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Complete List of Authors:	Rawson, Timothy Moore, Luke Hernandez, Bernard Castro-Sánchez, Enrique Charani, Esmita; Imperial College London, Centre for Infection Prevention and Management Ahmad, Raheelah; Imperial College London, National Centre for Infection Prevention and Management, Faculty of Medicine Holmes, Alison; Imperial College London, National Centre for Infection Prevention and Management, Faculty of Medicine
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Missed opportunities for engaging patients in decision making on infection management in secondary care: A qualitative investigation

*Timothy M Rawson^{1,3}

Luke SP Moore^{1,3}

Bernard Hernandez²

Enrique Castro-Sanchez¹

Esmita Charani¹

Raheelah Ahmad¹

Alison H Holmes^{1,3}

1. National Institute for Health Research Health Protection Research Unit in Healthcare Associated Infections and Antimicrobial Resistance, Imperial College London, Hammersmith Campus, Du Cane Road, London. W12 0NN. United Kingdom.
2. Centre for Bio-Inspired Technology, Imperial College London, London, South Kensington Campus, Exhibition Road, SW7 2AZ. UK
3. Imperial College Healthcare NHS Trust, Du Cane Road. London. W12 0HS. UK

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***Corresponding author:**

Dr Timothy M Rawson, National Institute for Health Research Health Protection Research Unit in Healthcare Associated Infections and Antimicrobial Resistance, Imperial College London, Du Cane Road, London. W12 0NN. United Kingdom.

Email: timothy.rawson07@imperial.ac.uk

Telephone: 02033132732.

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Abstract

Objective: To understand patient involvement in decision making around infection management in secondary care and the potential consequences associated with current practices.

Design: A qualitative investigation using in-depth semi-structured interviews

Participants: Fourteen members of the public who had received antimicrobials from a secondary care pathway in the preceding 12 months in the UK were identified for recruitment. Ten agreed to participate. Six participants had experience of infection management as a hospital in-patient with the remaining participants all having received antimicrobials from other secondary care pathways across a variety of South-East England healthcare institutes. These included the Emergency Department (ED), urgent care centres (UCC's) or consultant led out-patient clinics.

Results

Participants reported feelings of disempowerment during episodes of infection in secondary care. Information is communicated in a unilateral manner with individuals 'told' that they have an infection and will receive an antimicrobial (often unnamed), leading to loss of ownership, frustration, anxiety and ultimately distancing them from participation in decision making. This poor communication drives individuals to seek information from alternative sources, including on-line, which is associated with concerns over reliability and individualisation.

Failures in communication and information provision by clinicians in secondary care influence individuals' future ideas about infections and their management. This alters their future actions towards antimicrobials and can drive prescription non-adherence and loss-to-follow-up.

Conclusion

Current infection management and antimicrobial prescribing practices in secondary care fail to engage patients in the decision making process. Secondary care physicians must not view infection management episodes as discrete events, but as cumulative experiences which have the potential to shape future patient behaviour and understanding of antimicrobial use.

Trial registration: The study protocol was reviewed by the West London Regional Ethics Committee (REC) and considered to meet criteria for monitoring under service evaluation governance structures (*REC 15/LO/1269 / ICHNT Service Evaluation SE113*).

Strengths & limitations

- This study adds to the paucity of evidence surrounding the patient experience of infection management in secondary care pathways
- Our findings provide evidence to facilitate the development of interventions to address the findings described within our manuscript at a local level
- This study was an in-depth investigation of a small number of individuals who have been managed for infections within secondary care pathways within the last 12 months. Larger, investigative approaches are required to triangulate and confirm the generalizability of our findings to a wider population

Introduction

Shared decision making (SDM) is believed to optimise the patient-physician relationship and improve patient-reported outcomes [1]. The aim is to collaborate, mutually arriving at a decision on the best management or support system for that individual patient [2]. The importance of SDM has been emphasised globally. In the United States legislation has been passed, which prioritises SDM as a delivery system to allow patients to make informed treatment decisions [3]. Similarly, in the United Kingdom a variety of national interventions have been implemented across healthcare pathways to promote the uptake of SDM [2]. In a recent systematic review, the Cochrane group supported the potential for interventions promoting SDM to impact on antimicrobial prescribing in the treatment of respiratory tract infections in primary care demonstrating reductions in prescribing of up to 40% [4].

Evidence to support physician and patient desire for increased collaboration in the decision making process surrounding prescription of medications within secondary care pathways is now emerging [5]. This has supported by evidence that in other specialties, such as mental health and oncology, that SDM in secondary care has the potential to improve patient outcomes [6][7]. Despite this growing understanding of the potential benefits of SDM and its impact on antimicrobial use in primary care, there remains a paucity of evidence in secondary care describing the patient experience of engagement in decisions surrounding infection management and antimicrobial use. With antimicrobial resistance (AMR) now a leading political issue and major patient safety concern antimicrobial stewardship (AMS) programs have been introduced at local and international levels in an attempt to optimise the use of antimicrobials, aiming to achieve the best therapeutic outcomes whilst minimising harmful consequences [8][9][10][11][12][13][14]. Whilst most interventions have focused primarily on health care providers, the consequences of current patient engagement interventions (mainly via public health interventions) have been more difficult to assess [15][16] [17–26].

The aim of this qualitative study was to investigate patients' current experience of infection related decision making processes across secondary care pathways and map how these experiences influence their future engagement with infection management and antimicrobial use. Through generalization of our findings from this in-depth investigation we hope to inform future patient-focused interventions to

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2
3 address the issues identified and allow assessment of their impact on patient outcomes and AMR
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5 within secondary care pathways.
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10 **Method**

11 *Participant recruitment*

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13 In September 2015, 14 members of the public who had received antimicrobials from a secondary care
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15 pathway in the preceding 12 months in the UK were identified for recruitment (through *Cherry*
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17 *Picked, London, UK*) (four individuals declined to participate, giving no reason for this). Recruitment
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19 criteria are provided in **panel 1**. Individuals who had only received antimicrobials in the critical care
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21 setting were not invited for interview.
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26 Participants attended semi-structured group interviews, at Imperial College London (UK). This small
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28 sample size was selected to optimise our interview group numbers and allow in-depth analysis of
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30 individuals views, thus providing a richness to the data available for analysis [27]. All individuals
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32 were consented prior to participation. Participants completed a questionnaire collecting demographic
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34 data and previous healthcare experiences. A validated screening tool was included to assess the
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36 participant's level of health literacy [28]. A reimbursement of £65(\$100) was provided to participants
37
38 for their time.
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41 *Participant interviews*

42
43 The group was divided into two equally representative groups. Two healthcare professionals (TMR,
44
45 LSPM), following a pre-determined interview schedule (supplementary data 1; developed from a
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47 critical analysis of the literature), facilitated a 120 minute semi-structured interview. This aimed to
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49 explore participants' experiences of their involvement in decision making surrounding antimicrobial
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51 use in secondary care pathways. Two independent observers (one lay and one HCP; BH & ECS)
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53 directly observed the interviews and were asked to make notes of key observations. These were used
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55 to help triangulation of initial codes during analysis.
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Data analysis

Interviews were audio recorded and transcribed verbatim (using anonymous participant identifiers). Thematic analysis of transcripts was performed using a mixed deductive and inductive approach [29]. Two authors (TMR & LSPM), reviewed the focus group transcripts independently to allow initial codes to be generated from differing viewpoints [30][31]. The independent observers' comments were considered with the aim of complementing areas of reflexivity caused by the analysts' own prior experiences at this point of the analysis [32]. After familiarisation with the transcripts, the researchers independently coded the data generating a list of emerging categories from the codes addressing the aims of the study design. After meeting and agreeing on key categories and themes within the text, the two analysts independently preceded to systematically cross-review the text, coding passages based on these agreed codes and categories. On review, any discrepancies were discussed and consensus reached. Examples of key opinions and ideas from the text for each main theme identified were then charted to allow mapping and interpretation of the results [30].

Ethical approval

The study protocol was reviewed by the West London Regional Ethics Committee (REC) and considered to meet criteria for monitoring under service evaluation governance structures (*REC 15/LO/1269 / ICHNT Service Evaluation SE113*).

Results

Median age of participants was 52 (21-69) years with an equal gender divide. Six participants had experience of infection management as a hospital in-patient (in the non-critical care setting) with the remaining participants all having received antimicrobials from other secondary care pathways across a variety of South-East England healthcare institutes. These included the Emergency Department (ED), urgent care centres (UCC's) or consultant led out-patient clinics. Two out of ten participants were identified on screening as potentially having a low health literacy [28].

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3 Following thematic analysis, 92 individual codes and 12 categories were derived from the transcripts.
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5 Three interlinking themes were identified (**figure 1**). **Table 1** summarises key quotes informing the
6
7 individual categories and themes referred to within the text below. The participants described a failure
8
9 in communication and information provision from infection clinicians and support staff in secondary
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11 care which subsequently influences the individual's future ideas about infections and their
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13 management. This alters the individual's future actions towards infections and antimicrobials and can
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15 drive non-adherence to prescribed antimicrobial regimes and loss-to-follow-up after discharge from
16
17 secondary care.

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20 Participants described their experiences of being diagnosed with an infection in secondary care as one
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22 where they completely lose ownership of their condition. Control of their illness is taken over by a
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24 multitude of healthcare professionals (HCPs). Recurring instances were identified where HCP
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26 communication with patients became unilateral when antimicrobial decisions were being made, with
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28 patients being “*told*” information, often devoid of key aspects such as names of medications, durations
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30 of treatment and prospective plans about time courses and potential escalation / de-escalation of
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32 therapy. This led to a significant amount of anxiety and frustration as the individual searched for
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34 answers.

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36
37 *“I was told ‘you have an allergy [to penicillin], take this instead’ – Tell me what I am taking*
38
39 *and exactly what it is going to do for me!”* [65 year-old male]

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42 Moreover, in many cases participants did not feel as if they were involved in the decision making
43
44 process around their infection management with two-way communication with healthcare
45
46 professionals perceived as absent. When questioned about this the participants’ answered:

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48
49 Researcher: *“What involvement in the decision making around your diagnosis, discussing the*
50
51 *need for antibiotics, and deciding what was in your best interest did you have?”*

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54 30 year-old male: *“none”*

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56
57 Researcher: *“How much power did you feel like you had?”*
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Group: “none”

As well as HCP communication with patients, participants reported becoming frustrated by communication between HCPs. This is centred primarily on the way in which information about infections is communicated from secondary care doctors to primary care doctors on discharge from hospital. Whilst patients are provided with a discharge summary of their stay on leaving hospital, it was perceived that this often neglected information about their infection and the treatment which they received whilst in the hospital. Participants’ reported that they were often forced to communicate this information directly with their primary care physician on follow up visit or were otherwise lost to follow up after discharge due to lack of clear communication pathways.

The current volume and quality of information provided to individuals by HCPs in secondary care causes problems for patients as it is often poorly explained, with medical terminology routinely used. This leads to a feeling of dis-empowerment with individuals frustrated that they then have to “*go away and research it [their condition] themselves*” [23 year-old female]. Fear and anxiety follows when participants see serious side-effects of treatment “*like risk of death [and] no one has mentioned that to me!*” [30 year-old male]. This in-turn causes frustration as participants compare delivery of information on infections and antimicrobials to that provided for operations and medications for chronic disease, such as hypertension. In this example, patients are provided with explanations of their procedure/condition, their management, and potential complications which may arise and how these will be dealt with. In contrast, information on infection management is seen as a “*reactive*” process where information is only often provided once complications have occurred. Furthermore, patients are often unaware of the timeline for their treatment and the potential complications. This lack of clarity drives individuals to stop treatments early or potentially ignore side effects experienced due to false assumptions and misinformation.

Participants reported that this failure in communication about infections and antimicrobials drives them to seek information from a wide range of sources, often with varying degrees of quality. Participants commonly sought information independently due to “*difficulties in accessing [healthcare professionals]*” and the “*[time] pressures of work and children*” [69 year-old male]. A number of

Patient engagement in infection management

avenues were preferred such as the internet, information leaflets provided with medications and local pharmacies. Individuals will seek out recommended or official NHS sources of information which they believe that they can trust to provide them with information on their infection or treatment. Whilst these sources are seen as helpful, patients still prefer to discuss their infection and its management with a HCP as this provides “*individualised*” information compared to the “*standard-reply*” provided by alternative sources [69 year-old male]. This is because the information provided is seen as being based on the patient’s own specific situation and issues. Furthermore, the HCP is a “*trusted*” source being viewed as an “*expert*” [69 year old male].

The participants clearly described how these individual experiences of poor communication and information provision influence their future ideas and actions towards infection management both in secondary care and in the community. Influences were described from three sources; personal understanding / experiences, understanding by proxy, and understanding through the media.

For example, one personal experience was described by a participant who was told that he had an allergy to penicillin and told that he would be given a “*weaker*” type of antibiotic for his infection. When this was perceived not to be effective at clearing up the infection after two days, he stopped taking his medication as:

“You know the weaker ones [antibiotics] never seem to clear the infection up. They are not as strong so they don’t clear it up. The infection lasts longer” [60 year-old male]

This subsequently led to the participant having to return to secondary care for further treatment of his infection due to the poor information provision and engagement in the decision process surrounding his infection.

The media’s role in developing the participants’ understanding of infection management was explored by the group. This was through the portrayal of stories about complications of treatment and the dangers of antimicrobial resistance. This created fear and mistrust of medical professionals within our participant group, and caused participants to be “*cautious*” when interacting with medical

professionals at they are perceived to “*not say the full story*” [21 year-old, female]. This distrust was reported as driving non-adherence to therapy in the community by several members of the group.

Discussion

Within our participant group, individuals felt detached, frustrated and disempowered from involvement in decision making about their own infection management within secondary care. The consequences of the failure of HCP communication and information provision reached beyond secondary care, influencing the ideas and actions towards infections and antimicrobials during future healthcare interactions along a number of different pathways. This fosters feelings of frustration and anxiety during an individual’s journey through complex secondary care pathways and potentially drives non-adherence to prescribed antimicrobial regimes and loss to follow up after discharge. These findings highlight the need for specialists in secondary care to not view infection management episodes as discrete events, but as cumulative experiences which have the potential to drive future non-adherence to prescribed antimicrobial regimes and thus the promotion of antimicrobial resistance (AMR).

Importantly, HCPs must appreciate that engagement in decision making surrounding infection management may have an influence on future patient actions towards infections and antimicrobial use. These actions can be influence by personal experiences along with those of friends and family and what is described in the media. The way in which we communicate information to patients was reported as the most important aspect in our participants’ current experiences of infection management in secondary care and was the largest influence on future actions in terms of adherence to prescribed antimicrobial regimes and healthcare seeking behaviours. Participant perception of communication in secondary care infection-related pathways is of a unilateral process which does not invite patient participation. Greater emphasis needs to be placed on HCPs moving away from the decision-maker role [2] into a more bilateral structure. Difficulties such as time pressure on the HCP and the patient is perceived as a key factor by participants and must be taken into account when

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3 designing interventions to help facilitate improved communication and involvement in the decision
4 making process. The way that these interventions are designed must be mindful of health literacy,
5 ensuring that the information provided to patients is understandable. Within our small cohort, two of
6 ten participants met screening criteria for health illiteracy. Within the UK, it is estimated that up to
7 43% of the adults cannot understand currently available health information [33]. Therefore as well as
8 improvements in our approach to communication with patients, consideration of the wording and type
9 of health information supporting this communication is vital to allow patient investment in the
10 decision making process.
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15 Within our cohort, participants felt strongly that the choice of information provided about their
16 infection and antimicrobial therapy should be dictated by the patient's preference. Their focus was not
17 primarily on the end decision of whether or not to treat but on feeling involved in the process of
18 decision making. They described a belief that if a trusted clinician felt they had an infection which
19 required antimicrobial therapy then this is appropriate. This is supported by Edwards and colleagues,
20 who describe placing the focus of SDM primarily on involving the patient in the decision making
21 process, rather than on who actually makes the final decision on management [34]. Our participants
22 supported this by describing how they do become frustrated and distrusting of the recommended
23 therapy when supporting information about the infection and the proposed management is perceived
24 to be withheld from them.
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41 Participants currently view information provided about infections and antimicrobials as reactive in
42 nature with information only provided after a side effect occurs or the patient fails to respond to a
43 certain type of antimicrobial and therapy is escalated. Individuals want proactive information to help
44 them understand what they are receiving, what to expect and what the plan is if the treatment doesn't
45 go to plan. This allows them to feel "*prepared*", "*confident*" and invested in the healthcare they are
46 receiving. This is challenging for antimicrobial prescribing in secondary care which is often an acute
47 event, often requiring rapid decision making and only a short duration of therapy [35]. Moreover, this
48 highlights a key area of misunderstanding surrounding infections and antimicrobial therapy in our
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3 cohort which has been driven by previous experiences of poor communication and information
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5 provision within secondary care.
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8 This qualitative analysis aimed to map the current experiences of patients in antimicrobial decision
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10 making but it does have limitations. Group facilitation within our study was carried out by two HCPs,
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12 which may have influenced socially desirable participant responses to certain questions. To address
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14 this dynamic between interviewer and interviewee, two observers' comments were also considered
15
16 during initial coding to highlight where the interviewer's position may have directly influenced
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18 individual responses. For example, during discussion of participants perceptions of doctors attitude
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20 towards prescribing antimicrobials, one participant apologised after voicing an opinion about doctors
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22 simply wanting to
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25 *"...sign the prescription and get rid of the patient"* [69 year-old male].
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28 The noted anxiety about offending the HCP may have influenced other participants voicing their true
29
30 opinion on the matter. Finally, whilst small, this in-depth study provides key themes for future larger
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32 studies to explore the generalizability of, and inform the design and evaluation of appropriate
33
34 interventions.
35

36 37 38 **Conclusion** 39

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41 Within secondary care specialists are failing to engage their patients in the decision making process
42
43 surrounding infections and their management. This ultimately leads to misinformation, frustration and
44
45 anxiety during an individual's journey through secondary care pathways and potentially drives non-
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47 adherence to prescribed antimicrobial regimes and loss to follow up in the community. Clinicians
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49 must stop seeing infection episodes as discrete events and approach them with the understanding that
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51 previous negative experience is currently driving non-adherence to prescribed antimicrobial regimes
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53 and potentially disrupting follow up of patients post discharge from secondary care. Poor
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55 communication by HCPs and lack of quality information provided are the two leading causes for this,
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57 often driving individuals to seek standard information from untrusted, online sources. These findings
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Patient engagement in infection management

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3 have the potential to translate into other fields of secondary care where poor engagement in SDM also
4 exists and benefits in patient outcomes through SDM interventions are beginning to be reported. We
5 call for the development of clear and pragmatic mechanisms to provide patients with the proactive
6 information they require about their infection and its management and engage them in a shared
7 decision making process.
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For peer review only

Contribution statement

All authors contributed significantly towards the planning this study and production on this manuscript. TMR, LSPM, BH & ECS ran the semi-structured interviews & were involved in data analysis. TMR drafted the initial manuscript with all authors contributing significantly towards its finalisation for submission.

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Competing interests

AHH & LSPM have consulted for bioMérieux in 2013 and 2014 respectively. All other authors have no conflicts of interest to declare.

Data sharing

There is no additional, unpublished data available from this study.

References

- 1 Shay L A., Lafata JE. Where Is the Evidence? A Systematic Review of Shared Decision Making and Patient Outcomes. *Med Decis Mak* 2015;**35**:114–31. doi:10.1177/0272989X14551638
- 2 Coulter A, Collins A. Making Decision-Making a Reality: No decision about me, without me. 2011. http://www.kingsfund.org.uk/publications/nhs_decisionmaking.html
- 3 Frosch DL, Moulton BW, Wexler RM, *et al.* Shared decision making in the United States: policy and implementation activity on multiple fronts. *Z Evid Fortbild Qual Gesundheitswes* 2011;**105**:305–12. doi:10.1016/j.zefq.2011.04.004
- 4 Coxeter P, B Del Mar C, McGregor L, *et al.* Interventions to facilitate shared decision making to address antibiotic use for acute respiratory infections in primary care (Review). 2015.
- 5 Mohsin-Shaikh S, Garfield S, Franklin BD. Patient involvement in medication safety in hospital: An exploratory study. *Int J Clin Pharm* 2014;**36**:657–66. doi:10.1007/s11096-014-9951-8
- 6 Duncan E, Best C, Hagen S. Shared decision making interventions for people with mental health conditions. In: Duncan E, ed. *Cochrane Database of Systematic Reviews*. Chichester, UK: : John Wiley & Sons, Ltd 2010. doi:10.1002/14651858.CD007297.pub2
- 7 Coyne I, O’Mathúna DP, Gibson F, *et al.* Interventions for promoting participation in shared decision-making for children with cancer. In: Coyne I, ed. *Cochrane Database of Systematic Reviews*. Chichester, UK: : John Wiley & Sons, Ltd 2013. doi:10.1002/14651858.CD008970.pub2
- 8 WHO. Antimicrobial Resistance Global Report on Surveillance 2014. *World Health Organ* Published Online First: 2014. <http://www.who.int/drugresistance/documents/surveillancereport/en/>
- 9 European Surveillance of Antimicrobial Consumption. Report on Point Prevalence Survey of Antimicrobial Prescription in European Hospitals , 2009. 2009.
- 10 Department of Health, Department for Environment Food and Rural Affairs. UK Five Year Antimicrobial Resistance Strategy 2013 to 2018. 2013;:43. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/244058/20130902_UK_5_year_AMR_strategy.pdf
- 11 Howard SJ, Hopwood S, Davies SC. Antimicrobial resistance: a global challenge. *Sci Transl Med* 2014;**6**:236ed10. <http://www.ncbi.nlm.nih.gov/pubmed/24828073>
- 12 Ashiru-oredope D, Sharland M, Charani E, *et al.* Improving the quality of antibiotic prescribing in the nhs by developing a new antimicrobial stewardship programme: Start smart-then focus. *J Antimicrob Chemother* 2012;**67**:i51–63.

- 1
2
3 13 CDC. Core Elements of Hospital Antibiotic Stewardship Programs. 2014;:1–
4 25.<http://www.cdc.gov/getsmart/healthcare/implementation/core-elements.html>
5
6 14 Cruickshank M. *Antimicrobial stewardship in Australian hospitals*. 2011.
7 [http://www.safetyandquality.gov.au/wp-content/uploads/2011/01/Antimicrobial-](http://www.safetyandquality.gov.au/wp-content/uploads/2011/01/Antimicrobial-stewardship-in-Australian-Hospitals-2011.pdf)
8 [stewardship-in-Australian-Hospitals-2011.pdf](http://www.safetyandquality.gov.au/wp-content/uploads/2011/01/Antimicrobial-stewardship-in-Australian-Hospitals-2011.pdf)
9
10 15 Davey P, Brown E, Charani E, *et al*. Interventions to improve antibiotic prescribing
11 practices for hospital inpatients. *Cochrane database Syst Rev* 2013;4:CD003543.
12 doi:10.1002/14651858.CD003543.pub3
13
14 16 Charani E, Edwards R, Sevdalis N, *et al*. Behavior change strategies to influence
15 antimicrobial prescribing in acute care: a systematic review. *Clin Infect Dis*
16 2011;53:651–62. doi:10.1093/cid/cir445
17
18 17 Benson K. Electronic data collection tools for quality improvement: antibiotic
19 utilization project. *AMIA Annu Symp Proc* 2003;:788.
20
21 18 Butler CC, Kinnersley P, Prout H, *et al*. Antibiotics and shared decision-making in
22 primary care. *J Antimicrob Chemother* 2001;48:435–40. doi:10.1093/jac/48.3.435
23
24 19 Edgar T, Boyd SD, Palamé MJ. Sustainability for behaviour change in the fight against
25 antibiotic resistance: A social marketing framework. *J Antimicrob Chemother*
26 2009;63:230–7. doi:10.1093/jac/dkn508
27
28 20 Goossens H, Guillemot D, Ferech M, *et al*. National campaigns to improve antibiotic
29 use. *Eur J Clin Pharmacol* 2006;62:373–9. doi:10.1007/s00228-005-0094-7
30
31 21 Huttner B, Goossens H, Verheij T, *et al*. Characteristics and outcomes of public
32 campaigns aimed at improving the use of antibiotics in outpatients in high-income
33 countries. *Lancet Infect Dis* 2010;10:17–31. doi:10.1016/S1473-3099(09)70305-6
34
35 22 Mangione-Smith R, Stivers T, Elliott M, *et al*. Online commentary during the physical
36 examination: A communication tool for avoiding inappropriate antibiotic prescribing?
37 *Soc Sci Med* 2003;56:313–20. doi:10.1016/S0277-9536(02)00029-1
38
39 23 McClure JB, Richards J, Westbrook EO, *et al*. Research Letter. *Am J Prev Med*
40 2007;33:436–7. doi:10.1016/j.amepre.2007.07.027
41
42 24 Prevention C for DC and. Gaining Consensus Among Stakeholders Through the
43 Nominal Group Technique. *Centers Disease Control Prev* 2006;:1–
44 2.<http://www.cdc.gov/healthyouth/evaluation/index.htm>
45
46 25 Welschen I, Kuyvenhoven M, Hoes A, *et al*. Antibiotics for acute respiratory tract
47 symptoms: Patients' expectations, GPs' management and patient satisfaction. *Fam*
48 *Pract* 2004;21:234–7. doi:10.1093/fampra/cmh303
49
50 26 Wutzke SE, Artist M a, Kehoe L A, *et al*. Evaluation of a national programme to
51 reduce inappropriate use of antibiotics for upper respiratory tract infections: effects on
52
53
54
55
56
57
58
59
60

- 1
2
3 consumer awareness, beliefs, attitudes and behaviour in Australia. *Health Promot Int*
4 2007;**22**:53–64. doi:dal034 [pii]r10.1093/heapro/dal034 [doi]
5
6
7 27 Berg BL. *Qualitative research methods for the social sciences*. 2001.
8
9 28 Morris NS, MacLean CD, Chew LD, *et al*. The Single Item Literacy Screener:
10 evaluation of a brief instrument to identify limited reading ability. *BMC Fam Pract*
11 2006;**7**:21. doi:10.1186/1471-2296-7-21
12
13 29 Eliot & Associates. All rights reserved. Guidelines for Conducting a Focus Group.
14 2005;:1–13.
15
16 30 Pope C, Ziebland S, Mays N. Analysing qualitative data. *Nurse Res* 2011;**18**:4–5.
17 doi:10.1192/bjp.109.458.163
18
19 31 Bradley EH, Curry L A., Devers KJ. Qualitative data analysis for health services
20 research: Developing taxonomy, themes, and theory. *Health Serv Res* 2007;**42**:1758–
21 72. doi:10.1111/j.1475-6773.2006.00684.x
22
23
24 32 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research
25 (COREQ): A 32-item checklist for interviews and focus groups. *Int J Qual Heal Care*
26 2007;**19**:349–57. doi:10.1093/intqhc/mzm042
27
28
29 33 Royal College of General Practitioners. Health Literacy. 2014.
30
31 34 Edwards A, Elwyn G. Inside the black box of shared decision making: distinguishing
32 between the process of involvement and who makes the decision. *Heal Expect*
33 2006;**9**:307–20. doi:10.1111/j.1369-7625.2006.00401.x
34
35 35 Start Smart - Then Focus Antimicrobial Stewardship Toolkit for English Hospitals
36 About Public Health England. 2015.
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3 **Panel 1.** Selection criteria for participation in the patient and public engagement module on
4 current experience of shared decision making on infection management across secondary care
5 pathways.
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10 Age 18 or older.

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12 Equal gender mix.

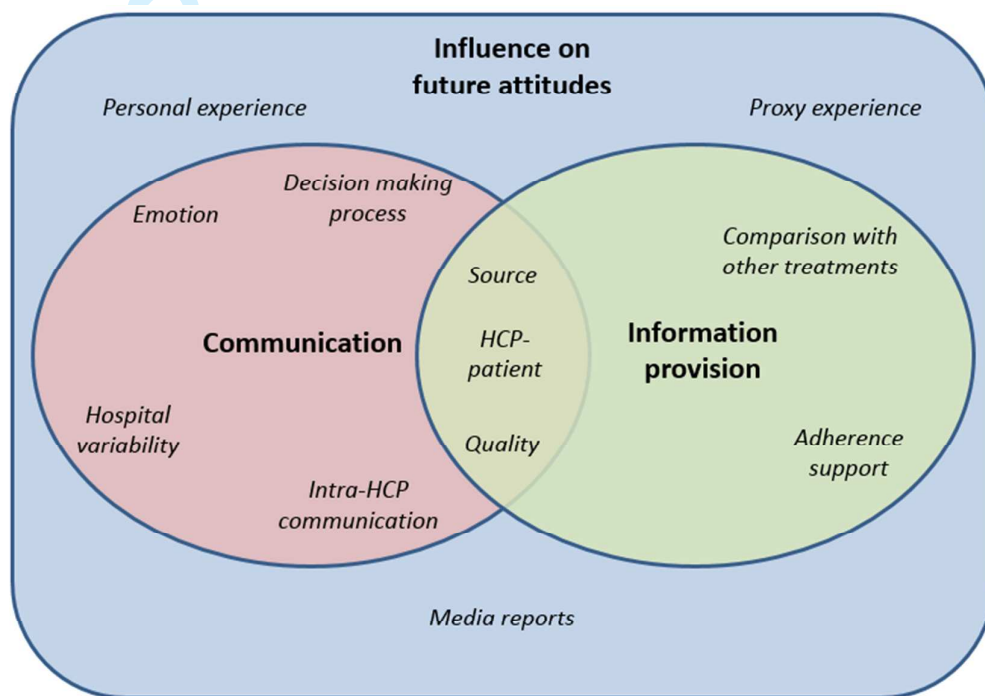
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14 Representative mix of ethnic backgrounds.

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16 Must have been treated with antibiotics in the secondary care setting (this could include, out-
17 patients, Emergency Departments, Urgent Care Centres or Ambulatory units) within the last
18 12 months. This should not have been level 2 or 3 care (e.g. high dependency units or
19 intensive care) only.*
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28 Preferable that they have been an in-patient in secondary care previously (but not an
29 exclusion criteria if the above criteria are all satisfied).
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36 * Individuals receiving antimicrobials in level 2 or level 3 care facilities only were excluded, given that they are
37 likely to have been critically ill at the time of antimicrobial prescribing.
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Figure 1. The distribution of themes and categories contributing to individuals’ experiences of decision making for infection management in secondary care pathways.



Legend. Healthcare professional (HCP) failures in communication and information provision influence individuals’ future ideas and attitudes towards infections and their management. This alters their future actions towards infections and antimicrobials and can drive non-adherence to prescribed antimicrobial regimes and loss-to-follow-up after discharge from secondary care.

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Table 1. An analytical framework developing categories and themes for patients' experiences of infection management in secondary care.

Quote	Category	Theme
<p>"I like to go and see the doctor... Online can't see me [sic]. Infection is a thousand different things and online can't confidently tell you, this is what you have..." [65 year old male]</p> <p>"...you are not an individual to them [corporate pharmacists]. In our case, I think we have the option to be sort of individuals. That is what I find lovely about our current pharmacy!" [69 year old male]</p>	Sources of information	Information provided
<p>"I think what the problem that I have experienced is, is that they will give you a leaflet to read and I will have to go and research it myself. This is rather than the doctor taking the time to sit down and talk about how it might affect you, what exactly is in it [the antibiotic] – you know a proper consultation. [23 year old female]</p> <p>"Rather than sitting down and taking the time to explain, because they use a lot of medical terminology that I do not know what they're talking about to be honest. I think that they need to take more time to be honest to sit down and make sure that the patient knows exactly what they are putting in your body and exactly what all the side effects were. Because I didn't know what I was reacting to..." [24 year old female]</p>	Quality of information	
<p>"I wasn't given any education into what to do [with my antibiotics]. The 5th day I felt well and so thought I would just stop taking the treatment. I was fortunate that my sister explained to me and made me complete the course" [24 year-old female]</p>	Adherence support	
<p>"Especially I think that you are often given more information when you are taking other medication... I have allergies to penicillin so always I have to know what kind of antibiotic I have been given. So unless your issues are more complicated, that's when they give you more information, otherwise I feel that they don't provide you with enough" [24 year old female No. 2]</p>	Antibiotics differ from other medications	Communicating decisions
<p>"When you go into hospital, you feel as though the illness is not yours. You go in to hospital and everyone takes over, like 'we do this then we do that later'. You have no ownership in a way. You are going through it but you have no ownership over what is being done for you or what medication you are receiving." [23 year old female]</p>	Decision making process	
<p>"Tell me yes or tell me no... If you can't fix it I don't want to see you again because there will be no point... We've tried this it's not worked so we tried that... it is endless..." [65 year old male]</p>	Emotion	
<p>"I think sometimes the doctors normally come and diagnose you they usually tell.... They don't necessarily tell you what they are giving you, they usually prescribe it. Then the nurse just comes along with a pot full of drugs and you just take them. I think, unless you are intrigued and ask for it then the nurse will give you that information." [30 year old female]</p>	HCP - Pt communication of information	
<p>You know, the hospitals I have experienced in [region] – I am not really keen based on the lack of information. It is more about; we're doing this operation – get you in, get you out." [23 year old female]</p>	Location / geography	
<p>"When I went to A&E I visited my GP ... It is more about telling your GP what the symptoms were and what treatment you had rather than exactly what the infection is" [30 year old female]</p> <p>"My GP never knew anything. She had scheduled me in to have the hernia, but the appendix went first. And she was "oh have you..." [53 year old male]</p>	HCP - HCP communication of information	

Patient engagement in infection management

<p><i>"For me, I do not know the difference between an allergy and side effects. I would normally just try and cope with it and not go back to the doctors."</i> [24 year old female]</p> <p><i>"I left it a long time and then I got an infection tracking all the way up [my leg]. I went into A&E as I couldn't walk. When I was there they brought some student doctors and said "how bad is this leg" and I thought [this is bad]!"</i> [60 year old male]</p>	<p>Personal Understanding</p>	<p>Influence of future attitudes</p>
<p><i>"They asked whether he was allergic and I said that I do not know he had never had them. After being given them he really severely reacted. He blew up with vomiting and was very very sick. We had to go back to casualty and get that sorted. So the thing that worries me about that is that I remember someone telling me that if you routinely have an operation, you are given penicillin routinely so it worries me whether that would have an effect if he was ill abroad..."</i> [52 year old female]</p>	<p>Understanding by proxy</p>	
<p><i>"I read an article a while ago about antibiotics and how they made people severely ill. A few people have died. I think it's just like... where I have heard about bad experiences.... you know they have never really pulled through for me."</i> [21 year old female]</p>	<p>Media</p>	

Legend: This data is an extract of quotes derived from thematic analysis of semi-structured group interviews exploring participants' experiences of infection management in secondary care pathways.

HCP: healthcare professional, GP: general (primary care) practitioner, A&E: accident and emergency department

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Patient & Public Engagement Workshop – Topic Guide

- Conducting a service evaluation to understand and improve the process of shared decision making during antimicrobial prescribing by clinicians in secondary care (inc. UCC / OP etc)
- We are interested in your own opinions and perceptions of this problem and not what you think others would want you to say
- Everything is kept confidential and no one within the Trust will know what has been said by you. To ensure that confidentiality is maintained you will be assigned a participant number
- We ask you however, NOT to reveal any specific personal information
- Time limit approx. **(as above)** to complete

Topic	Aims	My Questions
1. Introduction	<p>Consent</p> <p>Collect baseline demographic data</p> <p>Collect individual opinions for triangulation against collective group views</p>	<ul style="list-style-type: none"> • Welcome, brief outline of aims of day • Why you have been invited <p>Broad range of people who have been prescribed antibiotics in secondary care (or around) setting</p> <p>Want to explore what information you receive and how you engage with the decision making process</p> <ul style="list-style-type: none"> • Consent and baseline questionnaires (confidential). • Split into two groups to begin (delegated before session from participant charter provided by company)
2. Exploration of current issues during consultations	<p>Reflect on current level of information provided to patients by clinicians when prescribing antimicrobials</p> <p>Reflect on how this information is delivered in different settings (on the wards, admission vs. discharge)</p> <p>Explore whether this information is adequate</p> <p>Explore whether the participant feels as if they are involved in the decision making process in these scenarios</p> <p>Explore barriers to</p>	<ul style="list-style-type: none"> • Can you describe what kinds of information you were provided about the antibiotics you were prescribed last time you were in hospital (or similar) (i) at the point of prescription (ii) at the point of discharge • How did you receive this information? <p>Prompts for above:</p> <p><i>prescription? antimicrobial box insert? Printed information from the GP</i></p> <p><i>Did you read it?</i></p> <p><i>Did it give you the information you were looking for?</i></p> <ul style="list-style-type: none"> • Who gave you most of this information? <p>Prompt: Dr / Nurse / Pharmacist?</p> <ul style="list-style-type: none"> • Was there anything missing that you would like to have been told / had discussed with you? • What are the common questions about your infection/antibiotics do you ask your doctor? <p>Prompt: When do you ask these (during or after reflection)?</p> <ul style="list-style-type: none"> • Did you feel as though you were a part of the decision

	<p>“successful” use of antimicrobials (i) in hospital and (ii) on d/c with antimicrobials</p>	<p>making process when you were you and your doctor discussed your infection / treatment?</p> <p>1. Can you explain why you felt this?</p> <ul style="list-style-type: none"> • What extra information do you seek independently following discussion with the doctor? <p>Prompt: Is this because:</p> <ol style="list-style-type: none"> 1. There is not enough time to have questions addressed 2. The information provided is not clear 3. The patient has a personal view on allopathic meds? 4. Your were embarrassed to ask the question? <ul style="list-style-type: none"> • What are the day to day challenges (i) in hospital (ii) following discharge with adherence to a course of antibiotics <p>Prompt:</p> <p>Remembering to take the course / timings / monitoring for s/e’s</p> <p>Do you complete the course?</p> <ul style="list-style-type: none"> • What do they think is the major barriers to the above? <p>Prompt:</p> <p>? Lack of information</p> <p>? Lack of understanding over importance</p> <p>? Other</p> <ul style="list-style-type: none"> • When you visit the GP after a visit to hospital do they know all of the details about the infection & antibiotics that you received during your visit? • How do they receive this information? • Would you be able to explain to the GP which meds you are on and why? <p>Prompt:</p> <p>Do you tell them the majority of this info?</p> <p>If so how do you record it?</p> <p>Clinic letter / discharge summary? (do you feel they get the full picture from it?)</p>
<p>3. Feedback to group</p>	<p>Allow group to understand all issues identified during each groups session</p>	<ul style="list-style-type: none"> • Leads briefly summarise each groups key findings • Allow discussion and consensus on any major points of difference which arise between groups
<p>3. Generating approaches to solving these issues</p>	<p>Explore what further information patients would like to receive</p> <p>Explore what other</p>	<ul style="list-style-type: none"> • How do you go about finding information about the infection or antibiotics you are given? (a) during your hospital stay (b) once your are discharged with them? • On attaining this information do you feel that it helps you

	<p>support with antibiotic use patients feel they require</p> <p>Explore how patients currently acquire this information which they perceive as helpful / whether they receive this support</p> <p>Does this information empower them to take an active role in their infection / antimicrobial therapy</p> <p>Explore approaches that patients would like to be available to attain this information</p> <p>Investigate whether any other support would be helpful</p>	<p>participate more actively in discussions about your infection / antibiotic treatment with the doctors and other HCP's?</p> <p>Prompt: Do you feel as if you are involved in the decision making? Do you feel that your views and ideas are considered?</p> <ul style="list-style-type: none"> • Is there any difference in the information you require on this (i) when in the hospital c.f. (ii) at the point of discharge on antibiotics <p>Prompts: Do you look up things the doctor tells you about your infection / antibiotics? Is this more helpful in or out of hospital?</p> <ul style="list-style-type: none"> • Are there any other measures that would be helpful in helping you better understand your infection / support you in taking the course of antibiotics? • Brain storm ideas of how patients could receive / access this information / support - Rank using nominal group tech. • Consensus through discussion <p>Prompt: (a) Route of info (app / email / text message / interactive / recording / webcast / paper based) (b) What would be provided (c) Level of detail (d) Original info? Reputable source ? individuals own experiences (uncensored) (e) Ideal timing to receive this information</p>
<p>4. Triangulate</p>	<p>Confirm results generated through each group</p> <p>Explore whether there are any other comments / observations participants wish to make</p>	<ul style="list-style-type: none"> • Present both groups nominal group exercises • Summarise similarities and differences • Does anyone wish to discuss these?

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Table 1
Standards for Reporting Qualitative Research (SRQR)^a

No.	Topic	Item
Title and abstract		
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions
Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement
S4	Purpose or research question	Purpose of the study and specific objectives or questions
Methods		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale ^b
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability
S7	Context	Setting/site and salient contextual factors; rationale ^b
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale ^b
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale ^b
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale ^b
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale ^b
Results/findings		
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings
Discussion		
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field
S19	Limitations	Trustworthiness and limitations of findings

(Table continues)

Table 1

(Continued)

No.	Topic	Item
S20	Other Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

*The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than the options available; the assumptions and limitations of each; the choices made; and how the choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

should provide evidence (e.g., examples, quotes, or text excerpts) to substantiate the main analytic findings.^{20,29}

Discussion. The discussion of qualitative results will generally include connections to existing literature and/or theoretical or conceptual frameworks, the scope and boundaries of the results (transferability), and study limitations.^{10–12,28} In some qualitative traditions, the results and discussion may not have distinct boundaries; we recommend that authors include the substance of each item regardless of the section in which it appears.

Discussion

The purpose of the SRQR is to improve the quality of reporting of qualitative research studies. We hope that these 21 recommended reporting standards will assist authors during manuscript preparation, editors and reviewers in evaluating a manuscript for potential publication, and readers when critically appraising, applying, and synthesizing study findings. As with other reporting guidelines,^{35–37} we anticipate that the SRQR will evolve as it is applied and evaluated in practice. We welcome suggestions for refinement.

Qualitative studies explore “how?” and “why?” questions related to social or human problems or phenomena.^{10,38} Purposes of qualitative studies include understanding meaning from participants’ perspectives (How do they interpret or make sense of an event, situation, or action?); understanding the nature and

influence of the context surrounding events or actions; generating theories about new or poorly understood events, situations, or actions; and understanding the processes that led to a desired (or undesired) outcome.³⁸ Many different approaches (e.g., ethnography, phenomenology, discourse analysis, case study, grounded theory) and methodologies (e.g., interviews, focus groups, observation, analysis of documents) may be used in qualitative research, each with its own assumptions and traditions.^{1,2} A strength of many qualitative approaches and methodologies is the opportunity for flexibility and adaptability throughout the data collection and analysis process. We endeavored to maintain that flexibility by intentionally defining items to avoid favoring one approach or method over others. As such, we trust that the SRQR will support all approaches and methods of qualitative research by making reports more explicit and transparent, while still allowing investigators the flexibility to use the study design and reporting format most appropriate to their study. It may be helpful, in the future, to develop approach-specific extensions of the SRQR, as has been done for guidelines in quantitative research (e.g., the CONSORT extensions).³⁷

Limitations, strengths, and boundaries

We deliberately avoided recommendations that define methodological rigor, and therefore it would be inappropriate to use the SRQR to judge the quality of research methods and findings. Many of the original sources from which we derived the SRQR were intended as

criteria for methodological rigor or critical appraisal rather than reporting; for these, we inferred the information that would be needed to evaluate the criterion. Occasionally, we found conflicting recommendations in the literature (e.g., recommending specific techniques such as multiple coders or member checking to demonstrate trustworthiness); we resolved these conflicting recommendations through selection of the most frequent recommendations and by consensus among ourselves.

Some qualitative researchers have described the limitations of checklists as a means to improve methodological rigor.¹³ We nonetheless believe that a checklist for reporting standards will help to enhance the transparency of qualitative research studies and thereby advance the field.^{29,39}

Strengths of this work include the grounding in previously published criteria, the diversity of experience and perspectives among us, and critical review by experts in three countries.

Implications and application

Similar to other reporting guidelines,^{35–37} the SRQR may be viewed as a starting point for defining reporting standards in qualitative research. Although our personal experience lies in health professions education, the SRQR is based on sources originating in diverse health care and non-health-care fields. We intentionally crafted the SRQR to include various paradigms, approaches, and methodologies used in qualitative research. The elaborations offered in

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Patient engagement with infection management in secondary care: A qualitative investigation of current experiences

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Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Patient-centred medicine, Communication
Keywords:	INFECTIOUS DISEASES, antimicrobials, shared decision making

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Manuscripts

Patient engagement with infection management in secondary care: A qualitative investigation of current experiences

*Timothy M Rawson^{1,3}

Luke SP Moore^{1,3}

Bernard Hernandez²

Enrique Castro-Sanchez¹

Esmita Charani¹

Pantelis Georgiou²

Raheelah Ahmad¹

Alison H Holmes^{1,3}

1. National Institute for Health Research Health Protection Research Unit in Healthcare Associated Infections and Antimicrobial Resistance, Imperial College London, Hammersmith Campus, Du Cane Road, London. W12 0NN. United Kingdom.
2. Centre for Bio-Inspired Technology, Imperial College London, London, South Kensington Campus, Exhibition Road, SW7 2AZ. UK
3. Imperial College Healthcare NHS Trust, Du Cane Road. London. W12 0HS. UK

Running title: Patient engagement with infection management

***Corresponding author:**

Dr Timothy M Rawson, National Institute for Health Research Health Protection Research Unit in Healthcare Associated Infections and Antimicrobial Resistance, Imperial College London, Du Cane Road, London. W12 0NN. United Kingdom.

Email: timothy.rawson07@imperial.ac.uk

Telephone: 02033132732.

Search terms: Shared Decision Making, Antimicrobial Stewardship, Patient engagement, Antimicrobial Resistance, Secondary Care Pathways

Abstract: 250

Full text: 2970

Abstract

Objective: To understand patient engagement with decision making for infection management in secondary care and the consequences associated with current practices.

Design: A qualitative investigation using in-depth focus groups.

Participants: Fourteen members of the public who had received antimicrobials from secondary care in the preceding 12 months in the UK were identified for recruitment. Ten agreed to participate. All participants had experience of infection management in secondary care pathways across a variety of South-East England healthcare institutes. Study findings were subsequently tested through follow up focus groups with 20 newly recruited citizens.

Results: Participants reported feelings of disempowerment during episodes of infection in secondary care. Information is communicated in a unilateral manner with individuals 'told' that they have an infection and will receive an antimicrobial (often unnamed), leading to loss of ownership, frustration, anxiety and ultimately distancing them from engaging with decision making. This poor communication drives individuals to seek information from alternative sources, including on-line, which is associated with concerns over reliability and individualisation.

Failures in communication and information provision by clinicians in secondary care influence individuals' future ideas about infections and their management. This alters their future actions towards antimicrobials and can drive prescription non-adherence and loss-to-follow-up.

Conclusion: Current infection management and antimicrobial prescribing practices in secondary care fail to engage patients with the decision making process. Secondary care physicians must not view infection management episodes as discrete events, but as cumulative experiences which have the potential to shape future patient behaviour and understanding of antimicrobial use.

Trial registration: The study protocol was reviewed by the West London Regional Ethics Committee (REC) and considered to meet criteria for monitoring under service evaluation governance structures (*REC 15/LO/1269 / ICHNT Service Evaluation SE113*).

Strengths & limitations

- This study adds to the paucity of evidence surrounding the patient experience of infection management in secondary care pathways.
- Our findings provide evidence to support development of interventions to address identified failures of information provision and communication with patients locally.
- This study was an in-depth investigation of a small number of individuals who have been managed for infections within secondary care pathways over the last 12 months.
- Findings were tested with a separate cohort of 20 citizens for validation; this work will facilitate the development of targeted interventions to address the challenges identified within our initial study

Introduction

Antimicrobial resistance (AMR) is a global patient health and safety issue, with estimates that up to 10 million deaths each year may be attributable to AMR by the year 2050 [1]. Antimicrobial stewardship (AMS) programs have been introduced at local and international levels in an attempt to optimise the use of antimicrobials. These interventions aim to achieve the best therapeutic outcomes of treatment, whilst minimising the harmful consequences of antimicrobial therapy, such as toxicity and development of AMR [2–8]. To date, most AMS interventions have focused on health care providers with current patient engagement interventions around AMR and AMS (mainly via public health interventions) difficult to assess for efficacy [9–20].

Despite a paucity of evidence to support patient focused interventions within AMS programmes, a growing body of literature is emerging that describes physician and patient desire for increased collaboration in the decision making process surrounding the prescription of medications within secondary care [21]. However, there is currently no specific evidence describing patient experiences of infection management and antimicrobial prescribing within this setting. Within primary care, the role of shared decision making (SDM), where patients and clinicians come together, acknowledge that there is a decision to be made (i.e., between treatments and including no treatment), and consider the best available evidence with the patient's values, preferences, and context have been demonstrated to reduce the rates of antimicrobial prescribing for respiratory tract infections [22]. However in secondary care, where infections are often more serious, requiring urgent and highly protocol driven management, the role for the patient in this process remains unclear.

The aim of this qualitative study was to investigate patients' current experiences of infection related decision making processes across secondary care pathways and map how these experiences influence future engagement with infection management and antimicrobial use. Through generalization of our findings from this in-depth investigation we hope to inform future patient-focused interventions to address the issues identified and allow assessment of their impact on patient outcomes and AMR within secondary care pathways.

Method

Participant recruitment

In September 2015, 14 members of the public who had received antimicrobials from a secondary care pathway in the preceding 12 months in the UK were identified for recruitment (through *Cherry Picked, London, UK*; a specialist qualitative recruitment service). Four individuals declined to participate, giving no reason for this. Recruitment criteria are provided in **box 1**. Individuals that had only received antimicrobials in the critical care setting were not invited for interview.

Participants attended focus group interviews at Imperial College London (UK). A small sample size was selected in order to gain an in-depth understanding of individuals' views, thus providing a richness to the data available for analysis [23]. Furthermore, focus groups were selected over individual interviews as these allowed for group exploration of new ideas, point-counterpoint discussion, and resolution of views; allowing identification and consensus on common themes within the groups [23]. All individuals were consented prior to participation. Participants completed a questionnaire collecting demographic data and previous healthcare experiences. The validated Single Item Literacy Screener (SILS) screening tool was included to assess the participant's level of health literacy [24] to allow estimation of the groups rate of health literacy and comparison to that of the general population. This was felt to be important for consideration, given that the findings of this study may be used to inform future interventions in clinical practice. A reimbursement of £65(\$100) was provided to participants for their time.

Participant interviews

The group was divided into two equal groups based on age categories and gender. Two healthcare professionals (TMR, LSPM), following a pre-determined interview schedule (supplementary data 1; developed from a critical analysis of the literature), facilitated a 120 minute semi-structured interview.

This aimed to explore the participants' experiences of engagement with decision making surrounding infection management and antimicrobial use in secondary care pathways. Two independent observers

(one lay and one healthcare professional; BH & ECS) directly observed the interviews and were asked to make notes of key observations. These were used to help triangulation of initial codes during analysis.

Data analysis

Interviews were audio recorded and transcribed verbatim (using anonymous participant identifiers). Thematic analysis of transcripts was performed using a mixed deductive and inductive approach [25]. Deductive categories were identified based on review of the literature and findings from previous work exploring the users role in infection control [26]. For the inductive approach, two authors (TMR & LSPM), reviewed the focus group transcripts independently to allow initial codes to be generated from differing viewpoints by line by line coding for first order codes [27][28]. During line by line coding, the comments provided by the independent observers' were considered with the aim of complementing areas of reflexivity caused by the analysts' own prior experiences [29]. After familiarisation with the transcripts, the researchers independently coded the data generating a list of emerging categories from the first order codes and those identified deductively, addressing the aims of the study design. After meeting and agreeing on key categories and themes within the text, the two analysts independently preceded to systematically cross-review the text, coding passages based on these agreed codes and categories, subsequently grouping them into overarching themes. On review, any discrepancies were discussed and consensus reached. Examples of key opinions and ideas from the text for each main theme identified were then charted to allow mapping and interpretation of the results [27]. Following synthesis of our findings, 20 new participants were recruited using the same recruitment agency (*Cherry Picked*, UK) in May 2016 to take part in three further focus group sessions. As a part of these sessions the findings from the initial focus groups were tested for validation within a new group of citizens (data not shown). Through this exploratory work it was deemed that saturation of key categories and themes, identified in the original focus group sessions had been reached; allowing for progression onto the development and impact of specific interventions that addressed our findings to be explored.

Ethical approval

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3 The study protocol was reviewed by the West London Regional Ethics Committee (REC) and
4 considered to meet criteria for monitoring under service evaluation governance structures (*REC*
5 *15/LO/1269 / ICHNT Service Evaluation SE113*).
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10 11 12 **Results**

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14 The median age of participants was 52 (21-69) years with an equal gender divide. Seven of the
15 participants were white ethnicity. Six participants had experience of infection management as a
16 hospital in-patient (in the non-critical care setting) with the remaining participants all having received
17 antimicrobials from other secondary care pathways across a variety of South-East England healthcare
18 institutes. These included the Emergency Department (ED), urgent care centres (UCC's) or consultant
19 led out-patient clinics. Two out of ten participants were identified on screening as potentially having a
20 low health literacy, reporting that they sometimes, often, or always required help with written health
21 information on the SILS screening tool [24]. This indicates that our cohort are likely to be more
22 health literate than the average population, where approximately 43% of individual citizens would
23 require assistance with written health information [24,30].
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36 Following thematic analysis, 92 subcategories that fell into 12 categories were derived from the
37 transcripts. Three interlinking themes were identified (**figure 1**). **Table 1** summarises key quotes
38 informing the individual categories and themes referred to within the text below. The participants
39 described a failure in communication and information provision from infection clinicians and support
40 staff in secondary care which subsequently influences the individual's future ideas about infections
41 and their management. This alters the individual's future actions towards infections and
42 antimicrobials and can drive non-adherence to prescribed antimicrobial regimes and loss-to-follow-up
43 after discharge from secondary care.
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52 *Failures in communication*

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55 Participants described their experiences of being diagnosed with an infection in secondary care as one
56 where they completely lost ownership of their condition. Control of their illness was taken over by a
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3 multitude of healthcare professionals (HCPs). Recurring instances were identified where HCP
4 communication with patients became unilateral when antimicrobial decisions were being made, with
5 patients being “*told*” information, often devoid of key aspects such as names of medications, durations
6 of treatment and prospective plans about time courses and potential escalation / de-escalation of
7 therapy. This led to a significant amount of anxiety and frustration as the individual searched for
8 answers.
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16 *“I was told ‘you have an allergy [to penicillin], take this instead’ – Tell me what I am taking*
17 *and exactly what it is going to do for me!”* [65 year-old male]
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21 Moreover, in many cases participants did not feel as if they were involved in the decision making
22 process around their infection management with two-way communication with healthcare
23 professionals perceived as absent.
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28 As well as HCP communication with patients, participants reported becoming frustrated by
29 communication between HCPs. This is centred primarily on the way in which information about
30 infections is communicated from secondary care doctors to primary care doctors on discharge from
31 hospital. Whilst patients are provided with a discharge summary of their stay on leaving hospital, it
32 was perceived that this often neglected information about their infection and the treatment which they
33 received whilst in the hospital. Participants’ reported that they were often forced to communicate this
34 information directly with their primary care physician on follow up visit or were otherwise lost to
35 follow up after discharge due to lack of clear communication pathways.
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44 *Failures in information provision*

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47 The current volume and quality of information provided to individuals by HCPs in secondary care
48 causes problems for patients as it is often poorly explained, with medical terminology routinely used.
49 This leads to a feeling of dis-empowerment with individuals frustrated that they then have to “*go away*
50 *and research it [their condition] themselves*” [23 year-old female]. Fear and anxiety follows when
51 participants see serious side-effects of treatment “*like risk of death [and] no one has mentioned that to*
52 *me!*” [30 year-old male]. This in-turn causes frustration as participants compare delivery of
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3 information on infections and antimicrobials to that provided for operations and medications for
4 chronic disease, such as hypertension. In this example, patients are provided with explanations of their
5 procedure/condition, their management, and potential complications which may arise and how these
6 will be dealt with. In contrast, information on infection management is seen as a “reactive” process
7 where information is only often provided once complications have occurred. Furthermore, patients are
8 often unaware of the timeline for their treatment and the potential complications. This lack of clarity
9 drives individuals to stop treatments early or potentially ignore side effects experienced due to false
10 assumptions and misinformation.

11
12 Participants reported that this failure in communication about infections and antimicrobials drives
13 them to seek information from a wide range of sources, often with varying degrees of quality.
14 Participants commonly sought information independently due to “difficulties in accessing [healthcare
15 professionals]” and the “[time] pressures of work and children” [65 year-old male]. A number of
16 avenues were preferred such as the internet, information leaflets provided with medications and local
17 pharmacies. Individuals will seek out recommended or official NHS sources of information which
18 they believe that they can trust to provide them with information on their infection or treatment.
19 Whilst these sources are seen as helpful, patients still prefer to discuss their infection and its
20 management with a HCP as this provides “individualised” information compared to the “standard-
21 reply” provided by alternative sources [69 year-old male]. This is because the information provided is
22 seen as being based on the patient’s own specific situation and issues. Furthermore, the HCP is a
23 “trusted” source being viewed as an “expert” [69 year old male].

24 *Influences of future attitudes and behaviours*

25
26 Participants clearly described how these individual experiences of poor communication and
27 information provision influence their future ideas and actions towards infection management both in
28 secondary care and in the community. Influences were described from three sources; personal
29 understanding / experiences, understanding by proxy, and understanding through the media.
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3 For example, one personal experience was described by a participant who was told that he had an
4 allergy to penicillin and told that he would be given a “weaker” type of antibiotic for his infection.
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6 When this was perceived not to be effective at clearing up the infection after two days, he stopped
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8 taking his medication as:
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12 *“You know the weaker ones [antibiotics] never seem to clear the infection up. They are not as*
13
14 *strong so they don’t clear it up. The infection lasts longer”* [60 year-old male]
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16 This subsequently led to the participant having to return to secondary care for further treatment of his
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18 infection due to the poor information provision and engagement in the decision process surrounding
19
20 his infection.
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23 The media’s role in developing the participants’ understanding of infection management arose and was
24
25 further explored during the focus group. Participants reported that the media’s influence occurred
26
27 through the portrayal of stories about complications of treatment and the dangers of AMR. This
28
29 created fear and mistrust of medical professionals within our participant group, and caused participants
30
31 to be “cautious” when interacting with medical professionals as they are perceived to “not say the full
32
33 story” [21 year-old, female]. This distrust was reported as driving non-adherence to therapy in the
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35 community by several members of the group.
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41 Discussion

42 *Summary of participant impressions*

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45 Within our participant group, individuals felt detached, frustrated and disempowered from
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47 involvement in decision making about their own infection management within secondary care. The
48
49 consequences of the failure of HCP communication and information provision reached beyond
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51 secondary care, influencing the ideas and actions towards infections and antimicrobials during future
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53 healthcare interactions along a number of different pathways. This fosters feelings of frustration and
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55 anxiety during an individual’s journey through complex secondary care pathways and potentially
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Patient engagement in infection management

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3 drives non-adherence to prescribed antimicrobial regimes and loss to follow up after discharge. These
4 findings highlight the need for specialists in secondary care to not view infection management
5 episodes as discrete events, but as cumulative experiences which have the potential to drive future
6 non-adherence to prescribed antimicrobial regimes and thus the promotion of AMR.
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Opportunities for educating healthcare providers to improve patient engagement

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14 Importantly, HCPs must appreciate that engagement in the decision process for infection management
15 and antimicrobial prescribing may have an influence on future patient actions towards infections and
16 antimicrobial use. These actions can be influence by personal experiences along with those of friends
17 and family and what is described in the media. The way in which we communicate information to
18 patients was reported as the most important aspect in our participants' current experiences of infection
19 management in secondary care and was the largest influence on future actions in terms of adherence
20 to prescribed antimicrobial regimes and healthcare seeking behaviours. Participant perception of
21 communication in secondary care infection-related pathways is of a unilateral process which does not
22 invite patient participation. Greater emphasis needs to be placed on educating HCPs to move away
23 from the decision-maker role [31] into a more bilateral structure. Difficulties such as time pressure on
24 the HCP and the patient is perceived as a key factor by participants and must be taken into account
25 when designing interventions to help facilitate improved communication and patient education during
26 the decision making process. The way that these interventions are designed must be mindful of health
27 literacy, ensuring that the information provided to patients is understandable. Within our small cohort,
28 two of ten participants met screening criteria for health illiteracy. Within the UK, it is estimated that
29 up to 43% of the adults cannot understand currently available health information [24,30]. Therefore as
30 well as educating healthcare providers in how to improve communication with patients, consideration
31 of the wording and type of health information supporting this is vital to allow patient engagement
32 with the decision making process.
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Opportunities for improving patient engagement with decision making

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3 Within our cohort, participants felt strongly that the choice of information provided about their
4 infection and antimicrobial therapy should be dictated by the patient's preference. However, their
5 focus was not primarily on the end decision of whether or not to treat, but on feeling involved and
6 engaged with the process of decision making. This focused on education about their condition and
7 treatment, communicated effectively to them. They described a belief that if a trusted clinician felt
8 they had an infection that required antimicrobial therapy then this was appropriate. Whether this is
9 truly sharing the decision process or not is for consideration, as SDM classically acknowledges that
10 there is a choice to be made, with the patient and clinician coming together to consider available
11 evidence, the patients values and preferences before arriving at a decision [32]. However, Edwards
12 and colleagues, suggest that this can still be classed as sharing the decision (or engaging the patient in
13 the process) where the focus is placed primarily on involving the patient in the decision making
14 process, rather than on who actually makes the final decision on management [33]. Our participants
15 supported this approach to engagement by describing how they become frustrated and distrusting of
16 the recommended therapy when supporting information about the infection and the proposed
17 management is perceived to be withheld from them.

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34 Participants currently view information provided about infections and antimicrobials as reactive in
35 nature with information only provided after a side effect occurs or the patient fails to respond to a
36 certain type of antimicrobial and therapy is escalated. Individuals want proactive information to help
37 them understand what they are receiving, what to expect, and what the plan is if the treatment doesn't
38 go to plan. This allows them to feel "*prepared*", "*confident*" and invested in the healthcare they are
39 receiving. This is challenging for antimicrobial prescribing in secondary care, which is often an acute
40 event, requiring rapid decision making, and has a short duration of therapy [34]. Moreover, this
41 highlights a key area of misunderstanding surrounding infections and antimicrobial therapy within our
42 participant group that has been driven by poor communication and information provision during
43 previous experiences of infection management within secondary care. Therefore, future tools must
44 aim to promote patient engagement with infection management, considering how they define
45 engaging patients in the decision process. Moreover, these interventions must ensure that identified
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3 deficiencies in how HCP communicate and provide information to patients are addressed to facilitate
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5 improvements in the current patient experiences.
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7 *Strengths and limitations*

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10 This qualitative analysis aimed to map the current experiences of patients in antimicrobial decision
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12 making but it does have limitations. Group facilitation within our study was carried out by two HCPs,
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14 which may have influenced socially desirable participant responses to certain questions. To address
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16 this dynamic between interviewer and interviewee, two observers' comments were also considered
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18 during initial coding to highlight where the interviewer's position may have directly influenced
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20 individual responses. For example, during discussion of participants perceptions of doctors attitude
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22 towards prescribing antimicrobials, one participant apologised after voicing an opinion about doctors
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24 simply wanting to
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27 *"...sign the prescription and get rid of the patient"* [69 year-old male].
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30 The noted anxiety about offending the HCP may have influenced other participants voicing their true
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32 opinion on the matter. Secondly, whilst small, this in-depth study provides key themes for future
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34 studies to explore the generalizability of and inform the design and evaluation of appropriate
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36 interventions. Furthermore, our findings were subsequently tested for validation within an
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38 independent group of citizens to search for further categories and themes within our local population.
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40 Finally, on comparison of the health literacy of our selected cohort of participants, the group appeared
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42 to be more health literate than estimates for the general population. Therefore, during subsequent
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44 intervention development and exploration, this aspect must be highlighted and considered as this may
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46 affect the generalizability of our results across the population.
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51 *Conclusion*

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54 Within secondary care, specialists are failing to engage their patients with the decision making
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56 process surrounding infections and their management. This ultimately leads to misinformation,
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3 frustration and anxiety during an individual's journey through secondary care pathways and
4 potentially drives non-adherence to prescribed antimicrobial regimes and loss to follow up in the
5 community. Clinicians must stop seeing infection episodes as discrete events and approach them with
6 the understanding that previous negative experiences drive subsequent non-adherence to prescribed
7 antimicrobial regimes and potentially disrupting follow up of patients post discharge from secondary
8 care. Poor communication by HCPs and lack of quality information provided are the two leading
9 causes for this, often driving individuals to seek standard information from untrusted, online sources.
10 This aspect must be addressed through improving HCP education on patient engagement and through
11 development of interventions to support patient engagement in the process. Furthermore, these
12 findings have the potential to translate into other fields of secondary care, where poor engagement
13 also exists and benefits in patient outcomes through interventions promoting improved
14 communication and information provision are beginning to be reported. We call for the development
15 of clear and pragmatic mechanisms to educate HCPs and provide patients with the proactive
16 information they require about their infection and its management and engage them with the decision
17 making process.
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Contribution statement

All authors contributed significantly towards the planning this study and production on this manuscript. TMR, LSPM, BH & ECS ran the focus groups & were involved in data analysis. TMR drafted the initial manuscript with all authors contributing significantly towards its finalisation for submission.

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Competing interests

AHH has consulted for bioMérieux in 2013. LSPM has consulted for bioMérieux and DNA electronics in 2014. All other authors have no conflicts of interest to declare.

Data sharing

There is no additional, unpublished data available from this study.

References

- 1 O'Neill J. Antimicrobial Resistance : Tackling a crisis for the health and wealth of nations. 2014. [https://amr-review.org/sites/default/files/AMR_Review_Paper - Tackling a crisis for the health and wealth of nations_1.pdf](https://amr-review.org/sites/default/files/AMR_Review_Paper_-_Tackling_a_crisis_for_the_health_and_wealth_of_nations_1.pdf)
- 2 WHO. Antimicrobial Resistance Global Report on Surveillance 2014. *World Health Organ* Published Online First: 2014. <http://www.who.int/drugresistance/documents/surveillancereport/en/>
- 3 European Surveillance of Antimicrobial Consumption. Report on Point Prevalence Survey of Antimicrobial Prescription in European Hospitals , 2009. 2009. http://ecdc.europa.eu/en/activities/surveillance/ESAC-Net/publications/Documents/report_survey_antimicrobial_prescriptions_eu_hospitals_2009.pdf
- 4 Department of Health, Department for Environment Food and Rural Affairs. UK Five Year Antimicrobial Resistance Strategy 2013 to 2018. 2013;:43. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/244058/20130902_UK_5_year_AMR_strategy.pdf
- 5 Howard SJ, Hopwood S, Davies SC. Antimicrobial resistance: a global challenge. *Sci Transl Med* 2014;**6**:236ed10. <http://www.ncbi.nlm.nih.gov/pubmed/24828073>
- 6 Ashiru-oredope D, Sharland M, Charani E, *et al*. Improving the quality of antibiotic prescribing in the nhs by developing a new antimicrobial stewardship programme: Start smart-then focus. *J Antimicrob Chemother* 2012;**67**:i51–63.
- 7 CDC. Core Elements of Hospital Antibiotic Stewardship Programs. 2014;:1–25. <http://www.cdc.gov/getsmart/healthcare/implementation/core-elements.html>
- 8 Cruickshank M. *Antimicrobial stewardship in Australian hospitals*. 2011. <http://www.safetyandquality.gov.au/wp-content/uploads/2011/01/Antimicrobial-stewardship-in-Australian-Hospitals-2011.pdf>
- 9 Davey P, Brown E, Charani E, *et al*. Interventions to improve antibiotic prescribing practices for hospital inpatients. *Cochrane database Syst Rev* 2013;**4**:CD003543. doi:10.1002/14651858.CD003543.pub3
- 10 Charani E, Edwards R, Sevdalis N, *et al*. Behavior change strategies to influence antimicrobial prescribing in acute care: a systematic review. *Clin Infect Dis* 2011;**53**:651–62. doi:10.1093/cid/cir445
- 11 Benson K. Electronic data collection tools for quality improvement: antibiotic utilization project. *AMIA Annu Symp Proc* 2003;:788.
- 12 Butler CC, Kinnersley P, Prout H, *et al*. Antibiotics and shared decision-making in primary care. *J Antimicrob Chemother* 2001;**48**:435–40. doi:10.1093/jac/48.3.435

- 1
2
3 13 Edgar T, Boyd SD, Palamé MJ. Sustainability for behaviour change in the fight against
4 antibiotic resistance: A social marketing framework. *J Antimicrob Chemother*
5 2009;**63**:230–7. doi:10.1093/jac/dkn508
6
7
8 14 Goossens H, Guillemot D, Ferech M, *et al.* National campaigns to improve antibiotic
9 use. *Eur J Clin Pharmacol* 2006;**62**:373–9. doi:10.1007/s00228-005-0094-7
10
11 15 Huttner B, Goossens H, Verheij T, *et al.* Characteristics and outcomes of public
12 campaigns aimed at improving the use of antibiotics in outpatients in high-income
13 countries. *Lancet Infect Dis* 2010;**10**:17–31. doi:10.1016/S1473-3099(09)70305-6
14
15 16 Mangione-Smith R, Stivers T, Elliott M, *et al.* Online commentary during the physical
16 examination: A communication tool for avoiding inappropriate antibiotic prescribing?
17 *Soc Sci Med* 2003;**56**:313–20. doi:10.1016/S0277-9536(02)00029-1
18
19 17 McClure JB, Richards J, Westbrook EO, *et al.* Research Letter. *Am J Prev Med*
20 2007;**33**:436–7. doi:10.1016/j.amepre.2007.07.027
21
22 18 Prevention C for DC and. Gaining Consensus Among Stakeholders Through the
23 Nominal Group Technique. *Centers Disease Control Prev* 2006;:1–
24 2.<http://www.cdc.gov/healthyyouth/evaluation/index.htm>
25
26 19 Welschen I, Kuyvenhoven M, Hoes A, *et al.* Antibiotics for acute respiratory tract
27 symptoms: Patients' expectations, GPs' management and patient satisfaction. *Fam*
28 *Pract* 2004;**21**:234–7. doi:10.1093/fampra/cmh303
29
30 20 Wutzke SE, Artist M a, Kehoe L a, *et al.* Evaluation of a national programme to reduce
31 inappropriate use of antibiotics for upper respiratory tract infections: effects on
32 consumer awareness, beliefs, attitudes and behaviour in Australia. *Health Promot Int*
33 2007;**22**:53–64. doi:dal034 [pii]r10.1093/heapro/dal034 [doi]
34
35 21 Mohsin-Shaikh S, Garfield S, Franklin BD. Patient involvement in medication safety
36 in hospital: An exploratory study. *Int J Clin Pharm* 2014;**36**:657–66.
37 doi:10.1007/s11096-014-9951-8
38
39 22 Coxeter P, Del Mar CB, McGregor L, *et al.* Interventions to facilitate shared decision
40 making to address antibiotic use for acute respiratory infections in primary care. In:
41 Hoffmann TC, ed. *Cochrane Database of Systematic Reviews*. Chichester, UK: : John
42 Wiley & Sons, Ltd 2015. doi:10.1002/14651858.CD010907.pub2
43
44 23 Berg BL. *Qualitative research methods for the social sciences*. Seventh Ed. California
45 state, Long Beach: : Allyn and Bacon 2001.
46
47 24 Morris NS, MacLean CD, Chew LD, *et al.* The Single Item Literacy Screener:
48 evaluation of a brief instrument to identify limited reading ability. *BMC Fam Pract*
49 2006;**7**:21. doi:10.1186/1471-2296-7-21
50
51 25 Eliot & Associates. Guidelines for Conducting a Focus Group. 2005.
52 https://assessment.trinity.duke.edu/documents/How_to_Conduct_a_Focus_Group.pdf
53
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2
3 26 Ahmad R, Iwami M, Castro-Sánchez E, Husson F, Taiyari K, Zingg W H a. Defining
4 the user role in infection control. *J Hosp Infect* 2016;**92**:321–7.
5 doi:<http://dx.doi.org/10.1016/j.jhin.2015.09.018>
6
- 7 27 Pope C, Ziebland S, Mays N. Analysing qualitative data. *Nurse Res* 2011;**18**:4–5.
8 doi:10.1192/bjp.109.458.163
9
- 10 28 Bradley EH, Curry L a., Devers KJ. Qualitative data analysis for health services
11 research: Developing taxonomy, themes, and theory. *Health Serv Res* 2007;**42**:1758–
12 72. doi:10.1111/j.1475-6773.2006.00684.x
13
- 14 29 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research
15 (COREQ): A 32-item checklist for interviews and focus groups. *Int J Qual Heal Care*
16 2007;**19**:349–57. doi:10.1093/intqhc/mzm042
17
- 18 30 Rowlands G, Protheroe J, Price H, *et al.* Health Literacy. Report from an RCGP-led
19 health literacy workshop. 2014.
20
- 21 31 Coulter A, Collins A. Making Shared Decision Making a Reality: No decision about
22 me, without me. 2011.
23 http://www.kingsfund.org.uk/publications/nhs_decisionmaking.html
24
- 25 32 Collins A. Measuring what really matters: Towards a coherent measurement system to
26 support person-centred care. 2014. doi:10.7748/nr2011.10.19.1.25.c8768
27
- 28 33 Edwards A, Elwyn G. Inside the black box of shared decision making: distinguishing
29 between the process of involvement and who makes the decision. *Heal Expect*
30 2006;**9**:307–20. doi:10.1111/j.1369-7625.2006.00401.x
31
- 32 34 ESPAUR SSTF Implementation subgroup. Start Smart - Then Focus Antimicrobial
33 Stewardship Toolkit for English Hospitals. 2015.
34 [https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/417032/
35 Start_Smart_Then_Focus_FINAL.PDF](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/417032/Start_Smart_Then_Focus_FINAL.PDF)
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Box 1. Selection criteria for participation in in-depth focus group analysis of current experience of patient engagement with infection management and antimicrobial prescribing across secondary care.

Age 18 or older.

Equal gender mix.

Representative mix of ethnic backgrounds.

Must have been treated with antibiotics in the secondary care setting (this could include, out-patients, Emergency Departments, Urgent Care Centres or Ambulatory units) within the last 12 months. This should not have been level 2 or 3 care (e.g. high dependency units or intensive care) only.*

Preferable that they have been an in-patient in secondary care previously (but not an exclusion criteria if the above criteria are all satisfied).

* Individuals receiving antimicrobials in level 2 or level 3 care facilities only were excluded, given that they are likely to have been critically ill at the time of antimicrobial prescribing.

Table 1. An analytical framework developing categories and themes for patients' experiences of infection management in secondary care.

Quote	Category	Theme
<p>"I like to go and see the doctor... Online can't see me [sic]. Infection is a thousand different things and online can't confidently tell you, this is what you have..." [65 year old male]</p> <p>"...you are not an individual to them [corporate pharmacists]. In our case, I think we have the option to be sort of individuals. That is what I find lovely about our current pharmacy!" [69 year old male]</p>	Sources of information	Information provided
<p>"I think what the problem that I have experienced is, is that they will give you a leaflet to read and I will have to go and research it myself. This is rather than the doctor taking the time to sit down and talk about how it might affect you, what exactly is in it [the antibiotic] – you know a proper consultation. [23 year old female]</p> <p>"Rather than sitting down and taking the time to explain, because they use a lot of medical terminology that I do not know what they're talking about to be honest. I think that they need to take more time to be honest to sit down and make sure that the patient knows exactly what they are putting in your body and exactly what all the side effects were. Because I didn't know what I was reacting to..." [24 year old female]</p>	Quality of information	
<p>"I wasn't given any education into what to do [with my antibiotics]. The 5th day I felt well and so thought I would just stop taking the treatment. I was fortunate that my sister explained to me and made me complete the course" [24 year-old female]</p>	Adherence support	
<p>"Especially I think that you are often given more information when you are taking other medication... I have allergies to penicillin so always I have to know what kind of antibiotic I have been given. So unless your issues are more complicated, that's when they give you more information, otherwise I feel that they don't provide you with enough" [24 year old female No. 2]</p>	Antibiotics differ from other medications	Communicating decisions
<p>"When you go into hospital, you feel as though the illness is not yours. You go in to hospital and everyone takes over, like 'we do this then we do that later'. You have no ownership in a way. You are going through it but you have no ownership over what is being done for you or what medication you are receiving." [23 year old female]</p>	Decision making process	
<p>"Tell me yes or tell me no... If you can't fix it I don't want to see you again because there will be no point... We've tried this it's not worked so we tried that... it is endless..." [65 year old male]</p>	Emotion	
<p>"I think sometimes the doctors normally come and diagnose you they usually tell.... They don't necessarily tell you what they are giving you, they usually prescribe it. Then the nurse just comes along with a pot full of drugs and you just take them. I think, unless you are intrigued and ask for it then the nurse will give you that information." [30 year old female]</p>	HCP - Pt communication of information	
<p>You know, the hospitals I have experienced in [region] – I am not really keen based on the lack of information. It is more about; we're doing this operation – get you in, get you out." [23 year old female]</p>	Location / geography	
<p>"When I went to A&E I visited my GP ... It is more about telling your GP what the symptoms were and what treatment you had rather than exactly what the infection is" [30 year old female]</p> <p>"My GP never knew anything. She had scheduled me in to have the hernia, but the appendix went first. And she was "oh have you..." [53 year old male]</p>	HCP - HCP communication of information	

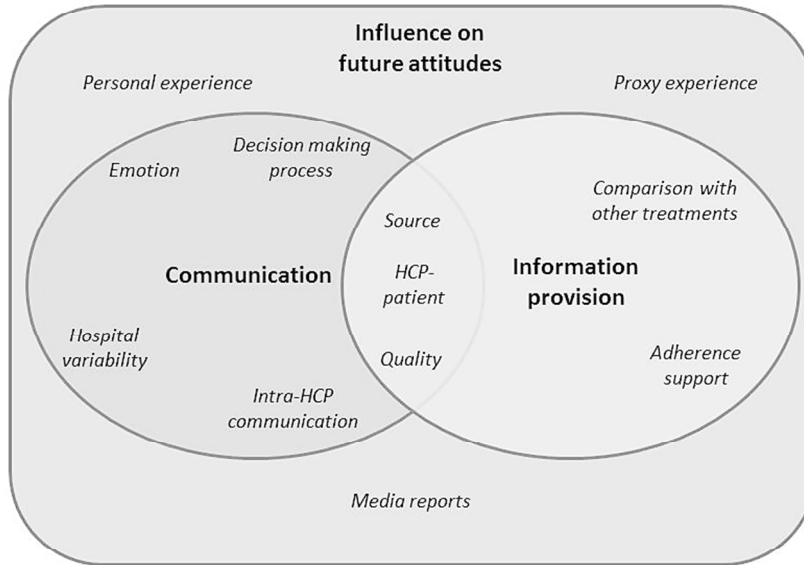
Patient engagement in infection management

<p><i>"For me, I do not know the difference between an allergy and side effects. I would normally just try and cope with it and not go back to the doctors."</i> [24 year old female]</p> <p><i>"I left it a long time and then I got an infection tracking all the way up [my leg]. I went into A&E as I couldn't walk. When I was there they brought some student doctors and said "how bad is this leg" and I thought [this is bad]!"</i> [60 year old male]</p>	<p>Personal Understanding</p>	<p>Influence of future attitudes</p>
<p><i>"They asked whether he was allergic and I said that I do not know he had never had them. After being given them he really severely reacted. He blew up with vomiting and was very very sick. We had to go back to casualty and get that sorted. So the thing that worries me about that is that I remember someone telling me that if you routinely have an operation, you are given penicillin routinely so it worries me whether that would have an effect if he was ill abroad..."</i> [52 year old female]</p>	<p>Understanding by proxy</p>	
<p><i>"I read an article a while ago about antibiotics and how they made people severely ill. A few people have died. I think it's just like... where I have heard about bad experiences.... you know they have never really pulled through for me."</i> [21 year old female]</p>	<p>Media</p>	

Legend: This data is an extract of quotes derived from thematic analysis of semi-structured group interviews exploring participants' experiences of infection management in secondary care pathways.

HCP: healthcare professional, GP: general (primary care) practitioner, A&E: accident and emergency department

Figure 1. The distribution of themes and categories contributing to individuals' experiences of decision making for infection management in secondary care pathways.



Legend. Healthcare professional (HCP) failures in communication and information provision influence individuals' future ideas and attitudes towards infections and their management. This alters their future actions towards infections and antimicrobials and can drive non-adherence to prescribed antimicrobial regimes and loss-to-follow-up after discharge from secondary care.

Figure 1
81x60mm (300 x 300 DPI)

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Supplementary data 1 - Workshop Topic Guide

- Conducting a service evaluation to understand and improve the process of shared decision making during antimicrobial prescribing by clinicians in secondary care (inc. UCC / OP etc)
- We are interested in your own opinions and perceptions of this problem and not what you think others would want you to say
- Everything is kept confidential and no one within the Trust will know what has been said by you. To ensure that confidentiality is maintained you will be assigned a participant number
- We ask you however, NOT to reveal any specific personal information
- Time limit approx. **(as above)** to complete

Topic	Aims	My Questions
1. Introduction	<p>Consent</p> <p>Collect baseline demographic data</p> <p>Collect individual opinions for triangulation against collective group views</p>	<ul style="list-style-type: none"> • Welcome, brief outline of aims of day • Why you have been invited <p>Broad range of people who have been prescribed antibiotics in secondary care (or around) setting</p> <p>Want to explore what information you receive and how you engage with the decision making process</p> <ul style="list-style-type: none"> • Consent and baseline questionnaires (confidential). • Split into two groups to begin (delegated before session from participant charter provided by company)
2. Exploration of current issues during consultations	<p>Reflect on current level of information provided to patients by clinicians when prescribing antimicrobials</p> <p>Reflect on how this information is delivered in different settings (on the wards, admission vs. discharge)</p> <p>Explore whether this information is adequate</p> <p>Explore whether the participant feels as if they are involved in the decision making process in these scenarios</p> <p>Explore barriers to "successful" use of antimicrobials (i) in hospital and (ii) on d/c</p>	<ul style="list-style-type: none"> • Can you describe what kinds of information you were provided about the antibiotics you were prescribed last time you were in hospital (or similar) (i) at the point of prescription (ii) at the point of discharge • How did you receive this information? <p>Prompts for above:</p> <p><i>prescription? antimicrobial box insert? Printed information from the GP</i></p> <p><i>Did you read it?</i></p> <p><i>Did it give you the information you were looking for?</i></p> <ul style="list-style-type: none"> • Who gave you most of this information? <p>Prompt: Dr / Nurse / Pharmacist?</p> <ul style="list-style-type: none"> • Was there anything missing that you would like to have been told / had discussed with you? • What are the common questions about your infection/antibiotics do you ask your doctor? <p>Prompt: When do you ask these (during or after reflection)?</p> <ul style="list-style-type: none"> • Did you feel as though you were a part of the decision making process when you were you and your doctor discussed your infection / treatment? <p>1. Can you explain why you felt this?</p>

	with antimicrobials	<ul style="list-style-type: none"> • What extra information do you seek independently following discussion with the doctor? Prompt: Is this because: <ol style="list-style-type: none"> 1. There is not enough time to have questions addressed 2. The information provided is not clear 3. The patient has a personal view on allopathic meds? 4. You were embarrassed to ask the question? • What are the day to day challenges (i) in hospital (ii) following discharge with adherence to a course of antibiotics Prompt: Remembering to take the course / timings / monitoring for s/e's Do you complete the course? • What do they think is the major barriers to the above? Prompt: ? Lack of information ? Lack of understanding over importance ? Other • When you visit the GP after a visit to hospital do they know all of the details about the infection & antibiotics that you received during your visit? • How do they receive this information? • Would you be able to explain to the GP which meds you are on and why? Prompt: Do you tell them the majority of this info? If so how do you record it? Clinic letter / discharge summary? (do you feel they get the full picture from it?)
3. Feedback to group	Allow group to understand all issues identified during each groups session	<ul style="list-style-type: none"> • Leads briefly summarise each groups key findings • Allow discussion and consensus on any major points of difference which arise between groups
3. Generating approaches to solving these issues	<p>Explore what further information patients would like to receive</p> <p>Explore what other support with antibiotic use patients feel they require</p>	<ul style="list-style-type: none"> • How do you go about finding information about the infection or antibiotics you are given? (a) during your hospital stay (b) once your are discharged with them? • On attaining this information do you feel that it helps you participate more actively in discussions about your infection / antibiotic treatment with the doctors and other HCP's? Prompt:

	<p>Explore how patients currently acquire this information which they perceive as helpful / whether they receive this support</p> <p>Does this information empower them to take an active role in their infection / antimicrobial therapy</p> <p>Explore approaches that patients would like to be available to attain this information</p> <p>Investigate whether any other support would be helpful</p>	<p>Do you feel as if you are involved in the decision making? Do you feel that your views and ideas are considered?</p> <ul style="list-style-type: none"> • Is there any difference in the information you require on this (i) when in the hospital c.f. (ii) at the point of discharge on antibiotics <p>Prompts: Do you look up things the doctor tells you about your infection / antibiotics? Is this more helpful in or out of hospital?</p> <ul style="list-style-type: none"> • Are there any other measures that would be helpful in helping you better understand your infection / support you in taking the course of antibiotics? • Brain storm ideas of how patients could receive / access this information / support - Rank using nominal group tech. • Consensus through discussion <p>Prompt:</p> <ol style="list-style-type: none"> (a) Route of info (app / email / text message / interactive / recording / webcast / paper based) (b) What would be provided (c) Level of detail (d) Original info? Reputable source ? individuals own experiences (uncensored) (e) Ideal timing to receive this information
<p>4. Triangulate</p>	<p>Confirm results generated through each group</p> <p>Explore whether there are any other comments / observations participants wish to make</p>	<ul style="list-style-type: none"> • Present both groups nominal group exercises • Summarise similarities and differences • Does anyone wish to discuss these?

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For peer review only

Table 1
Standards for Reporting Qualitative Research (SRQR)^a

No.	Topic	Item
Title and abstract		
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions
Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement
S4	Purpose or research question	Purpose of the study and specific objectives or questions
Methods		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale ^b
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability
S7	Context	Setting/site and salient contextual factors; rationale ^b
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale ^b
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale ^b
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale ^b
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale ^b
Results/findings		
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings
Discussion		
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field
S19	Limitations	Trustworthiness and limitations of findings

(Table continues)

Table 1

(Continued)

No.	Topic	Item
S20	Other Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

*The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than the options available; the assumptions and limitations of each; the choices made; and how the choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

should provide evidence (e.g., examples, quotes, or text excerpts) to substantiate the main analytic findings.^{20,29}

Discussion. The discussion of qualitative results will generally include connections to existing literature and/or theoretical or conceptual frameworks, the scope and boundaries of the results (transferability), and study limitations.^{10–12,28} In some qualitative traditions, the results and discussion may not have distinct boundaries; we recommend that authors include the substance of each item regardless of the section in which it appears.

Discussion

The purpose of the SRQR is to improve the quality of reporting of qualitative research studies. We hope that these 21 recommended reporting standards will assist authors during manuscript preparation, editors and reviewers in evaluating a manuscript for potential publication, and readers when critically appraising, applying, and synthesizing study findings. As with other reporting guidelines,^{35–37} we anticipate that the SRQR will evolve as it is applied and evaluated in practice. We welcome suggestions for refinement.

Qualitative studies explore “how?” and “why?” questions related to social or human problems or phenomena.^{10,38} Purposes of qualitative studies include understanding meaning from participants’ perspectives (How do they interpret or make sense of an event, situation, or action?); understanding the nature and

influence of the context surrounding events or actions; generating theories about new or poorly understood events, situations, or actions; and understanding the processes that led to a desired (or undesired) outcome.³⁸ Many different approaches (e.g., ethnography, phenomenology, discourse analysis, case study, grounded theory) and methodologies (e.g., interviews, focus groups, observation, analysis of documents) may be used in qualitative research, each with its own assumptions and traditions.^{1,2} A strength of many qualitative approaches and methodologies is the opportunity for flexibility and adaptability throughout the data collection and analysis process. We endeavored to maintain that flexibility by intentionally defining items to avoid favoring one approach or method over others. As such, we trust that the SRQR will support all approaches and methods of qualitative research by making reports more explicit and transparent, while still allowing investigators the flexibility to use the study design and reporting format most appropriate to their study. It may be helpful, in the future, to develop approach-specific extensions of the SRQR, as has been done for guidelines in quantitative research (e.g., the CONSORT extensions).³⁷

Limitations, strengths, and boundaries

We deliberately avoided recommendations that define methodological rigor, and therefore it would be inappropriate to use the SRQR to judge the quality of research methods and findings. Many of the original sources from which we derived the SRQR were intended as

criteria for methodological rigor or critical appraisal rather than reporting; for these, we inferred the information that would be needed to evaluate the criterion. Occasionally, we found conflicting recommendations in the literature (e.g., recommending specific techniques such as multiple coders or member checking to demonstrate trustworthiness); we resolved these conflicting recommendations through selection of the most frequent recommendations and by consensus among ourselves.

Some qualitative researchers have described the limitations of checklists as a means to improve methodological rigor.¹³ We nonetheless believe that a checklist for reporting standards will help to enhance the transparency of qualitative research studies and thereby advance the field.^{29,39}

Strengths of this work include the grounding in previously published criteria, the diversity of experience and perspectives among us, and critical review by experts in three countries.

Implications and application

Similar to other reporting guidelines,^{35–37} the SRQR may be viewed as a starting point for defining reporting standards in qualitative research. Although our personal experience lies in health professions education, the SRQR is based on sources originating in diverse health care and non-health-care fields. We intentionally crafted the SRQR to include various paradigms, approaches, and methodologies used in qualitative research. The elaborations offered in

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Patient engagement with infection management in secondary care: A qualitative investigation of current experiences

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Manuscripts

Patient engagement with infection management in secondary care: A qualitative investigation of current experiences

*Timothy M Rawson^{1,3}

Luke SP Moore^{1,3}

Bernard Hernandez²

Enrique Castro-Sanchez¹

Esmita Charani¹

Pantelis Georgiou²

Raheelah Ahmad¹

Alison H Holmes^{1,3}

1. National Institute for Health Research Health Protection Research Unit in Healthcare Associated Infections and Antimicrobial Resistance, Imperial College London, Hammersmith Campus, Du Cane Road, London. W12 0NN. United Kingdom.
2. Centre for Bio-Inspired Technology, Imperial College London, London, South Kensington Campus, Exhibition Road, SW7 2AZ. UK
3. Imperial College Healthcare NHS Trust, Du Cane Road. London. W12 0HS. UK

Running title: Patient engagement with infection management

***Corresponding author:**

Dr Timothy M Rawson, National Institute for Health Research Health Protection Research Unit in Healthcare Associated Infections and Antimicrobial Resistance, Imperial College London, Du Cane Road, London. W12 0NN. United Kingdom.

Email: timothy.rawson07@imperial.ac.uk

Telephone: 02033132732.

Search terms: Shared Decision Making, Antimicrobial Stewardship, Patient engagement, Antimicrobial Resistance, Secondary Care Pathways

Abstract: 250

Full text: 2970

Abstract

Objective: To understand patient engagement with decision making for infection management in secondary care and the consequences associated with current practices.

Design: A qualitative investigation using in-depth focus groups.

Participants: Fourteen members of the public who had received antimicrobials from secondary care in the preceding 12 months in the UK were identified for recruitment. Ten agreed to participate. All participants had experience of infection management in secondary care pathways across a variety of South-East England healthcare institutes. Study findings were subsequently tested through follow up focus groups with 20 newly recruited citizens.

Results: Participants reported feelings of disempowerment during episodes of infection in secondary care. Information is communicated in a unilateral manner with individuals 'told' that they have an infection and will receive an antimicrobial (often unnamed), leading to loss of ownership, frustration, anxiety and ultimately distancing them from engaging with decision making. This poor communication drives individuals to seek information from alternative sources, including on-line, which is associated with concerns over reliability and individualisation.

Failures in communication and information provision by clinicians in secondary care influence individuals' future ideas about infections and their management. This alters their future actions towards antimicrobials and can drive prescription non-adherence and loss-to-follow-up.

Conclusion: Current infection management and antimicrobial prescribing practices in secondary care fail to engage patients with the decision making process. Secondary care physicians must not view infection management episodes as discrete events, but as cumulative experiences which have the potential to shape future patient behaviour and understanding of antimicrobial use.

Trial registration: The study protocol was reviewed by the West London Regional Ethics Committee (REC) and considered to meet criteria for monitoring under service evaluation governance structures (*REC 15/LO/1269 / ICHNT Service Evaluation SE113*).

Strengths & limitations

- This study adds to the paucity of evidence surrounding the patient experience of infection management in secondary care pathways.
- Our findings provide evidence to support development of interventions to address identified failures of information provision and communication with patients locally.
- This study was an in-depth investigation of a small number of individuals who have been managed for infections within secondary care pathways over the last 12 months.
- Findings were tested with a separate cohort of 20 citizens for validation; this work will facilitate the development of targeted interventions to address the challenges identified within our initial study

Introduction

Antimicrobial resistance (AMR) is a global patient health and safety issue, with estimates that up to 10 million deaths each year may be attributable to AMR by the year 2050 [1]. Antimicrobial stewardship (AMS) programs have been introduced at local and international levels in an attempt to optimise the use of antimicrobials. These interventions aim to achieve the best therapeutic outcomes of treatment, whilst minimising the harmful consequences of antimicrobial therapy, such as toxicity and development of AMR [2–8]. To date, most AMS interventions have focused on health care providers with current patient engagement interventions around AMR and AMS (mainly via public health interventions) difficult to assess for efficacy [9–20].

Despite a paucity of evidence to support patient focused interventions within AMS programmes, a growing body of literature is emerging that describes physician and patient desire for increased collaboration in the decision making process surrounding the prescription of medications within secondary care [21]. However, there is currently no specific evidence describing patient experiences of infection management and antimicrobial prescribing within this setting. Within primary care, the role of shared decision making (SDM), where patients and clinicians come together, acknowledge that there is a decision to be made (i.e., between treatments and including no treatment), and consider the best available evidence with the patient's values, preferences, and context have been demonstrated to reduce the rates of antimicrobial prescribing for respiratory tract infections [22]. However in secondary care, where infections are often more serious, requiring urgent and highly protocol driven management, the role for the patient in this process remains unclear.

The aim of this qualitative study was to investigate patients' current experiences of infection related decision making processes across secondary care pathways and map how these experiences influence future engagement with infection management and antimicrobial use. Through generalization of our findings from this in-depth investigation we hope to inform future patient-focused interventions to address the issues identified and allow assessment of their impact on patient outcomes and AMR within secondary care pathways.

Method

Participant recruitment

In September 2015, 14 members of the public who had received antimicrobials from a secondary care pathway in the preceding 12 months in the UK were identified for recruitment (through *Cherry Picked, London, UK*; a specialist qualitative recruitment service). This involved identifying a sample of 500 individuals who lived in south-east England and met recruitment criteria (**box 1**) from a database of 20,000 citizens who had previously signed up to the recruitment service from around the UK. The sample cohort of 500 were contacted with an initial recruitment email to identify those available to take part in the focus group sessions. From there, participants were then stratified according to recruitment criteria and 14 selected based on their fit with the criteria and availability for the session. Two further contacts were made with identified participants following this to confirm their participation and provide directions to the venue. Four individuals declined to participate, giving no reason for this.

Participants attended focus group interviews at Imperial College London (UK). A small sample size was selected in order to gain an in-depth understanding of individuals' views, thus providing a richness to the data available for analysis [23]. Furthermore, focus groups were selected over individual interviews as these allowed for group exploration of new ideas, point-counterpoint discussion, and resolution of views; allowing identification and consensus on common themes within the groups [23]. All individuals were consented prior to participation. Participants completed a questionnaire collecting demographic data and previous healthcare experiences. The validated Single Item Literacy Screener (SILS) screening tool was included to assess the participant's level of health literacy [24] to allow estimation of the groups rate of health literacy and comparison to that of the general population. This was felt to be important for consideration, given that the findings of this study may be used to inform future interventions in clinical practice. A reimbursement of £65(\$100) was provided to participants for their time.

Participant focus groups

The group was divided into two equal groups based on age categories and gender. Two healthcare professionals (TMR, LSPM), following a pre-determined schedule (supplementary data 1; developed from a critical analysis of the literature), facilitated a 120 minute focus group. This aimed to explore the participants' experiences of engagement with decision making surrounding infection management and antimicrobial use in secondary care pathways. Two independent observers (one lay and one healthcare professional; BH & ECS) directly observed the sessions and were asked to make notes of key observations. These were used to help triangulation of initial codes during analysis.

Data analysis

Focus groups were audio recorded and transcribed verbatim (using anonymous participant identifiers). Thematic analysis of transcripts was performed using a mixed deductive and inductive approach [25]. Deductive categories were identified based on review of the literature and findings from previous work exploring the users role in infection control [26]. For the inductive approach, two authors (TMR & LSPM), reviewed the focus group transcripts independently to allow initial codes to be generated from differing viewpoints by line by line coding for first order codes [27][28]. During line by line coding, the comments provided by the independent observers' were considered with the aim of complementing areas of reflexivity caused by the analysts' own prior experiences [29]. After familiarisation with the transcripts, the researchers independently coded the data generating a list of emerging categories from the first order codes and those identified deductively, addressing the aims of the study design. After meeting and agreeing on key categories and themes within the text, the two analysts independently proceeded to systematically cross-review the text, coding passages based on these agreed codes and categories, subsequently grouping them into overarching themes. On review, any discrepancies were discussed and consensus reached. Examples of key opinions and ideas from the text for each main theme identified were then charted to allow mapping and interpretation of the results [27]. Following synthesis of our findings, 20 new participants were recruited using the same recruitment agency (*Cherry Picked*, UK) in May 2016 to take part in three further focus group sessions. As a part of these sessions the findings from the initial focus groups were tested for

validation within a new group of citizens (data not shown). Through this exploratory work it was deemed that saturation of key categories and themes, identified in the original focus group sessions had been reached; allowing for progression onto the development and impact of specific interventions that addressed our findings to be explored.

Ethical approval

The study protocol was reviewed by the West London Regional Ethics Committee (REC) and considered to meet criteria for monitoring under service evaluation governance structures (*REC 15/LO/1269 / ICHNT Service Evaluation SE113*).

Results

The median age of participants was 52 (21-69) years with an equal gender divide. Seven of the participants were white ethnicity. Six participants had experience of infection management as a hospital in-patient (in the non-critical care setting) with the remaining participants all having received antimicrobials from other secondary care pathways across a variety of South-East England healthcare institutes. These included the Emergency Department (ED), urgent care centres (UCC's) or consultant led out-patient clinics. Two out of ten participants were identified on screening as potentially having a low health literacy, reporting that they sometimes, often, or always required help with written health information on the SILS screening tool [24]. This indicates that our cohort are likely to be more health literate than the average population, where approximately 43% of individual citizens would require assistance with written health information [24,30].

Following thematic analysis, 92 subcategories that fell into 12 categories were derived from the transcripts. Three interlinking themes were identified (**figure 1**). **Table 1** summarises key quotes informing the individual categories and themes referred to within the text below. The participants described a failure in communication and information provision from infection clinicians and support staff in secondary care which subsequently influences the individual's future ideas about infections and their management. This alters the individual's future actions towards infections and

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3 antimicrobials and can drive non-adherence to prescribed antimicrobial regimes and loss-to-follow-up
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5 after discharge from secondary care.
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7 *Failures in communication*

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10 Participants described their experiences of being diagnosed with an infection in secondary care as one
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12 where they completely lost ownership of their condition. Control of their illness was taken over by a
13
14 multitude of healthcare professionals (HCPs). Recurring instances were identified where HCP
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16 communication with patients became unilateral when antimicrobial decisions were being made, with
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18 patients being “*told*” information, often devoid of key aspects such as names of medications, durations
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20 of treatment and prospective plans about time courses and potential escalation / de-escalation of
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22 therapy. This led to a significant amount of anxiety and frustration as the individual searched for
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24 answers.
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27 “*I was told ‘you have an allergy [to penicillin], take this instead’ – Tell me what I am taking*
28
29 *and exactly what it is going to do for me!*” [65 year-old male]
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32 Moreover, in many cases participants did not feel as if they were involved in the decision making
33
34 process around their infection management with two-way communication with healthcare
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36 professionals perceived as absent.
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39 As well as HCP communication with patients, participants reported becoming frustrated by
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41 communication between HCPs. This is centred primarily on the way in which information about
42
43 infections is communicated from secondary care doctors to primary care doctors on discharge from
44
45 hospital. Whilst patients are provided with a discharge summary of their stay on leaving hospital, it
46
47 was perceived that this often neglected information about their infection and the treatment which they
48
49 received whilst in the hospital. Participants’ reported that they were often forced to communicate this
50
51 information directly with their primary care physician on follow up visit or were otherwise lost to
52
53 follow up after discharge due to lack of clear communication pathways.
54

55 *Failures in information provision*

Patient engagement in infection management

1
2
3 The current volume and quality of information provided to individuals by HCPs in secondary care
4 causes problems for patients as it is often poorly explained, with medical terminology routinely used.
5
6 This leads to a feeling of dis-empowerment with individuals frustrated that they then have to “*go away*
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8 *and research it [their condition] themselves*” [23 year-old female]. Fear and anxiety follows when
9
10 participants see serious side-effects of treatment “*like risk of death [and] no one has mentioned that to*
11
12 *me!*” [30 year-old male]. This in-turn causes frustration as participants compare delivery of
13
14 information on infections and antimicrobials to that provided for operations and medications for
15
16 chronic disease, such as hypertension. In this example, patients are provided with explanations of their
17
18 procedure/condition, their management, and potential complications which may arise and how these
19
20 will be dealt with. In contrast, information on infection management is seen as a “*reactive*” process
21
22 where information is only often provided once complications have occurred. Furthermore, patients are
23
24 often unaware of the timeline for their treatment and the potential complications. This lack of clarity
25
26 drives individuals to stop treatments early or potentially ignore side effects experienced due to false
27
28 assumptions and misinformation.
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32 Participants reported that this failure in communication about infections and antimicrobials drives
33
34 them to seek information from a wide range of sources, often with varying degrees of quality.
35
36 Participants commonly sought information independently due to “*difficulties in accessing [healthcare*
37
38 *professionals]*” and the “*[time] pressures of work and children*” [65 year-old male]. A number of
39
40 avenues were preferred such as the internet, information leaflets provided with medications and local
41
42 pharmacies. Individuals will seek out recommended or official NHS sources of information which
43
44 they believe that they can trust to provide them with information on their infection or treatment.
45
46 Whilst these sources are seen as helpful, patients still prefer to discuss their infection and its
47
48 management with a HCP as this provides “*individualised*” information compared to the “*standard-*
49
50 *reply*” provided by alternative sources [69 year-old male]. This is because the information provided is
51
52 seen as being based on the patient’s own specific situation and issues. Furthermore, the HCP is a
53
54 “*trusted*” source being viewed as an “*expert*” [69 year old male].
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57 *Influences of future attitudes and behaviours*
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3 Participants clearly described how these individual experiences of poor communication and
4 information provision influence their future ideas and actions towards infection management both in
5 secondary care and in the community. Influences were described from three sources; personal
6 understanding / experiences, understanding by proxy, and understanding through the media.
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11 For example, one personal experience was described by a participant who was told that he had an
12 allergy to penicillin and told that he would be given a “weaker” type of antibiotic for his infection.
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14 When this was perceived not to be effective at clearing up the infection after two days, he stopped
15 taking his medication as:
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21 *“You know the weaker ones [antibiotics] never seem to clear the infection up. They are not as*
22 *strong so they don’t clear it up. The infection lasts longer” [60 year-old male]*
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25 This subsequently led to the participant having to return to secondary care for further treatment of his
26 infection due to the poor information provision and engagement in the decision process surrounding
27 his infection.
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32 The media’s role in developing the participants’ understanding of infection management arose and was
33 further explored during the focus group. Participants reported that the medias influence occurred
34 through the portrayal of stories about complications of treatment and the dangers of AMR. This
35 created fear and mistrust of medical professionals within our participant group, and caused participants
36 to be “cautious” when interacting with medical professionals at they are perceived to “not say the full
37 story” [21 year-old, female]. This distrust was reported as driving non-adherence to therapy in the
38 community by several members of the group.
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49 **Discussion**

50 *Summary of participant impressions*

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55 Within our participant group, individuals felt detached, frustrated and disempowered from
56 involvement in decision making about their own infection management within secondary care. The
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Patient engagement in infection management

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3 consequences of the failure of HCP communication and information provision reached beyond
4 secondary care, influencing the ideas and actions towards infections and antimicrobials during future
5 healthcare interactions along a number of different pathways. This fosters feelings of frustration and
6 anxiety during an individual's journey through complex secondary care pathways and potentially
7 drives non-adherence to prescribed antimicrobial regimes and loss to follow up after discharge. These
8 findings highlight the need for specialists in secondary care to not view infection management
9 episodes as discrete events, but as cumulative experiences which have the potential to drive future
10 non-adherence to prescribed antimicrobial regimes and thus the promotion of AMR.
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Opportunities for educating healthcare providers to improve patient engagement

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23 Importantly, HCPs must appreciate that engagement in the decision process for infection management
24 and antimicrobial prescribing may have an influence on future patient actions towards infections and
25 antimicrobial use. These actions can be influenced by personal experience along with those of friends
26 and family and what is described in the media. The way in which we communicate information to
27 patients was reported as the most important aspect in our participants' experience of infection
28 management in secondary care and was the largest influence on future actions in terms of adherence
29 to prescribed antimicrobial regimes and healthcare seeking behaviours. Participant perception of
30 communication in secondary care infection-related pathways is of a unilateral process which does not
31 invite patient participation. Greater emphasis needs to be placed on educating HCPs to move away
32 from the decision-maker role [31] into a more bilateral structure. Difficulties such as time pressure on
33 the HCP and the patient is perceived as a key factor by participants and must be taken into account
34 when designing interventions to help facilitate improved communication and patient education during
35 the decision making process. The way that these interventions are designed must be mindful of health
36 literacy, ensuring that the information provided to patients is understandable. Within our small cohort,
37 two of ten participants met screening criteria for health illiteracy. Within the UK, it is estimated that
38 up to 43% of the adults cannot understand currently available health information [24,30]. Therefore as
39 well as educating healthcare providers in how to improve communication with patients, consideration
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of the wording and type of health information supporting this is vital to allow patient engagement with the decision making process.

Opportunities for improving patient engagement with decision making

Within our cohort, participants felt strongly that the choice of information provided about their infection and antimicrobial therapy should be dictated by the patient's preference. However, their focus was not primarily on the end decision of whether or not to treat, but on feeling involved and engaged with the process of decision making. This focused on education about their condition and treatment, communicated effectively to them. They described a belief that if a trusted clinician felt they had an infection that required antimicrobial therapy then this was appropriate. Whether this is truly sharing the decision process or not is for consideration, as SDM classically acknowledges that there is a choice to be made, with the patient and clinician coming together to consider available evidence, the patients values and preferences before arriving at a decision [32]. However, Edwards and colleagues, suggest that this can still be classed as sharing the decision (or engaging the patient in the process) where the focus is placed primarily on involving the patient in the decision making process, rather than on who actually makes the final decision on management [33]. Our participants supported this approach to engagement by describing how they become frustrated and distrusting of the recommended therapy when supporting information about the infection and the proposed management is perceived to be withheld from them.

Participants currently view information provided about infections and antimicrobials as reactive in nature with information only provided after a side effect occurs or the patient fails to respond to a certain type of antimicrobial and therapy is escalated. Individuals want proactive information to help them understand what they are receiving, what to expect, and what the plan is if the treatment doesn't go to plan. This allows them to feel "prepared", "confident" and invested in the healthcare they are receiving. This is challenging for antimicrobial prescribing in secondary care, which is often an acute event, requiring rapid decision making, and has a short duration of therapy [34]. Moreover, this highlights a key area of misunderstanding surrounding infections and antimicrobial therapy within our participant group that has been driven by poor communication and information provision during

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2
3 previous experiences of infection management within secondary care. Therefore, future tools must
4 aim to promote patient engagement with infection management, considering how they define
5 engaging patients in the decision process. Moreover, these interventions must ensure that identified
6 deficiencies in how HCP communicate and provide information to patients are addressed to facilitate
7 improvements in the current patient experiences.
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10 11 12 *Strengths and limitations*

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14 This qualitative analysis aimed to map the current experiences of patients in antimicrobial decision
15 making but it does have limitations. Group facilitation within our study was carried out by two HCPs,
16 which may have influenced socially desirable participant responses to certain questions. To address
17 this dynamic between interviewer and interviewee, two observers' comments were also considered
18 during initial coding to highlight where the interviewer's position may have directly influenced
19 individual responses. For example, during discussion of participants perceptions of doctors attitude
20 towards prescribing antimicrobials, one participant apologised after voicing an opinion about doctors
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“...sign the prescription and get rid of the patient” [69 year-old male].

The noted anxiety about offending the HCP may have influenced other participants voicing their true opinion on the matter. Secondly, whilst small, this in-depth study provides key themes for future studies to explore the generalizability of and inform the design and evaluation of appropriate interventions. Furthermore, our findings were subsequently tested for validation within an independent group of citizens to search for further categories and themes within our local population. Finally, on comparison of the health literacy of our selected cohort of participants, the group appeared to be more health literate than estimates for the general population. Therefore, during subsequent intervention development and exploration, this aspect must be highlighted and considered as this may affect the generalizability of our results across the population.

58 *Conclusion*

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3 Within secondary care, specialists are failing to engage their patients with the decision making
4 process surrounding infections and their management. This ultimately leads to misinformation,
5 frustration and anxiety during an individual's journey through secondary care pathways and
6 potentially drives non-adherence to prescribed antimicrobial regimes and loss to follow up in the
7 community. Clinicians must stop seeing infection episodes as discrete events and approach them with
8 the understanding that previous negative experiences drive subsequent non-adherence to prescribed
9 antimicrobial regimes and potentially disrupting follow up of patients post discharge from secondary
10 care. Poor communication by HCPs and lack of quality information provided are the two leading
11 causes for this, often driving individuals to seek standard information from untrusted, online sources.
12 This aspect must be addressed through improving HCP education on patient engagement and through
13 development of interventions to support patient engagement in the process. Furthermore, these
14 findings have the potential to translate into other fields of secondary care, where poor engagement
15 also exists and benefits in patient outcomes through interventions promoting improved
16 communication and information provision are beginning to be reported. We call for the development
17 of clear and pragmatic mechanisms to educate HCPs and provide patients with the proactive
18 information they require about their infection and its management and engage them with the decision
19 making process.
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Contribution statement

All authors contributed significantly towards the planning this study and production on this manuscript. TMR, LSPM, BH & ECS ran the focus groups & were involved in data analysis. TMR drafted the initial manuscript with all authors contributing significantly towards its finalisation for submission.

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Competing interests

AHH has consulted for bioMérieux in 2013. LSPM has consulted for bioMérieux and DNA electronics in 2014. All other authors have no conflicts of interest to declare.

Data sharing

There is no additional, unpublished data available from this study.

References

- 1 O'Neill J. Antimicrobial Resistance : Tackling a crisis for the health and wealth of nations. 2014. https://amr-review.org/sites/default/files/AMR_Review_Paper_-_Tackling_a_crisis_for_the_health_and_wealth_of_nations_1.pdf
- 2 WHO. Antimicrobial Resistance Global Report on Surveillance 2014. *World Health Organ* Published Online First: 2014. <http://www.who.int/drugresistance/documents/surveillancereport/en/>
- 3 European Surveillance of Antimicrobial Consumption. Report on Point Prevalence Survey of Antimicrobial Prescription in European Hospitals , 2009. 2009. http://ecdc.europa.eu/en/activities/surveillance/ESAC-Net/publications/Documents/report_survey_antimicrobial_prescriptions_eu_hospitals_2009.pdf
- 4 Department of Health, Department for Environment Food and Rural Affairs. UK Five Year Antimicrobial Resistance Strategy 2013 to 2018. 2013;:43. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/244058/20130902_UK_5_year_AMR_strategy.pdf
- 5 Howard SJ, Hopwood S, Davies SC. Antimicrobial resistance: a global challenge. *Sci Transl Med* 2014;**6**:236ed10. <http://www.ncbi.nlm.nih.gov/pubmed/24828073>
- 6 Ashiru-oredope D, Sharland M, Charani E, *et al*. Improving the quality of antibiotic prescribing in the nhs by developing a new antimicrobial stewardship programme: Start smart-then focus. *J Antimicrob Chemother* 2012;**67**:i51–63.
- 7 CDC. Core Elements of Hospital Antibiotic Stewardship Programs. 2014;:1–25. <http://www.cdc.gov/getsmart/healthcare/implementation/core-elements.html>
- 8 Cruickshank M. *Antimicrobial stewardship in Australian hospitals*. 2011. <http://www.safetyandquality.gov.au/wp-content/uploads/2011/01/Antimicrobial-stewardship-in-Australian-Hospitals-2011.pdf>
- 9 Davey P, Brown E, Charani E, *et al*. Interventions to improve antibiotic prescribing practices for hospital inpatients. *Cochrane database Syst Rev* 2013;**4**:CD003543. doi:10.1002/14651858.CD003543.pub3
- 10 Charani E, Edwards R, Sevdalis N, *et al*. Behavior change strategies to influence antimicrobial prescribing in acute care: a systematic review. *Clin Infect Dis* 2011;**53**:651–62. doi:10.1093/cid/cir445
- 11 Benson K. Electronic data collection tools for quality improvement: antibiotic utilization project. *AMIA Annu Symp Proc* 2003;:788.
- 12 Butler CC, Kinnersley P, Prout H, *et al*. Antibiotics and shared decision-making in primary care. *J Antimicrob Chemother* 2001;**48**:435–40. doi:10.1093/jac/48.3.435

- 1
2
3 13 Edgar T, Boyd SD, Palamé MJ. Sustainability for behaviour change in the fight against
4 antibiotic resistance: A social marketing framework. *J Antimicrob Chemother*
5 2009;**63**:230–7. doi:10.1093/jac/dkn508
6
7
8 14 Goossens H, Guillemot D, Ferech M, *et al.* National campaigns to improve antibiotic
9 use. *Eur J Clin Pharmacol* 2006;**62**:373–9. doi:10.1007/s00228-005-0094-7
10
11 15 Huttner B, Goossens H, Verheij T, *et al.* Characteristics and outcomes of public
12 campaigns aimed at improving the use of antibiotics in outpatients in high-income
13 countries. *Lancet Infect Dis* 2010;**10**:17–31. doi:10.1016/S1473-3099(09)70305-6
14
15 16 Mangione-Smith R, Stivers T, Elliott M, *et al.* Online commentary during the physical
16 examination: A communication tool for avoiding inappropriate antibiotic prescribing?
17 *Soc Sci Med* 2003;**56**:313–20. doi:10.1016/S0277-9536(02)00029-1
18
19 17 McClure JB, Richards J, Westbrook EO, *et al.* Research Letter. *Am J Prev Med*
20 2007;**33**:436–7. doi:10.1016/j.amepre.2007.07.027
21
22 18 Prevention C for DC and. Gaining Consensus Among Stakeholders Through the
23 Nominal Group Technique. *Centers Disease Control Prev* 2006;:1–
24 2.<http://www.cdc.gov/healthyyouth/evaluation/index.htm>
25
26 19 Welschen I, Kuyvenhoven M, Hoes A, *et al.* Antibiotics for acute respiratory tract
27 symptoms: Patients' expectations, GPs' management and patient satisfaction. *Fam*
28 *Pract* 2004;**21**:234–7. doi:10.1093/fampra/cmh303
29
30 20 Wutzke SE, Artist M a, Kehoe L a, *et al.* Evaluation of a national programme to reduce
31 inappropriate use of antibiotics for upper respiratory tract infections: effects on
32 consumer awareness, beliefs, attitudes and behaviour in Australia. *Health Promot Int*
33 2007;**22**:53–64. doi:dal034 [pii]r10.1093/heapro/dal034 [doi]
34
35 21 Mohsin-Shaikh S, Garfield S, Franklin BD. Patient involvement in medication safety
36 in hospital: An exploratory study. *Int J Clin Pharm* 2014;**36**:657–66.
37 doi:10.1007/s11096-014-9951-8
38
39 22 Coxeter P, Del Mar CB, McGregor L, *et al.* Interventions to facilitate shared decision
40 making to address antibiotic use for acute respiratory infections in primary care. In:
41 Hoffmann TC, ed. *Cochrane Database of Systematic Reviews*. Chichester, UK: : John
42 Wiley & Sons, Ltd 2015. doi:10.1002/14651858.CD010907.pub2
43
44 23 Berg BL. *Qualitative research methods for the social sciences*. Seventh Ed. California
45 state, Long Beach: : Allyn and Bacon 2001.
46
47 24 Morris NS, MacLean CD, Chew LD, *et al.* The Single Item Literacy Screener:
48 evaluation of a brief instrument to identify limited reading ability. *BMC Fam Pract*
49 2006;**7**:21. doi:10.1186/1471-2296-7-21
50
51 25 Eliot & Associates. Guidelines for Conducting a Focus Group. 2005.
52 https://assessment.trinity.duke.edu/documents/How_to_Conduct_a_Focus_Group.pdf
53
54
55
56
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2
3 26 Ahmad R, Iwami M, Castro-Sánchez E, Husson F, Taiyari K, Zingg W H a. Defining
4 the user role in infection control. *J Hosp Infect* 2016;**92**:321–7.
5 doi:<http://dx.doi.org/10.1016/j.jhin.2015.09.018>
6
- 7 27 Pope C, Ziebland S, Mays N. Analysing qualitative data. *Nurse Res* 2011;**18**:4–5.
8 doi:10.1192/bjp.109.458.163
9
- 10 28 Bradley EH, Curry L a., Devers KJ. Qualitative data analysis for health services
11 research: Developing taxonomy, themes, and theory. *Health Serv Res* 2007;**42**:1758–
12 72. doi:10.1111/j.1475-6773.2006.00684.x
13
- 14 29 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research
15 (COREQ): A 32-item checklist for interviews and focus groups. *Int J Qual Heal Care*
16 2007;**19**:349–57. doi:10.1093/intqhc/mzm042
17
- 18 30 Rowlands G, Protheroe J, Price H, *et al.* Health Literacy. Report from an RCGP-led
19 health literacy workshop. 2014.
20
- 21 31 Coulter A, Collins A. Making Shared Decision Making a Reality: No decision about
22 me, without me. 2011.
23 http://www.kingsfund.org.uk/publications/nhs_decisionmaking.html
24
- 25 32 Collins A. Measuring what really matters: Towards a coherent measurement system to
26 support person-centred care. 2014. doi:10.7748/nr2011.10.19.1.25.c8768
27
- 28 33 Edwards A, Elwyn G. Inside the black box of shared decision making: distinguishing
29 between the process of involvement and who makes the decision. *Heal Expect*
30 2006;**9**:307–20. doi:10.1111/j.1369-7625.2006.00401.x
31
- 32 34 ESPAUR SSTF Implementation subgroup. Start Smart - Then Focus Antimicrobial
33 Stewardship Toolkit for English Hospitals. 2015.
34 [https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/417032/
35 Start_Smart_Then_Focus_FINAL.PDF](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/417032/Start_Smart_Then_Focus_FINAL.PDF)
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Box 1. Selection criteria for participation in in-depth focus group analysis of current experience of patient engagement with infection management and antimicrobial prescribing across secondary care.

Age 18 or older.

Equal gender mix.

Representative mix of ethnic backgrounds.

Must have been treated with antibiotics in the secondary care setting (this could include, out-patients, Emergency Departments, Urgent Care Centres or Ambulatory units) within the last 12 months. This should not have been level 2 or 3 care (e.g. high dependency units or intensive care) only.*

Preferable that they have been an in-patient in secondary care previously (but not an exclusion criteria if the above criteria are all satisfied).

* Individuals receiving antimicrobials in level 2 or level 3 care facilities only were excluded, given that they are likely to have been critically ill at the time of antimicrobial prescribing.

Table 1. An analytical framework developing categories and themes for patients' experiences of infection management in secondary care.

Quote	Category	Theme
"I wasn't given any education into what to do [with my antibiotics]. The 5 th day I felt well and so thought I would just stop taking the treatment. I was fortunate that my sister explained to me and made me complete the course" [24 year-old female]	Adherence support	Information provision
"Especially I think that you are often given more information when you are taking other medication... I have allergies to penicillin so always I have to know what kind of antibiotic I have been given. So unless your issues are more complicated, that's when they give you more information, otherwise I feel that they don't provide you with enough" [24 year old female No. 2]	Comparison with other treatments	
"I like to go and see the doctor... Online can't see me [sic]. Infection is a thousand different things and online can't confidently tell you, this is what you have..." [65 year old male]	Sources	Information provision / communication
"...you are not an individual to them [corporate pharmacists]. In our case, I think we have the option to be sort of individuals. That is what I find lovely about our current pharmacy!" [69 year old male]		
"I think what the problem that I have experienced is, is that they will give you a leaflet to read and I will have to go and research it myself. This is rather than the doctor taking the time to sit down and talk about how it might affect you, what exactly is in it [the antibiotic] – you know a proper consultation. [23 year old female]	Quality	Information provision / communication
"Rather than sitting down and taking the time to explain, because they use a lot of medical terminology that I do not know what they're talking about to be honest. I think that they need to take more time to be honest to sit down and make sure that the patient knows exactly what they are putting in your body and exactly what all the side effects were. Because I didn't know what I was reacting to..." [24 year old female]		
"I think sometimes the doctors normally come and diagnose you they usually tell.... They don't necessarily tell you what they are giving you, they usually prescribe it. Then the nurse just comes along with a pot full of drugs and you just take them. I think, unless you are intrigued and ask for it then the nurse will give you that information." [30 year old female]	HCP - Patient communication of information	Communication
"When you go into hospital, you feel as though the illness is not yours. You go in to hospital and everyone takes over, like 'we do this then we do that later'. You have no ownership in a way. You are going through it but you have no ownership over what is being done for you or what medication you are receiving." [23 year old female]	Decision making process	
"Tell me yes or tell me no... If you can't fix it I don't want to see you again because there will be no point... We've tried this it's not worked so we tried that... it is endless..." [65 year old male]	Emotion	Communication
You know, the hospitals I have experienced in [region] – I am not really keen based on the lack of information. It is more about; we're doing this operation – get you in, get you out." [23 year old female]	Hospital variability	
"When I went to A&E I visited my GP ... It is more about telling your GP what the symptoms were and what treatment you had rather than exactly what the infection is" [30 year old female]	HCP - HCP communication of information	
"My GP never knew anything. She had scheduled me in to have the hernia, but the appendix went first. And she was "oh have you..." [53 year old male]		

Patient engagement in infection management

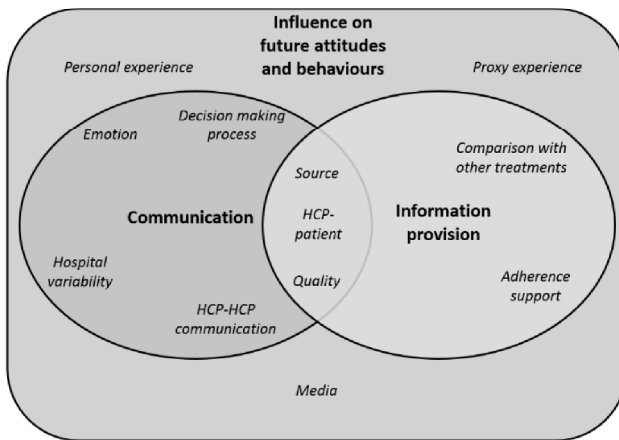
<p><i>"For me, I do not know the difference between an allergy and side effects. I would normally just try and cope with it and not go back to the doctors."</i> [24 year old female]</p> <p><i>"I left it a long time and then I got an infection tracking all the way up [my leg]. I went into A&E as I couldn't walk. When I was there they brought some student doctors and said "how bad is this leg" and I thought [this is bad]!"</i> [60 year old male]</p>	Personal experience	Influence on future attitudes and behaviours
<p><i>"They asked whether he was allergic and I said that I do not know he had never had them. After being given them he really severely reacted. He blew up with vomiting and was very very sick. We had to go back to casualty and get that sorted. So the thing that worries me about that is that I remember someone telling me that if you routinely have an operation, you are given penicillin routinely so it worries me whether that would have an effect if he was ill abroad..."</i> [52 year old female]</p>	Proxy experience	
<p><i>"I read an article a while ago about antibiotics and how they made people severely ill. A few people have died. I think it's just like... where I have heard about bad experiences.... you know they have never really pulled through for me."</i> [21 year old female]</p>	Media	

Legend: This data is an extract of quotes derived from thematic analysis of focus group interviews exploring participants' experiences of infection management in secondary care pathways.

HCP: healthcare professional, GP: general (primary care) practitioner, A&E: accident and emergency department

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Figure 1. The distribution of themes and categories contributing to individuals' experiences of decision making for infection management in secondary care pathways.



Legend. Healthcare professional (HCP) failures in communication and information provision influence individuals' future ideas and attitudes towards infections and their management. This alters their future actions towards infections and antimicrobials and can drive non-adherence to prescribed antimicrobial regimes and loss-to-follow-up after discharge from secondary care.

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Supplementary data 1 - Workshop Topic Guide

- Conducting a service evaluation to understand and improve the process of shared decision making during antimicrobial prescribing by clinicians in secondary care (inc. UCC / OP etc)
- We are interested in your own opinions and perceptions of this problem and not what you think others would want you to say
- Everything is kept confidential and no one within the Trust will know what has been said by you. To ensure that confidentiality is maintained you will be assigned a participant number
- We ask you however, NOT to reveal any specific personal information
- Time limit approx. **(as above)** to complete

Topic	Aims	My Questions
1. Introduction	<p>Consent</p> <p>Collect baseline demographic data</p> <p>Collect individual opinions for triangulation against collective group views</p>	<ul style="list-style-type: none"> • Welcome, brief outline of aims of day • Why you have been invited <p>Broad range of people who have been prescribed antibiotics in secondary care (or around) setting</p> <p>Want to explore what information you receive and how you engage with the decision making process</p> <ul style="list-style-type: none"> • Consent and baseline questionnaires (confidential). • Split into two groups to begin (delegated before session from participant charter provided by company)
2. Exploration of current issues during consultations	<p>Reflect on current level of information provided to patients by clinicians when prescribing antimicrobials</p> <p>Reflect on how this information is delivered in different settings (on the wards, admission vs. discharge)</p> <p>Explore whether this information is adequate</p> <p>Explore whether the participant feels as if they are involved in the decision making process in these scenarios</p> <p>Explore barriers to "successful" use of antimicrobials (i) in hospital and (ii) on d/c</p>	<ul style="list-style-type: none"> • Can you describe what kinds of information you were provided about the antibiotics you were prescribed last time you were in hospital (or similar) (i) at the point of prescription (ii) at the point of discharge • How did you receive this information? <p>Prompts for above:</p> <p><i>prescription? antimicrobial box insert? Printed information from the GP</i></p> <p><i>Did you read it?</i></p> <p><i>Did it give you the information you were looking for?</i></p> <ul style="list-style-type: none"> • Who gave you most of this information? <p>Prompt: Dr / Nurse / Pharmacist?</p> <ul style="list-style-type: none"> • Was there anything missing that you would like to have been told / had discussed with you? • What are the common questions about your infection/antibiotics do you ask your doctor? <p>Prompt: When do you ask these (during or after reflection)?</p> <ul style="list-style-type: none"> • Did you feel as though you were a part of the decision making process when you were you and your doctor discussed your infection / treatment? <p>1. Can you explain why you felt this?</p>

	with antimicrobials	<ul style="list-style-type: none"> • What extra information do you seek independently following discussion with the doctor? Prompt: Is this because: <ol style="list-style-type: none"> 1. There is not enough time to have questions addressed 2. The information provided is not clear 3. The patient has a personal view on allopathic meds? 4. You were embarrassed to ask the question? • What are the day to day challenges (i) in hospital (ii) following discharge with adherence to a course of antibiotics Prompt: Remembering to take the course / timings / monitoring for s/e's Do you complete the course? • What do they think is the major barriers to the above? Prompt: ? Lack of information ? Lack of understanding over importance ? Other • When you visit the GP after a visit to hospital do they know all of the details about the infection & antibiotics that you received during your visit? • How do they receive this information? • Would you be able to explain to the GP which meds you are on and why? Prompt: Do you tell them the majority of this info? If so how do you record it? Clinic letter / discharge summary? (do you feel they get the full picture from it?)
3. Feedback to group	Allow group to understand all issues identified during each groups session	<ul style="list-style-type: none"> • Leads briefly summarise each groups key findings • Allow discussion and consensus on any major points of difference which arise between groups
3. Generating approaches to solving these issues	<p>Explore what further information patients would like to receive</p> <p>Explore what other support with antibiotic use patients feel they require</p>	<ul style="list-style-type: none"> • How do you go about finding information about the infection or antibiotics you are given? (a) during your hospital stay (b) once your are discharged with them? • On attaining this information do you feel that it helps you participate more actively in discussions about your infection / antibiotic treatment with the doctors and other HCP's? Prompt:

	<p>Explore how patients currently acquire this information which they perceive as helpful / whether they receive this support</p> <p>Does this information empower them to take an active role in their infection / antimicrobial therapy</p> <p>Explore approaches that patients would like to be available to attain this information</p> <p>Investigate whether any other support would be helpful</p>	<p>Do you feel as if you are involved in the decision making? Do you feel that your views and ideas are considered?</p> <ul style="list-style-type: none"> • Is there any difference in the information you require on this (i) when in the hospital c.f. (ii) at the point of discharge on antibiotics <p>Prompts: Do you look up things the doctor tells you about your infection / antibiotics? Is this more helpful in or out of hospital?</p> <ul style="list-style-type: none"> • Are there any other measures that would be helpful in helping you better understand your infection / support you in taking the course of antibiotics? • Brain storm ideas of how patients could receive / access this information / support - Rank using nominal group tech. • Consensus through discussion <p>Prompt:</p> <ol style="list-style-type: none"> Route of info (app / email / text message / interactive / recording / webcast / paper based) What would be provided Level of detail Original info? Reputable source ? individuals own experiences (uncensored) Ideal timing to receive this information
<p>4. Triangulate</p>	<p>Confirm results generated through each group</p> <p>Explore whether there are any other comments / observations participants wish to make</p>	<ul style="list-style-type: none"> • Present both groups nominal group exercises • Summarise similarities and differences • Does anyone wish to discuss these?

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For peer review only

Table 1
Standards for Reporting Qualitative Research (SRQR)^a

No.	Topic	Item
Title and abstract		
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions
Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement
S4	Purpose or research question	Purpose of the study and specific objectives or questions
Methods		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale ^b
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability
S7	Context	Setting/site and salient contextual factors; rationale ^b
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale ^b
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale ^b
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale ^b
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale ^b
Results/findings		
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings
Discussion		
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field
S19	Limitations	Trustworthiness and limitations of findings

(Table continues)

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Table 1

(Continued)

No.	Topic	Item
S20	Other Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

*The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than the options available; the assumptions and limitations of each; the choices made; and how the choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

should provide evidence (e.g., examples, quotes, or text excerpts) to substantiate the main analytic findings.^{20,29}

Discussion. The discussion of qualitative results will generally include connections to existing literature and/or theoretical or conceptual frameworks, the scope and boundaries of the results (transferability), and study limitations.^{10–12,28} In some qualitative traditions, the results and discussion may not have distinct boundaries; we recommend that authors include the substance of each item regardless of the section in which it appears.

Discussion

The purpose of the SRQR is to improve the quality of reporting of qualitative research studies. We hope that these 21 recommended reporting standards will assist authors during manuscript preparation, editors and reviewers in evaluating a manuscript for potential publication, and readers when critically appraising, applying, and synthesizing study findings. As with other reporting guidelines,^{35–37} we anticipate that the SRQR will evolve as it is applied and evaluated in practice. We welcome suggestions for refinement.

Qualitative studies explore “how?” and “why?” questions related to social or human problems or phenomena.^{10,38} Purposes of qualitative studies include understanding meaning from participants’ perspectives (How do they interpret or make sense of an event, situation, or action?); understanding the nature and

influence of the context surrounding events or actions; generating theories about new or poorly understood events, situations, or actions; and understanding the processes that led to a desired (or undesired) outcome.³⁸ Many different approaches (e.g., ethnography, phenomenology, discourse analysis, case study, grounded theory) and methodologies (e.g., interviews, focus groups, observation, analysis of documents) may be used in qualitative research, each with its own assumptions and traditions.^{1,2} A strength of many qualitative approaches and methodologies is the opportunity for flexibility and adaptability throughout the data collection and analysis process. We endeavored to maintain that flexibility by intentionally defining items to avoid favoring one approach or method over others. As such, we trust that the SRQR will support all approaches and methods of qualitative research by making reports more explicit and transparent, while still allowing investigators the flexibility to use the study design and reporting format most appropriate to their study. It may be helpful, in the future, to develop approach-specific extensions of the SRQR, as has been done for guidelines in quantitative research (e.g., the CONSORT extensions).³⁷

Limitations, strengths, and boundaries

We deliberately avoided recommendations that define methodological rigor, and therefore it would be inappropriate to use the SRQR to judge the quality of research methods and findings. Many of the original sources from which we derived the SRQR were intended as

criteria for methodological rigor or critical appraisal rather than reporting; for these, we inferred the information that would be needed to evaluate the criterion. Occasionally, we found conflicting recommendations in the literature (e.g., recommending specific techniques such as multiple coders or member checking to demonstrate trustworthiness); we resolved these conflicting recommendations through selection of the most frequent recommendations and by consensus among ourselves.

Some qualitative researchers have described the limitations of checklists as a means to improve methodological rigor.¹³ We nonetheless believe that a checklist for reporting standards will help to enhance the transparency of qualitative research studies and thereby advance the field.^{29,39}

Strengths of this work include the grounding in previously published criteria, the diversity of experience and perspectives among us, and critical review by experts in three countries.

Implications and application

Similar to other reporting guidelines,^{35–37} the SRQR may be viewed as a starting point for defining reporting standards in qualitative research. Although our personal experience lies in health professions education, the SRQR is based on sources originating in diverse health care and non-health-care fields. We intentionally crafted the SRQR to include various paradigms, approaches, and methodologies used in qualitative research. The elaborations offered in