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44 Open Sharing of Behavioral Research Datasets: Breaking Down the Boundaries of the Research Team

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44.1 Introduction

Behavior is the lynchpin underlying many of the most vexing problems in public health. Behavior can contribute to the progression or prevention of disease, define a disorder or mark recovery, and provide mechanisms for therapeutic intervention. Clinicians and health researchers have many robust and reliable tools at hand—from blood assays to brain or whole body images—for measuring people's physical health. But the tools for measuring healthy and at-risk behaviors in the contexts where they naturally occur are markedly limited.

Nevertheless, a readily available, inexpensive, and profoundly powerful tool already exists to capture the complexity and richness of many health-related human behaviors— video recording. Video captures subtle, real-time dimensions of behavior that standardized observational or self-report instruments ignore or grossly simplify. Video captures the nuances and vital details of experimental procedures more completely and accurately than do written protocols or the "methods sections" of published articles (Adolph et al. 2017; Gilmore et al. 2018). Although video contains identifiable information such as faces and voices, video data can be securely but openly shared with other researchers by adapting existing policy frameworks and building on proven technology. In this chapter, we introduce Databrary (databrary.org), a digital data library that is specialized for storing and sharing video recordings of behavior and experimental procedures. In doing so, we describe the benefits of open video sharing, barriers to its widespread adoption, and solutions that Databrary has devised to overcome these barriers. We argue that by making commonplace secure video sharing about health-related behaviors and empirical procedures, we can break down barriers between diverse and geographically dispersed research teams, increase scientific transparency, improve the reproducibility of research

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results, and hasten the pace of disease prevention and health promotion.

44.2 Behavior and Public Health

Researchers have long recognized the central role of behavior in public health (Committee on Health and Behavior: Research, Practice, and Policy 1982). Unintentional injury—the result of risky behavior—is the leading cause of death through middle age (Centers for Disease Control n.d.). In older adults, heart, lung, cerebrovascular, and liver disease are leading causes of mortality—all diseases strongly associated with behaviors involving diet, exercise, and substance use. One in five Americans suffers from mental illness each year, and 1 in 25 suffers from a serious form of mental illness (Serious Mental Illness (SMI) Among U.S. Adults n.d.)—illnesses in part defined by, caused by, and treated by behavior. Developmental disabilities affect about one in six children (Developmental Disabilities Prevalence Trends | Key Findings | NCBDDD | CDC n.d.), and characteristic patterns of behavior distinguish the leading types of health problems including learning disabilities, attention deficit hyperactivity disorder, developmental delay, and autism spectrum disorder. Across health problems, medication is a primary source of treatment, but fewer than 50% of patients comply with recommended patterns of prescription drug therapies (WHO | Adherence to long-term therapies n.d.).

Despite the central role of behavior in health risk, assessment, and treatment, current tools used to capture health-relevant patterns of behavior have substantial weaknesses. Most tools do not rely on direct behavioral observation. Instead, the tools involve self-report questionnaires or reports by others (family members, teachers, co-workers), making such questionnaires susceptible to the vagaries of human memory and veracity (e.g., Boase and Ling 2013; Schoeller et al. 2013). Most tools are standardized instruments (patients or participants are assigned a normed summary score or set of scores) that can mask important dimensions of individual and cultural variation (Deevybee 2011). And even those tools that do involve direct behavioral assessments outside the clinical context may suffer from questionable reproducibility (Open Science Collaboration 2015; Gilbert et al. 2016). Video has largely untapped potential to overcome many of these weaknesses and thereby enhance and advance the study of behavior.

44.2.1 Making Video a Pillar of Social and Behavioral Research

Researchers who study human or animal behavior (Egnor and Branson 2016) have recognized the power of visual media to capture the richness and complexity of behavior as it unfolds in real time (Adolph 2016; Gesell 1946, 1991). Video closely mimics the visual and auditory experiences of live human observers, so recordings collected by one researcher for a particular purpose may be readily understood and reused by a different researcher for a different purpose. Behavioral video has research life and potential long after the original study is completed. This makes video an especially valuable raw material for discovery and treatment, especially *if it can be shared*.

Currently, video is the backbone of research for thousands of behavioral scientists who study learning and development, each of whom collects hundreds to thousands of hours of video each year. The scale and breadth of video data collection in the developmental and learning sciences is vast. For example, the Databrary Project has collected 45,000+ hours of video from 900+ research studies of infants, children, and adults in its first 5 years of operation. The Measures of Effective Teaching Project, funded by the Gates Foundation, generated more than 1000 videos from 3000 K-12 classrooms over a 3-year period. The data, constituting tens of terabytes of storage, are streamed to registered viewers across the country. The NSF-funded HomeBank project and TalkBank/CHILDES archive are collecting and sharing thousands of hours of audio recordings of language by and to children, some of which are accompanied by video. The Autism and Beyond Project at Duke University has deployed an iPhone application that will collect video images of thousands of children's facial expressions to evaluate the feasibility of using computer vision techniques

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to screen children in their homes for developmental disorders and risk of mental illness. Clearly, the widespread availability of low-cost, high-resolution cameras has made video a large and rapidly growing source of information about behaviors relevant to child development, classroom learning, language learning, and the prevalence of health risk. Video has also proven its utility in medicine as a diagnostic aid in telemedicine (mHealthIntelligence 2015), as a mnemonic aid for patients (Meeusen and Porter n.d.), and as a tool for medical training (JBJS Video Supplements n.d.).

44.2.2 Video Facilitates Transparency

Video has unique virtues for addressing researchers' growing concerns about reproducibility, transparency, and openness (Adolph et al. 2017 and Gilmore et al. 2018; Open Science Collaboration 2015; Gilbert et al. 2016; Gilmore and Adolph 2017; Nosek and Bar-Anan 2012; Nosek et al. 2012). Video documents the interactions between people and their physical and social environment unlike any other form of measurement. It captures when, where, and how people look, gesture, move, communicate, and interact (Adolph 2016; Curtis 2011; Derry 2007; Gesell 1946, 1991; Goldman et al. 2014). As such, video can capture essential details about empirical procedures that are overlooked or omitted in the most detailed and carefully written methods sections of scientific papers. Video can record how people gave consent to participate in research, what tasks participants performed, and in what order. Video can capture behavior in laboratory and classroom settings, at home, and in more public settings. It can capture the dynamics of computer-based tasks and displays used in laboratory research.

Videos of empirical procedures can and should be viewed as the gold standard of documentation across the behavioral sciences. Indeed, were the use of video for this purpose more widespread, many disagreements about whether empirical replications truly reproduced the original experimental conditions would be moot (Open Science Collaboration 2015; Gilbert et al. 2016). The power of video to document procedures should also be an attractive solution for scientists in fields that do not commonly collect or analyze video (Gelman 2012). The *Journal of Visualized Experiments (JOVE)* arose precisely to meet this need for making research methods more widely available, but more affordable and accessible tools for sharing videos of research methods are needed.

44.2.3 Video Poses Challenges to Sharing, but These Barriers Can Be Overcome

Personally identifiable information on video poses problems for the protection of participants' privacy. Most videos of people contain identifiable information—faces, voices, spoken names, and interiors of homes and classrooms. Removing identifiable information from video severely diminishes its value for reuse and puts additional burdens and costs on researchers. For years, policies have existed for sharing de-identified text-based data (U.S. HHS 2012), but video cannot be readily de-identified in the same ways as text data. Therefore, video sharing requires new policies that protect the privacy of research participants while preserving the integrity of raw video for reuse by others.

Large file sizes and diverse formats present technical challenges. Video files are large (1 h of HD video can consume 10 GB of storage) and come in various formats and sources (from cell phones to high-speed video). Many studies use multiple camera views to capture desired behaviors from different angles. Thus, sharing videos requires substantial storage capacity, significant computational resources, and specialized technical expertise to store and transcode videos into common formats that can be preserved over the long term.

Video sharing poses practical challenges of data management. Researchers lack time and resources to find, label, clean, organize, link, and convert files into formats that can be used and understood by others (Ascoli 2006). Most researchers lack training and expertise in standard practices of data curation (Gordon et al. 2015). Video coding tools represent the correspondence between video and coding files in tool-specific ways, or not at all. Few researchers

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reliably or reproducibly document workflows or data provenance. When researchers do share, standard practice involves organizing data after a project is finished, perhaps when a paper goes to press. This "preparing for sharing" after the fact presents a difficult and unrewarding chore for investigators, one that often exceeds the cost and time frame contemplated under federal data-sharing policies (discussed below). It also makes curating datasets a challenge for repositories.

Extracting behavioral patterns from video presents technical and practical barriers. Although machine-assisted image and video-tagging has made significant advances in recent years, it cannot yet replace the ability of human observers to recognize complex sets of behaviors (e.g., whether a mother is "responsive" to her infant's "bid" for assistance), distinguish similar behaviors (a reach versus a point), detect particular behaviors (parent and child speech amidst the noisy sea of television, music, and traffic in the everyday home), and assign new meanings to behaviors (an exploratory versus performatory action). Currently, researchers represent patterns extracted from video in a variety of ways, including paper and pencil, and so most codes cannot be easily exported to other tools. In principle, researchers could build on the videos and tags generated by others. But in practice, most researchers do not share coding files with researchers outside their labs. Moreover, coding files often contain proprietary and incompatible data formats making them difficult to push along the analysis pipeline and to share with other researchers. As a result, the hard-won, expensive-to-acquire human insights about behaviors extracted from research video remain difficult to analyze and largely hidden from the greater scientific community.

44.2.4 Federal and Journal Data-Sharing Policies Largely Ignore Video

Both NSF and NIH have had data-sharing policies in place for some time. NSF expects investigators to share with other researchers "primary data, samples, physical collections, and other supporting materials" associated with NSF-funded work "at no more than incremental cost and within a reasonable timeframe" (National Science Foundation n.d.). Since 2003, NIH has required grantees seeking more than $500,000 in direct costs in any single year to include in their application a plan for data sharing or a statement about why sharing is not possible (NIH 2003). NIMH has made data sharing an especially high priority, providing support for a specific repository infrastructure—the NIMH Data Archive (NDA)—that NIMH grantees are now required to use for depositing de-identified research data (NIMH 2015). In light of increased concern about transparency and reproducibility of published results, many journals have begun to enforce data-sharing requirements. Nonetheless, current data-sharing policies from research funders and publishers largely ignore video because recordings often contain potentially identifiable faces and voices. Until recently, requiring videos to be shared has seemed at best impractical. We describe in the next section how Databrary has overcome barriers to widespread video data sharing among researchers, making it easy and practical surprisingly straightforward (Gilmore et al. 2018).

44.3 Databrary Facilitates Sharing and Reuse of Research Video

Databrary is a digital data library that is specialized for the storage, management, and sharing of research video. It arose to meet the needs of researchers who collect video in laboratory, home, classroom, or museum contexts. The project is supported by awards from the National Science Foundation (BCS-1238599), the National Institute of Child Health and Human Development (NICHD U01-HD-076595 and R01-HD-094830), the Society for Research in Child Development, the LEGO Foundation, the James S. McDonnell Foundation, and the Alfred P. Sloan Foundation. The project team and digital library are housed at New York University. In launching and growing Databrary over the past several years, the PIs overcame critical barriers to sharing video, including

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solutions for respecting participants' privacy; for storing, streaming, and sharing video; and for managing video datasets and associated metadata (Gordon et al. 2015). Databrary's technology and policy framework established the foundation for securely sharing research videos. As of late 2019, more than 1,400 researchers from some 500+ institutions around the world have authorization to access more than 42,000 hours of video stored in Databrary. The files depict more than 11,400 research participants from 3 weeks to 60 years of age representing diverse racial, ethnic, and cultural backgrounds engaging in a wide range of behaviors. Databrary has also developed a free, open-source, video-coding tool called Datavyu (http://datavyu.org) to enable researchers to add annotations that are time-locked to individual frames or video segments. Databrary has targeted the developmental and learning sciences community because it is the PIs' intellectual home and a substantial source of research video, but we have specifically designed Databrary to be adapted for and used by other researchers in the behavioral sciences.

Databrary permits users to upload, store, organize, and share data with collaborators, the restricted community of authorized Databrary users, or the public, depending on the level of sharing permission granted by participants. Users may also search for, browse, view, and download videos stored on the site. They may view specific metadata such as participants' ages or recording context (e.g., home, lab, or school) for recoding and reanalysis. Databrary also empowers users to create, view, or download highlights—video excerpts that can be shown for educational or research purposes. Thus, Databrary supports sharing, reanalysis, and pre- or non-research uses of video while simultaneously solving some of the thorniest problems associated with sharing data that contain personally identifiable information.

44.3.1 Databrary's Policies Enable Sharing of Identifiable Data

Databrary's policy framework recognizes that the content of recordings must not be altered if we wish to maximize the potential for reuse. Thus, Databrary does not attempt to de-identify videos. However, to enable sharing of unaltered research video containing identifiable information, Databrary developed new policies to protect participants' privacy. First, Databrary restricts access to researchers who register and secure formal authorization from their institutions. These "authorized investigators," primarily faculty members, are eligible to conduct independent research at the institution, have research ethics training, and their institution accepts responsibility for the researcher's actions related to the use of Databrary. Second, Databrary shares identifiable data only with the explicit permission of the participants, and only at the level the participants specify. Databrary has created template language for seeking participants' permission to share data, which researchers may adapt for their own use. An online user guide fully describes these policies.

Unique among data repositories, Databrary authorizes both data use and contribution. However, users agree to store on Databrary only materials for which they have IRB/ethics board approval. Data may be stored on Databrary for the contributing researcher's use regardless of whether the records are shared with others. When a researcher chooses to share, Databrary makes the data available to the community of authorized researchers. We note that a 1000 researchers and their institutions have agreed to Databrary's framework.

44.3.2 Databrary Overcomes Technical Barriers to Video Data Sharing

To address the problem of diverse video formats, Databrary uses New York University's high-performance computing services to automatically transcode each recording into a common format suitable for web-based streaming (currently H.264 + AAC in MP4 for video). The system maintains a copy in the original format for long-term preservation. To address local file storage limitations, Databrary does not currently place limits on the number or size of files that can

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be uploaded. As a web-based application fully compatible with modern web-browsers, Databrary does not require special software for access. Databrary's assets total more than 65 TB and are stored on New York University's central IT storage, which provides one off-site mirror and regular long-term tape backups.

44.3.3 Databrary's Design Overcomes Practical Barriers to Sharing

All data types are enhanced when accompanied by rich and informative metadata, and Databrary supports the storage and sharing of multiple data types beyond video. But unlike other forms of data, video requires relatively little metadata to be useful to others. The only metadata that are strictly required are participants' preferences about sharing. Because many researchers find post hoc data curation to be aversive (Ascoli 2006), Databrary developed a novel "active-curation" framework that reduces the burden (Gordon et al. 2015). The system empowers researchers to upload and organize data as it is collected. Immediate uploading reduces the workload on investigators, minimizes the risk of data loss and corruption, and accelerates the speed with which materials become available.

To encourage immediate uploading, Databrary provides a complete set of controls so that researchers can restrict access to their own labs or to other users of their choosing prior to sharing. Datasets can be shared with the broader research community at a later point when data collection and ancillary materials are complete, whenever the contributor is comfortable sharing, or when journals or funders require it. Furthermore, any de-identified data associated with a dataset, including demographic and study metadata, stimuli or displays, coding manuals, and coding data, may be shared publicly, substantially broadening the availability of these materials.

To encourage active curation, Databrary employs familiar, easy-to-use spreadsheet and timeline-based interfaces that allow users to upload videos, add metadata about tasks, settings, and participants, link related coding files and manuals, and assign appropriate permission levels for sharing. Users can view videos, create highlights from them, and tag them in the web browser. Shared materials must be made available in findable, accessible, interoperable, and reusable formats to be maximally useful to others (Wilkinson et al. 2016). To that end, Databrary allows researchers to search for videos that meet their particular specifications. Each data set or study on Databrary has its own unique web page that when shared receives its own persistent identifier (DOI) that may be used to cite the resource.

Active curation poses few new burdens on researcher's time beyond current practices while offering significant benefits. In effect, Databrary acts as a researcher's personal lab file server and cloud storage, enabling web-based sharing among research teams and ensuring secure off-site backup. Moreover, by entering participant- and study-level metadata into Databrary, researchers make it possible for others to search for participants or studies that meet specific criteria. Thus, researchers who wish to reuse materials from Databrary for new studies can find exactly the videos and related metadata they need to address their question.

44.3.4 Video Coding Tools Enable Discovery

Most researchers who collect video deploy trained human observers to view the recordings and annotate them with specific tags that label the onset and offset of particular behaviors or events, the category or type of behavior, transcriptions of speech, and qualitative judgments about mood or other psychological characteristics. In the developmental sciences, spreadsheet software and paper-and-pencil are the most commonly used tools for annotating video, but an increasing number of researchers use specialized tools for video and audio annotation. The tools allow coders to play video forward and backward at varied speeds time-locked to the codes. This enables researchers to unpack the multi-layered complex patterns of human behavior as it unfolds in time. Following one or more coding passes, each of

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which focuses on a subset of behavioral dimensions, the tags or annotations are then exported for visualization and analysis using other tools.

One of us (Adolph) has pioneered the use of video coding tools for mining the data contained in video, and so the development of and support for video coding tools has been integral to the Databrary project from the beginning. To that end, Databrary has published a web-based best practices guide for coding video that is agnostic about the tool or tools a researcher chooses to use (Databrary n.d.). We have also continued to develop Datavyu, making it suitable for a variety of video coding use cases. Datavyu's Ruby scripting API makes it possible for users to customize the program and automate many routine tasks that would otherwise require significant time investment and often error-prone human intervention. Datavyu files, called spreadsheets, may be uploaded to Databrary and shared along with the videos they are linked to. This allows research teams in geographically separate locations—across campus or across the globe—to share video coding files and to validate or build upon each other's codes.

The rich set of time-locked annotations contained in the Datavyu files can be visualized on the Databrary timeline, but not easily searched. But empowering Databrary to import, display, make searchable, and export annotation from Datavyu and related video coding tools remains an important project goal. In the near future, a researcher will be able to search across Databrary for specific time segments in which a particular type of behavior occurred. For example, a researcher could search for all instances of crying, or all instances of vocalizations by English-speaking children between 12 and 24 months of age. To our knowledge, Databrary is the only data library in the social and behavioral sciences that stores individual- and session-level metadata in this way. We believe that indexing video and associated data elements by individual participant characteristics has the potential to break down boundaries between research teams and also to make it possible to ask and answer new important research questions that seem completely impractical today.

For example, imagine convening a team of experts representing a wide range of topical domains—e.g., language, emotion, cognition, physical activity, the environment—and asking them to develop a set of foundational codes that can be applied to video recordings collected from some form of natural human behavior. The joint time series of these moment-by-moment codes across domains, if openly and widely shared, would constitute a valuable resource for new discovery about patterns of behavior—within and across domains—especially if it were coupled with other traditional self-report and observational measures and individual-specific metadata. By committing to making video recordings of all procedures and using video exemplars to demonstrate code definitions, the team could substantially advance the transparency of its research innovations and ensure highly reproducible procedures are implemented even across geographically dispersed data collection sites.

As it happens, the authors and their colleagues have embarked on such an endeavor. The Play & Learning Across a Year (PLAY) project aims to collect, code, and share hour-long videos of 900 12-, 18-, and 24-month-old infants and their mothers engaged in natural home activities. A team of more than 65 experts representing diverse content domains has contributed to planning the protocol and designing the coding passes. All aspects of project planning, coding, and grant writing have relied upon and been documented with video stored on Databrary. Datavyu has been updated with features that make certain types of coding—especially speech transcription—easier. A web (wiki)-based protocol has been created that couples text- and static image descriptions of procedures and codes with video exemplars. So, our vision of how shared research video can transform team-based behavioral research is based on our own personal experiences. We are optimistic that other research teams will find value in making video a cornerstone of their behavioral research programs.

44.4 Conclusions

Biomedical research faces many challenges in the era of "Big Data" (Gilmore 2016), including the very real problem of meeting the public's high expectations about what ought to be achieved

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versus what actually can be achieved. Multidisciplinary, geographically dispersed research teams in the biomedical and health sciences face many barriers to collaborative discovery. Yet, we argue that researchers across the health sciences might take this moment to renew an interest in the complexities and marvels of behavior in all of its manifest forms, especially those that relate directly to the central questions about how to promote human health. Focusing on the limits of current measures in capturing essential properties of human behavior will help us ask better, more informed questions about what combination of factors leads to which health outcomes.

A curated, sharable, and reusable repository of video-recorded behavior could shed light on some of the most vexing issues in biomedical research. Researchers are already using video to record natural sleep behaviors in the homes of new parents (Batra et al. 2016), discovering that most parents put infants to sleep in environments with established risk factors even when they know they are being recorded. Video recordings of people with anorexia show differences in meal-time eating behaviors relative to healthy controls that could be important targets for therapeutic intervention (Gianini, et al. 2015). Video recordings of movement are being used in the diagnosis and treatment of Parkinson's disease (Reich et al. 2014). And video has even become part of an effort to make biomedical wet lab research protocols more reproducible through the Aquarium Project (http://klavinslab.org/aquarium-about.html).

To our knowledge, no one has yet proposed to measure the human "behavior-ome," but someone should. The PLAY project is our attempt to jumpstart a behavior-ome by focusing on a population we know about best and care about most. Our experiences thus far suggest that video recordings and tools for storing, managing, coding, and sharing videos like Databrary and Datavyu will be essential for comparable efforts with other target populations that intend to share data and procedures widely and openly. Policies for the sharing of identifiable data with the permission of research participants among a restricted group of authorized researchers who promise to uphold the highest ethical standards will also be needed. We believe that the infrastructure Databrary and Datavyu have established in the developmental and learning sciences—and which other data repositories are establishing in other fields—will help to break down barriers that confine the membership of research teams and limit the questions they can pursue. With a rich array of videos of actual human behavior accessible openly and readily alongside other types of measures, research team members can be located anywhere, and ask questions that are limited only by their own imaginations.

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