POSSIBILITY

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ICPSR Working Paper 2:
Best Practices for Measuring the Social, Behavioral, and Economic Impact of Epidemics

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This report reviews best practices for using data resources from ICPSR, its projects, and its collaborating partners for measuring the impact of epidemics. The report summarizes resources to identify measures of well-being, social connectedness, and other constructs to measure the social and behavioral effects of the COVID-19 epidemic on population health outcomes. The report suggests data resources to identify pre-crisis measures of social distancing, social networks, consumer confidence, unemployment, and the use of social media.

ICPSR Working Paper 2:
Best Practices for measuring the social, behavioral, and economic impact of epidemics

James W. McNally, Ph.D, Director, National Archive of Computerized Data on Aging (NACDA)
Kathryn M. Lavender, BA, Project Manager, NACDA
Margaret C. Levenstein, Ph.D., Director, Inter-university Consortium for Political and Social Research (ICPSR)

Contributors to this report include:
Libby Hemphill
John Marcotte
A. J. Million
Susan Jekielek
Amy Pienta
Sarah Rush
Michael Traugott

Introduction

The Role of the ICPSR Data Repository in Measuring the Impacts of Epidemics

ICPSR has a wide range of data resources on well-being, mental health, social networks, employment, access to care, and other key measures of resilience to crises such as epidemics. This report provides a brief overview of some of the data sets that examine these issues. In general, the most helpful data sets are those that were recently fielded (within the past five years) and which are routinely re-collected. In this brief overview, we focus on identifying a set of key terms that are commonly used in survey administration by multiple studies. Specifically, we identify studies that ask questions about "quality of life," "happiness," "crisis management," "general health," and "mental health."

- In terms of mental health, we review available data that use one of two standardized well-validated scales -- the Kessler 6 and the Center for Epidemiological Studies Depression (CES-D) scale. Commonly used in research, both the scales are easy to administer and well-validated across different populations and racial groups. The Kessler 6 is particularly useful as it is often taken as a proxy for community anxiety and is asked annually in studies such as the National Health Interview Survey.

- Quality of Life and happiness are more broadly defined constructs of well-being where data and measurement guidelines exist.

- Crisis management information is generally collected to measure financial hardship, loss of a job, or difficulty in paying for bills for medical care, so we find considerable consistency in question text across studies.

- Social network measures and reports of social isolation allow better understand

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of how social networks adapt to social-distancing requirements and the pre and post-term impacts of social isolation on physical and mental health and socio-economic indicators of crisis and, hopefully, recovery.

As a data repository for a wide range of major social science surveys. ICPSR has established relationships with major survey organizations who might add topical questions to ongoing data collection samples, allowing for a nimble response to emerging topics such as the COVID-19 outbreak. This includes   sudy data available from ICPSR on Hurricane Katrina and its impact on the southern United States. Katrina presents the most recent major disaster of note in the US, for which there is a considerable body of information and evidence. The Hurricane Katrina study might offer a useful comparison on crises behavior given its attention to crisis behavior and measurement. ICPSR's collections cover a wide array of international data sets, such as the HRS sister studies in Europe, Costa Rica, and Asia. International comparisons could be made based on these data resources.

Among the most useful studies to measure change before, during, and after the COVID-19 outbreak in the US are the routinely collected national studies such as the National Health Interview Survey, National Health and Nutrition Examination Survey (NHANES), and Behavioral Risk Factor Surveillance System (BRFSS). These studies routinely collect key measures of quality of life, mental health, and challenges currently being faced by economic or social conditions. A large number of federally funded surveys also offer useful measures across time. Just a short sampling of these studies includes the Survey of Consumer Attitudes and Behavior, Panel Study of Income Dynamics (PSID), Study of Women's Health Across the Nation (SWAN), Hispanic Established Populations for Epidemiologic Studies of the Elderly (EPESE), National Social Life, Health, and Aging Project (NSHAP), Midlife in the United States (MIDUS), and Americans' Changing Lives (ACL). Measuring the impact on adolescents would be possible

thorug Monitoring the Future (MTF).

This report provides details on these data and numerous other studies managed and distributed by NACDA and ICPSR. We offer examples of variables and concepts found across multiple studies and multiple years that can provide baseline information on pre-COVID-19 social behaviors. This report also provides guidance on how to search for specific topics using the ICPSR generated search tools. Finally, we offer information on how to obtain these data for research purposes. Our hope is this information will be valuable in identifying key baseline measures of social behavior, health, and employment before the COVID-19 epidemic, and this information can allow us to evaluate challenges and recovery once the crisis has passed. Both NACDA and ICPSR remain available 24 hours a day, 365 days a year, to assist researchers in locating and obtaining data related to their research. If any researcher has any questions on this report or any ICPSR related matter, we encourage you to reach out to us at the ICPSR help desk: ICPSR-help@umich.edu, or the NACDA help desk: icpsr-nacda@umich.edu.

Statement of the Problem

The COVID-19 pandemic presents research challenges for how we measure governmental, community, and population responses to a crisis. In other emergencies, we have utilized experiences based upon observed outcomes from past natural or human-caused disasters such as hurricanes, floods, earthquakes, outbreaks of malaria or cholera, and population displacement caused by civil upheavals. COVID-19 represents a unique case because it is a new virus with a novel impact profile and a long latency period. While there have been studies of coronavirus in the past, fundamental research into the population impact from this strain requires new information. "The Common Cold Project: 5 Studies of Behavior, Biology, and the Common Cold" (ICPSR 36365) study, for example, does look at coronavirus, but it is not directly applicable as it examines the 229E (alpha coronavirus) variant rather than COVID-

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19.

Similarly, the National Center for Health Statistics (NCHS) collects highly relevant data (much of which is available from NACDA) such as the National Hospital Discharge Series (NHDS)_ (see www.icpsr.umich.edu/icpsrweb/NACDA/series/43) or the National Ambulatory Medical Care Survey Series (see www.icpsr.umich.edu/icpsrweb/NACDA/series/37) routinely include the ICD code for coronavirus as a potential diagnostic outcome. The rarity of this diagnosis makes these cases of little research interest, and again, they do not address the current coronavirus variant affecting populations worldwide. The new ICD-10 code (U07.1) for COVID-19 will not be formally employed until April 1, 2020 (CDC, 2020).

The National Hospital Care Survey (NHCS) is a new NCHS survey that integrates inpatient data formerly collected by the NHDS with the emergency department, outpatient department, and ambulatory surgery center data collected by the National Hospital Ambulatory Medical Care Survey (NHAMCS). It is possible to link these survey data to the National Death Index and Medicaid and Medicare data to obtain a more complete picture of patient care.

Detailed and significant studies of the spread, containment, and treatment of COVID-19 will become available in the coming months and years, but our ability to extrapolate from past epidemics is limited. Drawing parallels to outbreaks, such as the 1918 Influenza Epidemic (Barry, 2004) and even the Black Plague (Schelden, 2020), can provide insight, but transformative changes in medical care, social behaviors, ease of transportation across borders, and our ability to operate on a 24-hour news and communication cycle all make the current pandemic unique. As such, it require novel approaches to measurement of outcomes and adaptation.

While the biomedical and epidemiological measures that will capture the full extent of the COVID-19 virus are being collected even as we speak, the social and population-level impacts

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of the response to this outbreak are of equal importance. Addressing this need requires a comparative research framework that examines pre-epidemic social behavior and compares it to post-epidemic behavior. Researchers are already building a thorough understanding of the COVID-19 pathology, its DNA structure, risk populations, disease progression, treatment, and reinfection rates. More work is needed to address the challenges to health and family care access, mental health, and socio-economic impacts at the individual and community level as part of the broad public health response that seeks to "flatten the curve" through social distancing efforts.

The central strategy currently promoted by public health officials to address the spread of COVID-19 is to encourage the general public, businesses, and group interactions to engage in social distancing, maintaining a fixed distance between yourself and other individuals to lessen the chance of disease transmission. This concept of distancing has been expanded, first in Asia, then Europe, and now the United States, to one of self-isolation, remaining in a fixed location and not going outside except when addressing critical needs such as medical care, grocery shopping, and caregiving. The concept of self-isolation is not new, but the work of historians such as Margaret Humphreys's (1999) study of Yellow Fever in the nineteenth century United States and John M. Barry's (2004) study of the 1918 Influenza Epidemic have reported on the general failure of this approach. Barry (2020), in particular, has argued that while social distancing and self-isolation should be effective, it fails due to the lack of strict enforcement. *"For interventions to work, people have to comply and they have to sustain that compliance; most of that depends on voluntary efforts and individual behavior."* Barry (2020) makes the point that enforcement is also a governmental responsibility. Echoing recent news stories, while speaking of the 1918 Influenza Epidemic, Barry (2020) states, *"In 1918 many cities imposed restrictions, lifted them too soon, then reimposed them. COVID-19's average*

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incubation period is more than double influenza's, so compliance may have to be sustained for months, and openings and closings may also have to be repeated. Again, if the public is going to comply over time, they will have to be led, inspired or compelled."

This level of demand upon social compliance and individual sacrifice at a national level is largely unprecedented in the United States since the end of World War II. While natural disasters such as Hurricane Katrina and Hurricane Sandy caused tremendous social disruption, suffering, material loss, and infrastructural damage, the impact was and remains relatively localized. Now found in all 50 states and the District of Columbia, the current COVID-19 epidemic has required the introduction of increasingly rigorous controls on population movement, work, and social gatherings. At present, 17 states, including Michigan, have instituted "stay at home" orders backed up by the potential for criminal charges in the face of noncompliance. This number of legislative orders to self-isolate will increase as infection rates continue to grow and could potentially continue into the summer of 2020.

The biomedical perspective is appropriately focused on epidemiological and etiological aspects of the COVID-19 epidemic; the role of Behavioral and Social Science Research (BSR) is different but equally important. The core contribution BSR approaches will be to offer a better understanding of the social consequences of conforming to the health requirements imposed by the spread of COVID-19. Unlike the understanding of the disease process itself, which will come in time, BSR techniques can provide a comparative window by examining social behaviors and life-course activities before the emergence of the virus. This understanding will, in turn, provide baseline measures to better interpret new behaviors and social outcomes immediately after the crisis emerged, and how social behaviors adapt and reassert themselves once the COVID-19 crisis has passed. This working paper is a summary of ongoing work by researchers at the NACDA Program on Aging and the Inter-university Consortium for Political and Social Science

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(ICPSR) to identify and share information, best practices, and tools to identify Common Data Elements (CDE) that capture routinely collected measures of social behavior to study change in the face of the COVID-19 pandemic.

Research concerns associated with social impacts of COVID-19

The COVID-19 crisis impacts social activity, interactions, and behaviors at multiple levels. Emotionally, social distancing and self-isolation activities can cause mental health issues, anxiety, and depression. Uncertainties associated with the disease itself, its rapid spread and high risk of infection, in the unknown duration of public health interventions to address disease progression also impact mental health issues. The consequences of social isolation are well-established. There is a rich literature on the impacts of loneliness (Yael and Yager, 2019), particularly among the elderly (Martin et al., 2019), and how it negatively affects behavior and the ability to cope with stress in a time of crisis.

Even with the availability of the Internet, social networks, and virtual communication such as FaceTime, Google Hangouts, and newer mediums such as TikTok, a number of studies have argued that the dependence on social networking can worsen depressive symptoms and feelings of isolation even during periods of normal activity (Yoon, 2019). Identifying and organizing pre-crisis measures of depression, anxiety, social networking, and levels of social isolation will provide an invaluable baseline to understand better how individuals and society both cope and adapt to the new realities imposed by attempts to reduce COVID-19 infections.

In addition to concerns related to social isolation and depression, other important social activities are impacted by the COVID-19 epidemic. The need to limit social interactions is severely reducing economic activity nationwide. We want to identify the impacts caused by the closures of "nonessential" businesses, especially large-scale layoffs of employees. Similarly, it

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is essential to measure outcomes for the large population of workers who must perform crucial duties that place them at a personal risk of infection due to ongoing contact with the general public. This group includes medical personnel, but also grocery store clerks, truck drivers, delivery workers, and a wide array of often low-paying but socially essential labor force activities. Consequently, there is not only the stress and uncertainty associated with potential job loss or income reduction, but there is also the clear economic impact of declining GDP, consumer purchases, and the contraction of day-to-day activities required for a healthy economy (Shambaugh, 2020).

Similarly, medical services are being severely stressed by the COVID-19 crisis in multiple ways. Medical care providers and support staff are at direct risk of infection due to daily contact with patients. There are also stressors imposed on social behavior due to concerns over shortages of supplies as fundamental as protective masks and disinfectants to essential equipment such as respirators, all required for day-to-day care and protection of care providers. Growing concerns over potential shortages of hospital space and medications also reflect the stresses that the epidemic is placing on state and national health care infrastructures. Abnormal responses to this stress have been expressed in the hoarding of basic protective equipment like face masks, causing severe shortages in areas hard-hit by infections (Ranney et al., 2020). The unnecessary purchases of nonessential items such as toilet paper, which does not address any of the main symptoms of COVID-19 has caused additional and unnecessary shortages of home care items nationwide.

More importantly, the ongoing orders for self-isolation may result in changes in the quality of medical care, its availability, and the ability of individuals to afford treatment for non-COVID-19 illnesses. There are already numerous examples of medical triage put in place at the local level, where patients are discouraged from seeking care for minor health complaints and

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instructed to avoid hospitals and medical care facilities unless there is an urgent need (AAFP, 2020). This response is due both to the fear of avoidable infections and the increasing strains upon capacity faced by many major care providers. Associated with potential economic downturns resulting from work reductions, layoffs, and job loss, the ability to seek healthcare is negatively impacted by the loss of health insurance or income reductions that could make paying for care difficult, if not impossible. Measures such as self-reported health, frequency of medical visits, and satisfaction with the quality of care are important indicators of changes in social behaviors and positive outcomes for the population.

Quality of Life

The measurement of baseline social behaviors such as mental health, physical health, employment and income, access to care and basis services, and the maintenance of positive social relationships can be categorized as being elements of Quality of Life (QoL). An overarching measure of interest in understanding changes in social behavior, QoL is a generalized term for measuring the quality for a variety of individual and societal milestones that can define life satisfaction. While expectations vary from place to place, QoL represents a desirable set of shared standards of attainment that summarize the expectations that individuals or communities have for experiencing a "good" life. These expectations are guided by the values, goals, and socio-cultural context in which an individual lives, so they are dynamic measures that can change rapidly in the face of crisis or benefice (Steptoe et al., 2015). QoL is a highly subjective, multidimensional concept that attempts to capture standardized indicators for emotional, physical, material, and social well-being, so there is no definitive agreement on how to measure QoL (McNally, 2009). Ultimately, it serves as a reference against which an individual or society can measure the different domains of life experiences using validated

measures that capture distinct elements of daily living (Lancet, 2016).

The analysis in this report focuses on available data resources that asked questions regarding overall "quality of life" and related measures including happiness, crisis management, general health, and mental health. The report also identifies other data resources that provide supporting information on topics such as crime and victimization, and the use of social media to convey general information and individual experiences. The analysis is by no means exhaustive, and both NACDA and ICPSR will be revising and expanding reported measures and studies as they are identified. Still, this report provides a practical guide of best practices to measure and identify pre-COVID-19 behaviors and activities in the United States and internationally.

Data Measures and Best Practices for Measuring Crisis Response

To identify best practices for measuring behavior and social change during a period of crisis, our researchers established a set of idealized parameters to guide data selection and variable search terms. ICPSR manages one of the largest data repositories in the world, with both contemporaneous and historical studies that look at different elements of QoL and societal responses to change and crisis. A recent publication by Protsiv et al., 2020, for example, looked at the relationship of body temperature, fever, and health across time using medical records collected from veterans of the Union Army taken from 1862 until 1940. The findings from this publication are now part of the *New York Times* news coverage of COVID-19 related issues (Tingley, 2020). These kinds of publications reflect the value and ongoing research use of ICPSR resources to understand health and social responses to change and why it is essential to ensure the long term preservation of data for future generations of researchers.

For the present analysis and summary of measures, we examine the breadth of

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information across the NACDA and ICPSR collections focusing on the critical issues of timeliness, consistency, and periodicity to suggest baseline measures concerning social responses to the COVID-19 crisis. Specifically, we were interested in when the studies were collected, whether they consistently asked essential questions in the same way, how frequently the data was collected. Based on these criteria, we identified a set of test studies that met these requirements and provided useful measures of baseline social behaviors related to QoL constructs.

In terms of timeliness, we highlight studies that were fielded within five years of the initial identification of the COVID-19 outbreak. This time range allowed us to include both longitudinal and repeat measure cross-sectional studies in our analysis. The one exception was the inclusion of the American Changing Lives Study (ICPSR 4690). The current version provides information up until 2011, but the 2019 update is currently in process at ISR and should become part of the NACDA collections in the coming year. In other cases, such as NHIS and NHANES, the variable examples provided are drawn from different years to reflect consistency across time. The NHIS is a particularly useful repeat measure cross-sectional study as it is fielded annually and consistently asks a series of important questions regarding health, access, employment, and behavior. The NHIS annual collection allows us to construct measures to examine point-in-time measures or cohort-based change across time analysis. NHANES offers similar advantages, with the added benefit of detailed health information and laboratory tests and results for a subset of its sample. While fielded annually, NHANES recommends pooling at least two years of data for consistent results, so the data needs to be enhanced for analysis purposes.

Longitudinal studies such as MIDUS, NSHAP, and the ACL, while fielded at longer time intervals, offer the advantage of allowing us to look at behavior changes at the individual level.

The selected longitudinal studies in our examples reflect the use of questions and variables comparable to each other and to the multiple studies maintained by ICPSR. As all of the longitudinal studies either have or plan to have new waves in the field post-COVID-19, they will provide invaluable measures of individual change and response to the current crisis. The Survey of Consumer Attitudes and Behavior (now the University of Michigan's Surveys of Consumers) has been tracking consumer behavior in the United States since the 1940s and offers a monthly evaluation of consumer activity, expectations, and concerns. The ISR research team has already released a series of reports on the economic response to the COVID-19 crisis and offers the most frequently updated information on consumer behavior currently available (ISR, 2020).

Overall, this report provides information from a wide range of studies, series, and collections that can look at both broadly defined measures of behaviors and commonly collected comparative measures such as happiness, access to care, employment status, and mental health. Again, the measures presented in this report are far from exhaustive. Still, they offer a solid overview of data, collections, and variables that will help researchers develop baseline measures of social response to the COVID-19 crisis. The best practices developed as part of this process are of further value as they can be expanded to other investigations of past and future challenges to social behavior and disaster remediation.

ICPSR Search Tools: Best Practices for Identifying QoL variables and Social Behaviors

Using ICPSR's search functionality, variables, datasets, data series, related publications, and standard assessments can be discovered by topic and narrowed by timeline or geographic area. When searching by topic or theme, it is best to use quotation marks around multi-word terms, and to break down ideas then match to layered research topics as needed. For instance, when searching for "quality of life" on the ICPSR site, it helps to consider the main goals and

hypotheses; a search for "quality of life" returns nearly 2000 studies, over 800 variables, and over 200 related publications. The search results can be filtered by timeframe and geography, as well as several other ways. The term "quality of life," if present in a study title, variable name, label, question text, or collection-level description, will have the most impact in later secondary user discovery from the site. This general approach is an excellent place to begin a search. The researcher can use the filtering tools to adjust and refine the search as they identify relevant studies (the study results are the default results view) and then begin to explore datasets and variables that address the research question.

When searching from the study results and ultimately the study pages, it is essential that users take time to read the information presented in the study page, commonly known as metadata. The study page contains all of the information a user needs to know before downloading the data. The "At a Glance" page contains the summary, tags, sampling information, timeframe, and often information about the associated datasets, among other things. The "Data and Documentation" tab is where users can preview available documentation, including codebooks, data producer readme files, questionnaires, etc., as well as the available data file types. Each study page also displays a "Variables" tab, allowing users to review the publicly available variables directly from the study page without any downloading, either by scroll and click or using search terms. The "Data-related Publications" tab displays any citations known to ICPSR for publications that analyzed data from the corresponding study, alerting users to what a research topic using the data have been explored and published. ICPSR study pages provide all archived content for any given study, allowing for a complete picture of the efforts and outcomes of a primary data collection.

Another approach would be to search for more in-depth topic specifics using the variable level search functionality. For example, when considering measures of social behaviors, using

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ideas together but in separate quotations, such as "community," "connected" would have a better chance of leading to studies and variables measuring whether a respondent feels connected to their community as opposed to using a general "connected community." Searching by specific variables is accessible from the ICPSR search page as a separate tab next to "Studies." This search tool reflects variables across every study in the ICPSR archives related to the given search terms. Once variables are identified with the desired question format, value range, and sample size, users can then shift to the study view for a given variable to find out more about the study methodology. Another benefit to searching at the variable level is the compare functionality; users can select multiple variables across search results reflecting various studies, then compare within the same site page view. Reviewing at the variable level can be an efficient method to lead secondary data users to whole studies and datasets using ICPSR's website breadcrumbs.

Reviewing, Comparing and Organizing Identified Variables

One of the strengths of the ICPSR search tools is our ability to rapidly index searches within and across our almost 15,000 studies, 5,525,082 variables, and our 88,793 data related publications. As discussed in the preceding section, using the appropriate search strings and filters can help you quickly refine your data exploration to a manageable number of variables and data sets. Once you have successfully identified your data of interest, you can further narrow your choices by comparing variables from either a single study or multiple studies with similar measures.

This capacity is particularly useful for the current analysis. To identify the data collections and variables presented in the report, ICPSR and NACDA researchers reviewed and explored dozens of studies and hundreds of variables and related publications. Being able to

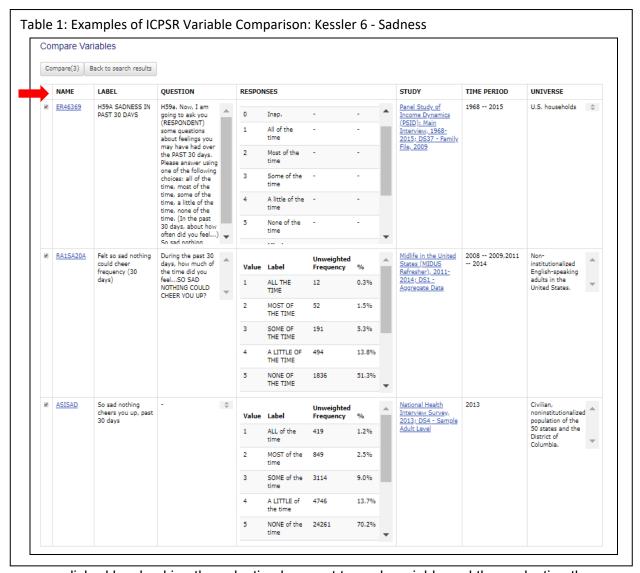ICPSR | INSTITUTE FOR SOCIAL RESEARCH UNIVERSITY OF MICHIGAN

compare variables across studies simplified the process of establishing consistency in question text, values, and responses. In this section, we will briefly describe how to use and view the compare variables tool as a component of the search functionality at ICPSR.

To offer an example of this process, we chose to search for one of the six variables typically used in administering the Kessler Screening Scale for Psychological Distress (K6) (Kessler, et al., 2010). This scale is routinely administered as part of multiple health surveys to measure rates of social anxiety efficiently. The K6 scale has been repeatedly validated across heterogeneous populations and racial groups worldwide. The K6 is a robust measure that is easily self-administered, calculated, and interpreted. As it has been a consistent element of several studies such as the NHIS for well over a decade, so it will represent a useful measure to examine social anxiety pre and post-crisis and offer insights into the ways different groups adapt to stress during an epidemic.

The research team first searched for the term "sad" and found over 500 studies that addressed that concept. We refined our search to the terms "sad" and "30", as 30-days is the common time measure for the stressors. This refinement narrowed the search into a manageable number of studies and identified 45 different variations of the classic question text: "During the PAST 30 DAYS, how often did you feel .... so sad that nothing could cheer you up?." Looking through the search results, we chose to compare the "sad" "30" results for the PSID, the MIDUS Refresher, and the 2013 Sample Adult Module of the NHIS. This task was

Table 1: Examples of ICPSR Variable Comparison: Kessler 6 - Sadness

accomplished by checking the selection box next to each variable and then selecting the

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Compare function of the search results. Table 1 presents the variable comparisons resulting from employing this search function.

As can be seen, the comparisons of the K6 sadness variable show minor variations in the question text, but all three studies employ the same 5 point scale in the correct inverse order required by the K6. The Compare function also offers additional information on the universe of the selected study, the time-period, and the variable name. While the number of variables you can compare at any given time is unlimited, we recommend the user look at a manageable number of variables for comparative purposes. Generally, comparing between five to ten variables at a time will provide the most useful results.

Examples from the ICPSR Data Repository: Data and Measures

Table 2 provides a summary of a small subset of variables and data sets that touch on the selected key concepts discussed in the introduction. This table represents only a small selection of available data that could be used to measure behaviors affected by COVID-19. ICPSR has hundreds of studies and thousands of variables that measure constructs of resilience and social behavior in response to stress. A thorough review, organization and harmonization of variables of interest is ongoing to allow the research community to use the publicly available tools at ICPSR efficiently. This Common Data Elements (CDE) approach will provide invaluable information to measure the pre-COVID-19 social environment, allowing us to track changes in behavior once the curve is flattened, and individuals return to their usual day-to-day activities.

As reflected in Table 2, the selected data collections all encompass measures that capture most of the critical concepts that measure social behavior pre-COVID-19. The MIDUS study routinely includes questions on all the constructs of interest, while the NSHAP study uses the UCLA Loneliness Scale as opposed to the Kessler 6. In contrast, the ACL does not directly

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measure anxiety or loneliness but does administer the CES-D as a standard measure of depression. The NHIS does not directly ask questions regarding the quality of life, though QoL measures can be constructed using appropriate variables from the study. NHIS also fielded a focused module in its 2010 round that collected detailed measures of Quality of Life in the US and offered a useful comparative baseline for other studies. While the NHIS does not administer the CDES, it has collected K6 measures for many years, giving a valuable picture of shifts in generalized anxiety in the US over time. While the NHANES study also lacks a specific question on QoL, like the NHIS, a proxy measure can be constructed from available variables in the study. The Survey of Consumer Attitudes and Behavior is a unique example of the value of the breadth of the ICPSR repository. While it lacks direct measures on QoL or mental health, it collects detailed information about individual and household economies and purchasing habits. The study also routinely gathers information about respondent feelings towards their family, neighborhood, and job, all factors placing new stressors on the individual due to the COVID-19 epidemic.

Table 2: Summary of key measures and surveys

	QoL	Happiness	Crisis/ Problems	Kessler 6	CESD	Health
MIDUS	X	X	X	X	X	X
NSHAP	X	X	X	*	X	X
ACL	X	X	X	-	X	X
NHIS	&	X	X	X	-	X
NHANES	#	X	X	X	X	X
Survey of Consumer Attitudes and Behavior	-	X	X	%	-	X

- * - UCLA loneliness scale used instead
- & - 2010 Supplement focused on QoL, otherwise constructed from variables

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- # - Quality of life scale can be approximated from available variables
- % - Various measures on feelings about family, neighborhood, job, etc.

Examples of detailed measures of well-being in selected studies

The following section offers detailed examples of specific questions asked by the identified sample of studies across multiple measurement years. The information shows the similarities and differences between concepts, measures, and question texts. By using the Compare function of the ICPSR search tools, a more granular examination of variables, scales, and measurement intervals can be performed, aiding the harmonization process for cross-study comparative analysis. Again, this represents only a small sample of available data collections and variables, but it does provide a useful picture of the research value of the ICPSR repository for conceptualizing the impact of COVID-19 on social, behavioral, and economic outcomes.

MIDUS Variable Examples:
- **QoL**
  K2Q51D
  Life's pleasures important for good life
  What is most important? - ENJOYMENT OF LIFE'S PLEASURES?
  Taken from: Survey of Midlife in Japan (MIDJA 2): Biomarker Project, 2013-2014.
- **Happiness**
  RA5SST10
  Spielberger state-trait anxiety inventory trait 10-I am happy
  I am happy
  Taken from: Midlife in the United States (MIDUS Refresher): Neuroscience Project, 2012-2016.
- **Crisis/Problems**
  J7B
  WHAT LIFE CRISIS ABOUT
  Taken from: Midlife in the United States (MIDUS): Psychological Experiences Follow-Up Study, 1998.
- **Kessler 6 Series**
  RA1SA20D
  Felt hopeless frequency (30 days)
  During the past 30 days, how much of the time did you feel...HOPELESS?
  Taken from: Midlife in the United States (MIDUS Refresher), 2011-2014.
- **CES-D**
  B4Q3F

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CESD Felt depressed
Taken from: Midlife in the United States (MIDUS 2): Biomarker Project, 2004-2009.
- **Health**
RA1SA1
Rate health current
Using a scale from 0 to 10 where 0 means "the worst possible health" and 10 means "the best possible health," how would you rate your health these days?
Taken from: Midlife in the United States (MIDUS Refresher), 2011-2014.

NSHAP Variable Examples:
- **QoL**
ENJLIFE
CESD: enjoyed life
During the past week I enjoyed life. (Now let's talk about thoughts and feelings you may have had during the past week. I will read a series of statements. Tell me how often during the past week you felt like this; rarely or none of the time, some of the time, occasionally, or most of the time? Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.)
Taken from: National Social Life, Health, and Aging Project (NSHAP): Wave 2 and Partner Data Collection, [United States], 2010-2011.
- **Happiness**
WASHAPY
CESD: was happy
During the past week I was happy. (Now let's talk about thoughts and feelings you may have had during the past week. I will read a series of statements. Tell me how often during the past week you felt like this; rarely or none of the time, some of the time, occasionally, or most of the time? Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.)
Taken from: National Social Life, Health, and Aging Project (NSHAP): Wave 2 and Partner Data Collection, [United States], 2010-2011.
- **Crisis/Problems**
LACKPRESMED
Skipped medications due to lack of insurance
In the past year, has a lack of adequate health insurance kept you from getting prescription medications? Note: asked in leave-behind in W3
Taken from: National Social Life, Health and Aging Project (NSHAP): Wave 3, [United States], 2015-2016.
- **Kessler 6 Series (UCLA Loneliness Scale)**
ISOLATED
ucla loneliness scale: feel isolated
How often do you feel isolated from others? Note: asked in leave-behind only
Taken from: National Social Life, Health, and Aging Project (NSHAP): Wave 1, [United States], 2005-2006.
- **CES-D**
FLTSAD
Center for Epidemiologic Studies Depression Scale (CES-D): felt sad
During the past week... I felt sad (Now let's talk about thoughts and feelings you may have had during the past week. I will read a series of statements. Tell me how often

during the past week you felt like this; rarely or none of the time, some of the time, occasionally, or most of the time? Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.) (USE HAND CARD X)
Taken from: National Social Life, Health and Aging Project (NSHAP): Wave 3, [United States], 2015-2016.

- **Health**
  PHYSHLTH
  self-rated physical health
  This section is about your physical health. First, we would like to ask you some general questions. Would you say your health is excellent, very good, good, fair, or poor? (HAND CARD)
  Taken from: National Social Life, Health, and Aging Project (NSHAP): Wave 2 and Partner Data Collection, [United States], 2010-2011.

ACL Variable Examples:
- **QoL**
  V13527
  W4.R's Perceived Quality of Health Care Index.4-item Mean Index
  Taken from: Americans' Changing Lives: Waves I, II, III, IV, and V, 1986, 1989, 1994, 2002, and 2011.
- **Happiness**
  V4323
  2B4:HOW HAPPY PRESENT
  Taken from: Americans' Changing Lives: Waves I, II, III, IV, and V, 1986, 1989, 1994, 2002, and 2011.
- **Crisis/Problems**
  V15813
  W5.MONEY.Difficulty managing money because of health or memory problem
  Taken from: Americans' Changing Lives: Waves I, II, III, IV, and V, 1986, 1989, 1994, 2002, and 2011.
- **Kessler 6 Series (Hopelessness Scale)**
  V16216
  W5.M4b.Hopeles2.The Future Seems Hopeless to Me and I Can't Believe that Things Are Changing for the Better
  Taken from: Americans' Changing Lives: Waves I, II, III, IV, and V, 1986, 1989, 1994, 2002, and 2011.
- **CES-D**
  V2618
  CESD-11, MEAN
  Taken from: Americans' Changing Lives: Waves I, II, III, IV, and V, 1986, 1989, 1994, 2002, and 2011.
- **Health**
  V5819
  2X13:RATE HEALTH OF R
  Taken from: Americans' Changing Lives: Waves I, II, III, IV, and V, 1986, 1989, 1994,

2002, and 2011.

NHIS Variable Examples:
- **QoL**
  2010 Supplement focused on QoL, otherwise constructed from variables
- **Happiness**
  HAPPY
  How often felt happy, past 30 days
  Taken from: National Health Interview Survey, 2001.
- **Crisis/Problems**
  MEDBILL
  Problems paying medical bills
  Taken from: National Health Interview Survey, 2012.
- **Kessler 6 Series (Hopelessness Scale)**
  HOPELESS
  How often felt hopeless, past 30 days
  Taken from: National Health Interview Survey, 2010.
- **CES-D**
  N/A
- **Health**
  PHSTAT
  Reported health status
  Taken from: National Health Interview Survey, 2001.

NHANES Variable Examples:
- **QoL**
  Quality of life scale can be approximated from available variables.
- **Happiness**
  V152
  HAPPY?
  Taken from: National Health and Nutrition Examination Survey I, 1971-1975: General Well-Being.
- **Crisis/Problems**
  SSQ051
  Anyone to help with financial support
  Target: B(40 Yrs. to 150 Yrs.) English Text: If {you/SP} need{s} some extra help financially, could {you/s/he} count on anyone to help {you/him/her}; for example, by paying any bills, housing costs, hospital visits, or providing {you/him/her} with food or clothes? English Instructions:
  Taken from: National Health and Nutrition Examination Survey (NHANES), 2003-2004.
- **Kessler 6 Series**
  V107
  FELT SAD AND HOPELESS?
  Taken from: National Health and Nutrition Examination Survey I, 1971-1975: General Well-Being.
- **CES--D**
  V161
  TOTAL CES-D SCORE

Taken from: National Health and Nutrition Examination Survey I, 1971-1975: General Well-Being.

- **Health**
  VAR0205
  GENERAL HEALTH
  Taken from: National Health and Nutrition Examination Survey I, 1971-1975: Health Care Needs, General Medical History and Supplements on Respiratory and Cardiovascular Data.

The Survey of Consumer Attitudes and Behavior Variable Examples:
- **QoL**
  N/A
- **Happiness**
  V407
  GENERAL HAPPINESS
  Taken from: Survey of Consumer Attitudes and Behavior, April 1990.
- **Crisis/Problems**
  V1003
  EVENTS OR CHANGES(2)
  B1. The next question concerns how people think about the past. There have been a lot of national and world events and changes over the past sixty years -- from about 1930 right up until today. Would you mention one or two national or world events or changes that seem to you to have been especially important? (IF NEEDED: There aren't any right or wrong answers to the question -- just whatever national or world events or changes over the past half century or so that come to mind as important to you) (IWER, IF ONLY ONE MENTION, ASK: Is there any other national or world event over the past sixty years that seems to you especially important). NOTE: This is a frame of reference code. We are trying to code the main area mentioned by R; affect may be either positive or negative. Except as noted by an asterisk following the event description, codes and associated descriptions are the same as in the codebook for the 1985 study. Codes added in 1994 indicated by ***
  Taken from: Survey of Consumer Attitudes and Behavior, January 1995.

V2115
5YR BUSINESS
A8.Looking ahead, which would you say is more likely -- that in the country as a whole we'll have continuous good times during the next 5 years or so, or that we will have periods of widespread unemployment or depression, or what?
Taken from: Survey of Consumer Attitudes and Behavior, January 1994.

- **Kessler 6 Series**
  Various measures on feelings about family, neighborhood, job, etc. Could make a proxy scale?
  (Not validated)

  V1350
  FEEL:ACCOMPLISHMENTS
  Taken from: Survey of Consumer Attitudes and Behavior, July 1993.
- **CESD**
  N/A

- **Health**
  <u>V1518</u>
  HEALTH VISIT
  F10. This next question is about your health visits to a medical doctor. Please answer yes or no. During the last two months, that is since the beginning of August, 1995, have you been treated or examined by a physician?
  Taken from: Survey of Consumer Attitudes and Behavior, October 1995.

Data on social networks and social isolation

One of the critical issues we seek to address in understanding how the COVID-19 epidemic is how it is impacting social behaviors and interpersonal interactions. To accomplish this, ICPSR is reviewing and organizing social networks and social isolation data to facilitate research in this area as the crisis is resolved, and people return to their jobs and gatherings. Examples of these kinds of studies are found through the repository, managed by a variety of projects. NACDA, for example, maintains the *Understanding How Personal Networks Change: Wave 1 (ICPSR 36975)*. The survey, fielded in 2016, is a longitudinal study that measures how network composition changes over time as a result of life course transitions and how these changes are related to health status and outcomes. NACDA is currently processing Wave 2 of this study and will release it in the coming months. NACDA also manages the NSHAP study, which has collected detailed information on the social networks and interactions since it was first fielded in 2006. As this is an ongoing study, it offers opportunities for a better understanding of how social distancing may impact the networks of elderly Americans. MIDUS asks questions about social networks such as "RA2DHT8D8: Past week, used social networking for health activity?"

Similarly, The Stress in America, United States, 2007-2018 (ICPSR 37288), managed by the Resource Center for Minority Data at ICPSR asks "Q7146_2: How helpful were each of the strategies you used?: Creating a social support network." A review of the collections finds several hundred studies that address some aspect of social networks, and several of these

studies have modules to support social network analysis approaches. Measuring changes in social networks and people's attitudes towards them will be a valuable addition to the research tools ICPSR will be able to provide the community in the coming years and organizing the pre-COVID-19 baseline data will allow researchers to begin this analysis more rapidly.

The National Longitudinal Study of Adolescent to Adult Health (Add Health, disseminated by Data Sharing for Demographic Research (DSDR) at ICPSR), a longitudinal study based on a nationally representative sample of students in high schools and middle schools in the United States during the 1994-1995 school year, has unique measures of the social network relationships among the individuals in the study. Add Health uses a clustered design, in part to facilitate the collection of extensive social network data. Because the Add Health study collected network data from all students who attended each participating school, both individual and school-level networks can be examined. This design allows for the creation of a baseline measure of easch individual's social network that could inform studies of the impact of and resilience in the face of the social distancing associated with COVID19. (AddHealth networking data is described at

https://www.icpsr.umich.edu/web/DSDR/studies/21600/versions/V21/datasets/3/files/1215772/downloadDoc/doc?path=/pcms/studies/0/2/1/6/21600/V21/files/1215772).   Add Health collects social, environmental and behavioral data and provides linkages with contextual and administrative data, thereby providing opportunities to examine the ways that social environments and behaviors in adolescence are linked to health and achievement outcomes in adulthood. The next wave of data collection (wave six) will examine study participants in middle age and could reflect their experiences with the COVID-19 pandemic.

Using Social Media and Digital Trace Data to Study the Impact of COVID-19

There are a variety of ways in which social media data can be used to inform our

understanding of the impact of COVID-19, along and in conjunction with survey data. We cite examples using Twitter data as it is the most commonly available social media source, although there are other platforms absent Facebook that also might be useful. The general approach is to employ an interrupted time series design or analysis, analyzing tweets pre and during the pandemic to look for changes or shifts in trends.

There are a number of standard approaches to analyzing tweets, involving topic analysis, sentiment analysis, and the formation and shifts in social networks. All of these analyses presume or require an assembly of a sample of tweets over time, with the length of the actual pre time period depending on the source of the tweets. Sampling is necessary because of the actual volume of tweets per unit of observational time (day or hour, for example).

When analyzing topics, as a general issue we would expect health-related concerns to become more frequent after the onset of the coronavirus. When sentiment is associated with these terms, the question is whether indicators of concern become associated with the health references over time. This inevitably raises the question of mental health status in the population. Another design strategy would be to draw a sample of tweets, identify their source, and then to construct the networks for those tweeters. Again, researchers would employ a standard set of network analyses to look at network size and how it shifts over time, the number of edges in each, and the centrality of specific individuals in the networks.

A major methodological issue in the analysis of tweets is the representative character of people who tweet and the general population or specific subgroups in it. This raises the prospect for both cross-validating survey measures and social media indicators of the same underlying concept. At the same time,those results might provide the opportunity for more frequent measurement of indicators of those same phenomena than the surveys themselves can provide because fielding those surveys is a major logistical effort that limits the frequency

with which they can be undertaken.

The actual process could work something like the following. The Kessler K-6 scale ismeasured relatively consistently in the NHIS surveys, meaning that there are time series of its values over time. An initial step might be to use the topics and sentiment in a longitudinal sample of tweets to assess their correlations with the survey measure time series. Such analyses will have to account for historical correlation across the entire available time series, in periods when the survey measures are historically high or low, and around specific events such as 9/11 that might elevate their values.

If and when confidence in the social media measures can be established, then it should be possible to establish a continuous monitoring of the "validated" measures on a timely basis that is more frequent than the survey measures will appear. Of course, the validation efforts will have to be continuous. But as confidence in the social media time series in the United States increases, it should be possible to extend the methodology to other countries where equivalent developmental work can be replicated.

Other sources of data on pre-COVID-19 social behaviors

ICPSR supports and manages over 20 specialty archives within its organizational structure. All of these units work collaboratively to promote research excellence in a variety of disciplines, from demography and population studies to gerontology, to child and adolescent studies, and HIV and Drug Abuse, to name a few. All of these units are led by researchers who have topic-specific knowledge about the data they manage and the research community they serve. Collectively, ICPSR brings multidisciplinary expertise to the problem of measuring social response to epidemics and crises. The following sections touch on some of these additional data resources we can bring to bear on this important and timely issue.

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Crime data of relevance to measuring the impact of epidemics

Data in the National Archive of Criminal Justice Data (NACJD) will not reflect the impact of the coronavirus for several (one to three) years. This is because the NIBRS and NCVS data series are official, federal reports of crime data. Both data series contain granular data that describe criminal incidents and unreported cases of criminal victimization on an annual basis. There is a lag between data collection and their release to the public.

When these two series are updated to include data for 2020, we expect to see a drop in some types of crime (assault) but increases in other types (domestic violence or cybercrime). The NCVS series will likely contain more accurate data on domestic violence information because it is survey-based and does not require respondents to file a police report.

A third data series that may reflect the impact of the coronavirus is the National Prisoner Statistics series. The NPS provides an enumeration of persons in state and federal prisons and collects data on key characteristics of the nation's prison population. When the 2020 data is released, it will likely reflect prisoner releases in response to the virus, as well as associated epidemic mortalities. The most current data available is for 2016. Updated data is not likely to be available for several (2-4) years. Below is a listing of some of the measures currently available that will be relevant to building a comparative baseline of pre-COVID-19 social behaviors.

Miscellaneous studies and measures

Measure	Concept	Source
Annual measures of Happiness; Job Stress; Substance Use; Social Media Use among 8th 10th and 12th grade students	Well-being	Monitoring the Future: A Continuing Study of the Lifestyles and Values of Youth, 2018 (ICPSR 37416) https://doi.org/10.3886/ICPSR37416.v1

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RATE OF SUBSTANTIATED MALTREATMENT OF CHILDREN AGES 0–17 BY AGE, 2008–2017	Child Abuse and Neglect	NCANDS Public access to data available through the archive at Cornell: https://www.ndacan.acf.hhs.gov/ (Also see the America's Children Annual Report https://www.childstats.gov/americaschildren/family7.asp
V6011 - UCR Arrest Offense Code (906 - Family Offenses, Nonviolent)	Child Abuse and Neglect; Domestic Violence	National Incident-based Reporting System, Extract Files (1991-2016); Data reported by states and municipalities to the FBI; (Lagging indicator - 2017, 2018 data is currently in process, and 2020 data will not be released for several years)
V3049, V3050, V3051 - First, Second, and Third Incident (26 - Crime against household other than any of the above; 29 - Unable to classify)	Child Abuse and Neglect; Domestic Violence; Other	National Crime Victimization Survey, Concatenated File (1992-2016); Data originates from a national survey to identify unreported crimes; (Lagging indicator - 2017, 2018 data released but not concatenated 2020 data will not be released for several years)
health interdependence (peer, family, neighborhood, and workplace drivers of health); values related to national and community investment for health and well-being; behaviors around health and well-being, including civic engagement on behalf of health, and the role of community engagement and sense of community in relation to health attitudes and values.	Culture of Health, Community Support, Well-being	National Survey of Health Attitudes (https://www.icpsr.umich.edu/icpsrweb/ICPSR/studies/37405) https://doi.org/10.3886/ICPSR37405.v1 Additional year being processed now; Rand will field a 3rd year soon.

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Health values and Beliefs	Health values and beliefs	American Health Values Survey (https://www.norc.org/Research/Projects/Pages/american-health-values-survey.aspx) Process two years now.
Stress and its impact on various aspects of well-being (explicitly, also physical activity, intent to modify behavior), and daily life	Stress and well-being	Stress in America (yearly, all surveys under the same study but each year is a dataset with slightly different codebook) (https://www.icpsr.umich.edu/icpsrweb/RCMD/studies/37288)
Most of the variables in the surveys are related to health and well-being	Health insurance; WIC and other benefits; Delayed medical care; General health; Employment	National Health Interview Survey (series) (https://www.icpsr.umich.edu/icpsrweb/RCMD/series/40/studies)
"The survey also sought the respondents' opinions on a wide variety of other issues such as immigration, the AIDS epidemic in Africa..."		Transatlantic Trends Survey, 2004
Change in neighborhood poverty level after epidemic (long-term)		Data and Code for: Loss in the Time of Cholera: Long-run Impact of a Disease Epidemic on the Urban Landscape https://www.openicpsr.org/openicpsr/project/111523/version/V2/view
"... the role of livelihood strategies in constraining risk avoidance decisions; and the dynamics of trust in authority figures, including health workers…"		Challenges to Ebola preparedness during an ongoing outbreak https://www.openicpsr.org/openicpsr/project/117869/version/V1/view

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Polling data on COVID-19 (as of March 24, 2020, per AAPOR.net)

ICPSR maintains an ongoing relationship with major polling and survey organizations. While we continue to archive many polls by organizations such as CBS and ABC, we work closely with numerous organizations that perform topical polls and studied. Below is a list of partner organizations that are currently doing polls and gathering respondent behavior in real-time with the COVID-19 epidemic.

Poll	Link
Kaiser Family Foundation	https://www.kff.org/global-health-policy/poll-finding/kff-coronavirus-poll-march-2020/
Gallup	https://news.gallup.com/poll/295505/coronavirus-worries-surge.aspx
Quinnipiac	https://poll.qu.edu/national/release-detail?ReleaseID=3657
NBC/WSJ	https://www.documentcloud.org/documents/6810602-200149-NBCWSJ-March-Poll-Final-3-14-20-Release.html
CNBC/Change Research	https://www.changeresearch.com/post/cnbc-battleground-voters-on-coronavirus
NPR/PBS-NewsHour/Marist	http://maristpoll.marist.edu/npr-pbs-newshour-marist-poll-results-coronavirus/#sthash.1zf4Lgwr.dpbs
HuffPost	https://big.assets.huffingtonpost.com/athena/files/2020/03/17/5e70fe10c5b60fb69ddf0b8d.pdf
CNN/SSRS	http://cdn.cnn.com/cnn/2020/images/03/09/rel2b.-.trump,.coronavirus.pdf
Axios/SurveyMonkey	https://www.surveymonkey.com/curiosity/axios-coronavirus-perception/?utm_source=newsletter&utm_medium=email&utm_campaign=newsletter_axiosam&stream=top

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Public Policy Polling	https://www.protectourcare.org/wp-content/uploads/2020/03/Coronavirus-Poll-Memo-And-Results-3-20.pdf#page=9
Economist/YouGov poll	https://docs.cdn.yougov.com/vrbl9mmctz/econTabReport.pdf#page=63
Morning Consult	https://morningconsult.com/wp-content/uploads/2020/03/200326_crosstabs_CORONAVIRUS_Adults_v4_JB.pdf#page=300
USA Today/Ipsos	https://www.ipsos.com/en-us/news-polls/americans-see-coronavirus-threat-economy-not-their-daily-lives
NYT/SurveyMonkey	https://www.surveymonkey.com/curiosity/nyt-march-2020-cci/
Civiqs	https://civiqs.com/results/coronavirus_response?uncertainty=false&annotations=true&zoomIn=true
Morning Consult/Politico	https://www.politico.com/f/?id=00000170-ec0d-ded4-ad7e-fdedb9890000
Pew Research	https://www.people-press.org/2020/03/18/u-s-public-sees-multiple-threats-from-the-coronavirus-and-concerns-are-growing/
RTI	https://www.rti.org/coronavirus-united-states-survey
USC	https://uasdata.usc.edu/index.php
ABC News/IPSOS	https://www.ipsos.com/en-us/news-polls/abc-news-coronavirus-poll
SurveyUSA	1. http://www.surveyusa.com/client/PollReport.aspx?g=f573dfc0-32dd-4b2d-93d7-d21e0d769605
HuffPost	https://www.huffpost.com/entry/poll-coronavirus-concerns-grow_n_5e7a422cc5b62f90bc523e82

Dynata	https://www.dynata.com/dynata-global-trends-report-special-edition-series-covid-19/?utm_source=linkedin&utm_medium=social&utm_campaign=special_edition_WWIAE&utm_content=post

ISR Surveys Directly Addressing COVID-19

There are a number of ongoing surveys that are in the field that have added questions addressing COVID-19. Monitoring the Future has a web-based survey of its panel respondents (the subset of panel member who respond on the web). Two items were added to the MTF Panel web-based surveys (ages 19-60) in March 2020 (data collection starting March 27, 2020). The two items are:

A. Have you been concerned about whether you have COVID19 (also known as the coronavirus) in 2020?	B. Have you been tested for COVID19 in 2020?
1) No 2) Somewhat 3) Yes	1) No 2) Yes, and test indicated that I do not have it 3) Yes, and test indicated that I do have it 4) Yes, and I am waiting for the results

The Survey of Consumers has also added COVID-19 related questions to its April 2020 data collection. The new questions are:

M1. How much has your life changed due to the coronavirus? Would you say to a great extent, somewhat, very little, or not at all?	•M2. Which of the following potential effects of the coronavirus concern you the most: the threat to your (family's) health, the required social isolation, or the impact on your personal finances?
•TO A GREAT EXTENT •SOMEWHAT •VERY LITTLE •NOT AT ALL •8. DON'T KNOW	•THREAT TO YOUR OR YOUR FAMILY'S HEALTH • REQUIRED SOCIAL ISOLATION • IMPACT ON YOUR PERSONAL FINANCES • 8. DON'T KNOW

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Outside of ISR, there is a proposed national survey by an economist at the Minneapolis Federal Reserve Bank, Abigail Wozniak (https://www.abigailwozniak.com/policyopinion). This proposal seeks to quickly build a daily survey by combining established population survey methods from social science and public health with advances in electronic data collection in the private sector. By asking about symptoms along with wellbeing, the survey would allow decision-makers to understand in real time: (1) whether and where infection rates might be rising, and (2) how the public is faring under the social and economic restrictions in place.

Measures Identified in Other Studies and Variables Maintained by ICPSR

The final section of this report looks at various data collections and variables that captured elements of the primary themes in this examination of best practice measures of wellbeing, social connectedness, and other things one would want to measure on the social and behavioral impact of the epidemic. These measures emerged from researcher searches and adds to the potential collection of resources that increase our understanding of social behavior in a time of crisis. Again, this listing is far from exhaustive or complete, but it reflects the immense value of ICPRS's continued to dedication to data quality and preservation for almost 60 years.

- **Quality of Life**
1. b11 self-reported quality of life
   a. Taken from: Chinese Longitudinal Healthy Longevity Survey (CLHLS) series
2. q7009: Rate overall quality of life
   a. Taken from: WHO Study on Global AGEing and Adult Health (SAGE): Wave 1, 2007-2010.
3. SCQageprc10 The quality of my social life in later years depends on me
   a. Taken from: The Irish Longitudinal Study on Ageing (TILDA), 2009-2011.
4. How would you rate your overall quality of life?
   a. Taken from: Research on Early Life and Aging Trends and Effects (RELATE): A Cross-National Study.
5. QLTY OF LFE FRM REF L12. We have been visiting you or your family for five years now and asking a lot of questions, but we are also interested in your overall impression of this period. How would you say things have gone for you during the past five years?--

QUALITY OF LIFE
   a. Taken from: <u>Panel Study of Income Dynamics (PSID): Main Interview, 1968-2015.</u>
6. <u>Quality of life</u> - Thinking about your quality of life at the present time, I'd like you to give it a rating where 0 represents the worst possible quality for you and 10 represents the best possible quality for you. Looking at this line, how would you rate your overall quality of life at the present time? Choose a number between 0 and 10.
   a. Taken from: <u>Study of Women's Health Across the Nation (SWAN), 2003-2005: Visit 07 Dataset.</u>
7. <u>Reported quality of life</u>
   a. Taken from: <u>National Health Interview Survey, 2010</u>.
8. <u>V195:SERIOUS-QUALITY LIFE</u> - (WAYS DAMAGE TO THE ENVIRONMENT APPEARS SERIOUS TO R)... IT LOWERS THE QUALITY OF LIFE
   a. Taken from: <u>Euro-barometer 29: Environmental Problems and Cancer, March-April 1988</u>.

<u>Data Sets</u>
9. Quality of American Life, 1971 (ICPSR 3508) Campbell, Angus; Converse, Philip E.; Rodgers, Willard L.
10. <u>National Health Interview Survey, 2010 (ICPSR 36144) United States Department of Health and Human Services. Centers for Disease Control and Prevention. National Center for Health Statistics</u>
11. <u>English Longitudinal Study of Ageing (ELSA) (ICPSR 139) National Centre for Social Research (NatCen); University College London; Institute for Fiscal Studies (IFS)</u>
12. <u>Chinese Longitudinal Healthy Longevity Survey (CLHLS), 1998-2012 (ICPSR 36179) Zeng, Yi; Vaupel, James; Xiao, Zhenyu; Liu, Yuzhi; Zhang, Chunyuan</u>
13. <u>Resources for Enhancing Alzheimer's Caregiver Health (REACH II), 2001-2004</u> (ICPSR 4354) Schulz, Richard; Burgio, Louis; Stevens, Alan B.; Burns, Robert; Czaja, Sara; Gallagher Thompson, Dolores; Gitlin, Laura N.; Belle, Steven; Nichols, Linda
14. <u>Hispanic Established Populations for Epidemiologic Studies of the Elderly (EPESE) Disabling Process Study: 2001-2002</u> (ICPSR 36203) Ottenbacher, Kenneth
15. <u>National Health and Aging Trends Study (NHATS), [United States], 2011-2017</u> (ICPSR 37107) Johns Hopkins Bloomberg School of Public Health; University of Michigan
16. <u>Hispanic Established Populations for Epidemiologic Studies of the Elderly (EPESE) Frailty Study: 2006-2009</u> (ICPSR 36321) Ottenbacher, Kenneth; Graham, James
17. <u>Well Elderly 2, Los Angeles, California, 2004-2008</u> (ICPSR 33641) Clark, Florence
18. <u>Hispanic Established Populations for the Epidemiologic Study of the Elderly (HEPESE) Wave 8, 2012-2013 [Arizona, California, Colorado, New Mexico, and Texas]</u> (ICPSR 36578) Markides, Kyriakos S.; Chen, Nai-Wei; Angel, Ronald; Palmer, Raymond
19. <u>United States National Health Measurement Study, 2005-2006</u> (ICPSR 23263) Fryback, Dennis G.
20. <u>CRELES-3: Costa Rican Longevity and Healthy Aging Study - Wave 3, 2009 (Costa Rica Estudio de Longevidad y Envejecimiento Saludable, Ronda 3) (ICPSR 35250) Rosero-Bixby, Luis; Brenes, Gilbert; Dow, William H.</u>
21. <u>The Irish Longitudinal Study on Ageing (TILDA), 2014-2015</u> (ICPSR 37106) Kenny, Rose Anne
22. <u>National Social Life, Health, and Aging Project (NSHAP): Wave 2 and Partner Data Collection, [United States], 2010-2011</u> (ICPSR 34921) Waite, Linda J.; Cagney, Kathleen A.; Dale, William; Huang, Elbert; Laumann, Edward O.; McClintock, Martha K.;

O'Muircheartaigh, Colm A.; Schumm, L. Phillip; Cornwell, Benjamin
23. Australian [Adelaide] Longitudinal Study of Aging, Wave 6: [1999-2000] (ICPSR 3679) Andrews, Gary R.; Myers, George C.
24. National Long-Term Care Survey: 1982, 1984, 1989, 1994, 1999, and 2004 (ICPSR 9681) Manton, Kenneth G.
25. SABE - Survey on Health, Well-Being, and Aging in Latin America and the Caribbean, 2000 (ICPSR 3546) Pelaez, Martha; Palloni, Alberto; Albala, Cecilia; Alfonso, Juan Carlos; Ham-Chande, Roberto; Hennis, Anselm; Lebrao, Maria Lucia; Lesn-Diaz, Esther; Pantelides, Edith; Prats, Omar
26. Americans' Changing Lives: Waves I, II, III, IV, and V, 1986, 1989, 1994, 2002, and 2011 (ICPSR 4690) House, James S.
27. Midlife in the United States (MIDUS 1) National Study of Daily Experiences (NSDE), 1996-1997 (ICPSR 3725) Almeida, David M.

- **Happiness**
1. How happy would you say you are? T4 On the whole, how happy would you say you are? Are you very happy, somewhat happy, not very happy, or not at all happy?
   a. Taken from: Hispanic Established Populations for Epidemiologic Studies of the Elderly, Wave IV, 2000-2001 [Arizona, California, Colorado, New Mexico, and Texas].
2. Current overall happiness Q26. Taken all together, how would you say things are these days - would you say that you are very happy, pretty happy, or not too happy? - Very happy - Pretty happy - Not too happy
   a. Taken from: Oregon Health Insurance Experiment, 2007-2010.
3. Your personal situation these days - Thinking about your personal situation these days, overall, are you very happy, somewhat happy, not very happy, or not at all happy?
   a. Taken from: Northwest Area Foundation Ventures Social Indicators Survey, June-September 2005.
4. Rate personal happiness - Generally speaking, how happy would you say you are--very happy, fairly happy, or not too happy?
   a. Taken from: CBS News/60 Minutes/Vanity Fair National Poll, April #2, 2011.
5. HAPPY - G1, G2, G3, G4 For each of the following statements, check the box that best describes HOW OFTEN YOU HAVE FELT THIS WAY DURING THE PAST WEEK. DURING THE PAST WEEK: I was happy.
   a. Taken from: Longitudinal Study of Generations, California, 1971, 1985, 1988, 1991, 1994, 1997, 2000, 2005.
6. Happy
   a. Taken from: Migrant and Seasonal Head Start Study, United States, 2017-2018.
7. Happy
   a. Taken from: CRELES-2: Costa Rican Longevity and Healthy Aging Study - Wave 2, 2006-2008 (Costa Rica Estudio de Longevidad y Envejecimiento Saludable, Ronda 2).
8. IS R HAPPY - TAKING THINGS ALTOGETHER, WOULD YOU SAY YOU'RE VERY HAPPY, PRETTY HAPPY, OR NOT TOO HAPPY THESE DAYS?
   a. Taken from: Retirement History Longitudinal Survey, 1977.
9. 2013 P01 VRY HPY THS DAY F1234 - Item number: 01190 F1234 Taking all things together, how would you say things are these days -- would you say you're very happy,

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pretty happy, or not too happy these days? 3="Very happy" 2="Pretty happy" 1="Not too happy"
   a. Taken from: Monitoring the Future: A Continuing Study of American Youth (8th- and 10th-Grade Surveys), 2013.
10. F1.WAS HAPPY IN PAST WEEK - Now think about the past week and the feelings you have experienced. Please tell me if each of the following statements was true for you much of the time during the past week. First, much of the time during the past week, you were happy. Would you say yes or no?
   a. Taken from: Survey of Consumer Attitudes and Behavior, September 2010.

Data Sets
11. Voice of the People End of Year Survey, 2011 (ICPSR 33504) Gallup International, Inc.
12. ABC News Listening to America Poll, May 1996 (ICPSR 6820) ABC News
13. Survey of Midlife in Japan (MIDJA), April-September 2008 (ICPSR 30822) Ryff, Carol D.; Kitayam, Shinobu; Karasawa, Mayumi; Markus, Hazel; Kawakami, Norito; Coe, Christopher
14. ABC News/Washington Post Poll, December 2005 (ICPSR 4525) ABC News; The Washington Post
15. Midlife in the United States (MIDUS 1), 1995-1996 (ICPSR 2760) Brim, Orville Gilbert; Baltes, Paul B.; Bumpass, Larry L.; Cleary, Paul D.; Featherman, David L.; Hazzard, William R.; Kessler, Ronald C.; Lachman, Margie E.; Markus, Hazel Rose; Marmot, Michael G.; Rossi, Alice S.; Ryff, Carol D.; Shweder, Richard A.
16. General Social Survey Cumulative File, 1972-1986 (ICPSR 8609) Davis, James A.; Smith, Tom W.
17. The 500 Family Study [1998-2000: United States] (ICPSR 4549) Schneider, Barbara; Waite, Linda J
18. Survey of Consumer Attitudes and Behavior, May 2010 (ICPSR 35433) University of Michigan. Survey Research Center. Economic Behavior Program

● **Crisis**
1. LAY-OFF MAJOR/MINOR CRISIS - All in all, would you say that your experience with the lay-off created a major crisis in your life, a minor crisis, or no crisis at all?
   a. Taken from: New York Times Economic Security Poll, December 1996.
2. WAS CRISIS INTERVENTION PROVIDED PRSNLLY - Was crisis intervention provided personally?
   a. Taken from: Gateways and Pathways Project (GAPP) 1997-2000, St. Louis, Missouri.
3. Was there another life crisis? - Was there another life crisis?
   a. Taken from: National Comorbidity Survey: Reinterview (NCS-2), 2001-2002 [Restricted-Use].
4. DID YOUTH NEED CRISIS INTERVENTION? - Was crisis intervention needed or recommended for this youth?
   a. Taken from: Gateways and Pathways Project (GAPP) 1997-2000, St. Louis, Missouri.
5. Q20. Do you think the countries most severely affected by the economic crisis are doing enough to combat the crisis themselves? (Asked only in the EU) - Q20. Do you think that

the countries most severely affected by the economic crisis are doing enough to combat the crisis themselves? (Only asked in the European Union)
   a. Taken from: <u>Transatlantic Trends Survey, 2014</u>.
6. Calming: Experts commenting on likely causes of crisis(Wave 3)
7. How much, if at all, have the following sources had a calming influence on you during this financial crisis? Experts commenting on likely causes of crisis (Wave 3)
   a. Taken from: <u>Financial Crisis: A Longitudinal Study of Public Response</u>.
8. Congress Handle Finance Crisis - Do you approve or disapprove of the way Congress is handling the current economic crisis?
   a. Taken from: <u>CBS News Monthly Poll #1, October 2008.</u>
9. BEEN AFFECTED BY CRISIS OR NOT - 28. Have you personally been directly affected by that crisis or not?
   a. Taken from: <u>ABC News/Washington Post Poll, July 1990</u>.

<u>Data Sets</u>
10. <u>Eurobarometer 80.1: Europe 2020, the Financial and Economic Crisis, European Citizenship and Information on EU Political Matters, November 2013</u> (ICPSR 35204) European Commission
11. <u>Effectiveness of Alternative Victim Assistance Service Delivery Models in the San Diego Region, 1993-1994</u> (ICPSR 2789) Rienick, Cynthia; Hoctor Mulmat, Darlanne; Pennell, Susan
12. <u>Army Study to Assess Risk and Resilience in Servicemembers (STARRS)</u> (ICPSR 35197) Ursano, Robert J.; Stein, Murray B.; Kessler, Ronald C.; Heeringa, Steven G.; Wagner, James
13. <u>Stress in America, United States, 2007-2018</u> (ICPSR 37288) American Psychological Association
14. <u>State of Michigan: Taking Action on Flint Water Test Results, 2015-2017</u> (ICPSR 36955) Michigan Department of Health and Human Services
15. <u>Midlife in the United States (MIDUS Refresher): Neuroscience Project, 2012-2016</u> (ICPSR 37094) Ryff, Carol D.; Davidson, Richard J.
16. <u>Survey of Consumer Attitudes and Behavior, August 2015</u> (ICPSR 37446) University of Michigan. Survey Research Center. Economic Behavior Program
17. <u>CBS News Poll, October #2 2013</u> (ICPSR 36062) CBS News
18. <u>The Irish Longitudinal Study on Ageing (TILDA), 2012-2013</u> (ICPSR 37105) Kenny, Rose Anne
19. <u>General Social Survey, 2012 Merged Data, Including a Cultural Module [United States]</u> (ICPSR 35478) Smith, Tom W.; Marsden, Peter V.; Hout, Michael

- **Mental Health**
- **Kessler 6**
1. feel worthless in past 30 days - During the past 30 days, about how often did you feel worthless?
   a. Taken from: <u>Understanding How Personal Networks Change: Wave 1</u>.
2. HOW OFTEN FEEL WORTHLESS PAST 30 DAYS - During the past 30 days, about how often did you feel worthless?
   a. Taken from: <u>Behavioral Risk Factor Surveillance System (BRFSS) Asthma Call-</u>

Back Survey, 2009.
3. hopeless in past 30 days - During the past 30 days, about how often did you feel hopeless?
    a. Taken from: Understanding How Personal Networks Change: Wave 1.
4. Felt hopeless in past 30 days - During the past 30 days, about how often did you feel hopeless?
    a. Taken from: Displaced New Orleans Residents Pilot Study (DNORPS).
5. During the past 30 days how often did you...feel hopeless about the future?
    a. Taken from: National Comorbidity Survey: Reinterview (NCS-2), 2001-2002 [Restricted-Use].
6. Feelings experienced in past 30 days: everything was an effort - G20. We'd like to know how people taking care of children feel about life. During the past 30 days, how often did you feel...that everything was an effort?
    a. Taken from: National Survey of Early Care and Education (NSECE), [United States], 2010-2012.
7. Past 30 days - feel hopeless - (WEB) How often in the past 30 days did you...feel hopeless (PHONE) How often in the past 30 days did you feel hopeless?
    a. Taken from: Army Study to Assess Risk and Resilience in Servicemembers (STARRS).
8. Did you feel hopeless? - How much of the time today did you feel HOPELESS?
    a. Taken from: Midlife in the United States (MIDUS 1) National Study of Daily Experiences (NSDE), 1996-1997.

Data Sets
9. Head Start CARES Demonstration: National Evaluation of Three Approaches to Improving Preschoolers' Social and Emotional Competence, 2009-2015 (ICPSR 35510) Morris, Pamela
10. Preventing Depression in Couples Facing Job Loss, 1996-1998: [Baltimore, Maryland, and Detroit, Michigan] (ICPSR 3567) Price, Richard H.; Vinokur, Amiram D.; Howe, George W.; Caplan, Robert D.
11. Flint [Michigan] Adolescent Study (FAS): A Longitudinal Follow-Up Study of Substance Use on Adult Transitional Events, 2000-2003 (ICPSR 37032) Zimmerman, Marc A.
12. National Health and Nutrition Examination Survey (NHANES), 2007-2008 (ICPSR 25505) United States Department of Health and Human Services. Centers for Disease Control and Prevention. National Center for Health Statistics
13. National Health Interview Survey, 2012 (ICPSR 36146) United States Department of Health and Human Services. Centers for Disease Control and Prevention. National Center for Health Statistics

- **CESD**
1. Baseline CESD calculated score
    a. Taken from: Sacramento Area Latino Study on Aging (SALSA Study), 1996-2008.
2. CESD > or = 28 - 6. Is the CES-D score greater than or equal to 28?
    a. Taken from: Resources for Enhancing Alzheimer's Caregiver Health, 1996-2001, Baseline and Follow-Up Data.
3. CESD caseness at Time 2 - Cutoff at 16 for caseness Total CES-D >=16 =1 caseness

a. Taken from: <u>Hispanic Established Populations for Epidemiologic Studies of the Elderly, Wave II, 1995-1996: [Arizona, California, Colorado, New Mexico, and Texas]</u>.

4. CESD: Mean of items 1 to 20, calculated after reversals when 18 items are present (higher score = more depression) - Center for Epidemiological Studies Depression Scale (CESD) - CESD: Mean of items 1 to 20, calculated after reversals when 18 items are present (higher score = more depression)
   a. Taken from: <u>The Family Life Project, Phase I, United States, September 2003-January 2008</u>.

5. CESD: was happy - During the past week... I was happy. [HAND CARD FF] (Now let's talk about thoughts and feelings you may have had during the past week. I will read a series of statements. Tell me how often during the past week you felt like this: rarely or none of the time, some of the time, occasionally, or most of the time? Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.)
   a. Taken from: <u>National Social Life, Health, and Aging Project (NSHAP): Wave 1, [United States], 2005-2006.</u>

6. SD CES-D score - 14. CES-D Score (questions 1 - 10): _____ (Questions #5 and #8 are reverse scored)
   a. Taken from: <u>Resources for Enhancing Alzheimer's Caregiver Health (REACH II), 2001-2004</u>.

7. Center for Epidemiologic Studies Depression (CES-D) depressive symptoms clinical score not divided by items
   a. Taken from: <u>Project STRIDE: Stress, Identity, and Mental Health, New York City, 2004-2005</u>.

8. Center for Epidemiologic Studies 10-item Depression Scale (CES-D) score category [derived variable]
   a. Taken from: <u>Migrant and Seasonal Head Start Study, United States, 2017-2018.</u>

9. CES-D Felt depressed - Center for Epidemiologic Studies Depression Scale (CES-D): Circle the number that best describes how often you felt or behaved in the following ways during the past week. I felt depressed.
   a. Taken from: <u>Survey of Midlife in Japan (MIDJA): Biomarker Project, 2009-2010.</u>

Data Sets

10. <u>Hispanic Established Populations for Epidemiologic Studies of the Elderly (EPESE) Frailty Study: 2006-2009</u> (ICPSR 36321) Ottenbacher, Kenneth; Graham, James

11. <u>Longitudinal Study of Generations, 1971, 1985, 1988, 1991, 1994, 1997: [California]</u> (ICPSR 4076) Bengtson, Vern L.

12. <u>Midlife in the United States (MIDUS 2): Biomarker Project, 2004-2009</u> (ICPSR 29282) Ryff, Carol D.; Seeman, Teresa; Weinstein, Maxine

13. <u>Cognition and Aging in the USA (CogUSA) 2007-2009</u> (ICPSR 36053) McArdle, John; Rodgers, Willard; Willis, Robert

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