

#### PRE-SCAN COUNSELING

# Review list of risk factors for AD with participant

- 1. Biggest risk factors:
  - Age (at age 85, ~40% of the population have AD)
  - Family history
- 2. Others include medical and lifestyle factors, many of which we have some control over (i.e. modifiable) such as
  - Exercise
  - Healthy diet
  - Blood pressure and blood sugar control
  - Smoking
- 3. New risk factor: -Amyloid PET Scan
  - Amyloid is a protein that is found in all our bodies
  - In AD, amyloid builds up in the brain and is present in AD (by definition)
  - The scan assesses whether amyloid is present in the brain
  - 1 of 3 people with no memory changes have elevated levels of amyloid in the brain (this does not mean the person has AD)
  - Not everybody that has elevated levels of amyloid will develop AD; this is not a diagnostic test for AD.
  - Elevated Amyloid
    - Does not mean you have AD or will go on to develop AD
    - Higher risk for AD
    - Does not yet tell us the magnitude of the risk (how much higher)
    - Don't know the timeframe (we think amyloid builds up in the
    - brain 15-20 years before AD)
  - Not Elevated Amyloid
    - Likely means you have a lower risk for AD
    - Does not mean amyloid will never be present in the brain
    - Does not mean you will never develop memory changes

# Confirm understanding with participant:

- 1. This information will not be shared with your PCP or become part of your medical record as it has a chance of being misinterpreted
- 2. This scan is optional. You have the option to withdraw at any time.

# The participant needs to:

- 1. Determine if they want to proceed with the scan and learn the results of the scan
  - \*Keep in mind that this is a new scan and there is a chance for a false positive or false negative
- 2. Understand the scan and its limitations
  - \*It is not a diagnostic test for AD



# Review what happens after they learn the results of the scan:

- 1. We will provide you feedback on lifestyle, diet, and exercise recommendations
- 2. Offer the option to participate in additional research studies
- 3. Emphasize the brochure, "Preventing Alzheimer's Disease: What Do We Know" (NIA ADEAR publication 12-5503)

# FEEDBACK SESSION (V3) (with same clinician at pre-scan and post-scan counseling when possible)

Prior to disclosure, remind the participants about what the results mean (give both scenarios for the meaning of an elevated result and a non-elevated result, regardless of their result)

# ■ Elevated Amyloid

- Does not mean you have AD or will go on to develop AD
- Higher risk for AD
- Does not yet tell us the magnitude of the risk (how much higher)
- Don't know the timeframe (we think amyloid builds up in the
- brain 15-20 years before AD)

# ■ Not Elevated Amyloid

- Likely means you have a lower risk for AD
- Does not mean amyloid will never be present in the brain
- Does not mean you will never develop memory changes

# Disclose results to participant

- 1. Review what their result means to them individually. Restate the information above for their result.
- 2. Our staff will provide feedback on lifestyle, diet, and exercise recommendations.
- 3. Discuss the currently enrolling prevention studies ongoing at the KU AD Center, regardless of amyloid status.