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Data-Driven Healthcare: Critically Examining the Role of Self-care and Data-Driven Decision-Making in Diabetes Management

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Abstract. The use of digital technology for self-care, such as self-management of chronic diseases, has emerged through mobile applications and wearables, often designed, developed, and used in everyday life outside the healthcare context. The new self-care practices may be beneficial in many ways but can also potentially pose risks, and there is a corresponding need to understand underlying algorithms and biases that may affect users. In this article, we describe the design and development of a mobile app for food nutrition information as part of diabetes self-management and critically discuss its implications for patients and designers. In conclusion, this study highlights the need to carefully consider how self-management tools are designed, developed, and used for self-care. We propose co-design to approach data-driven healthcare in general and data-driven decision-making tools in particular. Our findings show that patients need to balance overreliance and mistrust in augmented data-driven decision-making, which calls for ethical considerations and a critical approach for all future designers.
Keywords: Healthcare, Data-Driven Decision-Making, Data-Driven Healthcare, Self-Management, Mobile Application, Critical Research, Socio-Technical.

1 Introduction

Healthcare globally is facing significant challenges. Due to medical advances, we are seeing an increasingly aging population. People are more likely to survive previously fatal diseases, and more patients live longer with chronic diseases, e.g., [1]. At the same time, the resources within healthcare are getting increasingly scarce [2]. Attributed to that, there is increasing pressure to find new ways to prioritize, and best utilize the limited resources in a more sensible way to meet the gradually rising healthcare costs. The use of digital technology, such as for self-management or self-care delivered through mobile applications, wearable devices (data gathering sensors placed

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on the body) or nearable devices (data gathering sensors placed nearby the body), can achieve sustainable care, reduce costs, and increase medical quality, access, and quality of life [3], [4].

Since the resources are scarce, there is an open call for innovative digital solutions based on continuous, reliable data, where the patients can play a more prominent role in the care process. Self-tracking, also referred to as self-monitoring and quantified self has become widely used in people's daily lives and is increasingly common in healthcare [5], [6]. It refers broadly to various technologies (apps, sensors, wearables) that enable people to monitor their health and well-being automatically and systematically – e.g., diet, exercise, sleep, mood, blood pressure, heart rate, and so on – at a scale and aggregated over time [7]. The increased collection of data conducted by patients has led to significant growth of so-called patient-generated health data as well as of digitally empowered and engaged patients who are involved, informed, and take an active role in decisions about their health and treatment [5], [8], [9]. In that category, there is a newfound interest in understanding how mobile applications can assist in small decision-making processes related to healthcare in general and towards patient self-help or self-care in particular, and few attempts have been made to be proactive and use the power of apps to create new self-care trajectories that can help with everyday decision-making for patients [10]–[13].

Importantly, these new ways of patients' gathering data on a larger and more longitudinal scale and allowing healthcare professionals access to that data can lead to enabling the healthcare professionals to prioritize which patients to examine more closely, using hands where hands are needed, and technological advancements for the rest has therefore become an important element of change [12], [14]. That particular change is referred to as data-driven healthcare. Furthermore, both patients and other citizens today use multiple technologies and devices for work, entertainment and many engage in self-monitoring as a part of life, and thus they have higher demands and expectations of healthcare to provide the possibility to share their data which then can be used as an integrated part of the care delivery [15]. The notion of "flipped healthcare" has been used to illustrate the emerging new role of patients who are more engaged and bring information and data gathered from wearables, nearables, apps, and digital platforms designed, developed, and used outside of the healthcare context into their clinical interactions [16], [17].

In all, this calls for more research to capture the design, development, and use of a variety of digital technologies within healthcare, looking beyond traditional standalone systems and towards a more wholesome view on data-driven healthcare [14], [15]. The active gathering of patient-generated health data, both subjective and objective, can either be initiated by the healthcare provider or the patients themselves and adopt continuous monitoring of a relevant disease or lifestyle-related parameters originating outside the healthcare facilities. In this article, we focus on self-management trajectories initiated by the patients, specifically on the design, development, and use of a mobile application (hereinafter called app) for food nutrition information handling, as part of diabetes self-care. The overall aim is to contribute with insights that can help improve and innovate self-care practices and enhance the quality of life for patients with diabetes in particular while also addressing the need for more research on app design, development, and use related to data-driven healthcare and data-driven decision-making in general. The research question is: *How can an app be designed, developed, and used to enhance data-driven decision-making of nutrition choices for patients with diabetes, and what are the implications for patients and designers?*

The remainder of the article is structured as follows: first, we outline related research; we then describe research methods (case description, design method, user tests, and analysis); followed by the research findings and analysis; finally, we discuss the implications and end with a conclusion and outlook for future work.

2   Related Work

Digital health broadly refers to the use of information and communication technologies to deliver healthcare services remotely and help people monitor and manage their personal health and wellness [18]. It includes various heterogeneous technologies that allow information exchange,

patient education, consultations, and delivery of care in alternate forms, tied together by the concept of remote healthcare resources delivery [19], [20]. The development of mobile health applications (mHealth), wearable devices, and personalized medicine has provided new opportunities for improving healthcare service delivery and access to patients, with remote monitoring playing a crucial role, as demonstrated during the COVID-19 pandemic [4], [21]. Several studies have concluded that remote monitoring, especially in chronic conditions such as diabetes, provides benefits in quality of care and utilization, along with increased patient awareness and compliance [20], [21]. Remote monitoring is considered crucial, as it enables providers to tailor their recommendations and treatment based on health data generated by the patients, outside of the healthcare setting. Thus, this goes beyond changing the mode of healthcare delivery—from face-to-face and in real-time to remote and/or asynchronous—rather it transforms the form of care [22].

Historically, digitalization efforts in healthcare have mostly been large-scale and focused on national standards and strategic infrastructural changes that aim to integrate various digital solutions such as the electronic patient record (EPR), as support for healthcare practices. The EPR has been the most significant challenge since the early 2000s [23], but in recent years there has been a shift in focus from the EPR as a working tool to other parts of healthcare. Recent technological developments have resolved some of the complexities of using mobile applications, remote monitoring and sensors in healthcare. Still, challenges and implications remain to be addressed, for instance, regarding data privacy and security, data management, scalability, regulations, and interoperability [20], [24]. Research in this area has focused on remote patient monitoring in the context of chronic conditions, such as diabetes, as these patients are expected to benefit the most from it [21]. Obesity, for example, is known to impact people's health negatively and has been associated with chronic diseases such as diabetes, heart disease, and high blood pressure. Longitudinal observation of physical activity can promote a healthier lifestyle for older people and may reduce healthcare costs [24].

Research explicitly focusing on the use of mobile phones to support the self-management of diabetes has found support for clinical practice to encourage patients and promote physical activity. In contrast, more research is still needed to gain insights into provider perceptions and integration into healthcare practice and identify which groups find remote monitoring most valuable and how long it should be used [21], [25], [26]. However, although there is extensive research, the literature is broad and disparate, making it hard to get an overview, and the evidence is inconclusive [22]. A remaining issue to address is how to move beyond just adhering to prescription schedules and basic recommendations about nutrition and physical activity towards engaging and supporting patients and consumers in self-management through meaningful engagement and shared decision-making enabled by digital health technologies [10], [18].

Research on the topic of self-tracking and quantified self has increased in recent years, corresponding to the rise in interest and use of such solutions within healthcare and everyday life [5], [6]. A recent review of the state of the art found that studies have focused on the perspectives of i) end users, ii) patients and people with illnesses, and iii) health professionals and caregivers; among the areas identified for further work the review highlights cognitive and emotional aspects of the processing and interpreting of information and data gathered from tracking devices and apps; and the dark side of self-tracking (e.g., its adverse psychosocial consequences) [7]. Previous research highlights the importance of systematically collecting data over an extended period through a data-driven approach to forward clinical practice and research [12], [13]. In this context, it is vital to understand the interplay between technical aspects of app design and development, along with the social aspects of collaborative design that include stakeholder engagement and active participation in the design process [13], [14], [27].

This brings us to augmented intelligence. In recent years there has been a shift towards promoting digital tools, such as apps that rely on machine learning algorithms and their potential to revolutionize various parts of patient care. However, such efforts will and should not enhance some parts of the self-care process. Instead, intelligence augmentation (IA) might be more suitable

than artificial intelligence (AI) for specific areas. IA is commonly defined as computers and digital artifacts enhancing human intelligence through their design and is not meant as a replacement of any sort [28]. Instead, IA artifacts are intended to augment the learning process, aid the patient, and support the journey toward self-care. With the use of apps and other digital artifacts comes a vast amount of data, and the data analysis is within care, commonly done by humans. AIs might someday interpret the data, but today, traditional self-care like dietary recommendations and timing for diabetes as an example is an analog practice of coaxing information by reading food packages, packaging the food, and through trial and error, building up a knowledge base of what foods spike blood sugar more than others [29]. The patient-generated health data becomes a part of the clinical decision-making process and can be seen as a practice where intelligence augmentation through data and data produced in and for healthcare contexts calls for analytical skills both by the patient and the nurse to engage in the sense-making process together. While the data in the world is increasing and people are increasingly relying on data-driven decision-making, some application areas within healthcare are lagging and raise the question of what should be kept analog [8]. That shift is the change that we focus on in this particular article which extends the research presented in [11]. By critically examining the role of self-care and data-driven decision-making, we seek to contribute an in-depth understanding of how an app can help patients be independent by augmenting their decision-making process.

3   Research Approach

The empirical data is drawn from the design, development, and use of an app that could enable users to look up food nutrition information so that grocery shopping would become increasingly data-driven. The app primarily targets those who need to consider the intake of carbohydrates, sugars, fats, etc., such as a patient with diabetes, food intolerance, or severe allergies. The design approach is co-design, and the first phase included heavy engagement of patients with diabetes. The co-design was the first phase and started with crazy-8 [30], then gradually moving towards a working prototype of the app. Moreover, the design phase included eliciting requirements, user stories, and testing scenarios. More specifically, the first phase followed the methodology outlined in Islind [2]. Agile methodology was used during the project's development phase (second phase) to break down the long-term goals into smaller tasks. The development was divided into twelve sprints, each with a specific aim. Daily standup meetings were held in the mornings, and every second week of each sprint, a 'retrospective' was held, where the sprint was discussed, and the analysis included what had gone well and what could have been performed more efficiently. Gitlab was used to keep track of the development status, requirements, and programming code. The following section describes the development of the app, first front-end, then back-end and database connection. After that, the implementation phase is described, followed by a description of user tests, data gathering and analysis, which outlines the third phase herein.

3.1 Development Process and Environment

It is vital for patients with diabetes and others who need to closely monitor nutritional value to have digital aides by their side. However, there are few apps available that are co-designed in a user-centered manner. The app was not developed in collaboration with a specific company, but the data that is the backbone of this project was provided by a public entity that collects nutritional data on a large scale. The data was delivered in the form of a .csv file that contained over 1300 different foods along with their nutrition information. The front-end of the app was written in JavaScript, using Airbnb programming rules due to its large-spread and good documentation, and ESLint was used to review and ensure that they were enforced. The back-end was written in Python and used the PEP8 rules and PyLint addition to Vscode to refactor the code. The app was developed in ReactJS / React Native, which enabled the breakdown of the code into many small

parts, each with its own task. CSS was used to style the code. The Expo CLI was used for testing, enabling the app to be tested on computers and smart devices such as mobile phones.

The back-end was split to separate users and data. Users could log into the app with an email address. The data was stored in a PostgreSQL database hosted by Amazon AWS (Amazon Web Service). On that basis, the main data on food products were housed: nutritional value, vitamins, light description of contents, etc. Other information generated during the run, such as user settings and food that the user chose to save, were also set in PostgreSQL, the foundation. To retrieve data from the database and send to the front end, the python WebSocket server was built, but, when the script started to take shape, it was decided to move the functionality from it to the Apache server hosted by AWS. WSGI (Web Server Gateway Interface) plugin was added to Apache to allow it to send results from python code as http answers. This decision paid off because the Apache server could serve a larger group of people at once, was more convenient to use and was much faster.

In the first version of the database, the food was classified into its own food category and had a special origin, and the food also had data on the contents, which are vitamins, minerals, and nutrients. Whereas in the second version of the database, the food is classified into its own food category and has a special origin. The content of the food has been compiled under the name Nutrients, and in addition, there are users who have saved food and optional harvests. The excel file was provided through PostgreSQL database by Apache2 server with mod_wsgi plugin that runs Python to be a monkey for the script. Firebase is used to store user data and handle user authentication. Expo converts React JavaScript code into native smartphone widgets.

3.2 Co-design and user testing

In the Nordic countries where this particular project took place, as in most countries, the types of foods available in different stores are many and searching for nutrition information is often a tedious task. Due to that, there is a need for larger initiatives that take a large-scale view on diabetes management. In most countries, it is possible to search for individual products online according to the ingredient descriptions of individual foods, but often that information is not in an accessible or easy-to-read form and is definitely not aggregated into one app.

The need for high user experience and usability was identified in the first phase of this project; and having all nutritional information in one place was the driving force behind this digitalization process. The app, therefore, visualizes published information to its users on the nutritional value of food that is distributed on the market in a way that is simple and accessible. Moreover, the app enables users to select food items to a list and, through that, keep track of their food intake for self-management of diabetes as a supplement to insulin tracking. To achieve this goal of the design process—i.e., that enables users to search for food and ingredients in a simple way, track food intake in the app and see key information such as nutritional value—user tests were conducted with the intended users of the app and redesigned based on the results of those tests. Each user test consisted of an introduction, a pre-interview focusing on background information and demographics (including questions such as age, gender, diet, health problems related to food, smartphone literacy, and computer literacy); an assignment with tasks to do in the app; and a post-interview with questions focusing on user experience, suggestions for improvement and assessing user satisfaction.

To be able to adapt to the needs of most users, it is not enough just to have the right functionality. Great emphasis was also placed on the design. Initially, a rough prototype was created, which was used for user testing and user interviews (example screenshots are provided in Figure 1).

The usability tests followed a standard form created by the team to ensure that all tests were conducted in the same way, using the same data during the test. Each user test lasted about 30 minutes and was recorded. Due to restrictions in force during COVID-19, taking these tests on-site was not considered advisable; instead, testing through either Discord or Microsoft Teams was deemed appropriate. The user shared a screen to allow the administrator to monitor the resolution

of the to-do list, and the aim of these tests was to monitor and measure the following three main factors:

1. *Goal effectiveness:* Accuracy and enforcement that users achieve in pursuing a specific goal; Did the user complete the project? and; If not, what were the main obstacles?
2. *Efficiency:* Accuracy of the user in achieving his goal in the shortest possible time; How clear is this goal? and; How long was the user completing the project?
3. *Satisfaction:* Avoid the inconvenience and aim for a positive attitude from the user; How did you like the system? and; How would you rate it?
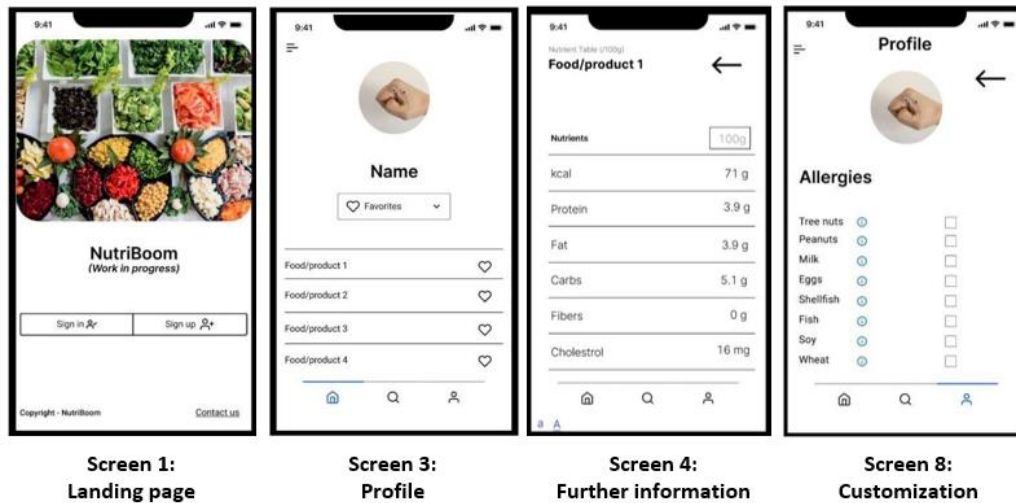

Figure 1. Prototype screenshots

The tasks were submitted to the user one by one. The "think-aloud" method [31] was used in which the users were encouraged to think aloud and describe what they were doing or expected to be able to do while performing the tasks. It is a well-established method for evaluating and understanding usability and user experience. The observer observed and noted the time it took to complete each task which was written down along with other comments and reflections from the observation. After completion of all user tests, results and comments were collected and summarized to draw conclusions and draft improvements in design, user experience, and functionality.

4   Findings

The findings are presented according to the design process: 1) identified user groups and respondent characteristics 2) artifact requirements, user comments, and suggestions for improvements, and 3) the prototype, which was tested and then the app that was designed and developed based on the results of the user testing.

4.1.   Identified User Groups and Respondent Characteristics

A majority of the respondents were in the age group between 31-40 years, followed by the age groups 20-30 years and 61-71 years. There was a fairly even distribution between men and women as well as between iOS and Android. When asked about their computer skills (scale of 1-10, where ten equals highly skilled), most of the respondents rated themselves between 5-8, but two users gave a rating of nine. Only two of the users said they had used a similar app before, almost none of them had dietary or health-related food restrictions, and when asked to determine their general knowledge of nutritional content, most users gave a rating between 5-10 (10 being the highest, see Figure 2).

User	Age	Gender	Computer skills	Smartphone skills	Smartphone	Used in a similar way before	Optional food restrictions	Health related restrictions	Knowledge of Nutrition content
1	26	Male	7	7	Android	No.	No.	Reflux	2
2	26	Female	8	8	iOS	Yes	No.	No.	7
3	27	Male	5	8	Android	No.	No.	No.	4
4	32	Female	9	9	iOS	Yes (My fitness pal)	No.	No.	5
5	33	Male	8	8	Android	Yes	No.	No.	5
6	38	Female	5	5	iOS	No.	No.	No.	2
7	38	Female	7	7	Android	Yes, but will not use again	No.	No.	5
8	59	Male	5	5	Android	No.	No.	No.	7
9	62	Female	7	5	iOS	No.	No.	No.	8
10	66	Female	6	8	iOS	No.	No.	No.	7
11	67	Male	10	9	Android	No.	Avoid cheese	No.	5

Figure 2. Respondent characteristics

When designing software, it is important to define user groups that can use it and prioritize them according to their intended importance Five user groups were identified: 1) General users where anyone can use the information; 2) Users with allergies as it is good for them to avoid certain foods; 3) Users with underlying diseases (e.g., diabetes) where it is imperative to monitor the nutritional content of the food consumed (e.g., carbohydrates); 4) Users with food intolerance, and 5) Users who need or choose to live on a special diet.

4.2 Artifact Requirements, User Comments, and Suggestions for Improvements

The user experience may be different, but it is essential to identify the requirements and functionality the system must fulfill. The main requirements considered important and/or would improve the user experience are summarized by priority (A-C) in Table 1 below. Requirement A are requirements the developers believe must be implemented to deliver a usable product. B requirements are not as important but are considered to improve the user experience considerably, and they will only be implemented when all A requirements are fulfilled. C requirements are requirements the developers thought were good to have but not necessary for scripts.

Table 1. Requirements list

Requirement	Priority
The user needs to be able to search for food in a simple way	A
Users with dietary restrictions should be able to save a diet that is safe in itself	A
The user must be able to log in to the system	A
The user should be able to create an ID in the system to install diet plan	A
The user should be able to see the nutrients in the food	A
The user should be able to see information about food that contains something they may not eat	A
When the user is searching, provide suggestions on what products the user is looking for	B
The user should be able to filter the list by specific food category	B
The user should be able to record their diet to monitor their diet	C
Users should be able to see suggestions for food products that connect to users after	C
The user should be able to save food products for access to them in a simple way	C
The user should be able to remove food from favorite his list	C

A summary of the user tests, and the time it took to complete each task in the assignment (compared to the estimated time), is provided in Table 2. Below is a summary of comments and suggestions for improvements made by users during the tests.

Table 2. Summary of user test results

Project no	The project	Average time	Estimated time	Difference
1	User logged in	34 sec	14 sec	20 sec
2	User registers health-related restriction	81 sec	30 sec	51 sec
3	User should edit email	18 sec	15 sec	3 sec
4	User should change personal information	11 sec	10 sec	1 sec
5	Look for specific foods	25 sec	14 sec	11 sec
6	Look for specific foods and add them to your favorites	38 sec	8 sec	30 sec
7	User enters food customization settings	23 sec	9 sec	14 sec
8	User enters allergy information	17 sec	6 sec	11 sec
9	User wants to edit profile picture	21 sec	14 sec	7 sec
10	User wants to remove food from favorite list	24 sec	4 sec	20 sec
11	Users want to view a list of their favorite foods	36 sec	15 sec	21 sec
12	The user receives information about the specific nutritional content dosage of food.	35 sec	16 sec	19 sec
13	User wants to contact administrators	23 sec	20 sec	3 sec
14	User returns to landing page	5 sec	4 sec	1 sec
15	User wants to be able to see "history"	22 sec	10 sec	12 sec

The user tests provided valuable feedback regarding how the users interacted with the app, and comprise an excerpt from the problems users encountered while dealing with tasks. Many users, to start with, perceived the 'favorites' feature as confusing. It was suggested that it would be more understandable if the dropdown contained categories (e.g., meat, dairy products, fish etc.) displaying everything that belongs to that category. Favorites could be one of these categories. Users also commented that they found it challenging to find health-related restrictions to tick and dietary restrictions to label if applicable. Related to this, users wanted to have the possibility to change favorites by pressing the heart and seeing it become empty or filled, depending on whether it is in favorites or not. Being able to add food to the default list and to see all food categories were also highlighted.

Other suggestions for improvements were to add the possibility of indicating that you are following a special diet, e.g., vegan, keto, carnivorous, etc., and to remove dietary restrictions from 'Settings' and place it directly under the burger to make it easier to find. Adding pictures of the food was also brought up during the user tests, along with suggestions for new functions and adding a bar code or QR signal reader. A specific suggestion addressed during the user tests was the possibility of keeping a food diary and calculating calories, for example, to find 'macronutrients' of food to track oral intake, as this would help with weight management. Another suggestion was to display certain information for a short period, which may be suitable for users that need to pay attention to their diet. Related to this, a link to the Directorate of Health's website was suggested regarding advice. Users also wanted to know if the food is environmentally friendly.

The user tests also highlighted functions that were experienced as unnecessary, e.g., 'location' and 'profile photo'. Users also suggested alterations to labels; for instance, 'Last viewed' could be redefined as 'History' to follow naming conventions in the technology sector. Explaining everything under 'my' was one label that was perceived as unnecessary and a bit personal. Finally, there were comments about the placement of links and information. For instance, according to the user test, 'Contact us' was located in a confusing place and could be placed in the footer instead. Some users inquired about a dark mode.

4.2.   The App and Findings from the User Testing of the App

The user testing revealed various challenges that could be addressed. For instance, the user testing showed that the landing page function (Figure 3a) which appears after the app, launched for the first time could be better explained to the users. It is necessary to log in to be able to push that particular function and that was not clear to all users during the user testing. Moreover, if the user does not have access, they can register for a new account, and it was also shown in the user testing that it could be better highlighted where to register. In addition to that, the users enter the registration screen by selecting 'Sign Up', which after the user testing round was better illuminated in the user interface. After the user logs into the app, the food item list is opened (Figure 3b), that particular step was included as the first thing that meets the user after the user testing showed that the users asked for that as the main item. After that, the users can scroll through the list and select from the list, or search for a name in a search bar located at the top of the screen. The app returns the list filtered with the food products that contain the search string. The users can also use choose the settings screen, and after selecting that, the user is prompted to select the conditions that apply to that particular user (Figure 3c, d). If the users click on the small (i) located next to each item, an information box will appear showing more details information on what each setting entails.
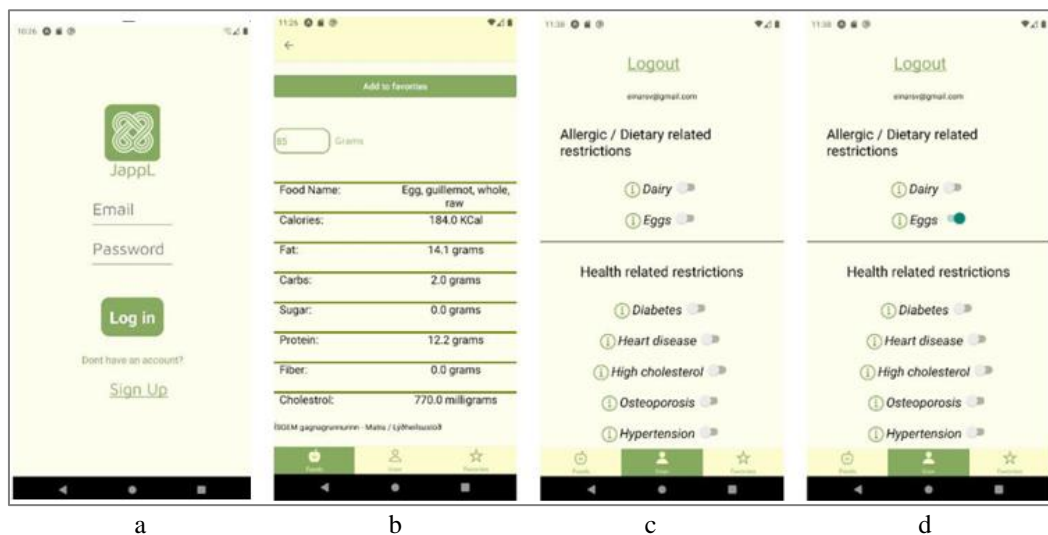

a   b   c   d

Figure 3. The app

When a user has entered their food preferences in the settings, the app notifies the user if the food they are viewing contains something that might be dangerous to them. The app shows this warning in the overall list and in the food information card for each food item (if it is selected). If the user clicks on the warning triangle in the info card, it will show the reason for the warning. Furthermore, the user can add the selected food favorites, and by doing so, the food item is also assigned to a list. When the user clicks on the function 'Add to favorites,' the food item is listed in the 'Favorites' tab, located on the bar at the bottom of the page. If the food is already a favorite, prior to clicking the item, an option is offered to the user to remove it from this list.

5   Discussion

Healthcare is rapidly changing as advances in medicine and the aforementioned scarce resources have resulted in an ongoing intriguing technological wave [3], [4]. The technology at hand generates large amounts of data, and the data has enabled patients to be more actively involved in their own care. More specifically, the tables are turning towards an increased focus on data-driven decision-making within healthcare settings [11], [12], [17], [27], [32], [33]. This particular wave is what we herein conceptualize as data-driven healthcare. To elaborate, the article does not see

the data as driving healthcare decisions; instead, the decisions are increasingly informed by data gathered by patients.

Our article outlines a contribution to that research agenda. Especially in this article, we describe the design, development, and use of an app for food nutrition information as part of diabetes self-management in order to allow patients to make more informed decisions in their everyday life based on data. In addition to that, we critically discuss its implications for patients and designers. The analysis of our findings revealed three critical aspects related to ethical considerations in data-driven decision-making in healthcare. Importantly, our article contributes to those as an embedded element of the future of data-driven healthcare.

First, and in line with prior research on digital health, our study highlights that using apps for self-care has the dual effect of enabling and constraining patients in self-managing their disease in their everyday life [10]. Whether initiated by healthcare or by the patients themselves, self-management, self-care, and continuous monitoring entail the integration of digital technology, which has a bearing on the meaning of care and has an influence on the role of both professionals and the patients [10], [17], [34], [35]. What we essentially mean by that is that relying on data can include a dichotomy. It can be an aid at the moment, but in our case of diabetes self-care, we also saw that the patients relied quite heavily on the app, much more than themselves, although they had been grocery shopping their whole life without an app.

Taking a panorama view on shifting some responsibility of care slowly from the healthcare provider to the patients, where part of the decision-making is in the app, the patients must have the ability, both in terms of access to reliable data and the skills and knowledge needed to make sense of the data therein. Their actions in response to decisions and recommendations are guided through an app that may directly impact their health and well-being, and because of that, all self-care and self-management tools should be designed, developed, and used with caution. It is truly important that the self-management tools are designed responsibly. Due to that, we recommend co-design; engaging the users early on and throughout the whole design and development process. Our findings support prior research that calls for socio-technical perspectives to unpack the interplay between the technical and social aspects of app design and development when designing for specific purposes or practices [13], [14], [27].

Secondly, the increased use of apps, wearables, nearables, and other types of self-management tools brings vast amounts of data, and, historically, data analysis within care settings has commonly been conducted by humans. This is shifting towards data-driven healthcare, but with this change comes responsibility [10], [17] for those who design the data visualizations and algorithms used for the data analysis. While artificial intelligence (AI) may in the future interpret the data, today, traditional self-care is a highly analog practice of coaxing information, such as in the case of diabetes management, through reading the packages of the food and slowly, through trial and error, building up a knowledge base of what food spikes the blood sugar more than others [29]. The patient-generated health data becomes a part of the clinical decision-making process and can be seen as a practice where intelligence augmentation (IA) through data and data produced in and for healthcare contexts calls for data analysis skills both for the patient and the healthcare professionals to allow for them to engage in a cohesive sense-making process. We argue that going from the analog practice, based primarily on memory, to data-driven decision-making might not be optimal for all. Instead, we propose that some apps stay as augmented intelligence devices and that in any case, they are all designed and developed with great respect for the context; and, once more, we would like to highlight the importance of collaboration with the users through co-design. In addition to that, we would like to forward that some things, for instance, self-management of diabetes and food intake coupled with that, can be done in a simple manner to avoid algorithmic bias, which is, in some cases, a large issue [36], [37].

Thirdly, healthcare is known for its reactive character, meaning that when people get sick, they seek healthcare. Data-driven healthcare and self-management through meaningful engagement and shared decision-making are illustrative for an ongoing shift of focus in healthcare at large toward prevention and democratization of healthcare processes, intended to provide equal care and the

patient's right to be more proactive in their health and wellness [3], [10], [18]. This is one aspect of the digital transformation of healthcare that has disrupted healthcare work and how healthcare is delivered [8], [17], [21], [22]. While a number of apps exist already for nutritional information, most of them are targeted toward fitness, with integrated features for keeping a food diary and logging exercises. Few are designed and developed in collaboration with patients to aid diabetes patients in their daily food choices. Coupled with that, we call for more research on preventive self-care and data-driven initiatives in healthcare that are both based on subjective as well as objective data gathering to aid the everyday life of patients outside the borders of healthcare.

We suggest the following design principles for others that would like to embark on the design and development of self-care apps in order to support diabetes patients and augment their intelligence: i) offer an interface where food producers have the opportunity to register their products with the foundation; ii) allow users to add food to the database. Add a barcode scanner, where the contents of a product can be viewed and its packaging barcodes scanned with just one click; iii) add data from other databases: loosely examined, data providing institutions exist in many countries, and we also found private information sources that offer similar information; iv) provide a food diary, where users could record food and size, and the app would keep the track of the number of nutrients that have been ingested.

6   Conclusion

In this article, we describe the design and development of a mobile app for food nutrition information as part of diabetes self-management and critically discuss its implications for patients and designers. Our findings show that there are important knowledge aspects connected to self-management and that there are risks involved if too much or too little reliance is placed on the app in the decision-making process. In conclusion, this study highlights the need for carefully considering the way self-management tools are designed, developed, and used for self-care. More specifically, this article calls for critically examining the role of quantified self and data-driven decision-making in general and diabetes self-management in particular as the design is conducted, as key implications for the decisions made later on. The new self-care practices that arise through the use of any kind of digital technology, such as in this case, an app, often designed, developed, and used outside of the healthcare context, may be beneficial in many ways but can also potentially pose risks, and there is clearly a need for understanding underlying algorithms and potential biases that may affect the users. In this context, socio-technical perspectives considering the technological aspects of designing and developing the app coupled with the social aspects of user involvement through co-design proved critical. Therefore, we propose co-design as a way to approach data-driven healthcare in general and data-driven decision-making tools in particular. In summary, our findings show that patients need to balance between overreliance and mistrust in augmented data-driven decision-making, which calls for ethical considerations and a critical approach for all future designers.

References

[1]   S. Pin and D. Spini, "Meeting the needs of the growing very old population: Policy implications for a global challenge," *Journal of aging & social policy,* vol. 28, no. 3, pp. 218–231, 2016. Available: https://doi.org/10.1080/08959420.2016.1181972

[2]   A. S. Islind, "Co-Design as a Driver of Change," *Performance Paradigm,* no. 17, pp. 166–180, 2022.

[3]   M. Gellerstedt, "The digitalization of health care paves the way for improved quality of life?" *Journal of Systemics, Cybernetics and Informatics,* vol. 14, no. 5, pp. 1–10, 2016.

[4]   R. Dwivedi, D. Mehrotra, and S. Chandra, "Potential of Internet of Medical Things (IoMT) applications in building a smart healthcare system: A systematic review," *J Oral Biol Craniofac Res,* vol. 12, no. 2, pp. 302–318, 2022. Available: https://doi.org/10.1016/j.jobcr.2021.11.010

[5]   D. Lupton, "The digitally engaged patient: Self-monitoring and self-care in the digital health era," *Social Theory & Health,* vol. 11, no. 3, pp. 256–270, 2013. Available: https://doi.org/10.1057/sth.2013.10

[6]   G. Neff and D. Nafus, *The Self-Tracking*. MIT Press, 2016. Available: https://doi.org/10.7551/mitpress/10421.001.0001

[7]   S. Feng, M. Mäntymäki, A. Dhir, and H. Salmela, "How Self-tracking and the Quantified Self Promote Health and Well-being: Systematic Review," *J Med Internet Res,* vol. 23, no. 9, 2021. Available: https://doi.org/10.2196/25171

[8]   A. S. Islind, T. Lindroth, J. Lundin, and G. Steineck, "Shift in translations: Data work with patient-generated health data in clinical practice," *Health Informatics Journal,* vol. 25, no. 3, pp. 577–586, 2019. Available: https://doi.org/10.1177/1460458219833097

[9]   V. Johansson, A. S. Islind, T. Lindroth, E. Angenete, and M. Gellerstedt, "Online Communities as a Driver for Patient Empowerment: Systematic Review," *J Med Internet Res,* vol. 23, no. 2, 2021. Available: https://doi.org/10.2196/19910

[10]   A. S. Islind, H. Vallo Hult, V. Johansson, E. Angenete, and M. Gellerstedt, "Invisible Work meets Visible Work: Infrastructuring from the Perspective of Patients and Healthcare Professionals," presented at the HICSS, January 5-8, 2021. Available: https://doi.org/10.24251/HICSS.2021.431

[11]   A. S. Islind and H. V. Hult, "Balancing Overreliance and Mistrust in Data-Driven Decision Making: A Critical View on the Role of Quantified Self in Diabetes Management," *8th International Workshop on Socio-Technical Perspective in IS Development (STPIS 2022),* Ceur-WS.org, vol. 3239, pp. 74–84, 2022.

[12]   A. S. Islind, H. V. Hult, K. Rydenman, and P. Wekell, "Co-creating a Digital Symptom Tracker: An App as a Boundary Object in the Context of Pediatric Care" *Co-creating for Context in the Transfer and Diffusion of IT*, A. Elbanna, S. McLoughlin, Y. K. Dwivedi, B. Donnellan, and D. Wastell, Eds., Springer, pp. 79–93, 2022. Available: https://doi.org/10.1007/978-3-031-17968-6_5

[13]   H. Vallo Hult, A. S. Islind, K. Rydenman, and P. Hällsjö Wekell, "Decreased Memory Bias via a Mobile Application: A Symptom Tracker to Monitor Children's Periodic Fever," *Stud Health Technol Inform,* vol. 294, pp. 915–919, 2022. Available: https://doi.org/10.3233/SHTI220624

[14]   A. S. Islind, "Platformization: Co-Designing Digital Platforms in Practice," PhD Dissertation, University West, Trollhattan, 2018.

[15]   H. Vallo Hult, "Digital Work : Coping with Contradictions in Changing Healthcare," PhD Dissertation, University West, Trollhättan, 2021. Available: http://urn.kb.se/resolve?urn=urn:nbn:se:hv:diva-16273

[16]   H. Vallo Hult and E. Wynn, "Information Integrity and Human Infrastructure in Digital Health Care," *Proceedings of the 25th Americas Conference on Information Systems*, 2019.

[17]   H. Vallo Hult, A. Hansson, L. Svensson, and M. Gellerstedt, "Flipped healthcare for better or worse," *Health Informatics Journal,* vol. 25, no. 3, pp. 587–597, 2019. Available: https://doi.org/10.1177/1460458219833099

[18]   M. Edmunds, "Promoting Consumer Engagement in Health and Health Care," *Consumer Informatics and Digital Health: Solutions for Health and Health Care*, M. Edmunds, C. Hass, and E. Holve Eds., Springer, pp. 3–24, 2019. Available: https://doi.org/10.1007/978-3-319-96906-0_1

[19]   L. Pang *et al.*, "Role of Telemedicine in Inflammatory Bowel Disease: Systematic Review and Meta-analysis of Randomized Controlled Trials," *Journal of medical Internet research,* vol. 24, no. 3, p. e28978, 2022. Available: https://doi.org/10.2196/28978

[20]   C. Wu *et al.*, "Evaluation of the clinical outcomes of telehealth for managing diabetes: A PRISMA-compliant meta-analysis," *Medicine,* vol. 97, no. 43, 2018. Available: https://doi.org/10.1097/MD.0000000000012962

[21]   M. Peyroteo, I. A. Ferreira, L. B. Elvas, J. C. Ferreira, and L. V. Lapão, "Remote Monitoring Systems for Patients With Chronic Diseases in Primary Health Care: Systematic Review," *JMIR Mhealth Uhealth,* vol. 9, no. 12, p. e28285, 2021. Available: https://doi.org/10.2196/28285

[22]   A. M. Totten *et al.*, "AHRQ Comparative Effectiveness Technical Briefs," *Telehealth: Mapping the Evidence for Patient Outcomes From Systematic Reviews*. Rockville (MD): Agency for Healthcare Research and Quality (US), 2016.

[23]   G. Fitzpatrick and G. Ellingsen, "A review of 25 years of CSCW research in healthcare: Contributions, challenges and future agendas," *Computer Supported Cooperative Work: CSCW: An International Journal,* vol. 22, no. 4–6, pp. 609–665, 2013. Available: https://doi.org/10.1007/s10606-012-9168-0

[24]   P. Yang and L. Xu, "The Internet of Things (IoT): Informatics methods for IoT-enabled health care," *Journal of Biomedical Informatics,* vol. 87, pp. 154–156, 2018. Available: https://doi.org/10.1016/j.jbi.2018.10.006

[25]   J. Connelly, A. Kirk, J. Masthoff, and S. MacRury, "The use of technology to promote physical activity in Type 2 diabetes management: a systematic review," *Diabetic Medicine,* vol. 30, no. 12, pp. 1420–1432, 2013. Available: https://doi.org/10.1111/dme.12289

[26]   S. H. Wild *et al.*, "Supported Telemonitoring and Glycemic Control in People with Type 2 Diabetes: The Telescot Diabetes Pragmatic Multicenter Randomized Controlled Trial," *PLoS medicine*, vol. 13, no. 7, p. e1002098, 2016. Available: https://doi.org/10.1371/journal.pmed.1002098

[27]   H. Vallo Hult, A. S. Islind, C. Master Östlund, D. Holmgren, and P. Wekell, "Sociotechnical Co-design with General Pediatricians: Ripple Effects through Collaboration in Action," presented at the AMCIS, Salt Lake City, UT, USA 2020.

[28]   P. C. Kyllonen, R. D. Roberts, and L. Stankov, *Extending intelligence: Enhancement and new constructs*. Routledge, 2007. Available: https://doi.org/10.4324/9781410617880

[29]   A. S. Islind and U. Lundh Snis, "From co-design to co-care: designing a collaborative practice in care," *Systems, Signs & Actions,* vol. 11, no. 1, pp. 1–24, 2018.

[30]   J. Knapp, *Sprint*. Bentang Pustaka, 2017.

[31]   H. Sharp, J. Preece, and Y. Rogers, *Interaction design: beyond human-computer interaction*. Wiley, 2015.

[32]   A. S. Islind *et al.*, "Individualized blended care for patients with colorectal cancer: the patient's view on informational support," *Support Care Cancer*. Available: https://doi.org/10.1007/s00520-020-05810-5

[33]   H. Vallo Hult, A. S. Islind, and L. Norström, "Reconfiguring professionalism in digital work," *Systems, Signs & Actions,* vol. 12, no. 1, pp. 1–17, 2021.

[34]   J. Pols, "The heart of the matter. About good nursing and telecare," *Health care analysis,* vol. 18, no. 4, pp. 374–388, 2010.

[35]   J. Pols and D. Willems, "Innovation and evaluation: taming and unleashing telecare technology," *Sociology of health & illness,* vol. 33, no. 3, pp. 484–498, 2011. Available: https://doi.org/10.1111/j.1467-9566.2010.01293.x

[36]   M. Kearns and A. Roth, *The ethical algorithm: The science of socially aware algorithm design*. Oxford University Press, 2019.

[37]   W. J. Orlikowski and S. V. Scott, "The algorithm and the crowd: Considering the materiality of service innovation," *MIS Quarterly,* vol. 39, no. 1, pp. 201–216, 2015.