

Talking about the End of (Digital) Life; Experiences from the Death Lab De Dooie Hoek at the Lowlands Festival in the Netherlands.

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BACKGROUND

The internet is the biggest and most "disruptive" force since the industrial revolution. As a result people are increasingly spending time on the internet and living a digital live. This has changed the value people place on their friends' and family members' digital legacy. However attention to preparation for digital death and digital legacies is lacking in society and in palliative health care^{1,2}.

AIM:

To investigate meaning of digital legacy in the lives of youngsters (by age or by heart).

METHODS:

Participants completed a questionnaire based on the online Digital Legacy Survey, addressing experiences with and preferences for the accessibility of social media profiles and digital assets (e.g. photos) after death, and digital afterlife.

SETTING:

The "Death Lab" De Dooie Hoek ("The Dead Corner") at the Science Compound at Lowlands Festival, a yearly 3-day cultural event in the Netherlands where 45.000 visitors enjoy music, art and science.

RESULTS

533 visitors were registered at our lab, 362 (68%) completed the Digital Legacy questionnaire.

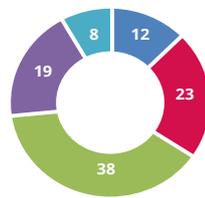
If someone you care about dies how important is it for you to be able to view their social media profile? (%)

Would you like your social media profiles to remain active once you died? (%)

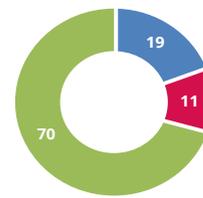
Have you made any plans for someone to get access to your media player or online accounts? (%)

PARTICIPANTS

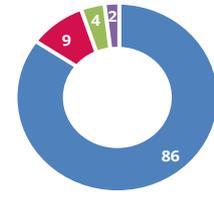
Gender female 215 (59%)
Age (Median, min-max) 26 (18-66)
Student 143 (40%)



Very important
Important
A little important
Not important
Unwanted



Probably yes
Probably not
Don't know



No
Yes, someone has access to some of my passwords
Yes, someone has access to all my passwords
Yes, no one has access to my passwords

CONCLUSION

Many festival visitors were open to think and talk about (digital) death. Although many participants prefer to view others' social media profiles after death, most of them want their own socials to be de-activated or removed. Only few had realized some plans for their digital legacy. These results mirror the limited international data¹ and implicate an urgent need for talking about digital end-of-life in palliative care.

REFERENCES

- 1) <https://digitallegacyassociation.org/wp-content/uploads/2019/11/Digital-Death-Survey-2014-2018>
- 2) Coop, H., & Marlow, C. (2018). Do we prepare patients for their digital legacy? A survey of palliative care professionals. Palliative Medicine, 33(1), 114-115.

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