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Public Health England: Knowledge Strategy

The PHG Foundation welcomes the PHE's Knowledge Strategy paper and commitments to data sharing, transparency and on-going evaluation. We highlight the need for maintaining public trust and the potential impact of draft EU regulations on data protection.

Introduction

The PHG Foundation is an independent health policy think-tank with the mission *making science work for health* and a special focus on genomics and other emerging biomedical health technologies that offer opportunities for better prediction, prevention and treatment of disease. We identify the most useful applications and accelerate their incorporation into medical and public health practice by analysing their projected impact on health systems and services and developing policy to support their translation into practice. This includes promoting a social and regulatory environment that is receptive to innovation, without imposing an undue or inequitable public burden.

General comments

1. Data quality and data sharing forms the basis for developing and delivering high quality services. We therefore welcome the publication of the PHE's Knowledge Strategy, which develops the PHE's role as part of the Power of Information strategy. The Knowledge Strategy paper makes explicit commitments towards realising these

goals as well as providing some clarity about the processes that will be adopted over the next few years.

In general, we support this approach which seems to provide a pragmatic and judicious balance of structure (such as identifying an Information Governance Management Framework) with flexibility (such as using common services, datasets and tools, but not prescribing inappropriate standards).

Commitment to improved data sharing

2. There a number of other aspects of this report that are commendable: first is the commitment to improving data sharing within PHE, and between PHE and associated stakeholders. Examples include the commitment to innovation (to create processes and systems that are dynamic and flexible) in a rapidly changing technological environment. Another example is to avoid unnecessary bureaucracy (page 12) creating processes to identify and evaluate the needs of users at local and national level, whilst also recognising that an integral part of the PHE's role relies upon being able to share information and expertise with a range of stakeholders.

Improving transparency

3. Second, we welcome PHE's commitment to use its existing resources more effectively, and improve transparency about processes. As an organisation focused upon translation of health innovations into practice, our view is that sharing and disseminating knowledge and experience is crucial. We support PHE's approach in developing a co-ordinated Knowledge and Information Service supported by federated knowledge and intelligence teams, and are pleased that the PHE are considering a range of means to improve knowledge dissemination, including developing collaboration software, and communities of practice. Our experience within the PHG Foundation, of translating genomic knowledge in order to facilitate changes in practice suggests that as well as providing an infrastructure to facilitate data and knowledge transfer, fostering a culture that promotes sharing of data and expertise may be crucial, and this requirement is acknowledged in the Knowledge Strategy paper. We have also found that using a multidisciplinary approach, articulating focused and tangible objectives, and securing high levels of stakeholder engagement, are all vital elements for success.

Developing consistent processes

4. Indeed it is noted that one legacy of the Health and Social Care Act 2012 was to create two parallel public health

systems and that the need to integrate these two culturally distinct systems into a single entity is challenging.

5. The paper notes that some tensions still remain, particularly regarding the use of pseudonymised records. Whilst we support the commitment to render datasets linkable and to publish pseudonymised data publicly and by default (commitment 7) we have some reservations about the ways in which genomic information might be pseudonymised and shared. This is because there is a lack of standardised datasets to inform the interpretation of genomic variants. This lack of standardisation applies to both human and pathogen genomes, an issue that is likely to become more pressing in the future as novel genomic technologies such as whole genome sequencing (WGS) and whole exome sequencing (WES) become used more widely in public health. This highlights the need to standardise the genomic information that is analysed, reported and retained. One potential concern is that in the future, if specific pathogen genomes are associated with very rare host genomes, it may be increasingly difficult to secure effective and proportionate pseudonymisation for this category of data.

Surveillance

6. PHE intends to evaluate existing surveillance systems, and identify gaps as well as deficiencies in current programmes. Our view is that whilst surveillance activities are often justified in terms of necessity, that continuing with programmes that are of doubtful value risks undermining public trust and confidence in public health institutions more generally. Thus we strongly approve of the commitment to assess surveillance strategies on the basis of what is necessary and proportionate (and affordable).

Secondary use of data

7. PHE should be aware that some of its proposed activities might be limited or curtailed if the draft EU Data Protection Regulation is implemented in its current form. In particular, the scope of the current draft Regulation has been widened to include pseudonymised data; existing exemptions from the requirement for consent for public health and scientific research have been significantly narrowed; and thresholds for processing pseudonymised data are much higher than under existing law. If the Regulation was adopted in its current form, it could have a significant impact on PHE activities.