

# Information ecosystem management

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# Information ecosystem management

## What?

Information ecosystem management aims at better and systematically capturing **stakeholders' needs, expectations, concerns and experience** to inform organisational decision-making and the Agency's strategy.

## Why?

### Available data sources

*Internally*

#### **Established channels for stakeholders' feedback**

(Stakeholder and media engagement, media and public queries, surveys, PCWP/HCPWP, public consultations, European Parliament queries)

*Externally*

#### **Social media Stakeholder communities Scientific literature**

## What's needed?

Systematic and validated process for analysis

**Our aim:**  
to promptly identify  
patterns, trends,  
data and insights

# Information Ecosystem management

## Pilot: RSV vaccines

### Misinformation management

- Acute health event, i.e. that has high public/media attention and where misinformation is likely to spread with impact on public health outcomes / EMA's reputation

## Pilot: Long Covid

### Stakeholder listening

- Anticipate issues & health crises
- Lack of trust in key areas (e.g. vaccines)
- Trends for patient experience, preferences (e.g. Public Hearings, outcomes, ADRs)
- Potential reputational damage (e.g. CoI)

Listening process

### Actions

- Identify stakeholders' conversation trends, information needs, gaps and potential misinformation
- Prepare communication, engagement and trust actions, LTT, proactive communications, social media
- Identify key scientific evidence discussed by stakeholders and escalate to experts as needed
- Inform RWE/vaccines monitoring platform/ research agenda
- Enhance monitoring of key topics

ADR: adverse drug reactions; CoI: conflict of interest; ETF: Emergency Task Force; LTT: Lines-To-Take; PhV: pharmacovigilance, Pharmacovigilance; RSV: respiratory syncytial virus; RWE: real-word evidence.

# Stakeholder listening: Long COVID pilot



# Pilot on Long COVID: rationale and objectives

- Urgent public health priority - >39 million people ([2024 OECD](#)); 400 mill cumulative global incidence ([Nat Med](#))
  - Impact on vaccine confidence as sometimes mixed with vaccine adverse reactions
  - Long COVID patient advocacy started in social media
- 
- **New disease; unmet medical need – 0 treatments**
  - No endpoints or biomarkers to date – all is **Patient Experience Data**

## Objectives:

1

Identify key scientific evidence, concerns and information gaps on Long COVID

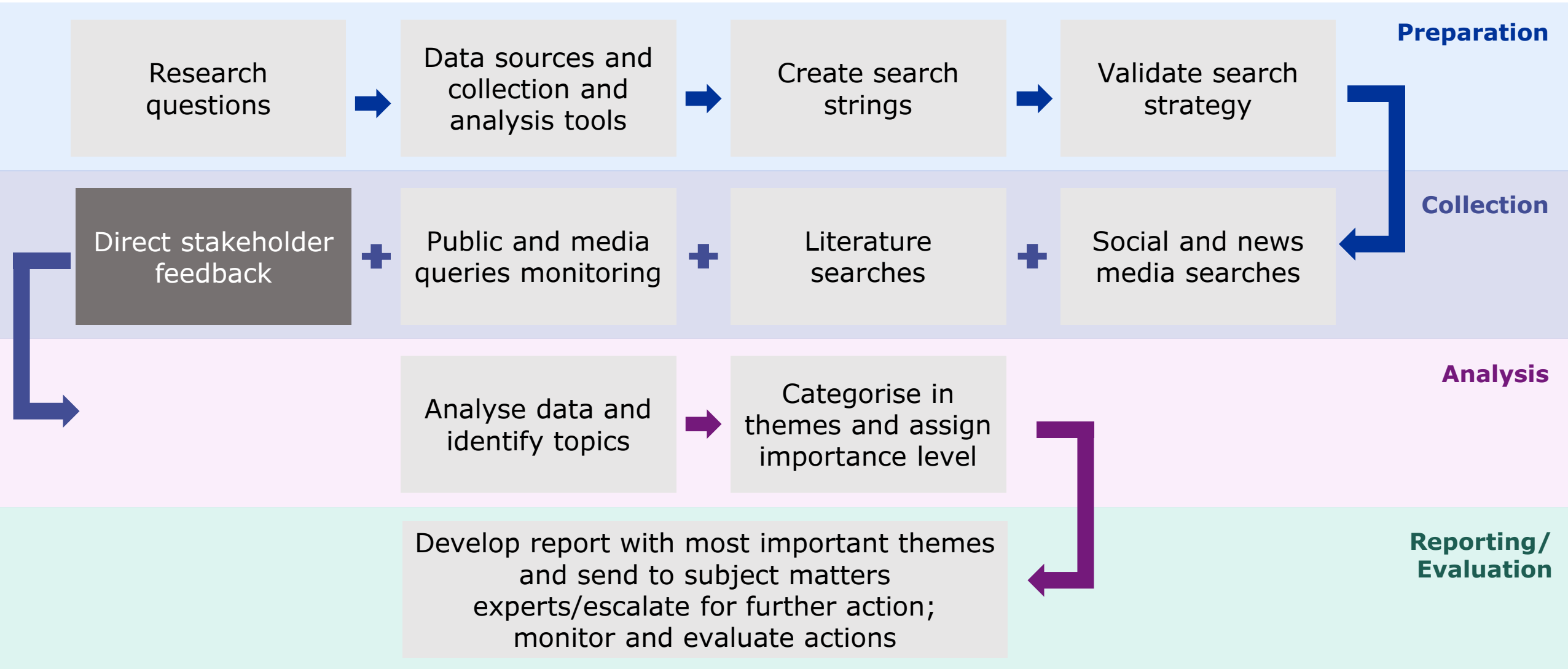
2

Explore the use of stakeholder listening as source of Patient Experience Data on Long COVID

3

Evaluate the use of stakeholder listening to support key EMA activities

# A step-by-step guide to stakeholder listening

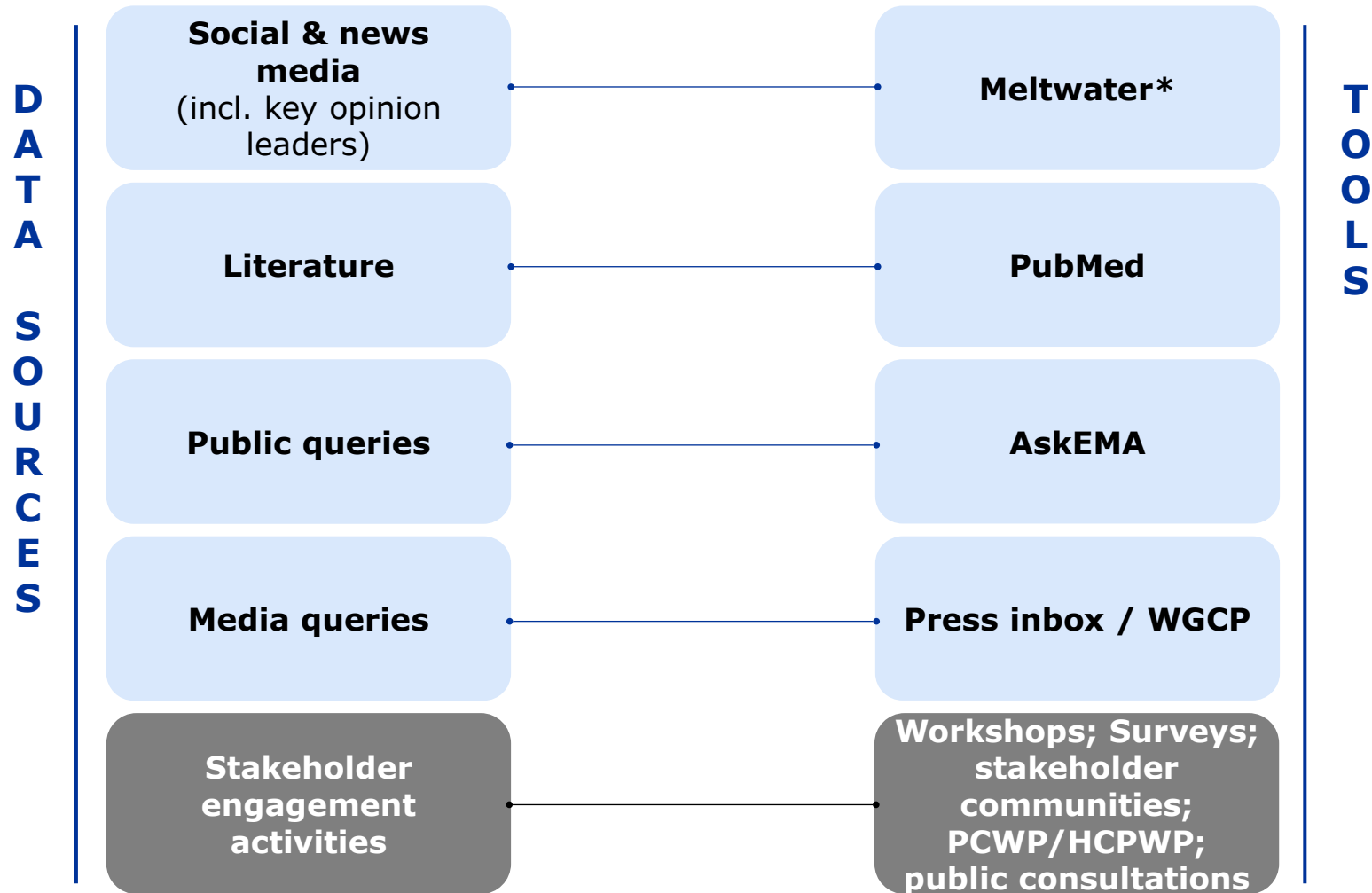


# Research questions

From stakeholders' point of view:





- What are the **long-term symptoms and sequelae** of Long COVID?
- Which are **potential treatments, preferred outcomes** and **prevention measures** for Long COVID?
- Does **vaccination protect** against Long COVID?
- Does vaccination induce a **post-vaccination syndrome** similar to Long COVID?

# Data collection strategy



\*Tool for online and social media intelligence gathering.  
WGCP, Working Group of Communication Professionals.

# Prioritising themes for reporting

	Potential impact on public health		
		<i>High</i>	<i>Limited</i>
Priority for EMA's activities	<i>Theme is a priority for EMA activities</i>		
	<i>Theme is not a priority for EMA activities or is outside of EMA remit</i>		

# Reporting and follow-up actions

## Example of report

**Stakeholder listening report**  
Reporting period: 1-19 January 2025

**Summary**

- Lorem ipsum dolor sit amet, summo volumus invenire cu eum.
  - Minimum assertion quo no. Has omnes scripta salutandi ea, eum munere deseruisse scriptorem ad, ea volumus lucilius referentur vel.
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**Mentions Trend by Search**

**Potential treatments, study design, patient preferences and prevention measures for long Covid**

The treatment landscape for Long COVID is still at an experimental stage, and in most cases, proposed treatment plans are largely based on patient experience

- A collection of self-reports from Long COVID patients published in Communications Medicine was popular on social and news media ([article 1](#), [article 2](#), [article 3](#), [article 4](#)). In this study, **prolonged Paxlovid use** showed some improvements for a subset of patients; however, it remains unclear which patient populations may benefit from its use ([publication](#)).
- This study uses direct reports from patients in a written format or interview and constitutes an example of both a patient-led research initiative and patient experience data in research.
  - A potential role of **COVID antivirals** in Long COVID treatment is proposed in a Commentary by Prof. Al-Aly in *Lancet Infectious Diseases* ([publication](#)).
- An NIH webinar highlighted relevant ongoing research in the area, including studies on treatment with **IV immunoglobulins**, **viral reservoirs**, and a planned clinical trial for **checkpoint inhibitors** ([link thread](#)).
- The use of **IV immunoglobulins** also showed some promising results in small cohorts, based on a review article ([publication](#)).

• Data were collected by searching public and media queries (Doris, Scopus, Medline, PubMed), social media posts (Doris, Weebly) and scientific literature (Doris, PubMed) using the search terms identified for each research question. Subsequently, the search results were analysed to identify preliminary themes. Only those themes that were considered as of high importance for public health and high relevance to EMA activities are included in this report.  
 • For a detailed overview of the methodology used, including data collection and analysis methods, please refer to the full protocol of the pilot. (Hyperlink to be added).  
 • The full data set is available in an Excel spreadsheet. (Hyperlink to be added).



**Relevant EMA teams**

If a (potentially) critical issue is identified, it will be escalated **immediately**

Discussion with cross-Agency teams on key issues

Agree on actions

Engagement & communication actions

Inform RWE research agenda

Raise awareness on scientific evidence discussed by stakeholders

Enhance monitoring of key topics



# Misinformation pilot : objectives and topic

## Develop an EMA integrated process for infodemic insights

- Be more proactive in addressing misinformation and communication voids, in case of an acute health event, building on learnings from other public health institutions

## Adapted to EMA context, with proposed actions

- Needs-based, risk-proportionate, and making best use of all data accessible to EMA
- Identify misinformation, concerns, communication voids directly relevant to EMA, i.e. on which we can act
- Complements other comms actions in the misinformation space (collaborations, building trust)

RSV: respiratory syncytial virus

We are testing our processes with **case study on RSV**, gathering retrospective insights on the 2024-25 cold season.

## Why RSV?

These are newly launched products, with high media and public interest, and focused on key populations (babies, pregnant women, elderly people).

# Adapt existing guidelines to EMA's specific mandate

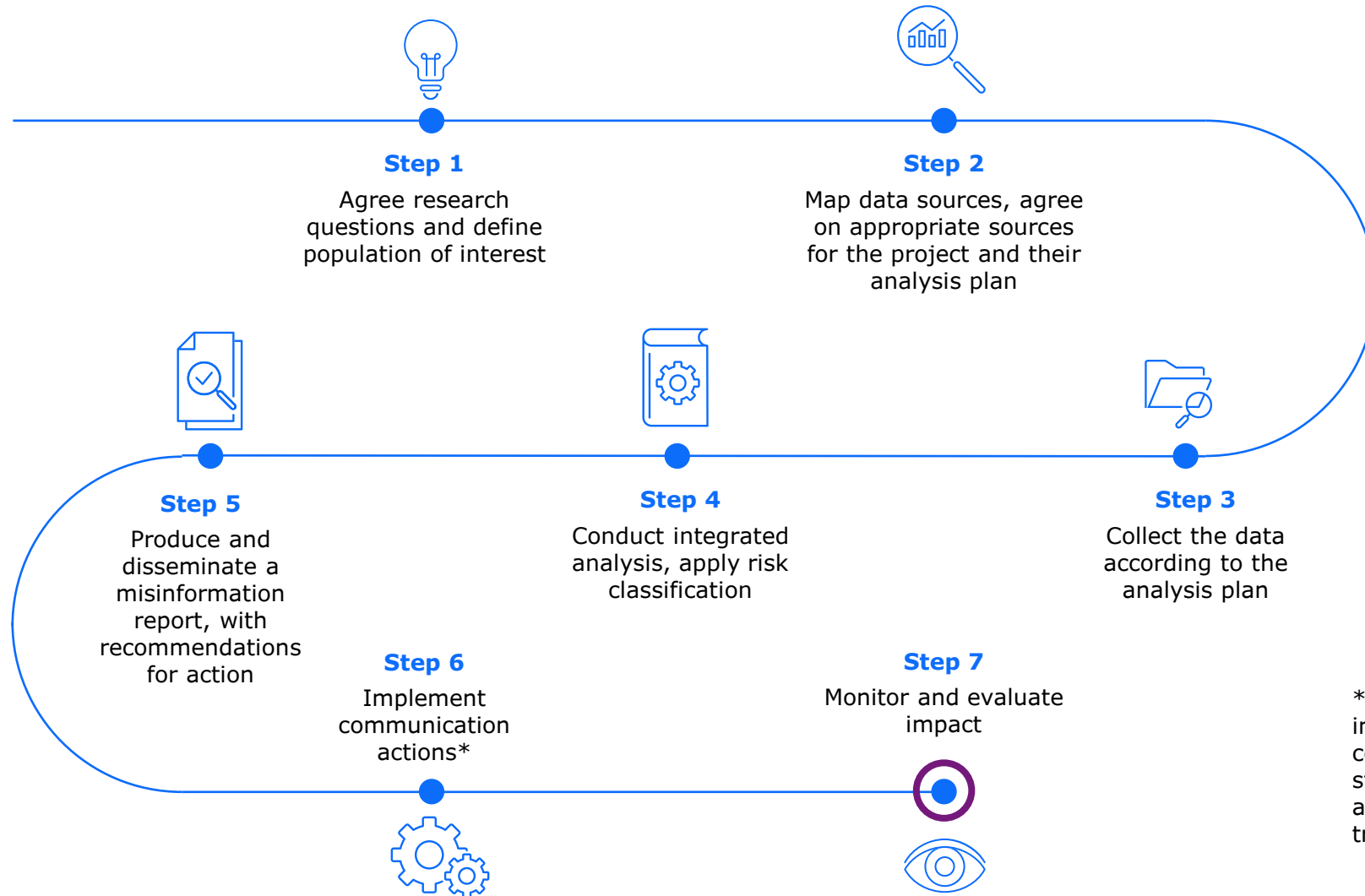
Working with a **collaborating expert**, specialist in infodemic management

**Resources** include:

- [WHO/UNICEF How to build an infodemic insights report in 6 steps](#)
- [Infodemiology.com](#)
- [Vaccine Misinfo Guide \(vaccinemisinformation.guide\)](#)



# Misinformation management - step-by-step



\*communication actions incl. filling information voids with proactive comms, media - social media and stakeholder engagement, amplifying accurate information, leveraging trusted messengers...

# Research question

**Which narratives are emerging over the safety and efficacy of new RSV medicines/vaccines that could negatively impact EMA's public health efforts and messaging?**



## Sub-questions:

What questions or concerns do EU citizens have about RSV infection and prevention measures?

How and why are narratives changing and evolving over time, and how is it appearing in different communities and what responses does it generate?

Which specific concerns are raised regarding protection of babies, maternal immunisation and vaccination of older people against RSV?

Which concerns are being discussed regarding the safety of new RSV medicines/vaccines?

Which concerns are being discussed with regards to how RSV medicines/vaccines have been approved?

# We welcome your perspectives



## Processes



Views on the proposed process and methodology for information ecosystem management



Finding best ways to involve you and your network in the process and collecting insights



Are there avenues for common actions?

## Long COVID pilot



Receiving feedback/concerns from your organisations on the Long COVID research questions

## Misinformation



Beyond the RSV project, do you have views/suggestions on engaging with us on misinformation issues?



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SCIENCE MEDICINES HEALTH

# Thank you

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