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? □ No □ 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)
   □ AD biomarker assays with better diagnostic accuracy
   □ Lower cost for assays and/or LP procedure
   □ More time for doing LPs / better reimbursement
   □ Better drugs that would improve the value of a more accurate diagnosis
   □ Other (SPECIFY): ________________________________________________
   □ N/A

   If you answered no to Question 4 above, then answer Question 5 and end questionnaire here.

6. Who usually asks the subject to have an LP? (CHECK ONLY ONE)
   □ MD □ RN □ Other (SPECIFY): ________________________________________

7. Why is CSF collected at your Center? (CHECK ALL THAT APPLY)
   □ Research □ Diagnosis □ Studies supported by industry (e.g., clinical trials)
   □ Other (SPECIFY): ________________________________________________

8. What percentage of subjects at your Center are asked to have an LP for research?
   ____ ____ ____  %

9. What percentage of subjects at your Center agree to have an LP for research?
   ____ ____ ____  %
10. What percentage of patients at your Center are offered an LP for diagnosis? 
   ___ ___ ___ %

11. What percentage of patients at your Center agree to have an LP for diagnosis? 
   ___ ___ ___ %

12. What tests are being ordered? (CHECK ALL THAT APPLY)
   □ Aβ
   □ Tau
   □ 14-3-3
   □ Check for infection
   □ 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:

<table>
<thead>
<tr>
<th>Study or grant number</th>
<th>Target number of Clinical Core participants</th>
<th>Number of Clinical Core subjects participating</th>
<th>Percentage of subjects receiving a single LP</th>
<th>Percentage of subjects receiving multiple LPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>a.</td>
<td>___ ___ ___ ___</td>
<td>___ ___ ___ ___ ___</td>
<td>___ ___ ___ %</td>
<td>___ ___ ___ %</td>
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<td>b.</td>
<td>___ ___ ___ ___</td>
<td>___ ___ ___ ___ ___</td>
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<td>c.</td>
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<td>d.</td>
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<td>e.</td>
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<td>f.</td>
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<td>g.</td>
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<td>h.</td>
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<td>i.</td>
<td>___ ___ ___ ___</td>
<td>___ ___ ___ ___ ___</td>
<td>___ ___ ___ %</td>
<td>___ ___ ___ %</td>
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</table>

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)
   □ Diagnosis of Alzheimer disease or other dementia
   □ Rapid cognitive decline
   □ Suspicion of complicating factors such as encephalitis
   □ Atypical young age of onset of dementia symptoms
   □ Other atypical presentation of cognitive syndrome
   □ Other (SPECIFY): __________________________

15. How many Clinical Core patients have been diagnosed with potentially reversible entities (e.g., infection) via LP over the past year? 
   ___ ___ ___ ___
### Educational material

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>16. What educational materials does your Center provide for subjects receiving an LP? (CHECK ALL THAT APPLY)</td>
<td>Video, Brochure, Web page resources, Participant meeting, Other (SPECIFY): None</td>
</tr>
<tr>
<td>17. For how long are the risks and benefits of LP usually discussed before asking for participation?</td>
<td>0 – 5 minutes, 6 – 10 minutes, &gt; 10 minutes</td>
</tr>
</tbody>
</table>
# 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:**
   - [ ] Physician
   - [ ] Nurse
   - [ ] Other clinic staff

### LP requestor: demographics

4. **Are you the person who usually asks a patient to have an LP?**
   - [ ] No
   - [ ] Yes

5. **Please provide the following information:**
   - a. **Your age:** __ __
   - b. **Your sex:**
     - [ ] Male
     - [ ] Female
   - c. **Your race:**
     - [ ] White
     - [ ] Black or African American
     - [ ] American Indian or Alaska Native
     - [ ] Native Hawaiian or other Pacific Islander
     - [ ] Asian
     - [ ] Other (SPECIFY):
       __________________________________________________________________
   - d. **Are you of Hispanic/Latino ethnicity?**
     - [ ] No
     - [ ] Yes

6. **When was the last time you performed an LP for research or diagnosis?**
   - [ ] I never perform LPs
   - [ ] I last performed an LP in (MM / YYYY):
     __ __ / __ __ __ __

7. **Do you actively perform LPs for reasons other than dementia research or diagnosis?**
   - [ ] No
   - [ ] Yes
### LP requestor: perceptions

8. **What is your perception of the value of LPs performed for AD research?**

   - Not valuable
   - Extremely valuable

9. **What is your perception of the discomfort caused to participants undergoing an LP for AD research?**

   - No discomfort
   - Extreme discomfort

10. **How much discomfort 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
   - Much more for LP

11. **How do you think the frequency of complications among patients receiving an LP compares with the frequency of complications among patients receiving a clinical colonoscopy?**

   - Many fewer for LP
   - Many more for LP

12. **How relevant to separating clinical and pathologic Alzheimer’s disease do you find published data on CSF Aβ42 and tau levels that are associated with pre-symptomatic or early-stage dementia diagnosis and prognosis?**

   - Not relevant
   - Extremely relevant

### LP requestor: personal history of LP

13. **Have you ever had an epidural?**

   - No
   - Yes

14. **Have you ever had an LP yourself?**

   - No (END FORM HERE)
   - Yes

15. **Please describe your reason(s) for having an LP (CHECK ALL THAT APPLY):**

   - Diagnosis
   - Research participant
   - 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?**

   - No
   - Yes

18. **Your own LP experience:**

   a. **How would you rate the discomfort level you experienced when receiving your own LP?**

      - No discomfort
      - Extreme discomfort

   b. **How disruptive, in terms of your daily routine and time and effort expended, was your overall pre- to post-LP event experience?**

      - Not disruptive
      - Extremely disruptive
<table>
<thead>
<tr>
<th>19.</th>
<th>Did you experience any post-LP complications? (Check all that apply)</th>
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<td></td>
<td>No</td>
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<tr>
<th>20.</th>
<th>If asked, would you agree to have an LP again? (Check all that apply)</th>
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<td></td>
<td>No</td>
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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:
   - [ ] Neurologist
   - [ ] Geriatrician
   - [ ] Psychiatrist
   - [ ] Internist
   - [ ] Resident (INDICATE SPECIALTY — e.g., neurology, psychiatry):

   [ ] Medical student
   [ ] Other (SPECIFY):

5. How experienced is this person in performing LPs?
   - [ ] Limited experience: has performed <10 LPs
   - [ ] Experienced: has performed 10–100 LPs
   - [ ] Very experienced: has performed >100 LPs

Patient demographics and medical history

6. Reason for performing LP (CHECK PRIMARY REASON ONLY):
   - [ ] Clinical research study
   - [ ] Clinical trial
   - [ ] Routine diagnosis
   - [ ] Other (SPECIFY):

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7. Patient’s clinical diagnosis:  
- AD (probable or possible AD, according to the NINCDS-ADRDA criteria)  
- MCI (MCI according to the Petersen criteria, regardless of progression)  
- Normal (normal elderly, e.g., individuals participating as normal controls at research centers)  
- Other dementia (e.g., FTLD, LBD, VaD, according to standard diagnostic criteria) — SPECIFY:  
- Psychiatric disorder (e.g., depression) — SPECIFY:  
- Neurologic disorder (e.g., Parkinson’s disease) — SPECIFY:  
- Other (SPECIFY):  

8. Basic patient data  
   a. Patient’s age: ____ ____ ____  
   b. Patient’s sex: □ Male □ Female  
   c. Patient’s MMSE score: ____ ____  

9. Patient’s race:  
- White  
- Black or African American  
- American Indian or Alaska Native  
- Native Hawaiian or Other Pacific Islander  
- Asian  
- Other (SPECIFY):  

10. Hispanic/Latino ethnicity:  
- No  
- Yes  

11. Patient’s medical history of headache (e.g., tension headache or migraine):  
- None or rare (no headache or not more than general population)  
- Mild (needing some medication or producing some disability)  
- Chronic  

12. Patient’s history of chronic pain disorders (e.g., fibromyalgia; do not include disorders such as rheumatoid arthritis or hip/knee arthrosis):  
- None or rare (no pain or not more than the general population)  
- Mild (needing some medication or producing some disability)  
- Chronic  

<table>
<thead>
<tr>
<th>Patient LP history</th>
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</table>

13. Has the patient undergone previous LPs in his or her adult life?  
- No  
- Yes (SPECIFY HOW MANY): ____________  

14. Has the patient experienced any complications with previous LPs?  
- No  
- Yes, LP headache  
- Yes, other complication (SPECIFY):  
- N/A  

15. How does the patient view the procedure?  
- Considers it a standard medical procedure  
- Considers it a frightening, invasive procedure
<p>| | |</p>
<table>
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</table>
| 16. Did the patient agree to undergo an LP? | ☐ No  
☐ Yes |
| 17. What is the patient's attitude toward undergoing an LP? | ☐ Calm, no problems  
☐ Somewhat reluctant  
☐ Very reluctant |
### QUESTIONNAIRE

The patient LP experience — follow-up

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 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.

<table>
<thead>
<tr>
<th>1. Today’s date (MM/DD/YYYY):</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>ADC name:</td>
<td></td>
<td></td>
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<tr>
<td>Patient ID (use ADC UDS ID):</td>
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</table>

### The lumbar puncture procedure

<table>
<thead>
<tr>
<th>4. Approximate time of day LP was performed (HH:MM):</th>
<th></th>
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<th>AM</th>
<th>PM</th>
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<tbody>
<tr>
<td>5. Was the LP performed with the patient in a fasted state?</td>
<td>No</td>
<td>Yes</td>
<td></td>
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<tr>
<td>6. Was the patient given any medication, not including local anesthesia?</td>
<td>No</td>
<td>Yes, a premedication (e.g., diazepam for anxiety)</td>
<td>Yes, other (SPECIFY):</td>
<td></td>
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<tr>
<td>7. Position of patient during LP:</td>
<td>Lying down (supine position)</td>
<td>Sitting</td>
<td></td>
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<tr>
<td>8. Type of needle used for LP:</td>
<td>Quincke (or similar needle with cutting edge)</td>
<td>Sprotte (or similar pen-point needle)</td>
<td>Other (SPECIFY):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Needle diameter:</td>
<td>21G (0.8 mm)</td>
<td>22G (0.7 mm)</td>
<td>23G (0.6 mm)</td>
<td>24G (0.5 mm)</td>
<td>Other (SPECIFY):</td>
<td></td>
</tr>
<tr>
<td>10. How was CSF obtained?</td>
<td>Free flow or drip (gravity flow)</td>
<td>Withdrawn via syringe using negative pressure</td>
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<tr>
<td>11. Was there any hemorrhage during the LP?</td>
<td>No (CSF was clear)</td>
<td>Yes, mild (initial CSF was slightly bloody)</td>
<td>Yes, marked (clearly bloody CSF)</td>
<td></td>
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<tr>
<td>Question</td>
<td>Response Options</td>
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</table>
| 12. How many attempts were made to enter the subarachnoid space and obtain CSF? | □ 1 (LP was easy)  
□ 2–4 (LP was slightly difficult)  
□ 5 or more (LP was difficult)  
(IF 5 OR MORE, SPECIFY REASONS FOR DIFFICULTY, e.g., patient girth, presence of scoliosis, arthrosis, or spondylosis): |
| 13. Total volume of CSF obtained during the LP:                          | □ < 5 mL  
□ 5–12 mL  
□ 12–20 mL  
□ > 20 mL |
| 14. How long was the patient allowed to rest, lying down, after the LP?  | □ < 1 hour  
□ 1–2 hours  
□ > 2 hours |
| 15. Did this patient experience any complications following the LP?      | □ No (END QUESTIONNAIRE HERE)  
□ Yes |
| **Complications following LP: needle site pain**                         |                  |
| 16. Did the patient experience pain at the LP needle site that appears to have been caused by the needle? | □ No  
□ Yes, mild discomfort  
□ Yes, moderate to marked pain for days |
| **Complications following LP: headache**                                |                  |
| 17. Did the patient have a headache that appears to have been caused by the LP, in accordance with International Headache Society criteria (below)? | □ No (SKIP TO QUESTION 22)  
□ Yes, typical post-LP headache  
□ Yes, nonspecific headache |
| • 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                        |                  |
| 18. Headache onset:                                                    | □ < 2 hours after LP  
□ 2–24 hours after LP  
□ 1–2 days after LP  
□ > 2 days after LP |
| 19. Headache severity:                                                 | □ Mild (patient can still function; headache not severe enough to require treatment beyond mild analgesics)  
□ 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)  
□ Severe (patient experiences disability severe enough to require hospitalization) |
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
</table>
| 20. Headache duration: | □ <1 day  
□ 1–2 days  
□ 3–4 days  
□ 5–7 days |
| 21. Headache treatment (CHECK / COMPLETE ALL THAT APPLY): | □ No treatment needed  
□ Oral or IV fluids  
□ Oral analgesics (SPECIFY):  
□ [Drug]:  
□ [Dose]:  
□ [Duration]:  
□ Caffeine (SPECIFY WHAT FORM):  
□ Blood patch (SPECIFY):  
□ If blood patch, how many days after LP was blood patch performed? |
| Complications following LP: other | □ No  
□ Yes, nausea  
□ Yes, dizziness  
□ Yes, vasovagal response (bradycardia, drop in blood pressure, loss of consciousness)  
□ Other (SPECIFY):  |
| 22. Did the patient experience other mild complications? (CHECK ALL THAT APPLY) | □ No  
□ Yes, nausea  
□ Yes, dizziness  
□ Yes, vasovagal response (bradycardia, drop in blood pressure, loss of consciousness)  
□ Other (SPECIFY):  |
| 23. Did the patient experience any severe complications (e.g., subdural hematoma, infection) that appear to have been caused by the LP? | □ No  
□ Yes (DESCRIBE COMPLICATION AND HOW IT MIGHT BE LINKED TO LP):  
□  
□  
□  
□  |