"I Am So Overwhelmed I Don't Know Where to Begin!"

Towards Developing Relationship-Based and Values-Based End-of-Life Data Planning Approaches

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ABSTRACT

To support people at the end of life as they create management plans for their assets, planning approaches like estate planning are increasingly considering data. HCI scholarship has argued that developing more effective planning approaches to support end-of-life data planning is important. However, empirical research is needed to evaluate specific approaches and identify design considerations. To support end-of-life data planning, this paper presents a qualitative study evaluating two approaches to co-designing end-of-life data plans with participants. We find that asset-first inventory-centric approaches, common in material estate planning, may be ineffective when making plans for data. In contrast, heavily facilitated, mission-driven, relationship-centric approaches were more effective. This study expands previous research by validating the importance of starting end-of-life data planning with relationships and values, and highlights collaborative facilitation as a critical part of successful data planning approaches.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in collaborative and social computing**; **Computer supported cooperative work**; **Empirical studies in HCI**.

KEYWORDS

digital legacy, end of life, inheritance, stewardship, memorial, memory, death, identity, legacy, heirlooms, data planning

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1 INTRODUCTION

The death rate is 100%. However, only 22% of people in the United States have any type of end-of-life plan for their legal assets or medical wishes [35]. One can imagine the number of people with an end-of-life *data* plan is much lower. As data increasingly makes up a greater percentage of what must be considered in end-of-life plans, approaches must be designed to improve data planning practices.

The most common data planning approaches people encounter are estate planning approaches — inventorying assets and determining management plans for those assets [1]. However, the degree to which these asset-based approaches are effective in creating effective plans that account for important intangible factors in data asset management, such as digital legacy [19], multi-generational considerations [11], and multi-user considerations [6], is untested.

End-of-life data assets are a broad category. For clarity, we define them as any online or offline account or piece of data that an end-of-life management plan can potentially be made around. For example, one can consider social networking accounts, email accounts, or photos on an external hard drive all as potential end-of-life data assets.

Although HCI research has a significant body or prior work on digital legacy planning [4, 6, 7, 11, 12, 15–19, 32, 33], data planning considerations outside of digital legacy (e.g., technical planning for a comprehensive variety of accounts and data) is a developing area that previous literature has identified as an important priority for future work [10, 11, 20]. Recent research has expressed hope that existing approaches for material asset planning (e.g., a will) might be able to be expanded to inform data plans that properly account for values and legacy [10]. However, the extent to which typical material planning approaches are effective in *data* planning is an open research question.

To help design more effective approaches for end-of-life data planning, we worked with fifteen participants to co-design end-of-life data plans across multiple planning sessions. Five participants participated in a pilot study using an asset-based inventory planning approach akin to estate planning approaches (the Inventory Stage). Upon participants finding immense difficulty in completing actionable plans using the asset-based inventory approach, the inventory document was amended into a new workbook document for the Workbook Stage, which comprised the main portion of the study that included ten participants. The workbook for the Workbook Stage was adapted in response to the specific challenges participants encountered in the Inventory Stage and took inspiration from design considerations outlined in previous literature. Compared to the asset-based inventory approach, the workbook approach was value-driven and relationship-centric. Additionally, in the Workbook Stage, we adapted our planning approach to be more heavily facilitated, closely walking participants through each step.

In the Workbook Stage, we successfully co-designed workbook plans with ten participants, creating actionable end-of-life data

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plans for each individual — a much more successful outcome than our pilot inventory approach. We found that the workbook was successful due to: (1) starting small and iterating, (2) planning around relational values, and (3) hands-on facilitation. We found that the workbook approach encountered lingering challenges with: (1) access decisions, and (2) planning for catch-all accounts. Considering our findings, we argue that designers of end-of-life data planning approaches should:

(1) Scope small for success and iteratively expand
(2) Connect relational values to data management
(3) Enable facilitation
(4) Support collaboration
(5) Move beyond a reliance on 'next of kin'
(6) Help identify what data is important
(7) Thoughtfully use common defaults

In the following sections, we first position this study within broader HCI end-of-life research and typical data estate planning practices. We then describe the development and deployment of our first approach — the Inventory Stage — followed by challenges we encountered that motivated us to develop a new approach. Our Workbook Stage section then describes our relationship-centered approach and presents our findings. Finally, in our Discussion, we present seven design considerations for data planning, situating our findings in the context of previous HCI research while identifying future research opportunities.

Through this study, we validate the importance of starting end-of-life data planning with relationships and values and the importance of collaborative facilitation in effective data planning approaches. This study demonstrates that relationships and values are critical starting points for creating effective plans, even when considering comprehensive technical plans for a wide array of accounts and data. Additionally, this study expands HCI research on end-of-life data planning by empirically testing the extent to which conventional material planning approaches are effective/ineffective in data planning, finding that there are fundamental challenges that those approaches encounter.

2 RELATED WORK

HCI research on the end of life is of increasing interest to scholars seeking to support people across their entire lifespan [29]. Prior work has covered diverse contexts, including digital heirlooms (e.g., [4, 32]), communal rituals (e.g., [21, 40]), online memorials (e.g., [17, 27, 30]), digital legacy (e.g., [11, 15–17]), and family archives (e.g., [23]). Researchers have noted that end-of-life scenarios present unique challenges for supportive design, including privacy challenges (e.g., [20, 26]), challenges of accounting for shifting motivations at different life stages [10, 39], and alignment challenges between user expectations and platform functionality [12].

The majority of HCI research on end-of-life account and data planning has been conducted in the context of social media platforms [6–9, 12, 13]. Prior work on planning has focused on access to accounts and data, inheritance considerations, and the relationship of a bereaved person managing the accounts and data of their deceased loved one [6, 7, 12, 13].

Work by Brubaker and Callison-Burch helpfully summarizes previous approaches to post-mortem data management as discussed in HCI literature or implemented in existing systems [6]. They organize approaches into three categories: configuration-based, inheritance-based, and stewardship-based approaches. Configuration-based approaches focus on enabling account holders to make decisions pre-mortem about what the system should do following their deaths. Inheritance-based approaches involve transferring ownership and control of a digital asset from the deceased to an heir. Stewardship-based approaches, such as the Facebook Legacy Contact feature that Brubaker and Callison-Burch highlight, focus on caring for the accounts and data within complex social relationships. Stewardship focuses on the responsibilities and duties of caring for the data of a deceased loved one and a grieving community, in contrast to inheritance approaches. Stewardship, which Brubaker and Callison-Burch present in response to the implied ownership of stories and memories in inheritance approaches, involves designating a person (not a system) to care for the needs of the deceased and community (not owning the account or data).

A primary tension identified in previous planning literature is the impact of complex social relationships on digital asset management. For example, Brubaker and Callison-Burch argue that digital asset-based inheritance models fail when there are no affordances to account for complex relationships [6, 7]. Brubaker and Callison-Burch additionally suggest that designing data inheritance features through a model of stewardship could help account for complex relationships and support users at the end of life. Our study expands previous work on inheritance approaches by considering how asset-based inheritance models (exemplified by our asset-based inventory planning approach) may succeed or fail when considering complex relationships in planning processes.

Previous research on planning has identified the difficulty of effectively managing the symbolic importance of a person's digital content [12, 22, 28]. For example, the challenges that digital legacy presents for end-of-life data planning, such as how people managing accounts and data can most effectively account for the identity persistence of the deceased, have been identified as thorny challenges for planning and data management [16]. Accounts and data retain meaning beyond financial or logistical use value. This study expands on previous literature examining the challenges of accounting for the symbolic importance of accounts and data at the end of life by studying how different planning approaches (asset-based and relationship-centric) account for the symbolic importance of accounts and data.

3 BACKGROUND: ESTATE PLANNING PRACTICES

When considering designing and testing actionable planning tools for end-of-life data planning, which is still a nascent space in HCI research and design, we took inspiration from conventional estate planning practices for material assets. Although research such as that by Brubaker and Callison-Burch has cautioned against a carte blanch approach to planning that treats digital content as assets, the same work has suggested that inheritance-based approaches that treat digital content as assets can be effective in certain use cases [6]. We began with an asset-based approach to tease out use cases for inheritance-based approaches in planning and see where barriers were and where a stewardship-like planning approach may

be more effective to account for other use cases. We expand on our justifications for beginning with an inventory-based approach in Section 5.1.

Estate planning involves advanced decision-making on the distribution of assets to the next of kin or intended person(s) or charitable organization(s) [2]. Estate planning can include the bequest of assets to heirs, loved ones, and charity [1]. Additionally, estate planning commonly includes planning for incapacity, reducing or eliminating uncertainties over the administration of probate (the judicial process whereby a will is certified in a court of law and accepted as a valid public document that is the true last testament of the deceased), and maximizing the estate's value by reducing taxes and other expenses [2]. While estate planning can be done independently, people typically seek professional guidance from an estate planning attorney, a certified public accountant, a certified financial planner, a trust officer, and a charitable gift planner.

The specific estate planning process can vary, but a guide published by the American Association of Retired Persons (AARP) explains that planning typically includes the following steps [1]:

(1) Build an estate planning team
(2) Exhaustively inventory your assets
(3) Create a will that designates specific wishes for your assets, and designates who will carry out those wishes
(4) Use your estate plan to create your legacy (e.g., beneficiary, charitable gifts, etc.)

During the inventory step, estate planning commonly takes exhaustive stock of a person's assets. Beginning the process by developing an inventory of assets allows the estate planning team to help people identify which heir, loved one, or charity each asset should be bequeathed to [1]. For conventional estate planning, creating a will, identifying management wishes, and using an estate plan to create a legacy are all predicated on initially completing an exhaustive inventory of assets.

Some existing approaches to estate planning consider online accounts and data. However, they largely follow conventional estate planning steps. For example, financial planning guidelines commonly ask people planning to list an exhaustive list of their online bank accounts along with the rest of their estate [38]. AARP extends the directive to other types of digital accounts: "You should think about your online legacy and your digital assets. These include social networking, email, online bank, and photo-sharing accounts. Each asset may need to be managed differently, so it is important to make a guide outlining what happens with each one" [1].

The conventional approach of exhaustively inventorying accounts and data in the same way as other material assets may at first appear to be the most effective approach for digital end-of-life planning. However, the unique challenges that HCI scholars have identified (e.g., privacy challenges [20, 26]), challenges of shifting motivations at different life stages [10], and challenges of alignment between user expectations and platform functionality [12]) raises questions about how estate planning processes for *material assets* would need to be amended to address *digital* accounts and data effectively.

4 METHODOLOGY

This study is informed by a community-based participatory design approach, co-designing end-of-life data management plans with participants through ongoing consultation via semi-structured interviews [31, 37]. Following Spinuzzi [37] and Muller & Kuhn [31], we leveraged participatory design to ground our design process in the democratic co-construction of design solutions based on participants' lived experiences and their interpretations of those experiences. This approach allowed us to adapt our research approach and tools (e.g., the inventory and workbook documents) as needed and in close collaboration with participants.

Taking inspiration from Chen et al.'s use of a design workbook to understand users' expectations when preparing their data for after death [10], we used a workbook format to consider more effective planning approaches for users' data. Distinct from Chen et al.'s study, which used research through design to evaluate speculative concepts represented in their design workbook, we used a workbook that structured the process participants used to create their own end-of-life data plans.

Below, we describe the two stages of our research, including additional methodological details. We start with (1) a pilot stage focused on the development and evaluation of an asset-based planning approach, followed by (2) the subsequent development and evaluation of a relationship-centric approach.

5 THE INVENTORY STAGE: A PILOT STUDY

We started with a pilot study exploring the viability of an inventory-centric approach to planning. Below we describe the development of our inventory document and the challenges that participants encountered when using it. We then share the challenges we identified and the findings of previous HCI literature that motivated the development of the workbook we used during the Workbook Stage.

5.1 Developing the Inventory

The pilot approach took inspiration from estate planning tools and practices — developing and evaluating an asset-based inventory approach. Our inventory document sought to follow the conventional estate planning process of helping an individual meticulously list their assets (in this case, digital assets) and then determine wishes for those assets [1]. In consultation with two estate planners, we adapted an existing digital estate planning guide sponsored by the Borchard Foundation on Law & Aging [44] to work for our exploratory and interactive methods. We began with an inventory approach because it reflects the most common approach taken in estate planning and has been recommended for end-of-life planning for data [1].

In addition to being a typical approach that people encounter "in the wild," our decision to begin with an estate planning-inspired approach sought to expand previous work on digital legacies [11, 17, 18]. Building on this work, we focused on developing a comprehensive management plan for all data (e.g., estate planning), rather than the more narrow focus of digital legacy. Additionally, recent research has expressed hope that existing workflows for preparing for death (e.g., a will) might be expanded to properly account for values and legacy [10].

Participant	Stage	Gender	Age
P01	Inventory	F	25
P02	Inventory	M	52
P03	Inventory	M	28
P04	Inventory	F	38
P05	Inventory	NB	26
P06	Workbook	F	34
P07	Workbook	F	61
P08	Workbook	M	35
P09	Workbook	F	55
P10	Workbook	M	62
P11	Workbook	F	71
P12	Workbook	F	44
P13	Workbook	F	56
P14	Workbook	F	62
P15	Workbook	M	53

Table 1: A table of all participants, including their stage of involvement (Inventory or Workbook), their gender, and their age.

We include the full inventory document in Supplemental Materials. At a high level, the inventory document consisted of three steps: (1) creating an exhaustive inventory of accounts and data, (2) providing context for the use of those accounts and data, and (3) listing management wishes for each of those accounts and data. To give a flavor of the contents of the inventory document, we provide a sample page in Figure 1 — depicting one task in the *inventorying* process.

5.2 Participants

We engaged in multiple planning sessions with five research participants. We recruited a convenience sample of graduate students from the research team's home institution (a research university located in Boulder, Colorado within the United States) via the department's main Slack channel. The inclusion criteria included a desire to create an end-of-life data plan and at least some level of end-of-life planning already in progress or completed (e.g., a will, an advanced directive, etc.).

Participants' ages ranged from 22-42 (22, 26, 27, 32, 42). Two identified as women, two as men, and one as non-binary. We intentionally sought a diversity of ages, as younger adults and older adults can differ in experience encountering death and end-of-life planning, as well as in technology practices [39]. However, for this pilot, participants skewed younger and were also very familiar with technology, notable limitations of our pilot.

We did not capture information about race or religion from participants in either stage, which is a further limitation. Race has previously been found to be a differentiating factor in the kinds of end-of-life planning practices people may engage in [34]. Likewise, religious affiliation has been identified as a predicting factor of end-of-life planning values for medical decisions [14]. Although we did not capture this demographic information, we believe that future HCI research should focus more intentionally on the impact of race and religion in future research on end-of-life data planning. A list of participants for both stages can be seen in Table 1

5.3 Methods

Each of the five participants participated in one information session and two planning sessions. The information session was 30 minutes or less and allowed us to answer questions about the study, obtain consent, and introduce the inventory document. We walked participants through the inventory page by page, confirming that they understood what their task was for each page. After answering questions about the document, we asked participants to complete the document to the best of their ability prior to our next meeting. As with estate planning (where clients often complete an inventory document prior to their first meeting with estate planners), we hoped our approach would also allow people to have preliminary planning conversations with family and plan at their own pace [1].

Our initial intent with the planning sessions was to discuss participants' experience planning with the inventory document, clarify participants' wishes, and then determine an actionable plan for next steps. In reality, due to factors we describe in Section 5.4, the first planning sessions instead typically focused on challenges participants encountered when filling out the inventory on their own. While discussing the challenges, the research team worked with participants to complete the inventory document, however sparesly. This document was sparse because, even with facilitation, participants could still not easily answer the inventory document's questions.

Before the second planning session, the research team reviewed and cleaned the inventory document to be shared with participants. At least a week before the meeting, participants were sent a PDF version of the inventory document to review. The second planning session lasted between 45 and 65 minutes with the goal of member-checking the inventory to ensure we captured their data and wishes accurately and to arrive at an actionable plan. While we met these goals, the majority of these conversations consisted of reflections on challenges participants encountered with the inventory document itself.

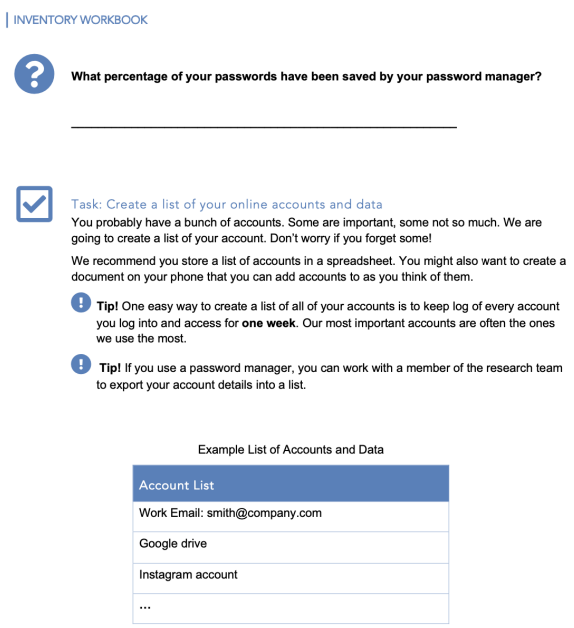


Figure 1: Sample inventory document page and tasks

We decided to make these challenges the focus of our analysis, where we followed Braun and Clarke's process for thematic analysis [5], informed by Saldana's approach [36]. Coding was inductive (iteratively and reflexively grouping codes into similar categories). During data analysis, members of the research team independently listened through each of the recordings and reviewed artifacts from the planning sessions (e.g., the plans, field notes). We then read through the transcripts, employing open coding to look for patterns in the data. After independent coding, researchers constructed a codebook in a shared Google Sheet, generating our initial codes. The research team then looked for relationships between those codes to construct preliminary themes.

Theme memos were written for preliminary themes [36]. As a team, we then considered how the preliminary themes in the theme memos related to one another, generating overarching themes. We iteratively returned to the data throughout the coding process. As an inductive thematic analysis process, themes were written, edited, and reorganized throughout the coding process. Before moving on to a new step in the coding process, all team members reached a consensus on codes and themes. In the case of disagreements, we discussed differences until a consensus was reached. Given the sample size of our pilot and our aim for thematic saturation, our findings may only reflect a subset of the issues (those where saturation was reached).

5.4 Results

When conducting planning sessions using the inventory planning document, we encountered several challenges to participants completing actionable plans. One symptom of these challenges was that participants could not finish the inventory tasks independently before the first planning session, with four of the five participants arriving at the first planning session with only the *Do you have a password manager?* question filled out. Another symptom was that participants felt paralyzed when asked to list their accounts and wishes, even in the facilitated planning sessions. Although facilitated sessions were more effective than participants independently filling out the document, the inventory document was largely ineffective in creating an actionable plan.

When asked about the underlying reasons for the difficulty, participants universally noted feeling overwhelmed as the reason they could not start or finish their inventory plans. Participants named feeling emotionally overwhelmed when considering any part of their end-of-life planning as one factor causing their paralysis. However, to a much greater degree, participants emphasized feeling overwhelmed by the logistical stress of managing data and accounts — compared to managing their more tangible assets like physical family heirlooms. For example, P02 said, "I know what to do with my cookbook. That goes to my son. But my Gmail account, I don't know… I'm overwhelmed even just thinking what's in that, set aside what I want to save and who I want that stuff to go to."

We found five main challenges that participants encountered that led to feeling overwhelmed:

(1) An Overwhelming number of accounts and amount of data
(2) Forgotten accounts and data
(3) Unknown data in accounts
(4) An inability to identify the most meaningful data in accounts
(5) Disorganized password management

Challenge 1: An Overwhelming Number of Accounts and Amount of Data. The primary challenge participants experienced resulted from the sheer number of accounts they maintained. For example, P02 discussed the paralysis that came over them when they attempted to brainstorm an exhaustive list of platforms, saying, "I'm sorry I wasn't able to finish this. I tried a few times to list out accounts, but the second I sat down to write them all down, I could only come up with a few, and then my mind kind of went blank. It was just too much." Despite language in the document that made room for incompleteness, being asked to create an exhaustive list of their perceived large number of accounts made it difficult for participants to identify or prioritize the accounts they were most interested in creating plans for. As P01 poignantly stated: "There is just so much. So many accounts to plan for... I am so overwhelmed I don't know where to begin!"

Challenge 2: Forgotten Accounts and Data. Feelings of paralysis were also attributed to feeling that there were an overwhelming number of accounts and online data that participants had created previously but had now forgotten. P03 noted that "I shouldn't even start unless I can really list all of my accounts, and to do that, I would have to go through my email, maybe ask my husband, go through my cookies, just to get a list [of the accounts I have forgotten]." P03 continued, "I know I've made like hundreds of accounts over the last ten years that I can't even remember. I don't know where I would start figuring out the loose ends, so I left the account list blank for now."

Challenge 3: Unknown Data in Accounts. When considering wishes for the accounts and data they *could* begin to name, participants

described challenges with the unknown content of those accounts and data. For example, although P02 could name that email was "probably" their most important account to plan for, they could not name what they wanted their plan to consist of because they could not name what data they had in the account. Not knowing what data they had in an account led to feelings of being overwhelmed and paralysis when creating an inventory and determining management wishes.

Challenge 4: Inability to Identify the Most Meaningful Content. When considering wishes for accounts that participants did know the contents of, participants had difficulty parsing out wishes for different data within the same account. Participants expressed uncertainty about the most important content to determine wishes for and how to categorize different content on the same account in their plans. For example, P01 was unsure whether photos and drawn art should be part of the same directive for their loved one to follow or whether they should write out different management plans for each.

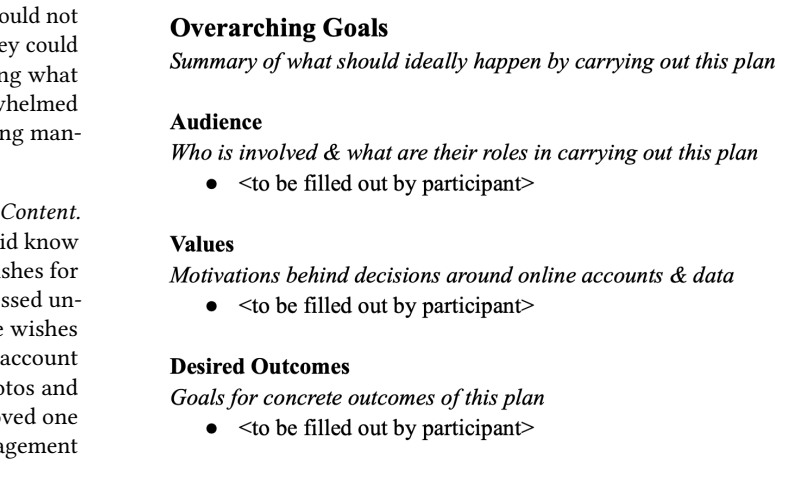
Challenge 5: Disorganized Password Management. Participants also cited the complex decentralized systems they used to archive and manage their account login information as a challenge to filling out the inventory. To help participants list their accounts, the inventory document asked participants to refer to their password manager, if they had one. While all participants had passwords listed in some form or another at the end of the planning sessions, participants said they were still overwhelmed due to their passwords being scattered across different mediums and locations.

5.5 Situating Inventory Stage Findings in Previous Literature

The Inventory Stage confirmed several challenges with end-of-life data planning and personal data management identified by previous literature. First, we found similar challenges to those highlighted by [19, 24] about managing the idiosyncratic, fragmented nature of people's archives and digital records. Second, highlighted by [11, 19], we found that people were challenged by making meaning of those digital records, leading to an inability to name wishes about their data. Third, highlighted in [43], we found that participants struggled with determining data narratives for a large volume of data.

The Inventory Stage validated that these larger data management concerns are key challenges in personal data management during end-of-life planning. It is perhaps unsurprising that we identified challenges similar to those in previous literature on data management. However, empirically validating and comparing these management challenges with the design considerations of previous digital legacy literature had utility as we adapted our study design for the Workbook Stage.

Most notably, in creating the workbook for the Workbook Stage, we drew from the design recommendations that Gulotta and colleagues provided in [19]. For example, we designed our workbook to provide additional opportunities for reflections on the meaning of their data (e.g., beginning the workbook with a question about the participant's values), provide opportunities for selective archiving (e.g., creating a plan around only a handful of the most important accounts), and provide additional opportunities for participants to involve their family in the planning process (e.g., a family discussion page at the end of the workbook). We additionally drew from Chen et al.'s focus on collaborative plan-making to create an approach more heavily facilitated by the research team and more intentionally incorporated the voices of participants' loved ones [10]. We detail the development of our workbook and specific adaptations in the following section.



Overarching Goals

Summary of what should ideally happen by carrying out this plan

Audience

Who is involved & what are their roles in carrying out this plan

- <to be filled out by participant>

Values

Motivations behind decisions around online accounts & data

- <to be filled out by participant>

Desired Outcomes

Goals for concrete outcomes of this plan

- <to be filled out by participant>

Figure 2: Sample workbook document page

6 THE WORKBOOK STAGE: A RELATIONSHIP AND VALUES-BASED PLANNING APPROACH

In this section, we describe the Workbook Stage of this study. Here, we describe the methods, the development of our new approach, and our thematic findings from the Workbook Stage.

6.1 Designing a New Approach

The challenges identified through the Inventory Stage were subsequently used to inform the creation of a new workbook approach. For example, the challenge of *unknown data in accounts* motivated the creation of a section in the workbook that could account for default wishes even when data was unknown. Considering both the challenges from the pilot study and related work, members of the research team met multiple times to brainstorm possible adaptations to the inventory document. After creating a list of possible adaptations, the research team reached a consensus on what adaptations should be implemented. The team implemented those changes to create the workbook document for the Workbook Stage.

The workbook focused on providing a relationship-centric approach that considered participant values and provided more intentional hands-on facilitation. We shifted the approach's focus away from identifying an exhaustive list of accounts and towards

identifying relationships and values that could inform their data management priorities.

One significant departure in our new workbook was in the framing of the plan's goals and purposes. Instead of a first page asking participants to list accounts, the first page of the workbook began by asking participants to identify a specific audience for the plan, the values that motivated their plan, and their desired social outcomes. For example, P07 named their husband as the audience, legacy as their value, and the plan's social outcome to reduce their loved one's logistical burden.

We also changed how we introduced the workbook document to participants. Instead of providing a workbook in advance like we had done with the inventory document, researchers shared it with participants during the first planning session, walking them through the workbook page-by-page. In the inventory approach, we focused conversations on completing the tasks outlined in the document. Meanwhile, in the workbook approach, we intentionally provided more room in planning sessions for reflection and additional prompts and examples from the research team. The inclusion of prompts and examples was found to be a useful approach when helping people curate their legacy in previous work by [10, 19].

Other major changes from the inventory to the workbook approach included:

(1) Participants being asked to focus on a few accounts rather than an exhaustive list
(2) An added timeline page where participants could make a list of tasks that they and their loved one can do immediately to assist their planning
(3) An added page that provided a space to identify a default action for a loved one to take if wishes for an account or data are unspecified
(4) An added page where participants could provide last words and images that should be shared with online communities after their death
(5) An added field in the workbook where participants could link their wills or other planning documentation
(6) An added page at the end of the workbook that signified that discussion with their loved one was an expectation of planning

To summarize, our workbook changes and additions prioritized relationships between participants and their loved ones, default wishes, specific timelines for participants and their loved ones, and connection to other planning documentation. Our workbook additionally sought to minimize participant's feeling overwhelmed by limiting the number of accounts participants were asked to list at the outset of the planning process.

The adapted workbook consisted of eight sections:

(1) Document overview
(2) Overarching goals (Audience, Values, Desired Outcomes)
(3) Guidance for Specific Content & Accounts
(4) Guidance if not specified
(5) Instructions (Access information, platform-specific resources)
(6) Death announcement (Template, Last Words, Images or Other Media)
(7) Timeline (Self and Loved One)
(8) Discussion

We include the workbook template in full in Supplemental Materials. We include the Overarching Goals page in Figure 2 to provide a sense of the value and relationship-based framing throughout the document.

6.2 Participants

Given recruitment limitations during the Inventory Stage, we intentionally recruited participants across a wider variety of ages and life stages. To do so, we recruited people through social media groups focused on end-of-life support. A list of Facebook and Reddit end-of-life support groups was collected, and recruitment text was posted. For example, we posted a call for participants in a cancer support group on Facebook. We contacted the moderator leadership of any community we posted on and received consent before posting.

Ten participants were recruited for the Workbook Stage. Participants' ages ranged from 34-71 (34, 35, 44, 53, 55, 56, 61, 62, 62, 71). Seven participants identified as female, and three participants identified as male. The participants' occupations varied, ranging from a minister to a physiologist to a retired accountant. We did not analyze for patterns across professions, but that is a fruitful area for future work. Familiarity with technology also varied. For example, P11 expressed they had very little social media knowledge and no social media accounts. Meanwhile, P14 self-identified as a "technology aficionado." A notable pattern in participants was that all participants identified themselves as "partnered" in some capacity. Interestingly, P11 identified themselves as "married," although their husband was recently deceased. Comparing patterns in planning support as they vary across different manifestations of romantic relationships is a prudent next step for end-of-life data planning research. Although we sought to recruit people with life-limiting diagnoses by recruiting through end-of-life support groups, only one participant identified as having a life-limiting diagnosis. All participants had some previous end-of-life planning, although the degree of planning varied from a formal legal will to having had informal conversations with loved ones.

6.3 Methods

The data collection steps for the Workbook Stage was done identically to the Inventory Stage. Participants participated in an introductory session lasting under 30 minutes. Participants then participated in two 45-90 minute planning sessions, with additional email correspondence to member-check specific plan information when necessary. The main distinction in data collection methods between the Inventory and Workbook Stages was that in the Workbook Stage, participants were not asked to fill out any documents before the first planning session. Rather, filling out the workbook document was facilitated in a more direct hands-on approach, with the first planning session consisting of the research team leading participants through the workbook section by section, answering questions as needed. Additional attention was paid to encouraging participants to ask questions about the process, the technical feasibility of their wishes, and what management options they had to choose from. Data collected in the Workbook Stage consisted of transcripts of planning sessions, field notes from conversations, and multiple versions of the workbook documents co-developed

with participants. Data analysis was conducted identically to the Inventory Stage.

6.4 Results

The workbook was better received than the inventory document. In stark contrast with the inventory document, participants rarely described feeling overwhelmed as a barrier to completing their plans. Over the two planning sessions with each participant, all ten Workbook Stage participants received what they considered to be complete and actionable plans. Because this study is focused on designing more effective planning approaches, we focus our findings on describing the affordances and challenges participants encountered when using our workbook approach.

Our analysis identified three themes of what participants found effective about the workbook approach: starting small and iterating, designing around relational values (legacy, memory, burden reduction), and active hands-on facilitation. Our analysis also identified two lingering challenges our workbook approach could not account for: access decisions, and creating plans for catch-all accounts. These two challenges caused the same feeling of being overwhelmed as the inventory document. However, in the Workbook Stage, these challenges did not stop the participants from completing what they considered an actionable plan.

6.4.1 *What Was Effective.*

Starting Small and Iterating. Participants said that starting with a small number of accounts, even just a single account, and then iteratively broadening to other accounts helped them feel that plan creation was a manageable task. For example, P10 said, "Once I figured out what to do with that one pesky work website, tackling more accounts was no problem." P15 highlighted that the research team helping them walk through their two most important accounts was an "empowering experience that gave me confidence in creating a plan for the rest of them."

When asked why starting with a small number of accounts was helpful, participants said that beginning with a small number gave them a manageable model to build from as they considered additional accounts. For example, P09 said that starting with only a handful of accounts allowed them to "get the hang of planning" and "practice how to speak the planning language in a small way before getting overwhelmed looking at everything all at once."

Participants also said that starting with a small number of accounts allowed them to identify their overall plan goals by focusing on their most meaningful accounts and data first. For example, one participant chose to focus their early planning solely on their Ancestry.com account and data. Going into the workbook process, the participant was clear that conveying the legacy of their ancestry to their descendants was the goal of their planning, with the planning of other accounts as secondary. This participant expressed that having the space to focus entirely on that single account helped them see that their family legacy was the most important consideration in all of their planning. They summarized, "By diving into [the ancestry.com account] without being distracted by all of the other ones, I was able to hone in on what I wanted for the rest of them."

Participants chose a variety of types of accounts and data when starting small: financial accounts, social media accounts, email accounts, professional websites, and photo archiving accounts were the most common. In each case, starting with only one or two types of accounts or data helped them iterate out as they began to plan for managing other types. One reason that starting small helped was that once participants planned for a small handful of accounts, it was easier for them to identify other accounts that were important to them. For example, after P12 created a plan for their brother to manage their most important accounts (a Facebook account, an email account, and a professional website), they excitedly mentioned an additional set of accounts to add (Hulu and Netflix) that they "would have never thought of before planning for the first several."

Designing Around Relational Values: Legacy, Memory, and Burden Reduction. Participants described that beginning the planning process by naming values and foregrounding the recipient of their plans helped them stay oriented and confident throughout the planning process. For example, when asked to reflect on what worked well for them in the planning process, P08 highlighted that "having named at the beginning that I wanted this plan to go to my spouse because I cared about how my legacy is carried on in my family… I was better able to build my technical wishes around it." Participants almost always coupled their values with relationship considerations, which we summarize as relational values.

Grounding plans in relational values helped participants clarify their planning even when encountering difficult decisions. For example, when P12 was certain that their Facebook account was important for them to plan for but unable to name what their wishes for it were, they could clarify their wishes when the facilitator asked them to reflect on the platform in the context of their stated value of "personal legacy." P12 clarified that their wish was for their loved one to create a memorialized profile page for their Facebook account following their death. Being reminded of their relational value helped P12 move past their confusion to being confident and specific in their wish.

All workbook participants were able to quickly identify the relational values on which they wanted to base their plan. The language for the relational values participants chose overlapped, suggesting that there may be commonalities in what values a broader population wants to drive their plans. There were three common categories: maintaining personal legacy, preserving collective memory, and reducing the burden experienced by their loved ones.

The majority of our participants indicated that maintaining a personal legacy was a value that motivated their planning. Our participants understood personal legacy as preserving their identities, values, and memories as they are passed down to future generations through digital accounts and data. For example, one participant summarized that their social media presence is a "testament to my identity, so, of course, I'd want [my social media presence] to stick around in its original form... maybe even grow if people discover my photos down the line" (P13). Another participant considered maintaining their career legacy as the defining goal for their planning, noting that they "do not want my publications to simply disappear... I want the knowledge that my work generated to outlast me" (P07).

The prevalence of legacy values in our plans suggests that platform features supporting plans should support processes that establish and maintain the digital legacy of users, supporting previous research that has found that digital legacy is an important consideration for end-of-life data planning [6, 15–18].

Participants also spoke about the value of their online accounts and data being used to preserve collective memory. Participants spoke about wanting to preserve their families' collective memory and their cultures' collective memory (P08, P11, P13). For example, one participant recently received digital images and written materials documenting the life of a relative and was considering how to manage these materials after their death. The relative had been a slave in the American South during the era of Jim Crow Laws. The materials had been shared by the descendants of the family that enslaved the participant's ancestor. This participant focused their plan on managing these materials after their death. Their planning revolved around how to most effectively preserve the collective memory of their ancestry and the tragic collective national history of slavery.

For this participant, they did not want the memory of their ancestor, and what their ancestor's enslavement represented in US history, to be forgotten in the passage of time. Based on the value of collective memory, their plan included post-mortem instructions for delivering the digital materials to a museum. Other participants noted that preserving digital images of family recipes and preserving written documents detailing cultural traditions were important motivators for their planning (P09, P14). The mission of preserving cultural memory was a common and helpful touchstone for participants as they constructed plans.

Another common relational value participants sought to ground their plans was reducing the burden for the loved ones managing their accounts. The majority of participants mentioned that a key motivating factor in their planning was the fear of their plan causing an emotional or logistical burden after they die. The types of burden that participants feared varied. Some participants stressed the technical burden of a family member being asked to learn the ins and outs of a new platform to delete an account (P11, P15). Other participants stressed the emotional burden of asking their spouse to sort through sentimental media such as wedding pictures (P12). A common value emerged across these varied types of burdens — participants wanted their plans to prioritize the reduction of burden on their loved ones.

Facilitation. Participants expressed that the hands-on facilitation of research team members within planning sessions was critical to creating successful plans. Facilitation allowed participants to achieve plans that were personalized for them and technically actionable. P10 highlighted that "Without help, I wouldn't have known how to put language to what I wanted… I wouldn't have even known what my options were." Similarly, P08 said they "Knew approximately what was important to me, but would have never known what could actually be accomplished."

The theme of not having the language to create a plan without facilitator support was common. For example, when first asked what they wanted to do with their Spotify account, P09 quickly responded, "I have no idea! I've never really talked about this end-of-life online stuff, I don't even know how to talk about it so it's tough for me to be able to imagine specific action items." P13 poignantly highlighted that "this death data thing is weird… how do we even begin to talk about something that we weren't taught the words for?"

Research team members were able to help give participants framing language by providing examples of possible ways to talk about their options. For example, when P11 became overwhelmed thinking through how to sort through all of the files in their Google Drive, the lead researcher reframed the task as identifying the most important files to be used by a specific loved one. The facilitator re-framing the task as identifying the most important files for a specific loved one to use gave P11 language for a more specific starting point that was more manageable to achieve.

Another common theme was participants needing facilitator assistance identifying the technical possibilities needed to achieve their wishes. As researchers in the end-of-life HCI space, facilitators had ample experience chronicling platform support for end-of-life data management. Facilitators leveraged that knowledge to help participants identify the available technical management options. For example, in response to P09's inability to generate specific wishes for their Spotify data, the lead researcher generated a list of options for them to choose between.

Additionally, facilitators could help participants identify what wishes were impossible to technically support. For example, in an early version of their plan, P14 wanted the contents of their password manager to automatically be shared with ten of their closest friends and family. The password manager in question did not have anything close to this functionality. Instead, the lead researcher researched what was possible and returned to P14 with several alternative options. In this case, the participant and researcher agreed that the best option was for P14 to provide their sister with the login information for the password manager and for the sister to allocate passwords to the other friends and family. The presence of a facilitator who could scope what was technically possible and impossible helped plans remain specific and achievable.

6.4.2 *Lingering Challenges.*

Access Decisions. The majority of Workbook Stage participants became overwhelmed and distressed when considering decisions of who could access their data after their death (e.g., who would be the audience for their plan). For example, when reflecting on difficulties in the planning process, P07 shared that "The most difficult moment [in creating the plan] was deciding whether my estranged mother should have access to my pictures in case I would die suddenly." P07 continued, "On one hand, I feel like my mother should be able to have pictures to remember her daughter by… but on the other hand, I don't want to give her access to the whole Google Drive, who knows what she would do with all of that and I just don't trust it."

While we assumed that participants would naturally follow the probate norm of the management of assets being directed at the next of kin, we instead encountered numerous cases where participants chose to nominate someone other than the next of kin as their manager. The decision to choose someone who was not next of kin, and the decision of who to choose, were always difficult. In one instance, a participant asked that the conversation be paused for several minutes as they needed a few minutes to sort through

their choices and the meaning of those choices. In the case of this participant, their next of kin was not medically capable of managing their data, and the choice of their brother as the person to manage their data meant speaking with their brother for the first time in a year. Choosing who could access their data meant that they had to consider complex family dynamics, which caused them to feel overwhelmed and struggle with filling out sections of the plan (e.g., the discussion page was difficult to curate together since the participant was unsure what resources would be helpful for having a difficult conversation with their estranged brother).

Participants felt overwhelmed when considering access decisions primarily because designating a person for access meant that they had to face and navigate complex and uncomfortable personal relationships. People who felt overwhelmed about who should be given access to their data were concerned about protecting their data's privacy and avoiding potential abuses of their online assets. For example, one queer participant said they were overwhelmed because, on the one hand, they wanted to choose their parents, but on the other hand, they did not want their parents to be exposed to content in their accounts that would out them as queer. This participant said, "I have to choose. Do I share the whole truth with my parents [by giving them access]? Or do I spare them that shock and choose someone who might not know me and my wishes as well?"

Another participant faced a difficult decision between choosing their father and a best friend. After going back and forth about their decision, the participant chose a close friend to manage their accounts and data because they did not want their father to access their online intellectual and financial property for fear of potential abuses. In this case, their father had previously committed financial abuse in the family, and the participant feared that their father would do so again if he was the person in charge of managing the data. The decision was painful for the participant because "Choosing meant I had to work through a secret that the family doesn't talk about too much." Although our workbook approach could help participants identify complex family dynamics and difficult decisions, the approach could not easily help them identify solutions to navigating those family dynamics.

Making Plans for Catch-all Accounts. The most difficult type of accounts for participants and the research team to develop achievable plans for were *catch-all* accounts like email or archival accounts such as Dropbox or Google Drive. Participants felt overwhelmed when considering plans for catch-all accounts due to not knowing what data is in the account, not knowing how to organize a large and varied amount of data, and not knowing how to write instructions for their loved ones to sort through the data. When participants felt overwhelmed by managing catch-all accounts, they tended to default to wanting the account to be permanently deleted or persist without anyone managing it (P06, P09, P10, P12, P13). Participants explained that they defaulted to these options because they would cause the least burden to loved ones.

Multiple participants at first listed email as the most important account to create a plan for, citing that it was a central hub for everything in their social and business lives. However, when researchers began asking follow-up questions about what specific wishes they wanted for their social and business content in email, participants said they could not distinguish between social and business content. P13 summarized: "I have the last 24 years of my life here. I don't even know what's important because I don't know what I have. There's just so much!" (P06). The participants who listed email as the most important account to plan for were largely our older participants, suggesting that addressing email planning issues is an especially critical consideration for older adults. Participants of all ages expressed that without knowing what the data in email and other catch-all accounts consisted of, and without the data being organized in a communicable and usable way, they would not feel comfortable passing the account to a loved one to manage.

7 DISCUSSION

Our findings demonstrate that even when considering comprehensive technical plans for a wide array of accounts and data (e.g., plans that consider more than the narrow scope of digital legacy and social media that much of prior HCI literature has focused on), relationships and values are critical starting points when creating effective plans. Our workbook approach additionally validates that collaborative facilitation processes are pivotal to creating actionable plans. Below, we discuss the successes and challenges of our workbook approach in the context of previous literature, enumerating design considerations for end-of-life planning and suggesting future research directions.

7.1 Design Considerations

Scope small for success and iteratively expand. Planning approaches should aim for quick success first and then iteratively expand. While estate planning often asks people to create a robust inventory of assets, these requests were overwhelming for participants and led to a paralysis of action. In contrast, in the Workbook Stage, we found that people will have more success if asked to choose one or a small handful of accounts and data, construct a smaller-scoped plan, and then iteratively add additional accounts. Not only did this approach prevent participants from feeling overwhelmed, the process of planning for a single account often helped people identify additional important accounts to add to their plan and articulate their wishes for those accounts with more confidence.

Previous research has argued for the importance of granularity in planning processes [20], and the importance of individuals feeling like they have agency of choice [10]. For our participants, starting in the weeds with only a handful of accounts and data gave them a feeling of greater agency and confidence in their choices, and ultimately had better results in producing an achievable plan.

Connect relational values to data management. Considering the importance of relational values to our participants, designers should consider including additional pathways for connecting relational values to management plans. To decrease people feeling overwhelmed, approaches should begin by identifying which relationships and values can provide a foundation for plans. Establishing this foundation *before* identifying accounts and technical wishes for those accounts can reduce the extent to which people feel overwhelmed.

Future research is needed to identify the generalizability of the common values identified by our participants (personal legacy, collective memory, reducing burden). However, the overlaps we

encountered between participants of different ages and genders suggest that there may be patterns in values that can be centered when designing future approaches. For example, previous research has argued that technologies interfacing with digital legacy should consider incorporating family-oriented archives and file management through selective archiving [18, 32, 33]. One can imagine a tailored planning approach for participants who identify a value of their plan as *legacy* could be deployed that more specifically accounts for common legacy needs such as family-oriented archives and selected archiving. A different approach could be tailored to *preserving collective memory*, and so on.

Existing HCI research on digital legacy presents several considerations that can inform the design of these pathways. Doyle and Brubaker, for example, argue that multi-user and multi-generational use cases should be prioritized [11]. One can imagine a planning approach that begins by asking people to consider their larger ancestral network — all of the people in past generations that have shaped their legacy, and all of the people in future generations that their digital legacy will shape. In the case of our participant who focused on Ancestry.com data such a framing could help connect their chosen relational value to their technical plan.

Enable facilitation. Compared to the Inventory Stage, in which participants could not even begin the inventory document without facilitator support, the hands-on page-by-page facilitation in the Workbook Stage was much more effective. However, even here, participants relied extensively on the support of the research team to create actionable plans — people who were experts in the workbook approach and the technical options. This facilitation allowed participants to ask questions and tailor plans to the specific needs of each individual, their data, and their family system. Although there is no one-size-fits-all solution [10], the success of facilitation in this study suggests that facilitation may be able to effectively adapt a single template to the unique needs of individuals.

The benefits of facilitation for end-of-life data planning have been previously documented [10, 12, 20]. For example, Holt et al. highlight that a facilitator can alleviate anxiety by providing advice on common planning pitfalls [20]. Chen et al. additionally highlight that a facilitator providing a list of management options can help people plan for legacy materials [10]. However, our study highlights the important role a person (rather than documentation, for example) can play. More than just avoiding pitfalls, facilitation provided a sounding board for participants and support for half-formed ideas that participants might otherwise discard. Given the success we found with active hands-on facilitation, designers should prioritize designing approaches that can be guided by facilitators, or even embed the facilitator into the approach itself.

Support collaboration. Incorporating the viewpoints of loved ones during the planning process proved crucial for participants – evidenced by the importance they placed on the discussion page of the workbook. While the approach in our workbook was simple, it once again highlights how end-of-life data management has different needs than the single-user versions of data management that platforms typically provide.

Collaborative planning between family members has been suggested by previous research as a strategy for effective planning [10, 19]. Expanding those considerations, our study generates several open design questions for planning approaches: What might it look like to conduct collaborative planning both with family members and planning experts? And are there other professionals or communities that should be involved in data planning?

Collaborative planning approaches are bound to encounter challenges. The overhead of coordination (be it for meetings or even just soliciting feedback) is perhaps the most obvious. Yet there are others. For example, one salient concern that arose in our study (and previous work [10, 11]) was how to account for abusive family dynamics. As such, designers should consider the tensions between designing for collaboration and harm reduction.

Move beyond a reliance on 'next of kin'. While providing a spouse complete access to an account may be a common approach, designers should not rely on providing default access to next of kin. Instead, they should prompt people to think more deeply about their relationships and allow them to more carefully state who can access what and when. Loved ones, such as chosen family or unmarried partners, were a common and important audience for our participants' plans. Especially given the concerns some of our participants had around parental abuse, designers should consider that providing default access to next of kin (a typical legal assumption) is not always appropriate.

Instead, we will echo calls for flexibility around what data is shared, when, and with whom. For example, Brubaker and colleagues have argued that allowing multiple people to steward an online memorial can allow next of kin to delegate responsibility, even temporarily, in ways that benefit both next of kin and those who support them [6, 7]. We would further highlight the importance of enabling planning at a more granular level than "the account." Accounts like e-mail have diverse content, only some of which might be appropriate for a given recipient. Our hope is that by questioning defaults around next of kin, designers will support the larger constellation of actors that our participants considered.

Help identify what data is important. Designers should consider methods that help people scan and organize their data — especially in catch-all accounts. However, supporting people without triggering the same feelings of being overwhelmed that our participants encountered when listing their data via an inventory likely necessitates new features that are designed with digital legacy in mind. While features like Facebook's Legacy Contact and Google's Inactive Account Manager are often referenced as north stars, none of these features adequately support people with identifying, organizing, and sharing important content.

Consider email: Even the simple ability to tag messages as "important for end-of-life planning" would be tremendously helpful for bereaved loved ones sorting through logistics after a death. Likewise, one could imagine legacy-specific storage features that, rather than focus on the number of messages or space used, are focused on providing insights into what the messages are about and what people are connected to them. The ability to plan for "all financial emails" or "letters between me and my sister" would be immensely beneficial.

Thoughtfully use common defaults. When participants felt overwhelmed, they tended to default to two options for their accounts

and data: deletion (e.g., permanent erasure of a data or account) or persistence (e.g., letting the data or account remain untouched, without any management requests). Designers should leverage defaults as a way to reduce the burdens on people. However, designers should also be aware that defaults might be bound up with what people perceive as "easy." One pitfall that we encountered is that "easy" did not always meet the full desires or needs of a participant. For example, in workbook planning sessions, facilitators gave an overview of account and data management options beyond deletion and persistence, such as memorialization, stewardship, transfer of data between accounts, and transfer of ownership of accounts. Although hearing these options did not cause participants to change their plans, several participants mentioned they would heavily prefer those options if they were "easier" to achieve (P06, P07, P10).

The challenge of defaults is similar to design debates between "convention" vs. "customization." Customization can be overwhelming, but convention (our defaults) might miss important details. Providing context for the defaults may provide the best path forward. Tools could inform people what options are typically selected (e.g., "selected by 82% of people") and when they might need further customization (e.g., "Do you have a child under 18 years old? Consider X...").

7.2 Future Research Opportunities

This study has provided an empirical extension to previous literature, highlighting that successful end-of-life data planning approaches should be relational and that collaborative processes are critical to generating actionable plans. Future work should expand this research by considering how to create approaches that can be agile enough to meet specific use cases, account for limited platform functionality in the wild, and incorporate diverse cultural norms into plans.

Adapting strategies according to use cases. While there were commonalities in plans, every workbook participant required a personalized plan informed by complex family systems and relational values. Due to the variability in needs and types of data people created plans for, there may very well be cases where a relationship-based plan may not be appropriate. Future research is needed to understand how different planning approaches can be mapped to different use cases. For example, although asset-based inventories may struggle to help people create data plans that account for relational factors, they may be quite effective at planning for asset-based accounts like bank accounts. In some use cases, an asset-based approach may be just as effective as a relationship-based approach. A useful follow-up study would be to empirically identify the types of accounts most commonly chosen as important for people to manage at the end of life, and determine which of those accounts may be more effectively managed by asset-based approaches or relationship-based approaches.

Exploring for technical viability. A next step for this scholarship is to ensure people's plans are technically viable and fully achievable. For example, many participants wanted to give their loved ones post-mortem access to their accounts. As such, the plans we developed typically relied on instructions to access an account using the login credentials of their deceased loved one. However, using the login credentials of a deceased loved one is a violation of the Terms of Service of most platforms. Violations aside, increasingly common security measures like two-factor and biometric authentication present additional challenges to the conventional wisdom of simply writing down your usernames and passwords.

Future research should identify how end-of-life data planning is constrained by platform functionality and what additional support is needed. Additionally, design explorations into cross-platform and relationship-centric approaches will be crucial in supporting people as they construct plans that span multiple platforms. Leveraging data portability tools such as Facebook's Download Your Information feature is a potential avenue to consider for cross-platform support. One can imagine future work developing and evaluating data portability prototypes that allow people to automatically assign specific data to be ported to other specific accounts after they die. One can also imagine a study that surveys the legacy-relevant functionality of popular platforms to identify what types of support are most commonly supported and where additional support is most needed.

Incorporating cultural norms into effective planning. A common trope in the popular press when reporting on death in the United States is that the US is a death-denying culture [25]. A death-denying culture has been cited as a barrier to end-of-life planning, with scholars arguing that people are not interested in confronting their mortality and subsequently avoid planning [25]. Future research is needed to connect the impact of cultural norms on effective planning. Considering the comments from participants about not having the language to describe their data plan wishes, we imagine that a death-denying culture may make it more difficult for people to identify options and effectively navigate those. After all, without a cultural norm that motivates conducting end-of-life planning more generally, people will struggle to conduct end-of-life planning for *data*.

While we saw that a workbook approach helped surface cultural factors, it is unclear to what degree cultural factors impact planning. Researching the implications of cultural norms (within and across cultures) for end-of-life planning is a prudent next step. Religion and family traditions, for example, vary across communities, geographies, and houses of worship. HCI tends not to focus on religion [3], but as recent work by Uriu and colleagues has demonstrated, religion is critical in determining end-of-life technology needs [41, 42]. Future research on how different cultures, religions, and spiritualities impact the efficacy of inventory-based and relationship-based planning approaches is critical to developing planning approaches that account for a wide array of human experiences.

8 LIMITATIONS

A primary limitation of this study is how the differences between the participants in the Inventory Stage and Workbook Stage may impact the findings — particularly the difference in the ages of participants between the two groups. Previous research by Thomas and Briggs has found that legacy considerations can differ in older adults compared to younger adults [39]. Although all participants were recruited due to an expression of a strong desire to create an end-of-life data plan and had some level of planning already

completed, per our inclusion criteria, the workbook participants skewed older than the inventory participants. It is possible that some of our findings are influenced by a difference in life stages between most of our inventory participants and our workbook participants, which limits the generalizability of our findings.

9 CONCLUSION

As the amount of data and accounts we generate increases year-over-year, the need for more effective end-of-life data planning approaches grows. To help identify more effective approaches for end-of-life data planning, this study has reported the challenges faced and insights gained through co-designing end-of-life data plans with 15 participants across multiple planning sessions. We have reported on using two approaches to data planning: one based on asset-based estate planning practices, and one based on relationships and values. Our findings validate the importance of starting end-of-life data planning with relationships and values, even when conducting comprehensive planning on a wide array of data. Our findings further highlight collaborative facilitation as a critical part of successful data planning approaches.

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REFERENCES

[1] AARP. 2023. *AARP: Personal Estate Planning Course Lessonbook.* https://giftplanning.aarp.org/documents/a/aarp-foundation/r1/downloads/lessonbook.pdf

[2] Faziatul Amillia Mohamad Basir, Wan Marhaini Wan Ahmad, and Mahfuzur Rahman. 2023. Estate Planning Behaviour: A Systematic Literature Review. *Journal of Risk and Financial Management* 16, 2 (Jan. 2023), 84. https://doi.org/10.3390/jrfm16020084

[3] Genevieve Bell. 2006. No More SMS from Jesus: Ubicomp, Religion and Technospiritual Practices. In *UbiComp 2006: Ubiquitous Computing*, David Hutchison, Takeo Kanade, Josef Kittler, Jon M. Kleinberg, Friedemann Mattern, John C. Mitchell, Moni Naor, Oscar Nierstrasz, C. Pandu Rangan, Bernhard Steffen, Madhu Sudan, Demetri Terzopoulos, Dough Tygar, Moshe Y. Vardi, Gerhard Weikum, Paul Dourish, and Adrian Friday (Eds.). Vol. 4206. Springer Berlin Heidelberg, Berlin, Heidelberg, 141–158. https://doi.org/10.1007/11853565_9

[4] Janne Mascha Beuthel and Verena Fuchsberger. 2022. Exploring Bodily Heirlooms: Material Ways to Prolong Closeness Beyond Death. In *Creativity and Cognition*. ACM, Venice Italy, 135–145. https://doi.org/10.1145/3527927.3532788

[5] Virginia Braun and Victoria Clarke. 2012. *Thematic analysis.* American Psychological Association.

[6] Jed R. Brubaker and Vanessa Callison-Burch. 2016. Legacy Contact: Designing and Implementing Post-mortem Stewardship at Facebook. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*. ACM, San Jose California USA, 2908–2919. https://doi.org/10.1145/2858036.2858254

[7] Jed R. Brubaker, Lynn S. Dombrowski, Anita M. Gilbert, Nafiri Kusumakaulika, and Gillian R. Hayes. 2014. Stewarding a Legacy: Responsibilities and Relationships in the Management of Post-Mortem Data. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, Toronto Ontario Canada, 4157–4166. https://doi.org/10.1145/2556288.2557059

[8] Jed R Brubaker and Gillian R Hayes. 2011. " We will never forget you [online]" an empirical investigation of post-mortem myspace comments. In *Proceedings of the ACM 2011 conference on Computer supported cooperative work*. 123–132.

[9] Jed R Brubaker, Gillian R Hayes, and Melissa Mazmanian. 2019. Orienting to networked grief: situated perspectives of communal mourning on Facebook. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW (2019), 1–19.

[10] Janet X. Chen, Francesco Vitale, and Joanna McGrenere. 2021. What Happens After Death? Using a Design Workbook to Understand User Expectations for Preparing Their Data. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. ACM, Yokohama Japan, 1–13. https://doi.org/10.1145/3411764.3445359

[11] Dylan Thomas Doyle and Jed R Brubaker. 2023. Digital Legacy: A Systematic Literature Review. *Proceedings of the ACM on Human-Computer Interaction* 7, CSCW2 (2023), 1–26.

[12] Katie Z. Gach and Jed R. Brubaker. 2020. Experiences of Trust in Postmortem Profile Management. *ACM Transactions on Social Computing* 3, 1 (March 2020), 1–26. https://doi.org/10.1145/3365525

[13] Katie Z. Gach and Jed R. Brubaker. 2021. Getting Your Facebook Affairs in Order: User Expectations in Post-mortem Profile Management. *Proceedings of the ACM on Human-Computer Interaction* 5, CSCW1 (April 2021), 1–29. https://doi.org/10.1145/3449248

[14] Melissa M Garrido, Ellen L Idler, Howard Leventhal, and Deborah Carr. 2013. Pathways from religion to advance care planning: beliefs about control over length of life and end-of-life values. *The Gerontologist* 53, 5 (2013), 801–816.

[15] Rebecca Gulotta, David B Gerritsen, Aisling Kelliher, and Jodi Forlizzi. 2016. Engaging with death online: An analysis of systems that support legacy-making, bereavement, and remembrance. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*. 736–748.

[16] Rebecca Gulotta, Aisling Kelliher, and Jodi Forlizzi. 2017. Digital systems and the experience of legacy. In *Proceedings of the 2017 Conference on Designing Interactive Systems*. 663–674.

[17] Rebecca Gulotta, William Odom, Haakon Faste, and Jodi Forlizzi. 2014. Legacy in the Age of the Internet: Reflections on How Interactive Systems Shape How We Are Remembered. In *Proceedings of the 2014 Conference on Designing Interactive Systems*. ACM, Vancouver BC Canada, 975–984. https://doi.org/10.1145/2598510.2598579

[18] Rebecca Gulotta, William Odom, Jodi Forlizzi, and Haakon Faste. 2013. Digital Artifacts as Legacy: Exploring the Lifespan and Value of Digital Data. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, Paris France, 1813–1822. https://doi.org/10.1145/2470654.2466240

[19] Rebecca Gulotta, Alex Sciuto, Aisling Kelliher, and Jodi Forlizzi. 2015. Curatorial agents: How systems shape our understanding of personal and familial digital information. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*. 3453–3462.

[20] Jack Holt, James Nicholson, and Jan David Smeddinck. 2021. From Personal Data to Digital Legacy: Exploring Conflicts in the Sharing, Security and Privacy of Post-mortem Data. In *Proceedings of the Web Conference 2021*. ACM, Ljubljana Slovenia, 2745–2756. https://doi.org/10.1145/3442381.3450030

[21] Jonna Häkkilä, Ashley Colley, and Matilda Kalving. 2019. Designing an interactive gravestone display. In *Proceedings of the 8th ACM International Symposium on Pervasive Displays (PerDis '19)*. Association for Computing Machinery, New York, NY, USA, 1–7. https://doi.org/10.1145/3321335.3324952

[22] Sue Jamison-Powell, Pam Briggs, Shaun Lawson, Conor Linehan, Karen Windle, and Harriet Gross. 2016. "PS. I Love You": Understanding the Impact of Posthumous Digital Messages. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*. ACM, San Jose California USA, 2920–2932. https://doi.org/10.1145/2858036.2858504

[23] Joseph 'Jofish' Kaye, Janet Vertesi, Shari Avery, Allan Dafoe, Shay David, Lisa Onaga, Ivan Rosero, and Trevor Pinch. 2006. To have and to hold: exploring the personal archive. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '06)*. Association for Computing Machinery, New York, NY, USA, 275–284. https://doi.org/10.1145/1124772.1124814

[24] Joseph 'Jofish' Kaye, Janet Vertesi, Shari Avery, Allan Dafoe, Shay David, Lisa Onaga, Ivan Rosero, and Trevor Pinch. 2006. To Have and to Hold: Exploring the Personal Archive. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, Montréal Québec Canada, 275–284. https://doi.org/10.1145/1124772.1124814

[25] Allan Kellehear. 1984. Are we a 'death-denying'society? A sociological review. *Social science & medicine* 18, 9 (1984), 713–721.

[26] Michael E. Locasto, Michael Massimi, and Peter J. DePasquale. 2011. Security and privacy considerations in digital death. In *Proceedings of the 2011 New Security Paradigms Workshop (NSPW '11)*. Association for Computing Machinery, New York, NY, USA, 1–10. https://doi.org/10.1145/2073276.2073278

[27] Michael Massimi. 2013. Exploring remembrance and social support behavior in an online bereavement support group. In *Proceedings of the 2013 conference on Computer supported cooperative work - CSCW '13*. ACM Press, San Antonio, Texas, USA, 1169. https://doi.org/10.1145/2441776.2441908

[28] Michael Massimi, Jackie L. Bender, Holly O. Witteman, and Osman H. Ahmed. 2014. Life Transitions and Online Health Communities: Reflecting on Adoption, Use, and Disengagement. In *Proceedings of the 17th ACM Conference on Computer*

Supported Cooperative Work & Social Computing. ACM, Baltimore Maryland USA, 1491–1501. https://doi.org/10.1145/2531602.2531622

[29] Michael Massimi, William Odom, Richard Banks, and David Kirk. 2011. Matters of life and death: locating the end of life in lifespan-oriented hci research. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '11)*. Association for Computing Machinery, New York, NY, USA, 987–996. https://doi.org/10.1145/1978942.1979090

[30] Wendy Moncur and David Kirk. 2014. An emergent framework for digital memorials. In *Proceedings of the 2014 conference on Designing interactive systems (DIS '14)*. Association for Computing Machinery, New York, NY, USA, 965–974. https://doi.org/10.1145/2598510.2598516

[31] Michael J Muller and Sarah Kuhn. 1993. Participatory design. *Commun. ACM* 36, 6 (1993), 24–28.

[32] William Odom, Richard Banks, David Kirk, Richard Harper, Siân Lindley, and Abigail Sellen. 2012. Technology Heirlooms?: Considerations for Passing down and Inheriting Digital Materials. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, Austin Texas USA, 337–346. https://doi.org/10.1145/2207676.2207723

[33] William Odom, Abi Sellen, Richard Harper, and Eno Thereska. 2012. Lost in translation: understanding the possession of digital things in the cloud. In *Proceedings of the SIGCHI conference on human factors in computing systems*. 781–790.

[34] Martina Orlovic, Katharine Smith, and Elias Mossialos. 2019. Racial and ethnic differences in end-of-life care in the United States: Evidence from the Health and Retirement Study (HRS). *SSM-population health* 7 (2019), 100331.

[35] Jim Parker. 2023. *Only 22End-of-Life Wishes*. https://hospicenews.com/2023/04/12/only-22-of-americans-have-documented-end-of-life-wishes

[36] Johnny Saldana. 2011. *Fundamentals of qualitative research*. Oxford university press.

[37] Clay Spinuzzi. 2005. The methodology of participatory design. *Technical communication* 52, 2 (2005), 163–174.

[38] Morgan Stanley. 2023. *Morgan Stanley: Estate Planning Checklist*. https://www.morganstanley.com/articles/estate-planning-checklist

[39] Lisa Thomas and Pam Briggs. 2014. An Older Adult Perspective on Digital Legacy. In *Proceedings of the 8th Nordic Conference on Human-Computer Interaction: Fun, Fast, Foundational*. ACM, Helsinki Finland, 237–246. https://doi.org/10.1145/2639189.2639485

[40] Daisuke Uriu, Noriyasu Obushi, Zendai Kashino, Atsushi Hiyama, and Masahiko Inami. 2021. Floral Tribute Ritual in Virtual Reality: Design and Validation of SenseVase with Virtual Memorial. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (CHI '21)*. Association for Computing Machinery, New York, NY, USA, 1–15. https://doi.org/10.1145/3411764.3445216

[41] Daisuke Uriu and William Odom. 2016. Designing for Domestic Memorialization and Remembrance: A Field Study of Fenestra in Japan. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*. ACM, San Jose California USA, 5945–5957. https://doi.org/10.1145/2858036.2858069

[42] Daisuke Uriu, William Odom, and Hannah Gould. 2018. Understanding Automatic Conveyor-belt Columbaria: Emerging Sites of Interactive Memorialization in Japan. In *Proceedings of the 2018 Designing Interactive Systems Conference*. ACM, Hong Kong China, 747–752. https://doi.org/10.1145/3196709.3196801

[43] Janet Vertesi, Jofish Kaye, Samantha N Jarosewski, Vera D Khovanskaya, and Jenna Song. 2016. Data Narratives: Uncovering tensions in personal data management. In *Proceedings of the 19th ACM conference on Computer-Supported cooperative work & social computing*. 478–490.

[44] Megan Yip. 2023. *Digital Assets Planning Guide: Borchard Foundation on Law and Aging*. https://www.meganlyip.com/digital-assets