

## Thanatos

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[https://thanatosjournal.files.wordpress.com/2012/12/waagstein\\_digitallegacy2.pdf](https://thanatosjournal.files.wordpress.com/2012/12/waagstein_digitallegacy2.pdf)

# An exploratory study of digital legacy among death aware people

**Astrid Waagstein**

IT University of Copenhagen

### Abstract

This article explores the awareness of and sentiments toward digital legacy through eleven semi-structured interviews carried out in Copenhagen in January 2013. It focuses primarily on the methodical aspects and considerations of the conducted study. In short, digital legacy in this review refers to the digital artefacts people consider worthy of preserving either for practical, historical, sentimental or even economical reasons, and which are most often inaccessible due to password protection (Waagstein 2013). The study is based upon the premise that very few people presumably give thought to their digital legacy<sup>1</sup> due to the subject matter's novelty. Death aware<sup>2</sup> respondents were chosen to increase the probability of getting valid data, since a large degree of death awareness is expected to correlate with the possibility that one also considers one's (digital) legacy. In this study, the death aware sample consisted primarily of hospice employees, who were implicitly asked whether they can relate to their digital legacy. They were also asked to what degree they felt that their digital legacy was important to them and what artefacts they regarded as valuable and potential heirlooms.

The study showed that the respondents were not aware of their digital legacy at all. Despite their death awareness and having experienced similar problems with inaccessible digital assets regarding family or friends, they had not considered the problems regarding their own digital legacy. However, following the interviews many of the respondents changed practice both professionally and personally, ensuring their digital access, should their spouse die unexpectedly, as well as addressing the topic with

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<sup>1</sup> The term digital legacy potentially applies to everything from digitised content, accounts, passwords, usernames and hardware since they are all interdependent: digital content cannot exist without being stored on hardware or cloud services, hardware would be worthless without its content and passwords are the key to accessing all the content. However, the majority of the valued digital legacy in this study applies to *content* like digital photos, diaries, letters, music etc., most often with sentimental value.

<sup>2</sup> The term *death awareness* refers to a state of consciousness emerging from being either terminally ill, a close relative to terminally ill person, a hospice employee, or the like. The awareness is evoked by the realisation of the irrevocability of death, and it notably affects thoughts and actions of a *death aware* person (Waagstein 2013).

patients and relatives. The study also identified the types of artefacts respondents considered as either practically or emotionally important, and worthy of preserving.

## Introduction

We need to treat the Internet as a new frontier that forms a part of our digital legacy. The things we create as an offshoot of our lives don't just live with us, in our homes; they live in new forms in a virtual world, which extends well beyond our immediate surroundings. (Richard Banks 2011, 123.)

As people are becoming digital, virtual belongings are becoming deeply integrated into our lives and subsequently our legacies, and these legacies comprise of a combination of life experiences, values and artefacts, including digital artefacts. (Gulotta, Faste & Forlizzi 2012; Gulotta, Odom, Forlizzi & Faste 2013). This means, that not only do we live a great part of our lives online, but we might also leave a great part of our online life behind when we die, and this post-mortem online life potentially constitute what we can call digital legacy.

Every individual produces approximately 88 GB content in a 75-year average lifespan according to Stephen Bulfer, CEO and founder of LifeCellar.com, who made the estimate in 2008 based on numbers from Google reporting, that stated, at the time, they processed 20 petabytes user-generated content each day. To get an idea of the magnitude, 88 GB corresponds to the individual producing approximately 17.6 million documents of size similar to this document, which is approximately 5 KB (see Table 1. below).

|                       |                 |
|-----------------------|-----------------|
| <b>Byte (B)</b>       | <b>8 bits</b>   |
| <b>Kilobyte (KB)</b>  | <b>1,000 B</b>  |
| <b>Megabyte (MB)</b>  | <b>1,000 KB</b> |
| <b>Gigabyte (GB)</b>  | <b>1,000 MB</b> |
| <b>Terabyte (TB)</b>  | <b>1,000 GB</b> |
| <b>Petabyte (PB)</b>  | <b>1,000 TB</b> |
| <b>Exabyte (EB)</b>   | <b>1,000 PB</b> |
| <b>Zettabyte (ZB)</b> | <b>1,000 EB</b> |

Table 1. Units of file sizes. (Screenshot by Waagstein, 11.3.2014, Peachpit.com.)

However, this estimate might already be obsolete, because not only has digital data become more sophisticated and extensive, the estimate covers only the content we share and produce online and not, consequently, the data we store locally (Carroll & Romano 2011, 39). Hence, we create, co-create and share a lot of digital content every day, and just as its analogue counterpart, digitised documents, letters, photos, music, I argue, play an important role in portraying a person's life and personality.

But what happens to these digital belongings when we are no longer around to maintain it? And how does our digital death affect ourselves, our loved ones and the generations to come? Let me start by answering the first question with a personal example before reviewing the study in question.

My (very tech savvy) grandmother died in June 2011. She was the one administering her own and my grandfather's online banking accounts, exchanging emails with the members of the local badminton club and fixing the computer hard- and software when needed. When she died, unsurprisingly she left behind several SNS-profiles<sup>3</sup> and password protected devices, which my grandfather had absolutely no idea how to manage or access, nor did his digitally native grandchildren. The effort trying to access her PC was unsuccessful, since no one knew her passwords, and suddenly a chain reaction of inaccessibility started: without knowing the password to her PC, we could not access her email account, and without being able to access her email account, we could not deactivate her Facebook profile and so forth. Eventually we managed to access her laptop, where digital photos, email contacts and other important documents were stored, by crosschecking little password-like pieces of paper, with network, computer, SNS and mobile-logins, but nevertheless the example illustrates that it can be rather complicated for both the individual and the descendants to die in the digital age.

Content is often no longer physically accessible in drawers and old shoeboxes like it was ten or fifteen years ago, but it is stored in the cloud and on password-protected devices, which can paradoxically only be accessed by the deceased. This means that if we do not plan ahead, which very few of us seemingly do, our digital legacy becomes inaccessible. This is a problem on several levels: the bereaved family becomes paralysed when trying to settle the digital estate – and forced data access might violate the posthumous privacy of the deceased, the descendants are without digital heirlooms, and society loses the ability to track the digital dimension of everyday culture. "If we look to the literature that describes things that happened politically, historically and artistically in the twentieth century, the most important research is based on private archives of letters, notes and manuscripts (...) It is therefore crucial to future historians, writers and journalists that this type of information is preserved digitally", notes Birgitte Possing, Professor of History at the State Archive (Dannemand Jensen, 2013).

Fortunately, there has been an increasing interest in studying the fields of the research situated at the intersection of death and technology, providing us with new information on how death and dying affects technology and its users and vice versa. Next I will go over related work, focusing on research primarily within the area of Thanatosensitive research. Thanatosensitive research refers to a humanistically-grounded concept that actively considers and integrates mortality, dying, and death into technological research and design, and the idea was introduced by interaction researcher, Michael Massimi, and PhD in English, Andrea Charise (Massimi & Charise 2009, 6-8).

### **Related work**

The relation between death and media is not a new phenomenon. From early print culture to the present digital age, media has always played a role in how we understand death, cope with it, hear and communicate about it and commemorate it (Jones 2004, 87). The difference in the relation between death and media today is, that although in modernity dying and grief are secluded from everyday view, the dead have been given more social presence in society through new communication technologies such as SNS (Walter, Hourizi, Moncur & Pitsillides 2011, 297).

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<sup>3</sup> See Boyd & Ellison, 2008.

Facebook profiles of the dead keep existing alongside profiles of the living, and bereaved relatives can have conversations with the dead through SNS's and thereby they are given the opportunity to continue the bonds with their deceased loved ones, almost as if the internet was some sort of digital heaven (Alexandra Sherlock 2013, 166). For some people this ongoing mediated conversation with the dead provides comfort and peace of mind, and for others it seems obscure and morbid. No matter people's preference, it would seem as if there is no happy medium regarding people's online presence post-mortem: either your digital footprints remain in cyberspace for eternity (or at least as long as the online services exists) or they become completely inaccessible. As a reaction to this, many online providers such as the Danish Aftercloud (<http://aftercloud.co>) or American-Canadian PasswordBox (<https://www.passwordbox.com>) that offers ante- and post-death digital asset management have begun to see the light of day. Some addressing their service to the bereaved family post mortem by helping them settle the digital estate, and others addressing the living intestate, meaning person formulating a non-legally binding will, helping them plan for their impending death. Evan Carroll and John Romano have also engaged in Thanatosensitive research field, concerning digital legacy management specifically. They have covered important fundamental issues on the safeguarding of digital legacy, and provided their readers with an elaborate strategy for securing their personal digital assets (Carroll & Romano, 2011). The emergence of these online death services, together with an increased research interest in the Thanatosensitive field, suggests that on one hand there is a need for gaining knowledge about how we safe-keep and inherit digital artefacts and on the other hand how we reflect on and perceive digital effects in the context of death and dying. On the basis of research of among other Richard Banks and David Kirk & Abigail Sellen, we have come closer to an understanding of the latter: the value people derive from looking back and the role technology heirlooms play in this regard. According to Banks, objects or heirlooms have the potential of triggering memories, emotions and thoughts of people, places and events, and this is true even for digital objects. Objects, whether they are digital or physical, hold the ability to connect us to ourselves, to other people and to the past (Banks 2011; Kirk & Sellen 2010; Unruh 1983). Thus, making them both sentimental and historically valuable. The notion is supported by studies of home archiving practices, suggesting that cherished and sentimental objects also involve digital items (Massimi & Baecker 2012; Gulotta et al. 2013).

The study in question will follow in the footsteps of the studies mentioned, exploring reflections and thoughts on digital effects, only it will be on a more fundamental level. It seems as though we have not yet tried to comprehend the fundamental awareness of sentiments toward digital legacy, which, in my belief, is an important first step in understanding how people in fact value the digital legacy in order to develop appropriate Thanatosensitive systems.

### **Problem formulation**

To explore the awareness of the digital legacy, I have implicitly<sup>4</sup> asked death aware respondents if they can relate to their digital legacy, and if so, how? I have also asked them to what degree they feel the digital legacy is important to them, and what artefacts they regard as valuable and potential heirlooms. The death awareness refers to a state of consciousness that emerges from being either terminally ill, a close relative or nursing staff to a terminally ill person or the like. The death awareness is evoked by the realisation of the irrevocability of death, and it notably affects thoughts and actions of the death aware which presumably might trigger thoughts on (digital) legacy (Waagstein 2013). "People tend to begin planning for death as they become more aware of the finite nature of their lives. This tends to be around middle age; however, death of a loved one can highlight the issue sooner." (Carroll & Romano 2011, 54.)

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<sup>4</sup> The term *implicitly* refers to the three-step methodological approach described next, which in particular refers to the way the interview guide was formulated and conducted, and the way the pre-presentation was held.

The main stakeholders in this complicated area are the living individual, also referred to as the intestates, and the bereaved family. These two groups of stakeholders are in a way interdependent. The intestate is capable of planning ahead and providing the relatives with access to important digitised content *ante-mortem*<sup>5</sup>, but bereaved relatives are able to assess what types of digital artefacts belonging to the deceased they value and wish to inherit post-mortem, since bereavement can cause an object's value to change:

Objects are polysemous (...) the same object can carry with it different meanings for different people, and these meanings can change over time and in accordance with the changing nature of the relationships we have with other people (Ekerdt & Sergeant 2006; Kirk & Sellen 2010). This is true even through bereavement, where artefacts can take on new meaning. (Banks, Kirk & Sellen 2012, 65).

Also, bereaved family members are the ones that experience the consequences of the individual's planning-or-not choice post mortem. The interdependence, therefore also refers to the shared interest regarding the management of digital legacy, which often exists between the two stakeholders. Family members usually wish to act in agreement with the wishes of their deceased:

*You can see how fast it goes [with death, dying, accidents etc.], and then I'm thinking, it must be nice to know the wishes of your loved ones. At any rate I know I would like to know the last wishes of my mom (Respondent A).*<sup>6</sup>

I will elaborate on some of the major challenges regarding post-mortem digital legacy management in the final chapter, but next I will turn to the methodological exposition. In addition, it should be noted that the research in question is not theoretical, but rather explores the methodology of this cross-disciplinary research field.

### **Methodological approach**

To gain a better understanding of the hospice environment and to be able to approach the study in the most ethical and moral manner possible, a careful preliminary study into the area of palliative care preceded the recruitment and data collection. The study consisted of a conference on possible methodological approaches with professionals specialized in palliative care<sup>7</sup>; Chief of Palliative Research Center, a hospice nurse of development, Chief of Secretariat in Hospice Forum Denmark, and a hospital pastor with specialization in palliative care. The article Tailoring traditional interviewing techniques for qualitative research with seriously ill patients about the End-of-Life was among other readings, a fundamental part of the research preparation. It offers field-tested techniques for interviewing seriously ill individuals and suggests tailored practices for discussions of end-of-life (EoL) issues with the patients (Schulman-Green, McCorkle & Bradley 2010). Even though proxy data was used instead of interviewing dying patients, my belief is that the thoughtfulness and carefulness prescribed in the encounter with EoL-patients is equally important when interviewing hospice employees. They work in a sensitive and emotionally demanding environment and face death and dying every day.

<sup>5</sup> See more on ante-, peri-, and post-mortem stages in Gotved 2014.

<sup>6</sup> All interview transcripts are anonymous, interviewed by Waagstein in February 2013, Copenhagen. Translations from Danish into English are author's.

<sup>7</sup> Palliative care means 'alleviating care' and captures the preventive effort made by professionals to alleviate the pain of people with life-threatening conditions such as cancer, heart failure, neurological conditions and the like. Palliative care exists to enhance the quality of life for the affected person and targets both the physical, psychological, social as well as the spiritual distress. (Palliativt Videncenter. 2013. Om palliation. Available at: <http://www.pavi.dk/OmPalliation.aspx> [accessed 17.3.2013])

The study is exploratory, which is why no initial hypothesis was put forward regarding the sentiments towards digital legacy. However, it is, as stated, highly motivated by the presumption that few people have thought about their digital legacy, and this is reflected both in the choice of the methodical approach as well as in the choice of respondents.

### **Empirical data**

The empirical, qualitative data consist of eleven semi-structured interviews with women aged between 22 and 64. They are employed by the Danish care sector<sup>8</sup> and the majority are between 40 and 50. Nine interviews were conducted with hospice nurses, one with a pedagogue student attending a grief therapy group and one with a doctor, which was also conducted as a pilot interview. The majority of the respondents are bereaved relatives; hence the death awareness, and they all have a certain degree of digital activity in common. Digital activity refers to a day-to-day use of tablets, PC, smart phones or the like.

In addition, an interview with digital legacy expert, Evan Carroll, was conducted together with an interview with the head of a secretariat of the Danish National Association Life and Death. The Carroll interview deals mainly with the perspectives on digital legacy management while the Association's interview deals with the creation and development of the association's My Last Will. The will is a non-legally binding document acquired and filled out by many Danes in preparation for their death and funeral, interestingly in August 2012 the Association added the option of writing down one's pass codes to the will. Furthermore, a discussion about Dane's perception of Death in the 21st century was initiated.

Apart from the preliminary study, I have operated with a three-step methodological approach consisting of 1) a recruitment process 2) a pre-meeting & presentation of subject and 3) the interviewing.

#### *Recruitment for interviews*

The hospice environment is a private and protective institution and for good reasons. A hospice's main purpose is to protect the privacy of dying patients, who above all need care, rest and peace of mind during the last days of their lives. The initial plan was to recruit dying patients since they are the closest one can get to death awareness, but interviewing patients at EoL stage has its ethical as well as practical challenges concerning both dying patients as well as researchers. Dying patients might be debilitated, their anxiety and emotions can be heightened, and although qualitative interviewers in general face challenges of building trust and obtaining answers to their research questions, these issues are intensified for interviewers of EoL issues because of the sensitive subject matter (Grumann, Mareile M. & Spiegel, David. 2003, 23; Schulman-Green et al. 2009, 90). But also the qualitative researcher can be emotionally affected when carrying out sensitive research. Qualitative researchers doing sensitive research risk burning out subsequently if they are not supported with clear research guidelines, e.g. in form of strategies to deal with emotions if research participants die during the research, or if they are not equipped with specific research strategies developed in conjunction with a research supervisor (Dickson-Swift, James, Kippen & Prancee 2007, 345–346).

In the study in question, proxy data was chosen instead of patient informants for three main reasons. Firstly, hospice employees would not be physically challenged by the interview situation like dying patients might be. Secondly, the subject matter would not be as sensitive for the employees to discuss as they were not terminally ill, and thirdly, if the patients were to react with the same surprise towards the existence of digital legacy, as it turned out the hospice

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<sup>8</sup> All referred to as *hospice employees* or *respondents* throughout the article.

employees did, it might cause the patients serious stress as they would not have the necessary time to prepare for their digital death.

The process of recruitment of death aware informants was carefully planned, since it can be difficult to gain access to clinical sites, and it began by collecting stamp of approval from hospice leaders, chief of Palliative Care centers and Grief support groups. The idea for this top-down approach comes from research scientists in Nursing Debra Lynn-McHale-Wiegand, Sally A. Norton and Judith Gedney Baggs (2008, 170-171), and has later been described in Schulman-Green, McCorkle & Bradley's recruiting techniques for patient informants concerning qualitative research in critical care:

If interviews are being conducted in an institutional setting such as a hospital, nursing home, or hospice, having a staff member introduce the study to other staff members can also assist with gaining access to patient participants (Schulman-Green, McCorkle and Bradley 2009, 92).

One hospice leader in particular found the research project interesting and helped in introducing it to her employees. Emails were sent out describing the study on behalf of the researcher, information posters were hung on the hospice's noticeboard and the leader agreed to the holding of an information- and recruitment meeting that would give the employees a basic understanding of the concept digital legacy. The pre-meeting was a fundamental part of the methodic approach, since the subject field might be too complex, novel and abstract for the uninitiated (and less tech savvy) to immediately reflect on. Also, it was not expected that the employees would be willing to volunteer merely on the basis of a poster.

#### *Pre-meeting and presentation*

The goal of the pre-meeting was to give the respondents a neutral, prior understanding of digital legacy. At this point the respondents had supposedly only read superficial newspaper articles about dead Facebook profiles existing amongst the living or about those upcoming digital death services. However, there is a big difference between having a sketchy consideration of the afterlife of one's Facebook profile, and reflecting on a post-mortem management of one's entire digital legacy. My assessment was therefore that an introductory presentation would be necessary since the chance of somebody being capable of answering questions about digital legacy would be rather small. Reflections on the possible negative effect of this pre-meeting on to the subsequent interviews will follow in the next chapter.

The presentation had four overall goals: 1) to enlighten the respondents on the subject field, 2) to make the subject matter as tangible, understandable and applicable to the respondents as possible, 3) to plant a seed of reflection on digital legacy, 4) and to use the pre-meeting as an opportunity to build trust between the interviewer and interviewees – an important step in qualitative research that touches upon death and immortality, and in which “the interviewer can also gain a sense of the participant through informal pre-interview talk (...)” (Schulman-Green, McCorkle & Bradley 2010, 95; Rubin & Rubin 2012, 92).

Perhaps most important goal of the presentation, however, was to present the subject matter in the most neutral and unbiased manner as possible. If the presentation was not impartial, the researcher would risk making a self-fulfilling presumption of the study. On the other hand, the presentation had to be profound enough for the interviewees to be able to apply information about digital legacy onto their reflections on their own digital legacy. I will reflect on the outcome of the delicate balance of these considerations later.

The three posters in Figure 1. were used at the pre-meeting for illustrating the fundamental problems of accessing and managing digital legacy.

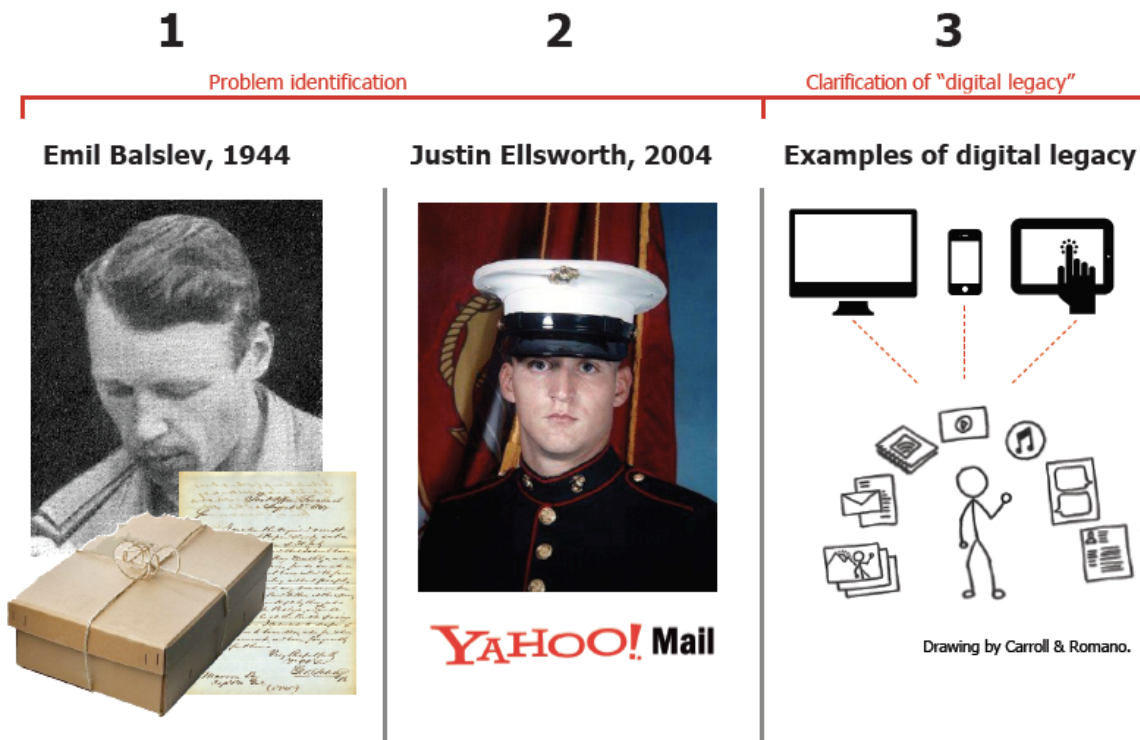


Figure 1. Three posters used at the pre-meeting for illustrating the fundamental problems of securing and managing digital legacy. (Figure: Astrid Waagstein)

Picture one illustrates the story of a Danish freedom fighter, Emil Balslev, who was executed in 1944. During World War II Baslev had exchanged handwritten letters with his wife Gudrun, one of them only a few hours before his execution. Gudrun hid all of her husband's letters in shoeboxes in their home in Roenne, Denmark, and the letters were therefore accessible to Gudrun as well as later generations. In fact, Balslev's last letter to Gudrun was published in 1945 together with 111 other farewell letters by executed freedom fighters in the anthology called *De Sidste Timer* [The Last Hours] (Gade 2012).

Picture two illustrates the story of an American soldier, Justin Ellsworth, who died 60 years after Balslev, in the Iraq war. During the war, Ellsworth had exchanged e-mails with his dad, John, just like Gudrun and Emil had, except that Justin and John's letters were electronically exchanged. When Justin died, his father wanted to make a scrapbook of Justin's emails and pictures, but he could not access his son's email account. Firstly, because he did not know his son's login information, and secondly, because the legal ownership of Justin's email account had automatically passed down to Yahoo!. To make a long story short, Justin's father took Yahoo! to court, won the trial and received a CD with the content of his son's email account (Carroll and Romano 2011, 11–13). Although this story had a happy outcome, the example illustrates that the access to documents, pictures or other important objects is no longer given. We cannot expect our belongings to be physically accessible when we die, but they depend on service providers, such as Google, Yahoo! or Dropbox, or the deceased to grant us access to the digital archives.

While the two first pictures identify the problem area of digital legacy, the third picture concretises our potential, digital legacy by displaying the artefacts we typically store online. The type and size of the digital legacy varies, but it can



consist of digital photos or videos, iTunes songs and playlists, digitized documents such as letters, diaries and songs or more official documents such as marriage certificate or contracts. I will describe the types of artefact digital legacy constitute in more detail in the results chapter.

### *Interviewing*

All interviews were conducted one to five days after the pre-meeting, and were for the most part semi-structured. The semi-structured interview form involves, as the name implies, a semi-structured approach to the interview. It can be conducted in various ways, but typically the researcher will follow a set of predetermined topics or open-ended questions that are based on the research question. These open-ended questions will not have a fixed range of responses or a specific order and the semi-structured interview is therefore both investigative and settled. (Given 2008.)

During interviews, five key questions were always asked in order to give the interviewees some sort of direction that could help to answer fundamental matters on digital legacy. Also, when the interviewer knows what she is asking about and why she is asking, a more reliable underlying basis for a later analysis can already be made during the interview by clarifying relevant statements and eliminating ambiguous ones (Kvale 2004, 136).

All questions were formulated partly on the basis of the study's problem formulation, and partly on the basis of a philosophical, phenomenological approach where the researcher asked herself what questions she would ask if she was to conduct an interview about digital legacy? This type of reflective, methodical grip is typical to the work of the anthropologists, who are as much in dialogue with others as they are with themselves, especially the branch of anthropology called Anthropology of Experience (Turner & Bruner 1986, 13-14).

The approach resulted in a gross list of questions and sub-questions that could be asked depending on the direction each interview took. Besides the five key questions, every interview was initiated with the question: Have you ever thought about the subject matter, digital legacy, before it was presented to you yesterday? It filled the function of giving the respondents time to adapt to the interview situation and, at the same time, getting an impression of the respondent's prior knowledge of digital legacy. Question 1.a to 1.d shown below were asked depending on the respondent's capacity to operate information about digital legacy. Together these constitute the first of five key questions:

1. (a) Have you prepared for your death in any way?
  - (b) How would you like to be commemorated?
  - (c) The inherent and personal memories of a physical, tangible object such as pictures or letters can help families reminisce about their deceased loved ones. Do you think some of your digital belongings could help your family reminisce about you?
  - (d) Do any of your digital effects have value to you at present, and do you think they could have value to your family post-mortem?
2. Are there any digital artefacts you would like to have deleted/made inaccessible upon your death?
3. Are there any digital artefacts you have doubts about deleting or securing for posterity?
4. Are there any digital artefacts you don't care about are being preserved, passed along or deleted?
5. Are there any digital artefacts (hardware, software, passwords etc.) you think would be clever to make accessible before death?

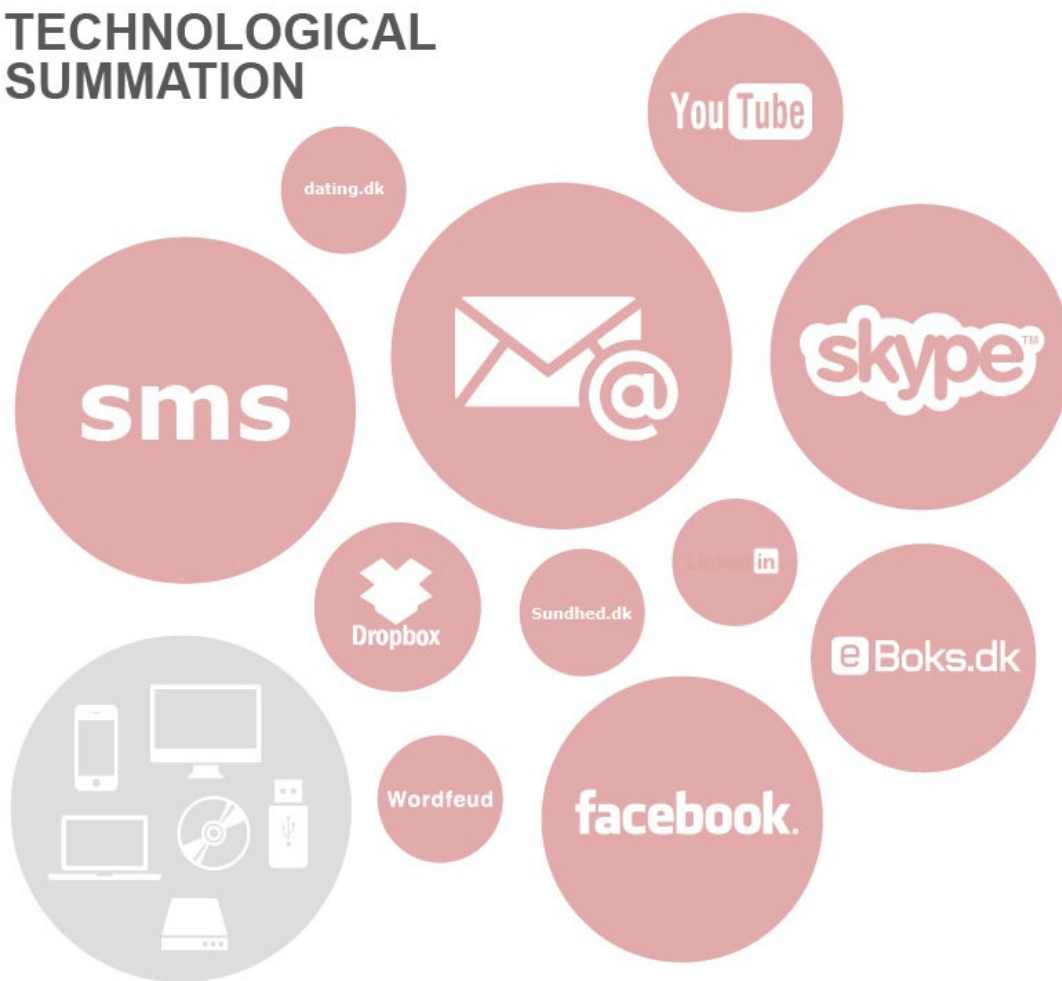
### *Methods for analysis*

The qualitative data was analysed with a mix of two qualitative methods called Summary of meaning and Ad hoc-meaning-establishment, respectively, formulated by Steinar Kvale, Professor of educational psychology and director of the Centre of Qualitative Research at the University of Aarhus. In the former, the researcher reads and listens through the complete transcript of the interview, and subsequently tries to identify the most significant units of content. These units will then be summed up as central themes, which again will be compared to the overall aim of the research study. In the present study the aim was to figure out what the themes tell us about the death aware respondents relation to their digital legacy.

The Ad-hoc-meaning-establishment method is a mixed method approach consisting of various techniques such as quantification of statements, visualising results, generation of patterns, search for plausibility, generation of general impressions etc. The methods can be used separately or jointly and are suitable for bringing out connections and structure in interviews that are not meaningful at first. (Kvale 2004, 201).

The application of Kvale's methods involved several simultaneous readings of and listenings to the interviews in practice. The readings were both exhaustive and superficial depending on the purpose at the time, and resulted in the emergence of important key themes. A counting of statements was also made, and resulted in the quantification of the respondent's digital activity illustrated in Figure 2. below, as well as the visualization of the findings of valuable digital assets (see Figure 3.). To discover patterns and obtaining data overview, a summary of all the interviews was performed, and in-depth readings were performed on selected significant statements in the end.

## TECHNOLOGICAL SUMMATION



Hardware: Every respondent owns 1-3 pieces of hardware each and approx. 90 pct. of the hardware is password protected

Figure 2. Bubblechart displaying the number of devices each respondent owns as well as the types of online services they make use of. The size of each bubble indicates the number of respondents using a certain service, thus, the bigger the circle the more users. The quantification of the respondent's digital activity also unveiled that ten out of eleven devices are password protected. (Figure: Astrid Waagstein.)

### Reflecting the Research Methods

As previously stated, perhaps the most important goal of the pre-meeting was to present the subject matter, on digital legacy, as neutrally and unbiasedly as possible. However, an evident question arises in the wake of this statement, namely, that whether the researcher could have avoided any issues on bias by simply failing to make a presentation? I suggest that the answer is no. It is due to the information provided at the pre-meeting that the respondents were able to reflect on a level resulting in the profound findings on digital legacy. Results, that clearly suggest a reflection was initiated by the presentation in the form of exclamations of surprise and the emergence of aha experiences.

Could one then argue that the presentation could have been more objective? Some may claim so, but my first counterargument is, based on humanistic-hermeneutic philosophy of science, that absolute objectivity does not exist but, rather, the interpretation will always depend on the anticipation of the interpreter as well as the context of the

study (Olsen & Pedersen 1999, 140). The late anthropologist Clifford Geertz said that it was not possible for social scientists to record tangible social realities, because reality will always be an interpretation of an interpretation. Analysis of personal experience lies in other words at the core of the research on human behavior and development (anthropology), and introspection therefore evidently becomes a part of the objective understanding (Geertz 1973, 3–32).

Moreover, the study's exploratory approach argues in favor of an unprejudiced presentation. The exploring researcher does not have an interest in hidden agendas, but is rather motivated by her neutral curiosity. Also, the respondents do not only repeat examples from the pre-meeting but also come up with personal exemplifications regarding inaccessible digital artefacts, an action that speaks against a prospective presupposition. However, one objection to this methodical approach is the rather narrow dispersion of informant types. All respondents are women mainly in the age between 40 and 50 and mostly employed by the care sector. Since the study is exploratory and not quantitative nor comparative, a wider dispersion would have been desirable. However, as the numbers of recruitment strategies are limited within EoL research and the sizes of samples for such research are reduced by recruitment problems unique to EoL studies, this naturally limits the power and generalizability of samples in EoL studies (Kirchhoff & Kehl 2008, 515).

I will discuss this in further detail and give my recommendation for future research designs in the section Discussion and Future work.

### **Relating to Digital Legacy**

The analysis is divided into three main sections each answering a question stated in the problem formulation. The first section answers the matter of the awareness, the second answers the matter of the respondents' relation and reactions to the subject and the third answers the matter of the value of the digital. The selected examples below are representative of the information contributed by the respondents through pre-meeting and interviews.

*Do the respondent's relate to their digital legacy?*

The term relate to refers to the respondents being aware of themselves possessing valuable digital artefacts. Consequently, they might have ensured the securement and accessibility of the valuable artefacts (without thinking directly along the lines of digital legacy, however). The short answer to the question, whether the respondents relate to their digital legacy, is no. The respondents were not aware of the existence of their digital legacy at all. Despite their death awareness, which among other things is revealed by their use of My Last Will and the fact that many respondents seem to have experiences with inaccessible digitised content both personally and through family, they have not drawn a parallel between these experiences and the existence of their digital legacy:

*Respondent B: Yeah, so I thought about the problematics before [when my brother-in-law had died and my sister had problems with accessing his computer, red.]. But not in the same way as after the presentation. It became more tangible, more systematic then.*

*Interviewer: Ok, so what did you think on the subject matter before the pre-meeting?*

*Respondent B: I hadn't thought about it, actually (...) and I certainly wasn't thinking of doing anything about it. You know securing it and preserving it. I just wasn't there yet. But suddenly some aspects were put into relief and I went straight home to my husband and said: How do we handle our digital assets if one of us dies?*

Another example illustrates that not even a personal experience with inaccessible hardware is tantamount to one considering making one's digital belongings accessible. One of the respondent reports that she lost access to her family's hard drive with all their family photos after her husband's death since he was the only one who knew the password.

Respondent C: *Yes, I have thought about the problems regarding digital legacy before you mentioned it yesterday, because my husband died two years ago. He was an IT engineer and he made sure that I could access all of his online accounts before his death. He had just forgotten about the external hard drive where all his digital photos were on.*

However, the same respondent had not thought about ensuring the access to her own hardware and software post-mortem for the sake of her daughter, despite the fact she has experienced problems with inaccessibility herself. This paradox is realised during the interview:

Interviewer: *Is your computer password protected?*

Respondent C: *Yes.*

Interviewer: *And your daughter, does she know the password?*

Respondent C: *...No, she doesn't (pause and thoughtfulness)...That it is actually completely ridiculous. I have been in the exact same situation and haven't even thought about this. (Interviewee C).*

In other words, neither one's relative's experiences with inaccessible artefacts nor one's personal experiences affects the respondent's general awareness toward digital legacy. However, a general tendency amongst many of the respondents seems to be that a deeper understanding and awareness of digital legacy arises during the interviews, and not only as a result of the pre-meeting. One respondent suddenly realizes that she doesn't know how to login into the Picasa family photo album, some thing that she apparently would like to be able to, should her husband die untimely;

Interviewer: *So where do you have those pictures now?*

Respondent D: *Well, they're on Picasa*

Interviewer: *And do you know how to access them?*

Respondent D: *(Pause) No I do not, actually, because my husband created the albums and he always invites me in.... you caught me there. That's not good.*

Interviewer: *Okay, so how many pictures do you think you've uploaded to Picasa so far?*

Respondent D: *Oh...a lot!*

In summary, both the interviews and the presentation contributed to a situation of change where reflections on digital legacy were initiated and broadened.

*How do they relate and react to the knowledge of digital legacy?*

With the respondents becoming aware of the existence of their potential digital legacy, it is interesting to examine how they relate to it. Do they consider the digital artefacts equally important as their physical belongings or does the digital have no importance to them at all? The fact that many of the respondents took action the very same day of the interview, making sure that they are able to access shared hard- and software post-mortem, suggests an appreciation of the digital. Action refers in this case to both the physical transfer of data and the obtainment of usernames, passwords and location of digital assets through clarifying conversations with family.

Respondent E: *I talked to my husband after that [the pre-meeting, red.], and asked him if there was anything I needed to be able to access should he be killed tomorrow” or as another respondent puts it: “When you told us about all this yesterday I raced home to my husband and asked him to tell me the password for his hard drive.*

Even though the hard drive turned out not to be password protected, the immediate reaction and urge to take action suggests the appreciation of the digital that is mentioned explicitly several times:

Respondent F: *I’m not a particularly tech savvy, but I think it’s a really interesting topic. The world is getting more and more digitised and that is why I think it’s important to pay attention to and think about. My son has probably never thought about it so I think we’re going to sit down and have a talk about it at some point.*

The respondents have also changed professional practices. A revisit at the hospice six months later unveiled that the employees had begun discussing digital legacy, and passing access codes from patients to relatives.

Securing digital legacy not only refers to the passing of access codes and login information, but also to the backing up of content – especially considering the increasing use of mobile devices. Mobility means that we are carrying valuable digital content around with us possibly resulting in the loss of digital content, if we do not get to back up our content:

Respondent G: *I have only transferred them [the iPhone pictures, red.] one time to my external hard drive. It happens that I forget to transfer them for at couple of years, and then suddenly they’re gone because the mobile has been stolen or broke.*

In fact, a surprising number of respondents report either broken or stolen hardware, which, besides inaccessibility, is a risk factor that challenges the safeguarding of digital legacy:

Interviewer: *Do you take (digital) pictures?*

Respondent H: *Yeah I do, in large numbers....but we’ve had burglary several times, actually four times in three years. I think we lost a computer twice and in that connection I lost some of my digital photos.*

Even though it turns out that some respondents ‘unknowingly’ backup their digital content due to the mentioned fragility of hardware, and write down their passwords in notebooks to support their own memory, the risk of inaccessibly post-mortem is still present. As we see, digital legacy is left with no heir in mind and descendants are left only with disconnected and scattered information, which might or might not be sufficient for post-mortem access.

In summary, the reactions and statements of the respondents suggest that they consider the subject matter relevant, important and topical. The new knowledge has resulted in the discovery of a need to deliberately secure their digital assets both professionally and personally as they appreciate the digital. Respondents also ‘unknowingly’ back up their digital content in order to prevail loss. However, this act alone does not secure access post-mortem as descendants might lack a transparent system for post-mortem access.

#### *The value of digital things*

While the previous sections showed that the respondents regard their digital belongings as valuable, this section outlines the type of digital assets that the respondents have, at some point, termed ‘worthy of preserving’. The majority of the digital artefacts that are considered valuable are digital content, which makes sense since typically the photos on the

camera, and not the camera itself are what has sentimental value to us (unless the camera belonged to, say, our deceased granddad).

However, in the digital age, hardware, content and passwords are interdependent. Digital content cannot exist without being stored on hardware or cloud services, hardware would be worthless without its content, and passwords are the key to accessing all the content. 'Digital legacy' therefore applies to everything from content, account passwords and usernames to hardware.

The degree of appreciation for the digital artefacts was assessed on the basis of statements, the statements' emotional accentuation and the context of the statements that resulted in a qualitative scale of value ranging from 'not valuable at all' to 'very valuable'. The most treasured digital artefacts between the respondents are displayed in Figure 3. Furthermore the value scale is divided into artefacts primarily representing a practical value, a sentimental value or a historical value. Next, I will give a few selected examples of digital artefacts with a sentimental, practical and historical value, respectively.

The ability to juxtapose digital objects with physical objects plays a great role in the assessment of the digital value to the respondents. People typically acknowledge the value of an old photo regardless of time and place, and thus it is so much easier to imagine the long-ranged value of a digital photo than it is to see the value of a blog or a Facebook profile. Maybe this could be one of the reasons why almost all the respondents stress the value of digital photos in particular:

*A patient once reminded me that you can always buy a new sofa, but you cannot buy new photos. I thought about it and realised that if your house burns down to the ground, it's potentially the memories of a whole lifetime that are lost... On the basis of this conversation I bought myself a new hard drive. (Respondent H).*

Also, digitised documents such as personal letters, poetry, songs, blogs, digital playlists and SMS's are denoted as sentimentally valuable. One of the respondent e.g. reports that she has kept and printed out the SMS's of her late husband which she received during his spell of sickness:

## VALUABLE DIGITAL ASSETS

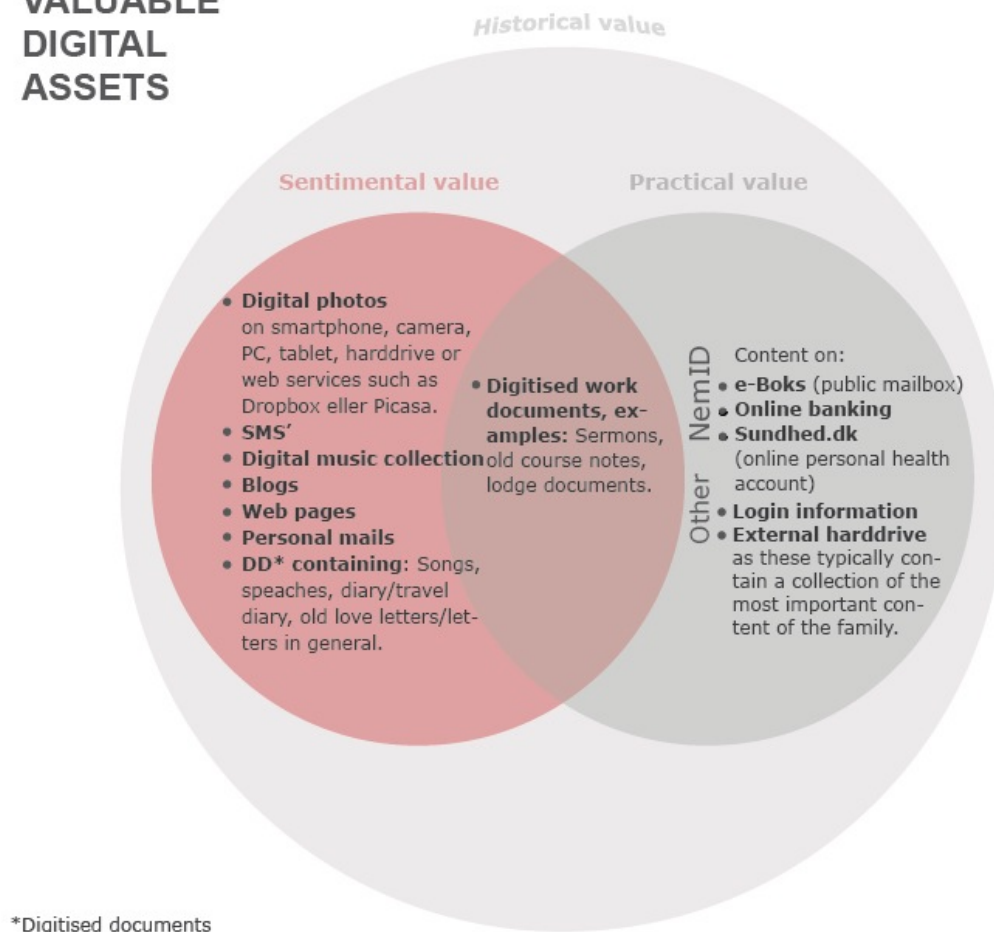


Figure 3. Outline of the digital effects that the respondents consider practically, historically or sentimentally valuable. Figure: Astrid Waagstein.

*I received a lot of texts from him when he was sick. Because he was hospitalised I wasn't allowed to stay overnight and so we texted each other. We texted a lot and I wanted to keep those text, so I sent them to my email address and printed them out. (Respondent C).*

In this case the text also takes the form of a digital heirloom that helps the respondent reminisce about her deceased husband. It does so in a manner very personal and vivid since the text was written by deceased. According to HCI researchers Richard Banks, David Kirk and Abigail Sellen (2013) who have focused some of their research on technology heirlooms, the recollection of the past is the first task of the heirloom:

Artifacts play an important role as triggers for personal memory. They help in the recollection of past experience and in reminiscing about people, places, and times gone by. Of particular interest to us is one type of artifact, the heirloom, which may also have rich connections with memory, but often through the lens of the life of a deceased member of a family, or a friend. (Banks, Kirk & Sellen 2012, 63).



The inherent stories and memories of places, people and a time gone by are also what constitute the historical value of an artefact, which in many cases are pointed out by the respondents:

Respondent F: *I remember when the whole family sat together and watched old slides. It was so fun to see how my grandmother was dressed at that time. And I'm thinking, that my digital photos might give my son the same joy eventually, because they [photos] do in fact represent a piece of history. You can see how people looked in the 60's, 70's and 80's.*

Another respondent reflects about the historical value in the following way:

Respondent I: *I want my daughter to be able to understand who I was even if I die young, and I hope she can do that through the stuff I leave behind - also the digital. I have always thought that old diaries, letters or photos were quite magical because of the insight they give you into another time.*

Though it is the sentimental value that is mainly discussed in the present study, many of the respondents touch upon issues with postmortem access to both public and private online services and settlement of estate – also digital. A young respondent whose father died recently expresses the overwhelming amount of practicalities her family faced after his death, many of which required online access and the knowledge of deceased's login information:

Respondent J: *There were so many things that we had to take care of... I can't remember them all, but it was things like cancellation of subscriptions, -memberships, -profiles, -orders, report moving, manage online banking affairs so my mother wouldn't be financially strained in the time after his death. And I remember that we were so grateful that we knew his passwords. I also remember that he had placed all these orders on camping gear but we didn't know where to pick up it up because the information was in some kind of mail we couldn't find...so in the end we just gave up.*

The example illustrates that the tasks of settling an estate can be extensive and, what is more, is often needs to be handled while simultaneously dealing with the loss and organizing the funeral. Also, much of the existing post-mortem settlement requires online access and knowledge of the deceased's login information – login-knowledge that has a practical value to the surviving family post-mortem, but which they often do not have. Two more things to add to this notion is that bereaved relatives might have to face uncomfortable situations when they handle unsettled digital legacies of those who die (Massimi and Baecker 2010, 1826), and forced data access might violate the posthumous privacy of the deceased. There seems to be very little support for post-mortem privacy – referring to an individual's right to preserve and control what becomes of his or her reputation, integrity and dignity after death – and it therefore needs a closer inspection in common law (Harbinja & Edwards 2013, 102–104; Tungare 2012, 1–2).

The issues described above are only some of the problems researchers encounter when trying to map out the landscape of digital legacy management. Unfortunately, there is no simple fix to ascribe to this subject matter but we can start by trying to at least frame some of the challenges of this highly complex and still changing culture.

### **Discussion and Future Work**

This exploratory study on the awareness of and sentiments toward digital legacy shows that even though respondents have had experience with inaccessible digital assets personally or through family or friends, they were not at all aware of their digital inheritance before the problem was presented to them. When made aware the respondents expressed a large desire towards ensuring their digital artefacts for their families and themselves, as they felt that their digital effects have

value. The validity of the respondent's statements can be confirmed since a revisit to the hospice unveiled that action on the matter of securing the digital had been taken: the employees had begun discussing digital legacy and passing access codes with patients. The digital artefacts reported worthy of preserving consist of everything from digital documents (personal letters, poetry, songs), digital photos, SMS's, blogs, playlists, e-Boks<sup>9</sup> contents, access to online banking, hardware and password itself, all of which are displayed in Figure 3. The value of the digital is classified as mainly sentimental or practical but all artefacts possess an inherent historical value on par with physical assets pointed out by the respondents. Respondents back up their digital content occasionally (with the exception of mobile hardware) due to the fragility of it, but since securement is not made with descendants in mind, the surviving family might be left only with scattered and unintelligible login information. Overall, the results suggest that dying in the digital age is rather complicated for both the individual and the descendants.

Although not representative, the study in question points towards important views on digital legacy of death aware. The awareness of the existence of digital legacy at present is still rather small, but as we slowly become aware of the existence of our digital legacy and realize the value of our digital belongings, the need for providing people with suitable ways of safekeeping their private digital belongings will increase. Next, I will give my recommendation for future research and I will reflect on some of the major challenges this research area currently face.

As stated earlier, the study is qualitative and therefore not exhaustive. The goal of this study was not to put forward an exhaustive list of potential digital heirlooms, but rather to explore the knowledge and sentiments toward digital legacy, and to see if digital objects are treasured at all. However, since previous studies (including this) seems quite limited in terms of dispersion of informant types and sample size, and because similar studies conducted on the subject matter draw different conclusions regarding the value of digital affects, further and broader investigation into the subject matter is needed: one study on home archiving practices comparing physical and digital mementos suggests that physical mementos are valued more than digital mementos (Petrelli and Whittaker 2010), and yet other studies rank the sentimental value of digital objects alongside physical (Kirk & Sellen 2010; Gulotta et al. 2013; Massimi & Baecker 2010). In addition, it is important to consider whether digital and physical objects should be compared at all in future, or if digital objects should rather be explored on their own terms. Furthermore, the distribution of male and female informants in future studies on digital legacy should be considered given the potential differences in attitudes towards materiality across gender: men presumably have a more instrumental approach whereas an affective approach seems to better reflect female behaviour (Doka & Martin 2010).

Cohort differences might also influence the outcome of such studies (Hunter & Rowles 2004, 344) and undoubtedly, there are still differences in what types of digital data that are meaningful and valuable to the intestate compared to those meaningful and valuable to the bereaved relative. Exploring these differences in stakeholder attitudes seems particularly relevant since studies show that surviving relatives might hold on to objects because they feel obligated to, not necessarily because they value them (Banks 2011).

As mentioned, there are also some challenges of greater scope on the road to an applicable solution. Besides the more "familiar" challenges such as incompatibility across platforms (Jones 2004; Carroll & Romano 2011), questions of longevity of digital data (Petrelli & Whittaker 2010; Waagstein 2013), alleged sequestration of death in Western societies (which might or might not affect our relation towards digital legacy and our interaction with Thanatosensitive systems) (Kübler-Ross 1969; Ariés 1975; Elias Nobert 1985; Howarth 2007; Walter et al. 2011); we are first of all challenged by

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<sup>9</sup> e-Boks is a digital platform for secure communication used by the public sector in Denmark.

people's general unawareness of digital legacy. Unawareness is not in itself problematic, but since it can cause inaccessibility and the potential loss of private digital legacy, it becomes an issue. As Carroll and Romano put it: "No matter what your wishes are for your digital content, access is an important issue to resolve" (Carroll & Romano 2011, 76). Secondly, we lack common practice and case law that allows us to manage, bequeath and organise our valuable digital possessions, not to mention laws and practices allowing us to take ownership over our digital assets (McCallig 2014). The study in question showed that respondents want to safe-keep their digital content for themselves and for their family. However, without applicable systems or laws that renders digital legacy management possible, there is only so much we can do to prepare for our digital death, and this is according to professor of Law Naomi Cahn "becoming a huge problem" (pbs.org 2013). A third major challenge concerns the immense and growing size of the private digital economy and the potential information overload we risk exposing our next of kin to (Banks 2011, 10; Bellamy, Arnold, Gibbs, Nansen & Kohn 2013). Van der Hoven et al. states: "People increasingly have vast collections of digital media about their pasts, including photos, texts and music files (...) and they collect because they can" (Van der Hoven, Sas & Whittaker 2012). The ease with which you can create, copy, share and distribute data in the digital age combined with people's resistance towards deletion and the fact that we are not as good as organising data as we might think, is already becoming a post-mortem issue (Bergman et al. 2009; Whittaker, Bergman & Clough 2010; Odom et al. 2010). Various research on how we organise, manage and archive our digital belongings has already been initiated and Thanatosensitive design prototypes has been developed (e.g. Gemmel et al. 2006; Wiley et al. 2011; Banks, Kirk & Sellen 2012; Kirk et al. 2010). However, it would be interesting to explore how might quantity affect people's perception and appreciation of the digital. In sum, addressing some of these challenges and suggested research approaches is part and parcel of making a sound argument for future interventions that will make the digital afterlife more easily managed, whatever form they may take.

***Biographical note:***

Astrid Waagstein holds a Master's degree in Information Technology from the University of Copenhagen and an undergraduate in Rhetoric from the University of Copenhagen. Her research interests lie in the cross-disciplinary field of thanatology (death studies) and HCI research and design, with a focus on the interplay between ante mortem and post mortem life and digital material culture. Contact: awaa@itu.dk.

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