Faith Community Person-Centered Workgroup: Summary of Launch Meeting and Initial Blueprint to Guide Partnership Efforts

March, 2017

The Faith Community Person-Centered Workgroup of the Coalition to Transform Advanced Care (C-TAC) estbalished the groundwork for a movement to improve how faith communities and stakeholders (health systems, health plans, clinicians, and researchers) *work together* to care for our country's sickest and most vulnerable people.

This blueprint is intended for faith communities and stakeholders to use to develop stronger partnerships, work together more effectively, and change advanced care delivery to be more person-centered more quickly.

Foundations of the Workgroup

Rooted in the Faith Community. The workgroup is an important part of a core C-TAC strategy to systematically link community-based and health system models of care in order to yield better access to care and better outcomes. The group is rooted in the faith community, which reflects the faith community's unique role and ability to reach, support, and advocate for people and families living with advanced illness. Moreover, the group's makeup reflects the centrality of faith for so many in the experience of living with advanced illness and in dying. C-TAC's vision is that all Americans, *especially the sickest and most vulnerable*, will receive comprehensive, high-quality, person-centered care that is consistent with their goals and values and honors their dignity. Thus, the faith-based composition of this workgroup also reflects the faith community's ability to reach and serve the sickest and most vulnerable, particularly minority populations in America who are disproportionately affected by advanced illness and inadequate access to medical and social care. Workgroup members represented African American churches in particular. But, as C-TAC carries out its strategy to link community-based and health system models of care, our goal is to grow and diversify our membership.

Reflecting Ubuntu. This workgroup articulated its grounding in the philosophy of ubuntu. The word ubuntu is South African. Nobel Peace Laureate Archbishop Desmond Tutu explains its meaning this way:

> [Ubuntu] is to say, "My humanity is caught up, is inextricably bound up, in yours...A person with ubuntu is open and available to others, affirming of others, does not feel threatened that others are able and good, for he or she has a proper self-assurance that comes from knowing that he or she belongs in a greater whole and is diminished when others are humiliated or diminished, when others are tortured or oppressed, or treated as if they were less than who they are.[1]
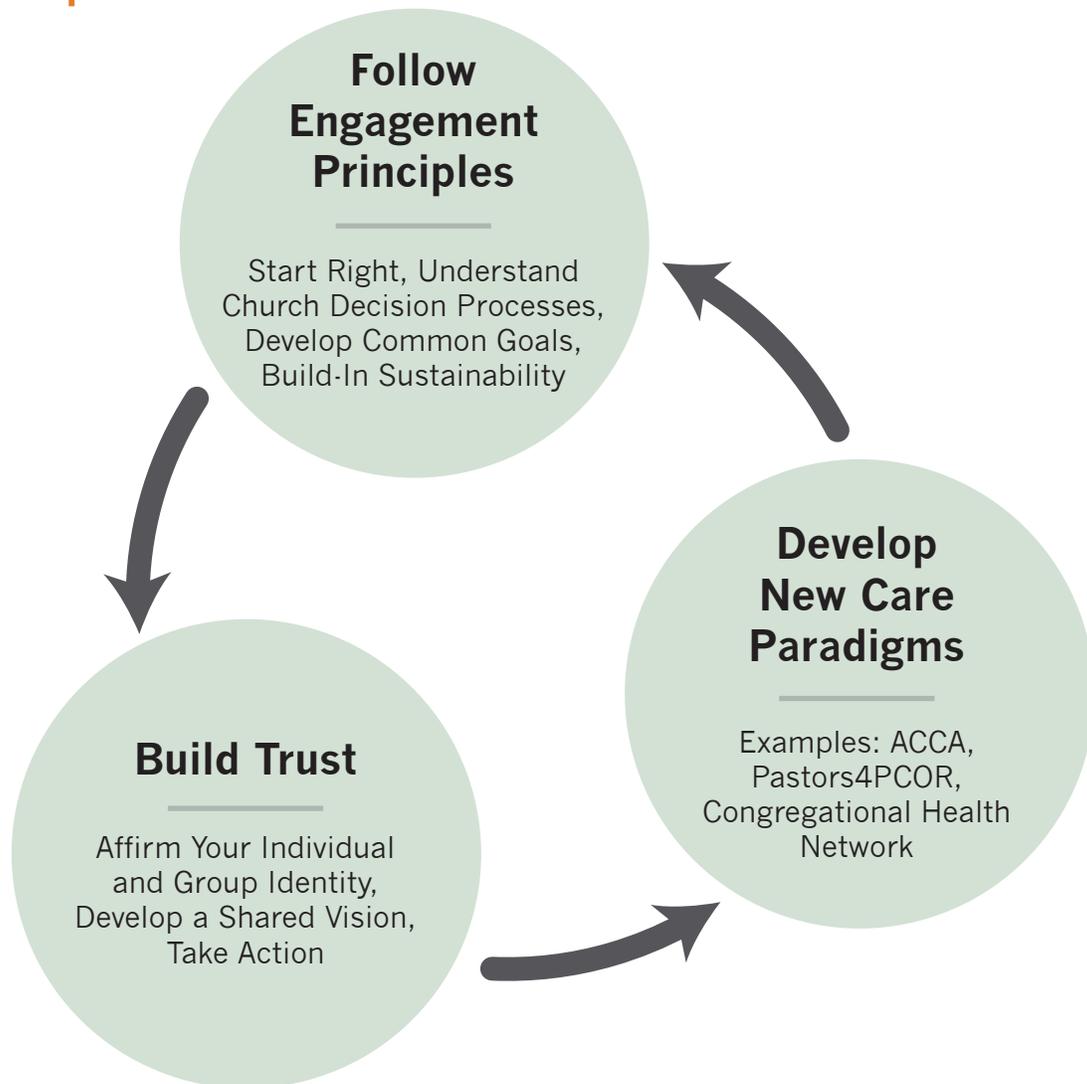
To embody ubuntu is to grasp one's own humanity by recognizing others' humanity. No one can be human alone. As the workgroup put it, "You are because I am. I am because you are." Just as individual humans are interconnected in this way, so are our institutions. Thus, the workgroup's blueprint (shared below) emphasizes the need for faith communities, health systems, health

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1. Tutu, Desmond. *No Future without Forgiveness.* New York: Doubleday, 1999. Print.

plans, clinicians, and researchers to connect and strive to fully understand one another in their shared work.

Developing New Paradigms. The workgroup recognizes that ubuntu stands in contrast to the common philosophy of rugged individualism, which stems from America's frontier culture and reflects the belief that individuals must take care of themselves. Thus, the workgroup acknowledges that transforming advanced illness care requires new paradigms. The blueprint emphasizes the ongoing, iterative nature of such work and that partnerships can achieve new paradigms.

The Blueprint[2]

Follow Engagement Principles

Start Right, Understand Church Decision Processes, Develop Common Goals, Build-In Sustainability

Develop New Care Paradigms

Examples: ACCA, Pastors4PCOR, Congregational Health Network

Build Trust

Affirm Your Individual and Group Identity, Develop a Shared Vision, Take Action

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2. The blueprint mentions three examples of new paradigms—the Alameda County Care Alliance (ACCA), Pastors4PCOR, and the Congregational Health Network. These examples are described in Appendix A.

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A problem that is inadequately defined will be inadequately solved.

—Dr. Rev. Yvonne Delk

1) Follow Engagement Principles

Start Right

Understand historical and current context. Trust is an important part of today's context. Partners seeking relationships with the faith community to improve advanced illness care for African Americans must understand how both history (e.g., the 40-year Tuskegee Syphilis Study which withheld treatment from African American men and was conducted without informed consent) and today's challenges (e.g., lack of access due to socioeconomic factors, racial bias, etc.) engender mistrust of the health system. "The reality is that it's a context of oppression," said Rev. Mendez. "On any given Sunday morning, people are coming to my church with the scars of having been humiliated during the week. You're talking to people who are living with prejudice, week-to-week. How can a new model of advanced care be a model of liberation for these people?" In sum, efforts to improve care must take context into account. The church must trust partners and partners must trust the church. And, always, church leaders feel deeply responsible for parishioners' trust and faith in the church. Nellie LaGarde explained:

> *Look, I get calls all the time from my insurance company telling me such-and-such is no-cost. Do you think I'm going to use it? No way. Why are they doing this? In the same way, if you come to my church and say that something's free, like a house-call program or hospice, that doesn't make a difference. That's not going to get through to me. Now, if my pastor were to say, 'You need to check out this care program,' then, yes, I'd give them a call. I'd let them into my house.*

Listen first. Learn. Engage people as active participants both in understanding the problems and determining solutions. Rather than presenting "a solution," clinicians, researchers, and others must fully engage with the community's needs and viewpoints. Dr. Rob Zalenski illustrated the need to listen, saying "In population health we're used to talking about health literacy and how 'these people' have low health literacy and that's a barrier to [their] informed decision-making. But, what if we asked clinicians, 'How good is your faith literacy?' 'How good is your community literacy?' That can be just as important as the community's awareness of the trajectory of illness and health system resources." Making a similar point, Rev. Delk explained, "We're used to being treated as objects—objects for research to improve a drug or a procedure or a technique for
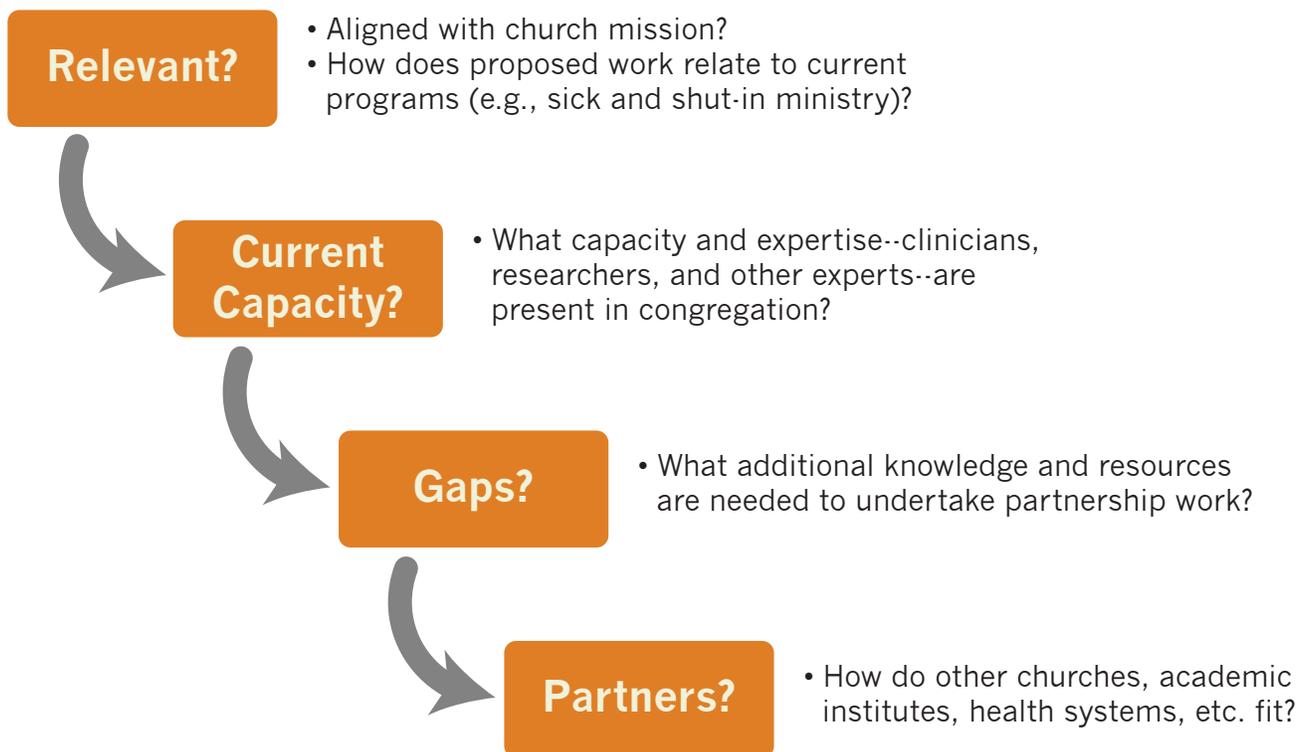
others. But we want you to relate to us as *subjects*. When you come in and start talking about your program or your product and don't start with what our needs and aspirations are, you're treating us as objects, passive members in the process."

Bring the right attitude. Bring the right spirit. Dr. Faith Hopp emphasized humility in research. Researchers' work can indeed provide resources for the community. Still, the community should set the agenda, not the other way around. Dr. Hopp explained that in her work at Wayne State University, "Developing the evaluation measures and methodology flows from [the community's] goals for the program...Our approach is, 'This is your model, it's not our work.'" The right attitude and spirit must be retained not only at the program level, but also in direct care, as Minister Angela Overton described in speaking of clinicians' compassion in caring for her as a person living with stage 4 cancer.

Understand Church Decision Processes

Be prepared for the questions churches will ask in assessing a potential partnership. Workgroup members stressed that organizations seeking partnership should be aware of the process that churches typically undertake to analyze a potential partnership. Common contours of the process are outlined below. Those seeking to work with churches should be fully prepared for the questions church representatives will ask—both to simplify work processes and to begin the relationship as one of mutual respect.

Outline of a Typical Church Partnership Assessment Process

Relevant?
- Aligned with church mission?
- How does proposed work relate to current programs (e.g., sick and shut-in ministry)?

Current Capacity?
- What capacity and expertise--clinicians, researchers, and other experts--are present in congregation?

Gaps?
- What additional knowledge and resources are needed to undertake partnership work?

Partners?
- How do other churches, academic institutes, health systems, etc. fit?

Relevant?

Representatives are likely to *first* ask whether the partnership's work is aligned with the church's mission and relevant to its ongoing efforts. "We get calls all the time from companies and organizations that want to access our people. They want to get their product to the church. And my perspective is, 'Look, thank you for the work that you do. But, the church is not the place for your product. You can sell that through other means.' We're only interested in services that align with our calling as a church. And advanced care is one of those programs," noted Rev. Carter. Still, partners should not assume that the relevance of advanced illness care is obvious. As Marge Betts, MD, described, "The pastors I talked to didn't get what I was talking about until I related it to something they were already doing, like the Sick and Shut-In Ministry." In this context, clinicians, health systems, and researchers can take care to use language that helps show the relevance of advanced illness care to the church's ongoing work. The workgroup illustrated this point by sharing terms that may help such as "people" (not patients), "fact finding" (not research), "ministry" (not care model), and "healing" (not curing). Lastly, making the need for advanced care work *tangible* can demonstrate its relevance. For example, two workgroup participants—the Alameda County Care Alliance (ACCA) and the South Eastern Michigan Alliance to Transform Advanced Care (SEMATAC)—highlight the great, ongoing need for advanced care among their parishioners by holding Caregiver Celebration events to honor caregivers. Similarly, Pastor Adams spoke of asking caregivers to stand at a service saying, "It's hard to avoid the issue when you *literally see* one-fourth of your 1,800 member congregation stand up and say that they're caring for someone with a serious illness."

Current Capacity?

An early step for many churches in considering a new program is to form a committee tasked with identifying resources and experts within their congregation. In the case of an advanced care program, they may look for clinicians, researchers, and chaplains, for instance. In addition, churches may consider the work already ongoing in the proposed program area in determining how a potential partnership fits and their capacity for additional work. For example, two workgroup members' churches were currently building large scale affordable housing (on 5 and 13 acres) for seniors in metropolitan areas.

Gaps?

Church decision makers will ask, "What knowledge and resources need to be obtained from outside of the church?" Workgroup members with experience in programs such as ACCA, Pastors4PCOR, and Winston-Salem's Congregational Health Network model described addressing gaps in:

- Knowledge of tools and resources (e.g., model advance directives, available social services, guidance in available research)

- Training and guidelines for those providing social support and care planning (e.g., care transitions, meals, transportation, home visitations, advance care planning)

- Training for clergy and lay leaders in integrating a person's spiritual care with clinical care.

Smaller churches may lack resources to develop their own advanced illness care programs, but models such as ACCA, SEMATAC, the Congregational Health Network model in use in Winston-Salem and Memphis demonstrate that partnerships among small and large churches can help bring about change. Likewise, robust partnerships often include a variety of organizations (e.g., churches, academic institutes, and health systems) that each contribute expertise and effort.

Develop Common Goals

Ensure church goals and partner goals intersect. For any partnership to succeed, the arrangement must be a win-win for those involved. For instance, in the ACCA and the Congregational Health Network models, the church community and the health system could agree on the need to prevent unwanted and unneeded hospitalizations. Other shared goals the workgroup noted may include:

- Reduced emergency room visits, or intensive care unit stays;

- Increased utilization of community- or home-based care (e.g. specialty primary care support);

- Improved patient and family care experience;

- Reduced level of caregiver burden;

- Increased access to hospice care;

- Lower costs for patients, families, and the healthcare system;

- Improved connection to spiritual or other community-based organizations, and;

- Improved quality of life measures.

Discussing goals often leads to the topic of evaluation—measuring success through data collection—as it did for the workgroup. It was noted that data collection may not be a strength or a priority in a church's work, which makes it especially important for partners to openly plan from the outset and identify evaluation methods that will work for all. Rev. Adams explained, "I think there's distrust on the part of researchers and clinicians of the community, just like sometimes...[our] community [distrusts] them. But their distrust with us is with record keeping and data collection. With many community projects, we're just not used to this kind of evaluation."

Build-In Sustainability from the Start

Commit. Plan how to maintain partnerships and momentum. The final engagement principle, setting up for sustainability, is forward-looking. As Teresa Cutts and others put it, churches are engaged because "it's a movement, not just a program." In the words of Rev. Cynthia Perrilliat:
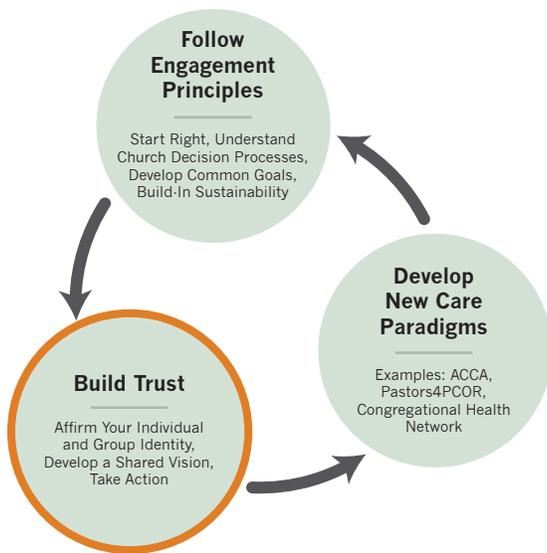
> *"We've gone too far to turn back. The need is too great. As such we don't think in terms of 'ending.' Projects have start and finish dates, movements don't work the same way. They're open ended. They're there until the mission is completed. This work is more along the lines of 'feed the hungry.' When does that end? Jesus said, 'When I was sick, you visited me. When I was hungry, you fed me. When I was cold, you comforted me.' That's what we need to do as a church, regardless."*

Use research as an asset to help identify how to strengthen the work. "Not every idea we have is a good one, that's why we need to look at what's working and what's not" said Rev. Smith. Pastor Adams mentioned that "a lot of the research projects that Wayne State and other of our academic partners have brought to us have turned into sustainable programs. And we're grateful for that. But at the same time we're always looking at sustainability, and research can help us get there."

Use these keys to sustainability—communication, resilient teams, innovation in the face of obstacles. The workgroup noted that the number and diversity of organizations in a partnership can be a strength, but can also unravel without regular communication and purposeful relationship-building. Regina Greer Smith observed that even some of the most basic approaches can help greatly such as establishing a Facebook page (proven especially useful for Pastors4PCOR) and agreeing to shared vocabulary (e.g., talking about persons who need care rather than "patients"). As with resilient sports teams, having a "deep bench" is important to resilient partnership teams. In other words, while champions and leaders are critical, there must be many who can carry the load. Nellie LaGarde shared a relevant example, saying:

People get upset in the church when the senior pastor can't visit them when they're sick. They're thinking, 'I've been a member here for 20 years, attended faithfully, served faithfully, tithed, and he can't come and visit me?' In truth, he's stretched so thin with 1,800 people that he needs a support team. We need a deep bench of pastoral support and that team needs to be recognized as at the same level of respect as the pastor, so that when one of them comes and visits, you don't feel like you're being overlooked or snubbed.

Lastly, when problems arise, strong and diverse teams innovate. For example, when a health system was planning to lay off cleaning staff in favor of contract workers, the Winston-Salem program team advocated on their behalf and persuaded the health system to retrain that staff as community health workers. Together, the health system and faith community established new positions called, "Connectors." Connectors earn $500 working one day per month to extend the work of the faith community navigators, build connections, and maintain the network with the churches. Similarly, the ACCA deepened their team by training 75 volunteers to support busy care navigators. Many other workgroup participants shared stories of innovating to overcome obstacles such as housing a primary care clinic at the church.

Follow Engagement Principles

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Develop New Care Paradigms

Examples: ACCA, Pastors4PCOR, Congregational Health Network

Build Trust

Affirm Your Individual and Group Identity, Develop a Shared Vision, Take Action

> *The truth is that there is mistrust. Some might take it as the church looking out for its own self-interest, "What's in it for us?" But it's deeper than that.*
>
> —Rev. Carter

2) Build Trust and Relationships

The workgroup cited trust as the greatest need—and, mistrust as a major barrier—in the relationships among the faith community and other stakeholders. Moreover, as Rev. Delk described:

> *Because it's a movement, things can get messy. Things have to, and will, change. It's not A to B to C to D. Sometimes it's A to D and then back to C and then sideways and then forward to E.*

The workgroup proposed several different engagement techniques, specifically affirming individual and group identities, developing a vision, and taking action. All of these techniques reflect ubuntu—both in self-reflection in a group effort—as the foundation of all relationships.

Affirm Your Individual and Group Identity

Reflecting on the reasons one joined a profession or a community renews energy. Discussing those reasons with others working in partnership clarifies the values that brought you together in the first place. For example, workgroup members said that they find a common theme among clergy, clinicians, and researchers is that they were drawn to their work in large part to care for those who are vulnerable. In other words, their goals are the same even as they strive in different ways through their professions and in their communities.

To affirm your individual and group identity, ask questions like:

- Why did I join this profession?
- Why did I join this community?
- Given my identity as person of faith, what am I called to do?
- Given my profession or my role in this work, what am I called to do?
- What motivates me in this partnership?

⫼ Who are we as a community?

⫼ What goals do we share in working together?

⫼ Given our identity as partners, what are we called to do?

For the faith community, drawing on a shared theology and history of caring for people is often what justifies church-based interventions for advanced illness care, especially for isolated individuals who do not have families or resources to draw upon.

Develop a Shared Vision

Partners must first envision the change they seek. Doing so both ensures shared goals and enables the group to work *toward* something.

To develop a shared vision, ask questions like:

⫼ If we had a magic wand, what would care for advanced illness look like in our community?

⫼ Can we imagine what a new paradigm of care might look like?

⫼ Does this paradigm reflect our community's values?

⫼ What role does the community, including those with advanced illness and their families, need to play in providing input or shaping and applying partners' ideas?

Given the emphasis on the most vulnerable, workgroup participants felt that new models of care would be those that are grounded in the community's values, built on community resources, and shaped and owned by the people that they are serving.

Rev. Mendez shared an example of the power of having a shared vision in the context of an effort to combat violence Winston-Salem, NC. In his words:

Violence in the community was getting so bad in Winston-Salem that my kids wouldn't want to go out on the weekends. There were fights starting all the time. I was part of a group of clergy that were called to the table with the police to start to work on strategies to end the violence in the community. This wasn't easy. We were enemies on a lot of issues. But we had to set aside differences (and our battles) for a shared goal. But one thing we shared that we used to inform our vision [was the belief that] both the police and the clergy were [typically] called in way too late to make a difference. We were called in to deal with the pain after the violence happened. But, we started to imagine a community where we could get to folks before the violence happened and prevent it. We recruited Wake Forest as an academic partner and they identified the target areas that needed help to reduce violence. I then went out along with the police and knocked on doors. We related that we were tired of the pain that came from the violence. And the families were glad that we were there talking with them, because they were worried about their kids. We ended up lowering the violence significantly and it has improved our relationship with the police and with the community. It was an effective partnership.

Take Action

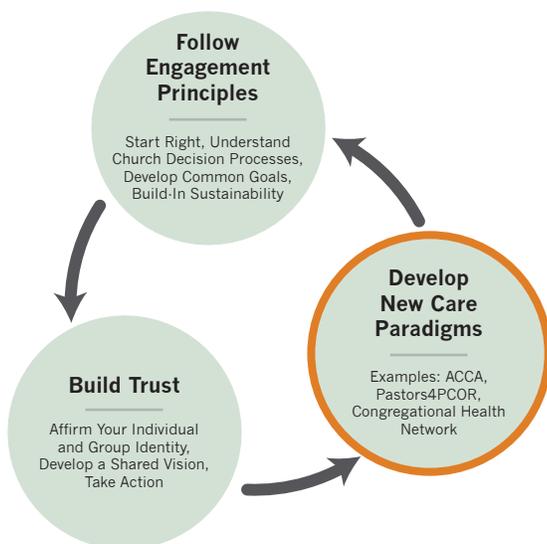As described above, the workgroup encourages potential partners to get started by:

- Preparing themselves so that they can **follow the engagement principles** laid out in this blueprint (i.e., start right, understand church decision processes,

- **Asking themselves the identity and vision questions individually and then together** as a partnership group.

The group will begin to see common themes emerge across their answers. In other words, the group will move from "I" to "We."

Once partners move from "I" to "We," ask action questions like:

- What can we do now?

- What role can each of us have?

- What resources do we have and how can we capitalize on them?

- What resources do we lack? Who in our community can help or bring to the table the viewpoints, connections, expertise, or skills we need?

- Is our community, in all its diversity, fully represented in our partnership?

- Do we have the strengths and skill sets we need at the table?

The workgroup emphasized that having contributing roles for people across the community to play is critical. A useful way to achieve this diversity of participation is to convene an initial group of community representatives who share a common vision and conduct a resource assessment of the community and potential partners. The more diverse the participants around the table the better, in the words of the workgroup.

Follow Engagement Principles
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Develop New Care Paradigms
Examples: ACCA, Pastors4PCOR, Congregational Health Network

Build Trust
Affirm Your Individual and Group Identity, Develop a Shared Vision, Take Action

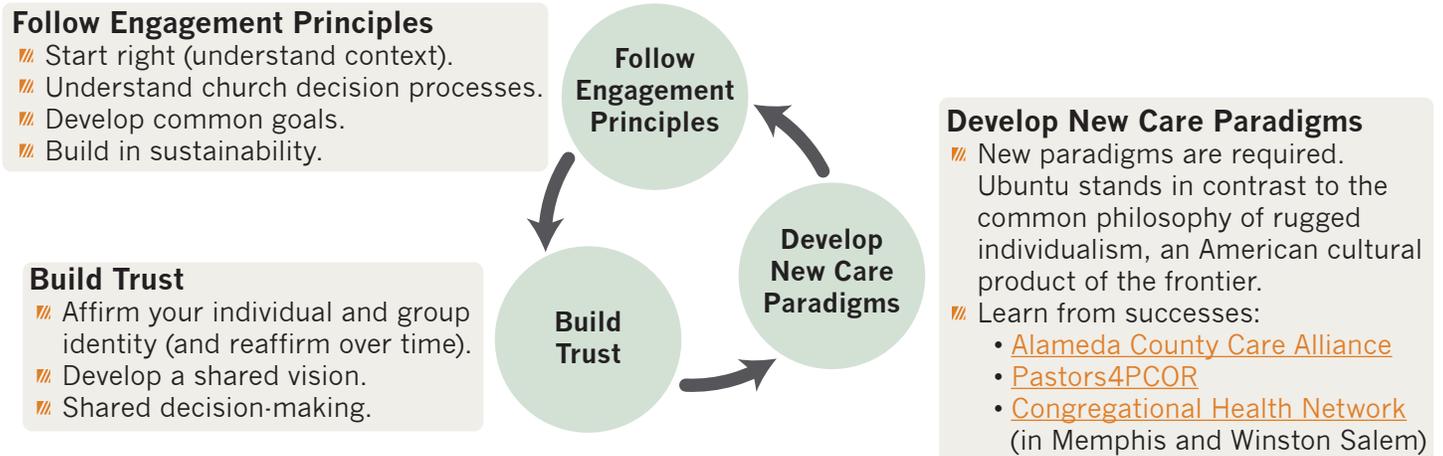## 3) Develop and Refine New Care Paradigms

The workshop examined three models that have demonstrated the feasibility of African American faith community partnerships with clinicians, researchers, and others to improve care delivery for the most vulnerable in the community.

- Alameda County Care Alliance (ACCA) Advanced Illness Care Program™ (AICP)

- Pastors4PCOR

- Congregational Health Network ("Memphis Model" replicated in Winston-Salem, NC)

A summary of each model can be found in Appendix A.

All three models demonstrate the powerful of partnerships in designing new models to deliver care and continuously improve through research and evaluation. Pastors4PCOR, especially shows that through a focused communications and relationship building plan, clergy can adapt and incorporate research as a tool for improving health care for the community across the board. More fundamentally, all three models started with the values and goals of the community and represent multi-year shared commitments by all the partners.

Reflecting on the Blueprint

Follow Engagement Principles
- Start right (understand context).
- Understand church decision processes.
- Develop common goals.
- Build in sustainability.

Build Trust
- Affirm your individual and group identity (and reaffirm over time).
- Develop a shared vision.
- Shared decision-making.

Follow Engagement Principles

Build Trust

Develop New Care Paradigms

Develop New Care Paradigms
- New paradigms are required. Ubuntu stands in contrast to the common philosophy of rugged individualism, an American cultural product of the frontier.
- Learn from successes:
  - Alameda County Care Alliance
  - Pastors4PCOR
  - Congregational Health Network (in Memphis and Winston Salem)

Just as all movements are messy, the model is iterative and requires both ensuring at the outset that engagement principles are followed, trust and relationships are built, and new care paradigms are brought forth *and* ensuring that these matters are regularly revisited and openly discussed among partners.

In the spirit of learning from our interactions, lessons learned for future Faith Community Person-Centered Workgroup meetings are shared in Appendix B. These lessons emphasize ideas potentially valuable in partnership meetings as well—such as flexibility in allowing high-engagement, strategic discussions to continue past scheduled end times, lengthening introductory time slots for full sharing, and allowing time for personal narratives.

Appendix A: Descriptions Of Three New Care Paradigms Underway Among Workgroup Members

Alameda County Care Alliance (ACCA) Advanced Illness Care Program™ (AICP)

The ACCA model was presented to the workgroup by Rev. Cynthia Carter Perrilliat, MPA, ACCA Director and Jill Joseph MD, PhD, Associate Dean for Research and Professor, Betty Irene Moore School of Nursing, University of California- Davis.

Founded in 2013, the ACCA is a faith community-led and –designed program to (1) extend and strengthen the health care delivery system, (2) improve the outcomes for persons needing care with advanced illness and their caregivers, (3) reduce caregiver burden, and (4) strengthen the community support infrastructure to meet the demand for advanced illness care. These goals are achieved through community, health system and academic partnerships. Care navigators from the community, who embed in churches, are selected and trained. Clergy leaders provide spiritual and decision-making support for ill parishioners. And, a network of volunteers provides social and emotional support to family caregivers and persons needing care.

Pastors4PCOR

The Pastors4PCOR model was presented to the workgroup by Regina Greer-Smith, President, Healthcare Research Associates LLC.

The vision of Pastors4PCOR is to inform, inspire, and engage congregations and their communities in research through partnership. In 2014, a partnership was formed with the Southland Ministerial Health Network, a coalition of churches dedicated to raising the voice of faith-filled justice, and S.T.A.R. Initiative, an organization devoted to increasing the participation of underserved communities and communities of color in patient-centered outcomes research. With the assistance of PCORI, Pastors4PCOR will develop "research ministries" in up to twenty faith-based entities in 2015-2017 through training and consulting support. Research-ready congregations will be well-positioned to develop meaningful partnerships and contribute to strengthening the ties among faith, academic, and medical communities.

Congregational Health Network ("Memphis Model" replicated in Winston-Salem)

The Congregational Health Network model was shared with the workgroup by Teresa Cutts, Ph.D., Assistant Professor, Social Sciences and Health Policy, Div. of Public Health and the Maya Angelou Center for Health Equity, Wake Forest School of Medicine

Founded in 2006, the Congregational Health Network or "Memphis Model" is a partnership between Methodist Le Bonheur HealthCare and 500+ places of worship, and is designed to support transition from hospital to home for vulnerable populations in the Memphis community. Now, this model is being replicated in Winston-Salem, NC in partnership with Wake Forest School of Medicine and nearly 300 faith community partners. The model consists of 13 paid staff (1 Director and 10 health navigators), 300 congregations, and hundreds of volunteer liaisons spanning the community to support congregants.

Appendix B: Lessons Learned To Strengthen Future Workgroup Meetings

The following are lessons learned from organizing the workgroup meeting. Importantly, these lessons can also serve as principles that might be applied to starting partnership discussions.

1. **Keep a strategic discussion moving, even if it's outside of the time on the printed agenda**, especially when participation and engagement is high. Find alternate ways to achieve the goals of the meeting. For instance, during the second day the plan of having two separate, small discussion groups was abandoned in favor of holding one large (30 person) discussion in circle. Participants afterwards commented that this help create a "safe" atmosphere for sharing opinions and also helped build a sense of unity, shared purpose and vision in the workgroup.

2. **Create space for personal narratives.** We had originally planned for 15 minutes for speakers to take "30 seconds" to say who they are and why they were there. This session took closer to 60 minutes, which gave participants an additional opportunity to use personal narratives to surface challenges (cultural, racial, other) that they had experienced, both professionally and in their personal lives.

3. **The program agenda should be flexible to allow participants engage in the discussion in a variety of means**, many of which will be culturally specific—singing, prayer, sermons, circle discussions, personal narrative and testimonies were all used over the two days.