ECDC Advisory Forum

Minutes of the Fifty-sixth meeting of the Advisory Forum

Stockholm, 19-20 February 2019

Contents

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

1. The meeting was opened by ECDC Director, Andrea Ammon, who welcomed the participants.

2. Mike Catchpole, Chief Scientist, ECDC, welcomed the AF members and other participants, in particular the newly appointed members for Turkey, Mustafa Gökhan Gözel and Cyprus, Linos Hadjihannas. Apologies had been received for Finland, Italy, Lithuania, Luxembourg, Malta, Slovakia, Slovenia, Commission and the World Health Organization's Regional Office for Europe.

3. There were no declarations of conflict of interest and the agenda was adopted.

Adoption of the draft minutes of the 55th meeting of the Advisory Forum (12 December 2018)

4. The draft minutes were adopted with two small amendments made by ECDC to the section on tuberculosis – point 18 on international country reviews should read 'country visits were prepared *in collaboration with WHO*' and point 19 feedback would be provided to *the TB national focal points* rather than to the AF.

IRIS prioritisation process – ECDC cross-organisational initiatives

5. Mike Catchpole, Chief Scientist, ECDC pointed out that ECDC was interested in the opinions of the AF Members as experts and reminded them that as members of the Advisory Forum they were not representing their Member States.

6. Andrea Ammon, ECDC Director, pointed out that the overall purpose of the AF was to give scientific advice to ECDC so that it could improve the scientific quality of its work and ensure that it did not go contrary to good practice or duplicate work already being done in the Member States.

Proposal 1 – Assess the feasibility and added value of using existing electronic health data in MS for EU surveillance

7. Bruno Ciancio, Head of Section, Epidemiological Methods, Surveillance and Response Support Unit, ECDC, introduced the poll.

8. Polling 2.1 On a scale of 1 to 5 score the quality of the proposal and the relevance of the approach to tackle the issue. The AF Members voted and the result was 4 – supported with minor changes.

9. Mike Catchpole asked if anyone who had felt that the proposal required major changes or was not fit for purpose (scoring 3 or less) would be interested in commenting. The key points raised in the ensuing discussion included:

- There was general support for the view that e-health offered significant potential benefits for epidemiology and the work of ECDC and its partners in Member States, but mixed views as to how soon or how easily these could be realised.
- There is considerable variation between Member States in the level of progress with implementing e-health systems, and similarly great variation in the format and coding of data in such systems as do exist, which ECDC might have underestimated and which might therefore require more effort than anticipated and/or that the timelines for completion may need to be extended.
- The variation in the level of implementation of e-health were considered to be both a challenge but also a rationale for undertaking the proposed work, particularly if the work would provide benefit to those countries that are less advanced in e-health. One member asked if financial support would be available from the relevant European Commission Directorate Generals.
- It would be important to clarify more exactly what the implications of a move to e-health based data collection would be for surveillance at the EU level
- It was noted that in some countries e-health initiatives were not engaging epidemiologists or other public health practitioners
- It was suggested that ECDC could compile an inventory on e-health systems in the EU by asking countries for information on their current status and what they were planning for the future. It was also suggested that with regards to the issues highlighted in the discussions

on e-health systems, that ECDC should make country visits to several countries to get a better idea of their systems, similar to the visits done for AMR.

10. In response to these comments, Mike Catchpole, Chief Scientist, ECDC, agreed that country visits would offer an excellent opportunity. He also confirmed that there were plans to carry out a survey to establish the current state of play in countries. He also confirmed that ECDC had invited colleagues from the Commission to the AF meeting in May to discuss the issue with AF members.

11. Andrea Ammon, ECDC Director, said that digitalisation was being introduced in this area that was not driven by public health. An e-health network had recently been set up in Europe which was trying to overcome some of the obstacles such as comparability, standards and support to countries and ECDC had invited a representative from this network to the next AF meeting in May to give a presentation on their efforts to date. She suggested that AF Members could get in contact with the representative of this e-health network in their country to hear what was going on. The greatest challenge would be to switch methodology and thinking and it was important to be involved from the beginning so as not to get left behind. The situation was similar to that with whole genome sequencing which had been discussed in the AF 10 years ago and was nowadays being used increasingly and getting cheaper. What ECDC wanted to do was to achieve slightly more equity by identifying difficulties and addressing them.

12. Bruno Ciancio, Head of Section, Epidemiological Methods, Surveillance and Response Support Unit, ECDC, responding to Members' concerns, did not believe that it was too early to act, given the development level in certain countries. He pointed out that the Commission had just published a Recommendation on a European Electronic Health Record exchange format on 6 February 2019. He explained that ECDC's work in this area would be a preparatory exercise, taking into account the disparities between countries. Regarding the issue of data use, one of the objectives of ECDC's work would be to gain a better understanding of the different obstacles. He thanked the participants for their comments which would be taken into account.

13. Polling 2.2. The majority of the participants voted for 3 'supported with changes'.

14. Mike Catchpole, ECDC Chief Scientist, thanked the participants for their helpful and supportive input and proposed moving on to the prioritisation of the specific proposals for proof of concept studies.

15. Barbara Albiger, Senior Expert, Scientific Quality, ECDC, gave a short presentation introducing the prioritisation of the eight proof of concept studies, and Bruno Ciancio, Head of Section, Epidemiological Methods, Surveillance and Response Support Unit, ECDC, clarified that the goal was to choose the projects from which the most information could be gained.

16. Following two rounds of polling (Polling 3.1 and 3.2) and discussion, the consensus was that priority should be given to the proposals related to antimicrobial resistance and/or healthcare associated infection and to the proposals related to improving the completeness of data reported to TESSy.

17. Mike Catchpole, Chief Scientist, ECDC, said that ECDC would now move forward with two of these proposals and invite Member States to participate in the proof of concept studies.

Proposal 2 - FORESIGHT

18. Barbara Albiger, Senior Expert, Scientific Quality, ECDC, introduced IRIS prioritisation exercise 2 on ECDC's cross-organisational initiative FORESIGHT.

19. With Polling 2.1 to score the quality of the proposal and the relevance of the approach for tackling the issue, the majority voted for 4 'supported with minor changes'.

20. With Polling 3.1 on prioritising the sequence of work, the majority voted for both of the topics AMR (anti-microbial resistance) and VPD (vaccine-preventable diseases) to start simultaneously in 2020'.

21. The key points raised in the ensuing discussion included:

- There was sufficient commonality between the drivers for antimicrobial resistance and healthcare associated infection for the results from Foresight studies on one to be of relevance to the other
- The lack of overlap between the two different theme areas that had been prioritised would mean that different contacts would need to be identified in each participating country

22. Jan Semenza, Acting Head of Section, Scientific Assessment, Surveillance and Response Unit, ECDC, agreed that both were of the issues presented in the prioritisation process were high-priority issues even though they were very different in nature. He thanked the participants for their input, the results of which would inform ECDC moving forward.

23. The question was also raised as to when the remaining (non-selected) issues would be tackled and how they would be prioritised.

24. Mike Catchpole, Chief Scientist, ECDC, said that at the September meeting a package of issues would be proposed for 2021. ECDC needed to look at how to prioritise and package, however the aim was to be able to present a wider range of issues in the future.

Draft ECDC Technical Report: ECDC strategic framework for integration of molecular and genomic typing into European surveillance and multi-country outbreak investigations 2019-2021

25. Marc Struelens, Chief Microbiologist, Microbiology Coordination, Office of the Chief Scientist, ECDC, introduced the report and the floor was opened for comments.

26. There was widespread support for the report and its proposed approach, with comments that it was an example of providing EU added value and that it provided a good source of evidence for advocacy for the use of molecular and genomic testing in Member States. Key points that were raised during the discussion included:

27. The issue of data sharing was emphasised by several members. It was noted that a model for possible bilateral agreement for whole genome sequencing (WGS) data sharing was missing from the document, and it was noted that it would have been helpful to include more on linkage to and exchange with other global databases outside Europe, and whether there were clear examples of how such systems had helped to date in solving global outbreaks.

28. The legal consequences associated with outbreaks also need to be reviewed as they relate to the old system of analysis. It was also noted that it is important to be able to combine isolates from food products easily with human isolates and this area was not tackled in the report, and it was suggested that there is a need to look at food safety issues with EFSA more closely in relation to WGS. It was noted that in at least one country there had been delays in detecting outbreaks using WGS and it was found out that the traditional methods still needed to remain in place.

29. While there was agreement that whole genome sequencing was the way forward, for many countries the costs still make it difficult to justify its use as 'routine', and so it would be useful address the issue collectively at the EU level, and also to specify what was meant by 'routine' and what it meant in public health terms. It was also noted that there is a need of more technical support from ECDC in some countries on how to start using the data acquired by means of WGS

30. The need to analyse WGS data together with other epidemiological data was noted, and it was suggested that caution was needed in setting the criteria for when to initiate an investigation of declare an outbreak when dealing with WGS data.

31. Mike Catchpole, Chief Scientist, ECDC said that the framework set out the rationale and looked at priorities for implementation but many of the participants' comments were associated with implementation (which was a related but separate issue). One outstanding issue ECDC would have to review was the financial situation. With regard to veterinary and animal health, ECDC had been working with EFSA and the reference laboratories for food and animals and looking at options for setting up a joint database at EU level.

32. Marc Struelens, Chief Microbiologist, Microbiology Coordination, Office of the Chief Scientist, ECDC – thanked the AF for their comments. He clarified that ECDC collaborated with EFSA on a daily basis and confirmed that the joint database had already been set up and was a work in progress. With regard to future issues such as the need for nomenclature for standard outputs and the unresolved issue of interpretation, he agreed that these could also be addressed, although he confirmed that there would be legal implications. Referring to the clarity of appropriate use of sequencing formation in terms of data ownership and access, this was addressed in the section on data management. Efforts had been made to ensure full compliance with the current legal framework and the issue would also be addressed for each individual area. He confirmed that more detail could be added to the explanation on the low visibility of viral pathogens. WGS did not offer the same added value for viral pathogens as it did for bacterial pathogens in terms of resolution and the technology was not so mature in this area. As a next step, a public health genomics workshop was being planned for October and this training would be offered to all countries that had expressed an interest.

33. Andrea Ammon, ECDC Director, said that there were lessons to be drawn from the current discussion and the previous one on e-health. The present discussion on WGS was at a completely different level to that three years ago, showing how much development had already taken place. WGS did not solve all the issues, it simply highlighted some of the pre-existing ones. It was important to remember that WGS was a tool and not a panacea. The same problems existed wherever the technology was introduced. With regard to the issue of redundant risk assessments, she pointed out that this was the question ECDC had asked when carrying out its survey in the Health Security Committee, however it had not received much feedback there. If risk assessments were produced that were not helpful, it was important for the members to inform ECDC so that it could refine its criteria.

34. Mike Catchpole, Chief Scientist, ECDC, summing up, noted that there appeared to be a broad consensus that the priorities and data management solutions set out in the document were appropriate and clear. There were some areas identified where additional clarification was required and this would be dealt with. Listeria was the first example that ECDC would take forward in 2019. The discussion was ongoing, particularly with regard to implementation, but there appeared to be endorsement for the framework. He thanked the participants for their input.

ECDC Surveillance and Response Unit update on Epidemic Intelligence and response support activities

a) Update on Ebola Virus Disease outbreak in Ituri and North Kivu Provinces, Democratic Republic of the Congo, 2018–2019

35. Vicky Lefevre, Acting Head of Unit, Surveillance and Response, ECDC, gave a short presentation on the latest evidence. From this overview, it appeared that security problems, community resistance and the political situation were hampering outbreak response efforts. The floor was then opened for discussion.

36. Several AF Members expressed their concern about the persistence of this ongoing outbreak. Although the response measures were initiated in an early stage (by the MoH, WHO, African CDC and other partners) and are still ongoing, including the compassionate use of vaccines and investigational therapeutics, these measures do not seem to be sufficient to control the outbreak. The situation is significant concern because of the prolonged humanitarian crisis, the unstable security situation and the community resistance. These issues need to be tackled urgently. One member believed that a meeting of the WHO Health Emergency Committee should be called and that the Ebola outbreak should be placed higher up on the agenda. The member therefore encouraged countries to sound the alarm as calls from Member States would be the most powerful tool for achieving this.

37. In addition, there was a discussion on the use of vaccines; although 80 000 people had been vaccinated there had been no information from WHO on the effectiveness of the vaccine. ECDC was asked to request such information from WHO.

38. ECDC shared the concerns expressed and confirmed that it was monitoring the situation very closely. ECDC would make enquiries about the vaccine efficiency but it was uncertain what information was in the public domain.

39. One member wondered if WHO had made any projections on deployment and staff needs for the current outbreak. UK said that there had been eight people deployed from the UK since August 2018. ECDC replied it had already deployed one expert with DG ECHO and was considering a follow-up. Since the call end of 2018, GOARN had not expressed any need further to ECDC for experts to be deployed.

b) Update on West Nile Fever investigation

40. Tamas Bakonyi, Head of Disease Programme, Emerging and Vector-borne Diseases, Office of Chief Scientist, ECDC, gave a short update on West Nile virus (WNV) which was followed by a discussion.

41. Comments and questions were focusing on the ecology of the virus, the possibilities of monitoring, and vector control options.

42. It was emphasized that although horse cases were used as one of the indicators in WNV activity, these animals are dead-end hosts and did not play a role in transmission. Birds are transmitters but information was limited as to which species were the most significant amplification hosts.

43. The development of modelling tools by ECDC for the estimation of environmental risk factors and for the application of mosquito control measures were appreciated and the need of similar approaches for tick-borne infections was emphasized. ECDC confirmed that the platform could be used for further integration of other diseases using after pathogen and vector-specific adaptations, and tick-borne encephalitis was one of the diseases in the preview studies.

44. Concerns were raised on the availability of facilities and application of vector control methods in case of significant outbreaks of WNV infections in the forthcoming seasons. ECDC was asked to provide support for mosquito control. It was noted that although public health crisis management is not in the remit of ECDC, support for mosquito control was being requested by an increasing number of Member States. There are ongoing studies including vector control trials on invasive mosquitoes. ECDC was keen to coordinate and collect scientific information and try to organise it in a guidance document however the final decision would on the application of vector control measures always be with the Member States.

c) Acute flaccid paralysis and myelitis in the EU/EEA due to non-polio enteroviruses

45. Eeva Broberg, Senior Expert, Microbiology Coordination Section, Office of the Chief Scientist, ECDC, gave a short presentation which was followed by a general discussion.

46. AF Members commented on their current AFP or enterovirus surveillance activities. AF Members from Czech Republic, Sweden and Spain confirmed that they had not observed an increase of AFP or AFM. In Norway, a slight increase had been observed. In France, a few cases of severe paralysis but no substantial increase had been observed.

47. A few AF members indicated that they were in support of further information being shared or, if necessary, collected regarding the situation across all Member States, in order to gain a better understanding the issue. However, other members noted that undertaking specific epidemiological surveys beyond the collection of AFP data required by, and reported to, WHO would be difficult, and emphasised that ECDC should not duplicate the work of WHO. It was also noted that any future proposal to undertake formalised surveillance of non-polio enteroviruses would need to have clear objectives formulated. Other comments included that whether or not the cause of the observed cases of AFP or AFM was a polio or non-polio enterovirus, it was necessary to investigate cases to understand the cause, and that verification was required as to whether this was a problem that could escalate.

48. Eeva Broberg, Senior Expert, Microbiology Coordination Section, Office of the Chief Scientist, ECDC, thanked the participants for their comments. ECDC had done a survey and been mapping enterovirus for the last three years and a report was due to be published soon on this subject which would shed some light on trends in enteroviruses. She noted that she had contacted WHO's Regional Office for Europe to see if it would be possible to use their AFP data for background, even if the two different case definitions for AFP and AFM makes it difficult to put all the cases in the same analysis. She also noted that ECDC is fully aware of the activities of the ENPEN network, with which it is collaborating as it is an open network. Currently, the network is developing protocols for various surveillance and burden of disease studies, such as serological, respiratory, hand, foot and mouth disease and other more severe neurological outcomes such as AFM studies.

49. Mike Catchpole, Chief Scientist, ECDC, summing up, said that there was no clear evidence of an overall substantial increase in the number of cases and given this and the lack of clear intervention strategies, there is currently no clear indication of a necessity to take concrete action. In view of the feedback from a number of AF members, he was doubtful that there would be any added value in asking Member States to collect further data and therefore ECDC would reflect in-house on the appropriate action going forward. He thanked all participants for their input.

Draft ECDC guidance on HPV vaccines – a second update

50. Edoardo Colzani, Senior Expert, Vaccine-preventable Diseases, Surveillance and Response Support Unit, ECDC, presented an updated version of the guidance. The floor was then opened for discussion.

51. There was broad support for, and endorsement of, the guidance document, although it was noted that its focus on 4 and 9 valent vaccines limited its utility for countries only using the bivalent vaccine. Other specific comments that were made included:

- There were several comments about the remaining uncertainty regarding the vaccination of males, and in particular the need for more evidence concerning male cancers, the other male aspects of HPV, and the vaccination of MSM. Osamah Hamouda, AF Member, Germany pointed out that the German NITAG 'STIKO' had looked at this issue thoroughly and recently reached the same conclusion as ECDC, that introducing the vaccination for boys was appropriate.
- It was suggested that there is a need for a wider discussion of the ethics of vaccinating only girls. In relation to vaccination ethics, it was suggested that ECDC could work with patient and stakeholder groups when compiling this type of guidance.
- It was suggested that an issue for further examination would be the variations in cross protection depending on the different adjuvants.
- It was commented that the analysis was largely confined to intermediate outcomes, and that the only data currently available for a patient-affected outcome was from Australia and this indicated that the effectiveness was possibly not as high as had been thought in the past. Although complications were discussed there was no mention of the study done in France on Guillain Barré, and there could be a case for some form of risk/benefit analysis that took into account such studies.
- It was suggested that it would be good to have a consolidated document of the older (2008 and 2012) and new versions of the guidance at one point.

- One AF member noted that their country had recently been through a health technology assessment process on the vaccination of boys but in the end a political decision had been taken to introduce the vaccine for boys before the assessment was finished.

52. Edoardo Colzani, Senior Expert, Vaccine-preventable Diseases, Surveillance and Response Support Unit, ECDC, responding to comments on the recommendation of which vaccine to use, said that this was not the original intention of the guidance. He was not aware of any head-to-head studies comparing HPV9 to HPV2 in males and for HPV2 there was no data. The only evidence ECDC could report on was immunogenicity. Regarding the comment referring to the French study on Guillain Barre, he pointed out that the panel had decided not to focus on safety aspects as very thorough assessments had already been done by WHO. With regard to the benefit risk analysis, the modelling had so far focussed on cervical cancer elimination, driven by WHO, but he agreed that a benefit/risk analysis could be a good idea for the future. ECDC was planning to do a public consultation as the next step.

53. Mike Catchpole, Chief Scientist, ECDC, said that the guidance focused on the evidence available but until studies were done (for example on the issue of vaccinating boys versus girls), there was no evidence available. He thanked the participants for their comments which would be taken into account before the public consultation.

54. Edoardo Colzani, Senior Expert, Vaccine-preventable Diseases, Surveillance and Response Support Unit, ECDC also informed the participants of a WHO-sponsored global study, led by John Hopkins University and supported by ECDC, on shifts in pneumococcal serotype/distribution of invasive pneumococcal disease and the impact of vaccine. The organisers were looking for data and countries might be contacted with a view to contributing.

EPHESUS: Evaluation of EU/EEA surveillance of antimicrobial consumption

55. Klaus Weist, Senior Expert, Antimicrobial Consumption, Surveillance and Response Support Unit, ECDC, gave an overview on the objectives, methods applied and the outcomes of the EU/EEA surveillance of antimicrobial consumption (AMC) evaluation (ESAC-Net) that had been performed in the second half of 2018.

56. Mike Catchpole, Chief Scientist, ECDC, said that ECDC was interested in hearing views on whether the recommendations supported the evidence and any specific area where there they did not. Evaluations were a way of seeking the views of experts in the field and therefore he wished the discussion to focus more on the general situation rather than getting caught up in specifics.

57. There was support from AF members for the overall EPHESUS recommendation to maintain the current surveillance network ESAC-Net and endorsement of the evaluation results presented in the Evaluation report, which had been sent ahead with the AF documents. Key points that were raised during the discussion referred mainly to the four other presented evaluation recommendations. These included:

- It was suggested that the timeliness of antimicrobial consumption data submission should be improved.
- A number of members commented on the recommendation on strengthening the link between data and public health action, with some noting that the costs of the proposed increase in granularity of the data may not be justified by the marginal benefits, and others suggesting that this is an area in which there could be benefit in sharing best practice between ECDC and WHO.
- It was asked whether the EMA has AMC data from the veterinary sector, and if there was, or would be, a similar AMC surveillance system in place such as ESAC-Net for the veterinary sector.
- A concern was expressed regarding making the data publicly available and whether such public access could be a problem since the data quality was quite different from country to country

58. Mike Catchpole, Chief Scientist, ECDC, responding to the question on data quality, said that there was no difference between this data set and other data sets publicly available ECDC always advocated the exercise of caution and the avoidance of direct country comparisons when reviewing data and this system was no different. He concluded with a general remark on the performed and ongoing EPHESUS evaluations of the ECDC surveillance networks. When all EPHESUS evaluations will be finished, ECDC plans to re-assess FTE allocations of ECDC staff for the different surveillance systems and potential re-prioritisations based on the EPHESUS recommendations regarding the number of ECDC staff involved and suggestions for additional activities of the evaluated surveillance networks.

59. Klaus Weist thanked the participants for their input and responded to remarks and questions raised in the discussions:

- To improve options for more timely data submission, ESAC-Net will hold an AMC data managers meeting in June 2019.

- He emphasised the mutual participation of the WHO/Euro AMC network staff members in ECDC coordination committees and network meetings. In June 2018, ECDC organised a joint ARHAI networks meeting with WHO/Euro where ESAC-Net members discussed on options to improve AMC data surveillance.
- Further enhancements under consideration included a pilot study currently underway with the ESAC-Net Disease Network Coordinating Committee on a hospital-based reporting protocol which would allow individual hospitals to collect data which would be passed to ECDC by a national coordinator, and suggestions that other indicators for antimicrobial use in the community, e. g. for antimicrobial groups of interest for stewardship purposes, should be added to the consumption data.
- With regard to data quality, the data were subjected to a number of checks and Member States had all approved the data and were able to compare the data from ECDC with those in their national reports. The EPHESUS recommendation to provide access to data at the substance level (5th ATC group level) is based on the stakeholders' feedback and would not need any additional break down of data reporting by Member States.
- He confirmed that the EMA has established a veterinary AMC surveillance network, ESVAC. Two Joint Interagency Antimicrobial Consumption and Resistance Analysis (JIACRA) Reports containing ESAC-Net and ESVAC data were performed based on a EC request and published in 2015 and 2017 and currently, a creation and analysis of a third report would be ongoing.

Advisory Forum Working Group topic: the use of social media in disease prevention and control

60. Tyra Grove Krause, AF Alternate, Denmark gave a brief introduction of the topic before the working groups met for discussions.

Day Two

Reporting from working group sessions on social media

61. Kevin Kelleher, AF Member, Ireland (Working Group A), Rebecca Moore AF Member, EIWH (Working Group B), and Anders Tegnell AF Member, Sweden (Working Group C), gave short presentations on the discussions in their respective groups.

62. From the WG discussions and the following discussion in plenary, some examples of how social media were addressed in the single countries/organisations was presented:

- Belgium: Each public institution are doing things differently. At the Scientific Institute of Public Health's Public Health and Surveillance Operational Direction, they are only mandated to use social media for laboratory communications and not, for example, for vaccination campaigns. There are three communications specialists working on social media. As for target audiences, in Belgium the preference is to communicate with researchers.
- Czech Republic: No strategy on paper, and no official spokesperson dealing with social media, but rather used by non-trained experts. The web pages of different institutions are used as feeds for social media.
- Denmark: Social media was used more for personal use.
- Iceland: They used their website to get messages across on risk assessment and response and people were generally very interested in health so messages got taken up by journalists straightaway. They did not use Twitter but preferred personal contact with journalists or used the institution's website.
- Iceland: Those who followed the agency on Facebook already supported it and therefore it was not reaching other harder-to-reach groups.
- Ireland: The agency was starting to use social media for specific campaigns – e.g. for pregnant women. In the beginning, they were overwhelmed by social media but now had one person working with it on a full-time basis.
- Netherlands: RIVM had a few people available to monitor and screen social media for trending topics. There had been problems with the dialogue aspect as they had found out that they were talking to trolls in some cases, which took up a lot of capacity. Recruitment of people for research studies using social media has been very successful. A promotional campaign for meningococcal vaccination had been carried out via YouTube to attract young people and this had been very successful, with an 86% uptake!

- Spain: the Ministry of Health had a specific office for targeted campaigns.
- UK: Public Health England (PHE) did not encourage staff to communicate independently on social media. Communication is on a corporate basis with specially trained staff providing the input. It is seen as very important not to engage with the convinced public (e.g. anti-vaccine campaigners.) PHE has focused on putting out positive information. A recent survey had shown that most people trusted their healthcare specialists (doctors, etc.) and therefore just because there was a lot of anti-vaccine activity on social media did not mean that people believed it. PHE was quite active on social media and had a reasonably strong communications team. They also had teams working on behavioural change (obesity, tobacco, etc.) and a digital programme. Referring to hard-to-reach groups, that these groups are actually reachable, one example being homeless people in London with whom PHE communicated in relation to TB. They were not starting to identify and stratify people more carefully for positive health messaging and vaccine messaging. In addition, although anti vaccine messages seemed to have increased it did not mean that there were growing numbers of anti-vaccine campaigners. PHE had carried out surveys which had shown that this was not the case.
- EIWH: Had had a citizens' consultation where they had invited the public to talk on what they liked. They had also run focus groups with school children and women of child-bearing age and were interested in running targeted campaigns to reach specific groups. They were a smaller organisation and found it difficult to reach certain groups.

63. The plenary discussion highlighted many challenges as well as opportunities when engaging in social media:

- There is an added value of social media monitoring and incident monitoring as an extra dimension, but it is necessary to monitor social media all the time so as to stay on top of developments.
- Many public health professionals often get it wrong by talking about the facts rather than getting to the emotional heart of the issue. It was also seen as more beneficial to focus on the positive rather than the negative when active on social media.
- Some members believed that public health agencies should be more available on social media as it would mean that people would trust their information more. However, there was a danger that social media activity might be seen as propaganda.
- ECDC's sources, e.g. risk assessments are useful as a clear, credible source of information. It would be useful to provide them with 'clout', templates for messaging.
- When it comes to staff engagement in social media, there were diverging views and policies in different countries, from active encouragement (due to limited resources) to a restrictive view. With active staff engagement some monitoring function needs to be in place, and it would be important that staff did not think that they could use the public health agency as their political platform.
- One member pointed out that since social networks could be used for social marketing strategies, it was good to understand the role of social marketing in social media and know the audience you wanted to reach and what you wanted to deliver. It was necessary to be very careful when using social media as a tool for institutional communication. His agency had younger people engaged in social media, who really knew how it worked, and they were developing the social marketing aspect.
- It was further suggested by one member that celebrities or famous personalities could help support a cause, as people are more likely to believe their social media posts than basic scientific facts.
- As the current discussion had not touched much on how we deal with vaccine hesitancy and the anti-vaccine lobby, one member wondered how nurses and doctors could be trained to talk to parents. Mike Catchpole, Chief Scientist, ECDC confirmed that tackling vaccine hesitancy would be a priority for ECDC in the next two years when it would be one of the main pillars of the upcoming strategy.

64. Mike Catchpole, Chief Scientist, ECDC, noted that a number of groups had touched on the issue of trust and emotion. Social messaging had not been a part of the scientific process in the past and social media was used for social dialogue where it was difficult to be in total control when putting out messages and there was the need to respond, which related to the issue of capacity. He also said that according to a recent US article, trolls were pushing both sides of the argument on vaccination in social media to encourage social divide.

65. Andrea Ammon, ECDC Director, said that the current session linked to the previous day's discussion on technological revolution. The old rules of communication still applied – it was important to know your audience and how to address them, but now the audience used different tools that public health experts and agencies were perhaps unfamiliar with. There were also ethical issues which created uncertainty. Although ECDC monitored social media, it had not yet started to analyse anti-vaccine campaigns, etc. She wondered whether

there really were thousands of people out there on social media conducting these campaigns. With regard to social marketing strategies, it was necessary to involve behavioural scientists in this work. Training for epidemiologists and public health experts needed to include social media training as they needed to be ready to deal with it upon graduating. The positive messages about vaccines were not getting through, the fact that vaccines protect people and it was important to highlight this without getting involved in the propaganda. So more training was needed in this area and there was still some research to be done to help analyse and address these messages more efficiently.

66. Karl Ekdahl, Head of Unit, Public Health Capacity and Communication, ECDC said that whenever social media was used, it was important not to forget the general principles of communication which applied to all media. There was a large group of professionals out there who were quite effective at reading and they represented probably 95% of all subscribers. However this was one-way communication. To change behaviour it was necessary to carry out research on how to reach a different target audience and this required more extensive input and resources. He pointed out that text messages did not tend to go viral, it was mainly video clips and info graphics. At ECDC, they recognised the need to do proper social media monitoring but this was hard when it involved so many countries and languages. There had been some discussion about providing tool kits and ECDC also planned to update its guidance on social media. ECDC would soon have a vaccine portal which would help to place greater emphasis on the whole vaccine issue. There had been a number of discussions on the issue of social media with the NFPs for Communications and ECDC provide feedback to them from today's discussion at their next meeting.

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

67. Andrea Ammon, ECDC Director, gave a short presentation. She then presented ECDC's draft vision statement ('Improving lives globally in Europe and globally through scientific excellence, empowering partners to drive public health policy and practice'). She said it might need to be rephrased to achieve consensus. The MB had already commented on the statement. She reiterated that ECDC did not address policy makers in Member States, it merely equipped colleagues in the countries whose task it was to brief policymakers. The intention at present was not go to beyond infectious diseases but some of ECDC's work already reached far beyond infectious diseases (e.g. preparedness, HPV and hepatitis B where there was also crossover into chronic diseases.) ECDC would be prepared to go further but it was a question of resources and having the mandate to do so. Decisions on this at the political level would need to be taken at high political level in the Council.

68. There was general support for the vision and strategy presented by the ECDC Director, with a few specific comments from AF members regarding the scope of ECDC's activities beyond the EU/EEA and the envisaged arrangements for working with third countries, the wider erosion of the traditional boundaries between infectious and non-infectious disease, and the rationale for focusing on 'lives' rather than 'health' in the vision.

69. In response to these comments, Andrea Ammon said that ECDC's focus was the EU/EEA, however in recent years it had also been working with the Enlargement and Neighbourhood countries which would be the natural extension of its focus. ECDC also had collaboration agreements with USA and Canada and was in the process of enhancing collaboration with the African CDC and China. There were different models for working with third countries. She could not say as yet which model specifically would apply to the UK after Brexit. With regards to the vision statement, she noted that what ECDC really aims to do is to improve peoples' lives so that they did not have to deal with infectious diseases

Update from the Chief Scientist's Office on ECDC scientific outputs – review of 2018, forward look 2019

70. Helena de Carvalho Gomes, Head of Section, Scientific Advice Coordination, Office of the Chief Scientist, ECDC and Barbara Albiger, Senior Expert, Scientific Quality, Office of the Chief Scientist, ECDC gave a short presentation.

71. The majority of the participants, responding to a poll as to whether they found the 2018 catalogue of planned scientific outputs useful, voted 'Yes'.

72. The majority of the participants, responding to a poll as to whether they had shared the catalogue, replied 'No.'

73. The majority of the participants, responding to a poll as to whether they thought the catalogue fulfilled its purpose of avoiding duplications, acknowledging work with the Member States and enhancing dialogue and collaboration, replied 'Yes'.

74. Mike Catchpole, Chief Scientist, ECDC said that ECDC tried to ensure that the lists of planned publications were also shared with the joint networks to try and avoid redundancy and engage in collaboration for joint authorship.

ECDC Chief Scientist's Annual Report on the work of the Advisory Forum in 2018

75. Mike Catchpole, Chief Scientist, ECDC, introduced the report and asked for comments from the floor.

76. Andrea Ammon, ECDC Director, said that when reading the report it was made clear to her again how valuable the AF meetings were and how important the input was from the forum. She thanked the members for their valuable advice and support.

77. Feedback from the AF included compliments on a comfortably short report which included the highlights, and a question about future plans for collaboration between the AF and the Management Board, with a view to improving complementarity.

78. Mike Catchpole said that this was still under discussion with the Management Board. There were plans for a number of other measures including induction packs for new members, and also another joint strategy meeting, for which a programme committee had been established made up of members from both groups and the competent bodies.

Implications of the General Data Protection Regulation (GDPR) follow-up discussion

79. Frode Forlund, AF Member, Norway gave a short introductory presentation.

80. Osamah Hamouda, AF Member, Germany, said that he had recently been informed by his data protection officer that the notifications being received without names, but the numbers could potentially be linkable to local health authorities and therefore it was necessary to take particular precautions with notification data. He asked if in principle the same terms would have to apply when forwarding these data to ECDC.

81. Andrea Iber, Head of Section, Legal Services and Recruitment, ECDC, said that, contrary to the Member States, ECDC had already had specific data protection provisions in place for quite some time regarding the handling of TESSy data before GDPR. These provisions, which had been updated and enforced for the EU institutions since December 2018, were more detailed than the GDPR but the legal basis and safeguards were similar. The legal basis for ECDC's data processing in TESSy was Article 5 of its Founding Regulations which was supplemented by Article 11 of ECDC's Founding Regulations and Article 6 of Decision 1082 relating to the legal framework. When it came to requests from researchers, ECDC was bound by Regulation 1049 regarding access of the public to information held by an EU body. There was one limitation in this Regulation which related to access requests to personal data. It had been decided that TESSy data with the record ID and case-based data should be treated as personal data. However, ECDC's supervisory authority had ruled that ECDC should assess whether the request established the necessity of transfer and if it was for research purposes and the specific request was in the public interest, this justified facilitating requests to researchers. There were many safeguards that had to be applied, such as asking researchers to sign a legally binding commitment on data usage (recorded declaration of commitment) whereby they undertook to only treat data for their specific research purposes. The whole process was also reviewed internally by experts and there was a possibility to escalate a case where necessary, with an entire mechanism for compliance in house. ECDC had undergone a lengthy process (prior checking) with the European Data Protection Supervisor, which ended two years ago, to ensure that they were in compliance. The one remaining question, relating to data transfers to WHO and adequacy of protection levels had also now been resolved. The findings would be transferred into a data privacy impact assessment form which would document the mitigation measures applied for each risk. In the EU institutions this process was quite harmonised and templates had been created for the data protection impact assessments. However, there could be discrepancies at national level which might cause difficulties for the Member States in aligning themselves. ECDC already had privacy statements to inform potential data subjects of publication on ECDC's website. The supervisory authority had underlined to ECDC the importance of clarifying the responsibilities at each stage of data processing (e.g. at national level in compliance with national laws and following transfer to ECDC, at which point ECDC was responsible for ensuring compliance.)

82. Mike Catchpole, Chief Scientist, ECDC, reiterated that the legal basis for ECDC's data handling was its Founding Regulation and Decision 1082, while Decision 1049 set out the basis for sharing data with third parties including for legitimate research purposes, such as for the benefit of public health.

83. Andrea Iber said that Article 6 of ECDC's Founding Regulations covered data reporting as related to the surveillance networks so ECDC had quoted this as a legal basis. ECDC had not asked the Member States to sign data processing agreements but had instead established terms of service which had to be accepted before a new user could sign up to TESSy in order to ensure the security and integrity of the data.

84. Several AF members noted that while the new GDPR provided for exceptions to be made to enable data sharing in specified circumstances, the interpretation of how these should be applied varied between and within countries, and that this was exacerbated by the current lack of legal precedents. Specific questions were also asked about the reporting of individual case data to ECDC and about the sharing of whole genome sequence data.

85. It was suggested that it would be useful if ECDC could provide Member States with a simple explanation of the interaction and data transfer activities with ECDC (why data was sent to ECDC, how it would be protected when using TESSy, EWRS, etc. and the legal basis for the interactions). This could then be placed in internal documents. A question was also raised about the responsibility of a state institution for data protection of group members when creating a Facebook group and sharing information.

86. Andrea Iber said that it was difficult to comment on the national context which would need to be clarified with the supervisory authority in each Member State. By way of example, she explained that the transfer of samples for ECDC was governed by contracts defining who was the controller of the action. ECDC had drafted a data transfer agreement model which it asked contractors to use with the party shipping the samples. ECDC used the contract as a tool to add instructions and what was possible/precluded and always included a safeguard clause stating that anything not regulated under the agreement with ECDC must be fully compliant with national conditions under the terms of the GDPR. Sometimes ECDC also imposed restrictions on the location of the contractor (e.g. that it had to be within the EU where the GDPR was applicable). ECDC worked with model contracts from the EU and there was already some coordination at EU agency level and draft templates were being used for this. With the new GDPR there was always a risk assessment element which might explain the differences between the lines taken by national agencies and those taken by ECDC. EU agency data protection officers met twice a year with the supervisory authority staff at EU level to discuss such issues but Member States would have to work at national level to ensure compliance.

87. Andrea Iber also noted that the European Court of Justice made a judgement in December 2018 on the use of social media websites by operators which concluded that such a situation would be a case of joint controllership. – i.e., not only Facebook but also the user/creator of the account. The court case provided a lot of analysis and ECDC could share the reference to this case which offered some guidance on the legal aspects of this particular case.

88. Mike Catchpole suggested that ECDC could try to supplement existing questions and answers on GDPR for the purposes of guidance but that any national documents would have to make reference to the Member States' own legislation. ECDC could identify the legislation that it applied to enable it to receive the data from the Member States but the individual Member States approach would of course always have to take account of national legislation.

Any other business

89. Jan Kynčl, AF Member, Czech Republic thanked ECDC for the new arrangements for the logistical aspects of booking travel and accommodation in relation to the AF meeting.

90. Mike Catchpole, Chief Scientist, ECDC thanked all the AF members for their participation and wished them a safe journey home. He looked forward to seeing them again at the next AF meeting on 14–15 May.

Annex: List of participants

Member State	Representative	Status
Austria	Franz Allerberger	Alternate
Belgium	Sophie Quoilin	Alternate
Croatia	Sanja Kurečić Filipović	Member
Cyprus	Linos Hadjihannas	Member
Czech Republic	Jan Kynčl	Member
Denmark	Tyra Grove Krause	Alternate
Estonia	Natalia Kerbo	Alternate
France	Jean-Claude Desenclos	Member
Germany	Osamah Hamouda	Member
Hungary	Zsuzsanna Molnár	Member
Ireland	Kevin Kelleher	Member
Latvia	Jurijs Perevoščikovs	Member
Netherlands	Jaap van Dissel	Member
Portugal	Carlos Matias Dias	Member
Romania	Florin Popovici	Member
Spain	Fernando Simón Soria	Member
Sweden	Anders Tegnell	Member
United Kingdom	Paul Cosford	Member
Observers		
Iceland	Thorolfur Gudnason	Member
Norway	Frode Forland	Member
Turkey	Mustafa Gökhan Gözel	Observer
Non-Governmental Organisations (NGOs)		
European Institute of Women's Health	Rebecca Moore	Member
European Public Health Association (EUPHA)	Aura Timen	Member