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Community-engaged research in the St. Louis metropolitan area: Mapping existing relationships

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WASHINGTON UNIVERSITY IN ST. LOUIS
Institute of **C**linical and **T**ranslational **S**ciences

Community-Engaged Research in the St. Louis Metropolitan Area: Mapping Existing Relationships



ACKNOWLEDGEMENTS

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EXECUTIVE SUMMARY

This report describes the first examination of community-engaged research for the Washington University Institute of Clinical and Translational Sciences (ICTS), the Institute for Public Health (IPH), and the Alvin J. Siteman Cancer Center at Barnes Jewish Hospital and Washington University School of Medicine (SCC). This project will be conducted on a biennial basis to assess changes in community-engaged research over time.

The current community-university research network in the St. Louis metropolitan area was identified in order to establish a baseline for future comparisons. Investigators from ICTS, IPH, and Siteman Cancer Center (SCC) were asked if they had conducted research with a community organization in the past 12 months. The community organizations identified by university investigators then received a survey to evaluate these relationships. Major findings include:

- A small number (4%) of ICTS, SCC, and IPH investigators reported community research partnerships.
- Investigators partnered with 86 community organizations across a wide variety of research topics.
- Six types of community organizations were identified: Health Services, Educational, Advocacy, Faith-Based, Government, and Foundation.
- Current research topics commonly included obesity, mental health, and violence & injury prevention.
- Community organizations anticipated increasing interest in health services research.
- Community organizations were mostly clustered into two locations: in the Central West End neighborhood surrounding the Washington University School of Medicine and downtown St. Louis.
- Research relationships were strongest and most frequent with health services organizations, and weakest and least frequent with foundations.
- Lack of capacity (funding, staff) and lack of time were the two biggest reported barriers to community-engaged research.
- Nearly half of the community organizations stated they had not heard of the ICTS prior to taking the survey.
- Despite limited awareness of ICTS among community organizations, partners had high interest in getting involved in future research.

The Center for Community-Engaged Research and the ICTS should work to strengthen existing research partnerships and look for opportunities to enhance partnerships by pairing individual ICTS investigators and community organizations with similar interests.

INTRODUCTION

Institute of Clinical and Translational Sciences

In September 2007, Washington University in St. Louis (WUSTL) was awarded a Clinical and Translational Science Award (CTSA) from the National Institutes of Health, enabling the creation of the Institute of Clinical and Translational Sciences (ICTS). The overall goal of the ICTS is to serve as the intellectual and physical home for clinical and translational research, clinical research training, and career development to help overcome the traditional boundaries between disciplines, departments, institutions, and external partners.

The Tracking and Evaluation (T&E) team was established to conduct the evaluation of the overall goals of the ICTS. The vision of the T&E team is to utilize evidence-based and innovative evaluation methods to 1) inform ICTS strategic planning and program improvement activities, and 2) assess the impact of ICTS on clinical and translational science that results in clinical applications and meaningful community health outcomes.

An important goal of the ICTS is the development of research relationships between ICTS investigators and community organizations. Many ICTS researchers are also affiliated with the Alvin J. Siteman Cancer Center at Barnes Jewish Hospital and Washington University School of Medicine (SCC) and the Institute for Public Health (IPH). All three research institutions were included in this project in order to gain an understanding of the extent and usefulness of community-engaged research at Washington University.

This report describes the first round of data collection examining community-engaged research by the ICTS T&E team. Future rounds will be administered on a biennial basis.

Center for Community-Engaged Research

The Center for Community-Engaged Research (CCER) was established by the ICTS in 2007 to foster collaborative research partnerships between and among the community at large, community organizations, ICTS partner institutions, community-based health providers,

and researchers. The overall goal of CCER is to facilitate active engagement and participation by community stakeholders as partners in all stages of the clinical and translational research process to improve community health. To achieve its goal, CCER has three specific aims:

1. Expand bi-directional communication with St. Louis communities to make research within the ICTS more relevant and responsive to the health needs and priorities of the entire community.
2. Provide ongoing education to ICTS investigators and trainees on the scientific and ethical principles of community-engaged research and provide them strategies to develop and disseminate culturally appropriate information about research findings. Provide ongoing education to the public and to St. Louis community organizations about the importance of participating in research to improve health and the quality of health care in the region.
3. Strengthen and expand collaborative research partnerships between ICTS cores, investigators, trainees, and community stakeholders to create synergy and facilitate effective and responsive community-engaged research to promote community health.

Report Purpose

This report outlines the key findings from the evaluation of community-engaged research among ICTS and WUSTL investigators.

The goal of this project is to identify the current community-university research network and establish a baseline for future comparison. This report will answer:

1. What does the community/university research network look like?
2. How useful do partners from community organizations find their research ties with university investigators?
3. How are ties between university researchers and community organizations used to support development of research activities?

This report is the first of its kind for the ICTS and is consistent with the direction of other CTSA: focusing

on the current landscape of community-engaged research partnerships and allocating resources to strengthen partnerships over time. Results from this report will be used to inform programmatic planning to enhance community-engaged research relationships and illustrate ICTS progress in meeting its aims over the next five years.

Community Engagement Surveys

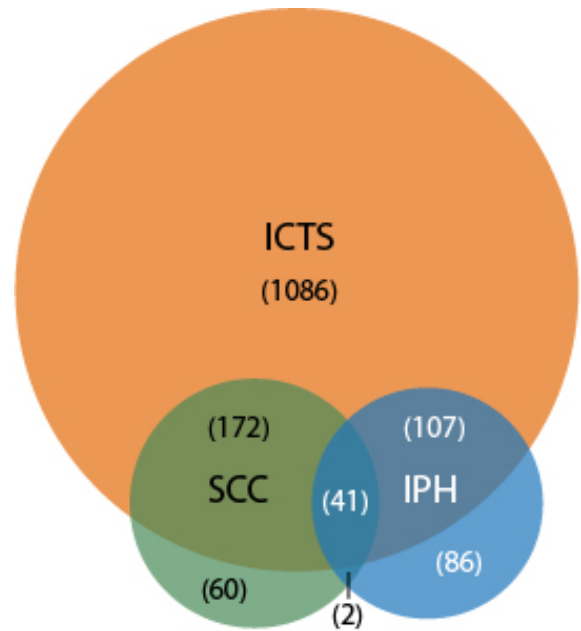
T&E administered surveys in two stages in order to collect information from both ICTS investigators and community organizations:

1. **Survey 1: WUSTL/ICTS Investigators**
Investigators from ICTS, SCC, and IPH received a survey to identify community organizations participating in current research partnerships.
2. **Survey 2: Community Organizations**
At least one representative from each identified organization was surveyed to collect information about those research partnerships.

Survey 1: WUSTL/ICTS Investigators

A survey was administered in the autumn of 2012 to every ICTS, SCC, and IPH member (N=1,554) asking if they conducted research with any community organizations in the St. Louis metropolitan area within the past 12 months (see Figure 1). Community organizations were defined as non-academic organizations that could include: community health coalitions, advocacy groups, foundations, or government/public organizations. Investigators were asked to list up to 10 community organizations they had engaged with for research purposes.

Figure 1. Affiliation of investigators who received the WUSTL/ICTS Investigators survey

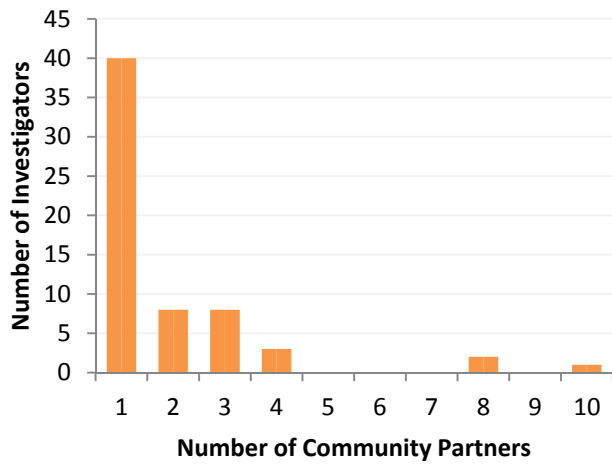


The survey remained open for two weeks and received 641 responses (41.2%) with 63 investigators (4%) indicating they had conducted research with a community organization in the last 12 months. Given the low response rate, this 4% figure should be considered a low estimate, as it is likely that some non-respondents had community partnerships.

4% of investigators reported community-engaged research partnerships

The 63 investigators identified 86 organizations with each investigator collaborating with an average of 1.9 community organizations (see Figure 2).

Figure 2. Number of community partners per investigator (of those who reported having community partners)



Survey 2: Community Organizations

A representative from each community organization identified in the WUSTL/ICTS Investigators survey received the Community Organization survey in the spring of 2013. Data were aggregated in cases where more than one person from an organization took the survey. There was an organizational response rate of 72% for this second stage survey.

The survey was designed to collect the following information:

- Level of partnerships with ICTS and WUSTL affiliated organizations
- Community organizations' current and future research interests
- Barriers to engaging in research
- General attitudes toward collaboration
- Knowledge about ICTS
- Interactions with other community organizations

FINDINGS

Partner Identification

The community organizations identified by investigators were mapped across the St. Louis region. Figure 3 shows the distribution and density of community organizations.

The community organizations were located across seven counties in the St. Louis metropolitan area—five counties in Missouri and two counties in Illinois.

Community organizations were concentrated in two general locations; one in the Central West End in close proximity to the WUSTL School of Medicine and another in downtown St. Louis. Additional GIS maps can be found in Appendix A.

Table 1 lists the community organizations and number of ICTS, SCC, and IPH investigators who identified them as being community research partners.

Figure 3. Location (main) and heat map (insert) of community organizations who were named as partners in the past 12 months

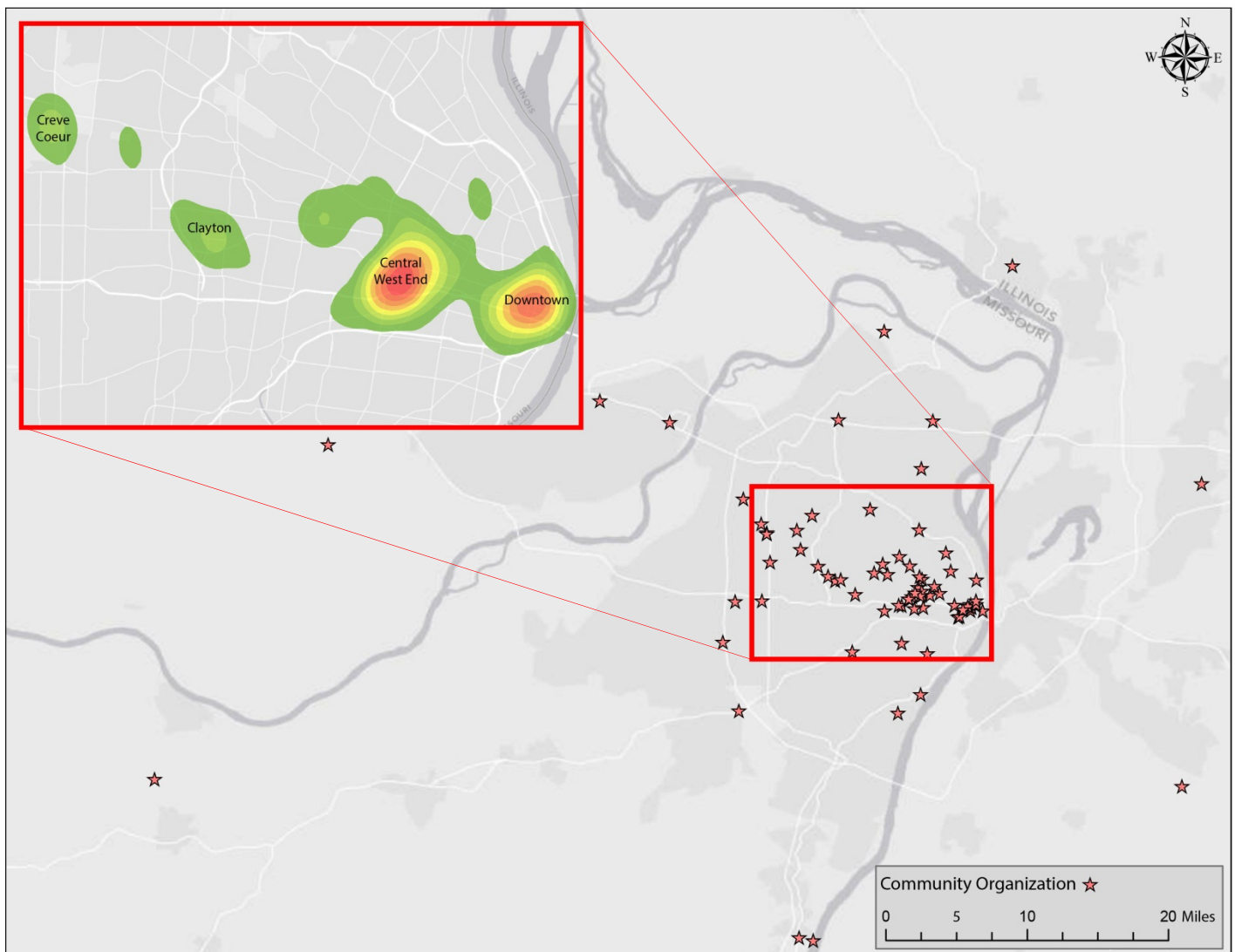


Table 1. List of community partners, type of organizations, and number of investigators who named them as a partner

| Community Organization | Type | # | Community Organization | Type | # |
|---|------|---|---|------|---|
| Alliance for Biking and Walking | ADV | 1 | Missouri Department of Corrections Division of Probation & Parole | GOV | 1 |
| Alton Memorial Hospital | HS | 1 | Missouri Department of Health & Senior Services | GOV | 2 |
| Alzheimer's Association - St. Louis Chapter | ADV | 3 | Missouri Foundation for Health | FOU | 3 |
| Ameren Corporation | HS | 1 | Missouri Social Services, Children's Division, St. Louis City & County | GOV | 1 |
| American Heart Association, Regional Chapter | ADV | 1 | Multiple Sclerosis Society Gateway Area Chapter | ADV | 2 |
| American Parkinson's Disease Association of Greater St. Louis | ADV | 1 | Murchison Tabernacle CME Church | FB | 1 |
| Barnes-Jewish St. Peters Hospital | HS | 1 | Muscular Dystrophy Association | ADV | 1 |
| Betty Jean Kerr People's Health Center | HS | 6 | Myrtle Hilliard Davis Comprehensive Health Center | HS | 1 |
| Boys & Girls Clubs of Greater St. Louis | EDU | 1 | National Children's Cancer Society | ADV | 1 |
| Cancer Support Community of Greater St. Louis | ADV | 1 | Nurses for Newborns | HS | 1 |
| Carpenters District Council of Greater St. Louis and Vicinity | ADV | 2 | PandemicPrep.org | HS | 2 |
| Carpenters Health and Welfare Trust Fund of St. Louis | FOU | 1 | Paraquad | HS | 3 |
| Chartwells School Dining Services | EDU | 1 | Parents As Teachers | EDU | 1 |
| Children's Discovery Institute | FOU | 3 | Planned Parenthood of the St. Louis Region & Southwest Missouri | HS | 1 |
| Christ Pilgrim Rest Missionary Baptist Church | FB | 1 | Prospect Hill Baptist Church | FB | 1 |
| Christian Hospital Northeast | HS | 1 | Prostate Cancer Community Partnership | HS | 1 |
| Christian Hospital Northwest | HS | 1 | Queen of Peace Center | HS | 1 |
| City of St. Louis | GOV | 1 | Ride on St. Louis | EDU | 1 |
| City of St. Louis Department of Health | GOV | 1 | Ritenour School District | EDU | 1 |
| Clayton Child Center | EDU | 1 | Special School District of St. Louis | EDU | 1 |
| Coleman Wright CME Church | FB | 1 | St. Louis Area Agency on Aging | ADV | 4 |
| Committed Caring Faith Communities | FB | 3 | St. Louis Children's Hospital | HS | 1 |
| Cystic Fibrosis Foundation | FOU | 1 | St. Louis City Juvenile Court | GOV | 1 |
| Exceptional Equestrians of the Missouri Valley, Inc. | EDU | 1 | St. Louis County Department of Health | GOV | 1 |
| Explore Transplant | HS | 1 | St. Louis Diabetes Coalition | HS | 1 |
| Faith Communities Joined for Health | FB | 2 | St. Louis Effort for AIDS | ADV | 4 |
| Faith Miracle Temple Church | FB | 1 | St. Louis Integrated Health Network | HS | 1 |
| Family Care Health Centers | HS | 3 | St. Louis Public Library | EDU | 1 |
| Family Resource Center | HS | 1 | St. Louis Public Schools | EDU | 2 |
| Gateway Immunization Coalition | HS | 1 | St. Louis Regional Breast Navigator Workgroup | HS | 1 |
| Grace Hill Health Centers | HS | 2 | St. Louis Science Center | EDU | 1 |
| Great Rivers Greenway | ADV | 1 | St. Louis Scott Gallagher Soccer Club | EDU | 1 |
| Healthier MO Communities | EDU | 1 | Supporting Positive Opportunities with Teens (The SPOT) | HS | 1 |
| Healthstreet | HS | 2 | Tabernacle of Life Church | FB | 1 |
| Hopewell Missionary Baptist Church | FB | 1 | The St. Louis American | EDU | 1 |
| Huntington's Disease Society of America | ADV | 1 | Therapeutic Horsemanship | EDU | 1 |
| International Institute of St. Louis | EDU | 1 | Trailnet | ADV | 1 |
| Jewish Community Center | FB | 2 | Washington University Cystic Fibrosis Family Advisory Board | ADV | 1 |
| Jewish Federation of St. Louis | FB | 1 | Washington University Pediatric and Adolescent Ambulatory Research Consortium (WUPAARC) | HS | 1 |
| Kellsie's Hope Foundation | FOU | 1 | West End Mt. Carmel Community Outreach Service | FB | 1 |
| March of Dimes - Missouri Chapter | ADV | 1 | Windsor C-1 School District | EDU | 1 |
| Metropolitan Police Department, City of St. Louis | GOV | 1 | Youth in Need Early Head Start & Head Start | EDU | 1 |
| Midwest Vapers Group | ADV | 1 | YWCA | EDU | 1 |

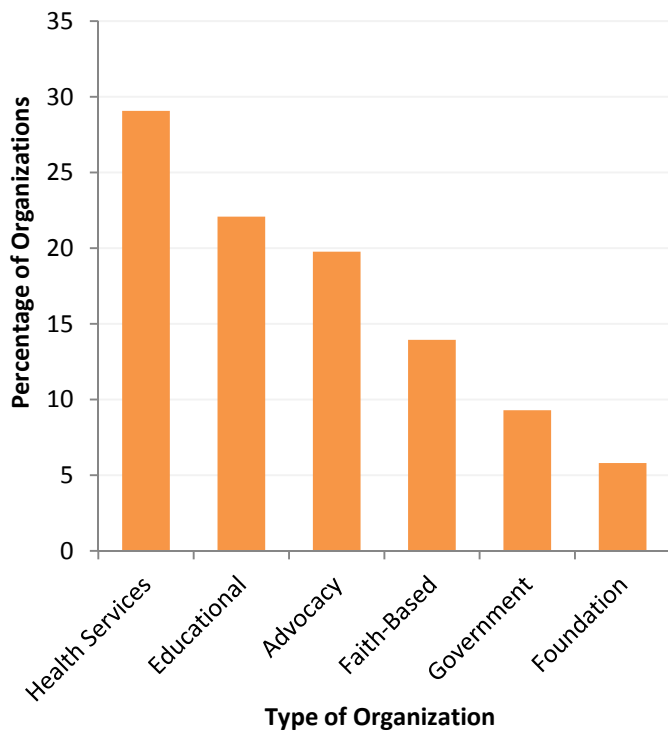
ADV: Advocacy EDU: Education FB: Faith-Based FOU: Foundation GOV: Government HS: Health Services

The majority of community organizations were identified by only one investigator, although 18 community organizations were identified by more than one investigator. Betty Jean Kerr People’s Health Center was identified most often, by six investigators. St. Louis Area Agency on Aging and St. Louis Effort for AIDS each had four investigators identify them as community research partners.

Partner Characteristics

Organizations were coded into six categories based on their missions and types of research. Health Services and Educational organizations were the most common organization types (see Figure 4).

Figure 4. Organization types identified with the WUSTL/ICTS Investigators survey



Research Topic Areas and Interests

Organizations reported research topics they were engaged in over the past 12 months as well as future research topic areas of interest. The topic areas were a combination of results from the 2009 Our Community,

Our Health conference¹ and the State of Missouri Health Disparities Report² from 2008.

Obesity & Physical Activity was the most common research topic that community organizations were engaged in and also had the highest interest for future research (Table 2). HIV/AIDS, Tobacco, and Sexually Transmitted Diseases were the three research topics that organizations expressed decreased interest in moving forward.

Table 2. What research topics are you currently engaged in, have done in the past, or may be interested in for the future?

| Topic Area | Current or Past Research | Future Research |
|---------------------------------|--------------------------|-----------------|
| Obesity/Physical Activity | 16.1% (10) | 25.8% (16) |
| Mental Health | 12.9% (8) | 22.6% (14) |
| Violence & Injury Prevention | 11.3% (7) | 16.1% (10) |
| Cancer | 11.3% (7) | 12.9% (8) |
| Aging Populations | 11.3% (7) | 11.3% (7) |
| HIV/AIDS | 11.3% (7) | 9.7% (6) |
| Tobacco | 11.3% (7) | 8.1% (5) |
| Sexually Transmitted Diseases | 11.3% (7) | 8.1% (5) |
| Substance Abuse | 8.1% (5) | 12.9% (8) |
| Asthma | 8.1% (5) | 11.3% (7) |
| Hypertension/Blood Pressure | 6.5% (4) | 8.1% (5) |
| Immunizations | 4.8% (3) | 8.1% (5) |
| Chronic Lung Disease | 4.8% (3) | 6.5% (4) |
| Diabetes | 3.2% (2) | 11.3% (7) |
| Cardiovascular or Heart Disease | 3.2% (2) | 9.7% (6) |
| Allergy | 3.2% (2) | 6.5% (4) |
| Chronic Kidney Disease | 1.6% (1) | 6.5% (4) |
| Flu/Pneumonia | 0.0% (0) | 6.5% (4) |

Refer to Appendix B for detail by organization type.

Community organizations were also asked about their broader research interests. Community-based research was the most common type of research currently engaged in and of interest for the future (see Table 3).

¹<http://wustl-icts.vsstaging.com/mm/files/OCOHsurvey.pdf>

²<http://health.mo.gov/living/families/minorityhealth/pdf/DisparityReport.pdf>

Table 3. What research types are you currently engaged in or may be interested in for the future?

| Research Type | Current Research | Future Research |
|-------------------|------------------|-----------------|
| Community-Based | 54.8% (34) | 46.8% (29) |
| Health Services | 19.4% (12) | 32.3% (20) |
| Clinical Research | 19.4% (12) | 16.1% (10) |
| Laboratory-Based | 6.5% (4) | 4.8% (3) |

Refer to Appendix B for detail by organization type.

Health Services research was the only type of research that increased from those who were currently engaged to those who were interested in that type of research for the future. Community organizations expressed a low interest in laboratory-based research.

Research Activities

Community organizations were involved in a wide variety of activities. Table 4 shows the research activities that have resulted from university-community partnerships in the past 12 months.

Table 4. For those research partnerships you have identified, what types of research activities have you conducted during the past 12 months?

| Research Activity | Percentage (n) |
|-------------------------------|----------------|
| Research Study | 59.7% (37) |
| Grant Proposal | 48.4 % (30) |
| Education/Training Activities | 46.8% (29) |
| Presentation | 27.4% (17) |
| Academic Publication | 14.5% (9) |
| Press Release | 11.3% (7) |
| Patent Application | 3.2% (2) |
| Clinical/Policy Guidelines | 3.2% (2) |

Refer to Appendix B for detail by organization type.

More than half of the participating community organizations worked on a research study within the past 12 months and close to half of the community organizations worked on a grant proposal and/or training activities. Patent applications and clinical/policy guidelines had the lowest response at 3.2% each.

Collaboration

Collaboration patterns were examined in three different ways:

1. From WUSTL/ICTS investigators to the community organizations (WUSTL/ICTS investigator survey)
2. From community organizations to WUSTL/ICTS investigators (community organization survey)
3. From community organizations to other community organizations (community organization survey)

WUSTL/ICTS Collaboration with Community Organizations

In addition to the large overlap ICTS membership has with SCC and IPH within WUSTL, a small number of

ICTS members were from outside of WUSTL. External affiliate institutions were Barnes Jewish Healthcare (BJC), Saint Louis University (SLU), Southern Illinois University Edwardsville (SIUE), St. Louis College of Pharmacy (STLCOP), and University of Missouri St. Louis (UMSL).

Table 5 shows the distribution of collaboration from WUSTL/ICTS affiliated investigators over the six community organization types. Investigators affiliated with SLU focused most collaborations with health services organizations, while investigators affiliated with WUSTL had many collaborations with all types of organizations with the exceptions of foundations and government offices.

Table 5. Pattern of nominated community organizations by investigator affiliation and organization type

| Institutional Affiliation | Advocacy | Educational | Faith-Based | Foundation | Government | Health Services | Total Nominations |
|---------------------------|-----------|-------------|-------------|------------|------------|-----------------|-------------------|
| <i>WUSTL</i> | | | | | | | |
| ICTS Only | 5 | 10 | 10 | 2 | 2 | 4 | 33 |
| ICTS & IPH | 9 | 3 | 2 | - | 3 | 8 | 25 |
| ICTS & SCC | 1 | - | - | 2 | - | 4 | 7 |
| ICTS, SCC & IPH | 3 | 4 | 2 | 2 | - | 6 | 17 |
| <i>Non-WUSTL ICTS</i> | | | | | | | |
| BJC | - | - | - | - | - | - | 0 |
| SLU | 2 | 1 | - | 1 | 2 | 7 | 13 |
| SIUE | 1 | - | - | - | - | - | 1 |
| STLCOP | - | - | - | 1 | - | - | 1 |
| UMSL | - | 1 | - | - | - | - | 1 |
| Total | 21 | 19 | 14 | 8 | 7 | 29 | |

Community Organization Collaboration with WUSTL/ICTS

Community organizations were asked to rate their level of collaboration with each of the WUSTL/ICTS institutions on a scale of 0 (none) to 5 (full partnership), with an option to indicate “don’t know” valued as 1. Figure 5 shows the pattern of collaboration as reported by the community organizations. Each of the non-

labeled small circles (nodes) represents a participating community organization, and the labeled nodes represent WUSTL/ICTS institutions. A line (link) between two nodes indicates that a community organization rated the level of collaboration at least as high as “don’t know,” indicating at least the possibility of having worked together. The size of the WUSTL/ICTS institution nodes is determined by the number of community organizations linked to them.

Figure 5. Community organization survey network: WUSTL/ICTS institution nodes sized by and labeled with number of incoming nominations

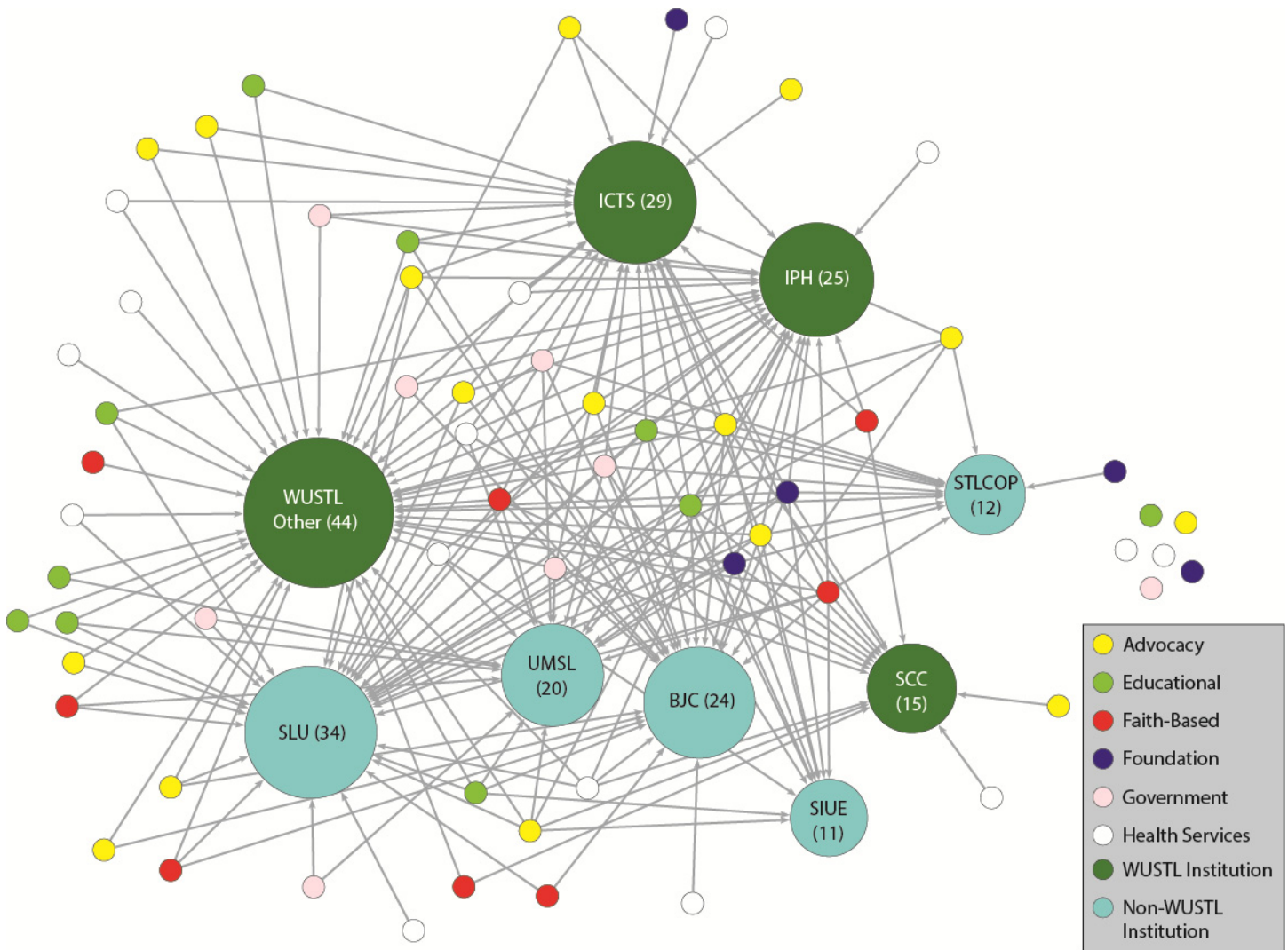


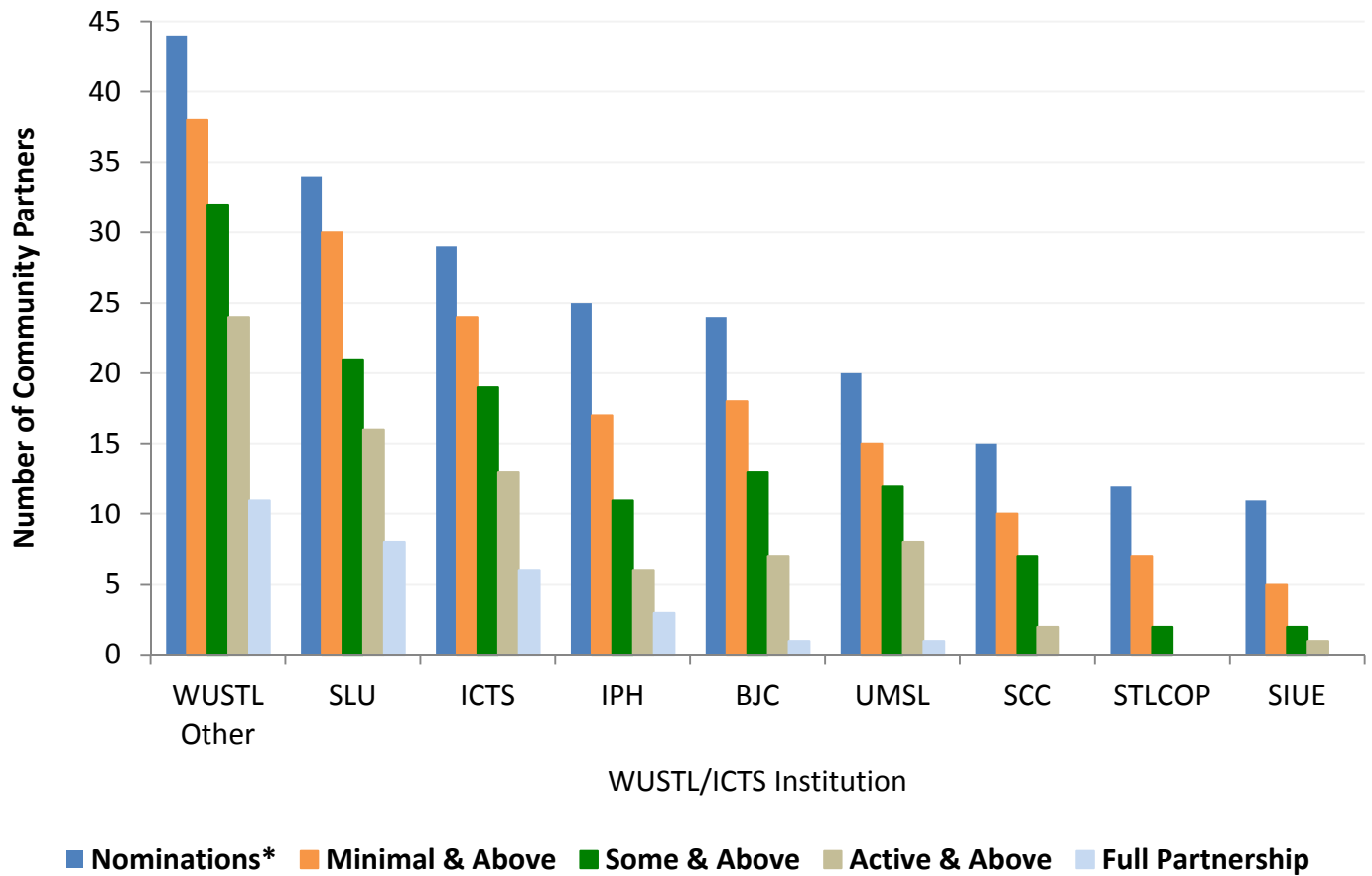
Figure 5 demonstrates a high level of activity, with community organizations reporting at least possible collaborations with an average of 3.45 WUSTL/ICTS institutions, and WUSTL/ICTS institutions receiving an average of 23.8 possible collaborations with community organizations. Community organizations were most likely to work with investigators with a WUSTL Other affiliation, followed by SLU, ICTS, IPH, and BJC (Figure 6). Figure 6 also demonstrates the distribution of partnership levels for each institution.

Note that a community organization’s response to a level of involvement with a particular institution may not be with an investigator who responded to the WUSTL/ICTS Investigators survey. For instance, a

community organization working with SLU or UMSL may or may not have worked with the ICTS members from that institution.

Table 6 lists the average level of existing partnerships with each institution across all six community organization categories. Health services organizations tended to have the highest partnership levels, and foundations had the weakest. Community organizations reported the strongest relationships with WUSTL Other, and the weakest with SIUE. Particularly strong relationships were reported by health services organizations for WUSTL Other and SLU, by government offices for SIUE, and by foundations for ICTS.

Figure 6. Number of incoming nominations for each partnership level by institution



*Including Don't Know

Table 6. Relationship strength averaged over each organization type for each institution

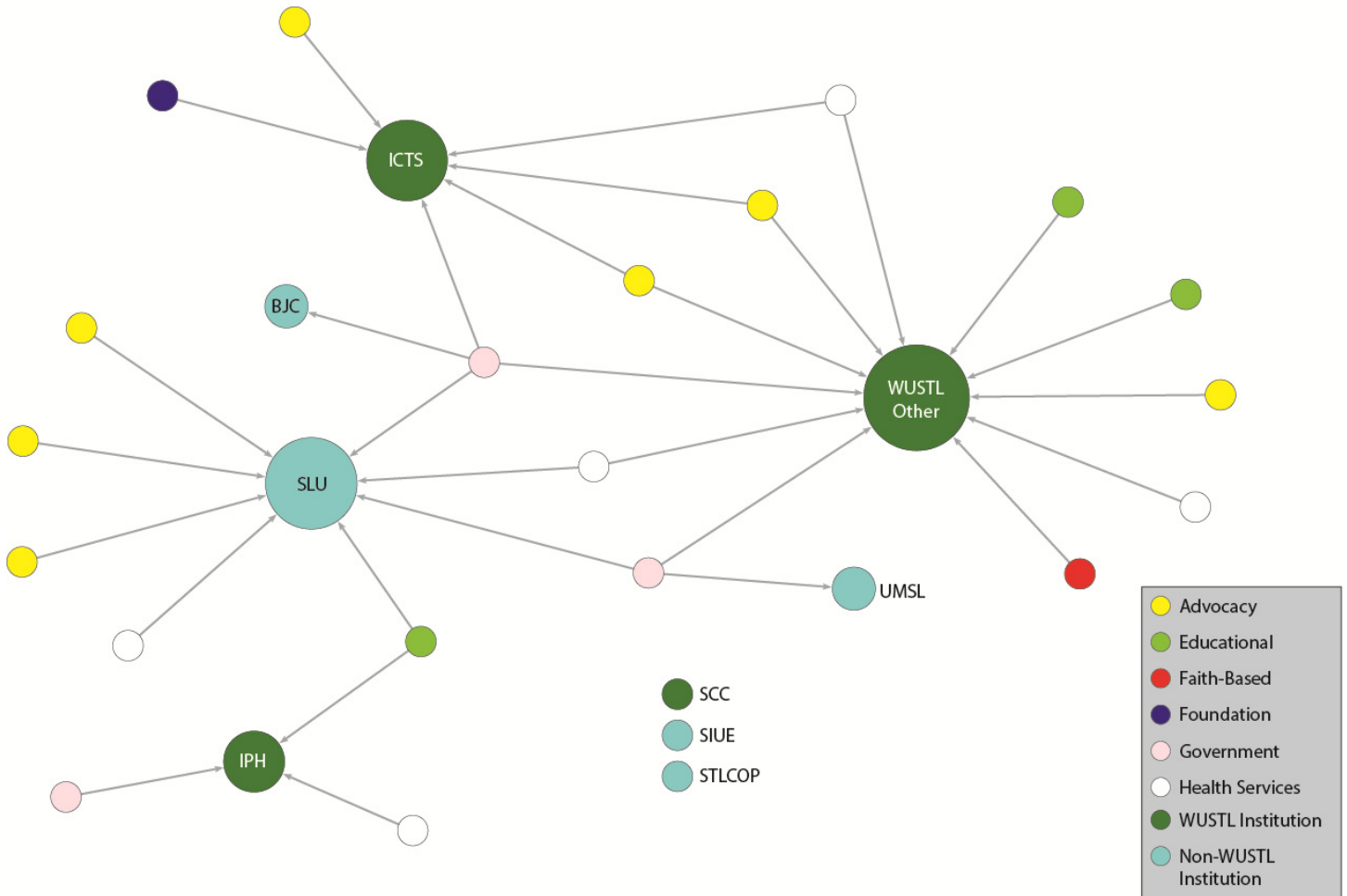
(1=Don't Know, 2=Minimal, 3=Some, 4=Active Partnership, 5=Full Partnership)

| Organization Type | WUSTL Other | SLU | ICTS | UMSL | BJC | IPH | SCC | STLCOP | SIUE | Mean |
|-------------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|
| Health Services | 4.13 | 4.00 | 3.00 | 3.50 | 3.50 | 2.80 | 2.00 | -- | 2.00 | 3.69 |
| Government | 3.50 | 3.83 | 3.00 | 3.80 | 3.50 | 2.25 | 3.00 | 2.50 | 4.00 | 3.27 |
| Faith-Based | 3.33 | 2.50 | 2.67 | 2.00 | 2.50 | 2.67 | 2.75 | 1.00 | 1.00 | 3.11 |
| Advocacy | 3.15 | 3.11 | 3.50 | 3.00 | 3.00 | 2.57 | 2.00 | 1.75 | 2.00 | 3.08 |
| Educational | 3.33 | 3.00 | 2.00 | 2.60 | 1.50 | 2.75 | 1.00 | 1.50 | 1.33 | 2.93 |
| Foundation | 2.00 | 2.50 | 4.33 | 1.00 | 1.00 | 1.00 | 2.50 | 1.67 | 1.00 | 2.89 |
| Mean | 3.39 | 3.21 | 3.14 | 2.80 | 2.63 | 2.48 | 2.27 | 1.75 | 1.73 | 3.21 |

Figure 7 displays the network of community organizations reporting full partnerships with at least one WUSTL/ICTS institution. Seven community organizations had full partnerships with more than one institution. These organization types include advocacy, education, government, and health services. Only one

faith-based organization and one foundation reported a full partnership. A government organization had the most full-partnerships, working with four institutions. No community organizations reported full partnerships with SCC, SIUE, or STLCOP.

Figure 7. Full partnerships among community organizations and WUSTL/ICTS institutions

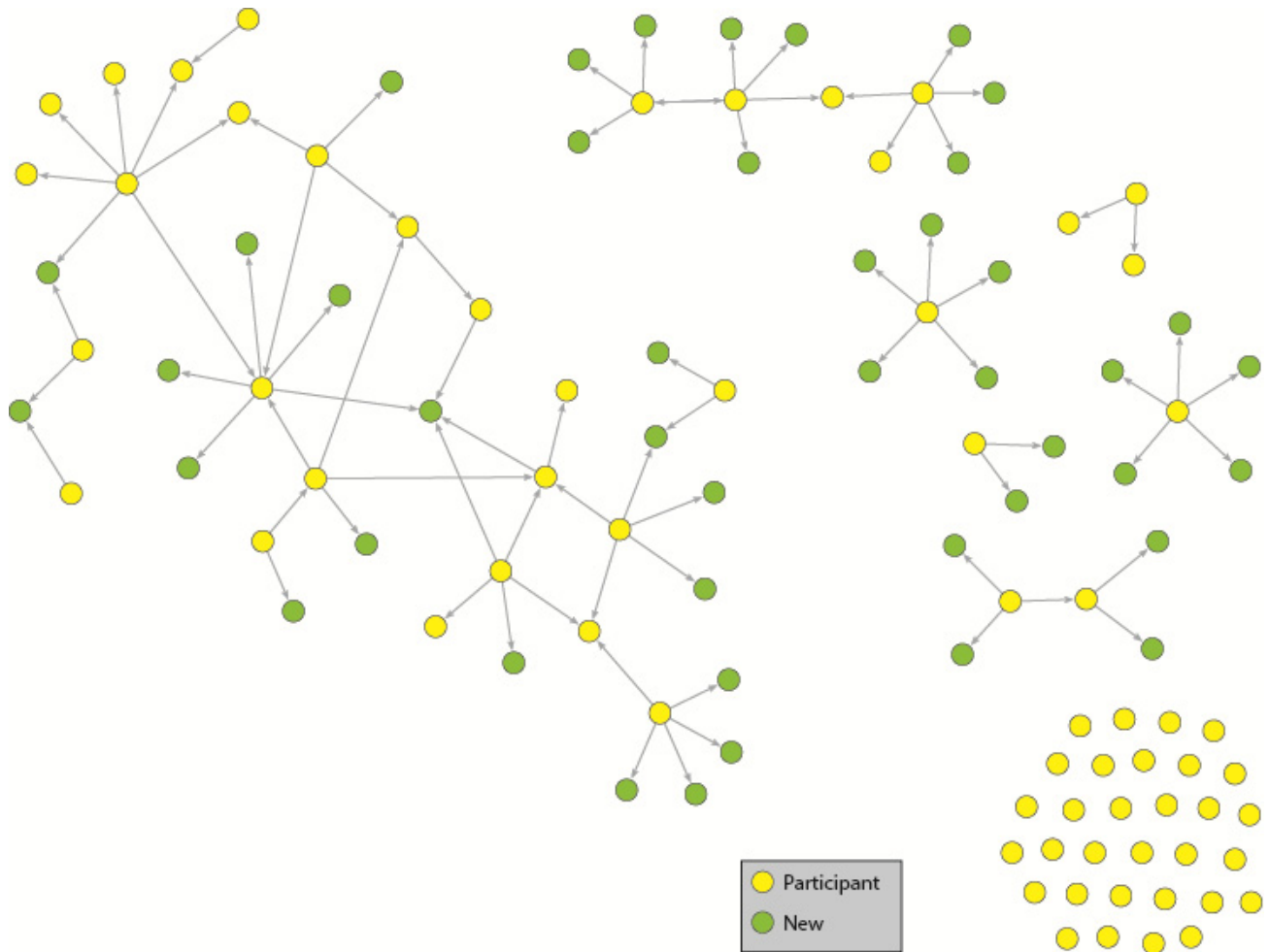


Community Partner Collaborations with other Community Partners

Community organizations were asked to identify up to five additional community organizations they worked closely with in the St. Louis metropolitan area. Figure 8 illustrates the partnerships between community organizations. Green nodes are additional community

organizations named by participating organizations (yellow). Note that several participating organizations indicated working together. The non-connected nodes (isolates) in this network were participating organizations that did not indicate having additional community partners. Given the response rate of 72%, there are organizations that did not participate that could otherwise be considered isolates but are not included in this figure.

Figure 8. Community partner collaborations



Challenges and Opportunities

The two most common barriers to research collaboration reported by community organizations were a lack of capacity and a lack of time (see Table 7). Lack of trust was the least common barrier to engaging in research. A more detailed breakdown of the barriers by organization type can be found in Appendix B.

Table 7. Which of the following factors impede your ability to engage in research with the partners listed before?

| Barriers | Percentage (n) |
|---|----------------|
| Lack of capacity (funding, staff, etc.) | 48.4% (30) |
| Lack of time | 46.8% (29) |
| Organizational structure/bureaucracy | 16.1% (10) |
| Unable to identify appropriate collaborator | 6.5% (4) |
| Benefits of collaboration are outweighed by the costs | 6.5% (4) |
| Research is a low priority | 6.5% (4) |
| Lack of trust | 1.6% (1) |

Community organization respondents were asked an open-ended question for clarification about the barriers. One organization responded,

“Sometimes there is a disconnect between researchers and practitioners about the goals of the research project, which leads to expectations that haven't or can't be met.”

Another organization responded,

“We are simply too busy to be as engaged and collaborative as we would like. The research and benefit derived is secondary to our core business objectives in the short-term ROI perspective.”

Respondents were asked about the benefits of their research collaborations pertaining to four general categories: mission, quality, health, and productivity. Each question had a Likert scale ranging from 1 (Strongly Disagree) to 5 (Strongly Agree). Figure 9 demonstrates that, on average, community partners were highly satisfied with their partnerships.

Figure 9. In general, our research collaborations have...



Respondents were given the opportunity to answer an open-ended question about the benefits of their research partnerships. Replies included:

“The Wash U team brings a different perspective to our program, and that fresh view is valuable in developing solutions that might not have been identified without their input.”

“I would be like to see our partnership continue, even if the grant is not awarded for this project. I think together we can make a greater impact on communicating to students and parents and the effects of how their daily food choices affect their overall health at home and school.”

“We love to have access to top researchers who are informed of best practices and can help us design effective programs and evaluation. It does need to be cost effective—we can't afford to spend a lot on evaluation that is too scientific and not applicable in program design now.”

“Having national research grants awarded to local researchers helps our chapter when we engage with local supporters. It provides us with local examples of how the money that is donated to our chapter is being reinvested locally by our organization.”

The majority of the qualitative responses were positive feedback about their research collaboration partners.

Opportunities for ICTS

Community organization respondents were asked three questions about the ICTS at the end of the survey: familiarity with ICTS, whether or not they had visited the ICTS website, and if they would like their contact information made available to ICTS investigators.

Nearly 47% of community organization respondents had not heard of the ICTS prior to taking the survey while 2.9% of community organizations reported working closely with ICTS members (see Table 8).

Table 8. How familiar are you with the Institute for Clinical and Translational Sciences (ICTS)?

| Familiarity with ICTS | Percentage (n) |
|--|----------------|
| I have not heard of the ICTS prior to taking this survey | 46.4% (32) |
| I have heard of the ICTS prior to taking this survey but I do not know its purpose | 17.4% (12) |
| I am familiar with the ICTS and its purpose | 21.7% (15) |
| I work closely with ICTS members | 2.9% (2) |

The ICTS constructed a new website in 2013³ in order to increase its scientific reach and impact. This website provides an opportunity for broader dissemination and communication to community partners. Fewer than 15% of respondents had visited the website in the last year (Table 9).

Table 9. Have you visited the ICTS website in the past 12 months?

| Visited Website | Percentage (n) |
|-----------------|----------------|
| Yes | 14.8% (9) |
| No | 85.2% (52) |

The Tracking and Evaluation team will monitor website traffic and experiment with web analytics to track changes in website activity.

Finally, respondents were asked if they would like their contact information made available for ICTS members to contact them about research opportunities in the future.

While most community organization respondents were not familiar with the ICTS and had not visited the

website, they were interested in being contacted by ICTS members for future research collaborations (Table 10).

Table 10. Would you like to have your name and contact information available to ICTS members so that researchers can contact you about future research opportunities?

| Contact Information | Percentage (n) |
|---------------------|----------------|
| Yes | 75% (45) |
| No | 25% (15) |

Limitations

Since the project was the first of its kind and exploratory in nature, there were some inherent limitations. Limitations arose due to the uniqueness of the project—surveying two separate groups of individuals but referring to the organizations instead of individuals in each survey. This could be particularly difficult for the community organizations since they may not know their research partners’ institution affiliations.

Other limitations include:

Low response rate: The WUSTL/ICTS Investigators survey had only a 41% response rate; close to 900 people did not indicate whether or not they conducted community-engaged research in the past 12 months.

Likely missing existing partnerships: This is most likely due to the low response rate from the first survey. Had more ICTS, SCC, and IPH members participated, additional community partners would have been included in the network.

³<http://icts.wustl.edu/>

CONCLUSIONS

Summary of Key Findings

- A small number (4%) of ICTS, SCC, and IPH investigators reported community research partnerships.
- Investigators partnered with 86 community organizations across a wide variety of research topics.
- Six types of community organizations were identified: Health Services, Educational, Advocacy, Faith-Based, Government, and Foundation.
- Current research topics commonly included obesity, mental health, and violence & injury prevention.
- Community organizations anticipated increasing interest in health services research.
- Community organizations were mostly clustered into two locations: in the Central West End neighborhood surrounding the Washington University School of Medicine and downtown St. Louis.
- Research relationships were strongest and most frequent with health services organizations, and weakest and least frequent with foundations.
- Lack of capacity (funding, staff) and lack of time were the two biggest reported barriers to community-engaged research.
- Nearly half of the community organizations stated they had not heard of the ICTS prior to taking the survey.
- Despite limited awareness of ICTS among community organizations, partners had high interest in getting involved in future research.

Discussion

Funding and time were the biggest barriers toward collaboration as indicated by the community organizations. With the information gained through this project, the ICTS is now aware of research interests of community organizations and can be more strategic in facilitating collaboration between university investigators and community organizations that have similar interests.

Nearly half of all participating community organizations had not heard of the ICTS prior to taking the survey. This suggests an opportunity and need to market the ICTS to a broader audience. CCER can view upcoming activities as opportunities to raise the visibility of ICTS and consider disseminating the new ICTS website among community organizations.

APPENDIX A: ADDITIONAL FIGURES

Figure 1. Would you like to have your name and contact information available to ICTS members so that researchers can contact you about future research opportunities?

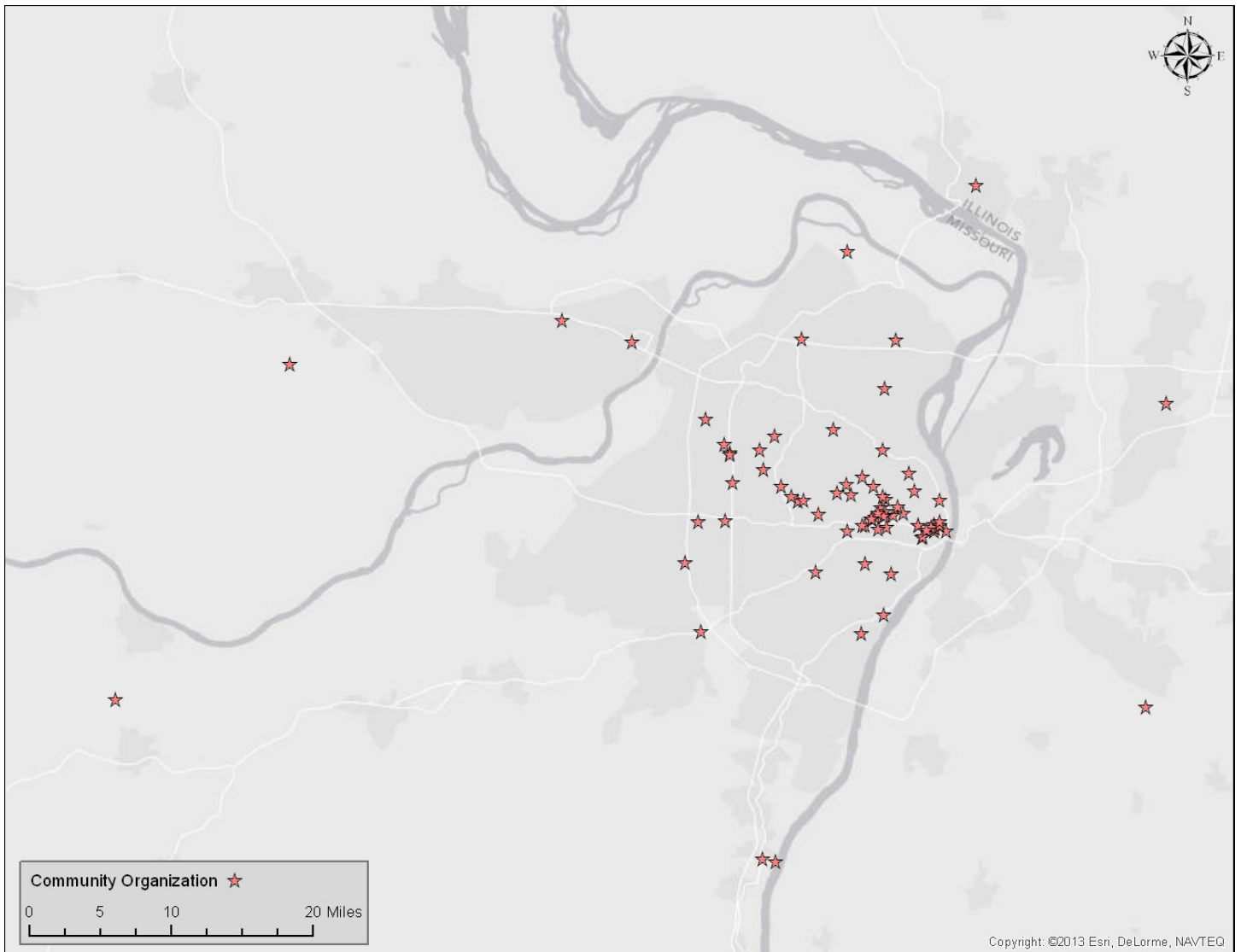
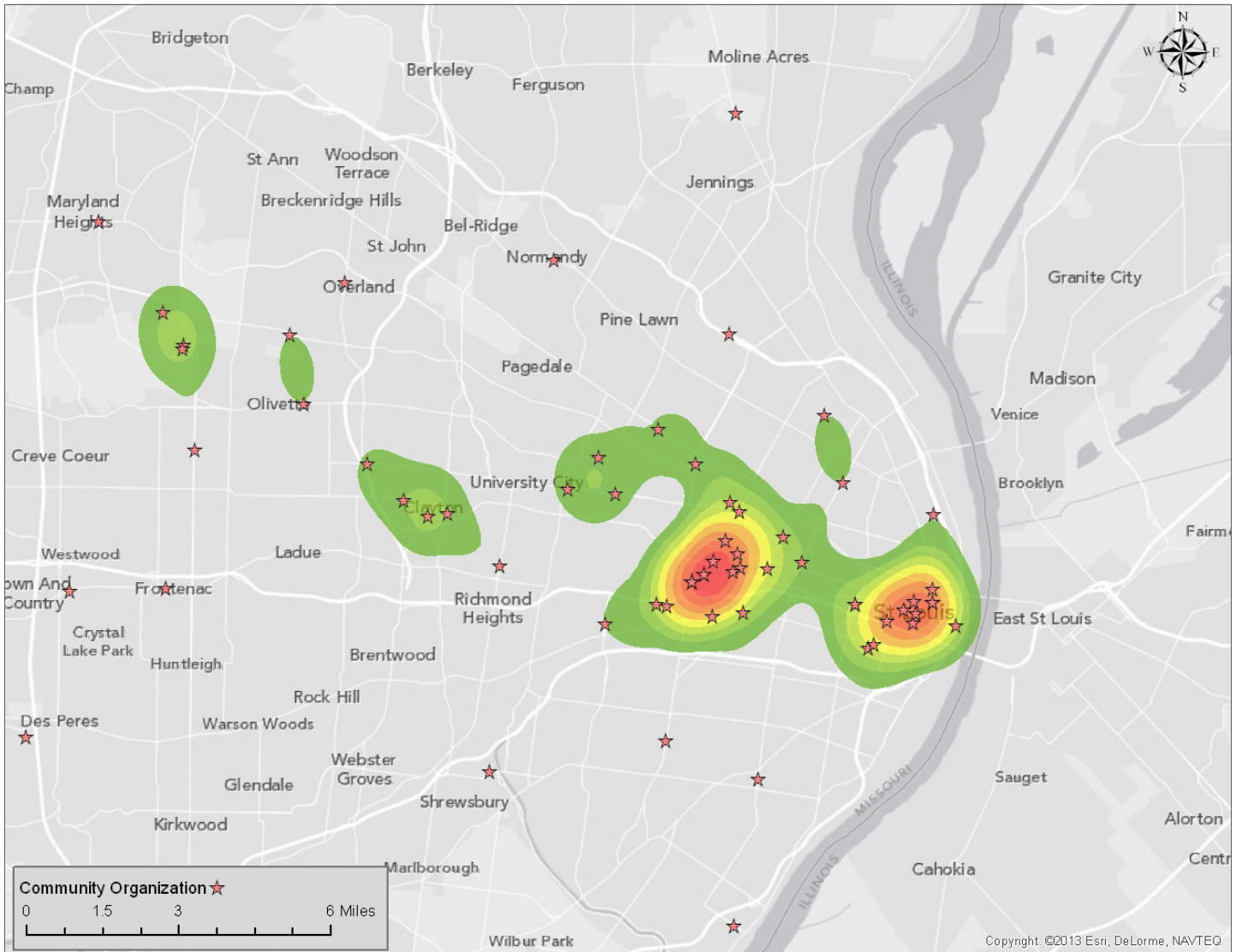


Figure 2. WUSTL community organization heat map



APPENDIX B: ADDITIONAL TABLES

Table 1a. What research topics are you currently engaged in or have done in the past?

| Topic Area | Current or Past Research | Advocacy | Educational | Faith-Based | Foundation | Government | Health Services |
|---------------------------------|--------------------------|----------|-------------|-------------|------------|------------|-----------------|
| Obesity/Physical Activity | 16.1% | 2 | 1 | 0 | 1 | 3 | 2 |
| Mental Health | 12.9% | 0 | 2 | 0 | 1 | 3 | 0 |
| Violence & Injury Prevention | 11.3% | 2 | 1 | 0 | 2 | 1 | 2 |
| Cancer | 11.3% | 0 | 3 | 0 | 0 | 1 | 0 |
| Aging Populations | 11.3% | 1 | 3 | 0 | 0 | 0 | 1 |
| HIV/AIDS | 11.3% | 0 | 2 | 0 | 2 | 2 | 0 |
| Tobacco | 11.3% | 0 | 2 | 1 | 2 | 1 | 0 |
| Sexually Transmitted Diseases | 11.3% | 0 | 1 | 0 | 3 | 2 | 0 |
| Substance Abuse | 8.1% | 0 | 1 | 0 | 2 | 1 | 0 |
| Asthma | 8.1% | 1 | 1 | 0 | 1 | 1 | 1 |
| Hypertension/Blood Pressure | 6.5% | 1 | 1 | 0 | 0 | 1 | 1 |
| Immunizations | 4.8% | 0 | 0 | 0 | 1 | 1 | 0 |
| Chronic Lung Disease | 4.8% | 0 | 1 | 1 | 0 | 0 | 0 |
| Diabetes | 3.2% | 0 | 0 | 0 | 0 | 1 | 0 |
| Cardiovascular or Heart Disease | 3.2% | 1 | 0 | 0 | 0 | 0 | 1 |
| Allergy | 3.2% | 0 | 0 | 0 | 1 | 0 | 0 |
| Chronic Kidney Disease | 1.6% | 0 | 1 | 0 | 0 | 0 | 0 |
| Flu/Pneumonia | 0.0% | 0 | 0 | 0 | 0 | 0 | 0 |

Table 1b. What research topics are you interested in for the future?

| Topic Area | Future Research | Advocacy | Educational | Faith-Based | Foundation | Government | Health Services |
|---------------------------------|-----------------|----------|-------------|-------------|------------|------------|-----------------|
| Obesity/Physical Activity | 25.8% | 2 | 3 | 4 | 0 | 3 | 4 |
| Mental Health | 22.6% | 3 | 4 | 1 | 0 | 3 | 3 |
| Violence & Injury Prevention | 16.1% | 1 | 4 | 2 | 0 | 3 | 0 |
| Cancer | 12.9% | 2 | 1 | 1 | 0 | 0 | 4 |
| Aging Populations | 11.3% | 2 | 1 | 3 | 0 | 1 | 0 |
| HIV/AIDS | 9.7% | 0 | 1 | 1 | 0 | 2 | 2 |
| Tobacco | 8.1% | 1 | 2 | 0 | 0 | 1 | 1 |
| Sexually Transmitted Diseases | 8.1% | 0 | 2 | 1 | 0 | 1 | 1 |
| Substance Abuse | 12.9% | 1 | 3 | 1 | 0 | 2 | 1 |
| Asthma | 11.3% | 1 | 1 | 2 | 0 | 1 | 2 |
| Hypertension/Blood Pressure | 8.1% | 0 | 1 | 2 | 1 | 0 | 1 |
| Immunizations | 8.1% | 1 | 1 | 2 | 0 | 1 | 0 |
| Chronic Lung Disease | 6.5% | 1 | 1 | 1 | 0 | 0 | 1 |
| Diabetes | 11.3% | 1 | 1 | 3 | 1 | 0 | 1 |
| Cardiovascular or Heart Disease | 9.7% | 1 | 1 | 3 | 1 | 0 | 0 |
| Allergy | 6.5% | 0 | 1 | 3 | 0 | 0 | 0 |
| Chronic Kidney Disease | 6.5% | 0 | 1 | 2 | 0 | 0 | 1 |
| Flu/Pneumonia | 6.5% | 0 | 1 | 2 | 0 | 0 | 1 |

Table 2a. What research types are you currently engaged in?

| Research Type | Current Research | Advocacy | Educational | Faith-Based | Foundation | Government | Health Services |
|-------------------|------------------|----------|-------------|-------------|------------|------------|-----------------|
| Community-Based | 54.8% | 10 | 5 | 6 | 1 | 5 | 7 |
| Health Services | 19.4% | 3 | 2 | 2 | 0 | 2 | 3 |
| Clinical Research | 19.4% | 3 | 2 | 1 | 3 | 1 | 2 |
| Laboratory-Based | 6.5% | 2 | 0 | 1 | 1 | 0 | 0 |

Table 2b. What research types are you interested in for the future?

| Research Type | Future Research | Advocacy | Educational | Faith-Based | Foundation | Government | Health Services |
|-------------------|-----------------|----------|-------------|-------------|------------|------------|-----------------|
| Community-Based | 46.8% | 9 | 6 | 3 | 0 | 3 | 8 |
| Health Services | 32.3% | 6 | 4 | 4 | 0 | 3 | 3 |
| Clinical Research | 16.1% | 4 | 2 | 1 | 0 | 1 | 2 |
| Laboratory-Based | 4.8% | 1 | 0 | 1 | 0 | 1 | 0 |

Table 3. For those research partnerships you have identified, what types of research activities have you conducted during the past 12 months?

| Research Activity | Percentage | Advocacy | Educational | Faith-Based | Foundation | Government | Health Services |
|-------------------------------|------------|----------|-------------|-------------|------------|------------|-----------------|
| Research Study | 59.7% | 9 | 7 | 5 | 2 | 5 | 9 |
| Grant Proposal | 48.4 % | 10 | 4 | 2 | 2 | 4 | 8 |
| Education/Training Activities | 46.8% | 10 | 5 | 4 | 1 | 4 | 5 |
| Presentation | 27.4% | 7 | 2 | 4 | 0 | 1 | 3 |
| Academic Publication | 14.5% | 4 | 1 | 1 | 0 | 1 | 2 |
| Press Release | 11.3% | 2 | 1 | 2 | 0 | 1 | 1 |
| Patent Application | 3.2% | 0 | 0 | 1 | 0 | 1 | 0 |
| Clinical/Policy Guidelines | 3.2% | 1 | 0 | 0 | 0 | 1 | 0 |

Table 4. Percentage of community organizations within each organization type reporting barriers

| Barriers | Advocacy | Educational | Faith-Based | Foundation | Government | Health Services |
|---|----------|-------------|-------------|------------|------------|-----------------|
| Lack of capacity (funding, staff, etc.) | 63% | 50% | 25% | 20% | 38% | 60% |
| Lack of time | 56% | 60% | 38% | 20% | 38% | 47% |
| Organizational structure/bureaucracy | 25% | 10% | 13% | 0% | 38% | 7% |
| Unable to identify appropriate collaborator | 13% | 0% | 13% | 0% | 0% | 7% |
| Benefits of collaboration are outweighed by the costs | 13% | 20% | 0% | 0% | 0% | 0% |
| Research is a low priority | 13% | 10% | 0% | 0% | 13% | 0% |
| Lack of trust | 0% | 0% | 0% | 0% | 0% | 7% |