Podcast Interview Transcript
Susan Sommer, Laurie Stillman, Polly Hoppin, and Leandris Liburd

In each volume of the Journal, the editors select one article for our Beyond the Manuscript post-study interview with the authors. Beyond the Manuscript provides the authors the opportunity to tell listeners what they would want to know about the project beyond what went into the final manuscript. The associate editors who handled the articles conduct our Beyond the Manuscript interviews.

Beyond the Manuscript podcasts are available for download at the Journal’s website at http://pchp.press.jhu.edu.

This issue’s Beyond the Manuscript podcast was conducted by REACH special issue Guest Editor Leandris Liburd and features Susan Sommer, Laurie Stillman, and Polly Hoppin, the lead author and community partners for “Children’s Hospital Boston Community Asthma Initiative: Partnerships and Outcomes Advance Policy Change” The following is an edited transcript of the Beyond the Manuscript podcast.

Leandris Liburd
Susan, can you provide a brief summary of your asthma project, including its purpose and any results you’ve found for everybody who is listening to give them an orientation to the project?

Susan Sommer
The Children’s Hospital Boston Community Asthma Initiative was founded as the result of an extensive community needs assessment back in 2003 and 2004. At that time, the community identified asthma as one of their four major pediatric concerns; in addition, from Children’s perspective, asthma was the number one cause of hospitalizations, and 70% of those children came from the five low-income neighborhoods very close to the Hospital. We also noted that there were very high rates for Latino and Black children, and in fact, three to five times the rate for White children. So there was a very marked health disparity that needed to be addressed and many social determinants of health that were underlying these statistics.

We identified four ZIP Codes within inner city Boston, largely African American and Latino communities, who were the populations hardest hit by these asthma rates. And at that point consulted, (and then we’ll get into this more) with many of our already existing partners and people working on asthma issues throughout the city and region as to how to go about addressing these disparities.

As a result, we developed a case management model with a strong home visiting component. Home visits were conducted by both nurses and community health workers, and delivered tailored asthma education as well as home environmental assessments, and a moderate level of remediation. Thanks to our partners, we had built in a strong evaluation component including cost analysis, and had very positive results, with a 79% reduction in hospitalizations, and a 64% reduction in emergency department visits after 1 year as well as a return on investment of 1.46.
Susan Sommer

We realized from the beginning that there were larger, systemic, policy issues that needed to be addressed. Certainly, many of them housing issues—a lot of substandard housing with many environmental triggers. We are active in coalitions working on that, but also looking for sustainable payment models for these kinds of asthma programs that clearly were very effective, but were really limited by grant funding. That’s where we turn to our partners and coalitions to work on that policy issue.

Leandris Liburd

These are quite impressive findings. You had a team of partners, and I know they included community as well as academic partners, that represented different disciplines and backgrounds. How was this an asset for the project?

Susan Sommer

We did, in fact, have a strong group of partners even before our particular project started, including the Boston Public Health Commission that was doing a lot of work around home environmental triggers, and in particular pests and mold in the houses. Inspectional Services, Boston Medical Center, and then a local advocacy group, Boston Urban Asthma Coalition was its name at the time. And then in addition, the Asthma Regional Council which is represented by Laurie Stillman today, and UMass Lowell represented by Polly Hoppin, who were instrumental in helping us set the policy agenda.

Laurie Stillman

The Asthma Regional Council of New England is a coalition of governmental, academic, and community partners in a bunch of different disciplines: Environment, health care, health education, and housing. They work together to address pediatric asthma and particularly the environmental aspects of pediatric asthma.

One of the objectives of the group was to see if there were ways that we could sustain and address housing triggers, asthma triggers, in the home, and get the health care sector to provide and finance environmental home assessments and interventions. We teamed up with the University of Massachusetts at Lowell and other organizations to try and move a policy agenda to get reimbursements for environmental home assessments for high-risk children with asthma.

We worked to look at the research and to see if there was a business case that we could establish that would convince both public and private insurers that providing educational and environmental assessments in the home would be a cost-effective measure. And so we engaged UMass Lowell researchers to look at that question.

Polly Hoppin

We decided to look at the research literature and to limit it to randomized control trials, because as everyone knows, that’s the gold standard of research. We reviewed articles that looked both at programs that were delivering asthma education in the home, and also in the clinics, so asthma education in a variety of different settings. And we also looked at a very limited number of studies that examined the effectiveness of programs that were focused exclusively on environmental interventions.
We also looked at nonrandomized control trials, program evaluations, on-the-ground programs being delivered by different kinds of organizations that combined asthma education, and environmental interventions. The conclusions of our analysis, which we wrote up in a report called *Investing In Best Practices for Asthma: The Business Case for Education and Environmental Interventions*, what we found was that when implemented in the home, programs to communicate to clients about how to better manage their asthma—how to identify environmental triggers, how to control those triggers—and then to provide minimal materials and tools such as vacuum cleaners, pest management kits—when those combinations of education and tools were provided in the home, to families that health outcomes improved, and that those services could be described as cost effective.

In the case of high-risk patients, asthma education programs in the home could be net cost savings, so you’d actually have a return on investment. More broadly, all of the programs were cost effective, meaning they were a reasonable cost for the improvement in health that we saw based on what people are willing to pay for other kinds of improvements.

The business case was published in a brief format, and then used with the Asthma Regional Council in a series of ways going forward.

I want to emphasize is that Children’s Hospital helped underwrite us being able to do this business case, and as Dr. Hoppin just mentioned, one of the findings was that there was really a limited number of cost evaluations concerning the environmental interventions in the home piece. And so when Children’s Hospital decided that they wanted to launch their program, their Community Asthma Initiative, one of the things that we really encouraged them do is to incorporate a cost analysis into their evaluation study so that we could add to the evidence base for this work and continue to be effective policy advocates.

This was a really important partnership, and it’s really gone beyond just the wonderful work that Children’s Hospital is doing in the Boston community, but the Asthma Regional Council is really working with insurers in Massachusetts and across New England using these tools and using their model so that other states can really replicate what’s happening in Massachusetts and at Children’s Hospital. That is one of the advantages of a New England-wide regional asthma advocacy initiative. People can learn from each other’s successes, and then replicate what’s happening in those states and, in fact, that is happening in Connecticut and it’s happening in Rhode Island, and we have been bringing along our Children’s partners to speak to those different partners about what they’re doing so that they can learn from their experience.

This is clearly why the large effort to bring together so many partners and to have the relationship be so effective. Were there particular challenges to getting any of the community or academic partners involved in the partnership?
Susan Sommer

We are in a unique position in the sense that a lot of these partnerships existed and
Children’s had been a part of them even before the official Community Asthma
Initiative was started. We had some interesting challenges in the sense that there was a
lot of good intentions, but not necessarily a lot of funding for some of the policy and
community work. And also a number of organizations were funded by governmental
agencies so there was limits on how much people could advocate directly with
politicians for change.

Children’s was able to dedicate a government relations person to work on these issues so
she was someone who was not funded by any of the grants, and had experience working
with legislators. And she chaired actually the coalitions Boston Urban Asthma Coalition,
now its name is Boston Healthy Homes and Schools Collaborative, and then a state
organization that was founded in 2007, the Massachusetts Asthma Action Partnership.
She was able to chair their health committee and really provide a lot of leadership and
support to the coalition around how to frame policy strategies to formulate a legislative
act that was presented by some of our champions in the state legislature to look at ways
to fund these kinds of programs.

So this was an act that was put forth in the legislature for several sessions, and allowed
the legislators to become more familiar, more educated around the issues. But resources
are always a challenge, and it can be helpful to have someone who is well versed in
policy to join the effort.

Leandris Liburd

Were there any challenges with getting the engagement of the African American and
Latino community, given that they were to benefit to a large degree from this project?

Susan Sommer

We actually did a lot of the initial needs assessment and ongoing needs assessment with
representatives of those communities. And we continued to get input through family
advisory boards, and interactions with a number of the community-based organizations
throughout the project.

People were actually very eager to get more services around asthma. This disease for
kids has really impacted the African American and Latino communities incredibly hard.
Kids miss often 15, 20, even more days of school a year. Parents are missing more work.
Everybody’s losing sleep. We discovered low expectations about how well controlled
children’s asthma can actually be. People from those communities, have been very
happy with the outcomes and have, spread the word among their communities.

Also, we’ve had a very strong community health worker presence in both our program
and other home visiting programs in the city and being aware that we really need to be
culturally competent, linguistically competent in our services, and I think that we’ve
found what many people have found—that that is a great way to bridge that gap.
Laurie Stillman

I’d like to add to that, which is Children’s Hospital, you know, partnered with the Boston Urban Asthma Coalition as well, and they’re a group of advocates, and they have a parent advisory committee. And the parents are exclusively Black and African American, and Latino parents mostly from the inner city, and they have children with asthma. And those parents are paid a stipend to help spread the word of available services, but also they have been important spokespeople to legislators and to the media about not only Children’s programs, but also other educational and home-based services as well. So they’ve been a very important component in doing the advocacy work.

Leandris Liburd

I know we’ve heard throughout our conversation so far some of the successes and challenges, but if you were to I guess identify five of the most important successes, and then five of the most important challenges to the project, as well as the factors that you believe led to these successes and challenges, what would they be?

Susan Sommer

I think in terms of successes, again we’re able to provide on-the-ground evidence in the community that these interventions work. It’s one thing to read about a study done in Seattle, and it’s another to have a program locally that’s well evaluated, that is showing good outcomes.

And from very early on when we first had some outcomes to report, it was I think a huge stimulus for people to look at how to expand these kind of services to other communities, and since then I think certainly there are a lot of different factors, but the Department of Public Health has gotten funding and has to a certain extent replicated some of our program design in several communities around the state.

As Laurie and Polly said, our outcomes were, you know, included actually in the business case when it was revised in 2010. And our legislative champions could see that these results were impacting their communities, and their constituents. And so that it became a much more concrete way for them to really see the benefits for their communities.

There are some very complicated and difficult social determinants of health that will continue to be challenges for a long time. Certainly people are living in very poor housing for the most part. You know, Boston is a city of very old housing, and a lot of it is in poor repair, and we have major problems in terms of infestations, in particular mice and cockroaches, which are asthma triggers. We have quite an epidemic of youth violence, and this has been shown to impact people’s abilities to control asthma, and certainly a lot of competing demands that make it hard for people to focus on the problem of asthma. Once the child is out of the hospital, other things take over.

It’s a complicated illness to control, and as I said, it’s about changing expectations, community expectations. There’s a lot of concern about the controller medications, in particular the inhaled steroids that are sort of the mainstay of asthma control. And so these are issues that are going to need to be addressed for a long time. But these programs are very successful at doing it, so finding ways to pay for these programs is the big challenge.
The legislative effort to get this Act to Improve Asthma Management through was stymied actually in the early years of Massachusetts’ health care reform. There was a moratorium on any new mandates for coverage, and so this was one of those mandates that really was stalled. And this was where Children’s and partners looked toward a different strategy for getting some movement on reimbursement, and rather than trying to go directly through a legislative act, looking at working with MassHealth or mandating MassHealth—that eventually occurred through a budget amendment—to come up with a pilot bundled payment project because about 70% of the children that all these various programs were working with were covered by MassHealth.

The Asthma Regional Council was limited in terms of its ability to do lobbying so it was really useful to be able to partner with an academic institution like UMass Lowell so that, when there was a need to participate in public hearings when the legislation was going through, they could speak about the research and the advocates where we were limited in terms of what we could do around legislative advocacy.

This bundled payment system is also a big challenge that’s part of the legislation for reimbursing for best practices in asthma care through Medicaid because it’s newly charted territory. So we’re all struggling with how this is going to exactly get paid for.

I think that another challenge is that we’re working successfully, ironically on the reimbursement systems, and being able to pay for some of this important community-based care, but the capacity to deliver that care is limited because it hasn’t been paid for in the past. And so there haven’t been many organizations who have delivered this kind of care, and so we have to develop capacity across the state and across the country to be able to deliver home-based asthma care from, you know, culturally competent providers.

I would say another success that has come out of this initiative is the engagement of Children’s Hospital in something called the Boston Asthma Home Visit Collaborative, which was established to meet the need that Laurie is talking about, which essentially is how do you scale up the kind of capacity that Children’s has developed and demonstrated the effectiveness of to ensure that all people who need these services can receive them.

And that involves both the organizations that can deliver the home visits effectively, and also the entities that would pay for those visits. Frankly, having clinicians aware enough about the opportunity of these kinds of services to improve their patients’ outcomes that they’re willing to refer to the programs. Also, that when they decide to refer, that it’s easy for them to do it. That they know who they can contact. That regardless of what the patient’s particular insurer is, that that doesn’t become a barrier for a clinician referring effectively.
Polly Hoppin

To try to address those various barriers, the Boston Public Health Commission, our local health commission, set up an initiative to bring together multiple partners—hospitals, community-based organizations, community health centers, some provider networks, along with the Public Health Commission—to jointly develop protocols for asthma home visits, and ultimately to be able to centralize a referral system for the city of Boston.

And Children’s Hospital has been a steady partner from the very beginning in the collaborative, and ultimately what we will be able to do is have clinicians in Boston refer to a centralized system and then the home visit allocated out appropriately to a given home visit provider according to geography, linguistic and cultural competency, and various other criterion to make sure that there’s a good match between the home visit provider and the client.

This is a really exciting success in the category of scaling up and developing the infrastructure for delivering these kinds of services over time. And as others have said, the reimbursement is challenging because these are not inexpensive services, and we have had a couple of Medicaid-managed care organizations in Massachusetts beginning to pay for these services, which is very exciting on the fee-for-service side. This MassHealth bundled payment initiative that Susan mention is a really exciting development, and yet time will tell to what extent it’s capable of reimbursing some of the smaller organizations that don’t have the infrastructure for billing and for bundling their services. So the jury’s still out on that, but many departments that have been involved in the Children’s project and in the citywide program and in the statewide and regional efforts that has been mentioned, also sit on this Asthma Bundled Payment Committee that has been established by the state to develop this reimbursement approach.

Leandris Liburd

The issue of scalability has become quite important, particularly in the work that we do around eliminating health disparities. I can say also on public health in general, I want to know—and I’ll direct this question to Susan. What aspects of this project are generalizable to other communities? And are there aspects of this project that are not generalizable to other communities?

Susan Sommer

You know, I think that many aspects are generalizable. Certainly, the models that we’re most familiar with are pretty much all set in urban communities, so there would certainly be some variability about how you would do this in more rural areas. But you know, I think that the use of community health workers, which again has been really key to our programs and other programs success is very important, and supported by the Affordable Care Act as a way to really address many of these health disparities across the country.

And we see the, other states looking to us to try and figure out this reimbursement issue. I think Massachusetts is ahead of a lot of states in terms of looking at innovative payment models, but we can be leaders hopefully in bringing about some of these changes in other areas.
One of the concerns that the Asthma Regional Council has speaking of the Affordable Care Act is that asthma doesn’t seem to appear as one of the top sort of diseases of concern as sort of the prevention oriented models are being looked at. And so the Asthma Regional Council as well as a number of other organizations, including Children’s Hospital, has sent letters to folks at the CDC asking that asthma be looked at both through the prevention-oriented funding models that are being looked at.

Because we do have the evidence base, the literature, the best practices, all in place for this disease, and even though there is some concern about looking at things from a disease-by-disease category, there certainly are you know, some unique aspects of asthma that needs to be reimbursed and to be looked at as part of the Affordable Care Act.

So if we’re going to scale up this work, we need to have this come both from the top down, and from the bottom up to make this work for many communities of need.

I was just going to add one more thing about the issue of generalizability. Children’s Hospital is a large institution and as Susan mentioned initially, the ability to provide Lisa Queenin Mannix as the governance affairs person to help lead the policy work was beneficial both to the Children’s Hospital program and also to the larger coalitions with which we all work. That is not necessarily generalizable to have that kind of capacity. That said, there are large hospitals in other locations, and I think we would just reiterate to what extent providing those kinds of resources can be really helpful for the scaling up issue, and for addressing some of the fundamental barriers to these kinds of services being incorporated over time.

Are there any final comments that you’d like to make for the listeners who might also be interested in pursuing this type of community health partnership to eliminate racial ethnic health disparities?

There are a lot of community initiatives that are being supported now, by the CDC and other agencies, and keeping some focus on pediatric issues is of great importance. And really ties into so many other quality-of-life issues that families’ experience. It’s very hard to separate out in many ways asthma from the other chronic problems that people have. Kids can’t exercise because they’re sick. They have more risk of becoming overweight and developing other chronic diseases as adults. I think a focus on pediatrics is very important and shouldn’t be lost.

Looking at costs, unfortunately in this day and age is very important when we’re speaking about limited monies and so I think that having that cost analysis really has helped us make our case.
**Polly Hoppin**

I would add to that the model Children’s Hospital used and is being shown to be effective elsewhere in the country as well, being a community health worker based model is really so important and to acknowledge not only the reduced cost, but the additional effectiveness of people who have an ability to relate to, to connect with the people that they’re serving. It’s a model of health care delivery with positive financial implications, which we think is really – needs to be the future of health care, at least an important element of health care in this country going forward. So just really tip our hat to Children’s and the other organizations that are persisting with this kind of model, and saying that the translation of these models from being grant-funded to being supported by the ways in which we finance our health care system, that this is just a really important shift so that these programs can be incorporated into the daily business of the delivery and financing of health care, and really a very exciting opportunity in this climate of constrained resources, and the need to do a better and better job with management and prevention in chronic disease.

**Laurie Stillman**

I would like to also say that some of the tools that we have put together, including the business case for health payers, the business case for businesses, and also insurance checklist for health payers and health performers who are looking for best practices for asthma care, particularly in high-risk communities, can all be found on the Asthma Regional Council website (www.asthmaregionalcouncil.org). None of the tools are copyrighted. People can use them in whatever ways they would like. And so we encourage folks to take advantage of these tools as they move forward in reaching out to low-income communities, and high-risk communities that need quality asthma care.

**Leandris Liburd**

Thank you again for your time and this rich discussion of your paper, the Children’s Hospital, Boston Community Asthma Initiative Partnerships and Outcomes Advanced Policy Change. We look forward to seeing the special issue of the journal comes out.