



A community-based public engagement with health experiment: Using English for speakers of other languages (ESOL) classes to empower immigrant communities with science

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Abstract

Our previous work with immigrant communities identified a lack of awareness of infections such as gut worm (helminth) infections in their countries of origin, and a lack of English language skills around medical and scientific terms. Furthermore, people from minority ethnic and linguistic backgrounds participate significantly less in public engagement with science practices or informal science learning activities. We suggest this may be due in part to their lack of language skills around scientific English. To start to address these issues of scientific language accessibility, we developed a bespoke set of English lessons that dealt with the theme of infection. A set of six lessons were delivered to adult learners from a variety of ethnic backgrounds in English for speakers of other languages (ESOL) classes. Feedback from students was positive, with students taking the opportunity to share their new knowledge with teachers, other students and their families. All students reported that they felt this would be invaluable to them in their everyday lives. We propose that developing programmes of this nature represents a potentially fruitful avenue for more-accessible public engagement with research and health education practices.

Keywords: inclusion; participation; cross-cultural communication; inclusive public engagement; minority ethnic groups

Key messages

- Scientific and medical English is not accessible and is rarely understood by speakers of other languages.
- Providing access to science and medical English language opened up dialogue between scientists and community participants, and also communities with each other.
- By removing language barriers we were able to dispel myths around the theme of infection and improve shared understanding.

Introduction

This paper presents an innovative case study of a health education and public engagement project that sought to work with immigrant learners in the UK, whose English language skills were minimal. Our previous work with immigrant communities identified a lack of awareness of infections such as gut helminth infections in their countries of origin, and a lack of English language skills around medical and scientific terms (NCCPE, 2017). Furthermore, research suggests that people from minority ethnic and linguistic backgrounds participate significantly less in public engagement with science practices or informal science learning activities, not only in the UK, but across Europe and the US (Dawson, 2014). In other words, immigrant communities represent a particularly vulnerable population in the context of health, health education and public engagement with science. However, few public engagement and health education projects have worked with immigrant learners in the UK; the project described here therefore represents a timely and innovative experiment.

Health care is fundamental to our society, so it is critical that patients understand medical decisions and health-care advice, and take appropriate preventative steps where possible. It is vital that people understand why health-care measures are implemented, so that they voluntarily participate and engage with the health-care process. In Europe and the US, fears about the safety of the measles vaccine have led to a drop in vaccine uptake, resulting in several measles outbreaks despite there being extensive research showing the safety of the MMR vaccine (CDC, 2017). News stories about the 2014 Ebola outbreak in West Africa also highlighted the need for effective health-care communication, with reports of villagers denying access to health workers and maintaining practices that spread contagion, due to lack of awareness about the virus. However, where health-care information is successfully implemented, it can be transformative to communities. Guinea worm infection infected 3.5 million people in 20 countries but now, due to simple health-care education on the need to avoid bathing in drinking water when infected and drinking clean water, the disease is on the way to being eradicated (WHO, 2017).

In the UK and USA, immigrant and minority ethnic communities have much worse outcomes in terms of health. The reasons for this are not fully understood, although social inequality and racism are thought to contribute (Nazroo, 2003). However, our previous community-based public engagement experiments (NCCPE, 2017) identified a key issue in accessing the scientific and medical terminology that would enable informed discussion and debate about medical or scientific topics. We suggest, therefore, that language barriers are underlying factors in access to health-care services. Furthermore, lack of access to the science literature further hinders informed scientific debate and discourse about issues such as vaccination of children or use of appropriate self-care measures. This paper presents a project that developed resources to overlap public engagement and health education within English for speakers of other languages (ESOL) classes, in order to improve participants' knowledge of medical language and to give them the confidence to engage positively with the UK health-care system.

Our project sought to disrupt the inaccessibility of health education and public engagement faced by immigrant communities, as well as to address specific health issues known to be faced by immigrant communities, through an exploratory project that delivered a health education and public engagement programme through the ESOL structure. Drawing on the work of researchers at the University of Manchester on parasite infection and immunology, and combining this with previous communitybased public engagement experiments (NCCPE, 2017), this project sought to support immigrant learners through talking about real science and, specifically, current research in the Manchester Immunology Group on parasite infection. Furthermore, we also sought to learn from immigrants' experiences of the infections we studied to inform our research and research direction. ESOL classes are a significant point of access for immigrant communities to the UK infrastructure, upon which access to further education, health and social services, as well as employment opportunities, can hinge. Furthermore, from the perspective of those developing and delivering public engagement with health projects and health education initiatives, ESOL classes represent an important route to access immigrant communities.

Community and public engagement with science

Public engagement with science (PES) has a growing role in research practices. Despite changes in PES rationales and practices over the last 30 years, however, such activities are still marked by a range of motivations, ranging from 'informing' to 'consulting' (Stilgoe et al., 2014). Within the broad range of activities that fall under the PES umbrella, those under the rubric of 'informal' science learning are more explicitly organized around the notion of education than some of the policy-oriented PES activities. As mentioned above, however, public engagement practices and informal science learning activities are not necessarily as 'public' as they might be. For instance, research suggests that urban, middle-class families from the dominant ethnic majority make most use of public science resources (Falk et al., 2015). Furthermore, even when public science resources are physically accessible, they may not be welcoming, linguistically accessible or relevant to people from minority groups (Dawson, 2014).

This project built on the concept of using real scientific research from a university research team to engage the public with science, but also drew on work in informal science learning and community engagement to try to develop activities that would empower the audiences for whom the project was developed. A previous community public engagement project developed by members of this team, Wriggling Rangoli, had sought to engage women and children from the Asian community in the Longsight area of Manchester with parasitic infections - worms and issues of global poverty. The project centred on a co-created artwork as a way to provoke discussions and questions about parasites, contemporary parasite research and community experiences of parasites. Three key pieces of learning emerged from Wriggling Rangoli, which inspired the ESOL project we report here. Among community members, parasite infections were rarely discussed and often confused with other illnesses. However, people found it useful to be able to discuss parasites and their own experiences of ill health more openly. Participants reported that little information was available about how to use the health system infrastructure in the UK. Significant language translation efforts were required for many of the participating women in Wriggling Rangoli to be able to get involved with the project. As a result, it became clear that there was space for a project that could support community members to learn English, while at the same time learning more about science, how to access health care in the UK and, in turn, share their own experiences with one another, as well as the health researchers.

We drew on two key concepts in this project. First, building on work in community engagement and public engagement with science, we sought to develop the project in a participatory manner, with the researchers, participants and ESOL teachers working together to develop a relevant and useful programme of activities (Arnstein,

1969). While we recognized that the community participants had much to offer in terms of their knowledge and experiences of global health (Irwin and Michael, 2003), the participants also pushed us for information and skills-development activities. Thus, the second set of ideas we worked with were those of Freire, who argued for the empowering value of community-driven learning (Freire, 1998; Freire and Freire, 1994). As such, developing ESOL materials that combined English skills, real science and knowledge about UK health-care systems was agreed upon by all three groups of stakeholders as a potentially useful activity.

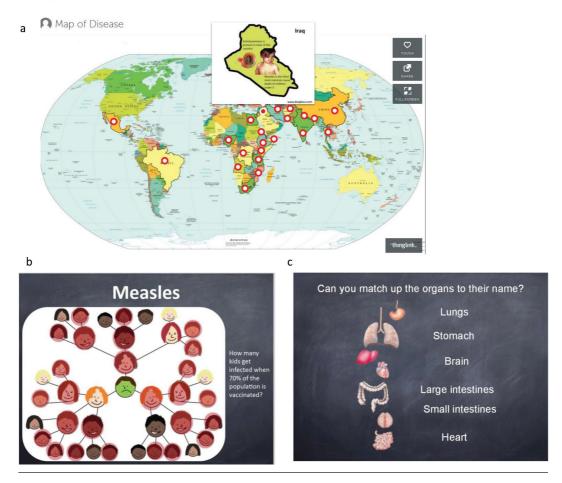
The project context

The project was at all times a collaborative partnership between the researchers in the University of Manchester Immunology Group (MIG), Bolton College ESOL tutors and their learners. The exchange of knowledge and ideas was a three-way process between the partners. The ESOL tutors agreed that the course needed to be pitched to Entry Level 3 or above in order for learners to be able to gain a clear understanding of the subject material and to be able to communicate their own experiences. As this was a course designed to embed real science into a 35-week accredited ESOL course, it was vital that the materials developed and tested the learners in the key competencies of reading and writing, as well as embedding the knowledge on infection. In order to ensure this was achieved, the planning process involved the following key stages:

- establish the scientific learning to be covered to achieve the aims and objectives
- identify the resources and materials to facilitate the learning
- adapt the resources to embed ESOL literacy skills
- establish six weeks as an effective timeframe to achieve the aims and objectives of the course.

The course was then segmented into five lessons to focus on: common infections (globally); infection transmission; infection in history; and vaccines, herd immunity and allergy. The final lesson was a consolidation and evaluation of the course. Bespoke resources were made for each session. These included paper-based reading and writing activities, speaking and pronunciation activities and card games, as well as interactive resources, including interactive whiteboard presentations and iPad activities, a Prezi map of infections and Nearpod games (see Figure 1). These resources were uploaded to the course virtual learning interface (VLE) to enable independent learning and for the learners to share the resources with family at home. For each lesson, we identified key vocabulary that would be repeated and consolidated into the lesson plan for that session. The science included was designed to link to areas that we had previously defined as important through our community project work and that linked to our research. We therefore included information about how worm infection is transmitted and treated, and the basic principles of immunology and vaccination, which then links to our work on the biology of parasitic worms, diagnosis, treatment and the development of vaccinations.

Figure 1: Screengrabs of bespoke interactive ESOL resources: (a) a map of the world where countries can be selected (indicated by pins) and examples of common disease highlighted - this is used to facilitate discussion about common diseases and shared experience; (b) herd immunity resource to demonstrate mechanisms of protection via vaccination, whereby students problem-solve jointly or individually to work out paths of infection and the role of vaccination; (c) organs resource for learning and applying science words for the organs and associated symptoms, for example intestines - diarrhoea.



The classes were developed in consultation with the two ESOL teachers and their learners, who were all adults aged between 24 and 45, with 24 per cent being male and 76 per cent being female (n=39). The students were Entry Level 3 ESOL students registered at Bolton College. The classes were a part of their 35-week accredited ESOL course. Lessons were held at the college campus or at one of its hubs in the Bolton area. The participants came from a variety of countries in the Middle East, Asia, Africa and Eastern Europe (see Figure 2). One class was all female. Educational background varied: 1/39 participants had no formal education, 10/39 had finished primary school only, with the remainder having completed secondary school (up to age 16). Of the participants who had attended high school, six students had completed post-16 further education and three had completed post-16 higher education.

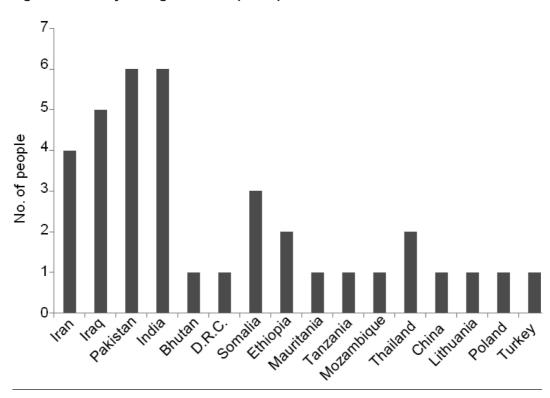


Figure 2: Country of origin of ESOL participants

Researching the project

The process of creating a course, teaching and learning about health issues pertinent to immigrant communities in the UK was explored by drawing on data from the ESOL teachers delivering the sessions, the sessions themselves and participants' perspectives. Researchers (two senior academics and two PhD candidates – all female, age range 22-51) co-developed the teaching resources with the ESOL teachers (all female, age range 42–55) and attended all sessions as active participants. The two ESOL teachers were interviewed throughout the project. The ESOL health education sessions were recorded through researchers' field notes and photographs. Participants' experiences and perspectives were explored through semi-structured interviews carried out before, during and six months after the project, as well as through a mixedmethods questionnaire completed at the end of the project. All data were transcribed, and were anonymized at the point of transcription. The students were consulted in advance about whether they would be interested in doing the topic and taking part in the project during their course, in advance of the course starting.

We held three-way discussions with participants and collected the many experiences that the group shared with us. Participants subsequently wrote about their infection experience, and produced drawings and stories of their experiences and learning during the project. As part of the ESOL teaching, techniques such as active listening (to monitor participants learning) and extended writing (for example, about vaccines or the history of infection) were used to ensure a constant feedback loop between participants, researchers and ESOL teachers. Since the focus of the project was on empowering participants, the data generated through the project were used primarily to support participants' learning and to reflect on the project in order to improve future iterations of the work. At the end of the course, participants, ESOL teachers and researchers also discussed what had and had not worked during the project. A key outcome from this was the need to promote more independent learning in the future to ensure all the resources are utilized. This will be reflected in the amended lesson plans.

Results

Literacies

Students learnt English, but they also learnt specific health/science vocabulary and how to apply these medical words in sentences or longer pieces of text. For example, based on acquired knowledge, students were able to write letters of advice about the MMR vaccination – what it was, how it worked and whether it was useful. This was a significant positive outcome, as most of the students were not previously aware of the importance of children having the MMR vaccine. Some students had also previously identified beliefs on disease prevention originating from their countries of origin that were at odds with established vaccination practices in the developed world.

Students enjoyed discussing alternative words and meanings, the context in which they may be used and the difference between how a word appears in text and its pronunciation. For example, the words 'poo' or 'shit' might be used colloquially but in a doctor's office the words 'faeces' or 'stools' are more usually used. A key part of the quality framework for ESOL lessons and Bolton College is to engage learners in a way that promotes independent learning. To facilitate this, students became proficient at using Google Translate to help them to prepare for the course. There was a lot of peer sharing and learning, and some of the weaker learners were motivated to try harder because they were shown what to do by other students. All students reported that they had improved their English, specifically that they felt more confident using medical or scientific words, and importantly that they wanted to share this new knowledge. For example, evaluation data about the evidence of the impact for participants found that, as one participant said: 'In my opinion my English was improved because I learnt something new, I made practice of writing and reading. So I am now confident for talking about health to other people who don't know it.' Another, female, participant said: 'my family think I am so clever now because I am learning about science.' These statements reflect several such comments, where students reported that they wanted to share their new knowledge with their friends and family and, importantly, apply the knowledge, suggesting greater empowerment and confidence. The teachers also reported the excitement in the classrooms as students were eager to discuss what they had learnt with each other, the teachers and researchers, and to share their ideas. Importantly for the college, the success rate for the exams that year was 100 per cent.

Learning about diseases

Prior to the course, the students were unhappy going to the doctor unless they had a translator. One student described the translator getting their symptoms wrong, leading to misdiagnosis. All students reported that they felt more confident in using the NHS, and using medical words after the course.

Our work with the students revealed a profound lack of awareness of significant health issues from their countries of origin. For example, despite worldwide campaigns to eradicate gut-worm infections, there was a lack of awareness of infection transmission and some embarrassment about discussing worm infection. There were perceptions that infections meant you were dirty and unhygienic, yet all the participants had had personal experiences of worm infection and once they realized this, they were noticeably more relaxed about discussing them. More worryingly, some diseases, such as the parasitic disease leishmaniasis, were thought by some students to be a curse from God; thus, very real stigmas about disease existed. The students had been unaware that many of these diseases are relatively preventable and treatable. They were also unaware of many common infections with great health and societal impact, such as elephantiasis (lymphatic filariasis) and schistosomiasis (bilharzia). Students asked a lot of questions, which extended out of the classroom environment. Notably, after learning about common diseases, how infections are transmitted and how common they are, students felt more confident about discussing their own experiences of infections and sharing their own stories with us and the class. For example, one participant described her daughter's roundworm infection and another shared local remedies for deworming. Data showed that overall the project impacted on students' learning, since all students reported that they felt they knew more now about infection. Comments included:

Yes, it is very useful because are things which we live every day in our lives and we can reach them every day. From now, we know how to be safe and how to prevent this things happen.

Yes, I do. I think this all information with one we learn is useful in our life. We learn a lot of new words, we know a lot of new things about our health. It's really help to us when we have a problem, when we go to see doctor.

All students also reported how they valued being taught by scientists, and having the scientists listen to them.

Peer-led discussions

Students shared knowledge in the classroom via peer-led discussions. Notable discussion centred on the availability of health care in their home countries, and access to drugs and vaccines. There was wide variation in student experience. Students from some Eastern Bloc countries talked about mandatory vaccination, whereas other students discussed the cost of vaccines and concerns about whether this dissuaded people from having vaccinations. Other students talked about a lack of access to common vaccines in their countries. Several students, and one teacher and researcher, had had personal experience of measles infections, and one student discussed a measles epidemic in her home country in her grandmother's time and how relieved her family were that they now had access to the MMR vaccine so it would not happen again. This level of discussion shows that the students and staff were able to engage in informed debate and to apply their own experiences alongside their new learning to inform perspectives on topics such as vaccination.

Teachers' reflections

The ESOL teachers reported that within the classroom there was a buzz about this project that was different from the normal language-learning sessions. Teachers saw the impact of the project in how students enjoyed taking their learning home with them and discussing it with their families, with many commenting on this during the course. The teachers reflected that one reason it was enjoyable was that there was no pressure about exams or being assessed at the end of the learning. The students appreciated being allowed to learn without an agenda, and having their own experiences being listened to and valued. The teachers also reported enjoying learning about new topics and applying their English and teaching skills to a new discipline. A key part of the quality framework for ESOL lessons and Bolton College is to engage learners in a way that promotes independent learning. We did this successfully, evidenced by tasks that the students completed on the hygiene hypotheses and herd immunity, suggesting the students did indeed feel empowered and a part of the project and community, and that we were all actively learning together via three-way engagement.

What we learned from the project

The project discussed in this paper suggests that working in collaboration with ESOL structures is a useful way to target/reach immigrant communities in the UK. Furthermore, our experiences of the project, and the data generated, show that developing a health education ESOL curriculum involving real science was perceived as useful by ESOL teachers and participants.

Participants particularly valued aspects of the course that they could see would have relevance to their children or families. They enjoyed all the resources, with most students stating that they liked all aspects. The interactive resources were the most highly commended. These included resources created for both group work and individual learning. The most commended were the resources developed on vaccines (herd immunity, group work) and how germs were transmitted (individual learning). The shared learning throughout, and being listened to, was something that was also appreciated. Generally, students reported that the topics covered were not too complicated, although one student said some topics were too complicated; all the students said they were useful.

We tried to ensure that we did not revert to a so-called 'banking' idea of education or deficit model of public engagement (Freire and Freire, 1994; Sturgis and Allum, 2004). However, this needed to be balanced by the need to inform about current research. Thus, although we endeavoured to adopt the philosophy underlying work by Arnstein (1969) on active participation in learning development and to work along the 'ladder of citizen partnership', we were constrained by our desire to share our research and the students' current understanding of our research. Furthermore, we needed to balance our desire to improve comprehension and debate with the needs of the ESOL teachers to be able to qualitatively assess English understanding and ability to apply new words in an appropriate way, such as sentence structure, letter writing and use of fonts. Thus, while we were mindful of the critiques of an information-provision approach to public engagement with health, at times it was simply necessary to take such an approach, and we note that, despite its pitfalls, information is a key feature of empowering people to make health decisions.

Topics for inclusion in the pilot course were informed by our previous community work and largely focused on areas directly relevant to our research, but we also included the topic of allergy, which was not closely linked to researcher work at that time. Allergy was an area of real concern for our immigrant communities. However, in response to working with the communities, allergy research has now become a major focus for the lead science researcher on the project via a citizen science project about allergies that aims to define the factors underlying increased allergy in the UK (www.britainbreathing. org). Furthermore, without the language to be able to discuss infection and medicine, we would create a 'culture of silence' that would instil a negative and suppressive view of medicine and health. For the students to be able to engage in dialogue, they would need to gain the tools (medical/scientific language and literacy) that facilitate meaningful two-way, or even three-way, dialogue. That students were able to share their stories with each other and us, and also critique the science, demonstrates that we have moved to a more empowered and informed community and achieved our core aims.

Study limitations

There were some limitations to this study, not least the amount of the researchers' and ESOL teachers' time that it takes to deliver the course. We also had to have a flexible and agile approach to course module development. To facilitate resource design on a limited budget, we enrolled two postgraduate students to develop the resources under supervision as a part of their placement work in their doctoral training programme, and the students were also involved in the delivery. All resources were critiqued and evaluated by the ESOL teachers and science researchers. Although there was an outline of what the course would be, and the components needed, the bulk of building the course resources could not really be started until the PhD students were in place to start the work. The students did not have an immunology background, so it was critical that all the science content was verified by the lead immunology researcher. The ESOL teachers then had to assess the English language aspects and English testing to ensure vocabulary usage was tested and applied throughout the course, and that each aspect of the course was fit for purpose. All this was happening alongside the lecturers' involvement in their day jobs, which meant that time management was a challenge and things went more slowly than anticipated. Delivering classes was also a significant time commitment for the researchers, as each session was about half a day long. To scale up to more classes, it would be necessary to develop a good pack of teacher resources that would enable the teachers, or new teachers, to be able to run the course more independently, as the teachers needed researcher support to feel comfortable discussing the science. However, having run the course, we are in a better position to define what resources might be needed. Another unexpected issue was that we had not appreciated that for such a multicultural group certain terms or words may be a 'distraction', as they are not familiar within all cultures. For example, the case study on whipworm infection had been set in Nigeria, with particular use of Nigerian names, details of a Nigerian city slum and a named organization involved in deworming in the area. While authentic, they were utterly unhelpful for those students unfamiliar with the area and became a distraction, as students were unsure how to pronounce the words or if there was significance to these terms. Similarly, descriptions of children playing dress-up and make believe, added to make the story more interesting, were distracting to the core message as they were not universal concepts. This has now been changed accordingly to make the case studies more focused.

Future plans

One way we have decided to develop this is to develop the course online, so that resources can be downloaded, be more standalone and be accessed freely. Work has been under way at the University of Manchester to develop freely available online versions of course resources.

Although online resources make the course more accessible and free up researcher time, there are benefits from having at least some one-to-one contact with the ESOL students. The teachers reported that having scientists there as part of the delivery team was beneficial in terms of support and engagement, and the ESOL students all stated that they particularly enjoyed working with the scientists and having visitors from the university. Furthermore, seeing the everyday relevance of research by working with the ESOL students was inspirational for the scientists involved, and informed and shaped their research direction, as in the example of the development of citizen science research to understand allergy (www.britainbreathing.org). Thus, moving forward, we decided that we would keep researcher involvement in some, but not all, of the lessons to maintain that connectivity of lived experiences with research. The course has been successfully repeated and expanded to involve more ESOL teachers at the college and larger cohorts of students, including young students aged 16 to 19.

Overall, this work revealed that, although barriers to engaging with medical and scientific work existed due to the difficulties around scientific English, by providing access to the language, we were able to open up effective dialogue between scientists and community participants, and even within communities. Importantly for us, we were able to dispel myths around infection, such as worms being dirty and what an infection is. We conclude that developing programmes of this nature represents a potentially fruitful avenue for more-accessible public engagement with research and health education practices.

Notes on the contributors

Indira Mclean and Marianne Rushton are highly experienced teachers of English for speakers of other languages and were critical for the development and implementation of the teaching resources to ensure that the lessons were appropriate and tested key competencies, as well as ensuring that they were at the right level for students.

Rosie Griffiths and Maria Giovanna Lizio were science BBSRC DTP PhD interns who wanted to gain expertise in public engagement, and helped to develop resources for the lessons and to deliver lessons.

Emily Dawson is a lecturer in the Department of Science and Technology Studies who specializes in research on public engagement and has authored several key papers on PE inclusivity. She advised on the evaluation and development of the project.

Sheena Cruickshank is an immunologist and professor of public engagement and biomedical sciences and the academic lead for public engagement with research at the University of Manchester. She has a track record in sharing her research with the public and co-developed the Worm Wagon as a way to share research with the public. She has subsequently also co-developed a citizen science project called Britain Breathing, which explores links between allergies and the environment. Sheena helped develop the content, as well as advise on the scientific aspects and implementation of the course.

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