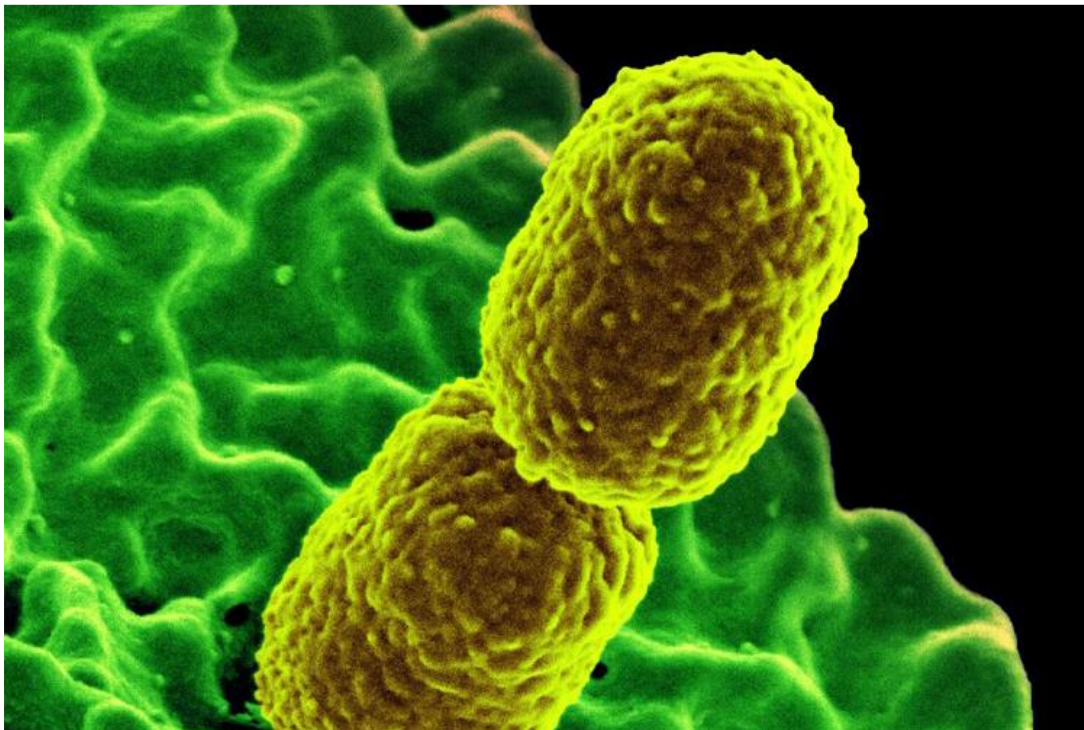


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Summary

The Policy Innovation Research Unit (PIRU) was commissioned to undertake an evaluation of the implementation of the UK Five Year Antimicrobial Resistance Strategy, 2013-2018 and some of the evidence underpinning its key mechanisms of change, with a view to contributing to the 'refresh' of the Strategy, planned for 2018. This report presents findings from our evaluation of the role of patients and the public in implementation of the Strategy.

We characterised the 'public' as being patients, consumers of food, pet owners and, in terms of public 'voice'. We used a range of methods to explore the role of the public in governance and implementation of the Strategy, comprising:

- analysis of key documents to describe the intended role of patients and the public in governance and implementation of the Strategy;
- interviews with actors involved in the national (n=41) and local (n=71) governance and implementation of the Strategy undertaken for the wider evaluation of the Strategy implementation; and
- facilitated discussion groups at a bespoke event whereby patients and members of the public discussed the current involvement of patients and the public in the Strategy, our interim findings on current involvement, and potential options for the future.

In addition, we triangulated our findings against data from focus groups (n=6) with members of the public, undertaken as part of the case studies exploring local implementation of the Strategy.

As there is a lack of understanding among members of the public about AMR, and policy officials are concerned that patients demand and use antibiotics inappropriately, initiatives intended to raise public understanding and awareness have been, and are still, considered to be an important part of the response to AMR at national and local levels. One of the most high-profile public-facing initiatives in England is the Antibiotic Guardian. While the number of Antibiotic Guardians is used as an indicator of success, the effectiveness of the programme in changing behaviour when seeking antibiotics, is yet to be determined.

Members of the public come into direct contact with antibiotics as patients (or parents/carers of patients) and pet owners. Patients described deliberately seeking antibiotics as a strategy for managing concerns about access to future appointments with their GP. Health professionals and members of the public agreed that antibiotics provide validation for patients, and that the prescription itself (as opposed to the promise of antibiotics) had some value. The potential role of non-drug prescriptions in reducing antibiotic use, may be an area that could be explored further with members of the public, patients, pet owners and health professionals.

While there is a potential role for the public as consumers of food to influence use of antibiotics in the food chain, there is a general lack of awareness about AMR and food, and initiatives aimed at consumers (for example, food labelling) could be problematic. However, approaches that focus on improved animal husbandry, and the importance of food hygiene in the home, may be fruitful.

Reflecting on the distinction between provision of information to patients and consumers, and engagement with patients and the public, there has been very little involvement of patients and members of the public in the governance of the Strategy as well as to enhance implementation of the Strategy. This seems anomalous given the high priority given to patient and public involvement in health-related research. Instead, the field of AMR policy tends to see the public almost exclusively as part of the 'problem' to be informed correctly how to behave, with the solutions to AMR lying in

the hands of experts. The report concludes with suggestions about existing infrastructure (for example, the National Voices coalition of 140 health charities, or the Voluntary Community and Social Enterprise Health and Wellbeing Alliance) that could be adopted to begin the process of raising the level of public and patient involvement in the UK's response to AMR.

Background

Antimicrobial resistance (AMR) is recognised as a significant threat to human health with major economic implications¹. The impact of increased AMR on patients and members of the public is likely to be significant, with the loss of important antibiotics resulting in routine medical procedures becoming increasingly dangerous¹ and estimates of up to 10 million additional deaths globally per year by 2050.

The UK Five Year Anti-Microbial Resistance (AMR) Strategy, 2013-2018² was released by the Department of Health (DH), with the Department for Environment Food and Rural Affairs (Defra) and Public Health England (PHE), in September 2013. The primary objective of the Strategy, which encompasses human and animal health, is to slow the development and spread of AMR. The Policy Innovation Research Unit (PIRU) was commissioned to undertake an evaluation of the implementation of the Strategy and some of the evidence underpinning its key mechanisms of change, with a view to contributing to the 'refresh' of the Strategy, planned for 2018.

Studies show that members of the public do not understand AMR, they do not have a clear understanding of how antibiotics work, and have a limited understanding of when antibiotics might be useful and when not³. Implementation of the UK Antimicrobial Resistance Strategy is likely to affect patients directly, particularly when attempts are made to reduce inappropriate prescribing of antibiotics to patients in primary and secondary care. For such reductions to be viable in the long term, the acceptance and support of patients, and a change in professional and patient behaviour, are likely to be required. A similar set of lay and professional changes relating to pet owners seeking antibiotics for their animals may also be required. The gap in public understanding of AMR may be an obstacle to these societal changes occurring, but it is important to recognise that the public's needs and demands for antibiotics are mediated by the professionals they consult.

While involving professionals in framing the Strategy as advisers and as potential implementers is clearly vitally important if the Strategy is to be successful, there is some evidence that involving patients and members of the public as sources of advice on policy content and as active participants in supporting policy implementation can also contribute to increasing the effectiveness of health care policies⁴. There is evidence that public involvement can increase public awareness and understanding of policies, and increase the competencies of lay participants to contribute further. The evidence for the direct instrumental benefits of public involvement is more limited. Despite this, there are also strong normative arguments in support of the intrinsic benefits of public involvement in public policy in democratic societies.

While organisations such as Healthwatch enable health and social care providers, policy makers and commissioners to have easy access to the populations they serve for consultation, review and advice, members of the public may also be a potentially untapped resource in more directly helping to tackle AMR⁵. The public can complement clinical and government efforts through "education of care providers, patients, families, and the public; co-design and development of materials, policies, improvement initiatives, and research; and participation in and promotion of public campaigns"⁵. Members of the public may also be involved in designing and conducting research on AMR. It is now a requirement of all National Institute for Health Research (NIHR)-funded studies to involve patients and members of the public unless there are very good reasons why it is not possible or necessary to do so (for example, in some laboratory-based studies or secondary analyses of routine datasets). The PIRU evaluation of the implementation of the UK Antimicrobial Resistance Strategy has been undertaken with lay involvement both in the project team itself and the advisory group. For

instance, the workshop included in this element of the evaluation was designed and led by one of the lay researchers on the project team.

The purpose of this element of the evaluation of the implementation of the UK Antimicrobial Resistance Strategy is to explore the role of patients and members of the public in the governance and implementation of the Strategy, and potential options for more meaningful involvement of patients and members of the public in future governance and implementation roles. While we include pet owners in the definition of the 'public', farmers are not considered to be within the scope of the definition of the 'public' we have adopted for this element of the project. They are regarded as an interest group with a direct economic interest in policy related to AMR similar to the rest of the food industry.

This element focusses on the following research questions:

- How are patients and members of the public currently involved in the governance and implementation of the Strategy?
- Can patient and public involvement be made more meaningful in Strategy development and future governance and implementation processes?

Methods

We used a range of methods to explore the role of the public in governance and implementation of the Strategy, comprising:

- analysis of key documents to describe the intended role of patients and the public in governance and implementation of the Strategy;
- interviews with actors involved in the national and local governance and implementation of the Strategy undertaken for the wider evaluation; and
- facilitated discussion groups at a bespoke event whereby patients and members of the public discussed the current involvement of patients and the public in the Strategy, our interim findings on current involvement, and potential options for the future.

In addition, we have triangulated our findings against data from six focus groups with members of the public, undertaken as part of the case studies exploring local implementation of the Strategy.

Documentary analysis: We undertook close reading of the UK Five Year Antimicrobial Resistance Strategy⁶, annual reports of progress (Annual progress report and implementation plan, 2014⁷; and the two latest annual progress reports, for 2015⁸ and 2016⁹), and the Government response¹⁰ to Lord O'Neill of Gatley's independent review into AMR¹, to describe and summarise all aspects of governance and implementation of the Strategy that involve patients, patient representatives and the public as individuals and their representatives.

Interviews: As part of interviews undertaken for the wider evaluation, we discussed how patients and members of the public have been involved in governance and implementation of the Strategy at national and local levels; how the involvement of patients and the public influenced governance and implementation of the Strategy; and plans for involving patients and members of the public in governance and implementation of Strategy initiatives in the future. Forty one interviews undertaken at national level, and 71 interviews undertaken at local level were included in the analysis. Interviews were undertaken across England, Scotland, Northern Ireland and Wales, with

both animal health and human health professionals. Interviews were transcribed and a thematic analysis undertaken using NVivo 11.

Workshop: Our provisional findings were presented and discussed at a one-day workshop that brought together members of the public (including pet owners) and patients in central London. The workshop was widely advertised (see Appendix 1 for the advertisement) and potential participants registered their interest in attending. The 24 participants that were then selected to attend covered a broad range of perspectives, and included parents of young children, healthy working-age adults, people with long term conditions, pet owners, and people with an interest in lay governance (in health and more generally). The group included males and females, and a range of ethnicities. All participants were working age and older; and all conversations were in English. The majority of participants had travelled from the Greater London area to participate in the workshop.

The workshop began with a session exploring the delegates' knowledge of AMR and related issues. The main body of the workshop consisted of facilitated small group discussions that explored the current and potential role of the public in governance and implementation of the Strategy from a range of perspectives. See Appendix 2 for the programme of the workshop. Note takers recorded a summary of each of the small group discussions. A thematic analysis of the summary notes was undertaken.

Case study focus groups: Six focus groups with members of the public were undertaken as part of the local case studies in the wider evaluation. The focus group discussions were recorded and transcribed and a thematic analysis undertaken. Focus groups were undertaken in West Norfolk (n=2), Blackburn with Darwen (n=2), and Camden (n=2).

Findings

Importance of awareness-raising activities

Patients and members of the public are described in the current Strategy as contributing to the problem of AMR through a lack of understanding of the issues, inappropriate expectations as to when antibiotics should be prescribed and inappropriate subsequent use of antibiotics. For example:

'Patients frequently believe, incorrectly, that antibiotics will help them recover from all respiratory tract infections faster. In addition, studies have shown that up to 25% of patients in England do not finish the course of antibiotics or keep them for later use, all practices that encourage AMR.'⁶ (p17)

'Patient consultations can be difficult when patients expect antibiotics for self-limiting infections. More needs to be done to educate patients and the public more generally about appropriate antibiotic use. Evidence on the benefits of informing patients about unnecessary antibiotic use is available'.⁶(p17)

Similarly, members of the public at our workshop suggested that the majority of the public did not know about AMR. In particular, the distinction between viral and bacterial infections was considered to be confusing, and there was a lack of understanding among participants about the role of vaccines in preventing bacterial infections. However, they believed that the role of clinicians, public health and veterinary agencies was generally more important than the role of the public, in tackling AMR, thereby potentially downplaying the potential impacts of a lack of understanding of AMR amongst members of the public.

In interviews, some policy officials and professionals noted that there was also some remaining misunderstanding among members of the public about the nature of resistance, but this was not considered to be a significant issue, for example:

‘I think some people sometimes think that they have become resistant to antibiotics, rather than the bugs have become resistant to antibiotics, but it’s not a major misconception. I think they are aware that antibiotics are precious and we shouldn’t be overusing them. Not everybody, obviously, but some people.’ (*Technical expert*)

Given the lack of public awareness of AMR issues, the Strategy includes commitments to ‘promote wider understanding of the need for more sustainable use of antibiotics’⁶; and policy officials that we interviewed suggested that increased awareness and understanding of AMR among the public was still an important policy goal. Policy officials suggested that public awareness may vary across the four nations of the UK, noting that AMR had more coverage in the media in England than, for example, in Northern Ireland. Actions set out in the current Strategy aimed at raising awareness of the public of the need to use antibiotics appropriately are:

- Continuing to raise awareness of AMR issues and participating in European Antibiotics Awareness Day each year
- Exploring how to encourage patients to use community pharmacies for advice
- Development of an outcome measure related to ‘improvement in public and professional knowledge and understanding of antimicrobials and their appropriate use’
- Increasing public engagement to promote key messages about antimicrobial use, including promotion of training of non-health professionals (for example, farmers who administer antibiotics)
- ‘Facilitating public debate to shift the societal view to raise awareness of antibiotics and ways to limit their use. This could include considering the potential for restricting the use of antibiotics for low risk self-limiting infections and/or restricting antibiotic use more widely to affect behaviour change.’⁶ (p35)

Annual progress reports released during the implementation of the Strategy also include ambitions relevant to public awareness, including an ambition for improved understanding of ‘the important messages relating to infection prevention, control and hygiene, and better vaccination uptake, to feed through into changes in antibiotic demand and use’⁷; and exploring how to use ‘behavioural change tools’ to improve public understanding of symptoms and management of self-limiting infections, when to seek advice from a GP or pharmacist, and when antibiotics will help, and the risks of taking them.⁸ We are not aware of the progress against these ambitions and the development of the definition of the outcome measure listed above.

In addition, in response to the recommendation of the O’Neill review for a global public awareness campaign, the Government committed to a ‘regional, highly targeted pilot campaign to determine the most effective way to raise awareness of antimicrobial resistance, and drive behaviour change amongst key audiences’¹⁰ (p8). Objectives of the campaign included ‘improving understanding of the issue, decreasing demand and increasing acceptance of a decision not to prescribe antibiotics’ (p8). Prior to the pilot campaign, public awareness and behaviour was monitored through a survey undertaken by PHE of use, knowledge and attitudes on antibiotics amongst adults in England¹¹ in 2015. Results of the PHE survey suggested that one in five people expected antibiotics when they visited their doctor, and four in ten believed antibiotics could be used to treat viral infections¹². Following the pilot, PHE reported 49% of consumers were aware of the campaign in the North West

of England, and GPs were less likely to report being asked to prescribe antibiotics frequently when not needed than before the campaign¹³.

Policy officials suggested that patient expectations influence prescribing behaviour of professionals, whereby GPs express concerns that they feel pressured to prescribe antibiotics. While policy officials that we interviewed noted there was little evidence that awareness-raising initiatives would result in an attitudinal change, there was a suggestion that enhanced public understanding was an important part of managing patient expectations.

‘They don’t need to be an expert in it but they do need to understand around what their GP might and might not... why they might and might not prescribe antibiotics, otherwise the GPs are going to be under the pressure.’ (*Policy official*)

Annual progress reports provide details of activities undertaken to implement the Strategy at national level. The main activity directed at the public in the first year of implementation was the launch of the Antibiotic Guardian initiative (see Figure 1), which was developed by the British Society of Antimicrobial Chemotherapy (BSAC), and then gifted to PHE which has subsequently led implementation of the Guardians initiative. While this pledge-based initiative was designed to be generally public-facing and has been picked up by, for example, schools and the Scouts, it has generated more interest from within the Health Service, with health professionals being the main participants. Members of the public at our workshop and focus groups had not heard of the Antibiotic Guardian scheme. Policy officials and professionals that we interviewed suggested that the number of pledges in the Antibiotic Guardian initiative may be off-putting to members of the public; and were concerned that uptake of the Antibiotic Guardian was being used as a measure of success, when the effectiveness of the initiative was yet to be proven.

Policy officials and professionals described a range of other initiatives aimed at providing information to members of the public and raising awareness of AMR (for example, the PHE AMR Toolkit for public engagement), and described working with colleagues across the four nations of the UK on initiatives timed to coincide with European Antibiotic Awareness Day. Activities aligned with European Antibiotics Awareness Day (for example, use of social media and messages from a One Health perspective), and the E-bug programme, which began in 2006, were also included in reports of activity. E-bug is aimed at school children and young adults, and promotes awareness of prevention of infection (for example, the importance of hand hygiene).

While members of the public at our workshop were generally supportive of awareness raising campaigns through development of leaflets and posters, they were skeptical of the effectiveness of these type of initiatives, and suggested that television and social media campaigns would be more effective, particularly where campaigns were linked with story lines in popular television programmes. Workshop participants were also supportive of educational initiatives in schools, and frequent opportunistic reinforcement of messages whenever patients came into contact with the NHS.

The most recent Strategy progress report described work with the public from Scotland and Wales. The Scottish Government produced new Stop Antimicrobial Resistance resources with an image of ‘scary bacteria’. The resources featured as the national Community Pharmacy Public Health campaign in the month preceding European Antibiotics Awareness Day and were also distributed to all Health Boards in Scotland for use in hospital and community settings. Planning was underway for a national public awareness campaign of antimicrobial resistance and appropriate prescribing in Wales but we did not find a report of the campaign or evaluation. Following the pilot campaign in North West England, PHE launched a national campaign (for England) in October 2017. Aims of the

campaign included alerting the public to the issue of AMR, and reducing public expectations of antibiotic prescribing¹³.

Policy officials also described making many tools and reports that had been developed primarily for professionals, publicly available, for example, the *Fingertips* dashboard, guidelines that had been developed for primary care and secondary care NHS Trusts, and reports of antibiotic use in animals; although there was no suggestion as to how the public was expected to use this information.

At the local level, many health professionals described small scale campaigns about resistance, prescribing, and infection control (for example, through local radio programmes, press releases, stands in hospitals, campaigns at bus stops and posters in pharmacy windows). These were often timed to coincide with European Antibiotic Awareness Day or World Antibiotic Awareness Week. Professionals contrasted these generally small scale awareness-raising initiatives for AMR with other, higher profile local initiatives, for example, going into mosques 'to get cervical cytology rates up' (*Health professional*), and outreach events outside supermarkets. Some of the local health professionals described relying on less costly forms of publicity (for example, using social media), as they had limited budgets for large campaigns, and suggested that any large scale campaigns must be delivered nationally rather than devolved to local level.

Policy officials and professionals referred to limited evaluation of public-facing initiatives and campaigns, and were unsure of the impact of the work. For example:

'So as part of the pilot project in the north west, they ran last winter a TV campaign with some singing antibiotics and bags that had messages on and posters. I know they have done some assessment and they reckon there was a 6% reduction in patients who said they would ask their GP for antibiotics... I'm not sure whether it's been fully evaluated.' (*Policy official*)

Policy officials and professionals were also unsure which particular groups should be targeted in a public awareness raising strategy, the best methods or approach, and exactly what the objectives of a campaign might be, for example:

'It is about the population, but ultimately, it's more about them, the fact that if I know that you don't need an antibiotic but my child does, so I think that whole personal responsibility thing hasn't got across to people. And I don't know that there's been enough done at a high level, either strategically or through a promotional campaign-type thing to make people sit up and think 'right enough, we don't need an antibiotic and actually, by protecting them, I'm protecting everybody' (*Policy official*)

In terms of language, policy officials suggested moving away from talking about 'antimicrobial resistance', and instead talking about 'hard to treat infections'; or shifting the conversation away from antibiotics altogether, and focusing more on how people should treat minor ailments and when to see a doctor. One policy official suggested developing an image-based campaign, to engage people with low levels of literacy, and policy officials recognized that social media would be an important part of any campaign aimed at younger people.

Similarly, members of the public described the current AMR messages as 'remote' and abstract. For example: 'it feels invisible to me'. They described the importance of understanding 'why we need to act', and what specifically they were required to do. Campaigns that promote handwashing were considered to be more relevant and actionable than campaigns directly focused on appropriate use of antibiotics. Members of the public expressed concern about television advertisements for products marketed for use in the home to remove bacteria (e.g. antibacterial wipes and cleaning products), and suggested domestic use of antibacterial products had led to increased resistance. Aspects of the AMR message that were considered to be important included statistics on the human

cost of AMR, adverse effects on the environment, and the message 'that this is about everyone, not just the individual'. Members of the public cautioned against stigmatising people who use antibiotics extensively but appropriately (e.g. people with long term conditions who may need to use antibiotics prophylactically). They also suggested that the WHO campaign that discouraged local populations from taking anti-malarial drugs for managing fevers that are not caused by malaria, might provide useful lessons for antibiotic use campaigns.

Enhancing interactions with patients in primary care and the community

Many policy officials raised the potential impact of the expectations of patients during GP consultations on the decision to prescribe an antibiotic, and indicated that they believed that patients generally expected to receive antibiotics when they were ill, particularly when patients pay for their care (as in private dentistry).

Members of the public noted that they are conscious that they may not be able to see their GPs again promptly if they need to in the near future, and described being likely to insist on receiving a precautionary prescription for antibiotics for precisely this reason. They also suggested it was particularly difficult for GPs to say, 'No' to patients when they live in very small communities where patients know the GPs very well.

Policy officials suggested that managing expectations of patients for self-limiting bacterial infections which would respond to an antibiotic was especially difficult, for example:

'We know that they face issues when they say to people, "actually you do have an infection but if you take these steps for the next five days we think your body will fix itself", and people are, like, 'no, I want that prescription"' (*Policy official*)

Similarly, members of the public at our workshop and in focus groups described a need for people to understand their bodies better and the need for education to be more willing to 'let nature take its course', and 'give their body time to deal with the condition'. There was also a very strong sense that members of the public must take more personal responsibility for their own health and engage in preventive activities such as hand washing. Members of the public suggested that the language used by health professionals could make a difference, for example, saying "sorry" for prescribing antibiotics, and highlighting side-effects they may experience from taking the drugs.

In terms of the consultation, health professionals suggested that a great deal of understanding is conveyed by a GP prescribing an antibiotic, and a broader approach to understanding the prescribing of antibiotics might be helpful for reducing patient demand.

'I think it's about saying, well, thinking of the person holistically. They're not just a machine that needs their oil tanked up' ... 'but I think there's something about the social side of the interaction that they need to maybe take into account. So, I think the marketing people could start working on some of that as well.' (*Technical Expert*)

Similarly, members of the public highlighted the social side of the interaction with their GP, describing the importance of the GP listening to the patient, but that GPs may not have enough time to explain why an antibiotic might not be required. Some policy officials and professionals described the value of an antibiotic in providing validation for the patient, acknowledging that they are in fact as ill as they thought they were, for example:

'As a patient, you're like, I'm really sick now if I'm getting an antibiotic' (*Policy official*)

Figure 1. Examples of Public awareness raising campaigns



Similarly, some patients described a sense of validation when they received a prescription from their GP, as it shows that 'it's serious'. Both policy officials and patients suggested that the paper prescription has a value, in and of itself, and that a printed document for the patient, similar to a prescription, might be helpful in managing patient expectations. One policy official described the potential role of a non-drug prescription in a patient interaction:

'For that member of the public to get that piece of paper, it's nearly as good as a prescription to them, because it shows that the GP or the prescriber has listened to them and they've said, "Yes, I think there might be an issue here. I don't think you have an infection, but let's look at this," and then they will be happier with that' (*Policy official*)

Many policy officials and professionals identified a potential role for diagnostic tools at the point of care in managing patient expectations, by demonstrating that antibiotics are not required. For example:

'I think we need to... [make] more use of the newer methods, diagnostic tools that might be out there, so some of the like throat swabs and some of the screening that you can do at the bedside or when you've got the patient with you so you can actually say to the patient, well here's the result and no we don't need an antibiotic on this occasion' (*Policy official*)

However, members of the public suggested that GPs do not have time to run such diagnostic tests.

Policy officials also raised the issue of patient expectations regarding access to diagnostics, and suggested that increased availability of some point of care diagnostic testing would be helpful. For example, one interviewee suggested increasing access to diagnostic tests through community pharmacists:

'Knowing that I can easily go to a pharmacy, even if it's a ... you know, last thing on a Friday night because I know the pharmacy will be open on a Saturday anyway, so it's about having these things in place for people to feel confident to perhaps not seek an antibiotic first, but to wait' (*Policy Official*)

Members of the public also suggested the potential for community pharmacists to have a more prominent role in prescribing, for example, through providing screening tests and advice to patients, and potentially reducing the need for the patient to visit the GP.

Working with pet owners

Policy officials and professionals noted that work with veterinarians relevant to AMR had largely focussed on the farming sector rather than owners of companion animals. However, some suggested that initiatives targeted at pet owners might be an effective element of an awareness raising campaign focusing on reducing demand for antibiotics.

Pet owners in our discussion groups noted the importance of keeping pets healthy, and described a range of reasons for taking pets to the vet, including serious wounds, abnormal behaviour, vaccination and euthanasia. Pet owners described the decision to seek treatment and take up treatment options (including use of antibiotics) being affected by the potential cost of treatment, the value of the animal to the owner (financial and emotional), and whether the owner had insurance. Pet owners described differences in experiences between practices that are independent and those described as being part of a chain of practices, suggesting practices that were members of a chain were more likely to try to sell products to pet owners. Unlike the separation between prescribing and dispensing of antibiotics in human health, pet owners were conscious of the potential conflict of interest among veterinarians, in that they work in the private sector and both

prescribe and dispense antibiotics. Some owners described veterinarians that 'just want to sell you antibiotics to make money'. They emphasised the importance of the relationship and trust between owner and veterinarian.

There was a great deal of confusion over the potential links between use of antibiotics in pets and AMR in humans. Pet owners described sources of information that they used in addition to veterinarian advice, including a range of websites, pet insurance helplines, animal breed associations, pet shops, and the RSPCA (and other shelters). Pet shops were identified as a potentially very helpful and widespread source of information that would be accessible to a broad range of people, including those who do not usually take their pet to the vet. While the pet owners we interviewed had not seen posters about AMR, they suggested it would be very helpful if messages about AMR targeting pet owners were consistent, regardless of location and target audience. Similarly, professionals described posters developed at national level that were relevant to human patients and pet owners that had been produced for GP surgeries and veterinary practice waiting rooms.

'The idea is that we've got some joined-up thinking and there's some simple messages to go in doctors' and vets' waiting rooms, we thought was a very, very useful model. Whether or not it makes a huge difference very quickly, I don't know, but it's a start, it's a start and it gets people thinking, so hopefully, people are more aware of the issue when they go to their doctor and they're more aware of the issue when they ask their vet for antibiotics'
(*Veterinarian*)

Potential role for consumer action in food

While food-producing animals may be treated for infections using antibiotics in the UK, the Food Standards Agency (FSA) requires that all food in the UK is free of antibiotic treatments at the point of sale. There is a potential synergy between FSA food safety requirements and regulations on antibiotics, and consumer preferences. Policy officials suggested that members of the public could be mobilised to influence prescribing of antibiotics in food-producing animals through their actions as consumers, thereby influencing food retailers, noting that consumers are not likely to want antibiotics in their food, for example:

'people won't want antibiotics in their food, they might want the antibiotics when they think they need them, to take them for their illness but I think people don't want, in this country, to feel that they're being given antibiotics unnecessarily.'
(*Policy official*)

Members of the public in our discussion groups had a generally low level of knowledge about how food is produced, and most participants had not considered food in the context of AMR before. For example, they did not mention the role of the veterinarian in treating sick farm animals, prescribing antibiotics, and advising on animal husbandry; and the benefits of improved animal health, and disease eradication, to reduce the need for treatment were only mentioned in passing. However, the role of food hygiene and cooking were identified as strategies to reduce exposure to bacteria (including those with resistant genes) in food in the home.

Members of the public in our discussion groups suggested a range of potential policy interventions specific to food. They were very supportive of awareness-raising and educational initiatives, particularly where the scope was broader than use of antibiotics and included general production practices. Use of celebrity chefs, and radio, and television shows such as *Country File*, were suggested as potential vehicles for awareness-raising initiatives. However, views on the potential role of government were mixed. While many participants saw an important role for government in

introducing policies such as taxes, incentives, or production standards, others rejected this approach as too patronizing describing these interventions as 'nanny state'. Members of the public at our workshop suggested policy should be evidence-based regardless of whether it was regulatory or awareness-raising.

Policy officials and professionals noted the importance of transparency for consumers of food, and members of the public discussed food labelling at length in our discussion groups. There was some disagreement, but most participants felt food labels contained too much information and that the topic was too complex for a label (although one participant suggested a risk rating system). Similarly, policy officials and professionals considered labelling to be a complex area. For example, labelling a product as 'antibiotic free' was described as potentially misleading to consumers, as some antibiotic substances may develop naturally: 'all food is clear of any antibiotic treatment, but there's no such thing as antibiotic free' (*Technical expert*). However, policy officials and professionals suggested that food retailers and quality assurance schemes could have a role in conveying accurate information about antibiotics and food.

Policy officials and professionals noted that food retailers are exploring incorporating responsible use of antibiotics into their supply chains, and suggested that while complex, an approach that focuses on improving animal husbandry, 'driving forward best practice without creating perverse incentives or the wrong impression [i.e. ensuring that animals are still treated when this is necessary]' (*Policy official*) might be a sensible way forward. Members of the public discussed food production at length, with some participants suggesting that 'organic' food production practices resulted in better animal health and welfare, and lower use of antibiotics. During discussions, members of the public suggested a range of financial incentives, including a tax on antibiotics (or food produced with antibiotics), an incentive-based system that would reward farmers who did not use antibiotics, and state subsidies for farmers (direct payments) that could be tied to low usage of antibiotics. Some members of the public suggested that government policies targeted at primary production would have a limited impact as most animal-derived food is imported into the UK. These discussions with members of the public about food production suggest that members of the public can be engaged in generating policy ideas worthy of consideration.

Improving involvement and engagement with patients and public

Models of engagement with patients and the public may include a range of activities, including, among others, consultation exercises, service user evaluations, participation in research and representation in governance processes. Interactions may be one-off, multiple or continuous; involving individuals and/or groups. The role of the patient or member of the public can vary along a continuum of engagement from a relatively passive recipient of information (as in awareness-raising exercises) to leading a publicly driven accountability process¹⁴.

While many policy officials emphasized the importance of engaging with the public, they noted that engagement had been patchy to date; and that while there had been information initiatives aimed at patients and members of the public, engagement on AMR at other points on the continuum of engagement described above was lacking. For example:

'our engagement with patients and patient groups so far has been ... is not good. It's been patchy. And I think that's something that we can improve on... I think we've done a bit about putting information out there, but actual engagement, direct engagement with patients and public about their understanding and what they expect ... I think there's probably more that could be done; we could be more imaginative.' (*Policy Official*)

Policy officials and professionals described the involvement of a small number of non-governmental organisations (NGOs) in implementation of the Strategy, for example, RUMA (Responsible Use of Medicines in Agriculture Alliance), whose membership comprises interests in agriculture, veterinary practice, animal medicines industry, farmers, retailers, consumers and animal welfare organisations, has been involved in development of targets alongside Government and other industry groups.

There has been very little involvement of NGOs in implementation of the human health aspects of the Strategy, with NGOs that represent patients and groups such as consumer lobbies largely absent from governance and implementation processes at national level in the four UK countries. Policy officials and professionals noted that there is considerably less civil society involvement in AMR than, for example, in HIV/AIDS policy, and suggested that this may be a reflection of the technical nature of the issue, although, even in genomic medicine, a similarly technical field, patient groups and wider stakeholders are involved in policy implementation. This more limited NGO involvement may be because AMR affects everybody, as opposed to a particular type of patient, or specific condition. Thus there is no obvious single patient group to take a strong interest. However, policy officials and professionals suggested patient groups that have frequent contact with health services and are immuno-compromised would be particularly relevant to AMR. While the Norwegian Cancer Society has identified AMR as one of its main priorities, condition-specific patient groups are yet to do so in the UK (although the Cystic Fibrosis Trust has funded research in the area).

Across the Devolved Administrations, policy officials and professionals at national level described a small number of governance arrangements that included patient groups or representatives, however, interviewees did not identify equivalent opportunities for involvement in England. For example, the Patient and Client Council in Northern Ireland was represented on a regional strategic group involved with delivery of Strategy initiatives; and recruitment was underway for members of the public to join the Regional Healthcare Associated Infection and Antimicrobial Stewardship Improvement Board, a regional multi-agency board responsible for driving implementation of AMR initiatives in Northern Ireland. Similarly, the SAPG (Scottish Antimicrobial Prescribing Group, a clinical multi-disciplinary forum) includes two lay members, although, one of the “lay members” was described as a retired chief pharmacist, as opposed to a person who might be able to bring a distinct lay perspective:

‘Well, you see, this is the problem. The patient public partners, the people who will agree to, in their retirement, take on roles where they go to committee meetings and things tend to be of a medical type background’ (*Technical expert*)

Policy officials and professionals suggested that more work was required in this area, for example:

‘Do patients’ associations really worry about drug resistance? Probably not actually, though they would worry about ... health care associated infections, so it’s probably an area where we haven’t maximised the opportunities’ (*Policy official, England*)

In addition to the involvement of lay people within policy governance and implementation, there was also a suggestion that the public could influence policy from outside the policy process, through exerting pressure, for example, from a One Health perspective:

‘It’s almost a matter of enough of civil society coming together across both the agricultural farming and human health side and also consumers to start putting pressure on governments and we don’t actually have that yet.’ (*Policy official, England*)

Policy officials noted invitations to patient representatives to attend events to discuss implementation of policy that had been declined but they were not able to explain why the invitations had not been accepted, and suggested that more thought was required to bring civil society into governance for AMR, for example:

'I think we're not quite there yet which is why we're, in effect, doing it through our expert committees and using our expert communities to push us from an evidential base to say actually you should be doing more on this' (*Senior policy official, England*)

Policy officials suggested that wider stakeholder engagement, for example, inclusion of patient representatives in groups charged with delivery of Strategy initiatives, might be options for increasing engagement with civil society. At the local level, health professionals described interactions with Patient Participation Groups attached to GP surgeries and to Clinical Commissioning Groups or equivalent (for example, local Health Watch), but no specific initiatives on AMR were identified.

While the members of the public at our workshop were likely to have been particularly interested in patient and public involvement (perhaps more so than people who would not choose to attend the workshop), they were very clear that increased patient and public involvement in governance and implementation of the Strategy was both desirable and feasible. One novel idea that emerged was the suggestion of a coalition of animal and human health charities to provide a public face to tackling AMR. Given that people with certain conditions are particularly reliant on antibiotics, charities representing them could promote a message along the lines of 'we rely on these antibiotics, please be responsible and help us preserve them' (*Member of the public*). It was suggested this might be especially effective if it represented people with health conditions across the life-course, and included charities representing neonatal patients, and people with cystic fibrosis, cancers, and chronic obstructive pulmonary disease (COPD). The Cystic Fibrosis Trust has funded research into non-antibiotic forms of therapy as part of its response to AMR¹⁵. Members of the public suggested many organisations that might be relevant to AMR across human health, animal health and the environment, including:

- RSPCA and animal events, e.g. Crufts
- Greenpeace
- SAGA
- AGE UK and other groups representing older people
- Parent-Teachers' associations and schools
- Condition-based charities, for example, the Cystic Fibrosis Trust and various cancer charities
- Veterinary colleges
- Patient Participation Groups and Young Carer Forums

In addition, members of the public suggested that celebrities, members of the Royal Family, and sports personalities could be influential in communications and engagement initiatives.

Discussion

There is a lack of understanding among members of the public about AMR³, and policy officials and professionals described patients demanding and using antibiotics inappropriately. Thus initiatives intended to raise public understanding and awareness have been, and are still, considered to be an important part of the response to AMR at national and local levels. Members of the public suggested that any advertising campaigns must be actionable, and that campaigns encouraging personal responsibility for maintaining health through hand washing might be more effective than campaigns promoting appropriate use of antibiotics. Professionals suggested that pilots of any large-scale public facing campaigns should be fully evaluated before being rolled out on a wider scale, and that a more targeted approach might be appropriate. For example, a recent report on the Swiss public awareness campaign about the need to use antibiotics more prudently and adopt preventive

measures (e.g. in relation to personal hygiene), describes a segmentation study that was undertaken that identified four population sub-groups that had different expectations of antibiotics, and would require four different approaches to awareness raising campaigns¹⁶.

One of the most high-profile public-facing initiatives in England is the Antibiotic Guardian, a pledge-based campaign aimed at both members of the public and health professionals. While the number of Antibiotic Guardians is used as an indicator of success, the initiative attracts more health professionals than members of the public, and effectiveness of the programme in changing behaviour when seeking antibiotics, is yet to be determined.

Members of the public come into direct contact with antibiotics as patients and pet owners. Patients described deliberately seeking antibiotics at a first GP consultation because they were concerned that they would be unable to have a follow-up appointment with their GP in a timely way should their infection turn out not to be self-limiting. Health professionals and members of the public agreed that antibiotics provide validation for patients, and that the prescription itself (as opposed to the promise of antibiotics) had some value. Potentially a non-drug prescription could provide information about how to manage symptoms, what to expect as the illness progresses and when to seek further treatment. While the impact of non-drug prescriptions on antibiotic use is not known, they have been used outside the field of infectious disease to help people manage their long-term conditions, for example, bibliotherapy and information prescriptions¹⁷, and Green Prescriptions for physical activity¹⁸. The need for patients to feel some validation from their GPs that they are unwell and the potential role of non-drug prescriptions in reducing antibiotic use, may be an area that could be explored further with members of the public, patients, pet owners and health professionals.

Reflecting on the distinction between provision of information, and engagement with patients and the public, policy officials and health professionals suggested that there had been very little involvement of civil society in governance and implementation of the Strategy. Given the high priority given to patient and public involvement in all kinds of health-related research in order to ensure that research takes the needs, priorities and perspectives of the users into account, it seems anomalous that the same logic is not applied to policy making in the case of the direction and implementation of the UK Antimicrobial Resistance Strategy. Instead, the field of AMR policy tends to see the public almost exclusively as part of the 'problem' to be informed correctly how to behave, with the solutions to AMR lying in the hands of experts.

There is established infrastructure that can be adopted to begin the process of raising the level of public and patient involvement in the UK's response to AMR, such as GP practice Patient Participation Groups and Healthwatch at local level in England, and groups such as MRSA Action UK at national level. Policy officials could also discuss mechanisms for future involvement of civil society in governance and implementation of the Strategy with the National Voices coalition of 140 health charities, or the Voluntary Community and Social Enterprise (VCSE) Health and Wellbeing Alliance (a partnership between 21 voluntary sector organisations and the health and care system, jointly managed by DHSC, PHE and NHS England). Alternatively, policy officials could establish a bespoke coalition of charities that includes animal, environmental and human health interests for this purpose. Potentially, lay members could be invited to join project teams or consideration could be given to involving lay representatives in steering groups charged with development and implementation of the Strategy. The Government's Civil Society Strategy, which is currently under development in England (Department for Culture, Media and Sport), may suggest mechanisms relevant to involvement of civil society in the governance and implementation of future AMR policy.

Appendix one – Advertisement for workshop

Workshop on Patient and Public Involvement in the UK Antimicrobial Resistance (AMR) Strategy

Date: 17 May 2018 **Time:** 11am – 3.30pm

Venue: Friends House, Euston Road, London

Are you interested in resistance to antibiotics? Perhaps you are a patient who has been given antibiotics for an infection, or a parent or carer who has sought antibiotics for your child/relative. You may have been prescribed antibiotics for your pet, or perhaps you are concerned about the antibiotics used in animals. Are you concerned about the best ways to prevent and stop the spread of infections? Would you be interested in discussing how the public and patients can be more involved in delivery of the UK Antimicrobial Resistance (AMR) Strategy?

If you can answer **yes** to any of the above and live in the London area then we would like to invite you to our workshop, and to hear your ideas on what the Government can do to tackle AMR. You do not require any specific experience or skills to attend the workshop – we are interested in gathering a broad range of perspectives.

Who are we?

We are a team of researchers who are funded by Department of Health to evaluate the UK Antimicrobial Resistance (AMR) Strategy. Our website (www.PIRU.ac.uk) provides more information about our work.

Format

The workshop will include a brief presentation and discussion in small groups. This will be an opportunity for people to share their experiences and views on the use of antibiotics in their everyday lives (e.g. for themselves and their pets), and how they think they might be able to influence the use of antibiotics more widely. Participants should be ready to discuss examples from their own experience. Participants will be sent a very short summary of the Strategy as background before the workshop.

A brief summary of the discussions will be sent to participants following the workshop.

Contact details

If you are interested in attending the workshop then please contact Elizabeth Eastmure (Elizabeth.eastmure@lshtm.ac.uk) by Friday, 4th May 2018, and tell us in a few sentences why you would like to attend. We are looking for about 20 people so we may not be able to take everyone who responds to this advertisement but we will ensure we have a diverse representation.

Your travel expenses will be paid for, lunch will be provided, and you will be given £70 in High Street vouchers for attending.



Appendix two: Programme for workshop on Patient and Public Involvement in the UK Antimicrobial Resistance (AMR) Strategy

Date: 17 May 2018 **Time:** 11am – 3.30pm

Venue: Marjorie Sykes room, Friend's House, Euston Road, London, NW1 2BJ

Tea and coffee available from 10:30am

- 11:00 Welcome and introductions
- 11:10 Brainstorming as large group on Flipchart: What does AMR mean to you and why is it important?
- 11:25 Presentation about the AMR Strategy and PIRU evaluation
- 11:40 Small group discussion (see attached)
- 12:20 First rotation
- 1:00 Lunch
- 1:50 Second rotation
- 2:20 Third rotation
- 2:40 Feedback from group work: Facilitators provide max 5 mins feedback from their group
- 3:20 Wrap up and close
- 3:30 Finish



Small group discussions

Each group to have about 6 participants, depending on actual numbers on the day. Each group to be supported by a facilitator and a note-taker from the project team.

Group A - Food

Consider the following questions and/or make up your own & write key bullet points to present to large group

1. As a consumer, what can you do about AMR and food?
2. What could the Strategy include to help consumers tackle AMR?

Areas to consider might be: how your food is produced, food safety, farming practices, what food to buy, where to buy food, food choice eg vegetarianism/veganism/organic/free range, growing own food, meat choices, product labelling.

Group B – Pets

Imagine you are a pet owner, or think back to a time you have had a pet. Consider the following questions and/or make up your own & write key bullet points to present to large group

1. As a pet owner, what can you do about AMR and pets?
2. What could the Strategy include to help pet owners tackle AMR?

Areas to consider might be: symptoms in pets, decision to take pet to the vet, communication around antibiotics (do you ask for them or wait for vet to suggest), how to know if your pet needs antibiotics, what instructions do you follow to give your pet antibiotics, where else other than vet do you get your information from regarding giving your pet antibiotics?

Group C – Patients and Parents/Carers/Family

Consider the following questions and/or make up your own & write key bullet points to present to large group

1. As a patient/parent/carer/family member, what can you do about AMR and your/your loved one's health?
2. What could the strategy include to help patients/parents/carers/families tackle AMR?

Areas to consider might be: how you prevent the spread of infection in and around the home; how do you prevent your family getting infections; how do you decide when to ask for/take antibiotics for yourself/for your family; do you have any concerns about your child/members of your family taking antibiotics); do you think vaccination could help; where do you get your information from about antibiotics; have you heard of any campaigns about antibiotics or handwashing, if so what do you think about them?

Group D – Public participation in decision making

Consider the following questions and/or make up your own & write key bullet points to present to large group

1. As a representative of an organisation (eg Age UK) or member of the public, what can you do about AMR?
2. What could the strategy include to help the public participate in tackling AMR?

Areas to consider might be: involvement in decision making around delivery of health and social care services, participation in development of local plans and strategies, involvement of NGOs in development of policy, participation of existing groups (eg school based, faith based, community groups), changing public perception of antibiotics, creating opportunities and mechanisms for public voice.

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