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Impact of antibiotic side effects and allergies on patient adherence and attitudes: a mixed methods study in England

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Abstract

Background

The overuse and misuse of antibiotics significantly contributes to antimicrobial resistance (AMR). Adverse reactions to antibiotics are well documented, but their impact on patients' behaviours requires further exploration.

Aim

To explore how side effects and allergies influence patients' behaviours to prescribed antibiotic use.

Design and setting

A mixed-methods explanatory sequential study in England.

Method

A survey of 1,059 adults with prior experience of antibiotic side effects was conducted. Descriptive statistics identified common side effects and behavioural responses, while chi-squared tests explored demographic differences. Focus groups were held with 21 participants, recruited through a research panel. Thematic analysis captured deeper insight into participants' personal experiences.

Results

Many antibiotic side effects were identified, presenting shortly after consumption and affecting several aspects of patients' lives. One-third of respondents (31%, n = 325; 95% CI: 28-34%) were unaware of potential side effects beforehand, citing inaccessible patient information leaflets and limited communication from healthcare professionals as barriers. Almost half (42%, n = 440; 95% CI: 37-47%) did not complete their antibiotic course following the side effects, with 32% (n = 142; 95% CI: 28-37%) stopping without medical advice. Many allergy diagnoses were made in childhood without follow-up assessments.

Conclusion

Antibiotic side effects can significantly disrupt patients' lives and discourage appropriate use of antibiotics. Providing accessible information before prescribing may help manage expectations and support self-management of side effects. Patients with longstanding allergy labels should be encouraged to undergo

reassessment to ensure that they are not contributing to AMR by unnecessarily avoiding the use of first-line antibiotics.

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Introduction

Antimicrobial resistance (AMR) poses a significant global threat, with projections suggesting it could become one of the leading causes of death by 2050 and cost the global economy up to \$100 trillion¹. In response, the UK published a 5-year National Action Plan (NAP) in 2019, which included an aim to optimise the use of antimicrobials with an underpinning action to reduce antibiotic-resistant infections in England by 10% by 2025². Whilst a 1.6% reduction was observed between 2018 and 2022³, progress remained below the desired trajectory.

Patients' use of antimicrobials plays an important role in the control of AMR. By taking antibiotics only when necessary and as prescribed, patients may help to keep antibiotics effective for longer⁴. However, limited public knowledge on antibiotics and their appropriate use can lead to patients demanding them for common infections⁵, which can drive overprescribing⁶. Over 70% of antibiotics are prescribed in primary care⁷, with other key drivers of overprescribing in these settings including time pressures and prescriber habits⁸.

Antibiotics commonly cause adverse reactions, in the form of allergies and side effects. For example, antibiotic-associated diarrhoea occurs in 5-35% of patients, depending on the type of antibiotic⁹, and approximately 6% of the UK population carry a penicillin allergy label¹⁰. If identified, adverse reactions to antibiotics can influence how and when they are prescribed for an illness. These reactions may also influence patients' perceptions of antibiotics and compliance with prescriptions.

Previous UK public surveys have indicated that 19% of people who didn't complete their full course of antibiotics stopped taking them because of perceived side effects¹¹, and that 20% of respondents reported that side effects to antibiotics were a major problem (a further 20% reported that they were a minor problem)¹². Despite this, public knowledge of antibiotic side effects remains limited¹³. We hypothesised that there is a gap in the evidence around public understanding and experiences of side effects from antibiotics and how this may translate into patient behaviours when prescribed antibiotics. Further understanding of this behavioural pathway is vital to developing successful behaviour change interventions that contribute to a reduction of AMR in the UK.

This study aimed to explore public experiences of, and attitudes towards, antibiotic side effects and allergies, and to understand how these influence antibiotic use.

Method

Study design

A mixed-methods explanatory sequential study design with two distinct stages was used¹⁴. An initial quantitative data collection and analysis stage examined respondents' personal experiences with oral antibiotics and their side effects; the second qualitative stage was used to provide more in-depth understanding on key stage one findings. Social grade was determined using the National Readership Survey (NRS) classification¹⁵ which categorises individuals based on their occupation.

Quantitative Survey

Development

The survey questionnaire comprised three sections: (1) experience of side effects during antibiotic use; (2) knowledge of and attitudes towards side effects to antibiotics; and (3) allergies to antibiotics (Supplementary Box 1). Each section contained a combination of single choice, multiple choice and free text questions. The list of side effects used as options in the survey was taken from a review of common adverse effects experienced from oral antibiotics regularly used in community care¹⁶.

Recruitment

The UK Health Security Agency (UKHSA) commissioned Basis Research, an independent market research company, to conduct an online quantitative survey with adults in England. The objective was to gather insights from individuals who had previously experienced side effects from antibiotics. Participants were recruited through an established online research panel. Screening questions were used to confirm eligibility prior to participation. Eligibility criteria required that all respondents had experienced side effects from antibiotics at some point in their lives, with 50% of the sample having experienced these within the past 12 months. The survey was conducted from 27 November 2023 to 4 December 2023 and quotas were applied to ensure demographic representation in line with the adult population of England.

Data analysis

Survey responses were entered into Microsoft Excel for descriptive analysis and visual presentation of the quantitative data. Pearson's chi-squared test, corrected for survey design, tested for differences in proportions across levels of categorical variables.

Focus groups

Recruitment

Participants were recruited through The People's Pulse, a market research panel provided by UKHSA and FlexMR, an independent research consultancy. Individuals were invited to participate if they had experienced side effects to antibiotics in the previous 12 months. Those interested completed a recruitment survey to provide demographic information and a profile of their experience with antibiotic side effects. These data were used to select a diverse panel of participants. All focus group participants provided written consent, and verbal consent was given by each participant before commencing the discussions. Participants were offered a £40 high-street voucher as an incentive for participation.

Data collection and analysis

Focus groups were conducted by two researchers (LC and CVH) who were unknown to the participants and continued until the researchers were satisfied that data saturation had been met. A total of six focus groups were held, involving 21 participants in total. Group sizes ranged from two to five participants. Discussions lasted between 60 and 90 minutes and were directed by a topic guide (Supplementary Box 2), which was designed using the Common-Sense Model (CSM) of illness representations¹⁷. This model has been established as a method to evaluate how an individual's thought processes and emotions influence their adaptation to an "illness danger"^{18 19}. The topic guide was iteratively adapted following the survey findings and before each focus group by the same two researchers. Data from the focus groups were fully anonymised and stored on secure, password-protected UKHSA systems, in accordance with the Data Protection Act 2018 and General Data Protection Regulations (GDPR).

Anonymised focus group transcripts downloaded from The People's Pulse platform were thematically analysed²⁰ using NVivo (2020) software and coded by both

researchers. The lead researcher (LC) used inductive thematic analysis to code and to generate themes from all transcripts, whilst the supporting researcher (CVH) separately coded 20% of the transcripts and generated themes. The researchers then discussed their findings and agreed upon the final themes.

Results

Participant characteristics

A total of 1,059 respondents completed the survey and 21 participated in focus groups (Table 1). Most respondents in both samples were female – 57% (n = 603) and 71% (n = 15) respectively, under 55 years of age – 61% (n = 647) and 53% (n = 11) respectively, and of white ethnicity – 81% (n = 858) and 90% (n = 19) respectively.

Of the survey respondents, 684 (65%) had taken antibiotics within the past year, with 401 (59%) having taken more than one course. Participants' most recently reported use of an antibiotic was for urine infection (n = 185, 17%), earache (n = 103, 10%), sore throat (n = 84, 8%), cough (n = 83, 8%), skin infection (n = 75, 7%), flu (n = 63, 6%), sinusitis (n = 55, 5%), common cold (n = 25, 2%) and other infection (n = 278, 26%).

All 21 focus group participants were recruited on the basis of having experienced side effects to antibiotics in the 12 months prior to interview. Several participants (n = 7) were regular users of antibiotics, taking 5 or more course within the past year for a long-term or chronic illness.

Quantitative survey findings

Of the 1,059 survey respondents, 529 (50%; 95% CI = 47-53%) had experienced side effects from antibiotics in the 12 months prior to completing the survey. Among those who had taken antibiotics within the past year (n = 684), 522 (76%; 95% CI = 73-80%) had experienced side effects during that time. From a predefined list of commonly reported side effects, the most frequently cited were diarrhoea (n = 309, 29%; 95% CI = 26-32%), nausea (n = 302, 29%; 95% CI = 26-31%), skin rash/itchy skin (n = 289, 27%; 95% CI = 25-30%), headache (n = 210, 20%; 95% CI = 17-22%) and vomiting (n = 198, 19%; 95% CI = 16-21%) (Figure 1). Most respondents (n = 766, 72%; 95% CI = 70-75%) noticed the side effects within two days of starting the antibiotics.

Two-thirds of respondents (n = 699, 66%; 95% CI = 63-69%) were aware of the possibility of side effects before taking the antibiotics, while 325 (31%; 95% CI = 28-33%) were not. Awareness was significantly higher among those aged 18-34 (n = 244, 75%; 95% CI = 70-80%; $P < 0.001$); those aged 75 and over were significantly less aware (53/103, 51%; 95% CI = 42-61%; $P = 0.002$).

When asked how they were made aware of potential side effects to antibiotics (multiple responses allowed), 530 (50%; 95% CI = 47-53%) read the information leaflet supplied with the antibiotics, 375 (35%; 95% CI = 33-38%) were advised by a healthcare professional – 238 (22%; 95% CI = 20-25%) during the consultation and 183 (17%; 95% CI = 15-20%) when collecting the antibiotics, 134 (13%; 95% CI = 11-15%) searched online and 106 (10%; 95% CI = 11-15%) were informed by friends or family. Female respondents read the information leaflet (n = 320, 53%; 95% CI = 49-57%) significantly more than male respondents (n = 210, 46%; 95% CI = 41-50%; $P < 0.001$). Respondents aged 18-34 were more likely to have searched online (n = 73, 22%; 95% CI = 18-27%; $P < 0.001$) and to have been informed by friends or family (n = 54/325, 17%; 95% CI = 13-21%; $P < 0.001$) and by healthcare professionals during a consultation (n = 105, 32%; 95% CI = 27-37%; $P < 0.001$) and when collecting antibiotics (n = 94, 29%; 95% CI = 24-34%; $P < 0.001$).

Most respondents rated their side effects as mild (n = 397, 37%; 95% CI = 35-40%) or moderate (n = 474, 45%; 95% CI = 42-48%), with 162 (15%; 95% CI = 13-17%) rating them as severe. Perceived severity increased with age, with those aged 55 years and over more likely to report severe side effects (Figure 2). Males were more likely to report mild side effects (n = 192, 42%; 95% CI = 37-46%) than females (n = 205, 34%; 95% CI = 30-38%; $P < 0.001$).

After experiencing side effects to antibiotics, 440 (42%; 95% CI = 39-45%) respondents did not complete their antibiotic course. Of these, 142 (32%; 95% CI = 28-37%) stopped of their own volition (Figure 3). Younger respondents (18-34) were significantly more likely to complete the course (n = 213, 66%; 95% CI = 60-71%; $P < 0.001$).

After noticing their side effects, the most common action was to contact a healthcare professional (n = 567, 54%; 95% CI = 51-57%), whilst 297 (28%; 95% CI = 25-31%) carried on with usual activities or took no action (Figure 3). Females were more likely

to take self-care remedies (n = 119, 20%; 95% CI = 17-23%) than males (n = 69, 15%; 95% CI = 12-18%; $P < 0.001$). Younger respondents (18-34) were more likely to self-care for their side effects; including taking extra rest (n = 114, 35%; 95% CI = 30-40%; $P < 0.001$), taking time off work (n = 68, 21%; 95% CI = 17-25%; $P < 0.001$) and taking self-care remedies (n = 97, 30%; 95% CI = 25-35%; $P < 0.001$). When seeking advice for their side effects, respondents aged 55-74 were more likely to contact their local GP practice (n = 66, 43%; 95% CI = 35-50%; $P < 0.001$), whereas younger respondents were more likely to ask advice of friends and family (n = 47, 14%; 95% CI = 11-18%; $P < 0.001$), and use other NHS services such as the NHS website (n = 41, 13%; 95% CI = 10-18%; $P < 0.001$), NHS 111 (n = 45, 14%; 95% CI = 10-18%; $P < 0.001$) and walk-in centres (n = 23, 7%; 95% CI = 4-10%; $P < 0.001$).

Respondents with mild side effects were more likely to complete the course (n = 277, 70%; 95% CI = 65-74%; $P < 0.001$) and continue with most of their usual activities (n = 128, 32%; 95% CI = 28-37%; $P < 0.001$). Those with moderate side effects were more likely to self-manage; including taking extra rest (n = 125, 26%; 95% CI = 22-30%; $P < 0.001$) and taking time off work (n = 86, 18%; 95% CI = 15-22%; $P < 0.001$). Those with severe side effects were more likely to seek urgent medical attention; including visiting an Accident and Emergency department (n = 20, 12%; 95% CI = 7-17%; $P < 0.001$), being admitted to hospital (n = 21/162, 13%; 95% CI = 8-18%; $P < 0.001$) and were less likely to continue with most of their usual activities (n = 5, 3%; 95% CI = 0.4-6%; $P < 0.001$). Respondents' attitudes towards future use of antibiotics following their experience with side effects is shown in Figure 4.

An antibiotic allergy was reported by 308 (29%; 95% CI = 26-32%) of all survey respondents, including 230 (22%; 95% CI = 19-24%) who reported penicillin allergy and a further 88 (8%; 95% CI = 7-10%) who were unsure. Among those reporting an allergy, 275 (89%; 95% CI = 86-93%) had it confirmed by a healthcare professional.

Qualitative findings

Six focus groups took place in total (n = 21), of which six themes were identified: 1) experience with antibiotics and their side effects; 2) awareness of potential side effects; 3) burden of side effects; 4) actions taken in response to side effects; 5) impact of side effects experience on future antibiotic use; 6) experience with

antibiotic allergies. A summary of these themes is shown in Table 2, with further details of subthemes explored in Supplementary Table 1.

Participants relayed that side effects presented within a few days of taking the antibiotic. Some found it difficult to associate the side effects to the antibiotic, particularly if they are *“fairly generic, like a headache”* (P8, Female, 18-34). However, they reported that the timing of taking the antibiotic and its consistency with the side effects could indicate a correlation:

“The only time I had a reaction to an antibiotic, it was immediate. So it was within, sort of, three or four hours, and was quite violent, so I was always sure it was that” (P19, Female, 55-74)

The severity of the side effects greatly impacted participants' lives, with some being unable to leave their homes due to the nature of their side effects:

“You can't leave the house, and you're in terrible pain. You just don't want to speak to anyone, you just want to lay on your bed, it's just like you have been poisoned.” (P7, Female, 55-74)

Side effects to antibiotics also had financial implications, some participants worried about whether they could afford the treatment for the potential remedy or subsequent prescription:

“If I'm gonna need antibiotics, so often for me, it's like I have to look at my money. Have I got enough money for the thrush treatment?” (P9, Female, 18-34)

Some would delay or even avoid making an appointment with their GP for their illness or side effects to try to avoid this cost:

“Sometimes I delay going to see the GP thinking, well if it will resolve itself, then I won't have to pay for any antibiotics or another prescription.” (P11, Female, 35-54)

Participants felt that the responsibility to make patients aware of potential side effects is shared between healthcare professionals, pharmaceutical companies and the patient, with each playing an important role.

“I think it's kind of across the board, really... So you get it from the doctor, you get some from the pharmacist, but I do think you're an adult, you're taking medication, you should also be responsible for some of that knowledge yourself.” (P20, Female, 35-54)

The patient information leaflets supplied with the antibiotics were generally perceived negatively by the participants, with many suggesting improvements to make them more user-friendly and accessible. Providing an option to access information specific to side effects online was a common suggestion, separating this from the other information contained within the leaflet and allowing for information to be specific and accessible.

“If you do it online, you can then also tailor the side effects more to people, so you could ask like... are you pregnant? Are you elderly? Are you younger?” (P5, Male, 18-34)

When side effects occurred, many participants did not seek advice, either because they didn't want to *“bother the doctor”* (P21, Female, 35-54) or they didn't think the doctor could help:

“I know what he's gonna say. So it's pointless.” (P7, Female, 55-74)

For some, the severity of the side effects prevented them from seeking medication elsewhere.

“But when you're feeling absolutely, excuse me but shitty, the last thing you wanna be doing is having to go out and source a medication from somewhere.” (P21, Female, 35-54)

Antibiotic allergies were perceived as more serious than side effects and present with different symptoms.

“I would look for anaphylaxis symptoms if I thought it was an allergy. So tightness of the chest, rashes, loss of consciousness, you know, stuff like that. But side effects are something which is just a nuisance.” (P3, Female, 55-74)

Discussion

Summary

This mixed-methods study explored patients who had experienced side effects or allergic reactions to antibiotics, to understand how these experiences influence attitudes and adherence to antibiotic use.

While most participants described their side effects as mild or moderate, severity tended to increase with age, with older adults more likely to report severe reactions.

They often disrupted daily life, impacting physical and mental health, work, daily activities and social interactions. In some cases, side effects also exacerbated existing health conditions. These impacts led to many patients being unable to complete their prescribed course of antibiotics. One-third of patients were unaware of the possibility of side effects before taking antibiotics; we suggest that side effects are more likely to be disruptive to patients and less well tolerated if they are unexpected.

When side effects occur, participants were likely to seek advice from a healthcare professional (HCP), although some were unable to do so, particularly those who were housebound due to their infection or the side effects themselves. This places greater importance on written information, such as the pharmaceutical patient information leaflet (PIL) provided with the antibiotics. However, only half of those who experienced side effects reported reading the PIL. Many found it difficult to navigate and understand, due to excessive information and poor formatting which make it difficult to read. Given that our sample had higher education levels than the general population for England²¹, and assuming this correlates with health literacy²², understanding may be even lower in the wider population. Additionally, the PIL may be inaccessible for those with limited proficiency in English and those with visual impairments or other disabilities that cause difficulty in processing information.

Strengths and limitations

This study used a mixed methods design, combining quantitative and qualitative data. The large survey sample enabled collection of a breadth of attitudes, beliefs and behaviours within the population, whilst the qualitative data, interpreted using the CSM, provided deeper insight into the behavioural responses of individuals.

The sample was selected to reflect the demographic population of England. However, the findings of the study may not be applicable for demographics who are underrepresented in this sample, for example individuals from non-white ethnic groups. The survey population were a self-selecting group of individuals who had reported side effects to antibiotics and were motivated to be involved in this type of research and may not be representative of the general population. Side effects were

self-reported by participants and may not have been clinically verified by healthcare professionals, which may introduce recall or reporting bias.

Comparison with existing literature

Previous research has shown that patients' perceptions of antibiotic side effects may influence their decision making when managing infections²³⁻²⁵. This study builds on this by offering a detailed understanding on the impact of adverse reactions on patients and identifies strategies to support the appropriate use of antibiotics.

Antibiotics have shown to cause many side effects, most commonly gastrointestinal (GI) effects, such as diarrhoea, and fungal infections, such as thrush, caused by the removal of healthy bacteria in the body^{26 27}. Prolonged exposure to antibiotics has also been linked to chronic GI conditions²⁸. In this group of participants, women experienced more antibiotic side effects than men, particularly GI effects, and men reported more mild side effects. Although this finding aligns with previous research²⁹⁻³¹, the study was not designed to determine gender differences and further research should be conducted to confirm these differences.

The UK NAP states that taking antimicrobials exactly as prescribed is crucial for minimising the risk of resistance³². However, almost half of participants in this study did not complete their course of antibiotics after experiencing side effects and many made this decision without medical advice. Whilst this contradicts NAP guidance, emerging evidence suggests that shorter courses of antibiotics may be equally effective as longer courses without causing unnecessary overexposure³³. Many prescribers now advocate for patients to stop their course when they start to feel better³⁴. Reducing course duration may also reduce the amount of leftover antibiotics, of which some participants admitted to saving for future use. Unused antibiotics should be returned to pharmacies for safe disposal³⁵, however recent studies undertaken in England found wide variation (9.7-51%) in the proportion of patients intending to use leftover antibiotics for future illnesses^{36 37}.

Patient information can help to manage expectations for infections and antibiotics³⁸³⁹. Participants trust advice from HCPs⁵, however time constraints often limit discussions about side effects⁴⁰, which may result in avoidable consultations or discontinuation of treatment. Written information has been shown to be more

effective that verbal information alone^{41 42}, however previous research also found that information within the PIL is difficult for patients to understand^{43 44}.

Many participants used self-care remedies to relieve side effects from antibiotics. Whilst evidence on probiotics to prevent GI side effects such as diarrhoea has previously been contrasting⁴⁵, a recent Cochrane review supports their effectiveness at reducing antibiotic-associated dysbiosis⁴⁶. Antifungal treatments are also commonly recommended for antibiotic-associated thrush^{47 48}. Despite their effectiveness, the cost of these remedies may be a barrier for some patients. The effectiveness of low-cost alternatives, such as yoghurt, remains inconclusive⁴⁹.

Around 6% of the UK population are labelled with a penicillin allergy¹⁰, however fewer than 10% of these are truly allergic⁵⁰, equating to an estimated 2.7 million adults in England with incorrect records¹⁰. Antibiotic prescriptions are almost twice as frequent in patients with a penicillin allergy¹⁰, particularly among antibiotics classified as 'high-resistance potential' by the World Health Organisation (WHO)⁵¹, increasing the risk of acquiring multidrug-resistant bacteria such as Methicillin-resistant *Staphylococcus aureus* (MRSA), *Clostridioides difficile* (C.diff) and Vancomycin Resistant *Enterococcus* (VRE)⁵². Penicillin allergy de-labelling interventions have been supported by both HCPs^{53 54} and patients⁵⁴, and many of these have already proven effective⁵⁵ and cost-saving^{56 57}. However, despite their long-term cost-effectiveness, the upfront costs and limited availability of allergy testing services remain significant barriers⁵⁸. Given the high prevalence of reported penicillin allergy, increasing access to testing could help to reduce inappropriate antibiotic use and improve patient outcomes.

Implications for research and practice

Improving patient awareness of antibiotic side effects is essential to support informed, shared decision-making, particularly for those who may request antibiotics. Participants in this study reported reconsulting due to side effects. When patients understand the potential risks, they may be better prepared to self-manage side effects and less likely to seek additional consultations. Each GP consultation (with an average duration of 11.7 minutes) costs approximately £34⁵⁹, therefore reducing unnecessary visits could save valuable time and resources. Patients generally trust and follow advice from HCPs⁵ and so discussions around side effects could prove

valuable. Prescribers should encourage shorter duration courses where clinically appropriate to reduce the onset of unnecessary side effects and the risk of exacerbating AMR.

Many patients found the antibiotic PIL format inaccessible and so they are not widely read. Alternative formats, such as educational leaflets or online resources, may help to improve this. Leaflets discussed during consultations are effective at facilitating shared communication with patients in primary care⁶⁰ and may save time during a consultation. Animated educational videos have also proven effective in increasing knowledge and influencing behaviour change around antibiotic use⁶¹ and could be explored as an option for delivering information on side effects.

Among those reporting an antibiotic allergy, most had been diagnosed over 10 years ago, often in childhood. Previous research suggests that many antibiotic allergy diagnoses may be inaccurate, particularly those based on dermatological symptoms which are common in children⁶². Because of this, patients should be encouraged to reassess longstanding antibiotic allergies to confirm that they remain valid. Incorrect penicillin allergy labels can discourage the use of first-line, narrow-spectrum antibiotics, potentially increasing the risk of AMR⁵¹.

Children under the age of 16 account for almost 15% of antibiotics prescribed in general practice⁷ and were not represented in this study. Future research should explore the experiences of side effects and allergies in children, including the role of parents and carers in managing these. Research should also explore how side effects affect other population groups, particularly those affected by health inequalities, as their experiences may differ from the findings in this study. Antibiotic side effects could also be explored from the HCP perspective to provide a balanced argument for implementing these recommendations.

This study showed that older adults tended to consult more with GPs, whilst younger adults used NHS 111 and online information more often. Further investigation is needed into how patients of different age groups seek advice, to ensure information on side effects is targeted to the most appropriate settings.

The accuracy of self-reported side effects and allergies, as relied upon in this study, remains uncertain. Participants also reported difficulty distinguishing between side effects, allergic reactions, and symptoms of their underlying illness. Future research

should explore the reliability of patient-reported side effects and identify potential resources to support these distinctions.

Conclusions

Antibiotic side effects significantly disrupt patients' lives and cause additional strain on healthcare settings through follow-up consultations. Improving the quality of information given to patients at the point of prescribing may help to manage their expectations and empower self-management of mild side effects. Many patients carry antibiotic allergy labels from childhood that may not be accurate. Encouraging reassessment of these labels could help to reduce unnecessarily avoiding first-line antibiotics and reduce the risk of contributing to AMR.

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Additional information

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Ethical approval

The study protocol was internally reviewed and approved by the UKHSA Research Ethics and Governance Group (REGG) (Reference: R&D 531).

Competing interests

No competing interests to declare.

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Figures

Figure 1. Side effects reported by survey respondents (n = 1,059; Male = 460, Female = 599). Grey bars illustrate the differences between male and female responses for each side effect. Shaded areas indicate statistically significant differences (P<0.05).

Figure 2. Perceived severity of most recent antibiotic side effects by age group (n = 1,059). * Statistically significant from total (P<0.05).

Figure 3. (a) Antibiotic course completion (n = 1,059) and reported reasons for not completing the course (n = 440). **(b)** Actions taken following side effects (n = 1,059) and self-care remedies used (n = 188).

Figure 4. Agreement with statements on future antibiotic use following their experience with side effects (n = 1,059).

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Table 1. Demographic characteristics of participants in the quantitative survey and qualitative focus groups.

		Survey respondents (n = 1,059)		Focus group participants (n = 21)	
		n	%	n	%
Gender	Male	460	43	6	29
	Female	599	57	15	71
Region	East Anglia	93	9	3	14
	East Midlands	106	10	1	5
	Greater London	168	16	6	29
	North East	57	5	1	5
	North West	134	13	2	10
	South East	185	17	3	14
	South West	101	10	2	10
	West Midlands	96	9	3	14
	Yorkshire and Humberside	119	11	0	0
Age (years)	18-34	325	31	5	24
	35-54	317	30	6	29
	55-74	314	30	8	38
	75+	103	10	2	10
Social grade	AB	361	34	13	62
	C1	268	25	3	14
	C2	150	14	2	10
	DE	280	26	3	14
Ethnic group	White	857	81	19	90
	Mixed/ multiple	34	3	0	0
	Asian / Asian British	84	8	0	0
	Black / Black British	68	6	1	5
	Other ethnic group	16	2	1	5

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Table 2. Themes identified from the patient focus groups.

Theme	Participant views	Quote
1. Experience with antibiotics and their side effects	Some kept leftover antibiotics and used them for later infections	<i>"I do keep the half-used packets, if it's azithromycin, and take them on holiday, I do admit to doing that, just in case me or my husband get ill abroad."</i> (P7, Female, 55-74)
2. Awareness of potential side effects	Many found the patient information leaflet to be inaccessible and not user friendly	<i>"They're 4 foot long, very small writing, it's never in an order because it's so wrapped up... it must be really difficult for people that have mobility problems, problems with their hands, elderly people, and I just think they are so un-user-friendly bits of paper."</i> (P12, Female, 55-74)
	Many received little or no information about the antibiotics from their healthcare professional	<i>"I don't remember my GP giving me any specific information... and when I collected them from the chemist, I don't think they gave me any information at all."</i> (P16, Male, 35-54)
	More information up front would allow patients to be better able to prepare for and manage side effects	<i>"If you know, and you're informed [about side effects], you can deal with it, but if you're not informed, you just think, oh it's just me, it's just me"</i> (P20, Female, 35-54)
3. Burden of side effects	Some were unable to complete their course of antibiotics due to the side effects	<i>"I never can finish the course... because it is literally like having food poisoning. I feel that ill with it"</i> (P7, Female, 55-74)
	Side effects from antibiotics were experienced more consistently than from other medications	<i>"I do normally get, well I always get some kind of mild reaction to antibiotics, which I don't get with other medications"</i> (P17, Male, 55-74)
4. Actions taken in response to side effects	Patients trusted the advice given to them by healthcare professionals on managing their illness and side effects	<i>"If I was ill and I saw the health professional, then I would take advice from them [about] what I needed, and I certainly wouldn't be keen to have any antibiotics if they didn't think I needed them"</i> (P7, Female, 55-74)
	GPs would often prescribe remedies to help manage side effects	<i>"I did have to go to the GP, cos it was like, so swollen... and they gave me another set of treatment for thrush"</i> (P20, Female, 35-54)
	Many were unsure if home or over-the-counter remedies helped with their side effects, but took them anyway due to their low risk of harm	<i>"So I take probiotics... I can't say that it works for sure, but I still do it because logically it feels like it [should], well it can't hurt anyway"</i> (P8, Female, 18-34)
5. Impact of side effects experience on future antibiotic use	Experiences with side effects have caused anxiety about taking antibiotics in the future	<i>"It's made me very wary about ever taking [antibiotics] again"</i> (P14, Female, 55-74)
	Side effects are often worth enduring in order to treat the infection	<i>"Antibiotics are so crucial for us, that you don't have the benefit of saying 'well, I'm going to avoid that one'. It's a question of 'how can we mitigate that?' Rather than 'I'm not having it'"</i> (P3, Female, 55-74)
	The decision on whether to take antibiotics in the future would primarily depend on whether the infection is perceived as being worse than the side effects	<i>"The sad part is that the symptoms of a UTI were far worse than vomiting, so I took the whole course of antibiotics, but I just had to be sick all the way through it, because I needed the UTI to go away"</i> (P6, Female, 18-34)
6. Experience with antibiotic allergies	Those with a reported allergy were diagnosed as a child and had not taken the implicated antibiotic since	<i>"I've been allergic to penicillin my whole life. So from being a baby, they found out I was allergic to it"</i> (P4, Female, 18-34)

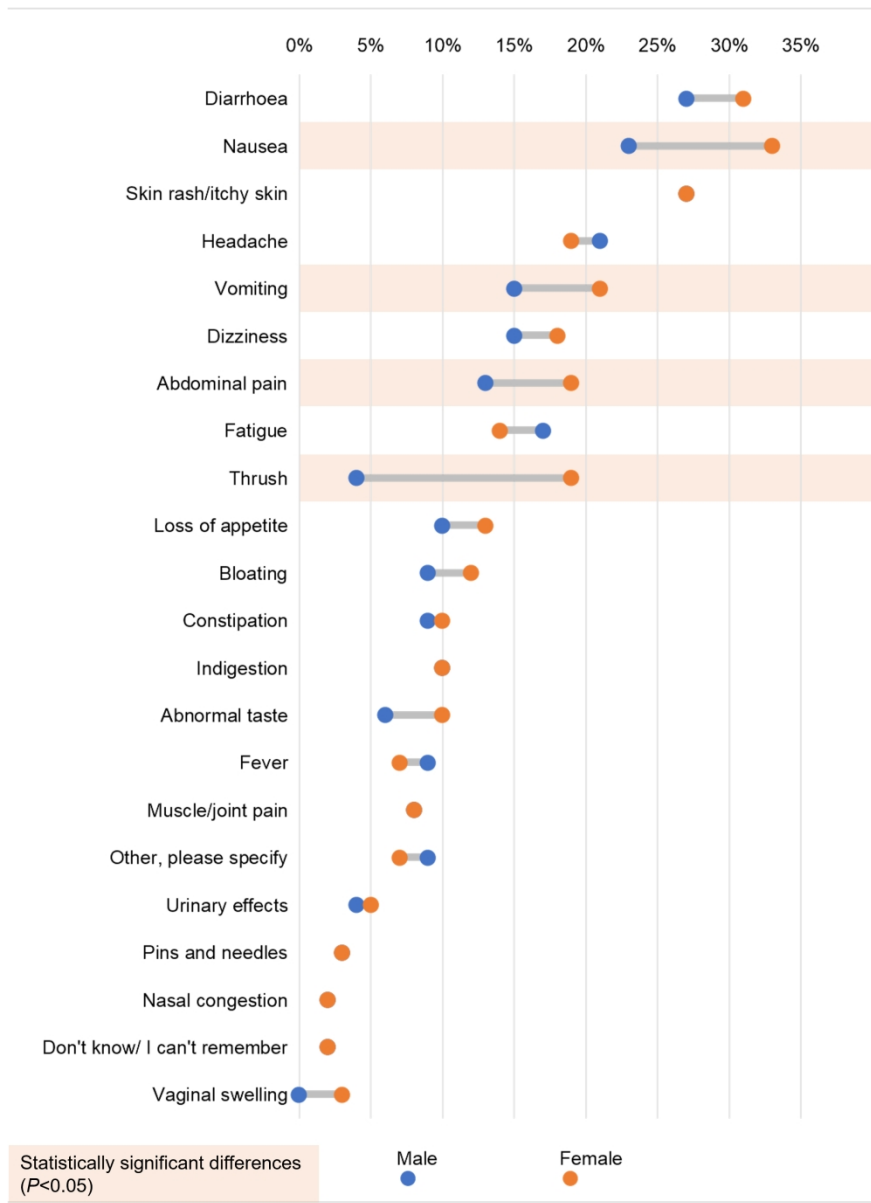


Figure 1. Side effects reported by survey respondents (n = 1,059; Male = 460, Female = 599). Grey bars illustrate the differences between male and female responses for each side effect. Shaded areas indicate statistically significant differences (P < 0.05).

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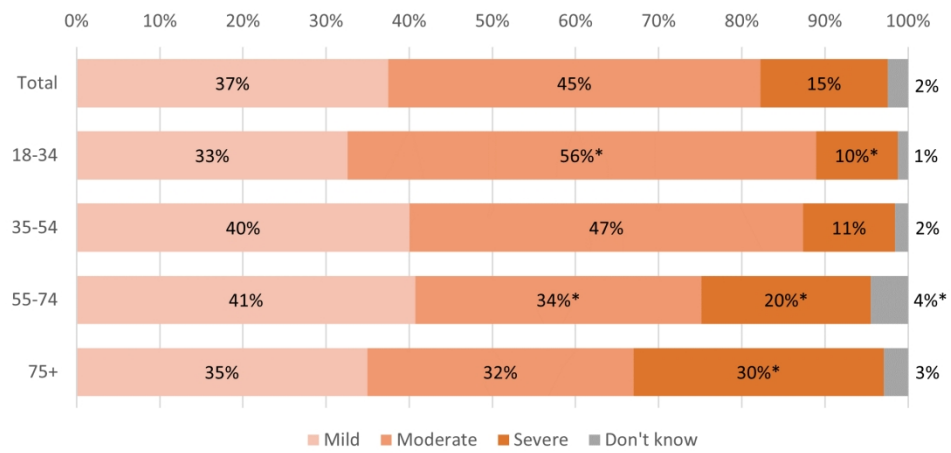
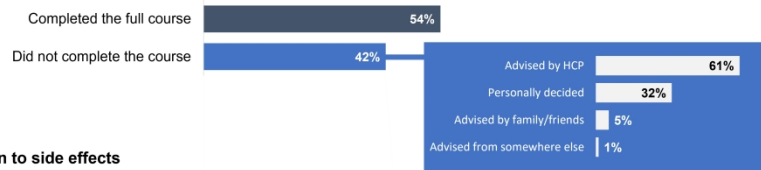


Figure 2. Perceived severity of most recent antibiotic side effects by age group (n = 1,059). * Statistically significant from total (P<0.05).

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(a) Antibiotic course completion



(b) Actions taken in relation to side effects

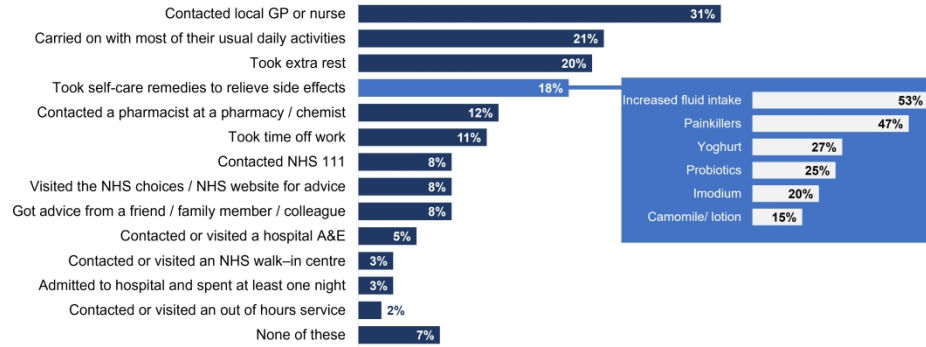


Figure 3. (a) Antibiotic course completion (n = 1,059) and reported reasons for not completing the course (n = 440). (b) Actions taken following side effects (n = 1,059) and self-care remedies used (n = 188).

996x608mm (130 x 130 DPI)

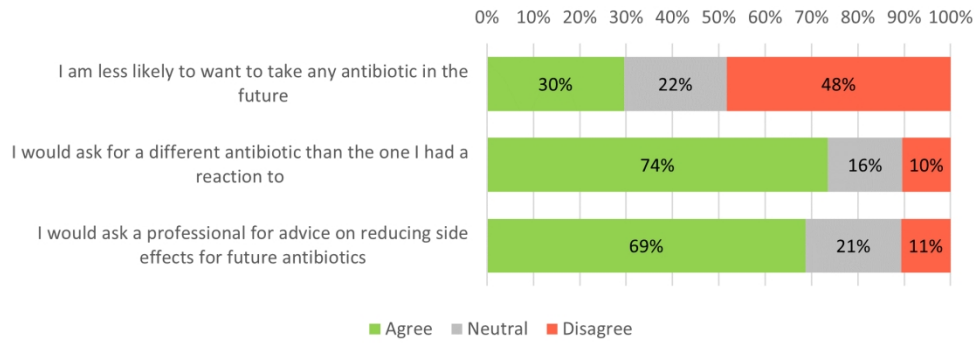


Figure 4. Agreement with statements on future antibiotic use following their experience with side effects (n = 1,059).

404x149mm (130 x 130 DPI)