

**ECDC CORPORATE**

# **Long-term surveillance strategy (revised)**

2014–2020

Suggested citation: European Centre for Disease Prevention and Control. Long-term surveillance strategy 2014–2020 (revised). Stockholm: ECDC; 2018.

Stockholm, October 2018

ISBN 978-92-9193-494-2

doi 10.2900/88780

Catalogue number TQ-03-13-448-EN-N

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## Amendments to the long-term surveillance strategy 2014-2020

The long-term surveillance strategy (LTSS, target 17, strategy 4) commits ECDC to conduct a mid-term review and, if necessary, revision of the LTSS. ECDC reviewed the LTSS and identified various targets and strategies that would benefit from updating or more rigorous editing. Guiding principles were to focus on strategies that have become obsolete or unrealistic in the light of recent developments and to refrain from adding new targets/strategies or extensively rewriting any of the sections describing the EU added value, the impact on the Member States and the risks and mitigations. The following amendments were endorsed by the National Focal Points for Surveillance and the ECDC Advisory Forum.

Target	Strategy	Original version	Amendment [and rationale]
1	1	ECDC evaluates the implementation of the long-term surveillance strategy 2008–2013 to identify and address possible shortcomings.	Drop. [Never done, now no longer likely to be of added value.]
2		Machine-to-machine reporting to TESSy in use by a majority of Member States.	Replace with: "Reporting quality data to ECDC has become less burdensome for Member States". [Machine-to-machine reporting is no priority for most Member States.]
2	2	ECDC offers technical support, including country visits, to help overcome possible obstacles.	Add: "... in Member States willing to implement machine-to-machine reporting."
2	3	ECDC explores alternative funding sources to support resource-poor Member States in implementing machine-to-machine reporting.	Replace with: "Successful data upload will only depend on very few TESSy systemic requirements being met. Automated data validation and instantaneous descriptive epidemiological feedback will enable data providers to verify/improve their data quality before approving their data submission." [Reflects improvements expected from ongoing Surveillance Systems Reengineering project.]
5	1	On behalf of the European surveillance networks and in collaboration with interested Member State experts, ECDC routinely publishes in-depth surveillance findings in peer-reviewed scientific journals.	Replace with: "On behalf of the European surveillance networks, ECDC routinely publishes in-depth surveillance findings in peer-reviewed scientific journals. To enable collaboration with interested Member State experts, ECDC shares a schedule of planned scientific publications through suitable channels."

			[As per ECDC Scientific Strategy.]
6	1	In collaboration with Member States, ECDC reviews the EU general and disease-specific surveillance objectives and identifies those that emphasise the EU added value.	Replace with: "The external evaluation of EU/EEA surveillance systems (target 1) also reviews the general and disease-specific surveillance objectives ...".  [Part of the ongoing "Evaluation of EU/EEA Public Health Surveillance Systems (EPHESUS)" project.]
6	1	ECDC and the Member States further agree on priority areas/diseases where the development of common standards would be most beneficial.	Drop.  [Standards are required for all diseases under EU/EEA surveillance.]
6	2-3	In collaboration with Member States, ECDC defines national and EU surveillance system descriptors by disease or group of diseases and disease surveillance standards for each of these descriptors. These standards are classified by intended use: <ul style="list-style-type: none"> <li>- for optimising the EU surveillance process (e.g. disease-specific frequency of reporting, list of diseases under EU surveillance);</li> <li>- for interpreting EU surveillance outputs (e.g. information on surveillance systems' characteristics);</li> <li>- for identifying weaknesses and planning support (e.g. indicators of surveillance system performance).</li> </ul> <p>ECDC develops processes and tools to further facilitate collecting, analysing, monitoring, disseminating and using information on standards. These processes and tools may include:</p> <ul style="list-style-type: none"> <li>- a simplified data collection system as part of the annual TESSy data calls</li> <li>- formalised analysis plans</li> <li>- standardised assessment processes and tools</li> <li>- means for sharing best practice between Member States</li> <li>- a review process for communicable disease reporting practices.</li> </ul>	Replace with: <ol style="list-style-type: none"> <li>2. In collaboration with Member States, ECDC defines national and EU surveillance system descriptors.</li> <li>3. Drawing on findings and recommendations from the external evaluation of EU/EEA surveillance systems, and in collaboration with Member States, ECDC defines a disease-specific standard for each surveillance system descriptor.</li> <li>4. As part of the annual TESSy data calls, Member States update their surveillance system descriptor data.</li> <li>5. ECDC uses these descriptor data to interpret EU/EEA surveillance data, monitor progress towards compliance with surveillance standards and identify Member State needs for support.</li> <li>6. ECDC regularly disseminates surveillance system descriptor data to facilitate sharing of best practices between Member States.</li> </ol> <p>[Simplify and disentangle surveillance system descriptors and standards.]</p>

7	2	ECDC holds regular disease surveillance network meetings and meetings of the National Focal Points for Surveillance.	Add "... to encourage sharing of experience and best practices between Member States."
7	3	ECDC ensures that at least 50% of the agendas of these meetings are dedicated to sharing and discussing countries' experience, where available.	Replace "at least 50%" with "a sizeable proportion". [Difficult to measure.]
8		Surveillance data quality assurance policies are in place at EU and Member State level.	"Advocate and support the adoption of surveillance data quality assurance policies in Member States." [EU level data quality assurance is axiomatic in the delivery of target 6.]
8	1	ECDC promotes standardisation of laboratory diagnostics and typing methods by: <ul style="list-style-type: none"> <li>- maintaining quality and capacity-building activities performed by disease surveillance laboratory networks (EQA, training);</li> </ul>	Add "..., taking into account cost-benefit considerations." [Align with ECDC EQA strategy and compendium.]
8	1	<ul style="list-style-type: none"> <li>- developing the EU_LabCAP initiative for appraisal and monitoring of public health microbiology laboratory capabilities across the EU for European surveillance of infectious diseases and for epidemic preparedness;</li> </ul>	Reword to: "Regular appraisal and monitoring of ..."
	2	ECDC monitors data quality and performance of surveillance systems as described under Targets 6 and 7.	Amend to "ECDC monitors data quality and performance of MS surveillance systems as described under Targets 6 and 7."
9		The quality of European surveillance data has improved sufficiently to enable the routine application of time-series analysis, spatial analysis and other advanced statistical methods, where appropriate, to better monitor, understand and predict epidemiological trends of communicable diseases in Europe.	Drop "The quality of European surveillance data has improved sufficiently to enable the". [This is not primarily about data quality but about advanced data analysis.]
10	3	In collaboration with Member States, ECDC expands the scope of epidemic intelligence activities, should the scope of the EWRS be extended to environmental and chemical threats, as proposed in the new serious cross-border health threat legislation.	Drop. [Goes too far beyond ECDC passive event-based surveillance of environmental and chemical threats.]

10	4	ECDC implements mechanisms for early detection of clusters and timely comparison of strains through molecular surveillance at EU level to guide control measures.	Add “and genomic-based” to “molecular surveillance”.
11		European behavioural surveillance data are used to identify and monitor risk groups, where appropriate.	Replace “European behavioural” with “Relevant determinant” and “risk groups” with “public health risks from infectious diseases”.  [Recommendation arising from the second external evaluation of ECDC.]
11	1-4	<p>In collaboration with Member States, ECDC explores the feasibility of helping behavioural surveillance systems develop further in the Member States for relevant diseases.</p> <p>In collaboration with Member States, ECDC defines common indicators for behavioural surveillance which Member States can adapt and use.</p> <p>In collaboration with the European Commission, ECDC explores the feasibility of increased EU-funded initiatives to carry out harmonised, periodic behavioural surveillance surveys among key risk groups related to certain priority diseases across EU countries (such as the EAHC-funded European MSM Internet Survey, EMIS).</p> <p>ECDC supports closer collaboration and sharing of knowledge and expertise in the area of behavioural surveillance across the EU, in order to promote robust, sustainable and cost-effective data collection methods, as well as to harmonise the existing indicators.</p>	<p>Replace with:</p> <ol style="list-style-type: none"> <li>1. ECDC identifies and validates relevant infectious disease determinant data sources.</li> <li>2. ECDC systematically includes determinant data, where appropriate, when analysing infectious disease surveillance data.</li> <li>3. ECDC provides access to EU/EEA determinant data through a user-friendly online platform.</li> </ol>
12	1	In collaboration with Member States and the European Commission, ECDC develops harmonised tools and frameworks to strengthen prevention programmes in the areas of TB, HIV, hepatitis, AMR, VPD, etc.	Drop.  [These particular activities are outside the scope of ECDC’s surveillance function.]
12	4	In collaboration with Member States, ECDC explores the feasibility of refining programme monitoring variables for relevant diseases in TESSy to simplify the collection of data as indicators of the success of	Replace with: “In collaboration with Member States, ECDC reviews and, where appropriate, revises programme monitoring variables for relevant diseases in TESSy to harmonise and strengthen their utility for policy, and to simplify the

		control and prevention measures taken in Member States.	collection of data as indicators of the success of control and prevention measures taken in Member States."
14		ECDC works effectively with the Commission, World Health Organization and other agencies to promote the development of a European policy environment that supports maintenance and development of effective Member State surveillance systems and avoids overlap or duplication.	Replace "policy environment" with "culture". [More appropriate wording.]
14	1	ECDC contributes to relevant public health policy and programme development initiatives of the Commission and promotes those that would be of most benefit to Member States.	Replace with: "ECDC acts as a voice of advocacy for the public health value of surveillance, providing clear evidence in support of its advocacy and for the further strengthening and development of EU capacity in surveillance."
14	2	ECDC gives advice on, brokers and facilitates suitable projects, including applied research, that would benefit the Member States.	Drop "brokers".
14	3	ECDC works closely with the Commission, WHO and other agencies to coordinate reporting requirements for Member States.	Replace with: "ECDC works closely with the Commission, WHO and other agencies to promote and coordinate the requirements made of Member States for reporting of data."
16		Relevant alternative data sources for surveillance and early threat detection have been fully explored (usefulness, data quality, potential for record linkage, etc.) and, if found to add value, are ready to be incorporated and used.	Drop "fully". [More realistic.] Drop "(usefulness, data quality, potential for record linkage, etc.)". [Shorten target.]

# 1 Executive summary

ECDC has launched the 'Strategic Multi-annual Programme 2014–2020: Working together to reduce the burden'. This long-term surveillance strategy covers the same period, 2014–2020, and should be seen as a further elaboration of this core activity as detailed in the broader multi-annual programme. Public health surveillance has been referred to as 'the epidemiological foundation for modern public health'<sup>1</sup>. In attempting to formulate strategies that will determine the EU's surveillance work over the next seven years, it is important to take into account the challenges that will need to be addressed during this period. A number of them will have a significant impact on surveillance work in the EU. For example, diseases targeted for eradication, like measles, will require more intensive surveillance; the expansion of social media and the routine use of sophisticated electronic devices like smart phones, together with an increasing public demand for surveillance data and information about the health threats and disease status of EU populations require a change to the way surveillance in the EU is carried out. A first discussion of the scope and thrust of this strategy was held at the Joint Strategy Meeting on 25–27 September 2012 with members of the Advisory Forum, Coordinating Competent Bodies, National Microbiology Focal Points and National Surveillance Focal Points. A first draft was discussed by the Advisory Forum in February 2013 and the Management Board in March 2013. In addition, the 'ECDC strategy and roadmap for integration of molecular typing into European level surveillance and epidemic preparedness' was discussed with the Advisory Forum and National Microbiology Focal Points in December 2012 and March 2013.

The final strategy is divided into six priorities:

- 1** Consolidating surveillance, increasing its efficiency and enhancing the outputs and their impact
- 2** Developing standards, improving data quality and sharing best practices in surveillance
- 3** Promoting use of surveillance data
- 4** Strengthening capacity in surveillance
- 5** Controlling expansion

Monitoring the strategy.

These priorities have been elaborated in 17 targets, each with strategic actions to achieve them, their European-added value and impact on the Member States as well as risks and their possible mitigation.

The planned actions are:

- To develop EU surveillance guidance, tools and standards (including indicators for data quality, comparability and timeliness)
- To consider alternatives to traditional passive surveillance (e.g. EU-wide sentinel surveillance for some common diseases or relying on event-based surveillance for some rarer ones) and focus more on priority conditions
- To more systematically integrate event-based and indicator-based surveillance
- To promote machine-to-machine data reporting, reducing the burden of data submission to TESSy while boosting data quality and timeliness of reporting
- To reorganise ECDC surveillance outputs making them more user-friendly, timely and accessible
- To exploit the advances in genomic epidemiology and information sciences, especially linkage with other important data sources not normally available to public health and news aggregators to expand the potential of epidemic intelligence
- To look into the needs for behavioural, mortality, syndromic or more systematic vector surveillance for relevant diseases
- To increase analytical epidemiology, including spatial analysis and advanced statistics (e.g. time-series analysis)
- To use social media and the proliferation of electronic devices such as smart phones for outbreak investigations, exploiting their geo-localisation features and potential for crowd-sourcing
- To integrate molecular genetic data where relevant and improve the linkage between notified case data and laboratory data, especially with respect to molecular typing for EU/EEA surveillance
- To review the list of health conditions to be reported routinely through indicator-based (TESSy) or event-based (EPIS/EWRS) integrated surveillance systems
- To offer policy-makers, public health officers, epidemiologists and the general public in Member States a 'situation awareness platform' for timely relevant information on emerging international threats and their evidence-based rapid assessment
- To implement joint approaches to threat assessment across the various areas of expertise and agencies in the EU.

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<sup>1</sup> Berkelmann RL, Stroup DF, Buehler JW. Public health surveillance. In: Detels R, McEwen J, Beaglehole R, Tanaka H, eds. Oxford Textbook of Public Health: The Methods of Public Health, vol 2. Fourth Edition. Oxford, England: Oxford University Press, 2002.

This strategy recognises that EU surveillance is only as strong as the surveillance activities of its constituent Member States. In these times of economic pressure, many Member States are facing cuts in vital resources such that they are no longer able to carry out more than the minimum surveillance. It is therefore of paramount importance that plans for any further development of EU surveillance activities over the next few years are kept realistic and do not add any burden to already stretched country resources.

The main focus of this strategy will be for ECDC to work together with other key stakeholders to ensure that Member States are able to develop and maintain efficient and effective national surveillance systems, despite the financial pressures that can be expected over the coming years.

## Vision, priorities and targets

By 2020, strong, harmonised and efficient European surveillance systems will serve the Member States, the European Commission and public health professionals by providing relevant data for the effective prevention and control of communicable diseases while minimising the burden on the Member States.

### Consolidating surveillance, increasing its efficiency and enhancing the outputs and their impact

- Target 1: Critical evaluation of indicator-based EU surveillance.
- Target 2: Reporting quality data to ECDC has become less burdensome for Member States.
- Target 3: Data processing is semi-automated while retaining a high quality, enabling ECDC routine surveillance outputs to be timelier, more easily available, user-customisable and thus perceived to be more useful by stakeholders.
- Target 4: The complementarity and synergy between indicator-based and event-based surveillance is improved.
- Target 5: ECDC and the Member State experts routinely communicate European surveillance findings through peer-reviewed scientific journals and other channels to better inform disease prevention and control as well as public health decision-making.

### Developing standards, improving data quality and sharing best practice in surveillance

- Target 6: European surveillance standards agreed and implemented.
- Target 7: The European surveillance network culture promotes systematic learning from the example of the high-quality data providers.
- Target 8: ECDC advocates and supports the adoption of surveillance data quality assurance policies at EU and Member State level.
- Target 9: ECDC routinely applies time-series analysis, spatial analysis and other advanced statistical methods, where appropriate, to better monitor, understand and predict epidemiological trends of communicable diseases in Europe.

### Promoting use of surveillance data

- Target 10: European event-based surveillance detects, assesses and monitors communicable disease threats to public health in near-real time.
- Target 11: Relevant determinant data are used to identify and monitor public health risks from infectious diseases, where appropriate.
- Target 12: European surveillance data are used to monitor and evaluate prevention programmes against agreed indicators.
- Target 13: European surveillance data generate hypotheses for further scientific investigation and influence the EU research agenda.

### Strengthening capacity in surveillance

- Target 14: ECDC works effectively with the European Commission, World Health Organization and other agencies to promote the development of a European culture that supports maintenance and development of effective Member State surveillance systems and avoids overlap or duplication.

### Controlling expansion

- Target 15: Routine molecular typing for surveillance of selected pathogens is fully established at European level.
- Target 16: Relevant alternative data sources for surveillance and early threat detection have been explored and, if found to add value, are ready to be used.

### Monitoring implementation of the strategy

- Target 17: The implementation of this long-term surveillance strategy is monitored and reported to the Member States on an annual basis.

## 2 Overall focus

*For surveillance systems to be useful, they must adapt to the changing environment in which they operate and accommodate emerging public health requirements that were not conceived previously.*

—Joseph S. Lombardo, MS, Johns Hopkins University Applied Physics Laboratory, and David L. Buckeridge, MD, PhD, McGill University<sup>2</sup>

This long-term strategy on the future surveillance of communicable diseases in the EU aims to guide the further development of the European surveillance system. It covers the years until 2020 and should be considered in conjunction with the overall ECDC Strategic Multi-Annual Plan covering the same period.

This is the third ECDC surveillance strategy. The first (covering 2006 to 2008) focussed on systematically evaluating the Dedicated Surveillance Network projects in place at the time and on setting up the infrastructure for integrated surveillance.

The second ECDC surveillance strategy, entitled 'Surveillance of Communicable Diseases in the European Union, a Long-Term Strategy (2008–2013)<sup>3</sup> focussed mainly on integrating the coordination of the Dedicated Surveillance Network projects and on setting up sustainable EU-wide laboratory and epidemiology network structures, while consolidating the TESSy platform and reporting systems.

This 2014–2020 strategy outlines the goal and scope of EU surveillance, its aims and objectives as well as the overall vision and lists the priorities for the next seven years, bearing in mind the resource limitations likely to be encountered. The main focus is to develop the quality, effectiveness and accessibility of the EU surveillance activities while ensuring that the burden on those contributing to these activities remains congruent with the benefits. For each priority we have identified several targets, stated their European added value, the impact of implementing this strategy and highlighted identifiable risks as well as ways to mitigate them.

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<sup>2</sup> US General Accounting Office (GAO). Challenges in improving infectious disease surveillance systems. Washington, DC: GAO; 2001:7. Publication no. GAO-01-722. Available at: <http://www.gao.gov/assets/240/232631.pdf>.

<sup>3</sup> Available from: [http://www.ecdc.europa.eu/en/aboutus/key%20documents/08-13\\_kd\\_surveillance\\_of\\_cd.pdf](http://www.ecdc.europa.eu/en/aboutus/key%20documents/08-13_kd_surveillance_of_cd.pdf)

## 3 Future challenges

There are a number of challenges that can already be foreseen and need to be taken into account when planning for the next seven years. At the same time, there will clearly be new challenges that cannot be predicted at this stage, so this strategy must be flexible enough to be able to be adapted to meet these challenges.

The following challenges have been taken into consideration:

- Some diseases are targeted for eradication, e.g. measles, and will require more intensive surveillance.
- The EU might enlarge or become more closely engaged in surveillance with a number of countries in the south-east and east of Europe.
- ECDC and WHO will need to continue to strengthen their cooperation in surveillance and ensure that there is no duplication of demands as new priorities emerge.
- European citizens are increasing their demands to make surveillance data more available and to inform the public about health threats to, and the disease status of, EU populations.
- The role of social media can be expected to continue to grow, creating more pressure for increased timeliness of reporting and interpretation of event-based surveillance.
- With increasing data protection awareness, surveillance experts will need to justify that data gathered are being used to advance public health and prevent disease.
- The recent economic downturn is unlikely to recover very quickly, and under pressure to spend less, ECDC will have to prioritise its work, for example reducing the list of diseases under surveillance and looking for more cost-efficient ways to obtain surveillance data.
- With surveillance activities becoming increasingly laboratory-driven thanks to quantum advances in efficient genomic typing technologies, laboratory-based surveillance data will need to be linked more closely with epidemiological surveillance data to better detect and monitor outbreaks and improve our understanding of epidemiological changes.
- The European Commission's serious cross-border health threat initiative will affect the way epidemic intelligence and response are carried out. In particular, the scope of ECDC's threat detection and assessments may be expanded to cover all threats to public health.
- There will be increasing pressure for those investigating outbreaks to make greater use of rapidly developing electronic devices for case-finding or determining exposure (risk factor investigations).
- The growing potential of crowd sourcing for monitoring crisis situations will require suitable tools.
- As several Member States will have their resources reduced during this period, ECDC will become the primary place some Member States will consult for information on emerging threats, their assessment, and guidance on how to best respond to them, saving them the trouble of having to set up their own systems for this work.

In addition, it is prudent to keep in mind existing elements that may increasingly influence surveillance priorities in the coming years, such as:

- the growing use of electronic health records for public health surveillance purposes and the potential for active surveillance using electronic searches;
- improved accuracy in estimating underreporting from passive surveillance by electronically linking several databases;
- the growing use of bedside diagnostic tests and ways to incorporate these in surveillance;
- management and interpretation of microbial genomic typing data (i.e. 'fingerprinting') alongside epidemiologic data;
- expansion of geographic information systems (GIS) into syndromic surveillance and outbreak mapping;
- the growing recognition of previously unidentified pathogens (especially viruses) through examination of their genes;
- new tools and strategies for controlling neglected diseases that are a significant burden in areas where treatments do not exist;
- strategies that increase the use of socio-demographic indicators or other potential risk factors and determinants such as:
  - austerity
  - ageing populations and increase in prevalence of chronic diseases
  - climate change, especially global warming
  - spread of vectors
  - migration
  - international traffic of food products
  - increasing vaccine scepticism
  - spread of antimicrobial resistance;
- surveillance systems for zoonoses that incorporate environmental surveillance (e.g., prevalence among vectors and/or vertebrate hosts) to detect pathogens and estimate risk;

- improved vector management methods, including development of novel pesticides and delivery systems and the way they influence the spread of infection;
- enhanced surveillance systems for migrating populations, immigrants, refugees, and travellers.

## 4 Surveillance objectives

In the public health sector, Member States generally agree that any EU-level action should be taken only where supra-national coordination 'adds EU value' (see Annex).

Surveillance at the EU level should similarly strive to add value for individual Member States and to the European Union by not simply duplicating what is done in the national surveillance systems. It is important to keep a clear view of the agreed goal of EU surveillance; that is to provide the information to promote effective evidence-based action that will result in the prevention and control of communicable diseases in Europe.

Similarly, such surveillance systems must have a clear statement of their objectives and agreed case definitions. The ECDC distinguishes between *general surveillance objectives*, which apply to all the diseases and special health conditions under surveillance at EU level, and *disease-specific objectives* that relate to individual diseases' specific features. The general objectives are further discussed in the Annex and the latest version of them is published online<sup>4</sup>. The disease-specific objectives are reviewed on an annual basis by the various disease networks and are published on their dedicated ECDC web pages.

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<sup>4</sup> [http://ecdc.europa.eu/en/activities/surveillance/legal\\_framework\\_strategy/Pages/surveillance\\_objectives.aspx](http://ecdc.europa.eu/en/activities/surveillance/legal_framework_strategy/Pages/surveillance_objectives.aspx)

## 5 Vision, priorities, targets and strategies 2014–2020

**Vision:** By 2020, strong, harmonised and efficient European surveillance systems will serve the Member States, the European Commission and public health professionals by providing relevant data for the effective prevention and control of communicable diseases while minimising the burden on the Member States.

### 5.1 Consolidating surveillance, increasing its efficiency and enhancing the outputs and their impact

#### Target 1: Critical evaluation of indicator-based EU surveillance.

##### *European added value*

Evaluating the indicator-based EU surveillance system will provide important feedback for improving its efficiency and impact.

##### *Strategy*

- 1 ECDC commissions an external evaluation of:
  - the TESSy platform, its architecture, functionality and user acceptability to guide future system upgrades;
  - the more general set-up, carrying out and public health usefulness of EU surveillance.
- 2 ECDC shares all evaluation results, practical implications and suggested next steps with relevant external stakeholders.

##### *Impact on Member States*

Member States will be invited to participate in the TESSy and surveillance system evaluations to contribute to improving systems and processes.

##### *Risks and mitigation*

The external evaluations may not be insightful enough to really extract the true issues. ECDC will therefore have to very carefully select appropriate evaluators and pay extra attention to their submitted evaluation protocols.

#### Target 2: Reporting quality data to ECDC has become less burdensome for Member States.

##### *European added value*

Reducing the reporting burden and improving data validation will improve data quality and timeliness of reporting.

##### *Strategy*

- 1 ECDC actively approaches each Member State to explore their willingness and ability to implement machine-to-machine reporting to TESSy.
- 2 ECDC offers technical support, including country visits, to help overcome possible obstacles in Member States willing to implement machine-to-machine reporting.
- 3 Successful data upload will only depend on very few TESSy systemic requirements being met.
- 4 Automated data validation and instantaneous descriptive epidemiological feedback will enable data providers to verify/improve their data quality before approving their data submission.

##### *Impact on Member States*

After an initial implementation effort, machine-to-machine reporting to TESSy will decrease Member States' workload in preparing, uploading, validating and updating the communicable disease surveillance data reported to ECDC. The validation feedback will be prompt and more meaningful. These changes might also serve as a model for modernisation of certain countries' own reporting systems from the local to the national level.

##### *Risks and mitigation*

Resource-poor Member States risk being left behind. Although ECDC cannot directly fund the development of Member States' public health infrastructure, it can help by sharing technical expertise, ad hoc advice and active support in tapping alternative funding sources.

Member States may underestimate maintenance requirements of machine-to-machine reporting systems. When approaching Member States, ECDC should therefore also emphasise the resource implications of sustaining these systems in the long run.

### **Target 3: Data processing is semi-automated while retaining a high quality, enabling ECDC routine surveillance outputs to be timelier, more easily available, user-customisable and thus perceived to be more useful by stakeholders.**

#### ***European added value***

ECDC is the main European public health agency collecting, analysing and disseminating communicable disease surveillance data from all EU/EEA Member States in this breadth and depth. Increasing the automation of data validation, cleaning and output production at ECDC should improve data quality, consistency, online accessibility and harmonisation across diseases, while also improving timeliness. European communicable disease surveillance experts will then be able to concentrate more on analysis and interpretation than on managing processes. Through improved timeliness, accessibility and usefulness, ECDC routine surveillance outputs will become an exceptional resource informing disease prevention and control efforts at EU and national levels.

#### ***Strategy***

- 1** ECDC introduces standard routines to automate surveillance data validation and cleaning.
- 2** ECDC creates an intermediate validated data repository for analysis.
- 3** ECDC uses this data repository for automated production of static and interactive standardised online outputs (including maps, tables and graphs).
- 4** These outputs form the cornerstone of all ECDC surveillance reports. Some of the time gained from ready-made data representations will be invested in enhancing data analysis and interpretation.
- 5** A public interactive online dashboard links the different data exploration options or user-customised online queries providing an intuitive and integrated epidemiological overview by disease and common relevant indicators.
- 6** All publicly available European surveillance outputs can be printed or downloaded in easily reusable formats.

#### ***Impact on Member States***

Member State experts will enjoy easier access to a range of useful and more timely European online surveillance outputs, including directly querying cleaned data. Integrated, easily navigable and reusable online content will replace large parts of the currently lengthy surveillance reports. These reports will in turn be shorter and focus more on data interpretation relevant to public health. The ECDC web portal will become the primary source of such information.

#### ***Risks and mitigation***

Increasing the availability of European surveillance data on a public web portal may invite non-experts to draw their own, possibly erroneous conclusions. ECDC will therefore need to ensure that no table, graph or map is posted online without highlighting the limitations of the surveillance systems generating the underlying data.

### **Target 4: The complementarity and synergy between indicator-based and event-based surveillance is improved.**

#### ***European added value***

Event-based surveillance carried out at the EU level adds value by providing a service for those Member States that do not have the resources to do this work. This is especially the case for the surveillance of threats originating outside of the EU. For certain rare diseases, event-based surveillance might replace the more resource-intensive and less timely indicator-based surveillance, thus potentially freeing up valuable expert resources. For most other priority diseases, the two branches of communicable disease surveillance complement each other: event-based activities tend to provide timely information on immediate health threats, whereas the less timely passive surveillance establishes baselines and thresholds, is more representative of populations and has its value in detecting trends and other epidemiological patterns.

#### ***Strategy***

- 1** Where justified by the surveillance objectives of particular (usually rare) diseases, ECDC replaces European passive surveillance with event-based surveillance after due consultation with the Member States.
- 2** ECDC explores the diseases for which prevention and control would benefit from a closer link between indicator-based surveillance data in TESSy and event-based data in EPIS;
- 3** ECDC links the disease-specific outputs of European indicator-based and event-based surveillance, where appropriate.

#### ***Impact on Member States***

Most Member States already rely heavily on ECDC's event-based surveillance and rapid risk assessments of detected threats. If in addition, for certain communicable diseases, event-based surveillance were to replace

indicator-based surveillance, scarce Member State resources could be used more efficiently. Member States will further benefit from the more complete picture obtained from linking the outputs of indicator-based and event-based surveillance, especially when considering the epidemiology of outbreak-prone diseases. Finally, linking TESSy and EPIS, where appropriate, makes ECDC and the Member States active partners in the continuum of passive surveillance, cluster detection and monitoring, additional case finding, exchange of pertinent non-structured information and follow-up of response and secondary prevention measures.

### ***Risks and mitigation***

Linking event-based and indicator-based surveillance platforms and processes creates challenges in joint management and communication of data from informal and formal sources. These challenges can be managed by careful design of operational processes and information flows, including consideration of personal data protection and confidentiality. If ECDC became the sole provider of non-EU threat assessments, Member States would be vulnerable to any changes in ECDC priorities or processes. Maintaining good collaboration with WHO should reduce any overlap and should ensure the availability of information to Member States from multiple sources.

## **Target 5: ECDC routinely communicates European surveillance findings through peer-reviewed scientific journals and other channels to better inform disease prevention and control as well as public health decision-making.**

### ***European added value***

Through peer-reviewed scientific articles and other communication channels such as mobile applications or social media, EU surveillance findings can be made more widely available than by simply posting online outputs on the ECDC web portal. A more ambitious publication policy can also foster further scientific collaborations between ECDC and Member State experts willing to engage and is likely to raise the international profile of European communicable disease surveillance as a whole.

### ***Strategy***

- 1** On behalf of the European surveillance networks, ECDC routinely publishes in-depth surveillance findings in peer-reviewed scientific journals. To enable collaboration with interested Member State experts, ECDC shares a schedule of planned scientific publications through suitable channels.
- 2** ECDC employs a wide range of communication tools (webpages, mobile applications, social media, etc.) to convey key surveillance findings and the resulting prevention and control messages.
- 3** ECDC's communication of surveillance findings and resulting prevention and control messages primarily targets public health professionals and policy-makers at EU and Member State level.

### ***Impact on Member States***

Member States will be able to more easily locate and reference European surveillance findings through scientific literature databases (e.g. PubMed). Member State experts will also have the opportunity to lead or contribute to scientific surveillance projects with ECDC, increasing Member States' sense of ownership and visibility.

Information made available by ECDC in different formats will better inform public health decision-making, prevention and control in the Member States.

### ***Risks and mitigation***

Public health messages issued by ECDC may not always be entirely in line with leading opinions held in every single Member State. This risk can be mitigated by thorough consultation and agreement on the lines to take prior to any public communication.

To avoid common tensions over first or senior authorship in joint publications, ECDC and the Member State colleagues involved should refer and adhere to the established principles of good scientific practice.

## **5.2 Developing standards, improving data quality and sharing best practice in surveillance**

### **Target 6: European surveillance standards agreed and implemented.**

#### ***European added value***

ECDC has worked together with surveillance experts in the Member States to develop surveillance standards in order to streamline EU surveillance and to improve data quality. These standards include agreed common case definitions, sets of reportable variables, data submission and reporting protocols, standardised validation and feedback. Given the current negative financial climate, further optimisation of surveillance efforts should have the main goal of reducing the burden on Member States while sustaining the value of EU surveillance. By

focussing on essential EU surveillance objectives and commonly agreed priorities, ECDC data requirements will be revised and unnecessary surveillance activities stopped accordingly. Setting a few agreed EU surveillance standards for priority conditions and monitoring them over time should enable ECDC to better tailor Member State support and to strive for data comparability only when appropriate. Efforts to improve the data quality should focus on diseases where: a) effective interventions for prevention and control are available and can be promoted at EU level (e.g. some vaccine-preventable bacterial infections, diseases under an EU/global target for control); b) relevant epidemiological trends and features are better described by combining data from multiple countries (e.g. seasonal spread of influenza activity and assessment of its severity); c) significant differences between countries are expected due to the different distribution of risk factors and hence public health interventions should be tailored to the most affected countries or populations (e.g. AMR/HAI, tuberculosis, HIV).

Maintaining accurate and up-to-date information on the Member State surveillance systems and their performance is essential for proper data interpretation, thus enhancing the public health value of EU surveillance.

### **Strategy**

- 1** The external evaluation of EU/EEA surveillance systems (target 1) reviews the EU general and disease-specific surveillance objectives and identifies those that emphasise the EU added value.
- 2** In collaboration with Member States, ECDC defines national and EU surveillance system descriptors.
- 3** Drawing on findings and recommendations from the external evaluation of EU/EEA surveillance systems, and in collaboration with Member States, ECDC defines a disease-specific standard for each surveillance system descriptor.
- 4** As part of the annual TESSy data calls, Member States update their surveillance system descriptor data.
- 5** ECDC uses these descriptor data to interpret EU/EEA surveillance data, monitor progress towards compliance with surveillance standards and identify Member State needs for support.
- 6** ECDC regularly disseminates surveillance system descriptor data to facilitate sharing of best practices between Member States.

### **Impact on Member States**

The aim of this target is to reduce the burden on Member States by optimising EU surveillance practices and supporting Member States in improving their compliance with EU standards. The target implies a revision of current surveillance objectives, focussing on those with the highest EU added value. The resulting reorganisation of surveillance operations will most likely reduce the number of diseases to be reported to TESSy, the frequency of reporting, and the complexity of some metadata sets. Member States can expect that they will only need to report on a well-justified list of priority diseases, with the frequency and amount of reporting being proportionate to each disease's public health relevance. In most Member States, the alignment of European reporting frequencies with European surveillance objectives may enable a redistribution of resources from reporting for retrospective description and analysis to reporting for timely public health action.

During the implementation of Target 6, Member States may be asked to:

- come to a European agreement on the criteria and processes for reviewing and prioritising communicable diseases notifiable at EU/EEA level and, at regular intervals thereafter, assist ECDC in the actual review and prioritisation;
- provide additional information on surveillance systems that is deemed necessary for data interpretation;
- provide information on their progress towards achieving agreed standards;
- strengthen their surveillance capacity on priority areas where a strong EU added value has been identified;
- facilitate ECDC assessments and supporting activities.

### **Risks and mitigation**

The main risk is due to the lack of resources at ECDC and in the Member States. Maintenance of a core surveillance group working across diseases and with a dedicated budget would provide an important resource for succeeding in a project that requires a holistic approach and coordination.

Endorsement of this project by disease experts at ECDC and in the EU surveillance networks may be a challenge as some firmly established surveillance processes might be revised. Lack of commitment should be overcome by ensuring a constant focus on activities that are considered priorities at EU level. This requires an active exchange of information promoted by ECDC, well defined feedback processes to disease-specific networks, and flexibility to adapt the project to Member States' needs and priorities.

Member States' surveillance objectives may differ from EU surveillance objectives for a given disease. This may pose problems if, for example, the expected European frequency of reporting exceeds the reporting frequency expected at the national level. Solutions might include using data provided from a smaller group of regular data providers and then extrapolating to the broader picture.

If the criteria and process for putting diseases under surveillance were too rigid, it might become too difficult or take too long to add new priority emerging diseases to the list. This would not only seriously hamper their surveillance, but also compromise their timely prevention and control. The review carried out before putting such

diseases under surveillance should therefore allow for an appropriate degree of flexibility. A newly emerging disease that has only caused a few cases might be better monitored by epidemic intelligence until the review process has been finalised and an indicator-based surveillance system has been agreed and set up.

Any review and prioritisation of communicable diseases risks being driven by hypothetical worst-case scenarios and potential media interest rather than actual, measurable public health impact that would represent the 'true' risk. While preparedness certainly has its place in establishing surveillance priorities, it should not lead to an overemphasis on rare pathogens simply because they may potentially have disastrous consequences, e.g. when released intentionally. Europe should rely on epidemic intelligence to capture such extraordinary events.

## **Target 7: The European surveillance network culture promotes systematic learning from the example of the high-quality data providers.**

### ***European added value***

Exchange of country experiences and good practice represent an efficient way to promote advances in surveillance systems across the EU. Such exchange can foster a culture of reciprocal support between EU countries and further strengthen surveillance networks.

This should ensure that:

- ECDC has a better understanding of the structure, strengths and limitations of Member State surveillance systems and is better able to interpret surveillance outputs and design projects to fill any gaps;
- Member States have a better understanding of each other's systems, are better able to collaborate and learn from others, incorporating best practice into their own systems;
- Member States are relieved of some of the load in further developing and improving their communicable disease surveillance systems.

### ***Strategy***

- 1** ECDC develops and maintains a European Communicable Disease Surveillance Systems Observatory as a platform for systematic sharing of standard information on Member State surveillance systems, EU standards and good practice. ECDC also develops and maintains a support framework that includes a range of tools, technical expert advice, technical support for assessing surveillance system performance, and training programmes.
- 2** ECDC holds regular disease surveillance network meetings and meetings of the National Focal Points for Surveillance to encourage sharing of experience and best practices between Member States.
- 3** ECDC ensures that a sizeable proportion of the agendas of these meetings are dedicated to sharing and discussing countries' experience, where available.
- 4** ECDC finds ways other than annual network meetings to update Member State partners on its projects and developments, thus giving more time to country presentations.

### ***Impact on Member States***

Member States may require some investment in providing the initial surveillance system information to the observatory and modest ongoing investment in annual updates. Countries with consolidated good practices may provide support in terms of training, advice, site visits to countries with less developed systems. Also, Member States should be ready to invest time in attending network meetings and working on network projects. Some resources may be required to support in-country self-assessments.

### ***Risks and mitigation***

Differences between Member State surveillance systems, health priorities, communicable disease epidemiology, availability of human and financial resources, and surveillance capacity (including IT development) may result in good practice in one country not being applicable to or feasible in another. Depending on available resources, ECDC could provide support to countries requesting it and promote bilateral collaboration/support between countries.

There may be insufficient country commitment or resources for collaborative network projects. Countries may not take up the various support tools, or find them useful. Member States may not take up the offer for technical advice, including in-country reviews as they may not have enough staff to spare to participate in these activities.

The disease-specific network experts may develop divergent approaches not consistent with overall European network strategies (mitigation: a central technical review process administered by ECDC reviews recommendations from networks).

## Target 8: ECDC advocates and supports the adoption of surveillance data quality assurance policies at EU and Member State level.

### *European added value*

There will be continuing emphasis on improving data quality and standardisation of data quality monitoring throughout the EU. All data potentially relevant to public health surveillance will benefit from better harmonisation across data reporting systems.

### *Strategy*

- 1 ECDC promotes standardisation of laboratory diagnostics and typing methods by:
  - maintaining quality and capacity-building activities performed by disease surveillance laboratory networks (EQA, training), taking into account cost-benefit considerations;
  - regular appraisal and monitoring of public health microbiology laboratory capabilities across the EU for European surveillance of infectious diseases and for epidemic preparedness;
  - progressive implementation of the roadmap on molecular typing for EU/EEA surveillance.
- 2 ECDC monitors data quality and performance of Member State surveillance systems as described under Targets 6 and 7.
- 3 ECDC promotes a wider application of EU case definitions and disease-specific reporting protocols in Member States.
- 4 ECDC improves the internal data quality monitoring processes in TESSy through pre-defined indicators and provision of regular feedback to data providers.
- 5 ECDC supports Member States by offering an online manual guiding the process of monitoring data quality and evaluating their surveillance systems.

### *Impact on Member States*

Member States will need to periodically report to ECDC on their surveillance system performance and laboratory capacity (Targets 6 and 7).

### *Risks and mitigation*

Member States may not perceive provision of better quality data to the EU level as a priority. The requested level of data quality should be directly related to the type of outputs needed to achieve the agreed surveillance objectives. Evaluation of surveillance systems is a time-consuming exercise and not always considered a priority in Member States. The provision of a trigger-driven approach to surveillance system evaluation would help with optimising the resources needed for evaluations. EPIET fellows could be an important resource for helping with system evaluations.

## Target 9: ECDC routinely applies time-series analysis, spatial analysis and other advanced statistical methods, where appropriate, to better monitor, understand and predict epidemiological trends of communicable diseases in Europe.

### *European added value*

Subtle disease trends can only be detected by pooling data from several affected countries. Emergence or re-emergence of certain diseases can thereby be detected earlier, improving the possibility for control. Similarly, longer term trends may be predicted, thus offering better opportunities for planning prevention and control interventions. This increasing use of analytical epidemiology and advanced statistics (e.g. GIS, time-series analysis) will enable ECDC to add further value by identifying relationships in data, providing thresholds for action, and producing more solid evidence for action.

The use of intelligent data-mining tools facilitates the analysis of relationships between data collected on several different types of events. ECDC will also support the application of mathematical modelling in predicting trends to explore the potential for supporting policy- and decision-making processes. This should improve the usefulness of the data for informing public health policy at Member State and EU level.

### *Strategy*

- 1 ECDC introduces systems to automatically detect unexplained increases in reported cases, triggering alerts that require further investigation and assisting epidemiologists in quickly reviewing relevant data in multiple epidemiological dimensions.
- 2 In collaboration with Member States, ECDC defines the level of required geographical granularity for each disease according to the surveillance objectives.
- 3 ECDC provides pooled EU data analysis to monitor the incidence, severity and mortality of communicable diseases in the EU and identify trends, especially resurgence of diseases. This pooled analysis informs the planning and delivery of targeted prevention programmes (e.g. vaccination, HIV testing).
- 4 ECDC increases the use of analytical epidemiology and advanced statistics (e.g. GIS, time-series analysis).

- 5 ECDC supports the development of mathematical modelling protocols and tools which could be used by Member States to assess the disease burden at national level.

### ***Impact on Member States***

For selected diseases Member States are expected to report cases with a higher geographical resolution. An acceptable level of data quality should be maintained over time to allow for reliable time series analyses.

### ***Risks and mitigation***

Some countries may not be able to provide data with the desired level of quality or granularity. This risk may be reduced by ECDC providing support for improving data quality (see Target 8). Moreover, ECDC will enable quicker access to analyses and outputs useful to Member States and this may boost the motivation of data providers.

## **5.3 Promoting use of surveillance data**

### **Target 10: European event-based surveillance detects, assesses and monitors communicable disease threats to public health in near-real time.**

#### ***European added value***

Some Member States may not have sufficient capacity to invest in detecting, assessing and monitoring emerging communicable disease threats in near-real time. They can benefit from ECDC's threat detection and monitoring activities without having to develop their own sophisticated systems.

#### ***Strategy***

- 1 ECDC increases its capacity to capture and filter information on public health disease threats and to link this information with existing surveillance and other relevant information for better threat detection and assessment.
- 2 ECDC investigates tools for crowd-sourcing in epidemic intelligence to increase insight on rapidly evolving public health events.
- 3 ECDC implements mechanisms for early detection of clusters and timely comparison of strains through molecular and genomic-based surveillance at EU level to guide control measures.
- 4 ECDC becomes the key service provider for Member States on epidemic intelligence related to health threats outside of the EU.

#### ***Impact on Member States***

Between 2014 and 2020, the EU might enlarge further than envisaged in 2013 or become more closely related to countries in the south-east and east of Europe. Newer Member States or those in the European neighbourhood are likely to have fewer public health resources than most existing Member States; nevertheless, these countries should be integrated into European communicable disease surveillance, its technical platforms and networks. Their capacity to detect and assess threats falling within the criteria of the early warning and response mechanism (EWRS) will have to be assessed, and this has implications for Member States in terms of availability of budget and resources to be allocated.

#### ***Risks and mitigation***

In the coming years, the financial pressures experienced by the EU are likely to continue to impact negatively on the resources devoted by Member States to public health, threat detection, assessment and response. Growing demands and expectations are therefore unlikely to be met by shrinking national budgets. Priorities at both EU and national level have to be established in order to minimise the negative impact of expected budget cuts.

## **Target 11: Relevant determinant data are used to identify and monitor public health risks from infectious diseases, where appropriate.**

### ***European added value***

Determinant data, e.g. from behavioural surveillance can, for some diseases, serve as an early-warning sign that the incidence of a disease may be at risk of increasing (e.g. changes in vaccination uptake in a certain population may precede an increase in disease prevalence). Determinant data are already used alongside biological surveillance data for a number of infectious diseases and their use can be expanded into other disease areas to better target risk groups, inform programmes and plan resources. Determinant data can be combined with biological disease surveillance data to track and describe the full picture of changes in disease prevalence over time.

In 2014–2020, ECDC surveillance activities will be gradually expanded to include determinant data for relevant diseases. These data will provide information not only to understand the drivers of epidemics but also allow monitoring of related risks, advocacy and planning and evaluation of prevention and control interventions.

### ***Strategy***

- 1** ECDC identifies and validates relevant infectious disease determinant data sources.
- 2** ECDC systematically includes determinant data, where appropriate, when analysing infectious disease surveillance data.
- 3** ECDC provides access to EU/EEA determinant data through a user-friendly online platform.

### ***Impact on Member States***

Member States gain access to epidemiologically useful determinant data for better disease prevention and control.

### ***Risks and mitigation***

Introducing elements of behavioural surveillance for additional diseases will be considered with caution, ensuring that the added value outweighs the extra burden on Member States, and only following general consensus. It would be important to promote the use of Commission-funded initiatives to resource EU-wide surveys in key risk groups.

## **Target 12: European surveillance data are used to monitor and evaluate prevention programmes against agreed indicators.**

### ***European added value***

Programme monitoring is an essential component in strengthening public health programmes and is increasingly used to ensure that programmes are efficiently implemented. Programme monitoring is used to demonstrate that programmes have a measurable impact on expected outcomes. By using surveillance data, programme monitoring helps to identify the most valuable and efficient use of resources. In times of reduced public health spending, it is critical that public health prevention programmes demonstrate desired effects. Programme monitoring helps programme managers and policy makers acquire the information and understanding they need in order to make informed decisions.

In 2014–2020, ECDC will play a major role in contributing to evidence-based programme monitoring in the EU for priority communicable diseases. By better describing the epidemiology of a disease alongside select programme indicators, ECDC reports will provide decision makers in Member States and the European Commission with high quality evidence to underpin their policy decisions and actions.

ECDC will continue to provide support to Member States by developing tools to strengthen national prevention programmes.

### ***Strategy***

- 1** In collaboration with Member States and the European Commission, ECDC supports the development of frameworks and indicators to monitor implementation of Council Recommendations, European Commission Communications and other relevant Action Plans pertaining to infectious diseases.
- 2** In collaboration with key international partners, such as WHO, UNAIDS, the European Monitoring Centre for Drugs and Drug Addiction, the European Medicines Agency and the European Food Safety Authority, ECDC ensures that monitoring systems and their indicators are harmonised in an effort to reduce the reporting burden on Member States.
- 3** In collaboration with Member States, ECDC reviews and, where appropriate, revises programme monitoring variables for relevant diseases in TESSy to harmonise and strengthen their utility for policy, and to simplify the collection of data as indicators of the success of control and prevention measures taken in Member States.

***Impact on Member States***

Programme monitoring and surveillance data will be better integrated at Member State and EU level. Public health decision makers in Member States should be able to make better programmatic and policy decisions. Monitoring of programme data would also help Member States to benchmark their targeted prevention efforts against other Member States with similar epidemiological profiles.

***Risks and mitigation***

Several Member States might not have sufficient capacity to invest in monitoring the effectiveness of their prevention and control programmes. ECDC will support Member States by providing expertise, facilitating the process of better integrating surveillance and programme data, monitoring the progress of national programmes (where needed) and ensuring that the reporting burden on countries is minimised.

## **Target 13: European surveillance data generate hypotheses for further scientific investigation and influence the EU research agenda.**

***European added value***

Hypotheses derived from EU surveillance data and subsequent research to test them may ultimately lead to an improved understanding of communicable diseases and scientific progress.

***Strategy***

- 1** In collaboration with Member States, ECDC increasingly uses EU surveillance data for analytical epidemiology and hypothesis generation.
- 2** In collaboration with Member States, ECDC makes cleaned and validated EU surveillance data more easily available for third-party research.
- 3** ECDC liaises with other EU bodies, scientific institutes, academia, and national and international stakeholders to identify priority areas for public health research that can be addressed using EU surveillance data.

***Impact on Member States***

Member States could choose between different degrees of involvement ranging from silent agreement to the most active contribution and even project leadership. Any more active involvement would require some national resources, but could yield international research experience that might in turn inspire a more scientific use of surveillance data within the Member State.

***Risks and mitigation***

Member States may show little interest or have insufficient capacity to join this collective effort. Some may even refuse to make their surveillance data available for any third-party research. ECDC would then work with those willing and able to collaborate and, provided they are reasonably representative, extrapolate possible findings to the EU.

## **5.4 Strengthening capacity in surveillance**

### **Target 14: ECDC works effectively with the Commission, World Health Organization and other agencies to promote the development of a European culture that supports maintenance and development of effective Member State surveillance systems and avoids overlap or duplication.**

***European added value***

The right culture will enable European-level policies, programmes, targets, and applied research projects that support the maintenance and development of Member States' surveillance systems and collaboration in these areas between countries. Avoiding duplication of reporting will increase efficiency.

***Strategy***

- 1** ECDC acts as a voice of advocacy for the public health value of surveillance, providing clear evidence in support of its advocacy and for the further strengthening and development of EU capacity in surveillance.
- 2** ECDC gives advice on and facilitates suitable projects, including applied research, that would benefit the Member States.
- 3** ECDC works closely with the Commission, WHO and other agencies to promote and coordinate the requirements made of Member States for reporting of data.
- 4** ECDC provides technical advice on training for key staff working with the surveillance system, including in-country assessments where required.

### **Impact on Member States**

Member States should benefit substantially from a European culture more supportive of communicable disease surveillance. For some initiatives, Member States may be expected to commit some local resources to set up systems in order to avoid duplication of reporting. However, the reduction of any duplication of data requests will certainly have a positive impact by making more efficient use of the meagre surveillance budgets in the Member States.

### **Risks and mitigation**

Proposals and developments of potential benefit to countries may not be achieved due to failure to reach agreements with other European-level agencies. Mediation could possibly be provided by the European Commission.

It may furthermore not always be feasible to keep track of all the new requests for communicable disease data that any of the other agencies makes. ECDC could solicit that information from the Member States at regular intervals.

## **5.5 Controlling expansion**

In the light of shrinking public health resources across Europe, careful consideration will be given before suggesting the inclusion of any new data to be reported, e.g. expanding molecular typing and other laboratory-based EU/EEA surveillance, collecting additional enhanced surveillance data or adding new diseases or conditions.

### **Target 15: Routine molecular typing for surveillance of selected pathogens is fully established at European level.**

This target assumes a decision to continue the collection of molecular typing data for multidrug-resistant TB, salmonella, VTEC and listeria beyond December 2013, when the existing pilot project for these pathogens will be reviewed. Other pathogens may also be included, if this is agreed between ECDC and the Member States.

#### **European added value**

For some pathogens, there is a need for integration of advanced molecular typing data with epidemiological data to improve surveillance and epidemic preparedness. The European added value is very disease-specific, but some of the key values are typically to rapidly detect dispersed or low-level international clusters/outbreaks, to investigate transmission chains and relatedness of strains across Member States and globally, to detect the emergence of newly evolving pathogenic strains (including antimicrobial resistance), to trace the source of an outbreak and to aid in studying the characteristics of a particular pathogen and its behaviour in a community of hosts.

#### **Strategy**

- 1** Based on feedback received from the projects for multidrug-resistant TB, salmonella, VTEC and listeria, ECDC reviews and, where necessary, revises the 'ECDC roadmap for integration of molecular typing into European level surveillance and epidemic preparedness'. Subsequently, the roadmap is reviewed annually.
- 2** ECDC and the Member States agree on molecular typing data access and use, publication rights, data management, sampling models and data reporting pathways and frequencies.
- 3** ECDC and relevant external stakeholders continually review and improve the technical platform(s) (TESSy and/or potentially others) for collecting molecular typing data to facilitate easier submission and provide useful analysis tools.
- 4** In collaboration with the Member States, ECDC regularly reviews the public health objectives for collecting and analysing molecular typing data at the EU level to ensure full alignment.
- 5** In collaboration with the Member States, ECDC follows the four-step process described in the 'ECDC roadmap' when considering molecular typing data collection for additional pathogens.
- 6** As a basis for discussion with the Member States, ECDC produces a plan for how to handle the rapidly emerging next generation of sequencing methods.

### **Impact on Member States**

Member States will be asked to provide input on the potential implementation of molecular typing for EU/EEA surveillance of any new pathogens, in accordance with the agreed process. Following any agreement to pursue EU-level data collection, Member States will be asked to provide typing data. Their input will also be sought when addressing the anticipated shift towards next-generation sequencing techniques.

### **Risks and mitigation**

Lack of resources available for molecular typing will require careful consideration and prioritisation by ECDC and the Member States in order to create a sustainable system. Some Member States may be prevented by national and/or regional legislation from linking molecular typing data with epidemiological case data for some (or all) pathogens. Typing methods require external quality assurance to ensure data compatibility, and this will be addressed through the disease networks for each pathogen in question. An overarching risk is that with greater

reliance on typing methods, fewer cultures will be carried out leading to less data comparability between Member States and with historical data.

## **Target 16: Relevant alternative data sources for surveillance and early threat detection have been explored and, if found to add value, are ready to be incorporated and used.**

### ***European added value***

Access to, and linkage with, a variety of pre-existing databases may enable more effective detection of EU treats, especially those caused by new syndromes and pathogens, or of unusual disease trends. The main advantage would be the relatively low cost of using data already collected for other purposes and possibly also improved timeliness of threat assessment. Furthermore, linking to other databases can possibly be used to test hypotheses of public health relevance such as: 1) effectiveness, impact and/or safety of interventions (e.g. vaccines), or 2) analyses of risk factors for disease occurrence (e.g. ecological studies, cohort studies, nested case–control studies). Existing datasets may contain much more comprehensive information than surveillance records; however, their value could be limited by data quality issues and, in some instances, data protection issues.

Additional data sources especially relevant for early threat detection are often based on monitoring health/disease information-seeking behaviour (usually through the internet) and/or healthcare utilisation patterns applying syndromic surveillance principles. Another possible source of information is social media monitoring. The main advantages of these systems are their timeliness, low cost, and the fact that they are often population-based, non-confidential and easily accessible. However, the true public health value of utilising such alternative (indirect) data sources has yet to be fully established.

Certainly more accurate estimates of disease burden are known to be possible by combining multiple data sources and using standard capture-recapture methods for estimation of underreporting. Specific studies can also be conducted from time to time, such as point prevalence surveys. These studies should be conducted in a sample of countries and results could be extrapolated to the wider region.

### ***Strategy***

- 1** In collaboration with the Member States, ECDC specifies the most relevant objectives of the potential analyses to be performed.
- 2** ECDC identifies and categorises possible data sources for such analyses in the EU (i.e. any datasets that may contribute to rapid threat detection and/or generation of relevant evidence for communicable disease prevention and control).
- 3** ECDC develops analytical standards and clear case/event definitions.
- 4** ECDC evaluates data sources for ease of access, data quality (timeliness, completeness, validity) and possibilities for linkage with other data sources and analyses with a different scope. ECDC shares these findings with the Member States.
- 5** Following agreement with the Member States, ECDC creates a suitable infrastructure (data warehouse) for rapid analyses, and, in collaboration with the Member States, establishes the required triggers, rules, responsibilities and timelines.
- 6** ECDC explores other alternatives to passive indicator-based surveillance, such as repeated population surveys or ad hoc epidemiological studies.
- 7** ECDC explores the public health value of monitoring relevant internet queries and social media.

### ***Impact on Member States***

There should be less demand for traditional or manual data reporting by Member States for those surveillance activities that can be enhanced by use of these alternative sources of data. However, the true impact of these innovative measures is difficult to estimate at this stage. Member States may be asked to support prevalence or capture–recapture studies conducted in their country, and this may require some resources and investment.

Replacing some of the passive surveillance reporting with repeated surveys or other epidemiological studies may require some investment of human and financial resources for the development of common protocols, setting-up of study teams, collection, pooling, analysis and dissemination of data, monitoring of study sites, adherence to protocols, organisation of meetings, etc. High quality outputs from well-designed multi-centre studies, however, are likely to generate information that is more useful for Member States than passive surveillance data. In most instances, studies could include a representative group of EU countries. Results could then be extrapolated and widely shared, thus potentially further reducing the burden on Member States.

### ***Risks and mitigation***

Member States may face significant data protection problems in allowing extraction and analysis of some of these datasets. Database linkages would need to be set up in accordance with the European Directive on the personal data confidentiality and safety (EU Data Protection Directive 95/46/EC). Access to and links between the various databases also require the approval of an ethical and good practice body. If this is not anticipated, long delays may render the analysis unsuitable for rapid threat detection and assessment. To overcome this problem,

pre-approval by national ethical committees could be sought for specific analyses and/or analyses could be limited to aggregate data.

Furthermore, when using electronic databases, the external validity would need to be verified. The population included in the database may not be representative of the general population. If the reason for non-inclusion in the database is related to the occurrence of the outcome, the results obtained would be biased.

Prevalence or capture–recapture studies may be difficult to implement in Member States facing a lack of resources. ECDC may help them by involving EPIET fellows.

## 5.6 Monitoring the long-term surveillance strategy

### Target 17: The implementation of this strategy is monitored and reported to the Member States on an annual basis.

#### *European added value*

Progress towards the targets of this strategy is formally monitored, assessed and communicated once every year. Both ECDC and the Member States are reminded of what has been achieved and what remains to be accomplished. Reasons for delays, indications for strategy changes or more fundamental issues will be identified and tackled in a timely manner. In addition, at the half-way point, a more global evaluation will offer an opportunity for adjustments that may need to be made in the light of any emerging priorities.

#### *Strategy*

- 1 ECDC produces a roadmap for implementing this strategy, identifying milestones to be reached every year.
- 2 These milestones are reflected in ECDC's annual work plans and are allocated appropriate resources.
- 3 Towards the end of each year under this strategy (2014–2020), ECDC assesses what progress has been made in reaching the milestones. The findings are reported to ECDC senior management and the Member States through their national surveillance focal points.
- 4 In 2017, ECDC evaluates this strategy for any adjustments or modifications that may need to be made in the light of any emerging priorities.

#### *Impact on Member States*

Member States receive annual updates on the strategic progress of European communicable disease surveillance and contribute to the discussion on any adjustments necessary to keep it relevant for their needs.

#### *Risks and mitigation*

Staff time allocated to achieving the milestones of this strategy will not be available for disease programme work. The possibility of contracting out elements of the monitoring and evaluation of this long-term surveillance strategy, especially the mid-term evaluation, will be considered.

# Annex: Surveillance – value, goals and objectives

## Added value of surveillance

The main points outlining the added value of surveillance at the European level were presented in the MB11/14 Rev.1 document on the previous long-term strategy, and they remain relevant for this strategy. In summary, the main added value is to:

- improve the regional comparability of data;
- reduce the complexity of surveillance across the EU;
- enable surveillance to be tackled in a synergistic way;
- avoid duplication of work;
- provide better quality public health evidence in the long term, based on more relevant and reliable data;
- make it easier to strengthen the national surveillance systems;
- be economically more efficient and sustainable;
- allow easier access to and use of the data;
- enhance the detection and monitoring of international outbreaks;
- contribute to capacity building;
- ensure the inclusion of communicable diseases in the surveillance and research agenda according to evidence-based EU priorities.

## Surveillance goals and tasks

The overall goal of surveillance is to contribute to reducing the incidence and prevalence of communicable diseases in Europe by providing policy advisors, decision makers and healthcare professionals with relevant and timely public health evidence based on reliable data. The ultimate goal is to promote effective action that will result in the prevention and control of communicable diseases in Europe.

When done effectively, surveillance can contribute to the timely identification of potential outbreaks (early warning) and trigger action to control them; identify longer-term trends to help better inform the allocation of resources to meet changing disease conditions and determinants; and assist the planning or adjustment of disease control programmes and their priorities and objectives to make them more effective (programme science). Good surveillance data can also be used to evaluate interventions and prevention or control programmes and even provide information for planning or conducting future research.

The surveillance tasks of ECDC, as detailed in Regulation 851/2004/EC are to:

- collect, collate, validate, analyse and disseminate relevant data at EU level;
- cooperate with the competent bodies in the Member States;
- develop procedures to facilitate consultation and data transmission and access with the Member States and the Commission;
- evaluate prevention and control measures at EU level;
- closely cooperate with the organisations operating in the field of data collection from the Community, third countries, WHO, and other international organisations;
- develop sufficient capacity to detect and characterise infectious agents and encourage collaboration between laboratories;
- operate the dedicated surveillance networks;
- maintain the database(s) for epidemiological surveillance; and
- develop the statistical element of this data collection in collaboration with Member States to promote synergy and avoid duplication.

Apart from this direct mandate, ECDC is an agency of the European Union. As such, it is committed to supporting the EU Public Health Programme and the actions of the European Commission's Directorate-General for Health and Consumers and to contribute to evidence-based public health decision making throughout the EU. The Commission's Health Threats unit are responsible for the risk management of communicable disease threats which ECDC supports through risk assessments based on surveillance data and other evidence.

## General and disease-specific surveillance objectives

ECDC distinguishes general surveillance objectives, that apply to all the diseases and special health conditions under surveillance at EU level, and disease-specific objectives that relate to an individual disease's specific features.

The general objectives are:

- Monitor trends in communicable diseases over time and across Member States to assess the present situation, respond to rises above warning thresholds and facilitate appropriate evidence-based action.
- Detect and monitor any multinational communicable disease outbreaks with respect to source, time, population and place in order to provide a rationale for public health action.
- Contribute to the evaluation and monitoring of prevention and control programmes targeted at communicable disease surveillance in order to provide the evidence for recommendations to strengthen and improve these programmes at the national and European level.
- Identify population groups at risk and in need of targeted prevention measures.
- Contribute to the assessment of the burden of communicable diseases on the population using such data as disease prevalence, complications, hospitalisation and mortality.
- Generate hypotheses on (new) sources, modes of transmission and groups most at risk and identify needs for research and pilot projects.

Disease-specific objectives will usually include:

- identification of trends over time or evaluating the impact of public health measures on these trends;
- support for determining aetiology;
- setting of priorities, including for research;
- determination of modes of transmission;
- clarification of risk factors associated with the disease and possible opportunities for prevention or control
- detection of low-grade outbreaks or epidemics;
- monitoring the quality of care and patient outcomes;
- recognising drug resistance among infectious disease agents;
- identification of underserved populations, and planning services.

The general objectives for surveillance are reviewed with all stakeholders periodically (every 3 to 4 years) in order to ensure that they remain relevant. The disease-specific objectives for surveillance are reviewed on an annual basis by the disease networks.