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Rush, Lynne (2023) *Are antimicrobial stewardship and sepsis awareness competing goals?* PhD thesis.

https://theses.gla.ac.uk/83461/

Are antimicrobial stewardship and sepsis awareness competing goals?

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Submitted in fulfilment of the requirement of the Degree of Doctorate of Philosophy

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November 2022

Abstract

Antimicrobial resistance (AMR) has emerged as one of the most significant threats to population health of recent times. It is estimated that its associated mortality could reach 10 million by 2050. Availability of effective antimicrobial prophylaxis is essential to allow many routine surgical and obstetric procedures to be performed safely. Reducing unnecessary antimicrobial use is integral to controlling the spread of AMR. As awareness of the need for judicious antimicrobial prescribing has grown, so has recognition of the importance of early diagnosis and management of sepsis, with high profile media reporting of selected cases, often involving children. Early administration of antibiotics to improve outcomes from sepsis conflicts, in part, with a drive to reduce antimicrobial prescribing. Previous research has suggested that AMR is often perceived as a distant and theoretical threat that has little personal impact, which may in part be related to how it is framed in news media. There is no evidence about how reporting of sepsis in children impacts on public understandings about antibiotic use. This PhD aims to better understand how the risks of antimicrobial resistance and sepsis are constructed in the popular news and how these impact on the attitudes and behaviour of the public, as parents and carers.

Content analysis of 616 articles from 6 national newspapers published between 1988 and 2018 demonstrated key differences in the way AMR and sepsis are framed. AMR is framed predominantly according to its potential impact on future global health. Its causes and solutions are presented as complex and dependent on co-ordinated actions between policymakers and the healthcare, farming and pharmaceutical industries. In contrast, sepsis is framed as an issue whose drivers lie predominantly within the healthcare sector and whose main solution is better awareness. The use of personalised narratives about individuals affected by sepsis increases its relevance and accessibility for the public. Thematic analysis of a subset of articles demonstrated that failings in the health service were portrayed as the cause of avoidable deaths in children, often through failure to prescribe timely antibiotics, with parents positioned as advocates for their children.

Exploration of these themes in 20 focus groups with 84 parents, carers and individuals with lived experience of sepsis demonstrated that decisions about when to seek health advice had to be balanced against a perceived moral duty to avoid placing excessive demands on healthcare resources. Health professionals were frequently perceived to be ambivalent about the need for antibiotics, with parent preference often influencing decisions. Few participants had direct experience of AMR, which was widely perceived to be a risk confined to individuals who use antibiotics inappropriately. There is a need to align

messages about the complex interplay between AMR, sepsis and antimicrobial use. Personal narratives about individuals affected by AMR, similar to those used in sepsis awareness campaigns, may increase accessibility of public health messaging about preserving the efficacy of antibiotics.

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Acknowledgements

I wish to express my sincere thanks to all the colleagues, fellow students and family members who supported me so generously during the course of my PhD.

To my supervisors, Professor Shona Hilton and Professor Lisa McDaid, I thank you for your guidance and experience throughout my research and for being so readily available and approachable to provide advice on all matters, both academic and practical, with such good humour and positivity. In particular, I am grateful that you encouraged me to follow my conviction in developing my research questions and methodology and for valuable guidance in developing my knowledge of sociological theory, which, as a clinician, was so important to the success of my research. Finally, I thank you for your friendship and kindness over the past few years, particularly when external events, both happy and sad, changed my anticipated course.

To my colleagues and fellow students in the research team, in particular Dr Chris Patterson, Dr Amy Nimegeer, Dr Gillian Fergie, Mrs Christina Buckton and Dr Marissa Smith for their valuable support and advice throughout the various stages in the research process.

To Dr Helen Sweeting, Dr Katie Buston and Dr Marion Henderson for their wisdom and guidance as student conveners and for being reassuring voices of reason on so many occasions.

To the colleagues in SPHSU who were so readily available to support me with the many practical tasks integral to the PhD process, in particular Indira Gray, Natalie Owens and Louise Hutcheon.

To all of the focus group participants who so generously gave up their time to share their views and experiences and to the gatekeepers of various organisations who facilitated this, in particular the Fiona Elizabeth Agnew Trust

And to my family – to my husband Kevin, thank you for your endless encouragement and providing a much-needed sounding board on many occasions and to my children, Dana, Mark and Kristen and their grandparents and aunts – thank you for your patience on all the days when mummy's work didn't end at 5pm!

Finally, I thank the latest two additions to our family – our daughter Sasha who we lost in 2020 and our son Benji who arrived in 2022. You have taught me more than you will ever realise and this thesis is for you.

Author's declaration

I certify that the thesis presented here for examination for PhD degree of the University of Glasgow is solely my own work other than where I have clearly indicated that it is the work of others (in which case the extent of any work carried out jointly by me and any other person is clearly identified in it) and that the thesis has not been edited by a third party beyond what is permitted by the University's PGR Code of Practice. The copyright of this thesis rests with the author. No quotation from it is permitted without full acknowledgement. I declare that the thesis does not include work forming part of a thesis presented successfully for another degree. I declare that this thesis has been produced in accordance with the University of Glasgow's Code of Good Practice in Research. I acknowledge that if any issues are raised regarding good research practice based on review of the thesis, the examination may be postponed pending the outcome of any investigation of the issues. I am submitting this thesis with the knowledge / approval of my supervisor. I fully understand my responsibilities in this context as a researcher under the University's policies, including the Code of Good Practice in Research.

Chapter 1 Introduction

Antimicrobial resistance (AMR) has emerged as one of the most significant threats to population health of recent times. As well as the role of antimicrobial drugs in treating acute infection, antimicrobial prophylaxis is an integral component of care in routine surgical and obstetric procedures and for patients receiving chemotherapy (1). In 2014 the UK Prime Minister, David Cameron, commissioned the Review on AMR to assess its international impact and propose solutions; it is estimated that AMR is currently responsible for 700, 000 deaths annually and that if the present situation continues unchecked that this could reach 10 million by 2050 (1).

In March 2015, at the 68th World Health Assembly, the World Health Organization (WHO) responded with a Global Action Plan on antimicrobial resistance that sets out five strategic objectives:

(1) to improve awareness and understanding of antimicrobial resistance;

(2) to strengthen knowledge through surveillance and research;

(3) to reduce the incidence of infection;

(4) to optimize the use of antimicrobial agents; and

(5) to ensure sustainable investment in countering antimicrobial resistance (2)

The plan reflects increasing global consensus that antimicrobial resistance poses a profound threat to human health and government strategies need to align. These objectives can be attained through the implementation of clearly identified actions.

In the UK, England's Chief Medical Officer, Professor Sally Davies, highlighted the therapeutic implications of AMR in her 2013 Annual Report, warning that failure to act could soon result in what are currently routine minor surgical procedures becoming potentially fatal due to the inability to treat common infections adequately (3). The UK's Five Year Antimicrobial Resistance Action Plan, initially published in 2014 and updated in 2019, focuses action to be taken around three key aims:

- Reduce the need for, and unintentional exposure to, antimicrobial drugs
- Optimise antimicrobial use
- Invest in the development of new antibiotics, diagnostics and novel therapies (4)

In Scotland, the Scottish Management of Antimicrobial Resistance Plan 2014-18 (ScotMARAP2), developed by the Scottish Antimicrobial Prescribing Group (SAPG), provides recommendations for improving the way antimicrobials are used, laying out objectives for use across all healthcare settings, from a whole organisational level through to guidance for individual prescribers (5). At an individual health professional level, objectives focus upon improving infection prevention and control practices; improving prescribing practice through implementation of antimicrobial stewardship programmes; and improving professional education, training and public engagement to promote wider understanding of the need for more sustainable use of antibiotics. The decision-making process regarding whether an antibiotic is prescribed is complex, involving interplay between a range of factors including clinical features, patient expectations and the perceptions of the patient and health professional of the risks associated with not prescribing.

To date, public health information interventions in the UK to reduce inappropriate antimicrobial prescribing have primarily centred on provision of written patient information and have shown little impact (6). In contrast, mass media campaigns in European countries that have been delivered in a more sustained manner have been associated with reduced antimicrobial prescribing and changes in public and professional attitudes (7-9). Qualitative research suggests that the language used in association with antimicrobial resistance is often poorly understood by non-health professionals and can be unhelpful in communicating intended key public health messages (7-9).

It is acknowledged that a commitment to reducing antimicrobial use that results in changes to practice has the capacity to produce unintended effects; for example, the incidence of mastoiditis has been shown to correlate with a reduction in antibiotic prescribing for otitis media (11). Recently, as recognition of the need for radical action on antimicrobial resistance grows, so too does an increasing awareness of the importance of early recognition and management of sepsis. The UK Sepsis Trust estimates that 37, 000 deaths result from sepsis each year while in September 2015 the Sepsis Alliance ran 'Sepsis Awareness Month' to raise the profile of the condition. Guidance for health professionals on the management of sepsis was published by the National Institute for Clinical Excellence (NICE) in 2016 (10).

Highlighting the early management of sepsis as a key health priority conflicts, in part, with a drive to reduce antimicrobial prescribing. This is likely to impact on perceptions of

antimicrobial use in the public realm and also has the potential to influence the behaviour of prescribers. In both the guidance produced for health professionals and in health information resources for the public, as well as in media reporting of AMR and sepsis, there is often little apparent connectivity between the importance of prompt recognition and management of infection through appropriate use of antibiotics and the need for responsible stewardship to preserve their efficacy.

To improve knowledge and understanding of antimicrobial resistance, we need to understand how people's views and interpretations of antimicrobial resistance are shaped and influenced. The news media plays an important role in setting agendas by selecting, controlling, and prioritising media messages. Previous research has suggested that antimicrobial resistance is often perceived as a distant and theoretical threat that has little personal impact (7). This may in part be related to the way in which the issues of antimicrobial resistance and sepsis are framed within the media. Literature on public perception of risk describes how public health messages have greater impact when presented in association with identifiable rather than anonymous victims (11). AMR tends to be reported in relation to its importance to global health and high-level public health strategy, using quantitative illustrations of risk to communicate its magnitude. In contrast, the narrative contained within articles related to sepsis is often highly personalised, with a strong human-interest element. Understanding the media portrayal of these two issues, both independently and as two interwoven themes, will enhance our ability to develop effective public health messages regarding antimicrobial resistance.

This timely PhD has two main aims:

1) To better understand how the risks of antimicrobial resistance and sepsis are constructed in the popular news

2) To understand how these impact on the attitudes and behaviour of the public, particularly parents and carers of young children to whom messages are often targeted

Chapter 2 Literature review

2.1 Rationale for presentation of literature

There were two distinct sections to this PhD: the media analysis, which was used to explore which factors associated with reporting of AMR and sepsis were most prominent and potentially most influential for a public audience, and the focus groups. which aimed to explore how these impacted views and attitudes.

The main literature review in this chapter which summarises background literature on AMR and sepsis was undertaken at the outset of the research and was integral in informing my approach to the media analysis. Reporting of sepsis in children was identified as an important aspect of media framing and deemed worthy of further exploration, thus the relevant background literature related to parental assessment of acute childhood illness was reviewed at a later stage in the research process while developing methodology for focus groups. To increase accessibility for the reader and cohesion of the thesis as a whole this literature is presented later as an introduction to the focus groups findings chapters.

2.2 AMR

AMR is currently a high-profile issue within mainstream news. Many of the most relevant publications, such as policy documents and strategies, are therefore readily accessible in the public domain. An initial scoping of this literature informed my PhD proposal.

AMR is a wide ranging and complex issue, and it was quickly identified that unfocused searches returned a large volume of articles. A list of key themes was identified (Appendix 1) and it was apparent that the most effective way to identify relevant material would be to develop separate search strategies within each theme. This allowed different approaches to be used as appropriate; for example, for wide topic areas, such as the history of AMR, more restrictive parameters were used in order to limit the number of articles generated. In contrast, for topic areas where it was anticipated that there would be fewer relevant published articles, for example, public awareness campaigns, search terms that widened the results as far as possible were used, with no restrictions applied. This pragmatic approach ensured that the most relevant articles for each topic were identified while keeping results manageable and relevant.

As this thesis compares and contrasts the framing of AMR and sepsis in the media and explores the way in which the public perceive these issues, where appropriate, sepsis is

considered alongside AMR in the relevant sections. Search strategies are recorded in Appendix 2.

To inform the initial section of the introduction, the first 100 articles from each search were reviewed and relevant ones added to the pool of literature already identified during the scoping phase. Articles whose titles suggested a very narrow focus, for example on one specific organism or on a group of patients with a very specific diagnosis, were excluded. For the introductory section, non-English language articles were excluded as the rate of publication of articles on this topic was sufficient to ensure that this approach generated a wide range of highly relevant literature in each of the major themes. Reference lists of the relevant articles were used to identify further key publications.

2.2.1 History of Antibiotic Use and AMR

The serendipitous 1928 discovery of penicillin by Alexander Fleming in a petri dish hastily stacked in the corner of his laboratory before a summer break is widely regarded as a pivotal moment in modern medicine (12). This discovery, and its subsequent development as a therapeutic drug by Florey and Chain, changed the course of therapeutics and, alongside the widespread introduction of vaccinations, heralded in a new post-infective era where the foregone biggest threats to human life became eminently treatable. What is less widely known is that even before penicillin was in use clinically, the ability of bacteria to produce enzymes capable of inactivating the bactericidal properties of penicillin had already been identified (13). The recent isolation of genes encoding resistance to beta lactam antibiotics from 30 000 year old permafrost samples confirms that AMR is an entirely naturally phenomenon, with the selection of resistant forms for survival where this poses an advantage in keeping with the evolutionary processes in evidence throughout the biosphere (14). What might be considered less natural is the extent to which the use, and overuse, of antimicrobial agents by humans has hastened this process. Had the therapeutic qualities of antimicrobials never been harnessed, resistance of organisms to the antimicrobial compounds that they encounter would certainly exist, endure and continue to develop; however, by using these compounds both where clinically indicated for patient and animal welfare, but also often where they are not, we create artificial exposure, forcing them to modify or die. Fleming himself was fully aware of the threat of AMR and gave a stark caution about the potential consequences of unrestricted antibiotic use as he received the Nobel prize for penicillin discovery, warning:

"The thoughtless person playing with penicillin treatment is morally responsible for the death of the man who succumbs to infection with the penicillin-resistant organism." (15)

Human ability to harness the therapeutic properties of antibiotic compounds therefore does not 'cause' development of resistance, but it does change the pace at which it develops.

The word 'antibiotic' was first used in 1941 as a term for capturing all of compounds that were being identified as having properties capable of inhibiting growth of bacteria (16). An OVID Medline search reveals that the term 'antimicrobial resistance' was in use by 1956. 'Antimicrobial resistance' is the term that is in use by the scientific community as it encompasses not just antibacterial agents but also those used to treat infection by fungi, viruses and parasites. The term 'antibiotic resistance' is also in common usage, arguably to a greater extent by the lay population – for example, comparing searches within title or headline on an academic database (Ovid Medline) and a news database (Lexis) on a given day (17/2/16) revealed that the term 'antibiotic resistance' yielded more articles than 'antimicrobial resistance' on both databases, but to a greater extent on the news database (4044 and 3358 versus 2508 and 749).

2.2.2 Emergence of clinically important resistance

Although recognised as a phenomenon from the outset of antibiotic use, the clinical impact of resistant organisms became more apparent in the late 1990s with the emergence of strains of the common skin commensal staphylococcus aureus that were found to be resistant to penicillin, including semi-synthetic classes that had been developed to combat resistance, including methicillin. These resistant species were designated 'methicillin-resistant staphylococcus aureus' (MRSA). Throughout the 2000s, MRSA made frequent headlines, often in the tabloid press, where it formed part of the 'superbug' narrative and was largely presented as a risk associated with hospital admission. Yet by 1997 the first reports of deaths from community acquired MRSA were being reported in patients with no pre-existing risk factors (17). Community acquired strains of MRSA are known to be more likely to produce the virulent toxin Panton-Valentine leucocidin (PVL). The most common presentation of PVL MRSA is with soft tissue infections such as boils or abscesses, however it can also cause a severe form of necrotising pneumonia that progresses rapidly in young adults and is associated with high mortality. Although resistant to the drugs that would commonly be used to treat staphylococcal infections, MRSA does remain amenable to treatment with alternative antibiotics including vancomycin and teicoplanin, and it is

likely that delays in prompt recognition and treatment of community-acquired MRSA rather than absence of treatment options contributed most to mortality (18).

In contrast, there are fewer treatment options available for the resistant Gram-negative organisms that have emerged over subsequent decades. Inevitably, the discovery of these resistant strains and their potential implications was met by alarm by the physicians who first encountered them. Dr Roger Wetherbee, then an infectious disease specialist at New York University's Tisch Hospital, recalls receiving the first report of drug-resistant Klebsiella in 2000. The only drug to which the strain was sensitive was colistin, developed decades earlier but abandoned due to concerns regarding nephrotoxicity:

"It was literally resistant to every meaningful antibiotic that we had… we had this report, and I looked at it and said to myself, 'My God, this is an organism that basically we can't treat."(19)

In late 2015, reports that colistin-resistant E Coli had been identified in food animals in China made international headlines, signalling an era where even the 'last-ditch' antibiotics are ineffective against emerging strains of infection (20).

Figure 1 shows a timeline of antibiotic discovery set against development of resistance. This demonstrates the relative 'discovery void' since the 1960s and highlights the need for a different approach in managing resistance in an absence of new available antimicrobial compounds (21).

Figure 1 Timeline of antibiotic discovery and resistance

(Reproduced with permission from Clatworthy et al, 2007, (21)).
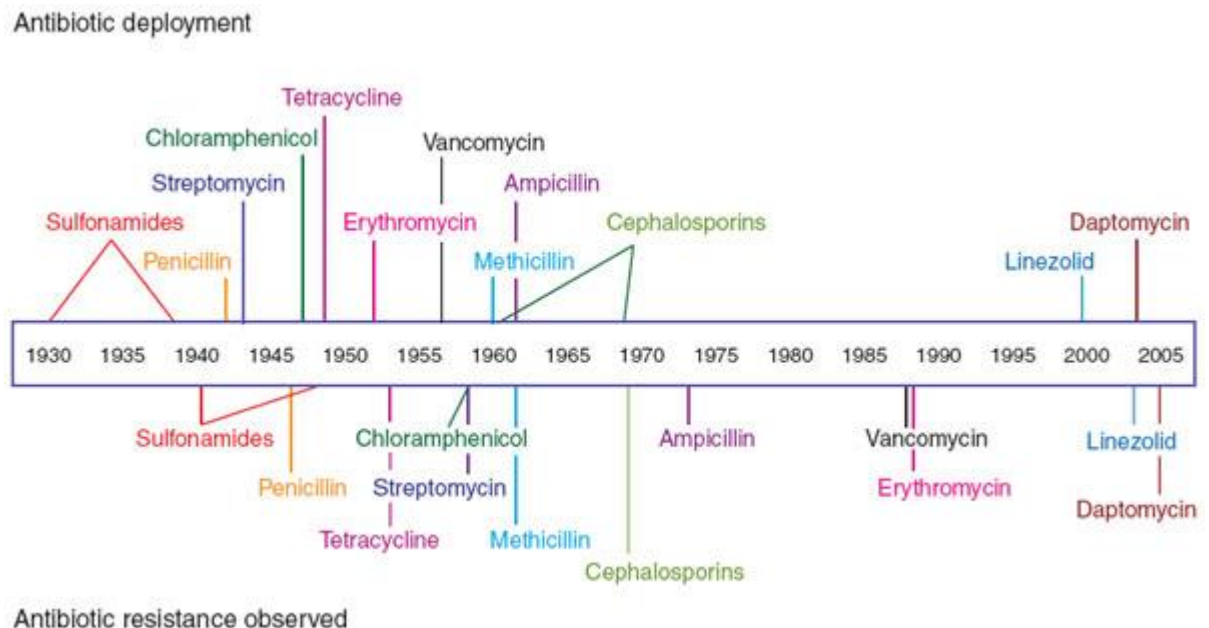
2.2.3 Mechanisms of resistance

To form some understanding of how antimicrobial resistance occurs it is necessary to have a basic understanding of how antibiotics work to kill or inactivate bacteria. It should be acknowledged that a major challenge in our understanding of how resistance develops lies in the fact that in many cases there is only partial understanding of how antibiotics themselves work and that there remain a great deal of unknowns at a molecular level (15). Levy and Marshall summarise the main classes of antibiotic and their mode of action (Appendix 3) (18). To provide some context, examples of possible target organisms and the clinical conditions that these may be associated with are also listed. These are merely single examples; the range of organisms that antibiotics within each class may be active against can be wide.

An understanding of AMR requires consideration of two aspects: the characteristic of the organism which confers resistance and the process through which this characteristic develops. Davies describes five main mechanisms through which organisms may be resistant to antibiotics (22):

- The organism may produce an enzyme that inactivates the antimicrobial drug
- The outer wall of the organism changes and becomes impenetrable
- The drug enters but is pumped out again (known as "efflux")
- The drug target portion of the organism is altered and becomes unrecognisable

- The intracellular metabolic processes may become altered so that the acting on the 'target' metabolic pathway becomes inconsequential

Tang helpfully categorises the above mechanisms in an alternative way via the 'bullet-target' concept; interruption of an effective interaction between drug and organism may be caused by alteration to the organism (or target) (points 2 and 4 and 5 in the list above) or the antibiotic (bullet) may undergo alteration (points 1 and 3) (23).

The way in which antibiotic resistance develops can, in the main, be assigned to one of two categories: vertical or horizontal. Vertical resistance develops because of spontaneous mutations during cell reproduction. Bacteria are prokaryotes, which means they do not contain a nucleus; rather, their genetic material is usually contained in a single chromosome within the cytoplasm, which contains the genes that code for the bacterial cell's proteins, made up of nucleic acid base molecules. Under optimal conditions, they can replicate extremely rapidly; a population can double in under ten minutes. Thus, replication requires copying of several million nucleic acid base pairs. A mutation occurs when one or more of the base pairs is copied incorrectly. The result of this mutation may be advantageous or disadvantageous to the organism. Over time, the mutations that confer advantage will start to become more common in each population, as these organisms have a survival advantage. At a mammalian level, this might mean persistence of chance mutations that produce a coat that allows the animal to camouflage itself from predators in its natural habitat. At a bacterial level, it can mean the persistence of bacteria in which spontaneous mutations have enabled them to 'hide' from predatory antimicrobial compounds to which they are exposed, by one of the mechanisms listed above, such as alteration of the target protein. As stated previously, spontaneous mutations occur regardless of therapeutic use of antimicrobial compounds, however their clinical application forces this process to occur far more rapidly than would occur without human intervention.

Horizontal transmission of resistance develops when genetic material is transferred from one organism to another in one of three ways (24, 25):

- Conjugation: introduction of a gene via a plasmid, which is a small segment of DNA separate from the bacterial cell's chromosome which can replicate independently.
- Transformation: acquisition and incorporation of free DNA from the environment (e.g., from dead bacterial cells) into the chromosomal complement

- Transduction: transfer of genetic material through infection with a bacteriophage (a bacterial virus)

Although there are variations in the frequency of the above mechanisms according to species, plasmid-mediated horizontal gene transfer is the most common, while phage transfer is a relatively rarer event (15). It seems inevitable that other, as yet, undiscovered modes of resistance gene transfer exist: "if resistance is biochemically possible, it will occur".

It would be possible to write a great deal regarding the individual organisms whose emerging resistance is of concern, however that is not a primary aim of this thesis. A summary of the main organisms identified as a threat to human health is listed in Appendix 4; these will be discussed where relevant in subsequent sections.

2.3 Drivers and solutions

The factors that have contributed to current levels of AMR are complex, as are the range of actions that may help to mitigate the impact. In this section, the main drivers, and potential solutions to each one is reviewed.

2.3.1 Human therapeutic use

There is increasing acknowledgement of the need to rationalise antibiotic use to optimise and preserve treatment options for resistant infections in the future. The system of activities and policies that are in place to ensure this is known as antibiotic stewardship. This incorporates many components (some of which are discussed in more detail later in this chapter), and surveillance measures that are in place suggest that these processes can be effective (26). However, there is wide variation internationally in both regulation of antimicrobial use and in stewardship systems. While some of the factors that drive overuse of antimicrobials in low- and middle-income countries are the same as those in the UK and other high-income countries, there are important differences to consider including usage without prescription and counterfeit trade. Although most antibiotics can only be obtained with a prescription in North America and Europe, non-prescription use remains common practice in many low- and middle-income countries where it is possible to purchase antibiotics 'over the counter'. Figure 2 shows the frequency of use of non-prescription antibiotic use in the general population, based on evidence identified in a systematic review by Morgan et al. (27). Even between high-income countries variation is apparent; for example, off-prescription use is notably higher in Southern compared to Northern

Europe. There were important limitations in this study, including reliance on self-reported use and a lack of available data for many regions; however, this research does serve to highlight international variation in how antimicrobial drugs are used. This reflects differences in the pathways through which individuals access healthcare as well as the policies in place to regulate antibiotic use, or alternatively the extent to which these policies are enforced.

Figure 2 Frequency of non-prescription use of antimicrobials in the general population based on published works.

(Reproduced with permission from Morgan et al, 2011 (27)
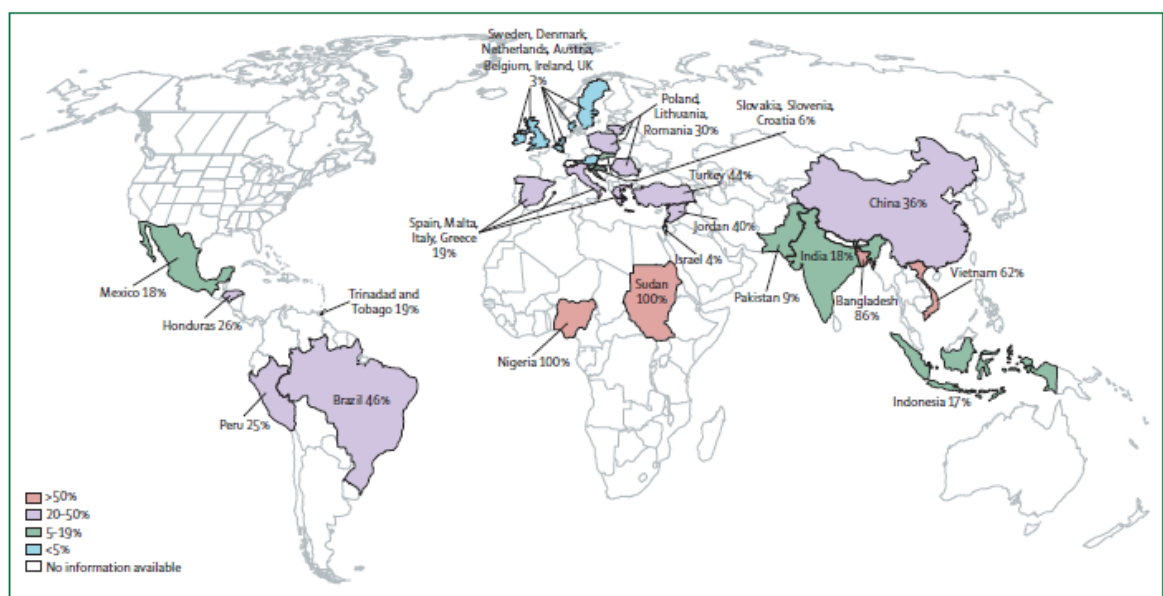
The importance of these findings is that non-prescription antibiotic use and self-management is associated with shorter courses of treatment, or incomplete treatment, as well as a lack of access to information about local resistance patterns to inform choice of antibiotic. Antibiotic use that is not monitored and adjusted as necessary by a health professional is therefore of substantial public health concern as a driver of resistance.

Poverty is a significant factor in driving the practices that promote AMR. With infectious diseases remaining the highest cause of disease in the developing world, there is a thriving counterfeit drug trade in antimicrobials; several studies have documented sale of drugs purporting to be antibiotics that contain little or no active ingredients (28). Financial incentives also drive prescriber practice. For example, in some healthcare systems, hospital funding may rely partly on pharmaceutical sales, which encourages overprescribing (29). A further consideration in some lower-income countries is the prohibitive cost of effective antibiotics. For example, in higher-income countries so-called 'last ditch' drugs, e.g.,

meropenem, are held in reserve for infections not amenable to any other drugs. In low-income countries, the higher cost of these drugs may promote use of less effective regimes that provide inadequate treatment and may ultimately increase resistance levels (30).

There are important ethical considerations in addressing antimicrobial use in developing nations where the benefits of antimicrobial therapy may not have been fully realised, as acknowledged in a report by the Lancet Infectious Diseases Commission: "a policy tension might arise between saving lives with short-term mass campaigns that advocate antibiotics and increased mortality as a result of antibiotic resistance" (29). Furthermore, it must be acknowledged that the priorities of health professionals in countries still experiencing high levels of mortality from infectious disease are inevitably distinct from countries where other disease families predominate, an ethical dilemma that has been referred to as 'access versus excess.' For example, one group of researchers working in Niger, Tanzania and Malawi evaluated the impact of using the antimicrobial drug azithromycin to treat trachoma, the leading cause of blindness in children in the developing world. An unanticipated associated outcome was a reduction in all-cause childhood mortality (31). Thomas Leitman, who led the research, is unequivocal in acknowledging that a less desirable unintended outcome is likely to be an increase in AMR: "We think we will select for antibiotic resistance. However, many of us believe that might be a price worth paying if there is truly a reduction in childhood mortality".

It should be noted however that wide variation in antimicrobial use is also present in higher-income countries. For example, community antimicrobial use is three times that in Cyprus than in the Netherlands (32). The factors that affect whether an antimicrobial prescription is issued in a primary care setting when a patient presents with symptoms that may be suggestive of a bacterial infection are incredibly complex and will be discussed in detail later in this chapter. Briefly, some of the main elements are: concerns regarding the impact of failure to issue a prescription on the prescriber-patient relationship; loss of paternalism and a move towards greater shared decision making when deciding on a treatment pathway; and fear of litigation where an antimicrobial prescription is not issued but subsequently demonstrated to have been indicated.

Just as the factors that drive AMR are complex, so are the potential solutions. Internationally, those countries that have implemented detailed strategies have made most impact on reducing and controlling resistance. As an example, the UK Five Year Antimicrobial Resistance Action Plan is based around seven key areas for action: infection control, optimising prescribing practice, education, new drug development, better

surveillance systems, prioritisation of research and increased collaborative working (4). The way in which these tenets of AMR control are interpreted and implemented will obviously vary with resource availability and must be capable of adaptation within different settings. Nonetheless, at present there is a lack of a detailed overarching universal approach to align priorities. It has been suggested that a route map that can be approached in a stepwise manner by individual governments may be the most appropriate solution (33).

At a local level, greater transparency, for example, through audit and feedback of individual prescribing patterns to healthcare professionals and public disclosure of rates, may improve prescribing practice; however, such endeavours that are designed to promote a degree of competition need to be balanced with ensuring patient safety.

A major factor in the issuing of unnecessary prescriptions within a primary care setting is diagnostic uncertainty in determining whether an infection requires antibiotic treatment. Clinical algorithms serve only as a guide to whether common infective symptoms may be derived from a bacterial or viral source, and ultimately the gold standard test is laboratory culture, the results of which are generally not reported before 48 hours (29). Rapid diagnostic tests aim to circumvent this waiting period, allowing much quicker definitive action on the need for antimicrobial therapy. There is certainly scope for a role for rapid diagnostic tests in identifying the causative organism in the most common presentations to primary care, for example, upper respiratory tract infections; however, the clinical benefit of these is unproven and there is reason to be cautious. Most diagnostic tests use nucleic acid amplification techniques to detect the presence of specific bacterial DNA – however, much as the reliability of forensic DNA evidence is often questioned in criminal justice processes, so it is difficult to determine whether the mere detection of a particular organism reflects infection or simply colonisation. This could lead to over-diagnosis and overuse of antimicrobial treatment, with associated negative impacts on resources and patient care.

The Review on AMR's publication on the role of diagnostics identifies four characteristics that the ideal rapid diagnostic test would be able to distinguish:

- Is the infection causing the illness viral or bacterial?
- If bacterial, what type of bacteria is causing the infection?
- Are the bacteria that are causing the infection resistant to available antibiotics?
- Are the bacteria that are causing the infection susceptible to existing drugs? (34)

No such test that fulfils all of these criteria currently exists and the diagnostic tests that do exist are expensive, whereas antibiotics are cheap; therefore incentives to prioritise the former are lacking in everyday practice. C-Reactive Protein (CRP) is an acute inflammatory marker that is increased to a greater degree in bacterial infections compared to viral. While the results are not specific to particular causative organisms, they offer a practical complementary diagnostic tool that can be used alongside clinical guidelines and may be particularly useful in community settings where there is less ease of access to other diagnostic tools and no capacity for ongoing direct observation prior to making a treatment decision. An evaluation led by the Scottish Antimicrobial Prescribing Group (SAPG) suggests CRP testing in primary care has a role in supporting avoidance of unnecessary antimicrobial prescribing (35).

There are indications that a commitment to reducing antimicrobial use in the community is working. Antimicrobial prescribing in primary care has decreased by 20% since 2016, indicating that the strategies detailed in the Scottish plan (ScotMARAP) may be starting to be effective (5). In contrast, prescribing in secondary care settings has shown an increasing trend since 2012 (26, 36). It has been suggested that this may be, in part, an unintended consequence of an increased focus on early recognition of sepsis in the hospital setting (26). It is also possible that this pattern reflects the more complex case-mix within the hospital setting that may require treatment decisions that are based on clinical judgement rather than rigid adherence to guidelines (37).

A further consideration is increased non-medical prescribing. In 2020, nurses prescribed 12% of antibiotics dispensed in the community (38). The impact of the type of healthcare professional on likelihood of issuing a prescription is not yet clear.

There have been concerns about the potential impact of COVID-19 as a novel driver of AMR. In a systematic review and meta-analysis, Langford et al found that three quarters of patients diagnosed with COVID-19 received antibiotics, which is higher than estimated co-infection with bacterial organisms and therefore likely to be unnecessary in many cases (39).

2.3.2 Pharmaceutical research and development

Research and development to produce new antimicrobial compounds had been keeping pace until the 1960s, with 20 new classes of antimicrobials introduced between 1930 and 1962. Since the 1970s, development has slowed and only two new classes have been

introduced, with the majority of new drugs being modifications of existing compounds (40, 41).

There are a number of explanations as to why research and development has stalled. There is inherent market failure associated with production of a new antimicrobial drug (42). First, in comparison to the chronic diseases that now predominate in the developed world such as hypertension, infectious diseases in the main do not require indefinite courses of treatment, limiting profitability. Second, most pathogens remain susceptible to existing drugs – any new compounds that are discovered will therefore tend to be kept in reserve for those patients infected by resistant organisms, meaning that only a small minority of patients will be eligible to receive them. Furthermore, the constantly evolving nature of AMR is such that any new drug that is developed inevitably becomes less effective over time, in contrast to drugs required for chronic conditions that may be used several times a day for decades. This creates a situation where pursuit of new antimicrobials makes no sound economic sense for pharmaceutical companies. The Office of Health Economics has estimated that, with restrictions, present net value of an antibiotic to a drug company is minus $50 million, whereas a new musculoskeletal drug, without restrictions, is worth $1 billion (29). At the same time, the cost to the healthcare system of the major antimicrobials in use is almost negligible. It has been said that "the cost of the oldest and most frequently used antibiotics is (probably) mainly in the packaging" (15). Thus, we have a highly undesirable situation where there is little immediate economic incentive from a healthcare system perspective to restrict use of existing antimicrobials, and little economic incentive from a pharmaceutical industry perspective to invest in the development of new agents.

A further factor that has hampered research and development of new agents has been the false hope placed in a genomics approach, which aimed to use bacterial DNA sequence information to predict enzymatic pathways that may be amenable to inhibition (41). Significant investment in this field has failed to deliver benefits. There has also been a lack of investment from the academic sector in antimicrobial research (29). Current emphasis within academic institutions is on translational research, i.e., the evolution from an idea into a marketable product. It is difficult for academics to attract investment required for drug products that are viewed as high-risk. It is also suggested that antimicrobial research is not viewed as a particularly prestigious area of academia. For example, it has been highlighted that that the main microbiology journals are viewed as lower impact than other subjects (impact being based predominantly on the number of citations an article receives) (43). As this is of huge importance in an academic career, it is understandable that

researchers are attracted to the subject areas that are likely to be most fruitful. It has also been claimed that infectious disease as a clinical specialty is held in lower regard in comparison to other fields within medicine, in part since there is little demand for private practice. A report by the Review on AMR found that, in a survey of 25 medical specialties, infectious diseases was the lowest paid, and had the second lowest application rates (43).

The solutions to the lack of new antimicrobials that are in development may be broadly categorised as developments in the drugs or therapeutics themselves and the policies and partnerships that support their development.

A range of potential directions for new therapeutic approaches to treating bacterial infection have been proposed and debated (14, 44, 45). A detailed discussion of these options is beyond the scope of this thesis, but the main categories are as follows:

- Adjuvant treatment with drugs not traditionally used as antimicrobials (e.g., the antidiarrheal drug loperamide and the antiplatelet drug Ticlopidine

- Antivirulence strategies designed to reduce capability of organisms to establish infection. For example, 'quorum sensing' is the process by which bacteria become capable of producing damage only when their numbers reach sufficient density; by interfering with this process the virulence of the organism, or capability to produce damage in the host, can be altered

- Biological therapies including use of bacteriophages, which are virus particles that are capable of infecting and killing bacteria

New approaches must of course be coupled with rational use of existing antimicrobials through the stewardship practices that have already been discussed and include limiting the use of broad-spectrum antimicrobials, ensuring optimal dosing and duration of treatment, and reducing risk of infection in the first place through hygiene measures and ensuring good vaccination coverage where appropriate.

In order to stimulate pharmaceutical investment in the development of new antimicrobials, both regulatory and motivational strategies are likely to be required, often referred to as 'push and pull' incentives. The Review on AMR recommends the following as priority interventions to support antimicrobial development (46):

1. Creation of a more predictable market for new antimicrobials by guaranteeing return for investment where a drug that meets an unmet need is developed, regardless of actual number of units sold

2. More focused funding on early-stage research

3. Modification of the way in which new antimicrobials are approved, with greater
   harmonisation between countries to simplify this process and reduce barriers to introducing
   new drugs, in a similar way to the modifications to clinical trial requirements already in
   place in Europe

2.3.3 Agricultural and veterinary use

Although human antimicrobial use tends to attract more discussion in the public arena, the
majority of antimicrobial use occurs in the agricultural, horticultural and veterinary sectors.
In the majority of countries worldwide, over 50% of antibiotics formulations that have
important clinical applications in humans are used in livestock, a figure that reaches over
70% in the USA (43). The Review on AMR's report on Antimicrobials in Agriculture and
the Environment points to three indications for antimicrobial use in farm animals (Figure
3) (47):

Figure 3 Current uses of antibiotics in livestock

Reproduced with permission from 'Antimicrobials in agriculture and the environment: reducing
unnecessary use and waste' (47)
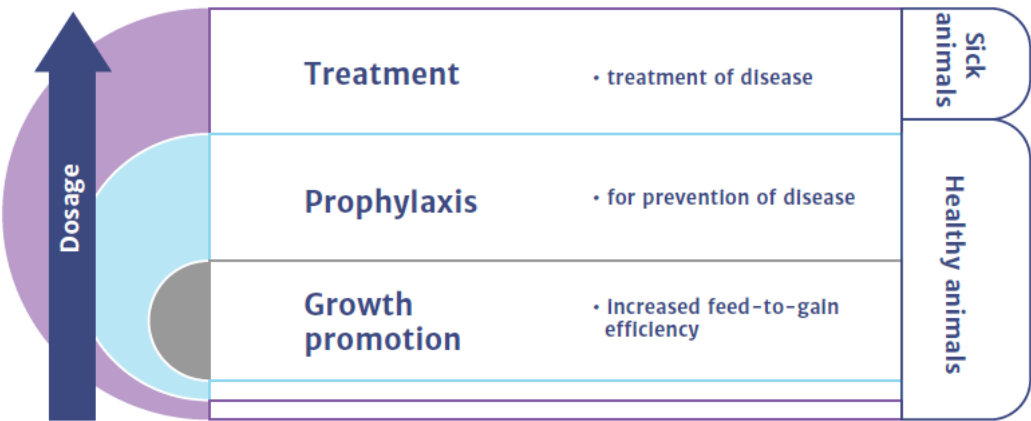
Use of antimicrobials as growth promoting agents (GPAs) began in the 1940s with the
discovery that tetracycline use in chickens had the secondary effect of increasing their
growth rate. The predominant mechanisms that account for this phenomenon are inhibition
of bacteria, thereby increasing availability of energy for growth, or through prevention of

diarrhoea (48). In subsequent decades, this practice became widespread, allowing both farmers and consumers to reap the benefits. From an animal welfare perspective, the use of antimicrobial prophylaxis in preventing infection has been used to compensate for the often unsanitary conditions that accompany factory farming practices that would otherwise have been detrimental to livestock and therefore profits (49).

With continued use however, it was apparent that increased carriage of resistant bacteria was present in farm workers and farm animals in farms who used GPAs compared to those who did not (50). It became clear that some form of restriction would be necessary and, prompted by identification of a rise of multidrug resistant Salmonella in the 1960s, the Swann Committee was convened in the UK to provide recommendations on what action should be taken. On the basis of these recommendations, the use of several substances important to human health, including tetracyclines and penicillin, was withdrawn (51). Following the UK's lead, the recommendations were implemented in other European countries and Canada. The approach taken by these countries is based on what has been described as 'the precautionary principle' whereby "when evidence points towards the potential widespread or irreparable harm to public health or the environment, options for avoiding that harm should be examined and pursued, even if the harm is not yet understood or proven" (50).

In contrast, the USA has been slow to act, although Federal Drug Agency guidance in 2012 has recommended a phased approach to reducing the use of medically important antimicrobials in animals (52). Even in Europe, however, use of other agents as GPAs continued and, although these are different compounds to those used in humans, they are often structurally similar and may share a bacterial target structure such that development of resistance of an organism to one compound effectively results in resistance to other closely related ones. In addition, often the distinction between when an antibiotic is clinically indicated and when it is not open to interpretation, further limiting the impact of restrictive measures. For example, withdrawing antimicrobials as GPAs but failing to improve hygiene conditions increases the incidence of gastrointestinal infections that had been held in check by low dose antimicrobial use. This justifies a therapeutic indication, allowing farmers to continue to benefit from GPAs without addressing animal welfare requirements, perpetuating an undesirable cycle.

Transmission of clinically important organisms from animal to humans is not a new threat, and Anomaly points to the Spanish flu epidemic of 1918 which is thought to have originated in farm animals, and to the avian and swine flu outbreaks of the early 21st

century (49). The overcrowded conditions that are synonymous with factory farming present ideal conditions for rapid animal to animal spread and, moreover, the subtherapeutic levels of antibiotics that are used are more likely to promote resistance than doses used where clinically indicated. That low dose antimicrobial use increases carriage of resistant strains of various pathogens in livestock is not debated; a wealth of evidence has accumulated since the 1970s (50). What has been more contentious however is the importance of this for human health.

Anomaly et al outlines the ways in which antimicrobial resistant bacteria may spread to human hosts (49):

First, farm workers and those in the meat industry who handle raw meat may acquire resistant bacteria through direct contact.

Second, bacteria may survive even after cooking and be transferred through ingestion.

Third, resistant bacteria may be transferred in animal waste used in fertilising crops or transferred via other animals and water systems (it is estimated that 75% of antimicrobials administered to animals pass through the body undigested) (53). Other environmental sources of water contamination should also be mentioned here; aquaculture is a major driver of AMR with wastewater from pharmaceutical companies a significant factor in contributing to the reservoir of resistance. Most antimicrobial manufacture takes place in China/India – partly because cost of manufacture (and of complying with manufacturing standards) is low. Disposal of waste by-products is often directly into the surrounding water bodies. There are currently no standards for acceptable levels of antimicrobials similar, for example, to those that exist for safe concentrations of bacteria in drinking water. One 2007 study tested concentrations of ciprofloxacin in a river adjacent to a pharmaceutical manufacturer and found that they exceeded levels toxic to bacteria by 1000-fold (47).

Direct spread of bacteria from animals to people was first reported by Levy et al in 1976, with identification of the same tetracycline-resistant strains of E. coli in chickens and chicken handlers (18). Newer genetic analysis techniques provide even more detailed evidence of the same molecular strains present in livestock and those in close contact with them; for example, Zhang et al identified the same apramycin-resistant gene in livestock and humans in a study of Chinese farm workers (apramycin is used in agriculture but not in human medicine) (20).

Some researchers hold the view that robust evidence for transfer of resistance from the food chain to humans is lacking. Phillips et al question the frequency with which transmission of resistance via direct ingestion of food truly occurs, pointing to other potential routes of acquisition, for example via contamination from sewage, and in difficulty in establishing the source (although this is surely no persuasive argument for unregulated use) (54). They also point out that identification of identical resistance genes in an animal species and humans does not prove a causal link, which would require establishment of temporal and spatial relationships. Critics of the 'precautionary principle' approach to regulation of antimicrobial use in food animals argue that even if transmission via the 'farm to fork' route does occur, the impact on human health is likely to be minimal:

"Whereas a theoretical hazard to human health arises from the use of growth-promoting antibiotics, an independent examination of the facts, free from commercial or political influence, shows that the actual risk is extremely small and may be zero in many cases" (54).

The political pressures that may support a reluctance to advocate a radical approach to the restriction of antimicrobial use in farming are clear. In a 2013 parliamentary debate on the link between farm antibiotic use and resistance in humans, Anna Soubry MP stated, "there is no conclusive evidence that food-producing animals form a reservoir of infection in the UK. Food is not considered to be a major source of infections resistant to antibiotics." This reflects the position statement of the Veterinary Medicines Directorate (VMD), a predominantly industry-funded executive agency of Defra (55).

In order to address the enduring uncertainty on a causal association between AMR in food animals and humans, the working group that leads the Review on Antimicrobial Resistance conducted a review of the available evidence (47). Of the 139 papers reviewed, the majority (72%) found evidence of a link between use in animals and AMR in humans; only 5% claimed no evidence of a link. The Review group concluded that there is sufficient evidence to support limiting the use of antimicrobials in agriculture and that the onus should be on those who oppose this to produce evidence rather than vice versa.

There is growing consensus, then, that more restrictions must be applied to the use of antimicrobials in animal food production; however, as with many public health actions that are known to be 'good' or 'right', it can be difficult to reverse the status quo. Anomaly summarises the difficult position in which the farming industry finds itself:

"Using antibiotics for non-therapeutic purposes gives farmers a small but significant advantage over those who decline to use them, thus creating a negative sum game in which the rational profit-maximising choice for each farmer gives no farmer any particular advantage over others but leaves nearly all animals and people worse off. Animals are worse off because of the cruel conditions in which they are kept. Famers are no better off using antibiotics for non-therapeutic purposes if their competitors are also permitted to use them. People are worse off because antibiotic-resistant bacteria often find their way into human hosts." (49)

Analogies may be made with gun control laws in the US or the use of drugs in sport – though the long-term advantages of change may be considerable, the relative disadvantage of being out of step with peers often precludes support for positive action.

It is argued that restricting use of antimicrobials would raise cost of meat production, and that this higher cost would be passed on to the consumer. There is now evidence, however, that the economic case may have been overstated; in the Netherlands and Denmark significant reductions in use of antimicrobials in livestock have been achieved without damaging their commercial success (47). In addition, improvements in hygiene and general living conditions for livestock have attenuated the benefits conferred by sub-therapeutic antimicrobial use. Furthermore, the potential long-term impact of failure to address AMR within the farming industry is no different to that which faces healthcare systems, with the possibility of loss of entire herds from untreatable infections.

The Review on AMR proposes three broad interventions to reduce the use of antimicrobials in agriculture and subsequent risk to human health:

1) A globally agreed target to reduce antimicrobial use in food production along with restriction of drugs important for human health
2) Development of minimum standards to reduce antimicrobial manufacturing waste released into the environment
3) Improved surveillance systems to monitor and target these problems

These measures fit with the overarching One Health approach that is supported by the WHO and aims to bring together and support collaboration between the medical, veterinary and agricultural sectors (56). It is recognised, however, that the strategic aims must be underpinned by specific measurable targets if meaningful progress is to be made.

2.4 Assessing the impact of AMR

The potential for AMR to impact adversely on human health and on the world economy in the coming decades is huge. Recognition and quantification of this may risk be an important driver of change but, although the potential for harm is widely accepted, estimates about the likely health and economic burden are subject to uncertainty for several reasons. As well as limitations in availability and reliability of data on current incidence of resistant infections, there are uncertainties regarding how quickly resistance will develop, whether onward transmission of specific infections will continue at the present rates and whether new therapeutic strategies will emerge to mitigate the effects of resistance. Referring to her 2013 report, the Chief Medical Officer was unequivocal in tone regarding the potential human impact of the threat (3):

"Antimicrobial resistance is a ticking time-bomb not only for the UK but also for the world. We need to work with everyone to ensure the apocalyptic scenario of widespread antimicrobial resistance does not become a reality. This threat is arguably as important as climate change." Dame Sally Davies

There is a balance however to be struck between overstating the potential threat in the absence of concrete evidence and the need to mobilise the public and professionals to action.

2.4.1 Health impact

To form a picture of the health burden associated with AMR infections, two types of data are required:

- Overall numbers of resistant infections
- The additional morbidity and mortality associated with resistant infections compared to those that are susceptible to treatment.

Quantifying the number of resistant infections

Quantifying the current burden of disease attributable to AMR infections is not straightforward and even recording of presence of infection at all may not be done accurately. Surveillance of resistance levels relies on monitoring of laboratory isolates i.e., infection detected in samples obtained from patients. The Review on AMR points to widespread failings in the surveillance systems that are currently in place to monitor resistance levels. Although many national and regional databases do exist, even the highest quality systems, e.g., the UK Clinical Research Collaboration (CRC) and European

Antimicrobial Resistance Surveillance Network EARSnet rely on voluntary release of data, and coverage is often inconsistent and information out of date (57). Obtaining data on resistance rates and trends in low and middle-income countries (LMIC) where robust systems for data collection are absent is even more challenging (58, 59).

Distinction must also be made between number of infections and number of clinically significant infections. Knowing that an infection has been present from laboratory data does not reveal anything about whether it has been related to a clinically significant event. Samples may have been obtained routinely (e.g., a swab from indwelling catheter) or for screening, and positive results do not necessarily confirm a clinically important infection. Furthermore, it is not possible to ascertain which samples relate to multiple episodes in one patient.

The main data sources for assessing the burden of disease in the population are hospital episode statistics and death certification. Information on the significant conditions is obtained from diagnostic codes allocated on discharge after an episode in hospital, in Scotland, known as the Scottish Morbidity Record (SMR1). Most patients affected by AMR have underlying co-morbidity and AMR as a contributory factor to illness may be overlooked. Although ICD 10 codes exist for resistant organisms, it is doubtful whether these are used consistently. It is known that the level of detail included in death certification in general is often inadequate, including for deaths involving sepsis. In one UK audit of death certification, the causative organism in deaths from sepsis was recorded in only 10.9% of cases (60). In an Irish audit that looked specifically at death certificates in patients who died in the 30 days following a positive MRSA diagnosis confirmed by blood culture, MRSA was listed as a secondary cause in only 25.4% (61). Estimates of AMR-associated mortality are therefore likely to be conservative.

The global action plan on AMR launched in May 2015 by the WHO included The Global Antimicrobial Resistance Surveillance System (GLASS), which aims to combine clinical, laboratory and epidemiological data on pathogens that pose the greatest threats to health globally in order to help develop a standardized approach to the collection, analysis and sharing of data on AMR at a global level (62). This initiative is in the early implementation phase, therefore current available data on AMR is far from adequate and is likely to underestimate the true burden of disease.

Quantifying the added health impact of resistant compared to susceptible infections

Resistant infections have been shown to be associated with greater morbidity and mortality than infections that are susceptible to antibiotics, but the extent of this has been difficult to quantify with accuracy. It can be difficult to pick out which factors are directly associated with the fact that an organism is resistant, and which are more indirectly associated. For example, it could be argued that, in assessing the impact of resistant infections in its truest form, it is the virulence of the organism that is the only important variable. In reality, all sorts of other factors influence this, including delays in establishing treatment and the potential for adverse effects associated with use of more powerful treatments needed (63).

As for many health conditions, it is ethically impossible to conduct randomised controlled trials to compare treatment versus non-treatment with antibiotics, therefore most evidence comes from observational studies which may be prone to confounding. Confounding factors are those variables that are associated with the exposure and outcome of interest, but which are not causal i.e., there may be important differences in patients who are more likely to develop resistant infections compared to the general population, or indeed compared to patients who develop infections that are susceptible to standard treatment regimes, that are associated with poorer outcomes, independent of the impact of the infection. Gandra et al discuss some of the limitations associated with studies that aim to quantify the health burden associated with AMR (64). They point to some of the important considerations that have often been omitted in studies that attempt to quantify the added burden of disease attributable to AMR infections:

- Length of hospital admission prior to infection
- Time-dependent nature of infection
- Comorbidity
- Antibiotic treatment
- Comparison group – infection v. non-infection or resistant v. susceptible infection
- Definition of resistance

When these variables are not considered and adjusted for, there may be an overestimation of the impact of AMR. For example, length of stay (LOS) in itself is a risk factor for hospital-acquired infection and patients with a longer LOS prior to diagnosis of infection are likely to have other factors that are associated with a poorer outcome (more severe underlying disease, greater number of invasive procedures etc). Failure to take this into account may overestimate the additional morbidity attributable to AMR. Studies that do not take account

of the time-dependent nature of infection may also overestimate the risk. Essentially, diagnosis of infection earlier in a hospital admission will be associated with an apparent longer subsequent LOS, but if this is coincidental the length of stay will appear artificially extended.

Failing to adjust for antibiotic therapy may also affect outcome. It could be argued that is not a valid comparison to compare outcomes in patients with resistant infection who are not receiving antibiotic therapy with those of patients with susceptible infection who are receiving effective antibiotic therapy – a fair comparison would be for neither group to receive antibiotics, which is obviously ethically impossible. Another consideration is that there is often a lack of clarity about whether studies are reporting specifically on resistant infections or simply hospital-acquired infections (which may or may not be resistant to standard antibiotic regimes). The definition of resistance is also important. For some infections this is less clear than others; for example, some infections such as acinetobacter and pseudomonas are designated according to degree of resistance i.e., multidrug resistant or extremely resistant. Invalid comparisons inevitably produce misleading results.

Various approaches have been used to address these limitations and include use of matched controls who are as similar as possible to the study subjects in every respect except the exposure of interest, and application of multistate models, where individuals have the ability to move in and out of different disease states in order to calculate the cumulative time spent with infection as opposed to either 'infected' or 'not-infected'.

As just one example, Barnett et al found that in an Argentinian prospective cohort study of patients admitted to 11 ICUs, using a multistate model that took into account timing of infection reduced the additional LOS associated with infection from 11.23 to 1.35 days (65). Note that this study reported on 'nosocomial' (i.e., healthcare associated) infection rather than specifically drug-resistant infection, but it serves to illustrate the wide variation in reported outcomes according to the methodology used.

If there is to be persuasive evidence for impetus for change, it is vital that as much confidence as possible can be placed in the estimates for the health burden associated with resistant infection. Bearing in mind the known shortcomings in surveillance, the estimated numbers of deaths from AMR infection in Europe and the USA are similar (23 000 and 25 000 respectively) (29). These figures are just that; estimates, and there are significant methodological challenges in assessing the additional morbidity and mortality associated with resistant compared to susceptible infections.

2.4.2 Economic impact

In a 2013 rapid review, Smith and Coast suggested that one of the reasons that AMR has not been prioritised as it should is a failure by health economists to demonstrate the potential financial impact (66):

"One reason (that more isn't being done) is that antibiotic resistance has fallen victim to evidence-based policy making, which prioritises health problems by economic burden and cost-effectiveness of interventions."

Based on the most extreme published estimate of the costs associated with AMR, they found that these were relatively low in comparison with other leading causes of morbidity (Figure 4). They suggest that current evidence on the cost of AMR significantly underestimates its impact by limiting analysis to the added cost of hospital treatment in AMR infections and failure to consider the effects of loss of antimicrobials from modern healthcare, and thus from the many treatment advantages that they have made possible.

Figure 4 Estimated annual cost of selected conditions in the US

(Reproduced with permission from Smith and Coast, 2013) (66))

Health problem	Societal cost ($bn, 2004)
Cardiovascular disease	380
Musculoskeletal conditions	300
Motor vehicle accidents	270
Occupational injury and illness	266
Mental disorders	260
Substance abuse	195
Cancers (all)	185
Diabetes	145
Alzheimer's disease	70
Antimicrobial resistance	55
Skin disease	48
Urinary incontinence	23
Asthma	16

In recognition of a lack of evidence on the projected future sequelae, the Review on AMR commissioned two multidisciplinary research teams from RAND Europe[1] and KPMG[2] to perform an assessment of the likely health and subsequent economic impact of AMR over the coming decades (1). It should be noted that both of these studies acknowledge the same important limitations that affect those previously discussed (i.e., failure to consider the loss of antimicrobials from modern healthcare) but do attempt to quantify the impact of the effect of loss to the labour market rather than simply the additional healthcare costs. As the AMR Review bases projected impact on these studies, they are key to the current dialogue about AMR and are summarised in Appendix 5.

RAND conclude that the main message from its analysis is that "it is not the current burden of AMR that is driving the urgency to recognise AMR as an important public health issue. Instead, it is the possibility of future costs that are orders of magnitude higher that render AMR a challenge of utmost importance." (1) KPMG conclude that "the impact of higher AMR is unlikely to be spread equally… with those more vulnerable likely to pay the highest price as low-income countries suffer the biggest loss of population and economic output." (1)

The authors of both reports urge caution when interpreting the results and point to the uncertainty attached to the estimates as a result of incomplete data, uncertainty over future infection rates and the potential future availability of as yet undiscovered antimicrobials. Several more specific limitations of the research are acknowledged; first, only six infections are considered, and the RAND study considered only hospital-acquired infections, while the KPMG study based projected figures on European infection and resistance rates, which are lower than global averages – therefore the true impact is likely to be far greater.

Second, only AMR-specific mortality rates were considered i.e., the additional mortality attributed to resistant compared to susceptible infections, rather than all mortality from resistant infections – again, this serves to underestimate the full impact of AMR.

Third, only loss to the labour market is considered and not additional health care costs or the potentially huge opportunity cost from loss of effective antibiotics in modern healthcare. These estimates therefore do not capture the full impact of AMR on our

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[1] a non-profit institution that helps improve policy and decision making through research and analysis
[2] A global network of firms providing audit, tax and advisory services

healthcare system. As mentioned in the introduction, a large proportion of the treatments and procedures carried out as part of modern healthcare are heavily reliant on the use of prophylactic antimicrobial therapy to prevent complications. We may face a reality where elective procedures that prolong years of life lived in good health are accompanied by such an unfavourable risk-benefit profile that they are no longer performed. The associated loss of employability could further add significant loss of productivity to the projected estimates. Smith and Coast are emphatic about the wider implications of AMR:

"From cradle to grave, antimicrobials have become pivotal in safeguarding the overall health of human societies. When viewed in this broader way, the costs of resistance are not limited to those associated with additional treatment for a primary infection, such as a "strep throat." Rather, they must encompass the costs that might relate to the loss of modern healthcare… resistance is not just an infectious disease issue; it is a surgical issue, a cancer issue, a health system issue." (66)

A literature review and modelling study by Teillant et al aimed to estimate the impact of rising AMR on outcomes from surgery and chemotherapy if antibiotic prophylaxis was to become less effective (67). Based on a 30% decrease in effectiveness of antibiotic prophylaxis against a range of organisms, the number of extra surgical site and chemotherapy associated infections in the US would be 120, 000 and the number of extra associated deaths would be 63 000.

A further trickle-down effect that has not been considered in these analyses is the effect of reduced global travel because of concerns over AMR transmission and its resultant impact on international trade and the labour market. Such impacts have been described following the recent Ebola outbreak in Africa, and of course have been even more far-reaching during the COVID-19 pandemic (68).

Based on the findings of these reports, the AMR Review group produced an illustrative representation of the potential health impact of AMR in comparison to other main causes of mortality in 2050 (Figure 5) (1). This shows that the likely deaths attributable to AMR annually would be 10 million – higher than the number of deaths from cancer:

Figure 5 Projected annual mortality from AMR in comparison to other major causes

Reproduced with permission from 'Review on Antimicrobial Resistance. Antimicrobial Resistance: Tackling a Crisis for the Health and Wealth of Nations', 2014 (1).
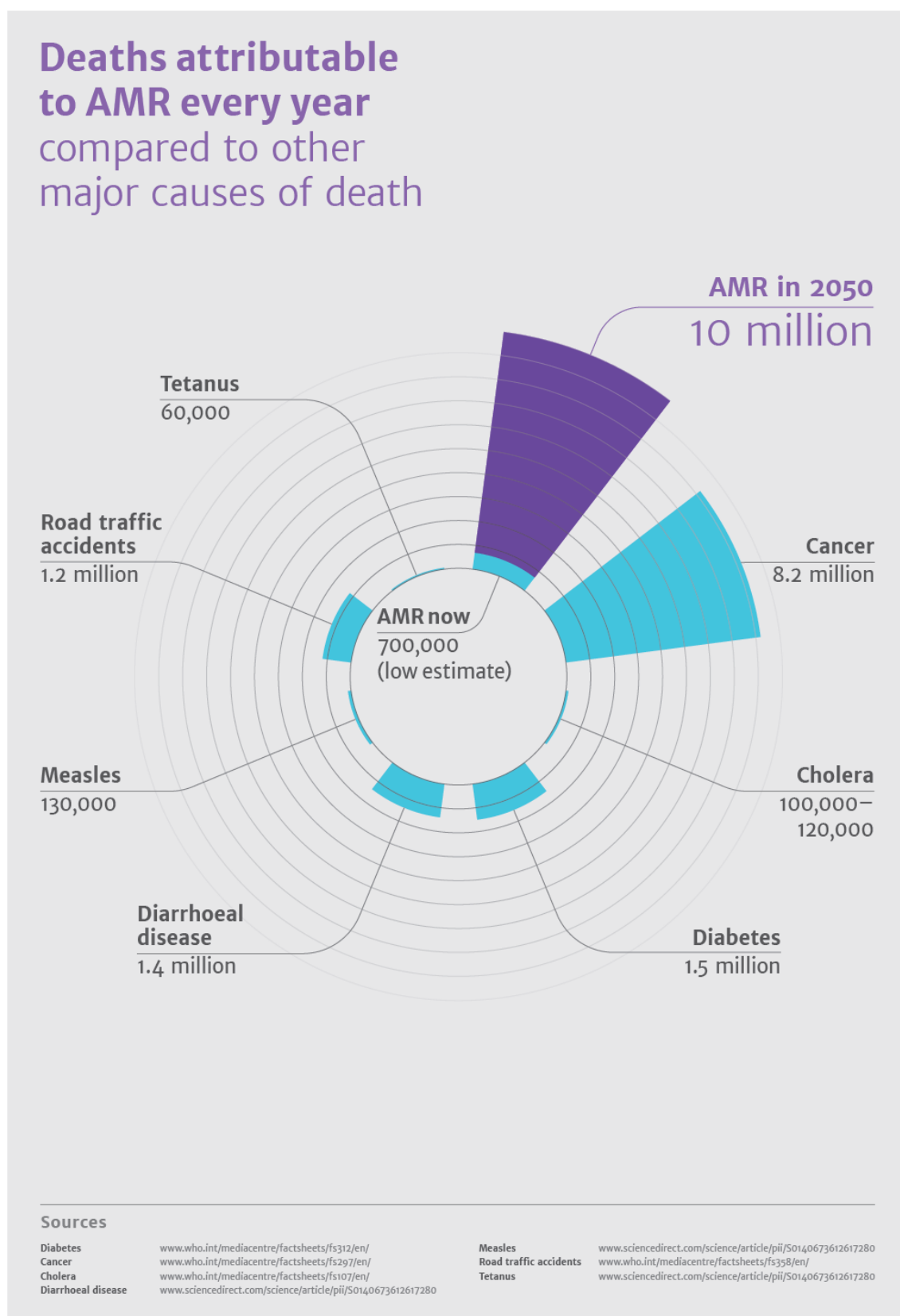
This gives a stark indication of the potential contribution of AMR to the burden of disease experienced by the population in the UK. If this scenario was occurring today, we would almost certainly see calls for more immediate and definitive action; the challenge is how to increase the urgency around this issue today to prevent the above scenario becoming a future reality.

2.5 Sepsis

For this section, the search was not limited to review articles, as a scoping search demonstrated that this excluded what appeared to be some key articles on, for example, clinical scoring systems to aid early detection of sepsis. The first 200 results from each search were reviewed on title for relevance. Further relevant evidence was identified by searching the reference lists of key publications.

2.5.1 Sepsis is a life-threatening condition resulting from the body's response to infection

Sepsis has been described as a life-threatening condition that arises when the body's response to infection injures its own tissues and organs (69). What begins as a localised infection in one part of the body, for example, pneumonia in the lungs, or a urinary tract infection in the kidneys, initiates a cascade of immune responses, with an accompanying release of inflammatory mediators. Though initially these are normal physiological responses that support the body in fighting infection, in sepsis, the inflammatory response continues unchecked and ultimately proves harmful. Inflammatory mediators cause the blood vessels to become more permeable (or leaky), causing excessive leakage of fluid into the tissues. This leads to hypotension (low blood pressure) which in turn causes tissue hypoperfusion (insufficient delivery of oxygen) and, eventually, organ failure. The associated mortality is high; of the estimated 245 000 cases diagnosed in the UK each year up to 48 000 die (70). Figure 6 displays a simplified version of the cascade of reactions that occur in sepsis.

Figure 6 From local infection to organ damage: the pathophysiology of sepsis

Adapted from 'What is Sepsis and Septicemia: Definition (ICD 10), Symptoms, Criteria, Treatment (emedicalupdates.com)'(71)
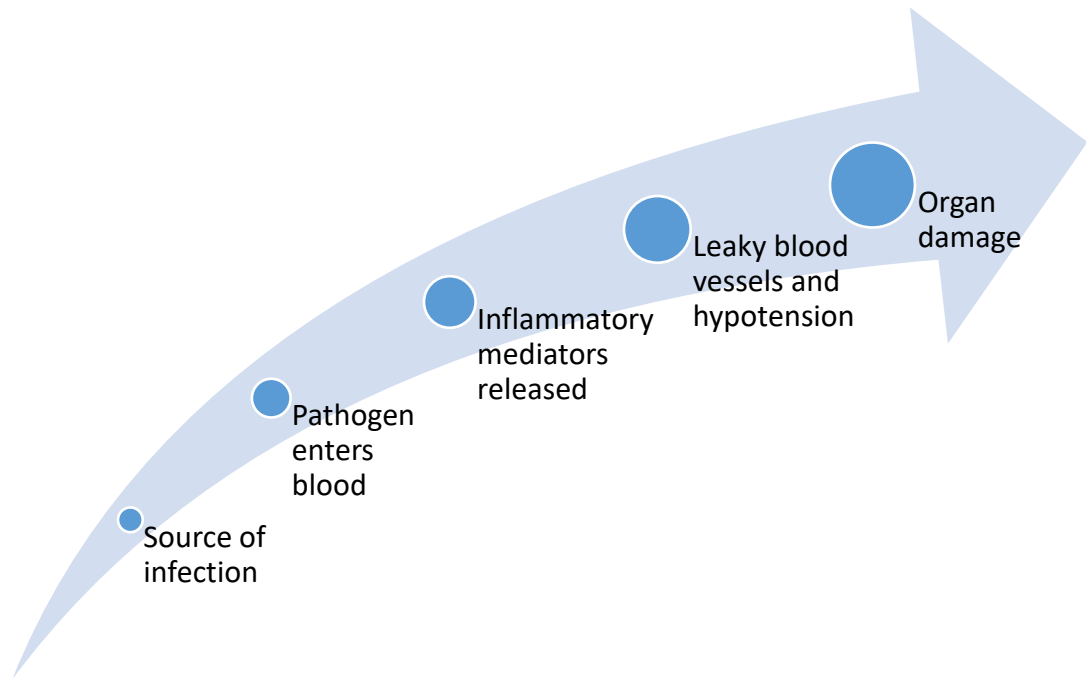
There have been many recent advances in understanding of the processes that occur during sepsis. The term itself dates back to Hippocrates (c. 460 – c. 370 BC), who used it to describe the process of putrefaction and 'miasma' (or bad air) arising from decaying matter in marshland (72). With acceptance of germ theory came a new understanding of sepsis as 'blood poisoning' (septicaemia) caused by entry to the body of pathogenic organisms (69). Although the advent of antibiotics was accompanied by dramatic reductions in sepsis mortality, there was also a realisation that sepsis could still be fatal even with full eradication of the initial infection. This highlighted the fact that individual host factors as well as virulence of the causative organism determine the clinical course (73).

Cohen et al describe a 'host, pathogen, system' model that demonstrates the interaction between the individual patient, causative organism and healthcare system in determining susceptibility (Figure 7) (33).

Figure 7 Factors determining the incidence and case-fatality rate of severe sepsis

(Reproduced with permission from Cohen et al, 2015 (33))
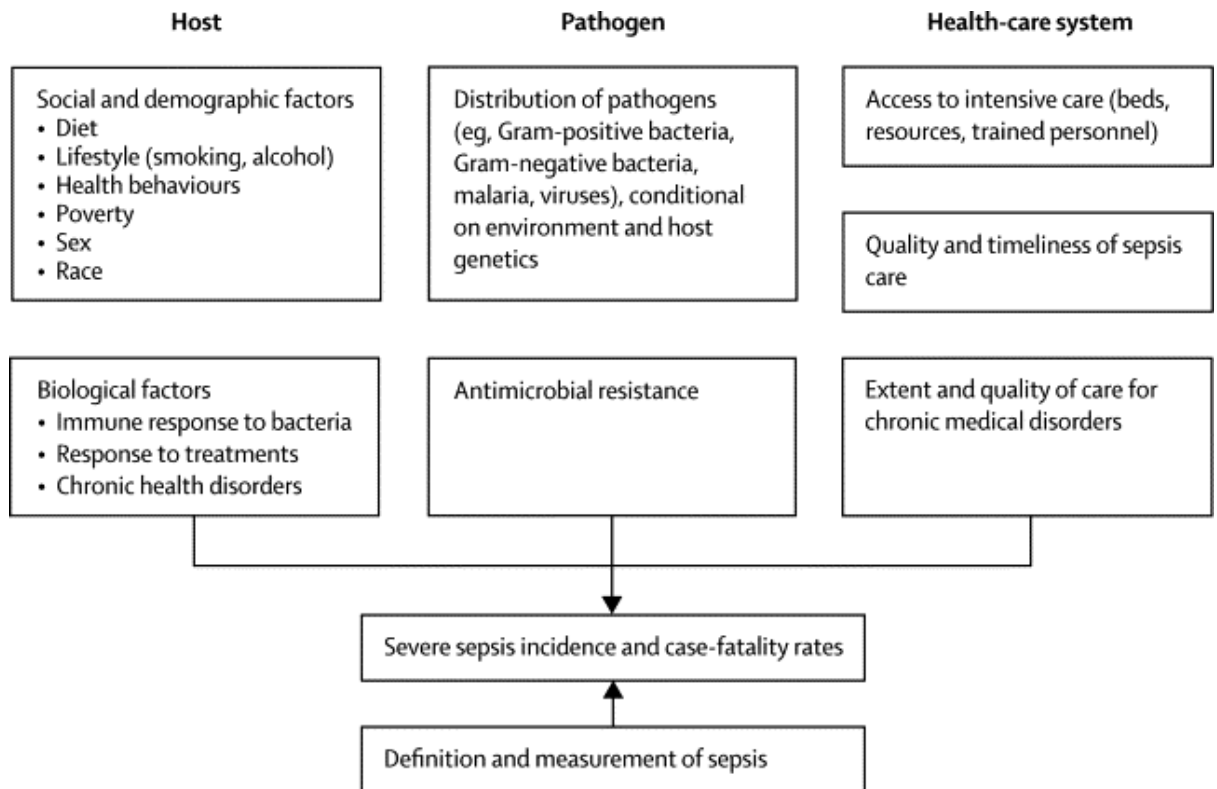
Cohen uses the example of Chronic Obstructive Pulmonary Disease (COPD) to illustrate this concept: individuals with COPD have an increased risk of sepsis due to a combination of factors. For example, there is an already increased frequency of respiratory tract infections and a degree of pre-existing lung damage. There may also be accompanying lifestyle risk factors e.g., smoking, and limited capacity for exercise. The microbiological environment within the respiratory tract may also differ in an individual with COPD, with repeated courses of antibiotics increasing the risk of colonisation with resistant organisms that are more difficult to treat. Healthcare provision too has an impact, via chronic management of the underlying condition and management of acute exacerbations. The reported incidence of sepsis is also influenced to a great extent by the definition used, as discussed below.

2.5.2 Consensus on a definition for sepsis has been difficult to reach

Sepsis is essentially an artificial construct that describes a syndrome rather than a specific disease entity (18). For one, patients with sepsis represent a heterogeneous group with

many underlying causes. For example, although the disease process may ultimately be similar, an infant with sepsis following meningitis infection is likely to have a very different initial presentation compared to an elderly patient experiencing sepsis as a complication of chemotherapy. For this reason, it can be difficult to conceptualise, not only for members of the public but for the health professional community also. Shankar-Hari et al articulate this problem:

"Of all critical care conditions, sepsis has shaped health policy, dominated the research agenda and entered the public lexicon with energetic, high profile educational campaigns vowing to reduce the attendant mortality. Yet, when asked to provide a concise definition, even practitioners who treat 'septic' patients may struggle.' (69)

An accepted universal definition for sepsis was devised in 1991 and revised in 2001 and again in 2016. The initial definition was agreed at a consensus conference convened among chest and critical care physicians with the goal of devising a framework to define the inflammatory response to infection.(74) This resulted in three definitions that have been widely used in clinical practice over the past two decades: severe inflammatory response syndrome (SIRS), severe sepsis and septic shock. These definitions were revisited and updated in 2001.(75) During discussions, it was noted that the diagnostic algorithm did not reflect practice, with very few patients diagnosed with sepsis based on the four SIRS criteria. In reality, it was acknowledged that clinicians tend to assess a patient at the bedside and declare, based on a range of signs and symptoms that they "look septic", prompting investigations to determine the source of infection. The 1991 definition was expanded to reflect the additional range of parameters that are used by clinicians to support a diagnosis of sepsis. The group did not find evidence to recommend use of a 'gold standard' biomarker on which to base a diagnosis in the way that there is for, for example, myocardial infarction or diabetes mellitus. In effect, the definitions remained largely unchanged for 25 years. It has been suggested that the non-specific nature of the only available therapy (antimicrobials and supportive treatment) meant that there was little impetus for refining these, as new definitions were unlikely to alter management (76).

During the most recent revision process, the original SIRS criteria were unanimously agreed to be unhelpful.(77) One main issue is that these criteria can often be present in patients experiencing an inflammatory response who absolutely do not have life-threatening infection. It has been remarked that it is possible for a patient to develop SIRS criteria simply by walking up the stairs in the hospital. Conversely, the criteria are absent in a sizeable minority of seriously ill patients with organ failure due to infection who

require admission to ICU. Thus, the criteria can be described as having poor discriminant and poor concurrent validity, respectively.

Following the most recent revision, a new agreed definition of sepsis is "life-threatening organ dysfunction caused by a dysregulated host response to infection". The new diagnostic algorithm focuses on the organ dysfunction that differentiates sepsis from uncomplicated infection and uses a validated scoring system (the SOFA score) commonly used in ICU to quantify this (Appendix 6). This scoring system has been shown to accurately discriminate those patients most at risk of severe illness; a score of 2 or more is associated with a 10% greater risk of mortality. In addition, use of a rapid bedside screening test 'Quick SOFA' (qSOFA) is recommended to aid identification of those patients at greatest risk of poor outcomes; this comprises just three variables and requires no blood tests: alteration of respiratory rate, mental status and systolic blood pressure. A score of 2 and above increases likelihood that sepsis is present. In addition, a more specific definition of septic shock is also provided. Under these new definitions, both SIRS and severe sepsis become redundant terms. The initial definitions and revisions are summarised in Appendix 7.

The importance of the lack of consensus around a definition of sepsis in the context of this thesis is twofold. First, inconsistencies in how sepsis is diagnosed make accurate surveillance difficult (see below). Second, the ambiguity and uncertainty that faces clinicians undoubtedly impacts on behaviour. The 2016 update makes this very point:

"…the various manifestations of sepsis make diagnosis difficult, even for experienced clinicians… health care practitioners require improved clinical prompts and diagnostic approaches to facilitate earlier identification…" (77)

2.5.3 Reported cases of sepsis are increasing but quantifying them accurately is complex

The reported incidence of sepsis is increasing, but the case mortality appears to be falling (33). Ascertaining the true underlying trend is made difficult due to complexities in how sepsis is coded. The WHO International Classification of Disease provides standard diagnostic codes for healthcare professionals to ensure consistency between different countries and healthcare systems. It is these codes that are used to record diagnoses on discharge records and death certificates, the key data sources on which trends in incidence and mortality are based.

The ICD10 coding procedure for sepsis and related terms is complicated and, since sepsis is not one disease but many, a combination of terms is required to capture the following:

- the site of underlying infection,
- the causative organism (if known)
- any associated organ dysfunction
- pre-disposing underlying conditions

It is quite possible to accurately record these parameters without including any terms for sepsis, and inconsistencies in assigning codes is acknowledged by Singer et al (77). For example, a patient with a history of COPD may be admitted due to an exacerbation of symptoms caused by pneumonia. This may trigger an inflammatory response, which may progress to respiratory failure, requiring a period of ventilation. Sputum cultures may confirm Haemophilus influenza as the underlying causative organism for pneumonia, which is successfully treated with IV antibiotics with resolution of symptoms. On discharge, the codes may be assigned as follows:

J14 Pneumonia due to Haemophilus influenza

J96 Acute respiratory failure

J44.1 Chronic obstructive pulmonary disease with acute exacerbation, unspecified

It may never occur to the attending clinicians to record a diagnosis of sepsis in the case notes, despite verbal concerns that the patient "is becoming septic" having been the driver behind all of the interventions carried out. "Because clinical care comes first, documentation isn't always a priority for physicians, says Steve Claypool, MD, vice president of clinical development and informatics at Wolters Kluwer Health. "Physicians, by tradition, will only identify sepsis in the chart when a patient is getting so ill that he or she is starting to die," he says. "That's usually the first time that you'll see documentation of sepsis or septic shock." (78)

These complexities must be recognised when considering the data that is available for trends in sepsis incidence and mortality. McPherson et al analysed multiple cause of death data from the Office for National Statistics (ONS) mortality database, extracting all deaths containing a sepsis-associated ICD 10 code on the death certificate, and found that 5.1 % of deaths occurring in England between 2001 and 2010 were associated with sepsis, with peak mortality occurring in 2006 (Figure 8) (79). In keeping with the issues described

already, only a minority of these (8.6%) had a sepsis-related code as the underlying cause of death, highlighting the difficulties in accurate surveillance using this parameter alone.

Figure 8 Sepsis-associated mortality in England, 2001-2010

(Reproduced with permission from McPherson et al (79))
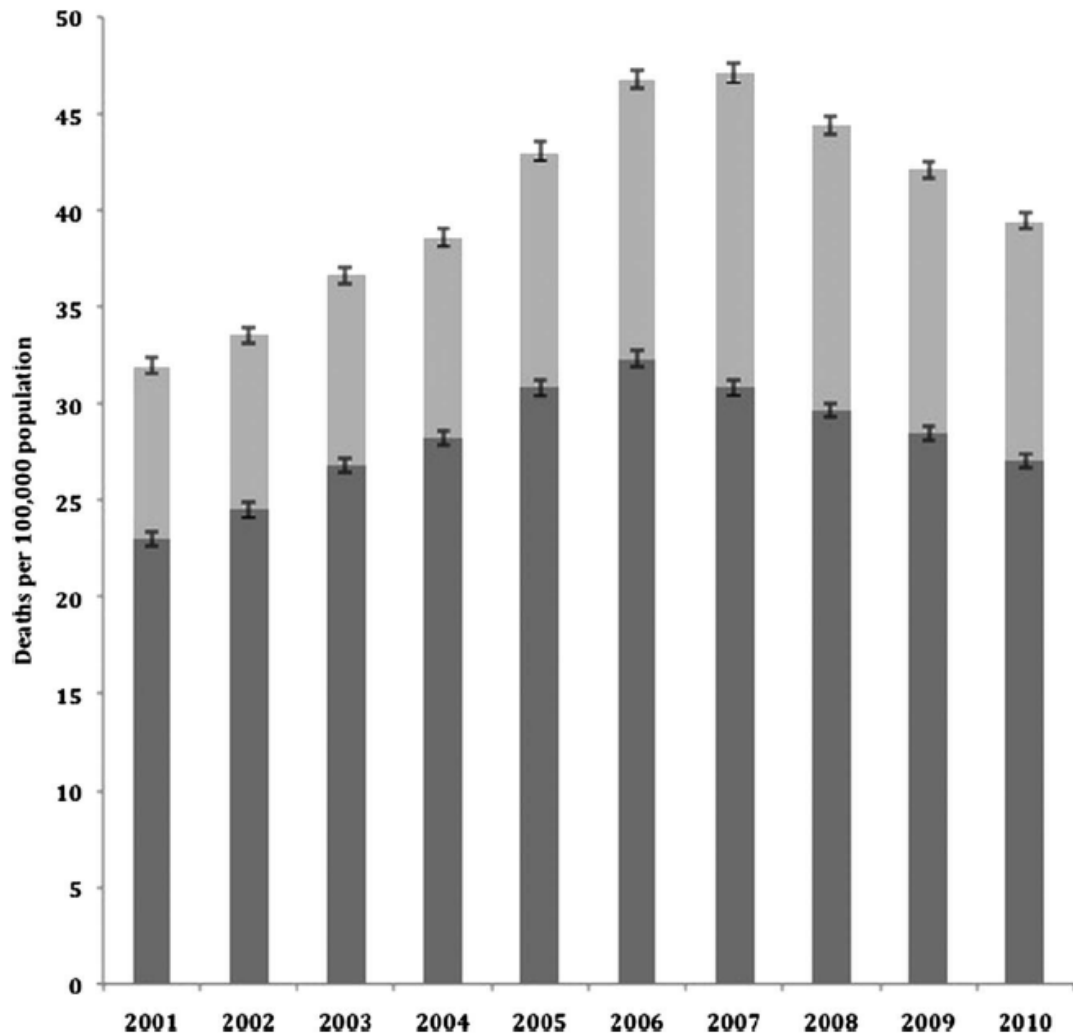
In a similar analysis in the US, Melamed and colleagues found that 6% of deaths in the US between 1999 and 2005 were sepsis-related (80). Similarly, only a minority (22.7%) had sepsis recorded as the underlying cause of death. In this analysis, the age-adjusted death rate for sepsis showed a slight downward trend, decreasing by 0.18% per year between 1999 and 2005. However, the crude sepsis-related mortality rate increased, highlighting the fact that population ageing will be a significant driver of sepsis mortality.

Monitoring trends in the overall incidence of sepsis is similarly complex and depends on the definition used. Gaieski et al demonstrated this via a comparison of sepsis-associated mortality in a representative US nationwide dataset using four different definitions

published in previous studies that ranged in their inclusiveness (81). They found that, depending on the sensitivity of the definition used, average annual incidence varied 3.5-fold between 300/100 000 population and 1031/10 000 population. Regardless of the definition used, there were similar increases in the annual incidence of sepsis over the period studied (13%), accompanied by a decrease in case-mortality. As with previous studies, total mortality increased, reflecting an ageing population.

In order to form a picture of the global burden associated with sepsis, Fleischmann et al performed a systematic review of 27 studies reporting population level data on incidence of sepsis from 7 countries that they used to extrapolate global estimates (82). The authors concluded that global annual incidence of sepsis was 31.5 million and severe sepsis 19.4 million, with 5.3 million deaths. No data from low- or middle-income countries was available.

Gaieski et al cite three possible reasons behind a persistent increase in incidence (81):

- A true increase due to ageing population with greater burden of chronic disease
- Greater awareness of sepsis among the public and health professionals through campaigns such as Surviving Sepsis, which encourage early diagnosis
- Changes in coding practices for reimbursement purposes

The contribution of reimbursement as an influencing factor is dependent on the way in which healthcare systems are structured. In the US, discharge diagnosis dictates reimbursement from a patient's medical insurance company to compensate for the greater healthcare costs associated with some conditions. The increased morbidity assigned to diagnostic codes that capture sepsis may reflect a reduction in use of other codes. For example, Lindenauer et al noted a 170% increase in incidence of sepsis between 2003 and 2009, but a concurrent 27% reduction in patients admitted with a primary diagnosis of pneumonia, with no change in overall mortality (83).

It is possible that the decrease in case mortality observed over the past decade is also due to changes in coding behaviour and may reflect greater awareness and inclusion of less severe cases within the definition, as opposed to more effective interventions, a phenomenon referred to as 'diagnostic creep' (84).

2.5.4 Timing of antibiotics impacts on outcomes

International guidelines for the management of sepsis have been in place since 2004 and were revised in 2008 and 2012 under the banner of the Surviving Sepsis Campaign (73). The guidelines are packaged into two 'bundles' of actions to be completed within 3 and 6 hours (Appendix 8).

Within this guidance are more specific recommendations regarding the timing of antibiotic treatment which state that intravenous antibiotics should be administered within the first hour of recognition of severe sepsis or septic shock. This is supported primarily by findings of Kumar et al, who demonstrated in a retrospective cohort study of patients with septic shock admitted to the ICU that time to antibiotic administration was the single strongest predictor of outcome (85). Administration of antibiotics within an hour of documented hypotension due to sepsis was associated with a survival rate of 79.9%. For every hour delay in administration over the following 6 hours, survival decreased by 7.6% (Figure 9).

Figure 9 Mortality risk with increasing delays in initiation of effective antimicrobial therapy

(Reproduced with permission from Kumar et al, 2006 (85))
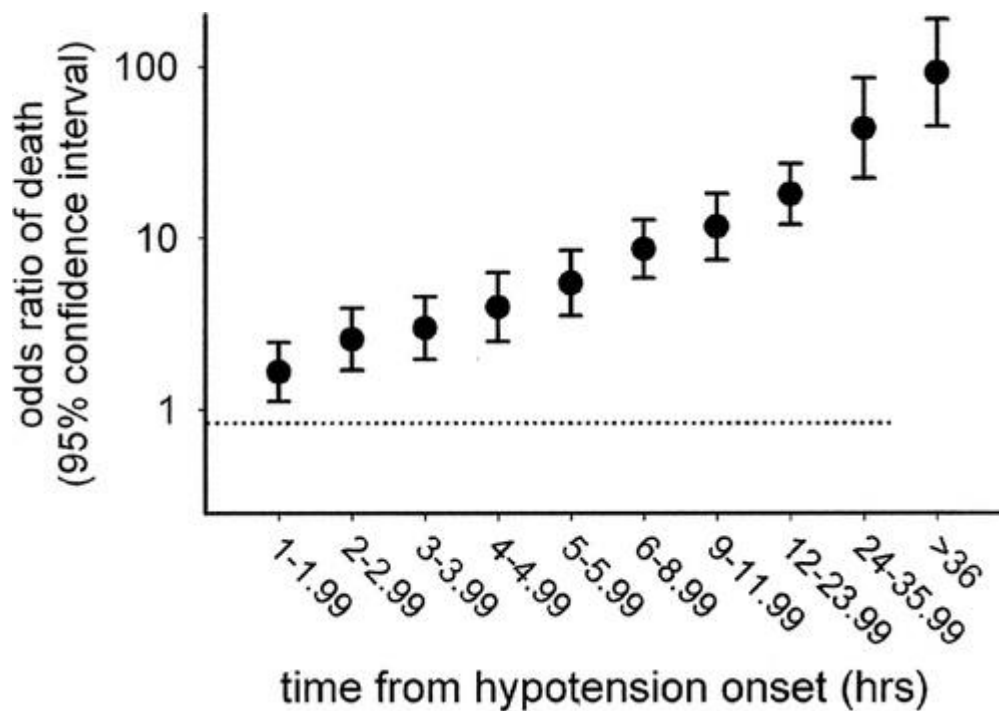
The authors conclude that this window represents a "golden hour" in which to intervene with antibiotics in order to optimise outcome. This study provided the main rationale for the introduction of this recommendation to the 2008 Surviving Sepsis guidance. Gaieski et al also demonstrated decreased mortality in patients presenting to the emergency department with severe sepsis or septic shock when antibiotics were administered within one hour of triage compared to after one hour in (19.5% v 33.2%) (81). A larger retrospective cohort study by Ferrer et al also demonstrated a linear increase in mortality risk for each hour delay in administration of antibiotics in patients with severe sepsis and septic shock (86).

More recent publications have cast doubt on the validity of the recommendation for 'antibiotics within one hour'. A systematic review and meta-analysis by Sterling et al that included 11 studies found no significant difference in mortality outcome in patients who received antibiotics before or after 3 hours, following diagnosis of septic shock (87). The authors conclude that the one-hour recommendation within the Surviving Sepsis Campaign guidance is not supported by available evidence. They also question whether it is plausible that a single dose of antibiotics could have the profound effect on survival that is claimed by previous researchers.

Other evidence points not only to no beneficial effect but to adverse effects with early antibiotic administration. Hranjec et al suggest that the decision to start antibiotic treatment in a critically ill patient who has possible (but not certain) infection must be based on three considerations (88):

- Certainty of the diagnosis
- Risk of delaying treatment
- Environmental damage caused by use of antimicrobial use (i.e., contribution to the development of AMR])

Clinicians have the option of beginning treatment immediately or waiting until a definitive diagnosis of infection is available through blood cultures or microbiology results from other sample sites that can guide appropriate antibiotic treatment. The authors tested the impact of these two courses of action in a before and after study that compared the effect of aggressive early treatment with antibiotics in patients with suspected sepsis with conservative management, where antibiotic treatment was initiated only when infection was confirmed objectively. Not only was there no survival benefit with aggressive early antibiotic therapy; the conservative approach was associated with lower all-cause mortality

(13% v 27%). The reasons for this finding are unclear. The authors hypothesise that early antibiotic administration delays initiation of appropriate antibiotics; therefore, patients who have infections not covered by standard regimes are at a disadvantage. They also found that early administration of antibiotics was associated with a longer overall duration of treatment and suggest that the adverse effects of prolonged treatment outweigh any benefits of beginning therapy before infection is confirmed. The authors conclude that there is no evidence that starting antibiotics before an infection is confirmed is beneficial.

In a subsequent review article, the same authors acknowledge the pressure on intensive care clinicians to commence treatment in patients suspected of having an infection, and suggest that more evidence is required to define the populations in which a 'wait and see' approach is safe (89). De-escalation of antibiotic treatment is an important aspect of stewardship; however, it is acknowledged that there are challenges for clinicians in making the decision to withdraw antibiotics once initiated, even in the absence of documented infection (90). This poses a particular dilemma if a favourable clinical response has been observed, even though this may well be due to other aspects of management such as fluid resuscitation and correction of metabolic abnormalities.

2.5.5 The significant economic and long-term health impact for survivors of sepsis is increasingly recognised

The financial costs associated with sepsis are huge; the US spends more money on hospitalisations for sepsis than any other condition, at a sum of over 20 billion US dollars annually (5.2% of all hospital costs) (91). What is also becoming more apparent is that the economic and health impacts associated with sepsis are not limited to the acute episode of illness. It is not the case that sepsis results in only two possible outcomes: death or full recovery. In fact, the long-term effects may be apparent for some time after discharge, or permanently. There is increasing focus on the long-term impact on quality of life and functional status in survivors of sepsis, and consequently its impact on health at a population level. It is suggested that sepsis must be considered in the same way as conditions such as cancer and stroke, where anticipation of long-term impacts are considered a central component of patient management and discharge planning (92).

The burden of long-term sequelae of sepsis has been quantified in several population-based studies. Some of the most important evidence includes persistent increased mortality, increased utilisation of health services and an increased risk of cognitive impairment. Linder et al demonstrated increased 10-year mortality in previously healthy individuals

(i.e., with no pre-existing comorbidity) who experience severe sepsis (30.5%) compared to the comparable general population (11.8%) AND to patients who experience non-septic critical illness (93). Readmission to hospital is a frequent occurrence, with Prescott et al demonstrating only 20% of survivors not requiring re-hospitalisation over 12-month follow-up (94). Survivors also demonstrate evidence of reduced levels of physical activity, exercise capacity and muscle strength compared to healthy subjects, persisting 3 months after discharge from hospital. There is also an increased incidence of cognitive impairment in survivors of sepsis during long-term follow-up compared to controls hospitalised for other reasons (odds ratios of 3.34 and 2.26) (95, 96).

Based on the findings of their 2010 study, Iwashyna et al modelled the burden of morbidity in the population of patients who had survived an episode of severe sepsis; they estimate that there are over 100 000 patients with moderate-severe cognitive impairment and 500 000 with a functional disability associated with sepsis (92). The authors point out the potential for marked downstream impacts, both on the individual and their caregivers, and the potential for economic impacts through increased health care consumption and loss of productivity in the workplace.

There have been various hypotheses regarding the pathway through which sepsis may impair cognitive function. The 'persistent inflammation' theory is based on studies that have shown a positive association between raised inflammatory makers including CRP and dementia. Others have hypothesised that it is a direct result of the reduced cerebral perfusion that produces lasting cognitive impairment. It is suggested that there is a limited window to intervene in the inflammatory cascade that leads to organ dysfunction, and that this highlights the importance of prompt definitive management, including administration of antibiotics.

2.5.6 High-profile sepsis cases have influenced policy

In the UK, findings of a 2015 enquiry into the death of one year old William Mead from sepsis following a chest infection in 2014 were widely reported in the Press (97). The official report was particularly critical of both out of hours General Practitioners and call handlers from NHS 111 to identify a drop in body temperature as a potential indicator of sepsis. Working with the UK Sepsis Trust, William's mother has lobbied the Health Secretary to put in place measures to raise awareness of the condition among the public and health professionals.

In the US, 12-year-old Rory Staunton died from sepsis in 2012 following a minor abrasion sustained during a school basketball game. Subsequent campaigning by his parents resulted in the passing of legislation in New York State that states that all hospitals shall have in place evidence-based protocols for the early recognition and treatment of patients with severe sepsis/septic shock. This statute has become known widely as 'Rory's Regulations' (98). Rory's parents have worked closely with the Sepsis Alliance, which was founded in 2007 by Carl Flately, a dental surgeon whose 23-year-old daughter died from unrecognised sepsis in 2004 following minor routine surgery (99).

Following the introduction of Rory's Regulations, it is anticipated that hospitals will be required to make public their rates of adherence to sepsis protocols and clinical outcomes. Rhee et al caution against such mandatory reporting and suggest that such measures could cause unintended harm through promoting inappropriate prescribing of early antibiotic therapy and unnecessary investigations (100). In the UK, the Commissioning for Quality and Innovation (CQUIN) Guidance sets out quality standards for healthcare performance in England (101). A new standard for sepsis screening and administration of antibiotics within one hour was added in 2015. Therefore, while evidence for the benefits of early treatment with antibiotics in the absence of proven infection remains contentious, the mandatory guidance for health professionals remains clear; the CQUIN guidance document states the following:

"While a range of actions are recommended for rapid implementation when a patient presents with sepsis, rapid administration of antibiotics is the single most crucial action that can prevent deaths from sepsis and can be relatively easily measured and reported on."

What is clear is that reducing mortality from sepsis is not only a matter of increasing awareness. Even with a high index of suspicion, making an accurate diagnosis of sepsis is incredibly challenging, even for experienced clinicians. Media reports of instances where failure to diagnose sepsis leads to serious disability or death often focuses on failure of health professionals to appreciate the significance of a single disordered parameter. It is noteworthy that body temperature is not included as a parameter in the most recently revised definition of sepsis, nor would this indicator alone have been enough to diagnose sepsis in the case of William Mead under the 1991 definition of SIRS.

A 2015 National Confidential Enquiry into Patient Outcome and Death that reviewed the management of patients with sepsis in the UK was critical of several aspects of care, including poor documentation of observations, delays in review by a consultant and delays

in carrying out essential investigations to identify the source of infection (102). Reference was made to failure to liaise with microbiology colleagues, resulting in inappropriate antibiotic prescribing. The findings prompted development of NICE guidance on recognition, diagnosis and management of sepsis, published in 2016 (10). This guidance references uncertainty surrounding when to use early antibiotic treatment and when to favour delayed targeted therapy, and a stratified approach is recommended, with consideration of most frequent underlying infective causes in different patient groups. This recognises the population of patients with sepsis as a heterogeneous group in whom a blanket approach to early administration of antibiotics is likely to be inappropriate.

Chapter 3 Methods

3.1 Philosophical approach

The thesis is not grounded in a single philosophical approach but rather drew from several theoretical frameworks that informed the different methodologies used. The design of the quantitative and qualitative media content analyses were informed by Moy et al's theory of agenda-setting, priming and framing, which have been used to explain the relative importance placed by audiences on issues reported, and by the various fright factors and media triggers identified by Bennet and Calman that can influence how risk is perceived (11, 103).

Sontag's theory on illness as metaphor' i.e. how particular characteristics of certain diseases are associated with blame and stigma was influential in informing my approach to the qualitative component of the media analysis, enabling me to identify the aspects of sepsis reporting that bear similarities with the diseases described by Sontag that secure its position as a disease with cultural significance (104).

In developing and conducting focus groups, I employed both an essentialist and social constructionist approach, placing value on pre-formed beliefs about illness held by individuals but also on those that appeared to develop as the result of group interaction during discussions (105). Finally, Goffman's theory of presentation of self and Murphy's work on maternal deviance were central to constructing a coding frame for analysis of focus group data, helping me to define how the perceived impact of childhood illness on participants' moral identities as parents influenced their response (106-108).

3.2 Media content analysis

As outlined in Chapter 1, sepsis and AMR have recently received substantial media attention. A primary hypothesis in planning this research was that reporting of sepsis has the potential to impact on perceptions of the magnitude of risk associated with common illnesses and subsequently on expectations about antibiotic requirements and prescribing practice. My aim was to explore this hypothesis using qualitative research methods with members of the public. Although it was apparent a priori that the way that AMR and sepsis were reported in the media differed markedly, I decided that the rigour of the research would be enhanced by performing a formal analysis of the messages contained in mass media communications about antibiotics in the context of sepsis and AMR.

In this section, I present a rationale for selecting media content analysis as an appropriate methodology by exploring:

- Why are media representation of health issues important?
- How can media content analysis be used to formally evaluate the nature of this representation for a particular issue?

3.2.1 How does the media shape public opinion?

Various media triggers and fright factors have been described that increase the public's interest in news stories and are associated with extensive coverage (Table 1) (11)

Table 1 Media triggers and fright factors associated with high press coverage

Adapted from Bennet P and Calman K. Risk Communication and Public Health (11)

Media triggers	Fright factors
Elements of blame	Involuntary (e.g., exposure to pollution)
Attempted cover ups	rather than voluntary (e.g., dangerous
Human interest through identifiable	sports or smoking)
heroes/villains/victims	Inequitably distributed (some benefit while
Links with existing high profile	others suffer the consequences)
issues/personalities	Inescapable by taking personal precautions
Conflict	Arise from an unfamiliar or novel source
Signal value – what now?	Result from man-made rather than natural
Many people potentially affected even if	sources
low risk level ('it could have been me')	Cause hidden and irreversible damage e.g.,
Strong visual impact, e.g., pictures of	through onset of illness many years after
suffering	exposure
Links to sex/crime	Pose some particular danger to small
	children or pregnant women, or more
	generally to future generations
	Threaten a form of death (or illness/injury)
	arousing particular dread
	Damage identifiable rather than
	anonymous victims
	Poorly understood by science
	Subject to contradictory statements from
	responsible sources (or worse, from the
	same source)

Audience perception of issues that are reported in the news can be influenced through agenda-setting, priming and framing (103). This section explains how these processes take place.

Agenda-setting

Agenda-setting describes the ability of the mass media to convey to the audience which issues are important by according them differential levels of coverage. Referencing Cohen,

Moy et al draw a distinction between success in telling the audience what to think and what to think *about* (103, 109). Although a case is presented for the powerful effects that agenda-setting can have on which issues the public regard as important, the authors acknowledge that the extent of this effect is dependent on individual-level and contextual factors. This perspective recognises that audience reception is more nuanced in comparison to earlier theories that positioned the audience as passive recipients, ready to absorb whatever messages are directed at them (110). Moy et al set out three factors that can modify the impact of agenda-setting on audiences:

First, effects tend to be strongest for issues with which individuals have little or no direct experience, i.e., the content of the news story must add something to that which the individual already knows. An illustrative example is provided here in Iyengar and Kinder's 1987 research that explored the impact on audiences of news reporting about increasing rates of inflation (111). They found that sustained exposure to news reporting had no demonstrable impact on perception of inflation as a priority issue concluding that, for subjects that the public have continued exposure to during their daily lives, agenda-setting by the media may have little additional impact in setting them as priority issues (i.e., perhaps they already are).

Second, they describe how agenda-setting effects are affected by the need for 'orientation' i.e., the extent to which individuals are motivated to understand an issue, which is in turn influenced by how relevant an issue is and the uncertainty that it holds for them based on their current understanding.

Finally, Moy et al point out that the media is only one information source to which individuals can turn. Personal communication with others offers additional viewpoints to those offered by the media, the nature and frequency of which is likely to alter the importance of agenda-setting by the media in influencing audience perception.

Priming

'Priming' describes the way in which new information received via media can activate pieces of pre-existing knowledge in audience members, making that knowledge more accessible and thus more likely to be used in interpreting and evaluating a news issue, when it may not otherwise have been applied. This process is described by Moy et al as dependent on four conditions:

- **Recency,** referring to the fact that accessibility of 'primed' knowledge will attenuate over time, making later application of the information to a stimulus (or news story) less likely

- **Repetition** i.e. the more often the nodes are primed, the greater the likelihood they will be applied to a 'target stimulus'

- **Applicability** i.e. the primed concept must be sufficiently closely related to the target stimulus to influence how the audience evaluates it

- **Subjective relevance** i.e. acknowledging the fact that perceived applicability has a subjective as well as an objective component; individuals must consider the 'media prime' relevant for evaluation of the target stimulus for it to have an impact (103)

As with agenda-setting, the extent to which media messages have the capacity to 'prime' audiences depends on individual factors: amount of existing knowledge; cognitive styles (a preference for complex thinking over the need for 'cognitive closure'); and the extent to which the issue is discussed informally with social contacts may all influence this process. Additionally, the magnitude of the priming effect depends on whether the issue specifically demands evaluation to inform a choice. The example used by Moy et al is the arrival at an opinion about a political candidate during an election campaign; an example related to decision-making about health is the need to form an opinion and make a subsequent decision about the reported health risks and benefits of immunisation programmes.

Framing

If agenda-setting refers to the selection of issues that are reported in the media, framing refers to how those issues are presented. In a sociological context, Goffman's frame analysis describes frames as 'schemata of interpretation' that allow individuals to make sense of our life experiences by attaching meanings to them (112). Robert Entman has described framing as follows:

"To frame is to select some aspects of a perceived reality and make them more salient in a communicating text, in such a way as to promote a particular problem definition, causal interpretation, moral evaluation and/or treatment recommendation for the item described." (113)

Iyengar summarises framing as 'the effects of presentation on judgement and choice' (111). At a fundamental level, he describes two varieties of frames: episodic and thematic. Episodic frames describe issues in the form of specific events or individuals, without exploring the wider context, while thematic frames explore the systemic nature of issues in relation to relevant social and political structures, often placing the issue in a historical and geographical context. Iyengar points out that, in practice, few news reports are entirely episodic or thematic in nature; articles that focus on an individual usually place the issue in

question in a wider context, while those that set out from a thematic approach frequently feature illustrative case histories about affected individuals. However, according to Iyengar, content analysis of television news coverage suggests that for most issues, one type predominates and there are several reasons why episodic framing may be more attractive to journalists as producers of news:

"Episodic reports tend to provide good pictures; they do not require reporters with subject-matter expertise; and, being devoid of interpretive analysis, they are less likely to be labelled as biased by media critics."

Iyengar demonstrated that the way in which issues are framed in television news coverage can impact on audience perception of who or what is to blame, with episodic framing of issues such as poverty and terrorism being more strongly associated with responsibility attributed to individuals as opposed to socioeconomic or political causes. For example, for poverty, participants exposed to episodic news frames were more likely to attribute the problem to factors related to individuals (lack of education or training), while those exposed to thematic frames more often identified societal drivers (e.g., economic conditions, the changing nature of work, racial prejudice or punitive welfare policies). Iyengar expresses concerns about the impact of such framing:

"By reducing complex issues to the level of anecdotal cases, episodic framing leads viewers to attributions that shield society and government from responsibility. Confronted with a parade of news stories describing instances of national issues, viewers come to focus on the individuals or groups depicted in the news rather than historical, social, political or other structural factors."

Two distinct stages have been described in relation to framing: frame-building and frame-setting. The first, frame-building, refers to the context in which journalists construct news stories. Moy et al describe three factors that are influential in how frames are produced:

The first and most fundamental is the cultural and social norms that both the journalist and audience members are subject to; essentially, journalists produce news as a product for public consumption, therefore the content must be acceptable to the audience.

Second, journalists are subject to organisational pressures and constraints. According to Moy et al these 'rules' are often unwritten, although in the UK some restrictions are in place, for example on reporting of political issues prior to elections to reduce bias. In addition, the Independent Press Standards Organisation attempts to formalise guidance for reporting in the Editors' Code, setting out recommendations for ethical conduct in

reporting of certain sensitive issues, including in relation to circumstances surrounding acts of suicide, identification of victims of sexual assault and reporting on stories involving children (114).

Third, Moy et al describe how newsworthy issues inevitably come attached to a body of people with interest in and opinions about them. According to Moy et al: "These people often have a direct stake in the frames that journalists use to present and explain events and issues in the news. Frame advocates (i.e., interest groups, corporations, government actors) can go to great lengths to develop and present frames for journalists. Thus, in important ways, frames serve the people and the groups that have an interest in an issue. The most effective advocates, of course, are those who produce frames that are consistent with a society's culture and norms and conform to the routines of everyday journalism."

Moy et al point out that an issue may have 'contesting advocates' whose frames may compete for public attention and acceptance; thus, frames for ongoing issues may well change over time.

The second stage, frame-setting describes how the way issues are presented influences audience beliefs and attitudes about issues, who or what is to blame and what solutions are available. Moy et al make an important distinction between frame setting and simple persuasion or learning; the latter is defined by acquisition of new knowledge, whereas in frame-setting the frame references pre-existing knowledge, feelings or beliefs that may then be used to interpret the issue when it is encountered subsequently.

3.2.2 Evidence for impact of media framing on health decision-making

Much of the body of research regarding how mass media can influence audiences relates to political coverage and how these impact on electoral outcomes; however, there is also evidence that media coverage of health issues can influence decision-making. Responses that may ultimately have positive and negative impacts on health outcomes have both been described. Wide coverage of reality television star Jade Goody's diagnosis of terminal cervical cancer and death in 2009 was associated with increased uptake of cervical screening during this period (115, 116). At its peak in March 2009, the month that Goody died, attendance was 70% higher than expected, with largest effects seen in women whose tests were overdue, and it is likely that lives were saved as a direct result. Although this effect was not sustained in the long term, it nonetheless demonstrates the substantial impact that media framing can have on perception of health risks and the actions available to audience members to mitigate against them.

Conversely, the impact of publicity surrounding a hypothesised association between the measles, mumps and rubella (MMR) vaccination and childhood autism, based on Andrew Wakefield's now retracted 1998 article in the Lancet, resulted in decreased uptake of the vaccine to levels insufficient to ensure herd immunity, the health impacts of which persist even now (117-120). Notably, reporting of both of these issues included 'episodic' framing, documenting the impact of cervical cancer and autism on real individuals and families. In the case of Jade Goody's illness, it has been observed that reporting frequently focused on domestic aspects, for example the impact on her children and her wedding, at the expense of providing the audience with information about the disease itself (116). This perhaps demonstrates the importance of a human interest 'hook' to attract audience attention, but also that translating this into sustained behaviour that will benefit health in the long term is likely to require the provision of information in a format that facilitates deeper understanding of the disease process itself.

3.2.3 Performing media content analysis

Content analysis has been used to study a broad range of media outputs that include newspaper and magazine articles and the content of films, television and radio programmes (121). The definitions used by different proponents of content analysis are varied. At its broadest definition, content analysis has been defined by Weber as 'a research method that uses a set of procedures to make valid inferences from text.' (122).

Other researchers offer a more prescriptive definition. According to Neuendorf, content analysis is 'a summarising, quantitative analysis of messages that relies on the scientific method' (123). She sets out what she considers essential elements that fulfil these criteria:

- **Objectivity** The analysis must be carried out in a way that minimises the introduction of bias by the researcher; an important element of this is selecting an appropriate sample. The most complete method of sampling is to select all of the material from the time period of interest; however, where a large volume of media coverage exists this may prove prohibitive. Alternative sampling strategies include taking a quota of material from different sources (e.g., different newspaper titles or genres) or only those published on certain days of the week.

- **A priori design** Neuendorf argues that, to provide assurance of objectivity, the list of issues or 'messages' of interest should be set out a priori before the analysis is begun, i.e., a 'deductive' approach, as opposed to adding new variables that are noted to be of interest

as the analysis progresses (an 'inductive' approach). They suggest that this can be achieved in a scoping exercise by conducting 'a qualitative scrutiny of a representative subset of the content to be examined', which is in keeping with the grounded theory approach set out by Glaser and Strauss (124). To ensure consistency, the issues of interest to be analysed are set out in a codebook that can be applied throughout the analysis.

- **Inter-coder reliability** In order to provide assurance of rigour and objectivity, Neuendorf asserts that performing a test of interrater reliability, at least on a sub-sample of the material for analysis, is essential to demonstrate that the codes set out are not dependent only on the subjective assessment of a single researcher (123). According to Neuendorf, this should be performed blind i.e., each researcher should be unaware of the code assigned by the other prior to completing their own assessment. A number of different indices for inter-coder reliability are available. At the most basic level, percentage agreement offers some indication of inter-coder reliability, but more sophisticated measures available via statistical software packages take into account the likelihood of chance agreement. Cohen's kappa is one such measure that has been frequently used, with correlation co-efficients of > 0.8 widely regarded as evidence of excellent agreement (125). Options for researchers where inter-coder reliability rating falls short of an acceptable level of agreement are to discard unreliable codes or provide greater clarity in defining how codes should be assigned. In this way, the codebook can be regarded as a living document that should be continually revised as necessary to ensure the analysis process is fully transparent and replicable by other researchers.

Macnamara describes reading and coding for content analysis as a "time-intensive process that produces a veritable 'data mountain'", but explains how, when the scientific method set out by Neuendorf is adhered to, coding enables this data to be reduced to a form that can be subjected to quantitative analysis (121). In its purest sense, quantitative content analysis involves measuring media messages by counting, for example, the frequency with which a keyword appears. Such data is often termed 'manifest' content, which describes surface level text, in contrast to 'latent' content, which refers to deeper meanings that require greater interpretation on the part of the researcher (126). While there are instances when pure quantitative analysis may be informative, for example, to identify trends in media reporting of an emerging issue, more often what is of interest is the message contained in the portion of text in which that keyword appears. For example, if there is interest in establishing whether electronic cigarettes (e-cigarettes) are represented in the

media as salutogenic or potentially harmful to health, there is little value in knowing simply the frequency with which 'e-cigarette(s)' are mentioned but, rather, whether those mentions occur in a positive or negative context. In practice then, the coding process undertaken during content analysis can be viewed as occupying a spectrum from manifest to latent and all but the most unequivocal of statements necessitate at least some subjective assessment on the part of the researcher. This highlights the importance of performing a test of inter-coder reliability and of maintaining a codebook that accurately records decision rules, which should contain sufficient detail to allow a subsequent researcher to reproduce the analysis in such a way that they would arrive at the same results.

According to Neuendorf, maintaining a deductive scientific approach demands that "all decisions on variables, their measurement and coding rules must be made before the observation begins." (123) This approach ensures consistency; however, with a large sample, and if there are multiple issues of interest, it may be unreasonable to anticipate that it would be feasible to finalise the codebook before commencing data analysis. Furthermore, there is a risk that adhering to such a rigid approach would compromise the value of the research being undertaken, as certain elements of reporting may appear in only a small minority of articles yet may be of substantial interest (and perhaps more so by virtue of their being present less frequently). Retaining the capacity to alter the codebook during the analytic process ensures that newly identified themes can be included. A pragmatic approach is to add new decision rules as necessary while undertaking the analysis; however, it is essential that the entire dataset is then reviewed again using the updated decision rules. For all but the most straightforward of analyses then, it is likely that it will be necessary to perform a review of the whole data set at least twice, and possibly more, reflecting the fact that the codebook and decision rules may go through several iterations.

In practice then, content analysis usually comprises an integrated approach, and even a predominantly quantitative approach necessitates some latent analysis. Maintaining a codebook with rigour and accuracy minimises the capacity for the researcher to introduce subjective biases to their interpretation of the data, while allowing for a more informative analysis than that which could be produced through word counts alone. Often, however, arriving at a deeper understanding of the issue in question requires an analytical approach that goes beyond the quantitative. Several commentators have expressed views about the limitations of quantitative analysis alone in analysis of media representations:

"Often coders simply tote up all messages they judge as positive and negative and draw conclusions about the dominant meanings. They neglect to measure the salience of elements of the text and fail to gauge the relationships of the most salient clusters of messages – the frames – to the audience's schemata" (113).

This sentiment is echoed by Shoemaker and Reese:

"Reducing large amounts of text to quantitative data… does not provide a complete picture of meaning and contextual codes, since texts may contain many other forms of emphasis besides sheer repetition." (127)

Shoemaker and Reese classify content analysis according to two traditions: behaviourist and humanist. The former identifies the potential future effects of media content (i.e., looks forward) and is best served by quantitative analysis methods, while the latter identifies what that content can tell us about the societal and cultural context in which it is produced and is best achieved through qualitative methods: "Behavioural content analysis is not always or necessarily conducted using quantitative or numerical techniques, but the two tend to go together. Similarly, humanistic content study naturally gravitates towards qualitative analysis."

 An alternative approach to a purely quantitative or qualitative analytical approach that allows the researcher to adhere closely to quantitative methods, while retaining the capacity to explore important messages within the text that require a qualitative approach, is to perform a mixed methods analysis. This involves a two-stage approach: identifying key themes and overarching messages in a quantitative analysis, then undertaking a qualitative analysis of which of these are deemed most important, either due to hypotheses about what they may mean from a behaviourist standpoint (i.e., their implications for audience understanding and behaviour) or from a humanist standpoint (i.e., why those issues are represented in this way and what societal insights those messages may offer). Content analyses that have employed this approach have been undertaken by Hilton et al and by Patterson et al. (128, 129). I decided to use this approach to compare news articles about sepsis and AMR, first carrying out a quantitative analysis with a view to exploring important differences identified in a qualitative analysis.

Finally, it should be noted that textual analysis itself is not a reliable predictor of audience effects. Understanding how representations of health issues in the media are perceived by audiences requires triangulation in the form of interviews or focus groups, although McNamara notes potential methodological issues: respondents may forget which

information came from media sources and which was from peer networks; they may wish not to disclose consuming certain forms of media (e.g. daytime television, tabloid newspapers); or they may be influenced by their perception of what the researcher expects to hear (121).

Selecting a sample

The following highly circulated UK newspapers and their Sunday counterparts were chosen: The Guardian and the Observer; the Telegraph and the Sunday Telegraph; the Daily Mail and the Mail on Sunday; the Express and the Sunday Express; and the Sun and the News of the World. These chosen publications comprised two broadsheet, two middle market and two tabloid publications and were selected in order to maximise diversity of readership regarding age, sex and political opinion. This typology has been used by Williams et al and Hilton et al in informing sample selection (130, 131).

Search process

The Nexis database was searched to identify publications with three or more mentions of the following terms: "sepsis" OR "septicaemia" OR "blood poisoning" OR "AMR" OR "antimicrobial resistance" OR "antibiotic resistance" (see Figures 10 and 11, Chapter 4). This strategy minimised the likelihood of identifying articles that mentioned the topics of interest as an incidental detail rather than its main focus. No date restrictions were applied; although a valid approach would have been to select only a specific time period for analysis, it was identified a priori that a transition was apparent in framing of sepsis over time that may have important implications for audience perception. Furthermore, scoping searches demonstrated that the number of articles returned by searching with no date restrictions would not result in a prohibitive volume of articles as may be the case with more widely covered topics, for example, obesity.

Initially, articles published until and including 31st December 2016 were included. This period was extended until 30th June 2018 to ensure the analysis remained relevant and to enable articles that documented important events that occurred after 2016 to be included, particularly in relation to reporting of sepsis.

Articles from regional editions were excluded. Where more than one version of an article was returned, the one from the latest edition was included; earlier editions of the same article were excluded. Further exclusion criteria were as follows: articles that were not about sepsis and AMR (for example, where the article had been identified due to the inclusion of 'AMR' as an acronym or proper noun; articles that were primarily about

business or finance; articles about data management within the healthcare system that mentioned sepsis or AMR as one of a range of conditions; articles that mentioned sepsis or AMR as an incidental detail only (for example, articles that were biographical in nature and mentioned sepsis or AMR only in passing in relation to an individual's health); and articles that were primarily about other health conditions. The latter category included articles that were primarily about meningitis or the meningococcal vaccine, as these were noted to form a separate narrative in the media, for example around eligibility criteria and debates about the ethics of obtaining vaccines privately. Articles about sepsis/septicaemia/blood poisoning that mentioned meningitis as an associated condition were included, providing that the primary topic area was sepsis.

Developing the coding frame

To construct a framework to code the manifest content of the article, a random selection covering the entire date range was read until saturation point i.e., until no new themes emerged, in keeping with the methods advocated by Neuendorf (123). Relevant themes were identified using both a deductive and inductive approach; it had been identified a priori that elements of reporting that related to aforementioned media triggers and fright factors was of interest, particularly those relating to blame and to identifiable 'victims.' Elements of reporting that had not been considered of major importance a priori that were identified during initial reading of articles were also incorporated into the coding frame, for example, placing sepsis/AMR in context for the reader by comparing its impact to other health conditions. Following this exercise, a face-to-face meeting was held with my supervisors, SH and LMcD, to discuss structuring the coding frame. It was determined that many themes could be grouped within three broad questions:

- How have the problems of sepsis and AMR been defined?
- What are the reported drivers of sepsis and AMR?
- What solutions to sepsis and AMR are presented?

A further category was added to capture whether a case history was included i.e., whether the article referred to an individual personally affected by either issue. In addition, fields were added to the coding frame to record the following: date, publication, main topic (sepsis or AMR) and word count. The initial coding frame also recorded the 'nature' of the headline (whether it was considered 'alarmist',' reassuring' or 'neutral' and whether words or phrases considered alarmist were used anywhere in the article (e.g., catastrophic, apocalypse, scandal). A definitions sheet was developed alongside the coding frame and

referred to and updated continuously throughout the process (Appendix 9). This contained decision rules about how each code should be applied, with recording of verbatim quotes where appropriate.

Assessment of inter-rater reliability

After coding of the first 200 articles, a random sample of 20 articles was selected, using the random number generator function on Microsoft Excel. These articles were double coded by a colleague with expertise in performing media content analysis. A face-to-face meeting was held to discuss themes where uncertainty had arisen during the coding process. Cohen's kappa was then performed for each variable to determine level of agreement between coders.

Of the 42 initial themes assessed, kappa was 0.8 or greater in 21, indicating substantial or complete agreement.

The remaining themes were explored by re-reading the articles and reviewing the nature of the disagreement in coding between reviewers to determine whether they should be discarded from the coding frame due to unacceptable ambiguity or whether decision rules could be more clearly defined.

Three themes were removed from the coding framework due to poor reliability. These were: 'nature of headline (alarmist, reassuring or neutral)', 'article contains alarmist words or phrases' and 'article states rates increasing.' The first was found to be highly subjective and even after discussion it was difficult to reach consensus about whether a headline was alarming or not, particularly where a headline contained quotes containing alarmist words that could be interpreted as intentionally selected for a sensationalist effect or, alternatively, as merely neutral reporting of facts. For 'contains alarmist words or phrases', an initial list of terms had been specified, however as the coding process progressed, further relevant words and phrases continued to be identified and the range was felt to have become too diverse to ensure that they were being coded consistently.

The 'problem definition' section of the coding framework initially contained the code 'states rates increasing,' however this was found to lack specificity and could be interpreted in a variety of ways – for example, 'rates have increased by 'x' % in the past decade' versus the more ambiguous 'more patients are being diagnosed with sepsis' or 'we must act to stop the spread of resistance.'

For the other themes that scored less than 0.8, the coding guidance was revised to ensure clarity in the decision process. Revisions were as follows:

- Drivers: human healthcare (systemic factors). Discrepancies between coders were found to have arisen because of actions that had been undertaken by several individuals in one setting that deviated from 'best practice.' This was felt to reflect the culture of an organisation rather than the lone actions of an individual, therefore these examples were recorded as 'systemic healthcare factors.

- Drivers: human healthcare (behaviour of individual). Discrepancy had arisen over whether the individual had to be named for this to be recorded as yes; it was decided that this was not necessary, provided they were identifiable in theory, i.e. based on the date and place where they had been working.

- Solutions: technical. Discrepancy had arisen over whether mentioning antibiotics as treatment should be coded as technical; the coding guidance was updated to reflect that only where the need for 'new' antibiotics, or research into their efficacy was mentioned should this be coded as yes.

- Solutions: early antibiotics/ 'sepsis 6'. Discrepancy had arisen over whether this was to be coded as yes if mentioned in relation to an individual case; it was decided that only if early treatment was presented as a solution to be applied in all cases should this be coded as yes.

- Identifiable victim: Discrepancy had arisen over whether a name was required; a new field was added to allow recording of whether the individual in the article was named, allowing the articles where an individual was referred to but not named to be recorded

All 200 articles that had already been coded were then reviewed to ensure consistency in coding of the themes above. The remainder of the articles were coded using the revised coding framework and guidance document. A paper template was completed for every article. Examples of illustrative headlines evidencing codes were recorded for reference. The final version of the coding template is attached (Appendix 10).

Statistical analysis

The data from the paper templates was entered into a spreadsheet on SPSS v 21. Linear regression was used to determine the statistical significance of trends in publication over time. Chi square tests were used to compare allocation of codes for AMR and sepsis, with significance set at $p < 0.05$.

Qualitative analysis

As identified in the previous chapter, there are limitations in using a quantitative approach on its own to examine complex issues. Although the quantitative analysis provided a 'broad-brush' picture of how AMR and sepsis have been constructed in the news media, it is the meanings within these 'frames' that provide the 'something else' that Krippendorff alludes to as necessary to further our understanding of an issue (132). By using a mixed methods approach, we can apply qualitative analytical methods to themes identified in the quantitative analysis as being of particular interest to arrive at a deeper understanding.

From the quantitative analysis, several themes were identified that were of particular importance and amenable to further exploration via qualitative methods. For example, the contrast between framing of AMR as a global health issue in comparison to the impact of sepsis within the UK is an important difference likely to alter how risks are perceived by audiences. Similarly, positioning of AMR as an issue driven by multiple sectors in contrast to constructions of sepsis as influenced by the healthcare setting alone is also of substantial relevance to how audiences are likely to perceive its relevance for them. However, the theme that was considered to represent the most important difference between framing of AMR and sepsis in UK newspapers was the use of personal narratives, a consistent feature of sepsis reporting that was largely absent in reporting of AMR. Although excluded from the final coding frame due to inter-rater ambiguity, headline rating had initially been recorded as 'alarmist; 'reassuring' or 'neutral'; over time the proportion of 'alarmist' headlines appeared to increase, many referencing deaths in children. Those articles in the original sample that contained personal narratives about deaths from sepsis in children were selected for qualitative analysis and were imported into the qualitative analysis software package (NVivo version 12.0). To code the content of these articles, a thematic analysis approach was used, as described by Braun and Clarke (133). I generated initial codes, informed by the findings of the quantitative analysis and by novel themes identified from close reading of the articles. Two additional researchers with extensive experience in qualitative analysis independently coded a random subsample of 10 articles. The suitability

of the draft coding frame, including duplications or omissions, was discussed by all three reviewers and was subsequently revised and refined, with the final version consisting of five overarching themes: sepsis; victims; the healthcare system; families; and antibiotics (Appendix 12). All articles were then re-coded using the revised coding frame to ensure consistency. Analysis of the coded content is presented alongside typical quotations.

3.3 Focus Groups

3.3.1 Using focus groups in sociological research

Kitzinger and Barbour define focus groups as group discussions that explore a specific set of issues that can be distinguished from other types of group interviews in that they encourage participants to talk to each other, asking questions, exchanging anecdotes and commenting on each other's experiences and points of view (134). According to Morgan, it is this interaction that is the hallmark of the focus group, "produc(ing) data and insights that would be less accessible without the interaction found in a group" (135). The origins of focus group use within sociological research lay with Merton and Kendall and is summarised in their seminal work 'The Focused Interview', published in 1946 (136). The method resurfaced as a market research tool in the 1950s and 60s; subsequently, its success in the private sector led to adoption by public sector organisations. In the following decades, focus group methodology has been used extensively within health research, including to explore responses to health-related messages in the media (120, 137-139).

Typically, focus groups have been used as an adjunct to other research methods, although they may also be used as the sole data collection method. As an adjunct, they have been used as an exploratory method as the basis for establishing a more structured interview schedule or survey design (105). Alternatively, they may be used as a follow-up method, perhaps helping to provide context to anomalous or surprising findings (134). Wilkinson suggests that in either case 'the use of focus groups permits the design and conduct of research based on a more detailed and sensitive understanding of the topic under consideration" (105).

From a theoretical perspective, focus groups offer a high degree of flexibility in that they are not tied to a particular epistemology, thus can be used within an essentialist or a social constructionist framework (105). Under an essentialist framework, the task of the researcher is to elicit individual ideas, opinions or understandings of participants, while according to a social constructionist framework, meanings do not develop in isolation but

are produced collectively during social interactions. According to Wilkinson, focus groups are therefore particularly suited to a social constructionist framework in that they provide opportunities for researchers to "observe how people engage in the process of collective sense-making: how views are constructed, expressed, defended and (sometimes) modified within the context of discussion and debate with others." However, Wilkinson notes that researchers rarely declare a distinct epistemological position and that frequently there is overlap between essentialist and social constructionist epistemologies.

Morgan describes focus groups as occupying an intermediate position between the two original methods of collecting qualitative information; participant observation and interviews (135). Participant observation offers the advantage of allowing group behaviour to be studied in a natural context. While practical considerations may rule out a full-scale participant observation study; according to Bloor focus groups allow a 'concentrated' study of group norms that would only be available to the ethnographic researcher over months or even years (140),(114). Additionally, Morgan argues that some processes, such as decision-making, and attitude formation are inherently unobservable; focus groups allow the directive questioning necessary to elicit this information (135).

In comparison to individual interviews, the obvious advantage of focus groups is the ability to observe interactions between participants, enabling the 'collective sense making' described above. Wilkinson describes focus groups as a particularly egalitarian method in that the researcher's influence over the discussion is minimised simply by the balance of numbers (105). To an extent, participants set the agenda by prioritising for discussion the themes most important to them. These may diverge from those of the researcher, challenging presumptions and introducing new directions. Agar and MacDonald have suggested that the individualistic nature of interviews yields more data from participants, with the onus on them to elaborate on their initial responses (141). However, Wilkinson argues that the interactive nature of focus groups, in which participants may have their views challenged and be required to defend them, can afford a fuller account than a one-to-one interview (105). This makes the method particularly useful when the research topic is the subject of media attention and likely to yield public debate.

It must be considered that the interactive dimension of focus groups could also be viewed as a limitation in that participants may modify their responses according to how they wish to appear to fellow participants. Wight explored this possibility by conducting both interviews and focus groups with the same participants (142). He found that those males who participated first in focus groups presented themselves as having a more 'macho'

persona, which continued in individual interviews, while those who first participated in interviews appeared to adopt a more sensitive stance which disappeared in the focus group setting. The possibility that this finding may be generalised to other focus group research, with participants altering their expressed views in the presence of other participants must be considered. It is essential to be mindful of this when analysing content generated within group settings, although how concerning this is in terms of validity of findings is likely to be related to the topic. For example, it is important to know if parental responses to illness are influenced by being in a group setting, as discussions and decisions about health seeking may often be made and enacted in this context. What participants say in public and do in private may differ, but it may be argued that it is less likely that participants could successfully 'conceal' actions related to tangible everyday behaviours (e.g., 'I do take my child to the doctor' or 'I don't take my child to the doctor') in comparison to more abstract issues.

3.3.2 Why use focus groups for this project?

Bloor suggests that where the main goal of research is to gather data that allow the study of group norms, focus groups should be the sociological method of choice (140). A research priority for me was to elicit whether the actions of parents and carers in response to childhood illness was modified in response to the opinions of others. My a priori hypothesis, based on Goffman's schema about how people choose to present themselves to others and on the impact of parental decision-making on moral identity, was that expressions of being risk averse by one participant may 'set the tone,' potentially influencing the responses of others. Alternatively, it was possible that participants who had given less risk averse responses would modify these if others in the group appeared to demonstrate a greater degree of caution (107, 108, 112, 143). The interactive nature of focus groups thus provided an obvious forum to explore this dynamic.

Morgan and Krueger suggest some specific situations where focus groups should be considered as the most appropriate qualitative method (144). They suggest that the method is particularly suited to the study of complex behaviours and motivations that may not be readily articulated, and that may not even be consciously acknowledged by the participant, but which may be elicited over the course of group interaction, described as a 'cuing method':

'As they hear others talk… they can easily identify the degree to which what they are hearing fits their own situation. By comparing, they can become more explicit about their

own views. In addition, as they do express their own feelings and experiences, they may find that answering questions from the moderator and other participants makes them aware of things they had not thought about before.'

An example of this was exploration of the role of parental instinct, which was identified in the qualitative analysis of news articles as vital for identifying when childhood illness was serious, but which is not well-defined. 'Gut feeling' is often used interchangeably with 'instinct' and has been defined as 'an instinctive feeling, as opposed to an opinion or idea based on facts' (145). This has been identified as an important factor that can influence clinical decision-making, through intuitive unconscious processes that are distinct from reasoned analytical ones (146, 147). I wanted to discover whether the same principles operate within parental decision-making about childhood illness and observing how participants made sense of this concept in a group setting offered the opportunity to explore what it meant for parents in the context of everyday life.

Morgan and Krueger suggest that focus group methodology may be particularly suited to issues where there is known to be a gap in understanding between professionals and their target audience, with 'language and logic too different and removed from the people they are trying to serve' (144). Previous qualitative research has identified that language used by scientists and academics in communicating about health risks associated with AMR has low meaning for many individuals and does not reflect how they discuss infection risk in the context of everyday life (7). No research has been identified that explores how the public understand professional language currently used to communicate about sepsis. According to Morgan and Krueger, 'through the interactions in focus groups a clear view is provided of how people think and talk in everyday life, exposing their reality' (144). Thus, I determined that using focus groups to discuss these issues would provide an opportunity to build on previous research about public understandings of AMR, applying this to the context of parental decision-making, and to offer novel insights on parental understandings of sepsis.

3.3.3 Planning the groups

Developing a topic guide

Bender and Ewbank recommend developing a one-page set of questions to guide and direct the focus group discussion (148). Using a topic guide that sets out the questions that will be used to generate discussion is not only helpful as a prompt for the researcher, but also

allows a degree of standardisation and produces a higher level of comparability between groups.

Redmond and Curtis summarise four broad criteria suggested by Merton to guide data collection within focus groups (136, 149):

- Discussion should address the maximum *range* of issues relevant to the topic
- Data collected should be *specific* to the topic
- Questioning should promote group interaction that allows exploration of participant's feelings in *depth*
- Discussion should acknowledge the *personal contexts* described by participants when giving their responses

Although it is desirable to cover a 'maximum' range of issues, Bender emphasises that the topic itself must be narrowly focused and that failure to ensure this is likely to produce diffuse data that is difficult to analyse and that contributes little in the way of new knowledge (148). I considered that it was therefore important to have realistic expectations about what constituted a sufficiently narrow topic. An example pertaining to my project might be questioning aimed at uncovering experiences and attitudes about emergency care; I considered the distinction between 1. unfocused questioning about attending emergency care in general and 2. a questioning approach that remained broad but that aimed to elicit specific views and experiences related to attending emergency care as the parent or carer of a child who has an acute infectious illness. The first represents an unmanageably wide topic that could generate discussion down endless paths, while the latter focuses on the range of perspectives and beliefs that pertain to a specific situation.

The initial topic guide was informed by a priori knowledge and by findings from the quantitative and qualitative content analysis of news articles about AMR and sepsis. Focus was on three main areas: responses to childhood illness including antibiotic use; knowledge and attitudes about AMR; and perspectives on media representations of sepsis. However, it was also important to utilise the opportunity to expand on new discussion areas that were recognised as important to participants through their repeated emergence across different groups. According to Bender, the topic guide should be just that and should 'guide not limit the questions that can be asked' (148). Morgan has described how a 'funnel' pattern may be used, beginning with a core set of questions then proceeding to a variable set of specific issues (150). This is essentially the structure I used in later groups, beginning with the same core questions, but incorporating questions about areas newly

identified as important, for example, the impact of employment on managing childhood illness. As identified by Morgan, this had 'the advantage of maintaining comparability across groups for the first part of each discussion but allowing the later section of each group to vary according to the emergent needs of the research' (150) (Appendix 13).

A separate topic guide was devised for use in groups with individuals who had lived experience of sepsis that incorporated participant's perspectives on awareness campaigns and messages about antibiotic use in the context of their experience (Appendix 14).

For all groups, I brought a folder containing examples of news stories about sepsis and AMR. I usually introduced these midway through the groups as an inroad to discussion of media representations of sepsis and AMR, but occasionally introduced them at an earlier stage if I felt a discussion prompt would be useful. Kitzinger suggests that using visual materials can be useful in helping to remove focus from the researcher and to focus discussion around key points of interest that can be compared between groups (134). In selecting the articles, I chose those that replicated distribution of articles as identified in the quantitative analysis i.e., predominantly articles from broadsheet newspapers about AMR and predominantly articles from tabloid newspapers about sepsis. I also included two articles that I felt best demonstrated the potential conflict between sepsis awareness and antimicrobial stewardship entitled that I had used several times in conference presentations (151, 152). Finally, in later groups I included newspaper articles about representations of sepsis in popular television programmes (Coronation Street and Call the Midwife).

Ethical considerations

Ethical approval was granted by the MVLS Ethics Committee in December 2017 (application number 200170054). There were two main considerations specific to this study. First, the intended subject matter for discussion had potential to cause distress to participants. Although for groups involving parents and carers there was no attempt to recruit participants who had been personally affected by sepsis, it was important to consider that the nature of discussions could act as triggers for any experience of serious illness or personal loss. If participants discussed an experience that was potentially distressing, I acknowledged this and ensured that they were aware that we could pause the recording and discussion.

A second concern was the potential for unintended consequences from the group discussion; one of the areas for exploration was whether the current media focus on sepsis awareness had the potential to create undue alarm and to cause parents to perceive the

threat from common childhood illness as greater than is supported by evidence. I felt it was extremely important that, as moderator of the groups, I did not cause parents or carers to perceive that I was suggesting that they should alter their usual response to childhood illness i.e., that I was advocating that they should be more or less risk averse. I did frequently allude to this during the groups, particularly when introducing the media discussion prompts i.e., making it clear that although there was a recognition that better awareness of sepsis was required, it remained a relatively unusual complication of infection in previous healthy children. This was a delicate balance to achieve, as this message seemed to contradict that of the media stories that I wanted to discuss. In preparation for any questions from parents about how to safely manage acute childhood illness I carried a supply of the health information leaflet 'When should I worry?' which has been produced by researchers at the University of Cardiff for this purpose and is available as a version for parents and carers in Scotland (153). I did not supply these to participants as a matter of course, as the purpose of the focus groups was not to educate, but was willing and ready to discuss the content of the booklet if this naturally arose and did distribute them to all participants at the end of one group where I felt there was a sense of uncertainty about how to recognise serious illness.

Finally, a more general consideration applicable to any focus group was confidentiality. Participants were ultimately in control of which health experiences they chose to divulge, although the potential that participants may disclose sensitive material in a group setting that they would otherwise withhold was considered (140, 154). There were no occasions where I felt that any information was disclosed that could have negative long-term consequences for participants but, on occasion, discussion about personal experiences involved naming of local health professionals. It would have been unrealistic to expect that this would not arise when a group of participants from the same locality were asked to discuss their experience of health services, but where this occurred, I tried to move the conversation on to a more general discussion as it seemed inappropriate to criticise specific individuals who could not defend their position.

Selecting the sample

Selecting a suitable sample for a focus group study differs intrinsically from quantitative research in that the aim is not to achieve a generalisable sample through random sampling but rather is driven by 'theoretically motivated sampling' (135).

The researcher faces two main choices in selecting a sampling method:

- To select participants according to a shared characteristic (segmented or homogenous groups) or to stratify participants with different characteristics to produce mixed groups
- To select participants who are already acquainted or who are strangers

According to Morgan, an advantage of using homogenous groups is that participants may feel more at ease with each other, promoting free-flowing discussion (135). He suggests that the researcher should question whether participants would feel at ease discussing the topic during normal day-to-day interaction and points out that wide gaps in social background or lifestyle may prevent this. Using segmentation also allows differences in views between groups with certain characteristics to be compared. A potential drawback is that views of participants may be more similar than in mixed groups which may produce less animated discussions than if participants had more varied characteristics. Designing groups where participants have been selected to ensure mixed characteristics (e.g., age, sex, socioeconomic status) may sometimes have advantages, but the value of this must be balanced against the increased time and organisation achieving this would require.

Morgan suggests that selecting participants who are strangers may be preferable to a group where participants are previously acquainted because this avoids reliance on shared assumptions that participants may not feel the need to vocalise, which may be the very views that the researcher is attempting to elicit (135). Furthermore, there may be reluctance to disclose certain beliefs or behaviours in a setting with acquaintances, whereas they may feel less inhibited discussing certain topics with strangers. Of course, for some participants the opposite may be true and familiarity with the other participants may be an important factor in facilitating discussion. However, Morgan acknowledges that often whether participants are known to each other is dictated by practical considerations and that if there are no specific concerns about how participants being previously acquainted will alter group dynamics then this need not be problematic. Bloor points out that focus groups are inherently unpredictable and dynamic and that even with stringent planning the researcher cannot predict or control how the discussion will unfold (140).

According to Morgan, "the aim of using a complex, segmented design is to create a variety of internally homogeneous groups that capture a wide range of potentially distinct perspectives" (135). He cites Kitzinger's study of public understandings of messages about AIDS that comprised 52 separate groups made up of individuals with different backgrounds, which Morgan acknowledges as ambitious in terms of both resources required and complexity of analysis. The nature of my study dictated that all participants in the main groups shared at least one characteristic; all were parents of or regularly cared for

infants or children aged between 0 and 5 years. As this was an exploratory study and not a comparison with any previous work identified, I had no pre-defined expectations that other characteristics that could have been used to segment the groups (e.g. male versus female, low v. high socioeconomic status, young versus older parents, one versus multiple children, in paid employment versus stay at home parent) would have particular influence on the data generated, thus comparison of parents and carers with different characteristics was not a research priority. Nonetheless, it was likely that these differences would have some influence on their views, even if I had no fixed prior hypothesis about how these differences might manifest; therefore, I aimed to cover a range of characteristics both within and between groups Table 2). I considered that my recruitment strategy (next section) was likely to enable me to recruit participants reflecting the range of characteristics specified, but was prepared to adapt my strategy if necessary. I also considered that it was likely that mothers would predominate among participants attending parent and child groups, therefore recruiting fathers and carers was likely to require definitive attempts.

Table 2 Sampling frame for focus groups

Desired spread of characteristics
Parents with babies and older pre-school children reflecting:
Range of socioeconomic status and educational level
Range of ages
Mix of first-time parents and those with older children
Mix of stay at home and working parents
Mix of family structures i.e., two parent and lone parent families
Target groups
Fathers
Individuals with caring responsibility
Individuals affected by sepsis personally or via a family member

In my supervision meetings we discussed whether to include individuals with direct experience of sepsis. In considering the issues involved in this we drew on SH's experiences of conducting focus groups with parents in relation to MMR vaccination, reflecting on the greater range of views that can be generated by including participants who have a connection to a particular topic (119). While we determined that it would be

important to elicit views of individuals who were personally invested in sepsis awareness as an important health issue, I was also concerned to ensure that I heard the views of parents and carers with no cause for special interest in sepsis beyond what they may have been aware of through the media or awareness campaign materials. For me, these parents represented the majority who were fortunately not directly impacted by serious childhood illness and whose views would be likely to have the most relevance for impact of sepsis awareness on service use and antibiotic prescribing. Furthermore, I considered that as sepsis in children remains relatively rare, it was unlikely that I would be able to recruit enough parents of affected children to convene a series of groups. I decided therefore not to purposely include individuals with experience of sepsis or other serious illness as part of the parents and carers groups, but instead to carry out several groups with individuals affected by sepsis after the parents and carers groups had been completed.

Recruiting participants

The above aims informed my recruitment strategy, and what followed can be best described as a combination of purposive and convenience sampling. I was aware that while parents of young children were not 'hard to reach' in the usual sense, there was a high possibility that they may be likely to have difficulty engaging in research that required a time commitment, even for a period of less than two hours. I anticipated that parents of young children may have reduced capacity to attend groups held in the evening and that those with older children to collect from school may have additional time constraints. I therefore felt it would be important to maximise opportunities for recruitment of these parents by making involvement as simple as possible. Based on my own experience as a parent of pre-school children, I identified that recruiting parents whose children attended pre-school education for the (approximately) 16 hours of free childcare provision per week had the potential to be a useful strategy. The standard 3-hour session offers limited time to complete other tasks and from a personal viewpoint I have often been happy to use this time to attend various groups held within my child's nursery if requested; based on this experience, I anticipated that sufficient parents would be willing to give up an hour of this time to participate in a group.

In contrast, I felt that recruiting through posters or online advertisements was likely to attract individuals whose views, while important, may be less reflective of mainstream opinion. I felt that it was important that views of parents who were particularly motivated to respond did not predominate, however, was mindful that the intention of qualitative research is to identify the range of views in existence on an issue. Consequently, I did

decide that I would use this strategy alongside directly contacting nurseries and early years centres. Finally, I also decided to contact groups run specifically for parents and babies to ensure I captured the views of parents of children who were younger than pre-school age.

The recruitment process commenced in February 2018 and the first 14 groups were completed between February and June 2018. I had anticipated that the beginning of a new year would be an optimal time to begin recruitment following the busy festive period. I kept a log of which organisations had been contacted and what actions had been agreed with gatekeepers, for example, requests for provision of more information or a request to make contact again later. Where possible, my preferred option was to make contact by telephone rather than email as I felt that this demonstrated that the request was genuine and not simply part of a speculative scattergun approach. Where I met with a positive response, recruitment posters and participant information sheets were sent by email to provide more information and to allow these to be distributed to potential participants if the gatekeeper approached agreed (Appendices 15 and 16).

Poor weather conditions in February 2018 delayed some processes; many schools and childcare establishments were closed for a period of several days or coping with reduced staff, and during this time speaking to a potential researcher was not a priority for gatekeepers. Following this, I encountered some challenges with my primary strategy of recruiting through schools, which was less straightforward than anticipated. My application to obtain research access in schools was refused by the first two local authorities that I contacted based on the volume of similar requests received. Following discussion with my supervisors, I enlisted the expertise of a colleague who had extensive experience of conducting qualitative research in educational establishments. They advised that they had often been met with more positive responses from authorities that are located further from the concentration of higher education institutions in the city centre as they are approached less frequently and therefore less affected by 'research fatigue'. This did indeed prove to be accurate; I was met with very enthusiastic responses by heads of service in four other local authority areas. Some agreed to place the recruitment poster in schools or nurseries; others were very proactive and offered to contact heads of local nurseries and early years centres on my behalf. This proved to be a fruitful approach and participants for six groups were recruited in this way. For these groups, sometimes nursery staff had identified participants who were willing to participate prior to my arrival; for others the approach was more opportunistic, and I would arrive at an agreed time at the start of a nursery session and identify parents or carers who had capacity to take part.

Responses from third sector organisations were variable, but I was fortunate to have positive responses from organisations that allowed me to convene a group with fathers and one with kinship carers. I also completed a group with participants who had involvement with an organisation that supported disadvantaged children. Carrying out these groups allowed me to increase the diversity of participant characteristics represented in the sample.

I had anticipated that breastfeeding groups would be a useful avenue to recruit mothers of younger children, however, the majority of these are run in partnership with the NHS and, as I had not sought ethical approval from the NHS ethics committee, I was unable to recruit participants in this way. As an alternative, I contacted a local non-NHS parent and baby group run by a third sector organisation and met with a very positive response. Participants for two groups were recruited in this way. Participants for a further group were recruited on my behalf by a librarian who was herself a parent and who regularly ran a story and music group for pre-school children; parents and carers who attended this group agreed on a convenient time to attend to participate in the focus group.

In addition to this strategy, I used a concurrent speculative approach, placing posters in various locations that I felt were likely to be frequented by parents of young children, e.g., libraries, community cafes where pre-school groups were held and a social enterprise organisation that provided pre-used baby equipment to the local community. Online adverts were also placed in an online parenting magazine, a 'sling meet' website and a website publicising an exercise class for mothers and babies. Expressions of interest from individuals in response to adverts were stored in a separate database on the Social and Public Health Science Unit (SPHSU)'s Q drive for sensitive project information. Although I did receive a reasonable number of responses to these advertisements, ultimately only one group was convened in this way due to logistical difficulties of bringing together participants from different areas in one location at a suitable time.

Group structure

This recruitment strategy produced a series of groups in which participants were homogenous in their status as parents or carers of pre-school children and their involvement with an educational establishment, third sector organisation or parenting group, but who did not necessarily share other characteristics. Thus, participants within each group varied in age, number of children, employment status, educational level, relationship status and socioeconomic background. One characteristic that differentiated

participants from each other was an occupational background in healthcare; this should hardly have been surprising given that the NHS is a major employer in the UK, but was not something that I had considered may be relevant. Several groups contained at least one participant who worked as a health professional, and this often offered a valuable insight into their perception of failings within the health service and of their dual identities as health professionals and parents when making decisions about their own child's health.

In all but two of the groups, participants were known to each other to some extent. At the outset of the research, I anticipated that this would be advantageous; Kitzinger highlights how working with pre-existing groups can be beneficial in that they represent one of the social contexts in which ideas are formed and decisions made (155). The exceptions were one group of strangers brought together through their response to an online advertisement and one group with only two participants whose children attended the same nursery but were unknown to each other. However, the extent to which the participants knew each other was very variable; some alluded to social activities that they participated in together outside the organisational setting, but none of the groups could be described as composed entirely of a friendship group.

Of note, one of the groups that generated some of the richest data contained four participants who were varied in terms of age, occupation and number of children (Group 14). It may have been that as this was one of the later groups I conducted I was more experienced as a moderator and better equipped to draw out contrasting views, however, it did seem that the range of characteristics present resulted in elicitation of greater depths of experience; perhaps participants felt greater need to explain or defend their views if they perceived that their own situation was unfamiliar to the other participants. This did make me consider whether stratifying groups according to different characteristics may have been worthwhile; this is unlikely to have been feasible in the time available, but I will consider the value of this when planning qualitative research in future.

Following completion of the first fourteen groups in June 2018, transcription and data checking was carried out. This allowed me to pause for a period of reflection on the data gathered thus far and to begin to identify key themes. In autumn 2018, participants affected by sepsis were recruited by contacting Sepsis Research FEAT (Fiona Elizabeth Agnew Trust), a third sector organisation that supports sepsis research and awareness raising. The gatekeeper for this organisation kindly agreed to place an advertisement for the study on their website. As a result of responses to this, four groups were convened containing ten

participants in total. As respondents were scattered geographically, these groups were held centrally in SPHSU.

Determining the size and number of groups

Although guidance typically recommends convening groups with between six and ten participants, ultimately the size will be determined by the purposes of the research and constraints of the field situation (140). Morgan sets out some of the advantages and]disadvantages of smaller and larger groups (135). While smaller groups allow participants more time to talk, if their involvement with a topic is low it may be difficult to maintain the discussion. Large groups on the other hand may be difficult to manage and may pose difficulties at the transcription stage if it is desirable to know who said what at an individual level.

The first group I conducted had four participants, and I found this to be a comfortable and manageable size that seemed to facilitate easy discussion between participants. Bloor has suggested that groups with small numbers mimic typical patterns of social interaction of women in everyday life, facilitating greater discussion (140). This was reflected in the discussion between participants in this group, although all the participants were fathers, suggesting that this phenomenon is not gender specific. In contrast, recruitment for the second focus group at a parent and baby group was more opportunistic and the parents had been advised that I would be attending but had not committed to participating prior to my arrival. Eight participants agreed to take part, all of whom had babies present, and I found that this to be a more challenging number in terms of managing the discussion and allowing each participant ample opportunity to talk. Due to the possibility that participants may be unable to attend on the day, some researchers advocate over-recruiting and simply asking participants who are surplus to leave (156). However, Bender acknowledges the logistical issues in being overly prescriptive about group size; "*if one is interviewing groups of women in their own community about a topic of concern to all of them (such as childhood illnesses or pregnancy and childbirth) it may be difficult to limit the group size without insulting the group members, and thus jeopardizing essential rapport*" (148). Although Bender's illustrative examples relate to research that took place in West Africa, my experience as a researcher in the West of Scotland was no different in this regard and I felt it was important not to damage rapport by excluding any willing participants. I did learn from this experience though and determined that a maximum of eight participants was the upper limit of what I felt comfortable with as a moderator, and preferably fewer if

they were accompanied by babies or children. I avoided excluding anyone who was keen to participate by making a commitment to return to run a further group if necessary.

Two of the groups with parents and carers and two of the groups with individuals affected by sepsis had only two participants. While most texts suggest that focus groups consist of at least three participants, I did not find that these groups provided fewer rich data than those with more participants. My own perspective is that this was related to the familiarity of the main discussion topic; almost every parent or carer had a wealth of experience about childhood illness to draw on and participants frequently freely offered up their experiences, providing the personal contexts to which Merton refers (136). If the discussion had been focused purely around awareness of sepsis or AMR, my feeling is that small groups would have worked less well, as in general participants had less to contribute on these issues. Of course, regardless of the intended aims at the planning stage, in practice a major influencer of the number and size of groups is availability of participants. Acknowledging once again the importance of the capacity for the researcher to draw comparisons between groups, Morgan advocates running a larger number of small groups rather than vice versa if recruitment is challenging, for example, if few participants are available or if they are highly dispersed geographically (135).

The overall number of groups held must also be guided by both the research aims and by constraints of time and resources. Morgan suggests that, regarding research aims, the most important goal is achieving saturation i.e., 'the point at which additional data collection no longer generates new understanding' (150). According to Morgan, variability of participants within and across groups is an important determinant of how many are required, with participants that share fewer characteristics more likely to have disparate views, thereby requiring a greater number of groups before saturation can be achieved. In addition, if a less rigid structure is used to moderate the discussion, more groups may be required to ensure the same issues are covered by different groups to enable comparisons to be drawn.

At the outset of the study, I aimed to recruit eighteen groups which I felt was achievable within the time available. Fourteen groups were completed by June 2018, followed by four groups with individuals with lived experience of sepsis in November and December 2018. Reviewing the data, I then decided it would be valuable to convene two final groups with parents and carers to revisit key themes which were completed in January 2019; in all, a total of 20 groups were carried out. I felt satisfied that 'saturation' had been achieved for some subjects, particularly those where participants had less personal investment (e.g.,

attitudes about the future health threat from AMR or to sepsis awareness materials). For other areas, however, I felt that there was likely to have been potential to collect valuable data from conducting further groups, particularly regarding experiences of recognising a seriously ill child. Because most parents had fortunately never experienced the death or life-threatening illness of a child, when participants did contribute material on this subject (either from personal experience or by proxy via those of friends or family members) they frequently brought new insights to the idea that parents instinctively know when a child is seriously unwell.

Limitations of sampling and recruitment method

Although the sampling and recruitment strategy used resulted in a good spread of characteristics within and between groups, some groups were underrepresented. The average age of mothers who participated at > 30 years reflects the rising age of motherhood but ideally, a greater number of younger mothers e.g. < 25 years would have been included, particularly as in some groups maternal age was identified as a factor that can influence both response to illness and attitudes of health professionals during consultations. It would have been useful to have more than one group of carers and more than one group of fathers to allow comparisons; some of the other groups did contain individuals who were male or who were present as carers rather than parents, however, it must be considered that their responses may have been influenced by group structure. All the participants identified as white Scottish or British and it would have been desirable to include individuals of varying ethnicity to identify potential cultural influences on managing childhood illness. All the participants were recruited from Glasgow and surrounding areas, and it is possible that views may differ in other geographical settings where access to primary and emergency care is structured differently.

Of the participants who had lived experience of sepsis, all cases were in adults. Two participants attended as the parents of a nineteen-year-old who had died suddenly from sepsis; this case bore greatest similarity to the media representations of sepsis that I was keen to explore. As noted previously, it may have been preferable to recruit parents of children affected by sepsis, but I felt it was unlikely that I would be able to identify this population without seeking approval from the NHS ethics committee.

Running the groups

Most groups were conducted in the same way; I arrived and allowed the representative from the nursery or group that I had contacted to introduce me. I distributed the participant

information leaflets (Appendix 16) to those participants who expressed an interest in participating and allowed them adequate time to read it, meanwhile ensuring that the room was set up appropriately with refreshments available and with toys and mats available for babies if present. I also took steps to minimise the sound within the room and assessed the most suitable place for the voice recorder. After checking that all participants had finished reading the participant information leaflet, I asked if anyone had any questions about the study. I then started the process of obtaining informed consent, explaining each point on the form and checking understanding (Appendix 17). Participants were also asked to complete a form with contact details and basic demographic information (Appendix 18). Finally, if there were babies or toddlers present, I ensured that parents and carers were aware that they should make attending to their needs a priority and that we could pause the discussion if required. After a final check that participants were happy for recording to begin, I first asked each participant to state their name and the ages of their child(ren) as an introduction, both for my benefit and to allow them to familiarise themselves with each other if they were unknown to each other or, as in the case of some of the nursery parents, acquaintances only. On completion of the group discussion, participants were issued with a £20 shopping voucher to thank them for their time. Travel expenses were given if required although this was unnecessary in many groups as they were carried out at a location that participants were attending for other purposes.

I quickly found that ensuring that I was well prepared practically was crucial to the smooth running of the group. I had developed an inventory to check I had all the equipment that was required at least 24 hours before the group, but nonetheless I encountered unanticipated issues; for example, on one occasion the batteries ran low on the voice recorder causing it to have to be re-started several times, and on another I had insufficient pens, which delayed completion of forms before the discussion could begin. While these issues may seem relatively trivial, attention to preparation before arrival conveyed a sense of professionalism that was likely to be reassuring for participants and demonstrated that I valued the time that they were willing to contribute.

As, by definition, all the participants had current caring responsibilities for young children, this was a key practical consideration. For parents of younger children who attended baby groups, the children were almost always present. Occasionally this presented challenges if noise of babies crying or babbling was picked up by the recorder, but in fact this rarely occurred. I had anticipated that it was possible that parents may be distracted by the needs of their child which may have affected the of the discussion but again, this was never

problematic. Only rarely did participants break away from the group because their child was distressed and on most occasions the babies either slept in a pram or pushchair or were content to be held by their parent or carer and in fact these discussions felt relaxed and organic, perhaps more so than if I had tried to organise the groups so that a gatekeeper or other parents had responsibility for supervising children while the discussion took place.

For parents with older children in school, there were several instances where the need to leave to collect them dictated a natural end to the group; again, this was not problematic and there was always at least an hour available for discussion; one exception occurred during the group with kinship carers when one participant had to leave unexpectedly following a phone call from her daughter.

My role as moderator

The role of the moderator is to facilitate rather than control the discussion by ensuring that the intended topic is covered and everyone has the opportunity to speak, but in a way that minimally disrupts the natural interaction between participants (140). The extent to which moderators become involved in directing the discussion is variable and will depend on the need to obtain answers to specific questions. Morgan warns against assuming it is the moderator who is the most important determinant of the data collected and suggests that a good topic guide should produce a discussion that largely manages itself (135). Some researchers have adopted a hands-off approach that allows groups to moderate themselves, only intervening if they get side-tracked (157). However, this approach presumes that participants will explain and justify their views in enough detail to meet the aims of the research. Greenbaum suggests that an important function of the moderator is to 'peel away the onion', delving into underlying reasons for behaviours or attitudes described (158). Fern describes how reflective listening can help to do this by seeking clarification when there is ambiguity, paraphrasing what was said to ensure you have understood correctly, reflecting the feelings that appear to have been expressed and summarising the main points as understood by the researcher (157). It is this latter approach that I adopted, as I anticipated that it was likely that participants would find it easy to discuss what they did when their child was unwell but perhaps be less likely to explain why. In larger groups, positioning myself as at the more involved end of the moderator scale also allowed me to encourage involvement from more reserved participants.

Morgan suggests that regardless of which approach is chosen, it is useful to introduce the topic in a general way for two reasons (135). First, participants may have difficulty

following the researcher's detailed thinking; and second, an overly detailed introduction may cause the group to restrict their discussion. I opened the groups with variations of the same statement: "Young children are ill fairly often and that's normal; can you think back to last time you felt your child was unwell and tell me what you usually do in this situation?" In making this statement I hoped that I would put participants at ease through the normalising of childhood illness i.e., ensuring I was acknowledging that admitting to their child being unwell was no reflection of their parenting ability. Unless the discussion 'took off' in a way that may have prevented capture of valuable details if I had interrupted the flow, I tried to ensure that every participant had the opportunity to give a response to this opening statement. Morgan suggests that asking the same question of all participants at the outset this can help to deter against 'groupthink' i.e., the tendency for those with different opinions from the majority (or from the most forceful members of the group) suppressing their views.

Barbour emphasises that the researcher must consider how their own persona may influence the data collected by modifying participant responses depending on the extent to which they identify with them i.e., is the researcher an 'outsider' or 'someone like us'? (134). Some researchers have argued that the best moderators 'blend in' with participants, most easily facilitated by making sure they are as similar as possible as the group members. For the purposes of my research, I do not feel that *not* being a parent would have been a substantial barrier in collecting the data I required; nonetheless, being able to identify as a parent of school age and pre-school children allowed me to develop an easy rapport in most cases. I did not make a definitive point of identifying myself as a parent, but sometimes referred to the ages of my children when chatting informally with participants while waiting to begin the group. In addition, I occasionally acknowledged points made by participants with statements such as 'yes, I find that too' if they volunteered responses about managing childhood illness or experiences of healthcare that reflected my own thought processes. Some researchers may actively avoid offering such personal insights for fear they may be sanctioning a viewpoint, but for the purposes of this project, I felt that being open to doing so where natural within the discussion facilitated a richer discussion. I did not disclose my identity as a doctor in any of the groups and strove to remain impartial if participants disclosed negative experiences that could be perceived as placing unjustified blame on aspects of the healthcare system, endeavouring to identify to a greater extent as a parent than as a health professional. This was important, because the aim of the research was to explore attitudes to childhood illness and not to try to change behaviour based on what I might have personally perceived to be unwarranted

assumptions. If asked directly if I had experience as a health professional, I would of course have been open and honest, but I felt that divulging this information was not only unnecessary but potentially detrimental to the research process by restricting the information that participants were willing to share about their experiences of healthcare. Nonetheless, it was important for me as a researcher to acknowledge that both my identity as a parent and as a doctor would inevitably have an influence on my analysis of the data collected.

As the groups progressed, it became clear that it was unrealistic to presume that the discussion time available would be equally divided between the three topic areas. Unsurprisingly, participants had far more personal experience to draw on that was related to managing common childhood illnesses than they did about drug resistance or sepsis. These were often recounted in great detail, inviting comparisons from other participants about their own experiences. It was therefore natural that a greater proportion of time was spent discussing these experiences. Although I was initially concerned that this reflected my relative inexperience as a group moderator, I came to understand over time that in fact this related to the relative importance of different subject matters to participants. Merton identifies the importance of being flexible enough to include issues not specified at the outset and in latter groups I allotted more time to discussing important themes that I had considered to be more peripheral at the outset (for example, relating to the desire to avoid unnecessary use of health services and to the added consideration of managing childhood illness when both parents are in paid employment outside the home) (136).

Of course, the emphasis on the first part of the topic guide was not universal among all participants, and many participants had firmly held views about antibiotic use that they expressed vehemently. However, personal experience of drug-resistant infection was infrequent and therefore conversations between participants about this element of the discussion tended to take a different shape; the natural evolution of one experience leading to another that was present in discussions about childhood illness simply did not occur in the same way and even where participants expressed strong views these often led to a 'dead end.' I, therefore, had more work to do as a moderator to ensure that this part of the discussion was covered fully. Morgan and Krueger caution the researcher against assuming that focus groups will reveal deep motivational insights on every subject; sometimes "I don't know, I've never really thought about it' is the truth (and potentially an important finding in itself) (144).

Transcribing, checking and preparing for analysis

After completion of each group, the audio recording was transferred to the SPHSU's project T drive at the earliest opportunity. Transcription was performed by the company Smallbiz, with whom the SPHSU has an established relationship. Encrypted sound files were transferred via the secure cloud facility. Transcripts were returned via cloud transfer as Word documents and files were deleted from the cloud as soon as they were downloaded to the T drive.

I checked each transcript for accuracy by comparing it with the original voice recording. Sound quality varied based on the acoustics of the room where the group took place or if there was background noise present, particularly where participants were accompanied by children, and occasionally, small portions of text were missing where the typist had difficulty deciphering speech. I was usually able to amend omissions by careful re-listening and there were few instances where words were undecipherable. Checking the transcripts was time consuming but provided a good opportunity to familiarise myself with the data generated, which was useful for helping develop my thoughts about which themes were most important. I also used this opportunity to create brief summaries of what had occurred in each group, including any particularly interesting dynamics between participants or important experiences shared. These were useful to refer to when I began to analyse the data, helping me place coded content in the context of the overall group discussion. Once checked, transcripts were anonymised; all names were changed and details that could place participants in a specific locality e.g., names of nurseries or local GP surgeries/hospitals were removed.

3.3.4 Analysis of focus group data

Which analytical approach?

According to Wilkinson, there is a relative paucity of guidance regarding analysis of focus group data in comparison to planning and conducting the research (105). They caution against the mistake that many researchers make the mistake in treating the data generated by focus groups as though it is comparable with that collected via individual interviews, overlooking the importance of interaction between participants in producing the data. Broadly, I followed the same steps that I took when organising, coding and interpreting data in the media content analysis, with some important differences that reflected the differences in analysis of focus group data (133).

Indexing the data

Checked anonymised transcripts were imported as files into the qualitative analysis software programme NVivo version 12.0. By this stage, I had listened to and read each transcript several times and had good familiarity with the content of the data. Although all portions of data collected in the context of a qualitative study will not necessarily be relevant to the topic and contain 'codable moments,' my experience when I came to organise the data was that there was actually very little content that wasn't relevant. My feeling is that this was for two reasons; first, although I had adopted a relatively unstructured approach to moderating the groups, allowing participants to largely direct the discussion, I had three distinct areas to cover within the time allotted and was conscious of moving on when necessary to ensure that this was achieved, allowing little opportunity for the discussion to stray into irrelevant territory. Second, because the topic of assessing childhood illness was so familiar to all the participants, everyone had relevant experiences and opinions to contribute, in comparison to what may have occurred with a subject that was more peripheral to their everyday experience (for example, if all the discussion had been focused around knowledge and experiences of resistant infections).

Indexing the data helps the researcher to organise the focus group data to make them more manageable by grouping together all the content that pertains to an issue or theme. Bloor suggests that at the beginning of the process index codes are likely to be quite broad, becoming narrower and more focused as the work progresses, which is likened to the creation of chapters and subheadings. In fact, I found that it was easier to perform this process in reverse. Because my perception was that most data were relevant, I was wary of missing important content by taking a broad-brush approach. Instead, I indexed each transcript line by line, using a descriptive code that deviated little from the original data, often repeating the words used by the participant or paraphrasing them. Inevitably, as the researcher works through the data, new index codes emerge; Bloor suggests that this necessitates repeating the coding process to include relevant data under this code (140). I took a slightly different approach and worked through the data in its entirety and did not become concerned with whether I was issuing duplicate codes at this stage. Once every transcript had been coded in this way, I checked for codes that could be considered duplicates and amalgamated these. For example, "doctors need enough time to see you" and "there should be more time to see patients" would be combined under "need for time." This initial process resulted in the creation of 484 distinct codes. I briefly considered which

codes occurred most frequently to help gain an overall sense of the most important themes within the data. Appendix 20 lists the 20 most frequently occurring themes.

Next, I grouped these 484 codes into 35 broader subheadings, then into seven overarching themes: managing childhood illness; the healthcare encounter; antibiotics; immunity; sepsis; AMR; and the media. While this process was highly effective in helping me to organise my thoughts about which concepts were most important, I recognised that at this stage the coding remained descriptive. Following discussion with my supervisors, I identified the importance of ensuring that my analysis remained sufficiently close to the data and that I did not allow my own background as a public health practitioner to dictate which themes should appear in the coding frame. Bender describes how a superior understanding of the meaning behind the data collected can be reached in moving beyond the systematic coding approach of content analysis to ethnographic summarisation:

"The rich context in which the words of the respondents are embedded offers a unique opportunity to search the text, and the context, for additional meaning, for a previously unknown clue explanatory of behaviour, or a nuance which yields a different interpretation of previous knowledge." (148)

To develop codes that reflected a deeper interpretative understanding, I revisited the data according to the original themes and took a different approach than at the initial indexing stage, frequently pausing to ask myself 'what is the participant really saying here?' This resulted in generation of a coding frame with 19 novel codes that I felt represented the views of the participants (Appendix 21).

Which unit of analysis?

As already identified, focus groups are distinct from other qualitative methods in their capacity to explore how group interaction influences responses of participants. Although the majority of instructive texts advocate using the group rather than the individual as the fundamental unit of analysis, Morgan suggests that this is unwarranted and suggests that attempting to understand group activity as purely the sum of that of its individual members is reductionist, as is interpreting the behaviour of individuals as the result of the overarching group process alone (135). Instead, it is suggested that the two are interdependent and that neither groups nor individuals should solely be considered the unit of analysis, but rather that a balance must be struck between these two levels of analysis. This is the approach that I took, assigning codes to what each individual participant in the group said, but also anticipating being able to draw comparisons between groups. To

prepare the data for intra- and inter-group analysis, I used the matrix function on NVivo to record instances of each code according to the group number. This produced a visual summary of what themes were important in which groups, similar to the grid approach described by Knodel (159).

To interpret the data within the themes, I drew on analytic induction techniques developed by Znaniecki (160). According to Bloor, analytic induction can be described as follows: the researcher begins by defining the phenomenon that requires explanation, then each case is compared to the hypothesis to identify whether they confirm or refute it (140). Where deviant cases are found, the researcher must refine the hypothesis or define conditions for exclusions. This comparative process continues until no further negative evidence is identified; in addition, those cases (groups) where the hypothesis is not identified can be examined to ensure they do not contain data that meets the hypothesis. Bloor suggests that systematising the analysis process in this way offers the researcher a clearer path when presented with the abundance of data that is generated by focus group research and ensures that the researcher identifies adequate evidence to refute or support the hypothesis, discouraging selective use of evidence for convenience because it supports a particular point.

3.3.5 Reporting the data

Despite interaction between participants being recognised as the defining feature of focus group methodology, there has been criticism that this is rarely reflected when findings are reported, with a tendency to report quotations from individuals instead of as interactive sequences of speech (105, 155). Morgan argues that the extent to which interaction must be reported depends on the goals of the research and whether it is the substantive content i.e., what' participants say' or the interactive dynamics of how this is produced that is of greatest interest (161). He has suggested three different formats for reporting quotations from focus groups that may be most appropriate in different circumstances: using individual quotes; using what he describes as 'lead ins' and 'lead outs' i.e., describing what takes place within the group discussion either side of the quote used; or reporting sequential quotes from different participants.

Chapter 4 Findings of Quantitative Analysis

An overview of articles is presented, followed by results of the comparative analysis of themes present in articles about AMR and sepsis alongside illustrative quotes.

4.1 Search results

Figures 10 and 11 show the results of the search processes with the number of exclusions at each stage. The final number of articles that were eligible for analysis was 616. Categories were mutually exclusive i.e.; no articles were included in both samples.

Figure 10 Search process (AMR)
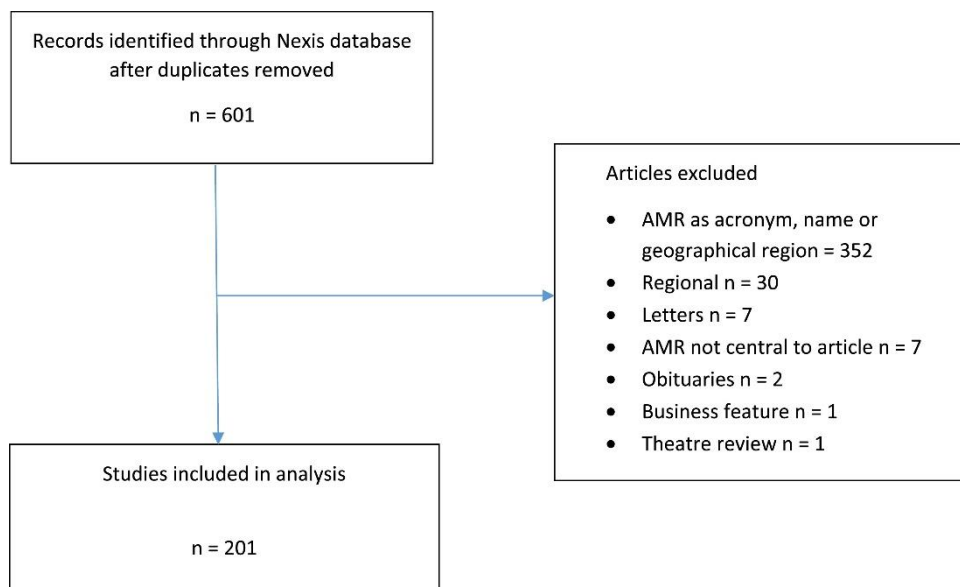
Figure 11 Search process (sepsis)

```
┌─────────────────────────────────┐
│ Records identified through Nexis│
│ database after duplicates removed│
│                                 │
│           n = 829               │
└─────────────────────────────────┘
                │
                │              ┌─────────────────────────────────────┐
                │───────────▶  │  Articles excluded                  │
                │              │                                     │
                ▼              │  • Regional editions n = 206        │
┌─────────────────────────────┐│  • Article is primarily about       │
│                             ││    meningitis n = 126               │
│  Studies included in analysis││  • Article's primary focus is another│
│                             ││    condition or aspect of healthcare n│
│           n = 415           ││    = 41                             │
│                             ││  • Non-health article, sepsis       │
└─────────────────────────────┘│    incidental detail n = 17         │
                               │  • Advertising feature n = 8        │
                               │  • Historical article n = 5         │
                               │  • Letter n = 3                     │
                               │  • Miscellaneous article type       │
                               │    (parliamentary proceedings,      │
                               │    'photo essay') n = 2             │
                               │  • TV/Book review n = 2             │
                               │  • Animal health n = 2              │
                               │  • Business feature n = 2           │
                               └─────────────────────────────────────┘
```
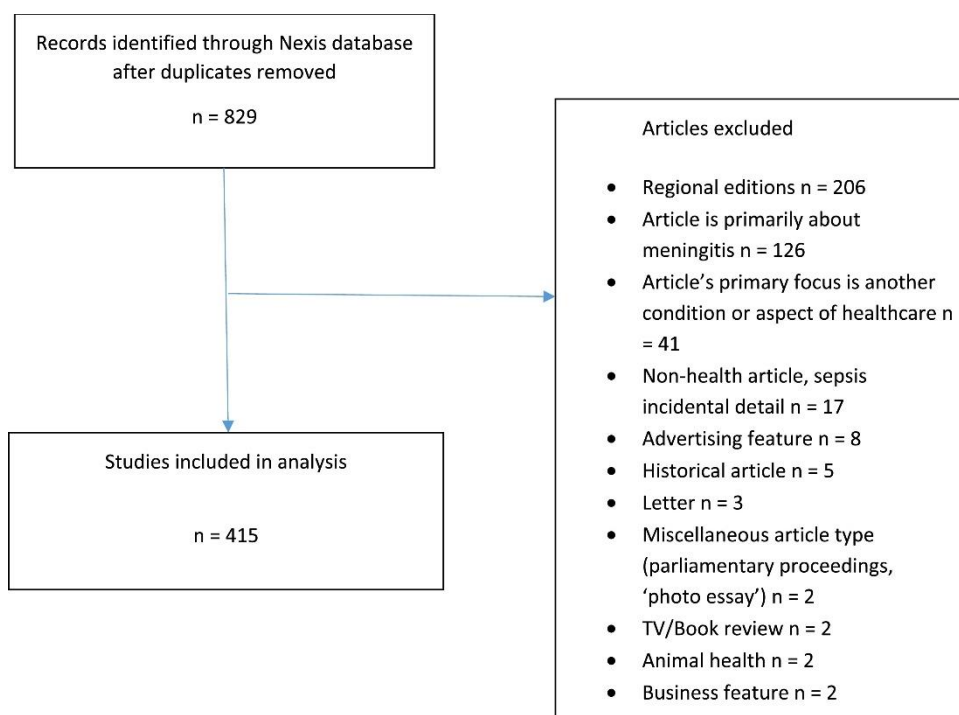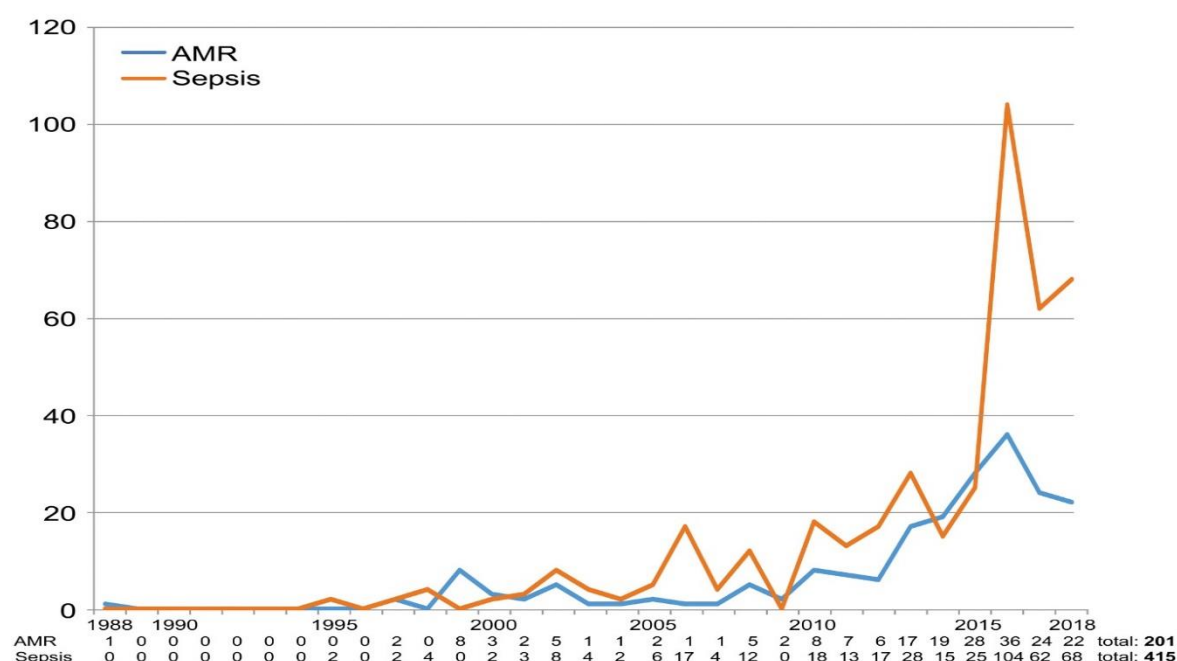
4.2 Location of articles and time trends in publication

Articles about AMR appeared more frequently in broadsheet publications, while for sepsis middle market publications dominated (Table 3).

Table 3 Summary of articles in the sample

Title	Sepsis (n = 415)	%	AMR (n = 201)	%
Broadsheet				
Guardian/Observer	48	11.6	87	43.3
Telegraph/Sunday Telegraph	50	12.0	51	25.4
Middle market				
Daily Mail/Mail on Sunday	202	48.7	42	20.9
Express/Sunday Express	31	7.5	15	7.5
Tabloid				
Mirror/Sunday Mirror	37	8.9	3	1.5
Sun/News of the World	47	11.3	3	1.5

The earliest identified articles about AMR and sepsis were published in 1988 and 1995 respectively. The frequency of articles about both AMR and sepsis increased over time (Figure 12). A simple linear regression demonstrated that progressive publication quarter was a statistically significant predictor of the number of articles published for both sepsis (coefficient 0.614, $p < 0.001$) and AMR (coefficient 0.620, $p < 0.001$).

Figure 12 Trends in articles published by year and subject

	1988	1990		1995		2000			2005			2010			2015		2018	
AMR	1 0 0 0 0 0 0 0 0 2 0 8 3 2 5 1 1 2 1 1 5 2 8 7 6 17 19 28 36 24 22																	total: **201**
Sepsis	0 0 0 0 0 0 0 2 0 2 4 0 2 3 8 4 2 6 17 4 12 0 18 13 17 28 15 25 104 62 68																	total: **415**

4.3 Framing sepsis and AMR

Table 4 illustrates the frequency of each thematic code within articles about sepsis and AMR and indicates the p-value of a chi-square test of association between each code and article topic.

4.3.1 Problem definition

Sepsis and AMR were presented largely as separate issues, with only a minority (9%) of the 616 articles that were included in the analysis mentioning both. Of the 201 articles that were primarily about AMR, only 27 (13.4%) mentioned sepsis, septicaemia or blood poisoning. For sepsis, the crossover was even lower, with only 29 (7%) of the 415 articles referencing AMR, antimicrobial resistance or antibiotic resistance.

Sepsis was most often presented in relation to its incidence within the UK rather than globally (41.7% v 3.4%), whereas AMR was described in both a UK (23.9%) and global (25.9%) context. AMR was also frequently presented as a problem whose greatest impact would be in the future (43.8% of articles), often referencing the year 2050 in relation to the predicted future estimates of the health impacts of AMR in the initial report released by the UK Review on AMR or containing statements like "the next few decades could see a return to the pre-antibiotic era." This framing as a future risk was seldom present in articles about sepsis. There was little difference in the proportion of articles that referenced the

economic impact of AMR/sepsis or that contextualised their impact for the reader by comparing them to that of other conditions.

Articles about sepsis were four times as likely to present infants and children and the elderly as groups within the population who are at increased risk, for example by referring to these groups as 'vulnerable' or 'susceptible' or by selecting them for comment in a way that indicated they were at particular risk e.g., "symptoms are particularly hard to spot in children" or referring to it as a leading cause of mortality in this population. Despite this finding, sepsis was also more frequently presented as a condition that is indiscriminate and that can affect all individuals in a population (5.5% v 1.5%), regardless of pre-existing risk factors.

4.3.2 Problem drivers

Similar proportions of articles presented systemic healthcare factors as drivers of sepsis (50.8%) and AMR (49.3%). These articles referred to widespread failures in diagnosing sepsis or initiating appropriate treatment or in directing patients through the healthcare pathway (e.g., escalating care where appropriate for individuals who consulted NHS 111 or primary care). For AMR, systemic healthcare failures related to the contribution of antibiotic overprescribing. Over one-third (40.2%) of articles about sepsis referred to the actions of potentially identifiable healthcare staff as at fault. In contrast, only one article about AMR referenced the actions of an individual health professional, and this was in relation to negative outcomes due to pressure from *not* prescribing antibiotics rather than to unnecessary prescribing.

As anticipated, articles about AMR frequently implicated the actions of the farming and food industries in relation to use of antibiotics in animals for non-therapeutic purposes, and of pharmaceutical industries through failure to invest adequately in research and development into new antibiotics and alternatives, highlighting the complexities of its causes.

Articles about AMR more frequently identified the behaviour of the public as a problem driver (19.4% v 1.4%). These articles referred to the capacity of the public as patients to put pressure on GPs to prescribe antibiotics when not required, but also in relation to other behaviours, for example, the impact of travel and tourism (including 'health tourism') on spread of resistance, and to consumer habits, e.g., demand for inexpensive meat that encourages antibiotic use in food animals.

Action (or inaction) of Government was more frequently defined as a problem driver in articles about AMR, for example, in relation to failure to take adequate legislative action on antibiotic use in farming, but this difference was not statistically significant.

4.3.3 Solutions

Solutions to AMR were presented predominantly as technical (51.2%) or systemic (61.2%). Technical solutions included the development of new antibiotic drugs or alternatives and improved diagnostic technology that could reduce unnecessary prescribing. Systemic solutions that were suggested included more effective regulation of antibiotic use in both human health and in food production and farming sectors (both within the UK and globally), and policies relating to funding of pharmaceutical research and development.

For sepsis, a wide range of systemic solutions were also proposed that included better implementation of management guidelines, improved clinical governance procedures (i.e., transparency in reporting cause of death) and financial penalties for hospitals that failed to demonstrate improvements in managing sepsis. Technical solutions to sepsis focused on improved rapid diagnostic techniques that could effectively differentiate between illnesses that do and do not require antibiotics. Articles about sepsis were more than twice as likely to present awareness-raising as a solution, either through suggesting the need for a formal campaign or simply by stating that greater awareness among the public or health professionals is required.

Just as few articles referenced both AMR and sepsis, so the potential conflict between solutions to each was overlooked; only 2.4% of articles about sepsis identified the need to reduce unnecessary prescribing. Although there was a lower prior expectation that articles about AMR would refer to the importance of early antibiotic treatment, this is clearly of relevance in relation to the contribution of resistant infections to the burden of sepsis, but was present in only 1% of articles.

Table 4 Comparison of themes within articles about sepsis/AMR

	Sepsis (n = 415)		AMR (n = 201)		p-value of chi square test of association between themes for sepsis/AMR
	n	%	n	%	
Problem definition					
Article about sepsis references AMR or vice versa	29	7.0	27	13.4	0·009
States rates within UK	173	41.7	48	23.9	<0.001
States rates out with UK	14	3.4	52	25.9	<0·001
States greatest health risk is in future	6	1.4	88	43.8	<0·001
States associated economic impact	20	4.8	22	10.9	0·005
Compares issue to other	55	13.3	22	10.9	0·417

health conditions					
Presents the following as 'at risk' group:					
Infants or children	50	12.0	6	3·0	<0·001
Pregnant women	8	1·9	0	0	0·048
Elderly	34	8.2	4	2.0	0·003
Individuals with pre-existing health conditions	44	10.6	22	10.9	0·897
Everyone	23	5.5	3	1.5	0·019
Problem drivers					
Human healthcare – systemic factors	211	50.8	99	49.3	0·711
Human healthcare – behaviour of identifiable individual health professional	167	40.2	1	0.5	<0·001

Behaviour of the public	6	1.4	39	19.4	<0·001
Actions of farming or food industry	6	1.4	83	41.3	<0·001
Actions of pharmaceutical industry	11	2.7	60	29.9	<0·001
Actions of Government	24	5.8	18	9.0	0·143
Solutions					
Awareness-raising	153	36.9	33	16.4	<0·001
Technical (e.g., diagnostic tests or drug development)	52	12.5	103	51.2	<0·001
Systemic (e.g., changes to protocols or regulation)	104	25.1	123	61.2	<0·001
Reduction in unnecessary prescribing of antibiotics in humans	10	2.4	86	42.8	<0·001
Treatment with early antibiotics	86	20.7	2	1.0	<0·001

4.4 Case histories

It was identified a priori that articles about sepsis were more likely to include narratives about affected individuals than those about AMR. This was confirmed by the results of the quantitative analysis; 74.9% of articles about sepsis included narratives about named individuals compared to just 7% of those about AMR.

Within these 311 sepsis articles, 45.7% referred to a baby or child and, of note, 23.5% involved high profile individuals likely to be known to the audience, from diverse fields including sport, music, acting and politics. Only two articles referenced elderly individuals, which is surprising given their identification as an at-risk group.

4.5 Discussion

Quantitative analysis of all available articles published until 30th June 2018 revealed important differences in how AMR and sepsis are framed in UK newspapers. Some of these had been identified a priori, for example, the more frequent use of case histories in articles about sepsis; performing a statistical analysis enabled quantification of these differences. Other differences that were observed were not anticipated at the outset, at least not to the extent identified in the analysis, for example, the lack of reference to AMR within articles about sepsis and vice versa. Still other findings contrasted with what was expected at the outset; for example, it had been anticipated that AMR would be more often framed in relation to its economic impact but, in fact, this frame was used equally for sepsis and AMR. In this section the most important differences and how these might impact on audience reception are discussed.

4.5.1 Key events related to trends in publication

Peaks in reporting for both sepsis and AMR occurred in 2016. Although a gradual upwards trend is apparent in sepsis reporting throughout the period studied, this accelerated in 2016, with one quarter of the articles published in this year alone. Key to this increase was the marked publicity that surrounded one case. William Mead was thirteen months old when he died suddenly and unexpectedly at home in December 2014. The inquest into his death (June 2015) reported that he died from sepsis associated with an undiagnosed chest infection and concluded that his death may have been avoided had he been referred to hospital by call handlers at NHS Direct. A subsequent enquiry by NHS England (January 2016) identified widespread failings in his care, prompting the then Health Secretary

Jeremy Hunt to issue an apology to his family on behalf of the NHS (97). This was widely reported in the press, as demonstrated in the analysis; of the 311 articles about sepsis that included case histories, 77 referred to William Mead. Backed by the Sepsis Trust and families of individuals affected by sepsis, including William's parents, the Daily Mail launched a campaign entitled 'End the Sepsis Scandal', publishing a host of articles that detailed similar cases, both current and retrospective. Reporting was sustained in the early part of 2018, in part associated with publicity surrounding the General Medical Council's (GMC) ruling to remove a junior doctor (Dr Bawa Garba) from the medical register after she was convicted of manslaughter by gross negligence, having failed to diagnose sepsis in a six-year-old boy (162). This decision provoked anger within the medical community, concerned about its implications for promoting an organisational culture that encourages transparency and learning, and has subsequently been overturned by the court of appeal, a decision welcomed by professional organisations including the British Medical Association (BMA) (163).

Key events in relation to reporting of AMR were the release of publications by the Review on AMR, beginning in December 2014, and first reports of resistance to colistin (referred to as 'antibiotics of last resort') in food animals in November 2015 (20).

4.5.2 Main themes in quantitative analysis

The relevant findings from the comparison of framing of sepsis and AMR can be grouped according to two main themes:

- Differential framing of sepsis and AMR and of their drivers and solutions, and how this may impact on audience reception
- Media constructions of sepsis and AMR as unconnected issues, with resultant failure to acknowledge a potential conflict in solutions posed

4.5.3 Differential framing of AMR and sepsis

Framing of AMR

In the articles in this analysis, AMR is framed according to its potential impact on global health, with its main impact in the future. Both its causes and solutions are presented as complex and dependent on co-ordinated actions between policymakers and the healthcare, farming and pharmaceutical industries.

Available evidence about public perceptions of AMR suggests a commonly held belief that it has little relevance for the majority of individuals, who feel that it does not directly

impact them(7). Qualitative research that explored responses to different 'ways in' to communicating AMR demonstrated that the least effective were those that focused on estimates of mortality and on the economic impact of resistant infections. What had greater impact on communicating its relevance as a population health issue was reference to its potential impact on aspects of healthcare that participants, or their relatives, were likely to have lived experience of (e.g., impact of lack of effective prophylactic antibiotics on routine surgery), and reference to specific causative organisms:

"Making it feel relevant and real and part of 'my world' is vital, and the 'ways in' most regularly used (cost/deaths) do not achieve this; specific bugs have more impact" (7).

This study also demonstrated that, for most participants, actions that could be taken at an individual level were perceived as tokenistic (for example, limited to actions around transmission of infection, such as using antibacterial hand gel) and that AMR is a problem that can only be addressed in a meaningful way by governments, the health sector and pharmaceutical companies.

This content analysis demonstrates that UK newspapers most often frame AMR in precisely the way that has been demonstrated to be least effective, through a focus on macro-level impacts, while largely omitting what it may mean for individuals. In keeping with the available qualitative evidence, its positioning in the media is as an issue whose solutions are so complex that they preclude meaningful action that can be taken by individuals. In this way, other commentators have drawn useful analogies between AMR and climate change. The latter has often been referred to as a 'tragedy of the commons.' Initially used by Hardin in 1968, this concept has frequently been used to describe situations where there are ethical and moral considerations in how 'common pool resources' (e.g., agricultural land, fish stocks and fossil fuels) are utilised. Ostrom describes how a consensus is emerging on the conditions that are most likely to promote effective self-organisation of resources:

"For users to see major benefits, resource conditions must not have deteriorated to such an extent that the resource is useless, nor can the resource be so little used that few advantages result from organizing. Benefits are easier to assess when users have accurate knowledge of external boundaries and internal microenvironments and have reliable and valid indicators of resource conditions" (164).

This statement may be equally relevant to how we communicate the impacts of AMR. Antibiotics can be considered a common pool resource in that they occupy a unique

position as medicines whose efficacy can be directly influenced by others' use. For most of the public, the present position is that antibiotics do work for any infection where they have been required, therefore fatalistic framing of AMR as an impeding apocalyptic scenario is unhelpful as it falls outside of the range of everyday experiences. 'Reliable and valid indicators of resource conditions' call for more nuanced communications about trends in current levels of resistance in organisms that are important for human health and evidence of the impact antibiotic use on resistant organisms, both on the individual microbiome and (ideally) at local, regional and population level. Present infrastructure and reporting systems make this an ambitious aim, but one that we should be working towards. Relying on communication strategies that have been demonstrated to be ineffective risks a 'boiling the frog' scenario i.e., the extent of AMR's health impacts may only be fully realised after it is too late to take meaningful action (165).

Although the drivers of AMR are presented as lying predominantly with health, farming and agricultural sectors, almost 20% of the articles cite the behaviour of the public as a contributory factor, either through their capacity to encourage unnecessary prescribing or via wider impacts related to travel and tourism and demand as consumers, e.g., for low-cost meat. Interestingly, as described by Kitzinger, stories about health risks lose traction in the media 'once blame is seen to lie at the door of ordinary individuals,' as seen, for example, in Miller and Reilly's observations of how reporting of the risk of salmonella in eggs in the UK disappeared from the media agenda once thorough cooking was determined to eliminate the risk, i.e., shifting responsibility from the producer to the consumer (166).

Framing of sepsis

In contrast to framing of AMR, this analysis demonstrates that sepsis was presented not only in relation to its global health impact but also in a UK context, while only a very small minority of articles position it as a problem that will have its main impact in the future. Immediately, this brings the issue 'closer to home' for the audience. Unlike AMR, sepsis was not constructed as an issue with multiple drivers but largely as one whose causes lie solely within the healthcare sector, both as a consequence of systemic factors, but also as a result of actions of individual health professionals in highly specific situations. Not only do the presented drivers seem more accessible, so too do the solutions. While systemic and technical solutions are acknowledged as important, better awareness is more than twice as likely to be proposed as a solution than in articles about AMR. The simplicity of this solution is inherent in the slogan that has been central to awareness-raising ('just ask – could it be sepsis?'). This could hardly be more accessible for a public

audience, requiring no training or specialist knowledge, in stark contrast to the interventions by policymakers or novel scientific discoveries required to have a meaningful impact on AMR.

The inclusion of case histories in most articles about sepsis contrasts with their use in only a small minority of articles about AMR. Furthermore, the nature of the individuals who feature in these histories ensure that they are likely to command audience attention. In addition to a high proportion of articles that featured the impact of sepsis on babies or children, a surprisingly high proportion involved individuals who are well known to the public in some form (or who are related to someone who is). Although individually these individuals may not necessarily enjoy huge celebrity status, collectively they contribute to sepsis' increasingly prominent public profile. Furthermore, the range of affected individuals from multiple arenas compounds the sense of sepsis as a condition that is considerably more common than previously imagined (i.e., if it can happen to so many people in the public eye how many ordinary people must be affected?). The number of associations with high profile individuals is indicative of the heterogeneity of sepsis as a condition; one would not expect to identify so many public figures affected by an infection caused by a single named organism, just as one would not anticipate a high number who were affected by a specific type of cancer.

For AMR, the small number of articles that did identify affected individuals tended to do so only in brief and for illustrative purposes, rather than as the driver behind the story. Only four examples of deaths due to resistant infections were presented, two of which occurred outside the UK. This contrasts sharply with the numerous examples of death or serious disability resulting from sepsis that are documented as having occurred within the UK healthcare system.

4.5.4 AMR and sepsis as separately constructed issues

The second major finding in the quantitative analysis is the lack of acknowledgment within media reporting of the relevance of sepsis to AMR and vice versa. From a biological standpoint, the relationship between the issues is clear; the proportion of cases of sepsis that occurs because of infection with resistant organisms is as yet unquantified but likely to be substantial. In the long term, reducing antibiotic use through antimicrobial stewardship measures to ensure that effective treatment for sepsis remains available is essential. Yet in the short term, this aim could be interpreted as in conflict with professional guidance that recommends a low threshold for suspecting sepsis, which, according to NICE, should be

considered in *any* patient presenting with infection, not only in those who appear severely unwell (10). For AMR, the main solution accessible to the public is to reduce expectations of and demand for antibiotics when not clinically indicated. For sepsis, the most important action is to adopt a high index of suspicion, allowing early diagnosis to expedite treatment. It is not difficult to see how these two objectives may be perceived as being in conflict. For patients meeting criteria for hospital admission, antibiotic treatment can be reviewed and amended as appropriate reasonably quickly in accordance with microbiology results. However, 80% of antibiotic prescribing takes place in primary care where decisions are rarely supported by diagnostics. There is evidence that decisions about prescribing are often influenced by non-clinical factors, including workload, perceived patient expectations, previous experiences of negative outcomes associated with not prescribing and even the time of day that a consultation takes place (146, 167, 168). It seems plausible that media reporting of sepsis could result in an increase in 'just in case' prescribing. Constructions of AMR and sepsis as separate issues results in a lack of clarity about optimum antibiotic use that compromises messages about the importance of balancing the need for sufficient access to antibiotics to protect individual health outcomes with safeguarding population health in the longer term.

4.5.5 Relationship to theories on media communication

Differences in reporting of AMR and sepsis may have important implications for audience reception through agenda-setting, priming and framing effects. In terms of 'telling the audience what to think about' (agenda-setting), both sepsis and AMR are likely to be issues with which the reader has little direct experience, therefore worth investing attention in. However, as pointed out by Moy et al, differences in the information provided that may act as media 'primes,' and differences in the frames through which the issues are presented, may impact on how relevant they are perceived to be and the extent to which the information provided is applied (103). Framing of AMR is largely thematic, with a relative lack of information about available action that can be taken by individuals that may limit their own risk. In contrast, sepsis is communicated using both thematic and episodic framing, referring to specific details about where healthcare may have gone wrong, often accompanied by visual images of the affected individual. Although the reader may have no direct experience of sepsis, they will invariably have other experiences of illness to draw on. In this way, the new information may act as a media 'prime', increasing availability of existing knowledge in evaluating this apparently novel threat to health that has the potential to affect anyone. Furthermore, the emphasis on awareness as a solution ('just ask,

could it be sepsis?') demands that the reader undertake an evaluative process of the information provided, considering what their own response would be if faced with the symptoms described, which, in the scenarios presented, frequently have dramatic sequelae. In contrast, AMR is largely framed thematically. While dramatic consequences are frequently referenced (e.g., the frequently referenced estimated ten million deaths per annum by 2050), they are not supported by accessible 'primes' in the same way as sepsis, therefore seem less likely to have a sustained impact on audience response.

Within the episodic frames that characterise sepsis, several of the media triggers and fright factors referenced in chapter 2 are well-represented. Although some of these points have already been drawn out in the previous section, it is worth making explicit reference here to theories of risk perception and which elements are relevant to AMR and sepsis. The quantitative analysis established that reference to identifiable individuals is a key difference in reporting of sepsis and AMR; this then becomes the vehicle through which other themes are communicated so that, for example, identification of elements of blame in sepsis reporting has seemingly higher human impact in comparison to charges of blame for health effects on theoretical individuals laid at the door of entire industries in reporting of AMR. A more thorough discussion of these points is undertaken in the next chapter in relation to episodic framing of sepsis; it is worth pointing out here however that many features of AMR as a health risk fit with certain of these fright factors, however, these are not necessarily in keeping with public understandings. For example, the potential for AMR to have widespread and devastating impacts on health is a result of the capacity for poorly controlled spread of resistant organisms in ways that the individual has little control over. Yet this is in opposition to evidence of firmly held beliefs about how resistance exerts its health effects, with negative health impacts of AMR widely considered to be a problem only for those who 'abuse' antibiotics, the perception being that it is the 'person' who develops resistance rather than the infecting organism (in other words, it may be considered to be to an extent 'voluntary') (7). While in one respect this is not untrue – mounting evidence demonstrates that alteration of the human microbiome may persist long after treatment is complete – it neglects the risk to human health posed by the spread of resistant strains of bacteria between human, animal and environmental sources, and the capacity for resistant genes to spread between species. Therefore, the very factors that have the potential for utilisation as effective health messages about AMR do not resonate with the way that most people characterise its associated risks.

4.6 Conclusions

The findings of this quantitative content analysis demonstrate differences in how AMR and sepsis are communicated in UK newspapers that may have important implications for perceptions about risk and antibiotic use. Although both issues are of sufficient importance to command audience attention in terms of agenda-setting ('what to think about'), differences in priming and framing processes are likely to result in more sustained interest in sepsis as an issue that is relevant as a health priority for the majority. Presenting sepsis through episodic frames, by referring to individuals affected, provides a human-interest element that may 'prime' existing knowledge i.e., recalling when they had similar symptoms to those described. Furthermore, the main solution posed 'just ask – could it be sepsis?' practically demands that reader consider what course of action they themselves would take in the situations described. In contrast, references to avoiding antibiotics for coughs and colds, while doing little to directly illustrate the consequences of *not* doing so, seems less likely to result in the emotional connection that is required to have a sustained impact on audience response. To mobilise existing knowledge and experience, details about the potential impact of AMR on procedures requiring prophylactic antibiotics, by providing examples of these that the public may be unaware of but can relate to (e.g., during obstetric or surgical interventions), may serve as more effective 'primes.'

The construction of sepsis and AMR in UK newspapers as separate issues fails to acknowledge the need to balance timely treatment with avoidance of unnecessary antibiotic use. The quantitative analysis demonstrated that 20% of articles about sepsis highlighted the need for early antibiotics, but understanding how these messages are communicated, and how this might influence audience reception, requires exploration of the latent content i.e., the context in which this solution is presented. In the next chapter, I explore the underlying messages contained in a subsample of the articles about sepsis that frame the issue episodically, using case histories about affected individuals.

Chapter 5 Findings of qualitative analysis

The qualitative analysis draws upon five themes from 140 articles and includes personal narratives about 52 different children (see Appendix 11). The findings in this chapter are presented in relation to the five main themes. Typical quotations are provided to illustrate the analysis.

5.1 Sepsis: the silent deadly killer

The language used to describe sepsis in the articles in the sample is woven throughout with references to its ability to kill, leaving the reader in no doubt about the seriousness of the threat that it carries (Table 5). Not only is it deadly; it is silent, it is fast, and it is common.

'Silent killer', the most frequently used descriptor, conveys the often charlatan nature of the condition, which can masquerade as a trivial self-limiting illness before suddenly launching a ravaging attack on the body, destroying organ systems and setting the victim on a trajectory to certain death if treatment is delayed. The familiarity of these initial symptoms makes them even more terrifying; 'simple sniffles', 'common colds' and 'tummy upsets', all frequent and usually unremarkable episodes within the normal parenting experience, are provided as examples of the first indications of terrible events to come. Not only are these initial symptoms apparently minor; they are also disparate in nature, arising as sequelae of infections that begin at different sites within the body.

The speed with which these illnesses, so much a part of normal childhood as to be almost insignificant, can render the sufferer moribund seems intended to evoke dread. Sepsis 'can develop rapidly following even the mildest of infections' (Daily Mail 9 Feb 2016), taking hold with 'devastating swiftness' (Daily Mail 14 June 2016) and 'terrifying speed' (Daily Mail 16 Feb 2018) and leading to 'rapid death' (Express 9 Feb 2016) in children who had appeared no more than mildly unwell just hours before. One parent, mother of three-year-old Samuel Morrish, describes how it took the life of her child in 'what felt like an instant.' (Sue Morrish, Daily Mail 14 Sep 2016)

Table 5 Descriptions of sepsis in UK newspapers

Silent killer
Every parent's worst nightmare
Devastating condition
Cruel, ruthless condition that doesn't discriminate and can affect anyone
Deadly illness
Common but lethal infection
Horrible disease
Fast moving and deadly condition
Extremely common and massively dangerous
Leading cause of avoidable death in UK
Severe and life-threatening condition
Killer by stealth

Along with William Mead's story, reporting of Samuel's death, which occurred in 2010, seems pivotal in the transformation of sepsis in the media from a rare and unpredictable occurrence that, while tragic, was unlikely to be of concern to most parents, into a threat that must be heeded by everyone. According to his parents, "We were told that Sam had died of something rare, fast-acting, hard to spot and therefore very hard to treat." (Sue and Scott Morrish, Guardian 19 July 2016). This would turn out to conflict with professional opinion from other sources; a subsequent investigation carried out by the Healthcare Ombudsman concluded in 2014 that Sam's death could have been easily prevented with antibiotics and criticised the initial internal enquiry for failing to be open to this conclusion.

Prior to this case, sepsis is framed as a tragic but uncommon occurrence that seems to be presented as worthy of media attention precisely *because* of its nature as an exceptional event. In earlier articles, it seems there is nothing to be done but sympathise with the families of these unfortunate victims, and certainly no recourse to blame. Following the enquiry into Samuel Morrish's death, a paradigm shift can be observed in how the healthcare system's response to how sepsis is viewed. Two articles that report deaths of children who died in similar circumstances evidence this change. In both cases, sepsis developed as a complication of chickenpox, and in both the child was repeatedly reviewed by doctors who reassured their parents that there was no cause for alarm. In the first case, which occurred in 2006, when this reassurance proved to have been tragically misguided, the outcome was presented to parents as regrettable but unforeseeable:

"The doctors said this could happen in one in a million cases and unfortunately we were that one.' (Hayley Graham, Daily Mail 23 May 2006)

In the second case, which occurred a decade later, the aftermath is entirely different, with expressions of anger from the parents at repeated failures to diagnose this rare but recognised complication of a common illness:

"We were treated very badly. They should have done tests. Any doctor should know it is an infection. They need to take sepsis more seriously. They didn't listen to us." (Alex Kasota, Daily Mail 3 Dec 2016)

In this case, the NHS trust admitted liability for the child's death, with and an out of court settlement was awarded. The parents' lawyer summed up the events as 'a tragic case of a girl whose life could have been saved.' (Sue Jackson, Daily Mail 3 Dec 2016)

Post-Sam, then, sepsis is no longer framed as rare but is 'the leading cause of avoidable death in the UK' (Daily Mail 23 May 2017). Numerous headlines proclaim the true extent of its previously untold impact, now contextualised in relation to the impact of other prominent conditions: "it affects more people than bowel, breast and prostate cancer combined" and every year "kills an estimated 44,000, of whom 1,000 are children." As Melissa Mead states starkly: 'that's not rare.' (Daily Mail 23 May 2017)

5.2 The victims: needless deaths

Although many articles acknowledge that sepsis is indiscriminate and can affect anyone, even those in good health, children are identified as one of the population groups at increased risk:

'It can strike previously healthy patients of all ages, but is most common in young children, pregnant women, the elderly and those with underlying illness.' (Daily Mail 3 March 2016)

Many articles refer to the proportion of mortality that occurs in children, and compounding the sense of tragedy within these stories is the recurrent theme of deaths from sepsis as avoidable, with the word 'needlessly' frequently used in relation to children who have died:

"11 babies and a mum needlessly died. How can it not be criminal?" (Sun 4 March 2015)

"I was touched deeply when I read about the anguish of parents who had lost children to sepsis… What hit me hard was the knowledge that kids had died needlessly." (Lord Ashcroft, Daily Mail 3 May 2016)

The positioning of these deaths as largely avoidable is not simply a result of journalistic endeavour to identify potential areas of conflict that may spark interest in the reader, but is reinforced by stakeholders within the health sector, most notably the Sepsis Trust, whose opinions feature frequently. Here, there is criticism of a perceived delay by the UK Government in establishing an awareness campaign, which was first pledged in 2014, with deaths from sepsis that have occurred since seemingly attributed directly to this delay:

"In all, says The UK Sepsis Trust, 55,000 adults and children have died of sepsis (in the past 14 months) since Mr Hunt pledged to act, of whom at least 16,000 could still be alive today if loved ones had known what to look for." (Daily Mail 15 March 2016)

Headlines that refer to deaths in children, already emotive by virtue of their subject matter, are made more so by the use of 'little', a seemingly extraneous descriptor that serves no purpose other than to compound the sense of tragedy for the reader:

"Sepsis and the little ones who should never have died" (Daily Mail 15 March 2016)

"One more little victim of a killer doctors are ignoring" (Daily Mail 9 Feb 2016)

Although reporting on unexpected deaths is inherently distressing, there is an added sense of loss for the reader in being confronted with sudden deaths in children. Several articles concerning deaths in older children paid tribute to their character by detailing their contribution to their school or local community, giving the sense of a future full of promise that had been snatched away.

5.3 The health service: a multitude of failures and inadequacies

Descriptions of the health service's management of sepsis in the articles in the sample is almost universally critical (Table 6). Much of the criticism is directed at the out of hours services NHS 111 (now NHS Direct), particularly in relation to William Mead's death; an enquiry led by NHS England into the circumstances surrounding his death concluded that the algorithms used by call handlers were inadequate for identifying sepsis in infants and children. The service is described as 'plagued by problems' (Daily Telegraph 27 Jan 2016) and 'bedevilled by failures' (Daily Mail 27 Jan 2016) and of no benefit to parents expecting to receive quality advice. In one editorial feature, the apparently non-systematic nature of advice given to concerned parents is observed:

"You might as well just ask your neighbour over the garden fence what they think you should do, or simply flip a coin." (Daily Mail 27 Jan 2016)

This view echoes sentiments expressed by Melissa Mead in an earlier article:

"I probably could have got more information from Google." (Melissa Mead, Daily Mail 29 Sept 2015)

The tone of these articles seems intended to undermine the reader's confidence, with several articles describing it as 'not fit for purpose.' One article reports how Health Secretary Jeremy Hunt himself admitted to bypassing the service, having told fellow MPs "I took my own children to an A&E department at the weekend precisely because I did not

want to wait until later on to take them to see a GP." (Jeremy Hunt, Daily Mail 27 Jan 2016).

Many articles highlighting the minimal training most call handlers receive before joining the service, which 'even employs teenagers who have just finished their GCSE exams' (Daily Mail 7 Sep 2016). One headline declares that the employee, whose handling of Melissa Mead's call the evening before William died was heavily criticised, is 'now training hotline staff' (Daily Mail 15 Feb 2016). In fact, in reading the body of the article the reader learns that he has been attending training sessions to share his experience with staff. This is entirely fitting with an organisational approach that puts clinical governance and shared learning at its core, however the headline seems intended to convey that the opposite is true.

Criticism is not however confined to NHS 111: "it's not just one rogue element of care that led to this tragic situation but a multitude of failures and inadequacies that point to a far bigger problem… this was only one weak link in a chain of care that is rusting and falling apart." (Daily Mail 27 Jan 2016).

Table 6 Descriptions of the NHS in the context of managing sepsis
Catalogue of mistakes
Catalogue of failings
Catalogue of errors, misdiagnoses and missed opportunities
Series of shameful blunders
String of NHS blunders
String of scandals
Multiple blunders
Shocking and truly scandalous tragedy
Next to useless
Not fit for purpose
Disastrous failure
Bombshell report
Inexperienced or incompetent

> Fobbed off with paracetamol
>
> Bedevilled by failures
>
> Whitewash
>
> Wall of silence
>
> Pompous and defensive
>
> Plagued by problems
>
> Truly, exceptionally bad
>
> Dysfunctional culture
>
> Obstruction and obfuscation
>
> Just one weak link in a rusty chain that's fallen apart

In William Mead's case, he had attended primary care with his parents several times in the months leading up to his death. This is reported repeatedly, and numerous articles detail similar instances of children sent home from Accident and Emergency (A&E) or primary care with reassurance that would turn out to be misplaced, or diagnoses that were inaccurate. Often these failings are attributed to inadequate knowledge and understanding about presenting signs:

"…awareness among medical professionals and the public is worryingly poor, delaying life-saving treatment." (Daily Mail 3 May 2016)

While highly concerning, this at least seems remediable. However, many articles are more caustic in their criticism, blaming dismissive attitudes of healthcare professionals that result in concerns being overlooked. 'Patronising' doctors are described as giving 'cursory examinations' (Daily Mail 18 Aug 2017); concerned parents are dismissed as 'overprotective' (Daily Mail 27 Jan 2016), 'paranoid' (Daily Mail 7 March 2018) and, in an earlier article, which was atypical for the time, simply seen as a 'nuisance' (Daily Mail 26 Jan 2007). For another child, who survived but underwent multiple amputations after developing sepsis as a complication of minor burns, staff were 'too arrogant' to consider sepsis as a diagnosis, even after his mother raised it as a possibility (Mail on Sunday 21 Aug 2016).

Even in the aftermath of tragedy, there are no assurances that the principles of clinical governance will prevail. Instead, multiple examples of apparent 'cover ups' are reported. Criticism of how enquiries were conducted range from accusations of an apathetic approach to blatant attempts to deceive. Julie Mellor, Health Services Ombudsman, describes how relatives frequently encounter a 'wall of silence' when endeavouring to understand the circumstances surrounding a family member's death (Daily Mail 1 March 2016). The parents of Sam Morrish describe the resigned attitude that they encountered in the aftermath of his death: "When we asked why Sam had been sent to the wrong hospital, shoulders were shrugged. When we asked why, after five months, investigations hadn't been completed, we were told 'don't (sic) pick a fight with the NHS: you won't win'" (Sue and Scott Morrish, Guardian 19 July 2016).

One article headlined 'the boy sent home to die of sepsis' describes the case of a nine-year-old boy who died six hours after being discharged from hospital following a 'two-minute consultation' at an overcrowded A&E department (Daily Mail 1 March 2016). During the enquiry into his death, his parents met with consultants who they described as 'pompous and defensive' and discovered that the consultant who assessed him on his initial presentation to hospital had considered sepsis as a possible diagnosis but withheld this information from his relatives because 'they were only laypeople who wouldn't understand.' Subsequently, the junior doctor who discharged him was suspended on suspicion of having fabricated clinical notes that suggested the child's observations were within normal limits. His mother is quoted as saying "I never thought there would be so much deceit over a child's death."

In another case reported in several newspapers, Olympic athlete Allyn Condon describes a series of apparent failings by healthcare staff prior to his baby son's death in hospital. The infant, who had been born prematurely but discharged home, was readmitted with respiratory symptoms. Despite repeatedly conveying concerns that his son was more unwell than staff realised, Mr Condon describes his fears being dismissed and assurances given that he had no more than a 'cold' (Guardian 21 June 2016). Following his death, Mr Condon and his wife asked to review his case notes and discovered discrepancies between the hospital records and what they had been told; blood samples that should have been sent to exclude bacterial infection had not been taken and instructions to administer antibiotics if his condition did not improve were not actioned until minutes before his death. When his parents met with hospital consultants after his death to discuss his management, they

inadvertently recorded a discussion on their mobile phone in which one of the consultants is heard to uphold their concerns:

"… they (the Condons) are absolutely right. These are not bolshy, these are not misinformed parents, are they?" (Mail on Sunday 6 Dec 2015)

Suddenly realising the conversation was still being recorded by the hospital machine, but unaware of the Condon's mobile phone, the other consultant is heard asking whether it would be possible to delete the comment because 'that could get us into difficulty.' The conversation continued in hushed tones, and with a finger apparently placed over the microphone, while they discuss the confusion surrounding why the infant did not receive antibiotics, before 'reverting to a perfectly audible voice' and acknowledging that he may have died even with the antibiotics. Although the hospital allowed the family access to the full transcript, Mr Condon believes the recording would have been edited had they not also recorded the conversation on their phone. Reporting of this episode demonstrates the complexity, uncertainty and potential conflict that surrounds prescribing decisions about antibiotics, even for professionals working within an acute care setting.

The most high-profile example of criticism associated with healthcare management surrounds the case of Dr Bawa Garba, who was the junior doctor convicted of manslaughter in a case that centred around her failure to diagnose sepsis in a 6-year-old boy, Jack Adcock. Jack presented with vomiting and diarrhoea and was diagnosed with gastroenteritis; when he suffered a cardiac arrest several hours later, he was mistaken for another patient who had a 'do not attempt resuscitation' order in place which caused resuscitation attempts to be paused in error, although this was not believed to have contributed to his death. Bawa Garba was charged with Jack's manslaughter, and the criticism levelled at her management of Jack widely reported. Her actions were described 'truly, exceptionally bad' (Daily Mail 5 Nov 2015), as having "robbed Jack of his chance, his probability of survival" (Daily Mirror 7 Oct 2015) and as having 'pushed him to the point of no return' (Daily Mail 5 Nov 2015). His father is quoted as follows: "Had he been given the correct treatment we know 99.9 per cent he would have still been here. It's totally disgusting' (Daily Mail 5 Nov 2015).

A subsequent GMC decision to remove her from the medical register sparked concern among doctors' groups about implications for practice. Further details were reported regarding the complex system failures that impacted on events on the day of Jack's admission: staff shortages, IT failures and failed communications about medication

between Bawa Garba, the nursing team and Jack's parents were all found to have played a part in the events that culminated in his death. There followed an outpouring of public support from Bawa Garba's peers. The GMC's decision has now been overturned, although her conviction for manslaughter stands.

5.4 The parents: obligatory advocates in the face of medical incompetence

Many articles contain highly emotive accounts from affected families regarding the devastation that sepsis had wrought on their lives:

"Our life now is empty, painful and will never be the same again. To say that we miss him does not do justice to our strength of feeling - Jack was an amazing son and one in a million." (Daily Mail 5 Nov 2015)

"I feel like my heart has stopped beating. When I wake up, I think I can't go through a whole day. I'm devastated. I just feel empty." (Express 25 Jan 2011)

"The hardest thing was closing the (coffin) lid and saying my last goodbye. When you lose a child, you lose their future and your future. There's no tomorrow. You just get through to the end of each day." (Daily Mail 27 Oct 2016)

Similarities can be drawn here with victim impact statements used within the justice system to allow the impact of a crime on victims and their families to be taken into consideration during sentencing or parole hearings (169). This perhaps serves to reinforce the idea of the transition of deaths of previously well children from sepsis from something tragic yet unavoidable to the result of a criminal act.

Alongside the powerful descriptions of grief experienced by parents are insights into other emotions; anger, particularly when bereaved parents learn that others have lost children in similar circumstances, bringing the sense that their precious child died in vain; alongside feelings of regret that different actions could have altered outcomes.

For Melissa Mead, "the worst thing in the world is knowing that his life could have been saved" (Daily Mail 26 Jan 2016). Allyn Condon asks himself, "what could I have done differently?" (Daily Mail 15 March 2016) and another parent "wishes (they) could turn back the clock" (Express 9 Feb 2016). Another parent, whose son has chronic disabilities after she developed sepsis while pregnant, told how with the awareness she now has, she would "have spent more time yelling at doctors" (Daily Mail 11 April 2017). In all of these

cases, parents had consulted doctors about their child's symptoms, sometimes repeatedly, but when it comes to recognising sepsis, the message is that this may not be sufficient.

One article warns "… it doesn't matter how diligent or loving you are, you still can't protect your child from institutionalised incompetence… the death of William Mead should never be forgotten. Not just because it exposes gaping holes in NHS care, because it unites us all as parents" (Daily Mail 27 Jan 2016).

The impact of this message is to shift responsibility on to parents, obligating them as advocates for their children where health professionals may fail. This is a role that is sanctioned by both experts and by fellow parents. Ron Daniels, Chief Executive of the Sepsis Trust, spoke of the need to 'empower' parents to recognise symptoms so that they can seek treatment immediately and be able to raise the question of sepsis if doctors do not: "We would urge parents to always trust their instincts and ask a medical professional, 'could it be sepsis?'" (Guardian 15 Dec 2011). The mother of a baby who died after repeated reassurance that there was nothing seriously wrong warns parents: 'A mother's intuition is key - the doctor is not always right' (Daily Mail 18 Aug 2017). The message here is that parental instinct is a tool that parents have at their disposal for which no amount of medical training can substitute.

But when parental instinct fails, there are terrible feelings of guilt, and some parents express the feeling that by accepting the judgement of health professionals they have been somehow complicit in their child's death. The mother of one child who died after being diagnosed with a simple ear infection said: 'I should have known but I trusted them' (Daily Mail 4 June 2018).

The actor Jason Watkins has spoken on many occasions about the loss of his two-year-old daughter Maude and says "you feel terrible guilt. We must have done something wrong… of course we didn't but part of you will always feel that (Daily Mail 9 Feb 2018). His wife is described as 'unable to shake the conviction that she is somehow to blame… "you have one job, to stop your child dying, and I couldn't do that."'

Jason Watkins urges fellow parents "My message to anyone is, even if there are just one or two symptoms, get straight down to A&E" (Express 9 Feb 2016).

The need to prevent others falling victim to the same fate imbues the warnings to other parents with an imploring quality and a sense of urgency, captured in this plea from Melissa Mead: "I will never hear my sweet child say, 'Mummy, I love you.' I will never

know the man that William would have grown to be. So please, it is too late for me to 'think sepsis' but it's not too late for you." (Guardian 15 Dec 2016)

Listening to parental instinct then (for parents themselves and health professionals), is the key to safeguarding against harm from this fast-moving, terrifying threat – but only until it fails. The parents who have experienced unimaginable losses find themselves newly in possession of knowledge about sepsis, only to discover that it doesn't necessarily provide them with agency to make confident decisions when their other children are unwell. Parents describe experiencing crippling self-doubt and being in a permanent state of worry about any childhood illness, however trivial. This is understandable based on the terrible loss they have endured, but also undermines better awareness as the alluring solution promised:

"When either of my kids gets any sort of illness, I'll go from being a normal human being to thinking they're going to die, even if it's something really minor. I think, "If it can happen once there's no reason to believe it can't happen again", so I live in a permanent state of insecurity" (Daily Mail 9 Feb 2016).

Melissa Mead, who gave birth to a second son in 2016, is described as 'beset by worries' when he is unwell: "Until (he) can talk I'll always assume the worst if he grizzles or has a cough or a temperature. Even though I know so much about sepsis now, there's always the fear I'll miss something' (Daily Mail 27 Oct 2016).

The terrible experience of losing a child unexpectedly to sepsis can alter not only the parent's response to health but their whole world view. Here, Clara Watkins describes this change as a loss of innocence:

"Before, I was innocent. I trusted the world. I trusted doctors. I trusted that if you were good, good things would happen to you. I was wrong" (Daily Mail, 9 February 2016).

5.5 Antibiotics: the simple solution

One of the most powerful messages in the articles analysed is the relative ease with which the terrible outcomes described could have been prevented by 'a simple dose of antibiotics', a phrase used in several articles and alluring in its apparent simplicity (Table 7). Antibiotics are presented not simply as one facet of treatment for sepsis but as the only one. 'If it is caught early, antibiotics can control the infection. If not, there is little doctors can do' (Daily Mail 25 May 2017). The consequences of treatment delays are recounted repeatedly, giving a sense of pivotal moments where treatment decisions mean the

difference between life and death. One article describes how William Mead's 'fate was sealed' by failure to refer him to hospital where he could have received the antibiotics that may have saved him (Guardian 26 Jan 2016). For Maude Watkins, as her parents observed her condition deteriorate following discharge from hospital the previous day, eventually arriving at the decision to re-attend, 'the window of opportunity to save her life was fast closing' (Daily Mail 9 Feb 2016). This time, she was given antibiotics but 'it was almost certainly too late for (the antibiotics) to have had any impact on the condition." This highlights the uncertainty regarding the point at which 'too late' occurs. This is important, because the message here is that treatment started once a child is very obviously unwell may be futile, which could be interpreted as a suggestion that treatment at an earlier stage (i.e., in primary care) may have averted the situation. In fact, this is precisely the verdict that the NHS England enquiry into William Mead's death reached. Repeated warnings about the dangers of delays in starting treatment are thus presented alongside uncertainty about when those delays can be considered to have occurred.

Table 7 References to 'a simple dose of antibiotics' in reporting of sepsis in UK newspapers

A simple jab of antibiotics would have saved him. (Mail on Sunday 29 Nov 2015)

Knowing that a simple course of antibiotics could have saved him is something his parents will have to live with for the rest of their lives. (Daily Mail 27 Oct 2016)

Blessing Matia's death could have been prevented with a simple dose of antibiotics if medical staff had been able to identify the condition. (Daily Mail 3 Dec 2016)

Experts said he would "probably" have survived if he had been given a simple dose of antibiotics. (Daily Telegraph 13 Feb 2016)

Not only do parents have to potentially fight to convince medics that symptoms may be serious, but they then have to navigate securing an antibiotic prescription, potentially creating conflict with doctors who are described as under 'constant pressure' not to prescribe (Guardian 26 Jan 2016). One article, more sympathetic in tone than most, refers to the conflicting priorities that doctors working in primary care face:

"(GPs) are in an impossible bind. On one hand they have cases like this where they are heavily criticised for not prescribing antibiotics in time. While on the other they are constantly criticised by health officials like the Chief Medical Officer Dame Sally Davies -

dubbed the nanny-in-chief for her diktats on how we should lead our lives - for prescribing antibiotics" (Daily Mail 27 Jan 2016).

This same article, while giving the semblance of presenting a balanced representation of the dilemma that faces practitioners, concludes that in light of the findings of the enquiry into William Mead's death, "surely it is better to err on the side of caution?" GPs may be 'in an impossible bind,' but there seems little room for ambiguity for the reader that the 'right' choice is prioritising the welfare of the individual.

It is notable that none of the articles that refer to pressure on GPs not to prescribe antibiotics connect this with efforts to reduce resistance, which is in keeping with the findings of the quantitative analysis. Instead, it is grouped alongside issues about managing resources, so that withholding antibiotics is placed as on a par with avoiding referring patients to crowded A&E units. This frames antibiotics as a treatment that patients may be denied *in spite* of the benefits they might confer rather than *because* of the harm that unnecessary treatment may cause. The small number of articles that do mention growing resistance to antibiotics do so in relation to its potential contribution to the overall burden of sepsis, but fail to acknowledge the paradoxical messages sent out about prescribing.

"Numbers (of sepsis cases) have leapt more than 50 per cent in five years, with experts partly blaming GPs' over-prescription of antibiotics" (Daily Mail 3 March 2016).

This creates a potentially confusing message for the audience, with health professionals to blame as individuals for failing to prevent deaths from sepsis by prescribing rapid antibiotic treatment where it may have been helpful, but also as a collective for creating the problem of resistance in the first place.

5.6 Discussion

Qualitative analysis of articles that contained narratives about sepsis in children revealed a picture of a previously unseen epidemic of deaths from sepsis, the result of a failing health service that can and must not be relied on to provide the care necessary to prevent death and disability. By relating the most dominant frames to the recognised media triggers described previously, it becomes apparent why sepsis has commanded such extensive and sustained press coverage; human interest elements, blame and cover-ups are all central to sepsis' narrative as constructed within UK newspapers. The various actors involved form an almost pantomime-esque ensemble: innocent and vulnerable children as the victims; arrogant or ignorant doctors acting with self-interest and failing in their duty to protect them; and parents, the reluctant heroes who must fight their corner. Blame is a dominant

theme, with accusations of cover-ups involving health professionals featuring heavily, particularly in more recent articles. This demonstrates a shift over a relatively short period of time in how death from sepsis is conceptualised, from something tragic but unpredictable to the result of dire failures in diagnosis and management that are inexcusable. This has the effect of framing sepsis, previously an unfortunate but accepted complication of infection, in the same way as the established list of 'never' events that should be preventable in a modern healthcare system (170). This shift in tone also betrays the uncertainty surrounding sepsis that exists within the medical profession itself. Such conflict is identified as one of the 'fright factors' that has the capacity to increase concern about a reported health risk (171).

Personal narrative stories involving children were of interest in this qualitative analysis for several reasons. Presentation of health issues as posing a particular risk to young children has been identified as a further 'fright factor' capable of inducing audience fears; in the quantitative analysis, articles about sepsis were twice as likely as those about AMR to present children as particularly vulnerable. Additionally, clinical factors associated with assessing children in primary care make this population an important group where avoidable prescribing may occur. Respiratory tract infections are the most common presentation in primary care among children under 5 years of age and the most common indication for antibiotics. Decisions about antibiotic prescribing are often complex and influenced by non-clinical factors, including the clinician's perception of what parents or carers expect (168). Furthermore, NICE guidance on sepsis (which urges health professionals to consider sepsis as a diagnosis in any patient presenting with infection) acknowledges that assessing young children is challenging due to age-related differences in physiological parameters (i.e., heart rate, respiratory rate and blood pressure) that form an important part of clinical assessment but that may be more difficult to interpret for general practitioners who do not have specialist paediatric experience (10). Finally, shifting constructions of what it means to be 'a good parent' position parents as responsible for considering and avoiding every potential risk to their child's wellbeing (172, 173). Constructions in newspaper reporting of children as an at-risk group has the effect of positioning sepsis as another risk that parents must familiarise themselves with in order to know how to protect their own child.

If the findings of the quantitative analysis of articles about AMR and sepsis offer a behaviourist perspective (Chapter 3) (i.e., what might the impact of media framing be on antibiotic use), then qualitative analysis of the themes within reporting of sepsis may offer

a humanist one; i.e., what insight does the media's construction of sepsis as a new and substantial threat to our children's health give us into the society in which they are produced? Other commentators, most notably Susan Sontag, have commented on the use of metaphor in media reporting of certain illnesses, describing how they can develop meanings that seem to extend beyond the disease itself:

'Nothing is more punitive than to give a disease meaning – that meaning being invariably a moralistic one. Any important disease whose causality is murky and for which treatment is ineffectual tends to be awash in significance… the disease itself becomes a metaphor. Then, in the name of the disease, that horror is imposed on other things.' (174) (p58)

Sontag identified certain characteristics of diseases that lend themselves to use as metaphors for other themes. For example, such diseases have causes that are not fully understood:

'All diseases for which the issue of causation has been settled, and which can be prevented and cured, have turned out to have a simple physical cause – like the pneumococcus for pneumonia, the tubercle bacillus for tuberculosis (TB), a single vitamin deficiency for pellagra… the notion that a disease can be explained only by a variety of causes is precisely characteristic of thinking about diseases whose causation is not understood. And diseases thought to be multi-determined (that is mysterious)… have the widest possibilities as metaphors for what is felt to be morally or socially wrong.' (174) (p60-1)

Sontag charts how as the causality underlying a disease process becomes apparent, so it loses its capacity to evoke fear and dread. They explain how TB was once regarded as… 'a mysterious affliction… with myriad causes – just as today… everyone acknowledges cancer to be an unsolved riddle'. Such uncertainty lends the disease a sense of mystique; for example, the very word 'cancer' is loaded with meaning and was once considered taboo. Sontag points out how this contrasts with other diseases that are equally likely to kill but not afforded the same reverence, for example, ischaemic heart disease, which she attributes to a more developed understanding of its pathophysiology. They go on to describe how cancer is 'not one but more than a hundred clinically distinct diseases, that each cancer has to be studied separately and that what will eventually be developed is an array of cures, one for each of the different cancers.' This has proved to be increasingly accurate; genes are isolated that can predict familial risk of certain cancers allowing early preventative intervention, and experts frequently advocate redefinition of certain cancers based on molecular classification rather than tissue of origin (175). Increasingly, the

mystery of cancer in its previous incarnation as a single entity is unravelled and, with it, its power to induce fear and dread.

Writing a decade on, Sontag describes how, as predicted, attitudes have evolved, with a diagnosis of cancer no longer having the stigmatising effect it once did (176). This, they attribute in part to the emergence of HIV and AIDS, whose capacity for stigmatisation was even greater, evoking the 'thoroughly old-fashioned forms of dread' that cancer and TB once did (p11). According to Sontag 'societies need to have one illness which becomes identified with evil, and attaches blame to its 'victims', but it is hard to be obsessed with more than one' (p16).

A second feature is that the disease needs to have the capacity to 'single out' victims rather than affect whole communities. As an example, Sontag describes how historically TB was understood as a 'mysterious disease of individuals, a deadly arrow that could strike anyone, that singled out its victims one by one' (p38). This contrasted with other epidemics (typhus, cholera) that affected each victim as a member of an afflicted community. Thus, the degree of fear it imbued was not lessened by its high incidence within the whole population, but related to how it affected the status of an affected individual within their own community. Third, the most terrifying illnesses are not just lethal but dehumanising, associated with rot and decomposition, with those that affect skin colour or appearance of the face particularly powerful, such as leprosy (p38-41). Fourth, Sontag describes how, where diseases are poorly understood, there is frequently a desire to find somewhere to channel blame. In the case of plague, people 'invariably looked for a scapegoat external to the stricken community', culminating in acts of mass genocide against Jewish communities (p71). For modern diseases, suggests Sontag, 'the scapegoat is not so easily separated from the patient'. Cancer has been historically positioned as the outward manifestation of negative emotion; Sontag describes psychological theories of illness as a powerful means of placing the blame on the ill. More recently, language around the 'fight' against cancer (or today, 'stand up to cancer') positions the sufferer as responsible for their own cure. 'Ostensibly, the illness is the culprit. But it is also the cancer patient who is made culpable' (p57). Regarding AIDS, blame can be seen as extending beyond the individual and to whole groups within society; as illustrated by summarising at risk groups at the outset of the epidemic using 'the 4 Hs' (haemophiliacs, heroin users, homosexuals and Haitians) (177). According to Sontag, such 'master illnesses' are specifically polemical, with modern metaphors suggesting 'a profound disequilibrium between individual and society, with society conceived as the individual's adversary' (p73).

In addition, the nature of the disease process as described in many of these narratives, and the speed with which sepsis exerts its devastating effects on fit and healthy individuals, enable it to 'arouse a particular type of dread'. This capacity to cause visible bodily destruction, with those who survive often undergoing multiple amputations, also resonates with features described by Sontag as likely to bring punitive meaning to a disease. Other explanatory features that Sontag describes can be identified; not only is there an absence of a single cause but the range of potential causes are seemingly so myriad as to include every childhood illness that parents may encounter. Although sepsis is recognised as a process rather than a disease, the causative organisms that underlie the initial infections that led to sepsis are rarely alluded to. Instead, the wide range of infectious processes responsible for the outcomes described are presented as though they are one entity. In effect, this is the reverse process that Sontag describes as having occurred for understandings of cancer in recent decades. In a clinical setting, recognition of sepsis as a single disease process aims to improve not only early recognition and management at the frontline of care, but also accuracy of recorded diagnoses and therefore monitoring and surveillance. However, for a public audience, a focus on sepsis to the exclusion of the conditions and organisms that underlie it may not be the most effective way of facilitating useful understandings about how it might present, or understandings about infectious disease processes in general terms.

The apparently indiscriminate way common infections may herald sepsis singles out not only its victims but their families too, with parents thrust into the unimaginable position of losing a child to an illness they were reassured was trivial. In some articles, there is a sense that failure of parental instinct in recognising that their child was seriously unwell in some way compromises their identity as a good parent. Furedi has described how modern constructions of what it is to be a good parent is dominated by parental determinism, with almost every element of parenting a potential source of harm and the wrong decision, even well intended, potentially met by judgement from peers (173). Being seen to be complacent with the welfare of one's child becomes a source of risk, not only for the child, but for the reputation of the parent. Several commentators have described how choices about infant feeding have a role in establishing the moral identity of mothers. Using formula in place of breast feeding may be seen as deviation from what is recommended as best practice, compromising the mother's image as acting in child's best interests and risking 'spoiling' of their identity as good mothers (107, 178, 179). According to McHugh, behaviour can only be labelled 'deviant' if conditions of conventionality (i.e., one could reasonably comply with the 'best' practice) and theoricity (i.e., one is aware that they are

breaking the rules by rejecting this practice) are met (180). In other words, acting in a way that contravenes accepted best practice may be excused if a convincing defence can be mounted, or simply by claims of not knowing any better. Murphy explains how, in this way, mothers who choose not to breastfeed can avoid charges of deviance if they can demonstrate that this decision is related to some alternative moral good; the need, for example, to return to employment, or a desire to allow their partner to be more actively involved in the feeding process (107).

 Relatively little evidence is available about the potential for parental decision-making in response to childhood illness to impact on moral identities. Prout identified that parents of school age children walk a line between being seen as overindulgent or uncaring in judging whether a child who complains of feeling unwell should attend school, while Cabral identified the desire to avoid social disapproval as a key motivator in primary care attendance i.e., the subjective norm is that parents ought to consult when a child is unwell (181, 182). Murphy explored parents' experiences of stillbirth and describes how mothers lose not only their child but potentially their identity as a moral mother who is able to protect and nurture her baby' (108). She describes how identity as a 'moral mother' begins even before birth, with a requirement to take, or abstain from, actions that will protect or harm the foetus during in utero development. Advice around diet, alcohol and smoking not only aim to modify behaviours but effectively label mothers as 'good' or 'bad' depending on whether they are willing or able to modify their identity to 'fit' with society's ideal, which may require significant departure from their usual identity, sometimes with limited justification. For example, even though there is no evidence that consuming moderate amounts of alcohol has any detrimental impact on foetal development, official advice from the Department of Health, and thus society's expectation, is for complete abstinence. According to Murphy, those individuals who publicly fail to comply with this advice run the risk of stigmatisation and compromise their identity as a responsible parent. For parents who had experienced stillbirth there was an even greater imperative to distance themselves from potentially harmful behaviours. Murphy describes how 'the death of a baby brought with it the danger that others might think that mothers were in some way to blame. Losing the veneer of maternal competence… is a risk… especially in cases where the stillbirth was unexplained.' Some mothers described how family members articulated that they felt they (the mothers) must be to blame; others described how any deviation from usual antenatal care (for example, declining ultrasound scans or opting for a home birth) was met with discrimination, even by mothers who had experienced similar losses. However, attribution of stillbirth to failures within the healthcare system offered protection against charges of

deviance. For example, one mother whose child died during labour won a negligence case against the hospital and remarked "I'm lucky. I have nothing to feel guilty about.' The implication here is that if the healthcare system is not to blame then it is maternal behaviour that is at fault, even though most intrauterine deaths are unexplained. Murphy concludes that woman who experience stillbirth must undertake 'identity work' to distance themselves from behaviours associated with an immoral mother.

No literature has been identified that explores how the loss of babies or children from acute illness impacts on parents' moral identity. For many parents in the articles in this sample, the guilt associated with their perceived failure to recognise the gravity of symptoms in a child with sepsis seemed overwhelming. This may be in part what drives the need to apportion blame to another source and to seek to raise awareness in others; in doing so, demonstrating that conditions for deviance, conventionality and theoricity are not met i.e., they could not reasonably have acted differently because they were reassured by experts that there was no need and, in many cases, weren't even aware of the word 'sepsis' let alone the presenting symptoms. Through the warnings issued to fellow parents, bereaved parents can restore some of their parental identity, as well as creating a legacy for their child. Melissa Mead describes how in the re-telling of William's story she can continue to be his mother and speaks of the comfort she finds in being contacted by parents who have told her that William's story may have saved their own children's lives:

"Parents have contacted me through the UK Sepsis Trust to say reading about William helped save their child. It makes me so proud. William will never be forgotten, and I believe he lives on in the lives of every child his story saves." (Daily Mirror 27 May 2018)

The sustained messages about sepsis as a risk to health in UK newspapers as communicated through episodic frames, with often detailed accounts of apparently insignificant events that immediately preceded severe illness or death, provide the audience with what are likely to be highly effective 'primes.' Through these narratives, the reader becomes an active participant by being forced to confront the possibility that they could encounter this same threat that brought sudden devastation to families like their own, potentially assimilating the messages in a way that may help them to safeguard their own children by being ready to challenge the judgement of health professionals. The escalating pattern of reporting ensured both recency and repetition, identified as important in determining whether 'primed' knowledge will be subsequently applied. This was particularly true of articles published in the Daily Mail, whose reporting as part of its 'End the Sepsis Scandal' campaign was organised rather than reactive, often featuring historical

cases that were framed as part of a current 'epidemic. Homogenous voices of both parents and experts, and eventually Health Secretary Jeremy Hunt, in their calls for sepsis awareness, positioned them as powerful frame advocates. While this was the only sound political manoeuvre by the Department of Health following two highly critical reports about care of patients with sepsis within the NHS, the consistent voices of government, health experts and members of the public is likely to be influential in convincing the audience of its importance (102, 183).

The importance placed on instinct or intuition, so difficult to define and yet sanctioned as a vital tool by both experts and parents, seems incongruous with a condition whose diagnosis hinges on specific and measurable physiological parameters. Ron Daniels speaks of the thousands of lives that could have been saved if an awareness campaign had been in place earlier. This message has been highly effective in putting sepsis on the heath agenda, but may be somewhat reductionist, leading to oversimplification of messages about responding to symptoms of sepsis, many of which may be consistent with self-limiting illnesses. Here, awareness seems presented as on par with, for example, funding for a previously unavailable cancer treatment or introduction of a mass vaccination programme. Modelling mortality outcomes on predicted impacts of greater awareness fails to acknowledge the heterogeneity of sepsis as a condition, or the complexity of decision-making when confronted with symptoms that 'might' be early indicators. Furthermore, parents who have lost children (and there can surely be no group more receptive to health messages about sepsis) are by their own admission ill-positioned to make confident decisions when confronted with subsequent episodes of childhood illness. It seems then that 'just ask – could it be sepsis?' may be presumptive in its simplification of a hugely complex condition.

What impact will media coverage of sepsis awareness have? It is highly likely that the raised profile of sepsis as a condition will reduce mortality through earlier diagnosis and management and the huge achievement of campaigners for sepsis awareness in raising its profile must be recognised. Furthermore, there is important learning in how this has been achieved that may be applied to communicating other health issues including AMR, as discussed in chapter 3. However, it should be considered that there is a potential for unintended consequences from press coverage that is almost unwaveringly negative in tone. The blame levelled at those within the medical profession may of course in some circumstances be appropriate, particularly where there are accusations of attitudinal problems or dishonesty. However collectively, the almost universal criticism of medics and

allied health professionals in managing sepsis seems incongruous alongside constructions of sepsis as difficult to diagnose (even for experienced clinicians) and as frequently requiring more than an assessment of the facts presented (i.e., parental intuition). This punitive framing directed not at victims (or their parents) but health professionals and practices within the NHS establishes sepsis as a 'master illness,' as described by Sontag, which represents not only the potential complications of an infectious disease process, but all that is wrong with the healthcare system. The shift in the media's portrayal of sepsis, as handled by medics, is consistent with a shift in how doctors as a professional group are portrayed in popular culture, as described by Lupton:

"Until quite recently, members of the medical profession were most often represented as omnipotent figures who had the power to save lives against all the odds… they were generally portrayed as successful, benevolent, knowledgeable and authoritative, with almost mystical powers to dominate and control the lives of others.' (184)

Laterally, however, Lupton notes that there is an increasing tendency to portray fictional doctors as fallible:

"Television dramas have begun to represent doctors as all too human characters, capable of making mistakes or lapses in judgement under pressure and coping with complicated private lives which sometimes affect their work'.

Lupton identifies this transition as a reflection of increasing erosion of public confidence in the medical profession as the result of high-profile reporting of unethical practices and criminal activity by doctors as individuals. More recently, high profile coverage of systemic failings within various NHS trusts in England have further undermined public confidence (185). Thus, reporting of failures of individuals and systems in managing sepsis is in keeping with reporting that undermines the public's confidence in safe provision of healthcare.

Major concerns have been expressed about the effect that the very public controversy surrounding Dr Bawa Garba's case will have on transparency within the NHS and that it may contribute to defensive practice by doctors who feel they will be left to carry the blame as individuals when things go wrong. Dr Jonathon Cusack, who acted as Dr Bawa Garba's educational supervisor on her return to work, spoke of the impact he had already observed on practice: "I've seen people behaving very defensively for understandable reasons, and trainers across the country are worried it's having an impact because it's such

a high-profile case" (Daily Mail 17 Feb 2018).

Whether this defensive practice will translate to defensive prescribing remains to be determined but seems to be a potential unintended consequence of better sepsis awareness that must be considered. As discussed in Chapters 2 and 3, prescribing in the community is influenced by a wide range of factors that are not related to the severity of presenting symptoms, as perceived by the clinician. These include previous negative experiences associated with not prescribing and perceptions of what outcome the patient (or parent) expects from the consultation. Thus, it is possible that media reporting of sepsis may influence prescribing behaviour either directly, through priming of prescribers' pre-existing knowledge and experiences (i.e., "Patient X might have been another William Mead") or indirectly, through parental assimilation of repeated pleas to challenge medical advice. As discussed in Chapter 3, content analysis of health issues portrayed in the media determine key messages presented to audiences, but not audience response to those messages. To better understand how these messages are understood and what impact they might have on behaviour, a triangulated approach is required. In the next Chapter, I report findings from focus groups in which I explored how messages about sepsis and AMR in UK newspapers and in awareness campaigns are received by parents and carers.

Chapter 6 Focus Group Findings 1

The purpose of this chapter is to describe reflections of parents and carers on how they undertake decision-making about consulting a health professional when their child is unwell. It will cover the following themes:

- the role of parental instinct in recognising illness
- views about how other parents navigate illness
- perceptions about resourcing within the NHS and how these impact on use
- the influence of external factors on decision-making.

6.1 Summary of literature about parental consulting decisions

6.1.1 Recognising normal – a role for mothers

Although the majority of acute childhood illness is managed at home without involving health professionals, most research in this area has focused on children with chronic illness; it has been suggested that 'the very commonality of acute childhood illness seems to have rendered it almost invisible in research terms (186). Neill reviewed literature about family experiences of acute childhood illness in the home, with the aim of establishing how parents identify and respond to acute illness, and their experiences of health services under these circumstances (187). Referencing Irvine and Cunningham-Burley, Neill found that parents assess their children's symptoms in relation to what they perceive to be their 'normal' state of health, which is based on both their prior knowledge about minor illnesses and the unique knowledge they have about their own child (188). Changes in behaviour, for example their usual eating and sleeping patterns, or changes in mood, such as increased irritability, were viewed as more important indicators of illness than specific symptoms, e.g., common cold symptoms or abdominal pain. Similarly, Lupton noted that mothers maintain 'constant vigilance' to fulfil their role as guardians of their child's health, continuously taking mental note of details such as the colour of their skin, energy levels and bowel habits (189). Neill points out that parents' concept of normality is not static but changes over time, with their knowledge evolving alongside their developing child and expanding with subsequent children (187).

In a subsequent study, Neill aimed to identify the psychosocial processes that take place within families when a child is acutely ill at home, and how these influence responses to the episode of illness (186). Families in this study perceived mothers as having primary

responsibility for the care of sick children, both emotionally and practically, while fathers saw themselves as responsible for maintaining their role as provider. Various reasons were suggested as to why this was the case; the importance of maternal instinct, a perception that mothers are more sensitive and responsive to their child's needs, a perception that fathers are less able to manage illness and a belief that children have a preference for their mother when unwell. In Lupton's study, mothers perceived that they had primary responsibility for identifying and managing illness in their children, positioning themselves as having better knowledge of their child's usual behaviour than their partner did (189). Good health was not viewed as a matter of luck but as a controllable outcome, achieved through careful maternal surveillance of their child. This included being instinctive when they felt a change in their child's behaviour or demeanour. She describes how societal norms dictate that mothers" must be able to determine at the subconscious or visceral level if something is wrong with their children… it is the mother's unique relationship with her child which underpins her special knowledge of her child's body: Only she is able to respond instinctively to her child's needs."

6.1.2 'Real' illness – when to consult

In Irvine and Cunningham-Burley's study, illnesses that were of particular concern were those that caused respiratory difficulties or that may be indicative of meningitis (188). Neill describes how parents separate these 'real illnesses' from illnesses that are seen as 'normal'; for example, many symptoms of minor illness were attributed to teething, seen as a normal part of childhood development (186). Similarly, infectious diseases like chickenpox may also be viewed as 'normal' childhood illnesses. In Neill's study, a common desire to 'contain' minor illness within the family unit as far as possible without recourse to seeking advice from health professionals was identified, with most parents positioning themselves as willing to do all they can to manage their child's illness at home. However, there was a belief that 'real' illnesses require that parents seek help. In her earlier review, Neill summarises reasons behind decisions to consult for childhood illness; most of these relate directly to perceptions about the severity of illness, including abnormal or worsening symptoms, and a perception that their own attempts to treat the child have been unsuccessful (187). However, consulting behaviour may also be influenced by factors unrelated to the perceived severity of the illness. In interviews with parents of pre-school children, Kai identified that the possibility that they could fail to recognise when non-specific symptoms could be consistent with meningitis provoked parental anxiety and was a key factor in influencing the decision to seek professional advice (190). The act of consulting was viewed

as a way to share responsibility for their child's illness. In a study of out of hours primary care use, participants describe experiencing episodes of illness that were more serious than initially believed, described by Hopton et al as 'past frights' – these experiences were often used as justification for subsequent consultations, particularly for children (191).

According to Neill, the main need of parents who consulted health professionals was the provision of reassurance and confirmation that they had taken the right course of action and not overlooked anything serious (186). Additionally, there was a desire to have their competence as a mother recognised by health professionals through an acknowledgement that their concern was legitimate. Neill identifies that, just as childhood illness is characterised by uncertainty, seeking help is, for parents, 'fraught with uncertainty of its own' about how this decision will impact on their identity as 'competent' parent, including exposing themselves to criticism for consulting too early or too late (186). Cabral explored views of parents and clinicians about primary care consultations in acute childhood illness (192). Two of the key motivators associated with consulting were the perception of children as a vulnerable group and a desire to avoid social disapproval. Parents in this study identified what Cabral describes as a conflict in subjective norms, with a perception that, in general, patients should avoid using valuable healthcare appointments for conditions that are likely to be self-limiting. Conversely, when a child is unwell, subjective norms demand that parents ought to consult.

6.1.3 Childhood illness as deviance

Prout explored maternal responses to childhood illness in school age children, following up instances of sickness absence in a class of 11-year-olds over two school terms (181). Drawing on the work of Dingwall, he describes how illness may be viewed as a form of deviance; in the case of childhood illness, it falls to the parent, and usually the mother, to mount a defence of her competence if she wishes to retain recognition as a good mother (193). He describes mothers as caught up in a 'paradox of robustness and vulnerability'; on the one hand having normal healthy children is important in establishing their identity as competent mothers, on the other, the 'constant day-to-day stream of minor symptoms that children present are potentially serious, and mothers are therefore required to execute complex manoeuvres in defence of their claim to be a good mother.' In this study, illness was not 'contained' within the family home, in that decisions had to be made about whether to send the child to school (181). Some mothers in this study described how they

felt that their mothering was 'judged and evaluated by teachers' and indicated that they felt 'under surveillance'. Other participants were critical of decisions made by their peers to send their children to school when they were unwell, particularly if the decision was based on requirements to avoid their own absence from work. However, allowing children to remain at home when they were not truly unwell was also viewed as in opposition to the duties of a good mother. Prout describes mothers as walking a tight rope: on the one hand they might be seen as too indulgent; on the other hand, of being uncaring (181).

6.1.4 Maternal employment and childhood illness

In Neill's study, construction of mothers as primarily responsible for managing illness had an impact on their capacity to attend work (186). According to one participant, despite widespread acceptance of the right, or requirement, that both parents work, this comes 'crashing down when a child is not well.' Thus, the gendered expectation that they would take responsibility for managing their child's illness creates uncertainty about 'the right thing to do' in order to fulfil competing responsibilities as mother and employee. Cunningham Burley et al explored constructions of health and illness by mothers in paid employment (194). The impact of childhood illness on mothers' identities as reliable employees is identified: "while establishing that they were not the kind of workers who took time off irresponsibly, respondents had to reconcile this with the gendered cultural expectations to be with their child when s/he was sick" (194). Women described having to demonstrate that they were 'extra' reliable, attending even when unwell themselves, in order to build up goodwill as 'insurance' to be used when they were required to be absent to care for their children. Some participants described trying to foster the same attitude in their children, discouraging absence from school for minor illness; however, if they were then called away from work if their child became unwell, they risked jeopardising their reputation with both their employer and the school; the authors suggest that 'reliable employees must also have reliable children.' Mothers in this study were often unaware of formal policies for sickness absence in their workplace but frequently relied on informal flexible working practices. Having the support of managers was important, but even more so was the observed behaviour of superiors; for example, even where absences to care for children were sanctioned in theory, employees remained reluctant to do so if this was not put into practice by those with greater authority. Childhood illness then, is described as an 'anticipated yet unpredictable event' that represents an ever-present threat to the precarious balance of maintaining home and work identities, but is ultimately a 'bottom line' where 'mother as carer' must come before 'mother as earner'.

6.2 Characteristics of focus group participants

Eighty-four participants took part in the study; 69 parents, five carers and 10 individuals affected by sepsis. Characteristics at group level are detailed in Appendix 19. Of the 69 parents, there were 63 mothers (age range 19 – 43 years, mean age 32) and six fathers (age range 27 – 44 years, mean age 35). Fourteen parents described themselves as single, divorced or separated; the remainder described themselves as married or in partnerships. Twenty-one parents had older children as well as children aged five or under. Twenty-seven parents described themselves as stay-at-home parents, 24 were in full-time employment, 17 in part-time employment and one described themselves as unemployed.

Five female participants participated in their role as carers for children other than their own (age range 36-60 years). Ten individuals affected by sepsis participated, five of whom had suffered from sepsis themselves and five who had affected family members. Ages of these participants ranged from 17-62 years.

Participants lived in a range of socioeconomic areas; Figure 13 demonstrates the spread of Scottish Index of Multiple Deprivation (SIMD) scores across the whole sample (data unavailable for two participants). SIMD is a measure of relative deprivation that ranks areas from most to least deprived, 1 being the most deprived and 5 the least deprived quintiles (195). Appendix 19 also shows the spread of educational experience between participants; 17 described their highest educational qualification as standard grades or equivalent while 33 had a university or college degree.

Figure 13 Distribution of SIMD score among focus group participants
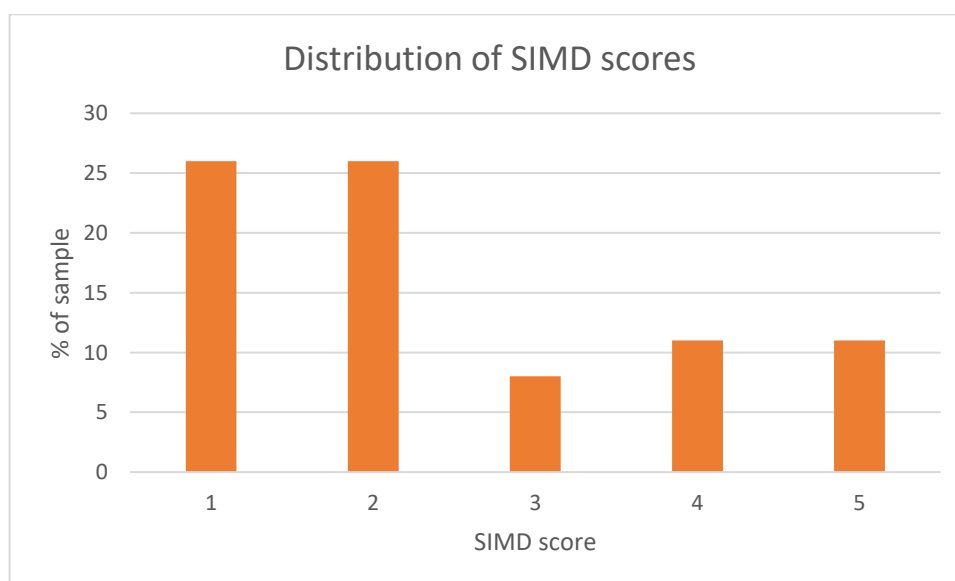
6.3 Findings from focus groups

6.3.1 The role of parental instinct: "you know when your kid's no' right"

As an opening question, I asked participants what their usual course of action was when their child was unwell and how they decided when an illness could be managed at home and when assessment by a health professional was required. The presence of a raised temperature and prolonged duration of illness were cited by some parents as factors that may indicate more serious illness, but a recurrent theme was that as a parent you 'just know' when your own child's illness is a cause for concern. When participants expressed this view, it frequently invited agreement from other members. In FG11, two participants described episodes where they felt health professionals had failed to act on their concerns. Carly described being 'fobbed off' with Calpol when her daughter developed a localised infection as a complication of chickenpox that had ultimately required surgical intervention and caused a lasting deformity to her upper limb. Tara described taking her son to hospital several times after a minor head injury which eventually led to him being admitted overnight for observation. I reflected that on this occasion she felt that she knew that he was unwell and asked if it was usually the case that parents could tell when something was wrong or if this was difficult. Three of the participants agreed that they believed they would recognise when an illness was serious by noticing that something was different about their child's demeanour or behaviour (Appendix 22). However, the basis of the 'knowledge' that participants described could not be defined by any specific symptom or parameter and it was challenging for participants to articulate what this meant in practice. In FG10, Catherine, who worked as a nurse, positioned herself as having a relaxed attitude towards her children's health, describing a recent episode where her infant daughter had a fever of over 40 degrees. Despite having physiological evidence of possible infection, she had felt confident that the condition could be safely monitored at home. She went on to describe a similar illness in her older child that had caused her more concern, prompting her to contact the out of hours service (the only occasion on which she had ever done so). She described her son's condition to the call handler as 'just not right' and was immediately given an appointment (Appendix 22). As she said this, she slowed her speech down, saying each of the words deliberately and emphatically, as though emphasising the powerful meaning contained within this seemingly simple phrase. When asked to elaborate on what this meant in practice, she described the importance of seeing the overall picture, rather than relying on a single sign or symptom. In FGs 7 and 14, two participants referred to the ability to recognise serious illness as 'a mother's instinct'; in FG6 a participant

described it as 'a mum thing'. The implication here is that the maternal role confers special knowledge that is unavailable to others. In FG8, Beth 34 highlighted that it is the capacity to distinguish 'normal' in one's own children that is the cornerstone of this specialist knowledge:

"I think a lot of it is you know your own baby better, so something that might not be normal in someone else's kid's normal in your kids… cause you know yourself if they've got a big change in energy levels and whatever."

Beth, 34 FG8 Baby Cafe

Thus, knowing when your child is unwell was viewed as an extension of knowing your child in general and therefore being able to recognise when behaviour deviates from normal. This was deemed to be more important than individual signs and symptoms. Unsurprisingly, being the person who is most frequently physically present with one's child was the key to knowing their norms. In FG6, Pippa described feeling concerned during an episode of illness when she was asked to collect her 3-year-old daughter from nursery. She described her as having no energy whereas she was usually 'bouncing off the walls.' Despite her concerns, she was refused a GP appointment and advised that the illness was likely to be viral; disclosure of the primary care staff's decision was met with disapproval by the other participants. Justine described how she would 'panic' when confronted with a change in normal behaviour of this nature, while Debbie suggested that dismissing Pippa's concerns in this way was unacceptable, comparing the prolonged contact that parents have with their child with the fleeting nature of interactions with health professionals:

"You're with your child 24/7, and a doctor knows them for seeing them 10 minutes every, whatever, couple of months…"

Debbie, 31 FG6 Group of pre-school parents

The relative time that parents spent caring for their children could also impact on roles in managing illness within a domestic partnership. In FG19, during a discussion about parental roles in managing illness, Suzanne described how expectations about recognising important signs altered according to how much contact a parent had with their child, which usually fell to the mother when they were with the child '24/7' during maternity leave but which became more equally distributed if both parents were working full-time (Appendix 22).

The ability to know when childhood illness is serious then, was largely constructed as something instinctive but that when unpicked is produced by the exclusive prolonged contact that parents, and especially mothers, have with their children. In FG7, Carol claimed that by exercising her mother's instinct she could avoid unnecessary primary care attendance when one of her three children had a minor illness and that "in eleven years, I've never been wrong." However, obtaining convincing 'proof of concept' that parents have an innate ability to know at what stage to consult is inherently problematic because, fortunately, in the majority of cases childhood illness is self-limiting. The sequence of events played out for most episodes of illness could be framed by parents as evidence that the correct decision had been made. For example, managing an illness at home that subsequently resolved was viewed as reinforcing the belief that parents were equipped to accurately make this judgement call. Similarly, a decision to consult that resulted in any definitive action or advice by a healthcare professional reinforced the belief that the correct course of action had been followed, even if this was unlikely to have altered the outcome. For example, in the case of the child admitted overnight after a head injury, the decision of medical professionals to admit him was interpreted by Pippa as confirmation that she was right to re-attend, even though no active treatment was required, and the outcome was likely to have been identical had she not consulted again. Thus, most parents could readily provide examples where both action and inaction were consistent with the overwhelming likelihood that a child will recover from acute illness. This may be seen to result in a form of confirmation bias that reinforces parental beliefs that they can make a reliable assessment of severity.

Even when consulting may have been considered delayed, in most cases this had no substantial impact on outcomes and is therefore likely to have a minimal effect on parents' perception of their ability to assess symptoms. For example, in FG15 Helen appeared to 'laugh off' the fact that she rarely took her children to the doctor, despite on one occasion being advised when she did eventually consult that he did in fact require antibiotic treatment:

"Oh, children? I never take them to the doctor. (Laughs)… one of the times my son had a really bad cough, and I kinda should've taken him to the doctor, but I didn't really know to take him tae a doctor. Turned out he had tonsillitis, a chest infection, and an ear infection. He was only eighteen months… I couldnae tell, I couldn't have said he, I knew was a bit unwell, but I wouldn't have said he had all of that. So, he did need antibiotics… I think if it

was anything serious, I think you would know but you're maybe a little bit more like, 'It'll be fine, you're not that bad.'"

Helen, 37 FG15 Participants affected by sepsis

Such outcomes are ambiguous in terms of their meaning for confirming or refuting the reliability of parental instinct and ultimately can still be viewed as 'successes' in that the child suffered no long-term detriment. In fact, the creation of acceptable delays may even be viewed as a morally superior course of action in demonstrating that parents were prepared to 'ride out the illness' (as one participant described it) for a little longer before seeking help.

Only rarely does failure to consult for acute childhood illness have devastating outcomes. In the 20 focus groups completed, just one example was given of a child whose death may have been impacted by the decision not to seek help. In FG10, Sarah described an extremely distressing event where the young daughter of her friend had died suddenly and unexpectedly after developing an acute respiratory tract infection. Here, she describes the difference of opinion between the child's parents about whether she required medical attention:

"The mum had sent him (the child's father) a video the night before 'cause they don't stay with each other, like 'cause it was the dad wanted her to take her to out of hours whereas the mum was like, "Well the doctor said it's gonna be okay," whereas he was like, "No, I think you should take her down." And… the video was… her, like waving, "Hi, Daddy, I'm fine." Like she, there was the mum saying it when you could see that she wasn't really that fine. And I was like… if she had showed it to somebody else then maybe somebody else would've known to… take her down. But, and it turned out that when she was sleeping the mum had woke up and she had already died, like at some point during the night."

Sarah, 27 FG10 Mother and child exercise class

This demonstrates the precarious position that choosing not to consult can place parents in. For most, this decision will be inconsequential, yet for a small minority, adopting a risk tolerant stance is disastrous, for their child and for their own identity as a competent parent. I was interested to discover how participants perceived the actions of parents in typical news stories about childhood sepsis. In each group, participants were shown a selection of recent news articles about parents whose children had ultimately died from sepsis after being reassured by health professionals that there was no cause for concern. In

FG14, Irene, whose children were grown up and who now cared for her granddaughter, volunteered that if she found herself in this position, she would follow her instinct and simply refuse to leave the hospital, claiming she had 'never been wrong', but then immediately described an episode when she personally had become seriously unwell with swine flu, resulting in a lengthy hospital admission, having initially dismissed her own symptoms as minor (Appendix 22).

Thus, there was a sense of 'never being wrong, until you are' that most parents will be fortunate enough not experience when it comes to their child's health. In FG4, during a discussion about symptoms that could indicate sepsis, Claire described feeling confident in her assessment of illness severity based on knowing what was normal for her own children. For example, when her sons were 'covered' in a rash she was reassured because the only associated symptoms were a 'runny nose' and she explained that she was confident they had no diarrhoea (one of the symptoms discussed) because she was familiar with their usual bowel habits. However, she then related this to the experience of the parents of William Mead, who featured in one of the news articles they were shown earlier in the group, speculating that 'just knowing' may only be apparent in hindsight (Appendix 22).

6.3.2 How other parents manage illness: NHS on speed dial

Knowing when your child is seriously unwell was presented as innate, however in many groups, participants described the actions of other parents as different to their own, often in that they consulted far more readily. This was frequently perceived as a negative attribute that demonstrated weakness, rather than being seen to reflect proportionate risk averseness. For some participants, being able to manage childhood illness in a calm and rational manner was integral to their identity as parents and being able to manage illness at home without having to enlist health professionals was evidence of strength and common sense. For most participants, this seemed preferable to being too risk averse, even though they acknowledged that this could be a high-risk strategy. For Claire, that she had never taken her children to hospital was something of a badge of honour, described as having 'one up' on other parents, but simultaneously acknowledged as having the potential to bring regret:

"I like to say…. "Oh, my wee guys havenae been to the hospital… I look after them, they're healthy …" And so, I feel bad if something bad happened that I never went because I don't want to take them to the hospital, because I don't want to lose that… it sounds bad as if I've got, like, one up on parents."

Angela, the only other participant in this group, had already described at length the involvement her daughter had with primary and secondary care as a result of recurrent ear infections. She described feeling upset that this had in effect spoiled the good record she had established with her son, who never had cause to visit the doctor, and didn't want to be seen as 'that person that's always at the doctors' (Appendix 22). Claire responded, as if to reassure Angela that she recognised that she did not fit this description:

Claire: "You get other mums that are the opposite, that love to be at the doctors all the time and love to say it."

Claire, 38 and Angela, 31 FG4 Group of pre-school parents

Thus, being viewed as a frequent attender carries a stigma, though those with a justifiable reason such as chronic illness can escape this. In FG14, Erica, a nurse with NHS 24, described her belief that parents are frequently unwilling to 'ride the storm' and wait for symptoms to resolve spontaneously. Marie challenged this by suggesting that sometimes parents feel 'fobbed off', describing a time when she had to take her son to the doctors three times before eventually asking outright for treatment. She defended her position by stating how she perceived her own identity in relation to consulting, saying "I'm not the type of mum who naturally runs to the doctor, you know?"

Several participants demonstrated how their approach to illness differed from others by juxtaposing their own behaviour with that of extended family members. Notably, there were several separate instances where mothers specifically referenced the behaviour of a sister-in-law as examples of disproportionate responses to illness. In FG8, Aileen had described herself as possibly 'too blasé' in her approach and admitted that sometimes she doubted herself. However, Beth reminded her that her children had never been seriously unwell. Aileen acknowledged this, agreeing that she should 'trust her own instincts.' Later in the discussion, Joanne compared her own attitude to that of her sister-in-law, positioning herself as similar in her outlook to Aileen:

… a bit like Aileen, I would say I'm a wee bit more blasé and be like, 'Right, well I'll leave you a coupla days then we'll go tae the pharmacist. And then if we have to we'll go to the GP'…. Whereas my sister-in-law's like "Oh there's a red dot. Doctor's appointment," and I'm like, 'Calm down, it could be absolutely anything.'

Her kids are always at the doctors, they're always sick and I'm like, are you kinda making them overly sick 'cause they think, 'Oh we have to go and get something the minute you see a mark.'...She's constantly on the phone tae NHS 24. I think she's got them on speed dial."

Joanne, 32, FG8 Baby Cafe

Here, the participant speculates that in being too ready to consult, her sister-in-law may transmit her own anxiety to her children which may cause them to overestimate the significance of minor symptoms. In comparison, she is 'blasé', unlike her sister-in-law who panics at seeing a red dot, which here may symbolise the fear that surrounds childhood rashes as a potential indicator of meningococcal disease. Initially, 'blasé' seems a strange choice of words to use in relation to assessing your child's health but seems to reflect the importance of being seen to have a measured response to symptoms; it is worth the risk of being seen as complacent to avoid the charge of being unduly anxious. However, the same participant went on to concede that there is a 'fine line' when deciding whether to consult and admitted to her own moment of panic that turned out to be unfounded (Appendix 22). Joanne's moment of panic was justified by the doctor's agreement that judging whether a respiratory tract infection requires treatment can prove challenging, in effect, sanctioning her attendance.

For Claire, who had already expressed her desire to avoid taking her children to the doctor, having agency to assess the situation for herself reflected a superior strength of character, when compared to her sister in law's propensity for panic:

"I like to think that I'm no' a panicker… I've got like a sister-in-law—who's a panicker and straight up to the doctors whereas I like to think… I'm a bit stronger, and I can make decisions for myself as well."

Claire, 38, FG5 Group of pre-school parents

When asked why some parents chose to consult more readily than others, in several groups participants suggested that the norms of childhood persist, informing decision-making for one's own children. For example, Rachel speculated that growing up in a household where there was nursing expertise had influenced her own response to illness:

"I don't know if it's… the way you're brought up… 'cause my mother was a nurse and… I didn't get much sympathy, so I think… that's why… I don't take him a lot 'cause I think, 'Oh, they're okay.'"

Rachel, 31 FG10 Mother and child exercise group

Her fellow participant, Catherine, had not grown up in a family with any specialist knowledge yet also felt that her own childhood experience of rarely seeing a doctor had influenced her own consulting behaviour as a parent (Appendix 22).

Despite this evidence for intergenerational transmission of parenting practices, some participants described experiencing conflict with their mothers, now in the role of a grandparent, regarding their approach to managing illness. Here, Paula describes how her mother's attitude to illness in her grandchildren differed from her own and the emotional impact that this has on her:

"I think my mum gets much more wound up about it than I do. Like she's… she's like always like "Oh, Paula, you know, something could happen at the drop of a hat, and get on the phone to the doctor." Where I'm, I'm a bit more like, "Oh, we'll just a wait a couple o' hours, and see what happens." I don't… I don't know why mum's like that. I don't think she was like that when I was young.

But she seems to be now she's got grandchildren, it's like the least little thing. Cause she's… she's watched my son in the past, and it's the smallest, smallest thing. And she'll, "Oh, get onto the NHS twenty-four. Get on Google, get on this." I was like, "I… I think he'll be fine." And she went "Oh, you need to be so, so careful."

And she makes me feel quite guilty sometimes, 'cause I am quite laidback."

I intimated that participants in other groups had described similar experiences, with older relatives appearing more cautious in their approach. Paula then continued, describing an experience she had with her eldest child when he became unwell while he was being looked after by her mother. She described feeling pressured by her mother to make a GP appointment that she believed was unnecessary:

"My mum was badgering me and badgering me, "Phone the doctors, phone the doctors," and it… I phoned thirty-eight times before I got through. And you, my mum's in the back room going "keep phoning, keep phoning, keep phoning," and I was like, "Mum, I'm doing my best.

In the end… I got through, and I was talking to the receptionist, and my mum's going "Make sure they give you an appointment, don't… don't let them fob you off." (Laughs) And I was like, "Mum, they're just doing their job." 'Cause I know… services are really stretched sometimes, and it's difficult. And… I was having to get an appointment for the next day and go after work. So, I eventually got it, which my mum was saying, "That's ridiculous, you shouldn't have to phone that much to get through." And I said, "Well what can you do, that's the system.""

Paula, 33 FG19 Baby Cafe

Here, there was an apparent conflict in priorities between Paula's mother, who prioritised seeking reassurance about her grandson's condition, and Paula, whose approach to consulting factored not only the health of her son but the capacity within the primary care system and her own obligation to fit an appointment around her work commute, reflecting the complex interplay of factors that influence decision-making for parents who have multiple identities to maintain.

For most participants them, being seen to be quick to consult without justification was to be avoided. A notable exception occurred in FG11 in which Carly, readily volunteered a preference to consult immediately (Appendix 22). Carly also described seeking reassurance from others including her mother, partner and nursery staff. She then recounted occasions when concerns about her child's health turned out to have been unfounded; for example, on one occasion she believed her child had a temperature but was advised by her GP that he was simply wrapped up too warmly. When asked directly whether she believed other people were likely to consult with the same symptoms, she expressed the view that seeking reassurance was a usual course of action for most people (Appendix 22).

Immediately, a fellow participant, Jill, was keen to distance herself from this view:

"See, I think I'm quite bad for no' going… and then usually when I do it's something like, "your child's got major tonsillitis". And I'm like "sorry". And you'd think I would be worse 'cause my daughter was really ill as a baby, she had streptococcus at sixteen weeks, so… but I don't know… I always think 'och they'll be a' right.'"

Jill, 27 FG11 Group of pre-school parents

Thus, in the context of this group it appeared to be of greater importance for Jill to identify herself as laid-back than as overly risk averse, despite having personal experience of a potentially serious infectious illness in her own child. Parents, then, must work out how to occupy an acceptable space between being sufficiently attentive and unduly alarmist. In FG14, Erica described how the 'wrong' action may lead to judgment by peers:

"If you be at Mother and Toddlers and, you know… my boy's had croup the last year, that winter there, and… I didn't take… them to the doctor until, like, the second night. But if I sat here and told you the symptoms of the first night, you'd be like, "You never took him to the doctor with that?" and you can be judged then… but then, you'd be like, "Oh, so then… I phoned up NHS 24 and took him to the doc…" "You're a good mum. You managed that situation really, really well.

Whereas I don't really care. Like, I knew that he was, like, oh, he's alright, we'll see how it goes, and we'll just maybe… But on the second night we went and seen a doctor. But there's a… how are you judged, how's your parenting style judged, especially when you go to all these groups like toddlers and whatever… There is a pressure – I think there is a pressure to act… to demonstrate that you're capable of being a parent to that child…"

Erica, 31, FG14 Library story and music group

Here, Erica appears to suggest that, while she felt capable of acting in accordance with her conviction, i.e., delaying consultation for 24 hours (perhaps due to her specialist knowledge as a nurse), this may not be the case for other parents whose consulting behaviour may be motivated by the desire to avoid judgement and maintain their identity as caring parents. In FG19, Leigh also described wishing to avoid being seen as a mother who delayed consulting (Appendix 22).

These examples demonstrate how consulting behaviour may be influenced not only by a parent's assessment of the situation but by anticipation of social disapproval; waiting longer for the cough to resolve may well produce the best outcomes for the child and for the healthcare system, but if it is believed that waiting would be unacceptable to peers then it is a course of action that becomes unavailable.

6.3.3 The disempowering effect of being a parent: from all knowing to clueless

The concept of confidently exercising parental instinct to avoid unnecessary consulting was a strong thread that ran through most groups. Yet there were of course caveats to this, and the very act of becoming a parent brought insecurity as well as empowerment. This was particularly prominent in one group where, during a discussion about sepsis awareness materials, Erica, who had previously worked as an ITU nurse and was currently employed at NHS 24, described how her whole perspective on risk had altered as a mother:

"Cause I know that… pre-kid, or pre-thinking, pre-mum… I worked in ITU before so… most of the patients were septic…but it is funny how as soon as you become a parent, you're

like, "What is this? I need to know everything about it 'cause what if my kid gets it…?" And even though I know how to identify an adult with it, if my kid got it, I'd be like, "Do you have this? Or do you just have a really bad cold? Or…? No, I'm going to get someone else's opinion." 'Cause then you're sleep deprived 'cause you've got all these kids and you're maybe not thinking straight and so you do go from, 'I'm totally knowledgeable,' to 'I actually don't have a clue and I'm going to go and seek… another opinion.'

Erica, 31, FG14 Library story and music group

In the same group, Marie suggested that many parents find themselves inadequately prepared for parenthood, particularly regarding expectations about illness (Appendix 22). Marie felt that, after infancy, support for managing illness ceased almost entirely, suggesting that this could be remedied with initiatives tailored to inform parents how to approach illness:

"See once they're a year old? You're lucky if you see anybody ever again until you go and get their jags or they are ill…I can count on one hand how many times Isaac's seen the health visitor since he's been a year old… most people take time off… once they've had their baby, and I think that probably is a good time to say, "Well, as part of you preparing as a mum, we're going to give you this course just to help you to, you know, if your child becomes ill, what the best thing to do is," you know, for you, 'cause… you get all different types of people."

Marie, 43, FG14 Library story and music group

Angela agreed that having some forewarning about the frequency with which young children experience mild illness had helped her to manage her anxiety (Appendix 22).

Interestingly, participants in this group (in which of the four participants, three held university or higher degrees) speculated that a higher level of education was not protective against feeling insecure about parenting decisions. In fact, it was suggested that younger parents and those who had spent less time in education, navigated potentially challenging situations with greater ease (Appendix 22).

There seemed to be a perception that the pursuit of knowledge that perhaps became habitual for those who became parents when older, perhaps after a longer period of education or

working in a professional environment, could place them at a disadvantage with regards to having confidence in their parenting ability; it is noted however that Carly, who was identified in the previous section as exhibiting a marked lack of confidence in decision-making, was among the youngest of all the participants.

Irene suggested that the extensive research undertaken by the current generation of parents in relation to everyday practices, as described by Andrea, represented a departure from her own experience, in which decisions were often influenced by older relatives ("we would just ask my granny…". Erica, an NHS nurse, suggested that a return to utilising traditional support networks in this way would be welcomed by the NHS as a way of reducing the need for advice about minor ailments. However, Marie voiced the belief that this was unfeasible as families become increasingly geographically dispersed (Appendix 22).

Substituting or supplementing traditional support with online research was common. Some participants viewed this as helpful but for others it increased anxiety. In FG3, Jenny described using an online forum to share health concerns with other parents (Appendix 22). When asked whether there was a tendency for members to adopt a risk averse position, Jenny suggested that this could be mitigated by responses from 'sensible' members but that otherwise the forum became a 'minefield', suggesting the need to tread carefully when offering advice.

LR: And do you feel as though people tend to err on the side of saying, "Get it checked out"?

Jenny: Yeah, I mean some people will always say, "Get it checked out," regardless. But, you know, there are a few sensible voices in the group as well who, you know, maybe are a bit more relaxed…and you've got the ones who have got older kids as well who… kind of hopefully reassure the ones who are doing it for the first time. Because it is a minefield when you don't…

Jenny, 32, FG3 Parent and baby group

6.3.4 Responsible use of resources: "the NHS is stressed oot"

In many groups, participants expressed the belief that the NHS struggles to meet the demands of service users and that this both affects the quality of care that they receive and influences their approach to service use. For some participants, this view was reinforced not only by

their own experiences as a parent or in accessing healthcare for their children, but through experiences they had of working in healthcare or social care themselves. In FG1, Alan recounted an experience he had in his capacity as a carer for individuals with additional learning needs. When attempting to arrange a medical review for an individual in his care who had an ear infection, he was advised by the GP surgery to seek advice from the pharmacy instead (Appendix 22). Joseph perceived that this reflected a gradual erosion of services, with access to primary care becoming progressively more difficult and the time allotted with a doctor gradually less:

"See inside to the bigger picture, the NHS is just stressed oot, it's stretched oot… there's nae funding for this, there's nae funding for that… and it's just passing it down the line."

Joseph, 27 FG1 Support group for lone fathers

Patrick agreed that in his experience even the process of securing an appointment was becoming increasingly complex (Appendix 22).

In FG14, Irene, who was present in her role as a carer for her grandchild, voiced frustration about a lack of capacity to see a doctor in person following the closure of the local out of hours centre. As a result of this closure, parents had to travel further to reach the nearest centre, and she expressed concern about the fact that some parents without transport may struggle to afford taxis, pointing out that the present system was entirely different to the one that she had grown up with when house calls were the norm (Appendix 22).

She also expressed a view that a decline in the availability of personalised care had been gradual, with home visits by the patient's own GP initially replaced by a local out of hours service (where a house call by a doctor could still be made if necessary) and now by the current (in her opinion) inadequate system.

Overwhelmingly, criticism of primary healthcare services was focused on the perception that the current structure does not provide adequate time for patients to tell their story and therefore diagnoses are made hastily based on limited information. In several groups, participants expressed the view that the main priority for doctors was drawing the consultation to a close in order to avoid late running of their clinic, often phrased as 'they just want you out the door' or similar (Appendix 22).

In FG12, Scott expressed a belief that the perceived time pressures that GPs are under prevented best prescribing practice being enacted, particularly in relation to antibiotic prescribing:

"I think they probably… do it more than they want to. I think if you asked most GPs to sit down and say, "There's last month's cases, you've got all day to go through them", they might look at some and go, "Actually, maybe I would have done this instead of that", you know? But they're under pressure themselves. It's a long day, I can imagine. I mean, whatever their appointment times are – bang, bang, bang, bang all day – emergency appointments coming in, you know, sometimes it's babies that are ill and screaming and can't tell them any more information and just kinda guesswork. I would hate to be in that position."

Scott, 36 FG12 Group of pre-school parents

Later in the discussion, Scott speculated that pressure on services was likely to contribute to deaths from sepsis, as detailed in the news stories that participants were shown (Appendix 22).

Although the idea that doctors are primarily focused on speed of consultation seems inherently negative, the tone of discussions was in fact frequently sympathetic towards health professionals. Unsurprisingly given the status of the NHS as a major employer, several participants had current or previous experience of working as health professionals or had family members who were employed by the NHS. This provided a degree of 'insider knowledge' that allowed a deeper insight into the challenges faced by staff. In response to being asked why some individuals are less inclined to consult about minor symptoms, Aileen offered the following insight, indicating that she was less likely to attend based on her sister's experiences:

"My sister's an A&E nurse, and I think I hear her go on quite a lot about how busy it is, like ridiculously busy, I mean she'll come home in tears sometimes because it's been so overwhelming."

Later in the discussion she described her cousin's experience as a junior doctor:

"I think the whole funding stuff annoys me as well because like my cousin's a doctor and he's like doing his GP training, he's in a hospital right now and he is so stressed out where like he was considering packing it in a coupla months ago. He's now put in an application for part-time working 'cause he's just like, "I've been asked to do things that I shouldn't be doing," like, you know, things that are above like where he is, like and he's just so concerned and worried about the stress and depression."

Aileen went on to reference the well-publicised case of Dr Bawa Garba, intimating how her friend who works as a doctor was 'fuming' at the treatment she (Bawa Garba) had received:

"It was a female doctor who'd been made a bit of a scapegoat… she'd been on for hours and hours and hours and, you know, I can't remember if someone had died, then the patient had obviously died which is horrendous but to then use this poor woman as, as being the scapegoat for it when actually they're so stretched, the NHS, it's ridiculous."

Aileen, 34 FG8 Baby Cafe

An unexpected finding that was identified in the first group and persisted as a central theme was the strongly held belief among most participants that they had a moral duty to avoid using valuable healthcare resources where possible. My expectation at the study design stage was that participants would be keen to position themselves as parents who were risk averse and that they would be willing to be seen as overly cautious and quick to consult in exchange for reassurance that their child was well. In fact, for most participants, being seen to use healthcare judiciously was a strong priority and integral to how they constructed their moral identities, at least in public. Thus, healthcare usage was influenced by a sense of responsibility to others in society as well as a belief that their parental instinct was reliable.

In several groups, participants expressed concerns about 'wasting time' if they consulted when not absolutely necessary. Notably, this concern sometimes appeared to override concern about being seen to be cautious with their children. For example, in FG19 Vanessa described experiencing a personal dilemma about whether her young daughter needed to be assessed by a doctor when she had diarrhoeal symptoms for three weeks:

"And I was there at like half seven really arguing back and forward wi' myself, around 'does she need this appointment?' And even when I went in, I said to the doc, I was like "I hope

I'm not wasting your time here" … and the doctor was like "No, no, you're fine tae bring her, you like, you know, we'll check it out." An' everything checked out to be fine and stuff like that, but she, like wasn't annoyed at it, 'cause I think that… I just, I'd hate tae think I was wasting somebody's time or taking up a space that somebody else needed."

Vanessa 34, FG19 Baby Cafe

Interestingly she indicated that because her daughter was 'fine' she risked disapproval from the GP, suggesting a belief that a consultation that ends only in reassurance was potentially a misuse of services. Here, her concern about being seen to misuse the primary care system seemed to override that of being seen to delay consulting about prolonged symptoms in a young child. When I expressed my surprise that she felt this way even though she was concerned enough to consult, she expressed how strongly she felt herself about misuse of healthcare resources (Appendix 22).

In FG20, Susie described delaying taking her daughter to A&E after she injured her arm due to fear about how she would be viewed as a parent if it resulted only in reassurance (Appendix 22). Following an X-ray, her daughter was diagnosed as having an upper limb fracture. In similarity to the previous example, the way this mother expressed her concern suggested that despite her attendance having been fully justified, concern about being seen to misuse resources was at the forefront of her decision-making. However, when I acknowledged that this could pose a difficult dilemma, she stated that she could accept 'looking stupid' if she knew she had acted in her child's best interests (Appendix 22).

In the same group, Audrey who worked as an NHS podiatrist, acknowledged that she probably delayed consulting due to being in possession of some specialist health knowledge. She asked her fellow participant Rosie, a nurse, whether her role affected her consulting behaviour in the same way. Rosie replied that her use of resources was influenced not necessarily by her knowledge but by awareness of the demand on health services. However, she admitted that these concerns were secondary to safeguarding the health of her child (Appendix 22). Later in the discussion, Rosie repeated this view, explaining that the same principles that guided her own use of services did not apply when making consulting decisions about her child, when she took on the role of 'the anxious mother' (Appendix 22).

Here, there are interesting parallels with Erica in FG14 who was experienced in managing seriously ill patients and was acutely aware of the demand on services, but who admitted to insecurity regarding decision-making as a parent.

In FG18, Kerry, who had experienced sepsis twice, described how she would not have consulted based on her symptoms if she had not already suffered from the condition (Appendix 22). She went on to speculate that concerns about misuse of resources may be contributing to sepsis cases by discouraging consultation even when necessary (Appendix 22). However, later in the discussion she described how a collective move towards feeling guilty about misuse of resources, which she described as a 'societal shame' could ultimately be beneficial with regards to reducing unnecessary antibiotic use:

"I do think that, I mean, most of the parents, and most of the people that I speak to now, are not looking for antibiotics. I think there is quite a big awareness amongst most people that, you know, you don't go to the doctor and, you know, and I think there's almost a bit of… societal shame in being seen as somebody that goes to the doctor at the drop of a hat now… and if it does carry on the way it's going, like I say, if there's already a sort of groundswell of people beginning to feel slightly shameful about going to the doctor at the drop of a hat and other avenues of saying, "We'll go to the pharmacy first…"

Kerry, 45 FG18 Group of individuals with lived experience of sepsis

These views from the same participant could be viewed as demonstrating the potential conflict between sepsis management and antimicrobial stewardship, or 'access versus excess'; on one hand, failure to consult when necessary, delays potentially lifesaving treatment for sepsis, on the other, requesting antibiotic treatment when not essential is seen as 'shameful'. This apparent contradiction is particularly salient coming from, as it does, an individual whose survival had been threatened by sepsis, and who it might be anticipated would be inclined to be more risk averse. Instead, Kerry appears to applaud growing awareness of the need to avoid antibiotic treatment where possible, demonstrating her recognition that the solution to sepsis cannot be early antibiotics in all cases of infection.

Several participants articulated that their reluctance to use resources was based on the belief that their own use of an appointment denies access to someone more deserving. In FG17, Bill described feeling like a fraud when comparing his perception of his relative need to

other patients, while in FG5 Claire expressed how her perception that there are others more deserving of appointments influences her behaviour during consultations, causing her to 'go through everything at a million mile an hour' to protect the GP's time (Appendix 22).

6.3.5 The influence of external factors: work or wellbeing?

A prominent theme was the impact of external factors on how parents make decisions during episodes of illness. By external factors, I refer to elements integral to daily life that impact on but are not directly related to illness, particularly the roles of paid employment and childcare. It is perhaps surprising that I had given this minimal consideration given my own identity as a working parent who has navigated the same inevitable challenges as any parent of young children. However, although I was all too aware of the short-term impact that illness frequently has on capacity for work, I had not fully considered that this relationship may be bi-directional and that it was possible that external influences could impact on individual health outcomes or have wider implications for population health through impacting on consulting and prescribing patterns. This was first identified by participants as an important consideration during FG5. As the fieldwork progressed, I grew more conscious that employment was a potentially important driver of health seeking behaviour and thus, in latter groups, I questioned participants about their experience and views of this. This approach is consistent with guidance produced by Morgan, who suggests that the topic guide must be sufficiently flexible to allow for changes in this way (154). It must therefore be considered that asking the same questions of participants in earlier discussions may have elicited different views.

In FG5, I asked a standard question regarding how decisions are reached about whether a consultation is required when a child has a fever or feels unwell. Claire responded as follows:

"…you're just paranoid… you just want somebody like just a professional to give you advice right away. And then, I know this sounds bad as well, but maybe if I've got like work the next day… I'm thinking, 'I need to get medicine into him right away, so he's better right away.' I know that sounds selfish for you because you've got work, but that's just life. That's me being honest, like."

Claire, 38 FG5 Group of pre-school parents

In FG20, Morag, who worked as a teacher, described an episode when her one-year-old child simultaneously had chickenpox and hand foot and mouth disease. Having contacted her school to inform them that she would arrive late because she had to take him to her GP, she described the internal conflict she felt at having had to take time off:

"Really the whole time I was at the doctors I was looking, thinking 'I need to get back'. And then I'm running up tae his gran's house, trying to relay the information to gran before I had to get back to work. And I'm thinking that's ridiculous, like I should be, I should be home with him, not his gran looking after him, but I had to go to my work. Fortunately, I'm a, like I said earlier, I'm a teacher so I could leave at three, but I know there's people that, some people that don't get in their house 'til six, seven at night. It's, it is, it's rubbish sometimes, work."

Morag, 30 FG20 Baby Cafe

In several groups, participants described having encountered negativity from employers when they had to be absent due to their own or their child's illness. In FG13, Judy, the mother of five children aged between nine months and nine years, described feeling that she was not 'flavour of the month' when she returned to work after being off due to her own illness the previous week. When asked whether anticipating having to be absent due to illness, acknowledged as inevitable even for healthy adults, was a source of stress, she described how you were 'made to feel like a bad employee' and pointed out that being the parent of young children brought increased exposure to illness (Appendix 22).

I asked Judy if the perception that recurrent infections that affected the whole household, and, as a consequence, attendance at work, could influence the desire for antibiotic treatment. Rather than suggesting that there was a belief that treatment with an antibiotic would speed symptom resolution, she expressed a belief that there was a need for employees to establish their illness as severe enough to justify absence, leading to consultations that were potentially unnecessary when conservative management may be all that was required, and to antibiotic seeking:

"Do you know what I think? When you phone to say that you can't come in, if you can phone and say that you've got an antibiotic then they'll believe that you're ill… but if you phone and say, well the GP says it's viral, they think 'there's nothing wrong with her, she could be at work.' So, you kinda feel like you need an antibiotic tae secure your right to be off work.

Or to be ill. To officially tell people that you're ill you need an antibiotic, 'cause that means that it's a real illness."

Judy, 37 FG13 Pre-school parents group

How employees were treated was highly variable and dependent on the attitudes of managers, which in turn was influenced by their personal circumstances. In FG20, Susie described how her manager had a reputation for being less than sympathetic regarding childhood illness (Appendix 22). Later in the discussion, she elaborated on this, describing her manager's expectation that his employees' approach to managing illness should be aligned with his own:

"My manager('s) … wife's a childminder and she does everything to do wi' the kids so he's never had a day off… I remember he made the comment to somebody, "Well, you know, when we had children we made the decision my wife was gonnae change career… so that she could… do it" - and it's like, well, not everyone can do that… so he was kind of projecting his personal circums(tances) - you know, "Well if I can do it, you can do it," kinda thing."

Susie, 33 FG20 Baby Cafe

In FG19, Paula expressed that in the absence of a supportive line manager she had felt the need to apologise when her child was unwell when "you've got nothing to be sorry about, your child's unwell."

In the same group, Vanessa described how her manager's approach to unanticipated absence had been influenced by her own experience as a mother:

"If I look at my Head o' Department now, she's got two kids, and she's quite a stressy mum. And… I know now, like if I was to tell her she wasn't well… it would be like, "oh it's fine", because she has called off, like, loads of times, and… she's kinda setting that scene. Whereas before that she was very career driven… and I think had it been a child excuse before she'd had a kid… you would definitely have felt as if you were maybe getting talked about a wee bit… whereas now, I think because she's got two kids of her own… she's like 100% flipped…"

Vanessa, 34 FG19 Baby Cafe

In FG20, Mandy explained how official policies often did not reflect the way parental absence was enacted, highlighting the importance of individual employer discretion (Appendix 22).

The ease with which participants were able to be with their child if required was inevitably influenced by the nature of their work, with some roles being more impacted than others, including teaching and healthcare. In FG19, Paula described having perceived negative reactions from colleagues when she had been absent from her teaching role in the past:

"I think when you're working, it's that whole thing, it's like people expect you to work like you don't have a child, but then people expect you to be a mum like you don't have a job. 'Cause I've… I'm a teacher, and I've not worked since she's been born, and I don't have a job right now, and it's… I feel quite relaxed about that, because in the past when I've had a job, I had my wee boy who's now nearly four, I feel like when you don't go in tae work because your child's sick, people are like 'not in because your child's sick,' and they're kinda rolling eyes at… people that aren't parents. And that's… that's really, really difficult. So, me and my husband try and like… because we're both teachers, "it's like right, okay, you don't go in this day, I will not go in that day", and it's… it's really, really hard. 'Cause it's like that's two classes getting disrupted, and as teacher you feel really guilty about the thirty-odd children don't have a teacher in that day. And as mum, you feel horrible leaving your wee one in the morning, and they're like 'mummy don't leave me,' and it's… it's heartbreaking. So, it's like you're getting pulled in all directions."

Paula, 33 FG19 Baby Cafe

Lorna agreed with her, voicing that she too had experienced conflicting priorities:

"I've kinda done kinda similar, like I've went to work when ideally I would've probably stayed off with my wee boy, at the time was unwell. But you feel guilty, you know? Aye, 'cause you… there's some people that just don't understand that you're off for your child."

Lorna, 33 FG19 Baby Cafe

Despite strongly expressed views about the difficulties that unanticipated absence caused, in FG20 where I specifically asked what procedure they were expected to follow there was widespread uncertainty among participants. In this group, Morag, a teacher, explained that she was entitled to 24 hours leave if her child was unwell. She admitted that she had considered telling her employer that she herself was unwell, as managing personal illness was more straightforward. Audrey, a podiatrist, admitted that she had considered taking the same action (Appendix 22).

When asked to clarify what the agreed course of action was after that 24-hour period, participants expressed uncertainty:

LR: "What are you expected to do if they're too unwell to go to nursery?"

(Mixed voices)

"Find an appropriate somebody to look after them. Would that be right? Wouldn't you…"

"I actually don't know, (yeah) like I don't know how it would work. I've not had to…"

"Is it 'carers leave' for NHS?"

There followed a discussion about definitions of parental leave and carers leave and conditions under which employees were entitled to utilise these. Susie then raised the issue that whether this was paid or not was variable and inevitably impacted on an employee's capacity to exercise this right. She went on to describe the cost associated with childcare, incurred regardless of whether her child was well enough to attend (Appendix 22).

Decisions about sending a child to their usual childcare provider could be challenging and were influenced by responsibilities to their employer and colleagues and to the children, parents and staff in the childcare setting, as well as to their own child. In FG8, Aileen described her frustration at having to keep her child off nursery when she had only recently returned to work after maternity leave (Appendix 22).

In the same group, Sarah described her own experience:

"My nursery's not too bad. See wi' like colds and whatnot they're okay. Obviously the usual wi' the bugs and stuff like that you have to give it forty-eight hours from the last they're

unwell. But they're not very, like they'll phone if they're really unwell but they're not really pestering me too much. Like, if you know what I mean? They're quite good that way."

Sarah, 35 FG8 Baby Cafe

Sarah's choice of language was interesting in that the possibility of being phoned about her young child's health while at work was described as being 'pestered.' This challenged my expectations about how participants would wish to be viewed as parents and suggests a perception that to be viewed as a reliable employee there is a requirement to minimise the impact of childhood illness. This was reinforced by Susie in FG20 who described herself as having a background in employment law and who acknowledged that some employees feel discriminated against based on their identity as parents (Appendix 22).

Yet in FG5, Angela described how parents risk judgement from fellow parents if they send a child to nursery when unwell:

"And then, you don't know if you're supposed to keep them off nursery or can you send them wi' a cold or… then everybody gets the cold and then you're the mum that sent the kid that gives them all the cold…"

Angela, 31 FG5 Group of pre-school parents

In FG6, this very concern appeared to be played out in an exchange between participants. Following a discussion about what illnesses necessitated absence from school or nursery, two participants appeared to voice judgement about fellow parents who they see as valuing employment over their child's health (Appendix 22). However, the same two participants did acknowledge that economic pressures faced by families impact on health decisions (Appendix 22). In FG14, the idea that parents have no choice over whether they work was disputed, with the suggestion that the pursuit of material wealth can be detrimental to family life (Appendix 22).

For many participants, navigating the dual roles of employee and parent was associated with feelings of guilt. Most participants were mothers, and the view that being with an ill child was ultimately a maternal role was voiced by some participants. In FG19, Colette described how she and her partner had tried to share childcare equally, though conceded that as his job

was currently particularly busy this was unlikely to be possible when she returned to work. Lorna responded that she felt it was her responsibility to be the one to stay home if required: "I think personally, I feel that I should be the one that's off." Paula responded: "…it's just that classic mum guilt, you feel guilty about absolutely everything." Vanessa, who had not yet returned to work following the birth of her first child, described her husband's employer as 'antiquated' and said that although they had not yet discussed this issue 'it'll probably be the case that should that ever occur it'll be me that does it, just because of the way the workplaces are, I would say."

The same view was articulated in FG20. Morag explained that having extended family available to take over when her child was too unwell to attend nursery did not relieve the feeling that she should be present:

"We've got a good support network, but I still felt like I should be at, this is my job, like you know, when they're not well, this is when I should be able to look after them… I'm a mum, that's my first job."

Morag, 30 FG20 Baby Cafe

Mandy agreed, recounting an occasion when she felt guilty about relying on assistance from grandparents:

"I just remember the nursery phoning me and my dad, my mum and dad live next door to the nursery so I phoned my dad and… he went and got her and I just thought, 'They've phoned me and said she's sitting in a wee corner, she's lethargic, she's got a temperature, she's just not herself.' And I thought, and my dad's turning up and she's gonna be looking up and thinking, 'Where's my mum?'

So… the guilt's mostly for them…it's their mum usually they want, sometimes their dad. You know, they love gran and papa but when they're not well…"

Another participant agreed (indistinguishable): "They just want their mum."

Mandy continued:

"When I wasn't well when I was wee it was always my mum and dad I wanted, you know? So… there's definitely guilt."

Mandy, 37 FG20 Baby Cafe

According to Lorna, how unwell a child had to be before absence from work was justified was unclear and simply wanting to be present with them was not sufficient:

"I think if you've not had children before, or you've not had to be off, I suppose it's knowing that kinda threshold of, should I be off with them? Should I feel guilty about being off, if it's just something fairly minor?... you probably feel like… that's not a good enough reason like to be off, to say that I would rather I was at home looking after them than somebody else."

Lorna, 33 FG19 Baby Cafe

The possibility that employment could have a deleterious impact on child health was intimated in different ways. In FG14, in a moment of stark honesty, Marie voiced the view that the sheer busyness of modern life and its resultant impact on mood and energy levels could influence decision about seeking advice:

"I think as well, you come in fae work, you're tired, you're hungry, you look at the child and they look unwell, but, actually, I'm tired and I really don't want to go to the hospital with them. That sounds terrible but… you're thinking 'I've had a really rubbish day at work, I'm going to have to take tomorrow off 'cause they're not well, my boss is gonnae give me a hard time for it… and you think, 'I really don't want to go to hospital tonight. I'll just leave it for the morning.' When, actually, if you'd been there all day, you'd think, 'Actually, they're really, really unwell. I'm just going to take them. I'm just going to get out my bed, have to get my mum to come over to watch the kids for me to drive and, you know…?'"

Marie, 43 FG14 Library story and music group

It is notable that Marie was the same participant who stated that she had reorganised her employment in order to be present for her children, perhaps indicating that she felt able to voice these views because, for her, the perceived barrier to caring for her children represented by work outside the home had been lifted.

The view that not being present was likely to affect the ability to recognise serious illness was also expressed by a Sarah in FG5:

"I work full-time Monday to Friday, nine to five. And I sometimes feel that, sometimes if my wee girl's… unwell it sometimes went a wee bit unnoticed for a bit because she was passed pillar tae post, so… she was at nursery or she was at grandparents. So, it wasn't 'til a coupla days and then you realise my goodness, she's not actually well and it's hard going as well when you've got… a job. I only get a coupla like family days… if your child's ill. It's hard tae get time off with your child as well, I feel."

Sarah, 35 FG8 Baby Cafe

This view is consistent with that expressed in the previous section i.e., that being physically present is an integral part of knowing a child's norms and challenges whether it is possible to successfully monitor deterioration in their clinical condition when employment demands that they are elsewhere. This role must therefore be devolved to others who are in loco parentis. In FG3, one participant described a scheme being piloted in nursery that involved recording what she referred to as 'baseline temperatures':

"My son's… nursery actually started getting all the children's… base temperatures because they are all different, so it meant that although you know, one at thirty-eight might signify illness, another one might not be ill until it like hits thirty-nine or so…so over a period of about a week, they took all the kids temperatures about three times a day, just to get like the kinda baseline…"

Unidentified participant, FG3 Parent and baby group

6.4 Discussion

The idea that parents, and especially mothers, know instinctively when a child's illness places them at risk of harm was a thread that ran throughout the groups. This was in keeping with Lupton's research, in which she identifies a societal expectation that mothers have primary responsibility for protecting their children's health through exercising their maternal instinct, which should alert them when something is wrong. Although some of the

participants volunteered that they shared responsibility for managing illness with their partner, for many there was recognition that the parent who spent the most time in the child's presence was best positioned to have intimate knowledge of the child's norms and routines, and this was frequently the mother.

In similarity with findings of Irvine and Cunningham-Burley, parents in this study report that they place greater importance on a child's overall demeanour and behaviour than on individual signs and symptoms (188). Being present with their child for prolonged periods afforded them an intimate knowledge of what constitutes 'normal' and it was widely believed that this would allow them to recognise when their child was seriously unwell and requiring care above that which can be delivered in the home. However, this assumption is inherently problematic in that parents are subjected to repeated confirmation bias, perceiving that they have made the right decision in choosing to consult or otherwise, because in most cases the outcome will be the same, i.e., resolution of illness. This may have the effect of increasing confidence during subsequent decision-making, reassuring them that they can accurately assess symptoms. However only a small proportion of apparently trivial symptoms will be indicative of serious illnesses like meningitis or sepsis, therefore there is little opportunity for parents to identify what differs in these cases and to apply this knowledge. It is notable that some participants who had extensive experience of working in healthcare admitted to insecurity in knowing when their own child was seriously unwell. Thus, 'just knowing' and the idea that parental instinct is a reliable tool for detecting serious illness may be a fallacy. This was acknowledged by the participants in FG5 who, in discussing the article about William Mead, suggested that parents can only be aware of these limitations retrospectively.

The belief that there is a moral responsibility to avoid wasting valuable appointments when illnesses could be managed within the home (the 'containment' referred to by Neill) was prevalent throughout the groups. There was clear disapproval expressed for 'other parents' who were seen to overuse services and it was notable that participants were keen to ensure that they were viewed as rational in their use of healthcare resources, even when it might reasonably be perceived that disclosing instances when they had delayed attendance may damage their reputation as cautious parents. Neill suggests that child health is closely linked with parental self-esteem and that the desire to normalise childhood illness may be an attempt by parents to preserve their identity as competent parents (186). According to Irvine and Cunningham Burley, the impression that mothers have of how they are

perceived by a practitioner affects their view of their own competence that in turn affects how likely they are to consult subsequently:

"If she has been made to feel that she has wasted the general practitioner's time she may be left with doubts and anxieties about her own adequacy as a mother. The sense of rejection is likely to be felt most keenly by those whose self-esteem is already vulnerable, such as the depressed or the young first-time mother, the more so if she is no nearer to resolving the anxieties about her child which caused her to consult initially. The more experienced and confident mother may feel anger that her legitimate status as the expert on her child's behaviour is not being acknowledged. Her perception of being fobbed off may be heightened if, in addition, she receives an unlooked-for prescription. In both instances, the process of deciding to seek professional help on a subsequent occasion will be much more fraught and might involve significant delay." (188)

In the literature reviewed, only the personal impact of consulting is of concern, while the impact on the wider health service is unmentioned, and for many parents in my study it may have been the case that avoidance of consulting was influenced by a desire to retain their identity as competent parents. However, great importance was also placed on preserving valuable appointments for those with greater need. Participants were acutely aware of well-publicised pressures on the NHS to meet increasing demands, and there was an altruistic concern that unnecessary use of an appointment could have a direct impact on the health outcomes of another by preventing them from utilising a needed appointment. For many participants, awareness of publicity about finite resources as an important public health issue seemed to outweigh messages about illnesses, including sepsis, which could affect children. Thus, the impact of avoiding unnecessary consultations extended beyond the personal but was imperative in order to be a 'good citizen,' as demonstrated by Kerry in FG18 who spoke of the 'societal shame' in being someone who consults too readily.

Perceptions of the healthcare system as becoming gradually eroded due to inadequate funding were widespread. In some groups, there were apparent generational differences in what constituted reasonable expectations of what the health service should be able to provide. This was particularly evident in FG14 in an exchange between Irene, who was attending as a grandmother and Erica, who worked as a nurse at NHS 24. Erica was critical of some parents who she saw as abusing the appointment system, requesting appointments when unnecessary to fit around their lifestyles. However, for Irene, this was not indicative

of selfishness but of a fundamental need to seek reassurance that the health service is progressively less able to meet. She expressed concern about the way in which out of hours care provision has changed from a system where it was the norm for a doctor to carry out a home visit, even for minor illnesses, to one where patients were expected to travel a considerable distance to be seen (if an appointment was offered at all). It was clear that seeking reassurance was not necessarily perceived to be a justifiable reason for attending primary care; in fact, for some participants there seemed to be a sense of relief when they received confirmation that their child had a definitive illness or injury or at the very least symptoms that warranted reasonable concern. This was exemplified by Susie in FG20 who was relieved that her GP was 'not annoyed' when she presented with her daughter who was suffering from a prolonged gastrointestinal upset. Thus, there is a dilemma for parents then in managing their child's health in that they must determine what level of risk they should absorb themselves and when it is acceptable to consult in order to meet societal expectations. However, the fundamental need that parents have for reassurance from someone with specialist knowledge that their child is not seriously unwell does not change over time; each new parent begins the process of learning how to evaluate their child's health afresh. It may even be argued that the need for parents to seek professional opinions has increased. Today's parents may have less experience of childhood illness compared to previous generations because of the success of childhood vaccination programmes and may be less equipped to distinguish self-limiting illnesses from those that are more serious. Additionally, the shift away from traditional family support networks and availability of seemingly infinite online information can leave parents struggling to determine 'the right thing to do.'

In similarity to the findings of Cunningham-Burley et al, parents in paid employment found that they had to manage competing obligations when their child was unwell (194). Minor childhood illnesses were unlikely to result in lasting harm but were unpredictable, and the decisions about what course of action to take impacted not just the child and its mother but had a ripple effect on partners, peers in their place of childcare, colleagues, and employers. Participants were aware that being absent to care for a child when ill could be met with disapproval from employers and colleagues and believed that minor illness was not an acceptable reason to take time off. Despite illness being an inevitable part of caring for young children, there was confusion about official workplace policies, with arrangements often being made according to discretion of line managers, perhaps adding to a sense that in seeking to be with their children when unwell that they were doing something wrong. There was also a lack of consensus about when an illness was serious

enough to warrant a parent being present. It was notable that in discussing illness in relation to employment, the majority of participants focused on practical rather than emotional factors; however, asking directly whether it was difficult to leave their children when unwell seemed to give participants permission to admit that they would prefer to be present and that failure to do so could create guilt and distress. It may be then, that to secure their image as reliable employees, mothers must first position themselves as impervious to the emotional impact of their child's illness, as exemplified by Aileen in FG8, who demonstrated her frustration at being unable to send her daughter to childcare when she had recently returned to work. This is at odds with Lupton's work, in which she describes an expressed need for mothers to be in close proximity to their children in order to maintain surveillance and provide comfort (189). She describes the impact of caring for an unwell child as 'an intense embodied experience for mothers (that)… may involve disrupted sleep and resultant tiredness... as well as the strong negative feelings that may be part of experiencing worry about an ill child…' However, in order to fulfil their role as reliable employees, mothers must largely set aside this emotional burden, as voiced by Paula in FG19 who summarised this dichotomy as follows: "I think when you're working, it's that whole thing, it's like people expect you to work like you don't have a child, but then people expect you to be a mum like you don't have a job."

As referred to in the findings section, before carrying out this research I had been conscious of the impact of childhood illness on employment but had not considered that parental working patterns could in turn have the potential to influence health outcomes. In several groups, statements by participants suggested that this was a possibility. In FG5, Sarah suggests that being cared for in multiple settings in childcare establishments and by family members, described as being passed from 'pillar tae post' could prevent recognition of developing illness, while in FG14 Marie suggested that having to meet obligations at work and at home may prevent parents from seeking help in response to illness when they may have done so if they had 'been there all day.' Even when the decision to seek help is taken, parents must manage the conflict that comes with competing demands, as demonstrated by Morag in FG20, who described being unable to concentrate on the doctor's advice during an appointment with her son because she was aware that she should be at work (Appendix 22).

Many of the findings in this section of the study have relevance to the way in which advice about sepsis has been communicated to parents. The cornerstone of sepsis awareness

campaigns endorsed by the Sepsis Trust has been 'just ask – could it be sepsis' and Dr Ron Daniels, its CEO, has been quoted repeatedly in the media as urging parents to 'trust their instincts' if they suspect sepsis and to challenge healthcare professionals if concerns are not taken seriously (196). This positions parents as uniquely positioned as being able to detect when an illness that may appear minor is in fact indicative of a potentially fatal infection. However, 'instinct' is ill-defined and its reliability untested, and the natural history of the majority of childhood infections dictates that parents may develop false reassurance in their ability to accurately detect serious illness.

Desire to avoid unnecessary use of resources was a dominant theme, with an apparent perception that this was essential to be viewed as a moral citizen. The strength of feeling demonstrated about this issue was unexpected and appeared to be influenced primarily by publicity abut under resourcing in the NHS, but also by a sense of appointments being necessarily rushed that came directly from doctors themselves. Participants expressed concern about being seen to 'waste the doctors time' by presenting with illnesses that were not deemed to be serious. Advice that advocates for parents to challenge the diagnosis of health professionals may be difficult to enact in this climate.

Chapter 7 Focus group findings 2

This chapter explores participants' understandings of infection and immunity and perceptions of management of these within the healthcare system, specifically:

- How acute childhood illness is assessed by health professionals
- Beliefs and understandings about AMR
- Beliefs and understandings about sepsis

7.1 Seeking assessment of acute childhood illness

7.1.1 Parental attitudes to receiving a viral diagnosis: 'Viral's just a word'

Deciding to seek medical review for a child's symptoms and subsequently being advised that they were due to a viral infection was a common experience. For some participants, this was interpreted as being told that there was nothing that could be done to help speed recovery, and this had a disempowering effect. For others, a viral diagnosis was felt to be meaningless and a catch all term for when the doctor was uncertain of the true diagnosis; according to Carol in FG7 'viral's just a word.' In FG14, Erica, who worked as a nurse at NHS24, described feeling frustrated when she had encountered such attitudes during telephone appointments with parents when they were advised, quite reasonably in her view, that their child's illness was likely to be caused by a virus. However, her fellow participant Marie disagreed, stating that she felt a viral diagnosis was a way of 'fobbing off' parents. She recounted taking her son to her GP several times before eventually insisting that he was given antibiotic treatment and felt that this delay had an ongoing negative impact on his health, leaving him with a 'weak chest' (Appendix 23).

In FG12, Katie described 'using her instinct' in seeking a second opinion when her son's rash was dismissed as viral but was in fact due to scarlet fever, caused by streptococcal infection and requiring antibiotic treatment. However, receiving a definitive diagnosis (viral or otherwise) was widely perceived to be uncommon. The apparent lack of requirement to identify which virus was likely to be responsible for symptoms reinforced the idea that 'just' viral meant that the doctor was not concerned and that the illness was mild, which was frequently out of keeping with how that illness was experienced within the family unit. In FG13, Judy described a recent initiative at her own GP practice where parents were provided with written information about the most likely viral diagnosis, in this case hand, foot and

mouth disease. She felt that this provided some authority when relaying the diagnosis to friends and family, who may otherwise have cast doubt on its validity (Appendix 23).

Thus, the ability to have some clarity about the identity and likely course of the underlying infection was welcomed, not only for the reassurance that this afforded them as parents, but also to justify re-attendance if required and to appease others who had a stake in their child's health. For Judy, even a simple information sheet detailing the likely diagnosis and course of illness was sufficient to feel that her child's symptoms were being taken seriously and satisfied her own concerns and those of others who might enquire about her child's condition. In turn, this fulfilled a related, yet distinct, need for Judy to feel she was being seen to act in her child's best interests. In contrast, leaving 'empty-handed' and with only a vague diagnosis relied on the clinician being able to minimise the child's symptoms to justify their management decision. The value of issuing written advice for presumed viral illnesses, and in selecting the most likely candidate where definitive testing is unfeasible, is worthy of further evaluation regarding its impact on parent satisfaction with the outcome of the consultation and on reducing unnecessary prescribing.

7.1.2 Perceptions about antibiotic prescribing decisions: 'Cause he's a baby…'

Despite widespread awareness that it was desirable to avoid using antibiotics where possible, many participants described feeling pushed towards accepting an antibiotic prescription. This was often perceived to be a strategy for bringing the consultation to a resolution as quickly as possible.

In keeping with known differences in prescribing patterns for different population groups, several participants perceived antibiotics as more readily prescribed for children. In FG10, Rachel described an experience when she had been prescribed antibiotics for her young son when he developed a temperature and rash. She perceived that the GP's decision to prescribe (having diagnosed a throat infection, believed to be due to streptococcal infection) resulted from a combination of a rushed appointment and genuine concern, and speculated that his decision was swayed by her son's young age.

Similarly, in FG9, Lynsey described an experience where a nurse practitioner 'made out' that she wasn't supposed to prescribe for throat infections but did so because the patient was a child, saying

"I tend tae give kids them a wee bit more sooner rather than letting it get that far." (expanded in Appendix 23)

Lynsey, 23 FG9 Baby Cafe

This sends out confusing messages to parents, with antibiotic prescribing presented as sometimes considered illicit and something that may be withheld, even though it may be beneficial. It also hints at unspoken concerns of health professionals, and the uncertainty surrounding the end goal of antibiotic prescribing without a clear indication; it is unclear whether phrases like 'get that far' refer to preventing avoidable discomfort or something far worse (including sepsis).

In FG1, June, who was an experienced practice nurse, was able to offer a unique perspective, having tragically lost her teenage son to sepsis. Although it might have been expected that she would have a precautionary approach to antibiotic use, her perspective was that her colleagues continued to prescribe them too readily, even where there was clear guidance to support not prescribing (Appendix 23). Later in the discussion, she rejected any idea that there has been a shift in prescribing practice in the community; in her experience certain presenting symptoms e.g., a chest infection, seemed to result in an automatic prescription for antibiotics (Appendix 23).

Many participants had experience of being asked whether they wanted antibiotics for their child, presumably to encourage shared decision-making, however, it was not always interpreted as such. For Anne, who took her grandson to the GP when he had a persistent 'rattle' in his chest, being asked if she felt an antibiotic was needed was perceived as equivalent to stating that it was not required (Appendix 23).

Delayed prescribing, a common strategy to reduce unnecessary prescribing where the patient is issued with a prescription but advised only to collect it if symptoms worsen or do not improve, was met with mixed approval. Some participants, such as Claire in FG5, valued the personal autonomy that this allowed, stating that when issued with one for her son it gave her 'a wee bit of control', even though she didn't use it. However, for participants in FG6, this was not welcomed and perceived as passing responsibility from doctor to the patient:

Debbie: "…it's putting the judgement back onto you, i'n't it?"

Rhona: "That's not right. I don't think that's right… if they're prescribing you a prescription then they should be saying you need to take it. That's not up to you to decide whether or not to take it."

Justine: "You're no' the doctor."

Debbie 32, Rhona 34 and Justine 31 FG6 Group of pre-school parents

Ultimately, involving parents in decision-making about prescribing was often interpreted as reflecting ambivalence on the part of the prescriber. In FG1, Joseph was asked if he felt his child needed antibiotics and expressed a preference to avoid them. When he asked for advice about natural alternatives, he was told, "to be honest wi' you... their immune system will deal wi' it on its own."

In FG6, Justine had encountered a similar attitude:

Justine: "when I told the doctor that Ariana wouldnae take the antibiotic, he told me the infection would clear whether you've taken it or no."

Jacqui: "So, it's pointless gi'ing you them in the first place."

Justine: "She just wouldnae take it, she spat it out and wasnae taking it, and I phoned – she had a bad ear infection – and I phoned, and I was going away on holiday for a few days, and he was like that, "Oh, it should be fine whether she takes it or not.""

Justine 31 and Jacqui 37 FG6 Group of pre-school parents

This message is concerning, suggesting that antimicrobials are sometimes prescribed as little more than a placebo, undermining messages about the need for judicious prescribing and, in turn, about the true threat from AMR; as far as parents are concerned, if the threat from unnecessary antimicrobial use is as great as predicted, then health professionals would be prevented from prescribing them for conditions that they believe will resolve without them.

Additionally, several participants expressed concern about the potential for harm from exposure to antimicrobials that were not required. This was particularly salient for parents whose children had chronic health conditions that necessitated recurrent treatment. For example, in FG5, Angela described her child as having had recurrent ear infections since infancy, and she felt that antibiotics were often prescribed as soon as she sought advice, without full consideration of whether they would be of benefit on that occasion. Such was her concern, she now disregarded medical advice and only administered treatment if she felt the symptoms were particularly severe.

In FG12, Katie described trying to communicate (unsuccessfully) her concerns that her daughter's symptoms were related to asthma, but instead was given antibiotics that she felt were unnecessary (Appendix 23). It is notable that Katie seemed unable to state the nature of her concerns explicitly, relying instead on giving the doctor 'clues.' This exemplifies the challenges that parents may face in establishing effective communication and calls into question how empowered they would feel to challenge medical opinion, particularly where such challenges undermine the clinician's ability to recognise serious illness, as recommended in sepsis awareness campaigns.

There were some exceptions; for example, in FG8, Nicola described noticing a recent shift in attitudes to prescribing. Similarly, in FG1, Anne expressed a view that although in some practices antibiotics are handed out too readily (and despite the aforementioned experience with her grandson), this was in fact not the norm in her own practice. However, the dominant experience for participants in this study was that antibiotics were readily given, and that as patients they could influence this by ensuring the doctor knew that this was their preference. Conversely, expressing that they would prefer not to have antibiotics for their child was met with ambivalence or less commonly, as in Katie's experience, disregarded.

7.1.3 Parental attitudes to health professionals: 'Doctors are only human'

In general, participants were sympathetic to the challenges faced by doctors in assessing diverse and complex symptoms, particularly given the limited time available during appointments. In FG20, Mandy recognised that, even for experienced doctors, there would inevitably be exceptions where a patient's illness would not progress as expected. Audrey suggested that it was the speed with which sepsis could develop that set it apart from other conditions (Appendix 23). The dilemma that prescribers face in balancing protecting patients

from potential harm with ensuring that the effectiveness of antibiotics is preserved as far as possible was articulated by Nicole in FG19:

"GPs are human beings… so it's like they've got that whole kinda thing where there's like, 'if I don't give an antibiotic it could turn into something serious, but then if I do give an antibiotic and it wasn't… something serious, then (the infection) could…, become resistant… it's like Catch-22…"

Nicole 30 FG19 Parent café

A recurrent theme that was voiced by participants in several groups was that doctors were no more than ordinary people, and therefore errors of judgement were not only understandable but inevitable. Views varied on how transparent clinicians should be regarding diagnostic uncertainty. In FG12, participants agreed that it was more reassuring if doctors were honest about the limitations of their capacity to provide a definitive diagnosis in a primary care setting (Appendix 23).

However, for other participants, acknowledging uncertainty was viewed as unprofessional. For Angela in FG5, being open about the limitations of their knowledge and actively checking information appeared to compromise her view of her doctor as in a position of authority that is dependent on being a member of a professional group whose members are unique in their possession of specialist knowledge:

"…I know that obviously, things change, legislation changes, the rules change. But I don't know how many times I've been to the doctors and they'll say, "Oh, yeah, it might be that…" And then they look up a book, and I think… "Oh, is that a book that I could be looking up. What are you looking for?" And, I know that obviously doctors need to check, and they're checking dosages and things, but I'm just thinking to myself, 'Well, it doesnae really look very… professional.'"

Angela, 31 FG5 Group of pre-school parents

Thus, in order to fulfil the expectations of some patients, doctors may feel a need to maintain a role as all-knowing, even if this is wholly unrealistic in a profession where guidance about evidence-based best practice changes frequently. In some groups, participants were more

explicit about their negative attitudes towards doctors. For example, in FG1, during a lengthy discussion about perceived problems associated with under-resourcing in the NHS, Patrick suggested that this problem could be solved by reducing doctors' salaries and diverting this money elsewhere in the healthcare system (Appendix 23).

Although apparently intended in part as a humorous comment, Patrick's suggestion raises an important point. As the most expensive health professionals employed in the healthcare system, doctors must be able to demonstrate their worth. This may be more important than ever as other healthcare professionals develop increasingly specialist roles. One way in which doctors can 'add value' to a consultation is by offering an antibiotic prescription that other professionals in the practice are unable to or may be able to do so only within strict parameters. In FG5, Claire described her frustration at being encouraged to see the nurse practitioner, who she was advised could do 'everything a doctor can do' but then having to wait to see her GP anyway to access the antibiotic the nurse practitioner felt was indicated (Appendix 23).

While this is a single example, and the antibiotic may well have been clinically indicated, it is possible to see how the power to prescribe may be held in reserve by clinicians as a potential tool for appeasing patients who may have had a lengthy wait, or for concluding challenging consultations. In the above scenario, an added consideration is managing the expectations of the colleague who determined that the child needed to be seen by a doctor; failure to then issue an antibiotic may be viewed as undermining that individual's own assessment of the situation. The ease with which individual practitioners are able to do this is likely to depend on many factors, including individual personality traits, level of experience and working relationship with colleagues.

7.2 Beliefs and understandings about AMR

7.2.1 Understandings about drivers of resistance: 'taking them for a cold'

There was a commonly held view that antimicrobial resistance always developed as a consequence of suboptimal use, rather than as an inevitable consequence of any antibiotic use. Inappropriate demand and prescribing (such as 'taking them for a cold' Patrick, FG1) and not finishing a prescribed course were the most frequently suggested drivers of resistance. In the UK, where antibiotics are only available if prescribed by a qualified practitioner, it seems implicit that inappropriate use by patients is associated with

inappropriate prescribing (except for retaining leftover antibiotics for future use or using someone else's drugs) and there were multiple occasions where participants expressed the view that overprescribing by doctors was also a key driver.

However, 'inappropriate' use was not always perceived to be within an individual's control. In FG10, Rachel had already recounted an experience where she had been prescribed antibiotics for her young son but had difficulty administering them. She perceived that failure to complete a course of antibiotics as prescribed was a key driver of resistance and, although she did intend to give the antibiotics, she was concerned that she may have placed her son at greater risk by failing to give a complete dose than if they had not been prescribed at all.

Many participants held a view that the risk of infection was related to lifestyle, therefore to a great extent the need for antibiotics is dictated by practices within the family unit. Many participants, particularly in groups 1, 6 and 12, alluded to the belief that early exposure to bacteria and other organisms is important for the developing immune system. In FG1, Joseph suggested that a desire to prevent exposure to dirt inadvertently exposes children to greater risk of harm (Appendix 23).

Later in the discussion, Joseph expressed the view that following a healthy lifestyle provided protection against infection or meant that it was more likely that if an individual did become unwell, they could be cured with a 'simple antibiotic.' Similarly, in FG8 when Aileen expressed the view that she rarely had to visit the GP with her children, Beth declared that this was similar to her own experience and suggested that good health behaviours protected her family from the risk of serious infection. For some participants then, requirements for antibiotics could be lessened by their health behaviour as individuals and, conversely, the need for frequent antibiotics could be viewed as arising from failure to take preventative action, whether in the form of maintaining a healthy weight and diet or avoiding harmful behaviours such as cigarette smoking. It is recognised that the desire to explain the development of a disease frequently involves identifying actions by the affected individual that are causative (197). Angela, whose mother died of sepsis as a complication of lung cancer, illustrated this, describing the assumption on behalf of both peers and health professionals that her mother, a lifelong non-smoker, must have caused her illness by smoking (Appendix 23). Although not directly related to antibiotic use, Angela's experience demonstrates perceptions of the 'victim' as responsible for their own illness that apply in many illness narratives. An analogy can be drawn with attempts by participants in this study

to identify a reason that accounts for antibiotic 'overuse' and subsequent drug resistance from which they can be excluded (e.g., lack of exposure to outdoors, poor diet); thus, not only are the main drivers within human healthcare seen as the result of irresponsible actions by individuals (both patients and prescribers), but requiring antibiotics at all is also seen by some as a failure to adequately protect the health interests of oneself and one's family.

7.2.2 Understandings of mechanisms of resistance: 'the body remembers it'

In similarity with findings of previous qualitative research, most participants believed that drug resistance was a relationship that existed between the antibiotic user's body and a specific antibiotic drug (7, 8, 198, 199). Resistance was usually constructed as something that happened internally, rather than as developing through selective pressure leading to predominance of resistant bacteria that could then pose a threat to others through onward transmission. Little is known about how doctors communicate about AMR with patients and, in general, participants felt that mechanisms of resistance were rarely explained when prescribing decisions were made. Few participants presented their understandings of resistance as having been communicated directly from health professionals, and there was a sense that participants relied on longstanding beliefs rather than explanations about AMR that they had encountered recently. Many participants described their belief that taking an antibiotic to treat minor infections meant that it would be ineffective if needed for a more severe infection. For many participants, this was articulated in vague terms such as the body 'getting used to it' or 'becoming immune.' In FG20, Mandy raises her concerns about the potential long-term impact of antibiotics in childhood, expressed as the child, rather than specific bacteria, 'putting up some kinda resistance to antibiotics' (Appendix 23).

In FG9, Natalie spoke of her concerns over what she perceived as an over-readiness on the part of her GP in offering an antibiotic, which she understood to be related to her history of recurrent tonsillitis. She explained that she often failed to take her antibiotic as prescribed because "I don't want to then build up an immunity to something that I'm gonnae get again." Natalie's belief seemed to be that frequent use of a particular antibiotic caused permanent changes that meant that it would never work again for her, overlooking the fact that her immune system may well encounter external bacteria de novo that the same antibiotic is just as likely to be effective against. A similar view was expressed by Carol in FG7 who described immunity to antibiotics developing in those who took them 'willy nilly' (Appendix 23).

Like Natalie, Carol's belief was that using an antibiotic has the potential to change the body's capacity to benefit from it indefinitely and perhaps forever, constructing the action (or inaction) of antibiotics as something highly individualised and demonstrating a failure to understand that the therapeutic action is on strains of bacteria rather than on the body as a whole entity.

In FG1, construction of the actions of antibiotics as individualised could be seen to inform Patrick's attitude to treatment; he explained that he chose not to take antibiotics because of a belief that they don't work for him:

Patrick: "I'm allergic to penicillin, so my basis for no' really using antibiotics… for myself, is that I have to get erythromycin anyway and I feel that it doesnae work… that's the usual one that they gi' me, the wee red tablets, and I feel that when I start taking them… I need a week, two weeks before it's away, and I'm thinking, 'My tonsillitis or whatever would've been away by then,' do you get what I mean? If I never took anything. I don't feel that it works that good for me. So, that was how I kinda got into no' really using them. Because they werenae working."

LR: "Do you mean that it works for the same bug in somebody else?"

Patrick: "Uh huh"

        Patrick 27 FG1 Support group for lone fathers

Thus, according to Patrick, certain antibiotics are *always* ineffective for certain individuals, demonstrating his perception that the therapeutic effectiveness of a particular antibiotic is unrelated to the characteristics of bacteria that make them sensitive to killing or otherwise but rather to the characteristics of the bodies that they invade. A related concept was that it is the 'strength' of an antibiotic drug that is the best indicator of efficacy, rather than the susceptibility of the infecting organism. A common understanding was that GPs would initially prescribe the 'weakest' available antibiotic, progressing to 'stronger' ones if the initial choice was ineffective, as opposed to broad-spectrum antibiotics that are effective against the widest range of organisms, switching therapy if necessary, when sensitivities become known. Others expressed the view that some people 'always' require two courses of antibiotics to treat an infection, indicating a belief that it is the body rather than the invading bacteria that is the key variable. A related idea expressed by some participants

was that antibiotic use invoked a feedback response i.e., that with recurrent use an individual required higher dosages to have the same effect, sometimes described as building up a 'tolerance'. In FG1, Alan suggested that becoming addicted to antibiotics was a driver of resistance (Appendix 23). A similar understanding was expressed by participants in FG6.

It was widely perceived then that drug resistance is a process that happens because of tolerance that develops within the body, rather than due to preferential survival of resistant strains of bacteria. In some respects, this belief is not wholly inaccurate, and there is mounting evidence that treatment with antibiotics may cause persistence of resistant forms of bacteria within the user (200). However, this belief conflicts with conventional understandings of resistance and the 'One Health' approach to messaging about risk that public health organisations endeavour to convey. In FG17, Sheila, who had been critically ill because of postoperative sepsis, eloquently articulated the widely held misperception that the risks of antibiotic use pertain only to the individual that she too shared until it was dispelled by her hospital consultant:

"I was very worried when I came out of hospital, 'cause I mean, I was on, I think every antibiotic going over the course of seven weeks. So, I'd had a huge amount of antibiotics into my system... and I was worried when I came out. I said, "What happens if I catch something else now? 'Cause I feel like I'll have no resistance to anything, and if they give me more antibiotics, if I catch something else, will the antibiotics work?" But, what I was told in hospital was they would. So, that's an individual, it's not the antibiotics you've had as an individual, which I always thought it was. I thought if you, as an individual, if you had too many antibiotics, your body built up a kind of resistance to them. But, I think my understanding had been wrong on that."

Sheila, 49 FG17 Group of individuals with lived experience of sepsis

So, for Shelia, fears over the potential for long-term harm associated with antibiotic treatment were allayed. That Sheila's perception was shared by so many participants in this study, and by those in previous research, highlights an important limitation of current messaging about AMR. The main risk that the public perceive through public health messaging is that antibiotic use may have serious health impacts primarily for the user, while the potential for harm for non-users is overlooked. Most antibiotic users will fortunately not be seriously impacted by drug-resistant infections in a personal capacity;

therefore, the experiences of most individuals offer no reinforcement of antibiotic use as a genuine health threat. It is unknown whether Sheila's infection was resistant to standard drug regimens, but even if this was the case it would have been unlikely that this could be linked to her own past antibiotic use with any reliability. This demonstrates that current messaging about AMR is ineffective in communicating that the development of drug-resistant bacteria through selective pressure of antibiotic use could affect anyone, regardless of their own personal antibiotic use. As a side note, it is notable here also that 'resistance' is used by Sheila to denote something positive, as though synonymous with immunity. The language used to communicate about AMR often seemed confusing for participants, with uncertainty about whether resistance – a survival benefit for bacteria – should also be used to denote something beneficial for the individual as a host.

In some respects, perceptions regarding the mechanisms of resistance were often presented as more complex than the reality. Many participants spoke in terms of antibiotics gradually reducing the body's ability to exert a response to infection over time. Here, Barbara, who described herself as 'not a doctor' but as having 'a medical background' offered a vivid illustration of her understanding about how resistance develops:

"…every time that you have a drug, the body remembers it so it knows what to do with it the next time you have it, how to combat sort of this infection, so it becomes used to it so much that the body sort of gets… not lackadaisical but it knows what to do and then the virus is going, 'Well, actually, I can beat that', and there's like this big fight going on. So, the antibiotics will hit it sort of at this level whereas actually you need it at this level, and then it becomes the point where it's just not worth giving you it because you're so used to hitting it, it needs more than your body can take to give it… and then that's when you get into things like sepsis because the infection is just spreading and spreading and spreading and then you need more and more to try and counteract it and things."

Barbara, 34 FG12 Group of pre-school parents

Here, Barbara conjures up imagery of a battle between a mighty invader (here, inaccurately imagined as a virus) and the unsuspecting host defences, duped into complacency by repeated reliance on antibiotics. In fact, the truth is more prosaic; those bacteria with traits that render them resistant to killing will eventually predominate over the susceptible forms. Thus, the processes involved in the development of resistance appeared to hold some

mystique for some participants that belied an understanding of its biological basis.

The belief that antibiotics should be avoided in young children due to the potential for harm to their developing immune systems was widely held but not well-formulated. For some, there was an apparent belief that using antibiotics in early childhood interfered with time-sensitive opportunities to develop effective immunity, as described by Shannon in FG6 (Appendix 23). Shannon's perception seemed to be that experiencing an infection offered lifelong immunity, with apparent failure to understand that the same infecting organism can cause illness repeatedly in the same individual. In this way, some childhood illnesses were seen as beneficial. For some participants, this was linked to vaccine hesitancy. In FG14, Irene, present in her capacity as a grandmother, expressed preferring natural remedies and described withholding the MMR vaccine from her own children due to perceived complications in a friend's child (Appendix 23). It is notable that illnesses like measles and mumps were perceived by Irene to be normal, and perhaps even beneficial, despite their potential to cause significant harm. The fear that can surround manipulation of a young child's immune system via vaccination was also apparent in the context of attitudes to early exposure to antibiotics. In FG9, Louise expressed concern that receiving antibiotics in the perinatal period to treat Group B streptococcal infection, as is standard protocol to avoid potentially devastating sequelae, may have caused long-term damage to her son's health by weakening his immune system (Appendix 23).

7.2.3 Who is at risk of AMR: the old, the young and the risk averse?

Just as the actions of antibiotics were perceived to be individualised, so too were the risks. Most participants agreed that groups at risk of harm from resistant infections were those who 'abuse' antibiotics and vulnerable groups including the very young, the elderly and the immunocompromised. The belief that certain groups are at increased risk was related to the belief that they were likely to be higher users of antibiotics than the general population. Very few participants demonstrated an awareness that previously healthy individuals could be affected by resistant infections regardless of their own antibiotic use, the very message that public health leaders wish to communicate. In FG5, Angela and Claire expressed the view that the young and old were at greatest risk, whereas Claire stated that she was 'not at all' worried about those 'in the middle' i.e., the general adult population, though immediately

appeared to contradict herself, saying that she had recently had antibiotics herself which she attributed to being exposed to illness through her child (Appendix 23).

Although the extent of personal use was perceived to be the key risk factor for harm from resistant infections, there was uncertainty about what level of antibiotic use should be considered excessive. In FG14, Irene and Angela debated whether they should consider themselves to be at risk of resistant infections and whether if they minimised their personal use they could escape harm (Appendix 23).

Similarly, in FG5, Claire perceived that risk from resistant infections was related to personal use but felt uninformed about what this meant in practice. Angela agreed that this was a source of uncertainty and suggested that warning of the risk without properly quantifying what constituted excessive use was 'scaremongering' (Appendix 23). Later, Claire speculated that lack of clarity about what constitutes excessive use of antibiotics was a function of the uncertainty that characterises knowledge about AMR, even for 'them' (health professionals) (Appendix 23).

A minority of participants demonstrated awareness of the capacity for person-to-person spread. Scott, who worked in gym settings as a personal trainer, was more conscious than most about infection risks that were present in the community:

"… the people who are out there taking every drug known to man, they're building up the tolerance and then you get these viruses that are resistant… if it is a viral infection, they're quite easily gonnae infect someone else, and the strain you've got is already resistant to everything on the market, so…you know, you'll end up with that whole process of having to get stronger and stronger stuff..."

   Scott, 36 FG12 Group of pre-school parents

In FG19, the risk of person-to-person spread was acknowledged, but only after the assumption that only certain groups are at risk was challenged (Appendix 23).

7.2.4 Personal experiences of resistance: 'she *is* old'

Very few participants were aware of individuals who had been impacted by a drug-resistant infection. When I asked about experiences, different examples were offered that illustrated the various ways in which individuals construct their ideas about how antibiotics might cause harm. Some participants gave examples of when antibiotics had been ineffective for family members, but it was unclear if this was due to the nature of the infection or to the severity of their underlying condition. For example, Angela described how the antibiotics her mother received after developing sepsis at the end of her life proved ineffective, when they had previously led to a marked improvement (Appendix 23).

In FG6, Shannon described the problems that her grandmother had experienced with urinary tract infections caused by drug-resistant bacteria but acknowledged that long-term mobility issues and her advancing age had contributed to this, conceding that 'she *is* old' (Appendix 23).

Other participants who worked in healthcare had experience of resistant infections in the form of MRSA, but this was limited to patients who were in particular 'at risk groups' in that they were long-term hospital in-patients or had indwelling therapeutic devices. In FG17, one of the groups formed of individuals with lived experience of sepsis, Bill's only direct reference point for resistant infection involved a family pet whose infection had failed to resolve with multiple courses of antibiotics.

In terms of negative personal impacts of treatment, very few participants could provide examples of adverse effects that could be directly attributed to antibiotic use. In FG18, in response to a query about experiences of resistant infections, Linda described being told that she had developed C. difficile infection as a result of the antibiotics she had received to treat her sepsis that had 'wiped out any resistance.' However, C. difficile infection, a common complication of broad-spectrum antibiotic treatment, is not synonymous with development of resistant bacteria that cannot be successfully treated with other antibiotics. It is noted that Linda's use of 'resistance' here denotes it as something positive that is compromised by antibiotic use, once again demonstrating the scope for confusion that surrounds language used in communications about AMR.

In FG19, (quoted previously), Leigh described experiencing the 'backlash' of antibiotic treatment, however, it is likely that she was referring to common side effects like

gastrointestinal disturbance or thrush. Other participants spoke about having experienced allergic reactions as examples antibiotic-related harm.

Thus, participants' experiences of resistant infections were confined to illness in individuals who had underlying risk factors in that they were elderly or hospitalised and had complex comorbidities, or in one case to a family pet. This is problematic for current messaging about AMR; participants perceive that personal use is presented as the main driver of harm associated with AMR, however, this message is not supported by their own experiences. In essence, public health leaders are trying to convey a message about required behaviour change to combat a problem that, at present, does not actually exist within the personal experience of most individuals.

7.2.5 Media framing of risks of AMR: 'just another bad news story'

To assist with eliciting views about how health risks related to antibiotics are portrayed in the media I introduced a selection of articles that represented typical stories about AMR and sepsis. My intention was to demonstrate the potential for conflict in the messages they contained although, in retrospect, it may have been more informative to introduce the articles about each topic at different stages in the group to be able to distinguish clearly which views pertained to which articles. Some participants appeared to interpret being presented with articles about both topics simultaneously as an intention to demonstrate that they were related. However, although my primary goal was to explore reactions to different ways of presenting health risks, this approach was useful in prompting discussion about understandings of the importance of resistant infections within sepsis and to what extent participants saw the issues as connected.

In FG5, Angela speculated that publicity about the risks of sepsis was related to increasing concerns about AMR:

"… it just seems… you hear about (AMR) and then you hear about the cases of sepsis. I don't know if they're trying tae… scare you, like, "don't take these antibiotics unless you need them because if you've got sepsis it might not work"

Angela, 31 FG5 Group of pre-school parents

In FG12, Scott appeared to demonstrate a perception that the 'risk' of inappropriate antibiotic use is sepsis but felt that the way in which the issues are framed was unhelpful and therefore he simply 'blocked it out'.

"...I don't want to say scaremongering 'cause obviously sepsis is a serious condition, but they don't really lead with, 'this is what happens when it goes wrong', they just kinda say, 'Oh, look, another child has died because of… viruses becoming resistant to antibiotics' … I think the important bit of the message is kinda missed out."

LR: "What do you think the important bit is?"

"The symptoms of what to look out for and how it can go wrong, cause… you know yourself when you've got an experience with something, like me with bronchiolitis, I'd heard of it before and never thought anything of it, but once you realise that children could actually die if you don't get them to hospital, you know, when it gets serious enough, I then become a lot more aware of it..."

Scott, 36 FG12 Group of pre-school parents

Thus, Scott suggested that, for him, it was only when he had personal investment in a health issue that he became receptive to messages, and despite having awareness of antibiotic overuse and sepsis as having prominence in the media, what he perceived as a lack of accompanying practical advice appeared to cause blurring of the two issues.

The term 'scaremongering' was used by participants in several groups, reflecting a perception that warnings about the risks associated with resistant infections were excessive. The views of Linda in FG18 were of particular interest, given her occupation as a journalist. Here, Linda and her co-participant Kerry give their reactions to typical news articles about AMR:

Linda: "...you know, I think a lot of people might view that as scaremongering and think, 'Nah, that's not going to happen. There'll always be something that will make me better, if it's just an infection I've got,'… and I don't think generally that the public are aware of how serious it is... that's a typical Daily Mail approach, isn't it? That dishing out too many antibiotics poses the same threat to humanity as terrorism. It's not a particularly informed and… balanced approach to it. While the sentiment of the story is probably accurate, you

know… that approach… I don't think is helpful… I am a journalist… and, we always say to people, "The best way to demonstrate something…"

"For example, let's say they're bringing in a new procedure in your office. We always say, "The best way to demonstrate it is not to say, 'We're bringing in a new procedure and this is what you will do.' It's saying, 'Kerry *(her co-participant)*, you've gone through this, tell us how it affected you, did you have any problems?'" You know, it's using case studies to show rather than tell about the risks… so if you look at the girl behind, the amputee charity, you know (reference to Corinne Hutton, a quadruple amputee who has campaigned extensively to raise awareness of sepsis, (201)) that's just done Kilimanjaro, she's showing what the effects were and the impact and the results… she's a very good example of, "This could be you… one minute you could be fine, and the next day you're not.""

LR: "Why do you think those sorts of stories are absent from reporting about antibiotic resistance as opposed to sepsis? Have you any thoughts on that?"

Linda: "It's probably more of a difficult one to illustrate because, you know, the risks that you're talking about occurring are death, for example, and, you know, obviously those people are no longer here. Although… families are very good at… talking honestly and, about their experience… I think it's like everything, you'll maybe be the same, that things don't really come on your radar until you're personally affected by them. Like, people become fundraisers for breast cancer because they lost their mother or whatever. I'm quite evangelical about sepsis because I suffered it, but it's not on most people's radar."

Kerry: "I think as well, I think just now there's so much to worry about, you know, I think in general people feel like the world is very fearful kind of, you know, it doesn't feel good just now, and something like sepsis or the antibiotic, the sort of resistance is…"

Linda: "It's not high on your list of priorities, is it?"

Kerry: "Yeah, it's just—yeah. It's like… it's just another bad news story, it's the apocalyptic sort of story about, "The End is Nigh," sort of thing and I think… I think a lot of people just now… are probably at saturation point with how, how terrible everything is everywhere."

Later in the discussion, Linda questioned the long-term implications of failure to communicate effectively about the risks associated with resistant infections if predictions about anticipated health impacts are accurate:

"It would be interesting... however many years down the line is when they say, you know, going in for a hip operation will become a dangerous thing or going in to get a wisdom tooth out, to see what the papers are saying and then what the public are saying, you know? "We told you so." Or, "Nobody ever told us about that." ... "And, I wouldn't have had those antibiotics," you know. And I suspect that is what will happen, that the public will say, "Nobody told us." They did. But you didn't listen, is probably a reality."

Linda, 52 and Kerry, 35 FG18 Group with individuals with lived experience of sepsis

7.3 Beliefs and understandings about sepsis

7.3.1 Understandings of sepsis: random cuts and rusty nails

In FG7, Carol described her knowledge about sepsis as 'bits and bobs, here and there', and this seemed to be a good description of participants' prior awareness of sepsis, which was derived from a variety of sources including friends, family members, colleagues or acquaintances who had been affected; television campaigns; and stories that circulated on social media. The most common conceptualisation of how sepsis develops was that it begins with entry of bacteria through a cut or open wound, as described by Kerry in FG18 who had suffered from sepsis herself (Appendix 23).

Similar perceptions were apparent in other groups, although this depended on individual experiences; for example, in FG8, participants had held the view that sepsis developed secondary to an infected cut or surgical wound, but this had been challenged when the child of one of the group members had recently been admitted to hospital with sepsis that was unrelated to any external injury.

Interestingly, for two participants in different groups, the most accessible example of sepsis was a story that had recently circulated on Facebook about an individual who had developed sepsis as a result of biting their nails. Despite proactive attempts to maintain a good awareness of prominent media stories about sepsis, this had gone unnoticed by me. Carol described this story as having had a substantial personal impact (Appendix 23).

It seems likely that certain aspects of this story afforded it prominence for participants who were exposed to it that enabled them to recall it readily; first, it fitted with constructions of how sepsis develops (i.e., entry of bacteria through a beach in the skin's integrity) and second, it was a course of events that participants could easily imagine happening to them, as it did not require them to identify as a member of a group perceived to be vulnerable.

Some participants described how, in retrospect, they had encountered sepsis but had been unaware of this at the time due to the language used in communications with medical staff. For example, Joan and Chelsea, the wife and daughter of Jim who had sadly died the previous year, had described to me how he had developed sepsis on two occasions. As I explored their understandings of the meanings associated with different terms, Chelsea actively demonstrated working out that her father had in fact developed sepsis on an earlier occasion, at the time referred to as 'blood poisoning.' Although they were aware that they described the same condition, Joan felt that they conveyed different meanings and that 'sepsis' suggested greater severity of disease:

> "Sounds worse, doesn't it? It sounds fatal. It makes me think that way anyway."

> Joan, 62 FG16 Group of individuals with lived experience of sepsis

In FG17, Bill recalled a memory of a neighbour who had died following complications from surgery (described as a 'nick in his bowel') which he felt today would have been attributed to sepsis and which he perceived to have been concealed at the time (Appendix 23).

The views of two participants were particularly illuminating in charting the changing image of sepsis. June and Gary had lost their 19-year-old son Rhys to sepsis in 2015. Although Rhys had recently been diagnosed with dilated cardiomyopathy, which he knew was likely to be life-limiting, he lived the full and busy life of a typical young adult and his death had been sudden and unexpected. In this respect, although Rhys was not a child, his story bears strong resemblance to many of the accounts in the qualitative content analysis. June described how despite being an experienced practice nurse, the possibility of sepsis had not occurred to her initially:

June: ...we got a phone call from (Rhys)... to say that he was in hospital with a chest infection/pneumonia. And when I went down to the hospital... he was on IV antibiotics, oxygen, everything like that. But nobody had said, had mentioned sepsis.

And obviously, I mean, in retrospect I should have known, but I just didn't. 'Cause… because again I hadn't heard of sepsis for so long. Now, perhaps if this had happened now, because we're more… well I'm more aware of sepsis and working in primary care, you know, we… are getting it drummed – and quite rightly so – drummed in tae us, 'think sepsis, think sepsis,' and anybody that comes in unwell, we have to do the like the score and scoring and things like that. So perhaps now I would think of sepsis, but three years ago I certainly didn't. So, it came as a shock, and then like... we're going, "That's septicaemia, that's really not good." And clearly the disease ran its course and ultimately took Rhys.

It is illuminating that despite June's occupation as a practice nurse, she did not equate Rhys's illness with sepsis, but considered that in a short space of time awareness had altered dramatically. I asked her to explain more about this:

June: "...when I was working in the hospital, you heard o' patients having septicaemia. But… I don't mean nobody really thought about it, but they were put on IV antibiotics and… "

Gary: "If it worked, it worked, if it didn't… aye."

June: "Basically, if they lived, they lived, and if they didn't, they didn't. I mean, it was as simple as that, there wasn't any of these early warning things… which thankfully we do have now…"

Gary: "I think that's changed."

June: "It was like… it was like almost a natural progression from, you know, somebody wasn't well…"

Gary: "A chest infection, pneumonia, whatever… aye."

June: "And then they had sepsis, or septicaemia. But now we're thinking that first."

June, 45 and Gary, 51 FG15 Group of individuals with lived experience of sepsis

7.3.2 Evolving constructions of sepsis: 'it's been rebranded'

Coincidentally, on their way to the focus group, June and Gary had encountered volunteers from FEAT (the Scottish sepsis charity who had obligingly publicised this study on their website), who were running a public engagement event. They had been asked for their views on how sepsis awareness could be improved and recounted their discussion (Appendix 23). Gary intimated that among his supermarket colleagues only a small minority were aware of sepsis, although more were familiar with septicaemia. However, June explained that this was not unique to lay people and described confusion over terminology among colleagues in her own workplace:

"Working as a general practice nurse… I had to Google what's the difference between sepsis and septicaemia... because I thought, 'is this a new thing, is this a new disease?' And… we were talking at work and one o' the doctors… was like that, "I was like that as well," she said "I always just called it septicaemia" ...." That's what that man said to us, from that 'FEAT', he says "It's been rebranded." And that's exactly what it is, it's been rebranded… and if that's going tae help people, fantastic, call it something else, that's great."

June, 45 FG15 Group of individuals with lived experience of sepsis

Thus, June perceived that there had been a substantial change in direction in how patients who presented in the community with symptoms suggestive of infection were managed since Rhys' death.

7.3.3 Professional reticence in acknowledging sepsis: 'No-one said sepsis'

A common theme for participants who had been affected by sepsis was that it was often not mentioned during management of their acute illness. Joan and Chelsea noted that, while sepsis was mentioned by the paramedic who initially attended Jim at home, it was overlooked during his initial management in hospital, and a sepsis checklist in his medical notes was not completed on admission. Only after several days in hospital was sepsis mentioned again, this time by a renal specialist who explained that it had caused his organs to fail.

Similarly, June had already articulated that 'sepsis' did not feature in initial communications with medical and nursing staff when Rhys was admitted to hospital, and she and Gary

presumed that he was suffering from a chest infection that would resolve easily with treatment. Sepsis was only mentioned several days into his admission when the severity of his illness was not in doubt.

Thus, for both Rhys and Jim, 'sepsis' was not used in communications with their family members until the point where it was acknowledged that they were gravely ill and suffering from organ failure. For both, there seemed to be an unspoken transition from an illness that was portrayed as 'just an infection' to sepsis, with no clear tipping point where one condition ended and the other began. This perhaps suggests that there are 'safe spaces' in which health professionals feel comfortable in saying sepsis. For the paramedic who admitted Jim to hospital, suggesting sepsis was perhaps felt to be of little risk to his professional reputation, given that he had already decided to escalate his care. It is unclear whether the GP who advised Rhys to go to hospital raised sepsis as a possible diagnosis, but similarly, it would have been safe to do so, having already decided that he warranted further assessment. At the other end of the care trajectory, it was safe for the specialists attending the patient in an intensive care environment to discuss sepsis, secure in the knowledge that all necessary steps had been taken to treat the condition. However, in the middle of this pathway, there may be far less security for those health professionals at the frontline of determining whether a patient will recover fully with minimal intervention or is at risk of rapid deterioration unless they escalate care appropriately.

For Linda, who developed sepsis postoperatively, the word was only mentioned when she pressed her surgeon for more information about her illness (Appendix 23). Linda speculated that doctors perhaps did not attempt to explain her illness to her because they believed she wouldn't understand:

"I think, maybe there's a perception among doctors that, "Patients aren't going to understand if I use technical language." But, when I said to my surgeon, the consultant, you know… how ill have I been? And, he said, "Why do you want to know that?" And, I said, "Because it will give me some perspective." And, at that point, he became very, he was a very decent doctor, he treated you like a person, but at that point, he became very professional and, "Right, you have this, this, this, this, and this…" …but, I don't think he would've said that, had I not asked… If I had come out not knowing what it was, I still wouldn't have been aware of sepsis, and the impact it can have. I would just have thought it's an infection."

Linda, 52 FG17 Group of individuals with lived experience of sepsis

In the same group, Kerry, who initially developed sepsis after a Caesarean section, described how she was able to recognise symptoms when she developed it again (Appendix 23).

Thus, Kerry was able to recognise significance of her symptoms when she developed sepsis on a second occasion due to her growing awareness of the condition, while Linda was only aware of the nature of her illness because she sought an explanation and perceived that it had been assumed that it was of no significance to her. Thus, reticence in openly communicating about sepsis with patients has implications for improving understanding that may be important in determining subsequent outcomes.

7.3.4 Uncertainty about inevitability of outcomes: If onlys

The same intense sense of regret that was apparent in findings of the qualitative news content analysis permeated experiences recounted by survivors and bereaved families in the focus groups. For Rhys' mother June, there were several points in the course of his illness where she perceived that, if certain things had been different, so might his outcome have been. June and Gary described how he lived life to the full despite a diagnosis of cardiomyopathy that he knew was likely to shorten his life expectancy. When he initially became unwell, he was at a friend's house party, and although Gary stated that he was glad that he spent his last few months doing what he enjoyed, June speculated that, had he been at home when he became unwell, she and Gary would have insisted that he went to hospital sooner.

Once in hospital, June expressed a feeling that she "should have known" how unwell he was, given her nursing experience. However, her main source of regret, and a theme that she returned to several times over the course of the discussion, was that she had not insisted that he was transferred from the district general hospital where he was initially admitted to a specialist cardiology unit. Although the transfer was eventually made, she speculated that this should happened earlier in the course of his illness, although conceded that it was ultimately unlikely to have altered the outcome. It was clear that this had been a source of some tension between them as a couple. Although at most times they presented a very united front and appeared mutually supportive in their grief, June was quick to correct any inaccuracies in Gary's recall of Rhys' care. Because Rhys' heart condition had been inherited from Gary, I wondered if there was an undercurrent of guilt and blame associated with this that manifested in disagreements about the details of his care. They recounted how, at a meeting after Rhys' death, his cardiologist at the district general hospital gently

suggested that he shared their opinion that his transfer should have taken place earlier (Appendix 23).

For Sheila, regret was focused on the hearing loss that she had suffered as a side effect of antibiotic treatment. She speculated that being admitted to hospital at the weekend may have influenced the quality of care that she received, and additionally that had she allowed her sister, a nurse, to visit then she may have recognised how unwell she was. She also conceded, however, that the parameters used to diagnose sepsis, i.e., her temperature and blood pressure, were not deranged at the point where she became unwell, and therefore it was possible that closer observation would not have enabled the condition to have been recognised earlier.

For Joan and Chelsea, their main regrets about Jim's care centred around failure by ambulance services to provide suitable transport. The initial injury to his feet that eventually led to sepsis was caused by trauma as he was transported home following an outpatient attendance, then when he was admitted to hospital for a final time there were delays in sending an appropriate vehicle. They had chosen to pursue a negligence case against the hospital, initially unconnected to sepsis. Joan described how their solicitor's attitude changed when sepsis was mentioned:

"… when I went to see the solicitor the last time, 'cause I went to read his notes, about the last two admissions he had, to see what was actually in them. And, well, when I went to see him, he just says "well there's nothing really there" …but… I said about the sepsis as well, and he says, "that's a different matter…I'll just see what I can do about that", and he just kinda turned it, you know, at the sepsis thing."

Joan, 62 FG16 Group of individuals with lived experience of sepsis

Here, Joan described how the solicitor's reading of the case – and indeed whether there was a case for the hospital to answer at all – changed at the mention of the word sepsis, giving an insight into the loaded nature of the word and its progression from a medical term used primarily by specialists in an intensive care setting to one that has meaning in other settings.

7.3.5 Roles and responsibilities in healthcare-associated harm: 'that blame game'

Some aspects pertaining to attitudes regarding the idea of 'blame' have already been covered in sections about assessing risk in childhood illness so I will focus here on attitudes towards perceived failures in managing sepsis, both of participants in the main groups and in the groups of individuals with lived experience of sepsis.

I was keen to explore participants' views on news articles that apportioned blame for deaths from sepsis to failings within the NHS. As mentioned previously, several groups included participants who worked in the NHS and who were, therefore, able to provide an 'insider' perspective. Although it was acknowledged that failings due to individual errors inevitably occur and should not be ignored, these participants felt it was important to view them within the wider healthcare system. Erica, an NHS 24 nurse, felt concerned that reporting was frequently one sided, reporting only the outcome without offering any insight into the preceding chain of events. As an example, she referenced a particularly distressing case that had recently been in the news about a medical tribunal investigating the death of a pre-term infant during delivery:

"I think people could read one newspaper and go, "Bloody NHS24 again…" But they weren't on the phone. You didn't hear the other end of the phone call… so… I acknowledge but ignore it because unless, you know, take... the Ninewells baby birth *(referencing a recent news story)* say all you want against the doctor, but you weren't in the room. And until you're in that room, it's really, really hard to judge what happened and make your opinion on that."

Erica, 31 FG14 Library story and music group

I then introduced the case of Dr Bawa Garba, which prompted discussion among the other participants about the challenges that staff working in acute settings face (Appendix 23).

June and Gary spoke extensively about the themes of responsibility and blame. Although they had some misgivings about certain aspects of Rhys' management, primarily around the decision to transfer him to a specialist hospital, ultimately, they were satisfied that all involved in his care had done the utmost to save his life and they did not hold anyone responsible for his death. This had clearly been a prolonged process that they had to work through, and at various stages in their grief they had questioned different aspects of his care.

Six weeks prior to his death, Rhys had been fitted with an implantable cardiac defibrillator. Gary recalls colleagues asking him if the infection that ultimately led to Rhys' death had been contracted in hospital, which caused him to question this himself (this was later refuted by hospital staff). He concluded that, for outsiders, there was a need to explain unexpected deaths, particularly those in young people, by identifying a cause and potential source of blame.

When asked about their perspective on the current media focus on sepsis, June and Gary described their previous awareness as very limited and had perceived that it was related to superficial injuries, as described by other participants. Gary described first being aware of sepsis reporting after Rhys's death through coverage of William Mead's story, and June had subsequently spoken to his mother Melissa by telephone. Gary felt that coverage of William's story had been highly effective at getting sepsis on the news agenda, but that this had not been maintained and had 'dropped away'. I was keen to elicit June and Gary's views on the tone of media reporting of deaths from sepsis. Gary speculated that identifying someone to blame was an integral part of the grieving process (Appendix 23).

It was interesting that, from June and Gary's perspective, their direct contact with Melissa Mead did not suggest that her agenda was to apportion blame on any organisation or individual, as media coverage of William's death may suggest. Thus, what can be a mutually beneficial relationship between the press and campaigners also has the potential to become an exploitative one, with journalists focusing on the sensationalist aspects of a story that are likely to be of greatest interest to the readers, potentially at the expense of accurately conveying the messages intended.

In FG20, participants made the link between grief, guilt and blame and acknowledged Melissa Mead's desire to find meaning in William's death by promoting awareness in other parents (Appendix 23).

In FG8, Nicola and Beth suggested that, while sensationalist stories are effective in gaining audience attention, the important factor in translating this into meaningful behaviour change is the presence of a 'takeaway' message; Nicola gives the example of warnings about choking hazards. Aileen suggested that articles that simply apportion blame alone are unhelpful:

Nicola: "...there's a lotta kinda articles that I've read about like regards to children and things that have happened that I now am wary of because of it. Like the whole eating a grape, because that little boy choked on one now, I won't give my kids grapes unless they're chopped. Whereas before I was giving my two-year-old whole grapes, not even thinking anything of it. So sometimes I think it depends on what the article is aiming at, if you know what I mean. ...

" ...when it comes to... the likes o' sepsis I think maybe more facts would be a bit better than… for me, but… and the likes of... like an accident or... like choking or something like that is more…"

Beth: "'Cause see the thing with the grape, right, so it's like that's good 'cause you've like a take-away from that, you now know to like half grapes and you can do that differently. But see if it was something that was more like, oh, they choked because the doctor did this, you know, like…"

Aileen: "Then it becomes that blame game."

Nicola 35, Beth, 34 and Aileen, 34 FG8 Baby café

The source of the story, i.e., whether accessed through traditional news sources or social media was also believed to influence audience perception. In FG10, participants perceived that publicising health risks through social media made risks of relatively rare conditions feel more acute (Appendix 23).

However, despite their capacity to pull audiences in, tragic stories could also be off-putting due to their potential to cause undue alarm. Here, Susie describes how she initially followed Melissa Mead's social media posts but stopped as she found them too distressing because she could easily identify with Melissa as a fellow parent (Appendix 23).

Participants in other groups also described a preference for remaining unaware of risks that they felt powerless to influence. This highlights the importance of tailoring the content of messaging appropriately when communicating about health risks by using simple messages that contain clear steps for participants to follow. In the next section, I will discuss the extent to which participants felt that awareness messages about sepsis achieved this.

7.3.6 The utility of sepsis awareness campaigns: 'What are we supposed to do?

Many participants knew that sepsis awareness was currently being actively promoted and many recalled having seen campaign posters or being aware of specific cases through television or social media. However, many were also dubious about whether the information conveyed could be translated into practical knowledge and whether they would be able to recognise symptoms of sepsis if their child was acutely unwell. The absence of a single sign or symptom on which to focus awareness seemed problematic, and the list of symptoms that appeared in information leaflets seemed to fit with parents' experiences of many self-limiting illnesses. In FG12, Scott described the signs and symptoms listed in sepsis awareness leaflets as being present in '90%' of childhood illnesses, while Katie and Barbara described them respectively as too 'vague' and 'non-specific' to be of use to parents (Appendix 23).

Very similar views were expressed by participants in FG13, where Tracey described attending hospital when her son displayed many of the symptoms listed that, in fact, turned out to be prodromal symptoms of chickenpox. In several groups, comparisons were made between sepsis and meningitis. Although not universally present in meningitis (and an indicator specifically of meningococcal septicaemia), the non-blanching rash that can be detected with the 'glass test' was viewed as a sign on which parents could focus their attention if they were concerned. However, there was no similar test for sepsis that could be used to either reinforce parental concern or offer reassurance. Some participants suggested that certain signs, specifically failure to pass urine and having cold extremities, were less commonly encountered than other symptoms listed and may be more useful in determining how concerned to be. However, in FG14, Irene spoke of the difficulty in identifying 'the line' where help should be sought and suggested that by the time these signs are present it may be too late to administer effective treatment. Erica suggested cold hands and feet as useful indicators of severe disease but conceded that by this point it was likely that the child was likely to be very unwell and requiring intensive intervention for circulatory support (Appendix 23).

Thus, there was recognition that to prevent serious harm, intervention was necessary *before* a child displayed signs of circulatory compromise. However, it was unclear how this point could be identified and how those children who were on the path to serious illness could be distinguished from those who would quickly recover. In FG8, Joanne echoed this, saying "I

walk past the chemist like every single day, and it says 'Sepsis, phone 999' and I'm like well how do I know when it's that? Like at what point can I do that?"

Insights into the views of individuals who had experienced sepsis themselves reinforced the problematic nature of a lack of focus for sepsis awareness materials. According to Kerry, who had experienced sepsis a second time, she realised how unwell she was based on her previous experience but felt that the information contained in campaign materials alone would not have enabled her to recognise that she had sepsis, particularly as she felt she had not displayed many of the symptoms listed. Linda agreed that this had been her experience also.

Later in the discussion, Linda and Kerry speculated about the potential impact of an awareness campaign that encompasses such broad signs and symptoms on parental concern. Linda suggested that concerns about demand on services was responsible for initial reluctance to run a campaign in Scotland:

Linda: "As you said earlier, you know, something like meningitis, there's a hook, and it's just so unfortunate that with that, with sepsis… there isn't (one thing) that you can say to parents."

Kerry: "Yeah, and I think if you, if you did raise awareness of parents giving them those sort of symptoms to look for, you would have an awful lot of…"

Linda: "Freaked parents."

Kerry: "Very concerned, ill-informed, but very worried parents."

Linda: "And, as you say, pressurising then the NHS... someone did actually say to me that one of the reasons the Scottish government didn't want to do an awareness campaign was for that very reason, because they thought the NHS would be overwhelmed with people. If they could find a way of saying, you know, to parents, to anyone, "If it's this, but it gets to this point." But, I don't know what the point would be."

Kerry, 45 and Linda, 52 Group of individuals with lived experience of sepsis

In FG14, Marie gives some insight into the potential for messaging about sepsis to make parents feel simultaneously burdened with responsibility and powerless to detect what according to the media is frequently missed by qualified health professionals with years of experience:

"but saying there, look, the more parents know, the quicker they can act. Right? But if these parents are taking their children to professionals and they don't spot it…, what are we supposed to do?"

Marie, 43 FG14 Library story and music group

This demonstrates the complexity that characterises messaging about sepsis; when the signs and symptoms are openly acknowledged by experts as frequently inadequate to reliably detect sepsis, expecting the public to do better seems to be both an unreasonable expectation and potentially an exercise in futility. Thus, while there was a widely held view that any initiative that increased public awareness about important health issues was essentially positive, sepsis awareness campaign materials were perceived to list signs and symptoms that were too broad and non-specific to be of practical use and also to have the potential to cause undue alarm. Despite good awareness of attempts to publicise sepsis, there was no 'take home message' that parents could easily retain. Furthermore, it was not felt that campaign materials were helpful in identifying the point at which treatment was required. However, some participants gave insights into what types of information-giving may be more effective. In FG10, Rachel recalled receiving a sepsis awareness leaflet as part of a newborn pack in hospital following the birth of her son and, although she had retained the leaflet it did not enhance her understanding; instead, she describes only considering sepsis as relevant to her own family after viewing a storyline on 'Call the Midwife' that had a lasting impact on her.

The relative lack of effectiveness of written information was also expressed by Joanne in FG8. She had taken her son to the GP for assessment of respiratory symptoms, and it seemed she (the GP) had initially tried to empathise with the difficulty that parents face in knowing when symptoms give cause for concern. However, Joanne seemed to feel that in providing her with written information, the GP was handing responsibility back to her as a parent, which on this occasion was unwelcome:

"I kinda think she was kinda trying tae cover her own back as well as kind of reassure me at the same time by saying it is hard to tell. Because it was a case of, "Well I'll just give you this leaflet and have a wee look at that and that'll tell you." And I'm like, "Well if you can't tell me how the heck's a leaflet gonnae tell me?"

Joanne, 32 FG8 Baby Cafe

Interestingly, this contrasts with the previously discussed experiences of the Judy in FG13 who welcomed written guidance; it may be that there is a distinction between illnesses where a definitive diagnosis is suggested and those that are characterised by professional uncertainty.

In FG14, Erica voiced her view about the benefits of communicating information visually to 'show' rather than 'tell' parents what to look for. She described the effectiveness of a recent Coronation Street storyline, which had been developed in consultation with the Sepsis Trust, in communicating this:

"… the literature available for parents isn't good enough, and it's making us get phone calls from kids that are very well… the parents are very unsure. And, so, I think… there needs to be more… what would your child look like – rather than…words, I think a lot of people learn from… videos.

"It's like the Coronation Street thing… it needs to be more like videos of things so people can visually see what it is, what does a sick child look like?... not a lot of people know what a sick child actually looks like, so it's hard to kinda see. Not that you want to know what a sick child looks like, 'cause you want to be able to see it before. You want to be able to capture it before that…."

Erica, 31 FG14 Library story and music group

Later in the discussion she returned to the importance of visual resources in communicating about severity of illness:

It's addressing people's different learning requirements, so, some people are happy to sit and read a document on how to identify sepsis, but then other people are like, "I don't really read

documents. I like to watch it on TV." So, a wee advert…, "This is what a baby would look like if they were getting really unwell." "This is what your three-year-old will look like if they're getting really unwell," stuff like that. 'Cause they're different, they're totally different…"

Erica, 31 FG14 Library story and music group

The combination then, of conveying information visually and/or through a narrative was highlighted, as was the importance of being able to condense key messages and maximise their simplicity. However, while specific conditions such as meningitis may be amenable to the latter, this is far more challenging for a condition like sepsis whose meaning has intentionally been expanded to broaden public and professional understandings of its causes as widely as possible. The views of participants, both those who had been affected by sepsis and those who had no experience of it, suggests that while awareness campaigns had been prominent, it was not easy to retain and recall information about symptoms that pointed to a diagnosis of sepsis and that when considered as a whole were felt to be consistent with a wide range of childhood illnesses, including those that were likely to resolve without intervention.

7.4 Discussion

For some participants in this study then, decisions about seeking help in managing childhood illnesses were influenced by beliefs about their ability to detect serious illness and by external factors such as employment patterns. However, a further factor that had a role in determining whether help was sought from outside the family unit was the perceived value of contact with health professionals during episodes of acute illness. Many participants felt that a definitive diagnosis was rarely offered and that non-specific symptoms were frequently attributed to 'a virus.' This generic term was often perceived to be a way of dismissing symptoms as trivial, and this was a source of frustration and also concern for parents whose child had previously received a viral diagnosis that proved to be wrong. This is in keeping with research by Cabral et al, who identified that, for the parents in their study, attributing a range of apparently different illnesses as due to a virus undermined the credibility of the diagnosis (192, 202).

Public health messaging has long focused on viral diagnoses as being synonymous with absence of justification for prescribing antibiotics. This often has the effect of minimising an illness that may in fact be causing severe symptoms and may appear discrepant with

advice about the need to take definitive steps to manage illness through rest and minimising contact with others to prevent onward transmission. This may be particularly problematic for those in paid employment for whom following such advice may be seen as incompatible with fulfilling obligations as a reliable employee in the absence of a diagnosis of 'real' illness. The problematisation of acute illness begins far earlier than on entering the workplace; even pre-school age children are rewarded for one hundred percent attendance during the academic year, exemplifying the societal expectation that it is achievable to never require time away from usual daily activities due to illness. Yet this is entirely out of keeping about what we know to be usual for a child with normal immunity and risks undermining public health advice about best practice regarding infection control.

Thus, although some participants expressed that they felt antibiotics had been withheld when they were indicated, for others it was not the lack of a prescription but the vagueness of a generic viral diagnosis that was problematic. It may be that this belief could be countered by changing how viral diagnoses are conceptualised and presented to patients in primary care, and by emphasising that individuals may well experience severe symptoms that disrupt normal activities in the absence of bacterial infection. In FG13, Judy described how being provided with written information not only aided her own understanding but was also helpful in providing evidence for others that her child's illness had been taken seriously. The value of issuing written advice for presumed viral illnesses, and in selecting the most likely candidate where definitive testing is unfeasible, is worthy of further evaluation regarding its impact on parental satisfaction with the outcome of the consultation and on reducing unnecessary prescribing.

In similarity with perceptions about those parents who seem to 'overuse' health services, there was an attitude prevalent among some participants that antibiotic use was inherently bad and to be avoided. This is in keeping with perceptions of antibiotic overuse and resistance as an issue for individuals, the risks of which are subject to their control. This may well be a function of messaging that focuses on how the public can mitigate against drug resistance and the language chosen to communicate this (203). 'Victim blaming' is seen frequently in relation to many illnesses that have behavioural components as risk factors, even if unfounded, as demonstrated in Angela's mother's experience of being diagnosed with secondary lung cancer as a non-smoker (FG5) (197). It is possible that this phenomenon results from a desire to believe that we can exert control over factors that pose a risk to our health. An analogy can be drawn with attempts by participants in this study to identify a cause for antibiotic 'overuse' and resultant drug resistance from which they can be excluded

(e.g., lack of exposure to outdoors, poor diet); thus, not only are the main drivers within human healthcare seen as the result of irresponsible actions by individuals (both patients and prescribers), but requiring antibiotics at all was also seen by some as a failure to adequately protect the health interests of oneself and one's family.

In keeping with previous qualitative research, most participants believed that drug resistance was a relationship that existed between the antibiotic user's body and a specific antibiotic drug (10, 166, 167). In FG1, Alan expressed the belief that repeated use of antibiotics resulted in tolerance (Appendix 23) and in several groups, participants referred to overuse as associated with needing 'stronger' antibiotics to ensure effectiveness. Analogies can be drawn with other classes of medication, particularly analgesics, in relation to the perception that the treatment rationale is to start with the weakest drug and increase strength as required, and more specifically with opiates or benzodiazepines, in that with prolonged use increasing quantities are required to achieve the same therapeutic effect. It is possible that patients draw parallels between opiates and antibiotics in that use is restricted because of their capacity to be misused. This may contribute to a perception that antibiotic use is inherently bad, and that 'good' patients avoid asking for them. There is some truth underlying the assumption that strength of antibiotic is important; to be effective against a specific bacterium a threshold must be reached, whether in the laboratory or in the patient's body, termed the 'minimum inhibitory concentration' (MIC). The idea, therefore, of greater quantities of drug having greater efficacy does have a biological basis. However; once again, this relationship was perceived by participants to be at the level of the individual's body and the drug, overlooking the importance of whether a particular drug is effective against a specific organism.

Thus, the main risk that the public perceive being communicated through public health messaging is that antibiotic use may have serious health impacts primarily for the user, while the potential for harm for non-users is overlooked. This demonstrates that messaging about AMR has been ineffective in communicating that the development of drug-resistant bacteria through selective pressure of antibiotic use could affect anyone, regardless of their own personal antibiotic use, which is central to the One Health agenda of ensuring that drug resistance is recognised as a health threat without barriers. The individualised nature of messaging is exemplified by the tag line of the 'Keep Antibiotics Working' campaign, which forms the basis of the UK's public awareness campaign; taking antibiotics when not required puts you and your family at risk' (173). This message is inherently problematic in that participants perceive that personal use is presented as the main driver of harm

associated with AMR, however, this message is not supported by their own experiences. At present, the vast majority of individuals who use antibiotics (one third of the UK public on an annual basis) will not experience harm as a result of resistant infections. For participants in this study, experiences of resistant infections were associated with underlying risk factors e.g., advanced age or complex comorbidities. In essence, public health leaders are trying to convey a message about required behaviour change to combat a problem that, at present, does not actually exist within the personal experience of many individuals, undermining the status of AMR as a genuine health threat.

Although many participants described feeling concerned about AMR, the term scaremongering was often used in relation to how risks are presented in the media. In FG18, Linda's description of comparisons between AMR and terrorism as a 'typical Daily Mail approach' suggested a perception that the newspaper has inflated the risk for maximum impact. However, this comparison was not created by Daily Mail journalists but came direct from the Chief Medical Officer's annual report; thus, if tabloids can be accused of using scare tactics than so too can the experts (3). In keeping with views expressed by participants in other groups, Kerry suggested that negative framing alone is ineffective in commanding audience attention about health risks, while Linda identified that narrative framing that demonstrates impact at an individual level is often effective. Linda suggested that such framing is absent from communications about AMR due to its association with mortality, which may be off-putting; however, the most prominent stories about sepsis have focused on individuals who have died. Thus, there must be an alternative explanation about why AMR is not framed in the same way. Perhaps the most likely explanation is that those affected by AMR are more often elderly or with complex co-morbidities, with resistant infections perceived to be a contributing factor rather than the primary cause of death, or alternatively that deaths that seem to be more in keeping with the usual life course are perceived as less tragic and less commanding of attention than unexpected deaths in younger people.

The apparent ineffectiveness of current communications about AMR raises important ethical considerations about who is ultimately responsibility for health risks associated with antimicrobial prescribing. While at a population level it seems unlikely that individuals or organisations could be held responsible for a lack of effective antibiotics, at an individual patient level it is not unrealistic that long-term health impacts perceived to be the result of antibiotic prescribing that may have been unnecessary could be the source of legal challenge. This may well be reinforced by the Keep Antibiotics Working campaign's

messaging about unnecessary use putting patients at risk; antibiotics are unavailable without a prescription in the UK therefore this implies complicity by a health professional in creating this 'risk'.

Experiences of some participants in the study demonstrated the way in which sepsis awareness has reconceptualised public and professional understandings of deaths from infection and the progression in how the term has been used, from a medical term used primarily by specialists in an intensive care setting to one that is increasingly heard in everyday use. The most commonly held understanding of sepsis (often referred to as septicaemia or blood poisoning) was as originating from a cut or wound. Many participants appeared to struggle to link this with sepsis as depicted by current campaigns. This is unsurprising, when part of the rationale for establishing a campaign was that awareness of sepsis was recognised to be low, even among health professionals. This was exemplified by the experiences of participants in this study who worked in healthcare, who reported a recent shift in attitudes to risk when assessing individuals with acute infective illness.

Reference to changing constructions of sepsis as a 'rebranding' seemed to be an apt summary; an obvious question that follows is why this was necessary. One possibility is that the assumption that many people hold that external injury is a pre-requisite for sepsis impedes recognition of its other causes. The tag line of the sepsis awareness campaign supported by the Sepsis Trust, 'just say sepsis', demonstrates acknowledgment of a reticence to bring sepsis as a possible diagnosis into conversations that take place in a healthcare setting. Sepsis is thus approached in a different way to other conditions; for example, it seems unlikely that patients or doctors would have any discomfort in discussing the possibility of site-specific infections such as tonsillitis or cellulitis. It may be that this reflects uneasiness about a potential sepsis diagnosis as indicating severe illness, yet it is the role of the physician to identify red flag symptoms and take necessary steps to exclude serious causes. This is what practitioners do throughout the course of every working day, and there has been no need to centre awareness campaigns around empowering patients to suggest other serious conditions, such as heart disease or cancer, as possible diagnoses, despite early detection invariably being associated with better outcomes. This suggests that there are features that are specific to sepsis that create barriers to open discussion between patient and health professional.

Joan and Chelsea's experience with their solicitor (FG16) demonstrates how 'sepsis' has become 'imbued with meaning', (as Sontag has described occurring for other diseases), conjuring up ready images of negligence and blame (171). That the very mention of the word

was apparently sufficient to convince a legal professional that there may well be cause to suspect medical negligence, when the rest of the evidence presented did not, gives an insight into its capacity to create unease in health professionals. As mentioned previously, to suggest sepsis as a differential diagnosis carries risk for practitioners in that once raised as a possibility, they must immediately expedite care, given the time sensitive nature of management. Thus, practitioners who manage acutely unwell patients may well decide that a precautionary approach that initiates sepsis treatment where the diagnosis is in question is the only sensible course of action to ensure that they are protected against legal challenge.

In FG17, Bill observed that in the past, deaths resulting from complications of surgery that may have been due to sepsis were 'covered up', suggesting that this has always been viewed as an unacceptable failure of hospital care. The qualitative analysis demonstrated that while deaths from sepsis associated with a cut or wound sustained in the community were previously perceived to be unfortunate yet unavoidable, even where the individual had consulted with a health professional, this perception has now changed and missed opportunities to diagnose sepsis are now deemed unacceptable in the same way as deaths that result from sepsis associated with surgical intervention. With the expansion of 'sepsis' to encompass serious infections from any source, e.g., respiratory and urinary tract infections, the scope for unacceptable failings in diagnosis and management has become far wider than events that take place within the operating theatre or outside a healthcare setting, and may now include a vast range of encounters with healthcare workers both in acute care settings and in the community, where assessment and treatment decisions are made rapidly without access to diagnostic facilities. Thus, the most comfortable positions for practitioners to occupy are, at one end of the spectrum, dismissal of sepsis as a potential diagnosis, supported by recording of vital signs and behaviour, or at the other extreme, fully embracing it as a possibility, resulting in immediate escalation of care. The middle ground, where there is uncertainty about the significance of symptoms and likely course of illness, is likely to be far less comfortable territory in which to open up discussions about sepsis, particularly with young children who are more difficult to assess and whose parents must advocate on their behalf.

Another possibility is that the distinction between lay and clinical definitions of sepsis may render it a hindrance to effective communication. While for the public, 'sepsis' has come to be synonymous with serious complications of infection, in clinical terms a diagnosis of sepsis relies on measuring several specific parameters. However, this does not necessarily

reflect how clinicians think, and when communicating with families it may be more natural to focus on specific aspects of treatment, (e.g., 'we are treating hypotension with fluids, we are treating infection with antibiotics') than to communicate about treating the combination of these that defines sepsis. Thus, failure to mention sepsis may reflect an attempt to communicate with patients and families in a more accessible way, yet there is the sense for patients that receiving a retrospective diagnosis of sepsis suggests a degree of concealment by healthcare staff. This message was apparent in some of the news articles included in the qualitative analysis; for example, following the death of nine-year old Thomas Hull just hours after discharge from hospital, consultants were criticised for failing to communicate the possibility of sepsis to his family, dismissing them as 'lay people who wouldn't understand' (170). Failure to communicate effectively about a sepsis diagnosis also impedes opportunities for educating patients that may have later consequences.; Melissa Mead discovered that she herself had been diagnosed with sepsis years before William's death during a session with a counsellor who had access to her medical records. She has publicly speculated whether William's outcome might have been different if that opportunity had been used to educate her about signs and symptoms of sepsis.

The apparent reluctance by health professionals to 'say sepsis' that calls into question how easily members of the public as patients and parents can be expected to do so, yet this is the cornerstone of recent messaging. Despite good awareness of campaigns, and a belief that any initiatives that raised its profile were to be welcomed, there was a widely held view that the symptoms listed were too generic to be of practical use and that the lack of a central sign or symptom that could be seen as a reliable indicator of sepsis compromised the effectiveness of messaging. It was unclear for participants when they would be reasonably expected to seek help were their child to display any of these symptoms. The focus of public health communications about sepsis in children appears to rely on constructions of parents as risk averse and exercising constant vigilance over their children. Yet for the parents in this study, many factors influenced the likelihood of seeking help during episodes of acute illness including time spent in employment outside the home, perceptions about scarcity of primary care resources and the perceived value of contact with health professionals during acute illness, with many participants reporting rushed appointments and feeling dismissed regardless of whether the outcome was an antibiotic prescription or a viral diagnosis. Thus, communications to parents about recognising and managing sepsis fail to consider the societal context in which healthcare decisions are made.

Although effective in attracting the attention of a public audience, the episodic framing used in sepsis reporting must be supported by effective health messaging if it is to positively impact health behaviours and outcomes. This was demonstrated by analysis of media coverage of the death of Jade Goody, which identified that the human-interest aspects of the story dominated reporting, while potentially 'mobilising' information about the role of Human Papillomavirus (HPV) vaccination and screening in preventing cervical cancer were usually omitted. That an initial uptake in screening was not sustained suggests that this omission may have been a missed opportunity. For sepsis reporting, although many articles contained a summary of guidance about how to manage sepsis, this was rarely incorporated into the main body of the article with a focus instead on how quickly children with apparently mild symptoms deteriorated. Thus, there was no take home message for parents that gave them agency to manage possible sepsis; instead, some aspects of sepsis reporting and campaign messaging only served to increase uncertainty about how to manage illness, given that the advice they contain seems to contravene strongly held beliefs about the importance of being able to self-manage minor illness, the containment within the family unit to which Neill refers (186). This demonstrates that although stories about affected individuals provide memorable frames, these must be backed by clear action points to effect behaviour change.

Chapter 8 Conclusion

The key aim of this PhD was to explore how media framing of antimicrobial resistance and sepsis impacts on public perception, in particular for parents of young children to whom messages about sepsis awareness are often targeted. This is important because conserving antibiotics is key to securing their future effectiveness. The UK Review on AMR makes clear the potential for drug resistance to have catastrophic impacts on the world's health as well as far reaching economic consequences. However, at an individual level the short-term welfare of patients takes priority for clinicians, and in the absence of accurate near testing to identify bacterial infection, a variety of factors influence decisions about the need for antimicrobials.

Quantitative analysis of news articles demonstrated that antimicrobial resistance and sepsis are framed differently in the media, with AMR presented as an issue whose key drivers and solutions lie with policymakers at a global level, and whose main impact will be felt decades in the future, with little visibility of identifiable individuals who are affected. In contrast, sepsis is most often reported in relation to its impact on individual patients and its solutions presented as relatively simple: recognise its symptoms, seek help, and start antibiotics as quickly as possible. This message is compounded by the case histories that accompanied three quarters of articles, almost half of which concerned babies and children, which is not representative of overall case numbers. Thematic analysis of these articles demonstrated a picture of a health service that is failing vulnerable children through systemic and individual error, many of whose deaths could have been prevented had antibiotics been given earlier. Parents are presented as advocates for their children and must follow their instincts if they suspect their child's illness is more serious than health professionals assess it to be or risk compromising their personal and social identities as good parents.

Further exploration of this theme via focus groups with parents of young children demonstrated that, in keeping with literature, parents perceive that knowing what is normal for their own child is the most important factor in being able to reliably assess when their response to illness as parents requires escalation beyond usual care at home. However, this knowledge was dependent on time spent in their presence, and other factors inevitably impacted on this, primarily time spent in paid employment outside of the home. Conflict in responsibilities at home and work was a common theme, with many participants expressing uncertainty about work regulations regarding parental leave for childhood illness, and also moral uncertainty about how unwell their child had to be to justify absence

from work. Experiences were frequently perceived to be driven by personal attitudes of line managers as opposed to official organisational policies.

It was common for participants to experience ambivalence from doctors regarding the need for antibiotics during episodes of childhood illness. Decisions were often perceived as being handed back to them as parents and there was often apparent willingness to prescribe in accordance with parental choice, even if the illness was deemed self-limiting. In the absence of reliable near testing, the ability to prescribe may allow doctors to retain authority in the face of uncertainty. In contrast. a consultation that concluded with a diagnosis of a probable viral infection was viewed by some parents as futile.

Despite media framing of AMR as a global issue, it was widely perceived by focus group participants to be an individualised risk only for those who 'misused' antibiotic drugs, reducing their effectiveness when required subsequently. There was little awareness of person-to-person or environmental transfer of resistant bacteria or of the wider impact on healthcare. For the few participants who had personal experience of resistant infection, this was limited to relatives with long-term conditions, reinforcing the idea of AMR as a threat only for vulnerable groups. Even where antibiotics were indicated for bacterial infection, there was a perception among some parents that this could be avoided by optimising immunity through diet and exercise, and also by ensuring that their children were exposed to environmental sources of infection from a young age.

The changing language around sepsis was a source of confusion not only for patients but also apparently for some health professionals, and those who had lived experience reported inconsistencies in how readily it was discussed. The reasons for this are unclear but it may be that the all-encompassing nature of sepsis as a condition precludes discussion about individual signs and symptoms that perhaps has more synergy with the way we conceptualise illness. Reticence may also be related to the perceived potential for ramifications if management is subsequently found to have been suboptimal, with time to treatment accepted to have a substantial impact on outcomes. Materials and campaigns designed to increase awareness and empower parents to recognise sepsis were widely believed to lack clarity over at which point in the course of an illness escalation was required. This is perhaps unsurprising when health professionals themselves struggle to communicate effectively about sepsis, as evidenced by the messaging contained in 'just say sepsis' campaigns and suggests our understanding of sepsis as a condition is perhaps not yet sufficiently embedded to allow easy discussion. Some participants' suggestions that

visual imagery as a tool to educate parents on when childhood illness was serious was an important one.

An unexpected finding in the quantitative analysis was the very small minority of articles about sepsis that highlighted the need to reduce unnecessary prescribing. This overlooks the fact that resistant organisms are implicated in a substantial proportion of sepsis cases and highlights the way in which they are constructed in the media as largely separate issues, with resultant implications for public understanding.

With regards to focus group discussions, an unexpected finding was the importance placed by participants on being seen to use healthcare resources judiciously. I had anticipated that most parents would be keen to be perceived as exercising caution in decision-making about when to seek help for their unwell child; however, in fact, many participants seemed at lengths to dispel a persona as an anxious parent, driven both by a need to appear able to manage illness in a calm and competent manner, but also borne from a sense of societal responsibility and a perceived duty to conserve resources for those with greater need. Many participants expressed feeling conscious of a sustained media focus on excessive demands on the healthcare system. Contrary to a priori assumptions, it appeared that, for the parents in this sample, this belief was more likely to influence health seeking behaviour than awareness of news stories about sepsis.

8.1 COVID-19 context

It would be imprudent to complete a thesis that focuses on public perceptions of infection without careful consideration of how the pandemic caused by COVID-19 contextualises its findings. The most obvious impact is one of re-prioritisation; for many months, the substantial morbidity and mortality associated with COVID-19 dominated every aspect of life at a societal and individual level in a way that no other infectious disease has done in living memory. It is inevitable that those illnesses that were seen as a less imminent threat received less attention. However, as we continue to live with COVID-19, part of the legacy of the pandemic will be how we perceive and respond to other sources of infection. This has the potential for both positive and negative impacts on human health. Here, I will discuss how these may relate to the findings of this thesis.

Many of the interventions recommended to reduce AMR are aimed at minimising the need for antibiotics (as per the UK Antimicrobial Resistance Action Plan) are the same as those put in place to reduce COVID-19 transmission (4). While some of these, such as social distancing, were temporary, it is likely that measures such as better hand hygiene and

improved ventilation in public spaces will endure, which may have a positive effect on antimicrobial use. However, the counter effect of these behaviour changes is likely to be reduced exposure to circulating microbes of all kinds, which in turn reduces passive immunity. A recent increase in cases of viral hepatitis in children has been associated with infection with adenovirus, likely in part due to reduced exposure in this cohort during lockdown (204). It seems feasible that reduced immunity to bacterial pathogens is also likely and the net effect on the need for antimicrobials is unclear.

A likely legacy of COVID-19 is increased public understanding of the language used by health professionals to describe infection. Previously, point of care testing for specific infections was unusual, however, this became routine for most with the introduction of lateral flow testing. It is possible that the need to arrive at a definitive answer about whether symptoms were due to COVID-19 to inform pragmatic decisions (i.e., whether to self-isolate) will increase patient expectations that a causative organism be identified when they experience signs and symptoms that suggest infection. However, alongside this, the open dialogue between experts and the public that was achieved through frequent press conferences and other media appearances may lead to a deeper insight into the limitations of medical knowledge and the challenges of assimilating emerging evidence into practice. It is possible that this may increase tolerance for uncertainty within consultations and allow clinicians the space to acknowledge this without compromising their professional identity.

Although most people experience mild self-limiting illness following infection with COVID-19, the significant morbidity and mortality seen at population level may alter perceptions that a viral diagnosis minimises illness severity. Improved recognition that viral illness causes a spectrum of disease and may require bedrest, supportive treatment, and a recovery period before return to work may help to reduce demand for antibiotics to legitimise these measures.

Even prior to the pandemic, there was widespread media coverage of under-resourcing in the health service and increasing challenges in meeting public demand. Although there have been previous examples where the public were asked to limit attendance at primary care and A&E, for example during the swine flu pandemic of 2009, the reduction in available health services during the lockdowns of 2020 and 2021 far exceeded this, and face to face consultations are still less frequent, with a greater emphasis on triage by telephone. There is a possibility that this could increase the frequency of 'just in case' prescribing. During the height of the pandemic, advice to the public from health experts was to attend A&E only if their condition was life-threating. The extent to which such

messages are assimilated by the public was greater than expected based on the responses of focus group participants. Thus, the behaviour expected of the public to protect the health service during times of increased demand conflicts with messaging about sepsis that urges them to to seek early professional advice if they have any suspicion that symptoms suggest sepsis.

It is possible that this challenge may be in part offset by changes to working patterns for some parents as a legacy of the pandemic. The realisation for many organisations that, for certain roles, productivity is not dependent on physical presence in the workplace may reduce the time that parents spend commuting and working away from their children. Furthermore, a changing attitudes towards the societal significance of minor illness may be a legacy of the pandemic that presents an opportunity to reset behaviour. Previously, decisions about attending work or school while suffering mild to moderate illness were a matter of balancing duty to employers and colleagues with minimising transmission of infection that could inconvenience others. Prioritising the latter could be met with charges of revealing oneself to be an unreliable employee. Post-COVID-19, there is greater recognition that transmission of infection that causes minor illness in one individual could pose far greater risk for more vulnerable members of society. Of course, in reality this was always true for the many pathogens that can cause a spectrum of disease depending on the host response, but there is a possibility that a proportionate response to minor illness will be more acceptable than previously, removing some of the conflict that working parents regularly face.

8.2 Recommendations for policy

8.2.1 Re-framing of AMR as an important health risk now

There is acknowledgement that current ways of communicating with the public about AMR lack necessary impact. Commanding the attention of the public requires messaging that conveys that AMR is a risk for all and not only for vulnerable groups or those who 'misuse' antimicrobials. Lessons about how this can be achieved can be learned from messaging about sepsis, which focuses on human stories. Campaigns should reference individuals affected by AMR today, rather than projected mortality figures that the public have difficulty engaging with. Its consequences should be presented in a way that is relevant for the majority, for example through the impact on important routine healthcare procedures that depend on the availability of effective antibiotics. These recommendations echo the conclusions of the Wellcome Trust Reframing Resistance report (8).

An additional insight from my research is recognition of the limitations for effective risk communication in current framing of AMR as a concept rather than a condition in its own right. In the same way that individuals are frequently described as having died 'with' rather than 'from' COVID-19, AMR is frequently recorded as a contributing factor rather than a cause of death. This greatly limits the visibility of its impact. Clarity on the proportion of deaths recorded as due to sepsis or other infective causes that are due to resistant organisms would help to focus attention on AMR as an issue that already has a substantial impact on human health.

8.2.2 Recognition of the complex relationship between optimising sepsis management and reducing AMR

There is a tension between messages about reducing antibiotic use and the need for early antibiotics when sepsis is suspected. Despite being inter-related issues, they are not currently presented as such, with, for example, separate campaign materials in healthcare establishments. It is unacceptable to position individuals as irresponsible because they are concerned about the impact of not receiving antibiotics when counter messaging suggests that they should challenge this position. There is a need to align these messages and to publicly acknowledge that there are frequently diagnostic challenges in determining the need for antibiotics. In addition, there is a need to acknowledge that messages about sepsis awareness and early diagnosis may conflict with messaging about restricting use of acute services.

8.2.3 Clarity on workplace policies for parental leave

Competing obligations for parents to be economically active and to be present with their unwell child has the potential to compromise their ability to recognise any deterioration in their condition. This is particularly relevant for sepsis but could also apply to non-infectious acute illness. The value placed on instinct by both parents and health professionals may be ill-founded and has the potential to impact adversely on health outcomes. There is a need for a public conversation about the emotional and financial burden that normal childhood illness places on families. Employers must provide clarity about their expectations when an employee's child is unwell and this should be translated into clear organisational policies on parental leave. There must be reconsideration of policies that construct illness caused by transmissible disease as abnormal rather than inevitable, such as attendance awards, both in the workplace and in educational establishments.

8.3 Recommendations for practice

8.3.1 Improving communication about the health impact of AMR

There is a clear need for improved communication about the risks associated with AMR, which is currently perceived to be under the control of individuals through their judicious use of antibiotics. There are parallels here with vaccination, and with COVID-19, in that actions at a population level are required to protect against important health risks that, for individuals, is relatively small. Crucially, the public need to know that they are at risk from harm from resistant infections, even if they do not use antimicrobials themselves.

Many participants interpreted attempts by health professionals to facilitate shared decision-making by involving them in choices about antibiotic treatment as ambivalence. If health professionals do not judge an antimicrobial to be necessary based on clinical history and examination, then they should question why it is appropriate to be willing to prescribe. Defensive prescribing undermines the impact of messages to reduce antimicrobial use and reinforces the public's belief that AMR is a theoretical health threat rather than one which causes significant morbidity and mortality today.

8.3.2 Reframing of viral illness

The meaning behind a diagnosis of likely viral illness needs reframed. At present, a viral diagnosis is often interpreted as meaningless and a denial of symptoms. In the same way that sepsis has been 'rebranded', the recent pandemic presents opportunities for health professionals to assert that viral infection can produce severe symptoms and to repackage non-antimicrobial management as something dynamic, emphasising that a period of rest and self-care may be required for personal recovery and to avoid onward transmission.

8.4 Recommendations for further research

8.4.1 Impact of sepsis awareness on antimicrobial prescribing

The impact of sepsis awareness campaigns on the attitudes of clinicians towards prescribing of antimicrobials has not been formally investigated. Anecdotal evidence suggests that defensive prescribing is a natural consequence of high-profile reporting of sepsis deaths where health professionals have been portrayed as at fault. Exploration of the impact of sepsis awareness on attitudes of clinicians using qualitative methodology would enhance understanding of its role within the range of factors that influence antimicrobial prescribing.

8.4.2 Impact of remote consulting in primary care on prescribing patterns

Since the COVID-19 pandemic, face-to-face consultations in primary care remain less common, with increased reliance on telephone consulting. Remote consulting has been associated with increased antimicrobial prescribing (205). In Scotland, an initial increase in prescribing at the beginning of the pandemic was followed by a relative decrease compared to previous years but it is likely that this was due to a reduction in transmission of infection during imposed lockdown and social distancing measures (36). The impact of changed models of consulting in the community on antimicrobial prescribing as behaviour patterns revert to normal will require close surveillance.

8.4.3 The role of audio-visual resources to promote sepsis awareness

Finally, the limitations of current communications about sepsis awareness were apparent from the responses of focus group participants, who felt that lists of symptoms used in existing materials were too non-specific to be of practical application. Several participants pointed to the value of portrayals of sepsis on fictional television dramas in 'showing' rather than 'telling' what sepsis looked like. Audio-visual materials that demonstrate early signs and symptoms of sepsis may be a valuable adjunct to existing ways of educating parents and carers about recognising the range of presentations of childhood illness and when to escalate care. The feasibility of this is an important area for further research.

Appendix 1 Main themes identified for literature review during scoping phase

Policy context

Estimates of impact

Quality of evidence

Mechanism

Drivers – therapeutic use, agriculture and animal use, waste

Global context

Solutions – reduce demand, increase supply

Current strategies to reduce AMR – what are the important legislations etc?

Sepsis – mechanism, history of definitions, history of management approach

General literature: risk, prescribing, what works to change health behaviour (mass media), parenting culture

What is known about what the public think about AMR/sepsis

What affects prescribing decisions about antibiotics

What works to reduce unnecessary prescribing

How do parents approach minor illness in children

Appendix 2 Literature search strategies

Literature search strategy (AMR)

Database	Search terms	Limits	Date of search	Sort by
OVID Embase	Antimicrobial resistance OR Antibiotic resistance	Title Human(s) Review articles	1/12/15	Most recent
Web of Knowledge	As above	Title	16/12/15	Most recent
British Library online catalogue	As above	Title	16/12/15	Most recent

Literature search strategy (sepsis)

Database	Search terms	Limits	Date of search	Sort by
OVID Embase	Sepsis OR Sept*	Title Human(s)	14.3.16	Most recent
Web of Knowledge	Sepsis OR Sept*	Title	3.5.16	Most recent
British Library online catalogue	Sepsis OR Sept*	Main title	3.5.16	Most recent

Appendix 3 Main classes of antibiotics and mode of action (Levy and Marshall 2004)

Mode of action	Antibiotic class	Example of drug	Example of target organism	Possible clinical indication
Inhibition of cell wall synthesis	Penicillins Cephalosporins Carbapenems	Amoxicillin Cefalexin Meropenem	Group A streptococcus	Scarlet fever
Inhibition of protein synthesis	Tetracyclines Aminoglycosides Macrolides	Doxycycline Gentamicin Clarithromycin	Legionella pneumophila	Legionella Pneumonia
Inhibition of DNA synthesis	Fluoroquinolones	Ciprofloxacin	Gonorrhoea	Gonococcal urethritis
Inhibition of RNA synthesis	Rifampicin	Rifampicin	Mycoplasma tuberculosis	Tuberculosis
Inhibition of folic acid synthesis	Sulfonamides Trimethoprim	Co-trimixazole	Pneumocystis jirovecii	PCP (pneumocystis carini pneumonia)

Appendix 4 Main resistant organisms identified as having an impact on human health

Mycoplasma tuberculosis. TB remains an infection of huge global significance; currently one third of the world's population is infected with latent TB and are at risk of long-term morbidity.(206) Drug resistance was noted soon after the application of streptomycin in its management and multi-drug resistant TB (MDR-TB) (classed as resistance to isoniazid and rifampicin, the two standard first-line drugs in the management of TB) is now widespread. The alternative regimes that are available require a considerably more prolonged duration of treatment. Extensively drug resistant TB (XDR-TB), in which resistance develops to the most effective second-line drugs. is increasingly common, particularly in India, Russia and China.

<u>**Gram positive organisms**</u>

Staphylococcus aureus. Much confusion exists around staphylococcal infection, largely as a result of its notoriety through extensive media reporting of MRSA in previous decades. In fact, it exists as a commensal in the nasal passages of up to one third of humans and clinical infection is often limited to minor skin infections such as boils (15). Resistance of staphylococcus aureus to penicillin was noted in the late 1950s prompting development of the first semi-synthetic penicillins including methicillin. Resistance to these compounds too also rapidly emerged. The term MRSA is now used to signify multi-drug resistant staph. aureus as opposed to those organisms only resistant to methicillin. As mentioned in Section 1, MRSA is now a significant presence in the community, often associated with PVL toxins which can produce devastating disease. This is not only a risk to the ill and immunocompromised but to healthy individuals; several severe infections in previously well patients have been traced to use of gyms and sports facilities.

Clostridium difficile is part of the normal gut flora; clinically significant infection is associated with antibiotic treatment which depletes the Gram-negative intestinal bacteria allowing proliferation of C difficile which leads to gut colonisation. C. difficile has been associated with high profile outbreaks within hospital settings with significant associated mortality.

The **Enterococci** species (Enterococcus faecalis and Enterobacter faceium) form part of the normal gut flora but at other sites are capable of producing severe infections such as urinary tract infections, endocarditis and blood-borne sepsis.

Gram-negative organisms

In simple terms, Gram-negative organisms have greater defences against being killed by antimicrobial drugs via the thicker cell wall (the same cell wall that prevents uptake of the Gram stain, hence 'Gram-negative).

Escherichia coli is a bacterium that forms part of the normal gut flora. In other sites it can produce symptoms, for example urinary tract infections. Some strains that are found in the environment can produce severe food poisoning and produce toxins that may cause a serious complication called haemolytic uraemic syndrome, particularly in the young and elderly. As mentioned in Section 1, resistance to the ultimate 'last resort antibiotic' colistin has recently been confirmed as a reality.

Salmonella enterica, Vibrio cholera, Shigella flexneri - globally, these enteric infections are of major significance. As with E coli, these organisms produce extended spectrum bet lactamases that destroy penicillins and caphalosporins. Strains resistant to the 'last resort' antibiotics (carbapenems) that are reserved for the most serious of infections.

Neisseria gonorrhoea is transmitted sexually and can cause urethritis in males and cervicitis in females as well as extra-genitourinary complications such as pharyngitis and arthritis. Globally, it is of significance in that inadequately treated gonorrhoea infection may facilitate transmission of HIV. Resistance to fluoroquinolones that have been traditionally used in its management emerged in the 1990s/2000s and resistance rates continue to increase; resistance is also rapidly increasing to the newer combination therapies used (ceftriaxone and azithromycin) (207).

Hospital-associated infection

Pseudomonas aeruginosa is a Gram-negative organism that was previously most often associated clinically with infection of burn wounds. The development of resistant forms means it is now of great concern for patients with cystic fibrosis and has also been associated with outbreaks in neonatal intensive care units affecting ventilated patients.

Acinetobacter baumannii thrives in warm, humid conditions and although it is primarily of risk to hospitalised patients, complicating wound infections and associated with invasive treatments such as in-dwelling catheterisation, it has been associated with military personnel working in the field and victims of natural disasters such as the 2004 tsunami in Indonesia (15, 19). Acinetobacter is particularly competent at acquiring resistance through uptake of environmental DNA (transformation, as described in Section 2).

Appendix 5 RAND/KMPG modelling to predict economic impact of AMR

Both reports modelled the projected impact on human health and the global economy until the year 2050 of a limited subset of 6 organisms:

- Klebsiella pneumonia
- E coli
- Staphylococcus aureus
- Tuberculosis
- Malaria
- HIV

The specific methods and findings of the two studies are discussed below:

RAND Europe analysis

The RAND study states the following two ways in which AMR impacts negatively on the economy:

- Increased mortality, which reduces the size of the working age population
- Increased morbidity, which reduces the available working population directly, and potentially indirectly through impact on carers who may otherwise be economically active
- In order to explore the range of impacts that AMR might have over the next few decades, 3 scenarios were considered:
- A future where resistance levels have been managed and maintained at a low rate of 5%
- A 'medium' rate of 40% resistance
- A worst-case scenario resistance rate of 100%

In addition, different start points for development of these levels of resistance were considered: beginning immediately and beginning in 15 years. This resulted in 8 different scenarios that compared to a baseline of a world with 0% resistance. In this study, incidence of each infection was considered to remain constant at current levels.

Results

Full results can be found in the original papers, but to illustrate the findings regarding the potential impact one possible outcome is summarised here. Using one of the 'medium impact' scenarios (40% resistance beginning in 15 years with resistance remaining at current rates until then), and compared to a theoretical 0% resistance rate, the models predict the following human and economic impacts by 2050:

- World working age population loss of 74.17 million
- World cumulative GDP loss of 14.1 trillion US dollars

It is noted that the impact differs by region – in absolute terms, the highest fall in gross domestic product (GDP) will be in high income countries but relative to overall GDP the biggest impact will be in Sub-Saharan Africa. The impact of AMR in different populations is uncertain and likely to differ. It is possible that the greatest impact will be experienced in higher income countries whose healthcare systems rely on a supply of effective antibiotics. Alternatively, regions where infectious disease remains the most common cause of mortality may have inadequate infrastructure to manage spread of resistant infections and may be affected to a greater extent than high income countries.

KPMG analysis

Based on the same six pathogens as in the RAND study, KPMG considered the impact of 4 different scenarios, ranging from least to most extreme:

- A absolute increase in resistance of 40%
- B absolute increase in resistance of 100%
- C absolute increase in resistance of 40% and a doubling of infection rates
- D absolute increase in resistance of 100% and a doubling of infection rates

Results

Figure X shows the estimated reduction in the world population by 2050 – based on the most extreme scenario - is loss of 700 million people, with Africa and Asia the regions most affected, due to relatively higher baseline infection rate.

Chart 10: Estimated reduction in world population by 2050 under each scenario
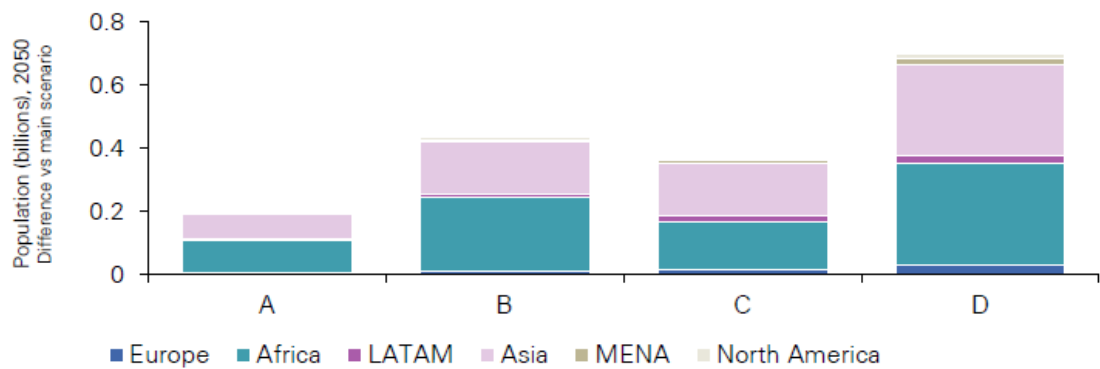
Table A below shows the predicted annual reduction in GDP based on each scenario.

Table A Reduction in annual GDP based on KPMG analysis

Scenario	A	B	C	D
Annual reduction in GDP by 2050	1.66%	3.4%	3.44%	6.08%

Once again, the projected impacts are not felt equally throughout different regions, with low- and middle-income countries disproportionately affected (e.g., loss of GDP in most extreme Scenario D ranges from 3.17% in N America to 20% in Africa).

Appendix 6 Sequential organ failure assessment (SOFA) score

SOFA score	0	1	2	3	4
Respirationa PaO$_2$/FIO$_2$ (mm Hg) SaO$_2$/FIO$_2$	>400	<400 221–301	<300 142–220	<200 67–141	<100 <67
Coagulation Platelets 10^3/mm^3	>150	<150	<100	<50	<20
Liver Bilirubin (mg/dL)	<1.2	1.2–1.9	2.0–5.9	6.0–11.9	>12.0
Cardiovascular[b] Hypotension	No hypotension	MAP <70	Dopamine <∕=5 or dobutamine (any)	Dopamine >5 or norepinephrine <∕=0.1	Dopamine >15 or norepinephrine >0.1
CNS Glasgow Coma Score	15	13–14	10–12	6–9	<6
Renal Creatinine (mg/dL) or urine output (mL/d)	<1.2	1.2–1.9	2.0–3.4	3.5–4.9 or <500	>5.0 or <200

Appendix 7 Consensus definitions of sepsis and septic shock

Year	Summary of definitions
1992	**Systemic Inflammatory Response Syndrome (SIRS)** Defined by two or more of: Temperature > 38C or < 36C Heart rate > 90/min Respiratory rate > 20/min or $PaCO_2$ < 32mmHg White cell count > 12 000/mm or <4000/mm or > 10% immature **Severe sepsis** Sepsis complicated by organ dysfunction **Septic shock** Sepsis-induced hypotension that persists despite adequate fluid resuscitation
2001	Definition of SIRS altered to: 'infection – documented or suspected and **some** of the following': Same criteria as above, plus: Altered mental status Significant oedema or positive fluid balance (>20 ml/kg over 24 h) Hyperglycemia (plasma glucose >110 mg/dl or 7.7 mM/l) in the absence Plus, an extensive list of other parameters reflecting inflammation, haemodynamic and coagulation abnormalities and organ dysfunction (see appendix)
2016	**Sepsis** Definition altered to reflect detection of organ dysfunction: Suspected or documented infection and > 2 SOFA points **Septic shock** Sepsis and vasopressor therapy needed to elevate MAP > 65 mm Hg

Appendix 8 Surviving Sepsis Campaign Bundles

TO BE COMPLETED WITHIN 3 HOURS:

1) Measure lactate level

2) Obtain blood cultures prior to administration of antibiotics

3) Administer broad spectrum antibiotics

4) Administer 30 mL/kg crystalloid for hypotension or lactate 4mmol/L

TO BE COMPLETED WITHIN 6 HOURS:

5) Apply vasopressors (for hypotension that does not respond to initial fluid resuscitation)

to maintain a mean arterial pressure (MAP) ≥ 65 mm Hg

6) In the event of persistent arterial hypotension despite volume resuscitation (septic

shock) or initial lactate 4 mmol/L (36 mg/dL):

- Measure central venous pressure (CVP)*

- Measure central venous oxygen saturation (ScvO2)*

7) Remeasure lactate if initial lactate was elevated*

*Targets for quantitative resuscitation included in the guidelines are CVP of ≥8 mm Hg,

ScvO2 of 70%, and normalization of lactate.

Appendix 9

Sepsis/AMR MCA Coding guidelines

Exclusion criteria

- Exclude letters
- Exclude articles where sepsis/AMR is incidental detail only– e.g., referred to as factual information as background to story and not elaborated on, e.g., 'X missed participating in (sporting tournament) as he was receiving treatment in hospital for septicaemia' would be recorded as 'no' but if article goes on to explain what sepsis is or to include personal account of the impact it has had then this would be recorded as 'yes'
- Exclude articles that are specifically about meningitis/meningitis vaccine. These tend to be presented as part of a different narrative, for example, many articles include statements such as 'although the public are aware of the risks of meningitis, sepsis has gone largely unnoticed'. Judgment to be made where article refers to terms such as 'meningococcal septicaemia' or 'septicaemia due to the bacteria that causes meningitis'
- Where article is published in more than one edition include the latest one
- Include only UK editions – not regional ones
- Do not exclude articles on basis of being in a section of newspaper other than the main news section if the article is about sepsis/AMR, e.g., Editorials, Features, Show business, Health, Weekend, Sports

1 Article IDs

ID numbers are unique six-digit numbers. First two letters correspond to abbreviation for newspaper as follows:

Newspaper Publication	
Guardian (GU)	1
Observer (OB)	2
Daily Telegraph (DT)	3
Sunday Telegraph (ST)	4
Daily Mail (DM)	5

Mail on Sunday (MS)	6
Express (EX)	7
Sunday Express (SE)	8
Mirror (MI)	9
Sunday Mirror (SM)	10
Sun (SU)	11
News of the World	12

2 Date – self-explanatory

3 Headline – self-explanatory

4 Headline rating

Err on side of neutral. Distinction between alarmist and alarming. Alarmist headlines have to use language that exaggerates a problem or seek to cause alarm, not just use colloquial emotive language.

Where alarmist language is contained within a quote, judgment is required about whether the newspaper is simply reporting a newsworthy story or has selected the quote in order to be intentionally alarmist. These examples will be noted for consistency.

Examples

England's CMP warns of 'antibiotic apocalypse' – recorded as neutral as paper simply states facts without adding further dramatic emphasis.

5 Article is about AMR or sepsis – self-explanatory

6 Word count – self-explanatory

7 **Newspaper publication** – self-explanatory (see 1)

8 Sepsis article mentions AMR and vice versa – self-explanatory – coded this way to avoid unnecessary 'N/A' fields

9 Case history

If the article refers to an 'identifiable victim' i.e., by name, this is recorded as 'yes'. If individual is referenced but with no name, e.g., "Dr X recalls one 45-year-old lady who developed condition x…" then this is recorded as 'no'.

Definitions of 'victims' as follows:

- **Baby or child** (under 16 years)
- **Pregnant or new mother** (within 28 days following birth)
- **Young adult** (use arbitrary cut off as 50 years to capture working age population less likely to have pre-existing health conditions)
- **Older adult (> 50)**
- **Elderly person (> 80)**
- **Celebrity or relative of celebrity** (inclusion criteria is that story is deemed to have been reported as of interest to the public because of identity of 'victim', regardless of how minor celebrity status is, rather than newsworthiness of story in itself)
- '**William Mead**' included as a separate category as scoping exercise identified that a substantial volume of articles published in 2016 reference this high profile case that has been an important aspect of narrative. Tick as 'yes' if mentioned at all in article, even if article also refers to another 'victim'. Do not tick 'yes' for baby or child when named victim is William Meade.

10 Problem definitions

The following should be self-explanatory:

- **States sepsis/AMR rates in UK**
- **States sepsis/AMR rates out with UK**

Note for the above, they do not need to specifically state incidence to be coded 'yes' – denoting a change over time is sufficient. Modelled results coded as 'no', i.e., 'study suggests there could be up to X no. infections by year X'

- **States rates of sepsis/AMR are increasing** – needs to make some comment to emphasise idea of increasing rates – e.g., 'accelerating', crisis has 'grown' 'is now killing' – anything to imply change in rate over time. Can be about individual infection e.g., E coli rather than AMR as a whole, etc. Only record as 'yes' if it is clear that the numbers/rates refer to

clinically important infections in humans – i.e., not just levels of resistance in the environment or in animals. Note that this refers to the subject of the article – i.e., only code as yes if AMR article refers to rising AMR and vice versa.

Other examples that can be coded as 'yes'**:**

'Has become more/most common reason for admission'
'Antibiotics are becoming powerless'
'Need to slow the emergence'
'AMR already kills X… and predictions for the future are frightening'

Mentions the main risk to health as a future problem - for example many sepsis articles reference the year 2050 and this would be recorded as 'yes', however does not need to state year – also tick yes if states 'likely to be even more of a problem in future' or 'next few decades could see a return to pre-antibiotic era'. Use of word 'potential' or 'impending' should also be recorded as indicating that problem is in future – e.g., 'AMR is a potential public health catastrophe'. 'Threat' is not taken to indicate problem in future as this could indicate a present danger. Record as 'no' if simply states that rates are increasing, as this is already captured above. Describing risks as 'rapidly approaching' not coded 'yes' for in future as this implies imminent nature of problem.

- **Other examples that can be coded as 'yes'**

  'The projected figures are worrying'
  'Could kill within decades'
  'We risk entering a post-antibiotic era'
  'Prospect of post-antibiotic age'
  'Post-antibiotic age awaits'
  'Time bomb'

- **States associated economic impact (either on healthcare system or local/global economy)** – this definition is kept fairly broad and can refer to, for example, 'cost to NHS' or 'loss of GDP'

- **Compares risk to other health conditions** – for example states that AMR infections/sepsis 'causes more deaths than all types of cancer combined' either now or that this is projected in future

Again, the following should be self-explanatory:

Mentions babies/children as 'at risk' group

Mentions pregnant woman 'at risk' group

Mentions elderly 'at risk' group

Mentions those with pre-existing health conditions 'at risk' group

Language used may also be 'vulnerable', 'susceptible', 'likely to be affected', 'one of the commonest causes of death among children'. If the article does not specifically state 'at risk' or similar but mentions a series of cases that all belong to one group, such that it would be a reasonable interpretation by the reader that this is the only group affected/most affected then tick 'yes'. Also, code as 'yes' if one group is picked out for comment e.g., 'sepsis is a leading cause of rapid deterioration in children' or 'every day a child needlessly dies…' or 'symptoms are particularly hard to spot in children', i.e., picks them out as a group giving the reader no other interpretation than they are at particular risk. Stating 'X no children die each year' or no. cases of sepsis/resistance in children each year not coded 'yes' as this may only be a result of what data is available. If states 'those with low immune systems at risk' code as 'yes' but mention that chemotherapy/transplantation will become more risky not enough to code yes in itself.

Mentions 'everyone/anyone' is at risk

For this last category, record as 'yes' if article states that anyone can be affected, even if stated alongside the fact that some population groups are particularly at risk, i.e., although the article may make reference to the fact that AMR/sepsis are conditions

that do not discriminate, this is not necessary in order to record
this category as 'yes'. In one article the phrase 'young and old'
was taken to be a proxy for 'anyone' (note – in this example
'children' was NOT ticked yes based on this phrase).

Drivers

Human healthcare – systemic factors

In order to allow comparison between AMR/sepsis reporting this section is kept
necessarily broad.

For example, 'human healthcare system' as a driver could refer to

- inappropriate prescribing of antibiotics by healthcare professionals
- failure to recognise and treat early symptoms of sepsis
- failure of healthcare systems (e.g., NHS 111) to direct patients appropriately

Record as 'yes' if prescribing of antibiotics by health professionals is mentioned as a driver
of AMR, even if there is no explicit mention that this behaviour may be inappropriate.
'Difficult for staff to recognise signs of sepsis' recorded as systemic factor.

Clarifications added after validity exercise:

Issues related to contaminated healthcare products – code as yes as related to NHS
procurement processes and likely to impact on public confidence.

Actions taken by several health professionals in a unit that do not comply with best
practice – record as yes as reflects culture (and do not code as individual driver).

Need to recognise sepsis earlier – code as yes, as already stated above.

Racism affecting patient care – likely to be single article but code as systemic factor.

Human healthcare – behaviour of individual health professional

This is to capture the articles (more often about sepsis) where the actions of an individual
health professional is presented as a driver – for example, failure to identify signs of sepsis
– rather than the collective actions of healthcare professionals (e.g., in having insufficient
awareness of sepsis/overprescribing of antibiotics). This will be approached in a similar
manner to the criteria for 'identifiable victim' i.e., should only be ticked as 'yes' if a

specific, potentially traceable individual related to a particular case is referenced. Cf exclusion of 'anecdotal' case histories that may be only based on factual accounts.

Record as 'yes' if a negative outcome is clearly attributed to the actions of health professional/healthcare system, even if this does not relate to negligent actions. For example, record as 'yes' if article includes phrase such as "I just know if the first doctor had sent us to hospital 'X' would be alive today", even if there is no explicit suggestion that medical error was involved.

Record as 'no' if there is no mention of potential for different outcome if things had been done differently, for example if the article uses very factual language in its description of events such as: "'X' was seen by dr on Mon and diagnosed with a viral throat infection. By the end of the week 'X' was no better and was seen at out of hours, at which point 'X' was admitted to hospital". If there is no subsequent mention that the first contact should/could have had a different outcome (e.g., "if 'X' had been given antibiotics in the first place this wouldn't have happened" OR "doctors shouldn't be so quick to say that everything is down to a virus"), then this can be recorded as 'no'. Neutral phrases such as 'we'll never know if antibiotics would have made a difference' can be recorded as 'no', but if these are also associated with negative or critical comments (for e.g., "but I just wish we'd been listened to/ taken seriously/seen by a doctor") they will be recorded as 'yes'. This is likely to be one of the most ambiguous sections and the range of justifications for recording as 'yes/no' will be added to as necessary.

If a series of 'failings' by health professionals is described – i.e., not simply actions of one individual although relating to one case – then 'systemic factors' should be ticked yes. Similarly, if 'hospital managers/bosses' are described as at fault, this will be seen to represent systemic causes as they will obviously not have been responsible for direct prescribing decision. On some occasions both individual and systemic factors will be ticked yes.

Behaviour of the public

This could refer to:

- Failure of members of the public to seek timely medical attention for themselves or children
- Failure to heed warnings regarding public health threat of AMR

- Inappropriate demands for unnecessary antibiotics
- Demand for cheap meat associated with overuse in farming/food production

Simply referring to a general lack of awareness among the public about sepsis/AMR (as opposed to more specific behaviours) will be recorded as 'no'. However, if specific reference is made to not seeking attention early enough – e.g., 'in 60% of cases where sepsis pts presented late it was because they had not contacted drs – it was people not picking up the phone' then this will be recorded as 'yes'.

From scoping phase, it is unlikely that articles will blame actions of parents in not seeking earlier medical attention for children (unless reported in relation to a child neglect case) but this may occur in relation to adults, e.g., "despite noticing that the redness was spreading, 'X' refused to see dr until it was too late". This example would be recorded as 'yes'.

If the only mention of blame in relation to behaviour of the public is contained within a personal quote this will be recorded as 'no', unless reinforced by copy elsewhere in the article. For example, "I just wish we had insisted on a second opinion sooner" will be recorded as 'no' as this seems to be an expression of personal grief and not necessarily an objective view. However, if this is accompanied by a phrase such as: "experts believe that one of the problems is that parents do not seek help for the symptoms of sepsis early enough" then it will be recorded as 'yes'.

Phrases about lack of understanding of mode of action of antibiotics recorded as no unless goes on to say something like 'despite being informed that antibiotics are ineffective against viruses some patients put pressure on health professionals to prescribe them'

'Half the population do not know antibiotics are inappropriate to treat colds…' – recorded as no.

'Britons can't get enough of cheap chicken' – consumer habits – record as yes.

Farming and food industries

Record as 'yes' if use of antibiotics within farming/food production industries is mentioned as a cause (of AMR). Does not need to refer to negligent behaviour, simply mentions that this is one of the causes. It is acknowledged that there is a distinction here between human use and animal use i.e., use of antibiotics as growth promoters (at all) could be viewed as inherently wrong while the same cannot be said of therapeutic use in humans. Some

ambiguity may arise as it is acknowledged that some animal use is obviously for valid therapeutic indications. Refine as necessary.

Although mentioning reducing antibiotic use in farming as a solution implies that it is a driver this will be recorded no unless explicitly stated e.g., 'Prince Charles has switched to organic farming because of the growing threat of AMR' implies that conventional farming is a driver, but this interpretation relies on some prior knowledge therefore is coded 'no' for driver.

Pharmaceutical industry

Record as 'yes' if failure to develop new antibiotics/failure to invest in research and development of new antibiotics is mentioned as a cause of AMR. As with farming and food industries, does not need to be critical in tone (e.g., referring to industry as driven by profit/greed), just that this contributes to the problem.

Failure of Government(s)

Again, this is broad and may refer to:

- Under resourcing of healthcare system
- Failure to make necessary policy change/enforce adequate legislation, e.g., in relation to antibiotic use in farming industry

Some articles about sepsis include mention of an apology from the government, e.g., to families affected by sepsis. In general, these will be coded as referring to failure within the healthcare system (e.g., 'The Health Minister has apologised on behalf of the NHS trust…'), however if there is reinforcement of the theme of failure on the part of the Government elsewhere in the article e.g., 'the Health Minister admits that the Government has failed to act quickly enough…' then these will be recorded as 'yes'. Phrases such as 'wake-up call for government' recorded as yes. "The politicians… are keeping their heads down. They hope everyone will have forgotten about it." - yes

Solutions

Note that for this section, mention of a 'driver' does not automatically imply it is being put forward as a 'solution'. For example, 'there is a lack of awareness about the importance of AMR as a public health issue' is a driver. 'Greater awareness about AMR is required in order to help combat this issue' is a solution.

Awareness raising/behaviour - greater awareness of sepsis/AMR among health professionals and/or the public

This category should be recorded as 'yes' if the solution is presented as simply "greater awareness of (problem) is required" OR if need for an awareness campaign is mentioned. This should also be recorded as 'yes' if the required solution is presented as a change in behaviour that is associated with greater awareness e.g., "doctors/parents need to know what to look for" OR "rapid action is required if sepsis is suspected". Statements such as 'we need to make the public realise/understand…' coded as 'yes'. Stating that the function of the sepsis trust is to campaign for greater awareness is recorded as no unless this is elaborated on as a requirement. Statements such as 'I am concerned about a lack of awareness' coded as 'no' as does not explicitly offer a solution.

Other examples that can be recorded as 'yes':

'Action plan to support professionals to diagnose and treat sepsis'
'Needs to be a culture shift… so people think of sepsis…'
'Needs to be on the radar of health professionals'
'We need to be educating health professionals and members of the public'.

Technical - more effective ways of diagnosing/treating sepsis/AMR e.g., rapid diagnostic tests, new antibiotics, alternatives to antibiotics

This should be recorded as yes if any of the above is mentioned. 'Enough new antibiotics aren't being developed' – taken to mean new antibiotics are being presented as a solution, record as 'yes'.

Note that this should only be recorded as 'yes' if NEW treatments/investigations, or research into these, are advocated, not simply better use of existing ones (this would be a systemic solution)

Systemic - protocols and guidelines, data management systems, clinical governance, regulation

Tick yes if mention of any of the above. Includes a wide range of clinical guidelines; data management systems (e.g. electronic systems for notifying health professionals of resistance rates and antibiotic susceptibilities or better access to patient case notes for out of hours staff); clinical governance procedures within hospitals (e.g. transparency in

reporting of cause of death); more effective algorithms for use by NHS call centre staff; more effective regulation of antibiotic use in human health (UK and global)/farming sectors; policy related to funding for pharmaceutical research and development (as opposed to the actual production of new drugs). If two solutions are presented together then both will be recorded as 'yes', for example a phrase such as 'greater priority should be given to providing funding to enable development of new drugs' then both 'technical' and 'systemic' will be recorded as 'yes'.

The phrase 'treat sepsis with same urgency as heart attacks' is recorded as a systemic solution as this is felt to imply following a clinical guideline in the same way as would occur with a suspected heart attack.

The following two specific solutions are included to illustrate the potential conflict between sepsis management/antimicrobial stewardship:

Implementation of sepsis 6/specific mention of need for early antibiotics as a solution. Includes 'sepsis bundle' which is often used as synonym for Sepsis 6. Sepsis 6 is the clinical pathway used as best practice to manage suspected sepsis (and includes early administration of antibiotics as a component). If only this is mentioned, then do not tick 'yes' for systemic solutions to avoid double counting (but obviously tick 'yes' if other systemic solutions are mentioned. If antibiotics are mentioned only as part of the narrative of an individual case e.g., 'he was then admitted to intensive care and given strong antibiotics which saved his life' or 'he should have been given antibiotics with those symptoms' do not tick as 'yes' – only if antibiotics are presented as a solution to be applied to all cases.

Reduce prescribing of antibiotics. This is likely to be linked to other solutions – greater awareness etc – so it is likely that more than one solution will be recorded as 'yes' where this is ticked. This only refers to reduction in human prescribing – calls for reduction in veterinary/food industry prescribing should be recorded under systemic solutions.

Stating that overuse is a cause is not sufficient to record reduced prescribing as a solution.

Other examples that can be recorded as 'yes':

'We need to promote responsible use by doctors'

11 'Alarmist' language

Self –explanatory – record as 'yes' if article refers to AMR/sepsis using the following phrases:

Silent killer/hidden killer

Scandal/scandalous

Catastrophe/catastrophic

Time bomb

Disaster/disastrous

Apocalypse/apocalyptic

Post-antibiotic era/age

Appendix 10 Coding sheet for news articles about AMR/sepsis

Coding Sheet: Sepsis/AMR

1	Article ID		
NUMBER	NUMBER	NUMBER	NUMBER

2	Date		
Day		Month	Year

3	Word Count		
NUMBER	NUMBER	NUMBER	NUMBER

4	Headline (full)

6 Article is about	
Sepsis	1
AMR	2

7 Sepsis article mentions AMR and vice versa?	
Yes	1
No	2

5 Newspaper Publication	
Guardian	1
Observer	2
Daily Telegraph	3
Sunday Telegraph	4
Daily Mail	5
Mail on Sunday	6
Express	7
Sunday Express	8
Mirror	9
Sunday Mirror	10
Sun	11
News of the World	12

8	Are any of the following expressed in the text?	YES	NO
Problem definition	States sepsis/AMR rates in UK (quantifies scope/ statistics)	1	2
Problem definition	States sepsis/AMR rates out with UK (quantifies scope/ statistics)	1	2

Problem definition	Mentions that greatest health risk is in the future	1	2
Problem definition	States associated economic impact (either on healthcare system or local/global economy)	1	2
Problem definition	Compares AMR/sepsis to other health conditions	1	2
Problem definition	Mentions babies/children as 'at risk' group	1	2
Problem definition	Mentions pregnant women as 'at risk' group	1	2
Problem definition	Mentions elderly as 'at risk' group	1	2
Problem definition	Mentions those with pre-existing health conditions as 'at risk' group	1	2
Problem definition	Mentions 'everyone' is in 'at risk' group	1	2
Drivers	Human healthcare – systemic factors	1	2
Drivers	Behaviour of identifiable individual healthcare professional	1	2
Drivers	Behaviour of the public	1	2
Drivers	Farming or food industry	1	2
Drivers	Pharmaceutical industry	1	2
Drivers	Government	1	2
Solutions	Awareness raising - greater awareness of sepsis/AMR among health professionals or the public	1	2
Solutions	Technical - more effective ways of diagnosing/treating sepsis/AMR e.g. rapid diagnostic tests, new antibiotics, alternatives to antibiotics	1	2
Solutions	Systemic - protocols and guidelines, data management systems, clinical governance, regulation	1	2
Solutions	Implementation of Sepsis 6/early antibiotics	1	2
Solutions	Reduction in unnecessary prescribing of antibiotics (humans)	1	2
other		1	2
other		1	2

9 Includes case history with 'identifiable victim' :	Yes	No
Baby or child	1	2
Pregnant or new mother	1	2
Young adult - < 50	1	2
Older adult - > 50	1	2
Elderly > 80	1	2
Celebrity or relative of celebrity	1	2
William Meade	1	2
Other	1	2
Named?	1	2

Appendix 11 Summary of cases in news stories in qualitative analysis

Victim name	Age	Year of death or illness	Description of case
Thomas Hull	9	2013	Discharged from A&E with diagnosis of mild chest infection, died at home following day. Doctor involved accused of altering notes to protect reputation.
Franchesca Pawson	12	2016	Discharged twice from NHS walk-in centre, died following day from sepsis related to empyema.
Christie Holt	14	2011	Saw GP with sore throat and headache and sent home, deteriorated and died in hospital following day.
Lavae DaSilva	3	2011	Died on holiday in Cuba after complaining of abdominal pain. Cause of death meningococcal septicaemia.
Chloe Holmes	3	1999	Underwent amputation of fingers after developing streptococcal septicaemia as complication of chickenpox.
William Mead	12 months	2014	Died from sepsis as a complication of a chronic chest infection. An official enquiry found that call handlers at NHS 111 failed to recognise signs of deterioration in the hours before his death.
Holly Deegan	4	2008	Died four days after being diagnosed with viral infection by GPs and hospital doctors; her father committed suicide two months later.
Jessica Lamph	10 days	2003	Died of sepsis-related organ failure having been delivered 5 weeks prematurely due to confusion over true gestational age.
Faye Grace	8 months	2006	Died of sepsis as complication of chickenpox.
Andrew Sutherland	6 months	2006	Died from sepsis after becoming unwell at home following two surgical procedures. Press coverage related to parents' discovery that organs had been retained after post-mortem.
Lee Readitt	12	2000	Developed sepsis after scratching leg in garden; recovered after operation to remove abscess from heart.
Kelly Fitzgerald	15	1993	Died in hospital from sepsis after prolonged history of physical abuse by parents.
Imran Khan	15	1998	Died in hospital after developing sepsis related to insertion of chest drain during treatment of injuries sustained during an assault.
Sam Morrish	3	2010	Died from sepsis as a complication of pneumonia; ombudsman's report found multiple failings in his care.
Chloe Welch	4	2012	Died after staff at NHS 111 helpline repeatedly failed to recognise indicators of sepsis, diagnosing her with norovirus when her parents consulted after she developed vomiting.
Sebastian Randle	11 weeks	2013	Died of sepsis related to rare form of meningitis; staff at NHS 111 helpline failed to recognise significance of high temperature after his parents consulted about cough symptoms.
Joshua Titcombe	9 days	2008	Died from pneumococcal infection; inquest found his parents' concerns were dismissed repeatedly and that he is likely to have survived if antibiotics had been given.
Maude Watkins	2	2011	Died hours after being discharged from hospital with breathing difficulties.
Jack Adcock	6	2011	Died in hospital from sepsis as complication of pneumonia; the doctor who treated him was found guilty of manslaughter and gross negligence though this was overturned on appeal.
Lewis Lyons		2015	Developed sepsis as complication of chickenpox. Recovered but mother critical over administration of ibuprofen by hospital (contraindicated during chickenpox).
Blessing Matia	3	2016	Died at home from sepsis as complication of chickenpox having been discharged from A&E with reassurance.

Freddie Taft	2	2016	Recovered from sepsis after mother recognised signs having heard William Mead's story.
Amelie Perry	1 day	2016	Recovered from neonatal sepsis caused by Group B streptococcal infection.
Yousef al-Kharboush	9 days	2014	Died from sepsis associated with contaminated parenteral feeding product.
Rosie Oyoo	2	unspecified	Developed sepsis as complication of chickenpox, eventually recovered in hospital after having been sent home by two doctors.
Reuben Harvey-Smith	3	2016	Developed sepsis associated with minor burns, significance of symptoms initially dismissed by doctors. Survived with quadruple limb amputations.
Tilly Moores	7 months	2010	Developed sepsis as complication of chickenpox; recovered with some developmental delay.
Charlie Jermyn	1 day	2015	Died of sepsis after being born suddenly at home; attending midwife failed to recognise signs of respiratory distress.
Phoebe Willis	10	2012	Died from sepsis after incorrect insertion of parenteral feeding tube at home by nurse.
Oliver Anderson	1 day	2015	Recovered from sepsis after signs were recognised by community midwife.
Ben Condon	8 weeks	2015	Died from sepsis in neonatal unit after staff failed to act on parents' concerns and errors concerning investigation performed and treatment administered.
Layla Benton	14	2013	Developed sepsis after receiving bite from venomous spider on leg, made full recovery.
Jeremiah Kerr	4 days	2011	Died of neonatal sepsis on same day as his mother. Microbiology results reported before their initial discharge had not been acted on.
Callum Cartlidge	8	2016	Died of sepsis hours after being discharged from A&E with diagnosis of gastroenteritis.
Paddy Dear	16	2017	Died after accidental fall during school trip having developed sepsis associated with tonsillitis.
Felicity George	8 weeks	2017	Died at home from sepsis associated with pneumonia, having been sent home from NHS out of hours centre with reassurance the previous evening.
Connor Horridge	6	2016	Died of sepsis associated with streptococcal infection; sent home four times by doctors in out of hours centre and A&E having complained of sore throat and earache.
Bryan-Andrew Lock	3	2016	Died from sepsis associated with Group A streptococcal infection secondary to chickenpox.
Layla-Rose Ermenekeli	6	2017	Died from meningococcal sepsis, rash initially dismissed by doctor.
Tommy Roden	6 days	2017	Died from sepsis after being born 8 weeks prematurely.
Vlada Dzyuba	14	2017	Russian child model, died from organ failure due to sepsis while working in China, article relates illness to inadequate restrictions on long hours worked.
Nyah Smith	1	2013	Died from sepsis in hospital, earlier discharged from A&E with symptoms dismissed as viral infection.
Dylan Day	12	2018	Died in hospital after developing sepsis as complication of flu.
Chloe Goulborn	11 weeks	2017	Became unwell suddenly at home with poor feeding and respiratory distress, taken to GP who recognised signs of sepsis and called ambulance immediately, made full recovery in hospital.
Connie Young	Newborn – 6 mths	2017	Born at 23 weeks, developed sepsis four times in first few months of life but has since made full recovery.

Alfie Coxon	2	2018	Died from meningococcal sepsis hours after symptoms being misdiagnosed by nurse practitioner as due to ear infection.
Tony Smith	1 month	2014	Developed sepsis secondary to severe physical abuse by parents, underwent lower limb amputations but survived.
Kavele Kerr	6	2015	Died from sepsis as complication of sickle cell disease.
Aoife Davies	9 weeks	2014	Developed respiratory distress and poor feeding, referred to hospital by GP, signs of sepsis recognised by Dr Ron Daniels (CEO of Sepsis Trust), made full recovery after treatment.
Alfie Scambler-Holt	10	2017	History of cerebral palsy having been born prematurely at 25 weeks. Developed respiratory distress at home, died hours later in hospital despite treatment.
Ethan Hunt	16	2018	Died from sepsis in hospital a month after becoming unwell with what was initially believed by parents to be flu or another viral infection.

Appendix 12 Codebook for qualitative analysis					
	Antibiotics	**Families**	**Healthcare system**	**Sepsis**	**Victims**
Subthemes	AMR	accountability	attitudes of medical staff	adjectives and metaphors	avoidability
	AMR as cause of sepsis	anger	cover-ups	death is avoidable	celebrity
	antibiotics in primary care	battle metaphors	ignorance	difficult to treat	character reference
	antibiotics only solution	blood run cold	Jeremy hunt as father	doesn't discriminate	childhood illness
	antibiotics refused	Calpol	misdiagnosis	sepsis is common	'epidemic' of preventable deaths
	competing priorities for medics	criminal act	negative language	sepsis is difficult to diagnose	failed by NHS
	complications even with antibiotics	empathy	NHS culture	sepsis is easy to treat	pivotal moments
	conflict with medics	empowerment	persistence	sepsis is rare	stolen future
	consequence of delays	expressions of grief	praise for NHS	speed	vulnerability
	danger of simple infections	guilt	punishment		Victims
	early treatment	legacy	rewards		avoidability
	easily treated	nigtmarish	systemic failings		celebrity
	IV antibiotics	parental instinct	undermining confidence		character reference
	just in time	redemption			childhood illness
	rapid diagnostics	regret			'epidemic' of preventable deaths
	simple dose of antibiotics	responsibility with public			failed by NHS
	too late	self-doubt			pivotal moments
	uncertainty of timing	support from medics			stolen future
		survivor's luck			vulnerability
		the parent as expert			Victims
		unimaginable			avoidability
		vulnerability			celebrity
		warning to others			character reference
					childhood illness

Appendix 13 Topic Guide

Typical newspaper articles about sepsis and AMR will be used as prompts to help facilitate discussion among participants about the impact of media reporting on their beliefs and understandings. The following topics will be covered, with LR acting as group facilitator as required.

Structure (aim for 1 hour duration)

- Reiterate purpose of study and uses of data collected.
- Consent forms – reiterate method for data storage and sharing, confidentiality
- House rules
- Introductions and ice breaker

Section 1

Childhood illness inc. sepsis 15 mins

- When was the last time your child was unwell? Tell me about what happened?
- What do you find difficult when your child is unwell (anxiety, disturbed sleep, time off work etc)?
- Do you get advice from anyone else when your child is unwell? Which resources do you use for advice (family, friends, online, pharmacy, NHS 111 etc)?
- How do you decide whether medical advice or assessment is required?
- What symptoms would raise your level of concern?
- What else raises your level of concern? (past experience, experiences of others, having healthcare expertise or perhaps having no healthcare expertise, child having other chronic illnesses)
- How do expectations of others (e.g., family, other parents, nursery teachers) affect your response when your child is unwell? Do you ever seek medical attention because you feel others expect you to?
- What are your expectations when you attend a doctor/nurse/other health professional when your child is unwell?
- Do some symptoms/illnesses cause more concern than others? Meningitis, respiratory illnesses (croup, bronchiolitis), vomiting
- Do you feel that when you attend the doctor with your child that your concerns are taken seriously? Do you have any examples of times when they have not been taken seriously?
- Have you heard of sepsis? What is it?
- Do you know anyone who has been affected by sepsis? What happened?
- What signs and symptoms of sepsis are you aware of?

- How is sepsis treated?
- Is the possibility of sepsis something that worries you when your child is unwell?

Antibiotics 15 mins

- What are antibiotics for and when are they needed?
- How do you know if your child requires an antibiotic?
- How do health professionals know if your child requires antibiotics?
- What is antibiotic resistance/antimicrobial resistance/AMR?
- How does AMR develop? (human overuse of antibiotics, less regulated use in some countries (e.g., over the counter), use in farming and food production)
- Who is at risk of resistant infections? What groups – young, elderly, chronic disease?
- Are all countries affected equally?
- Do you know anyone who has been affected by infections that were resistant to antibiotics? What happened?
- How can AMR be managed? Is how we use antibiotics in human health important? What else is important? (reducing antibiotic use in food production, development of new drugs, policy and legislation)
- How does AMR affect your attitude to taking antibiotics (if at all)?
- Have you ever felt you or your child has not had an antibiotic prescribed when needed? Have you ever felt an antibiotic was prescribed when you didn't think it was needed?
- How easy is it to talk to doctors or other health professionals about antibiotics? What makes it easier or more difficult – age, how busy surgery is, established relationship with doctor

How does the media affect how you view these issues? 30 mins

- What sources of news do you access – newspaper, online, social media feed, TV, radio, magazine programmes on TV
- How are stories about health risks to children reported in the news?
- Which stories about health risks in children can you remember?
- What makes you pay attention to a news story about health risks?
  Examples:
  level of harm i.e., death or disability
  Could have been preventable
  Caused by mistakes or delays by healthcare staff
  Involves celebrity
  Photos of victim
  Accompanying stories by victim or victim's family

- What do you know about how sepsis has been reported in newspapers?
- Do stories about sepsis make you concerned?
- How do news stories about sepsis affect how you respond when your child is unwell (if at all)?
- What do you know about how AMR is reported in the media? Can you think of any headlines or news stories that you have seen?
- Do the stories about AMR in the media make you concerned? Why or why not?
- Are messages in the media about when antibiotics are needed clear?

Appendix 14 Topic guide for groups with participants with lived experience of sepsis

Introductions

1. Personal experiences with sepsis

   Focus in on symptoms – what did you first feel wrong? Did you realise it was serious? When? What was different from other episodes of illness? When did you first see health professional? What happened? Were they concerned? Were family members/friends concerned? Is there anything that could/should have been done differently?

2. How sepsis is reported in media

   How aware are you of media reporting of cases of sepsis? Which cases? Show examples. Wm Mead, Dr Bawa Garba. Why has sepsis received so much media attention recently? What do the media say causes sepsis? Is it one disease or many? Is it important to know what infection has caused sepsis? How do representations in newspapers compare with your own experiences? Is coverage fair? Is anyone to blame when there are bad outcomes from sepsis? What might be the impact of media reporting that apportions blame?

3. Antibiotics

   What are your thoughts on antibiotic use? Are there risks associated with antibiotic use? What is antimicrobial resistance/antibiotic resistance? What will its impact be? On who and when? How is AMR portrayed in media? How does this compare with how sepsis is portrayed? Do you think the public are concerned about AMR? Are health professionals concerned about AMR? How do we balance the need for early antibiotics when someone is unwell with sepsis with the need to reduce unnecessary prescribing?

4. Awareness campaigns about sepsis

   What ones are you aware of? Just ask – could it be sepsis? Is this a helpful message? What about the symptoms you are asked to be aware of? Would it have been helpful to have had these reminders when you were unwell? If you or someone you know developed these symptoms again would you recognise them and would it change what you decided to do?

Do you think sepsis campaigns may cause anxiety? Is this a worthwhile trade off? Could they result in unnecessary antibiotic prescribing? Are there differences when evaluating symptoms in children compared to in adults? If so, why?

Appendix 15 Recruitment poster

Appendix 16 Participant Information Sheet

Simplified title: Parents awareness of sepsis and antibiotic resistance

You are being invited to take part in a research study. It is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and decide whether or not you wish to take part. You can discuss it with others if you wish.

What is the purpose of this study?

Illnesses caused by bacteria are getting harder to treat with antibiotic drugs. This is called antibiotic resistance. Scientists think that antibiotic resistance will increase in future and this will be a big threat to health. Avoiding use of antibiotics when they are not needed, for example, when you have a viral illness, is important to reduce antimicrobial resistance but it is important that they continue to be taken when needed. Sepsis is a serious complication of infection that requires treatment with antibiotics. There have been lots of newspaper articles about sepsis recently. This study aims to explore perceptions and awareness among parents and carers about sepsis and the uses, risks and benefits of antibiotics and how the media represent these issues.

Who is carrying out this research?

The study is being carrying out by Dr Lynne Rush, who is based at the MRC/CSO Social and Public Health Sciences Unit, University of Glasgow. The research is supervised by senior colleagues in the unit.

Why have I been chosen?

The study team are very interested in the views of parents and carers of pre-school children. We would like parents and carers of children from pre-school groups and nurseries/family centres to take part. Up to twelve focus groups will be carried out around the Glasgow area. Each group will have six to eight parents and carers.

Do I have to take part?

You can decide whether or not to take part. If you decide to take part, you will be given this information sheet to read and keep. You will also be asked to sign a consent form. If you decide to take part, you can change your mind at any time and without giving a reason. If you decide to withdraw consent for the research after taking part in the focus group and would like us to remove your quotes from the data we will do our best to identify these, although it may not be possible to identify every word.

What will happen to me if I take part?

Taking part in the research is very straightforward. You will be asked to discuss a variety of topics related to infection and antibiotics in a group setting. You do not need to know about these issues before coming to a focus group. Discussions will last for about one hour and will be recorded. Participants will be given a £15 'Love to Shop' voucher to thank them for taking part.

Will my data be kept confidential?

All information collected will be kept strictly confidential. Your name and contact details will be held securely on file within the university in case we need to contact you. The researcher will remove your name and address and other personal details from the research data. Contact information and research data will be kept securely for at least ten years.

What will happen to the results of the research study?

The results will be reported in academic journals and in talks to researchers and the public. Details such a names and addresses will be removed or changed so that it will not be possible to recognise you from any quotes that are used. Other researchers may ask to use the data from this study to understand more about sepsis and antibiotic resistance. Other researchers will only be allowed to use the data if they follow the same strict rules on confidentiality. A summary of the research findings will be made available to participants on request.

Who is funding the research?

This research is funded by the Medical Research Council. The researcher works at the Medical Research Council/Chief Scientist's Office Social and Public Health Sciences Unit, University of Glasgow.

Who has reviewed the study?

The project has been reviewed by the College of Medical and Veterinary Life Sciences Ethics Committee, University of Glasgow.

Contact for further information

You can ask questions about the study before, during or after taking part. If you want more information about the study please contact:

Dr Lynne Rush

MRC/CSO Social and Public Health Sciences Unit, 200 Renfield Street, Glasgow

Telephone:

Email:

Alternatively, you might like to speak to someone who is not directly involved in the data collection. You can speak to or email Dr Shona Hilton

Many thanks for your participation in this research.

Appendix 17

University of Glasgow | College of Medical, Veterinary & Life Sciences

Centre Number:
Project Number: 171336-01 / 171339-01

CONSENT FORM

Title of Project: Are sepsis awareness and antimicrobial stewardship competing goals?
A qualitative study using focus groups informed by a mixed methods content analysis of UK newspapers

Name of Researcher(s): Lynne Rush

Please initial box

I confirm that I have read and understand the information sheet dated
 1.3.18 for the above study and have had the
opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.

I agree for the data collected during this research to be used in anonymised form in articles that will be published in academic journals and used in presentations to other researchers and to the wider public

I agree that the anonymised data can be shared with other researchers if requested both within and out with the University of Glasgow

I agree to take part in the above study.

_____   _____   _____
Name of participant   Date   Signature

_____   _____   _____
Researcher   Date   Signature

(1 copy for subject; 1 copy for researcher)

Appendix 18 Focus group participant details
Focus group participant details

01	**What is your date of birth?** (Please **write in** - for example: 30/03/1983)

🖊 [D D] / [M M] / [Y Y Y Y]

02	**What is your postcode?** (Please **write in**)

🖊 [ ][ ][ ][ ]   [ ][ ][ ]

e.g.   K   A   1   4   8   R   J

G   1   2   8   R   Z

03	**Which religion are you?** (Please tick **one box only**) (Please tick **all that apply**)

None [ ] 1   Buddhist [ ] 1

Protestant [ ] 1   Hindu [ ] 1

Roman
Catholic [ ] 1   Jewish [ ] 1

                               Muslim [ ] 1

                               Sikh [ ] 1

Other Christian [ ] 1   Other [ ] 1
(Please **write in**)   (Please **write in**)

🖊 _____   🖊 _____

Appendix 19 Characteristics of focus group participants

Group 1 Lone fathers' support group (pre-existing group)

Participant's pseudonym	Alan	Joseph	Patrick	Michael
Age	38	27	27	36
Status as parent/carer	Parent	Parent	Parent	Parent
Employment status	Full-time	SAHP	unemployed	SAHP
Level of education	Standard grades	HNC	NVQ	Standard grades
SIMD category of residence	2	1	2	1
Relationship status	In partnership	Single	Single	Single
Ages of children in household	10, 6, 3	6, 4	Not specified	10, 3

Group 2 Kinship carers group (pre-existing group)

Participant's pseudonym	Anne	Janette	Michelle
Age	60	36	42
Status as parent/carer of pre-school children	Carer	Parent and carer	Parent and carer
Employment status	SAHP (grandparent)	SAHP	SAHP
Level of education	University or college degree	Standard grades	None
SIMD category of residence	1	2	1
Relationship status	Widowed	In partnership	In partnership
Ages of children in household	16, 4, 3, 7 months	12, 4, 3	14, 4, 4 weeks

Group 3 Parent and baby group (pre-existing group)

Participant's pseudonym	Jade	Laura	Jenny	Siobhan	Leanne	Marianne	Abby	Julie
Age	26	Not given	num	33	27	32	27	29
Status as parent/carer of pre-school children	Parent	Parent	Parent	Parent	Parent	Parent	Parent	Parent
Employment status	Full-time	Part-time	SAHP	Full-time	Full-time	Full-time	Full-time	Full-time
Level of education	Higher/ Advanced higher	University or college degree	HNC	University or college degree	University or college degree	University or college degree	Standard grades	University or college degree
SIMD category of residence	1	1	2	1	1	5	1	3
Relationship Status	In partnership	In partnership	In partnership	In partnership	In partnership	In partnership	In partnership	In partnership
Ages of children in household	4 months	8, 5, 5 months	5, 7 months	8 months	11 months	10 months	2 months	9 months

Group 4 Parent and baby group (pre-existing group)

Participant's pseudonym	Eileen	Kerry	Jodie
Age	50	32	19
Status as parent/carer of pre-school children	Carer (grandparent)	Parent	Parent
Employment status	Full-time	SAHP	SAHP
Level of education	Not given	HNC	Standard grades
SIMD category of residence	3	3	3
Relationship status	In partnership	In partnership	Single
Ages of children in household	9 months	2 months	9 months

Group 5 Parents of children attending pre-school

Participant's pseudonym	Claire	Andrea
Age	38	31
Status as parent/carer of pre-school children	Parent	Parent
Employment status	Part-time	SAHP
Level of education	HNC	HNC
SIMD category of residence	2	2
Relationship status	In partnership	In partnership
Ages of children in household	6, 4	7, 3

Group 6 Parents of children attending pre-school

Participant's pseudonym	Debbie	Justine	Pippa	Kelly	Claire	Rhona	Gemma	Shannon
Age	32	31	27	37	37	34	25	24
Status as parent/carer of pre-school children	Parent	Parent	Parent	Parent	Parent	Parent	Parent	Parent
Employment status	Part-time	Part-time	SAHP	SAHP	Part-time	Part-time	SAHP	Part-time
Level of education	HNC	Standard grades	Standard grades	Standard grades	University or college degree	HNC	HNC	University or college degree
SIMD category of residence	2	2	2	2	3	2	2	2
Relationship status	In partnership	Single	Single	In partnership	Separated	In partnership	Single	Single
Ages of children in household	8, 4	7, 4	7, 4	2	7, 5	4	4	3, 9 months

Group 7 Parents in contact with organisation for disadvantaged families

Participant's pseudonym	Carol	Brian
Age	42	44
Status as parent/carer of pre-school children	Parent	Parent
Employment status	SAHP	SAHP
Level of education	Stannard grade	HNC
SIMD category of residence	1	1
Relationship status	Single	Single
Ages of children in household	11, 9, 4	4

Group 8 Parents attending 'baby café' (pre-existing group)

Participant's pseudonym	Aileen	Nicola	Beth	Joanne
Age	34	35	34	32
Status as parent/carer of pre-school children	Parent	Parent	Parent	Parent
Employment status	Full-time	Full-time	Part-time	Full-time

Level of education	University or college degree	Standard grades	University or college degree	University or college degree
SIMD category of residence	1	4	2	1
Relationship status	In partnership	In partnership	In partnership	Divorced
Ages of children in household	3, 9 months	3, 10 months	2, 2 months	6 months

Group 9 Parents attending 'baby café' (pre-existing group)

Participant's pseudonym	Lynsey	Vicky	Natalie	Cheryl
Age	32	31	29	33
Status as parent/carer of pre-school children	Parent	Parent	Parent	Parent
Employment status	SAHP	Full-time	SAHP	Part-time
Level of education	Higher/advanced Highers	University or college degree	HNC	Higher degree
SIMD category of residence	1	2	5	5
Relationship status	In partnership	In partnership	In partnership	In partnership
Ages of children in household	7, 2 months	6 months	3, 9 months	3, 9 months

Group 10 Parents attending mother and baby exercise class (not previously acquainted)

Participant's pseudonym	Rachel	Sarah	Catherine
Age	31	27	38
Status as parent/carer of pre-school children	Parent	Parent	Parent
Employment status	SAHP	Part-time	Part-time
Level of education	University or college degree	HNC	University or college degree
SIMD category of residence	2	1	2

Relationship status	In partnership	Single	In partnership
Ages of children in household	1	3	4, 9 months

Group 11 Parents of children attending pre-school

Participant's pseudonym	Tara	Kelly	Carly	Jill
Age	37	24	23	27
Status as parent/carer of pre-school children	Parent	Parent	Parent	Parent
Employment status	SAHP	SAHP	Part-time	SAHP
Level of education	Standard grades	Standard grades	Standard grades	Standard grades
SIMD category of residence	1	2	1	2
Relationship status	Single	In partnership	In partnership	Single
Ages of children in household	10, 3	5, 3, 3 weeks (twins)	4, 3	7, 4, 1

Group 12 Parents of children attending pre-school

Participant's pseudonym	Barbara	Katie	Gillian	Scott
Age	34	23	29	36
Status as parent/carer of pre-school children	Parent	Parent	Parent	Parent
Employment status	SAHP	SAHP	SAHP	Full-time
Level of education	HNC	HNC	HNC	University or college degree
SIMD category of residence	2	1	1	5
Relationship status	In partnership	Single	Single	In partnership
Ages of children in household	8, 4	4, 9 weeks	3	3

Group 13 Parents of children attending pre-school

Participant's pseudonym	Tracey	Judy	Yvonne	Caroline	Heather	Danielle	Amanda	Samantha
Age	29	37	35	32	42	29	32	31
Status as parent/carer of pre-school children	Parent	Parent	Parent	Parent	Parent	Parent	Parent	Parent
Employment status	SAHP	Full-time	Part-time	SAHP	Part-time	SAHP	SAHP	SAHP
Level of education	University or college degree	Standard grades	Standard grades	Highers/advanced Highers	University or college degree	None	Standard grade	HNC
SIMD category of residence	1	1	1	1	5	3	1	1
Relationship status	In partnership	In partnership	Single	In partnership	In partnership [	In partnership	In partnership	In partnership
Ages of children in household	6, 2	9, 8, 5, 3, 9 months	3	9, 4	4, 1	4, 3	4, 2	10, 6, 2

Group 14 Parents attending library story and music group (pre-existing group)

Participant's pseudonym	Irene	Marie	Erica	Andrea
Age	56	43	31	39
Status as parent/carer of pre-school children	Carer (grandmother)	Parent	Parent	Parent
Employment status	SAHP	Full-time	Part-time	Full-time
Level of education	Standard grades	University or college degree	Higher degree	University or college degree
SIMD category of residence	2	2	4	5
Relationship status	In partnership	In partnership	In partnership	In partnership
Ages of children in household	1	8, 6, 3	3, 1, 5 months	3

Group 15 Individuals with lived experience of sepsis

Participant's pseudonym	June	Gary	Helen
Age	45	51	37

Sepsis survivor or relative of affected individual	Mother of teenage boy who died of sepsis	Father of teenage boy who died of sepsis	Survived sepsis after childbirth
Employment status	Part-time	Retired	Full-time
Level of education	University or college degree	Highers/advanced Highers	University or college degree
SIMD category of residence	2	2	5
Relationship status	In partnership	In partnership	In partnership

Group 16 Individuals with lived experience of sepsis

Participant's pseudonym	Joan	Chelsea
Age	62	32
Sepsis survivor or relative of affected individual	Wife of individual who died of sepsis	Daughter of individual who died of sepsis
Employment status	Unemployed	Full-time
Level of education	Higher/advanced Highers	Higher/advanced Highers
SIMD category of residence	3	4
Relationship status	Widowed	In partnership

roup 17 Individuals with lived experience of sepsis

Participant's pseudonym	Bill	Sheila	Courtney
Age	53	49	17
Sepsis survivor or relative of affected individual	Sepsis survivor	Sepsis survivor	Daughter of Sheila
Employment status	Full-time	Part-time	Part-time
Level of education	University or college degree	University or college degree	Highers/advanced Highers
SIMD category of residence	3	5	5
Relationship status	Single	In partnership	Single

Group 18 Individuals with lived experience of sepsis

Participant's pseudonym	Kerry	Linda
Age	45	52
Sepsis survivor or relative of affected individual	Sepsis survivor	Sepsis survivor
Employment status	SAHP	Full-time
Level of education	University or college degree	HNC
SIMD category of residence	4	4
Relationship status	In partnership	In partnership

Group 19 Parents attending 'baby café' (pre-existing group)

Participant's pseudonym	Leigh	Nicole	Colette	Paula	Lorna	Suzanne	Vanessa
Age	29	30	38	33	33	30	34
Status as parent/carer of pre-school children	Parent	Parent	Parent	Parent	Parent	Parent	Parent
Employment status	Incomplete	Full-time	Part-time	SAHP	Full-time	Full-time	Full-time
Level of education	Incomplete	University or college degree	Higher degree	University or college degree	University or college degree	HNC	University or college degree
SIMD category of residence	4	4	5	unavailable	4	1	4
Relationship status	Incomplete	In partnership	In partnership	In partnership	In partnership	In partnership	In partnership
Ages of children in household	Incomplete	2 months	5, 2 months	3, 3 months	2, 6 months	7 months	7 months

Group 20 Parents attending 'baby café' (pre-existing group)

Participant's pseudonym	Caitlin	Mandy	Morag	Rosie	Susie	Audrey
Age	32	37	30	30	33	38
Status as parent/carer of pre-school children	Parent	Parent	Parent	Parent	Parent	Parent
Employment status	Full-time	Full-time	Full-time	Full-time	Part-time	Full-time
Level of education	University or college degree	University or college degree	University or college degree	University or college degree	Higher degree	University or college degree
SIMD category of residence	unavailable	4	2	4	2	5

Relationship status	In partnership	In partnership	In partnership	In partnership	In partnership	In partnership
Ages of children in household	5 months	2, 4 months	2, 7 months	5 months	4 years, 4 months	4 years, 8 months

Appendix 20 Twenty most frequently occurring codes at indexing of focus group data

1. Signs or symptoms that require action
2. 'It's just viral'
3. Time pressures in primary care
4. How other parents manage illness
5. Specialist knowledge based on occupation
6. Access to appointments in primary care
7. Understandings of resistance
8. Knowing your own child
9. Family members as source of information and support
10. Expectations of others in managing child's illness
11. Social media as news source
12. Blame
13. Duration of illness
14. Impact of employment on response to childhood illness
15. Body's capacity to self-heal
16. How other people respond to illness
17. Non-specific signs of sepsis
18. Awareness of sepsis in media
19. Challenging doctors
20. Pharmacy as source of information

Appendix 21 Coding frame for focus group transcripts

Main heading	Subheading	Description	Example
Managing childhood illness	1a Beliefs about the body and infection	Views about how the body responds to infection	"See if you have maybe a good, active healthy lifestyle, nine times out of ten you'll be generally well and you'll no' need to go to the doctors, or if you dae go to the doctors, you dae become unwell, you take a wee simple antibiotic and you'll be better again." "'Cause their body ain't… like if you think back, your body maistly fixes itself, do you know what I mean?"
	1b Sources of information and support	Where parents/carers go to access advice about childhood illness including online sources, peer and family networks and NHS resources	"No, I don't look online because then you just see hunners of, "It could be…" "See, my mum's a nurse, so I would usually go to her first."
	1c Managing risk	Views about how parents/carers respond to potential health threats. This is a wide category and contains further subheadings as follows:	
		Changing trends in attitudes to risk: how responses to risk has altered over time, including generational differences	"And some of the things that she comes away with, you're 'I'm not doing that to my child.' But they didn't… I suppose they didn't have… they just kinda got on, had to get on with it…"
		Role of instinct: the importance of parental instinct in assessing whether a child is at risk	"Oh, well, I know my kids, so if I feel I need to phone the doctor's, I will. I know if my kids are no' well, I know they're no' well." "It's a mum thing, innit."
		Being more risk averse: expressions of preferring to take a cautious approach when child is unwell	"But, like that, if it's your kid, it's totally different." "Even if they get a rash, I still get the glass out. I know it's

			just… I do it every time. But, and I know nine times out of ten, it's not gonnae be that, but you just, you're—it's always in the back of your mind, 'Think the worst before…' "
		Being less risk averse: expressions of taking a more relaxed approach when child is unwell	"Because some days I think I'm too blasé and then like I think it's not 'til you speak to other people and you go, "Is this normal? Is this… is this…?" "Yeah, I might have put it off a bit longer. You know, just to go like, "Wait and see if it clears up," type thing."
	1d Influence of others in managing childhood illness	Views about how perceptions of others (including partner, family members, peers, childcare staff and health professionals) influence management of childhood illness	"So, you always go with what the doctor says but I think maybe I could've, I could've questioned it. But you don't want to be like, "Oh I don't…" you don't want it to look like you're not caring or like giving them…" "I was gonna say, I'm the actual opposite. I don't really think about what anybody else thinks or says."
	1e Attitudes towards seeing doctor	Views about appropriateness of seeking medical review for childhood illness	"I don't, again, I'm saying this sounds bad, but I like to say that, I like to say that, "Oh, my wee guys havenae been to the hospital, they're… I look after them, they're… they're healthy, they're this and that…" And so, I feel bad if something really bad happened that I never went because I don't want to take them to the hospital, because I don't want to lose that…" "See I've got like a sister-in-law…who's a panicker and straight up to the doctors whereas I like to think I've got, I'm a bit stronger, and I can make decisions for myself as well."
	1f Wider impacts of childhood illness	Views about external factors that influence response to illness,	"I think it's just, you're just paranoid as well and you're just, you just want somebody

| | | including employment, childcare, family structure and support networks | like just a professional to give you advice right away. And then, I know this sounds bad as well, but maybe if I've got like work the next day or I've got work, I'm thinking, 'I need to get medicine into him right away, so he's better right away.'"

"I think as well, you come in fae work, you're tired, you're hungry, you look at the child and they look unwell, but, actually, I'm tired and I really don't want to go to the hospital with them. That sounds terrible but you have got that, you're thinking 'I've had a really rubbish day at work, I'm going to have to take tomorrow off 'cause they're not well, my boss is gonnae give me a hard time for it and make me know that I'm taking the day off, and you think, 'I really don't want to go to hospital tonight. I'll just leave it for the morning.' When, actually, if you'd been there all day, you'd think, 'Actually, they're really, really unwell. I'm just going to take them." |
|---|---|---|---|
| The Healthcare Encounter | 2a Gaining access to healthcare | Views about ease or otherwise of accessing primary care appointments | "Aye, getting an appointment at the doctors is a nightmare."

"…sometimes I just think, 'Well if I don't get an appointment, if I phone up and they won't give me one for my daughter, then I'll just phone NHS 24." I just wait 'til after six and you phone, and I know fine well that if there's, like if I tell them what's wrong then I will get an appointment. but it's just sometimes it's annoying 'cause you have to wait 'til like six o'clock." |
| | 2b Diagnosing the problem | View about how doctors assess children and arrive at a working diagnosis | "…every time I go along it's always like, "Oh it's viral," or "just give them Calpol," or "see how they are," like or, you know, "watch out for |

			this, but it's okay." I don't feel like I've ever went to all that effort o' going and then had anything particularly that I didn't know myself."
	2c Decisions about prescribing antibiotic	Views about how doctors arrive at decisions about whether an antibiotic prescription is required	"Aye, but see the thing is, it's no' that—they're probably looking at it, "I've got three minutes to get them. I'm ten minutes behind wi' all these people. In antibiotics, get them happy, get them oot." Do you get what I mean?" "I think wi' certain surgeries, the doctors are too quick to just haun them oot to get rid o' you. That's my personal opinion, especially that wan doon there, isn't it?"
	2d How encounter makes you feel	Views and experiences about level of satisfaction/reassurance after appointment has ended	"And she's like, "I wouldn't have said that you were being melodramatic but at the same time, like you, there's no (overtalk) need for you to be here." And I'm like, "Well that made me feel great, thanks for that." "And at the start I used to go, and I'd say… and he'd come back, and he'd say, "oh it's just a virus." And you'd go 'oh here we go again.' But now, you know, in all fairness, you know, he's never had antibiotics and he does get over things. So, I do… I do have that trust."
	2e System factors	Views about how external factors (i.e., not specific to individual health professional) influence consultation	"I think if you asked most GPs to sit down and say, "There's last month's cases, you've got all day to go through them", they might look at some and go, "Actually, maybe I would have done this instead of that", you know? But they're under pressure themselves. It's a long day, I can imagine. I mean, whatever their appointment times are – bang, bang, bang, bang all day – emergency appointments coming in, you know, sometimes it's babies that are ill and screaming and can't tell them any more information and just kinda

			guesswork. I would hate to be in that position."
	2f When things go wrong	Experiences of healthcare gone wrong e.g., illness misdiagnosed	I think they're afraid of litigation. Like, and that's a shame that it's got to that point that…they almost probably can't do their job properly You don't want to get the blame, and then I suppose it's quite easy to pass the blame off to Doctor Whoever or Nurse Whoever.
	2g Beyond primary care	Special category containing insights from one participant who worked for NHS 24	"…it's taking yourself into the room and trying to get a feel of what's going on. I've got a mum – this is her eighth phone call now to the service, within the evening – who, you're either, usually get a doctor to phone them back if you know that their kid's okay. Or saying, "Why are you phoning eight times? What is going on with this mum that's phoning eight times?" Just get them saying, what is going on, what am I missing?"" "But it's… the literature available for parents isn't good enough, and it's making us get phone calls from kids that are very well, that the kids are—that the parents are very unsure. And, so, I think the… there needs to be more, sort of, like, what would your child look like – rather than, like, words, I think a lot of people learn from, like, videos."
AMR	3a Attitudes to AMR	Views about relevance of AMR to participant's own lives and extent of risk posed.	"…there's so much in the press over the last few years, about we shouldn't be prescribing antibiotics that I don't really read any of the articles anymore. It's just all the same as far as I'm concerned." "Do you know like if I had an infection that they reckoned wouldn't get better without antibiotics, you know, I would take it and, you know, hope that, the research

			continues and gets better for future generations."
	3b Understanding drivers of resistance	Views about mechanisms of drug resistance and its causes.	"Every time that you have a drug, the body remembers it so it knows what to do with it the next time you have it, how to combat sort of this infection, so it becomes used to it so much that the body sort of gets… not lackadaisical but it knows what to do and then the virus is going, 'Well, actually, I can beat that', and there's like this big fight going on."
	3c Understanding solutions to AMR	Views about strategies to limit development of drug resistance.	"I don't think there's enough health awareness for kids at school at sort of teenager level, just before they become, well, whatever the definition for adult is these days, but I think it would probably help more in the nursery side, you know, the induction day, you get a wee packet of the classes and all the rest of it – I don't understand why there's maybe not something in there about health and infections. Maybe they don't want people thinking about it when you're enrolling in nursery, but it would actually probably be useful." "They just said because they were chopping and changing the antibiotics, they weren't leaving her on one like penicillin, amoxicillin, whatever it is. She got another one, I can't remember, it started wi' an M, it had a very big, long name. They said because they were changing it, she wasn't getting too used to one…"
	3d Perceptions of who's at risk	Views about which individuals and groups are impacted by drug resistance.	"Aye, young ones, but also like… I'm a bit worried about the older generation as well. In the middle totally not…"

Antibiotics and immunity	4a Understandings and beliefs about antibiotics	Expressions of knowledge and understanding about mode of action of antibiotics	"..it depends on that person as well, doesn't it? If they— they might think, 'Well, I need them, I need to keep taking them…'" "…the other thing that pissed me off is my dad's older and he takes like chest infections every year and every time he goes to the doctor they give him an antibiotic that doesn't work. And he has to take that for a week before he'll go back and get a stronger one that actually works."
	4b Making decisions as a parent about antibiotics	Expressions of feelings and concerns about antibiotic use in children	"She just wouldnae take it, she spat it out and wasnae taking it, and I phoned – she had a bad ear infection – and I phoned, and I was going away on holiday for a few days, and he was like that, "Oh, it should be fine whether she takes it or not.""
	4c Positive aspects of antibiotic use	Expressions of positive attitudes to antibiotic use (perceived or experienced)	"Oh, yeah, yeah, he was—he stopped complaining of pain within about two days of having it, do you know, and it was, it was the nursery as well, you know, were saying that he'd been complaining of earache at nursery and things like that."
	4d Negative aspects of antibiotic use	Expressions of negative attitudes to antibiotic use (perceived or experienced)	"Well, I'm allergic to penicillin, so my basis for no' really using antibiotics espec—like, for myself, is that I have to get erythromycin anyway and I feel that it doesnae work like if, when I get erythromycin, or any—I think I've had a couple, but that's the usual one that they gi' me, the wee red tablets, and I feel that when I start taking them, it's—I'm like that, I need a week, two weeks before it's away, and I'm thinking, 'My tonsillitis or whatever would've been away by then,' do you get what I mean? If I never took anything. I don't feel that it works that good for me. So,

			that was how I kinda got into no' really using them."
	4e Children and infection	Views and perceptions about why children become ill	"…there's a point where when the child is actually sick and there's a consequence when they're not giving you antibiotics because they're then left with, I feel like my wee boy is left wi… a weak chest."
	4f Positive influences on developing immunity	Perceptions of how children develop effective immunity	"I'm no' saying you want them to get unwell, but we (stutter) when we were kids, we were unwell, and then it built immunity, and then we got a wee bit older, we went longer spells without being unwell…"
	4g Negative influences on developing immunity	Perceptions about factors that can affect developing immunity adversely	"There's always that sort of that battle of risk aware, risk averse, and trying to get that balance right, I think… I think there's a danger now that you look after, everything has to be sprayed with antibacterial, everything, you know, and you think, 'Well, when I was growing up, you know, just washed your hands, made sure they were clean', but you still went out and sort of made mud pies and, you know…?"
Sepsis	5a Understandings of sepsis	Expressions of knowledge and understandings about what sepsis is, how it develops and who's at risk	"…my understanding of it is it's an infection in the blood and it can come from an infection anywhere, that's usually secondary to somewhere else in your body. It's life-threatening. It can only really be managed in hospital. And children are incredibly ill with it. It can present in all different ways." "I don't know really too much about children, but I've heard quite a lot about people that after they've given birth and there's a few people that have been in groups that we go to that have had that as well."

	5b Experiences of sepsis	Insights into sepsis via personal experiences or those of friends/family	"…my friend's dad was in a car crash, and he went to A&E. And he had a sore back, and they just sent him home thinking nothing was wrong. But it turned out he'd actually broken a bone in his back, and that led to sepsis, and he died from it." "Well one of the girls that comes here usually, she's actually, her wee boy's in hospital right now and it's suspected septicaemia so… but he hasn't had a cut or anything so they're obviously trying to figure out..."
	5c Awareness campaigns	Attitudes towards current campaigns designed to increase awareness and recognition of sepsis	"It's not so much it's new, it's just killing everybody so easily and kids are just going down so quickly with it, and so that's the new way. I think it's just, like, the next thing that we've kinda moved onto." "It's addressing people's different learning requirements, so, some people are happy to sit and read a document on how to identify sepsis, but then other people are like, "I don't really read documents. I like to watch it on TV." So, a wee advert in between that, "This is what a baby would look like if they were getting really unwell." "This is what your three-year-old will look like if they're getting really unwell," stuff like that. 'Cause they're different, they're totally different. "
Media	6a Attitudes to news media	Expressions of general views about the news media	"I'd rather no' know about them if I… if I'm gonnae get it, I'm gonnae get it, but I'd rather no' know two, three months in advance." "I'm always very sceptical when any news story comes up. I don't know whether it's because like research background and stuff that I just question—unless it's somebody, an expert in the field that comes on to talk on the television, then I'll be

			like, 'Right, I'll…' I would rather make my own judgement there sort of thing."
	6b News sources accessed	How participants access news, including print media, TV and radio, online sources, smartphone apps and social media	"It's really bad, but I just like to just not know kinda thing (laugh). So, but as I have been up in the morning and stuff like, whatever's getting showed on morning TV, I kinda pay attention to now, but, I wouldn't sit and watch the news, do you know what I mean?" "I do like to read the Guardian but again it's online so I'm probably picking and choosing what I'm clicking into. And then just any other kinda, it will be through social media but it tends to be like articles people have shared or that kinda thing."
	6c Awareness of sepsis/AMR messages in media	Expressions of knowledge of issues related to sepsis/AMR based on presence in media	"I'm only more aware of it 'cause an episode of Call the Midwife, I don't know if you know it, that really, that got me checking everything else then…. that really gave me big awareness of sepsis and I must say that made me very paranoid for quite a while and I made sure I researched all the symptoms." "There seems to be loads and loads on Facebook like these past months about it. Like, I don't know where it's obviously came fae, but I just, I just remember like the past few months it's just, it was every other kinda share was getting done and it was about sepsis and I thought, 'I don't know…' Like, it makes you aware, obviously, but I was like, "Where is this all coming fae? Why is it happening now?""
	6d Framing of health risks	Attitudes to how stories about to potential health risks are presented in the media	"…it's more a kind of… you know, like the kinda… I don't want to say scaremongering 'cause obviously sepsis is a serious condition, but they don't really lead with 'This is what

| | | | happens when it goes wrong', they just kinda say, "Oh, look, another child has died because of… viruses becoming resistant to antibiotics", but, you know, that's kind of what they lead with. I think the important bit of the message is kinda missed out."

"I think it's just 'cause you—when—'cause you hear… about baby, like babies getting unwell and it does put it in your mind thinking about it like, 'Well, I hope that never happens to me.' But it still sticks in your mind sometimes." |
| --- | --- | --- | --- |
| 7. Outlying views | Miscellaneous category containing themes that don't fit within main framework that are of interest in analysis by virtue of their nature as peripheral viewpoints | Themes include conspiracies involving governments and pharmaceutical companies, impact of immigration and relating media stories about responsibilities of doctors to Madeleine McCann narrative | "The pharmaceuticals don't want anything to cure you, because if they cure you, then they're no' gonnae make any money…. they say there's meant to be a cure for cancer, years ago, didn't they? You know what I mean? It's pharmaceuticals will never bring it out, because it's so much money."

"I'm no' being cheeky or nothing but it's like that Madeleine McCann story. There's hunners of weans went missing…see if they were fae ma street they'd have been lifted…" |

Appendix 22 Chapter 6 Additional quotes from focus groups

Tara: I think you know… when your kid's definitely no' right.

Carly: If it was dead serious, I think I would.

Jill, I mean obviously you're admitting that you kinda panic, but… still. I think you know. If they said to you, like, "just give him Calpol", you would know if it was different, from how they usually are.

Carly: And I think if it was something different fae normally, then I'd be like "naw, there's something different like this time".

Jill: You know their behaviour better than anybody, you know.

Tara, 37 Carly, 23 and Jill, 27 FG11 Group of pre-school parents

I think that is it, it's kinda when you just can tell that wi' their character, they're either a wee bit just clingier than they normally are or just not responding the same. But yeah, there's not kind of one exact thing you can kinda say, "Oh this is what is wrong." It's just, feels like there's lotsa things that are just not, yeah, not right.

Catherine, 38 FG10 Mother and child exercise group

I think a lot of it is you know your own baby better, so something that might not be normal in someone else's kid's normal in your kids… cause you know yourself if they've got a big change in energy levels and whatever.

Beth, 34, FG8 Baby cafe

You're with your child 24/7, and a doctor knows them for seeing them 10 minutes every, whatever, couple of months post-COVID majority of children likely to have no ongoing contact with HP

Debbie, 31 FG6 Group of pre-school parents

I think it depends, as well. I think when we're on maternity leave, we're with the babies 24/7, so it's easy for us to pick up on… like, you know, when things… I think if we were both working full-time, it might be bit more equal.

Suzanne, 30 FG19 Baby cafe

Oh children? I never take them to the doctor. (Laughs)… one of the times my son had a really bad cough, and I kinda should've taken him to the doctor, but I didn't really know to take him tae a doctor. Turned out he had tonsillitis, a chest infection, and an ear infection. He was only eighteen months… I couldnae tell, I couldn't have said he, I knew was a bit unwell, but I wouldn't have said he had all of that. So he did need antibiotics… I think if it was anything serious I think you would know but you're maybe a little bit more like, 'It'll be fine, you're not that bad.'"

Helen, 37 FG15 Group of individuals with lived experience of sepsis

The mum had sent him (the child's father) a video the night before 'cause they don't stay with each other, like 'cause it was the dad wanted her to take her to out of hours whereas the mum was like, "Well the doctor said it's gonna be okay," whereas he was like, "No, I think you should take her down." And… the video was… her, like waving, "Hi, Daddy, I'm fine." Like she, there was the mum saying it when you could see that she wasn't really that fine. And I was like… if she had showed it to somebody else then maybe somebody else would've known to… take her down. But, and it turned out that when she was sleeping the mum had woke up and she had already died, like at some point during the night.

Sarah, 27 FG10 Mother and child exercise class

I wouldn't leave the hospital… and do you know what, this is not joking – I've never been wrong. apart from myself who I had viral meningitis and swine flu at the same time last year and I literally during the day felt cold and I'm always roasting and sweating and I felt cold and funny and I went to my bed and John came up a few hours later and knew right away that I was ill. Phoned an ambulance and I was in for 12 days.

Irene, 56, FG10 Library story and music group

Claire: And maybe all parents… think that, and maybe this woman said that about wee William. That she thought that she knew her wee guy…"

Angela: "That's it, you don't know until it happens to you.

Claire, 38 and Angela, 31 FG4 Group of pre-school parents

Claire: I like to say…. "Oh, my wee guys havenae been to the hospital… I look after them, they're healthy …" And so I feel bad if something bad happened that I never went because I don't want to take them to the hospital, because I don't want to lose that… it sounds bad as if I've got, like, one up on parents."

Andrea: I was never at the doctors wi' Dylan… it's inside you, so it's in your mind… you just don't want to be the person that somebody always goes, "Oh, she's always at the doctors. She's (a) hypochondriac"

Claire: You get other mums that are the opposite, that love to be at the doctors all the time and love to say it.

Claire, 38 and Angela, 31 FG4 Group of pre-school parents

… a bit like Aileen, I would say I'm a wee bit more blasé and be like, 'Right, well I'll leave you a coupla days then we'll go tae the pharmacist. And then if we have to we'll go to the GP'…. Whereas my sister-in-law's like "Oh there's a red dot. Doctor's appointment," and I'm like, 'Calm down, it could be absolutely anything.'

Her kids are always at the doctors, they're always sick and I'm like, are you kinda making them overly sick 'cause they think, 'Oh we have to go and get something the minute you see a mark.'...She's constantly on the phone tae NHS 24. I think she's got them on speed dial."

Joanne, 32 FG8 Baby Café

"Alfie had a cold that sounded like it went intae his chest last week and I'm like, 'Crap, he's got a chest infection, now he needs antibiotics.' Went to the doctor and she's like, "It's viral." And I'm like, "Well at what point did I need to be here then?" And she's like that, "It is so hard to tell…"

I like to think that I'm no' a panicker… I've got like a sister-in-law—who's a panicker and straight up to the doctors whereas I like to think… I'm a bit stronger, and I can make decisions for myself as well.

Claire, 38 FG5 Group of pre-school parents

My sister-in-law was on holiday and her wee boy got diarrhoea and she flew home from the holiday… I think she just panicked 'cause she was maybe in a foreign country, but, I thought, like, taking a child that's got sickness and diarrhoea, on a plane, and infecting everybody else on the plane...

Andrea, 39 FG14 Library story and music group

I think sometimes it depends on what kind of patient you are. I mean, I never take antibiotics for anything, like I rarely go to the doctor, so I've got that mentality in my head, whereas my sister-in-law, like, I feel like her children are always on antibiotics. Like, always. Like they've got croup every single… like every six months, and I thought, 'Well, it's quite rare for you to keep getting it'… but then it might just be that they're susceptible to things.

Marie, 43 FG14 Library story and music group

I don't know if it's… the way you're brought up… 'cause my mother was a nurse and… I didn't get much sympathy so I think… that's why… I don't take him a lot 'cause I think, 'Oh, they're okay.'

Rachel, 31 FG10 Mother and child exercise group

I think what you're saying about being brought up as well, like my mum… wasn't medically trained or anything like that which I don't think we ever went to the doctor…. I was

constantly in battles and bruises when I was younger. And never visited the doctor and like I don't actually remember too much when I was little ever visiting a doctor. So I think, yeah, if that's kinda been the way they've been brought up and I think you're probably quite similar to doing yourself.

Catherine, 38 FG10 Mother and child exercise group

I think my mum gets much more wound up about it than I do. Like she's… she's like always like "Oh, Paula, you know, something could happen at the drop of a hat, and get on the phone to the doctor." Where I'm, I'm a bit more like, "Oh, we'll just a wait a couple o' hours, and see what happens." I don't… I don't know why mum's like that. I don't think she was like that when I was young.

But she seems to be now she's got grandchildren, it's like the least little thing. Cause she's… she's watched my son in the past, and it's the smallest, smallest thing. And she'll, "Oh, get onto the NHS twenty-four. Get on Google, get on this." I was like, "I… I think he'll be fine." And she went "Oh, you need to be so, so careful."

And she makes me feel quite guilty sometimes, 'cause I am quite laidback.

Paula, 33 FG19 Baby Café

My mum was badgering me and badgering me, "Phone the doctors, phone the doctors," and it… I phoned thirty-eight times before I got through. And you, my mum's in the back room going "keep phoning, keep phoning, keep phoning," and I was like, "Mum, I'm doing my best."

In the end… I got through, and I was talking to the receptionist, and my mum's going "Make sure they give you an appointment, don't… don't let them fob you off." (Laughs) And I was like, "Mum, they're just doing their job." 'Cause I know… services are really stretched sometimes, and it's difficult. And… I was having to get an appointment for the next day and go after work. So I eventually got it, which my mum was saying, "That's ridiculous, you shouldn't have to phone that much to get through." And I said, "Well what can you do, that's the system."

I just constantly go to the doctors. I freak oot when they're no' well… if they cough I'm like, phone the doctor. Rather than waiting. Or I'd phone my mum.

Carly, 23 FG11 Group of pre-school parents

Aye, I think maist people would just go… just so they know, get an actual opinion fae somebody that knows mair than you.

Carly, 23 FG11 Group of pre-school parents

See, I think I'm quite bad for no' going… and then usually when I do it's something like, "your child's got major tonsillitis". And I'm like "sorry". And you'd think I would be worse 'cause my daughter was really ill as a baby, she had streptococcus at sixteen weeks, so… but I don't know… I always think 'och they'll be a' right'.

Jill, 27 FG11 Group of pre-school parents
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If you be at Mother and Toddlers and, you know… my boy's had croup the last year, that winter there, and… I didn't take… them to the doctor until, like, the second night. But if I sat here and told you the symptoms of the first night, you'd be like, "You never took him to the doctor with that?" and you can be judged then… but then, you'd be like, "Oh, so then… I phoned up NHS 24 and took him to the doc…" "You're a good mum. You managed that situation really, really well."

Whereas I don't really care. Like, I knew that he was, like, oh, he's alright, we'll see how it goes, and we'll just maybe… But on the second night we went and seen a doctor. But there's a… how are you judged, how's your parenting style judged, especially when you go to all these groups like toddlers and whatever… There is a pressure – I think there is a pressure to act… to demonstrate that you're capable of being a parent to that child…

Erica, 31, FG14 Library story and music group

I would just hate to think that people thought… that I wasn't doing what I should do for her, like if somebody's like 'oh why haven't you dealt with that?'… I think you just always want tae hope that you're doing the best that you can… for their health. So if something's wrong and I don't feel it's improving, I want tae know that I've done everything I can to make sure that it gets better. And if it takes somebody to go 'she's had that cough for ages, and she's not done anything about it'…

Leigh, 29 FG19 Baby Cafe

Cause I know that… pre-kid, or pre-thinking, pre-mum… I worked in ITU before so… most of the patients were septic…but it is funny how as soon as you become a parent, you're like, "What is this? I need to know everything about it 'cause what if my kid gets it…?" And even though I know how to identify an adult with it, if my kid got it, I'd be like, "Do you have this? Or do you just have a really bad cold? Or…? No, I'm going to get someone else's opinion." 'Cause then you're sleep deprived 'cause you've got all these kids and you're maybe not thinking straight and so you do go from, 'I'm totally knowledgeable,' to 'I actually don't have a clue and I'm going to go and seek… another opinion.'

Erica, 31 FG14 Library story and music group

When you're at school… there's no preparation for you to become a parent, right? And I think even when you're pregnant, there isn't much preparation for you becoming a parent. You're offered classes but they're sporadic, most people are still working and they can't… fit it in. You know, even like people going tae the classes preparing for birth, loads o' people don't go to them 'cause they just don't get the time off. And I think as a parent you're unprepared for the medical things unless you've done a first-aid course, and even that is very basic and it's usually about somebody's heart stopping, and it doesn't really prepare you for becoming a parent. I think… if they invested a wee bit intae how tae recognise your child being sick… it would probably save the NHS a lot o' money, and say, "Well, actually, your child's sick, but… if they're going to get better you're just going to have to ride it for a couple of days."

Marie, 43 FG14 Library story and music group

I know… my little girl goes to nursery one day a week… and somebody helpfully said to me, "For six months, she's going to be ill." And she… was, you know? She caught everything that was going.

Andrea, 39 FG14 Library story and music group

Marie: See once they're a year old? You're lucky if you see anybody ever again until you go and get their jags or they are ill…I can count on one hand how many times Isaac's seen the health visitor since he's been a year old… most people take time off… once they've had their baby, and I think that probably is a good time to say, "Well, as part of you preparing as a mum, we're going to give you this course just to help you to, you know, if your child becomes ill, what the best thing to do is," you know, for you, 'cause… you get all different types of people.

Andrea: As soon as you're a parent you have to make hundreds of decisions every day.

Marie: Yeah. And I think you're not prepared for it. It's quite an enormity, 'cause do they not say that… I don't mean this bad, they say that women who are educated are continuously at the health visitor, seeking reassurance and support – where the mums who are not well educated, and I don't mean this unkindly, just get on with it. They just get on with it. And I think it's to do wi', I think educated people are continually looking for support, "How do you do it? Why do you…?" You know, they're wanting led.

Andrea: I think I was like that. I had my wee girl through IVF and I just was paranoid about anything happening and I read every book under the sun, and, you know, if I was going to buy a… baby sling, I would research it to a hundred… and then I went and I worked at a young… but, honestly, I would be there, like, for days, researching things and then I went to a young mums group that I was helping, I was doing Bookbug and helping support these mums who were like 15, 16, 17, and they were so relaxed… they were just doing, you know, 'I'm going out with the baby swimming', I'm like (stutter). And I'd, like, thinking about taking my baby swimming, I had talked myself out of it three or four times, and I thought, 'Oh, you know, what if she gets this or what if I've not got the right swim nappy on?… they're so relaxed about anything.

The perception here then seemed to be that the pursuit of knowledge that perhaps became habitual.

Cause we would just ask my granny, you know? See what your granny tell't you?

Irene: That's what NHS 24 would love for people to do. "What does your mum do? What does your gran do?"

Erica: I know, and I think that is the problem wi' society now is that people don't live next to their parents. And then, sometimes in your street, you can be the only mum in that street, right? And you go to (name of baby group) to find other mums… cause I think… people used to get married at a certain age, people would have kids at a certain age, but nowadays you've got people from 16 right through to their mid-40s and 50s, and… that covers a vast range o' people.

Marie, 43; Andrea, 39; and Irene, 57 FG14 Library story and music group

I've got a Facebook group, a lot of us have… (indicates to babies) around the same time. And… sometimes… people message and say…"How serious is this?" And people who have been through it before are like that, "Oh, you know, it's probably nothing, or you know, maybe you should get that checked out."… I guess it's kind of like the new version of like, the kind of village, that they talk about… but obviously it's kind of an online village.

Jenny, 32 FG3 Group of pre-school parents

LR: And, do you feel as though people tend to err on the side of saying, "Get it checked out"?

Jenny: Yeah, I mean some people will always say, "Get it checked out," regardless. But, you know, there are a few sensible voices in the group as well who, you know, maybe are a bit more relaxed…and you've got the ones who have got older kids as well who… kind of hopefully reassure the ones who are doing it for the first time. Because it is a minefield when you don't…

Alan: The guy cannae speak or anything like that, so he cannae tell you… I ended up phoning my team leader and saying, "Look, there's something no' right here… we'll need to get this looked at." He says to me, "Just go straight to the doctor and see if we can get him seen now." When I took him in, they're like, "Naw, just go tae the pharmacist and they'll help you wi' whatever he needs." And I thought, again, wi' additional needs you don't know how bad it is or whatever, you know? And, I thought, 'Naw… that really shouldnae be happening. They should be looking, at least if they've got maybe five minutes.' Alright, they might be running behind, but they can still make time…

Jospeh: See inside to the bigger picture, the NHS is just stressed oot, it's stretched oot… there's nae funding for this, there's nae funding for that… and it's just passing it down the line.

Patrick: Your slots get smaller, it's harder tae get an appointment, like you need to get mair stuff you have tae dae to get an appointment…. you cannae walk into the doctors and get an appointment. You need to phone them up if you're wanting an appointment that day…You're like that, "But, I've nae credit, can I no' just come in at the same time as I would've phoned you." "Naw."

Alan, 38; Joseph, 27; and Patrick 27 FG1 Support group for lone fathers

"When we were wee, if you were sick, a doctor came to the house."

Irene, 57 FG14 Library story and music group

I think they probably… do it more than they want to. I think if you asked most GPs to sit down and say, "There's last month's cases, you've got all day to go through them", they might look at some and go, "Actually, maybe I would have done this instead of that", you know? But they're under pressure themselves. It's a long day, I can imagine. I mean, whatever their appointment times are – bang, bang, bang, bang all day – emergency appointments coming in, you know, sometimes it's babies that are ill and screaming and can't tell them any more information and just kinda guesswork. I would hate to be in that position.

Scott, 36 FG12 Group of pre-school parents

You feel more and more the health service is getting chipped away and chipped away and chipped away that it can only fail, you know? There's no way it can succeed the way it is. And I think some of these cases, unfortunately, are gonnae get worse. My personal feeling is you're gonnae get more cases of that and it's getting missed and people dying because they are under so much pressure.

Scott, 36 FG12 Group of pre-school parents

My sister's an A&E nurse, and I think I hear her go on quite a lot about how busy it is, like ridiculously busy, I mean she'll come home in tears sometimes because it's been so overwhelming.

Aileen, 34 FG8 Baby Café

I think the whole funding stuff annoys me as well because like my cousin's a doctor and he's like doing his GP training, he's in a hospital right now and he is so stressed out where like he was considering packing it in a coupla months ago. He's now put in an application for part-time working 'cause he's just like, "I've been asked to do things that I shouldn't be doing," like, you know, things that are above like where he is, like and he's just so concerned and worried about the stress and depression.

Aileen, 34 FG8 Baby Cafe

It was a female doctor who'd been made a bit of a scapegoat… she'd been on for hours and hours and hours and, you know, I can't remember if someone had died, then the patient had obviously died which is horrendous but to then use this poor woman as, as being the scapegoat for it when actually they're so stretched, the NHS, it's ridiculous.

Aileen, 34 FG8 Baby Cafe

And I was there at like half seven really arguing back and forward wi' myself, around 'does she need this appointment?' And even when I went in, I said to the doc, I was like "I hope I'm not wasting your time here" … and the doctor was like "No, no, you're fine tae bring her, you like, you know, we'll check it out." An' everything checked out to be fine and stuff like that, but she, like wasn't annoyed at it, 'cause I think that… I just, I'd hate tae think I was wasting somebody's time or taking up a space that somebody else needed."

Vanessa, 34 FG19 Baby Cafe

Aye, you hear o' people calling ambulances when they've got a cold, see.   And then it just makes my blood boil, it just makes me really, really angry, and I would hate to ever be seen as somebody that was wasting, like NHS resources.

Vanessa, 34 FG19 Baby Cafe

I fully expect them to say, "No, you're," you know, "you're just a worried mum… on the way over, I was driving and I was thinking… 'I'm gonnae look like a neurotic mother.

Susie, 33 FG20 Baby Cafe

I'm just always overridden by if it is something I'll kick myself. So even if I go and I look stupid then it might look stupid for ten minutes but at least I'll be reassured. And then if it is something then I'll know that I've done the right thing in that case it was.

Susie, 33 FG20 Baby Csfe

It's probably not the right thing to say because I know that, like, our NHS is, I work for the NHS so I know it's like, you know, we haven't got lots of resources and we're overspent and blah-de-blah. But I don't really think of those things when it comes to my child.

Audrey, 38 FG20 Baby Cafe

I just find that for me, like I know how like underfunded everything else and how stretched the NHS is and I think, 'Oh God, am I wasting this, this doctor's time,' it's ten minutes of his time and somebody else could've had that (yeah) appointment. but I find that that was more about me and when it comes to her, I'm like an anxious mother…

Rosie, 30 FG20 Baby Cafe

Kerry: I do know that if I hadn't had sepsis before, I would never have, I would've been embarrassed to…

Linda: —waste their time.

Kerry: Exactly. I wouldn't have been, no way I would've been phoning an ambulance, or even probably phoning the GP. I would've just taken paracetamol and tried to… And, part of that would be because I don't want to waste GPs time and I don't want to be on medication.

Kerry, 45 and Linda, 52FG18 Individuals with lived experience of sepsis

Could it be that there's a lot of people like that, that don't go to their GPs and that's… partly why the sepsis rate has gone up… because there are a lot of people that are really aware of, of not wanting to take antibiotics and not wanting to waste GPs time and knowing how stretched the whole thing is…

Kerry, 45 FG18 Individuals with lived experience of sepsis

I do think that, I mean, most of the parents, and most of the people that I speak to now, are not looking for antibiotics. I think there is quite a big awareness amongst most people that, you know, you don't go to the doctor and, you know, and I think there's almost a bit of… societal shame in being seen as somebody that goes to the doctor at the drop of a hat now… and if it does carry on the way it's going, like I say, if there's already a sort of groundswell of people beginning to feel slightly shameful about going to the doctor at the drop of a hat and other avenues of saying, "We'll go to the pharmacy first…"

Kerry, 45 FG18 Individuals with lived experience of sepsis

I don't go to the GP very often… you always think, 'Well, you're a fraud. You don't need to do that…' Most times, small things go away. It's only… things that you can't fix. That you go there. Because there always seem to be a lot more folk in the waiting room who are worse off than you. Look around you, they're all kind of limping, and crawling in, in wheelchairs and things like that.

Bill, 53 FG17 Individuals with lived experience of sepsis

As soon as you go in you think like, you think that you're taking up their time, wi' maybe somebody that's really… sick, even although you look out and it's like the older generation all sitting waiting, which is fair enough, I understand that, that's because they're older and they need more doctors attention and stuff like that. But, every time I go in, I sit down, and I go through everything like at a million mile an hour, 'cause I feel like I'm taking up their time.

Claire, 38, FG5 Group of pre-school parents

…you're just paranoid… you just want somebody like just a professional to give you advice right away. And then, I know this sounds bad as well, but maybe if I've got like work the next day or I've got work, I'm thinking, 'I need to get medicine into him right away, so he's better right away.' I know that sounds selfish for you because you've got work, but that's just life. That's me being honest, like.

Claire, 38 FG5 Group of pre-school parents

Really the whole time I was at the doctors I was looking, thinking 'I need to get back'. And then I'm running up tae his gran's house, trying to relay the information to gran before I had to get back to work. And I'm thinking that's ridiculous, like I should be, I should be home with him, not his gran looking after him but I had to go to my work. Fortunately I'm a, like I said earlier, I'm a teacher so I could leave at three but I know there's people that, some

people that don't get in their house 'til six, seven at night. It's, it is, it's rubbish sometimes, work.

Morag, 30 FG20 Baby Cafe

I find that I catch stuff more often because you've got young kids that are mixing more, and then they're bringing it home. So you're more likely to catch colds and for them to be going on for weeks and weeks.

Judy, 37 FG13 Group of pre-school parents

Do you know what I think? When you phone to say that you can't come in, if you can phone and say that you've got an antibiotic then they'll believe that you're ill… but if you phone and say, well the GP says it's viral, they think 'there's nothing wrong with her, she could be at work.' So you kinda feel like you need an antibiotic tae secure your right to be off work. Or to be ill. To officially tell people that you're ill you need an antibiotic, 'cause that means that it's a real illness.

Judy, 37 FG13 Group of pre-school parents

My boss was kinda known for being quite, you know, he kinda feels as if, well… if you're a parent you've got to accept that your child will be ill and you've got to make arrangements for that. An' the arrangements won't involve you being off your work basically.

Susie, 33 FG20 Baby Cafe

I think the… the other thing is it depends, you know, who people's managers are so, like my manager('s)… wife's a childminder and she does everything to do wi' the kids so he's never had a day off… I remember he made the comment to somebody, "Well, you know, when we had children we made the decision my wife was gonnae change career… so that she could… do it" - and it's like, well, not everyone can do that… so he was kind of projecting his personal circums(tances) - you know, "Well if I can do it, you can do it," kinda thing.

Susie, 33 FG20 Baby Café

It depends who your boss is, like I worked in a nursery, and the manager was a mum, she had two kids and if there was anything she was like, 'oh no, it's your child, your child comes first… don't worry about work.' And that was really nice, 'cause you never felt like that whole guilt going in to work, 'cause I think if your boss didn't have kids… or even sometimes it's a man who doesn't understand… you're kinda like 'oh I'm really sorry'… and you've got nothing just to be sorry about, your child's unwell.

Paula, 33 FG19 Baby Cafe

I think whether they've got kids definitely has a… if I, like if I look at my Head o' Department now, she's got two kids, and she's quite a stressy mum. And like I know now, like if I was to tell she wasn't well, I've not been back to work, but like it would be like, "oh it's fine", because she has called off, like, loads of times, and as a Head of Department, like she's kinda setting that scene. Whereas before that she was very career driven and, you know, and I think had it been a child excuse before she'd had a kid, it would've been… she wouldn't… our work's really, really flexible, so it wouldn't have been an issue, but there would… you would definitely have felt as if you were maybe getting talked about a wee bit, do you know that way? Whereas now, I think because she's got two kids of her own… she's like 100% flipped…

Vanessa, 34 FG19 Baby Cafe

I feel in work, like I'm quite lucky as well and it probably is not necessarily a good thing, but like our head teacher and everything, a lot of that is down to discretion at times as well and I've never had any issues with having to take time for anything. And I don't know anybody who has. But that might be different in a different school… like if I had to say I was going home because of something it wouldn't need to be in black and white all the time you know, it would be a kind of, "Right, on you go. Your child's not well."

Mandy, 37 FG20 Baby Cafe

I think when you're working, it's that whole thing, it's like people expect you to work like you don't have a child, but then people expect you to be a mum like you don't have a job. 'Cause I've… I'm a teacher, and I've not worked since she's been born, and I don't have a job right now, and it's… I feel quite relaxed about that, because in the past when I've had a job, I had my wee boy who's now nearly four, I feel like when you don't go in tae work because your child's sick, people are like 'not in because your child's sick,' and they're kinda rolling eyes at… people that aren't parents. And that's… that's really, really difficult. So me and my husband try and like… because we're both teachers, "it's like right, okay, you don't go in this day, I will not go in that day", and it's… it's really, really hard. 'Cause it's like that's two classes getting disrupted, and as teacher you feel really guilty about the thirty-odd children don't have a teacher in that day. And as mum, you feel horrible leaving your wee one in the morning, and they're like 'mummy don't leave me,' and it's… it's heart-breaking. So it's like you're getting pulled in all directions.

Paula, 33 FG19 Baby Cafe

Susie: I've kinda done kinda similar, like I've went to work when ideally I would've probably stayed off with my wee boy, at the time was unwell. But you feel guilty, you know? Aye, 'cause you… there's some people that just don't understand that you're off for your child.

Morag: You get one day, like that, like the kind of day of illness and then if it's a child then that, like if it's your child then naw. And sometimes you think 'am I actually better just phoning in sick?'… 'cause then you can self-certificate for a week.

Audrey: Aye, I know, I've thought that as well.

Morag: So. And just not tell them. (laughs)

LR: What are you expected to do if they're too unwell to go to nursery?

(Mixed voices)

Find an appropriate somebody to look after them. Would that be right? Wouldn't you… (overtalk)

I actually don't know, (yeah) like I don't know how it would work. I've not had to…

Is it carers leave for NHS?

Susie, 33; Audrey, 38; and Morag FG20 Baby Cafe

The other thing is what comes intae a lotta people's factors is whether you're gonnae get paid or not… so in my work, I get paid for a certain amount o' days a year. My husband doesn't… so we would prefer it to be me but then my boss says, "Well, you know, that's not our problem," kinda thing, "you should be sharing it." So there's all these things that come into it as well.

Forty-odd quid a day for nursery and you think, you know, and I'm not sending you knowing maybe the girl, chicken pox for a week, you know. It's… she's barred from nursery for a week so what are you supposed to do?... So that, in those situations you're kinda phoning round family and saying, "Who can help?" … but ultimately the buck stops wi' you.

Susie, 33 FG20 Baby Cafe

I think at first, when she first went in, 'cause I was already back at work before she started nursery and within like the first like three weeks or something, I was like already having to take time back and it was quite kinda unsettling her and myself as well going back and it was a bit like, oh, for goodness sake. But no, when they're that wee, like the nursery was like, she's got like three whatever normal nappies, can I come in?

Aileen, 34 FG8 Baby Cafe

My nursery's not too bad. See wi' like colds and whatnot they're okay. Obviously the usual wi' the bugs and stuff like that you have to give it forty-eight hours from the last they're unwell. But they're not very, like they'll phone if they're really unwell but they're not really pestering me too much. Like, if you know what I mean? They're quite good that way.

Sarah, 35 FG8 Baby Cafe
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The harsh reality is that a lot of employers, you know, feel that their parent employees are less reliable because, 'Oh you're gonna be off if you've, you know, you've got a child.'…obviously there's family-friendly sort of sectors like government, like NHS, you know, like teaching, but even in those sectors there's still pressure, (mmhmm) you know. And pressure from colleagues as wel, to think, 'Oh,' you know, ''cause they've got a kid,' you know, 'they're off again,' kinda thing.

Susie, 33 FG20 Baby Cafe

And then, you don't know if you're supposed to keep them off nursery or can you send them wi' a cold or… then everybody gets the cold and then you're the mum that sent the kid that gives them all the cold… how much higher are stakes with covid?

Angela, 31 FG5 Group of pre-school parents

I think some folk, tae, nae disrespect to parents like that, "Oh, I'm working. I've got naebody else to watch them."

Kids come first, don't they?

So, they need to go to the school. But it should be the other way aboot, it should be your health and your kid's health that comes first before anything else.

I think society, it has got harder. Aye, I think it has got harder.

'Cause you need to work now, don't you?

Aye, 'cause folk are thinking, 'Oh, if I don't go to work, I'm no' gonnae get paid. If I don't get paid, how am I going to pay the bills?' It is hard.

It is awfy hard.

Mixed unidentified voices, FG6 Pre-school parents group

Marie: I think as a mum you're pulled in all different… see stay at home mums, right? They actually had it made. Nowadays, we're forced, a lot of mums are forced to go out to work.

Irene: See, I stayed at home, right? Unfortunately, something happened during one o' the births, like, I had to stay at home, and I've never worked since, but we just had tae cut our cloth to suit, you know? When you knew you were never gonnae work again, there's… well, you just have tae use what you've got, then.

Erica: Yeah. That's what this generation of mums don't…

Irene: Don't get.

Erica: Don't understand.

Irene: They don't get that. "We have to work." No, you don't have to work.

Marie: I gave up my job and, you know, just fortunately over time I've became self-employed. And I… I do juggle it. Like, you know, I'll have people coming tonight for fittings and I'll be, like, trying to cook the dinner…

Andrea This is the first time I've ever seen Marie without children.

Marie And sometimes there is a wee bit of you going, "Well, I can't have that nice holiday abroad and I can't have that fancy car." But at the end of the day, I see it fae a different point of view, I know that my boys have got me there at home, I can see them. But we'll get that.

Erica "Aye, but we're going away on holiday on Saturday, so I need my child seen." Well, that's just a flag to my face… I'm just like, "Oh, really?" I was like, "You need to prioritise. Is it your child or is it your holiday?" I mean, I appreciate you've worked hard to probably go on that holiday, but they're like, "You need to get me an appointment because I'm away on my holidays on Saturday." I'm just like, "I'll get you an appointment if I decide you need an appointment." Literally, usually it ends up not in their favour.

Maria, 43; Irene, 56; Erica, 31; and Andrea, 39 FG14 Library story and music group

Lorna: I think personally, I feel that I should be the one that's off.

Paula: it's just that classic mum guilt, you feel guilty about absolutely everything.

Vanessa: 'it'll probably be the case that should that ever occur it'll be me that does it, just because of the way the workplaces are, I would say.

Lorna, 33; Paula, 33; and Vanessa, 34 FG19 Baby Cafe

We've got a good support network, but I still felt like I should be at, this is my job, like you know, when they're not well, this is when I should be able to look after them… I'm a mum, that's my first job.

Morag, 30 FG20 Baby Cafe

Mandy: I just remember the nursery phoning me and my dad, my mum and dad live next door to the nursery so I phoned my dad and said, "Are you…" he was off and he went and got her and I just thought, 'They've phoned me and said she's sitting in a wee corner, she's lethargic, she's got a temperature, she's just not herself.' And I thought, and my dad's turning up and she's gonna be looking up and thinking, 'Where's my mum?'

So… it's more about, it's not, it's, the guilt's mostly for them, you know, they and it's mostly like, you know, you've said, it's their mum usually they want, sometimes their dad. You know, they love gran and papa but when they're not well…

Unidentified voice: They just want their mum

When I wasn't well when I was wee it was always my mum and dad I wanted, you know? So… there's definitely guilt. Mandy 33

Mandy, 33 and unidentified participant FG Baby Cafe

I think if you've not had children before, or you've not had to be off, I suppose it's knowing that kinda threshold of, should I be off with them? Should I feel guilty about being off, if it's just something fairly minor?... you probably feel like, you- that's not a good enough reason like to be off, to say that I would rather I was at home looking after them than somebody else. I felt like if I was to say that, it wouldn't really make a difference.

Susie, 33 FG19 Baby Cafe

I think as well, you come in fae work, you're tired, you're hungry, you look at the child and they look unwell, but, actually, I'm tired and I really don't want to go to the hospital with them. That sounds terrible but you have got that, you're thinking 'I've had a really rubbish day at work, I'm going to have to take tomorrow off 'cause they're not well, my boss is gonnae give me a hard time for it and make me know that I'm taking the day off, and you think, 'I really don't want to go to hospital tonight. I'll just leave it for the morning.' When, actually, if you'd been there all day, you'd think, 'Actually, they're really, really unwell. I'm just going to take them. I'm just going to get out my bed, have to get my mum to come over to watch the kids for me to drive and, you know…?'

Andrea, 39 FG14 Library story and music group

I work full-time Monday to Friday, nine to five. And I sometimes feel that, sometimes if my wee girl's… unwell it sometimes went a wee bit unnoticed for a bit because she was passed pillar tae post, so… she was at nursery or she was at grandparents. So it wasn't 'til a coupla days and then you realise my goodness, she's not actually well and it's hard going as well when you've got a, a job. I only get a coupla like family days, if you know what I mean, know how like if your child's ill. It's hard tae get time off with your child as well, I feel.

Sarah, 35, FG8 Baby Cafe

My son's old nursery actually started getting all the children's kind of base temperatures because they are all different, so it meant that although you know, one at thirty-eight might signify illness, another one might not be ill until it like hits thirty-nine or so…so over a

period of about a week, they took all the kids temperatures about three times a day, just to get like the kinda baseline, 'cause it is, it's very individual as to a temperature that's high

Unidentified voice, FG3 Group of pre-school parents

Appendix 23 Chapter 7 Additional quotes from focus groups

I know it's really difficult for doctors because they're told, really, cut back…

but then there's a point where when the child is actually sick and there's a consequence when they're not giving you antibiotics because they're then left with, I feel like my wee boy is left wi'… a weak chest… sometimes I think the doctor's decision to cut back on the antibiotics is not always… in the best interest.

Marie, 43 FG14 Library story and music group

Judy: I've noticed... now, when you go, initially you would o' went and they'd have said "oh it's just a viral infection," and send you off. Now when they say it's a viral thing, quite often I've had a printout... and it tells you exactly what the viral… or what they think the viral infection is. And what the timescale o' it to go away is… you don't have drugs to take away, but you've still got…

Caroline: I think the idea, the fact that you're saying it gives you a timeline. Because I think if you've went and they've said it's a virus, you don't know how long you should be giving your child to get better before you should go back...

Tracy: Yeah, and then you don't feel so bad about going back if they've said, 'right...'

Caroline: Uh-huh, yeah, but you feel like kinda you're annoying them if you…

Judy: Aye, you feel like you're kinda going away wi' a wee bit o' information, rather than you go home and people say "so what's wrong with him?" And you say, "I don't know, just viral." ... I don't really know what's wrong wi' him, that's it.

Caroline: And that's when everyone puts in their, all their opinions, isn't it? Oh, I've seen this, it can't be viral, get them back and go straight up to A&E.

(Laughter and overtalk)

Caroline: Potatoes in their socks and get them up to A&E… yeah.

Judy, 37; Caroline, 32; and Tracy, 29 FG13 Group of pre-school parents

…she kinda made as if like they're not supposed to, and then she said to me like, "Because it's kids," she said, "she tends to give them out a bit easier, rather than if it was adults." But then she said

because he didn't have the whole kinda pus in his throat, like she said, "Just give him Calpol and see how he is in a few days…

I says to her, "Like I don't want him to go on for another week and he's still no' well." And she says like, she says like, "I tend tae give kids them a wee bit more sooner rather than letting it get that far."

Lynsey, 32 FG9 Parent café

I think from doctors and Anne, our ANP, she gives a lot of antibiotics for things that I wouldn't. And I'm obviously very, very aware of sepsis. But I think you've got, you know, you've got really good guidelines to indicate whether or not this person has got possible sepsis, and then you're sending them to hospital anyway, so you're not gonnae prescribe antibiotics...

we've got an eleven o'clock surgery every single day at work for children, primary school age... and it's a great service. But it's really open tae abuse. And a woman cane to see me for something, and her wee boy was there. Now he was about eight, eight or nine, he was a cracking wee boy. Talking away and blah, blah. The wee boy was neither up nor down, he was completely fine. She's been to see the doctor. I says "Oh, why's he going to the doctor?" "He needs antibiotics, he's got tonsillitis." And he's talking away absolutely fine…
I don't think there's been a culture change for like the GPs, even just like for myself like if you go with like… like a chest infection, you get the antibiotics, or if you go in with an infection, they'll give you antibiotics.

June FG1

I felt as if, well, the doctor was saying tae me "Look, there's no' really an antibiotic needed here. That's no' my opinion but, you know, if you really feel that it's gone too long and you need an anti… then you need the antibiotic…"... If he needed it, the doctor would've gi'ed him it.

Anne, FG2 Kinship carers group

Katie: 'Cause I just kept telling her that, like, this keeps happening and I was trying tae tell her that her dad had asthma, she didnae want tae know. Like, you know, I was trying tae give her wee clues to try and work out what it was, but, no, she didn't want to know, it was antibiotics and that was that.

Katie, 23 FG12 Group of pre-school parents

Mandy: It must be so difficult 'cause every case is different. It doesn't happen the same way every time…

Audrey: A…from… experience sometimes it can happen very, very, very quickly.   in twenty-four hours they're in sepsis. An' other times it's more kind of gradual progression that's kind of led into it, you know…

Mandy, 37 and Audrey, 38 FG20 Parent café

Katie: If they weren't sure, I'd rather they said that, you know, they've just guessed.

LR: Why do you think they don't do that?

Katie: So they don't worry you… but then it's not a problem because they're still worrying you if they don't give you a definitive answer.

LR: What do you think, Gillian, do you prefer to know if they've got uncertainty themselves?

Gillian: Yeah. I mean, obviously, they're just human at the end of the day, going on experience, but, aye, I think if you're no' sure then at least be honest to the person, say "Look, I can find out or I can try my best, see what my other colleagues think" or instead o' just saying, "Oh, it's viral."…

…but, obviously, they, they can only do their best, like. They don't want tae worry you with something else that might not be it, like.

LR: Sometimes maybe trying to sort of be certain when they're not, it's less helpful than…

Gillian: Yeah. Especially when you've got something in the back of your head, and that's saying, "No, it's not that." Like, if they spoke with you and said, "Oh, I've got a feeling it might be something else but we're not sure", like, you'd feel a bit more trusting, wouldn't you, like?

LR: What do you think?

Scott: I'm the same. I would rather know. If they said to me, "This is what I think it is, however, there are other options. This is what you do and this is what to look out for if anything's changing",

you then feel happy going back to them. But if they say, "No, look it's definitely this" and then it turns out they're wrong, then it doesn't matter if you see that same GP or another GP you're always gonnae have that nagging doubt of, 'Well, you were wrong last time, so how are you gonnae be right this time?' And they are human, you know, and I worry about how little time they're given to see patients and how many patients they have to see, and that's why they create this atmosphere of 'Right, I need you out and the next person in.'

> Katie, 23; Gillian, 29; and Scott, 36 FG12 Group of pre-school parents

Do you know what, cut half the doctors' money doon, and employ double the amount of doctors. They're on like a hundred and odd grand a year and all that. I get a motor, a hundred grand a year, like, whit?! And they're filing people out after six minutes.

> Patrick, 27 FG1 Support group for lone fathers

Claire: I went, the two o' mines had chicken pox, and I knew it was the chicken pox, but Cara's was looking like they were infected and I phoned up and I says, "She needs—I need to see if these are infected." "Oh, we'll get you an appointment wi' the nursing practitioner." And, I've not really had a… great deal o' experience wi' them. And I said, "Right, okay, that's fine." And the very first thing she said was, "Oh, I don't know. I'll need to get a doctor in," (laugh). And I thought, 'Well… I asked for a doctor's appointment.' "No, the nursing practitioner can do everything a doctor can do."…

Right. Okay. So, why do they have doctors then? Why are they not doctors? And, I know it's—I'm not taking away from any—what they've done and things like that, but just that day… the doctors were all in wi' patients, so I had to wait and Cara was getting antsy and she was scratching, and I was like, "I just need somebody to tell me…

> …and then she got an antibiotic cream for them because they were infected.

> Claire, 38 FG5 Group of pre-school parents

My mum had lung cancer, and she never smoked a day in her life… she was... forty-two when she was diagnosed... and, it went into lung cancer and then it went into secondary ovarian cancer... and, people say, "Oh, did you not go for your smears?" Or, "Oh, how much do you smoke?" And, my mum's like, "I never smoked." And see when she says, "Never smoked." They used to go, "But you must have smoked." And she's like, "I can tell you, I've never…"

..when she went to her first appointment at the oncologist, he says, "We need to get you to smoking cessation." And my mum went, "Why do I need to go to smoking cessation?" And he says, "Oh, well, it's not really ideal if you're on chemotherapy if you're still smoking—"

And my mum says, "I've never smoked a day in my life." And he was like, "Oh…" He says… "I've never had a patient in since I've transferred to specialist lung," he says, "I've never had a patient that wasn't a smoker."

Angela, 31 FG5 Group of pre-school parents

I think that's what, like why I would be reluctant to ask for an antibiotic for a child because you don't want them later in life to have something that they then can't cope with because they've put up some kinda resistance to antibiotics.

Mandy 37 FG20 Baby café

Well, people go tae the doctors an' aye, they get immune tae it, and... they think, 'oh, I've got a cough, oh it's in my chest, antibiotics.' See if they're getting them willy nilly, you are going tae (sic) immune tae them. Overusing them is no' gonnae do the job, it's only gonnae go do the job if infection's in you. To fight it. And then it's, it's kinda building your system up tae… if anything was to really happen and there was an infection, is it gonnae fight it properly? 'Cause you're immune tae them, as you say, you know what I mean?

Carol, 42 FG7 Organisation for disadvantaged families

(in response to earlier question about causes of resistance):

Alan: …getting addicted to them

Patrick: Do you?... It's usually painkillers if anybody's getting addicted to, no' antibiotics.

Alan: But then it depends on that person as well, doesn't it? If they—they might think, 'Well, I need them, I need to keep taking them…'

Alan 38 and Patrick 27, FG1 Support group for lone fathers

Well, the main reason to no' gi'e children antibiotics is so that their body can learn to fight off viruses… that infection and learn how to fight it off, so… obviously, if you're given antibiotics at a young age, when they dae get that infection or illness, like, when they are older, their body's no' gonnae fight it off.

Shannon, 24 FG6 Group of pre-school parents

Well… none of my kids even got their MMR jags because one o' my friends, her only child got it and it was tragic what happened, and he actually ended up, he died at 14. But, so, I never got any of my – none of my kids have it, and, you know, I had health visitors about, "You know, they can go blind wi' measles, they can go…" But, you know, we had all those things when we were young, we had measles, we had mumps. I mean, my head was sitting on my shoulders at one point wi' mumps, you know? But I don't think there's anything wrong wi' your kids taking they things.

Irene, 56 FG14 Library story and music group

I think I just worry about everything because my second wee boy, when he was born, I had to have antibiotics when I was labour and then he had to have antibiotics for three days. So, wi' the first one Logan, he's always fine and I don't really worry, but as soon as it's Max, like, I'm dead paranoid. 'Oh, he's had antibiotics.' You always hear, like, oh, if they've had antibiotics when they're dead young, it does make their immune system dead weak.

Louise 37 FG9 Baby Café

Angela: I would say the… like young ones 'cause they seem tae just give them for anything now. Obviously they're gonna build up a resistance for long term.

Claire: Aye, young ones, but also like… my… father-in-law, he seems to take a lot o' antibiotics and I'm kinda getting a bit worried. He was actually on the phone this morning trying to get the doctor, 'cause he's got a chest infection. He's constantly got chest infections and I'm thinking…

Angela: I says that… my granda' does the same actually. He's always, "This cough's not going away, I need an antibiotic," and you're like...

Claire: I'm a bit worried about the older generation as well. In the middle totally not, 'cause I, I mean funny enough I did have tonsillitis as well, Harry gave me tonsillitis at the beginning of the year and I ended up on antibiotics (laugh) I know. I've no' had an—I've no' had tonsillitis since I was young. But, see when you have children, oh my god.

Angela, 31 and Claire, 38 FG5 Preschool parents group

LR: Do you feel as if antibiotic resistance is something that's affecting people today?

Irene: Well, I would take my doctor's word. See if he says to me that, you know, that wouldn't work for that, that's stopped working for that, then I would believe him… that's the trust I'm looking for off the professionals, you see? So, they kinda stories frighten me. But, if they're saying it's not working, is it not working because it's been overused, or it's not working because the virus – well, not the viruses, but the bugs – are getting worse?

Andrea: So, I wondered, like, that as well, like, because I'm somebody that's not taken antibiotics much, would I be alright, you know? Or it is, like, if you're taking—

Irene: But does it matter…

Andrea: If I had taken hundreds of antibiotics, I'm more susceptible to these?

Irene, 56 and Andrea, 39 FG14 Library story and music group

Claire: I just feel as if we've no' got enough information, what do they mean resist? Does that mean if you're taking them once a month or once a year or…

Angela: how frequently?

Claire: I think we definitely need more information.

Angela: It's scaremongering.

Claire: I mean, I feel like it's scaremongering. That's all you hear.

Angela: Mm hmm. They're not giving you, they're only telling you the bad things, like they're not, as I say, they're not giving you the right information like, I'm panicking how many times like

yourself, how many times a year are you allowed to take antibiotics then before you start building up a resistance to them or is it over long term? Is it people taking them all the time or is it… Who does take antibiotics constantly? Nobody. It's only when you're not well you take them.

Claire: Exactly, I know.

Angela and Claire

Angela: The whole resistance thing, it's just like, how much is… the limit?

Claire: Maybe they don't know. Maybe they don't know exactly.

Angela: Uh-huh. Obviously like that.

Claire: Or they would be telling you, wouldn't they?

Claire, 38 and Angela, 31 FG5 Preschool parents group

LR: Who's at risk of antibiotic- of resistant infections?

Leigh: Anyone that… as I said to everyone, you know, I've been on like antibiotics, before I kinda… maybe just trust your doctor when you go with anything that I have been on quite a lot of courses of antibiotics over the years for different things, and I have experienced the backlash from them. Like the negative side of it as well, obviously like clearing up what you've got, but then being left with something else, another kinda thing.

LR: Okay. Any other thoughts on who's at risk?

Paula: People with compromised immune systems… like my sister's had a kidney transplant, so she… she's at like big risk from like skin cancer. Like she has to be really, really careful, and obviously like making sure like kids have had their vaccinations and everything like that. 'Cause she can get really sick.

LR: Something that's come up in the other groups is, some people have had the perception that it's only the people who are taking the antibiotics that are gonna be at risk. Is that something that anybody's ever thought… or do you think there's an understanding that actually even if you're never gonna need an antibiotic, you can still pick up an infection that's mutated?

Lorna: Is it not just everybody, because yeah, if you're gonnae pick up an infection that's gonnae be resistant to…

Colette: Yeah, that's my understanding, yeah.

Vanessa: That's even more scary. (Laughter) That's awful!

LR: I think some people are under the perception that actually if you don't overuse them, if you don't take them then, you know, you're not actually at risk. But clearly, everyone here understands that.

Lorna: I can understand people thinking that, though.

Leigh, 29; Paula, 33; Lorna, 33; Colette, 38; Vanessa, 34 FG19 Baby Cafe

…the first time… they managed to get the antibiotics in quick, I think, within the first two hours or something they get, she was fine, and then she was in hospital for about a week that time and then the second time, as I say, it was about a month before she died, she was in the hospice, and she'd taken it again and she was getting antibiotics, but they just weren't working. They were keeping it at bay, she wasn't getting any worse, but she wasn't getting any better, and then they decided, they says to her, "Look, she's not gonnae get any better." So, we took her home.

Angela, 31 FG5 Group of pre-school parents

LR: …has anybody had... experience of a resistant infection, or a relative that's had an infection that they've been told is resistant to antibiotics?

Shannon: My gran. Yeah… she's 79 noo, so she is old. And she's… basically, it's she's needed two new knees fae I was a wee lassie, I can remember she's always struggled, so, it's kind of became a bit of a routine. She just sits there all day and she doesnae move. Like, she's had two new knee replacements but because the muscles in her legs are just totally gone, like, she's no' really getting the use of the new knees, so she still is really struggling to go to the toilet. And she would just… she's on, like, incontinent pads an' that noo and she would just sit there...

...and she's just holding her pee in, holding it in, holding it in, so she's causing infection in herself... and that's been happening for about three year noo, so it's noo got to the point that about two weeks ago she was put on a bag because there's just…

LR: Okay. And has she been told that the bugs are resistant to antibiotics?

Shannon: Yeah. She's just on one antibiotic, another one, she's got an antibiotic in her blister pack. She's got one for the night-time, she's got one for the morning. So, at one point, she was on four different antibiotics, just to clear this one urine infection, but it's… it's bad. It's… even though it's affecting her health, it's draining the family an' a'.

Shannon, 24 FG6 Group of pre-school parents

Kerry: I remember being told by that as a wee girl, you know, if you cut your finger on a rusty nail— a rose thorn and that kind of thing... but, I don't think ever seen anybody saying, just from a urinary tract, you know, infection, you could end up with...

LR: Or from a throat infection.

Kerry: Or from a throat infection. It's not as common to see it sort of flagged up in that way. It still kind of is that, you know, a random cut of your finger on a rusty nail.

LR: Something foreign gets in.

Kerry: Uh huh. Yes.

LR: Yeah, as opposed to something kind of—

Kerry: And, a blood infection rather than, you know…

Kerry, 45 FG18 Group with individuals with lived experience of sepsis

...I heard that, I'm one for biting my nails, and my kids are one for biting their nails, they say it's a nerve thing, I don't know. But it's round the skin, and I read on Facebook... the guy was biting his nails, and roond the skin, like these bits, and he nearly died. Nearly died, it went into 'septis,' so it did. That's gave me the fright o' my life. Don't get me wrong, I'm still biting them. But no' as much, know what I mean?

Carol, 42 FG7 Organisation for disadvantaged parents

I can remember when I was younger... one of my parents' neighbours, now he was a man in his forties, went into hospital... for a bowel operation, and he took, well probably it was sepsis, and he

died within a matter of days. And, they just hushed it all up at the time... it was just a, one of these things, and he was quite young. He was a strong, fit man...

The man's sister actually was in the NHS herself and she was really upset. She thought they were covering up, at the time, what had happened with him. But, he had a... nick in his bowel, something happened, and probably was something like sepsis and in those days, that was that. It's just, end of.

LR: So, it's probably something that did used to happen to people, but—

Bill: It did happen, but it wasn't reported.

Bill, 53 FG17 Group of individuals affected by sepsis

Gary...this phrase 'could it be sepsis?' This is… this is the phrase everyone's using now, when a child - or anybody's admitted to hospital showing symptoms.

June: Think… sepsis is the…

Gary: Think this is sepsis. And even ask, know, one of the specialists, the nurses, the doctors, whatever, like could this be sepsis? Because if they then sort o' run the five or six questions and say "Well it could be that." Then it's trying tae do it straight away. But don't wait for the six hours or eight hours or ten hours, and try tae second guess what it is. It's a simple question. And even, as you say, when I was in the hospital, my brother-in-law passed away in August, and even DGH, then there was signs on the wall 'Could this be sepsis?' ... and it's that kinda awareness which, because we're in this sort o', know, circle, then we know it. And because I look out of for these kinda things, but Mr and Mrs Smith who walk past, then, would they notice that, and would they ask that question? I don't know. I don't know.

June: Probably not, but I think… the educated public do think of it, 'cause we get… at work, we get… phone calls, not often, but occasionally like from carers, you know, like council carers that have maybe been on a course about sepsis, so they go in and they see a patient and the… they maybe notice something different, so they'll phone up the doctor and say "Oh, I think they could be sepsis."

Gary: Because that is your line of work. That is… aye.

June: That's my… exactly, yeah. I think within groups o' society in, you know, whether it's medicine, nursing, caring, that type o' thing, I think the message is getting out there... people are thinking 'sepsis.' I don't know…

Gary: Even once I started back work... I work for Tesco – maybe about twelve hundred, fifteen hundred people in our place. And I'd say 90% o' people who ask me what happened to Rhys and I told them, didn't have a clue what sepsis was...they would say septicaemia, 'cause some o' the older ones…

June: I had to… I know, but I mean, me as a nurse and work… and working as a general practise nurse as well, I had to Google what's the difference between sepsis and septicaemia... because I thought, 'is this a new thing, is this a new disease?' And we were, you know, we were talking at work and one o' the doctors at my work, she was like that, "I was like that as well," she said "I always just called it septicaemia," ...

LR: Well it's interesting what you say there about the word 'new,'... I've been looking at, the background, actually the word itself date backs to Hippocrates... the condition is actually no different to it always was, you know, it's as old as life itself. But it seems as though using 'sepsis,'… it's almost a kind of attempt to get people to think differently about it, to think about it as something new.

Gary: More catchier, aye.

June: That's what that man said to us, from that 'FEAT', he says "It's been rebranded."

Gary: Aye.

June: And that's exactly what it is, it's been rebrandedJune: And if that's going tae help people, fantastic, call it something else, that's great.

June 45 and Gary 51, FG15 Group of individuals with lived experience of sepsis

...it was only when I asked my surgeon how ill I actually was that that was the first time he used the word "sepsis" and while I was vaguely aware of what sepsis was, I didn't realise the impact that it could have, and how quick that impact could be... and, I'm not sure that it actually would've been had I not asked... the only visitors that were permitted were my parents and my husband and they were never told I had sepsis or severe sepsis. And, as I say, it was only when I asked my surgeon to score me, in the way that they do, you know, "How's your pain?" I said, "From zero to ten, where…" how ill was I? And, at that point, he said, "You've got severe sepsis, multiple organ failure, etc." So, at no point was it mentioned...during the time there. And, that was quite late on.

Linda: I think, maybe there's a perception among doctors that, "Patients aren't going to understand if I use technical language." But, when I said to my surgeon, the consultant, you know… how ill have I been? And, he said, "Why do you want to know that?" And, I said, "Because it will give me some perspective." And, at that point, he became very, he was a very decent doctor, he treated you like a person, but at that point, he became very professional and, "Right, you have this, this, this, this, and this…"... but, I don't think he would've said that, had I not asked.

LR: So, did you feel there was almost a kind of reluctance to… not that anything was being hidden from you, but... it wasn't perhaps sort of within the sort of comfort zone of just talking freely about…

Linda: I don't think they thought it was important… I don't think they thought it would've made any difference to me to know what I had... whereas it did. It made a huge difference to me. If I'd been discharged from hospital, having been, you know, so ill that I actually said to the doctor, "Just give me something. End it. Because I can't cope with this." If I had come out not knowing what it was, I still wouldn't have been aware of sepsis, and the impact it can have. I would just have thought it's an infection.

Well, I managed to get it twice... I had a C-section for twins, and about a week after that, and as I said, I didn't know anything about sepsis, and my husband works in hospitals and he was wheeling me up and down from the NICU to see my babies and there were all these posters for sepsis and saying, "Think sepsis. Say sepsis." And, I happened to say to him, "What is sepsis?" Having never heard of it before, and him being a, from a medical background gave me a very sort of graphic sort of definition of what sepsis was and

explained, you know, it's… "It's when you get an infection, but your body has an odd reaction to it, and it's really dangerous and … people can die of it really quickly, and so it's difficult to catch," etc.

So, he told me all this and then, I don't know, forty-eight hours, seventy-two hours later, and I was actually down in intensive care and I didn't feel right, but it was kind of, I was on a lot of drugs 'cause of the, all the sorts of things that were going on. However, I'd just about collapsed in the intensive care, in the NICU and they sort of wheeled me back up and it was all… I realised, nobody had said "sepsis" at that point either, and I certainly didn't, it wasn't anything I was thinking of. But, I could tell that there was a lot of people in the room, and they were all quite sort of concerned and I knew that I'd been put on the sepsis, is it the Sepsis Six Pathway or something? Sepsis Pathway? And, because I had asked my husband just a few days before what sepsis was, when I heard I was on this Sepsis Six Pathway or whatever, I… I was really quite worried because I was saying, "Have I got sepsis? Have I got sepsis?" And, at that point, they didn't say yes, they didn't say yes. So, anyway, I was put down to sort of intensive care twenty-four hour observation and they kept me on IV antibiotics for, I think seventy-two hours, three days, but really twenty-four hours later, I felt, I—better. I mean, given I just had a C-section and my babies were ill and there was a lot going on.

So, as far as I was concerned that was kind of over and done with and then about three months later when I was home, and I just got my girls home, they were on oxygen, so there was quite a lot going on, and I started to feel unwell and I knew that it felt exactly like I felt when I was in the hospital and I was just at home with my mum who is seventy with my babies and my husband was at work, and I had to get my older son to the nursery and thought, 'If I can just get him to nursery…' And, I didn't want to worry my mum, and I was also thinking, 'I don't know what she's gonna do because both girls were on oxygen and they were particularly vulnerable and they weren't feeding well, and there was a whole load of stuff going on. So, anyway, I phoned my husband and he sort of said, you know, "You need to…" And, by that point, I'd gone into rigors and I really knew that it was the same as last time. So, he said, "Phone an ambulance." So, I ended up back in hospital and this time they gave me all the IV antibiotics for ten days.

Linda and Kerry, FG Group of individuals with lived experience of sepsis

Andrea: You do feel sorry for… I mean, if we make a mistake in our work then it's…

Marie: I mean, if it's hard for them to diagnose, how are we meant to diagnose it? It's… you know, it's quite a…

Andrea: But then human error is human error, everybody's human and making… and if they've been on a long shift and they're looking after multiple…

Erica: But then it's why has the nurse not told the doctor? Why has the nurse not pulled that doctor back and said…? So, it's a shame for that doctor (Andrea: It's usually a chain of things, isn't it?) because actually… it was everyone's responsibility to look after that child, not just that one doctor. But then you don't know what actually happened, what actually went on.

Andrea, 39; Erica, 31 and Marie, 43 FG14 Library story and music group

Susie: It's maybe, wi' these cases, you know, where children have died, it's maybe a coping mechanism when you're grieving as well to be able to say, you know…

Unidentified voice: It was their fault.

Susie… it was their fault because there will be... those parents, I mean they've taken their kid to the hospital twice... the parents'll probably still be saying, "I shoulda, I should've refused to leave... or I shoulda went a third time."... and I'm not saying it is their fault but any parent would blame their self in that situation.

Mandy: Of course you would.

Audrey: I think to have any sort of closure you need to have something (yeah) to say that's where the buck stops... shut a door on it and you can then move on from that.

Mandy: And also if there's a reason behind it you can work out the reason to try and stop it happening.

Susie: And that's why... that William Mead story, you know, his mother's done all these talks around the country to raise awareness and that'll be another way o' helping her deal with it... and I think I'd read somewhere that she said, you know, "If all this saves one child from sepsis then, you know, it's worth it." So that's a way of her coping wi' what happened to her son I think as well.

Susie, 33; Mandy, 37 and Audrey, 38 FG20 Baby Café

Catherine: I wonder whether things like social media and that have an effect as well kinda thing 'cause I think a lotta the time all you see on these things... are negatives... you hear about the one sad case and that preys on your mind, whereas there's probably been a thousand kids that have not got it, but you don't hear that and I think that's the case in all kinda papers and social media. But I think social media probably for our generation and younger is such a kinda almighty force kinda thing that that probably does have a big impact on…

LR: ...so do you think social media potentially has more impact on the traditional news, newspapers and television news?

Sarah: I would say with younger people yeah... I spend a lotta time on social media and stuff like if I'm about and then a lot of people in my work they're more younger as well, they're always on Facebook, Instagram and... they share like lots of posts as well and it's mostly like negative stories as well. Like not all of them but lots of these horror stories and stuff and you see them sharing it and they've got like millions of shares and stuff.

Rachel: That's kind of the way it's written… it's never giving you a balanced view... it's always just some kind of attention grabbing… that makes you go 'gosh'…

Catherine, 38; Sarah, 27 and Rachel 31 FG10 Parent and child exercise group

Susie: I was first aware of (sepsis) when my oldest daughter was born. There was a wee boy in the press, William Mead he was called. And then he died just after my wee girl was born 'cause I remember being in floods of tears at the news at the thought of this wee boy dying.

And I started following his mum on Instagram. And I later unfollowed her because all her posts upset me, which sounds really horrible but it's just the way I felt at the time. And that really scared me that it could just happen. And then a girl that I work with, one of her friend's husbands like banged his leg on a filing cabinet or something and he had like a scab and then the next minute it was sepsis and he died. So it's just like not knowing, you know, just something ordinary every day, you know?

LR: ...when you say that her posts upset you, that's interesting. So what aspect of it, d'you think, was upsetting?

Susie: It was, 'cause her Instagram handle was something like 'a mother without a child' or something... and I think it was just, you know... she was a women that had a child slightly older than mine, and I was quite anxious when my older daughter was born about, you know... that she could suddenly die in the night, you know, and it was really for my own… she was posting a lot about, you know, not having a child and I think she subsequently does have another child now... and it was more for my own kinda mental health if you like, 'cause I just, you saw, I saw these things and just wanted to cry when I saw them.

Audrey: I think when you have children as well you're so much more emotional … and you can relate everything back to how you would feel if that was you.

Susie: Well I mean... I wouldn't have batted an eyelid at that story... before and I don't mean that in a heartless way, I just mean you see things in the news all the time but, you know, since I've had children any stories about children being very ill or dying, you know, are really quite triggering, you know, so that was what upset me about it more.

Susie, 33 and Audrey, 38 FG20 Baby Cafe

LR: …having a look at the kind of symptoms it highlights in some of the campaigns, I just want to know what you think about these. So, the symptoms it tells you to look for: high or low temperature, shivering, fast heartbeat, fast breathing. And then beyond that, feeling dizzy or faint, confusion, diarrhoea, nausea and vomiting, slurred speech, muscle pain, breathlessness, not passing as much urine as normal, cold or blotchy hands and feet, and loss of consciousness. Tell me what you think about that list of symptoms.

Scott: Sounds like 90% of the stuff they're getting.

Gillian: A virus, aye.

Scott: Until they can talk, it's very hard tae get a lot of that out.

LR: Do you think that list... would it be helpful to you as a parent?

Katie: Probably not 'cause it is just…

Barbara: Vague.

Katie: Uh huh. It's no', there's nothing… specific.

Scott, 36; Gillian, 29; Katie, 23; and Barbara, 34 FG12 Group of pre-school parents

Irene: It's hard to kind of judge sometimes at what point, you know?

Erica: Yeah, at what point do you phone someone? What point do you get someone involved?

Irene: Like, if they had fever and their hands and feet were cold then that would signal to me that there is something wrong wi' them.

Erica: Unless, are their hands and feet always cold? There are cold kids, stuff like that.

Irene: Well, you know, if I knew that, aye.

Erica: Isn't it? And—

Irene: But there's nothing – like the meningitis thing you knew, if there was a rash.

Erica: But it's if their hands are freezing cold, so they're really shut down.

Irene: Aye, sort of—

Erica: The bloods not getting tae it and they're ice-cold.

Marie: See, that would resonate with you then, if they said to you, if your kids hands are really, really freezing cold, then you would go, "Oh, that is a…" something that you wouldn't normally see in a normal…

Irene: But how far into the infection are you then?

Erica: Aye, you're not very well at that stage! (laughter)

Irene: Too late. Do you know what I mean? Where is the line? Where is the…? There doesn't seem to be a clear-cut…

Erica: There's not… there's not that.

Andrea: You've just got to use your instincts, haven't you?

Irene: You know, maybe once they've got to their hands and feet are cold, they're past the stage o' anything that's gonnae help them.

Erica: No, no, not at all. No, they can be in full-blown sepsis and still recover from it. But they're not doing good at all. But if their hands and feet are ice cold, there's just, you know, you can still get, there's still, you know, it is, it's an ambulance to hospital but, you know, they can still be saved.

Andrea: Antibiotics at that point.

Erica: Oh, it's, yeah, it's intensive care, it's intubated, it's having them taken over, completely managed.

Erica, 31; Irene, 56; Marie, 43; and Andrea, 39 FG14

I know it's really difficult for doctors because they're told, really, cut back…

but then there's a point where when the child is actually sick and there's a consequence when they're not giving you antibiotics because they're then left with, I feel like my wee boy is left wi'… a weak chest… sometimes I think the doctor's decision to cut back on the antibiotics is not always… in the best interest.

Marie, 43 FG14 Library story and music group

Judy: I've noticed... now, when you go, initially you would o' went and they'd have said "oh it's just a viral infection," and send you off. Now when they say it's a viral thing, quite often I've had a printout... and it tells you exactly what the viral… or what they think the viral infection is. And what the timescale o' it to go away is… you don't have drugs to take away, but you've still got…

Caroline: I think the idea, the fact that you're saying it gives you a timeline. Because I think if you've went and they've said it's a virus, you don't know how long you should be giving your child to get better before you should go back...

Tracy: Yeah, and then you don't feel so bad about going back if they've said, 'right...'

Caroline: Uh-huh, yeah, but you feel like kinda you're annoying them if you…

Judy: Aye, you feel like you're kinda going away wi' a wee bit o' information, rather than you go home and people say "so what's wrong with him?" And you say, "I don't know, just viral." ... I don't really know what's wrong wi' him, that's it.

Caroline: And that's when everyone puts in their, all their opinions, isn't it? Oh, I've seen this, it can't be viral, get them back and go straight up to A&E.

(Laughter and overtalk)

Caroline: Potatoes in their socks and get them up to A&E… yeah.

Judy, 37; Caroline, 32 and Tracy, 29 FG13 Group of pre-school parents

…she kinda made as if like they're not supposed to, and then she said to me like, "Because it's kids," she said, "she tends to give them out a bit easier, rather than if it was adults." But then she said because he didn't have the whole kinda pus in his throat, like she said, "Just give him Calpol and see how he is in a few days…

I says to her, "Like I don't want him to go on for another week and he's still no' well." And she says like, she says like, "I tend tae give kids them a wee bit more sooner rather than letting it get that far."

Lynsey, 32 FG9 Parent café

I think from doctors and Anne, our ANP, she gives a lot of antibiotics for things that I wouldn't. And I'm obviously very, very aware of sepsis. But I think you've got, you know, you've got really good guidelines to indicate whether or not this person has got possible sepsis, and then you're sending them to hospital anyway, so you're not gonnae prescribe antibiotics...

we've got an eleven o'clock surgery every single day at work for children, primary school age... and it's a great service. But it's really open tae abuse. And a woman cane to see me for something, and her wee boy was there. Now he was about eight, eight or nine, he was a cracking wee boy. Talking away and blah, blah. The wee boy was neither up nor down, he was completely fine. She's been to see the doctor. I says "Oh, why's he going to the doctor?" "He needs antibiotics, he's got tonsillitis." And he's talking away absolutely fine…

I don't think there's been a culture change for like the GPs, even just like for myself like if you go with like… like a chest infection, you get the antibiotics, or if you go in with an infection, they'll give you antibiotics.

June FG1 Individuals with lived experience of sepsis

I felt as if, well, the doctor was saying tae me "Look, there's no' really an antibiotic needed here. That's no' my opinion but, you know, if you really feel that it's gone too long and you need an anti… then you need the antibiotic…"... If he needed it, the doctor would've gi'ed him it.

Anne, FG2 Kinship carers group

Katie: 'Cause I just kept telling her that, like, this keeps happening and I was trying tae tell her that her dad had asthma, she didnae want tae know. Like, you know, I was trying tae give her wee clues to try and work out what it was, but, no, she didn't want to know, it was antibiotics and that was that.

Katie, 23 FG12 Group of pre-school parents

Mandy: It must be so difficult 'cause every case is different. It doesn't happen the same way every time…

Audrey: A…from… experience sometimes it can happen very, very, very quickly.   in twenty-four hours they're in sepsis. An' other times it's more kind of gradual progression that's kind of led into it, you know…

Mandy, 37 and Audrey, 38 FG20 Parent Café

Katie: If they weren't sure, I'd rather they said that, you know, they've just guessed.

LR: Why do you think they don't do that?

Katie: So they don't worry you… but then it's not a problem because they're still worrying you if they don't give you a definitive answer.

LR: What do you think, Gillian, do you prefer to know if they've got uncertainty themselves?

Gillian: Yeah. I mean, obviously, they're just human at the end of the day, going on experience, but, aye, I think if you're no' sure then at least be honest to the person, say

"Look, I can find out or I can try my best, see what my other colleagues think" or instead o' just saying, "Oh, it's viral."…

…but, obviously, they, they can only do their best, like. They don't want tae worry you with something else that might not be it, like.

LR: Sometimes maybe trying to sort of be certain when they're not, it's less helpful than…

Gillian: Yeah. Especially when you've got something in the back of your head, and that's saying, "No, it's not that." Like, if they spoke with you and said, "Oh, I've got a feeling it might be something else but we're not sure", like, you'd feel a bit more trusting, wouldn't you, like?

LR: What do you think?

Scott: I'm the same. I would rather know. If they said to me, "This is what I think it is, however, there are other options. This is what you do and this is what to look out for if anything's changing", you then feel happy going back to them. But if they say, "No, look it's definitely this" and then it turns out they're wrong, then it doesn't matter if you see that same GP or another GP you're always gonnae have that nagging doubt of, 'Well, you were wrong last time, so how are you gonnae be right this time?' And they are human, you know, and I worry about how little time they're given to see patients and how many patients they have to see, and that's why they create this atmosphere of 'Right, I need you out and the next person in.'

Katie, 23; Gillian, 29; and Scott, 36 FG12 Group of pre-school parents

Do you know what, cut half the doctors' money doon, and employ double the amount of doctors. They're on like a hundred and odd grand a year and all that. I get a motor, a hundred grand a year, like, whit?! And they're filing people out after six minutes.

Patrick, 27 FG1 Support group for lone fathers

I went, the two o' mines had chicken pox, and I knew it was the chicken pox, but Cara's was looking like they were infected and I phoned up and I says, "She needs—I need to see if these are infected." "Oh, we'll get you an appointment wi' the nursing practitioner." And, I've not really had a… great deal o' experience wi' them. And I said, "Right, okay, that's fine." And the very first thing she said was, "Oh, I don't know. I'll need to get a doctor in," (laugh). And I thought, 'Well… I asked for a doctor's appointment.' "No, the nursing practitioner can do everything a doctor can do."…

Right. Okay. So, why do they have doctors then? Why are they not doctors? And, I know it's—I'm not taking away from any—what they've done and things like that, but just that day… the doctors were all in wi' patients, so I had to wait and Cara was getting antsy and she was scratching, and I was like, "I just need somebody to tell me…

…and then she got an antibiotic cream for them because they were infected.

Claire, 38 FG5 Group of pre-school parents

My mum had lung cancer, and she never smoked a day in her life… she was... forty-two when she was diagnosed... and, it went into lung cancer and then it went into secondary ovarian cancer... and, people say, "Oh, did you not go for your smears?" Or, "Oh, how much do you smoke?" And, my mum's like, "I never smoked." And see when she says, "Never smoked." They used to go, "But you must have smoked." And she's like, "I can tell you, I've never…"

..when she went to her first appointment at the oncologist, he says, "We need to get you to smoking cessation." And my mum went, "Why do I need to go to smoking cessation?" And he says, "Oh, well, it's not really ideal if you're on chemotherapy if you're still smoking—"

And my mum says, "I've never smoked a day in my life." And he was like, "Oh…" He says… "I've never had a patient in since I've transferred to specialist lung," he says, "I've never had a patient that wasn't a smoker."

Angela, 31 FG5 Group of pre-school parents

I think that's what, like why I would be reluctant to ask for an antibiotic for a child because you don't want them later in life to have something that they then can't cope with because they've put up some kinda resistance to antibiotics.

Mandy, 37 FG20 Baby Café

Well, people go tae the doctors an' aye, they get immune tae it, and... they think, 'oh, I've got a cough, oh it's in my chest, antibiotics.' See if they're getting them willy nilly, you are going tae (sic) immune tae them. Overusing them is no' gonnae do the job, it's only gonnae go do the job if infection's in you. To fight it. And then it's, it's kinda building your system up tae… if anything was to really happen and there was an infection, is it gonnae fight it properly? 'Cause you're immune tae them, as you say, you know what I mean?

Carol, 42 FG7 Organisation for disadvantaged families

(in response to earlier question about causes of resistance):

Alan: …getting addicted to them

Patrick: Do you?... It's usually painkillers if anybody's getting addicted to, no' antibiotics.

Alan: But then it depends on that person as well, doesn't it? If they—they might think, 'Well, I need them, I need to keep taking them…'

Alan 38 and Patrick 27, FG1 Support group for lone fathers

Well, the main reason to no' gi'e children antibiotics is so that their body can learn to fight off viruses… that infection and learn how to fight it off, so… obviously, if you're given antibiotics at a young age, when they dae get that infection or illness, like, when they are older, their body's no' gonnae fight it off.

Shannon, 24 FG6 Group of pre-school parents

Well… none of my kids even got their MMR jags because one o' my friends, her only child got it and it was tragic what happened, and he actually ended up, he died at 14. But, so, I never got any of my – none of my kids have it, and, you know, I had health visitors about, "You know, they can go blind wi' measles, they can go…" But, you know, we had all those things when we were young, we had measles, we had mumps. I mean, my head was sitting on my shoulders at one point wi' mumps, you know? But I don't think there's anything wrong wi' your kids taking they things.

Irene, 56 FG14 Library story and music group

I think I just worry about everything because my second wee boy, when he was born, I had to have antibiotics when I was labour and then he had to have antibiotics for three days. So, wi' the first one Logan, he's always fine and I don't really worry, but as soon as it's Max, like, I'm dead paranoid. 'Oh, he's had antibiotics.' You always hear, like, oh, if they've had antibiotics when they're dead young, it does make their immune system dead weak.

Louise 37 FG9 Baby Café

Angela: I would say the… like young ones 'cause they seem tae just give them for anything now. Obviously they're gonna build up a resistance for long term.

Claire: Aye, young ones, but also like… my… father-in-law, he seems to take a lot o' antibiotics and I'm kinda getting a bit worried. He was actually on the phone this morning trying to get the doctor, 'cause he's got a chest infection. He's constantly got chest infections and I'm thinking…

Angela: I says that… my granda' does the same actually. He's always, "This cough's not going away, I need an antibiotic," and you're like...

Claire: I'm a bit worried about the older generation as well. In the middle totally not, 'cause I, I mean funny enough I did have tonsillitis as well, Harry gave me tonsillitis at the beginning of the year and I ended up on antibiotics (laugh) I know. I've no' had an—I've no' had tonsillitis since I was young. But, see when you have children, oh my god.

Angela, 31 and Claire, 38 FG5 (Preschool parents group)

LR: Do you feel as if antibiotic resistance is something that's affecting people today?

Irene: Well, I would take my doctor's word. See if he says to me that, you know, that wouldn't work for that, that's stopped working for that, then I would believe him... that's the trust I'm looking for off the professionals, you see? So, they kinda stories frighten me. But, if they're saying it's not working, is it not working because it's been overused, or it's not working because the virus – well, not the viruses, but the bugs – are getting worse?

Andrea: So, I wondered, like, that as well, like, because I'm somebody that's not taken antibiotics much, would I be alright, you know? Or it is, like, if you're taking—

Irene: But does it matter…

Andrea: If I had taken hundreds of antibiotics, I'm more susceptible to these?

Irene, 56 and Andrea, 39 FG14 Library story and music group

Claire: I just feel as if we've no' got enough information, what do they mean resist? Does that mean if you're taking them once a month or once a year or…

Angela: how frequently?

Claire: I think we definitely need more information.

Angela: It's scaremongering.

Claire: I mean, I feel like it's scaremongering. That's all you hear.

Angela: Mm hmm. They're not giving you, they're only telling you the bad things, like they're not, as I say, they're not giving you the right information like, I'm panicking how many times like yourself, how many times a year are you allowed to take antibiotics then before you start building up a resistance to them or is it over long term? Is it people taking them all the time or is it… Who does take antibiotics constantly? Nobody. It's only when you're not well you take them.

Claire: Exactly, I know.

Angela: The whole resistance thing, it's just like, how much is… the limit?

Claire: Maybe they don't know. Maybe they don't know exactly.

Angela: Uh-huh. Obviously like that.

[Claire: Or they would be telling you, wouldn't they?

Claire, 38 and Angela, 31 FG5 Preschool parents group

LR: Who's at risk of antibiotic- of resistant infections?

Leigh: Anyone that… as I said to everyone, you know, I've been on like antibiotics, before I kinda… maybe just trust your doctor when you go with anything that I have been on quite a lot of courses of antibiotics over the years for different things, and I have experienced the backlash from them. Like the negative side of it as well, obviously like clearing up what you've got, but then being left with something else, another kinda thing.

LR: Okay. Any other thoughts on who's at risk?

Paula: People with compromised immune systems… like my sister's had a kidney transplant, so she… she's at like big risk from like skin cancer. Like she has to be really, really careful, and obviously like making sure like kids have had their vaccinations and everything like that. 'Cause she can get really sick.

LR: Something that's come up in the other groups is, some people have had the perception that it's only the people who are taking the antibiotics that are gonna be at risk. Is that something that anybody's ever thought… or do you think there's an understanding that actually even if you're never gonna need an antibiotic, you can still pick up an infection that's mutated?

Lorna: Is it not just everybody, because yeah, if you're gonnae pick up an infection that's gonnae be resistant to…

Colette: Yeah, that's my understanding, yeah.

Vanessa: That's even more scary. (Laughter) That's awful!

LR: I think some people are under the perception that actually if you don't overuse them, if you don't take them then, you know, you're not actually at risk. But clearly, everyone here understands that.

Lorna: I can understand people thinking that, though.

Leigh, 29; Paula, 33; Lorna, 33; Colette, 38; Vanessa, 34 FG19 Baby cafe

…the first time… they managed to get the antibiotics in quick, I think, within the first two hours or something they get, she was fine, and then she was in hospital for about a week that time and then the second time, as I say, it was about a month before she died, she was in the hospice, and she'd taken it again and she was getting antibiotics, but they just weren't working. They were keeping it at bay, she wasn't getting any worse, but she wasn't getting any better, and then they decided, they says to her, "Look, she's not gonnae get any better." So, we took her home.

Angela, 31 FG5 Group of pre-school parents

LR: …has anybody had... experience of a resistant infection, or a relative that's had an infection that they've been told is resistant to antibiotics?

Shannon: My gran. Yeah… she's 79 noo, so she is old. And she's… basically, it's she's needed two new knees fae I was a wee lassie, I can remember she's always struggled, so, it's kind of became a bit of a routine. She just sits there all day and she doesnae move. Like, she's had two new knee replacements but because the muscles in her legs are just totally gone, like, she's no' really getting the use of the new knees, so she still is really struggling to go to the toilet. And she would just… she's on, like, incontinent pads an' that noo and she would just sit there...

...and she's just holding her pee in, holding it in, holding it in, so she's causing infection in herself... and that's been happening for about three year noo, so it's noo got to the point that about two weeks ago she was put on a bag because there's just…

LR: Okay. And has she been told that the bugs are resistant to antibiotics?

Shannon: Yeah. She's just on one antibiotic, another one, she's got an antibiotic in her blister pack. She's got one for the night-time, she's got one for the morning. So, at one point, she was on four different antibiotics, just to clear this one urine infection, but it's… it's bad. It's… even though it's affecting her health, it's draining the family an' a'.

Shannon, 24 FG6 Group of pre-school parents

Kerry: I remember being told by that as a wee girl, you know, if you cut your finger on a rusty nail— a rose thorn and that kind of thing... but, I don't think ever seen anybody saying, just from a urinary tract, you know, infection, you could end up with...

LR: Or from a throat infection.

Kerry: Or from a throat infection. It's not as common to see it sort of flagged up in that way. It still kind of is that, you know, a random cut of your finger on a rusty nail.

LR: Something foreign gets in.

Kerry: Uh huh. Yes.

LR: Yeah, as opposed to something kind of—

Kerry: And, a blood infection rather than, you know…

Kerry, 45 FG18 Group with individuals with lived experience of sepsis

...I heard that, I'm one for biting my nails, and my kids are one for biting their nails, they say it's a nerve thing, I don't know. But it's round the skin, and I read on Facebook... the guy was biting his nails, and roond the skin, like these bits, and he nearly died. Nearly died, it went into 'septis,' so it did. That's gave me the fright o' my life. Don't get me wrong, I'm still biting them. But no' as much, know what I mean?

Carol, 42 FG7 Organisation for disadvantaged parents

I can remember when I was younger... one of my parents' neighbours, now he was a man in his forties, went into hospital... for a bowel operation, and he took, well probably it was sepsis, and he died within a matter of days. And, they just hushed it all up at the time... it was just a, one of these things, and he was quite young. He was a strong, fit man...

The man's sister actually was in the NHS herself and she was really upset. She thought they were covering up, at the time, what had happened with him. But, he had a... nick in his bowel, something happened, and probably was something like sepsis and in those days, that was that. It's just, end of.

LR: So, it's probably something that did used to happen to people, but—

Bill: It did happen, but it wasn't reported.

Bill, 53 FG17 Group of individuals affected by sepsis

Gary...this phrase 'could it be sepsis?' This is… this is the phrase everyone's using now, when a child - or anybody's admitted to hospital showing symptoms.

June: Think… sepsis is the…

Gary: Think this is sepsis. And even ask, know, one of the specialists, the nurses, the doctors, whatever, like could this be sepsis? Because if they then sort o' run the five or six questions and say "Well it could be that." Then it's trying tae do it straight away. But don't wait for the six hours or eight hours or ten hours, and try tae second guess what it is. It's a simple question. And even, as you say, when I was in the hospital, my brother-in-law passed away in August, and even DGH, then there was signs on the wall 'Could this be sepsis?' ... and it's that kinda awareness which, because we're in this sort o', know, circle, then we know it. And because I look out of for these kinda things, but Mr and Mrs Smith who walk past, then, would they notice that, and would they ask that question? I don't know. I don't know.

June: Probably not, but I think… the educated public do think of it, 'cause we get… at work, we get… phone calls, not often, but occasionally like from carers, you know, like council carers that have maybe been on a course about sepsis, so they go in and they see a patient and the… they maybe notice something different, so they'll phone up the doctor and say "Oh, I think they could be sepsis."

Gary: Because that is your line of work. That is… aye.

June: That's my… exactly, yeah. I think within groups o' society in, you know, whether it's medicine, nursing, caring, that type o' thing, I think the message is getting out there... people are thinking 'sepsis.' I don't know…

Gary: Even once I started back work... I work for Tesco – maybe about twelve hundred, fifteen hundred people in our place. And I'd say 90% o' people who ask me what happened to Rhys and I told them, didn't have a clue what sepsis was...they would say septicaemia, 'cause some o' the older ones…

June: I had to… I know, but I mean, me as a nurse and work… and working as a general practise nurse as well, I had to Google what's the difference between sepsis and septicaemia... because I thought, 'is this a new thing, is this a new disease?' And we were, you know, we were talking at work and one o' the doctors at my work, she was like that, "I was like that as well," she said "I always just called it septicaemia," ...

LR: Well it's interesting what you say there about the word 'new,'... I've been looking at, the background, actually the word itself date backs to Hippocrates... the condition is actually no different to it always was, you know, it's as old as life itself. But it seems as though using 'sepsis,'… it's almost a kind of attempt to get people to think differently about it, to think about it as something new.

Gary: More catchier, aye.

June: That's what that man said to us, from that 'FEAT', he says "It's been rebranded."

Gary: Aye.

June: And that's exactly what it is, it's been rebranded… and if that's going tae help people, fantastic, call it something else, that's great.

June 45 and Gary 51, FG15 Group of individuals with lived experience of sepsis

...it was only when I asked my surgeon how ill I actually was that that was the first time he used the word "sepsis" and while I was vaguely aware of what sepsis was, I didn't realise the impact that it could have, and how quick that impact could be... and, I'm not sure that it actually would've been had I not asked... the only visitors that were permitted were my parents and my husband and they were never told I had sepsis or severe sepsis. And, as I say, it was only when I asked my surgeon to score me, in the way that they do, you know, "How's your pain?" I said, "From zero to ten, where…" how ill was I? And, at that point, he said, "You've got severe sepsis, multiple organ failure, etc." So, at no point was it mentioned...during the time there. And, that was quite late on.

Linda: I think, maybe there's a perception among doctors that, "Patients aren't going to understand if I use technical language." But, when I said to my surgeon, the consultant, you know… how ill have I been? And, he said, "Why do you want to know that?" And, I said, "Because it will give me some perspective." And, at that point, he became very, he was a very decent doctor, he treated you like a person, but at that point, he became very

professional and, "Right, you have this, this, this, this, and this…"... but, I don't think he would've said that, had I not asked.

LR: So, did you feel there was almost a kind of reluctance to… not that anything was being hidden from you, but... it wasn't perhaps sort of within the sort of comfort zone of just talking freely about…

Linda: I don't think they thought it was important… I don't think they thought it would've made any difference to me to know what I had... whereas it did. It made a huge difference to me. If I'd been discharged from hospital, having been, you know, so ill that I actually said to the doctor, "Just give me something. End it. Because I can't cope with this." If I had come out not knowing what it was, I still wouldn't have been aware of sepsis, and the impact it can have. I would just have thought it's an infection.

Well, I managed to get it twice... I had a C-section for twins, and about a week after that, and as I said, I didn't know anything about sepsis, and my husband works in hospitals and he was wheeling me up and down from the NICU to see my babies and there were all these posters for sepsis and saying, "Think sepsis. Say sepsis." And, I happened to say to him, "What is sepsis?" Having never heard of it before, and him being a, from a medical background gave me a very sort of graphic sort of definition of what sepsis was and explained, you know, it's… "It's when you get an infection, but your body has an odd reaction to it, and it's really dangerous and ... people can die of it really quickly, and so it's difficult to catch," etc.

So, he told me all this and then, I don't know, forty-eight hours, seventy-two hours later, and I was actually down in intensive care and I didn't feel right, but it was kind of, I was on a lot of drugs 'cause of the, all the sorts of things that were going on. However, I'd just about collapsed in the intensive care, in the NICU and they sort of wheeled me back up and it was all… I realised, nobody had said "sepsis" at that point either, and I certainly didn't, it wasn't anything I was thinking of. But, I could tell that there was a lot of people in the room, and they were all quite sort of concerned and I knew that I'd been put on the sepsis, is it the Sepsis Six Pathway or something? Sepsis Pathway? And, because I had asked my husband just a few days before what sepsis was, when I heard I was on this Sepsis Six Pathway or whatever, I… I was really quite worried because I was saying, "Have I got sepsis? Have I

got sepsis?" And, at that point, they didn't say yes, they didn't say yes. So, anyway, I was put down to sort of intensive care twenty-four hour observation and they kept me on IV antibiotics for, I think seventy-two hours, three days, but really twenty-four hours later, I felt, I—better. I mean, given I just had a C-section and my babies were ill and there was a lot going on.

So, as far as I was concerned that was kind of over and done with and then about three months later when I was home, and I just got my girls home, they were on oxygen, so there was quite a lot going on, and I started to feel unwell and I knew that it felt exactly like I felt when I was in the hospital and I was just at home with my mum who is seventy with my babies and my husband was at work, and I had to get my older son to the nursery and thought, 'If I can just get him to nursery…' And, I didn't want to worry my mum, and I was also thinking, 'I don't know what she's gonna do because both girls were on oxygen and they were particularly vulnerable and they weren't feeding well, and there was a whole load of stuff going on. So, anyway, I phoned my husband and he sort of said, you know, "You need to…" And, by that point, I'd gone into rigors and I really knew that it was the same as last time. So, he said, "Phone an ambulance." So, I ended up back in hospital and this time they gave me all the IV antibiotics for ten days.

Linda and Kerry, FG Group of individuals with lived experience of sepsis

Andrea: You do feel sorry for… I mean, if we make a mistake in our work then it's…

Marie: I mean, if it's hard for them to diagnose, how are we meant to diagnose it? It's… you know, it's quite a…

Andrea: But then human error is human error, everybody's human and making… and if they've been on a long shift and they're looking after multiple…

Erica: But then it's why has the nurse not told the doctor? Why has the nurse not pulled that doctor back and said…? So, it's a shame for that doctor (Andrea: It's usually a chain of things, isn't it?) because actually… it was everyone's responsibility to look after that child, not just that one doctor. But then you don't know what actually happened, what actually went on.

Andrea, 39; Erica, 31; and Marie, 43 FG14 Library story and music group

Susie: It's maybe, wi' these cases, you know, where children have died, it's maybe a coping mechanism when you're grieving as well to be able to say, you know…

Unidentified voice: It was their fault.

Susie… it was their fault because there will be... those parents, I mean they've taken their kid to the hospital twice... the parents'll probably still be saying, "I shoulda, I should've refused to leave... or I shoulda went a third time."... and I'm not saying it is their fault but any parent would blame their self in that situation.

Mandy: Of course you would.

Audrey: I think to have any sort of closure you need to have something (yeah) to say that's where the buck stops... shut a door on it and you can then move on from that.

Mandy: And also if there's a reason behind it you can work out the reason to try and stop it happening.

Susie: And that's why... that William Mead story, you know, his mother's done all these talks around the country to raise awareness and that'll be another way o' helping her deal with it... and I think I'd read somewhere that she said, you know, "If all this saves one child from sepsis then, you know, it's worth it." So that's a way of her coping wi'
what happened to her son I think as well.

Susie, 33; Mandy, 37 and Audrey, 38 FG20 Baby café

Catherine: I wonder whether things like social media and that have an effect as well kinda thing 'cause I think a lotta the time all you see on these things... are negatives... you hear about the one sad case and that preys on your mind, whereas there's probably been a thousand kids that have not got it, but you don't hear that and I think that's the case in all kinda papers and social media. But I think social media probably for our generation and

younger is such a kinda almighty force kinda thing that that probably does have a big impact on…

LR: ...so do you think social media potentially has more impact on the traditional news, newspapers and television news?

Sarah: I would say with younger people yeah... I spend a lotta time on social media and stuff like if I'm about and then a lot of people in my work they're more younger as well, they're always on Facebook, Instagram and... they share like lots of posts as well and it's mostly like negative stories as well. Like not all of them but lots of these horror stories and stuff and you see them sharing it and they've got like millions of shares and stuff.

Rachel: That's kind of the way it's written… it's never giving you a balanced view... it's always just some kind of attention grabbing… that makes you go 'gosh'…

Catherine, 38; Sarah, 27; and Rachel 31 FG10 Parent and child exercise group

Susie: I was first aware of (sepsis) when my oldest daughter was born. There was a wee boy in the press, William Mead he was called. And then he died just after my wee girl was born 'cause I remember being in floods of tears at the news at the thought of this wee boy dying. And I started following his mum on Instagram. And I later unfollowed her because all her posts upset me, which sounds really horrible but it's just the way I felt at the time. And that really scared me that it could just happen. And then a girl that I work with, one of her friend's husbands like banged his leg on a filing cabinet or something and he had like a scab and then the next minute it was sepsis and he died. So it's just like not knowing, you know, just something ordinary every day, you know?

LR: ...when you say that her posts upset you, that's interesting. So what aspect of it, d'you think, was upsetting?

Susie: It was, 'cause her Instagram handle was something like 'a mother without a child' or something... and I think it was just, you know... she was a women that had a child slightly older than mine, and I was quite anxious when my older daughter was born about, you know... that she could suddenly die in the night, you know, and it was really for my own… she was posting a lot about, you know, not having a child and I think she subsequently does

have another child now... and it was more for my own kinda mental health if you like, 'cause I just, you saw, I saw these things and just wanted to cry when I saw them.

Audrey: I think when you have children as well you're so much more emotional … and you can relate everything back to how you would feel if that was you.

Susie: Well I mean... I wouldn't have batted an eyelid at that story... before and I don't mean that in a heartless way, I just mean you see things in the news all the time but, you know, since I've had children any stories about children being very ill or dying, you know, are really quite triggering, you know, so that was what upset me about it more.

LR: …having a look at the kind of symptoms it highlights in some of the campaigns, I just want to know what you think about these. So, the symptoms it tells you to look for: high or low temperature, shivering, fast heartbeat, fast breathing. And then beyond that, feeling dizzy or faint, confusion, diarrhoea, nausea and vomiting, slurred speech, muscle pain, breathlessness, not passing as much urine as normal, cold or blotchy hands and feet, and loss of consciousness. Tell me what you think about that list of symptoms.

Scott: Sounds like 90% of the stuff they're getting.

Gillian: A virus, aye.

Scott: Until they can talk, it's very hard tae get a lot of that out.

LR: Do you think that list... would it be helpful to you as a parent?

Katie: Probably not 'cause it is just…

Barbara: Vague.

Katie: Uh huh. It's no', there's nothing… specific.

Scott, 36; Gillian, 29; Katie, 23; and Barbara, 34 FG12 Group of pre-school parents

Irene: It's hard to kind of judge sometimes at what point, you know?

Erica: Yeah, at what point do you phone someone? What point do you get someone involved?

Irene: Like, if they had fever and their hands and feet were cold then that would signal to me that there is something wrong wi' them.

Erica: Unless, are their hands and feet always cold? There are cold kids, stuff like that.

Irene: Well, you know, if I knew that, aye.

Erica: Isn't it? And—

Irene: But there's nothing – like the meningitis thing you knew, if there was a rash.

Erica: But it's if their hands are freezing cold, so they're really shut down.

Irene: Aye, sort of—

Erica: The bloods not getting tae it and they're ice-cold.

Marie: See, that would resonate with you then, if they said to you, if your kids hands are really, really freezing cold, then you would go, "Oh, that is a…" something that you wouldn't normally see in a normal…

Irene: But how far into the infection are you then?

Erica: Aye, you're not very well at that stage! (laughter)

Irene: Too late. Do you know what I mean? Where is the line? Where is the…? There doesn't seem to be a clear-cut…

Erica: There's not… there's not that.

Andrea: You've just got to use your instincts, haven't you?

Irene: You know, maybe once they've got to their hands and feet are cold, they're past the stage o' anything that's gonnae help them.

Erica: No, no, not at all. No, they can be in full-blown sepsis and still recover from it. But they're not doing good at all. But if their hands and feet are ice cold, there's just, you know, you can still get, there's still, you know, it is, it's an ambulance to hospital but, you know, they can still be saved.

Andrea: Antibiotics at that point.

Erica: Oh, it's, yeah, it's intensive care, it's intubated, it's having them taken over, completely managed.

Erica, 31; Irene, 56; Marie, 43; and Andrea, 39 FG14 Library story and music group

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