

PROTOCOL

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The People's Review protocol: planning an innovative study powered by the public

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Abstract

Background Systematic reviews provide the best quality evidence about the effectiveness of health treatments. However, systematic reviews and the important role they play in healthcare are not well understood beyond the walls of academia and healthcare. Systematic reviews can help the public make more informed health choices, based on the best available evidence. The People's Review aims to provide an opportunity to members of the public to plan and complete a full systematic review online in a supportive and engaging manner. It will be a learning-by-doing experience to support the public's understanding of what reviews are, how they are done, why they matter, and how they can be used to support everyday health decisions.

Methods In The People's Review the public will conduct a full systematic review, deciding the review question, planning the review, working on the parts of the review, and deciding how to share the review findings, in a 'learning by doing' process. The review will be conducted online in eight stages using Cochrane Crowd, an existing citizen science platform. The team working behind-the-scenes of The People's Review will design, produce, and share learning material to support the public's understanding at each stage of the review.

Discussion Involving the public in a systematic review online will enable members of the public to understand and use systematic reviews in everyday health choices. It provides the public with a unique 'learning by doing' opportunity to get to grips with what systematic reviews are and how they are produced. This article describes how we plan to involve the public in The People's Review. It is not a protocol for the systematic review itself – this will be published separately once the project has commenced, and the public have decided the review question.

Plain English summary

It can be difficult to make health decisions today. We are exposed to a huge amount of information available 24/7 on a smartphone. It is easy to find all sorts of news, figures, and advice about healthcare. However, not everything is reliable. Our decisions should be based on the best evidence available — but how do we find it? A systematic review is a method used by researchers, clinicians, and others to find all the evidence that has been published about a healthcare treatment. Systematic reviews use clear and careful steps to find relevant studies, assess the trustworthiness of the studies, and put together the results of those studies. These steps give us the best evidence available about whether a healthcare treatment works or not. However, the methods of systematic reviews can be complex and hard to understand. The People's Review is an innovative project that will give the public the

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opportunity to learn about systematic reviews by doing a systematic review. Anyone can take part and help us do a systematic review together. People will learn about what systematic reviews are, how they work and why they matter. We will support the public throughout, so that everyone will learn new skills. In the end, we will have a systematic review led and conducted by the public. This article describes how we plan to involve the public in all the key stages of The People's Review through an easy-to-use online platform. Our plans were also formulated and decided with members of the public on the planning group.

Keywords Citizen science, Systematic review, Patient and public involvement (PPI), learning by doing, Making sense of science, Public partners, Evidence-based healthcare, Evidence synthesis, Health research

Background

In the current age of information overload [1], there is a huge amount of information about health (some accurate and some not) available at our fingertips [2–4]. Online sources (or 'Doctor Google') are often the first-place people go to seek information to help make health choices [5–8] but the sheer quantity of information is overwhelming for members of the public [9] and clinicians alike [10, 11]. Many health claims online are unreliable and not based on scientific evidence. It can be difficult for people to find evidence-based health information and to assess whether this is reliable and trustworthy, particularly when information is conflicting [12–15]. Decisions made using unreliable or inaccurate health claims can lead to an array of public health concerns including vaccine hesitancy, fear and panic, false hope, under or overuse of treatments, financial loss, delayed access to treatment and unnecessary human suffering [16–19]. Healthcare decisions made by the public, clinicians and policymakers should be based on evidence from the best quality research.

Systematic reviews bring together all available evidence to answer a specific research question (for example, whether a treatment is effective or not). When conducted and reported well, systematic reviews are considered the best evidence source of information for deciding whether a treatment works or not because they use explicit and systematic methods pre-specified in a protocol to minimize bias [20–22]. Systematic reviews play a crucial role in ensuring healthcare is based on high-quality, up-to-date, reliable information. They are an important tool to inform healthcare policy, practice guidelines, resource allocation and patient decision-making [23].

Several barriers to the implementation of systematic reviews into practice and policy have been reported including lack of perceived usefulness, awareness, familiarity and access [23, 24]. This suggests an overall lack of understanding about what systematic reviews are, why they are important and how they can be a useful tool at the individual patient decision-making level and the policy level. Several organizations, such as Cochrane and the Global Commission on Evidence to Address Societal Challenges, have highlighted the need for targeted approaches to support members of the public to find,

understand, judge and use health evidence when making choices [25, 26].

In recent years, there have been some initiatives to support the public to find, understand and use evidence, including systematic reviews. For example, Deliv and colleagues produced an animated video about evidence synthesis [27, 28]. Similarly, Cochrane Crowd and Evidence Synthesis Ireland produced a series of videos explaining the key steps in a systematic review [29]. While these initiatives serve as a useful learning resource to help people understand what systematic reviews are, they do not provide the public with an opportunity to do a systematic review. In order to meet the call from global organisations to support the public to find, understand, judge and use evidence [25, 26], we must draw on adult theories of learning to inform future initiatives, for example, a 'learning by doing' [30, 31]. Cochrane Crowd, a citizen science platform for health evidence synthesis, provides an opportunity to learn about, and contribute to health evidence synthesis by participating in individual tasks within the systematic review pipeline, for example, screening records [32, 33]. We aim to build on the learning from Cochrane Crowd and invite the public to get involved in the full systematic review process— from deciding the review question, to designing and conducting the review.

In 2020, The People's Trial launched online as an opportunity for members of the public to take part in designing and participating in an online randomised trial, in an effort to support the public's understanding of randomised trials [34, 35]. Over 3000 people from across the globe were involved in conducting a randomised trial to answer the question: *'Does reading a book before bed increase your sleep quality compared to not reading a book before bed?'* We aim to use a similar approach to The People's Trial but apply it to a systematic review. We call it The People's Review.

This paper presents how we plan to conduct (i.e., the protocol) The People's Review. As such, we will describe what The People's Review is, how the public can get involved and how we are developing this project. This is not a protocol for the systematic review itself – this will be published separately once the project has commenced.

Methods

Aims

The overall aim of The People’s Review is to support the public to understand what systematic reviews are, why they matter and how they can be used to support health choices. We will do this by involving members of the public in the design and conduct of a systematic review on a question chosen by them, in such a way that they learn to systematically review the literature by doing it. Secondary aims of The People’s Review are to support the public to think critically about health claims they encounter, and to develop a new method for involving the public in systematic reviews.

Study design and setting

The People’s Review will be a systematic review co-created online with members of the public. We plan to conduct a systematic review of randomised trials, about the effectiveness of a healthcare intervention, involving members of the public in all stages of the review. The public will be involved in eight, separate but sequential stages including: (1) Suggest a Question, (2) Choose the Question, (3) Plan the Review, (4) Select the Studies, (5) Check for Bias, (6) Interpret the Results, and (8) Share the Results (see Fig. 1). Involvement will occur entirely online through The People’s Review website [36] and the citizen science platform Cochrane Crowd [37].

The systematic review will explore the effectiveness of a healthcare intervention by searching for, analysing and synthesising all the randomised trials that try to answer the review question. The systematic review will follow the Methodological Expectations of Cochrane Intervention Reviews (MECIR) Standards [38]. We are committed to open science and will ensure that the systematic review and its protocol are pre-printed and published in an open-access journal. We will register the review protocol with PROSPERO and use the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Protocols checklist [39] to develop and report

the protocol. The review will be reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist [20] and appropriate extensions, such as PRISMA-Search [40]. The ACTIVE framework will be used to report the involvement of the public in each stage the review including the level of involvement (leading, controlling, influencing, contributing, and receiving), and details about who was involved, recruitment, and the mode of involvement [41].

Approach

Similar to The People’s Trial [34, 35], The People’s Review will adopt a ‘learning by doing’ [30, 31] approach to support the public to understand what systematic reviews are and why they matter. The People’s Review is a citizen science project and endeavours to follow the European Citizen Science Association’s (ECSA) 10 Principles of Citizen Science [42] (outlined in Table 1). In this review, we will not use the term ‘citizens’; instead, we will use the term the people, the public, or members of the public interchangeably, as we feel these are more inclusive terms that capture human experience regardless of citizen status or being a ‘patient’ with a specific health condition.

The project team — who is involved in designing, planning and developing The People’s Review?

The People’s Review is being led by a team at Evidence Synthesis Ireland at the University of Galway with support from global partners, including an international steering group and Cochrane Crowd. The international steering group was established in December 2022 to oversee The People’s Review. The nine members of the steering group come from Bangladesh, Brazil, Canada, Ireland, and the United Kingdom, and bring a wide range of expertise and experience in public involvement, evidence synthesis, lived experience, online engagement, and communication. There are four public partners within the steering group, who bring an essential public perspective to the project. All members have been

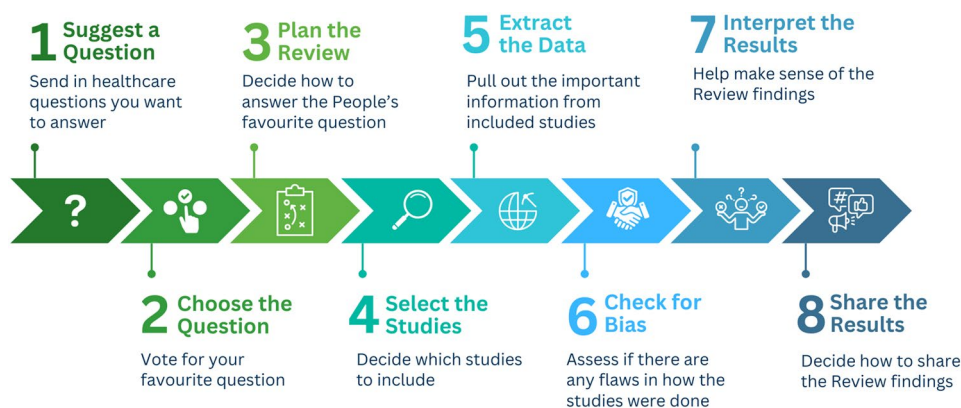


Fig. 1 The People’s Review Pathway

Table 1 The way the people's Review adopts the ECSA principles of Citizen Science [42]

| ECSA 10 Principles of Citizen Science | The People's Review application |
|--|--|
| 1. "Citizen science projects actively involve citizens in scientific endeavour that generates new knowledge or understanding. Citizens may act as contributors, collaborators, or as project leader and have a meaningful role in the project." [42] | The public will be involved in the planning and production of a systematic review of the effectiveness of a health intervention. The public will be involved in deciding the review question, planning the review, doing parts of the review tasks, and deciding how the results are shared. The public will also be contributing to the development of this novel method for involving the public in systematic reviews, and whether this method could be used in the future to support people's understanding and use of evidence. |
| 2. "Citizen science projects have a genuine science outcome." [42] | The People's Review will produce a full systematic review protocol and report of the effectiveness of a healthcare intervention, in line with best practice guidelines. |
| 3. "Both the professional scientists and the citizen scientists benefit from taking part." [42] | The public will benefit as they will learn about systematic reviews, and the important role they play in healthcare. Scientists (systematic reviewers) will benefit as the systematic review will be informed by the public's decisions, thereby making it more relevant and impactful. We will also be able to test this new way of involving the public in systematic reviews which might be useful for systematic reviewers in the future. |
| 4. "Citizen scientists may, if they wish, participate in multiple stages of the scientific process." [42] | The public will be invited to take part in eight different stages of a systematic review process. They can decide if they would like to be involved in one, some, or all stages. |
| 5. "Citizen scientists receive feedback from the project." [42] | The public will receive feedback through updates on The People's Review website, social media and email communication. There will be a transparent and open feedback loop with the project team and the public about all aspects of the project including outcomes from each stage, lessons learned, and any project outputs. |
| 6. "Citizen science is considered a research approach like any other, with limitations and biases that should be considered and controlled for." [42] | We acknowledge the limitations of this project. The stages for which the public are involved in have been carefully selected and planned to ensure the people get a sense of what is involved in the conduct of a systematic review and to ensure that the quality of the review is not compromised. We endeavour to mitigate limitations and biases through quality control checks and consultation with experts in systematic review and meta-analysis techniques. |
| 7. "Citizen science project data and meta-data are made publicly available and where possible; results are published in an open access format." [42] | The project will have its components regularly shared in the Open Science Framework (OSF) platform, including all protocols, methods, and data publicly available. The results will be published as an open-access peer-reviewed journal article and available at The People's Review website. |
| 8. "Citizen scientists are acknowledged in project results and publications." [42] | The public will be offered authorship or named acknowledgement in the publications prepared in line with the International Committee of Medical Journal Editors Recommendations [43]. |
| 9. "Citizen science programmes are evaluated for their scientific output, data quality, participant experience and wider societal or policy impact." | The People's Review will be formally evaluated using the Informed Health Choices [44–46] and Theoretical Framework of Acceptability [47]. |
| 10. "The leaders of citizen science projects take into consideration legal and ethical issues surrounding copyright, intellectual property, data sharing agreements, confidentiality, attribution, and the environmental impact of any activities." [42] | The People's Review project co-ordinators (ÉQ, SH CN & DM) are considering and responsible for all legal and ethical issues related to this project. The People's Review has received ethical approval, and the research will be conducted in line with University of Galway legal and ethical standards. |

involved in the conception, design, planning and development of processes for The People's Review, and also in the decisions contributing to this protocol. The steering group will not be involved in the production of the systematic review itself; their role is advisory. Systematic review procedures that require specialist training (for example, search strategies or statistical analysis) will be provided by the team's network of collaborators. We are also collaborating with Cochrane Crowd to design, build and host The People's Review within their existing citizen science platform.

Who can get involved in The People's Review?

The People's Review is open to members of the public. We use a definition based on Staley and colleagues [48] of 'the public' as ordinary people in general, without any particular health interest or concern. The People's Review is open to all – we do not seek to recruit people with a

specific lived experience, or from a specific patient group (as is often appropriate in other health research projects). We value the input of people from all walks of life, with different lived experience and backgrounds. People can get involved as long as they are over 18 years of age, have access to the internet (phone, tablet or computer), are able to provide informed consent, and can understand and speak English. No previous understanding of health research or systematic reviews is required.

The People's Review process

Pre-launch campaign & recruitment

We will use a broad social and traditional media campaign to create awareness about The People's Review. We will share content on social media platforms including X (formerly Twitter) [49], Instagram [50], Facebook [51], Bluesky [52] and YouTube [53]. We will use existing

connections and networks to spread awareness and promote involvement.

The online platforms

The People's Review will be hosted within the Cochrane Crowd citizen science platform [37]. A unique The People's Review Pathway is under development within Cochrane Crowd to host each of the eight stages of The People's Review. Members of the public who wish to get involved will be asked to register and login into the Cochrane Crowd platform to take part in each stage and track their progress. In addition to Cochrane Crowd, we will develop a unique, open-access website, similar to The People's Trial [34, 35, 54] to provide further information and updates as we progress through the review and provide links to further resources.

Supporting involvement

For each stage of The People's Review, we will produce a short learning module to explain key concepts; for example: randomised trial, PICO (patient, intervention, control, and outcome), bias, forest plot, and meta-analysis, and guide the public through each stage. This will include short animations and practice material. There will also be pop-out features, quick reference guides and a 'Help Me Decide' feature (with prompt questions and hints) within the Cochrane Crowd platform itself to support the public throughout. We will plan, create, build, and pilot the materials and processes before each stage opens to the public. To maximise accessibility, the website and Cochrane Crowd tasks will be designed to support engagement on mobile phones, and we will use plain language in all communication. Volunteer testers, including public partners, will review all aspects of the online material and process to ensure they are user-friendly, engaging and easy to understand.

Members of the public who participate in The People's Review will be able to track their progress within the Cochrane Crowd platform. At each stage they will be able to earn a virtual badge. Members of the public who contribute to The People's Review will be invited to become authors of the review report, in line with the International Committee of Medical Journal Editors (ICJME) recommendations [43], and all authors will have their contributorship described in the publications using the CRediT Contributor Role Taxonomy [55] if the publisher adopts it. Those who prefer not to be involved with the manuscript's preparation will be acknowledged, with their consent.

To produce a methodologically-sound systematic review we will also integrate safeguards at each stage of The People's Review to ensure the quality of the review is not impacted— particularly in the more technically-challenging stages. These safeguards include the integration

of 'resolvers,' when consensus amongst the public has not been reached. Resolvers will be members of the project team. The process for resolving disagreements in each stage varies and is described in more detail below, where relevant.

Stages of public involvement in The People's Review

The people will be involved in eight separate and sequential stages, aligned with the typical stages of a systematic review [41]. Members of the public can get involved in any stage, independent of each other. This means they can get involved in one stage, several stages, or all stages of The People's Review, and they can join in at any stage along the process.

An overview of involvement in each stage is explained below. A more detailed account of what the public and project team will do during each stage is outlined in Table 2.

Before joining

As people can join a stage at any point, all information, about previous stages will be accessible on The People's Review website – to provide enough information for people to be able to join at later stages. Before joining for the first time, people will be asked to complete the informed consent process, and a short survey through The People's Review website. All information required to support the informed consent process including information about the benefits, risks, and data protection will be made available on The People's Review website. The survey will include brief demographic and baseline questions outlined below in 'Evaluating The People's Review'. After completing the consent form and survey, the public will then be directed to the Cochrane Crowd website where they will be asked to sign-up to Cochrane and proceed to the stage that is open. Individuals will only have to complete the consent process, evaluation form, and sign-up to Cochrane the first time they join a stage. Following this they will be able to login directly to Cochrane Crowd.

Suggest a Question

The public will send in healthcare questions they would like The People's Review to answer via an online survey using a similar approach adopted in the iHealthFacts fact-checking website (Does [*type intervention*] make a difference to [*type outcome*]?) [56, 57]. The project team will explain the types of questions we can answer using example questions, and that the review will include randomised trials only (because these are the best way to figure out if an intervention works or not). The project team will check to ensure the questions are feasible and appropriate and group together similar questions.

Table 2 Detailed account of what the public and project team will do during the people's review

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|---|--|
| <p>Stage 1: Suggest a Question What the public will do Members of the public will suggest health topics and related review questions using a structured approach similar to iHealthFacts [54,55] and based around the PICO (Population, Intervention, Comparison, Outcome). We will explain that we will only be able to answer questions that:</p> <ol style="list-style-type: none"> 1. Are about a health intervention, 2. Are accessible 3. Have enough randomised controlled trials available to complete a reasonably sized systematic review, 4. Have not been answered already with a recent, high-quality systematic review. <p>When the task closes to the public, two members of the project team will assess the questions for eligibility, with a third member resolving any disagreements if necessary.</p> | <p>What the public will do</p> <p>Outputs</p> <ul style="list-style-type: none"> • List of all feasible review questions ready for the public to prioritise. • List of review questions that were excluded with reasons for exclusion. |
| <p>Stage 2: Choose the Question <i>This stage will occur in two rounds.</i> What the public will do Round 1: Members of the public will rate how interested they are in each eligible question using a 5-point scale.</p> <p>Round 2: Members of the public will rank the top 5 eligible questions in order of preference.</p> | <p>What the project team will do</p> <p>The team, including an information specialist, will conduct scoping searches to ensure that there are enough trials to answer the question. From this scoping exercise, the team will aim to bring forward 5 eligible questions for Round 2 for members of the public to rank.</p> <p>The team will analyse the results from round 2 and present the final question.</p> <p>Outputs</p> <ul style="list-style-type: none"> • The final The People's Review question that will be answered with the systematic review. |
| <p>Stage 3: Plan the Review What the public will do</p> <p>The public will plan how to answer The People's Review question and contribute to the review protocol. We will ask the public to define the PICO, suggest search terms and any other relevant questions related to the protocol.</p> | <p>What the project team will do</p> <p>The team will prepare a survey with a series of questions about how to answer the chosen question.</p> <p>The team will use the public decisions to write-up the review protocol.</p> <p>Outputs</p> <ul style="list-style-type: none"> • Publication of the review protocol in an open-access journal with open peer-review. • Registration of the review in PROSPERO. |
| <p>Stage 4: Select the Studies What the public will do</p> | <p>What the project team will do</p> <p>Outputs</p> |

Table 2 (continued)

| | | |
|--|--|--|
| <p>The public will decide whether studies are relevant to the review or not by screening the title and abstracts of potential studies, yielded from searching the databases. We will use methods similar to what has been used, and evaluated by Cochrane Crowd before [33,34,57]. Each title & abstract will be checked by four different members of the public. Each member of the public will screen part of the whole pool of studies.</p> | <p>The team, including an information specialist, will search the chosen databases for studies to be included in the review. They will remove duplicate studies and input the title and abstracts (short summary of the study) into Cochrane Crowd.</p> | <ul style="list-style-type: none"> • Studies to be included in the review. • Search strategy and video demonstrating how the search was completed. |
| <p>If there are conflicting decisions by the four public reviewers, the team will act as a resolver to make the final decision about whether the record should be brought forward to full-text screening. Two members of the team will conduct full-text screening. A third member of the team will resolve any conflicting decisions.</p> | <p>What the project team will do The team will develop a data extraction form with the questions suggested by the public and other main characteristics of studies necessary for systematic reviews.</p> <p>Where there is less than 80% agreement by the public for each data extraction item, a member of the team will act as a resolver and make the final decision.</p> <p>Two members of the team will complete all other data extraction, with a third member resolving any conflicting decisions.</p> | <p>Outputs</p> <ul style="list-style-type: none"> • Fully extracted data from all studies. • Information regarding disagreements, how they were resolved and lessons learned. |
| <p>The public will extract information related to PICO from the studies. Information will be extracted by a minimum of four different members of the public.</p> | <p>What the project team will do The public will complete 4 out of 7 of the sections within the Risk of Bias tool [58] including (1) random sequence generation, (2) allocation concealment, (3) blinding of personnel and (4) blinding of participants. We have chosen these 4 domains as they can be assessed using only the final report of an RCT. Each study will be assessed by at least four different members of the public.</p> | <p>Outputs</p> <ul style="list-style-type: none"> • Complete risk of bias assessment. • Information regarding disagreements, how they were resolved and lessons learned. |
| <p>Stage 5: Extract the Data What the public will do</p> <p>Stage 6: Check for Bias What the public will do</p> <p>Stage 7: Interpret the Results What the public will do</p> | <p>What the project team will do</p> <p>Where there is less than 80% agreement by the public for each domain, a member of the team will act as a resolver and make the final decision of low, high, or unclear risk of bias for the domain. Two members of the team will complete the remaining 3 out of 7 domains not completed by the public.</p> | <p>Outputs</p> |

Table 2 (continued)

| | | |
|---|---|---|
| <p>Preliminary findings, including a forest plot, if available, will be presented and members of the public will be invited to interpret the findings. Learning material, including how to interpret forest plots, will be included also.</p> | <p>The team will use the data extracted from previous stages to synthesis (bring together all the studies) and analyse the data using meta-analysis where possible.</p> | <ul style="list-style-type: none"> • Systematic review results and discussion. |
| <p>Stage 8: Share the Results What the public will do</p> <p>The public will decide how and where the review findings will be shared.</p> | <p>The team will use information from the public to interpret and present the final results.</p> | <p>What the project team will do</p> <ul style="list-style-type: none"> • The systematic review <p>The team will prepare the first draft of the manuscript of the full review for submission to an open-access peer-reviewed journal. The team will create and share dissemination resources as directed by the public's decisions.</p> |

Choose the Question

The public will vote online for their favourite question in two rounds of Delphi surveys. Survey 1 will involve the public rating how interested they are in the questions suggested using a 3-point scale. Survey 2 will involve ranking the top 5 questions. Feedback between Survey 1 and Survey 2 will be provided on the website. After the two rounds of surveys, we will then have The People's Review question.

Plan the Review

The public will decide how to answer the people's favourite question. Through an online survey the public will make key decisions that will contribute to the review protocol. For example, they will be asked how to define the PICO, suggest search terms, and other decisions depending on the question chosen by the people. The project team will then use this information to prepare the systematic review protocol. The protocol will be registered in PROSPERO, published in an open-access peer-reviewed journal and made available on The People's Review website for the public to view.

Select the Studies

The public will decide which studies to include by screening titles and abstracts of potential records based on the decisions made in stage 3. A similar approach to Cochrane Crowd's tried and tested 'Screen 4 Me' task will be used [32, 33, 58]. This approach includes features to support public engagement including a 'Help Me Decide' feature, and practice abstracts embedded in training. An agreement algorithm embedded in Cochrane Crowd will be used to decide whether each abstract should be included or excluded. Each abstract is screened by four different members of the public. If there are conflicting decisions amongst the four individuals, then the abstract will be sent to a 'resolver' (a member of the project team) to make the final decision about whether the abstract should be included or not. To help balance the maximum public involvement, with the highest quality review outcomes, full-text screening will be completed by the project team.

Extract the Data

The public will pull out important information from the included full-text studies. For example, they will look for information related to the PICO in the studies. Again, features within Cochrane Crowd will support the public through this process. We will implement an 80% agreement level for each item within this stage to resolve disagreements by the public. This means that if there is less than 80% agreement for each item within this stage, the resolver (a member of the project team) will interpret the public's decisions, and make the final judgement.

Check for Bias

The public will assess if there are any features of the study methods that may bring some uncertainty (or bias) to the results, using the tool called the Risk of Bias (ROB) [59]. The public will be involved in four of the seven parts of the ROB tool including: random sequence generation, allocation concealment, blinding of personnel and blinding of participants. Features within Cochrane Crowd will support the public through this process, for example a 'Help Me Decide' function which will highlight relevant parts of the text related to the question. The remaining three parts of the ROB (incomplete outcome data, selective reporting and other bias) will be completed by the project team. Additionally, the project team will act as resolvers if there is less than 80% agreement by the public.

Interpret the Results

The public will help make sense of the review findings. Preliminary results will be presented, and the public will assist with interpretation of these results by answering an online survey. This will involve looking at the overall results presented graphically in a scaffolded and supported approach.

Share the Results

The public will decide how and where the review findings should be shared, through an online survey. The systematic review results will then be shared as per the public's decisions determined through this survey.

The eight stages were chosen by the project team to ensure that participation opportunities for the public could contribute in a meaningful way to key decisions of the review and provide a useful learning opportunity for the public. Feasibility and methodological quality were considered in these decisions. There are some aspects of this review that will be conducted by the project team and expert advisors where necessary; for example, an information specialist to support with the search strategy. We aim to be open, transparent with the public, responsively answer questions and update The People's Review website with all decisions made.

Evaluating The People's Review

We will evaluate the acceptability and impact of The People's Review as a way to support the public to understand what reviews are, why they matter, how they can be used to support everyday health choices and to think critically about health claims. The evaluation will be guided by the Theoretical Framework of Acceptability (TFA) [47] and the Informed Health Choices framework [44–46].

Before joining The People's Review, members of the public will be invited to complete a short survey to capture baseline information, including age, gender, country

of residence, role (for example, patient, public, researcher, clinician), and previous experience with research, including systematic reviews. This survey will include adapted items from the Claim Evaluation Tools [60] database, which has been validated and tested in several contexts and settings [61–65]. This database includes a bank of multiple-choice questions that assess people's understanding of the Informed Health Choices Key Concepts which help people assess treatment claims and make informed health choices. Included in the list of Key Concepts are principles specifically about systematic reviews e.g., *Item 2.2a Consider whether summaries were systematic* [45]. The Claim Evaluation Tools is a flexible battery that can be adapted for use in specific contexts and therefore we will use this database to create the baseline survey to measure the public's understanding of concepts related to systematic reviews and intended behaviour and attitudes towards health claims.

We will repeat this survey again after The People's Review closes, with some additional questions to measure the acceptability of The People's Review based on the TFA Acceptability Questionnaire including items regarding affective attitude, burden, ethicality perceived effectiveness, coherence, self-efficacy, opportunity costs and general acceptability [66]. While the TFA Questionnaire includes only closed questions, we will also include a small number of open-ended questions so people can provide some detailed feedback, and we will use basic content analysis methods.

Furthermore, to evaluate the reach of The People's Review, we will capture and report on the number and demographics of people in each of the eight stages. We will report the results of each of the individual stages of The People's Review throughout the project on our website [36] and in the final evaluation report. We will also report on the data gathered from website analytics (e.g., traffic to the site) and social media analytics (e.g. number of views, followers, likes and shares).

Discussion

Systematic reviews are considered the highest form of evidence about the effectiveness of healthcare interventions [20–22]. However, the general public have limited understanding of what systematic reviews are and the important role they play in healthcare [23, 24]. Therefore, The People's Review has the potential to expand the public's understanding of what reviews are, and why they matter, through a novel online citizen science methodology, which will hopefully also increase their ability to think critically about health claims. With the growing support for public involvement in research, including systematic reviews [41, 67, 68], we have seen the positive impact this has for all parties, including members of the public, and researchers alike. Members of the public

involved in research report that while their motivations are altruistic, with the aim to improve other patient's lives or healthcare provision, they often also gain valuable knowledge and skills in understanding and using evidence, health literacy, and critical thinking [69–71]. Similarly, researchers have seen the positive influence public involvement has had to improve relevance, quality and impact of their work [67, 71, 72]. Therefore, The People's Review seeks to leverage this mutually beneficial relationship and support the public to get involved in designing and conducting their very own systematic review.

Typically, public involvement in a systematic review includes small groups of people mostly through a 'top-and-tail' approach [41]. Members of the public, patients or carers, are invited to collaborate at the start of the review to prioritise and plan the review, and at the end of the review to help disseminate the findings e.g., in plain language summaries, but not actually doing the review. The People's Review aims to use a continuous, flexible approach to involvement throughout the full review cycle. There will be no limit to the number of people who wish to get involved.

This work builds on the success of The People's Trial [34, 35] using a 'learning by doing' [30, 31] citizen science approach to support the public to think critically about health claims they encounter online, and find, understand and use evidence to support everyday health choices. While The People's Trial, and other online initiatives, such as Cochrane Crowd [32, 33, 37], show promising results as a new way to support people to be involved in health research, we have not overlooked the challenges of online involvement, particularly asynchronous online involvement. Challenges with online involvement include: higher drop-out rates [74], language barriers [74, 75], excluding specific group including older adults, those experiencing digital poverty or low digital literacy [74–76] and technical difficulties [76]. It is not possible to address all of these challenges, for example digital poverty and literacy, within the scope of this project. However, we do endeavour to mitigate some of these risks as much as possible.

To try an ensure wide and diverse involvement— we will use broad recruitment strategies, not limited to just social media. We are fortunate to have a diverse team working on The People's Review, and we will use the whole teams existing collaborations, networks, and communities to support recruitment— as recommended within literature exploring recruitment of public partners to research [78–81]. Another key factor in supporting ongoing engagement and retention online, is the usability, and accessibility of digital portals [81–83]. Therefore, we will try to ensure the website, processes, and materials are easy for the public to understand, and navigate. Our

public partners, and other team members with expertise in online engagement, and software development will play a crucial role in ensuring the public interface is usable, accessible, and engaging. Additionally, the team will be contactable throughout the project to assist with any technical difficulties. We endeavour to ensure there is an open, and transparent feedback loop between the project team and the public. We will continuously engage with, and update the public through email, on the website, and on social media to support retention [80, 84]. Finally, to ensure that participants are appropriately recognised [84, 85] for their contributions, and thus motivated to continue to engage throughout, we will provide virtual badges, and offer authorship as appropriate.

Given the technically complex nature of some systematic review tasks [41, 67] we have given careful consideration to 'what' and 'how' people are involved throughout the systematic review. These decisions have been guided by both acceptability, and feasibility. We seek to ensure that all opportunities for involvement, genuinely contribute to the systematic review itself, and that the public's experience is engaging and meaningful. Learning material and guidance will be offered in a variety of formats (to suit different learning preferences) including animations, written text, imagery, and practice questions. Features within the Cochrane Crowd platform will be built in to support engagement including a 'Help Me Decide' feature with prompt questions, and hints. Additionally, it will be highlighted throughout, that no aspect of The People's Review is mandatory, and people can choose to opt out of any stage (or parts of a stage) if they do not have the interest, availability, or capacity.

As with all citizen science projects – we hope to produce rigorous piece of research [42] – in this case, a methodologically-sound systematic review. We will follow best practice guidance in systematic review conduct and reporting [20, 22, 38, 41], and integrate safeguards during each stage of the review to ensure the quality is not impacted – particularly in the more technically-challenging stages. We have drawn on the learning from Cochrane Crowd to plan these safeguards [32, 33, 57]. However, for Stage 5- Extract the Data and Stage 6.- Check for Bias, which involve reviewing full-texts, we have chosen to use an approach based on 80% level of agreement. The agreement algorithm used within Cochrane Crowd, based on 4 people reviewing each abstract, is not appropriate for our full-text tasks, as it is likely that more than 4 people will be reviewing each full-text. Therefore, to ensure there is consistency with the data extracted and decisions made about risk of bias, we propose that resolvers will review any decisions with less than 80% agreement. We have chosen a high percent agreement to ensure that the extractions and decisions are accurate, and consistent [86]. We aim to explore the

consistency and accuracy of the public's decisions in data extraction and risk of bias assessment, compared to the approach typically performed in systematic reviews. This will be reported on in future publications.

Potential strengths & limitations

A strength of this protocol is that we have drawn on existing best practice guidelines and frameworks [20, 33, 38, 41, 42] to develop The People's Review. While The People's Review is a novel approach for involving the public in a systematic review, we hope that the learnings from The People's Trial [34, 35], and Cochrane Crowd [32, 33] will guide us through the process. As outlined above, we anticipate some challenges with this approach including recruitment, drop-out, online involvement, technical difficulties, and accessibility. However, we have a range of strategies and supports to help mitigate these challenges. We are not naïve to the fact that this project is ambitious, and we may encounter unanticipated challenges along the way. However, this is a pilot project, and we look forward to reflecting on, and sharing lessons learned in future publications. We also acknowledge the risk of selection bias as individuals who are already interested in or already involved in health research, are likely to take part in The People's Review, and this may not be representative of the general public. However, we will capture details to analyse the extent of this [87]. A limitation that we cannot overlook is that the project is only open to those who can read and understand English. While we believe it would be better to support involvement in multiple languages, due to budget constraints this is not possible within the scope of this project.

Conclusion

This paper has outlined The People's Review, a systematic review powered by the public. We aim to support the public to learn-by-doing a systematic review in an accessible and engaging environment. By transparently informing the scientific community and the public of how The People's Review will involve the public in a full systematic review, we begin this project with a commitment to open-science and citizen science principles that will continue through to its end. We believe The People's Review will facilitate public awareness of the utility of systematic reviews for informed health choices, and further inform and improve public involvement in systematic reviews.

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Author contributions

Conceptualization: ÉQ, SH, CN, DM, PL, ST, AOB, SH, CY, DS, MS, JH and SD
Funding Acquisition: SH through Evidence Synthesis Ireland Methodology: ÉQ,

SH, CN, DM, PL, ST, AOB, SH, CY, DS, MS, JH and SD Project Administration: ÉQ, SH and CN Supervision: SH, CN and DM Writing – Original Draft Preparation: ÉQ Writing – Review & Editing: ÉQ, SH, CN, DM, PL, ST, AOB, SH, CY, DS, MS, JH and SD All authors read and approved the final manuscript. The order of authorship for this project was decided as follows. ÉQ is listed as first author as she led the preparation of this protocol. CN, DM and SH are listed as last authors as supervisors of this project. All other authors (SD, JH, SH, PL, AOB, MS, DS, ST & CY) are listed alphabetically as they contributed equally to this work.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

The People's Review has received ethical approval from the University of Galway Research Ethics Committee (2023.06.012).

Consent for publication

Not applicable to this article as no individual data have been collected for this study yet.

Competing interests

The authors declare no competing interests.

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