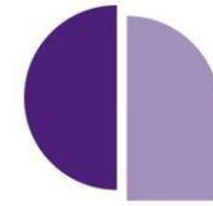




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EPAD – FRAMTÍÐARSÝN Í GREININGU HEILABILUNAR  
SIRRÝ SIF SIGURLAUGARDÓTTIR, FRÆÐSLU- OG VERKEFNASTJÓRI



ALZHEIMER  
SAMTÖKIN

# Hvað er EPAD?

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- Samstarfsverkefni 36 stofnana um grunnrannsóknir á heilabilunarsjúkdómum
- Áhersla á forvarnir og snemmgreiningar
- Hvar og hvenær byrjar heilabilun?
  - Mun fyrr en áður var haldið

EPAD

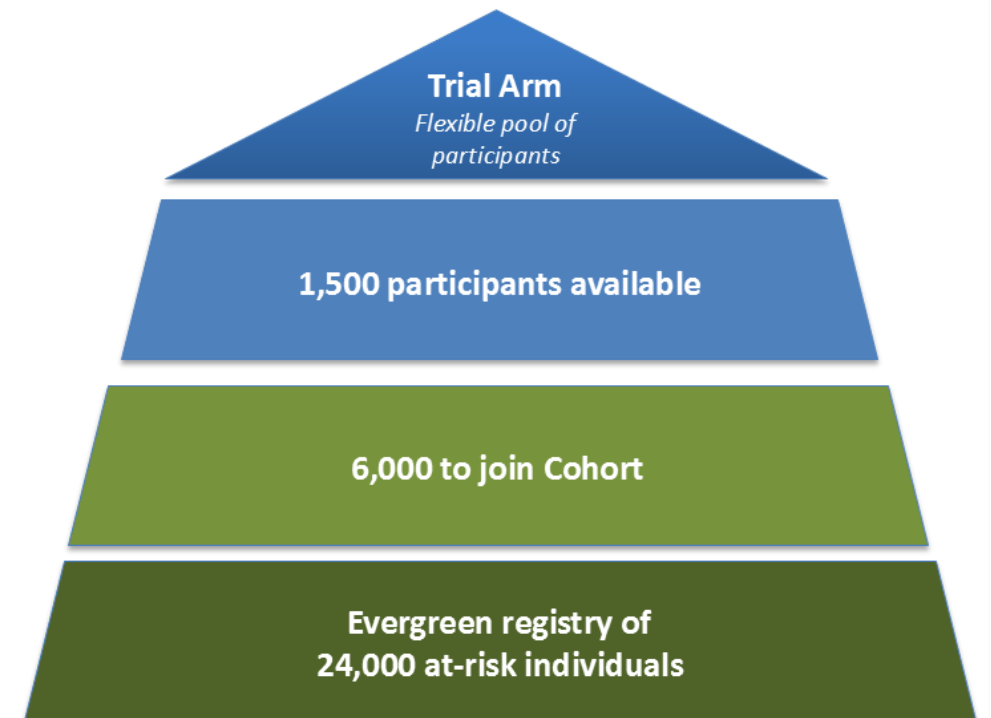
European Prevention of  
Alzheimer's Dementia Consortium





## Markmið EPAD

- Samræma rannsóknir og nýtingu á niðurstöðum
  - Fræðasamfélag + lyfjafyrirtæki > notandi
- Skilgreina hvar og hvenær heilabilun byrjar, t.d. Alzheimer
- Finna sjúkdóminn áður en einkenni koma fram
  - Alzheimer's disease / sjúkdómur
  - Alzheimer's dementia / heilabilun
- Rannsóknir nú



# Framtíðarsýn EPAD

- Sameiginlegt markmið okkar allra?
- Markmið íslenskra stjórnvalda?
- Arfgerðargreining (genotyping)
- Lífmerki (biomarkers)
- Geta greint áhættuhópin  
  - Hverjir eru líklegir til að fá heilabilun?
  - Í UK hægt að skrá sig til þáttöku í rannsóknum



# Viljum við vita?

- Viltu vita hvort þú munt fá heilabilun?
- Vita þeir sem veikjast af greiningunni?
  - Rannsókn AE, 2/3 vissu ekki.
- Margar siðferðislegar spurningar
- Hvaða upplýsingar er réttlætanlegt að veita?
  - Meðan ekki til lækning
  - Meðan ekki eru fleiri úrræði
  - Meðan fólk er einkennalaust

Belmams et al. *Alzheimer's Research & Therapy* (2016) 8:46  
DOI 10.1186/s13195-016-0212-z

Alzheimer's  
Research & Therapy

RESEARCH

Open Access

## Psychological, behavioral and social effects of disclosing Alzheimer's disease biomarkers to research participants: a systematic review



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### Abstract

**Background:** Current Alzheimer's disease (AD) research initiatives focus on cognitively healthy individuals with biomarkers that are associated with the development of AD. It is unclear whether biomarker results should be returned to research participants and what the psychological, behavioral and social effects of disclosure are. This systematic review therefore examines the psychological, behavioral and social effects of disclosing genetic and nongenetic AD-related biomarkers to cognitively healthy research participants.

**Methods:** We performed a systematic literature search in eight scientific databases. Three independent reviewers screened the identified records and selected relevant articles. Results extracted from the included articles were aggregated and presented per effect group.

**Results:** Fourteen studies met the inclusion criteria and were included in the data synthesis. None of the identified studies examined the effects of disclosing nongenetic biomarkers. All studies but one concerned the disclosure of APOE genotype and were conducted in the USA. Study populations consisted largely of cognitively healthy first-degree relatives of AD patients. In this group, disclosure of an increased risk was not associated with anxiety, depression or changes in perceived risk in relation to family history. Disclosure of an increased risk did lead to an increase in specific test-related distress levels, health-related behavior changes and long-term care insurance uptake and possibly diminished memory functioning.

**Conclusion:** In cognitively healthy research participants with a first-degree relative with AD, disclosure of APOE e4-positivity does not lead to elevated anxiety and depression levels, but does increase test-related distress and results in behavior changes concerning insurance and health. We did not find studies reporting the effects of disclosing nongenetic biomarkers and only one study included people without a family history of AD. Empirical studies on the effects of disclosing nongenetic biomarkers and of disclosure to persons without a family history of AD are urgently needed.

**Trial registration:** PROSPERO international prospective register for systematic reviews CRD42016035388. Registered 19 February 2016.

**Keywords:** Alzheimer's disease, Biomarkers, Disclosure, Risk, Psychological effects, Behavioral effects, Social effects, Prevention studies, Clinical research, Ethics

# Lækning eða forvörn?

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- Vonandi hvort tveggja
- Horfum til krabbameins eða lífstílssjúkdóma
  - Öll þróun miðar að því að fyrirbyggja frekar en að meðhölda þegar skaðinn er skeður
  - Hjartaáföll
  - Hár blóðþrýstingur
- Þróun úrræða þarf að eiga sér stað samhliða nýrri tækni við greiningar

Takk fyrir 😊

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