Initiative on Islam and Medicine
INSTILLING HIKMAH IN HEALTHCARE

Toolkit for Patient-Centered Outcomes Research in Islamic Schools

A Beginner's Resource Guide for Health Research in Islamic Schools

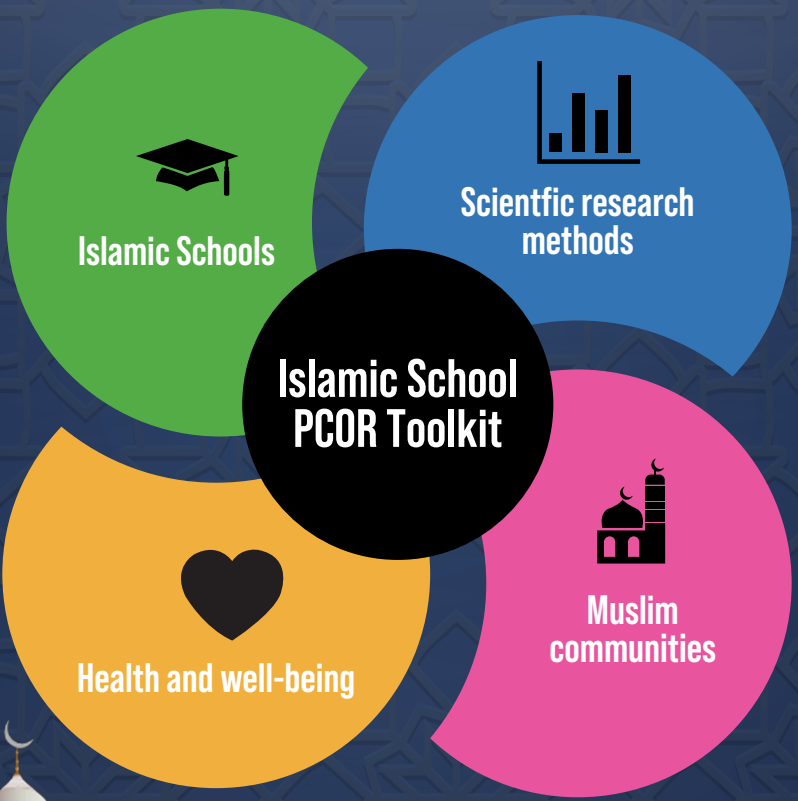

Table of Contents

ACKNOWLEDGEMENTS **4**

SECTION I - INTRODUCTION TO THE TOOLKIT **5**

Why a toolkit for health research in Islamic schools? 6
How to use this toolkit? 7
Intended Audience 8
A Case Study: Ihsan Islamic School 8
American Muslim Health Outcomes 10
Islamic Schools, Health, and Healthcare 11

SECTION II - THE NORTH AMERICAN ISLAMIC SCHOOL CONTEXT **12**

An Overview of Islamic Schools in North America: History, Challenges & Opportunities 13
The Legal and Administrative Structure of an Islamic School 13
Supporting the Development & Growth of Healthy Islamic Schools 14
Application to Case Study 14

SECTION III - PLANNING A PATIENT-CENTERED OUTCOMES RESEARCH STUDY WITHIN AN ISLAMIC SCHOOL **15**

Who are Islamic school stakeholders? 16
Why engage Islamic school stakeholders in planning a patient-centered outcomes research study in Islamic schools? 16
What engagement principles from patient-centered outcomes research can be applied to health research in Islamic schools? 18
Setting up a steering committee for a patient-centered outcomes research study an Islamic school 21
Levels of engagement by stakeholder type and by phases of research in a patient-centered outcomes (PCOR) research project 26

SECTION IV - CONDUCTING A PATIENT-CENTERED OUTCOMES RESEARCH PROJECT IN ISLAMIC SCHOOLS **27**

Framing Research Activities in the Islamic School Context 28
Engaging in Research: How to get started? 30
Navigating IRB? 32
Data: Collection, Privacy, Storage and Ethics 33
Overview of Recruitment & Retention 34
Participant Recruitment Strategies 34
Best Practices for Islamic School-Based PCOR Recruitment 35
Participant Retention 35
Project Evaluation 36

SECTION V – DISSEMINATION, FUNDING, AND ENGAGING EDUCATORS IN PCOR..... 37

Dissemination of patient-centered outcomes research findings- Overview..... 38
Dissemination Opportunities & Strategies Within the Islamic School Community 38
Dissemination Opportunities & Strategies Within the Broader Community served by Islamic Schools 40
Finding Funding for patient-centered outcomes research project..... 41
Professional Development Opportunities and Training for Administrators and Educators to engage in patient-centered outcomes research projects..... 42

REFERENCES..... 43

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Section I - Introduction to the toolkit

Topics covered in this section:

- Why a toolkit for health research in Islamic schools?
- How to use this toolkit?
- Intended Audience for the toolkit.
- A Case Study
- American Muslim Health
- Islamic Schools, Health, and Healthcare

Phases of Research in a PCOR Project

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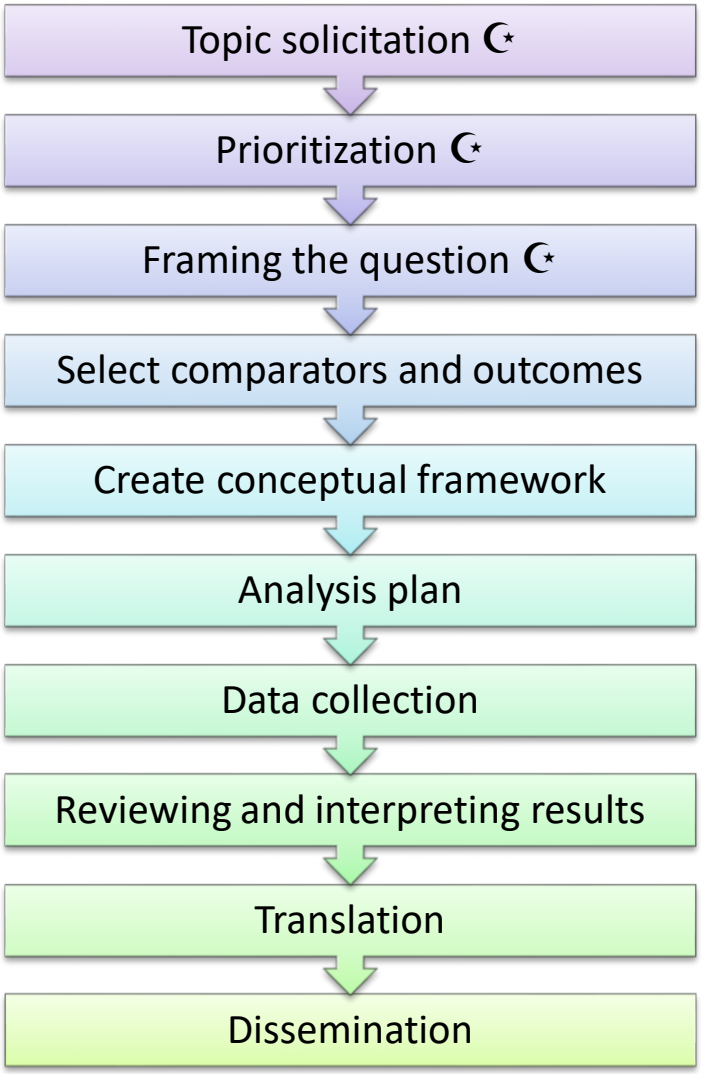


Why a toolkit for health research in Islamic schools?

This toolkit is intended to help Islamic school stakeholders understand and prepare to engage in patient-centered outcomes research (PCOR) in Islamic schools. Patient-centered outcomes research is a specific type of health research that ultimately "helps people and their caregivers communicate and make informed healthcare decisions."[1]

In the context of Islamic schools, the category of patients can include students and their caregivers, teachers, and staff, as well as individuals in the broader Muslim community where Islamic school students live, pray, and play.

We want to begin by considering three questions that build upon each other:

1. Why is it important to engage in research in Islamic schools?
2. Why is it important to engage in health research in Islamic schools?
3. Why is it important to engage in patient-centered health outcomes research in Islamic schools?

1. Why is it important to engage in research in Islamic schools?

Research provides people with data to better understand problems and how to solve them. While personal experiences and perspectives are valuable, research methodologies allow for garnering data systematically and therefore generate insights into problems or issues that are backed by evidence that has been rigorously collected and assessed for biases by experts in the field. Findings from the research are meant to help individuals or groups of people make better decisions.

2. Why is it important to engage in health research in Islamic schools?

When one thinks about school-based research, academic outcomes and behavioral issues are two areas of study that often come to mind. However, there are many health and health-related issues that Islamic schools may face or can help address, including:

- controlling disease outbreaks in the school and broader community, like recently experienced with the COVID-19 pandemic,
- understanding and reducing mental health issues in children and adolescents, such as anxiety, depression, and self-harm,
- measuring the effectiveness of interventions that seek to reduce at-risk behaviors, like pre-marital sex and substance use/abuse, and
- increasing knowledge and opportunities to integrate healthy behaviors that optimize students' health outcomes.

3. Why is it important to engage in patient-centered health outcomes research in Islamic schools?

[1] https://www.pcori.org/research/about-our-research/patient-centered-outcomes-research

Patient-centered health outcomes research engages stakeholders who are connected to the school community and impacted by the health issue at hand at every stage of the research process i.e., from the identification of the health-related issue that will be researched, to how it is researched, and the data is interpreted, and eventually to the implementation of a solution, and project dissemination.

The use of patient-centered health outcomes research often means that:

- patients' perspectives are centered,
- stakeholders are more likely to trust the research and findings, and
- stakeholders are more likely to use research findings to make future decisions.

Centering the perspective of patients, or in our context Islamic school students, caregivers, and stakeholders, means giving greater weight to their advice and input by involving them in some capacity in each of the ten phases of patient-centered outcomes research (see the phases on section cover page).

In addition to the general benefits of using proven research techniques and tools to understand a problem or solution, engaging in patient-centered outcomes research can assist schools in meeting national or regional school accreditation requirements. Specifically, patient-centered outcomes research aligns with the following accreditation standards (#3, #24, #25, and #29)[2] set by Cognia, one of the leading accreditation agencies in the United States. Further, collaborating on a patient-centered outcomes research study can facilitate obtaining the skill-sets and networks to facilitate applications for large federal grants that help the Islamic school obtain resources to enhance the health and well-being of their school community.

How to use this toolkit?

Based on the premise that patient-centered outcomes research can be useful for K-12 Islamic schools, this toolkit aims to provide background research and information, checklists, templates and more that can assist Islamic school leaders in using patient-centered outcomes research to identify and address health and health-related issues in Islamic schools.

This toolkit was written by a team of public health researchers, medical professionals, educational researchers, and Islamic school practitioners. We have drawn upon our varied expertise to create a toolkit that covers the many facets of patient-centered outcomes research in Islamic schools. We

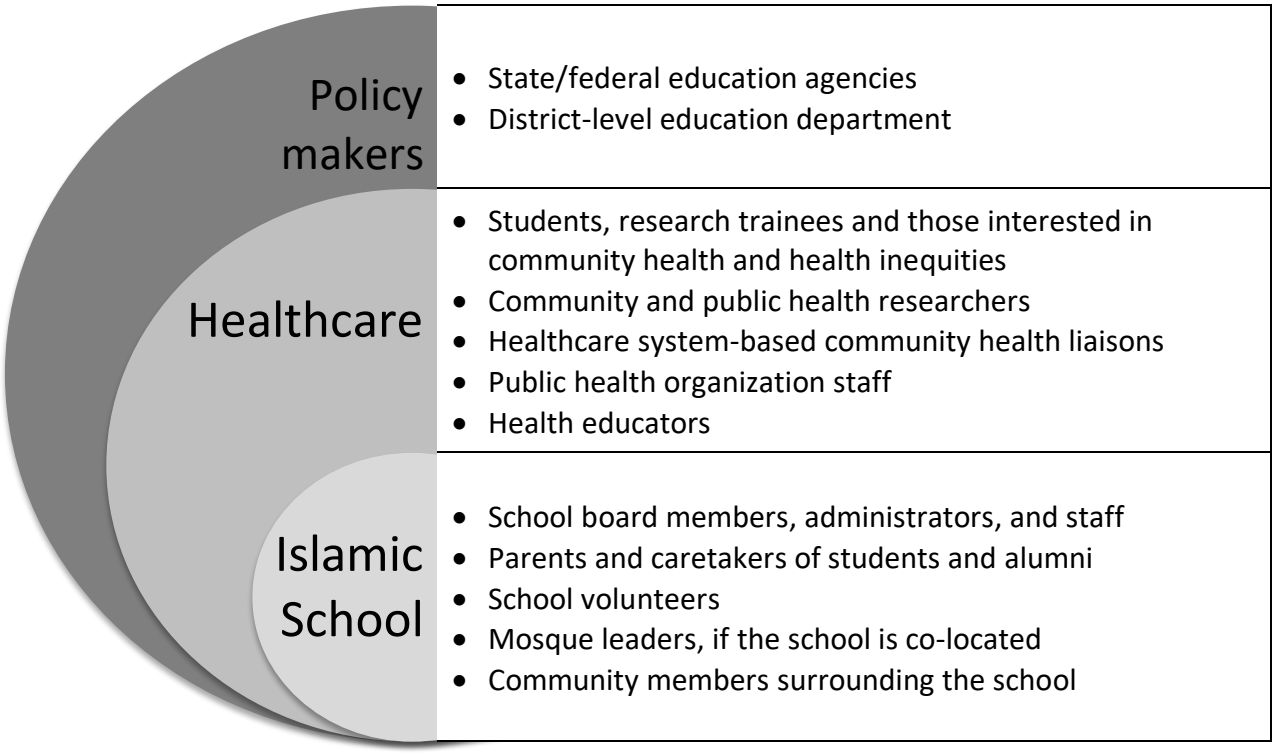
[2] Cognia STANDARD 3: Leaders actively engage stakeholders to support the institution's priorities and guiding principles that promote learners' academic growth and well-being.
Cognia STANDARD 24: Leaders use data and input from a variety of sources to make decisions for learners' and staff members' growth and well-being.
Cognia STANDARD 25: Leaders promote action research by professional staff members to improve their practice and advance learning.
Cognia STANDARD 29: Understanding learners' needs and interests drives the design, delivery, application, and evaluation of professional learning. (Resource: https://www.cognia.org/wp-content/uploads/2021/08/Performance-Standards.pdf)

suggest that anyone interested in engaging in patient-centered outcomes research in Islamic schools read this toolkit once from start to finish and then revisit relevant sections depending on the stage of their intended or in-progress study.

Sections 1 and 2 provide background context and motivation for studying health outcomes in Islamic schools using patient-centered outcomes research methods. Sections 3 and 4 provide the theoretical basis and practical steps for conducting patient-centered outcomes research in Islamic schools. Sections 5 and 6 provide guidance on disseminating research findings and on sustaining programs based on research within Islamic schools.

Intended Audience

This toolkit is written for individuals who may participate in or benefit from patient-centered outcomes research conducted in Islamic schools. Our intended audience includes:



A Case Study: Ihsan Islamic School

To bring to light the different aspects of a patient-centered outcomes research study and how it might be implemented in a full-time Islamic school in the U.S., we introduce this fictional case study of "Ihsan Islamic School." This case will be referenced throughout this toolkit as we work through PCOR principles and methods. The inspiration for this case study is drawn from our (the authors of this

toolkit) familiarity with Islamic schools and the challenges that teachers and students presently confront, particularly after the COVID-19 pandemic.

Ihsan Islamic School (A Fictional School)

Ihsan Islamic School was established 15 years ago in a suburb outside of a growing metropolitan city and serves 350 students between grades KG-12.

Recently, teachers at the school noticed some troubling issues amongst a growing number of students in all grade levels. Specifically, they noted increased student absenteeism and emotional outbursts towards teachers and other students. There was also a rise in the number of students failing academically than in years prior.

Teachers wondered if these academic and behavioral outcomes were related to anxiety and depression amongst the students. Their suspicion was further supported by students' comments about feeling stressed out and unmotivated.

The teachers raised their concerns at a staff meeting with school administration, where they advocated for an intervention to be implemented at the school immediately, before things got worse. Some teachers insisted that the school hire a professional mental health counselor or behavioral health intervention specialist who could work with students who exhibited these signs. Another teacher suggested that additionally the school purchase a school-wide curriculum that supports students' social-emotional learning. The principal decided to investigate these options and then obtain board approval for the non-budgeted interventions.

In this case study, staff are calling for an intervention to identify their students' possible mental health issues. By identifying and addressing students' mental health issues, the teachers hope students' academic performance and behavioral health will improve. Patient-centered outcomes research methods utilized for this case study could support administrators, teachers, students, and other stakeholders, like board members and parents, in understanding the problem at hand, finding an intervention that addresses it, and scaling, modifying, or concluding that intervention as needed.

In subsequent sections, we will refer to this case study to show how the stakeholders at Ihsan Islamic School move from exploring and identifying a health-related issue to engaging in patient-centered outcomes research. This case study also illustrates how factors outside of the school may impact academic and health outcomes inside the school. To better understand these factors (outside the Islamic school setting), let us briefly review the overall health of American Muslims. This will help us identify which factors are modifiable and which ones are not within the Islamic school setting.

American Muslim Health Outcomes

Before we delve into the specifics of the patient-centered outcomes research methodology and principles, it helps to understand more about American Muslims as a unique religious demographic, and to explore selected findings out the population's health issues and outcomes.

American Muslims number nearly 5 million persons and are expected to double in size by 2050.[1] 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.[2] Notably, 56% of American Muslims are immigrants, and approximately 33% live at or below the federal poverty line.[3]

While American Muslims 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 and health decisions across racial and ethnic lines aligns with both theory and available research evidence.[4-12] 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.[6] Muslim values of modesty have also been found to impact health-seeking behavior, cancer screening practices, and patient-physician communication across sociodemographic lines.[5,13] Additionally, Islamic law and ethics influence Muslim behaviors and attitudes towards biomedical interventions such as vaccines, organ transplantation, and end-of-life care.[14,15] These religion-related factors are inadequately addressed by conventional health research and programming, and contribute to unmet healthcare needs.[6,7,12,16] Religious-based discrimination, perceived discrimination, as well as directed bias and prejudice have also been connected with experiences, attitudes, health-seeking behaviors, and health outcomes of American Muslims adults and youths.[17-23]

In addition, additional barriers that make it harder to conduct health research on American Muslims include lack of data on religious affiliation in national healthcare databases, limited capacity of American Muslim institutions and community-based organizations to conduct their own research, and lack of trust between American Muslim communities and health researchers. Data collection on health-related issues in the United States is primarily tracked along racial, ethnic, gender, and sociodemographic lines. Because data is collected along these lines, inequities along racial, ethnic, gender, and sociodemographic lines can be identified. In turn, government, and private institutions, such as the National Institute of Minority Health and Health Disparities (NIMHD), focus on interventions that eliminate these health equity gaps. Though there is a need for more systematic research, the available evidence suggests that the American Muslim community experiences lower levels of health and poorer quality healthcare than other groups.[6,24] Limited capacity of American Muslim institutions to address the mental health needs of American Muslim Youth and a need for more consensus-building projects between American Muslim community-based organizations and diverse stakeholders have been identified as barriers that make it harder to conduct health research on American Muslims.[25,26] Recent community-engaged research studies[4,9,11] have also identified that trust between researchers and the American Muslim community is another barrier that must be addressed to conduct health research with American Muslim communities. Of relevance to this toolkit is health research on Muslim youth, teachers, and families are part of the Islamic school community.

Patient-centered outcomes research on health and well-being in Islamic schools offers a major step forward towards addressing some of these barriers. First, partnering with existing and national American Muslim institutions, like the Islamic Schools League of America (ISLA), leverages the trust that already exists between ISLA and Islamic schools, which are a connected to the American Muslim community from where students attend the Islamic school. During the COVID-19 pandemic ISLA was a critical asset for Islamic schools by providing data-driven support on the impact of the pandemic on enrollment.[27] Second, data collection within a school setting is likely easier than fielding a community-wide survey assuming that a trusting relationship exists between those collecting data, which is typically researchers, and those providing data, which is typically students and their caregivers. Lastly, from an organizational perspective, Islamic schools may have a greater interest compared to other settings, such a mosque or individual households, in addressing health needs of students given the influence of student health outcomes on student academic outcomes. Furthermore, being able to use data related to health in Islamic schools can help make decisions that benefit the well-being of students, staff, and the broader community.

Islamic Schools, Health, and Healthcare

Now that we have a better idea of factors outside the school setting that may be relevant to academic and health outcomes inside the school, we can better identify how Islamic schools may play a role in addressing health outcomes and meet the healthcare needs of students in Islamic schools. Islamic schools typically include students in pre-kindergarten to Grade 8 and some go up to Grade 12. The academic mission, pedagogy, and curriculum is often guided by Islamic morals, etiquettes, and ethics in Islamic schools, which sets them apart from other schools. Some Islamic schools are co-located with a mosque but not always. Schools, in general, play a role in a student's health and well-being in several ways. For example, schools can be an accessible source for mental healthcare,[28] and attending to mental health of students can improve academic performance.[29,30] Islamic schools can play a critical role in, the health and well-being of Muslim students, yet there is limited health research in Islamic schools.[26,31]

There are about 300 Islamic schools in the United States.[32] Many include a mission to foster their students' identities, religion, and to be contributors in their own society and community. Students and faculty may come from several counties and neighboring cities outside of their school district to attend their Islamic school of choice. Muslims of various religious, ethnic, linguistic, and socioeconomic backgrounds may comprise the student population.

Islamic schools can assist in research that identifies and addresses Muslim health and healthcare inequities. They can help establish action-oriented partnerships for research capacity building within the community of need. Importantly, they also offer windows into the health status of the American Muslim community, which is otherwise hidden in aggregate national health data. Furthermore, Islamic schools can implement changes that serve the students, faculty, and other stakeholders to improve student and caregiver health.

Section II - The North American Islamic School Context

Topics covered in this section:

- Overview of Islamic Schools in North America- History, Challenges & Opportunities
- The Legal and Administrative Structure of an Islamic School
- Supporting the Development & Growth of Healthy Islamic Schools

Phases of Research in a PCOR Project

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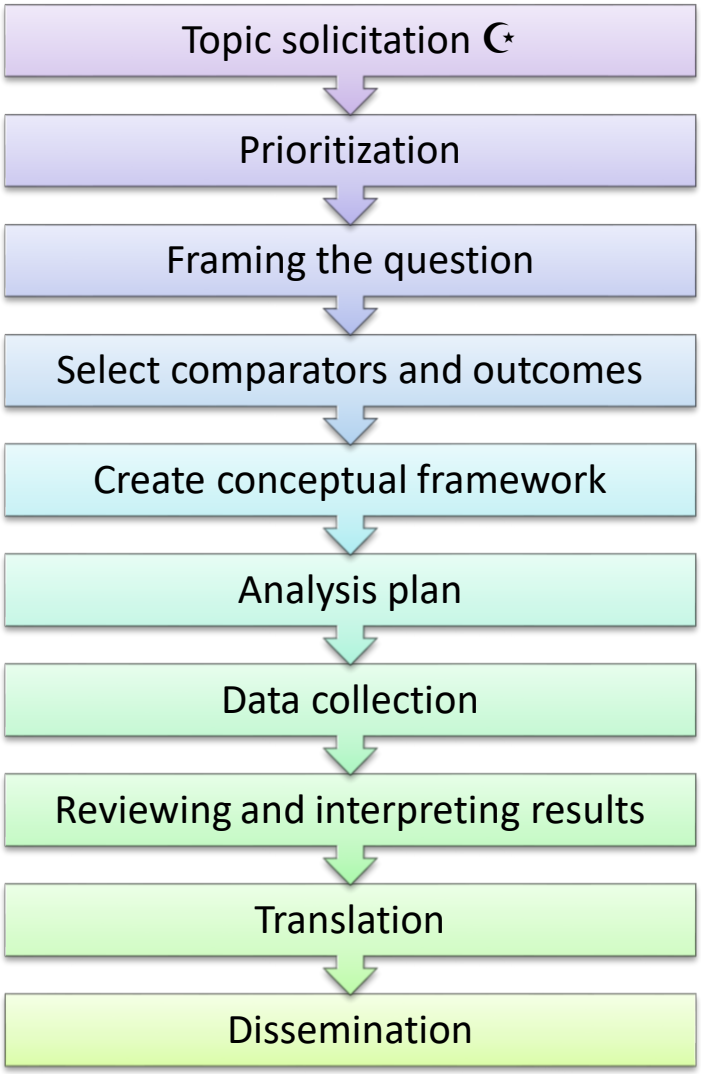

An Overview of Islamic Schools in North America: History, Challenges & Opportunities

According to the Islamic Schools League of America (ISLA), there are at least 300 full-time Islamic schools in the United States, with the largest concentrations in California (n=32), New York (n=28), Texas (n=27) and Florida (n=22)[27]. Most Islamic schools share a common goal of creating a safe space in which Muslim children can learn about and practice Islam -while pursuing academic success. Professional Islamic school organizations provide a reliable platform for collaboration and professional development. Furthermore, many Islamic schools pursue and have obtained national and regional accreditation. Islamic schools across the United States have seen their student demographics become more diverse, in part a reflection of the diversifying and growing Muslim population in America. While serving an estimated less than four percent of Muslim students in the United States, Islamic schools play an important role in providing direct instruction on Islam, Qur'an, and Arabic to American Muslim youth. These schools have also contributed to the development of close-knit Muslim communities across America, where Muslim parents have moved to surrounding neighborhoods to be closer to full-time Islamic schools.

Khan and Siddiqui[33] note, "They [Islamic schools] are more engaged in their communities in terms of activities than the Islamic centers, which largely only provide activities in the evenings and weekends. Islamic schools have employees, students and parents that can be more active within those institutions' missions". Their adherence to professional standards has been certified by national and international accreditation agencies. Yet, room for improvement remains as community Islamic schools struggle with board governance, finances, recruitment and retention of leadership and staff, and developing and deploying a curriculum that is firmly grounded in an Islamic worldview.

The Legal and Administrative Structure of an Islamic School

Almost all full-time Islamic schools in the United States operate and administer services as 501(c)(3) organizations with a volunteer board of directors. There are several different organizational structures for Islamic schools:

- an independent non-profit with a separate board
- a non-profit organization that is associated with an Islamic religious entity, such as a mosque, sharing the same board of directors.
- a non-profit organization that is associated with or co-located with an Islamic religious entity, such as a mosque, with distinct boards of directors.

Boards will hire a head of school or principal to lead, supervise, and provide guidance to the school community of staff, students, parents, and alumni. Roles of school leaders vary depending on the school's organizational structure. A wide variety of decisional authority and governance structures must be kept in mind when designing stakeholder engagement protocols.

Supporting the Development & Growth of Healthy Islamic Schools

While Islamic Schools continue to develop and grow around the United States, there is a need for continued research, professional development, and funding to support their positive trajectory. Given the limited data on the health needs and challenges of Muslim students and caregivers from which Islamic school leaders and staff can draw, Islamic school leaders, often utilize anecdotal evidence and draw upon lived experiences to make decisions about curriculum, student programming and the like. Greater systematic and focused research is needed in Islamic schools to empower these leaders with the evidence upon which to support student and caregiver health and health decisions. Funding preferences should follow constituent-identified priorities. Training, resource development and more are areas where financial and human resources can be invested to create solutions to the problems facing Islamic schools. For example, if Islamic school staff identify burnout as a key factor impacting their mental health and ability to remain in the profession, then research on best practices to combat burnout amongst educators can be engaged and programs implemented.

What is key is that supporting the development and growth of healthy Islamic schools requires a systems-wide approach, and that voices from all constituents, such as teachers, students, families, and staff are considered. Focusing solely on one constituency may not yield as impactful results.

Application to Case Study

Let's apply the ideas from this section to the Ihsan Islamic School case study to see how these ideas may play out in a real-world scenario.

Case Study: Ihsan Islamic School (A Fictional School)

Ihsan Islamic school's Board of Directors are new to health research even though they include those with backgrounds in medicine, business, law, and engineering. When the principal approached the Board with a request for an evidence-based intervention to address student academic and behavioral health outcomes, the Board members could take the following approach to ensure all voices are considered in their decision to allocate funding for this non-budgeted request:

- Seek an expert in student behavioral health outcomes. This would ideally be a Muslim professional or someone who has experience working with the local Muslim community.
- Seek input from teachers and staff who see students daily.
- Connect with a local public school district that has a behavioral health intervention specialist to learn about funding, qualifications, and operationally how to best deploy such an individual within a school setting.
- Reach out to Islamic Schools League of America, other Islamic school accreditation organizations, or Board members at other Islamic schools to explore whether and how others have considered and implemented similar requests. If so, then what was the short- and long-term outcomes of funding such a position.

Section III - Planning a patient-centered outcomes research study within an Islamic school

Topics covered in this section:

- Who are Islamic school stakeholders?
- Why engage Islamic school stakeholders in planning a patient-centered outcomes study in Islamic schools?
- Engagement principles in patient-centered outcomes research
- Setting up a stakeholder advisory group in Islamic schools
- Levels of engagement by stakeholder type and by phases of research in a patient-centered outcomes (PCOR) research project

Phases of Research in a PCOR Project

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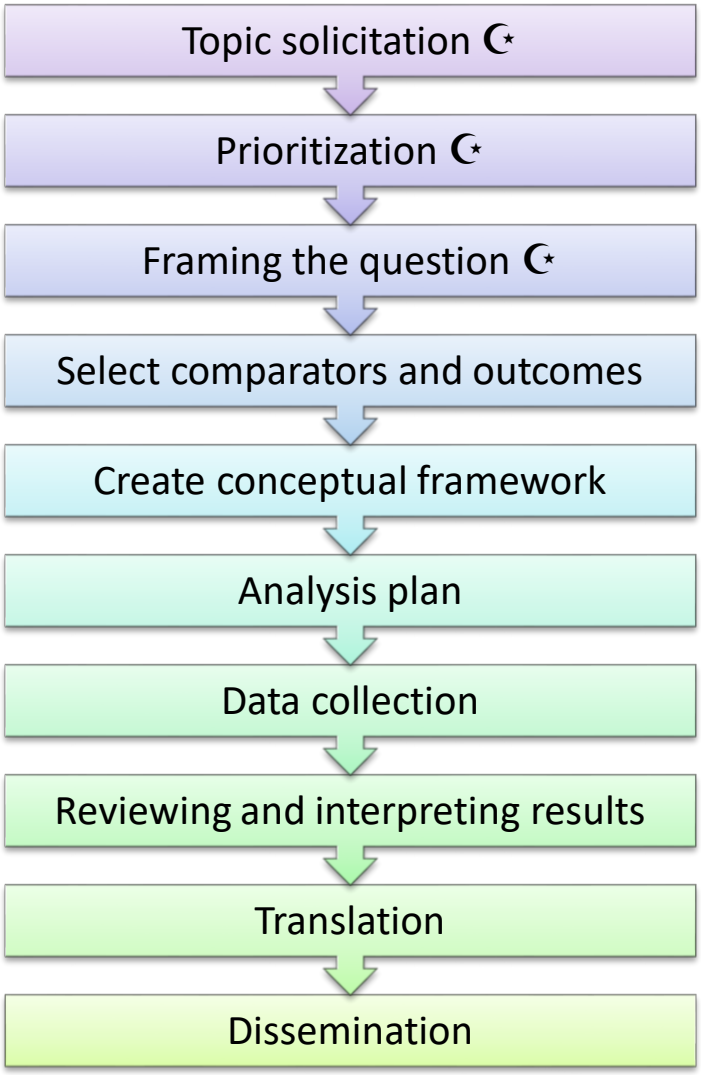


Who are Islamic school stakeholders?

While there are many internal and external stakeholders involved with Islamic schools, this section identifies stakeholders in the context of research on health and well-being outcomes within an Islamic school. The word cloud below highlights some stakeholders who may be worthwhile to engage with at the start of the planning process for conducting patient-centered outcomes research within an Islamic school.

Why engage Islamic school stakeholders in planning a patient-centered outcomes research study in Islamic schools?

Some reasons to engage Islamic school stakeholders in the planning stage (i.e., research phases of topic solicitation, prioritization and framing the question).

Reason #1. Stakeholders can help students, educators and researchers determine the right questions to ask, and later during the analysis plan stage of the project advise on using culturally-appropriate and practical research tools and techniques.

Reason #2. Stakeholders can collaborate with academic researchers to determine which health and well-being outcome(s) to study and identify how these are connected to academic outcomes.

Reason #3. Involving diverse stakeholders can give researchers who are working with Islamic schools a wider perspective on the problem space. Stakeholder can help to fill in gaps in understanding the problem as well as help researchers avoid developing a solution that would either be lacking or not be sustainable or feasible in the Islamic school setting.

Let's now look at our case study to see how this may work in a real-world setting:

Case Study: Ihsan Islamic School (A Fictional School)

The school's co-located masjid (Arabic word for mosque) noticed a low turnout for youth-oriented programming, such as the weekly high schoolers halaqa (Arabic word for knowledge circle) and the annual youth conference. When the mosque's youth director held informal conversations with the youth on this topic two common themes emerged: lack of interest in youth programs and preference to stay home and not be around other students. Some youth mentioned that socializing with other youth at the masjid made them feel uncomfortable, anxious, and nervous, especially if they were also attending the same school (e.g., Ihsan Islamic school).

Based on the above situation, the key stakeholders to engage based on PCOR engagement principles include:

- youth directors of the co-located mosque with Ihsan Islamic School,
- community-based organizations who serve the needs of Muslim youth,
- the community surrounding the school,
- parents and caretakers of students, and
- current and former students of Ihsan Islamic school.

These key stakeholders would ideally be engaged at the start of the health research study so that the behavioral health intervention specialist who is eventually hired by the school is a good match for the specific needs of students and general needs of the surrounding community where students live, study, pray, and play.

Now that we have a better understanding of who the stakeholders might be and why it is important to engage with them when planning a patient-centered outcomes research study we will review several principles from patient-centered outcomes research and discuss how they may be applied in real-world settings. These principles can also be used to solicit topics for a proposed health research study.

What engagement principles from patient-centered outcomes research can be applied to health research in Islamic schools?

Engaging stakeholders from a patient-centered outcomes research lens involves adhering to six key principles. These expert-vetted principles have proven effective in building coalitions for impactful health research. The table below lists each of the six principles with examples of how Islamic schools and their stakeholders may apply them in real-world settings. The case study about Ihsan Islamic School further illustrates the application of these principles.

Table 1. Engagement principles from patient-centered outcomes research as applied to Islamic school-based research.

Principle	**Principle Description**	**Examples of applying the principle to Islamic schools**
Reciprocal Relationships	Collaborations are bidirectional with equal share in decision-making authority. Role and decision-making authority are clearly stated and defined collaboratively among all research partners including patients and other stakeholders.	- Teachers, students, and parents are all involved in coming up with research questions, including topics of interest. - A memorandum of understanding clearly states the roles and responsibilities of each stakeholder, including the researchers. - A student, who is a type of patient based on PCOR stakeholder types, is not treated differently than a principal when asking about important issues affecting their health and well-being in an Islamic school. Application to example of Ihsan Islamic School: A memorandum of understanding (MOU) is co-developed by the research team, students, parents, school board members and school administrators. The MOU is based on Islamic ethics and values and uses the SMART framework for defining project goals including timelines, financial, and legal responsibilities.
Co-learning	Researchers should help stakeholders understand the research process while also learning about what matters most to	- Researchers attend school events, board meetings, and teacher/staff training events to learn about the Islamic school culture.

Principle	Principle Description	Examples of applying the principle to Islamic schools
	patients and other stakeholders.	- Researchers provide opportunities and host forums for Islamic school stakeholders to become familiar with PCOR tools and methods. Application to example of Ihsan Islamic School: A documentary on mental health of Muslim youth is followed by a discussion panel featuring a public health researcher, the local mosque's youth director, a graduate of Ihsan Islamic school who is in recovery and a parent with a student in treatment. The discussion can be an opportunity for the researcher to learn about the needs of the community based on the feedback from those who attend the movie screening and discussion.
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.	- Ask school administrators or a local champion about appropriate level of compensation for time commitment of students, families, teachers, and staff. - Use inclusive language (e.g., from Muhsen and other organizations) when recruiting participants at every stage of the research project. Application to example of Ihsan Islamic School: If the hiring committee for the counselor or intervention specialist includes individuals who are spending time outside of their regular working/school hours, then compensate them a fair amount ($/hour) for their time commitment. Ask them what a fair amount of compensation for their time is.

Principle	Principle Description	Examples of applying the principle to Islamic schools
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.	- Setup regular meetings at a time, location, and mode (in-person or online) that works for as many partners as possible. - Use a method of communication that partners are comfortable with using for keeping in touch. Use different methods for different purposes, such as instant messaging apps for short and quick questions, meetings for longer discussions, and email for sharing documents. - Often individuals have multiple responsibilities within an Islamic school and, therefore, it is important to communicate honestly and frequently with the research time when other responsibilities are a priority over participating in the health research study. Modulate expectations as needed as the project moves forward. Application to example of Ihsan Islamic School: Checking the credentials and references of a potential hire for the counselor/intervention specialist position and sharing all application materials, including reference letters, with the hiring committee demonstrates transparency, honesty, and trust in the hiring process. For the health curriculum, inviting the authors or the lead author of the curriculum to answer questions from teachers, staff, school board members, parents and students will help to build trust in a transparent and honest manner before the rollout of the curriculum. Be sure to include sufficient time for a question-and-answer session during the discussion.

Setting up a steering committee for a patient-centered outcomes research study an Islamic school

Structures, such as a steering committee, advisory boards, or operations teams, are an important part of carrying out patient-centered outcomes research in Islamic schools. Depending on the phase of research, which are listed on the first page of each section of this toolkit, and the type of stakeholder (Table 2), different levels of engagement (Table 3) may be relevant when conducting a health research project in an Islamic school setting.

Engagement mechanisms in patient-centered outcomes research emphasize that the engagement principles (Table 1) be used to formulate a shared vision between researchers and stakeholders to move a project forward successfully. Patient-centered outcomes research also requires that infrastructure is put in place, and engagement plans are designed, to facilitate the participation of important stakeholders in all phases of the project (as far as possible). In our view, engagement activities should converge towards the research questions, e.g., problem to be tackled, and then how best to go about understanding the issues and solving them. Based on our collective experiences we recommend the following engagement structures for patient-centered outcomes research in Islamic schools.

A patient-centered outcomes research steering committee is a proven technique that brings together diverse stakeholders, ensures timely input from community members, and builds a trusting and transparent partnership. Such a steering committee may also be called a CAB or Community Advisory Board. Recent patient-centered outcomes research 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.[34] When considering the composition of the steering committee or the CAB, we recommend thinking through the project from original concept to implementation. For an Islamic school-based project, this includes the processes that you must navigate to enter the Islamic school setting and buy-in from the larger Islamic school community and building trust with students, parents, school administrators and Board members. As described previously, the community surrounding the Islamic school may include other institutions (mosques, clinics, social service organizations) and representatives from these ancillary organizations should be invited to the steering committee.

In the list below, we describe several important considerations when forming a steering committee or CAB prior to starting a patient-centered outcomes research study in an Islamic school.

1. Because Islamic school stakeholders members come from different disciplinary backgrounds, we recommend capitalizing on this diversity by inviting members that come from at least 4 of the suggested PCOR categories of stakeholders (Table 2).
2. Avoid relying entirely on 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 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 the students and caregiver group who are the primary voices that make the project 'patient'-centered.

3. The group should be inclusive in terms of race, ethnicity, and gender so that diverse experiences can inform each phase of the project.

In the table below we mention several important voices and functionaries within the Islamic school community who could be invited to participate on the steering committee or CAB.

Table 2. Types of stakeholders who may be part of a patient-centered outcomes research project in an Islamic school. Some or all these stakeholders may be involved based on the phase of research and level of engagement.

Stakeholder	Definition and examples (modified from original text[35])
Patients	Persons, including students, and their caregivers, as well as educators, with current or experience of illness or injury who are associated with an Islamic school in any way. Examples: - a middle school-aged boy who has an Individual Education Plan based on a clinical diagnosis of anxiety - a school principal with limited physical mobility due to an injury sustained in a refugee camp - a high school-aged girl who has been diagnosed with rheumatoid arthritis - an advocacy group that seeks accommodations for Muslim children and adults living with disabilities (e.g., Muhsen)
Clinicians	Providers of health care in a clinical setting, including physicians, nurses (including school nurses), physician assistants, rehabilitative professionals, pharmacists, mental healthcare providers, complementary and alternative healthcare providers, and professional societies serving clinicians Examples: - School nurse - Pediatricians seen by Muslim families with children who attend the Islamic school - Free clinics for underinsured or uninsured individuals - National medical/health advocacy organizations (e.g., American Muslim Health Professionals, Islamic Medical Association of North America)
Researchers	Those who conduct health-related research, including investigators or funders of research and organizations or associations representing the research community. Examples: - Islamic School League of America (ISLA) and the researchers who work with them

Stakeholder	Definition and examples (modified from original text[35])
	- Non-profit research organizations, such as the Family of Youth Institute, Khalil Center, Institute for Social Policy and Understanding and others. - Researchers at a local university who have an interest in Muslim youth, education, and health outcomes
Purchasers	Those who purchase health benefits for employees and their dependents, including Islamic schools. Also, includes coalitions that may represent Islamic schools at a regional or national level where the coalition or business purchases health benefits for all employees of the schools run by that coalition or business. Examples: - An umbrella organization that operates multiple Islamic schools
Payers	Those who function as financial intermediaries in the health system, including private insurers and public insurers, and organizations representing insurers, such as America's Health Insurance Plans Examples: - Health insurance companies (e.g., Aetna, Optum, Blue Cross Blue Shield, Humana, United Healthcare) - Accountable care organizations focus on children's health (e.g., a children's hospital that provides and pays for healthcare) - State Department of Medicaid if a significant majority of student population is Medicaid eligible
Industry	Companies that design, invest in, or manufacture diagnostics, devices, pharmaceuticals, electronic records systems, and mobile apps connected to health monitoring and healthcare delivery, and organizations that have an interest in health data. These might also include student information management companies who offer a health module and curriculum developers and publishers who distribute books on health and well-being that are taught or used in Islamic Schools. Examples: - Google, Apple, and other app developers - Companies that develop and manage Education Management Information System (EMIS) software - Islamic school curriculum authors, developers, and publishers

Stakeholder	Definition and examples (modified from original text[35])
Hospitals and Health Systems	Organizations where care is delivered, including public and private hospitals and health systems, urgent care centers, retail health clinics, and community health centers, and organizations representing these facilities. Can include an Islamic school's nursing office, or co-located mosque-based clinic. Examples: - Local children's hospital - Federally Qualified Health Center and community health clinics - Free clinics (e.g., IMAN Clinic, UMMA Clinic, HUDA Clinic) - University of Chicago Medicine
Policy Makers	Those who help craft public policy at any level of government, including federal, state, and local government officials; federal, state, and local units of government; and organizations that represent policy makers Examples: - Islamic school research organizations (e.g., Islamic Schools League of America) - School accreditation organizations (e.g., Council of Islamic School of North America, Cognia) - State or federal department of education - Legislators who regulate policies affecting non-public schools - Local school districts
Training Institutions	Those that deliver health professional education include public and private universities and colleges, individuals affiliated with the delivery or administration of health professional education, and trade or professional associations representing these institutions, organizations, and individuals. Examples: - Ohio State University School of Public Health - Teacher education programs in universities

Levels of engagement by stakeholder type and by phases of research in a patient-centered outcomes (PCOR) research project

Table 3. Involvement of stakeholder types by phase of research in a PCOR project in an Islamic School and types of PCOR grants to fund phases of research. A check mark (✓) indicates that a stakeholder type might be involved in the indicated phase of research in a PCOR project based on the Case Study: Ihsan Islamic School presented earlier in this toolkit. In other PCOR projects, all stakeholder types could be involved in each phase of a PCOR project.

		Stakeholder type						
Type of PCORI grants	**Phases of research in a PCOR project[36]**	**Patients**	**Clinicians**	**Researchers**	**Purchasers/ Payers / Industry**	**Hospitals and Health Systems**	**Policy Makers**	**Training Institutions**
Engagement	1. Topic solicitation	✓					✓	
	2. Prioritization	✓					✓	
	3. Framing the question	✓	✓		✓		✓	
Implementation	4. Select comparators and outcomes	✓	✓	✓	✓		✓	
	5. Create conceptual framework	✓	✓	✓	✓		✓	
	6. Analysis plan	✓		✓			✓	
	7. Data collection	✓	✓	✓			✓	
	8. Reviewing and interpreting results	✓	✓	✓	✓		✓	
Dissemination	9. Translation	✓	✓	✓	✓	✓	✓	✓
	10. Dissemination of project findings	✓	✓	✓	✓	✓	✓	✓

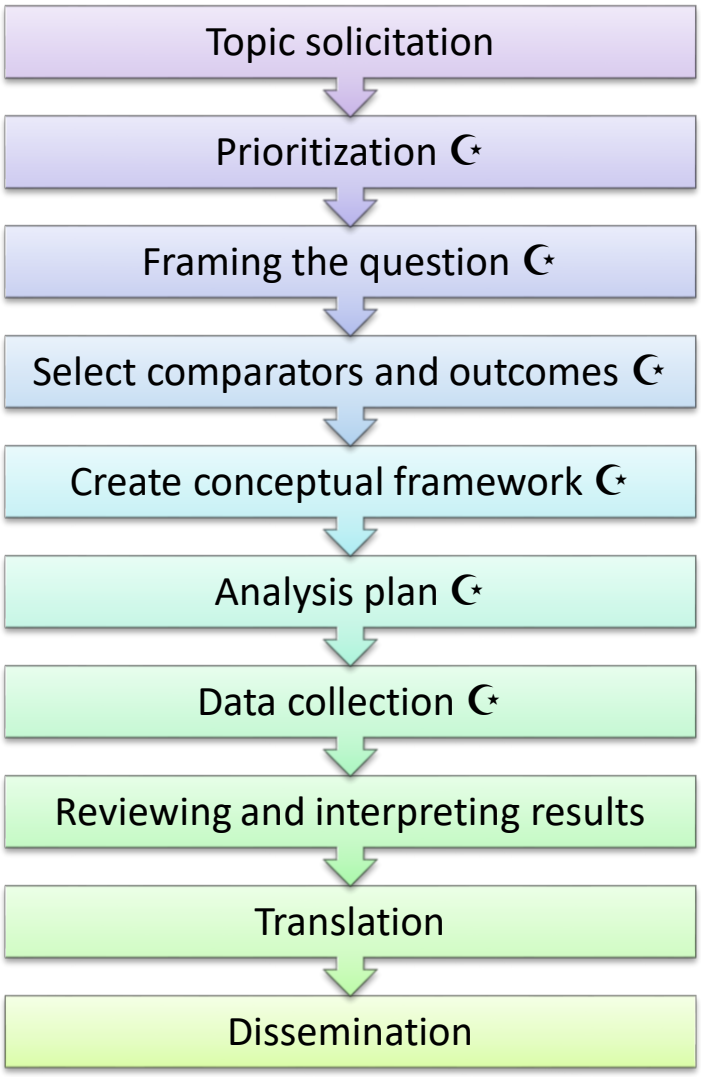
Section IV - Conducting a patient-centered outcomes research Project in Islamic Schools

Topics covered in this section:

- Key Considerations for Conducting Islamic School-Based patient-centered outcomes research projects
- Engaging in Research: How to get started? Navigating IRB?
- Data: Collection, Privacy, Storage, and Ethics
- Participant Recruitment & Retention
- Project Evaluation

Phases of Research in a PCOR Project

The crescent (☪) indicates which phase is covered by this section.



Framing Research Activities in the Islamic School Context

Now that you and your team have adopted PCOR principles to engage Islamic school stakeholders and have also collaboratively settled on a research topic, you are ready to move into the research conduct phase. To be sure, the research topic may yet be a general idea and the research project may still require mapping out, but the fundamental foundations for success are mostly in place; there is a research agenda, there is a team, and there is motivation to move ahead. Before you launch ahead, however, a few critical discussions must be had, and important details ironed out.

The first key determination that must be fleshed out is whether the Islamic school (and its representatives) view themselves as leading the research project, or alternatively see themselves as collaborators/partners to an 'academic' research team (See previous section on What are the key PCOR Engagement Principles?). Clarity on this point is critical as roles, responsibilities, and remuneration all flow from this determination. *Should the school be the lead then ethical, fiscal, and organizational responsibilities fall upon its representatives. On the other hand, a collaborative role circumscribes some duties.* Certainly, a co-leadership model can be employed, but in our experience external commitments and value propositions differ between school leaders, community representatives, and academic researchers. Hence co-leadership can be more aspirational than practical. Regardless, project success will depend on a strong partnership that may evolve as the project proceeds. Indeed, knowledge sharing between the school representatives and academic researchers will generate trust, allow for capacity building on both ends, and produce beneficial outcomes for the community.

The second key determination revolves around whether the proposed research project and its outcomes are central to the aims of Islamic education. Or stated more accurately, do the Islamic school representatives see the project aligned with the core missions of the Islamic school or is the project and its aims more secondary. Certainly, one could frame almost any research endeavor as part of an Islamic call to seek knowledge. There are plentiful statements attributed to the Prophet Muhammad (Peace Be Upon Him) that reify seeking knowledge as meritorious. For example, one report exhorts "*seeking knowledge is a duty upon every Muslim…*"[3]. Similarly, another states "*whoever seeks knowledge, he is atoning for what has passed (in terms of sins)*"[4]. Relatedly the Qur'an instructs the Prophet, and by extension believers, to pray for increase in knowledge[5]. Yet, beyond this surface-level framing, initial Islamic school stakeholder buy-in as well as durable partnerships may be facilitated by purposively delineating research aims that align with the core missions of Islamic school instruction. Moreover, framing the research endeavor within the context of those aims is key.

Such alignment must be deep-rooted, and the project framed as authentically linked to an Islamic ethos. Given this critical importance, a brief foray into the core mission of Islamic

[3] Sunan Ibn Majah, 224
[4] Jami` at-Tirmidhi 2648
[5] Qur'an, Chapter 20, Verse 114

schooling may aid the reader. From a theological perspective, the essence of education is the inculcation of *adab*.

The term *adab* conveys a variety of meanings within the Islamic intellectual tradition including virtue, moral conduct, ethics, proper manners, etiquette, and praiseworthy qualities and dispositions. Arabic lexicographers commonly derive the word adab from the root 'a-d-b', the act of inviting (hospitality), or a marvelous thing; thus, *adab* relates to calling or inviting people to something good[37]. In the field of education, *adab* can be conceptualized as moral instruction or character development, and has cognitive, affective, and behavioral components. With respect to these, Syed Muhammad Naquib al-Attas, a contemporary Islamic authority in the philosophy of Islamic education, notes that *adab* is the "*recognition and acknowledgement of the reality that knowledge and being are ordered hierarchically… and of one's proper place in relation to that reality and to one's physical, intellectual and spiritual capacities and potentials.*"[38]

In terms of behavior, *adab* is reflected in maintaining the proper comportment considering the relationship one has to the audience one is in front of. At the 'highest' ontological level, one must behave with the knowledge that they are always in front of God, as reflected in the well-known and oft-quoted hadith where the Prophet Muhammad instructs his followers that the behavioral aspect of *ihsan*, excellence, is to worship God as though one is seeing and standing in front of Him. This direct connection with God is also reflected in a saying attributed to the Prophet Muhammad (Peace Be Upon Him) which relates that "*my Lord has instructed me in the best of adab.*" Hence the circle begins with knowledge about *adab* coming from God through both parts of revelation, the Qur'an and the statements, actions, and tacit approvals of the Prophet Muhammad (Peace Be Upon Him) and is completed when *adab* is actualized in one's behavior towards others in cognizance of God's gaze being upon them. Islamic education becomes Islamic through its utilization of revelatory knowledge to instill *adab*. This notion is affirmed by, Omar Qureshi, former Provost of Zaytuna College in the United States, and a scholar of Islamic educational philosophy, who connects links cultivation of *adab* to the profession of teaching within an Islamic worldview when he writes "*cultivating adab…is the highest good of education in the Islamic tradition. Adab is a quality of the soul and is considered a habitus (malaka) by Muslim scholars of education. To acquire adab as a habitus requires certain exercises that constitute adab, an askēsis of sorts. This askēsis exists in adab manuals, which the student and teacher are expected to put into practice and eventually embody. Each craft, in the Islamic tradition, has its manuals of adab. When a craft is practiced in a certain manner, it will be practiced with adab. This is what makes any craft, including education, distinctively Islamic.*"[39]

This discussion of *adab* helps us to design, as well as frame, research projects that may be conducted in the Islamic school setting. Research that delineates Islamic virtues and moral frameworks, identifies ways to better instill virtues and good character, or that promotes practices of *adab* in student and teacher relations will likely be considered as intrinsically aligned with the goals of Islamic schools.

On the other hand, health-related research may be seen a bit tangential. Yet, one could design health-related research that connects with the aims of Islamic education. For example, descriptive research that examines correlations between various health conditions and educational outcomes related to *adab* may reveal barriers and facilitators to Islamic education. In this way the students' potential patient identity is foregrounded thus effecting patient-centered outcomes research. Similarly, research on how aspects of Muslim religiosity, particularly the maintaining proper *adab* with God, e.g., religious coping mechanisms, conveys or protects against certain health risks aligns the goals of Islamic education with health outcomes. These sorts of projects do more that give lip-service to the idea of seeking knowledge through research, rather they firmly connect *adab* and health.

As the team hones in on the research topic and project goals, revising or reframing the patient-centered research idea so that it aligns with the goals of Islamic education, or incorporates an element that does so, may generate sustainable, resilient, and effective partnerships as the value proposition for Islamic school leaders, students, parents and similar stakeholders to participate becomes intrinsically linked to the reasons that they are affiliated with Islamic education.

Engaging in Research: How to get started?

While the PCORI engagement rubric (see What are the key PCOR Engagement Principles?) provides the principles for engagement and the types of stakeholders are important to consider, the steps below provide a practical guide on how to start a patient-centered research project in an Islamic school.

1. Human Subjects Research and Data Privacy: Determine if the proposed research is considered human subjects research (see Navigating IRB? for what is meant by human subjects research) and whether or not you will collect personal health information (PHI). Collecting personal health information may require additional safeguards under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) to be in place prior to conducting the research. If you are conducting human subjects research and collecting personal health information, then you may also need to become familiar with the Family Educational Rights and Privacy Act (FERPA), which applies to educational data of students in publicly funded institutions. FERPA may not be applied by every Islamic school so be sure to identify what data privacy guidelines are in place at the Islamic school(s) that will be a partner in the project. Additional details and a comparison of FERPA and HIPAA is available at this website. You will likely need to consult with a researcher to ensure that proper guidelines are going to be followed in the research project.

2. Research Plan: The research plan consists of the research question or hypothesis, the proposed methods, and additional details about feasibility, potential challenges, and solutions, and expected outcomes. The research plan can be a written document that is used to develop a research protocol, which is submitted to an Institutional Review Board. An Institutional Review Board is typically part of a university or research hospital, but

independent Boards also exist to which non-profit organizations may submit a research protocol. The research plan does not mean you have started the research study. Given the importance placed by decision-makers on research quality data and evidence-based interventions it is important to spend the time to get the research plan right and follow proper research guidelines.

3. Implementation of Research Activities: When a research protocol receives Institutional Review Board approval, then the proposed research activities can be carried out by the research team. The amount of time it takes to carry out research activities depends on the methods in the approved research protocol. Sometimes a revision to the research protocol is necessary based on unexpected situations, such as the emergence of a global pandemic, low enrollment of study participants requiring changes in amount of compensation or more inclusive criteria for participation in the study. Research activities in a patient centered outcomes research project include additional phases of data collection, data analysis, and data dissemination.

   Data collection requires getting consent to collect data (if collecting data from students or other types of study participants) and collecting the data over a period. Data analysis requires exploring the data using statistical software or identifying themes in the data using methods from qualitative research. Data analysis provides insights into the data and is used to test the research hypothesis or research question. In patient centered outcomes research, there are specific standards for selecting comparators and outcomes. We highly encourage you to consult a researcher familiar with PCOR methods prior to performing any data collection and analysis. We also recommend using the PCORI Methodology Standard for more information on how to select outcomes and comparators.

   Comparators are an important type of outcomes in comparative effectiveness research, which is a type of patient-centered outcomes research where the effectiveness of a current intervention or usual care is compared to a new intervention. In the case of Islamic schools, this could be as simple as measuring how aware students are about mental health topics in a Grade 8 class where one class receives health education using a newly developed Islamic school health education curriculum and another class does not take part in this new curriculum.

   Another type of research activity might include creating a conceptual framework that will guide all research activities. The following document offered by PCORI can help Islamic schools and researchers develop such a conceptual framework: Developing Conceptual Frameworks to Inform and Guide PCOR.

4. Dissemination and translation: After research activities are completed, which includes data collection, analysis, and interpretation of results, the research team may choose to translate their findings into practice or disseminate their findings in the scientific (e.g., conference presentations, academic lectures) and non-scientific (e.g., community lecture, townhall

meeting, public webinar, executive summary) community. See next section for more on dissemination.

Navigating IRB?

IRB stands for *institutional review board*. The IRB is a group of individuals who review and approve human subjects research prior to the start of research activities. As noted above, IRBs are often part of research organizations, such as academic institutions or governmental agencies. Applying for approval of a research study is typically done by the project leader (also termed principal investigator) of the study. The documentation usually required by an IRB includes the following: a research protocol, a recruitment script, and a sample consent form (if needed), an interview guide or survey questions (depending on research activities), and other study materials, such as flyers or data collection worksheets.

There are several challenges associated with submitting and working with IRB prior to initiating research activities. The first set of challenges are related to terminology, which is often not easy to navigate for those with no or limited experience with conducting research. For example, a "human subject" is defined as "a living individual about whom an investigator (whether professional or student) conducting research:

- Obtains information or biospecimens through intervention or interaction with the individual, and uses, studies, or analyzes the information or biospecimens; or
- Obtains, uses, studies, analyzes, or generates identifiable private information or identifiable biospecimens."[6]

Based on this definition, some types of research in an Islamic school setting may not meet the criteria of human subjects research, and therefore may only an IRB to judge them as exempt from the need for oversight. A useful decision tool for determining whether you are doing human subjects research is the "Am I Doing Human Subjects Research?" website. It is recommended that this decision tool be used in partnership with a researcher who is leading or part of a research study involving Islamic schools. Another set of challenges is related to the amount and variety of documentation that is often required by IRB for review.

Two types of IRB exemptions may apply to health research in school settings. The educational exemption which states "Research, conducted in established or commonly accepted educational settings, that specifically involves normal educational practices that are not likely to adversely impact students' opportunity to learn required educational content or the assessment of educators who provide instruction. This includes most research on regular and special education instructional strategies, and research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods."[7] Examples of this type of research might include delivering health education in Islamic schools and comparing the level of knowledge on health topics between classes receiving or not

[6] https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/index.html
[7] https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/common-rule-subpart-a-46104/index.html

receiving the health education content. Another type of IRB exemption is survey research or interviews where one of the three conditions[8] are met. Examples of this type of research in Islamic schools might include interviewing students about anxiety and depression, level of knowledge about various health topics of interest to the steering committee. Once again, we highly recommend working with a researcher to determine what level of IRB review will be needed for the selected research question(s).

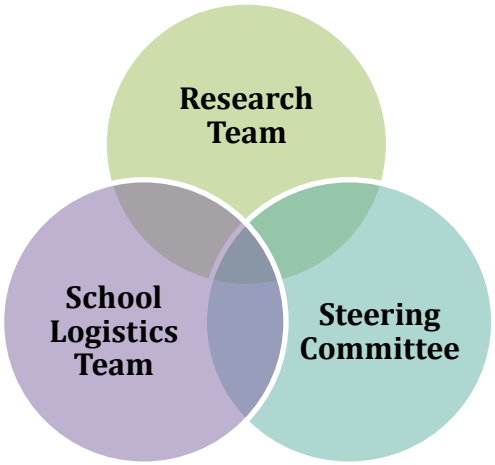
Data: Collection, Privacy, Storage and Ethics

Typically, there are two types of data: A) Qualitative, such as quotes, interviews, and notes collected through interviews or focus groups and B) Quantitative, such as numbers, maps, or charts, collected through databases or surveys and analyzed using statistics and data analytics methods. In addition to types of data, there are different safeguards and regulations that must be followed based on type of information. Data may be classified as personal health information (PHI) if they contain any health data, such as weight, height, blood pressure, medications, or diagnosis. Data may be classified as personally identifiable information (PII) if they contain any data that might be used to identify an individual, such as name, address, and social security number.

In a patient-centered outcomes research study within an Islamic school, if a survey asks students among symptoms of anxiety or depression and collects their name and grade, then these data would be quantitative personal health information and subject to more strict data storage and privacy rules. These data may need to be stored on computer servers that meet certain security protocols, such as HIPAA-compliance or protected data environment. On the other hand, we could also ask students an open-ended question during class and only writing down their responses without collecting any identifying information. These types of data would be qualitative data without any classification for privacy since there would not be any way to identify individuals who provided the data. This would require less stringent data security and storage requirements and storing them on school-managed computers may suffice depending on IRB approval of the research study.

[8] (i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects.
(ii) Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or
(iii) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by §46.111(a)(7).

Overview of Recruitment & Retention



Along with the PCORI Engagement Principles described above, the following techniques and best practices can improve participant recruitment and retention in Islamic school settings. Here, the researcher (from the Research Team) should consider how steering committee/community advisory board members can support and enhance the Islamic school and school stakeholder's interest for, and awareness about, the patient-centered outcomes research project. A School Logistics Team may also be needed to plan and implement on-the-ground logistics related to research activities, such as administering surveys with students at the least disruptive time or distributing and collecting consent forms in multiple languages from parents. The research team should also utilize the various social networks connected to the school, such as board members, local mosques, youth groups, and parent teacher organization (PTO), to communicate the value of the project to potential participants in cultural vernacular.

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

- Identify the most promising venues at the school, such as parent-teacher conference nights, for recruitment activities depending on the nature of the research activities
- Ensure that the design of recruitment materials (flyers, announcements, etc.) are appropriate culturally and most poised to communicate the value proposition to all stakeholders in the research project
- Actively recruit participants into the study through their networks and functioning as trusted cultural liaisons

Participant Recruitment Strategies

The social structures of Islamic schools 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, Islamic schools are host to several academic and extracurricular activities, social events (e.g., fundraisers), and modes of communication. However, effective execution of an Islamic school-based recruitment strategy relies upon support from Islamic schools leadership, which should be represented on the steering committee, and an Islamic schools logistics team comprised of key Islamic school administrators and staff who can ensure the research team has access to relevant venues. As in the figure above, a successful recruitment strategy incorporates the research team, steering committee,

and the school logistics team. Members of the research team must present a provisional recruitment plan the steering committee, who may include the School Board member, the school principal, and teachers, for permission as well as implementation advice. Once support has been obtained from this high-level group, the school logistics team should discuss data collection logistics, establish lines of communication throughout the various Islamic school community networks and organizations, and develop staffing plans for recruitment.

Best Practices for Islamic School-Based PCOR Recruitment

Table 3. Efficiency of different recruitment modalities or methods based on experiences of authors of this toolkit.

Recruitment Modality	**Efficiency**
Recruitment tables before and after Friday Jummah prayer service (if offered at the school)	High
Recruitment tables at social meetings, cultural events, and school functions	High
Announcements made by Islamic school leaders during worship services or other events	High
Sign-ups through school newsletters	Low
Sign-ups through flyers	Low
Sign-ups generated through social media postings	Low

While a range of potential recruitment avenues exist to an Islamic schools-based patient-centered outcomes 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, Islamic schools 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

Retention is a term used in research to describe how many study participants remain involved in research activities over the course of the research project. 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 an Islamic school -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 steering committee members to maintain interest.

Project Evaluation

Project evaluation is the systemic collection of information about the activities, characteristics, and outcomes of the project. The information collected through project evaluation can help make decisions about the project and improve the effectiveness of future projects. Project evaluation is important for making changes to the implementation of findings from a project in other Islamic schools, which may not look the same as where the initial project findings were based on in the first place. Therefore, seeking a project evaluation as part of the overall patient-centered outcomes research project ultimately helps to generalize the findings of the project for the benefit of other students, parents, teachers, and staff. A detailed description of how to do project evaluation is beyond the scope of this toolkit. We recommend using the following resources to learn more about project evaluation and other types of evaluation as they relate to your specific health research project in the Islamic school setting. As well, reaching out to ISLA, who have experience with evaluation, is recommended.

Evaluation resources:

- Program Evaluation for Public Health - Link
- Types of Evaluation in Health Promotion and Disease Prevention Programs - Link
- The Evaluation Center, Checklists for Evaluation - Link

Section V – Dissemination, Funding, and Engaging Educators in PCOR

Topics covered in this section:

- Dissemination- Overview
- Dissemination Within the Islamic School Community
- Dissemination Within the Broader Community
- Finding funding for patient-centered outcomes research project
- Engaging Administrators and Educators in patient-centered outcomes research projects

Phases of Research in a PCOR Project

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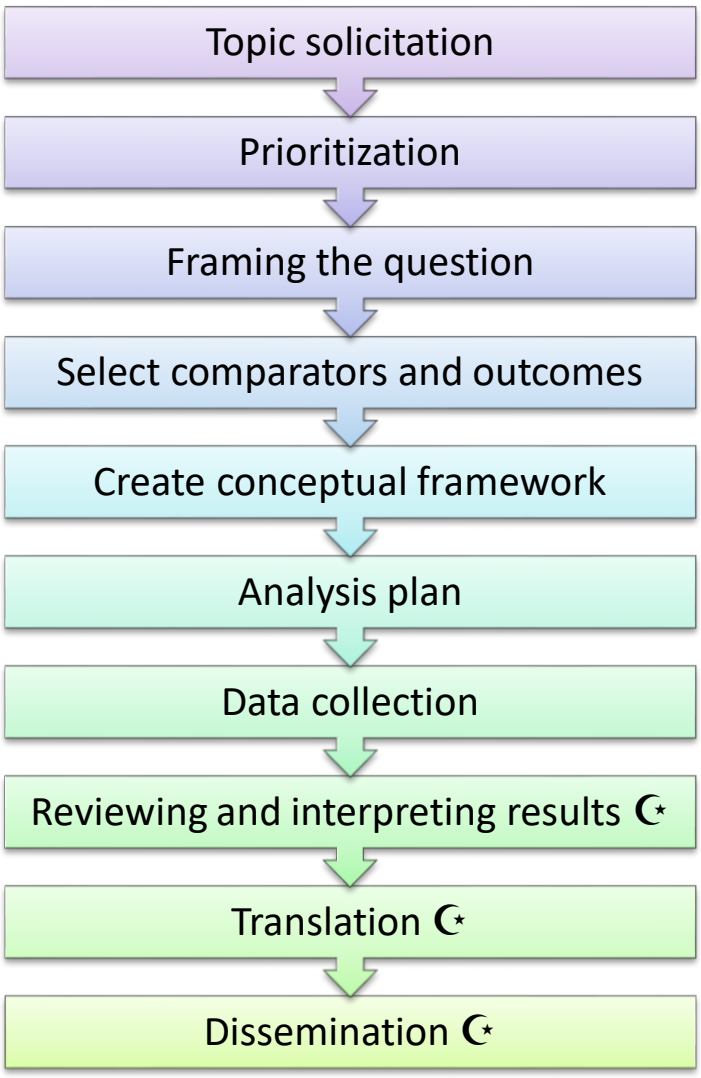

Dissemination of patient-centered outcomes research findings- Overview

With respect to dissemination of the study findings, patient-centered outcomes research requires documenting outcomes in a way that is meaningful and useful for all stakeholders. Hence, it is crucial for the steering committee or advisory board and the research team to be deliberate and strategic about 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 and link them to stakeholder audiences (see previous section on Islamic school stakeholders for examples).

For example, a presentation documenting project findings could be linked to the Islamic school community, in particular, parents, staff, and board members. This could be a Google Slides or PowerPoint presentation with a few slides using simple and easy-to-understand language about the overall project. The presentation could be disseminated through a town hall forum, and then modified for an academic conference. Key findings could also be presented as highlights to teachers, for age-appropriate dissemination via school and classroom newsletters, and incorporated into content-related, project-based classroom lessons for students.

The exact dissemination products, and the key audiences project findings ought to be disseminated to, will depend on the project. Regarding Islamic schools, there are *two distinct communities to consider*, those within the Islamic school community, and those within the broader community served by Islamic schools. Dissemination linkage between the two communities may be found through the associated Islamic entity via sermons, newsletters, and events that share content and community members, where this is ethically appropriate and in-line with school, masjid/mosque, and community culture.

Below we will consider different types of dissemination plans as they relate to the two different Islamic school communities.

Dissemination Opportunities & Strategies Within the Islamic School Community

Within the Islamic school community there are distinct key audiences which require targeted and tailored dissemination methods: students, parents, and school staff (admin, teachers, support personnel, and board members).

Table 5. Methods of disseminating to community and academic audiences within the Islamic school community.

Output	**Community Dissemination**	**Academic Dissemination**
Presentations (staff-oriented & classroom-	Get stakeholders to become champions for the cause. Have	Tailor presentations for academic outlets such as webinars,

Output	Community Dissemination	Academic Dissemination
oriented)	staff members, who were involved in the project in any way, share project findings at school events, such as professional learning communities, staff meetings, and professional development session, to inform peers. In addition, ensure that the information disseminated to inform students in the classroom is in age-appropriate methods such as classroom discussions, projects, and focused lessons that relate to the curricular standards.	professional journals, conferences, and professional development workshops.
Presentations (student-led)	Get stakeholders to become champions for the cause where students can share key findings to peers and community members in classroom and school events, such as debates, halaqas, awards ceremony, sermons, assembly programs, and newsletters.	Tailor presentations for academic outlets such as student academic journals, and regional debates.
Presentation (parent-led, parent-focused)	Get stakeholders to become involved where parents can share findings with other parents, staff and school members at town halls, webinars, and in school newsletters. Staff can also present findings to parents in a similar manner. Parents and staff who are active in social media groups can share data and findings as posts in the groups within these platforms (X/Twitter, Instagram, LinkedIn, Facebook, etc.).	Tailor presentations for academic outlets such as conferences, press releases, and webinars.

Output	Community Dissemination	Academic Dissemination
Reports	Use the school's existing communication channels such as classroom & school newsletters, student newscast, classroom & school blogs/newsletters, school Facebook, school & classroom websites to announce project developments 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 patient-centered outcomes researchers. Content can be adapted and included for classroom use through inclusion in school curriculum guides and lesson plans related to the content of the findings. Conduct a workshop on implementing findings through interventions.

Dissemination Opportunities & Strategies Within the Broader Community served by Islamic Schools

Within the broader community served by Islamic schools, there are several constituencies served. These include those individuals in the general geographical neighborhood (Muslim and non-Muslim). Another constituency is the broader school and religious community, including friends, family, alumni, business associates, and worshipers at the religious prayer space which is often located at or near an Islamic school.

Table 6. Methods of disseminating to community and academic audiences withing the broader community.

Output	Community Dissemination	Academic Dissemination
Presentations	Get stakeholders to become	Tailor presentations for

	champions for the cause. Have staff members share out findings at community-wide school events such as holiday celebrations, sermons, lectures, webinars, and other public events. Alumni can also share out and/or have information shared with them by other school community members. Highlights of findings can also be included in the information shared with community visitors, on school tours, and with visiting dignitaries.	academic outlets such as webinars, professional journals, conferences, and press releases, as well as TV news interviews.
Reports	Use the school's existing communication channels such as school newsletters, mosque bulletin, marquee, stadium signage, community/city newspapers, website, Facebook, etc., to announce the project closings and share study findings.	Publish study findings in peer-reviewed journals, policy reports, and school publications.
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.

Finding Funding for patient-centered outcomes research project

Funding is one of the first questions when it comes to starting a health research project. The following resources offer a starting point for Islamic schools and researchers interested in engaging stakeholders, conducting research, implementing evidence-based programs, and research dissemination related to patient-centered outcomes research.

- Patient-Centered Outcomes Research Institute offers engagement awards, research

awards, and dissemination and implementation awards.

- School-based Health Centers are being funded in parts of the United States. We recommend searching for partnerships with such Centers, which often have a research and evaluation component.
- Federal agencies, such as the US Department of Education, National Institutes of Health, and the National Science Foundation offer grants to conduct research on academic and health outcomes of students. The Centers for Disease Control and Prevention also offers grants to build capacity of schools for improving children's health outcomes.
- Partnering with researchers at the Islamic Schools League of America is a great option since they might be able to facilitate connections with health researchers from academic institutions.
- Foundation, such as the Robert Wood Johnson Foundation, also offer funding from time to time to support children's health in and out of educational settings.

Professional Development Opportunities and Training for Administrators and Educators to engage in patient-centered outcomes research projects

A limited number of conferences specifically tailored to Islamic school educators, administrators, and teachers, currently occur in the United States on a regular basis. These conferences present a strong opportunity for professional development and training for administrators and educators to engage in patient-centered outcomes research projects. In addition, webinars and online workshops are increasingly popular, as accessibility is increased due to the virtual nature of these events. These can be scheduled in a way to maximize participation by hosting them during "slower" times in the school calendar, i.e., October, February, March or April (though these vary depending on region and schools).

<u>Professional development and training for administrators and educators should focus on:</u>

1) Buy-in: Informational webinars and other forms of communication that inform educators about what patient-centered outcomes research is, and why it is beneficial for use in school settings.
2) Communicating the scope and diverse range of studies that could be approached using a patient-centered outcomes research framework.
3) Case studies of actual PCORI funded projects in school settings.
4) Coaching on PCORI grants to support the development and implementation of patient-centered outcomes research projects in Islamic schools.
5) Partnership development between health researchers and Islamic school administrators and teachers to strengthen relationships that can serve as the foundation of future patient-centered outcomes research projects.

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