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Secured web-based video repository for multicenter studies

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Abstract

Background—We developed a novel secured web-based dystonia video repository for the Dystonia Coalition, part of the Rare Disease Clinical Research network funded by the Office of Rare Diseases Research and the National Institute of Neurological Disorders and Stroke. A critical component of phenotypic data collection for all projects of the Dystonia Coalition includes a

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Competing Interests

The authors declare that they have no competing interests.

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standardized video of each participant. We now describe our method for collecting, serving and securing these videos that is widely applicable to other studies.

Methods—Each recruiting site uploads standardized videos to a centralized secured server for processing to permit website posting. The streaming technology used to view the videos from the website does not allow downloading of video files. With appropriate institutional review board approval and agreement with the hosting institution, users can search and view selected videos on the website using customizable, permissions-based access that maintains security yet facilitates research and quality control.

Results—This approach provides a convenient platform for researchers across institutions to evaluate and analyze shared video data. We have applied this methodology for quality control, confirmation of diagnoses, validation of rating scales, and implementation of new research projects.

Conclusions—We believe our system can be a model for similar projects that require access to common video resources.

Keywords

Video repository; clinical trial; secured access; dystonia; video protocol

Background

Evaluation of patients with movement disorders requires visual pattern recognition which is important for diagnosis as well as communication about these patients. This was one of the key justifications in 1986 for adding video segments to the journal *Movement Disorders*, one of the first journals to have this capability.[1] Journals that permit video downloads either require protection of patient identity by masking parts of the face or requiring authors to obtain patient consent for public access. Authors are directly responsible for protecting patient confidentiality or obtaining patient permission for public access to identifiable videos, but journal editors must ensure that these obligations are met before publishing or posting such videos. Multicenter studies that require universal video collections can benefit from a centralized platform for video storage and secured sharing. However, the sharing of video specifically must prevent unauthorized download of personal health information (PHI), such as full-face videos needed to evaluate cranial dystonia, as required by United States law described in the Health Insurance Portability and Accountability Act (HIPAA) and other international laws governing confidentiality of health information.

Dystonia patient videos are often used as essential data in various studies. However, varying local protocols and storage methods at recruiting sites present barriers for sharing and comparison. The Dystonia Coalition, sponsored by the Office of Rare Disease Research (ORDR) and the National Institute of Neurological Disorders and Stroke (NINDS), parts of the National Institutes of Health, aimed to establish a comprehensive clinical data and biospecimen repository from thousands of participants with isolated focal and segmental dystonia at multiple domestic and international centers. Two of the projects in the coalition require a centralized video repository of all research participants for multiple purposes, including confirmation of diagnosis and assessment of inter-rater reliability. In addition,

electronic access to these videos permits multiple additional independent studies of the same patient groups. This repository must maintain properly secured, yet easily accessed videos. Commercial systems such as NETFLIX, a publically available video content repository, have employed internet based software with the requisite characteristics. We now describe the development and implementation of a video repository that addresses these needs and may have wide spread applicability.

Methods

There are five critical steps in our video repository system: recording a standard video protocol, uploading to a central site, re-encoding into a universal cross-platform format, storing on a central server and providing secured internet access.

(1) Video collection

A video protocol developed by the Dystonia Study Group[2] provided the basis for our protocol. An international panel with expertise in various types of dystonia then modified this protocol. The panel removed items considered not useful based on prior experience or redundancy. This protocol addressed multiple needs for comprehensive assessments of different body parts. This included voice recordings; observations to permit ratings such as the Global Dystonia Rating Scale (GDRS)[2], Burke Fahn Marsden (BFM)[3] rating scale and Toronto Western Spasmodic Torticollis Rating Scale (TWSTRS)[4]; and capture of the common data elements required for the NINDS Human Genetics Resource at Coriell, The panel added items to more carefully document spasmodic dysphonia, lower limb dystonia and task specific dystonias. The panel also recognized the frequent overlap with tremor and included many items to assess different types of tremors. Most importantly, the protocol balanced the need to be comprehensive with the need to be efficient and brief enough to encourage its use while making transfers feasible. The current video protocol is shown in the Table. This protocol was sent to recruiting sites along with a demonstration video. The video protocol typically takes 10 to 15 minutes to complete. Videos can be collected in any one of multiple formats (wma, mp3, wav, wmv, mov, dvr-ms/wtv, mjpeg, avi, mpeg-2, mpeg-4, TS, MP3/H.264, avchd, m2ts, aac, and ac3).

(2) Uploading to a central site

Each recruiting site can securely upload video via a file transfer protocol (FTP) using FileZilla, an open source, freely available utility (www.favfiles.com/c/filezilla?keyword=filezilla&source=267247-11415-169-32091) to a central server hosted at Washington University School of Medicine (WUSM). FileZilla has a drag and drop interface that simplifies data transfer. The remote user is provided with an authorized username and password and the secured FTP (SFTP) server name permitting connection and secure uploading of files (see Figure). A new root folder is created for each remote user that connects to the SFTP site. Each remote user only can access the folder containing videos from their site.

SFTP allows for secure uploads and permits user permissions that tie into Microsoft Active Directory. Standard FTP is disabled on the server software. Logging is enabled to facilitate

troubleshooting, should problems arise. A list of online users and past connections is maintained in the software, and an idle timeout of 30 minutes is set to close unused connections. Thus, remote users may start uploads, lock his/her screen and leave the job running. Once the job completes, the connection will close after 30 minutes of idle time.

This Dystonia Coalition system provides a secured FTP protocol that meets HIPAA guidelines for security. This transfer protocol has been approved by the Human Research Protection Office at WUSM.

(3) Video encoding

We use Silverlight© (Microsoft; www.microsoft.com/silverlight/), a free web browser plug-in that works with most major web browsers running on most Microsoft or Mac operating systems. To enable appropriate streaming capability, we encode all videos using Microsoft Expression Encoder version 4 SP2©. Each video file is encoded to an mp4 format that is accessed by an .html pointer file. The following technical settings must be selected in Microsoft Expression Encoder to ensure compatibility with Silverlight:

- Encoding for Silverlight
- H.264
- High Speed Broadband VBR
- Source Frame Rate
- Source Resolution

The encoding process creates a new folder with a time-date stamp on the BlueArc (now Hitachi) storage area network (SAN) system, but any secured disk array could work. We then rename the folder, the .html file and the .mp4 file using a standardized naming convention for the videos.

During the encoding process, each video undergoes an initial quality control to ensure that the video protocol was followed properly and image quality is adequate. This also provides an opportunity to quickly do a quality check on proper diagnosis and body parts involved in the dystonia.

(4) Video storage

Once the videos have been encoded to the proper format and renamed, they are added to the Dystonia Coalition website. Video filename, study number, date, diagnosis, project, site, location and any comments are entered into the web interface (https://dystonia.wustl.edu). The web interface permits assignment of selective permissions for each video file. Designation of groups, defined by video access permissions, is controlled with Microsoft Active Directory. This strategy permits flexible and multiple group assignments that allows easy responsivity to changing research and security needs. The information is passed from the web interface to an SQL 2008 database. The video name is used to identify the location of the video and to make it available to remote users immediately after the information is entered. Security is assigned to each video at this time by using the site, diagnosis and project that is entered into the web interface.

The video files then are moved to the newly created folder on a secured large capacity BlueArc (Hitachi) SAN. The original video is stored until the encoded video has been reviewed and then is stored off-line on a DVD. The BlueArc (Hitachi) SAN storage system is located in a HIPAA-approved data center. An off-site, replicated, disaster-recovery backup system also is located in a HIPAA approved data center. The backup controls in place on the BlueArc (Hitachi) SAN Storage system include daily snapshots which serve as incremental backups and off-site replication that occurs every 3 hours.

(5) Video viewing

Videos can be streamed from the website via Silverlight© (Microsoft; www.microsoft.com/silverlight/) using Windows Server 2008 IIS Smooth Streaming technology. This process permits viewing but blocks downloading of video files to a user's desktop. However multiple means of pirating streaming videos can bypass the download blocking. Additionally, the images could be copied by using a video camera aimed at the computer screen. Hence, we limit access to videos to those that provide a written agreement not to download or copy videos. User login with Active Directory limits access only to permitted groups. A new Active Directory group and corresponding SQL server group can be created for any new site that joins the Dystonia Coalition. New projects also can be added by simply adding corresponding Active Directory and SQL server groups. With appropriate IRB approval and agreement with WUSM, users within a permitted group, like an enrolling site, can search and view specific videos on the website by various criteria including diagnosis, project or clinical feature. Videos are available through the Dystonia Coalition video website (https://dystonia.wustl.edu). The public can identify what types of videos are available but no PHI is accessible and additional permissions are required to view videos. These permissions can be obtained through formal request to the Dystonia Coalition Executive Committee and then set up as described above. A request for access to videos can be sent to the administrative coordinator of the Dystonia Coalition found by following the links for professionals to "get involved" at dystoniacoalition.org.

Hardware

The primary server used for the Dystonia Coalition Video Repository website is a Dell Precision T7400 with Intel Xeon 3.2 gigahertz processor and 4 gigabytes (Gb) of RAM running Windows Server 2008 R2. The responsibilities of the primary server include hosting the SFTP site, running IIS 7.0 and hosting the database. The primary server also acts as temporary storage of the videos, and a separate virtual server is used for encoding the videos. The virtual server is configured with Windows Server 2008 R2 with 8Gb of RAM (random access memory) and running using Hyper V. The virtual machine is strictly used for encoding to ensure that all resources are available for this processing.

Software

The software used includes: Microsoft Visual Studio, Microsoft Expression Encoder, Microsoft SQL Database 2008 and Microsoft Active Directory Services. The front end website for viewing videos was designed using Microsoft Visual Studio. The site is created using ASPX (ASP.NET source file). The website for data entry for new videos also uses Microsoft Visual Studio and is written in ASPX. Microsoft SQL Database 2008 provides the

repository of permissions for all of the videos. The database contains all of the sites, diagnoses and projects and directly connects to Microsoft Active Directory Services.

Overall Security

Upload Security—Remote users upload content using File Transfer Protocol (FTP) over Secure Shell (SSH).[5] SSH is a network protocol that allows data exchange via a secure channel between two networked devices. The encryption used by SSH provides confidentiality and integrity of data over insecure networks, such as the Internet.

User Permissions—Permissions for remote users who wish to use the Dystonia Coalition Video Repository are assigned by creating a Windows active directory account. Each user account group assignment matches the University or other designation identified by the Dystonia Coalition. Each user from that group has permission to access all videos uploaded from that site. Other groups can be defined based upon research project with access granted to selected videos, which can include videos originally uploaded from any of the recruiting sites. However, this access requires local IRB approval before such permissions are granted. Open access is permitted to anyone who wants to determine what videos with selected criteria such as diagnosis or recruiting site are available, but this open access does not permit viewing videos.

Viewing of Videos—Users with adequate permission securely connect to the Video Repository server via an HTTPS protocol which utilizes SSL/TLS (secured socket layer/ transport layer security) encryption.

Compliance Review—Since the Dystonia Coalition Video Repository contains patient identifiable information, it falls under HIPAA regulations. The video server has been added to the HIPAA inventory of servers at Washington University in St. Louis and security controls are reviewed on a periodic basis. All remote sites with video view access are listed with the Washington University institutional review board (IRB). All participants signed written informed consent documents approved by their local institutional IRB.

Results

Recruiting Sites

As of Sept 1, 2014, 37 active sites are collecting videos for the longitudinal Natural History and cross sectional Biorepository project of the Dystonia Coalition. These sites include seven non-US sites (three Canadian, one German, one Italian, one French and one British) and 30 US sites. Each site has provided quality control videos with five sites requiring modifications to meet Dystonia Coalition quality standards prior to granting permission to upload participants into the Video Repository. These 37 sites include 100 individual users with remote access privileges. A total of 2150 videos have been uploaded to the Video Repository and are available for access. Relevant clinical data for each participant are stored on a separate web-accessible database (http://clinportalquery.wustl.edu/pentaho/Home?userid=DYSTONIA_OPENI&password=DYSTONIA) but the data in this web-accessible

tool are not identifiable by study number and cannot be linked to a specific video without permission granted from WUSM and the Dystonia Coalition.

Quality Control Measures

Each uploaded video has been checked for technically adequate quality and diagnostic accuracy. Videos with questionable diagnoses have been subsequently reviewed by a quality control subcommittee of the Dystonia Coalition. The quality control step has led to the identification of four videos that were considered to have disorders that did not represent isolated dystonia syndromes. Two were psychogenic and two had Parkinson disease. These videos were not eliminated from the collection, but are flagged so that they may be excluded from studies where they are not appropriate.

Development and Validation of Cervical Dystonia rating scales

Project 2 of the Dystonia Coalition evaluated 208 participants with cervical dystonia with each having the standard videos entered into the repository thereby facilitating the testing of inter- and intra-rater reliability of video-based ratings of cervical dystonia severity. Permissions were granted for 11 domestic and ten international investigators to review and rate forty five unique videos from participants that were not from that rater's own site.

Research Projects

The Dystonia Coalition Video Repository already has been used for novel research projects. These projects tested a computerized automated method called computerized expression recognition toolbox (CERT) to quantify facial and neck movements in participants with dystonia. One project focused on either upper or lower facial dystonia and included 136 videos. The other CERT project focused on cervical dystonia accessing a separate group of 125 videos. Access to these large groups of participants occurred within one week of the investigator obtaining IRB approval. Another study investigated the nature of alleviating manuevers (sensory tricks) in 154 participants with cervical dystonia.[6]

Discussion

We created a web-based video repository that facilitates collaborative research in dystonia. The protocol includes collecting a standardized video, uploading a variety of file types to a central site, centralized encoding to a uniform format, quality control checking, storing in a HIPAA-secured database, providing redundant backup systems and permission-based streaming to remote sites. Several key aspects of this system enhance its research capabilities. The system can scale to accommodate large video repositories. We have more than 2150 videos in this system, requiring only 600 gigabytes of storage (with additional 600 gigabytes of off-site disaster recovery storage). Storing all videos from a multicenter study at a single site substantially facilitates use of this resource since all data can be accessed through a single website. Researchers can quickly search to determine what videos reside in the database without allowing direct viewing. Thus, a potential investigator can determine whether the video repository contains the material needed to test a specific research hypothesis before investing additional effort to obtain IRB and Dystonia Coalition approvals. Flexibility of permission-based access to HIPAA-protected videos allows for

efficient addition of new recruiting sites or creation of new research groups that want to access to selected videos. Using a standardized video protocol ensures that uniform and comprehensive evaluations are available for each subject. Streaming without downloading permissions minimizes security risks of unauthorized copies of videos. Although we cannot prevent someone from directly using a video camera to record the streaming video, all users must obtain local IRB approval and agree to the rules of the Dystonia Coalition that forbid this activity. Groups of users also can view the same video simultaneously to permit group discussions about relevant clinical features. This is particularly valuable for training new investigators. Finally, redundant backup systems protect this valuable resource and include an off-site disaster recovery site with data transfers every three hours.

Successful implementation and access of this video repository by the Dystonia Coalition demonstrates its utility. Quality control has helped ensure agreed-upon diagnoses, which is especially useful in a condition like dystonia in which opinions can vary. Thus far, this capability has permitted discussion and consensus agreement on three different participants within the Coalition. Phenotypic homogeneity is particularly important for genetic investigations that may be done on biologic samples from the participants in this repository. Confirmation of diagnosis helps ensure this homogeneity and highlights additional key aspects of this video repository – linkage to demographic and biosample repositories. A partial data set of demographic and family history information along with DNA is stored at the NINDS Genetics Repository at Coriell. More detailed demographic, family history and clinical data are stored and easily searchable through the ClinPortal interface (www.clinportal.wustl.edu) at WUSM. Questions about specific clinical characteristics of participants found to have selected genetic mutations can be addressed by viewing the standardized videos. Others have used the video sample to determine the relative frequency of tremor in people with various forms of idiopathic focal dystonia or the characteristics of sensory tricks in cervical dystonia.[6]

This type of video repository provides flexibility to revise a study plan or develop an entirely new study that can be conducted rapidly and efficiently without the need to recruit additional participants. For example, modifications of a video-based rating, frequently an iterative process involving multiple investigators rating many videos, can be done with existing videos in the repository. Other new projects, such as identifying co-morbid tremor frequency and characteristics can be facilitated without recruiting a new cohort. Such investigations only require defining a new group and setting permissions for investigators to access the appropriate videos.

Conclusions

The methods we used to develop the video repository system can be useful not only for Movement Disorders but also for any multicenter investigation in which video or audio sampling may be required. Such studies could benefit from the advantages that this Dystonia Coalition Video Repository system provides such as required HIPAA-compliant safeguards of personal health information, secured sharing of videos, simultaneous video review from anywhere with internet access and flexibility in controlling access at different levels.

Finally, the cost of the system is quite modest although admittedly, an extant SAN for storage simplified our implementation.

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List of Abbreviations

DVD	digital video disk
PHI	private health information
HIPAA	Health Insurance Portability and Acccountability Act
ORDR	Office of Rare Disease Research
NINDS	National Institute of Neurological Disorders and Stroke
GDRS	Global Dystonia Rating Scale
BFM	Burke Fahn Marsden rating scale
TWSTRS	Toronto Western spasmodic Torticollis Rating Scale
WUSM	Washington University School of Medicine
FTP	file transfer protocol
SFTP	secured file transfer protocol
SAN	storage area network
Gb	gigabytes
RAM	random access memory
ASPEX	ASP.NET source file
SSH	secure shell
SSL/TLS	secured socket layer/transport layer security
CERT	computerized expression recognition toolbox
IRB	institutional review board

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- Development of a secured video repository that permits permission-based access
- Prevents direct file download of videos
- Development of broad-based video protocol for patients with dystonia or any movement disorder

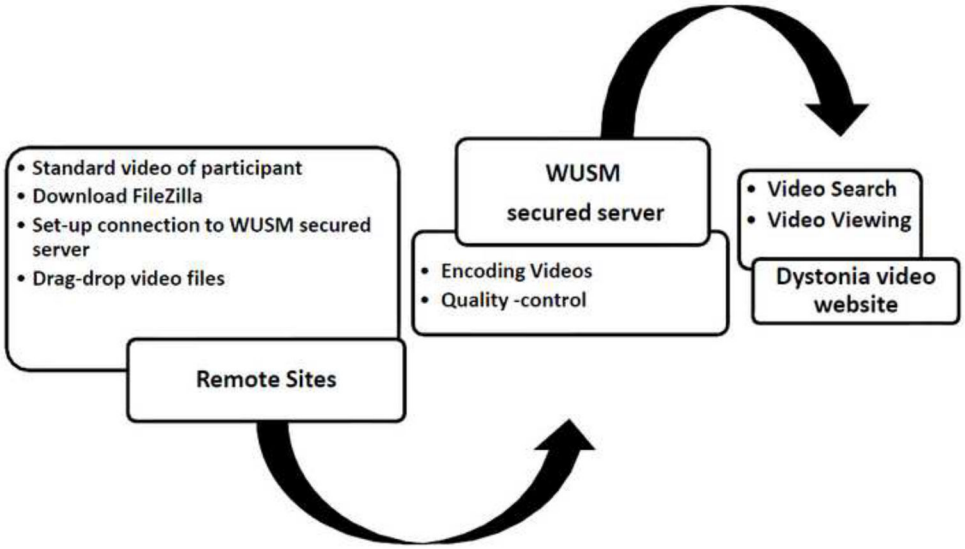

Figure.
Video collection work flow.

Table

Video Exam Protocol

General Instructions

- Remove shoes and socks. Remove glasses, if applicable. Remove any food items or chewing gum from mouth.
- Use a tripod if available. Make sure lighting is appropriate.
- Video should be taken from straight in front of the participant, except where stated otherwise.
- Avoid recording the participant's name, date of birth, or other identifiers.
- Record the following statement at start of video: This is subject Dystonia Coalition ID #, (state age of subject if Clinportal ID is not available) enrolled at (site name) on (current date & year)."

Part I: Participant is seated in a chair without head support. Feet are resting on floor and hands are resting in lap. Zoom camera in to capture head and shoulders only

1 At rest, eyes open for 10 secs

2 At rest, eyes closed gently for 10 secs

3 At rest, after opening eyes, for another 10 secs

4 Forced eyelid closure, 3 times, or 1 sec each, then ovserve effect for 5 secs

5 Ask participant to repeat each sentence below, one at a time:

- **a.** "We mow our lawn all year"
- **b.** "We eat eggs every day"
- **c.** "He had half a head of hair"
- **d.** "The puppy bit the tape"

6 Ask the participant to repeat aloud rapidly: TaTaTa, then GaGaGa, then PaPaPa

7 Ask the participant to hold long vowel sounds:

- **a.** "AHHHHHH" (5 secs)
- **b.** "EEEEEEE" (5 secs)

8 Stick tongue out as far as possible and hold for 5 secs

9 Open and close mouth as wide as possible 3 times

10 Ask: "do you have trouble swallowing?" If yes, ask: "occasional or frequent?"

11 Ask: "do you choke?" If yes, ask: "occasional or frequent?"

Part II: Participant is seated in a chair without head support. Feet are resting flat on floor and hands are resting in lap. Zoom camera out to capture upper body, including head and both upper limbs

12 Front view, at rest, eyes **closed:** instruct participant to let head drift to its most comfortable (dystonic) position, 10 secs

13 Front view, at rest, eyes **open**: instruct participant to keep head straight at midline for 1 minute. Assist verbally if necessary for initial placement. Do not ask participant to reposition if their head drifts.

14 Front view of participant doing most effective sensory trick or a trial of touching right cheek, left cheek and back of head

15 Front view, with **maximum range of motion**, instruct participant to:

- **a.** Turn head to right, then left, both as far as possible, hold each position for 2–3 secs
- **b.** . Tilt ear to right shoulder, then left shoulder, both as far as possible, hold each position for 2–3 secs
- **c.** Look up and extend neck, then look down and flex neck, both as much as possible, hold each position for 2–3 secs

16 Lateral view (from either side), instruct participant to let head drift to its most comfortable (dystonic) position, 10 secs

17 Lateral view (from the same side): with **maximum range of motion**, instruct participant to:

- **a.** Turn head to right, then left
- **b.** Tilt ear to right shoulder, then left shoulder
- **c.** Look up, and then look down

18 **Sleeves up for both arms, viewing video from the front of the participant, both hands above desk:**

- **a.** Write “TODAY IS A NICE DAY” 3 times with dominant hand on associated recording form
- **b.** Write a series of loops across page with non-dominant hand on associated recording form
- **c.** Draw spiral with right hand, then left hand on associated recording form (do not rest drawing hand on table, keep other hand on table)
- **d.** Hold up written page for video

Part III: Participant stays seated. Zoom camera out further to capture entire body, including head and all limbs

19 Extend arms/hands supinated towards camera for 5 secs eyes open, then 5 secs eyes closed

20 Extend arms/hands pronated towards camera for 5 secs eyes open, then 5 secs eyes closed

21 Flex elbows and hold hands/arms steady without touching in front of chest 5 secs eyes open, 5 secs eyes closed

22 Finger-to-nose test, slow enough to captue accuracy, 5 trials for each hand

23 Finger tapping (thumb and forefinger) 5 secs for each hand, as big and fast as possible

24 Open and close both hands all the way, simultaneously and rapidly, 5 times

25 Tap heel on floor then toe on floor in rapid alternations, 5 repeated pairs each side

Part IV: Participant stands. Zoom camera out further to capture entire body, including head and all limbs

26 Standing frontal view (5 secs)

27 Standing lateral (right) view (5 secs)

28 Standing back view (5 secs)

29 Standing lateral (left) view (5 secs)

30 Walking at least 10 steps away from camera (posterior view) and at least 10 steps towards camera (front view)

31 Walking on toes at least 10 steps away from camera, and on heels at least 10 steps towards camera

32 Walking in toe-heel-tandem, at least 10 steps away from camera and at least 10 steps back towards camera

Part V (if applicable): If participant has a task specific dystonia not captured in protocol above, such as playing musical instrument, chewing etc, please videotape the dystonic symptoms while participant performs such tasks.