

## Impact and economic analysis of human T-cell lymphotropic virus type 1 (HTLV-1)-targeted antenatal screening, England and Wales, 2021

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**Supplementary Table S1.** Prevalence of infections and diseases or syndromes that are screened for in the antenatal and neonatal care in the United Kingdom, in 2024 compared with HTLV-1 infection.

Infection or disease/syndrome	Positive tests	Number tested	Prevalence per 10,000	95% CI
<i>HTLV-1 (parents born in the Caribbean)</i>	NA		169.0	92–283
Hepatitis B	2,214	642,448	34.5	33–36
<i>HTLV-1 (parents born in other endemic area)</i>	NA		32.0	15–59
Down's syndrome	NA		26.5	25–28
Syphilis	1,019	642,433	15.9	15–17
HIV	621	642,434	9.7	9–10
Congenital hypothyroidism	443	591,851	7.5	7–8
Edward's' syndrome	NA		7.4	7–8
Sickle cell disease (newborns tested)	227	589,542	3.9	NA
<i>HTLV-1 (overall prevalence in the UK)</i>	NA		3.1	2–54
Cystic fibrosis	165	593,581	2.8	2–3
Patau's syndrome	NA		2.7	2–3
Phenylketonuria (PKU)	69	591,947	1.2	0–1
Medium-chain acyl-CoA dehydrogenase deficiency (MCADD)	40	591,946	0.7	0–1
Isovaleric acidaemia (IVA)	21	591,946	0.4	NA
Maple syrup urine disease (MSUD)	3	591,946	0.1	0–1
Glutaric aciduria type 1 (GA1)	3	591,947	0.1	NA
Homocystinuria (HCU)	1	591,946	0.02	NA

CI: Confidence Interval, HTLV-1: Human T cell lymphotropic virus type 1, NA: Not available, UK: United Kingdom.

References:

Ades AE, Parker S, Walker J, Edginton M, Taylor GP, Weber JN. Human T cell leukaemia/lymphoma virus infection in pregnant women in the United Kingdom: population study. *BMJ*. 2000;320(7248):1497-501.

<http://dx.doi.org/10.1136/bmj.320.7248.1497> PMID:10834889

Office for Health Improvement and Disparities. NHS Fetal Anomaly Screening Programme (FASP). NHS screening programmes in England: 2020 to 2021. London: gov.uk. [Accessed: 17 May 2024]. Available from:

<https://www.gov.uk/government/publications/nhs-screening-programmes-annual-report/nhs-screening-programmes-in-england-2020-to-2021#nhs-fetal-anomaly-screening-programme-fasp>

National Health Service (NHS). NCARDRS Congenital Anomaly Official Statistics Report, 2020. London: NHS England; 2022. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/ncardrs-congenital-anomaly-statistics-annual-data/ncardrs-congenital-anomaly-statistics-report-2020/prevalence-t21-t18-t13#top>

National Screening Committee. Antenatal screening programme: HTLV. London: gov.uk; 2022. Available from: <https://view-health-screening-recommendations.service.gov.uk/htlv>

**Supplementary Table S2.** Live births in England and Wales (2021) from parents born in HTLV-1 endemic areas.

Live births England and Wales, 2021	
<b>Country of birth of mothers (high prevalence of HTLV-1)</b>	
Western Africa	10,487
Central Africa	1,838
Southern Africa	3,018
Central America	494
South America	4,238
Caribbean	2,124
Middle East	8,676
India	15,260
Pakistan	15,791
Romania	15,894
<b>Total</b>	<b>77,820</b>
<b>Country of birth of fathers (partners of mothers from low prevalence area)</b>	
Western Africa	3712
Central Africa	600
Southern Africa	2149
Central America	191
South America	1180
Caribbean	1956
Middle East	3093
India	2010
Pakistan	6285
<b>Total</b>	<b>21,176</b>
<b>Total to be screened</b>	<b>98,996</b>
<b>Total number of pregnant women England and Wales (2021)</b>	<b>624,628</b>

**Supplementary Table S3.** Live births (numbers and percentages) for the ten most common countries of birth of mother for non-UK-born mothers, England and Wales in 2021

Ref: [Parents' country of birth - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk)

Country of birth of mother	2021 Rank	2021 Number
Romania	1	15,894
Pakistan	2	15,791
India	3	15,260
Poland	4	13,373
Bangladesh	5	6,790
Nigeria	6	5,907
Germany	7	3,511
Lithuania	8	3,499
United States of America	9	3,446
Albania	10	3,260

**Supplementary Table S4.** High HTLV prevalence countries according to ECDC report  
Geographical distribution of areas with a high prevalence of HTLV-1 infection (2015)

**America**

Argentina  
Barbados  
Brazil  
Chile  
Colombia  
Dominican Republic  
French Guyana (France)  
Guadeloupe (France)  
Guyana  
Haiti  
Jamaica  
Martinique (France)  
Panama  
Peru  
Suriname  
Trinidad and Tobago  
Venezuela

**Europe**

Romania

**Africa**

Benin  
Burkina Faso  
Cameroon  
Central African Republic  
Chad  
Congo  
Cote d'Ivoire  
Democratic Republic of the  
Congo  
Equatorial Guinea  
Gabon  
Gambia  
Ghana  
Guinea  
Guinea-Bissau  
Liberia  
Mali  
Mauritania  
Mozambique  
Nigeria  
Senegal  
Seychelles  
Sierra Leone  
South Africa  
Togo

**Arabian Peninsula and Asia**

Iran  
Japan  
Taiwan

**Supplementary Table S5.** HTLV-1 prevalence in pregnant women in the UK according to the country of origin:

Reference: [Ades et al 2000](#).

	Anti-HTLV antibody	
	Total tested	Prevalence (per 1000)
<b>Africa</b>		
Western	2325	3-3.4
Central	559	3.65
Rest of Africa	4250	0
<b>America</b>		
Caribbean	914	16.4-17.5
South	490	2
Central and North	801	0
<b>Asia</b>		
Japan	233	4.3
Rest of Asia	12590	0
<b>Europe</b>		
UK	69013	0.33-0.38
Other Northern	1948	0
Southern	1143	0
Eastern	494	0
Western	1204	0.8
Oceania	529	0

## Supplementary Table S6. Life Table UK

Reference: [Office for National Statistics accessed 09 May 2023](#)

\*Average  $q_x$  (i.e the mortality rate between age  $x$  and  $(x + 1)$ , that is the probability that a person aged  $x$  exact will die before reaching age  $(x + 1)$ ) for male and female was calculated.

age	$q_x$	age	$q_x$	age	$q_x$
0	0.0038635	33	0.000725	67	0.012168
1	0.0002215	34	0.000787	68	0.013475
2	0.0001205	35	0.000846	69	0.0147035
3	0.0000985	36	0.0009165	70	0.0160665
4	0.000075	37	0.001056	71	0.017216
5	0.000074	38	0.0010545	72	0.0191405
6	0.000078	39	0.0011625	73	0.021544
7	0.000061	40	0.001265	74	0.024232
8	0.0000635	41	0.001352	75	0.027033
9	0.0000555	42	0.001475	76	0.0300635
10	0.000072	43	0.001627	77	0.034027
11	0.000066	44	0.0017775	78	0.038304
12	0.0000795	45	0.0019755	79	0.042986
13	0.0001015	46	0.0021355	80	0.047877
14	0.0001125	47	0.0022435	81	0.0535785
15	0.0001425	48	0.002463	82	0.059697
16	0.000168	49	0.002674	83	0.0673205
17	0.0002345	50	0.0029055	84	0.076219
18	0.00031	51	0.0031365	85	0.085612
19	0.000333	52	0.003328	86	0.0973705
20	0.000356	53	0.003583	87	0.109363
21	0.000359	54	0.003842	88	0.122726
22	0.000371	55	0.0041645	89	0.138061
23	0.0003695	56	0.004615	90	0.1499775
24	0.0003895	57	0.004994	91	0.1683815
25	0.0004305	58	0.005531	92	0.1859475
26	0.000432	59	0.005973	93	0.2062745
27	0.0004695	60	0.0065795	94	0.226238
28	0.0004975	61	0.007136	95	0.249589
29	0.000533	62	0.008026	96	0.2718325
30	0.000579	63	0.008685	97	0.2959945
31	0.0006145	64	0.009275	98	0.317578
32	0.000663	65	0.0102865	99	0.344926
		66	0.0113115	100	0.370624

## Detailed information of inputs used in the model

### Incidence of breastfeeding in the UK

Asian (95%), Black (96%), or Chinese or other ethnic origin (97%) ,mixed race (89%), White (79%).

### [Breastfeeding rates UK](#)

[https://sp.ukdataservice.ac.uk/doc/7281/mrdoc/pdf/7281\\_ifs-uk-2010\\_report.pdf](https://sp.ukdataservice.ac.uk/doc/7281/mrdoc/pdf/7281_ifs-uk-2010_report.pdf)

**Cost of screening test:** £1.4 per test

\*Based on quote for Murex anti-HTLV-1/2 ELISA £670 for 480 tests.

**Cost of Western blot: £ 19.75 each**

\* Based on quote for HTLV Blot 2.4 £711 for 36 tests

### Cost of formula up to 6 months

The cost of 800g formula powder is £9.9 (Sainsbury 10/05/2023) and £10.5 (Tesco 10/05/2023). In Brazil the recommendation is 66-77 formula for a baby up to 6 months (Portaria RN).

This results in a total cost of respectively £653.4 - £762.3 or £693 - £808.5

<https://static1.squarespace.com/static/5efa4a95af311446a53c8cab/t/5fd0990c5347e801a823f769/1607>

### Cost of formula up to 12 months

Initial 66-77 formula up to 6 months followed by 72 (12 units x 6 months, introduction solid foods) = 138-149 units.

Total cost is £1,366.2 - £1,475.1 or £1,449 - £1,564.5

### Cost of formula 3-6months

36-42 units of Formula £356.4 - 415.8 and £378 - 441

### Cost of formula 3-12months

36-42 +72 equates to 108-114 £1069.2- 1128.6 or £ 1134 - 1197

### Cost of Cabergoline

1mg tablets: 20 units costs 6425 p

1 tablet = 321.25 = 3.22 pounds



Ref: [NHS Electronic Drug Tariff](#) accessed in 12th May 2023

**Breastfeeding incidence:**

96% Black Caribbean [NHS Digital. Infant Feeding Survey – UK, 2010.](#)

**Breastfeeding prevalence at 6 months:**

61% Black Caribbean [NHS Digital. Infant Feeding Survey – UK, 2010.](#)

**Utility values in the UK**

Asymptomatic infection (Mean (SD)): 0.7802 (0.209) [Rosadas et al 2020](#)

HAM (Mean (SD)): 0.2025 (0.297) [Rosadas et al 2020](#)

Utility values people in the UK: 0.91 [Janssen et al 2018](#)

**Annual Cost of Treating HTLV-1 Asymptomatic patient**

£2900 (Imperial College Healthcare NHS Trust Resource Group)

**Annual Cost of Treating HTLV-1 Associated Myelopathy (HAM)**

£16000 (Imperial College Healthcare NHS Trust Resource Group)

**Annual Cost of Treating Adult T cell Leukaemia**

\*Annual Cost of Treating Aggressive ATLL

£18016 (Imperial College Healthcare NHS Trust Resource Group)

\*Annual Cost of Treating Indolent ATLL

£12907 (Imperial College Healthcare NHS Trust Resource Group)

75% Aggressive + 25% Indolent =  $13512 + 3226.75 = £16,739$