RISE-Vac: Co-production of vaccine education materials with people living in prison

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**Abstract**

Increasing vaccination knowledge is effective in addressing hesitancy and is particularly important in populations deprived of liberty who may not routinely have access to health information, ensuring health equity. RISE-Vac is an EU-funded project aiming to promote vaccine literacy, vaccine offer and uptake in European prisons. We consulted people living in prisons in the UK (through the Prisoner Policy Network), in France, in Italy and in Moldova in order to understand their vaccination knowledge gaps, the information they would like to receive and how they would like to receive it. We received 344 responses, 224 from the UK, 70 from France, 50 from Moldova. Participants were particularly interested in learning about the effectiveness, side effects and manufacturing of vaccines. These responses guided the development of educational materials, including a brochure that will be piloted in European prisons. People with experience of imprisonment were involved in every stage of this project.

**Introduction/Background**

There is a higher prevalence of infectious diseases among incarcerated people than the general community *(1)*. This can be linked to many factors, including: contextual factors of the prison setting, such as overcrowding, delays in diagnosis and treatment, and high population turnover *(2)*; and population characteristics including higher prevalence of smoking cigarettes and engaging in commercial sex work *(3,4)*. However, some diseases with higher prevalence amongst prison populations - such as Human Papilloma Virus (HPV), influenza and viral hepatitis *(5,6)* - can be prevented through vaccination. Vaccination remains one of the most cost-effective public health interventions in the community; in the prison context, vaccination could help control infectious disease transmission and outbreaks, reducing morbidity and mortality in PLP as well as protecting prison staff and the rest of the community *(7,8)*. However globally there is poor data on vaccination in prisons; a recent study examining COVID vaccination found that in the six countries that had prison vaccination data, rates were lower than the general population (9).

“Reaching the hard-to-reach: Increasing access and vaccine uptake among prison populations in Europe (RISE-Vac)” is a three-year project funded by the European Union’s Health Programme (2014-2020) *(10)*. RISE-Vac is led by the University of Pisa in Italy and made up of eight further Consortium partners based in Cyprus, France, Germany, Italy, Moldova and the UK. The project seeks to increase vaccine access and uptake in prison populations across Europe. In this context, prisons include both pre-trial and post-adjudication facilities. One such intervention is the development and implementation of educational tools aimed at increasing vaccine knowledge in people living in prison. Educational interventions, including knowledge dissemination through posters, pamphlets or brochures, have previously been implemented in the prison context, and have been shown to increase vaccine literacy and uptake of screening programmes *(11)*. Whilst the pandemic raised awareness of the importance of vaccination in controlling infectious diseases and the problems of vaccine hesitancy, this project is not focusing on a specific vaccine, but vaccination in general, acknowledging that acceptability differs according to the infection.

People who have been or are currently imprisoned are too often left out of the development of interventions targeting prison populations *(12)*. The perspective of those who have this direct experience is likely to be key to increasing the effectiveness and relevance of these interventions. Although there is an absence of robust evidence for engagement of incarcerated populations in co-production, the World Health Organization (WHO) advocates for this approach in patient populations, stating, ‘resources may be better used if they are aligned with patients’ priorities’ *(13).* The RISE-Vac project partnered with people who had been imprisonedfrom the Prison Reform Trust (PRT), a charity in England, to co-produce educational tools on vaccination for people living in prison across Europe. In this article we present this co-production methodology and the resulting educational tool, developed with the input of people have been imprisoned and those who are currently in the UK, France and Moldova.

**Methods**

In order to direct the development of the educational materials, in early 2022, UK Health Security Agency, the UK partner, set up an advisory group consisting of experts in the field of prison health with knowledge of vaccination in prisons, experts in developing educational materials for people living in prison, and people with lived experience of imprisonment from across Europe. We aimed for a minimum of one person per country participating in RISE-Vac to ensure the context of all participating countries was represented; each country did not provide an expert in each area but we ensured that the advisory group as a whole had experts in all relevant areas. The terms of reference and composition of this group can be found in Appendix 1.

The PRT has a network named the Prisoner Policy Network (PPN) comprising over 700 people living in all prisons across the four countries across the UK, as well as people now back in the community. PPN membership is open to anyone who has been in or is currently in prison in the UK. During the last 6 months of 2022, PRT consulted the PPN in order to obtain their views on vaccines and understand what further information they would like to receive about vaccination. All PPN members were eligible to participate regardless of the vaccination status or views. Integrating feedback from the advisory group, PRT produced a set of seven questions to draw out the views of those living in prison. PRT piloted those questions in His Majesty’s Prison (HMP) Rye Hill with a group of 10 incarcerated people who extended this pilot to their social network. PRT received 30 written responses from HMP Rye Hill, as well as oral feedback on the questions asked. In response, PRT adjusted the order of the questions and included two additional questions regarding family views of vaccines. The final nine questions are shown in Table 1 below.

Table 1. Consultation questions

|  |  |
| --- | --- |
| Q1 | Have you had any vaccines in your life? |
| Q2 | Tell us your opinion about vaccination and vaccines in general (not only covid-19 vaccines). |
| Q3 | What do you already know about vaccines? |
| Q4 | What more would you like to know about vaccines? |
| Q5 | Are you confident you have enough reliable information about vaccines? |
| Q6 | Who do/would you trust to give you that reliable information? |
| Q7 | What is the opinion of your friends and family about vaccination and vaccines in general (not only covid-19 vaccines)? |
| Q8 | Does the opinion of your family and friends about vaccination matter in your decision to vaccinate? If so, how? |
| Q9 | How would you like to receive the information you want about vaccines? (verbally, short leaflet, detailed manual, video, audio, discussion groups) |

In early 2023, PRT set out to consult people from all RISE-Vac partner countries with these questions translated into Romanian, French and Italian. The RISE-Vac leads in Moldova and France distributed the translated questions to all people living in prison in two prisons in their country. Data was not collected on the demographics of those who responded. At this time PRT ran a focus group in the community in the UK comprising four people who had been imprisoned and who identified as vaccine hesitant with one moderator with experience of incarceration. The same questions were asked to these participants.

All written responses were translated into English if necessary, collated and analysed using thematic analysis to determine the key concepts *(14)*. After familiarisation with the data, initial codes were developed (open coding) by an individual from PRT and two members of UKHSA, with expertise in qualitative methods. The data was coded independently and then agreed in an initial meeting and subsequently refined by a series of discussions. These discussions led to the organisation of the codes into conceptual categories, themes and sub-themes. This guided the development of a brochure that is to be distributed in all European prisons to enable vaccine learning.

The RISE-Vac project has received ethical approval from the Committee on Bioethics of the University of Pisa (Prot. 0049433/2022). This specific piece of work did not require ethical approval as it was a consultation exercise as part of a health improvement initiative. No personal identifiers (for example demographic information) were recorded on the response form. No incentives for participation were provided.

**Results**

PRT received 224 responses from incarcerated people in the UK, 50 from Moldova, and in France 70. Responses were received from both male and female prisons but data on respondent demographics was not collected at an individual level. It was not possible to establish how many people had been approached and therefore the number of people who refused to participate.

Although this convenience sample was not selected on the basis of vaccination status, all respondents had received at least one vaccine in their lifetime. The key themes were common across the three participating countries: views of vaccination, prior knowledge about vaccines, areas of appetite for learning, and availability of reliable information, preferred mechanism for information sharing.

Views of vaccination

Despite a generally positive view of vaccines from the UK respondents, some were not as convinced about the benefits of vaccines as others:-

*“They're not 100% but they help people and save lives…”*

*“I have a certain amount of trust in vaccines, but you can never be 100% about them as after all it is a foreign body going into your own body.”*

Similarly, some Moldovan respondents expressed doubts about the effectiveness of vaccines:

*“My opinion is that the vaccine is not the best method for protecting your own health.”*

*“All vaccines do not inspire confidence in me. My opinion is that these vaccines are tests for the population”*

In France, respondents were more positive about vaccines in general, but were particularly sceptical about COVID-19 vaccines:-

*“I believe in traditional vaccines, because they have been researched for years. I have no confidence in COVID-19 vaccines; how come we haven't been able to find vaccines against AIDS since 1985, and just like that we found vaccines for COVID in two years.”*

*“It could be good for preventing diseases but the anti-vax discourse also has good arguments.”*

In the focus group, participants expressed scepticism about the rapid production of the COVID-19 vaccines, as well as the perceived pressure put on the public to take the vaccines. They were more comfortable with established vaccines including vaccines required for tropical diseases when travelling.

Prior knowledge about vaccines

There was a desire and a need for more information than the basic knowledge they already had regarding vaccines. In the UK, incarcerated people reported having the following information about vaccines:

*“Nothing scientific really, I try to pick up on any advice and guidance out there. But it can be confusing or misleading”*

*“They build or prepare your immune system to effectively fight the virus, allegedly.”*

Moldovan respondents expressed these thoughts:-

*“That thanks to them, I can get immunity to diseases”*

*“We practically do not have any information to confirm that these vaccines help…"*

In France, some respondents said they didn’t know anything, or only very little, although others said that they were aware vaccines aided with immunity and protection from diseases.

Areas of appetite for learning

When asked what additional information they wanted to receive about vaccines, many respondents in the UK felt they already had enough information to make decisions on vaccination, however most wanted access to more information, particularly about side effects of vaccines:

*“[Nothing] especially. I think I know the basics.”*

*“Possible side effects. Effectiveness against different viruses. Basic make up and formulation.”*

Moldovan respondents repeatedly asked for detailed information about vaccines.

*“Detailed information – where the vaccine is produced, in which laboratory, the consistency of the vaccine”*

*“Everything possible: Vaccine types, possible side effects, why do I need them?”*

In contrast many French respondents didn’t want any more information. However, some participants asked for more information on vaccine efficacy, vaccine production processes, contents of vaccines and side-effects of vaccines.

Availability of reliable information

 Many UK respondents felt they did not have access to reliable information while in prison, although a majority of respondents felt they already had enough information to make a decision.

Most Moldovan respondents did not feel they had enough information to make an informed decision, and this was echoed in France where most felt they did not have enough information.

Trusted source for reliable information

Most incarcerated people expressed that they would trust medical professionals to deliver vaccine information more than other sources such as custodial staff. The respondents’ thoughts regarding family views varied across the countries consulted. In Moldova respondents’ families’ views emerged as an important factor affecting their decision in contrast to respondents from the UK and France where it was not.

Preferred mechanism for information sharing

In the UK a short leaflet was the delivery mode most incarcerated people preferred, followed by verbal delivery, then video. In Moldova discussion groups with medical professionals was the most favoured delivery mechanism followed by a detailed manual. In France verbal delivery was most popular although a short leaflet and video were also favoured mechanisms.

Materials developed

In line with the findings of the consultation, we produced an illustrated brochure (see Appendix 2).

**Discussion**

The results of the consultation demonstrate the desire from incarcerated people to be equipped with accurate information to make informed decisions about vaccines. Many complained of the lack of information they have access to in prison and felt limited by this. We were in a position to remedy this by producing materials that can be made accessible to people living in prison, and hopefully encourage vaccine uptake in prisons.

Incarcerated people and/or those who have been imprisoned were involved at all stages of development of this brochure, including the leadership of the work, consultation, drafting of the brochure and this manuscript. The advisory group and immunisation experts provided support, ensuring the robustness of content from a scientific perspective. This true co-development approach is necessary for the development of relevant and ethically developed materials. Although not yet widely piloted, we hope that the process of development will ensure that incarcerated people will engage with the materials which have been informed by their peers. This is important as a recent scoping review examining Covid vaccination in prisons found high levels of vaccine hesitancy among incarcerated people and that a lack of educational materials about vaccines increased any concerns, potentially leading to feelings of apathy or beliefs in conspiracy theories (15). The impact of these educational resources will be evaluated during the RISE-Vac study using a questionnaire survey examining knowledge, attitudes and behaviours prior to and 1-3 months after the implementation. Longer term and more extensive evaluation is not possible within study resources and timeframes.

There are some limitations of this work. The consultation process may have been exclusionary to certain cohorts. Firstly, by its written nature we may have excluded those with low literacy. Secondly, we may have discouraged some people with negative views of vaccines to participate just by asking them to respond on the subject at a time where there is some sensitivity regarding vaccination choices, especially in prison. In addition, while the PPN in the UK does include women and younger incarcerated people, its members are overwhelmingly adult men. Therefore, it’s possible that the needs of those with low literacy, vaccine resistant, women, and younger incarcerated people may have not been captured. As we did not collect data on the demographics of responders and non-responders, we cannot be certain about whose views were not gathered. Furthermore we were unable to collect denominator data and therefore cannot be sure of the response rate nor how this differed by demographics.

All materials will be piloted and translated into the languages of all RISE-Vac partner countries and additional languages as relevant to their prison context. In addition, a video animation covering the brochure content will also be developed and dubbed. These materials will be disseminated across Europe through RISE-Vac. Study funding limits meant that there were not resources to develop materials to support discussion groups with medical professionals, the preferred option but this should be considered as a priority in the future. Similarly, this work demonstrates that participants might benefit from information about specific vaccines. Whilst it has not been possible to undertake this work within RISE-Vac, this should also be a key development. Creators of such materials will be able to build on this work, whether in response to pandemics/outbreaks or for routine vaccination.

Through the consultation we recognised a need for vaccine information in prison; incarcerated people should have access to this to make informed decisions. Prisons do not exist outside of society, and so prison healthcare is connected to and impacts public health: prison health is public health *(16)*. We have aimed to address the educational and information needs of incarcerated people about vaccination in order to enable them to make informed decisions, ultimately improving vaccine uptake in prisons and aiding society as a whole to improve protection from vaccine-preventable diseases.

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**Biographical sketch**

Femi Laryea-Adekimi is a Network Coordinator at the Prison Reform Trust, based in London. He helps manage the Prisoner Policy Network who were consulted in the UK regarding the production of the materials. The Prison Reform Trust is a charity primarily focused on improving conditions within prison across the UK.

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**Supplemental Materials**

**Appendix 1 - Terms of reference of advisory group**

**Appendix 2 - Brochure**