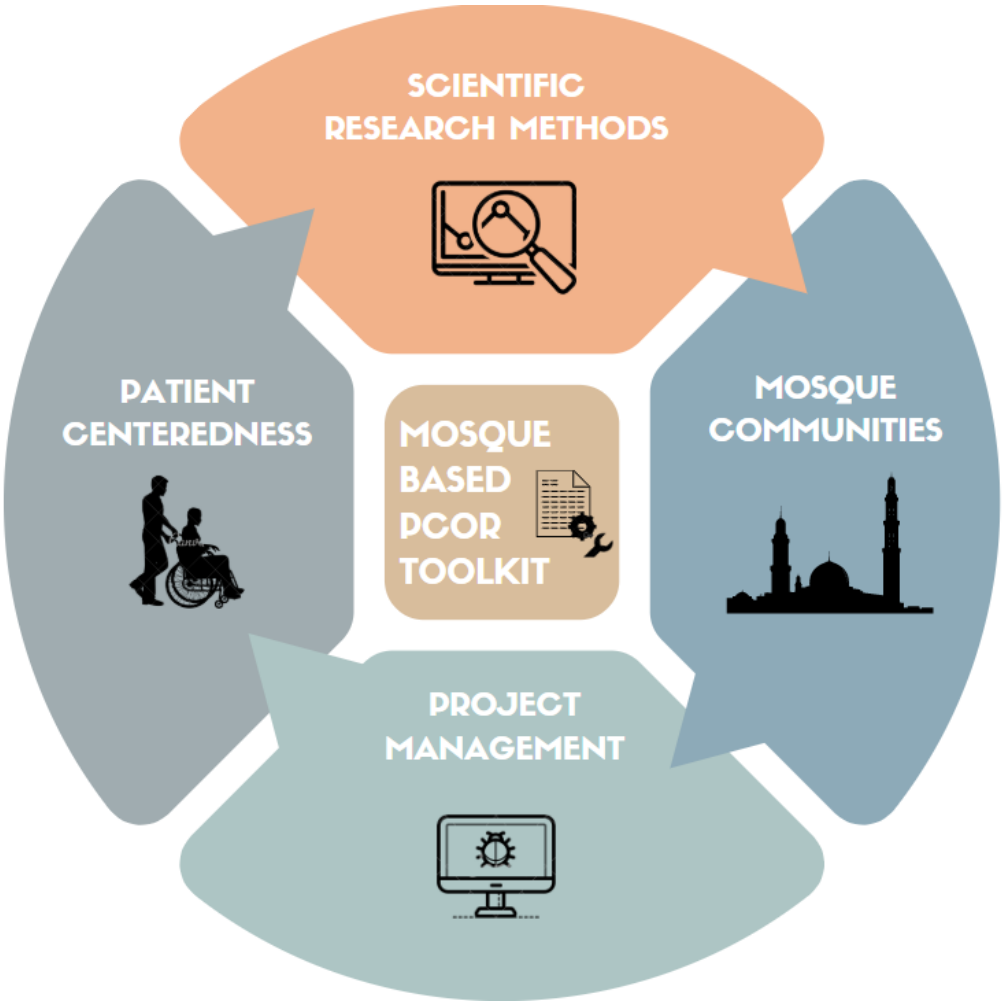

A TOOL-KIT FOR MOSQUE-BASED PATIENT-CENTERED OUTCOMES RESEARCH

A resource guide for conducting PCOR in Muslim communities

EMARCH / Mosque PCOR Vision Statement:

To build the capacity of mosque communities to participate in patient-centered outcomes research by (i) engaging mosque-community members and stakeholders in identifying Muslim health priorities, (ii) developing a cohort of Muslim community-based researchers with the skills and motivation to conduct health research and evidence-based health programs, and (iii) adapting PCOR tools for use in mosque-based research.

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Section I - Introduction

Why a Mosque-Based PCOR Toolkit?

The growing complexity of the American healthcare system and continued existence of health and healthcare inequities has spurred leading institutes and funders to develop novel methods and enhanced strategies by which to conduct, implement, and disseminate health outcomes research. Central to these efforts has been the focus on bringing value to patients by measuring outcomes of import to them, and on partnering with stakeholders across multiple sectors including the healthcare industry, community-based organizations, policy makers, and the academy so that health research and programming is better situated to the broader contexts of healthcare delivery within the US.

These efforts are ongoing as healthcare leaders search for effective ways to incorporate a patient lens into the process of evidence gathering, to facilitate the adoption of evidence-based guidelines across healthcare systems, and to engage stakeholders within and outside of traditional healthcare systems. Accordingly, the past several decades have witnessed the rise of community-based participatory research frameworks, patient-centered healthcare delivery models, health action-focused research strategies, and other paradigms which diversify the lenses through which health outcomes research is conducted and health programs are designed. The advent of the Patient Centered Outcomes Research Institute (PCORI) in 2010 accelerated this work as it systematically began to develop and fund an improved set of techniques, tools, and strategies to revolutionize the way health research is conducted, evaluated, implemented, and disseminated.[1] This toolkit leverages these resources in bringing PCORI methods and tools to bear upon Muslim American community health through the venue of mosque communities.

Muslim American Health

Healthcare disparities, i.e. minority-majority gaps in healthcare outcomes, are primarily tracked along racial, ethnic, and sociodemographic lines within the United States.[2] Differences between rural and urban populations, as well as biological sex, are also assessed by relevant agencies.[2] Over the past several decades, health differences and healthcare disparities continue to persist across the country, and as such the National Institute of Minority Health and Health Disparities (NIMHD), continues to champion individual-, community-, and population-level interventions in order to eliminate these health equity gaps.[3]

Regrettably national healthcare surveys and databases do not routinely collect religious affiliation data, and thus preclude assessing the overall health status and healthcare outcomes of religious groups. Hence how Muslim American health compares to that of

other groups is not a question that can be easily answered, and this knowledge gap frustrates the development of targeted programs that tackle specific health challenges that cut across this growing and diverse community. Though systematic research remains wanting, the available evidence suggests that this community experiences lower levels of health and poorer quality healthcare than other groups.[4]

American Muslims number nearly 5 million persons and are expected to double in number by 2050.[5] The population is racially and ethnically diverse; roughly 41% of American Muslims are of Arab or Middle Eastern descent, 28% are Asian, 20% are black or African American, and 8% identify as Hispanic.[6] Notably, 56% of American Muslims are immigrants, and approximately 33% live at or below the federal poverty line (ISPU American Muslim Poll, 2018).[6,7] Given these sociodemographic characteristics a significant proportion of Muslim Americans likely experience poor healthcare access and healthcare literacy thereby compounding health and healthcare disparities.

While Muslim Americans are diverse, their religion serves to somewhat unify their health behaviors and healthcare experiences. The shared influence of religious beliefs, values, and experiences in informing health across racial and ethnic lines aligns with both theory and available research evidence.[8,9] For example, American Muslims have been found to have a God-centric view of healing, with many using supplication and recitation of the Qu'ran as additional forms of disease treatment.[10] Muslim values of modesty have also been found to impact health-seeking behavior, cancer screening practices, and patient-physician communication across sociodemographic lines.[11] Additionally, Islamic law and ethics influence Muslim behaviors and attitudes towards biomedical interventions such as vaccines, organ transplantation, and end-of-life care across national borders.[12-15] These religion-related factors are inadequately addressed by conventional health research and programming, and contribute to unmet healthcare needs.[16-18]

In light of this background of inattention to Muslim community health by national organizations and policy-makers, the paucity of high-quality research evidence on Muslim community health outcomes, and the likelihood of Muslim Americans suffer from health and healthcare disparities given their sociodemographic profile and the adverse sociopolitical climate, a multi-sectoral partnership was formed to engage Muslim community health stakeholders at the grassroots level. Specifically, four organizations came together to design the *Engaging Muslim Americans in Research on Community Health [E-MARCH]* project which sought to develop community capacity for health research.

The collaborative involved the Initiative on Islam and Medicine at the University of Chicago (II&M), a community health research and intervention platform focused on Muslim Americans and Islamic bioethics with a long history of mosque-based research, Worry Free Community, a community-based organization institution that is involved in

healthcare coordination and mosque- based health programs, University Muslim Medical Association (UMMA) Clinic, the first Federally Qualified Health Center organized by Muslim Americans in the US, and The Whitestone Foundation, a community capacity-building organization that cultivates ideas and solutions to produce exemplary Muslim communities. The two-year E-MARCH program, by means of PCORI funding and methods, built capacity for mosque-based PCOR research among key Muslim health stakeholders, identified specific priorities for patient-centered Muslim community health research, and convened a three-day conference (October 2019) to seed broad-based and multi-sectoral partnerships to tackle American Muslim health issues.

In addition, project partners produced this mosque-based PCOR Toolkit to provide community leaders, researchers, project managers, and other stakeholders with the resources needed to participate in, and conduct, health research in their own contexts. This publication explains the mosque context, provides techniques for engaging Muslim patients and mosque-community stakeholders, presents best practices for recruitment and retention of research participants and community stakeholders, lists dissemination strategies, and offers a model for project implementation and sustainability. Besides drawing upon existing PCOR strategies, this toolkit also incorporates established Project Management (PM) methods to bolster synergistic relations between all project partners.

Intended Audience

- Community Health Researchers
- Healthcare System-based Community Health Liaisons
- Public Health Organization Staff, as well as Research Administrators and Consultants supporting health research and education programs in community settings
- Mosque Community Leaders and Health Educators
- Health Project Managers working with American Muslim communities
- Healthcare Students, Research Trainees, and others interested in community health and health inequities
- Payors and others desiring understand nuances of the mosque community and Muslim American health

The Toolkit's Intended Goals

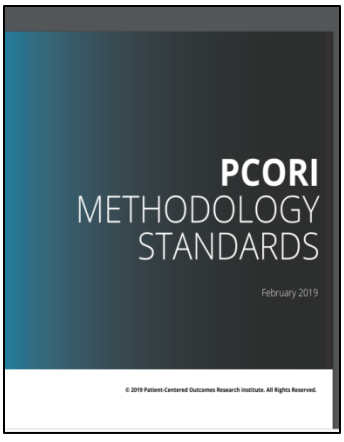
1. Highlight specific elements of the PCOR framework, as well as specific PCOR methods, to provide various stakeholders with a practical understanding of how to embark on a mosque-based PCOR project
2. Describe the American Muslim mosque community context and how they can serve as venues for PCOR

3. Provide tools for meaningful engagement with mosque community stakeholders throughout the research project lifecycle
4. Identify effective recruitment and retention strategies for project participants and stakeholders
5. Share a model for religiously tailored message design that can facilitate participant recruitment, stakeholder engagement, and communication among stakeholders
6. Highlight strategies for dissemination through community engagement while allowing unique opportunities for local asset utilization and shared decision-making
7. Offer a sustainability model to implement the study findings and/or facilitate adoption of evidence-based practices, effectively transforming a project into a program at the mosque community level

The Current Landscape of Healthcare

The establishment of Center for Medicare and Medicaid Innovation (CMMI) and PCORI under the Patient Protection and Affordable Care Act (PPACA) in 2010 was a strategic response to the lower-than-expected quality, and higher-than-expected cost, of the US healthcare system. Indeed, American healthcare was ranked 37th (Emanual) globally by World Health Organization in 2010, with poor performance on many indicators including life expectancy, infant mortality, immunization rates, blood pressure control and deaths from hospital-acquired infections.[19] PPACA responded by funded CMMI $10 billion for the years 2011 through 2019 to encourage innovation in health research by addressing health disparities and healthcare quality gaps.[20] While CMMI has taken the traditional route of clinical research and has captured the attention of the large health systems and insurance payors; PCORI was tasked to develop techniques and strategies for giving patients and their caregivers, as well as other traditionally neglected stakeholders, critical voice in the research enterprise.[1]

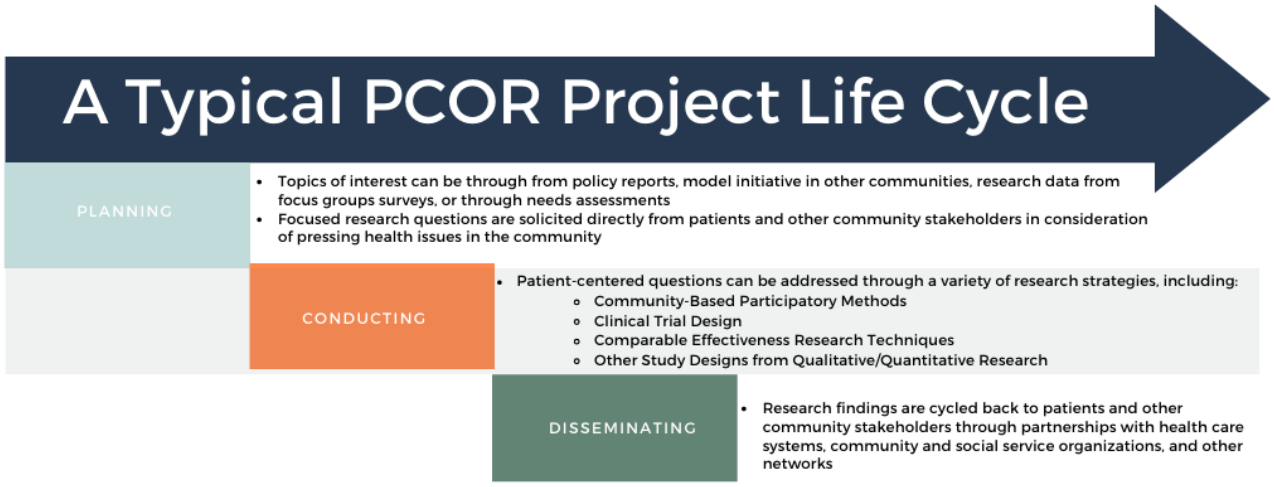
The Promise of PCORI



Accordingly, PCORI affirmed patients as the central stakeholder in all health research and programming and adopted a vision for comparative effectiveness research that promotes a culture of “Research through Engagement” by tasking researchers with ensuring patient engagement throughout the continuum of the research project lifecycle.[21,22]

During the first decade of PPACA era, PCORI funded over $2.5 billion to more than 700 projects.[23] These include original research using patient-centered and/or comparative clinical effectiveness research methods, as well as projects that develop enhanced tools and

the general infrastructure for PCOR. This path-breaking shift in research culture draws attention to questions and outcomes that are of import to patients and caregivers/families, and for strategically engaging other pertinent stakeholders in the conduct and dissemination of research. Today, the PCORI Methodology Committee has created or endorsed standards that provide guidance on 16 health topics, with a total of 65 standards for planning, conducting, and disseminating PCOR. In addition the manual details PCOR engagement principles such as co-learning, reciprocal relationships, partnership, trust, transparency and honesty. Under the guidance of PCOR methodology committee, these standards continually evolve to include best practices from completed PCORI studies.[24]

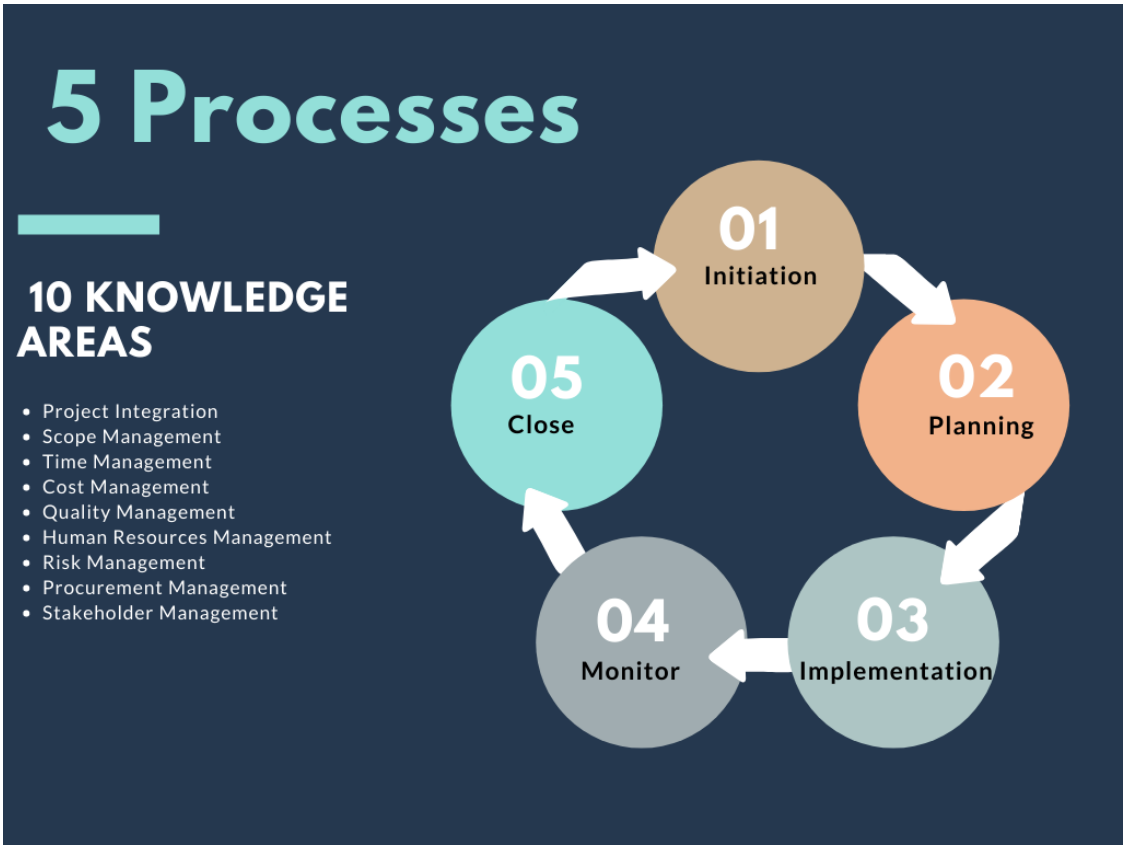


Coupling PCOR with Project Management Tools and Techniques

If treated as a separate country, US healthcare would represent the 5th largest national economy in the world, and as such US healthcare has many vested stakeholders that drive healthcare innovation in order to achieve economic and health returns.[25] Although these stakeholders come from all business sectors and apply different disciplines to tackle issues of health and healthcare, many utilize established Project Management (PM) tools in their daily work.[26] This widely accepted, and broadly implemented, methodology ensures on-time, at-budget delivery of project deliverables while also executing timely and focused management of relationships with project stakeholders.

According to PM, a typical project life cycle has 5 processes or phases (see figure below), which are governed by 10 separate knowledge areas or areas of specialization. Each process/phase is further broken down into well-defined activities (PMBOK) with specific tools and techniques used to manage the knowledge area.[26] Importantly, stakeholder management extends across all five phases of the life cycle. Because of this detailed mapping and logging of project activities upon a time scale, both project

staff and stakeholders can quickly visualize the project's status and troubleshoot any problem areas.

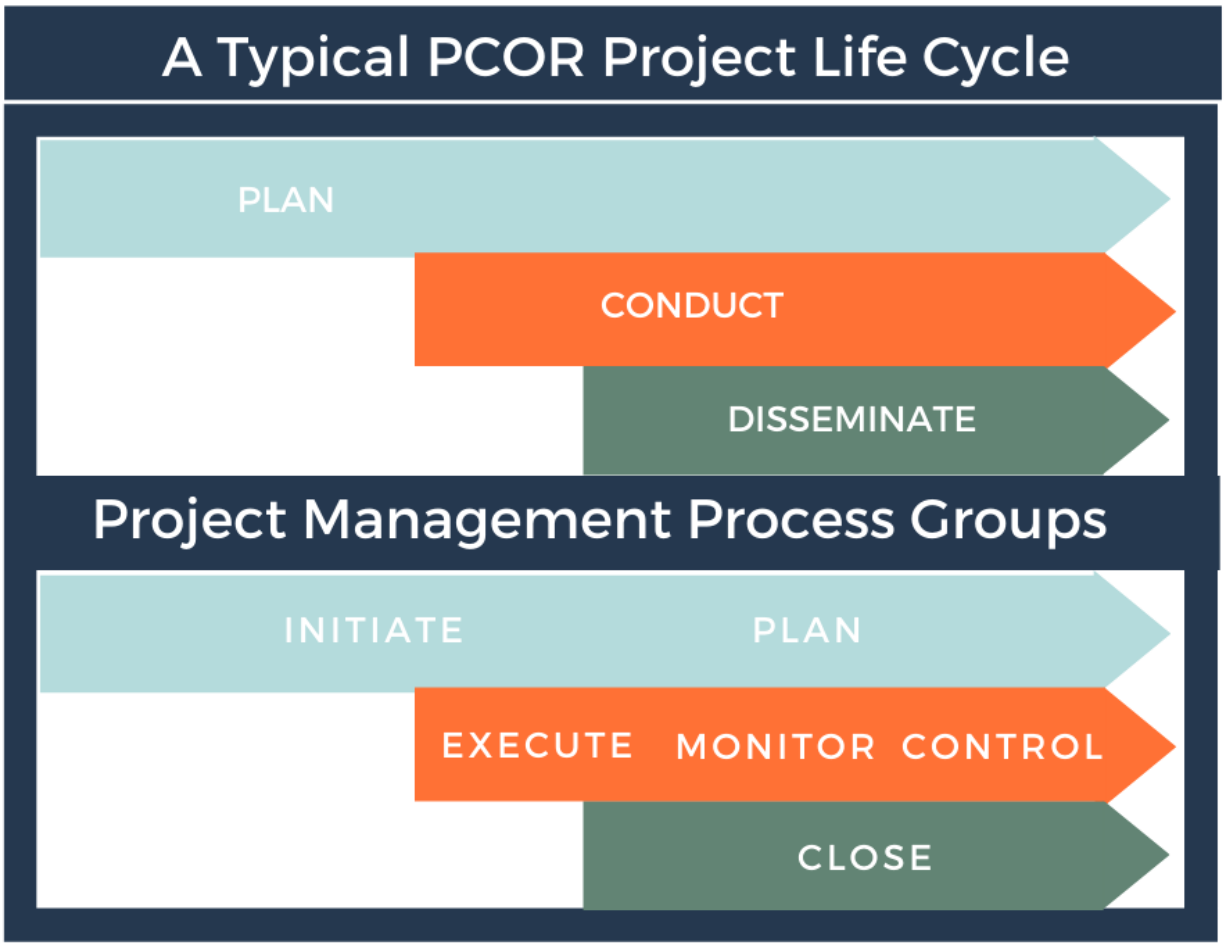


Blending the PCORI's standards and Engagement Rubric with the project management tools and techniques offers synergy; combining the two approaches and technique can further enhance timely project completion, effective communication across stakeholder groups, and better research conduct.[27,28]

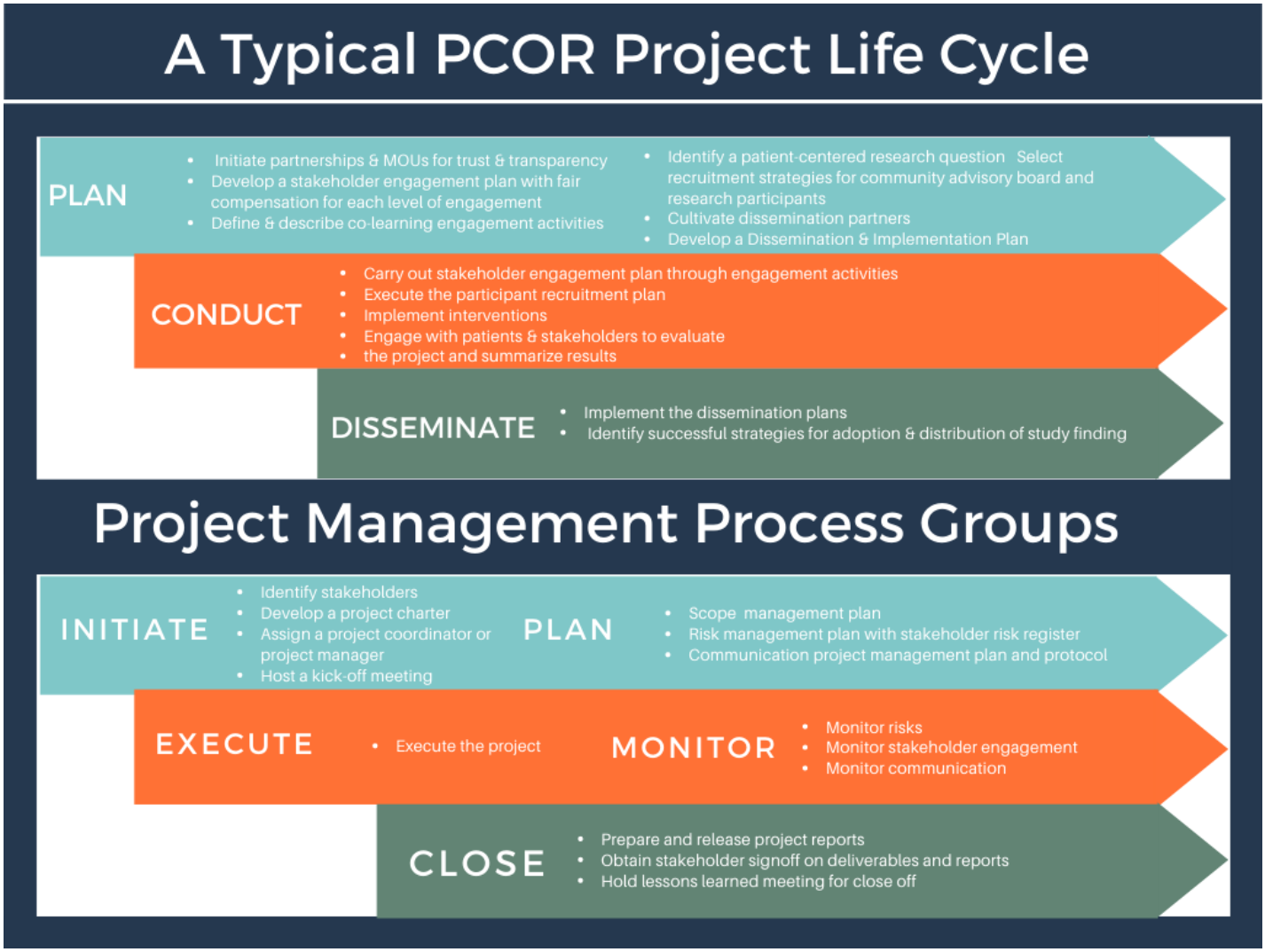
PCORI methods assist with creating a detailed engagement plan that brings in patient, caregiver, and stakeholder voices in the process of formulating the PCOR research question, defining characteristics of study participants, selecting outcomes of interest to the community, as well in the implementation and dissemination phases of the study. Project Management tools and techniques synergize in the conduct phase by emphasizing the prevention of scope creep that would make the project unmanageable, establishing quality control and change control mechanisms to enhance accountability and communication, and thus increasing the project's impact.

Project management's call for every activity to be followed within its own timeframe helps to maintain the research team's momentum throughout the project life cycle and even in the post project phase. Aligning PCOR activities with the project process groups can provide a more robust approach throughout the project lifecycle and adoption. The

figure below overlays PCOR with PM, and the table aligns each phase of the PCOR lifecycle with project management activities.



Overlaying the typical PCOR project lifecycle with the project management process groups provides an opportunity to clearly define best practices and considerations during each phase of the project (see figure below).


A Typical PCOR Project Life Cycle
PLAN
Initiate partnerships & MOUs for trust & transparency
Develop a stakeholder engagement plan with fair compensation for each level of engagement
Define & describe co-learning engagement activities
Identify a patient-centered research question Select recruitment strategies for community advisory board and research participants
Cultivate dissemination partners
Develop a Dissemination & Implementation Plan
CONDUCT
Carry out stakeholder engagement plan through engagement activities
Execute the participant recruitment plan
Implement interventions
Engage with patients & stakeholders to evaluate
the project and summarize results
DISSEMINATE
Implement the dissemination plans
Identify successful strategies for adoption & distribution of study finding
Project Management Process Groups
INITIATE
Identify stakeholders
Develop a project charter
Assign a project coordinator or project manager
Host a kick-off meeting
PLAN
Scope management plan
Risk management plan with stakeholder risk register
Communication project management plan and protocol
EXECUTE
Execute the project
MONITOR
Monitor risks
Monitor stakeholder engagement
Monitor communication
CLOSE
Prepare and release project reports
Obtain stakeholder signoff on deliverables and reports
Hold lessons learned meeting for close off

Section II – The American Muslim Mosque Context

What is a Mosque Community?

A mosque community is identified geographically as a location centered by a mosque and accompanying ancillary institutions that are linked to the mosque such as Islamic schools, social service agencies, health clinics, community halls, youth centers, and the like. A mosque community thus represents all individuals that interact with one or more of these mosque-connected institutions. In geographically dense areas with large Muslim populations, mosque community members may live proximate to the central mosque, however is more dispersed areas with fewer Muslim institutions, individuals may travel significant distances to partake in social, religious, or other activities at mosque or mosque-linked institutions. Given that nearly 50% of Muslim Americans attend mosque worship services weekly, and that mosques are cultural, social, as well as religious institutions, these sites hold promise for health research and stakeholder engagement.[29,30]

Recent work on the Social Determinants of Health (SDOH) has demonstrated that over 50% of one's health status relates to individual behaviors and social network influences.[31] A mosque's location, its legal and administrative structure, its leadership, programs, and means of communications all reflect upon the collective health of the community and heavily influence the living, learning and work environments of its community members. While being diverse in term of ethnicity, race, socioeconomic status, many Muslims, particularly those who are part of a mosque community, uphold a sense of Islamic identity that has health relevance. For example, many view health holistically as a combination of bodily, religious, and psychological well-being, and utilize prayers and supplication as a regular means of healing.[10,17,32] Moreover Islamic ethics and law impact their health and healthcare seeking behaviors, and such norms may require accommodation from the healthcare system, such as provision of gender-concordant care, neutral prayer spaces, and *halal* food.[17,18] Since patient-centeredness and patient engagement is core to PCOR projects, it is important to understand the dynamics of mosque community and its relevant health stakeholders before embarking on a PCOR project.

The Legal and Administrative Structure of a Mosque

Almost all mosques operate and administer services as a 501(c)(3) organization with a volunteer administrative board that oversees operations. These boards cater to the religious, social, cultural and educational needs of the community through by establishing programs and services. Typically, all boards hire a single religious leader, Imam, who leads prayers and provide religious guidance to the community. He may be assisted by other deputy or assistant Imams who also lead worship services and perform religious rituals. This structure allocates decisional authority and control to the

board and Imam, and must be kept in mind when designing stakeholder engagement protocols.

The Role of Imam

In addition to leading prayer services and delivering sermons, Imams also provide counseling and ethics consultation. Both of these roles can profoundly impact the health behaviors of community members. Sermons can be used as a health education modality, framing positive health behaviors in the context of a religious life. The imam's social, marital, and indeed mental health, counseling also has health impacts as they can inform the ways in which community members interact with the allopathic healthcare system. Finally, their ethics consultation encompasses healthcare decision-making, as individuals and families might seek counsel before engaging in a decision about pursuing health treatment or abstaining from it.[33] In fact, a study done on the acceptability of using Friday sermons as a modality for health promotion and education showed that theologically-framed health messaging is acceptable within sermons to American Muslim mosque communities.[34] Therefore, Imams must be treated as major stakeholders in a mosque community projects even though they may not be involved at the planning or execution levels of the project.

Mosque Health Programs

As noted above, mosques play significant roles in the lives of the Muslims within the US. In addition to hosting prayer services, many also have additional services and facilities such as parochial schools, senior services, baby and day care, summer camps, and after school services. In addition, clinicians, healthcare professionals and lay health workers within the mosque community are increasingly hosting health screenings, free clinics, and other health education events in larger mosques within the US. These forums provide an important untapped venue for data collection and research on the health of community members and their healthcare needs.

From a PCOR perspective, mosques are community centers where many healthcare and social transactions take place and thus contain many healthcare "stakeholders." Of course patients are present, but healthcare professionals, religious leaders, peer health educators, and others as well. Indeed many of these individuals already volunteer their services to mosque programs. In Enroll America's *Muslim Faith Engagement Toolkit* for engaging the Muslim community in health programming and health coverage enrollment, Min. David Street highlighted the role of the mosque volunteers and mosque health programs in addressing barriers to healthcare among Muslim communities. This idea has taken root in many cities around the country.[35] For example, Compassionate Care Network is a largely volunteer-led organization that uses mosque communities

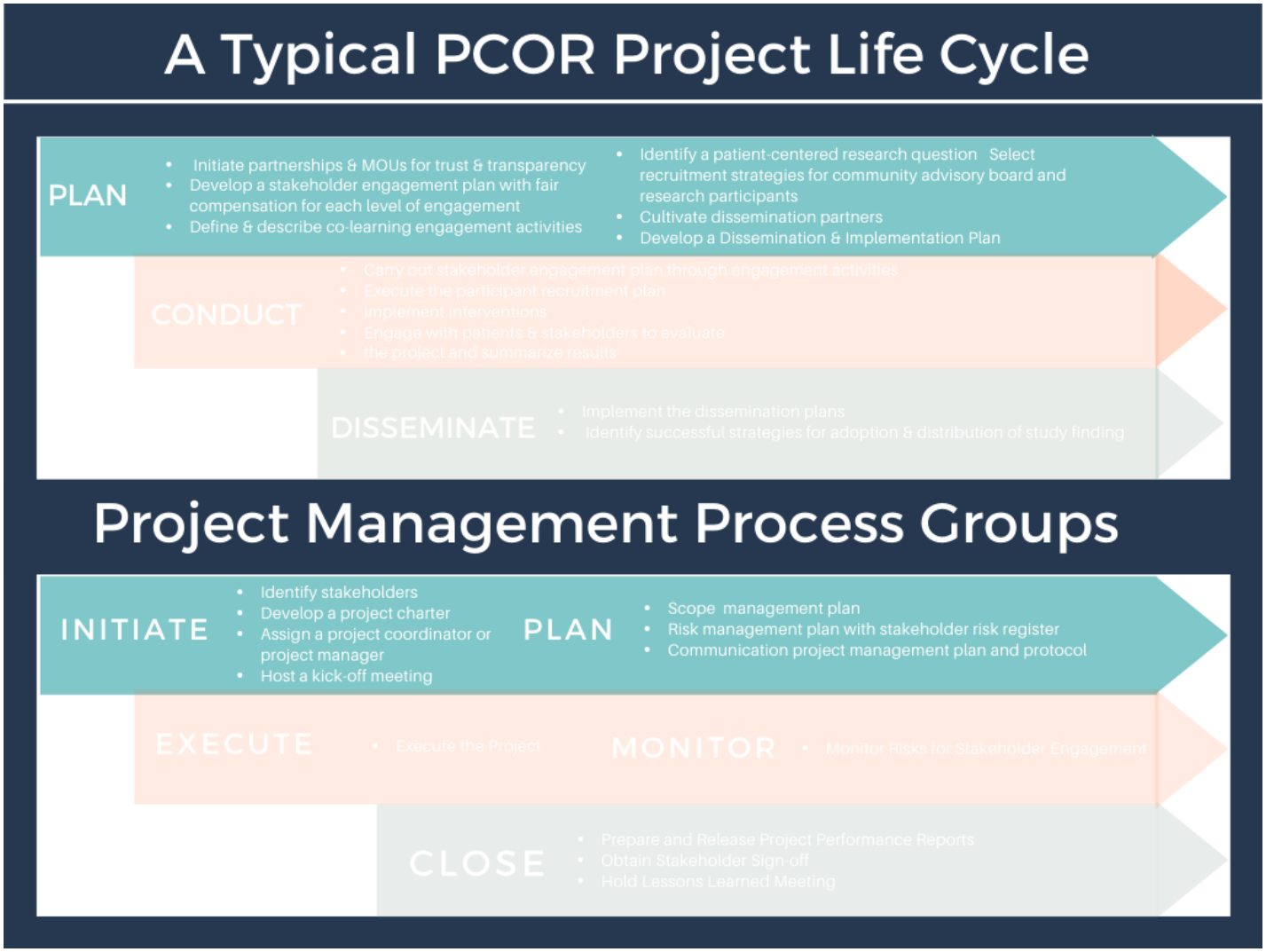
around Chicagoland to educate Muslims on PPACA and provide guided healthcare enrollment as well as targeted health screening.[36]

The mosque environment is well suited for PCOR engagement as individuals from different healthcare sectors can be brought together to help conduct a PCOR project and provide insight from the lens of their discipline. Certainly, the mosques have the space and human resources to host health programs, and contain diverse groups of stakeholders that can be leveraged for PCOR project success and sustainability.

Mosques' Channels of Communication

There are several communication channels within mosques that can be leveraged for PCOR stakeholder engagement, participant recruitment, and project dissemination. For example, mosques have print or electronic newsletters where advertisements can be placed. Similarly, mosque websites and social media groups (WhatsApp) can be advantaged to publish communication and advertising materials. Researchers however should not underestimate word-of-mouth communication. Often times, individuals on the board, or the Imam, link into word-of-mouth communication groups that can reach dozens of individuals. These networks and stakeholders should be capitalized upon for PCOR recruitment and stakeholder engagement.

Section III – Planning a PCOR study within a Mosque Community



Why engage Mosque Community Stakeholders in Planning a PCOR Study?

Mosques support their communities at many different levels, from meeting the basic religious needs of individuals to providing social and educational services. Given the influx of economic migrants and refugees into Muslim communities in the US, there is a constant need for mosques to find better and creative ways to maximize their resources to support the growing community. As a result, a basic level of interdependency exists among organizers of the mosque programs and the community members. These relationships can be leveraged in many ways to engage mosque community members for a patient-centered outcomes research study.

Before delving into aspects of engagement it is not only critical to recognize that engagement is an essential part of the philosophy of patient-centered research, and that stakeholder input will be invaluable for detailing a *project plan*. According to PM, developing a project plan is not just one activity, rather it is a document that gathers together several "plans" for aspects of the project, and incorporates the aforementioned PM knowledge areas (see figure above). For a mosque-based PCOR study, we recommend the research team work with mosque community stakeholders to map out the following "subplans" that will be compiled together into a single overall project plan: (i) a *stakeholder engagement plan* that identifies stakeholders important for project success and how these relationships will be managed through the project lifecycle, (ii) a *participant recruitment plan*, (iii) a *project scope management plan*, i.e. a document that outlines how threats to scope creep will be mitigated, (iv) a *communications management plan* that identifies communication protocols related to different audiences (public, mosque community, research academy, funders, sponsors, and others), and (v) a *dissemination plan* including concrete deliverables and outputs. Failing to appropriately engage stakeholders for their input into these plans will result in loss of transparency and lack of interest and threaten PCOR project success. The reader is directed elsewhere for examples of such plans.[37] With that goal in mind let us now move to discussing key principles underlying stakeholder engagement.

What are the key PCOR Engagement Principles?

The PCORI Engagement Rubric details six basic principles providing the ethos for designing and selecting of the engagement strategies, activities, and plans. [28] The table below provides a practical approach to the applying the principles in a mosque community.

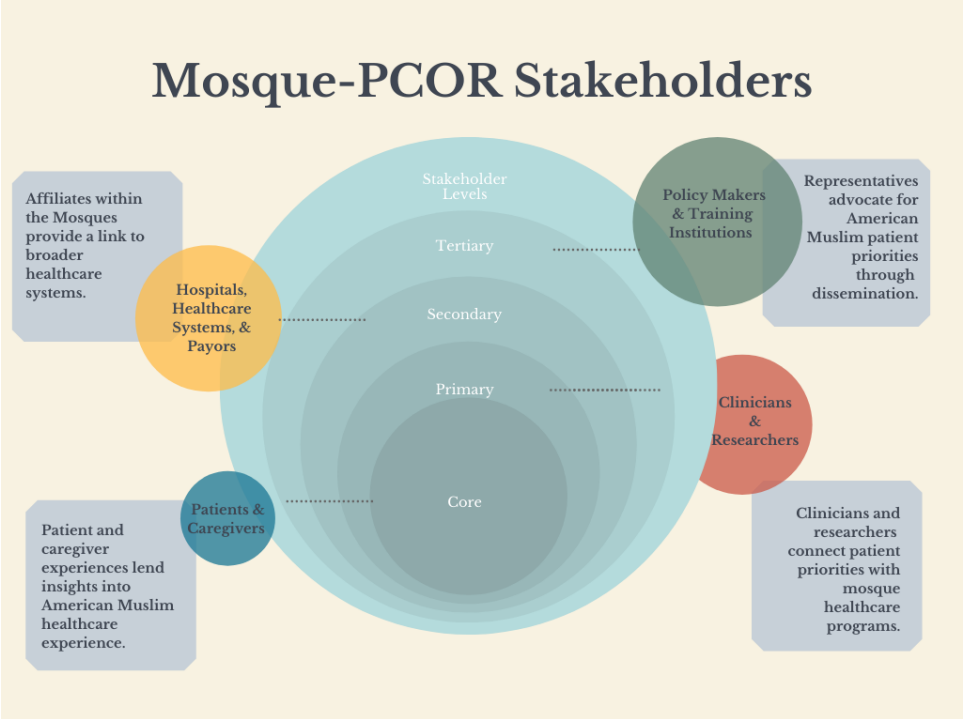
PCOR Engagement Principles and their application within a Mosque-Based PCOR project

Engagement Principle	*PCORI Language – Principle is demonstrated when:*	*Applying PCOR Principles to Mosque Community: Suggested activities*
Reciprocal relationships	Collaborations should be bidirectional with equal share in decision-making authority. Roles and decision-making authority is clearly stated and defined collaboratively among all research partners including patients and other stakeholders.	• Researcher identifies mutual benefits and responsibilities for each stakeholder group • Consider patrons, volunteers, board members, teachers, or business leaders as part of the project leadership team and inquire as to what unmet health needs or health issues are most pressing to them • Decisional authority should be shared between community stakeholders and the research team, be sure to include Imams and mosque board members in all critical decisions and provide them with “veto” power as necessary.
Co-learning	Researchers should help stakeholders understand the research process while also learning about what matters most to the patients and these other stakeholders.	• Researchers need to learn the cultural and religious values impacting the health issue of concern; community members develop the understanding of theory-driven, evidence-based research methods and tools. • Researchers need to identify specific knowledge gaps and fill these in through mutual learning and knowledge sharing activities.
Partnership	The time and contributions of stakeholders are valued at a fair financial compensation level. Thoughtful requests for time commitment are made to all stakeholders, and researchers are sensitive to cultural needs and special accommodations needed by some stakeholders.	• Given the volunteer status of mosque staff, any research project is considered unwanted work unless the staff buys the project vision. Hence make the value proposition clear. • Partnership development at the mosque level will require negotiations for mission, vision and fair compensation depending on the time effort commitment of the staff or community member. • Meetings and events should be scheduled to avoid religious and prayer events as timed by lunar calendar
Transparency, Honesty and Trust	These principles are demonstrated when major decisions are made inclusively and information is shared readily with all research partners. Open and honest communication is shared with everyone associated with the project.	• Communicating important messages through the Imams can help reciprocate and promote trust. • Consider using existing communication channels at mosques, i.e. newsletters and bulletins for status updates to promote transparency. Poster and digital bulletin boards can also feature project timelines, status updates, and milestones.

Who are Mosque Community Stakeholders?

Multi-sectoral stakeholder engagement is the hallmark of all PCOR projects. A very broad range of individuals are considered "S*takeholder Partners"* in PCOR and include clinicians, community members, healthcare purchasers, payors, industry representatives, hospital administration, policy makers, health education institutions, and academic researchers. The figure below describes the proximity to, and role within, a mosque-based PCOR project for key stakeholders. Given the salience of religion to Muslim health behaviors, and that we are discussing mosque-based PCOR, we suggest that mosque board members and Imams also be considered as stakeholder partners for PCOR.

The term *"Research Partner"* refers to the special category of these stakeholders who care for, live with, advocate for, or treat individuals with the specific health issue being studied. Such research partners provide proximal insight into specific kinds of patient-centered issues that research should be focused upon. Of course those most directly impacted by the health issue under study are the patients themselves, thus *"Patient Partners"* detail their lived experiences and represent the target population being studied. PCORI takes this broad conceptualization of stakeholders and groups them into nine separate classes, so that researchers can make targeted efforts to involve these groups in their projects, and so that recruitment and retention can be easily tracked. Though mosque communities are homes to each of these classes of PCOR stakeholders, Patients, Caregivers and Clinicians are readily at-hand, and of particular importance because of direct involvement with the health issues to be investigated.



Potential Engagement Mechanisms

PCOR methods emphasize that the aforementioned engagement principles be used to formulate a shared vision between researchers and stakeholders that can help the project move forward and end successfully. PCOR also requires that infrastructure is put in place, and engagement plans are designed, so as to facilitate the various project stakeholders participate and are involved in all phases of the project cycle (as far as possible). In our view engagement activities in mosques should draw from both the PM and PCOR tools and techniques, and be focused on honing in on the PCOR project question and design, as well as preparing the mosque community for the PCOR project. Based on our collective experiences we recommend the following engagement structures for mosque-based PCOR.

Creating a Mosque-PCOR Community Advisory Board (CAB)

Establishing a CAB is a proven technique that brings together diverse stakeholders, ensures timely input from community members, and builds a trusting and transparent partnership. Recent PCORI projects such as ”Inspiring Change” have demonstrated the value of having interdisciplinary members on the CAB as it facilitates not only the project at hand but also is a vehicle for community-capacity building and knowledge transfer.[38] When considering the composition of the CAB, we recommend thinking through the project from original concept to implementation. For a mosque-based project, this includes the processes that you must navigate to gain entry into the mosque, and buy-in from the larger mosque community and build trust. As described previously, the mosque community may include other institutions (schools, clinics, social service organizations) and representatives from these ancillary organizations should be invited to the CAB.

In the list below, we describe several important considerations when forming your CAB.

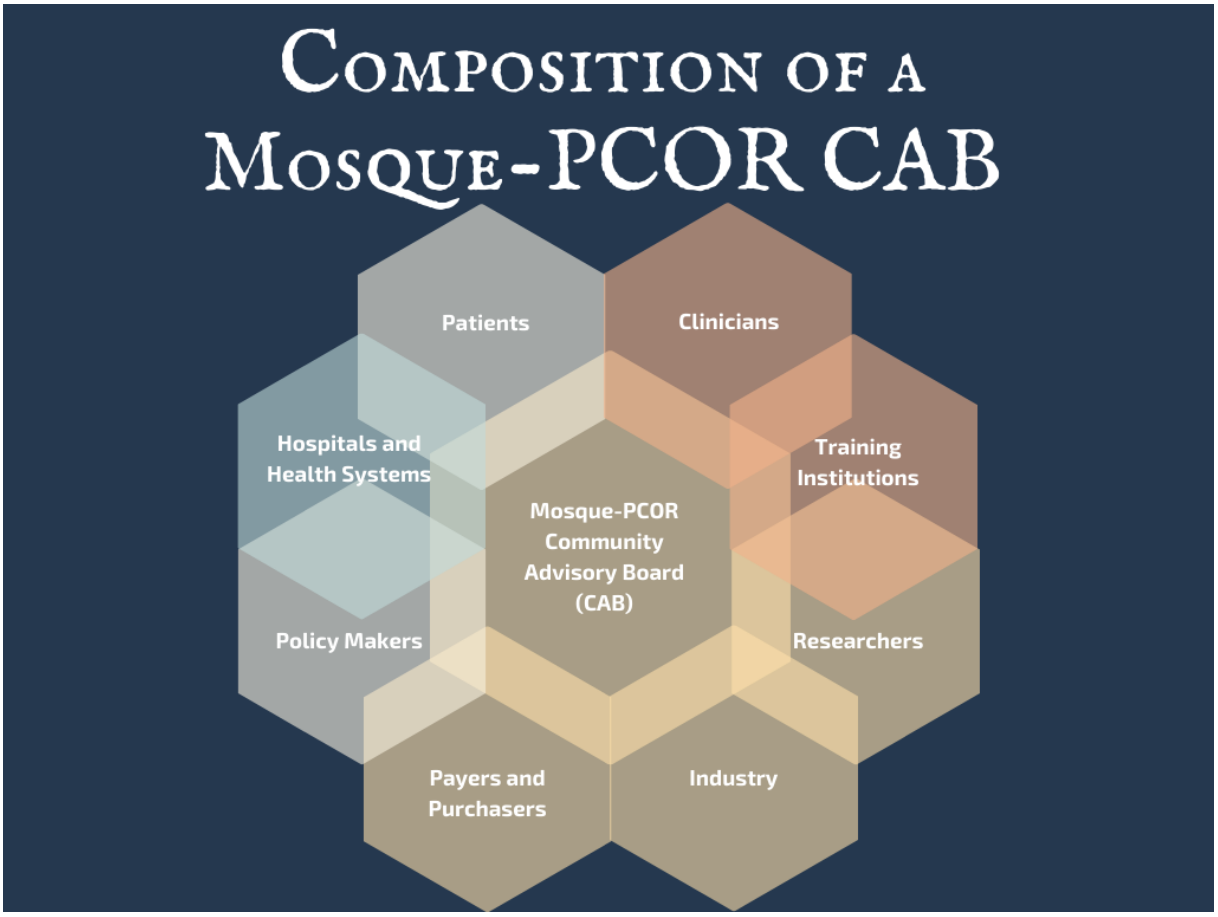
Four Considerations for a Mosque-PCOR CAB

1. Because mosque community members come from different disciplinary backgrounds, we recommend PCOR researchers capitalize on this diversity by inviting members that come from at least 4 of the suggested PCOR categories of stakeholders.
2. Avoid relying entirely on CAB members who have dual stakeholder roles (e.g. relying on an individual who serves as a religious leader but is also the sole healthcare industry representative). It is important to have each CAB member, as so far as possible, represent a single stakeholder group. In other words, their primary role is to speak to a single stakeholder perspective. This is critically

important for patient partner who has to represent the patient voice in patient-centered outcomes research and not also represent other stakeholder groups.

3. The CAB should be inclusive in terms of race, ethnicity, and gender so that diverse experiences can inform the project design, implementation and dissemination.
4. Members should be culturally and linguistically concordant to the community being engaged.

In addition to the stakeholders shown in our Mosque Stakeholder figure, your CAB needs to ensure that it accounts for key mosque stakeholders. In the table below we mention several important voices and functionaries within the mosque who should be invited on the CAB.



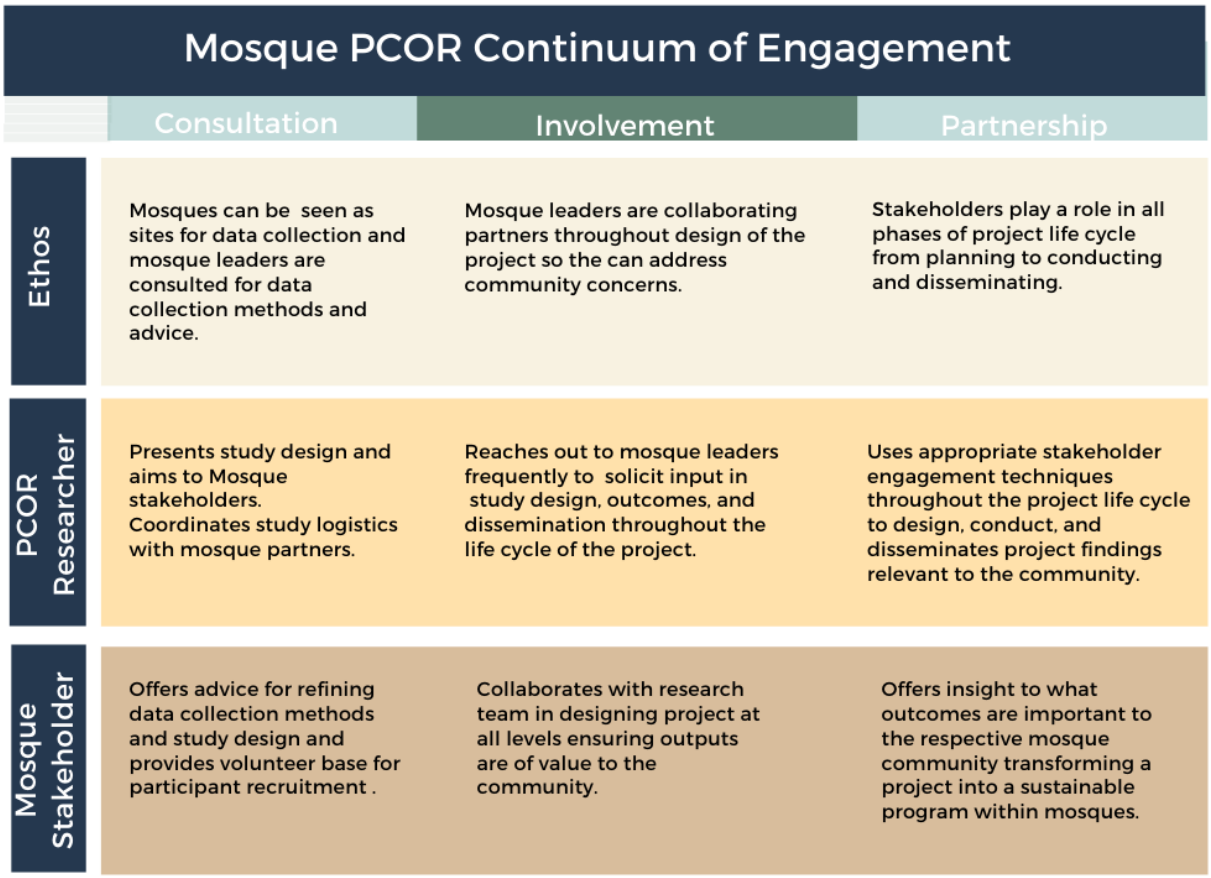
Mosque-Specific Community Advisory Board Stakeholders

Stakeholder	Role
Mosque patient partners	Mosque community members (as patient partners) can give voice to their perspectives and experiences by helping define patient-centered outcomes and the "Muslim" dimension of the project.
Mosque board members and imams	These leaders hold authority and convening power in the mosque. Inclusion of these stakeholders will enable your project to gain insight into pressing issues and build community trust. Additionally, they likely will play a key role in gaining entry into the mosque community.
Mosque volunteers	This stakeholder group directly serves the social and healthcare needs of the community and can provide insight into needs, receptiveness, and pressing issues.
Topical experts or community advocates	Similar to mosque volunteers, topical experts and community advocates who attend regular prayer services are attuned to the community needs.

Depending on the nature of the project, CAB members can either be from a single mosque or from multiple mosques within a geographic region to amplify the impact. One of the main challenges for a CAB that has a large membership, or encompasses individuals spread out across a large geographic area, relates to convening the entire group together for a single meeting and maintaining consistent attendance. Though in-person meetings are valuable and typically lead to greater participation and transparency, we suggest that the frequency of meetings as well as modality (teleconference, videoconference, in-person) be negotiated with CAB members at the project outset to ensure expectations are set and met by all. Additionally, PCORI suggests that all research partners and organizations to be appropriately compensated based on the level of engagement expected.[39] We suggest all CAB members be remunerated at the same level for the purposes of fairness, though adjustments may be necessary based on additional project roles and opportunity cost to be on the CAB.

As the project plan is put together the CAB's input is critical, particularly as they are the primary conduit by which researchers come to understand what health issues and outcomes are important to the community, and what data collection and dissemination plans align with mosque culture and capacities. As such the CAB must remain engaged throughout the study. At the same time one must be careful not to cause "project fatigue" by burdening CAB members with too many meetings and too many questions.

While not necessarily related to creating a CAB, it is important for researchers to recognize that individuals approached for the project may not have the capacity for CAB involvement due to time limitations. And it may be that there is a difference in the level of engagement among CAB members. This variance needs to be mitigated but is also expected, and that is why PCOR involves a differential compensation framework. Additional the idea of a "continuum of engagement" that acknowledges different intensities of engagement by stakeholders is part of PCOR.[22,40] The continuum is a multidimensional framework which suggests that all project engagement happens at three separate levels: (i) direct care; (ii) organizational design and governance, and (iii) policy making. These levels vary in intensity from "consultation" to "direct involvement", and then to "partnership" which is the highest form of collaborative engagement. Though the Continuum of Engagement targets the patient and family directly, the model is relevant to shared decision-making with mosque leaders as well because they are individuals who "govern" the site of engagement and venues for project activities. The figure below represents the Continuum of Engagement framework and provides parallels with the mosque-based PCOR project considerations.[22]



Identifying a Research Domain

Prior to defining your research question and relevant outcomes, the mosque community can help identify a Muslim PCOR amenable research domain/topic. A number of evidence-based methods exist to build consensus and identify relevant research domains. For researchers that have access to stakeholders with an intimate knowledge of community needs, the Delphi Method provides a structured communication technique for group decision-making and forecasting.[41] In contrast, deliberative methods employed in projects such as Choosing Healthplans All Together (CHAT) provide an easy, informative, and interactive method for exploring health and healthcare topics or decision-making.[42] Through our E-MARCH project, we took steps to begin this discussion through engagement of a diverse, national cohort of American Muslim "community leaders." Some example domains identified through this project can be seen in the table below.

Top Health Concerns for American Muslims Identified by the E-MARCH Project

Issue	Subtopics
Mental Health	Stigmatization, lack of education, underutilization of services, community trauma, untreated depression
Lack of culturally appropriate or religiously sensitive healthcare	Gender concordant care, medical interpreters, discrimination, stereotyping
Underutilization Preventative HealthCare	Breast cancer screening, cervical cancer screening, HPV vaccination
Reproductive and Sexual Health	Lack of access to information, stigmatization, infertility treatment decision-making
Substance Abuse	Stigmatization, lack of education, prevalence among youth
Lack of Islamic Bioethics Knowledge	Organ transplantation, end-of-life care, medication avoidance, tension between Islamic teachings and Western medical practice, lack of knowledge
Interpersonal Trauma	Care seeking behavior, domestic violence, sexual violence, emotional abuse
Islamophobia-related health impacts	Impact on Muslim identity, internalization, impact on youth
Elder Care	Underutilization of elder care facilities/hospice
Immigrant Health	Assimilation, xenophobia, disconnect between immigrant parents and U.S. born children, social isolation and segregation, stress/PTSD

Developing a Shared Vision for Continuous Engagement

For the mosque community to be engaged, CAB members and other community leaders need to "visualize" the value and purpose of the project. PCOR methods suggest that this vision be developed through collaboration between the multiple project stakeholders, and it doing so the mutual benefit for all parties is clearly delineated. Additionally, by allowing the stakeholders to assist in shaping the project vision, the research team is better positioned to keep the various stakeholders engaged throughout the study as the vision unfolds. The shared vision then works its way into all elements of the study design from the patient-centered question to be addressed to the designation of study outcomes and dissemination products. We suggest that the first activity CAB members engage in is developing the project vision, and then using that to create a project charter.

PM project charters are very effective in getting everyone on the same page. They set out the vision for the project in a few (and ideally one) succinct sentence and then describe key elements of the study such as: purpose, goals, milestones, resources, budget, timelines, outcomes, and importantly the names of the project sponsor and project manager or project coordinator. Indeed, project charters also record responsibilities for project team members facilitating transparency and keeping the group on task. Optionally, project charters can also document the relevant connections and networks the core project team has outside of this project, so that dissemination channels come into relief. A sample *project charter* is presented in appendix I.

Once the charter is designed we recommend a public forum, a kick-off meeting, be convened in the mosque to memorialize the development of project charter and obtain signatures of the relevant parties who will play key roles in the project's execution. This serves to publicize the project's embeddedness within the mosque community, gives public recognition at the inception of the project to all those who helped to create the charter, and draws community attention to the agreements between various stakeholder (and in doing so increases accountability). This kick-off meeting is also a good opportunity for the research project manager to generate interest from the broader community in the project and thus forecast data collection and participant recruitment activities to come. We suggest that the mosque's Imam be invited to give a benediction and introduce the project, as this further lends credibility to the project and sets its implementation within a religious framework.

Specifying the PCOR question(s) and Project Plans

Once the mosque CAB is in place, a project charter with partners and responsibilities outlined, and the stakeholders are identified, the PCOR research question can be specified. As noted above while a general health topic or concern has

been agreed upon and was the basis for the project charter, detailing more concrete questions can only be done once a dedicated CAB is in place. These individuals will be able to speak to the religious dimensions of the health domain, the outcomes that are important to the mosque communities, and how social relationships and mosque networks can be advantaged of for a PCOR project. At the outset we suggest addressing two activities that will allow for a data-driven approach to PCOR question specification and *project plan* development: (1) a community health assessment (CHA), and (2) a mosque strengths, weaknesses, opportunities, and threats (SWOT) analysis as it relates to research conduct and dissemination.

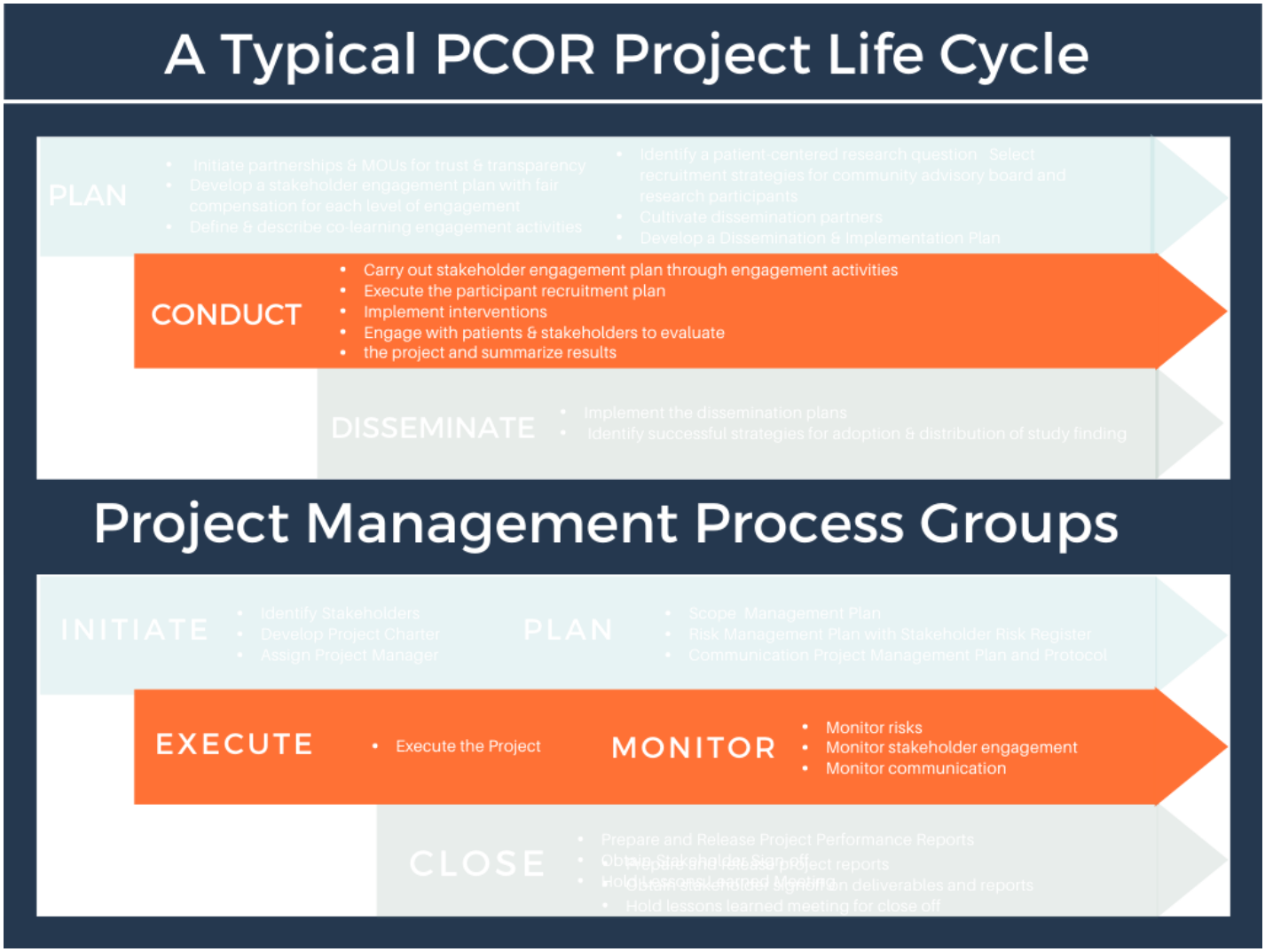
Obtaining data from a formal community health needs assessment (CHA), or a more informal assessment garnered through conversations with CAB members and relevant stakeholders, is aimed at determining what pressing health issue is amenable for PCOR in that particular mosque or geographic region. Local data allows for prioritizing among different pressing health topics, and honing in on its patient-centered dimensions. A SWOT highlights the strongest mosque community partners with the most capacity to contribute, as well as those with most to gain from a PCOR project. Engaging the CAB and other mosque stakeholders in the SWOT and CHA can be a powerful engagement strategy that enhances interest and motivation to undertake the PCOR project. Additionally, this engagement strategy builds intellectual capacity and skills of mosque community members to collect and interpret data and reveals potential synergies among the researchers and the mosque leadership. As the project moves along the phases of its lifecycle, some of these “trained” individuals may be interested in helping with aspects of data collection, analysis and dissemination. Or they may be conduits to other interested parties from within the mosque who would benefit from such roles. In this community capacity is enhanced, and truly partnered research effected.

The CHA and SWOT allow for the CAB to hone in on the research question, and also will help with determining how the study will be conducted and disseminated. In addition it will help a key question relevant to all mosque-based PCOR: is the research going to be faith-*based* (i.e. focused on the religious dimensions of health and health behaviors) and/or faith-*placed* (i.e. focused on using mosques as simply a venue for research and education)?[43]

As noted above, despite diverse social and cultural backgrounds, Muslims share a religious worldview that can shape mosque community members health-related behaviors and interactions with the healthcare system, Islamic religiosity can both hinder and promote the health of American Muslims. In fact, religion contributes to a “cultural construction” of clinical reality by shaping the way Muslims perceive, label, and evaluate their illness. Deciding, in concert with the CAB, how linked religious beliefs and values are to the study question, is critical. This relationship will impact the way the project is marketed to participants and community leaders, what sorts of tools and

methods are used to collect and interpret data, and the implications of the project findings. As it is beyond the scope of this tool-kit to detail how religion impacts Muslim health disparities, and how religion-related messaging can be leveraged to improve health, readers are directed to other publications as they consider their PCOR projects.[8,9,43] In considering faith-based vs. faith-placed PCOR, consensus between the CAB and research team members should be sought. A CHA and SWOT can make this decision data-driven by providing you necessary data on community needs and resources.

Section IV – Conducting a PCOR Project in Mosque Settings

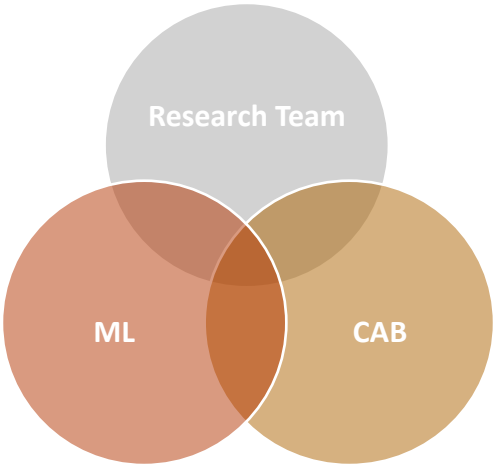


Key Considerations for Conducting Mosque-Based PCOR Projects

As described above, mosque settings provide an ideal venue through which to examine the health and healthcare-seeking behaviors of, and health disparities among, American Muslims in a patient-centered way. When conducting PCOR in mosques, researchers should employ the aforementioned techniques found in the planning section as successful conduct relies on engaging stakeholders in meaningful ways, maintaining open channels of communication between research teams, advisory boards, and mosque staff, and collaborating together to mitigate threats to the project as they arise.

Moving from project planning to conduct, each PCOR project will have elements that are unique to the research question and to the study design. However in what follows we share best practices for common elements involved in mosque-based research: participant recruitment and retention, religiously-tailored message design, and project evaluation.

Participant Recruitment & Retention



Along with the PCORI Engagement Principles described above, the following techniques and best practices can improve participant recruitment and retention in mosque-based settings. Here, the researcher should consider how CAB members can support and enhance the mosque community's interest for, and awareness about, the project. The research team should also utilize the various social networks connected to the mosque, and enlist cultural insiders (in addition to CAB members as necessary) to communicate the value of the project to potential participants in cultural vernacular.

Regardless a successfully established, informed, and engaged CAB is key and can strengthen with participant recruitment and retention in the following ways:

- Identify the most promising mosque community sites/venue for recruitment activities

- Ensure that the design of recruitment materials (flyers, announcements, etc.) are appropriate culturally and most poised to communicate the value proposition to community members
- Actively recruit participants into the study through their networks and functioning as trusted cultural liaisons

Participant Recruitment Strategies

The social structures of mosques provide a numerous *venues* and *avenues* to advertise the project and recruit participants. In the table below, we list best practice recruitment modalities that we have tested in our prior studies and their relative efficiency for participant recruitment. As described in the previous sections, mosques are host to a number of services, social events, and modes of communication. However, effective execution of a mosque-based recruitment strategy relies upon support from mosque leadership, which should be represented on the CAB, and a mosque logistics (ML) team comprised of key mosque members who can ensure your recruitment team has access to relevant venues. As in the figure above, a successful recruitment strategy incorporates the research team, CAB, and ML team. Members of the research team must present a provisional recruitment plan the CAB, who may include the Imam and members of the board of mosque-based clinic and social services teams, for permission as well as implementation advice. Once support has been obtained from this high-level group, the ML team should discuss data collection logistics, establish lines of communication throughout the various mosque community networks and organizations, and develop staffing plans for recruitment.

Best Practices for Mosque-Based PCOR Recruitment

Recruitment Modality	Efficiency
Recruitment tables before and after Friday Jummah prayer service	High
Recruitment tables at social meetings, cultural events, and school functions	High
Announcements made by mosque leaders during worship services or other events	High
Sign-ups through mosque newsletters and organizational listservs	Low
Sign-ups through flyers	Low
Sign-ups generated through social media postings	Low

While a range of potential recruitment avenues exist to a mosque-based PCOR researcher, not all modalities will yield the same results and no single strategy will prove effective on its own. Depending on the demographic make-up of your target population,

consideration should be given to whether recruitment materials should be translated into other languages. Additionally, mosques should maintain autonomy over the choice of recruitment methods and a multi-modal recruitment approach needs to be employed to ensure adequate sample sizes and representation.

Participant Retention

Depending on the chosen study design, retention may or may not be considered by the researcher. For studies that require multiple assessments, surveys, or repeat testing, consideration should be given to your retention strategy. Despite varied efforts for recruitment, retention of participants in a mosque-based study has proven difficult. For example, in our health education intervention studies that required participants to attend two half-day sessions on weekend mornings, we saw attrition rates of 10-43% between the first and second workshops.

Potential strategies for retaining participants include: phone calls, letters in the mail, emails, and text message reminders. As with recruitment, researchers should employ a multi-modal strategy to maintain connections to participants. Additionally, compensation and engagement of participants should be considered early in the planning phase. If attrition is anticipated, the researcher should consider higher levels of compensation and greater involvement of CAB members to maintain interest.

A Religiously-Tailored Communication Model

As alluded to previously, a successful mosque-based PCOR project relies upon effective communication with the CAB, mosque leadership, and study participants. The 3R model, originally designed as a guide for developing religiously-tailored health messages for behavioral change, can be adapted for use in designing your mosque-based PCOR communication plan. When properly employed, the 3R model can serve as a communication modality for flyers and conversations with patients in a way that ensconces the health behavior within their religious worldview, for engaging the CAB and guiding CAB meetings and interviews, or in its original form to promote religiously-informed behavioral change.

The 3R model, in its original form, addresses previously identified barrier beliefs (i.e. beliefs that prevent or hinder adoption of the desired health behavior) through three means: i) reframing the belief within a relevant religious worldview, ii) reprioritizing the belief by introducing another religious belief that has greater resonance with participants, and iii) reforming the belief by uncovering logical flaws and/or theological misinterpretation.[43]

Through partnership with religious leaders and/or religious scholars, we propose the use of the 3R model, more specifically the reframing and reprioritizing modalities, as an effective way to deliver religiously-tailored communications to relevant project stakeholders. For example, if your project aims to improve rates of a specific preventive care, you can use the reprioritization approach to elevate the value of preventive care, (e.g. while a mammography may be physically uncomfortable, early detection of breast cancer can significantly improve outcomes). In a project where religiosity may play a significant role in healthcare decision making, the reforming approach can be used to tailor your marketing strategy with religiously informed questions, (e.g. “have you ever wondered about the religious arguments in favor of and against living organ donation?”).

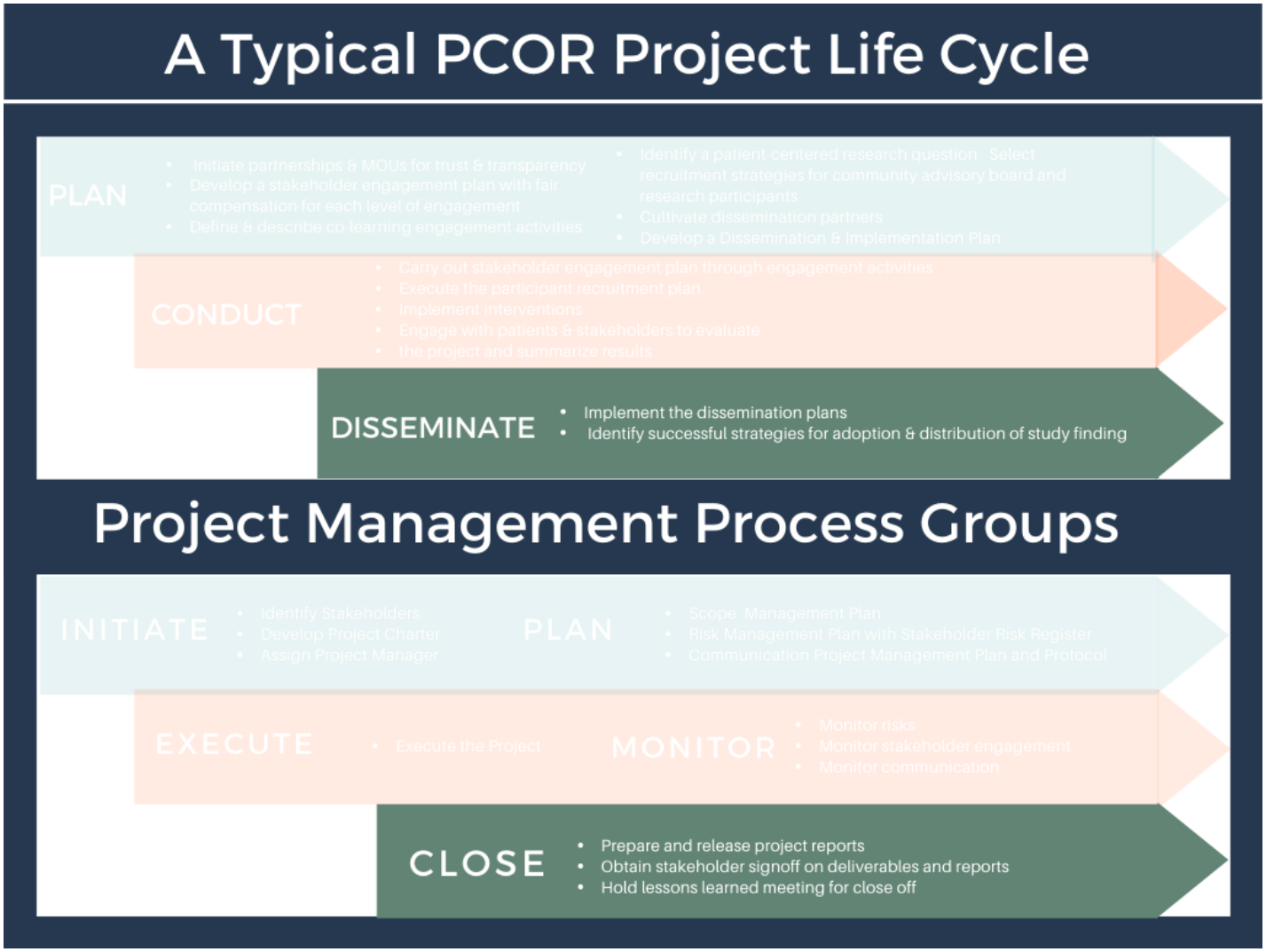
Project Evaluation

In order to assess the healthiness and engagement of both your CAB and your research participants, particularly in longitudinal studies, it is important to regularly evaluate your stakeholder concerns. Such concerns can be addressed through CAB meetings using a survey that evaluates member satisfaction with project progress, the perceived impact of the project on stakeholder groups, and the continued relevance to CAB members. Given that mosque-based PCOR is in its infancy, evaluation should consist of interviews with CAB members at each phase of the project (planning, conduct, and dissemination) by an individual that is not a member of the core research team to assist the researcher. These interviews will provide an understanding of the benefits, relevance, and feasibility of the project and, combined with key metrics, will enable the researcher to identify and forecast potential risks, develop an early understanding of the impact that their project is having on the mosque community, and create a foundation for mosque-based PCOR. The results of these surveys and/or interviews should be presented back to the CAB for shared decision-making and identification of any necessary solutions. Recruitment and retention data provides a valuable metric when monitoring participant engagement and uptake of your intervention (see table below).

Recruitment and Retention Metrics for Project Evaluation

Number of Sign-Ups	N/A
Contact Rate	$\frac{\#\ Contacted}{\#\ of\ Sign\ Ups}$
Consent Rate	$\frac{\#\ Consented}{\#\ of\ Sign\ Ups}$
Cooperation Rate	$\frac{\#\ Consented}{\#\ Contacted}$
Attendance/Completion Rate	$\frac{\#\ Completed\ Time\ 1}{\#\ Consented}$
Attrition Rate	$\frac{\#\ Lost\ between\ Time\ Points}{\#\ Completed\ Previous\ Time\ Point}$

Section V – Disseminating Findings at the Mosque Community



Dissemination Opportunities & Strategies within the Mosque Community

With respect to dissemination of the study findings, PCOR requires documenting outcomes in a way that is meaningful and useful for all stakeholders. Hence, it is crucial for the CAB and research team to be deliberate and strategic about to what data is collected so that it can be relevant to both academic and community audiences. The project dissemination plan created at the planning stage should detail various project outputs (reports, presentations, webinars) and link them to stakeholder audiences. For example, a presentation documenting project findings could be linked to a mosque community audience and be disseminated through a townhall forum, and that presentation could also be modified for an academic conference. Similarly a report of findings could be crafted for a public audience and disseminated via a mosque newsletter or website, and another report could be crafted for policy-makers. The exact dissemination products, and the key audiences project findings ought to be disseminated to, will depend on the project. Sermons by the imams offer a unique opportunity for PCOR project dissemination, and have been used as health education and behavior change modalities in Muslim health studies.[33,34,44,45] We suggest mosque-based PCOR researchers consider using this modality where ethically appropriate and in-line with mosque culture. The table below outlines several potential products and avenues for dissemination of mosque-based PCOR.

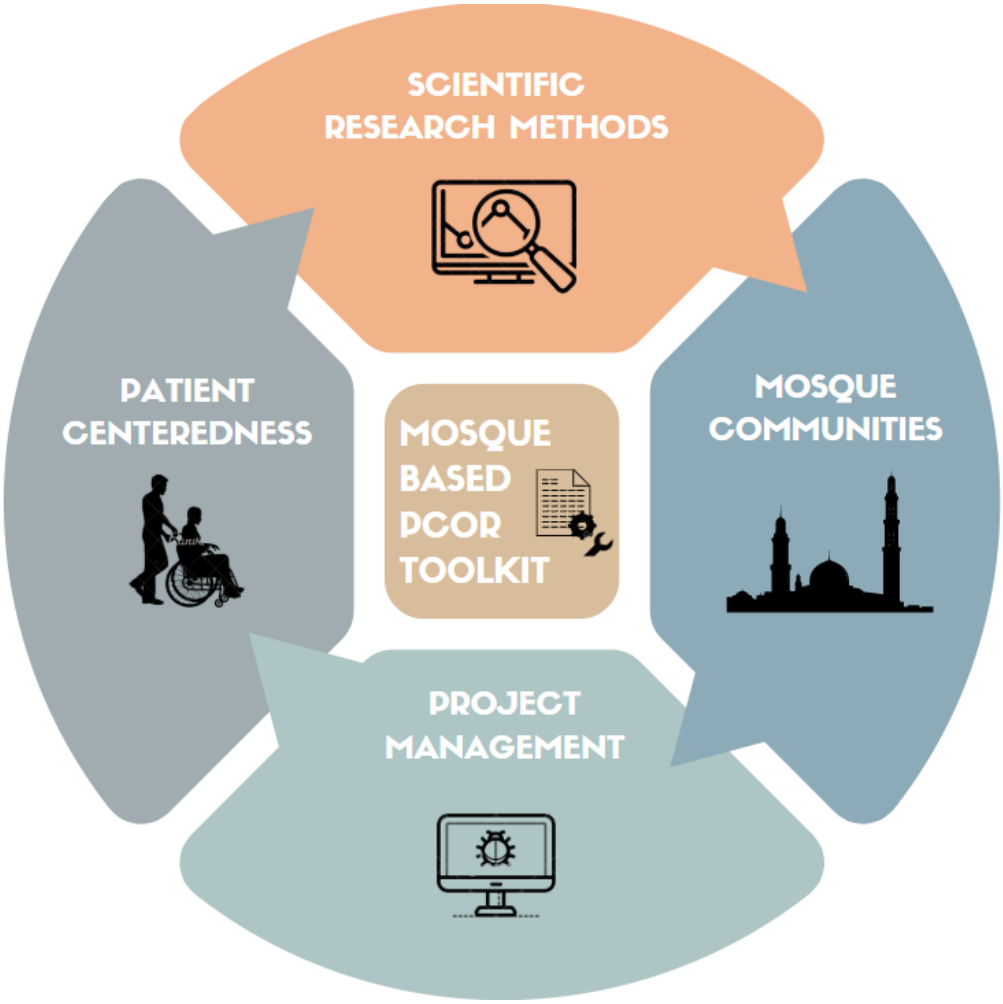
Potential Dissemination Activities for Mosque-Based PCOR

Output	Community Dissemination	Academic Dissemination
Presentation	Get stakeholders to become champions for the cause. They can present or share study findings at different mosque events or community events, such as townhalls.	Tailor presentations for academic outlets such as conferences, press releases, and webinars
Reports	Use the mosque's existing communication channels such as newsletters, bulletin board, Facebook, and website to announce the project closing and share study findings.	Publish study findings in peer-reviewed journals, replication guides, and policy reports.
Replication Guides	Create replication guides for continued implementation of successful interventions.	Create white papers, toolkits, and replication guides outlining your project process and best practices for PCOR researchers

Depending on the project, and the specific findings, implementation of mosque-based PCOR may be facilitated through mosque-based clinics and health programs. These venues offer ready access to Muslim clinicians and patients who could adopt the evidence-based strategies found in mosque-based PCOR. Again consultation with the CAB members will provide insight into whether, and how, project findings can be implemented within particular mosque communities.

After executing the dissemination (and implementation) plan we recommend adapting the 'Closing Process Group' tactic from the Project Management methodology.[26] This process involves recording targeted and tailored dissemination activities as well as holding a "lessons learned" meeting for CAB and ML members. A closing meeting parallels the project kick-off meeting and the project charter can be revisited to evaluate how partnerships and processes worked out over the course of the project. In the table that follows we list several potential dissemination activities to consider in the context of a mosque-based PCOR project.

Section VI - Implementation & Sustainability



What Happens at the Mosque After the Project Is Over?

Unlike a corporate project where a product is delivered as an outcome for the stakeholders to hang on to, research projects very often leave a void. The research team returns to their "day jobs" and the CAB and project communication channels dissolve. To restore trust for the health research projects, PCOR addresses this conventional ending by asking researcher to consider "sustainability" during the project planning and design phases.

To facilitate the continuation of the relationships built during the project, and to keep the mosque community engaged after the project cycle ends, and to continue bringing benefit to mosque community members, we propose to have a translation mechanism from *project to program*. In other words, the project led by the health researchers must be translated into an ongoing program run by a local community-based organization or a healthcare entity.

Translating Projects into Programs

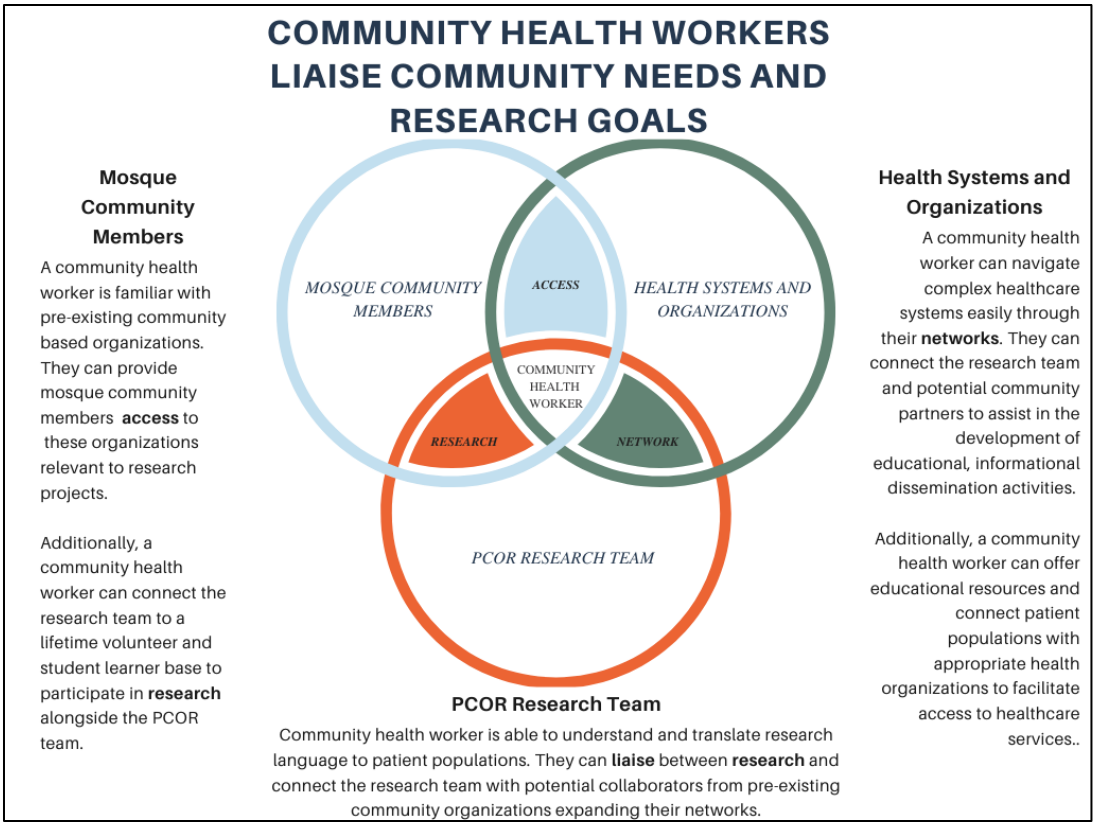
Once the mosque community members are engaged in a reciprocal and mutually beneficial PCOR project, they are more likely to be motivated to push forward with practical initiatives in the mosque community after the project closes. This momentum can be sustained by partnering with local community health organizations to provide ongoing community support for health education programs that incorporate the PCOR project's findings. Alternatively other PCOR projects can be initiated that build on the recently closed project findings. Generating funds for the operation of such programs is critical for translating a project into an ongoing program. Described below are two sustainability models, one where the transition happens to a local community health agency, and the other where local colleges or mosques generate sustainability.

Sustainability Model 1: Internships at the Mosque

Mosques provide an opportunity to train the lay health workers, public health students and other healthcare professionals by hosting and running ongoing health programs for their community members. The researcher team and CAB can build partnerships with the local allied healthcare training programs to provide Internship opportunities for local students to deliver health education or to conduct follow-on research relevant to the recently conducted PCOR project. Such internships can be overseen by the CAB and professors from the academic institution jointly, and have the added benefit of increasing community capacity to effect health programs and research. At the same time, as more mosque community members become involved with health education, the health literacy level of the entire community will be raised.

Sustainability Model 2: Community Health Workers at the Mosque

After the research project is over, the researcher should consider redeploying the patient partner and research partner resources to develop a community health worker model within mosques. Local healthcare agencies, jointly with mosque board members, may be willing to commit funding a Community Health Worker position at the mosque mirroring health ministry models in some Christian communities or community health nurse models elsewhere. This individual would bring manifold benefits to the mosque community as it addresses both the knowledge and infrastructural gap for health education and research through mosques (see figure below). We recommend that the CHW position be staffed by a local hospital or a healthcare entity but should be housed at the mosque to provide patient navigation and other community health services. For the healthcare entities, the CHWs can provide additional help in capturing standardized data for their community patients impacted by the social determinants of health. A recent CMS publication highlights the opportunity for healthcare entities to support their patient needs and wellbeing by way of Z-codes as published by International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM). These Z-codes are used for patient billing to capture "factors that influence health status and contact with health services."[46] They apply to all health care settings and must be accompanied by any performed procedure codes.



Closing Recommendations for Mosque-PCOR Stakeholders

Mosque communities are windows into how well the US healthcare system serves the health needs of American Muslims. Given the lack of national data on Muslim health outcomes, mosque communities offer a largely untapped setting through which to study and intervene upon Muslim health and healthcare disparities. In what follows we suggest next steps for both the mosque community stakeholders and community health researchers to undertake in order to initiate mosque-based PCOR.

Recommendation for the Mosque Board Members and Leaders of Affiliated Organizations

Multiple mosque communities within a geographic region, state or national level should consider establishing a formal *"Mosque-PCOR Advisory Board"* that will oversee the following:

- Oversee the adoption and dissemination of this mosque-based PCOR toolkit
- Ensure that the mosque community health programs are evidence-based and theory-driven
- Evaluate the suitability of mosques for engaging in PCOR
- Provide oversight to all mosque-based health research so that it reflects the needs and priorities of the community, and includes appropriate dissemination and sustainability plans

Recommendation for the Community Health Researchers (and PCOR Teams)

- Many mosque communities' boards members are professional from non-health disciplines, consider coupling project management tools and techniques with established health research frameworks so that a shared understanding of processes is reached between researchers and community stakeholders
- Identify key stakeholders within mosque communities and engage them using PCOR principles to help generate "buy-in" and offer tangible value/benefit to the community from the research
- Develop project plans that pay attention to community needs and cultural values, and in partnership with the aforementioned stakeholders including mosque boards and imams.

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