STAKEHOLDER ENGAGEMENT METHODOLOGY REPORT

Engaging Stakeholders in Patient-Centered Comparative Effectiveness Research on Substance Use Disorder Treatment

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ABSTRACT
Through a Patient Centered Outcomes Research Institute-funded Engagement Award effort (1070-UCLA), the University of California, Los Angeles’ Integrated Substance Abuse Programs initiated and facilitated the Stakeholders’ Substance Use Research and Treatment Information Exchange (SSURTIE). SSURTIE brought together a wide array of stakeholders in Los Angeles County who are not traditionally at the same table in conversations about opioid use disorders, their treatment, and research. Individuals with opioid use disorders, family members of those individuals, different types of providers, researchers, and policymakers all engaged in a process of sharing knowledge and perspectives on treatment services and created fresh insights and perspectives on how these services can become more patient-centered. After two years and thirteen meetings the group established a working patient-centered research agenda for opioid use disorder treatment and developed capacity to create highly competitive scientific research proposals. The collaborative infrastructure developed in the project proved to be feasible and effective, can be expanded to other types of substance use disorders (those involving alcohol, stimulants, etc.), and can be implemented in other communities. In this report we outline the process used to achieve meaningful stakeholder engagement in SSURTIE and discuss the highlights, pitfalls, and lessons learned for other groups also interested in initiating and sustaining stakeholder engagement processes focused on substance use disorders.
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In memory of our friend and colleague Morris Mesler, M.D.
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INTRODUCTION

Though billions of dollars are spent on medical research each year in the United States, patients, providers, and policymakers often lack the information they need to make decisions about health care. Comparative effectiveness research—research that compares the relative benefits and harms of interventions and treatments—holds promise as a way to make sure that studies create answers to questions that are of concern to the people who receive and deliver health care. When conducting comparative effectiveness research, engagement of stakeholders—individuals, organizations, and communities that have a direct interest in health care decisions—is critical to ensure that research questions are relevant to the real-world decisions that patients, family members, and providers face. Stakeholder engagement is also valuable since it can help researchers identify outcomes that matter to patients and design studies to test how effective interventions are at achieving these outcomes. Consequently, funding agencies and researchers have become increasingly interested in developing methods to engage stakeholders in comparative effectiveness research in recent years.

One medical specialty that could particularly benefit from comparative effectiveness research is the treatment of substance use disorders involving alcohol, cannabis, opiates/opioids, cocaine, methamphetamines, and other drugs. Substance use disorders are chronic, relapsing brain diseases that are characterized by compulsive substance use in spite of harmful consequences. Though the treatment of substance use disorders can be difficult, evidence shows that like other chronic conditions, they

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can be controlled with appropriate monitoring, behavior modification, and evidence-based treatment. Yet there is currently a dearth of evidence to inform decisions that patients, their family members, providers, and payers need to make about substance use disorder treatment. Because substance use disorders have traditionally been treated as vices or moral problems rather than diseases in the United States, there has historically been little concern about treatment choice; providers and medical systems have utilized a “one size fits all” treatment approach for substance use disorders with little regard for patient preferences or needs.

There have been significant advances in substance use disorder treatment knowledge in recent years, and numerous evidence-based behavioral and pharmacological treatment options now exist to treat substance use disorders. Furthermore, attitudes and policies concerning substance use have evolved, and substance use disorders are increasingly treated within medical systems where patients, family members, and providers can collaboratively decide on treatment choices. As the available menu of substance use disorder treatment options grows, it will become essential for patients, family members, and providers to have knowledge about the comparative effectiveness of different interventions. However, to date there has been little comparative effectiveness research on substance use disorder treatment, and most of the comparative effectiveness studies that have been published have not been informed by input from patients and other key stakeholders.

To help address this knowledge gap, researchers from the University of California, Los Angeles’ Integrated Substance Abuse Programs (UCLA-ISAP) convened the Stakeholders’ Substance Use Research and Treatment Information Exchange (SSURTIE) from March 2015 through February 2017. SSURTIE was supported by a Patient Centered Outcomes Research Institute’s (PCORI) Eugene Washington Engagement Award (1070-UCLA). The focus of SSURTIE was the treatment of

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The experience of SSURTIE yielded valuable lessons about how to engage patients, family members, providers, and other stakeholders.

The purpose of this methodology report is to outline the process used to create SSURTIE and share lessons learned as UCLA-ISAP established and developed the group over a two-year period. The experience of SSURTIE was somewhat specific in that it focused on substance use disorders related to one substance (opiates/opioids) and it only included stakeholders living in one metropolitan area (Los Angeles). Nonetheless, the experience of SSURTIE yielded valuable lessons about how to engage patients and other stakeholders in comparative effectiveness research focused on issues concerning substance use. In documenting the experience of SSURTIE, this methodology report is designed to serve as a guide that researchers across the United States can use to create their own stakeholder groups for whichever substance use disorders (opioid use disorders, methamphetamine use disorder, cannabis use disorder, alcohol use disorder, etc.) are most pressing in their communities. Each geographic area and psychoactive substance will have distinctive characteristics that may require adjustments to the steps presented. This guide is designed to be instructive by delineating the process of creating and maintaining an engaged and diverse stakeholder group focused on issues related to substance use and highlighting special considerations related to substance use disorder-focused comparative effectiveness research stakeholder processes. To enhance the utility of the report UCLA-ISAP also recommends doing some things that SSURTIE did not do that in hindsight would have likely enhanced the group and its activities.

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Organization of the Report

The first section of the methodology report provides an overview of challenges specific to substance use disorders that warrant particular consideration during stakeholder engagement. We define four characteristics of substance use disorders and their treatment that make stakeholder engagement for these disorders different from that of other health conditions: 1) the impacts that substance use disorders have on behavior, 2) the treatment of substance use disorders as criminal problems, 3) stigma against substance use disorders, and 4) the divergent beliefs about treatment and recovery.

The second, third, and fourth sections provide a step-by-step overview of the process used to convene and facilitate stakeholders in substance use disorder comparative effectiveness research, with consideration of how issues specific to substance use disorders and related treatment may color both the content and structure of group activities. We identify thirteen steps to walk through the key components of laying group foundations, implementing the engagement process, and utilizing engagement to develop new research:

Laying the Foundations:

- Step One: Developing the Project Team
- Step Two: Ensuring Confidentiality and Institutional Approval
- Step Three: Identifying and Engaging Stakeholders
- Step Four: Establishing Meeting Logistics
- Step Five: Establishing a Community Advisory Board

The Engagement Process:

- Step Six: Setting the Ground Rules
- Step Seven: Building Mutual Respect and Trust
- Step Eight: Sharing Questions, Answers, and Opinions
- Step Nine: Identifying Themes
- Step Ten: Subgroup Discussions
- Step Eleven: Creating a Research Agenda

Taking Engagement to Research:

- Step Twelve: Identifying and Pursuing Research Opportunities
- Step Thirteen: Moving Beyond Just Research

The final section concludes with a summary of lessons learned from the SSURTIE process and issues that other groups interested in comparative effectiveness research focused on substance use disorders may want to consider as they begin their stakeholder process.
SECTION 1: SPECIAL CONSIDERATIONS FOR SUBSTANCE USE DISORDER TREATMENT STAKEHOLDER ENGAGEMENT

The process of engaging stakeholders in comparative effectiveness research for substance use disorders utilizes many of the same principles, steps, and concepts that are used for other health conditions.9 However, there are characteristics of substance use disorders that necessitate adjustment to ordinary engagement strategies. In particular, the impacts of substance use disorders on behavior, the treatment of substance use disorders as criminal problems, stigma against those who use substances, and contested views about evidence-based treatment for substance use disorders distinguish them from other health conditions and demand special consideration by stakeholder engagement facilitators.

The Impact of Substance Use Disorders on Behavior
While most health conditions are associated with some changes in behavior, temperament, and mood, substance use disorders have a particularly strong impact in these areas. Substance use disorders are chronic brain diseases rooted in alterations that prolonged and regular use of psychoactive substances can cause in the brain. Consequently, many of the most profound symptoms of substance use disorders are manifested as changes in behavior and the ways in which individuals with substance use disorders interact with others. Substance use disorders dramatically impact decision-making and lead to impulsive behavior and actions that may jeopardize individuals' personal and professional relationships. Individuals with substance use disorders often become emotionally distant, causing suffering for not only the patient but also their friends and loved ones. Thus the physical and cognitive consequences of substance use are frequently accompanied by increased isolation. Furthermore, unlike most other health conditions, denial is a hallmark of a substance use disorder — many who require treatment do not acknowledge that their substance use behaviors are problematic. The tremendous impact that substance use has on behavior and relationships differentiates these disorders from other health conditions and needs to be considered when planning and implementing substance use disorder stakeholder engagement activities.

9 Deverka et al., 2012; Hoffman et al., 2010; Mullins et al., 2012; Concannon et al., 2012.
Substance Use Disorders are usually Treated as Criminal Problems, not Medical Ones

Though attitudes and policies concerning substance use are beginning to change, drug laws still prohibit the non-medical use of most psychoactive substances. Individuals with a substance use disorder are at risk for arrest either because they are caught in possession of controlled substances or because they are involved in other illegal activities (e.g. stealing, drug dealing) to get money for drugs. Furthermore, erratic behavior and poor decision-making associated with the use of alcohol and drugs increases the risk that individuals with a substance use disorder will become involved with the criminal justice system. Consequently, in addition to dealing with the medical and psychiatric issues associated with substance use, individuals with substance use disorders also often have to tackle significant legal, economic, and social challenges.10

Conversely, most individuals with substance use disorders do not receive treatment; under twelve percent access care in specialty substance use disorder treatment programs.11 Given that many individuals with substance use disorders are accustomed to having their conditions being handled as criminal matters rather than medical issues, stakeholder group facilitators need to take extra care to make their engagement processes warm and welcoming. Moreover, engagement meetings need to be safe places where individuals with substance use disorders do not feel judged or persecuted.

Stigma

The stigma associated with substance use also needs to be accounted for when engaging substance use disorder stakeholders. In spite of scientific evidence indicating that substance use disorders are chronic diseases that impair the ability to control use, many still believe that substance use disorders are moral problems and that substance users can stop using if they simply choose to. Stigmatizing beliefs that individuals with substance use disorders are responsible for their illnesses and generally untrustworthy remain prevalent and contribute to the poor and disrespectful treatment they receive in educational, professional, and social settings. Even health professionals harbor stigmatizing attitudes towards individuals with substance use disorders, believing they are not trustworthy or that they have ulterior motives for seeking care (like seeking psychoactive medications to abuse). These attitudes can exacerbate the tendency of individuals with substance use disorders to become isolated, mistrustful, and accustomed to being mistreated. Consequently, it is particularly important for stakeholder engagement facilitators to create warm and supportive environments and to ensure that group participants remain respectful of all stakeholders—particularly individuals with substance use disorders.

Divergent Beliefs about Treatment and Recovery
The substance use disorder treatment field differs from other medical subspecialties in the strength and ardency of different beliefs about treatment and recovery. Because of stigma, insurance barriers, and legal restrictions, professional substance use disorder treatment has always been difficult to access; many individuals with substance use disorders have received treatment and achieved recovery through mutual support and twelve-step groups such as Alcoholics Anonymous and Narcotics Anonymous. Many of these programs have traditionally viewed treatment and recovery as predominantly spiritual processes and have been distrustful of outside medical expertise, evidence-based behavioral treatments, and pharmacological interventions. In particular, opposition to the use of medications remains strong in many self-help programs. It is likely that when convening a group that includes substance use disorder patients and treatment providers there will be a mix of individuals with opposing opinions about evidence-based treatment, and substance use disorder medications in particular. It is critical that group facilitators be familiar with these issues and prepared to create a space that fosters dialogue among stakeholders with divergent beliefs about treatment while also ensuring that differences in opinion do not become overly divisive or distract from group activities.

SECTION 2: LAYING THE FOUNDATIONS

For a research stakeholder group to succeed it needs to have an array of individuals with different experiences—as patients, as family members, as providers, as researchers, as policymakers/payers—collaborate. Having a variety of perspectives—particularly those of patients and family members—at the table during stakeholder engagement is particularly important since substance use disorders can so profoundly impact patients’ interpersonal and social relationships and because individuals with substance use disorders have historically had their perspectives and preferences discounted due to stigma. The five foundational steps described in this section—developing a diverse project team, ensuring confidentiality and institutional approval, identifying and engaging a robust and representative stakeholder group, establishing logistics for well-planned meetings, and establishing a Community Advisory Board—are essential preconditions for fruitful substance use disorder stakeholder engagement.

Step One: Developing the Project Team
It is recommended that the project team consist of at least two members—one group facilitator and one coordinator/administrator. Beyond these two individuals the project team can be of different sizes or compositions, but it is essential for project teams to include individuals with the knowledge, experience, expertise, professional and personal connections, and skill sets needed to help build and sustain a productive stakeholder group. Based upon experience conducting SSURTIE it is recommended that the project team have individuals with the following knowledge, skills, and attributes:

- **Group Facilitator:** One member of the project team needs to play the role of group facilitator. This individual needs to have strong reflective listening and moderation skills that can be used to guide the flow of conversation and ensure that all participants’ perspectives are heard and considered by the entire group. Making certain that patients’ voices are heard and respected is particularly important in substance use disorder stakeholder groups because patients may have past experiences when their opinions or perspectives were dismissed because of stigma. It is also beneficial to have a group facilitator with strong qualitative skills that can be used to quickly identify common themes in various stakeholders’ perspectives and leverage these areas of
common concern to advance group discussions and activities. Most importantly, the group facilitator needs to be adept at fostering an environment where all stakeholders are considered experts with valuable and valid opinions regardless of their formal training and/or personal experience. Establishing an atmosphere of mutual respect and learning among stakeholders with disparate sets of experiences, attitudes, and opinions is the most important job of the group facilitator. Between group facilitation activities, analysis of group discussions, and meeting preparation activities, it is recommended that the group facilitator dedicate 25% of their time to establishing and facilitating the stakeholder process.

- **Coordination/Administrative Support**: Identifying and engaging stakeholders is a labor- and information-intensive process that requires significant coordination and administrative support. A coordinator or project director with strong organizational skills is essential to handle logistics, and this individual should also have strong interpersonal skills to effectively and efficiently communicate with a diverse array of stakeholders. In addition, stakeholder meetings require significant administrative support to arrange transportation/parking, prepare meeting rooms, arrange refreshments, document meeting minutes, and complete other tasks. The time needed to oversee the administration and coordination of group activities vacillates, with the periods just prior to and after each meeting requiring the greatest effort. It is recommended that the coordination/administrative lead for the substance use disorder comparative effectiveness research stakeholder process devote 65% of their time to organizing the group and overseeing project activities.

- **Other Team Members**: Aside from the Group Facilitator and Coordinator/Administrative Support Staff, it is recommended that the project team include individuals with the following knowledge, skills, and attributes to initiate and implement substance use disorder research stakeholder processes:
o Scientific expertise: It is recommended that at least one member of the project team has extensive academic and scientific knowledge about substance use disorders and their treatment. This knowledge can be used to address questions or confusion that group members may have about scientific issues related to substance use and to provide perspective on common misconceptions that group members may have about substance use disorders and their treatment. While scientific expertise is helpful for any research stakeholder process, it is particularly important for a substance use disorder stakeholder group because of how common mistrust of scientific evidence and professional expertise are in substance use disorder treatment and recovery circles.

o Policy and Insurance expertise: A major issue that emerges in discussions about substance use disorder treatment is the problem of health care policies and insurance restrictions leading to suboptimal care. Given the ubiquity of these challenges it is helpful for project teams to include at least one individual with expertise on policy and insurance issues; their perspectives can help inform discussions about policy and insurance and educate stakeholders about what is feasible and what is not possible within the confines of the current health care policy and insurance environments.

o Provider expertise: At least one member of the project team should have experience working as a provider treating substance use disorders. Having project team members with real-life experience treating numerous patients with substance use disorders will allow the project team to contribute to group discussions by sharing experiences and perspectives gleaned from working with a broad range of patients. Furthermore, by discussing their experiences working with patients, members of the research team with clinical expertise can demonstrate a nuanced understanding of the dilemmas and challenges that patients with substance use disorders face, thereby overcoming some of the mistrust some stakeholders may have of treatment professionals.

o Lived experience with substance use disorders: Any project team facilitating a stakeholder process for research regarding substance use disorders would ideally include at least one individual who has had a substance use disorder in the past. These individuals’ input can anchor the group activities in the patient experience while also demonstrating that patient perspectives and values are respected. This is particularly important in substance use disorder stakeholder groups given the importance of self-help and mutual support in facilitating recovery for
many substance use disorder patients and the experiences of stigma, marginalization, and disempowerment that many substance use disorder patients may have had in the past.

- Lived experience as a family member of someone with a substance use disorder: Family dynamics are highly impacted by substance use disorders, and family members often play a key role in both getting their loved ones into treatment and supporting their recovery. Thus input from individuals who have had family members experience substance use disorders can be critical for the project team.

Step Two: Ensuring Confidentiality and Institutional Approval
In a stakeholder process focused on sensitive issues like substance use, it is critical that group conversations and activities remain confidential. Though some stakeholders have no problem self-identifying as people with substance use disorders or as family members of people with these conditions, the project team needs to create an environment where potential participants who are more concerned with privacy feel safe self-disclosing and discussing their experiences. At the outset of the stakeholder process, the project team will need to lay out rules and procedures to protect the privacy of individual stakeholders and the content of group meetings. Keeping project records in secure locations or on password-protected/encrypted computers can help prevent the inadvertent sharing of sensitive materials with people outside of the project team. Similarly, developing protocols where all stakeholders agree to not share information about group participants or discussions outside of stakeholder meetings can help promote confidentiality and address the concerns of participants who want to safeguard their privacy. Most major health care and research organizations have Institutional Review Boards (IRBs) that review procedures to ensure confidentiality and appropriate protection of project participants’ interests. All institutions have different rules, definitions, and criteria concerning protection of project participants, and different procedures for determining if IRBs need to provide approval before beginning project activities. Before engaging stakeholders and beginning other project activities, it is essential to create policies and procedures to protect the interests of project participants and to acquire whatever institutional approvals are necessary to proceed with the engagement process.

Step Three: Identifying and Engaging Stakeholders
Once the project team is assembled the next task is to engage substance use disorder stakeholders – individuals, organizations, or communities that have a direct interest
in comparative effectiveness research outcomes – in the group. To incorporate a full range of perspectives on substance use disorder treatment and how research can help improve it, it is critical to ensure that the stakeholder group includes patients, family members, service providers, researchers, and policymakers/payers (e.g. individuals who represent insurance companies or health departments that often pay for substance use disorder treatment). Flyers, brochures, personal letters/emails, websites, and social media can be used to promote the creation of the stakeholder group and recruit prospective participants. Contact information for the project coordinator/administrator need to be included in these materials, and people interested in the study should be instructed to contact the project coordinator/administrator by telephone or email to participate in the group.

In recruitment and promotional materials, it is essential to emphasize that the stakeholder group is not simply a “focus group,” and that it is designed to facilitate an innovative form of research that brings stakeholders with different perspectives (as patients, family members, providers, etc.) together to collaboratively advance research on how to improve substance use disorder care. Emphasizing the fact that individuals other than the “usual suspects” involved in research will be participating and that all stakeholders’ input will be considered equally can help improve the appeal of the group, particularly for patients who have had their perspectives and preferences dismissed because of stigma, and for family members who have had difficulty helping their loved ones access quality substance use disorder care.

In developing materials promoting the group it can be helpful to tailor messages about what the group can accomplish so that they are of particular interest to different types of stakeholders. For example, in communications for patients and family members, recruitment materials can emphasize how the project will generate knowledge that will help make care more responsive to patient needs and more effective at facilitating recovery. In communications for treatment providers, they can focus on how the group’s work will develop knowledge that can be used to improve care. Materials for policymakers and payers can emphasize how lessons learned from substance use disorder comparative effectiveness research can improve the quality of care and make it more cost effective.
Once recruitment messages and materials are created there are several strategies that can be used to recruit substance use disorder stakeholders:

- **Self-help/mutual support groups:** One effective way to identify and recruit stakeholders with substance use disorders is to advertise the group through flyers and brochures distributed or posted at local self-help/mutual support groups such as Alcoholics Anonymous or Narcotics Anonymous. In addition, advertising the stakeholder group at support groups for family members of individuals with substance use disorders—groups such as Al-Anon and Nar-Anon—can help facilitate family member engagement in stakeholder activities.

- **Treatment programs:** Another effective way to recruit both patients and providers is to post flyers at local substance use disorder treatment programs. Rates of substance use are particularly high among patients who suffer from chronic pain and individuals who have mental health disorders, so recruiting at pain clinics and mental health programs may also be effective.

- **Advocacy Organizations:** In some communities there are advocacy organizations devoted to spreading awareness of substance use disorders or advocating for more effective public policies to address them. This is particularly the case for opiates/opioids which have become highly problematic in many communities across the United States in recent years. The individuals involved in advocacy around substance use disorder-related issues are likely to be interested in comparative effectiveness research focused on how to improve substance use disorder treatment.

- **Online:** SSURTIE participants reported that online forums such as Internet discussion boards and social media websites (e.g. Facebook) could also help recruit individuals with substance use disorders and their family members. Due to the stigma often associated with substance use disorders many individuals and their family members do not seek in-person help and instead go to online communities for support and information. Identifying these online forums and publicizing the creation of the stakeholder group in these digital venues can be an effective way to engage otherwise hard-to-reach individuals with substance use disorders and their family members.
• **Social Service Programs:** Since many individuals with substance use disorders encounter significant legal, social, and economic challenges, agencies and organizations that provide social services can be good places to recruit patients who are actively using substances or are in recovery. In group discussions, SSURTIE members suggested that a diverse array of programs, such as those that provide economic assistance for the needy, housing agencies, gang prevention programs, probation departments, criminal justice re-entry programs, and other places that serve high-needs populations could be good places to recruit potential stakeholders with lived experience.

• **Public Spaces:** Because of stigma, many individuals who suffer from substance use disorders, have lived experience with substance use disorders, or have family members with substance use disorders may be reluctant to attend groups or settings that focus on them. Consequently, it is important for recruitment efforts to occur in locations where individuals with substance use disorders or their family members may go, but that are not necessarily substance use disorder-focused. These places could include doctors’ offices, community centers, schools/universities, houses of worship, and other spaces where community members regularly congregate.

• **Personal Connections:** Though recruitment through community-based programs and organizations can be effective, the experiences in SSURTIE demonstrated that the most efficient way to spark interest in the stakeholder process was through personal connections of project team members. This is particularly the case for policymakers and payers, who can be difficult to recruit using other methods. Project team members who are substance use disorder experts and providers may have established working connections with other individuals who are dedicated to improving substance use disorder services and who may be able to leverage their connections to recruit other interested professionals. Treatment professionals can also recruit current and former patients and their family members. Project team members who are patients with lived experience with substance use disorders can serve as invaluable entrees into networks of substance use disorder patients either through their social circles or their involvement in self-help and mutual support groups. Individuals recruited via other methods described above can share information about the stakeholder group with other community members they know through word of mouth, thus creating a “snowball effect” that enhances recruitment efforts. Given that substance use disorders are such highly stigmatized conditions and that many patients and family members are unwilling to self-disclose, it is particularly critical to utilize the personal
connections of project team members and individuals who have successfully been recruited to develop a robust substance use disorder stakeholder group.

Once individuals express interest in participating in the group, the project coordinator/administrator can send formal invitation letters or emails to prospective participants. If they do not have reliable email or a home address (e.g. if they are transient or homeless), the project coordinator/administrator can communicate about group meetings by telephone, text message, or in person visits to treatment programs, shelters, or other places where they can be reached. These communications should: (1) describe the purpose of the project, emphasizing that its goal is to create knowledge that will be of interest to real-world patients, family members, providers, and policymakers/payers; (2) provide contact information for members of the project team if prospective participants have any questions; (3) include information about any financial compensation that will be provided for participants; (4) request that participants communicate which days of the week and times work best for them to attend stakeholder meetings; and (5) request information about dietary restrictions or other special accommodations that stakeholder group participants may need.

Overall, the project should strive to recruit at least three stakeholders from each group (patient, family member, provider, researcher, policymaker/payer) if possible.

**Step Four: Establishing Meeting Logistics**

After finalizing the list of stakeholders, the project coordinator/administrator can lead the process of choosing a meeting location and time that is convenient for as many participants as possible. Ideally, meetings should be at a location that is roughly equidistant for all participants, accessible via public transportation, scheduled for times of day when they do not interfere with stakeholders’ work or family schedules, and occur when traffic and parking will not be difficult.

Conference rooms are ideal locations for stakeholder meetings, since they generally have layouts that accommodate large groups in configurations that are conducive to conversation and interaction. If possible, objects such as tables, podiums, and speaking platforms should be removed from the room, both because they can impede communication by blocking visual cues, and because they may inadvertently communicate that certain individuals are “leading” the group instead of having a completely egalitarian group discussion.

In addition to the project team, extra staff should be present at meetings to help set up food and refreshments, assist with parking, sign people in, disburse reimbursements, and assist with other logistics as needed. In addition, all meetings should be recorded and transcribed since an accurate and detailed record of group proceedings is needed to inform the development of stakeholder group ideas, priorities, and activities.
Step Five: Establishing a Community Advisory Board

In the process of recruiting stakeholders the project team can begin identifying particularly enthusiastic participants to serve as members of a Community Advisory Board. The work of the Community Advisory Board is to guide the development of project activities, and serve as a sounding board for the project team as it makes decisions about meeting and research activities. To ensure that the Community Advisory Board has perspectives from a representative group of stakeholders, it is ideal for its members to include at least one patient, one family member, one provider, one researcher, one policymaker, and one payer from the general stakeholder group. Ideally, the Community Advisory Board could convene once every month or two, either in person, by phone, or through an online meeting platform.
SECTION 3: THE ENGAGEMENT PROCESS

Once the stakeholder group has been established, the work of stakeholder engagement—the process of actively exploring the knowledge, experience, judgment, and values of group participants—can begin. Though the ultimate product of comparative effectiveness research stakeholder engagement is research ideas and project proposals, a significant amount of time and effort needs to be spent establishing a trusting relationship among stakeholders and identifying areas of interest to the group. The steps described in this section—setting ground rules, discussing treatment experiences, sharing questions, answers, and opinions, theme identification, subgroup discussions, and creation of a research agenda—can be used to create a sense of mutual trust and cohesion among stakeholders while also elucidating the issues that are of greatest interest to the stakeholder group.

Step Six: Setting the Ground Rules

Beginning with the initial meeting it is important to foster trust and emphasize the importance of mutual collaboration and respect among stakeholders and project team members. To ensure that all stakeholders understand and support this vision, the initial stakeholder meeting needs to include a clear presentation of the group’s purpose and ground rules for discussion. These could include the following:
- Emphasizing that the group values the perspectives and input of all members equally, and that no member’s opinion will be considered to be of greater or lesser validity because of their background, personal education, or history.

- Communicating that group members cannot interrupt each other or talk over each other during group discussions.

- Highlighting that group members can “agree to disagree” if they choose to. This is particularly important to emphasize in a substance use disorder stakeholder group given how common it is for group members divergent experiences and opinions about treatment.

- Stating that if any group members feel that their views are being marginalized or discounted they should inform the project team and the group facilitator will make extra effort to ensure that all participants’ viewpoints receive appropriate consideration.

- Encouraging participants to come to the project team privately if they have any issues that concern them about the stakeholder process or group conversations that they do not want to share in the group setting.

**Step Seven: Building Mutual Respect and Trust**

Establishing a group dynamic where stakeholders respect and trust each other is essential, particularly for substance use disorder stakeholder engagement since many group members will have histories of troubled relationships, social marginalization, and isolation as a result of their substance use disorder. The group’s initial meeting(s) should be dedicated to creating an environment that fosters mutual self-disclosure while also providing opportunities for participants to enjoy themselves and learn from others. Activities that can help facilitate this process can include ice-breakers and team-building exercises that create positive and enjoyable interactions between stakeholders from different backgrounds. In addition, initial meetings should include opportunities for every group member to share their personal stories about substance use disorders—what their experience with substance use disorders is, how substance use disorders have impacted their life, and questions they have about substance use disorders and their treatment—that the group may want to explore in its research activities.
Step Eight: Sharing Questions, Answers, and Opinions

Once the group has established a trusting relationship the group facilitator should steer discussions toward systematically exploring the stakeholders’ most pressing questions about substance use disorders and substance use disorder treatment. Some stakeholder questions may be simple points of fact that can be answered with brief explanations, while others may be more philosophical or require more detailed exploration. Given that group members will have varying levels of formal education and expertise, some of the questions and answers may seem simple to trained professionals in the group; consequently, it may be necessary to communicate that given every group member’s different experience, the group may need to review information or concepts that some stakeholders already know well. It is important to minimize the use of substance use disorder jargon and acronyms in order to ensure that all stakeholders are able to understand and easily follow group conversations. Displaying data or statistics in visual form or through use of laymen’s terms can help minimize confusion.

During this process, there is potential for asymmetrical dynamics to develop, with patients and family members asking questions and the formally trained experts in the group providing answers. If this occurs, the group facilitator should make efforts to also bring up questions and topics that can be informed by the experiences of patients and family members, but not the more formally trained professionals in the room (e.g. How does substance use disorder affect family relationships? What makes people with substance use disorder decide to enter treatment?). In the event that questions emerge that no group members can answer during group discussions, the group facilitator might invite an outside expert to join a meeting and educate the group.

The group facilitator can help highlight issues that emerge as areas of interest during question and answer discussions or lead more structured brainstorming sessions designed to draw out group opinions on areas where treatment can be improved or there are unanswered questions. In SSURTIE, for example, the group facilitator did this by organizing treatment into three phases—pre-treatment (deciding to seek substance use disorder care, finding a substance use disorder treatment program), treatment (actually receiving substance use disorder services), and aftercare (issues related to achieving and sustaining recovery)—and leading more focused discussions.
of each phase in a group meeting. Other ways to stimulate stakeholder opinions and perspectives could include discussing different types of treatment (self-help, medications, structured behavioral interventions), treatment outcomes (sobriety, physical health, mental health), or experiences in different types of programs (e.g. outpatient, residential).

**Step Nine: Identifying Themes**
To advance from general discussions of stakeholder perspectives to more focused questions that can be addressed in research, the project team will need to systematically define which themes and concepts were most prominent in initial group meetings. The group facilitator, in collaboration with other team members, can analyze transcripts from initial group meetings to determine which themes, concepts, or topics were of greatest concern during stakeholder discussions. Ideally analysis will yield a list of concerns or topics of interest that were of interest to individuals from each stakeholder group—patients, family members, providers, researchers, policymakers, and payers. Upon completion of this analysis the group facilitator can present findings to the Community Advisory Board, which can provide input to correct any misinterpretation of qualitative data and/or help refine definitions of major themes and issues that emerged from group discussions.

**Step Ten: Subgroup Discussions**
Subgroup meetings—meetings consisting exclusively of members of each stakeholder group (patients, providers, etc.)—can further elucidate stakeholder perspectives while also providing information that can be used to refine themes identified in previous group discussions. Subgroup discussions serve multiple purposes:

- First, they provide a smaller forum for group discussions, creating greater opportunity for individuals to voice their opinions, concerns, and perspectives that may not have been expressed in larger group meetings.

- Second, subgroup discussions provide opportunities for participants to say things that they fear may offend other stakeholders within the larger group; for example, subgroups can serve as a space for family members to say things that they fear would offend substance use disorder patients, or for patients to speak more frankly about negative experiences they had in treatment. Given the contentious nature of disagreements about substance use disorder treatment and the pervasive stigma about substance use, it is particularly important to create a space to allow for stakeholders to voice potentially
controversial or unpopular viewpoints that they may not be comfortable sharing within the larger stakeholder group.

- Third, disagreements or issues that emerge during subgroup discussions can reveal ways that even within stakeholder groups there can be significant heterogeneity. In SSURTIE, for example, subgroup discussions highlighted significant rifts between the perspectives of psychiatrists and those of other treatment professionals (psychologists, social workers, and substance use disorder counselors). This information impacted the way in which the SSURTIE project team interpreted input from providers in the larger group meetings and led to the creation of a separate sub-group—one exclusively for treatment professionals other than psychiatrists—to allow these stakeholders to clearly articulate their perspectives. Another unanticipated divide that emerged during subgroup processes was within the patient stakeholder group, as patients in recovery and patients who were not in recovery had different perspectives and points of view on some topics. Taking this into account, SSURTIE convened a separate subgroup for patients who were not in recovery and created a separate space for them to articulate their perspectives on pertinent issues.

**Step Eleven: Creating a Research Agenda**

Subgroup discussions can reveal new issues of concern to group members that did not emerge in broader group discussion, provide data that contradicts assumptions the research team made in its original construction of group themes, or provide details...
that add nuance and depth to themes that had already been identified. Upon completion of subgroup discussions the project team can draft a preliminary research agenda—a list of research topics or areas that are of interest to the stakeholder group—that will guide the group as it pursues future research activities. Ideally, each item on the research agenda will be something that stakeholders in each subgroup endorsed or agreed should be a priority area for future activities.

To ensure that the research agenda is in line with stakeholder perspectives, the project team can initially present the agenda to the Community Advisory Board, and then to the entire stakeholder group, for discussion and revision. Once the project team modifies the research agenda to reflect all stakeholders’ perspectives the Community Advisory Board and stakeholders can provide final approval for the research agenda.
Once stakeholders are engaged and have endorsed a research agenda, the group will be ready to begin competing for research funding and carrying out studies. In fact, it will be essential to find a project for the group to pursue together, or else there is risk that group members may lose interest and disengage from the group. Consequently, identifying and pursuing research opportunities is critical, both to fulfill the aims of the stakeholder process and to ensure that the individuals engaged during the stakeholder process remain actively involved in group activities.

Step Twelve: Identifying and Pursuing Research Opportunities
After the research agenda is completed it is essential to maintain group momentum by identifying and pursuing opportunities for the stakeholder group to compete for—and secure—research funding. Without a project to collaborate on it will be difficult to keep stakeholders engaged in the group. Consequently, it is recommended that the project team find a research opportunity to pursue in collaboration with stakeholders at least once every three-to-six months.

Using the research agenda endorsed by the stakeholder group as a guide, the project team will need to find opportunities to secure funding that can be used to conduct research on questions of interest to the stakeholder group. PCORI, the National Institutes of Health, and private foundations often put out announcements of funding for research on issues related to substance use disorder treatment, and the project team will have responsibility for identifying opportunities that the stakeholder group could pursue. Ideally, research opportunities will cohere with stakeholder-identified research priorities. When the project team finds potential funding opportunities for the group it can contact stakeholders to inform them about the potential for a research application, briefly describe the proposed study, and set up a meeting (in person, telephone, or online) to collaboratively develop research ideas and begin developing an application. To avoid overburdening stakeholders the project team needs to clearly communicate that stakeholders are not required to participate in any project, and that their contributions for every project are welcome, but not required.

Unfortunately there is no guarantee that the research priorities identified by the stakeholder group will match those of research funding agencies, so the project team

“Substance use disorders are critical issues for our nation. The conversation must continue to evolve, and must expand to include as many people as possible”

Patient Stakeholder
and stakeholders may need to be amenable to pursuing opportunities that do not directly match their research agenda. For example, though the SSURTIE group identified several aspects of substance use disorder treatment to explore, there were no direct funding announcements for comparative effectiveness research on these issues during the project period. However, PCORI did issue a funding announcement (PFA) on an issue that had come up in several SSURTIE discussions: the inappropriate prescription of opioid medications for pain and the prevention of iatrogenic addiction. When the project team saw this PFA it reviewed notes from stakeholder meetings and saw that even though opioid prescribing for pain was not on the stakeholder group’s research agenda it was still an issue that had come up repeatedly in SSURTIE group discussions. Noting this overlap, the project team emailed SSURTIE stakeholders and convened a group of interested stakeholders who collaborated on the application to conduct a comparative effectiveness research trial concerning opioid prescribing for patients with pain.

**Step Thirteen: Moving Beyond Just Research**

Though the focus of stakeholder engagement activities is research, it is possible in the course of group discussions that stakeholders may develop ideas for activities they would like to pursue other than the development of studies. In SSURTIE, for example, several stakeholders reported that the opportunity to share and hear other peoples’ perspectives during the group discussions inspired them to become more engaged in issues surrounding substance use disorders, but not narrowly related to research. As one patient wrote on a survey soliciting their feedback contributing to SSURTIE, “I chose to get involved (in the group) because substance use disorders are critical issues for our nation. The conversation must continue to evolve, and must expand to include as many people as possible.”

Devising ways to galvanize the energy that the group developed in areas other than research emerged as a priority in SSURTIE. In particular, group members expressed interest in engaging in grass-roots advocacy to improve treatment, public education, stigma reduction, and mutual support activities for families impacted by the opioid epidemic. As one provider participant elaborated, to narrowly focus exclusively on research would be to miss a tremendous opportunity to have a positive impact at the community level. “This (process)” she explained, could be “so wonderful for different
small communities so that people actually get together and have conversations and can help each other make changes.”

Consequently, it may be beneficial for stakeholder groups to pursue other activities in addition to formal research activities. This can accomplish three interrelated goals critical to the continued engagement of a stakeholder group. First, as discussed above, though it may be difficult to find research opportunities that match up with stakeholder groups’ interests, it is essential to have a steady stream of activities to keep participants engaged in the group. By participating in advocacy, public awareness, and other community-level activities, stakeholder groups can maintain contact and engagement of members even when research opportunities are limited. Second, by pursuing non-research activities that are of interest to stakeholders, groups can take steps to ensure that it remains truly stakeholder-led, focused on addressing the interests and concerns of all participants, and not just group members who are research professionals. Third, by actively engaging in their communities, stakeholder groups can publicize the group to potential participants, thereby developing relationships with local policymakers, service providers, advocates, and patient groups who can be partners in future research activities.

“This (process could be) so wonderful for different small communities, so that people actually get together and have conversations and can help each other make changes.”

Provider Stakeholder
SECTION 5: LESSONS LEARNED

In the first two years of SSURTIE both the project team and stakeholders learned several key lessons about how to build and sustain a strong and engaged group of stakeholders focused on comparative effectiveness research related to substance use disorders. In this section we provide an overview of the major lessons learned that could benefit other groups as they engage stakeholders in patient-centered research on substance use disorders and their treatment. While several of these points are true for all health-related stakeholder engagement processes, the experience in SSURTIE showed that the following points are particularly critical when engaging stakeholders in substance use disorder research.

Lesson One: Have Face-To-Face Meetings
SSURTIE participants strongly agreed that having meetings face-to-face, and not exclusively relying on telephone calls or digital platforms such as Skype, was essential to the group’s success. Since substance use disorders are associated with high levels of stigma, patients and family members reported that they needed to have strong levels of personal connection and trust in other group members in order to participate in the group. As one patient stakeholder explained, “substance use disorders were, for decades, seen as dehumanizing things that are just barely barely barely getting a human face…so there has to be a human connection.” Consequently, it was critical to
establish a safe environment through meetings that were as emotionally intimate as possible, with individuals all talking to each other in the same room. Moreover, given the shame and emotional discomfort that some patients and family members had due to substance use, in-person rapport building was an essential step towards open engagement in conversations about their personal experiences and perspectives. Initial group discussions that focused on sharing personal experiences and building trust were essential to laying the groundwork for group activities, and stakeholders reported that in-person meetings were essential to creating group cohesion. As one provider stakeholder elaborated, “I think the rapport that’s been built (in this group) is immeasurable, and I don’t know that you can accomplish the same thing if you have everybody dial in at a certain time.”

Lesson Two: Virtual/Telephone Meetings Can Work for Selected Purposes

Though in-person meetings were essential for rapport-building and in-depth discussions, some SSURTIE activities were effectively carried out over the telephone. Generally, these were less in-depth conversations that focused on reviewing meeting plans and/or discussing specific project proposals. Participants reported that these meetings were helpful in minimizing the time burdens associated with group participation, particularly those related to dealing with rush hour traffic. Some group members suggested that having more telephone or virtual meetings (on digital platforms such as Skype) could have helped more stakeholders remain engaged in SSURTIE longer. In particular, greater use of these platforms could have been helpful in sustaining the participation of particularly hard-to-engage stakeholders such as payers and policymakers in group activities.

Lesson Three: Everyone Has Something To Learn.

Throughout SSURTIE discussions and surveys, participants continually emphasized that they were pleasantly surprised at how much they learned in group meetings. All participants considered themselves to be knowledgeable about opioid use disorders and treatment at the beginning of the project, but they reported that they nonetheless learned new information or perspectives as a result of their participation in the group. Having structured presentations by scientific experts on areas that emerged as “hot
topics” of interest to the group (such as the use of medication in opioid use disorder treatment) provided invaluable information for group participants and informed group members’ perspectives and thoughts as they discussed potential research ideas. More importantly, for individuals with higher levels of scientific training (e.g. researchers, providers), the stakeholder engagement process provided a unique opportunity to learn about opioid use disorders and treatment from the real-world perspectives of patients and families. As one provider summarized on a survey about stakeholder experiences in SSURTIE, the group provided a unique opportunity to both share professional knowledge and learn from the experiences of patients and families:

“We can really learn from the perspectives of others. The chance to have a voice in such a critical discussion was a very empowering experience. I felt like I was able to help other stakeholders gain a new perspective and expand their understanding of what the experience of suffering from substance use disorder is like for a patient. I also learned from other stakeholders enabling me to broaden my understanding of substance use disorders, and communicate more effectively about the issue.”

Lesson Four: Ensure All Voices Are Heard

In SSURTIE meetings, creating a space for all individuals to make their voices adequately heard was a challenge. In particular, it was difficult to prevent researchers and medical professionals in the group from giving what others in the group perceived to be “lectures” about their clinical or scientific perspectives. As one patient stakeholder wrote on a survey about SSURTIE, “it may have been helpful to confront the couple of very verbal and opinionated MDs and suggest they be more prudent when expressing their thoughts so that we could hear the thoughts of others.” Yet at the same time, other providers were cognizant of this problem, and felt that they did not have space to share their opinions since they wanted to create more space for patients to share their views. “There were a couple of occasions,” wrote one provider participant, “where I held back my views in deference to individuals identifying as addicts.” Consequently, it is critical for the group facilitator to ensure that discussion remains open with equal opportunities for all stakeholders to speak and contribute their perspectives to the group.

Lesson Five: Agree to Disagree on Controversial Issues

Though there are areas of disagreement in virtually all areas of medicine, the treatment of substance use disorders is especially contentious. In particular, the use of medications such as naltrexone and buprenorphine in substance use disorder treatment is controversial even though research shows that these treatments are highly effective. The proliferation of information and misinformation on the Internet has complicated these issues further as individuals may form opinions based on erroneous facts or conspiracy theories that they read online.
Yet as several group participants pointed out, there are also legitimate reasons to openly discuss the potential benefits and harms of treatments that researchers and providers currently consider the state of the art in substance use disorder treatment. As one psychiatrist in the group who regularly prescribes medication reminded the group:

“Don’t forget that we (the “experts”) are not always right. Today’s great treatment is tomorrow’s bane to man. Nobody knows for sure what the long-term implications of all the things that we’re giving people that were never indicated for long term use. No one has ever studied any of these drugs more than one year.”

Consequently, it is essential that throughout group activities the facilitator emphasizes the importance of letting participants “agree to disagree” on contentious issues such as medication. This can be difficult, particularly for researchers and treatment professionals who have dedicated their lives to the treatment of substance use disorders and consider themselves “experts.” To address these issues the group facilitator should remind all participants at the beginning of each meeting that the purpose of the group is not to change anybody’s mind or opinions on controversial issues, but rather to find common ground that can be used as bases for research activities. Emphasizing the importance of “agreeing to disagree” on contentious issues is critical to maintaining a positive environment in the group and keeping meetings constructive.

Lesson Six: Regularly Elicit Feedback and Make Adjustments Accordingly
Feedback from participants is essential for informing changes that the project team may need to make to ensure the success of the stakeholder project. For example, after one contentious SSURTIE meeting several group members informed the project team that they were dissatisfied with the tone of group discussion and said they were going to stop participating if changes were not made. In response, the project team elicited suggestions on how to improve group discussions, and made structural changes to group activities by creating sub-groups for different groups of providers and patients. Due to open lines of communication between stakeholders and the project team, SSURTIE was able to maintain the continued participation of these individuals while also improving the way in which group activities were organized.

On another occasion several stakeholders were offended by discussion of a controversial topic (the use of medication in opioid use disorder treatment). However, rather than sharing their concerns they simply stopped attending group meetings, and the project team only learned of their reasons for quitting the group through a secondhand source over a year later. If the project team had more actively elicited regular feedback from the group it could have taken steps to address these individuals’ concerns and keep them engaged in the stakeholder process.
Regular feedback from stakeholders, and the project team’s willingness to take action based on this feedback, is critical to ensuring the continued engagement of participants. It also provides invaluable information about how to improve group activities. In addition to encouraging participants to share their perspectives with the project team, surveys and telephone calls can be used to “check in” with participants and elicit feedback on the stakeholder engagement process.

Lesson Seven: Be Flexible with Stakeholder Activities
SSURTIE was funded particularly to develop a stakeholder group capable of conducting patient-centered comparative effectiveness research. However, at the time the group was engaged and ready to prepare project proposals there were no opportunities to conduct research in areas that were of the greatest interest to the group. Consequently, the group needed to be flexible and instead developed a proposal on a topic that was of tangential interest to the group (pain management) rather than areas that group members were more eager to pursue. As discussed above (Step 11), this type of flexibility is essential since the opportunities for research funding may not exactly match the stakeholder group’s main interests.

Furthermore, as discussed above (Step Thirteen) group members may want to pursue activities other than research, such as community advocacy, stigma reduction, and mutual support. Though these activities may fall outside of the purview of a stakeholder group focused on generating research knowledge, project teams should nonetheless encourage them since they are great ways to maintain stakeholder enthusiasm and conduct activities other than research that may be of special interest to group members.
CONCLUSION

Communities across the nation continue to grapple with the consequences of substance use disorders and the health care system is continually adapting new strategies to address the needs of the millions of Americans afflicted by these conditions. Further engagement of stakeholders with varying backgrounds and perspectives—as patients, as family members of patients, as providers, as researchers, as payers, and as policymakers—will be essential to informing the development of treatment research and policy, and ensuring that substance use disorder treatment is responsive to the real-world needs and preferences of patients and their families. Our hope is that the experience of SSURTIE can inform communities across the country, and provide them with useful guidance on how to engage stakeholders in efforts to collaboratively solve some of the most pressing challenges associated with substance use.