ADVOCATING FOR THE GREAT FORGOTTEN:

Public Data-Sharing Infrastructures

SUMMARY

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terra nova
LE THINK TANK PROGRESSISTE

THINK-DO-TANK
DIGITAL NEW DEAL

Our Approach

Developing ambitious, collective and field-based guidelines to move forward

In 2016, when Clément Bertholet and I wrote "*Blockchain the State! Before others do it for you*" following the work of Henri Verdier and many others, we were told it was already outdated and that we should have written "*Blockchain the State! Before others do it for you*". In 2020, during the early months of the Covid crisis, while we worked around the clock to establish the numerous data-sharing infrastructures essential for screening, contact tracing, managing vaccine logistics and traceability, handling side effects, sending masks and respirators, identifying available hospital beds and transferring patients, we faced many simultaneous questions about how artificial intelligence was being used to manage the pandemic. In reality, **AI's role in addressing critical problems in the medium term was minimal, if not nonexistent**.

Data-sharing infrastructures are not glamorous. Like physical infrastructures (water and sewerage networks, the Internet…), their underlying technologies are rarely spectacular. Their use cases are widespread, their execution is complex and long-term. Just as elected officials prefer inaugurating a building (a hospital, school, or start-up incubator) over a sewerage system, politicians, the press, and investors are more drawn to tangible, innovative digital services than to intangible digital infrastructure.

However, data-sharing infrastructures are essential for designing and implementing public policies. These include managing Covid screening (via SI-DEP) or improving city-hospital coordination and health prevention (via My healthcare space, increasing farmers' income for adopting environmentally responsible practices (with Agdatahub), managing teacher absences and school buildings (via the Education Infrastructure), implementing environmental labelling, optimizing mobility and accelerating home renovation to combat poor insulation and fraud (with Footprint database and the Actual Product Base, EONA-X and moB, the Digital housing space).

A data-sharing infrastructure structures, aggregates and connects data. Through this data, public and/or private stakeholders can exchange, understand one another and collaborate to reform dysfunctional systems, aiming to move forward together toward a shared future. What could be more important? It's time to rediscover our sense of purpose: the appeal of a digital project lies not in its underlying technology, but in the goals it strives to achieve.

Opposition to data-sharing infrastructures is rarely explicit. Most discussions are scattered and remain superficial. When they do reach to appropriate level, they often emphasize concerns about framing or execution rather than questioning the need for such infrastructure: "*we're using a sledgehammer to crack a nut*", "*it won't get validated by the Data Protection Agency*", "*we can't afford it*" or "*we'll be nowhere near what the private sector could do*", etc.

However, as with the management of the Covid or the climate crisis, **the essential question is not "Will we succeed? But rather "How will we succeed?"** or at the very least, how can we give our best effort? Successful cases (e.g imports.gouv.fr, SI-DEP…) show that it is possible. More often than not, we simply haven't tried hard-or smart enough.

The gap between the massive stakes associated with Public Data-Sharing Infrastructures and the amateurism with which they are still often implemented is no longer bearable. We have to do much better, and we can do much better, if we develop a shared vision. As the few civil servants who work on these issues, it is our responsibility to raise our voices and, above all, to contribute to our collective improvement. That's why we created a **practical, field-based, collective and ambitious guide to help us progress.**

1 WHY?

Reorganising the mess in order to meet the challenges of the century

The guide opens with an overview of the current landscape and the raison d'être of the work carried out—**an essential step to lay a solid foundation.**

Before delving into data-sharing infrastructures specifically, this section takes a broader look at digital technology: is it truly necessary to meet the major challenges of our century? Some fear that it diverts attention from more pressing issues, arguing that "*it's not at the core of our business*" ("*our priority is to decarbonize the industry*"). Others believe digital tools fail to answer the fundamental question: what kind of future do we want? In the context of ecological transition, for example, what should our lives look like tomorrow? Worse still, digital technology is sometimes seen as harmful— data breaches, digital divide, environmental impact, techno-solutionism, runaway productivity gains, weakened resilience, misinformation, filter bubbles… These are serious and legitimate concerns. Yet digital technology is also an indispensable lever for the effective implementation of public policies, such as decarbonizing the economy. More than just enabling change, it can foster deep transformations: reimagining the doctor-patient relationship, shifting from ownership to renting models, and more.

We must therefore embrace complexity. To launch a ship is to also accept the risk of it sinking. **As long as the cost-benefit ratio remains favorable, the ship must sail—while proactively minimizing risks by anchoring digital development in ethical, humanist, and civic values.**

Public Data-Sharing Infrastructures play a pivotal role. Known at the UN level as Digital Public Infrastructures and within the European Data Strategy as Data Spaces, these platforms enable the secure and structured exchange of sensitive data among a defined group of stakeholders. They organize the fluid and secure sharing of data, which is not intended to be open because of its sensitivity, within a closed circle of stakeholders. They urbanize data exchange, instead of leaving each player to fiddle about in a sort of shantytown where everyone pulls their own electric cables and scrambles to manage their waste. They are the top layer of the "public platform". As such, they rely on rules of ethics, interoperability, security, databases and tools for identification and consent management built by the public in a logic of "commonality" (foundations of the building on the next page). Conversely, digital services with added business value and observatories (walls and roofs), mainly developed externally, rely on them to circulate data in the service of general-interest use cases.

The benefits—both direct and indirect—are considerable.

For the sectorial and budgetary efficiency of public authorities. Numerous audits highlight the lack of data-sharing as a major bottleneck in the collective implementation of public policies. These infrastructures are intended to overcome this challenge. While often more expensive than conventional digital services, they are far cheaper than physical infrastructures, and the savings they enable frequently exceed their cost. For example, *Mon espace santé* is expected to significantly reduce redundant medical procedures in radiology and biology, which currently costs between €1-5 billion annually (!)[1].

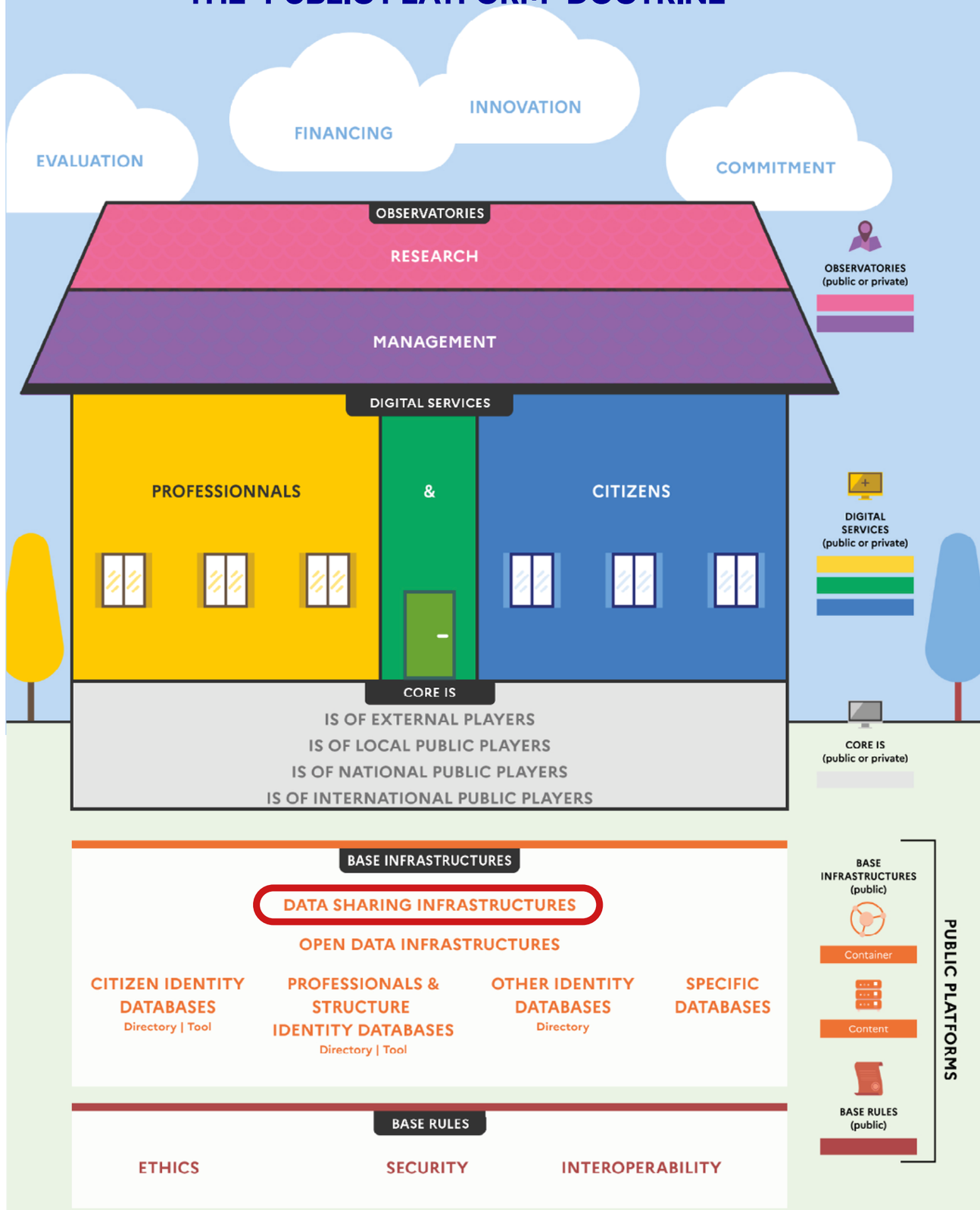
For the environmental and economic efficiency of businesses. These infrastructures streamline administrative processes. They allow companies to submit data to public authorities once, avoiding repetitive efforts. This was one of the main demands of French farmers during the 2023 crisis. These infrastructure also promote environmental sustainability. Features like vaccination and health check reminders help reduce the need for medical interventions, thereby lowering the sector's ecological footprint. Lastly, these infrastructures support reindustrialization, with projections showing a 15% improvement in customer satisfaction and an 11% cost reduction in the first few years of implementation[2].

For an innovative and sovereign digital development. These infrastructures underpin the broader public platform. When a hospital connects to *Mon espace santé*, it strengthens its access controls, enhancing cybersecurity and personal data protection on the whole. They also enable the development of new digital services that would otherwise be impossible. For example, the flow of data from ProNote could allow EdTech startups to create AI-powered educational tools. Ultimately, controlling these infrastructures is essential to "democratic" sovereignty: the public—not private—sector must govern these strategic assets, as they are critical to delivering on public policy promises. It is also a matter of "technological" sovereignty: mastering the data that powers AI models is a prerequisite for nurturing strong French and European private players. In return, technological sovereignty reinforces democratic sovereignty by ensuring that public actors have access to trusted, sovereign service providers capable of delivering white-label infrastructures.

The development of these infrastructures is not only necessary—it is entirely achievable if we set the "winning machine" in motion. ■

[1] Estimates from studies : The value of health care information exchange and interoperability; Improving safety and eliminating redundant tests: cutting costs in U.S. hospitals; What proportion of common diagnostic tests appear redundant?; Repeat abdominal imaging examinations in a tertiary care hospital; Trauma: the impact of repeat imaging.
[2] Cap Gemini's estimations

THE "PUBLIC PLATFORM" DOCTRINE



2 WHAT?

Setting the winning machine in motion for each sharing infrastructure data

The co-elaborated guidelines considerably clarify the principle of public platform presented in "*Blockchain the State! Before others do it for you*". They examine 17 questions from the 7 infrastructures on the following pages and deduce guidance to help infrastructure developers capitalize on existing experiences. **They constitute a version 0 which is intended to be adapted and completed.**

GUIDELINES v0

Why?
Is a data-sharing infrastructure necessary?
What should be the associated values framework?

1. Macro needs] From a sectoral point of view, what does each stakeholder need to do and with which data?
2. [Micro needs] What are the first envisioned use cases?
3. Are there any internal or external initiatives already set to build such an infrastructure? From which stakeholders?
4. What are the reasons behind the failure of existing initiatives, and/or the arguments against constructing the infrastructure?
5. What is the relevant geographical level (local, national, European, international)?
6. What are the risks associated with this infrastructure, and what values should govern it?
7. If this infrastructure does not exist, what are the alternative scenarios and what are their risks?

What?
What should the technical, economic and governance characteristics of this infrastructure be?

8. Should there only be a single infrastructure, or can there be several?
9. How should this infrastructure be governed in terms of public/external roles?
10. What should the economic model for this infrastructure be?
11. Should this infrastructure be centralized or decentralized?

How?
What are the criteria for the successful development and deployment of this infrastructure

Internal transformation:
12. What organization and support?
13. What human and financial resources?
14. What work culture and HR attractiveness factors?

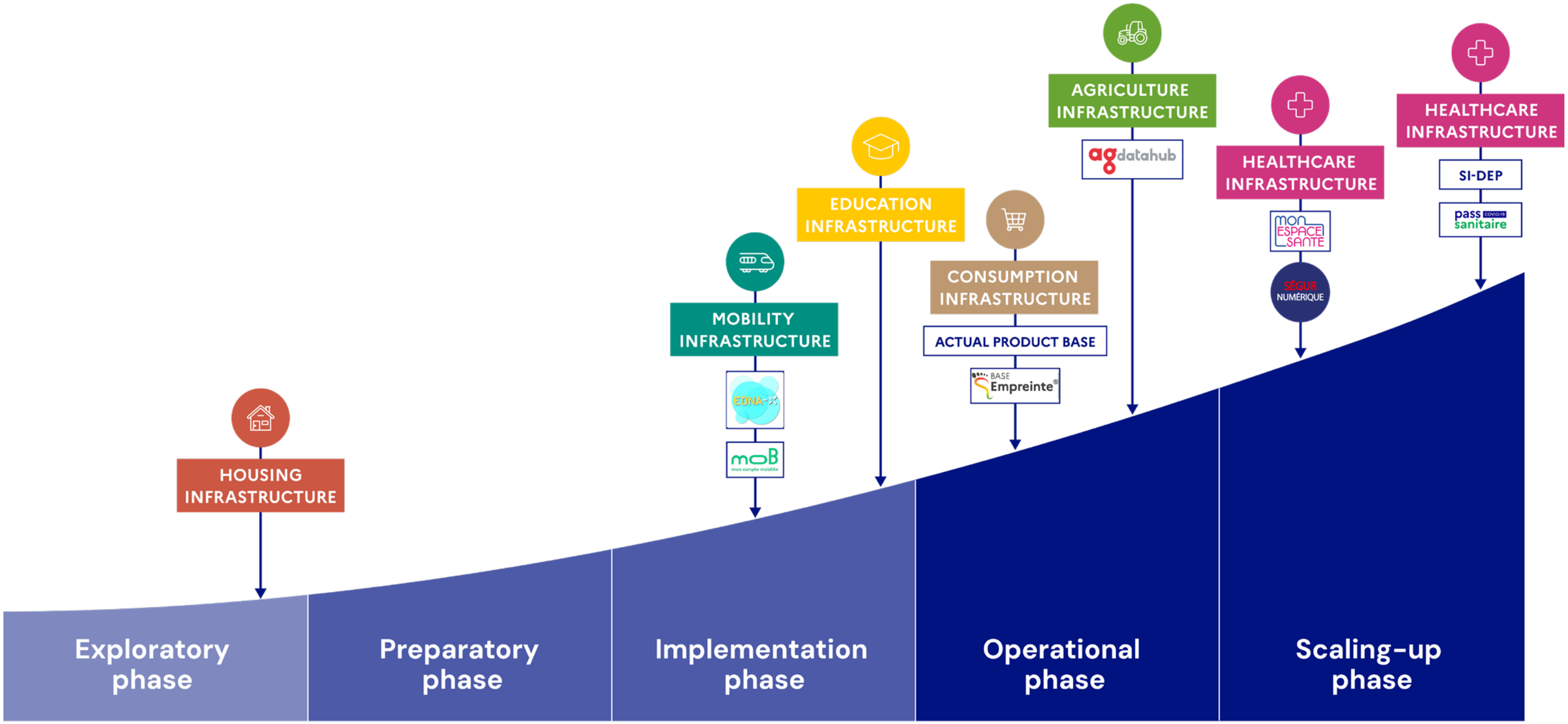
External regulation for effective co-construction and deployment:
15. What levers of stakeholder commitment?
16. What coercive levers ("sticks")?
17. What incentive levers ("carrots")?

The guidelines are first designed to help develop a convincing "why", i.e the infrastructure's *raison d'être* and the framework of values to be associated with it. They indicate, for example, that it is necessary to present both the generic needs that the infrastructure is designed to cover, and the very specific use cases that will help the interlocutors plan ahead. They also indicate that the use cases concerning the use of data for primary purposes (e.g. enabling local authorities to reduce the energy consumption of schools) are less controversial and therefore more likely to win over stakeholders than the use cases using data for secondary purposes (e.g. identifying schools that have more difficulty replacing absent teachers). They also indicate that the existence of repeated previous failures is more often the mark of a real need rather than that of a bad idea (e.g. the DMP, predecessor of *Mon espace santé*; the housing information booklet). They also recommend making the threat of uberization explicit: the *status quo* is often riskier than change. This is a challenging but essential step to ensure that all stakeholders are fully convinced of the need and are determined to find solutions to the problems that will inevitably arise in the future.

If the need is confirmed, then the "what?" helps to determine the questions that systematically arise concerning the technical and economic characteristics and the governance of the infrastructure. If this infrastructure is essential to the implementation of a public policy, then it must be unique and publicly managed within the scope of the concerned use cases. In this sense, "the Digital and Data for Ecological Planning" roadmap has notably announced the change to a public governance of the Agdatahub company and the creation of a digital space for public housing. If the paper version of the health records does not belong to a Big Pharma, the digital health records cannot belong to a private stakeholder either, even a French one. On the other hand, it is not up to the State to develop professional software or e-health apps. The following questions on the economic model and the centralized/decentralized nature of the infrastructure are obviously important but often monopolize the debate to the detriment of the other 15 questions in the guidelines, which are just as necessary.

The "how" then sets out the 6 criteria which enable to set the winning machine in motion. This part is by far the most important, most complex and most frequently overlooked. It is what enabled SI-DEP to be set up in 3 weeks and to meet the deadline of the first lockdown while its predecessor "3labos" had been struggling to emerge for the past 8 years. After only 3 years of existence, *Mon espace santé* had been used by more than 20 million French people. This tool automatically collects medical documents from almost all the hospitals and from the majority of liberal healthcare workers, while its predecessor, the DMP, had remained an empty shell since 2004. The criteria concern both the internal transformation of public organizations and their way of co-constructing and regulating externally. Internally, this involves creating a team attached to the highest level, which consolidates all the necessary digital expertise. This team must develop the infrastructure by taking the best of both worlds between the State startup culture and the large-scale IT project model. This method can be summarized as follows: "*You have to go from the pebbles to the stars. A star to dream on and to inspire, and small pebbles to set things in motion and mark out the path.*" (Jean-François Caron, *trans*, on building a sustainable city). This section also provides some advice on how to obtain political support, as well as human and financial resources. Externally, the goal is to break away from the traditional model in which a small group of decision-makers make choices among themselves, and implement them half-heartedly afterward. Instead, we must embrace a rigorous, ongoing and field-based approach of participatory democracy—one that actively involves representative bodies as well as individuals directly engaged in collective decision-making. Once decisions are made collectively, their implementation should be firm and coordinated, akin to a kind of "collaborative dictatorship." In this spirit, and following the logic proposed by Bruno Latour in "*Where to Land?*", a precise to-do list is defined for each stakeholder. To ensure that everyone can fulfill their role—and actually does so—we must combine supportive incentives with appropriate forms of pressure, thereby moving beyond the stalemate of the prisoner's dilemma. The process as a whole should be structured around transparent milestones, which help build trust, foster natural coordination, and offer opportunities for shared celebration with each achievement. Ultimately, this approach is about reintroducing method and humanity into the democratic process—making it more dynamic and more pleasant for everyone. ■

THE 7 EXAMPLES OF INFRASTRUCTURES



The feedback from these 7 examples of infrastructures was made possible thanks to the extremely invaluable contributions of the people mentioned below. In addition to this report, they share their exciting adventures in the podcast "*Ambition Publique*", which we invite you to listen to by clicking this link. A huge thank you to them for their contribution to a doctrine that goes beyond their own design, for their talent, courage, and sense of the public interest <3

Olivier Clatz, Hela Ghariani, Raphaël Beaufret and Etienne Amy of the Ministry of Health and the AP-HP (*Assistance Publique–Hôpitaux de Paris*)

Sébastien Picardat and Etienne Achille of Agdatahub and of the Ministry of Agriculture

Pascal Dagras of the Ministry of Ecology

Stéphane Trainel and Audran le Baron of the Ministry of Education

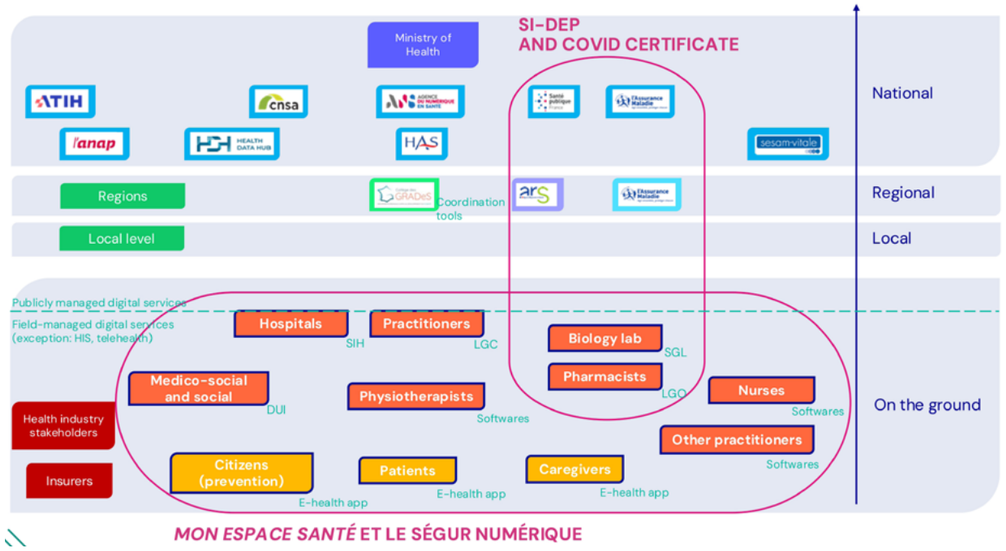
Ghislain Delabie, Dominique Epardeau, Jonathan Huffstutler and Patrick Gendre of La Fabrique des Mobilités, EONA-X, and the Ministry of Ecology

Philippe Vaillant and Guillaume Levieux of the National Housing Agency and the Ministry of Ecology

HEALTHCARE EXAMPLES

Each infrastructure is schematically described by: the stakeholders involved in data sharing, the role of the infrastructure within the "building" of the relevant public policy, its macro and micro use cases, and its technical architecture.

STAKEHOLDERS



MON ESPACE SANTÉ ET LE SÉGUR NUMÉRIQUE

CARTOGRAPHY

MON ESPACE SANTÉ AND SÉGUR

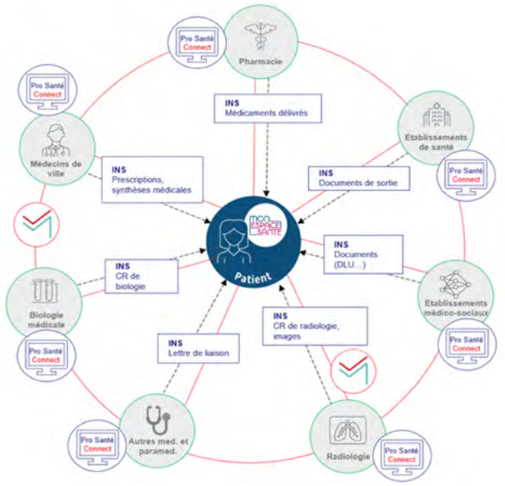
Mon espace santé is the online health record for French people. It allows each person to store and share their health documents and data with their healthcare team in complete confidentiality. Launched in 2022, it is based on the modernized infrastructure of its predecessor, the *Dossier Médical Partagé* (Shared Medical File, or DMP). Its connection to all healthcare and medico-social establishments and professionals is supported by the Segur program.

SI-DEP AND THE COVID CERTIFICATE

SI-DEP gathers biological data on the Covid virus from hundreds of laboratory management systems, covering nearly 5,000 sites. It especially enables the Covid Certificate to be issued. It was launched in 2020 during the first wave of Covid, taking over from a similar IS for other infectious diseases, particularly dengue fever, which had not worked. SI-DEP is being extended to other pathologies, in its new version "Labo-SI".

USE CASE

MON ESPACE SANTÉ AND SÉGUR



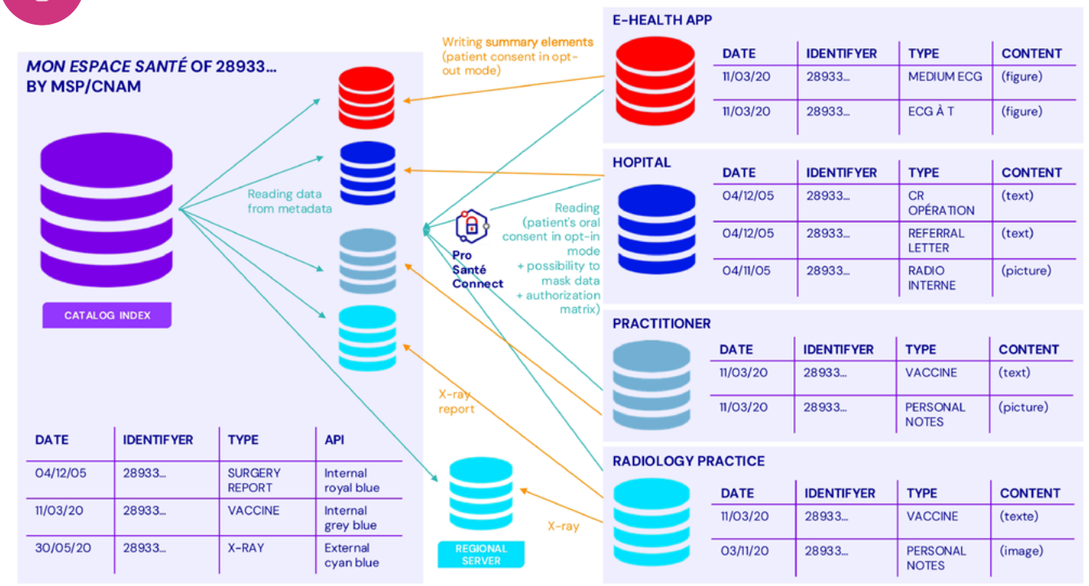
[MACRO] IN GENERAL:

- **Patients** must retrieve their own personal data in order to be actors in their own healthcare: understand and act, seek a second opinion, etc.
- **All healthcare and medico-social professionals involved in a person's care team** (attending physician, nurse, physiotherapist, pharmacist, hospital, EHPAD, SAMU, etc.) must exchange data concerning the patient to provide them with proper care.
- **E-health industry stakeholders** need access to certain patient data in order to offer, both the patient and professionals, innovative digital services (sending reminders/alerts, personalized prevention services, diagnostic assistance, training AI, etc.).

[MICRO] FOR EXAMPLE:

- Patients automatically retrieve their hospitalization report to find out how the surgery went and share the document to their physiotherapist so they can adapt the rehabilitation program accordingly.
- Patients who have lost their prescription and need to go back to the pharmacy to get their prescription can find it in their health space and send it automatically, or via secure messaging, to the pharmacist before or when they go.
- Patients who have lost their proof of vaccination (Covid, yellow fever, etc.) required for international travel. They can find it in *Mon espace santé*, where it has been automatically inserted and securely stored.
- Without asking the patient to download their results but simply by asking for authorization to access their structured biology reports in *Mon espace santé*, an app developed by the private sector (e.g. "understanding my biology results") can offer a service that it would not otherwise have been able to offer.

ARCHITECTURE



DATE	IDENTIFYER	TYPE	API
04/12/05	28933...	SURGERY REPORT	Internal royal blue
11/03/20	28933...	VACCINE	Internal grey blue
30/05/20	28933...	X-RAY	External cyan blue

E-HEALTH APP	DATE	IDENTIFYER	TYPE	CONTENT
	11/03/20	28933...	MEDIUM ECG	(figure)
	11/03/20	28933...	ECG À T	(figure)

HOPITAL	DATE	IDENTIFYER	TYPE	CONTENT
	04/12/05	28933...	CR OPÉRATION	(text)
	04/12/05	28933...	REFERRAL LETTER	(text)
	04/11/05	28933...	RADIO INTERNE	(picture)

PRACTITIONER	DATE	IDENTIFYER	TYPE	CONTENT
	11/03/20	28933...	VACCINE	(text)
	11/03/20	28933...	PERSONAL NOTES	(picture)

RADIOLOGY PRACTICE	DATE	IDENTIFYER	TYPE	CONTENT
	11/03/20	28933...	VACCINE	(texte)
	03/11/20	28933...	PERSONAL NOTES	(image)

3 HOW?

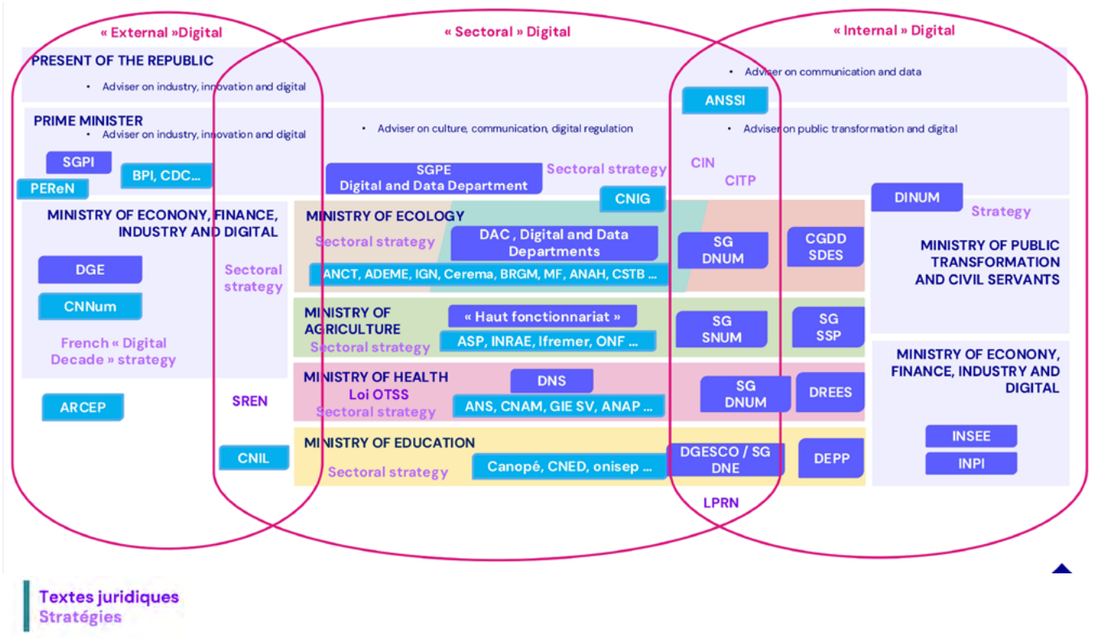
Endorsing a common interministerial vision at the nation, European and international lever and effectively implementing it

As with any systemic issue, data-sharing infrastructures raise complex governance challenges. Internally, the matter is currently addressed by three main types of stakeholders. First, there are the sector-specific digital stakeholders aligned with public policy domains—officials from ministries such as Health, Education, Agriculture, Ecology, Interior, Economy, Defense, Justice, Culture, and others, along with the operators who support them. These are the actors responsible for identifying and implementing the infrastructures required for their respective public policies. Second, there are transversal stakeholders responsible for internal digital services that support public sector transformation, such as the Interministerial Digital Directorate (DINUM), INSEE, and others. While their historical focus was on tools for civil servants and public publications, their missions have significantly evolved to include sectoral concerns like open data and State startups. Third, there are transversal stakeholders concerned with external digital issues tied to economic development—entities such as the Directorate General for Enterprises, the General Secretariat for Investment, Caisse des Dépôts, BPI France, and others. On the regulatory side, their role has expanded from overseeing physical digital networks (e.g., telecoms) to regulating digital platforms and increasingly, sector-specific data in alignment with European legislation. On the support side, they champion initiatives like French Tech and assist companies that contribute to ministerial digital strategies.

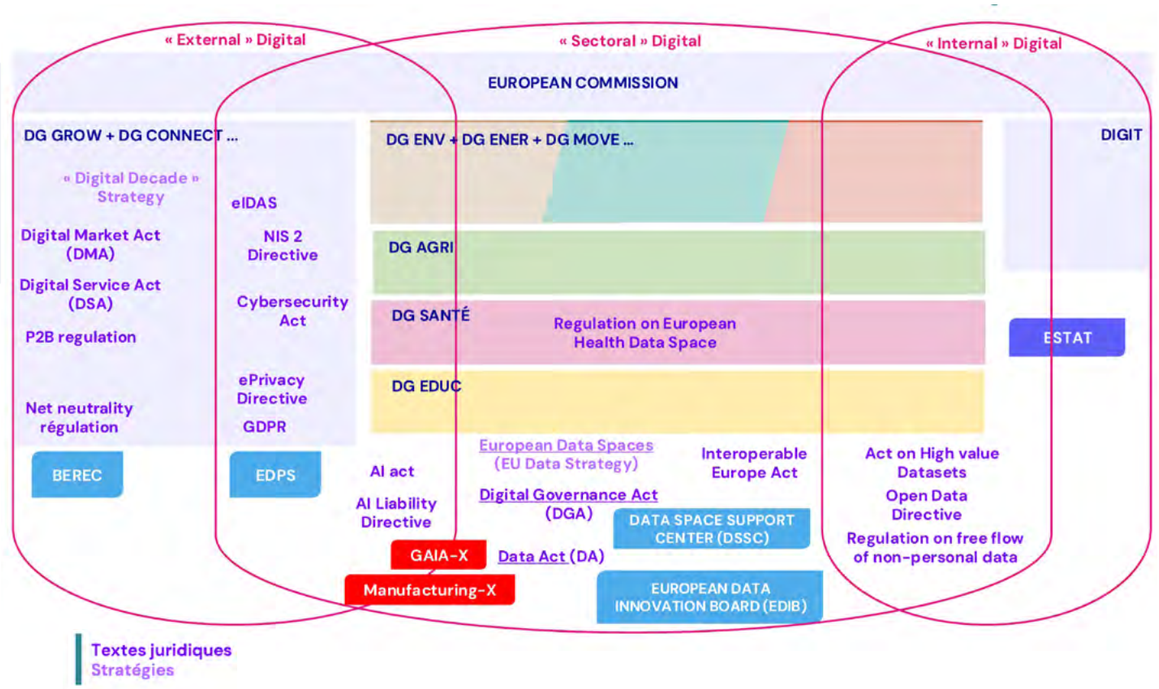
Currently, the absence of a shared interministerial vision often results in fragmentation, lack of coordination, and insufficient political support. This hampers national-level project development and prevents France from fully assuming a pioneering role on the European and global stage. These version 0 guidelines should be challenged and enriched through feedback from all relevant internal and external stakeholders, paving the way toward formal version 1 guidelines. When an infrastructure is sector-specific, its ownership must lie with the competent ministry to ensure that it is designed as closely as possible to the operational realities on the ground. The ministry must also be capable of clearly and convincingly communicating its relevance to all stakeholders. It would be beneficial for the Interministerial Digital Directorate and the Directorate General for Enterprises to form a joint "internal/external" duo. This duo would act both as a regulator—ensuring clarity in the public/private role distribution—and as a support body, helping ministries negotiate governance models, human and financial resources, and offering cutting-edge expertise.

There is, however, broad consensus on one essential point: beyond the method, at the end of the day, it's all about people. It comes down to public servants, at both national and local levels, and to committed external actors who work in service of the common good. These are people capable of cutting through bureaucracy, challenging the status quo, and imagining new frameworks better suited to the public interest. People who "betray" in the sense of Aurélien Barrau in Hypothesis K, referring to scientists who question the role of science and the scientific process. People who "betray", "*not the given words, and even less honesty. It's about betraying inherited practices and implicit followings. Betraying the origin. Betraying the expected. Betraying inertia. Displeasing out of righteousness, disappointing out of integrity. Because not betraying, in the face of deviation, is more of a betraying. Betraying out of love, [...] in genuine infidelity. To take the time to confront contradictory injunctions. To welcome the possibility of a meta-fidelity to life. To the future, to the improbable, to beauty, to hope*". The present work is also an opportunity to thank them. ■

CURRENT NATIONAL GOVERNANCE



CURRENT EUROPEAN GOVERNANCE



Digital New Deal

Digital New Deal supports private and public decision-makers in the creation of an Enlightened, European and Humanist Digital Age. Our conviction is that we can offer a third digital path by aiming for a dual objective: to defend our values by proposing a framework of trust through regulation (think-tank); and to defend our interests by creating ecosystems of trust through cooperation (do-tank).

Our publishing activity aims to shed as much light as possible on developments at work in the context of "digital sovereignty", in the broadest sense of the term, and to develop concrete courses of action for economic and political organizations.

Olivier Sichel (Founding Chairman) and Arno Pons (Managing Director) navigate the strategic direction of the think-tank under the regular supervision of the Board of Directors, which includes Sébastien Bazin, Nathalie Collin, Nicolas Dufourcq, Axelle Lemaire, Alain Minc, Denis Olivennes, Odile Gauthier, Judith Rochfeld, Bruno Sportisse and Robert Zarader.

Terra Nova

Founded in 2008, Terra Nova is an independent progressive think tank dedicated to developing and broadcasting innovative political solutions in France and in Europe. Terra Nova is a non-profit organization which promotes proposals in all areas of public policy through publications and events. Supported by a large group of volunteer experts from the academic world, senior civil service officials and civil society, Terra Nova publishes its work free of charge to a wide audience via its website and social networks. The association is currently chaired by Lionel Zinsou and managed by Thierry Pech.

A huge thank you to Digital New Deal and Terra Nova for their invaluable insight and support.

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