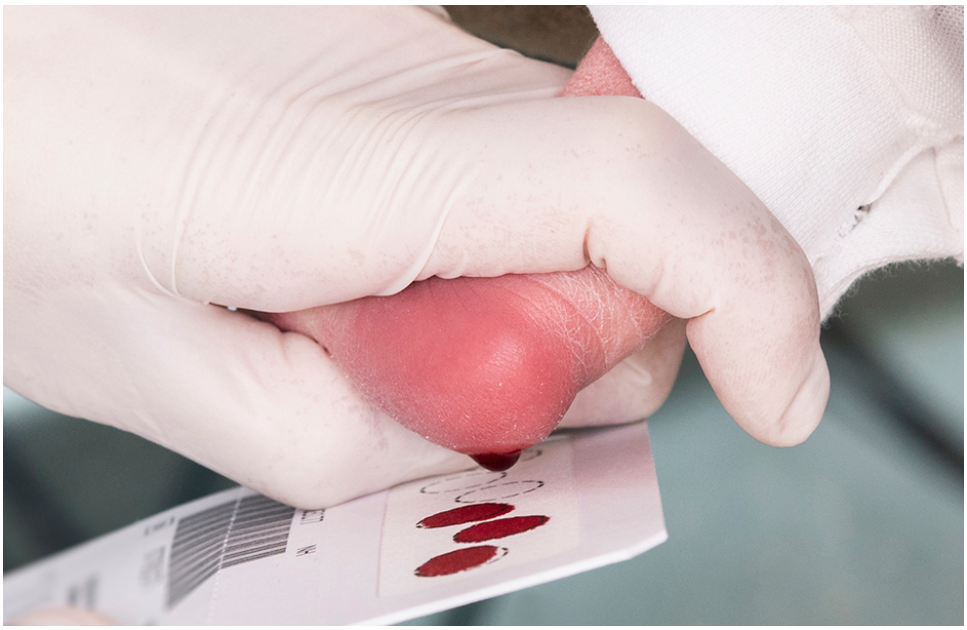
THE NEWBORN BLOOD SPOT SCREENING IN THE NETHERLANDS

MONITOR 2021



TNO innovation for life

The aim of the Newborn Blood Spot screening programme (NBS) is the early detection of a number of serious, rare, congenital conditions in newborns. The target disease is the variant of the disorder we want to detect with neonatal screening. The screening is designed to preferably detect all children with the target disease and no or as few as possible children with another variant (secondary finding). If these target diseases are detected early, irreversible health damage can be prevented or limited through timely treatment with, for example, medication or diet.

The national monitor with main results of the NBS is carried out annually by TNO at request of the RIVM-CvB. The monitor enables insight into the functioning of all aspects of the NBS as well as insight into a possible need for extra measures to allow for an improvement in functioning of the screening programme. A separate monitor is made about the NBS in the Caribbean Netherlands (in Dutch).

SUMMARY

Table 1
Results of the most important indicators for children born in 2021 and 2020

	2021	2020
Number of screened children (eligible)	179,095 (180,606)	168,683 (169,734)
Participation rate	99.2%	99.4%
Number referred (incl. OCTN2) (%)	522 (0.29%)	450 (0.27%)
Number with target disease (excl. OCTN2)	206	176
Number with still unknown diagnosis	10	15
Detection rate per 1000	1.150	1.043
Positive predictive value (all target diseases combined)	42% [1]	42%
Sensitivity	99% [2]	98%
Specificity	99.839%	99.854%
1st heel prick taken within 168 hours	98.3%	98.5%
1st heel prick in recommended period (72-96 hours after birth)	39%	40%
1st heel prick taken 72-120 hours after birth	70%	71%
Repeated 1st heel prick (by condition; %)	0.10% - 0.35% [3] HbP 0.47%	0.04% – 0.26% HbP 0.43%
Timely diagnosis CAH, CH, MD, HbP, CF, SCID (%)	73, 80, 88, 82, 72, 90	90, 88, 89, 81, 77, -
Costs per child screened	€ 133	€113
Objection to use of residual blood for scientific research	7.9%	7.1%

Green: target value met; red: target value not met
[1] In 2021, target values for the positive predictive value of individual diseases are met for all diseases except SCID (3%; target >10%)
[2] Two children born in 2021 were reported as false-negative (1 for CH, 1 for CF). The target value of 100% for sensitivity of CH and CF was thus not achieved. Furthermore, one child from an earlier birth year was reported as missed. This child was born in 2020 and was diagnosed as having CF without meconium ileus.
[3] Target values for the repeated heel prick rate (≤0.30% for all conditions, except HbP ≤0.50%) were achieved in 2021 for all conditions except BIO (0.35%), MPS I (0.33%) and SCID (0.31%).

RECOMMENDATIONS

Existing recommendations that are still valid:

- Intensify actions to improve **timeliness of the first heel prick.**
- Improve the **timeliness of diagnostics** for CAH, CH, MPS I, HbP and CF.
- Continued attention to **timely and clear registration** of diagnostic data.
- Continued attention to **false-negative results and missed patients:** it remains important to investigate the cause and discuss whether they can be prevented.

New recommendations:

- Set a target value for the recommended period for first heel prick (72-96 hours after birth or in case of simultaneous hearing screening 72-120 hours after birth).

DATA SOURCES

The screening data in this monitor originate from the Praeventis registration system of the RIVM. Diagnostic data originate from the NEORAH registration system of the RIVM (http://www.neorah.nl).
In previous years diagnostic CH data were registered by TNO; from 2018, paediatricians register these diagnostic CH data in NEORAH. The NEORAH data related to metabolic diseases have been retrieved from the Dutch Diagnosis Registration Metabolic Diseases (www.ddrmd.nl). Notifications of the Dutch Paediatric Surveillance System (NSCK) have been used to detect possible missed cases until 1st of January 2020. From 1 January 2020, paediatricians report missed patients to RIVM (see draaiboek hielprikscreening (in Dutch)–Kinderarts) because the NSCK has been discontinued. This monitor concerns **children who were born in 2021** (Praeventis reference data: 1-3-2022, NEORAH: 8-7-2022 or later[1]).

[1] The reference date was 28-7-2022 for PA, 22-8-2022 for MMA and 27-9-2022 for HbP and missed children, 26-10-2022 for SCID, 16-11-2022 for CAH and 17-11-2022 for CF.

READING GUIDE

This monitor differentiates between the first heel prick, a repeat first heel prick, a second heel prick and a repeat second heel prick:

- First heel prick: the first heel prick that has been carried out;
- Repeat first heel prick: the newborn blood spot collection that is repeated because insufficient blood has been collected during the first heel prick in order to carry out the required laboratory analyses ('insufficient filling') or because the material is unreliable (contamination), or because the first heel prick was taken too early (within 48 hours after birth), or because a child received a blood transfusion within 24 hours before the heel prick was carried out. If a blood transfusion with erythrocytes has been carried out, the heel prick needs to be repeated after 91 days to test for haemoglobinopathies (HbP);
- Second heel prick: carried out if the first heel prick gives an inconclusive laboratory result;
- Repeat second heel prick: as in repeat first heel prick.

In this monitor the colours green and red indicate whether the results meet the prior indicated signal- or target values.

- The values which fall within the indicated limits are indicated in green.
- Values outside the formulated limits are indicated in red. If possible, actions can be taken to improve the results or to get the results to fall within the limits of the target value.
- Signal- or target values for trends do not exist. Trends which require vigilance, are indicated in orange. Stable trends are indicated in green.

WHICH CONDITIONS ARE INCLUDED IN THE SCREENING?

- **Congenital adrenal hyperplasia (CAH)**
- **Cystic fibrosis (CF)**
- **Congenital hypothyroidism (CH)**
- **Severe combined immunodeficiency (SCID)** *(new, since January 1st, 2021)*
- **Hemoglobinopathies (HbP):**
  - Sickle cell disease (SCD)[1]
  - HbH-disease (HbH), a form of alpha-thalassemia
  - Beta-thalassemia major (bTM)
- **Metabolic diseases (MD):**
  - 3-Methylcrotonyl-CoA carboxylase deficiency (3-MCC)[2]
  - Biotinidase deficiency (BIO)
  - Carnitine palmitoyltransferase deficiency type 1 (CPT1)
  - Galactokinase deficiency (GALK)
  - Galactosemia (GALT, formerly called GAL)
  - Glutaric acidemia type 1 (GA-1)
  - HMG-CoA-lyase deficiency (HMG)[2]
  - Isovaleric acidemia (IVA)
  - Maple syrup urine disease (MSUD)
  - Medium-chain acylCoA dehydrogenase deficiency (MCADD)
  - Methylmalonic acidemia (MMA)
  - Mucopolysaccharidose type 1 (MPS I) *(new, since March 1st, 2021)*
  - Multiple CoA carboxylase deficiency (MCD)[2]
  - Phenylketonuria (PKU)
  - Propionic Acidemia (PA)
  - Trifunctional Protein deficiency/ Long-chain hydroxyacyl-CoA dehydrogenase deficiency (TFP/LCHAD)
  - Tyrosinemia type 1 (TYR-1)
  - Very-long-chain acylCoA dehydrogenase deficiency (VLCAD)

More information about these conditions can be found on the RIVM website:
https://www.pns.nl/hielprik

[1] OCTN2 deficiency and SCD carrier status are not part of the screening programme, these are secondary findings. However, the result is reported to parents (the SCD carrier status is only reported if parents did not object to receive the result).
[2] These three conditions are reported combined under one name, 3-MHM, since they have the same screening marker.

PARTICIPATION

In 2021 180,606 children were eligible to participate in the NBS. A heel prick was performed on 179,095 children. This means that the participation rate in 2021 is 99.2%, which is higher than the target percentage of 99.0% but slightly lower than in 2019 (99.3%) and 2020 (99.4%) (Figure 1).

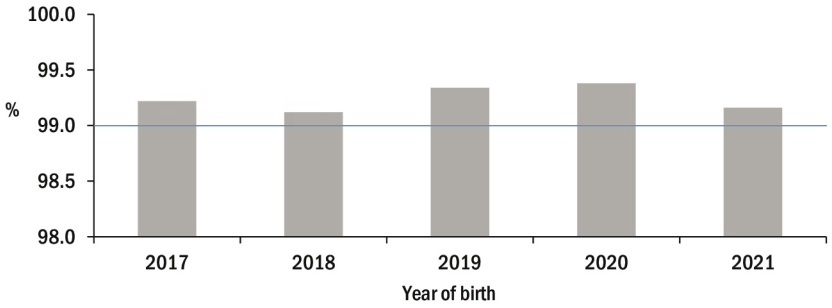


Figure 1
Participation rate of the neonatal screening programme by year of birth (2017-2021); to support readability the y-axis starts at 98%; the blue line indicates the target value .

Figure 2 shows that parents more often object to participate than previous years (0.61% in 2021 versus 0.42% in 2020). 'Tested elsewhere', such as a heel prick abroad, is in 2021 (0.19%) similar to 2020 (0.18%), and smaller than the years before (0.23% in 2019 and 0.27% in 2018). The reasons 'left' (e.g. left the country, or child untraceable) and 'unknown' are rare (both 0.02% in 2021).

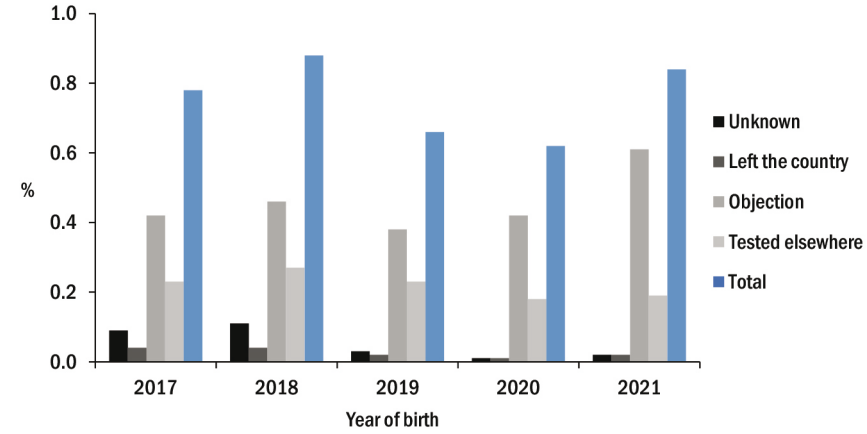


Figure 2
Reasons for non-participation in the neonatal screening programme by year of birth (2017-2021)

TIMELINESS OF BLOOD COLLECTION

The first heel prick should be carried out within 168 hours (7 days) after birth, but ideally as soon as possible after 72 hours after birth. In 2021 the percentage of first heel pricks carried out within 168 hours after birth is 98.3% (excluding children born abroad). This is lower than in previous years (98.5% in 2020, figure 3). The target value of at least 99.0% still has not been achieved (figure 3). Late birth registration and weekend days complicate timely screening.

In 38.7% of children, newborn blood spots were collected in the recommended period between 72 and 96 hours after birth. This seems to be a good outcome in the current situation, as circa 77% of the heel pricks is combined with the hearing screening, with the latter to be performed from 96 hours after birth. In 70.3% of children, the heel prick was performed 72-120 hours after birth.

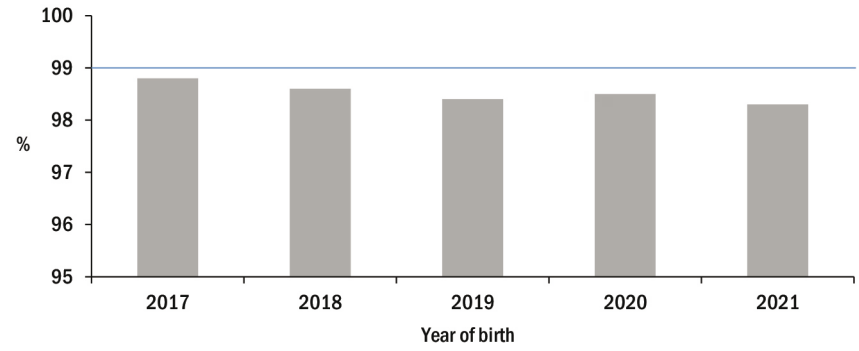


Figure 3
Timeliness of the blood spot collection by year of birth (2017-2021). Children born outside the Netherlands are excluded (the blue line indicates the target value; to support readability the y-axis starts at 95%)

REPEAT FIRST HEEL PRICK

Some of the blood spot collections need to be repeated, for example because insufficient blood was collected on the heel prick card. From 2017 to 2021, there has been a decreasing trend in the percentage of repeated first heel pricks for all conditions (table 2). However, in 2021, the rate of repeat heel pricks has increased for all conditions. Despite this increase, in 2021 the target values were met for all conditions except BIO, MPS I and SCID (analyses for MPS I and SCID are performed last and are therefore more likely to be omitted in the analysis of the first heelprick in case of insufficient blood). In the years before 2021, target values were higher (see footnote below table), but the current tightened target values were achieved in 2019 and 2020 for all conditions.

Table 2
Repeat first heel pricks* according to birth year (2017-2021)

% of repeat first heel pricks		2017	2018	2019	2020	2021	Number in 2021	Target value[1]
CAH		0.09	0.08	0.06	0.04	0.06	100	≤0.30
CH		0.503	0.42	0.27	0.22	0.27	486	≤0.30
CF		0.52	0.42	0.30	0.24	0.30	536	≤0.30
HbP		0.70	0.59	0.47	0.43	0.47	847	≤0.50
MD	3-MHM	0.20	0.18	0.18	0.12	0.14	242	≤0.30
	BIO	0.46	0.37	0.29	0.26	0.35	621	≤0.30
	CPT1			0.15	0.12	0.14	253	≤0.30
	GALK				0.10	0.14	253	≤0.30
	GALT	0.23	0.18	0.15	0.11	0.13	237	≤0.30
	GA-1	0.20	0.18	0.18	0.12	0.14	242	≤0.30
	IVA	0.20	0.18	0.18	0.12	0.14	242	≤0.30
	MSUD	0.17	0.14	0.12	0.09	0.10	179	≤0.30
	MCADD	0.20	0.18	0.18	0.12	0.14	242	≤0.30
	MMA			0.15	0.12	0.14	246	≤0.30
	MPS I					0.33	507	≤0.30
	PA			0.15	0.12	0.14	246	≤0.30
	PKU	0.17	0.14	0.12	0.09	0.10	178	≤0.30
	TFP/LCHAD	0.20	0.18	0.18	0.12	0.14	242	≤0.30
	TYR-1	0.17	0.14	0.12	0.09	0.10	179	≤0.30
	VLCAD	0.20	0.18	0.18	0.12	0.14	242	≤0.30
	OCTN2	0.17	0.14	0.12	0.10	0.10	177	≤0.30
SCID						0.31	555	≤0.30

* Based on 'unclassifiable' result, i.e. insufficient/unreliable blood or <24 hours after blood transfusion. Heel pricks that were carried out too early (n=28 in 2021) are not included.
[1] From 2021, the target values have been tightened, from ≤0.50% for all target diseases except HbP (≤0.80%) to ≤0.30% for all target diseases except HbP (≤0.50%).

SECOND HEEL PRICK

In 2021 0.044% of the CAH-results of the first heel prick indicated the need for a second heel prick. For CH, OCTN2 and SCID this was 0.28%, 0.036%, and 0.052% respectively. The target values for this indicator were reached for all conditions (table 3).

Table 3
Percentage second heel prick according to birth year (2017-2021)

% of second heel pricks	2017	2018	2019	2020	2021	Number in 2021	Target value
CAH	0.065	0.072	0.042	0.049	0.044	(78)	≤0.09
CH	0.21	0.36	0.36	0.28	0.28	(503)	≤0.50
OCTN2[1]	0.032	0.045	0.054	0.027	0.036	(64)	≤0.04
SCID					0.052	(93)	≤0.06

[1] OCTN2 is an incidental finding. In the event of an inconclusive result for OCTN2, a second heel prick is performed. If both results are inconclusive, the child will be referred. In that case, other metabolic disorders with a screening based on acylcarnitines are unclassifiable and are further examined in the hospital. No target value was used in the years 2017-2018.

REFERRALS

In 2021, a total of 522 referrals were made as a result of the heel prick (table 4). This includes 18 referrals for the incidental finding OCTN2.[1] This gives a total referral rate of 0.29% of the number of screened children in 2021. This is comparable to previous years.

The referral rates for individual conditions are similar to previous years. Only for MCADD the referral rate is slightly lower in 2021 (0.009%) in comparison to previous years (0.011-0.013% in 2017-2020).

Table 4
Referrals according to birth year (2017-2021)

% referrals		2017	2018	2019	2020	2021	Number in 2021	Trend
CAH		0.016	0.016	0.012	0.012[1]	0.012	22	stable
CH		0.14	0.15	0.15	0.14[1]	0.15[1]	242	stable
CF		0.016	0.021	0.022	0.016	0.022	40	fluctuates
HbP	*subtotal*	*0.023*	*0.032*	*0.032*	*0.022*	*0.025*	*44*	
	SZ	0.014	0.018	0.024	0.014	0.017	30	fluctuates
	HbH	0.005	0.007	0.006	0.004	0.005	9	stable
	bTM	0.004	0.007	0.002	0.004	0.003	5	stable
MD	*subtotal*	*0.098*	*0.095*	*0.079*	*0.081*	*0.081*	*145*	
	3-MHM	0.005	0.009	0.006	0.007	0.006	10[2]	stable
	BIO	0.018	0.013	0.010	0.005[4]	0.005	9	2020: decrease
	CPT1			0.002[3]	0.001	0.002	4	stable
	GALK				0.002[3]	0.001	1	stable
	GALT	0.021	0.025	0.004[5]	0.006	0.006	11	2019: decrease
	GA-1	0.001	0	0.002	0.001	0.001[1]	2	stable
	IVA	0.002	0.002	0.002	0.004	0.003	6	stable
	MSUD	0.010	0.002	0.003	0.002	0.001[1]	1	stable since 2018
	MCADD	0.011	0.012	0.013	0.013[1]	0.009	16	2021: decrease
	MMA			0.013[3]	0.014	0.016	28	stable
	MPS I					0.003[3]	5	-
	PA			0.007[3]	0.001	0.002	3	stable
	PKU	0.008	0.010	0.008	0.007	0.007[1]	12	stable
	TFP/LCHAD	0.001	0.001	0.002	0.001	0.001	1	stable
	TYR-1	0.002	0.001	0.002[6]	0.005[6]	0.004	7	2020: increase
	VLCAD	0.011	0.008	0.007	0.007	0.006	11	stable since 2018
	OCTN2	0.009	0.011	0.014	0.008	0.010	18	fluctuates
SCID						0.016	29	-
Total referral rate		0.29	0.31	0.29	0.27	0.29	522	stable

[1] Excluding children who died before a referral could be made. In 2021, 8 for CH, 1 for GA-1, MSUD and PKU.
[2] 3-MHM: including one child (settler) whose data were not yet in the datafile from Praeventis.
[3] Figure applies to only a part of the year: PA, MMA and CPT1 added to the screening programme per 1-10-2019, GALK per 1-10-2020, MPS I per 1-3-2021.
[4] BIO: possibly as a result of adapted reference values for BIO per 27-1-2020.
[5] GALT: possibly as a result of adapted reference values for GALT per 1-1-2019.
[6] TYR-1: possibly as a result of adapted reference values per 1-4-2019.

[2] OCTN2 is not a target disease of the screening programme but is an incidental finding. Nevertheless, the C0 level is determined for each child, because a possible deficiency makes the acylcarnitine profile unreliable, which may cause that children with the metabolic diseases MCADD, VLCAD, TFP/LCHAD, IVA, GA-1 and 3-MHM remain undetected.

DIAGNOSTIC RESULTS

In 2021, 504 children (excluding OCTN2) were referred for a target disease of the screening programme. In 206 (41%) cases one of the conditions was confirmed (table 5). This is comparable to 2020 (40%). Children with a referral for OCTN2 deficiency (n=18, of which one was diagnosed with OCTN2) are not included in these numbers, because this condition is not a target condition of the screening programme, but an incidental finding. For 10 of the 504 referred children (2.0%), no diagnosis was yet known at the time of writing this monitor.

Of the children born in 2021, one child was reported with a false-negative result for CH, and one child was reported with a false-negative result for CF.

Table 5
Diagnostic results of referred children born in 2021 (excl. OCTN2)

2021		Referred	Diagnosis confirmed	No target disease	Diagnosis (still) unknown	False-negative (test wrongly indicates no need for referral)[1]	Missed/ other[1]
CAH		22	10[2]	12[3]	0	0	0
CH		242[4]	82[4]	153	7	1	0
CF		40	27[5]	11	2	1	0
HbP	SZ	30	30	0	0	0	0
	HbH	9	6	3[6]	0	0	0
	bTM	5	4	1	0	0	0
MD	3-MHM	10	3	7	0	0	0
	BIO	9	2	7	0	0	0
	CPT1	4	1	3	0	0	0
	GALK	1	0	1	0	0	0
	GALT	11	1	10	0	0	0
	GA-1	2	0	2	0	0	0
	IVA	6	2	4	0	0	0
	MSUD	1	0	1	0	0	0
	MCADD	16	15	1	0	0	0
	MMA[7]	28	1	26	1	0	0
	MPS I[8]	5	3	2	0	0	0
	PA	3	1	2	0	0	0
	PKU	12	11	1	0	0	0
	TFP/LCHAD	1	1	0	0	0	0
	TYR-1	7	0	7	0	0	0
	VLCAD	11	5	6	0	0	0
SCID		29	1	28	0	0	0
Total		**504**	**206**	**288**	**10**	**2**	**0**

[1] 'False-negative (test wrongly indicates no need for referral)' refers specifically to children who have not been detected by the screening test. Missed patients for other reasons (e.g. administrative) fall under the indicator 'Missed/other'.
[2] CAH: all 10 had classic salt-wasting CAH.
[3] CAH: 3 of 12 have (possibly) a heterozygous form of CAH (carrier), without standard clinical follow-up.
[4] CH: excluding two children with CH who were not refered because they were already in the hospital and received in-hospital diagnostics immediately after the non-conclusive result.
[5] CF: including 2 children with meconium ileus (MI).
[6] HbH: all with mild form of alpha-thalassaemia.
[7] MMA: the definition of target disease is still under review: the diagnostic results may change.
[8] MPS I: this condition has been added to the screening programme per 1 March 2021.

DETECTION RATES AND VALIDITY

Table 6 shows the detection rates (per 1000 screened children), the positive predictive value (PPV), the sensitivity (Sens) and specificity (Spec) of the programme.

The detection rates of 2021 are comparable to those of previous years for most conditions (stable since 2017). However, the detection rate of MCADD is somewhat lower compared to the years 2017-2020 (15 children with MCADD in 2021, compared to 18-21 children in 2017-2020).

In 2021, almost all target values of the positive predictive value (PPV) have been reached: CAH (>15%), CH (>15%), CF (>65%), SCD (>90%), PKU (>60%), MCADD (>70%). Only for SCID (>10%) this was not the case. The overall PPV (42%) is similar to the average in the period 2017-2021 (44%).

In 2021, the target values for sensitivity were not achieved for CH and CF due to false-negative results for CH and CF. The target values for specificity were met for all conditions.

Table 6
Detection rate, positive predictive value (PPV), sensitivity (Sens) and specificity (Spec) in children born in 2021 and the period 2017-2021 (excl. OCTN2)[1]

		2021				2017-2021[1,2]				Trend detection rate 2017-2021
		Detection rate (per 1000)	PPV[3] (%)	Sens (%)	Spec (%)	Detection rate (per 1000)	PPV[3] (%)	Sens (%)	Spec (%)	
CAH		0.056	45	100	99.993	0.064	50	**98.214**	99.994	stable
CH		0.458[4]	35	**98.8**	99.915	0.420	31	**98.093**	99.907	low in 2018 and 2020
CF excl. MI		0.140	69	**96.2**	99.994	0.120	71	**93.636**	99.995	fluctuates
incl. MI		0.151	71	**96.4**	99.994	0.142	74	**94.574**	99.995	fluctuates
HbP	SZ	0.168	100	100	100	0.172	99	100	99.999	fluctuates
	HbH	0.034		100	99.998	0.021	**39**	100	99.997	stable
	bTM	0.022		100	99.999	0.021	**55**	100	99.998	stable
MD	3-MHM	0.017		100	99.996	0.027	**43**	100	99.996	stable
	BIO	0.011		100	99.996	0.025	**24**	100	99.992	stable
	CPT1[2]	0.006		100	99.998	*0.003*	*14*	100	99.999	-
	GALK[2]	0		-	99.999	-	-	-	-	-
	GALT	0.006		100	99.994	0.014	**11**	100	99.989	stable
	GA-1	0		-	99.999	0	0	100	99.999	stable
	IVA	0.011		100	99.998	0.013	48	100	99.999	stable
	MSUD	0		-	99.999	0.002	7	100	99.997	stable
	MCADD	0.084	94	100	99.999	0.107	92	100	99.999	2021: decrease
	MMA[2]	0.006	4[2]	100	99.985	*0.013*	*9*[2]	100	***99.988***	-
	MPS I[2]	0.020		100	99.999	-	-	-	-	-
	PA[2]	0.006		100	99.999	*0.008*	*38*	100	99.999	-
	PKU	0.061	92	100	99.999	0.072	94	100	99.999	stable
	TFP/LCHAD	0.006		100	100	0.002	20	100	99.999	stable
	TYR-1	0		-	99.996	0.005	**16**	100	99.998	stable
	VLCAD	0.028	45	100	99.997	0.026	34	**95.652**	99.995	stable
SCID[2]		0.006	**3**	100	99.984	-	-	-	-	-
Total[2]		**1.150**	**42**	**99.0**	**99.840**	**1.132**	**44**	**98.379**	**99.854**	

[1] The PPV, Sens and Spec of five years combined are calculated because for some conditions only few children are referred per year. For these conditions a calculation over several years gives a more stable outcome.
[2] The total at the bottom of the table excludes conditions added to the heel prick screening less than 5 years ago. The total is thus without CPT1, MMA and PA (added per 1-10-2019, although the average over 2 years based on 7, 57 and 8 referrals, respectively, is shown in italics), and without GALK (per 1-10-2020), SCID (per 1-1-2021) and MPS I (per 1-3-2021). The definition of target disease MMA is still under review: the diagnostic results may change.
[3] Only a few children per year are referred for HbH, bTM and for many of the metabolic diseases. Therefore no target values for the PPV have been established. Due to the small numbers, the PPV is omitted.
[4] CH: excluding two children with CH who were not referred because they received in-hospital diagnostics immediately after the non-conclusive result. Including thse children results in a detection rate of 0.469.

TIMELINESS OF DIAGNOSTICS

The timeliness of diagnosis is calculated based on data from all referred children. In 2021, only the target value for SCID was met (table 7).

Table 7
Timeliness of diagnostic results among children born in 2017-2021

Screening	2017	2018	2019	2020	2021	Target value
CAH	81	77	86	90	73	≥90%<15 days
CH	85	84	86	88	80	≥90%<15 days
CF all referrals	85	77	58	77	72	≥90%<30 days
excl. MI	86	74	53	74	70	≥90%<30 days
HbP[1]	97	91	100	81	82	≥90%≤6,0 weeks[2]
MD (excl. OCTN2)	74	76	91	89	88	≥90%<10 days (most MD) or <14 d (PA/MMA)
SCID					90	≥90% < 15 days if TREC ≤2; <30 days if TREC >2 - ≤10; <15 days from aterme date (for preterm children)

[1] All children referred for HPLC patterns matching with sickle cell disease, HbH-disease and beta-thalassemia.
[2] The target value has been changed to ≥90% ≤6.0 weeks since 1-1-2020 (this was ≥90% ≤12.0 weeks).

COSTS

The costs of the screening programme (excluding diagnostics) were about 23.8 million euro in 2021 (source: Final bill NBS, RIVM-CvB, excluding the costs for Caribbean Netherlands). Screening costs per child are approximately 133 euro. Compared to last year, there is a cost increase of approximately 17% per child screened, whereas until 2020 this was 3-4% per year, and in 2020 this was 12% (figure 4). The substantial increase is explained by indexation of fees for blood collection and laboratory analyses, but mainly by the expansion of heel prick screening with MPS I and SCID.

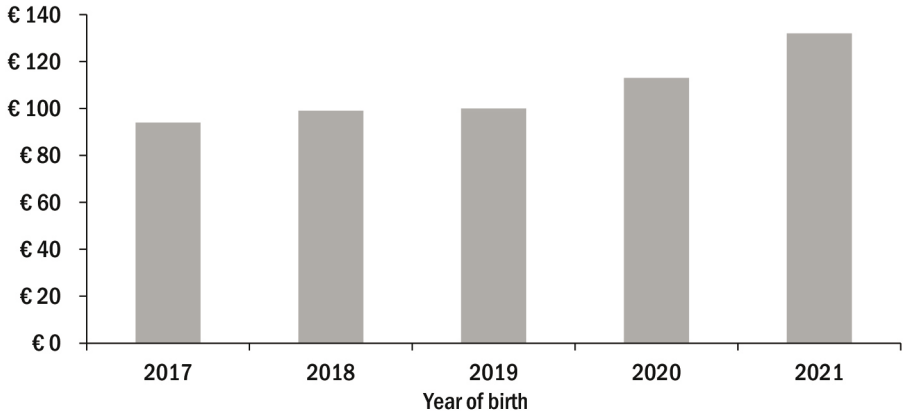
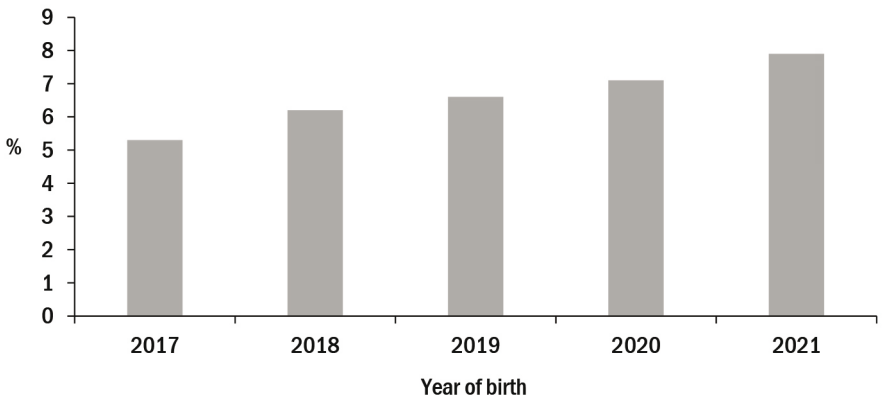


Figure 4
Costs of the screening programme per screened child according to year of birth (2017-2021)

OBJECTIONS AGAINST STORAGE OF NEWBORN BLOOD

In 2021 7.9% of parents objected against the storage of the NBS blood residuals for the purpose of (non-identifiable) scientific research. This percentage shows a upward trend over time (figure 5).



Figurr 5
Objection of parents against the storage of NBS remnants for anonymous scientific research, by year of birth (2017-2021)

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