

# Substance Use Disorder Treatment Journeys



## Individual, Clinician, & Pharmacist Perspectives on Medication for Opioid Use Disorder

### Executive Summary

February 1, 2022

## Background

As many as 40 million people in the United States live with a substance use disorder (SUD).<sup>1</sup> As individuals, families, caregivers, and the health care system struggle to address SUDs, the U.S. Food and Drug Administration (FDA) plays an important role in reviewing potential treatments to address SUDs and helping to limit the abuse and misuse of FDA-approved products. Particularly pressing in the regulatory environment is the need for continued focus on opioid use disorder and new efforts to address stimulant use disorder.

FDA's Center for Drug Evaluation and Research (CDER) partnered with the Reagan-Udall Foundation for the FDA to gain a deeper understanding of individuals' experiences with SUDs – and specifically with SUD treatment. Our approach was to create a series of maps (See appendix) that tracks individual treatment journeys to identify the specific challenges they faced and the supports they found helpful. Our goal is to use this ethnographic research to identify potential system improvements and engagement opportunities that can help inform FDA's work in the prevention and treatment of SUDs.

For this project, we looked at two specific issues:

1. Experience exploring or using medication for opioid use disorder (MOUD), and
2. Trajectory of treatment for individuals who have gone through treatment for SUD more than once.

### Medication for Opioid Use Disorder

Individuals exploring the use of medication to treat an SUD do not travel their path alone. They are connected to networks of providers, peers, and family members who may have their own experiences, opinions, training, and expertise. Mapping the individual experience led us to also mapping the experiences – and potential influences – of prescribers, non-prescribing clinicians such as counselors/therapists, and pharmacists. Individuals and these provider groups demonstrated generally positive views of MOUD (sometimes referred to as medication-assisted treatment, or MAT, by participants), with emotional responses primarily ranging from neutral to positive.

**Individuals** typically had difficulty finding information about MOUD, but ultimately connected with useful resources (See Figure 1). Despite similar socioeconomic characteristics, the journey looked different for two cohorts of individuals, with cohort B experiencing more stress and challenge at the start of the MOUD journey; both groups ultimately had positive thoughts and emotions about their treatment. A potential barrier in finding information may be the stigma encountered both externally and internally, with individuals reporting “my worst part was information which came from people who knew what mat was but were uneducated and would give me information based on stigma” and “I was too ashamed to talk to Drs about MAT, google told me it was just trading one drug for another...”

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<sup>1</sup> Using 2020 NSDUH data: Substance Abuse and Mental Health Services Administration. (2021). Key substance use and mental health indicators in the United States: Results from the 2020 National Survey on Drug Use and Health (HHS Publication No. PEP21-07-01-003, NSDUH Series H-56). Rockville, MD: Center for Behavioral Health Statistics and Quality, Substance Abuse and Mental Health Services Administration. Retrieved from <https://www.samhsa.gov/data/>.

Another specific area of challenge was making the decision to commit to MOUD, which was again more difficult for Cohort B than for Cohort A. Specific comments focused on paying for care and navigating insurance as challenges in this area. In open-ended questions, both groups identified the role of peers with SUDs as influential, although not always easy. One respondent noted that “talking to other addicts is a[n] awesome way to get info about medication,” while another shared that peer influence was not always encouraging: “people in my life (other addicts) said I could abuse it to get high.” Additional difficulties cited were paying for medication, limited local MOUD resources, need for other supports such as Narcotics Anonymous/Alcoholics Anonymous meetings, and transportation, with some citing commutes of an hour or more. Finally, respondents also stressed the need for additional medications for MOUD: “Meds are the most realistic option for me but not when there isn’t anything good to treat meth.”

#### Comments from Individuals with MOUD Experience

- *“It’s been another tool in my armory to be in recovery and save my life.”*
- *“I was too ashamed to talk to Drs about MAT, google told me it was just trading one drug for another and people in my life (other addicts) said I could abuse it to get high, by this point I wasn’t looking to get high anymore”*
- *“Just finding any kind of treatment when I needed it. I live in a small town and those resources were not and still not in this area. We have now 4 MAT doctors in the area, but we need more AA NA counseling and group counseling. More meetings for people to go to.”*
- *“The best part was having control for the first time the worst is that I still have to take something”*
- *“Meds are the most realistic option for me but not when there isn’t anything good to treat meth”*

Overwhelmingly, individuals in both groups were happy with their decision and would go the medication route again if needed, in spite of the challenges they encountered. One respondent summed it up saying the experience was “Terrifying but greatest decision I’ve ever made...”

**Non-Prescribing and Prescribing Clinicians** also reported overall positive experiences and views of MOUD (See Figures 2, 3). Like individuals, both prescribers and non-prescribers experienced the most difficulty at the start of the journey in finding information on MOUD. Prescribers found this challenge slightly more significant, yet both groups reported strong positive associations with what was learned. Both groups also reported strong collaboration with others as helpful in their journey.

The other negative experiences for prescribing and non-prescribing clinicians occurred around the decision phase of the journey. Prescribers, in particular, felt there were few alternatives to consider during this phase; although they also reported that MOUD compared very well to other types of treatment. Stigma could also play a role here as one clinician highlighted “challenges with team members who have not had training or have misconceptions about medication for SUD.” One clinician summed it up by stating “the main factors in our area are lack of resources and small mindedness.”

In addition to stigma, clinicians are also concerned about income-based access, other treatment supports, and social determinants of health. One clinician reported, “The single most detrimental issue is when clients are wanting MAT but have insecure or no housing.” Another who reported believing “strongly in MAT” finds “it to be least effective for my clients when they are prescribed medication for their Opiate disorder and receive no other treatment or medical care.”

Program setup was also identified as a challenge by some respondents. “Most programs make it hard to access MAT for clients who are not already high functioning, by requiring them to be on time for appointments, withholding meds if client has positive [urinary analysis], not giving clients a phone number, they can call or text clinic at.”

While acknowledging the challenges, both prescribing and non-prescribing clinicians had extremely positive reactions to the overall journey with MOUD, reporting that they would support/prescribe this treatment again when appropriate for their clients.

**Pharmacists** are overall very positive about MOUD, although they did express concerns about access to counseling and support services, insurance, and socioeconomic factors (See Figure 4).

Pharmacists clearly started with a higher level of information about MOUD than clinicians or individuals and did not struggle to find information. They began the process with very positive views, with the biggest challenge encountered at the point of decision making, slightly more so for pharmacist Cohort B. Primary stresses at this stage are comparing MOUD to other forms of treatment and concern about a lack of other patient assistance, including access to a range of treatment and support services: “MAT should be paired with social support, other medical support to address other medical conditions, psychological support, and workplace reintegration. I only know of a select few facilities or programs that offer that approach.”

### Prescribing Clinicians and Non-Prescribing Clinicians on MOUD

- *“Social stigma is very high - even clients with consistent, reliable access to MAT face discrimination in the community if their use is known”*
- *“We need regulatory and policy changes that enhance access and are supported by 30 plus years of research on addiction treatment. Access to MAT in Urgent and emergency setting with easy linkages to outpatient prescribers is critical and must be expanded to prevent overdose and engage larger numbers of clients in MAT care.”*
- *“I worry about clients only receiving MAT services without additional supports”*
- *“Ability to pay is the biggest barrier especially as individuals wait for their Medicaid... [private insurance] typically very high deductibles and copays which make certain medications and other counseling services no longer affordable.”*
- *“I love MAT. its free of the expectations that we have in other parts of our practice and enabled us to validate and support patients in a new way “*
- *“Rate of relapse still high and poor support systems for patients”*
- *“There is a lot of stigma and not enough funding.”*
- *“Best part - it’s evidence based so you have a high chance of success. Worst part - addiction is multifaceted and Social determinants oftentimes make MAT fail.”*

### Pharmacists on MOUD

- *“I believe that not many people are aware of MAT and that more efforts should be put into place in order for them to understand the benefits of the treatment program. Education in community pharmacies would greatly increase awareness and improve the health of those with SUD.”*
- *“Initially, many prescribers would not accept insurance or obtain prior authorizations for patients, causing them to weigh the cost of treatment with the cost of continuing their addiction or attempting to quit cold turkey. I feel that MAT should be paired with social support, other medical support to address other medical conditions, psychological support, and workplace reintegration. I only know of a select few facilities or programs that offer that approach.”*
- *“I think there are barriers to treatment that are mostly related to finding a provider that is authorized to provide the services”*

Pharmacists also reported good collaborations with others in the journey, but in open-ended responses noted that their own expertise may not be utilized to the fullest, with one respondent noticing it “can be difficult finding other providers who will take advantage of a pharmacist’s strengths helping provide MAT therapy to patients.” Open-ended comments also made it clear that patient access to qualified prescribers was a concern, noting that “finding a prescriber continues to be a barrier.” There was also concern expressed about the quality of some practices: “Many clinics are simply not following proper procedures, and our pharmacy will not establish a relationship with them for that reason.”

Pharmacists highlighted the impact of race and ethnicity in MOUD treatment. “Patient access is adversely affected in Minority

communities,” said one respondent, while another cited, “The racism inherent in drug laws have wide-ranging consequences, especially for BIPOC [Black, Indigenous, and People of Color], raising additional barriers to basic needs and structural determinants of health as listed.”

Other systemic issues were also noted by pharmacists from industry (“companies focusing on prescription counts instead of pharmacy services”) and regulatory practices (“Limiting factors include regulations and a still fairly conservative attitude re supporting patients with substance use disorder”).

While being vocal about challenges to MOUD, pharmacists overall ended the journey with highly positive responses, seeing the benefit to patients and being committed to continuing MOUD services to patients.

### Pharmacists on MOUD

- *“The racism inherent in drug laws have wide-ranging consequences, especially for BIPOC, raising additional barriers to basic needs and structural determinants of health as listed.”*
- *“Meds are break even propositions when provided by Pharmacists, with no defined payment model that adequately reimburses pharmacist for clinical Care extra time it takes to provide optimum MAT to patients”*

## Trajectory of Treatment

Once we gained an understanding of the experience of individuals, providers, and pharmacists with MOUD, we decided to compare those findings with journeys through broader sets of treatment. For this phase, we gathered input from two cohorts of individuals who have completed a range of treatments for SUD and who have traveled through treatment more than once.

Trajectory of treatment journeys reflected similar themes to the MOUD journeys conducted in the first phase of work; however, the participants responded with more modulated responses – the highs and lows of the journeys demonstrated less movement when compared to the MOUD journeys (See Figure 5).

Both cohorts reported collaboration with others as highly positive, yet the details of these interactions varied greatly. Some individuals cited peers (often in support groups or 12-step programs) and peer specialists/counselors as instrumental, while others found professionals who “listened and stayed the course” crucial to recovery. For many, a combination of “seeing my sponsor, therapist, and NAMI [National Alliance on Mental Illness] Peer-to-Peer class” seemed most helpful, with at least one respondent citing use of an app as incomparable: “Nothing is comparable to the connections app because theres [sic] nothing like it.”

Consistency of engagement and accountability were motivators for some individuals: “A lot of my doctors helped to keep my sober because of the drug tests to make sure my baby was healthy, the councilors put me on call in report for probation which makes me feel responsible and I keep sobriety going to stay reliable and not let them down.”

Treatment journeys for individuals with SUD varied, but common themes included feeling like they were in “life and death situations,” starting treatment for their family, or in many cases, participating in mandated treatment following interaction with the legal system.

Similar to the MOUD journey, individuals noted difficulty finding information and getting started in treatment as a primary challenge, with one respondent stating, “I wanted to try outpatient stabilization/coaching support, but was unable to manage the research, phone calls, and follow-

### Individual Comments on Trajectory of Treatment\*

- *“My doc was any and all opiates/opioids, i was shot at 16 and had been perscribed pain meds.. it grew to heroin and meth. I went to countless detox programs, sober living homes, methadone clincs and suboxon.”*
- *“There was lack of support and continuity in the system as well as an overall lack of trust with peers and professionals. Learning to be empowered, self-sustainable, grateful, and resourceful were the most effective treatments.”*
- *“I am barred from ever accessing other forms of treatment because of my medical cannabis use. I am not allowed to go to recovery housing, residential treatment, medical detox, and any other of the range of services available to people with SUD because of my participation in the medical cannabis program.”*
- *“I didn't "work with professionals" but am fortunate enough to have friends family and peers in the mental health and substance disorder treatment careers, who also had personal familiarity with substance use issues. Getting over my fears and pride and TALKING with them aided me in finding the right program for myself.”*

\*Quotes taken directly from online free-text responses.

up required before my attentions were diverted to addressing my unstable housing/divorce/etc.”

Open-ended responses demonstrate the ongoing challenge of stigma and its impact on the

#### Individual Comments on Stigma of Treatment

- *“Shame and concern for my career prevented me from talking to anyone.”*
- *“Worst-methadone shaming at the clinic and being treated inhumanely; best-a friend took me to harm reduction mtg and it changed my life”*
- *“There was lack of support and continuity in the system as well as an overall lack of trust with peers and professionals. Learning to be empowered, self-sustainable, grateful, and resourceful were the most effective treatments.”*
- *“Fear of stigma when inquiring about options led to anxiety. Hearing from people who have battled addiction was an AMAZING help in finding what treatment options and what level of treatment I was likely to benefit most from.”*

timeliness of seeking treatment: “I wish it weren't so stigmatized. I probably would have sought some help sooner had I known that my fears were not justified.” Another common thread of comment is the endpoint, with some individuals citing harm reduction as specifically helpful: “a friend took me to harm reduction mtg and it changed my life” and “Harm Reductionists educated and supported me thru decision process. If I had met them or heard about their principles it would not have taken me 14 years to stop using heroin.”

One observation from the trajectory of treatment phase is that once an individual has been through treatment for SUD multiple times, their journey map demonstrates a combination of positives and negatives but not significant swings. Overall, thoughts and reactions remained in the neutral-to-positive zone, with the highest positive being “no regrets; would pursue treatment again if necessary.”

#### Opportunities

The journey map process identifies touch points that are opportunities to increase success and effectiveness or address a problem that is impeding success. The consistency of the two phases – examining both MOUD and the general trajectory of treatment – provide insights that FDA may further explore as it expands its work in this arena. A few opportunities are highlighted below.

- We often talk about treatment accessibility, but less attention is given to *finding information* on how to access treatment. Both the MOUD and Trajectory of Treatment responses clearly demonstrated the need for easier access to information.
- The positive aspects of collaborating with others – coupled with the mixed responses (possibly based on knowledge and stigma) among who people found helpful – illustrate the need for more education for individuals, families, peers, clinicians, pharmacists, and others in the substance use ecosystem.
- Supporting collaboration that builds to strengths may be useful to professionals, peers, and individuals.

- Broader exploration around the endpoint of treatment is a worthy endeavor, as many open-ended responses discussed harm reduction as an endpoint and/or as a step toward abstinence.
- The growing positive view of MOUD among individuals and professionals, paired with comments about not yet having the right medication for some individuals, illuminates the need for ongoing development.
- More information and examples of MOUD working in tandem with other types of treatment and supports are needed, as are more services. Relatedly, continued efforts to address homelessness and other social determinants of health are also critical to treatment and recovery.
- Further research is needed, perhaps in the form of listening sessions, to better understand the decision support that would be useful to both individuals and professionals.

## **Methodology**

The Reagan-Udall Foundation for the FDA engaged Journimap, cloud-based application specialists, to conduct ethnographic research in early 2021 to produce both visual journey maps and text-based findings from generated data. Visual journey maps represent an experience from the respondents' perspective starting with initial discovery through decision and engagement, and then also chart positive and negative touch points reported by participants. Survey respondents also provided rich commentary in open-ended text boxes. In the MOUD cohorts, more than 50% of respondents participated in the open text boxes, representing a high level of engagement.

Participants were recruited through a variety of avenues including advocacy and professional organizations, social media, and individual outreach. Some organizations received incentives to assist with recruitment that were in some cases passed directly to participants.

Journimap conducts remote ethnography qualitative research with target audiences based on specifically tailored scenarios. Two batteries of 18 or more respondents per scenario are required to validate qualitative findings. This work exceeded those minimums. Data gathering was conducted via a HIPAA-compliant mechanism, and no identifiable information was stored or transferred.



## Appendix

Journey maps are qualitative research built on input from multiple people to illustrate how a person may experience a process. Based on the information collected, a persona is developed to illustrate how a person thought, felt, and recalled an experience. This insight helps identify challenges that can be addressed, opportunities for support, and examples of what works well. The image below details how to interpret a journey map. The maps that follow represent the findings detailed in this report.

## How to read a journey map

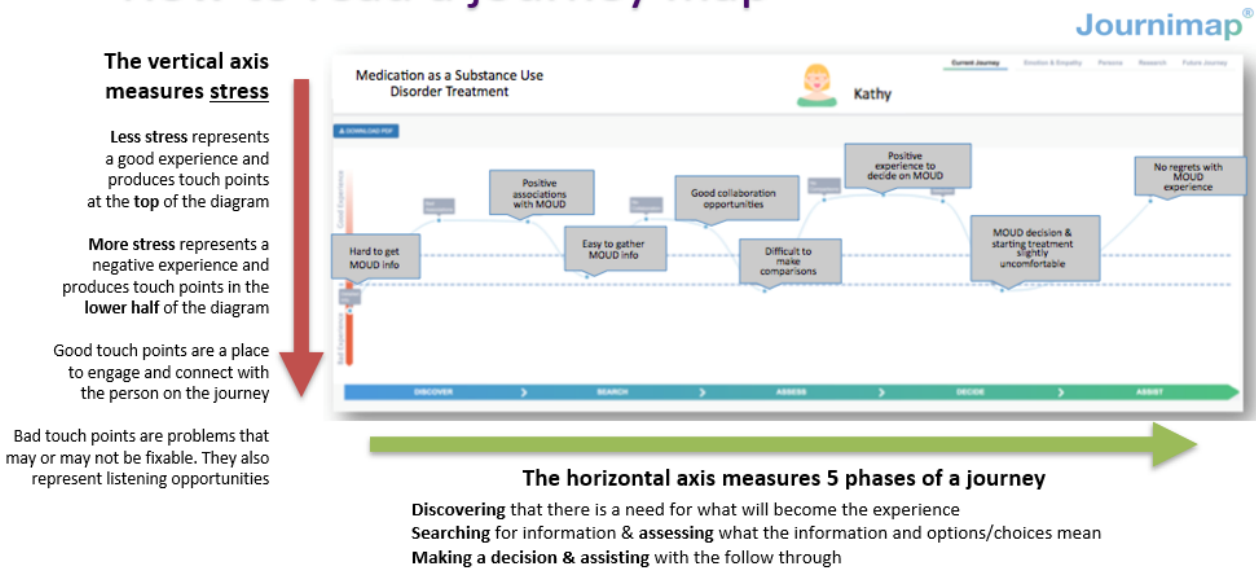


Figure 1: Individual Journey Map for MOUD

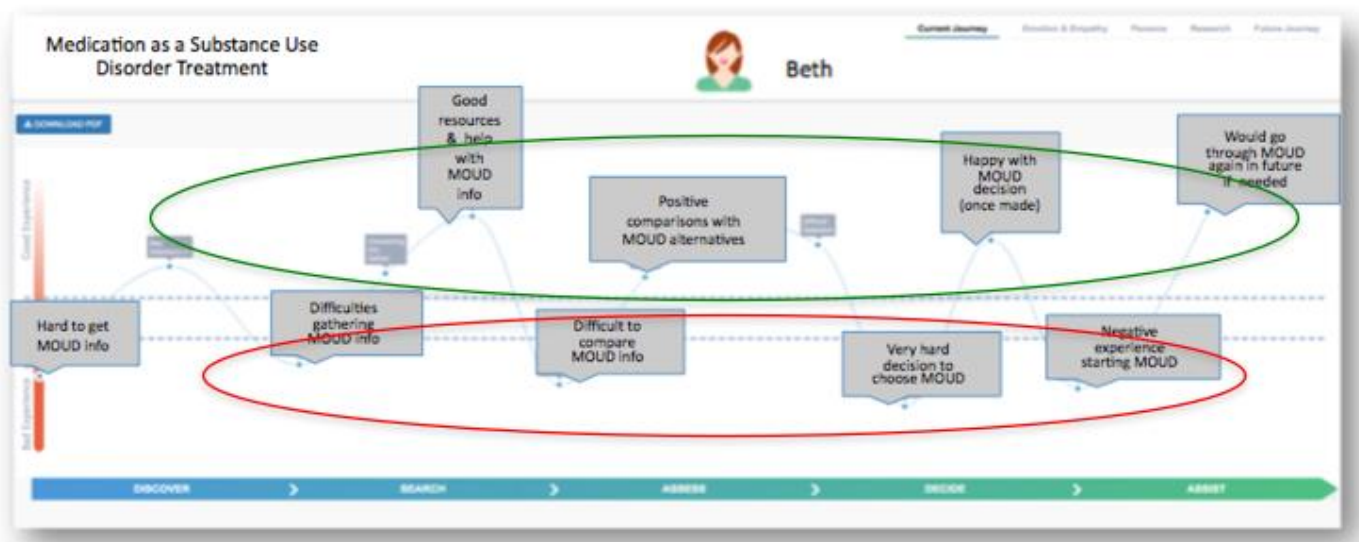


Figure 2: Journey Map of Non-prescribing Clinician for MOUD

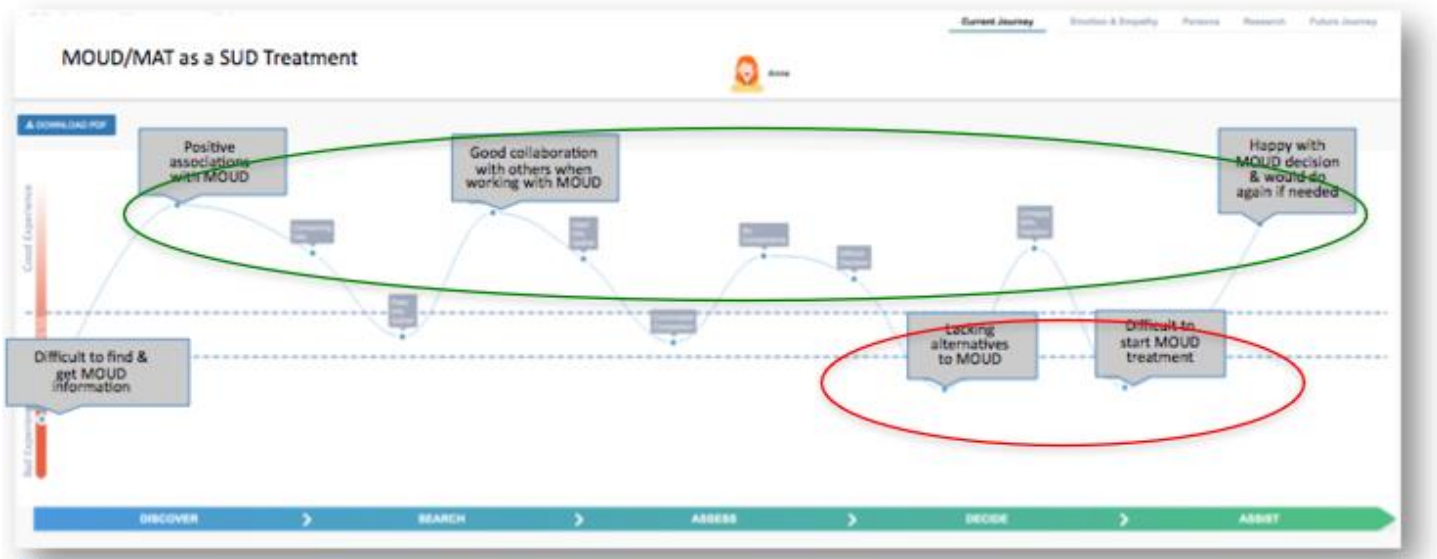


Figure 3: Journey Map of Prescribing Clinician for MOUD

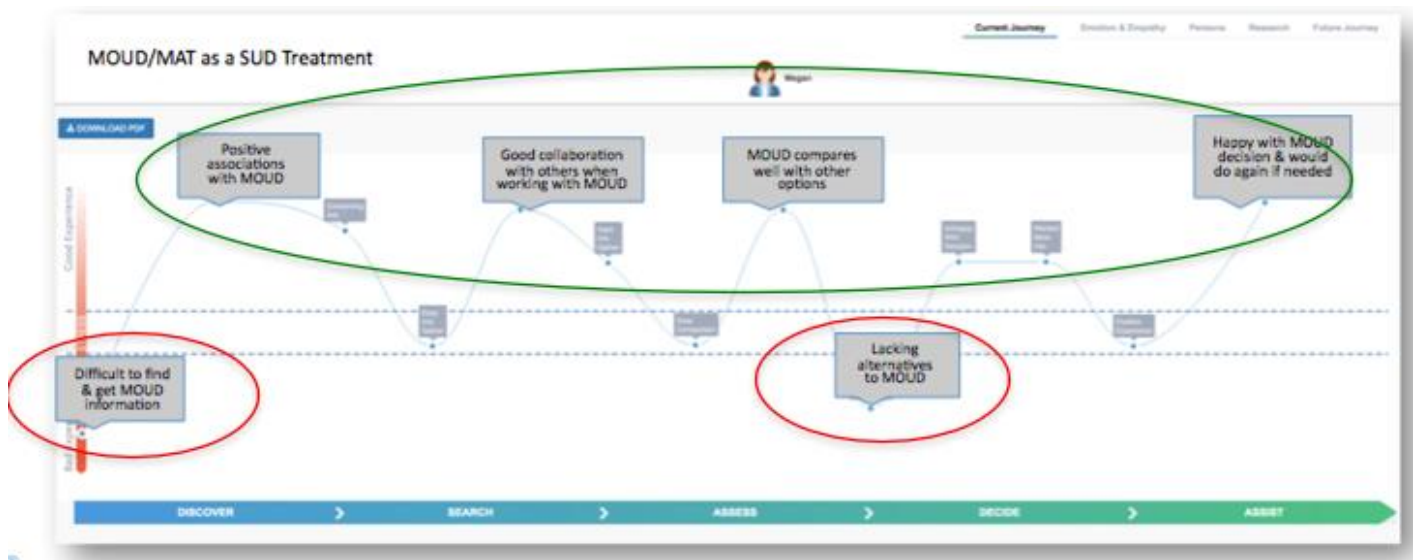


Figure 4: Journey Map of Pharmacists for MOUD

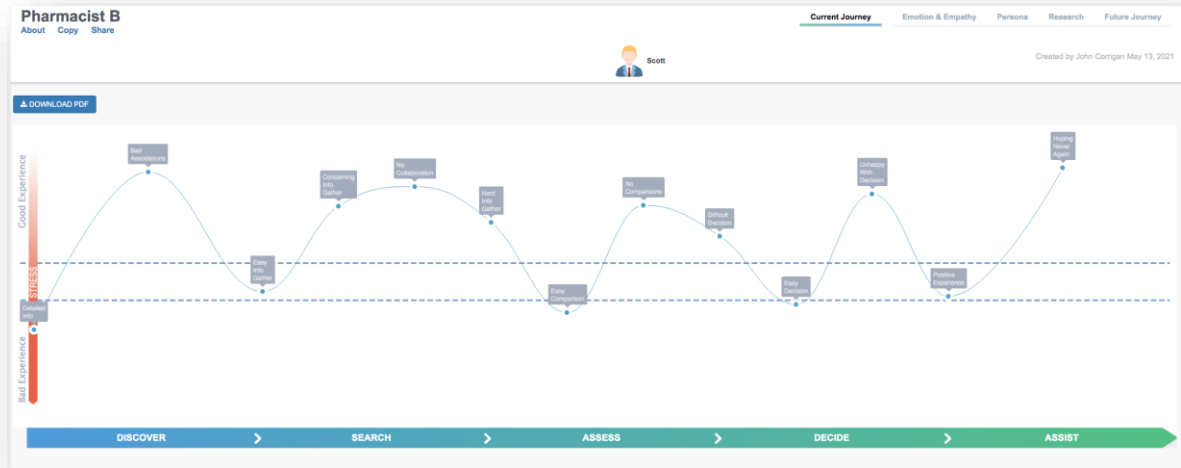


Figure 5: Trajectory of Treatment Journey Map (Individuals)

