Where should screening take place and how do we effectively communicate the results?

Chantal Mathieu, MD, PhD

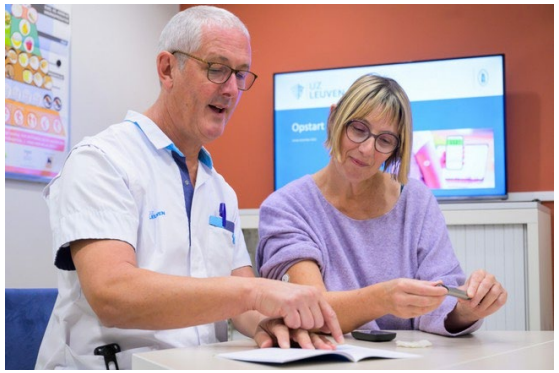
Breakthrough T1D™
Formerly JDRF

Conflicts of interest

Serves or has served on the advisory panel for Novo Nordisk, Sanofi, Eli Lilly and Company, Novartis, Dexcom, Boehringer Ingelheim, Bayer, Roche, Abbott, Medtronic, Insulet, Biomea Fusion, SAB Bio and Vertex. Financial compensation for these activities has been received by KU Leuven; KU Leuven has received research support for CM from Medtronic, Novo Nordisk and Sanofi; CM serves or has served on the speakers bureau for Novo Nordisk, Sanofi, Eli Lilly and Company, Medtronic, Dexcom, Insulet, Abbott, Vertex and Boehringer Ingelheim. Financial compensation for these activities has been received by KU Leuven. CM is president of EASD. All external support of EASD is to be found on www.easd.org.

Recommendations for context and settings for screening

IAb testing should be embedded in established public health activities that minimize the barriers to participation and leverage existing structures. These can include, but are not limited to, vaccination clinics and well-child clinic appointments. It is expected that different healthcare services will adopt the screening context that is most appropriate to their regional public health capacity and process.[E]
IAb screening should promote equity of access for all individuals, independent of socioeconomic status, ethnicity or regional location.[B]

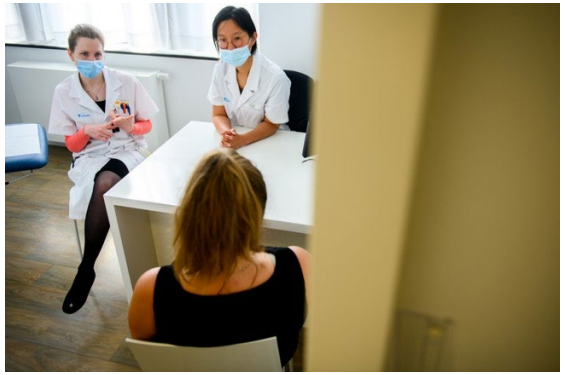


Pictures UZLeuven

Breakthrough T1D™ Formerly JDRF

Recommendations for context and settings for screening

Whenever and wherever screening is offered, the provider (the person managing the screening visit) should be knowledgeable on key points relevant to the screening process, including the components of prescreening awareness and information, the screening event, the delivery of results and any necessary referral process. It is expected that adequate reimbursement for these activities is available.[E]

Breakthrough T1D™ Formerly JDRF

Pictures UZLeuven

Effective communication of results

Communications planning before and after the immediate IAb screening activity is the responsibility of national or regional stakeholders. At minimum, communication should clarify both the purpose of IAb screening, what can be expected at the screening appointment and in the immediate period thereafter.[C]

Frlda

Autoimmunity Screening for Kids
ask
A SIMPLE TEST TO DETECT
Type 1 Diabetes (T1D) + Celiac

Type 1 Diabetes TrialNet
Breakthrough T1D™ Formerly JDRF

TYPE 1 DIABETES National Screening Pilot
SIMPLE TEST
BIG OUTCOMES
TEST FOR TYPE 1 DIABETES

EDENT1FI

DO YOU WANT TO BE SCREENED?
Click here!

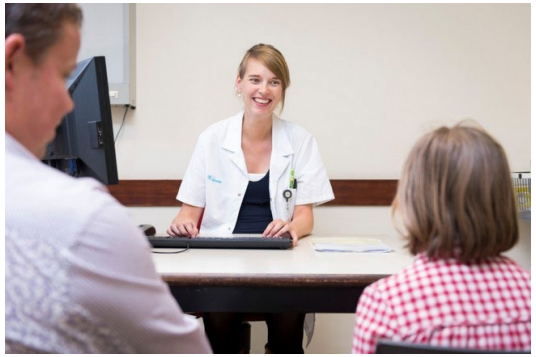
Useful links

- GPPAD
- INNODIA (non-profit organization)
- Hippo & Friends
- European pre-T1D Registry
- SWEET
- Br1dge
- T1D STEP AHEAD

Effective communication of results

Use clear and neutral terminology when communicating a screening test result. Until a screening result that detects the presence of IAb is confirmed, it is important to avoid language that creates avoidable anxiety for the screened individual.[E]
When communicating screening and confirmatory test results to the individual or caregiver, a personal contact should be offered to allow for the explanation of results. [E] All individuals should have the opportunity to express their immediate needs for information and support. [B]

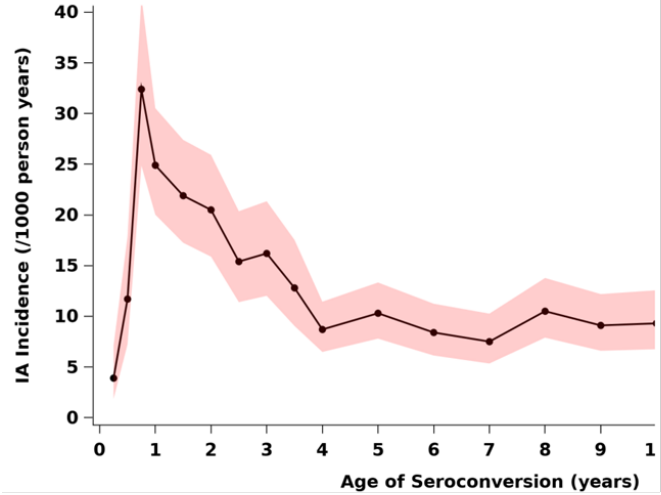




Pictures UZLeuven

Effective communication of results

Communication that IAb were not detected must emphasize that the current result does not preclude T1D in the future and rescreening may be recommended, particularly if the person is young or has a personal or family history of autoimmune disease.[C]



Diabetologia 2012, Diabetologia 2015

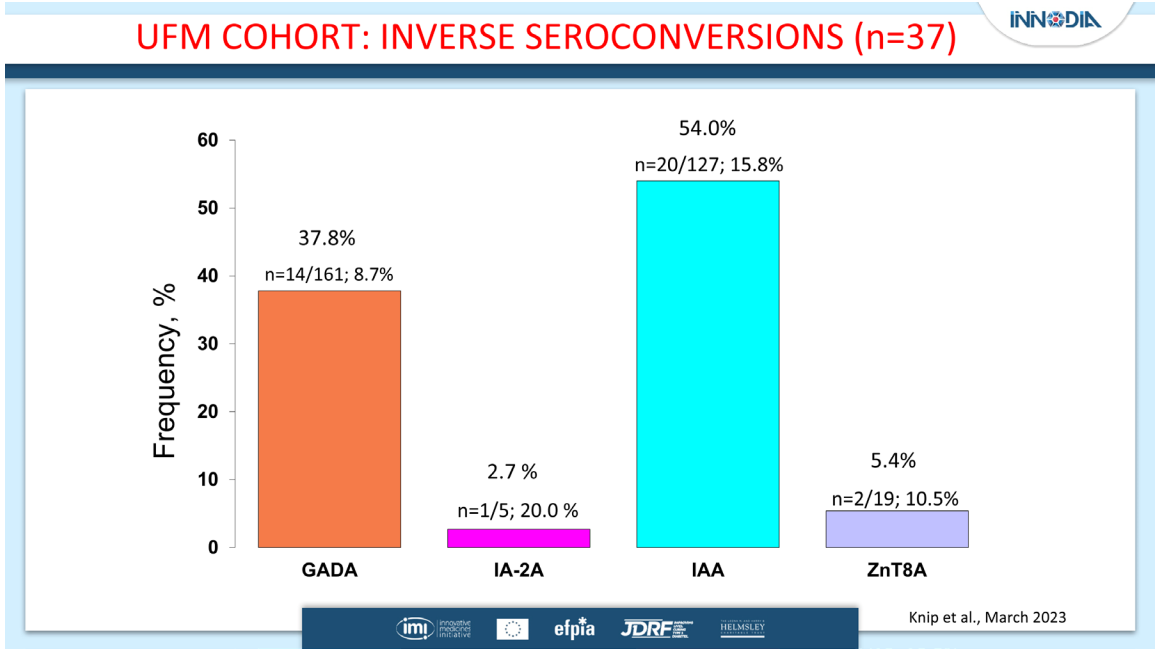
	Sensitivity
One screening: age 3-4 years (BABYDIAB, TEDDY, T1DI):	**40%**
Two screenings: age 2-3 and 6-7 years (TEDDY, T1DI, Fr1da):	**65%**
Three screenings: age 2-3 and 6-7 and 10 years (T1DI, Fr1da):	**80%**

BMJ open 2016
Diabetes Care 2019
Lancet Endocrinol 2022
Lancet Child Adolesc Health. 2023
Diabetologia 2025
DOM 2025

Breakthrough T1D™ Formerly JDRF

Effective communication of results

If a single IAb is detected, future rescreening may be recommended based on age and other factors.[B]



Breakthrough T1D™
Formerly JDRF

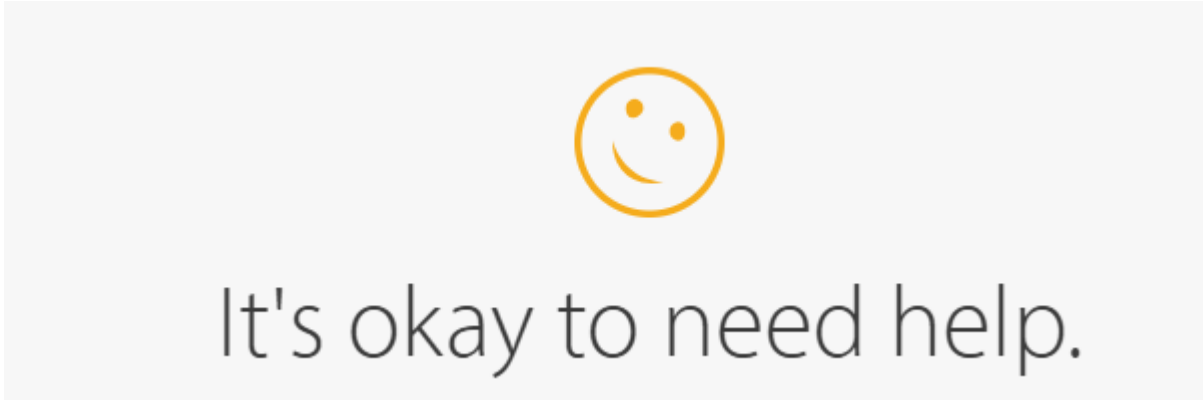
Effective communication of results

All screening participants should be provided with clear information about identifying the symptoms of T1D.[E]

Breakthrough T1D™ Formerly JDRF

Effective communication of results

HCPs should be aware of psychological reactions to the delivery of a diagnosis of early-stage T1D, in order to take actionable steps (e.g. provide information/education, referral and/or monitoring plan). When necessary, professional psychological support should be offered to reduce anxiety [C]



Childrenwithdiabetes.com

Breakthrough T1D™
Formerly JDRF

Evidentiary gaps

Should we screen adults for early stage T1D?

Single antibodies and their meaning?

What is the optimal setting for screening and follow up?

Can we get good/better assays at low cost?

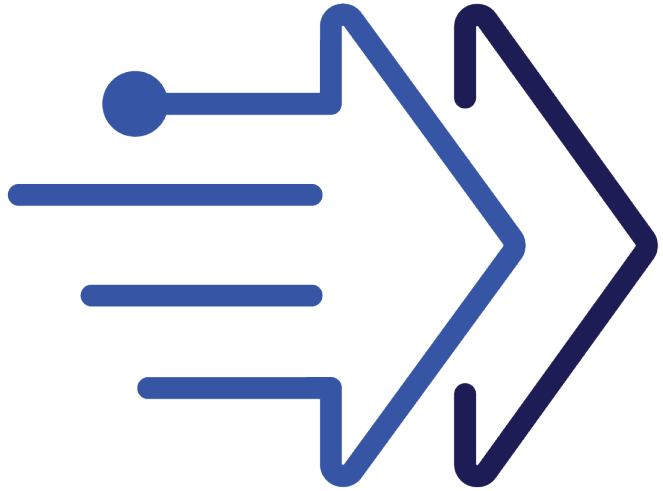
How about early-stage T1D and disease progression in non-white ethnicity demographics?

Rate of progression in an individual: how can we harness precision medicine to come to a personalized approach in monitoring and interventions with disease modifying therapies?

Next steps and timeline

Peer Review with EASD and ADA

Public comment and endorsement from global diabetes societies and organizations

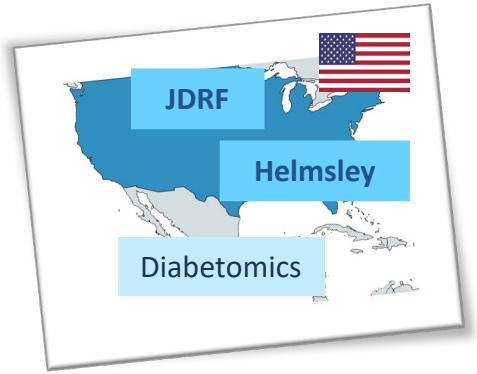


Implementation and research to fill the evidentiary gaps

Breakthrough T1D™
Formerly JDRF

Many questions left for general population screening for early stages of T1D implementation

- How to organize screening in a specific country/region, with a specific health care system
- How to organize screening in the setting of specific belief backgrounds (religion, emotion, trust in system…)
- How to communicate to the general population about T1D and importance of early detection
- How to define benefit of early detection
- How to organize monitoring
- How to integrate early detection in HC systems
- How to communicate to HCPs, HC systems and regulators on importance of early detection
- How to measure impact (beneficial and harmful) of early detection
- How do people (with T1D) see this early detection



Chantal Mathieu, KUL, Leuven, Belgium
Anette G. Ziegler, HMGU, Munchen, Germany
Mark Peakman, Sanofi, Frankfurt, Germany
Carmen Hurtado (TBC), US, JDRF

ULUND

UTU, Turku
TAU, Tampere

DiaUnion

KCL, London
UOXF, Oxford
UoB, Birmingham
CU, Cardiff

RegionH, Copenhagen

NovoNordisk

SUM, Katowice
MUW, Warsaw

Medtronic

Digostics Limited

C-Path

HMGU, Munchen
TUD, Dresden
HKA, Hannover

Barnard Health

RSR

KUL, Leuven
EUDF, Brussels

Sanofi

Imcyse

UH Motol, Prague

MUG, Graz

ADPD, Lisbon

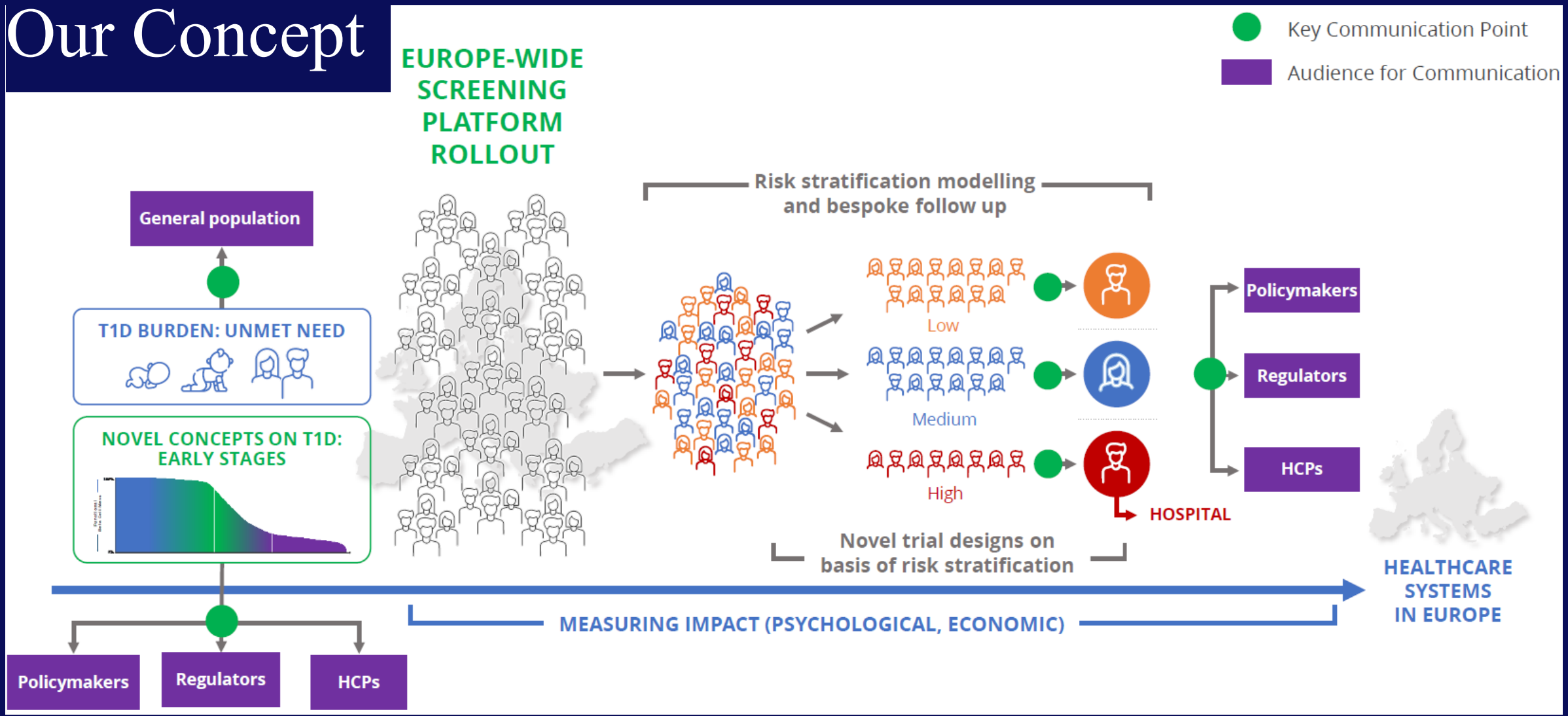
Univ. De Açores

UNISI, Siena
OSR, Milan

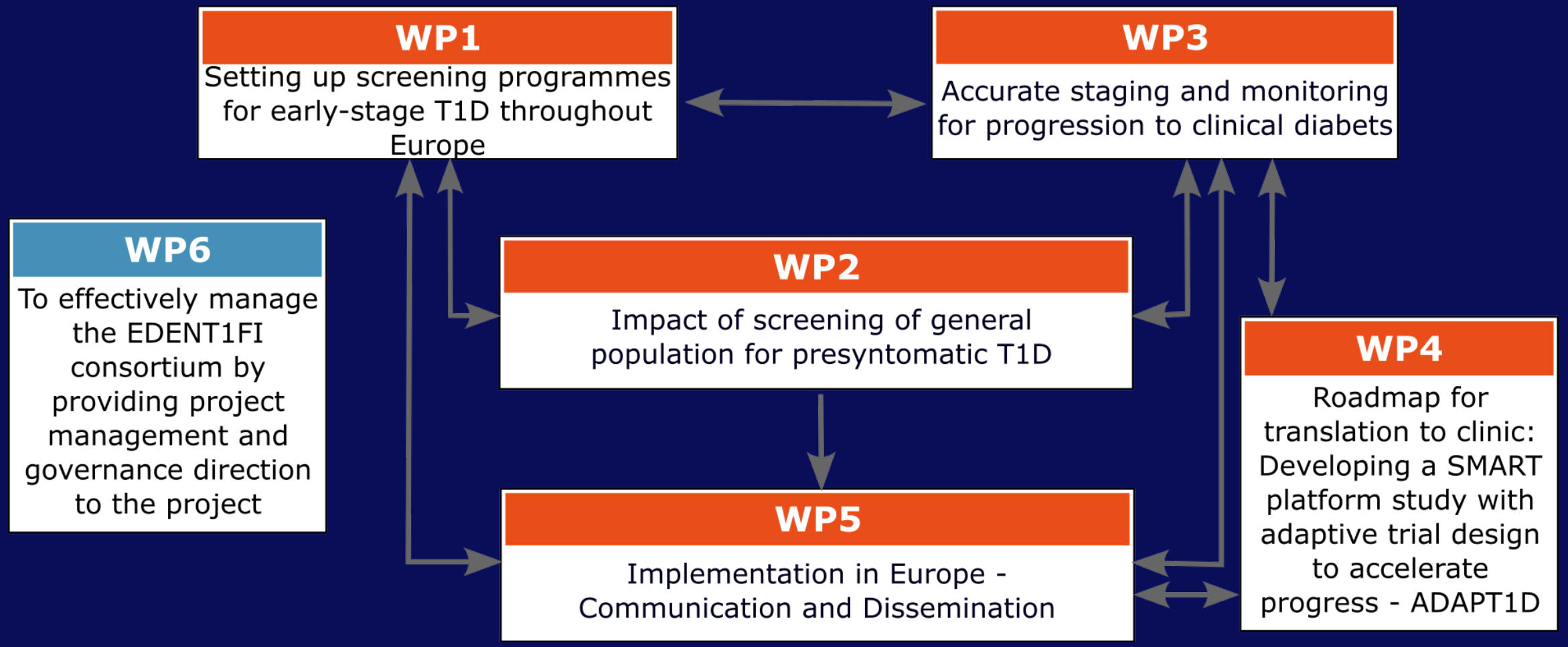
We are EDENT1FI

www.edent1fi.eu

Our Concept


Key Communication Point
Audience for Communication
EUROPE-WIDE SCREENING PLATFORM ROLLOUT
Risk stratification modelling and bespoke follow up
General population
T1D BURDEN: UNMET NEED
NOVEL CONCEPTS ON T1D: EARLY STAGES
Low
Medium
High
HOSPITAL
Policymakers
Regulators
HCPs
Novel trial designs on basis of risk stratification
HEALTHCARE SYSTEMS IN EUROPE
MEASURING IMPACT (PSYCHOLOGICAL, ECONOMIC)
Policymakers
Regulators
HCPs

OUR WORK PACKAGES

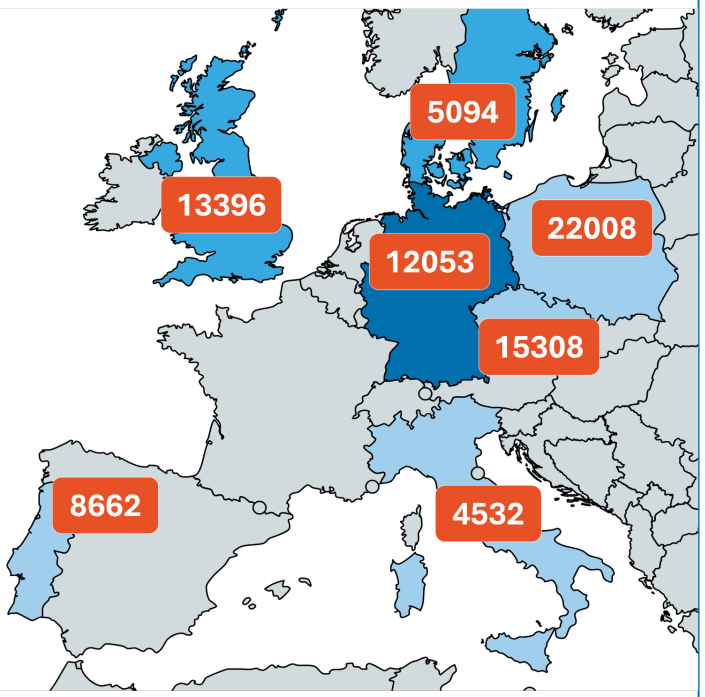


OUR SCREENING PROGRAMS

Screening results within EDENT1FI so far: **81 053 children screened!**

	COUNTRY (INSTITUTE)	200 000
LEVEL 3	***Established programs*** Germany (HMGU Munich) Germany (HKA Hanover)	***Target*** 35 000 10 000
LEVEL 2	***Planned or started prior to EDENT1FI*** Germany (TUD Dresden) Denmark/Sweden (SDCC-RH) UK (UoB Birmingham)	***Target*** 15 000 40 000 20 000
LEVEL 1	***New regions*** Italy (OSR Milan) Czechia (UH Motol Prague) Poland (MUW Warsaw) Poland (SUM Katowice) Portugal (APDP Lisbon)	***Target*** 15 000 22 000 23 000 10 000 11 000

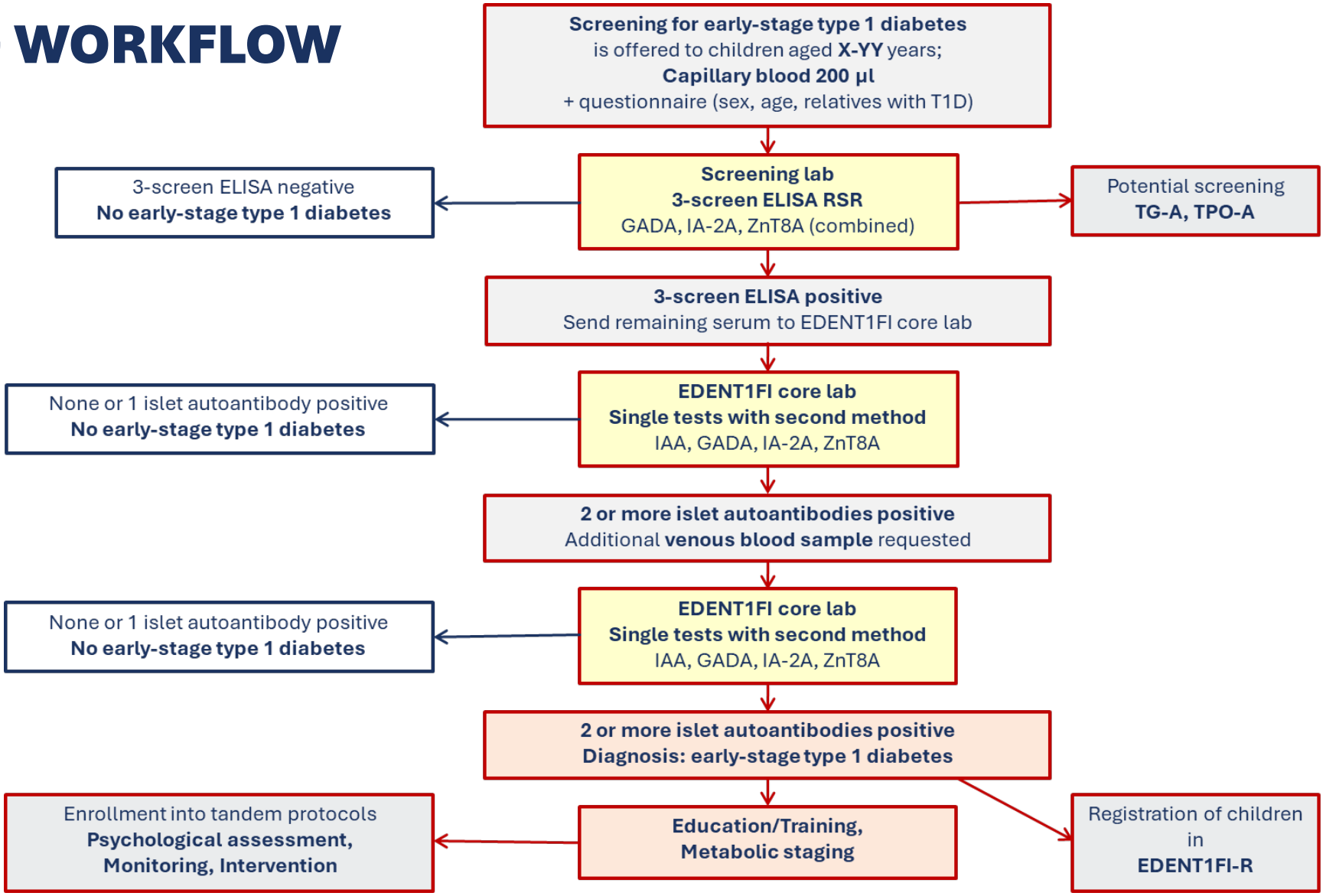
Sample obtained (October 9, 2025)



Frida Typ 1 Diabetes: Früh erkennen – Früh gut behandeln · DiaUnion · ELSA · D1Ce Screen · Betty · EDENT1FI European action for the Diagnosis of Early Non-clinical Type 1 diabetes For disease Interception · apdp Associação Protectora dos Diabéticos de Portugal

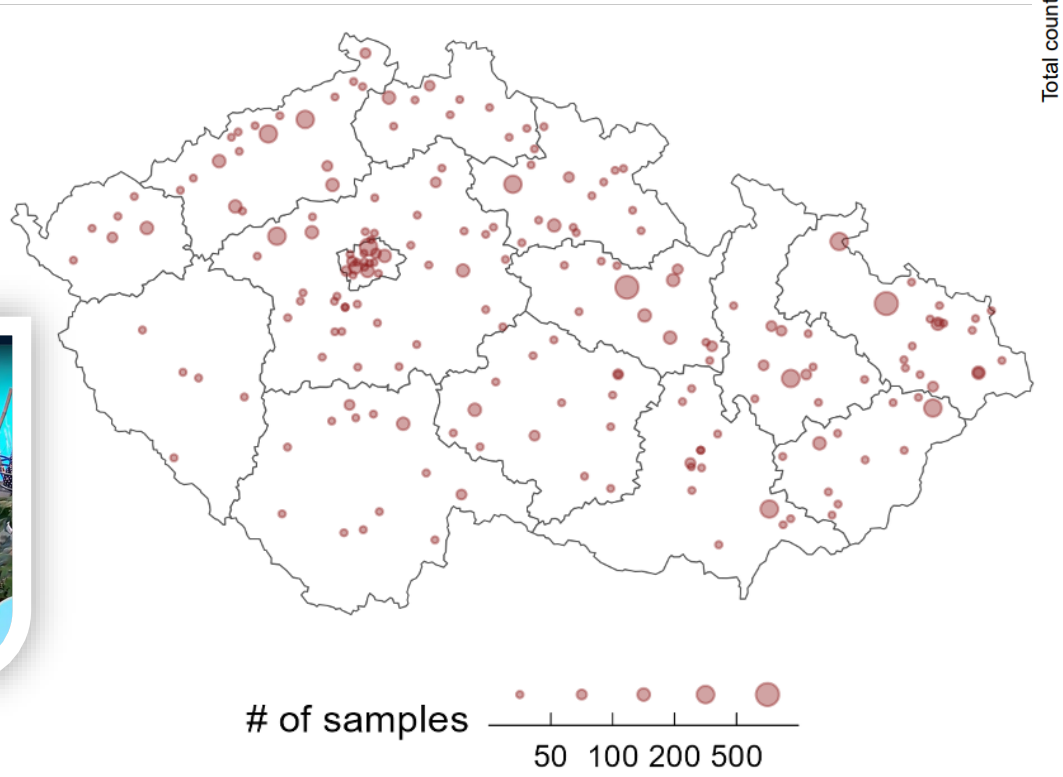
Updated in October 2025

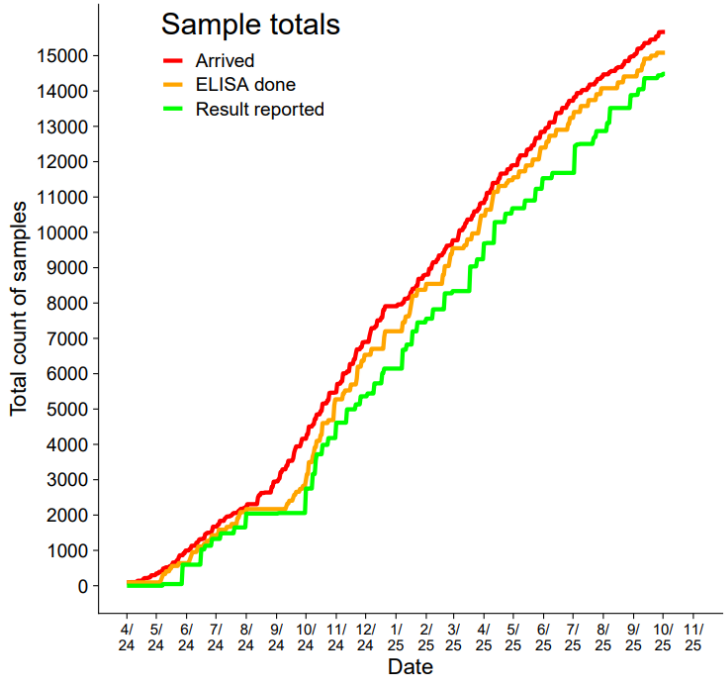
SCREENING WORKFLOW



EXAMPLE: CZECHIA

- Screening in more than 260 sites;
- Including primary care, pediatric diabetologists, departments of pediatrics.

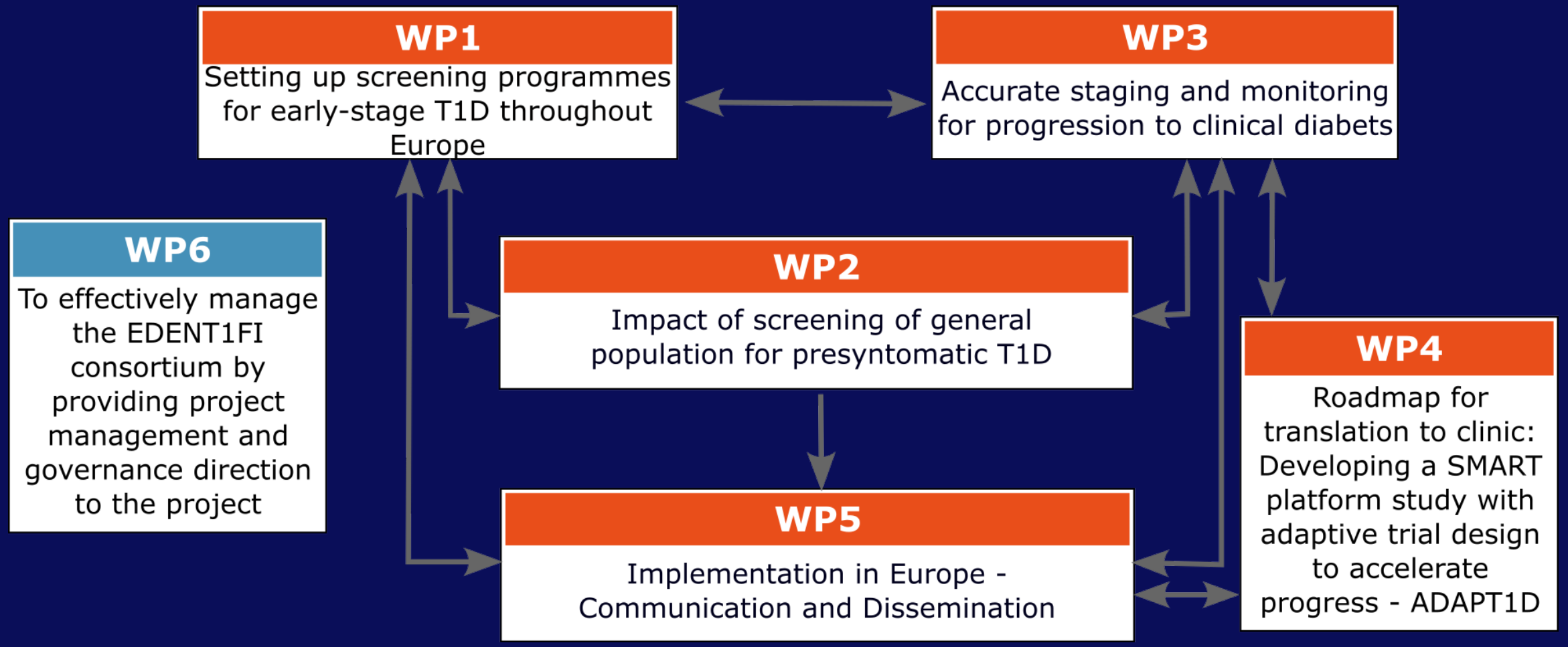




15.308 CHILDREN SCREENED!

Updated in October 2025

OUR WORK PACKAGES



sanofi Early Cost-Effectiveness Model of Screening for Type-1 Diabetes

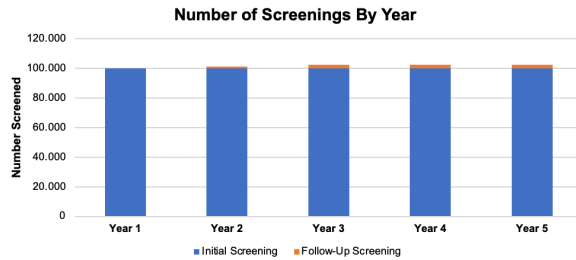
Organisational Impact

Screening Programme

Number of individuals screened	Year 1	Year 2	Year 3	Year 4	Year 5
Number of initial screenings	100.000	100.000	100.000	100.000	100.000
Number of follow-up screenings	0	1.263	2.526	2.526	2.526
Total screenings	100.000	101.263	102.526	102.526	102.526
Cumulative	100.000	201.263	303.789	406.314	508.840

Source: Placeholder

Distribution of positive screens	Year 1	Year 2	Year 3	Year 4	Year 5
Total confirmed positive screens	3.191	3.191	3.191	3.191	3.191
Multiple autoantibodies at screening	459	459	459	459	459
Single autoantibody at screening	2.545	2.545	2.545	2.545	2.545
Will develop T1D	382	382	382	382	382
Won't develop T1D	2.163	2.163	2.163	2.163	2.163
No autoantibodies at screening	187	187	187	187	187

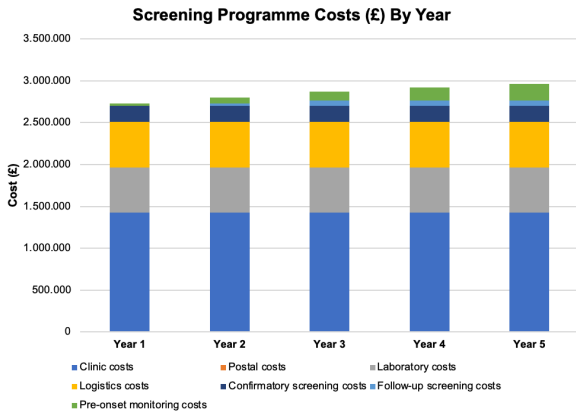


Cost of Screening Programme (£)

Option for organisation of screening: Fr1da

Go to Cost Inputs

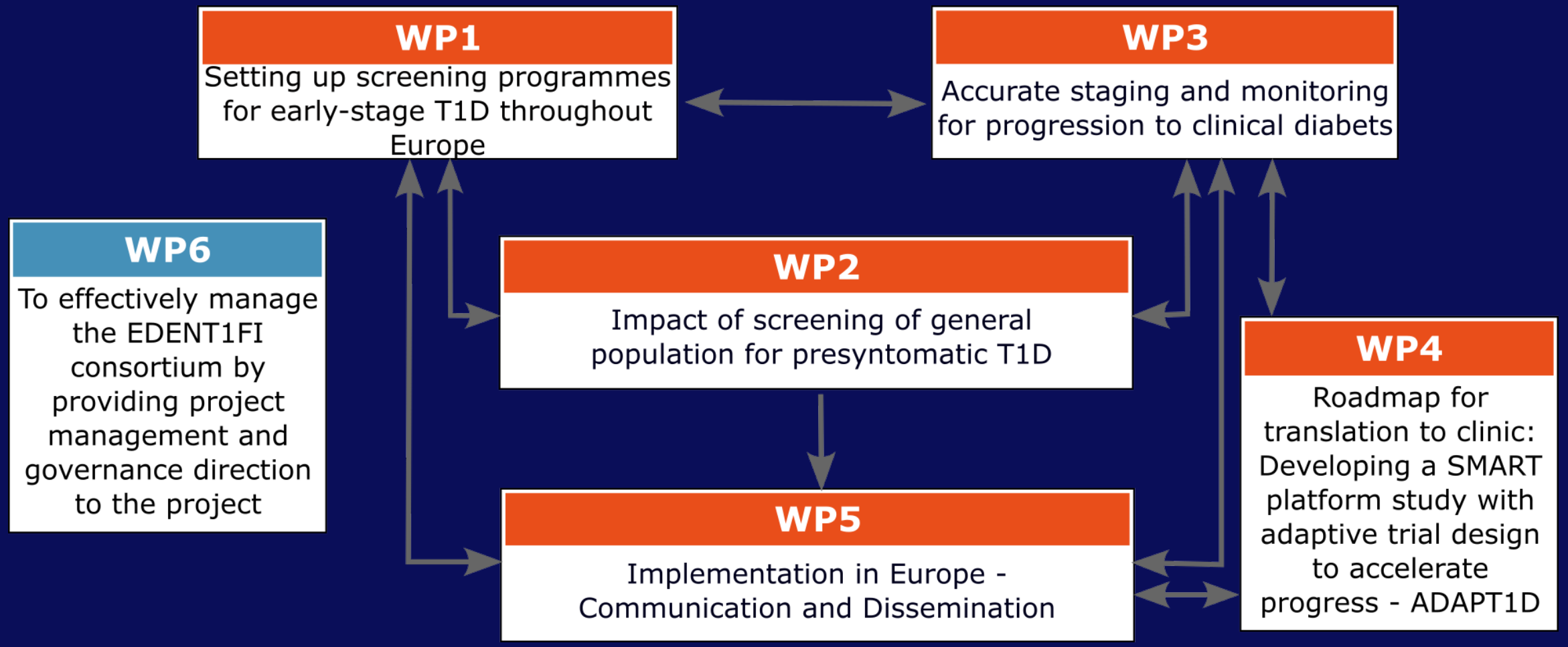
With Screening	Year 1	Year 2	Year 3	Year 4	Year 5
Clinic costs	*1.424.618*	*1.424.618*	*1.424.618*	*1.424.618*	*1.424.618*
Postal costs	*0*	*0*	*0*	*0*	*0*
Laboratory costs	*543.099*	*543.099*	*543.099*	*543.099*	*543.099*
Logistics costs	*543.099*	*543.099*	*543.099*	*543.099*	*543.099*
Total initial screening costs	2.510.817	2.510.817	2.510.817	2.510.817	2.510.817
Cumulative	2.510.817	5.021.633	7.532.450	10.043.267	12.554.084
Confirmatory screening costs	186.965	186.965	186.965	186.965	186.965
Cumulative	186.965	373.931	560.896	747.862	934.827
Follow-up screening costs	0	34.782	69.564	69.564	69.564
Cumulative	0	34.782	104.347	173.911	243.475
Pre-onset monitoring costs	33.288	66.673	107.071	153.061	198.078
Cumulative	33.288	99.961	207.032	360.093	558.171
TOTAL COSTS	**2.731.070**	**2.799.237**	**2.874.417**	**2.920.407**	**2.965.425**
Cumulative	**2.731.070**	**5.530.308**	**8.404.725**	**11.325.133**	**14.290.557**



DKAs With Screening vs Without Screening

Incremental	Year 1	Year 2	Year 3	Year 4	Year 5
Number of DKAs at onset	-7	-17	-29	-43	-58
Cumulative	-7	-24	-53	-96	-155
Deaths from DKA at onset	0	-1	-1	-2	-3
Cumulative	0	-1	-3	-5	-8
Cost of DKA at onset (£)	-12.709	-32.148	-55.415	-81.118	-110.023
Cumulative	-12.709	-44.857	-100.272	-181.390	-291.413

OUR WORK PACKAGES

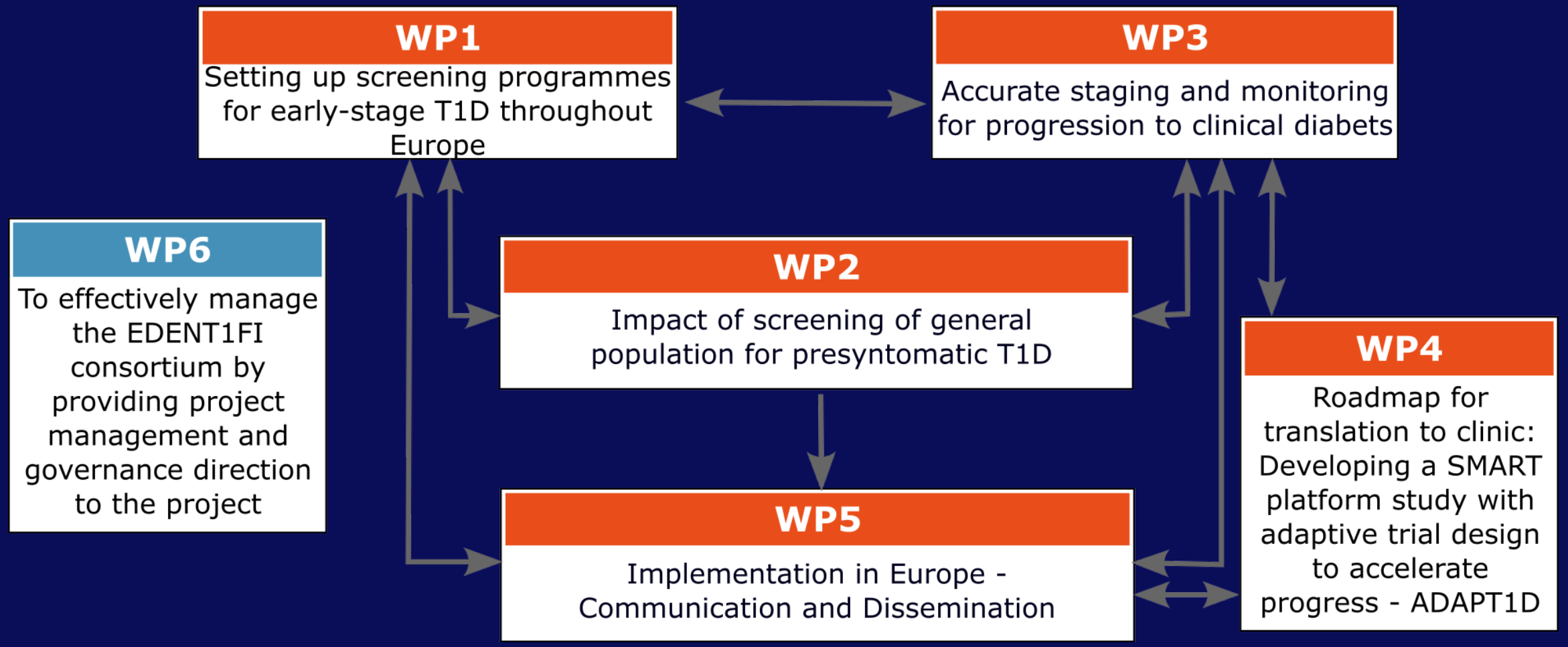


EDENT1FI MONITORING PROTOCOL

EDENT1FI WP3 follow-up	Tier 1 Low (2 yr rate: <5%)	Normoglycemia* Age over 2 y Progression score <0.5	Baseline Yearly	Times of illness/ symptoms	Baseline Yearly	Baseline 2 yearly	yearly	Yearly: PBMCs, PAX tube, Flow tube Yearly in Tier 1, 6-monthly in Tier 2 & 3: Serum for small RNA, inflammation, virus antibodies At baseline, Year 1 and initiating insulin: EQ5D, HADS, SAI
	Tier 2 Moderate (2 yr rate: 20%)	Normoglycemia and age < 2y or with progression score 0.5 – 4.0	Baseline 6-monthly	6-monthly, Times of illness/ symptoms	Baseline 6-monthly	Baseline 2 yearly	6-monthly	
	Tier 3 High (2 yr rate 50%)	Dysglycemia (Stage 2)* Or Progression score >4.0	Baseline	Monthly, Times of illness/ symptoms	Baseline 3-monthly	Baseline 2 yearly	3 monthly	
Light Touch recommendations **	Undefined		Baseline, 6-monthly if IA2 negative	Times of illness/ symptoms	Baseline 6-monthly	Baseline		Contact and information on diabetes development requested

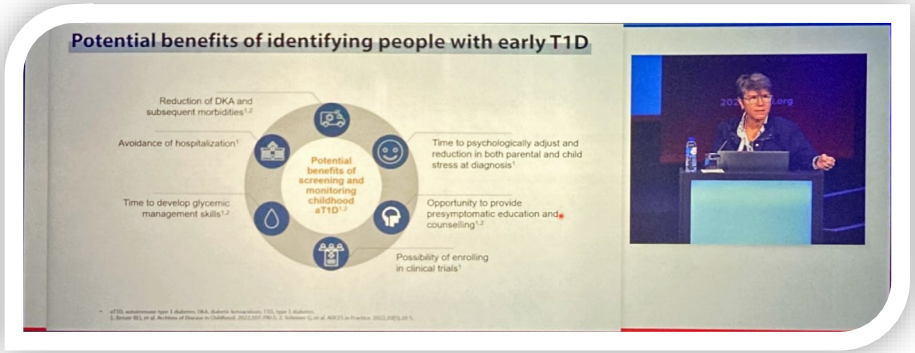
Updated in October 2025

OUR WORK PACKAGES



EDUCATING HCPs

EASD 2024



IDS 2024

THE BR1DGE SUMMIT 2025

ISPAD 2024

ATTD 2025

EASD 2025

PRESENCE IN THE MEDIA

Home › Badania › Katowice na froncie walki z cukrzycą typu 1. Rusza europejski program badań dzieci

Katowice na froncie walki z cukrzycą typu 1. Rusza europejski program badań dzieci

Cukrzyca typu 1 atakuje dzieci często bez ostrzeżenia, a rozpoznanie zbyt późno może kosztować życie. Dlatego w Katowicach rusza bezprecedensowy projekt – EDENT1FI – którego celem jest wczesne wykrycie choroby zanim ujawni się choćby jeden objaw. To nie tylko nadzieja dla tysięcy rodzin, ale także szansa na całkowitą zmianę podejścia do diagnostyki i prewencji tej wyniszczającej choroby.

Paediatric Diabetes

This Feature episode, introduced by EASD President Chantal Mathieu, focusses on some much-debated topics in paediatric diabetes care. Anette-Gabrielle Ziegler, who established the Fr1da Study, explains why screening for T1D in children. ISPAD President Carine De Beaufort addresses the special needs of small children living diabetes and the evidence-based treatment options which reduce disease burden, referencing the KidsAP study and the 2022 ISPAD Clinical Practice Consensus Guidelines. First author of the ISPAD Guideline on insulin treatment, Eda Cengiz, expands on the possible future use of AID systems and builds a bridge to learning technology for patient and staff education.

APDP | crianças | deteção precoce | diabetes tipo 1 | EDENT1FI | JOVENS | Prevenção | rastreios | saúde pública

APDP realiza mais de 5 mil rastreios à diabetes tipo 1 em apenas 6 meses

3 de Abril 2025

A campanha "O Dedo Que Adivinha", liderada pela APDP no âmbito do projeto europeu EDENT1FI, ultrapassou cinco mil rastreios de diabetes tipo 1 em crianças e jovens em Portugal. Em apenas seis meses, a iniciativa alcançou metade da meta nacional prevista para os próximos quatro anos.

COMMUNICATION CAMPAIGN FOR THE GENERAL PUBLIC

www.itsinyourhands.eu

ENGAGING WITH LOCAL AND EUROPEAN POLICY MAKERS

European Diabetes Forum (EUDF)International
Europe)Parliamentarians for Diabetes Global
Diabetes Federation (FEDE)

Sep 19, 2024 | 16:00 | 6 min. read

Euractiv is part of the Trust Project

Print Share

This article is part of our special report Diabete

Last week key stakeholders from across the dia
the 60th Annual Meeting of the European Assoc
On this occasion, the European Diabetes Forum
Federation (IDF) Europe, the Spanish Diabetes Federation (FEDE), the Parliamentarians

EURACTIV

Ukraine The Capitals VDL 2.0 Defence | Newsletters Podcasts Events Jobs Intelligence

Health Promoted content

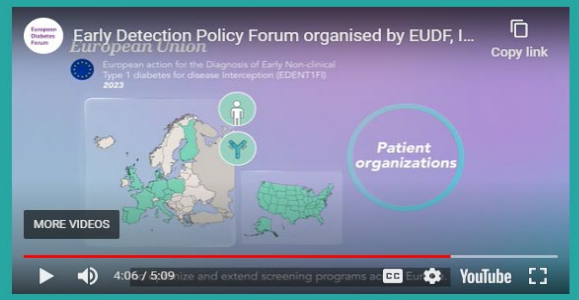
Type 1 Diabetes can be fast, but we can be faster! A call to boost early detection

Early Detection Policy Forum

For the advancement of policies for early detection of type 1 diabetes (T1D), we brought together key stakeholders from the T1D community in Madrid to take part in the Early Detection Policy Forum.

Following the success of the Early Detection Policy Forum, we are delighted to share this joint call to action to boost EU policies to ensure early detection for T1D published by Euractiv.

Call to Action



November 4th 12:00-14:00
European Parliament, Brussels

EARLY DETECTION, BETTER OUTCOMES

Addressing unmet needs in type 1 diabetes

We are EDENT1FI