The Alzheimer Lumbar Puncture Survey

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Rationale

- Success rates for lumbar puncture (LP) for research/clinical purposes vary widely across country, culture, and center
- What influences consent for LP?
  - Perceptions of site personnel?
  - Patient experience (e.g., LP headache)?
  - Other?

Aims

- Document current experience and use of LP at each ADC
- Examine current experience and perceptions regarding LP for all ADC personnel who request consent for LP, and re-assess one year later
- Determine characteristics of the patients/research volunteers who do or do not agree to undergo LP
- Determine the patient/research volunteer's experience with LP to allow complications to be assessed
- Over 2 y, obtain a qualitative and quantitative database of the experience of ADC personnel and all patient/research volunteers who are requested to have an LP

Survey Implementation

Survey Component	Completed by:	Completed when:
ADC LP Experience	One designated individual per ADC (limited to the Director, Administrator, or the Clinical Core Leader)	• Initially • After one year
LP Requestor	Any and all ADC personnel who are responsible for explaining the LP procedure to patients/research volunteers	• Initially • In the event of a new requestor • After one year for each person completing the initial survey
Patient LP Experience	One designated patient coordinator (nurse, social worker, or other health professional) per site who has knowledge of the LP procedures of patients/research volunteers	• Just after the patient/research volunteer is requested to undergo LP (for the entire two years of the study)
Patient LP Experience – Follow-up	Same person who completed the Patient LP Experience form	• One week after LP (for the entire two years of the study)

Benefits of Participation

- Alzheimer's Association grant to NACC will cover some ADC personnel costs to complete the survey
  - Up to $2000 (direct) per ADC
  - Maggie Dean (NACC) will contact Administrators with details
    - » $1000 initially to all ADCs
    - » At 1 yr, additional $1000 to sites completing ≥10 patient surveys (initial and follow-up)
- All ADCs contributing a sufficient number (TBD) of Patient LP Experience survey components will be invited to nominate a member of their site to serve as co-author on any resulting manuscripts

Potential IRB Concerns

- The Patient LP Experience components were approved by the University of Washington IRB for NACC, because the survey is limited to patients/research volunteers who have completed the UDS and thus are covered by their NACC consent
- Completion of the LP Requestor survey by any ADC personnel is entirely voluntary
  - Individuals may choose not to answer any questions that they believe might place them in personal or professional jeopardy
  - Data on LP requestors will only be available in aggregate (not individually)
  - Separate consent forms (*e.g.*, for LP requestors) are not utilized in similar surveys of ADC activity by NACC