

## Cerebrospinal Fluid Biomarkers

# Cerebrospinal fluid collection: An informative animation video for patients and caregivers

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### Abstract

Daily clinical practice has shown that patients are often hesitant to undergo a lumbar puncture (LP) because of unfamiliarity with the awaiting procedure and/or unrealistic ideas concerning post-LP complications. In light of increased number of LPs in diagnostic and research settings, our institute has developed an educational video for patients and caregivers in which we inform them about and prepare them for the LP procedure. This video was based on the latest literature and was developed with the help of communication experts, medical doctors, and two separate patient panels.

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### Keywords:

Lumbar puncture; LP; Video; LP video; Educational; Educational Video; Patients; Caregivers; Patient information; Cerebrospinal fluid; CSF; Biomarkers

## 1. Introduction

Cerebrospinal fluid (CSF) biomarkers such as amyloid  $\beta$  1–42 ( $A\beta_{42}$ ), total tau (Tau), and tau phosphorylated at threonine 181 (pTau) have proven to be a valid proxy of the underlying neuropathology of Alzheimer's disease and are of increasing value in Alzheimer's disease diagnosis and research [1–5]. As such, these CSF biomarkers, which are obtained through lumbar puncture (LP), are increasingly applied in daily clinical practice resulting in an increased number of LPs.

In daily practice, patients are often anxious to undergo the LP procedure because of unfamiliarity with the procedure and/or unrealistic ideas concerning post-LP complications. In fact, a large multicenter memory clinic study has shown

that patients' fear of the LP procedure and specifically their fear of post-LP complications actually increase the risk of post-LP complications and complaints [6]. Adequate preparation through education and the provision of accurate information may be beneficial for those patients [7–9]. Specifically, the provision of audio-visual information about the LP procedure and the risk of complications, in addition to the spoken information from the physician, may address unrealistic expectations and help patients better understand and prepare for the LP procedure [10]. Therefore, we aimed to develop an animation video in which we audio-visually present information about the LP procedure and (the risk of) complications.

## 2. Methods

The content for the video was drafted by the core team consisting of a medical doctor, the head of the neurochemistry laboratory, and several communication researchers.

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### 2.1. Prerequisite requirements

The core team established a few predetermined requirements for the video: (1) the content of the video was to be based on insights from the latest literature; (2) the duration of the video should not be longer than 2 to 3 minutes to ensure viewers' attention, and (3) an animation video seemed more appropriate than a live video of the procedure [6,11,12].

### 2.2. Iterative developmental process

The animation video was developed through an extensive and iterative process in co-creation with stakeholders (i.e., doctors, patients, and caregivers). The developmental process went as follows:

1. A script was drafted by the core team and reviewed by a panel of medical doctors (n = 4) who perform LPs on a routine basis in a tertiary memory clinic. The panel of medical doctors was not involved in the development of the script. In addition, the script was reviewed by a patient and caregiver panel (n = 5). Based on feedback from both panels, changes were made to the script by the core team.
2. A storyboard for the video (i.e., graphics were added to the script) was developed in collaboration with a company specialized in developing animation videos for the medical domain. This storyboard was reviewed by the core team and revised accordingly.
3. The first version of the video was reviewed and revised on several occasions. The core team as well

as a second larger patient and caregiver panel visiting the memory clinic of the Alzheimer Center Amsterdam UMC (n = 60) took part in this reviewing process. The patient and caregiver panel gave feedback by making use of a questionnaire. The questionnaire assessed the content and the esthetics of the video (e.g., understandability, duration, and the voice-over). Moreover, the video was presented during an ABIDE (Alzheimer's Biomarkers In Daily practicE)-project [13] team meeting in which several communication experts, medical doctors, neuropsychologists, and neurochemistry laboratory members openly exchanged thoughts on the video and provided feedback. Finally, the video was presented in a meeting by the Alzheimer's Association Global Biomarker Standardization Consortium, a consortium aimed at the standardization and implementation of fluid biomarker tests for use in clinical practices around the world, who also provided feedback [9].

### 2.3. Revisions

Feedback obtained during each step of the developmental process was discussed within the core team to make decisions on revisions. Feedback was deemed relevant when it suited the aim of the video, that is, providing understandable preparatory information about the LP procedure and (the risk of) complications, or when the same remark was given repeatedly. For an overview of the iterative developmental process, see Fig. 1.

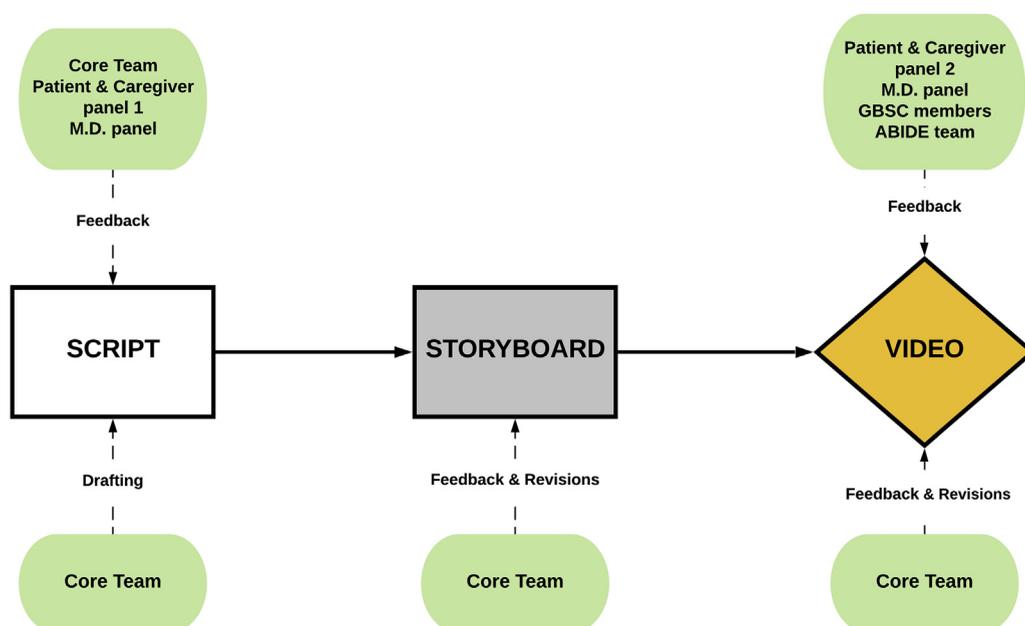


Fig. 1. Schematic overview of the iterative developmental process of the educational video for patients and caregivers. Abbreviations: MD, Medical Doctor; ABIDE, Alzheimer's Biomarkers In Daily practicE; GBSC, Global Biomarker Standardization Consortium.

### 3. Results

Our efforts resulted in the animation video enclosed in Supplementary Data (eVideo).

### 4. Discussion

Future steps include investigating improvement of patients' knowledge and psychological outcomes, for example, reduction of anxiety regarding the LP procedure and/or (the risk of) complications, after viewing the video.

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Disclaimer: Amsterdam UMC has composed the information in this video with great care and has strived for accurate and current information. However, despite all efforts, Amsterdam UMC cannot guarantee that this information is or will remain entirely correct over time. Therefore, no rights can be derived from the information presented in this video. Amsterdam UMC cannot accept any liability toward anyone in any way whatsoever, nor can Amsterdam UMC be held responsible or liable for any direct or indirect harm or damages that might occur as a result of this animation video. Moreover, this video can only be used as a supplement to the patient information to be provided by a medical professional. This video cannot replace the information duty of the medical professional. Although the video provides an overview of the procedure, we acknowledge that this is not the only possible way to collect cerebrospinal fluid. Many parts of this video are subject to intellectual property rights of third parties. The contents of this video, for example, drawings, pictures, texts, and other graphic elements are protected by copyright. Therefore, it is not permitted to copy, disclose, and/or modify any part of the video, in whole or in part, without the prior written consent of the makers of this video.

### Supplementary Data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.dadm.2019.04.005>.

### RESEARCH IN CONTEXT

1. Systematic review: The authors reviewed the literature using traditional (e.g., PubMed) sources and meeting abstracts and presentations.
2. Interpretation: Both daily clinical practice and previous research show that patients are often anxious to undergo a lumbar puncture (LP) because of unfamiliarity with the procedure and/or unrealistic ideas concerning post-LP complications. Moreover, patients' fear of the LP procedure and specifically their fear of post-LP complications have been shown to actually increase the risk of post-LP complications and complaints. Our educational video prepares patients through education and the provision of accurate information and may, therefore, address unrealistic expectations and help patients better understand and prepare for the LP procedure.
3. Future directions: Future steps include investigating improvement of patients' knowledge and psychological outcomes, for example, reduction of anxiety regarding the LP procedure and/or (the risk of) complications, after viewing the video.

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