

TABLE 1: Number of cases, year of incidence and follow-up by country. Neuroblastoma and Wilms tumours, JARC pilot study

COUNTRY	NEUROBLASTOMA number	WILMS number	Diagnosis year	Follow-up year	Stage missing number	Total number
Belgium	15	19	2014	2018	1	34
Denmark	10	10	2011-2012	2018	0	20
Estonia	12	13	2010-2015	2017	0	25
France	136	78	2014	2017	17	214
Greece	103	78	2010-2014	2017	0	181
Germany	122	107	2009 and 2013	2017	21	229
Hungary	12	11	2015	2017	0	23
Italy	81	64	2002-2015	2007-2018	13	145
Malta	11	12	2000-2011	2017	1	23
Norway	12	14	2014-2015	2018	0	26
Portugal	12	10	2016	2018	0	22
Slovakia	16	13	2011-2012	2018	0	29
Slovenia	11	10	2011-2015	2018	1	21
Spain	58	43	2007-2015	2013-2018	1	101
Switzerland	10	12	2014	2019	1	22
All cases	621	494	2000-2016	2007-2018	56	1 115

Note: Italy (Barletta, Campania, Pavia, Varese and 3 registries from Sicily), Portugal (South Portugal) and Spain (Basque countries, Girona, Granada, Murcia, Navarra) are covered by regional registries. Denmark, France, Switzerland, Hungary, Greece and Germany are covered by national paediatric registries. All the other countries are covered by national general registries.

TABLE 2: Sources used for staging. Neuroblastoma and Wilms tumours, JARC pilot study

Sources used for staging	Neuroblastoma		Wilms tumours	
	number	%	number	%
Administrative files	4	0.6	2	0.4
Pathological report	18	2.9	84	17.0
Pathological report + Administrative files	13	2.1	18	3.6
Clinical report	19	3.1	23	4.8
Clinical report + Administrative files	6	1.0	5	1.0
Pathological report + Clinical report	296	47.7	142	28.7
Pathological report + Clinical report + Administrative files	129	20.8	99	20.0
Clinical trial/study report ^a	122	19.6	107	21.7
Other	10	1.6	10	2.0
Missing	4	0.6	4	0.8
Total	621	100	494	100

^a all from the National German registry

TABLE 3: Stage distribution of incident cases by age. Neuroblastoma and Wilms tumours, JARC pilot study

Tumor	Stage		Age							
			≤18 months		19-60 months		5-14 years		All ages	
	number	%	number	%	number	%	number	%	number	%
Neuroblastoma^a										
L1	117	36	32	15	17	23	166	27		
L2	77	24	43	19	14	19	134	22		
MS	67	20	0	-	0	-	67	11		
M	57	17	139	63	41	56	237	38		
missing	9	3	7	3	1	1	17	3		
Total	327	100	221	100	73	100	621	100		
Wilms tumours^b										
			<1 year		1-4 years		5-14 years		All ages	
	number	%	number	%	number	%	number	%	number	%
I/yI	47	61	120	39	29	26	196	39		
II/yII	11	14	66	22	26	23	103	21		
III/yIII	10	13	56	18	27	24	93	19		
IV	2	3	36	12	25	22	63	13		
missing	7	9	26	9	6	5	39	8		
Total	77	100	304	100	113	100	494	100		

^a Only Tier 1 stage is included for all German cases and other 5 cases from Malta CR : 27% Localized, 14% Locoregional, 12% MS, 45% metastatic and 2% missing.

^b Only Tier 1 stage is included for 8 Wilms tumours' cases in 4 different CRs.

TABLE 4: Three-years survival by age and stage for neuroblastoma and Wilms tumours, JARC Pilot Study

Neuroblastoma ^a		Stage				
Age		L1	L2	MS	M	Total
≤18 months	number	84	61	50	40	235
	%survival (95%CI)	100	95 (85-98)	84 (70-91)	70 (53-82)	90 (86-93)
19-60 months	number	30	36		101	167
	%survival (95%CI)	97 (78-100)	88 (72-95)		53 (43-62)	69 (61-75)
5-14 years	number	14	13		30	57
	%survival (95%CI)	100	85 (51-96)		56 (36-72)	74 (60-84)
Total	number	128	110	50	171	459
	%survival (95%CI)	99 (94-100)	92(84-95)	84 (70-92)	58 (50-65)	80(76-84)
p value		0.0007		0.2839		0.0003

Wilms tumours ^b		Stage				
Age		I/yI	II/yII	III/yIII	IV	Total
<1 year	number	45	11	9	1	66
	%survival (95%CI)	98 (85-100)	82(45-95)	89 (43-98)	100	94 (85-98)
1-4 years	number	112	64	55	35	266
	%survival (95%CI)	96 (91-99)	100	87 (75-94)	76 (58-87)	93 (89-95)
5-14 years	number	28	24	26	23	101
	%survival (95%CI)	100	100	88 (68-96)	78 (55-90)	92 (85-96)
Total	number	185	99	90	59	433
	%survival (95%CI)	97 (94-99)	98 (92-99)	88 (79-93)	77 (64-86)	93 (90-95)
p value		0.002 ^c	<0.0001 ^d	0.0087	0.0878	<0.0001 ^e

^a excluding 163 cases: missing stage, Hungary, Germany and Portugal

^b excluding 61 cases : missing stage and Hungary, Portugal

^c between I/yI+II/yII vs III/yIII

^d between I/yI+II/yII vs III/yIII+IV

^e between I/yI+II/yII+ III/yIII vs IV

TABLE 5: Adjusted risk of dying for neuroblastoma and Wilms tumours, JARC Pilot Study

	Neuroblastoma	Hazard Ratio	P value	95% Conf. Interval	
Stage	L1	1			
	L2	14.8	0.01	1.9	115.8
	MS	32.7	<0.001	4.0	266.6
	M	70.6	<0.001	9.7	515.2
	missing	30.6	<0.001	3.1	301.5
Age	≤18 months	1			
	19-60 months	2.2	0.01	1.2	3.8
	5-14 years	2.0	0.05	1.0	4.2
Sex	boy	1			
	girl	1.1	0.59	0.7	1.7

Wilms tumours		Hazard Ratio	P value	95% Conf. Interval	
Stage	I/yI	1			
	II/yII	1.0	0.98	0.2	5.5
	III/yIII	7.0	<0.001	2.1	23.2
	IV	17.7	<0.001	5.3	59.5
	missing
Age	<1 year	1			
	1-4 years	0.9	0.83	0.2	3.2
	5-14 years	0.7	0.65	0.2	3.1
Sex	boy	1			
	girl	0.7	0.27	0.3	1.4

Note: Hazard Ratio adjusted by age, sex, stage and country