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The State-of-the-Art in Electronic Vaccination Registries in the European Union, the United Kingdom, Norway, Switzerland, and Serbia

Summary Report

By OpenSky Data Systems and MSD



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ACRONYM LIST

EVR	Electronic Vaccination Registry
VCR	Vaccine Coverage Rate
ICT	Information & Communications Technology
EHDS	European Health Data Space
IIS	Immunisation Information System
EHR	Electronic Health Record
HPV	Human Papillomavirus
AEFI	Adverse Events Following Immunisation



REPORT OBJECTIVES

This report aims to map Electronic Vaccination Registries across the European Union, the UK, Norway, Switzerland and Serbia – identify the best-in-class EVRs in place for offering rapid and reliable information on Vaccine Coverage Rates (VCRs), spot the European divides in terms of preparing and using EVRs, and issue recommendations for overcoming the divergences.

KEY CONCLUSIONS AND RECOMMENDATIONS

- The existence and relevance of EVRs are crucial for higher VCRs
- In all countries, there is a will to increase vaccination rates
- In all countries, there are information and communications technology (ICT) solutions in place for registering vaccinations
- Inertia often plays a particular role in delaying the implementation of new ways to register vaccination
- Full use must be made of the opportunities offered by the European Union's European Health Data Space
- Europe needs the common denominator of an EVR template to allow interoperability

THE REASONS BEHIND THIS RESEARCH

The extensive use of ICT in health seems to be thoroughly incorporated by all stakeholders. So why is research necessary to highlight this well-known fact?

The extensive use of ICT in any field is a function of several variables, e.g., political willingness, priorities, budget, commercial opportunities, technology, and specialists. The interdependence of these factors significantly affects the possible outcomes we tried to measure with our research. How can we make the best use of this positive impact of developments from the general population's perspective?

For objective reasons, this question remains unanswered in most areas. Yet there is at least one area that contains the action triggers: vaccination.

Prevention is cost-effective and reduces the impact on healthcare services. In terms of specialised medical intervention, there is nothing even remotely comparable to the prophylactic impact of vaccination on the general population. The recent pandemic proves that, aside from the obscurantist approaches of some, we are ready to make the best use of what we have learned so far in vaccination, both in terms of medicine and ICT.

After more than 15 years of well-documented successful usage, everything is in place to accelerate the optimal coverage rate. The uniqueness of the social-political-cultural-administrative/bureaucratic-economic-academic mix in Europe makes it the best candidate for a decisive and coordinated move towards optimal coverage rates of HPV vaccination for a substantial proportion of the population. The political consequences of Brexit are irrelevant to this course of action, and why we covered UK4 as well as EU27.

Two factors are crucial to achieve this aim: a combination of political will and ICT solutions. The next step is an EU-wide political decision towards establishing a common approach for electronically registering HPV vaccinations. This research aims to offer decision-makers the information they need to make the appropriate analysis.

Executive Summary

Digitisation is transforming our lives in profound manners, at all levels and in every area. The ever-increasing pace of creating and adopting new digital technologies and solutions exerts constant pressure on governments. This new reality exacerbates the difficulty of finding a balance between the European Union's role and the need for administrative coherence at the national and supranational levels.

There are numerous EU initiatives covering this matter. However, this report will focus on the EU Digital Decade unveiled in the past 12 months after the COVID-19 pandemic. The most relevant development is the European Health Data Space, related to the European Data Strategy (February 2020)[1] and the Digital Governance Act (November 2020)[2].

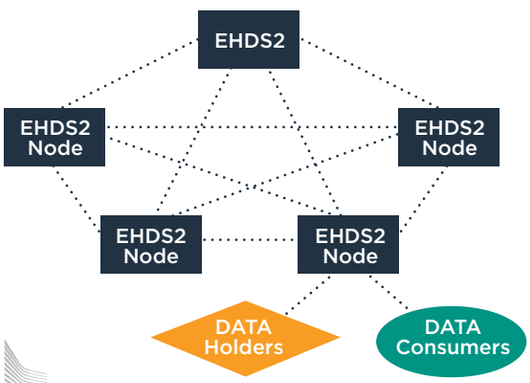
HPV vaccination was used as a case study in the favourable context of Europe's Beating Cancer Plan. This case study strongly emphasises a consistent correlation between the existence of evolved Electronic Vaccination Records and higher Vaccine Coverage Rates. As the EVRs scoreboard within this report shows, the results of our EVRs analysis are very diverse, corresponding to concrete action taken in terms of integrated national approaches instead of regional ones, continuity in programme implementation, and fighting inertia.

European Health Data Space

The EHDS will enable better measurement of health outcomes and exchange of data across the system, from the development of medicines and treatments through the entire patient journey. As stated by the European Commission, this new approach will empower patients and create new ways of communication between healthcare professionals and patients.

The implementation of the EHDS is a priority for the European Commission because it will promote better exchange and access to different types of health data, to better support healthcare delivery, health research and health policy-making. On 3 May 2022, the European Commission launched a proposal for a Regulation on the European Health Data Space.

EHDS Concept



EHDS2 Nodes are the entry point for stakeholders into the EHDS

EHDS2 Nodes can be established by National or Trans-national stakeholders

EHDS2 Nodes follow common policies and interoperability specifications

DATA holders make health data available for research and policy-making

DATA consumers use data for research or policy-making

Source: https://health.ec.europa.eu/system/files/2021-02/ev_20201027_co03_en_0.pdf

1 European Strategy for Data https://www.eumonitor.eu/9353000/1/j9vvik7m1c3gyxp/vl6bhq5mueyy
2 Regulation (EU) 2022/868 of the European Parliament and of the Council of 30 May 2022 https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32022R0868

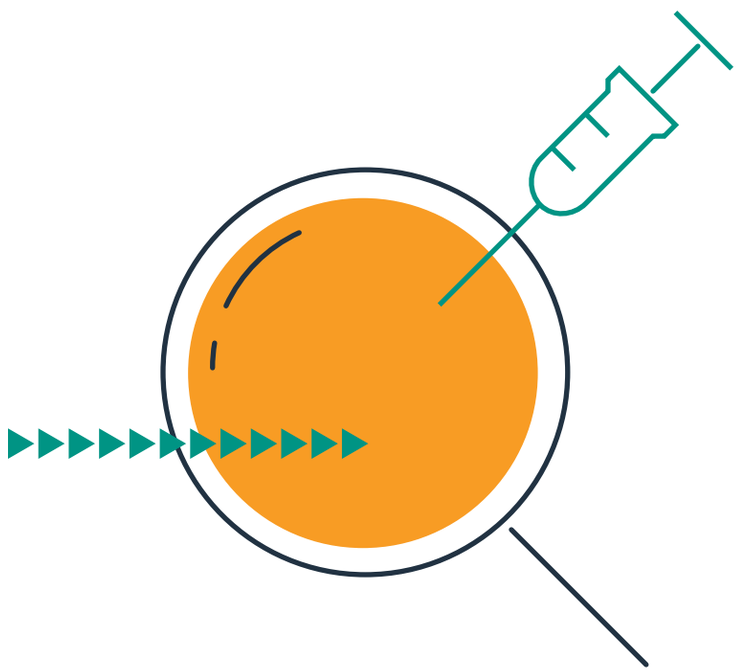
Research Objectives

As the latest pandemic has proved, an EU-wide political decision towards establishing a common approach to electronically registering vaccination is crucial for reaching the optimum Vaccine Coverage Rate. The systems created for COVID-19 vaccination availability, scheduling, coverage, and certificates are essentially virus agnostic. We need to further adapt them to other vaccination campaigns.

To fulfil our analysis, we identified the current state-of-the-art Electronic Vaccination Registries in the EU, the UK, Norway, Switzerland and Serbia, emphasising HPV vaccination. Additionally, we performed an in-depth analysis of registers in several countries selected on specific criteria. These two complementary approaches became the distinct phases of this dedicated research.

The report highlights the correlation between the Electronic Vaccination Registries and Vaccine Coverage Rates. A Scorecard and the subsequent Heatmap were created, together with scatter charts revealing compatability of relevant variables.

The model created allows the ingestion of new data for scalability. The scoreboard was created using the data obtained through desk-based research, so we cannot assume that it indisputably reflects today's reality for a country, region, territory or other.



RESEARCH STRATEGY

Timeline of Activities

PHASE 1
October 2021 - March 2022

1. We identified the current state-of-the-art of Electronic Vaccination Registries in the EU, the UK, Norway, Switzerland, and Serbia, emphasising HPV vaccination.
2. We performed an in-depth analysis of registers in several countries selected on specific criteria. These two complementary approaches become the distinct phases of dedicated research.

PHASE 2
June 2022 - September 2022

3. Use all the findings and lessons learned to inform decision-makers about possible ways to increase VCRs in the EU, the UK, Norway, Switzerland, and Serbia.
4. An in-depth analysis of the (HPV) Electronic Vaccination Registries in several countries and territories will be performed.
5. A virtual model of a desirable common minimal/optimal EVR architecture will be designed before September 2022, integrating relevant features of various EVRs currently in use.

*Norway, Switzerland, and Serbia were mapped in July-August 2022.

THE NEED FOR IMMUNISATION INFORMATION SYSTEMS

"Immunisation Information Systems (IISs) are centralised repositories of personally identifiable vaccination information for individual members of a served population."[1]

"Immunisation information systems (IISs) are confidential, population-based, computerised information systems that record, store, and provide access to consolidated individual immunisation information. They aim to be comprehensive and community-wide, covering individuals in a specific geographic area across multiple healthcare providers."[2]

Tracking vaccine coverage rates at individual and population levels is a precondition for continuing advances in the battle against dangerous viruses. This is not new. But we need to create systems that mirror the ever-growing sophistication and relevance of vaccines.

To synthesise the relevance of COVID-19 for the use of Immunisation Information Systems, we will briefly mention two long-lasting divides: the digital divide and the vax/anti-vax divide. The pandemic has deepened both; for the purposes of this research we will focus on the former. While the latter is generated by choice, the former is the result of various inequalities. What the COVID-19 pandemic shows is that not only does the digital divide diminish the quality of life, but when it is seen in the light of vaccination, it is about life and death.

Due to vaccines and vaccination, the COVID-19 pandemic is currently under control, and the world will be better prepared for future pandemics. However, this most recent pandemic created a powerful momentum that must be used to apply lessons learned to longer-lasting battles such as the one against HPV.

This research highlights how the use of ICT systems in different regions of Europe has affected the uptake of vaccination in those regions. Considering all the above, now is the perfect moment to tackle the digital divide in the vaccination context in the EU.

1 Atkinson, Mithani, Bell, Rubens-Augustson, Wilson - The digital Immunisation system of the future: imagining a patient-centric, interoperable Immunisation information system, in Therapeutic Advances in Vaccines and Immunotherapy, Sage Journals, 2020, https://journals.sagepub.com/doi/full/10.1177/2515135520967203 accessed March 2022

2 European Centre for Disease Prevention and Control. Designing and implementing an immunisation information system. Stockholm: ECDC; 2018, https://www.ecdc.europa.eu/sites/default/files/documents/designing-implementing-immunisation-information-system_0.pdf accessed March 2022

HEATMAP OF EU COUNTRIES, THE UK, NORWAY, SWITZERLAND, AND SERBIA

This heatmap highlights the correlation between Electronic Vaccination Registries and Vaccine Coverage Rates throughout the EU, the UK, Norway, Switzerland, and Serbia. The data was obtained through desk-based research in Q2&Q3 2022.

Country	Weighted score
Denmark	99%
Finland	96%
Netherlands	94%
Norway	94%
England	92%
Sweden	92%
Wales	90%
Ireland	86%
Scotland	86%
Northern Ireland	85%
Latvia	81%
Malta	81%
Slovenia	76%
Belgium	75%
Portugal	74%
France	73%
Spain	72%
Germany	70%
Romania	66%
Estonia	65%
Italy	64%
Hungary	60%
Slovakia	59%
Luxembourg	58%
Switzerland	53%
Serbia	51%
Lithuania	48%
Austria	44%
Czech Republic	40%
Croatia	38%
Greece	36%
Cyprus	36%
Poland	34%
Bulgaria	33%



SCORECARD OF EU COUNTRIES AND THE UK

Country/ Territory	Vaccine register	HPV vaccination in the register	Vaccine related information on the Data set	Level of interest in using ICT in Health (EHR etc.)	Level of the register development	Cancer screening register	Cancer register	Integrated national approach	Relative replicability as a Best Practice	Reporting Data Interval Frequency (Months)	Weighted score
Denmark	1	1	1	3	4	1	2	2	9	5	99%
Finland	1	1	1	3	4	1	1	1	9	4	96%
Netherlands	1	1	1	3	4	1	1	1	9	3	94%
Norway	1	1	1	3	4	1	1	1	9	3	94%
England	1	1	1	3	4	1	1	1	8	3	92%
Sweden	1	1	1	3	4	1	1	1	8	3	92%
Wales	1	1	1	3	4	3	1	1	8	4	90%
Ireland	1	1	1	3	3	1	1	1	8	2	86%
Scotland	1	1	2	3	4	1	1	1	8	2	86%
Northern Ireland	1	1	1	3	3	2	1	1	7	3	85%
Latvia	1	1	1	3	3	1	1	1	4	2	81%
Malta	1	1	1	3	3	1	1	1	6	1	81%
Slovenia	1	1	2	3	3	1	1	1	5	1	76%
Belgium	1	1	1	3	3	1	1	3	7	1	75%
Portugal	1	1	2	3	3	3	1	1	7	1	74%
France	2	1	1	3	1	2	1	1	8	2	73%
Spain	1	1	2	3	4	2	1	3	5	2	72%
Germany	1	1	2	3	3	2	1	3	8	1	70%
Romania	1	2	2	2	3	2	1	1	4	1	66%
Estonia	2	1	2	3	1	1	1	1	5	1	65%
Italy	1	2	1	3	1	2	1	2	5	3	64%
Hungary	1	2	2	2	1	1	1	1	3	1	60%
Slovakia	1	3	3	3	3	2	1	1	3	1	59%
Luxembourg	1	2	3	2	2	2	1	1	3	1	58%
Switzerland	2	2	3	3	2	2	1	3	2	2	53%
Serbia	2	3	3	2	2	1	1	3	2	3	51%
Lithuania	1	3	3	2	1	3	1	1	3	1	48%
Austria	1	3	3	3	1	3	1	3	4	1	44%
Czech Republic	3	3	4	1	1	1	1	1	2	1	40%
Croatia	3	3	4	2	1	3	1	1	2	1	38%
Greece	3	3	2	1	2	3	1	3	3	1	36%
Cyprus	3	3	4	1	1	3	1	1	2	1	36%
Poland	3	3	3	2	1	1	1	2	2	1	34%
Bulgaria	3	3	4	1	1	2	1	2	2	2	33%

VACCINE REGISTER	**1** Yes **2** There is an equivalent **3** Not yet
LEVEL OF THE REGISTER DEVELOPMENT	**1** Incipient **2** Pilot **3** Funtional **4** Advanced
LEVEL OF INTEREST IN USING ICT IN HEALTH (EHR ETC.)	**1** Low **2** Moderate **3** High
CANCER REGISTER	**1** Yes **2** Information not clear or available for the moment **3** No
CANCER SCREENING REGISTER	**1** Yes **2** Information not clear or available for the moment **3** No
INTEGRATED NATIONAL APPROACH	**1** Yes **2** Information not clear or available for the moment **3** No
VACCINE-RELATED INFORMATION ON THE DATA SET	**1** Yes **2** Most probably yes **3** Information not clear or available for the moment **4** No
RELATIVE REPLICABILITY AS A BEST PRACTICE	On a 1-10 scale, with 1 being least desirable and 10 most desirable
REPORTING	**1** Unavailability/unable to source or confirm **2** Data available at least annually (but with delays in reporting) **3** Data available at least annually and up-to-date **4** Data available quarterly and up-to-date **5** Access to reporting, up-to-date

Note: The scorecard does not reflect the ratio to an ideal model but to what we have identified as the State-of-the-Art. For example, the 99 points out of 100 obtained by Denmark do not mean that an absolute maximum has been reached there. It tells us that the Danish system is more or less advanced than those used in other countries.

The Digital Immunisation System of the Future

The way to optimise the use and impact of IISs is to make all systems interoperable. It's not about aligning all approaches with the most developed ones, but designing a common framework around a specific data set. The data set should be quickly able to deliver a meaningful image of the vaccination process and outcome while using the minimum quantity of data possible. It would be similar to a least common denominator. Of course, this is not an end, but a means to adapting dedicated policies and practices.

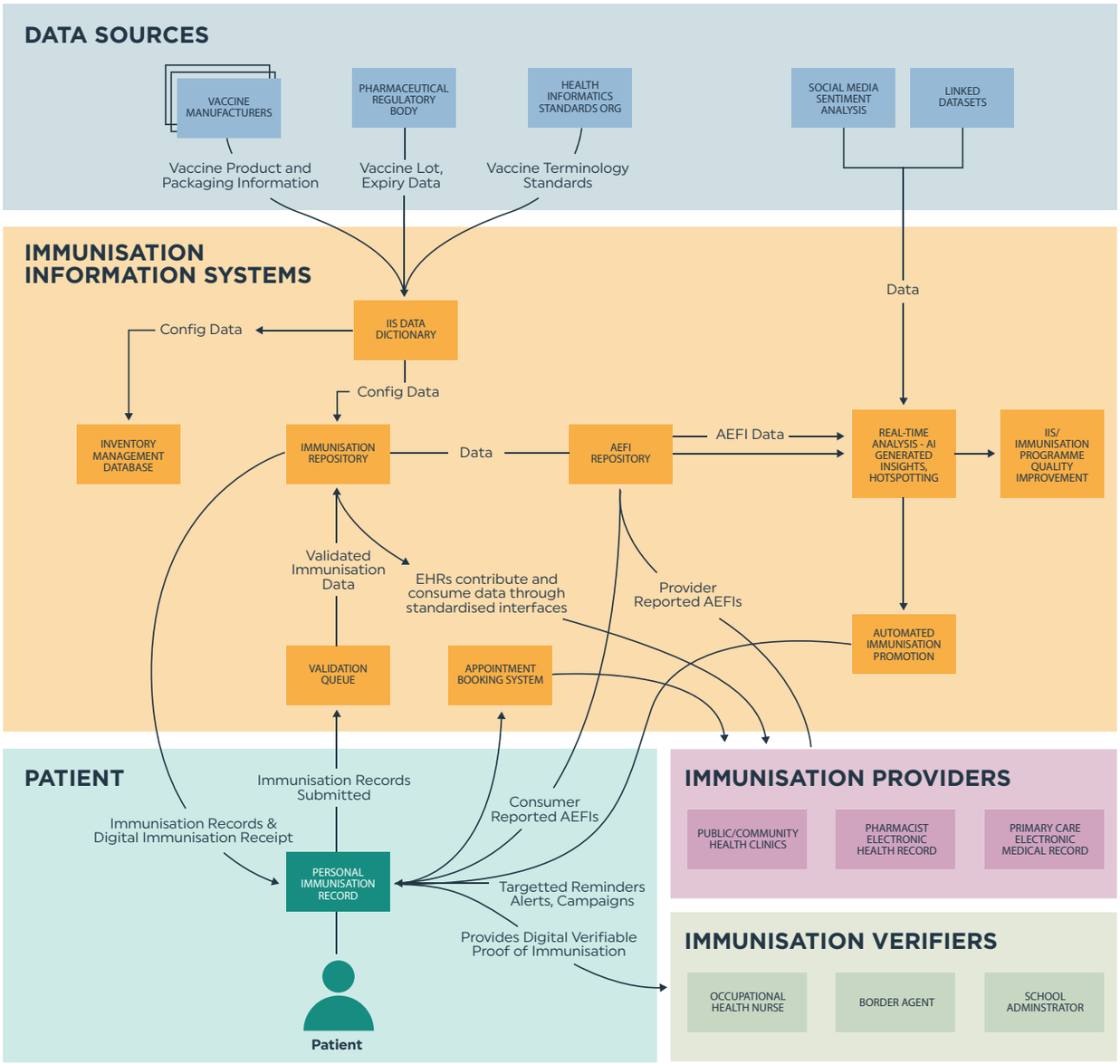


Figure 5. Source: The digital immunisation system of the future: imagining a patient-centric, interoperable immunisation information system[6]

IDENTIFIED OPPORTUNITIES

Opportunity 1: The focus of the European Commission on digitalisation
The implementation of the EHDS is a priority for the European Commission because it will promote better exchange and access to different types of health data, and support healthcare delivery and health research and health policy-making purposes. On 3 May 2022, the European Commission launched a proposal for a Regulation on the European Health Data Space.

Opportunity 2: The emphasis on interoperability
When developing new systems or performing significant developments of existing ones, there is a need to identify national and European funding sources (e.g., EU4Health, Digital Europe, Recovery and Resilience Facility) to avoid the risk of changing priorities with new governments.

There is a need to develop an EVR template for the EU, starting from a minimum/optimal common denominator to allow interoperability.

Opportunity 3: The quantitative results of the past 15 years
During the past 15 years, a well-documented successful usage of HPV vaccines has been accumulated. The vaccination campaign substantially reduced the burden of HPV-related diseases.[3] In the context of the coordinated European response generated by the COVID-19 pandemic, a powerful momentum exists for accelerating optimal coverage rates in the EU and the UK.

Furthermore, following various outbreaks including COVID-19, the European Commission reacted with initiatives both in the area of policy and by financing limited projects to do with Electronic Vaccination Registries, culminating with the significant COVID-19 certificate system. It is time for a more proactive approach that is sustained by consistent technological innovation.

Opportunity 4: The practices catalysed by the COVID-19 pandemic
The COVID-19 pandemic had a mixed influence. On the one hand, it left other vaccination campaigns in the shade. On the other hand, it accelerated the development of an integrated supranational approach, emphasising Electronic Vaccination Records. The will to increase vaccination rates in general, HPV included, is necessary for every country.

It is time to strongly emphasise a consistent correlation between the existence of evolved Electronic Vaccination Records and higher Vaccine Coverage Rates. This will trigger a cascade of positive effects to the benefit of public health.

3 Lei J, Ploner A, Elfström KM, et al. HPV vaccination and the risk of invasive cervical cancer. New England Journal of Medicine. 2020;383(14):1340-1348.
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