Betsy Johnson Storyboard

Purpose and Overview

This storyboard adapts and extends the patient persona for Betsy Johnson, created by the Electronic CKD Care Plan Working Group of the National Institutes of Health's (NIH) National Institute of Diabetes and Digestive and Kidney Diseases, to address challenges with the transfer of health information and transitions of care for patients with chronic kidney disease (CKD). Electronic care plans are intended to facilitate longitudinal transfer of key patient data across settings, providing access to the patient and all health care professionals who provide care to the patient. Because frequent transitions of care are common among patients with CKD, an electronic person-centered care plan, based on FHIR standards, could potentially improve patient outcomes by helping to ensure that critical patient data are consistently available to all members of her care team.

Although the NIH working group efforts do not directly address the formation and management of care teams for multidisciplinary and multi-provider care, the patient and provider personas illustrate a realistically complex scenario for care team analysis. The personas, including Betsy Johnson, are fictitious individuals whose stories are based on interviews with actual patients and care providers, plus the challenges and barriers they face while managing chronic health conditions. Key elements from Betsy's persona are summarize in this document, but see the original NIH persona description for more context on the perspectives of each care team member.

Patient Profile: Betsy Johnson

Demographics

- 60 years old
- Retired school teacher
- Widowed
- Lives in Springfield, IL, with daughter; son in another city

Problem List

- Type 2 diabetes mellitus (DM), onset 20 years ago
- Progressive chronic kidney disease (CKD), onset 10 years ago
- Diabetic retinopathy with visual loss, onset 6 years ago
- Sedentary lifestyle, onset 5 years ago
- Dyslipidemia and peripheral vascular disease, onset 4 years ago
- Congestive heart failure (CHF), onset 2 years ago
- Anxiety, onset nearly 1 year ago

Care Team

The NIH CKD care plan working group created personas for six core members of Betsy's care team. They are included in this summary table, along with a few additional members of the multidisciplinary care team, e.g. the care coordinators, community service organizations, and home health care providers. These care teams and members are not a complete picture for a patient like Betsy, who is living with three chronic conditions. The care team for nephrology was expanded to illustrate a specialty care team from a different provider organization. However a similar care team for diabetic care is not included here, e.g. to include an ophthalmologist and podiatrist along with their organizational teams.

Member Name	Role	Relationship to Betsy	Comment
Betsy	Patient		
	Daughter		Betsy Lives with
	Son		Lives in another city
Debra Smith	Care Coordinator		Rose Valley Primary Care
Dr. John Carlson	Primary Care Provider		Rose Valley Primary Care
Maria Gonzalez, RD	Nutritionist		Rose Valley Primary Care
Dr. Vince Jones	Nephrologist		Nephrology Clinic
Sarah King	Care Coordinator		Nephrology Clinic
Multidisciplinary Care Team			Nephrology Clinic
Meals-on-Wheel (**To Be added)**			Community Services
Home health Services	Home health aid service (SNOMED 385781007)		Home health agency

Use Case Scenarios

These use case scenarios were created by Motive Medical Intelligence in support of HL7 FHIR connectathons for care planning and care management. The scenarios illustrate interactions among Betsy Johnson's care team members during routine care and office visits.

Wednesday, November 1, 2017 – Periodic System Run (Day 1)

Debra Smith, the Rose Valley Primary Care Clinic care coordinator, reviews the results of the previous evening's CDS system run. She sees that Betsy has not yet received a 23-valent pneumococcal polysaccharide vaccine (PPSV23) and that Betsy is also due for appointments for ongoing management of her heart failure, diabetes, and diabetic retinopathy.

Debra calls Betsy and works with her to schedule an appointment with Dr. John Carlson, Betsy's primary care provider (PCP). She knows that the ophthalmology clinic also has access to the care plan, so she tells Betsy to also expect a call from the clinic's care coordinator.

Wednesday, November 29, 2017 – Health Management Visit (Day 2)

Betsy arrives at her primary care clinic to be seen by Dr. Carlson. When she checks in, her chart is opened, causing the CDS rules to run. Her appointment status is changed to "arrived." Dr. Carlson's medical assistant, Janice Rogers, sees that Betsy has arrived. Janice calls for Betsy and brings Betsy to a vacant room. Janice then logs in and pulls up Betsy's chart so she can enter vital signs. When she does this, Janice sees a notification that Betsy is due for a body mass index (BMI) determination. Janice takes Betsy's vital signs, including height, and records them as follows.

- Height: 64 inches
- Weight: 167 pounds
- Blood pressure: 138/84 mm Hg
- Pulse: 76
- Oxygen saturation: 97%

The electronic health record (EHR) automatically calculates and displays the BMI as 28.7 kg/m^2.

Janice confirms that Betsy is present for management of her chronic conditions.

Janice leaves the room to let Dr. Carlson know that Betsy is ready.

Dr. Carlson enters the room, greets Betsy, and logs into the EHR. He then performs a directed history and physical exam. During the evaluation, Betsy expresses confusion regarding the conflicting dietary recommendations she has received for her diabetes, CKD, hypertension, dyslipidemia, and heart failure. She also is having trouble understanding her medication regimen. This is causing her a lot of anxiety.

Dr. Carlson talks with Betsy regarding her current state of health, including treatment options should her kidneys fail. He expresses understanding of her frustrations regarding her complicated dietary and medication regimens. He reviews her medications with her and suggests that she speak with a dietitian to gain a better understanding of her dietary needs. He also talks to her about the potential benefits of increasing her physical activity level, suggesting ways she can walk more. He recommends using a pedometer to see how many steps she walks in a day.

Dr. Carlson enters a referral request for Betsy to see an in-house dietitian. When he opens the order screen to order a metabolic panel, Dr. Carlson sees proposed orders for urinary albumin-to-creatinine ratio (URAC), creatinine with an estimated glomerular filtration rate (eGFR), and a hemoglobin A1c (HbA1c). He approves the URAC and HbA1c orders, rejects the eGFR order, and adds an order for a comprehensive metabolic panel (which includes an eGFR). He also sees an immunization request for a PPSV23, which he approves.

Dr. Carlson then signs out of the computer and leaves the room. Janice returns to the room, administers the PPSV23, and directs Betsy to the laboratory.

Betsy walks to the lab, has her blood drawn, and submits a urine sample. She then walks to the check-out desk, where the care coordinator, Debra, is waiting for her. Debra has seen the referral request, so she works with Betsy to set up an appointment with the in-house registered dietitian. Debra then changes Betsy's appointment status to "fulfilled."

Wednesday, December 6, 2017 – Final Lab Results Available (Day 3)

Betsy's labs are updated to include final results. Her HbA1c is within her goal range at 6.8%, but her URAC is elevated at 742 mg/g and her eGFR has fallen to 28 $mL/min/1.73m^2$. The chart update results in processing of the rules. Her abnormal URAC and eGFR trigger notifications, which are reviewed by Janice, who brings them to Dr. Carlson's attention.

Dr. Carlson reviews Betsy's labs and decides to refer her to a nephrologist for further evaluation and management of her kidney disease. He calls Betsy to discuss her results and his recommendations. Dr. Carlson then fills out an external consult request, which is routed to Debra.

Debra sees the referral request, so she checks the list of preferred area nephrology clinics and makes calls to determine their availability. She then works with Betsy and the nephrology clinic care coordinator, Sarah King, to schedule an appointment.

Betsy arrives at the clinic to be seen by dietitian Maria Gonzalez, RD. When she checks in, her chart is opened, causing the CDS rules to run. Her appointment status is changed to "arrived." When Maria logs on to her office computer, she sees that Betsy is waiting. She reviews Dr. Carlson's referral note and key components of Betsy's records, including her problem list, weight and lab trends, medications, and dietary recommendations. She notes that Betsy has been referred to a nephrologist.

Friday, December 15, 2017 – Dietitian Visit (Day 4)

Maria then retrieves Betsy from the waiting room and brings her back to a vacant patient room. Maria discusses Betsy's nutritional needs with her in the context of Betsy's concerns and medical problems. She makes initial dietary recommendations but needs more information to create a diet plan. Maria lets Betsy know that she will be following up with Dr. Carlson and that she will want Betsy to return after that occurs. She then concludes the visit.

Betsy walks to the check-out desk, where Debra greets her. Debra has already seen Maria's plan to follow up with Dr. Carlson, so she tells Betsy to expect a call after that occurs. Betsy leaves the clinic.

Meanwhile, Maria has returned to her office and is writing a response to Dr. Carlson regarding the referral. She requests 10 more visits with Betsy, at which time she will determine whether more visits are needed. She also requests a phosphorous level.

Dr. Carlson receives the referral response, approves the visit request, and enters an order for the phosphorous level. Debra sees the order, notes that it is marked as routine, and calls Betsy to let her know that she should visit the lab for blood to be drawn.

Thursday, January 4, 2018 – Nephrology Clinic Visit (Day 5)

Betsy is seen at the nephrology clinic by Dr. Vince Jones. He sends a response to Dr. Carlson's referral, recommending that Betsy continue to be seen at the nephrology clinic, where a multidisciplinary care team is available to manage her severe kidney disease. As part of her ongoing care, Dr. Jones would like to keep a close eye on Betsy weight trends and also would like to ensure that Betsy is following her nutritional plan. Dr. Jones orders home health services so Betsy can receive assistance with her activity of daily living (ADLs) with initial orders for home health aid services on the days Betsy's daughter is not available to assist Betsy.

Citations

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