EMA
EUROPEAN MEDICINES AGENCY

Information ecosystem management & building trust on vaccines

Industry Standing Group

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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

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

What's needed?

Systematic and validated process for analysis

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

Listening process

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)

Actions

- Identify stakeholders' information needs, gaps and potential misinformation
- Prepare communication, engagement and trust actions
- 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; ETF, Emergency Task Force; PhV, Pharmacovigilance; RSV, respiratory syncytial virus; RWE, real-word evidence.

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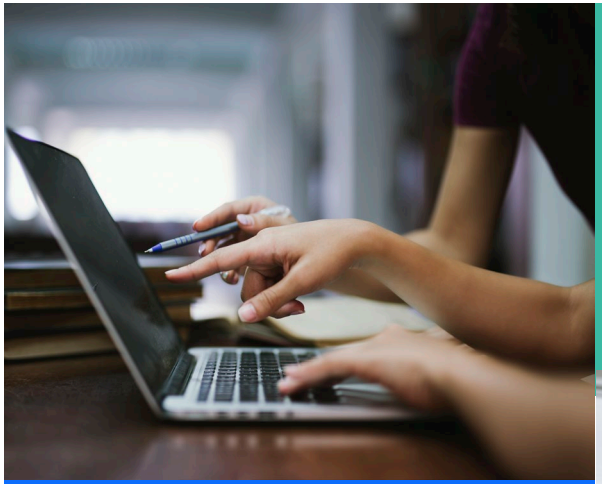
Update on EMA's misinformation framework



Collaboration

Build bridges with regulatory partners (EU, international level) and communities to share best practices, information and possibly campaigns.

Insights to drive misinformation management

Develop an integrated process for infodemic insights, in case of an acute public health event

Build trust in public health efforts

Support trust in EMA and science through targeted actions, informed by EMA and external expertise

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

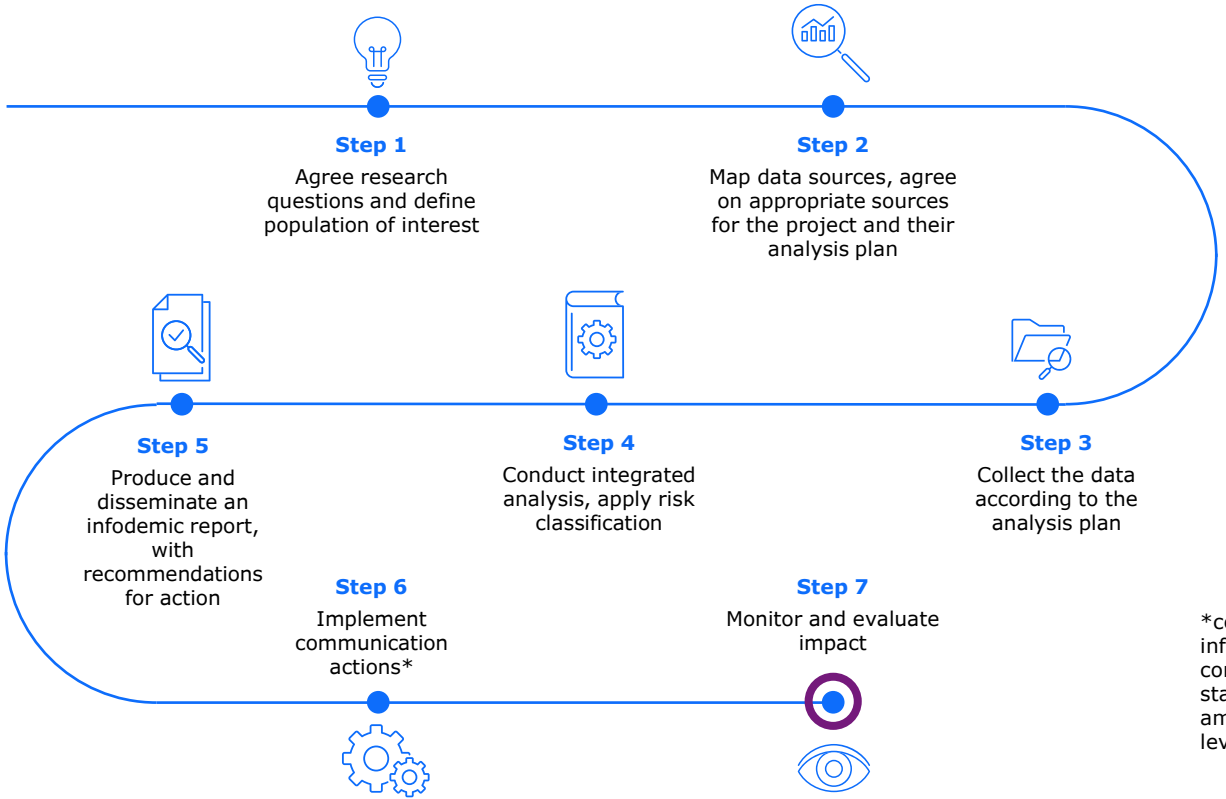
- Needs-based, risk-proportionate, and making best use of all data accessible to EMA
- Identify misinformation, concerns, communication voids directly relevant to EMA, i.e. on which we can act
- Complements other comms actions in the misinformation space (collaborations, building trust)

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).

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…

Build bridges with regulatory partners and communities

- Work with EU sister agencies, and with national competent authorities
- International collaboration, notably through ICMRA
- Engage with communities through our existing channels (patient/consumers, healthcare professionals, academics)
- Horizon scanning of other possible European and international initiatives/partners

Collaboration

Support trust in public health efforts

- Provide **accurate and science-based information** in areas of misinformation/misconceptions (e.g. dedicated webpage for European immunization week with data visualisation on measles and HPV).
- Experiment new approaches to reach new audiences, including young people (18-34 years olds): we are establishing a pool of European **influencers.**
- Diversify our reach on social media: encouraging EMA colleagues to be effective **ambassadors** of EMA's public health actions.

We stand up for science and support trust throughout our comms activities

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Stakeholder listening: Long COVID pilot

Pilot on Long COVID: rationale and objectives

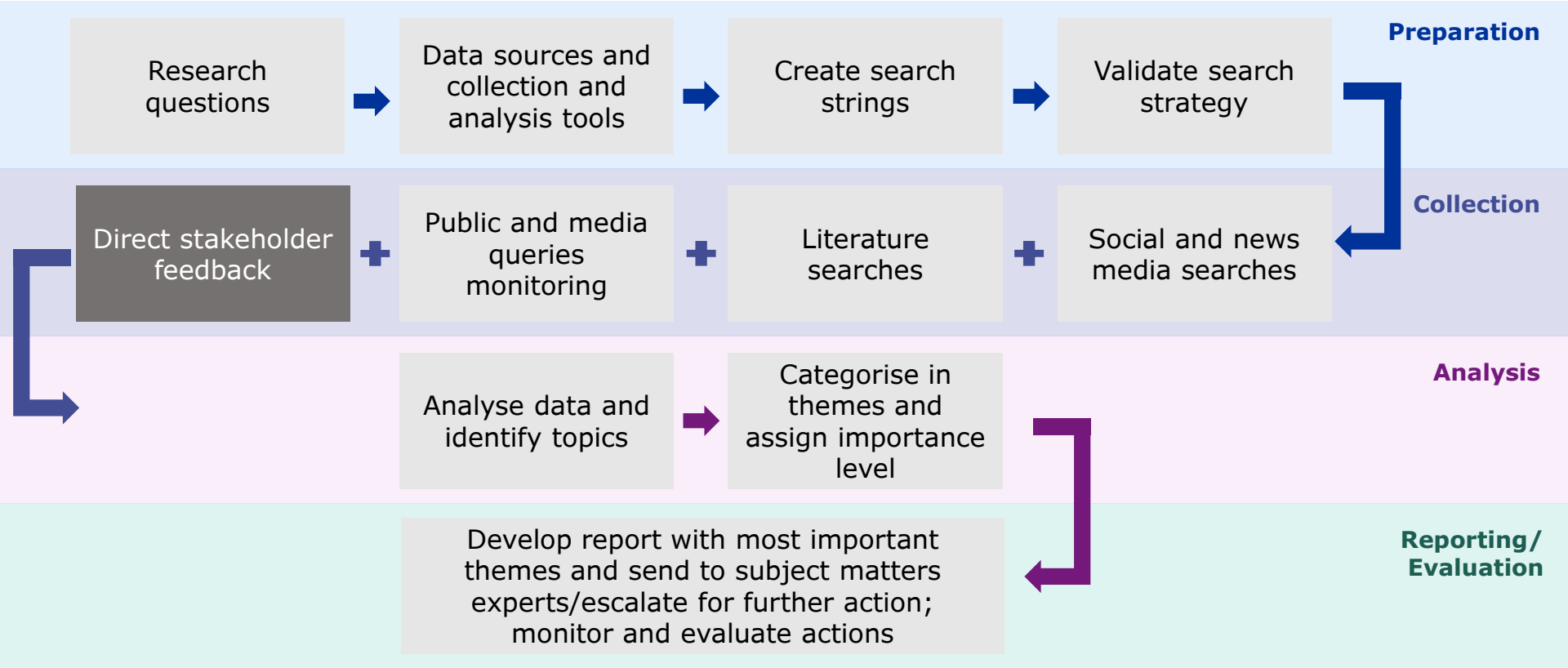
- Urgent public health priority ->39 million people (2024 OECD); 400 mill cumulative global incidence (Nat Med)
- Impact on vaccine confidence as sometimes mixed with vaccine adverse reactions
- Long COVID patient advocacy started in social media

- **New disease; unmet medical need – 0 treatments – lack of public awareness**
- 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



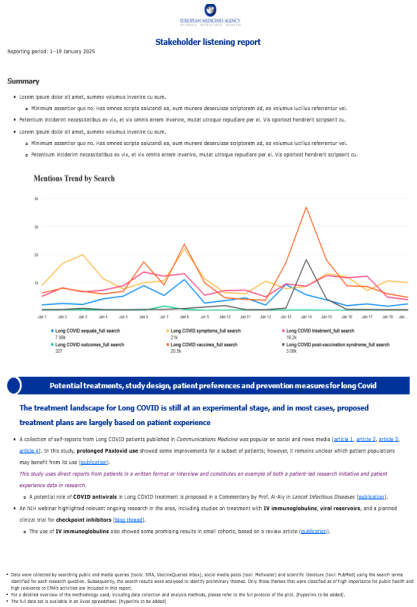
Research questions

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?

Internal reporting and follow-up actions

Example of report



Stakeholder listening report

Reporting period: 1–19 January 2025

Summary

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

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

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Thank you

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