



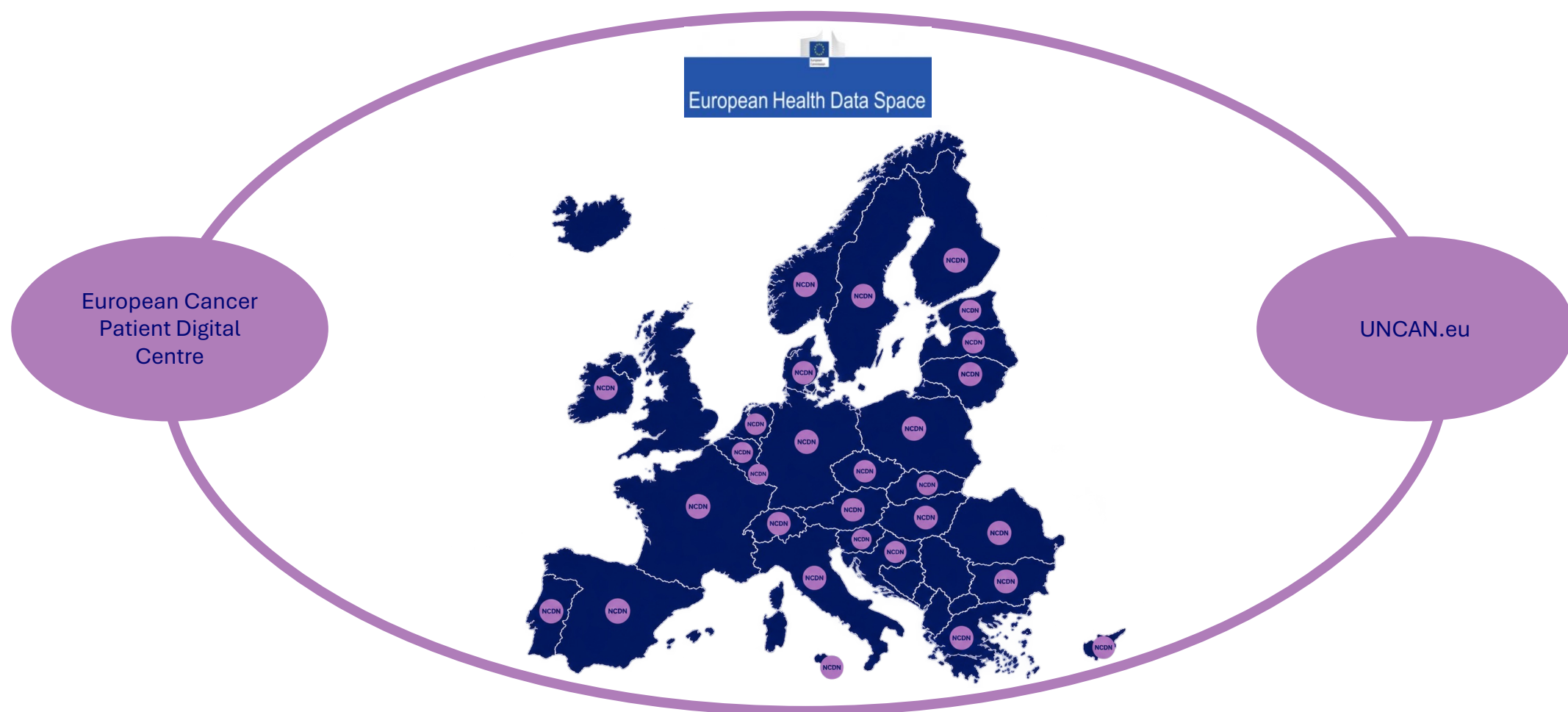
Sparking EHDS-ready solutions, Transforming cancer care

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Modernize Medicine!

❑ Data infrastructure is **an alien term** for many users, especially the MDs.

‘How should I know?’

‘Why should I know?’

❑ **Overstructured data infrastructure/architecture ≠ better patient care.**

❑ Billions of EU-funding are dissolved when projects end, with **close-to-ZERO** accumulation of expertise at national level.

3-year project (2025-2028), CSA, funded under the Cancer Mission Program-CANDLE today is 1 yr 4 months old

What

To develop national cancer data nodes

- For data users to find the right tools, services, navigation through the EHDS ecosystem;
- For data holders to find data standards, practical solutions comply with EHDS;
- NOT a new centralized data center, NOT a new organization, but something built on existing structures

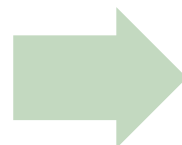
How

- Synergizing infrastructure solutions
- Being the national focal point of oncology communities
- Bring real-life questions to the node
- Formulate topical working groups, within and cross-countries
- Value proposition and policy-dialogue (at national and EU levels)

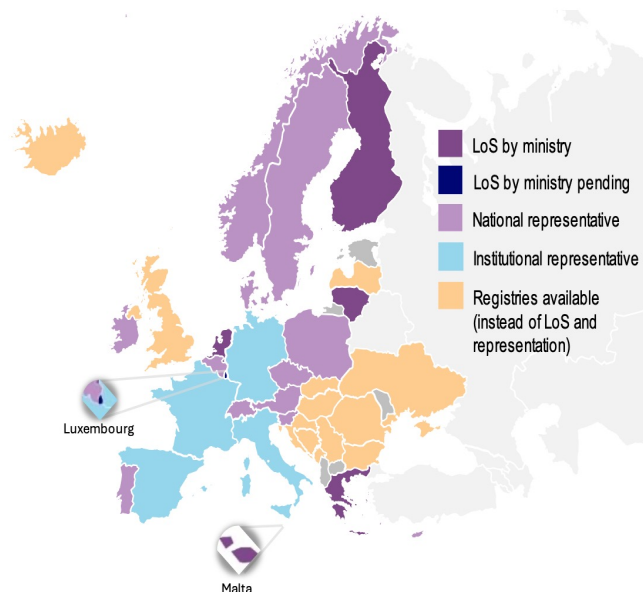
NCDN candidate nodes 2025-2026



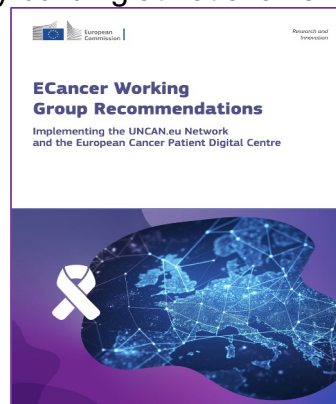
2025
6 NCDN candidates



2026
20 NCDN candidates



- Provide tools to improve data quality of cancer data at source
- Provide tools for cancer data analysis to be used in secure processing environments (SPEs)
- Ensure all cancer datasets have a metadata record in the EU dataset catalogue
- Provide advice on common variables for cancer datasets
- Capacity building at national level



Potential National Cancer Data Node Organisations in Europe

Illustrative country examples

 1. National cancer institute / centre	 2. Research infrastructure node	 3. Registry / registry-based body	 4. Ministry / public health agency	 5. University hospital / research institute
 Austria BBMRI.at or ELIXIR-AT or Austrian Comprehensive Cancer Network	 Germany German Cancer Research Center (DKFZ) or Cancer registries (DKFZ e.V.) or German Centre for Cancer Registry Data (RKi)	 Norway Cancer Registry of Norway		
 Croatia Research Institute Ruder Bosković or UHC Zagreb	 Hungary National Institute of Oncology		 Poland Maria Skłodowska-Curie National Research Institute of Oncology	
 Czechia ELIXIR-CZ or BBMRI-CZ node	 Ireland ELIXIR-IE node		 Portugal Serviços Partilhados do Ministério da Saúde (SPMS)	
 Cyprus National cancer registry under the Ministry of Health	 Latvia National Cancer Centre			
 Estonia University of Tartu	 Lithuania National Cancer Registry or University Hospitals		 Romania Oncology Institute Cluj-Napoca	
 Finland Finnish Cancer Centre (FICAN)	 Luxembourg National Cancer Institute (Luxembourg Institute of Health)		 Slovakia National Health Information Centre (NCZI) or Slovak Centre of Scientific and Technical Information	
 France Institut national du Cancer (INCa)	 Netherlands Health-RI node in close collaboration with the Netherlands Comprehensive Cancer Centre (KNCL)		 Slovenia National Institute for Cancer	

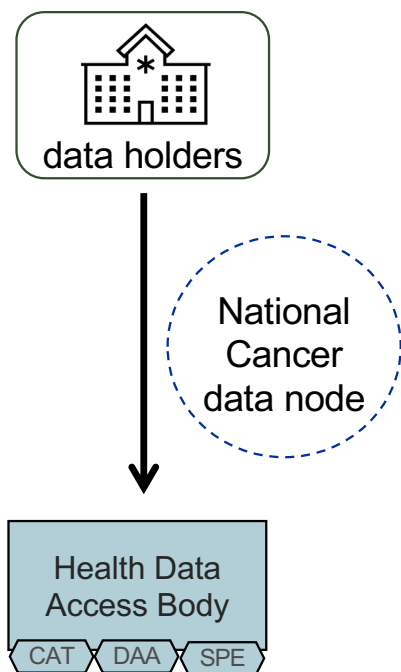
Examples are indicative and may evolve with national governance decisions.



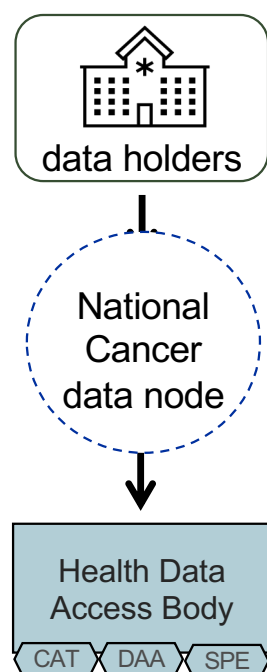
EUROPEAN UNION

Developing digital capabilities for national cancer data nodes to support EHDS national implementation

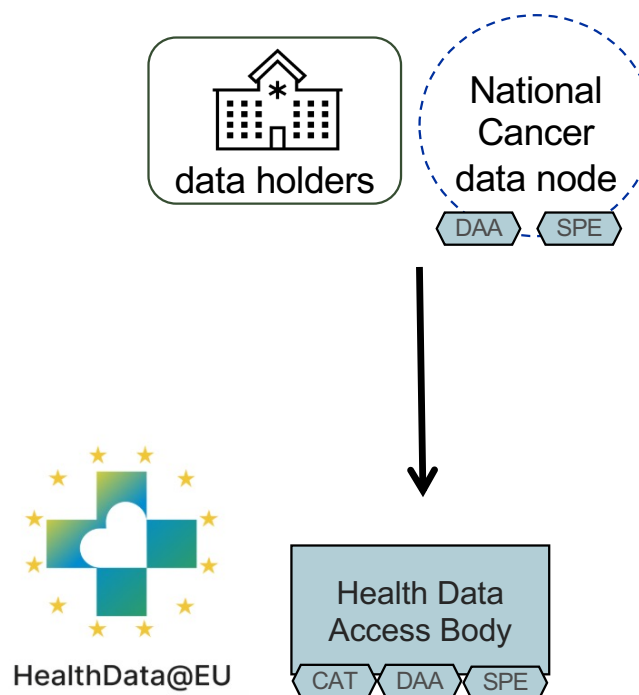
OPTION A Body not integrated with the HD@EU



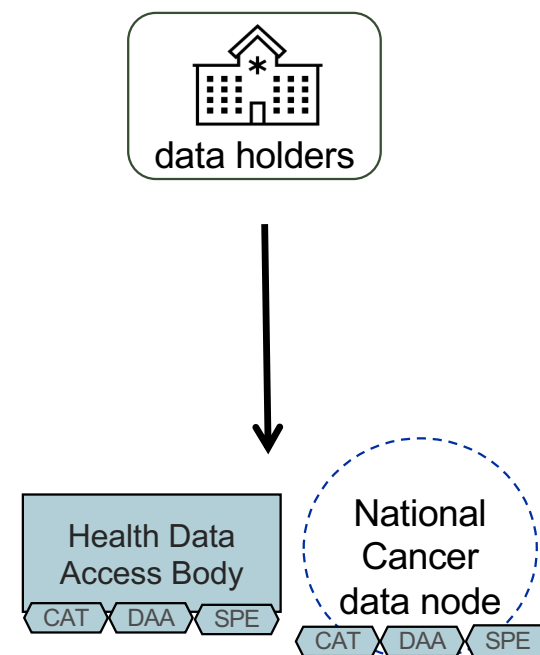
OPTION B Health Data Intermediation Entity [Art. 50]



OPTION C Trusted Health Data Holder [Art. 72]

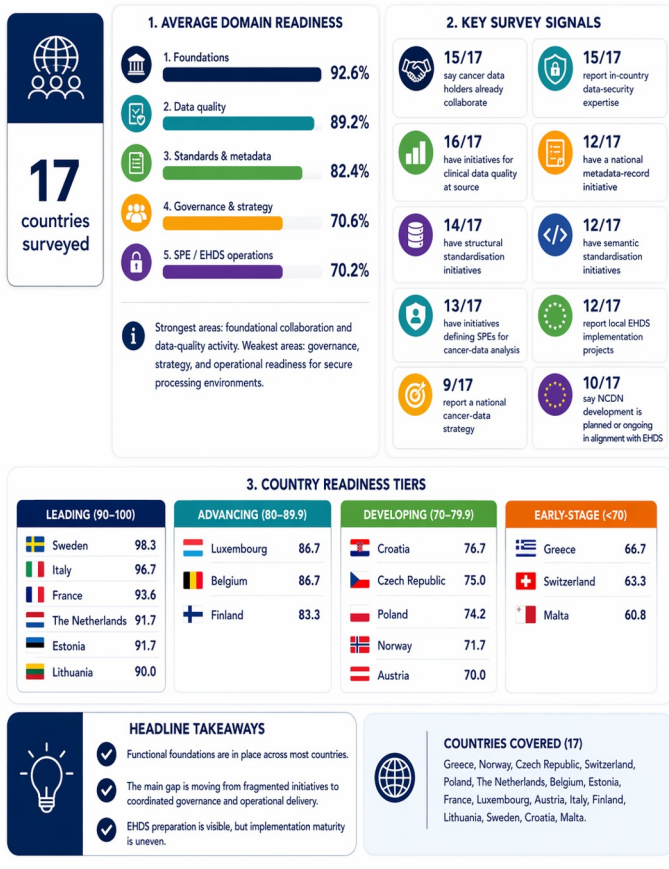


OPTION D (thematic) Health Data Access Body [Art. 50, 55, 57, 58, 59, 63, 64]



Achievement Year 1

National Cancer Data Node (NCDN) Survey: Executive Summary



National Cancer Data Node (NCDN) Maturation Model

Overview of the domains, core functions, and maturity pathway

Based on the Maturation Model – March version



07/09/2026

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Cancer Data Personas: Simplified Needs Summary

Roles shown only. Combined overview of primary focus, top needs, data highlights, and shared priorities.

Shared priorities

- Better data access and linkage
- Better data quality, FAIRness, and metadata
- Stronger standards and interoperability
- Clear governance with practical implementation

Patient

Primary focus

Use health data to improve care, empowerment, transparency, and access to information

Top needs

- Accessible information in lay language
- Clear consent and opt-out communication
- Trust-building and early inclusion

Data highlights

- Transparency on how personal data is used
- Reduced fragmentation across regions and countries
- Visible evidence of patient benefit

Research Infrastructure

Primary focus

Enable discoverable, interoperable, reusable cancer data for research and NCDN interaction

Top needs

- Structural and semantic standards
- ETL/ELT and data integration support
- Better metadata, provenance, and terminology mapping

Data highlights

- Interoperability across heterogeneous datasets
- Strong metadata and provenance documentation
- Clear interaction model with NCDNs

Research Organisation

Primary focus

Access high-quality, diverse cancer data quickly and support reproducible collaborative research

Top needs

- Fast and transparent data access
- Clear entry points and practical workflows
- Training on curation, anonymisation, and ethical reuse

Data highlights

- High-quality reusable datasets
- Better metadata for research usability
- Practical integration between NCDNs and data providers

Cancer Registry

Primary focus

Produce complete, high-quality, standardised, timely cancer data for surveillance, research, and policy

Top needs

- Standardised national formats and reporting definitions
- Better source data and clinical workflow integration
- Sustainable funding, staffing, and QA tools

Data highlights

- Better source data quality
- Interoperable tools and validation mechanisms
- Capacity to handle more complex cancer data types

Healthcare professional / provider

Primary focus

Improve patient outcomes, continuity of care, and patient guidance

Top needs

- Simpler workflows
- Tools to find similar patient trajectories
- Better-quality data infrastructures

Data highlights

- Comparable patient outcomes
- Connected systems and standards
- Trusted evidence sources

National Cancer Data Node

Primary focus

Improve access to cancer data, connect data holders, and harmonise datasets

Top needs

- Coherent data access pathways
- Source-level data quality and FAIR support
- Implementation guidance for standards

Data highlights

- Metadata and interoperability
- Data quality at source
- Operational coordination models

Health Data Access Body and Policy Maker

Primary focus

Apply EHDS in a workable way, support lawful access, and enable policy use

Top needs

- Clear roles and responsibilities
- Secure workable access systems
- End-to-end implementation models

Data highlights

- Governed data access
- Interoperable standards
- Scalable cancer-data workflows

Bottom line: different personas have different operational needs, but all require better data access, data quality, interoperability, governed access, and practical implementation support.



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Technical elements mapped to NCDN functions – summary table

Source: Preliminary table MS5, 24 Apr 2026 | 98 listed technical elements

Function area	Count	Representative technical elements	Main users	Primary data-user value
 Improve data quality at source	4	Data centre-certification program; Federated Data Quality Framework; Data Quality and Utility Tool; ED-EHR	Data holders; research infrastructures	Analyse data / make data reusable
 Provide advice on common variables	5	OMOP CDM; HL7 FHIR; RDF/FHIR; 1+Million Genomes Minimal Dataset for Cancer; ISO/IEC 27001	Data engineers; researchers; IT teams	Make data reusable
 Ensure metadata records in the EU dataset catalogue	4	crMDR; Directory; Dutch national health catalogue; User Portal	Clinicians; researchers; HDABs; data holders	Search and find data
 Provide tools for analysis in SPEs	7	cBioPortal; XNAT; crDSR; BioMedIT B-Space; EHDS; ATLAS; LS-AAI	Data holders; researchers; HDABs	Analyse data / request access
 Capacity building at national level	3	EU-CIP patient portal; RDMtoolkit; EU network of federated trusted research environments	Patients; researchers; national stakeholders	Information / capacity building
 Extension roles: discovery, access, and sharing	11 coded entries	Beacon for cancer; LocalEGA; Locator; Negotiator; EUCAIM Central Hub	Researchers; clinicians; HDABs; data holders	Search, request, and share data



Key takeaways

- The strongest explicit mapping is to 5 core NCDN functions.
- Most tools support data discovery, interoperability, or secure analysis workflows.
- 71 of 98 rows have no explicit data-user coding, so the table should be read as a preliminary landscape, not a complete inventory.

Abbreviations: HDAB = Health Data Access Body; SPE = Secure Processing Environment.



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Real transformation happens when solving real-life clinical questions



Working groups to test, validate and refine NCDN functions

1

Sharing of genomic data

GDI / 1+MG · NCDN-NL, NCDN-IT



2

European common cancer data model

HL7 Europe · NCDN-NL, -GER, -IE, -LUX



3

EHDS-compliant data management plans

JA-PCM · relevant NCDNs



4

Minimal datasets for Molecular Tumour Boards

EUnetCCC · relevant NCDNs



5

cBioPortal working group

BBMRI-ERIC · NCDN-IE, -NL, -GER · MSKCC, DFCI



6

Patient-level data linkage methodology

NCDN-NL · JRC · EORTC

7

Support to Cancer Mission Cluster projects

all involved NCDNs

Each group starts from one defined question — with a convener, named experts, an achievable output and a review date

4

Minimal datasets for Molecular Tumour Boards

EUnetCCC · relevant NCDNs



Problem statement

- heterogeneity in data collection/linkage
- lack of key outcome data
- tedious data workflow within and between hospitals
- limited involvement of patients
- missed connection with EHDS primary use



Consequences

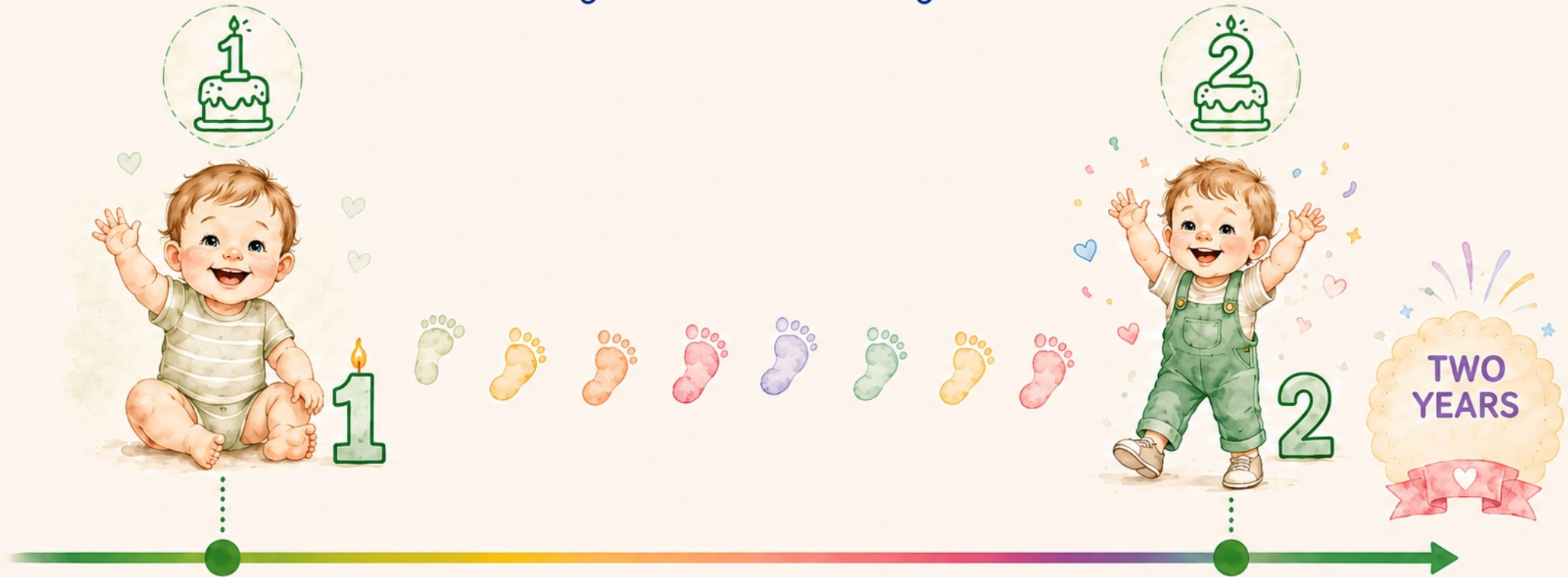
- jeopardized patient outcomes
- impossible comparisons of MTB outcomes on all levels
- inefficient and ineconomic procedures which limited in application for broader patient groups

CANDLE solutions

- define CDM and minimal database for MTB across NCDNs
- develop MTB-support tools (e.g. cBioportal)
- develop EHDS-compliant data linkage methodology
- ensure data quality
- engage NCDN communities and set up mutual learning across MS to optimize implementation

The CANDLE Project Journey

From 1 year old to 2 years old



✦ Growing together. ♥ Lighting the way. ✦

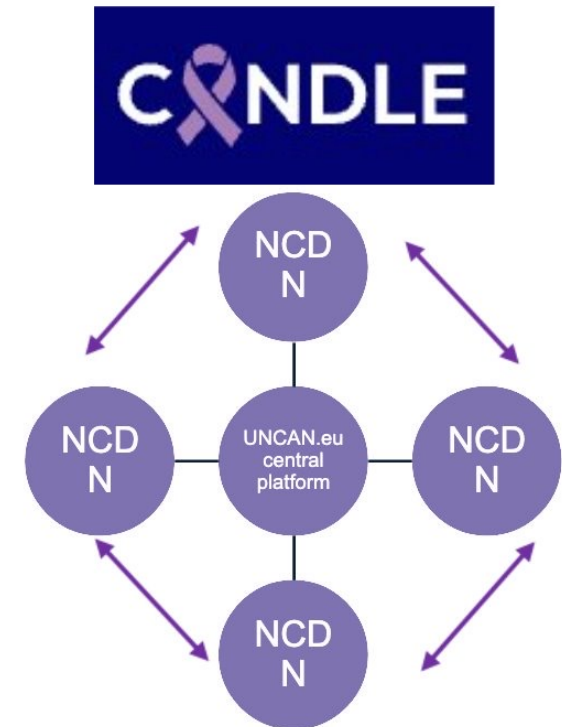
Looking forward to year 2

1. Establish the UNCAN.eu network of national cancer data nodes

- Topical working groups (incl. governance, data infrastructure, clinical)
- Work flow connecting national and central platforms
- National focal point
- National brain pool

2. Develop the blueprint of digital capabilities for national cancer data node

3. Implement roadmaps to onboard mature national cancer data nodes



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Thank you!



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