Epidemiological Obfuscation

Historical and Contemporary Case Studies

Edited by Freya L. Jephcott, Hillary A. Ash and
Coreen McGuire

First published 2026

ISBN: 978-1-032-84701-6 (hbk)
ISBN: 978-1-032-89003-6 (pbk)
ISBN: 978-1-003-54075-5 (ebk))

Chapter 2

Distributed Ignorance, Tricky Cases, and Low Hanging Fruit: Targeting Antibiotics and Treating Bladders

Eleanor Kashouris

DOI: 10.4324/9781003540755-3

The Open Access version of chapter 2 was funded by Wellcome Trust.

Routledge
Taylor & Francis Group
LONDON AND NEW YORK

2 Distributed Ignorance, Tricky Cases, and Low Hanging Fruit

Targeting Antibiotics and Treating Bladders

Eleanor Kashouris

Introduction

Urinary tract infections (UTI) are common conditions, especially in women. They are the most commonly seen bacterial infections in general practice (Lecky et al. 2020) and are one of the most common acute reasons for adult women to seek health care (Butler et al. 2015). The first-line treatment for UTI is antibiotics, and a diagnosis of UTI is one of the most frequent reasons for prescribing antibiotics (Dolk et al. 2018). ‘Uncomplicated’ UTI is a widely used clinical term for UTIs caused by ‘typical uro-pathogens in a non-pregnant woman with no known relevant anatomical or functional abnormalities of the urinary tract and no predisposing comorbidities’ (National Institute for Health and Care Excellence [NICE] 2024). Infections with an increased risk of treatment failure are classified as ‘complicated’ UTIs. Uncomplicated UTIs, which are categorised as more easily resolvable without antibiotic intervention, are therefore a key target of intervention in policymaking around antimicrobial resistance (AMR).

Reducing antibiotic use by raising the threshold to prescribe has been a major effort of policymaking (Roope et al. 2020). This aligns with global approaches, as antibiotic resistance has been seen primarily as a problem of antibiotic overuse (Chandler 2019). The UK national anti-stewardship programme for primary care, developed by the United Kingdom Health Security Agency (UKHSA) in collaboration with NICE and the Royal College of General Practitioners, is called TARGET. TARGET stands for ‘Treat Antibiotics Responsibly, Guidance, Education and Tools.’ The image of a target references strategies to target antimicrobials more effectively at those more likely to benefit than be harmed by them. A target also connotes a precise and unambiguous group of cases, a ‘targeted’ solution, which may foreclose consideration of other cases.

The starting point of this chapter and this analysis is the visibility of a patient group made up of patients classified as suffering from ‘uncomplicated’ UTI, who nevertheless experience persistent symptoms after treatment. Therefore, uncomplicated UTI is held to be normally easily resolvable whilst simultaneously encompassing a category of patients who have unresolved

DOI: 10.4324/9781003540755-3

symptoms even after treatment. There have long been efforts to make these experiences visible in patient mobilisations such as the U & I club in the 1980s (Saxby 2021), groups on social media and, increasingly, coverage in the popular press (Arnold-Forster 2021; Fearn 2022; BBC News 2014). In an era of global policy mobilisations against AMR, with uncomplicated UTI a target of intervention, this longer history of patient mobilisation and advocacy around complex experiences of uncomplicated UTI prompts exploration of what and who is made (in)visible in the process of targeting antimicrobial stewardship (AMS) interventions.

In this chapter, I analyse AMS campaign policy documents to explore how certain groups of patients and conditions are made visible and how other groups of patients and conditions are removed from scope in the service of efforts to target and reduce antibiotic prescribing. I do not explore the process through which, in clinical practice, a patient is identified as in need of antibiotics or not. Instead, this is a study of how populations and publics are imagined in designing AMS interventions on a public health level. As Ledin (2024) argues, 'the established procedures of imagining publics in science communication [...] is a normative practice' (7). I show that the imagined target of public health intervention is an un-differentiated public that does not need antibiotics and leaves more complex experiences that often involve antibiotic use out of scope.

Removing complex experiences from the scope of public health intervention may constitute a decision to defer trickier cases to clinical care. However, I show that this same group is also removed from the scope of clinical care. Finally, I consider the consequences and stakes of these parallel obfuscation processes in the same patient group, such that they continue to experience painful and disruptive symptoms, often over long periods.

Conceptualising Ignorance

In analysing how a patient group that experiences persistent symptoms after treatment for UTI comes to lie outside the scope of clinical care, work in the sociology of ignorance is instructive. In moments when these patients come together to advocate for themselves, they often identify health care professionals' (HCP) ignorance as a driver of the lack of care they have experienced. As we shall see later, this ignorance is conceptualised as a deficiency in awareness of more complex experiences of urinary infection, often traced back to medical school training. Patient advocacy and mobilisations have therefore centred around HCP education, raising awareness by differentiating unresolved experiences of UTI from more standard experiences and producing information sheets to share with doctors unaware of this illness experience (Chronic Urinary Tract Infection Campaign [CUTIC] 2020).

However, work in the sociology of ignorance has emphasised that ignorance is not merely a lack of knowledge to be corrected but is often produced and productive. One of the main ways that ignorance has been analysed as necessary and productive is in the way that it 'allows us to get on with work' (Heimer 2014, 26). Heimer's (2014) concept of 'distributed ignorance' describes when people focus 'intently but exclusively on their own work' (18). Ignorance is therefore not limited to the epistemic realm in its effects. Ignorance not only organises and structures what is to be known, but organises and structures practices, what is to be done. Rayner (2012) argues that the 'social construction of ignorance is not only inevitable, but actually necessary for organisations (122). And indeed, divisions of labour facilitated by a studied ignorance are highly productive in medical work, where different specialists have responsibility for different disorders (Bowker and Star 2000; Rosenberg 2002). These insights from the sociology of ignorance can also be related to conceptualisations of clinical disposal, which see HCPs as engaged in the task of producing knowledge for situated action (Street 2011, 825; Mol 2002, 69; Berg 1992, 155). HCPs look for what they expect to find. In Mol's study of atherosclerosis, the vascular surgeon looks for pain when walking. When he finds the pain on walking that he expects to find, he establishes that there is something he can do about it, issues a diagnosis and sets the patient down a care pathway. But when confronted with a patient who describes pain on resting, the vascular surgeon shrugs his shoulders and discharges the patient (Mol 2002, 43). What happens to that patient? They are discharged back to the general practitioner (GP), who must find another specialist. This new specialist must find what they expect to find in order to be able to treat the patient. This is clinical disposal, and this way of looking for what is already expected, focusing intently but exclusively on your own work, has been extensively analysed as productive of care, including in the case of uncomplicated UTI (Kashouris 2024).

Heimer's concept of 'distributed ignorance' elucidates how work may be removed from view, not because it is unknown, but because an intent and exclusive focus can be productive. If the problem of poor care is one of distributed ignorance, it will not, therefore, be resolved by increased knowledge. Instead, to improve clinical care, we must confront that which ignorance is productive of and find ways of doing care differently. In this case, I will argue that an intent and exclusive focus on 'easier' cases is productive of AMS goals to reduce antibiotic prescribing as more complex cases are removed from view.

Methods

In Science and Technology Studies, there has been much interest in how policymakers imagine publics when they have identified a need to engage with them. Scholars have drawn attention to this as a normative practice (Ledin 2024, 7), questioning who is invited to participate in an issue (Wynne 2007), who is excluded from care as a result of the way the issue has been assembled (Puig de la Bellacasa 2011), and who can imagine themselves as participating publics (Castro and Mouro 2016). Mold et al. (2019) and Hinchliffe et al.

(2018) draw attention to particular tensions in public health around imagining who or what 'the public' is between individuals, differentiated groups, and undifferentiated masses.

Here, I draw on documentary analysis (Rapley and Rees 2018) to explore how 'the public' has been imagined as a target of intervention (Hinchliffe et al. 2018) in public health interventions on AMR. I then consider how these imagined groups relate to groups making themselves visible in response to their exclusion from clinical care. I analyse the production of target groups in policy work relevant to current AMS mobilisations, particularly in resources relevant to UTI. This includes modelling work where public health workers explicitly define their targets, but also public engagement materials where, drawing on a performative strand of critical work on public engagement strategies (Warner 2021), publics are brought into being through the very interventions which putatively target pre-existing publics.

Sources comprise the current UK AMR public engagement campaign, Antibiotic Guardian, a current World Health Organization (WHO) AMR public engagement campaign, the AMR survivors' taskforce, and modelling work performed by the UKHSA. Additionally, I draw on interview data as a supplementary dataset to explore the production of different groups in the clinical space. Interview data from semi-structured interviews with microbiologists and infectious diseases specialists and patients experiencing persistent symptoms after treatment for a UTI were selected from a larger dataset of interviews, including a diverse range of UTI patients, diverse specialisms of HCPS and other stakeholders involved in the issue of UTI and AMR. These interviews were selected where they expounded upon processes of categorisation or (un)differentiation in clinical practice.

This interview data was analysed in Nvivo, using a grounded theory approach to code development (Charmaz 2008). The clinicians all worked at consultant level within the UK National Health Service and were interviewed online from June 2020 to February 2022. Patients were recruited via a poster and were all based in the UK. All had experience of being treated for UTI under clinical guidelines written for uncomplicated UTI in women, although not all identified as women. All research participants provided informed consent and interview data was pseudonymised. Interviewed patients were offered a £20 shopping voucher in compensation for their time. Ethical approval for the study was granted by the University of Sussex Social Sciences & Arts C-REC. The approval number to interview health-care practitioners was [ER/CW82/10] and approval to interview patients was [ER/EK403/6].

Public Health and Antimicrobial Resistance: UTI Comes within Scope

Distributed Ignorance in Prescribing Data

In this section, I argue that public health work aims to identify and target a central reservoir of putatively easy cases by focusing on cases where antibiotics are clearly not needed. Cases that clearly should not involve antibiotic use are easy wins for policymakers attempting to reduce prescribing. This way of removing tricky cases from the scope of public health intervention is a process of distributed ignorance and is, therefore, productive of the intended work.

Modelling work completed by the UKHSA's National Infection Service aimed to provide evidence of baseline antibiotic prescribing in primary care in England. This work was produced to inform policy in light of the government's ambition to halve inappropriate prescribing in humans (Smieszek et al. 2018, ii35) and, more specifically, to evaluate the success of this ambition (Dolk et al. 2018, ii2). This work established that at its most conservative, 8.8% of all antibiotic prescriptions in English primary care were inappropriate. In its least conservative mode, 23.1% of all antibiotic prescriptions were identified as inappropriate. The methodology used to retrospectively establish prescriptions as appropriate or inappropriate from infamously unreliable prescribing data is highly complex. For instance, one-third of all antibiotic prescriptions lacked a diagnostic code allowing its appropriateness to be fully evaluated. Here, I draw attention to two methodological decisions relevant to my argument about drawing some patient groups into scope and the obfuscation of others through distributed ignorance.

Firstly, a large amount of data was excluded from this study of appropriateness in order to focus on uncomplicated cases (Smieszek et al. 2018, ii37; Pouwels et al. 2018, ii20). The authors noted that this approach left a substantial proportion of inappropriate prescribing out of their calculations (Smieszek et al. 2018, ii39) but rationalised this methodological choice thus:

> While reducing unnecessary prescriptions in uncomplicated presentations […] can be seen as 'low-hanging fruit' in terms of reducing antibiotic prescribing, there will be further potential for reductions in patients with comorbidities and in long-term use of antibiotics that could not be assessed in this work.
>
> (Smieszek et al. 2018, ii41)

Importantly, for my case study, all cases of prescribing for recurrent UTI were excluded from the data. This methodological choice, therefore, is productive of a pool of cases for policy intervention that has been established to be a) made up of easy wins and b) substantial enough to have an impact on reducing prescribing. If inappropriateness is less clear cut in more complex cases such as recurrent UTI, excluding complex cases is productive of a focus on cases where antibiotics are *clearly* not indicated. Even with complex cases excluded, where HCPs may be more likely to erroneously prescribe, there is still a substantial proportion of inappropriate prescribing, which could be reduced through more effectively targeting antibiotics.

Secondly, whilst it is noted that 'inappropriate prescribing' could constitute under-prescribing, over-prescribing, or prescribing a sub-optimal type of antibiotic (ii37), in this chapter the focus is exclusively on overprescribing (ii37).[1] Inappropriate prescribing was, therefore, defined as 'any antibiotic prescribing that is likely to have marginal or zero patient benefit and be outweighed by the potential risks of prescribing' (Smieszek et al. 2018, ii37). This methodological decision reflects global trends in AMS policymaking, which have focused on AMR as a problem of antibiotic overuse (Chandler 2019), seeing reducing prescribing as a predominant type of AMS (Will 2018, 1). Therefore, this work from key policymakers in the UK produces a central pool of easy cases where antibiotics are clearly not needed by marginalising within the data more complex cases with a higher level of uncertainty.

As a public health strategy, this distributed ignorance (more complex cases are recognised but removed from view) is productive of a target of intervention and, therefore, reproduces AMS goals to reduce prescribing. The stakes of this obfuscation in terms of clinical care do not follow directly from the obfuscation of this patient group in public health policy. Removing complex cases from the scope of public health intervention may represent a *recognition* of their clinical complexity. However, in a later section, I argue that, in this case, the reduction of complexity is consistent across public health and clinical settings as attention is directed to 'easy' cases. First, I show that distributed ignorance of more complex cases is not only at play in the internal rationalisations of public health work. It is also at play as a communication strategy to engage the public on AMR, where there is, I argue, a consistent thread of counter-posing genuinely antibiotic-needing patients against an undifferentiated public not in need of antibiotics. This framing obfuscates the complexities and uncertainties inherent to antibiotic use and may have unanticipated effects when publics come together to resist the framing of their antibiotic use as unnecessary.

Distributed Ignorance in Public Engagement

The WHO recently inaugurated a WHO task force of 'AMR Survivors.' Survivors are identified as being 'those who have themselves survived a drug-resistant infection.' They are called upon to advocate for accelerated AMR mitigation efforts and investments, drawing legitimacy from their experience of drug resistance (2022). Whittaker et al. (2023) question this notion of 'AMR survivorship' promoted by the WHO. In interviews with people with diverse experiences of infection, the authors found that these individuals did not necessarily constitute themselves as 'survivors' as a biosocial group with potential for activism (11). Here, I extend Whittaker et al.'s findings to argue that people with complex experiences of infection do not constitute themselves as 'AMR survivors' because they are quite explicitly not invited to do so. When the WHO calls upon those who have survived a 'drug-resistant infection' to advocate for AMR politically, they conjure a superbug imaginary of AMR to invoke the figure of a genuinely antibiotic-needing patient against a public not in need of antibiotics. People who have suffered a life-threatening, drug-resistant, complex infection are invited to advocate for AMR. People who use antibiotics to manage complex experiences of uncomplicated infection are not.

As Brown and Nettleton (2017) outline, 'very different accounts of 'resistance' [are] expressed at different moments in the development of the AMR debate' (294). The WHO invokes survivors of 'a drug-resistant infection,' people who have survived life-threatening infections for which few antibiotics were available, as those with the greatest legitimacy to advocate around AMR. Another way of understanding who has experienced drug resistance would be to say that many people who have had a bacterial infection have survived a drug-resistant infection. Drug resistance is all around us, and it is problematic in everyday clinical practice. *E. coli* organisms cultured from urine samples[2] in routine data in the UK from November 2017 to February 2018 displayed non-susceptibility to amoxicillin/clavulanic acid (~40%), trimethoprim (~29%), ciprofloxacin (~11%), and cefalexin (~7%). It was rising resistance to trimethoprim which precipitated a change to nitrofurantoin as first-line treatment for uncomplicated UTI in UK clinical guidance (Huttner et al. 2015; Watts et al. 2020), a clinical intervention around which there is considerable uncertainty (Kashouris, Joseph, and Lewis 2023). When a patient is treated for an uncomplicated UTI with nitrofurantoin, the first choice across the UK, this is because of AMR. There are, of course, important differences between experiences of everyday infection treated as a routine part of medical care and an infection involving last-line antibiotics. But by noticing that both involve health care constrained by AMR, we can start to question what a focus on 'superbugs' achieves. Brown and Nettleton (2017) argue that catastrophist formulations of AMR are politically mobilised to project the financial market into an anticipated future whilst Nerlich and James (2009) argue that it mobilises government resources and public action on AMR. Here, I offer a different argument. The WHO's decision to focus on catastrophist superbug stories draws a distinction between AMR survivors (who genuinely need antibiotics) and the general public as AMR drivers (who unnecessarily use antibiotics). But most critically ill patients in need of urgent antibiotic treatment were at one stage suffering from a more routine infection which either wasn't successfully treated or wasn't treated at all. Others will have been overtreated. Distributed ignorance of the complexities of routine uses of antibiotics obfuscates the ways in which routine health care is shaped by AMR already and how we are all, therefore, affected and implicated in AMR.

Looking at the current public engagement campaign on AMR in the UK, I argue that this strategy of counter-posing a genuinely antibiotic-needing patient against a public not in need of antibiotics is consistently identifiable as a way of removing tricky cases and focusing on putatively straightforward cases through distributed ignorance. In this public engagement work, similar to the WHO AMR survivors' task force, specific patient experiences and specific patient narratives are called upon to draw a distinction between those in need of antibiotics (victims) and those who are not (over-users). In the following section, I explore the stakes of attempts to reduce antibiotic use by engaging the public in this victim/over-user distinction. I argue that people are unlikely to recognise their own antibiotic use as unnecessary and may resist such framings with unanticipated consequences.

Antibiotic Guardian (2014) is the current national public engagement campaign in the UK. The campaign features a series of patient stories to show how AMR has affected individuals. The story about community UTI features a video of a young woman, Kelly, who was diagnosed with a UTI by her GP and prescribed antibiotics. Kelly's story is real, and my interest here is not in analysing what she says, but in how her story is employed as a patient story to engage the public on AMR. The antibiotics relieved her symptoms at first, but she later returned to her GP with continued symptoms. A culture determined non-susceptibility to the antibiotic she had been given, as well as to many others: a multi-drug resistant infection. On her GP's advice, she went to the hospital, where she was given antibiotics intravenously. Ten days later, Kelly's condition deteriorated, and she was admitted to intensive care. Kelly explains that she thinks antibiotics are being 'overprescribed, leading to greater resistance.'

If Kelly's story of a life-threatening infection is intended as a lesson against the indiscriminate use of antibiotics, the lesson is not about Kelly's own use of antibiotics. Instead, Kelly warns others not to overuse antibiotics. The presumed mechanism of this strategy can be parsed as prompting members of the public to recognise themselves as people who may be over-using antibiotics unnecessarily. Here, a 'low hanging fruit' approach, which imagines itself to be targeting a central pool of easy cases where antibiotic use is clearly unwarranted, is not only identified as a public health strategy but is also an engagement strategy. The message to the public is that 'good' patients do not use antibiotics. They are invited to recognise that they have perhaps been bad patients in the past and have the potential to be bad patients in the future.

Will (2020) has argued that public health work around AMR has fundamental difficulties in understanding the public as reflective, instead preferring to work with different forms of public ignorance. This approach, which Will names 'shrug,' is less interested in what people know or do not know, so long as they behave in desirable ways around antibiotics. This, therefore, sidelines people who 'demonstrate knowledge and take independent decisions to use antibiotics' (Will 2020, 72). These antibiotic users are removed from view because their intentional and knowledgeable use of antibiotics clashes with the message that 'good' patients do not use antibiotics. However, this frame of victim versus over-user is unhelpful for several reasons, which help us to think through the stakes of removing the complexity of antibiotic use from view.

Firstly, whilst both clinicians and public health experts may recognise inappropriate antibiotic use in patients and publics, it is not clear that members of the public recognise this in them/ourselves.[3] Sociological work shows that people often engage in performative talk around avoiding medications (Eborall and Will 2011; Polak 2017), which suggests that opportunities to boost awareness of the undesirability of over-using medications are limited. Moreover, research has shown that publics tend to place moral responsibility on other people for the development of AMR (Brown and Nettleton 2017; McCullough et al. 2015). Davis et al. (2020) note that it is hardly surprising that individuals are unwilling to accept responsibility for what may seem like an overwhelming social and biological challenge (1404). It, therefore, seems unlikely that anyone would recognise themselves as using antibiotics unnecessarily.

Secondly, given that antibiotics are only formally available in the UK on a prescription basis, it might be reasonable to suppose that patients and publics may defer prescribing to their HCPs as an expert matter. Indeed, in a systematic review of public knowledge and beliefs about AMR, McCullough et al. (2015) found not only that people believed that others were largely responsible for the development of AMR, but that people held clinicians responsible for over-prescribing. This idea is supported by a wealth of broader research across the Sociology of Health and Illness, which points out that patients are highly unlikely to directly challenge medical expertise, take great care to negotiate lay/professional boundaries (Pilnick and Dingwall 2011; Stevenson et al. 2021) and ultimately are not always ready to take responsibility for themselves, instead feeling happy to trust their GPs to make decisions for them (Henwood et al. 2003). Within this context, it is not at all clear that attempting to engage people who have been prescribed antibiotics as problematic over-users constitutes a useful communications strategy. On the other hand, HCPs may indeed recognise that their prescriptions were not clinically indicated (Broom, Broom, and Kirby 2014, 87). Therefore, messaging around antibiotic over-use may even undermine confidence in HCPs to make good prescribing decisions. Undermining trust in HCPs may have far-reaching and unanticipated consequences.

These issues relate to the issue of agency amongst patients and publics, a factor which has been extensively analysed in social studies of AMR, as mentioned earlier. Whittaker et al. (2023) add that this way of employing sensationalised patient narratives misses opportunities to reflect upon the social burden of AMR in terms of morbidity as well as mortality. I extend this point to argue that this ‘low hanging fruit’ approach represents a missed opportunity to reflect upon moments when antibiotics are needed and on the consequences for people who use them.

Kelly’s story demonstrated that she did urgently need antibiotics and yet serves only as a reminder not to use antibiotics. Therefore, as the low hanging fruit approach imagines its target to be a pool of easy cases, this approach also marginalises and obfuscates trickier cases. Antibiotics are often prescribed, used, and deemed appropriate at a policy level in cases of UTI (Pouwels et al. 2018; Smith et al. 2018; Hoffmann et al. 2020).

Stories of victim/survivors with life-threatening conditions are employed to suggest to others that they are the ones over-using antibiotics, not the ones personally implicated in AMR. However, there is a high level of uncertainty in UTI about when antibiotics are needed. Therefore, although public health attempts to target a central pool of simple over-uses of antibiotics through distributed ignorance of tricky cases, this can obscure how even ‘simple’ cases in public health can be highly complex in clinical settings. As Davis et al. (2020) argue: ‘the AMR public is hailed somewhat obliquely; AMR communications address everyone, but no one in particular’ (1396). The public at large is addressed as over-users of antibiotics, but it is not clear that anyone identifies themselves as the ones being addressed.

Moreover, everyone who is treated with antibiotics for UTI has been treated within a context of drug resistance, and our personal futures are all implicated in antibiotic futures. There could be ways to reflect on uses of antimicrobials, as well as non-uses, and to thereby bring the experiences of those who do use antibiotics back within the scope of AMS. Will (2020) argues that the turn towards public ignorance depletes AMR of its potential for participatory action. Obfuscating cases where it is unclear whether antibiotics are needed is a process of distributed ignorance, which produces a large pool of ‘easy wins’ to reduce prescribing. But I suggest that this strategy of obfuscating moments when antibiotics are needed and focusing on cases where antibiotics are clearly not needed has a similarly depletive effect on the potential for public participation.

Patient mobilisations can bring visibility to their experiences of antibiotic use and what is at stake for their health. But when people who use antibiotics are excluded from participating in mobilisations on AMR in the role of victim/survivor (or otherwise highly implicated) and live with messaging hailing over-users of antibiotics, they can easily imagine that their personal future is opposed to AMS policy aims. Within this context, their participation in the issue of AMR is not always what would be considered desirable from a public health perspective. We can start to see this in patient mobilisations around UTI in the UK, which often cast AMR interventions as willing to sacrifice individual patient care to population-level health and resist this by organising around access to antibiotics. These mobilisations are an example of the unanticipated consequences at stake in excluding people highly implicated in antibiotic futures from the scope of AMS by focusing on over-uses and over-users of antibiotics.

In the Clinic: Attempting to Make Complex Experiences Visible

In the previous section, I argued that public health work around AMR has both identified a central pool of ‘easy’ cases where antibiotics are not needed and has attempted to communicate this to the public as a way to reduce antibiotic use. Publics have been encouraged to identify their own antibiotic use as straight-forward over-use by consistent framing of a victim versus an over-user. Producing easy cases as 'low hanging fruit' has reproduced AMS goals to reduce antibiotic use. I have pointed out that we are all already implicated in AMR and emphasised that both people suffering from multi-drug resistant fatal or near-fatal infections and people taking antibiotics for uncomplicated infections are using antibiotics within a context of drug resistance. These are not separate groups; most patients critically ill with an infection would have been under-treated for a routine infection. Therefore, whilst a case can appear as straightforwardly not involving antibiotics for public health, the same may not be true in the clinic for either prescriber or patient. This is a basic insight evidenced by the fact that much antibiotic prescribing is consistently identified in policy settings as inappropriate (Pouwels et al. 2018). Distributed ignorance can focus policy attention on cases where there is little uncertainty that antibiotics are or are not needed, but such an exclusive focus on easy cases can obscure the complexity of clinical presentations.

Uncertainty is key to clinical use of antibiotics (Kashouris, Joseph, and Lewis 2023). In the following section, I express doubt that straightforward over-uses of antibiotics exist for patients or prescribers in clinical settings. Deferring what are readily identified as 'tricky' cases to clinical autonomy may make sense as a way to ensure good care whilst achieving public health goals. However, I explore how complex experiences of uncomplicated urinary infection are also removed from the scope of clinical care and the consequences of these parallel processes of distributed ignorance running alongside each other. In my argument, following Mol (2002), Berg (1992), and Street (2011), clinically easy cases are not easy because they are less serious or less complex. Instead, the orientation of clinical care towards what can be done makes easy cases out of those where an HCP expects to find what they are looking for and has practices and routines readily available for care. An example of this when it comes to urinary symptoms might be an acute UTI that presents as expected and resolves with first-line treatments. But an easy case might also be a complicated UTI precipitated by a structural problem that requires very complex urological surgery or a multi-drug-resistant urinary infection that requires complex and risky antibiotic therapy. In the sense of the analysis here, all of these situations are within scope of clinical care because relevant HCPs know what they are looking for before they start the examination. The urological surgeon looks for a problem to be resolved via surgery, a stone, or a structural problem. The GP looks for a UTI in a woman complaining of pain on urinating and cloudy urine, which will be resolved via a three-day course of antibiotics. The microbiologist looks for a positive urine culture result and an appropriate antibiotic.

Here, I draw on patient experience to show how complex experiences of what has been classified as uncomplicated UTI are removed from the scope of clinical care. Nicole, Laura and Sarah all suffer from persistent and painful symptoms after antibiotic treatment for UTI. In these extracts, they identify differences in what has happened to them, compared to what is expected to happen, and what has happened to others they know.

Nicole: I suppose probably because, you know, what you learn in your GP training is to give, you know, a three-day course of antibiotic and then you should be better. That probably works for 99% of people, but obviously for, you know, exceptional people that isn't working.

Laura: When you're not fine, you're an anomaly and then the clinician just sees you the next time and if you have a positive culture, oh you have a UTI, let's give you three to five days of antibiotics [...] it's just the standard approach every single time.

Sarah: But no, like my sister gets them a bit. Like she's had maybe (she's ten years older) and she's maybe had like five in her life. Um, my mom has just had one, but they haven't plagued her like me at all. My dad has also just had one. And yeah, I mean obviously, like people know that's a woman's problem, but no one has had them like I've had them.

Nicole, Laura and Sarah all emphasise that their experiences of UTI go beyond how a UTI is standardly described and experienced. Sarah compares herself to others around her, and their experiences of a supposedly common infection and concludes: '*but no one has had them like I've had them.*' Laura and Nicole mark themselves as '*an anomaly*' or '*exceptional.*'

Nicole, Laura and Sarah all, I argue, identify ignorance as a reason why they are not visible to HCPs. When Sarah says *I mean obviously, like people know that's a woman's problem, but no one has had them like I've had them,* ignorance is more generalised. People know about recurrent UTI as a problem for women but do not know of the nature or scale of Sarah's problem. For Nicole, this is located in a deficit in GP education and training: *what you learn in your GP training is to give, you know, a three-day course of antibiotic and then you should be better*. For Laura, ignorance is located in the HCP's ignorance of the patient's history, causing them to revert to an acute treatment plan each episode: *then the clinician just sees you the next time and if you have a positive culture, oh you have a UTI, let's give you three to five days of antibiotics [...] it's just the standard approach every single time*. Nicole and Laura quite explicitly express that the problem of clinical care is that their HCPs do not, in their cases, find what they expect.

But at the same time, many HCPs I spoke with recognised a patient group poorly served by existing approaches, i.e., they were not ignorant of the existence of this patient group. The three HCPs quoted below all worked at the consultant level within the NHS in microbiology or infectious diseases specialisms.

HCP 1: I wouldn't want to say it's a small patient group, because I suspect it probably isn't, to be honest […] the problem is because we don't understand – and this is true of so many different aspects of medicine – but yeah, medicine has a way of not understanding something, and therefore putting it away in a box – oh, too hard, I'm not going to worry about it.

HCP 2: There's a whole group of people there, who are just…we're all struggling with really, and don't really have good answers for.

HCP 3: I was talking to a surgeon the other day, he just does knees, that's all he does, is knees. You know, that's one joint in the body and that's all he does. But he loves that and that's what he's interested in. But if you go along and try and get him really excited about a hip patient he's not going to be interested. So, you have to understand that I think when patients don't fit into our boxes and our interests we're very quick to try and push them off to someone else and put them in someone else's box and someone else's interest.

Here, all three doctors suggest that there is problem of clinical care for this group that goes beyond recognising them and their need for help. In TARGET training resources aimed at HCPs, public health workers carefully navigating their desire for behavioural change in antibiotic prescribing amongst overstretched GPs are keen to emphasise that advice does not apply to complicated patients, referring instead to 'high volume consultations' (TARGET 2021). By this, they refer to the large, imagined pool of easy cases, which is ripe for public health intervention. As expounded in the previous section, Laura, Nicole, and Sarah might all be recognised as these tricky cases, and it might therefore be reasonable that they are excluded from the scope of public health intervention, their management deferred to clinical autonomy.

However, it is notable that all three HCPs speak about the problem of care for this group not in terms of professional ignorance, but in terms of distributed ignorance: '*there's a whole group of people*'; '*when patients don't fit into our boxes*'; '*putting it away in a box*.' It is these processes of classification and standardisation that designate a particular specialist to particular symptoms, body parts, bodies, and disorders. What is articulated here is a supremely clinical outlook; when there is nothing to be done, nothing to be found when a specialist looks for what they expect to find, the problem must be passed on to someone else (Mol 2002, 43). This is a productive way of organising medical care; HCPs focus intently on their own work (Heimer 2014) in order to get work done. But it is these same processes of classification and standardisation that necessitate ignorance of other symptoms, body parts, bodies, and disorders. Difference in itself, here an HCP not finding on examination what they expect to find, is not a problem for distributed clinical work, as scholars have shown that work can be coordinated (Mol 2002) and collaborative (Bowker and Star 2000) across different scales and communities. One way that this can be done, as Mol (2002) outlines, is when an HCP does not recognise what they expect to find and refers a patient to another specialist (43). But in these cases of unresolved urinary symptoms, it is not clear who a specialist might be; this is a group that HCPs are '*all struggling with*' and is '*too hard*.'

What is tricky about these cases is that no one seems to recognise what they expect to find. There is no specialist available who will find what they expect to find, no specialist for whom this will be an easy case. Even when clinicians are aware of the patient's history and that antibiotics have not helped fully resolve their symptoms in the past, it is not clear what else they can do. Instead, as Nicole and Laura both report, they are treated within a standard antibiotic approach and removed from view as a tricky case of uncomplicated infection. As a result, many people live with painful bladders, using antibiotics as the only help available. This is also noted in bio-medical literature which retrospectively demonstrates high levels of antibiotic prescription in groups already identified as unlikely to benefit (Epp et al. 2010; Pouwels et al. 2018). Sociological work has sought to explain how AMS agendas can end up sustaining antibiotic prescription because they are highly interested in two pre-determined outcomes; to prescribe or not to prescribe antibiotics (Kashouris 2024). When antibiotics are prescribed for UTI, this is constituted as an easy case; it has been clear what to do. But if antibiotics seem less appropriate because they have not resolved symptoms, it is less clear what to do. However, the tricky case can be reclassified as an easy case by removing this patient history from view and prescribing antibiotics anyway. It is not that HCPs are ignorant of these tricky cases where antibiotics have not helped; it is that they productively distribute ignorance towards a case where it is clear what might be done.

Conclusion

Overall, in both public health and clinical care, these complex UTI experiences are removed from scope due to a process of distributed ignorance, which focuses attention on easy cases. There is a dogged determination to focus on 'easy' cases where it is clear what can be done in both clinical care (Mol 2002) and public health. This focus is productive of clinical care for easy cases of UTI (Kashouris 2024) and is productive of public health goals around reducing antibiotic prescription.

However, in the case of recurrent uncomplicated UTI, distributed ignorance of complex cases in public health corresponds with distributed ignorance of how to manage these cases clinically. AMR policy has reduced complexity, and this is consistent with a clinical disposal, which creates categories of easy cases in order to produce care (Berg 1992). However, patients who regularly use antibiotics (such as recurrent UTI patients) and those for whom it is not clear what can be done are obfuscated by these dual processes. Therefore, people managing complex illnesses after treatment for UTI fall outside of the scope of clinical care and also live with public health messaging around antibiotic use for UTI, which attempts to engage people as problematic over-users of antibiotics. This leaves a patient group living with persistent and painful symptoms and pushes this same group (who are highly personally implicated in antibiotic futures) away from the scope of public participation in AMR, potentially leading to unintended consequences. For example, these same people may come together to resist AMR public health messaging by organising around access to antibiotics. There is certainly a missed opportunity to engage with a group with complex messages about infection and antibiotic use.

There may be ways to bring these complex experiences back within scope. To improve clinical care for this group, we must confront that which distributed ignorance is productive of and find ways of doing care differently. In public health work, people who have suffered 'superbug' infections have fallen outside the scope of clinical care, making them fall within the scope of AMR advocacy. People who use antibiotics to manage complex illnesses outside the scope of clinical care could similarly be invited to advocate for mobilisation on AMR, not by encouraging others to recognise themselves as over-users, but by sharing more about the consequences of using antibiotics for personal and public futures. The need to establish a pool of cases where antibiotics are clearly not indicated would then be reduced. As a result, the productivity of obfuscating the clinical complexity of antibiotic use and of obfuscating groups of antibiotic users would also be reduced. In clinical care, a patient's history is obfuscated when they have continued to experience symptoms after antibiotic treatment. Ignorance is distributed so that care is productive of cases when antibiotics will help. We must find ways of broadening our care practices beyond antibiotic practices so that easy cases may be made of patients for whom antibiotics have not helped.

Acknowledgements

The research upon which this chapter is based was undertaken during Wellcome-funded doctoral study at the University of Sussex under the guidance of Professor Bobbie Farsides, Dr Ulla McKnight, Professor Catherine Will, and Dr Liz McDonnell (grant number 214954).

The work was written up during a Mildred Blaxter Postdoctoral Fellowship at Newcastle University, funded by the Foundation for the Sociology of Health and Illness, under the guidance of Dr Gethin Rees.

Notes

1 This is also an instance of distributed ignorance. By ignoring other ways of prescribing inappropriately, the work is focused on the intended goal of reducing prescribing.

2 Clinical guidelines for uncomplicated UTI in primary care in England recommend sending urine specimens for microbiological examination only in cases of treatment failure, recurrent UTI or increased likelihood of resistant infection. Therefore, routine surveillance data from laboratories may overestimate the levels of resistance circulating in the community. However, data from a sentinel surveillance system with organisms cultured from a wider range of urine samples suggested that routine surveillance data provides adequate estimates of non-susceptibility to key antimicrobials in community-acquired UTIs in England (Watts et al. 2020).

3 This includes moments when clinicians and public health experts become patients themselves.

References

National Institute for Health and Care Excellence [NICE]. 2024. “Clinical Knowledge Summary.” Available at: https://cks.nice.org.uk/topics/urinary-tract-infection-lower-women/background-information/definition/

Antibiotic Guardian. 2014. “Patient Stories.” https://antibioticguardian.com/stories/.

Arnold-Forster, Agnes. 2021. “Failure to treat Chronic UTIs exposes how our health system does not work for women.” *i*. October 4. https://inews.co.uk/opinion/uti-common-condition-treatment-testing-inadequate-women-suffer-decades-1188843

BBC News. 2014. “Antibiotics Patient: ‘They weren’t sure I was going to make it’” BBC News. July 2. https://www.bbc.co.uk/news/av/health-28135067

Berg, Marc. 1992. “The Construction of Medical Disposals: Medical Sociology and Medical Problem Solving in Clinical Practice.” *Sociology of Health & Illness* 14 (2): 151–80.

Bowker, Geoffrey C., and Susan Leigh Star. 2000. *Sorting Things Out: Classification and Its Consequences*. MIT Press.

Broom, Alex, Jennifer Broom, and Emma Kirby. 2014. “Cultures of Resistance? A Bourdieusian Analysis of Doctors’ Antibiotic Prescribing.” *Social Science & Medicine* 110: 81–88.

Brown, Nik, and Sarah Nettleton. 2017. “There Is Worse to Come’: The Biopolitics of Traumatism in Antimicrobial Resistance (AMR).” *The Sociological Review* 65 (3): 493–508.

Butler, Chris C., Meredith KD Hawking, Anna Quigley, and Cliodna AM McNulty. 2015. “Incidence, Severity, Help Seeking, and Management of Uncomplicated Urinary Tract Infection: A Population-Based Survey.” *British Journal of General Practice* 65 (639): e702–7.

Castro, Paula, and Carla Mouro. 2016. “Imagining Ourselves’ as Participating Publics: An Example from Biodiversity Conservation.” *Public Understanding of Science* 25 (7): 858–72. https://doi.org/10.1177/0963662515581303

Chandler, Clare. 2019. “Current Accounts of Antimicrobial Resistance: Stabilisation, Individualisation and Antibiotics as Infrastructure.” *Palgrave Communications* 5 (53): 1–13. https://doi.org/10.1057/s41599-019-0263-4

Charmaz, Karma. 2008. Grounded Theory. In *Qualitative Psychology: A Practical Guide to Research Methods*, edited by Jonathan A. Smith. Sage.

Chronic Urinary Tract Infection Campaign [CUTIC]. 2020. "Chronic UTI Information for Medical Professionals." August 1. https://cutic.co.uk/wp-content/uploads/2023/02/GP-Information-Fact-Sheet.pdf

Davis, Mark. D. M., Davina B. Lohm, Andrea Whittaker, and Paul Flowers. 2020. "'Willy Nilly' Doctors, Bad Patients, and Resistant Bodies in General Public Explanations of Antimicrobial Resistance." *Sociology of Health & Illness* 42 (6): 1394–1408.

Dolk, Christiaan K., Koen B. Pouwels, David R. M. Smith, Julie Robotham, and Timo Smieszek. 2018. "Antibiotics in Primary Care in England: Which Antibiotics Are Prescribed and for Which Conditions?" *Journal of Antimicrobial Chemotherapy* 73 (suppl 2): ii2–ii10.

Eborall, Helen C., and Catherine M. Will. 2011. 'Prevention Is Better Than Cure, But…': Preventive Medication as a Risk to Ordinariness?" *Health, Risk & Society* 13 (7–8): 653–68.

Epp, Annette, Annick Larochelle, Danny Lovatsis, Jens-Erik Walter, William Easton, Scott A. Farrell, and Lise Girouard et al. 2010. "Recurrent Urinary Tract Infection." *Journal of Obstetrics and Gynaecology Canada* 32 (11): 1082–90.

Fearn, Hannah. 2022. "Dismissed, Ignored and Ridiculed: How Doctors are Letting Women Down When It Comes to UTIs." *Independent* January 24. https://www.independent.co.uk/life-style/women/uti-cystitis-kidney-infection-medical-sexism-b1998111.html

Heimer, Carol A. 2014. "Inert Facts and the Illusion of Knowledge: Strategic Uses of Ignorance in HIV Clinics." In *An Introduction to the Sociology of Ignorance*, edited by Linsey McGoey. Routledge.

Henwood, Flis, Sally Wyatt, Angie Hart, and Julie Smith. 2003. "Ignorance Is Bliss Sometimes': Constraints on the Emergence of the 'Informed Patient' in the Changing Landscapes of Health Information." *Sociology of Health & Illness* 25 (6): 589–607.

Hinchliffe, Stephen, Mark A. Jackson, Katrina Wyatt, Anne E. Barlow, Manuela Barreto, and Linda Clare et al. 2018. "Healthy Publics: Enabling Cultures and Environments for Health." *Palgrave Communications* 4 (57): 1–10. https://doi.org/10.1057/s41599-018-0113-9

Hoffmann, Tammy, Ruwani Peiris, Chris Del Mar, Gina Cleo, and Paul Glasziou. 2020. "Natural History of Uncomplicated Urinary Tract Infection without Antibiotics: A Systematic Review." *British Journal of General Practice* 70 (699): e714–22.

Huttner, Angela, Els M. Verhaegh, Stephan Harbarth, Anouk E. Muller, Ursula Theuretzbacher, and Johan W. Mouton. 2015. "Nitrofurantoin Revisited: A Systematic Review and Meta-Analysis of Controlled Trials." *Journal of Antimicrobial Chemotherapy* 70 (9): 2456–64.

Kashouris, Eleanor. 2024. "When All You Have Is a Hammer, Everything Has to Be a Nail': Managing Diagnostic Uncertainty in Urinary Tract Infection." *Sociology of Health & Illness* 46 (8): 1668–85.

Kashouris, Eleanor, Amelia Joseph, and Tom Lewis. 2023. "Nitrofurantoin: What Is the Evidence for Current UK Guidance?" *Journal of Antimicrobial Chemotherapy* 78 (11): 2605–11.

Lecky, Donna M., Jessica Howdle, Christopher C. Butler, and Cliodna AM McNulty. 2020. "Optimising Management of UTIs in Primary Care: A Qualitative Study of Patient and GP Perspectives to Inform the Development of an Evidence-Based, Shared Decision-Making Resource." *British Journal of General Practice* 70 (694): e330–38.

Ledin, Chase. 2024. "Fugitive Publics: Sex, Sexuality, and Science Communication." *Journal of Science Communication* 23 (4): Y02.

McCullough, Amanda, Samir Parekh, Joanne Rathbone, Chris del Mar, and Tammy Hoffmann. 2015. "A Systematic Review of the Public's Knowledge and Beliefs about Antibiotic Resistance." *Journal of Antimicrobial Chemotherapy* 71 (1): 27–33.

Mol, Annemarie. 2002. *The Body Multiple: Ontology in Medical Practice*. Duke University Press.

Mold, Alex, Peder Clark, Gareth Millward, and Daisy Payling. 2019. "Imagining Publics." In *Placing the Public in Public Health in Post-War Britain*, edited by Alex Mold, Peder Clark, Gareth Millward, and Daisy Payling. Palgrave.

Nerlich, Brigitte, and Richard James. 2009. "The Post-Antibiotic Apocalypse' and the 'War on Superbugs': Catastrophe Discourse in Microbiology, Its Rhetorical Form and Political Function." *Public Understanding of Science* 18 (5): 574–90.

Pilnick, Alison, and Robert Dingwall. 2011. "On the Remarkable Persistence of Asymmetry in Doctor/Patient Interaction: A Critical Review." *Social Science & Medicine* 72 (8): 1374–82.

Polak, Louisa. 2017. "What Is Wrong with 'Being a Pill-Taker'? The Special Case of Statins." *Sociology of Health & Illness* 39 (4): 599–613.

Pouwels, Koen B., F. Christiaan K. Dolk, David RM Smith, Julie V. Robotham, and Timo Smieszek. 2018. "Actual Versus 'Ideal' Antibiotic Prescribing for Common Conditions in English Primary Care." *Journal of Antimicrobial Chemotherapy* 73 (suppl. 2): 19–26.

Puig de la Bellacasa, Maria. 2011. "Matters of Care in Technoscience: Assembling Neglected Things." *Social Studies of Science* 41 (1): 85–106.

Rapley, Tim, and Gethin Rees. 2018. "Collecting Documents as Data." In *The Sage Handbook of Qualitative Data Collection*, edited by Uwe Flick. Sage.

Rayner, Steve. 2012. "Uncomfortable Knowledge: The Social Construction of Ignorance in Science and Environmental Policy Discourses." *Economy and Society* 41 (1): 107–25.

Roope, Laurence. S. J., Sarah Tonkin-Crine, Natalie Herd, Susan Michie, Koen B. Pouwels, and Enrique Castro-Sanchez et al. 2020. "Reducing Expectations for Antibiotics in Primary Care: A Randomised Experiment to Test the Response to Fear-Based Messages about Antimicrobial Resistance." *BMC Medicine* 18 (1): 110.

Rosenberg, Charles. E. 2002. "The Tyranny of Diagnosis: Specific Entities and Individual Experience." *The Milbank Quarterly* 80 (2): 237–60.

Saxby, Chelsea. 2021. "Sex and the Sitcom: Constructing Love, Sex, and Marriage on British Television, 1954-1981." PhD thesis. University of Birmingham.

Smieszek, Timo, Koen B. Pouwels, F. Christiaan K. Dolk, David R. M. Smith, Susan Hopkins, and Mike Sharland, et al. (2018). "Potential for Reducing Inappropriate Antibiotic Prescribing in English Primary Care." *Journal of Antimicrobial Chemotherapy* 73 (suppl. 2): ii36–ii43.

Smith, David RM, F. Christiaan K. Dolk, Koen B. Pouwels, Morag Christie, Julie V. Robotham, and Timo Smieszek. 2018. "Defining the Appropriateness and Inappropriateness of Antibiotic Prescribing in Primary Care." *Journal of Antimicrobial Chemotherapy* 73 (suppl. 2): ii11–ii18.

Stevenson, Fiona A., Geraldine Leydon-Hudson, Elizabeth Murray, Maureen Seguin, and Rebecca Barnes. 2021. "Patients' Use of the Internet to Negotiate about Treatment." *Social Science & Medicine* 290: 114262.

Street, Alice. 2011. "Artefacts of Not-Knowing: The Medical Record, the Diagnosis and the Production of Uncertainty in Papua New Guinean Biomedicine." *Social Studies of Science* 4 (6): 815–34.

TARGET. 2021. "Antimicrobial Prescribing in Primary Care" [Webinar]. November 25. [Online].

Warner, Michael. 2021. *Publics and Counterpublics*. Princeton University Press.

Watts, Vicky, Benjamin Brown, Maria Ahmed, André Charlett, Carolyn Chew-Graham, and Paul Cleary et al. 2020. "Routine Laboratory Surveillance of Antimicrobial Resistance in Community-Acquired Urinary Tract Infections Adequately Informs Prescribing Policy in England." *JAC-Antimicrobial Resistance* 2 (2): dlaa022.

Whittaker, Andrea, Trang Thu Do, Mark D. Davis, and Jeremy Barr. 2023. "AMR Survivors? Chronic Living with Antimicrobial Resistant Infections." *Global Public Health* 18 (1).

Will, Catherine M. 2018. "Beyond Behaviour? Institutions, Interactions and Inequalities in the Response to Antimicrobial Resistance." *Sociology of Health & Illness* 40 (3): E1–E9.

Will, Catherine M. 2020. "The Problem and the Productivity of Ignorance: Public Health Campaigns on Antibiotic Stewardship." *The Sociological Review* 68 (1): 55–76.

Wynne, Brian. 2007. "Public Participation in Science and Technology: Performing and Obscuring a Political-Conceptual Category Mistake." *East Asian Science, Technology and Society* 1 (1): 99–110.