

Antibiotic Citizen Engagement (ACE) Science Project

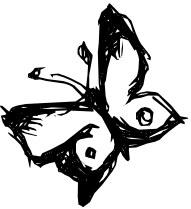


OK SO WHAT IS CITIZEN ENGAGEMENT OR CITIZEN SCIENCE ANYWAY?

Citizen Science is research done with the help of the general public.

Ordinary people volunteer their time and enthusiasm to help gather data.

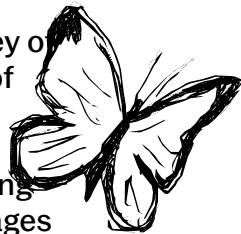
Without help from the public many of these projects would be impossible because not enough data would be gathered, or because the amount of work needed is too big for one research team to do.



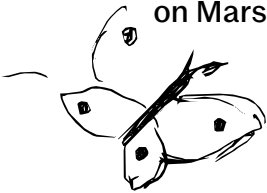
THAT SOUNDS INTERESTING AND IMPORTANT! CAN YOU GIVE SOME EXAMPLES OF PROJECTS?



The Big Butterfly Count, started in 2010 asks people to record the butterflies they spot in 15 minutes of watching. It is nPow the world's largest annual survey of butterflies, allowing scientists to monitor the state of butterfly populations.



NASA also runs lots of citizen science projects inviting people to look at the night sky or search data or images from their space missions to identify things like clouds on Mars or asteroids.



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SO WHAT DOES **THIS** CITIZEN SCIENCE PROJECT NEED PEOPLE TO DO?

Our project is asking for people to interview friends, family and trusted neighbours.

We have an electronic survey for you to use, developed on a system called Epicollect that has been used for hundreds other research projects.



Epicollect can be downloaded for free as an app to a smartphone or tablet, or accessed online from your desktop computer.



There are 10 questions, some are about the person you are interviewing and some are about what they know about a type of medicine called antibiotics.



We are interested in understanding how people get antibiotics when they are needed, how they dispose of them when they aren't needed anymore and what they know about them.

WHAT IF I WANT TO TAKE PART, BUT DO NOT HAVE AN ELECTRONIC DEVICE I CAN USE?



We can send you a paper questionnaire if you do not have a device. Write to us at ACE project 7th Floor, Commonwealth Building, Hammersmith Hospital, Du Cane Rd, London, W12 0NN.



OK, SO I GET WHAT YOU WANT ME TO INTERVIEW PEOPLE ABOUT ANTIBIOTICS BUT I DON'T KNOW WHAT THEY ARE OR WHY THEY ARE IMPORTANT. DOES THAT MATTER?

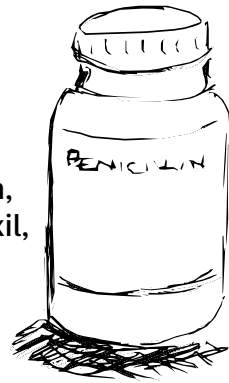


You don't need to know anything about antibiotics to help with the survey, but one of the aims of this project is to hopefully make more people understand what they are and why they matter.



Antibiotics are a special kind of medicine which treat infections. You or someone you know will almost certainly have had them at some point but may not have realised.

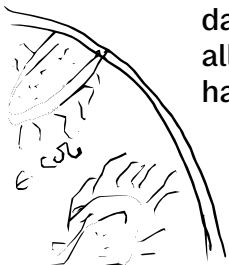
You might recognise the name of specific antibiotics such as penicillin, amoxicillin, co-amoxiclav, cefalexin, doxycycline or brand names like aratoin, macrobid, oxil, trimox.

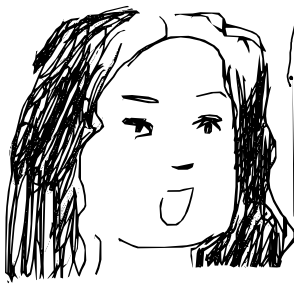


Antibiotics are specifically for treating infections caused by bacteria (eg TB, sepsis, strep throat, whooping cough, bacterial pneumonia or meningitis) rather than infections caused by viruses (e.g the common cold, COVID-19).

Before antibiotics existed around one in 20 children died before their first birthday and a simple scratch or graze could kill.


Today antibiotics are also important because they not only allow doctors to cure you when you get a dangerous bacterial infection but also because they allow surgery of all kinds and cancer treatments to happen safely.






SO ANTIBIOTICS SEEM PRETTY IMPORTANT, BUT WHAT HAS INTERVIEWING MY FAMILY AND FRIENDS GOT TO DO WITH IT?


Antibiotics are essential to lots of areas of medicine and to treatments for lots of diseases but they are now not working properly. This is because we have not used them sensibly over the last 70 years since they became available.



This means different types of bacteria that could once have been killed by antibiotics in the past have now developed ways to survive. Scientists call this antibiotic or antimicrobial resistance.

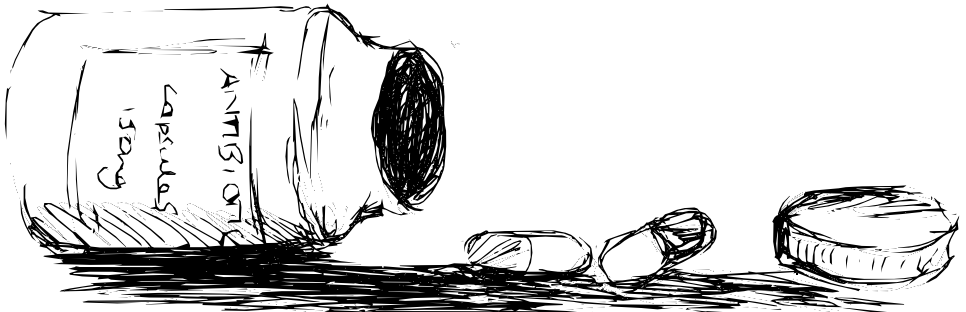



The infections caused by these drug resistant bacteria are very hard to treat and over a million people worldwide die of them every year. With levels of resistance growing, it is estimated that in less than 30 years it will be as big a killer as cancer.



Understanding what your friends, family and neighbours do with their antibiotics and what they know about drug resistant infections is important in helping us slow down antimicrobial resistance.

The information you provide can help us design better public information about the problem and understand what areas to focus our research on.



WHAT HAPPENS TO THE INFORMATION I COLLECT? WHO GETS TO SEE IT AND DO THEY KNOW WHO HAS PROVIDED WHICH ANSWERS?



The information you provide joins all the other project data in Epicollect.

We will not be asking for any information such as a name or date of birth that would allow for answers to be linked to an individual.

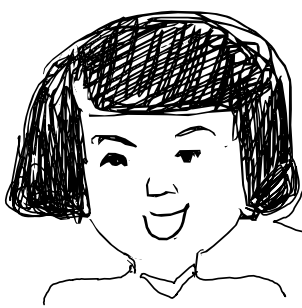
The data will only be seen by researchers at Imperial College London and will only be used for research purposes.

BUT YOU DID SAY EARLIER THAT THE SURVEY ASKS SOME QUESTIONS ABOUT THE PERSON AND NOT JUST ABOUT THE ANTIBIOTICS. WHAT ARE YOU ASKING AND WHY?

The survey only asks for person-information such a gender or age group to help us see patterns in the data at group level.

For example looking at data by group might show that men under 34 have less knowledge about drug resistant infections than women. It might also show, for example, that women are more likely to share antibiotics with a family member than men.

This information would enable us to target information to those two groups differently, addressing these separate issues.



OKAY, I AM INTERESTED IN TAKING PART! WHAT DO I NEED TO DO AND BY WHEN?

This project is taking place during the next two weeks.

You can download the free epicollect app to use on a phone or tablet and collect data at anytime during this period but if the device you plan to use is not yours please ask permission from the owner first.

To download the App go to the App Store and search for "epicollect5". Click the cloud symbol to download to the device, then open.

Click on the + add project button to get the search box and type "Imperial College ACE", click + add entry to begin the survey.

To access the survey on a computer go into your usual web browser and type www.epicollect.net. Then click "find project" in the top right of the screen then "search" and in the, "filter projects by name" box type "Imperial College ACE"

The survey is intended for you to use with friends, family, trusted neighbours and members of any clubs you are a member of (e.g Guides/sporting clubs etc). Please do not "cold call" or knock on the doors of strangers.

The survey may also be run as a school science project or an awareness raising project. Please contact head.ops@imperial.ac.uk for more information on how we might support this or see our public engagement material at www.imperial.ac.uk/medicine/hpru-amr

Downloadable versions of the survey and project updates or publications can be found on our dedicated project pages www.imperial.ac.uk/medicine/hpru-amr/patient-and-public-information/antibiotic-citizen-engagement-ace-project.

Thank you!



Public understanding and behaviours in relation to antimicrobial resistance (AMR) in the UK Participant Information Sheet

Antibiotic Citizen Engagement (ACE) project

This citizen science project has been developed to enable school children and other interested people, to become “citizen scientists” gathering survey data about the UK public’s understanding and behaviours in relation to antimicrobial resistance (AMR).

In particular we want to know how people access, use and dispose of antibiotics.

1. *What is Antimicrobial Resistance and why is it important?*

Antibiotics are a special kind of medicine that treat infections caused by bacteria (e.g. tuberculosis, sepsis, ‘strep throat’) rather than infections caused by viruses (e.g. the ‘common cold’, ‘flu, COVID-19). Antibiotics are very important because they allow doctors to cure you if you get a dangerous bacterial infection. Antibiotics also allow a range of medical procedures, surgeries of all kinds and cancer treatments to happen safely. You might recognise the name of specific antibiotics such as penicillin, amoxicillin and co-amoxiclav or others by their brand names such as augmentin, macrobid or trimox.

Antibiotics are essential to the delivery of healthcare and to different treatments for lots of diseases, but they are not working as well as they once did. This is because we have not used them sensibly over the last 70 years. As a result, the types of bacteria that could have been killed with antibiotics in the past have now developed ways of resisting treatment. Scientists call this antimicrobial resistance.

These drug- resistant infections are very hard to treat and 1.27 million people worldwide died of them in 2019. In less than 30 years this number is estimated to increase to 10 million people per year, making antimicrobial resistance as big a killer as cancer.

Understanding what you and others do with your antibiotics, how you get them and what you know about drug-resistant infections is important in helping us slow down antimicrobial resistance. The aim of asking you to provide this information is to help us understand what areas we need to focus on and to design better public information about antimicrobial resistance.

2. *Why have you been invited to take part?*

As part of this project, our Citizen Scientists have been asked to invite parents, family-friends, extended family, known neighbours and members of any sporting, social or religious communities with which they have a connection, to take part in our survey.

There is no upper or lower age limit to take part, although if you are under 16 many of the questions may not apply to you.

Your participation is entirely voluntary: you do not have to take part if you do not want to.

Taking part will help us understand how to shape our research questions for the benefit of the public, how best to address behaviours that contribute to AMR, and what the public understanding of AMR is.

3. *What will happen and what do I have to do?*

Our Citizen Scientist will ask you a series of questions about antibiotics. These will relate to how you get them, how you use them and how you dispose of them.

Your answers will be captured on an App called Epicollect, which has been used for hundreds of research projects like this, or on a paper version of the survey.

Your responses entirely anonymous.

The electronic survey, also contains functionality for participants to upload a photo of any antibiotics stored at home which are not the result of any current prescription. You may wish to submit a photograph of these but do not have to.

The activity is estimated to take no longer than 5 minutes and you may choose not to answer all the questions.

4. Are there any potential risks or benefits to taking part in this study?

There are no risks in taking part in this study.

There are no direct benefits to you from taking part either, but you will be helping to shape our research questions for the benefit of the public.

5. Expenses and payments

There are no payments for involvement in this study or reimbursement of expenses. Participation is entirely free and voluntary.

6. What happens to the data provided and will finding from the event be published?

Our research team will download the data from the epicollect app. Any survey results received on paper will be added by our researchers. The resulting data will be stored confidentially on Imperial College London premises and university computer network. Responsible members of Imperial College London may be given access to data for monitoring and/or audit to ensure that the research is complying with applicable regulations and to help shape future research questions. The collected data may be used in future research and/or made available to other research projects.

We hope to publish the findings in peer-reviewed scientific journals and the findings may be presented at scientific conferences.

7. Who is organising and funding this event?

This work is being funded by the National Institute for Health Research (NIHR). It is being organised by Researchers from the Health Protection Research Unit in Healthcare Associated Infections and Antimicrobial Resistance at Imperial College London and the Centre for Antimicrobial Optimisation.

8.. Who has reviewed this study?

This study has been reviewed by the Research Ethics team at Imperial College London.

9. Who do I contact if I have a concern about the study or I wish to complain?

If you have a concern about any aspect of this study, please contact head.ops@imperial.ac.uk who will do her best to answer your query and should acknowledge your concern within 10 working days. If you remain unhappy or wish to make a formal complaint, please contact the Imperial College London's Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

10. Further information and contact details

If you have any questions, please contact one of the study researchers, Dr Zhu, study coordinator, by email, phone or post (contact details are below). If you would like to receive a copy of the final report at the end of the study please also contact Dr Zhu. **Dr Nina Zhu, Hammersmith Hospital, Commonwealth Building, Du Cane Road, jiayue.zhu09@imperial.ac.uk.**

To access survey

via the app: Search the App Store for "Epicollect5" and then "Imperial College ACE"	via the web: 	Via a paper-based survey: Ask your Citizen Scientist, or write to us at ACE Project, 7th Floor Commonwealth Building, W12 0NN.
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