An open innovation approach to co-produce scientific knowledge: an examination of citizen science in the healthcare ecosystem

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Abstract

Purpose – The article applies the citizen science phenomenon – i.e. lay people involvement in research endeavours aimed at pushing forward scientific knowledge – to healthcare. Attention is paid to initiatives intended to tackle the COVID-19 pandemic as an illustrative case to exemplify the contribution of citizen science to system-wide innovation in healthcare.

Design/methodology/approach – A mixed methodology consisting of three sequential steps was developed. Firstly, a realist literature review was carried out to contextualize citizen science to healthcare. Then, an account of successfully completed large-scale, online citizen science projects dealing with healthcare and medicine has been conducted in order to obtain preliminary information about distinguishing features of citizen science in healthcare. Thirdly, a broad search of citizen science initiatives targeted to tackling the COVID-19 pandemic has been performed. A comparative case study approach has been undertaken to examine the attributes of such projects and to unravel their peculiarities.

Findings – Citizen science enacts the development of a lively healthcare ecosystem, which takes its nourishment from the voluntary contribution of lay people. Citizen scientists play different roles in accomplishing citizen science initiatives, ranging from data collectors to data analysts. Alongside enabling big data management, citizen science contributes to lay people's education and empowerment, soliciting their active involvement in service co-production and value co-creation.

Practical implications – Citizen science is still underexplored in healthcare. Even though further evidence is needed to emphasize the value of lay people's involvement in scientific research applied to healthcare, citizen science is expected to revolutionize the way innovation is pursued and achieved in the healthcare ecosystem. Engaging lay people in a co-creating partnership with expert scientist can help us to address unprecedented health-related challenges and to shape the future of healthcare. Tailored health policy and management interventions are required to empower lay people and to stimulate their active engagement in value co-creation.

Originality/value – Citizen science relies on the wisdom of the crowd to address major issues faced by healthcare organizations. The article comes up with a state of the art investigation of citizen science in healthcare, shedding light on its attributes and envisioning avenues for further development.

Keywords Citizen science, People engagement, Research, Innovation, Co-creation
Paper type Research paper

1. Introduction

Healthcare is undergoing a profound process of institutional, technological, and social change (Lega and Palumbo, 2021). Such a transition reframes the innovation processes of healthcare institutions, revising conventional management and organizational practices in light of the opportunities disclosed by digitization (Kraus *et al.*, 2021). Three phenomena are driving the future of innovation in healthcare (Lee and Lim, 2018): the computerization and datification of health services, the transition toward personalized medicine, and the adoption of a people-centred approach to drive the functioning of the healthcare system (see, among others: Lim and Ting, 2012; Thakur *et al.*, 2012; Thimbleby, 2013; Lim, 2016; Pianykh *et al.*, 2020). The conjoint action of these three phenomena brings us towards an ecosystem view of healthcare (Lim, 2021; Randhawa *et al.*, 2020). The ecosystem metaphor conceives healthcare as a "...*relatively self-contained self-adjusting system of resource integrating actors connected by shared institutional logics and mutual value creation through service exchange*" (Akaka and Vargo, 2014, p. 368).

Understanding healthcare as a service ecosystem requires the adoption of an open innovation perspective to envision the future shapes of health services' design and delivery (Barile and Polese, 2010; Ciasullo *et al.*, 2017; Secundo *et al.*, 2019). Indeed, the ecosystem metaphor assumes that the actors who participate in the healthcare service system enter a co-creating partnership (Palumbo *et al.*, 2017), which enables them to share information and resources with the purpose of co-producing innovations intended to advance the quality and the appropriateness of care (Sehgal and Gupta, 2019; Schiavone *et al.*, 2021). Inter-organizational relationships represent the most common instruments employed by healthcare institutions to recontextualize their innovation activities according to an open approach (Thune and Gulbrandsen, 2017; Schiavone *et al.*, 2020). Alongside increasing the healthcare institutions' capability of to anticipate evolutions of the task environment, inter-organizational relationships enhance the collective effectiveness to address innovation processes and practices in the healthcare ecosystem, exploiting synergies among different institutions (Schiavone and Simoni, 2019).

More recently, increasing attention has been paid to the role of users in driving innovation and in co-creating novel health services' delivery models inspired to a patient-centred perspective (Lundberg *et al.*, 2013; Wass and Vimarlund, 2016; Ciasullo *et al.*, 2020). Literature has articulated heterogeneous frameworks to conceptualize users' engagement in an open-innovation effort aimed at achieving organizational excellence, such as patient-led innovation (McNichol, 2012) and patient involvement in the design of risk prevention and health promotion initiatives (Pushparajah *et al.*, 2015). Lay people engagement enables healthcare institutions to collect timely and rich information about users' preferences and expectations, as well as about their health-related needs, thus adding to the timeliness and effectiveness of innovative approaches intended to improving the functioning of the healthcare ecosystem (Magnusson *et al.*, 2017).

Lay people may play a variety of role in open innovation (Palumbo *et al.*, 2021). Even though patient involvement has been generally targeted to the collection of big data to solicit advancements in scientific research (Beier *et al.*, 2019), users can perform several tasks that are crucial to set the conditions for innovation (Bjørkquist *et al.*, 2015). In particular, patients can be embedded in professional networks, collaborating with professionals to give shapes to

innovation processes and practices (Pauget and Wald, 2018). *Inter alia*, citizen science is arising as an open-innovation model that is reconfiguring the way scientific research and innovation activities are accomplished in the healthcare ecosystem (Gristwood, 2019). Citizen science is conceived of as "... *the general public engagement in scientific research activities when citizens actively contribute to science either with their intellectual effort or surrounding knowledge or with their tools and resources*" (Broeder *et al.*, 2018, p. 506). Citizen scientists participate in collecting, classifying, analyzing, and reporting evidence about scientific issues, providing expert scientists with a support to perform time-expensive activities that are instrumental to knowledge generation and, consequently, to innovation (Wiggins and Wilbanks, 2019).

As previously anticipated, citizen science may be targeted to heterogeneous outcomes, ranging from the collection of large amounts of data to foster the transition towards personalized medicine (Petersen *et al.*, 2020) to lay people's empowerment in order to boost their participation in health services' co-production (Bonney *et al.*, 2016a, b; Palumbo, 2016) and value co-creation (Tran *et al.*, 2019). From this point of view, citizen science can be targeted to achieving different targets, ranging from the implementation of incremental improvements to enhance the appropriateness and the efficiency of healthcare to the development of disruptive solutions to rethink health services' design and delivery (Buyx *et al.*, 2017; Benis *et al.*, 2021). However, management, organizational, and ethical concerns affect the exploitation of citizen science to boost innovation in the healthcare ecosystems (Borda *et al.*, 2019; Petersen *et al.*, 2020). Even though citizen science represents a phenomenon which is modifying the way actors in the healthcare ecosystem collaborate to create innovative solutions aimed at health promotion and risk prevention (Yeung *et al.*, 2020), previous studies have cautioned about the rhetoric of lay people's involvement in healthcare (Woolley *et al.*, 2016).

These considerations call for a more comprehensive understanding of the attributes of citizen science as an open innovation approach. Also, they stress the need for additional research intended to illuminate the challenges that undermine the implementation of citizen science. Among others, three main gaps prevent us from fully acknowledging the contribution of citizen science to healthcare innovation. Firstly, little is known about the distinguishing attributes of citizen science in healthcare: this does not allow us to delineate the models of lay people's involvement in knowledge co-production (Skarlatidou *et al.*, 2019). Secondly, there is limited agreement about the reality of citizen science in the healthcare ecosystem; therefore, it is hard to overcome the rhetoric about lay people's involvement in healthcare-related innovations (Fiske *et al.*, 2019). Thirdly, insights into the citizen science's contribution in enacting an ecosystem response to unprecedented challenges that undermine the sustainability of healthcare organizations are still missing (Ulahannan *et al.*, 2020). These gaps darken the value of open-innovation in healthcare.

The article intends to fill in these voids, contributing to the advancement of what we currently know about the role of citizen science in enacting virtuous innovation dynamics in the healthcare ecosystem. Going more into details, three research questions (RQs) nurtured this study:

RQ1. What are the attributes of citizen science approaches that are implemented to sustain innovation in healthcare?

RQ2. What is the role of lay people in co-producing knowledge and co-creating value in healthcare-related citizen science projects?

RQ3. How does citizen science contribute to addressing unprecedented challenges that put the viability of the healthcare ecosystem under stress?

A mixed research design was arranged to answer these research questions, consisting of a realist literature review combined with a multiple case study. The rest of the article

progresses as follows. Section 2 describes the methods employed to collect evidence about the characteristics of citizen science in healthcare. It is articulated in three subsections, that provide a detailed account of the study methodology. Section 3 reports the research findings, providing some food for thought to advance what we currently know about citizen science in healthcare. Findings are critically discussed in Section 4, which emphasizes the study's contribution to theory and practice. Section 5 concludes the paper, acknowledging the research limitations and emphasizing its management implications.

2. Methods

2.1 Research strategy

Figure 1 portrays the mixed methodology which was arranged to answer the three RQs inspiring this article. A similar research design has been used in previous studies focusing on different research topics (Gremyr and Raharjo, 2013; Greenhalgh *et al.*, 2016). It was articulated in three steps, which were reciprocally related and fully consistent with the study aims. A realist literature review was conducted to achieve a comprehensive contextualization of citizen science as an open-innovation model to be applied to the healthcare ecosystem (Step 1). The realist review allowed us to build a theoretical foundation for the two ensuing steps. The decision to undertake a realist review was motivated by the purpose of identifying and explaining the interaction between the context (healthcare ecosystem), the mechanism (citizen science as an open-innovation model) and outcome (the enhancement of risk prevention and health promotion initiatives) investigated in this study (Bergerum *et al.*, 2019). Since we did not intend to systematize what is currently known about citizen science in the healthcare context and we were not interested in articulating an overview of extant publication trends in this research field, neither a systematic literature review nor a bibliometric analysis were contemplated in crafting the study design. Drawing on the insights obtained from the realist review, a comparative case study was conducted on completed healthcare-related citizen science projects to outline the key attributes of lay people's involvement in research and innovation activities implemented by healthcare institutions (Step 2). Lastly, a further

	Focus	Purpose	Expected outcome
Step 1 Realist Literature Review	Analysis of the interplay between the context (healthcare), mechanism (citizen science) and outcome (open-innovation)	Collection of preliminary insights to address the case study analysis of CS projects implemented in the healthcare domain	Development of a conceptual background to contextualize CS to healthcare
Step 2 Comparative case study on completed CS project in the healthcare field	Investigation of completed on-line CS projects focused on health-related issues and on medicine-related topics	Analysis of the distinguishing attributes of CS projects implemented in healthcare and investigation of lay people's roles	Arrangement of a taxonomy to shed light on lay people's contribution to value co-creation
Step 3 Comparative case study on completed CS project targeted to COVID-19	In-depth examination of extant CS projects targeted at involving lay people to handle the evolving challenges raised by COVID-19	Enhancing our understanding of lay people's role in partnering with expert scientists to overcome COVID-19	Contextualization of CS to an unprecedented health challenge to obtain conceptual and practical take-aways

Figure 1.
An overview of the study design

comparative case-study analysis was run on recently launched citizen science projects intended to tackle the extraordinary challenges brought by the COVID-19 pandemic on the viability of healthcare ecosystems across the world (Step 3). This study design permitted us to contextualize citizen science to healthcare and to shed light into avenues for further developments.

2.2 The realist literature review

A realist approach was taken to conduct a literature review about citizen science in healthcare. The realist approach is considered to be especially consistent to investigate complex social phenomena (Pawson *et al.*, 2005) which entail large and system-wide transformations in the healthcare ecosystem (Best *et al.*, 2012). The main aim of a realist review is to obtain insights into the relationships between the context, the mechanisms, and the results of phenomena being examined based on theoretically-grounded assumptions (Bendermacher *et al.*, 2017).

A systematic design was implemented to retrieve scientific contributions to be included in this realist review. Two citation databases were concomitantly queried to collect relevant items. As recommended by literature (Bergman, 2012), both Elsevier's Scopus and Clarivate Analytics' Web of Science (WoS) were interrogated. On the one hand, Scopus records a catalogue consisting of more than 5,000 publishers and accounting from more than 75 million items. On the other hand, WoS is presented as the world's most trusted publisher-independent global citation database, indexing about two billion cited references from over 171 million records. Since these two sources provided us with a comprehensive access to extant scientific literature, other sources, such as Google Scholar and other citation databases, were not queried (Pranckutė, 2021).

A standard search string was run in the search engines of the two citation databases. The authors had a meeting to identify a query that was consistent with the study aims and – at the same time – facilitated the elicitation of the largest number of scientific contributions focusing on citizen science in the healthcare context. The search string consisted of a primary and a secondary term. Attention was primarily paid to the "citizen science" concept, which represented the main topic of interest for this study. In order to account for all the potential variations of this construct, the term "citizen sci*" was used as the primary search term, with the asterisk (*) allowing us to contemplate different articulations of this concept. The secondary research term was related to the particular context that was analyzed in this study. In order to contemplate different spelling conventions, both "health care" and "healthcare" were included in the query. The resulting research string was implemented for "article title, abstract and keywords" on Scopus and for "topic" on WoS. The final query was hit on February, 15th 2021 and led to the collection of 112 scientific contributions.

A preliminary screening analysis was conducted to refine the initial dataset. Duplicates and articles not available in English language were retracted. Besides, records that were not accompanied by an abstract were not taken into consideration. Next, an examination of titles, abstracts, and keywords of remaining items was performed. Three exclusion criteria were formulated: (1) the items that did not focus on the contribution of citizen science to research and innovation in the healthcare context were rejected as "off scope"; (2) the items that did not delve into the role of lay people in co-producing knowledge in the healthcare ecosystem were removed as "off topic"; and (3) the items that did not provide adequate evidence into the value of citizen science for innovation purposes were dismissed as "off purpose".

Figure 2 displays a flow diagram that graphically articulates the process of items' screening. The authors independently analyzed the records in light of the exclusion criteria reported above. A meeting was held to discuss consistencies amongst authors' analysis. When inconsistencies were met, a discussion was started to reach a consensus. An agreement
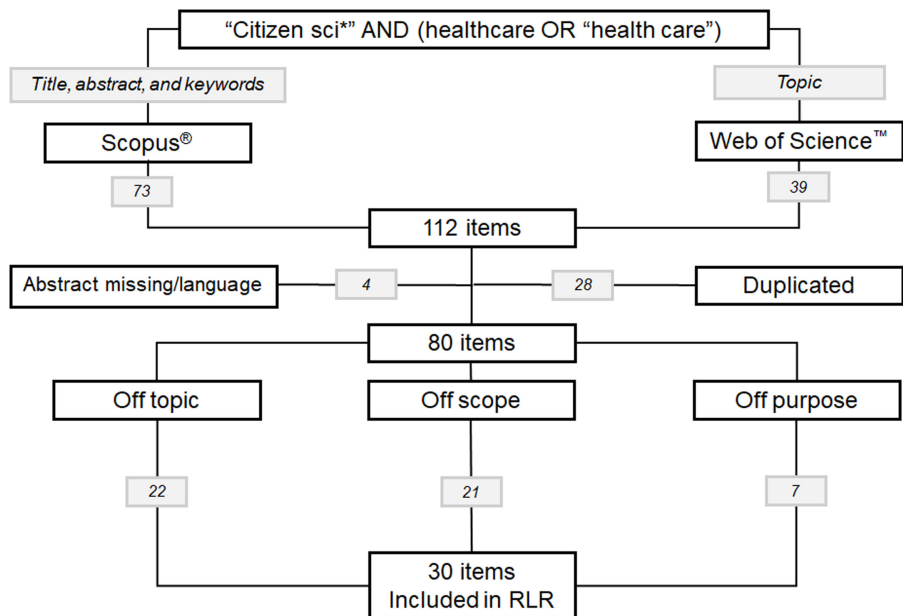
Figure 2.
Realist literature
review flow-chart

was found when most of the authors (three in four authors) were consistent either in rejecting or in maintaining the disputed items. As a result, 30 items were included in this realist review. A narrative approach was taken to substantiate the report of this literature review.

2.3 The case analysis on completed citizen science projects
A comparative case study was accomplished on three finalized citizen science projects hosted by Zooniverse and concerning healthcare-related issues. Zooniverse is one of the most popular web-based platform for citizen science research (Simpson *et al.*, 2014). It is powered by the Citizen Science Alliance, a collaboration of scientists and software developers utilizing people-centred research through internet-based citizen science projects (Masters *et al.*, 2016). To select the citizen science initiatives to be examined in the case analysis, all the projects listed as "finished" as of February 2021 were taken into consideration. Three projects that fell in the medicine/healthcare area were analyzed: "Where are my body organs", "Etch a cell", and "Cell sliders".

Secondary sources were collected to obtain information about these projects and to shed light on lay people's contribution to knowledge co-production. More specifically, three different sources were queried: the Zooniverse platform, the web pages dedicated to the three projects, and additional data retrieved in social media and other web-based sources. Data about these three projects were stored in an electronic worksheet, which was shared amongst the authors. A manual coding approach was used to systematize evidence about these three projects. The coding was intended to elicit information about: (1) the method used to recruit participant, (2) the process of lay people training, and (3) the engagement of lay people in the accomplishment of research activities. The authors independently analyzed collected data and prepared an individual report for each project. A meeting was held to exchange individual perspectives and to achieve a consensus about the distinguishing characteristics of each citizen science project. At the end of the meeting, the authors agreed on a final report, which inspired the articulation of the findings presented below in Section 3.

2.4 The case analysis on citizen science projects targeted to COVID-19
The last step of this study consisted of a comparative case-study analysis of current citizen science projects aimed at engaging lay people in tackling the unprecedented challenges raised by the COVID-19 pandemic. A large search for identifying citizen science initiatives focusing on COVID-19 was performed on SciStarter, a global, online citizen science hub whose aim is to enable and encourage people to participate in scientific research (Hoffman *et al.*, 2017). A search by keywords was conducted to retrieve citizen science projects intended to draw on the wisdom of the crowd to address the challenges related to COVID-19. Different terms were used to conduct the query (e.g. "COVID-19", "Corona Virus Disease" and "COVID") in order to access all potential citizen science projects of interest for this study. Altogether, 14 different initiatives were fetched. They were carefully screened by the authors to check their consistency with the study aims. Citizen science projects that were indexed with the "COVID" label, but that were not aimed at engaging lay people in a co-creating partnership directed to address the pandemic were excluded from the analysis. Hence, 7 projects were consistent with the study aims and included in the analysis: "CoronaReport", "COVID-19 Citizen Science Project", "COVID Near You/Outbreaks Near Me", "COVID Twitter Analysis", "CovidWatcher", "Respiratory Health Study", and "World Community Grid". The other citizen science projects were only indirectly related to the COVID-19 and did not entail lay people's involvement in tackling the pandemic.

As in the previous step, various secondary sources were consulted to collect in-depth information about these citizen science projects. Both projects' summary reported in the SciStarter web page and additional information retrieved on the main websites of the projects and on social media were investigated. All relevant data were stored in an electronic worksheet. A manual coding analysis was implemented, based on an inductive strategy intended to delineate the role of lay people in knowledge co-production and their contribution in advancing an open innovation approach to tackle the pandemic. Firstly, the authors individually examined the citizen science initiatives focusing on COVID-19. Individual reports were discussed in a meeting, which fostered the achievement of a consensus about the distinguishing attributes of citizen science initiatives. At the end of the meeting, a final report was drafted, which informed the research findings.

3. Findings
3.1 Contextualizing citizen science to the healthcare ecosystem
The first step of this study consisted of a realist literature review involving 30 scientific items. Publication years ranged between 2012 and 2021. Most of the records were published after 2015 (80%). The majority were peer-reviewed articles published in international journals (86.7%). Two editorials, one research note, and one conference proceeding were taken into consideration. On average, the items were cited 24 times ($\sigma = 52.7$), ranging from a minimum of one citation to a maximum of 288 citations. The number of citations reflected the publication year of scientific contributions, wherein the latest publications are relatively less cited as compared to earlier ones.

In line with the distinguishing attributes of a realist review, the report of the findings was aimed at eliciting the context, the mechanisms, and the outcomes of citizen science in healthcare. An overview of the key results obtained from the review of the literature is presented in Table 1. Citizen science projects in healthcare show peculiar features, that can be articulated in four main approaches to citizen science (Broeder *et al.*, 2018):

(1) *Crowdsourcing*. Limited degree of lay people involvement in the accomplishment of research activities and innovation efforts. Citizen scientists basically act as data collectors and/or tabulators, participating in projects that are led by expert scientists—it is not characterized by lay people involvement in co-design of research endeavours.

Citizen-science attributes	Mechanisms	Main outcomes	Main references
Crowdsourcing	Web-based platforms and infrastructures to recruit and retain citizen scientists in professional-led research projects; limited degree of lay people involvement in the co-design of research activities	Training of machine learning technologies to foster big data analytics	Katapally *et al.* (2018), Meakin *et al.* (2019)
Distributed intelligence	Web-based platforms and mobile devices are concomitantly exploited to enable lay people to perform data collection and data analysis in a perspective of distributed inquiry; alongside hard mechanisms, some soft mechanisms are implemented to ensure lay people training and durable involvement	Creative collective thinking and lay people increased awareness of health-related issues	Kovacic *et al.* (2014), Lee *et al.* (2018)
Participatory science	Web-based platforms and digital tools are primarily exploited to establish a co-creating relationship between lay people and expert scientists; soft mechanisms are significantly used to boost the establishment of fair exchanges between citizen scientists and expert scientists	Innovative idea generation and advancement of individual and collective health-related knowledge	Den Broeder *et al.* (2018), Katapally *et al.* (2020)
Extreme citizen science	Web-based platforms gather lay people who led research initiatives that are intended to push forward scientific knowledge; soft mechanisms are primarily aimed at creating citizen scientists' motivation and engagement in citizen science	Establishment of a community-based and collaborative model of care based on personalized medicine and openness	Kempner and Bailey (2019), Ashepet *et al.* (2021)

Table 1.
An overview of citizen-science projects' attributes from the realist literature review

(2) *Distributed intelligence.* Citizen scientists have additional roles alongside data collection and transcription. The success of citizen science relies on volunteers' thinking and on their involvement in evidence's interpretation and classification.

(3) *Participatory science.* Lay people are significantly engaged in knowledge co-production, and they have a voice in defining problems and articulating the process of knowledge development. Notwithstanding, the citizen science project is led by expert scientists.

(4) *Extreme citizen science.* Lay people co-led the citizen science project, behaving as co-creating partners of expert scientists to generate knowledge and encourage innovation.

Drawing on this taxonomy, citizen scientists are assigned with varying responsibilities in accomplishing knowledge co-production efforts. Firstly, they may perform as members of the crowd, delivering big data to expert scientists that may corroborate scientific evidence established on conventional clinical data (Swan, 2012). Secondly, they may act as co-producing

partners of expert scientists, collaborating with them in the co-design and co-delivery of research endeavours and contributing both in data collection and evidence interpretation (Grant *et al.*, 2019). Lastly, lay people may act as the main driver of research activities, guiding the process of distributed data collection and extracting relevant information from retrieved data (Gimbert and Lapointe, 2015). Different mechanisms enable lay people's engagement in citizen science projects. Such mechanisms include the design of hard infrastructures to promote and sustain citizen scientists' involvement and the implementation of soft interventions to boost the establishment of a co-creating partnership between expert scientists and lay people (Palumbo *et al.*, 2021). Two hard ingredients are concomitantly required in the recipe for effective citizen science projects. On the one hand, advisory boards composed of representatives of expert scientists and lay people should be enacted to set the conditions for a fair and equitable partnership targeted to knowledge co-production (Patel *et al.*, 2016). On the other hand, focused web-based portals and platforms should be settled to gather citizen scientists and to provide them with the basic information and resources to participate in scientific research (Chung *et al.*, 2016). Digital platforms are especially useful to facilitate the virtual encounter of expert scientists and lay people (Puhan *et al.*, 2018) and to guide the latter throughout the participatory approach to scientific research (Steinemann *et al.*, 2018). This is possible by providing lay people with tailored educational materials intended to empower them to perform as knowledge co-producers (Valle *et al.*, 2018) and value co-creators (Katapally *et al.*, 2018) and by developing proper digital tools that foster the continuous exchange of data and information (Younis *et al.*, 2019).

Soft interventions complement hard mechanisms and are intended to act on the attitudes and behaviors of citizen scientists, encouraging them to enter a durable co-producing relationship with expert scientist (Ashepet *et al.*, 2021). Soft initiatives involve empowering lay people to participate in citizen science projects through training activities aimed at increasing the individual and collective awareness of their potential contribution in scientific research (Watson *et al.*, 2020), building fair relationships based on trust and loyalty amongst citizen scientists and expert scientists (Rodríguez-Gómez *et al.*, 2019), and tackling social and cultural factors that may trigger a limited involvement of underserved groups of the population in citizen science projects (Fiske *et al.*, 2019). It is worth noting that digital tools may establish a bridge between hard and soft mechanisms, creating a positive environment for lay people involvement in citizen science through gamification (Cigarini *et al.*, 2018) and edutainment (Laut *et al.*, 2015).

Literature has associated manifold outcomes to citizen science. Sticking to a crowdsourcing approach to citizen science, it has been argued that lay people have a critical role in training machine learning algorithms to deal with big data (Meakin *et al.*, 2019) and in supporting expert scientists to accomplish low value-added and time-spending data classification (Lee *et al.*, 2017). Besides, drawing on a distributed-intelligence perspective, citizen scientists' involvement entails a greater awareness of health-related issues among lay people, which fosters the development of creative thinking (Dick, 2017) and paves the way for their engagement in participatory research activities (Kovacic *et al.*, 2014). From this standpoint, citizen science nurtures ideas' generation intended to advance the functioning of the healthcare ecosystem (Tran *et al.*, 2019), as well as the development of impactful health recommendations in a perspective of value co-creation (Kempner and Bailey, 2019). Lastly, citizen science may lead to the establishment of a community-based and collaborative model of care (Díez *et al.*, 2018), which relies on personalized medicine and openness (Beck *et al.*, 2018; Tzovaras *et al.*, 2019).

3.2 The peculiar attributes of citizen science projects in the healthcare setting
Three completed citizen science projects focusing on healthcare-related issues were retrieved from Zooniverse. A detailed account of the characteristics of these initiatives follows. Table 2

Citizen-science project	Main purpose	Approach	Mechanisms	Outcomes
Cell Slider	Analysing tissue samples and cells to determine the number and the type of ill cells	Crowdsourcing: lay people classify cells' images, following standard guidelines and protocols designed by expert scientists	Hard mechanisms aimed at standardizing lay people contribution in classification activities and at training them. Limited use of soft mechanisms to ensure lay people engagement and retention	Nimble and effective analysis of large amount of data, accompanied by savings of expert scientists' time and resources. Training of automated algorithms and machine learning tools to foster big data analytics
Etch a Cell	Segmenting cells and obtaining information about the structures that make up molecules, cells and tissues	Crowdsourcing: lay people autonomously analyze cells' images, segmenting their nucleus according to prescriptions and guidelines asynchronously provided by expert scientists	Hard mechanisms aimed at training lay people and at formalizing their tasks. Formalization of communication and information exchanges between expert scientists and lay people. Soft mechanisms intended to motivate lay people and sustaining their engagement in citizen science projects	Processing of large amounts of data. Training of deep learning tools to enhance big data analytics. Lay people's engagement in scientific research and acknowledgement of their formal contribution to the achievement of research aims
Where are my body organs?	Collecting evidence about the anatomical knowledge of the general public and about socio-demographic and cultural factors influencing individual anatomical knowledge	Crowdsourcing: lay people self-appraise their knowledge by undertaking a quiz about anatomy	Predominantly hard mechanisms, intended to formalize and routinize the exchanges between lay people and expert scientists and standardizing the process of data collection	Construction of a large dataset to conduct scientific research. Promotion of public education about anatomy

Table 2.
The characteristics of completed healthcare citizen-science projects hosted on Zooniverse

reports a summary of the projects. Even though all of them can be classified as crowdsourcing citizen science initiatives, they show some peculiarities both in the mechanisms used to engage lay people and in the outcomes that were achieved through the establishment of a partnership between expert scientists and citizen scientists.

3.2.1 "Cell slider". "Cell slider" is a citizen science project led by Cancer Research UK, a charity established in the United Kingdom to promote and conduct cutting-edge research into the prevention, diagnosis, and treatment of cancer. It was launched on Zooniverse on October, 2012. The main aim of the project was to recruit a large number of people to accomplish a broad, crowdsourced analysis of large amount of data embedded in pictures and images of human cells. Citizen scientists were asked to visualize and analyze tissue samples provided by the institution that led the research project, spotting and highlighting particular features

of cells according to protocols and research guidelines delivered by expert scientists. Hence, "Cell slider" can be conceived of as a crowdsourcing citizen science project, characterized by a limited involvement of lay people in the co-design of research activities.

As the virtual platform hosting citizen scientists, Zooniverse acted as the main mechanism to coordinate the exchange between lay people and expert scientists. Before starting their classification activities, citizen scientists were asked to participate in a quick tutorial session intended to increase their confidence with the scientific tasks they had to accomplish. Furthermore, expert scientists implemented a standardization and formalization of individual activities to substantiate the engagement of citizen scientists in data analysis and classification. This permitted them to maximize the potential contribution of lay people to processing a large amount of data and, at the same time, allowed expert scientists to enhance lay people' coordination and to save time devoted to guidance and support to citizen scientists.

Amongst the key results of the project, a particular emphasis was placed on the citizen scientists' ability to collect details that were impossible to be retrieved by relying on machine learning and artificial intelligence exclusively. The inputs provided by lay people provided the research institutions with a nimbler and more effective analysis of a large amount of data, training automated algorithms and systems to enact big data analytics. However, only limited attention was paid to provide feedback about individual and collective performance. This hints that lay people education and empowerment about healthcare-related issues represented only a latent purpose of this citizen science project. Nevertheless, citizen scientists were found to be highly accurate in analyzing and classifying available data (Dos Reis *et al.*, 2015).

3.2.2 "Etch a cell". "Etch a cell" is a citizen science project guided by the Francis Crick Institute, a biomedical research institution located London. The main research purpose was to understand the fundamental biology underlying human health and disease. Some characteristics of "Etch a cell" make it akin to "Cell slider". In particular, this initiative was primarily aimed at building a community of engaged lay people, who were asked to perform some basic data-elaboration activities based on images of cells produced using an electron microscope. Therefore, "Etch a cell" can be understood as a crowdsourcing citizen science project, in which citizen scientists are asked to perform some basic elaborations based on the instructions and guidelines provided in an asynchronous way by expert scientists.

As in the previous case, the web-based platform acted as the main mechanism to establish a bridge between expert scientists and lay people. Before being involved in accomplishing research activities, citizen scientists had to complete a brief training session, which included all basic information to effectively participate in segmenting the cells' nucleus. Some soft mechanisms were also implemented to sustain the lay people's engagement in the project. *Inter alia*, a talk section embedded in the institutional web page of "Etch a cell" permitted lay people to communicate with peers and with expert scientists to share their own experience, provide feedback on their research activities, and recommend improvements. Moreover, as an acknowledgement to lay people involvement in the project, the full names of all participants were published in the main web page of the initiative.

More than 7,000 lay people participated in this citizen science project, accomplishing more than 10,000 segmentations on 500 cells' representation. The main outcome of the project was twofold. It paved the way for a faster and less onerous segmentation and transcription of a large amount of data to support the training of automated algorithms, machine learning technologies, and artificial intelligence applications for big data analytics (Spiers *et al.*, 2020). Besides, "Etch a cell" somewhat concurred to lay people's education and empowerment, engaging them in a vivid community of science enthusiasts who are aware of their potential contribution to the realization of more or less complicated research activities. Such a community, which is known as the Etchiverse, works on different citizen science projects that rely on the successful experience of "Etch a cell".

3.2.3 "Where are my body organs". "Where are my body organs" is a citizen science project led by a team of researchers affiliated to the medical school of Lancaster University and to the School of Medicine of the University of Namibia. Drawing on the findings of a preliminary study (Taylor *et al.*, 2018), the project was intended to understand the anatomical knowledge of the global public and to shed light on the socio-demographic and cultural factors affecting individual knowledge about anatomy. Once again, a crowdsourcing approach to citizen science was adopted. However, in this circumstance lay people acted as the object – rather than the subject – of the project. By answering a quiz about anatomy, lay people provided the team of expert scientists with a large amount of data to collect evidence about the general public's anatomical knowledge.

The Zooniverse platform represented the main mechanism used to connect lay people and expert scientists. However, in light of the specificities of this project, citizen scientists were not asked to undertake a training activity or a tutorial before being involved in the project. In consideration of the limited degree of engagement of lay people in the co-design and co-delivery of research activities, soft mechanisms were almost completely overlooked. The main outcome of the citizen science project manifested in the construction of a large dataset to assess the anatomical knowledge of lay people. Even though the enhancement of lay people's education and awareness of health-related issues was listed among the main aims of the project, no formal mechanisms and approaches were implemented to achieve this purpose. Similarly, a limited attention was paid to the establishment of an information exchange and a co-creating partnership between the team of expert scientists and the population of citizen scientists.

3.3 Leveraging citizen science to address unprecedented healthcare challenges

Table 3 synthesizes the key attributes of the citizen science projects intended to engage lay people to tackle the challenges raised by the COVID-19 pandemic. Seven projects indexed in the SciStarter platform were identified and analyzed for the purpose of this study. A detailed report of these project is articulated below.

3.3.1 "CoronaReport". "CoronaReport" is a citizen science project guided by the Scottish Collaboration for Public Health Research and Policy, a research center concerned with public health issues affiliated to the University of Edinburgh. The project's main aim is to democratize the process of data collection and reporting on the spread of COVID-19, enabling lay people to create personal, but anonymous diaries to store information about how the pandemic affected individual life and community dynamics. Lay people interact to exchange their views and perceptions about the impact of COVID-19 on individual and collective life. They are provided with some insights included in a user manual and a section on frequently-asked questions to get all the information needed to participate in the project actively.

The engagement of citizen scientists is mediated by a digital app, which acts as the point of encounter between citizen scientists and expert scientists and as the field where data collection is accomplished. Ensuring lay people's access to the data and information recorded by peers and enacting a community of engaged citizen scientists, "CoronaReport" can be understood as a distributed intelligence project. Its key outcomes include the collection of a large amount of data to analyze the implications of COVID-19 on daily life and lay people's empowerment to make sense out of the implications of COVID-19 pandemic.

3.3.2 "COVID-19 citizen science project". The "COVID-19 Citizen Science Project" is led by a team of researchers affiliated to the University of California in San Francisco. This citizen science project adopts a crowdsourcing approach. In particular, lay people are asked to self-report and share some personal data to provide expert scientists with first-hand and in-depth information to discover how the pandemic is spreading throughout the world and which factors are likely to boost further infections. The project basically relies on hard mechanism to

Citizen science project	Main purpose	Approach	Mechanisms	Outcomes
CoronaReport	Engaging citizen scientists in a distributed effort to collect data and evidence on the impact of Covid-19 on daily life	Distributed intelligence: lay people are involved in data collection, autonomously participating in systematization and reporting of relevant information. Lay people have the access to peers' information	The engagement of lay people is mediated by a mobile app, which enacts exchanges and communication among citizen scientists and between citizen scientists and expert scientists. Trust and motivation are embedded in the social exchanges among the peers	Large collection of data about the impacts of Covid-19 on individual and social life. Enhancement of lay people's awareness on the implications of Covid-19 on private life and social life throughout the world
Covid-19 Citizen Science Project	Collecting primary data about lay people's health conditions and exposure to risks associated with the Covid-19 pandemic	Crowdsourcing: citizen scientists primarily perform as self-reporter of personal data about individual health conditions and risk factors. A limited involvement in the co-design of research activities is experienced	The Eureka web-based platform and mobile app allow expert scientists to standardize and formalize the involvement of lay people in the process of data collection. Although the project intends to retain citizen scientists, there is only a limited use of soft mechanisms	Construction of a worldwide dataset to keep track of the evolution of the pandemic and get evidence about relevant risk factors. Establishment of a community of lay people interested to support expert scientists in their research activities
COVID Near You/Outbreaks Near Me	Enabling ley people to self-report their health conditions, in order to enhance the timeliness of Covid-19 and flu outbreaks' tracking	Crowdsourcing: citizen scientists are not involved in co-designing or co-delivering research activities in partnership with expert scientists. Rather, they primarily act as data contributors	The project web-site represents the key mechanism to recruit citizen scientists and to enable them to self-report their data. Although information and educational materials is included in the web-site, soft mechanisms are not exploited to empower/engage citizen scientists in advanced research activities	Timely and distributed reporting of Covid-19 and flu outbreaks. Visualization of Covid-19 cases to track the spread of the pandemic. Enhancement of public awareness about Covid-19 and flu facts

(*continued*)

Table 3.
The characteristics of citizen-science projects aimed at tackling COVID-19 indexed in SciStarter

Citizen science project	Main purpose	Approach	Mechanisms	Outcomes
Covid Twitter Analysis	Involving citizen scientists in classifying large amount of data related to self-reported Covid-19 symptoms. Engaging citizen scientists in predicting future outbreaks of the pandemic	Participatory science: lay people perform as crowdsources, supporting expert scientists in the analysis of big data, and as value co-creators, having the opportunity to draw on crawled data to design innovative models and tools to predict the spread of the pandemic	The web-based platform is conceived of as the virtual space hosting the interaction among expert scientists and citizen scientists. Also, it stores data and materials to empower lay people and engage them in value co-creation. Soft mechanisms based on trust building and motivation are exploited to sustain the durable involvement of lay people in the project	Nimbler and timely analysis of tweets concerning Covid-19 symptoms to forecast future outspread of the pandemic. Lay people empowerment and engagement in value co-creation activities aimed at enhancing the systemic ability to tackle the Covid-19 pandemic
Covid Watcher	Engaging lay people in providing first hand data about Covid-19 symptoms, medical needs, resource needs, and behaviors during the pandemic to inform policy and decision making activities	Crowdsourcing: citizen scientists are not involved in value co-creation. They perform are self-reporters of personal data, providing policy makers and decision makers with fresh information to take timely decision aimed at tackling the pandemic	The project predominantly relies on hard mechanisms, consisting of a web-based platform and a mobile app. Since the project does not involve the participation of citizen scientists in accomplishing research tasks, soft mechanisms are virtually non-existent	Construction of an updated and comprehensive dataset about individual and collective medical and resource needs during the pandemic to inform policy making. Collection of reliable information about behaviors during the pandemic to tackle the spread of Covid-19 at the local level

(continued)

Table 3.

Citizen science project	Main purpose	Approach	Mechanisms	Outcomes
Respiratory Health Study	Inviting lay people to collect data about individual behaviors and health conditions in order to build a large source of information to inspire empirical scientific research	Crowdsourcing: lay people do not collaborate with expert scientists to accomplish research tasks. They are asked to take part in surveys and personal data information sharing to provide expert scientists with first-hand information to advance current scientific knowledge about Covid-19	The project is based on a mobile app, which enacts a bridge allowing lay people to share personal information with expert scientists. Few soft mechanisms are used to increase the engagement of citizen scientists in the project, including the assignment of control over contributed personal data to lay people	Collection of large amount of data about individual health conditions and risk factors. Involvement of lay people in data collection as representatives of the community in medical research. Empowerment of people and engagement in health promotion and risk prevention activities
World Community Grid	Lay people are invited to donate the spare computing power of their devices, but they do not participate in accomplishing specific research tasks and/or activities	Crowdsourcing: lay people donate their spare computing power, which is exploited to enact a distributed computing process enabling expert scientists to rely on a greater computing power to perform their scientific research	Soft mechanisms are completely absent. The unique mechanism used in the web-based interface allowing lay people to donate their spare computing power. Lay people do not have the possibility to actively participate in scientific research and to exchange data and/or information with expert scientists	Enactment of distributed computing by gathering the spare computing power donated by lay people

Table 3.

engage lay people in data collection. Such mechanisms are embedded in the Eureka web-based platform and mobile apps, which are powered by the National Institutes of Health (NIH), a nation-wide research center that is part of the US Department of Health and Human Services. Lay people have to answer some survey questions, which permit expert scientists to access information about respondents' personal data and previous experiences.

Soft mechanisms are virtually non-existent, since citizen scientists are not involved in practical research activities alongside crowdsourcing their personal information. However, the "COVID-19 Citizen Science Project" aims at building a sustainable engagement of lay people in research initiatives, an example being the request for the recommendation of additional questions to be added to the survey addressed to the citizen scientists who participated in the earlier stages of the project. The project acts as an initial step to the development of long-term engagement of citizen scientists, paving the way for a full-fledged co-creating relationship between expert scientists and lay people. From this point of view, two main outcomes can be associated with the project. On the one hand, the initiative is targeted to the construction of a worldwide dataset to monitor COVID-19-related symptoms, to keep track of the impact of the pandemic, and to identify factors that help preventing infections. On the other hand, it fosters the establishment of a community of engaged lay people, who may be interested in undertaking more complex and challenging research activities to address the COVID-19 pandemic.

3.3.3 "COVID near you/outbreaks near me". The "COVID Near You/Outbreaks Near Me" is a project co-led by the Boston Children's Hospital and the Harvard Medical School in partnership with Ending Pandemics, a philanthropic organization involved in the design of demand-driven and sustainable solutions to report outbreaks of pandemics, and Flu Lab, a charitable organization performing cutting-edge research to help discover and share transformative solutions to influenza. It adopts a crowdsourcing approach, which makes it akin to the "COVID-19 Citizen Science Project". However, lay people act as contributors of data about health symptoms related to COVID-19 and flu outbreaks.

Citizen scientists are recruited via a dedicated web page, which functions as the main hard mechanism to involve lay people in data collection. Its main purpose is to collect evidence and identify trends about the diffusion of the COVID-19 pandemic before local and national public health agencies by empowering people to self-report their health conditions. Citizen scientists can visualize trends of COVID-19 spread at both the local and national level. Even though they can access some information materials and educational resources about the pandemic, their engagement in value co-creation in partnership with expert scientists is limited. The latter are assigned with data systematization and analysis, with an absent involvement of citizen scientists in data classification and/or elaboration. Hence, the project is predominantly intended to build a large dataset to nourish empirical scientific research performed by expert scientists.

3.3.4 "COVID Twitter Analysis". The "COVID Twitter Analysis" is an open-source project that is powered by the Interaction Data Lab and the Peer-Produced Research Lab of CRI Research Collaboratory, a research unit established by the University of Paris and the *French Institut National de la Santé Et de la Recherche Médicale* (INSERM). In this case, a participatory citizen science approach is embraced. Lay people have the opportunity to take part in a variety of research activities, which are inspired by an open-science spirit.

The web-based platform of the project is the virtual space hosting the exchanges among citizen scientists and expert scientists. The project is focused on the analysis of tweets about self-reported health symptoms related to COVID-19 in order to extract evidence and insights to anticipate and predict further outbreaks of the pandemic. Lay people are asked to examine the tweets crawled by expert scientists, classifying them according to their connection with the description of acute COVID-19-related symptoms. Several soft mechanisms are exploited to empower citizen scientists and engage them in participatory research. Among others,

citizen scientists can download both tweets and annotation to contribute either individually or collectively in designing analytical tools to obtain evidence about COVID-19 outbreaks. Moreover, lay people can manage and visualize data to forecast forthcoming waves of the pandemic. The expected outcome of the project is twofold. Firstly, it allows expert scientists to draw on the voluntary contribution of lay people to analyze a large and continuously expanding mass of data. Secondly, it empowers citizen scientists and enables them to take part in challenging research activities aimed at increasing the healthcare ecosystem's ability to tackle the COVID-19 pandemic.

3.3.5 "CovidWatcher". The "CovidWatcher" project is steered by the Columbia University in collaboration with several community partners established in the New York city. It basically works as a crowdsourcing project, with lay people being asked to fill in several surveys intended to assess medical needs, resource needs, behaviors during the pandemic, and COVID-19 symptoms. The engagement of citizen scientists is realized though digital devices, consisting of web-based platforms and mobile apps. These hard mechanisms permit lay people to take part into data collection activities designed by expert scientists.

No soft mechanisms are introduced to promote the involvement of citizen scientists in advanced research activities aimed at value co-creation. The main purpose of the project is to collect a large and reliable set of data and information to inspire policy making and decision making of institutions involved in tackling the implications of COVID-19 at the individual and collective levels. Even though citizen scientists are enabled to explore and visualize data, they are not engaged in participatory research aimed at exploiting the wisdom of the crowd against the pandemic.

3.3.6 "Respiratory Health Study". The "Respiratory Health Study" is a citizen science project powered by Google Health Studies. It is conducted in collaboration with the Harvard Medical School and the Boston Children's Hospital. Echoing the approach taken in most of initiatives reported above, this project sticks to a crowdsourcing model of citizen science. Going more into details, lay people indirectly interact with expert scientists using a mobile app, which allows them to monitor their own health-related and behavioral data, to share them with expert scientists, and to provide additional information to nourish empirical analysis by answering surveys.

Once again, far from performing as value co-creators and partners of expert scientists, lay people mainly behave as representatives of the community in medical research, providing expert scientists with first-hand data and information to obtain reliable evidence about strategies and initiatives to fight the outbreak of the pandemic. Acting as a virtual bridge to allow lay people to share their data with expert scientists, the mobile app is a repository of health information, which may support patient empowerment and engagement with health promotion and risk prevention activities.

3.3.7 "World Community Grid". The "World Community Grid" cannot be treated as a COVID-19-specific citizen science project, as it is a public computing grid coordinated by IBM to allow people to donate the spare computing power of their devices to enact a distributed computing process aimed at helping scientists in accomplishing their research endeavours. More specifically, lay people participating in this project undertake a passive role in the citizen science initiative. By logging in the web-based platform hosting the grid, they can donate their spare computing power, without performing any scientific task in collaboration with expert scientists. Donating their spare computing power, lay people unconsciously carry out simulated experiments on potential treatments for COVID-19 and accelerate research to tackle the pandemic.

The main outcome of the project is the expansion of the computing power on which expert scientists can rely to conduct their scientific research. Being not directly involved in accomplishing research activities, citizen scientists do not benefit from an enhancement of their expertise or awareness of their potential contribution to the advancement of scientific

research. Consequently, it is a purely crowdsourcing citizen science project, with a very limited engagement of lay people in an empowerment process intended to increase their awareness of the challenges related to the COVID-19 pandemic.

4. Discussion

Figure 3 graphically summarize the main takeaways which can be collected from the research findings. Citizen science is slowly reshaping the way scientific research and innovation activities are accomplished in the healthcare ecosystem (Williams and Caley, 2021). Setting the stage for a collaboration between expert scientists and lay people, citizen science reframes conventional research activities accomplished in the healthcare domain, powering them with the contribution of the crowd (Borda *et al.*, 2019). Moreover, citizen science enacts a process of democratization of scientific knowledge, letting lay people to enter a co-creating dialogue with expert scientists in order to steer the future attributes of healthcare (Woolley *et al.*, 2016). Lastly, yet importantly, citizen science boosts public education and appreciation of timely and relevant health-related issues, concurring in underpinning their literacy and their ability to properly function in modern societies (Den Boeder *et al.*, 2018).

Further steps are needed to overcome the rhetoric of lay people involvement in scientific research and to make citizen science a reality for healthcare institutions. Engaging lay people in knowledge co-production and innovation is key to achieve an increased quality of care in a perspective of people-centredness and to enhance the appropriateness of risk prevention and health promotion interventions (King *et al.*, 2021). However, drawing on the research findings, several shortcomings affect the exploitation of citizen science to boost the innovation capability of healthcare institutions. Even when unprecedented health-related challenges are concerned, such as the COVID-19 pandemic (Katapally, 2020), lay people are primarily involved in innovation endeavors as sensors and collectors of data, who enhance the expert scientists' ability to build large and comprehensive datasets to perform their research activities in a nimbler and more effective way (D'Ignazio and Zuckerman, 2017). In other words, lay people's involvement primarily serves the expert scientists' need for obtaining large amounts of information (Maramis *et al.*, 2019) and/or to analyze, transcribe, and classify available data to train machine-learning algorithms and artificial intelligence tools
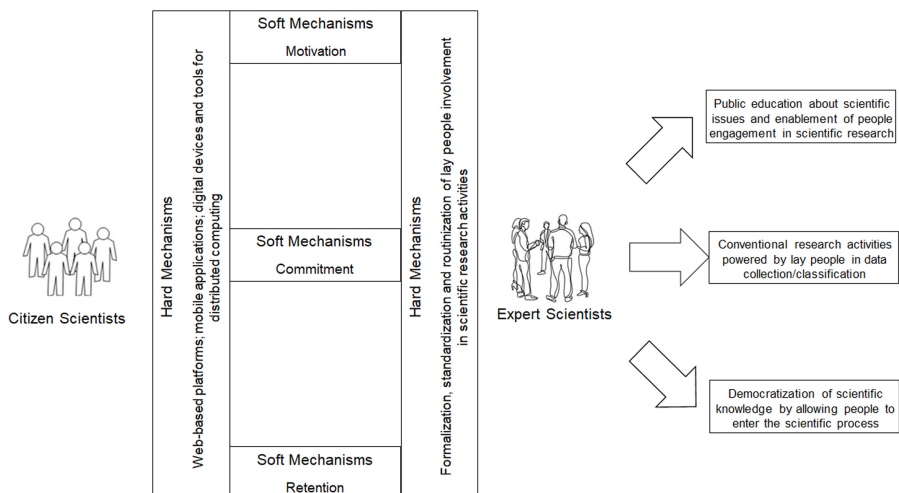

Figure 3.
A graphical representation of the study's results

(Koepnick *et al.*, 2019). Whilst this enacts a distributed computation process (Fisher *et al.*, 2012), it falls short in enabling lay people to contribute in knowledge co-production and value co-creation actively (Palumbo *et al.*, 2021), thus undermining the positive implications of citizen science on the democratization of science and on the enhancement of individual and collective literacy (Woolley *et al.*, 2016).

Web-based platforms and mobile applications are exploited as the fundamental mechanisms to establish a bridge between expert scientists and lay people. However, far from implementing a rich and intense connection among lay people and expert scientists, such mechanisms are primarily used to formalize and routinize citizen scientists' participation in research activities, with limited attention paid to their empowerment and engagement in co-producing knowledge (Ali *et al.*, 2021). Soft mechanisms, which aim at leveraging lay people's motivation and at boosting their involvement and retention in citizen science projects, are generally embedded in hard mechanisms and poorly exploited to foster citizen scientists' commitment to scientific research (Palumbo *et al.*, 2021). This greatly reduces the expert scientists' ability to build a direct and co-creating relationship with lay people, who are seldom asked to partake in the co-design and co-delivery of research endeavors (Barrie *et al.*, 2019). Training and asynchronous tutorial activities are developed to prepare lay people to perform basic and low value-added research endeavors. Exchanges between expert scientists and citizen scientists are indirect and focused on delivering to the latter the basic skills they need to smoothly participate in scientific efforts, with a limited attention paid to their enablement for value co-creation (Gristwood, 2019).

This paves the way for the preponderance of the crowdsourcing approach to citizen science in health care. It is consistent with the expert scientists' expectation to obtain an additional and relatively inexpensive processing and computing capability to collect and handle big data. However, it is not fully in line with the acknowledgement of a greater role to lay people in inspiring and driving the innovation paths undertaken by healthcare institutions. In spite of these considerations, the study findings point out that some gains can be offered by the involvement of citizen scientists in crowdsourcing citizen science. In particular, two indirect advantages are associated with it. On the one hand, lay people's engagement in data collection, analysis, and classification may foster a process of individual activation, which paves the way for a better knowledge of timely scientific challenges, thus contributing to advancing the scientific and health literacy of the public. On the other hand, by nurturing the awareness of individual and collective potential contribution of lay people to the accomplishment of scientific research, their participation in crowdsourcing citizen science may be conceived of as a first step for a greater involvement in distributed intelligence or participatory research projects, which are intended to democratize science and to empower citizen scientists to act as knowledge co-producers and value co-creators in partnership with expert scientists.

The study results provide us with some cues to answer the RQs and to advance what we currently know about citizen science in healthcare. Although the extant literature has largely emphasized the growing importance of citizen science and its implications on the reconfiguration of conventional scientific research models (Bonney *et al.*, 2016a, b), a constraining approach to lay people's involvement is still prevailing in the healthcare ecosystem (Riesch and Potter, 2013). Lay people are predominantly conceived as mere contributors of information or, at best, as classifiers of data, working under the continuous (although indirect and mediated by digital tools) supervision of expert scientists. Hence, a crowdsourcing perspective inspires most of attempts that are directed at involving lay people in accomplishing research activities in collaboration with healthcare institutions. Whilst crowdsourcing is an important form of citizen science, initiating a dialogue between expert scientists and lay people to advance the public understanding of science (Del Salvio *et al.*, 2016), it does suffer from some relevant limitations. Among others, it applies the

transformative power of citizen science to lay people, exclusively. Indeed, it does not necessarily require a transition of extant research infrastructures and scientific processes implemented by expert scientists, who may replicate conventional approaches to knowledge production, regardless of lay people involvement (Bela *et al.*, 2016). This urges us to question whether lay people's participation in scientific research in healthcare is a reality or a rhetoric (Woolley *et al.*, 2016).

Targeted policy and management interventions are imperative to realize the full potential of citizen science in healthcare and to advance lay people's engagement in inspiring and moulding innovation dynamics of healthcare institutions. Health policies intended to affirm people-centredness in the functioning of the healthcare ecosystem should acknowledge the role that lay people may play in envisioning the future shapes of healthcare delivery models. People-centredness should not be conceived as a sheer customer-orientation of healthcare institutions, which incites health services' providers to revise their relationship with patients in a perspective of increased quality of the patient-provider relationship. Rather, it should be contextualized as a new philosophy inspiring the identity of the healthcare ecosystem, whose structural attributes and operational processes should be arranged in light of the distinguishing needs and value expectations of patients. This calls for a larger participation of lay people throughout the steps of the value creation process enacted by healthcare institutions, ranging from the delivery of health promotion and risk prevention services to the development of new solutions to enhance the appropriateness and the effectiveness of care.

At the same time, proper management interventions are required to sustain citizen science projects and to encourage the transition from a crowdsourced approach to lay people's involvement to a distributed and participatory approach to scientific research. Although necessary to establish a bridge between expert scientists and lay people, hard mechanisms are not enough to underpin the viability of citizen science projects and to support lay people's commitment in scientific research. Healthcare institutions interested in exploiting the wisdom of the crowd in innovating healthcare delivery models should rely on soft mechanisms, empowering lay people to actively participate in knowledge co-production in partnership with expert scientists. This involves arranging adequate motivational measures, training sessions, and formal and informal rewards to align the perspectives of expert scientists and citizen scientists and to make the latter committed to co-producing scientific knowledge and co-creating value in collaboration with the former.

5. Conclusion

5.1 Study limitations and avenues for further development

Acknowledging the study limitations allows us to advance our interpretation of the study findings. The qualitative, cross-sectional approach used in this article prevented us from obtaining lengthwise evidence of lay people's involvement in citizen science projects (Jackson *et al.*, 2015). Nevertheless, it permitted us to get an overview of the state of the art, which triggers interesting avenues for further developments. Besides, the breadth of this research was constrained by the focus on web-based citizen science platforms to retrieve relevant citizen science projects. Notwithstanding, since Zooniverse and SciStarter are the most popular platforms hosting citizen science projects (Vohland *et al.*, 2021), it can be argued that focusing the research query on these two sources did not undermine the representativeness of our research. Lastly, whilst the mixed methodology employed in this article permitted us to get in-depth qualitative insights into citizen science in healthcare, it did not herald the collection of compelling quantitative evidence of the implications of lay people's involvement on the advancement of scientific knowledge (Jordan *et al.*, 2015).

Further research is required to shed light on the participation of citizen scientists in initiatives intended to democratize scientific knowledge production in healthcare. Attention

should be primarily paid to the dynamics of lay people's involvement and engagement in citizen science initiatives, accounting for the ethics of citizen scientists' participation in accomplishing research endeavors. Most of citizen science approaches are not tailored to the specific needs and resources of underprivileged group of the population, such as minorities and people living with disabilities. This undermines both the democratization of scientific research and the comprehensive engagement of people in value co-creation. In addition, issues related to the protection of personal data of people who accept to participate in citizen science initiatives should be addressed to overcome legal and institutional obstacles to the spread of participatory research.

Further empirical studies are greatly needed to assess the contribution of citizen scientists to the advancement of scientific knowledge. To the best of the authors' knowledge, there is still limited agreement on the impact of lay people's engagement on the advancement of scientific research. This may constrain both the healthcare institutions' proactiveness to espouse a citizen science-based model to conduct scientific research and the lay people's willingness to partake in participatory research. Finally, yet importantly, a review of existing participatory citizen science projects in healthcare is required to contextualize the drivers that stimulate lay people's engagement in co-creating efforts intended to push forward scientific knowledge targeted to health promotion and risk prevention.

5.2 Study contribution
Citizen science reconfigures the process of scientific knowledge production according to a value co-creation perspective. Some ambiguities characterize the state of the art of citizen science in healthcare. Even though it has been understood as a people-centric model of knowledge generation, it seems that a tension towards techno-centricity and a crowdsourcing orientation diminish the degree of people-centredness in citizen science projects. In most of the cases, lay people are involved in routinary research activities, such as self-reporting of personal data and evidence classification, which slightly contribute to their empowerment for the purpose of value co-creation. In other words, the involvement of lay people in accomplishing scientific endeavours is put at the service of technological advancements. Alongside allowing expert scientists to smoothly process huge amounts of data, activities contributed by citizen scientists are crucial to train machine-learning algorithms and artificial-intelligence tools, which provoke an estrangement of lay people from the democratization of science. Hence, there is the risk that citizen science falls short in its attempt to engage lay people in a fruitful and sustainable debate with expert scientists, which is essential to enhance scientific literacy and awareness of relevant research issues.

Crowdsourcing may be understood as the initial step of the journey which brings us towards the democratization of science and to the involvement of lay people in the establishment of a co-creating partnership with expert scientists. For this to happen, tailored interventions should be implemented to take advantage of the contact among lay people and expert scientists, transforming it into an enabling process. Lay people's empowerment has a twofold aim. Firstly, it provides citizen scientists with the basic skills and expertise that are needed to have an active role in the community for the purposes of health promotion and risk prevention, thus making the transition toward people-centered healthcare ecosystems a reality. Secondly, it sustains lay people's awareness of their contribution to the advancement of scientific knowledge, determining a greater willingness and desire to partner with expert scientists and to be actively involved in knowledge co-production.

Obviously, implementing citizen science in the healthcare context is not free from concerns. Challenges related to both the privacy and the ethics of sharing personal health-related data across a multitude of actors composing the healthcare ecosystem should be carefully addressed. Besides, attention should be paid to formally and informally

acknowledging the contribution of lay people to the advancement of scientific knowledge and making their role in value co-creation explicit. Lastly, the dehumanizing effect of exploiting web-based platforms and mobile apps to implement citizen science initiatives should be overcome, putting emphasis on the direct, co-creating relationship between lay people and expert scientists.

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