

## Governance of Digital Health Data on Cooperatively Organized Platforms – a Design Thinking Approach

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### Abstract

*More and more stakeholders are collecting data for improving their services: from scientific research over public administration to commercial enterprises. Existing data management services offer few rights of co-determination for their users. Data cooperatives aim to provide a democratic alternative to this. Through such a platform cooperative members are supposed to be enabled to share their data in a self-determined way. In this paper, we present a design thinking-based user research with stakeholders of data cooperatives in a health-data context. We provide an overview of motivations, expectations, and interfaces between a cooperative and individuals as cooperative members, organizations, representatives from research, and policy makers. In an iterative process, 34 interviews were conducted with different stakeholder groups, from which 7 personas were subsequently derived. For these, 4 prototypes were developed and tested with potential users. Our results show that all interviewed groups were very interested in the concept of data cooperatives. At the same time, it proves challenging to reconcile the conflicting internal and external requirements and to implement attractive value propositions for all stakeholders.*

**Keywords:** data cooperative, data governance, health data, smart cities, data sovereignty, data platform

### 1. Introduction

Personal data is permanently collected and aggregated in all areas of life – from treatment data collected in clinical contexts, to the use of apps that follow our behavior or even wearables that evaluate vital data in real time. Countless valuable pieces of information about us as individuals, customers, or citizens lie in data silos and are thus mostly excluded from organization-overarching research (van Roessel et al., 2017). Digital service providers in the meantime collect and commercialize the customer's data, and build monopole structures through network effects, which to some extent impede a free market competition and thus free choice of customers (Song et al., 2018). The role of individuals in the emerging field of data platforms, data ecosystems and data economy as a whole is of emerging societal relevance (Lauf et al., 2022). Customers supposedly care about their data governance. At the same time however, they don't want to miss out on convenient services and

disregard their own concerns, which is referred to as the privacy paradox (Kokolakis, 2017). When it comes to health data, data privacy concerns are able to actually influence individual behavior insofar that people tend to act less permissive in this field (Taitingfong et al., 2020). Particularly regarding health and wellbeing, data integration across silos withholds great potential: business-wise for providing platforms, for individuals who profit from personalized information, but also for public good as a prerequisite for a stronger focus on preventional behavior and supportive public structures. Cooperatives are discussed as a possible advocacy organization for citizen's interests in the field of tension between data economy and data sovereignty (Otto & Burmann, 2021). Data cooperatives are not only part of academic discussion but have emerged as frontrunning projects with the goal of enabling individuals to regain governance over their data, form a strong player opposing the dominating tech platforms, while at the same time making data available for the common good and using it beyond the initial service (Calzada, 2021; Hafen, 2019; Hardjono & Pentland, 2019). Supporters of this idea argue in favor of the democratic structure of the business model, which invokes a bottom-up principle through the fact that the members of the cooperative are also co-creators of the organization (Blasimme et al., 2018). Gathering many single perspectives into one organization with active and democratic involvement of individuals by voting on how to handle member data is intended to jointly strengthen the autonomy of members towards big data monopolies. Data cooperatives are thus intended to provide more data sovereignty and co-determination (Hafen et al., 2014).

The proposition that governing data through cooperatives might represent a promising counterproposal to commercial offerings for data management can be derived from literature (CORDERY & HOWELL, 2017; Lauf et al., 2021; Otto & Burmann, 2021). According to research, the need for cooperatively organized governance models exists due to the lack of representation of end-users' perspectives in commercial data usage. The necessity for a structure which mediates data usage, data economy and data sovereignty of individuals is claimed (Mählmann et al., 2017; Tanwar et al., 2021; Turin et al., 2020). Several model projects exist that aim at implementing cooperatives to democratize data handling, similar to the vision described above: strengthening data sovereignty in data ecosystems by summarizing individual perspectives through an embracing democratic structure (Healthbank; Holland Health Data Coöperatie; MIDATA; polypoly coop; SALUS COOP). However, most of the data

cooperatives seem to be in exploratory stages and few of the organizations exist beyond the concept. This can be attributed to the complexity involved in putting such an endeavor into practice, to funding challenges and lacking commitment of individuals (Blasimme et al., 2018). This also suggests a classic research-practice-gap, which occurs when both relevance and rigor of a theoretical concept do not mirror practical situations or cannot be translated into a practical setting (Barrett & Oborn, 2018). Within this paper we focus on the translation of the idea of data cooperatives into practice and present a design-oriented research approach, which focuses on the following research questions:

- 1) *Which motivations and expectations do relevant stakeholder groups hold towards data cooperatives?*
- 2) *How can these expectations be facilitated through a data cooperative information system?*

Therefore, we incorporate potential stakeholders in an iterative, user-centered design thinking approach. We chose to model a health-data-related scenario, since in this field people are increasingly likely to translate data concerns into action (Taitingfong et al., 2020). The followed methodology as well as the results are described in the subsequent sections.

## 2. Methodology

The investigation of organizational structures such as cooperatives and associated technical platforms can be assigned to the field of Information System (IS) research (Bartsch et al., 2020). Regarding platforms and governance structures de Reuver et al recommended to “advance methodological rigor by employing [...] design research”, among others (2018). Design-oriented methods combine practice and research to understand social situations and organizational contexts and the emergence of artifacts (Peffer et al., 2007; Sein et al., 2011). At the same time, design-oriented research not only aims at description of socio-technical systems but also at creating suitable information systems for the mentioned situations and contexts (Sein et al., 2011). Answering the presented research questions necessitates and combines contributions from multiple scientific disciplines. We thus follow the design thinking methodology which aims at finding practically relevant solutions in complex and multidisciplinary research settings (Wylant, 2008). In parallel we explore the formal cooperative founding process, in order to understand practical challenges. This process includes founding consultancy, drafting of a cooperative statute and a business plan. The insights of both streams are continuously included into

each other. Since a cooperative founding process is accurately defined, we focus this paper on the design oriented research stream, which follows the Stanford Design Thinking procedure (Meinel et al., 2011). That is a five-step process which sequentially builds from *empathizing over definition*, *ideation* and *prototyping* to *testing*. These steps are supposedly carried out in iterative loops, while the framework allows situational adaption and incremental improvement through return to previous process steps (Wylant, 2008). As a preparation for the design-oriented user research we conducted a scoping literature review. Both steps are subsequently described.

## 2.1 Literature Review

In order to gain a broad and deep overview of the theoretical background of social-, health- and wellbeing- related data cooperatives a scoping review of both scientific papers and grey literature was carried out (Munn et al., 2018). The search included nine databases (PubMed, EconBIZ, EconLit, Scopus, Sociological Abstracts, Sociohub, WiSo, Web of Science and Cochrane Library) and applied combinations of the keywords social care, health care, primary care, cooperative, health care data, health data, and data cooperative. The identified sources were then analyzed in an abstract as well as subsequently in a full text screening for contentual relevance. Additionally, a backward search and a Google Scholar search were carried out following the same procedure. All included articles and sources were then analyzed regarding the categories aim and type of the cooperative, member structure, founding process, financing, activity status and country. While the initial review is published as a separate article [(Data-)Cooperatives in health and social care as new paths to digitalization – a scoping review, currently in publication], the search accompanied the project and was updated regularly.

## 2.2 Design Thinking Approach

Within the first step of the design thinking process, *empathizing*, the goal is to gather an encompassing qualitative understanding of stakeholders' perspectives of a specific topic (Meinel et al., 2011). To generally approach practical relevance of data cooperatives, understand stakeholder problems and encircle potential areas of application we conducted semi-structured interviews (Gill et al., 2008). We identified four groups of stakeholders, from whom further understanding of their interests and motivation towards data cooperatives was required: citizens, organizations, public administration, and scientists.

We incorporated representatives from each of these four stakeholder groups in the interviews. Group 1 enclosed seven citizens with no health-data or research background. Group 2 comprised seven representatives from organizations with a potential interest in access to citizen's health- or wellbeing-data such as health insurance or company health service. Group 3 encompassed six representatives from politics or public administration (PA), and group 4 included four scientists with relation to health data processing. The interviews were carried out between April and May 2021 through a video-conference system by two researchers per interview, one focusing on the interview conduction and one on documentation. The interviews took about an hour and followed a semi-structured guideline (Longhurst, 2010) along (1.) general introduction of the interviewers and concept of cooperatives in context of data, health, and wellbeing, (2.) general introduction of the interviewees background, professionally and regarding the inquired topic, (3.) problems and interests regarding personal data use, access, and provision, and (4.) interaction, role and desired functionalities of a data cooperative and a respective platform. In a second wave of the survey, three citizens, one representative from a health insurance company and three from city administrations and three psychologists were additionally interviewed. The latter were included due to a potential focus of the cooperative on mental health which was discussed in interview wave one. In total, 34 interviews were conducted.

**Table 1. Interviewees per stakeholder group and interview phase.**

Stakeholder group	Phase 1	Phase 2
Citizens	7	3
Organizations	7	1
Politics/PA	6	3
Scientists	4	3

Following the interview conduction, we synthesized the observations in the *definition* phase. This phase aims at articulating the circumstances, needs and stakeholders. Therefore, we qualitatively analyzed the interview documentation. We followed an inductive approach and carried out the steps of data preparation, grouping, categorization, and abstraction (Elo & Kyngäs, 2008). In order to define the stakeholders, we grouped the problems which a data cooperative could solve and merged these outcomes into personas. In parallel we created multiple scenarios following the design thinking tool suggestions of Chasanidou (2015) in the *ideation* phase. Ideation serves as a brainstorming phase, in which all thinkable solutions are gathered to explore a wide range of ideas.

This gathering was carried out in a workshop with ten representatives from the research team. The workshop participants had backgrounds in social and health research, systems engineering and public and international structures, and from their research role prior knowledge of the general construct of cooperatives. The scenario development aims at describing a specific value the data cooperative provides for a target group or persona, the problem it solves for the respective group and the way the target group handled those issues so far. Additionally, the unique benefit created through the cooperative and the functionality through which the value is delivered is defined within a scenario. The scenario description categories are depicted in Figure 1.

Value created	Problem solved	Target group	Handling so far	Unique benefit Coop	Problem-solving function
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**Figure 1: Scenario description**

As a preparation a clustering and prioritization of scenarios was carried out for the subsequent *prototyping* and *testing* phases. *Prototyping* serves as the phase where ideas are transformed into tangible artifacts. Three clusters were selected for further outline in four wireframe prototypes (Arnowitz et al., 2010). Following the understanding, development and prototyping, *testing* aims at gathering productive feedback from stakeholders. The four prototypes were thus eventually tested through a thinking-aloud-procedure with newly recruited test persons (Krahmer, 2004). The parallel cooperative founding consultancy led to the choice of including foremost the stakeholder group citizens into the testing phase. This was identified as the main driving group for a democratically and self-organized structure like a cooperative with the purpose of joint advocacy.

### 3. Results

#### 3.1 Literature Review

In the literature review 7596 articles were identified, from which 3574 duplicates were excluded. 329 articles were then chosen for further analysis in the full text screening, from which 14 articles presented cooperative structures. Via backward search and Google Scholar search 9 additional approaches were identified, which were included into the detailed analysis. The following data extraction was clustered according to their aim into cooperatives with focus on workers' rights (3), cooperatives with focus on service provision to clients (4) cooperatives of institutions (2), consumer cooperatives (6), cooperatives of general practitioners (1), cooperatives as health insurance models (2) and health data cooperatives (5).

As a mutuality of the analyzed cooperatives their aim to overcome obstacles in their field of activity was identified, which was previously described as humanistic of even utopian effort (Mackay et al., 2000). While most of the included cooperatives publicly present their general ideals and principles, little information could be identified about success, structure, and revenue model of the cooperatives. However, one major challenge all identified cooperatives had in common was to build a clear purpose, which is easy to adopt by potential members and triggers intrinsic motivation to participate.

The succeeding results focus on and follow along the design thinking process.

#### 3.2 Empathizing and Definition

From the interviews, a total of 7 prioritized users were derived, which were subsequently detailed as personas: 1. the city (Carmen), 2. citizen altruist (Maria), 3. citizen self-interest (Sascha), 4. scientist (Gunter), 5. psychologist (Sabine), 6. occupational health management (Barbara), and 7. health insurance (Dennis).

1. The City – Carmen, 45 years old: Carmen is the head of the social psychiatric service at the health department and is also the president of a local trade union. She is interested in mental health and well-being. She would like to have access to regional health data, preferably from health insurance companies. Additionally she desires the ability to link data from different areas to be able to evaluate it. She hopes that working with a data cooperative will lead to productive collaborations with local stakeholders and health insurance companies. Her current challenges at the health department include limited financial resources and a lack of translation of evaluation results into practice. In addition to the lack of available health data, she also lacks ways to link and use the data in a meaningful way. She expresses concerns that increased data evaluations could have a negative impact in the future if this confirms biases, for example, against minorities. She would like to use current health data to be able to identify regional needs in health care and target group-specific needs. Health data could also be the basis for joint projects with local stakeholders. In the long term, she would like to see the health department establish itself more strongly as an advisory center for citizens.

2. Citizen Altruist – Maria, 48 years old: Maria works part-time as a teacher and mother of two teenage children. Both for her students and for her children, she would like to see a neighborhood with a high quality of life. Therefore, she volunteers in the gymnastics and sports club and participates in

demonstrations for social and ecological issues. Maria would like to see parks with a high recreational value, clean benches with enough trash cans, and more spaces for intergenerational exchange in her neighborhood. As a well-connected resident of her neighborhood, she knows about the infrastructural problems on site: older people have problems with curbs that are not lowered and sidewalks that are too narrow, dog owners and people with small children complain about trash in the park. She and many of the young neighbors would like to see more bike lanes to the downtown area. As a citizen, she often feels that she is not heard by the city administration, which is why she would appreciate an organization to help her with such concerns. Maria is not well versed in health data, but she could imagine that numbers could help to convince the city of her ideas. She likes the cooperative approach because she appreciates the democratic structures and forms of participation. She hopes that the data cooperative will help as an intermediary and facilitate communication between engaged citizens and decision-makers.

3. Citizen Self-interest – Sascha, 37 years old: Sascha is an IT project manager and has no health problems. Thus, he is not concerned with this topic overall. However, as he gets older, his health becomes more present, and he visits doctors more often for preventive checkups. Since he frequently moves within the country due to his professional activities, he is forced to change his physicians on a regular basis. It bothers him that he has to request his treatment data himself each time and those medical histories are not accessible in a digital file for his new practitioners. Due to his busy daily life, it is difficult for him to think about his checkups on a regular basis. He would like to have a feature that reminds him of this task, as it is important to him to stay healthy. It would be important to him that his health data is stored safely and securely on a German cloud. For all the advantages such a platform would have for conveniently managing his health data, Sascha is still concerned that using it could be risky for him. As an IT expert, he would find an open-source solution particularly confidence-inspiring. He would also be interested in making his data available for research, but only on if it is well protected and anonymized. Sascha is not an expert on cooperatives and has so far paid little attention to activities of this form of organization. He is unsure what benefit a data cooperative would have for him compared to a trustworthy commercial provider.

4. Scientist – Gunter, 28 years old: Gunter develops Artificial Intelligence technologies at a research institute. Therefore, he relies on large amounts of data. He invites people from his immediate environment or patients of his projects' clinical

partners to record data to incorporate this into his work. To do so, he has them sign a consent form allowing him to use this data for research purposes. He uses a standard consent template created by his institute that allows the same data to be reused for multiple research projects. If he needs to share these datasets with other researchers, he has them sign a license agreement limiting use to research activities. The datasets are stored on his organization's servers (data hosting provider with classic cybersecurity features), so all employees can potentially access those datasets. A collaboration with a data cooperative would be interesting for him for easier and faster access to the ecosystem and to the datasets of the other stakeholders, as well as to manage the relationships with the citizens who provide their data. He finds the cooperative approach intriguing, as he hopes it will lead to collaborative work with civilians through a resilient ethical framework.

5. Psychologist – Sabine, 38 years old: Sabine is a psychologist and works as a research assistant at a university. She regularly needs data from surveys to conduct her research and publish her work. In her experience, subjects are not easy to recruit and cooperation between institutions works only to a limited extent when it comes to both recruitment and data exchange. Without providing incentives, recruiting subjects is particularly difficult, especially since data processing without benefit can even be a deterrent. There also remains the ambivalence that subjects are interested in learning about offers, but at the same time do not want to disclose data. A collaboration with a health data cooperative could make it easier for her as a scientist to access data and promote interdisciplinary and interinstitutional exchange, also because trust in the cooperative would be greater compared to an outside research group. As a psychologist, it is important to Sabine that the data platform is designed with the involvement of subject experts. E.g., if the results of surveys are returned to participating citizens, should not worsen the health condition by making inappropriate recommendations. She believes it makes sense to motivate participants through gamification.

6. Occupational Health Management – Barbara, 56: Barbara works for a public transport company in the field of occupational health management and is active in an advisory and conceptual function. Her tasks include regular collection of data to reduce absenteeism and to identify stressful situations. She extracts indications of stress situations from quantitative and qualitative data from the transport service or the maintenance department. The data is collected internally via employee surveys or as part of health workshops and is not intended for use outside

the company. Only the employers' liability insurance association, as an external party, is given access to the data to provide insurance cover for employees. The data includes, e.g., gender and age distribution, number of accidents at work, lost working hours and interventions. At present, no digital systems are used; surveys are conducted in paper form. Exchanges with other companies take place on a metalevel in the form of industry comparison with other transport companies or health insurance companies. A cooperation with a data cooperative would allow the transport company to learn about offers in the region via the platform, which it could also use for its employees. A cooperative could also provide the opportunity to promote exchange with other transport companies and standardize the data collected to ensure better comparability and derive effective measures from it. If the employees of the transport company were members of the cooperative, they could take advantage of discounted prevention offers in the areas of exercise, relaxation, and recreation.

**7. Health Insurance – Dennis, 40 years old:** Dennis works in an executive position at a health insurance company. The main task of the health insurance is to cover the costs of services and thereby provide healthcare for its members. Digitization also plays a major role in this context, because with the introduction of the electronic patient record, health data is now digitally available to the insured and, with consent, also to their service providers. The health insurance company has an online office where all matters arising between the insured and the health insurance company can be managed. Because of the competition between health insurance companies, there is constant pressure to reduce administrative costs and become more efficient. It would be interesting for health insurance companies to cooperate with a data cooperative to gain access to health data to which they otherwise would have no access. Of particular interest to Dennis would be regional data pooled with his customers' data for evaluation purposes. In addition, he considers a data cooperative to be a good point of contact for requesting access to fully evaluated data analyses and reports on health care in specific regions.

### 3.3 Ideation

Goal of the ideation phase was to create a comprehensive set of solution scenarios which address implicit or explicit needs of the designed personas through a data cooperative. In a multidisciplinary workshop with 10 representatives from the research team we gathered scenarios which are supposed to create specific value for the described personas. We

designed 17 scenarios, which we subsequently clustered into content areas through keyword tagging of the application areas and value propositions of the scenarios. This resulted in three content areas: individual health optimization, contribution to research and contribution to urban environment and development. In addition to the clustering, we carried out a prioritization of scenarios through the research group. This resulted in the inclusion of four scenarios for further detailing through description of a user story, wireframe prototyping and testing.

### 3.4 Prototyping

The selected scenarios, value cluster and envisaged target groups are outlined in the following prototype description. For each prototype a user story, a process-supporting set of wireframes as well as target persona profile were drafted.

**Prototype 1:** The first prototype aims at provision of existing or creation of new data for research purposes. The user story is designed from an external stakeholder's perspective, who is formulating a data query towards the cooperative. Target group of prototype 1 is thus group 4, researcher. External data requests can be addressed in three ways: 1. channeling of existing data from the cooperative through a consenting process, 2. creation of a new dataset through distribution of a data creation tool (e.g., a survey) or 3. a suggestion to synchronize data from external data sources (e.g., tracking devices). Such external data requests can also be formulated by organizations. This scenario creates an access channel to data from individuals who are willing to contribute to Research & Development purposes. At the same time data sovereignty of individuals is ensured through a use and access process destined by the joint advocacy, in addition with a defined and technically supported consenting process.

**Prototype 2:** The second prototype focuses on contribution to data-based optimization of the urban environment. Target group is group 1, citizens, who are organized within the cooperative and are interested in contributing to directly perceptible urban development. The user story is designed from a citizen's perspective, who is willing to contribute to a data basis for decision making regarding urban planning measures. Such data can include behavioral data queried through surveys, demographic data, and data from external sources. These data sources can potentially be combined with data from public administration. The envisioned value for citizens is contribution to health- and wellbeing centered, data-based urban environment planning and thus directly tangible change of the living environment.

Prototype 3: The third prototype aims at contribution to data-based optimization of the urban environment, just as prototype 2. The target group is also citizens organized within the cooperative, exceeding the interest of contribution of data by the willingness to foster the transfer of cooperative activities into political and environmental decision making. Additional functionality exceeding prototype 2 is the opportunity to voluntarily engage with working groups or topic-related task forces. These working groups identify relevant topics within the cooperative's database, prepare these topics for as well as transfer them into external decision-making bodies. Value provided through this prototype is also contribution to health- and wellbeing centered, data-based urban environment planning, while the probability of transfer into political action is increased through voluntary engagement of committed cooperative members.

Prototype 4: The fourth and last prototype aims at individual health optimization. Target group are citizens who are interested in tracking and analyzing personal health data and optimizing their personal health situation. The user story describes the perspective of an individual, interested in tracking information, improving personal wellbeing, and monitoring progress. This user is likely to be receptive for gamified incentives. Functions provided through this prototype are processing of behavioral and health data, presentation of data based on the personal data history, comparison with peer groups, and provision of algorithm-based personalized health messages. Value created is the integration, monitoring and presentation of person-related wellbeing and health data, as well as the provision of personalized health messages.

### 3.5 Testing

Concurrent to the design thinking process focusing on a cooperative's value proposition the research team explored the formal founding process. The interaction with formal founding consultants led to the realization, that a sustainable founding foremost requires intrinsically motivated individuals, who share a vision. Motivations of external stakeholders are not relevant during the founding phase, but for sustainable operation. In the concluding testing phase, we thus set a focus on feedback from stakeholder group 1 citizens as the driving group for initialization of a cooperative structure. Each prototype was tested by 2-3 test persons, who followed the thinking-aloud-procedure. The main outcomes of the testing phase are outlined per prototype in the following.

Prototype 1: Process flow and value was found comprehensible but overloaded with information. It is

important to note, that the test persons were citizens, and thus no representatives from the prototype's target group researchers. Further details were asked for regarding use and access, as well as the consenting process. Motivation to contribute to a "higher good" was triggered, while personally perceptible benefit for citizens was found to be not obvious.

Prototype 2: The value proposition of the second prototype was well understood. The wireframe was found to require revision to better convey this value. Furthermore, a presentation of individual and collective data produced and provided, as well as information on resulting consequences (political decisions and structural changes) was asked for. Additionally, a gamified approach to ensure continuous participation was suggested.

Prototype 3: The value proposition of prototype 3 was found to be coherent by the test persons. Interestingly, the ambition to foster wellbeing-centered structural changes of the urban environment was mainly motivated by creating a healthy and livable environment for one's own children. In scenario 3 the algorithm-based provision of processed information was suggested. The necessity to be a member of the cooperative as a prerequisite to channel transfer into political decisions was questioned.

Prototype 4: The individual health optimization prototype was found to be appealing regarding the specific scenario of a wellbeing index and a heart attack risk score. Since the test persons were healthy adults, the value of disease related risk scores was found to be interesting, but rather a motivation for a one-time use. Additionally, regarding health and wellbeing data presentation, the added value compared to data representation of established fitness tracking apps was assessed to be improvable.

Prototypes 2 and 3 and the presented value of contributing to a health and wellbeing centered design of urban environment were found to be most appealing for the testing group. Prototype 1 did not quite convince, since the benefit promised was indirect (contribution to research and thus the common good) and too abstract. Prototype 4 was found to be valuable, but not differentiated enough compared to established service providers of personal data monitoring and analysis devices and applications.

## 4. Discussion

Our findings from the literature review as well as the user research suggest that the most important stakeholder group for initiating a cooperative founding process are citizens, who are willing to engage with the formulated vision. In order to motivate participation, the value proposition must be obvious

and understandable for this respective group (Werner & Jellema, 2019). A convincing and directly perceivable value proposition for this main stakeholder group is crucial for a successful cooperative. In the interview phase we discussed the general goal to strengthen individual interests by aggregating them into a larger group to mitigate the tension between data economy and data sovereignty. Although the topic was understood, this alone seldom triggered an eager want to participate in such an endeavor. Additionally, none of the interview or testing participants reported active measures due to data privacy concerns such as avoidance of a digital service. This supports what the privacy paradox describes: people use a service when they see a benefit (Kokolakis, 2017). We found it thus crucial to identify areas where additional value can be created through the cooperative. This finding led to further concretization of value propositions of a data-related cooperative in the ideation, prototyping and testing. Interestingly, motivation to support the mentioned general goal of the cooperative was triggered just as much in representatives of professional groups, in organization as in citizens. This might result from the fact that the incorporated citizens did not have an explicit data-related background while the professional representatives were able to relate the discussed fields of application to their work. However, professional representatives are also citizens, and their perspectives might intermingle to some extent. This certainly led to a bias in the personas, which mainly represent a well-off middleclass. Grossklags and Barradale also find in their research, that status assignment significantly correlates with security and privacy concerns (2014).

During the user research we identified several aspects of interest when we discussed motivation to participate. Main aspects of discussion in the citizen's interviews and in the testing phase were data representation and comparison to peer groups. These optional value propositions of a data cooperative were found appealing. At the same time, they were feared to be fewer convincing copies of well-established wearable devices and related applications. Health and activity monitoring, as well as personalized risk scores were found interesting. On the one hand they were rated as not sufficient for a regular use of a cooperative platform, especially in comparison with established health tracking systems and health apps. These functions were found too specific for a general value proposition which motivates a broad spectrum of individuals to participate in the cooperative. These specific functionalities were suggested to be provided customizably, e.g., through an "app store" or integration of external applications.

Main motivating value proposition in the testing phase was contribution to data-based decision making and thus wellbeing-centered structural changes of the urban environment through data provision. Interestingly, the term smart cities not only refers to the digitization of urban administration, but also to the creation of structures designed to serve the lives of local citizens, improve quality of life as well as wellbeing (Oliviera et al., 2014). There are many model projects for smart cities, but very few of them focus on the incorporation and structured evaluation of individual (health) data.

The main challenge identified was to reconcile the conflicting interests of the various stakeholder groups and to create value propositions that form an attractive cooperative for all affected groups. Value must be perceivable foremost for individuals (in the context of smart cities as citizens), as this is the main driving group for establishing and growing a cooperative.

The exploration of the cooperative value propositions through prototypes was found comprehensible by the test persons. Intuitiveness of the user experience of the digital solution was found to be crucial, which is expectable from prior research (Venkatesh et al., 2003). On the one hand the digital solution was expected to enable scaling of the number of participants in the data cooperative. This was found a necessity, since the larger the number of participants (and thus datasets), the better the standing of the cooperative in the encompassing ecosystem. On the other hand, it was asked for opportunities to administer the cooperative itself, its members and decision making. We thus resulted in a twofold platform idea, where participants contribute through integration of their data, and members get further involved into the organizational structure of the cooperative.

The design-oriented research approach cannot claim representativeness of the results. During the interview-phase representatives from four stakeholder groups of the cooperative were included. Three groups of these were external stakeholders, and only one the internal group citizens. The latter was found to be the most relevant group to establish and grow the cooperative in the first place. Insights from the external groups had to be considered carefully in the ideation phase, since the original idea of a cooperative is to represent common interests through a jointly owned and democratically-controlled organization (Pezzini, 2018). Nonetheless, these perspectives were found important, since a value proposition based on citizens interest regarding their data cannot be detached from other players in the data ecosystem. In the testing phase this led to the limitation that the prototype 1 was not tested by its actual target group researchers, but by the internal group citizens.



## 5. Conclusion

For the stakeholder group representatives incorporated into our user centered design thinking procedure, there were various motivations for participating in a data cooperative. The professional representatives saw advantages in gaining better access to health data to become better acquainted with their own customer group or to supplement research with data that is still missing. Also, the legal protection provided by the cooperative business model with its democratic principles was found to be an advantage which would create security on all participating sides. For citizens, the aspect of secure data storage on European servers, access to and an overview of their own health situation were marginally motivating. More convincing was the opportunity to participate regionally on behalf of their community and to foster local data-based decision making.

The initially from scientific literature derived potential of health-related data cooperatives was largely confirmed in our user research. Furthermore, it showed that a data cooperative might be a suitable accompanying structure for smart cities, where citizens, politics, urban planning, and public administration can cooperate. The greatest motivation to participate in a health and wellbeing centered data cooperative was the creation of a social hub where citizens and stakeholders from the data ecosystem meet at eye level. Goal of this hub is to share health data for the public benefit to create a livable environment. Main motivation was to enable urban planning and creation of a livable environment in a data-based, well-being-oriented manner.

A cooperative information system was asked to on the one hand enable facilitation of the cooperative administration through the shareholders. On the other hand, participation without becoming a part of the organizational structure was also asked for, e.g., through data provision.

Limitation of this study is the over-representation of participants from a well-off middleclass. Further research on data cooperatives in general and in smart city environments is thus required in a wider range of population segments.

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