

Current Status and Challenges

Sharing healthcare data generated by industries

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Current status and challenges of industries' data sharing – Key takeaways (1/3)

I. What is **Data Sharing** ?

- *Sharing*: Sharing can be defined **by its level of openness** , with closed sharing and open sharing at the two extremes.
- *Industries' data*: data generated **at the patient level** for which the company is responsible for processing, or finances/participates in the financing of its generation, can therefore be **pre-clinical data , clinical data or even real-life data** .

II. Why share?

- The interest of sharing lies in what can be done with the data collected, which could go **beyond their primary objective**

Current status and challenges of industries' data sharing – Key takeaways (2/3)

III. Which sharing models?

- The possibility and willingness to share depend on the **nature of the data** (clinical trial data, real-life data) and the **relevant stakeholders** (public actors, private actors).

IV. In what context to share?

- Shares must be **governed** :
 - **Governance scenarios** must be defined
 - The commitment must be **on the one who uses the data**
 - **Prohibited purposes** should also be defined
- The terms of sharing may differ depending on the type of data shared.
 - As **clinical trial** data is more strategic, it is necessary to apply **reinforced prohibited purposes**.
 - Regarding **real life data** , the latter also require **AUP (acceptable use policies)**, even if they will be less strict.

Current status and challenges of industries' data sharing – Key takeaways (3/3)

V. Where are we today?

- **A practice that is developing** but remains limited
- Certain actors are **reluctant to share** their data (industries or academic)
- It is **the relatively closed sharing that is most practiced** by industries.
For clinical data, 100% of the shares are closed shares.

VI. What are the main obstacles to sharing?

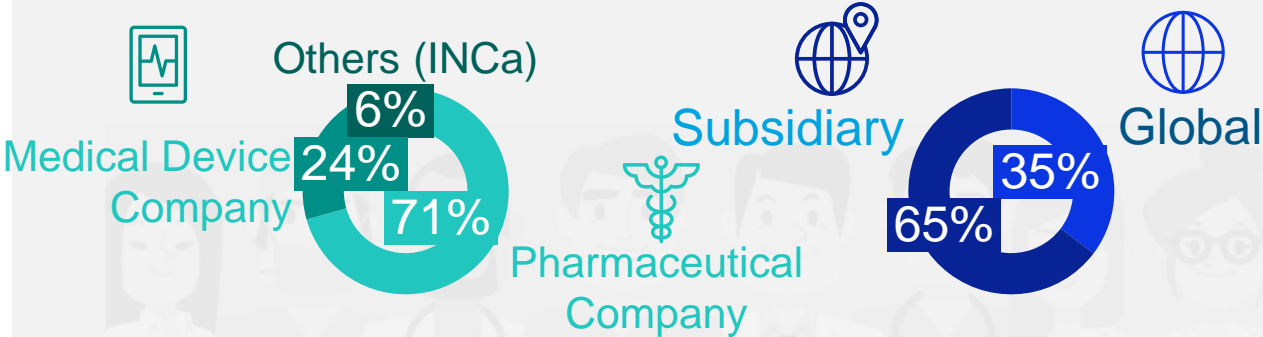
- Excessive **external administrative** procedures
- **Company's strategy** in data sharing is poorly developed
- **Industrial and ecosystem prerequisites** must be established

Presentation of the preliminary results of the survey "Current status of the sharing of data generated by industries"

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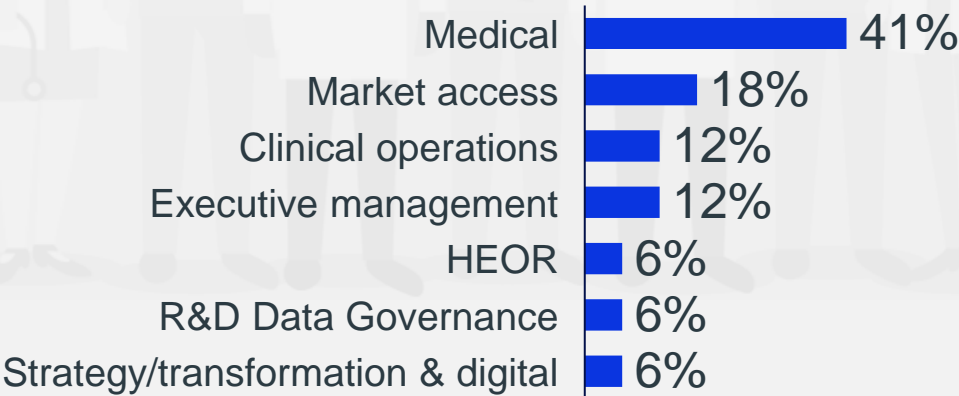
Respondents are mainly subsidiaries of laboratories operating in oncology

Type of business / Scope of responsibility



Questions A1. Your business is...; A3. Your scope of responsibility

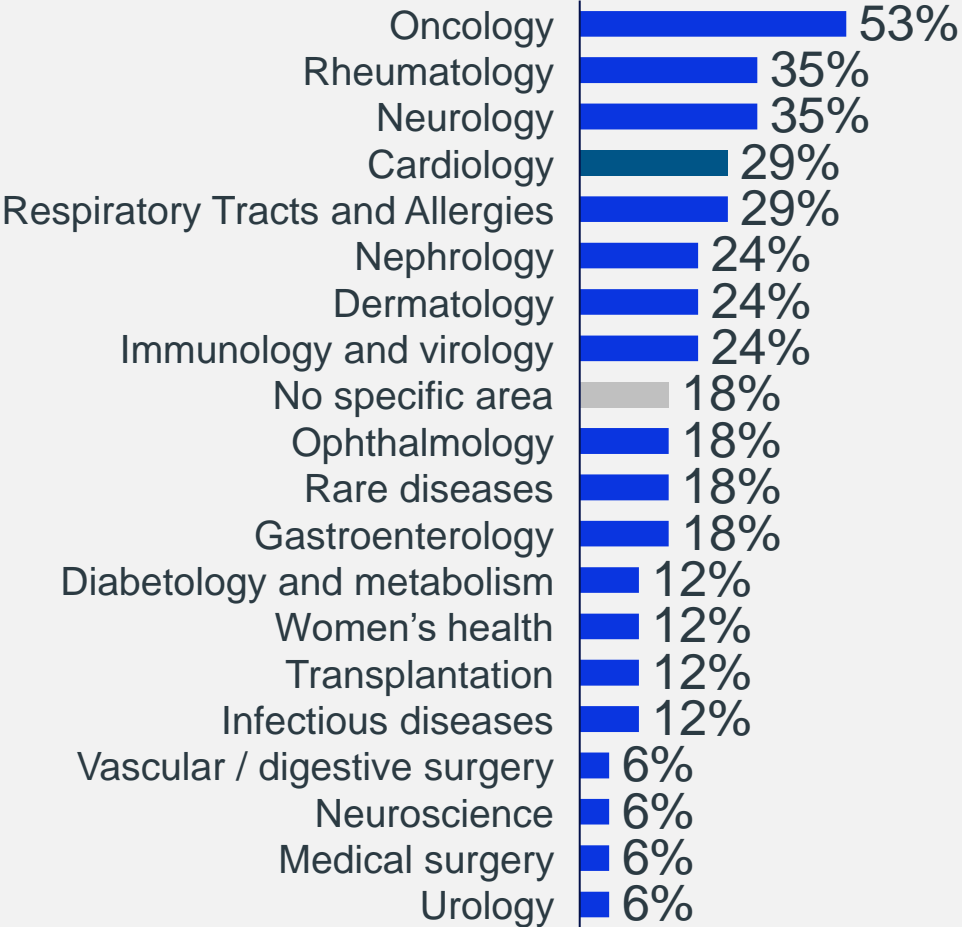
Department



Question A4. What department do you belong to?

Base: 17 respondents

Therapeutic area

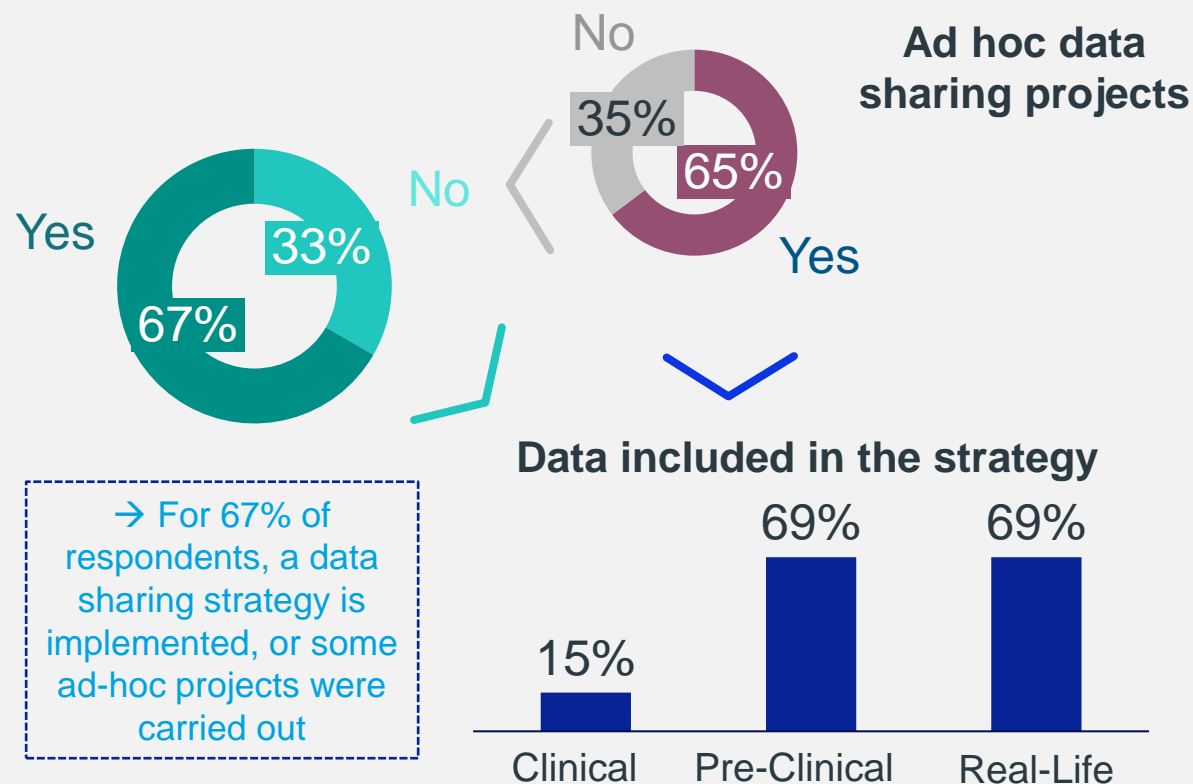


Question A6. Do you work on a specific therapeutic area?

Base: 17 respondents

Two-thirds of laboratories have started working on this sharing topic and mainly on preclinical data and real-life data

Data sharing strategy implemented in the company

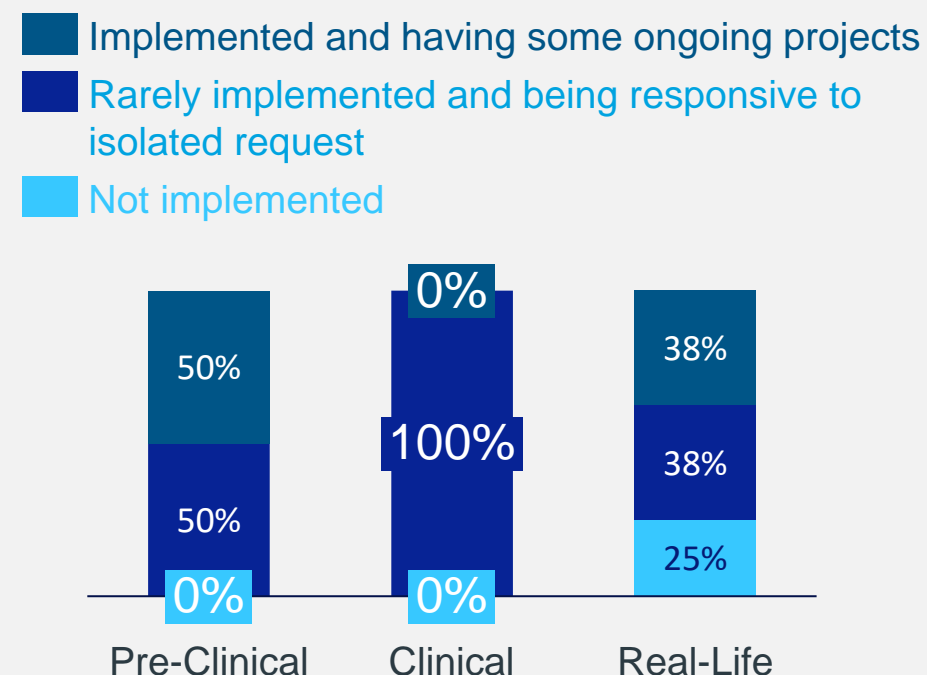


Questions B1. Does your company have a data sharing strategy in place? ; B1bis. If you don't have a defined data sharing strategy in place, are you aware of any specific data sharing projects in your company? ; B2. Does this data sharing strategy include the data

Base: 17 respondents

* Among respondents with data sharing experience ("yes" answer to questions B1 or B1bis)

Status of sharing with industries or other stakeholders in the health ecosystem*

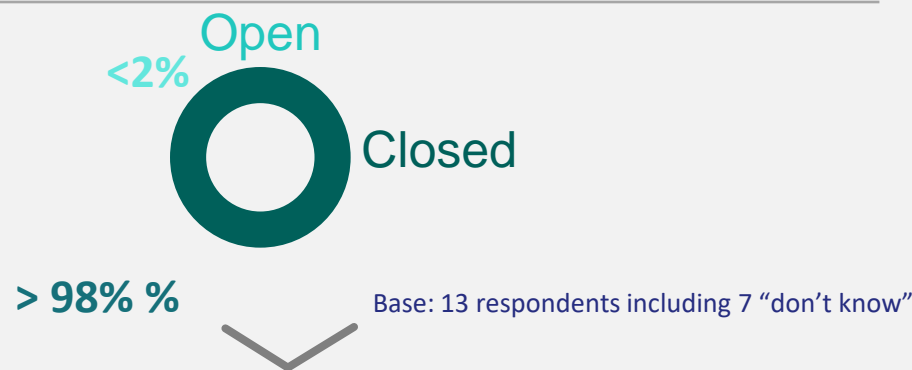


Questions B3/B4/B5. Is this sharing of preclinical/clinical/real-life data with industries or other players in the health ecosystem (institutional, patient associations, academics, hospitals, etc.)

Base: respectively 2, 9 and 9 respondents (including 1 "don't know")

Regardless of the type of data the shares made are mainly closed or semi-open

Type of sharing carried out – Preclinical and clinical data*

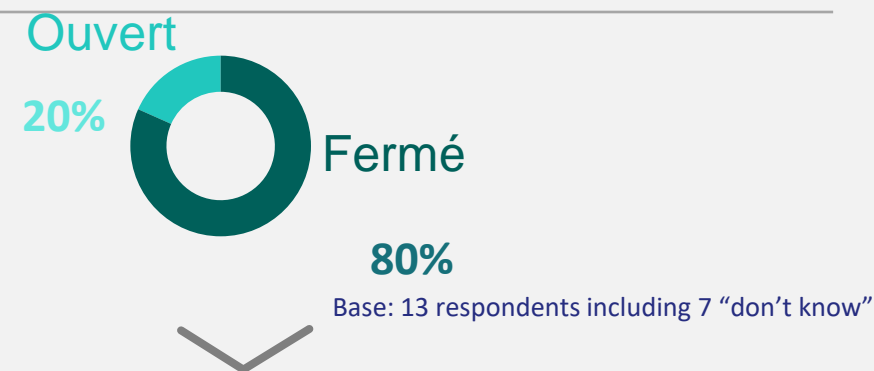


- Open sharing: provision of data that can be reused under defined conditions: HDH type
- Multi-stakeholder closed sharing: European consortium, multi-industrial type
- Bilateral closed sharing between your company and a specific stakeholder

Questions B7. In general, the sharing of preclinical or clinical data of which you are aware falls under a..? B8. And more precisely what type of sharing..?

Base: 6 respondents including 2 “don’t know”

Type of sharing carried out - Real life data*



- Open sharing: provision of data that can be reused under defined conditions: HDH type
- Multi-stakeholder closed sharing: European consortium, multi-industrial type
- Bilateral closed sharing between your company and a specific stakeholder

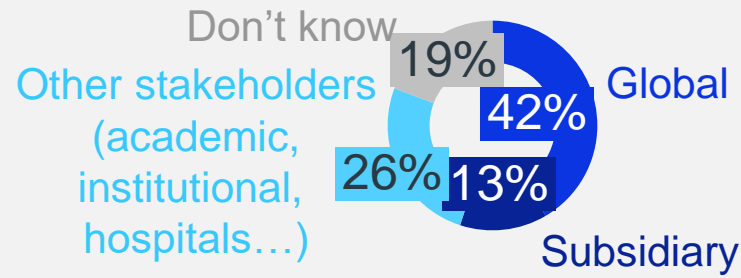
Questions B9. In general, the real-life data sharing that you are aware of falls under a..? B10. And more precisely what type of sharing?

Base: 6 respondents

* Among respondents with data sharing experience (“yes” answer to questions B1 or B1bis)

These data sharing projects are still very strategic and decided at the global level and in ¾ of cases the company has generated the data without fully benefiting from it

Initiators of data sharing projects*



Base: 13 respondents

Question B6. In general, the data sharing projects you are aware of are initiated by

Average number of data sharing projects over the past 5 years*

4 Subsidiary-level data sharing projects

Base: 13 respondents including 9 “don’t know”

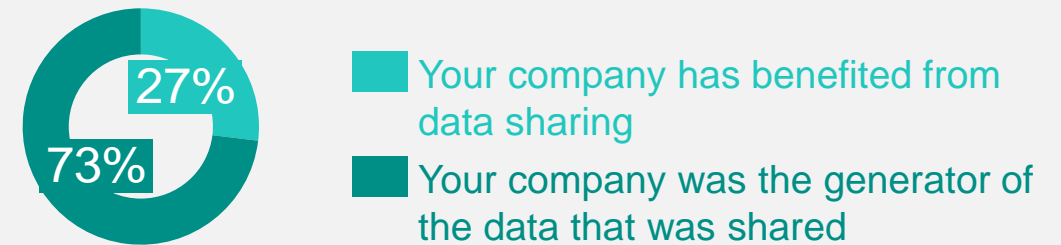
NA Global data sharing projects

Base: 13 respondents including 12 “don’t know”

Question B10bis. Can you estimate the total number of data sharing projects that have taken place at your subsidiary? or globally? Over the last 5 years.

* Among respondents with data sharing experience (“yes” answer to questions B1 or B1bis)

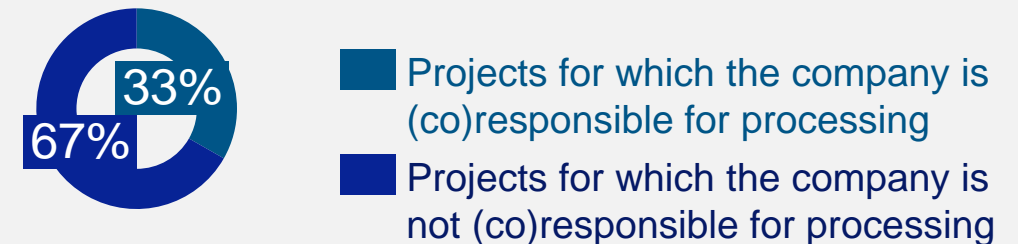
Company's role in data sharing*



Question B13. In your sharing experiences, were you the one who shared the data or the one who benefited from the sharing:

Base: 13 respondents

Co-responsibility for processing in the sharing of real-life data*

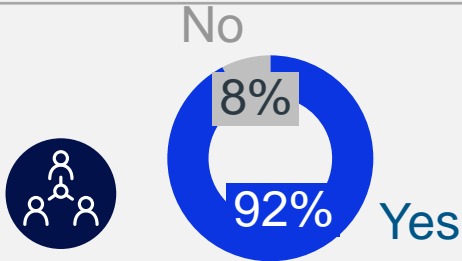


Question B11. Out of 100 real-life data sharing projects, what is the % of projects for which you are (co) responsible for processing?

Base: 13 respondents including 5 “don’t know”

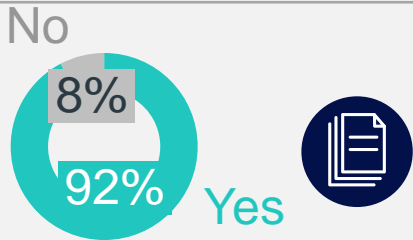
Internal governance rules seem to be established but dedicated human and financial resources are still inadequate

Governance program regulating data sharing projects*



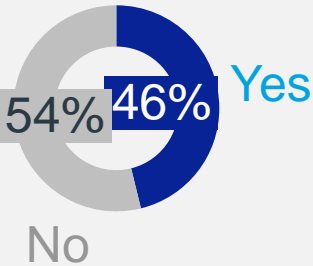
Question B14. Does your company have governance measures for data sharing projects?

Specific procedures for the operational implementation of projects*



Question B15. Within your company, are there specific procedures for the operational implementation of data sharing projects?
Base: 13 respondents

Internally dedicated human and technical resources*



Average number of dedicated FTEs

2 FTEs

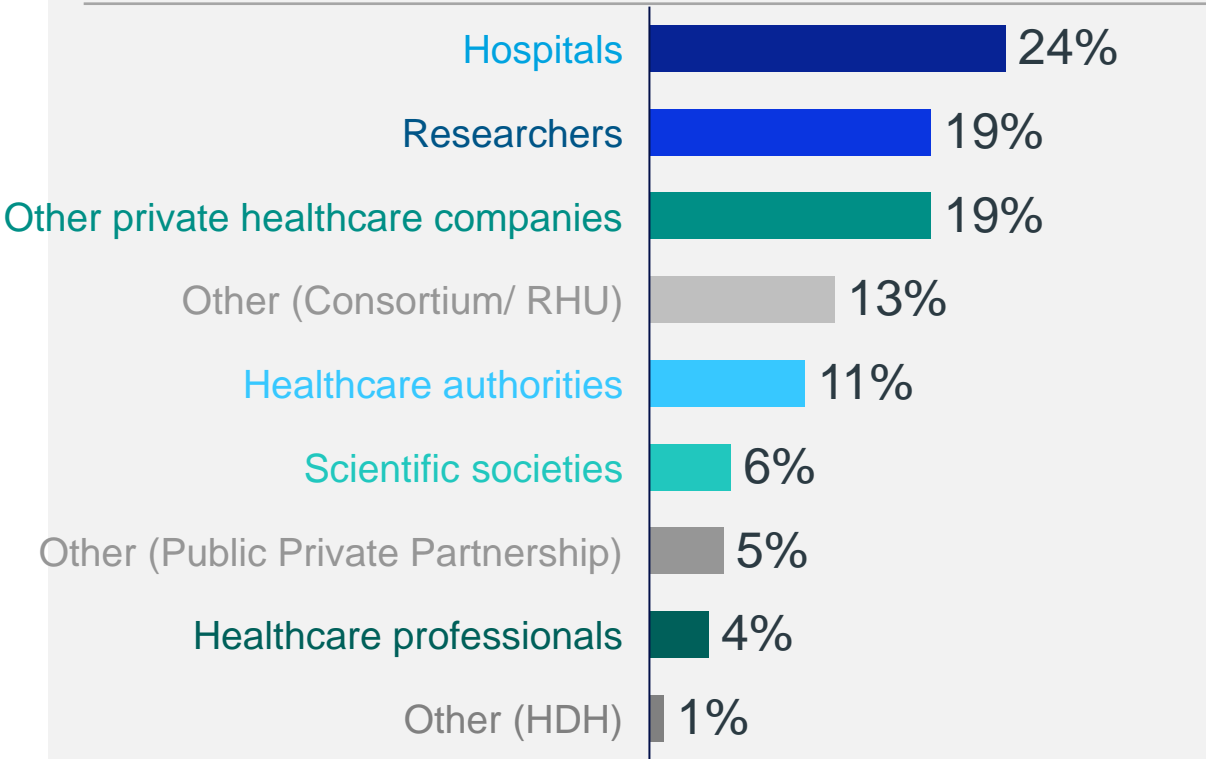


Question B16. Do you have human and technical resources dedicated internally to the management of data sharing projects? / Number of resources
Base: 13 respondents

* Among respondents with data sharing experience ("yes" answer to questions B1 or B1bis)

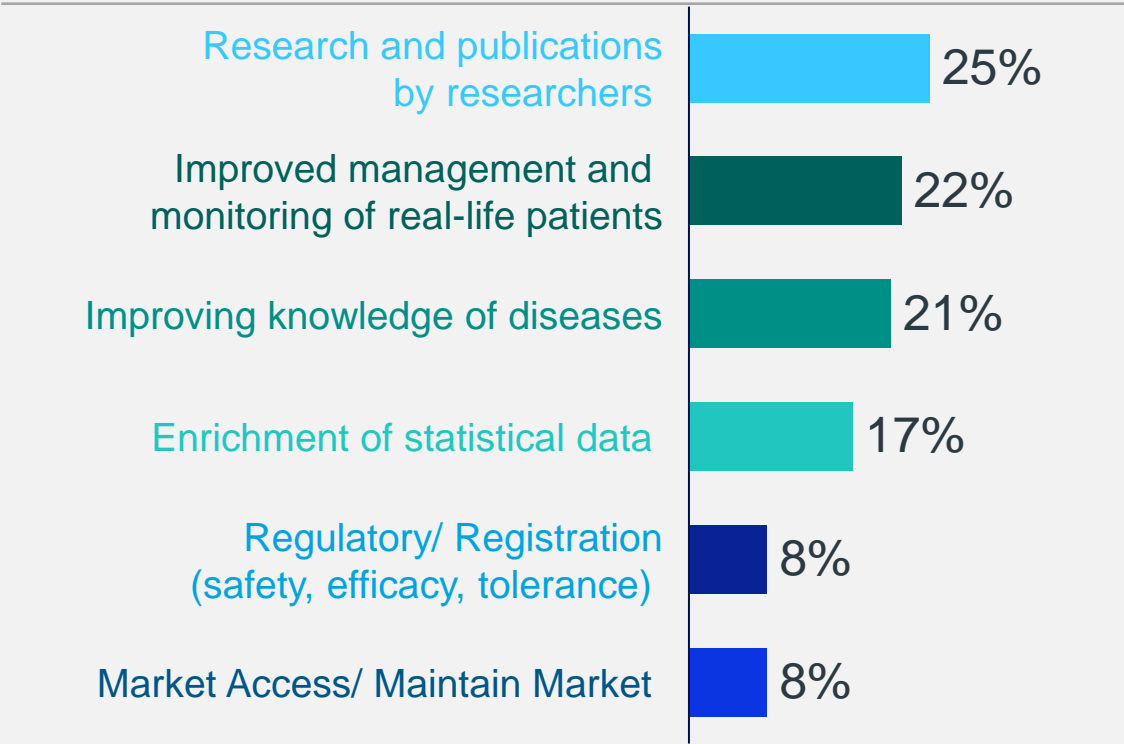
The stakeholder with whom the laboratories have shared their data are diverse with various purposes showing the importance of sharing at all levels

Stakeholder with whom data sharing was carried out*



Question B12. Who were the stakeholders with whom data sharing was carried out and in what proportion?
Base: 13 respondents including 3 “don’t know”

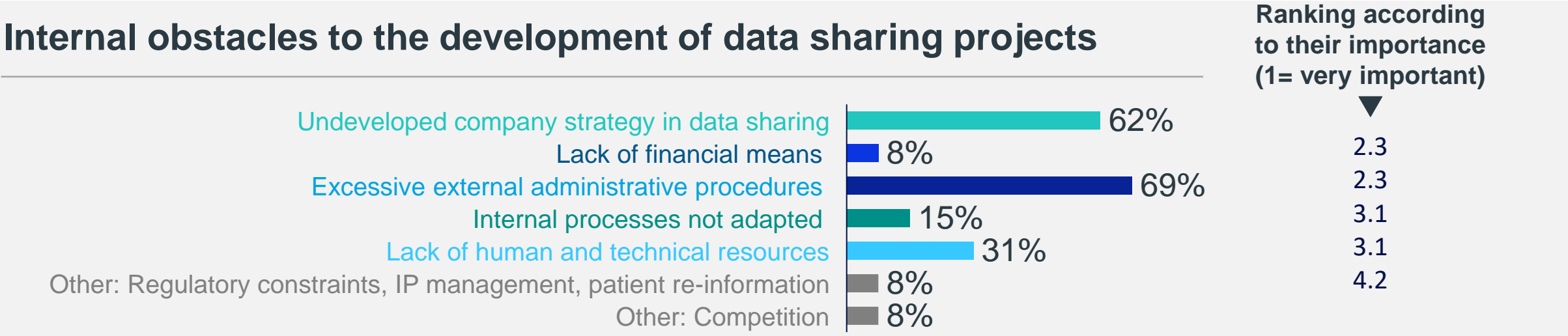
Purpose of data sharing projects*



Question B17. What are the purposes of the data sharing projects that you are aware of?
Base: 13 respondents, 3 of whom “don’t know” or “cannot be assessed”

* Among respondents with data sharing experience (“yes” answer to questions B1 or B1bis)

The main obstacles to data sharing are excessive administrative procedures and the best leverage to promote sharing would be reciprocity of commitments by all private and public stakeholders.



Questions B18. Within your company, what are the internal obstacles to the development of data sharing projects? ; B18bis. Please rank these barriers from most important (1) to least important (5):

Base: 17 respondents

External levers favorable to the development of the data sharing strategy



Question B19. What are the external leverage that would be favorable to the development of your data sharing strategy?

Base: 17 respondents including 1 “don’t know”