ECDC Advisory Forum

# Minutes of the Fifty-seventh meeting of the Advisory Forum

## Stockholm, 14-15 May 2019

# Contents

# Opening and adoption of the programme (noting the Declarations of Interest and Specific Declarations of Interest, if any)

1. Andrea Ammon, Director, ECDC, opened the meeting and welcomed all participants.

2. Mike Catchpole, Chief Scientific Officer, ECDC, greeted the AF and welcomed Ms Inese Sviestina, the representative from the European Association of Hospital Pharmacists. Apologies were received from Cyprus, Iceland, Slovakia, and Spain. In addition, the following countries did not attend the meeting: Bulgaria, Greece, and Poland. Mike Catchpole asked about any specific conflicts of interest; none were declared.

# Adoption of the agenda

3. The agenda was adopted with one additional request by Kevin Kelleher, AF Member, Ireland, for the topic of measles to be added to the agenda, which was confirmed. A brief update on rabies in Norway (Frode Forland, AF Member, Norway) had also been added to the agenda.

# Adoption of the draft minutes of the 56th Meeting of the Advisory Forum (19-20 February 2019)

4. The draft minutes were adopted without amendment.

# Lyme disease – country support needs potentially arising from implementation of neuroborreliosis reporting

5. Tamás Bakonyi, Head of Programme, Emerging and Vector-borne Diseases, ECDC, presented on Lyme borreliosis[1], as Lyme neuroborreliosis had recently been added to the list of EU reportable diseases. After a brief historical overview of ECDC's activities in this area (expert consultations, fact sheets, communications toolkits, etc.), he focused on surveillance. For Lyme neuroborreliosis EU level surveillance has been recently introduced, as this is the most significant manifestation of the disease, and also relatively easy to confirm. Unfortunately, there remains a lack of a gold standard diagnostic method for borreliosis, and there is no standard case definition currently in use by clinical services in all EU/EEA Member States. It was noted that, in addition, there were no clear, standardised treatment protocols in Europe, and many healthcare providers have not adopted existing treatment guidelines. The European Parliament resolution of 15 November 2018 on Lyme disease (borreliosis) (2018/2774(RSP)) called for a number of measures with regard to diagnostics, uniform case definition, mandatory surveillance and prevention guidelines. ECDC will evaluate the data of the 2018 Lyme neuroborreliosis surveillance (reported to TESSy until 31. May 2019) and will provide assistance to the Member States for improvement. Additionally, ECDC will investigate the possibilities of implementing the calls of the European Parliament resolution. These activities will involve temporary consultation services of Lyme disease experts. The floor was then opened for discussion.

6. A number of AF Members reported that borreliosis surveillance was already established in their country, although it was also noted that in several of these countries problems had been identified with regards to the validity of reported diagnoses and in differentiating the different clinical manifestations (to the extent that in one country neuroborreliosis was currently no longer reported).

7. The need for clear treatment guidelines was emphasised by a number of AF Members. Examples were given of the problems of defining and implementing such guidelines, including the occurrence of heated public discussion with regard to treatment options (e.g. the benefits of longer versus shorter treatment regimens), and legal objections to the publication guidelines in one country.

8. It was noted by several AF Members that Lyme disease was the subject of strong lobbying by patient groups, although at least one Member reported that there was no such public attention in their country, and concerns were raised that making borrelioisis reportable at the EU level might result in further activity by lobbying groups, and thus clear and careful communication of the results would be important in order not to make the situation more difficult in some countries. In this respect, Rebecca Moore, Observer, European Institute of Women's Health, expressed support for a dialogue with patient group representatives. Kåre Mølbak, AF Member, Denmark, mentioned a Danish TV documentary that followed the experiences of a group of perfectly healthy Danish journalists who were tested for Lyme disease in Germany. All tested positive for the disease and were urged to

[1] Lyme Disease – country support needs potentially arising from implementation of neuroborreliosis reporting (T Bakonyi)

spend substantial amounts of money for treatment. This had immediately ended the debate on Lyme as an 'underdiagnosed disease' in Denmark.

9. Frank Van Loock, EU Commission, Directorate-General for Health and Food Safety, said that this debate needed proper science more than anything else. The Commission's Directorate-General for Research and Innovation was already working on diagnostic issues. He also thought that focussing only on neuroborreliosis cases was helpful to obtain reliable incidence data while avoiding too many diagnostic concerns. If Member States had problems collecting these data, they should receive additional support.

10. Overall, mixed opinions were expressed about the added value of implementing EU level surveillance of neuroborreliosis, with some members expressing support, and others suggesting that in-depth epidemiological studies might be a more valuable approach. There was, however, more general support for a survey of the feasibility of different approaches to surveillance, and an agreement that better information on the epidemiology of borreliosis was needed.

11. Masoud Dara, WHO Regional Office for Europe, said that 'What gets measured gets done', emphasising the relevance of identifying clear, measurable issues and supporting them with data. He also expected that case numbers (80 000 cases/year in the WHO European Region) would rise further, mostly due to climate change.

12. Mike Catchpole, Chief Scientist, ECDC, summarised the discussion and said that the public health and political issues could not be ignored. Monitoring with greater diagnostic precision was possible for neuroborreliosis, but even for neuroborreliosis, the most precisely diagnosable form of Lyme disease, there were challenges to overcome. Information for action was needed to address real and perceived concerns. He also noted parallels between unfounded public fears about Lyme and vaccine hesitancy. He recommended engaging in a dialogue with the general public and patient groups. He reassured the Austrian AF member that ECDC had no plans to extend surveillance to other forms of Lyme, despite the European Parliament's resolution.

13. Andrea Ammon, Director, ECDC, felt reminded of the situation 20 years ago when problems with diagnostics and patient groups were very similar. The patient–doctor dialogue, she said, should be put on a different footing, and trust between science, doctors, and patients had to be re-established. In addition, behavioural and social aspects had to be taken into account in the debate, hopefully leading to an approach that transcended simple surveillance.

**Conclusions and Actions**

ECDC will engage with and support Member States in the implementation of the surveillance of neuroborreliosis, as required in the most recent update to the list of EU-reportable diseases. ECDC will investigate the possibilities for the standardisation of diagnostic methods and improvement of estimation of Lyme disease burden in the Member States.

## Evaluation of IRV Disease Programme including EPHESUS Evaluation of EU/EEA surveillance of influenza

14. Pasi Penttinen, Head of Disease Programme, Influenza and other Respiratory Diseases, Office of the Chief Scientist, presented the results of the evaluations[2] and the floor was opened for comments on the validity of the findings and the priorities for response.

15. There was a wide-ranging discussion of the report, with a clear consensus that the report provided an accurate and comprehensive evaluation of the Disease Programme, and that it demonstrated that ECDC's work on influenza was providing added value for Member States. A number of other points were made during the discussion, including:

16. A number of AF Members commented that ECDC's focus with respect to influenza vaccination should be on gathering and synthesising evidence on the effectiveness of different policy options and leave the actual programme decisions to the countries themselves rather than focussing on communication materials and advocacy for increased vaccination coverage, decisions on which are the responsibility of Member States.

17. A few AF Members questioned whether ECDC should be doing more with respect to Respiratory Syncytial Virus (RSV) in view of the likelihood of vaccine availability in the near future. Mike Catchpole, Chief Scientist, ECDC, reminded the AF that respiratory syncytial virus had previously been discussed and the consensus was that it was a challenge and not to be actively pursued at present. He also noted that RSV was not as yet on the EU list of diseases for which reporting was mandatory. It was noted by another AF Member that the RESCEU project, which

[2] Influenza and ORV DP: EPHESUS and Disease programme evaluation (P Penttinen)

is being administered by SSI and RIVM, would provide outputs relevant to RSV monitoring in preparation for any vaccine in the coming years.

18. One AF Member suggested that there was one gap in the report relating to changing testing behaviour in the healthcare system, noting that systems were not sufficiently prepared for the introduction of point-of-care testing (which represented up to 30% of positive tests in Denmark), how it would influence results and what this would mean in the future.

19. Other areas that were each noted by at least one AF Member as potential topics for further development included: assessments of the burden of influenza disease; strengthening and standardisation of surveillance of severe disease; assessment of the effectiveness of control measures overall; guidance on methods, including which testing methods to use and how to determine the number of tests required for a given population size; and expansion of virological surveillance.

20. Frank Van Loock, European Commission, referring to the Member States' input on the surveillance data, believed that there were still weaknesses in some places where further guidelines and support could be useful to help identify problems. With regard to surveillance for other respiratory viruses, he pointed out that there was no legal limitation on ECDC to take this forward. The guidelines mentioned in the two reports highlighted the need to have gold standards in order to determine what the mutual expectations were, but overall ECDC's Influenza Programme had shown its benefits and strengths over the years.

21. Masoud Dara, WHO Regional Office for Europe, thanked ECDC for the excellent cooperation in this area over the years.

22. Mike Catchpole, Chief Scientist, ECDC, noted that the most common theme was the added value from reviewing the impact of interventions and how to make evidence on various intervention strategies, including vaccination strategies, available at European level. He noted the comments on surveillance and the changing landscape in testing, the importance of strengthening mortality surveillance and the value of guidance on virological monitoring and testing. With the advent of an RSV vaccination in the future, it would be important for the Member States to undertake surveillance, but the role of surveillance at EU level was still unclear and there was no compelling reason to take resources away from influenza to deal with that issue. He thanked the participants for their input.

23. Pasi Penttinen, Head of Disease Programme, Influenza and other Respiratory Diseases, Office of the Chief Scientist, thanked the AF for its positive feedback on disease programme. With regard to the need for overall control measures and ECDC's role, ECDC was collating information on measures that could be useful for Member States. With regard to scientific support for vaccination strategies, ECDC efforts in the near future would focus extensively on priorities defined by National Immunisation Technical Advisory Groups (NITAGs) in Member States, as part of ECDC's NITAG Collaboration Project. He agreed that point-of-care tests were changing the landscape for laboratory surveillance and was aware that everyone was finding this challenging. Increasing numbers of respiratory viruses were being detected by clinical testing so it was quite possible that in the future it would be necessary to think more about respiratory disease surveillance based on SARI/ICU surveillance involving a range of pathogens. He noted that RSV surveillance remained a topic of discussion, and reiterated that the IMI funded project RESCEU led by RIVM and SSI was working on providing guidelines to Member States. He observed that for the surveillance to be useful it would be necessary to have surveillance programmes running in those countries where the new vaccine was to be introduced in sufficient time to establish a baseline before the vaccine was introduced in order to have comparison data.

**Conclusions and Actions**

ECDC will take into account the feedback provided by the Advisory Forum in formulating its plans for responding to the conclusions of the Evaluation Reports on Influenza surveillance and on the Influenza and Respiratory Viruses Disease Programme.

## Evaluation of Food and Waterborne Disease Programme

24. Johnna Takkinen, Head of Disease Programme, Food- and Waterborne Diseases and Zoonoses, Office of the Chief Scientist, ECDC) presented the results of the evaluation[3] and the floor was opened for comments on the validity of the findings and priorities for response out of the seven recommendations.

[3] Evaluation of FWD programme (J Takkinen)

25. There a clear consensus that the report demonstrated that ECDC's work on food and water borne diseases was providing added value for Member States. A number of other points were made during the discussion, including:

- A wish to see better communication with stakeholders and with EFSA to harmonise the slightly different approaches as sometimes reports were delayed that were needed for public health action.
- Views were expressed that training courses were too focused on the laboratory aspects of whole genome sequencing and bioinformatics and that instead there should be more training for epidemiologists and microbiologists on how to proceed, use and analyse WGS data and on the more basic aspects of field epidemiology.
- Given the very few cases Creuzfeldt-Jakob disease, which still came within the scope of the food and waterborne programme, that arose, it was questioned whether the level of investment in risk monitoring and response was proportionate.
- There should have been more analysis and emphasis on EPIS in the evaluation report, as Member State colleagues found this tool to be particularly useful.

26. Mike Catchpole, Chief Scientist, ECDC said that in both DP evaluation reports there were comments about it being unclear how feedback from stakeholder groups was taken on board by the Disease Programmes. He therefore wondered if any of AF members had ideas on how to improve this. He also asked if anyone had concerns about how ECDC took on board AF advice. No opinions were expressed in response to these questions.

27. Frank van Loock, European Commission, said that he believed that the legionnaires network would need to be further refined and he asked the AF to consider how to achieve this. He also noted that delays in co-production of reports with EFSA had in the past been due to EFSA's internal processes and since 2019 this situation was supposed to have improved so he was interested in obtaining feedback on whether this was the case. He also noted that he felt there was insufficient in-depth analysis in the report on EPIS which was a very important tool. He expressed concern that often information involving food products communicated through EPIS did not reach the food authorities through the appropriate reporting channels. He therefore asked ECDC to moderate in EPIS where possible, to ensure that food-related information reached the appropriate authorities in the future.

28. Mike Catchpole, Chief Scientist, ECDC, suggested that Creuzfeldt Jakob disease would be a good topic for discussion in the AF in the near future. With regard to the emphasis being given to WGS in the area of training and capacity development, he pointed out that WGS was one of the largest developments in diagnostics for many years, although he took the point that it was important not to lose sight of other aspects of epidemiology and infection control.

29. Johanna Takkinen, Head of Disease Programme, Food and Waterborne Diseases and Zoonoses, ECDC, thanked the AF for the feedback on the added value of the work of the Disease Programme and noted that Member States had also been instrumental in delivering this added value. Communication with EFSA had indeed improved greatly over the past two years and EFSA now had a permanent mandate to respond to joint rapid outbreak assessments which had reduced the waiting time. With regard to training and the focus on WGS, she pointed out that it was the fundamental basis for all future work in the field of epidemiology which was why it was so important for the countries to have this capacity and capability. She agreed that it would be useful to add EPIS to the report. Regarding the comment by the Commission representative on the sharing of food information, this was a challenge but one key objective was constantly trying to foster collaboration between the food and public health sectors and this was improving slowly and there was now more cross sectoral collaboration, with the result that the territorial thinking was gradually disappearing.

**Conclusions and Actions**

ECDC will take into account the feedback provided by the Advisory Forum in formulating its plans for responding to the conclusions of the Evaluation Report on the Food and Waterborne Disease Programme, and will bring a paper to a future Advisory Forum meeting to seek advice on the approach it should take to its work related to CJD.

# ECDC Surveillance and Response Support: update on Epidemic Intelligence and response support activities

## *Ebola Update*

30. Vicky Lefevre, Acting Head of Unit, Surveillance and Response Support, ECDC, began by giving an update on the situation with Ebola in the Democratic Republic of the Congo[4] and the floor was then opened for discussion.

31. In response to a question from an AF Observer, Frank Van Loock, European Commission, said that the Commission was working with the DRC in accordance with its Strategic Response plan via the DRC Ministry of Health and through the intermediary of WHO. The main areas where financial assistance was provided were in relation to access to healthcare and diagnostics; supporting community screening facilities; infection prevention and control; support to community engagement and humanitarian assistance to survivors. One aspect was providing humanitarian assistance in the form of ECHO flights from Kinshasa to the affected areas carrying passengers, cargo and personnel (84 flights so far since 1 August 2018). EU humanitarian experts had been deployed to DRC on short-term assignments, including one ECDC colleague in December 2018. The EU Civil Protection mechanism had been activated twice, once in August 2018 and once in April 2019. Under this mechanism Norway had dispatched a team to train people in the use of high-tech isolation units for medical evacuation. The EU was financing 85% of the transport costs for this assistance. EU humanitarian funds had also been provided to reinforce preparatory and prevention measures in countries bordering the affected regions. So far EUR 175 000 had been provided to Burundi, Rwanda, South Sudan and Uganda. Over EUR 160 million had been provided towards the development of Ebola vaccines – both the existing vaccine (Zebov) and the new (NVA) vaccine which would soon be available from Johnson and Johnson. A total of EUR 7 million had been provided for Ebola treatments and diagnostics tests. The EU and developing countries clinical trial partnership, EDCTP, had provided EUR 2.2 million in emergency research funding for Ebola virus disease and five projects had been launched. DG SANTE had conducted a survey in 2018 to see how many Member States would be willing to accommodate returning international aid workers and received positive responses from 22 countries, of which 8 were willing to accommodate returnees without restrictions. The operational mode of this medical evacuation facility would soon be tested through EWRS. There were a number of limitations that had caused some NGOs to pull their teams out of area and this had left gaps in the delivery of support at local level. A number of experimental treatments were also being funded and research networks engaged.

32. In response to a question from an AF Member on further ECDC actions and security issues, Vicky Lefevre, Acting Head of Unit, Surveillance and Response Support, ECDC said that ECDC's main role was to provide scientific support in terms of regular risk assessment updates and inform on the state-of-play through the weekly Communicable Disease Threat Reports (CDTR) and the daily Round Table Reports. ECDC had deployed one expert earlier in the outbreak last year, but the security risks were too great and DG ECHO was not considering any further deployments at present. She also said that the access and security situation was still a major concern. DRC Ministry of Health personnel and health care workers operating in the area were currently being accompanied by the military. However, this had not decreased the attacks nor had it improved the situation.

## *Measles Update*

33. Lucia Pastore Celentano, Head of Disease Programme, Vaccine-preventable Diseases, ECDC, gave an update on the situation with measles[5].

34. Comments and questions from AF Members included:

- ECDC's rapid risk assessments were noted to be useful and comprehensive tools in efforts to tackle measles immunisation.
- How had WHO decided on its measles elimination aims and why the target date had been set for 2020, since this had resulted in critical feedback and a loss of credibility.
- To what extent does ECDC coordinate its rapid risk assessments and analysis with WHO reporting/indicators, since ECDC appeared to be focusing on different aspects from WHO, and it would be more efficient if the two organisations agreed on the most appropriate indicators for success, etc.
- More specific questions to ECDC included:

[4] Update Ebola virus disease (EVD) outbreak in Ituri and North Kivu Provinces, Democratic Republic of Congo, 2018-2019 (V Lefevre)
[5] Who is at risk for measles in EU/EEA? (L Pastore Celentano)

- What information is available on mortality?
- In view of the fact that in one Member State it had been found that 20% of those affected had been vaccinated with two doses, what is known about the infectiousness of those vaccinated?
- With regards to recommendations on vaccination of infants prior to travel, it was pointed out that when vaccinating at six months the level of immunity conferred was lower than when it was done later, and ECDC was asked for more information on the recommendation for infants.
- What is the overall proportion of measles cases in Europe that were imported?

35. Masoud Dara, WHO Regional Office for Europe agreed that the numbers were not encouraging but this should not mean it was not possible to have elimination targets in the future, especially given that a vaccine was widely available. On 6 May 2019, WHO had conducted an internal assessment and determined measles as a health emergency grade 2. This meant that further resources could be mobilised and it also gave a message to the countries that that the situation was unacceptable and more needed to be done. In the WHO European Region there had been more than 117 000 measles cases since January 2018, and 34 000 in the first two months of 2019, with over 90 deaths since 1 January 2018, indicating that current tactics were not working. The WHO European Region was the only one where a Grade 2 emergency response had been declared for measles. Countries identified as priority were Bosnia & Herzegovina, Georgia, Israel, North Macedonia, Kazakhstan, Kyrgyzstan, Serbia, Romania and Ukraine. WHO was attempting to identify the pockets of unvaccinated people in these countries and see what could be done to reach out to them.

36. Lucia Pastore Celentano, Head of Disease Programme, Vaccine-preventable Diseases, ECDC, replying to comments, said that its assessment was based on the latest WHO position paper from 2017 and the SAGE document 'Roadmap to immunity'. ECDC was always invited to the Regional Verification Commission and was therefore fully involved in the revision of data. The elimination framework revolved around the distinction between endemic cases and imported cases. This was challenging because in the EU with its open borders it was much easier to eliminate measles at country level than at regional level. In answer to a question on the number of imported cases in Europe, she said that only 4% of cases were imported. Moreover, countries were often unable to trace the origins of cases adequately to determine whether they were imported. Europe had a huge number of susceptible people (adults) who missed vaccinations 20 or 30 years ago so one possible solution would be to identify gaps in each group. For example, there was a large proportion of unvaccinated people in the adult 30+ years age group. In response to a question on mortality, she said that there had been 84 deaths in the last three years and 45% were in infants under one year who were too young to be vaccinated. She confirmed that there is good evidence that vaccinated cases are much less infectious. Anders Tegnell, AF Member, Sweden, added that a recent paper published in Gothenburg, Sweden concluded that the contagiousness of those vaccinated against measles was extremely low. In response to the question about the vaccination of infants before travel, Lucia Pastore Celentano noted that the dose given to children travelling when under six months was a low dose and children still had to receive two doses in-country.

37. In response to a follow-up question on whether the beginning and/or end of the school cycle should be used as an opportunity to check for vaccination status or provide vaccinations and whether a third booster at the age of 18 should be recommended, Mike Catchpole, Chief Scientist, ECDC said that this was a cost-benefit risk ratio question and was a country-dependent issue. There was no specific answer suitable for all of the EU.

### *Rabies*

38. Frode Forland, Observer, Norway, gave a short presentation on recent rabies cases in Norway and the floor was then opened for discussion.

39. Mike Catchpole, Chief Scientist, ECDC said that Public Health England had extensive algorithms available for the management of rabies contacts and exposures and encouraged members to contact colleagues from Public Health England if they were interested in these.

## Virtual country visit to Croatia

40. Aleksandar Šimunović, AF Alternate, Croatia gave a presentation on the activities of the Croatian Public Health Institute focusing on the measles outbreak in Croatia in 2018, and preparedness activities related to the Ebola outbreak in West Africa (2014-16) and DRC (2018-19)[6].

[6] Virtual country visit to Croatia (A Šimunović)

## E-health network - DG CNECT and DG SANTE

41. Monika Lanzenberger, Head of Sector, Research Coordination, DG Communication Networks, Content and Technology, European Commission and Katja Neubauer, Senior Expert, Digital Health Unit, DG SANTE, European Commission, gave a presentation of their current activities in the area of the e-health network and cross border exchange of digital health data and plans for the future.[7] [8]

42. Carlos Matias Dias, AF Member, Portugal said that in recent years the Portuguese government had created a new agency devoted to health information which had now set up a national network enabling citizens to get their prescriptions via mobile phones, doctors to access clinical records and providing access to a summary of health information in a 'health wallet'. There were several apps currently available and every citizen could now access their health portal by using a digital key. The popularity of the service was growing fast. In the health sector the main problem was that data had to be manually entered and this caused problems for doctors, nurses and hospital personnel who had to spend too much time on administration.

**Day Two**

## Advisory Forum Working Group topic: E-health and how Member States can benefit from initiatives in this area

43. Bruno Coignard, AF Alternate, France, presented the findings from Working Group B.[9] The floor was then opened for comments.

44. Kåre Mølbak, AF Member, Denmark, said that in Denmark they had developed a national real time system of surveillance for healthcare-associated infections and surgical site infections which had been well received in hospitals and data had now been integrated into the quality systems of hospitals, management systems and infection unit systems. Open websites meant that patients were able to see the incidence of these infections in real time online so it was a very transparent system. The case definitions were based on data in the registries. It was important to coordinate this approach as increasing numbers of countries would be introducing similar systems and ECDC had a role to play in developing those systems and stimulating the exchange of experience.

45. Andrea Ammon, ECDC Director, said that this was a good example of how the way in which data was gathered, analysed and interpreted would change and this aspect would need to be taken into account alongside the results of the EPIET evaluation when available.

46. Marta Grigič-Vitek, AF Alternate, Slovenia, presented the findings from Working Group A and the floor was then opened for comments.[10]

47. Monika Lanzenberger, Head of Sector, Research Coordination, DG Communication Networks, Content and Technology, European Commission said that participating in the Working Group had been very interesting. She pointed out that e-health solutions were increasing in their variety as the digital environment was broadening and expanding.

48. Katja Neubauer, Senior Expert, Digital Health Unit, DG SANTE, European Commission said that the examples mentioned, such as that from Portugal, showed that many technological aspects of e-health were already working in practice in our daily lives.

49. There was a wide-ranging and active discussion following the presentation of the two groups. A number of common themes were raised by AF Members, including in particular:

50. The need to ensure that public health, including public health as it relates to the prevention and control of infectious disease, needed to be more engaged in the design and implementation of e-health solutions; it was observed that currently the main driving force for e-health was not within the field of public health and, and that the main focus of e-health was now one-to-one relationships (doctor-to-patient or service-to-service) and it was necessary to demonstrate that group/population problems were just as important as individual level questions. It was suggested that it would be useful to have a clearly formulated vision and a common understanding of what e health entailed in relation to infectious diseases (ideally in a very concise form), and that such a higher-level vision was required as individual groups would never solve the problem on their own. It was also suggested that in this

[7] The Digital Transformation of Health and Care (M Lanzenberger)
[8] E-health DG SANTE (K Neubauer)
[9] E-health and how MS can benefit from initiatives in this area – WG B report (B Coignard)
[10] Opportunities and challenges in realisation of benefits of E-health initiatives for public health – WG A (M Grigič-Vitek)

respect ECDC could put together best practices from all over Europe at local, regional and national level and also find examples from other sectors.

51. E-health is driving a change in thinking on data-ownership, with a move towards greater ownership by patients, who want to be able to go online securely and see their health records, just as they could see their bank account. While some AF Members argued that the public also expected that their data would be accessible in the system for legitimate use by clinical and public health authorities, others expressed the opinion that in the future, public health experts would no longer be able to control data, instead individuals would control their own data and the experts would have to seek legal permission for use. Another view that was expressed was that with the involvement of greater numbers of e-health IT solution providers the ownership of health data could be taken over by other organisations, which could impede the rapid access and collation of data for public health surveillance purposes.

52. The issue of the size and complexity of current IT systems in healthcare was also raised as challenge to the realisation of the benefits of e-health to public health functions such as surveillance. This was a particular concern for larger countries with large numbers of different systems. It was noted that in Germany there were 60 000 doctors, 150 different types of software, 5 000 laboratories and 350 health insurance organisations so standardisation was quite a challenge. It was noted that interoperability required planning and vision. Perspectives and requirements were very different and unless all actors worked together and incorporated each other's interests, the required interconnectedness would never be achieved.

53. It was noted that it was important to define terminology and understand what was meant by e-health, since e-health is understood differently between individuals, professional groups, and possibly also between countries. It was also suggested that technology advances in other areas need to be taken into consideration, such as whole genome sequencing, which would give a better understanding of processes in the body which would blur the divide between infectious and non-infectious diseases, signifying the beginning of a new era and ECDC would have to think in broader terms to accommodate this. Technology was also changing the landscape in middle-income countries, moving everything from computers to mobile phones and this was both interesting but challenging.

54. Several AF Members suggested that e-health is an issue for which a younger generation of public health professionals were needed to brainstorm what other data could be used in the future and how. It was also proposed that there was a need to involve not only the younger generation, but also other actors, including people from other areas of science and technology, social, cultural and anthropological specialists. In this respect it was noted that although e-health systems would help to improve analytical epidemiology in the long run, the current capacity of epidemiologists in many countries is insufficient to do all of the analytical work which would be created. A specific suggestion was that there could be some way of engaging the young epidemiologists joining EPIET and incorporating this issue into their training at the public health institutes.

55. Andrea Ammon, ECDC Director, noted that the discussion had come back around to training needs and upscaling of skills. What was also assumed was that once the system worked it would be much faster, making life much easier for epidemiologists, laboratory workers and hospital personnel.

56. Monika Lanzenberger, Head of Sector, Research Coordination, DG Communication Networks, Content and Technology, European Commission said that now was a good time for ECDC to develop a vision to bring e-health to the fore since the EU was currently preparing for the new Commission. At present, there was a great deal of discussion on where to invest and what to focus on in the future, how to foster interoperability, how to use new technologies, etc. and therefore she encouraged ECDC to move forward with these ideas.

57. Katja Neubauer, Senior Expert, Digital Health Unit, DG SANTE, European Commission said that the concept of fragmentation of e-health depended on perspective. From an IT point of view there was not such a big difference. She suggested always including a usage case when working on a vision –e.g. how was e-health use in the public domain - as this helped to clarify what was meant. It was also important to identify where public health fitted in to the bigger picture.

58. Andrea Ammon, ECDC Director agreed that it was important to strengthen the connection with the e-health network and to ensure that public health needs were taken into account. She noted that the suggestion from the AF Member for Portugal to look at best practices was already in ECDC's work plan. Discussions on e-health could possibly become a standing item at AF meetings as a way of gradually defining needs for the future.

**Conclusions and Actions**

ECDC will work to strengthen its connection with the EU e-health network with the objective of ensuring that public health needs are represented. ECDC will also assess the extent to which best practices relevant to e-health are already in its work plan, and will consider further, and bring back to the Advisory Forum a paper, on making e-health a standing item at AF meetings as a way of gradually defining needs for the future.

# Update from ECDC on the main activities since the last Advisory Forum meeting

59. Andrea Ammon, ECDC Director, gave a short update.[11] She added that she had had a meeting with DG SANTE on 8 March 2019 to discuss how ECDC and other agencies could give input for the new Commission and Horizon Europe, the new research programme. The European agencies involved in health had made the point that they wanted to be a part of the priority setting and possibly also the evaluation processes in order to avoid overlap.

60. In response to a question about what ECDC could do outside the EU, Andrea Ammon, ECDC Director said that ECDC had done assessments in the Ukraine and Moldova to date and was now planning to do one in Georgia in October. ECDC's assessments were more in-depth than the joint external evaluations and involved a complete evaluation of the health system for communicable diseases in a country. The country was then usually supported with the setting up and implementing of an action plan.

61. In response to a question about whether there were any specific questions in connection with the upcoming European elections which could affect ECDC, Andrea Ammon, ECDC Director replied that although there was nothing specific, there were of course parties and fractions that were not interested in working within the EU. The prognosis was that the bigger parties would lose out and that voting would be much more spread out and fragmented this time around.

# Update on the planning of the third ECDC Joint Strategy Meeting (JSM)

62. Andrea Ammon, ECDC Director gave a short update on the status of the planning.[12] The joint strategy meeting would take place back-to-back with the Advisory Forum meeting in May 2020 to avoid a potential clash with the World Health Assembly. The dates have been provisionally set as 13-14 May 2020.

63. Frank Van Loock, European Commission asked ECDC to ensure that all those Commission services involved with the agency would be represented at the JSM.

**Conclusions and Actions**

ECDC will confirm the dates of the third Joint Strategy Meeting and will continue to work with the Joint Strategy Meeting Programme Committee to define the programme and background papers for the meeting.

# Briefing on the International Centre for Antimicrobial Resistance Solutions (ICARS)

64. Kåre Mølbak, AF Member, Denmark gave a short briefing on the newly established centre in Denmark.[13] He invited AF Members to share slides with their experts in country and to ask for any additional information they required. They were also welcome to visit the new centre. It was expected that the centre would start work on projects in the autumn.

65. Frode Forland, Observer, Norway, congratulated the AF Member on the newly established centre for which there was a great need. Despite the numerous action plans to tackle AMR very little was yet known about their effect so he looked forward to hearing more on this topic once the centre began work.

66. Frank Van Loock, European Commission, hoped that the Commission would be able to provide support for the centre in specific areas as AMR was such an important area. He hoped the centre would bear fruit in the future.

67. Bruno Coignard, AF Alternate, France asked if the centre had any connection with the project for European Joint Action on Antimicrobial Resistance.

68. Kåre Mølbak, AF Member, Denmark confirmed that they had had meetings with the project and were collaborating with them closely to prevent overlaps. They had also had meetings with the Fleming Fund and were

[11] Update on ECDC activities (A Ammon)

[12] ECDC Third Joint Strategy Meeting (A Ammon)
[13] International Centre for Antimicrobial Resistance Solutions (K Mølbak)

planning to work in countries where the Fund was assisting with surveillance. They were also in close contact with the Welcome Trust which was also very active in this area and it was likely that the Trust would include the Centre in its programme from 2021 which would possibly entitle it to support. He was pleased that the initiative had been received so positively in general to date.

# Update from the European Commission

69. Frank Van Loock, European Commission gave an update on ongoing activities. **Vaccines:** work was continuing on the Council Recommendation. ECDC and EMA were involved, with ECDC supporting the implementation of the 13 actions. The European Vaccine network had seen the first meeting of the Member State Committee, attended by DG SANTE together with the stakeholders' forum. The Coalition for Vaccination, convened on 4 March 2019, would eventually lead to a declaration which was currently being drafted. A vaccination summit was being planned for 12 September, at the initiative of Jean-Claude Juncker and Dr Tedros. ECDC was part of the programme committee and it was hoped that the summit would bring together actors from across the globe on issues such as vaccine confidence, research and development and access to vaccines. Joint action on vaccination was moving forward, with EUR 3.5 million invested from the health programme. The work was being coordinated by France and areas of particular relevance were the cooperation with the NITAGs and work on vaccine hesitancy. ECDC was fully involved and DG SANTE was relying on its input. **Preparedness:** joint action on preparedness is led by Finland, with 26 EU/EEA and neighbouring countries participating and almost EUR 8 million of funding currently being finalised so work could start. The aim was to improve preparedness and response planning for serious threats to health and the coordination among microbiologists and laboratories (SHARP – Strengthening of International Health Regulations on Preparedness). Another area in which joint action linked to preparedness was underway was on healthy gateways. Here the Commission was working with SHIPSAN and other transport networks (ground/air crossings and maritime transport). As part of the aviation package an exercise had taken place in February 2019. A work package on maritime transport (ship inspections) was also due to be prepared shortly. Training courses had been organised in March in Greece and also some useful webinars were available, with more scheduled in the areas of chemical threats and disinfection of aircraft in the near future. A best-practice workshop on entry screening for infectious disease had been organised, with number of actors from the transport sector and other international bodies, and a useful report on the workshop was now available. In the area of early warning and response, the Commission hoped to run a medical evacuation simulation exercise soon. Work on a module to interlink alert systems (RASFF, TESSy and RABRATC) was due to complete in October 2019. With regard to the joint procurement mechanism for Member States to procure medical supplies, 24 Member States had signed up. Botulinum antitoxin had been the first procurement successfully concluded with four Member States. A second procurement was currently underway for pandemic influenza vaccine involving 18 Member States. A third joint procurement for PPE had been temporarily suspended and a fourth for diphtheria antitoxin, tuberculin and BCG vaccines was in the pipeline. **Antimicrobial resistance:** the Commission had been busy with the Romanian presidency which had scheduled a number of events. A Ministerial Conference on AMR was held in Bucharest in March 2019. A workshop on AMR in pre-accession countries together with ECDC, EFSA and WHO in late February had been welcomed by all participants and there was more follow-up still to come, including the Commission looking at future funding from 2021 onwards, since the Western Balkan countries still needed more support in dealing with AMR. Country assessment visits had been made to Bulgaria and UK, Estonia would soon be finalised and a visit to Ireland was planned later in 2019. **Funding:** As part of Horizon Europe, funding had been approved by the relevant councils (for projects detailed by DG CNECT during the e-health session the day before), but the final budgetary agreement would only be available once a decision had been taken regarding the future of UK participation in the EU. Research funds had been divided into five thematic clusters, one exclusively devoted to health with EUR 7.7 billion. The other thematic clusters included the topics of digital transformation and healthy cities so they would also have funding available for those aspects related to health. Under the European Social Fund, a proposal had been tabled to obtain resources via DAT which could mean that non-EU countries would be eligible for further funding in the areas of preparedness, crisis response, laboratory capacity and AMR. The Health Security Committee had been delayed for one month to early July and when it met measles would be on the agenda.

70. Andrea Ammon, ECDC Director, thanked all the participants for their contributions to the discussions. The next AF meeting would be on 24–25 September 2019. She wished everyone a safe journey home and a good summer.

# Annex: List of Participants

| Member State | Representative | Status |
|---|---|---|
| Austria | Franz Allerberger | Alternate |
| Belgium | Herman van Oyen | Member |
| Croatia | Aleksandar Šimunović | Alternate |
| Czech Republic | Jan Kynčl | Member |
| Denmark | Kåre Mølbak | Member |
| Estonia | Natalia Kerbo | Alternate |
| Finland | Mika Salminen | Member |
| France | Bruno Coignard | Alternate |
| Germany | Osamah Hamouda | Member |
| Hungary | Zsuzsanna Molnár | Member |
| Ireland | Kevin Kelleher | Member |
| Italy | Silvia Declich | Member |
| Latvia | Jurijs Perevoščikovs | Member |
| Lithuania | Loreta Ašoklienė | Member |
| Luxembourg | Isabel De La Fuente Garcia | Member |
| Malta | Tanya Melillo Fenech | Alternate |
| Netherlands | Jaap van Dissel | Member |
| Portugal | Carlos Matias Dias | Member |
| Romania | Florin Popovici | Member |
| Slovenia | Marta Grgič-Vitek | Alternate |
| Sweden | Anders Tegnell | Member |
| | Birgitta Lesko | Alternate |
| United Kingdom | John Watson | Alternate |
| **Observers** | | |
| Norway | Frode Forland | Member |
| Turkey | Mustafa Gökhan Gözel | Observer |

| Member State | Representative | Status |
|---|---|---|
| **Non-Governmental Organisations (NGOs)** | | |
| European Institute of Women's Health | Rebecca Moore | Member |
| European Association of Hospital Pharmacists (EAHP) | Inese Sviestina | Alternate |
| **European Commission** | | |
| DG Santé | Frank Van Loock | |
| **WHO** | | |
| | Masoud Dara | |