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Integration of disease surveillance in the English context: a qualitative study

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ABSTRACT

Objectives: The world is experiencing increasing threats from infectious diseases and environmental hazards. Integration of disease surveillance systems has been put forth as one way to ensure more timely analysis of data and response. This study sought to explore the current context and state of integration of disease surveillance in England, including the barriers and facilitators to integration, as well as opportunities for improvement.

Study design: Qualitative study with focus groups and key informant interviews.

Methods: Focus group discussions (FGDs) and key informant interviews (KIIs) were conducted with key national, regional, and local stakeholders involved in surveillance activities in August and September 2022. These discussions and interviews were recorded, transcribed, and coded using a within-case content and thematic analysis.

Results: In total, five FGDs and 10 KIIs were conducted with 27 participants. Participants had different views on what integration is, though mostly agreed that surveillance systems in England are not integrated. Lack of standardisation, governance and oversight, and structural and financial barriers were hindering the current system from being more integrated. The additional benefits of integration above and beyond the 'status quo' during response activities were questioned by some.

Conclusion: England does not have a single integrated disease surveillance system but has a range of disease-specific surveillance systems that have evolved largely independently to meet operational needs. Greater integration may be desired and to a certain extent is important, but it is essential that it is understood as a means to an end and the overall purpose of surveillance is kept in mind.

Introduction

Infectious disease and environmental hazard reports are increasing globally, as evidenced by the 2014-16 Ebola outbreak that spread to 10 countries and caused 11,325 deaths, an outbreak of Mpox virus in more than 30 countries in 2022, and the COVID-19 pandemic.[1,2] As evidenced increasingly in One Health research, environmental issues and global climate change are contributing to the emergence and re-emergence of infectious diseases.[3] In the UK, the government has ranked pandemics as the threat with the potential for greatest impact in its National Risk Register and sets out in its pandemic preparedness plans the need for robust surveillance.[4,5]

Surveillance is an essential component of any national health protection system, underpinning its ability to detect and assess the impact of hazards to inform a response. In most countries, distinct surveillance systems for a range of health threats often operate independently or are integrated to varying degrees. The integration of disparate surveillance systems should improve information sharing and more accurate and timely analysis of data to inform action.[6] Integration of surveillance is purported to be part of a solution to prevent recurrence of delayed decision-making and deficient responses, such as those seen in many countries during the COVID-19 pandemic.[6,7,8] Much of the published work on integration of surveillance systems has focussed on lower-middle income country settings or on integrated disease surveillance and response (IDSR), which is a specific strategy for implementing surveillance and response systems advocated by the World Health Organization

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(WHO) African Region.[9] While IDSR is a strategy specific to the WHO African Region, there is little literature on the state of integrated disease surveillance (which includes response as a core component of surveillance) as a concept (referred to in this report as IDS) in other regions of the world.

In England, the UK Health Security Agency (UKHSA) is the government agency responsible for public health protection and infectious disease surveillance. It has a remit to 'develop a robust health intelligence system that is accessible and integrated for the timely identification and prevention of public health threats reaching the UK'.[10] UKHSA took on these responsibilities from, now dissolved, Public Health England in October 2021. It also serves as the International Health Regulations (IHR) National Focal Point for the UK on behalf of the four nations (Scotland, Northern Ireland, Wales, and England). UKHSA has several directorates and teams whose work is important for IDS. These include national, regional, and local field epidemiology service teams, data and analytical sciences, and health protection teams. In addition, certain public health functions relevant to surveillance sit with local authorities, the National Health Service (NHS), and the Office of Health Improvement and Disparities (OHID). However, there is little published information on the state of integration of surveillance systems in England.

The aim of this study was to explore the current context and state of integration of disease surveillance in England, including the barriers and facilitators to integration, as well as opportunities for improvement.

Methods

Study setting

This study is part of a wider multicomponent programme funded by the Bill and Melinda Gates Foundation (BMGF) and delivered by International Association of National Public Health Institutes (IANPHI) of which the UKHSA is a member. This programme seeks to obtain a comprehensive understanding of the current state of IDS implementation globally as well as elucidate the available evidence-base for IDS. The content, methods, and findings of the programme are published fully elsewhere, including summary findings from the individual deep dives.[11,12] This article specifically focuses on one component, the in-depth study of IDS in England, and seeks to provide a more comprehensive overview of the findings from this study that is not published elsewhere.

Study type

The study used qualitative methods to assess and understand the state of integrated disease surveillance in England. Five domains considered necessary for IDS, using a bespoke framework based on the WHO IDS framework and Morgan et al. (2021), were overarching themes for analysis, namely: 1) governance, 2) system and structure, 3) financing, 4) core functions, and 5) resourcing requirements.[8,13]

Qualitative data

Qualitative data were collected through key informant interviews (KIIs) and focus group discussions (FGDs) with stakeholders in human health, animal health, and environmental health disciplines working at national, regional, and local levels of the England administrative system. Invitees to the FGDs and KIIs, included individuals specialising in screening and immunisations, health protection, field services, healthcare public health, environmental hazards, COVID-19, and public health intelligence.

FGDs and KIIs were conducted in English, lasted between 45 and 90 min, and were moderated by trained members of the project team, who were all UKHSA employees or held honorary contracts with UKHSA. In the FGDs, each moderator was assisted by a note-taker. One FGD and one KII were attended by an external observer from the Public Health Agency of Canada. Topic guides for the IANPHI project were adapted to the English context and provided questions and prompts for the semi-structured interviews and discussions (Supplementary File 1). Each moderator and note-taker attended training in qualitative interview and FGD methods. All FGDs and KIIs were conducted online via Microsoft Teams and digitally recorded for transcription and analysis purposes. All identifying information collected during the FGDs and KIIs was kept confidential. Recordings and transcripts were saved in a secure cloud folder accessed only by the project team. Participants were sent information in advance about the study. Participation was voluntary, and participants could decline to participate or leave at any time.

Analysis

A within-case content and thematic analysis was conducted once all KIIs and FGDs were complete. Two analysts (who had facilitated, interviewed, and/or observed the FGD and KIIs) reviewed the summary notes. A deductive-inductive approach was used for the thematic analysis. Responses were compared across different topic areas, health system levels, departments, and organisations to identify patterns that emerged, which were then grouped into five thematic categories based on the framework domains (governance, systems/structures, core functions, finance, and resourcing). The data were also reviewed for new emerging themes. Our results describe the state of integration of surveillance in England according to the framework domains and two novel thematic areas: consensus on integration definition and the need for integration.

Results

Five FGDs were conducted with a total of 17 stakeholders. Ten senior stakeholders from different organisations (including UKHSA, Animal and Plant Health Agency [APHA], and OHID) participated in KIIs. Each of the five FGDs had participants from UKHSA as well as other organisations.

State of surveillance in England

Participants were able to describe details of surveillance systems in England that were not readily available in academic or grey literature. Some explained there was no single overarching surveillance structure that spans across specialists, instead there are multiple separate surveillance systems. These systems use different tools and interfaces, though most are electronic with some manual linkages or data entry required. Many stakeholders were able to describe their specialist area of surveillance, either by topic (e.g., gastrointestinal infections, environmental), discipline (e.g., field epidemiology), or geography (e.g., local authority area), but admitted they did not have a complete understanding of and were unable to describe or list other surveillance systems within England. Most of the surveillance systems were described as highly developed and standardised in terms of topic areas covered and data flows at the regional or national level. However, those seeking information on local occurrences of a disease must go to multiple places to find the information. A participant explained that UKHSA is moving towards a more integrated system in England; there is now a clear technical objective to create systems that do so and new platforms are in development.

The list of [where] integration doesn't happen is a lot longer than the list of [where] integration does happen, but the few instances where it does happen shows that a) [it] is feasible and b) [it] is real. (KII, UKHSA, National)

The findings also corroborate the key domains identified a priori as necessary for integration. These are presented as follows.

Governance domain

Within England, laws and other regulations facilitate surveillance by mandating reporting and providing a legal instrument for sharing of data, e.g., the notification of infectious diseases (NOIDs), IHR, and changes to legislation during the COVID-19 response, which allowed for increased sharing of data. However, not all hazards of public health importance are supported by legislation (including some environmental hazards); there is no law to mandate integration of surveillance, and no requirement to report or record negative test results outside of enhanced investigations and research studies.

The legal duty to spell out [where surveillance] should happen is [in fact] a powerful mechanism by which integration can happen (KII, UKHSA, National)

COVID-19 was a game-changer in terms of data sharing … it made [it] much easier for us to actually share data with other organisations and … quite granular information. (KII, UKHSA, Regional)

Is there a single set of overarching guidance or even a legal instrument?… Not at all (KII, UKHSA, National)

Stakeholders explained that there is no single overarching governance body for human health surveillance across the UK, though activities must occur within the governance controls set out by separate organisations. In contrast, APHA has the UK Surveillance Forum, chaired by the four Chief Veterinary Officers of the four nations in the UK. This group oversees different aspects of surveillance across multiple species.

Participants felt that UKHSA should ideally have influence over the quality of data collection, particularly in terms of how data are collected and standardisation of systems, definitions, and tools. Currently, it lacks the authority to do this since most data are initially collected by the NHS. UKHSA can provide guidance but does not have the authority to mandate a change in the system. Some stakeholders felt that there was a natural separation between which organisations assess risks and those that take decisions to manage public health risk; some felt that UKHSA should not play both roles. Notwithstanding, stakeholders described that UKHSA does have the responsibility for ensuring system governance to effectively detect disease threats and to have intelligence to respond to them effectively.

Key thing is the overall strategic leadership of surveillance with a purpose and therefore some rational priority setting (KII, DHSC, National)

There is a bit of statute on who's allowed to take actions, especially at the national level, and it almost always defaults back to a politician, government, to ministers (KII, UKHSA, National)

I'm not a full advocate… in separating risk assessment from risk management…I personally feel UKHSA provides the expert input…. If something is not feasible to implement, that's for the risk managers, which in my opinion is… government [to deal with]. I feel that when UKHSA slightly puts a foot in both camps, that's where things potentially could go wrong (FGD, National)

Systems and structure domain

In England, many different organisations are involved in surveillance to varying degrees (Supplementary File 2). Organisational boundaries within England and national boundaries within the UK make integration difficult because each one has different access to data assets, IT systems (even within the same organisation), and procedures, and may use different definitions and denominators. Trust, relationships, and goodwill between colleagues help to overcome some of these boundaries by sharing of information, on often an ad hoc basis, via networks and meetings. However, public health system restructuring has redefined organisational remits for disease surveillance and disrupted previous relationships.

What I do think is probably essential is that we have the right people talking to each other and informing each other about what data are available so that they, as the experts, can work together on deciding which data to share (KII, APHA, National)

The constant [public health system] reorganisations … are not helping, changing rules and responsibilities (FGD, Regional)

Part of the difficulty is that half the people [who used to work on surveillance together have] moved out of the agency (KII, UKHSA, National)

When systems do not support access to data across organisations, further delays may be experienced if there is siloed working (within or across organisations) or an unwillingness to share, for example, due to information governance concerns or professional concerns about appropriate use of data sets. Some described a risk that if data are given away too freely, it may be misinterpreted, and wrong decisions or actions may be taken based on those assumptions.

You lose some of the nuance of each of the data sets as they're collected because each individual data set has its own…quirks and foibles that you as an asset owner…as an expert know about….[when] things get shifted and pushed into one big pool of data you lose that nuance and you lose that understanding of what the data can and can't tell you (FGD, National)

Finance and resource requirements domains

Technology to enable integration of surveillance exists, but a lack of funding means activities to make use of this technology and fully realise its benefits cannot be conducted. Budget cycles are usually only a few years long, so long-term sustainability of surveillance funding is not guaranteed. New collaborative surveillance activities may also have the problem of lack of clarity as to which agency will fund which aspects.

One of the big problems is that no one wants to fund surveillance. People will fund research….That's quite an important difference (KII, OHID, National)

We have to stop expecting the highest level of results without funding things (FGD, Regional)

We've never really had the money to do this (KII, UKHSA, National)

Core functions domain

In terms of core functions, the need for standardisation was highlighted by many stakeholders who reported the lack of sufficient standardisation in definitions, units of analysis, denominator populations, reporting styles, testing availability and approaches, geographical boundaries, quality, and other components across the health system are major barriers to integration. In addition, a lack of metadata limits in-depth understanding of exposures and outcomes, which necessitates research. Measures to increase the standardisation of reporting, such as the development of an internationally agreed set of definitions and the provision of Standard Operating Procedures or guidelines, and incentives to improve standardisation of reporting, were suggested by stakeholders.

> *If we are working to be able to integrate our disease surveillance or integrate our disease data…. we have to be collecting it in a consistent and standardised way, using the same definitions (KII, UKHSA, National)*

> *I don't feel like we have enough influence or control over the standardisation of data and tests and reporting of tests… (KII, UKHSA, Regional)*

There were also two emerging themes from the study, namely the lack of consensus as to what integration means in practice, and questions regarding the need for it.

What is integration?

There was no consensus among participants as to what integration means in the English context. The question 'what do we mean by integrated disease surveillance?' was frequently asked at the beginning of the KIIs and FGDs by participants. Some viewed it as the system's ability to converge the most detailed level of data in one place to conduct joint analysis, while others viewed it as the ability of users at the frontline of health care provision to access information in a timely and efficient manner (thereby demonstrating the performance of the entire system), linking with response, or being able to follow a patient's journey throughout the public health system. For all interpretations, stakeholders felt that most systems were not integrated in England. While data are frequently shared with individuals and organisations through networks, forums, or ad hoc communications, stakeholders did not feel this qualified as integration.

> *There is very good synthesis of insight across multiple surveillance systems…But I don't think that they are integrated in the sense that we can present them for interrogation in the same kind of analytical environment. (KII, UKHSA, National)*

> *Just talking to each other, sharing effectively… that is not surveillance integration… that is just using the surveillance information wisely (FGD, Regional)*

Need for integration

While integration was viewed positively by some stakeholders, one interesting finding was that some stakeholders questioned the need or benefit from additional or total integration of surveillance and demonstrated a wariness towards a universal solution. The scope and nature of surveillance integration should be determined by the aim of the disease surveillance system, which is based on individual, organisational, and political priorities, and these may not be aligned. Therefore, questions around 'what and who are we integrating surveillance for?' were raised. The aims of the surveillance system should be borne in mind and some integration may risk losing nuance and compromising aims. Some were concerned about the risks of a single system leading to an 'unwieldy' IT infrastructure that would have a substantial disruptive impact if it were to stop functioning.

> *It would take… lots of time and manpower and resources and money to do [integration]. And what would that enable us to do that we can't at the moment? (FGD, Regional)*

> *We can have an integrated surveillance system, but what is the purpose? What do you need to know? … are we sharing it with you for [a] purpose? (FGD, Regional)*

> *If we have one consolidated set up, we are even more at risk …. when something goes wrong that we would all lose access to the data that we need to enact public health action. (FGD, National)*

It was, however, noted that integration of surveillance systems should not just be for infectious diseases. It is essential to include both environmental hazards and animal health, utilising a One Health approach to effectively manage health threats.

Discussion

To the best of our knowledge, this is the first time the state of disease surveillance integration in England has been assessed. The surveillance system in England is not integrated, but participants felt the existing systems were mostly fit for current purposes. Due to the plurality of surveillance systems, it is uncertain whether a fully integrated disease surveillance system within England can be realised. There was a lack of consensus among stakeholders as to what integration means, as well as a questioning of the additional benefit integration would provide.

Whilst integration can have significant benefit for research purposes, key informants were less sure if there would be an additional benefit to acute service work and response activities. However, this could be due to lack of awareness of the potential benefits integration provides. Enthusiastic advocacy is important for promoting and enabling integration of surveillance systems, including human, animal, and environmental hazards. Surveillance must be an ongoing process, if it is stopped signals are missed, and if restarted, missing data impede trend analysis. Therefore, it is necessary to have the long-term resources to reflect the longitudinal nature of the work and adequate funding to deliver additional beneficial action beyond the current status quo.[6] If pursued, it is clear there needs to be political support and prioritisation, and adequate funding.

While the current remit for UKHSA states that it should 'develop a robust health intelligence system that is accessible and integrated', stakeholders did not seem aware of this, or at least did not mention it.[10] Additionally, most stakeholders directly involved in surveillance activities reported they didn't have much knowledge of the other surveillance activities in England, which implies no single group or person has full understanding of the whole surveillance system. It would be a considerable undertaking to go from the current status quo of iterative surveillance system reform to a 'one size fits all' approach. However, current surveillance systems could be improved to be more automated and agile, with data sharing agreements in place.[6] This requires willingness to fund improvements to these systems during 'down-times', which may not be seen as cost-effective as the impact and value of surveillance system activities changes with context. Further clarity on what is

meant by 'integrated', and the role and responsibility of UKHSA and other stakeholders would be beneficial. This is especially in terms of whether the UKHSA's role is to assess or manage disease risks, or both. Surveillance activities are also undertaken by organisations outside of UKHSA. Should governance of England's surveillance systems be strengthened, those responsible could make use of WHO's TAPIC framework.[14]

It is important to understand where integration adds value and how it achieves intended population health outcomes. Further cost-benefit analysis on the value of integrated disease surveillance in systems with good disease prevention, mitigation, and preparedness measures would inform distribution of resources for action.

The findings of this study must be considered in light of its limitations. Participation rates were low for the FGDs and KIIs due to the limited availability of potential participants. The researchers were UKHSA staff, which may have introduced bias when interviewing other members of the same organisation. Finally, the participants are drawn from England and may therefore not be generalisable to the other UK nations (Wales, Scotland, and Northern Ireland).

While there are mechanisms to enable data-sharing, England does not have a single integrated disease surveillance system. Further integration may be desirable to ensure improved outbreak detection and response but will only be feasible by certain conditions being met: clarity on the scope and nature of integration, political will and support, additional sustained funding, and clarity of organisational governance. Integration to a certain extent is important, but it is essential that it is understood as a means to an end and the overall purpose of surveillance is kept in mind.

Author statements

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Ethical approval

This study received organisational approval from UKHSA to be conducted in England. Separately, an ethical waiver was sought and received from the Institutional Ethical Review Board at Emory University, on behalf of IANPHI, on 8 July 2022 that covers the IANPHI global study of which this study is a subcomponent.

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Competing interests

AL is the co-editor-in-chief of the journal.

Authorship contribution statement

All authors were involved in data collection, analysis, and interpretation. JW drafted the article and SM, HW, and AL provided revisions. All authors approved the final version.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.puhe.2023.07.027.

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