

Citizen Science in Human Medicine and the Use of Software-Systems: A Rapid Scoping Review

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Abstract. Citizen science allows involving interested citizen in the entire research process in science. In the past, various citizen science projects have been performed in different research fields, especially in human medicine. We conducted a rapid scoping review to determine which citizen projects in human medicine already used software-based systems to engage citizens in the research process. Furthermore, we analysed which of the software-systems are publicly available, especially in the field of rare diseases, how citizens can participate using those tools and whether the usability was rated by the participants. To get insights for our project “SelEe (Seltene Erkrankungen bürgerwissenschaftlich erforschen)”, which is a citizen science project in rare diseases funded by the Federal Ministry of Education and Research (BMBF), we aimed to identify projects in this research area. We searched PubMed for articles between 2011 and 2021 and performed a title- and abstract screening, as well as a full-text screening. Finally, 12 studies were identified in different research areas like public health, genetic research and infectious diseases. We could not identify any study directly associated with rare diseases. None of the studies investigated usability of those systems. Furthermore, five publicly available citizen science software-systems were identified. Three of them are general systems that allow creating, operating, managing citizen science projects and including citizens in the research process. In further investigations, we will check and compare these systems, if they are appropriate for use in our SelEe-project.

Keywords. Citizen Science, Scoping Review, Rare Diseases

1. Introduction

“Citizen science” projects allow citizens without any knowledge in sciences or the scientific process to participate in scientific projects by formulating research questions, performing observations and measurements, as well as evaluating and publishing data [1]. In the last 20 years, citizen science has developed as an instrument that makes it possible to involve citizens in improving scientific knowledge and goals. The use of

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citizen science is becoming increasingly popular and is not limited to any scientific field [2]. Therefore, various examples of applications in human medicine are also available, e.g. in the research of COVID-19 [3, 4, 5]. The growth of citizen science projects is also supported by the increasing use of websites or mobile applications that allow citizens to collectively contribute, analyse or publish results [6].

In Germany, the Federal Ministry of Education and Research (BMBF) is funding 15 different citizen science projects, starting in 2021. In this initiative, four projects are being funded in the field of human medicine [4]. One of these projects is “SelEe: Seltene Erkrankungen bürgerwissenschaftlich erforschen” (www.selee.de), with the aim of including citizens in the research of rare diseases (RDs). Since only a small part of the population is affected by RDs and knowledge about these diseases is often low, citizen science projects are one possibility to improve research knowledge in this area [8, 9]. Within the SelEe-project, citizens from Germany will be involved in the entire research process. They can actively shape the selection of RDs that should be studied in the project and formulate research objectives. All data and information in the project will be collected and made available via an online-based platform called “SelEe citizen science platform”, in which citizens can participate.

Despite the overall increasing number of software-based systems like web-applications and mobile-apps [10], we are not aware of any reviews about developments and current systems used in the context of citizen science in human medicine. Therefore, the objectives of this study were to perform a rapid scoping review to give interested researchers in citizen science an overview of (1) which studies are available using software-based systems in human medicine citizen science projects and if were in the field of rare diseases. Furthermore, we investigated (2) which systems are available (e.g. as open-source software) and (3) how citizens can participate using those tools. Furthermore (4) it was of interest whether the usability of those systems were rated by the citizens.

2. Methods

The reporting of this scoping review complies with PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews). We considered 19 out of 22 PRISMA-ScR items. Two items were optional, another item, which is about study-registration, was not considered, since the study was not registered online [11]. We searched PubMed for peer-reviewed articles from March 07, 2011 through March 07, 2021. Keywords for the search were derived through an initial search and authors’ experience. The result was a set of keywords including “citizen science”, “software” and “rare diseases”, using MeSH-terms (Medical Subject Headings) and non-MeSH terms. This results in a final search query, shown in Table 1.

Table 1. Final query of the entire search

(Citizen Science[MeSH Terms] AND Software [MeSH Terms]) OR (Citizen Science[MeSH Terms] AND Rare Diseases [MeSH Terms]) OR ((Citizen Science) AND Software) OR ((Citizen Science) AND rare diseases)

In accordance to PRISMA-ScR, we performed two screening rounds to select publications: a screening based on bibliographic data and a full-text screening. In the first screening round, publications were included if they contained a peer-reviewed

article and/or conference proceedings written in English with an available abstract. Publications were only included if a citizen science project in human medicine was described where citizens could interact and participate in the project. Articles about other sciences, e.g. ecology or animal biology, were excluded. The full-text publications were screened where accessible, if the articles described the use of software-systems in the citizen science project. In both screening rounds, the screening was performed by one and compared by another author. To analyse and present the results (called data charting in scoping reviews), we defined the following data items and linked them to our research questions: “study/aim (1)”, “research area” (1), rare diseases (1), “software availability (2)”, “software type (2)”, “citizen participation (3)” and “usability checked (4)”

3. Results

The search identified 85 articles in PubMed (shown in Figure 1). As there were no duplicates, the 85 were used for title and abstract screening. In this context, 60 articles were excluded and 25 were considered as further relevant. This number was further reduced because full text was not accessible for 5 articles. After assessing the eligibility of the remaining 20 articles, 8 articles were excluded because they did not describe a software-system in the context of citizen science in human medicine. Therefore, 12 articles were identified for further analysis, as shown in Table 2.

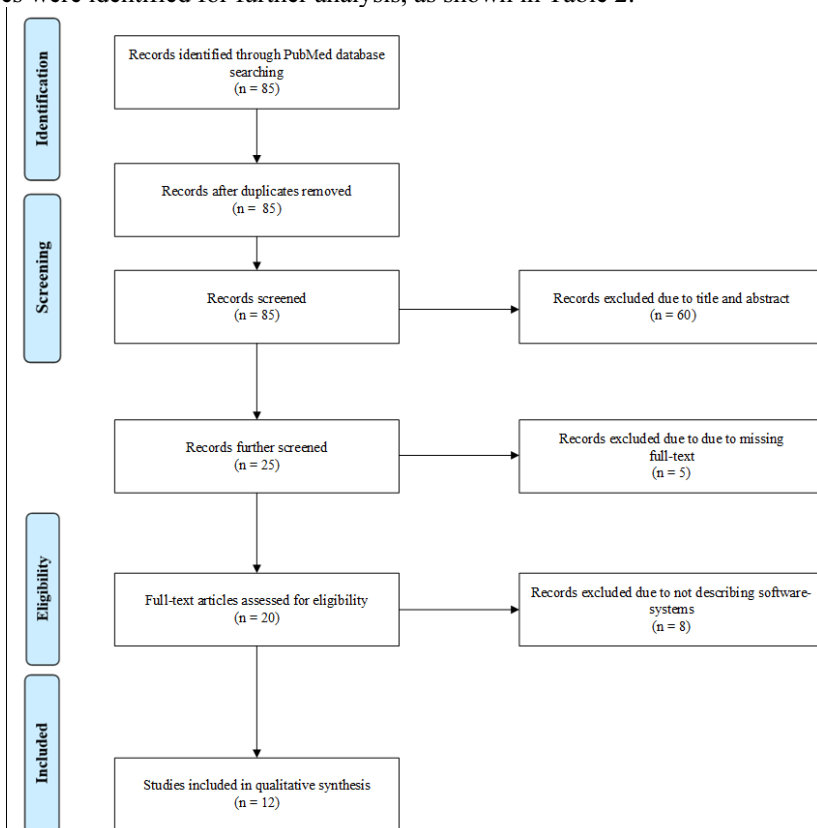


Figure 1. PRISMA-ScR flow diagram

Table 2. Results of the qualitative synthesis

Study/Aim	Research area	Citizen participation	Usability checked	Software type
[3] Caputo et al.: Monitor perception of mosquito abundance and nuisance in Italy and beyond	Public Health	ZanaMapp, a mobile app that allows users to answer questions about mosquito presence, abundance and nuisance, as well as geolocalization.	No	Mobile Application
[4] Ulahannan et al.: Open data visualization of COVID-19 outbreak in Kerala, India	Infectious diseases	Citizen-provided, visualized, distributed and interpreted data on a COVID-19 web-platform: https://team.covid19kerala.info/	No	Web-Application
[12] Hartshorne et al.: Pushkin, an open-source platform for designing and conducting citizen social sciences projects	Citizen science software	Sharing experiments data, provide personal feedback and discuss in forums. Own script language for behavioural experiments.	No	Web Application
[13] Vicens et al.: Platform to assist the deployment of human behavioural experiments	Citizen science software	Collect decision of participants while interacting with virtual real-life situations in a computer-game.	No	Web Application
[14] Wang et al.: Provision of a citizen science platform, where projects can be started and managed	Citizen science software	The entry of citizen-based data is supported by a meta-data model approach to standardize the data described.	No	Web Application
[15] Klepac et al.: citizen science experiment in UK to study outbreaks of pandemics	Infectious diseases	Use of a smartphone app, which records volunteers' movements and allows submitting self-reported contacts.	No	Mobile Application
[16] Candido Dos Reis et al.: Cell Slider is a project, where citizens can score tumors based on images of breast cancer	Oncology	Access to a web-platform (http://www.cellslider.net/), training of scoring tumors, scoring of images based on closed questionnaires.	No	Web Application
[17] Meakin et al.: Segmentation of anatomy from medical images through citizen	Anatomy	Citizens were recruited via social media. They used an image dataset and segmentation data which includes images of magnetic resonance imaging.	No	Desktop Software
[18] McGehee et al.: Protein folding via a visual simulator used by citizen	Genetic research	Citizens can use the software Polyfold to visually simulate the distance-based protein folding process without any knowledge in protein biochemistry	No	Desktop Software

Study/Aim	Research area	Citizen participation	Usability checked	Software type
[19] Kawrykow et al.: To improve multiple sequence alignment through citizen scientists	Genetic research	Phylo is a web-based game that allows citizen scientists to support the multiple sequence alignments in the research of genetic diseases.	No	Web Application
[20] Tuckett et al.: Increase physical activity in older adults	Public health	Citizens used a mobile web app with the goal to geocode photos and to create audio narratives of their physical environment (e.g. parks, playgrounds or crosswalks). Citizens use the results to advocate for improvements regarding physical activity in their community.	No	Mobile Application
[21] Sheats et al.: Motivate residents to use a mobile app to assess and advocate for healthy food environments	Public health	Usage of a mobile app to collect data (geocoded photos, audio narratives) about aspects of their environment that promote or inhibit healthy nutrition. Citizens use the results to advocate for improvements regarding healthy food in their community.	No	Mobile Application

4. Discussion

Our scoping review is the first to summarize the evidence of citizen science projects in human medicine, where citizens can participate in the projects by using software-based systems. Regarding to research question (1), we identified 12 relevant studies between 2011 and 2021. The results show that the studies are from different research areas. However, several studies are available in the field of public health, genetic research and infectious diseases [3, 4, 14, 18-21]. There were no studies available in the field of RD's.

We identified "citizen science software" that are available for usage in citizen science projects (research question 2), for example to administer projects or to involve citizens [12-14]. These tools allow researchers of citizen science projects to create and operate platforms for their project at an early stage. While the systems of Hartsthorne et al. [12] and Vicens et al. [13] are open-source and thus individually expandable, Wang et al. [14] only provides an online platform where their own citizen projects can be started. In addition, there are two other studies that make their source code publicly available [4, 18]. In summary, only 5 of 12 software-systems are publicly available. The majority of the studies (10 of 12) allow participation via mobile apps or web applications. Only two systems are desktop software.

Regarding citizen participation in the studies (research question 3), it can be stated that the identified projects allow different participation possibilities, from the creation of one's own research data to the active evaluation and discussion of the data. However, this publication did not investigated how many citizens used the software and whether research questions were able to be answered using those systems. For the SelEe project, the existing systems must be checked for their applicability. These selection process will take place together with the participating citizens. They will define requirements to those systems and then it is checked whether the systems fit these requirements. In a next step,

we will conduct a focus group in which the systems are presented and the participants vote on which system will be used in the project.

Concerning research question 4, the studies identified in this review focus on the evaluation of their research questions in their research area, but did not investigate the acceptance by the user or usability of their tools. This may have an impact on the research results created by citizens and should be investigated in further studies. However, there are studies outside the medical environment available, which make clear, that the inclusion of the user in an early stage of the project is necessary to increase success and acceptance [22]. Therefore, a user-centred design approach could be a possibility to allow the participation of citizen in the design of the software and not just in the research process [23, 24]. Hence, we derive this user-centricity as an essential criterion in the implementation for our SelEe-project.

4.1. Limitations

This work provides a broad overview of 12 software-systems to support the citizen science process in the medical area. In other science domains, there could be further suitable systems. Furthermore, not every system could be explained in detail. For example, no further technical details were omitted. Nevertheless, future studies can use this as a basis to carry out more detailed investigations, e.g. if data could be exported into statistic software-systems. However, the data collection of this review was limited to PubMed and not published literature was not covered. Additionally, the study selection and data charting were only performed by one author, but results in any phase of the study were approved by all authors. Furthermore, as mentioned above, we could not identify any evidence of RDs projects in citizen science in this review. Due to the fact that 5 articles were excluded because of missing full-text, this could have an impact on the completeness of this review. In addition, we do not address the risk of bias. However, the use of a high methodological standard with PRISMA-ScR could minimize a possible bias across the study.

5. Conclusions

In this review, we summarized the literature of citizen science projects in human medicine between 2011 and 2021. Our study provides insights of how citizens were involved by using software-based systems and we identified software-systems in each citizen science project to manage projects and involve citizens.

Declarations

Conflict of Interest: The authors declare that there is no conflict of interest.

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Author contributions: JAS and MN designed the review, formulated research questions and performed study selection as well as data analysis. The results of this scoping review

were summarized and reported by JAS and reviewed by MN. JS, HS and MS revised the article. The final manuscript was written by JAS and approved by all authors.

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