Clínica Universidad de Navarra | Biomedical Imaging Laboratory

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INSTITUTE OF DATA SCIENCE AND ARTIFICIAL INTELLIGENCE

Perspectives on Data Sharing and AI Among participants in Renal Clinical Studies

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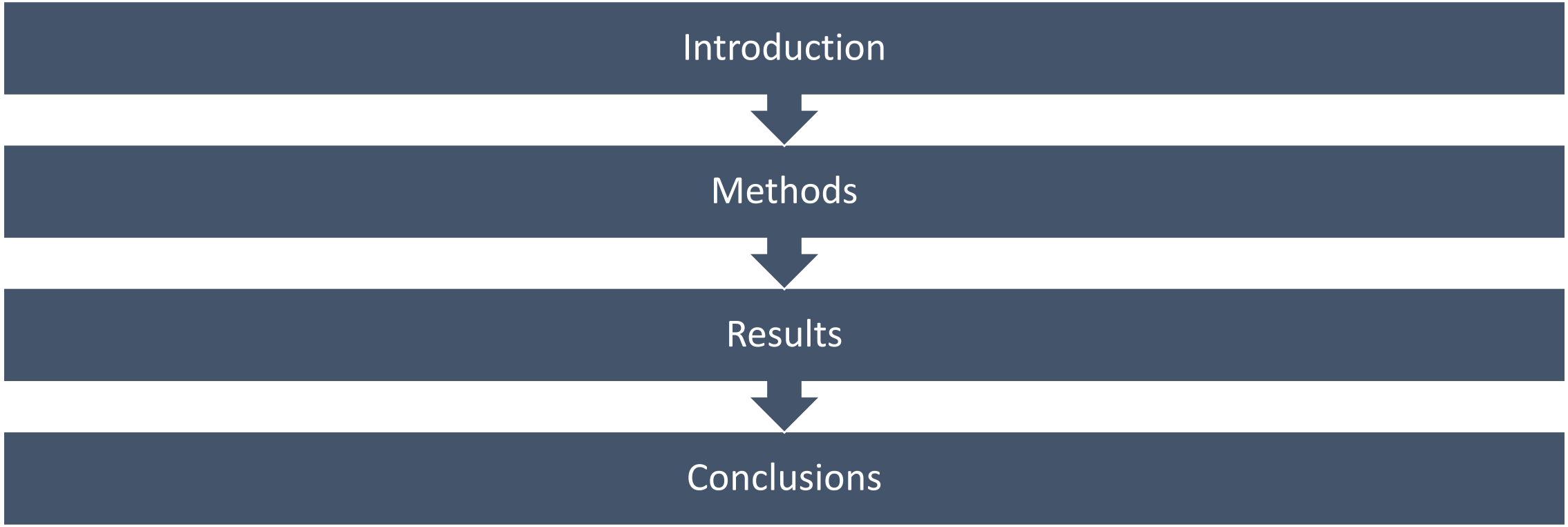
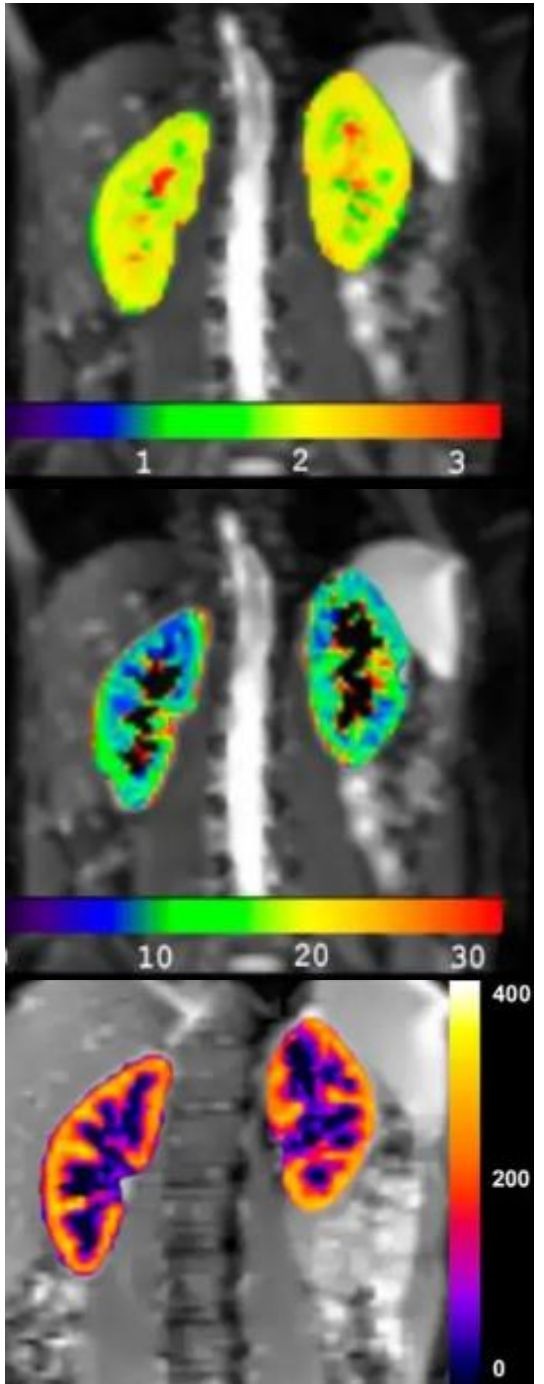


Introduction

Kidney diseases are a growing global health concern:

- It is the 3rd fastest-growing cause of death worldwide
- Massive volumes of data are generated in clinical studies
- Data sharing and the use of artificial intelligence (AI) can advance research in these pathologies



Objetives

To explore the attitudes of European participants in renal clinical studies towards **data sharing** and the use of **AI** through a structured survey and applying analysis methods to facilitate interpretation.

Hypothesis

Participants maintain a positive view of data sharing and AI use

Methods. Survey design

Included **42 questions (114 items)** organized into *Data sharing*, *AI* and *explanatory variables (e.g., d*emographics trust, computer skills) sections.

a **Data sharing question:**

•How much do you think sharing anonymous, individual clinical study data can…

	A great deal	A lot	A moderate amount	A little	Not at all
…help get answers to scientific questions faster using information that others have already gathered?					
… help ensure that research money is spent as wisely as possible?					
…lower the cost of developing new medical products?					
…help patients and groups of patients learn more about health problems that affect them?					
…help scientists check the accuracy of research results announced by other scientists or companies (by re-doing the analyses)?					
…support learning about diseases that only a small number of people have (by combining data from many clinical studies)?					
…discourage scientists and companies from hiding or distorting their clinical study results (by making it possible for others to check their analyses)?					
…help lawyers prove their case in lawsuits claiming that medical products are unsafe?					
…make sure people's participation in clinical studies leads to the most scientific benefit possible?					

b **AI question:**

•To what extent would you support the use of 'artificial intelligence' to…

	Strongly oppose	Tend to oppose	Neither support nor oppose	Tend to support	Strongly support
develop technology that could potentially offer earlier diagnosis and more accurate treatments to patients?					
interpret healthcare imaging as an aid for doctors when reporting these images?					
process clinical data, (such as magnetic resonance images (MRI), blood and urine analysis results, etc.), acquired during a clinical study?					

c **Explanatory question:**

- **What is your age group?**

☐ Under 18

☐ 18-40

☐ 41-60

☐ 61-75

☐ 76 or over

Methods. Survey distribution

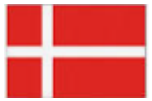
204 surveys were distributed to research participants (patients and healthy subjects) in clinical centers across **5 Countries**:


Spain (44 participants)


Germany (8 participants)

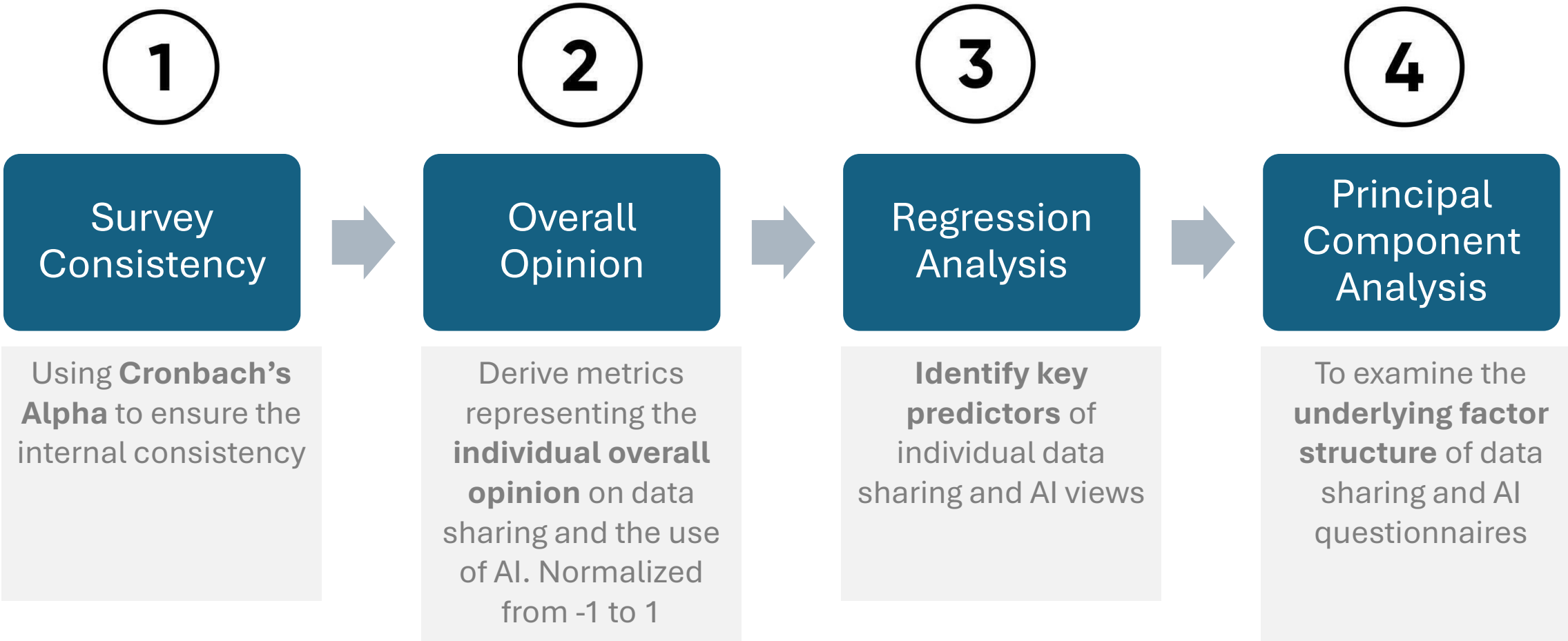

Italy (56 participants)


UK (79 participants)


Denmark (17 participants)

Study period: April 2023 – May 2025

Methods. Statistical Analysis



Results. Participant Profile

Clinical Category

57.4% Patients with the studied disease (64.7% Chronic Kidney Disease)

22.1% Healthy volunteers

4.9% Healthy person at risk

15.7% NA

Motivation

67.2% Altruism

22.5% Health benefit

4.9% Other

5.4% NA

Institutional Trust

Highest trust in **Universities (74.5%)** and **Doctors (79.4%)**

Health status

76.9% rated their health positively (61–100 points on a 0–100 scale)

Results. Internal Consistency

Data Sharing

$\alpha = 0.91$

AI

$\alpha = 0.93$

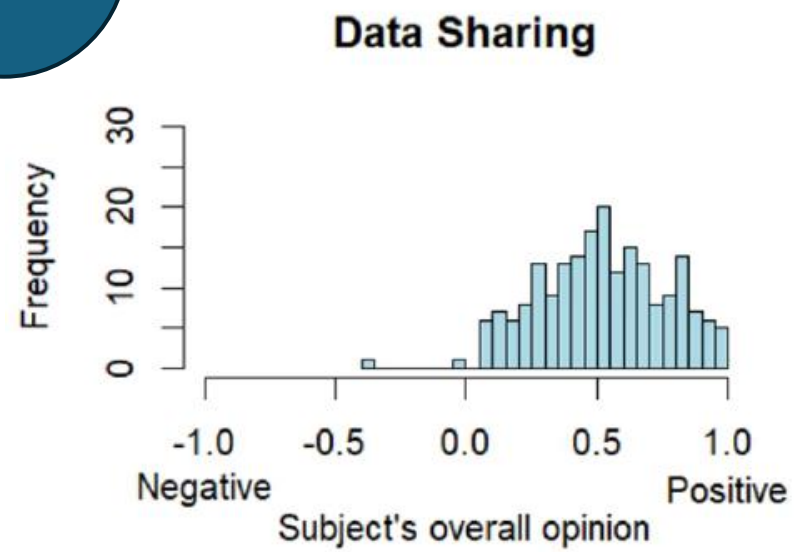
*Values > 0.70 indicate high reliability.

Results. Overall attitude

Data Sharing

0.52

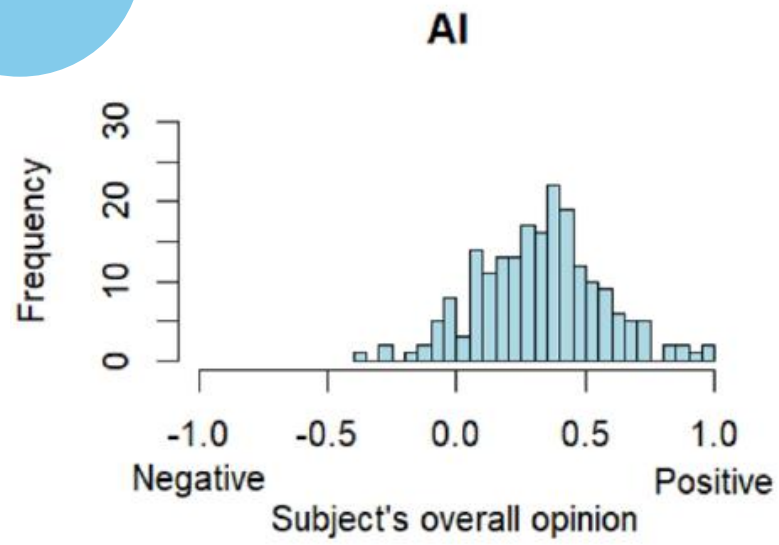
Overall Attitude: Highly positive



AI

0.33

Overall Attitude: Positive



Results. Perceived benefits and concerns

Data Sharing

MOST CONCERNING CONSEQUENCE

8.8% Personal information theft and its impact on family

MOST IMPORTANT BENEFIT

26.5% Accelerating scientific research using existing data

AI

MOST CONCERNING TO PARTICIPANTS

possibility of AI devices

29% Making inadequate medical decisions

28.9% Leading to medical errors

MOST IMPORTANT BENEFIT

52% develop technology that can offer earlier diagnosis and more precise treatment

Results. Regression

Data Sharing

Predictors

Institutional Trust (P< 0.001)
Family income (P<0.0192)

AI

Predictors

Health status(P< 0.013)
Institutional Trust Average (P<0.0008)
AI Technical Knowledge (P<0.049)

Results. PCA

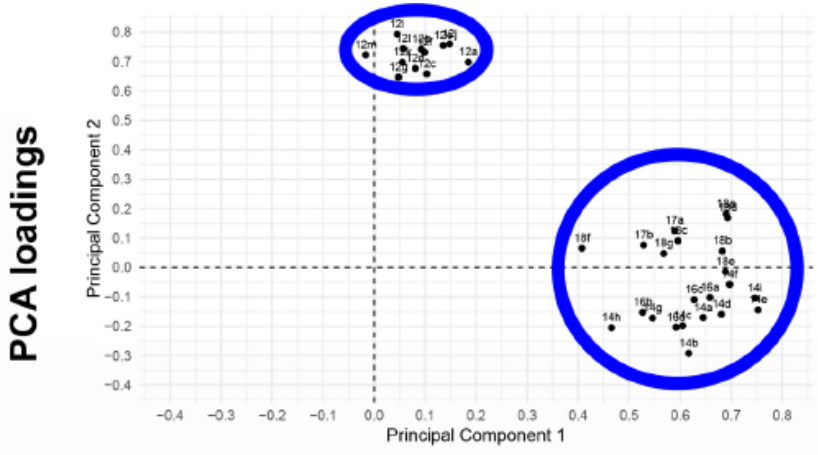
Data Sharing

2 Components

- Explained 45.9% of the variance

2 Dimensions:

- Scientific benefits
- Privacy concerns



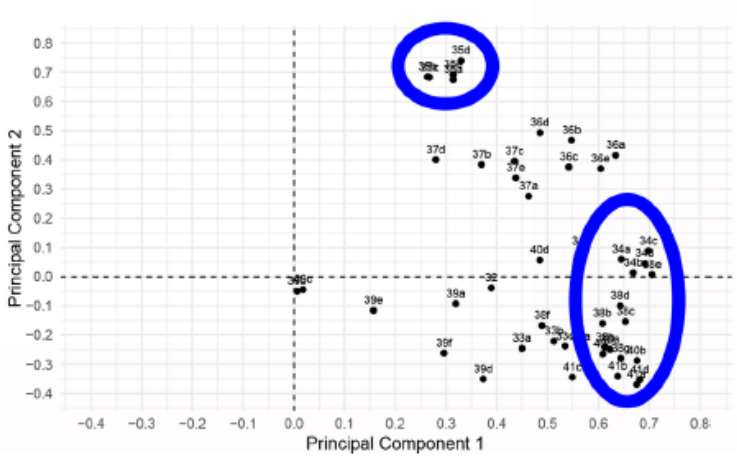
AI

2 Components

- Explained 31.4% of the variance

Multidimensional:

- Perceived benefits of AI
- Concerns with AI
- Additional items (e.g. efficiency)



Conclusions

- **Positive attitudes** on data sharing and AI in renal research.
- **Key factors** include institutional trust, family income, health status, and technical knowledge of AI.
- **Future implications** comprise the importance of improving institutional trust and AI education to foster engagement

Takeaway

Promoting AI education and building institutional trust is important to enhance engagement

Acknowledgements

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