SCALE 1.0 Synthesis Report

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Engaging Community Residents with Lived Experience

100 Million Healthier Lives

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About the SCALE Series

From January 2015 to January 2017, with the generous support of the Robert Wood Johnson Foundation, four 100 Million Healthier Lives partner organizations (Institute for Healthcare Improvement [IHI], Communities Joined in Action [CJA], Community Solutions [CS], and Network for Regional Healthcare Improvement [NRHI]) began learning how to support communities across a wide range of contexts to accelerate their journeys toward a Culture of Health. Each partner brought complementary expertise to the table. The Institute for Healthcare Improvement (which serves as the convening partner for both 100 Million Healthier Lives and SCALE) brought a wealth of experience as a leading innovator in helping organizations and communities worldwide apply improvement science to solve complex problems at scale (100,000 Lives, Project Fives Alive). Community Solutions brought expertise in applying improvement science to create practical solutions in the social sector to address challenges such as homelessness at scale in the 100,000 Homes campaign. Communities Joined in Action brought its experience in convening communities across the country in pursuit of 100% access and 0 disparities. The Network for Regional Healthcare Improvement brought its experience in Aligning Forces for Quality and in applying technology to create community connection.

Through the ***S***preading ***C***ommunity ***A***ccelerators through ***L***earning and ***E***valuation (SCALE) initiative, three of these partners (IHI, CJA, CS) co-developed a strengths-based model of community transformation, called Community of Solutions, in partnership with communities. A fourth partner (NRHI) learned how to support community transformation virtually. A formative evaluation, led by Dr. Abraham Wandersman, provided a rich context and an opportunity to rapidly understand what worked and to refine the model with communities. This paper is part of a series of synthesis reports commissioned by the Robert Wood Johnson Foundation to harvest the key lessons learned from the SCALE initiative as a practical offering to the field. The papers in this series are:

1) Overview of SCALE and a Community of Solutions
2) Foundations of a Community of Solutions
3) SCALE: Using Improvement Methods and Design Thinking to Guide Action
4) Engaging Community Residents with Lived Experience in SCALE
5) Leading for Abundance: Approach to Generative Sustainability

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Introduction

At the start of the first phase of the 100 Million Healthier Lives SCALE initiative (SCALE 1.0), teams were asked a simple set of questions: "Whose lives will be improved by your work?" "Who isn't thriving?" "What would it take for that to change?" As a primary strategy to help communities develop better solutions and cultivate leadership in community residents most affected by inequity, SCALE committed to full partnership with those residents. We call those residents "community residents with lived experience."

The creators of SCALE believed that communities would create far better, more effective solutions if they were guided by the individuals who lived and breathed the experiences the community was trying to address. In addition, engaging people with these experiences would help communities access an untapped source of leadership and resources. This approach would shift the work on equity, from a deficit view of people with resources giving things up to help others in need, to an interconnected view, in which everyone has something to offer and something to gain. More information about the overall approach toward equity can be found in the 100 Million Healthier Lives Equity Program Brief.

While many initiatives ask community residents what they need, and others engage residents in advocacy roles, SCALE challenged each community to find those individuals who struggled with the issues at the heart of the work needed to improve health, well-being, and equity in that community, and who had insights and leadership to offer in creating the solutions. These individuals were approached as respected, invaluable resources for their community's SCALE work and were engaged as partners and leaders in co-designing solutions. SCALE asked each community to integrate community residents with lived experience into their core community improvement teams. These community members were part of a "tripod" leadership structure, made up of formal leaders engaged in improving the community (e.g., business leaders, public health leaders, agency leaders, health care leaders), community connectors (people who served in a natural facilitator and connector role), and community residents with lived experience (community champions).

Over an 18-month period, the 24 SCALE 1.0 communities engaged 64 people with lived experience as community champions. Community champions were identified among youth, active drug users, people experiencing homelessness and food insecurity, members of refugee populations, and community residents in areas at risk for infant mortality, diabetes, high crime, violence, and more. While engaging community residents with lived experience proved to be one of the most challenging aspects of the SCALE journey, it also proved to be one of the most meaningful (see SCALE 1.0 Evaluation Report). Team leaders reported that this partnership was crucial to their work. "Results are stronger," noted Will Douglas, Tenderloin Health Improvement Partnership, describing his community's work with active drug users, concerned residents, police, and others. He described the engagement of residents with lived experience as "necessary for identifying real solutions," and other leaders agreed. Working at every level in SCALE communities, community residents with lived experience helped set priorities, surfacing hidden challenges and resources, and acting as crucial partners in designing, implementing, and assessing the SCALE work.

In this report, we will focus primarily on the way in which traditional community leaders and community champions formed partnerships with one another on SCALE teams. To complement this report, an accompanying toolkit focuses more broadly on engaging community residents with lived experience in communities at all levels of experience in improving health, well-being, and equity.

In the spirit of SCALE's collaborative, shared leadership, this report has been written by SCALE

community champions, team leaders, and faculty, with input from other SCALE community team members and SCALE coaches. Based on the evidence and insights this group has gathered, we will describe:

- The growth of communities toward full partnership with community residents with lived experience, including different strategies for engagement;
- How teams prepared to engage community residents meaningfully at each stage;
- The role played by community champions and other community residents with lived experience when working with SCALE teams;
- What we learned about engaging community residents with lived experience, from recruitment to integration, ongoing engagement and support; and
- How people with lived experience and community leaders grew in their roles.

We will touch on only high-level best practices and recommendations in each section; these are described more fully in the accompanying toolkit for those looking to engage individuals with lived experience in their own communities. The toolkit is available at: http://tinyurl.com/LivedExpSCALEtoolkit.

Growing into Partnership: Core Concepts

Engagement of community residents with lived experience in a design and leadership capacity transformed SCALE communities, but it was a journey. Both SCALE teams and community champions grew into this collaboration and evolved their understanding and practice of it over time. This section provides:

- An overview of the spectrum of engagement;
- Strategies appropriate for each stage; and
- Two brief case studies from SCALE communities.

SCALE community leaders identified engaging community residents with lived experience as important from the beginning of the initiative, but most communities were not ready to do this when they began SCALE (Mann Z. , CHILA 3 prep Engaging People With Lived Experience, 2016; Mann Z., Community Champions: CHILA 1-3, 2015). They struggled with concerns about how to approach individuals; how to effectively and meaningfully integrate community residents with lived experience into the work; and how to share the complex challenges of their community without creating expectations that the issues could be quickly resolved. Most community members with lived experience were not ready to be included in this way. They were typically unfamiliar with the terms and concepts related to improvement science and data-driven change, and had never seen themselves as leaders in the community.

SCALE recognized that there is a continuum of ways in which community members might be engaged (**Table 1**). Activities across this continuum are valuable and complementary for fully understanding the experiences of communities. Including community residents on an improvement team is a complement, not a substitute, for getting wider community feedback through surveys or community organizing. The strategies represent interconnected approaches to fully design and implement a system for improving the well-being of communities. Accordingly, SCALE developed a support system that would start by meeting communities wherever they were on the continuum, emphasizing the value of strategies at each level. Communities were then asked to assess where they were in terms of community engagement and how they might move forward. To support this growth, SCALE communities received training in the life cycle of engagement, including strategies to recruit, engage, retain, and transition community members with lived

experience from one level of engagement to the next, as described in **Table 1**. They also received training in design thinking and ways to engage community members with lived experience in design and improvement processes.

Table 1. Levels of Engagement of Community Residents in Community Health Improvement Work

	Consultation	Engagement	Leadership
Direct service provision	Asking what a client would want/need in terms of a service *Examples:* patient preference assessment	Engaging clients in developing the treatment plan *Examples:* Motivational interviewing; health literacy trainings; shared decision-making	Community member-led delivery of services/peer-to-peer supports *Examples:* community health workers delivering navigation services; diabetes or addictions groups led by community members
Community health improvement	Passive understanding of experience *Examples:* Participation in focus groups; needs assessments; journey-mapping; empathy maps	Engaging community members in actively designing solutions *Examples:* Community members on Advisory Board; active partnership in design and improvement processes	Community members with lived experience as full member of improvement team or directly leading improvement initiatives *Examples:* Leadership Academy to train community residents with lived experience to serve on improvement teams
Policymaking and governance	Soliciting community input into community decisions *Examples:* Town hall meeting; community survey; community organizing to determine resident priorities about a policy issue	Community recommendations drive change *Examples:* Community organizing to grow community leadership with a constituency; community members serve on Advisory Board	Equal representation in major decisions about policy and resource allocation *Examples:* Member of leadership entity that determines how shared savings or grant dollars are allocated to address community needs

Over the course of SCALE, we observed teams transitioning from one level to another, learning to engage members of the community and community leaders in a flexible, adaptive way. An example of this shift is described below in the story of the Laramie County Community Partnership.

Laramie County Community Partnership

When SCALE 1.0 started, community leaders in Laramie County, Wyoming were afraid to even acknowledge the problem of youth homelessness, and were clearly not ready to integrate homeless youth at the leadership level. Laramie's first effort was engaging youth experiencing homelessness as a focus group (*consultation*); the youth worked on a design team and described their experience of homelessness, while addressing where and how support might best be leveraged. Their ideas led to an innovative, simple, scalable solution (*engagement*): to pay small stipends to the people whose couches they were sleeping on, to stabilize this housing and develop an expectation of support. Meanwhile, the Laramie County Community Partnership SCALE team worked with community leaders to de-stigmatize the issue and rally behind the youth. By the end of SCALE, they had successfully stabilized the lives of youth experiencing homelessness; high school graduation rates rose from 38 percent to 50 percent. The grades of homeless students improved from D's and F's to A's and B's. These youths walked with their graduating class and became community leaders (*leadership*).

When asked to describe their plan for sustaining their SCALE work, Laramie County Community Partnership focused on engaging those with lived experience in their work as a primary strategy to achieve sustainability:

> Through the education and encouragement received through our SCALE journey, we have become more thoughtful and intentional about engaging people with lived experience. We have done this very well in some initiatives, and not as well in others. We hope to eventually have all of our initiatives designed with significant involvement from those who the work will directly impact.
>
> We have launched a Parent Leadership Training Institute program to increase the number of civically engaged parents in our community. The first cohort of participants graduated in March, 2017. The next cohort is scheduled to start in January. We are doing other specific trainings in monthly coalition meetings around ways to be engaged in the policy-making process (e.g., how to communicate with legislators, how to testify in committee meetings, where to go to register to vote).
>
> We need to continue to increase the engagement of people with lived experience and the use of process improvement. We are on our way, but these are the areas for greatest potential improvement. Most communities or organizations will say lack of funding is the major barrier to a significant breakthrough. Financial resources are important, and every community would benefit from extra dollars. However, so much can be accomplished with existing resources. Expertise and leadership are in every community waiting to be commissioned. One year from now, we would like to say we have made process improvement a more consistent part of our work, and people with lived experience are participating in all community health improvement projects our coalition undertakes.
>
> -Community Leader from Laramie County Community Partnership

This kind of progression from passive engagement to full leadership occurred over and over again in communities across SCALE; growth happened at the pace of community readiness and was facilitated by tools and training that prepared teams to get from one stage of change to another.

Building Coalition Readiness to Partner with People with Lived Experience

A key element of the SCALE approach was the preparation of community coalition leaders to be able to partner with community members with lived experience—as well as the preparation of community members with lived experience to partner with coalition improvement teams. The majority of this paper will focus on strategies to recruit and support community members with lived experience to engage in improvement activities. However, it is important to first highlight what the SCALE coalition teams needed to do to prepare for this integration.

Prior to the first SCALE Community Health Improvement and Leadership Academy (CHILA 1), SCALE leaders set the expectation that community residents with lived experience would be a core part of each SCALE community team. CHILA 1 itself modeled some of the behaviors necessary for successful engagement—making the first key interactions accessible to anyone, using "jargon cards" to encourage clarification of unfamiliar terms (see Glossary of Terms), and holding training sessions on how to partner meaningfully with others. SCALE faculty shared the spectrum of engagement and identified reasons to develop deeper levels of partnership with community members with lived experience. In addition, the following success factors for partnership were identified—key elements that teams needed in order to be ready to integrate community champions into their processes:

- Engaged leadership
- An effective team
- Clarity about the team's role
- Clarity about community champion's role and value
- An effective team launch to develop team norms and agreements together
- Trust, relationships, and effective team facilitation strategies
- Effective onboarding, including compensation for community champions
- Ongoing support and resources available to help coalition team members and community champions grow into their roles (Mann, Stout, & Brennan, 2015)

SCALE communities grew into these skills throughout SCALE 1.0 with many moments of "failing forward" on the path to meaningful engagement, as demonstrated by Healthy Waterville's story.

HEALTHY WATERVILLE

In 2014, there were no people with lived experience involved in decision-making about community health in Waterville, Maine. When SCALE began in 2015, the Healthy Waterville SCALE team was determined to make collaboration and co-design central to their work on poverty and food insecurity. They began with one community resident with lived experience and learned quickly.

By the end of SCALE 1.0, 42 percent of the Healthy Waterville Action Team members were residents with lived experience. As Barbara Leonard, CEO of the Maine Health Access Foundation explained in a recent radio interview, "The key piece of what they're doing is that they have community members who sometimes use these resources giving them input on what they need and want and how it's best to provide that. I think that's a really critical element to success" (Leonard, 2017).

Susan Foster, an evaluator, noted that these community champions were doing far more than providing input. "Healthy Waterville has made impressive inroads into improving the way that free food is accessed

and delivered, with the understanding that food and community connection are inextricably linked. Further, the people who actually experience food insecurity are guiding the initiative." In fact, Foster explained, Healthy Waterville had moved fully into co-design with community residents with lived experience. "Healthy Waterville committed to engaging people who live with poverty and food insecurity in the design of their initiative, but they went further than that—the Action Team now has ownership over the implementation process. Prioritizing and decision making are now driven to a large extent by community residents who may have had little prior experience in systems change or leadership and who have often experienced trauma, mental health and substance use" (Foster, 2017).

Healthy Waterville's learning curve was steep, and reflects that of other SCALE communities. Engaging those with lived experience is now a core element of Healthy Waterville's approach, as described in Healthy Waterville's "Leading Together" story, "Everyone can learn, and everyone can lead" (see Resources below).

> Waterville was the first community in our state to try Power Mapping. We focused on who had the power to increase donations of healthy food to the food bank. Our facilitator engaged everyone, as the diverse group mapped many organizations and decision-makers. Members of the community with lived experience of poverty asked where food bank clients [are] on the Power Map. They were upset with the answer: Without an organized effort, individuals have no power.
>
> People with lived experience had a voice and got on the map when the Healthy Waterville Action Team formed. The agenda became "Who's not thriving?" [and] the group decided to do community surveys to collect data. The Power Map fell to the floor.
>
> We learned that an intentional space is necessary to build trust among participants. Those most affected by the broken system need to decide the best way to make change. We needed to focus on our culture of trust, share tools, and let participants decide what changes to make and when.
>
> - Healthy Waterville, Team Formation Story

Resources

- For more about Laramie County Community Partnership:
  - About Laramie County Community Partnership
  - Sustainability plan (Laramie Community Partnership, 2017)
- For more about Healthy Waterville:
  - About Healthy Waterville
  - Team Formation: Failing Forward With Purpose
  - Leading Together story
- Jargon cards

The Evolving Role of the Community Champion

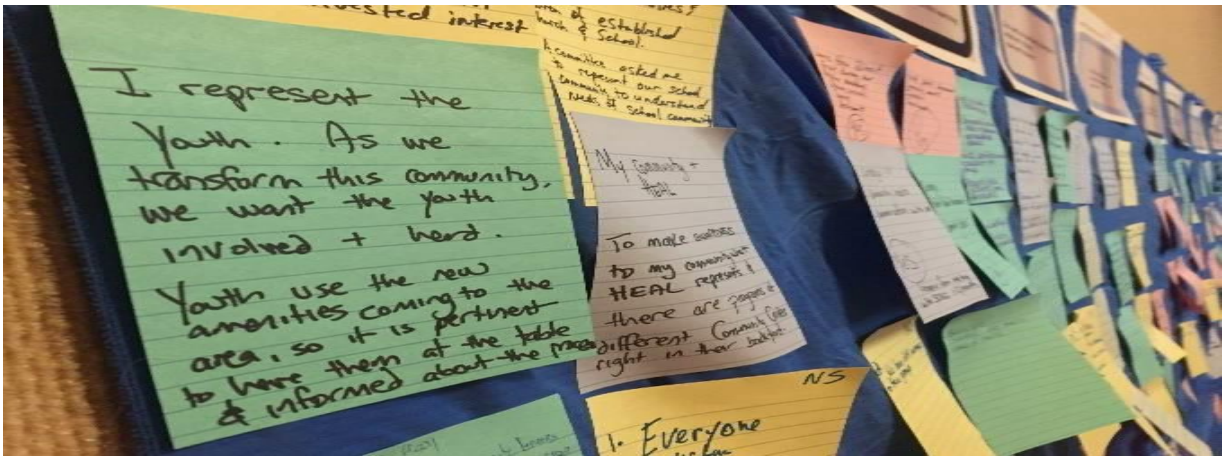

Figure 1. The "Wall o' Learning" from the community champions' track at CHILA 4.

This wall was covered with post-it notes describing aspects of the community champions' work, including comments from community champions unable to attend in-person. *Photo provided by Ziva Mann.*

Community residents with lived experience participated in all levels of the work done by SCALE communities. The community champions were community residents with lived experience who worked as members of the core SCALE community team. At this level, they engaged with the other organizations or coalitions working to improve health, well-being, and equity within their community. They brought their own personal experience with the issues or challenges central to the team's work, as well as the experience of their peers, giving them a depth of understanding of the situation that was critical to the community's work. As an emerging role, the role of community champion was designed and executed by individuals in a range of different ways. This section describes:

- The areas of work done by community champions;
- How community champions described their role; and
- Three major role variants, and their implications.

Community residents with lived experience came to the work with varying degrees of experience and readiness for the role of community champion. For example, many communities initially engaged a community coalition leader to fill the role of community champion before recruiting residents with lived experience who may or may not have been in a leadership role in their community. This meant that community champions from some SCALE communities had already been working to improve their community, while community champions from other SCALE communities reported that before SCALE, they had never even been asked their opinion about an issue in their community or been invited to participate in planning or designing a solution to the problem. In addition to this wide range of experience, skills, and readiness for the SCALE work, there was a range in the readiness of community champions to see themselves as leaders – emerging or otherwise. Regardless of the individual community champion's experience, skills, or readiness for the role, this kind of initiative was new territory for both the community champions and for their SCALE teams. The result was a wide range in the roles played by the community champions, as described below.

To better understand this emerging role, community champions and SCALE faculty co-designed a half-

day session to understand the primary focus, areas of work, and variations in the role of community champions. Information was collected from SCALE community champions both before and during the conference and presented during the conference's storyboard session. The analysis showed that community champions developed multiple descriptions for their role in community transformation work, including:

- **Voices for lived experience**;
- **Community stewards,** or leaders already at work in their community;
- **Knowledge holders**, learning from and giving voice to the residents of the community;
- **Change-makers,** ready to do the work of co-designing, implementing, and evaluating programs and policies;
- **Bridges,** or links to social networks, groups and individuals, often deeply engaged in serving their communities, connecting people to essential resources and services;
- **Cultivators,** helping groom the next community champions, supporting the sustainability of this new, emerging role. All community champions saw themselves as cultivators, and felt responsible for sustaining their role by preparing other community residents for the work.

All versions of the role map onto the areas of work in **Figure 2**.

Figure 2. Areas in which community champions worked (Mann & Coleman, Community Champions Areas of Work, 2016)

From looking at interview transcripts, surveys and assessments completed over the course of SCALE by SCALE faculty, the evaluation team, and the community champions themselves, it was clear that — depending on their skills, capacity, and understanding of their value — community champions gravitated to three major variants of the role: 1) a voice for lived experience; 2) a community steward; and 3) a bridge for and to the community (SCALE, 2017). None were mutually exclusive, and each version of the role had different challenges and advantages.

1. **Voice for lived experience:** Community champions in this role saw their primary focus as using their personal lived experience to inform and guide the work of their team. All spoke from their own experience, while some *also* acted as the voice of a group of peers with shared experience (a constituency) and developed practices to mine the insights of their peers. At the same time, a number of community champions who identified themselves as a voice for personal experience expressed discomfort with the idea of representing the experiences of others, limiting their capacity to represent the experiences of those most affected by the work.

2. **Community steward:** Community members in this role described themselves as identified change agents in the community, with a base to whom they reported. While not all community stewards had personal lived experience, they were well-positioned to gather feedback from those most affected by the SCALE work. They used creative, engaging ways to communicate the work of the team, ranging from community television, podcasts, social media messaging, and organizing community gatherings on key issues. Community stewards spoke about capacity building and paradigm shifting in the community, and the need to bring people together and engage them. None of the community members in this role expressed discomfort with representing the experiences of others.

3. **Bridge:** Most community champions described taking on elements of this role, whose primary focus was on communicating the work of the SCALE team to community residents and engaging them in the work. A number of these community champions came to the role from existing community work, such as violence prevention, community solutions specialist, and community health worker. Prior to SCALE, some of these community champions held paid positions in which they were responsible for gathering feedback from the community. This background brought both strengths and challenges to the “bridge” role. Community champions who primarily saw themselves as bridges were willing to share issues or needs that they identified in the community. However, a number expressed discomfort in representing the lived experiences of community residents as a whole, limiting their capacity to represent the experiences of those most affected by the work.

The community champions’ drive to communicate helped communities get past their prior experiences with similar improvement efforts. “Before we started SCALE, I had given up on institutions to help in community efforts,” said Loretta Brown, a Proviso Partners for Health community champion. A number of SCALE communities had previously been approached by groups that had good intentions for improving the community but did not necessarily follow through. We are “building trust that we're not just going to do a survey and then go away,” said another community champion. The inclusion of community members in the community champion role demonstrated SCALE’s commitment to collaborative, community-led co-design. Furthermore, by communicating the work, community champions made it accessible to the community’s residents — often, literally translating for community members who were unfamiliar with the language and concepts of improvement science. By enabling transparency, they made it possible for community residents to truly feel like the work was accessible, and to join in.

Recommendations: While the various roles of community champions were shaped by their capacity, skills and expectations, as well as the expectations and hopes of their teams, the focus and types of work that community champions took on expanded over the course of SCALE. As a result, we suggest preparing for flexibility and growth: embrace a variant of the role that will best fit the individual and the work in which they are engaging, and expect that role to evolve. Ultimately, everyone should be clear about the goal of incorporating community members with lived experience as meaningful contributors to SCALE work at all levels, with community champions at the heart of the core team.

Resources:

- Overview: Engaging community residents with lived experience in SCALE
- Preparing to engage community residents with lived experience
- Co-designing the role (includes areas of work framework)

Recruiting Community Champions

Figure 3. Nate Siggers, Healthy in the Hills community champion, held Community Conversations on topics such as race and equity. *Photo provided by Healthy in the Hills.*

As the first step toward co-design, recruitment proved challenging for many SCALE communities. But with care and planning, teams were able to move forward with a strong vision of the role and a strategy for recruitment. This section will describe:

- The process of recruitment; and
- The three main challenges faced by teams: planning, focus and breadth.

The process of recruiting community residents with lived experience started with planning: identifying the value that these residents could bring to the SCALE work, and a range of ways that they could shape and support the work. SCALE teams then reached out to their community contacts to find residents who were interested in supporting or even leading the work. In some cases, community residents were already reaching out to the teams, having heard about the SCALE community's plans. After a discussion of mutual hopes, needs, and expectations, and a little problem-solving to make the team meetings and processes work for all involved, they were ready to go. Teams worked to make it easy for the community residents to attend meetings, by discussing their needs (e.g., time, transportation) and how the team could adapt (e.g., phone calls or mail versus email). For many teams, the key challenge wasn't finding community residents who could contribute; the three primary challenges were in planning, focus, and breadth.

Depending on their experience and readiness to partner with people with lived experience, SCALE leaders noted, this early planning phase could be particularly challenging. Some SCALE teams had experience collaborating with community leaders but not with community residents. Others were concerned about making the experience work well for all involved, while integrating individuals whose daily life and skills seemed far from a conference room and improvement work. These community residents included those with mental health challenges, active drug users, and youth. SCALE team leaders responded by creating an environment where people felt comfortable expressing their concerns, in part by explaining the core philosophy behind co-design with people with lived experience. They also invited coalition leaders to work through how community residents could fit into existing teams or working groups, or add to the current coalition structure. Teams connected with other communities that were partnering with community champions and other residents with lived experience to see how those partnerships worked. Once they addressed their initial concerns, teams strategized about how community residents with lived experience could support, plan, and lead the work.

Once a SCALE community had agreed on a shared vision for partnering with community residents with lived experience, the next main hurdle was focus and/or breadth. Teams working on multiple challenges in their community needed to decide which type of lived experience to focus on in their recruiting. Other teams worked to balance a focus on engaging residents with key lived experience with, as one SCALE community leader said, “a broader engagement that included all of the diverse community voices into planning discussions and implementation of community improvement plans.” Another team, observing the rich cultural and tribal diversity in their area, invited community leaders to help them design an effective way to bring all voices to the table. Community leaders decided to establish a group of community representatives who would advise the community champions working with the SCALE team. By inviting community members to help plan the work, SCALE coalitions found that they built trust and deepened the community’s engagement in the work.

Resources:

- Connecting with the community: Connect & Learn
- Common Concerns & What To Do About Them
- ECOR’s experience with engaging those with lived experience
- Recruiting community residents with lived experience section of the toolkit includes steps and strategies for role design and recruiting,

Integrating Community Champions

Integrating community champions into existing work creates opportunities for the team to revisit the way it works together. This section describes:

- The process of integrating a community resident with lived experience into the team;
- Common challenges identified by community champions; and
- Challenges that teams experienced.

Once a community resident with lived experience had been identified and recruited, SCALE leaders began by preparing their teams, planning facilitation strategies, and then orienting their new team members. Teams found that it was valuable to revisit how they work with their new teammate. Sometimes, this process helped teams to clarify team norms (how frequently they will meet, communication expectations, decision-making, etc). They highlighted facilitation strategies as especially useful in integrating the community champion and other community residents with lived experience into the work. Some aspects of the integration process were familiar to teams: sharing information about previously completed work and offering training in core concepts and skills. Although many teams had never taught quality improvement to community residents before, a number of them reported success. Other elements were more challenging, such as connecting the community champion to others in the community who they may not know personally and integrating active, ongoing collection of feedback from peers into their role. Most importantly, SCALE improvement teams needed to co-design the role with their new team member. Team leaders who approached integration as part of an ongoing co-design of the role were able to identify the community champion's existing strengths, adapt to their needs, and respond. Support— an initial concern for many teams — became flexible and "just-in-time," that is, suited to the needs, goals, and timing that they agreed upon with their community champions.

The most common challenges identified by the community champions were:

- Learning how to represent themselves and others,
- Guiding teams in engaging the community; and
- Making the concepts and language accessible to someone new to the jargon, history, and structures of the work.

As Shemekka Ebony Coleman, Southeast Raleigh YMCA community champion who guided the work with community champions across all SCALE teams, said, "Translate what needs to be translated [language, jargon]. [Teach people about] making it personal via your vision of health, your plan, building groups, asking what matters to you, and where are you in the larger vision?" (Mann Z. , CHILA 3 prep Engaging People With Lived Experience, 2016). Many teams used a "jargon card" to surface terms that were not familiar to all, and team members enjoyed "flagging" as a way to make sure all understood and were able to engage in the discussion. With a little support and encouragement, teams found, community champions were able to find their feet and get to work.

Teal VanLanen, Live Algoma SCALE community's local improvement advisor, chose to grow youth leaders by offering an online IHI quality improvement course to a group of high school seniors. VanLanen described watching the concepts of quality improvement ripple through the high school and local elementary school. "It was incredible. Amazing. Not only are these students leaders, but they are passionate, driven individuals with lived experience who don't see the same obstacles adults do. They want to create an impact, and they have the necessary ingredients. It takes...us to give them a few extra tools in their pockets, like improvement science...to make sustainable change in our community." Their teacher, Brenda Pairolero, explained that "once they realized that others [adults] wanted to know what they thought, they were much more engaged." Any hesitation about engaging teens as change-makers seems to have evaporated quickly. Instead, "all the adults involved were extremely impressed by the students' thoughts and wanted to hear more." The group went on to create a nine-step blueprint for youth engagement: 1) Dream big, start small; 2) Create a shared vision for tomorrow; 3) Build coalitions; 4) Unity of message; 5) Moving pillars of power; 6) Leave no one who wants to be involved with us behind; 7) Develop your strategy and tactics; 8) Build momentum; and 9) Finish what you started (SCALE, 2017).

For reasons often linked to resources, skills and preference, community champions proved to be far more comfortable with input from peers with shared lived experience, than with the quantitative demographic data and needs assessments done by SCALE improvement teams. This input was essential for their role, as the Healthy Livable Communities Consortium of Cattaraugus County community champion explained, allowing them to be "the person that's actually in the community, knows the community, has the connectivity with the community, and can bubble some of the issues from the community level up to the consortium/SCALE level." They were also able to speak beyond their own personal experience to offer a broader perspective, based on the experiences of others. With coaching and mentorship, community champions were able to build their skills in representing the experience of a range of people and to see how this ongoing learning was valuable to their SCALE community's work.

"The [community champion] role needs to be driven by the people in the community, not overshadowed by a singular voice."

-Cindy Lau, Pueblo Triple Aim Corporation Community Champion

For some teams, the greater challenge for integration was one of team cohesion. While some team members had expressed concern that a community resident might feel alienated in an unfamiliar setting, some found themselves working to foster an environment that, as one SCALE community team member explained, "didn't marginalize or tokenize *any* member of the team," whether organizational or agency leaders, or community champions. Accommodating local leaders and people with lived experience could be especially challenging when there were already disagreements about priorities among the community's coalition. "Most people come into the room with their own priorities," said one local

improvement advisor (LIA), and “we need to have systems and ways to listen to that. Use input with that of partners and practitioners; weight it equally.” Meeting facilitation skills were critical for LIAs, such as setting shared codes of conduct, sharing information, using clear language, and engaging the entire team in vision and process. For a number of teams, integrating a community resident with lived experience became a process of building equity for each team member, in creating an environment in which all could thrive, and offering each team member the support that they needed to engage fully in the work at hand..

The challenges of team cohesion surfaced also in the reluctance of many community champions to be singled out as the only member of the team designated to speak for people who have experienced a particular issue. SCALE community teams were designed to integrate individuals who represented different segments of a coalition and different sections of the community, including those with lived experience. This team structure risked creating silos, with each team member tasked to speak to a specific group or set of priorities. Seeing themselves as members of the team as well as voices for the community, community champions advocated for engaging the whole team in absorbing and actively referring to the knowledge learned from the community. Rather than relying on the community champion to be the only person to raise the question, SCALE coaches encouraged teams to ask and think about community demographics and what it means to be a steward for others’ experiences. Design thinking tools such as experience mapping and personas helped all team members to fully adopt different perspectives (Mann Z. CHILA 3 prep Engaging People With Lived Experience, 2016). Teams found the design thinking tools to be an appealing way to keep the learning from community members visible and accessible (Bridge Period Engagement Survey (Responses), 2017). In addition, tools like “Seven Stories” (Stout & Lewis, 2016) and other design methods helped to include a broader range of community experiences in formats accessible to community champions.

Recommendations: Based on the community champions’ reporting of their experiences using the teams’ collected data, we recommend that community transformation teams:

1) Think carefully about the community champion’s resources, and how they might affect their ability to access information, whether data or team communications.
2) Look to broaden the types of data that the team uses, so that data are accessible and effective for the entire group, whether local community leaders or residents with lived experience. A major emphasis of the SCALE curriculum was reminding teams of the value of narrative in identifying, mapping, and humanizing an issue. Narrative and other types of qualitative data allow teams to interpret a need, issue, or experience at an individual or structural level and plan a targeted, focused response. By broadening the kinds of data that are valued and gathered, teams can adapt their approach to take better advantage of the community champions’ strengths, enabling them to participate and share their learning.
3) Given the impressive relational skills of the community champions of SCALE 1.0, teams should prioritize strong connections between the community champion and a group of peers with shared lived experience. Teams should plan for ongoing discussion regarding the community champion’s connections to their peers, and their capacity to gather the feedback and information that they need to be effective in their role.
4) Introduce tools for gathering a broader range of community experiences early in the improvement team’s work, and teams should be prepared to collaborate with community champions to set up effective, accessible ways to gather, share, and use that information.

Resources:

- A blog post on IHI.org describing Live Algoma's youth leaders and their tests of change, including a draft of their Live Algoma Blueprint for youth engagement.
- Integrating community residents with lived experience section of the toolkit includes recommendations and strategies for making information visible, managing jargon, facilitating meetings, and connecting community champions to their peers, and a discussion guide for co-designing the role, intended for ongoing use.

Engaging Community Champions

Figure 4. Community Champions and Community Leaders at a Community Health Improvement Leadership Academy. Photo provided by Shemekka Coleman.

Meaningfully engaging community champions was an ongoing process. Over time, teams were able to close gaps, moving closer to meaningful engagement with community residents with lived experience, in ways that were valued by all involved. This section describes:

- Key limiting factors for engagement; and
- Teams' strategies in supporting community champions.

In the Healthy Livable Communities Consortium of Cattaraugus County, the community champion pointed out a lack of full engagement of community members early on in their work: "They come to the consortium [meetings], but not as far as really...drilling deeper into what some of the local issues are that they're concerned about. They come to four consortium meetings a year, but they're not really sitting at the table." She was very clear about the difference between engaging someone as an information source rather than as a full partner in shaping, implementing and evaluating a priority, program, or policy (SCALE, 2016). For many SCALE communities, SCALE communities learned what meaningful engagement looked like by thoughtfully working with community champions. Community champions were able to achieve meaningful engagement with information sharing, capacity building and support.

The most successful community champions were those who valued and were able to engage deeply with the opportunity, education, experience, and training that they received in their role. Community champions shared what would make it possible for them to participate more fully on the team, and other team members learned how to provide supports, such as stipends, gift cards, referrals to needed services, skill-building, and one-to-one leadership development training opportunities. Some SCALE communities looked to create career pathways and paid positions for community residents participating in leadership on teams. Both community champions and other team members reported the importance of matching the supports to the community residents' needs and goals. This included looking for ways to offer payment to community champions, in order to support their engagement as well as to recognize their value and to support their professional development and growth as leaders. The SCALE implementation team recommended paying community champions a living wage for sustained engagement. As Will Douglas, Tenderloin Health Improvement Partnership community leader, pointed out, "Just about everyone else in the room is paid to be there."

> One of our community leadership group members, a person with lived experience, has been active in her community for many years. When I met her, I thought that she was a natural leader, especially in our one-on-one conversations. However, when she was in the leadership meetings, she was reluctant to contribute. She later told me that she was intimidated by the "smart people" in the room. From then on, I always made it a point to ask her for a comment or her thoughts in meetings. Over time, she began to trust her voice and see the value that she adds to the overall conversation and the work that we do. Now, she is one of the primary leaders of our community work and has begun to develop projects on her own. Organizations looking to partner with groups in our community reach out to her first, and that has led to the growth of our work in the community.
>
> - Robyn Bussey, SCALE Community leader, excerpted from ARCHI: Partnering with Lived Experience

Limited resources of various types (e.g., a lack of appropriate technology, transportation issues, time and location of meetings) affected residents' ability to participate as fully as other SCALE team members. In response, teams worked to lower barriers to participation by, for instance, carefully scheduling meetings to accommodate everyone's schedules and adapting their use of technology. The Live Algoma SCALE community brought their transformation to a wide spectrum of youth with lived experience by integrating quality improvement and change-making content into the high school, then middle and elementary school curricula. When a community champion or other team member was dealing with current trauma, upheaval, and urgent needs, SCALE community teams adapted when those needs took priority over the team's planned work. Understanding that there is a natural cycle of community resident engagement in improvement teams helped teams to be prepared for turnover. Teams working with multiple community champions were often best prepared when a community champion needed to step back for a time.

Ongoing check-ins with all team members allowed teams to fine-tune their efforts, whether in mixed-group gatherings or in meetings with other community residents with lived experience who had engaged with the group. These meetings also gave community champions time to process ideas or to ask questions they didn't feel comfortable asking during the meeting. The SCALE teams centrally and locally learned to use a range of encounters and strategies to support learning and growth, such as orientation sessions over meals, jargon cards, buddies, skill building, and more. Community champions valued the opportunity to connect with and learn from others in the same role, which started with peer discussion groups at the

CHILAs), and eventually also occurred at a whole pre-day track at CHILA 4.

Teams took a number of approaches to skill building within communities:

- Buckeye HEAL's local improvement advisor chose to combine engagement, information sharing, and skill building by inviting a council of community members with lived experience to help design a driver diagram. The council "remarked that the driver diagram process helped them to understand their role in and impact on the HEAL efforts."
- The Southeast Raleigh YMCA offered community champion engagement trainings**,** focused on providing other community voices the wherewithal to inform and engage fellow community residents.
- Live Algoma and the Women of Skid Row focused on skill building and peer education. Both communities hosted book clubs and adapted the content to suit the community members. Both reported enormous growth in those engaged in the book clubs. Sarah Callender, the Women of Skid Row's local improvement advisor, also reported using the book club as a way to "distill SCALE concepts and make sure they're up to speed with everything we're doing." She noted that one of the Skid Row community champions in the book club began designing her own projects, assessing the quality of food offered in various soup kitchens, then co-designing a healthy eating guide for women experiencing homelessness. That community champion became a central figure in guiding the team's work, helping them recognize mental health needs as a barrier to taking advantage of existing supports for housing and healthy behaviors.

By offering a range of co-designed, "just-in-time," fine-tuned supports, SCALE community teams not only sustained the engagement of community champions, but also laid a foundation for community champions to partner in co-design, implementation, and assessment, and to continue to grow into leaders, cultivators of other future community champions, bridges to new partners, funding opportunities, co-presenters at events, and more.

Resources:

- ARCHI's story of Partnering with Lived Experience
- Learn more about ARCHI's community
- Engaging and Supporting Community Residents with Lived Experience section of the toolkit. Includes a discussion guide for co-designing the role with the community resident; strategies for meaningful, effective engagement and for growing capacity; and examples.

Growing into Leaders

Figure 5. A group of SCALE community champions with Minnesota Commissioner of Health, Dr. Ed Ehlinger. Community champions met with Dr. Ehlinger to discuss their work and strategize for growing their role. *Photo*

During CHILA 3 and CHILA 4, community champions identified the value of peer-to-peer support and asked the SCALE Implementation Team to help develop a network of peers with access to shared resources. This would allow people in the community champion role to better support and mentor each other.

Teams noted with pride community champions who were emerging as leaders. By the end of SCALE 1.0, a number of community champions were leading peer groups as well as co-designing the team's programs. Community champions including Ms. Coleman and others, became visible leaders representing their SCALE work. Two community champions from Ethnic Community-based Organization for Refugees (ECOR) co-authored and presented their research at the American Public Health Association annual conference in 2016 (Munene & Muiga, 2016). A number of teams, such as the teen community health workers of Atlanta Regional Collaborative for Health Improvement (ARCHI) and Proviso Partners for Health's Champions for Change, noted the accomplishment of their youth leaders. Reflecting on their youth-led program for healthy eating, San Gabriel Valley Health Cities Collaborative leaders commented that "when youth drive, community health promoter programs can be a force for achieving equity."

For many community champions, their involvement in SCALE provided an opportunity to access a network that could benefit them in other areas of their lives, such as employment or education. They were able to explore untapped leadership potential and cultivate skills in quality improvement, outreach, program development, community organizing, and a range of other areas. This experience was transformative. As one community champion explained:

> I got educated. I got to learn how to speak in public and use different words, put them together correctly. I got a chance to be around people on a higher level…doctors, people with a higher education…and felt that I could communicate with them. It felt like they were glad for me to be around. It felt great. Everybody was looked at as a [real] person. I came from being an addict, sitting on the street doing dope, to being in a meeting! We all have challenges…we are all going through something.
>
> -Denise, Women of Skid Row Community

Denise began by describing how different she was from the other members of her team, and refers to the other team members as "they," or "them." The turning point in the quote appears to be when she describes how the team members approach each other, seeing each as "a [real] person." This degree of respect is meaningful for Denise, who concluded her description with "we," and a sense of shared challenge.

Many community champions showed a strong interest in educating and spreading skills in their community. Community champions applied for and received grants, one of which was for teaching financial planning to youth. Proviso Partners for Health's youth leaders designed ways to engage their peers, while the Live Algoma high school students taught improvement science to younger students. The students used their learning to create a nine-step blueprint for youth engagement, and their work led to the establishment of an academy to support hands-on learning and leadership development as a part of the Algoma school district curriculum.

One capstone of SCALE 1.0 for community champions was a co-designed and co-facilitated community-champions track at the final Community Health Improvement Leadership Academy (CHILA 4). A core group of seven community champions from six teams co-designed and co-led the pre-work and the track. A leader of that co-design team, Shemekka Ebony Coleman, went on to work with SCALE faculty, synthesizing the learning from that track into a storyboard, presented during the CHILA 4 storyboard session. She went on to present about community champions and 100 Million Healthier Lives in other professional conference settings. She was identified as a community champion leader for the SCALE 1.0 bridge grant period, and co-led the work to produce this report and the accompanying toolkit.

Resource:

- Growing Emerging Leaders section of the toolkit. Includes resources and strategies for supporting emerging leaders.

Concluding Thoughts and Recommendations

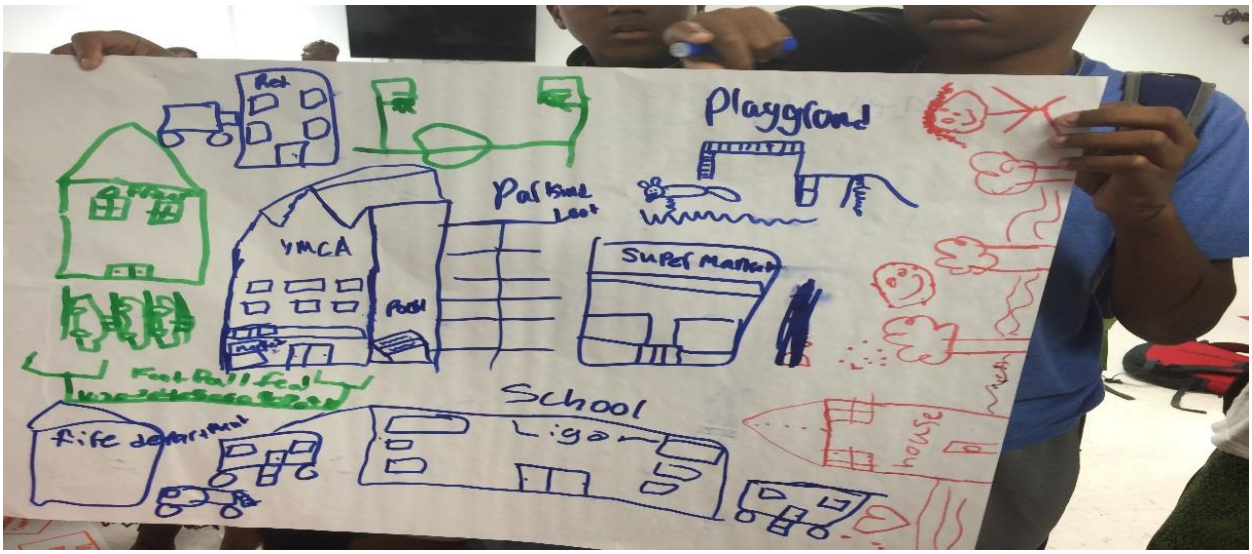

Figure 6. Children from Southeast Raleigh YMCA SCALE Community, holding their design for the community. *Photo provided by Melvin Jackson.*

When the authors asked community champions and SCALE community leaders about their vision for the road ahead, the common thread was one of collaborative, shared leadership:

> "In looking ahead, the vision for the role of community champion must at all times be co-designed by community champions representing people with lived experience. As communities represent diverse needs, and champions engage communities in various ways, there is no single vision of what this role should look like without community input. I envision the role of community champions as a common thread of community leaders with lived experience, at the forefront of leading change within their community."
> - Shemekka Ebony Coleman (Southeast Raleigh YMCA community champion)

> "My vision for the future — I hope partners can put their differences aside and see the community as a whole for the benefit of the entire community. [We] have come together for collective good, we need to do more of that."
> - Loretta Brown (Proviso Partners for Health community champion)

> "Through the SCALE project, the Women of Skid Row community learned that meaningfully improving health outcomes for the target population [women with or at risk for diabetes] could not have happened without learning from community champions about barriers to care and the need for flexible, patient-centered approaches. After having participated in this project, this community feels strongly that including this role in future efforts relating to improved health and well-being is both doable and essential. Further, the community believes that community champions must be part of helping to select program and policy priorities from the beginning of the process. The challenge will be gaining support from those not familiar with this process, institutionalizing this process, and holding each other accountable when this is not happening."
> - Sarah Callender (Women of Skid Row Community local improvement advisor)

> "My vision for my community is that it will someday be a community full of networks, local champions and change agents for equality. A community that is thriving…"
> -Aaron De'Angelo Knuckles (BuckeyeHEAL community champion)

Other leaders of SCALE teams identified engaging community residents with lived experience as one of the most effective strategies of SCALE in co-designing, co-implementing, and assessing programs and policies. Community champions "make my job easier," Will Douglas (Tenderloin Health Improvement Partnership) wrote. "They are crucial for sustainability of the programs we have co-designed," noted Esther Munene (Ethnic Community-based Organization for Refugees). They are "invaluable," said Aimee Budnik (Summit County). Lena Hatchett (Proviso Partners for Health) described how her SCALE community approaches community residents with lived experience. "We build relationships, not just programs," she wrote, "and we focus on hope, not despair." It's an approach that has changed the tenor of her work, Hatchett noted in her TEDx talk (Hatchett, 2017).

As teams have recognized the value of the community member with lived experience in their work, they have been looking for ways to make that role a reflexive, sustainable part of the work and to encourage other groups or organizations to do the same. In a recent white paper, SCALE community members explain, "Women with lived experience of chronic health conditions and homelessness provide insight and outreach to other women…[this] has been invaluable to SCALE's successes" (Callender et al., 2017). The paper suggests that health care providers, housing and shelter providers, and program and policymakers "ensure that women with lived experience are active participants in any and all healthcare delivery...in planning and administering any and all housing and shelter services," or "in any and all program and policy development." The paper further recommends "invit[ing] them to fully participate on steering committees and/or advisory boards to ensure that their input results in program design elements that reflect their needs" (Callender, et al., 2017).

While there are challenges in engaging community residents with lived experience, these primarily come from the shared work all team members need to do together in growing into the skills and behaviors needed for co-design. With support, such as the kind the SCALE teams received from their peers and from SCALE faculty, coaches, and SCALE implementation team members, teams become ready first to focus on a particular population, then to recruit additional residents with lived experience central to that community's SCALE work if they are not yet at the table. With careful integration, community champions and their teams have the foundation they need to thrive and to lead. Even when community champions doubt their own leadership or the value that they contribute (which SCALE community champions did report), co-designing the work with the SCALE leaders helps focus both the support and the community champions' sense of their own current and future value. And, as SCALE community leaders, local improvement advisors, and community champions noted over and over, with mentoring and opportunities to develop skills and leadership, community champions will grow beyond all expectations — as will the team's capacity and impact. "You cannot possibly create an improvement in your community without people with lived experience at the table to co-design," said Teal VanLanen, Live Algoma's local improvement advisor. By working together, wrote Jody Anderson from Live Algoma, we are "bringing the possible to life."

Recommendations

Moving into SCALE 2.0, the authors recommend exploring further the ways that both the community champions and their teams need to grow into co-design. All those engaged in efforts to enhance health, well-being, and equity in communities must strengthen the understanding that community champions are not single voices, but a cohort of residents with lived experience who are actively connected to their peers, serving as conduits for vital information. It is also essential to strengthen our understanding of how community champions engage with data and to continue to support teams in learning what is possible when bringing community residents with lived experience to the table.

The companion toolkit includes supports for the ongoing process of co-designing the community champion role, developed from the learning from SCALE 1.0. Other curricular elements are necessary, such as materials designed to teach quality improvement to community residents (currently in development). Based on feedback from SCALE improvement advisors, coaches, and community champions, we recommend building on the current flexible model of support and learning for teams and community champions. We suggest that it include one-to-one support early in SCALE 2.0 for community champions, team leaders, and coaches, with the goal of identifying, integrating, and cultivating community members with lived experience. We believe that this will lay a strong foundation for the rest of SCALE, both for SCALE 1.0 communities continuing their work and for communities new to SCALE and 100 Million Healthier Lives, as well as in other community transformation initiatives worldwide.

Financial need proves to be an ongoing challenge. We recommend being strategic, creative, and without fail asking community residents with lived experience what kinds of financial or practical supports are most needed. And we recommend communities learn from each other about their experience in engaging community members with lived experience. SCALE teams proved to be a key resource for each other, especially for those that were just beginning to engage community residents with lived experience; they offered each other examples of what they were doing, and inspired each other to try new things. Similarly, community champions and other community residents with lived experience can and do benefit from a peer network of their own. At CHILA 4, a key request of community champions was for support to create a network of their peers, to share resources and strategies, and to offer each other support. The community champions began crafting such a network partway through SCALE 1.0, and we look forward to seeing that work developed and made an integral part of SCALE 2.0.

SCALE 1.0 demonstrated that communities have the capacity to engage those with lived experience, and that this engagement would transform the work and the way it was done. Furthermore, SCALE 1.0 demonstrated that community champions can become leaders, shaping their coalitions, attracting funding, and deepening the community engagement that is essential for sustainability. We look forward to the transformations that will come as these emerging leaders continue to grow, as part of a community of practice centered on open, authentic, and catalytic collaboration.

Toolkit

To complement this paper, we offer a Toolkit for Engaging Community Residents with Lived Experience co-designed with SCALE communities. The toolkit is designed to be accessible at different points, depending on where the user is on the path towards co-design with the community.

- For those looking to understand the concept of co-design with community residents with lived experience, the toolkit offers:
  - 5 key principles necessary for co-design and engagement with community residents with lived experience, in accelerating progress in their communities' journey to health, well-being, and equity;
  - An overview of engaging community residents with lived experience (as told by SCALE communities); and
  - An index of stories and videos from the SCALE communities.
- For those ready to implement co-design with community residents with lived experience, the toolkit maps the steps to engagement and co-design with community residents with lived experience and links to documents and online resources for each step.

Glossary of Terms

100 Million Healthier Lives Well-Being Survey	A short survey used by 100 Million Healthier Lives to measure the different dimensions of well-being, including physical and mental health, and social and spiritual well-being.
Aim	A statement of what an improvement team intends to accomplish. It is time-specific and measurable, defining how much, by when, and for whom a community is working. The aim helps everyone in the community understand what the community is trying to do, sets a pathway for the choices of which projects and interventions can achieve that aim, and builds will among community stakeholders to join the effort.
Bright Spot	A set of activities, an intervention, or a program that a community is working on to improve health, well-being, and equity. It is scalable and shows evidence of the impact of the work on the population or subpopulation in the community.
Change Idea	A change idea is an actionable, specific idea for changing a process. It can come from a review of the evidence from research; from best practice; or from talking to those with lived experience of the issues, or with other teams, organizations, or communities that have tested changes and demonstrated improvement on a specific issue.
Change Sustainability	Refers to the sustainability of the change process itself. There are three components of change sustainability: program sustainability, outcome sustainability, and process sustainability.
CHILA	**C**ommunity **H**ealth **I**mprovement and **L**eadership **A**cademy (CHILA) is the series of in-person leadership training sessions for the SCALE local improvement advisors (definition below) and other members of the pacesetter and mentor communities. There were four CHILA sessions over the 20-month time period for SCALE 1.0.
CHILA Faculty	Faculty for CHILA have deep experience in a skill or topic that matters for community health improvement. Together with members of the SCALE Implementation Team, they lead sessions during CHILA and the monthly SCALE webinars.
CHIP	Community Health Improvement Plan (CHIP) is a comprehensive guide used by SCALE communities to guide their journey to improving health, well-being, and equity.
Co-design and Co-production	Co-design is the process of engaging community members directly in identifying and planning changes that are needed in their community to achieve health, well-being, and equity. Co-production is the process by which community members directly carry out the changes created during the co-design.

Community Champion	A community champion is a community resident with lived experience who works as a member of the core transformation team in the SCALE community. This person is a community member who has "lived experience" with the health issues in the community (e.g., a woman who was formerly or is currently experiencing homelessness who can offer insight into that experience) and is ready to be actively involved in efforts to improve the health of the community.
Community Leader	A community leader guides and organizes people, resources, and processes within a community to improve health, well-being, and equity. A community leader may be an elected or appointed governmental or agency official or someone who has been elected to a leadership position within a partnership or coalition or within their organization or community group.
Community of Solutions	Community of Solutions is a framework that supports communities in cultivating behaviors, processes, and systems that, over time, results in a Culture of Health and sustainable improvements in health, well-being, and equity.
Community Resident with Lived Experience	Someone who has lived (or is currently living) with the issues the community is focusing on and who may have insight to offer about the system as it is experienced by consumers (e.g., a woman who was formerly or is currently experiencing homelessness who can offer insight into that experience).
Design Principles and Methods	A set of approaches and tools to better understand the experience of community members with programs (e.g., an employment program or a diabetes prevention program), systems (e.g., the homelessness system or the child welfare system), or places (e.g., a neighborhood with poor health outcomes), and then to use this understanding to improve their design and effectiveness.
Driver Diagram	A driver diagram is an illustration of the structures, processes, and norms that are believed to require change in the system; this is one way to illustrate the team's shared theory of change.
Emerging Bright Spot	A set of practices, programs, or policies that show some initial evidence of far better outcomes than the norm; however, it may not yet have been replicated in other contexts.
Empathy Mapping	Empathy Mapping allows a program, system, or community to better understand the people they work with by "walking a mile in their shoes" and going beyond surveys, interviews, and focus groups. By more fully understanding the wants, needs, fears, and frustrations of community members, it is possible to gain insights that can result in effective change ideas.
Environmental Sustainability	Refers to the stability and possibility for growth in the physical, political, social/cultural, financial, and technology/innovation environment.
Equity	Conditions in which all people have the opportunity to attain their highest possible level of health and well-being, without barriers that prevent them from doing so.

Equity Action Lab	Equity Action Lab uses a structured set of activities to bring together a diverse group of community stakeholders to set a goal that is important to them and to design and take action over a 100-day period to make progress toward that goal. (Community Solutions, Designing an Action Lab, 2016)
Failing Forward	The notion that mistakes are not only to be accepted as an occasional occurrence in improvement projects, but should be viewed as critical parts of the learning and improvement process. It embraces the belief that teams that fail forward quickly learn faster, reach higher levels of performance, and create a safe environment for a wide variety of ideas to be suggested and tried.
Formative Evaluation	Evaluation that is intended to assess and improve the project design during the course of the initiative (in this case, SCALE) while it is happening. Using diverse methods including direct observation, surveys, interviews, and feedback from the project Implementation Team, the formative evaluation seeks to collaboratively learn what it takes to accelerate progress within and among communities.
Generative Sustainability	A set of practices and conditions that enables a change process to grow and scale.
Habits of the Heart	Habits of the Heart are a set of practices developed by the Center for Courage and Renewal that enable community members to openly and honestly engage with one another, to develop shared understanding, and to be able to take action together based on that understanding.
HealthDoers	HealthDoers is the online platform supported by the Network for Regional Health Improvement (NHRI). It connects SCALE communities as well as individuals, initiatives, and organizations across the country, including those involved in the 100MLives movement, who are forging local solutions to advance health and well-being.
Improvement Science	An applied, multidisciplinary science that emphasizes innovation, rapid-cycle testing in the field, and spread in order to generate learning about which changes, in which contexts, produce improvements. It is characterized by the combination of expert subject knowledge with improvement methods and tools.
Jargon Card	A small posterboard card with the work "jargon" on it; during CHILAs, any person could raise a jargon card at any time when an unfamiliar term was used without being defined, so that everyone could fully understand the remarks.
Leading for Equity	Refers to the application of Leading from Within, Leading Together, and Leading for Outcomes to address equity at a population and structural level.
Leading for Outcomes	Includes the skills of innovation, improvement, implementation, and systems change and refers to the application of design skills to co-create a theory of change, identify measures, test the theory, and then plan for both implementation and scaling up in a way that makes these tasks easier.

Leading for Sustainability	The development of a continuing process of transformation in a community (generative sustainability) as opposed to maintaining programs as they are.
Leading for Abundance Framework = Community of Solutions Skills	A set of practices and key concepts that the SCALE partners tested together related to: reflective practice in leadership (Leading from Within), collaboration (Leading Together), design thinking and improvement science (Leading for Outcomes), equity (Leading for Equity) and generative sustainability (Leading for Sustainability); taken together, these elements make up the Community of Solutions skills.
Leading from Within	The inner and reflective work of leadership and one's inner journey as a leader.
Leading Together	The skills of working together, grounded in seeing the community as a dynamic network of interacting people, organizations, structures, and systems that are related to a place. It is necessary to lead together with others in a community to create effective, equitable change.
Local Improvement Advisor (LIA)	A person from a SCALE community with the knowledge and skills to facilitate both the development of relationships across community stakeholders and the improvement process of the community.
Mentor Community	A community committed to health and equity that has made significant progress in addressing multiple determinants of health across sectors (e.g., health care, education, public health, business, social services, etc.); agrees to provide an experienced change agent who can share learning; and is willing to support others in the SCALE network. While mentor communities have made progress, they also want to continue to learn from others and make even more progress in their own journey toward a healthier community. There were four mentor communities in SCALE 1.0.
Model for Improvement	Developed by Associates in Process Improvement, the Model for Improvement is a simple tool for accelerating improvement. It contains three questions that help to create an aim, measures, and a set of changes together with a structured way to test changes in practice (Plan-Do-Study-Act, or PDSA cycles).
Massive Open Online Course (MOOC)	A free online course offered to a large number of people.
Mr. Potato Head Exercise	An exercise that engages participants in testing ideas as a way to illustrate the importance of each step in the PDSA cycle.
Pacesetter Community	A pacesetter community is a community committed to health and equity with at least three partnering organizations capable of addressing the determinants of health across sectors (e.g., education, public health, social services, health care, etc.). Pacesetter communities have at least some experience in improving the health of their communities, and have the hunger and passion to do more, to learn from others, and to contribute to a vibrant shared learning community. There were 20 pacesetter communities in SCALE 1.0.
Pathway to Pacesetters (P2P)	A virtual capacity-building program that grew out of SCALE 1.0. It supports communities in accelerating their improvement journey, no matter where they are. The goals of Pathway to Pacesetter are:

	1. Support local leaders working together across sectors to be effective in achieving their goals for improving health, well-being, and equity in their communities. Accelerate the spread of good ideas and practices between communities through the development of relationships, peer-to-peer networks, and an effective learning system for spread.
PDSA Cycle	A Plan-Do-Study-Act (PDSA) cycle is a structured way of testing a change in the real world — by planning it, trying it, observing the results, and acting on what is learned.
Peer Community Team	A Peer Community Team is composed of the following: the SCALE Coach, a mentor community, and five selected pacesetter communities that have a common focus, community type (e.g., urban, rural, etc.) and/or some other identified affinity. There were four Peer Community Teams in SCALE 1.0.
Readiness	The general capacity, innovation capacity, and motivation of a community to do a particular task. Readiness was formally assessed throughout SCALE by the evaluation team and used to guide curriculum development and coaching.
SCALE 1.0	**S**preading **C**ommunity **A**ccelerators through **L**earning and **E**valuation (SCALE) 1.0 was a 20-month intensive "learning and doing" program made possible by the generous support of the Robert Wood Johnson Foundation. It was designed to assist communities to achieve unprecedented results in improving the health and well-being of people, populations, and the community at large. SCALE 1.0 was the first time this program was funded (SCALE 2.0, also supported by the Robert Wood Johnson Foundation, began in May 2017). SCALE supports communities in their efforts to address factors that contribute to health, to lead complex change, and to advance equity.
SCALE Coaches	Individuals experienced in leading improvement efforts in community health and in coaching teams to develop and carry out plans to improve the health and vitality of their communities. The SCALE coaches are nominated by SCALE Community Partners and lead the Peer Community Teams.
SCALE Community Partners	The four SCALE 1.0 Community Partners are Community Solutions (CS), Communities Joined in Action (CJA), the Network for Regional Healthcare Improvement (NRHI), and the Institute for Healthcare Improvement (IHI).
SCALE Communities	The communities participating in the SCALE Initiative. In SCALE 1.0, there were 24 SCALE communities (see beginning of this report for a list).
SCALE Community Improvement Team	The improvement or transformation team in each community.
SCALE Tripod Leadership Team	A leadership structure, encouraged for SCALE Communities, which combines formal institutional leaders, community connectors, and community residents with lived experience.

***Switch* Thinking**	A concept from the work of Dan and Chip Heath in the book, *Switch: How to Change Things When Change Is Hard.* The idea is that by understanding how to motivate the emotional brain (the Elephant) using the rational brain (the Rider), it is possible to provide direction and make the environment for change (the Path) as hospitable as possible. Individuals, groups, and entire communities can thereby make and sustain changes.
Theory of Change	A tool that helps to describe a group's belief (theory) about how a concrete goal (aim) will be achieved, including its primary contributors (primary drivers), possible secondary contributors (secondary drivers), and often, possible changes that could be tried (change ideas).

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SCALE Communities

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Bernalillo County Community Health Council: Albuquerque, New Mexico

Brooklyn Park: Minneapolis, Minnesota

BuckeyeHEAL: Cleveland, Ohio

Ethnic Community-based Organization for Refugees: Salt Lake City, Utah

Healthy Livable Communities Consortium of Cattaraugus County: Salamanca, New York

Healthy in the Hills: Williamson, West Virginia

Healthy Monadnock: Keene, New Hampshire

Healthy Waterville: Waterville, Maine

Health Improvement Partnership of Maricopa County: Phoenix, Arizona

Jackson Collaborative Council: Jackson, Michigan

Laramie County Community Partnership: Cheyenne, Wyoming

Live Algoma: Algoma, Wisconsin

North Colorado Health Alliance: Evans, Colorado

Proviso Partners for Health: Chicago, Illinois

Pueblo Triple Aim Corporation: Pueblo, Colorado

San Gabriel Valley Healthy Cities Collaborative: Los Angeles, California

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