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MEASUREMENT, LEARNING & EVALUATION

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MEASUREMENT, LEARNING & EVALUATION

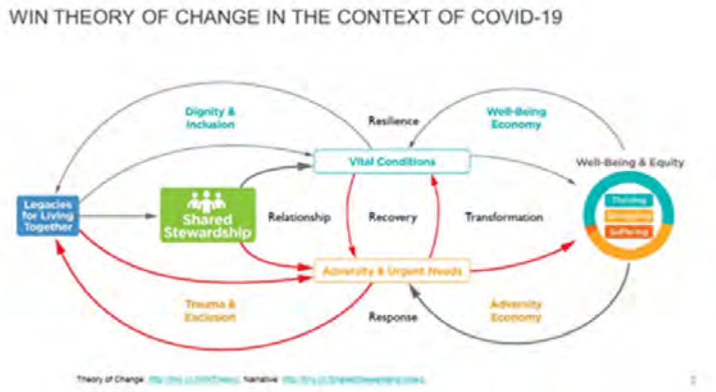
> *"Maybe stories are just data with a soul." —Brené Brown*

INTRODUCTION

The COVID-19 pandemic has uncovered the societal fault lines of our nation's inequities. These fault lines, at the intersection of race, place, health, and wealth, have led to a pattern of surviving and thriving in some groups of people and of struggling, suffering, job loss, and premature death in many others. While these inequities have come into stark relief in the context of this pandemic, they reflect underlying conditions of interpersonal and structural racism and injustice which has contributed to a pernicious and perpetuated legacy of poor well-being for generations.

An equitable measurement approach to support a Springboard for Equitable Recovery and Resilience must therefore address both the COVID-19 pandemic today and build a path for equitable recovery and resilience in the future. Aligned with the overall theory of change, we propose a measurement system that answers the following questions:

- Was the COVID-19 response equitable in process and outcomes?
- Were the vital conditions needed for community resilience equitably advanced in the places that had the farthest to go?
- Did system transformation take place such that we:
    - Shifted inequitable legacies to reduce trauma and exclusion and advance dignity and inclusion in our processes of assessing, responding and planning?
    - Built relationships and shared stewardship between system stewards, community members and those affected by inequities?
    - Advanced civic infrastructure in measurement, data infrastructure and community process to create a more equitable and empowered response?
    - Changed policies, culture and systems to address the root causes of structural racism and other inequities?
- Did we create enabling systems to sustain these changes (changes in financing, data systems, etc) so that they become the new norm?
- Was there a difference in the percent of people surviving that bent the curve of inequities?
- Did the balance of people thriving, struggling, and suffering change in communities involved and in the nation over time?


WIN THEORY OF CHANGE IN THE CONTEXT OF COVID-19

Theory of Change: Narrative:

This chapter of the Springboard outlines the key criteria of what such a measurement system could look like, informed by national organizations, communities and people with lived experience of inequities. It draws its measures from both community improvement efforts that equitably addressed community transformation, such as the 100 Million Healthier Lives SCALE initiative, and from several national measurement efforts that align efforts across sectors and chart a path toward an equitable learning measurement system to support a learning health system over the next decade, including the Well Being In the Nation measures and Healthy People 2030.

Finally, the authors offer a vision for what an equitable and connected data and measurement infrastructure could look like that allows community residents experiencing inequities, system change stewards, and policymakers to learn and create change together. A few building blocks for these are detailed below.

AN EQUITABLE PROCESS TO ACHIEVE EQUITABLE OUTCOMES

A system can only achieve equitable outcomes if equity in process is part of its DNA. There are several key steps to achieving equity in process, based on our experience working with hundreds of communities around the nation. This adapts the 100 Million Healthier Lives Communities of Solutions frame to the WIN Theory of Change:

- **Leading from within.** An awareness and acknowledgment among a critical mass of stewards in a community of how past legacies have contributed to current outcomes.
- **Leading together.** The integration of system stewards, community facilitators and community residents with lived experience of inequities in co-design, co-implementation and co-evaluation of efforts.
- **Leading for outcomes.** The use of disaggregated data with a focus on understanding how people who experience inequities in particular are doing; a focus on measures and data that matter and are accessible to local communities as well as infrastructure to support community residents to ask and answer their own questions about their community's well-being and equity.
- **Leading for equity.** A targeted universalism approach which prioritizes populations experiencing inequities for programming and investments as part of assuring the vital conditions everyone needs to achieve well-being.
- **Leading for sustainable system change.** An examination of new and existing policies and systems that reproducibly perpetuate inequitable outcomes or are needed to achieve or sustain equitable outcomes.

AN EQUITABLE MEASUREMENT SELECTION

Our proposed approach to measurement offers a menu that was derived from the input of 100+ organizations and communities who collaborated together to develop the Well Being In the Nation (WIN) measures and tested these measures in communities. These communities also gave input into what measures matter to them in the context of COVID-19. However, we suggest that a few common measures be adopted across communities, while the rest of the measures—as well as additional measures that communities identify are relevant for them given their context—be used to guide improvement efforts. Communities vary widely in context, assets and focus. A common measure of thriving and surviving, with equity breakdown, can be complemented with the relevant measures by vital conditions, using WIN as a guide. Finally, we propose that communities be given tools to assess their own progress toward equitable system transformation.

AN EQUITABLE DATA INFRASTRUCTURE

Measures cannot be divorced from the systems that produce them, and equitable measures are difficult to create if those systems are siloed, inaccurate, or inherently biased. Therefore, attention must be paid to the ecosystem within which measures are created and the stages of their development: the idea of collecting data in the first place, defining what is to be collected, how it will be collected and by whom, responsibility for storage and security, how the data will be interpreted and disseminated, and any other element of data use and governance.

At each stage of data collection and management, those involved have the opportunity to reflect values of equity and the principle that community members and people with lived experience are able to exert stewardship and control over their own and their community's self-understanding and -description through data. This is especially important as the data systems created by community collaborations and institutions become more complex and sophisticated. This infrastructure—defined as the software, hardware, and systems that allow data to be shared over multiple organizations and uses—is expensive to create and maintain, and is not typically responsive to community definition and voice. For data to be sustainably equitable, the processes that generate it will need to be equitable as well.

IDENTIFYING MEASURES THAT MATTER TO UNDERSTAND THRIVING

The COVID-19 pandemic and associated physical distancing policies have elevated awareness of the broad array of factors that contribute to thriving, and have illuminated equity gaps in which people and places have access to these factors. The pandemic has highlighted the importance of financial stability and meaningful work, social connectedness and support, trust in neighbors and in government, as well as physical, mental, and emotional health. Though inequities in these factors existed along racial and economic lines prior to the pandemic, it has both highlighted and exacerbated these inequities.

The United States has experienced higher rates of infections and deaths from COVID-19 among low-income and minority populations, as well as higher rates of unemployment and anxiety among these groups. As the United States and its communities prepare to emerge from the crisis set forth by the initial peak of the pandemic, it is paramount that we not only measure and track factors related to COVID-19 infection, but also the factors that contribute to equity and a high-quality life, as well as set up systems that promote better and more equitable outcomes in health and well-being in the future.

To develop a comprehensive measurement strategy that drives improvement in population health and well-being during both the response phase and the recovery phase—as well as the next 10 years as part of a larger equitable resilience phase—that leaves communities capable of responding to any pandemic, we must recognize that multiple factors and sectors affect the health and well-being of populations. As such, we must include holistic measures of health and well-being, such as thriving, in addition to measures of determinants or drivers of health and well-being, to guide recovery efforts and sustain equitable systems. Finally, all of these measures need to be evaluated using an equity lens that includes race, place, immigration status, and wealth. To drive collaborative improvement in population health and well-being, these measures must cross sectors; address economic and social determinants of health, well-being, and equity; and improve the health and well-being of people and of places.

EQUITABLY MEASURING THE HEALTH AND WELL-BEING OF PEOPLE AND PLACES

Measuring COVID-19

Measures that capture rates of new infections, severity of infections, and premature mortality from infections with SARS-CoV-2 are essential. In addition, measuring testing capacity is critical to monitoring and controlling spread. Also, tracking the economic and social effects of physical distancing policies is important to understanding fully tradeoffs being made between public health measures to manage disease spread and financial and social insecurity.

Measuring the well-being of people

The well-being of people captures and values how people think and feel about their own lives in a holistic, equitable way. We recommend using Cantril's Self-Anchoring Scale, a two-item measure of evaluative well-being that assess current life evaluation, future life optimism, and overall life evaluation, categorized into thriving, struggling, and suffering., This measure is well-validated and has been used to measure and track population well-being worldwide at the national level and within the United States at state and local levels for more than ten years. It is recommended by the OECD as a measure of population health and well-being. At the county level, thriving is associated with better population health outcomes.,,

We also recommend measuring other important domains of well-being, including perceived overall health, financial security, social connectedness, and sense of meaning and purpose in life. The 100 Million Healthier Lives Well-being Assessment is a brief tool composed of validated items to measure these different domains of well-being. These subjective measures of how a person is doing, in combination with an objective measure of health—life expectancy—provides a comprehensive picture of a population's health and well-being.

Measuring the well-being of places

Places (e.g., communities) provide the context within which the well-being of people may be achieved, and influences how easily well-being can be achieved. Understanding the well-being of places requires measuring the characteristics of places that contribute to placemaking and community life. These characteristics include the built and social environment. For example, walkability, perceived safety, and sense of belonging, as well as access to housing and reliable transportation, are several of the characteristics that describe a community and influence the health and well-being of the people who live there. To support communities in selecting measures of well-being of place, the National Committee on Vital and Health Statistics Framework for Community Health and Well-being adopted an index approach across the multiple domains of place.

Measuring equity

Eliminating differences in outcomes among different subpopulations is essential to achieving improvements in population health and well-being. Continually tracking key outcomes stratified by sociodemographic characteristics that have historically been associated with poorer health and well-being outcomes is paramount. As described above, COVID-19 disproportionately affected communities of color, and it is essential to track outcomes in these subgroups if we are to know whether interventions are succeeding in reducing these inequities. We recommend stratifying all of the above measures by age group, gender identity, preferred language, race/ethnicity, and education level or income. In addition to tracking measures stratified by sociodemographics, it can also be helpful to measure the upstream structural, programmatic, or policy factors that create, sustain, and influence equity gaps.

DEVELOPING A MEASUREMENT STRATEGY

MEASURING FOR OUTCOMES, IMPROVEMENT, AND SYSTEMS TRANSFORMATION

We recommend using three complementary measurement strategies: measuring for outcomes, measuring for improvement, and measuring for systems transformation. Measuring for outcomes refers to using measurement to assess whether the intervention has resulted in an intended change (typically comparing the magnitude of an outcome measure before and after an intervention). Measuring for improvement refers to rapid-cycle measurement to assess whether processes are leading to desired outcomes and allows for adapting interventions as needed along the way. Measuring for systems transformation refers to a multi-level measurement strategy that includes a suite of process and outcome measures to assess whether all parts of a whole system are working together towards achieving the common goal(s).

Measuring for improvement is usually done using sequential, frequent, observable tests using small samples. The goal of measurement for improvement is to assess whether changes are actually leading to improvement. A measurement strategy for an improvement initiative involves tracking a parsimonious set or family of multiple measures (e.g., outcome, process, and balancing measures) with the data collection occurring frequently (e.g., monthly) to allow learning from rapid changes in support of improvement. Selecting a small, highly relevant set of measures that really matter to people is ideal, as is integrating data collection and tracking into usual workflow as best as possible. This measurement is best supported by the use of visual displays of data over time that inform and motivate improvement efforts (e.g., lead to adaptation of an activity).

In contrast, measuring for outcomes is performed less frequently and among a larger number of participants. The goal is to assess an outcome for an entire population. For this purpose, it is important to get information from all participants (whole cohort) or from a random sample of participants that can approximate results from all participants.

Measuring for whole systems transformation involves selecting and tracking measures that catalyze and sustain improvement in how community outcomes are produced. This involves choosing measures that drive collaboration across sectors and includes process and outcome measures as well as short- and long-term measures. Complementary measures are selected at multiple levels to assess each person's, site's, department's, and/or sector's contribution to the shared goal. In addition, variation in performance among sites can be identified and addressed.

Measure subjective and objective outcomes

To measure what matters, a measurement strategy will include not only objective measures (e.g., mortality rates from SARS-CoV-2 infection, income inequality) but also subjective measures (e.g., perceived safety, sense of belonging). Moreover, a holistic measurement strategy that supports "whole person, whole system, whole community" improvement will include measures of overall well-being (e.g., overall life evaluation) in addition to measures specific to a particular outcome or process (e.g., daily new COVID-19 diagnosis rate; social support)

Measure with passive versus active data collection

To design a measurement strategy that maximizes efficiency and reduces burden, we recommend using passive data collection when possible. Passive data collection utilizes data that are already being gathered for another purpose. Repurposing data that is already being collected is an efficient way to inform existing efforts.

It is important, however, to recognize that there may be limitations on how these data can be generalized and interpreted based on the mechanism by which they are collected for their originally intended purpose. We recommend performing a landscape analysis across sectors to understand what data are being collected that can also serve the current purpose, and then leveraging these data to contribute to the overall measurement strategy (e.g., using food purchase data). Then any available resources for active data collection (e.g., surveying) can be allocated to collect complementary and highly important data, such as assessing subjective well-being.

Measure at multiple levels

Thriving for people and places is fostered or undermined by factors at multiple levels, from the community and systems levels to the interpersonal and individual levels. To understand the system of factors that are influencing thriving, and how improvement activities are changing them, it is essential to measure at multiple levels. Choosing measures that assess thriving at the individual level (i.e., residents' overall life evaluation), interpersonal level (i.e., levels of social support), community level (i.e., social capital, sense of belonging to community), and systems level (i.e., organizational collaboration) provides a mechanism to monitor that all of the interconnected parts of a community are being leveraged to collectively foster thriving.

When selecting measures, consider the below criteria adapted from National Quality Forum Measure Evaluation Criteria.

Category	Specific Criteria
Important	Potential to drive improvement in health Potential to drive improvement in social drivers of well-being Potential to drive improvement in equity Aligned with major national/global strategy Potential to develop new knowledge about what creates well-being
Objective & effective	Strong evidence that this improves health, well-being, and equity Valid Reliable Benchmarking available

Category	Specific Criteria
Feasible	Data already collected, analyzed, and/or reported Cost of additional collection/availability of resources to support collection Burden of collection and reporting Groups ready to adopt
Usable & useful	Timeframe within which data changes Timeliness of data availability Usefulness to communities Usefulness to researchers/national stakeholders Meaningfulness to people with lived experience Level of data availability

MEASURING WHAT MATTERS IN THE CONTEXT OF COVID-19

Measures that matter in the context of the COVID-19 and associated physical distancing policies include measures that can drive improvement in the on-going response to the pandemic, improvement in inequities, and improvement in conditions that support community recovery, resilience, and transformation.

POTENTIAL TO DRIVE IMPROVEMENT IN RESPONSE TO COVID-19

To drive collaborative improvement in response to COVID-19, we recommend selecting measures that: include outcomes that matter across sectors, address economic and social determinants, and improve health, well-being, and equity of people and places. A measurement strategy that includes both health and well-being of people supports an integrative approach to monitoring outcomes such as mortality from COVID-19 and the economic and social implications of policies to limit spread of infection. Including well-being of place allows communities to understand how place-based factors both affect risk related to COVID-19 and are affected by COVID-19.

In selecting measures, consider those that assess the vital conditions for community health and well-being: basic needs for health and safety (e.g., COVID-19 testing, COVID-19 outcomes), humane housing (e.g., conditions, stability), reliable transportation (e.g., access, safety), thriving environment (e.g., drinking water safety, energy use), meaningful work and wealth (e.g., employment, small business closures), and lifelong learning (e.g., access to high quality childcare, equity in access to distance learning).

POTENTIAL TO DRIVE IMPROVEMENT IN INEQUITIES

Given the inequities that the COVID-19 crisis has not only illuminated, but also exacerbated, it is essential to include measures that assess equity over time and drive improvement in inequities. To assess equity, we recommend developing a measurement strategy in which process, outcome, and balancing measures are disaggregated or stratified across sociodemographic characteristics (e.g., race, ethnicity).

We also recommend measuring racism as well as upstream structural factors that create and maintain inequities. If communities do not pay close attention to inequities in health, well-being, and their determinants, their COVID-19 recovery efforts could maintain, or even worsen, existing inequities. Alternatively, if mindful, communities can use this crisis as an opportunity to improve systems to create and sustain gains in equity over time.

Potential to drive improvement in the vital conditions that support community recovery, resilience, and transformation

In striving for community recovery, resilience, and hopefully long-term transformation, communities may measure aspects of their community that support their efforts. The sense of belonging and civic muscle within a community can support recovery, resilience, and transformation. Measures to assess belonging and civic muscle might include measures of social connection, cohesion, and capital; loneliness and social isolation; financial stress and well-being; trust in community and government; discrimination, tolerance, and hate; and volunteerism and voting, among others.

In addition to belonging and civic muscle, other levers to create and strengthen community resilience have been described in the setting of recovery from natural disasters, and these levers can be adapted for recovery from the current pandemic as well as preparation for any future threats to population well-being. Physical resilience of people (i.e., physical health) and of places (i.e., infrastructure systems), psychological resilience (i.e., mental and emotional health), and organizational resilience (i.e., have built in redundancies and are capable of adapting quickly) have been described as key components of community resilience.

Other important levers for community resilience include measures aligned with the vital conditions, such as access to care, education (i.e., effectively informing the public of risks and preparedness), housing (including housing density), access to meaningful work and wealth, and civic infrastructure (i.e., promoting participatory decision-making). Using data to measure levels of resilience across each of these levers, and then tracking these data over time to drive improvement in each of these levers creates the vital conditions that support health and well-being of a community and that withstands threats to the health and well-being of that community.

BALANCING PROCESS AND OUTCOME MEASURES

To encourage community transformation, we recommend a measurement strategy that includes a balance of process and outcome measures. Process measures that support transformation include those that assess and track elements of community transformation frameworks such as Collective Impact and Community of Solutions., These include process measures such as development of stewardship, community engagement, and numbers of system changes implemented. Outcome measures that drive transformation include changes in percentage of population thriving, struggling, and suffering; years of potential life gained for populations at risk; mortality rates from COVID-19; and composite metrics such as health adjusted life expectancy or well-being adjusted life years (in development).

In selecting outcome measures, we recommend considering measuring outcomes related to COVID-19, well-being of people, well-being of places, and equity. We have highlighted measures that should be part of a core measure set below with an asterisk. Here is a table with selected measures to consider in each of these areas.

Area	Outcomes to Consider	Measures to Consider
COVID Outcomes	COVID-19 mortality*	Mortality rate from COVID-19
	Years of potential life lost due to COVID-19*	Years of potential life lost before age 75 attributed to COVID-19
	COVID-19 testing*	Rates of COVID-19 testing
	New COVID-19 cases	Daily rates of new COVID cases
	Excess unemployment *	Unemployment rate above expected based on historical trends

MEASUREMENT, LEARNING & EVALUATION

Area	Outcomes to Consider	Measures to Consider
Well-being of People	People's perception of their own well-being*	Cantril's ladder: • Mean current life satisfaction • Percent of people thriving, percent of people struggling, percent of people suffering
	Life expectancy*	Life expectancy at birth
	Hopefulness*	Cantril's ladder: Mean difference between future life optimism and current life satisfaction; percent of people with future life optimism greater than current life satisfaction
	Social support*	Percent of adults 18 years and over who report not receiving sufficient social-emotional support
	Social isolation*	Percent of adults reporting feeling lonely
	Racism*	Percent of adults who have felt emotionally upset, for example angry, sad, or frustrated, as a result of how they were treated based on their race in the past 30 days
	Mental Health*	Deaths of despair: Deaths due to drug overdose, alcohol, or suicide (# per 100,000 population)
	Substance use*	Rates of binge drinking or rates of ED visits and hospitalizations for alcohol intoxication and opioid overdose
Well-being of Places related to the Vital Conditions	**Basic Needs for Health & Safety:** Child poverty rate*	Percent of population under age 18 living under 100 percent of the federal poverty level
	Basic Needs for Health & Safety: Social/policy protections	Number of people receiving public benefits (e.g., unemployment, SNAP benefits, free/reduced lunch)
	Basic Needs for Health & Safety: Food insecurity	Percent of population who state that within the past 12 months were worried that food would run out before having money to buy more
	Lifelong Learning: High school graduation rate*	Percent of students who graduate high school within 4 years of entering 9th grade
	Lifelong Learning 3rd grade reading level	Percent of students entering 4th grade who are at age-appropriate reading level
	Lifelong Learning, Basic Needs for Health & Safety, Meaningful Work and Wealth Access to internet*	Percent of people with access to high-speed internet or smartphone
	Meaningful Work and Wealth: Unemployment rate	Unemployment rate: percent of civilian labor force, age 16 and older, that is unemployed but seeking work
	Meaningful Work and Wealth: Financial insecurity*	Percent of adults who would still be able to pay all of their current month's bills in full if faced with a $400 emergency expense
	Meaningful Work and Wealth: Childcare	Availability of childcare (measure in development)
	Humane Housing: Household size	Number of people residing in a household
	Humane Housing: Homelessness	One-day sheltered homeless rate (number per 10,000)
	Reliable Transportation: Access to transportation	Percent of people commuting by each: car, foot, bike, public transport, and working from home
	Belonging & Civic Muscle: Trust in government*	Percent of adults who trust and have confidence in the local governments in the area where they live when it comes to handling local problems
	Belonging & Civic Muscle: Trust in police*	Percent of adults who trust their local police department to make decisions that are good for everyone in their city
	Belonging & Civic Muscle: Voting rate	Percent of total voting- age citizens who cast votes in the most recent mid-term or presidential election
	Belonging & Civic Muscle: Community belonging*	Percent reporting strong sense of belonging to community

Area	Outcomes to Consider	Measures to Consider
Equity	Differences in COVID-19 mortality rates*	Mortality rate from COVID-19, stratified by differences in demographic factors
	Differences in premature death from COVID-19 and in general*	Years of potential life lost attributed to COVID-19 and in general before age 75, stratified by differences in demographic factors (per 100,000 population)
	Differences in rates of new COVID-19 cases	Daily rates of new COVID-19 cases, stratified by differences in demographic factors
	Differences in rates of COVID-19 testing	Rates of testing for COVID-19, stratified by differences in demographic factors
	Differences in excess unemployment*	Unemployment rate above expected based on historical trends, stratified by differences in demographic factors
	Area deprivation index or social vulnerability index*	Multidimensional evaluation of a region's socioeconomic conditions, which have been linked to health outcomes
	Differences in hopefulness	Hopefulness, stratified by differences in demographic factors
	Income inequality	County GINI coefficient for income inequality
	Differences by sociodemographic factors in other measures that matter*	Race/ethnicity, age, place (zip code), urban/rural, gender identity, primary language, educational attainment

To identify other measures to include in a measurement strategy to optimize community response to, recovery from, and transformation through COVID-19, we recommend using the Well-being in the Nation measure set as a resource, particularly for measures of vital conditions for well-being. Example measures include overall health (percent of adults self-reporting fair or poor general health), early education (percent of 4th-grade students reaching "proficient" or above in English Language Arts standardized test), built environment (Walkability Index), and public safety (percent of adults who feel safe walking on their street after dark), among many others.

MEASURING SYSTEM CHANGES

> *"Every system is perfectly designed to get the outcomes it gets." —Dr. Paul Batalden*

Current systems structure in the United States created the context within which SARS-CoV-2 was able to rapidly spread among a population with high levels of chronic disease, leading to massive rates of infection and death, as well as stark inequities along racial and economic lines in these rates of infection and death. To alter these trends, systems transformation is necessary not only in the near term to prevent spread of infection, but also to set up for successfully achieving the goal of better and more equitable population health and well-being outcomes over the next ten years. Measurement should be used to constructively guide this transformation. Strategically choosing measures that catalyze cross-sector collaboration, such as thriving, increases likelihood of success over time.

Whether it is educating fourth graders, increasing access to green spaces for exercise and socialization, caring for the elderly, or providing access to safe, efficient, and reliable transportation—every sector understands what they can contribute to creating a thriving community, making it easier for us all to work together to achieve a shared goal. In addition, having more proximal measures relevant to each sector is also important in order to understand whether planned progress within each sector has intended effects both on the sector-specific measure(s) and on the shared goal of increasing percent thriving.

We recommend choosing, measuring, and tracking process and outcome measures over time that are inclusive of all collaborating sectors to create a "learning management system" that uses harmonized data shared transparently to work together to achieve a common goal of creating an equitable, thriving community.

This learning management system can inform the journey towards a thriving community, with guideposts designated by tools such as the community transformation map or the AACT tool. These self-assessment tools, which have been tested in 100+ communities each, offer a readiness-capability model for communities on the journey to equitable processes and outcomes. Rather than asking communities to assess whether they are equitable on a Likert scale, they integrate an understanding of what improvement looks like into the tool itself, with links to resources for communities to advance their outcomes. For example:

- Are community residents with lived experiences of inequities integrated through surveys? Focus groups? Part of the improvement team? Co-leading work and helping to set priorities and identify solutions? Each of these might represent a different stage of development.
- Similarly, who has access to the data for the community? Is it understandable at a 5th grade level? Who helps to interpret it? Who helps to set priorities for data collection?

Most communities desire to be equitable, but have not mapped the processes they would need to follow or set goals around these. Tools like the CTM, which are useful to communities and can be leveraged for evaluation, help to bridge this gap.

Each community has different capacities and capabilities for measurement that range from minimal to robust. At minimum, we recommend selecting and tracking meaningful measures that are passively being collected across as many sectors as possible. Stratifying these measures by sociodemographic characteristics that have been historically associated with inequities is critical. If possible, we also recommend obtaining other relevant objective measures (e.g., COVID-19 testing rates) and subjective data (e.g., perceived well-being). These measures should be obtained as frequently as possible to be able to monitor trends over time. They should then be reviewed among a community-wide, multi-stakeholder, cross-sector collaborative to implement changes to improve selected measures.

An example worth noting comes from the Delaware Department of Substance Abuse and Mental Health, which used well-being measures in real time to identify who in their population might not be thriving, and in what domain. By assessing Cantril's ladder and additional questions related to financial insecurity, loneliness, and social support, they were able to identify a substantial increase in suffering in these areas. They rapidly mobilized to provide support—from unemployment benefits to housing, to legal aid, to peer supports—and have now watched the percentage of people suffering return to close to baseline.

BUILDING AN EQUITABLE AND CONNECTED DATA AND MEASUREMENT INFRASTRUCTURE

Much has, and should be made, of the need to create and use standardized measures of health, well-being, and equity. Less attention, however, has been paid to the source of those equitable measures. We outline below the principles of equitable and connected data and measurement infrastructure.

Equitable ownership and access

An equitable and connected data infrastructure is necessary to support the systems that address individual suffering and development as well as to support the policy and system change toward a society that prioritizes well-being. Equitable data systems are those that reflect the operational and measurement priorities of those who use them, including persons with lived experience, the organizations that work with them, their partners in program operations and data exchange, and their funders, public or private. The key to making equitable and connected data instratructure is to ground all aspects of the system development and use the experience and control of the people and communities whose experiences are documented in the systems.

The role of connected data systems is to support a variety of functions, such as assessment, service delivery, resource and referral management, reporting, advocac,y and measurement. Communities across the country are at all different stages of system development, from gathering and planning to full-fledged multi-sector data interchange. These data "systems" range from simple shared spreadsheets to sophisticated community information exchanges, and usually begin in response to a local expression of a need or opportunity felt by multiple people in a single community. Examples include community dashboards and engagement platforms, geographic hotspotting and targeting, platforms that support universal needs screening and community resource referrals, open data initiatives, integrated data systems, and health and community information exchanges.

For many community-based health and human service organizations, their first exposure to data management systems was primarily for funder metrics reporting. For organizations that have been able to piece together components of a "client information system," they are often required to maintain multiple systems that require duplicate data entry, have limited internal reporting tools, and allow for no interconnection between them.

This tradition of providing community-based organizations with technology that benefits external partners to the exclusion of the CBO continues with the rash of information and referral platforms that enable health care entities to interact with social service providers. Typically, the value of those connections is realized by clinical providers that provide the system, because access to the software does not typically come with additional resources for the services provided or for the participants being referred. Equitable ownership and control over data is proposed as an equalizer. These points are addressed further under data sharing agreements and protections below.

Data infrastructure for coordinated response and resilience

An equitable data and measurement infrastructure should enable coordinated response across sectors to support individuals and families and tracking of data at a local level to see if areas with historically poorer outcomes are catching up. Unfortunately, there are serious limitations to existing data. The US Small-area Life Expectancy Estimates Project (USALEEP) data demonstrate dramatic differences in life expectancies across small distances. Similarly the COVID-19 pandemic has laid bare extreme inequities in vulnerability to exposure, morbidity, and death.

Sharing data across sectors for coordinated response is hampered by trends we have already seen in the sharing of health care data (data silos, lack of standards, lack of will to share with market competitors, top down approaches, inadequate legal framework) and made worse because leaders in different sectors lack a shared language and vision. Most importantly, there is little financial incentive to share data, which drives *trade-offs* between:

- Granularity and timeliness: Data collected at a local level is often averaged over multiple years, or not collected with sufficient frequency to measure change over time
- Granularity and precision: Small numbers lead to wide confidence intervals and inability to make inferences about differences in estimates over time and place.

Local data may not exist for rural areas or small towns: having a sufficient sample requires including a larger geographic area—averages thus do not represent localities

To address current weaknesses, we recommend maximizing the use of connected data systems composed of data collected in the course of providing services, and investment in systems to collect hyperlocal data directly from community members and people with lived experience.

Connected data systems

Frequently, measurement for improvement takes advantage of data generated as part of operations. Data are collected from individuals and families in the course of providing health, social, educational, or other services. Increasingly, health care, public health, community based organizations and others are connecting these data systems as they work to build systems of care across sectors that address the health and social needs of individuals and families in a coordinated manner. Such data allow service providers to screen for multi-faceted health and social needs, make referrals across sectoral boundaries, divert people from inappropriate settings (such as the criminal justice system or emergency departments) to address the underlying issue, among other benefits.

Where developed and integrated, these connected data systems have been applied to respond to the COVID-19 pandemic.

- LA County redirected their data hub to begin focusing on the response to the virus and related factors by: identifying homeless clients with a positive COVID-19 diagnosis to limit contact and promoting safe isolation practices, informing shelter workers of a positive COVID-19 diagnosis so that they can take appropriate precautions.
- Allegheny County has developed internal and public facing dashboards to monitor the impact of COVID-19 on the county's most vulnerable residents. Examples include a public facing dashboard that monitors calls to child welfare, calls for housing assistance, calls for involuntary commitments, calls for older adult protective services, etc.

- Children's Optimal Health in Austin is working with United Way to analyze the 211 data to understand the requests for assistance they are receiving. They are creating a set of maps for a multi-county area looking at requests by ZIP related to housing, food, utility assistance, health care, unemployment, financial assistance, and possibly other areas. We are tracking need requests as they change over time.

While there are bright spots such as these described above, it is important to note that data systems supporting health and social service screening and referral also have significant limitations: the majority of initiatives do not have a sustainable funding source; and many efforts originated by health care entities do not prioritize equitable participation of community residents or community based service providers.

Importantly, these systems should not be used to create narrow networks, new data silos, or require community based organizations to participate in multiple platforms; they should facilitate measurement at the community (population) level, not only for a specific set of clients or patients.

Collecting Hyperlocal Data

Community dashboards that include visualization and mapping are an important component of a data ecosystem for measuring well-being and addressing the immediate and long-term needs of a resilient community. There are many examples of such dashboards being leveraged for responding to COVID-19 and documenting resilience for the future. Open data initiatives are important policy and infrastructure components enabling these dashboards.

Western Pennsylvania Regional Data Center maps assets available for COVID-19 response, using a dataset originally developed for Census 2020 outreach. The Data Center provides a technological and legal infrastructure for data sharing to support a growing ecosystem of data providers and data users; it maintains Allegheny County and the City of Pittsburgh's open data portal, provides a number of services to data publishers and users, and is managed by the University of Pittsburgh's Center for Social and Urban Research, a partnership of the University, Allegheny County and the City of Pittsburgh.

Data sharing and agreements

Effective and collaborative data sharing depends on the cultivation of authentic relationships with clearly defined use cases for sharing data. Self-determination is a collective human right that ensures personal freedom to make decisions about an individual's data. The design of equitable data agreements to protect the individual while enabling meaningful cross sector collaboration is critical. Data use and consent require substantial investments in the mindful creation of policy leveraging the existing legal and regulatory framework. This complicated process to identify the applicable laws for the persons involved, the data sharing partners, the data itself, and the particular use case is lengthy.

Data sought is often governed by consent to share. Privacy and data sharing policies and laws are constructed to protect individuals and individual health data. When equity and well-being are centered on a person and their data is utilized to support the ultimate goal of health and well-being, community organizations are better able to provide the supports needed to meet that individual where they are.

Community based organizations share a collective commitment to mission and vision that drives the need for person-granted access to data. For example,

> *"If the COVID-19 response is to be effective, it must be underpinned by robust science and quick access to data. Some of this data will constitute personal data and so be regulated by data protection rules. (It is important to note that data that is not personal may be shared freely, as far as privacy and data protection law are concerned, but must still be done in a way that is ethical, compliant with human rights, and public trust.)"*

Attention to the Social Determinants of Health (SDOH) have expanded the interest in non-medical personal data to identify key factors that contribute to access and availability of resources for health and well-being. Types of data sharing (i.e. individual level or population level) will identify data sharing platforms, existing agreements, and key governmental or non-governmental partners that can be helpful. Data sharing and agreements are critical to extend these protections in communication with partners. Cross sector organizations likely have unique data, systems, reporting and agreements that govern each.

> Advancing Data-Driven Partnerships: Accountable care organizations, accountable communities for health, and the federally-driven CMMI AHC model (mentioned above) are all emerging examples of data-driven partnerships between health providers and CBOs. A July 2017 national request for information (RFI) survey, carried out by the Scripps Gerontology Center at Miami University, discovered that nearly half of the 593 responding CBOs already have or are pursuing partnerships with healthcare providers. Many of these partnerships have established some form of data sharing that enables the CBO to share data about client referrals with the health provider. For example, a Washington accountable care organization is receiving data through dashboards hosted as part of the state's Analytics, Research and Measurement (ARM) strategy.

In the context of well being and health equity the role of existing legal and policy constructs can serve as guideposts to determine what rules apply, how to be compliant and how these can be the foundation to build upon new community focused data sharing agreements.

THE VISION FOR DATA INTEROPERABILITY

A lack of interoperability hinders data sharing within health care and across human service sectors. Interoperability is "the ability of different information systems, devices and applications ('systems') to access, exchange, integrate and cooperatively use data in a coordinated manner, within and across organizational, regional and national boundaries, to provide timely and seamless portability of information and optimize the health of individuals and populations globally."

Achieving interoperability is a compelling vision but many barriers must be overcome for it to be realized. Data do not in fact flow seamlessly across sectors. Efforts are underway to develop standards where needed, promote adoption of standards and map concepts and data elements across domains. For instance, health care systems have not traditionally measured social factors such as housing status, transportation needs, or food insecurity. The Gravity Project seeks to standardize definitions and codes to store these data within health care data systems, and then produce implementation guides. Implementing the codes will require policy and funding. As new software systems expand explicitly to collect social determinants data for exchange between health and community services, it is important to ensure that those systems don't also create new data silos and barriers to interoperability.

Within human and other community services, efforts are being made at Federal and state levels to standardize around the National Information Exchange Model (NIEM). This work requires commitment and investment to update many legacy systems. As that proceeds, connecting across NIEM and health care standards will be a challenge. "As NIEM's adoption continues to expand, non-clinical NIEM domains that utilize health data elements for information exchange will require support to successfully navigate through the complexities of the health IT/health information exchange (HIE) environment. Furthermore, operational health IT/HIE safeguards must be in place to ensure the legal, secure and private exchange of health information." The National Interoperability Collaborative seeks to demonstrate further that it is possible to map data items between health care data standards and NIEM.

INDIVIDUAL AND COMMUNITY PROTECTIONS TO ENSURE RESILIENCY

While shared data systems have the capability to inform better interventions, they can also exacerbate inequities. Practitioners must go further to identify root causes to the inequities we see reproduced in data, and form interventions that address and protect. These interventions, which also include legal and data protections, are constantly evolving, with some emerging out of the COVID-19 epidemic. Though we may be well intentioned in our pursuit for equitable data, below are common examples of how inequities can be reproduced in a data system, and ways they can be addressed.

For multi-sector data sharing, the goal is to connect data that appears in siloes or that one sector would not have had access to without a partnership or data-sharing agreement in place. Because of the nature of one-dimensional data, sectors may have a hard time agreeing on what to report, what to collect, etc. The UK Department for Digital, Media, Culture & Sport recommends interrogating these questions at the onset of the data collection process by demonstrating clear intent and public benefit.

Protections challenge our notions of who needs access to what data and why. As digital technology and its use as a data collection tool become widespread, more and more communities ask about their privacy. Actionable Intelligence for Social Policy recommends looking at a data sharing initiative's benefit and risk along an axis grid, with those actions being considered a high-benefit to society and a low risk to vulnerable populations being most ideal (such as mapping initiatives that allocate resources to high-need communities); and steering away from low-benefit, high-risk behaviors such as sharing social media activity to local law enforcements.

Even more so important during the COVID-19 pandemic, policy can enforce or push for certain reporting criteria. This is with the caveat that some data sharing endeavors can be low-risk, high-benefit, and others can have a high risk (which we want to avoid). An example of a low-risk and high-benefit data sharing move is the push by Data4BlackLives to record open data reported by race during the peak of COVID-19 cases in the United States. Explicit reporting by race lets practitioners and researchers alike understand disparate impact and potential reasons. Strategies such as these, in turn, allow public servants to see what short-term (i.e. providing PPE to essential workers) and long-term (increasing funding to hospitals, staffing capacity in a heavily impacted area) interventions are possible, feasible, and equitable.

Among all of these recommendations is the suggestion to continue to involve community members in the data sharing and collection process. Ensuring that the language and technology we use is accessible to all will increase the potential for vulnerable populations to be able to have power over their data and its impacts. Creating and maintaining equitable data systems is an active process. The data we use must measure how successful our policy and programmatic changes have been; as well as continue to develop baselines and progress points towards community goals. As such, data harm mitigation practices can offer an opportunity to rethink what community engagement and public access can look like.

THE PATH FORWARD

Recommendations for a learning measurement system to support a resilient and equitable health and well-being strategy

We have been learning at an unparalleled pace in the context of the COVID-19 pandemic, which has resulted in not only massive shifts in public health and health care, but also in the economy, modes of social connection, and mental health. The sections above outline specific recommended measures for thriving, struggling, and suffering, as well as for an equitable measurement process and equitable data infrastructure to support resilience. We recommend:

- A small set of common measures to assess overall outcomes, along with a menu of measures based on the vital conditions, with additional measures available in the WIN measures and other sources that relate to the vital conditions for well-being.
- A balance between people reported outcome measures to assess thriving, struggling, and suffering, using tools such as Cantril's ladder, and objective measures such as years of life lost or gained.
- An equitable process by which communities identify measures that matter among the vital conditions that relate to the context of their communities.
- A process for communities to assess their own journey in equitable transformation.
- The development of an equitable data infrastructure that is accessible to community residents, connected and interoperable across sectors, and equitably governed.

A Springboard for equitable recovery and resilience would be incomplete without an equitable learning and measurement system across sectors and that can help us learn quickly and adapt our systems rapidly. To support the development of such a system, we recommend that Congress invest in the development of an equitable data and measurement infrastructure across communities with a focus on communities that are most affected by inequitable outcomes from COVID-19 and underlying social vulnerability.

In addition, we recommend that the Federal Data Strategy and measurement approach be aligned to give communities the supports they need. In particular, we recommend that:

- Federal data, gathered at taxpayer expense, needs to be publicly available and accessible in an equitable way to local communities, meaning at the sub-county level or lower.

- The input of communities and other cross-sector stakeholders should drive national priorities in the federal data strategy, in addition to the input of federal agencies.
    - This includes what data is accessible to support measurement, based on a process that has received substantial input from communities and nonfederal stakeholders, such as Well-Being In the Nation measurement framework (which includes data related to the County Health Rankings and Roadmaps and the US News and World Report Healthiest Community Rankings) and the measures included in this Springboard.
    - Where analytic capability is focused to collect and make data available at the local (sub-county) level.
    - How data are made available for sociodemographic subpopulations to assure that we can understand disproportionate harm as well as opportunities.
    - How data is available at the local level to support national objectives, such as those captured in Healthy People 2030.
- Identification of data priorities should be based on fair and equitable processes, and ideally a public-private partnership, such as the one conducted for the development of the Well Being In the Nation measures to identify these priorities.
- Data availability and capacity-building for local communities to use the data be achieved through public-private partnerships in collaboration with federal agencies.
- Protections be put into place to assure that data cannot be used to target a population or individuals in any way that would adversely impact their well-being.
- Passive data be utilized, with consent from people whose data it is and that such data be made publicly accessible in the commons.
- Use of algorithmic based data be approved by a data equity expert before being used or supported by federal or state dollars.