

QUESTIONNAIRE

The ADC LP experience

INSTRUCTIONS: The information reported on this survey must be certified by the ADC Director. This form should be completed by the ADC Director, Administrator, or Core Leader who can authoritatively report ADC experience and/or policy concerning LP procedures. Only one form per center should be submitted.

1. Today's date (MM/DD/YYYY): ____ ____ / ____ ____ / ____ ____ ____ ____	
2. ADC name: _____	
3. Name and role of person completing this form: First name _____ Last name _____ Your position: _____	
Center LP activity	
4. Are LPs performed as part of Center-related activities?	<input type="checkbox"/> No <input type="checkbox"/> Yes
5. If your Center does not perform LP or if it performs LPs on less than 10% of subjects, what would be needed to increase the number of LPs performed at your Center? (CHECK ALL THAT APPLY) <i>If you answered no to Question 4 above, then answer Question 5 and end questionnaire here.</i>	<input type="checkbox"/> AD biomarker assays with better diagnostic accuracy <input type="checkbox"/> Lower cost for assays and/or LP procedure <input type="checkbox"/> More time for doing LPs / better reimbursement <input type="checkbox"/> Better drugs that would improve the value of a more accurate diagnosis <input type="checkbox"/> Other (SPECIFY): _____ <input type="checkbox"/> N/A
6. Who usually asks the subject to have an LP? (CHECK ONLY ONE)	<input type="checkbox"/> MD <input type="checkbox"/> RN <input type="checkbox"/> Other (SPECIFY): _____
7. Why is CSF collected at your Center? (CHECK ALL THAT APPLY)	<input type="checkbox"/> Research <input type="checkbox"/> Diagnosis <input type="checkbox"/> Studies supported by industry (e.g., clinical trials) <input type="checkbox"/> Other (SPECIFY): _____
8. What percentage of subjects at your Center are asked to have an LP for <u>research</u> ?	____ ____ ____ %
9. What percentage of subjects at your Center agree to have an LP for <u>research</u> ?	____ ____ ____ %

10. What percentage of patients at your Center are offered an LP for <u>diagnosis</u> ?	_____ %
11. What percentage of patients at your Center agree to have an LP for <u>diagnosis</u> ?	_____ %
12. What tests are being ordered? (CHECK ALL THAT APPLY)	<input type="checkbox"/> A β <input type="checkbox"/> Tau <input type="checkbox"/> 14-3-3 <input type="checkbox"/> Check for infection <input type="checkbox"/> Other (SPECIFY): _____ _____

LP research details

13. For each LP study you have done in the last five years that included participants from your ADC's Clinical Core, please provide the following:

	Study or grant number	Target number of Clinical Core participants	Number of Clinical Core subjects participating	Percentage of subjects receiving a single LP	Percentage of subjects receiving multiple LPs
a.		_____	_____	_____ %	_____ %
b.		_____	_____	_____ %	_____ %
c.		_____	_____	_____ %	_____ %
d.		_____	_____	_____ %	_____ %
e.		_____	_____	_____ %	_____ %
f.		_____	_____	_____ %	_____ %
g.		_____	_____	_____ %	_____ %
h.		_____	_____	_____ %	_____ %
i.		_____	_____	_____ %	_____ %

Clinical use of LPs

14. Which clinical characteristics does your Center use to determine whether a patient will be offered a diagnostic LP? (CHECK ALL THAT APPLY)	<input type="checkbox"/> Diagnosis of Alzheimer disease or other dementia <input type="checkbox"/> Rapid cognitive decline <input type="checkbox"/> Suspicion of complicating factors such as encephalitis <input type="checkbox"/> Atypical young age of onset of dementia symptoms <input type="checkbox"/> Other atypical presentation of cognitive syndrome <input type="checkbox"/> Other (SPECIFY): _____
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15. How many Clinical Core patients have been diagnosed with potentially reversible entities (e.g., infection) via LP over the past year?	_____
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Educational material

16. What educational materials does your Center provide for subjects receiving an LP? (CHECK ALL THAT APPLY)	<input type="checkbox"/> Video <input type="checkbox"/> Brochure <input type="checkbox"/> Web page resources <input type="checkbox"/> Participant meeting <input type="checkbox"/> Other (SPECIFY): _____ <input type="checkbox"/> None
17. For how long are the risks and benefits of LP usually discussed before asking for participation?	<input type="checkbox"/> 0 – 5 minutes <input type="checkbox"/> 6 – 10 minutes <input type="checkbox"/> > 10 minutes

QUESTIONNAIRE

The LP requestor

INSTRUCTIONS: This form should be completed by each ADC member who actually asks an ADC patient/subject to undergo an LP.

1. Today's date (MMDDYYYY): ____ / ____ / _____	
2. ADC name: _____	
3. Position of person completing this form: <input type="checkbox"/> Physician <input type="checkbox"/> Nurse <input type="checkbox"/> Other clinic staff	
LP requestor: demographics	
4. Are you the person who usually asks a patient to have an LP?	<input type="checkbox"/> No <input type="checkbox"/> Yes
5. Please provide the following information:	<p>a. Your age: ____</p> <p>b. Your sex: <input type="checkbox"/> Male <input type="checkbox"/> Female</p> <p>c. Your race:</p> <input type="checkbox"/> White <input type="checkbox"/> Black or African American <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Native Hawaiian or other Pacific Islander <input type="checkbox"/> Asian <input type="checkbox"/> Other (SPECIFY): _____
6. When was the last time you performed an LP for research or diagnosis?	<input type="checkbox"/> I never perform LPs <input type="checkbox"/> I last performed an LP in (MM / YYYY): ____ / _____
7. Do you actively perform LPs for reasons other than dementia research or diagnosis?	<input type="checkbox"/> No <input type="checkbox"/> Yes

LP requestor: perceptions	
8. What is your perception of the <i>value</i> of LPs performed for AD research?	Not valuable <input type="checkbox"/> ¹ <input type="checkbox"/> ² <input type="checkbox"/> ³ <input type="checkbox"/> ⁴ <input type="checkbox"/> ⁵ <input type="checkbox"/> ⁶ Extremely valuable
9. What is your perception of the <i>discomfort</i> caused to participants undergoing an LP for AD research?	No discomfort <input type="checkbox"/> ¹ <input type="checkbox"/> ² <input type="checkbox"/> ³ <input type="checkbox"/> ⁴ <input type="checkbox"/> ⁵ <input type="checkbox"/> ⁶ Extreme discomfort
10. How much <i>discomfort</i> is experienced by a patient having an LP as compared to the discomfort experienced by a patient receiving a clinical colonoscopy?	Much less for LP <input type="checkbox"/> ¹ <input type="checkbox"/> ² <input type="checkbox"/> ³ <input type="checkbox"/> ⁴ <input type="checkbox"/> ⁵ <input type="checkbox"/> ⁶ Much more for LP
11. How do you think the <i>frequency of complications</i> among patients receiving an LP compares with the frequency of complications among patients receiving a clinical colonoscopy?	Many fewer for LP <input type="checkbox"/> ¹ <input type="checkbox"/> ² <input type="checkbox"/> ³ <input type="checkbox"/> ⁴ <input type="checkbox"/> ⁵ <input type="checkbox"/> ⁶ Many more for LP
12. How <i>relevant</i> to separating <i>clinical</i> and <i>pathologic</i> Alzheimer's disease do you find published data on CSF A β 42 and tau levels that are associated with pre-symptomatic or early-stage dementia diagnosis and prognosis?	Not relevant <input type="checkbox"/> ¹ <input type="checkbox"/> ² <input type="checkbox"/> ³ <input type="checkbox"/> ⁴ <input type="checkbox"/> ⁵ <input type="checkbox"/> ⁶ Extremely relevant
LP requestor: personal history of LP	
13. Have you ever had an epidural?	<input type="checkbox"/> No <input type="checkbox"/> Yes
14. Have you ever had an LP yourself?	<input type="checkbox"/> No (END FORM HERE) <input type="checkbox"/> Yes
15. Please describe your reason(s) for having an LP (CHECK ALL THAT APPLY):	<input type="checkbox"/> Diagnosis <input type="checkbox"/> Research participant <input type="checkbox"/> Other (SPECIFY): _____
16. How old were you when you had your first LP?	___ ___
17. Do you feel that having an LP was justified by the information that was obtained from it?	<input type="checkbox"/> No <input type="checkbox"/> Yes
18. Your own LP experience:	
a. How would you rate the <i>discomfort</i> level you experienced when receiving your own LP?	No discomfort <input type="checkbox"/> ¹ <input type="checkbox"/> ² <input type="checkbox"/> ³ <input type="checkbox"/> ⁴ <input type="checkbox"/> ⁵ <input type="checkbox"/> ⁶ Extreme discomfort
b. <i>How disruptive</i> , in terms of your daily routine and time and effort expended, was your overall pre- to post-LP event experience?	Not disruptive <input type="checkbox"/> ¹ <input type="checkbox"/> ² <input type="checkbox"/> ³ <input type="checkbox"/> ⁴ <input type="checkbox"/> ⁵ <input type="checkbox"/> ⁶ Extremely disruptive

<p>19. Did you experience any post-LP complications? (CHECK ALL THAT APPLY)</p>	<p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Yes, LP headache</p> <p><input type="checkbox"/> Yes, other complication: _____</p>
<p>20. If asked, would you agree to have an LP again? (CHECK ALL THAT APPLY)</p>	<p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Yes, for diagnosis</p> <p><input type="checkbox"/> Yes, for research</p>

QUESTIONNAIRE

The patient LP experience

Adapted from the Alzheimer's Association Multi-center Study on Lumbar Puncture, Kaj Blennow et al. and the Alzheimer's Association; used by permission

INSTRUCTIONS: Please complete this form for each ADC patient/subject who is asked to undergo an LP. This form is to be completed by the LP clinician at the time a patient is first asked to have an LP. Information should be based on medical records, patient or co-participant report, and clinician observation and/or judgment.

1. Today's date (MM/DD/YYYY): ____ / ____ / ____	
2. ADC name: _____	
3. Patient ID (use UDS ADC patient ID):	_____
Practitioner information	
4. Person performing the LP:	<input type="checkbox"/> Neurologist <input type="checkbox"/> Geriatrician <input type="checkbox"/> Psychiatrist <input type="checkbox"/> Internist <input type="checkbox"/> Resident (INDICATE SPECIALTY — e.g., neurology, psychiatry): _____ <input type="checkbox"/> Medical student <input type="checkbox"/> Other (SPECIFY): _____
5. How experienced is this person in performing LPs?	<input type="checkbox"/> Limited experience: has performed <10 LPs <input type="checkbox"/> Experienced: has performed 10–100 LPs <input type="checkbox"/> Very experienced: has performed >100 LPs
Patient demographics and medical history	
6. Reason for performing LP (CHECK PRIMARY REASON ONLY):	<input type="checkbox"/> Clinical research study <input type="checkbox"/> Clinical trial <input type="checkbox"/> Routine diagnosis <input type="checkbox"/> Other (SPECIFY): _____

7. Patient's clinical diagnosis:	<input type="checkbox"/> AD (probable or possible AD, according to the NINCDS-ADRDA criteria) <input type="checkbox"/> MCI (MCI according to the Petersen criteria, regardless of progression) <input type="checkbox"/> Normal (normal elderly, e.g., individuals participating as normal controls at research centers) <input type="checkbox"/> Other dementia (e.g., FTLD, LBD, VaD, according to standard diagnostic criteria) — (SPECIFY): _____ <input type="checkbox"/> Psychiatric disorder (e.g., depression) — (SPECIFY): _____ <input type="checkbox"/> Neurologic disorder (e.g., Parkinson's disease) — (SPECIFY): _____ <input type="checkbox"/> Other (SPECIFY): _____
8. Basic patient data	a. Patient's age: ____ ____ ____ b. Patient's sex: <input type="checkbox"/> Male <input type="checkbox"/> Female c. Patient's MMSE score: ____ ____
9. Patient's race:	<input type="checkbox"/> White <input type="checkbox"/> Black or African American <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Native Hawaiian or Other Pacific Islander <input type="checkbox"/> Asian <input type="checkbox"/> Other (SPECIFY): _____
10. Hispanic/Latino ethnicity:	<input type="checkbox"/> No <input type="checkbox"/> Yes
11. Patient's medical history of headache (e.g., tension headache or migraine):	<input type="checkbox"/> None or rare (no headache or not more than general population) <input type="checkbox"/> Mild (needing some medication or producing some disability) <input type="checkbox"/> Chronic
12. Patient's history of chronic pain disorders (e.g., fibromyalgia; do not include disorders such as rheumatoid arthritis or hip/knee arthrosis):	<input type="checkbox"/> None or rare (no pain or not more than the general population) <input type="checkbox"/> Mild (needing some medication or producing some disability) <input type="checkbox"/> Chronic
Patient LP history	
13. Has the patient undergone previous LPs in his or her adult life?	<input type="checkbox"/> No <input type="checkbox"/> Yes (SPECIFY HOW MANY): _____
14. Has the patient experienced any complications with previous LPs?	<input type="checkbox"/> No <input type="checkbox"/> Yes, LP headache <input type="checkbox"/> Yes, other complication (SPECIFY): _____ <input type="checkbox"/> N/A
15. How does the patient view the procedure?	<input type="checkbox"/> Considers it a standard medical procedure <input type="checkbox"/> Considers it a frightening, invasive procedure

16. Did the patient agree to undergo an LP?	<input type="checkbox"/> No <input type="checkbox"/> Yes
17. What is the patient's attitude toward undergoing an LP?	<input type="checkbox"/> Calm, no problems <input type="checkbox"/> Somewhat reluctant <input type="checkbox"/> Very reluctant

QUESTIONNAIRE

The patient LP experience — follow-up

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INSTRUCTIONS: Please complete this follow-up form for each ADC patient/subject who was reported on the initial "Patient LP experience" form and who actually underwent an LP. This form is to be completed by the LP clinician — based on records, observation, and/or patient report — approximately one week after the patient's LP is done.

1. Today's date (MM/DD/YYYY): ____ / ____ / ____	
2. ADC name: _____	
3. Patient ID (use ADC UDS ID): _____	
The lumbar puncture procedure	
4. Approximate time of day LP was performed (HH:MM):	____ : ____ <input type="checkbox"/> AM <input type="checkbox"/> PM
5. Was the LP performed with the patient in a fasted state?	<input type="checkbox"/> No <input type="checkbox"/> Yes
6. Was the patient given any medication, not including local anesthesia?	<input type="checkbox"/> No <input type="checkbox"/> Yes, a premedication (e.g., diazepam for anxiety) <input type="checkbox"/> Yes, other (SPECIFY): _____
7. Position of patient during LP:	<input type="checkbox"/> Lying down (supine position) <input type="checkbox"/> Sitting
8. Type of needle used for LP:	<input type="checkbox"/> Quincke (or similar needle with cutting edge) <input type="checkbox"/> Sprotte (or similar pen-point needle) <input type="checkbox"/> Other (SPECIFY): _____
9. Needle diameter:	<input type="checkbox"/> 21G (0.8 mm) <input type="checkbox"/> 22G (0.7 mm) <input type="checkbox"/> 23G (0.6 mm) <input type="checkbox"/> 24G (0.5 mm) <input type="checkbox"/> Other (SPECIFY): _____
10. How was CSF obtained?	<input type="checkbox"/> Free flow or drip (gravity flow) <input type="checkbox"/> Withdrawn via syringe using negative pressure
11. Was there any hemorrhage during the LP?	<input type="checkbox"/> No (CSF was clear) <input type="checkbox"/> Yes, mild (initial CSF was slightly bloody) <input type="checkbox"/> Yes, marked (clearly bloody CSF)

<p>12. How many attempts were made to enter the subarachnoid space and obtain CSF?</p>	<p><input type="checkbox"/> 1 (LP was easy) <input type="checkbox"/> 2–4 (LP was slightly difficult) <input type="checkbox"/> 5 or more (LP was difficult) (IF 5 OR MORE, SPECIFY REASONS FOR DIFFICULTY, e.g., patient girth, presence of scoliosis, arthrosis, or spondylosis): _____</p>
<p>13. Total volume of CSF obtained during the LP:</p>	<p><input type="checkbox"/> < 5 mL <input type="checkbox"/> 5–12 mL <input type="checkbox"/> 12–20 mL <input type="checkbox"/> > 20 mL</p>
<p>14. How long was the patient allowed to rest, lying down, after the LP?</p>	<p><input type="checkbox"/> < 1 hour <input type="checkbox"/> 1–2 hours <input type="checkbox"/> > 2 hours</p>
<p>15. Did this patient experience any complications following the LP?</p>	<p><input type="checkbox"/> No (END QUESTIONNAIRE HERE) <input type="checkbox"/> Yes</p>
Complications following LP: needle site pain	
<p>16. Did the patient experience pain at the LP needle site that appears to have been caused by the needle?</p>	<p><input type="checkbox"/> No <input type="checkbox"/> Yes, mild discomfort <input type="checkbox"/> Yes, moderate to marked pain for days</p>
Complications following LP: headache	
<p>17. Did the patient have a headache that appears to have been caused by the LP, in accordance with International Headache Society criteria (below)?</p> <ul style="list-style-type: none"> • headache develops within seven days after an LP; • headache comes on or worsens within 15 minutes after assuming an upright position and disappears or lessens within 30 minutes after resuming recumbent position; AND • headache disappears within 14 days after an LP 	<p><input type="checkbox"/> No (SKIP TO QUESTION 22) <input type="checkbox"/> Yes, typical post-LP headache <input type="checkbox"/> Yes, nonspecific headache</p>
<p>18. Headache onset:</p>	<p><input type="checkbox"/> < 2 hours after LP <input type="checkbox"/> 2–24 hours after LP <input type="checkbox"/> 1–2 days after LP <input type="checkbox"/> > 2 days after LP</p>
<p>19. Headache severity:</p>	<p><input type="checkbox"/> Mild (patient can still function; headache not severe enough to require treatment beyond mild analgesics) <input type="checkbox"/> Moderate (patient experiences impaired function, has to rest or stay in bed for periods of the day; full or partial relief can be obtained with oral analgesics) <input type="checkbox"/> Severe (patient experiences disability severe enough to require hospitalization)</p>

20. Headache duration:	<input type="checkbox"/> <1 day <input type="checkbox"/> 1–2 days <input type="checkbox"/> 3–4 days <input type="checkbox"/> 5–7 days
21. Headache treatment (CHECK / COMPLETE ALL THAT APPLY):	<input type="checkbox"/> No treatment needed <input type="checkbox"/> Oral or IV fluids <input type="checkbox"/> Oral analgesics (SPECIFY): DRUG: _____ DOSE: _____ DURATION: _____ <input type="checkbox"/> Caffeine (SPECIFY WHAT FORM): _____ <input type="checkbox"/> Blood patch (SPECIFY): _____ IF BLOOD PATCH, HOW MANY DAYS AFTER LP WAS BLOOD PATCH PERFORMED? ____ _
Complications following LP: other	
22. Did the patient experience other mild complications? (CHECK ALL THAT APPLY)	<input type="checkbox"/> No <input type="checkbox"/> Yes, nausea <input type="checkbox"/> Yes, dizziness <input type="checkbox"/> Yes, vasovagal response (bradycardia, drop in blood pressure, loss of consciousness) <input type="checkbox"/> Other (SPECIFY): _____
23. Did the patient experience any severe complications (e.g., subdural hematoma, infection) that appear to have been caused by the LP?	<input type="checkbox"/> No <input type="checkbox"/> Yes (DESCRIBE COMPLICATION AND HOW IT MIGHT BE LINKED TO LP): _____ _____ _____ _____