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From development to success: the European surveillance scheme for travel associated Legionnaires' disease

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Background: EWGLINET, the European surveillance scheme for travel associated Legionnaires' disease, was established in 1987 following the identification of the disease in 1976. In 1998, the European Commission's Decision 2119/98/EC provided a legal framework for EWGLINET's operation, and its aims and objectives were formalised. Since its inception, the scheme has encountered a number of challenges which have influenced its development as a Disease Specific Network. The solutions to these challenges, and their successes, may be of interest to similar schemes. **Aim:** This article traces the development of the scheme and its responses to the challenges it has encountered. **Results:** One especially significant document developed by the scheme is the European Guidelines for Control and Prevention of Travel Associated Legionnaires' Disease;[1] its history is explored. In addition, EWGLINET's relationship with collaborating centres and other groups such as tour operators is highlighted. **Conclusions:** Despite changing over time, the collaborations and partnerships have been maintained and continue to ensure a close cooperation, maximizing public health effects.

Keywords: EWGLINET, historical development, international surveillance, legionnaires' disease

Introduction

On 6 August 1976 the Morbidity and Mortality Weekly Report (MMWR) published details of an outbreak of respiratory infection associated with an American Legion convention in Philadelphia.[2] On 18 January 1977, a special edition of the MMWR reported that the agent had been isolated and matched serum taken from two earlier unsolved outbreaks of pneumonia.[3] The agent was *Legionella pneumophila*, and the infection came to be known as 'Legionnaires' disease'. With the rapid rise in mass tourism during the 1970's, it soon became apparent that package holiday hotels could be the source of outbreaks of Legionnaires' disease in European resorts. The potential existed for tourists from many different countries of residence to be exposed to a common source of infection in one country and for such an outbreak not to be recognized by any individual country alone.

This article documents the history and development of the international surveillance scheme for travel associated Legionnaires' disease (EWGLINET). It highlights some of the milestones and some of the difficulties and challenges encountered over the last 20 years.

Methods

Minutes from early meetings and recent annual reports were examined to provide the historical background within which EWGLINET was established, in order to determine how the scheme has undertaken its role to achieve public health goals at the European level; to understand the evolving relationship between national and international public health policy and the way in which this might affect collaborations, and to monitor the effectiveness of the scheme in achieving its stated aims and objectives.

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Results

The historical context

The World Health Organisation (WHO) held the first of a series of meetings on Legionella, the new disease with an unknown epidemiology, in 1981 in Austria, and was attended by delegates from 12 countries.[4] A second WHO Working Group meeting was held in 1985 to review the environmental aspects of the control of Legionellosis.[5] In 1986, 23 European epidemiologists and microbiologists working on Legionella from 12 countries held their own meeting (two further countries were unable to attend)[6] and established the European Working Group for Legionella Infections (EWGLI).[7]

EWGLI's surveillance objectives in 1986 were the early detection of common source outbreaks to enable rapid application of control measures, the identification of changes in the pattern of Legionnaires' disease, and the evaluation of preventive and control measures. In 1987 EWGLI launched the international surveillance scheme for travel associated Legionnaires' disease (EWGLINET) with agreed aims and objectives. The WHO Collaborating Centre for Legionellosis, at the National Bacteriological Laboratory (NBL), Stockholm became the co-ordinating centre for EWGLINET. Between 1986 and 1991 annual joint WHO/EWGLI meetings were held and many developments were funded by WHO. In 1989, case definitions were agreed and adopted for the purposes of international reporting.[8] These were published, along with microbiological reporting criteria, as a WHO Memorandum in 1990.[9]

At the sixth WHO/EWGLI meeting in 1991, some founder members argued that the surveillance scheme was not functioning at the level necessary for rapid detection of travel associated clusters of Legionnaires' disease since very few cases were being reported and reporting was not timely. They threatened to withdraw unless action was taken. An opportunity to rethink the scheme occurred in 1992 through a new European funded public health initiative.[10] A bid for these funds was made by England who then successfully sought support from collaborators to transfer the scheme to London. The enhanced European Commission (EC) funded EWGLI surveillance scheme was formally launched

from the Communicable Disease Surveillance Centre (CDSC) (now the Health Protection Agency Centre for Infections) in London on 1 July 1993. A new surveillance protocol and computer software for reporting and receiving information were developed, legal advice on aspects of confidentiality and international reporting was sought and formal participation and confidentiality agreements from new and existing collaborating centres were obtained. EWGLI separated from WHO leadership and support in 1992 but has since retained an international reporting and liaison link with this organization.

In 1998, the EC adopted Decision 2119/98/EC regarding the setting up of a Community Network for the epidemiological surveillance and control of communicable diseases in the community.[11] This Decision provided the legal framework in which to operate for networks that conduct the actual surveillance activities required by the EC. It also made it mandatory for networks such as EWGLINET to formalize its operational procedures and its relationship with the EC. Until that time, EWGLI had existed as an organization without a formally constituted steering committee. Decision 2119 set the following objectives for networks:

(i) To detect and control communicable diseases and prevent further transmission.
(ii) To identify their cause through surveillance and investigation of outbreaks.
(iii) To identify their control measures through investigation of cases of human disease.

In addition, in 1999/2000, EWGLI set objectives for the EWGLINET surveillance scheme as follows:

(i) To continue to develop and maintain a European surveillance scheme for travel associated Legionnaires' disease.
(ii) To enhance the capability within the EU to detect common source outbreaks early, enabling member states to implement timely preventive action.
(iii) To inform all those that need to know about travel associated Legionnaires' disease to promote primary preventive action and collaborative investigations.
(iv) To provide a dedicated website for enhancing EWGLI's information resource.

Significant developments

Case definitions

EWGLINET's transfer to England in 1993 under a new protocol significantly improved operational procedures, satisfaction levels within the group and effectiveness of the scheme. The number of European collaborating countries taking part increased from 23 in 1993 to 35 in 2005 (figure 1) and reporting of cases became more timely and complete. Improved surveillance at the national level in many countries also resulted in better ascertainment of cases at the international level. All collaborators adhere to a set of clinical and microbiological case definitions, first published in 1990[9] and updated in 1998[12] and a common protocol for reporting and receiving information on cases of travel associated Legionnaires' disease. Details of these are published elsewhere.[13] National collaborators report to EWGLINET all cases of travel associated Legionnaires' disease from their country that satisfy the definitions (figure 2).

Additionally, EWGLI defined the status of travel cases. Non-cluster travel cases were cases who, in the 2–10 days before onset of illness, stayed at or visited an accommodation site that was not associated with any other cases of Legionnaires' disease, or cases who stayed at an accommodation site linked

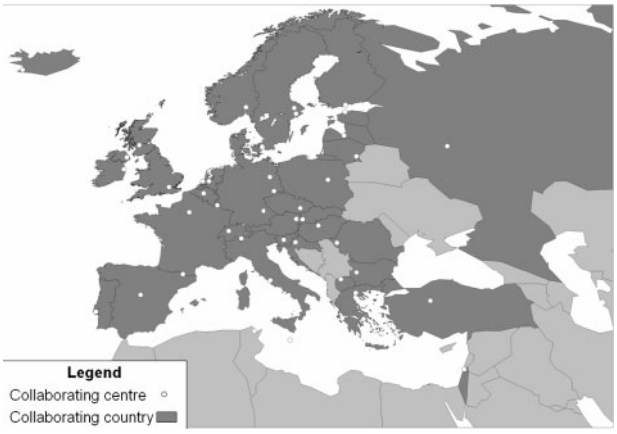

Figure 1 Countries participating in EWGLI in 2005, with collaborating centres

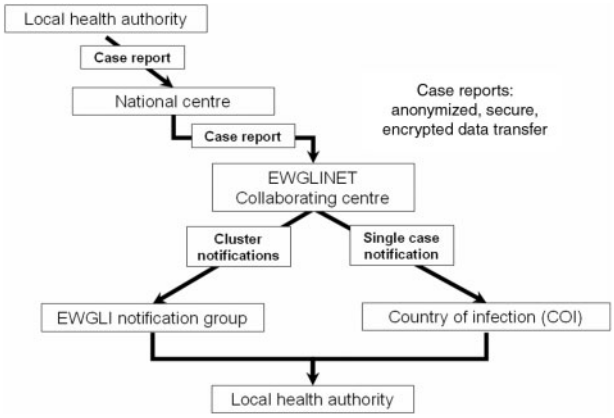

Figure 2 The flow of case-information through EWGLINET

to other cases of Legionnaires' disease but more than 2 years previously. In 1992, a cluster was defined as two or more cases who stayed at or visited the same accommodation site in the 2–10 days before onset of illness and whose onset was within the same 6-month period. 'Linked' cases were two or more cases that stayed at or visited the same accommodation site but whose onset was more than 6 months apart from each other.

In 2000, the EWGLINET Steering Committee noted that a large number of linked cases were falling just outside the cluster definition period, and decided to simplify the definition to one whereby a cluster was to include two or more cases who stayed at or visited the same accommodation site within a 2-year period. The 'linked case' definition was then removed.

Laboratory diagnosis

In EWGLI's early years, most cases of Legionnaires' disease were diagnosed either by culture from clinical material or by estimation of a patient's specific antibody response to the organism.

In 1979, the first urinary antigen test [Enzyme-Linked Immunosorbent Assay (ELISA)] was developed, and was described by Tilton.[14] Several further assays were subsequently reported, with a reduced time required to perform them. Despite the fact that the urinary antigen test has been available since the 1980s, it only began to be commonly used in the 1990s. At EWGLI's 1998 meeting in Helsinki, the diagnostic

definitions were revised to include the urinary antigen test as a confirmatory result.

The absolute number of cultures taken has remained relatively stable over time, but because of the increase in the number of cases diagnosed by the urinary antigen test, the relative number of cases diagnosed by culture has decreased markedly.[15,16]

External Quality Assurance schemes were introduced by the group in 1994 to support and improve the laboratory diagnosis and detection of Legionella in clinical and environmental specimens.

Sequence based typing

Between 2003 and 2005, a Sequence-Based Typing (SBT) scheme for clinical and environmental isolates of *Legionella pneumophila* was developed by members of EWGLI[17] and evaluated for implementation in the investigation of outbreaks caused by *L. pneumophila*. This consensus method aims to assist primarily with travel associated cases, allowing a rapid computer-based comparison of isolates obtained in more than one country.

Web based reporting

In 1999 electronic reporting via a website was introduced by EWGLINET with access to data restricted to collaborators via a secure part of the website.

Freedom of information acts

Adherence to confidentiality of clinical and travel data has always been a strict requirement of EWGLI membership, together with a mutual trust between collaborators for sharing data and an understanding that the data would be used for the purposes for which it was intended. A major threat to EWGLINET's future occurred in September 2000 when speculative media reports and names of hotels associated with clusters of Dutch cases in the last 5 years were published over several days by a leading Dutch national newspaper,[18] 'in the public interest'. The information was released through a Freedom of Information (FOI) request to the Dutch collaborator and Dutch Government. On 1 October 2000, as a consequence of political and media pressure, the Dutch Ministry of Health regularly began publishing EWGLINET data on their government website that included the names of all hotels linked to clusters, where no information could be obtained on what control measures had been taken.[19] This procedure was implemented without agreement from EWGLI collaborating countries and threatened to compromise the relationship between national interests and international collaborations. Many countries, some of whom chose not to respond to reports of clusters associated with their tourist hotels, feared their country's tourism and economic position would be damaged by the actions of EWGLI, whereas certain other countries wished to move towards more open information for their nationals in the interests of consumer health protection. More than one collaborating country began withholding case reports as a consequence of this issue. More recent FOI requests elsewhere in Europe have been dealt with more sensitively and without media attention or adverse publicity.

The EWGLI guidelines

Following the FOI difficulties encountered in the Netherlands and EWGLI's overall disapproval of the Dutch Government's Legionella website and use of its data, a small group from EWGLI was established to develop European Guidelines for the Control and Prevention of Travel Associated Legionnaires' Disease.[1] The guidelines sought to standardize approaches to preventing, detecting, reporting and responding to Legionella infections associated with travel throughout Europe, regulating the circumstances under which details of accommodation sites would be made public. The guidelines were submitted for approval to all collaborating countries and the EC Network Committee operating under Decisions 2119/98/EC and 2000/96/EC[20] and were enacted on 1 July 2002. In 2003, they were fully endorsed by the EC. They have now been in operation for 4 years.[21]

Once a cluster has been notified to the country of infection, the collaborator in that country must complete a Form A report within 2 weeks, confirming that a risk assessment has been conducted and control measures have been initiated. After a further 4 weeks, a Form B report is also required, giving the results of investigations and sampling carried out, and confirming that control measures have been completed. When investigations are not conducted at an accommodation site in accordance with the EWGLI guidelines, details of the accommodation site are published on the public EWGLI website (www.ewgli.org), since EWGLI cannot be sure that the risk of Legionella at that site is under control. The posting is removed once the appropriate documentation has been submitted to the co-ordinating centre. Subsequent to the introduction of the guidelines, the Netherlands agreed to close their own Legionella website.

Within the EU, all countries signed up to the guidelines with the support of their Ministries of Health (or equivalent). Collaborators in other European countries were required to obtain written support from their Ministries of Health before adopting the guidelines. Currently, 98% of collaborating countries approve the use of the website postings in situations where the guidelines have not been followed. The legality of the postings on the website has not yet been challenged.

The role of tour operators

Following the implementation of the EC Directive for Package Travel[22] (90/314/EEC) in 1996, some countries, such as the UK and The Netherlands, introduced procedures for reporting cases of travel associated Legionnaires' disease to tour operators. The Directive gave tour operators responsibility for the health of their tourists. EWGLI encouraged individual countries to report information on single cases and clusters of Legionnaires' disease in their residents to their respective national body of tour operators. If the report was for a single case, hoteliers were reminded of the need for proper maintenance of their hotel water and air conditioning systems, using a checklist provided by the Health Protection Agency (formerly the PHLS). On receipt of a cluster alert, tour operators considered immediate withdrawal of their clients from the hotel, their decision being influenced by the actions taken by the hotel and the local health authorities, together with the number and timing of the cases involved.[23]

In July 2002, the EWGLI guidelines were introduced as described earlier, and included a change in policy in relation to reporting to tour operators. The co-ordinating centre in London no longer routinely reports clusters of travel associated Legionnaires' disease to any group of tour operators. This was necessary because many were responding to cluster reports by commissioning commercial companies to carry out investigation and control measures at the accommodation site. These were rarely done in collaboration with local public health staff

and the results of their investigations were not made available to the EWGLINET surveillance scheme. The fact that <50% of all holiday bookings are made through tour operators was an additional reason for changing policy. The majority of tourists might not be protected by the interventions carried out by tour operators.

If a cluster site fails to properly implement the EWGLI guidelines, details of the site are published on the EWGLI website. Members of the public and tour operators alike are then able to choose whether or not to continue to use the hotel in question. When the cluster falls in a country not signed up to the guidelines, or when three or more cases are associated with a cluster within a 3-month period, there is a need for immediate action at a site and tour operators are therefore informed regardless of the public health action being carried out, in order to better protect tourists at the site.

Funding

EWGLINET was originally run from Sweden, with limited WHO funding. The scheme transferred to England in 1993, with funding from the EC. The EC's Directorate General V (subsequently DG Sanco) programme agreed to cover 70% of the costs of the scheme, whilst the Public Health Laboratory Service (PHLS) (now the Health Protection Agency) funded the remainder. CDSC was required to re-apply for a new grant every one to 3 years, and over time the amount of co-funding provided by the EC dropped from 70% to <60%. As of 2007, funding will transfer to the European Centre for Disease Control and Prevention (ECDC). This institution was formally opened in 2005 and has taken over responsibility of the networks from the EC.

A success story

It is widely acknowledged that the EWGLINET surveillance scheme has been highly successful in meeting its European public health goals. The number of cases reported each year has increased annually from <10 in 1987 to around 700 in 2005. Over 5000 cases are now on the database.[24] The use of the urinary antigen detection method for diagnosing Legionnaires' disease has contributed to the rapid reporting of cases and the early recognition of clusters associated with hotels or other types of accommodation. Over time, the quality of information has improved and more complete information on travel histories and patient outcome is being reported. Strengthened collaborations between participating countries and measures taken at the national level have also contributed significantly to the effectiveness of the scheme although success would be further enhanced if all countries that have cases associated with travel within their own country also reported these cases to the scheme, in order to increase the number of clusters detected. Unilaterally bringing data into the public domain in the Netherlands spurred the group to produce European guidelines which fortuitously were universally adopted, leading to rapid, coordinated and standardized action in collaborating countries, an improvement in control and prevention measures and a more effective public health surveillance scheme.

The value of international collaboration is proven by the fact that the surveillance scheme has detected 40% more clusters than would have been detected by individual countries alone.[24] International collaborations have also led to more timely public health responses, including pan European outbreak investigations, many of which have been published or presented at international conferences. EWGLI has made a major contribution in raising awareness of the risks involved in improper management of water systems and cooling towers in tourist accommodations in Europe and elsewhere. The combined pressure of public health authorities and tour operators has resulted in the implementation of preventive measures in most, if not virtually all, major tourist accommodations in Europe. Through the collaborative actions of EWGLI members, public health officials and tour operators, travellers from many European countries are being protected from Legionella infection within and outside their own country of residence.

The future

On 1 January 2005, a new Freedom of Information Act was introduced in the UK.[25] This Act is unlikely to impact on the scheme to the same extent as the Netherlands' act because of the extensive guidelines which EWGLI has now put in place, however, it could still have some implications since the scheme is coordinated from London. To date, one incident has arisen for EWGLI as a result of this new Act.[26]

The ECDC is currently in the process of deciding which Dedicated Surveillance Networks, if any, should be transferred to Stockholm. What impact this will have upon the scheme remains unknown at this time. However, it would be unthinkable that the public health gains will be lost after a possible transfer.

Whoever ends up running EWGLINET in the future, it is almost certain that the scheme will continue to widen its international collaborations—both with European countries who do not currently participate in the scheme and with countries outside Europe with whom EWGLI enjoys a cooperative relationship. The continued success of the scheme depends as much on the enthusiastic support given to it by the collaborators as it does on the scientific knowledge base in which it operates.

Conclusion

Constraints, conflict and control have been identified as contributing factors in the history of EWGLINET. Many countries were constrained early on by their inability to contribute as equal partners. Improving the level of their national surveillance was necessary for data to be available to meet the scheme's objectives and for them to effectively participate in the scheme. Conflict arose when response to cluster alerts was inappropriate or completely lacking, either by the country of infection, the tour operators or when perceived breaches of confidentiality occurred. Control was exercised by collaborators when deciding whether or not to retain information on clusters or forward it for further action. Over the years all of these issues have been confronted by the scheme. However, the resilience and robustness of the collaborators and constituent parts of the scheme has enabled it to respond in a positive way and incorporate new technological developments, as well as internal and external policies and practices. We are confident that it will continue to grow and operate as a successful network in the future, meeting all of its objectives at the highest level possible.

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Conflicts of interest: None declared.

Key points

- The success of the EWGLINET scheme for the surveillance of travel associated Legionnaires' disease has depended to a large extent on the close cooperation of collaborating countries during its development.
- Freedom of Information Acts have posed challenges for the scheme, but have resulted in the introduction of the European Guidelines for Control and Prevention of Travel Associated Legionnaires' Disease.
- The European Guidelines have led to a more standardized approach to investigations across all European countries, ensuring that high standards are achieved and maintained and that travellers are better protected.

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Annex 1

Main abbreviations used

CDSC = Communicable Disease Surveillance Centre (now part of the Health Protection Agency)
EC = European Commission
ECDC = European Centre for Disease Prevention and Control
ELISA = Enzyme-Linked ImmunoSorbent Assay. A technique to detect the presence of antigen
EWGLI = European Working Group for Legionella Infections
EWGLINET = European Surveillance Scheme for Travel Associated Legionnaires Disease
FOI = Freedom of Information
NBL = National Bacteriological Laboratory
PHLS = Public Health Laboratory Service (now part of the Health Protection Agency)
SBT = Sequence Based Typing. A consensus method, allowing rapid computer-based comparison of isolates obtained in more than one country.
WHO = World Health Organisation

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