Best practices for the design, implementation, analysis and reporting of participatory surveillance for influenza-like illness
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Contents

Acknowledgments v
Abbreviations vi
Glossary vi
Executive summary ix
1. Introduction 1
   1.1 Background and document development history 2
   1.2 Role of participatory surveillance in influenza surveillance 3
   1.3 Scope of the document 4
   1.4 Target audience and intended use 4
2. Objectives of participatory surveillance for influenza-like illness 5
3. Considerations and practices for conducting participatory surveillance for influenza-like illness 8
   3.1 Preparatory considerations 8
   3.2 Stakeholders 8
   3.3 Human resource planning 9
      3.3.1 Startup and development 9
      3.3.2 Deployment and maintenance 10
      3.3.3 Data analysis and reporting 10
      3.3.4 Communications 10
   3.4 Financial support 12
   3.5 Ethics and privacy 12
      3.5.1 Ethics 12
      3.5.2 Terms and conditions and privacy policies 13
   3.6 Recruitment 16
      3.6.1 Promoting the system 16
      3.6.2 Promotional channels 17
      3.6.3 Recruitment messaging 18
   3.7 Participant engagement and retention 18
   3.8 Data collection and management 19
      3.8.1 Mode of data collection/technology platform 19
      3.8.2 Participant accounts 20
      3.8.3 Questionnaire development 20
      3.8.4 Data storage and protection 22
      3.8.5 Terms and conditions and privacy policies 23
      3.8.6 Data sharing and data use agreements 23
   3.9 Data analysis and interpretation 24
      3.9.1 Accounting for biases in the data 24
      3.9.2 Selection bias 24
      3.9.3 Information bias 26
      3.9.4 Confounding bias 27
      3.9.5 Determining the denominator and the symptoms combination for incidence calculations 27
      3.9.6 Other adjustments 28
   3.10 Data visualization and dissemination 28
## Contents

4. **Evaluation and further validation**  
   4.1 Timeliness  
   4.2 Validity  
   4.3 Data quality  
      4.3.1 Representativeness  
      4.3.2 Completeness  
   4.4 System experience  
      4.4.1 Usefulness  
      4.4.2 Flexibility  
      4.4.3 Acceptability  
      4.4.4 Portability  
      4.4.5 Stability  

References  

Annex 1: Inventory of existing influenza-like participatory surveillance systems  

Annex 2: WHO development process for preferred product characteristics and management of conflicts of interest
The World Health Organization (WHO) would like to thank the many individuals who contributed to the development of this document. This document was prepared by Aspen Hammond and Katelijn Vandemaele, Global Influenza Programme (GIP), WHO, based upon an extensive consultation process beginning in December 2019. GIP is grateful to Daniela Paolotti, ISI Foundation, Italy for leading the development of the technical content. GIP also acknowledges the contribution of Adam Crawley, Ending Pandemics, United States of America (USA) in the development of the document.

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Abbreviations and acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ARI</td>
<td>acute respiratory infection</td>
</tr>
<tr>
<td>COVID-19</td>
<td>coronavirus disease 2019</td>
</tr>
<tr>
<td>GIP</td>
<td>Global Influenza Programme</td>
</tr>
<tr>
<td>GP</td>
<td>general practice (ILI surveillance system)</td>
</tr>
<tr>
<td>ILI</td>
<td>influenza-like illness</td>
</tr>
<tr>
<td>PPV</td>
<td>positive predictive value</td>
</tr>
<tr>
<td>SARI</td>
<td>severe acute respiratory infection</td>
</tr>
<tr>
<td>SARS-CoV-2</td>
<td>severe acute respiratory syndrome oronavirus 2</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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</tbody>
</table>

Glossary

**Absenteeism:** the habitual failure to appear for work or other regular duty. Workplace or school absenteeism may be monitored as part of syndromic surveillance (1).

**Acute respiratory infection (ARI):** a collection of symptoms that may indicate an acute infection with a respiratory virus. Surveillance systems for respiratory virus infections often utilize a standard case definition for ARI to consistently monitor trends in the number of people presenting or reporting symptoms consistent with the case definition. The case definition for ARI is not necessarily intended to capture all cases but to monitor trends over time. Case definitions for ARI usually include sudden onset of symptoms and at least one respiratory symptom such as cough, sore throat, shortness of breath or coryza, and a clinician’s judgement that the illness is due to infection. The ARI case definition is more sensitive and less specific than the influenza-like illness (ILI) case definition for influenza – adapted from (2).

**Community-based surveillance:** the systematic detection and reporting of events of public health significance within a community, by community members (3).

**Data use agreement:** a legal contract between the entity that owns access to a data source, typically a dataset or database, and a secondary entity that will receive the data, or a subset of it, for re-use (4).

**e-health:** the cost-effective and secure use of information and communications technologies in support of health and health-related fields, including health care services, health surveillance, health literature, and health education, knowledge and research (5).

**Event-based surveillance:** surveillance based on information about events that might signal a potential risk to public health. This information can be rumours and other ad hoc reports transmitted through formal and informal channels (for example, the media, health workers and nongovernmental organization reports). Unlike traditional surveillance, event-based surveillance is not based on the routine collection of data and automated thresholds for action but rather on unstructured descriptions and reports (6).

**Facility-based surveillance:** surveillance in which the starting point for notification is the identification by a health care facility of a patient with a particular disease or syndrome – adapted from (7).

**Health care seeking behaviour:** generally defined as the usual behaviour of people regarding their use of professional help from health care providers in relation to their health, and which depends on the health care system, cultural, socio-demographic and economic factors, and on the specific disease (8). In the context of this document, health care seeking behaviour typically refers to the proportion of individuals with ILI who seek professional health care services.
Household: either one person living alone or a group of people, not necessarily related, living at the same address with communal housekeeping (for example, sharing at least one meal per day or sharing a living room – adapted from (9)).

Influenza-like illness (ILI): an illness with symptoms that may indicate an acute infection with a respiratory virus. Surveillance systems for respiratory virus infections often use a standard case definition for ILI to consistently monitor trends in the number of people presenting or reporting symptoms consistent with the case definition. The case definition for ILI is not necessarily intended to capture all cases but to monitor trends over time. The WHO case definition for ILI is an ARI with measured fever of ≥ 38°C and cough, with onset within the last 10 days – adapted from (10).

Intake questionnaire: a questionnaire covering demographic factors (age, gender), geographical factors (location of home and work/school expressed at the municipality or zip code level), socioeconomic factors (household size and composition, occupation, educational level, daily transportation means) and health-related factors (including vaccination status against influenza in the current and previous seasons, diet, pregnancy status, smoking habits and medical conditions associated with a higher risk of influenza complications).

Participants: “general participants” are individuals who have signed up for a participatory surveillance platform (obtaining a username and a password) and who have completed an intake questionnaire. These are also defined as “primary users” (owners of the credentials to access the platform). Each primary user can also create a household entry and insert information (that is, compile intake and weekly questionnaires) for their children; who are then defined as “household members”. “Active participants” are defined according to the disease being monitored and the reporting behaviour (that is, the definition of an active participant for people participating during an influenza season outside of an influenza pandemic might differ from that during coronavirus disease 2019 (COVID-19) outbreaks).

Participatory surveillance: a form of surveillance that relies on recruiting self-selected volunteers from the general population to report on their health status.

Privacy policy: a policy that explains to participants how their data will be used and what steps will be taken to protect their data, and that covers confidentiality and site encryption, public sharing of data and analyses, and the sharing of contact information with third parties.

Public health and social measures: actions that people and communities can take to help slow the spread of an infectious disease – also known as community mitigation strategies.

Recall bias: a systematic error due to differences in accuracy or completeness of recall to memory of past events or experiences (1).

Reporting bias: the selective revelation or suppression of information (for example, on past medical history, smoking and sexual experiences) or of study results (1).

Respondent: a participant who completes a symptoms survey in a participatory surveillance platform.

Rollout: the first season or round of data collection during which a platform starts enrolling participants in a specific country.

Selection bias: bias in the estimated association or effect of an exposure on an outcome that arises from the procedures used to select individuals into the study or the analysis (1).

Sentinel surveillance: surveillance based on selected population samples chosen to represent the relevant experience of particular groups. In sentinel surveillance for influenza, data from a limited number of surveillance sites are systematically collected using standard case definitions and protocols. Ideally, the sites are chosen to be representative so that the information gathered can be applied to the population as a whole or, in certain cases, among subpopulations at higher risk of developing severe influenza (11).
Severe acute respiratory infection (SARI): an infection characterized by symptoms and severity of illness that may indicate an acute infection with a respiratory virus that requires hospitalization. Surveillance systems for respiratory virus infections often use a standard case definition for SARI to consistently monitor trends in the number of people presenting and hospitalized with symptoms consistent with the case definition. The case definition for SARI is not necessarily intended to capture all cases but to monitor trends over time. The WHO case definition for SARI is an ARI with history of fever or measured fever of ≥ 38°C and cough; onset within the last 10 days; and which requires hospitalization – adapted from (10).

Severity: disease severity is defined by the presence, frequency and intensity of observed or patient-reported symptoms. Severe cases of influenza may be cases requiring hospitalization either directly as a result of the disease or due to underlying risk factors which predispose individuals towards developing severe disease.

Signs and symptoms questionnaire: a questionnaire in which individuals are asked if they have experienced symptoms such as fever, chills, runny or blocked nose, sneezing, sore throat, cough, shortness of breath, headache, muscle/joint pain, chest pain, feeling tired or exhausted, loss of appetite, coloured sputum, watery/bloodshot eyes, nausea, vomiting, diarrhoea or stomach ache. If symptoms are reported, further questions are asked to characterize participant behaviour (for example, consulting a doctor or taking medication) to assess the syndrome (for example, with regard to suddenness of onset and onset date) and to evaluate if laboratory test results are related to the reported symptoms. The questionnaire used can vary slightly from one platform to another.

Syndrome: a group of symptoms which consistently occur together, or a condition characterized by a set of associated symptoms.

Syndromic surveillance: surveillance that uses clinical case features (that precede definitive laboratory diagnosis) to classify a patient into a “syndrome” of illness (12).

Terms and conditions: text that explains the rights of an organization receiving data and what the participant is agreeing to by registering or submitting data.

Transmissibility: the probability of a secondary infection following contact between an infected individual and a non-infected individual.

Validation: the process of establishing that a method is sound or that data are accurately measured (1).

Vaccine effectiveness: the degree of reduced risk of disease among vaccinated individuals attributed to vaccination in real-world conditions and estimated using observational studies (13).
Executive summary

Epidemiological information on influenza comes from multiple sources. Health care facility-based surveillance systems and information from vital statistics provide detailed and consistent data on circulating influenza viruses and other public health threats (11). Proactively engaging members of the community to regularly report on health events has been an approach adopted in many countries for different public health objectives.

Participatory surveillance is a form of surveillance that relies on the participation of self-selected volunteers from the general population. Such surveillance involves routinely receiving and transmitting health-related data through direct engagement with the general population. Participatory surveillance for influenza and influenza-like illness (ILI) is one approach for gathering information from the community to monitor trends in influenza, while also helping to inform other important public health issues. The approach should be considered to be complementary to other sources of influenza surveillance information.

One advantage of participatory surveillance is that information comes from both asymptomatic and symptomatic individuals, and from symptomatic individuals who may not initially seek health care. Information may also come from members of the population who may be underrepresented in traditional facility-based surveillance. Where participatory surveillance for influenza and ILI has been implemented experience indicates that such systems are accurate, flexible, cost-effective and robust with regard to changes in health care seeking behaviour. However, there are also a number of limitations, challenges and biases that must be taken into consideration.

This WHO document provides globally applicable guidance on implementing participatory surveillance for influenza and ILI based on expert input and abundant experience from countries in which such surveillance has been implemented. The document sets out best practices for public health officials to consider, either when looking to implement a participatory surveillance system or when making changes to an existing system.
Best practices for the design, implementation, analysis and reporting of participatory surveillance for influenza-like illness
Participatory surveillance involves the regular bi-directional process of receiving and transmitting health-related data through direct engagement with the general population. Participatory surveillance for influenza and influenza-like illness (ILI) is one approach for gathering information from the community to monitor trends in influenza, and can also inform other important public health issues. The approach should be considered to be complementary to other sources of influenza surveillance information.

Traditional facility-based influenza surveillance systems capture information on infected individuals who seek health care, and so health care seeking behaviour thus plays a vital role in determining the ILI incidence estimates obtained from such systems. Specifically, health care seeking behaviour for ILI varies by:

- age
- gender \( (14–16) \)
- presence or absence of a fever \( (17) \)
- perception of the disease severity
- public awareness
- media coverage of the disease or outbreak
- presence or absence of a pandemic \( (17-19) \)
- law and policy on sick leave and medical certificates \( (20) \)
- Health care cost concerns
- country \( (21, 22) \).

Estimates of the exact proportion of individuals with ILI who seek medical care range widely but one meta-analysis from 2018 indicated that around half of symptomatic individuals sought health care \( (17) \). In participatory surveillance, questions about health care service usage provide age- and gender-dependent measures of health care seeking behaviour. Such information can be used to complement traditional surveillance by measuring the use of health care services and detecting behavioural changes with minimal delay \( (23–26) \).

In several countries in the past decade, innovative syndromic surveillance systems have emerged (either in parallel with or integrated into national public health surveillance infrastructures) that aim to monitor influenza activity by directly engaging people to self-report their health status through web-based surveys \( (27–31) \). These systems have been classified under the umbrella term “participatory surveillance” \( (32) \). Many such systems are structured around the self-reported health status of individuals in the general population (for example, with regard to the presence or absence of symptoms of illness) rather than reports of suspected cases of a particular disease by a physician. This approach allows for flexibility in applying case definitions and for the expanded routine monitoring of the community at large, which can lead to the identification of trends and burden of disease estimates when coverage is sufficient. In low- and middle-income countries in particular, where traditional disease surveillance systems (including laboratory capacity) may be limited by financial and human resource constraints, participatory surveillance approaches can serve as a cost-effective method for routine health monitoring.

Participatory surveillance systems for ILI have proven to be accurate and reliable, with the detected timing and relative intensities of influenza epidemics being consistent with those reported by sentinel surveillance systems \( (20, 33–36) \). Furthermore, it has been shown that participatory surveillance systems can also provide relevant information for estimating age-specific influenza attack rates \( (37-40) \) and influenza vaccine effectiveness \( (24, 41) \), assessing health care service usage \( (42) \) and identifying risk factors for ILI \( (43) \). Even the feasibility of virological confirmation through self-swabbing has been explored within this approach \( (44, 45) \).
Despite the challenges and limitations of participatory surveillance systems (detailed below in section 1.2 on the role of participatory surveillance in influenza surveillance), they can have many advantages, including: (a) the ability to monitor ILI in the general population in a timely manner, including among individuals who do not seek medical care; (b) sensitivity in detecting significant changes in population health, possibly earlier than traditional surveillance systems \(^{39,40,46,47}\); (c) potential scalability to large numbers with limited costs; (d) flexibility in exploring different ILI definitions; (e) detailed profile data allowing for individual-level epidemiological analyses generally not possible in standard systems; (f) consistent data collection across diverse geographical areas that is often not possible with traditional surveillance; and (g) robustness to changes in health care seeking behaviour.

When complemented with virological data, participatory surveillance can provide near real-time information on the trends of disease due to influenza, especially among symptomatic individuals who may not seek health care, thus filling a data gap and complementing the data gathered from traditional surveillance systems in countries. In addition, health alerts and educational messaging can be shared with populations directly through participatory surveillance systems to improve health literacy or support public health interventions. Such an approach also has the potential to be extended to other diseases \(^{48–50}\).

### 1.1 Background and document development history

Following the 2009 H1N1 influenza pandemic, efforts to establish a standardized approach to influenza epidemiological data collection resulted in the publication of the World Health Organization (WHO) Global epidemiological surveillance standards for influenza in 2013 \(^{11}\). As facility-based sentinel ILI and SARI surveillance are the foundations of these standards, the information obtained is limited to those individuals seeking medical care.

Participatory surveillance systems for ILI have existed since 2003 \(^{20}\) and were used in some countries during the 2009 H1N1 influenza pandemic \(^{24}\). These systems have expanded and the methods used validated via comparison with traditional facility-based surveillance for influenza \(^{35}\). Participatory surveillance systems have also been demonstrated to be relatively cost effective, flexible and scalable.

A strategic objective of the WHO Global influenza strategy 2019–2030 \(^{51}\) is to strengthen global influenza surveillance, increase influenza data utilization and monitoring, and build a strong evidence base for understanding the impact and burden of influenza. The key benefits of improved influenza surveillance include:

- better understanding of the seasonality and disease and economic burden of influenza, especially in low- and middle-income countries;
- real-time evaluation of the burden and severity of influenza to better understand its variable impact on public health, health systems and society;
- promotion of innovative modelling and use of new data sources to improve forecasting of the emergence, timing and severity of influenza outbreaks;
- better understanding of the impact of both pharmaceutical interventions and of public health and social measures.

These aspects are also aligned with the WHO public health research agenda for influenza \(^{52}\) which recommends conducting research studies on feasible and effective surveillance in resource-limited settings, better understanding the seasonality and spread of influenza in different settings, refining denominator, burden and severity estimates through the use of e-health data in addition to other sources of data, and developing novel methods for improved assessment of real-time pandemic severity and forecasting.
The aim of the current document is to consolidate and translate the abundance of existing information on participatory surveillance into practical guidance for public health institutions interested in implementing participatory surveillance for ILI. Reviews of existing participatory surveillance systems for ILI in the published literature contributed much of the initial information on objectives and best practices. Consultations with influenza surveillance professionals and those heavily involved in participatory surveillance for ILI and other diseases provided additional perspectives on objectives and best practices, and on the implementation and integration of the approach with other influenza surveillance objectives and systems.

1.2 Role of participatory surveillance in influenza surveillance

Information on influenza epidemiology is derived from multiple sources. Health care facility-based surveillance systems and information from vital statistics provide detailed, consistent data on outbreak or epidemic timing, circulating viruses, if combined with sampling and virological surveillance, and other public health aspects. Innovative surveillance approaches beyond such facility-based systems may contribute to several of the priority surveillance objectives identified in the three domains of the WHO framework on “crafting the mosaic” of resilient surveillance for respiratory viruses of epidemic and pandemic potential. The main goal of participatory surveillance is to capture information from individuals among the general population. This may include individuals who do not seek health care consultations for their symptoms. Moreover, participatory surveillance can provide valuable information on the population under surveillance who are not affected by the disease. Such information is usually not captured by sentinel surveillance and is thus complementary to information captured through existing surveillance systems. Finally, participatory surveillance can also provide individual-level information in a timely fashion, for example on individual symptoms and duration, disease trends 1–2 weeks in advance of routine health care facility-based surveillance, vaccine uptake, perceived severity and health care seeking behaviour.

Participatory surveillance has several limitations, some of which can be mitigated. One of the most relevant limitations is that ILI symptoms self-reported by participants do not have medical confirmation by a physician. ILI cases detected by participatory surveillance systems are also not virologically confirmed – though this is also the case for traditional facility-based ILI surveillance, unless either are combined with virological surveillance. This may hinder assessment of the seasonality of specific viral respiratory diseases, especially as multiple viruses may be co-circulating. Such limitations can be mitigated by the 10-year process of validation of the ILI incidence signal detected by participatory surveillance systems. Another potential limitation is that participant samples may not always be representative of the general population. Participatory surveillance samples are biased towards young adults, with no children, living in urban areas. However, this is also a population group less likely to seek health care consultations for their symptoms, thus further emphasizing the complementarity of participatory surveillance with respect to traditional approaches. Moreover, biases related to age group can be corrected for during the analysis and processing of symptom data. Finally, in some participatory surveillance initiatives, small sample size (for example, less than several hundred participants) and lack of representativeness can be overcome only by enrolling additional participants through large-scale communication campaigns. Further information on biases is provided below in section 3.9 on data analysis and interpretation.
The information generated through participatory surveillance should complement information derived from existing surveillance systems. This could include incorporating the findings into routine influenza situation updates, risk assessments and communications. Ideally, participatory surveillance systems should be integrated into respiratory disease surveillance programmes to supplement data obtained from traditional facility-based surveillance systems because they can provide information that would otherwise be unavailable on individuals who do not seek healthcare (21). Participatory surveillance data can thus be used together with data on consultation rates to improve estimates of community burden (18).

1.3 Scope of the document

The objectives and principles of participatory surveillance for ILI are set out in this document. The use of participatory surveillance for other disease syndromes can be considered (for example, for ARI) but this is not specifically covered.

Participatory surveillance for ILI is intended to complement traditional influenza surveillance and is not intended to function as event-based surveillance. Some but not all of the objectives of participatory surveillance are similar to those described in the WHO Global epidemiological surveillance standards for influenza (11). Where relevant, the added value of participatory surveillance is highlighted in the current document.

The document includes:
- a glossary of important terms;
- a list of objectives of participatory surveillance (with corresponding data needs, examples, added value and limitations);
- a list of the concepts and best practices for establishing participatory surveillance for ILI (including cost, recruitment and retention of participants, data management and analysis, and ethics);
- links to resources such as example questionnaires and resources for analyses;
- a full list of references; and
- an inventory of existing influenza-like participatory surveillance systems (Annex 1).

Although the document relies heavily on experiences gained from existing systems it is recognized that these may not be generalizable to all countries.

1.4 Target audience and intended use

This document is intended to be a valuable resource for:
- public health institutions and partners considering or tasked with designing a complementary and independent source of data on ILI;
- WHO technical officers who advise countries on influenza surveillance; and
- end users of data generated from participatory surveillance systems.

The document is intended for use when:
- establishing participatory surveillance systems for ILI for the first time;
- expanding existing participatory surveillance for ILI to meet additional objectives of influenza surveillance; or
- expanding/adapting existing participatory surveillance for other syndromes to capture information on ILI.

The size and cost of a participatory surveillance programme will depend heavily on the intended objectives. Participatory surveillance should be designed to be flexible, adaptable, scalable and cost effective, as objectives may change over time.

As information on symptoms is collected from each participant, different case definitions can be used to monitor different syndromes. However, the guidance provided below focuses on ILI, and adapting existing participatory surveillance for ILI to capture other syndromes or diseases is outside the scope of the current document.
2. Objectives of participatory surveillance for influenza-like illness

As participatory surveillance systems can be both flexible and scalable, their objectives and expectations may be changed over time. For example, during the first season of use or roll-out, the objective may be to recruit and engage participants, and to test the feasibility of internet or mobile phone based surveillance. If more objectives are planned, additional questions can be added to the routine questionnaires or additional analysis can be performed of the data already routinely collected. Table 1 shows the range of objectives that existing participatory surveillance systems have achieved, according to degree of priority and category. Additional information on these objectives is provided in Annex 1.

**TABLE 1: OBJECTIVES**

<table>
<thead>
<tr>
<th>Objective</th>
<th>Priority</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capture the burden and trends of ILI and ARI among cohorts under-represented in other surveillance systems (non-medically attended illnesses and certain age groups)</td>
<td>Primary</td>
<td>Monitor disease trends</td>
</tr>
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<td>Primary</td>
<td>Monitor disease trends</td>
</tr>
<tr>
<td>Understand health care seeking behaviour and testing behaviour among symptomatic and asymptomatic participants by age, gender, disease severity, geographical region, access to health care and other sociodemographic variables, and follow the trends over time</td>
<td>Primary</td>
<td>Monitor health care seeking behaviour</td>
</tr>
<tr>
<td>Capture the timing and trends of ILI and ARI rates that correlate with those from existing surveillance systems</td>
<td>Primary</td>
<td>Monitor disease trends</td>
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<td>Primary</td>
<td>Monitor disease trends</td>
</tr>
<tr>
<td>Ensure more timely detection of ILI activity compared to other surveillance systems</td>
<td>Primary</td>
<td>Monitor disease trends</td>
</tr>
<tr>
<td>Support the monitoring of pandemic influenza when other systems may be overwhelmed or severely biased</td>
<td>Additional opportunity</td>
<td>Monitor disease trends in a unique situation</td>
</tr>
<tr>
<td>Estimate ILI and influenza age-specific attack rates in the general population</td>
<td>Additional opportunity</td>
<td>Estimate attack rates</td>
</tr>
<tr>
<td>Monitor the impact of influenza on absenteeism</td>
<td>Additional opportunity</td>
<td>Severity assessment</td>
</tr>
<tr>
<td>Monitor the seriousness of ILI symptoms over time (severity and duration)</td>
<td>Additional opportunity</td>
<td>Severity assessment</td>
</tr>
<tr>
<td>Improve geographical granularity and data consistency across geographical regions for ILI activity compared to other surveillance data</td>
<td>Additional opportunity</td>
<td>Monitor disease trends</td>
</tr>
<tr>
<td>Provide rough estimates of vaccine coverage or effectiveness by including questions on vaccination status to support estimates of vaccine effectiveness obtained by more robust approaches</td>
<td>Additional opportunity</td>
<td>Vaccine coverage and effectiveness</td>
</tr>
<tr>
<td>Assess population attitudes or sentiments towards vaccines or other public health interventions</td>
<td>Additional opportunity</td>
<td>Surveys</td>
</tr>
</tbody>
</table>
Contribute to forecasting seasonal influenza activity and other forecasting and disease-modelling efforts

Capture further details related to health care seeking behaviour, for example by tracking the prescription of antiviral or antibiotic medications, whether a diagnosis was made and if laboratory test results were received

Share health alerts and educational messaging directly with populations through participatory surveillance systems to improve health literacy or support public health interventions

Link symptom reports with laboratory confirmation by providing at-home testing kits to participants for self-swabbing to provide additional validation of self-reported symptoms (45, 60)

Gain experience with digital surveillance systems and recruitment, and provide an acceptable internet community-based ILI surveillance system

Capture the start of the season (with adequate preparation and communication campaigns to enhance participation before the epidemic begins)

Capture any unusual uptick of respiratory illness in the community

Identify gaps and further research opportunities to be tested

### TABLE 1: OBJECTIVES

<table>
<thead>
<tr>
<th>Objective</th>
<th>Priority</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contribute to forecasting seasonal influenza activity and other forecasting and disease-modelling efforts</td>
<td>Additional opportunity</td>
<td>Contribute to modelling efforts</td>
</tr>
<tr>
<td>Capture further details related to health care seeking behaviour, for example by tracking the prescription of antiviral or antibiotic medications, whether a diagnosis was made and if laboratory test results were received</td>
<td>Additional opportunity</td>
<td>Monitor health care seeking behaviour</td>
</tr>
<tr>
<td>Share health alerts and educational messaging directly with populations through participatory surveillance systems to improve health literacy or support public health interventions</td>
<td>Additional opportunity</td>
<td>Communications</td>
</tr>
<tr>
<td>Link symptom reports with laboratory confirmation by providing at-home testing kits to participants for self-swabbing to provide additional validation of self-reported symptoms (45, 60)</td>
<td>Additional opportunity</td>
<td>Virological surveillance</td>
</tr>
<tr>
<td>Gain experience with digital surveillance systems and recruitment, and provide an acceptable internet community-based ILI surveillance system</td>
<td>Additional opportunity</td>
<td>Build capacity</td>
</tr>
<tr>
<td>Capture the start of the season (with adequate preparation and communication campaigns to enhance participation before the epidemic begins)</td>
<td>Additional opportunity</td>
<td>Timing of disease activity</td>
</tr>
<tr>
<td>Capture any unusual uptick of respiratory illness in the community</td>
<td>Additional opportunity</td>
<td>Monitor disease trends</td>
</tr>
<tr>
<td>Identify gaps and further research opportunities to be tested</td>
<td>Additional opportunity</td>
<td>Surveys</td>
</tr>
</tbody>
</table>
3. Considerations and practices for conducting participatory surveillance for influenza-like illness

3.1 Preparatory considerations

Exploratory activities to consider before the development and launch of a participatory surveillance system for ILI include:

- performing a context analysis to determine how participatory surveillance could complement existing influenza surveillance systems, the extent of internet coverage, which technology platforms could support the system, what are the technical limitations, identify potential stakeholders, and assess human resource needs and financial support;
- gauging interest, attitudes and perceptions among stakeholders and the population; and
- assessing participant preferences, for example with regard to reporting platform and languages.

More details on several of these specific elements are provided in the following sections.

3.2 Stakeholders

Identifying key stakeholders and establishing partnerships are crucial to the successful deployment of a participatory surveillance system. Existing systems highlight the importance of a multisectoral approach to establishing and maintaining an effective participatory surveillance system.

Key considerations when identifying appropriate stakeholders include:

- Who will provide staffing support and scientific expertise? Who will interpret the data and disseminate the insights gained from the surveillance system?
- Who will provide technological support and who will own and maintain the data?
- Who will provide financial support for the programme? Financial sources need to bring a trusted reputation/brand that participants will feel safe engaging with and have confidence in.
- Who will provide legal support and advice to ensure the institution is legally protected? This is important in situations such as when the use of a mobile app is being considered to ensure compliance with mobile app provider regulations and with all country-specific data regulations.
- Who are the end users of the data?

Although these may vary by country, examples of stakeholder organizations include:

- The National Public Health Institute and Ministry of Health – these government institutions may serve a number of roles including the provision of scientific expertise, technological support and/or funding. Typically, government institutions are vital for defining surveillance objectives, ensuring the use of participatory surveillance data to inform disease control and prevention efforts, and providing scientific and epidemiological expertise to support the ongoing use of the system and the information generated by it, as well as in articulating new data needs. Specifically, the teams responsible for influenza surveillance should be involved and government officials such as chief medical officers and other policy-makers should be considered as stakeholders.
3.2 Stakeholders in participatory surveillance

- **Research institutions and research ethics committees** – universities and other research institutions can play a role in providing scientific and technological expertise in establishing and maintaining participatory surveillance systems, and supporting data analysis and dissemination of findings. Some participatory surveillance systems might receive financial support through research grants and similar funding sources.

- **Technology organizations** – both for-profit and non-profit technology organizations can play a role in establishing participatory surveillance systems. Such organizations, specifically telecommunication companies, may be well positioned to advise on the best tools for reaching populations of interest (via SMS, email, mobile apps, etc.) and on the designing of digital systems that will meet the surveillance objectives.

- **Philanthropic organizations and foundations** – private foundations and other philanthropic organizations may be important stakeholders in terms of both financial support and as potential sources of scientific or technical expertise to support operations and data analysis.

- **Industry associations** can provide support and may be end users of the data generated by the system.

- **Global agencies and organizations** can provide guidance and support.

Additional information on stakeholders in existing participatory surveillance systems is provided in Annex 1.

### 3.3 Human resource planning

The human resources required to develop and maintain a participatory surveillance system will vary by country, surveillance objectives and the method used to capture reports (Table 2). At a minimum, most systems will require the support of at least one software developer and a dedicated programme manager with public health expertise. Stakeholders should evaluate the technological, programme operations, communications and analytics needs to determine the required human resources, as well as to identify existing human resource capacities in other surveillance programmes that could be leveraged. The duration of the campaign is also something that will need to be decided – for example, will it continue throughout the year or only during the influenza season?

#### 3.3.1 Startup and development

The resources required to develop a participatory surveillance system may be higher at the outset as more technical resources will be needed to establish the system and greater efforts may need to be expended on recruitment. However, if the system is being created through an existing technology platform, the technical resource needs may be lower for establishing the system. This might be especially relevant given that there are numerous initiatives (such as Influenzanet) that rely upon open-source software developed with the goal of benefiting the overall community.

If creating a new system, then the dedicated time of at least two software developers may be needed (this might vary by country depending on the scope and languages to be incorporated). In addition, at least one dedicated project manager focusing on recruitment strategy, communications and stakeholder engagement is likely to be a minimum staffing requirement (this can also vary depending on the scope of the system). Communications consultants can potentially be engaged on short-term contracts during the initial launch and promotion of a system.
Where resources and experience are limited, consideration should be given to already existing survey platforms (such as REDCap) that can provide initial platform support which can then be followed by the establishment of a development team with a chosen technology.

### 3.3.2 Deployment and maintenance

The equivalent of one full-time software developer may be sufficient for routine technology maintenance of a participatory system. However, both “front end” (user interface, website) and “back end” (web servers, database management) software skills will be needed and not all software developers will have expertise in both. Long-term maintenance is also an important issue in guaranteeing sustainability, security, access to data and so on. Funding for long-term maintenance has to be secured to ensure that all these aspects are taken into account. A project manager will be crucially important in supporting recruitment and engagement efforts, developing reports, responding to participant concerns and engaging key stakeholders. Depending on the scope of these activities, a single full-time project manager may not be sufficient. Routine analytics support in managing, reviewing and disseminating data will also be vital for both stakeholder engagement and for sharing information back to system participants.

It will also be highly important to test the system before deployment through small internal pilots, with the goal of stress testing the application and assessing participant acceptance. These are important steps towards the full deployment of the participatory system.

### 3.3.3 Data analysis and reporting

Consideration should be given to the type and frequency of reporting and analysis that will be required of the system and of the stakeholders involved. If integrated into official government systems, there may be routine reporting requirements or expectations. Having analytics support and expertise to evaluate system performance and validate the epidemiological signals generated will be a crucial ongoing need. Working closely with consumers of the data such as those responsible for influenza surveillance, the Ministry of Health or partners (such as research institutions and universities) will be crucial from the start. Having a focal point in these institutions will be invaluable in being able to react to their data demands for decision-making.

### 3.3.4 Communications

Having a dedicated communications staff member may be useful for recruitment and retention efforts. The use of social media messaging, crafting press releases and working to highlight participatory systems in mainstream media may require a unique skill set not found among epidemiological or public health staff.
**TABLE 2: Human resource roles and responsibilities**

<table>
<thead>
<tr>
<th>Role</th>
<th>Responsibilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Project manager/Coordinator</td>
<td>Responsibilities may include engaging project stakeholders (for example, the Ministry of Health, funders, etc.), managing staff and budget, responding to participant concerns, overseeing consultants or vendors, reporting on results and evaluation efforts, and ensuring the sustainability of funding and other resources.</td>
</tr>
<tr>
<td>Researcher/Analyst</td>
<td>Responsibilities may include reviewing and revising participatory surveillance questionnaires, assessing reporting and participation rates and evaluating the performance of the system based on volume of reporting, assessment of participant representativeness compared to the general population and validation of the epidemiological signals against other data sources. May also support data management functions as well as the preparation of reports and research studies.</td>
</tr>
<tr>
<td>Communications/Engagement</td>
<td>Legal advice is especially important for public health institutions and research partner/company collaborations involving intellectual property and licensing aspects.</td>
</tr>
<tr>
<td>Software developer(s)</td>
<td>Responsibilities may include drafting communications for weekly reporting reminders to participants, providing periodic updates or results to participants, developing recruitment strategies, managing social media accounts, drafting press releases and other promotional communications, identifying and coordinating with partner organizations for recruitment or promotional campaigns, administering participant satisfaction surveys, and analyzing the effectiveness of various recruitment and retention strategies. Responsibilities may include selecting and periodically updating the technology stack and specifications for the system, designing a relational database based on surveillance objectives, standing up back-end servers, creating a website and mapping out the participant interface, developing mobile applications for iOS and/or Android phones, establishing an SMS reporting option and troubleshooting reported errors.</td>
</tr>
<tr>
<td>Legal advisor(s)</td>
<td></td>
</tr>
<tr>
<td>Communications/Engagement</td>
<td>Responsibilities may include drafting communications for weekly reporting reminders to participants, providing periodic updates or results to participants, developing recruitment strategies, managing social media accounts, drafting press releases and other promotional communications, identifying and coordinating with partner organizations for recruitment or promotional campaigns, administering participant satisfaction surveys, and analyzing the effectiveness of various recruitment and retention strategies.</td>
</tr>
</tbody>
</table>

1. Considerations and practices for conducting participatory surveillance for influenza-like illness
TABLE 2: Human resource roles and responsibilities

<table>
<thead>
<tr>
<th>Role</th>
<th>Responsibilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Software developer(s) (front end and back end)</td>
<td>Responsibilities may include selecting and periodically updating the technology stack and specifications for the system, designing a relational database based on surveillance objectives, standing up back-end servers, creating a website and mapping out the participant interface, developing mobile applications for iOS and/or Android phones, establishing an SMS reporting option and troubleshooting reported errors.</td>
</tr>
<tr>
<td>Legal advisor(s)</td>
<td>Legal advice is especially important for public health institutions and research partner/company collaborations involving intellectual property and licensing aspects.</td>
</tr>
</tbody>
</table>

3.4 Financial support

Participatory surveillance has emerged in the past decade as a new approach to supplement “traditional” disease surveillance by leveraging digital platforms to directly engage the public in actively providing information about their own health. To estimate the expense of developing and deploying systems, it is necessary to distinguish between two cost items:

- **Startup and development costs** – that is, the resources needed to design and develop the prototypical system with all the required functionalities and to conduct startup campaigns. These activities may require considerable resources and a large interdisciplinary team to define system requirements, and to design and develop the system.

- **Deployment (including recruitment campaigns) and maintenance costs** (including participant retention campaigns) – that is, the resources needed to deploy the prototypical system in a specific country context and the resources needed to maintain the platform, animate the content, manage participant interactions, etc.

For existing systems, financial support programmes vary considerably and are very much influenced by the types of activities (for example, simple routine surveillance versus additional more complex studies) undertaken by the system. Additional information on financial support schemes for existing participatory surveillance systems is provided in Annex 1.

3.5 Ethics and privacy

3.5.1 Ethics

WHO published comprehensive guidelines on ethical issues in public health surveillance in 2015 (61) and 2017 (62). Distinguishing between public health research and public health practice (such as surveillance) is often considered the main criterion for ethical oversight of the activity, with research being subject to independent ethical review. However, making this distinction is not always simple or easy. Therefore, current approaches focus instead on identifying the objectives of the activity and its associated risks to guide the distinction (with research associated with generating new knowledge but also increased risk following the intervention or exposure) rather than categorizing the activity as either public health research or public health practice.
For participatory surveillance, the distinction is not always clear as it can be implemented both as public health practice (disease surveillance or monitoring in the affected population) and as public health research (collecting data to produce or contribute towards knowledge that may be generalizable to different populations).

Implementers of participatory surveillance for ILI should consider how the above WHO guidelines on ethical issues are relevant in their context, identifying their objectives and any risks to participants associated with the collection and storage of the data. Incorporating such practices will help build trust among participants that their data is secure, which will be vitally important in ensuring the sustainability of a good quality system. When the need for an independent ethics review is unclear, implementers of participatory surveillance are advised to consult with national and institutional research ethics committees. Further selected examples of guidelines on ethical considerations in the context of participatory surveillance are listed below (63, 64).

Participatory surveillance systems often seek informed consent from all participants to enable the collection, storage and processing of data, and their publication in de-identified, processed and aggregated forms for scientific and public health purposes, even if the system is considered part of public health surveillance and is only intended to follow trends in symptoms among the population under surveillance. Individuals who are part of the system team and who download and analyze data should only be able to download de-identified data.

The participation of individuals under 18 years of age (or the locally defined age of a minor) can be achieved through the participation of a parent/guardian who has the right to report on behalf of the younger person. Different levels of consent for different kinds of participation will need to be included in the participatory surveillance platform. The specific risks and benefits of including minors should be clearly stated in the ethics committee application.

The collection of additional information besides symptoms should be clearly justified. In addition, approval by an ethical review board or ethics committee should be obtained, where needed and according to country-specific regulations. An example of using participatory surveillance for research purposes would be the collection of information on health care seeking behaviour. This information is considered to be mildly sensitive with the risk of participation in such surveillance considered to be low (64).

3.5.2 Terms and conditions and privacy policies

Participatory surveillance systems should have both a set of Terms and conditions and a privacy policy. These are both legally binding, with the Terms and conditions required to protect the organization collecting the data and a privacy policy required to protect participants.

The Terms and conditions explain the rights of the organization receiving the data and what the participant is agreeing to by registering and submitting data. Privacy policies explain to participants how their data will be used and what steps will be taken to protect their data, and will cover confidentiality and site encryption, public sharing of data and analyses, and sharing of contact information with third parties.
Implementers should ensure that advice is obtained from legal representatives in countries and institutions so that participatory surveillance systems are being conducted in accordance with country-specific regulations on privacy and data collection and processing.

Table 3 has been adapted from the components of an ethical framework proposed by Genevieve et al (64). Relevant additional resources, such as examples of Terms and conditions and privacy policies are provided in Annex 1.

### TABLE 3: Ethical components

<table>
<thead>
<tr>
<th>Component</th>
<th>Considerations</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consent</td>
<td>Ensure informed consent is obtained from participants at enrolment, if applicable. This may depend on whether participatory surveillance is considered public health practice or research. If informed consent is required, it can be obtained electronically at enrolment (for example, using a clearly worded electronic consent form requiring a digital signature and submitted at the time of registration).</td>
<td>Electronic consent involves no personal and direct communication between researchers and participants; thus participants may not be fully informed about the conditions, risks, terms and privacy policies of the system. This could be addressed by requiring a digital signature on a multilingual document (rather than simply clicking on an agreement box) and/or requiring the completion of learning tools at enrolment.</td>
</tr>
<tr>
<td></td>
<td>For participants providing data on members of their households, additional statements indicating the informed consent of these third parties should be obtained. If this involves a child, then data collection must be aligned with the relevant country-specific regulations.</td>
<td>Issues may arise when retrospective research is desired but not foreseen in the initial informed consent. This could be addressed by maintaining an opt-out policy at all times, or by pairing consent with a waiver removing the need for researchers to seek separate consent for any secondary uses of the data.</td>
</tr>
<tr>
<td></td>
<td>It should be ensured that participants are able to easily refuse further participation (opt out) at any time.</td>
<td></td>
</tr>
</tbody>
</table>
### TABLE 3: Ethical components

<table>
<thead>
<tr>
<th>Component</th>
<th>Considerations</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consent</td>
<td>Ensure identifiable data are properly secured and not displayed to reduce the risk of re-identification. For participatory surveillance, this means de-identifying sensor data (for example, geolocation data) from mobile phones, storing de-identified data in a central database, collecting only postcode resolution data and displaying only aggregated data. The sharing of data with other institutions should prioritize anonymization and data security, and participants should be informed on what data can be used for research purposes and under what conditions. The number of identifiable variables collected should be limited as far as possible. This will minimize risk and increase the chance of research ethics committee approval.</td>
<td>The “digital divide” remains a hurdle to ensuring open participation for all of society.</td>
</tr>
<tr>
<td>Access to information on disease and prevention</td>
<td>Ensure that participation in surveillance is free, voluntary and open to all eligible individuals (that is, non-discriminatory). Ensure the rapid feedback of results to all stakeholders, including the public, especially in the case of a public health emergency, using different communications channels.</td>
<td></td>
</tr>
</tbody>
</table>
TABLE 3: Ethical components

<table>
<thead>
<tr>
<th>Component</th>
<th>Considerations</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research ethics committees</td>
<td>Involve research ethics committees in the design and implementation of participatory surveillance systems.</td>
<td>There remain ethical and legal grey zones in this field of digital surveillance.</td>
</tr>
<tr>
<td></td>
<td>Ensure appropriate ethical approval with national authorities is obtained if needed and that the surveillance is aligned with local privacy legislation.</td>
<td>Introduction of new legislation could cause conflicting situations with surveillance systems and data.</td>
</tr>
</tbody>
</table>

3.6 Recruitment

3.6.1 Promoting the system

There are many ways to promote a participatory surveillance system among the general public. Therefore, it is important to consider the best channels for recruitment, the best messages to deploy and the most appropriate language (or languages) to use to motivate participation.

The determinants of participation have been studied for several existing platforms (40, 57, 65–67). In one review of factors associated with consistent participation (that is, participants completing at least two symptom surveys within 30–60 days of their first symptom survey) in systems in seven European countries during the 2011–2012 influenza season, higher educational level, non-smoking, receiving an influenza vaccination and higher age were all associated with increased participation. These associations were also consistently detected in separate analyses by country (65).

In the United States of America (USA), active participants were, overall, more likely to be females and reporting for additional household members, have a higher educational and income level, and not reporting ILI symptoms on the first symptom survey completed. In general, the probability of being a regular participant increased with age. In addition, 70% of participants in the Flu Near You (now Outbreaks Near Me) system in the USA identified themselves as either retired or employed in the health, education or social service sectors (57). As broad participation is desirable, consideration should be given to the best methods for reaching specific sub-populations to boost engagement and increase representativeness.

Moreover, understanding the motivations for participation is also crucial. For example, the results of a survey of Great Influenza Survey participants in the Netherlands (Kingdom of the) indicated that the desire to contribute towards a scientific goal is the most important motivator for all types of participants (67).
3.6.2 Promotional channels

Traditional media, including TV, radio, newspapers and magazines (both online and print) might highlight the existence of a national participatory surveillance system when writing or broadcasting stories on a particular outbreak, peaks in seasonal influenza activity or related issue. Communications staff can develop press releases and other materials to help attract such media attention. Having readily accessible, clickable hyperlinks directly from online stories typically results in the best returns. For example, national media attention on Flu Near You (now Outbreaks Near Me) in the USA immediately led to significant increases in registrations and reports (56). Paid advertising can also be considered if funds allow.

Social media channels (such as X, formally known as Twitter, Facebook, Instagram and YouTube) can also be valuable ways of increasing participation. Having social media accounts and posting content regularly can help to draw followers, while the use of paid advertisements on social media channels has also been shown to increase recruitment (66). Most social media programmes have tools that allow for testing messages with different groups and for tracking the characteristics of followers.

Organizational newsletters and email lists from supporting or partner organizations (such as health systems, universities and funders) can provide access to large numbers of individuals who might be more inclined to consider registering if they receive the invitation from a trusted source that they are already subscribed to. In-person events may also provide opportunities for recruitment but may require a larger investment of time and resources. Academic conferences, science fairs and other events may allow for such promotional opportunities.

Existing participants can also be leveraged by encouraging them to enroll and report on behalf of their household members (if the system is designed with such a feature). Existing participants can also be encouraged to recruit friends, family and colleagues.

This can be facilitated by providing current participants with readily available links and other tools. Setting targets – such as “recruit two friends” – has been shown to make these appeals more effective (66).

Trusted, high-profile personalities should be identified who can endorse participation in the system and encourage others to join. These might be leaders in the health sector, celebrities or media personalities, who might also have significant social media influence. Engaging community and/or religious organizations can also be considered, especially to attract participants from potentially under-represented demographic or religious groups.

Barriers to enrolment can be reduced by considering whether there are any steps that might discourage some participants from joining. Registration information should be limited to only the information that is needed, and participants should not be required to click through numerous steps or web pages. Requiring usernames and passwords may reduce take-up rates and these should only be used where needed for privacy concerns, such as when providing data intended for research and requiring informed consent.
3.6.3 Recruitment messaging

The use of focus groups or other forms of market research may be considered to inform the types of messages and communications to develop. These opportunities can be used to understand what messages resonate with audiences and what motivates individuals to join a participatory disease surveillance system.

The use of “split” or “A/B” testing can help to determine what types of promotional messages result in the most participant registrations and engagement. Any variations in the effectiveness of such messages by age, gender, location or other factors should be identified, and consideration given to whether the messaging is likely to attract participants who will consistently contribute to the system.

3.7 Participant engagement and retention

Continuous reporting is essential to ensure high-quality data and long-term reliable information. Retaining participants from one season to another or in year-round reporting is one of the biggest challenges for participatory surveillance.

Key aspects of ensuring engagement and retention include:

- Consideration of what motivates participants – both Flu Near You (now Outbreaks Near Me) in the USA and the Great Influenza Survey in the Netherlands (Kingdom of the) have found that most participants are primarily motivated by a desire to contribute towards science or disease tracking. Many consider participatory disease surveillance to be a form of “citizen science” and helping participants to feel as if they are contributing to scientific understanding or supporting public health may help to ensure their long-term contribution (67).

- Clearly explaining to participants the importance of “healthy status” reporting – many participants may not feel it is important to report “no symptoms” or “I am feeling healthy” and that it is only helpful to report when they or a member of their household are sick (see section 3.9.3 below on information biases). Ensuring that participants understand the importance of healthy status reporting can help ensure higher reporting rates and larger denominators, and make the practice routine.

- Providing feedback and relevant information to ensure that participation will be seen as valuable. Rapidly reporting results through dashboards using interactive maps, graphs and charts will help participants to understand what they are contributing to while also providing opportunities for health education. Participatory surveillance sites can also link to relevant information such as the location of vaccine clinics and other health resources. Mid- or end-of-season certificates, lotteries or badges of participation could be used to gamify the participant experience and enhance their engagement with the platform.

- Seeking feedback from participants on system design, messaging, and other features – this can both inform new versions of the system while also giving participants a sense of engagement. As a system evolves over time, the preferences of participants may shift and it is important to make appropriate updates.
Ensuring that information reported to participatory surveillance systems is secure (see section 3.5 above on ethics and privacy) – this is paramount in ensuring long-term participation. Participants must know how their information is being used and that it is protected against theft and abuse. Loss of faith in the ability of an organization to protect participant data and privacy can quickly and severely undermine a participatory surveillance system.

Considering how the surveillance objectives might inform the timing and duration of the system’s operation – some participatory disease surveillance systems operate for a defined period of time each year, such as an influenza season (for example, Influenzanet in Europe and FluTracking in Australia and New Zealand). Other systems (for example, Flu Near You (now Outbreaks Near Me) in the USA, and DoctorMe in Thailand) operate throughout the year. There may be different considerations, including for participant engagement and retention, for systems that start and stop versus those that run continuously.

Making the rationale for system operational choices clear to participants – systems that have defined starting and stopping points offer the opportunity to give participants a break and then to re-engage them with new messaging at the start of the next season (but may risk losing some participants who choose not to return). Conversely year-round systems, such as Flu Near You (now Outbreaks Near Me), might lose participants who tire of year-round reporting or who do not see the relevance of reporting at certain times of the year, for example outside the influenza season.

Sharing opinion pieces to engage the population on the importance of participatory surveillance, along with developments and FAQs that might be of interest, can help sustain participation.

3.8 Data collection and management

3.8.1 Mode of data collection/technology platform

Participatory disease surveillance can be carried out using a variety of methods and technologies. Many systems, such as Influenzanet, FluTracking and Flu Near You (now Outbreaks Near Me), rely primarily on an email reminder and reporting system. However, participants might also be engaged and reached through mobile applications developed for smartphones, through simple SMS messaging or through digital hotlines. It is important to consider the population under recruitment and whether the chosen technology is well suited to reaching this group. Multiple approaches might be employed to ensure wider reach or to ensure that participants have several options for how they can engage and report their information. Consideration should also be given to the extent of internet penetration in the country and how best to send and receive information and send reminders etc. Moreover, if low internet penetration in some areas makes the implementation of an online platform impractical, then the possibility of using offline technologies should be considered.

Usability testing to evaluate how representative participants interact with the system interface is important both prior to launch and routinely throughout the maintenance of participatory surveillance. Data collection approaches and interfaces should be revisited intermittently and adjusted if participant satisfaction evaluations indicate that different approaches would work better. The implementers of FluTracking in Australia routinely conduct usability testing to evaluate their system interface (66).
Email – many participatory surveillance systems send weekly email reminders to participants encouraging them to report the presence or absence of symptoms (54, 56, 68). Providing simple links that allow participants to report their information with minimal effort helps to reduce barriers to participation.

Mobile application – some participatory surveillance systems (such as DoctorMe in Thailand) have been developed exclusively as a mobile platform where participants may receive push notification reminders to report and can submit information from their mobile device (69). In countries with a high degree of smartphone use this may help to reach a segment of the population who are more likely to engage via smartphone rather than at a laptop or desktop computer. It is important to note that the resources needed to develop and maintain mobile applications, especially when maintaining both Android and iOS applications, can add to the cost of a participatory surveillance project.

SMS – there are many examples of reporting disease surveillance information via SMS messaging. In areas where email or mobile applications are not widely used, this may be another useful option. However, the cost of sending text messages for both the participants and the system administrators should be taken into consideration. Sending text message reminders to participants can add costs to a programme and reporting symptoms via text may come at a financial cost to the participant as well.

Hotlines – there are numerous examples of hotlines created for public health purposes and participatory surveillance systems could potentially employ a similar approach if suitable for the setting and the population. With digital hotlines (such as the 115 hotline in Cambodia) callers can interact with a menu of options by entering information through the keypad or speaking directly to an interactive voice-response system. For example, callers could enter a postcode using the keypad and then select from certain numbers corresponding to a range of symptoms.

Chatbot – more recently, some initiatives have explored the possibility of relying on chatbots to ask about health status (such as the Sabaidee project in Thailand).

3.8.2 Participant accounts

Consideration should be given to the inclusion and exclusion criteria to be used for participants. The inclusion criteria for most existing systems are that participants subscribe with an email address and a postcode. In some countries/communities, email might not be the most inclusive option and phone number might be more apt. Any potential biases should be addressed, for example by allowing for the creation of multi-participant accounts to allow for the registration of multiple individuals in a household through a single account (55). Consideration should also be given to what social unit of engagement is most appropriate (for example, individual versus household).

3.8.3 Questionnaire development

There are a number of issues to consider when selecting the series of questions to be used in a participatory surveillance system questionnaire. A balance will be required between the need to capture enough information to inform the surveillance objectives and the need to keep the questionnaire simple and easy to complete for participants. It is also important to protect participant security and privacy by only collecting information required to meet the surveillance objectives.
The survey questions should be aligned with the surveillance objectives, and consideration given to what objectives are priorities and to ensuring that the corresponding questions are included in the initial questionnaire or weekly surveys. For example, to compare ILI cases by sociodemographic group it is important to collect information on age, gender and area of residence (for example, postcode). Consideration should be given to testing the usability of enrolment and weekly surveys among a focus group prior to deployment. Such early investment may enhance participant engagement and retention during the campaign.

**Language** – while many countries may have one dominant language, it is important to consider how many languages and dialects might be spoken in the population under surveillance. The questionnaire should be made available in any language widely used and specifically in any languages spoken by populations of interest.

**Minimum viable dataset** – the minimum required data for reporting should be considered. For some systems, such as Flu Near You (now Outbreaks Near Me), this has been defined as month and year of birth, postcode, gender, influenza vaccination status and symptoms. Registered participants do not need to re-enter their demographic information as it is stored in the system and linked to their report. However, it is important to add functionality allowing participants to update their information when necessary.

**Intake questionnaire** – whereas Flu Near You (now Outbreaks Near Me) captures only a few data points about participant demographics and characteristics, some systems (such as Influenzanet) ask participants to complete an intake survey at the start of each season to provide additional information that can be used to assess risk factors and provide other insights. This can include information on educational level, employment, chronic health conditions and smoking habits. Consideration should be given to how much detail the target population might be willing to share in such intake surveys – the potential for gaining additional insights must be balanced against the risk of creating barriers that would make people less likely to participate. Local culture and government policies may also play a role in the amount of information that can or should be collected.

**Weekly questionnaires**

- Initial questions – consider having only one initial question in the weekly survey that allows participants to indicate if they have symptoms or not. If not, then the questionnaire is complete. If symptoms are reported to be present, the participant will then proceed to the supplemental questions.

- Supplemental questions – depending on the answers given to the initial survey question(s), additional questions can be triggered to gather further information. These questions should only appear if truly necessary and may include the following:
  - If a participant reports “Fever”, they are asked to record their temperature, if known.
  - If a participant reports any symptoms, they are asked on what date they started feeling ill (onset date).
  - If a participant reports any symptoms, they are asked if they visited a health professional.
• If they report seeing a health professional, they are asked where they sought care (for example, doctor’s office, urgent care department, hospital or virtual visit).
• They are also asked whether they received an influenza and/or COVID-19 test and if so, whether the results were positive or negative.
• They are also asked if the health professional made a diagnosis (for example, influenza, COVID-19, pneumonia or strep throat).

The questionnaire design should be thoroughly tested with both health professionals and with a sample of participants from the target population to ensure that the questions are easily understood and that response options are sufficient.

As part of the questionnaire design, a rationale should be provided at the start of each section to explain to participants why particular data are collected. For example, if there are questions related to their use of public transport, or on the number of people they come into contact with at work/school, then consider prefacing the section with text such as “The following questions may help to determine your risk of exposure to spreading events”.

3.8.4 Data storage and protection

No identifying information (such as name or address) is usually collected by participatory surveillance systems. Email and IP address are kept strictly confidential and stripped from any datasets prior to analysis to ensure participant privacy and protection – though security measures may vary by country and regulatory authority. Emails are only used by the platform to invite participants to complete the weekly survey or to convey information regarding changes to the system or the occurrence of unique surveys. In all cases, email information is not accessible to researchers analyzing the data.

These and other steps to protect participant data should be taken in accordance with country-specific laws and policies. Any additional personal information that needs to be collected (such as name or physical address) must be justified and any required amendments made to the ethics committee application or approval. In some circumstances (for example during the COVID-19 pandemic), a number of platforms (such as Flusurvey in the United Kingdom) have started to collect names and physical addresses to involve participants in self-swabbing activities.

Organizations may have the choice of storing data on local servers or on cloud servers. Local servers are machines stored at a local facility (for example, within the Ministry of Health or at a university). Cloud servers leverage options such as Amazon Web Services, Microsoft Azure or Google cluster, with the data being stored remotely. Table 4 summarizes the pros and cons to consider with regard to cloud versus local server systems. All organizations must consider and adhere to all national data protection laws.
TABLE 4: Data storage servers

<table>
<thead>
<tr>
<th>Server</th>
<th>Pros</th>
<th>Cons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local server</td>
<td>Provides physical control over backup options; third parties cannot access information if proper security measures are put in place; internet connection not required for access.</td>
<td>Requires hardware investment and maintenance; requires in-house IT support and management; susceptible to physical damage.</td>
</tr>
<tr>
<td>Cloud server</td>
<td>Storage and services can be scaled as needed; no upfront hardware investment required; backup and restore options initiated from multiple machines/locations.</td>
<td>Loss of internet connectivity restricts access; may not have option to store data in-country (though may have regional localization options; may conflict with organizational data protection policies).</td>
</tr>
</tbody>
</table>
3.9 Data analysis and interpretation

As with any other disease surveillance tool, uniform and harmonized data collection will be crucial to success. Existing systems are not fully harmonized in the way they collect data – for example, Influenzanet collects information on about 20 individual symptoms (respiratory, systemic and gastrointestinal), Flu Near You (now Outbreaks Near Me) collects a similar though slightly smaller set, while FluTracking only collects information on fever and cough (and sore throat if “yes” to both fever and cough). Despite these differences, it is still possible to use various aggregations of individual symptoms to detect ILI cases (70). Moreover, it is still possible to have data integration/sharing among systems to provide a global overview (see for example, Global Flu View at www.globalfluview.org/chart). During the COVID-19 pandemic, many existing systems expanded the list of symptoms that participants could report on by including symptoms such as shortness of breath, runny nose, and changes in taste and smell. More details on this are provided below in section 4.4.2 on system flexibility.

The direct involvement of individuals from the general population in data collection can also cause issues for data analysis and interpretation due to variability in reporting behaviours, the individual’s own interpretation of the terms used for surveillance, and potential inaccuracies in their self-assessments (50). However, while such biases may exist, many will be consistent within a country over time thus allowing for reliable trends to be observed (35, 71).

Biases encountered in participatory surveillance systems include selection, information and confounding biases. These present significant challenges when making inferences based on the data collected. Each of these biases, and approaches to accounting for them, are covered in more detail in the following sections.

3.9.2 Selection bias

Selection bias is defined as bias in the estimated association or effect of an exposure on an outcome that arises from the procedures used to select individuals into the study or the analysis (1). Participatory surveillance systems generally suffer from selection biases, causing the sample to be non-representative of the general population. Participants in participatory surveillance systems for ILI volunteer to participate (participation or self-selection or volunteer bias). The self-selection of participants and their underlying interest in the subject under surveillance could introduce differences among those who volunteer to participate and those who do not (55).

As shown in Table 5, people who participate in existing participatory surveillance systems tend in general to differ from the general population in demographic characteristics, socioeconomic status, health factors (including health care seeking behaviour and vaccination status) and geographical factors which are also linked with access to the internet (coverage bias). Spatial biases are also potentially present in participatory surveillance systems – for example, in relation to urban versus rural inequalities. This bias is among the most common threats to validity when making inferences.
In a review of the representativeness of participants during three influenza seasons (from 2012–2013 to 2014–2015), participants aged 40–79 years and female accounted for the majority of participants. Scores on an index of socioeconomic status (combining levels of education and income) were also greater among participants compared to the general population.

Since at least 2013, the majority of participants have been female, aged 35–64 years and with a university degree.

Adults under 65 years, women, urban residents and those vaccinated against seasonal influenza were all similarly over-represented among participants compared to the general population.

Flu Near You (now Outbreaks Near Me) (USA)

FluTracking (Australia and New Zealand)

FluWatchers (Canada)

Grippenet (Switzerland)

Influenzanet

<table>
<thead>
<tr>
<th>System(s)</th>
<th>Bias</th>
<th>Reference(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flu Near You (now Outbreaks Near Me) (USA)</td>
<td>In a review of the representativeness of participants during three influenza seasons (from 2012–2013 to 2014–2015), participants aged 40–79 years and female accounted for the majority of participants. Scores on an index of socioeconomic status (combining levels of education and income) were also greater among participants compared to the general population.</td>
<td>(56, 57)</td>
</tr>
<tr>
<td>FluTracking (Australia and New Zealand)</td>
<td>Since at least 2013, the majority of participants have been female, aged 35–64 years and with a university degree.</td>
<td>(59, 71)</td>
</tr>
<tr>
<td>FluWatchers (Canada)</td>
<td>Adults under 65 years, women, urban residents and those vaccinated against seasonal influenza were all similarly over-represented among participants compared to the general population.</td>
<td>(58)</td>
</tr>
<tr>
<td>Grippenet (Switzerland)</td>
<td>The age group 30–64 years and females were over-represented with participants also tending to have higher educational status, live in larger households, have fewer chronic illnesses, be non-smokers and have greater influenza vaccination rates compared to the general population. Respiratory allergies were more prevalent in participants compared to the general population.</td>
<td>(72)</td>
</tr>
<tr>
<td>Influenzanet</td>
<td>In a review of the representativeness of seven Influenzanet systems (in Belgium, France, Italy, Netherlands (Kingdom of the), Portugal, Sweden and United Kingdom), the age cohort 40–69 years was over-represented compared to younger and older age groups. Gender representativeness varied by country but participants were generally more likely to be female. Participants were also more likely to belong to a larger household and to have a higher educational level (in systems in which educational status was known), to be non-smokers, to not have diabetes, to have access to the internet in their households (including broadband) and to reside in the regions hosting the laboratory or institution conducting the participatory surveillance compared to the general population. Asthma prevalence and influenza vaccination coverage in individuals over 65 years of age varied by country.</td>
<td>(55)</td>
</tr>
</tbody>
</table>
Although such selection biases do not affect the robustness and accuracy of the epidemiological signal (trends in ILI) detected through participatory surveillance, systems need to continue to recruit new participants and to expand into areas where the general population is not well represented so that the data collected and disseminated are representative of the general population. Participatory surveillance systems may need to design targeted communication campaigns for under-represented age, gender and geographical groups. For example, GrippeWeb undertook a targeted approach to increase the participation of people 60 years of age and older by providing short text templates on GrippeWeb to editors for inclusion in free newspapers widely read by that age group. As lack of internet access is linked with the under-representation of certain groups, increasing representativeness will also involve investigating the most appropriate platforms and ensuring that systems are accessible to under-represented groups. Implementers should also ensure an optimal participant experience based on a smart and simple online interface and the use of short and simple questionnaires. Making it possible for participants to report on household members such as children may increase the representation of younger age groups in the surveillance system.

3.9.3 Information bias

Recall and reporting biases are types of information bias, which is another potential challenge when making inferences from participatory surveillance data. Participants could potentially report inaccurate information either deliberately or by mistake due to the nature of the survey methods.

Recall bias

Recall bias is defined as the systematic error due to differences in accuracy or completeness of recall to memory of past events or experiences and is a type of information bias. Memory effects leading to recall bias are expected to occur when surveying participant behaviour across a large set of indicators regarding events or experiences from the past. Studies have found that online participant responses contain less random and systematic error than those obtained by telephone. This was explained as an effect of the lack of social compliance towards the interviewer and the availability of a longer time to process the information at the individual’s own pace.

Surveys should be kept as simple as possible and should use appropriate wording to avoid incorrect information being entered by mistake due to misunderstanding of the question. Systems can be set up to check for mistakes in some fields (such as dates or gender) but not all.

Reporting bias

Reporting bias is defined as the selective revelation or suppression of information influenced by cognitive processes, social desirability and survey conditions (for example, past medical history, smoking and sexual experiences) or of study results. In the context of participatory surveillance, reporting bias refers to participants being more likely to report when ill, thus potentially biasing inferences from the system. In one analysis of FluTracking data from 2011 to 2017, participants were more likely to report on time if they or a household member were symptomatic. This participant behaviour led to overestimation of the weekly ILI prevalence during every season, especially when ILI prevalence was highest (during the peak of the season).
To account for this bias, several approaches, or combination of approaches, have been used. The approach of dropping the first (or more) symptom reports for each participant (when symptoms are reported before or on the registration date) has been used in the analysis of data from several systems (20, 40, 47, 50, 56, 75, 77). Such exclusion increased the correlation between participatory surveillance ILI trends and those derived from the sentinel GP ILI surveillance system (50, 56). Limiting analyses to active participants who regularly report following their registration (complete the intake survey and complete at least a defined number of weekly symptom surveys per season) is another additional approach (20, 35, 50, 54, 55, 75, 77) – though this may reduce the sample size (50). Noise-filtering algorithms have also been employed to adjust for unexpected large spikes in ILI incidence (56).

Reporting bias could also result from the reluctance of participants to provide accurate information on health factors such as smoking or influenza vaccination status, knowing that the surveillance is coordinated by a public health institution, and mindful of the potential consequences of reporting accurate information. The effect of this bias would be expected to be minimal due to the relative anonymity of the surveillance and data privacy protection (72).

3.9.4 Confounding bias

Confounding biases should be considered if inferences on causal associations between exposures and outcomes are derived from participatory surveillance. For example, when analyzing the data to assess the risk factors for ILI or influenza among participants, there is the potential for confounding due to age, gender, educational status, smoking status or underlying chronic conditions which may be associated with both the risk factor of interest and outcome (1, 42). Other associations often derived from participatory surveillance data which could be affected by confounding include the apparent determining factors for participation and retention (65, 67). Confounding bias may also affect vaccine effectiveness estimates derived from participatory surveillance as some groups may be more or less likely to be vaccinated, while some vaccinees may have an underlying chronic disease (confounding by indication). The effect of vaccination on the measured outcome may consequently be biased higher or lower than the true estimate (1, 26, 78, 79).

3.9.5 Determining the denominator and the symptoms combination for incidence calculations

The participation of individuals exhibiting variable reporting behaviours during the season, variable interpretation by individuals of the terms used for surveillance, and the unknown accuracy of self-assessments bring unique challenges when analyzing data generated by participatory surveillance systems (50). A small number of such aspects have previously been analyzed in isolation (42, 46, 47, 77). Participatory surveillance is further complicated by the choice of the appropriate definition used to identify influenza cases. Because of the lack of specificity of influenza symptoms, national sentinel systems have adopted ILI or ARI definitions – two of the most common quantitative indicators. However, these indicators are defined at country level and no defined standard exists at the international level (80). Participatory systems have the advantage of being flexible in which case definitions to adopt as case definitions can be built on different combinations of reported symptoms without requiring an a priori definition as used by sentinel systems. Some studies have attempted to assess how different combinations of self-reported symptoms perform in the accurate estimation of influenza incidence – that is, estimates which can be compared to available sentinel estimates (50, 70).
Moreover, the crude incidence measured by an internet-based system appears to be influenced by individuals who participate only once in the survey and who appear more likely to be ill. This can distort the overall incidence trend. Concentrating on individuals who report more than once results in a time series of ILI incidence that matches the trend of case estimates reasonably closely (24). Internet-based monitoring of ILI can also capture the trends in case numbers if appropriate weighting is used to correct for differential response. The overall level of incidence is, however, difficult to measure. Internet-based systems may be a useful adjunct to existing ILI surveillance systems as they capture cases that do not necessarily seek health care. However, further research is required before they can be used to accurately assess the absolute level of incidence in the community (24).

3.9.6 Other adjustments

In cases where participants report ILI episodes for multiple consecutive weeks, adjustments can be made to avoid the counting of one ILI episode as multiple episodes. One approach is to discard weekly ILI reports for individuals who have also reported ILI during the preceding week(s) (37, 50) or in the same week (46). Recurrent ILI episodes can be considered if one week without ILI symptoms is reported between two weeks of reporting ILI symptoms (40, 46).

Approaches to address missing weekly reports using imputation have also been studied (75). However, in most systems, missing reports are not assumed to be equivalent to absence of symptoms, and inclusion criteria for the denominator depend on a participant’s pattern of participation over several weeks and no imputation is applied.

Filtering out false participants is not possible but unusual participation patterns can be detected and filtered out of the incidence calculations.

3.10 Data visualization and dissemination

Data visualizations are important because they can provide information on the results obtained that can be disseminated among the general public. This can in turn enhance engagement and participation and provide a clear way of demonstrating to the public how the data are analyzed and used. Moreover, data visualization dashboards can support the monitoring of metrics and results acquired by the platforms (81). The most commonly used data visualizations adopted by participatory surveillance platforms include: incidence curves, maps showing the geographical coverage of participants, maps showing the geographical distribution of the disease, and histograms showing age and gender distributions. Maps should be shown at a subdivision level that preserves participant privacy and is meaningful when comparing disease trends with official sources (for example, NUTS3 level in Europe).

Efforts should be made to regularly connect with stakeholders responsible for implementing routine influenza surveillance, and to integrate and disseminate information from the system with influenza surveillance data from other systems, such as facility-based surveillance systems. Incorporating the participatory surveillance ILI trends into regular influenza bulletins alongside the data from traditional systems can provide more comprehensive situation updates.
There are several aspects to consider when monitoring and evaluating a participatory surveillance system. Standard elements required for surveillance system monitoring and evaluation include system performance indicators (such as timeliness, validity and data quality) as well as system experience indicators (such as usefulness, flexibility, acceptability, portability, stability and cost). All of these are appropriate aspects to consider for participatory surveillance systems (82).

4.1 Timelines

Timeliness is generally considered to be one of the main strengths of participatory disease surveillance systems. Such systems are usually internet-based, receive and process reports in near real-time, and provide online mechanisms for rapidly sharing results. Assessing the timeliness of a participatory surveillance system can involve:

- evaluating the time from illness onset in participants to time of reporting to provide insights into how rapidly the system detects illness in the population; and
- evaluating the timing of symptom trends in comparison to other disease surveillance systems to provide insight into whether a participatory surveillance system might detect early signals of disease transmission – for example, by detecting symptom reports in a community several days before an increase in ILI detected by the sentinel GP ILI surveillance system (39, 40, 46, 47, 50, 72).

4.2 Validity

Positive predictive value (PPV) refers to the proportion of cases reported each week of the disease under surveillance (for example, proportion of total influenza cases). Measuring sensitivity typically requires an external dataset such as trusted “gold standard” surveillance data to determine the true frequency of the disease in the population (82). This approach can be complicated by the fact that a participatory surveillance system might detect cases of mild illness not reported to traditional disease surveillance systems. Participatory surveillance systems are typically considered to be sensitive but may not be particularly specific since they typically lack a direct mechanism to validate a report.

- Many participatory surveillance systems have compared how well they correlate with “gold standard” systems such as symptom reporting from medical providers and rates of laboratory-positive tests (40, 56, 75, 83, 84).

- To assess PPV, laboratory testing to confirm a reported case could be considered but may be resource intensive. Limited studies have linked self-reported symptom data to laboratory testing, and have provided examples of how such confirmation might be conducted (45, 60). In early 2020, the Flusurvey platform in the United Kingdom enrolled participants into self-swabbing initiatives to allow for laboratory testing of self-reported symptoms to develop point prevalence estimates of COVID-19 infections and to determine the PPV of reported symptoms (85).

- Alternatively, some participatory surveillance systems allow participants to report whether they received a laboratory test and whether it was positive or negative. While this approach still places an emphasis on trusting participant reports, it provides a less costly method of assessing the frequency with which ILI reports might be true cases of influenza (86). Unpublished data from FluTracking indicates that the PPV for influenza from the self-reporting of a positive influenza test is around 50%.
4.3 Data quality

4.3.1 Representativeness
Participatory surveillance systems should monitor and evaluate the representativeness of participants in relation to the larger population under surveillance by comparing variables (for example, age, ethnicity, gender, geographical location and prevalence of risk factors) from the cohort with those of the general population. Understanding what sectors of the population may be under- or over-represented can inform decisions on how to target recruitment efforts to ensure a balanced and representative cohort. While participatory surveillance systems typically collect only a limited amount of participant data, some of this information can be used to estimate or infer additional characteristics of the cohort.

4.3.2 Completeness
Complete and consistent data are necessary for a reliable surveillance system, and participatory surveillance systems can face particular challenges in this respect when relying on reports from the general public. It is important to assess the consistency and frequency of reporting at the individual level – such as how many reports the average participant submits during a season, and whether they only report when sick or if they also include “healthy” reports (77). Monitoring the percentage of participants that provide variables such as postcode, age and gender (which may be optional rather than required fields) is important for assessing the degree to which data can be stratified by certain variables. Finally, data collection processes should be closely monitored to ensure that system errors do not prevent or obstruct participant reporting. A standard dashboard of error checks should be specified and run weekly (for example, changes in response by question, number of unsubscribers and occurrence of server errors).

4.4 System experience

4.4.1 Usefulness
Assessing the usefulness of participatory surveillance systems involves asking questions such as:
- Are the data useful for public health surveillance and decision-making?
- Who is making use of the data? Are data being shared with public health stakeholders?
- Are data also made available to participants and the general public?
- What benefits are derived by participants and the wider general public?

A review of the usefulness of GrippeWeb during the COVID-19 pandemic found that information from the system was able to show very accurately throughout the pandemic how far contact-limiting measures such as lockdowns (among others) reduced conditions for the transmission of respiratory pathogens in general (87).

4.4.2 Flexibility
Participatory surveillance systems may have inherent flexibility to rapidly add symptoms to a questionnaire, quickly recruit new participants in a particular geographical area or even push communications to participants to prompt good reporting habits (see Box 1). This characteristic might thus allow for rapid changes to be made to scale up data collection and analysis during emergencies, outbreaks or similar situations. At the same time, it is important to consider that any changes made will affect the longitudinal dataset, potentially complicating analyses.
GrippeNet.fr (as COVIDnet.fr) used to estimate COVID-19 incidence in France – GrippeNet.fr was adapted as part of the COVID-19 response to collect weekly self-reports from existing GrippeNet.fr participants on symptoms compatible with COVID-19. Self-reporting participants also provided information on their health care seeking behaviour and outcomes of SARS-CoV-2 testing. Data indicated that, in line with estimates obtained from seroprevalence studies, only about one third of participants reporting symptoms sought health care. The symptomatic incidence rate estimated from the participatory surveillance system for the end of June 2020 was about 2–3 times greater than the virologically confirmed incidence rate, and similar to the predicted incidence rate. In light of these diverse results, the under ascertainment of COVID-19 cases was suspected and this provided a rationale for improving COVID-19 case detection capabilities as part of the pandemic response (88).

GrippeWeb used to describe COVID-19 incidence in Germany – in 2022, GrippeWeb migrated to a new platform and added further questions, including questions on symptoms and on confirmation of infection with respiratory pathogens (including SARS-CoV-2) based on self-testing. COVID-19 incidence trends obtained using GrippeWeb were similar to those obtained through the mandatory COVID-19 reporting system but with an estimated 2.6-fold higher incidence – possibly reflecting the under-reporting of cases to the mandatory reporting system (87).

Experiences from Influmeter.dk used to launch COVIDmeter.dk in Denmark – in March 2020, Influmeter.dk included several symptoms compatible with COVID-19 infection in the questionnaire and enabled participants to also specify whether they considered any of their self-reported symptoms to be caused by COVID-19. During April 2020, the experience gained was used to guide the launch of a similar system (COVIDmeter.dk) which only monitored COVID-19. This and other COVID-19 surveillance efforts enjoyed strong support among the Danish public and COVIDmeter.dk ran throughout the pandemic phase until spring 2023 – whereupon activities switched to analysing the data collected during the 3 years the system was functioning and to disseminating the findings.
4.4.3 Acceptability

Acceptability can be assessed by looking at indicators such as participation and retention rates, and by understanding participant motivations for contributing (67).

4.4.4 Portability

The portability of participatory surveillance systems can be characterized by considering how easily such a system could be replicated in another setting. It could be contended that the modern participatory disease surveillance approach for monitoring ILI has been replicated many times over, with one of the earliest examples being The Great Influenza Survey in the Netherlands (Kingdom of the), which began in 2003 (77). Since that time, systems have been established across Western Europe, North America, Australia, New Zealand, Brazil, Thailand and elsewhere (32).

4.4.5 Stability

The stability of a system will be affected by several factors and this aspect should be considered separately from data quality and completeness (82). Factors such as system downtime and maintenance, system errors in data collection processes, and challenges due to staff turnover or financing can all affect the stability of a participatory surveillance system. However, participatory surveillance systems may offer the advantage of stability during a pandemic when health care provision and health care seeking behaviours change.
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Annex 1: Inventory of existing influenza-like participatory surveillance systems

Note: available information on existing systems is provided in the tables below. The objectives, where included, were obtained through a rapid literature review (1).

<table>
<thead>
<tr>
<th>SYSTEM</th>
<th>CoughWatchSA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td>South Africa</td>
</tr>
<tr>
<td>Link</td>
<td><a href="http://www.nicd.ac.za/coughwatchsa-health-survey/">www.nicd.ac.za/coughwatchsa-health-survey/</a></td>
</tr>
<tr>
<td>Description</td>
<td>CoughWatchSA is a pilot digital participatory surveillance platform launched by the National Institute for Communicable Diseases (NICD) from 9 March to 31 October 2022. The platform will be deployed officially in 2023 as part of existing pneumonia surveillance programmes in South Africa. This platform is open to all South African residents aged 18 years or over. Participants are asked to report on symptoms related to ILI and COVID-19. In addition, demographic data and information on lifestyle factors, underlying medical conditions and vaccination status for seasonal influenza and COVID-19 are also captured.</td>
</tr>
<tr>
<td>Approximate development or deployment cost</td>
<td>No costs involved. Participant acquisition was leveraged through public relations with media houses, TV broadcasting channels and radio stations, which were all free. For the data platform, the proprietary software REDCap was used which was already paid for by NCID. Human resources for development and deployment work were paid through salaries. All of this applies only to the pilot study and will change for the main deployment.</td>
</tr>
<tr>
<td>Approximate maintenance cost</td>
<td>No cost for the pilot study – this will change for the official deployment starting from 2023.</td>
</tr>
<tr>
<td>Terms and conditions</td>
<td><a href="https://redcap.core.wits.ac.za/redcap/surveys/?s=NK9CEKLYCKD3CH3F">https://redcap.core.wits.ac.za/redcap/surveys/?s=NK9CEKLYCKD3CH3F</a></td>
</tr>
</tbody>
</table>
Flusurvey is a webtool managed and monitored by the United Kingdom Health Security Agency (UKHSA – formerly Public Health England) and is designed to monitor trends in infectious diseases in the community. Originally set up during the swine flu pandemic in 2009 by researchers at the London School of Hygiene and Tropical Medicine, Flusurvey forms part of a Europe-wide initiative with eight other countries to monitor ILI activity, but has now been adapted to monitor a range of diseases, including COVID-19. Any member of the United Kingdom public aged 18 years or over can register on the platform to report respiratory symptoms they may experience. The data is then used by UKHSA to monitor disease trends in the United Kingdom. There are currently more than 10 000 people from all over the country participating in this survey.

<table>
<thead>
<tr>
<th>SYSTEM</th>
<th>FluMob</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td>Singapore</td>
</tr>
<tr>
<td>Description</td>
<td>To serve as a complementary surveillance system for influenza in addition to existing surveillance systems designed exclusively for health care workers (89).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SYSTEM</th>
<th>Flusurvey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td>United Kingdom of Great Britain and Northern Ireland</td>
</tr>
<tr>
<td>Link</td>
<td>flusurvey.net/</td>
</tr>
<tr>
<td>Description</td>
<td>Flusurvey is a webtool managed and monitored by the United Kingdom Health Security Agency (UKHSA – formerly Public Health England) and is designed to monitor trends in infectious diseases in the community. Originally set up during the swine flu pandemic in 2009 by researchers at the London School of Hygiene and Tropical Medicine, Flusurvey forms part of a Europe-wide initiative with eight other countries to monitor ILI activity, but has now been adapted to monitor a range of diseases, including COVID-19. Any member of the United Kingdom public aged 18 years or over can register on the platform to report respiratory symptoms they may experience. The data is then used by UKHSA to monitor disease trends in the United Kingdom. There are currently more than 10 000 people from all over the country participating in this survey.</td>
</tr>
<tr>
<td>Approximate development or deployment cost</td>
<td>£65 000+</td>
</tr>
<tr>
<td>Approximate maintenance cost</td>
<td>£10 000+ per year</td>
</tr>
<tr>
<td>Data use agreement</td>
<td>flusurvey.net/media/uploads/privacy_policy_Updated_14_09_21_new.pdf — Currently being updated.</td>
</tr>
<tr>
<td>SYSTEM</td>
<td>FluTracking</td>
</tr>
<tr>
<td>--------</td>
<td>-------------</td>
</tr>
<tr>
<td>Location</td>
<td>Argentina</td>
</tr>
<tr>
<td>Link</td>
<td>flutracking.com.ar/</td>
</tr>
<tr>
<td>Description</td>
<td>The FluTracking Argentina project is a joint initiative of the Argentina Society of Infectious Diseases and the Australian FluTracking team, with funding from the Department of Foreign Affairs and Trade (DFAT) Council on Australia Latin America Relations (COALAR).</td>
</tr>
<tr>
<td>Data use agreement</td>
<td><a href="https://flutracking.com.ar/privacidad/">https://flutracking.com.ar/privacidad/</a></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SYSTEM</th>
<th>FluTracking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td>Australia and New Zealand</td>
</tr>
<tr>
<td>Link</td>
<td>info.flutracking.net/</td>
</tr>
</tbody>
</table>
| Description | FluTracking is a joint initiative of the University of Newcastle, Hunter New England Population Health and the Hunter Medical Research Institute, and is funded by the Australian Government Department of Health and Aged Care. In May 2018, FluTracking expanded to include New Zealand by partnering with the Public Health Group from the Ministry of Health of New Zealand which funds FluTracking in the country. In New Zealand, more than 6000 people, representing 507 postcodes across North Island and South Island, registered with FluTracking in its first year. The approximately 4000 people per week participating represents a participation rate of 1 in every 1200 New Zealanders. 

In total, more than 210 000 new participants (96 859 Australians plus 117 328 New Zealanders) registered with FluTracking from 2020 up to 2022, representing over 3000 postcodes. 

During 2022, an average of 98 000 responses were received per week, with more than 154 000 participants completing at least one survey. |
### FluTracking Hong Kong

**Location**: China, Hong Kong SAR

**Objectives**: The FluTracking Hong Kong project is a joint initiative of the School of Public Health, University of Hong Kong, and the Australian FluTracking team. FluTracking Hong Kong was started in 2021 and as of 2023 had 1000 active participants.

**Approximate development or deployment cost**: USD 100 000

**Approximate maintenance cost**: USD 40 000 per year

**Data use agreement**: [https://www.flutracking.sph.hku.hk/privacy-policy](https://www.flutracking.sph.hku.hk/privacy-policy)

---

### FluTracking Australia and New Zealand

**Location**: Australia and New Zealand

**Objectives**: To compare ILI syndrome rates in vaccinated and unvaccinated participants; to detect interpandemic and pandemic influenza and provide early confirmation of vaccine effectiveness or failure; to provide consistent surveillance of influenza activity across all jurisdictions and over time; to provide year-to-year comparison of the timing, incidence and severity of influenza (71, 90–92).

**Approximate development or deployment cost**: Average A$ 460 000 per year during 2021–2023 (combined costs in both countries)

**Terms and conditions**: [www.flutracking.net/Join/AU](http://www.flutracking.net/Join/AU) and [www.flutracking.net/Join/NZ](http://www.flutracking.net/Join/NZ)

**Data use agreement**: [www.flutracking.net/Join/AE/Policy](http://www.flutracking.net/Join/AE/Policy) – Australia; [www.flutracking.net/Join/NE/Policy](http://www.flutracking.net/Join/NE/Policy) – New Zealand
<table>
<thead>
<tr>
<th>SYSTEM</th>
<th>FluWatchers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td>Canada</td>
</tr>
<tr>
<td>Description</td>
<td>FluWatchers is both funded and maintained by the Public Health Agency of Canada. The FluWatchers programme is an important part of Canada's national influenza surveillance programme, FluWatch.</td>
</tr>
<tr>
<td>Objectives</td>
<td>To track community ILI activity; to capture the spread of ILI among individuals who do not seek medical care (<a href="#">58, 93</a>).</td>
</tr>
<tr>
<td>Data use agreement</td>
<td><a href="https://cnphi.canada.ca/fluWatcher/register">https://cnphi.canada.ca/fluWatcher/register</a></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SYSTEM</th>
<th>gripenet.pt</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td>Portugal</td>
</tr>
<tr>
<td>Description</td>
<td>Managed by the Instituto Nacional de Saúde Dr Ricardo Jorge (INSA) which is a public institution under the Portuguese Ministry of Health.</td>
</tr>
<tr>
<td>SYSTEM</td>
<td>Grippenet</td>
</tr>
<tr>
<td>--------</td>
<td>-----------</td>
</tr>
<tr>
<td>Location</td>
<td>Switzerland</td>
</tr>
<tr>
<td>Link</td>
<td><a href="https://grippenet.ch/welcome">https://grippenet.ch/welcome</a></td>
</tr>
<tr>
<td>Description</td>
<td>Grippenet is a participatory surveillance system that contributes to the detection and surveillance of ILI and COVID-19 in Switzerland. It aims to provide a better understanding of the transmission of these diseases. The project was launched and implemented in 2016 in collaboration with the Institute of Global Health, University of Geneva, the Laboratory of Computational Epidemiology, Turin, Computational Social Sciences, Zurich, the Laboratory of Digital Epidemiology, Lausanne, and the National Reference Center for Influenza, Geneva.</td>
</tr>
<tr>
<td>Objectives</td>
<td>Grippenet is part of the larger-scale project Influenzanet, which is a European monitoring system introduced in 2003 – initially in the Netherlands (Kingdom of the) and Belgium, and later ratified by 10 other European countries, including Switzerland in 2016. Since March 2020, Grippenet.ch also contributes to the monitoring of the COVID-19 pandemic. The project is funded by the Institute of Global Health, University of Geneva.</td>
</tr>
<tr>
<td>Approximate development or deployment cost</td>
<td>CHF 67 500</td>
</tr>
<tr>
<td>Approximate maintenance cost</td>
<td>CHF 405 000 in total (2017–2022)</td>
</tr>
<tr>
<td>Terms and conditions</td>
<td><a href="https://grippenet.ch/privacy">https://grippenet.ch/privacy</a></td>
</tr>
<tr>
<td>Data use agreement</td>
<td><a href="https://grippenet.ch/privacy">https://grippenet.ch/privacy</a></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SYSTEM</th>
<th>GrippeNet.fr/COVIDnet.fr</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td>France</td>
</tr>
<tr>
<td>Link</td>
<td><a href="http://www.grippenet.fr">www.grippenet.fr</a></td>
</tr>
<tr>
<td>Description</td>
<td>GrippeNet.fr was set up in January 2012 by the Sentinelles network, Inserm, Sorbonne University, and Public Health France (formerly Institut de Veille Sanitaire). In March 2020, GrippeNet.fr became GrippeNet.fr/COVIDnet.fr.</td>
</tr>
<tr>
<td>Description continued</td>
<td>This surveillance and research project aims to collect epidemiological data on influenza and COVID-19 directly from the public, via the internet and anonymously. The project is funded by Public Health France and receives no private funding. During the 2022–2023 winter season, approximately 5700 people were participating in the surveillance.</td>
</tr>
</tbody>
</table>
### SYSTEM | GrippeNet.fr/COVIDnet.fr
--- | ---
**Objectives** | To estimate ILI frequency among the GrippeNet cohort in France; to describe the epidemiology of seasonal influenza during the influenza season among pregnant women (Grossesse-GrippeNet) (94); to identify the factors associated with ILI infections; to support epidemiological and public health monitoring and research (50, 78).

**Terms and conditions** | [https://www.grippenet.fr/fr/mentions-legales/](https://www.grippenet.fr/fr/mentions-legales/)

### SYSTEM | GrippeWeb
--- | ---
**Location** | Germany

**Link** | [https://www.rki.de/DE/Content/Infekt/Sentinel/Grippeweb/grip-peweb.html](https://www.rki.de/DE/Content/Infekt/Sentinel/Grippeweb/grip-peweb.html)

**Description** | GrippeWeb is an online portal of the Robert Koch Institute and is funded by the Institute. Founded in 2011 with financial aid from the Ministry of Health, it is the first web portal that monitors the activity of acute respiratory diseases in Germany, using information provided directly by the population. In 2022, GrippeWeb was migrated to a new platform to improve its cybersecurity. In addition, further questions were added, including on symptoms and on laboratory confirmation of infection with a respiratory pathogen.

**Approximate development or deployment cost** | €50 000–€70 000

**Approximate maintenance cost** | €150 000–€200 000 per year

**Terms and conditions** | [https://www.rki.de/DE/Content/Infekt/Sentinel/Grippeweb/grip-peweb_teilnahme_node.html](https://www.rki.de/DE/Content/Infekt/Sentinel/Grippeweb/grip-peweb_teilnahme_node.html)

**Data use agreement** | [https://grippeweb.bund.de/datenschutz](https://grippeweb.bund.de/datenschutz)
## Hälsorapport ("Health Report")

<table>
<thead>
<tr>
<th>Location</th>
<th>Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Link</td>
<td><a href="https://halsorapport.se/sv/">https://halsorapport.se/sv/</a></td>
</tr>
</tbody>
</table>

**Description**

Hälsorapport is run by the Public Health Agency and is a web panel that consists of people throughout Sweden. The purpose of the Health Report is to obtain current knowledge about the population’s health and views on health. Health Report has been running since 2015. Every 1–2 years, invitations are sent out via post to randomly selected people in the population (last invitation May 2023; n = 35 000). Approximately 8000 people between the ages of 1 and 96 participate in Health Report.

**Objectives**

To obtain up-to-date knowledge on population health and population views on health.

**Terms and conditions**

[https://www.halsorapport.se/sv/hjalp/hjalp-copy/](https://www.halsorapport.se/sv/hjalp/hjalp-copy/)

**Data use agreement**

[https://www.halsorapport.se/sv/hjalp/fakta-om-datainsamlingen/](https://www.halsorapport.se/sv/hjalp/fakta-om-datainsamlingen/)

## Infectieradar.be

<table>
<thead>
<tr>
<th>Location</th>
<th>Belgium</th>
</tr>
</thead>
<tbody>
<tr>
<td>Link</td>
<td><a href="https://survey.infectieradar.be/welcome">https://survey.infectieradar.be/welcome</a></td>
</tr>
</tbody>
</table>

**Description**

People who have registered as participants in Infectieradar.be report once a week on whether they have had a fever or other symptoms in the past week. This allows for the monitoring of the national distribution of symptoms and of how the situation develops over time. The data are also used for scientific research into the spread of respiratory infections. Participants receive an initial registration form with questions about their background, employment, age, and any existing diseases and conditions. They then receive an email every week asking if they have had any symptoms in the past week and if so, which ones.

It is important for the questionnaire to be completed even if a participant has had no symptoms. If this is the case, it takes about 30 seconds to answer the questions – if there are symptoms it takes about 3–5 minutes.

Infectieradar.be is run in collaboration with the University of Antwerp and the University of Hasselt, and receives financial support from the EU Horizon 2020 and Horizon Europe programmes, along with FWO support.
<table>
<thead>
<tr>
<th>SYSTEM</th>
<th>Infectieradar.be</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data use agreement</td>
<td><a href="https://survey.infectieradar.be/privacy">https://survey.infectieradar.be/privacy</a></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SYSTEM</th>
<th>Infectieradar.nl</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td>Netherlands (Kingdom of the)</td>
</tr>
<tr>
<td>Link</td>
<td><a href="https://www.infectieradar.nl/welcome">https://www.infectieradar.nl/welcome</a></td>
</tr>
<tr>
<td>Description</td>
<td>Infectieradar.nl is managed and run by RIVM, part of the national infectious disease surveillance system. Between 15 000 and 20 000 participants report at least once per month. Currently, the system also offers the possibility for participants to obtain free COVID-19 self-tests and, depending on the result of the test and on whether or not they are symptomatic, participants are invited to send in a nose/throat sample using the materials provided.</td>
</tr>
<tr>
<td>Approximate development or deployment cost</td>
<td>RIVM made contributions towards the open source Influenzanet software and invested in an analytical R-pipeline (including automatic reporting, participant monitoring dashboard and results dashboard (<a href="https://www.infectieradar.nl/results">https://www.infectieradar.nl/results</a>).</td>
</tr>
<tr>
<td>Approximate maintenance cost</td>
<td>Due to automation, running this syndromic surveillance system requires little ongoing investment.</td>
</tr>
<tr>
<td>Terms and conditions</td>
<td><a href="https://www.infectieradar.nl/privacy">https://www.infectieradar.nl/privacy</a></td>
</tr>
<tr>
<td>Data use agreement</td>
<td><a href="https://www.infectieradar.nl/privacy">https://www.infectieradar.nl/privacy</a></td>
</tr>
<tr>
<td>SYSTEM</td>
<td>Influenzanet</td>
</tr>
<tr>
<td>------------</td>
<td>------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Location</td>
<td>Europe</td>
</tr>
<tr>
<td>Link</td>
<td><a href="https://influenzanet.info/">https://influenzanet.info/</a></td>
</tr>
<tr>
<td>Description</td>
<td>In 2008, a large-scale integrated project (Epiwork – <a href="https://cordis.europa.eu/project/id/231807">https://cordis.europa.eu/project/id/231807</a>) funded by the 7th Framework Program of the European Commission led to the creation of the first prototype system that was then deployed in the various countries now participating to Influenzanet. In most of the countries participating in Influenzanet, the platform is run by the national institute of public health. Each platform is also supported by the hosting institution which provides personnel for platform management, data analysis and reporting, and editing and communications activities. More recently, two Horizon 2020 projects (Epipose and PANDEM-2) have provided extensive funding to support the technological renovation of the system’s infrastructure. Initially conceived to make scientific information accessible to a broad public and to kindle student enthusiasm for science; to serve as a complementary system to traditional public health surveillance in disease reporting (20).</td>
</tr>
<tr>
<td>Objectives</td>
<td>Approximate development or deployment cost: The startup cost of around €300 000 was covered by the Epiwork project. Approximate maintenance cost: Additional funding of around €20 000 per annum for technological maintenance has been provided by the ISI Foundation.</td>
</tr>
</tbody>
</table>

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<thead>
<tr>
<th>SYSTEM</th>
<th>Influmeter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td>Denmark</td>
</tr>
<tr>
<td>Link</td>
<td><a href="https://influmeter.dk/welcome">https://influmeter.dk/welcome</a></td>
</tr>
<tr>
<td>Description</td>
<td>In 2014, Statens Serum Institut, under the auspices of the Danish Ministry of Health, launched the participatory ILI surveillance system Influmeter. Influmeter is an epidemiological monitoring tool designed to monitor the spread of influenza-like symptoms in Denmark. Influmeter is run by the Statens Serum Institut and is part of a European collaboration (Influenzanet) with participation from approximately 10 European countries with similar systems. Monitoring is based on voluntary efforts from participants who, regardless of whether they have sought health care or received treatment, report each week on whether they have had symptoms, thus contributing to knowledge of the spread of ILI in the country. During the 2022–2023 influenza season, around 4000 reports were received each week.</td>
</tr>
<tr>
<td>Objectives</td>
<td>To monitor self-reported ILI in the general population (47).</td>
</tr>
<tr>
<td></td>
<td>Approximate development or deployment cost: Two months of work and around €10 000</td>
</tr>
<tr>
<td></td>
<td>Approximate maintenance cost: One month of work each year and around €3300 per year</td>
</tr>
<tr>
<td>Terms and conditions</td>
<td>One month of work each year and around €3300 per year</td>
</tr>
<tr>
<td>Data use agreement</td>
<td><a href="https://influmeter.dk/privacy">https://influmeter.dk/privacy</a></td>
</tr>
</tbody>
</table>
### Influweb

<table>
<thead>
<tr>
<th>SYSTEM</th>
<th>Influweb</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td>Italy</td>
</tr>
<tr>
<td>Link</td>
<td><a href="https://influweb.org/welcome">https://influweb.org/welcome</a></td>
</tr>
<tr>
<td>Description</td>
<td>Influweb is supported by Fondazione ISI, Fondazione CRT and by the European projects Epipose and PANDEM-2 (part of the EU Horizon 2020 programme). Influweb is the Italian node of Influenzanet, which monitors ILI activity in more than 10 European countries.</td>
</tr>
<tr>
<td>Objectives</td>
<td>To provide epidemiological information directly from the general population using self-reports from volunteers who complete weekly questionnaires during the influenza season, thus obtaining data even from those not seeking medical advice.</td>
</tr>
<tr>
<td>Approximate development or deployment cost</td>
<td>Two months of work and around €10 000</td>
</tr>
<tr>
<td>Approximate maintenance cost</td>
<td>One month of work each year and around €3300 per year</td>
</tr>
<tr>
<td>Terms and conditions</td>
<td><a href="https://influweb.org/privacy">https://influweb.org/privacy</a></td>
</tr>
<tr>
<td>Data use agreement</td>
<td><a href="https://influweb.org/privacy">https://influweb.org/privacy</a></td>
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</table>

### Outbreaks Near Me

<table>
<thead>
<tr>
<th>SYSTEM</th>
<th>Outbreaks Near Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td>Canada, Mexico and the USA</td>
</tr>
<tr>
<td>Description</td>
<td>In the USA, Outbreaks Near Me was developed as the next generation of Flu Near You by the Boston Children's Hospital Computational Epidemiology Group – a non-profit research organization that operates the system and supports data analysis. Launched in 2011 as Flu Near You, the system was created through collaboration between the American Public Health Association, Boston Children’s Hospital and Ending Pandemics (formerly Skoll Global Threats Fund). With support from the US Centers for Disease Control and Prevention, FluLab and Ending Pandemics, Outbreaks Near Me was launched in March 2020 to track signals of respiratory illness and health behaviours at the onset of the COVID-19 pandemic. Current collaborators include Momentive (Survey Monkey), Delphi Group and the COVID Symptom Study. Data are shared with the US Centers for Disease Control and Prevention, and with state and local health departments through data use agreements.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SYSTEM</th>
<th>Outbreaks Near Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objectives</td>
<td>To be used in conjunction with traditional surveillance systems; to assess influenza attack rates in specific cohorts (37, 57, 83).</td>
</tr>
<tr>
<td>Approximate development or deployment cost</td>
<td>Outbreaks Near Me development and startup were funded by FluLab and Ending Pandemics with grants totalling around $1 500 000. These funds supported application development leveraging the Flu Near You technology as well as platform promotion, recruitment and expansion.</td>
</tr>
<tr>
<td>Approximate maintenance cost</td>
<td>Subsequent direct cost funding to maintain the system and support some research activities has averaged between US$ 300 000 and US$ 500 000 per year.</td>
</tr>
<tr>
<td>Terms and conditions</td>
<td><a href="https://outbreaksnearme.org/us/en-US/terms">https://outbreaksnearme.org/us/en-US/terms</a></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SYSTEM</th>
<th>Sicksense</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td>Thailand</td>
</tr>
<tr>
<td>Link</td>
<td><a href="https://www.sicksense.org/">https://www.sicksense.org/</a></td>
</tr>
<tr>
<td>Description</td>
<td>Sicksense is a participatory surveillance platform powered by a network of public volunteers who anonymously report their daily symptoms via the LINE chatbot Sabaidee (<a href="https://www.opendream.co.th/en/project/sabaidee-chatbot-en">https://www.opendream.co.th/en/project/sabaidee-chatbot-en</a>) or the mobile application DoctorMe (<a href="https://www.opendream.co.th/en/project/doctorme-en">https://www.opendream.co.th/en/project/doctorme-en</a>). The data collected by these digital tools are aggregated into a real-time map of ILI across Thailand and displayed on the Sicksense website. The Sicksense project is a collaboration between Skoll Global Threats Fund (now Ending Pandemics), the Thai Health Promotion Foundation (ThaiHealth) and Opendream.</td>
</tr>
<tr>
<td>Objectives</td>
<td>Opendream received a US$ 195 000 grant to adapt the system to include a module for symptom reporting and shares symptom data with health authorities and through the website <a href="https://www.sicksense.org/">https://www.sicksense.org/</a>.</td>
</tr>
<tr>
<td>Data use agreement</td>
<td><a href="https://www.opendream.co.th/en/doctorme-privacy-policy">https://www.opendream.co.th/en/doctorme-privacy-policy</a></td>
</tr>
<tr>
<td>SYSTEM</td>
<td>Symptometer</td>
</tr>
<tr>
<td>--------</td>
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</tr>
<tr>
<td>Location</td>
<td>Norway</td>
</tr>
<tr>
<td>Link</td>
<td><a href="https://www.fhi.no/ss/korona/symptometer">https://www.fhi.no/ss/korona/symptometer</a></td>
</tr>
</tbody>
</table>

**Description**
Symptometer was created in autumn 2020 by the Norwegian Institute of Public Health (NIPH). Symptometer surveils self-reported COVID-19-related symptoms, testing activity and vaccination status among participants. The system was established and financed by NIPH. Helsenorge.no, a national web solution for health-related services and information, is used as the technical platform for the weekly questionnaires. Initially, 36,000 people agreed to participate in autumn 2020, with a weekly response rate of approximately 50%. As of September 2023, 23,000 people were participating, with a weekly response rate of around 18%.

| Approximate development or deployment cost | Not available. |
| Approximate maintenance cost | Costs now primarily comprise person time and SMS costs. |
| Terms and conditions | https://www.fhi.no/ss/korona/symptometer/til-invitere-deltakere-i-symptometer/ |
| Data use agreement | https://www.fhi.no/ss/korona/symptometer/til-invitere-deltakere-i-symptometer/ |

**Reference**
Annex 2: 
WHO development process for preferred product characteristics and management of conflicts of interest

As part of the development of this document, a rapid review of the available literature was conducted to explore the performance of participatory surveillance systems for influenza and influenza-like illness worldwide. WHO developed a draft document with contributions from external subject matter experts on the technical content. The draft document was posted for public consultation in October 2023. Feedback received during the public consultation period were reviewed and, where appropriate, addressed in a revised version of the document.

Assessment and management of conflicts of interest

WHO processes were used to assess declared interests and to manage any conflicts of interest. All external experts involved in the technical development of content in this document submitted to WHO a declaration of interest disclosing potential conflicts of interest that might affect, or might reasonably be perceived to affect, their objectivity and independence in relation to the subject matter of the document. WHO reviewed each of those and had concluded that none could give rise to a potential or reasonably perceived conflict of interest related to the subjects covered in this guidance.