

The development and growth of the English national real-time syndromic surveillance programme: a tutorial on the key developments and lessons learnt from the first two decades

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Abstract

Background: Syndromic surveillance now forms an integral part of the surveillance for a wide range of hazards in many countries. Establishing syndromic surveillance systems can be difficult due to the many different sources of data which can be used, cost pressures, the importance of data security and different technologies.

Objective: We describe major points in the development of the UK Health Security Agency (UKHSA) English real-time syndromic surveillance service over its first two decades (1998 to 2018) and key wider themes we believe are important in ensuring a sustainable and useful syndromic surveillance service.

Methods: We conducted semi-structured interviews with current members of the UKHSA syndromic surveillance team who were involved from the earliest stages and previous senior colleagues who were supportive of the syndromic surveillance work during the early phases. We asked their views about the development of syndromic surveillance, the key drivers and the challenges.

Results: Using the results of the discussions and our personal experience of running the syndromic surveillance service from inception and over decades, we summarise our recommendations for establishing and running sustainable syndromic surveillance systems.

Conclusions: In this age of increased automation, with the ability to transfer data in real-time and to utilise machine learning and artificial intelligence, we are approaching a 'new age of syndromic surveillance'. We consider the focus on the public health questions, relationships and collaboration, leadership and true teamwork should not be underestimated in the success of and usefulness of real-time syndromic surveillance systems.

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Original Manuscript

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Conclusions: In this age of increased automation, with the ability to transfer data in real-time and to utilise machine learning and artificial intelligence, we are approaching a 'new age of syndromic surveillance'. We consider the focus on the public health questions, relationships and collaboration, leadership and true teamwork should not be underestimated in the success of and usefulness of real-time syndromic surveillance systems.

Keywords: syndromic surveillance; epidemiology; England; health protection; infectious disease; all hazard

Background

Syndromic surveillance provides early warning of public health incidents, situational awareness of ongoing incidents and reassurance during large scale events. Used globally, syndromic surveillance uses real time automated data captured from sources such as general practitioners, emergency departments (EDs), telephone health helplines and websites, and pharmacists. This allows for the early identification, distribution and influence of public health hazards to be determined. Although syndromic surveillance now forms an integral part of the surveillance of a wide range of hazards in many countries, establishing syndromic surveillance systems can be difficult because of the numerous different sources of data available, cost pressures, the importance of data security and different technologies.

Syndromic surveillance in England developed from a small pilot project in 1998 based in the West Midlands to a suite of systems used nationwide and constituting a key element of surveillance for communicable and non-communicable diseases [1]. Elliot et al (2024) recently described the evolution of technical and data aspects of this development [1], but there is little in the literature describing the process of development and the lessons learnt for those developing syndromic surveillance across the World.

We here describe major points in the development of the UK Health Security Agency (UKHSA) English real-time syndromic surveillance service over its first two decades (1998 to 2018) and key wider themes we believe are important in ensuring a sustainable and useful syndromic surveillance service. We draw upon over a century's collective experience from the England syndromic team members, and from key public health stakeholders who 'championed' the development in the early stages.

Methods

The UKHSA national real-time syndromic surveillance programme currently consists of six national systems, each monitoring an anonymised feed of health data obtained from a different part of the National Health

Service (NHS). Daily feeds include: NHS 111 calls (telehealth); NHS 111 online assessments, ED attendances, general practitioner (GP) in-hours consultations, GP out-of-hours contacts, and ambulance dispatch calls. Daily data are received from each system, then analysed, interpreted and assessed, then, where necessary action is taken. Analysis and assessment include epidemiological, statistical and risk assessment [2,3]. The team running the surveillance (the Real-time Syndromic Surveillance Team, ReSST) is a multi-disciplinary team of consultants, medical epidemiologists, epidemiological scientists, experts in informatics and database management and statisticians (approximately 10 people).

We conducted informal semi-structured discussions between October 2023 and April 2024 with past and current members of ReSST who were involved in establishing and developing syndromic surveillance in England from an early stage. In addition, we spoke to senior public health professionals who were supportive of the syndromic surveillance work during the early phases (termed syndromic ‘champions’).

Altogether ten semi-structured discussions were undertaken (three team members, two current or past team managers and five champions). All discussions were conducted by GES using a semi-structured questionnaire via video conferencing. The discussions were informal, between colleagues/ex-colleagues (some of whom are authors on this paper), and consent was given for the discussions to be recorded. Within the discussions, the reasons behind the sustainable development of the surveillance service were explored, alongside the drivers of the development and significant events or outputs.

In the first instance, GES reviewed the transcripts and extracted key themes that were important in the development of the surveillance service. Following discussion with NRJ, key themes were refined and developed into the discussion reported here. This was also supported and supplemented through the collective experience of GES and AJE who have led the development of syndromic surveillance in England since its inception. In addition, GES reviewed key documents of the team including notes of strategic meetings; reports on the work; and surveillance outputs (both routine and

in support of incidents) between 1998 and 2018.

We divided the evolution of syndromic surveillance in England into three time periods, named according to the phases in syndromic surveillance development: 1998 to 2005 ('the beginnings'); 2006 to 2011 ('the growth phase'); and 2012 to 2018 ('mainstream'). For each of these phases we considered three areas of development: the main drivers and events; the team and system; outputs and uses.

Results

Summary of the main drivers, team and system; and outputs and uses

The following summarises key events in the development of the syndromic surveillance service (key examples are given here rather than the details of the chronology, Supplementary Tables S1-S3)

Main drivers

During 'the beginnings' (1998-2005), key drivers of the development of syndromic surveillance in England included concern about the early detection of influenza outbreaks, and fears over biological terrorism, driven in part by the deliberate release of Anthrax in the US in 2001 [4-6]. Between 2006 and 2011 ('the growth phase') factors driving the further development of syndromic surveillance included environmental incidents such as the aftermath of the 2003 European heatwave [7] and the 2010 Icelandic ash plume [8], alongside the need to expand and further develop the service to support surveillance of mass gatherings especially the London 2012 Olympic and Paralympic Games [9,10]. Once syndromic surveillance had become 'mainstream' (2012-2018) the development of the surveillance continued to be driven by both acute infectious and non-infectious incidents [11,12], alongside the desire to support research, for example on the impact of vaccines [13,14], and the understanding of the value in early warning [15].

Team and system

In 'the beginnings', there was little designated support to the team, and much of the work focussed on collaboration with NHS Direct and relied on communication via 'fax' of small amounts of data.

In ‘the growth phase’ the systems expanded considerably with the inclusion of GP in and out of hours data and the ED system. The automation of the systems improved, and staffing was expanded, in large part because of the London 2012 Olympic and Paralympic Games. During the ‘mainstream’ phase, statistical methodologies were refined to support the increasing amount of data and the scope of the systems including the use of ambulance data and online data.

Outputs and uses

Throughout ‘the beginnings’, the surveillance was used to herald the rise of influenza in the community [4,16] and to provide real-time intelligence on presenting symptoms during events such as the Buncefield Fire [17]. Within ‘the growth phase’ the systems were used in an increasing scope of infectious (such as the 2009 H1N1 influenza pandemic [18]) and non-infectious (such as assessing the impact of heatwaves [7]) incidents. In the ‘mainstream’ phase the surveillance was considered to be ‘all hazard’ and increasingly used to support a variety of infection and environmental incidents [11,12].

Key themes for success of and growth of the service

The qualitative analysis of the information captured from interviews and discussions revealed the emergence of five key themes:

Theme 1: integration into the public health system

Many interviewees commented on the focus of the surveillance being primarily and fundamentally practical public health and that the team was grounded in a public health organisation:

“... it was always informed by a real solid understanding and involvement, particularly through you [GES] in that frontline Health Protection response.”

“... here we were sort of coming at it from a real pure public health perspective.”

Additionally, the importance of the integration of the surveillance into the wider public health system was highlighted. The initial idea for using a new national telephone health service, NHS Direct, for syndromic surveillance [4] came from the Regional Director of Public Health in the West Midlands (an English Region) with strong public health support from leaders in the Communicable Disease

Surveillance System:

“... because they [public health colleagues] were very much what does this mean for public health.”

“... what's the added value which I think was something that gave us a bit of an edge.”

Others mentioned the multi-purpose nature of the surveillance. Although originally used for influenza, syndromic surveillance was developed to be part of bioterrorist surveillance, infectious disease surveillance, environmental type hazards and mass gatherings:

“The ability of syndromic surveillance to respond to potential terrorism events was hugely important in providing a sense of security after the events of 9/11 - in that atmosphere of a national threat, I felt its [syndromic surveillance] future was safe.”

“Not underestimating the ‘power of being able to walk into a room and provide reassurance’ in for example the 2012 Olympics.”

Theme 2: creativity and ability to ‘build on a good idea’

There was no formal syndromic surveillance programme in England prior to 1998, and interviewees commented on the importance of being able to “take a good idea and run with it”. Starting very small, with minimal resources and as a pilot project [16], the originators were able to show benefit and then be creative in considering the public health benefit over multiple areas [1]:

“A good idea is a good idea only when you know it’s a good idea.”

“There was something early on about just allowing it to kind of grow a bit.”

“You’ve got the creative people, but you’ve got to have people that will let them be creative as well.”

During “the beginnings” no other group in the UK was developing this form of surveillance, and few globally. This was at the time a ‘niche area’ that was ripe for public health evaluation. The public health/epidemiological approach and determination ensured that the work was validated and expanded into other areas, and the team were given time and freedom to explore this novel approach

(without undue bureaucracy). Being right at the beginning of this development of the system that eventually became syndromic surveillance was perceived as being exciting and groundbreaking.

“It was really exciting, felt a little bit like we were at the forefront of public health surveillance, like globally as well.”

“There's sort of a gradual progression to say move from being an interesting surveillance thing to being part of public health to being part of the response and to be focused on generating action.”

Theme 3: collaboration and teamwork

Most interviewees stressed the importance of good collaboration and teamwork. This applied within the public health organisation hosting the syndromic surveillance, and also across the organisations involved with supplying data e.g. the Royal College of General Practitioners (RCGP) and the Royal College of Emergency Medicine (RCEM). Such multi- agency and multi-disciplinary collaborations were felt to be vital to the development and success of the systems. Although it was important to foster close links with technical colleagues and those responsible for transferring data, in the early stages we felt the development of relationships with those with strategic leadership in organisations (and particularly those with who understood the potential public health/clinical benefit) was crucial. Such senior ‘champions’ in the organisations were able to effect changes and ensure the ‘technical’ and data requirements followed.

“Following initial idea needed a senior person with understanding how it could be used strategically and operationally and to link up with all the other surveillance systems and partners in the field and across the NHS.”

“So not just the quality of the relationships, but how do you work in partnership.”

Interviewees stressed the importance of personal connections and people ‘getting’ what we were trying to do. Colleagues valued the time spent working through what was trying to be achieved from a public health perspective in advance of the systems being used in a live public health event.

Colleagues stressed the importance of these networks and personal connections and the importance of not neglecting these relationships or letting them 'lie fallow'.

“And the networks and the connections, then they can, you know, facilitate things happening...”

For those developing the surveillance, we very much valued working with colleagues who had a different focus/priority and who were able to look at our work with a different 'lens'. Clinical colleagues working on the front line also provided essential knowledge (for example about what diagnostic codes might be used by clinicians for evolving conditions) and were able to challenge our assumptions about the interpretation of the data. Collaborating colleagues in front line healthcare services were also crucial for shaping the surveillance outputs to ensure that they not only met public health and epidemiological needs, but also the needs of health services.

“You do need people to sort of wave a flag for things to get going. It has been my experience. If it hadn't actually proved to be useful it those people wouldn't have been able to continue to support it in the way.”

“Because of champions like yourself [ReSST] and others in other organisations that enable this to happen, because I think without that it would just become a data thing or you know.”

From early stages we established system steering groups to guide the work with champions across clinical organisations, public health and academia. However, the leadership for the surveillance was embedded in a health protection organisation body.

“I learned a lot from you [GES] in terms of bringing steering groups together of people with different skills that prepare to challenge, not necessarily people that were gonna agree with you.”

“... set up quite a broad thinking group think that that's really, really important as well.”

“... ability to work with other people and other disciplines....”

Theme 4: leadership, determination and perseverance

Several interviewees mentioned the importance of determination and perseverance in the initial work needed to get the syndromic surveillance accepted as part of wider surveillance e.g., as part of the surveillance programme for influenza. Although the use of syndromic surveillance is now widely accepted as part of the surveillance ‘jigsaw’, this was not the case in the early stages. We received challenge and ‘pushback’ from those who felt that microbiological confirmations were needed for surveillance and that ‘clinical’ and symptom-based surveillance had little to offer. We needed to both validate and conduct the research to demonstrate its worth – but also the leadership and determination to do so.

“... have done such a great job over the years – the expertise of course, but also a dogged dedication and perseverance in the face of (one or two!) adversities and the development of a fab team that has offered such continuity – to have retained team members over such a long period of time must be a real rarity and is certainly a great achievement underpinning success.”

“This [establishing the syndromic surveillance systems] was not a walk in the park.”

“There were lots of other things that you could have done that would have been an awful lot easier.”

“... leadership and continuity and determination and drive.”

One further theme that emerged was the longevity of the team members. Although the team started very small and there was no dedicated support other than a part-time epidemiologist, as the team started to grow many members stayed in their roles for many years (several over 20 years). This team stability was a feature noted by several interviewees and although the reasons may be varied, we think the novelty and constant evolution of the syndromic systems (and thus interest); the ability to support multiple types of event; the mutual support and ‘feeling of belonging’; and being involved in a unique surveillance area were important.

“... and you know, I mean the team has been together for a remarkable length of time, 20

years”.

“... leadership and continuity and determination and drive and the fact that you've you know you've had a team who've been so focused and dedicated for such a long time because this really wasn't an easy project”.

“... the development of a fab team that has offered such continuity – to have retained team members over such a long period of time must be a real rarity and is certainly a great achievement underpinning success”.

Theme 5: ‘nimble’ and adaptable to new and emerging threats

Interviewees commented on the importance of being ‘nimble’ and adaptable to emerging threats. Although the initial work was focussed on the surveillance of influenza- like-illness, it rapidly became clear that syndromic surveillance is ‘multi-purpose’ and could be used not only for a variety of infectious diseases (such as respiratory or gastrointestinal infections), but also for environmental hazards (such as the impact of heatwaves).

“We've learned how to use it, how to, and you know when, when it worked, when it's best to use and I mean in some situations, obviously when the numbers are too small or we haven't got representative data or whatever, it doesn't work.”

“The big events that have been drivers that have pushed us up pushed us into the spotlight.”

“... as much politics as epidemiology.”

We needed to be aware of the ongoing and potential public health threats and flexible enough to be able to use the data to support a variety of public health events such as climate change related, emerging infections etc.

“you've been able to develop and exploit its potential to a significant extent.”

“... enable us to sort of say quite firmly I think what we could and what we couldn't and sort of detect really and what the added value was.”

Throughout the development we were able to ‘piggyback’ on NHS systems which were developed to

manage clinical care. We used only anonymous data which were generated as part of a patient's interaction with health care services. We were careful to not ask anything additional of those working in clinical care, but rather to use (with appropriate information governance procedures in place) the routinely generated data. This ensured that additional time was not needed for those working clinically and also kept costs to a minimum. Although the syndromic data were not 'bespoke' for each event – we gained increasing familiarity about where syndromic surveillance could be useful and where it was unlikely to add to existing surveillance systems (for example, local small gastrointestinal outbreaks). Throughout the development we tried to be as clear as we could about what could and couldn't be detected using syndromic surveillance and our evidence for this evolved as the systems developed. We felt it important to retain our focus and efforts on those events for which we believed that we could add value, for example a generalised rise in vomiting suggestive of community norovirus activity rather than a small, localised rise in infections which may present in a variety of ways clinically.

Discussion

Using semi-structured discussions and a qualitative analysis, here we provide feedback and views from key experts and stakeholders who were integral to the initial concept and further development of the national syndromic surveillance programme in England. We summarise the key developments in the surveillance service and, using the results of the discussions, draw out the views of respondents on the factors they considered important in enabling the syndromic surveillance to develop, grow and become a mainstream component of surveillance for health protection in England today.

This feedback provides valuable lessons for successful development and deployment of syndromic surveillance systems but can also be applied outside of the field of syndromic surveillance. The interviews focussed on understanding the reasons why the national syndromic surveillance programme was successful. Key themes emerging included the importance of: integration into the

public health system; creativity and ability to ‘build on a good idea’; leadership, determination and ‘doggedness’; being ‘nimble’ and adaptable to new and emerging threats. These themes particularly revolved around people rather than technology or data [19]. This is an interesting result as often surveillance is focussed on developing technical solutions to extract, transfer and analyse data. However, without the human skills and input required to initially identify and develop collaborations and working relationships with data providers to access data, the most sophisticated technological solutions would be fruitless.

In this age of increased automation, with the ability to transfer data in real-time and to utilise machine learning and artificial intelligence, we are approaching a ‘new age of syndromic surveillance’ [1]. Now much larger volumes of clinical data can be contemporaneously analysed and linkage can be made between individual symptoms, signs and investigations (or test) results of the patient. These increasingly refined analyses may enable the identification, using syndromic surveillance, of rarer but more serious emerging illnesses in real time (e.g. Shiga toxin-producing *Escherichia coli* infections and encephalitis). However, our ‘look back’ at the history of the development of syndromic surveillance in England suggests that the importance of focus on the public health questions, relationships and collaboration, leadership and true teamwork should not be underestimated in the success of and usefulness of real-time syndromic surveillance systems.

Using the results of the discussions and our personal experience of running the syndromic surveillance service from inception and over decades, we summarise our recommendations for establishing and running sustainable syndromic surveillance systems (Textbox 1).

Textbox 1. Recommendations for developing and maintaining sustainable syndromic surveillance systems.

- Focus on the public health questions and contribution of the syndromic surveillance (the data are important but should follow the questions).
- Integrate the surveillance into a health protection focused public health system.
- Get the ‘buy in’ of senior public health colleagues (champions), you’ll need their ongoing support to start and then develop the syndromic surveillance system(s).

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Authors' Contributions

GES and AJE conceptualised the work and drafted the manuscript. NRJ helped with the thematic analyses and drafted the manuscript. SH, SS, PL, SI, DC, BM and AJE contributed to the discussions about the original development of the syndromic surveillance. All authors reviewed and revised drafts and approved the final version for submission.

Conflicts of Interest

None declared.

Abbreviations

ED: emergency department

GP: general practitioner

HPA: Health Protection Agency

NHS: National Health Service

ReSST: Real-time Syndromic Surveillance Team

UKHSA: United Kingdom Health Security Agency

References

1. Elliot AJ, Hughes HE, Harcourt SE, Smith S, Loveridge P, et al. From fax to Secure File Transfer Protocol: the 25-Year evolution of real-time syndromic surveillance in England. *J Med Internet Res*. 2024 Sep 17;26:e58704. [doi: 10.2196/58704] [Medline: 39288377]
2. Morbey RA, Elliot AJ, Charlett A, Verlander NQ, Andrews N, Smith GE. The application of a novel 'rising activity, multi-level mixed effects, indicator emphasis' (RAMMIE) method for syndromic surveillance in England. *Bioinformatics*. 2015 Jul 20;31(22):3660-3665. [doi: 10.1093/bioinformatics/btv418] [Medline: 26198105]
3. Smith GE, Elliot AJ, Ibbotson S, Morbey R, Edeghere O, et al. Novel public health risk assessment process developed to support syndromic surveillance for the 2012 Olympic and Paralympic Games. *Journal of Public Health (Oxford)*. 2017 Sep 1;39(3):e111-e117. [doi: 10.1093/pubmed/fdw054] [Medline: 27451417]
4. Cooper DL, Smith GE, Hollyoak VA, Joseph CA, Johnson L, Chaloner R. Use of NHS Direct calls for surveillance of influenza--a second year's experience. *Commun Dis Public Health*. 2002 Jun;5(2):127-131. [Medline: 12166298]
5. Baker M, Smith GE, Cooper D, Verlander NQ, Chinemana F, et al. Early warning and NHS Direct: a role in community surveillance? *J Public Health Med*. 2003 Dec;25(4):362-368. [doi: 10.1093/pubmed/fdg096] [Medline: 14747597]
6. Cooper DL, Smith GE, O'Brien SJ, Hollyoak VA, Baker M. What can analysis of calls to NHS direct tell us about the epidemiology of gastrointestinal infections in the community? *J Infect*. 2003 Feb;46(2):101-105. [doi: 10.1053/jinf.2002.1090] [Medline: 12634071]

7. Leonardi GS, Hajat S, Kovats RS, Smith GE, Cooper D, Gerard E. Syndromic surveillance use to detect the early effects of heat-waves: an analysis of NHS direct data in England. *Soz Praventivmed*. 2006;51(4):194-201. [doi: 10.1007/s00038-006-5039-0] [Medline: 17193781]
8. Elliot AJ, Singh N, Loveridge P, Harcourt S, Smith S, et al. Syndromic surveillance to assess the potential public health impact of the Icelandic volcanic ash plume across the United Kingdom, April 2010. *Euro Surveill*. 2010;15(23):pii=19583. <https://doi.org/10.2807/ese.19515.19523.19583-en>. [Medline: 20546694]
9. Elliot AJ, Morbey RA, Hughes HE, Harcourt SE, Smith S, et al. Syndromic surveillance - a public health legacy of the London 2012 Olympic and Paralympic Games. *Public Health*. 2013 Aug;127(8):777-781. [doi: 10.1016/j.puhe.2013.05.007] [Medline: 23870845]
10. McCloskey B, Endericks T, Catchpole M, Zambon M, McLauchlin J, et al. London 2012 Olympic and Paralympic Games: public health surveillance and epidemiology. *Lancet*. 2014 May 20;383(9934):2083-2089. [doi: 10.1016/S0140-6736(13)62342-9] [Medline: 24857700]
11. Hughes HE, Morbey R, Fouillet A, Caserio-Schonemann C, Dobney A, et al. Retrospective observational study of emergency department syndromic surveillance data during air pollution episodes across London and Paris in 2014. *BMJ Open*. 2018 Apr 19;8(4):e018732. [doi: 10.1136/bmjopen-2017-018732] [Medline: 29674360]
12. Hughes HE, Morbey R, Hughes TC, Locker TE, Shannon T, et al. Using an emergency department syndromic surveillance system to investigate the impact of extreme cold weather events. *Public Health*. 2014 Jul;128(7):628-635. [doi: 10.1016/j.puhe.2014.05.007] [Medline: 25065517]
13. Hughes HE, Elliot AJ, Hughes TC, Hungerford D, Morbey RA, et al. Using emergency department syndromic surveillance to investigate the impact of a national vaccination program: A retrospective observational study. *PLoS One*. 2020;15(10):e0240021. [doi: 10.1371/journal.pone.0240021] [Medline: 33031389]

14. Sinnathamby MA, Warburton F, Andrews N, Boddington NL, Zhao H, et al. Uptake and impact of vaccinating primary school children against influenza: Experiences in the fourth season of the live attenuated influenza vaccination programme, England, 2016/2017. *Influenza Other Respir Viruses*. 2022 Jan;16(1):113-124. [doi: 10.1111/irv.12898] [Medline: 34405555]
15. Hughes HE, Morbey R, Hughes TC, Locker TE, Pebody R, et al. Emergency department syndromic surveillance providing early warning of seasonal respiratory activity in England. *Epidemiol Infect*. 2016 Apr;144(5):1052-1064. [doi: 10.1017/S0950268815002125] [Medline: 26415918]
16. Harcourt SE, Smith GE, Hollyoak V, Joseph CA, Chaloner R, et al. Can calls to NHS Direct be used for syndromic surveillance? *Commun Dis Public Health*. 2001 Sep;4(3):178-182. [Medline: 11732356]
17. Mohan R, Walton HA, Thomson D, Webster H, Wilkinson P, et al. The buncefield oil depot fire of 2005: potential air-pollution health impacts under alternative meteorological scenarios. *PLOS Curr*. 2012 Feb 2;4:RRN1300. [doi: 10.1371/currents.RRN1300] [Medline: 22453896]
18. Smith S, Smith GE, Olowokure B, Ibbotson S, Foord D, et al. Early spread of the 2009 influenza A(H1N1) pandemic in the United Kingdom--use of local syndromic data, May-August 2009. *Euro Surveill*. 2011;16(3):pii=19771. <https://doi.org/10.12807/ese.19716.19703.19771-en>. [Medline: 21262185]
19. Smith GE, Elliot AJ, Lake I, Edeghere O, Morbey R, et al. Syndromic surveillance: two decades experience of sustainable systems - its people not just data! *Epidemiol Infect*. 2019 Jan;147:e101. [doi: 10.1017/S0950268819000074] [Medline: 30869042]

For Supplemental files

Table S1. Examples of the **main drivers for the development** of the UK Health Security Agency syndromic surveillance service (1998 to 2018).

‘The beginnings’: 1998 to 2005
1998: Initial driver was for influenza surveillance and to detect influenza early. Original idea and support for concept was by the then West Midlands RDPH – supported by Regional Epidemiologist, Director and Deputy Director of national Communicable Disease Surveillance and Control department for England. 2001: ‘The deliberate release of anthrax in the United States in autumn 2001, with heightened fears over the possibility of biological terrorism, led to joint project between the Communicable Disease Surveillance and Control department for England and NHS Direct. Aim of the project was to detect local or national increases in symptoms likely to be reported by callers about people in the prodromal stages of illness caused by the deliberate release of a biological or chemical agent. In monitoring these data, we also hoped to be able to detect community outbreaks of more common infectious diseases. 2003: Initial challenges included convincing people of the worth of syndrome/clinically based surveillance rather than microbiologically based surveillance (considered the ‘gold standard’ for surveillance).
‘The growth phase’: 2006 to 2011
2006: First time analyses used to support heatwave response: first qualitative evaluation of the <i>usefulness</i> of primary care surveillance outputs for stakeholders 2009: Part of a European bid to assess and develop guidelines for Syndromic Surveillance Systems in Europe

2010: Increasing focus on mass gatherings with the upcoming London 2012 Olympic and Paralympic Games
2010: Requests for uses for environmental incidents such as the impact of the Icelandic ash plume - only sources of real-time health data.
‘Mainstream’: 2012 to 2018
2014: Cold weather indicators defined and demonstrated to be useful in the identification and monitoring of the impact of extreme cold weather on health.
2015: Considered an ‘All Hazard’ service
2016: Increasing requests in support of infection and environmental incidents

Table S2. Examples of the important developments in the **team and systems** of the UK Health Security Agency syndromic surveillance service (1998 to 2018).

‘The beginnings’: 1998 to 2005
1999: Received a daily fax of 3 lines including NHSD ‘cold/flu’ calls from the West Midlands site only
1999: First ‘bulletin’ produced based on NHS Direct data only.
2001: First publication called ‘syndromic’ based on the pilot work: Can calls to NHS Direct be used for syndromic surveillance? Describing the pilot at three NHS Direct sites.
2003: Linked to obtain daily GP data for surveillance.
2004: First paper suggesting the use for early warning: ‘Early warning and NHS Direct: a role in community surveillance?’
‘The growth phase’: 2006 to 2011
2008: Now called the ‘Real-time Syndromic surveillance team’

2010: Developing the out of hours system planned and driven by the upcoming Olympic and Paralympic Games.
2011: Scientist appointed to develop the Emergency Department Surveillance System (EDSSS)
‘Mainstream’: 2012 to 2018
2012: 22 ED sites reporting and 80% Out of hours coverage.
2013: Developed new statistical methodologies to enable automated ‘alarms’.
2013: NHS 111 was introduced and thus the NHS Direct system was discontinued, and the new NHS 111 system rebuilt.
2014: Co-lead theme on ‘Enhancing Syndromic Surveillance for early detection and assessing the extent of disease’ in the National Institute for Health and Care Research Health Protection Research Unit for Emergency Preparedness and Response (research grant). GP syndromic surveillance schemes had a joint coverage of 30 million population
2015: Pilot of an ambulance syndromic surveillance system

Table S3. Examples of the **main outputs and uses** of the UK Health Security Agency syndromic surveillance service (1998 to 2018).

‘The beginnings’: 1998 to 2005
2004: detected a significant rise in NHS Direct ‘cold/flu’ calls. This surveillance ‘signal’ heralded a rise in influenza circulating in the community.
2005: Provided support to the ‘Buncefield Fire Incident’- key event showing usefulness in an incident needing real time intelligence on presenting symptoms.
‘The growth phase’: 2006 to 2011
2007: National rise in NHS Direct ‘difficulty breathing’ calls about the under 1 yr age group pre-dated reporting of, and then supported evidence of an earlier than expected rise in respiratory syncytial virus in England and Wales.

2007: Provided real time data and interpretation for flooding response.
2009: Provided regular reports during the H1N1 ‘swine flu’ pandemic, used as part of the evidence of established community spread.
‘Mainstream’: 2012 to 2018
2012: Provided real time monitoring for three months during the London 2012 Olympic and Paralympic Games.
2018: The ‘Beast from the East’ winter storm heralded a significant spell of snow and low temperatures in the UK with clear impacts upon health and the health service usage observed.