Clinical studies including more than 50 patients with LCH, by publication year. Studies dealing exclusively with adults were not included as well as the epidemiological studies. The percentage of organs involved was calculated, including documentation of sites of recurrence

Reference	Institutions	Years of study	Adults incl.	Focus of the survey	Multi center Study	No of patients	Male (%)	Bone (%)	Skin (%)	DI (%)	Liver (%)	Lung (%)	Hem (%)	Liver or Lung or Blood (%)	Overall survival (%)
(Lahey, 1975)	CCSG	1966-1975 (?)	-	Therapeutic trial	+	83	56	5	-	20	-	-	-	40	71
(Carlson et al., 1976)	Mayo Clinic	1962-1973	-	Lung	-	81	-			-	-	8.6	-	-	-
(Nezelof et al., 1979)	Necker Paris	1952-1979	-	Multi-visceral	-	50	70	82	80	40	36	60	26	76	52
(Komp et al., 1980)	SWOG	-1971	-	Long term sequelae	+	75	-	68	-	20	-	-	-	-	80)
(Greenberger et al., 1979)	Boston	1941-1975	+	-	-	127	60	83	63	23	53.5	40	35	72	37.8
(Broadbent, 1986)	London GOS	1961-1982	-	-	-	70	60	82	54	N/A	15.7	21	13	21 at least	89
(Berry et al., 1986)	POG	-1982	-	-	+	92	54	72	58	29	7.6	5.4	12	15	15
(Chomette et al., 1987)	Pitié, Paris	1966-1986	+	Stoma-tology	-	61	72	100	2	N/A	0	26	0	26	97
(Rivera-Luna et al., 1996)	Mexico	1972-1986	-	-	-	124	53	82	55	19	51	23	46	N/A	63
(Raney & D'Angio, 1989)	Philadelphia CHOP	1970-1984	-	-	-	64	57	76	30	3.1	8	3.1	6.3	14	89
(Ceci et al., 1988)	Italian Group	1983-1988	-	Treatment study	+	90	64	80	20	20	7	3.5	10	12.2	93 at 4 years
(Gadner et al., 1994;Grois et al., 1995)	DAL HX 83 GPOH	1983-1989	-	Treatment study	+	106 among 199	-			15.1				19.8 **	90
(Kilpatrick et al., 1995)	Mayo Clinic	1915-1995	-	Bone	-	263	61	100	13	15	5	7	4	N/A	95
(Rivera-Luna et al., 1996)	Mexico	1978-1988	-	Age <2 years	-	55	55	69	76	N/A	38	29	63	71	36
(Willis et al., 1996)	San Francisco UCSF	1969-1994	+	-	-	71	-	92	45	26	-	-	-	39	77% at 20 years
(Lieberman et al., 1996)	NY Memorial Sloan-Kettering	1942-1994	+	Pathologic registry	-	298	65.9	71	4.4	6.7	0	4.7	0	4.7	93.3% (60% of death in adults)
(The French LCH Study Group, 1996)	Cooperative French Centers	1983-2002	-	-	+	348	55	81	39	15.8	14	13	11	16	91% at 5 years
(Braier et al., 1999)	Garahan Institute	1987-1996	-	-	-	123	58	93	24	14	10	11	11	15	86
(Howarth et al., 1999)	Mayo Clinic	1946-1996	++	-	-	314	-	60	24	14	1.6	41	0	43	91.1
(Nanduri et al., 2000)	London GOS	1966-1998	-	Endocrine	-	144 (MS of st 275)	-	-	-	44 (18 of overall survey	-	-	-	-	86.9
(Surico et al., 2000)	Italian Group	1982-1995	-	Ear involvement	+	220	55	-	-	15.7 (of survivors)	-	-	-	15.8	91.5
(Minkov et al., 2000)	DAL HX 83-90	1983-1991	-	Treatment MS patients	+	63 of 324	52	-	-	17.5	-	-	-	-	81 (5-y survival)
(Titgemeyer et al., 2001)	DAL HX 83-90	1983-1991	-	Therapeutic study SS patients	+	178 of 275	61	87	10	3	0	0	0	0	100
(Gadner et al., 2001)	HS Study	1991-1995	-	Rando-mised trial	+	143	50	-	-	25	-	-	-	-	80
{Braier, 2002 280 /id;Braier, 2004 4679 /id}	One institution			Focus liver + lung inv.											
{Donadieu, 2004 DONADIEU2004 /id}	Cooperative French Centers	1983-2002	-	Endocrine	+	589	55	80	45	24% (at 10 yrs)	17	16	13.4	37	85% (at 15 y)
{Donadieu, 2004 DONADIEU2004B /id}	Cooperative French Centers			Evaluation of disease activity		605									
{Haupt, 2004 HAUPT2004 /id}	3 institutions			Focus on permanent consequ.	+										
{Jubran, 2005 4828 /id}	One institution				-										
{Bernstrand, 2005 4829 /id}	One institution			Long term outcome	-										
{Morimoto, 2006 4833 /id}	Japan nation wide study					92									
{Gadner, 2007 4722 /id}	LCH II study			Rando-mised trial	+	193									
{Morimoto, 2010 4832 /id}	Japan nation wide study	1995-2006		Single system		146									