

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)



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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"



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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"?



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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 a doctor 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



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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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WEBSITE: lifebrain.uio.no

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