

# “Data + Organization = Change”

Community-Based Participatory Research  
as a Strategy for Changing Health Care Policy





# Data + Organization = Change

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the access project

# Participatory Research

## **WHAT IS Community-Based Participatory Research?**

**In** community-based participatory research (CBPR),

researchers and community groups become partners in a collaborative effort. Unlike traditional research projects, in which community members are often the object of study, in CBPR they take an active role in determining the purpose and goals of research and fully participate in all of its phases, including research design, data collection and analysis, and dissemination of findings.

The advantages of this approach are many, both for researchers and for communities.

The participation of community members can provide access to groups that might otherwise be hard to reach, such as minority groups and those who speak languages other than English, and thus to information that might otherwise be hard to collect. It can help ensure that research efforts are informed by an understanding of the

local context, and that questions are asked in ways that make sense to those who are being asked to respond. For community groups, participating in CBPR projects can strengthen their members' skills, for example in conducting surveys and analyzing data, which can then be applied to future work.

Perhaps most importantly, however, research done in partnership with local groups is more likely to be used to effectively advocate for real-world policy change. Participation in the research process allows groups to gather information on issues that they see as important in improving their communities, enhances their standing in policy debates, and gives them a true stake in using the findings to achieve desired change.

# Advocate For Change

## **THE ACCESS PROJECT: Helping Communities Advocate for Change**

Since 1998,  
The Access Project (TAP)

has served as a national resource for community organizations working to improve health and health care access. TAP recognizes that real reform requires systemic policy changes at the local, state, and national levels. Its work is founded on the belief that such reform will only come about with the participation of informed grassroots groups that promote change within their communities and join with others to support change at higher levels.

TAP focuses on providing customized technical assistance to local organizations with strong roots in their communities, to support their initiatives to meet the health care needs of those who are underserved.

In its work with community groups throughout the country, TAP has found CBPR to be one of the most effective strategies to achieve these ends. Through its affiliation with the Schneider Institute for Health Policy at Brandeis University, the relationships it has established with other academic and policy experts, and its strong connections with local community organizations, TAP is able to bring together experts and community leaders to undertake high quality research projects that local groups can use to benefit their communities.

# Theory Into Practice

## **THE COMMUNITY ACCESS MONITORING SURVEY: Putting Theory into Practice**

**A** major issue facing the groups TAP works with is how to provide access to health care in their communities for people without insurance. The number of uninsured in the United States has risen dramatically in the last 15 years; in 2001, 41 million people were uninsured, a 33% increase since 1987. Most analysts expect the number of uninsured to continue to grow as the economy slows and health care costs and premiums rise.

With the failure of health care reform efforts nationally, states and communities have been left to deal with the problem of providing care for the uninsured. Many communities rely on

safety-net hospitals and clinics to provide this care. Local advocates working with community residents were aware that, even when such facilities were available, the uninsured still faced many barriers to accessing care. However, local officials and hospital administrators could easily dismiss these stories as aberrations. In 1999, TAP undertook the Community Access Monitoring Survey (CAMS) initiative to gather data from the uninsured on their experiences at local hospitals and clinics that would help local groups enhance their advocacy efforts.

## CBPR IN PRACTICE: Cincinnati, Ohio

### Hospital Adds Financial Aid Counselors for Patients

**F**or the CAMS project in Cincinnati, Ohio, the Legal Aid Society surveyed patients who received care at a large safety net hospital. Almost 85% of the respondents said that they needed help paying medical bills, but almost half of these respondents said the hospital never offered assistance.

“We had been hearing all of these stories that people who can’t pay their bills are getting turned over to collection agencies,” says Trey Daly, senior attorney at the Legal Aid Society of Greater Cincinnati. “But when we’ve told hospital officials these stories, they tended to be very dismissive, saying it’s not characteristic, it’s an anomaly. With the survey, we could say that it’s more widespread than that. The survey is a nice objective tool.”

After discussions between Legal Aid representatives and hospital officials about the survey results, the hospital agreed to add seven financial counselors to its patient accounts staff. It also revised its financial assistance application form to make it easier to complete, and placed applications in locations where eligible patients might easily obtain them. In addition, the hospital is adding a voice mail option to its phone system that allows callers to receive information on financial assistance after regular business hours.

As a result of the survey, The Legal Aid Society also formed a community group called the Greater Cincinnati Health Care Access Project. It hopes the new group will broaden the voices calling for increased access to health care in Cincinnati. “We attempted this coalition in large part because The Access Project demonstrated that it could be effective. In the past, we haven’t focused on working with consumer and other community-based agencies,” Daly says.



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# Implementing CAMS

## **Implementing CAMS: A Collaborative Effort**

**TAP** staff worked with Dennis Andrulis, PhD, research professor at SUNY Health Science Center in Brooklyn, New York to develop a survey instrument that asked uninsured people who had used local facilities about their experiences when obtaining care. It included questions on a range of issues, such as satisfaction with staff, waiting times, access to interpreters, and difficulties paying for care. The instrument was piloted in four sites; this experience was used as the basis for initiating a large-scale study.

In January 2000, TAP sent letters to nearly 2,000 community health leaders describing the CAMS project, offering small contracts to support the effort, and requesting proposals from those interested in participating. In their proposals, groups were asked to present action plans outlining how they would use the survey data to promote increased access for the uninsured in their communities.

Out of 92 applicants, TAP selected 24 community partners. They included advocacy organizations, medical societies, primary care associations, county health departments, legal services organizations, health care providers, and research institutes. The ways in which they planned to use the findings spanned a wide range, including challenging institutional policies, sharing information with participating facilities to improve service, advocating for expansion of programs to provide care for the uninsured, and developing policy proposals to bring to policy makers, the media, and the public at large. The selected organizations were located in 18 states and 24 communities.

In April of 2000, TAP brought together all of the community partners, TAP staff, and Dr. Andrulis at a meeting in Chicago, Illinois, to further describe the project and gather input on its design. The discussions resulted in some significant changes to the survey. For example, advocates reported that many clients had trouble paying their hospital and clinic bills, so Dr. Andrulis added questions about medical debt. These questions ultimately yielded some of the survey's most important findings.

To ensure consistent administration of the surveys across organizations, TAP hired The Medical Foundation in Boston, Massachusetts to provide an on-site, one-day training for each participating organization. Five of the trainings were conducted in Spanish for groups using surveyors who spoke only Spanish.

Each organization selected the hospitals and clinics in its community to include in the study, based on local needs and problems. Some communities that had experienced rapid growth in their non-English speaking populations chose to focus on facilities where these residents commonly sought care. Some wanted to compare experiences at clinics with those at hospitals. Others wished to examine the impact of the closing of a hospital on the experiences of the uninsured at remaining hospitals in the area. TAP field coordinators worked with each of the local partners to help them plan their project in detail.

# A Collaborative Effort

The organizations hired local people, often community residents, to administer the face-to-face surveys. Using local residents helped organizations expand the skills of their members. In addition, it often enabled interviewers to gather information that otherwise would have been difficult to obtain, especially in immigrant communities where people may feel wary of outsiders. “We have the trust of the community,” says David Lubell, community outreach coordinator of Latino Memphis in Memphis, Tennessee. “Trust is a big factor in a community where there are a lot of undocumented immigrants. If you don’t trust someone, you’re not going to let them come into your house and you’re not going to give them all of your personal information.”

In order to get enough responses to provide meaningful results, TAP encouraged groups to collect at least 150 responses for each facility included in the study. Depending on their needs and capacity, community groups studied between 1 and 6 facilities. In the end, over 10,000 respondents completed the survey.

Participants collaborated on creating a local report to present the findings for each community. TAP provided background on the scope of the problem and the consequences of lack of insurance on people’s health and well-being. Communities provided information about the local context for the surveys, the surveyed facilities, and how they conducted the surveys. Dr. Andrulis and his colleagues analyzed the data. Everyone reviewed the completed reports and agreed on revisions and changes.

Groups used a variety of methods to disseminate their findings, including organizing press conferences, writing articles, and making presentations at county meetings.

TAP encouraged many groups to first meet with hospital and clinic administrators to discuss identified problems, and if possible, to agree on solutions and jointly release the data. According to Dr. Andrulis, “There is a quietness of data that can really work effectively. The combination of research and advocacy can tone down the rhetoric and make a point with some evidence. Let the numbers speak in context. You don’t overstate the data and people find it harder to simply dismiss.”

In addition to the local analyses, Dr. Andrulis and TAP staff analyzed the aggregate data from all of the participating sites, which revealed some important information. The findings indicated that the uninsured face serious financial barriers to obtaining care, even at safety net facilities: more than half of CAMS respondents said that they needed help in paying for their care, and nearly half were in debt to facilities where they received care. About a quarter of those who were in debt to their facilities said that the debt would deter them from seeking care there in the future.

In addition, people with limited English proficiency faced serious linguistic barriers to care. Four out of ten respondents who needed an interpreter said that getting one was sometimes, often, or always a problem. Respondents who needed but didn’t get an interpreter were much less likely to understand the instructions for using their medications than respondents without language barriers. They were also much less likely to be offered help in paying for their care.

## CBPR IN PRACTICE: Alexandria, Virginia

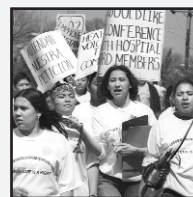
### Hospital Slashes Debts of Uninsured

**In** Alexandria, Virginia, the Tenants' and Workers' Support Committee (TWSC) coordinated the CAMS project. TWSC works mainly with low-income Latino residents. Many are recent immigrants from Central and South America; they often work two or three jobs to pay the rent and have little, if any, money left over for health care. Since most speak Spanish as their primary language, communication with medical providers can be difficult.

In Alexandria, volunteers conducted most of the surveys. Many were lay health promoters who had participated in a ten-week course on health promotion sponsored by TWSC, as well as the one-day training on surveying provided by The Medical Foundation. The surveyors identified respondents by going door-to-door at apartment complexes likely to have eligible respondents; by the end of the project, they had visited 1,000 apartments representing approximately 4,000 residents, and completed 221 surveys. After the CAMS report was completed, TAP also conducted a training for community residents in negotiating with the hospital administrators for desired policy changes.

The survey found that 37% of respondents—about 80 people—owed money to the local hospital. Because respondents could not afford to pay these bills, they experienced credit problems and received frequent notices from collection agencies. TWSC began negotiations with hospital officials to relieve this burden. As a result, it was discovered that many of those with debt were eligible for public or charity care programs, and \$200,000 of the debt was eliminated.

According to the project coordinator, Silvia Portillo, the experience of participating in the trainings and conducting the surveys was valuable in building the skills of the participants. Through the process, they gained confidence and learned to generalize from individual stories to identify community-wide problems. They also learned how to present their individual stories effectively to key decision-makers.



*“From CAMS we learned...*

*the power of data combined with organization to achieve actual change.”*

## CBPR IN PRACTICE: Memphis, Tennessee

### Hospital Adds Interpreter Services and Cultural Sensitivity Training

**In** Memphis, Tennessee, Latino Memphis works to build relationships between the Latino community and the greater Memphis community. Drawn by the availability of construction and other jobs, the Latino community more than quadrupled between 1990 and 2000. Hospital and health services, however, had not changed to meet the needs of the population. The CAMS survey found that interpreter services at the regional public hospital were often unavailable or of poor quality. In addition, patients were often not told that they could apply for charity care, forcing many to default on their hospital bills.

The Latino Memphis staff arranged a meeting with the CEO of the hospital to discuss a number of problems identified by the survey, including issues related to cultural competency and access for people who speak little English.

"[The hospital officials] had to pay attention to our findings because statistics are powerful," says David Lubell, community outreach coordinator for Latino Memphis. "It definitely helped us get in the door."

Since those meetings, the hospital has established a multi-cultural division, and hired more interpreters as well as a coordinator to oversee these services. The hospital has also begun cultural sensitivity training and provides patients with options in paying for their hospital care.

"The project helped motivate us to look at some problems on an institutional level," Lubell says. "It's also helpful because we can show our community something concrete that we have done."



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# Achieving Change

## **Outcomes: Strengthening Community Organizations and Achieving Change**

**The** CAMS project aimed to strengthen local organizations and help them reduce barriers to care that the surveys had identified. In many communities, the CAMS project has made a difference in a variety of ways.

### **Identifying gaps and strengths in local programs**

In several CAMS communities, survey results suggested gaps or problems in existing programs for the uninsured. Sometimes health care administrators or local officials did not know about these difficulties. In other cases, the survey results documented the success of existing programs and provided support to continue or expand them.

### **Developing organizational and advocacy skills**

Many community partners reported that members developed new skills and more confidence through conducting the surveys and negotiating with community and facility leaders. Many found that the training in survey administration developed skills they could use not only for the CAMS project, but in other activities as well.

### **Facilitating working relationships**

Almost all of the community partners requested meetings with health care administrators to discuss the results of the survey. Frequently, the meetings included the executive directors or CEOs of the facility, as well as key departmental

staff. In many cases, these meetings were the first time that the local organizations had had face-to-face discussions with these key leaders, and many of the meetings resulted in agreements to continue to work together. The CAMS project also helped community partners establish working relationships with local elected officials, as well as with other community organizations and advocates working to expand access to health care for the uninsured.

### **Raising public awareness**

An important component of the CAMS project was raising public awareness about the obstacles faced by the uninsured in their communities when they attempted to obtain care. In many communities, local press wrote articles presenting the study findings; some local TV stations also carried reports. Groups also distributed their reports to local officials and other key community leaders, and presented findings at local government and community meetings.

### **Achieving policy change**

The ultimate goal of the CAMS project was to help local partners achieve significant policy changes that increase access to health care for the uninsured in their communities. Many of the community organizations that participated in CAMS were able to use the findings as a powerful tool in achieving needed changes at the facility, community, and county levels.

## CBPR IN PRACTICE: Fresno, California

### County Demands That Hospital Address Deficiencies

**In** Fresno, California, a local hospital system had a contract to run the county's indigent health care program, and wished to extend the contract to include mental health services. However, Central California Legal Services (CCLS), TAP's local partner on the CAMS project, had heard anecdotally that indigent and uninsured patients were having difficulty obtaining care at the hospitals. When CCLS interviewed uninsured patients who had received care at the hospitals, results showed high levels of dissatisfaction with long wait times, lack of information about free or discounted care, and resulting indebtedness. These results contrasted sharply with surveys the hospital system had conducted that claimed high levels of patient satisfaction.

The Fresno Bee reported on the problems identified by the survey. The article provoked further discussion, including a response by the CEO of the hospital system. An editorial in the newspaper advocated that the hospital system "take a hard look at the survey, the results and the methodology, and determine how this new information will affect the organization."

CCLS presented the survey results at a meeting of the Board of Supervisors, who were responsible for overseeing the indigent care contracts. CCLS staff highlighted the need for better monitoring of the county's current contract with the hospital system. As a result, county contract managers sent a letter to the hospital system outlining quality standards and requesting that it file a corrective action plan. In addition, the hospital system decided not to pursue the extension of its contract to include services for the mentally ill.

"The surveys are very important because they are not biased," says Manuel Romero, of CCLS. "They are unattached from the local political climate and that's where you get a true picture of what is happening."



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## CBPR IN PRACTICE: Tallahassee, Florida

### Tax Passed to Fund Primary Care for the Uninsured

**In** Tallahassee, Florida, community advocates had unsuccessfully lobbied the county commissioners for years to raise taxes to pay for needed primary health care services. The two primary care clinics were operating beyond capacity and could not take on more patients. The area had a large number of people with incomes below the federal poverty guidelines. It also had high incidences of breast cancer, cervical cancer, and infant mortality. The We Care Network, which provides free specialty medical care, had taken the lead in advocating for better access to primary care for the poor. Advocates from We Care argued that when people do not have access to primary care, they inappropriately use the emergency room, driving up health costs for everyone. But until the survey, they did not have data to back up their claims.



*“We achieved a landmark change. [The survey] was one of the tools that we used to create momentum for that change.”*

“The CAMS survey gave us information on how patients inappropriately access care at emergency rooms when they don’t have emergency room needs,” says Robin McDougall, program coordinator at the We Care Network. “That crowded our ERs so that people with true emergencies have to wait for care. The survey helped us develop the case that we needed for increased funding for primary care.”

The county commissioners later passed a \$1.4 million increase in property taxes that allowed the two primary care clinics to expand. The CAMS survey added legitimacy to the claims that advocates had been making for years, McDougall says.

“We achieved a landmark change. This was one of the tools that we used to create momentum for that change,” she says. “The county commissioners had never acknowledged fiscal responsibility for primary care before. That shift was very dramatic for our community.”

# Lasting Results

## BEYOND THE SURVEY: Lasting Results

**F**or most of the organizations that participated in CAMS, the project was one component of ongoing campaigns to improve health and access to health care in their communities. Some organizations achieved important policy changes as a direct result of the CAMS initiative; many continue to employ the skills and lessons learned from the project in continuing and new initiatives. Based on its experiences working on CAMS, a group in Cleveland, Ohio is expanding its networking with other community organizations. Because of CAMS, the Legal Aid Society of Greater Cincinnati has expanded its advocacy tools beyond legal research to include surveys and statistical research; recently it applied these tools to a project on child support enforcement. The Progressive Leadership Alliance of Nevada (PLAN), an advocacy group of 45 organizations, has begun focusing on health care issues as a result of its work on CAMS. A PLAN representative now serves on the board of directors of the Nevada Health Care Reform project. Rather than simply reacting to proposed laws as it has in the past, PLAN now proposes its own legislation to respond to the community's health care needs.

TAP also learned a great deal from its experience with CAMS about the value of community-based research. It published two issue briefs based on the aggregate CAMS data that pre-

sented findings on the impact of interpreters on the health care experiences of uninsured people with limited English proficiency, and on the financial consequences of obtaining care. As a result of these findings, it is undertaking a project in three sites that will support efforts to advocate for Medicaid reimbursement for interpreter services. It has also recently started a new community-based research project on medical debt. This initiative, in partnership with organizations in four communities, seeks to estimate the extent of medical debt and document its effects on the finances, health, and well being of individuals and their families. As in the CAMS project, community partners are directly involved in planning and carrying out the research, which they expect to use to bring about change in their communities.

“The approach of The Access Project staff is professional and enthusiastic,” says Paul Brown, PLAN’s Southern Nevada Director. “You need to have an expectation of getting solid results. We lose sight of that in the non-profit world. They were thinking beyond the survey to how you could use the data to make a difference in your city and state.”

But Silvia Portillo of the Tenants’ and Workers’ Committee in Alexandria, Virginia may have said it best. From CAMS, she said, they learned “the power of data combined with organization to achieve actual change.”

Written for The Access Project by Susan G. Parker

We want to thank all of the community organizations that participated in the Community Access Monitoring Survey; without their hard work, this study would not have been possible. We acknowledge and thank The Robert Wood Johnson Foundation and the Annie E. Casey Foundation for their support of this publication.

The Access Project is affiliated with the Heller School for Social Policy and Management at Brandeis University. It has served as a resource center for local communities working to improve health and healthcare access since 1998. The project receives its funding from a variety of public and private sources.

The mission of The Access Project is to strengthen community action, promote social change, and improve health, especially for those who are most vulnerable. The Access Project conducts community action research in conjunction with local leaders to improve the quality of relevant information needed to change the health system. It seeks to enhance the knowledge and skills of community leaders to strengthen the voice of underserved communities in the public and private policy discussions that directly affect them.

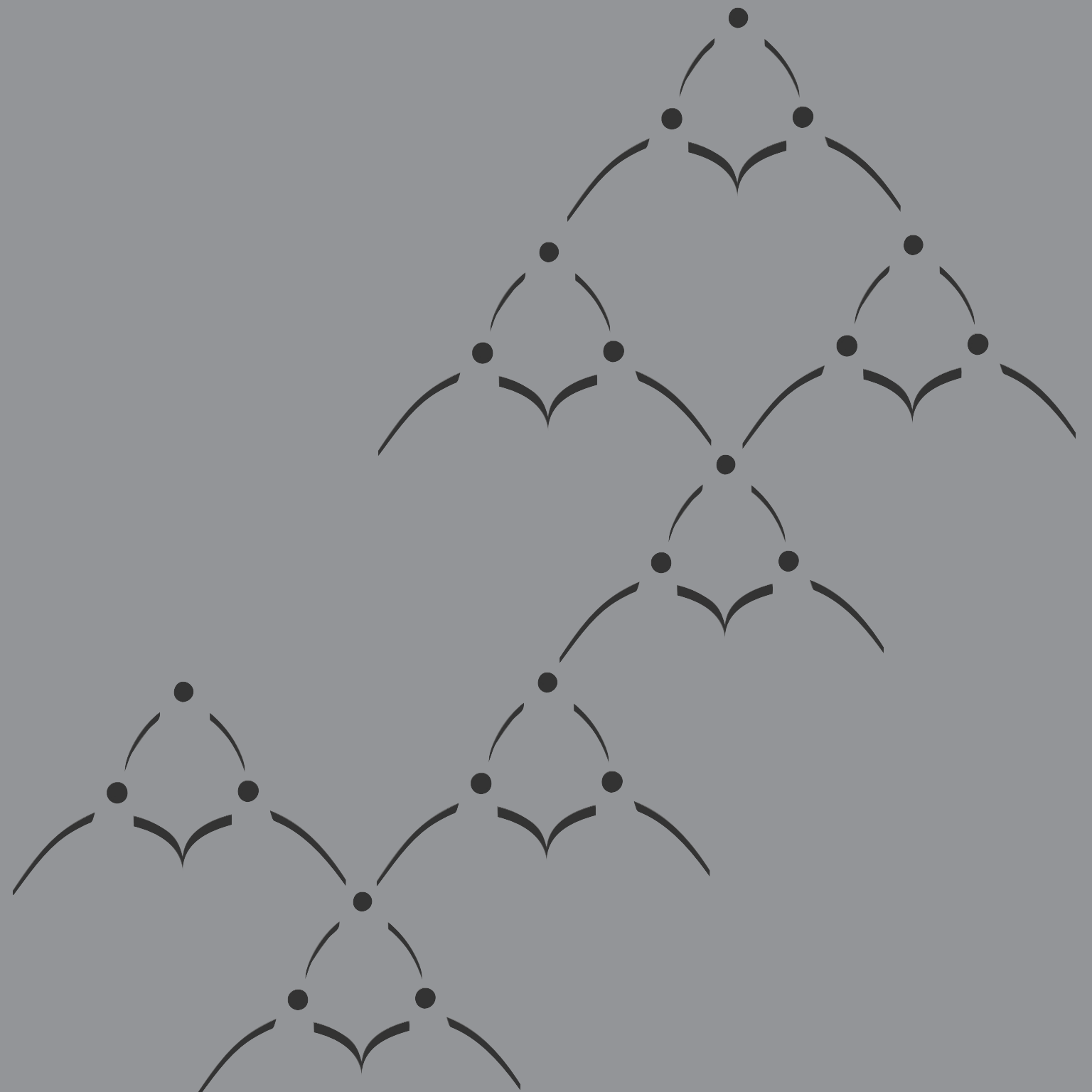
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