

Forum to Explore the Role of Patient Organisations in Vaccination

Expert Meeting Report

**6 December 2019
London, United Kingdom**

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The "Forum to Explore the Role of Patient Organisations in Vaccination" was funded by an unrestricted charitable donation from Pfizer UK. Pfizer had no involvement in the event or in the development of this report.

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Background

People with chronic diseases such as HIV, heart disease and lung disease, as well as those with complement deficiencies, are generally at a higher risk of developing complications from vaccine preventable diseases such as influenza, pneumonia and meningitis. These complications can lead to sustained and diminished loss in functional ability, hospitalisation and even death.¹ The highest rates of pneumonia in the United Kingdom (UK), for example, are found amongst people with respiratory, heart and kidney disease,² individuals with rheumatoid arthritis have double the risk of infection compared with the general population,³ and adults living with HIV are at an approximately 40-times higher risk of invasive pneumococcal disease compared with age-matched HIV-negative adults.⁴

Immunisation is one of the most successful public health practices in history in the prevention of many debilitating diseases.⁵ With the increasing need for long-term condition management alongside an ageing population, improving vaccine uptake is more critical than ever.

Patient and health advocacy organisations in the UK represent a wide range of populations, including those most vulnerable to the life altering consequences of vaccine preventable conditions. These organisations are also often considered a trusted source of information with outreach to thousands of individuals and their families.

To strengthen collaborations and build partnerships around the common agenda of improving vaccination rates throughout life, the International Federation on Ageing (IFA) and Meningitis Research Foundation (MRF) convened the 'Forum to Explore the Role of Patient Organisations in Vaccination'. Leaders of health and patient advocacy organisations, alongside experts in immunisation, public health and health policy, gathered in an open and unbiased forum to develop tangible actions around groups at-risk to vaccine preventable diseases in the UK. The forum brought unlike groups together and challenged them to look across sectors and disciplines and learn from one another.

Barriers patient and health advocacy organisations face in advocating vaccination to their constituents

Patient and health advocacy organisations face a multitude of challenges when promoting vaccination to their constituents. For some organisations, it is a question of capacity, and for others, there are competing priorities reflecting broader issues and needs.

A further challenge some organisations face is the complexity surrounding the formation of messages needed to promote vaccination to their members. The topic of vaccination can at times be controversial, with many not wanting to 'poke the bear', and very complex in terms of determining whether the vaccine is appropriate and / or available to a specific group of people. Processes for patients to follow for vaccination varies between at-risk groups and depends on the underlying health condition in question, which makes it even more difficult to give clear and simple advice.

These difficulties exist within the context of structural barriers deriving from factors such as fragmentation of commissioning and service provision which, in some cases, can lead to confusion over where clinical responsibility for vaccinating is held.

Good Practice

Sharing good practices helps to build the capacity of organisations by responding to knowledge gaps, gaining an understanding of how common barriers have been addressed, and encouraging confidence that organisations do not have to work in isolation, but rather appreciate that there is a common agenda.

The forum environment enabled delegates to share not only good practices taken to manage barriers and promote vaccination, but also their failures and lessons learned as a result. This executive summary provides insights into the work of attendees as well as the cross-cutting challenges and opportunities that may exist beyond the forum.

Health Policy Partnership

The Health Policy Partnership (HPP) is a specialist health policy consultancy that works to create policy initiatives to help resolve complex issues facing healthcare systems by bringing together multi-stakeholder groups to effect change in health policy.⁶

HPP has led two key projects related to vaccination. 'A life course approach to vaccination: adapting European policies'⁷ was undertaken to support engagement with policymakers to improve vaccination uptake across the life course. An expert multi-stakeholder group was formed to guide the research and gain consensus on the five pillars to increase vaccination uptake across the life course. Promotional materials for different audiences, including infographics, letters, and a short video were then developed and launched at the European Health Forum.⁸

This body of work contributed to the dialogue on the inclusion of a life course approach in the *European Council recommendation on strengthened cooperation against vaccine preventable diseases* (2018/c/466/01). Nurturing relationships with major stakeholders was critical for developing a compelling and credible consensus narrative which is recognised to have a life beyond the report through adaptation to suit various target audiences.

'Implementing a Life Course Approach to Vaccination'⁹ aimed to support policymakers looking to implement a life course approach to immunisation by sharing lessons from successful country approaches. A literature review was conducted which informed interviews and case studies, drawing upon the policy framework to assess progress and thereafter compare specific elements of life course immunisation policy. Although some countries have implemented successful and innovative life course immunisation policies, all are at different stages of development, with only few doing so comprehensively.¹⁰

Central to these projects is multi-stakeholder collaboration between unique groupings, providing an opportunity for all to hear 'the other side of the story' and work together to address barriers to a life course approach to vaccination.

JDRF

Internationally, JDRF is the world's leading charitable funder of type 1 diabetes research. JDRF works with academia, industry, and government to ensure that the lives of people with type 1 diabetes now and in the future benefit from targeted and meaningful research outcomes.¹¹

JDRF promotes vaccination through two key pathways. First, through the education of its supporters and staff on the serious, life altering consequences of vaccine preventable diseases such

as influenza for individuals with type 1 diabetes. Through social media, blogs, and emails, JDRF challenges common misconceptions surrounding influenza vaccination, and promotes the message that 'prevention simply makes sense'.

Secondly, the prevention of type 1 diabetes through vaccination is a growing body of science supported by JDRF. Research by Lalwani et al., (2019) found that both genetic factors and environmental triggers may play a role in the onset of type 1 diabetes, which in turn led to the suggestion that, in the future, people with an increased genetic risk of type 1 diabetes can be vaccinated against particular viruses to help prevent the condition.¹²

Meningitis Now

Established in 1986, Meningitis Now was the first meningitis patient group in the world. Their vision is a future where no one in the UK loses their life to meningitis and everyone affected gets the support they need to rebuild their lives.¹³

Life-saving vaccines are available in the UK to protect against the five groups of meningococcal disease – A, B, C, W and Y. Meningitis Now dedicates significant time and resources to raise awareness of the importance of these vaccines, as well as vaccines that protect against other diseases such as pneumonia which can cause meningitis and septicaemia.¹⁴

Over many years, Meningitis Now has targeted its vaccine awareness activities at different audiences, including the general public, 'at risk' groups, politicians, policy-makers, and healthcare professionals. These activities relate to both vaccine uptake by individuals and the adoption of vaccines as a matter of policy by government and the NHS.

A key 'lesson learnt' that applies across all these activities has been understanding the diverse range of motivations that relate to individuals in respect of vaccination, which can range from the 'rational' (e.g. audiences that respond to evidence-based, scientific information) to the 'emotional' (e.g. people who respond to hearing the 'lived experience' of meningitis). It is crucial that advocacy efforts on vaccination target both ends of this spectrum. It is reasonable, for example, to deploy both a photograph of a child with meningitis as an emotional 'tactic' to increase vaccination rates alongside more evidence-based statements on the effectiveness of vaccination and the risk of not being vaccinated. These target both rational and emotional reasoning, and have been shown to be effective in relation to both public and professional audiences.

Advocacy organisations therefore have a role in articulating a range of information, and also generating it too – such as when Meningitis Now commissioned a major study of the after-effects of meningococcal disease amongst children and adolescents, which was published in the Lancet and helped form part of the economic, health and emotional case for the introduction of vaccines.¹⁵

Lupus UK

Lupus UK is a national charity helping people with the presently incurable immune system illness lupus. They support approximately 6000 members through their Residential Groups and advise many others on the symptoms prior to diagnosis.¹⁶

The question of whether people with lupus should be vaccinated against diseases such as influenza is complicated. Most vaccines are effective and safe for people with lupus, mitigating the risk of infection, reducing the risk of developing complications such as pneumonia, and reducing the risk of triggering a lupus flare. However, live vaccines can pose a risk of infection to a small subset of

people with lupus, as there has been a history of lupus 'flares' linked to vaccination.¹⁷

For these reasons, Lupus UK faces difficulties when determining how to promote vaccination to their members in simple, clear messages. Lupus UK has, however, found it useful for their members to gather information from peers through an online patients' forum, where people with lupus can share their personal experiences of being vaccinated against influenza.

Age UK

Age UK is the country's leading charity dedicated to helping everyone make the most out of later life, through information and advice services, awareness raising and research projects, and influencing policymakers.¹⁸

Every year, Age UK holds a 'Keep Well This Winter' health campaign, which encourages older people to take steps to ensure their health throughout the winter season.¹⁹ Within this campaign, a wide variety of health materials are disseminated including cold weather alerts and messaging through their website and social media.

As an element of the 'Keep Well This Winter' campaign, Age UK promotes the importance of influenza vaccination to older people. The organisation has found that when promoting vaccination, it is important to 'go back to the basics' in order to educate people and dispel myths surrounding vaccination. It is also worth investing time and research to determine barriers to vaccination and what messaging works to promote vaccination to older people, as well as working alongside intermediaries and trusted groups.

Meningitis Research Foundation

Meningitis Research Foundation (MRF) is a UK charity that brings together people and expertise to defeat meningitis and septicaemia wherever it exists. MRF envisions a world free from meningitis and septicaemia where effective vaccinations can protect everyone, and where people with the diseases have access to the most effective diagnosis and treatment possible.²⁰

MRF promotes vaccinations that protect against meningitis. One way they do this is by advocating for the value of vaccination to key stakeholders. In 2013, the J. Craig Venter Institute (JCVI) delivered an interim position statement regarding the Meningitis B vaccine stating, 'routine infant or toddler immunisation is highly unlikely to be cost effective at any vaccine price.'²¹ MRF advocated against this statement, by educating JCVI on the unsuitable parameters their current study used to evaluate cost-effectiveness, which ultimately resulted in JCVI releasing a positive recommendation for the meningitis B vaccine.²²

Further strategies undertaken by MRF to promote vaccination include lobbying efforts, campaigns, petitions, and targeting students to be vaccinated before entering university. They also work in collaboration with organisations such as the World Health Organization (WHO) on efforts including the WHO Global Plan to Defeat Meningitis by 2030.²³

Through MRF's advocacy efforts, they have learned several important lessons. Firstly, constituents can become vaccine advocates quickly, and are ready responders to negative vaccine comments on social media. Secondly, communicating to the group of individuals who can actually create change is important. For example, after government campaigns aimed directly at students failed to increase uptake rates, MRF targeted their mothers, who are often the 'family gatekeepers' of health, which had much more positive results. Lastly, determining the underlying reason for low vaccination uptake rates before implementing a strategy is crucial. Misguided assumptions that low vaccination

uptake rates are due to vaccine hesitancy, when in reality it may be due to a different factor, such as lack of access, can result in a waste of time and resources.

British Lung Foundation

The British Lung Foundation (BLF) is a UK charity focused on making sure that one day everyone breathes clean air with healthy lungs. BLF supports research on lung conditions; helps people affected by lung conditions through a helpline, support groups, and a web community; and campaigns to prevent lung disease.²⁴

One in five people in the UK have a lung disease, and people with chronic lung disease are seven times more likely to die if they catch the flu.²⁵ For these reasons, BLF is a strong advocate for influenza vaccination through a variety of activities, including a partnership with Public Health England to provide health information on the topic, and through strategies executed on BLF's social media and website, including infographics that can be shared. BLF also conducts policy work on influenza vaccination, including inputting on the development of the government's Vaccine Strategy. The BLF also provides the secretariat to the Taskforce for Lung Health, a coalition of patients, health care professionals, charity and industry, who came together to develop a five-year plan to improve lung health in England. The Taskforce makes recommendations in its plan on increasing uptake of the flu vaccine and on collecting data.

Through BLF's efforts, the organisation has learned that understanding the true needs, specific gaps in knowledge, and concerns of the patient group is critical. Communication must be multi-faceted and across disciplines to impact different groups of people.

NAT (National AIDS Trust) and Positively UK

NAT is the UK's HIV policy and campaigning charity and is dedicated to transforming the UK's response to HIV. NAT's goals are to achieve effective HIV prevention; prompt diagnosis of HIV; universal access to HIV treatment, care and support; the eradication of HIV-related stigma and discrimination; and increased public awareness and understanding of HIV and AIDS.

Positively UK protects the health and wellbeing of people living with HIV by providing tailored peer support, promoting positive attitudes and equitable access to health for people living with HIV. Positively UK advance education and research about health, particularly in relation to HIV and campaign against HIV discrimination, increasing the involvement, voice and visibility of people living with HIV in all aspects of life.

A number of vaccinations are recommended for people living with HIV in the British HIV Association (BHIVA) vaccination guidelines, which are accredited by NICE.²⁶ They include vaccinations for hepatitis A, hepatitis B, influenza, HPV and pneumococcus. However, there is clear evidence that a high proportion of people living with HIV are not being vaccinated as clinically recommended. An audit by BHIVA found, for example, that for the pneumococcus vaccine only 26.4% of patients had been vaccinated; for influenza 21.1% had been vaccinated in the HIV clinic with a further 36.2% advised to get the vaccine from their GP; for hepatitis A 11.9% were unvaccinated with a further 24% having no vaccination status recorded.²⁷

The recommended vaccinations are not funded nationally, and therefore they are all affected by the fragmentation of commissioning at a local level. This fragmentation has resulted in uncertainties and inefficiencies in commissioning, funding and provision across a wide range of services, including vaccination provision.

There is confusing and inconsistent practice as to whether HIV clinics can offer the vaccination, with an increasing number told they must refer patients for these vaccinations to the GP, but referral and liaison with GP practices are very often patchy and poor, meaning, even before any question of funding, GPs are not universally aware of the recommendation to vaccinate and its importance.

NAT's response is not vaccine-specific, but a challenge to the structural and systemic problem of poor communication and referral between the HIV clinic and primary care and lack of engagement and clarity across all relevant commissioners as to their roles and responsibilities. We are working with NHS England's HIV Clinical Reference Group to produce a model of long-term condition management that overcomes fragmentation. In terms of improving vaccination rates our intended outcome is that the HIV clinic communicates effectively an agreed template of required medical services, including all recommended vaccines, to the GP clinic, with follow-up and with engagement of the person living with HIV. Thus, the HIV clinic will prioritise effective communication of the need for vaccination to the GP and the person living with HIV will know what to ask for in the GP practice. Both will support increased vaccination coverage.

Conclusion and Next Steps

Vaccination is a critical element of a public health strategy to improve and maintain the health and function of people with long-term conditions who are at greater risk from certain vaccine preventable diseases and their associated complications.

Many UK patient and health advocacy organisations have taken vital steps to improving uptake rates amongst their constituents, from which there is much to be learned. However, there remain many common barriers to be addressed in order to maintain and improve the health of at-risk groups. The 'Forum to Explore the Role of Patient Organisations in Vaccination' enabled delegates from across disciplines, health categories and sectors to have a conversation about creating actionable change through the following areas:

1. Continue the Momentum

In comparison to other countries, the UK is often considered one of the leaders in regard to vaccination uptake rates, with 72% of the at-risk group of older people vaccinated against influenza in 2018-19.²⁸ While this progress is important, it is also fragile, and there is still room for improvement. Health advocacy organisations and key stakeholders must work together and beyond influenza vaccination to ensure momentum across all age groups.

2. Acknowledge and address barriers organisations may face in promoting vaccination

Patient and health advocacy organisations face a multitude of barriers when promoting vaccination to their constituents. For some organisations, it is a question of capacity, and for others, there are competing priorities reflecting broader issues and needs.

There are also structural barriers in place that may prevent organisations from promoting vaccination to their constituents. For example, in the UK there is confusing and inconsistent practice around whether HIV clinics can offer vaccinations, and patchy liaison between clinics and general practitioners (GPs) means that some GPs are not aware of the vaccination recommendations and their importance. It is vital that these structural barriers are removed to allow organisations to promote vaccination effectively.

3. A Life Course Approach to Vaccination is Essential

Vaccination must be normalised across the life course rather than being a discrete event in childhood. Vaccines are crucial to the health and functioning of adolescents, adults and older people as well.

4. Assuming Responsibility

Vaccination 'as a conversation' is most likely to happen between a person and their GP, however this is not always the case. For this reason alone, associations that represent members and constituents play a critical role in education and promotion about vaccination schedules that can complement advice from a clinical expert.

5. Cross-Sectoral Collaboration

The formation of a cohesive, collective voice in the UK among unlike groups (including health advocacy organisations, health care providers and academics) is crucial to improving the delivery of vaccination information and promoting vaccination to at-risk groups. This collective voice must support a central agenda while at the same time acknowledge the differences and similarities of where organisations currently are in their response to vaccination promotion.

The closer alignment of patient organisations and vaccination experts will promote the credibility of organisations in providing vaccination advice, and can also provide a platform for organisations to share best practices and support those who are new to promoting vaccination to move forward successfully.

6. Forming Effective Messaging

Forming clear and effective messages on vaccination for people with different risk profiles is critical yet complex, with a paucity of scientific research on the topic. The topic of vaccination can at times be controversial with many not wanting to 'poke the bear', and very complex in terms of determining whether the vaccine is appropriate and / or available to a specific group of people. Processes for people to follow for vaccination varies between at-risk groups and depends on the underlying health condition in question, which makes it even more difficult to give clear and simple advice.

Nevertheless, organisations have a role to play in informing popular narratives, as well as individuals, through a strong understanding of the targeted audience and meaningful and appropriate messages. It is worth investing time and research into the nature and format of messages and communication channels to determine what works for what populations.

In conclusion, vaccination across the life course is paramount to the health and functioning of groups at-risk from vaccine preventable diseases. Patient and health advocacy organisations representing at-risk groups have an important opportunity to maintain and improve the health of their constituents through the promotion of vaccination, and many have already stepped up to do so. Cross-sectoral collaborations between these organisations are essential to learn from one another and continue to move forward in a positive direction.

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