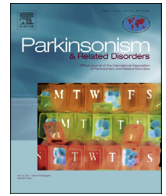




Contents lists available at ScienceDirect

Parkinsonism and Related Disorders

journal homepage: www.elsevier.com/locate/parkreldis

Editor's comment: Video documentation of medical conditions is widely used by the medical community. This is especially true for movement disorders specialists who have always been at the forefront of this diagnostic and research tool, beginning with the publication of videos alongside meaning manuscripts published in our specialty's journals. However, until now, access to unique and/or carefully accumulated collections of movement disorder videos have not been readily available to the wider universe of clinicians and investigators who could use them for educational and scientific purposes. In this article Yan et al. have demonstrated how a web-based dystonia video repository can be safely created and used for these purposes. They pay special attention to privacy and security issues, both extremely important facets of repositories in this era of widespread hacking and stringent patient privacy regulations. This publication is a very timely and well-executed step in the development of these procedures for use by the medical community.

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Secured web-based video repository for multicenter studies



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ARTICLE INFO

Article history:

Received 9 December 2014

Received in revised form

4 January 2015

Accepted 11 January 2015

Keywords:

Video repository

Clinical trial

Secured access

Dystonia

Video protocol

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 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.

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Abbreviations: DVD, digital video disk; PHI, private health information; HIPAA, Health Insurance Portability and Accountability 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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<http://dx.doi.org/10.1016/j.parkreldis.2015.01.011>

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1. 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

Table 1

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 s
2. At rest, eyes closed gently for 10 s
3. At rest, after opening eyes, for another 10 s
4. Forced eyelid closure, 3 times, or 1 s each, then observe effect for 5 s
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 s)
 - b. "EEEEEEE" (5 s)
8. Stick tongue out as far as possible and hold for 5 s
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 s
13. Front view, at rest, eyes open: instruct participant to keep head straight at midline for 1 min. 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 s
 - b. Tilt ear to right shoulder, then left shoulder, both as far as possible, hold each position for 2–3 s
 - c. Look up and extend neck, then look down and flex neck, both as much as possible, hold each position for 2–3 s
16. Lateral view (from either side), instruct participant to let head drift to its most comfortable (dystonic) position, 10 s
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 s eyes open, then 5 s eyes closed
20. Extend arms/hands pronated towards camera for 5 s eyes open, then 5 s eyes closed
21. Flex elbows and hold hands/arms steady without touching in front of chest 5 s eyes open, 5 s eyes closed
22. Finger-to-nose test, slow enough to capture accuracy, 5 trials for each hand
23. Finger tapping (thumb and forefinger) 5 s 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 s)
27. Standing lateral (right) view (5 s)
28. Standing back view (5 s)
29. Standing lateral (left) view (5 s)
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.

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