

Participant Retention in the Look AHEAD Study



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Navajo Nation Human Research Review Board Conference, October 2017



Sponsors

- National Institute of Diabetes and Digestive and Kidney Diseases
- National Heart, Lung and Blood Institute
- National Institute of Nursing Research
- Office of Research on Women's Health
- National Center on Minority Health and Health Disparities
- Centers for Disease Control and Prevention
- Indian Health Service

Look AHEAD

- ❖ **Multicenter randomized clinical trial**
- ❖ **5145 participants with type 2 diabetes joined 2001-2003**
- ❖ **91 participants joined in Shiprock**

- ❖ **Intensive Lifestyle Intervention (ILI)**
- ❖ **Diabetes Education Support (DSE)**

- ❖ **Look AHEAD began in 2001 and was originally planned for 9 years**
- ❖ **Look AHEAD has continued and is currently planned through 2020**



Primary Hypothesis and Findings

- Cardiovascular disease events (heart attacks and stroke) will be reduced with a Lifestyle Intervention compared to a Diabetes Support and Education Intervention.
- Even though the lifestyle group successfully lost weight and improved fitness, after a median follow-up of 9.5 years, the interventions were stopped in 2012 because the rates of cardiovascular disease events were similar in both groups and there was a 1% probability of observing a significant positive result.

Current Participant Retention-Shiprock

After 14-16 years of participation...

92.3% of originally enrolled participants are available for visits

- 76.2% for all Look AHEAD Clinics

96.4% of available participants continue to attend visits

- 61.4% for all Look AHEAD Clinics

Keys to Retention Success



Recruitment is the Key to Retention

Friendly listener

Honest

Ppt practice study
procedures before
randomization

At randomization talk about feelings
with treatment group assignment

Navajo staff and
translation

Be clear about study design and expectations
during the consent process

Respect in Relationship

- ▶ The participant is a person, not a study ID or disease
- ▶ Positive, kind, caring interactions using motivational interviewing
- ▶ Be welcoming and say thank you for their time
- ▶ Acknowledge life events happening outside study like family births, deaths, change in marital status, retirement-listen as participants share
- ▶ Maintain privacy of what you learn in the study
- ▶ Honest in what you can and can't do within study relationship
- ▶ Treat participants equally
- ▶ Help with medical appointment scheduling, answer or find the answer to health and other life questions
- ▶ Send birthday and holiday cards



OPEN DOOR POLICY

Make Clinic Visits and Classes ‘Easy’

- ▶ Give participants a written schedule for clinic visits and classes
- ▶ Use phone call or mailed visit reminders
- ▶ Be ready for the visit when the participants walks in and greet them
- ▶ Organized visit, professional data collection
- ▶ Data collectors are highly skilled and confident in study procedures
- ▶ \$15 gas cards to help with transportation if live more than 15 miles
- ▶ At the end of a visit, remind participants of their next visit
- ▶ Send individual results letters to participants and their health providers for body measurements, blood and urine tests, and other relevant study procedures

Group Intervention Classes

Develop participant relationships with each other- helps retention

Topics of interest, relevant to study goals, incorporate local culture, organized delivery

Accept and encourage participant no matter what success they have

Deal with conflict between participants during or outside of class

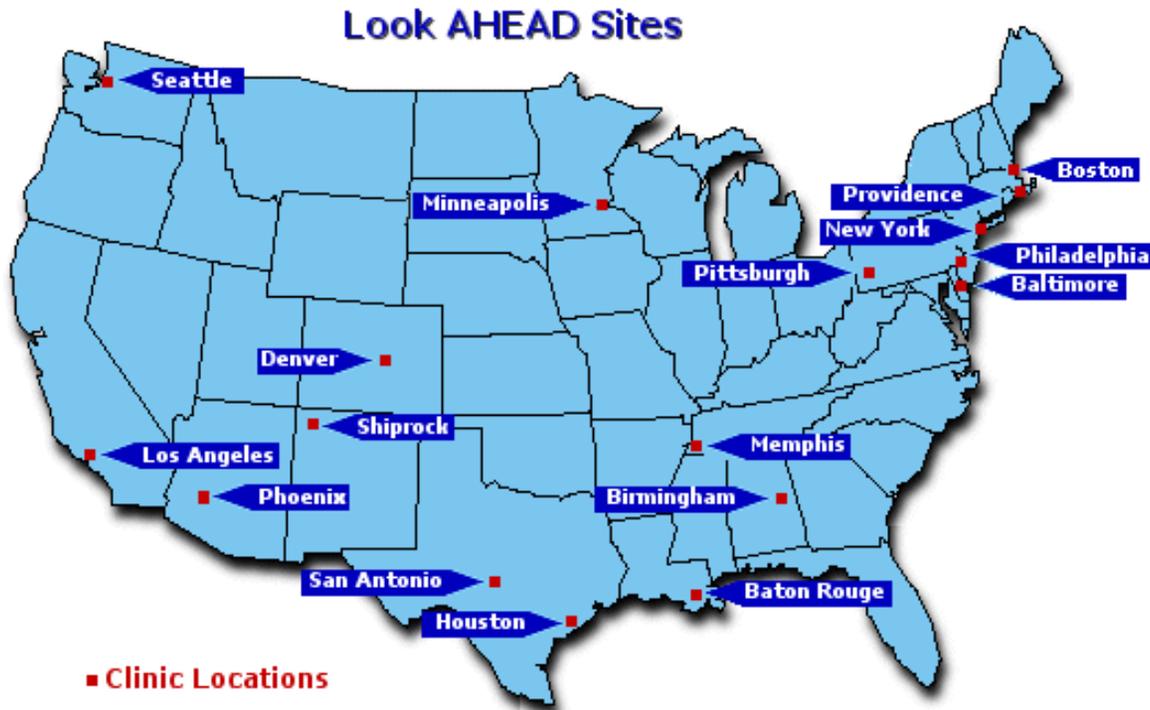
“If I didn’t join Look AHEAD I don’t know where I would be with my health”

Research Team



Participating in National Effort

- Periodic mailed newsletter including study updates
- Periodic retention social events to share study results



- * There was no participant reimbursement during recruitment and screening
- * Do NOT use participant reimbursement as a recruitment tool
- * Participant reimbursement has changed over the years and still people remain engaged

Incentives are Less Important to Retention

A hé hee'

- ▶ Shiprock Look AHEAD Participants for all you have shared and taught us
- ▶ Navajo Nation Human Research Review Board for believing in us
- ▶ Indian Health Service, especially Northern Navajo Medical Center
- ▶ Dr. Knowler and Dr. Michaels for your leadership
- ▶ Each of you who has helped and supported Look AHEAD