

Mind the Grey

What routine documents tell us about a patient's path – and what the EHDS could add

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Session 4: What Can We Build Together? Project Perspectives

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DigiNutzenDat | BMFTR | ESF Plus |
2026 – 2028

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THE PROBLEM

Years of care arrive as one letter



Illustrative patient with ADPKD

Überweisung Nephrologie

Sehr geehrte Kolleginnen und Kollegen,
wir überweisen Ihnen Frau K. zur Mitbeurteilung.

Familienanamnese positiv.

Seit Wochen Flankenschmerz.

Hypertonie bekannt.

Mit freundlichen Grüßen

Köln, 14.03.2022

Family history

Flank pain

Hypertension

all dated 14.03.2022



○ when it really happened: unknown ● date of the letter

What happened over years reaches the clinic on one date – and is pieced together by hand.

Known problem: discharge summaries reached the follow-up physician by the first visit in only 12–34 % of cases (Kripalani et al., JAMA 2007).

OUR PROJECT

Three university hospitals, one shared question



How can the data we already have help our patients – without more documentation?

“Machine learning models are rarely translated into clinical care.”

Sendak et al., EMJ Innovations 2020



ADPKD: about 1 in 1,000 people; about 5 % of patients on dialysis or transplant (MSD Manual)



Clinicians, data scientists and design partners in one project



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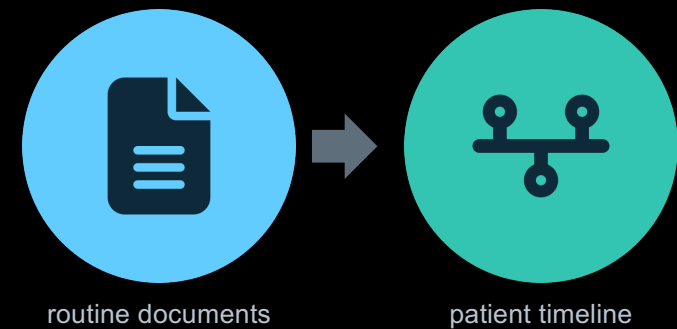


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OUR APPROACH

Periplus

Periplus reads the routine documents a clinic already has and turns them into a coded patient timeline that clinicians can check – without extra documentation.



GOAL 1

Make the lived care pathway visible

GOAL 2

Compare it with the guideline

GOAL 3

Reuse routine data without extra work

A research prototype we are working on in DICE-CD (work package 1). Open-source release planned.

Periplus: from routine documents to a patient timeline



Read

the documents we already have

HL7 FHIR + KDL



Protect

names and IDs removed first

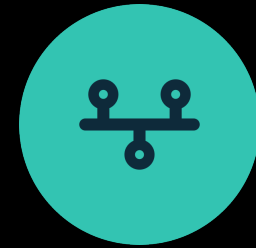
pseudonymise, anonymise



Understand

AI finds findings, tests and diagnoses

SNOMED CT, LOINC, ICD-10-GM



Show

a timeline clinicians can check

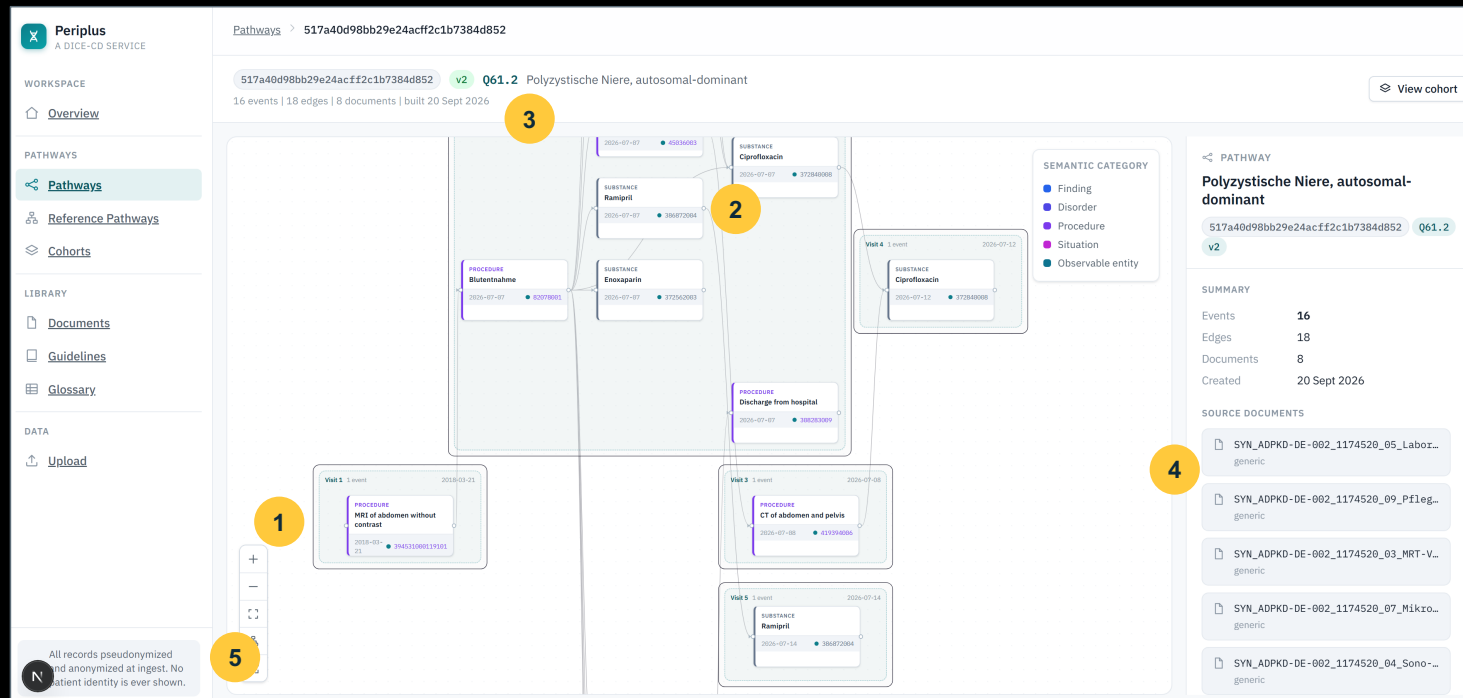
versioned graph, BPMN-based



- ✓ Every entry links back to its sentence in the source document
- ✓ Pseudonymised and anonymised before storage – the AI only sees anonymised text
- ✓ Clinicians correct entries directly
- ✓ Designed to run locally in the hospital; operation on MeDIC infrastructure planned

PERIPLUS: A FIRST IMPRESSION

A first look at the prototype



- 1 Visits in time order; every event is one coded step
- 2 SNOMED CT code on every event, e.g. Ramipril 386872004
- 3 Diagnosis as ICD-10-GM Q61.2
- 4 Linked to the source documents it was built from
- 5 Pseudonymised and anonymised at ingest

Periplus prototype in development, synthetic ADPKD test documents (build of 20 Sept 2026).

One language for all data: FHIR and standard codes

SOURCES

Hospital system (ORBIS)

Lab system (LIS)

Imaging (PACS)

Letters and scans

ePA from earlier care

EXCHANGE

HL7 FHIR R4

Patient

Condition

Observation

Procedure

DocumentReference

MII core data set profiles via the data integration centre (MeDIC)

MEANING

Standard codes

KDL (document type)

AU050102

Überweisungsschein

SNOMED CT

247355005

Flank pain

LOINC

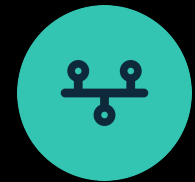
2160-0

Creatinine in serum or plasma

ICD-10-GM

Q61.2

Polycystic kidney, autosomal dominant



**Comparable
timelines and
process models**

across patients, clinics and
the guideline

Same codes everywhere – so care pathways become comparable across patients, clinics and countries.

Builds on what exists: HL7 FHIR R4 services and core data set profiles at the UKK data integration centre (Medical Informatics Initiative).

Three findings, one date

Everything that happened before arrives on the day the referral letter was written.

FINDING

14.03.2022

Family history of polycystic kidney disease

SNOMED CT 160389004

FINDING

14.03.2022

Flank pain

SNOMED CT 247355005

DISORDER

14.03.2022

Hypertensive disorder

SNOMED CT 38341003

Diagnosis **ICD-10-GM Q61.2**

Polycystic kidney, autosomal dominant

FINDING

02.04.2022

Cyst of kidney

SNOMED CT 722223000

CLICK ON FLANK PAIN: THE SOURCE

„Seit Wochen Flankenschmerz.“

Referral letter, 14.03.2022

KDL AU050102 Überweisungsschein



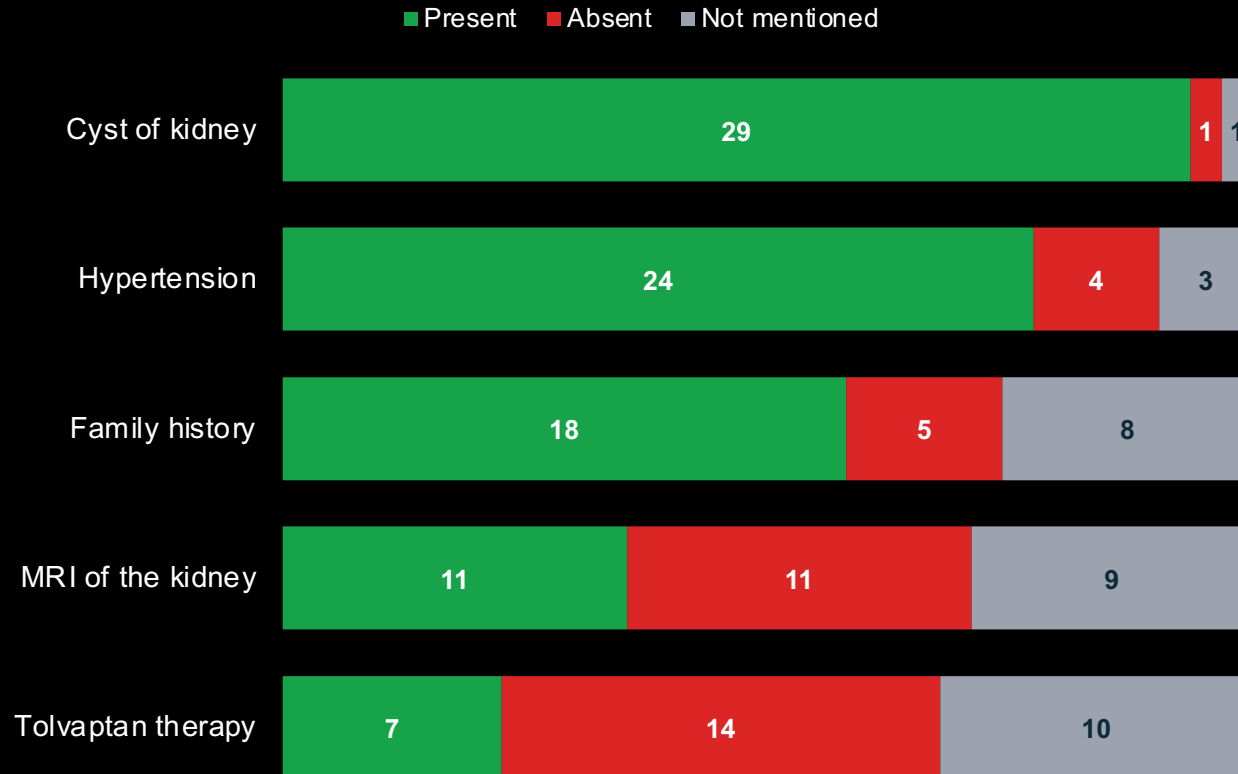
A wrong entry?
Clinicians fix it on
the spot.

14.03.2022

02.04.2022

ILLUSTRATIVE DATA

Grey means: nobody wrote it down



8 of 31

patients: family history not mentioned
in any letter



**Not mentioned does
not mean not there.**

ILLUSTRATIVE DATA

31 patients, ICD-10-GM Q61.2; each bar is one SNOMED
CT concept

Three views, one conversation



vs.



vs.



What happened

one patient, step by step

What we usually do

all patients combined

What we should do

the ADPKD guideline, e.g. KDIGO 2025

All three share one BPMN-based process model: same step types, same codes, same time logic.

The differences start a conversation in the team – not an audit.

One clinic sees only part of the picture.

MISSING:

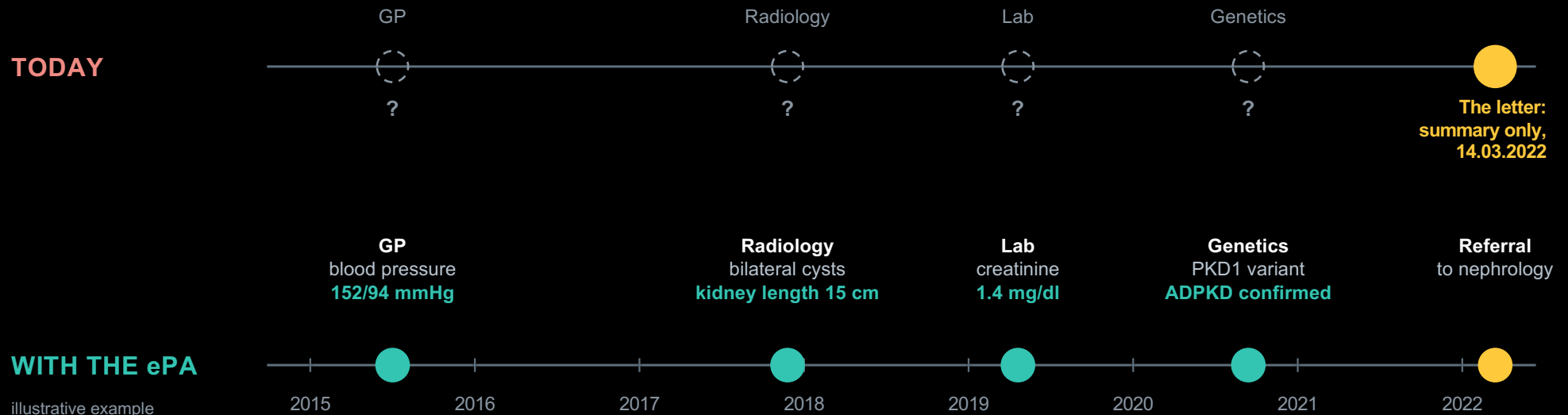
- 1 the patient's history before the first visit
- 2 the patterns in other clinics



1 LOOKING BACK: BEFORE THE PATIENT CAME

With the ePA, earlier findings keep **their date and detail**

Today: one summary sentence, no date, no values. With the ePA: the original finding, with its date and details.



since 2025 ePA for everyone, mandatory for providers since Oct 2025 2029 EU patient summaries 2031 imaging, lab, discharge letters

Today the ePA holds mostly PDF documents; structured, FHIR-based records (MIOs) follow step by step. Periplus is designed to read both.

2 LOOKING ACROSS: OTHER CLINICS

Compare patterns across clinics, **not patients**



UKK Cologne



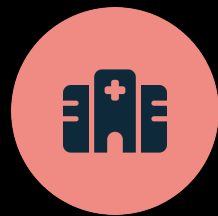
records stay here



UKD Düsseldorf



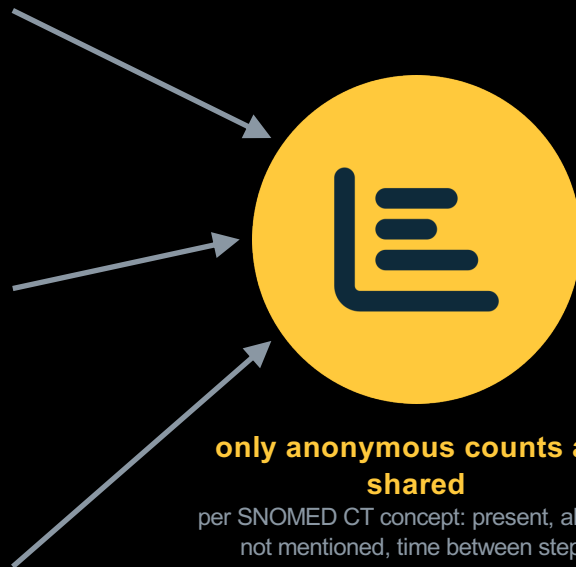
records stay here



Charité Berlin



records stay here



only anonymous counts are shared

per SNOMED CT concept: present, absent,
not mentioned, time between steps

Is what we see a local habit – or a pattern across clinics?



From 2029, the EHDS (Regulation (EU) 2025/327) opens this route: anonymised by default, via national health data access bodies.

THE WAY FORWARD

From one clinic to Europe

● in progress ● planned in DICE-CD ● what we would like to build with you



One clinic

understand our own care



Three clinics

local habit or pattern?



Germany

MII data integration centres
and FHIR core data set



Europe

- 1 EHDS secondary use:
evidence for guideline groups
- 2 EHDS primary use: close
gaps in care data exchange

Thank you!

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Mind the grey – let's close it together.

CONTRIBUTORS

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Periplus is a research prototype in development, not a medical device. Data shown is illustrative.



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Backup: references and sources

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SNOMED CT (International Edition 2025-02-01) and LOINC codes checked via tx.fhir.org; KDL codes against the KDL 2024 code system. Patient data and cohort figures in this deck are illustrative.