, PCPs thought, were better suited for non-physicians and would afford them more time for patient interactions. These included outreach panel management to ensure adherence to clinic visits, immunization schedules and BP monitoring. When discussing ways to improve patient BP, one provider mentioned:

"I waste a lot of time trying to figure out how to get these patients back in. And I'm not necessarily the right person. I think that could be a nurse or a pharmacist ... doing a BP check [and] adjusting their medication with doctor supervision. A health coach who's trained under specific protocols could be meeting with that patient and talking about their salt intake and why it's important to control blood pressure."

However, while many PCPs believed that some tasks can and should be done by other staff, they recognized the importance of maintaining a balance. Avoidance of overloading one health care team member versus another was identified as an important issue.

"Any sort of panel management initiative requires us to change clinic workflows. It's hard when the protocols become more complicated. We'll be trying to find some middle ground where we have enough protocol driven actions but not so many that [the staff] are just completely bogged down."

Importantly, PCPs cited a need to give staff protected time in order to use the CKD registry, perform chart review and prepare for their extra responsibilities in caring for patients with CKD.

"... the registry requires protected administration time that's outside of the visit clinic encounter – it's a totally different model of managing populations."

#### Unique Complexities of CKD That Might Limit the Benefit of a CKD Registry

While PCPs did state that CKD registries with team-based care would be useful for primary care management of CKD, they also emphasized the idea that point-of-care protocols and metrics needed to be carefully thought-out prior to implementation because of the complexity of CKD care. Examples of such complexities include the varying etiologies of CKD and the difficulty in prescribing medications (indications and contraindications) in a setting of impaired drug clearance due to decreased kidney function.

"There's always some underlying condition that often times is a chronic disease. So, part of treating chronic kidney disease is treating the underlying condition."

"... and there are medications. You know the indications and contraindications of each of them, which populations benefit from which medications, etc. It's not so clear-cut, I think, when it comes to chronic kidney disease. So I think those would be probably the reasons that I would cite as to why CKD feels different."

Additionally, while most PCPs did not know where to find CKD guidelines, those who did thought that the guidelines were unclear and cited this as a contributor to CKD complexity and a potential limitation of a CKD registry.

The intricate interaction of the kidneys with other organs and the varying complications that arise with progressive CKD are other aspects of CKD care that make it more complex than other chronic diseases. While a CKD registry could provide all of the data pertinent to bone health, for example, without detailed explanations of the data, it may be hard for PCPs to use the registry to improve mineral bone disorder management at point-of-care. One PCP illustrated this by stating:

"Relative to like diabetes, I think that CKD's more complex. The bone relationships and the fluid balances ... I can see how it could be dangerous for providers who don't ask for support to get in the trap of treating patients and then creating subsequent complications as a result."

#### A CKD Registry Aligns With Current Priorities Within Primary Care Delivery

Primary care delivery is now revolving around care management practices, including patient empanelment, performance feedback and team-based care. Many participants emphasized the importance of team-based care and how non-physician health staff could aid PCPs in the delivery of high-quality care by carrying some responsibility: providing immunizations, performing cancer screening and testing glycated hemoglobin among diabetic patients. PCPs believed that a CKD registry aligns with this priority.

"I'm very excited about (team based care) coming down the line because I think it will take some of the burden off. Having a team-based approach and clear standing orders [in the registry] ... allowing providers to sort of step back to both focus more on some of the more complex medical things and feel as though they're not just constantly being pulled away or challenged to get done just the basic things."

Patient empanelment was also cited as a very important aspect in the current public health care system, which experiences a "constant flux of patients" due to changes in insurance coverage. Registries have been instrumental in providing clinicians with updated patient lists and panels, which, coupled with team-based health care delivery, could greatly enhance patient management and care coordination. One clinician noted:

"We're defining teams and teamlets where panels of patients are owned by the other multidisciplinary staff. We hope to delve into more care coordination and population management functions and beef up the roles that multiple members of the team are playing, both for in-reach panel management and outreach panel management."

#### **Discussion**

Our study suggests that safety-net PCPs in San Francisco believe that a CKD registry has the potential to improve the care they provide to patients with CKD, particularly if it performs the following tasks: identifies patients with CKD who have fallen out of care, allows early recognition of CKD progression, tracks CKD quality metrics, provides alerts for abnormal laboratory results and makes available decision support in the form of evidence-based algorithms and referral strategies. System re-design, including changes in clinic work-flow, expansion of the roles of non-physician staff in patient care and protected time for staff to engage in these new roles were cited as facilitators for implementation of a sustainable and clinically-useful CKD registry. Participating PCPs, who at the time were directly involved with EHR implementation, thought that the time was ripe to create and implement a CKD registry, as it aligned with current national healthcare priorities of team-based care and performance feedback as well as local changes in clinical documentation and work-flow. 15, 19

These findings are not surprising, as chronic disease registries have proven successful for population management of diabetes, depression and other chronic diseases. <sup>20</sup> But, while CKD registries have provided rich data for research and surveillance purposes, <sup>21, 22</sup> they have not yet proven themselves to be clinically useful. For example, Drawz *et al* reported that a CKD registry that provided PCPs with pertinent demographic and clinical data, along with twice yearly academic detailing, had no impact on PCP adherence to guidelines (with exception of parathyroid hormone measurement) or clinical outcomes. <sup>10</sup> While this registry included many of the key components cited by our study subjects (i.e., identification of patients with CKD, provision of evidence-based treatment guidelines, routine performance feedback) it did not identify patients who were lost to follow-up, did not include electronic alerts, and focused on individual clinicians rather than the entire health care team. Notably, only 5 of 37 PCPs who had access to the CKD registry in that trial actually used it during the

12-month study period. The CKD registry studied by Abdel-kader *et al* differed in that it did include electronic alerts, however, it too was focused on individual PCPs rather than the entire team. <sup>12</sup> Empowering non-clinician members of the health care team to use a registry to highlight gaps in high-quality CKD care and contact CKD patients who have fallen out of care might have enabled these interventions to provide meaningful improvements.

Many PCPs believed that the complexity of CKD care might make CKD decision support more difficult to automate in a registry, as compared to support embedded in registries for other chronic diseases. These beliefs are consistent with previous studies that demonstrated PCP desire for nephrology guidance and their relative unawareness of CKD guidelines. <sup>7, 23</sup> In addition, PCPs emphasized the need to be thoughtful and cautious when developing CKD decision support. CKD management may differ based on etiology of the decreased kidney function, stage of CKD and timing of insult (acute vs. subacute vs. chronic), which are not always readily apparent. A CKD registry must provide simple and clear algorithms about undisputed management strategies to improve kidney health and not attempt to address all of the complexities of CKD care, which may include starting/discontinuing medications among patients with reduced kidney function. If tackled, creation of such decision support, with an eye towards quality and patient safety, would require extensive PCP and nephrologist input.

Interestingly, PCPs overwhelmingly viewed a CKD registry that provided evidence-based decision support and routine performance feedback as a potential solution to their patients' limited access to nephrology care. National statistics suggest that for every one nephrologist, there are approximately 3,700 non–dialysis-dependent CKD patients in the United States,<sup>24</sup> a striking ratio. Shortages of nephrologists are even more pronounced in safety-net settings, perhaps due to higher rates of kidney disease in minorities and the poor.<sup>4</sup> In our study, PCPs thought that a nephrologist shortage hindered their ability to receive specialist input for all of their CKD patients. A registry that increases PCP and supporting medical staff's knowledge and confidence in managing less complicated CKD could thus decrease demand for nephrology referrals for patients with early CKD, allowing nephrologists to focus on patients who are in most need of their specialist expertise.

Participating PCPs also noted that a CKD registry for public health clinics could help their team maintain better continuity-of-care with their CKD patients. Lack of care continuity is pronounced in safety-net settings, often due to changes in insurance status and patient need to relocate to maintain an income. Having the ability to track and call CKD patients who have fallen out of care to ensure their safety is an important aspect of a CKD registry for health care teams.

Like all qualitative studies, our results have limitations. In particular, despite the diversity of our participants, the small sample size and reliance on clinician leaders within one health care delivery system may limit the generalizability of our findings. Further studies should include perspectives from clinicians who work in other settings, including non-physician health care staff. However, there are few studies to date that have examined provider beliefs regarding CKD registries and how to improve the use of such registries in clinical settings. This study informs healthcare and technology leaders of primary care settings about the essential features of a clinically useful CKD registry, as well as the important facilitators for its sustainable implementation. For example, results of this study have directly informed the development of a CKD registry for the Federally Qualified Health Centers in which the study participants work. The new CKD registry, still in pilot testing, alerts medical assistants at point of care if a patient with CKD has not had quantification of albuminuria within the last year or is out of date with respect to immunizations and empowers them to send a urine sample for albuminuria testing or give immunizations, independent of the PCP. The registry also includes two focused point-of-care alerts for primary care providers: receipt of an ACE

inhibitor/ARB and level of albuminuria >300 or <300 mg per gram of creatinine. Quarterly feedback to multi-disciplinary teams (PCPs, nurses, medical assistants and clerks) focus on BP control, empowering non-physicians to bring patients in for BP titration according to predetermined algorithms. Reports also include links to management recommendations from local nephrologists.

Since passage of the Affordable Care Act, which increased funding to community health centers caring for the underserved, <sup>25</sup> clinicians are experiencing shifts in care paradigms that focus on the delivery of patient-centered, team-based care. Additionally, there are newfound energy and resources to focus on preventive services and incentives for improvements in quality and care coordination. <sup>26</sup> Our results suggest that a CKD registry with a focus on clinical quality improvement and the functionality to track, standardize and enhance CKD care through decision support aligns with these changes to safety-net primary care and should be actively developed and tested to enhance the quality of CKD management in primary care settings.

#### Box 1

# Semi-structured interview guide used with clinic directors and quality champions.

- 1. We are currently in a period of transition with regards to health care provision in this country. Can you describe to me what kinds of changes are occurring in this clinic?
- 2. How do you approach providing optimal chronic disease care in your clinic?
- **3.** Chronic disease registries have emerged as an important way to provide patient-centered care. Have you worked with a disease registry before in this clinic? For what and for how long?
- **4.** A CKD registry is being built within the CHNSF network. How might this registry be most helpful for you? In an ideal setting, what would this registry do for (a) clinician/clinic and (b) patients?
- **5.** If this registry identified individuals with CKD and whether they are receiving guideline-concordant care, at point-of-care how would you envision this to help/hurt your current clinic flow?
- **6.** If this registry identified individuals with CKD for panel management (not at point of care) how would this help/hurt your clinic work flow?
- 7. Which option would you prefer (point of care or panel management) and why?
- **8.** Are you familiar with any national CKD guidelines?

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#### **Abbreviations**

**CKD** chronic kidney disease

**CHNSF** Community Health Network San Francisco.

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Table 1

# Participant characteristics.

Characteristic	n (%)
Sex	
Male	6 (30)
Female	14 (70)
Race*	
White	10 (50)
African American	1 (5)
Latino	1 (5)
Asian	9 (45)
Time since medical school graduation	
<10 y	4 (20)
10-15 y	6 (30)
>15 y	10 (50)
Specialty*	
Family practice	13 (65)
Internal medicine	7 (35)
Other	1 (5)
Non-English languages spoken with patients*	
Spanish	10 (50)
Cantonese	3 (15)
Other	6 (30)
No. of clinic half-days/wk	
2	4 (20)
>2	16 (80)

<sup>\*</sup> Categories not mutually exclusive.