

Deliverable D7.3

Report on public engagement activities

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1. Executive summary

This deliverable is an overview of public outreach activities in the context of the BY-COVID project. The goal is to inform the public about the project's goals and activities by creating materials that cover its main objectives and basic values and principles.

The strategy deployed to reach a diverse public is twofold:

1. The creation of ten concise, easy to understand, original and creative 'cases', each describing a practice, a value or a principle underlying the BY-COVID project.
2. An educational toolkit, ready for use by teachers from all over Europe.

These materials were co-developed with relevant work packages to ensure veracity and disseminated through the BY-COVID network and already existing networks where teachers can find educational material for their students.

2. Contribution towards project objectives

This deliverable describes the work towards disseminating project information via collaboration with relevant WPs and translating/communicating it with the project's target stakeholders in order to achieve public outreach and maximise impact. The goal was to inform the public about the BY-COVID project by creating materials that cover the main objectives and basic values and principles behind the BY-COVID project.

During the development of several cases, the exercise of having to explain the purpose, methods and overall utility of activities within and across certain work packages to the general public helped the project partners to clarify their mission and vision in relation to their activities, and to determine their key messaging and added value to third parties and policy makers.

The big picture goal is to contribute to a broader understanding in society about the importance of good data governance and management, towards improving European readiness for future pandemics. This in turn will engage citizens in the development of the ethical, legal and societal framework for the developing data ecosystem as they are better informed and empowered to participate in this societal debate.

3. Methods

There are many ways to reach out to the general public. Because the topics, concepts and terms that the BY-COVID project works on and uses, e.g. “pandemic preparedness”, “metadata”, “digital research objects” are very complex for the general public, while they might also have different nuances for different scientific disciplines, the BY-COVID task on public outreach focussed on developing informational materials and their dissemination in different communication platforms and existing educational systems.

In collaboration with several BY-COVID work packages, depending on the specific case, the core principles behind the BY-COVID project that would help students (mainly high school students, between 15-18 years old) and non-experts understand it, were identified. To be able to provide clear and specific information, different cases¹ were developed. The cases are short, easy to understand and quick to consume, in the form of a factsheet per topic, concept or activity. They are focussed on one idea and a visual. For each topic, a ‘hook’ was developed: an analogy, a visual representation or an interesting fact that grabs the attention of the public and potentially offers new insights. In addition to the hook, each case features some general information, a description of the activities within BY-COVID and some links to more in-depth information about the topic.

To ensure scientific reliability, a literature review was carried out, and a collaboration with other WPs and organisations was established. Meetings with WP5 (Use cases) (from which most of the topics were taken) were set up, so that they could explain their work and check the veracity of our texts. All cases were reviewed and validated by WP7 (communication), with whom we held specific "outreach to the public" meetings every month, with ELIXIR² and CESSDA³. Additionally, there were monthly meetings of the Sciensano⁴ team working for BY-COVID, bringing together WP3, WP5, WP6 and WP7⁵. Several sources and educational materials about health data in general were co-developed with the TEHDAS⁶ WP8 citizen consultation team.

¹ BY-COVID Use Cases: <https://by-covid.org/usecases> [accessed 27/09/2023]

² ELIXIR Europe website: <https://elixir-europe.org/> [accessed 27/09/2023]

³ CESSDA website: <https://www.cessda.eu/> [accessed 27/09/2023]

⁴ Sciensano website: <https://www.sciensano.be/en> [accessed 27/09/2023]

⁵ BY-COVID About page: <https://by-covid.org/about#structure> [accessed 27/09/2023]

⁶ TEHDAS website: <https://tehdas.eu/project/> [accessed 27/09/2023]

4. Description of work accomplished

4.1 Cases

A total of 10 cases were produced. Under each case, an open feedback box allows citizens to share their perspective with the BY-COVID team. Every contribution is forwarded to a dedicated email address. This table shows an overview of the topics of the cases:

Table 1. An overview of the BY-COVID Use Cases

CASES	SHORT EXPLANATION
School of fish ⁷	The more data and datasets are combined, the more precise the research can be.
Policy action ⁸	Data is useful for providing good information to policy makers, who can make decisions based on it.
Wastewater ⁹	Data can be found in unexpected places, such as wastewater.
Positive side effects ¹⁰	How a crisis situation can bring together scientists from all over the world, enabling scientific breakthroughs beyond the realm of COVID-19.
Metadata ¹¹	What metadata is and why good standards are needed.
Future pandemics ¹²	Thanks to the knowledge and experience gained throughout COVID-19, we will be better able to anticipate future pandemics.
Umbrella ¹³	Access to reliable data influences public opinion.
FAIR data ¹⁴	A common structure and approach is needed to link different types of data and to ensure the data is managed responsibly and efficiently.

⁷ School of fish use case: <https://by-covid.org/usecases/school-of-fish/> [accessed 27/09/2023]

⁸ Policy action use case: <https://by-covid.org/usecases/policy-action/> [accessed 27/09/2023]

⁹ Wastewater use case: <https://by-covid.org/usecases/wastewater/> [accessed 27/09/2023]

¹⁰ Positive side effects use case: <https://by-covid.org/usecases/positive-side-effects/> [accessed 27/09/2023]

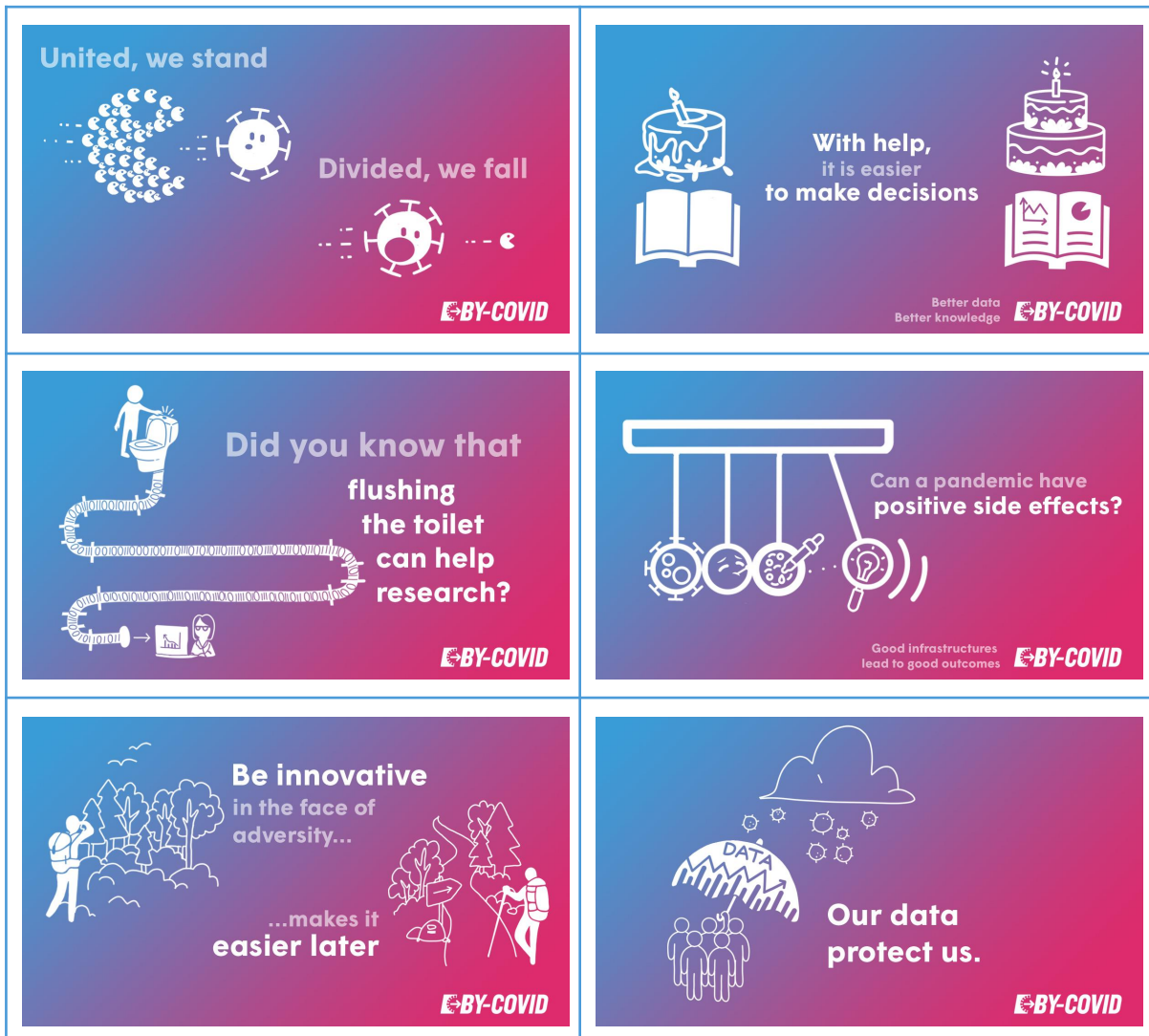
¹¹ Metadata use case: <https://by-covid.org/usecases/metadata/> [accessed 27/09/2023]

¹² Future pandemics use case: <https://by-covid.org/usecases/future-pandemic/> [accessed 27/09/2023]

¹³ Umbrella use case: <https://by-covid.org/usecases/umbrella/> [accessed 27/09/2023]

¹⁴ FAIR data use case: <https://by-covid.org/usecases/fair-data/> [accessed 27/09/2023]

Federated systems ¹⁵	How these data systems enable better application of the FAIR principles and better data protection.
Collaboration for innovation ¹⁶	Collaboration between the private and public sectors in times of health emergency is essential for the common good, even if interests diverge.



¹⁵ Federated systems use case: <https://by-covid.org/usecases/data-visiting-sharing/> [accessed 27/09/2023]

¹⁶ Collaboration for innovation use case: <https://by-covid.org/usecases/collaboration-for-innovation/> [accessed 27/09/2023]

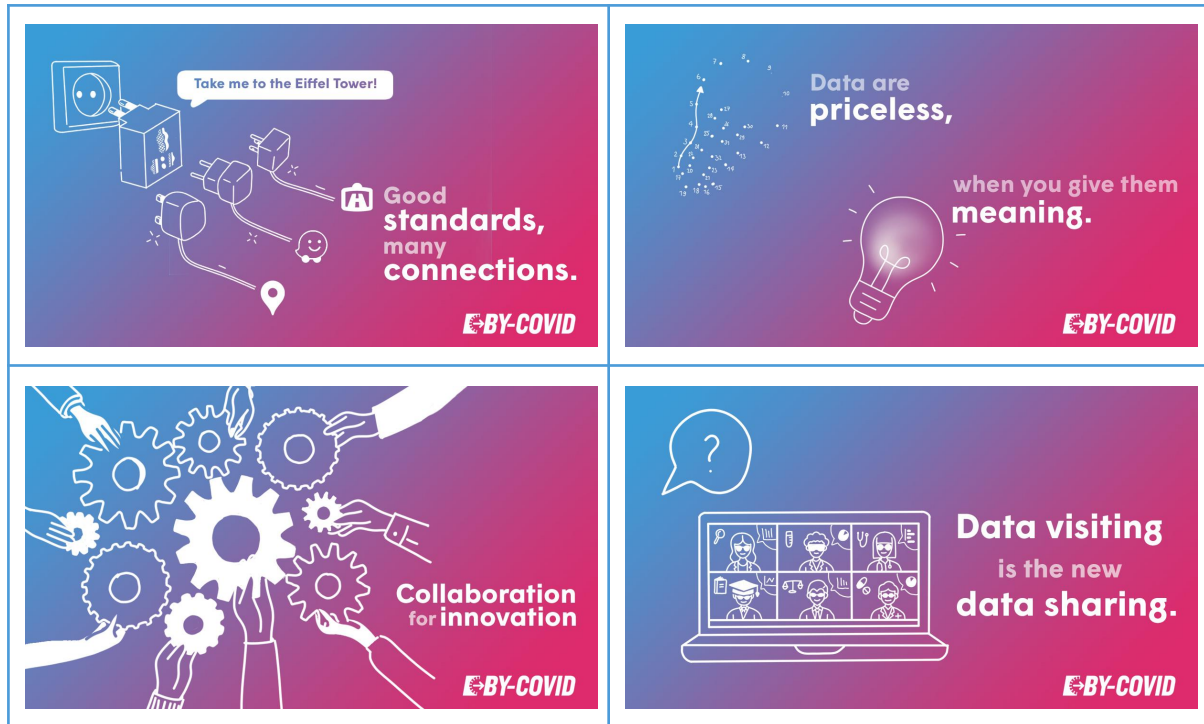


Figure 1. An overview of the visuals created in task 7.3

All cases have been translated into French, Dutch, Czech, Italian, German and Spanish. The English¹⁷ and French¹⁸ cases are currently available on the project website, the others are available in the translations of the educational toolkit.

4.2 Educational toolkit

We have also produced an educational toolkit¹⁹ (for high school teachers. The aim of this toolkit is to enable a target audience to question the use of data in general, using the BY-COVID project as a starting point. With this guide, teachers can guide their own lessons by choosing the topics they want from the list provided. The topics are case-based and cover themes such as:

- How do we address the ethical implications of data selection and exclusion in shaping policy decisions?
- Privacy
- Aggregated data
- Data security
- Trust

¹⁷ BY-COVID use cases: <https://by-covid.org/usecases> [accessed 27/09/2023]

¹⁸ BY-COVID use cases French page: <https://by-covid.org/usecases-fr> [accessed 27/09/2023]

¹⁹ BY-COVID - Educational Toolkit: <https://zenodo.org/record/8363521> [accessed 27/09/2023]

- Data quality
- FAIR principles
- AI and health data

To access schools and teachers, a dissemination plan has been created. This plan groups together specialised sites, platforms or groups of teachers. The dossier has been translated into French²⁰, Dutch²¹, Spanish²² and Czech²³, each containing a dissemination plan for these countries.

Table 2. An overview of the dissemination strategy

Countries	Activities	Members
United Kingdom	Platforms (5)	
	Facebook Groups (2)	97 500, 13 400
Spain	Facebook Groups (13)	14 900, 2 500, 1 400, 20 600, 23 200, 73 480, 16 200, 19 216, 5 400, 4 400, 8 300, 4 700, 2 600
	Instagram Groups (3)	29 200, 420 000, 97 500
	Editorials (6)	
France	Facebook Groups (2)	1 400, 14 400
	Platforms (3)	
Czech Republic	Facebook Group (1)	31 000
	Contact with the Ministry of Education	
Belgium	Facebook Groups (5)	5 000, 1 400, 14 400, 26 000, 2 800
	Platforms (4)	
TOTAL	42	

²⁰ BY-COVID - Educational Toolkit French:

https://by-covid.org/pdf/By-COVID_Educational_Toolkit_FR-PDF.pdf [accessed 27/09/2023]

²¹ BY-COVID - Educational Toolkit Dutch:

https://by-covid.org/pdf/By-COVID_Educational_Toolkit_NL-PDF.pdf [accessed 27/09/2023]

²² BY-COVID - Educational Toolkit Spanish:

https://by-covid.org/pdf/By-COVID_Educational_Toolkit_ES-PDF.pdf [accessed 27/09/2023]

²³ BY-COVID - Educational Toolkit Czech:

https://by-covid.org/pdf/By-COVID_Educational_Toolkit_CZ-PDF.pdf [accessed 27/09/2023]

N.B. Platforms are websites that publish open access educational materials for teachers, but generally do not require membership. Two facebook groups mentioned target both French and Belgian teachers (in purple).

The pedagogical toolkit was discussed and reviewed by two high school teachers (one religion/philosophy teacher and one biology teacher) and by the WP7 (communication) coordination team and tested in different formats in two Belgian high schools.



Figure 2. The educational toolkit

The toolkit attempts to digest complex terminology into formats that work with non-experts, by using visuals, metaphors and a layered structure (visual -> low level 'hook' -> scientific information -> BY-COVID activities -> more in-depth information).

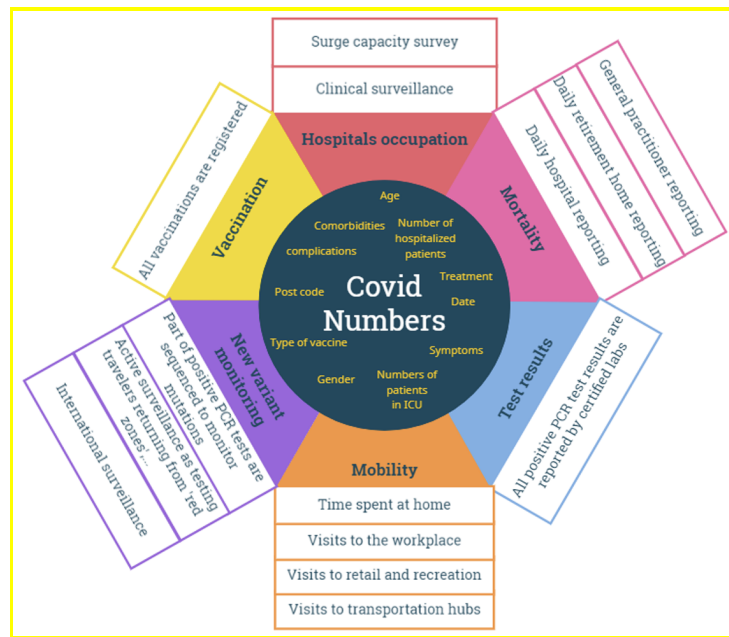


Figure 3. Example of a visual from the toolkit that illustrates the complexity of COVID-19 data flows

4.3 Problems and solutions

Initially, it was difficult to create a dialogue with the public going beyond a relationship of informing and sensitising. A communication channel has been set up to allow anyone to leave their opinion. A link to a feedback form can be found at the end of each case or on each case thumbnail. For each contribution, a notification is sent to the email address linked to the form.

When it came to creating content, it wasn't always easy to work out highly technical cases, such as the 'metadata' case. Experts in the field corrected the draft and pointed out numerous errors or statements that could be misconstrued due to oversimplification. In the end, no fewer than 13 people reviewed the document. In the end, this balancing act was mutually beneficial, improving the understanding of the public outreach team and pinpointing the key messages of the BY-COVID project.

To disseminate the educational toolkit, we were turned down by several Facebook groups and teacher platforms because we are not teachers ourselves. We had to look for other platforms/groups that accepted us.

5. Results

The 10 cases were published on the BY-COVID website²⁴, shared on the BY-COVID Twitter (X)²⁵ and LinkedIn²⁶ social networks and showcased in the project website newsletter (the cases were published in the Winter 2022²⁷, Spring²⁸ and Summer 2023²⁹ newsletters).

Preliminary versions of the educational toolkit were tested twice in different contexts:

- Two regular highschool classes in Leuven (Belgium) with 20 students in the fourth grade of high school (15-16 years old)
- A theme day around ethics and philosophy in Rotselaar (Belgium), where 80 students from the fifth and sixth grade of high school (16-18 years old) engaged with the materials for four hours



Figure 4. The educational toolkit in action in a Belgian school

²⁴ BY-COVID use cases: <https://by-covid.org/usecases/> [accessed 27/09/2023]

²⁵ BY-COVID Twitter (X): https://twitter.com/BYCOVID_eu [accessed 27/09/2023]

²⁶ BY-COVID LinkedIn: <https://www.linkedin.com/company/by-covid/> [accessed 27/09/2023]

²⁷ BY-COVID newsletter: <https://preview.mailerlite.com/h6o2i4a1q6> [accessed 27/09/2023]

²⁸ BY-COVID newsletter: <https://preview.mailerlite.com/b4x4j2o3n1> [accessed 27/09/2023]

²⁹ BY-COVID newsletter: <https://preview.mailerlite.com/a0i1x0y1h8> [accessed 27/09/2023]

6. Conclusions

The public outreach task aims to contribute to the understanding of the health data ecosystem, primarily by targeting existing networks and educational systems. Original visuals, analogies and metaphors were developed to ensure maximum accessibility. Fact checking and scientific value were assured through collaboration with relevant scientists active in work packages within the BY-COVID project.

7. Impact

The impact of public outreach is notoriously hard to measure: what does one click, download or view actually mean in terms of improved understanding or actual engagement with the materials? How do you measure a teacher downloading a pedagogical toolkit once and using the materials for ten years, reaching thousands of students over the course of many hours? Moreover, impact takes time to develop and is typically outside of the sphere of influence of a project. Yet, efforts will be made to collate evidence of the use of the materials and reported back at the end of project report.

The main impact envisioned by the public outreach team is to spread original and engaging information about BY-COVID and the health data ecosystem in general. Some specific areas of impact include:

- The dissemination of the educational toolkit in 5 languages and on over 40 dedicated teacher platforms
- The publication of the cases on the BY-COVID website, on different social media platforms and in the newsletters
- Setting up a feedback form³⁰ for citizens related to each case
- A collaboration with the JA TEHDAS³¹ citizen engagement team
- Understanding Patient Data³² has shown an interest in the cases to ensure their continued use
- Two high school test events

8. Next steps

³⁰ Citizens use-case feedback form:

https://docs.google.com/forms/d/e/1FAIpQLSdknfycEDMrIJBD2_eLHYFeWMIqXwt2s1b_hDgTL6uAT5HAqw/viewform [accessed 27/09/2023]

³¹ TEHDAS website: <https://tehdas.eu/> [accessed 27/09/2023]

³² Understanding patient data website: <https://understandingpatientdata.org.uk/> [accessed 27/09/2023]

The next stages will focus on the continued dissemination of the educational package. Direct contact with teachers has been established in the United Kingdom, Belgium (Flanders - Wallonia - Brussels), Spain and the Czech Republic. Dissemination targets are social media (Facebook or Instagram groups), platforms for teachers (for courses or mutual support) and editorials.

The interaction with the public will continue through the comments section on the BY-COVID website.

The cases will continue to be used in existing networks, for example the TEHDAS Healthy Data community³³, Understanding Patient Data³⁴, Sciensano³⁵ and CESSDA³⁶.

³³ TEHDAS project website: <https://tehdas.eu/project/> [accessed 27/09/2023]

³⁴ Understanding patient data website: <https://understandingpatientdata.org.uk/> [accessed 27/09/2023]

³⁵ Sciensano website: <https://www.sciensano.be/en> [accessed 27/09/2023]

³⁶ CESSDA website: <https://www.cessda.eu/> [accessed 27/09/2023]