ECDC Advisory Forum

Minutes of the Fifty-fourth meeting of the Advisory Forum

Stockholm, 25-26 September 2018

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 Dorit Nitzan, WHO Regional Office for Europe, Frank Van Loock, Directorate-General for Health and Food Safety, European Commission, Rebecca Moore, a new observer for the NGO European Institute of Women's Health, Aura Timen from the European Public Health Association (EUPHA), and John Watson in his new official role as AF alternate Member for the United Kingdom. Apologies had been received for Cyprus, Estonia, Finland, Greece, and Italy.

3. There were no declarations of conflict of interest and no proposed amendments to the draft programme, which was adopted.

Adoption of the draft minutes of the 53rd Meeting of the Advisory Forum (25-26 September 2018)

4. The draft minutes were adopted with the following changes: Hungary requested amendments to points 25 and 119 and Masoud Dara, WHO Regional Office for Europe had requested amendments to points 100, 121 169, 173 and 174, and these had been taken into account. Two minor changes were also requested by Portugal.

5. Mike Catchpole would investigate whether the results of the discussion on NITAGS during AF53 had been relayed to the networks.

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

6. Andrea Ammon, ECDC Director, gave a brief update of the main activities since the last Advisory Forum meeting. There was broad support for the proposed new ECDC Vision statement, although there was brief discussion regarding why infectious disease had not been mentioned specifically and whether the vision should include explicit mention of the global impact of ECDC's work.

IRIS prioritisation exercise: principles and process

7. Barbara Albiger, Senior Expert, Scientific Quality, Office of the Chief Scientist, ECDC, introduced the exercise and explained the process.[1] She clarified that the exercise was a test trial and that some fine-tuning might still be required and that it would be possible to postpone proposals after prioritisation had taken place. The revised IRIS process focuses on suites of proposals, instead of individual projects, providing a mechanism for the AF to advise on the broader strategic direction of the Centre's activities, including activities that could be downscaled. It was also noted that it is envisaged that the prioritisation procedure could be used in other areas in the future.

Proposal 1 – E-health and digital strategy

8. Bruno Ciancio, Head of Section, Epidemiological Methods, SRS, ECDC, gave a short introduction to the initiative.

9. **Polling stage 1: round 1** – On a scale of 1 to 5 the AF scored the relevance of the issue for European public health and whether it requires collective engagement. Result: broadly supportive (mean 4.2; median 4).

10. Discussion after the first poll included feedback from several AF members that experience in their countries had highlighted important issues and barriers to the implementation of e-health systems, with some issues being more specific to larger or to smaller countries. There were a number of comments that ECDC's initiative would be welcomed, particularly since Public Health was not always

[1] IRIS prioritisation exercise – principles and process (B Albiger)

recognised as an important stakeholder. Andrea Ammon, ECDC Director, said that digitalisation was driven by the healthcare sector and it would go ahead regardless of public health engagement. It was clear that there were still many issues but for those countries struggling, there is a golden opportunity to identify the barriers and help with structuring.

11. **Polling stage 1: round 2** – the largest shift was from scores of 4 to scores of 5 (mean 4.3; median 5) (i.e. towards stronger support).

12**.** **Polling stage 2: round 1.** On a scale of 1 to 5, the AF scored the quality of the proposal and the relevance of the approach to tackle the issue. Overall, the poll indicated that the AF supported the proposal with minor changes (mean 3.3; median 4).

13. Discussion after the first poll included feedback from several AF members that the proposed projects appeared to be too complex (i.e. involved integration of data from too many disparate systems) or that the disease topics were not ideal. Concerns were expressed regarding resources, varying standards, and about difficulties that might be posed by the recently implemented General Data Protection Regulation (GDPR). Bruno Ciancio said that the topic selection had been driven by the need to learn from the exercise. Other suggestions were welcome, although it was important to choose topics that required data linkage from different data sources to test the system. He noted that a recent Commission Communication defining the scope of e-health had also been very helpful. With regard to differing standards, he wondered whether it was the standards or the conversion mechanism that was the problem.

14. **Polling stage 2: round 2** – The poll following the plenary discussion changed towards "Support with changes" (mean 2.9; median 3).

Proposal 2 - Foresight programme

15. Jan Semenza, Acting Head of Section, Scientific Assessment, SRS, ECDC, presented a short introduction to the Foresight Programme for the enhancement of early warning and preparedness for infectious disease threats in Europe.

16. **Polling stage 1: round 1** – On a scale of 1 to 5 the AF scored the relevance of the issue for European public health and whether it requires collective engagement. Result: broadly supportive (mean 4.2; median 4).

17. Discussion following the first poll included requests for clarification on the kind of events/scenarios that might be recognised at an earlier stage, and suggestions that the initiative should also consider changes regarding demographics and increased lifespan and their impact in terms of reforms to the healthcare system, and public perception as this could affect attitudes and behaviour. Jan Semenza, referring to the type of events and scenarios that might be recognised, said that highly catastrophic events were very difficult to predict and we do not claim we can. He noted that systems at ECDC focus more on individual events, for example, the environmental climatic precursors of a disease, or the social, economic and environmental factors. The idea was to take a more systematic, structured approach, casting a wider net to bring in other disciplines and approaches. This would add value by determining where additional resources were needed. He also agreed it was necessary to address vulnerability and societal risk factors and this would be part of the FORESIGHT initiative.

There was no second round for the polling stage 1.

18. **Polling stage 2: round 1** – On a scale of 1 to 5, the AF scored the quality of the proposal and the relevance of the approach to tackle the issue. Overall, the poll indicated that the AF supported the proposal with changes (mean 3.5; median 3).

19. Feedback from the AF following this round of polling included questions about how this project would affect other aspects of ECDC's work on preparedness and response, how existing data streams managed by ECDC would be used for Foresight activities, and whether the programme would involve diverting existing resources from other programmes. It was remarked that it could also be useful to focus on more common diseases, rather than only rare and emerging threats, and that it would be important to ensure that what other services in the Commission were doing should be taken into account. Jan Semenza noted that a mapping exercise would be undertaken to determine what was already being done so as not to reinvent the wheel. With regard to resources, he confirmed that there were people already working on the project at ECDC but that others might be needed from other programmes in the future, depending on availability. He agreed that it was also necessary to look the

factors causing increases and decreases in more common diseases rather epidemic events, and confirmed that ECDC was already looking at this, for example, in its attempts to quantify burden of disease.

20. **Polling stage 2: round 2** – the second round of polling led to the same result (mean 3.5; median 3).

21. The AF were then asked to indicate, by polling, which disease areas ECDC should start with in FORESIGHT? The polling results ranked antimicrobial resistance first, followed by vaccine-preventable diseases, while food and water-borne diseases and emerging and vector-borne diseases were ranked lowest.

22. Finally, the AF were asked to indicate, by polling, (a) how they perceived the revised IRIS tool, and (b) how they perceived the process? The majority view was that the revised tool is useful, and that the process is easy, but time-consuming. It was also noted that the process had worked well with only two proposals and that the number of proposals should be kept to a manageable number in the future.

23. Mike Catchpole, Chief Scientist, ECDC, said that the two proposals would be reviewed in the light of feedback from the AF. He thanked the participants for their input.

Conclusions and Actions

It was agreed that ECDC would review and further develop the proposals and that both proposals would be brought back to the AF in February 2019 for another round of discussions and polling.

Evaluations of EU/EEA public health surveillance systems (EPHESUS)

a) Evaluation of EU/EEA surveillance of seven priority food and waterborne diseases

24. Therese Westrell, Expert, Food and Waterborne Diseases, Surveillance and Response Support Unit, ECDC gave a short introduction[2] and the Advisory Forum were asked to give their opinions on whether the surveillance system met its objectives, whether the evaluation findings indicated the need for specific change and whether there were any deficiencies.

25. There was general agreement that the report indicated that the surveillance system met its objectives. A number of specific comments were made on the findings and recommendations, including:

a) Many of the recommendations required further consideration. In particular, it was noted that it was necessary to look critically at some of the issues such as *Campylobacter* surveillance and ascertain how useful this was at EU level. It was suggested that priority be given to the areas where the data was used for action – where there were multinational outbreaks with significant challenges.

b) Concern was expressed regarding recommendations on the use of whole genome sequencing to confirm outbreaks, particularly whether this would be cost effective for all outbreaks at present. Several members noted that more support for smaller countries in the area of whole genome sequencing would be useful

c) The importance of ECDC and EFSA collaborating on surveillance and outbreak investigations was emphasised.

d) There were suggestions that future cluster investigations should include more direct involvement of the food industry, although Frank van Loock, European Commission, DG SANTE, noted that the Commission was not keen to see the food industry included and did not think it was a good idea to give ECDC access to the RASFF Food and Feed System.

[2] EPHESUS: Evaluation of EU/EEA surveillance of 7 priority Food- and Waterborne Diseases (FWD) (T Westrell)

e) With regard to the recommendation to make hepatitis E reportable, it was suggested that some form of assessment of the likely impact of such reporting activities on the control and prevention of disease is needed.

f) The suggestion in the report that ECDC should consider giving higher priority to annual epidemiological reports was challenged.

g) The added value of the recommendation of establishing an EU reference laboratory was felt to be unclear.

h) Dorit Nitzan, WHO Regional Office for Europe, said that the suggested recommendations were all strongly supported by WHO.

26. In addition, the following comments were made regarding the overall quality of the evaluation report:

a) The evaluation did not appear to look at whether the EU surveillance system met the needs of the Member States and had helped to reduce the number of outbreaks.

b) It seemed that some recommendations applied more to certain countries than others.

27. Mike Catchpole, Chief Scientist, ECDC noted that the report appeared to have been broadly welcomed as comprehensive, and that the evaluation provided ECDC with a reassurance that it was meeting its objectives, but that now ECDC needed to look at how to prioritise the recommendations.

Conclusions and Actions

The report was broadly welcomed as comprehensive and the evaluation provided ECDC with a reassurance that it was meeting its objectives with regards to surveillance of the foodborne pathogens in question. The AF also expressed broad support for greater collaboration with EFSA, but did not support the recommendation that more emphasis be given to the annual epidemiological reports. ECDC will reflect on other specific comments, including whether there was a case, based on EU-added value, for hepatitis E and certain high-incidence diseases being made reportable.

b) Evaluation of EU/EEA surveillance of Legionnaires' disease

28. Lara Payne Hallström, Senior Expert Respiratory Diseases – Legionnaires' Disease, Surveillance and Response Support Unit, ECDC gave a short presentation of the results of the evaluation[3]. The floor was then opened for discussion.

29. There was general agreement that the report indicated that the surveillance system met its objectives. A number of specific comments were made, including:

a) Several AF members commented that they did not believe that the amount of information collected on each case through these systems should be increased.

b) Mixed opinions were expressed about the importance of recommendations on training, with some AF members noting support for this and others questioning the value.

c) Dorit Nitzan, WHO Regional Office for Europe, thanked ECDC for the excellent collaboration and emphasised the need to further improve the flow of information between ECDC, WHO and country offices.

[3] EPHESUS: Evaluation of EU/EEA surveillance of Legionnaire's disease (L Payne Hallström)

Conclusions and Actions

The general consensus was that these systems were meeting their objectives but that there was not much support for adding new variables to the system. ECDC needed to look at how to improve the timeliness of TALD reporting and at outcomes – the frequency and size of clusters and the impact of legislation and measures.

Implementing whole genome sequencing for EU-wide surveillance of listeriosis

30. Johanna Takkinen, Head of Disease Programme, Food and Waterborne Diseases and Zoonoses, Office of the Chief Scientist, ECDC, gave a short presentation[4] and the floor was opened for discussion.

31. There was a broad consensus of support for the principle of moving to the use of whole genome sequencing (WGS) for EU-wide surveillance of listeriosis.

32. A number of common points were raised during the AF discussion of the ECDC paper, the main concerns and opinions expressed being:

a) The proposal to use twelve months as the period over which case numbers would be accumulated for determining whether a threshold number of cases had occurred, and that cases dated back up to twelve months would be included in case-control studies and trace-back investigations, was too ambitious.

b) Other criteria for determining whether to mount an outbreak investigation that were suggested included an assessment of "preventability" (i.e. whether the investigation into the ongoing outbreak would be likely to either facilitate control the ongoing outbreak or to prevent a similar outbreak at a later date), and/or the existence of a matching strain from food.

c) Mixed opinions were been expressed about the degree of genetic closeness to use to define matching cases

d) There was a majority view that six cases was an appropriate number to trigger an active response (outbreak investigation).

e) Epidemiological capacity for responding to the envisaged increased rate of detection of clusters is likely to be a constraint, and also the workload of the national reference laboratories and the clinical laboratories was also a major concern.

f) Frank van Loock, EU Commission, praised the excellent cooperation between ECDC and EFSA and the increased speed at which they could respond by providing an outbreak assessment, often within 48 hours.

g) Further discussion of the topic is required, and in this respect ECDC should foster closer collaboration with the Member States on the issue of WGS to capitalise on their experience with its use, and there were strong expressions of the opinion that the issue should be discussed with the NFPs/OCPs for food and waterborne diseases.

33. In response to the points raised in discussion, Johanna Takkinen noted that the AF paper addressed a specific aspect of a broader protocol that was under development for WGS-based surveillance of listeriosis, which would be consulted with the FWD NFP/OCPs. She noted that the proposal of a 12-month timeframe for aggregation of case numbers was in order to look at microbiological linkages between cases to ensure that there were no cases with same strain/clone beyond one year, indicating that it could be considered as a recent introduction into the food chain. She also noted that a joint ECDC-EFSA working group is currently looking at how to upgrade the joint molecular typing database, with a view to increasing the number of food isolates being reported to the database.

[4] Implementing whole genome sequencing for EU-wide surveillance of listeriosis (J Takkinen)

34. Andrea Ammon, ECDC Director, noted that approaches and methods to WGS had to be adapted as the technology was evolving, and that the proposal to have a more general discussion on how to deal with this kind of information was a good idea because the more WGS was introduced and used, the more pressing the situation would become in terms of the ability to investigate. WGS was a very valuable tool but only a tool and not a single solution for outbreaks and it needed to be combined with epidemiological data. She suggested that further discussion would help to see how Member States were dealing with this issue and help to avoid further discrepancies. If there were different WGS-related algorithms for surveillance and cluster detection of pathogens in the various countries, they would then be able to explain the reasoning behind this.

35. Mike Catchpole, Chief Scientist, ECDC, confirmed that the discussion would be broadened to include the relevant NFPs, and that there could be a case for an expert group to synthesise the output from those discussions, all with a view to help with a more long-term approach. In moving to WGS for listeria surveillance, he noted that the main concerns appeared to be whether the allelic difference should be 4 or 7, whether six cases was an appropriate number to trigger an active response (outbreak investigation) and whether or not cases older than 12 months should be taken into account. that there seemed to be a consensus on focusing on a more recent time frame and the adoption of a threshold of six matching cases to trigger an active response (e.g. outbreak investigation). Mixed opinions had been expressed about the degree of genetic closeness to use to define matching cases, and that since this question would likely require further expert consultation he proposed using the threshold of 7 SNPs, as an internationally accepted standard, as the starting point for discussion with the relevant NFPs. He also confirmed that the opinions and comments provided by the AF would be taken into account and reflected in the documentation that would now be taken to the relevant networks for further discussion. Discussion would be broadened to include the relevant NFPs and an expert group could possibly be set up to synthesise the output from discussions and determine a long-term approach.

Conclusions and Actions

There was a majority view in favour of focusing on a more recent time frame for cluster definition and follow-up, and a preference for more sensitive criteria for defining clusters in terms of the genetic difference between strains. ECDC proposed to use the algorithm based on a threshold of 7 SNPs for linkage of cases to a cluster, as an internationally accepted standard, and the adoption of a threshold of six matching cases to trigger an active response, as a starting point for discussion with the NFPs. Comments by the AF would be taken into account and the paper would be taken to the relevant networks for further discussion.

Advisory Forum Working Group topic – ECDC Evaluations – Food and Waterborne and IRV Disease Programme Evaluations and the Third External Evaluation. Feedback from Working Group discussions

36. Kåre Mølbak, AF Member, Denmark gave feedback from Group A Food- and Waterborne Diseases and Zoonoses Disease Programme.[5]

37. John Watson, AF Alternate, UK gave feedback from Group B, Influenza and other Respiratory Viruses Programme.

38. There were a number of common themes in the feedback from the working groups on the evaluation of the two Disease Programmes, including:

a) Stakeholder engagement with NFPs and other more immediate stakeholders works well, but engagement with other stakeholders and users of ECDC's outputs who are not NFPs is variable

b) Priority setting appears to focus almost exclusively on continuing existing and starting new activities, but less so on what can be stopped.

[5] Feedback from Group A: Food- and waterborne diseases and zoonoses Programme (K Mølbak)

c) Consideration of EU and Member State competencies should also take into account Member State priorities and challenges

d) There was broad consensus that the DPs have been effective in contributing to EU and national level coordination and capacity development respectively through their involvement in external meetings and country visits, although it was noted that country visits are resource-intensive

e) The extent to which the Disease Programme had contributed to determining research priorities was felt to be difficult to assess because input came from many sources. However, comparisons of disease occurrence, prevention and control among European countries was a valuable means for stimulating research. It was felt that ECDC could be more engaged in setting the research priorities and with DG Research.

f) Both working groups felt unable to answer the question on the alignment of the DP specific objectives and the overall ECDC strategy in the absence of a list of ECDC strategy objectives

g) There was broad consensus that both Disease Programmes provided added value, particularly through data sharing, cross-border intelligence, risk assessments, coordination of responses, bridging to other agencies of relevance, and training. The working group on the IRV Disease Programme evaluation also noted a few areas in which greater added value could be achieved.

h) Dorit Nitzan, WHO Regional Office for Europe, emphasised the complementary roles where ECDC had many more legal entry points than WHO did through IHR (for example via country visits) which was why it worked so well when WHO and ECDC collaborated.

39. In response to a question about how the working group sessions would be followed up, Mike Catchpole, Chief Scientist, ECDC, explained that the contractors would extract all the information from the sessions, report back, discuss and share their findings with the AF.

40. Tsvetelina Blagoeva, PwC EU Services gave feedback for Working Group C, Intervention Logic Workshop – Third External Evaluation[6]. She noted that the Logic Model had been updated in the light of the feedback received. Particular points noted in discussion included:

a) Some activities, such as the monitoring of the Dublin Declaration and EU LabCap monitoring process, did not comfortably fit into surveillance, which was why an additional public health programme monitoring box had been created.

b) Networking and coordination activities, which are one of ECDC's key outputs, were felt not to have been defined in the original Logic Model.

c) The group also felt that an outcome in the area of knowledge, attitudes, behaviour and practices should be included. The positive perception of ECDC by the public health institutes was also felt to be important.

d) There was some discussion about whether it was sensible to mention global impact, however, if ECDC was supposed to have an impact on EU health, it would therefore be difficult for it not to have a global impact. In this respect, Andrea Ammon, ECDC Director, said that this had been included in ECDC's vision and that there were already examples of global impact, for example the Zika maps which had been used by the Brazilian authorities for their policy decisions.

e) There were several comments on the issue of evaluating impact. It was noted that public health was successful if no-one heard about it and it was very difficult to measure what had been prevented, which was what counted. Other comments related to the perceived poor quality of existing measures of impact in the field of public health, with the view that there was a general need for further work in this area. It was also suggested that it was not appropriate to apply measures in areas where it was difficult for ECDC to have an impact. For example, recognition by the public and conveying messages to them, although other

[6] Third Independent Evaluation of ECDC – Results from the workshop on ECDC Intervention Logic Model (T Blagoeva)

members noted that there was reasonable evidence of impact of European Antibiotics Awareness Day as a major health communication process that was well received in the Member States. Another proposed approach was to "work backwards" to establish the type of impact that stakeholders would like ECDC to have – for example preventing Ebola from coming into Europe and measles from being exported from Europe.

f) Frank van Loock, EU Commission, said that for the purposes of the evaluation it was necessary to look back at the areas where ECDC had made a difference, noting that there were many areas where ECDC had made an impact – e.g. MEDIPIET, the Neighbourhood policy, ECDC teams sent to help with Ebola in West Africa and interactions between ECDC and the African CDC, to name but a few.

41. Tsvetelina Blagoeva, PwC EU Services, thanked the AF Members for their feedback. She noted that her job as an evaluator was to capture the effects of ECDC's contribution and to measure this using indicators. She understood that the discussion about global impact was very nuanced but ultimately it was about finding a balanced approach to addressing this.

Conclusions and Actions

The opinions provided by the AF will be used by the external contractors undertaking the evaluations of the FWD and IRV Disease Programmes and the Third External Evaluation of ECDC respectively. The recommendations arising from these evaluation processes will be brought to a future AF for discussion.

Measles case definition – is there a need for an update?

42. Ana Maria Correia, AF Alternate, Portugal, gave a presentation on measles in Portugal, and making the case for a new measles case definition[7]. Tarik Derrough, Senior Expert, Vaccine-Preventable Diseases, ECDC, gave a short reply to the proposal, providing information collated from a survey of the relevant NFPs in Member States, and outlining a number of options for responding to the concerns raised by Portugal.[8] The floor was then opened for discussion.

43. Dorit Nitzan, WHO Regional Office for Europe, said that the main issue, both globally and in the Region, was low coverage. WHO's strategic advisory group of experts was going to look at the proposals for a modified case definition, however until WHO had evidence of waning immunity they would recommend continuing to use the WHO and EU case definition. It was also noted that WHO's SAGE group was working on a new case definition for measles, and that changes of the type proposed by Portugal had not been adopted in the regions that had eliminated measles, such as North America.

44. A number of AF members noted that as the public health significance of 'modified measles' was not clearly established there was little justification for carrying out potentially expensive laboratory investigations to diagnose such cases. Several members also emphasised the importance of maintaining alignment of the definition used by all EU/EEA Member States.

45. Andrea Ammon, ECDC Director, noted that one reason for doing surveillance was to keep track of elimination. She therefore asked whether the addition of the proposed definition for 'modified measles' cases might jeopardise the confirmation of elimination goals. Tarik Derrough, Senior Expert, Vaccine-Preventable Diseases, ECDC, also pointed out that all EU countries had anti-vaccine groups and that it was important to be very careful when communicating on so-called 'modified measles' to prevent damage to the reputation of vaccines.

46. Mike Catchpole, Chief Scientist, ECDC, thanked Portugal for the presentation and noted that clear consensus view in the AF was not to change the EU case definition ahead of any WHO SAGE

[7] Measles in Portugal – A new paradigm for measles case definition (A M Correia)
[8] Measles case definition – is there a need for an update? (T Derrough)

proposals. ECDC could, however, look at providing some advice on approaches to outbreak investigations.

Conclusions and Actions

There was a clear consensus view in the AF that the EU case definition should not be changed ahead of any WHO SAGE proposals. ECDC would look at providing some advice on approaches to outbreak investigations.

ADVANCE Blueprint update and consortium plans for sustainability

47. Piotr Kramarz, Deputy Chief Scientist, Deputy Head, Office of the Chief Scientist/Head of Section, Disease Programmes, Office of the Chief Scientist, ECDC, gave a short update on the status of the project and asked for comments on the added value of the framework for accelerated post marketing evaluation of vaccine benefits and risks and the sustainability of the framework.[9]

48. The paper was then opened for discussion, during which the following points were emphasised:

a) There was broad appreciation for all the work that had been done and the opinion that there would be added value in publishing the works for posterity or future use.

b) There was considerable scepticism about the sustainability of the proposed framework, and particularly its use by many public health authorities, unless funding could be secured that would enable a suitably trusted secretariat and framework custodian to be established. Several members expressed the opinion that ECDC should be resourced to coordinate a sustained framework based on the project. It was also suggested that the European Medicines Agency should be engaged in future coordination.

c) A number of AF members commented on the role of industry within the project, with comments that included that: there was perceived to have been too great a dependence on the role played by industry and that this was unacceptable to a large part of the public health community; while others noted that although the role of industry had not been solved, some of the input had proved useful on how to tackle such an issue.

49. Piotr Kramarz responded to the AF comments, noting that a proof of concept study based on the framework model had been successful and ECDC could see if the framework described in the Blueprint could be used and tested in real life. He also pointed out that in 2019, ECDC would initiate its project on supporting the work and the collaboration of NITAGs, and if the representatives of NITAG could see a need for this suite of tools, ECDC would see how to make them available.

50. Mike Catchpole, Chief Scientist, ECDC, concluded that the overall message from the AF was that this was a potentially useful project but unlikely to be used by public health institutions for public health benefit unless funding was found for a trusted custodian of the tools.

Conclusions and Actions

The AF considered the deliverables in terms of the tools and definition of potential data sources as valuable, but also considered that the preferred model of sustainability was that the coordination structures and tools to be used for public health purposes should be through an entirely publicly funded stream in an EU agency, such as ECDC. He noted that the AF opinion indicated that unless a suitably trusted custodian, that was responsible for updating and maintaining the links, could be identified and adequately resourced, the legacy of project would probably not be sustained.

[9] ADVANCE Blueprint update and consortium plans for sustainability (P Kramarz)

Implications of the General Data Protection Regulation (GDPR)

51. Andrea Iber, Head of Section, Legal Services and Acting Head of Section, Procurement, Resource Management and Coordination Unit, ECDC, gave a short presentation[10] and the floor was then opened.

52. Frank van Loock, EU Commission suggested that this issue should be revisited in 2–3 months' time after Regulation 45 (2001) had been updated. He agreed that it was a good idea to approach national authorities with questions.

53. In response to a question about whether data that had been collected previously could be used later for further research or for investigating some further aspects of a particular disease in the future, Andrea Iber, Head of Section, Legal Services and Acting Head of Section, Procurement, Resource Management and Coordination Unit, ECDC explained that data had to be collected for a specific purpose so it would depend on the initial purpose for collecting the data. She also pointed out that access and ownership of data was going beyond data protection and into the area of intellectual property, rights, and freedom of access to information, which were different legal frameworks.

54. Andrea Iber, Head of Section, Legal Services and Acting Head of Section, Procurement, Resource Management and Coordination Unit, ECDC, responded to questions about data held and processed within TESSy, noting that ECDC had had discussions with the European Data Protection Supervisor (EDPS) and the verdict was that ECDC would treat the data in TESSY as pseudonomised. She also noted that there was a joint controllership between ECDC and the national institutes, so ECDC was not a processor, but a co-controller as soon as data was handed over to it. ECDC had also discussed the issue of molecular data with the EDPS and made some proposals relating to conditions in some of its contracts involving WGS to safeguard against the use of personal data. It was now waiting to hear if the proposals were acceptable. In response to a question about whether pseudonomised data needed to be anonymised after a certain period of time, she responded that with regard to anonymising data after a period of time, there was a legal obligation to only keep data as long as was necessary. If the purpose continued indefinitely and could be justified the data could be kept, but this needed to be decided on a case-by-case basis.

ECDC Advisory Forum meeting dates for 2019 and 2020

55. Ewelina Aydin, Corporate Governance, Director's Office, ECDC, announced the dates for the AF meetings in 2019: 19-20 February 2019, 14-15 May 2019, 24-25 September 2019 and 10-11 December 2019, and in 2020: 18-19 February, 19-20 May 23-24 September and 15-16 December 2020.[11]

56. Mike Catchpole, Chief Scientist, ECDC thanked all the participants for their contributions and wished them a safe trip home. The next AF meeting would take place in the form of an audio conference on 12 December 2018.

[10] Implications of the General Data Protection Regulation (A Iber)
[11] ECDC Advisory Forum meeting dates for 2019 and 2020 (E Aydin)

Annex: List of participants

Member State	Representative	Status
Austria	Petra Apfalter	Member
Belgium	Sophie Quoilin	Alternate
Croatia	Aleksandar Šimunović	Alternate
Czech Republic	Jan Kynčl	Member
Denmark	Kåre Mølbak	Member
France	Bruno Coignard	Alternate
Germany	Osamah Hamouda	Member
Hungary	Zsuzsanna Molnár	Member
Ireland	Derval Igoe	Alternate
Latvia	Jurijs Perevoščikovs	Member
Lithuania	Nerija Kuprevičienė	Alternate
Luxembourg	Isabel De La Fuente Garcia	Member
Malta	Tanya Melillo Fenech	Alternate
Netherlands	Jaap van Dissel	Member
Portugal	Carlos Matias Dias	Member
	Ana Maria Correia	Alternate
Romania	Florin Popovici	Member
Slovak Republic	Henrieta Hudečková	Alternate
Slovenia	Marta Grgič-Vitek	Alternate
Spain	Isabel Noguer	Alternate
Sweden	Anders Tegnell	Member
United Kingdom	John Watson	Alternate

Observers		
Iceland	Thorolfur Gudnason	
Norway	Frode Forland	
Turkey	Gamze Aktuna	
Non-Governmental Organisations (NGOs)		
European Institute of Women's Health	Rebecca Moore	Member
European Public Health Association (EUPHA)	Aura Timen	Member
European Commission		
DG Santé	Frank Van Loock	
WHO		
	Dorit Nitzan	