

A Re-imagination of Policy and Health

Toward the Creation of an
Arts/Health/Policy Nexus

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Introduction

Our perceived notions of health—whether in relation to our physical body, the bodies of others, or our surrounding community—naturally overlap in many ways with the well documented notion that the arts have the ability to create openings for contemplation and learning, and to expand agency, voice, and capacities to heal and thrive. Our values, beliefs, and attitudes as a society influence our organizing institutions and structures, practices that in turn promote and determine the distribution of resources and who has access to them. Therein lies the value of examining the processes by which the arts evolve meaning for individuals and communities, and their necessary overlap with an ability to influence and transform the social and political institutions that traditionally define health regulation and care.

Musagetes is a Canadian philanthropic arts organization founded on a deep belief in the transformative power of the arts. We strive to help restore the power of imagination in individuals by placing artistic thinking and inquiry in relation to everyday life and to the urgencies and struggles of our societies and communities. Our research and artistic projects over the past few years have given us greater clarity on the role of art in social evolution—the processes by which the arts evolve meaning for individuals and communities. Our newest program, the [ArtsEverywhere.ca](https://www.ArtsEverywhere.ca) online platform and its related projects, offers an expanded forum for us to consider the role the arts can play in addressing the faultlines of modern society and the deep and perplexing problems that of contemporary life.

Our belief in the arts as transformative in their cumulative impact on social and political institutions led us to begin an exploration of the various intersections of arts and policy. Over the next year, we will commission a series of papers exploring these issues. While we recognize that, transformation, at times, can be rapid and easily documented (other organizations and entities have created a strong foundation for naming the issue areas and challenges) we wish to highlight the complexities and tiny shifts in our collective thinking that accumulate into new ways of imagining the world. With this paper, we hope to demonstrate that shifts in thinking about our approaches to health and health policy not only accumulate, but also manifest into concrete possibilities and guidelines for re-imagining the world.

A comprehensive review of the intersections between art and health would require consideration of a number of domains, such as the conditions of institutional, formal or professional art making compared to aesthetic operations, practices of cultural production and reproduction, and various expressive or poetic forms embedded within everyday life. Similarly, the multiple formations and concerns that constitute notions of health produce a range of existential, social, scientific, and political regimes and discourses, and variations in cultural and social contexts may manifest regionally and linguistically in terms of class and other markers of social distinction such as race, ethnicity, and gender and sexual identity. Together, these articulate geographies of material and conceptual difference that anthropologists, art and medical historians, and health practitioners and activists, among others, have already mapped using a variety of methodologies and tools.

While this paper acknowledges the extraordinary richness of the field, our aim is to offer a productive glimpse into examples of work that combines elements of art, health, and policy. By providing an introductory literacy on trends in policy and health, we hope to articulate a set of working propositions around the implications of arts and health intersecting with policy, citing initial examples drawn from various contexts, namely North American and European settings.¹ We acknowledge limits to this initial sampling based on our research methodologies, which focused primarily on web-based searches and information gleaned through formal networks. Through this work, we learned that many public examples appropriate to our thesis have been expressed through the lens of institutions. We recognize the limits of obtaining a more diverse sample through these means, and that this paper provides limited information about a host of illustrative examples occurring globally that may not be formally connected or funded in some way to government or non-governmental agencies and organizations.

As a connector and language that can bridge seemingly disparate realms of thought, practice, and communication, art is central to the creation of a model that supports more engaged and informed approaches to policy making and health creation for citizens, practitioners, institutions, and governments. More importantly, we wish to provide inspiration for what is possible, the work that can be done across a variety of settings and sectors. We hope this paper can provide inspiration for personal agency in health and community action, ways to expand one's own work and practice, to form local collaborations, and to engage in cross-sector projects that draw upon the wisdom of fellow community members in new ways, contributing to a more comprehensive and international discourse that considers the array of forces driving health and policy today.

About the Author

Nicolle Bennett is an artist, administrator, and educator with over 10 years of experience serving health, educational, and arts organizations and communities. A former health educator and trainer with the National Cancer Institute, she works as Program Director for *Feel the Music!*, a New York City-based organization that connects teaching artists with hospitals, non-profits, and other community-based partners, and consults with a variety of organizations to build capacity. Nicolle completed her cross-disciplinary graduate studies at the Gallatin School at New York University, where she focused on the varied roles of arts and technologies in facilitating community and policy change. A former National Art Strategies Creative Communities Fellow and natural connector, she is passionate about creating opportunities for co-creation, collaboration, and innovation. Contact her at nicolle@feelthemusic.org.

Executive Summary

The active citizen voice is increasingly recognized as essential to holistic policy formation and health creation, as health policies begin to incorporate a broader set of health determinants and providers embrace more engaged, co-creative approaches to health/care. As definitions of policy and health expand, artistic practice and thought are ideally situated to become the tools that can help to re-integrate what have become disparate elements in our ideas of individual and community health and agency, allowing us to re-imagine conceptualizations of and approaches to health and policy.

Policy is traditionally formed and informed by a finite set of players, sources, and rules within both institutional bodies and government. Similarly, health/care systems most commonly derive from and rely upon biomedical conceptions of health as the absence of disease, which provide an important but incomplete glimpse into the factors that may constitute health for individuals and communities. Trends in policy making and health, more specifically, health policy making, are beginning to call for an expansion of these models; allowing for more collaboration and the creation of spaces and structure for more people to become actively involved in processes affecting their individual and collective lives. Artistic practice and thought is increasingly becoming an amplifier of the cross-disciplinary intersections that allow for the creation of these spaces.

As a nexus is defined² as a connection or series of connections linking two or more things, and as the central point or place, it seems fitting that we use the term to embody the various connections taking place and their convergence as a launching pad for more engaged, enlightened and informed interactions. In describing the formation of an arts/health/policy nexus, then, we seek not to create arbitrary connections, but to exemplify the ways in which the arts are already connecting to and allowing connection among people, communities, and sectors; and that the convergence of these connections is a place from which more collaborative and creative approaches to policy and health formation can continue to take place. This nexus embraces a range of practice (artistic methods or interventions) and thought (creativity, improvisation, and imagination), whether carried out by artists, health practitioners, institutions, community organizations, policy makers, and/or individuals; any range of players interested in improving and expanding upon and engaging with issues of health and policy in new ways.

The paper seeks to provide an introductory glimpse into where we are and to demonstrate ways of imagining where we can go in relation to health policy, health care, and the varied/possible intersections between artistic practice and health; providing literacy and language for those working across or interested in these areas, along with suggestions for various ways to engage with and thus expand upon this work. By focusing on the integration of arts, health, and policy, we can create the spaces needed for collaboration and innovation, allowing for a re-imagination of possibilities for care across citizens and sectors.

With an explicit focus on research and examples that explore the scope of activity that engages arts, health, and policy from a range of artistic practices, geographic locations, and cultural communities, the goal of this paper is neither to define art or policy narrowly, to make an argument against biomedicine nor to prove the merits of arts in health. We also are not looking to elevate the abilities of artists within these settings to a point of professional specialization that further fragments rather than connects. Instead, the hope is to demonstrate the range of natural connections, the ways that arts can and do support current trends in health and policy with multiple points of entry for creating change, and to inspire ways in which we might move from the space of ideas and research to demonstrable action.

Key Insights:

- Research shows increased recognition of the need for more integrated and engaged approaches to care that are patient-centered, considerate of the role that individuals and communities play in managing and maintaining their own health, and that recognize the importance of exchange between communities, providers, and institutions. Trends also show that studying biomedical approaches to health care alongside social determinants can increase the likelihood of creating more collaborative and participatory structures to facilitate better care and outcomes.
- While traditional research efforts like studies, trials, and questionnaires are expanding, a noticeable shift toward human engagement processes and multi-disciplinary collaboration is occurring. Notions of what constitutes qualitative and quantitative evidence are also expanding in this area.
- The degree to which individuals and communities have a sense of agency in decisions impacting their lives directly relates to their capacity to thrive. A recognition of those voices, along with consideration of “top-down” and “bottom-up” approaches to power execution and distribution is crucial for anyone looking to understand and create system change.

- **Artistic practices can and do play a role in facilitating the participatory involvement, communication, and collaboration that is required in these broadening approaches to health and policy creation. Including aesthetic practices expands and/or changes narratives, integrates institutional and community exchange, connects thought to action, and creates spaces for realizing possibility.**

A problematic theme highlighted throughout the paper is the siloing of thought, practice, information flow, and influence in the policy-making process. This paper seeks to combat this notion and demonstrate how artistic thought and practice can help to combat this tendency via its subject matter and methodology, by seeking out and articulating connections that ultimately attempt to disrupt what could be understood as the standard, often prescriptive realms of thought and practice around health and policy making that currently exist.

The projects highlighted as part of the arts/health/policy nexus reveal a range of collaborations, openings, and methods of engagement regardless of artists working with or in institutions to make or illuminate these connections. Such creative methods used by multiple actors allow for increased engagement with health and policy processes and makers, various levels of personal and group agency using artistic process, and multi-sector collaborations with creative process at the core. The connecting thread within this vast (and ever-evolving) range of examples is an engagement across all three areas of arts, health, and policy, and a call to expand our conceptions of what these can mean and who can participate. Through highlighting these connections, we hope to inspire additional thought, research, and engagement in active process by and among individuals and institutions. Despite the method or practice employed, art can contribute to the formation of spaces that lead to our desired outcomes with policy and health; by creating language anew, shedding light on experience and prompting possibility.

State of Health Policy

An understanding of how policies, specifically health policies, are traditionally defined, formed, and informed, along with trends in policy-making, provides a basis for understanding the potential intersections between policy and artistic practice, and the ways in which the arts can support more informed and holistic policy making.

What is policy?

While definitions of public policy³ vary, there is a general consensus that policy can be informed by multiple players, is intended for the good of the people, and is ultimately enforced by governments and/or other institutional bodies. The website of the Center for Civic Education broadly states that a public policy is “simply what government (any public official who influences or determines public policy, including school officials, city council members, county supervisors, etc.) does or does not do about a problem that comes before them for consideration and possible action.” According to the Centers for Disease Control and Prevention (CDC), public policy generally includes the laws, regulations, procedures, administrative actions, programs, and practices of governments and/or institutions that address and govern a particular need or problem.⁴ In theory, policy is made in response to an issue or problem on behalf of the public, embodies what the governing body chooses to do or not do about that particular issue or problem, and is oriented toward a particular goal or state (such as the problem’s solution).

The Malcolm Wiener Center for Social Policy at Harvard University more specifically describes social policy as “public policy and practice in the areas of health care, human services, criminal justice, inequality, education, and labor.”⁵ Social policy may also be described as actions that affect the well-being of members of a society through shaping the distribution of and access to goods and resources in that society.

These definitions are a mere glimpse into the multiple characterizations of a process assumed to be powerful and open, yet ultimately perceived by many as inaccessible.

To further narrow the scope and definitions of policy around a specific issue such as health, we can look to the World Health Organization (WHO), which defines health policy thusly:

Decisions, plans, and actions that are undertaken to achieve specific health care goals within a society. An explicit health policy can achieve several things: it defines a vision for the future which in turn helps to establish targets and points of reference for the short and medium term. It outlines priorities and the expected roles of different groups; and it builds consensus and informs people.⁶

This description takes policy actions a step beyond that of a governing body providing a solution to a problem; it suggests policy is something that provides an imaginative peek into the future, bringing people together and informing publics. In this sense, policy embodies sensibilities inherent in artistic practice.

How are policies made?

Policies are typically created using a specific type of process, also defined in multiple ways.

The EDUCAUSE Review describes the policy process life cycle⁷ as one that typically involves five stages: (1) discussion and debate (triggered by events and demanding careful study to determine outcome) (2) political action (by political actors, e.g., advocates, lobbyists, and others, who use their position of influence to force action or change) (3) legislative proposal (on the part of a governing body) (4) law and regulation (on the part of a governing body) (5) compliance (by those affected).

The Institute for Wishful Thinking (IWT), a collective of self-declared artists-in-residence for the U.S. government, offers an additional analysis⁸ of the typical policy-making process, and a glimpse into the policy life cycle that suggests a variety of players and creative approaches:

Recognition: identification of the problem

IWT proposes that this stage can be initiated by a variety of players; community groups, nonprofits, organized interests, concerned citizens, policy analysts, artists, scientists, public officials, or others who identify the problem and propose a policy change.

Formulation: conception of ideas that address the problem/proposal creation

IWT cites this as the creative stage where ideas are produced and shaped, and generally includes estimation by policy analysts, technical experts, budget analysts, economists, scientists, public officials, journalists, or academics. They note that artists are not generally (if ever) included in this stage, but suggest the unique contributions that artists can make at this and other stages, by offering an approach to problem-solving and solution building—imagining solutions that are outside convention or expectation.

Selection: governmental acceptance or rejection of the proposal

This stage, according to IWT, can involve competing advocates, organized interests, and others trying to persuade policy makers to adopt one policy option or another due to particular agendas.

Implementation: the formal carrying out of the policy

Those affected find ways to carry out (or sometimes subvert or ignore) the policy selected by policy makers.

Evaluation: observing, measuring, and studying benefit, cost, and other outcomes of the implemented policy

Typically carried out by policy maker.

Modification: the policy continues, changes, or is terminated

Given the assumed formality of the policy-making process, David Dery, head of the Federman School of Public Policy at Hebrew University, explores what he deems an important feature of public policy making that has been somewhat neglected: that many policies are largely made by the way of making other policies. This notion of “policy by the way” conveys a reality in which many areas of concern are ultimately touched by public policy indirectly, by way of others areas of concern.

Effective policy making, in Dery’s view, crucial variables of policy success, failure and policy change, is likely to be found not in the policy in question, but in the policies surrounding it: “A positive theory of policy-making and change would therefore seek to identify the variables—policy attributes, types, or circumstances—that are likely to produce policy by the way, or policies that are highly susceptible to the influence of other policies.” In this sense, a holistic approach to policy making mirrors a holistic approach to health called for by trends in reform.

This notion particularly applies when thinking about how health policies are informed (and how they could be) and conversely, the influence of policy on our individual and public health. According to the CDC’s website, policies (can) influence health outcomes as they relate to individual behavior and access to resources:

The health of our nation can be influenced by public health policies, such as a tobacco control policy, and by policies in many other sectors. For example, transportation policies can encourage increased physical activity, and school nutrition policies can ensure healthier meals are provided in schools. Many national health strategies, plans, and initiatives, such as Healthy People 2020, have policy implications. Policy decisions are also frequently reflected in resource allocations.⁹

In a sense, this is “health by the way” of policy, and assumes a more expanded view of health, influenced by policy that considers a myriad of social factors.

Who makes it?

Considering the traditional policy-making process and potential involvement of multiple players throughout, who then is deemed responsible for making policy? According to the Center for Civics Education, policy is “ultimately made by governments, even if the ideas come from outside government or through the interaction of government and the public.” This general understanding that policy is made only by governments has led us to think of the formation of policy, or “Policy,” as an act disengaged from the practice of individual and community life, and performed only by a distinctive group of players, all while imparting significant influence on many lives.

Ideally, policy is a manifestation of the principles of a people. According to West’s Encyclopedia of American Law, public policy:

. . . manifests the common sense and common conscience of the citizens as a whole that extends throughout the state and is applied to matters of public health, safety, and welfare. It is general, well-settled public opinion relating to the duties of citizens to their fellow citizens. It imports something that fluctuates with the changing economic needs, social customs, and moral aspirations of the people. Public policy enters into, and influences, the enactment, execution, and interpretation of legislation.¹⁰

How can we create policy that manifests the ideals of a people, and represents citizens as a whole (versus a select few)? Are current trends moving toward more engaged forms of policy making and of creating spaces for increased engagement of policy making with the changes it hopes to perpetrate?

How is health policy traditionally informed?

Traditionally, policies—specifically, health policies—are informed by the research of institutions, organizations, or agencies in collaboration with institutions, advisory committees, and by other research-reporting bodies. In fact, most large national organizations in the U.S. have a “policy arm” that works to advance policy within its respective field(s), and/or to outline policy priorities pertaining to that field.¹¹ The institution works as a governing body to influence programming and policy within its own field of practice and sphere of influence, and to influence decision makers in policy decisions that affect that field as a whole. In this sense, many institutions are seeking to advance a specific agenda rather than the public good.

The Center for Disease Control, for example, has a number of policy-focused offices and programs that deal with and inform public health issues. The CDC and similar organizations use guidelines and recommendations developed in collaboration with entities outside the agency to produce documents that include recommendations, strategies, and information, assisting decision makers (e.g., healthcare providers, federal, state, or private agencies, employers, public health officials, the public) in choosing among alternative courses of action in specific health-related situations. Ultimately, these web-based documents¹² are focused on providing actionable steps to address a specific issue of importance to public health, ranging from recommendations for vaccine usage to the design of public swimming facilities.

Other U.S. national organizations, associations, and councils serve the public health system via policy analysis and health advocacy.¹³ State organizations such as the New York Academy of Medicine (NYAM) provide evidence to decision makers via research reports, convenings, and other distribution channels:

Our work provides evidence to decision makers to help them address many of the key issues related to disparities, such as access to healthy foods, safe spaces to exercise, and quality health care, as well as important health disparities in immigrant health, maternal mortality, and health problems related to drug policy and the criminal justice system.¹⁴

References to evidence and research go hand in hand with discussions of health policy. Notably, fields such as health informatics¹⁵ produce substantial amounts of data that inform reports produced by a variety of health institutions, which are ultimately referenced by legislators. While hard evidence is often referenced to inform policy, the journal *Health Affairs*¹⁶ suggests that health policies are akin to creating large-scale experiments with a poor understanding of the risks and benefits to the endeavor, and alternatively suggests ways to improve health policy research, such as expanded study methods and evaluation plans, so that evidence can inform policy with more consistency.

What, then, constitutes evidence? At a 2016 convening of the Ligo Project,¹⁷ Dr. Deepu Gowda,¹⁸ seeking to explore cross-collaborative, creative approaches in science, discussed the benefit of using a mixed methodology approach to health care and policy—suggesting that while “numbers” can and should continue to inform policy, policies also need to be informed and interpreted in nuanced ways that involve other players, and use language that speaks to broader audiences. Using a “numbers only” approach, in many ways, compartmentalizes benefit and effectiveness, perpetuating a narrowing view of health. Numbers are essential in realms such as prognostics, for example, but in the realm of prevention (one strong focus of U.S. health reform), social, environmental, and creative processes also come in to play. We need to optimize

the conditions of creation that allow for preventive measures to take hold in addition to numerical outcomes, balancing and considering both, while bringing that which is considered evidentiary and informed policy making into question.

It is important to note that, when used in context, a credible range of numbers can provide a valuable glimpse into the healthcare needs of a community; they can also be a tool for advocates looking to expand services and identify gaps. The New York City Department of Health and Mental Hygiene's Community Health Profiles¹⁹ provide such a tool, visually demonstrating inequities between neighborhoods by highlighting examples of poor health outcomes clustered in communities of color and impoverished areas. The information is accessible through visual snapshots that conclude health issues should not be determined by location. These tools use indicators²⁰ that reflect a broad set of physical, environmental, and social conditions impacting health, thereby encouraging policy makers, health professionals, researchers, and community groups to work together for systemic change.

As views on health expand, other organizations, including funders, are seeking to provide and expand upon evidence to substantiate systems and policies that support a more holistic view of health. Since 2014, the Robert Wood Johnson Foundation has sought to build a "Culture of Health" through a collection of research reports aimed at providing "policy makers, congressional staffers and administration officials with evidence-based non-partisan material that clearly explains health policy issues that consider factors such as thriving communities, healthy children, quality of care, and affordable coverage."²¹

Building Healthy Communities (BHC), a 10-year, comprehensive community initiative launched by The California Endowment in 2010, is seeking to advance a more holistic view of health alongside more democratic policy making through changed narratives and place-based initiatives that increase local capacity and demonstrate the multitude of factors that allow individuals and communities to thrive. Though implemented by an institution, the BHC initiative aims to "change the rules" at the local level, purporting that the evidence ultimately leading to the creation of healthier communities derives from embracing a more holistic view: where everyone has access to the opportunities and resources needed, where locally-driven narratives around health are embraced and implemented, and where individuals and communities have the opportunity and agency to give genuine input into decision-making "beyond the minimal and often superficial methods typically used by institutions."²²

Expanding ideas/definitions of policy and of health: Call for new voices, new approaches

Calls for more engaged involvement in policy making are mirroring ever-expanding views on health. Medical bodies/research institutions (such as the *Journal of the American Medical Association*²³) are considering issues such as gun violence, racism, and socioeconomics as public health issues alongside disease studies and clinical trial outcomes, encouraging an expanded view by policy makers and a renewed focus on the personal agency of citizens in relation to health and to policy making.

Organizations such as Code for America and Policy Lab UK²⁴ encourage more open, transparent dialogue and information exchange between citizens and government. Organizations such as PolicyLink aim to “craft equitable public policy by lifting up the wisdom, voice, and experience of local residents and organizations,” and are “guided by the belief that those closest to the nation’s challenges are central to finding solutions.”²⁵ They work to focus attention on how people are successfully using local, state, and federal policy to create conditions that benefit everyone, especially people in low-income communities and communities of color. The Roosevelt Institute Network’s *The Next Generation Blueprint for 2016*,²⁶ a recently completed, crowd-sourced vision for change, seeks to challenge who sets the “rules” by surveying 1,000 young people across 160 college campuses in the U.S., to outline an aggressive policy vision and action plan (including issues such as the reduction of health care costs, a focus on prevention/public health, and food insecurity) for distribution to local, state, and federal legislators in the first 100 days of their upcoming terms.

Equally if not more important to institutional and organizational efforts to engage citizens are citizen-led efforts to engage with health. Kokua Kalihi Valley Comprehensive Family Services (KKV) in Honolulu was first formed by Kalihi Valley community members in response to the absence of accessible and appropriate health care services for the area’s low-income, Asian and Pacific Island immigrant population. Staff originally consisting of one coordinator and four outreach workers (who combed the valley connecting residents in need with existing services) now includes 180 employees working from nine locations, not only to provide health services that “make sense for that region” by providing medical, dental, and behavioral health care to prevent diseases, but also to promote overall well being by “sharing food and laughter, celebrating elders and children, dancing, planting, and remembering how to be a community.”²⁷

Similarly, individual agency, desire, and need often contribute to the expansion of collective efforts to engage with communities and institutions in relation to activism and policy. Veronica Ramirez,²⁸ a mother, community educator, leader, and advocate for the rights of women, children, and immigrant communities, began *Mujeres en Movimiento*,

a collective of mostly immigrant Latina women that encourages mutual health and empowerment through movement, out of her own desire to expand her own health. Veronica is now a leader in the IMI Corona (Queens) Community Council, a volunteer-led community space serving to re-imagine the role of migrants and immigrants in society and to change unjust situations. IMI Corona also serves as a laboratory for merging arts and activism in politically charged spaces.

Harriet's Apothecary (HA) is an intergenerational collective of local healers, artists, health professionals, and other community members in Brooklyn who are not only committed to providing and co-creating healing spaces for their immediate community, but also to partnering and sharing their methods with movement-building organizations across the U.S. and Africa to advocate for policy changes related to social and health justice. Dancer, choreographer, and teaching artist Margot Greenlee created *Woman with Sword*, an events series exploring current issues around health equity, access, pollution, etc., within communities to explore answers to questions like, "What activities help people come together to learn something new?" and "How can heavy topics be transformed into irresistible invitations?" The events use performance and theater to bring citizens together with local institutional influencers to better engage with and learn from one another.

Can artistic thought and practice help bring together institutional (typically vertical or hierarchical) and community-led (often horizontal or peer-based) efforts to create more sustained and informed engagement with health and policy?

The active citizen voice is becoming an important factor in support of policy creation, as health policies begin to support a more holistic set of health determinants. A nexus of collaborative and creative approaches to policy making and health is steadily forming.

State of Health/Care

As in policy, there is a move in health care toward more integrated and engaged approaches that consider the relationships of individuals and communities to their own health, and the biomedical alongside the social determinants of health.

Quality of care

Beginning in 1996, the Institute of Medicine (IOM) began an ongoing effort to assess the quality of healthcare in the U.S. This effort produced a series of reports (issued over a period of a decade or more) that marked the beginnings of a Quality Initiative which, in its first phase, sought to document the serious and pervasive nature of the nation's overall quality²⁹ problem, concluding that "the burden of harm conveyed by the collective impact of all of our health care quality problems is staggering."³⁰ One such report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, defined six aims toward quality care—that care should be safe, effective, patient-centered, timely, efficient, and equitable—along with 10 rules for care delivery redesign; overall, it called for a focus on more patient-centered approaches, patient agency, prevention, and cooperation among and across professionals as ways to improve care. From 1999 to 2001, the Committee on Quality of Health Care in America laid out a vision for how the health care system and related policy environment must be radically transformed in order to close the chasm between "what we know to be good quality care and what actually exists in practice."

In addition to a call for a higher quality of care, there is an emerging recognition of the benefit of more engaged approaches, a focus on prevention,³¹ and of conceptions of health that cut across all aspects of our lives, individually and socially. While the IOM reports on care quality begin to address this by including patient-centered, communicative, and cooperative mandates in their analysis of quality improvement, there is an ongoing need to address the multi-varied elements that make up our conceptions of health.

Indeed, the Robert Wood Johnson Foundation estimates that just 20 percent of a person's health is related to health care; the rest stems from behavioral, environmental, and social factors—the social determinants of health. As defined by the American Public

Health Association (APHA), the social determinants of health are conditions that can affect your health and well-being, and include factors such as exposure to violence, job opportunities, community design, and access to care. According to APHA, both they and U.S. federal officials are working to refine the national health agenda around social determinants, prompting a movement called Public Health 3.0.³²

The political economy of health, as described by Assistant Professor of Interdisciplinary Arts at The New School (New York) Robert Sember,³³ asks us to consider what it means to think of health as a social, collective, and political issue. Within the sub-context of a political economy, health is generally discussed in three contexts: health disparities (inequitable burdens of illness, injury, disability, or mortality), care disparities (inequitable access to and quality of care), and the structural and social determinants of health (related to the distribution of power and resources).

One example of disparity made clear is a snapshot of New York City: According to data compiled by the Department of Health and Mental Hygiene,³⁴ New York City houses the wealthiest and the poorest congressional districts in the United States—both within a distance of five subway stops. Health disparities between these two districts are vast, even as overall death rates for all income levels across the city have dropped due to various public health efforts. Despite this progress, race and class inequalities remain in place, denoting a social topography that remains uneven. Building Healthy Communities³⁵ posits that “health happens in community, school, and the places people spend their time.... When people think of health, they often think of doctor’s offices and vitamins, not power and place.” One’s zip code should not be a determining factor in mortality, but too often, it is. Death rates among black residents of both wealthy and poor neighborhoods, for example, remain higher than their white neighbors, demonstrating that class mobility alone does not determine health; the burden of racism remains and needs to be addressed. But, as Mary Bassett, NYC’s health commissioner, states in the *New England Journal of Medicine*:

The ongoing exclusion of and discrimination against people of African descent throughout their life course, along with the legacy of bad past policies, continue to shape patterns of disease distribution and mortality. I believe that the City’s budget—by addressing income inequality, improving affordable housing, and reducing the number of low wage jobs in our City—will improve public health in our five boroughs.³⁶

Biomedicine and access to high quality care are vital, but it is becoming increasingly clear that our conceptions and realities around health reach far beyond biomedicine. Despite the tremendous transformations taking place due to changes in health reform, factors such as racism and inequality, along with the stresses they trigger, remain. The exclusion of individuals from care due to income or immigration status persists, despite reform efforts³⁷ such as the Affordable Care Act (ACA). While producing much benefit,

the ACA arguably reproduces the class inequities of a system dependent on large-scale market gain. While there are increasing efforts to focus on screening patients based on social factors and financing programs that meet those needs,³⁸ conversations about healthy policy and the intersections of health with a variety of sectors still often come down to cost-benefit analyses that demonstrate how an intervention can simultaneously reduce expenditures while elevating quality of care. Since the economic market drives the system as a whole,³⁹ priorities in data recognition and credibility, public health messaging, health literacy, and ultimately, public health actions and outcomes are driven by its whims. In a health care system so heavily propelled by the market, what are the levers of change?

Participants of the January 2014 Global Health Summit⁴⁰ call for a citizen-centered approach to begin restoring the balance that is needed between economic and social development to fully consider the range of impacts on health worldwide, including inequity. A white paper from the Summit in which players gathered to imagine and reimagine health concludes:

Health systems can provide leadership to changes supporting sustained health, but do not always do so. Help is needed to lever upstream integration of wellbeing into all activities and strengthen prevention, to ensure solidarity and link individual measures with those for public health and to build participatory involvement within health systems.⁴¹

Statistics from the World Health Organization⁴² show that, generally, the higher the level of inequality in a society (despite overall poverty level), the lower the life expectancy. This disparity ultimately produces distrust and competitiveness, tearing at society's fabric. When considering the varied relationships between the social and physical health of individuals and communities, we can easily conclude as Professor Sember has that "health sits at the fundamental intersection of society" and that we are "not just losing people, we are losing life."⁴³ This intersection calls into play the relationship between individual and collective autonomy, and how our sense of agency affects our relationship to our surrounding community and overall sense of well-being.

How do we restore this dissonance? We need different levels of action, communication, and a broader conceptualization of health supported by those actions, allowing for a locus of control that includes individual and professional agency regarding health.

Peter R. Doliber, of the Alliance of Massachusetts YMCAs, is a public health provider based in Boston, Massachusetts, who, in discussing ideas of power, personal agency, and person-centered approaches to health conceptualization and care, recognizes:

Many people [were] not in a position where they could take action for themselves. They often faced daily struggles of safety and security and were, to a great extent, overlooked by traditional health systems. Years of neglect and emergency-only interaction had left them distrustful of the system and of anyone from those outside their community. If they were to receive help, it needed to come from insiders, not well-educated and well-intended outsiders. More had to be done from within the community; by people for people, not to people. And while our clinic made great efforts, we knew we'd barely started a necessary and enormous process.

Creating health

The idea of health not being done “to,” but “by and with” people, is embodied in the work and research of the Creating Health Collaborative (CHC).⁴⁴ In August 2014, the IOM held a meeting titled “Designing Evaluations for what Communities Value,”⁴⁵ which sought to “re-envision how we evaluate community health initiatives using designs that better match their purpose, advantages, and realities” by working directly within an example community to illustrate ways of ensuring that interventions were consistent with the community’s aims, sharing approaches across fields to designing evaluations, and fostering connections among people who want to think differently about health evaluation. The CHC, one of the meeting’s planners, is a champion of this approach, which seeks to collaborate with individuals and communities to build upon perceptions of their own health and care. CHC is a group of international collaborators working to understand and create health “beyond the lens of health care.” They ask: “What would happen if design, implementation, and evaluation of health interventions became something we did *with* communities rather than *to* them?” [emphasis added] and whether the well-intentioned quest to support health through the lens of disease has detracted from supporting other activities that have the potential to allow for health creation in the settings of everyday life.

Person-centered care⁴⁶ embodies the notion that individuals are (or should be) at the center of the narrative regarding their own health and care. Ko Awatea,⁴⁷ a New Zealand-based, collaborative and holistic health center of excellence embedded within Counties Manukau District Health Board (CM Health), provides an example of person-centered practice in action, related to a study they conducted examining the best methods to translate cultural mental health research into improved clinical practice and policy. They gathered data for this study by simply asking local South Asian adults recovering from mental illness the following question: “What is the process of recovery for South Asian people accessing mental health services in New Zealand?” The responses, in their view, allowed them to generate a grounded theory that effectively contributes to a broader

understanding of mental health recovery, by “listening to the participant’s words and their meanings with cross-cultural ears and cultural sensitivity.”

In shaping a system that supports this notion (along with an expanded consideration of contributors to health), the Building Healthy Communities initiative employs actions around what they term “narrative change”—that shifting narratives and norms around who matters in our society and how best to invest in community health will reset the terms of public debate on key policy issues. A key component of narrative change is in “developing community residents’ capacity to effectively drive the local dialogue on health away from conventional debates about access to health care to include addressing the social determinants: the existence of poverty, racism and hopelessness and the absences of all of the resources and opportunities people and communities need to be healthy, such as good schools, jobs, housing and so on.”⁴⁸ An embrace of expanded narratives by policy makers and health providers can not only increase their understanding of the impact of social needs, but impact patient relationships and methods/standards of care delivery, through emerging humanity-based fields such as narrative medicine (detailed in [Arts/Health/Policy Nexus, pg. 33](#)). Arguably, arts-based methodologies such as the use of narrative can contribute to the deeply subjective as well as systemic and policy dimensions of person-centered care, perhaps improving our abilities to address and amplify people instead of issues in relation to health and health care.

Groups such as CHC are advocating for measures that allow for community voice and agency to be a central component in informing health care and policy, alongside biomedicine and quantitative research. Their work rests on the notion that the health sector tends to dominate typical definitions of health, and while there is general acknowledgement of the social and biological determinants of health by other sectors, the perspectives of individuals and communities are often left behind. Their newest report, *Eleven Principles for Creating Health*,⁴⁹ provides a set of potential actions and principles for those organizations and sectors looking to engage in collaboration and to allow further engagement with communities.

Other reports, such as the *National Academies of Sciences, Engineering, and Medicine (NASEM)* report, *Primary Care and Public Health: Exploring Integration to Improve Population Health* (2012)⁵⁰ advocate for a multi-sector and multi-voice approach, recognizing that a realistic and truly holistic view of health, and of policies meant to shape health, is not the sole responsibility of the health sector. This shift accounts for a renewed interest not only in collaboration, but also in the need for a community-based, health-creating system that involves a broad cohort of players.

What better to catalyze the creation of such a system than the arts?

Artists can and do play a role in facilitating the participatory involvement, communication, and collaboration across disciplines that is called for in health and policy creation. Engaging and empowering, connecting, leveling, and imagining possibility, and artistic practice and thinking, employed by artists across disciplines as well other actors across disciplines, already embody the holistic view that is needed to broaden our conceptions of health, and trends in connection to policy making that more and more people are looking to embrace.

The Asia Centre, which serves as a networking hub for civil society in Southeast Asia, has put out an open call for a workshop, to take place in October 2016⁵¹, that seeks to engage with art and cultural practitioners and researchers in the region in order to deepen understanding, create cross-sector collaboration, and deliberate on methodologies of working in public with people-centered processes around art and health. Residency Unlimited artists at Project H.E.A.L. (Health Equity and Arts in Louisville, Tennessee)⁵² explores health issues identified by the community members of Smoketown (Louisville's oldest African-American neighborhood) using arts and culture tools to discover and bring awareness to health inequities, devise innovative ways to measure health outcomes and to promote well-being. Nancy Knopf is a social worker for the Columbia Pacific Coordinated Care Organization, which uses narrative methodologies steeped in artistic practice to co-create and map community needs pertaining to health and health outcomes.⁵³

A multi-national and multi-disciplinary nexus has formed and is continuing to grow; one with artistic practice/thought at its core. Policies can in fact be created to shape environments conducive to a broader conception of health and civic life, and policy/health can be created through acts of collective imagination. Artists can spark much-needed community conversations and collective visioning in these realms.

Jaroslav Andel, an artist and curator writing for the Council of Europe's conference and platform *Smart Creativity, Smart Democracy* (2015), says it clearly:

Art invites participation and thus transcends the division between observation and activism. Art inspires insights that resonate across disciplines. Art helps to situate science and technology in public space by symbolically and reflexively representing their roles in society. Art fosters imagination and creativity, capacities that are crucial in its impact on the individual and the community.

Arts and Health/Policy

Where does artistic practice intersect with these identified challenges and needs related to more patient-centered approaches, attention to the social and biological determinants of health, and the exchange between communities and providers or institutions of health and policy? Can artistic/aesthetic practice help us to re-integrate, re-inform, and re-imagine solutions that consider broader, more collaborative approaches to health and policy?

Traditionally, art is conceived to intersect most commonly with health and healthcare at the therapeutic and clinical level. Creative arts therapists and other artists contribute immensely to those who have experienced trauma and those with chronic illness, across a variety of areas of concern. The field of Arts in Healthcare continues to grow as increasing numbers of clinicians and other professionals from the medical community work side by side with arts professionals in both healthcare and community settings; around the world, in fact, the arts are emerging as an important and integral component of healthcare.

Numerous studies⁵⁴ have demonstrated the benefits of music, visual arts, and dance in clinical settings ranging from the management of pain, adherence to treatment and self-care, coping, stress relief, increased mobility/dexterity, aiding in diagnosis, non-verbal communication/clarity, increased communication, and trust between patients and providers. According to the *State of the Field Report: Arts in Healthcare* (updated in 2014):

Throughout recorded history, we see evidence that pictures, stories, dances, music, and drama have been central to healing rituals. Today's renewed focus on humanistic care is leading to resurgence in the knowledge and practice of incorporating the arts into healthcare services.⁵⁵

These well-documented and extensive physical/biological benefits of music and arts participation not only help to create nurturing spaces for individual healing and growth, but also are increasingly seen as part of the holistic approach necessary in creating and sustaining healthy communities.

The central goal of this section is not simply to make a case for the already well-established and important relationship between arts and the therapeutic aspects of healthcare; it is to examine and begin to demonstrate how the arts can and do intersect

with and build upon the needs identified in health and policy: expanded/holistic views of health for individuals and communities, engagement between communities and decision makers, and a reintegration of the dissociated aspects of the individual in relation to the community. Arts practice, working in collaboration with other practices and fields, is not only helping to expand upon these approaches to health and informed policy making, but the use of imagination/improvisation (i.e., artistic and aesthetic) methods is becoming common practice, as people across fields and communities of practice seek to improve health for all.

Creating change

*Describe a kind of medicine that might not readily be known as such.
What would a policy that incorporates our ideas of medicine look like?*

In May 2015, a group of artists working across spaces of health gathered at the World Policy Institute⁵⁶ to answer this question, to discuss how artists can and do connect with those from other disciplines, and consider the tools and training needed to further engage in community-based processes pertaining to health, concluding that art is necessary in shifting our understanding of health. Artists, it was discussed, when working with communities, tend to embrace a method of “intra”-vention, which embodies the notion that nothing can or should be done to communities, without the direct involvement of a community’s members (i.e., person-centered care). In this sense, artists can work to bridge silos of information, practice, and thought. As translators, artists provide the language of communities, i.e., policy, often without realizing it. They can provide language where no language exists, thereby changing the conversation to inform policy and other decision makers about the myriad factors contributing to health, and facilitating an environment of co-creation that can only enhance the biomedical aspects of care.

In her book, *New Creative Community*, writer and social activist Arlene Goldbard⁵⁷ discusses how artists use art to transform society, claiming that artists often feel the pulse of the times and can predict social events long before newspapers or politicians know what is happening. She shares two hopes of artists and organizers: first, that “the expectation that people facing social exclusion [in health or any arena], when given the opportunity to express their individual truths in the language of their own creative imaginations, will become aware of their common concerns and common capacity to take action in their own interests and may even join together to actualize their awareness.” To effect change on a larger scale, this type of program must take into account Goldbard’s second hope that “gatekeepers and others who wield power will be reached by such expressions, and will be moved to respond constructively.”

What would happen, then, if people, providers, and policy makers were able to ask and answer the question above collaboratively? Can artists help to inspire questions and connect answers, to create a more comprehensive and informed approach to health for communities?

Arguably, the key to creating community-based change of any kind is through bridge building. Dr. Theda Skocpol, the Victor S. Thomas Professor of Government and Sociology at Harvard, in discussing bridges that enable social change, warns that “leaders must avoid the simple theories of change that suggest it occurs from a top-down or a bottom-up approach,” arguing that both approaches are necessary, simultaneously, for change to occur. In her historical analysis of changes in the U.S., including the civil rights movement, she suggests that “what matters most are not grassroots efforts or well-designed policies ... instead, deep and lasting change of entrenched behaviors occurs by leveraging pre-existing social groups, such as artisan communities ... which are able to coordinate local action across the country.”⁵⁸

In *Culture of Possibility*, Goldbard discusses two societal paradigms; Datastan (where “macroeconomics, geopolitics and capital are valorized”) and a Republic of Stories, where “nuance, particularity, imagination, and empathy are given their rightful places as capacities that enable essential knowledge about ourselves, the world, and our choices within it.” She entertains the notion and possibility of a paradigm shift, “one where an old idea of the world can no longer say enough to encompass reality, it has to yield to a new idea that transcends the old and subsumes what can usefully be carried forward.”

Similar to the ways in which health/care are traditionally informed, the need/use of evidence and numbers alone to establish benefit and inform policy has, arguably, confined and minimized the acknowledged benefits of the arts to a specific set of instrumental attributes (which ultimately relate to market value). These similarities make the arts well suited to sitting centrally in integrated, yet pragmatic approaches to policy, to reintegrate the individual into the community, and to bring together the seemingly disparate elements of what make us healthy, not dismissing numbers, but allowing us to access, consider, and utilize a broader definition and range of “evidence” conveyed from all sides.

Creating community

The myriad ways that artistic practices effectively intersect with policy are made more clear by examining art’s relationship to individuals and society, which, in one vein, lends itself well to the practice of pragmatism, a philosophy that embodies a sense of action in melding theory with practice. The philosopher, educator, and activist John Dewey

was pivotal in developing the philosophy of pragmatism⁵⁹ and subsequently of aesthetic theory. His views, first introduced in the early 20th century, still form the basis for many of the most fundamental and pertinent ideas surrounding the effects of the arts: their abilities to inspire possibilities within us, and the ways those possibilities translate to social sensibilities through an authentic interaction with the environment.

Dewey emphasizes that when art, as a universal mode of language and communication, is able to enter into attitudes that determine our experience, continuity is affected. When this occurs, our own experience does lose its individuality, but its significance expands. This can lead to a sense of collective individualism, allowing a creation and/or restoration of a sense of community and collaboration that is called for in regards to health.

The report, *Gifts of the Muse: Reframing the Debate About the Benefits of the Arts*,⁶⁰ suggests that several communities of thought and practice have begun to look to multiple viewpoints to create frameworks for system change, due to concern about the decline of civic engagement and social cohesion throughout the socioeconomic spectrum, and at every level of community. This sense of “civic crisis”⁶¹ has combined with the realization that socially connected and civically engaged communities exhibit more successful outcomes in education, urban poverty, unemployment, health, crime, and drug abuse, causing many academics, policy experts, and intellectual leaders to focus on issues of community and agency in forming a larger picture of health.

Maria Rosario Jackson (currently of the National Council on the Arts and the Kresge Foundation), in a discussion about arts and non-arts partnerships for the Urban Institute, talks about art as a great translator, and its use as a space for reframing and expanding change on the community level. This ability of art to translate, both verbally and visually, is key; it communicates in ways that other media do not. Jackson encourages the integration of the arts into thinking about community and civic life:

If you want to understand the role of art and culture in communities at the city level, at the regional level, the thing that is so important is to not view art and culture in a bubble exclusively ... pay attention to how art and culture naturally intersect with other dynamics.⁶²

Cultural knowledge plays a role in establishing social cohesion and the sense of a common identity not merely because it is shared, but because of the sustained forms it takes; in other words, our knowledge is shared and passed down through narrative and other forms of expression, perpetuated via the arts. The stated and beneficial use of narrative methodologies in both social and medical practice (detailed in [Arts/Health/Policy Nexus, pg. 33](#)) demonstrates the important overlap between embracing cultural and other forms of knowledge and building a more substantive engagement with health.

Creating and informing policy

How does artistic thinking/practice intersect with the policy sphere?

A compilation titled *Imagining Science* (2008) features artwork and writing from a number of artists and scientists exploring various social and aesthetic concerns about science, advances in biotechnology, and the ways in which policy is (and can subsequently be) informed. In an included essay titled “Policy making and Poetry,” scientist and scholar Bartha Maria Knoppers⁶³ emphasizes the importance of the creative voice and argues that, while seemingly incongruous, “training in the art of poetry [for example] can be useful for the arduous and often inchoate world of policy making,” recounting historical examples where surreal protest via art and poetry “forces the colonizer to listen to the colonized, and accept change.” From her perspective as a biotechnologist, a field whose research outcomes most certainly inform health policies, the “hopeful” outcome of policy making is a dynamic policy built on principles and vision, a creation that sincerely speaks to the individual and so to the universal.⁶⁴ Her examples give way to a “policy by the way” that calls for engagement in a “surreal” policy making process:

But law and poetry would only be tools—poor and paltry—if lost in political generalizations and ideologies. Passion is required for praxis. Where, then, comes the energy to truly transform? Not in party platforms, not in sound bites, but in principles. There is poetry in the 1948 Universal Declaration of Human Rights. There is power and policy in Hamlet. Look at the lessons of the fall of the Berlin wall and the tragedy of new walls being constructed—a testimony to our failure to use the passion necessary to achieve peace.⁶⁵

To create health—and as we’ve seen, to create policy—we need not only process, but also to visualize process, an integral component to every artistic and creative endeavor. In *RSVP Cycles*, Lawrence Halprin⁶⁶ emphasizes that making processes visible goes to “the root-source of human needs and desires:” a focus on process (rather than result) allows for communication, participation and feedback from all parties. This notion pairs with our tendency as a society (and arguably, in our approaches to health care and policy making) toward goal-orientation, which often ignores the process involved; in fact, Halprin argues that what we want and need as humans and citizens is a close and creative involvement in process, one that embodies an idea of “doing”⁶⁷ whereby our input is visible, significant, and useful, and where no one point of view is consistently held as definitive.

We thus can go from art to policy, from imaginative principles to practice and procedure, and, from policy to art, from pragmatism to promise/imagination, from the personal to the universal. Herein lies the dialectic for a dynamic of change that lends itself

to addressing the complexities of problems in health and community. As Knoppers emphasizes:

The intersection of policy and poetry lies in the truly authentic and honest voice free of ideology and political maneuvering; the truly personal voice can contribute to the construction of universal principles [the voice of the community, contributing to the voice of health].... Policy built with the common good in mind resonates across boundaries and creates living, dynamic networks. Only then will policy be both personal and universal.⁶⁸

Relationships and collaborations between artists and scientists are already embodying these intersections. Organizations such as the Ligo Project work to actively create spaces and new paradigms for cross-disciplinary collaboration, particularly between artists and scientists ([Arts/Health/Policy Nexus, page 33](#)). Dubbed the “godfather of bioart,” Joe Davis has been an artist-in-residence at MIT for over a decade and has created ways to encode messages in DNA. Law professor Lori Andrews and lawyer, artist, and community activist Joan Abrahamson, in their essay “Making Art, Making Policy,” suggest that a way to explore scientific and technological impacts is to analyze the issues artists predict will arise:

Artists (from representational artists to fiction writers) can provide a map to the personal and societal issues a new scientific development will raise . . . Artists highlight political issues regarding the unpredictability of outcomes, the incentives within science and society for pursuing particular technologies, and the power struggles within society that will influence how the technologies are implemented.⁶⁹

Art can inform health and health policy, “by the way.”

Re-imagining health

The transformations that are occurring in approaches to health and policy making and their creation are acts of imagination and possibility. Artistic practices are constantly intersecting with practices around improving health and informing policy, and professionals across disciplines and sectors are using aesthetic techniques at these intersections.

Tara Forrest, Senior Lecturer at the University of Sydney, examines the ways in which artistic practices create spaces for possibility, by “de-neutralizing the current state of affairs, then to cleave open a space within history’s so-called march of progress toward the future within which the possibilities of both the past and the present can be imagined and explored anew.”⁷⁰ The renowned Columbia University educational philosopher Maxine Greene wrote extensively on the concept of imagination, possibility, and “wide awake-ness” as it relates to art throughout her career, influenced by the

work of Dewey, who writes that changes in the imagination are the precursors to changes in society: “only imaginative vision elicits the possibilities that are interwoven within the texture of the actual.... The first intimations of a better future are always found in works of art.”⁷¹ Brodie Boland, a scholar of organizational behavior, makes a case for “citizens as designers,”⁷² arguing that the current problems faced by our society call more for engaged creativity and innovation than for debate.

Scientists, scholars, and other disciplines are recognizing the need for creative/imaginatory practice, empathy, the removal of silos of practice and thought, and the need to reposition authority structures and to reach out of common linguistic and other frameworks to foster dialogue, all which can be facilitated not only by artists, but also by a range of players employing art-like tools and actions, as we see in the following collaborative examples.

Convenings/Models of Imagination at Work:

Dreaming of Health and Science in Africa: Aesthetics, Affects, Poetics and Politics Wellcome Trust Conference Center, UK, June 2015⁷³

This forum provided examples/explorations of work being done across practice areas to reimagine public health and clinical care in Africa, including doctors and other clinical workers, public health practitioners, social practitioners, and others. Presentations addressed the applicability of imagination to clinical research and capacity building, stakeholder engagement in health research, creating an “archive of the plausible” for public health, performance as a mediator of memory/history, cross-sector practitioners co-existing to provide healing, examining which publics are served by health institutions, transience and ephemerality as important resources for well-being, and socio-political salience and the affective power of scientific images, all in hopes of creating a “medical imaginary” based on a “political economy of hope.” The presenters asked:

What is the effect of delivering ‘humanitarian health’ divorced from the social worlds of the ill? How is this divorce associated with the social production of amnesia in the health establishment, and how can new practices be brought forth?

Dreaming the Future of Health for the Next 100 Years White paper from the Global Health Summit, Beijing China, January 2013⁷⁴

This summit sought to stimulate reflection, debate, and submissions from a range of actors that play a role in sustained health, and to engage young people with a future of health that they will both shape and live in. The ideas presented had the intent to enrich the activities and priorities of leaders and stakeholders who work for social change, especially for vulnerable people, and to inform the Rockefeller Foundation’s goals, grant-making priorities, and networks. Through

this, it envisaged the multiple potential futures that may emerge, the choices that determine them, and where we could act, even now, to shape futures of sustained health, ultimately asking, “How will we enable the growth and development of healthy societies over the next 100 years?”

Summit delegates argued that the actions needed to secure the future of sustained health need to be based on values of equity and solidarity, on cross-disciplinary thinking and on participatory and practice-linked learning, claiming that most of the incentives for managing change are directed within institutions, and most of these challenges ... require engagement across sectors. The summit proposed a combination of socioeconomic convergence, social cohesion, public policy and state action as providing more conducive conditions for health-promoting developments to reach those with highest health need. Society, in this scenario, may be better able to address the certainty of shocks to health from climate change, urbanization, energy and resource scarcities, and demographic change, and to share the benefits to health of increased connectivity and new ways of learning (emphasizing the important of health and other literacies):

In this scenario, health and well-being, including in terms of planetary health - are integrated within economic and technological development. States, guided by values of equity and clear goals and learning for planetary health, social well-being and economic progress, convene co-operation across social and economic actors, within and across megacities, regionally and globally. Social cohesion, active citizenship, and solidarity are key features of society and in relations with innovative enterprise.

Overall, the white paper makes explicit the critical assumptions and uncertainties about the future of healthy societies, and the different plausible futures they imply, as a basis for creative thinking about how to shape the future.

The Roosevelt Institute⁷⁵

The Roosevelt Institute reimagines America as a place where hard work is rewarded, everyone participates, and everyone enjoys a fair share of collective prosperity, believing that when the rules work against this vision, it's our responsibility to recreate them. Roosevelt brings together thousands of emerging and established leaders across various focus areas, such as Rethinking Communities, which gives students the tools to work with their institutions of higher learning and communities to identify and advance solutions that promote broadly shared economic progress, the *10 Ideas* series, Roosevelt's premier student publication featuring the top policy proposals generated by Roosevelt students nationwide, and The Next Generation Blueprint, a crowd-sourced articulation of a vision for change, laying out an aggressive policy agenda for legislators across issue areas while rethinking how young people can and should engage in the decision-making process.

Performing the World⁷⁶

First created in 2001 by the East Side Institute, an international educational, training, and research center for developing and promoting alternative and radically humanistic approaches in psychology, therapy, education, and community building, Performing the World (PTW) is a yearly international gathering that explores and celebrates performance, improvisation, and creative practice as catalysts for human and community development and culture change. The gathering was founded based on the role of performance in human development and learning in therapeutic, educational and community-organizing settings, and the work of other sectors such as social-constructionist psychology, who themselves were turning toward performance, particularly by experimenting with new performative modes of presenting research and scholarship. PTW is inspired by and contributes to the growth of the global performance movement, not only as a conference/performance festival but also a unique community event bringing people together to create and “perform” a new world.

The U.S. Department of Arts and Culture (USDAC)⁷⁷

The USDAC is the United States’ first people-powered department, founded on the truth that art and culture are our most powerful and under-tapped resources for social change. Radically inclusive and vibrantly playful, the USDAC aims to spark a grassroots, creative change movement, inciting creativity in the service of empathy, equity, and social imagination through a variety of multi-disciplinary events and convenings.

Liminus Institute⁷⁸

Based in Canada and part of a larger project called Gros Morne Summer Music, the Institute seeks to continually explore the question, “What good are the arts?” Liminus is considered part sustainable community development initiative, part international think tank, part Banff Centre, and part Post-secondary field station. It is a project that brings together international leaders and thinkers, regional researchers, communities, students, artists, and the general public, all in pursuit of a reimagined world. Dedicated to problem-solving through the integration of several broad themes: arts, health, technology, sustainability, indigeneity, and the natural world, Liminus has three fundamental commitments: 1) an awareness that we are a part of complex adaptive systems, necessitating 2) deeply interdisciplinary approaches, in terms of methods, disciplines, language, and epistemologies, along with a practice of 3) engagement not as a political afterthought (meaning that public contexts are not where we take our knowledge but where we make our knowledge). The 2016 meeting of the Liminus Institute, among others, will explore themes such as innovation in primary health care, ways of cultivating health “in our own backyard,” and imagining health futures.

The intersection of art with policy can create new spaces that allow for creative, cross-directional input between policy makers and communities, more engaged outlooks and practice related to health, and can re-situate individual agency as contributing to health (and subsequently, policy). Art can serve as a conduit and translator between a system and those it serves, while imagination, improvisation and other forms of aesthetic practice redesign and inform new methods of social thought and practice.

Imagine if...

- Scores were utilized in town hall meetings to make government-related processes visible and to allow direct input from communities.
- Artistic articulations of an individual's experience of mental health or the experiences of artists with HIV/AIDS were considered by policy makers.⁷⁹
- Artist residencies served as "bridges in action" and exchange between and within institutions and communities.
- Collaborations between artists and scientists were understood as central to and overlapping with practices across areas affecting human well-being.
- Individually created bodymaps and co-created community health maps were used to inform policy and health practice.

Many of these types of intersections are already taking place. Residencies are serving as exchanges between individual voice and systemic reform and practice. Artistic practice is being used by health practitioners to enhance empathy, improve the capacity of caregivers, and enhance the delivery and exchange of information across the spectrum of care. We already know what needs to be done—and the arts are helping us to do it.

*"If you don't create the future, the present extends itself."
— Srinath Reddy, Public Health Foundation of India, 2013*

Arts/Health/Policy Nexus

After considering the trends established thus far, and building upon the cross-disciplinary examples already provided, below we seek to highlight an evolving ecology around the ways arts intersect with and build capacity across all areas of health, community, and policy. All of these intersections seek to inform both health and policy in their own ways. These examples are not meant to be exhaustive, but demonstrative; to provide a glimpse into work that is being done, to act as strong indicators of what is possible, and to inspire thought, action and imagination around an array of arts-led intersections that can take place between government, health institutions, academia, practitioners across disciplines, communities, and individuals.

The author notes that the greatest learning opportunities that came from attempting to research and articulate the foundation of a nexus came from reaching out to others and making connections without certainty (or definition) of success; the connections made themselves clear in the process. In the same way, artistic process, wherever and by whomever it is facilitated or brought forth, makes things known, while allowing for the unknown. The hope is for people, individually and collectively, to bring this work to life in their own way, to allow them to imagine new possibilities to engage and connect, whatever their role in community/society, and to bring more experiences, thoughts, and examples to this hopefully ever-growing and ongoing body of work and thought.⁸⁰

Beautiful Distress Foundation

The Beautiful Distress Foundation, headquartered in Amsterdam, uses art in an attempt to “open up the world of psychiatry and battle the stigma attached to it,” believing that art is pre-eminently capable of articulating and depicting the human condition. Their goal is public awareness: to garner attention with and through art that leads to acceptance of those with mental illness. By initiating and developing ideas and projects together with artists, and subsequently sharing them with the public, Beautiful Distress uses art to tell the stories of psychiatry to a large audience that does not come into contact with people suffering from mental illness or the practice of psychiatry on a daily basis.

In 2016, Beautiful Distress (and The Fifth Season⁸¹) will organize an exhibition of artists who spent a period as artist-residents at various psychiatric institutions, showcasing their impressions of mental illness to create awareness among the public.

Along with the exhibition, debates and discussions will be organized with representatives of various interest groups: patients and their families, policy makers in health care and psychiatry, government, artists, and the general public. The views and observations of the artists, resulting from their intense experiences with patients and staff, will be bundled into a “manifesto,” which will form the starting point for discussion. The aim of the discussions will be to formulate new ideas and recommendations for policy makers in government and mental health care and the general public, and to fight prejudices and create more understanding and compassion for those suffering from mental disorders and their immediate environment.

The hope here is that patients and their families find the courage to talk about their situation sooner, that the connection between art and psychiatry creates a new perspective and leads to more public understanding, and that, through the observations of the artists, new and different ideas and solutions can be formulated and offered to decision-makers in healthcare and government. Here, changed institutional and patient narratives are directed toward members of the surrounding community/general public and those making mental healthcare/policy decisions in government and beyond. One example of this work in action takes place at Kings County Hospital Center, in Brooklyn, NY.⁸²

Kings County Hospital Center

“From my point of view ... I am looking for opportunities to shift the narrative here at [Kings County Hospital Center](#) (KCHC). As a city hospital with a complicated and negative narrative, we are looking for different ways to engage our community.”

Founded more than 175 years ago, KCHC has a long history with its surrounding Brooklyn community. Carlos J. Rodriguez-Perez, Director of the Wellness and Recovery Division at KCHC, seeks to enhance not only the patient experience and care within the system, but to change the institution’s interactions and relationship with the surrounding community, combatting stigma of mental health institutions, mental health care and those receiving it. When tasked to ensure that the Behavioral Health Service at KCHC would move into compliance with a Settlement Agreement with the Department of Justice and the Plaintiffs, he and his team decided that “we not only wanted to be in compliance with the Settlement Agreement; we wanted to take this amazing opportunity to develop a center of excellence, to transform this service and shift the culture.”

How? Via the arts. They built one of the largest teams of creative arts therapists in a single institution, “moving away from simply keeping recipients busy while under our care to actually delivering thoughtful and relevant interventions to the particular treatment needs for each recipient.” KCHC has also been the recipient of original art installations via organizations such as RxArt, hosted performances by visiting artists such as Nacho Arimani of the Flamenco Festival, and hosted their first exhibition and community talk/s featuring artwork by residents; all with an aim to shift the image from a hospital where people come to die, to one where people feel cared for and engaged.

KCHC recently became a hosting site for artists-in-residence in partnership with the Beautiful Distress Foundation (see above), which engages artists as studio residents within the hospital campus, creating space for art production that is not attached the core mission of a healthcare setting; expanding the traditional definition of artist residencies and, in the process, allowing for more outward connection with the community.

“It is my hope that we can engage the community we serve in a different narrative ... one that is moving away from a traditional medical/paternalistic model to one of collaboration and engagement. Institutions like KCHC can and do become very insular from the very community [they intend] to serve. We now need to have a different relationship with our community. It is my aim to have arts initiatives to assist with the evaluation and change of the old narratives to new narratives, one we hope to be of wellness and health. We aim to engage in a conversation about how we assist our community to remain healthy, as opposed to simply treating their ailments. I believe that the arts are best suited to assist in this change/evolution to a new narrative that is based on collaboration and sustaining health.”

Moving beyond compliance, to shifting the culture, utilizing interactions with art and artists to transform an institution, while providing a model for artist residencies that can initiate and redefine connections – this can shift perceptions of mental health institutions and patients within the surrounding community. Notably, many hospitals are recognizing the important role they play in the health of not only their existing patients, but their surrounding community.⁸³ Here, they are using art and interactions with artists to rally their efforts to produce new models and definitions of health, to conduct and influence health care, while reframing their relationship to their surrounding community.

Varied interventions by and interactions with artists have allowed them to embrace a more patient-centered approach to care, and a different perception/relationship with the surrounding community: inward and outward connections. Shifting the narrative of an institution and its interactions with those it serves provides a model for restoring dissonance, and for policy creation across areas of health.⁸⁴

For the Best, Residency Mark Storer & Anna Ledgard

Another residency that ultimately worked to change narrative, inspired by and created with adults and children attending hospitals in London and Liverpool, For the Best is a participatory arts project, a site-specific performance and an imaginative, creative exploration of a family's experience of living with renal disease, the result of two long-term artist residencies within inpatient care facilities.

Here, the artists saw it as their duty to reflect an authentic experience of coping with illness, bringing the patient's understanding of biomedical science to the forefront through an innovative and co-created performance and ongoing discussion/collaboration across the spectrum of care. Narratives began to change, in this case, for direct-care providers and administrators, as they caught a different glimpse of the patient experience. Over a long engagement, Mark Storer's creative process broke down barriers between patients and staff, with the clinicians involved saying their understanding, empathy, and communication with patients and improved as a result, and hospital policies were enacted to co-create settings to better account for patients' needs.

The process also led to a comprehensive evaluation report, where results point toward a legacy of changed attitudes; Storer's process (developing "communities of curiosity") results in what the report calls an immediate, sensitive, and deeply personal response to scientific learning, along with the breaking of frames by making applied arts in health contexts. As one participant in the project said, "There are no limits to the imagination."⁸⁵

Narrative Medicine: Healing Healthcare via Narrative at Columbia University

Embracing the impact and need for changed narratives across the spectrum of health, Columbia University Medical Center created a Narrative Medicine program which "seeks to strengthen the overarching goals of medicine, public health, and social justice, as well as the intimate, interpersonal experiences of the clinical encounter ... by educating a leadership corps of health professionals and scholars from the humanities and social sciences who will imbue patient care and professional education with the skills and values of narrative understanding."

Here, then, we have clinicians and others within the clinical setting embracing artistic tools to advance their work. A core tenet of the program is that the care of the sick, and ultimately, the improvement of health and health care, unfolds in stories. They believe that the effective practice of healthcare requires the ability to recognize, absorb,

interpret, and act on the stories and plights of others, and that medicine practiced with narrative competence is a model for humane and effective medical practice, by giving voice to patients and caregivers, and by changing the ways care is given and received. This interdisciplinary practice and field challenges divisions and seeks to bridge divides inherent in approaches to health care, whether access, divides between professionals and patients, or divides among professionals.

According to Dr. Deepu Gowda, Director of Clinical Practice:

When I was a medical student and I was starting to work with patients, I recognized that there were things about health care and one's experience of illness that weren't adequately described in scientific literature, or even social science literature. I recognized that experiences of health and illness that are conveyed through art, through literature, through other creative means, communicate a kind of knowledge about illness that [is] important, and give us information that isn't captured elsewhere.

I also started recognizing that so much of what happens in healthcare is experienced differently by the various individuals who are affected by it. A medical student appreciates a healthcare encounter differently than the resident, differently than the attending, differently than the patient or family member. We see this incredible web of individuals who are affected by what's happening—and not only affected, they're impacted in a very deep and profound way. The stories that are contained in our community are very rich and need to have a place to be told, and a way to be heard, by patients, policy makers, and professionals across disciplines.⁸⁶

Bodymapping

Bodymapping is an art therapy and narrative/memory methodology used in a variety of contexts, from individuals who have experienced trauma to adults living with HIV. The process, according to the *International Coalition of Sites of Conscience* website,⁸⁷ is broken down into a series of creative exercises that ask participants to visualize their pasts, futures, and experiences to create a literal and figurative "map" of their bodies:

At one end of a large poster, participants sketch a past experience, before the trauma. At the other end, they sketch their vision or hopes for the future. Linking this past to future, the participants trace life-size silhouettes of their bodies. Within the figure, they list or draw the physical effects of their experiences: scars, injuries, and pain inflicted during trauma. But they also sketch the relationships, inspirations, and events that have given them strength to move toward their vision. Participants share their work at the end of each exercise and discuss how it reflects their personal experiences.

The Coalition has facilitated bodymapping workshops in several communities (typically led by an artist, a staff member, and a member of the participating community). In Liberia, in order to begin memorializing the country's 14-year civil war, Liberians from

different communities (including widows and amputees from the war, as well as those who were children during the conflict) came together to share their diverse experiences of the war and create a visual public record through their stories, depicted in individual bodymaps. The Liberians added their bodymaps and other artworks to a section of an exhibit, which they titled *Breaking the Silence: The Liberian Story Begins*. As the Coalition describes, the project was hailed by former Truth Commissioners and the media as a critical first step in implementing the Liberian Truth and Reconciliation Commission's recommendation for memorialization. BBC's Jonathan Paye-Layleh said, "If what started as an exhibition on campus at the University of Liberia is nationalized, it will certainly go a long way in fulfilling a key recommendation in the TRC report." This work has led to workshops in several areas,⁸⁸ including Kenya, where communities have expressed a desire for (highly politicized) memorialization initiatives to instead highlight the courage and efforts of everyday Kenyans.

In 1999, the clinical psychologist and narrative therapist Jonathan Morgan, then director of the "Memory Box Project" at the University of Cape Town, South Africa, integrated bodymapping into his group work with adults living with HIV/AIDS. In this context, bodymapping was initially conceived of and used as a way to collect and weave together memories as a legacy to one's children. With the increasing availability of life-prolonging anti-retroviral (ARV) treatment, bodymapping workshops soon developed a more life-enhancing and celebratory quality. Participants were encouraged to look to their HIV-positive future with hope and dreams. The resulting bodymaps were shown in public in order to fight social stigma and to campaign for greater availability of ARV medication.

Ted Kerr, Canada's first artist-in-residence at HIV Edmonton,⁸⁹ a community organization that provides support, education, and advocacy in relation to HIV/AIDS, said, "People with HIV can be in charge of their own representation. AIDS quilts were created to commemorate those lost to AIDS by others left behind. The unique stories depicted in these bodymaps are not dealing with the prospect of death, but represent what it is like to live with HIV and AIDS."⁹⁰

Here, we see bodymaps as another way for an artistic/narrative method to shed light on experience, supporting a visual, creative process of personal reflection and making meaning that relates to one's lived experience of, in these cases, trauma and illness. It can be used in care settings to augment medical histories by contributing to the understanding of the patient as a whole person, which may, in turn, yield supplementary information that is relevant to treatment, patient education, and increased support for and awareness of need by institutional bodies.

Beyond the personal reflection and healing the maps afford, they can also serve as an advocacy tool, a way to articulate personal and community vision and hope for

the future. Two years after the Liberia workshops were conducted, the Coalition conducted a follow-up evaluation with participants, which showed that the participants' desired alliances and visions for the future very much unfolded in the ways they were originally articulated. One participant, having drawn trees on his map, now works for the Forest Service (not having thought of this possibility before). In this sense, the maps have worked as a bridge between personal healing, community struggle, and visionary hope/action. While some use the maps initially to articulate personal visions, others immediately wish to use the bodymaps as advocacy tools, taking part in public exhibitions, and taking maps directly to government representatives and/or advocates for victim's rights. Of note is that the Coalition enters into communities where they are invited, identifies needs with those communities, and adapts the method accordingly—co-creating a tool that will work for that community.⁹¹

Regardless of the context, these co-created, visual methods of representation influence and bridge both personal and social narratives, giving voice to and amplifying these narratives in the ways that participants and communities choose and need.

Re-visioning and Co-planning for Community Spaces in New York City

Arts-led co-creation within the community can help to inform and impact change. New York City is working to engage with communities via artists to co-plan community spaces, all in efforts to improve health. Elizabeth Hamby, an artist and activist, has developed innovative tools and processes to help everyday people plan for the future of waterfront parks and open spaces, and now, as part of her position with the Center for Health Equity at the New York City Department of Health and Mental Hygiene (DOHMH), Hamby shares those tools and works with communities to identify and develop projects in the built environment that will improve health by promoting active transportation.

Hamby, as part of her collaborative practice with fellow artist Hatuey Ramos-Fermin,⁹² also designed Mind the Gap/La Brecha, a temporary art and education hub located at the Blue and White Laundromat in the Bronx. For four months in 2012, she and Ramos-Fermin worked with their neighbors to propose new ways of connecting the community to green space along the waterfront within the South Bronx and Randall's Island. By mapping and sharing the relationships—both visible and invisible—that shaped the issues affecting their community, Mind the Gap/La Brecha built connections between people and place, bringing new voices to the conversation around the future of the neighborhood.

A separate initiative with the New York City government, via the New York City Department of Cultural Affairs, will create artist residencies to be embedded in multiple municipal agencies, under the premise that art-government partnerships will bring new perspectives to the work of creating health equity. As part of the DOHMH, an artist residency will be framed at a District Public Health Office to explore the role of local culture in local food systems (the cultural relevance of local food systems informs the holistic work of these offices). In this role, artists will be “helping to develop a meaningful, legible process to help community residents build consensus around the future of health in their neighborhood, and work together with city agencies, citywide nonprofits, and local community-based organizations to realize their vision and goals.”⁹³

Here, making process visible (as Halprin recommends) via artistic practice allows for a shift in the locus of control, advancing individual and collective agency.

Harriet’s Apothecary

The power of people coming together, in an effort to meet personal/local needs, fueled by artistic thought and practice, can facilitate change on a larger scale. Harriet’s Apothecary (HA) is an intergenerational healing village and collective formed and led by Black Cis⁹⁴ women, Queer and Trans healers, artists, health professionals, magicians, activists, ancestors, and community members that is “committed to co-creating accessible, affordable, liberatory, all-body loving, all-gender honoring, community healing spaces that recognize, inspire, and deepen the healing genius of people who identify as Black, Indigenous and People of Color and their allies.” They promote an expanded concept of personal and community health by engaging in community skills shares, mapping activities, and dialogues about the body’s ability to attract the components it needs for health.

In addition to its work with individuals and communities, HA partners and shares process with movement-building organizations throughout the country to advocate for policy changes related to racial justice, LGBTQ justice, anti-violence liberation and healing justice. They are currently working with the Ella Baker Center for Human Rights and the ACLU to develop Justice Teams for Truth and Reinvestment. (Justice teams are local rapid-response networks across the State of California that will build infrastructure to support victims and survivors of state violence and mass criminalization.) These teams will also work to advance local Truth and Reinvestment campaigns that will raise the visibility of a long history and current reality of state violence and mass criminalization, while advocating for the redirection of resources toward employment, education opportunities, and public health-based responses to drugs and violence.

They are also working with the Astraea Foundation to coordinate the wellness initiative within their CommsLabs Kenya/SouthAfrica contingent. CommsLabs is building a network of linked activists and technologists from the Global South and East working independently and together to strengthen the next generation of LGBTI human rights advocacy, through the use of communications and technology tools.⁹⁵

Mujeres en Movimiento, IMI Corona, IM International

Veronica Ramirez began Mujeres en Movimiento, a collective of mostly immigrant Latina women that encourages mutual health and empowerment through movement/dance, out of her own desire to expand her health; she embodies another example of personal and social agency that she amplifies with creative process. As a mother, community educator, leader, and advocate for the rights of women, children, and the immigrant community, Ramirez believes that access to health and education should not be a privilege but rather a right for all, and that Popular Art, which is born from the knowledge and experiences of the people, is a powerful tool for these struggles.

Veronica serves as a leader in the IMI Corona (Queens) Community Council, a volunteer-led community space for alternative education, a think tank to reimagine the role of (im)migrants in society, and a laboratory for the merging of arts and activism. Since 2014, IMI Corona has been led by the Community Council, a body that exists to “help us break the doors that lock us in, so that our mind can fly more, so that we can connect our experiences and imagine new ways to live, to follow our dreams, and to fight and struggle together to make them a reality. We are a group that is sharpening skills to organize and be active in the social justice movement based on the needs of (im)migrant mothers, women, children, and young people that are the majority of participants of IMI Corona.”

IMI Corona is a part of IM International, a community space where practical knowledge is merged with creative knowledge, using a holistic approach to education that is open to all, regardless of legal status. IM International is a lab, practicing activist tactics and new tools for communication in the public sphere to access political dialogue in an effort to transform social affect into political effectiveness and engagement.⁹⁶

Woman with Sword

Education, knowledge, and tools for dialogue and exchange are recurrent themes in our quest for engagement with health and policy issues. *Woman with Sword* is a method of combining theater with “expert testimony,” serving as a powerful tool in public policy discourse and learning environments. These practices have examined health equity as

it plays out in different arenas: in two particular cases, chemical industry pollution along Toms River, New Jersey, and access to dental care in Prince George's County, Maryland. Dr. Jane E. Clark, Dean of the University of Maryland's School of Public Health and Dr. Stephen B. Thomas, Director of the Maryland Center for Health Equity served as willing partners in these experiments. The seriousness of the subjects was countered with periodic shifts in the audience's emotional landscape with surprising performance elements: jokes and a rant, props and a polka. This method provides a step beyond traditional learning environments; it allows all the participants—facilitator, experts, performers, and, most importantly, audience members — to actively engage to their fullest capacity. People remember specific content details as well as the experience of talking with each other and connecting their own stories to the topic. They speak of listening with more investment and curiosity when related news stories hit the press, even several weeks post-performance.

Woman with Sword's first project for the 2016–2017 season will be in Brazil for a pre-conference day-long event affiliated with the Association for Women in Development conference, with topics of child, early, and forced marriage and sexuality.⁹⁷

Promethean Community: HEAL Labs

Translation of knowledge into effective education and discourse around health is also a focus of HEAL (*Health Education Arts-based Labs*), a service of Promethean Community. HEAL are public health, arts-based social innovation labs that create and test more effective public health interventions and that bring together community members, service providers, local institutions and governments, and local artists. These labs translate “evidence-based” health trainings into interactive, arts-based educational experiences and quickly test and refine these interventions that use art (also known as art-based prototypes) with feedback from the community, taking in to account the social determinants of health and the current limitations of health education approaches.

HEAL are like an experimental kitchen for health policy making and action: inviting local community members and other stakeholders from areas such as Washington, D.C., and Panama City, Panama, to quickly create and test recipes for success. These artist-led facilitations ultimately model effective collaboration and create innovations and interventions with, and not for, community members, bringing them together with government officials, health educators, and other stakeholders using the performing arts.

Promethean Community seeks to design transformative group experiences and convenings that build trust, improve communication, and catalyze collaboration, and is specifically focused on helping organizations in Latin America deepen their partnerships with community members to address their health needs.⁹⁸

Wellcome Trust: funding collaboration and creative exchange

Funders are increasingly recognizing collaborative efforts and the contributions of artistic and creative endeavor and exchange as well. The *For the Best* residency, the *Dreaming of Health and Science in Africa* convening (both mentioned above), and myriad other collaborative efforts are funded by the Wellcome Trust, which encourages creative collaborations between art and science. They believe that artists have a distinct approach to understanding and communicating ideas that can illuminate and challenge perceptions within society, that the arts have an invaluable role to play in engaging the public with biomedical science, and that this exchange generates powerful, personal, and visceral art and inspires interdisciplinary research and practice that can inform practice across a variety of areas.⁹⁹

The Ligo Project: Science (as) Culture

To more closely examine the varied and potential overlaps between art and science, Science (as) Culture, conceived of by the Ligo Project, uses a format inspired by Lois Weaver's conversation as performance project *The Long Table*, which is informal, participatory, and nonhierarchical. Special guests are invited to "seed" the conversation, but the "audience" is invited to take a seat at the table and join in. The rules of engagement are such that free thought and open exchange are highly encouraged at all times—everyone's voice is heard.

Science (as) Culture aims to create a "call to action" to take positive steps in the community to improve integration and communication across disciplines. Multi-media summaries of discussions serve as a platform for: a white paper, blog and/or other article(s) in order to more broadly distribute the ideas exchanged in discussions to decision makers, editors of newspapers and other media sources, and to distribute ideas and needs to other organizations with relevant missions: all as a means to coalesce a wider community around positive action, and to seed content and context for additional public town hall-style discussions and events that will work toward new and creative contexts for cross-collaboration. This event seeks to imagine a way forward that encourages less siloing of knowledge and experience and more collaboration, toward a common goal of a more engaged, healthy, and equitable society.¹⁰⁰

The Vaccine Project

An example of collaborative and creative knowledge sharing and effort in action, the Vaccine Project is an interdisciplinary project headed by Professor Steven Hoffman, (University of Ottawa, Canada) Professor Natalie Loveless, and Professor Sean Caulfield, (University of Alberta). Funded by the Research Council of Norway, the initiative seeks to collectively explore the complex issues related to the use and distribution of vaccines in the world today.

The project is based on emerging questions related to the safety, effectiveness, and proper use of vaccines, having generated an extremely heated and polarized international public debate that has arisen over the last several years, stimulating discourse around a number of broader ethical issues related to international health care delivery such as access to health care, as well as balancing personal/cultural freedom and public health. The forces behind the polarized vaccine debate are complex, involving many players including the media, funding agencies, corporations, and the scientific/academic community itself. The project's premise rests on the idea that this complexity generates anxiety that hinders society's ability to have a reasoned, rational, and respectful discussion around vaccines, and that art/creative research has the potential to play an important role in helping to foster a more nuanced discourse around vaccines, by articulating elusive or emotionally charged issues in ways that other forms of communication often cannot.

With this in mind, the Vaccine Project was envisioned as a collaborative and interdisciplinary initiative that will bring together a team of artists, researchers, advocates, and healthcare professionals in workshops to share research and creative expertise in order to work collectively. The workshops will be followed by an exhibition(s) and culminate with a publication addressing public perceptions of vaccines today, policy issues related to vaccine use and distribution, speculations about the role art can play in discourse around vaccine and public policy, as well as discussions around interdisciplinary research in which theoretical knowledge is translated into creative practice.

The project's creative research team recognizes the complex and multifaceted relationship that exists between art/social practice and public policy, and that the impact of art/social practice on public policy and political discourse can be profound, but this impact can often manifest over very long periods of time, and be felt through indirect routes. In particular, the role of art in the context of the project is not seen as only a communication tool between policy makers and the public, but as an active player in a broader discourse around vaccines that ultimately helps to foster a space of reflection and contemplation for all.¹⁰¹

In the Power of Your Care

Artistic exhibitions, both within and outside traditional venues, provide another opportunity for contemplation and exchange. *In the Power of Your Care* is an exhibition about health and health care as a human right, and the interdependencies of care in our culture, from personal relationships to government policy. Addressing issues such as the politics of institutionalized care in hospitals and military detention centers, the Food and Drug Administration ban on blood donations from Gay and Bisexual men, and the challenges posed by medical treatments of cancer and HIV/AIDS, *In the Power of Your Care* powerfully proposes that health care as a human right can be upheld through community-based efforts and policy change.

The artists featured courageously question how health is defined in our culture, highlighting blind spots in public policy surrounding care. A common theme connecting many of the works in the exhibition is the unstable definition of physical and mental health, its relationship to beauty, and the illusive nature of being cured.¹⁰²

The Waiting Room and Free People's Medical Clinic

Artist Simone Leigh (b. 1968, Chicago, IL) is known for an object-based, sculptural exploration of female African American identity, with a practice informed by ancient African and African American object-making. For her 2016 exhibition and residency at the New Museum, *The Waiting Room*, she focuses specifically on an expanded notion of medicine, with references to a wide range of care environments and opportunities—from herbalist apothecaries and *muthi* [medicine] markets in Durban, South Africa, to meditation rooms and movement studios—and involves a variety of public and private workshops and healing treatments that the artist refers to as “care sessions.” Avoiding pragmatist and authoritarian arguments about the failures of public health and related conditions, Leigh finds inspiration in parallel histories of agency and intervention within social movements and black communities, past and present, and, as an artist, brings those strategies to light.

Troubling the notion of separate narratives, she implicates institutionalized control and indifference as the conditions under which forms of self-care and social care can (and arguably, have) become radical or alternative. Blurring the distinction between bodily and spiritual health, or between wellness and happiness—and, in doing so, countering the perception of holistic care as a “luxury good”—Leigh convenes holistic health practitioners who view social justice as integral to their work, engaging community partners in an “underground” series of intimate, in-depth workshops and classes to take place while the Museum is closed to the public, along with a series

of talks, performances, and events conceptualized as medicinal dialogues on aging, disobedience, abortion, healing performances, and toxicity that are open to all. The project also takes into account a history of social inequalities that have necessitated community-organized care, traditionally provided by women.¹⁰³ *The Waiting Room* suggests that creating a space for wellness may require both the making of a sanctuary and an act of disobedience against the systemic enactment and repudiation of black pain.

This project developed out of an earlier iteration of Leigh's socially engaged work *Free People's Medical Clinic* (2014), organized by Creative Time, which asked viewers to consider the often-overlooked players, most especially the unknown Black women nurses, osteopaths, gynecologists, and midwives, who have over-served an underserved population for centuries, by providing free treatments and workshops over the course of four weekends in the former Bedford-Stuyvesant, Brooklyn, home of Dr. Josephine English, the first black ob-gyn in the state of New York.¹⁰⁴

Her work is an intervention, a living and breathing example of overlapping areas of practice and thought; it not only attempts to represent the topic(s) at hand in its subject matter, but itself is an "act of disobedience" in its successful disruption of power and place in regards to wellness. As we've established, health is intimately tied to power and place, and as such, to the burdens of racism and poverty (among others). Shedding light on these determinants of wellness can be a first step in allowing us to create more spaces for wellness, for all.

A Beginning...

What did you hear?

What did you see?

What did you feel?

Ultra-red, a sound art collective founded by two AIDS activists in 1994,¹⁰⁵ proposes a project that asks (given our understanding of organizing as the formal practices that build relationships out of which people compose an analysis and strategic actions):

How might art contribute to and challenge those very processes?

How might those processes already constitute aesthetic forms?

These questions shed light on the role that art and aesthetic forms can effectively play when confronted with social processes/problems; that their importance in these arenas relies less on an artistic end result and more on a contribution to process that leads to a desired social outcome; in its varied ways of making known what was previously unknown, while also looking ahead to future (unknown) possibility. In this way, art restores the dissonance between individual and community that overlaps with our limited views of health and policy formation, allowing transformation to take place within individuals and institutions, and thus facilitating new ways of imagining the world.

In this light, we hope this to be a beginning, rather than a conclusion; a foray into what is possible moving forward. As Ultra-red, rather than inviting people simply to listen to the sounds they had made, began asking, “What did you hear?” we would invite all those who engage with this paper not only to listen, but to engage in an active process; changes in the ways health is perceived, care is delivered, and policies are made, will then emerge.

Notes/Resources

- 1 Having worked in the U.S. as a health educator and arts administrator for nearly 10 years, the author's work on this paper began with a long-held desire to examine and elucidate the varied connections between arts, health, science/technology, and policy making more deeply, and also expand upon formal studies in which she sought to research and better understand frameworks (real and imagined) for creating change. Accordingly, the scenarios, examples and resources referenced here stem from this lens of experience/study and from multiple collaborative convenings, taking place at the World Policy Institute and the Queens Museum in 2014/15, which brought together artists, community members, community organizations, and institutions working across these areas; providing a small glimpse into some of the extraordinary work being done and a fueling a desire to create similar spaces for collective thinking and imagining. A review of available literature on trends in health policy and care (and on art's overlap with community and policy change) began with compiling available research reports/white papers, existing research/literature reviews, surveying organizations and individuals, putting out calls for resource inclusion to others working across these areas (both within both institutions and communities), and supplementing these efforts with online research.
- 2 See http://www.oxforddictionaries.com/us/definition/american_english/nexus for full definition.
- 3 Aside from initial definitions provided, specific distinctions/analysis of the terms policy, social policy, and public policy go beyond the scope of this paper; throughout, the term policy will imply any set of regulations set forth by a governing body or institution that affects the functioning and/or well-being of individuals and communities.
- 4 To learn more about the CDC's definition of policy and related policy topics, see <http://www.cdc.gov/stltpublichealth/policy>.
- 5 See <https://www.hks.harvard.edu/centers/wiener>.
- 6 See http://www.who.int/topics/health_policy/en.
- 7 To learn more about each stage in the process, see <http://er.educause.edu/articles/2009/3/the-policy-process-life-cycle>.
- 8 For a complete listing of all process components, see <http://www.theiwt.com/index.php/about/about-government-policy>.
- 9 Centers for Disease Control and Prevention. (2015, November 9). Policy and Health. Retrieved November 29, 2016 from <http://www.cdc.gov/stltpublichealth/Policy/>
- 10 "Public Policy." West's Encyclopedia of American Law. 2005. [Encyclopedia.com](http://www.encyclopedia.com/doc/1G2-3437703589.html). (August 10, 2016).<http://www.encyclopedia.com/doc/1G2-3437703589.html>

- 11 A comprehensive list of organizations that influence policy reaches beyond the paper's scope; the goal here is to provide insight in to the ways in which policy is typically informed/influenced.
- 12 The topical areas covered include surveillance, investigation, diagnosis, treatment, intervention, prevention, control, and public health preparedness among others for several diseases and conditions.
- 13 For a listing of these organizations referenced by the CDC, see <http://www.cdc.gov/stltpublichealth/policy/national-organizations.html>.
- 14 See <http://nyam.org/about> to learn more about the Academy's initiatives and partners.
- 15 See the American Medical Informatics Association, at <https://www.amia.org>. It is important to note that significant overlaps are emerging between health and technology; in relation to data gathering, which effects care, and also in relation to digital and health literacy, which carry over in to the social determinants of health. Further dialogue/research should be conducted in this realm. With more health information readily available to patients, health literacy has a new level of importance. For some examples of health care technologies that are emerging, visit <https://www.startuphealth.com>. To learn more about the U.S. Action Plan for Health Literacy, and for an example of a website focused on person-centered care and education, visit: <https://health.gov/communication/initiatives/health-literacy-action-plan.asp> and <http://www.dragon-claw.org>.
- 16 *Health Affairs* (2009, 28, 5).
- 17 The Ligo Project is a 501(c)(3) non-profit organization based in New York City that fosters scientific research by translating it for the general public to consume in a very creative, non-traditional way, linking scientists to artists to work together to learn, indulge and communicate scientific research. See ligoproject.org and sections III and IV of this paper for additional information.
- 18 Physician, Associate Professor of Medicine; Director of Clinical Practice, Program in Narrative Medicine at Columbia University Medical Center
- 19 The New York City Community Health Profiles capture the health of 59 community districts across the city. Considered most comprehensive reports of neighborhood health ever produced, they look beyond traditional health measures to define a broader picture of neighborhood health including conditions such as housing quality, air pollution, and types of food accessible. Community Health Profiles can serve as a critical resource for improving health, and marks a step towards participatory public health. See <https://www1.nyc.gov/site/doh/data/data-publications/profiles.page>.
- 20 Indicators include environment, social and economic conditions (education, income, violence), self-reported health, health living (diabetes, smoking, substance use), access to health care, prevention, and health outcomes (conditions, hospitalization, causes of death).
- 21 See <http://www.rwjf.org/en/culture-of-health.html>.

- 22 See <http://www.calendow.org/building-healthy-communities> for an overview of this initiative.
- 23 See <http://jama.jamanetwork.com/collections.aspx> for a listing of published articles by issue area.
- 24 See <https://www.codeforamerica.org> and <https://openpolicy.blog.gov.uk/category/policy-lab> for additional information.
- 25 See <http://www.policylink.org/about> to learn more about PolicyLink and their supported programming.
- 26 See <http://rooseveltinstitute.org/next-generation-blueprint-2016-report> for a complete copy of the report.
- 27 See <http://www.kkv.net> for a more in-depth description of the philosophies and services of KKV.
- 28 The work of Veronica Ramirez, Harriet's Apothecary and Margot Greenlee are featured in the [Arts/Health/Policy Nexus, page 33](#) of this paper.
- 29 IOM Definition of Quality: The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.
- 30 See full listing of reports related to this initiative here: <http://www.nationalacademies.org/hmd/Global/News%20Announcements/Crossing-the-Quality-Chasm-The-IOM-Health-Care-Quality-Initiative.aspx>.
- 31 Some examples of priorities for health prevention in the U.S. can be found in Roosevelt's Next Generation Blueprint for 2016 (<http://rooseveltinstitute.org/nextgenblueprint>), the NYC State Health Plan Prevention Agenda 2013–2018 (https://www.health.ny.gov/prevention/prevention_agenda/2013-2017), and on the website of the Prevention Institute (<http://www.preventioninstitute.org>).
- 32 See The Nation's Health series on the social determinants of health, August, 2016: <http://thenationshealth.aphapublications.org/site/misc/socialdeterminants.xhtml>.
- 33 In a presentation given at the Queens Museum on November 22, 2015, as part of an event titled Artists Creating Health, exploring the role of artists in creating health for and with communities; to learn more about this event, see <http://www.queensmuseum.org/events/artists-creating-health>.
- 34 See https://www1.nyc.gov/assets/doh/downloads/pdf/data/2015_CHP_Atlas.pdf and <http://www.marketplace.org/2012/04/24/elections/real-economy/richest-poorest-new-york-city>.
- 35 See <http://www.calendow.org/building-healthy-communities>.
- 36 Testimony before the NYC Council Committee on Health, May 20, 2015 (<http://www1.nyc.gov/assets/doh/downloads/pdf/public/testi/testi20150520.pdf>)
- 37 See the Commonwealth Fund's Health Reform Resource Center (<http://www.commonwealthfund.org/interactives-and-data/health-reform-resource-center#/f:@facasubcategoriesfacet63677=%5BIndividual%20and%20Employer%20Responsibility%5D>) and the American Public Health Association's health reform

- page (<https://www.apha.org/topics-and-issues/health-reform>) for additional data related to health reform in the U.S.
- 38 See http://ssir.org/articles/entry/the_community_cure_for_health_care to learn more about initiatives that are shifting focus onto social health as cost beneficial.
- 39 An example of market-driven care: Since the 2008 financial crisis, private equity firms have increasingly taken over public services like emergency care and firefighting, often with dire effects: <http://www.nytimes.com/2016/06/26/business/dealbook/when-you-dial-911-and-wall-street-answers.html>.
- 40 See *Arts and Health/Policy*, pg. 23, of this paper for more information on the Summit and its subsequent white paper.
- 41 *Dreaming the Future of Health* (white paper from Global Health Summit), pg. 23.
- 42 See the World Health Organization’s fact file on health inequities, from the World Conference on Social Determinants of Health: <http://www.who.int/sdhconference/background/news/facts/en>.
- 43 Quoted from Sember’s presentation at the Queens Museum (noted above). To learn more about Robert’s work, visit <http://www.veralistcenter.org/engage/people/1828/robert-seMBER>.
- 44 Additional information on the collaborative and their reports can be found here: <http://www.pstamber.com/the-collaborative>.
- 45 See <http://www.nationalacademies.org/hmd/Activities/Global/PublicPrivatePartnershipsForum/2014-AUG-27.aspx> for additional information on this convening.
- 46 A variety of health organizations are embracing person-centered approaches and care (two U.S.-based examples include the Camden Coalition of Healthcare Providers, <https://www.camdenhealth.org> and Connected Health Resources <http://www.connectedhealthresources.com>), as well as societies such as The Society for Participatory Medicine (<http://participatorymedicine.org/>) and new fields such as Minimally Disruptive Medicine (<https://minimallydisruptivemedicine.org/category/views-from-the-frontline-of-care>).
- 47 See <http://koawatea.co.nz/sun-raha-hai-are-you-listening-translating-mental-health-research-into-improved-clinical-practice-and-policy>.
- 48 See <http://www.calendow.org/report/drivers-of-change/#6> for information on this and other drivers of change as part of this initiative.
- 49 Full report is available here: <http://community-wealth.org/sites/clone.community-wealth.org/files/downloads/Report-Creating%20Health%20Collaborative%20-%20copy.pdf>.
- 50 Following the release of the NASEM report, Duke University Medical School’s Department of Community and Family Medicine, the de Beaumont Foundation, and the Centers for Disease Control and Prevention partnered to launch the *Practical Playbook: Public Health & Primary Care Together* to provide detailed guidance to support improved collaboration and document partnerships that have worked. See <http://www.pstamber.com/home/5/29/2016:achieving-health-how-we-can-just-start?rq=nasem> for additional information.

- 51 See <http://asiacentre.co.th/event/working-with-people-centred-processes-art-education-cross-sector-collaboration>. The planned workshop will subsequently inform a publication in 2017.
- 52 Residency Unlimited supports the creation, presentation, and dissemination of contemporary art through unique residency programs and year-round public programs. See <http://residencyunlimited.org/programs/from-kentucky-to-new-york-project-h-e-a-l> to learn more about RU's partnership with Project H.E.A.L.
- 53 See http://ssir.org/articles/entry/connecting_big_picture_theories_with_community_experience to learn more about Nancy's work as it relates to the Institute of Medicine and Creating Health Collaborative.
- 54 For a comprehensive/evolving listing of literature pertaining to art's physical benefits, see <http://www.feelthemusic.org/benefits-of-music>.
- 55 Full report is available here: <http://www.thesah.org/doc/reports/ArtsInHealthcare.pdf>.
- 56 See <http://www.worldpolicy.org/blog/2015/06/09/art-policy-and-wellness> for addition information. To learn more about the artist roundtable concept, see <http://www.worldpolicy.org/blog/2014/11/04/artist-roundtable-art-art-and-politics>.
- 57 Arlene Goldbard is a writer, speaker, social activist, and consultant who "works for justice, compassion and honor in every sphere, from the interpersonal to the transnational." She serves as Chief Policy Wonk of the U.S. Department of Arts and Culture (www.usdac.us), an action network of artists and cultural workers mobilizing creativity in the service of social and environmental justice.
- 58 Quoted in Wilson 2010, 23.
- 59 Pragmatism is a philosophical tradition centered on the linking of practice and theory. It describes a process where theory is extracted from practice, and applied back to practice to form what is called "intelligent practice." See The Pragmatism Cybrary (<http://www.pragmatism.org>) for a full history and introduction to pragmatism and its theorists. For a discussion on the limits of a narrowed pragmatist approach to public policy, see <http://eppc.org/publications/the-limits-of-pragmatism>.
- 60 Full report is available here: http://www.rand.org/content/dam/rand/pubs/monographs/2005/RAND_MG218.pdf.
- 61 An overlap between artistic and political participation permeates much of the literature and thinking regarding art and social change. Many studies, such as the National Endowment of the Arts (NEA) report (written by the Arizona Commission on the Arts) titled "The Arts and Civic Engagement: Involved in Arts, Involved in Life" create somewhat of an instrumental link between art and civic engagement. Art serves as a form of civic engagement not in that it is considered a social indicator of healthy life or community, as it was referred to in the SIAP study, but as a democratic form of communication, it opens up spaces for civic-mindedness and transformation to take place and develop. Participation in the arts is not merely an indicator of other forms of civic participation; its value lies in the fact that it engages.

- 62 See <http://www.urban.org/sites/default/files/alfresco/publication-pdfs/900244-Arts-Culture-and-Community.pdf> for a full transcript of this interview with Maria Rosario Jackson.
- 63 Director of the Centre of Genomics and Policy, Faculty of Medicine, Department of Human Genetics, McGill University
- 64 See [Arts/Health/Policy Nexus, bodymapping, pg. 27](#), for an additional example.
- 65 In her essay "Policy making and Poetry," in *Imagining Science* (2008, 58).
- 66 Considered by many the forefather of urban renewal, Halprin was a landscape architect, designer and educator. RSVP stands for resources, scores, value action, and performance; all considered a continuous part of the procedure inherent to the creative process.
- 67 *RSVP Cycles* (1970, 4).
- 68 In "Policy making and Poetry," pg. 59.
- 69 See essay "Making Art, Making Policy" by Lori Andrews and Joan Abrahamson in *Imagining Science* (2008, 1-2).
- 70 Tara Forrest (2008, 15).
- 71 Dewey (1934, 345-46).
- 72 See [http://ssir.org/articles/entry/citizen as designer](http://ssir.org/articles/entry/citizen_as_designer).

Convenings/Models of Imagination at Work

- 73 See <https://africanbiosciences.wordpress.com/events/dreamingscience> for full program.
- 74 See <https://www.rockefellerfoundation.org/blog/dreaming-the-future-of-health-for-the-next-100-years>.
- 75 See <http://rooseveltinstitute.org>.
- 76 See www.ptw.org.
- 77 See www.usdac.us.
- 78 See <http://gmsm.ca/liminus-institute>.
- 79 See <https://www.visualaids.org/projects/detail/duets> for information about DUETS, a series of publications that pairs artists, activists, writers, and thinkers in dialogues about their creative practices and current social issues around HIV/AIDS; and *Mental Health and Sexuality: Practicing Radical Consent as a Mad Person*, by ELLIOT, accessible here: <https://drive.google.com/file/d/0BxhpCgBoXsGJVkViNfNjT2lha3c/view>.

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- 80 All information in these listings is adapted from information shared on each organization's website and/or personal interviews.

- 81 Het Vijfde Seizoen (The Fifth Season) is a studio house on the grounds of the psychiatric institution Altrecht, the Willem Arntsz Hoeve in Den Dolder, the Netherlands. See <http://www.vijfde-seizoen.nl/en/about/concept>.
- 82 Adapted from www.beautifuldistress.org.
- 83 For more information on hospitals building healthier communities as “anchor institutions,” visit: <http://democracycollaborative.org/content/hospitals-building-healthier-communities-embracing-anchor-mission>.
- 84 Interview with Carlos Rodriguez-Perez, MA,LCAT, RDT/BCT, Director of the Wellness and Recovery Division at KCHC.
- 85 The report can be found here: http://annaedgard.com/wp-content/uploads/forthebest_evaluation.pdf.
- 86 Adapted from feedback Deepu Gowda, Associate Professor of Medicine at the Columbia University Medical Center (CUMC), the Director of Clinical Practice in the program in Narrative Medicine at CUMC, and member of the New York City Board of Health, and <http://sps.columbia.edu/narrative-medicine>.
- 87 Visit <http://www.sitesofconscience.org> to learn more.
- 88 Additional workshop interest has been shown from locations such as Sierra Leone, Jordan, and Morocco.
- 89 <http://www.hivedmonton.com>.
- 90 See: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2659820>.
- 91 Adapted from http://www.cssr.uct.ac.za/asru_about.html, www.bodymaps.co.za, Catie; <http://www.catie.ca/en/bodymaps/bodymaps-gallery>, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2659820>, Body mapping: embodying the self living with HIV/AIDS by Pamela Brett-MacLean, Co-Director Arts and Humanities in Health and Medicine, University of Alberta Edmonton), <http://www.sitesofconscience.org> and comments from the Coalition’s Executive Director, Elizabeth Silkes.
- 92 See <http://www.metalocal.net/about> for more information on Fermin’s work.
- 93 Adapted from <http://www.worldpolicy.org/blog/2016/02/11/artist-residencies-new-york-city> and <http://performingpublicspace.org/elizabeth-hamby>.
- 94 The Oxford English Dictionary describes the word “cisgender” (often abbreviated to “cis”) as an adjective and defines it as “Denoting or relating to a person whose self-identity conforms with the gender that corresponds to their biological sex; not transgender.” Learn more here: <http://www.advocate.com/transgender/2015/07/31/true-meaning-word-cisgender>.
- 95 Adapted from <http://www.harrietsapothecary.com>.
- 96 Adapted from <http://immigrant-movement.us> and information provided by Silvia Juliana Mantilla Ortiz, IMI Corona Community Organizer and Queens Museum Artist Services Coordinator.
- 97 Adapted from www.bodywisedance.com and Margot Greenlee, Director of Bodywise Dance.

- 98 Adapted from <http://prometheancommunity.com/about-us.html>
- 99 To learn more about the Trust's work: <http://www.wellcome.ac.uk>.
- 100 Adapted from www.ligoproject.org
- 101 Adapted from <http://www.thevaccineproject.com>.
- 102 The exhibition was on view April 19 to August 12, 2016, at The 8th Floor, the exhibition and programming space for The Shelley & Donald Rubin Foundation, located at 17 West 17th Street, New York City. See <https://www.visualaids.org/events/detail/in-the-power-of-your-care>.
- 103 These include the United Order of Tents, a secret society of nurses that has been active since the time of the Underground Railroad, and volunteers in the Black Panther Party's police-embattled clinics that were active from the 1960s to the 1980s.
- 104 See <http://www.newmuseum.org/exhibitions/view/simone-leigh-the-waiting-room> and <http://creativetime.org/projects/black-radical-brooklyn/artists/simone-leigh/> for information on Leigh's current and former projects.
- 105 Ultra-red have expanded over the years to include artists, researchers, and organisers from different social movements including the struggles of migration, anti-racism, participatory community development, and the politics of HIV/AIDS. See <http://www.ultrared.org/mission.html>.

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