Risk Perception and Immunization Practices for Adults with Immunological Diseases
A Survey of the European Federation of Internal Medicine, 2003

During the past few years, articles in the medical and popular press, as well as in television programs, have caused concern among the public and doctors that immunization may be linked to new cases or flare-ups of immunological diseases, i.e. auto-immune diseases or related clinical syndromes in which tissue damage appears to result from aberrant responses of the immune system*. In the USA, the Advisory Committee on Immunization Practices has made recommendations for the use of vaccines for persons with weakened immunocompetence ¹, but not for persons with immunological diseases. Official recommendations in developed countries on immunizations include the vaccination of all adults against tetanus and poliomyelitis. Immunizations against rubella, influenza, hepatitis B, and pneumococcus or other diseases may be proposed according to individual risks such as professional exposure or travel. In adults presenting with immunological diseases, data or guidelines for immunization are incomplete. Only a few open trials or small placebo-controlled studies have been conducted to assess the efficacy and safety of immunization against influenza, pneumococcal, haemophilus B, poliomyelitis and hepatitis B vaccines, in patients with multiple sclerosis, chronic renal disease, rheumatoid arthritis, Sjögren’s syndrome, or systemic lupus erythematosus (²⁻²⁵). Therefore, the problems concerning the schedule, efficacy, benefit and side effects of immunization in adults with immunological diseases have not yet been solved. When making medical decisions for the immunization of a patient with an immunological disease, physicians take account of available data on risk-benefit assessment. If evidence-based data are missing, this assessment can be radically altered by the physician's risk perception, based on personal or published experience of adverse events, and also on the patient's risk perception ²⁶. In this context of uncertainty, our objective is to determine what are the European physicians’ immunization practices for adults with immunological diseases.

We would be grateful to you if you would accept to respond to the following ≈15 minutes-questionnaire, regarding your position on immunization for adults with immunological diseases. There are no conflicts of interest in connection with this study which is conducted on behalf of the European Federation of Internal Medicine. The results of this study will be submitted for publication in a peer-reviewed journal.

Thank you for your help.

Yours sincerely.

Loïc Guillevin and Thomas Hanslik

*Immunological diseases to which we refer in the present study (non-restrictive list):
- Diffuse immunological diseases: systemic lupus erythematosus, rheumatoid arthritis, Sjögren’s syndrome, systemic sclerosis, polymyositis, systemic vasculitides (e.g. periarteritis nodosa, microscopic polyangiitis, Wegener granulomatosis, Churg and Strauss disease, giant cell arteritis)
- Organ specific immunological diseases: multiple sclerosis, Guillain-Barre syndrome, glomerulonephritis, myasthenia gravis, Grave’s disease, auto-immune thromcytopenia, auto-immune hemolysis
References


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Name: 
Country: 
City: 
Phone: 
Email: 

1. Here are two clinical cases. When the underneath mentioned vaccines are indicated for these two patients, what would be your attitude regarding immunization (i.e. would you vaccinate or not?):

<table>
<thead>
<tr>
<th>Vaccine</th>
<th>Vaccinate</th>
<th>Don’t vaccinate</th>
<th>Vaccinate</th>
<th>Don’t vaccinate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tetanus</td>
<td>[ ]</td>
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<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Poliomyelitis (inactivated)</td>
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<tr>
<td>Influenza</td>
<td>[ ]</td>
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<tr>
<td>Pneumococcus</td>
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<tr>
<td>Meningococcus</td>
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<tr>
<td>Hepatitis A</td>
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</tr>
<tr>
<td>Hepatitis B</td>
<td>[ ]</td>
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</tr>
<tr>
<td>Rabies</td>
<td>[ ]</td>
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<td>[ ]</td>
</tr>
<tr>
<td>Rubella (live vaccine)</td>
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<td>[ ]</td>
</tr>
<tr>
<td>Varicella (live vaccine)</td>
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<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Yellow fever (live vaccine)</td>
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</tbody>
</table>

Case 1.
A 35-year-old woman is treated since 3 years for a systemic lupus erythematosus with visceral involvement. Immunosuppressive treatment has been suspended 12 months ago. She has no organ damage. She is now doing well and receiving prednisone, 10 mg per day.

Case 2.
A 40-year-old man was treated 6 years ago for a Churg and Strauss disease. Immunosuppressive and corticosteroid treatments have been suspended 3 years ago. He is doing well.

2. Globally, how do you perceive the risks carried by the immunization of adults with immunological disease (irrespective of the type of vaccine)? Please rate on the following scale from 0 (very low risk) to 10 (very high risk):

Risk of flare-up of the disease: 1 2 3 4 5 6 7 8 9 10

Risk of lack of efficacy: 1 2 3 4 5 6 7 8 9 10
3. When the contraindications reported in the summary of product characteristics are respected, how do you rate the risk of infection by live vaccines? Please rate on the following scale from 0 (very low risk) to 10 (very high risk):

Risk of infection by live vaccine: 1 2 3 4 5 6 7 8 9 10

4. Is there a disease (see list in the table of the accompanying letter) for which you think that the risk of flare-up after an immunization is particularly important?

☐ No opinion  
☐ No  
☐ Yes, the following disease(s):

5. Is there a vaccine for which you think that the risk of flare-up of the disease after an immunization is particularly important?

☐ No opinion  
☐ No  
☐ Yes, the following vaccine(s):

6. In a patient treated only with corticosteroid for a long-standing period, e.g. more than 6 months, do you consider that there is a maximal dose above which yellow fever immunization is contra-indicated?

☐ No opinion  
☐ Contra-indicated whatever the prescribed dose  
☐ 5 mg daily  
☐ 10 mg daily  
☐ 15 mg daily  
☐ 20 mg daily

7. In a patient treated only with corticosteroid, do you consider that there is a maximal duration of treatment beneath which you consider that yellow fever immunization is possible, whatever the prescribed dose?

☐ No opinion  
☐ Contra-indicated whatever the prescribed duration  
☐ 1 week  
☐ 2 weeks  
☐ 4 weeks  
☐ 2 months  
☐ 3 months
8. In a patient with an immunological disease, do you ensure appropriate vaccinations as recommended in the schedule of your country?:

<table>
<thead>
<tr>
<th>Vaccine</th>
<th>Never</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tetanus</td>
<td></td>
<td></td>
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<td>Hepatitis B</td>
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<tr>
<td>Rubella (live vaccine)</td>
<td></td>
<td></td>
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</tbody>
</table>

9. When vaccinating a patient with an immunological disease:

a. Do you wait a the disease has enter remission before vaccination?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Always</th>
</tr>
</thead>
</table>

b. When possible, do you check the residual antibody level so as to dispense from vaccinating is there is a protective antibody level?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Always</th>
</tr>
</thead>
</table>

c. When possible, do you check the residual antibody level so as to dispense from vaccinating if there is a “protective” level?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Always</th>
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</thead>
</table>

d. After immunization, do you control the antibody level so as to assess vaccine “efficacy” and to administer additional doses if necessary?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Always</th>
</tr>
</thead>
</table>

10. When vaccinating a patient with immunological disease, what information do you give him regarding the risk of flare-up of the disease?

<table>
<thead>
<tr>
<th></th>
<th>No specific information</th>
<th>“A risk of flare-up exists”</th>
<th>“There is no risk of flare-up”</th>
<th>Does not apply to my patients</th>
</tr>
</thead>
</table>

11. As much as you can remember, when you last saw a patient with a flare-up of his immunological disease, did you ask him if he had recently been vaccinated?

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
<th>I don’t remember</th>
<th>Does not apply to my patients</th>
</tr>
</thead>
</table>
12. Among the patients you are following for an immunological disease, have you already observed a flare-up of the disease following a vaccination?

- [ ] I don’t remember
- [ ] Does not apply to my patients
- [ ] No
- [ ] Yes. If yes:

<table>
<thead>
<tr>
<th>Year</th>
<th>Involved vaccine</th>
<th>Immunological disease</th>
</tr>
</thead>
</table>

13. You are practising since:

- [ ] <10 years
- [ ] 10-20 years
- [ ] >20 years

14. Your professional setting is:

- [ ] Hospital-based
- [ ] Community based
- [ ] Other:

15. Your gender is:

- [ ] Female
- [ ] Male

16. How many patients are you treating for an immunological disease?

- [ ] None
- [ ] <5
- [ ] 5-20
- [ ] >20