



THE PEOPLES REVIEW

Participant Information Leaflet

What is The People's Review?

The People's Review is an online citizen science project inviting members of the public to get involved in several stages of a health-related systematic review.

The People's Review aims to:

Support the public to understand what systematic reviews are, why they matter, and how they can be used to help make health choices.

Help researchers understand different ways to involve people in systematic reviews.

Why are we doing The People's Review?

Systematic reviews bring together all the available research on a topic. They help us figure out if healthcare treatments work or not. We want to spread the love about systematic reviews, and provide an opportunity for the public to learn about systematic reviews, by doing a systematic review!

We also believe that it is really important to include the public in research, and we hope that The People's Review will help researchers learn about ways to involve the public in systematic reviews.

Who can take part in The People's Review?

You are very welcome to join if:

- You are over 18 years of age
- Have enough English to understand this flipbook
- Have access to a device (smartphone, laptop, tablet) with internet

You don't need any special skills or previous experience with science, research or systematic reviews.

What does The People's Review involve?

The People's Review is an online citizen science project. It is broken up into eight different stages. You are invited to take part in one, some, or all eight stages of The People's Review.

Each stage compliments the typical stages of a systematic review, and will involve tasks like choosing our review question, planning our review, finding studies to include in our review,, and deciding how to share the results.

You can learn about each stage in the '[How It Works](#)' section of our website.

When you join The People's Review for the first time:

- Step 1: You will be invited to complete a short survey with questions about yourself (age, gender, country of residence, role, understanding of systematic reviews).
- Step 2: Sign-up to Cochrane Crowd. All stages of The People's Review will be hosted within Cochrane Crowd. By signing up to Cochrane Crowd you must agree to their [Terms of Use](#) and [Data Protection Policy](#).

Important information: Please use the same email address in the survey and Cochrane Crowd. This is so we can link your data and track your decisions throughout the whole process.

How much time will participating in The People's Review take?

The time for each stage of The People's Review will vary. However, each stage will take no longer than 30 minutes.

We expect the project to last about 9 months. Each stage will be 'open' for different lengths of time. Some stages might be open for one week, while others might be open for longer. We will email you when each stage opens.

There will be periods when no stage is 'open' as the team working behind-the-scenes are preparing the next stage.

What are the possible benefits of joining The People's Review?

- Learn about systematic reviews - what they are, how they are conducted, and why they matter.
- Learn about how systematic reviews can be used to make everyday health choices.
- Gain skills in thinking critically about health claims you might encounter.
- Maybe even have fun!

We believe The People's Review will help researchers understand how to involve the public in systematic reviews.

What are the possible risks of taking part in The People's Review?

The risks involved with The People's Review are very low. In the unlikely event that you are impacted by this research in anyway, do not hesitate to contact the researchers at thepeoplesreview@universityofgalway.ie.

Data Protection - Your Personal Information

- There is always risk involved with sharing personal information. We take data security very seriously.
- The only personal information we will collect is your name, email address and country of residence. We need this so we can contact you when each stage 'opens', to update you about the project, and to track your progress through the review.
- Only Éile Quinn, Dr. Sinéad Hynes, Chris Noone, Anna Noel-Storr, Gordon Dooley and David Anstee will have access to your email address.
- You will only be contacted about The People's Review.

How will we store your data?

- During the project, we will handle and store information carefully with encryption and password-protection. We will do this in line with [GDPR \(General Data Protection Regulations\) laws](#), [UK's Data Protection Act 2018](#), [University of Galway Data Protection policies](#).
- Cochrane Crowd is based in the United Kingdom and therefore your personal data (email address) will be transferred outside of the EU.

What will we do with your data after the project ends?

After the project is completed we will anonymise the data. This means that your personal information (i.e., email address) will be permanently deleted from the dataset and will not be published.

After the project is completed anonymised data will be stored by the research team for 7 years in line with [University of Galway policies](#).

Open Science and Sharing Your Data

- [We are committed to open science](#). Therefore, to increase visibility and transparency, we will publish anonymised data in [OSF](#) after the project is completed.
- We will respect your privacy and anonymity and adhere to the 'as open as possible, as closed as necessary' principle.

- Data will be published in a FAIR (Findable, Accessible, Interoperable and Reusable) manner.
- Important information: only anonymised data will be made available. No identifiable or personal data will be made publicly available.
- More information on open-science and open-data, [here](#).

Confidentiality and Authorship

- You can choose for your participation to remain confidential or not. You will be given the opportunity for your name to be listed as an author on the systematic review that we produce.
- We will contact you when the systematic review has been drafted to invite you to review, provide feedback, and add your name to the list of authors. Only your name will be shared. No other identifying information e.g. email address will be shared.
- There will be a separate opt-in consent process for having your name listed as an author on our review.
- Only people who opt-in to the authorship consent process will have their name listed as an author on the review. If you do not opt-in to this, your participation will remain confidential. Neither your email, name, nor any identifying details will be published.
- Confidentiality cannot be guaranteed by the researchers and can only be protected within the limitations of the law. If any participant should disclose information during the project regarding issues of risk, the researcher is obliged to report this information to the appropriate management/authority. In such cases, confidentiality may be broken.

Voluntary Participation And The Opportunity to Withdraw Consent

Participation is voluntary and you can withdraw at any time* without consequence or without providing a reason. If you withdraw from the project, you have the right to have your data deleted. If you wish to withdraw, you can contact a member of the research team on thepeoplesreview@universityofgalway.ie.

*However, it is not possible to withdraw after your data has been anonymised and subsequently analysed, after which all the data will be merged, and it will not be possible to identify or remove your data. Data will be anonymised after the final survey is closed to all participants.

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The People's Review has received ethics approval from the University of Galway Research Ethics Committee: ethics@universityofgalway.ie

If you wish to raise a complaint regarding how your data is collected or handled contact the University of Galway Data Protection Officer at dataprotection@universityofgalway.ie