Vaccines boss: Clear privacy rules are needed for electronic immunisation record system



Patricia Massetti: "Harmonisation is important for an electronic immunisation record system to work. Only in this way can proper data flows and usage be ensured." [Tasos Fokas]

This article is part of our special report Electronic immunisation record.

An electronic immunisation record system, which aims to better monitor vaccination among populations, will need clear privacy rules and individuals should be the owners of their own data, Patricia Massetti told EURACTIV.com in an interview.

Patricia Massetti is an associate vice-president and European Vaccines Lead at MSD. She is also a Board member at Vaccines Europe, which represents the major European vaccine companies.

She spoke to EURACTIV.com's Sarantis Michalopoulos on the sidelines of the European Health Forum in Gastein (4-6 October).

A number of EU countries have been experiencing large outbreaks of measles in 2017. Many see the movement against vaccines behind the case. What went wrong? Is it down to a lack of communication? Is it a policy problem?

I would argue that it is due to a number of reasons, which are all interconnected. Yes, vaccine hesitancy is definitely a factor, but it's not the only one. Infectious diseases do not respect national borders.

In Europe, we need to set a common roadmap involving governments, health authorities, scientific societies, healthcare professionals, civil society and industry. This is the objective of the Joint Action on Vaccination launched by the Commission earlier this year. The Joint Action aims to provide the much-needed political leadership to move forward and ensure public health crises, such as the measles outbreak, do not re-occur.

How can EU policymakers put an end to the growing scepticism towards immunisation?

Addressing vaccine hesitancy is not an easy task. Different factors such as confidence, convenience or complacency must be taken into consideration. Vaccination hesitancy may lead to decreased vaccination coverage. Therefore, maintaining confidence in it is critical for sustainable immunisation programmes to ensure good public health.

There is no single solution to all these issues, but there are a number of relevant stakeholders who can help in addition to policymakers. For example, healthcare professionals have proven to be an important determinant in vaccine uptake. This is relevant for them but also in recommending vaccines to the general public as well as to at-risk populations. Additionally, access can be a barrier. As a result, some countries have extended their access points for vaccination by considering alternative channels. An option includes vaccination by pharmacists and onsite vaccination in hospital wards.

What are the main challenges vaccines are currently facing within the EU?

As mentioned by the European Commission at the European Health Forum Gastein, fragmentation is one of the major issues Europe is facing. This pertains to healthcare systems and directly affects successful implementation of existing immunisation programmes.

The absence of common tools to monitor vaccine coverage rates, and predict potential outbreaks, is an important issue and can be the cause of supply and demand challenges within countries.

This is frustrating as vaccination is one of the greatest public health success stories of the last two centuries. Disease prevention enables better health outcomes, while also reducing unsustainable expansion in health spending. Of course, this is a debate that needs to take place under the umbrella of a more general discussion on health systems and their focus. Prevention should be a key priority.

Vaccines Europe has identified a number of areas, which could significantly strengthen vaccination in Europe such as reinforcing European surveillance capabilities to support National Immunisation Strategies and Programmes, engaging healthcare professionals in actively increasing vaccination coverage, addressing the root causes of vaccine shortages, and ensuring an open and continuous multi-stakeholder collaboration to overcome barriers/blocking factors to the discovery and development of the next generation of vaccines.

The upcoming Joint Action on Vaccination will have a major role in the development of effective guidance to support the establishment and implementation of well-functioning national immunisation programmes in member states.

In what way could the EU member states better monitor the vaccination of the population? Do you support an EU-wide approach?

Monitoring population vaccination is a very difficult endeavour given the current context. The systematic collection, analysis and dissemination of health-related data are essential for decisionmaking and public health at all levels. We need data for evidence-based programmes and assessing the effectiveness of what is being done.

Furthermore, as we heard at the 'Exploring the needs and the future developments of immunisation records in the EU' EHFG event, an electronic immunisation record system (also called Informed Immunisation System or IIS) would represent an important part of the solution. Through this data gathering, EU countries would be able to monitor properly the vaccination rates of the population and enhance cross-border cooperation in the event of disease outbreaks.

Ideally, we are hoping for a European Immunisation Registry fed by national systems. However, major obstacles, such as data ownership and protection, interoperability within the healthcare systems, uniformity of data coding, IT performance and funding have to be overcome.

The current focus on eHealth and the EU's Digital Single Market provides an opportunity for immunisation information systems to become an integral part of electronic health systems and benefit from a structured framework.

During that workshop, it was also said that the European Centre for Disease Prevention and Control (ECDC) is working on guidelines for immunisation registries to be used by all member states, expected early 2018. Of course, it's too early to tell how this could work, as there is a series of challenges that need to be addressed such as interoperability of these systems and compliance with already existing ones. However, we could see that a concrete action plan is now underway.

How do we deal with the data collection issue? Will the member states take over that responsibility?

We would need a clear EU-wide mandate and approach. I mentioned the challenge of interoperability. This cannot be solved without an EU-wide approach. We could go into many more details here and discuss all kinds of legal, operational, semantic and technical obstacles, but I am afraid I would have to keep you here for hours!

All these obstacles can be overcome through cooperation between the member states with the guidance of the European Commission. Harmonisation is important for an electronic immunisation record system to work. Only in this way can proper data flows and usage be ensured.

Such a system also needs to be transparent and accessible to the public. Data ownership is key, and the individual should be the clear owner of his or her own data. We need clear privacy rules that will help build up trust in the system. A system that is not trusted will not work.

We need strong support for electronic immunisation record systems, allowing each citizen to manage his or her vaccination status and remain up-to-date with his or her immunisation throughout the lifespan. These systems can help increase vaccination coverage rates, prevent future outbreaks and monitor public health performance. They can also potentially allow for personalised recommendations on vaccination according to the individual's characteristics, such as health, age and gender, lifestyle and occupation. It's encouraging that the European Commission shares the same view.

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