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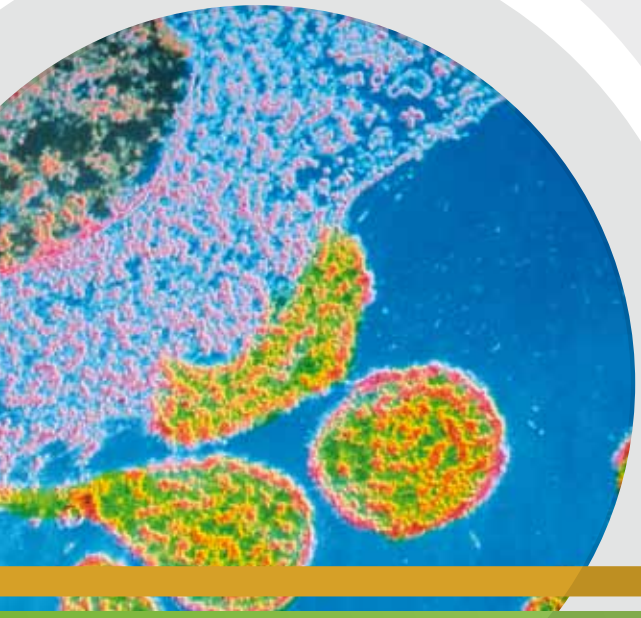

TECHNICAL REPORT

Survey on rubella, rubella in pregnancy and congenital rubella surveillance systems in EU/EEA countries

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Contents

Abbreviations

CRI	Congenital rubella infection
CRS	Congenital rubella syndrome
ECDC	European centre for disease prevention and control
EEA	European economic area
GP	General practitioner
IgG	Immunoglobulin G
IgM	Immunoglobulin M
NRC	National reference centre, Belgium
WHO	World health organization
WHO-EURO	World health organization regional office for europe

Country codes

AT	Austria	IT	Italy
BE	Belgium	LT	Lithuania
BG	Bulgaria	LU	Luxembourg
CY	Cyprus	LV	Latvia
CZ	Czech republic	MT	Malta
DE	Germany	NL	Netherlands
DK	Denmark	NO	Norway
EE	Estonia	PL	Poland
ES	Spain	PT	Portugal
FI	Finland	RO	Romania
FR	France	SE	Sweden
GR	Greece	SI	Slovenia
HU	Hungary	SK	Slovakia
IE	Ireland	UK	United Kingdom
IS	Iceland		

Summary

The European Centre for Disease Prevention and Control (ECDC) supports EU/EEA countries to achieve the World Health Organization European Region's goal of rubella elimination and congenital rubella syndrome (CRS) prevention by 2015. From October 2011 to September 2012, EU countries reported over 30 000 rubella cases, with a proportion of laboratory-confirmed cases ranging from 0 to 100% among countries. The World Health Organization recommends maintaining high vaccination coverage and strengthening surveillance systems by rigorous case investigation and laboratory confirmation of cases. ECDC launched a survey to obtain an overview of surveillance systems of rubella, rubella in pregnancy and congenital rubella in EU/EEA countries. Currently data on congenital rubella are not collected at EU level. Hence, a thorough understanding of surveillance systems in place is required in order to prepare for enhanced CRS surveillance in the EU

A cross-sectional survey was conducted between June and November 2012 among 29 EU/EEA countries. Three questionnaires were prepared and piloted in five countries. They investigated characteristics and coverage of surveillance systems for rubella, rubella in pregnancy and congenital rubella, epidemiological investigation procedures, and reference laboratories' skills. Respondents were ECDC expert contact points for rubella.

All 29 countries replied. Regarding rubella surveillance, 26 countries have a mandatory and comprehensive rubella surveillance system: 25 at national level and one at sub-national level. Twenty-two countries adopted the EU case definition for rubella. Vaccination status is collected in all countries, laboratory details in 24, and source of infection (imported/indigenous cases) in 20. Laboratories report cases in 20 countries. Twenty countries routinely conduct epidemiological investigation of suspected cases. Zero-reporting is required in three countries and all the 26 countries have a national reference laboratory for rubella.

Regarding congenital rubella, 28 countries have a national CRS surveillance, mostly mandatory (26/28), comprehensive (27/28) and case-based (27/28). Eight countries had active surveillance and six countries require zero-reporting for CRS surveillance. Twenty-seven countries collect laboratory results and 24 have adopted the EU case definition for CRS. Asymptomatic infections are reported to central level in 11 countries and are monitored to detect if symptoms occur over time in 13 countries. All countries have a reference laboratory for confirmation of suspected congenital rubella cases.

Information regarding rubella infections occurring during pregnancy is collected in 25 countries; in five countries there is a specific surveillance system for rubella in pregnancy, while in 20 countries it is included in the rubella surveillance system. Still births and fetal deaths due to congenital rubella infection are monitored in 13 countries; therapeutic and spontaneous abortion in eight and seven countries respectively.

Although most EU/EEA countries monitor rubella, rubella in pregnancy and CRS incidence through mandatory comprehensive systems, surveillance could be improved through the implementation of a rubella surveillance system in all countries, universal use of zero-reporting, collection of information on imported/import-related cases, and adoption of uniform case definitions. Laboratory capacity is available at EU level but the proportion of laboratory-investigated cases should be increased in several countries to achieve an adequate confirmation of cases. Collection of incidence data on congenital rubella infections seems to be feasible at EU level. Coordination of rubella and congenital rubella surveillance by ECDC would allow introduction of common indicators and harmonisation of laboratory procedures to ensure data comparability data between countries, supporting the WHO elimination goal. Sensitivity of the systems should be also investigated.

1 Introduction

The World Health Organization Regional Office for Europe (WHO-EURO) has recommended measures to be undertaken by European region countries to eliminate measles, rubella and congenital rubella by 2015 [1]. WHO have recommended the maintenance of high vaccination coverage as well as strengthening surveillance systems by rigorous case investigation and laboratory confirmation of suspected cases. ECDC supports EU Member States and EEA countries to collaborate with WHO-EURO and reach this goal.

The Commission Decision of 22 Dec 1999 for epidemiological surveillance in the EU included rubella in the list of communicable diseases notifiable at EU level [2]. An official EU case definition exists for rubella and congenital rubella [3].

In September 2011, rubella surveillance was integrated into ECDC after the transfer of the EUVAC.NET[i] network. On a monthly basis, Member States submit individual notification data on rubella cases through the European Surveillance System. ECDC does not request Member States to submit data on congenital rubella syndrome (CRS) cases and congenital rubella infection (CRI) at the present time.

In 2008, EUVAC.NET and WHO-EURO conducted a survey on surveillance systems and sources of information used for rubella and congenital rubella [4].

In the period of June to November 2012, ECDC launched a new survey to obtain an updated overview of surveillance systems for rubella, rubella in pregnancy and congenital rubella in EU/EEA countries.

ECDC is planning to launch and coordinate CRS surveillance in Member States. Hence, a thorough understanding of surveillance system in place is required.

2 Objectives

- To describe the surveillance systems for rubella, rubella in pregnancy and congenital rubella currently in place in EU/EEA countries.
- To critically appraise findings in relation to officially recommended actions required to meet the elimination goal.
- To evaluate the feasibility of setting up a surveillance system for congenital rubella at EU level.

[i] EUVAC.NET was a European surveillance network for selected vaccine-preventable diseases hosted at the Staten Serum Institute (SSI), Denmark.

3 Methods

After a review of the literature, WHO guidelines, global plans and the results of the European survey on rubella and congenital rubella conducted by EUVAC-NET in 2008, and taking into account the new elimination goals, a new survey was designed in order to assess the current situation regarding rubella, CRI and CRS surveillance systems in Europe. The 27 European Union countries plus Norway and Iceland were invited to participate in the survey. Liechtenstein was not invited to participate in the survey.

The aim of the survey was to describe the existing national surveillance systems; exploring the type of surveillance system, case definitions used, variables collected, frequency of collection, epidemiological investigation and follow up of cases, notification flow, existence of reference laboratories and types of tests performed, method and frequency of data dissemination. For countries declaring no surveillance systems, plans for the future were investigated. The questionnaire was prepared in an Excel format; it consisted of three separate sheets for rubella with 27, 26 and 28 questions respectively. The questionnaire was pre-filled with data available from the previous 2008 survey.

An invitation letter explaining the objectives and the methods of the project was also prepared and respondents were identified by ECDC among the ECDC contact points working with rubella surveillance.

In mid-July 2012 the questionnaire was piloted in five countries (France, Romania, Italy, Belgium and Germany), in order to verify its completeness and clarity. They were asked to fill out the questionnaire and comment on both the format and content of the survey. By the first week of September 2012, all five pilot countries had filled out the survey and returned it for analysis. All countries filled out the questionnaire correctly and declared that it was clear, comprehensive and easy to complete. Some questions were subsequently modified based on the results of the pilot and a new questionnaire was sent to all participating countries at the end of September 2012. The questionnaire was sent via email to the identified contact points together with the invitation letter. In November 2012, all questionnaires were analysed and a first report was produced and sent to all countries for validation. A presentation specifically on congenital rubella surveillance systems was undertaken during the annual ECDC vaccine preventable disease meeting, 21–23 November 2012. A final report was produced in January 2013.

4 Results

The result section is divided into five parts:

- a general summary table of existing surveillance systems (4.1)
- results for surveillance systems for rubella (4.2)
- results for surveillance systems for rubella infections during pregnancy (4.3)
- results for surveillance systems for congenital rubella (4.4)
- plans for the future (4.5)

4.1 Overview of surveillance systems in EU/EEA countries

All 29 EU/EEA countries that were invited to take part responded to the survey; 20 countries (69%) validated data by December 2012.

Twenty-six countries (89.7%) have a surveillance system for rubella (one or two different systems), 25 countries (86.2%) have a surveillance system for rubella in pregnancy (specific or included in the rubella system) and 28 countries (96.5%) have a surveillance system for congenital rubella (table 1). Belgium, Denmark and France have a surveillance system for congenital rubella, although they do not have a system for rubella.

Table 1. Presence of surveillance system for rubella, rubella in pregnancy and congenital rubella, by country

Country	Rubella	Rubella in pregnancy	Congenital rubella
Austria (AT)	Yes (one system)	Yes (included in rubella system)	Yes
Belgium (BE)	No	No	Yes
Bulgaria (BG)	Yes (one system)	No	Yes
Cyprus (CY)	Yes (one system)	Yes (included in rubella system)	Yes
Czech republic (CZ)	Yes (one system)	Yes (included in rubella system)	Yes
Germany (DE)	Yes (one system)	No	Yes
Denmark (DK)	No	Yes (specific)	Yes
Estonia (EE)	Yes (one system)	Yes (included in rubella)	Yes
Spain (ES)	Yes (one system)	Yes (included in rubella)	Yes
Finland (FI)	Yes (one system)	Yes (included in rubella)	Yes
France (FR)	No	Yes (specific)	Yes
Greece (GR)	Yes (two systems)	Yes (included in rubella)	Yes
Hungary (HU)	Yes (one system)	Yes (included in rubella)	Yes
Ireland (IE)	Yes (two systems)	Yes (included in rubella)	Yes
Iceland (IS)	Yes (one system)	Yes (specific)	Yes
Italy (IT)	Yes (one system)	Yes (specific)	Yes
Lithuania (LT)	Yes (one system)	Yes (included in rubella)	Yes
Luxembourg (LU)	Yes (one system)	No	No
Latvia (LV)	Yes (one system)	Yes (included in rubella)	Yes
Malta (MT)	Yes (one system)	Yes (specific)	Yes
Netherlands (NL)	Yes (one system)	Yes (included in rubella)	Yes
Norway (NO)	Yes (one system)	Yes (included in rubella)	Yes
Poland (PL)	Yes (one system)	Yes (included in rubella)	Yes
Portugal (PT)	Yes (one system)	Yes (included in rubella)	Yes
Romania (RO)	Yes (one system)	Yes (included in rubella)	Yes
Sweden (SE)	Yes (one system)	Yes (included in rubella)	Yes
Slovenia (SI)	Yes (one system)	Yes (included in rubella)	Yes
Slovakia (SK)	Yes (one system)	Yes (included in rubella)	Yes
United Kingdom (UK)	Yes (one system)	Yes (included in rubella)	Yes
Total	26	25	28

Regarding the year of introduction of surveillance systems, Italy was the first country to introduce the rubella surveillance in 1934, while Ireland was the first one to introduce a surveillance system for rubella, rubella in pregnancy and congenital rubella in 1948. In 12 countries the three systems were introduced in the same year (table 2).

Table 2. Year of introduction of surveillance systems for rubella, rubella in pregnancy and congenital rubella, by country

Country	Rubella	Rubella in pregnancy	Congenital Rubella
Austria (AT)	2007	2007	2007
Belgium (BE)			2006
Bulgaria (BG)	1940		2001
Cyprus (CY)	1984	1984	2004
Czech republic (CZ)	1961	1961	1961
Germany (DE)	2001		1961
Denmark (DK)		1994	1994
Estonia (EE)	1979	1979	1979
Spain (ES)	1981	1981	1987
Finland (FI)	1995	1969	1969
France (FR)		1976	1976
Greece (GR)	1998	2004	1998
Hungary (HU)	1973	1976	1976
Ireland (IE)	1948	1948	1948
Iceland (IS)	1977	1977	1977
Italy (IT)	1934	2005	2005
Lithuania (LT)	2003	2003	2003
Luxembourg (LU)	2004		
Latvia (LV)	1999	1999	1999
Malta (MT)	2004	2004	1997
Netherlands (NL)	1950	2004	2004
Norway (NO)	1975	1994	1977
Poland (PL)	1966	1966	1966
Portugal (PT)	1987	1987	1987
Romania (RO)	2010	2010	2000
Sweden (SE)	1996	1996	1996
Slovenia (SI)	1977	1977	1977
Slovakia (SK)	1976	1976	1976
United Kingdom (UK)	1995	1971	1971
Total	26	25	28

< 1970 | 1970–1999 | ≥ 2000

DE: Rubella surveillance system: the five 'New Länder' introduced rubella surveillance at different dates (2001–2009)

4.2 Rubella surveillance

Twenty-six out of 29 countries (89.7%) have a surveillance system for rubella. Greece and Ireland have more than one system for rubella surveillance (table 3).

Table 3. Is there a surveillance system for rubella in your country?

	Frequency	Percentage	Countries
No surveillance	3	10.3	BE*, DK, FR
Yes	26	89.7	AT, BG, CY, CZ, DE, EE, ES, FI, GR*, HU, IE*, IS, IT, LT, LU, LV, MT, NL, NO, PL, PT, RO, SE, SI, SK, UK
Total	29	100.0	

**BE: In Belgium a network of sentinel laboratories, consisting of 58% of all laboratories, reports on a voluntary basis to the Institute of Public Health. For rubella, IgM positive cases are reported, however clinical information or vaccination status is not collected for these cases. Data from the National Reference Centre (NRC) for measles and rubella could be considered for surveillance purposes.*

**GR: In Greece two surveillance systems are present: a comprehensive system and a sentinel one. The sentinel system is passive and voluntary; physicians from selected primary health care services as well as private physicians are asked to notify suspected rubella cases. The case definition is clinical (clinical picture compatible with rubella: i.e. sudden onset of generalised maculo-papular rash and arthralgia/arthritis, lymphadenopathy or conjunctivitis, without any other obvious cause).*

**IE: Ireland, other than the national comprehensive surveillance system for rubella, has a sentinel surveillance system for syndromic diseases, including GPs from all over the country (it is part of the Influenza like illness (ILI) sentinel surveillance system). The GPs in the sentinel surveillance system are anonymous and the data are more used to cross check the occurrence of viral rashes in the community.*

The following analysis includes the 26 countries that have a rubella surveillance system. For Greece and Ireland only the comprehensive systems have been included in the analysis. In 20 out of 26 countries (76.9%) the rubella surveillance system was introduced after 1970 (table 4).

Table 4. When the surveillance system for rubella was introduced in your country?

Year	Frequency	Percentage	Countries
1930–1939	1	3.8	IT
1940–1949	2	7.7	BG, IE
1950–1959	1	3.8	NL
1960–1969	2	7.7	CZ, PL
1970–1979	6	23.1	EE, HU, IS, NO, SI, SK
1980–1989	3	11.5	CY, ES, PT
1990–1999	5	19.2	FI, GR, LV, SE, UK
2000–2009	5	19.2	AT, DE, LT, LU, MT,
2009–2012	1	3.8	RO
Total	26	100.0	

All 26 countries replied that the target population of the system is represented by the general population.

Almost all countries (25/26) have a nationwide surveillance (table 5), except Germany, where a nationwide surveillance system is planned but not yet implemented.

Table 5. Which level of coverage has the surveillance system for rubella in your country?

	Frequency	Percentage	Countries
Nationwide surveillance	25	96.2	AT, BG, CY, CZ, EE, ES, FI, GR, HU, IE, IS, IT, LT, LU, LV, MT, NL, NO, PL, PT, RO, SE, SI, SK, UK
Sub national surveillance	1	3.8	DE
Total	26	100.0	

Most countries (23/26) have case-based data at a national level (table 6), and 92.3% (24/26) of the countries have case-based data at a sub national level (table 7). Regarding countries with case-based data (25), all countries collect information about age, gender and vaccination status; most countries (24/25) collect the date of onset of clinical symptoms and laboratory details (tables 8 and 9). Nineteen countries (76%) collect information regarding the notification source (imported, import-related or indigenous case). Eighteen countries (72%) record the status of pregnancy. Poland has aggregated cases both at the national and the sub national level, by age, gender, vaccination status and case classification.

Table 6. What type of data for rubella is available at a national level?

	Frequency	Percentage	Countries
No data	1	3.8	DE
Case-based	23	88.5	AT, BG, CY, CZ, EE, ES, FI, GR, HU, IE, IS, IT, LU, LV, MT, NL, NO, PT, RO, SE, SI, SK, UK
Aggregated	2	7.7	LT, PL
Total	26	100.0	

Table 7. What type of data for rubella is available at a sub national level?

	Frequency	Percentage	Countries
No data	1	3.8	CY
Case-based	24	92.3	AT, BG, CZ, DE, EE, ES, FI, GR, HU, IE, IS, IT, LT,LU, LV, MT, NL, NO, PT, RO, SE, SI, SK, UK
Aggregated	1	3.8	PL
Total	26	100.0	

Table 8. If case-based, which data are collected?

	Frequency	Percentage	Countries
Age	25	100.0	AT, BG, CY, CZ, DE, EE, ES, FI, GR, HU, IE, IS, IT, LT, LU, LV, MT, NL, NO, PT, RO, SE, SI, SK, UK
Gender	25	100.0	AT, BG, CY, CZ, DE, EE, ES, FI, GR, HU, IE, IS, IT, LT, LU, LV, MT, NL, NO, PT, RO, SE, SI, SK, UK
Notification source	22	88.0	AT, BG, CY, CZ, DE, EE, ES, FI, GR, HU, IS, IE, IT, LT, LU, LV, MT, NO, PT, SE, SI, SK
Date of onset of clinical symptoms	24	96.0	AT, BG, CY, CZ, DE, EE, ES, FI, GR, HU, IE, IT, LT, LU, LV, MT, NL, NO, PT, RO, SE, SI, SK, UK
Clinical picture	12	48.0	AT, CZ, ES, FI, GR, HU, IS, MT, NO, PT, RO, SK
Clinical complications	15	60.0	AT, BG, CY, CZ, DE, ES, FI, GR, HU, IS, LT, NO, PT, RO, SK
Hospitalization	22	88.0	AT, BG, CY, CZ, DE, EE, ES, FI, GR, HU, IS, IT, LT, LU, LV, MT, NL, NO, RO, SI, SK, UK
Laboratory details	24	96.0	AT, BG, CY, CZ, DE, EE, ES, FI, GR, HU, IE, IS, LT, LU, LV, MT, NL, NO, PT, RO, SE, SI, SK, UK
Genotype	12	48.0	AT, BG, ES, FI, HU, IE, LT, LU, LV, NO, RO, UK
Vaccination status	25	100.0	AT, BG, CY, CZ, DE, EE, ES, FI, GR, HU, IE, IS, IT, LT, LU, LV, MT, NL, NO, PT, RO, SE, SI, SK, UK
Prior evidence of serological immunity	2	8.0	LT, LU
Source of infection	19	76.0	AT, BG, CZ, DE, EE, ES, FI, HU, IT, LT, LU, LV, MT, NL, NO, RO, SE, SK, UK
Status of pregnancy	18	72.0	AT, BG, CZ, EE, ES,FI, HU, IS, LT, LU, LV, MT, NL, NO, PT, RO, SK, UK
Gestational age at time of infection	13	52.0	AT, BG, CZ, ES, FI, HU, IS, LT, NL, NO, RO, SK, UK
Previous pregnancies or deliveries	2	8.0	IS, LT
Outcome of pregnancy	7	28.0	CZ, ES, IS, LT, NO, SK, UK
Case classification	18	72.0	AT, BG, CY, CZ, DE, EE, ES, FI, GR, HU, IE, IS, LV, MT, NL, RO, SE, SK

DE: Notification of clinical symptoms to national level is not mandatory

Table 9. If case-based, which data are collected?

	Age	Gender	Notification source	Date on onset of clinical symptoms	Clinical picture	Clinical complications	Hospitalization	Laboratory details	Genotype	Vaccination status	Prior evidence of serological immunity	Source of infection	Status of pregnancy	Gestational age at time of infection	Previous pregnancies or deliveries	Outcome of pregnancy	Case classification
AT	X	X	X	X	X	X	X	X	X	X		X	X	X			X
BG	X	X		X		X	X	X	X	X		X	X	X			X
CY	X	X	X	X		X	X	X		X							X
CZ	X	X	X	X	X	X	X	X		X		X	X	X		X	X
DE	X	X	X	X	X	X	X	X		X		X					X
EE	X	X	X	X			X	X		X		X	X				X
ES	X	X	X	X	X	X	X	X	X	X		X	X	X		X	X
FI	X	X	X	X	X	X	X	X	X	X		X	X	X			X
GR	X	X	X	X	X	X	X	X		X		X	X				X
HU	X	X	X	X	X	X	X	X	X	X		X	X	X			X
IE	X	X	X	X				X	X	X							X
IS	X	X	X		X	X	X	X		X			X	X	X	X	X
IT	X	X	X	X			X			X		X					
LT	X	X	X	X		X	X	X	X	X	X	X	X	X	X	X	
LU	X	X	X	X			X	X	X	X	X	X	X				
LV	X	X	X	X			X	X	X	X		X	X				X
MT	X	X	X	X	X		X	X		X		X	X				X
NL	X	X		X			X	X		X		X	X	X			X
NO	X	X	X	X	X	X	X	X	X	X		X	X	X		X	
PT	X	X	X	X	X	X		X		X			X				
RO	X	X		X	X	X	X	X	X	X		X	X	X			X
SE	X	X	X	X				X		X		X					X
SI	X	X	X	X			X	X		X							
SK	X	X	X	X	X	X	X	X		X		X	X	X		X	X
UK	X	X		X			X	X	X	X		X	X	X		X	

All countries (26/26) have comprehensive and mandatory reporting surveillance systems.

Greece and Ireland also have a sentinel surveillance system. Ireland has a sentinel surveillance system for syndromic diseases (it is part of the influenza like illness sentinel surveillance system), which includes GPs from all over the country. In Greece, the sentinel system is passive and voluntary; physicians from selected primary health care services as well as private physicians are asked to notify suspected rubella cases.

The rubella surveillance system is passive in most countries (22/26). Only the Netherlands and Iceland reported that they have an active surveillance system (table 10).

Table 10. What type of surveillance system exists: active or passive?

	Frequency	Percentage	Countries
Active	2	7.7	IS, NL
Passive	22	84.6	AT, BG, DE, EE, ES, FI, GR, HU, IE, IS, IT, LT, LU, LV, MT, NO, PL, PT, RO, SK, SI, SE, UK
Other: both	2	7.7	CY*, CZ*
Total	26	100.0	

**CY: There is an established weekly communication through telephone calls with all the public sector hospitals (paediatric) that enables direct reporting. This was established in order to reduce the chances of under-reporting.*

**CZ: Infections are reported by physicians to the local public health authorities, which investigate index case and trace the contacts. All information flows through regional public health authorities to the National Institute of Public Health and Ministry of Health to the nationwide reporting system EPIDAT.*

Physicians report cases in most of the countries (25/26), hospitals and laboratories in 76.9% (20/26) of countries (tables 11).

Table 11. Who is reporting cases?

	Frequency	Percentage	Countries
Physicians	25	96.2	AT*, BG, CY, CZ, DE, EE, ES, FI, GR, HU, IE, IS, IT, LU, LV, MT, NL, NO, PL, PT, RO, SE, SI, SK, UK
Hospitals	20	76.9	AT*, BG, CZ, DE, EE, ES, GR, HU, IE, IS, IT, LT, LV, MT, NO, PL, RO, SE, SK, UK
Laboratories	20	76.9	AT*, BG, CZ, DE, EE, FI, GR, HU, IE, IS, LU, LV, MT, NL, NO, RO, SE, SI, SK, UK
Other	1	3.8	AT*

AT: According to national epidemic law

Twenty-two out of 26 countries (80.8%) have a case definition compatible with the 2008 EU case definition; only one country has a case definition compatible with WHO case definition and in two countries the case definition does not fit either the EU or WHO case definition; Italy does not have a case definition for rubella, but is going to implement a new enhanced surveillance system and the EU case definition will be adopted shortly (table 13).

Table 13. Is there a case definition of rubella for reporting purposes?

	Frequency	Percentage	Countries
Yes, compatible with the 2008 EU case definition	22	84.6	AT, BG, CY, CZ, EE, ES, GR, HU, IE, IS, LT, LU, LV, MT, NL, NO, PL, PT, RO, SE, SI, SK
Yes, compatible with WHO case definition	1	3.8	DE
No	1	3.8	IT*
Yes, other	2	7.7	FI, UK*
Total	26	100.0	

IT: Modification of the system including adoption of EU case definition is awaiting approval (see section 7.5)

UK: They do not correctly follow either of these definitions (WHO and ECDC definitions), as they perform testing on oral fluid as well as serum and sometimes do not have the clinical information before performing the testing. Also the virus isolation technique is used as method of confirmation of cases

Twenty-five out 26 countries report confirmed cases; 22 countries report probable cases and 18 also possible cases; seven countries report discarded cases (table 14). Italy, that does not have a case definition for rubella, and reports all suspect cases both on clinical, epidemiological and laboratory criteria.

Table 14. What type of cases are reported to the health authorities?

	Frequency	Percentage	Countries
Possible cases	18	69.2	AT*, BG, CY, CZ, ES, GR, HU, IE, LU, LV, MT, NO, PL, PT, RO, SE, SI, SK
Probable cases	22	84.6	AT*, BG, CY, CZ, DE*, ES, GR, HU, IE, IS, LT, LU, LV, MT, NL, NO, PL, PT*, RO, SE, SI, SK
Confirmed cases	25	96.2	AT*, BG, CY, CZ, DE*, EE, ES, FI, GR, HU, IE, IS, LT, LU, LV, MT, NL, NO, PL, PT, RO, SE, SI, SK, UK
Discarded cases	7	26.9	BG, EE, ES, LV, MT, PL, RO
Other	3	11.5	AT, DE, IT*

**AT:The Austrian epidemic law contains a list of mandatory reportable diseases. For these diseases every suspected and confirmed case as well as every death has to be reported.*

**DE: Kind of reporting differs in the five new Länder; notification of possible cases to national level is not mandatory*

**PT: Probable cases are reported, as in Portugal most rubella cases are reported only based on clinical diagnosis without laboratory confirmation.*

**IT: Suspected cases (modification of the system including adoption of EU case definition is awaiting approval: possible, probable, confirmed and discarded cases will be notified)*

Only in three (Lithuania, Romania and the United Kingdom) out of 26 countries (11.5%) is zero reporting required at a national and a sub national level (table 15).

Table 15. Is zero-reporting required?

	Frequency	Percentage	Countries
No	23	88.5	AT, BG, CY, CZ, DE, EE, ES, FI, GR, HU, IE, IS, IT*, LU, LV, MT, NL, NO, PL, PT, SE, SI, SK
Yes, at national level	0	0	
Yes, at all levels	3	11.5	LT, RO, UK
Total	26	100.0	

**IT: Not yet, modifications for this purpose are ongoing*

WHO recommends that rubella surveillance should be integrated with measles surveillance: all sera from suspected rubella cases which test negative for rubella IgM antibodies should be tested for measles IgM antibodies and vice versa. Fifteen out of 26 countries (57.7%) have an integrated system for rubella and measles. In two countries (7.7%) modifications for introducing an integrated system are ongoing (table 16).

Table 16. Is the surveillance system integrated for measles and rubella?

	Frequency	Percentage	Countries
No	9	34.6	DE, GR, LV, MT, NL, NO, PL, SE, SI
Yes	15	57.7	AT, BG, CY, CZ, EE, ES, FI, HU, IS, LT, LU, PT, RO, SK, UK
Not yet, modifications at this purpose are ongoing	2	7.7	IE,IT
Total	26	100.0	

For most countries (20/26), epidemiological investigation of suspected cases of rubella is routinely conducted (table 17).

Table 17. Is epidemiological investigation of suspected cases of rubella routinely conducted?

	Frequency	Percentage	Countries
No	6	23.1	AT, DE, IE, IT, PL, SI
Yes	20	76.9	BG, CY, CZ, EE, ES, FI, GR, HU, IS, LT, LU, LV, MT, NL, NO, PT, RO, SE, SK, UK
Total	26	100.0	

All countries (26/26) have a national reference laboratory; Immunoglobulin M (IgM) and Immunoglobulin G (IgG) antibody detection is performed in all national laboratories (tables 18). Thirteen countries are able to perform virus genotyping.

Table 18. Which kind of laboratory tests does the national reference laboratory perform?

	Frequency	Percentage	Countries
IgM and IgG antibody detection	26	100.0	AT, BG, CY, CZ, DE, EE, ES, FI, GR, HU, IE, IS, IT, LT, LU, LV, MT, NL, NO, PL, PT, RO, SK, SI, SE, UK
IgG avidity test or other tests to confirm recent infection	17	65.4	AT, BG, CY, CZ, DE, ES, FI, GR, HU, IT, LU, LV, NO, PT, RO, SK, UK
Viral RNA detection by RT-PCR	18	69.2	AT, CZ, DE, EE, ES, FI, GR, HU, IT, LU, LV, NL, NO, PL, PT, RO, SK, UK
Virus isolation	16	61.5	AT, CZ, DE, ES, FI, GR, HU, IT, LU, LV, NL, PL, PT, RO, SI, SK
Genotyping	13	50.0	AT, DE, ES, FI, HU, IT, LU, LV, NL, NO, PT, RO, UK
Other	1	3.8	HU*

**HU: Hemagglutination inhibition*

In Belgium, where a rubella surveillance system is not in place, there is a National Reference Centre (NRC) for measles and rubella and data from this laboratory could be considered for surveillance purposes. Criteria for delivering the tests in the context of the reference activities are diagnosis of congenital rubella syndrome, laboratory confirmation for rubella symptoms, confirmation of a first line test and diagnosis in IgM positive pregnant women. The NRC for measles and rubella delivers the following laboratory tests on a routine basis: IgM and IgG antibody detection, IgG avidity test and other tests to confirm recent infection. Molecular diagnosis is performed on nose and throat smear (in-house nested RT-PCR). The annual report of the NRC is available on the website[i].

Most countries could report cases from the national level to the European level monthly (84.6%). Two countries (7.7%) could report cases annually and two countries (7.7%) could report cases weekly (table 19).

Table 19. How often would it be possible to report cases of rubella from the national level to the European level?

	Frequency	Percentage	Countries
Only during outbreaks	0	0.00	
Annually	2	7.7	CZ, IT*, PL
Monthly	22	84.6	AT, BG, CY, CZ, DE*, EE, ES, FI, GR, HU, IS, LT, LU, LV, MT, NO, PT, RO, SE, SI, SK, UK
Weekly	2	7.7	IE, NL
Not regularly	0	0.00	
Other	0	0.00	
Total	26	100.0	

**IT: With the introduction of the integrated surveillance system for measles and rubella, it will be possible to report cases monthly*

DE: After introduction of nationwide case-based surveillance system

[i] The National Reference Centre for measles and rubella. Belgium. http://nrchm.wiv-isp.be/default.aspx

The minimum frequency of feedback reports from the national level to the public health administrative level varies among countries. Portugal was the only country that declared no feedback mechanism (table 20).

Table 20. What is the minimum frequency of feedback reports from the national level to the public health administrative level regarding rubella epidemiology?

	Frequency	Percentage	Countries
No feedback mechanism	1	3.8	PT
Only during outbreaks	0	0.00	
Annually	7	26.9	DE, GR, IT, NL, NO, RO, SE
Monthly	8	30.7	CY, EE, IE, IS, LT, LU, LV, MT
Weekly	5	19.2	CZ, ES, HU, SI, SK
Not regularly	0	0.00	
Other	5	19.2	AT*, BG*, FI*, PL*, UK*
Total	26	100.0	

***AT: Via EMS any public health officer can automatically see all anonymous data at any time. Additionally, monthly reviews are provided at www. bmg.gv.at*

**BG: Daily - through a web-based informational system*

**FI: Continuously*

** *PL: Feedback mechanism is based on publications on the Institute website: biweekly with cumulative data and annually as Infectious Diseases Bulletin.*

UK: Quarterly

In most of countries (23/26) rubella surveillance data are uploaded onto a public website (table 21). Table 22 shows the link to the website where incidence data for rubella, rubella in pregnancy and congenital rubella are reported.

Table 21. Are rubella surveillance data uploaded on a public website?

	Frequency	Percentage	Countries
No	3	11.5	LT, LU, NL
Yes	23	88.5	AT, BG, CY, CZ, DE, EE, ES, FI, GR, HU, IE, IS, IT, LV, MT, NO, PL, PT, RO, SK, SI, SE, UK
Total	26	100.0	

Table 22. Name of public website

Country	Electronic link	Rubella	Rubella in Pregnancy	Congenital rubella
AT	www.bmg.gv.at – aggregated data for rubella. CRS and Rubella in Pregnancy included	X	X	X
BE	http://nrchm.wiv-isp.be/default.aspx (Rubella cases from NRC) http://www.wiv-isp.be/pedisurv (Congenital rubella cases)	X	NA	X
BG	www.ncipd.org	X	NA	X
CY	http://www.moh.gov.cy/MOH/mphs/mphs.nsf/All/99AF51617DD444FFC22577FB002F8245?OpenDocument	X	-	X
CZ	http://www.szu.cz	X	X	X
DE	http://www3.rki.de/SurvStat/	X	NA	X
DK	http://www.ssi.dk/Smitteberedskab/Sygdomsovervaagning/Sygdomsdata.aspx?sygdomskode=RUBE&xaxis=Aar&show=&datatype=Individual&extendedfilters=False#HeaderText	NA	X	X
EE	www.terviseamet.ee	X	X	X
ES	http://www.isciii.es/ISCIII/es/contenidos/fd-servicios-cientifico-tecnicos/fd-vigilancias-alertas/fd-enfermedades/fd-enfermedades-prevenibles-vacunacion/plan-eliminacion-sarampion-rubeola-espana.shtml	X	X	X
FI	www3.ktl.fi www.tartuntatautirekisteri.fi/tilasto www.thl.fi/fi_FI/web/potilasturvallisuus-fi/hilmo	X	X	X
FR	http://www.invs.sante.fr/surveillance/renarub/default.htm	NA	X	X
GR	www.keelpno.gr	X	missing	X
HU	www.oek.hu	X	X	X
IE	https://www.hpsc.ie/hpsc/A-Z/VaccinePreventable/Rubella/EpidemiologicalData/	X	-	X
IS	http://www.landlaeknir.is/	X	-	-
IT	http://www.salute.gov.it/malattieInfettive/paginaInternaMenuMalattieInfettive.jsp?id=812&menu=strumentieservizi	X	-	-
LV	http://www.spkc.gov.lv/infekcijas-slimibu-statistika/	X	NA	X
NO	www.msis.no	X	-	-
PL	http://www.pzh.gov.pl/oldpage/epimeld/index_a.html	X	-	X
PT	http://www.dgs.pt/	X	--	X
RO	http://www.insp.gov.ro/cnscbt (Main Menu - Rapoarte anuale - "Raport de activitate CNSCBT pentru anul 2011".)	X	X	X
SI	Data are published monthly in a Monthly surveillance report (enBOZ) available on web page of NIPH	X	X	X
SE	http://www.smittskyddsinstitutet.se/statistik/roda-hund/	X	-	X
SK	www.epis.sk	X	X	X
UK	http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/Rubella/EpidemiologicalData/	X	-	-

NA: Not applicable

-: not available

Ten out of 26 countries (38.5%) declared that rubella cases are not under-reported in their country (table 23). In table 24, methods used to assess under-reporting in five countries are shown (table 24).

Table 23. Is there under-reporting of rubella in your country?

	Frequency	Percentage	Countries
No	10	38.5	CY, ES, FI, HU, IS, LT, SE, SI, SK, UK
Yes	7	26.9	CZ, DE, GR, IT, NL, PT, RO
I don't know	9	34.6	AT, BG, EE, IE, LV, LU, MT, NO, PL
Total	26	100.0	

Table 24. If yes, what method is being used to assess under-reporting?

	Frequency	Countries
Evaluation using other sources	3	DE, GR, IT*
Other	2	PT*, RO*
Total	5	

***IT: Evaluation using a paediatric sentinel surveillance system (it was discontinued in 2010)*

**PT: In Portugal all rubella cases are reported based only on clinical diagnosis without laboratory confirmation. According to the epidemiological and laboratory data it is not possible to say that rubella virus is no longer circulating in Portugal. Except for pregnant women, rubella is considered a mild disease so it is possible that some reporting rubella cases (clinical based) are not true rubella cases and that not all the true rubella cases are reported.*

**RO: 'There is no assessing method for under-reporting, but there are many private clinics/hospitals which don't report because of 'confidentiality' and there are also many ill people who do not visit the doctor.'*

More than half of the countries (15/26) have identified indicators compatible with WHO recommended indicators; whereas nine countries did not identify any indicator for surveillance purposes (table 25).

Table 25. Have performance surveillance system indicators been identified?

	Frequency	Percentage	Countries
Yes, compatible with WHO recommended indicators	15	57.7	AT*, BG, CY, CZ, EE, ES, FI, GR, IE, LT, PT, RO, SI, SK, UK
Yes, other	2	7.7	DE*, NL*
No	9	34.6	HU, IS, IT, LU, LV, MT, NO, PL, SE
Total	26	100.0	

**AT: Except discarded cases*

**DE: Some evaluations of the German system according to CDC-indicators have been published and a method to prioritise infections for notification has been developed in German*

**NL: Several projects looking at timeliness of reporting*

4.3 Rubella in pregnancy surveillance

Twenty-five out 29 countries (86.2%) have a specific surveillance system for rubella in pregnancy, 20 of them (80%) as part of the rubella surveillance (table 26).

Table 26. Is there a surveillance system for rubella in pregnancy in your country?

	Frequency	Percentage	Countries
No surveillance	4	13.8	BE, BG, DE, LU
Yes, a separate system for rubella in pregnancy	5	17.2	DK, FR, MT, IS, IT
Yes, included as part of rubella surveillance	20	69.0	AT, CY, CZ, EE, ES, FI, GR, HU, IE, LT, LV, NL, NO, PL, PT, RO, SE, SI, SK, UK
Total	29	100.0	

The following analysis includes the 25 countries that have a system for rubella in pregnancy. Most of the countries (80%) introduced the surveillance system for rubella in pregnancy after 1970 (table 27).

Table 27. When was the surveillance system for rubella in pregnancy introduced in your country?

	Frequency	Percentage	Countries
1940-1949	1	4.0	IE
1950-1959	1	4.0	IT
1960-1969	3	12.0	CZ, FI, PL
1970-1979	7	28.0	EE, FR, HU, IS, SI, SK, UK
1980-1989	3	12.0	CY, ES, PT
1990-1999	4	16.0	DK, LV, NO, SE
2000-2009	5	20.0	AT,GR, LT, MT, NL
=>2010	1	4.0	RO
Total	25	100.0	

All countries (25/25) have nationwide surveillance.

All countries except Lithuania and Poland (23/25) have case-based data at the national level (table 28). Lithuania has case-based data at the sub national level, while Poland has aggregated data at the national and sub national level (table 29).

Regarding case-based data, all countries (24/24) collect data about age, date of onset of clinical symptoms, laboratory details and vaccination status (table 30). Eighteen countries (75%) collect information regarding the notification source (imported, import-related or indigenous case). Eleven countries (46%) collect information on the outcome of the pregnancy. Poland collects data aggregated by age, gender, vaccination status and case classification.

Table 28. What type of data for rubella in pregnancy is available at the national level?

	Frequency	Percentage	Countries
Case-based	23	92.0	AT, CY, CZ, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LV, MT, NL, NO, RO, PT, SE, SI, SK, UK
Aggregated	2	8.0	LT, PL
Total	25	100.0	

Table 29. What type of data for rubella in pregnancy is available at the sub national level?

	Frequency	Percentage	Countries
No data	1	4.0	CY
Case-based	22	88.0	AT, CZ, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LT, LV, NL, NO, PT, RO, SE, SI, SK, UK
Aggregated	1	4.0	PL
Missing	1	4.0	MT
Total	25	100.0	

Table 30. If case-based, which data are collected?

	Frequency	Percentage	Countries
Age	24	100.0	AT, CY, CZ, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PT, RO, SE, SI, SK, UK
Notification source	21	87.5	AT, CY, CZ, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LT, LV, MT, NO, PT, SE, SI, SK
Date of onset of clinical symptoms	24	100.0	AT, CY, CZ, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PT, RO, SE, SI, SK, UK
Clinical picture	15	62.5	AT, CZ, DK, ES, FI, FR, GR, HU, IS, IT, MT, NO, PT, RO, SK
Clinical complications	16	66.7	AT, CY, CZ, DK, ES, FI, GR, HU, IS, IT, LT, NO, PT, RO, SK, UK
Hospitalisation	19	79.2	AT, CY, CZ, DK, EE, ES, FI, GR, HU, LT, LV, MT, NL, NO, PT, RO, SI, SK, UK
Laboratory details	24	100.0	AT, CY, CZ, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PT, RO, SE, SI, SK, UK
Genotype	10	41.7	AT, ES, FI, HU, IE, LT, LV, NO, RO, UK
Vaccination status	24	100.0	AT, CY, CZ, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PT, RO, SE, SI, SK, UK
Prior evidence of serological immunity	4	16.7	FR, IT, LT, UK
Source of infection	18	75.0	AT, CY, CZ, DK, EE, ES, FI, GR, HU, IT, LT, LV, MT, NL, NO, RO, SK, UK
Gestational age at time of infection	18	75.0	AT, CY, CZ, DK, ES, FI, FR, HU, IS, IT, LT, MT, NL, NO, PT, RO, SK, UK
Previous pregnancies or deliveries	6	25.0	CY, FI, FR, IS, IT, LT
Outcome of pregnancy	11	45.8	CZ, DK, ES, FI, FR, IS, IT, LT, NO, SK, UK
Case classification	18	75.0	AT, CY, CZ, DK, EE, ES, FI, FR, GR, HU, IE, IT, LT, LV, NL, RO, SE, SK

Notification is mandatory in 24 of 25 countries; it is only voluntary in France (table 31).

Table 31. What is the legal basis of reporting?

	Frequency	Percentage	Countries
Mandatory reporting	24	96.0	AT, CY, CZ, DK, EE, ES, FI, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PL, PT, RO, SE, SI, SK, UK
Voluntary reporting	1	4.0	FR
Total	25	100.0	

All countries (25/25) have a comprehensive surveillance system. Twenty-one out of 25 countries have a passive system. Only France, Iceland and the Netherlands declared to have an active system (table 32).

Table 32. What type of surveillance system exists?

	Frequency	Percentage	Countries
Active	3	12.0	FR*, IS, NL
Passive	21	84.0	AT, CY, DK*, EE, ES, FI, GR, HU, IE, IT, LT, LV, MT, NO, PL, PT, RO, SE, SI, SK, UK
Other: both	1	4.0	CZ*
Total	25	100.0	

**FR: The Rénarub network unites the clinical diagnostic laboratories carrying out anti-rubella IgM serology and PCR. Information is gathered at two levels: a) from the microbiologists who receive a half-yearly request to report rubella infections diagnosed in pregnant women or newborn infants (specific form); b) from family doctors, gynaecologists, obstetricians, and paediatricians who made the prescription for laboratory testing. They provide by questionnaire demographic, laboratory, and clinical information on the infected woman, newborn, or fetus. Laboratories are actively contacted twice a year (or more if needed) and have to report « 0 cases ».*

**DK: Currently passive, however, with the development of a national database covering all microbiological tests made in Danish laboratories (MIBA), it will be possible to extract data on rubella diagnostics and makes active surveillance possible on the laboratory level.*

**CZ: Infections are reported by physicians to the local public health authorities, which investigate index case and trace the contacts. All information flow through regional public health authorities to the National Public Health Institute and Ministry of Health to the nationwide reporting system EPIDAT.*

Regarding the notification of cases, physicians report cases in 23 out of 25 countries (92%), hospitals in 18 countries (72%) and laboratories in 16 countries (64%) (table 33).

Table 33. Who reports cases?

	Frequency	Percentage	Countries
Physicians	23	92.0	AT, CY, CZ, DK, EE, ES, FI, GR, HU, IE, IS, IT, LV, MT, NL, NO, PL, PT, RO, SE, SI, SK, UK
Hospitals	18	72.0	AT, CZ, DK, EE, ES, GR, HU, IE, IS, IT, LT, LV, PL, NO, RO, SE, SK, UK
Laboratories	16	64.0	AT, CZ, EE, FI, FR, GR, HU, IE, IS, LV, NL, NO, SE, SI, SK, UK
Other	3	12.0	AT*, DK*, RO

**AT: According to national epidemic law*

**DK: The Department of Virology at Statens Serum Institut will inform the Department of Infectious Disease Epidemiology in case of a positive rubella test in a pregnant woman*

Among the five countries that have a separate system for rubella in pregnancy, four countries (Denmark, France, Iceland and Italy) report to have a case definition of rubella in pregnancy. Definitions are reported below.

In Denmark, the case definition is 'Detection of rubella virus by PCR and/or culture OR detection of rubella IgM- and/or IgG-antibodies in pregnancy'.

In France, three levels of definition for primary infections are considered: confirmed, probable and possible. A confirmed primary infection is defined as the presence of a history of infectious contact, clinical signs of rubella, a seroconversion or a significant increase in IgG titres with positive IgM, positive IgM and a low IgG avidity index or when an antenatal diagnosis is positive or if IgM are detected at birth. A probable primary infection is defined as the presence of a rash with an increase in IgG title and positive IgM. A possible primary infection is defined as an increase in IgG titer or both IgG and IgM.

In Italy, the current definition includes suspected, possible, probable and confirmed cases. Suspected cases are all cases suspected for clinical manifestations that do not fully satisfy criteria for possible cases, including cases with only IgM positivity. Possible cases are clinical criteria are satisfied (acute macupapular rash and arthralgia/arthritis, lymphadenopathy or conjunctivitis). Probable cases are cases with clinical symptoms compatible with rubella and an epidemiological link with a confirmed case. Confirmed cases are cases with clinical symptoms compatible with rubella and confirmed by laboratory tests. Asymptomatic infection is defined as an asymptomatic case confirmed by laboratory tests.

All countries report confirmed cases (100%); 20 countries (80%) report probable cases and 16 countries (64%) possible cases; five countries (20%) report discarded cases (tables 34).

Table 34. What type of cases are reported to the health authorities?

	Frequency	Percentage	Countries
Possible cases	16	64.0	AT, CY, CZ, ES, GR, HU, IE, IT, LV, MT, NO, PL, RO, SE, SI , SK
Probable cases	20	80.0	AT, CY, CZ, ES, FR, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PL, RO, SE, SI, SK
Confirmed cases	25	100.0	AT, CY, CZ, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PL, PT, RO, SE, SI, SK, UK
Discarded cases	5	20.0	EE, ES, LV, MT, RO
Other	1	4.0	AT*

**AT: The Austrian epidemic law contains a list of mandatory reportable diseases. For these diseases every suspected and confirmed case as well as every death has to be reported.*

Zero-reporting is required in only four out of 24 countries (16%): France, Lithuania, Romania and the United Kingdom (table 35).

Table 35. Is zero-reporting required?

	Frequency	Percentage	Countries
No	19	76.0	AT, CY, DK, EE, ES, FI, GR, HU, IE, IS, LV, MT, NL, NO, PL, PT,SE, SI, SK
Not yet, modifications at this purpose are ongoing	2	8.0	CZ,IT
Yes, at national level	3	12.0	FR, LT, UK
Yes, at all levels	1	4.0	RO
Total	25	100.0	

Nineteen out of 25 countries (76%) routinely conduct an epidemiological investigation for suspected cases of rubella in pregnancy (table 36).

Table 36. Is epidemiological investigation of suspected cases of rubella in pregnancy routinely conducted?

	Frequency	Percentage	Countries
No	6	24.0	AT, FR, IE, LT, PL, SI
Yes	19	76.0	CY, CZ, DK, EE, ES, FI, GR, HU, IS, IT, LV, MT, NL, NO, PT, RO, SE, SK, UK
Total	25	100.0	

There are two countries (8.3%) where outcomes of suspected or confirmed rubella infection in pregnancy are not monitored. All the newborns from women that have contracted rubella infection during pregnancy (including uninfected infants) are monitored in five (20.8%) countries; infants with congenital rubella syndrome are monitored in 22 out of 24 countries (91.7%) and infants with asymptomatic congenital rubella infection in 15 countries (62.5%). Still births and fetal deaths with congenital rubella infection are monitored in 13 countries; therapeutic and spontaneous abortion in eight and seven countries respectively (tables 37).

Table 37. What outcomes of suspected or confirmed rubella infection in pregnancy are monitored?

	Frequency	Percentage	Countries
Outcomes are not monitored	2	8.3	LV, SI
All uninfected infants	5	20.8	ES, FR, IS, IT, SE
Infants with congenital rubella syndrome	22	91.7	AT, CY, CZ, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LT, MT, NO, PL, PT, RO, SE, SK, UK
Infants with asymptomatic congenital rubella infection	15	62.5	CY, CZ, DK, ES, FR, GR, HU, IE, IS, IT, PT, RO, SE, SK, UK
Still births/fetal deaths with congenital rubella infection	13	54.2	CZ, DK, ES, FI, FR, GR, HU, IE, IS, IT, RO, SE, UK
Therapeutic abortions	8	33.3	ES, FI, FR, HU, IS, IT, SE, UK
Spontaneous abortions	7	29.2	ES, FR, HU, IS, IT, SE, UK

Missing country: NL

Regarding reference laboratory for rubella in pregnancy, 23 out of 25 countries have a national reference laboratory, which is the same of rubella. France has a national reference laboratory for rubella in pregnancy but is not the same as the rubella one, as no surveillance system for rubella is in place in France (table 38). Italy has different sub national reference laboratories and the laboratory tests that the sub national reference laboratories perform differs among laboratories. All national reference laboratories plus Italy's subnational laboratories perform IgM and IgG antibody detection. Twelve countries are able to perform genotyping (table 39).

Table 38. Has a reference laboratory for rubella in pregnancy been identified in your country?

	Frequency	Percentage	Countries
Yes, a national reference laboratory (the same of national reference lab for rubella)	23	92.0	AT, CY, CZ, DK, EE, ES, FI, GR, HU, IE, IS, LT, LV, MT, NL, NO, PL, PT, RO, SE, SI, SK, UK
Yes, a national reference laboratory (different from the national reference lab for rubella)	1	4.0	FR
Yes, one or more sub-national reference laboratories (the same of sub national reference labs for rubella)	0	0.0	
Yes, one or more sub-national reference laboratories (different from sub national reference labs for rubella)	1	4.0	IT
No	0	0.0	
Total	25	100.0	

Table 39. Which kind of laboratory tests does the national reference laboratories perform?

	Frequency	Percentage	Countries
IgM and IgG antibody detection	24	100.0	AT, CY, CZ, DK, EE, ES, FI, FR, GR, HU, IE, IS, LT, LV, MT, NL, NO, PL, PT, RO, SE, SK, SI, UK
IgG avidity test or other tests to confirm recent infection	15	62.5	AT, CY, CZ, DK, ES, FI, FR, GR, HU, LV, NO, PT, RO, SK, UK
Viral RNA detection by RT-PCR	17	70.8	AT, CZ, DK, EE, ES, FI, FR, GR, HU, LV, NL, NO, PL, PT, RO, SK, UK
Virus isolation	15	62.5	AT, CZ, DK, ES, FI, FR, GR, HU, LV, NL, PL, PT, RO, SI, SK
Genotyping	12	50.0	AT, DK, ES, FI, FR, HU, LV, NL, NO, PT, RO, UK
Other	1	4.2	HU*

**HU: Hemagglutination inhibition*

In IT laboratory tests performed depend on the sub national reference laboratory.

Most countries (19/25) could report cases monthly from the national level to the European level. Three countries (12%) are not able to report cases regularly (table 40).

Table 40. How often would it be possible to report cases of rubella in pregnancy from the national Level to the European level?

	Frequency	Percentage	Countries
Only during outbreaks	0	0.0	
Annually	2	8.0	FR, PL
Monthly	19	76.0	AT, CZ, DK, EE, ES, FI, HU, IS, IT, LT, LV, MT, NO, PT, RO, SE, SI, SK, UK
Weekly	1	4.0	NL
Not regularly	3	12.0	CY, GR, IE
Other	0	0.0	
Total	25	100.0	

Regarding the frequency of feedback reports from the national level to the public health administrative level, there are two countries that have no feedback mechanism (table 41).

Table 41. What is the frequency of feedback reports from the national level to the public health administrative level regarding rubella in pregnancy epidemiology?

	Frequency	Percentage	Countries
No feedback mechanism	2	8.0	IT, PT
Annually	8	32.0	CY, ES, FI, FR, LV, NL, RO, SE
Monthly	5	20.0	EE, IS, LT, MT, SI
Weekly	4	16.0	CZ, DK, HU, SK
Only during outbreaks	1	4.0	GR
Not regularly	2	8.0	IE, NO
Other	3	12.0	AT*, PL, UK*
Total	25	100.0	

**AT: Via EMS any public health officer can automatically see all data at any part of time (anonymous). Additional, monthly reviews are provided at www. bmg.gv.at*

**UK: Quarterly*

Eleven countries upload surveillance data on a public website (table 42) (see table 22.

Table 42. Is rubella in pregnancy surveillance data uploaded on a public website?

	Frequency	Percentage	Countries
No	13	52.0	CY, IE, IS, IT, LT, LV, MT, NL, NO, PL, PT, SE, UK
Yes	11	44.0	AT, CZ, DK, EE, ES, FI, FR*, HU, RO, SI, SK
Missing	1	4.0	GR
Total	25	100.0	

**FR: Annual report published on the website*

Thirteen out of 25 countries (52%) report that cases of rubella in pregnancy are not under-reported (table 43). The United Kingdom assessed under-reporting through the comparison of laboratory data with those deriving from the mandatory notification system. In Italy no systematic method is used but the comparison of rubella in pregnancy and congenital rubella infections data supports this consideration.

Table 43. Is there under-reporting of rubella in pregnancy surveillance data in your country?

	Frequency	Percentage	Countries
No	13	52.0	CY, CZ, DK, ES, FI, HU, IS, LT, LV, SE, SI, SK, UK
Yes	3	12.0	GR, IT, NL
I don't know	9	36.0	AT, EE, FR, IE, MT, NO, PL, PT, RO
Total	25	100.0	

4.4 Congenital rubella surveillance systems

All countries except Luxemburg (28/29, 96.6%) have a specific surveillance system for congenital rubella (table 44).

Table 44. Is there a surveillance system for congenital rubella syndrome in your country?

	Frequency	Percentage	Countries
No	1	3.4	LU
Yes	28	96.6	AT, BE, BG, CY, CZ, DE, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PL, PT, RO, SK, SI, SE, UK
Total	29	100.0	

The following analysis includes the 28 countries that have a congenital rubella surveillance system.

Ireland was the first country to introduce the surveillance system for congenital rubella syndrome in 1948. Eight countries (28.6%) introduced rubella surveillance in pregnancy in the last decade (table 45).

Table 45. When the surveillance system for congenital rubella syndrome was introduced in your country?

	Frequency	Percentage	Countries
1940-1949	1	3.6	IE
1950-1959	1	3.6	SK
1960-1969	4	14.3	CZ, DE, FI, PL
1970-1979	8	28.6	EE, FR, HU, IS, NO, SI, SK, UK
1980-1989	2	7.1	PT, ES
1990-1999	5	17.9	DK, GR, LV, MT, SE
2000-2009	8	28.6	AT, BE, BG, CY, IT, LT, NL, RO
Total	28	100.0	

All countries (28/28) have a nationwide surveillance system for congenital rubella syndrome.

Case-based data are available at the national level in all countries, except Bulgaria (table 46). Bulgaria has aggregated data at the national and the sub national level (table 47).

Regarding case-based data, all countries collect information about age and laboratory details; 18 countries (67%) collect information on maternal history and 23 countries (85%) on the notification source (imported, import-related or indigenous case) (tables 48 and 49)

Bulgaria has aggregated data by gender and case classification.

Table 46. What type of data for congenital rubella syndrome is available at the national level?

	Frequency	Percentage	Countries
No data	0	0.0	
Case-based	27	96.4	AT, BE, CY, CZ, DE, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PL, PT, RO, SK, SI, SE, UK
Aggregated	1	3.6	BG
Total	28	100.0	

Table 47. What type of data for congenital rubella syndrome is available at the sub national level?

	Frequency	Percentage	Countries
No data	2	7.2	CY, MT*
Case-based	25	89.3	AT, BE, CZ, DE, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LT, LV, NL, NO, PL, PT, RO, SK, SI, SE, UK
Aggregated	1	3.6	BG
Total	28	100.0	

**CY, MT: Since CY and MT are such a small countries, all data is collected centrally (national data)*

Table 48. If case-based, which data are collected?

	Frequency	Percentage	Countries
Age	27	100.0	AT, BE, CY, CZ, DE, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PL, PT, RO, SK, SI, SE, UK
Gender	26	96.3	AT, BE, CY, CZ, DE, DK, EE, ES, FI, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PL, PT, RO, SK, SI, SE, UK
Notification source	25	92.6	AT, BE, CY, CZ, DE, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LT, LV, MT, NO, PL, PT, RO, SK, SI, SE
Clinical picture	20	74.1	AT, BE, CZ, DE, DK, ES, FI, FR, GR, HU, IE, IS, IT, MT, NO, PL, PT, RO, SK, UK
Laboratory details	27	100.0	AT, BE, CY, CZ, DE, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PL, PT, RO, SK, SE, SI, UK
Maternal history	18	66.7	BE, CZ, DE, DK, ES, FI, FR, GR, HU, IE, IS, IT, LT, MT, PL, PT, RO, UK
Source of infection	23	85.2	AT, BE, CY, CZ, DE, EE, ES, FI, GR, HU, IE, IT, LT, LV, MT, NL, NO, PL, PT, RO, SK, SE, UK
Genotype	11	40.1	AT, BE, DK, ES, FI, HU, LT, LV, NO, PT, UK
Case classification	22	81.5	AT, BE, CY, CZ, DK, ES, FI, FR, GR, HU, IE, IS, IT, LT, LV, NL, PL, PT, RO, SK, SE, SI

Table 49. If case-based, which data are collected?

	Age	Gender	Notification source	Clinical picture	Laboratory details	Maternal history	Source of infection	Genotype	Case classification
AT	X	X	X	X	X		X	X	X
BE	X	X	X	X	X	X	X	X	X
CY	X	X	X		X		X		X
CZ	X	X	X	X	X	X	X		X
DE	X	X	X	X	X	X	X		
DK	X	X	X	X	X	X		X	X
EE	X	X	X		X		X		
ES	X	X	X	X	X	X	X	X	X
FI	X	X	X	X	X	X	X	X	X
FR	X		X	X	X	X			X
GR	X	X	X	X	X	X	X		X
HU	X	X	X	X	X	X	X	X	X
IE	X	X	X	X	X	X	X		X
IS	X	X	X	X	X	X			X
IT	X	X	X	X	X	X	X		X
LT	X	X	X		X	X	X	X	X
LV	X	X	X		X		X	X	X
MT	X	X	X	X	X	X	X		
NL	X	X			X		X		X
NO	X	X	X	X	X		X	X	
PL	X	X	X	X	X	X	X		X
PT	X	X	X	X	X	X	X	X	X
RO	X	X	X	X	X	X	X		X
SE	X	X	X		X		X		X
SI	X	X	X		X				X
SK	X	X	X	X	X		X		X
UK	X	X		X	X	X	X	X	

Notification is mandatory in all countries except Belgium and France (table 50).

Table 50. What is the legal basis of reporting?

	Frequency	Percentage	Countries
Mandatory reporting	26	92.9	AT, BG, CY, CZ, DE, DK, EE, ES, FI, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PL, PT, RO, SK, SI, SE, UK*
Voluntary reporting	2	7.1	BE,FR
Total	28	100.0	

**UK: For the CRS cases. This is because there is an additional reporting system used by paediatricians that report cases they have seen in their practice.*

All countries except Belgium have a comprehensive system (table 51); twenty of 28 countries (71.4%) have a fully passive surveillance system (table 52).

Table 51. What type of surveillance system exists?

	Frequency	Percentage	Countries
Comprehensive	27	96.4	AT, BG, CY, CZ, DE, DK, EE, ES, FI, FR*, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PL, PT, RO, SK, SI, SE, UK
Sentinel surveillance	1	3.6	BE*
Total	28	100,0	

**FR: Only congenital infections detected during pregnancy or at birth are reported through Renarub (Pregnancy outcome data from the maternal questionnaire)*

**BE: Pedisurv: paediatric surveillance network, covers about 40% of total paediatricians in Belgium.*

Table 52. What type of surveillance system exists?

	Frequency	Percentage	Countries
Active	5	17.9	BE*, FR*, IS, NL, UK*
Passive	20	71.4	AT, BG, CY, DE, DK, EE, ES, FI, GR, HU, IE, IT, LT, LV, PL, PT, RO, SK, SI, SE
Other: both	3	10.7	CZ, MT*, NO*
Total	28	100.0	

**BE: Monthly reminder is send out to participating paediatricians*

**FR: They are actively contacted twice a year (or more if needed) and have to report « 0 cases ».*

**MT: Passive notification plus active visits of members of health information to obstetrics/gynaecology/echocardiography units every week for collecting data directly and review patients notes.*

**NO: Yearly matching of the national surveillance database (MSIS) with the national patient registry for diagnoses related to CRS and with the national birth registry (NFR). If cases, we contact the hospital/ physician and ask for report to MSIS.*

**UK: Monthly requests to all paediatricians for new cases of CRS*

In most of countries (23/28) physicians report cases. Hospitals report cases in 21 countries and laboratories in 18 countries (tables 53).

Table 53. What is the source of reporting?

	Frequency	Percentage	Countries
Physicians	23	82.1	AT, BE, BG, CY, CZ, DK, EE, ES, FI, GR, HU, IE, IS, IT, LV, MT, NL, NO, PL, SK, SI, SE, UK
Hospitals	21	75.0	AT, BG, CZ, DK, EE, ES, GR, HU, IE, IS, IT, LT, LV, MT, NO, PL, PT, RO, SE, SK, UK
Laboratories	18	64.3	AT, BG, CZ, DE, EE, FI, FR, GR, HU, IE, IS, LV, MT, NL, NO, SK, SE, UK
Other	3	10.7	AT*, DK*,DE*

**AT: According to national epidemic law*

**DK: The Department of Virology at Statens Serum Institut will inform the Department of Infectious Disease Epidemiology in case of a positive test.*

**DE: Surveillance system will be changed in 2012 and notification mandatory for physicians, hospitals and laboratories*

The 2008 EU case definition (probable/confirmed) is adopted by 24 out 28 countries (85.7%); the WHO case definition (clinical CRS, lab confirmed CRS, epi CRS) is adopted by only one country (3.6%) and Denmark (Clinical diagnosis of congenital rubella syndrome AND detection of rubella virus by PCR and/or specific rubella IgM antibodies) and France (A congenital rubella syndrome is defined by the presence of clinical criteria, but not listed specifically, and either an epi criteria or a lab criteria; a congenital rubella infection is defined by the absence of clinical signs of CRS and the presence of lab criteria).do not precisely follow either of these definitions (7.1%) (table 55).

Table 55. Is there a case definition of congenital rubella syndrome for reporting purposes?

	Frequency	Percentage	Countries
No	1	3.6	DE
Yes, compatible with the 2008 EU case definition	24	85.7	AT, BG, CY, CZ, EE, ES, FI, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PL, PT, RO, SK, SI, SE, UK
Yes, compatible with WHO case definition	1	3.6	BE
Yes, other	2	7.1	DK, FR
Total	28	100.0	

Confirmed cases are reported in all countries (100%), probable cases are reported in 20 countries (71.4%); discarded cases are reported in five countries (17.9%) (table 56).

Table 56. What type of cases are reported to the health authorities?

	Frequency	Percentage	Countries
Probable cases	20	71.4	AT, BE, CY, CZ, DE, ES, GR, HU, IE, IS, IT, LT, LV, NL, PL, PT, RO, SK, SI, SE
Confirmed cases	28	100.0	AT, BE, BG, CY, CZ, DE, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, LT, LV, MT, NL, NO, PL, PT, RO, SK, SI, SE, UK
Discarded cases	5	17.9	EE, ES, LV, RO, SI
Other	1	3.6	AT*

**AT: The Austrian epidemic law contains a list of mandatory reportable diseases. For these diseases every suspected and confirmed case as well as every death has to be reported.*

Zero-reporting is required in only six out of 28 countries (21.4%) (table 57)

Table 57. Is zero-reporting required?

	Frequency	Percentage	Countries
No	22	78.6	AT, BG, CY, CZ, DE, DK, EE, FI, GR, HU, IE, IS, IT*****, LV, MT, NL, NO, PL, PT, SK, SI, SE
Yes, at national level	4	14.3	BE, ES, FR, UK
Yes, at all levels	2	7.1	LT, RO
Total	28	100.0	

**IT: Not yet, modifications at this purpose are ongoing*

In 23 out of 28 countries (82.1%) epidemiological investigation of suspected congenital rubella infections is routinely conducted (table 58).

Table 58. Is epidemiological investigation of suspected congenital rubella infections routinely conducted?

	Frequency	Percentage	Countries
No	5	17.9	AT, DE, FR, MT, SI
Yes	23	82.1	BE, BG, CY, CZ, DK, EE, ES, FI, GR, HU, IE, IS, IT, LT, LV, NL, NO, PL, PT, RO, SK, SE, UK
Total	28	100.0	

Regarding what outcomes of congenital rubella infection are monitored for surveillance purposes, 13 out of 28 countries (46.4%) follow up asymptomatic congenital infections and 10 countries (35.7%) also monitor suspected cases that do not have laboratory confirmation at birth (tables 59).

Table 59. What outcomes of congenital rubella infection are monitored for surveillance purpose (final case classification)?

	Frequency	Percentage	Countries
No monitoring is performed	2	7.1	LV, SI
Congenital rubella syndrome cases	24	85.7	AT, BE, BG, CY, CZ, DE, DK, EE, ES, FI, FR, GR, HU, IE, IS, IT, MT, NO, PL, PT, RO, SE, SK, UK
Asymptomatic congenital rubella cases	13	46.4	CZ, DK, ES, FR, GR, HU, IE, IS, IT, RO, SE, SK, UK
Suspected cases which do not have laboratory confirmation at birth	10	35.7	CZ, DK, ES, FR, HU, IE, IT, LT, RO, UK

Only 11 out 28 countries (39.3%) report CRIs to central level (table 60).

Table 60. Are asymptomatic congenital rubella infections reported at acentral level?

	Frequency	Percentage	Countries
No, only congenital rubella syndrome cases are reported	16	57.1	AT, BE, BG, CY, DE, EE, FI, GR, IE, LV, MT, NO, PL, PT, SK, SI
Yes	11	39.3	CZ, DK, ES, FR, HU, IS, IT, LT, RO,SE, UK
Missing	1	3.6	NL
Total	28	100.0	

Twenty-seven countries have a national reference laboratory for congenital rubella syndrome; it is the same as rubella in 26 countries (in France there is no rubella surveillance system). Italy has sub national reference laboratories (table 61). Table 62 reports the laboratory tests performed in the reference laboratories; in Italy laboratory tests performed depend on the sub national laboratory.

Table 62. Has a reference laboratory for congenital rubella syndrome been identified in your country?

	Frequency	Percentage	Countries
Yes, a national reference laboratory (the same of national reference lab for rubella)	26	92.9	AT, BE, BG, CY, CZ, DE, DK, EE, ES, FI, GR, HU, IE, IS, LT, LV, MT, NL, NO, PL, PT, RO, SK, SI, SE, UK
Yes, a national reference laboratory (different from the national reference lab for rubella)	1	3.6	FR*
Yes, one or more sub-national reference laboratories	1	3.6	IT
No	0	0	
Total	28	100.0	

**FR: No national reference lab for rubella because no surveillance system for rubella*

Table 62. Which kind of laboratory tests does the national reference laboratories perform?

	Frequency	Percentage	Countries
IgM and IgG antibody detection	27	100	AT, BE, BG, CY, CZ, DE, DK, EE, ES, FI, FR, GR, HU, IE, IS, LT, LV, MT, NL, NO, PL, PT, RO, SE, SI, SK, UK
Viral RNA detection by RT-PCR	20	74.1	AT, BE, CZ, DE, DK, EE, ES, FI, FR, GR, HU, LV, NL, NO, PL, PT, RO, SI. SK, UK
Virus isolation	15	55.6	AT, CZ, DE, DK, ES, FI, FR, GR, HU, LV, NL, PL, PT, RO, SK
Genotyping	15	55.6	AT, DE, DK, ES, FI, FR, GR, HU, LV, NL, NO, PT, RO, SI, UK
Other	1	3.7	FI

Eighteen out of 28 countries (64.3%) could report monthly congenital rubella cases from the national Level to the European level (table 63).

Table 63. How often would it be possible to report congenital rubella cases reported from the national Level to the European level (WHO/ EUVAC.NET/ECDC)?

	Frequency	Percentage	Countries
Only during outbreaks	0	0.0	
Annually	6	21.4	FR, IS, MT, PL, RO, UK
Monthly	18	64.3	AT, BG, CY, CZ, DE*, DK, EE, FI, GR, HU, IT, LT, LV, NO, PT, SE, SI, SK
Weekly	2	7.1	ES, NL
Not regularly	2	7.1	BE, IE
Other	0	0.0	
Total	28	100.0	

**DE: After introduction of nationwide case-based surveillance system*

Regarding the frequency of feedback reports from the national Level to the public health administrative level regarding congenital rubella epidemiology, 13 out of 28 countries (46.4%) report annually (table 65).

Table 65. What is the frequency of feedback reports from the national level to the public health administrative level regarding congenital rubella epidemiology?

	Frequency	Percentage	Countries
Only during outbreaks	1	3.6	BG
Annually	13	46.4	BE, CY, DE, ES, FI, FR, GR, IS, MT, NL, NO, RO, SE
Monthly	4	14.3	EE, LT, LV, SI
Weekly	4	14.3	CZ, DK, HU, SK
Not regularly	1	3.6	PT
No feedback mechanism	1	3.6	IT
Other	4	14.3	AT*, IE*, PL*, UK*
Total	28	100.0	

**AT: Via EMS any public health officer can automatically see all data at any part of time (anonymous). Additional, monthly reviews are provided at www. bmg.gv.at*

**IE: Immediately when a case occurs*

**PL: Feedback mechanism is based on publications on the Institute website: biweekly with cumulative data and annually as Infectious Diseases Bulletin.*

**UK: Quarterly*

Twenty-one out of 28 countries (75%) upload congenital rubella surveillance data on a public website (table 65). (See table 22 to see the link to the website)

Table 65. Are congenital rubella surveillance data uploaded on a public website?

	Frequency	Percentage	Countries
No	7	25.0	IS, IT, LT, MT, NL, NO, UK*
Yes	21	75	AT, BE, BG, CY, CZ, DE, DK, EE, ES, FI, FR, GR, HU, IE, LV, PL, PT, RO, SE, SI, SK
Total	28	100.0	

**UK: These cases are identified in the quarterly reports but are not uploaded as a dataset*

Thirteen out of 28 countries (46.4%) declared that congenital rubella cases are not underreported (table 676. Table 67 shows methods used to assess under-reporting in some countries (table 67).

Table 66. Is there under-reporting of congenital rubella syndrome cases in your country?

	Frequency	Percentage	Countries
No	13	46.4	CY, CZ, DK, ES, FI, HU, IS, LT, MT, SE, SI, SK, UK
Yes	7	25.0	BE, DE, GR, IT, NL, PL, RO
I don't know	8	28.6	AT, BG, EE, FR, IE, LV, NO, PT
Total	28	100.0	

Table 67. If yes, what method is being used to assess under-reporting?

	Frequency	Countries
Evaluation using other sources	4	DE, GR*, NO*, PL
Other	3	BE*, IT*, RO*
Total	7	

**GR: Comparison of laboratory data with those deriving from the mandatory notification system.*

**NO: Yearly matching of the national surveillance database (MSIS) with the national patient registry for diagnoses related to CRS and with the national birth registry (NFR). First done in 2012*

**BE: PediSurv surveillance network is a sentinel surveillance based on voluntary participation of paediatricians*

**IT: Rumours (personal contacts with local health units)*

**RO: There is no assessing method for under-reporting (but there are many private clinics/hospitals which don't report because of 'confidentiality 'and also, there are many ill people who do not visit the doctor).*

Eleven out of 28 countries have no other sources to detect cases of congenital rubella syndrome. Seven countries (25.9%) have hospital records, seven countries (25.9%) have birth-defects registers, one country (3.7%) has rare disease registers and six countries (22.2%) have national statistics on causes of death (table 68).

Table 687. Have you got other sources (other than surveillance system) to detect cases of congenital rubella syndrome?

	Frequency	Percent	Countries
No	11	40.7	BG, CY, CZ, EE, GR, HU, LV, RO, SE, SI, SK
Hospital records	7	25.9	AT, DE, ES, IE, IS, IT, LT
Birth-defects registers	7	25.9	DK, FI, IE*, IS, MT, PL, PT
Rare disease registers	1	3.7	DK
National statistics on causes of death	6	22.2	DE, DK, IS, LT, PL, UK
Other	4	14.8	BE*, FR*, NO*, UK*

**IE: They don't routinely use it but will be doing so for rubella elimination phase*

**BE: Congenital diseases surveillance network 'EuroCat' (European Surveillance of Congenital Anomalies). Additive test screening at well-baby clinics*

**FR: Statistics provided by certified laboratories to the Agence de Biomédecine - Birth defects registers are regional and do not cover the whole population*

**NO: National patient registry for diagnoses (NPR) and national birth registry (NFR)*

**UK: BPSU (British Paediatric Surveillance Unit)*

4.5 Plans for the future

Nine out of 29 countries (31%) have plans for changing the rubella surveillance system (table 69).

Table 69. Are there any plans for introduction or changes of the surveillance system for rubella in the future?

	Frequency	Percentage	Countries
No	20	69.0	BE, BG, CY, EE, ES, FI, FR, GR, HU, IS, LT, LV, MT, NL, NO, RO, SE, SI, SK, UK
Yes	9	31.0	AT, CZ, DE, DK, IE, IT, LU, PL, PT
Total	29	100.0	

Notes reported by countries are shown below:

AT: Austria is currently working on a national action plan for measles and rubella elimination (with the support of WHO and ECDC). In this plan all measures for enhanced surveillance for measles and rubella are included.

CZ: Adoption of ECDC definition since August 2012 for rubella and congenital rubella.

DE: A nationwide surveillance system for rubella and congenital rubella (mandatory reporting by doctors and laboratories) is planned for autumn 2012. After planned revision of the surveillance system in 2012, case definition of congenital rubella will be compatible with EU and WHO and it will be possible to differentiate between CRS, CRI and suspected cases with no lab confirmation; a monthly report will be conceivable.

DK: With the development of a national database covering all microbiological tests made in Danish laboratories (MIBA), it will be possible to extract data on rubella diagnostics, i.e. the number of positive tests out of number of persons tested, including a personal identifier. All pregnant women are offered screening for rubella immunity status during early pregnancy: this data can be extracted from MIBA.

FR: The current rubella in pregnancy and congenital rubella surveillance system is considered as satisfactory and adequate by the Health Authorities.

IE: An enhanced surveillance form for rubella, rubella in pregnancy and congenital rubella has been developed to obtain more data on notifications. It is not routinely implemented yet.

IT: Italy is planning to integrate measles and rubella systems, to introduce zero reporting, to introduce genotyping in the form notification, to develop a series of indicators compatible with WHO indicators; to introduce reporting of discarded cases for rubella, rubella in pregnancy and congenital rubella; to adopt EU case definitions for rubella and congenital rubella; to modify the current case definition for rubella in pregnancy (starting from EU case definition of rubella and adding lab details: presence of IgM positivity associated to IgG with low avidity). These modifications are being evaluated and waiting for the final approval.

NO: Annually reporting of congenital rubella cases from the Norwegian Birth Registry and the Norwegian Patient Registry started in 2012. It must be evaluated after a few years.

PL: Strengthening the rubella surveillance system, increasing number of suspected cases and laboratory confirmation and the introduction of case-based reporting system are perceived as an indispensable necessity in Poland. Also under discussion is the possibility to introduce surveillance for rubella in pregnancy. Cooperation between gynaecologists and obstetrics and epidemiologists from sanitary-epidemiology stations and modification from passive to active surveillance system for congenital rubella are being evaluated.

PT: New guidelines for rubella and congenital rubella surveillance are being made to improve the surveillance system and to alert the clinicians to report all the suspicious rubella cases and to ask for laboratory confirmation of the cases.

5 Discussion

Over 30 000 rubella cases were reported by EU/EEA countries from October 2011 to September 2012, most of them reported by the two EU Member States Poland and Romania [5]. This puts Europe at a certain distance from the WHO European Region's goal of rubella elimination planned to be achieved by 2015.

Strengthening of surveillance systems is one of the key strategies towards the objective of eliminating measles and rubella, together with the maintenance of very high vaccination coverage in infants and providing immunisation opportunities for susceptible populations [6]. High-quality surveillance systems are required to detect and facilitate rigorous investigation and laboratory confirmation of clinical cases.

The results of this survey provide complete information on the status of surveillance for rubella, rubella in pregnancy and congenital rubella infections in the EU/EEA countries.

Rubella incidence is monitored in most EU/EEA countries. All countries have a rubella surveillance system, except Denmark, Belgium and France. In Denmark and France, long established surveillance systems for cases of rubella during pregnancy and congenital rubella cases are notifiable and enable progress towards disease elimination; Belgium has a voluntary sentinel surveillance system for congenital rubella.

All the 26 surveillance systems for rubella are comprehensive and mandatory but they are not all homogeneous in Europe. All systems but one are nationwide; Germany conducts surveillance for rubella at sub-national level only, but the implementation of a national system is on-going.

The adopted case definition is compatible with the 2008 EU case definition in 22 countries and compatible with the WHO case definition in one country. Two other countries do not correctly follow either of these definitions. Italy is the only country that does not have a case-definition, but will implement a new enhanced surveillance system and the EU case definition will be adopted shortly. The use of a common case definition would increase comparability of incidence data among EU/EEA countries.

Most countries report possible, probable and confirmed cases to health authorities. Estonia, Finland and the United Kingdom only report confirmed cases. WHO-EURO is also asks countries to report discarded cases on a monthly basis. Discarded cases are defined as cases with signs and symptoms consistent with clinical criteria that are investigated and confirmed to be neither, either through laboratory testing or an epidemiological link to a case that is laboratory confirmed to be another disease. According to WHO, surveillance performance indicators, an annual rate of two clinically suspected rubella cases discarded as non-rubella cases per 100 000 population should be considered a minimum at national level. Among the surveyed countries, seven states notify discarded cases to health authorities.

Surveillance systems should be case-based in order to provide accurate information on individual cases and determine whether cases can be linked. Case-based data are available at the national level in 23 countries and case investigation is routinely conducted in 20 countries.

Vaccination status is collected in all countries. Information regarding the source of infection is available in nineteen countries. This information is important to understand the reasons for the occurrence and transmission of disease, such as failure to vaccinate, failure of the vaccine, importation of the infection. The elimination of rubella is defined as the interruption of indigenous transmission; there may still be imported cases, but circulation of the virus following importation ends naturally without intervention, usually after a limited number of generations of disease transmission (import-related cases). However, outbreak could occur if vaccination coverage is suboptimal and control measure inadequate.

Most systems are based on passive reporting of cases, that is known for under-reporting and incompleteness of data. WHO recommends introducing zero-reporting at all levels of the systems, in order to monitor disease elimination at every level. Up to this point, zero-reporting has only been introduced in three countries.

Fifteen countries have an integrated surveillance system for measles and rubella. Testing for measles or rubella IgM-negative specimens for the other disease is cost-effective given that the symptoms of the two diseases are very similar and both diseases commonly affect the same age groups.

Simple and accurate indicators are essential to evaluate completeness, timeliness, sensitivity, effectiveness of the surveillance system, in order to correctly interpret incidence data provided by each system. WHO has defined a set of indicators that should be adopted for measles and rubella for every level of the system and regularly monitored; these indicators include timeliness and completeness of reporting, laboratory investigation rate, detection rate, number of chains of transmission identified with virus genotype data, source of infection identified, and adequacy of investigation. Seventeen out of 26 countries have identified performance surveillance system indicators that are compatible with WHO recommended indicators in 15 countries.

Countries were asked if rubella cases are under-reported by their systems. In seven countries the likelihood of under-reporting, assessed through different methods, has been reported.

Surveillance and follow up of rubella in pregnancy is important because it is one of the entry point for congenital rubella surveillance and also because the incidence of CRS would be affected by spontaneous or voluntary termination of pregnancy. Twenty-five countries are able to detect rubella cases occurring during pregnancy; among them, five countries have a specific surveillance system, in the other cases it is part of the rubella surveillance system. Among the four countries (Belgium, Bulgaria, Germany, Luxembourg) that do not have surveillance of rubella cases in pregnancy, Luxembourg and Bulgaria collect the information regarding the status of pregnancy within the rubella surveillance system.

All the 25 countries able to detect rubella infection in pregnancy have a comprehensive nationwide reporting system. Notification is mandatory in all countries but France. The French system, specific for rubella in pregnancy and congenital rubella, is voluntary and laboratory based; in France the introduction of a mandatory notification of all rubella cases was under discussion at the Ministry of Health level at the time of this survey.

Outcomes of pregnant women with confirmed or clinical rubella should be monitored in order to detect congenital infections, including spontaneous abortion or stillbirth that may occur following rubella infection in early pregnancy. In two countries the outcomes of suspected or confirmed notified rubella infection in pregnancy are not monitored, but all these two countries have a surveillance system for congenital rubella. Instead five countries monitor all the newborns from women that have contracted rubella infection during pregnancy, including uninfected infants. Still births and fetal deaths with congenital rubella infection are monitored in 13 countries; therapeutic and spontaneous abortion in eight and seven countries respectively.

All countries except Luxemburg have a surveillance system for congenital rubella, which is nationwide, mandatory and comprehensive in the most of the countries. Case-based data are available at the national level in all countries except one. Most countries (24/28) use the 2008 EU case definition. Zero-reporting is required in six of twenty-eight countries.

Congenital rubella does not always present as CRS; some infected children can be asymptomatic (CRI). Eleven countries report both CRS and CRI, while 16 countries report only CRS.

Some infants with less severe manifestations and those with hearing loss are more likely to be detected later in infancy; additionally laboratory confirmation of congenital infection is not always possible at birth. In case of infants that are IgM negative at birth only the monitoring of the level of IgG specific for rubella allows the exclusion or confirmation of the diagnosis (a sustained level of IgG over 6-12 months indicates that IgG are not maternal antibodies, but they are produced by the newborn). Therefore monitoring of asymptomatic or suspected cases is necessary for a final classification of cases. Less than half countries follow up asymptomatic infected cases and suspected cases which do not have laboratory confirmation at birth.

A laboratory assessment is required to distinguish rubella, as up to fifty percent of rubella infections can be asymptomatic or present only minimal symptoms and other infections can have a clinical picture similar to rubella.

All the countries with a surveillance system for rubella, rubella in pregnancy or congenital rubella have a national reference laboratory. The only exception is represented by Italy, that have a national reference laboratory for rubella but several sub national reference laboratories for rubella in pregnancy and congenital rubella.

All respondent countries reported that reference laboratories are able to perform rubella-virus-specific IgM and IgG detection; a certain number of laboratories are able to do IgG avidity tests or other tests to confirm recent infection, RT-PCR or virus isolation and less than half laboratories can perform genotyping. Complementary tests such as rubella-specific avidity tests especially for pregnant women should be made available in all countries; also molecular characterization tools are needed to prove link between cases and provide information about circulating strains, indigenous or from other countries.

Therefore laboratory capacity is available at EU level, however laboratory confirmation of reported rubella cases in EU/EEA countries is not adequate. Most of the incidence data available at EU level refer to clinically-confirmed cases of rubella with comparatively few cases that are laboratory-confirmed. Data from January to December 2012 the 'WHO Epidemiological Brief' (a WHO monthly bulletin on vaccine preventable disease and immunisation data) report a laboratory investigation rate ranging from 0 to 100% among EU/EEA countries [7].

Regarding timeliness, most countries would be able to report incidence data at EU level monthly or more frequently, also for congenital rubella.

6 Conclusions

Although most EU/EEA countries are monitoring rubella incidence through mandatory comprehensive systems, reporting procedures including case definitions and case classification vary among countries. Rubella surveillance could be improved through universal use of zero-reporting, collection of information on imported/import-related cases, adoption of uniform case definitions.

A national surveillance system should be set up in all countries.

Collection of congenital rubella incidence data at ECDC level seems to be feasible. A good understanding of surveillance systems for congenital rubella (mostly countrywide, comprehensive, case-based and mandatory) that are in place in all countries but one will allow for correct data interpretation.

The added value of monitoring asymptomatic congenital infections and other outcomes of rubella infected pregnant women (still births, fetal deaths, abortions) should be discussed and promoted.

Laboratory capacity is available at EU level but the proportion of laboratory-investigated cases should be increased in several countries to achieve an adequate confirmation of cases. Also use of genotyping should be encouraged in order to characterize the chains of transmission.

The next step should be to introduce common surveillance indicators, to harmonise laboratory procedures to allow the comparability of data between countries, to establish the procedures of a collection of congenital rubella data at EU level and identify the variables to be collected.

References

1. Eliminating measles and rubella: Framework for the verification process in the WHO European Region. World Health Organization.2012. http://www.euro.who.int/en/what-we-do/health-topics/communicable-diseases/measles-and-rubella/publications/2012/eliminating-measles-and-rubella-framework-for-the-verification-process-in-the-who-european-region
2. Commission decision of 22 December 1999 on the communicable diseases to be progressively covered by the Community network under Decision No 2119/98/EC of the European Parliament and of the Council. http://eurlex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2000:028:0050:0053:EN:PDF
3. Commission Decision no 2008/426/EC of 28 April 2008 laying down case definitions for reporting communicable diseases: http://ec.europa.eu/health/ph_threats/com/docs/1589_2008_en.pdf
4. Muscat M et al. Toward rubella elimination in Europe: an epidemiological assessment. Vaccine 2012;30: 1999–2007.
5. ECDC Surveillance Report. Measles and rubella monitoring, December 2012 http://ecdc.europa.eu/en/publications/Publications/Forms/ECDC_DispForm.aspx?ID=1022
6. WHO 2009. Surveillance Guidelines for Measles, Rubella and Congenital Rubella Syndrome in the WHO European Region. http://www.euro.who.int/en/what-we-do/health-topics/disease-prevention/vaccines-and-immunization/publications/2012/surveillance-guidelines-for-measles,-rubella-and-congenital-rubella-syndrome-in-the-who-european-region
7. WHO Epidemiological Brief. Monthly summary table 1: Reported measles cases for last 12 months, January 2012 — December 2012 (data as of 1 March 2013) http://www.euro.who.int/__data/assets/pdf_file/0017/183230/Epi_Brief-Reported-measles-cases-for-last-12-months,-January-2012-December-2012-data-as-of-1-March-2013-final.pdf