

## Personalizing Longitudinal Care Coordination for Patients with Chronic Kidney Disease

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### Abstract

Chronic care coordination efforts often focus on the needs of the healthcare team and not on the individual needs of each patient. However, developing a personalized care plan for patients with Chronic Kidney Disease (CKD) requires individual patient engagement with the health care team. We describe the development of a CKD e-care plan that focuses on patient specific needs and life goals, and can be personalized according to provider needs.

### Keywords:

Precision medicine; Renal Insufficiency, Chronic

### Introduction

Chronic kidney disease (CKD) is a significant medical challenge that affects between 8-16% of the world's population [1]. CKD patients are often faced with multiple medical problems, the management of which may be impeded by poor interoperability of digital information and insufficient communication amongst providers and with patients. CKD patients are prescribed many medications, require frequent procedures, are at high risk for acute events, and experience frequent transitions across multiple care settings [2]. Due to its complexity and severity, CKD patients may hold different life goals that should significantly influence decision-making points that occur throughout their illness. In each case, it is essential to tailor treatment and care plans to meet patient specific life goals. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), one of the National Institutes of Health of the USA, sought to personalize care for CKD patients via an e-care plan tailored to capture patient specific needs that could be transferred across multiple care sites.

### Methods

The NIDDK's Kidney Disease Education Program convened an expert working group comprising of patients, nephrologists, and primary care physicians to facilitate the development of an e-care plan to facilitate a longitudinal transfer of key patient data across providers and health care settings using HL7 Consolidated Clinical Document Architecture (C-CDA) [3]. It also conducted a series of patient phone interviews to inform this process via the identification of significant decision points and CKD care goals of value to patients.

### Results

We identified 55 indicators for inclusion in the CKD e-care plan. These indicators range from measurements such as serum creatinine levels to other predictive clinical factors, renal replacement therapy decisions, evaluation for mental

health status (including depression), functional status, activities of daily living and achievement of personal health goals. For each indicator, we assigned numeric and categorical priority scores based on the working group's recommendations. We also identified appropriate clinical terminology spread across LOINC, SNOMED, ICD-10 (diseases) and CPT codes (procedures). We found that many data elements essential to optimal CKD care lack appropriate clinical terms for information sharing across settings. This included specific patient focused terms such as choice for renal replacement therapy, patient education, patient goals and much more. Standard codes were used. Where standard LOINC codes were unavailable, we contacted LOINC to create new codes. A draft data set was published online [4] and welcomes feedback. Out next step is to pilot and test the data set at multiple settings.

### Conclusions

A common data set is essential for developing an e-care plan. However, the plan must also have the flexibility to allow multiple views of the data, including a personalized patient perspective as well as functionality for individual providers to create personalized templates or dashboards that present the common set of data elements based on the needs of their clinical disciplines. The e-care plan must also find an appropriate balance between brevity and comprehensiveness. It should also be person, and not solely disease-centric. A disease-based focus could yield numerous, uncoordinated plans for people with multiple chronic conditions. Many data elements essential to optimal CKD care lack standards and codes for sharing information uniformly across settings. Additionally, global issues with interoperability, inadequate clinical terminology, inconsistent health information exchanges, and medication and other clinical reconciliation challenges pose problems for implementing the care plan.

### References

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