



Patient Map Narrative- Destination Change: A Journey of Recovery

The California Consortium of Addiction Programs and Professionals (CCAPP) is California's largest association of for-profit and non-profit substance use disorder (SUD) treatment agencies and addiction-focused professionals. We provide services in residential, private, and outpatient settings and also actively advocate for patients, providers, and the recovery community at large. In making this patient map, we took an approach that combined our unique reach in the SUD patient community with evidence-based tools to portray the patient journey in a manner that brings to light major pain points of the patient experience.

First, to best format discussion, we determined the phases of the patient journey we wished to include on this map. Initially, we wanted to come up with unique phases but upon further thought felt it was more appropriate to utilize the Transtheoretical Model (TTM): Stages of Change. The Stages of Change originates from a study on smoking cessation by Dr. Carlo DiClemente and Drs. Prochaska; it is an integrated model for conceptualizing intentional behavioral change often used in describing changes in behavior related to addictive behaviors. The TTM: Stages of Change are Pre-contemplation, Contemplation, Preparation, Action, Maintenance, and Relapse. We felt these stages accurately reflected changes patients experienced while being widely applicable to the multiple avenues that patients may take in seeking treatment and recovery. We understand that patient journeys are rarely linear and often split into various forks and roads resulting in fairly diverse encounters with the health system. We felt these phases applied to whatever roads an individual encountered on their journey whether they entered inpatient and went the treatment avenue, solely participated in outpatient services, or utilized medication-assisted recovery (MAR). These phases also allowed us to show that the SUD patient journey requires a chronic care model by including phases such as "maintenance" and "relapse" indicating that the journey requires continuous work in building and maintaining recovery capital.

Then, using our connections to various entities from every corner of the SUD community, we gathered first-person thoughts on the patient journey. We decided to draw upon these experiences through focus group interviews with representatives from our patient advocacy organization, the California Coalition of Addiction Recovery Advocates (CCARA), and CCAPP program members to get the best picture of experiences on the ground. These individuals all have intimate lived experiences with the patient journey and have continued involvement in the patient experience as valued advocates representing the voices of those who are currently experiencing the patient journey today. There were a total of 38 interviewees which included individuals in recovery from substances ranging from opioids, stimulants, to benzodiazepines.

CCARA is a coalition of thirteen organizations: CCAPP, Addiction Recovery Communities of California (ARCC), Faces and Voices of Recovery, National Alliance of Medication Assisted Recovery, National Alliance for Recovery Residences, A New Path/Moms United to End the War on Drugs, SMART Recovery, the Phoenix, the Purpose of Recovery, Orange County Recovery Collaboration, Many Paths One Destination, Young People in Recovery, and Shatterproof. These organizations are vocal patient advocates that have represented the interest of individuals in recovery statewide and nationally. The focus group interview occurred during an online meeting where representatives with lived experience from each organization were asked what they thought encouraged patients and deterred patients at



each phase of the patient journey. This led to a discussion in the group at each phase of the different experiences they have had with the health care system and what they thought were pain points in the patient journey. Similarly, a focus group interview was also used in gathering input from the CCAPP program network. The interviews were hosted online on two separate occasions.

All this input was then organized under each phase and refined to be more concise and free of redundancies. This information was then used as the basis for the pain points and system supports indicated on our map. Next, to better connect individuals viewing our map to the contents, we decided to utilize an evidence-based toolkit, the R1 Learning Discovery Cards produced by R1 Learning. The R1 Learning Discovery Cards are evidence-based assessment tools commonly used to spark meaningful insight and self-discovery from individuals struggling with addiction. The cards are made up of statements that reflect feelings, emotions, and thoughts individuals on their recovery journey may feel. We selected some of the card statements that best reflected input from our focus groups and the phases we selected to include on our patient map. We felt these statements widened the breath of connection individuals viewing our map may feel and created good benchmarks for characterizing each phase we indicated. We have received written permission from the R1 Learning Discovery Cards creator, Tom Karl to utilize the contents of their cards on our patient map.