

# Complex narratives of health, stigma and control:

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## Complex narratives of health, stigma and control: Antimicrobial resistance screening among non-hospitalized refugees



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### ABSTRACT

Antimicrobial resistance (AMR) is often presented as a major public health problem globally. Screening for AMR usually takes place in clinical settings. Recent developments in microbiology stimulated a series of studies focusing on AMR in communities, and particularly in travelers (any mobile individual), which was argued to be important for identifying potential public health risks. Against this background, microbiologists have become interested in non-hospitalized refugees as one of the traveler groups. However, this attention to refugees has provoked some professional debates on potential stigmatization of refugees as dangerous “others”. To contribute to these debates, and to explore the idea of AMR screening of non-hospitalized refugees from different perspectives, we conducted a qualitative study among four groups of stakeholders who were chosen because of their associations with potential microbiological screening: microbiologists, public health physicians, public health nurses, and refugees. The study took place in a Dutch city from June to August 2016 and had 17 participants: five microbiologists, two public health nurses, four public health physicians, and six refugees. While microbiologists and public health physicians demonstrated a de-contextualized biomedical narrative in arguing that AMR screening among non-hospitalized refugees could be important for scientific research as well as for AMR prevention in communities, public health nurses displayed a more contextualized narrative bringing the benefits for individuals at the center and indicating that screening exclusively among refugees may provoke fear and stigmatization. Refugees were rather positive about AMR screening but stressed that it should particularly contribute to their individual health. We conclude that to design AMR prevention strategies, it is important to consider the complex meanings of AMR screening, and to design these strategies as a process of co-production by diverse stakeholders, including the target populations.

### 1. Introduction

The ever-increasing global level of antimicrobial resistance (AMR) is often presented as a major public health threat, resulting in an estimated number of human deaths that will dramatically increase from 700,000 in 2015 to 10 million in 2050 if left unresolved (O'Neill, 2016). AMR is defined by the WHO (2015) as an evolutionary process of development of microorganisms that acquire the ability to withstand antimicrobial drugs, thus making treatment of infections ineffective, and increasing the risk of resistant microorganisms spreading among

people, animals, and the environment. Microbiologists cite different sources of the emergence and dissemination of AMR, such as misuse of antibiotics in humans, animals, and the environment; mobility of human populations between regions and between care facilities (Selgelid, 2007).

Microbiological studies have focused on the emergence, control, and prevention of AMR within health practices. Scientists have studied the prevalence of resistant microorganisms in different groups of patients, for instance, in pediatric and intensive care units (Gaspari et al., 2006; Khurana et al., 2017). Based on similar studies, countries have

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developed their national guidelines on the prevention of AMR in hospital settings. For instance, the Netherlands developed a so-called “search and destroy” policy for AMR, that involves AMR screening of all hospitalized patients and isolation of those patients who are considered to be at risk groups (Kluytmans-Vandenbergh et al., 2005). Such risk groups include patients who received treatment in a foreign hospital within two months prior to hospital admission in the Netherlands, and farmers and members of their families who have contact with pigs, calves, or chickens (Werkgroep Infectiepreventie, 2017).

Recently, microbiologists in the Netherlands (Arcilla et al., 2017), Sweden (Tangden et al., 2010), and Australia (Kennedy and Colliqnon, 2010) conducted AMR studies among non-hospitalized populations such as international travelers (where “travelers” are understood as people who move from one territory to another, crossing national borders regardless of the purpose of their travel), and showed that travel can contribute to the dissemination of resistant bacteria from endemic to non-endemic parts of the world (Penders et al., 2013). In this regard, since 2014, refugees have attracted the attention of microbiologists and public health professionals as a mobile demographic group traveling between geographic areas (de Smalen et al., 2016; Heudorf et al., 2016).

Refugee studies on AMR have been conducted among hospitalized refugees upon their admission to clinics (Reinheimer et al., 2016; Tenenbaum et al., 2016). For example, in their research on AMR among hospitalized refugees in Germany, Reinheimer et al. (2016) showed that 61% of 143 refugees carried AMR, compared to 17% in the German population. Based on these data, the authors proposed that refugees admitted to hospitals be required to undergo a compulsory AMR screening, which entailed a departure from regular AMR control practices in Germany (we have to add, however, that since the end of 2016, individuals that have been in a refugee center in the past two months are screened for AMR upon hospital admission in the Netherlands and several other European countries, including Germany). Other scientists have also suggested that AMR screening should be compulsory for refugees admitted to hospitals (de Smalen et al., 2016; Maltezou et al., 2017). Considerably fewer studies (Angeletti et al., 2016; Heudorf et al., 2016) have been conducted among healthy refugees (“healthy” and “non-hospitalized” will be used as synonyms for the remainder of the article), and therefore the data on the prevalence of AMR among healthy refugees is scarce.

AMR screening involving both healthy and hospitalized refugees provoked discussions about vulnerability and potential stigmatization of refugees as subjects of AMR screening (Walter et al., 2016). The question of stigmatization of refugees with regards to AMR has been analyzed by social scientists and anthropologists. For instance, in their analysis of politics of AMR in the UK, Brown and Nettleton (2016) demonstrate how the political discourse of AMR is framed in the concepts of “trauma” and “catastrophe”. They argue that the meaning of AMR in British politics has been shifted from being understood as “biological resistance” into “resistance of economies”, creating a platform for articulation of new political discourses, which associate the “catastrophic” threat of AMR with politics of immigration. In addition, the same authors, in their analysis of debates about antibiotics and AMR that take place among “lay people” on a popular online forum, showed how debates on antibiotics resistance became entangled with debates on public politics and personal responsibility (Brown and Nettleton, 2017). AMR, they argue, provokes a moral reflection on biopolitical responsibility of citizens for their individual immunary practices, such as antibiotic use, hygiene, or immunization (Brown and Nettleton, 2017). Other scholars have analyzed the use of the notion of responsibility with regard to carriers of communicable diseases like SARS, Ebola, and HIV, transforming victims into agents (Wald, 2000, 2007). In his work, Wald reflects on the theory of Mary Douglas (1966) who described how the dichotomy between “dirty” and “pure” relates to the distribution of power in society. Douglas explained that social order entails the construction of controlling mechanisms that restrict

potential dangers and “sources of disorder” caused by “others”, and the dirt-pure dichotomy helps to facilitate that.

These studies show the complex relationship between health, stigma and control as a fruitful lens to study AMR screening among refugees as a traveling group. Discourses of catastrophism and responsibility for acquisition of AMR may create a potential danger that refugees coming from endemic areas are held responsible for disseminating resistant bacteria to host countries and imposing a danger upon other people. AMR screening of refugees can be seen as a mechanism that helps to control the dangers coming from “others” who bring potential threats to the bacterial order of a host community. From the perspective of these studies, discussion about AMR screening may construct refugees not merely as people seeking asylum but as bodies polluted by foreign bacteria (Chandler and Hutchinson, 2016). Therefore, when speaking about AMR screening of refugees, it is important to analyze the complex meanings of such an intervention.

Current debates regarding justification or non-justification of AMR screening among non-hospitalized refugees take place in scientific journals between different scientists (Kempf and Heudorf, 2016; Walter et al., 2016). Refugees, however, do not often have a voice in these debates. The present article aims to fill that knowledge gap and to explore the voices of different professionals as well as refugees regarding the idea of AMR screening. For this purpose, we conducted a qualitative study involving microbiologists, public health physicians, public health nurses, and refugees. We explored how these four groups give meaning to potential voluntary AMR screening among healthy refugees, and how they consider the possible rationale, benefits, and harms of such screening. To be sure, when discussing AMR screening, we mean voluntary microbiological screening among non-hospitalized refugees. Although we acknowledge the complexity of the concept, for our study we opted for a broad definition of screening. When discussing it with participants, we spoke about AMR screening as a broad practice that included collection of stool samples for research and/or public health purposes.

## 2. Methodology

We studied four stakeholder groups who are already involved with health issues of refugees, and who potentially could be involved in AMR screening among healthy refugees: microbiologists, public health physicians, public health nurses, and refugees originating from Syria. Refugee participants included both people who had already obtained their official status of refugees and received their residence permits, and those who were still in the process of applying for asylum. The study was conducted in a Dutch city from June to August 2016. It involved a variety of qualitative methods, including observations of participants in their daily life and professional activities, in-depth interviews, group interviews, and informal discussions with participants. We decided to use qualitative methods as they provided us with an opportunity to analyze in-depth meanings that different stakeholders gave to the phenomenon of AMR and to the idea of AMR screening of refugees.

### 2.1. Research participants

Microbiologists who participated in the study had experience working with AMR in clinical (diagnosis, therapy, and prevention) and research settings, including microbiological screening of travelers. At the time of our study, two microbiologists were actively involved in developing a research proposal for AMR screening of non-hospitalized refugees in the Netherlands. Therefore, the interviews and discussions were of particular interest for them.

The public health physicians and nurses have practical experience and knowledge in working with hospitalized patients who carry resistant bacteria, as well as experience in working with national AMR prevention programs. In addition, participants from these two groups have experience in communicating with refugees in the context of

implementation of prevention strategies in asylum centers. It is important to note that public health physicians and public health nurses who participated in the study worked at the same organization in one office, and therefore they knew each other and collaborated with each other on various public health programs.

With regard to refugees, we chose to narrow our focus to Syrian refugees, because at the time of the study they comprised the largest refugee group in Europe (UNHCR, 2017). We collaborated with one of the master's program students from Maastricht University in the Netherlands, who himself was Syrian and worked as a physician in a hospital in Syria before his arrival in the Netherlands. His background and knowledge of the Arabic language helped us to build contacts with people in the asylum-seeker centers. He assisted as a translator during two interviews with refugees and explained language nuances.

## 2.2. Qualitative study

The study involved 17 participants: five microbiologists (two female and three male), two public health nurses (two female), four public health physicians (two female and two male), and six refugees (three female and three male). The number of participants was determined by data saturation. The age distribution at the year of the study among refugees was between 24 and 60 years old, and among professionals between 35 and 63 years old. The first author visited microbiologists and public health professionals at their offices, and refugees were interviewed at asylum-seeker centers, either in their private rooms or in interview rooms. All interviews were conducted in English, apart from two interviews with refugees that were conducted in both English and Arabic at the request of the interviewees.

All interviews were tape-recorded after written informed consent was provided, and participants received a copy of the consent form with the researchers' contact information and affiliations. Interviews were coded for anonymity and transcribed verbatim. Interviews were read and discussed with all authors. Based on the literature from sociology of diagnosis and anthropology of AMR, the first author defined categories for interview analysis that were relevant to the study. These categories were discussed with the other authors, and subsequently modified. The final analysis of the interviews was discussed with and modified by all authors.

The process of inviting refugees to take part in the qualitative study required several steps. After having obtained permission to visit two asylum-seeker centers from the centers' administration, we visited the centers four to six times over two weeks to introduce ourselves, our study, and the issue of AMR to potential participants. During these weeks, we met the administration of the center and refugees from various countries, not only Syria. In the next months, we visited the asylum-seeker centers one to three times per week. During this fieldwork, we heard stories about the process of immigration and the previous lives of refugees in their countries of origin.

During our initial visits to asylum centers we introduced ourselves as researchers and approached people whom we met in communal areas, such as kitchen, common rooms with tennis table and TV, and communal spaces outside the buildings of the centers. Syrian refugees who expressed their interest in participating in the qualitative study were provided with detailed oral and written information about the research, and its aims and objectives. Information was provided in both English and Arabic. In addition to voice-recorded qualitative interviews, the first author conducted observations of the daily life of refugees and asylum seekers and made notes on the informal discussions with participants.

After the study was completed, a report was sent to all the participants in order to receive their agreement or disagreement with the authors' interpretations of the data collected. We received feedback from all public health nurses and physicians, and four microbiologists provided their comments. However, none of the refugees replied to the report. One of the participants explained that he did not have time to

read through it; another person commented that it was too difficult for her to read long texts in English. In addition, some of the people who participated in the study moved to other asylum centers or received their housing by the time the report was sent out, and therefore we could not trace them.

## 2.3. Ethical clearance

According to Dutch regulations, qualitative studies do not require a legal approval from an ethics committee. However, we made a decision that it was crucial that the study be conducted in an ethical way and therefore applied for ethical clearance. The study was approved by the Medical Review Ethics Committee of the Maastricht UMC+ (approval number METC 16-4-117.1/ab).

## 3. Findings: understanding AMR from different perspectives

### 3.1. Screening is required for prevention and research

Both the microbiologists and the public health physicians presented AMR as an alarming public health problem, and therefore, generally supported the idea of AMR screening of healthy refugees. They provided a rather de-contextualized justification of AMR screening, arguing that screening of refugees entering the country can be essential for public health as well as for the necessity of research. In interviews, microbiologists argued that non-hospitalized refugees are an important and large population that cannot be ignored when it comes to potential health threats.

There are so many people [refugees] coming in right now, it should not be ignored, it is public health and it should be studied. (M2).

It is research [AMR screening of healthy population] that has a rationale in knowing more about to which extent resistance is threatening us and will threaten us in the future. (M3).

By the time the study was conducted, unless a refugee had been treated in a foreign hospital in the last two months before her hospital admission in the Netherlands, she did not need to undergo obligatory screening for AMR. Public health physicians argued that the AMR study among non-hospitalized refugees would help to determine whether refugees should be added to the category of a risk group for obligatory AMR screening during their admission to a hospital regardless of whether they were in a foreign hospital before.

It is useful to have some background information about the risk levels within our community, or within our region. ... If we find that AMR is high in refugees that would necessitate hospitals to deal with them in the same way as with people who spent some time abroad or who were admitted to a hospital in a foreign country – isolate them, screen them, and treat them if necessary. (PHD3).

In addition, microbiologists pointed out that AMR studies among healthy populations, including refugees, could be important for developing scientific knowledge in the field of microbiology.

The data not primarily used for the participants [healthy populations], it primarily used to get further in the professional field. And that is something which also has to be considered, which research should be done which is good for the professional field. (M3).

While the participants came up with a biomedical justification of AMR screening of refugees and do not refer to political issues, social scientists have demonstrated that this distinction between science and politics is difficult. Brown and Nettleton (2016) described how in the mid-2000s in the UK, conservative politicians were trying to lobby a policy that would impose "compulsory screening of migrants prior to departure from their countries of origin". Such policies, as the authors emphasized, merge discourses of bio-politics of race with those of

infectivity, thereby stigmatizing newcomers as dangerous, and shaping the image of AMR as a threat coming from the outside.

Although ideas about the scientific rationale for AMR screening of healthy refugees were widely accepted by microbiologists and public health physicians, not every interviewee agreed with them. One of the microbiologists, who was working as an internist in infectious diseases, was not particularly convinced about the potential clinical benefits of AMR screening of non-hospitalized refugees. While he agreed that the data from such screening might be interesting, he emphasized that it was hard for him to see why microbiological screening of healthy refugees would be necessary.

When there is no problem [when refugees are healthy], well, it's a lot harder for me to see the importance of screening. Because why should you screen, there is no problem there. No, there is no problem there. Maybe you might screen them just as a baseline. For example, we do not know anything about refugees and about antimicrobial resistance prevalence so you want to know at the baseline what is actually the prevalence of antimicrobial resistance among healthy refugees. When it is 0, then we do not have to be afraid, but when it is 80%, maybe we have a problem there. So for research, maybe it is interesting just to know, is the carriage of resistance a problem there, in that population. (M5).

However, the same participant indicated that microbiological screening of healthy populations who are not refugees might be beneficial for public health in general and clinical practice in particular.

With regards to the screening of the healthy population, well, I think we all want to better understand, for example, how resistance is transmitted. Is it taken from abroad and then introduced for example to the Netherlands? And how is it, by hand contact, or by fecal contamination, or by air? You can think of all kind of things. So I think when you want to fight against antimicrobial resistance and you see that as a problem, I think it is really wise to understand how does it really spread among the population. And one way to look at it might be to screen healthy volunteers who have traveled all over the world, and screen if they carry antimicrobial resistance bacteria. (M5).

One of the limitations of AMR screening among healthy refugees that was mentioned in the interviews was the lack of any personal benefits for participating refugees, because there is no treatment for resistant bacteria in healthy people. The screening may, for instance, indicate that a healthy refugee carries the  $\beta$ -lactamase gene, but this knowledge will not benefit her, as she cannot be treated for it. One of the microbiologists explained this difficulty while talking about the AMR study conducted with international travelers:

We screened them [travelers] for antimicrobial resistant bacteria in gastrointestinal tracts of healthy subjects basically, and if a person is positive, we know that. Before travel 6% of the travelers were positive, when they came back, 34% were positive so there was a huge increase. But we cannot do anything with that, we can only tell them that you have antimicrobial resistant bacteria and that's it, people don't have any benefits from it, there is no treatment from it, there is also not any harm as far as we now know as long as they are healthy. ... We were very reluctant in telling people whether they are positive for antimicrobial resistant bacteria, we did not want to worry them ... We really think it was not very wise to scare people with something. .... Then we decided not to communicate results individually to people. (M2).

However, other microbiologists and public health physicians emphasized that the decision to not report individual results back to participants might also be problematic, because people often want to know their data. Emphasizing this complexity, one of the microbiologists described how she herself felt uncomfortable not knowing her individual results from the AMR study in which she participated.

We are mainly studying resistance in the total community, so also in common cells, so we are saying to also the people that help us in the study, and to participants, that we don't really know yet what it means if you have this. And of course, I mean, like I participated in some of our own studies as well and all of a sudden, you know, then you start wondering like, "Hmm, do I have a resistance in me or not?", you know. It is, it is just strange, what does it mean and I tell everyone, "Oh, it does not mean anything, we do not know, we have not seen any evidence yet that you have more risk of infection", but still when it was all of a sudden, when it was about me, I thought, "Hmm, I actually want to know if I have or not have it." So yes, but in general, since we do not know what it means we do not report it back to people. (M1).

Microbiologists understand that while the technology of screening may provide them insight in the bacterial world of a healthy person, it does not give them an instrument to control this world. In this context, AMR screening of healthy individuals reveals unruly "intolerant bodies" that pose potential risks to these persons themselves and to others (Anderson and Mackay, 2014). Both microbiologists and public health physicians emphasized that the knowledge from AMR screening can be used in developing medical guidelines for healthcare practice, and they generally expressed support for the potential AMR screening of healthy refugees. The arguments for such screening are rooted in a de-contextualized biomedical discourse that does not anticipate the contextual risks of associating refugees with AMR.

### 3.2. Screening is not fruitful for healthy persons

As opposed to the discourse of microbiologists and public health physicians, public health nurses expressed a more personal and contextualized orientation to AMR, and they were hesitant about the idea of AMR screening of healthy refugees. They doubted whether such a study could bring any benefits to refugees, and whether possible public health benefits outweighed personal considerations. Public health nurses argued that microbiological screening would only stimulate worries among refugees about their health status as well as uncertainties regarding the screening itself, because AMR is not a common medical concept. According to nurses, AMR screening is a technique that is used in hospital settings, but one that should not be offered in the context of a general, non-hospitalized population.

The population is not ill at the refugee center; there is no need to do screening. It [AMR] does not do anything with healthy people. ... If you test them at refugee center, what would you do? You can't do anything with this knowledge, you can't treat them. (PHN1).

Public health nurses who participated in our study always worked with individuals (e.g. for STD or TB testing), and they had experience as nurses in hospitals, as well as in providing AMR training for nurses, and in providing educational programs about AMR in secondary schools. The direct interactions with diverse publics may explain why they were rather negative about the idea of offering microbiological screening to all refugees for public health purposes. Based on their experience of educating laypeople about AMR, public health nurses expressed that the lack of knowledge about AMR among the general public can cause prejudice, hostility, and stigma toward people with AMR or groups that would be offered AMR screening. They argued that this could particularly affect refugees, who are already presented by many media channels as dangerous others. This worry is mirrors the understanding of stigma as fear of otherness and "anomaly" (Douglas, 1966; Goffman, 1968). As Douglas (1966) points out in her analysis of the notion of dirt, societies marginalize people if they have been in contact with unknown "danger". In the context of AMR, this danger comes from resistant microbes. However, as microbes are embodied within bodies of people, they transform carriers from being "victims" of microbial activity to "agents" that represent bacteria-host relationships (Wald, 2007). One of

the examples given was about a boy with AMR who had problems with going to a school for people with disabilities because he was claimed to be dangerous to other children.

One child who has MRSA [resistant bacteria], and he is going to new school and there is some rumors, some negative excitement about it in the school. Really, really bad. It is a school for children who are disabled, and some people worried a lot about consequences of MRSA for other people and for themselves. (PHN2).

Moreover, public health nurses emphasized that there is a lack of knowledge about AMR among nurses in hospitals who often do not fully understand what AMR means and why some actions must be taken, for example, isolating patients with AMR:

When I was a nurse in the hospital, I just got the instructions that this is the person with MRSA, here is your coat, and your gloves, and your mask. But they did not explain to me really what the point was, I was a bit concerned that if it is MRSA, then I have to be very careful, and I was tested afterwards if I was clean or not. But they never explained to me well why I had to do it, I just did it very carefully because I was scared. And it is also stress for the patient because even the nurse can't explain him why these measures are taken. (PHN2).

With this background of communicating with different patients who carry AMR and must be isolated in hospitals, public health nurses applied more contextualized approach to patients and potential volunteers in AMR screening. When speaking about the idea of AMR screening of refugees, they were focusing not merely on public health benefits, but rather on the complexity involved in the concept of AMR. They point to the lack of familiarity with AMR among both patients and nurses and the potential for provoking fear among both refugees, who are not able to do anything about their AMR status, and the general public, who may perceive refugees as carriers of dangerous microorganisms.

### 3.3. What kinds of benefits does it bring us?

All refugees who participated in the qualitative study had been living in the Netherlands for at least six months. All participants came to the Netherlands through Turkey and Italy, traveling from Italy to the Netherlands by train or car. Two of the participants had a high school education, and another four had either finished higher university education or not yet finished (because of the war in Syria).

The phenomenon of AMR was introduced to refugees in two steps. First, we had informal conversations in small groups in both English and Arabic about AMR, its causes and possible health consequences for a person with resistant infection. Then, written information in both languages was provided. Most of our participants had never heard the English term “antimicrobial resistance” before; however some of them were familiar with its Arabic analog. They explained that AMR is a bodily condition that relates to the ability to fight a disease.

Antimicrobial resistance is a resistance of your body against microbes, if you have enough white blood cells your body will fight the disease, but if you have less white blood cells you have immune deficiency and your body will not fight the disease. (R5).

Another person elaborated the reasons for AMR by making a connection between the development of resistance and consumption of antibiotics:

In Syria we take a lot of antibiotics. So maybe the genes they have immunity for this medication. ... Because we take a lot of antibiotics in Syria, our body gets used to it. So how much stronger from antibiotic [no matter how strong the antibiotic], it will not affect us. (R1).

At the same time, refugees argued that they had to consume

antibiotics anyway because they help in treating diseases. One participant explained that although he understood that overuse of antibiotics may harm his body, he still wanted to use them because it can help alleviate pain. Such idea, as they explained it, is rooted in practices that people followed in Syria, where they could access and use antibiotics whenever they thought they were needed.

In our country, we were taking antibiotics when we had something, or even a small pain in our body. (R4).

This way of understanding antibiotics as something essential for healthy living is not unique. Scientists in anthropology use the metaphor of “charm” to describe how different people understand this medicine as “magic bullets” that have the power to heal (Chandler and Hutchinson, 2016). Unwanted effects of antibiotics, such as AMR, are either unknown or deemed to be unimportant in comparison with the treatment capacity of the drug. The Dutch system of antibiotic regulation was foreign to our participants who arrived from Syria. They preferred to consult their pharmacists instead of general practitioners, and to buy medications directly from a pharmacy while avoiding medical consultations.

Our pharmacy is our own doctors ... I hate Dutch hospitals because when you call them they tell just to take paracetamol. ... Paracetamol will not make any difference if you are sick. Some people in Syria take antibiotics every day for headaches, most people have headaches. (R2).

When discussing the idea of AMR screening among healthy refugees, some participants were rather positive about potential participation, because they considered participation in screening as a way to get more insights into their personal health problems and to get advice that would help them to maintain their health.

It [screening] would be helpful for me, I can take care about myself. If there is something bad with me, the researcher will tell me. (R1).

It [screening] will be helpful to take care of myself if there is any problem. So it is good for me. (R2).

One of the participants explained that potential AMR screening is an important preventive health measure for individuals, and thus he would like to participate in it:

If person has something wrong they [researchers] try to fix it, they are trying to make him better. ... Research is for the person. They will do research to know what medicine is good for the person. ... If someone has something not good they will try to get him better, to get him in a hospital, it [screening] is better for us. (R1).

People participating in our qualitative research considered it necessary that potential information obtained through the AMR screening be shared with them and that it should benefit them. They pointed out that the practices of antibiotic use in their home country were the only ones that they knew and believed to be right, but they argued, if these practices may actually harm them, researchers must tell them and share their knowledge about better practices.

You should tell us what to do to make us feel better without taking antibiotics, because I don't know how. (R4).

We also explored concerns and worries about potential harms of AMR screening. When we discussed general medical checks that refugees are required to undergo upon their arrival in the Netherlands and the possibility of voluntary microbiological screening, it became clear that people felt a little awkward: One person said: “We are clean, really” (R2). Another person mentioned: “... do not tell the media about it [AMR screening]. Because if you tell the media, media will tell it all wrong” (R1). In this context, all Syrian interviewees questioned why potential AMR screening was discussed only with respect to refugees. They argued that if this screening has important health benefits, it must

be offered to everyone and not exclusively to refugees. One of the participants raised a number of questions about the rationale of offering AMR screening exclusively to refugees.

What will affect me, what will I have, what the benefit from it on me, does it help me, does it help all the refugees, is there anything wrong, did you suspect something, I have all these questions. So, did you suspect something from me as a refugee, why you are doing this research only for Syrians, are you suspect something, or just trying to help us? (R1).

Some people worried that if they showed some signs of a serious health problem, their asylum applications would be rejected. In fact, one of the refugees was reluctant to ask for medical assistance for her son before they arrived to the Netherlands.

My son [4 years old] had a very high temperature [during their travel to the Netherlands], but I had medicines with me. Also, you know, when we had a problem, we were afraid to go to the doctor because we have to arrive to Europe without any problems. ... So I just gave him some antibiotics, he felt better, and we continued. (R4).

The refugees with whom we spoke demonstrated a complex narrative about AMR screening. They consider the benefits of screening for public health, but they also add that then AMR screening should be offered not only to refugees but to other travelers as well. They also consider the benefits of AMR screening for the individual health of refugees, but they express fears that promises of anonymity will be broken and that results of AMR screening could affect their asylum applications in a negative way.

#### 4. Discussion and recommendations: complex narratives about health, stigma and control

The purpose of our study was not to judge which perspective on microbiological screening of healthy refugees was the most scientifically sound or ethically justifiable. Instead, our aim was to understand how different stakeholders give meaning to AMR screening, and how they understand “proper” AMR screening of healthy refugees.

It is important to note some limitations of our study. First, the study involved a small number of participants – 17 people. However, this allowed us to make an in-depth analysis of the complex narratives of the participants. Second, we decided to focus on four stakeholder groups who may be actively involved in the process of AMR screening of healthy refugees, although the spectrum of perspectives on this issue can be broader. Third, we deliberately involved only English-speaking refugees who had experience of direct communication with Dutch health professionals, although it excluded other potential participants who might have different perspectives on AMR and AMR screening. In addition, as was emphasized at the beginning of the article, our study was focused on voluntary AMR screening, because microbiological studies are currently at the stage of studying the prevalence of AMR among refugees. However, if microbiological screening demonstrates a high level of AMR among refugees, it is probable that obligatory AMR screening will be recommended for this group. Therefore, we would like to elaborate that further studies and ethical reflections on the potential stigmatization are important in this developing field.

While biomedical discourses about AMR tend to distinguish the scientific insights about AMR from the political issues, social scientists have shown that AMR discourses are more complex and that symbolic meanings about purity and danger, and self and others are intertwined with AMR policies and practices (Brown and Nettleton, 2016; Chandler and Hutchinson, 2016). Our study shows that stakeholders engaged in discussing AMR screening among refugees express different perspectives: we found a narrative about screening that emphasizes the problem of AMR and the benefits for science and public health, but also narratives that articulate the ambiguities of screening healthy refugees,

pointing to the health benefits for refugees and communities as well as to the risks of stigmatization and exclusion. When discussing making AMR screening of healthy refugees a national or European practice, it is important to realize that policies are always developed in concrete contexts where complex narratives are operative.

Following the work of Fleck (1979) on thought styles and thought collectives, Penders et al. (2009) argued that different thought styles also produce different notions of “proper” science. From this perspective, we can interpret the different perspectives of the stakeholders as reflecting different thought styles, different practices, and different notions of “proper AMR screening”. For microbiologists as well as for public health physicians who worked mainly with public health issues on the level of the laboratory and statistics, the crucial argument for screening was the potential threat of AMR to the community and the opportunity for monitoring on a population level. For them, this could be done anonymously, and the subject of screening with her social status, cultural background and political affiliations may be unknown. The practice of public health nurses, on the contrary, entails meeting and caring for individual patients. Therefore, they considered AMR screening to be important on the level of detecting personal health risks, not merely on the statistical level of public health. From this perspective, AMR screening of healthy refugees was not considered fruitful. At the same time, Syrian refugees saw AMR as a bodily, personal health condition that affects people when they are ill but that could be prevented if a person has appropriate information about, for instance, antibiotic use. From this perspective, the refugees could see the benefits of screening of healthy refugees, but only when the results will be made beneficial for broadening AMR screening to larger populations.

These different perspectives on proper AMR screening that stem from different everyday practices and thought styles mirror broader ethical discussions about AMR, known as “the tragedy of the commons”. Whether AMR is recognized as a public or a personal problem would require putting either the community before an individual or vice versa (Foster and Grundmann, 2006; Hardin, 1968). Various studies have demonstrated that professionals in the medical and public health fields have different ideas about this dilemma and give preference to either personal health (Broom et al., 2014; Metlay et al., 2002) or public health (Oczkowski, 2017). However, our study suggests that the debate about potential AMR screening among healthy refugees should not only consider prioritizing an individual or society, but also how eventual AMR screening of a healthy population is framed and organized. In that respect, the input of the refugees is illuminating. While they demonstrated a belief in antibiotics as “magic bullets”, they also argued that they would like to be informed about their individual AMR status and potential ways to protect their health (such as proper intake of antibiotics). Moreover, refugees stressed the importance of framing AMR screening among healthy refugees in a non-stigmatizing way, for instance by labeling it “AMR screening among travelers” instead of “AMR screening among refugees”.

Science and Technology Studies (STS) (Jasanoff, 2004; Rabeharisoa and Callon, 2004) stresses that production of knowledge and technologies requires co-production of science and society. More specifically, Oudshoorn and others have demonstrated that “users matter” (Oudshoorn and Pinch, 2003; Oudshoorn et al., 2004): interaction with diverse users is crucial for designing and developing robust knowledge and “working” technologies. Several studies have emphasized that co-production requires constructing a dialog and interaction between different styles of practices that in turn may lead to the creation of new collective identities around a particular issue (Brown, 1992; Rabeharisoa and Callon, 2004). Because public health has developed as a policy-driven field that is dominated by epidemiology, it has difficulty relating to diverse publics (Horstman, 2013). The lessons of STS are highly relevant for this field. Our study can be considered a first step toward co-production around the discussion of AMR screening of healthy refugees. Instead of assuming what is scientifically or ethically

proper AMR screening, we explored thought styles and practices among different actors, because the making of scientifically, socially, and ethically proper screening depends on collaboration and dialog between these actors. Instead of relying only on technical experts, including the voices of others reminds us that the tragedy of the commons is not an immutable problem, but is one that can be shaped and reshaped through engaging diverse actors representing different styles and practices in processes of co-production.

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