The Lifebrain study: Are people ready to endorse personalized brain health?

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Study objectives

Investigate the views of healthy adults participating in brain research studies on brain health and personalized brain health prevention.

- Perceptions of the brain and brain health
- Interest in maintaining a healthy brain
- Willingness to know more about own brain health
- Intention to act to maintain a good brain health and prevent brain disease development



Study design

Qualitative study conducted in 2 steps

Step 1 (ongoing):

- Individual interviews following an interview guide at 4 study sites: Barcelona, Berlin, Oxford, Oslo
- 10-12 brain research participants per site (>18, M/F, healthy, employment status/education level)





Study design

Example of questions:

- What does a healthy brain mean for you?
- In your opinion, which factors influence brain health?
- What do you personally and purposefully do to maintain a healthy brain?
- Would you want to know about the likelihood that you may develop a brain disease in the future?
- If you were told that you can prevent or delay brain disease development by changing your lifestyle, what would you be willing to do?





Study design

Step 2 (start fall 2018):

- Anonymous online survey
- Set up in 4 languages (Norwegian, English, Spanish, German)
- Same core questions set up as MCQ
- Survey to be distributed widely (with your help?)
- Pilot with participants at this workshop?





Study outcomes

- Increased understanding of what may/may not motivate individuals to take better care of their brain and follow personalized brain health advice
- Formulation of potential strategies that may promote brain health and inform public policy
- Results to be openly accessible and provided in various forms (scientific publications, information online/on social media)





Quotes from interviews in Norway (1)

Brain health is...

Cognitive health or mental health

- "function normally in the daily life"/"able to manage daily life rationally"
- "able to talk, learn new things, remember"
- "it covers mental health too, but first it is about memory"

Personal experiences influence interest in brain health

"I had a grandmother with dementia, and the mother of my friend has Alzheimer. I am also forgetting things. It would be nice to know more about brain health" (a young interviewee)





Quotes from interviews in Norway (2)

Justification for not acting

"I know I should have more physical activity in my life, then I could tolerate sleep deprivation better, too"

"I have a hedonist approach to life. I must admit though... I am aware that I should do more sports, eat less fatty food, drink less alcohol. But I don't do much. Meanwhile I find mental health very important. There is a discrepancy there".

Justification for acting: one step at a time

" I have found this 5-2 diet, it works for me, it helps improve brain health"

"I meditate almost every day, it is the mind that keeps the brain healthy"

"I am always feeling much better after spending time in nature"

"I am following a language app daily"





Quotes from interviews in Norway (3)

Family history of brain disease influences interest in testing

"Sometimes it is better not to know what the future might bring: it would bring too much worries to my life" (interviewee with previous experience of cancer)

VS.

" It is interesting to see how the body functions"

" If it is free, I would try it"

Lifespan perspective

Focus on early and late life, what about the "sandwich generation"?





Quotes from interviews in Norway (4)

Support needed to make lifestyle changes

"should be based on tangible suggestions"

"can be relatively easily implemented"

"I needed <u>a doctor</u> to tell me to stop smoking (due to my heart problems)"

"I can implement changes for a period, but if I don't pay enough attention, I fall back to the old routines"

Support from family, health app, brain health professionals, social workers





Quotes from interviews in Norway (5)

Role of public authorities vs. the individual

- "In the end, it is the individual who does something with his/her life"
- "The state should provide information about risk and protective factors, set brain health on the agenda»
- "Introduce meditation in schools"
- Employers: "They can do a lot to reduce stress among employees"





Next steps

- Data analysis (step 1)
- Preparation of the online survey (step 2)
- Dissemination of results







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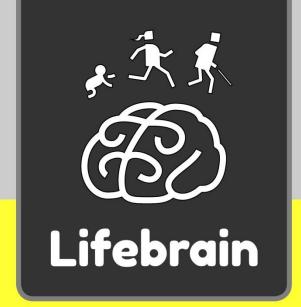


Stakeholder engagement in Lifebrain

- Stakeholder workshop, Barcelona, November 2018
- Stakeholder workshop, Oslo, June 2018
- Lifebrain conference, Berlin, November 2019
 - Patient organizations-led session
- Yearly public lectures







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