

PATIENT ORGANISATIONS' NEEDS AND ROLE REGARDING VACCINATION



INFORMATION NEEDS OF PATIENT COMMUNITIES

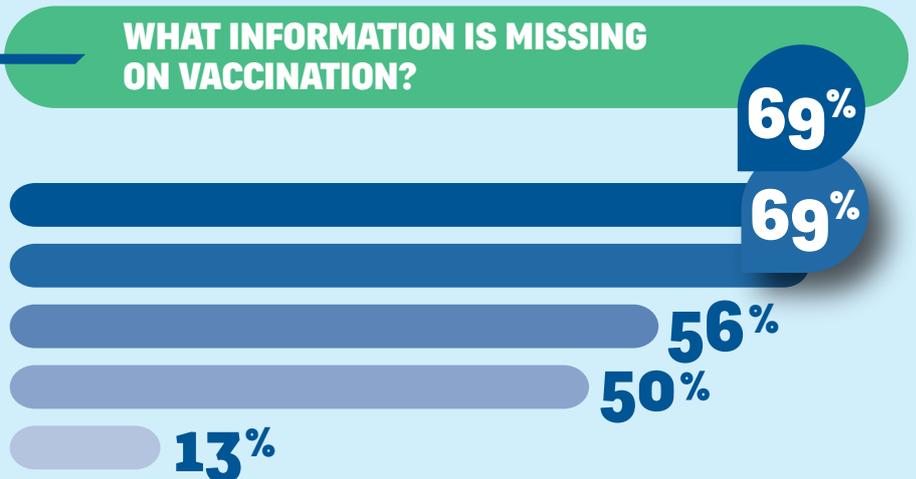
Vaccination is an important priority for patient organisations. Many say they would like to be more active on vaccination in their communities. But they cannot easily find comprehensive, reliable and patient-friendly information.

Patients want information on benefits and risks of vaccines, communicated in a understandable way to a lay person, put in context and balanced with other risks (e.g. risk of diseases, risk of not vaccinating).



WHAT INFORMATION IS MISSING ON VACCINATION?

- Information on specific risks for patients with a chronic disease
- Information on the risks of not being vaccinated
- Information on the benefits of vaccination
- Information on the diseases that can be prevented through vaccination
- Information on where/how to get vaccinated



Source: EPF vaccination survey, April 2018

WHERE DO PATIENTS GET INFORMATION?

Health professionals (nurses, doctors, pharmacists...) are key providers of information to patients, and are generally trusted. Patients say they do not always get enough information on vaccination from professionals; or information may exist but the professional does not always bring it to the patient's attention.

Patients sometimes get contradictory information from different healthcare professionals. Their advice has an important impact on patients' attitudes towards vaccination.

Patients also use the Internet. It is important that people can easily find evidence-based, reliable information even through simple searches. The "good" information should be at the top!

Healthcare workers should be vaccinated – or if they are not they should inform patients by wearing a mask or a badge. If professionals do not lead by example to protect the population they care for, how can they be credible and convey a message of good care?

Guy, Diabetes Type2, France



PATIENT ORGANISATIONS CAN HELP INCREASE UPTAKE OF VACCINATION

Patient organisations are key sources of information on vaccination to patients. They can support and coordinate national and international awareness campaigns on vaccine effectiveness and safety. They can share scientific, evidence-based information and patient experiences, countering myths and mis-information and helping to address vaccine hesitancy in patient communities.

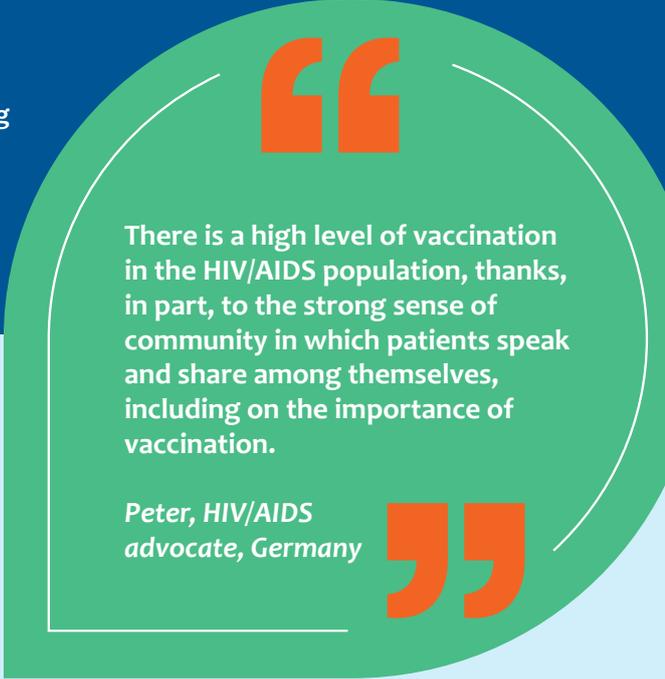
Patient organisations would like to work with professionals to better inform and share knowledge on vaccination for adults living with chronic diseases.

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→ **AVNIR** is the initiative of 12 French organisations representing people who are immunocompromised and at risk of infection because of their illness or treatment. Its objective is to reflect on the issue of vaccination from the perspective of these people and develop actions to meet their needs and expectations.

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→ **France Assos Santé**, an EPF member, published a position paper on vaccination in 2017 and contributed to an EU public consultation. They also set up an internal working group on vaccination.



There is a high level of vaccination in the HIV/AIDS population, thanks, in part, to the strong sense of community in which patients speak and share among themselves, including on the importance of vaccination.

Peter, HIV/AIDS advocate, Germany

KEY RECOMMENDATIONS

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1. Easily accessible, evidence-based information in lay language on the benefits and risks of vaccination for patients with specific chronic conditions – ideally through a one-stop, EU-level online portal
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2. Patients should be better informed about the risks of NOT being vaccinated
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3. Adult patients' vaccination needs should be assessed regularly to ensure patients know the recommendations and are offered vaccination where needed
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4. Vaccination should be integrated in the treatment plans of chronic diseases
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5. Professionals should be trained on communicating about vaccination to reinforce a trust relationship. Messages should be consistent, and low uptake of vaccination and hesitancy within healthcare professions should be tackled
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6. National institutions should work with patient organisations to understand their communities' needs and formulate effective strategies
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7. Vaccination should be regarded as a public health priority also for adults living with chronic conditions



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Find out more about our work on vaccination!



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