Journal of Public Health
https://doi.org/10.1007/s10389-024-02226-x

REVIEW ARTICLE

(Data-) Cooperatives in health and social care: a scoping review

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Received: 1 August 2023 / Accepted: 22 February 2024

Abstract

Aim To gather information about the structure of cooperatives in health and social care, in general, and data cooperatives, in particular, to derive implications for their future implementation.

Subject and methods Health and social care systems are currently under pressure due to rising costs and demands. Many hopes lie on digitization, digitalization, and the potentials of health data. A scoping review was conducted searching nine databases and grey literature. Data on information about aim, type, and structure of the cooperatives, member structure, founding process, and their way of financing were extracted.

Results All searches resulted in 9080 articles and websites. Overall, we included 26 cooperatives and categorized them as follows: (1) worker cooperatives with focus on workers' rights and service provision to clients, (2) consumer cooperatives, (3) consumer and worker cooperatives, (4) cooperatives of institutions, (5) general practitioner (GP) cooperatives, (6) cooperatives as health insurance models, and (7) health data cooperatives.

Conclusions Information provided on (data) cooperatives differed greatly in detail. Their common goal is to tackle and overcome existing barriers in their field such as working conditions or unequal health care. We identified five challenges: (1) salary structures; (2) cooperating with other providers and surrounding institutions; (3) building an identity and recruiting potential members; (4) motivation of members to participate actively; and (5) distinction from other types. Benefits are: (1) improvement of conditions; (2) being stronger together; (3) support of research; and (4) data governance. When successful and competent, (data) cooperatives can be powerful tools on public, scientific, and political levels.

Keywords Scoping review · Digitalization · Data cooperative · Data sovereignty · Data economy · Health care · Social care · Digital technology (MeSH)

Background

Health and social care systems in the European Union (EU) and beyond are currently under pressure. Several reasons lead to a rise in healthcare costs. The medical technical progress combined with demographic developments and thus an increasing number of multimorbid patients are the obvious reasons, yet inefficiencies considering the intersectoral use of medical and health-related information should not be underestimated. New ways of organizing health and social care systems are being discussed on the European and national levels. Against this background, many hopes lie on the potential of digitization and digitalization of health and social care (European Commission n.d.). A central aspect of digital health is personal data. In addition to medical data already gathered within health care systems (i.e., produced in health care

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Published online: 15 April 2024

delivery and stored in electronic medical records), sensors in smartphones and in smart home devices collect all kind of health-related information. Consequently, more health-related data is produced and stored, but, as critics argue, not made accessible and/or used to improve health care provision (Hafen et al. 2014). In addition, the question arises how this data will be controlled – and by whom. To this regard, Zuboff (2015) warns that if data is controlled by private companies or public organizations, those organizations could become increasingly alienated from the data subjects. Upon that, Mòdol (2019) provides several cases in which publicly controlled health data was made accessible for third parties without patients consent, which eventually led to mistrust (see also (Hern 2017; Martin 2017). The main problem these authors see is the circumstance that "rights about the access and reuse of personal data are unevenly distributed" (Mòdol 2019). In view of debates on citizens as "prosumers" (Toffler 1990) or co-providers of services on the one hand and data on the other, this uneven distribution of power and rights has recently been questioned. Additionally, users tend to be very critical regarding data sharing in theory, but practically voluntarily share a multitude of personal data with big tech enterprises, when in return they can use, e.g., social media. This is phrased the privacy paradox phenomenon (Kokolaki 2017). Thus, people not being ready to share personal health data for usage, e.g., in research due to trust issues might be a concern.

To overcome these issues, several authors argue for new approaches to using this data and for new forms of data governance (Hafen et al. 2014; Mòdol 2019; Otto and Burmann 2021; van Roessel et al. 2017). One of these new approaches are data cooperatives (DCs). DCs are defined as "digital platform centered on data subjects who pool their PHD [personal health data], designed for secondary use of their PHD, and sustained by cooperative governance" (Mòdol 2019). They have recently become increasingly popular as they are seen as a promising way to tackle the aforementioned challenges.

Arguing the privacy paradox phenomenon, trust in data sharing would not be enough for DCs to be successful. If the value proposition of such cooperatives would be convincing enough, the privacy matter would become less of a hurdle.

Cooperatives

DCs are based on the general concept of cooperatives. There are approximately 250,000 cooperatives with more than 160 million co-owners active in the EU (European Commission n.d.). There, cooperatives need to meet several preconditions which are described in the Council Regulation (EC) No. 1435/2003. According to the independent, non-governmental organization International Co-operative Alliance (ICA), which represents cooperatives worldwide, "a co-operative is an autonomous association of persons united voluntarily to meet their common economic, social, and cultural needs and aspirations through a jointly owned and democratically controlled enterprise" (Girard 2018). ICA further describes seven principles for cooperatives: (1) voluntary and open membership; (2) democratic member control; (3) member economic participation; (4) autonomy and independence; (5) education, training, and information; (6) cooperation among cooperatives; and (7) concern for community (International Cooperative Alliance 2018). According to Bierhoff and Wienold (2010), cooperatives are based on three core-principles: the principle of membership promotion, the principle of identity, and the principle of democracy. Membership promotion is not only limited to direct financial yields but can also be other advantages on the market in comparison to solo entrepreneurship. Koopmanns (2006) provides another definition and specifies a cooperative as a "member-controlled association for producing goods and services in which the participating members, individual farmers or households share the risks and profits of a jointly established and owned economic enterprise." Within the context of health care, a fourth definition comes from the United Nations (2018): "Cooperatives represent an enterprise model that competes in the marketplace like any other, but does not need to pay returns to its shareholders, and so reinvests all its profits in improving services, thereby guaranteeing sustainability." Comparing these definitions, it becomes clear that a cooperative is an organization democratically controlled by its members who share common goals. These goals can be economical or normative. The question if a cooperative may be profitable or not, however, seems to be contested. Although it is not their primary purpose to be profitable, cooperatives are in many cases allowed to turn profit and distribute it among its members (Cordery and Howell 2017).

Against the background of the social-digital transformation, economic crises, and increasing inequalities, cooperatives have received attention lately (Apitzsch and Ruiner 2022).

Cooperatives are found in various fields such as housing (Schelisch et al. 2019), energy (Becker and Naumann 2017), and agriculture (Chaddad and Cook 2004), as well as within health and social care (Cordery and Howell 2017). Looking at the field of health and social care, several European member states have a long history of cooperative governance. For instance, cooperatives in primary care are found in the Netherlands, the UK, and Denmark (Grol et al. 2006), as well as in Spain where a large share of health care is provided by cooperatives (United Nations 2018). According to the United Nations, more than 3300 cooperatives are found in the field of health care worldwide, covering a broad range of structures and aims, including doctors' cooperatives, cooperatives managing hospitals and health care facilities or institutions focused on health promotion or disease prevention (United Nations 2018).

Within the literature, several approaches to typologize cooperatives are found (Chaddad and Cook 2004). This includes, among others, workers cooperatives, production cooperatives, or

user cooperatives. DCs are treated as a special type of cooperative, which have been recently discussed in nearly all those fields (Hardjono and Pentland 2019; Pentland et al. 2019). However, literature on DCs in the field of health care is scarce – with few examples (Blasimme et al. 2018; Hafen 2019; Hafen et al. 2014).

Objective of this paper

This review was conducted as the authors aimed to facilitate the foundation of a DC in Germany to mediate individual interests regarding data sovereignty with public and economic interests in health data.

Although cooperatives in the field of health and social care offer a lot of potential in theory, no review on cooperatives within the field of health and social care was identified, particularly not on DCs. To address this gap, a scoping review on cooperatives in this field was conducted. The objective was to specifically gather information on the structure of cooperatives in health and social care and to derive implications for their impact on the future of health and social care and (health-)data-ownership. The screening of health and health-data-related cooperatives should support the interpretation regarding their role of data within the cooperative model. Data cooperatives were considered as a useful source of information and therefore included into this review but are not prerequisites because all cooperatives in the sector are of interest. As this was not the first attempt to build a DC for the benefit of citizens, the authors intended to learn from experiences of earlier attempts. The findings do not only give an overview about what is known so far, but most of all give useful advice for implementing future cooperatives.

Methods

Within this paper the methodology of a scoping review was followed as this form of review is especially useful for mapping the scope of (scientific) literature on a particular topic. This includes identifying the nature of the literature, gathering information on key topics such as cooperative structures, and identifying knowledge gaps (Munn et al. 2018). Its methodological framework was first published by Arksey and O'Malley (2005) and later adapted by Levac et al. (2010). Contrary to a systematic review, search terms can be adjusted along the process of a scoping review (Arksey and O'Malley 2005; Peters et al. 2015). This was beneficial in our case, as the scope and nature of the literature was unclear at the beginning. To conduct the present scoping review, the guidelines of Peters et al. (Peters et al. 2015) and the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (Tricco et al. 2018) were used.

Search strategy and selection criteria

The search strategy involved a systematic literature search in nine databases. This was complemented by backwards tracking of reference lists for further relevant studies, a grey literature search of identified cooperatives in the Google search engine and a search of the first 20 pages of Google Scholar. The inclusion and exclusion criteria for all the described searches were defined during the systematic literature search as follows and used for the other search techniques as far as possible.

The systematic literature search was conducted in the databases PubMed, EconBIZ, EconLit, Scopus, Sociological Abstracts, Sociohub, WiSo, Web of Science, and Cochrane Library on the cut-off date 20 November 2020. Due to the extensive and time-consuming process of study selection and submission, the search was updated with the deadline of the 26 January 2024. The program Citavi (Swiss Academic Software GmbH, Switzerland) for literature management and the platforms Rayyan (Rayyan Systems, Inc., USA) and Covidence (Veritas Health Innovation Ltd, Australia) were used. The latter supports evidence synthesis in accordance with high scientific standards during the screening process and is also used by the Cochrane Collaboration for systematic reviews. The following keywords were applied in varying combinations and spellings for the systematic search: (1) social care, (2) health care, (3) primary care, (4) cooperative, (5) health care data, (6) health data, (7) data cooperative. The combination of search teams for PubMed as an example were:

1. ((“primary care”[Title/Abstract]) OR (“social care”[Title/Abstract]) OR (“health care”[Title/Abstract])) AND ((“cooperative”[Title/Abstract]) OR (“co-operative”[Title/Abstract]))
2. “health care data”[Title/Abstract] AND ((“cooper*”[Title/Abstract]) OR (“co-oper*”[Title/Abstract]))
3. “health data”[Title/Abstract] AND ((“cooper*”[Title/Abstract]) OR “co-oper*”[Title/Abstract])
4. “data cooper*”[Title/Abstract] OR “data co-oper*”[Title/Abstract].

The search terms had to be adapted for the requirements of each database, but it was ensured that the search terms were similar in content for all databases.

Articles were included for the title and abstract scan if they were written in English or German and if they were published before 20 November 2020, respectively, 26 January 2024. If the title and/or abstract screening indicated a cooperative settled in health or social care, articles were eligible for full-text screening.

During the full-text screening, the following additional inclusion and exclusion criteria were defined. Articles were selected for the scoping review if they contained information about the structures of specific cooperatives or described the concept of cooperatives in health or social services. Articles were excluded from the scoping review, if the publication was (1) not of a scientific nature, (2) not accessible, (3) describing cooperations instead of cooperatives or using cooperative as a verb/adjective, (4) describing the Chinese Cooperative Medical Scheme *(voluntary insurance system subsidized by the government)*, (5) only naming cooperatives without describing them, (6) providing only limited and superficial information on the cooperative, (7) published before 01 January 2000 (8) or describing a cooperative outside of the health or social care sector.

Process of study selection

For the title and abstract screening as well as the full text screening of the systematic literature search, two authors reviewed each article independently to decide on the inclusion or exclusion of the article. In case of contrary decisions on inclusion or exclusion, the authors tried to reach a consensus by discussion. If no consensus could be reached between both authors, a third author had to decide on the inclusion or exclusion of an article. Before the actual title and abstract screening, a pretest screening with the first 200 articles was performed to validate the inclusion and exclusion criteria. After the pretest, respectively, the title and abstract screening, the exclusion criteria were specified and adapted as described above.

In case of the backward tracking of the reference lists, the grey literature search and Google scholar, one researcher conducted the search and included, respectively, excluded the cooperatives. Regular meetings within the study group were held to discuss cases of doubt and make decisions regarding the review process. Figure 1 shows the flowchart summarizing the stages of the study selection.

Data extraction

According to the aim of the scoping review, data on the structure of the cooperatives from the included articles were extracted and collated in determined categories. The categories of the self-developed data extraction scheme included information about the aim and type of the cooperative, the member structure, the founding process, the structure of the cooperative, and the way of financing. Additionally, captured baseline information on authors, year of publication, activity status, and the country in which the cooperative is settled were collected.

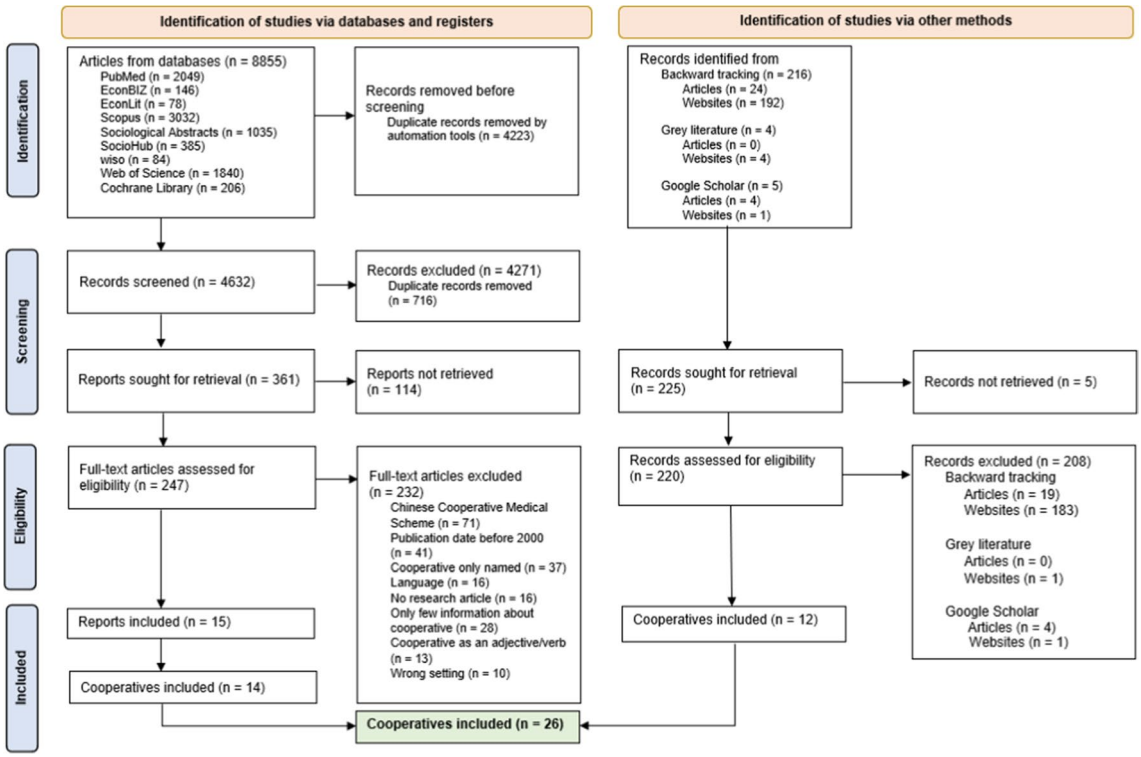

Fig. 1 Flowchart of the study selection

Results

From 8855 articles identified through the database research, 4223 duplicates were excluded (Fig. 1). The remaining 4632 articles passed the title and abstract screening as mentioned above, and 361 articles of them were chosen for the full text screening. Therefrom, 15 articles describing 14 different cooperatives were included for the data extraction. In addition to the literature search in the databases, 216 articles and websites were identified through backward tracking and were further screened. Additionally, the grey literature as well as the Google Scholar search provided four, respectively, five hits. After screening, 12 cooperatives were included for data extraction. In sum, 26 cooperatives were included in the analysis (Fig. 1) and details are displayed in Table 1. However, for some cooperatives and data categories, the information provided in the records were incomplete; therefore, the results were structured in such a way to exploit the available information in as much detail as possible. To structure the results of the data extraction, the identified cooperatives have been categorized according to their aim by founding members as follows: (1) worker cooperatives with focus on workers' rights and service provision to clients, (2) consumer cooperatives, (3) consumer and worker cooperatives, (4) cooperatives of institutions, (5) general practitioner (GP) cooperatives, (6) cooperatives as health insurance models, and (7) health data cooperatives. Some cooperatives can be accounted to more than one category; for the sake of simplicity, and to keep a clear structure in tables and throughout the paper, the cooperatives were then assigned to the best fitting category. The categories of cooperatives can take place in different settings (e.g., regional focus) or with different target groups (e.g., marginalized groups).

Worker cooperatives

For worker cooperatives two subcategories can be distinguished: worker cooperatives with focus on workers' rights and with focus on service provision to their clients.

Worker cooperatives—focus on workers' rights

Three cooperatives operating in the field of home care were identified, who differ slightly in the underlying motivation for setting up the cooperative.

The *Cooperative Home Care Associates* (CHCA) mainly aims at offering employment prospects to their members, which are economically disadvantaged women (Gunn 2004; Inserra et al. 2002). The cooperative was founded in the early 1980s and started as a sponsored community economic development program which founded worker-owned firms. After successfully completing three months of work in the care sector, the employed women get the opportunity to become shareholders in the *CHCA* (Gunn 2004; Inserra et al. 2002). The cooperative employs about 2000 people in 2022 (www.chcany.org 2022). The costs for the cooperative share are then deducted from the workers' salaries. One share is priced at $1000, the initial payment amounts to $50 and a weekly payment of $3.65 is required (Gunn 2004; Inserra et al. 2002). Annual dividends are paid based on the cooperative's profitability (www.chcany.org 2022). *CHCA* can sustain its funding by offering home care as a paid service to their clients, but also receives funding from public and non-profit institutions (Gunn 2004; Inserra et al. 2002).

Sunshine Care Cooperative aims to improve the quality of care provision and to better meet their clients' needs, which, according to them, was not possible within the rules of employment at a public care facility (Fisher et al. 2012). The cooperative was founded in 2008 by four women who were also employed in the care sector (Fisher et al. 2012). At the time of publication, the cooperative had two employees, five clients and the employees can become members of the cooperative after six months of work. However, the sustainability of the cooperative turned out to be challenging, even though funding was provided by local authorities (Fisher et al. 2011, 2012). Due to its small size and low profile, it was difficult to scale. Lack of clients and financial resources made it difficult to offer the employees a better salary than a public institution. Administrative hurdles in registering a care service business further complicated the development. The founders of the cooperative therefore maintained their employment contracts with the public institution for financial reasons and provided significant amounts of unpaid work for the cooperative (Fisher et al. 2011, 2012).

Caring Support aims at the provision of high-quality care (Fisher et al. 2011, 2012). It is a multi-stakeholder cooperative, founded by service users and care givers. One of the founders has multiple sclerosis and wanted to establish the cooperative primarily because of her experience of care, but the cooperative also has a political and socialist ethos as motivation for foundation (Fisher et al. 2011, 2012). The cooperative board consists of members, service users and care workers while employees, families, and service users are involved in cooperative decision making (Fisher et al. 2011, 2012). Except for the manager, none of the directors of the cooperative receive any reimbursement for their work; care givers are both paid and unpaid. Relatives of the cooperative members support *Caring Support* with unpaid work, for example with administrative tasks and networking (Fisher et al. 2011, 2012).

Table 1 Overview of 26 included cooperatives

Cooperative	Country	Aim of the cooperative	Members
Worker cooperatives—focus on workers' rights			
Cooperative Home Care Associates (CHCA) (Gunn 2004; Inserra et al. 2002; www.chcany.org 2022)[1]	USA (South Bronx, New York City)	Provide employment to (economically) disadvantaged women and to provide high-quality home care to its customers	Economically disadvantaged women An employee eligible to become a cooperative member after performing satisfactorily on the job for the 3-month probationary period
Sunshine Care (Fisher et al. 2012, 2011) [1, a]	United Kingdom	To improve quality of care provision and to offer services that meet the needs of care recipients	Cooperative staff eligible of membership after 6 months of employment
Caring Support (Fisher et al. 2012, 2011) [2, a]	United Kingdom	Provision of high-quality care	*No information provided*
Worker cooperatives—focus on service provision to clients			
The Multicultural Health Brokers Co-operative (MCHB) (Torres Ospina 2014; www.mchb.org) [1, b]	Canada (Edmonton, Alberta)	To promote health of immigrants and refugees through health education, community, and advocacy work	30 members, 24 non-member workers (effective in 2012) Majority of members female (49/54) and health brokers
Equal Care Co-op Limited (*Cooperative and Community Benefit Societes Act 2014* 2018; www.Equalcare.Coop 2022) [1]	England	To deliver a co-owned and relationship-based care and support service	Four categories: Supported members, advocate members, investor members, worker members Membership possible for individuals, corporate bodies and nominees of corporate bodies
Brave (www.brave.coop)[1]	Canada/USA	Prevention of drug overdose	Four categories: Labor members, investing members, customer members, steward members
Health care cooperative system in Costa Rica (Gauri et al. 2004)	Costa Rica	Introduction of market mechanisms in health care provision	Members are individuals living in the catchment area of the cooperative and receiving care from the clinics
Consumer cooperatives			
"Texel samen beter" (TSB; Texel better together) (Werner and Jellema 2018; www.texelsamenbeter.nl 2022) [1]	The Netherlands (island Texel)	Make decisions in the regional health care sector in the region itself. Promotion of the quality, supply, affordability and accessibility of care on Texel, where care is seen as the entire chain of prevention, lifestyle awareness, promotion of self-reliance, curative care and home care, all in the broadest sense. Improve the quality of care on the island and to manage its member's interests, e.g., to be independent from the mainland and to enable the elderly to stay at home as long as possible.	Full-aged Citizens of the Dutch island Texel (natural persons) Board is made up of a combination of founding and non-founding members, all volunteers 13 founding members. At the beginning 109 members; after the first recruitment campaign 600 members and after a second campaign additional 100 members In 2021: 450 members
Lucas zorg (LZ; Lucas Care) (Wagenaar 2019) [2]	The Netherlands (Amsterdam)	Providing informal home care (cleaning, attention, medical care) and preventing social isolation (people who dropped out of social/health care are offered individualized care)	Citizens from suburbs of Amsterdam-West Area, which are characterized by high percentage of ethnic minorities, high unemployment, antisocial behavior of young people, and high poverty. Care is mostly provided by lower educated female Muslims from the area

Table 1 (continued)

Cooperative	Country	Aim of the cooperative	Members
Zorgcoöperatie Hoogeloon (ZH; care cooperation Hoogeloon) (Wagenaar 2019; www.zorgcooperatie.nl) [1]	The Netherlands (Hoogeloon: rural area in the South-east)	Providing care for the elderly in the village Hoogeloon (because the regional care company stopped care for elderly due to economically inefficiency)	Citizens from Hoogeloon (2200 inhabitants); mostly the elderly in need of care. Non-members are not turned away if they urgently require services but do not benefit from reduced prices or have to buy in by paying up to two years' fees. Numbers of members in: 2015: 227 members 2018: 242 members 2019: 227 members 2020: 199 members 2021: 294 members
Group Health Cooperative (GHC) (Gunn 2004) [2]	USA (Seattle, Washington)	New way to organize health care. Idea of prepaid group medical coverage	Citizens of the Washington State region. About 600,000 members (about 1/10 of the state residents) and < 10,000 employees
Patient Critical Co-op (www.patientcritical.com)[1]	Canada	Improve Healthcare in Canada and follow the will of patients. Working to build partnerships with government, healthcare providers and businesses, find common solutions	Individual members
Savvy Cooperative (www.savvy.coop) [1, c]	USA	Enhancing health innovations through patient's experience	Patients
Consumer and worker cooperatives			
North-West Care Co-Operative (NWCC) (www.nwcarecoop.co.uk)[1]	United Kingdom (Northwich)	To provide a community whose members care about and support each other and to enable the clients to "live life well"	Three kinds of members: Principal members (mostly young adults) receiving support, Personal Assistants providing support, and supporting members (e.g., parents of clients)
Co-operative Care Colne Valley (CCCV) (www.valleycare.coop) [1]	United Kingdom (West Yorkshire)	Everyone receiving and delivering care – User Members, families, staff, and the wider community – to work cooperatively for the benefit and well-being of all	Members are the recipients of care and their families, as well as the people working for the cooperative. Individuals and organizations can also become supportive members
Care Cartrefi Cymru (CCC) (www.cartrefi.coop n.d.) [1]	United Kingdom (Wales)	Support people with mainly learning disabilities	Members are the recipients of support, as well as the employees of the cooperatives and interested members of the community
Cooperative of institutions			
Geriatric Cooperatives in Southwestern Ontario (Gutmanis and Hillier 2018)	Canada	Bring together members representing relevant cross-sectoral services, leveraging local capacity, and coordinating and improving linkages between sectors and services	Members representing relevant cross-sectoral services/institutions and families of individuals in need of care
Palliative Care Research Cooperative Group (PCRC) (Abernethy et al. 2010; https://palliativecareresearch.org/ 2022)[1, c]	USA/ international	Improve research in the field of palliative care	Researchers, representatives (research assistants, professors) from research and care institutions of various disciplines (ethics, social work, oncology, etc.) in the field of palliative care

Table 1 (continued)

Cooperative	Country	Aim of the cooperative	Members
General practitioner (GP) cooperatives			
Primary care physician (PCP) cooperatives *(no specific cooperative named, they are spread over the country)* (Giesen et al. 2011)	The Netherlands	Reorganisation/Improve-ment of after-hours primary care. Reduction of the workload of the general practitioners (GPs)	40 to 250 PCPs take care of their patients ranging from 100,000 to 500,000 citizens in one region. In 2005, about 95% of the Dutch PCPs were members of cooperatives. In total > 130 PCP cooperatives serve more than 90% of the Dutch population
Cooperatives as health insurance models			
Ithaca Health Fund (IHF) (Gunn 2004; www.ithacahealth.org) [1]	USA (Ithaca, New York)	Achieve economic development for poor communities in the wealthy nation. Informal insurance plan; but also keep costs low by negotiation of discount prices for services (including alternative medical services) and support the local economy	Non-/under-insured citizens of New York (estimated with about 1/3 in the area) and health care providers (physicians, massage therapists, etc.) In 2002: > 500 members and 120 member health care providers. Nowadays active membership of 700 people
Common Ground Healthcare Cooperative (CGHC) (Giaimo 2013; www.commongroundhealthcare.org)[1]	USA (Wisconsin)	Provide individuals and small businesses with access to health insurance, as they may have problems finding affordable health insurance in comparison to large employers	Small businesses of 50 or fewer employees, nonprofits, and individuals in seven southeastern Wisconsin counties Members are individuals covered under health insurance policies issued by the cooperative. For the individual market, members must reside within the service area of the cooperative, and for the group market, the employer's principal place of business must be located within the service area of the cooperative
Health data cooperatives			
Sc polypoly coop SCE mbH (www.polypoly-citizens.eu/de/)[1]	Germany	"enabled by the community (its members), the cooperative strengthens citizens within data ecosystems by (further) developing technology to strengthen data sovereignty: building a decentralized infrastructure for the storage of personal data that makes it possible to retrieve, store, manage, use, share and rent data."	Citizens aged 18 and older, mainly from Europe, but explicitly excluded are citizens with U.S. citizenship. Legal entities, such as companies are not eligible for membership. 333 members at 15.12.2020
MIDATA Cooperative (Gille and Vayena 2021; www.midata.coop 2022) [1]	Switzerland	Member-owned data cooperative that contributes to research and ultimately to the benefit of society via aggregated data stored by people in their MIDATA account	Individuals residing in Switzerland
Salus Coop (www.salus.coop)[1]	Spain	Citizen data cooperative for non-profit health research	36 Cooperative members named on website
Healthbank Cooperative (www.healthbank.coop 2021) [1]	Switzerland	Health data exchange	Membership open to everyone Everyone able to buy crypto-shares of an organization can be shareholder of the cooperative
Holland Health Data Cooperative (https://www.linkedin.com/company/holland-health-data-cooperative; www.hhdc.nl)[1]	The Netherlands	To empower citizens and patients to effectively manage their own health; to build an alternative to IT companies in health data economics; to enable the development of a health based economy	*No information provided*

[1] Active;[2] Inoperative

Secondary classification: [a] Consumer cooperative, [b] Worker cooperatives—focus on workers' rights, [c] Health data cooperatives

Worker cooperatives—focus on service provision to clients

Three worker cooperatives with focus on service provision and one general description of a health cooperative system in Costa Rica were identified.

The Multicultural Health Brokers Cooperative (MHCB) in Canada was founded in 1998 and is dedicated to improving the living conditions of especially female refugees and immigrants (Torres Ospina 2014). This improvement is achieved by promoting their health through education, community, and advocacy work. Being a member of *MHCB* implies being a decision-maker, owner, and employee of the cooperative at once. However, employees can work for the cooperative without membership. Their opinions are then recognized in decision-making, but they are not entitled to vote on decisions. A membership further requires working for the cooperative for at least two years (Torres Ospina 2014). The cooperative had 14 members in its founding phase (www.mchb.org). In 2012, the number of working members amounted to 30 and the number of workers without membership was 24 (Torres Ospina 2014). The only information provided about the founding process is that it was supported by appointed consultants. The organizational structure of *MHCB* is based on the cooperative's board of directors and its management. The board consists of five to nine representative members which supervise the implementation of the cooperative's policies and maintain the business relationships (Torres Ospina 2014). The management is responsible for operative tasks such as program development or coordinating finances and resources. However, all strategically important decisions are made with all members at regularly held general meetings. *MHCB* mostly finances itself through short-term contracts with local and national sources and through funding proposals. From 2008 to 2009, for example, a total of US$ 2.1 million was raised (Torres Ospina 2014).

Equal Care Co-op is a registered and regulated personal care provider based in England which pursues to establish a co-owned and relationship-based care and support service (*Cooperative and Community Benefit Societes Act 2014* 2018). Personal care is the main business, but the cooperative also provides services regarding mental health and well-being, administrative support, and informal advocacy (www.equalcare.coop 2022). There are four membership categories which are accessible to individuals, corporate bodies and their nominees and require purchasing at least one cooperative share with a value of £1: (1) Supported membership, (2) advocate membership, (3) investor membership, and (4) worker membership. A supported membership is accessible after one month of support at a minimum of two hours a week while an advocate membership is reserved to family and friends of care recipients which are not eligible for membership themselves. Membership is not obligatory for receiving care in general though. Worker members get paid or work on a voluntary basis (*Cooperative and Community Benefit Societes Act 2014* 2018). There was no information available about the founding history of *Equal Care*. The cooperative board consists of at least three members while its composition should correspond to the number of members in each membership category. Every member has one vote although the votes of investor members are limited to a weight of 10% of the final vote. As a multi-stakeholder cooperative, it is owned by care givers and care recipients (*Cooperative and Community Benefit Societes Act 2014* 2018). Contributions of care givers and recipients are an important component of the cooperative's financing. Care giver's charge £14 to £18 per hour of care and deduct 5% of their fee as cooperative contribution while care recipients additionally pay 15% of the hourly fee as contribution (www.equalcare.coop 2022).

Brave, based in Canada and the USA is a multi-stakeholder and platform cooperative which offers technology tools aiming to prevent individuals from drug overdose (www.brave.coop). The cooperative is owned and governed by its members although membership is not necessary for using the cooperative's technology. *Brave* distinguishes four categories of members: (1) labor members, (2) investing members, (3) customer members, and (4) steward members. Steward membership is reserved for members who helped establish *Brave*. These members have a vote in cooperative decisions but do not receive dividends. Membership requires purchasing one share of the cooperative while the fee of a share differs for the membership categories. Customer members pay $10 per share, labor members $100 and investor members $1000. Investments are valid starting from $10,000. Membership in multiple categories is possible too, but each person can only purchase one share of each membership category. Membership is optional for all involved parties except for *Brave* employees. Again there was no information provided on the founding process of *Brave*. In case of a surplus, $50,000 or 30% of it are put aside, debts are paid, and investors receive 8% of their investment as payback. The remaining surplus is distributed between the eligible member categories. The labor and customer category receives 35% of the remaining surplus each and the investing members 30%. Within the categories the individual dedication of a member to the cooperative, quantified by a scoring system, defines the allocated surplus (www.brave.coop).

The *health cooperative system in Costa Rica* was established aiming to implement market mechanisms and to achieve more efficiency in health care provision. Therefore, public primary health care clinics were transformed to health cooperatives (Gauri et al. 2004). Members of the cooperative were individuals who lived in the catchment area of the cooperative and received health care from the clinics. Thus,

membership served as a form of health insurance. Non-members could also obtain primary care from the cooperative clinics in exchange for fees that usually would have been charged at a public clinic. However, these fees were de facto not charged. The first cooperatives were founded in 1988 (Gauri et al. 2004). Employees of the respective clinic established the cooperatives by taking over the responsibility for a yearly fee of about US$1 from the Costa Rican Social Security Institute (CCSS). Health care was then provided solely according to the guidelines of the CCSS. The structure of the cooperative system was characterized by employees not only being shareholders but also partners of the cooperative. The partnership implied that parts of their salary were retained to build up social capital (Gauri et al. 2004). Although the cooperatives were autonomous and non-governmental institutions, they were bound to requirements of the CCSS and the Ministry of Health such as presenting financial reports, being limited in service provision, or being supervised by the CCSS. The election of the administrative board and management took place within the cooperative. The board was elected by the general assembly every two years and in turn appointed the management. For the estimated number of members, the cooperative received an annual capitation fee, which they could freely dispose of, and which was exempted from income tax. This income was distributed to the employees as shareholders of the cooperative. Further profits were reinvested into the cooperative or distributed to the members (Gauri et al. 2004).

Consumer cooperatives

Six consumer cooperatives were identified, mostly born from the need for regional or individual health and social care.

The cooperative *Texel samen beter* (TSB; *Texel better together*) is located on the Dutch island Texel and aims to improve the regional quality of health care and to manage its member's interests. The cooperative achieves this by enhancing quality, supply, affordability and accessibility of health care (Werner and Jellema 2018; www.texelsamenbeter.nl 2022). Care is seen in a broad sense from prevention, curative care, and home care (www.texelsamenbeter.nl 2022) and includes, e.g., to be individual from the mainland and to enable the elderly to stay at home as long as possible (Werner and Jellema 2018). The focus lies on the coordination of services rather than providing services. The cooperative is supported by a health insurance company and a city council member for health care (Werner and Jellema 2018). However, it seemed challenging to engage the members, e.g., the elderly in Texel (Werner and Jellema 2018). The board consists of voluntary founding and non-founding members; a short period with paid staff engaging with the relevant stakeholders has failed, so this was no longer considered (Werner and Jellema 2018). Members of TSB are individual persons of full age who are citizens of the island, but non-members might also profit from the cooperative (www.texelsamenbeter.nl 2022). The founding process started in 2013 and went on for several years, starting with a dozen motivated board members engaging in network activities with health care actors, but without a shared philosophy. It took several years and changes of board members, including the retirement of the former very engaged president, to define clearer goals and the alignment of perspectives (Werner and Jellema 2018). Therefore, recruitment of members and engagement with stakeholders grew slowly. Starting with 109 members and after running several recruitment campaigns, TSB had about 700 members in 2017 (Werner and Jellema 2018) and about 450 members in 2021 (www.texelsamenbeter.nl 2022). Membership fees were €100 for the first two years from 2014 on and €25 each year afterwards and could be reimbursed from the health insurance (Werner and Jellema 2018). This resulted in voluntary membership and therefore the cooperatives' income was very low (Werner and Jellema 2018).

The Dutch cooperative *Lucas Zorg* (LZ, *Lucas Care*) is located in a suburb in Amsterdam-West and aims to offer informal home care (e.g., cleaning, attention, medical care) and care for people in social isolation like those who dropped out of social or health care (Wagenaar 2019). Members are the citizens of the suburbs. According to Wagenaar (2019), these suburbs are characterized by a high percentage of ethnic minorities, high unemployment, antisocial behavior, and high poverty. *LZ* was part of a bigger community initiative called Lucas community (LC), but there were no details provided on the founding process, the statutes, or the exact membership fees – except that they are low (Wagenaar 2019). LC rents an abandoned school from the city council for a nominal price and offers the space, trainings, and support from external entrepreneurs for members, who are mostly female Muslims from the area. They can propose a small business and as voluntary peers they are familiar with the local circumstances. On the one hand, this is in favor of institutions because unreachable clients can be addressed. On the other hand, institutions question the quality of work and claim requests that cooperatives barely can provide, e.g., expensive and tedious certificates and years of education to be reimbursed for their care (Wagenaar 2019).

The Dutch *Zorgcoöperatie Hogeloon* (ZH, *health cooperation Hogeloon*) is also part of LC and provides care for elderly residents in the village Hogeloon in the Southeast, where the regional care company stopped their offers because they rated them as economically inefficient (Wagenaar 2019). In 2021, ZH had 297 members who were the - mostly elderly - citizens of Hogeloon (www.zorgcooperatie.nl). Non-members can also use the services but do not get discounts. The founding procedure started in 2005, but no further details were provided. Volunteers provide informal services such as household and gardening tasks, transport or

day-time occupation and are partly volunteers from vulnerable groups (Wagenaar 2019). ZH contracts care providers for formal care, which are paid by personalized "budget" of the residents. The personal budget is part of a national program for home care provision. The membership fee is 20 € per year. The cooperative employs a coordinator at half-time and four service providers at zero-hour contracts (Wagenaar 2019). The board consists of members.

The *Group Health Cooperative* (GHC) was founded in Seattle, USA, and is also a health insurance company (Gunn 2004). It aims to organize health care in a new way and follows the idea of a prepaid group medical coverage (Gunn 2004). Members are the citizens of the Washington State region, and with 600,000 members and 10,000 employers, it is the largest health care organization in the country (Gunn 2004). In 1947, farmers, consumers, patients, and people from other cooperatives founded *CHG* and started with buying a small hospital. CHG affiliated with a health company in 1997 and owned several health care facilities and affiliations with 48 other care providers in the early 2000s (Gunn 2004). CHG has three main characteristics: its cooperative structure, its focus on prevention, and its competitiveness with for-profit insurers. Membership is for free (Gunn 2004). CHG is a complex organization where members own and run the cooperative by, e.g., electing the board, making changes to bylaws, and shaping policies (Gunn 2004).

The *Patient Critical Coop* is located in Canada and aims to build partnerships with the government, health care providers and businesses to find common solutions and therefore to improve health care in Canada (www.patientcritical.com). Members are individuals and membership fees are €20 per lifetime (www.patientcritical.com). *Patient critical coop* was founded in 2017 to serve the will of patients and was the first of its own kind in Canada. Members can elect directors, vote on businesses and volunteer (www.patientcritical.com).

The *Savvy cooperative* enhances health innovations through patients' experiences by bringing together researchers and companies with patients in the USA (www.savvy.coop). Members are patients who participate in, e.g., surveys, interviews or product testing. Therefore, they receive a reward in the form of gift cards, discounts, or coupons (www.savvy.coop).

Consumer and worker cooperatives

Three consumer and caregiver cooperatives were identified, where both groups are equal members and shape the cooperative. Additionally, supportive members are also welcome.

The *North-West Care Co-Operative (NWCC)* was established in 2019 as an innovative person-centered approach to deliver more than just care (www.nwcarecoop.co.uk). Care providers, clients, and supporting members are equivalent members of the cooperative and strive to form a community where all members take care of and support each other actively rather than being only a care provider organization. Founding members were parents of adult children who are receiving support and therefore had the idea to build a community that could outlive the parents and empower the clients to "live life well" without them (www.nwcarecoop.co.uk). Clients decide about the activities with the carers, the so-called Personal Assistants. This may be cooking or going for a walk and provides clients more independency while taking off the pressure of the parents. The cooperative has no step-by-step plan, but rather see its development as an explorative journey. *NWCC* is registered with the Care Quality Commission as a domiciliary care agency and consists of a service and a location from which the service operates. The service company is a not-for-profit business and is responsible for the operational running of the cooperative, e.g., holding the liabilities of the business, employing the Personal Assistants, and managing the outputs (www.nwcarecoop.co.uk). The cooperative itself is registered as the location and is made up of the members who are the decision makers. The budget and the associated possible support are defined with each client in advance, mostly for one year. The costs are charged per month and an account for each member records the actual support costs, which can be adapted to the usage and needs of the client. *NWCC* charges a small amount to cover the costs of the cooperative (www.nwcarecoop.co.uk).

Co-operative Care Colne Valley (CCCV) is a 2019 founded British multi-stakeholder cooperative situated in West Yorkshire (www.valleycare.coop). The cooperative was set up by a group of local people motivated by different experiences with care (https://www.communitycatalysts.co.uk/story/cccv-a-community-co-operative-approach-to-care/). Both the people receiving care and the people working at the cooperative mostly in the home care sector can hold a share in the cooperative. Additionally, any legal or natural person can buy a "community share." This gave the founding process a boost with 132 people investing £ 80,000. The business operates on cooperative principles and is a member of cooperatives UK (https://www.communitycatalysts.co.uk/story/cccv-a-community-co-operative-approach-to-care/). As "staff members" they do not necessarily recruit people with previous training in the delivery of care, but rather look for "kind, caring, empathetic individuals with a loving heart who want to dedicate their time to helping care for people" (www.valleycare.coop). After on-boarding they train those individuals for their tasks as carers. Each "User Member" (the recipients of care) have their own plan of care adjusted to their needs. They either need to cover the cost of care themselves, or can be supported, e.g., by the government, if eligible (www.valleycare.coop).

Care Cartrefi Cymru (CCC) is a Welsh cooperative mainly aiming at supporting people with learning disabilities (www.cartrefi.coop n.d.). With 1200 employees they

support 650 people. *CCC* is designed as a multi-stakeholder cooperative. This means that the carers as well as the recipients of care are members of the cooperatives. Besides that, organizations and individuals can become members to support the work done by the cooperative. They deliver mainly domiciliary care to people with learning disabilities and other vulnerable groups but also organize short periods of being away from home to enable family carers to have some free time (www.cartrefi.coop n.d.). They became a cooperative in 2016 but were founded in 1989 as a not-for-profit charity. The cooperative is governed by a board of elected member representatives and is led by democratic principles (www.cartrefi.coop n.d.).

Cooperatives of institutions

Two resources could be identified describing cooperatives where members are representatives of institutions (e.g., universities or cross-sectoral services). Both of those cooperatives are associations of health care institutions.

The *Geriatric Cooperatives of Ontario* (Gutmanis and Hillier 2018) were founded in Canada in 2012 and are centered around, led, and administered by a hospital with mental health care beds. The geriatric cooperatives aim to enhance the quality of care for their patients by building local professional networks for the care of geriatric patients. Members are representatives from cross-sectoral institutions and relatives of geriatric patients. The cooperatives are not dependent on extra funding, as they present an intersectoral cooperation between already funded institutions (Gutmanis and Hillier 2018).

The *Palliative Care Research Cooperative* (*PCRC*) aims to enhance the ability of conducting meaningful research in the field and was described as an association of several researchers and multidisciplinary research institutions and led by a steering committee (Abernethy et al. 2010). *PCRC* was founded in 2010 by a group of investigators with backgrounds in palliative care research and aimed to generate high-quality evidence on prioritized, clinically relevant topics in palliative care (Abernethy et al. 2010). The group intends to decrease the burden of suffering and to improve outcomes for patients with life-limiting illness through their work (Abernethy et al. 2010). Multi-site and multi-institution studies were considered as an appropriate approach so that the *PCRC was* established to facilitate a cooperative organization between institutions. *PCRC* identifies a potential lack of funding as a risk of the cooperative but appraises funding to be easier for a group than for individual research institutions. PCRC was funded by the National Institute of Nursing Research (https://palliativecareresearch.org/ 2022).

General practitioner (GP) cooperatives

Although no specific GP cooperative was described in the reviewed literature, a narrative review about the quality of the after hour primary care in the Netherlands was included to provide information about those cooperatives (Giesen et al. 2011). Around the turn of the millennium, Dutch primary care physicians (PCP) joined together in cooperatives with the aim to reorganize and improve the after-hours primary care and to reduce their workload (Giesen et al. 2011). They developed from small rotation groups to large-scale PCP cooperatives, mostly located in or near a hospital. In 2005, approximately 95% of the PCPs in the Netherlands were members of cooperatives and more than 130 PCP cooperatives were responsible for more than 90% of the population (Giesen et al. 2011). This means that 40 to 250 PCPs are caring for about 100,000 to 500,000 patients in one region. Patients call the PCP cooperative via a regional telephone number, where trained and supervised nurses conduct telephone triage and divide patients into telephone advice, center consultation, or home visits by PCPs (Giesen et al. 2011). PCPs take turns in on call-shifts within one of the three working areas, with a fixed salary of 65 € per hour and only an average of four hours duty per week, in comparison with formerly 19 h (Giesen et al. 2011). Next to the reduction of the workload, PCPs reported a better job satisfaction and satisfaction with the organizational model. Additionally, patients were also satisfied with the care provided by the cooperatives, despite some areas of improvement mostly regarding personal and structural difficulties (Giesen et al. 2011). No information about the founding process and financing or the involvement of governmental structures is provided.

Cooperatives as health insurance models

Two cooperatives were identified as health insurance models.

Gunn et al. (Gunn 2004) describe an at that time non-profit-start-up insurer in Ithaca, New York. The so-called *Ithaca Health Fund* aims at achieving economic development for poor communities in the wealthy nation. Therefore, it provides an informal insurance plan while simultaneously lowering costs by negotiating discounts for services and supporting the local economy (Gunn 2004). Members are non-insured citizens receiving non-limited basic low-overhead service and health care providers (e.g., physicians or massage therapists) listed in the fund. In 2002, more than 500 members and 120 member health care providers were counted (Gunn 2004), and nowadays it counts 700 members (www.ithacahealth.org). The *Ithaca Health Fund* focusses on solving local problems based on the members' needs and sets funds aside for community health programs (Gunn

2004). It was founded in 1997, had 12 board members, and was run by volunteers. Individual members pay yearly fees of $100 for adults, $75 for partners, $50 for a child, while member health care providers pay between $30 and $100 (Gunn 2004).

The *Common Ground Healthcare Cooperative* (CGHC) aims to provide individuals and small businesses in Wisconsin, USA, access to health insurance. Usually these two groups have, in comparison to large scale employers, difficulties finding affordable health insurance (Giaimo 2013). Members are individuals, businesses with less than 50 employees, and nonprofits with their principal place of business in the service area of the cooperative (Giaimo 2013; www.commongroundhealthcare.org). CGHC was founded in accordance to the Affordable Care Act (ACA), which requires cooperatives to provide health insurance to individuals and smaller businesses with aggravated access to affordable health insurances (Giaimo 2013). Staff and board members come from the health care industry, health care management, and consumer representatives. In 2019, the board consisted of nine voting members and had 145 employees (www.commongroundhealthcare.org). *CGHC* was funded by the government in 2012 with up to $56.4 million to cover startup costs (Giaimo 2013) and was profitable by 2018 (www.commongroundhealthcare.org). CGHC's challenge is to compete in the well-established market and to overcome political and technical challenges, partly because of the restrictions by the ACA (Giaimo 2013).

Health data cooperatives

Five health data cooperatives were identified.

Pc polypoly coop SCE mbH is a Berlin based citizen cooperative for data governance, that has set the goal of strengthening the data sovereignty of its members (www.polypoly-citizens.eu/de/). To this end, a decentralized infrastructure was created that enables the storage, management, and use of personal data, which can also be shared or rented out. The decision on whether data may be donated or rented out lies solely with the citizens. In some cases, data can be traded commercially, and the monetary funds acquired are distributed to all cooperative members. All European citizens who are 18 years or older may become members of the cooperative (www.polypoly-citizens.eu/de/). However, an explicit exclusion criterion for membership is U.S. citizenship (to avoid litigation in U.S. courts) and legal entities such as companies. The project was founded in 2020 with the support of numerous private supporters. As of mid-December 2020, there were 333 members in the cooperative. The cooperative is partly financed by membership fees of 5€ per member while half of the fees are withheld for legal reasons. In the long term, the goal of the data cooperative is to generate revenue from the data made available for rental and sale. The cooperative offers personal and person-related data, which are independently imported into the database by the members. The focus is primarily on social media and other platforms, but less on health data. In PolyPedia, a common database, analyses and meta-insights are calculated and stored (www.polypoly-citizens.eu/de/).

The Swiss data cooperative *MIDATA* was founded with the aim to enable secondary use of personal citizen data through a platform to manage data access, release, and data integration (Gille and Vayena 2021; www.midata.coop 2022). The focus of this cooperative is on data use in the context of medical research projects, especially of the ethical and legal aspects. The data will be stored and managed by the citizens themselves in a secure IT platform available to members and non-members of the cooperative (Gille and Vayena 2021; www.midata.coop 2022). According to *MIDATA*, the cooperative will particularly strengthen data protection, data ownership, and informed consent. The cooperative was founded in 2015 at the Swiss Federal Institute of Technology Zurich and Bern University of Applied Sciences by a group of researchers. Only residents of Switzerland can become members. Similar to *PolyPoly*, the cooperative is financed by providing services or data transactions via the platform (Gille and Vayena 2021; www.midata.coop 2022). A special feature at *MIDATA* is the data ethics council, which is made up of three to seven members who are elected every two years. These members should not be members of the administration at the same time. *MIDATA* supports the establishment of national and regional *MIDATA* cooperatives that share the infrastructure of the data platform (Gille and Vayena 2021; www.midata.coop 2022).

Salus Coop is a Spanish citizen data cooperative founded in 2017 that aims to enable data donations for non-profit health research (https://www.saluscoop.org 2023; www.salus.coop). With the support of the Mobile World Capital foundation and the consultancy "Ideas for Change," the "Salus Common Good" license was developed based on citizen preferences, allowing the donation of data for research under five conditions: (1) use for health research, (2) use by non-profit entities, (3) open sharing of the results of the conducted research, (4) anonymization of the data at the highest possible level, and (5) use of the data until the consent of the donor is withdrawn (https://www.saluscoop.org/ 2023). The Salus Common Good (SCG) License may be used by research projects that adhere to the conditions above. This gives projects access to members' pseudonymized health research data. No information about funding streams can be found on the website. Currently, the data cooperative has 36 members (https://www.saluscoop.org/ 2023).

Founded in 2019 in Switzerland, *Healthbank Cooperative* provides a platform for the exchange of health data, which can originate from any source and can be in any format (www.healthbank.coop 2021). Membership is generally

open to anyone. Anyone who can buy crypto shares of an organization can become a shareholder of the cooperative. The cooperative is funded through Initial Coin Offerings (ICOs) and Security Token Offerings (STOs). ICOs are a way of raising funds in an unregulated environment by offering a cryptocurrency token that can then be held or traded. Such crypto shares are backed by tangible assets such as stocks, shares, or even profits of the company. In this case, they allow for shareholdings and dividends (www.healthbank.coop 2021). To become a member of the cooperative, at least one share of CHF 100 must be purchased. After that, users have full control over their data and can withdraw the sharing of their anonymized data at any time for any reason. If authorized, the data can be shared with any partners, such as doctors, care teams, relatives, and anyone else who has an internet connection. Researchers can purchase the data from the cooperative, which compensates its members in return. A prerequisite for such trading is the informed consent from participating users. Currently, integration of some health data types and sources is possible and a gradual expansion is planned (www.healthbank.coop 2021).

The *Holland Health Data Cooperative* (HHDC) was founded in 2017 by several private and public institutions with the goal of empowering citizens to manage their own health and providing an alternative to IT companies in the health data economy (www.hhdc.nl). The cooperative aims to collectively use data in the interest of its members, who always have control over their data and can release it for the purpose of health research. The data is intended to improve prevention, self-management, products, services, and treatments. Revenue generated from the sale of the data is reinvested in the health care industry (www.hhdc.nl).

Discussion

During the process of our scoping review, 26 cooperatives described in papers and websites were identified. However, the degree of information as well as type of information made available in these sources varied tremendously. This made it challenging to compare the different structures of identified cooperatives as well as their aims and demographic features.

During the analysis, different types of cooperatives in health and social care across cultural and geographic contexts could be identified. The results reveal a common denominator: They try to tackle and overcome existing barriers in their field such as working conditions or unequal health care. Overall, they try to follow what Mackay, Carne, and Beynon-Davies (Mackay et al. 2000) call a humanistic, democratic, or even utopian approach.

While there is a long tradition of assessing cooperatives from different perspectives in scientific publications, the findings show that this does not appear to apply to health (data) cooperatives. The publications and websites of the identified cooperatives often do not provide this information in detail, or at all. Instead, the websites mainly provided information on general aims and principles rather than facts or reports about the cooperative structure. This increases the necessity of conducting more on-site research, which could be very promising as cooperatives might "fly under the radar" in recent discourses on the digital transformation. Moreover, they might even have untapped ideas of higher relevance in the discourse on the digital transformation of health and care than realized as they address multiple challenges by applying digital tools and new ways of governance.

Nevertheless, with respect to these issues described above, the review allowed us to derive five common challenges from the present results that (data) cooperatives in the health and social care sector must face in order to be successful:

(1) Salary structures: Health and social care cooperatives often struggle to obtain long-term, sustainable financing. This can partly be attributed to the circumstance that cooperatives typically emerge from a bottom-up movement. As a result, most new cooperatives of this type do not have a large budget available. Many cooperatives rely on donations and support from subsidies, especially in their founding phase. To raise such funds, a sufficient amount of people must be convinced by the idea of the cooperative. Since cooperatives tend to be a grassroots movement, a consensus must be established among potential members, which can take more time depending on the group. This also relates to questions about how to handle the health data collected in the cooperative, the sale of which finances some of the data cooperatives (www.healthbank.coop 2021; www.polypoly-citizens.eu/de/). Another challenging part is the filling of important corporate positions by volunteers, who often run the organization without any financial reimbursement. The voluntary nature of participation implies that reliability is not always given. A high degree of idealism must prevail on the part of the volunteers and a real added value must be recognized in the cooperative. However, since the volunteers are often professionally trained in other contexts and perform the activities involved in the founding on a part-time basis, professionalizing the cooperative is another challenge.
(2) Cooperating with other providers and surrounding institutions: Cooperatives are often in competition with commercial providers in terms of the services they offer (Fisher et al. 2012). Forming cooperations can be an opportunity to secure the cooperative's financial base and to maintain the cooperative work. As the results of

this work showed, such cooperations are often formed with public or rather governmental institutions. These have a politically motivated interest in promoting the region-specific services of the cooperatives. However, the cooperatives also risk losing their autonomy to meet the need for voice and control of their cooperation partners. The *health cooperative system in Costa Rica* (Gauri et al. 2004) is a suitable example of how a cooperation with local authorities enabled the implementation of the cooperative system in the first place, but at the same time strongly regulated the cooperatives' scope of action. This also underlines the importance of the national context of any such endeavor, due to legal, cultural, and other differences between countries. Moreover, the cooperation can be fragile because the power might be unequally distributed (Wagenaar 2019). Additionally, institutions might ask for prerequisites the cooperatives barely can provide, e.g., the Dutch cooperative *LZ* was asked for a formal certificate to be able to provide formal care, which requests several years of professional training (Wagenaar 2019).

(3) Building an identity and recruiting potential members: To successfully recruit new members, the identity finding process of every cooperative is a difficult but crucial step. The identity of a cooperative has a great influence on the organizational performance and subsequently on what the cooperatives offer as benefits for potential members and stakeholders. While defining its own identity, a cooperative has to weigh internal pressure against external expectations (Werner and Jellema 2018) and must have the capacity to react to heterogeneous stakeholders. Differing opinions, the change of board members and the exit of well-known leaders can significantly affect the process of establishing identity (Werner and Jellema 2018). A defined identity leads to clarity about the cooperative's structure and enables the cooperative to present potential benefits and advantages to stakeholders and future members. If potential members do not have a clear idea what to expect and what is expected of them, they are unlikely to join the cooperative. This will likely have a negative impact on the growth of the cooperative (Werner and Jellema 2018). This is especially relevant for DC, which needs a significant number of members, who donate their data, to function properly.

(4) Motivation of members to participate actively: A common challenge for cooperatives after recruiting members is to motivate them to participate actively and, in the case of DC, share their data. The cooperative therefore needs to develop a business model that is rewarding for its members and provides measurable value. In addition to a strong vision (Werner and Jellema 2018) that motivates members to commit to common goals over the long term, additional value propositions should be created to make participation in the cooperative attractive. One approach is reimbursement programs, where membership fees can be refunded if members participate in partner health plans (Werner and Jellema 2018). However, once members have shared their information and benefits are free, there is no need for members to actively participate. Unfortunately, without active members, cooperatives do not build capital or generate money that can be redistributed among members.

(5) What makes a cooperative a cooperative rather than a cooperating network? Finally, the fifth challenge seems to be a more fundamental one. The principles described by each cooperative vary and are often not transparent. Due to the lack of shared information on cooperative websites and in publications, it is often unclear whether they really function as cooperatives or if they are more likely acting as a network of cooperations. For example, the *Geriatric Cooperatives of Ontario* (Gutmanis and Hillier 2018) or the *PCRC* (Abernethy et al. 2010) rather seem to be a cooperating network of individual institutions. By legal standards, the *GHC* (Gunn 2004) was never a cooperative and appears rather like a corporation in the health sector, while *TSB* recently changed their legal form from a cooperative to an association to save fees (www.texelsamenbeter.nl 2022). Compared to the principles issued, for example, by the International Cooperative Alliance (International Cooperative Alliance 2018), these institutions seem to interpret the term cooperative in different ways. The same applies to the GP-cooperatives (Giesen et al. 2011) as it remains unclear to what extent these can be seen as cooperatives in the narrow sense. In these cases, a debate arose among the authors of the present review on whether to include the cooperatives or not. Although these cooperatives may not be cooperatives according to the provided definition and legal form, useful information was derived from them which therefore, in the eyes of the authors, justifies their inclusion.

In contrary to those challenges, several benefits of (data) cooperatives could be identified:

(1) Improvement of conditions: The engagement in a cooperative could improve the working conditions of the employees in some of the cooperative examples. The working hours were reduced in the GP cooperatives (Giesen et al. 2011) and people with poor career prospects participating in the *CHCA* were given new perspectives (Gunn 2004; Inserra et al. 2002). Further, the care receivers' situation seem to be improved. Marginalized groups or groups difficult to reach have been addressed by cooperatives such as *LZ* and *ZH* (Wagenaar 2019).

(2) Stronger together: Joining forces strengthened the projects and the intention of its members. The regional focus

of several cooperatives was an advantage because (founding) members knew their region, stakeholders and local challenges and therefore could elaborate regional solutions. Further, the motivation of cooperative members was expectedly higher as they engage in a cooperative to change their environment for the better. Members had the opportunity to get socially involved and contribute actively to the improvement of local health promotion, e.g., as in *NWCC*, *CCCV*, and *CCC* (www.nwcarecoop.co.uk; www.valleycare.coop; www.cartrefi.coop n.d.). Additionally, even non-members benefited from the offers of the cooperative (Gauri et al. 2004; Wagenaar 2019; Werner and Jellema 2018). Synergies were exploited, e.g., engagement with the municipality or other institutions had a positive influence on the success of the cooperative. For *LZ*, the city council granted discounts on real estate (Wagenaar 2019), while for *CGHC* even governmental funding was provided (Giaimo 2013). Cooperatives benefit not only from financial and structural support but also a degree of credibility. Thus, both sides can benefit from such cooperation agreements.

(3) Support of research: Members can actively support research by donating their health data. Several cooperatives, especially the consumer and data cooperatives, use their members' data for research purposes. Additionally, the research of palliative care was revolutionized by founding *PCRC* (Abernethy et al. 2010). The collaboration of all member institutions enhanced the exchange of information and therefore improved care.

(4) Data governance: Regarding DCs, the users have the power over their own data through data sovereignty. The DC will provide a platform where members can enter their data and access, share, and delete their own information at any time. This distinguishes the DC from other (commercial) data management options.

Limitations

Accessing the desired information about existing cooperatives proved difficult due to a lack of transparency and uncertainty as to whether they were cooperatives and not merely cooperative networks. For example, many papers emerged on the *Chinese Cooperative Medical Scheme*, which does not meet the cooperative definitions, as the term "cooperative" is presumably used in the sense of a joint effort and not to depict a business model form. In addition, we rarely could verify the cooperative principles in our identified cooperatives due to the lack of publicly available relevant information. Furthermore, the question arises if (data) cooperatives will meet their ideals and be successful in a long-term perspective, which can barely be answered due to the scarcity of data. Finally, the characteristics of our topic led to partly diffuse results. Due to the low availability of scientific literature, for example, the inclusion criteria had to be extended, which further led to less precise hits and publications of varying quality. This is partly because very few cooperatives were founded out of a scientific research context. The inconsistent use of the term cooperative also led to the identification of heterogenous organizational forms, which were thus difficult to compare.

Conclusions

The findings of our review show that scientific information about cooperatives in health and social care, in general, and data cooperatives, in particular, is often scarce and incomplete. Based on our scoping review, we do not only present an overview of the existing information, but we were also able to identify the main barriers to successfully build a (data) cooperative and to also illustrate the benefits of doing so. Therefore, our paper significantly adds insight into the current landscape of (data) cooperatives as well as their structural organization and management.

From a scientific point of view, especially DCs hold the potential to accelerate, inform, and motivate research by allowing access to a great number of relevant data sets, such as for cancer research. From a public point of view, (data) cooperatives hold the power to strengthen regional health care structures by building cooperation networks with local providers. On a political level, (data) cooperatives can potentially influence local decision makers and, for example, thereby improve urban planning. From an individual point of view, (data) cooperatives can increase the empowerment of the users and enable them to positively shape their own environment.

However, in order to be successful, (data) cooperatives have to overcome the illustrated challenges and barriers.

Abbreviations *ACA*: Affordable Care Act; *CCC*: Care Cartrefi Cymru; *CCCV*: Co-operative Care Colne Valley; *CGHC*: Common Ground Healthcare Cooperative; *CHCA*: Cooperative Home Care Associates; *DC*: Data cooperative; *EU*: European Union; *GDPR*: General Data Protection Regulation; *GP*: General practitioner; *ICA*: International Co-operative Alliance; *LZ*: Lucas Zorg; *NWCC*: North-West Care Co-Operative; *PCP*: Primary care physician (*Managing Hybrid Organizations: Governance, Professionalism and Regulation*, 2018); *PCRC*: Palliative Care Research Cooperative; *PHD*: Personal health data; *PRISMA-ScR*: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews; *TSB*: Texel samen beter; *ZH*: Zorgcoöperatie Hoogeloon

Acknowledgements The authors would like to thank the partners of the project "Coop4Health" for their general support: Faculty of Social Science of the Ruhr-University Bochum (Germany), Maastricht University (the Netherlands), and Fraunhofer ISST (Germany).

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Authors' contributions BH, SM, and HCV applied for the project funding. RL, SM, JB, HL, PN, HCV, and IO designed the review. RL was the leader of the review. RL, JB, HL, and PN performed the review, including the search of the databases, the title-, abstract-, and fulltext-screening and the data extraction. HL, PN, BH, and AB searched for grey literature and performed its data extraction. RL, SM, JB, HL, PN, HCV, and IO wrote the manuscript. All authors read and approved the final manuscript.

Funding Open Access funding enabled and organized by Projekt DEAL. The review was conducted within the project "Coop4Health. NRW" which was funded by the Leitmarktagentur NRW. The authors acknowledge the financial support from the State of North Rhine-Westphalia and the European Union (EFRE-0801796; LeitmarktAgentur. NRW: LS-2–2-028f). They both had no influence in the design of the study and collection, analysis, and interpretation of data and in writing the manuscript.

Availability of data and materials and code availability Not applicable.

Declarations

Ethics approval, consent to participate and consent for publication Not applicable.

Competing interests The authors declare that they have no competing interests.

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