Complete list of the key points to consider from the Chatham House Guide to Sharing the Data and Benefits of Public Health Surveillance

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Building Trust

General points

Have the expectations of all stakeholders affected by the data sharing been taken into account?

The purpose of sharing data should be explicit and transparent. If data providers are coerced into sharing data (for example by another organization or by a higher level within their own organization), trust can be more difficult to establish and maintain. Data sharing works well when those directly involved in the process know each other; personal connections and joint activities such as workshops and joint publications help create an environment that facilitates sharing. Other stakeholders' perceptions, including public perceptions, can also play a part in the success of data sharing. It is therefore important to consider public engagement and the protection of the population from which the data originate, in particular when public health surveillance data are crowdsourced and in cases where anonymization is difficult.

How has the data sharing agreement been developed?

A combination of personal interaction and supporting documentation can help to create the right environment for data sharing. The level of trust between parties will affect the type of agreement they develop, and its terms. Agreements should be developed and implemented collaboratively. The terms of the agreement should meet the expectations of all parties, be realistic and be achievable. The process should be transparent, and should give each party a clear understanding of what is expected of them, and what they can expect of others. An agreed scope of accountability, and respecting and delivering on the terms of the agreement, are essential components of trust.

Will there be equitable benefit sharing?

In addition to direct public health benefits, data sharing can also help create a trusting environment and improved capacity at the local, national or regional level. In addition, it can create opportunities, for example for scientific publications and the ability to analyse pooled surveillance data to inform public health decisions. Such positive externalities require careful consideration and collaboration between the parties, and should be embedded in the agreement. Consideration should be given to the fact that the use of certain software packages for analysis or for making the data ‘open’ can lead to unfair access to data, since both rely on information technology expertise and facilities that may not be available to all parties.

Does the agreement reflect the rights and responsibilities of each party equitably?

There should be transparency in the use of data, and accountability that allows redress if data misuse has occurred. Any alternative data uses that have not been considered or
that do not form part of the initial sharing agreement should be discussed and agreed between the parties prior to any such use. The data and resulting information should be accessible to all parties equitably. Restricting providers’ access to their own data – such as by failing to share analytical results or to involve providers in a meaningful way – harms trust, reduces the value proposition of sharing, and compromises long-term access to data. Where one party does not adhere to the agreed terms, other parties should be empowered to terminate the agreement.

**Have parties agreed on frequency and means of communication?**

Planning appropriate communication by phone, email and, in particular, face-to-face meetings can help build a lasting and trusting relationship, as can joint approaches to evaluating the sharing process and the resulting data.

**Data recipients**

**Are there likely to be additional uses of the data that have not been discussed with the data provider?**

The data recipient should ensure that the data are used within the parameters of any agreement. Further use of data (for example publications, additional analysis or sharing beyond the duration of the agreement) should be discussed with the data provider and mutually agreed by all parties as an amendment to the existing agreement.

**Are there any specific requirements to ensure the provision of the required data to expected standards?**

Requirements can include, for example, skills and knowledge transfer, as well as the provision of financial, technical and/or human resources.

**Have the limitations of the data provided been made explicit?**

Public health surveillance data can have limitations in terms of accuracy, completeness or other factors. The data provider should be most familiar with the data and should have the opportunity to communicate any limitations, and to work with the data recipient to address them.

**Data providers**

**Can data be provided to agreed quality standards?**

Provision of high-quality data increases the likelihood that the data sharing activity will have the desired outcome – a positive public health impact – and is therefore an important part of building trust. Any barriers to providing high-quality data, including a lack of financial, technical and/or human resources, should be discussed with the data recipient at the outset.

**Have opportunities for further collaboration, beyond providing data been considered?**
There are opportunities for ongoing collaboration after the data are shared, including data providers being involved in data analysis, contributions to academic outputs, and ongoing collaboration as part of a sustained surveillance network.

Are there any concerns about sharing the data?

If there are concerns about the data, for example because they are of low quality or because they are particularly sensitive, these concerns should be communicated by the data provider prior to sharing. The data provider should have the opportunity to work with the data recipient to address any concerns.

State organizations

Are those involved in the data sharing activity at the appropriate level within their organization?

Initiating data sharing in a government organization requires buy-in from senior management, particularly when sharing potentially sensitive public health surveillance data. Although the data sharing process itself can occur at a lower, operational level, data sharing requires strong support at a political and strategic level to be successful.

Are those involved in the data sharing activity at the appropriate level within their organization?

State organizations are often tax-funded and accountable to their population. They can have a legal or moral duty of transparency towards that population. These organizations should therefore consider whether and how the public needs to be informed about any data shared with others.

Non-state organizations

Have the limitations of any non-traditional data sources been made explicit?

Public health surveillance data from non-traditional sources, such as digital disease detection, may be considered experimental, and its analysis and interpretation can differ from that of routine surveillance data collected by traditional public health surveillance systems. It is important for those involved to understand the limitations of the data, in particular when used to inform public health, trade or travel decisions.

Are all potential benefits being considered?

Commercial organizations tend to focus primarily on the commercial implications of sharing public health surveillance data. When sharing with other types of organizations, all benefits, including those of a non-commercial nature, should be considered and shared equitably.
Emergency contexts

Have the long-term benefits of creating the right environment been considered?

Developing relationships with counterparts in other countries or organizations can be very important during emergencies, when the ability to speak informally with counterparts greatly increases the likelihood of a successful outcome.
Articulating the Value

General points

Have the public health benefits that will result from the data sharing been made explicit?

When initiating any data sharing activity, it is important that the public health purpose for doing so is made clear, along with the need it aims to address. This reduces the risk that the sharing may be perceived as having little benefit to those from whom the data originate.

Have any public health actions intended to be taken as a result of the data sharing been made explicit?

All stakeholders should be aware of what the public health benefits are, and how they can be achieved. Options for actions resulting from the data sharing should be discussed with stakeholders when the data sharing agreement is created.

Are potential risks and benefits clear to all stakeholders?

Both potential risks and benefits to participating organizations and to the communities from which the data originate must be taken into account. In addition to improved public health, benefits include academic opportunities, publications and capacity-building. Risks include data misuse, and inadequate safeguards concerning data privacy, consent and security.

How will the costs of data sharing be covered?

Sharing public health surveillance data has cost implications in terms of human, technical and material resources. Ensuring that costs for data sharing can be met in an equitable and sustainable manner should increase the likelihood of effective data sharing, and can help build capacity.

Data recipients

Has the public health purpose for accessing data been made explicit?

The benefits of the sharing process should be clear to data providers – not only the benefits for wider public health, but also for the providers themselves. Approaches that are not truly collaborative can erode trust and increase reluctance to share.

Is there an action plan based on findings from the data?

The data recipient should plan in advance how they intend to use the data and be able to demonstrate the public health benefit.

Have the interests of the data provider been identified and considered?
This may involve using data analysis packages with which data providers are familiar, training data providers in data management and/or analysis, and including data providers in academic opportunities as appropriate. The extent of such measures should be agreed at the outset.

**Has the capacity of the organization providing data been taken into consideration?**

Providing data to acceptable standards requires resources, which can put pressure on data providers with limited capacity. In such situations, data recipients should consider how they can help meet the human, technical and material requirements of the providers.

**Data providers**

**Are there risks for the population from which the data originate that need to be considered?**

Shared data can contain identifiable information, collected without individual consent. Preserving confidentiality of individual-level data is critical as people with infectious diseases can be stigmatized and discriminated against. Population-level data can also be sensitive and might, for example, expose high disease frequency among certain vulnerable groups and could lead to inappropriate interpretation and misuse. These risks should be made explicit and discussed between all parties.

**Has sharing been considered as an opportunity to develop skills, expertise, academic opportunities and capacity?**

Data providers should benefit from inclusion in academic opportunities resulting from the data. Prior to sharing taking place, data providers should agree with the data recipients the extent to which they wish to be involved in the data analysis, including authorship on potential future manuscripts. Opportunities to learn new skills and increase individual or team capacity should also be explored.

**Can the data sharing process compromise other functions of the provider organization?**

Providing data has human, technical and material resource implications. Organizations providing data need to have the capacity required to provide the data requested. Where this is not the case, providers and recipients should discuss resource implications at the outset and agree how best to meet the requirements.

**Non-state organizations**

**Are the shared data linked to a public health intervention mechanism?**

Organizations that are not part of traditional public health surveillance systems may not have ready access to the systems and processes necessary to ensure that the data they
provide or receive lead to public health action. Prior to sharing, data providers and recipients should discuss how data are linked to public health intervention mechanisms.

**If the data recipient is a non-state actor, do they have the mandate and ability to act on the data?**

The mandate and capacity to act on public health information often rests with government organizations. When surveillance data are shared with other types of organizations, the mechanism by which sharing will benefit the health of populations should be made explicit.

**Emergency contexts**

**Are data collected in a manner that protects confidentiality?**

Providing timely data and information during public health emergencies should not risk compromising confidentiality. During infectious disease outbreaks, those infected and their contacts can be discriminated against and even verbally or physically threatened. In instances where sharing confidential individual-level data is required, security protocols that ensure confidential processing of data should be discussed and implemented.
Planning for Data Sharing

General points

Has the allocation of responsibilities been considered for each step of the data management cycle?

The data management cycle includes collection, processing, analysis, preservation, access, reuse, and disposal. There are implications for all steps of the cycle, and each should be considered by both those providing and those receiving the data, with attention given to what resources are required and who is responsible for providing them. In some instances, a step-by-step approach to the data management cycle can be an opportunity for skills and knowledge transfer between those involved.

Are the data managed in a way that facilitates sharing?

Data should be collected in a recognized format, using software available and familiar to all parties, providing a description of the data (metadata), signposting other parties to the data, and storing confidential information using mutually agreed standards (including security standards). The possibility of later data reuse should also be considered, with attention paid to matters such as the technical and legal issues associated with linking datasets, and how data will be discovered and accessed in the future.

Have the necessary steps been taken to protect the population from which the data originate?

The necessary steps include adequate anonymization and secure storage. When considering adequate anonymization procedures, the possibilities of data linkage using other readily available sources should be taken into account. Where consent is required, this should be managed in a way that balances public health benefits with individual privacy concerns. This may require a managed access procedure, with terms and conditions for access agreed between parties. Requirements of national and international law must be observed when sharing across national borders. For example, there may be specific restrictions for disaggregated data containing confidential or personal information. Aggregated and anonymized data are subject to fewer legal restrictions, providing data have been anonymized to acceptable standards.

Have the relevant technical standards been considered and applied?

While no universal standards have yet been developed for public health surveillance data, there are existing clinical and functional standards that are relevant. There are also existing standards for the steps of the data management cycle. These standards should be identified and used where appropriate to ensure effective data use for public health action.
Are the necessary resources available to manage data sharing to acceptable quality standards?

These include financial, technical and human resources. If the planning of data sharing identifies gaps in resources and capacity, measures to address them should be implemented as part of the collaboration between the parties and with any data sharing facilitators. This has the potential to both improve capacity and establish trust between parties. Mechanisms to promote longer-term, sustainable data sharing should also be considered alongside more immediate goals.

Which existing data management models have been considered when planning for data sharing?

There are existing data management models that can provide useful information on planning for data sharing, data management and how to develop agreements. It is useful to refer to such models when approaching new data sharing arrangements, to reduce duplication of effort and the risk of isolated approaches that inhibit wider collaboration and data reuse.

Data recipient

Is the data management plan proportionate to the expertise, skills and capacity of the data provider?

Any expectations on the data management plan must be proportionate to the provider's expertise, skills and capacity. Decisions such as what software to use can affect the success of the collaboration if the provider is unfamiliar with the chosen software. The sharing process itself can be used as an opportunity for capacity-building by transferring analytical skills, knowledge of specific software packages, and other IT skills.

Have necessary steps been taken to protect the population from which the data originate?

Suitable confidentiality and security measures for data should be agreed by all parties in a data management plan. Patient identifiable information should be shared on a need-to-know basis. If individual-level data are requested, the organization requesting the data must be able to justify why aggregated data are not adequate.

Has the capacity of the organization providing data been taken into consideration?

Providing data to acceptable standards requires resources, which can put pressure on data providers with limited capacity. In such situations, data recipients should consider how they can help meet the human, technical and material requirements of the providers.

Data provider
Are the data provided suitable for the intended purpose?

Agreeing with the data recipient on the format of the data to be shared, the frequency of sharing, and a future data analysis plan should improve the efficiency and effectiveness of sharing. This provides a foundation for timely and high-quality data sharing. The planning process can also be used as an opportunity to develop capacity in a sustainable way by transferring analytical skills, knowledge on specific software packages, and other IT skills. The benefits extend beyond the specific data sharing activity.

Have necessary steps been taken to protect the population from which the data originate?

Suitable confidentiality and security measures for data should be agreed by all parties in a data management plan. Patient identifiable information should be shared on a need-to-know basis, recognizing that national legislation can include exceptions for sharing personal data for public health action. Any organization requesting individual-level data must be able to justify why aggregated data are not adequate. When sharing individual-level data, the provider must put in place appropriate confidentiality measures.

Can the data sharing process compromise other functions of the provider organization?

Providing data has human, technical and material resource implications. Organizations providing data need to have the capacity required to provide the data requested. Where this is not the case, providers and recipients should discuss resource implications at the outset and agree how best to meet the requirements.

State organizations

Have all relevant regulations been taken into account?

Certain types of data from government sources may be subject to specific regulations, either government-wide or specific to the government agency providing the data. For example, patient identifiable information can sometimes only be moved within a single email server and not between different government email domains, in compliance with strict security standards.

Is the organization mandated to adhere to specific standards?

State organizations can be bound by specific processes and standards – both as recipient and provider. These standards should be adhered to so that the shared data can be used for the intended purpose.

Multilateral organizations

Have all relevant regulations been taken into account?

Certain types of data from multilateral organizations may be subject to specific regulations, such as UN-wide or agency-specific regulations.
Is the organization mandated to adhere to specific standards?

Multilateral organizations can be bound by specific processes and standards – both as recipient and provider. These standards should be adhered to so that the shared data can be used for the intended purpose.

Emergency contexts

**Have the needs for planning data management been balanced with immediate public health needs?**

During public health emergencies, the steps of the data management plan that lead directly to public health action might be prioritized over others.

**Are data collected in a manner that protects confidentiality?**

Providing timely data during public health emergencies should not risk compromising confidentiality. During infectious disease outbreaks, those infected and their contacts can be discriminated against and even verbally or physically threatened.

**Are data being shared in as timely a manner as possible?**

During emergencies, when time is of the essence, there should be a plan in place to allow for delivery of the data to an acceptable standard in the shortest amount of time. Lower quality data may be acceptable in emergency situations, although the minimum standards required should be mutually agreed.

**Are there emergency-specific data management models that need to be considered?**

Models have been developed, or are currently in preparation, at the global level (e.g. by WHO and the Wellcome Trust) following the 2014-16 West Africa Ebola outbreak. These should be taken into account where possible during any sharing activity in an emergency situation.
Achieving Quality Data

General points

Are the data of adequate quality for the intended purpose?

Data do not have to be ‘perfect’, but should be of good enough quality for the intended purpose. Sharing may improve data quality through a feedback mechanism. However, setting unnecessarily high standards could inhibit data sharing in certain contexts. It is important to consider whether sharing some data could be better than holding back the data entirely.

Have the relevant technical standards been considered and applied?

There are existing standards for the steps of the data management cycle, and these should be identified and used where appropriate. This can reduce duplication of effort, help to ensure that minimum data quality requirements are met, and allow for data comparison across organizations and countries. Where specific standards are applied, they should be explicitly detailed. Organizations specializing in data sharing have described essential elements of data quality such as relevance, accuracy, timeliness, accessibility, interpretability and coherence.

What key attributes of the data are most relevant to the intended use?

When public health surveillance data are shared, it is important to identify which characteristics such as relevance, accuracy, timeliness, accessibility, interpretability and coherence are most relevant to the intended public health purpose, and to prioritize improvements in these areas where possible. Third-party organizations specializing in data sharing can help address shortfalls in data quality.

What aspects of the sharing process can be automated?

Automation can reduce the risk of error, improve efficiency and decrease human resource requirements. Stakeholders involved in data sharing should identify relevant parts of the process where automation is appropriate, feasible and cost-effective.

What resources are necessary to achieve the required data quality?

Sharing data of sufficient quality requires a skilled workforce and technical capacity. Stakeholders should ensure that resource requirements are met in order to ensure data quality is sufficient to achieve the intended public health purpose.

Data recipients

Will the data allow public health decision-making?
Recipients can work with providers to improve data quality where necessary. This can benefit the recipient by achieving higher quality data, and also the provider by increasing capacity (for example, through provision of training or equipment). Enhanced capacity for longer-term sustainable data sharing will also benefit public health more widely.

**Have data specifications been made explicit?**

When data are requested, requirements such as data quality, storage, access, re-use, disposal, and frequency, should be specified at the outset. Technical standards for data management can be found on the data management resources page of this guide.

**Have case definitions been agreed?**

The objective of the data sharing will determine how cases are defined, prioritizing either sensitivity when all cases need to be identified or specificity when the priority is to ensure the proportion of false positives is minimized. In all circumstances, parties should agree on what constitutes a case. Standards for case definitions can be found on the Data Management Resources page of this guide.

**Has the capacity of the organization providing data been taken into consideration?**

Providing data to acceptable standards requires resources, which can put pressure on data providers with limited capacity. In such situations, data recipients should consider how they can help meet the human, technical and material requirements of the providers.

**Data providers**

**Are the data of good enough quality to be shared?**

Data do not have to be 'perfect', but there needs to be sufficient confidence in them when used as the basis for major decisions on public health or issues such as trade or travel. Sharing data of insufficient quality comes with a number of risks, including reputational risks for the data provider, and the caveats around such data should be made explicit and sharing deferred if necessary. Practical steps to improve quality can also be taken, such as provision of training or equipment.

**Can agreed standards be met?**

What standards to apply should be agreed by all parties at the outset. Where the data provider does not have the technical, human or material capacity to comply with agreed standards, parties should discuss how to help the data provider meet the agreed standards.

**Can the data sharing process compromise other functions of the provider organization?**
Providing data has financial, technical and/or human resource implications. Organizations providing data need to have the capacity required to provide the data requested. Where this is not the case, providers and recipients should discuss resource implications at the outset and agree how best to meet the requirements.

**Have case definitions been agreed?**

The objective of the data sharing will determine how cases are defined, prioritizing either sensitivity when all cases need to be identified or specificity when the priority is to ensure the proportion of false positives is minimized. In all circumstances, parties should agree on what constitutes a case. Standards for case definitions can be found on the Data Management Resources page of this guide.

**State organizations**

**Is the organization mandated to adhere to specific standards?**

State organizations can be bound by specific processes and standards – both as recipient and provider. These standards should be adhered to so that the shared data can be used for the intended purpose.

**Multilateral organizations**

**Is the organization mandated to adhere to specific standards?**

Multilateral organizations can be bound by specific processes and standards – both as recipient and provider. These standards should be adhered to so that the shared data can be used for the intended purpose.

**Emergency contexts**

**Has the need to comply with standards been balanced with the need for timeliness?**

During public health emergencies, sharing data in a timely manner is key. Planning and standards should be used to help deliver data to an acceptable standard in a timely manner.

**Have all steps been taken to facilitate timely data sharing?**

During public health emergencies, sharing data in a timely manner is key. However, this does not mean that all data should be shared regardless of quality, in particular if there is a risk of poor decisions being made based on erroneous data. Data recipients should work with data providers to ensure sufficient data quality in a timely manner.

**Can data sharing be prioritized?**

In the early stages of a public health emergency, the priorities of the data provider can shift to the acute response and, in the case of a humanitarian crisis, all staff may be mobilized for an acute response. This could limit the provider's ability to produce high-
quality timely data, and the data recipient should be sensitive to the provider’s immediate needs.
Understanding the Legal Context

General points

Have the relevant legal frameworks been fully utilized to facilitate data sharing?

The legal issues relevant to data sharing are not necessarily barriers to sharing. Barriers to data sharing are more often political or motivational, but those who oppose sharing the data sometimes cite legal barriers when the obstacles are more political or motivational. Knowledge of the relevant legal frameworks, including national and international law, as well as institutional data sharing policies, can help facilitate sharing when other barriers exist.

How relevant is international law for public health data sharing?

As countries have primary legal authority over activities within their borders, they are responsible for implementing the International Health Regulations (2005), the principal international health law. However, there is no enforcement mechanism to ensure compliance. Another relevant area is international human rights law, which contains a well-established approach for balancing respect for individual rights with other important interests. For example, the International Covenant on Civil and Political Rights requires states to respect the right to privacy, but recognizes that states can waive the right to privacy for public health reasons. Sharing public health surveillance data across borders has legal implications when the type of data shared is protected by national or international law. One example is disaggregated data containing confidential or personal information. Aggregated and anonymized data are subject to fewer legal restrictions, providing data are anonymized to acceptable standards.

Is the agreement compliant with relevant laws and regulations?

Data sharing agreements should comply with institutional data sharing policies, the national laws of all countries involved, regional and global legislation, and any other legally binding agreements. Both data providers and data recipients must comply with the prerequisites, conditions and limitations established by data sharing law. However, while data recipients may not be directly affected by law that relates to the data provider, any legal prerequisites, conditions and limitations relating to the data provider should be included in the agreement to achieve compliance.

Has the ownership of resulting outputs been agreed?

Shared data may be used for a variety of analyses and purposes. It is important that the intellectual property status of datasets, for example, as well as authorship for any expected academic outputs, is agreed at the outset.

Have local customs and sensibilities been taken into account?
Adherence to and respect for relevant laws and customs, particularly relating to the country from which the data arise, will help to promote trust and confidence among local stakeholders.

**Are there pre-existing agreements in place that need to be taken into consideration?**

Pre-existing agreements between organizations, whether focused on data sharing or wider agreements with data sharing components, may restrict sharing the same data with a third party. When data are shared between multiple organizations and multiple agreements are in place, these should be compliant with each other.

**Have different types of agreements been considered?**

The legal implications of data sharing, and therefore what type of agreement is most suitable, can depend on various factors, including geographical location, type of institution involved, type of data, and level of public health threat. This means that legally binding agreements may not always be necessary.

**Have the risks associated with different types of agreements been considered?**

Informal agreements do not mean that the need to respect the rights and interests of all stakeholders is in any way diminished. Unless there are compelling reasons to keep an agreement verbal, written agreements should always be used. The risks associated with different types of agreements should be identified and taken into account when deciding which type to use.

**State organizations**

**Have organizational guidelines been considered?**

State organizations can sometimes have particular requirements for certain types of data sharing agreements. For example, data release might be regulated by a dedicated department. Such requirements might restrict the types of agreements that can be considered for use.

**What type of data is being shared by each organization?**

National legislation generally focuses on the sharing of disaggregated data containing confidential or individual-level information. Although aggregated and anonymized data are usually subject to fewer legal restrictions, state organizations might be bound by agency specific or cross-governmental data sharing policies.

**Non-state organizations**

**What type of data is being shared by each organization?**
National legislation applies to non-state organizations in the countries in which they operate and generally focuses on the sharing of disaggregated data containing confidential or individual-level information. There are usually fewer legal restrictions on non-state organizations when sharing aggregated and anonymized data, providing data are anonymized to acceptable standards.

**Has the legal status of the data been clarified?**

The legal status of data from non-health sources, such as social media and other online sources, may vary – from public data, with no restrictions for sharing, to data owned by private organizations, with the attendant restrictions. The necessary enquiries should be made prior to any data sharing activity to ensure that intended actions are in line with the status of the data.

**Multilateral organizations**

**Has good practice for multilateral organizations been identified?**

National and international legal frameworks are often not enforceable with regard to multilateral organizations, particularly UN agencies. Although these organizations might not be legally required to share or withhold data, they should identify and adhere to good practice.
Creating Data Sharing Agreements

General points

**Have all parties to the agreement contributed to it?**

It is important to consider the needs and expectations of all parties when drafting an agreement. Addressing any issues at the outset will help create a better first draft document and expedite any discussion regarding the terms. Failure to do so may lead to inequitable sharing of burdens and benefits, and to the interests of some parties being over- or under-represented. A collaborative approach to data sharing agreements helps ensure that all interests are considered, that benefits are shared equitably, and that a trusting environment is created.

**Is the agreement appropriate to the specific context in which data sharing is taking place?**

Data sharing agreements can take different forms depending on the nature of the data being shared, the type of stakeholders involved, any pre-existing relationship between stakeholders, and whether or not the agreement needs to be legally binding. Parties should discuss and understand what type of agreement is most appropriate.

**Have the right people been involved in creating the agreement?**

The context and the objective of the data sharing, as well as the nature of the parties involved, may require different levels of authorization. This could range from an informal agreement at the local, technical level to a formal ministerial authorization. It is important to ensure that signatories to the agreement have the necessary authority. In addition, stakeholders should check that all ethics approval(s) required for the intended use of data have been obtained.

**Are the interests of all parties represented?**

The data sharing agreement is an opportunity for all parties to identify and articulate the value of sharing data, and to agree on how it can be achieved. This creates trust, and sets a positive precedent to help public health surveillance data sharing become the norm. It also helps to ensure that benefits are shared equitably and according to expectations.

**Have all intended uses of the data been specified?**

Intended uses include the public health action resulting from the data, as well as related activities and outputs such as the production of reports and academic publications. Any intellectual property implications should be identified, and provision should be made for the possibility of further discussion in the event that any unanticipated intellectual property issues arise from data reuse. Parties to the agreement should decide what degree of departure from agreed uses requires approval from the data provider.
Is the language used in the agreement understandable to all parties?

This includes the language in which the agreement is written, as well as any specific technical or legal terms used. Access to technical and legal resources may vary. Therefore, the language used should reflect the level of technical and legal expertise available to all parties.

Have existing international agreements relevant to data sharing been consulted?

Existing international agreements should be taken into account where relevant. The Pandemic Influenza Preparedness (PIP) Framework and the Nagoya Protocol on Access and Benefit-sharing are examples of agreements that consider a range of data sharing issues, and these may be useful both in articulating the data sharing agreement and more widely in the data management cycle.

Are those approving the data sharing authorized to do so?

The request to share data might not always be directed to those who can authorize it. Someone with the necessary authority should be identified and approached prior to sharing taking place. They must also be included in the process of creating a data sharing agreement.

Data recipients

Will the agreement allow the desired public health outcomes to be achieved?

The agreement should make clear that an improvement to public health is the primary objective, justifying the request for data. Any public health benefits resulting from the data should be made available to those who provided the data. There may also be additional benefits, such as the creation of academic collaborations and outputs. Data recipients should take the necessary steps to ensure providers are able to realize such additional benefits.

Are the ways in which the data can and cannot be used clearly understood and agreed upon by the recipient?

It is important that those involved in sharing data are able to discuss and understand the planned uses of the data, and the resulting benefits. The most commonly used framework to facilitate such discussion is a data sharing agreement.

Data providers

Does the agreement involve the provider to the desired level?

Sharing data provides an opportunity to create academic collaborations and outputs, and to strengthen skills and capacity. When data are shared, any request by the provider
to be involved in subsequent analysis, publications or other outputs should be discussed at the outset and included in the agreement.

**Are the ways in which the data can and cannot be used clearly understood and agreed upon by the provider?**

It is important that all parties involved in sharing data are able to discuss and understand the planned uses of the data, and the resulting benefits. The most commonly used framework for such discussion is a data sharing agreement.

**State organizations**

**Are there procedures or protocols in place to govern data sharing agreements?**

State organizations might have to follow specific procedures or protocols when releasing data. There might also be a need for approval from certain departments (e.g. legal departments) and sign-off at a certain level of seniority. These procedures and protocols should be considered carefully when entering into any data sharing activity.

**Non-state organizations**

**Are there any restrictions on sharing the data requested?**

The use of certain types of data (such as commercial data belonging to private companies, data from social media or data from other sources not collected primarily for surveillance purposes) might be subject to particular rules. Such restrictions should be considered carefully prior to entering into any data sharing activity.

**Multilateral organizations**

**Are there procedures or protocols in place to govern data sharing agreements?**

Multilateral organizations might have to follow specific procedures or protocols when releasing data. There might also be a need for approval from certain departments (e.g. legal departments) and sign-off at a certain level of seniority. These procedures and protocols should be considered carefully when entering into any data sharing activity.

**Routine contexts**

**Will the agreement facilitate future responses to public health emergencies?**

The nature of a data sharing arrangement can help facilitate ongoing communication and joint problem-solving. It can also provide an evidence base for future data sharing agreements, either as a continuation of an existing data sharing relationship or in a new context, such as an emergency.

**Emergency contexts**
Is the agreement appropriate in an emergency?

During public health emergencies, sharing data in a timely manner is key, and there may be less time to consider the expectations of all parties. However, not paying due attention to the needs of the data provider can set a negative precedent for future data sharing relationships, such as failing to share any benefits with the local public health authorities who provided the data.

Is a formal agreement required?

Informal arrangements can facilitate more timely data sharing during emergencies than formal agreements. Ideally, the level of trust between parties should allow sharing to take place without the need for a time-consuming agreement process, which might not be compatible with public health needs. However, informal arrangements should not be allowed to compromise the equitable sharing of benefits by all stakeholders.
Monitoring and Evaluation

General points

Have instances of data sharing been documented?

Documenting what is shared with whom, and how the data are used, can help in the dissemination of success stories, and in learning lessons to help improve future data sharing. This documenting process applies to all steps of the data management cycle. See the data management resources page of this guide.

Have expected outcomes been defined?

An important early step in monitoring and evaluating data sharing is defining what constitutes success or failure in a specific context. This should be decided collaboratively to ensure buy-in and mutual understanding of the aims of the data sharing relationship.

Has data sharing produced the desired outcome?

Data sharing agreements should describe the intended uses of the data, and any resulting public health actions should be discussed as part of creating the agreement. Once data have been shared, it is important to evaluate whether the uses and outcomes match expectations. When data are openly accessible, recording data reuse and its public health impact can help improve the perceived value of sharing.

How are outcomes recorded?

Monitoring and evaluation frameworks can help all stakeholders to understand and assess data sharing operations. At the beginning of the data sharing relationship, parties should decide collaboratively what will constitute a positive outcome of the data sharing process and its impact. If this outcome is not achieved, root causes should be analysed. Common reasons for failure are the data not addressing a specific need, not being visible, not being shared in a timely manner, or not being provided in a usable format.

How have monitoring and evaluation been integrated into the data sharing process?

The most successful monitoring and evaluation systems are those that are fully integrated into the programme of work at the outset, and that factor in the human and material cost. Ensuring that monitoring systems are fully integrated into the data sharing process can increase the accuracy of evaluations, and can help identify and correct errors in the system at an early stage. Failure to plan for monitoring and evaluation can leave individual parties to bear the cost, and can compromise the data sharing activities. Therefore, both parties should discuss who will be responsible for the relevant tasks, and how costs should be covered.
How will data and benefit sharing outcomes and lessons learned been communicated?

Capturing the data and benefit sharing process, and defining and documenting the outcomes and lessons learned, may not be sufficient. In some instances, the outcomes and lessons learned need to be communicated actively to stakeholders, including the general public. This should help to increase transparency and maintain trust between stakeholders. Furthermore, it can be particularly important since surveillance systems are often publicly funded. Disseminating successful outcomes and lessons learned should help to increase the evidence base and encourage further sharing.

State organizations

Are there particular auditing procedures that need to be followed?

State organizations might have to follow specific auditing procedures that apply to data sharing. Those involved in the data sharing agreement should ensure that such procedures are identified and followed.

Do the funders involved require reporting on specific outcomes of the data sharing agreement?

Where projects are externally funded, sharing of any resulting data can be a condition of the grant. Those involved in the data sharing agreement should ensure that grant requirements are identified and followed.

Multilateral organizations

Are there particular auditing procedures that need to be followed?

Multilateral organizations might have to follow specific auditing procedures that apply to data sharing. Those involved in the data sharing agreement should ensure that such procedures are identified and followed.

Emergency contexts

Has the outcome of data sharing been evaluated?

In emergencies the focus is often on timeliness, and monitoring and evaluation might not be prioritized. Activities should be monitored and appropriate records kept so that when the emergency is over a proper evaluation can be completed.