

# BUILDING PRIVACY AWARENESS INTO (CLINICAL) WORKFLOWS

S. Irem BESIK

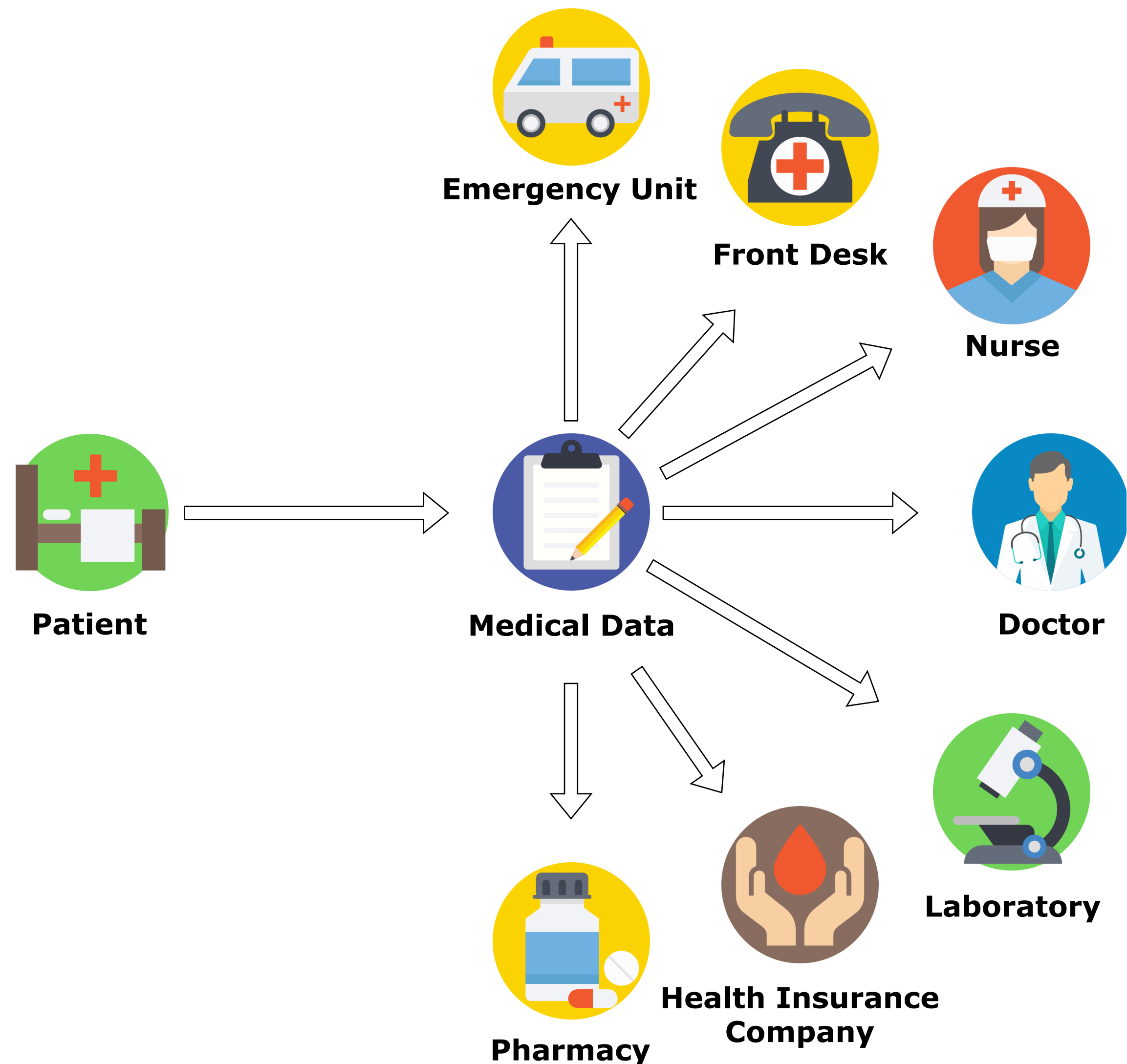
*besiksal @ informatik.hu-berlin.de*

**Supervisor:** Prof. Johann-Christoph Freytag, Ph.D.





# MOTIVATION: **PRIVACY** IN CLINICAL DOMAIN



- ◆ patients' personal medical data
- ◆ different healthcare providers

# MOTIVATING EXAMPLE: NEWBORN SCREENING

2011-14

**Dieses Feld mit den Daten der Mutter ausfüllen:**

Krankenkasse bzw. Kostenträger		
Name, Vorname des Versicherten		
geb. am		
Kassen-Nr.	Versicherten-Nr.	Status
Betriebsstätten-Nr.	Arzt-Nr.	Datum

**Leerkarten-Grund:** ☐ verstorben  
(bei Einsendung ohne Material ankreuzen) ☐ Verlegung

**Daten des Kindes:** ☐ Entl. < 36 h

**Screening-ID**

**Abrechnung:** ☐ Privat Privatversicherte bitte hier unterschreiben

Nachname				Vorname							
Geburtsdatum				Datum/Uhrzeit der Abnahme:				Geburtsgewicht		Geburtenbuch-Nr.	
Tag	Monat	Jahr	Std.	Min.	Tag	Monat	Jahr	Std.	Min.	g.	
Geschlecht		Gestationswoche		<input type="checkbox"/> Mehrling		<input type="checkbox"/> Wiederholungsuntersuchung		<b>Hörscreening:</b>			
<input type="checkbox"/> M	<input type="checkbox"/> W		+								
				Ifd. Nummer				<input type="checkbox"/> nicht durchgeführt			
								TEOAE: <input type="checkbox"/> un auffällig		<input type="checkbox"/> auffällig	
								AABR: <input type="checkbox"/> bds.		<input type="checkbox"/> R <input type="checkbox"/> L	

**Besonderes:** ☐ Transfusion am: . . .

☐ weiteres: . . .

**Bitte vollständig durchtränken**

SN B00362101

SN B00362101

Barcode

Four dashed circles for marking



# MOTIVATING EXAMPLE: NEWBORN SCREENING



Desk



Pediatrician



Lab

**demographic data**

**sensitive blood data**

**medical data**

Dieses Feld mit den **Daten der Mutter** ausfüllen:

Krankenkasse bzw. Kostenträger

Name, Vorname des Versicherten

geb. am

Kassen-Nr. Versicherten-Nr. Status

Betriebsstätten-Nr. Arzt-Nr. Datum

Labor-Nr.

Telefonnummer der **Mutter** mit Vorwahl

Einsender

Telefonnummer des **Einsenders** mit Vorwahl

**Besonderes:**

☐ Transfusion am: . . .

☐ weiteres: . . .

**Leerkarten-Grund:** ☐ verstorben ☐ Verlegung ☐ Entl. < 36 h

**Daten des Kindes:** Nachname Vorname

Geburtsdatum Datum/Uhrzeit der Abnahme: Geburtsgewicht Geburtenbuch-Nr.

Tag Monat Jahr Std. Min. Tag Monat Jahr Std. Min. g.

Geschlecht Gestationswoche ☐ Mehrling ☐ Wiederholungsuntersuchung

☐ M ☐ W ☐ Ifd. Nummer

**Screening-ID**

**Hörscreening:** ☐ nicht durchgeführt ☐ un auffällig ☐ auffällig

TEOAE: bds. ☐ R ☐ L

AABR: bds. ☐ R ☐ L

**Abrechnung:** ☐ Privat Privatversicherte bitte hier unterschreiben

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Bitte vollständig durchtränken



# PRIVACY BY DESIGN VIA CLINICAL WORKFLOWS



Clinical Workflow includes  
a series of tasks for clinical services

also how tasks are  
performed, in what order, and by  
whom

~~Reactive~~  
Proactive

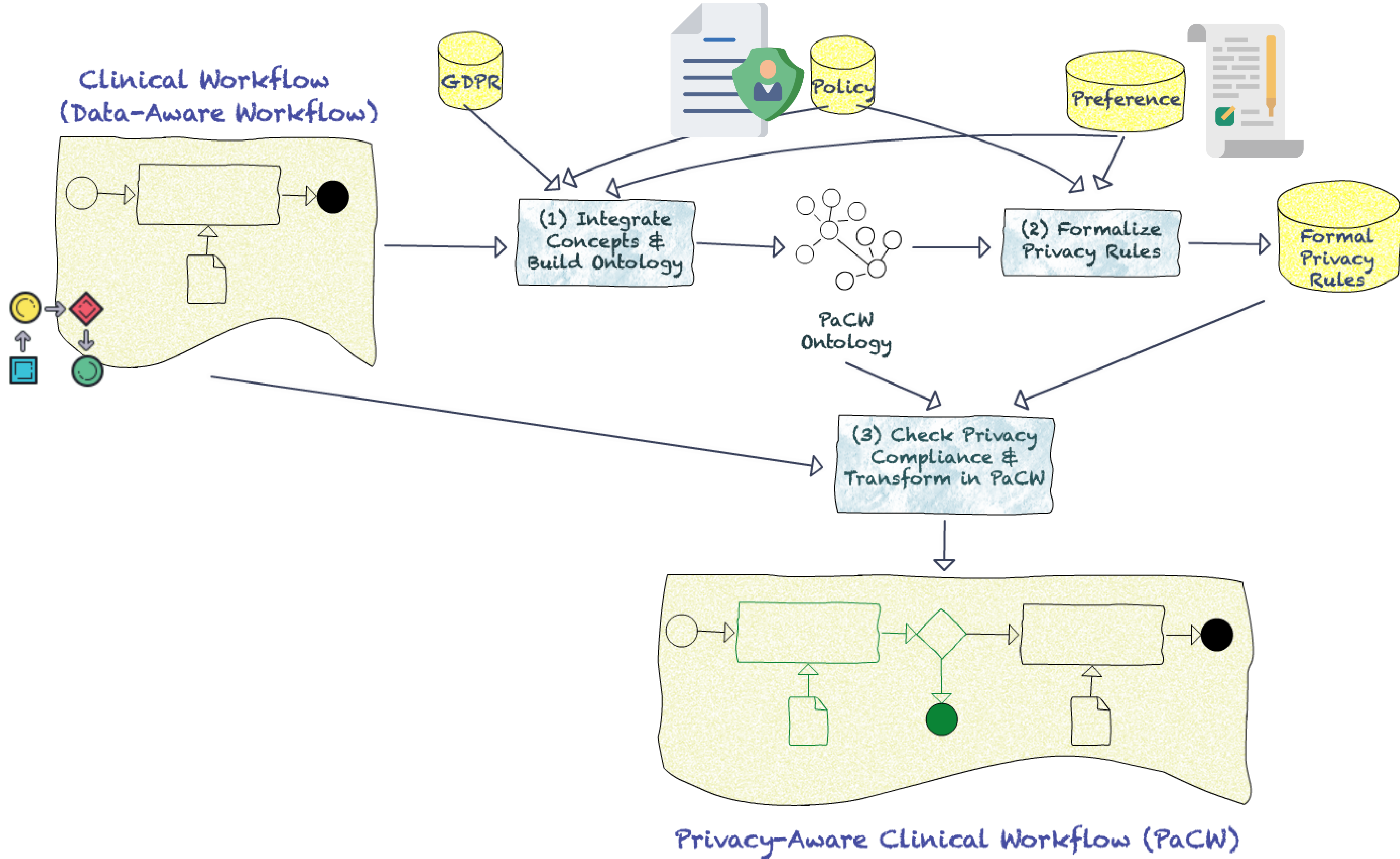




# RESEARCH PROBLEM

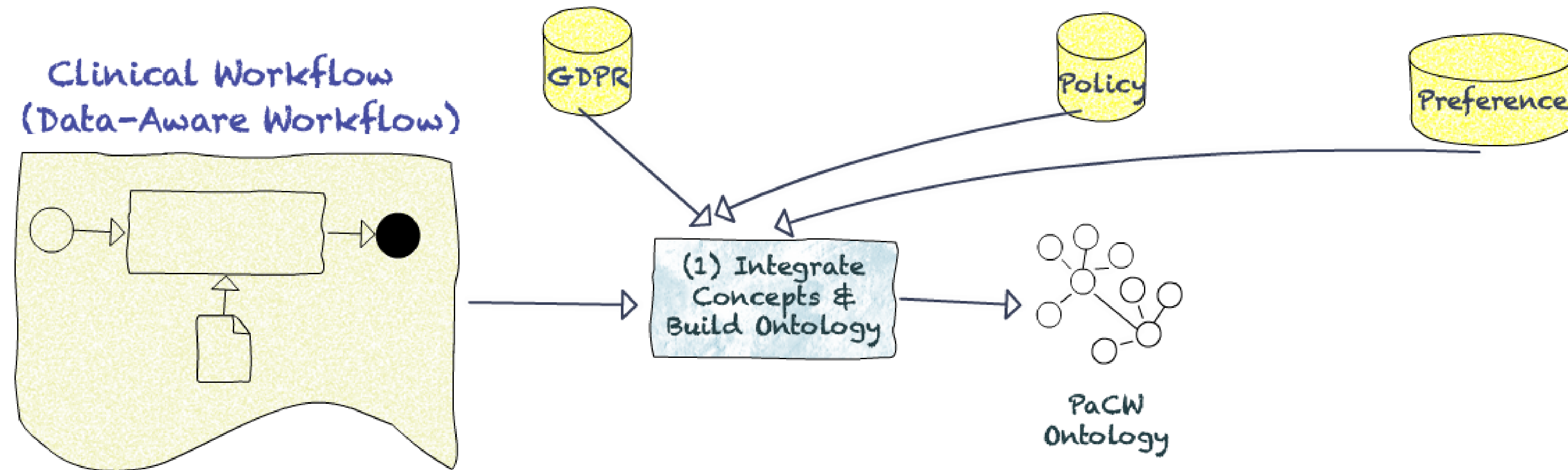
- Transforming non-privacy-aware clinical WFs into **privacy-aware** ones
- **Privacy-aware WF** is compliant with:
  1. **privacy principles** based on the EU General Data Protection Regulation (GDPR)
  2. **privacy policies** by healthcare providers
  3. **privacy preferences** of data subjects (patients)







# (1) INTEGRATE CONCEPTS



semantically represent privacy concepts and BPMN-based clinical workflows



**Privacy-aware Clinical Workflow (PaCW) Ontology**



# PRIVACY PRINCIPLES BASED ON GDPR



© marketoonist.com

## GDPR, Europe's Data Privacy Law, Is So Long and Boring It Could 'Sedate a Buffalo'

By Sissi Cao • 06/04/18 2:02pm



A BBC announcer-narrated GDPR will cure your insomnia in minutes. JEWEL SAMAD/AFP/Getty Images



# PRIVACY PRINCIPLES BASED ON GDPR



- Purpose Specification: Personal data be collected for **specified purposes**
- Consent Check: Data processing is lawful with **an explicit consent of a data subject**. (*e.g. optional procedures like newborn screening*)
- Limited Retention Period: Personal data be kept **for no longer than is necessary**
- Data Minimization: Personal data be **limited to what is necessary**

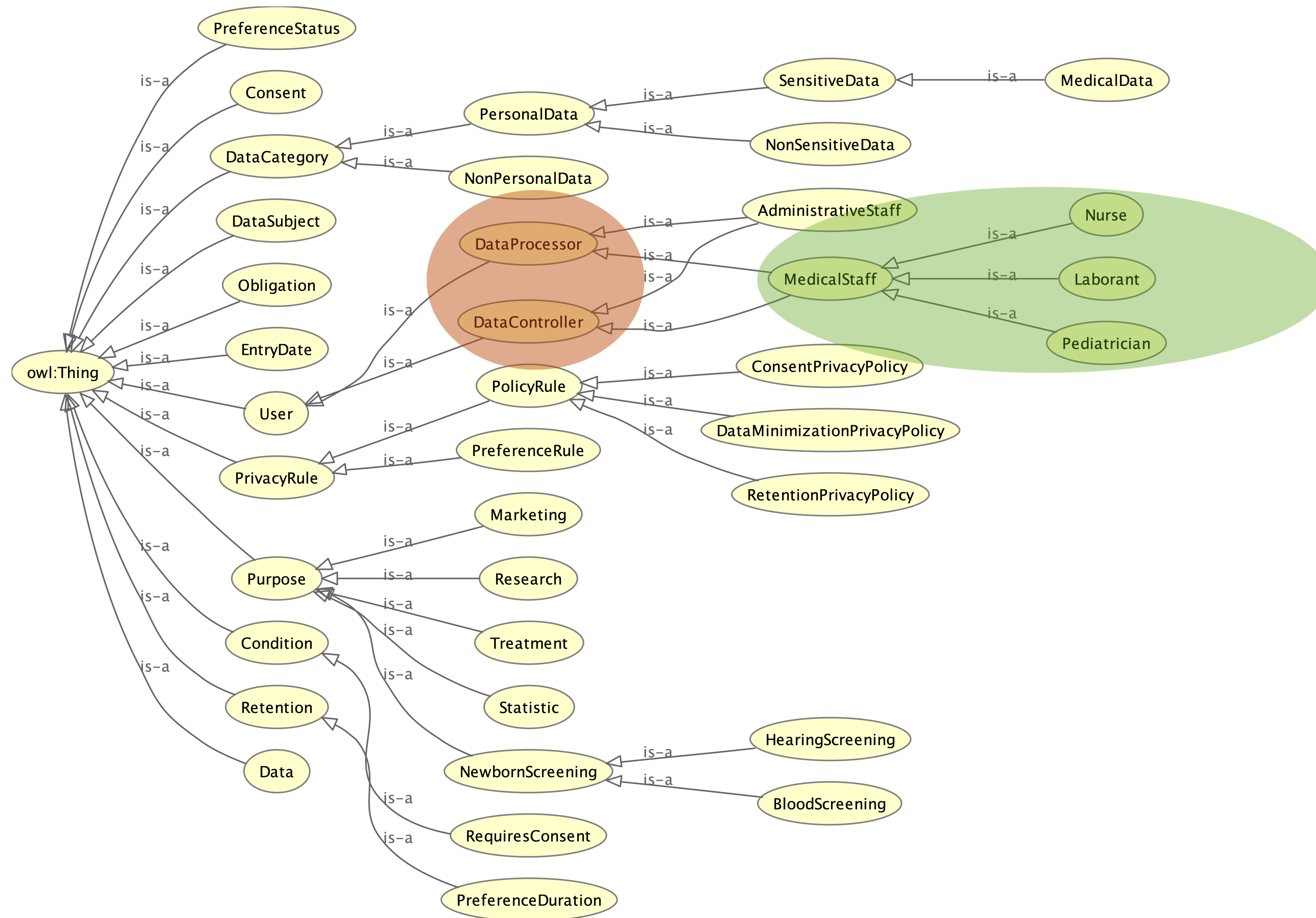


# Privacy-aware Clinical Workflow (PaCW) Ontology



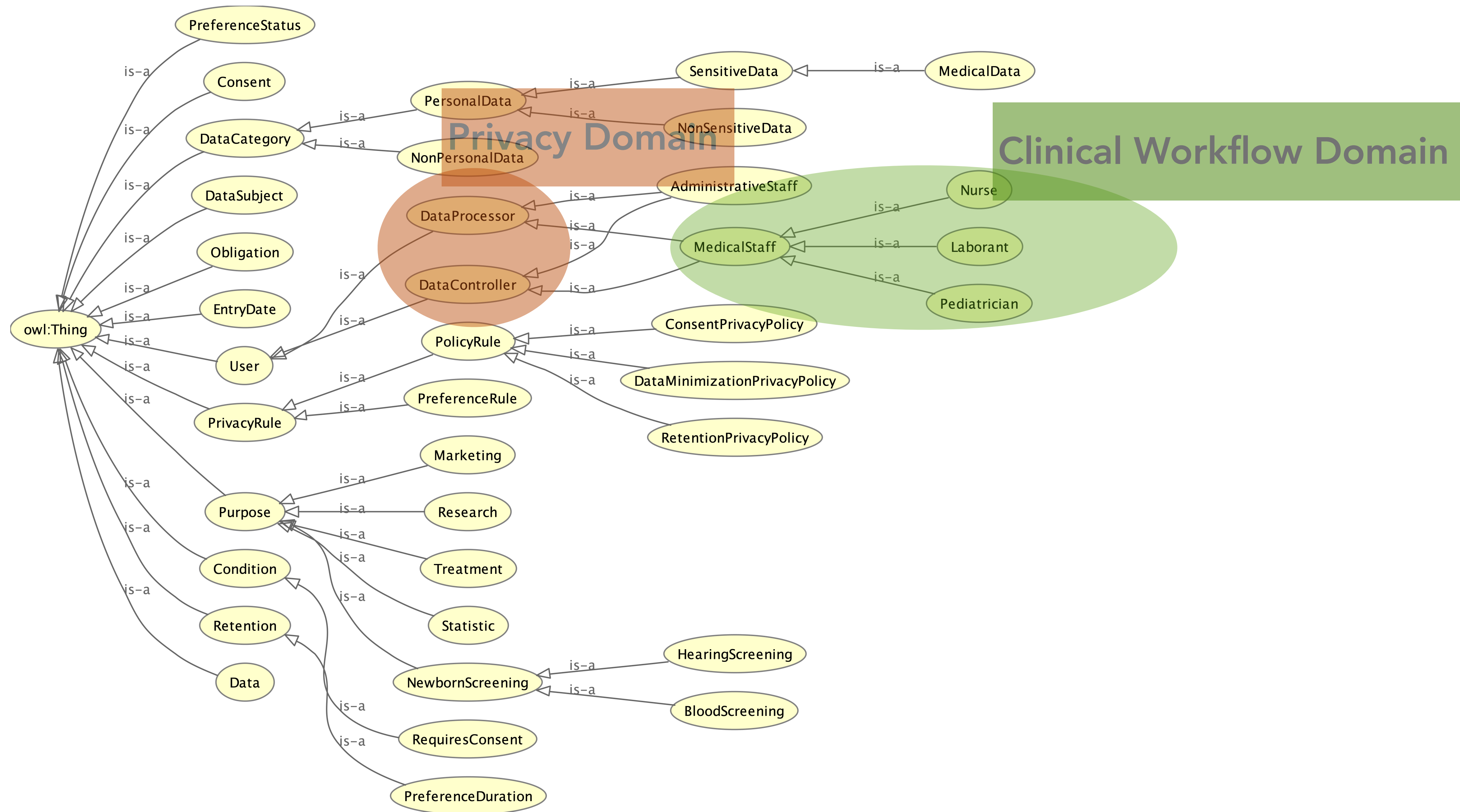


# Privacy-aware Clinical Workflow (PaCW) Ontology





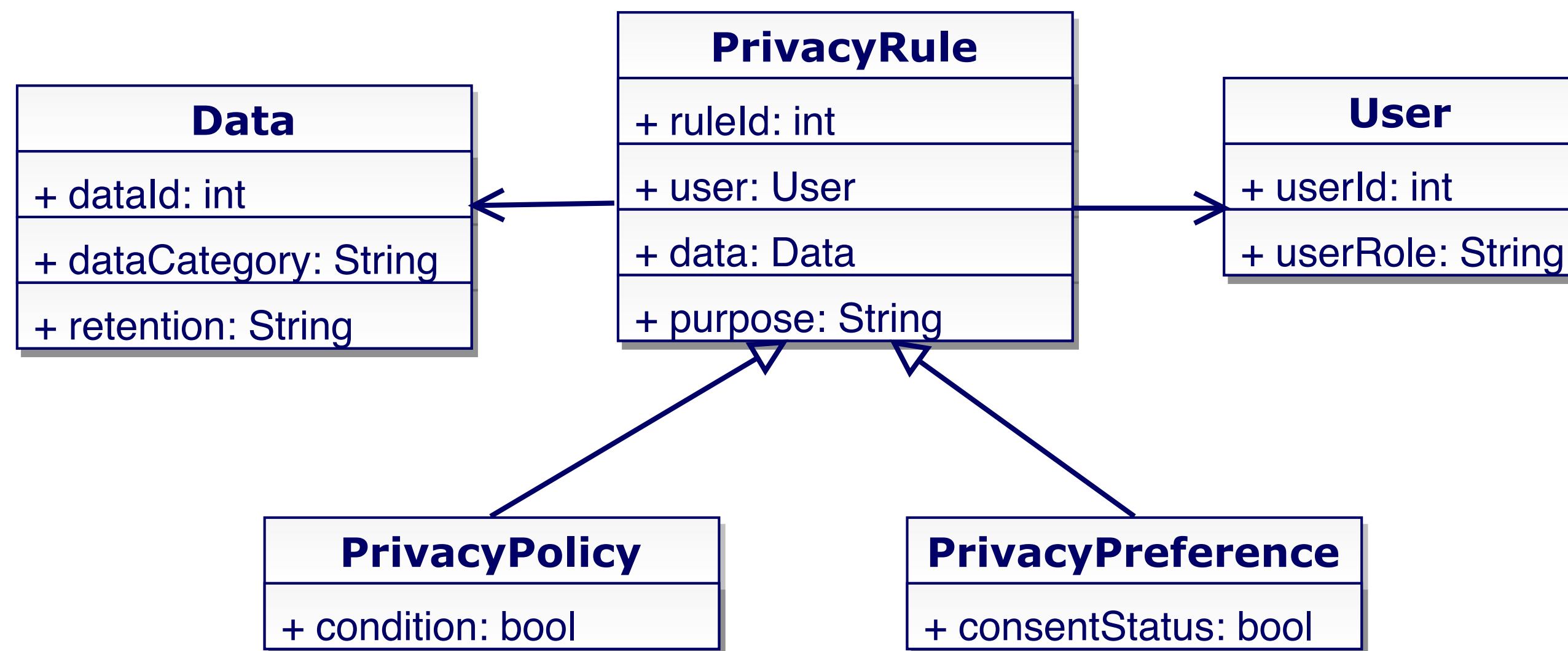
# Privacy-aware Clinical Workflow (PaCW) Ontology





# PACW ONTOLOGY

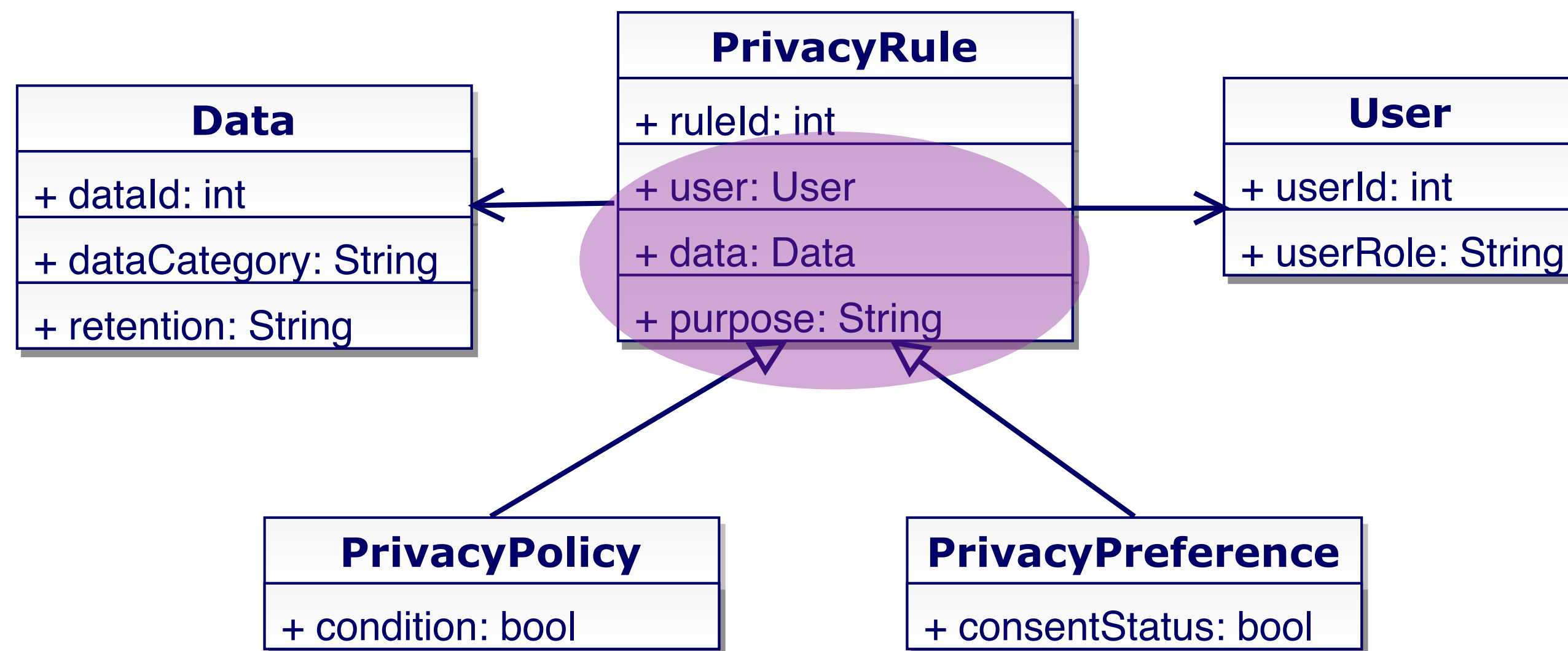
## Privacy Domain



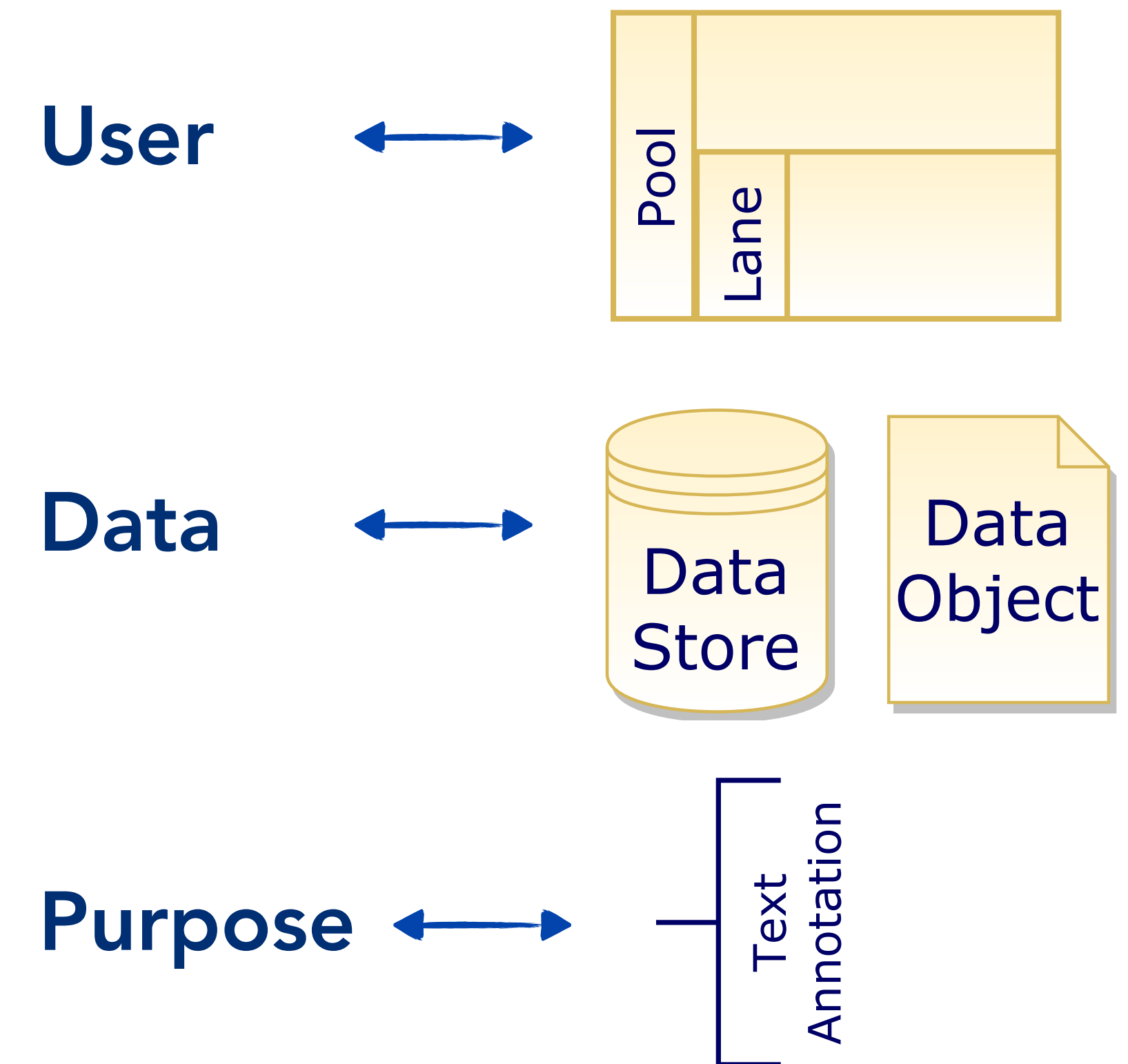


# PACW ONTOLOGY

## Privacy Domain

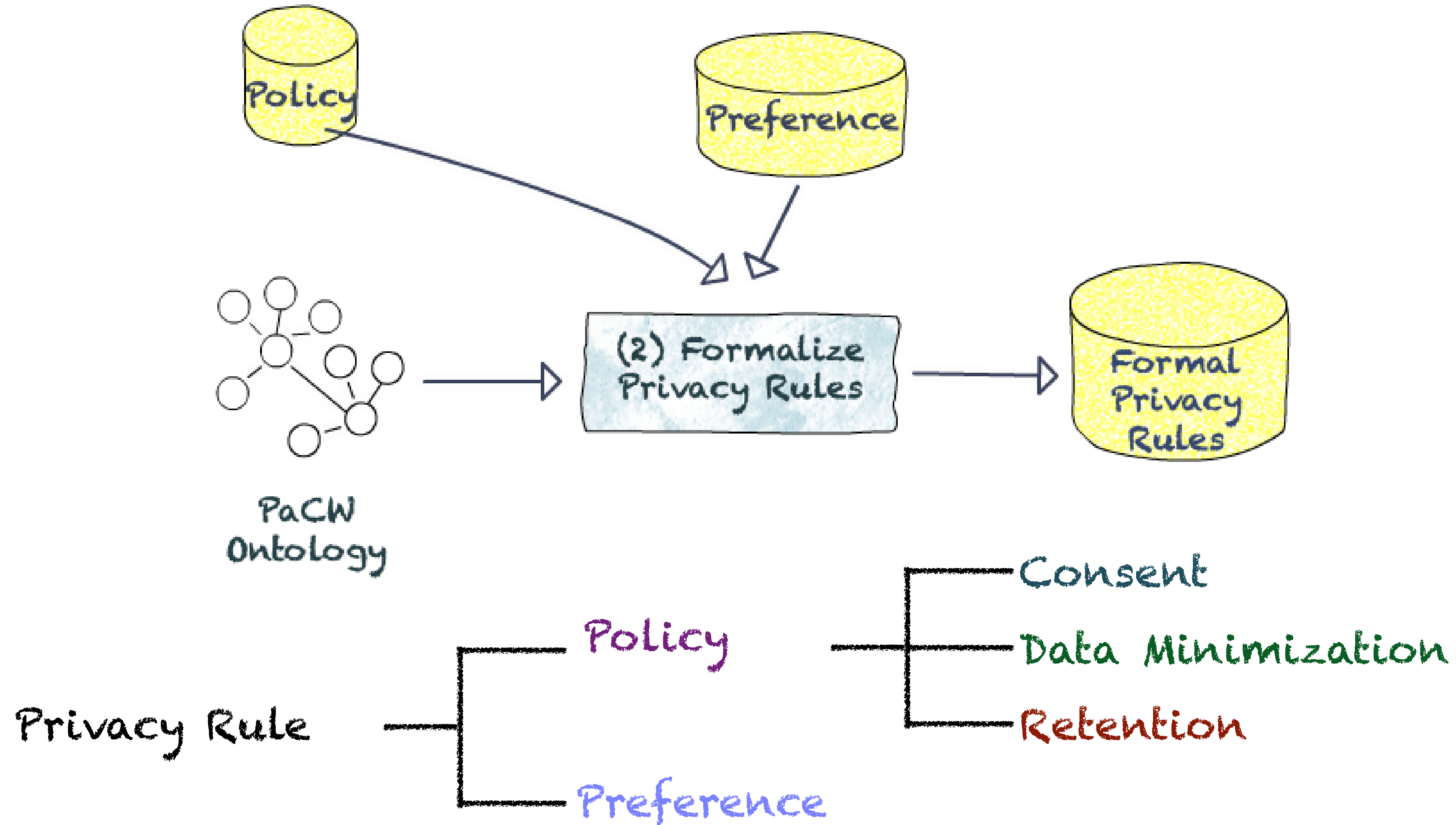


## Mapping





## (2) FORMALIZE PRIVACY RULES





# PRIVACY POLICY



**WASLW00**  
The Internet Saver

**Episode VIII**

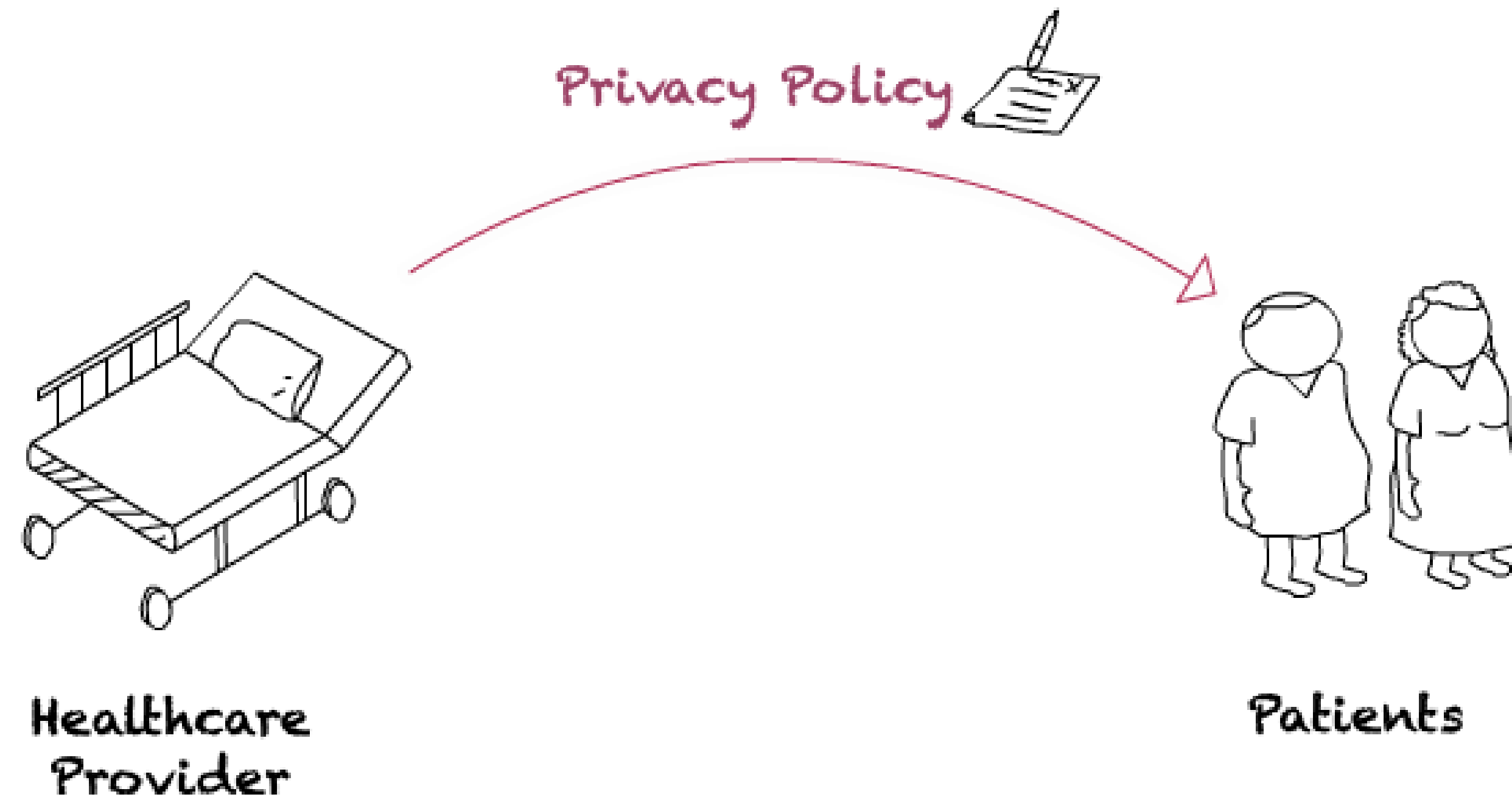
## **THE LAST JEDI**

***We have updated and extended  
our Privacy Policy as part of our  
ongoing commitment to be  
transparent about how we use  
your data and keep it safe.***

# PRIVACY POLICY



- what data is collected
- who can use it for what purposes
- the modality of data processing, whether it is obligatory or voluntary
- how long it is retained





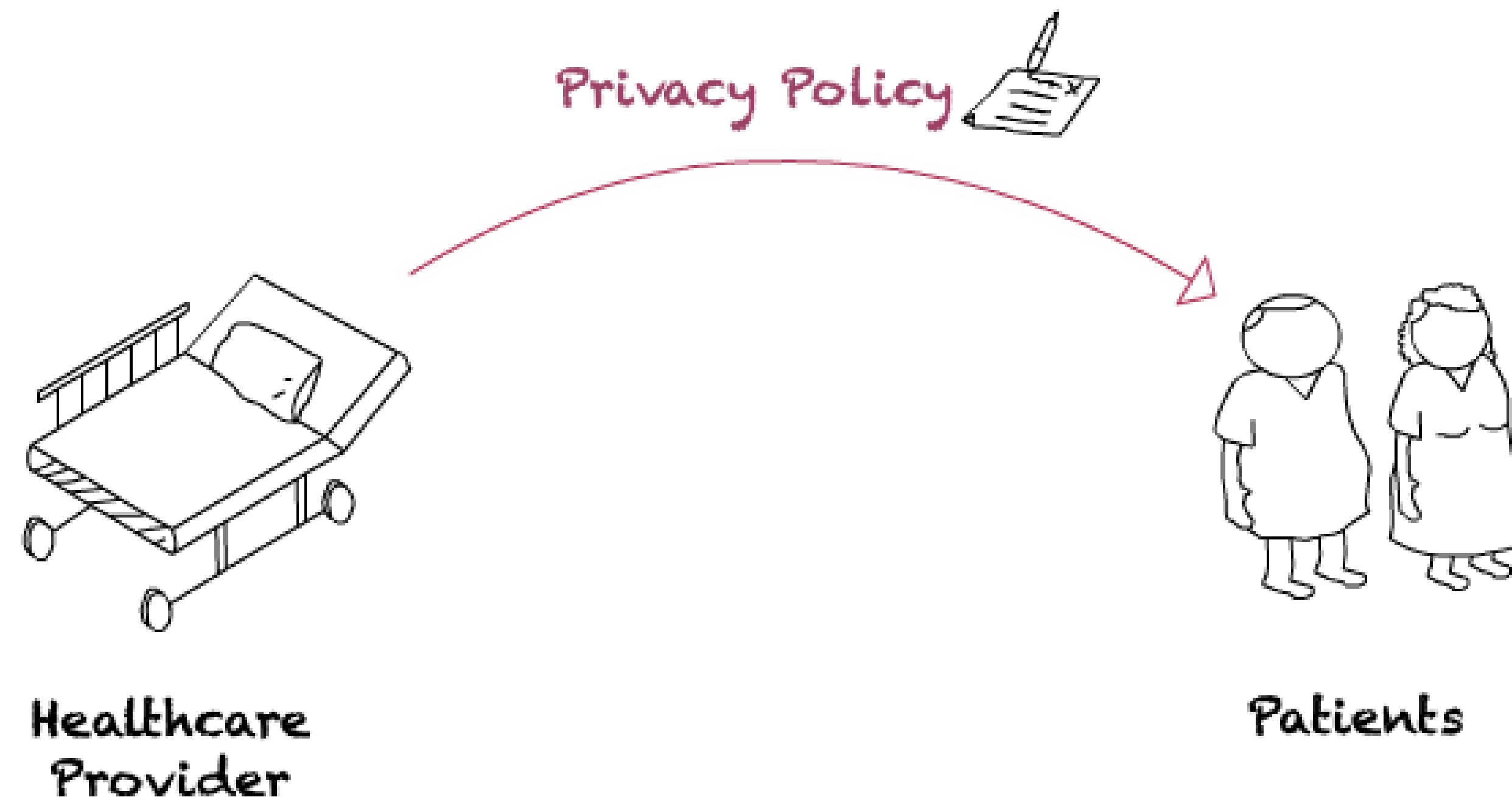
# PRIVACY POLICY



- what data is collected
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- the modality of data processing, whether it is obligatory or voluntary
- how long it is retained — Retention

Data Minimization

Consent



## Definition 1 [Consent Privacy Policy]

A consent privacy policy PC consists of rules represented as 2-tuple

$pc = (\text{purpose}, \text{requiresConsent})$ , where:

- *purpose* is the reason for which data is accessed;
- $\text{requiresConsent} \in \{\text{true}, \text{false}\}$

### Example:

P1: An explicit consent is required for newborn hearing screening.

↓ *formal representation ?*



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*formal representation ?*

*(newborn-hearing-screening, true)*



## Definition 2 [Data Minimization Privacy Policy]

A data minimization privacy policy PD consists of rules represented as 4-tuple

$pd = (user, purpose, data, condition)$ , where:

- *user* is the set of individuals who access the personal data;
- *data* is a set of data objects;
- *condition* indicates additional conditions.

### Example:

P2: A pediatrician can access the result of the lab examination only if the result is abnormal for blood screening.

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↓ formal representation ?

*(pediatrician, blood-screening, examination-result, examination-result.isAbnormal)*

### Definition 3 [Retention Privacy Policy]

A retention privacy policy PR consists of rules represented as 4-tuple

$r = (\text{user}, \text{purpose}, \text{data}, \text{retention})$ , where:

- **retention** is the period of time the data is stored.

### Example:

P3: A hospital can save results for the purpose of hearing screening with a retention limit by 3 years.



formal representation ?



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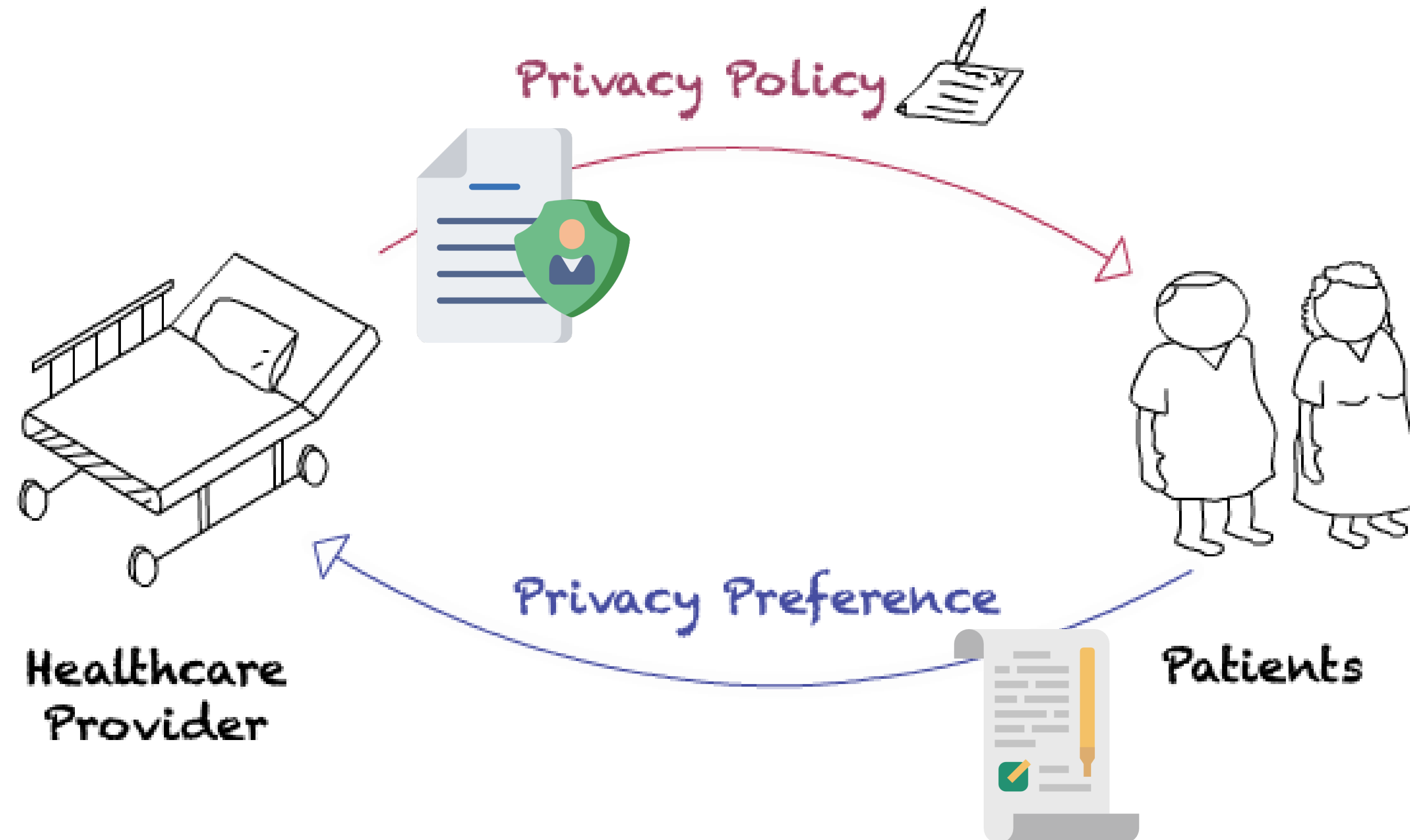


formal representation ?

$(\text{hospital}, \text{hearing-screening}, \text{result}, 3 \text{ years})$



**Privacy Preference:** expresses a data subject's (patients) preferences on sharing / processing their personal data



## Definition 4 [Privacy Preference]

A privacy preference R consists of rules represented as 6-tuple

$r = (\text{dataSubject}, \text{user}, \text{purpose}, \text{data}, \text{duration}, \text{entryDate})$ , where:

- *dataSubject* is the individual whom personal data is about;
- *duration* is the duration of preference;
- *entryDate* is the entry date of preference.

### Example:

R1: Alice gives consent that only pediatrician Bob can perform hearing screening for 6 months on June 19, 2019.



formal representation ?



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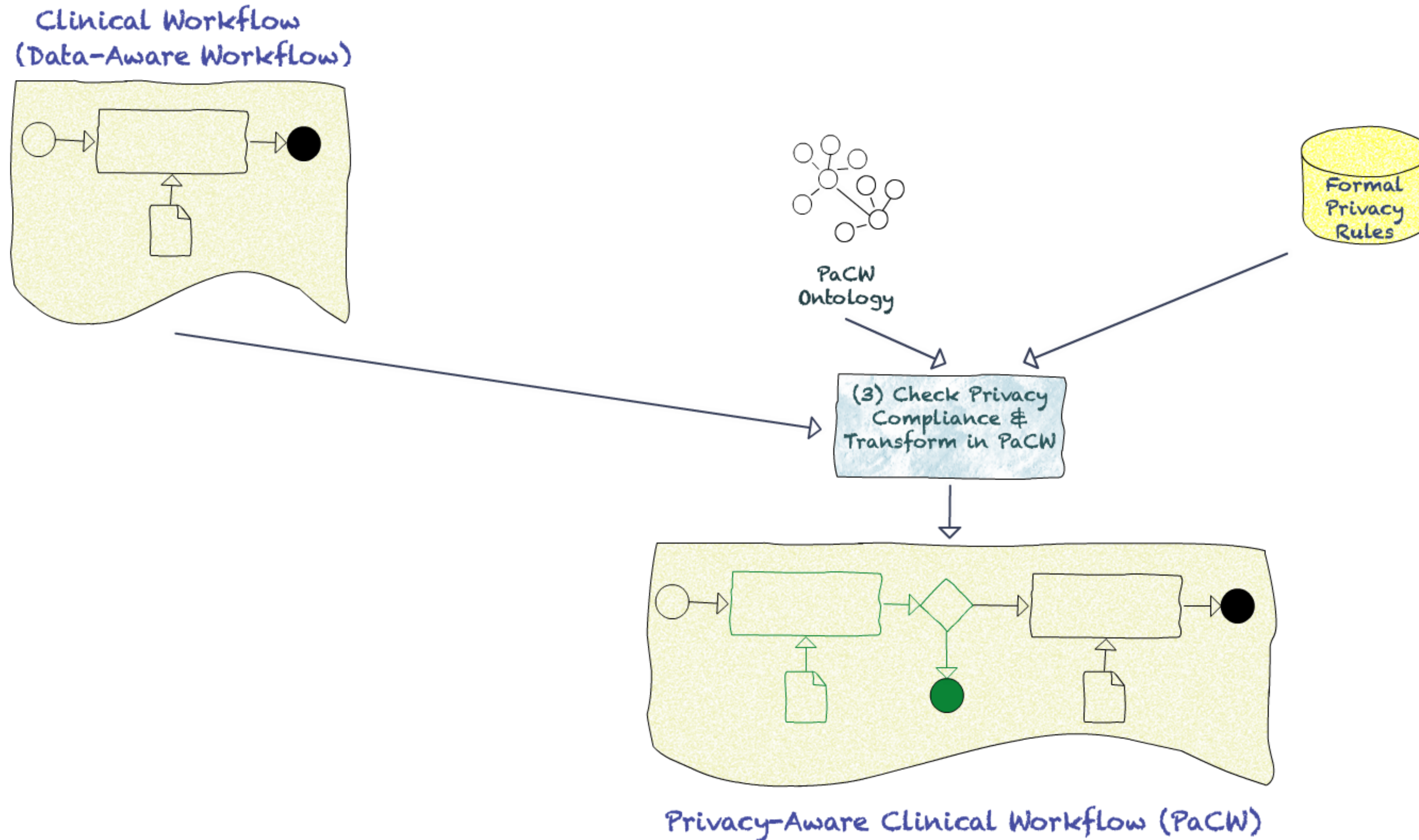


formal representation ?

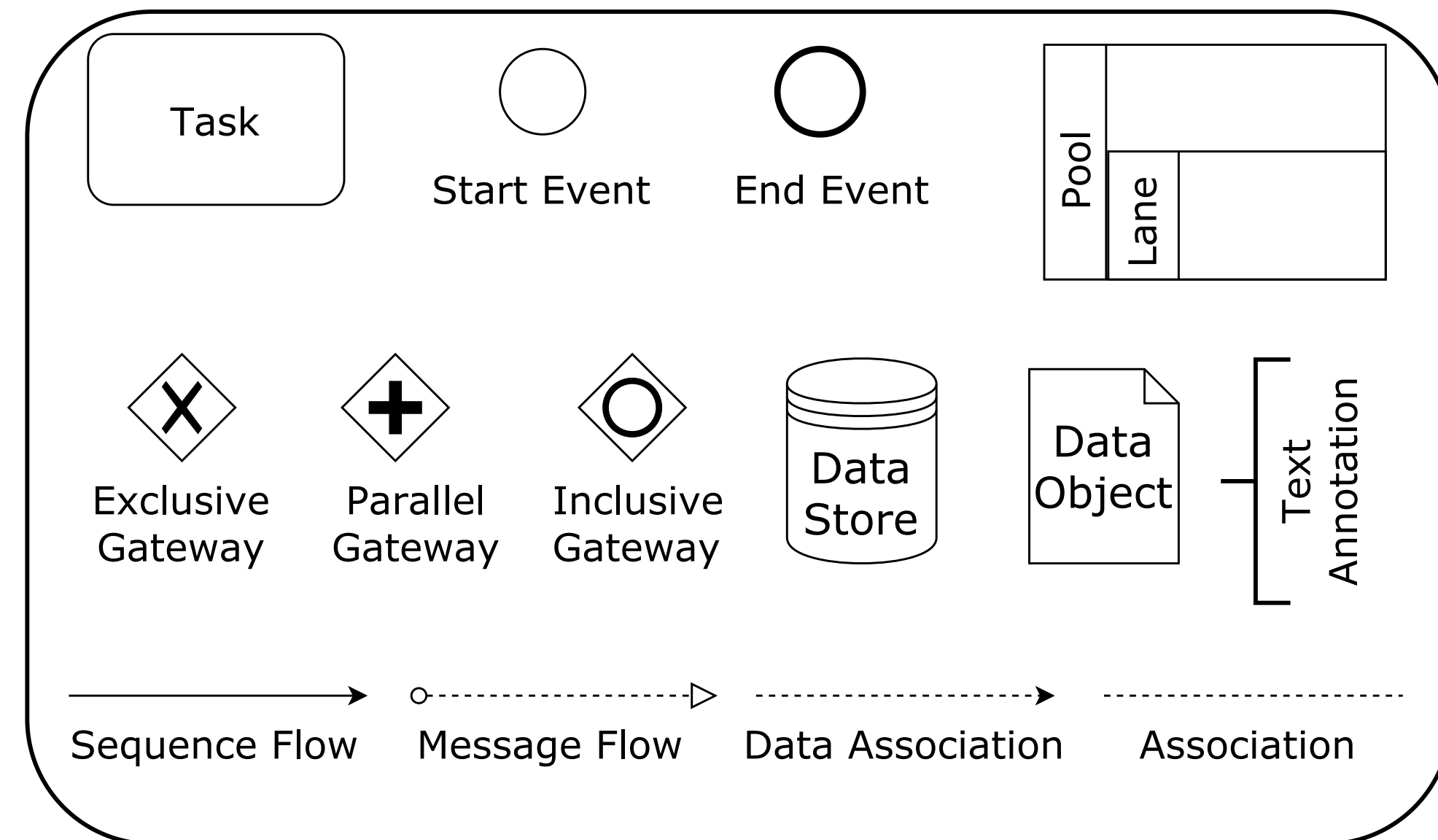
*(Alice, only Bob, hearing-screening, any, 6months, 2019-06-19)*



# (3) CHECK PRIVACY COMPLIANCE & TRANSFORM INTO PRIVACY-AWARE CLINICAL WORKFLOW (PACW)

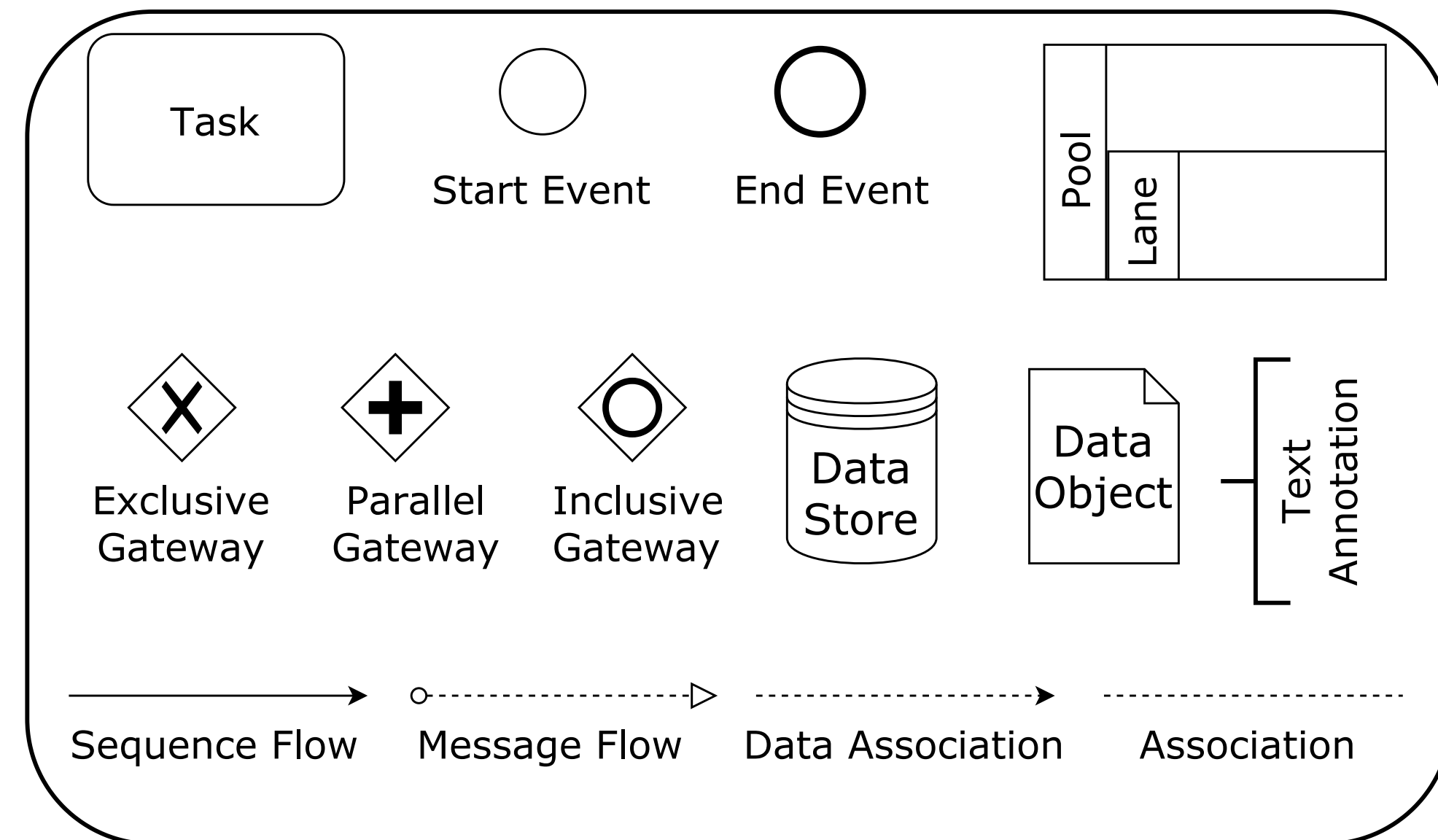
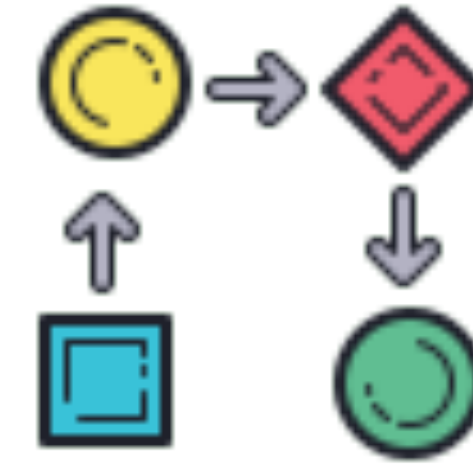


# Clinical Workflow

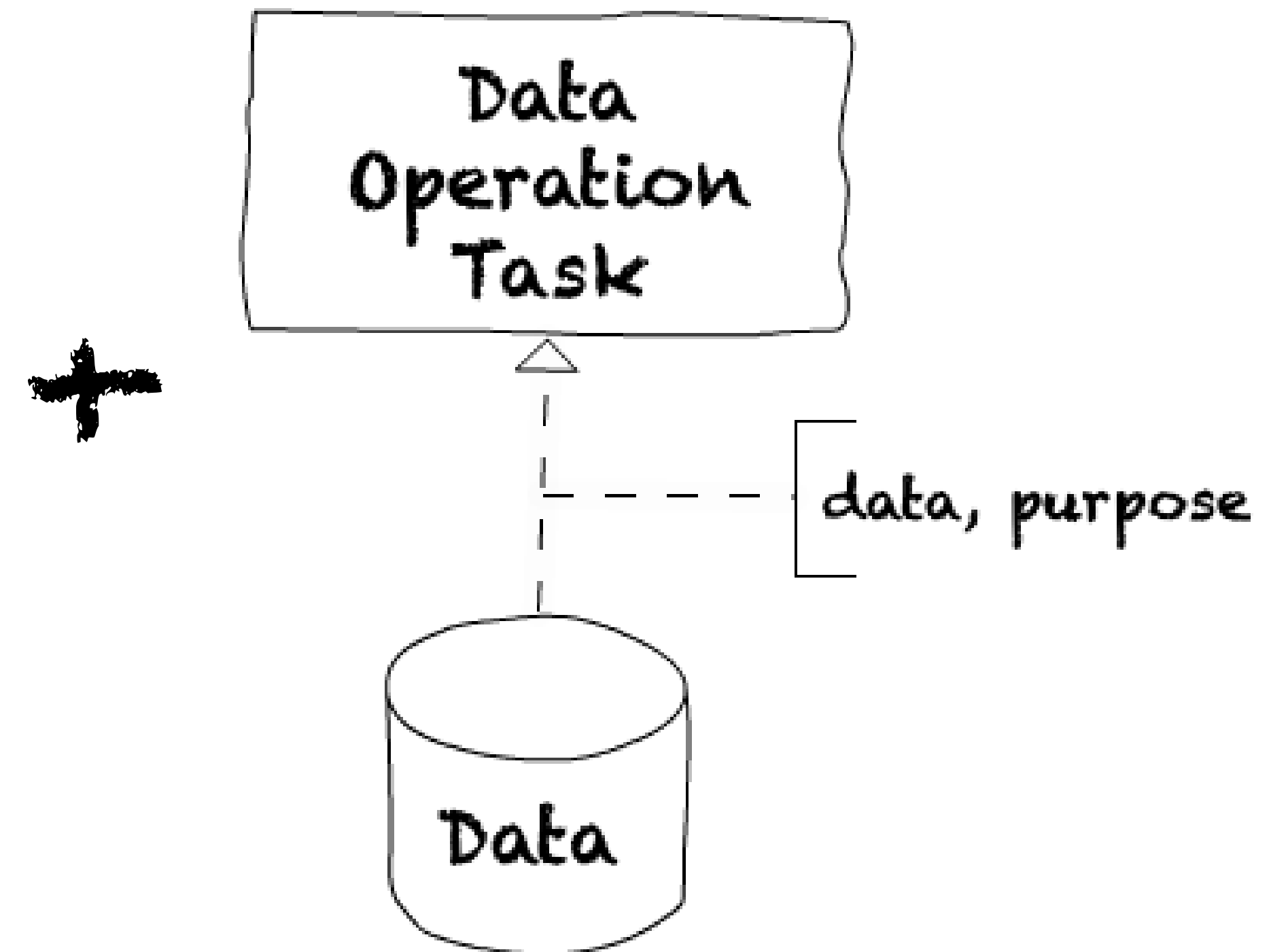


## BPMN Core Elements

# Clinical Workflow => Data Aware Workflow

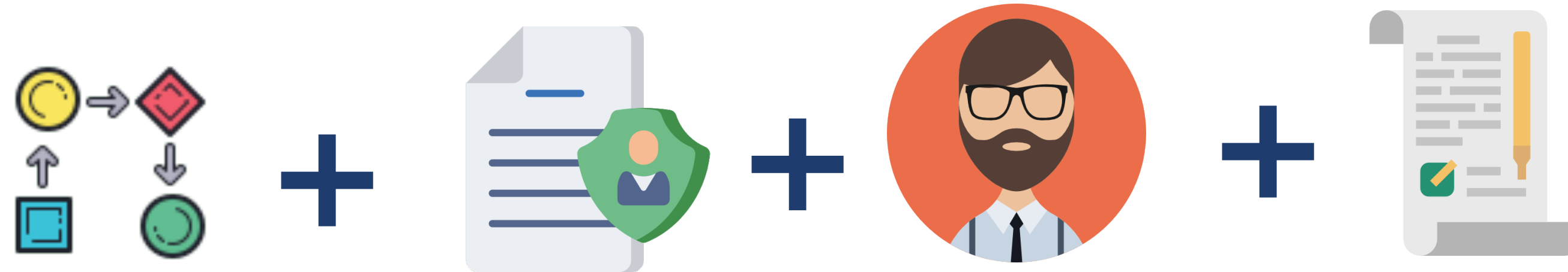


BPMN Core Elements





## Case



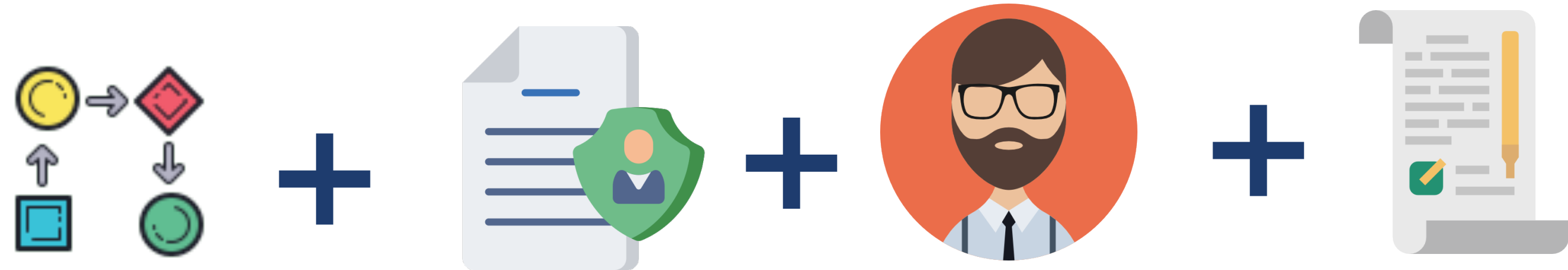
Data-Aware WF

Policy

Data Subject

Preference

## Case



Data-Aware WF

Policy

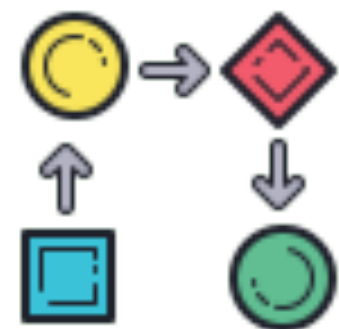
Data Subject

Preference

## Privacy-Aware Case



## Privacy-Aware Case



compliant with Purpose Specification Principle

Data-Aware WF



compliant with  
Consent Check  
Principle

Data-Aware WF

Policy

Data Subject

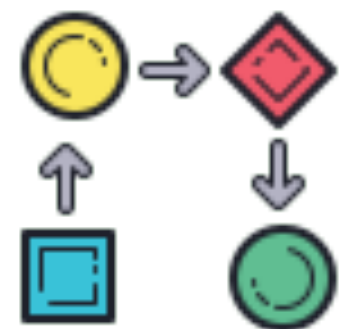
Preference

compliant with Data Minimization Principle

compliant with Limited Retention Principle



## Privacy-Aware Case



compliant with Purpose Specification Principle

### Data-Aware WF



compliant with  
Consent Check  
Principle

Data-Aware WF

Policy

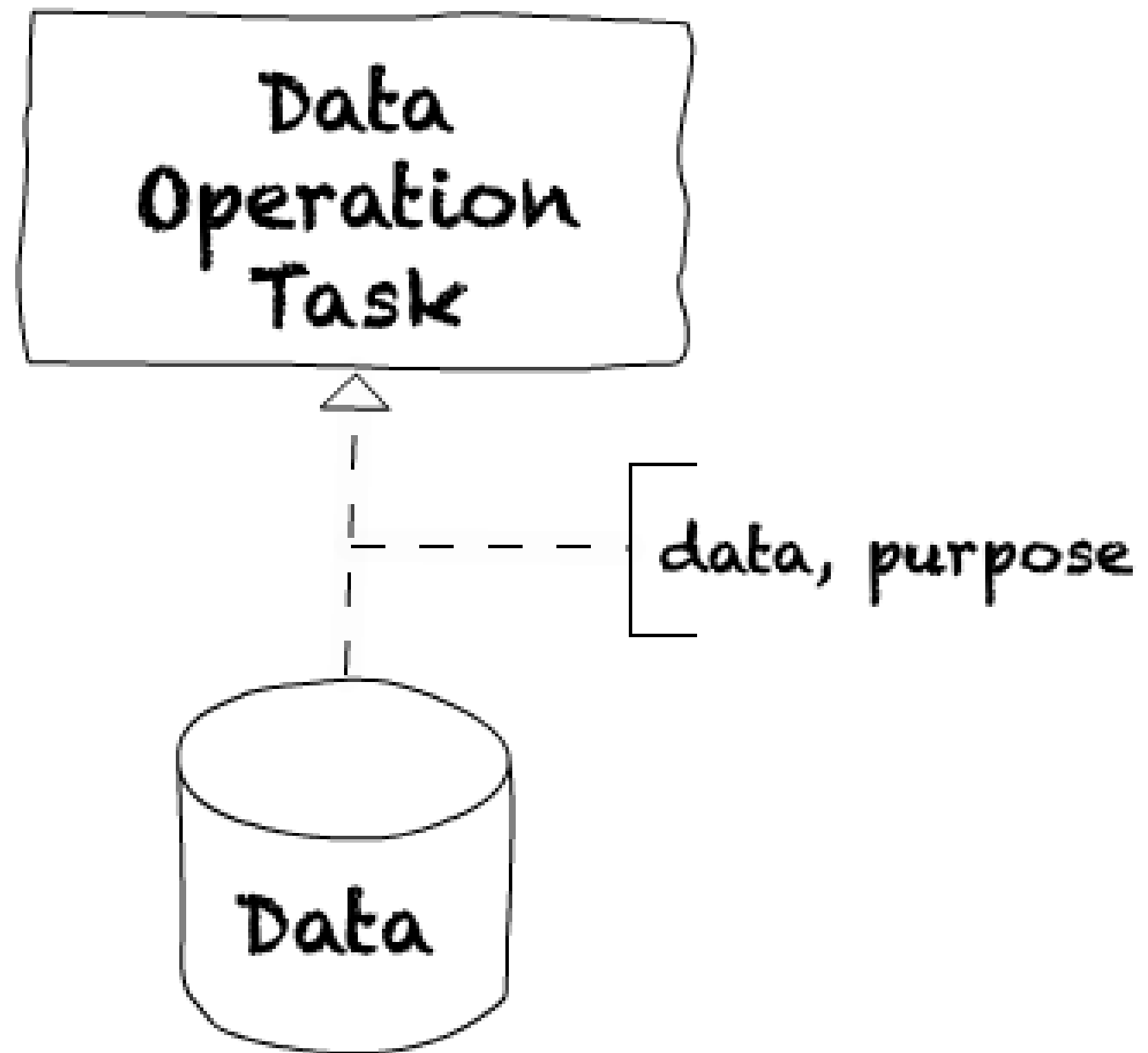
Data Subject

Preference

compliant with Data Minimization Principle

compliant with Limited Retention Principle

# PURPOSE SPECIFICATION COMPLIANCE CHECK



$F \rightarrow$  a set of data associations

$D \rightarrow$  a set of data objects

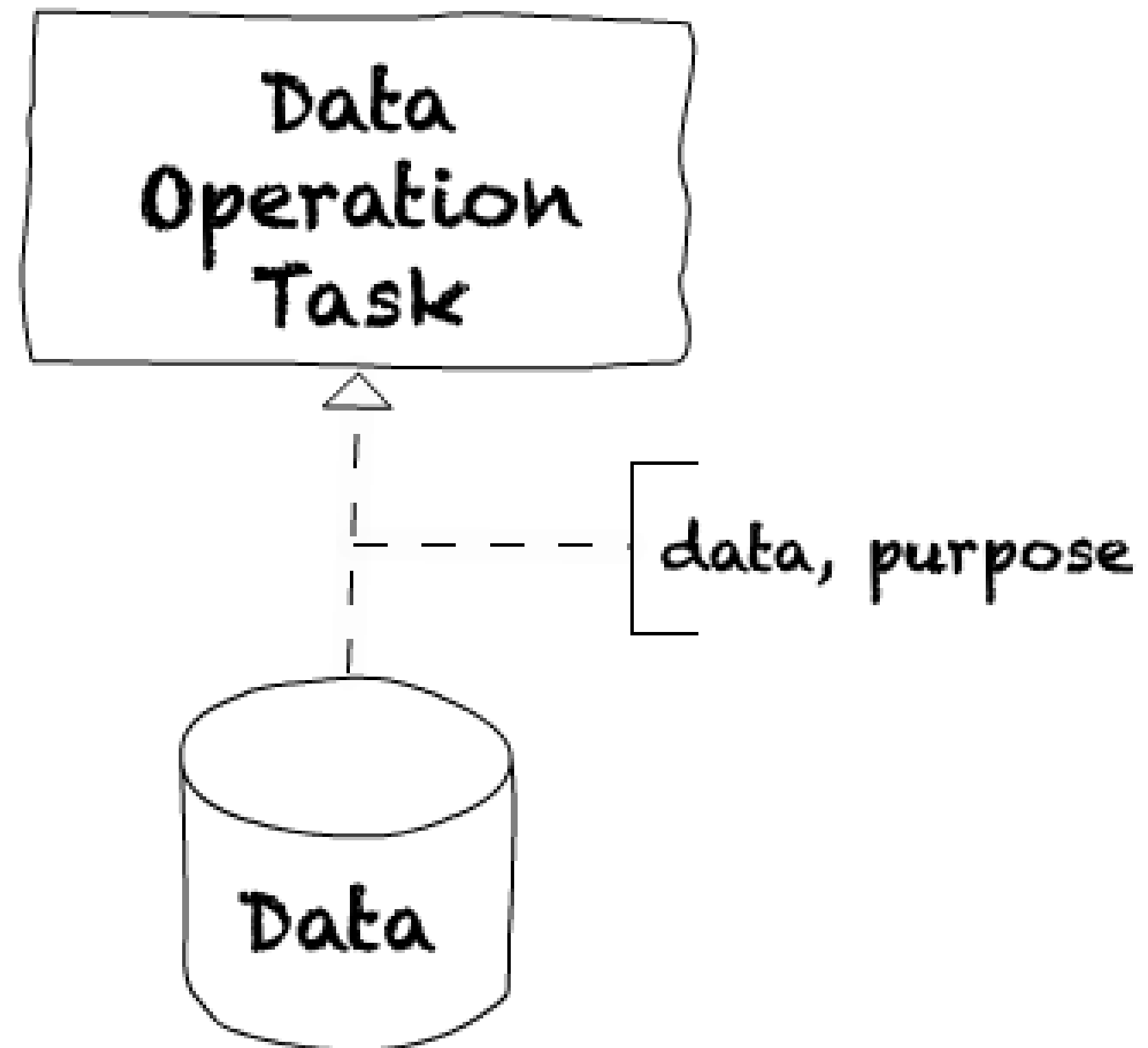
$p \rightarrow$  a purpose

$\lambda: F \rightarrow (D, p)$

$\lambda_1(F) = D, \lambda_2(F) = p$

$\forall f \in F, \lambda_2(f) \neq \emptyset$

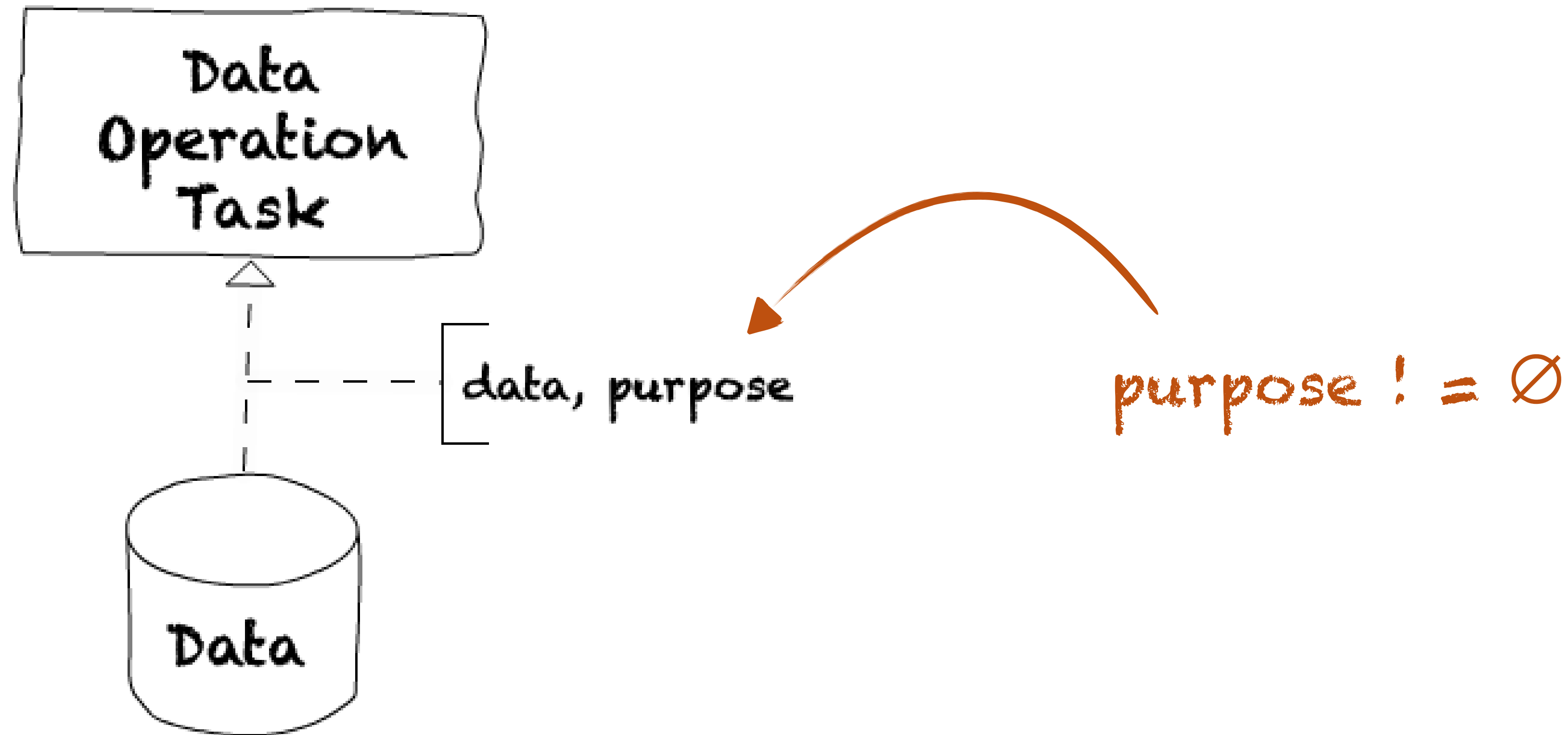
# PURPOSE SPECIFICATION COMPLIANCE CHECK



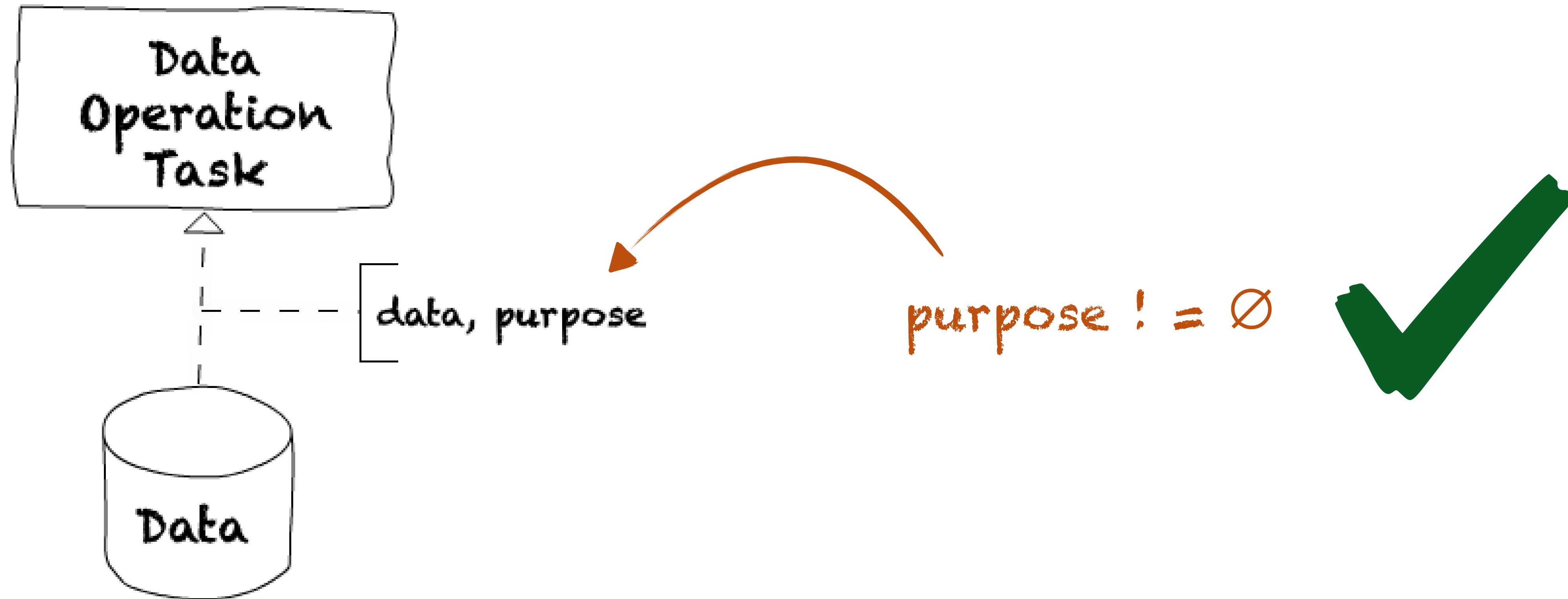
$F$  - set of data operations  
 $D$  - set of data objects  
 $p$  - purpose  
 $\lambda: F \rightarrow D$   
 $\lambda_1 (F) = p$   
 $\lambda_2 (F)$



# PURPOSE SPECIFICATION COMPLIANCE CHECK

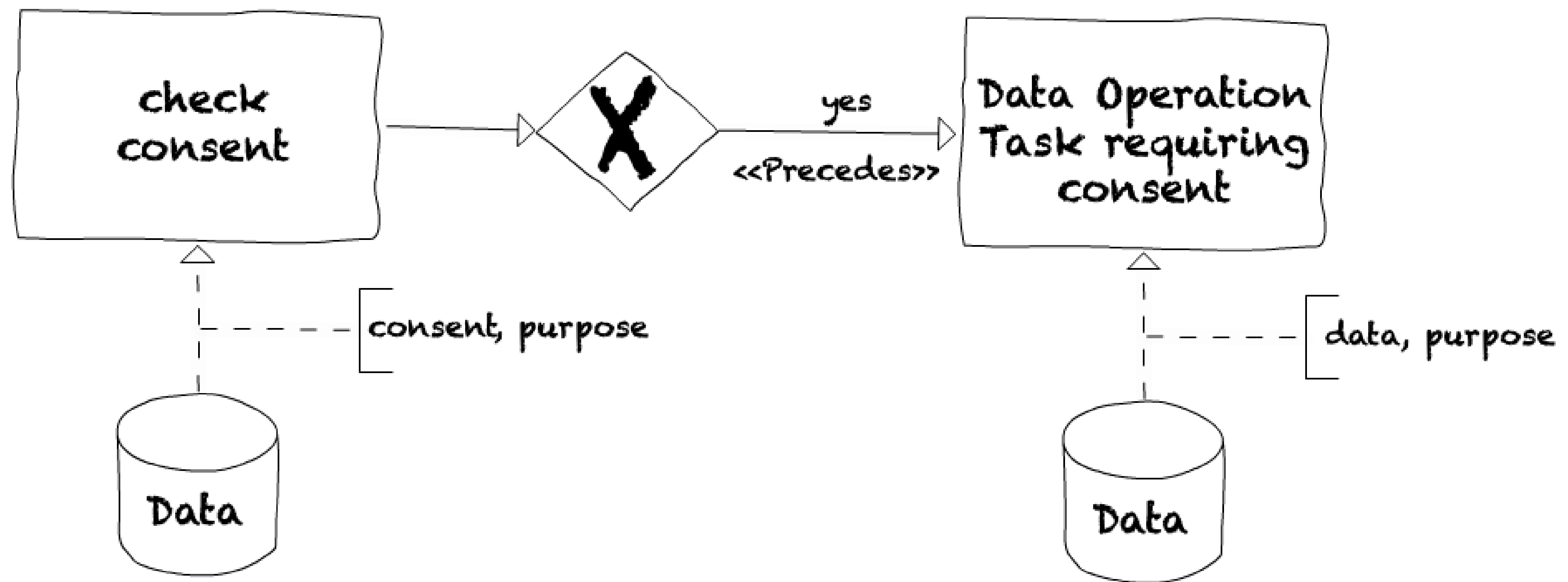


# PURPOSE SPECIFICATION COMPLIANCE CHECK



# COMPLIANCE WITH CONSENT CHECK (1)

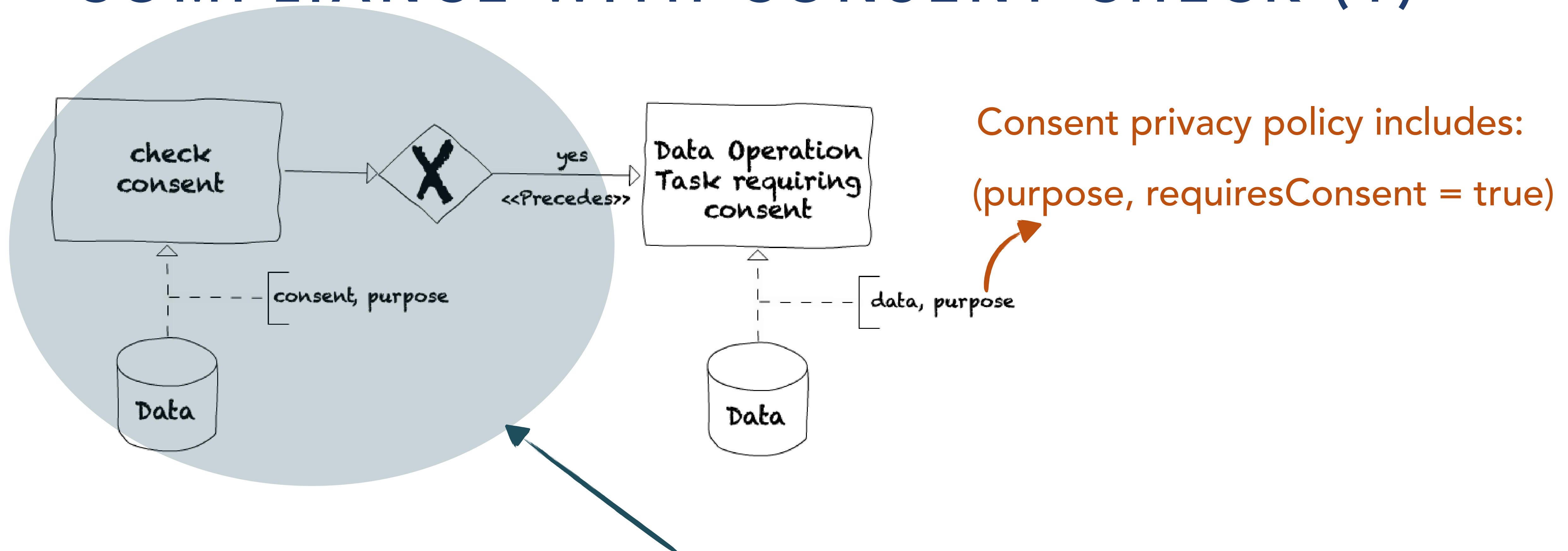
During design time: Consent Check Pattern



A **<<Precedes>>** B means that B can occur only if A occurred before.

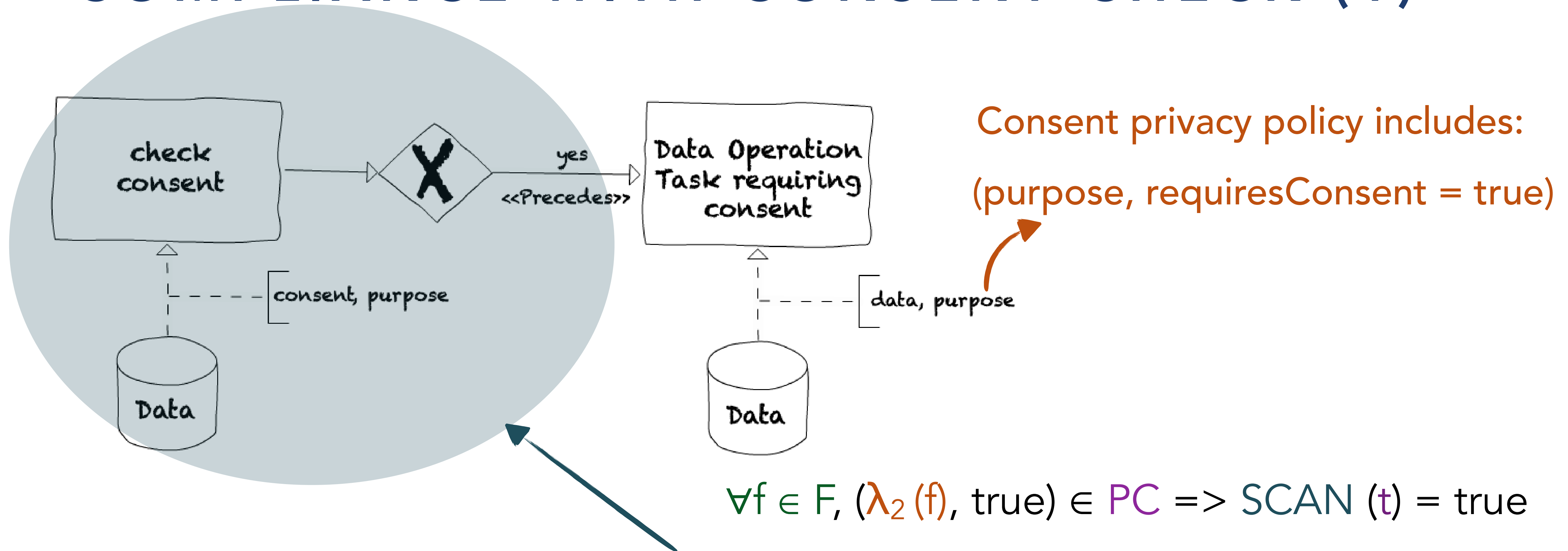


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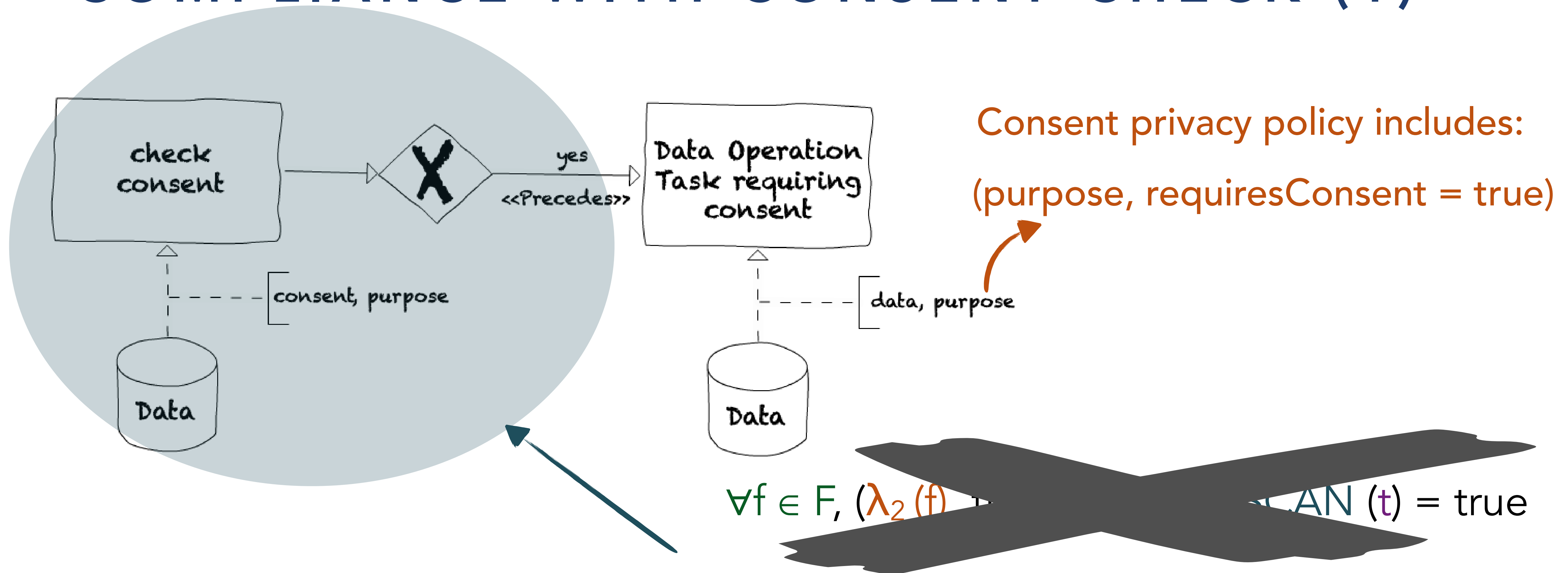
Given a Data-aware WF, check **Consent Check Pattern** predeces Data Operation Task

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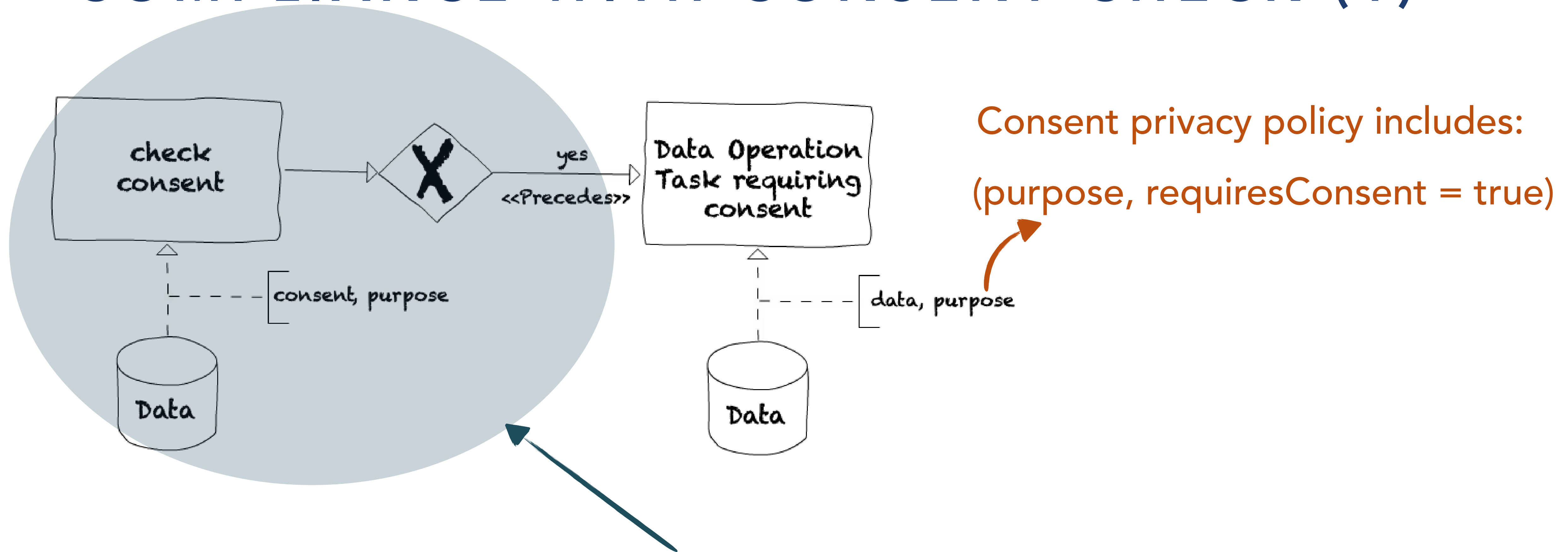
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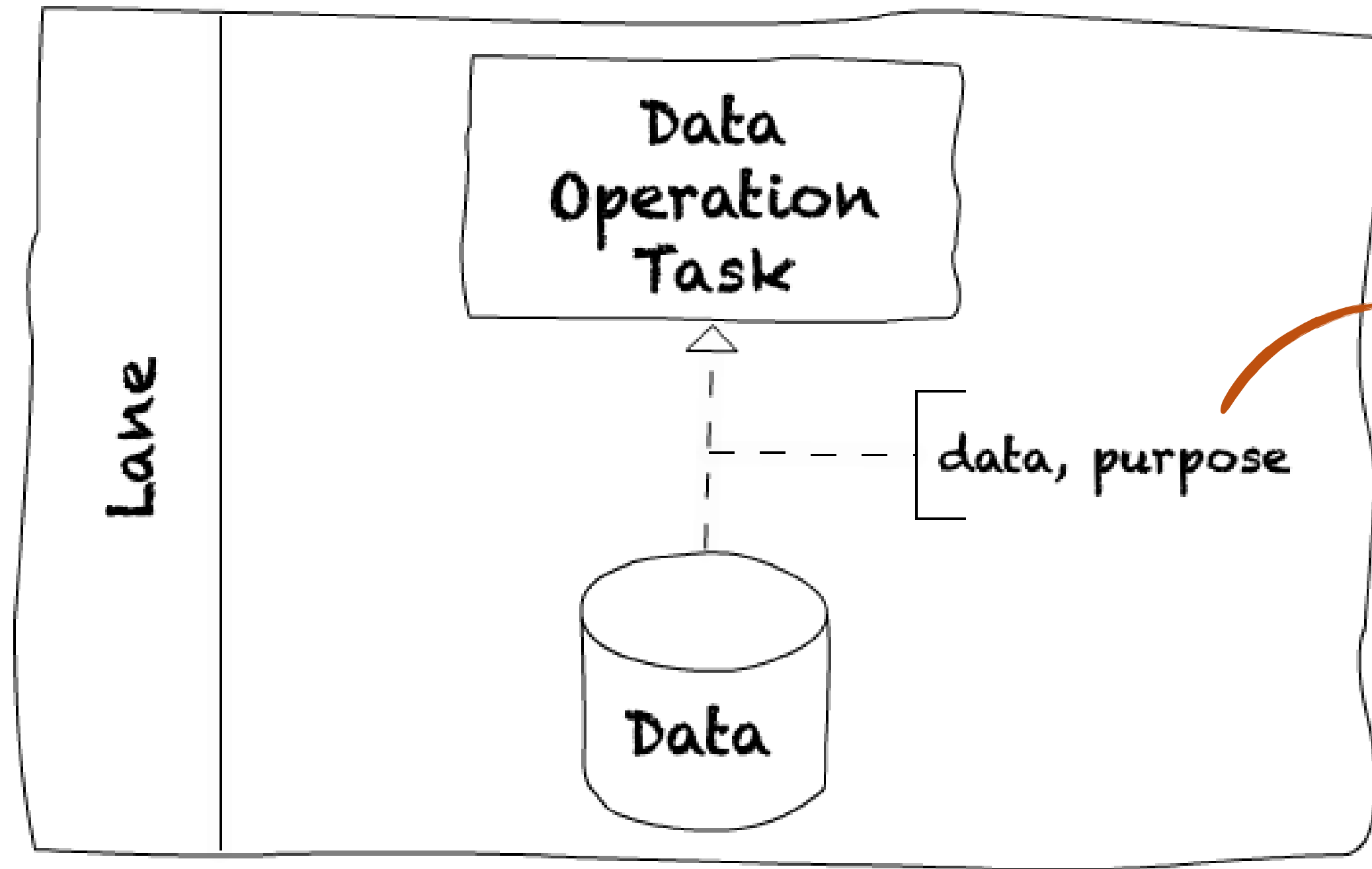


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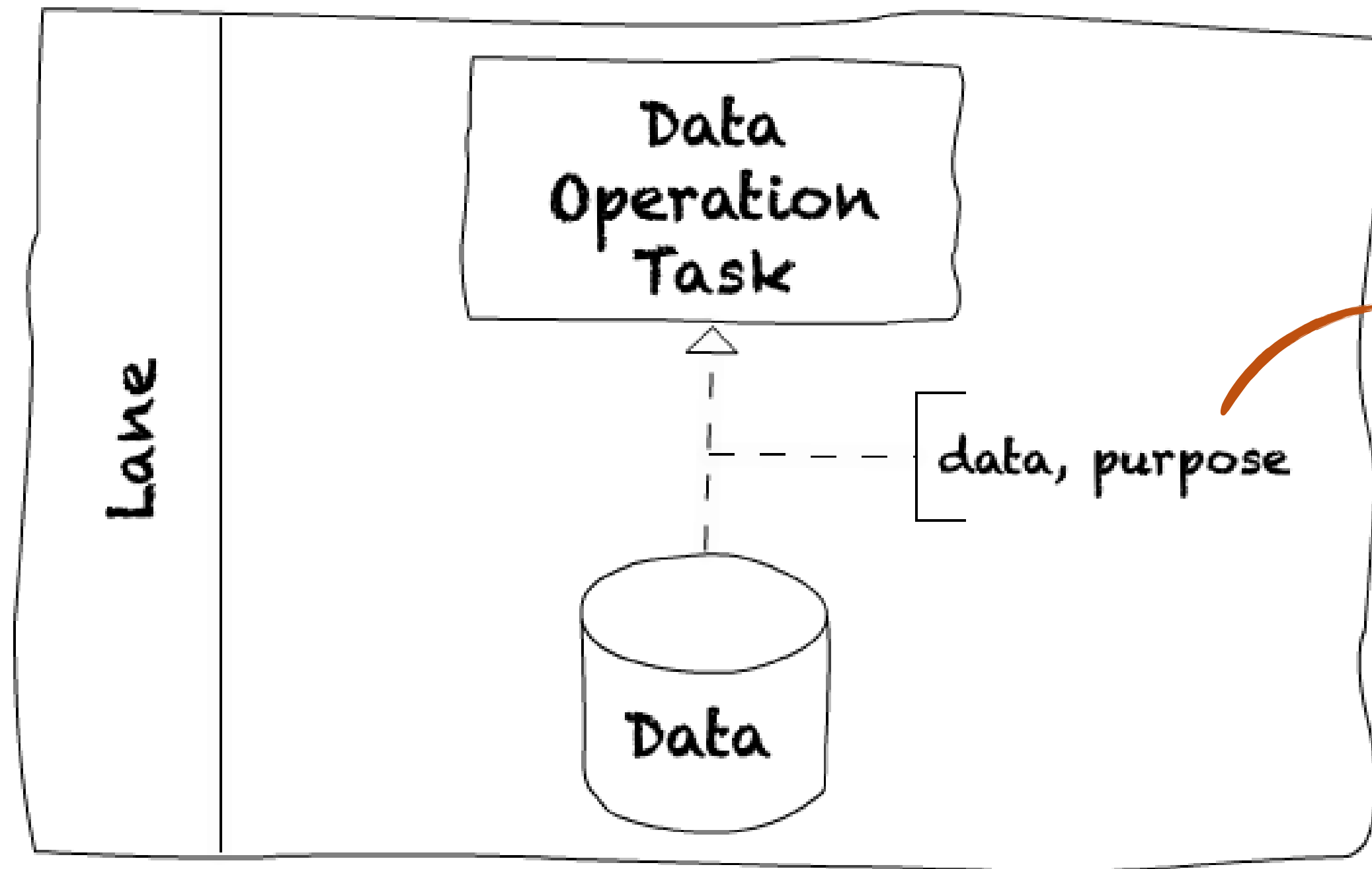
Given a Data-aware WF, check **Consent Check Pattern** predeces Data Operation Task  
created a function traversing all sequence flows reaching Data Operation Task

# COMPLIANCE WITH CONSENT CHECK (2)



Consent privacy policy includes:  
(purpose, requiresConsent = true)

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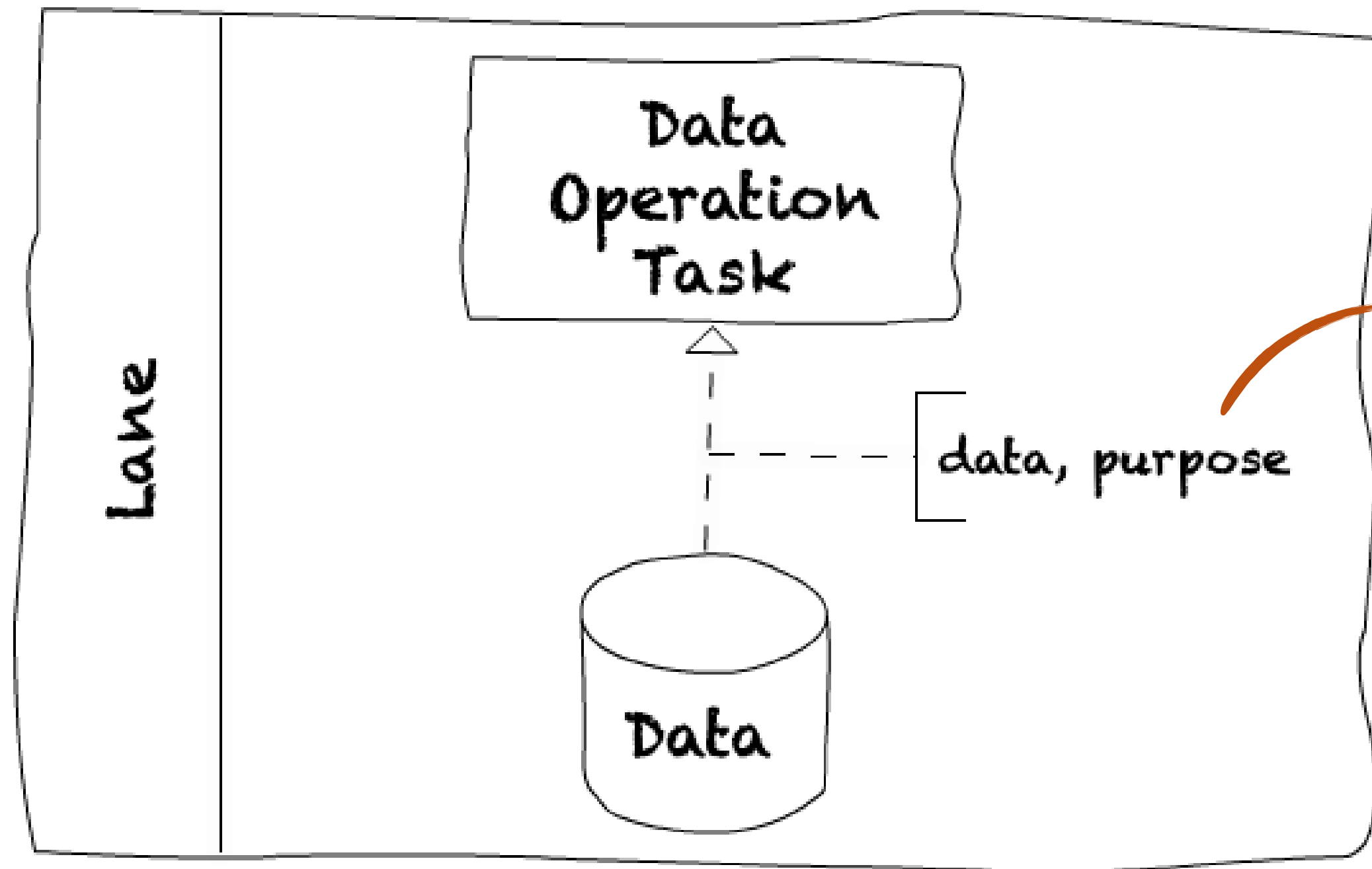
During run time: Check Privacy Preferences



**DataSubject**

**Preference**

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Consent privacy policy includes:  
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During run time: Check Privacy Preferences



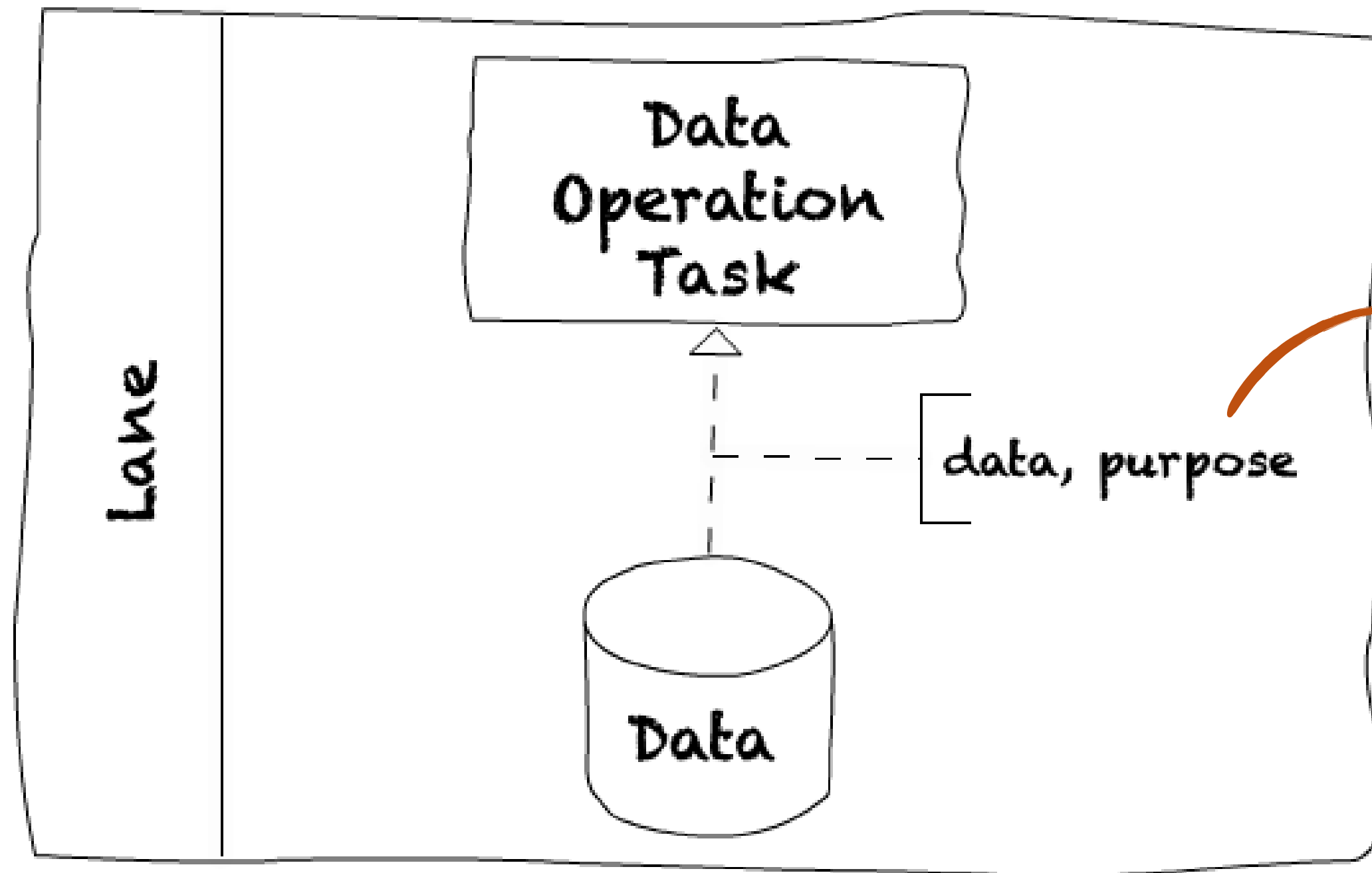
**DataSubject**



**Preference**



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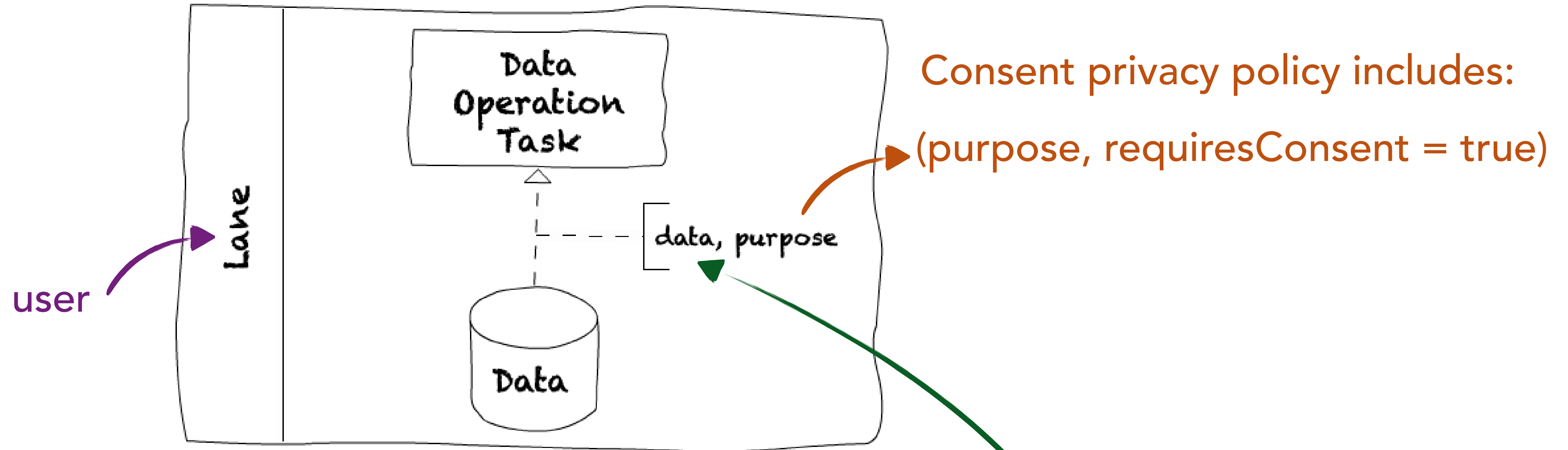
Consent privacy policy includes:  
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During run time: Check Privacy Preferences

 +   $r = (\text{DataSubject}, \text{user}, \text{purpose}, \text{data}, \text{duration}, \text{entryDate})$  ?

*DataSubject*      Preference

# COMPLIANCE WITH CONSENT CHECK (2)

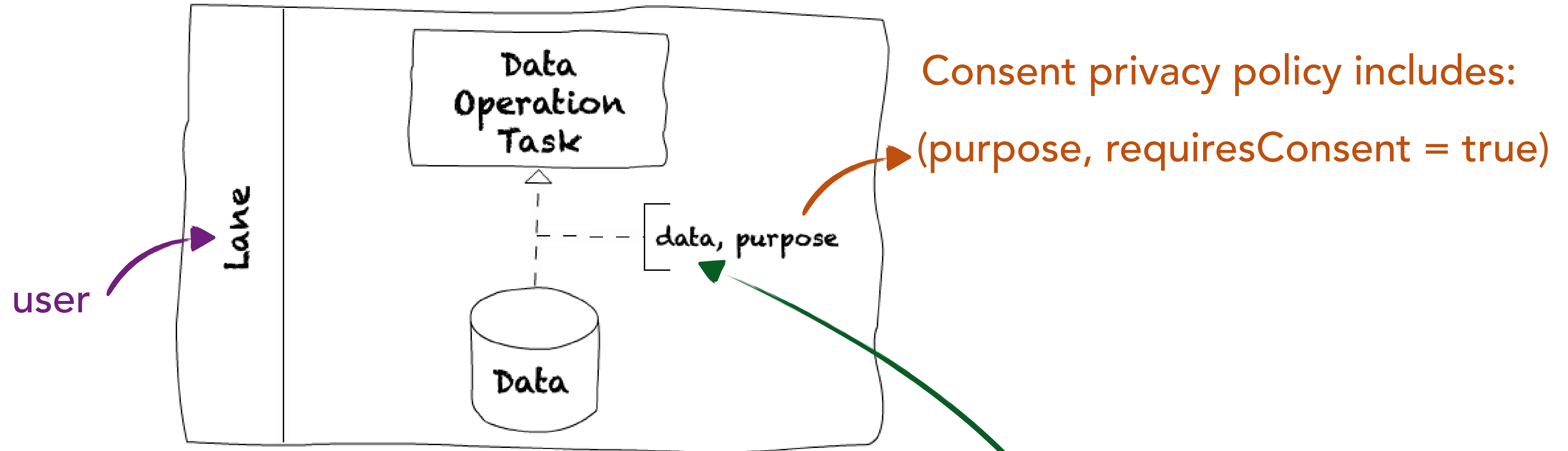


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*DataSubject* Preference

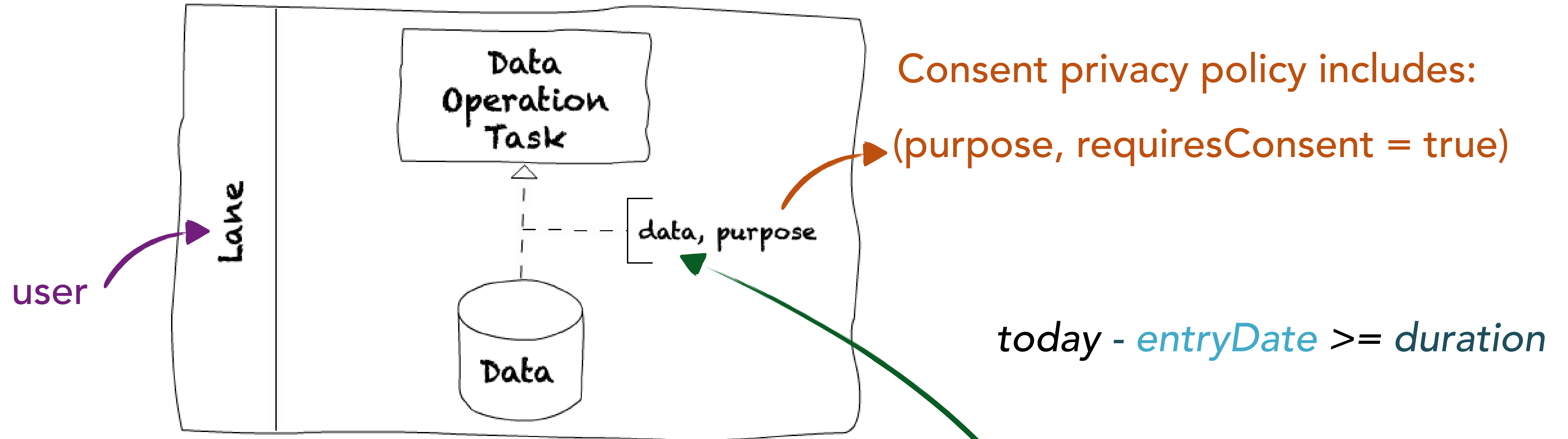
# COMPLIANCE WITH CONSENT CHECK (2)



During run time: Check Privacy Preferences



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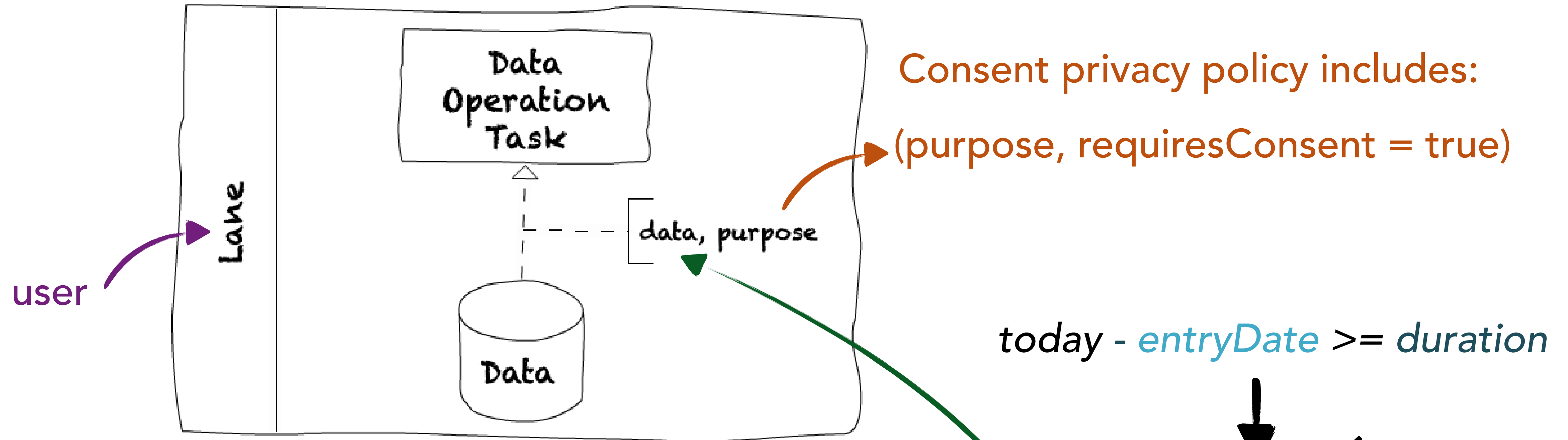


During run time: Check Privacy Preferences





# COMPLIANCE WITH CONSENT CHECK (2)



During run time: Check Privacy Preferences



# TRANSFORMATION

**predefined transformation actions** for the privacy violations  
captured during compliance check

**Purpose Specification:** *at least one specific purpose* for each data operation

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**predefined transformation actions** for the privacy violations  
captured during compliance check

**Purpose Specification:** *at least one specific purpose* for each data operation

When no purpose specified  $\longrightarrow$  *privacy violation*

**transformation action**  $\longrightarrow$  return message as a warning

# TRANSFORMATION - CONSENT CHECK

Some tasks are legitimate only with an **explicit consent** of a data subject.

consent required, but no consent → *privacy violation*

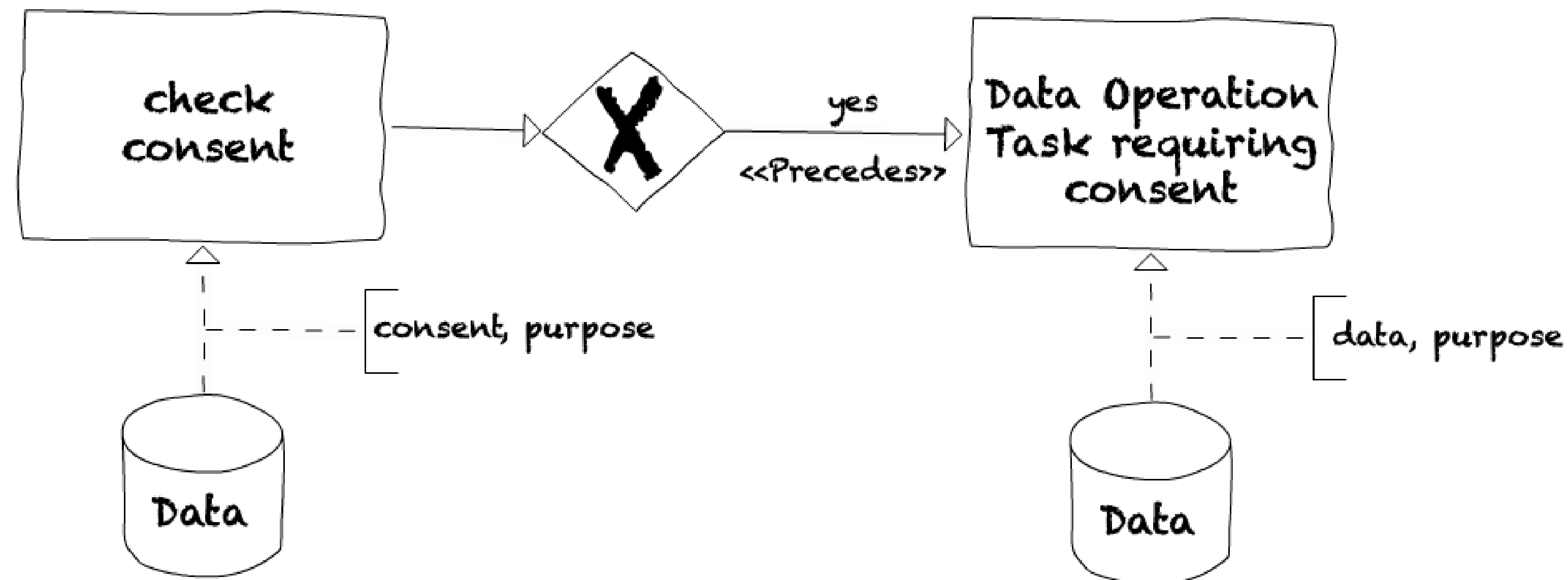


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Some tasks are legitimate only with an **explicit consent** of a data subject.

consent required, but no consent ➡ *privacy violation*

transformation action ➡ adding consent check pattern beforehand

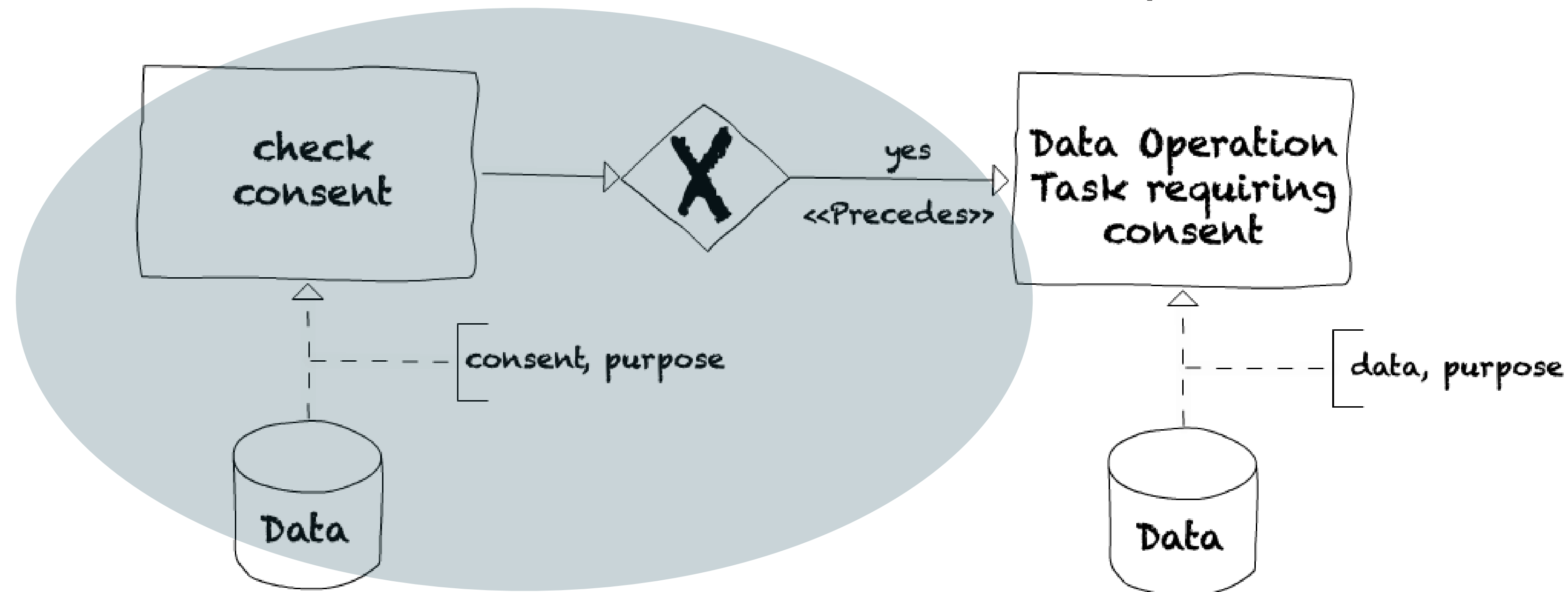


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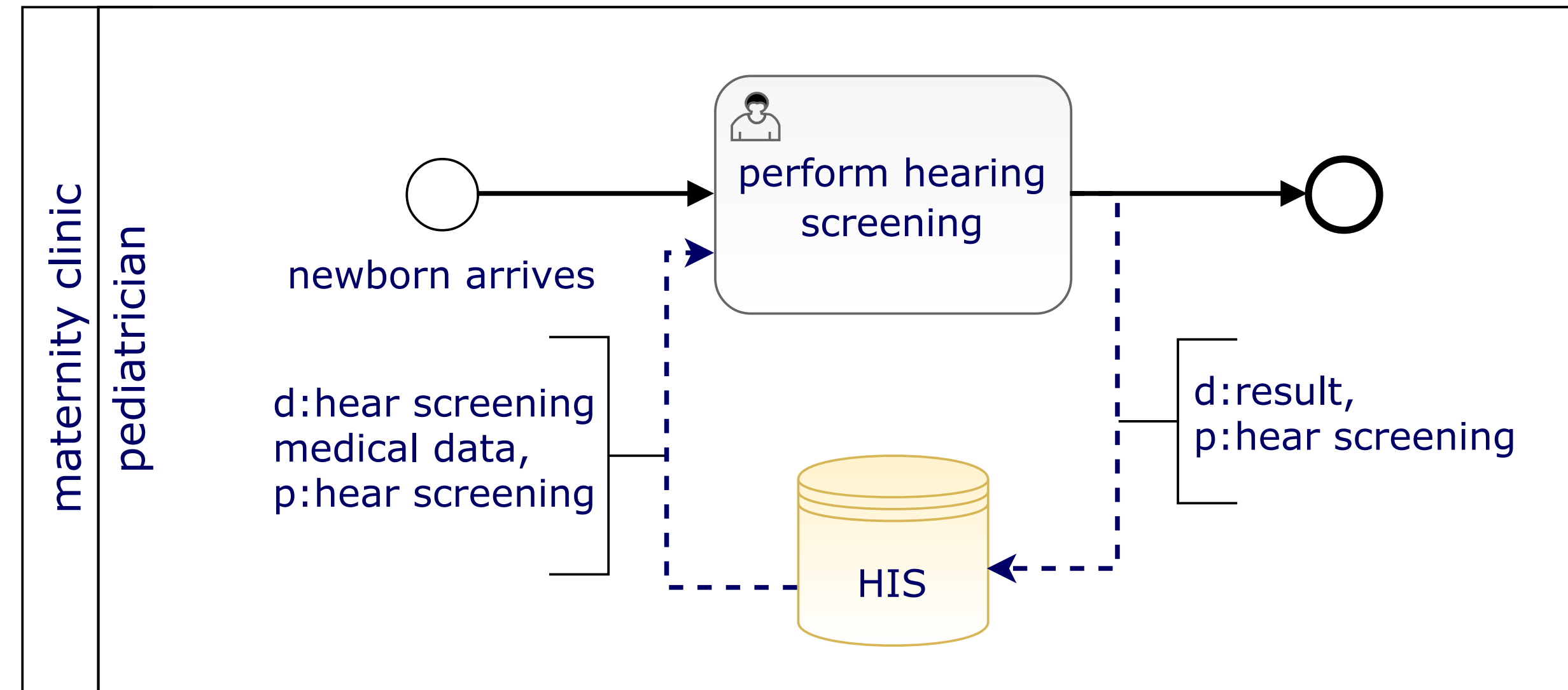
Some tasks are legitimate only with an **explicit consent** of a data subject.

consent required, but no consent ➡ *privacy violation*

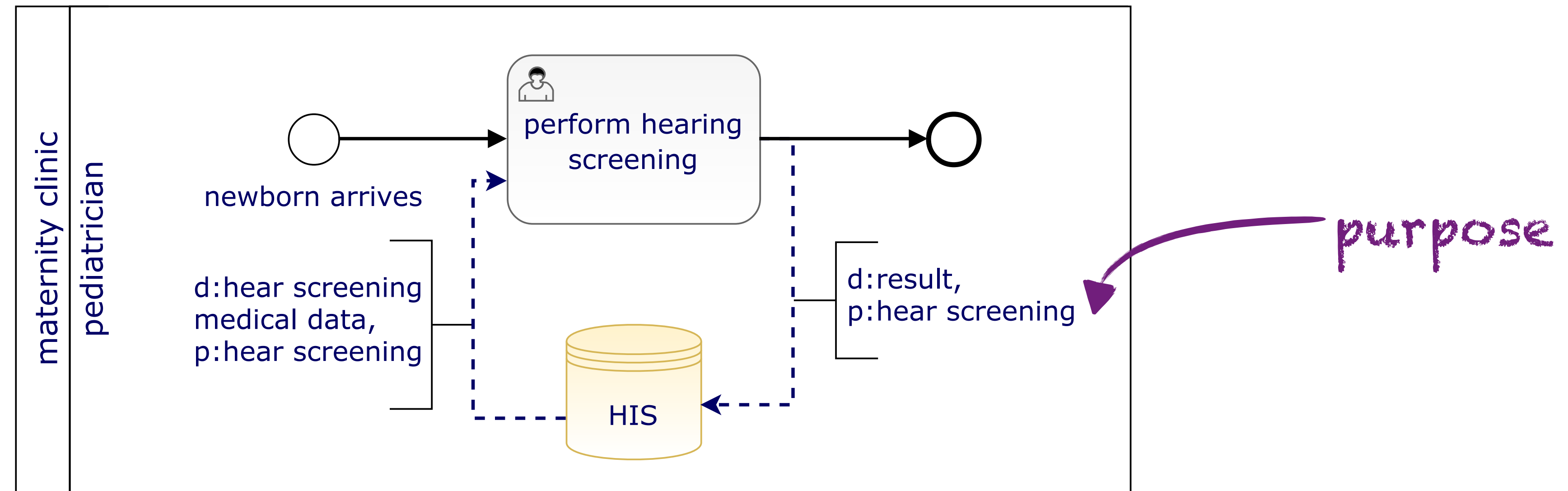
transformation action ➡ adding consent check pattern beforehand



# EXAMPLE: HEARING PROCEDURE - BEFORE TRANSFORMATION



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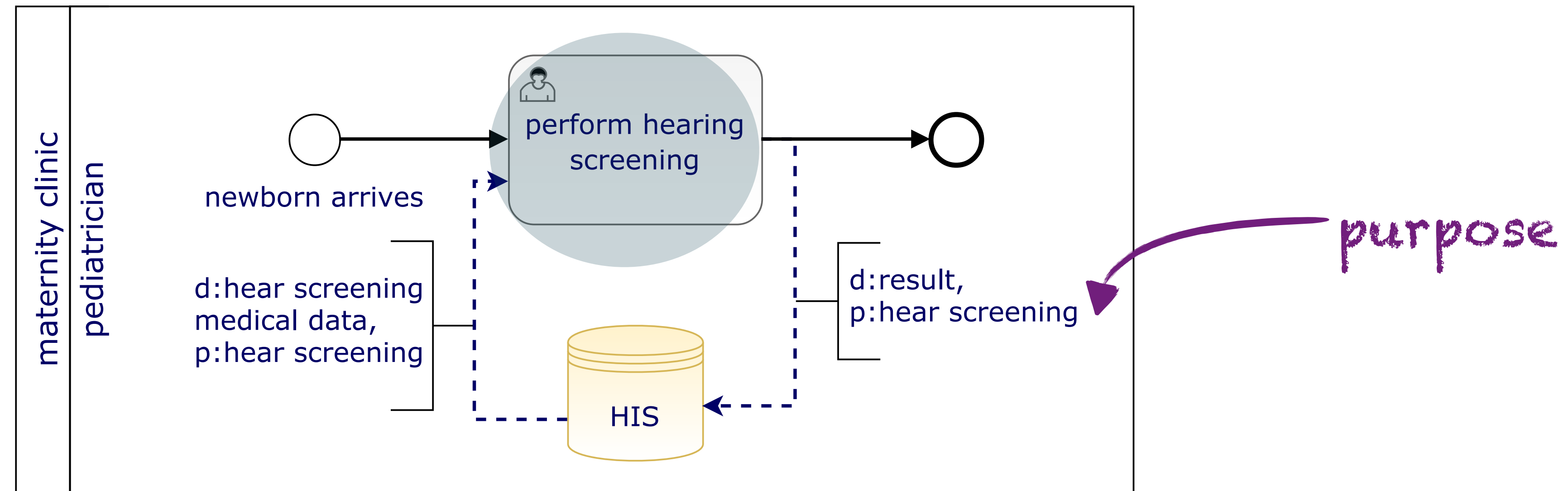


*P1: An explicit **consent** is required for **newborn hearing screening** procedure.*

*(**hearing-screening**, true) ∈ Consent Policy*



# EXAMPLE: HEARING PROCEDURE - BEFORE TRANSFORMATION



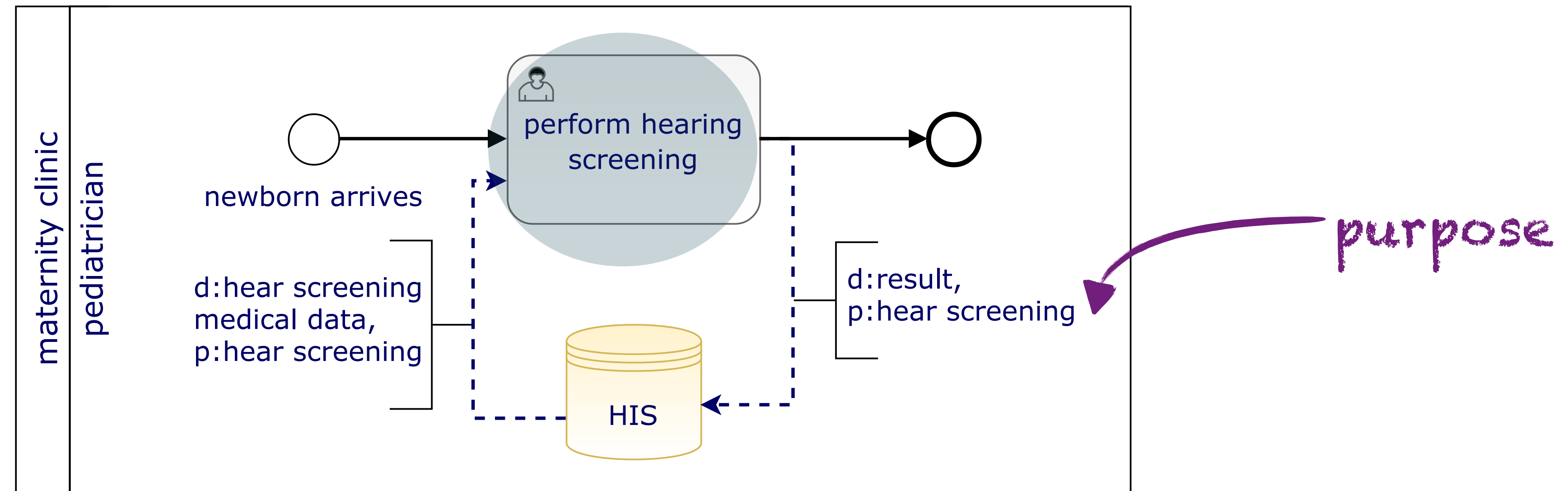
*P1: An explicit **consent** is required for **newborn hearing screening** procedure.*

*(**hearing-screening**, true) ∈ Consent Policy*

check **Consent Check Pattern** precedes “perform hearing screening”



# EXAMPLE: HEARING PROCEDURE - BEFORE TRANSFORMATION



*P1: An explicit **consent** is required for **newborn hearing screening** procedure.*

*(**hearing-screening**, true) ∈ Consent Policy*

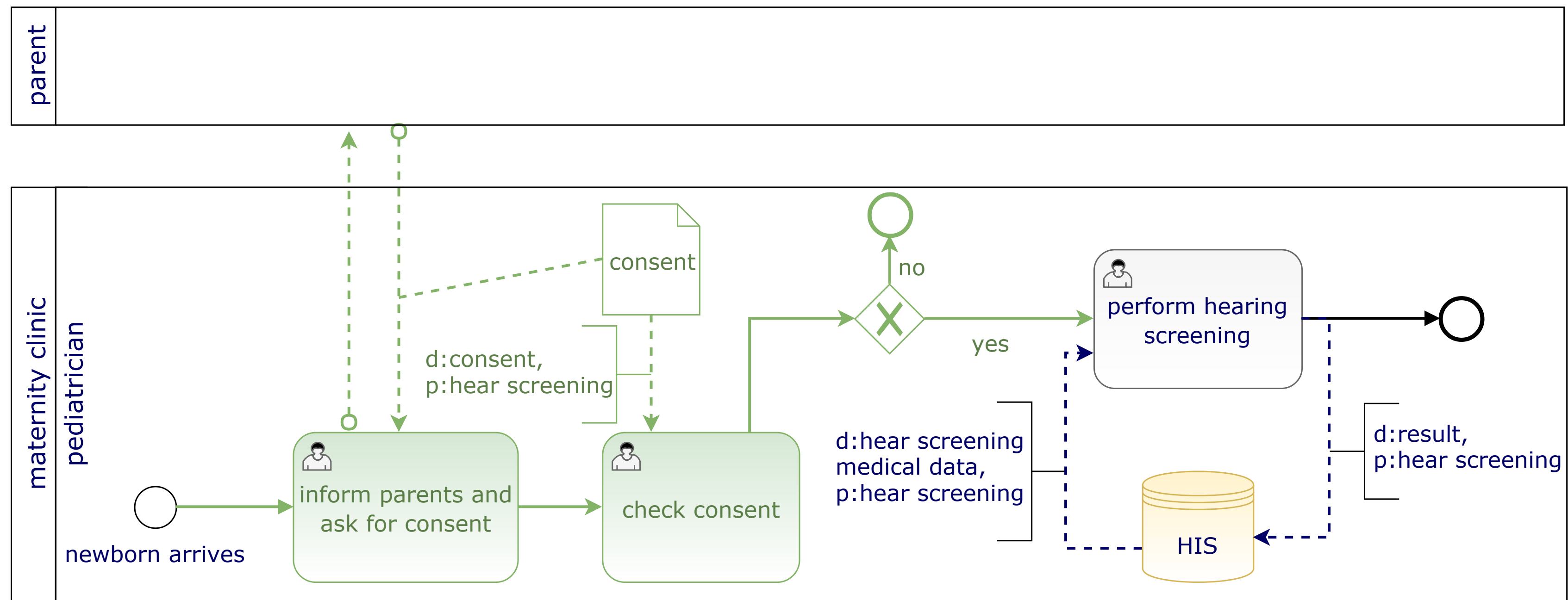
check **Consent Check Pattern** precedes “perform hearing screening”



# HEARING PROCEDURE - AFTER TRANSFORMATION

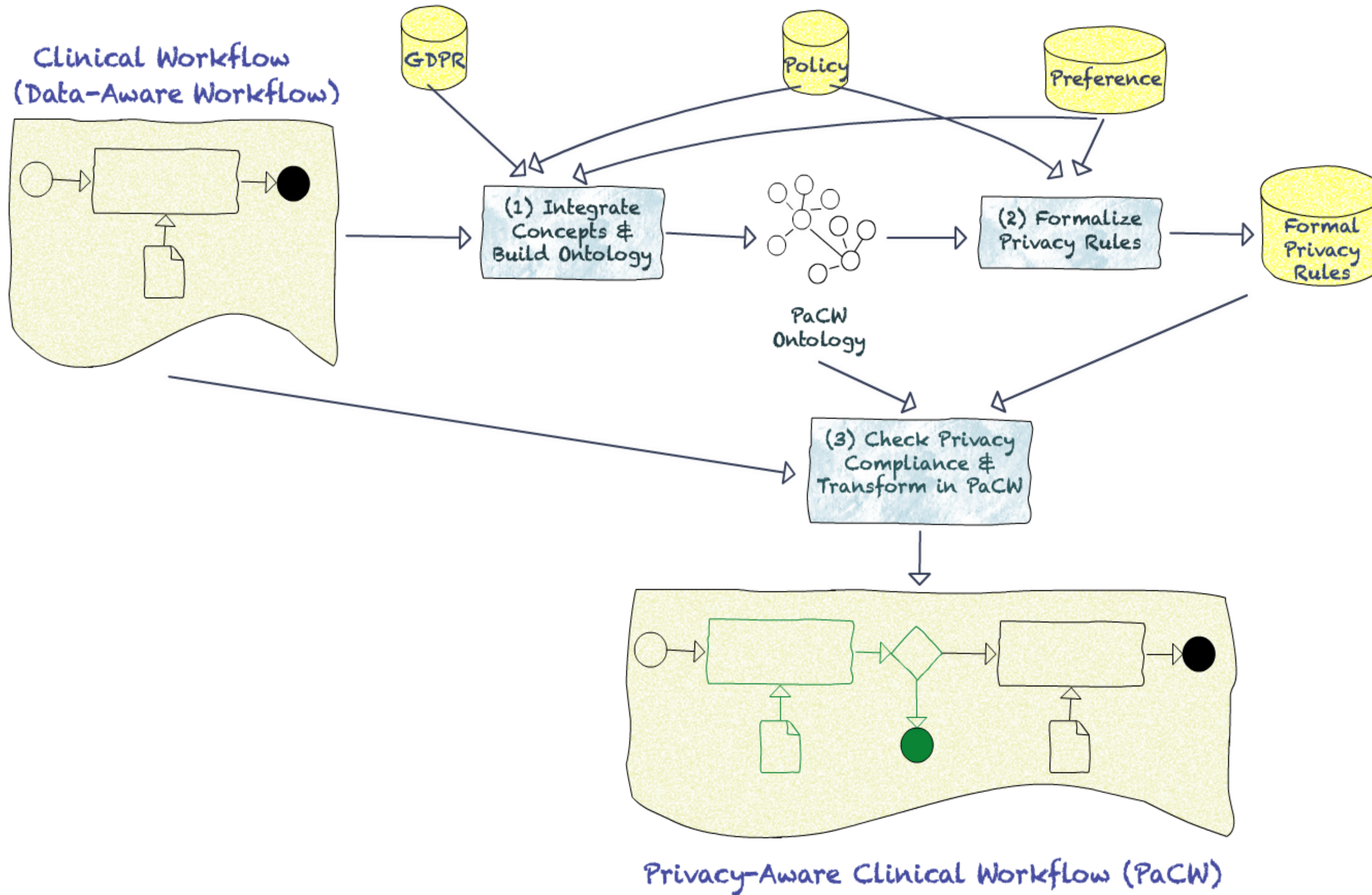
rule triggered due to performing hearing screening without consent check

corrective action: add consent check pattern beforehand



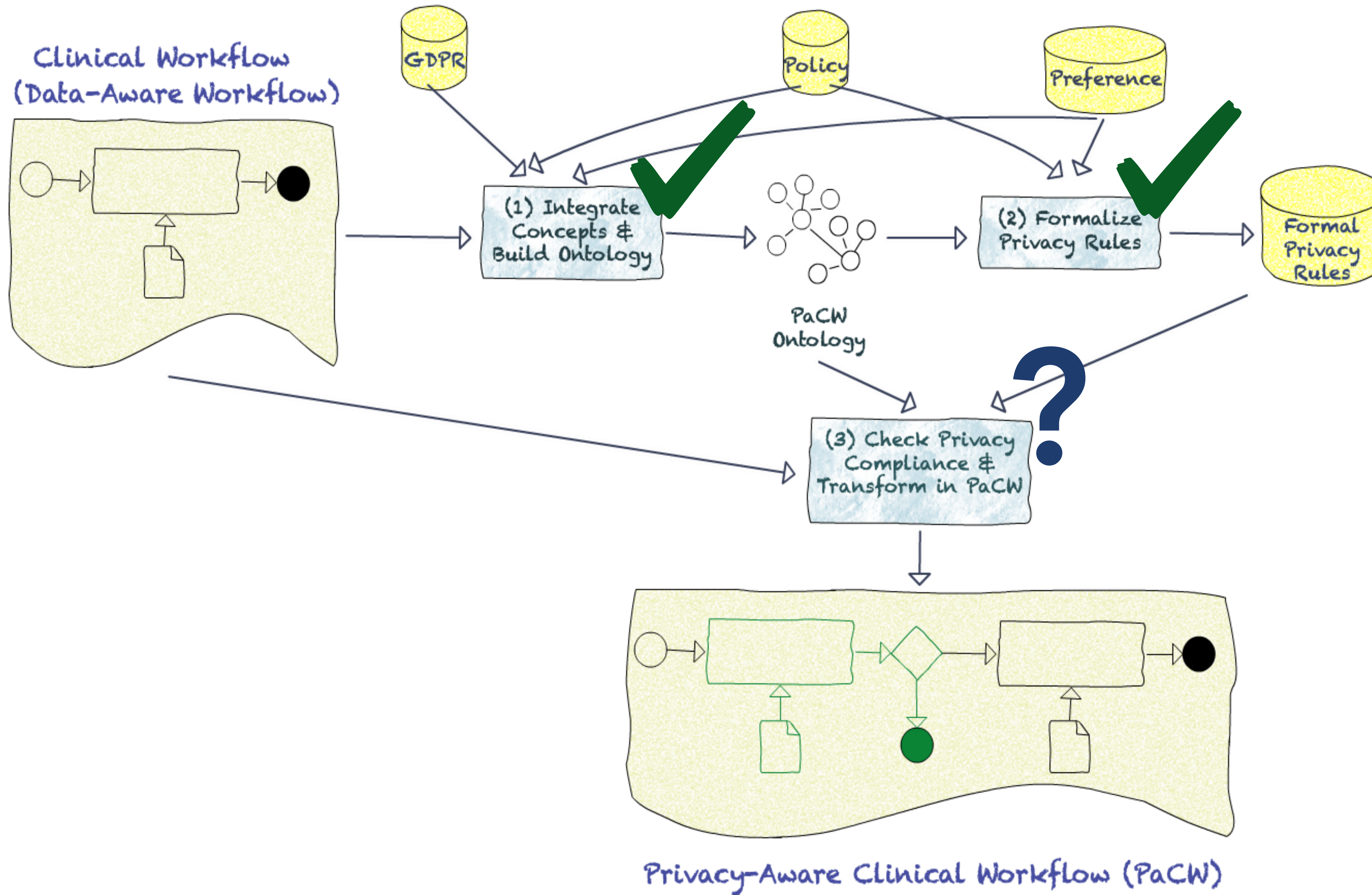


# SUMMARY





# SUMMARY





MATT KENYON

THANK YOU! QUESTIONS??

