Summary of Public Comments Received for the Multiple Chemical Sensitivity Report

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Prepared For:
National Center for Environmental Health
Centers for Disease Control and Prevention
4770 Buford Highway, NE MS-F29
Atlanta, GA 30341

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APPENDICES

1.0 Overview and Purpose of Project

In 1995, The Environmental Health Policy Committee, Department of Health and Human Services, formed an Interagency Working Group on Multiple Chemical Sensitivity (MCS). MCS is a health outcome, with a debatable validity, that poses policy and medical challenges to federal agencies and health practitioners. From the interagency collaboration, a draft report entitled "A Report on Multiple Chemical Sensitivity (MCS)" was developed, and considered relevant scientific literature, previous recommendations of various experts and current as well as past federal actions. After assessment by a panel of experts, the report was made available to the public for review and comment.

The purpose of this project was to summarize and categorize the comments received from individuals and organizations. By reviewing and summarizing the comments received in response to the MCS report, the extent and nature of this complex problem can be examined. This project report may serve as a foundation for recommendations on future actions for federal agencies to consider.

2.0 Methods

An inventory of the 460 public comments was taken, and the comments were marked with the appropriate public inquiry number. This public inquiry number, which was assigned by ATSDR, appears throughout this report. An inventory number was developed for each comment, which not only serves to protect the identity of the individual, but also accounts for numerous comments submitted by the same individual or organization. The index, which is included as Appendix A, links the public inquiry number to the inventory number. Comments are identified by the public inquiry number.

Once the inventory of the comments was developed, the process of sorting, abstracting, and summarizing the comments was completed. For each comment the index identifies the source of the comment, such as a health care professional or an individual reporting that they have MCS or a related condition. Comments received from organizations are identified by name and include support groups for people with MCS, private industry, governmental organizations, or other non-governmental organizations.

Each comment was read and a short abstract that summarized the content of the comment was prepared. These abstracts include a brief summary and indicate the tone and substance of the comment. These comments appear in Appendix B of this report. The comment medium (written, video tape, e-mail); the overall nature and degree of support provided by the comment; and inclusion of new references (including peer reviewed literature and other MCS publications and literature) are provided in Appendix A. New references cited in the comments appear in Appendix C. The citations appear as cited in the comment. In some instances incomplete citations were provided. In reviewing the comments, it was determined that a large number of letters came from a similar source, as the content and frequently the format were identical. These responses have been defined as form letters, and appear in their entirety in Appendix D. The form letters appearing in Appendix D are identical to those received, and any grammatical or spelling errors were not corrected. In total, 144 form letters were received including 130 from individuals, 11 from individuals with MCS, and 3 from organizations.

Charts and graphs depicting the nature of comments that were received are included in Appendix E. Categories include: source of comments (Exhibit E-1a and 1b), comment medium (Exhibit E-2a and 2b), comments citing additional references (Exhibit E-3a and 3b), overall nature and degree of support provided by comments (Exhibit E-4a and 4b), additional references cited most frequently (Exhibit E-5a and 5b), and degree of support stratified by source (Exhibit E-6a through 6i).

3.0 Results

Approximately 87% (n=402) of respondents chose to send a written comment, whereas only 13% (n=57) choose to use email. This is noteworthy, as numerous citizens complained of the reactions they were having to paper products as they were responding. The solitary video entry represents less than 1% (n=1) of the comments received.

The breakdown of respondents was as follows: 4% (n=19) of the respondents were health care professionals, 37% (n=174) were individuals who identified themselves as having MCS, 11% (n=47) came from organizations, and 48% (n=220) came from individuals who did not identify themselves as having MCS.

Comments with attached references not in the initial report made up 40% (n=183) of

respondents. Not only was more recent literature called for, but less biased literature was also requested. These references are attached, and the accompanying chart (Exhibit E-5a and 5b) illustrates the references most frequently cited. The work of Landrigan was cited most frequently. The number of times his work was cited may be skewed, as it was referenced in one of the form letters.

When including form letters, approximately 70% (n=282) of the responses were not supportive of the report and recommended substantive changes, or that no final report be produced (Exhibit E-4a). The other 30% (n=110) included those who were supportive of the report as written or with editorial changes (Exhibit E-4a). After excluding the form letters, the breakdown was more evenly divided with 55% (n=138) not supportive of the report, and 45% (n=110) supportive of the report (Exhibit E-4b). Comments with no opinion on the report as well as requests for copies of the report were not included. The degree of support varied among groups submitting comments. Government agencies were the most supportive in which 4/4 (100%) comments expressed some degree of support (Exhibit E-6i), and individuals, as a category, were the least supportive because 183/208 (88%) comments expressed a lack of support (Exhibit E-6b).

4.0 Conclusions

In response to the Interagency draft report on MCS, 460 comments were received. Comments were received from health care professionals, individuals, individuals with MCS, and organizations. Government agencies were the most supportive and individuals were the least supportive.
Many of the comments citing limitations of the report can be generalized as follows: Frank Mitchell's involvement in the writing of the report is a conflict of interest, and ultimately biases the report; the report should include information from other government agencies as well as findings of MCS doctors who study/treat those with MCS; the bibliography is incomplete and more literature needs to be reviewed and included in the report; the report should recommend avoidance measures; and the report should be used as a tool for health care professionals, government agencies, employers, and the general public, and as such, it should be free of any and all biases.

Public comments citing the strengths of the report can be generalized as follows: the report is a good start to recognizing MCS, the report is a comprehensive review of the issues encompassing MCS, and the document is a useful tool for those who deal with MCS.

Appendix A
Index of Comments

Index of Comments

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
27	2	X	--	Written	2	Y	R121, R122, R240
28	3	X	--	Written	2	Y	R121, R122, R240
29	4	MCS	--	E-mail	3	Y	R68, R118
30	5	X	--	E-mail	N/A	N	--
31	6	MCS	--	E-mail	N/A	N	--
32	7	MCS	--	E-mail	2	N	--
33	8	HCP	--	E-mail	3	N	--
34	9	HCP	--	E-mail	4	N	--
35	10	MCS	--	E-mail	N/A	N	--
36	11	MCS	--	E-mail	N/A	N	--
37	12	X	--	Written	2	N	--
11	13	--	National Center for Environmental Health Strategies	Written	1	N	--
19	14	X	--	Written	2	Y	R10, R14, R37, R59, R67
23	15	X	--	Written	3	N	--
38	16	MCS	--	Written	N/A	Y	R27, R28, R29, R11
39	17	X	--	Written	2	N	--
40	18	MCS	--	Written	2	N	--
41	19	--	Boston Self Help Center	Written	2	N	--
42	20	--	Boston Self Help Center	Written	2	N	--
43	21	MCS	--	Written	3	N	--
44	22	MCS	--	Written	3	N	--

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
45	23	X	--	Written	3	Y	R14
3	24	--	MCS Referal and Resources	Written	2	Y	R3, R43, R210, R211, R212, R213, R214, R215, R216, R217, R218, R219, R220, R221, R222
6	25	MCS	--	E-mail	3	Y	R241
47	26	MCS	--	E-mail	2	Y	R241
48	27	X	--	E-mail	3	N	--
49	28	MCS	--	E-mail	4	N	--
50	29	X	--	E-mail	2	N	--
20	30	--	Environmental Sensitivities Research Group	E-mail	3	Y	R97, R108, R114
51	31	MCS	--	Written	3	Y	R21, R23, R41, R47, R75, R76, R82, R154, R191, R192, R193, R194, R195, R196, R197, R198
52	32	X	--	Written	3	N	--
53	33	X	--	Written	2	N	--
54	34	X	--	Written	2	Y	R137, R141, R153
9	36	MCS	--	Written	2	N	--
55	37	MCS	--	Written	N/A	N	--
16	38	X	--	Written	2	N	--
9	39	MCS	--	Written	2	N	--
56	40	HCP	--	Written	3	Y	R236, R237
57	54	HCP	--	Written	2	Y	R54
58	55	HCP	--	Written	4	N	--
59	56	--	NIEHS	Written	4	N	--

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
61	58	HCP	--	Written	3	N	--
4	59	HCP	--	Written	N/A	N	--
62	60	--	ACCEH	Written	N/A	N	--
63	61	MCS	--	Written	N/A	N	--
64	62	MCS	--	Written	2	N	--
65	63	HCP	--	Written	2	Y	R3, R14, R17, R27, R33, R38, R44, R71, R72, R83, R93, R98, R99, R105, R110, R111, R157
66	64	--	APHA	Written	3	Y	R95
67	65	MCS	--	Written	N/A	Y	R161, R162
68	66	X	--	Written	2	N	--
69	67	X	--	Written	2	Y	R135, R136, R137
16	68	X	--	Written	2	N	--
70	69	MCS	--	Written	2	Y	R163, R164
71	70	MCS	--	Written	2	Y	R50, R51, R53
15	71	MCS	--	Written	2	Y	R43, R134
72	72	MCS	--	Written	2	N	--
73	73	X	--	Written	2	N	--
74	74	MCS	--	Written	2	N	--
75	75	MCS	--	Written	3	N	--
76	76	MCS	--	Written	3	N	--
8	77	MCS	--	Written	3	Y	R73
77	78	X	--	Written	2	Y	R121, R122, R240
78	79	X	--	Written	2	Y	R121, R122, R240
79	80	X	--	Written	2	N	--

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
80	81	X	--	Written	2	Y	R121, R122, R240
81	82	--	Novartis	Written	3	Y	R30, R31, R32, R34, R52, R58, R60, R62, R66, R90, R92
82	83	X	--	Written	2	Y	R121, R122, R240
83	84	X	--	Written	2	Y	R22, R121, R122, R162, R169
84	85	--	Environmental Health Association	Written	3	N	--
85	86	MCS	--	Written	N/A	N	--
86	87	--	Ohio Network for the Chemically Injured	Written	3	Y	R20
87	88	MCS	--	Written	3	Y	R72
2	89	MCS	--	Written	N/A	N	--
88	90	MCS	--	Written	N/A	N	--
89	91	MCS	--	Written	3	Y	R77, R127, R230
90	92	X	--	Written	2	Y	R121, R122, R240
91	93	MCS	--	Written	N/A	N	--
92	94	X	--	Written	N/A	N	--
25	96	X	--	Written	2	Y	R4, R8, R45, R77, R80, R86, R127, R241
94	97	X	--	Written	2	N	--
95	98	X	--	Written	2	N	--
96	99	MCS	--	Written	2	Y	R176
97	100	X	--	Written	2	Y	R85
98	101	X	--	Written	2	N	--

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
99	102	X	--	Written	2	Y	R176
100	103	MCS	--	Written	N/A	N	--
101	104	MCS	--	E-mail	4	N	--
102	105	X	--	Written	2	N	--
103	106	X	--	Written	2	Y	R121, R122, R240
22	107	MCS	--	Written	N/A	N	--
104	108	X	--	Written	2	Y	R121, R122, R240
105	109	X	--	Written	2	Y	R121, R122, R240
106	110	X	--	Written	2	Y	R121, R122
107	111	MCS	--	Written	N/A	N	--
108	112	X	--	E-mail	N/A	N	--
109	113	X	--	Written	1	N	--
110	114	MCS	--	Written	N/A	N	--
111	115	MCS	--	Written	N/A	N	--
112	116	X	--	Written	2	N	--
113	117	X	--	Written	2	Y	R121, R122, R240
10	118	MCS	--	Written	N/A	Y	R77, R126, R127
114	119	X	--	Written	2	Y	R233, R234, R235
115	120	X	--	Written	2	Y	R121, R122, R240
8	121	MCS	--	Written	3	Y	R94, R131, R132, R88, R133
116	122	X	--	Written	2	Y	R134, R135, R136, R155
117	123	MCS	--	Written	1	N	--
118	124	--	N.C. Chemical Injury Network	Written	2	N	--

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
46	125	--	MCS/CI Support Group	E-mail	3	Y	R176
119	126	X	--	Written	2	N	--
120	127	MCS	--	Written	3	N	--
121	128	X	--	Written	2	N	--
122	129	X	--	Written	2	N	--
123	130	X	--	Written	2	N	--
124	131	X	--	Written	2	N	--
125	132	X	--	Written	2	N	--
126	133	X	--	Written	2	N	--
127	134	X	--	Written	2	N	--
128	135	X	--	Written	2	N	--
129	136	X	--	Written	2	Y	R176
130	137	MCS	--	Written	2	N	--
131	138	X	--	Written	2	N	--
5	139	--	NTEU	E-mail	3	Y	R6, R26
19	142	--	Chemical Sensitivity Disorders Association	Written	2	Y	R3, R5, R25, R36, R43, R46, R64, R103, R107, R116, R241
24	143	MCS	--	Written	3	N	--
7	144	X	--	E-mail	2	N	--
132	145	--	Satasota-manatee Task Force on the Health Effects of Pesticides	Written	2	Y	R24, R65, R172, R173, R175
133	146	MCS	--	Written	2	N	--
134	147	--	MCS:Health and Environment	Written	3	Y	R10, R134, R148, R158, R241

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
26	148	--	Ecological Health Organization	E-mail	2	Y	R12, R15, R40, R42, R43, R48, R64, R79, R99, R121, R122, R161, R183,
135	149	MCS	--	Written	3	N	--
136	150	X	--	Written	2	Y	R121, R122, R240
137	151	X	--	Written	2	Y	R121, R122, R240
138	152	X	--	Written	2	Y	R121, R122, R240
139	153	MCS	--	Written	3	Y	R137, R165, R166, R167
140	154	MCS	--	Written	3	N	--
141	155	MCS	--	Written	N/A	N	--
142	156	--	Center for Occupational and Environmental Medicine	Written	3	Y	R167, R168, R196, R201, R202, R203, R204, R205, R206, R207, R224
143	157	X	--	Written	2	N	--
144	158	MCS	--	Written	2	N	--
145	159	X	--	Written	2	Y	R176
146	160	MCS	--	Written	3	N	--
147	161	--	Environmental Illness Assoc. of Tallahassee	Written	3	Y	R136, R199
148	162	MCS	--	Written	2	Y	R3, R25, R36, R42, R43, R46, R56, R64, R107, R116, R121, R122
149	163	X	--	E-mail	2	N	--
150	164	X	--	Written	2	Y	R241
151	165	MCS	--	Written	2	N	--

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
152	166	X	--	Written	2	N	--
153	167	X	--	Written	2	N	--
154	168	X	--	Written	2	N	--
155	169	MCS	--	Written	2	Y	R69, R84, R89, R104, R109, R119
156	170	--	Health Council of Marin	Written	2	N	--
157	171	--	Health and Habitat	Written	2	N	--
158	172	X	--	Written	2	Y	R176
159	173	HCP	--	Written	2	Y	R19, R40, R43
26	174	--	Ecological Health Organization	Written	2	Y	R12, R15, R40, R42, R43, R48, R64, R79, R99, R121, R122, R161, R183, R241
160	175	MCS	--	Written	1	N	--
161	176	X	--	Written	2	N	--
162	177	X	--	Written	2	N	--
10	178	MCS	--	Written	N/A	N	--
163	179	X	--	Written	2	N	--
164	180	MCS	--	E-mail	N/A	N	--
165	181	MCS	--	Written	2	N	--
166	182	MCS	--	Written	2	N	--
167	183	MCS	--	Written	N/A	N	--
168	184	MCS	--	Written	2	N	--
169	185	X	--	Written	2	N	--
170	186	--	WASTE	Written	2	Y	R176
171	187	X	--	Written	2	Y	R102

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
172	188	MCS	--	Written	3	N	--
173	189	X	--	Written	2	N	--
174	190	X	--	Written	2	Y	R121, R122, R240
175	191	X	--	Written	2	N	--
176	192	MCS	--	Written	2	N	--
177	193	X	--	Written	2	N	--
178	194	X	--	Written	2	N	--
180	196	MCS	--	Written	2	N	--
181	197	MCS	--	Written	2	N	--
23	198	X	--	Written	2	N	--
182	199	HCP	--	Written	3	Y	R182
183	200	MCS	--	Written	N/A	N	--
24	201	X	--	Written	3	N	--
7	202	MCS	--	Written	4	N	--
184	203	X	--	Written	3	N	--
185	204	MCS	--	Written	2	N	--
186	205	MCS	--	Written	3	N	--
187	206	MCS	--	Written	N/A	Y	R70
188	207	HCP	--	Written	3	Y	R56, R79
5	208	--	NTEU Chapter 280	Written	3	Y	R6, R26
189	209	MCS	--	Written	2	Y	R134, R136, R137, R153, R154, R155, R156
190	210	MCS	--	Written	2	Y	R121, R122, R240
191	211	X	--	Written	2	Y	R121, R122, R240
192	212	MCS	--	Written	2	N	--

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
193	213	X	--	Written	3	Y	R150, R151
194	214	X	--	Written	2	N	--
195	215	X	--	Written	3	Y	R157
196	216	MCS	--	Written	2	N	--
197	217	MCS	--	Written	2	Y	R121, R122, R240
198	218	MCS	--	Written	N/A	N	--
199	219	MCS	--	E-mail	1	N	--
200	220	X	--	Written	N/A	N	--
201	221	X	--	Written	2	N	--
202	222	X	--	Written	2	N	--
203	223	X	--	Written	2	N	--
204	224	X	--	Written	2	N	--
205	225	X	--	Written	2	N	--
206	226	X	--	Written	2	N	--
207	227	X	--	Written	2	Y	R241
208	228	X	--	Written	2	N	--
209	229	X	--	Written	1	N	--
210	230	--	Chemical Specialities Manufacturers Association	Written	3	Y	R173, R187, R188, R189, R190
211	231	MCS	--	E-mail	N/A	N	--
212	232	X	--	Written	2	Y	R85
213	233	X	--	Written	2	N	--
214	234	X	--	Written	2	N	--
215	235	X	--	Written	2	N	--
216	236	MCS	--	Written	3	N	--

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
217	237	X	--	Written	2	N	--
218	238	MCS	--	Written	2	Y	R176
219	239	X	--	Written	2	N	--
220	240	MCS	--	Written	2	Y	R57
221	241	X	--	Written	2	N	--
222	242	X	--	Written	2	N	--
223	243	X	--	Written	2	N	--
17	244	X	--	Written	2	N	--
224	245	X	--	Written	2	N	--
225	246	X	--	Written	2	N	--
226	247	X	--	Written	1	N	--
227	248	X	--	Written	2	Y	R121, R122, R240
228	249	X	--	Written	2	N	--
229	250	X	--	Written	2	Y	R121, R122, R240
230	251	X	--	Written	2	Y	R176
17	253	X	--	Written	2	N	--
232	254	X	--	Written	2	Y	R85
233	255	X	--	Written	2	N	--
234	256	--	Amer. College of Occupational and Environmental Medicine	Written	3	N	--
19	257	MCS	--	E-mail	2	Y	R10, R14, R37, R59, R67, R241
235	258	HCP	--	Written	2	Y	R49, R178, R179, R180, R241
11	259	--	NCEHS	Written	1	Y	R117
6	260	MCS	--	E-mail	3	Y	R241

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
236	261	MCS	--	Written	3	N	--
237	262	MCS	--	E-mail	2	Y	R12, R42, R144, R150
238	263	MCS	--	Written	3	N	--
239	264	X	--	Written	3	N	--
15	265	MCS	--	Written	2	Y	R43, R134
240	266	X	--	Written	2	N	--
2	267	MCS	--	Written	3	N	--
20	268	--	ESRI	E-mail	3	Y	R97, R108, R114
241	269	MCS	--	Written	2	N	--
242	270	MCS	--	Written	N/A	Y	R125
243	271	MCS	--	Written	3	Y	R138, R139
244	273	X	--	Written	2	N	--
245	274	X	--	Written	2	Y	R16, R35
246	275	MCS	--	Written	3	N	--
247	276	X	--	Written	2	N	--
248	277	X	--	Written	2	Y	R121, R122, R240
249	278	X	--	Written	2	Y	R121, R122, R240
250	279	X	--	Written	2	Y	R121, R122, R240
251	280	X	--	Written	2	N	--
252	281	X	--	Written	2	N	--
22	282	MCS	--	Written	2	N	--
253	283	MCS	--	Written	2	Y	R7, R101, R112, R115, R136, R140, R141
254	284	X	--	Written	2	N	--
255	285	MCS	--	Written	N/A	N	--

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
256	286	X	--	Written	2	N	--
257	287	X	--	Written	2	N	--
258	288	X	--	Written	2	N	--
12	289	MCS	--	Written	2	Y	R3, R5, R25, R36, R43, R46, R64, R103, R107, R116, R241
12	290	--	MA. Association for the Chemically Injured	Written	2	Y	R3, R5, R25, R36, R43, R46, R64, R103, R107, R116, R241
259	291	--	Am. Academy Clinical Toxicology	Written	3	N	--
260	292	MCS	–	Written	3	N	--
261	293	HCP	–	Written	2	N	--
262	294	MCS	–	Written	3	N	--
263	295	HCP	–	Written	3	N	--
4	296	HCP	–	Written	4	N	--
264	297	MCS	–	E-mail	2	N	--
265	298	MCS	–	E-mail	2	N	--
266	299	MCS	–	Written	N/A	N	--
267	300	X	--	Written	N/A	N	--
268	301	X	--	Written	3	Y	R78
21	302	--	HHS	Written	3	N	--
3	303	--	MCS Referral and Resources	Written	2	Y	R183, R184, R185, R186
269	304	MCS	--	Video	3	N	--
270	305	X	--	Written	N/A	Y	R12
271	306	MCS	--	Written	3	Y	R139

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
272	307	X	--	Written	2	Y	R81
273	308	X	--	Written	4	Y	R39
274	309	X	--	Written	3	Y	R142
275	310	--	Portland Allergy & Chemically Injured Group	Written	2	N	--
276	311	MCS	--	Written	N/A	N	--
277	312	X	--	Written	2	Y	R121, R122, R240
278	313	MCS	–	Written	3	N	--
279	314	--	Anderson Lab	Written	2	Y	R159, R226, R227, R228
280	315	X	--	Written	N/A	N	--
281	316	MCS	–	Written	3	Y	R56
282	317	MCS	–	Written	2	Y	R121, R122
283	318	MCS	–	Written	2	N	--
284	319	MCS	–	Written	N/A	N	--
285	320	MCS	–	Written	2	N	--
286	321	MCS	–	Written	2	N	--
25	322	X	--	Written	2	Y	R4, R8, R45, R80, R86, R77, R127, R241
287	323	MCS	--	Written	2	Y	R121, R122, R240
288	324	X	--	Written	2	Y	R121, R122, R240
289	325	X	--	Written	2	Y	R121, R122, R240
290	326	MCS	--	Written	3	N	--
291	327	MCS	--	Written	N/A	N	--
292	328	MCS	--	Written	N/A	N	--
293	329	X	--	Written	2	Y	R121, R122, R240

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
294	330	X	--	Written	2	Y	R121, R122, R240
295	331	MCS	--	Written	2	N	--
296	332	MCS	--	Written	1	N	--
297	333	MCS	--	Written	N/A	Y	R109
298	334	HCP	--	Written	3	Y	R170
299	335	--	Electrical Sensitivity Network	Written	3	Y	R208, R209
300	336	MCS	–	Written	3	N	--
9	337	MCS	--	Written	2	N	--
301	338	X	--	Written	2	Y	R121, R122, R240
302	339	X	--	Written	2	Y	R121, R122, R240
303	340	X	--	Written	2	Y	R121, R122, R240
304	341	MCS	--	Written	2	Y	R71, R126
305	342	MCS	--	Written	N/A	N	--
306	343	--	Human Ecology Action League	Written	3	Y	R100, R241
307	344	MCS	--	Written	3	Y	R61
308	345	X	--	Written	2	Y	R121, R122, R240
309	346	MCS	--	Written	N/A	N	--
310	347	X	--	Written	2	Y	R74, R113, R229, R231, R232, R239, R241
311	348	MCS	--	Written	2	Y	R121, R122, R240
312	349	--	Chemical Impact Project	Written	N/A	N	--
313	350	X	--	Written	2	N	--
6	351	MCS	–	Written	3	Y	R241
314	352	MCS	--	Written	2	Y	R121, R122, R240

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
315	353	X	--	Written	2	Y	R121, R122, R240
316	354	X	--	Written	2	Y	R121, R122, R240
317	355	MCS	--	Written	1	Y	R121, R122
318	356	X	--	Written	2	N	--
319	357	MCS	--	Written	N/A	N	--
320	358	X	--	Written	2	Y	R121, R122, R240
321	359	MCS	--	Written	N/A	N	--
322	360	MCS	--	Written	2	Y	R56, R87, R96, R126, R134, R241
323	361	MCS	--	Written	2	N	--
324	362	MCS	--	E-mail	2	Y	R121, R122, R240
325	363	--	Chemical Injury Information Network	Written	2	Y	R9, R140, R181, R223, R225
326	364	--	AFLCIO	Written	3	N	--
327	365	MCS	–	Written	2	Y	R14, R45, R96, R123, R124, R241
328	366	HCP	–	Written	2	Y	R63
329	367	X	--	Written	2	Y	R121, R122, R240
1	368	MCS	–	E-mail	N/A	N	--
330	369	MCS	–	Written	N/A	N	--
331	370	MCS	–	Written	3	N	--
332	371	MCS	--	Written	3	N	--
333	372	MCS	--	Written	3	Y	R45, R126, R238
334	373	X	--	E-mail	3	N	--
335	374	MCS	--	Written	2	N	--
18	375	X	--	Written	2	Y	R128, R129
337	377	X	--	Written	2	N	--

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
338	378	MCS	--	E-mail	N/A	N	--
339	379	MCS	--	E-mail	N/A	N	--
340	380	X	--	Written	2	N	--
341	381	X	--	Written	2	N	--
342	382	MCS	--	Written	2	N	--
343	383	--	USDA	Written	3	Y	R91, R120, R147, R149, R152, R160, R174, R177, R215
344	384	MCS	--	Written	N/A	N	--
345	385	X	--	Written	2	N	--
346	386	MCS	–	Written	2	Y	R121, R122, R240
347	387	X	--	Written	2	N	--
348	388	X	--	Written	2	Y	R176
349	389	HCP	--	Written	4	N	--
350	390	MCS	--	Written	3	Y	R55, R56, R88, R146
351	391	MCS	--	Written	2	N	--
352	392	--	Environmental Illness Association of Hawaii	Written	1	N	--
353	393	MCS	--	E-mail	1	N	--
354	394	MCS	--	Written	3	N	--
355	395	MCS	--	E-mail	3	N	--
356	396	MCS	--	E-mail	N/A	N	--
357	397	X	--	E-mail	4	Y	R143, R144
358	398	X	--	E-mail	3	N	--
359	399	MCS	--	Written	2	N	--

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
360	400	--	Steptoe & Johnson for the American Chemical Manufacturers Association	Written	2	Y	Extensive List
361	401	X	--	Written	2	N	--
13	402	--	Environmental Health Network	E-mail	2	Y	R72, R78, R121, R122, R126, R144, R145
362	403	X	--	Written	2	Y	R121, R122, R240
363	404	X	--	Written	2	Y	R121, R122, R240
364	405	X	--	Written	2	N	--
365	406	X	--	Written	3	Y	R56
366	407	X	--	E-mail	N/A	N	--
367	408	X	--	Written	2	Y	R121, R122, R240
368	409	X	--	Written	2	N	--
369	410	X	--	Written	2	N	--
370	411	MCS	–	Written	N/A	N	--
371	412	MCS	--	Written	3	N	--
372	413	HCP	--	Written	3	N	--
1	414	MCS	--	E-mail	N/A	N	--
373	415	X	--	Written	2	N	--
374	416	MCS	--	Written	N/A	N	--
375	417	X	--	Written	2	Y	R121, R122, R240
376	418	MCS	--	Written	2	N	--
377	419	X	--	Written	1	N	--

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
378	420	MCS	--	Written	4	N	--
46	421	–	West Coast (FL) MCS/CI Support Group	Written	3	Y	R176
379	422	MCS	--	Written	2	Y	R42, R45, R71, R157
380	423	MCS	--	Written	3	Y	R10, R106
381	424	X	--	Written	3	N	--
382	425	X	--	Written	2	N	--
14	426	X	--	Written	2	Y	R121, R122, R240
383	427	X	--	Written	2	Y	R121, R122, R240
384	428	X	--	Written	2	Y	R128
385	429	X	--	Written	2	N	--
386	430	X	--	Written	2	Y	R121, R122, R240
387	431	MCS	--	Written	N/A	Y	R171
388	432	MCS	–	Written	N/A	N	--
389	433	X	--	Written	2	N	--
390	435	MCS	--	Written	N/A	N	--
391	436	MCS	--	Written	2	N	--
392	437	X	--	Written	2	N	--
393	438	X	--	Written	2	N	--
394	439	X	--	Written	2	N	--
395	440	X	--	Written	2	N	--
396	441	X	--	Written	2	N	--
397	442	X	--	Written	2	N	--
398	443	X	--	Written	2	N	--
399	444	X	--	Written	2	N	--

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
400	445	X	--	Written	2	Y	R121, R122, R240
401	446	X	--	Written	2	Y	R121, R122, R240
14	447	X	--	Written	2	Y	R121, R122, R240
402	448	X	--	Written	2	Y	R121, R122, R240
403	449	X	--	Written	2	Y	R121, R122, R240
404	450	X	--	Written	2	Y	R121, R122, R240
405	451	X	--	Written	2	Y	R121, R122, R240
406	452	X	--	Written	2	Y	R121, R122, R240
407	453	X	--	Written	2	Y	R121, R122, R240
408	454	X	--	Written	2	Y	R121, R122, R240
409	455	X	--	Written	3	N	--
410	456	X	--	Written	2	Y	R176
411	457	X	--	Written	2	N	--
21	458	--	HHS	Written	3	N	--
412	459	X	--	Written	2	N	--
413	460	X	--	Written	3	N	--
414	461	--	USEPA	Written	N/A	N	--
415	462	X	--	Written	N/A	N	--
416	463	X	--	Written	2	Y	R71, R101, R112, R134, R135, R136, R137, R155
13	464	--	Environmental Health Network of CA	Written	2	Y	R72, R78, R121, R122, R126, R144, R145
417	465	X	--	Written	2	Y	R121, R122, R240
418	467	MCS	--	E-mail	N/A	N	--
419	468	X	--	E-mail	N/A	N	--

Inventory Number[1]	Public Inquiry Number[2]	Source[3]		Medium[4]	Supportive of Report?[5]	Additional References Cited[6]	
		Individual	Organization			Y or N	List
420	469	X	--	E-mail	3	N	--
421	470	X	--	E-mail	N/A	N	--
422	471	X	--	E-mail	3	N	--
423	472	X	--	E-mail	3	N	--
424	473	X	--	E-mail	3	N	--
425	474	X	--	E-mail	3	N	--
426	475	X	--	E-mail	3	N	--
427	476	X	--	E-mail	N/A	N	--
428	477	MCS	–	E-mail	2	N	--
429	478	MCS	--	E-mail	N/A	N	--
18	479	MCS	--	E-mail	2	N	--
18	480	MCS	--	E-mail	3	N	--
430	481	MCS	--	Written	N/A	N	--
431	482	X	--	Written	2	N	--
432	483	X	--	Written	2	N	--
433	484	X	--	Written	2	Y	R1, R2, R13, R18, R44, R56, R126, R200, R241
3	485	--	MCS Referral & Resources	Written	1	Y	Extensive List

[1] Internal Inventory numbering system
[2] Public inquiry number on comment received from CDC
[3] Source: individual (X), persons with MCS (MCS), or health care professionals (HCP).
[4] Medium: written, video tape (tape), or email.
[5] Overall supportive nature of the comment: Supportive of the report as written (4); supportive of the report but with editorial changes (3); believes report is biased, and recommends substantive changes in report and recommendations (2); not supportive of report and recommends that no final report be written (1), and no indication of support level (N/A).
[6] Comment cites additional literature (yes or no); if yes, please see attached references.

Appendix B
Compendium of Comments

Compendium of Comments

Public Inquiry #	Comment
2	Form Letter 1. See Appendix D.
3	Form Letter 1. See Appendix D.
4	In this brief E-mail, this MCS sufferer encourages the workgroup to examine more research. This reader believes that by conducting more research, MCS sufferers will be better understood, and not criminalized or diagnosed as hysterical.
5	Comments are from an individual and details the struggle with the disorder. No specific comments are given on the report.
6	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
7	In a short letter, this MCS sufferer reports feeling that MCS is downplayed as a psychological disorder. Individual feels that not all MCS sufferers could have the same psychological problems - so MCS must be a physiological disease.
8	This healthcare provider believes that the subjective nature of the complaints among MCS persons is problematic for epidemiologic studies. This individual also believes that lab tests used by environmental physicians have not been standardized sufficiently to be useful for defining a population group. The author suggests that any research conducted should refer to specific chemicals by name or CAS number so that work can be replicated, and we can pinpoint all problematic chemicals.
9	In this brief comment, the healthcare provider believes that the focus of MCS should be on identifying specific causes of occupational cancer and asthma instead of focusing on vague conditions such as fibromyalgia and chronic fatigue.
10	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
11	In this brief comment, a MCS sufferer asks the workgroup to look into the connection between candidiasis and chemical sensitivity. No specific comments are given on the report.
12	Form Letter 2. See Appendix D.

Public Inquiry #	Comment
13	This group feels that the report is inaccurate, inadequate and disappointing, and represents an enormous waste of time, energy, and money. Agencies who deal with programs or policies addressing MCS should have been included in the interagency workgroup (HUD, DOJ, DOEd etc.). Due to the uncritical examination of MCS and the biases throughout the report, this document will likely be an obstacle to future action on MCS. The report heavily relies on professionals who regularly testify for industry and is heavily weighted in favor of anti-MCS research, and it seriously underestimates the prevalence of chemical sensitivities and MCS, and misrepresents the design, purpose and impact of the EMU. The group feels that all references to the Berlin conference on MCS should be deleted, and reference all studies available. The group recommends that the current Interagency Workgroup be disbanded and the document be withdrawn..
14	The author stresses that MCS is a multi-organ disease, and he believes that the workgroup would benefit by sharing information with other government agencies, and the US military.
15	The author suggests multiple editorial changes.
16	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
17	In this brief letter, the individual objects to report as written and urges action to address the proliferation of chemicals in the U.S.
18	This MCS sufferer believes that Frank Mitchell's position on the board is unethical and biased. The author stresses the importance of an ICD code in order to estimate the prevalence of the disorder.
19	Form Letter 2. See Appendix D.
20	Form Letter 2. See Appendix D.
21	Letter written by mother who has been diagnosed with MCS along with her two sons. She feels that the greatest failure of the report is not investigating Sick Building Syndrome. Numerous editorial changes are suggested.
22	This MCS sufferer states that the report is well written and objective, probably too objective, and that any psychiatric component of MCS is a result of MCS, not a cause of it. The author stresses the need for an ICD-9 code to determine MCS prevalence.
23	The author of this comment believes that the serious research is ignored in this report. In addition to seriously biasing the report, it will contribute to the suffering and death of those afflicted with MCS.

Public Inquiry #	Comment
24	The MCS organization is concerned about both the report's content and the integrity of the process by which it was drafted. It finds that the report is seriously undermined by the closed and biased process by which it was drafted (without any input from MCS patients or their physicians; by the misleading nature of its content that gives far too much credence to the now thoroughly discredited notion that MCS merely is some kind of psychiatric phenomenon; and by its many more misleading omissions that cover up the significant federal MCS research funding and findings). The literature review is inadequate, and the report does not reveal the identity, affiliations and potential conflicts of interest of the 12 so-called "expert" reviewers whom the Workgroup asked to review its August 1997 draft. In addition there are numerous editorial changes were suggested.
25	This MCS sufferer believes that an ICD-9 code is necessary for MCS, as it must be a reportable disease in order to determine the scope of the illness. In addition, the individual suggests revising the report every five years as new knowledge becomes available.
26	This MCS sufferer states that Frank Mitchell's version of the report has to be disregarded, and a new author must undertake the rewriting the report. The author suggests that the federal, state and local policies regarding funding are incomplete in the report. In addition, the author believes that there exists supportive laboratory tests and agreed upon clinical manifestations for MCS.
27	The importance of non-biased third party research cannot be emphasized enough. Comprehensive biomedical and clinical research is fundamental for developing a definition and inherent understanding of the syndrome.
28	This MCS sufferer wants the government to commit more money for MCS research and treatment.
29	Include in the draft information gathered by the Social Security Administration (SSA) and Housing and Urban Development (HUD), the author of the report and his affiliations, and issue a response to comments in the Federal Register, summarizing how comments were addressed.

Public Inquiry #	Comment
30	This organization finds the report to be a reasonable first attempt to address the history of federally funded research on MCS in an unbiased manner. The report is the first step toward pooling the efforts of public health agencies to provide a unified research agenda and coordinated research funding strategy. Although there are details which have been omitted, the conclusion of the report reflects the respect the agencies have for the sincerity of individual beliefs, and an acknowledgment of the current lack of scientific support for these beliefs. ESRI supports the workgroups conclusion of the necessity of targeted research to reduce uncertainty and to put scientific knowledge into the context of risk and benefits. ESRI strongly supports the workgroup's recommendations on not offering ineffective, costly or potentially dangerous treatments and not withholding or delaying appropriate care. Additionally, they support the need for an overall strategic plan for MCS to articulate the research effort and offer guidance on communication, education of health care providers and MCS sufferers, and the initiation of offering phased efforts in conducting targeted research. ESRI commends the workgroup for its emphasis on objective measures to reduce experimental bias and suggests that no further attempts to qualify the number of affected people should be undertaken until an objective and standardized case definition is established. They believe that the report needs a comprehensive yet non-provocative term which does not presume causation and that the report should differentiate between lists of self-reported intolerances and causal agents.
31	This MCS sufferer believes that the report places too much emphasis on the possibility of psychological factors/origins of MCS, and that it needs to identify the biased nature of the source of these studies.
32	The author of this comment believes that much of the pertinent MCS research has been omitted. The report needs to consider all studies on MCS including those on Toxic Carpet Syndrome and chemical Hypersensitivity, as well as information gathered by such agencies as SSA and HUD among others.
33	Form Letter 2. See Appendix D.
34	The report is unacceptable in its current state. The workgroup should have a disinterested party such as the National Science Foundation or GAO to conduct a complete literature search. Whole sections of MCS literature are missing from the report. The report fails to recognize that: various chemicals are toxic and that even small amounts of some chemicals cause damage, and an environmental chamber produces useless data and is potentially unethical. A summary of the professional background and discipline of each workgroup member should be provided to the public so that they understand the expertise provided by the workgroup.
36	This MCS victim believes that the draft reads like a document prepared by the chemical industry for the purpose of defending it's economic interests. As papers have shown that .2% to 6% of the population suffers from MCS, it should receive extensive funding. In addition, numerous editorial changes were suggested.

Public Inquiry #	Comment
37	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
38	Individual believes that the report is biased & discriminatory, and it minimizes significance of MCS. In having Frank Mitchell as author or the report, it shows that report is biased
39	This MCS victim believes that the draft reads like a document prepared by the chemical industry for the purpose of defending it's economic interests. As papers have shown that .2% to 6% of the population suffers from MCS, it should receive extensive funding. In addition, numerous editorial changes were suggested.
40	Report should point out that the various mechanisms referred to in the section 'psychological mechanisms' are not mutually exclusive. This health care provider believes that people receiving the diagnosis of MCS are heterogeneous, and cannot all be labeled as experiencing odor-triggered panic attacks.
54	This health care provider feels the executive summary does not add to understanding of MCS. The report is incomplete, unscientific and shows a prejudice of the workshop. The views of patients, scientists and clinicians who have extensive experience with MCS are under-represented and ignored. The report should acknowledge F. Mitchell's employer.
55	This health care provider believes that the completed draft is quite good. MCS is such a controversial topic that anyone involved can find points of disagreement. An editorial suggestion is also included.
56	This government agency believes that the document is a well-written comprehensive review of the issues. The consequences of MCS need to be dealt with effectively, and the document lays the framework for doing just that. In addition, the group believes that there is enough suggestive evidence to warrant further research in MCS.
58	This health care provider thinks patients with hay fever or asthma and other allergic manifestations should not be separated from patients with autoimmune diseases and MCS. In addition, the author feels that studies cannot just look at patients who have no other sensitivities. This provider would like money to be spent on educating physicians and the public.
59	Correspondence is a request for report only. There are no comments on the report.
60	Correspondence is a request for report only. There are no comments on the report.
61	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
62	This MCS sufferer encourages the workgroup to exclude ESRI and RISE from the report, which would make it less biased.

Public Inquiry #	Comment
63	Report takes status quo approach, and reviews a few studies that everyone already knows about. The studies with psychological basis are not critically reviewed, while studies that have a physiological basis received more individual critiques. This health care provider recommends an extensive study of all aspects of chemical induced injury.
64	The APHA points out that the report cites only 169 references, less than 1/3 of peer reviewed literature on MCS published since 1952, and it does not report many findings from any federally-funded MCS research. In addition, the workgroup didn't consult other federal authorities that have already adopted policies or funded MCS research. The organization urges the workgroup to include: a comprehensive bibliography, detailed listing of federally-funded research projects on MCS or chemical sensitivity, a comprehensive listing of government policies on MCS.
65	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
66	Individual feels report doesn't go far enough, and is requesting a congressional investigation of MCS.
67	Individual feels that the report misrepresents cited studies several times and disregarded diagnostic procedures that show neurological damage.
68	Individual feels that report is biased and discriminatory, and it minimizes the significance of MCS. The individual feels that the report wrongly assumes that there is no end organ disease associated with MCS. In addition, the individual feels that by having Frank Mitchell as author, it shows that report is biased
69	This MCS sufferer feels that the report is biased, and would like to include information from EPA and OSHA in the report.
70	This MCS sufferer feels that the report is wrongly focused on whether MCS actually exists, and given the known facts, the continued questioning of the existence of MCS is puzzling. In addition there are editorial changes suggested.
71	This MCS sufferer wants the workgroup to withdraw the report and assign it to a different workgroup. The report is incomplete, inaccurate, and offers little effective guidance for MCS public policy and research. The report had an inadequate literature review, a misrepresentation of examined data, omission of critical MCS policies, statements, experiences, and research by numerous federal agencies. In addition, this MCS sufferer feels that Dr. Mitchell's position is a conflict of interest.

Public Inquiry #	Comment
72	This MCS sufferer calls for a congressional or Government Accounting Office (GAO) to disclose the connection of the chemical industry to the research studies cited in the report, and the affiliations of those who worked on the report. Begin by defining MCS, because without this, physicians cannot diagnose MCS, prevalence is underestimated, and funding research and medical coverage is ignored. In addition, conduct thorough review of MCS literature and include physicians who treat MCS, include DOJ, SSA, HUD, Equal Employment Opportunity Commission, National Council on Disability and the National Park Service in the report. Don't include Department of Defense or Department of Energy in MCS research - they have tried to cover up Gulf War Syndrome and they have no real medical expertise. Finally there were many editorial suggestions.
73	Individual feels that Frank Mitchell's position is a conflict of interest and shows that the report is biased. The individual would like the report to include research and input from MCS physicians and researchers, as well as data from SSA, HUD and other government agencies that deal with MCS.
74	Form Letter 2. See Appendix D.
75	This MCS sufferer is glad that MCS is being looked into, but fears the influence of Dr. Mitchell on the initial draft. Individual believes that research with an existing MCS clinic should be conducted, and the link between MCS and food allergies should be examined. The individual would like the concept of masking explained more clearly.
76	This sufferer of MCS believes that the report should call for: education of the public, a mechanism to put pressure on industry to create fewer problematic products, and establishment of a channel(s) to collect MCS data.
77	This MCS sufferer writes of her workplace and her daily exposures to dust, glue and smelly furniture. She wants the workgroup to know that MCS does exist.
78	Form Letter 1. See Appendix D.
79	Form Letter 1. See Appendix D.
80	Individual feels the report is biased, as evidenced by Frank Mitchell's affiliation with report, and the fact that numerous studies which prove MCS is physiological, are omitted from report. Individual would like the report to define MCS so progress can be made.
81	Form Letter 1. See Appendix D.

Public Inquiry #	Comment
82	Novartis' interest in MCS is in ensuring that ATSDR and EPA use the best available validated scientific principles in conducting research or surveillance activities id MCS is to be investigated as an endpoint associated with exposure to chemicals and pesticides. Most of the comments are in the form of recommendations directed at future research including: epidemiologic studies, development of biomarkers, psychological and microbiological aspects of sick building syndrome into MCS investigation. This company believes that an operational definition of MCS is needed, and the term Idiopathic Environmental Illness (IEI) should be used in place of MCS as it is more descriptive. In addition, they would like to see one organization oversee MCS research so as to avoid duplication and allocate research funds. The company feels that the draft did not include a full review of the literature, and that studies published after the completion date should be considered before the finalization of the document. They feel that due to the lack of consensus and high degree of controversy that has surrounded this issue, a substantial amount of research is called for. All these research efforts should be subject to adequate peer review as MCS is so controversial.
83	Form Letter 1. See Appendix D.
84	This individual believes industry bias permeates the report, so it is unacceptable. He would like the workgroup to include the MCS policies of other federal agencies that are originally omitted.
85	This association feels that James Bovard (line 2019) should not be included in the report, as he is not qualified to discuss MCS. His criticism of Ecology House, a home for disabled citizens, is unfounded. In addition, the report leaves out important evidence and includes flawed research.
86	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
87	Group feels that more current and representative MCS literature should be included in the report, as some of the reports included suggesting a psychological origin are biased, misleading and unscientific. Group feels that MCS is being labeled as having a psychological origin although it is no different from many other diseases except that MCS sufferers can pinpoint the source of their illness. The group would like to see the area of nutrition mentioned in the report, and recommends public education, combining medical testing and chemical laboratory studies and conducting correlation studies. Additionally, the group hopes that the workgroup is not misdirected by the chemical industry who would rather have psychological problems examined.
88	This MCS sufferer would like report to include input from physicians who treat MCS victims as well as the victims themselves. In addition, the MCS sufferer would like the workgroup to know that tests do exist to determine MCS, if the right doctor knows the right labs to use..

Public Inquiry #	Comment
89	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
90	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
91	This MCS sufferer states that the work of the Interagency Workgroup is extensive, even though it neglects a couple of historical precedents. Author would like the workgroup to examine the Randolph House in Peoria, Illinois, which is one of several safe houses encouraged by physicians in the American Academy of Environmental Medicine. It should be looked at with regards to an environmental testing unit. Several editorial changes were suggested.
92	Form Letter 1. See Appendix D.
93	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
94	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
96	Individual feels that the report is seriously flawed and gives an inaccurate and misleading picture of the current situation. To improve the report, it needs to use all MCS literature available, and should have a section to recognize MCS (under various names) for the last 150years. In addition there are several editorial suggestions.
97	Form Letter 2. See Appendix D.
98	Form Letter 2. See Appendix D.
99	Form Letter 3. See Appendix D.
100	This individual believes that the report is a biased representation of MCS, and recent research pointing to a true neurological basis for the illness has been omitted. Individual encourages the workgroup to rewrite the document to better reflect the reality of what is known about MCS.
101	Form Letter 2. See Appendix D.
102	Form Letter 3. See Appendix D.
103	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
104	This MCS sufferer states that the draft is a great start to recognize MCS, and that it is a reasonable explanation of MCS.
105	Individual believes report is inadequately researched (it omits many studies) and as such, contains misleading, inadequate, and inaccurate information and conclusions

Public Inquiry #	Comment
106	Form Letter 1. See Appendix D.
107	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
108	Form Letter 1. See Appendix D.
109	Form Letter 1. See Appendix D.
110	The author of this comment believes that the report is extremely biased and minimizes the significance of the disease. In addition, it fails to mention that at least 14 federal agencies have recognized MCS. Individual encourages the workgroup, when finalizing report, to consider the impact that the report on MCS will have on the health care community and on the public.
111	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
112	Correspondence is a request for report only. There are no comments on the report.
113	Individual is calling for a Congressional Investigation of MCS, as more research and investigation needs to be done.
114	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
115	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
116	Individual believes that the report is a biased and incomplete representation of MCS, and has omitted much research. MCS must be a standard diagnosis with an ICD-9 code, so physicians can understand the true prevalence.
117	Form Letter 1. See Appendix D.
118	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
119	Individual believes that the report should consider MCS as one of many illnesses related to the increasing degradation of the environment. 'action - not more research - is needed to rid society of its most dangerous chemicals and thus relieve the suffering of many millions'.
120	Form Letter 1. See Appendix D.
121	This sufferer of MCS believes that the report downplays the existence of MCS. The relationship between MCS and electromagnetic sensitivity should be investigated.

Public Inquiry #	Comment
122	Individual believes that flaws in physiological studies were pointed out whereas those in psychological studies were not. Much relevant literature was missing, and the workgroup consistently used the lowest statistics possible. In addition, numerous editorial suggestions were given.
123	Report is totally biased against those with MCS - Its tone and wording signify a government cover-up. This MCS sufferer questions what chemical companies or food manufacturing conglomerates have influenced the report.
124	The report has a biased and discriminatory tone, and it appears as though attempts were made to drain credibility from MCS research by attacking study design, validity of diagnostic tools, and subjective reports. The group feels that the report generates the false understanding that end-organ disease is not prevalent, when the truth is that no end-organ disease studies have been undertaken for MCS. The Workgroup experts should be doctors/researchers that understand MCS. The so- called experts on the panel do not understand MCS and its associated health problems. The report should also include appropriate disclosures such as funding sources for cited studies, affiliations of researchers, and conflicts of interest. Additionally Form Letter 1 is attached. See Appendix D.
126	Form Letter 2. See Appendix D.
127	MCS sufferer wants the workgroup to recognize that MCS is not a psychological illness, and believes that someone with MCS or a physician who treats MCS victims should be included in the workgroup.
128	Form Letter 2. See Appendix D.
129	Form Letter 2. See Appendix D.
130	Form Letter 2. See Appendix D.
131	Form Letter 2. See Appendix D.
132	Form Letter 2. See Appendix D.
133	Form Letter 2. See Appendix D.
134	Form Letter 2. See Appendix D.
135	Form Letter 2. See Appendix D.
136	Form Letter 3. See Appendix D.
137	In this brief letter, the MCS sufferer states that he would like the workgroup to rewrite report out of fairness to all MCS sufferers.

Public Inquiry #	Comment
138	Individual feel that meeting the criteria to characterize an environmental health issue is difficult as many in the medical community argue the existence of MCS, and others have a vested interest in drug companies. Individual fears, that by obtaining direct public input on research, the report could be an opportunity for the chemical companies to use their power and influence.
139	This group suggests a refinement of the study approach with a definition of MCS. They feel that a case definition based on Koch's postulate is not as important as the operational definition - need to identify a population with the problem and carry out a series of studies over time, to determine association. They do not believe that the development of an animal or elucidation model of the basic disease process is the first consideration in matters of public health. This organization would like the report to include complaints received by EPA, CPSC, and OSHA that involve reports of induction of MCS. It should also use more recent articles. Report places too much emphasis on psychological mechanisms and too little emphasis on neural mechanisms. Report needs to identify 12 experts mentioned on page 95 and match the recommendations to the appropriate person. Dr. Mitchell's affiliation with ESRI should be acknowledged in the report. Additionally, the report needs to compile and evaluate data on agents suspected or identified to induce MCS. They call for specific improvements and a complete re-write of the report.
142	This letter supports the Massachusetts Association for the Chemically Injured (MACI), and strongly supports: a working definition of MCS, a medical diagnostic code for physicians, and government funding for MCS research. The group is concerned that the report emphasizes a psychological basis of MCS, and repeatedly underestimates the prevalence and severity of the problem. The group would like to incorporate into the report: input from clinicians who treat and study MCS patients, information from the Social Security Administration, Housing and Urban Development, and others that deal with MCS, and disclosure of the conflict of interest in having Dr. Frank Mitchell author the draft. The group feels that excellent literature is missing from the report, the draft is incomplete in its description and characterization of MCS, the draft report should point out the limitations of MCS prevalence as there is no ICD-9 code, and the report needs to include a summary to provide for the physiologic basis and the weight of data reported in the literature. In addition there were numerous editorial changes suggested. In general the policy recommendations proposed by the workgroup are weak and unacceptable. Basic research is needed to elucidate the mechanisms of the illness in order to offer patients the effective treatment they deserve. The diversity of groups reporting MCS- like illness suggests the existence of a real problem. Finally, the group feels that MCS case registries would be very valuable and that the report should be revised using the comments received.
143	In this brief letter, the MCS sufferer asks the workgroup to advocate for money to conduct research.

Public Inquiry #	Comment
145	This organization feels that the draft is severely biased in favor of the chemical industry, and that it fails to disclose any ties Frank Mitchell may have to the chemical industry and the role he played in the report. They would like the draft withdrawn and completely rewritten, as it fails to include essential data, information and conflicts of interest. This organization feels that the facts and circumstances of the Berlin Workshop are not accurately portrayed in the text. The controversy and official disclaimers should be represented in the draft. They feel that TILT (toxicant-induced loss of tolerance) doesn't receive the attention it warrants in the text, nor does it appear in the terminology and definitions sections. The group would like the identities of the 12 experts who reviewed an earlier version to be disclosed.
146	This MCS sufferer feels that members of the workgroup are biased, and that many studies were omitted. More research on MCS is needed.
147	This organization would like the workgroup to include all MCS literature in the report, and give more credence to MCS case histories. They also feel that the precautionary principle, which states "when an activity raises threats of harm to human health or the environment, precautionary measures should be taken even if cause and effect relationships are not fully established scientifically. The organization believes that more research is definitely needed on the thousands of chemicals and their synergistic effects.
148	Organization suggests the use of Dr. Cullen's definition with minor adjustments to compensate for the restrictive nature of the definition. They would like to designate a CDC code for MCS, since the lack of a classification has hampered research funding, delayed diagnosis, treatment and insurance coverage for the illness. The group believes that the report is lacking in depth of research information on critical issues and with prevalence data. The report overemphasizes the psychological aspects of MCS. Organization recommends the expansion of the workgroup to include other federal agencies and doctors treating patients with MCS. In addition, suggests that a thorough and complete review of the literature on MCS be done by an unbiased researcher (notes Frank Mitchell's conflict of interest). They believe that the education of the public and the medical community regarding the public health importance of MCS is critical.
149	The MCS sufferer's principal concern is the education of mainstream healthcare professionals about the reality of MCS. All physicians should be informed of symptoms in table 4. MCS patients must practice avoidance, and the report should not encourage otherwise. Federal action is needed to conduct epidemiology research and develop a definition for MCS. In addition numerous editorial suggestions were given.
150	Form Letter 1. See Appendix D.
151	Form Letter 1. See Appendix D.
152	Form Letter 1. See Appendix D.

Public Inquiry #	Comment
153	This MCS sufferer thanks the workgroup for it's indulgence and dedication to the continuation of the work. Report could be made more valuable by involving MCS physicians, as not all MCS individuals have the same level of exposure or impairment. Individual feels that end organ damage is an issue, and at a certain level of severity, the patient suffers permanent brain damage.
154	This MCS sufferer wants the workgroup to recognize that MCS is a real disease and not just psychological. Environmental Control Units should not be used to prove MCS is real, as they can significantly harm the patient.
155	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
156	This organization feels that the workgroup did a satisfactory job in outlining the issues regarding MCS, but found it disturbing that after 81 pages of text and 17 pages of references that the executive summary concludes that 1) MCS is probably not a distinct disease entity with a single accepted case definition 2)MCS is a symptom based diagnosis without supportive laboratory tests 3) No evidence in the literature exists for end-organ damage attributable to MCS. These faulty conclusions are the only things that the medical establishment and governing authorities will remember. MCS is a major public health issue and people are suffering. The workgroup should be made aware that there are objective laboratory tests and reports in the literature of end organ damage attributable to MCS. This organization feels that the development of the MCS database should be run by a specific department of HHS e.g., CDC in conjunction with an experienced AAEM member panel.
157	Form Letter 2. See Appendix D.
158	This MCS sufferer feels that although the report is a welcome first step, it is flawed. Report fails to include information from other federal agencies, and Dr. Mitchell's involvement means the report is biased. This MCS sufferer would like more research by the true experts (doctors who treat MCS) in the field.
159	Form Letter 3. See Appendix D.
160	This MCS sufferer hopes that the report can help the severely inadequate system which is in dire need of repair. In addition, the individual feels that input from MCS subjects is very important, as are studies by both occupational and environmental medicine practitioners.
161	Organization supports conducting epidemiology studies and exposure assessment, state by state via questionnaire focusing on what adverse reactions the population has to toxic chemicals and substances. The organization feels that very important studies are omitted from the report. Avoidance of chemicals and toxic substances in the environment is a survival necessity for persons with MCS/EI, and the report should emphasize this. MCS/EI is spreading at a frightening rate, so the problem has to be addressed. Several editorial changes were also suggested

Public Inquiry #	Comment
162	Report omits important information, and includes biased research. A Government Accounting Office (GAO) Investigation is needed to disclose all research studies on MCS. This MCS sufferer would like the workgroup to: define MCS, assign a CDC code for MCS, establish accepted tests, conduct complete review of MCS literature, determine MCS prevalence, include children in report, and expand the workgroup to include DOJ, SSA, HUD and others.
163	Individual feels that there is no credible scientific or medical evidence that can support the theory that MCS is caused by psychological factors.
164	Individual believes that much of the MCS literature is missing from the report, and the psychological studies mentioned in the report were flawed. In addition, Frank Mitchell's position means that report is biased. Several editorial changes were also suggested
165	MCS sufferer believes the report downplays the prevalence of MCS, as it only considers people who have received a specific diagnosis of MCS by a physician. Frank Mitchell's position on the workgroup is a conflict of interest. Avoidance is one of the absolutes in the treatment of MCS.
166	Form Letter 2. See Appendix D.
167	Form Letter 2. See Appendix D.
168	Form Letter 2. See Appendix D.
169	Report is just another stalling tactic to keep the truth from the public. MCS sufferer believes that Gulf War Syndrome and MCS are the same induced illnesses.
170	This organization commends the report for acknowledging the importance of MCS, assessing current research and recommendations on MCS, reviewing related federal actions, and proposing technical and policy recommendations. However, the organization believes that the draft report includes a multitude of inaccuracies and misinterpretations, does not objectively assess current research on MCS, and does not offer effective recommendations for addressing MCS as a health and environmental issue. It notes that many other federal departments and agencies have developed policies on MCS which were not represented in the report, and the report failed to mention results of study by NJ Environmental Hazards Research Center, and from EPA which found that the most commonly identified chronic health effect of exposure to the pesticide chlorpyrifos was MCS. Additionally, the group suggested that the workgroup report the IPCS disclaimer on the MCS Workshop. The council also notes the failure to acknowledge the workgroup's ties with the chemical industry and the obvious conflict of interest this presents.

Public Inquiry #	Comment
171	This organization commends the report for acknowledging the importance of MCS, assessing current research and recommendations on MCS, reviewing related federal actions, and proposing technical and policy recommendations. However, the organization believes that the draft report includes a multitude of inaccuracies and misinterpretations, does not objectively assess current research on MCS, and does not offer effective recommendations for addressing MCS as a health and environmental issue. It notes that many other federal departments and agencies have developed policies on MCS which were not represented in the report, and the report failed to mention results of study by NJ Environmental Hazards Research Center, and from EPA which found that the most commonly identified chronic health effect of exposure to the pesticide chlorpyrifos was MCS. Additionally, the group suggested that the workgroup report the IPCS disclaimer on the MCS Workshop. The council also notes the failure to acknowledge the workgroup's ties with the chemical industry and the obvious conflict of interest this presents.
172	Form Letter 3. See Appendix D.
173	This health care provider believes that the report consistently over-emphasizes on what is not known or proven and consistently under-emphasizes or omits what is known. The report ignores federal data on MCS, and written literature has been inadequately and incompletely reviewed. The epidemiology overview of the report gives the misleading impression that little is known about the epidemiology of MCS, and the workgroup ignores the major overlap of MCS with chronic fatigue syndrome and fibromyalgia. This individual is unconvinced that any amount of modification can correct the basic problem that this paper was written by Frank Mitchell, an industry consultant.
174	Organization suggests the use of Dr. Cullen's definition with minor adjustments to compensate for the restrictive nature of the definition. They would like to designate a CDC code for MCS, since the lack of a classification has hampered research funding, delayed diagnosis, treatment and insurance coverage for the illness. The group believes that the report is lacking in depth of research information on critical issues and with prevalence data. The report overemphasizes the psychological aspects of MCS. Organization recommends the expansion of the workgroup to include other federal agencies and doctors treating patients with MCS. In addition, suggests that a thorough and complete review of the literature on MCS be done by an unbiased researcher (notes Frank Mitchell's conflict of interest). They believe that the education of the public and the medical community regarding the public health importance of MCS is critical.
175	This MCS sufferer believes the draft to be inaccurate and biased. The report should state who funded the report and what industries are represented in the group of researchers.
176	Form Letter 2. See Appendix D.
177	Form Letter 2. See Appendix D.

Public Inquiry #	Comment
178	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
179	Form Letter 2. See Appendix D.
180	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
181	This MCS sufferer asks not to use conclusions in the 8/24/98 report for public policy making, and to find more MCS information before drafting a new report. Remove Dr. Mitchell and involve individuals with no conflict of interest.
182	This MCS sufferer feel that the current draft should be abandoned unless the government is willing to disclose that all federal MCS research data that has been omitted.
183	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
184	This MCS sufferer feels the report is biased toward the chemical industry, but it doesn't acknowledge those connections.
185	Form Letter 2. See Appendix D.
186	Form Letter 3. See Appendix D.
187	Individual feels that the report should be extensively revised (Frank Mitchell's position makes report biased), and that grass roots groups of MCS patients should be involved in the writing of the report.
188	This MCS sufferer believes that there needs to be a reporting code for MCS, which would make epidemiological studies and data more accurate. More accurate counts would allow the problem to be addressed correctly.
189	Form Letter 2. See Appendix D.
190	Form Letter 1. See Appendix D.
191	Severity of the problem is underestimated, which is why we need a working definition of MCS and a medical diagnostic code. Report needs: unbiased research, all relevant research as well as input from SSA and HUD, and input from physicians who treat MCS. The report is biased because of Frank Mitchell's involvement, and the Simon study is biased and inaccurate.
192	This MCS sufferer feels that the workgroup is to be commended for efforts on MCS, but there is still a need to eliminate industry bias. Much relevant research has been omitted which does document the reality of MCS as a psychological disorder, and not all agencies had recommendations in the draft report. Much money has been spent on meetings and conferences, and now it is time to spend some money on studies.

Public Inquiry #	Comment
193	Form Letter 2. See Appendix D.
194	Form Letter 2. See Appendix D.
196	This MCS sufferer believes that the report is embarrassingly and unforgivably inaccurate and weak. The definition of MCS should be decided by physicians who treat MCS, MCS victims and researchers. Additionally, individual feels Dr. Mitchell's involvement is inappropriate.
197	Form Letter 2. See Appendix D.
198	Individual resents corruption of medical research into MCS by vested interests, and feels that many of the sources cited reflect industry biases.
199	Report should better reflect fact that there is a lack of good scientific evidence to prove the existence of MCS. This health care provider feels it would be inappropriate to educate the entire health community of MCS when we don't know if it is a real disease entity, and that the public should not play a role in the research process. Individual believes that more scientific evidence is necessary to prove or disprove various hypotheses about causation before establishing policy, alerting physicians and possibly alarming the public to the possible role of chemicals in the production of these syndromes.
200	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
202	This MCS sufferer is glad to know that the government is looking into MCS, but more money needs to be spent. We need a good registry system to count those with MCS, CS, Gulf War Illness, CFS, Lupus, MS, Fibromyalgia etc.
203	Individual believes that more money needs to be spent on MCS.
204	This MCS sufferer believes that much relevant literature and data from other federal agencies is missing from the report. Additionally, Frank Mitchell's position biases the report.
205	This MCS sufferer feels that it is a good idea not to study MCS separately from similar illnesses, as it will give a better understanding of health and disease in general. Given that symptoms come and go with exposures, MCS can't be studied like a traditional disease. Report should include orthomolecular science, scientists who study sleep disorders, electrical sensitivity, recombinant DNA, and religious-scientific-pseudoscientific practitioners (like Henry Wright).
206	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.

Public Inquiry #	Comment
207	This health care professional states that the draft is a good first step into the discovery of the workings of chemical sensitivity, but warns that chemical sensitivity is but one aspect of environmental illness. Author feels that physicians who treat MCS should be included in place of the several physicians included in the report who do not understand chemical sensitivity. In addition, numerous editorial changes were suggested.
208	This group suggests a refinement of the study approach with a definition of MCS. They feel that a case definition based on Koch's postulate is not as important as the operational definition - need to identify a population with the problem and carry out a series of studies over time, to determine association. They do not believe that the development of an animal or elucidation model of the basic disease process is the first consideration in matters of public health. This organization would like the report to include complaints received by EPA, CPSC, and OSHA that involve reports of induction of MCS. It should also use more recent articles. Report places too much emphasis on psychological mechanisms and too little emphasis on neural mechanisms. Report needs to identify 12 experts mentioned on page 95 and match the recommendations to the appropriate person. Dr. Mitchell's affiliation with ESRI should be acknowledged in the report. Additionally, the report needs to compile and evaluate data on agents suspected or identified to induce MCS. They call for specific improvements and a complete re-write of the report.
209	Many important references have been omitted from the report as has information from other government agencies. Additionally, the MCS sufferer believes that the report is biased by including work of Drs. Gots and Terr, and having Frank Mitchell as author.
210	Form Letter 1. See Appendix D.
211	Form Letter 1. See Appendix D.
212	This MCS sufferer believes that a lack of information, downplaying significant data, and false and misleading information is evident in report. Having Frank Mitchell as an author is a conflict of interest. Include all published studies and the policies of the additional federal agencies that have recognized MCS, and recognize that many studies indicating that MCS is psychogenic in nature have been found to be seriously flawed. MCS is under reported because there is no ICD-9 code.
213	Individual was impressed with the writing and organization of the draft. The report could benefit from the input of an environmental doctor, or a physician who deals with MCS patients. Report should address the number of people with MCS, typical occupations associated with MCS, expenses incurred for diagnosis and treatment, reliable diagnostic tools currently used. Include MCS victim/activist on the workgroup. Frank Mitchell as author is a conflict of interest.
214	Form Letter 4. See Appendix D.

Public Inquiry #	Comment
215	Excellent report on MCS. Individual believes that MCS should also encompass breast implant disease, lyme disease, mercury amalgam disease and candida overgrowth. As the research community continues to explore MCS, patients should be considered experts on MCS. In addition, there are numerous editorial suggestions.
216	Physiological causes must be ruled out before a psychological diagnosis can be assigned to MCS. People with the illness deserve validation of their condition. All participants of the workgroup should be required to divulge from whom research monies were obtained, and those participants having a conflict of interest should be eliminated from the study. This MCS sufferer believes that the following tests can interpret MCS: PET, SPEC, BEAM, SCANS, blood, urine, and tissue. Individual requests a full-scale investigation into MCS.
217	Form Letter 1. See Appendix D.
218	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
219	This MCS sufferer feels that the report should be withdrawn, and that it is an inaccurate and gross misrepresentation of the illness.
220	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
221	Form Letter 2. See Appendix D.
222	Form Letter 2. See Appendix D.
223	Form Letter 2. See Appendix D.
224	Form Letter 2. See Appendix D.
225	The tone of the report insinuates that MCS doesn't merit credence or adequate funding. The report is biased due to Frank Mitchell's involvement.
226	Form Letter 2. See Appendix D.
227	Report is misleading and harmful and is full of chemical industry bias. The prevalence of MCS is unknown, as there is no definition and no ICD-9 code. Patients should have costly treatments available as is the case for other diseases
228	Report has factual errors and is missing important and unbiased MCS research.
229	Report should be withdrawn as it doesn't reflect MCS individuals' situation.

Public Inquiry #	Comment
230	The Chemical Specialities Manufacturers Association states that overall, the report is successful because it provides a public health evaluation of the extent and nature of the complex problem and recommends future actions for federal agencies to consider. Report documents the inadequacy of current scientific literature on the association between human exposure to chemicals and the development of MCS to put each analysis into proper context. The report's discussion on the risks and benefits of chemicals is without foundation and thus inappropriate. This association recommends that all 'substances' that allegedly cause or exacerbate MCS should be listed in the report to demonstrate complexity of the problem and to preclude placing an unfair stigma on certain ones.
231	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
232	Individual feels that the report is biased, and asks the workgroup to reflect reality of MCS in next revision.
233	Form Letter 2. See Appendix D.
234	Form Letter 2. See Appendix D.
235	Form Letter 2. See Appendix D.
236	This MCS sufferer is grateful for the attention workgroup has given MCS, but feels the report puts too much emphasis on psychological testing. This individual would like nutritional factors and prevention to be examined.
237	Form Letter 2. See Appendix D.
238	Form Letter 3. See Appendix D.
239	Draft omits the majority of significant and unbiased MCS research, and Frank Mitchell's involvement is an insult.
240	This MCS sufferer feels that the report fails to mention other federal authorities who have gained experience and data on MCS, and Dr. Mitchell's involvement is a conflict of interest
241	Form Letter 2. See Appendix D.
242	Form Letter 2. See Appendix D.
243	Form Letter 2. See Appendix D.
244	Form Letter 2. See Appendix D.
245	Form Letter 2. See Appendix D.
246	Form Letter 2. See Appendix D.

Public Inquiry #	Comment
247	Report shows disregard of existing research findings on MCS, and fails to include input from MCS patients. Frank Mitchell as author is a conflict of interest.
248	Form Letter 1. See Appendix D.
249	Form Letter 2. See Appendix D.
250	Form Letter 1. See Appendix D.
251	Form Letter 3. See Appendix D.
253	Form Letter 2. See Appendix D.
254	Report is biased and incomplete, as much recent research is omitted. The desire to change the name from MCS shows bias. MCS must be diagnosed, or individuals will disappear from the data. Rewrite the report to reflect what is known about MCS.
255	Form Letter 2. See Appendix D.
256	The American College of Occupational and Environmental Medicine commends the workgroup for a detailed and through evaluation of available information on MCS. This organization strongly agrees that the appropriate way to design research for MCS, is in coordination with the consideration of other syndromes which present with disabling symptoms, but lack objective lab or clinical evidence of disease. They do not agree that the Environmental Health Policy Committee of DHHS is a broad enough entity to address the task of considering all of the diverse syndromes listed in the report. The group recommends that specific action and time tables be developed to implement the workgroups recommendations with respect to the overall strategic plan for MCS, and that research funds be a priority.
257	This MCS sufferer suggests that the workgroup request the Department of Defense to share the research models they use for biological/chemical weapons creation, for MCS research, as virtually every aspect of MCS, including symptoms and end organ damage, has been studied and documented by the US military.
258	Report is an uncritical recitation of biased work with faulty logic, and fails to explore perspective that MCS could be a new general class of disease other than a single entity. This health care provider notes a major problem with the Cullen definition in that it excludes other diagnosable conditions such as asthma, and with the Selner and Staudenmeyer challenge study in terms of subject selection and their failure to unmask patients prior to challenge. This health care provider also notes an ECU or EMU is not a form of exposure chamber. Additionally, the health care provider suggests a new questionnaire be made available containing scales for assessing chemical sensitivity which was developed in accordance with CDHS guidelines. Individual feels discussion of TILT was inadequate and that Berlin conference should not be featured in the report.

Public Inquiry #	Comment
259	The National Center for Environmental Health states that the report is inaccurate, inadequate, and disappointing. Due to the uncritical examination of MCS and the biases throughout the report, this document will likely be an obstacle to future action on MCS. Report heavily relies on professionals who regularly testify for industry and is heavily weighted in favor to anti-MCS research, and it seriously underestimates the prevalence of chemical sensitivities and MCS, and misrepresents the design, purpose and impact of the EMU. The group recommends that the current Interagency Workgroup be disbanded and the document be withdrawn.
260	MCS must be a reportable disease in order to determine the scope of the illness. This MCS sufferer believes that the report should be revised every five years as new knowledge becomes available.
261	This MCS sufferer believes that the report should include responsibility of the petrochemical industry and the role of politics in MCS. MCS should be replaced with a specific diagnosis.
262	This MCS sufferer feels that the report doesn't reflect the concern for the health and well-being of a person with MCS. The report should include MCS experts and agencies involved with MCS, and individuals with strong chemical industry affiliations such as Gots and Terr should be recognized as chemical industry people.
263	This MCS sufferer believes that the public needs to be educated in addition to the medical community, and he would like to see the work of physicians who see MCS patients, not just studies which have been done by chemical companies. Individual believes that since fetuses are highly susceptible in the formative stages, it is worth being mentioned in the report. In addition, the individual suggested numerous editorial changes.
264	Individual believes that the report is mostly wonderful, but ALL definitions of MCS in Table 1 are flawed, and not all relevant reports from all public agencies are included. Additionally, the individual suggested numerous editorial changes.
265	This MCS sufferer encourages the workgroup to withdraw the report and assign it to a different workgroup. The report is incomplete, inaccurate, and offers little effective guidance for MCS public policy and research. The report had an inadequate literature review, a misrepresentation of examined data, omission of critical MCS policies, statements, experiences, and research by numerous federal agencies. Additionally, the individual believes that Dr. Mitchell's position is a conflict of interest.
266	Individual feels that the report wrongly gives credence to the psychological basis of the disease, and underestimates the prevalence and severity of MCS. The workgroup should include physicians who treat and research MCS, and recognize that having Frank Mitchell as author is a conflict of interest. The report would be improved by including input from Social Security Administration (SSA) and Housing and Urban Development (HUD).

Public Inquiry #	Comment
267	This MCS sufferer would like to see the workgroup and report support avoidance measures, and feels that the burden should not fall on business, but on the government. Additionally, the individual believes that Dr. Mitchell's position on the draft is upsetting and makes for a biased report.
268	This organization finds the report to be a reasonable first attempt to address the history of federally funded research on MCS in an unbiased manner. The report is the first step toward pooling the efforts of public health agencies to provide a unified research agenda and coordinated research funding strategy. Although there are details which have been omitted, the conclusion of the report reflects the respect the agencies have for the sincerity of individual beliefs, and an acknowledgment of the current lack of scientific support for these beliefs. ESRI supports the workgroups conclusion of the necessity of targeted research to reduce uncertainty and to put scientific knowledge into the context of risk and benefits. ESRI strongly supports the workgroup's recommendations on not offering ineffective, costly or potentially dangerous treatments and not withholding or delaying appropriate care. Additionally, they support the need for an overall strategic plan for MCS to articulate the research effort and offer guidance on communication, education of health care providers and MCS sufferers, and the initiation of offering phased efforts in conducting targeted research. ESRI commends the workgroup for its emphasis on objective measures to reduce experimental bias and suggests that no further attempts to qualify the number of affected people should be undertaken until an objective and standardized case definition is established. They believe that the report needs a comprehensive yet non-provocative term which does not presume causation and that the report should differentiate between lists of self-reported intolerances and causal agents.
269	This MCS sufferer feels that the report is biased because of Dr. Mitchell's position, and it makes no mention of the Chemical Industry and how it should be held accountable. The report could be improved by talking to MCS patients, and by recommending avoidance measures.
270	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
271	This MCS sufferer believes that MCS should not be a low priority item, as the nature and extent of MCS cannot be determined (a diagnostic code for MCS is needed). Additionally, this individual feels that challenging an MCS person in order to do research is unethical.
273	Form Letter 2. See Appendix D.
274	Report has included biased studies and has downplayed facts about MCS.
275	This MCS sufferer feels that the report is good, but that there are more MCS cases than reported.
276	Form Letter 2. See Appendix D.

Public Inquiry #	Comment
277	Form Letter 1. See Appendix D.
278	Form Letter 1. See Appendix D.
279	Form Letter 1. See Appendix D.
280	Form Letter 2. See Appendix D.
281	Form Letter 2. See Appendix D.
282	This MCS sufferer believes that the workgroup is using definitions as an excuse to ignore the issue. He believes that a new workgroup should be formed, which includes the Chemical Injury Information network and the National Center for Environmental Health Strategies, as well as physicians who work with MCS patients. Perfect studies don't exist, but there is lots of MCS literature missing from the original report. Individual urges the workgroup to call for labeling of all products.
283	This MCS sufferer believes that Dr. Mitchell's position as author is unethical, and the involvement Dr. Ronald Gots is inappropriate, as his views represent the Chemical Industry. The workgroup could benefit by including SSA, HUD, and DOJ, and the report would benefit by including the findings of other government agencies. Individual believes that the International Program on Chemical Safety shouldn't be included in report. In addition, the Simon et al paper cited has been criticized by peers, and other cited literature was funded by those with vested interests, and is therefore biased. In addition there were numerous editorial suggestions.
284	Individual would like the report to include input from individuals with MCS, the Social Security Administration (SSA), Housing and Urban Development (HUD), physicians who treat and research MCS, and researchers who work on the disease.
285	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
286	Form Letter 2. See Appendix D.
287	Form Letter 2. See Appendix D.
288	Form Letter 2. See Appendix D.

Public Inquiry #	Comment
289	This letter from a MCS sufferer strongly supports: a working definition of MCS, a medical diagnostic code for physicians, and government funding for MCS research. The author is concerned that the report emphasizes a psychological basis of MCS, and believes that the report needs to include a summary to provide for the psychologic basis and the weight of data reported in the literature. The author would like to incorporate into the report: input from clinicians who treat and study MCS patients, information from the Social Security Administration, Housing and Urban Development, and others that deal with MCS, and disclosure of the conflict of interest in having Dr. Frank Mitchell author the draft. In addition, this individual believes excellent literature is missing from the report, and as a result, the draft is incomplete in its description and characterization of MCS. The draft repeatedly underestimates the prevalence and severity of the problem and should point out the limitations of MCS prevalence as there is no ICD-9 code, and encourage the use of MCS case registries. In general the policy recommendations proposed by the workgroup are weak and unacceptable. The draft report should call for immediate research. Basic research is needed to elucidate the mechanisms of the illness in order to offer patients the effective treatment they deserve. Proper research in the area of biomarkers is also needed. The report should be revised using the comments received. Additionally, there were numerous editorial changes. The letter is Form Letter 2 with embellishments. See Appendix D.
290	This letter from the Massachusetts Association for the chemically Injured strongly supports: a working definition of MCS, a medical diagnostic code for physicians, and government funding for MCS research. The group is concerned that the report emphasizes a psychological basis of MCS, and believes that the report needs to include a summary to provide for the psychologic basis and the weight of data reported in the literature. The author would like to incorporate into the report: input from clinicians who treat and study MCS patients, information from the Social Security Administration, Housing and Urban Development, and others that deal with MCS, and disclosure of the conflict of interest in having Dr. Frank Mitchell author the draft. In addition, this organization believes excellent literature is missing from the report, and as a result, the draft is incomplete in its description and characterization of MCS. The draft repeatedly underestimates the prevalence and severity of the problem and should point out the limitations of MCS prevalence as there is no ICD-9 code, and encourage the use of MCS case registries. In general the policy recommendations proposed by the workgroup are weak and unacceptable. The draft report should call for immediate research. Basic research is needed to elucidate the mechanisms of the illness in order to offer patients the effective treatment they deserve. Proper research in the area of biomarkers is also needed. The report should be revised using the comments received. Additionally, there were numerous editorial changes. The letter is Form Letter 2 with embellishments. See Appendix D.

Public Inquiry #	Comment
291	The American Academy of Clinical Toxicology has taken a position against MCS as a unique pathophysiologic entity. The Academy is concerned that there was, to their knowledge, no certified medical or clinical toxicologist on the workgroup. The Academy believes that to have the report produced without formal input of the clinical toxicology community, would leave the draft open to considerable criticism so they have offered to review and comment on the report. They feel that if called upon, that their potential endorsement of the final draft would have heightened impact.
292	This MCS sufferer would like the report: to define MCS clinically, be used to educate the public, encourage the development of materials for family and friends of an MCS victim, and to include a protocol for treatment.
293	This health care provider believes the report draft to be biased, as it quoted physicians such as Gots, Terr, and Staudenmayer (who have a negative bias against MCS). Additionally, this individual would like the International Program on Chemical Safety to be removed from the report, as it was widely discredited.
294	MCS needs to be taken seriously. This MCS sufferer would like the workgroup to collect data and keep the public informed.
295	This health care provider suggests that the report should note that probably only a proportion of those affected by chemicals would develop symptoms and be able to recognize the triggering exposures, which is important for funding some policy analysis around this issue.
296	This health care provider believes that the document is a fine beginning and clearly documents the story of this serious yet to be understood disease condition. This physician states he has seen many MCS patients, and although there is a pathophysiologic mechanism, the psychological overlay in this condition plays a role. Author hope the report will stimulate more and more people to think about this problem.
297	MCS sufferer believes that researchers with ties to the Chemical Industry have had too much influence on the report, and there has been a tendency to hide these ties.
298	This MCS sufferer believes that all important studies supporting a physical basis for MCS have been omitted from the reference list, by omitting these and including Gots & Terr, Frank Mitchell is biasing the report.
299	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
300	Correspondence is a request for report only. There are no comments on the report.

Public Inquiry #	Comment
301	Individual feels that the report doesn't reflect the vast amount of medical and technical literature available. Report should be thought of as a tool to educate physicians and government agencies and should include people with MCS. Draft should include findings from other government agencies that deal with MCS (including DOJ, HUD, SSA) and strategies for future research/work/and policy development.
302	The report is well written and should prove very useful to those interested in learning more about MCS. Additionally there are numerous editorial changes.
303	This organization suggests the misuse and misappropriation of federal funds from ATSDR's postgraduate research program (PRP) in having Frank Mitchell listed as a consultant. With no written contract to draft the report on MCS and without disclosing the source of Dr. Mitchell's funding or the obvious conflict of interest. The group questions Dr. Mitchell's eligibility to apply for funding from the PRP and wonder if Dr. Barry Johnson and other officials at ATSDR violated federal law and agency policies and regulations by approving PRP funds, despite Dr. Mitchell's apparent ineligibility (no written contract and no disclosure of the funding in the report).
305	Correspondence is a request for report only. There are no comments on the report.
306	This MCS sufferer believes that the report should include more research articles, and should serve as a tool to inform the healthcare community about MCS.
307	Individual feels that Frank Mitchell's affiliation biases the report. Additionally, this individual would like the report to include information from other federal agencies.
308	Document is extremely useful for those having to deal with MCS (patients, health care providers, social worker). The report in the final form should be sent to libraries and made available via the web.
309	This individual would like the workgroup to investigate the synergistic effects of chemicals to which we are commonly exposed, and urges the workgroup to keep research on MCS and related issued alive.
310	This group feels that more research is needed to pinpoint the causes, triggers, and treatments for MCS. They feel that the report is severely biased, and tainted by denial and political pull of chemical industry paid representatives.
311	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
312	Form Letter 1. See Appendix D.
313	Report should include recent EPA findings linking MCS to chlorpyrifos and the policies of governing agencies such as DOJ, EEOC, SSA, HHS, HUD and others that may recognize and address MCS concerns. This MCS sufferer feels that Frank Mitchell's position is a conflict of interest

Public Inquiry #	Comment
314	Anderson Laboratories commends the workgroup for tackling this difficult subject and for taking a stand in favor of further research on MCS. This organization agrees with the need for further epidemiological studies, better description of the presentation and natural course of the disease, better double blinded exposure data and federal agency funding of studies. Report does not acknowledge the influence of political pressures on the funding and reporting of information about MCS. This group notes the need for aggressive funding by federal agencies to find a way to curtail anti-MCS lobbies. The report could be improved by reviewing more literature. This group feels that the workgroup should search for physical causes before considering psychological etiologies of MCS, and should stop reviewing the problem and instead should recommend actions.
315	Comments detail the individual's struggle with the disorder. No specific comments are given on the report.
316	Report should include physicians who diagnose and treat MCS. In addition, this MCS sufferer would like known sensitizing chemicals to be limited and the harmful effects publicized.
317	Report failed to mention that MCS is recognized by 14 federal agencies and many state agencies as a debilitating physical condition. This MCS sufferer would like the report to include industry affiliations of researchers and conflicts of interest of quoted parties.
318	This MCS sufferer believes that the report omits the pervasive influence exerted by the chemical industry. Chemical Industry lobbying, intimidation and pressure allows perpetuation of social attitudes and misconceptions about MCS. Dr. Mitchell's affiliation doesn't help with this. "Idiopathic environmental intolerances" is a name proposed by physicians/lobbyists employed by the chemical industry so as to de-link MCS from chemicals.
319	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
320	This MCS sufferer believes the report lacks credibility because of Dr. Charles Mitchell. His professional associations must be disclosed in the document. Related experiences from other federal agencies is missing, and additionally the draft under reports the history of MCS.
321	This MCS sufferer is concerned that report doesn't accept MCS as a "real" medical problem, and encourages the workgroup to listen to MCS patients. In addition, the individual agrees with and encourages requests for research.
322	Report is seriously flawed and gives an inaccurate and misleading picture of the current situation. It could be improved by using all MCS literature available, and including a section to recognize MCS (under various names) for the last 150years. It should not advocate Environmental Control Units (ECU's), as they discover no information to benefit patients, and they have actually killed people. Numerous editorial suggestions were also suggested

Public Inquiry #	Comment
323	Form Letter 1. See Appendix D.
324	Form Letter 1. See Appendix D.
325	Form Letter 1. See Appendix D.
326	This sufferer of MCS states that MCS is not a psychiatric disorder, and the report should not emphasize this without reviewing all the literature.
327	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
328	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
329	Form Letter 1. See Appendix D.
330	Form Letter 1. See Appendix D.
331	This MCS sufferer believes that the report is an injustice to people who are genuinely ill or disabled. To understand the mechanism of MCS, study it instead of minimizing its existence.
332	This MCS sufferer deplores the theft of public money in the guise of helping the chemically damaged and believes that the report defends the chemical industry.
333	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
334	This health care provider believes that all future research funds should be allocated for treatment centers, and no further funds should be spent attempting to define MCS, measure its prevalence, or look for obscure causes.
335	Although the report mentions some of the illnesses known to co-occur with MCS, the report failed to mention that electrical sensitivity (non-cancer symptoms due to electromagnetic exposures) commonly occurs with MCS. This organization would like the report to mention the relationship between electrical sensitivity and MCS.
336	This MCS sufferer has been in contact with the AMA and ACOEM, and states that they have a different position on MCS other than those highlighted in the report. Individual believes that genetic differences to explain susceptibility to MCS should be investigated. Numerous editorial suggestions were given.
337	This MCS victim believes that the draft reads like a document prepared by the chemical industry for the purpose of defending it's economic interests. As papers have shown that .2% to 6% of the population suffers from MCS, it should receive extensive funding. In addition, numerous editorial changes were suggested.
338	Form Letter 1. See Appendix D.

Public Inquiry #	Comment
339	Form Letter 1. See Appendix D.
340	Form Letter 1. See Appendix D.
341	This MCS sufferer believes that the report doesn't reflect the situation of people who have MCS. The choice of wording in the report is not objective, and it fails to give appropriate disclosures. It is premature to imply or give emphasis to the idea that MCS is psychological. The controversy surrounding MCS deflect attention from the toxic chemicals which are the real problem. The report can be improved by incorporating the rapid growth in grassroots activity and publications about MCS, and focus less on MCS treatments that are unproven.
342	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
343	Group appreciates the high level of federal agency interest and involvement reflected in the report, but feels that the literature review is inadequate, so therefore the report on which the literature is based is also inadequate. The workgroup may have misidentified the main problem that proposed definitions of MCS have provoked. It will be difficult to make the definition acceptable to all interested parties, as many have already made up their mind about the characteristics of MCS. Absence of a physiological causal mechanism for MCS doesn't justify claims of a psychological cause. The group is concerned that the psychological explanation of MCS may obscure physiological underpinnings of disease. Group feels that basic research is badly needed, and that health care providers need to be informed about MCS. In addition, numerous editorial changes were suggested.
344	This MCS individual commends the workgroup for its work on MCS. Individual feels that the workgroup needs neutral parties evaluating diagnostic tools, and would like the report to educate physicians about MCS.
345	Form Letter 1. See Appendix D.
346	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
347	This individual feels the inadequate literature review, the mixed impression given of MCS, the confusing recommendations and conceptual vagueness in the report point to the necessity of overhauling the entire report given that it may be used to shape policy. Report needs a more comprehensive literature review, or it should be stated that the entire report is based on a limited literature review. This individual believes both physiological and psychological explanations of MCS should be held to the same standard or rigor in examination of their claims. Due to the inadequacies of the report, this individual is concerned that the report may be taken to mean that MCS is not worthy of federally funded research.
348	Form Letter 1. See Appendix D.

Public Inquiry #	Comment
349	Correspondence is a request for report only. There are no comments on the report.
350	Report is biased toward a psychological explanation for MCS, which is not surprising, given Frank Mitchell's affiliation. Report should include research conducted by other government agencies. In addition, several editorial suggestions were given.
351	This MCS sufferer feels that MCS must be a reportable disease in order to determine the scope of the illness. The workgroup should revise the report every 5 years as new knowledge becomes available.
352	Form Letter 1. See Appendix D.
353	Form Letter 1. See Appendix D.
354	Form Letter 1. See Appendix D.
355	This MCS sufferer believes the report to be intellectually and factually dishonest and dangerous.
356	Individual believes that the report is biased, and notes the conflict of interest present in the report. Individual recommends a consensus panel, and recommends conducting a double-blind placebo controlled exposure challenge test in an ECU.
357	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
358	Form Letter 1. See Appendix D.
359	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
360	This MCS sufferer feels that the report is callous and deceptive - it's flip skepticism, stonewalling and dismissiveness do a huge disservice to the American public. The report is biased as is evidenced by Frank Mitchell's involvement and the inclusion of Gots literature. Workgroup should be aware that Louisiana's's registry is used more often to harass than to protect. Compliance by applicators of pesticides is voluntary. In addition, numerous editorial suggestions were given.
361	This MCS sufferer believes that many publications have been omitted from the report. This individual believes that most MCS cases are mis-diagnosed or not even reported, so an ICD code and registry to report MCS is needed. Report should mention children and their concerns. Numerous editorial suggestions were also given.
362	Form Letter 1. See Appendix D.

Public Inquiry #	Comment
363	This group states that the workgroup deliberately plays down the prevalence of the statistics by only listing the lowest possible figures and they fail to mention the increase in the number of people who have MCS. Additionally, they try to dismiss the debate over whether psychiatric symptoms are a cause or effect of MCS by deliberately omitting research on the topic. There is a disparity between the way physiological and psychological mechanisms and related literature are addressed in the report. Report fails to mention that the IPCS has been criticized by several government agencies, and mentioning the sponsors of the IPCS gives erroneous impression that the organizations approved and/or sanctioned the actions taken by the IPCS. This group believes that there is a distinct conflict of interest in hiring Frank Mitchell to write the draft report while he was serving on the medical advisory board of ESRI.
364	This organization believes more research needs to be done including workplace studies. In addition, they urge the workgroup to define MCS, and encourage more information be given to health care providers.
365	This MCS sufferer points out that the executive summary does not reflect the substantive contents of the rest of the report. This individual believes that the tables illustrate a small percentage of those writing on MCS believe it is of psychological origin, yet the text portrays it as one of 3 major theories. The International Program on Chemical Sensitivity is an organization composed of several major chemical companies, and this should be stated.
366	This health care provider feels that the report makes the mistake of assuming that there is some causal connection between exposure to chemicals and adverse health effects even when there is no consistent response.
367	Form Letter 1. See Appendix D.
368	Correspondence is a request for report only. There are no comments on the report.
369	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
370	This MCS sufferer believes the report demonstrates that there is a faction which doesn't want to recognize that MCS is a serious medical problem. The idea to name MCS "idiopathic environmental intolerance" is absurd.
371	This MCS sufferer comments that the document seems more concerned with conceptual research than protecting human health. There were no recommendations to agencies that would acknowledge and provide protection to the population affected.
372	MCS sufferer believes that there is no such thing as a MCS diagnosis, but that MCS is just a term for a group of syndromes. Individual comments that the awarding of benefits and chemical regulations are taking precedence over dealing with the medical issues.

Public Inquiry #	Comment
373	U.S. should cooperate with Scandinavian and other European countries. It would be useful to have a world-wide identical statement. Additionally, numerous editorial suggestions are given.
374	This MCS sufferer believes that although there is no objective test available to distinguish if the MCS is a learned behavior, a biological problem in the nervous system, or a sensitivity to trace substances, there is nevertheless a real cluster of symptoms.
375	Individual feels that the document is crafted to appear objective, but the conclusions reflect the domination of those who don't view MCS as an environmentally induced disorder. Research cited is sponsored and used by corporations with economic motivation to prevent official recognition of MCS as an illness.
377	Form Letter 2. See Appendix D.
378	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
379	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
380	Form Letter 2. See Appendix D.
381	Form Letter 2. See Appendix D.
382	Form Letter 2. See Appendix D.
383	This group believes the draft to be a valuable reference for medical professionals and scientists. However, the workgroup only reviewed MCS literature from publications and reports prior to 1997. A large number MCS literature has been published since then, and should be included in the report. They suggest several studies, theories and causation mechanisms, immune mechanisms and neurologic mechanisms to include in the report.
384	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
385	Form Letter 2. See Appendix D.
386	Form Letter 1. See Appendix D.
387	Form Letter 2. See Appendix D.
388	Form Letter 3. See Appendix D.
389	Respondent is a clinical psychologist and participant in a local MCS support group who endorses the recommendations in the report.

Public Inquiry #	Comment
390	This MCS sufferer wants MCS to be recognized as a true illness. A significant amount of published scientific research is not mentioned or referenced. Author supports continued effort and additional research funding.
391	MCS is not psychological - report is biased by the inclusion of "anti MCS" physicians and researchers. This MCS sufferer feels that the workgroup does not understand the range of severity presented by MCS.
392	Report is full of lies and should be thrown out. This group feels that anyone with any knowledge of MCS or science would laugh at the blatant attempts to manipulate the facts. This group condemns the US government for colluding with the chemical and insurance industries to hide the truth. The report made blatant attempts to manipulate the facts.
393	This MCS sufferer is disappointed and appalled over the deceptive content or conclusion of the draft and feels it must be trashed and investigated by Congress.
394	This MCS sufferer feels that the workgroup should include MCS victims on advisory board.
395	This MCS sufferer feels that MCS should be diagnosed whenever possible so that employers and the health care system will recognize that it is a real disease.
396	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
397	Individual feels that the workgroup did a terrific comprehensive job with the report. Would like workgroup to determine if viral activity may be activated when the immune system is compromised (see R143), which is why disease looks like post viral syndrome (PVS) in many.
398	Workgroup needs to define MCS in order to explore prevalence.
399	Report should not include ESRI or RISE members in the report (Dr's Mitchell and Gots). This MCS sufferer would like workgroup to include the 80% of missing research on next report.

Public Inquiry #	Comment
400	In this extensive response, this organization feels that the report is well written, but is concerned because MCS as a theory is scientifically and medically unsound. They point out that MCS is not considered in most courts that have been asked to review the syndrome. This group does not feel that the workgroup should be so evenhanded in the discussion of the merits of the alleged syndrome when the medical and scientific evidence is so clearly against it. This group would like additional research to determine if the syndrome actually exists, and suggests that the research be conducted by outside and neutral experts. This organization includes numerous court decisions which highlight some scientific data on which decisions were based, reports and position statements from medical organizations, clinical studies on MCS, and peer review and commentary on MCS.
401	Report is biased - studies are omitted, the flaws of included studies aren't pointed out, the industry affiliations and conflicts of interest of researchers aren't revealed. Report minimizes MCS symptoms and neglects known effective treatments.
402	This group is appreciative of the workgroup's initial attempts to define the scope and policy issues surrounding MCS, but finds the report do no justice to the problem or to the patients suffering from it. This group feels that there is a chemical industry bias ingrained in the report. Report omits key studies and is biased due to Frank Mitchell as author. Report needs more discussion of toxin induced porphyria. Additionally, research done by EPA, US National Institute on Deafness and other Communication disorders, and other federal authorities that deal with MCS should be included in the report. This group feels that taxpayers and policy makers deserve more thoroughness in such reports that are costly to research and produce. The next report should consider how it will affect those living with chemical injuries and disabilities, as well as methods to prevent future cases of chemical injury.
403	Form Letter 1. See Appendix D.
404	Form Letter 1. See Appendix D.
405	Form Letter 4. See Appendix D.
406	Individual believes that education of physicians is necessary, and that the report should serve to do so. Additionally, an ICD-9 Code is necessary as prevalence estimates are understated and MCS victims don't know to whom they should report.
407	Correspondence is a request for report only. There are no comments on the report.
408	Form Letter 1. See Appendix D.
409	MCS Report is distorted, and shouldn't be released without major modifications. Much relevant information is missing, and Frank Mitchell's involvement is a conflict of interest. The report should alleviate not exacerbate the lives of thousands/millions.

Public Inquiry #	Comment
410	Report is inaccurate and misleading, and the funding source of the report as well as the industry affiliations of researchers must be identified so as to highlight the conflicts of interest. No end-organ disease studies have been undertaken for MCS, so do not assume that there is no end-organ disease produced by MCS. Report should stress that functional changes in the workplace and home should be considered and implemented for better health. Individual feels that MCS is grossly under-reported because no ICD-9 code exists.
411	Correspondence is a request for report only. There are no comments on the report.
412	This MCS sufferer is relieved that MCS is being studied, and believes that the corrected report should be used as a tool to educate physicians and families. This individual recommends that the workgroup include additional government agencies (Department of Agriculture and other environmental agencies) and physicians who treat MCS. Additionally, would like the workgroup to examine the connection between MCS and chronic fatigue syndrome.
413	This health care provider wants the workgroup to know that MCS is a real and debilitating disease, and that MCS research should not be funded by the chemical or pharmaceutical companies who could bias the findings.
414	Correspondence is a request for report only. There are no comments on the report.
415	Form Letter 2. See Appendix D.
416	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
417	Form Letter 1. See Appendix D.
418	This MCS sufferer feels that the report is missing many MCS related studies.
419	This individual feels that the report should be scrapped and wants investigation to determine what protections were utilized to prevent undue influence from those with vested interests. Frank Mitchell's position is a conflict of interest, and the workshop of the International Program on Chemical Sensitivity was mired in controversy. The report omitted important research by DVA, DOD, CDC, DOE, EPA, ATSDR, NIEHS, and NIOSH. Individual feels that the report should mention people affected by MCS and what their experiences are, and is quick to point out that the findings and recommendations appear to address only the concerns of industry looking for relief from change or liability. In addition, there are numerous editorial suggestions.
420	This MCS sufferer feels that the report is very good and much needed, and would like the workgroup to advise MCS patients of the best tests so they don't have to get dangerous tests.

Public Inquiry #	Comment
421	This group commends the workgroup for its efforts, particularly regarding the public health aspects of MCS. They are concerned about the omission of specific citings on sound research related to MCS, the omission of findings documenting MCS by other government agencies, the attempt to portray the cause of MCS as psychiatric, and the lack of acknowledgment that the author of the report has ties to the chemical industry. In addition, the group recommends including expanded prevalence studies to document the numbers of people affected by MCS, comprehensive education of health care providers, lawyers and insurance companies, an unbiased medical diagnostic code, involvement of public health leadership, input from clinicians and the public, detailed recommendations on acceptable research all without the tainting of ties to interested industries or their advocates and recognition of MCS as already acknowledged by other federal industries.
422	This MCS sufferer feels that the description of MCS as a symptom-based diagnosis without supportive lab tests and no evidence of organ damage in patients is inaccurate. Report makes irrelevant and inappropriate conclusions based on psychiatric diagnostic criteria, and cites studies with inadequate demographic data. The report needs to present evidence of known health dangers of common triggering agents, and needs to overcome the conflict of interest in the current report.
423	This MCS sufferer believes that exposure is the issue, not the question of end-organ damage attributable to MCS. Additionally, there is a detailed discussion of pesticides.
424	Individual believes that much of the previous research isn't valid or relevant because of the bias of the funding party and/or researchers.
425	Form Letter 4. See Appendix D.
426	Form Letter 1. See Appendix D.
427	Form Letter 1. See Appendix D.
428	Individual feels that scientific data demonstrates a causal relationship between low-dose human exposure to chemicals and exacerbation of MCS. Workgroup should focus on cases of MCS attributable to a common initiating chemical agent in which persons sought medical care during the developmental stages or onset of the condition.
429	Form Letter 4. See Appendix D.
430	Form Letter 1. See Appendix D.
431	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
432	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
433	Form Letter 2. See Appendix D.

Public Inquiry #	Comment
435	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
436	This MCS sufferer feels that the report in current condition could mislead physicians and have them believe that MCS is a psychological disease. MCS needs to have a ICD-9 code so we can begin to learn the true prevalence. Additionally, Frank Mitchell's position on workgroup is a conflict of interest.
437	Form Letter 2. See Appendix D.
438	Form Letter 2. See Appendix D.
439	Form Letter 2. See Appendix D.
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449	Form Letter 1. See Appendix D.
450	Form Letter 1. See Appendix D.
451	Form Letter 1. See Appendix D.
452	Form Letter 1. See Appendix D.
453	Form Letter 1. See Appendix D.
454	Form Letter 1. See Appendix D.
455	Individual would like report to include more federal agencies (SSA, OSHA, EPA, DOJ, FDA, Dept. of Agriculture, Veteran's Affairs, DOD, HUD, Dept. of Education, DOE). The idea that MCS is solely caused by stress, that MCS patients are hypochondriacs, or that psychological treatment will cure MCS are false. Individual suggests that a section in the report which gives a day in the life of an MCS patient would be useful. Additionally, there are numerous editorial suggestions.

Public Inquiry #	Comment
456	Form Letter 3. See Appendix D.
457	Report should be re-written so it can serve as an educational tool for doctors, employers, co-workers, and families of MCS victims.
458	The report is well written and should prove very useful to those interested in learning more about MCS. Additionally there are numerous editorial changes.
459	Report is inadequately researched as it omits many studies. By having individuals who had interests that represented the chemical industry on the review board, it means that the report is biased.
460	Individual makes several editorial suggestions.
461	This government agency discusses how it regulates pesticide exposures, and allows it to assess the health effects of all non-occupational exposures to a pesticide. Additionally, the agency is responsible for registering pesticide products on the basis of scientific data adequate to show that they will not pose unreasonable risks to human health or environment. All new pesticides need to be registered, and older pesticides reviewed.
462	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
463	Report has clear industry bias and Dr. Mitchell is a conflict of interest. In addition, the report has nothing from scientists who have published on MCS. Literature which proves MCS is not psychiatric should also be examined. Avoidance is a necessity and should not be challenged by the review board.
464	This group is appreciative of the attempt to define the scope and policy issues surrounding MCS, but finds that the draft does no justice to the problem or to the patients suffering from the condition. Report omits key studies, and is biased due to Frank Mitchell as author. Report should include research done by EPA, US National Institute on Deafness and other Communication disorders, and other federal authorities that deal with MCS should be included in the report. Report needs more discussion of toxin-induced porphyria. It is not acceptable to draft a document which might lead employers, co-workers, health care professionals and public policy makers to perceive chemically injured persons wrongly. Consider how report will affect chemically injured persons and how to prevent future cases of injury in the next draft.
465	Form Letter 1. See Appendix D.
467	This MCS victim feels that the report should serve to educate medical professionals and general public about MCS, as few physicians know how to deal with MCS.
468	Comments detail the individual's struggle with the disorder. No specific comments are given on the report.

Public Inquiry #	Comment
469	By making the statement that MCS is "without supportive laboratory tests or agreed-upon signs of clinical manifestation", a negative evaluation of existing diagnostic methods has been made.
470	Correspondence is a request for report only. There are no comments on the report.
471	Not enough research has been done on MCS to adequately characterize even the most basic aspects of the condition.
472	There is insufficient scientific and medical evidence to arrive at any definitive conclusion about virtually every aspect of this condition.
473	Report should not advise patients to avoid expensive treatment. Patients should choose ineffective, costly, and potentially dangerous treatments if they want to, as treatments may not cure, but they can improve patients quality of life.
474	Individual would like to see the Social Security Administration memo recognizing MCS as a medically-determinable impairment (Creamer V Callahan) included in the next draft of the report.
475	The report does not help people with MCS, and many people with MCS will deteriorate while they remain in the workplace or home settings that are harmful to their health.
476	Comments detail the individual's struggle with the disorder. No specific comments are given on the report.
477	This MCS sufferer feels that the draft does not do justice to the problem or to the patients suffering from the condition, and chemical industry bias is evident in report (Frank Mitchell). Individual feels that there is enough evidence of physical causation, that psychological causation must be ignored.
478	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.
479	This MCS sufferer believes the report shows the bias of the Chemical Industry (Frank Mitchell & Ronald Gots), and that many involved in the chemical and medical insurance industries have moved to prevent recognition of MCS because of the economic impact it would have on them.
480	This MCS sufferer wants the workgroup to know that MCS is real, and it's prevalence is downplayed because MCS is found predominantly in women.
481	Comments are from a MCS sufferer and detail the individual's struggle with the disorder. No specific comments are given on the report.

Public Inquiry #	Comment
482	Individual feels report was obsessed with psychological etiology of MCS. Individual feels that MCS investigations would be better if the latent sexism was expunged. In addition, he calls for federally funded research, and a congressional investigation on MCS.
483	Report is dishonest and misleading and was difficult to acquire. As such, this individual is calling for congressional investigation of MCS
484	A new draft report needs to be created due to Dr. Mitchell's participation. The workgroup should have consulted with individuals prominent in the MCS community, and used a larger subset of MCS-related articles. The report neglects to discuss the role that toxic chemicals have played in the initiation of MCS. MCS should not be classified as an physiological or psychiatric illness until there is proof acceptable to both mainstream and environmental medicine physicians that MCS does or does not have a physiological etiology.
485	Letter deals with the organizations belief that a misappropriation and misuse of federal funds occurred by hiring Dr. Mitchell as a consultant without disclosing the source of Dr. Mitchell's affiliations. Organization is concerned that Dr. Mitchell may not have applied for funding properly or complied with the programs public disclosure and reporting requirements. They feel that Dr. Johnson, ATSDR, and DoE may have violated federal law or agency policies by hiring Frank Mitchell using funds from the PRP and without any written contract. Organization questions if Dr. Mitchell did any of the work he was funded for given that the first draft of the report is lost, and wonders if private citizens acting on the governments behalf can recover the funds. Finally, the organization wonders what responsibility the Workgroup members have for failing to report the allegations against Dr. Mitchell to the appropriate agency authorities.

Appendix C
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* Citations appear as cited in comment. In some instances incomplete citations were provided.

Appendix D
Form Letters

FORM LETTER 1

November 1998

ATSDR Information Center
Attention: Alice Knox
Federal Register Notice No. 63 FR 46225
1600 Clifton Rd. NE, MS-E-57
Atlanta, GA 30333

Comments on the Draft Report on Multiple Chemical Sensitivity

To Whom It May Concern:

Thank you for your attention to the issue of multiple chemical sensitivity (MCS).

It is very common for non-supporters of MCS patients to minimize the significance of MCS by using expressions such as "no laboratory findings", "no objective evidence," "unproven diagnostic tools," "self-reported MCS," "iatrogenic," etc., in an effort to discredit patients and render their complaints meaningless. This biased and discriminatory tone is apparent in several parts of the report, especially in the section describing theories of cause and MCS research reviews.

It appears as though attempts were made in this report to drain credibility from MCS research by attacking study design, validity of diagnostic tools and subjective reports. However, the state of the science on MCS is very compelling, has interesting animal models, and would indicate the importance of a swift priority health response.

You make the unscrupulous assumption that there is no end-organ disease produced by MCS, without relying on any scientific evidence that this is true. Here, you generate the false understanding that end-organ disease is not prevalent. The truth is that no end-organ disease studies have been undertaken for MCS, and this should be firmly stated in the report.

The report minimizes existing indicators of the prevalence of MCS. Studies included in the report showed that "the prevalence of feeling ill after exposure to chemicals or being sensitive to chemicals ranges from 15 to 37 percent". Other studies documented in the report showed that "self-reported physician-diagnosed MCS ranges from published values of 0.2 percent in college students to 4.0 percent in elderly persons and an unpublished value of 6 percent among randomly selected California residents." These numbers-which I understand were validated in a follow-up-study-extrapolate to over a million people in California alone. These numbers are even more dramatically significant when you consider that MCS is grossly underreported because no ICD-9 code is available to physicians for reporting this illness.

The summary states that "Every technology, no matter how beneficial, can exert a negative impact on some sector (s) of society...The *reality* of public health will always involve balancing maximum benefit and minimum harm to the public's health and well-being." Policies calling for the use of least-toxic products would maximize the health and well-being of all members of society. This needs to be clearly stated in the report, following the above quote.

The summary states that "persons should not be offered ineffective, costly, or potentially dangerous treatments." This recommendation is inconsistent with treatment options and policy for cancer, AIDS and other illnesses. There are few treatments available today for any condition that are not costly, potentially

dangerous, and ineffective for some people.

The summary states that "appropriate care for well-characterized medical and psychological illnesses should not be withheld or delayed." Without the appropriate qualifications, this statement could inadvertently contribute to a premature, and inaccurate, psychological diagnosis and treatment protocol. It is imperative to emphasize the importance of first ruling out a chemically-induced reaction which manifests with psychological, emotional and/or behavioral abnormalities. It needs to be clearly stated that physicians, psychiatrists, psychologists and other mental health professionals will be unable to make an accurate diagnosis and unable to interpret psychological test scores accurately unless they are knowledgeable about the primary and secondary effects of MCS, or unless they consult with professionals who are trained in this area. They need to know the American Medical Association and the American Lung Association have stated that MCS should not be dismissed as a psychogenic illness.

Davidoff reviewed the studies which suggest that MCS is psychogenic in nature, and found these studies to be seriously flawed. You need to reveal these flaws in this report. You did not include the reports published in 1983 and 1985 by Dr. Philip Landrigran of the U.S. National Institute on Occupational Safety and Health linking toluene and other solvent exposures to a severe MCS-like "neurasthenic syndrome." Nor have you included any studies reported since 1995. The report also fails to mention the policies of at least 14 federal agencies that have recognized MCS.

The summary of this report states that "The ramifications of recommending functional changes in workplace or home settings should be considered carefully." For the person with MCS, not making appropriate accommodations in the home and workplace can exacerbate the loss of health and can be life-threatening. Doctors who do not recommend accommodations in the home and workplace for patients with MCS are causing unnecessary harm. Such practices are in violation of the Hippocratic oath-a point which needs to be included in this report.

The report fails to include appropriate disclosures. Funding sources for studies documented in the report are not identified, industry affiliations of researchers are not disclosed, and conflicts of interest presented by some parties making policy recommendations are not disclosed. It is alleged that Dr. Frank Mitchell wrote the initial drafts of this report. Mitchell was a board member of the Environmental Sensitivities Research Institute, an anti-MCS group funded by the chemical industry. He is listed in the report only as a consultant, with no disclosure of his affiliation or any other role he has served in the creation of this report.

Unless all of this information is included, your recommendation that the health-care community be better informed about MCS is a dangerous proposition. The health-care community must be educated by fair, unbiased sources who are aware of all the studies and can distinguish between biased and unbiased research. These sources should not include industry stakeholders.

In its present form, this report is misleading and presents a threat to public health and safety.

Sincerely,

_____(Signature)

_____(Address)

_____(City, State, Zip Code)

FORM LETTER 2

ATSDR Information Center
Attention: Alice Knox
1600 Clifton Rd. N.E. Mail Stop E-57
Atlanta, GA 30333

RE: Comments on the Interagency Workgroup Document, *A Draft Report on Multiple Chemical Sensitivity (MCS)*

Dear Ms. Knox:

Thank you for the opportunity to comment on the Interagency Workgroup Draft document, *A Report on Multiple Chemical Sensitivity (MCS),* August 24, 1998. It is my understanding that the Massachusetts Association for the Chemically Injured (MACI) has submitted to you detailed recommendations and concerns on *A Report on MCS* that are summarized below. I am writing today to voice my strong support of MACI's recommendations and concerns. I encourage immediate action to address these concerns and recommendations on the *Draft Report on MCS.*

I strongly support:

- The urgent need for a working definition of MCS. It will provide a solid basis for conducting epidemiological studies that reflect the prevalence of this illness in the population and undertaking reproducible research studies.
- A medical diagnostic code for physicians. This is an essential requirement to enable progress in the area of epidemiological studies and patient care.
- Government funding for research on MCS. A substantial increase in Government funding is vital to producing objective research.

Unfortunately, I find the Interagency Workgroup's Draft Document "A Report on Multiple Chemical Sensitivity (MCS)" to be severely deficient and uncompromisingly biased. I reject this Draft Document and ask that it be withdrawn. The Interagency Workgroup must undertake a major revision of this document. The public is entitled to, and expects from, an interagency Government report an unbiased presentation of the facts.

I concur with the major concerns that are as follows:

- Emphasis was given to a proposed psychological basis of MCS, minimizing the experiential observations of clinicians and researchers and discounting the weight of the scientific data supporting a physiologic basis for this complex medical disorder.
- Repeated underestimation of the prevalence and severity of the problem. The obvious omissions and less than objective presentation of this report promotes misinformation on MCS.
- Failure to recommend actions consistent with Workgroup's findings. I recommend immediate support for research, physician education, protocols for early detection and avoidance, in order to thwart the enormous health consequences that threaten society if the illness is ignored.
- Representation on the Workgroup and input from clinicians who follow chemically sensitive patients and from individuals affected with the illness is notably absent.
- Only limited information from eight Federal agencies is included. There is a failure to disclose the MCS policies and data from other prominent Federal authorities, e.g. Social Security Administration (SSA) and Housing and Urban Development (HUD).
- Failure to disclose the obvious conflict of interest posed by hiring Dr. Frank Mitchell, a member of the board of directors for the Environmental Sensitivities Research Institute, and his key role in the writing and editing of the Draft Report.

Sincerely,

Print Name _____

Address _____

City, State, Zip Code _____

Date _____

FORM LETTER 3

December 9, 1998

Agency for Toxic Substances and Disease Registry
Dept. of Health and Human Services
ATSDR Information Center
1600 Clifton Road Mail Stop E57
Atlanta GA 30333
ATTN: Ms. Ann Knox

ATSDR: Comments on the predecisional draft of the Report on Multiple Chemical Sensitivities

Since numerous other responses to this report will address that there are omissions of specific citings on sound research dealing with the many aspects and effects of MCS and related disorders, that the findings documenting MCS by other governmental agencies are omitted, that this report is an attempt to lay the cause of MCS as psychiatric rather than physiological, and that the author of this report's first draft has ties to the chemical industry, the following comments will discuss other issues.

Starting with your foreword, in the first paragraph," ...MCS is the term most commonly applied to a condition that challenges patients, healthcare providers, and health and environmental agencies alike." Not true! Be assured that those of us who must deal with all the aspects of this illness on a daily, or even hourly, basis are far more challenged than anyone else could possibly imagine.

In the Environmental Directory of membership support, advocacy, and educational organizations published by the Chemical Injury Information Network are listings of nearly 100 national groups, over 400 state groups, individuals, groups from 16 foreign countries, related publications and web sites. While there is diversification in the thrust of these organizations i.e. smoking and health, latex allergies, safe food, fibromyalgia, environmental research, MCS, advocacy for Gulf War syndrome, CFIDS, and right-to-know, there is only one clear-cut, common denominator. All of those involved have, in some way, been adversely affected by the chemical components in what we eat, drink, breathe or touch. Many members do have multiple symptoms which can vary with different exposures, as is noted in 144-5, 391, 396-7, 402, 414-15, 513-15, 860-62, and 1104-5. Furthermore, not all who are ill have had just a single, clearly apparent exposure to which they can link the onset of their illness. It is common for the effects of exposures to build over a period of time. This must be considered in any further research to be conducted.

Regarding "Information on fiscal cost to society is scarce" 41-42, have governmental agencies been contacted to determine how many individuals are on disability from these related disorders, and how many more are attempting to receive the benefits to which they are rightfully entitled? There is, in fact, no way to measure the true extent of the serious losses of income and home, the cost of uninsured health care, and the further losses of family, friends and a sense of self. The latter cannot be measured in monetary terms alone! These losses are due, in part, to the fact that there is still not enough recognition and acceptance of MCS, particularly by health care providers. A critical quote on 1790-94 "Only limited efforts are being made within federal health and environmental agencies to communicate to health care

providers what is known and not known about MCS...and this lack of education for health care providers is accompanied by increasing public concern about MCS." The full extent of the public's concern has not yet become evident, because of the lack of opportunity for the public to share its concerns in person, and thus describe the serious impact of MCS.

For decades, the adverse affects of low level chemical exposures, and MCS as the result, have been a public health issue. In the 1960s the then Surgeon General LeRoy E. Burney, MD, stated: "The unprecedented speed with which we are developing and using new substances and new materials has outdistanced our ability to determine and control their composite impacts on public health and well-being." And further, "The chemical findings reported here offer a supreme challenge to the public health physicians. Our problem is one of chronic exposure-lifelong, 24 hours a day." (Public Health Reports, vol. 76, April 1961, titled "Governmental Responsibilities in Environmental Health") To date, only a little progress has been made by the interagency workgroup. Other than many meetings, much valuable time, and spending large sums of money, as noted line 1323 "In fiscal year 1993, Congress appropriated $250,000 to ATSDR...for workshops", 1478-79 "CDC will be allocated $300,000 to conduct the conference, and in fiscal 1998, $400,000 will be added to an NIH grant..." more has to be done that would directly benefit those with MCS and related disorders. The report does acknowledge in 1496-97 that "...only limited progress has been made by federal agencies on many of the recommendations listed." Almost hidden is the statement, 1786-87 "These recommendations, if addressed, should advance the public health response..." We wonder why are they not being addressed?

This report repeatedly cites recommendations of the following: 1.) Education of health care providers about MCS, 2.) Surveys on prevalence, 3.) Involvement of public health leadership, 4.) Input from the public, 5.) Determination of the fiscal costs to society of MCS, and 6.) Further research with which we concur. Yet, "the pressure of constrained budgets and tight personnel ceilings make it essential that agencies carefully weigh and prioritize research and protective actions directed towards an imposing list of environmental problems." 1803-05, and then 1819-20 "...MCS is unlikely to receive extensive research support as a single entity" appear to be statements preparing us for this agency's excuse as to why it is not moving forward on this critical problem. Other than funding the MCS prevalence study in California, lines 1712-13 "no other epidemiology studies are currently being sponsored by the workgroup's agencies." "No department or agency is expressly sponsoring an effort to develop a case definition," lines 1723-24, and on conduct challenge studies, 1725-26, "No agencies of the workgroup are sponsoring or conducting these studies."

We do agree with your quote, lines 1743-46 "It is appropriate for the public health leadership to work to mitigate illness in persons with disorders that are not yet fully explainable. In doing so, it must recognize the chemical agents found to be noxious by a significant portion of the population may, and often do, present health hazards that lead to health concerns such as MCS." An honest, broad based effort finally must be made to determine the true numbers of those affected by MCS and overlapping disorders, why these numbers are increaasing, and what must be done to stop the escalation.

Therefore, we ask for details as to exactly just what specific research on MCS would be required to be considered acceptable, and then fund it, for follow through on the other workgroup recommendations without further delays, for acknowledgment, as other federal, state and local government agencies already have done, that MCS does exist, and instead of wasting more of our taxpaying money, for concrete action to be taken immediately. <u>Finally, either correct this report, or withdraw it.</u>

One must question, if this illness had a different name, would the misrepresentations, omissions, and biases, which are obvious, be in this report? Would there still be refusal, by this agency, to acknowledge that such an illness as MCS exists and that it is a serious public health problem that may ultimately affect our entire population? We can no longer be ignored. Our voices must be heard!

Written by XXXXX

XXXXX is a board member of a support group for MCS in one state, a group leader in another state, and an officer of a national organization dealing with MCS.

I support XXXXX comments.

Name:
Address:

Signature:

FORM LETTER 4

October 26, 1998

Agency for Toxic Substances and Disease Registry
Dept. of Health and Human Services
ATSDR Information Center
1600 Clifton Road, MS-57
Atlanta, GA 30333
ATT: Alice Knox

RE: Comment on A Report on Multiple Chemical Sensitivity–Predecisional Draft

Dear ATSDR:

This is a comment on your recent Predecisional Draft on A Report on Multiple Chemical Sensitivity, dated August 24, 1998.

The conclusion of your Draft indicates that it is an area that needs major research and review due to the complexities of the syndrome. However, instead of advocating the need for this study, you put forth that this is unlikely to occur due to the complex nature of this syndrome.

What a sorry state of logical and studied analysis !!! Are not complex and difficult syndromes just what should be studied ??? If this syndrome is so complex and bewildering, should not that be the very reason it should be given priority ??? I must ask you to analyze your own narrow and poorly drawn conclusion. If this is how you rationally decide what to study, it shows very poor skills on you part.

I imagine that you hope no one would be able to read your report. Or notice that you omitted many studies. And that your review board included individuals who had interests that represented drug companies and chemical companies who by their definition are fearful of accurately assessing the negative impact of their products on consumers.

This report is narrow, inadequately researched, it omits many studies, and thus, contains misleading, inadequate and inaccurate information and conclusions. It is a disservice to the thousands of individuals like myself whose health had been affected by pervasive and ubiquitous environmental toxins in our daily work and home environments.

Please do not avoid the Issue of Multiple Chemical Sensitivity. Please hear us as we demand honest, accurate, and sincere efforts regarding this problem.

Sincerely,

Appendix E
Tables and Charts

Exhibit E-1a - Source of Comments (including form letters)

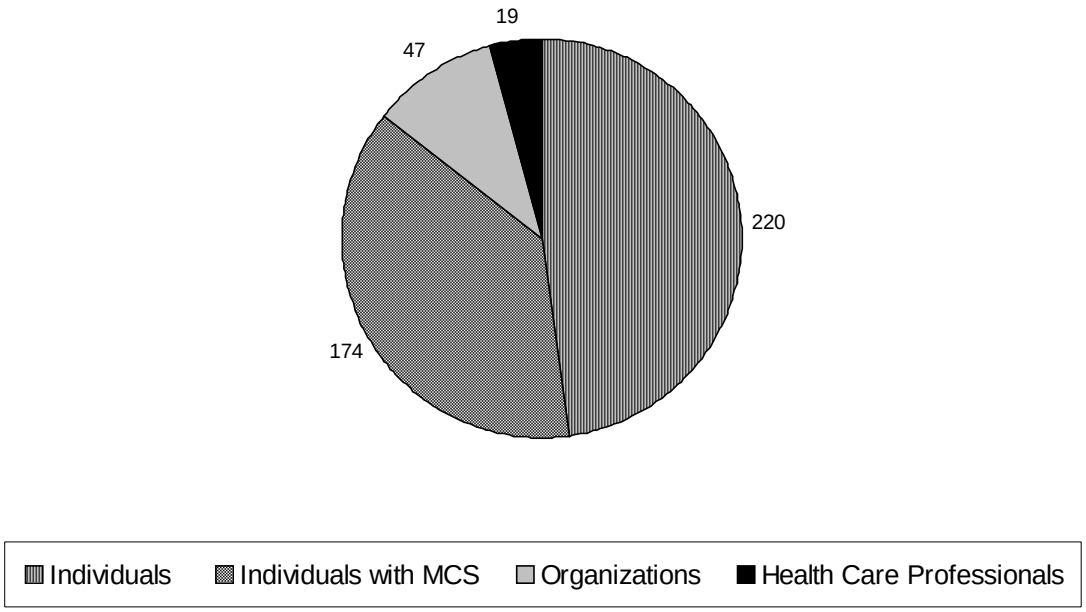


Exhibit E-1b - Source of Comments (excluding form letters)

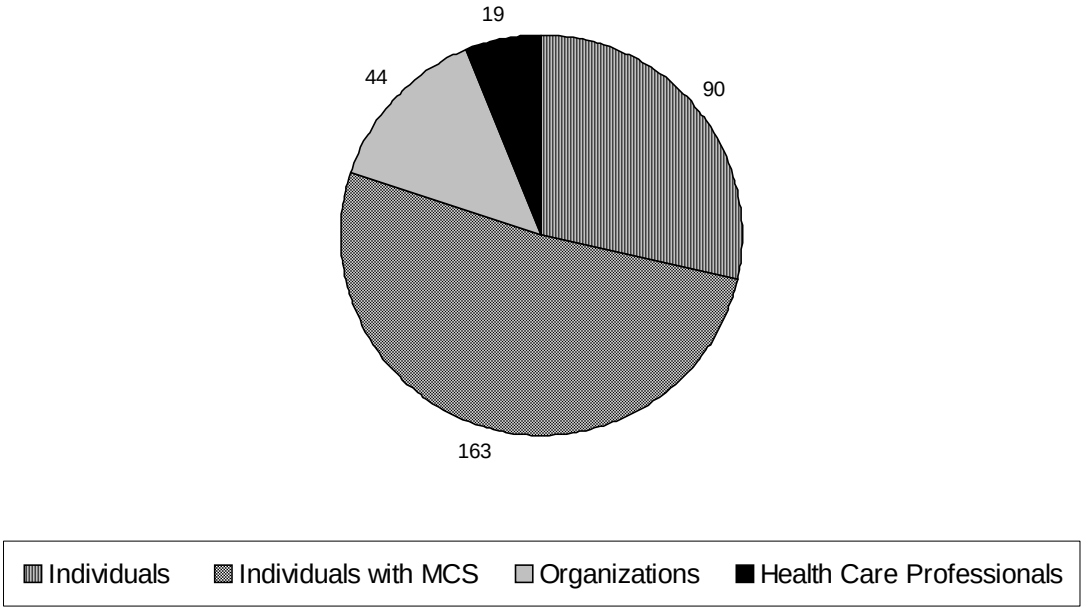


Exhibit E-2a - Comment Medium (including form letters)

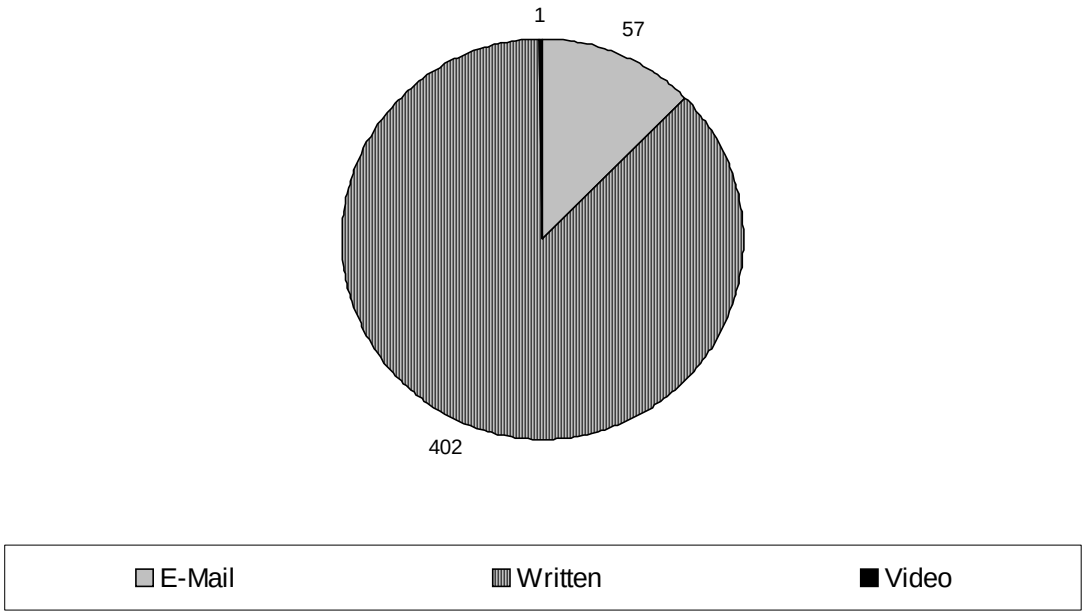


Exhibit E-2b - Comment Medium (excluding form letters)

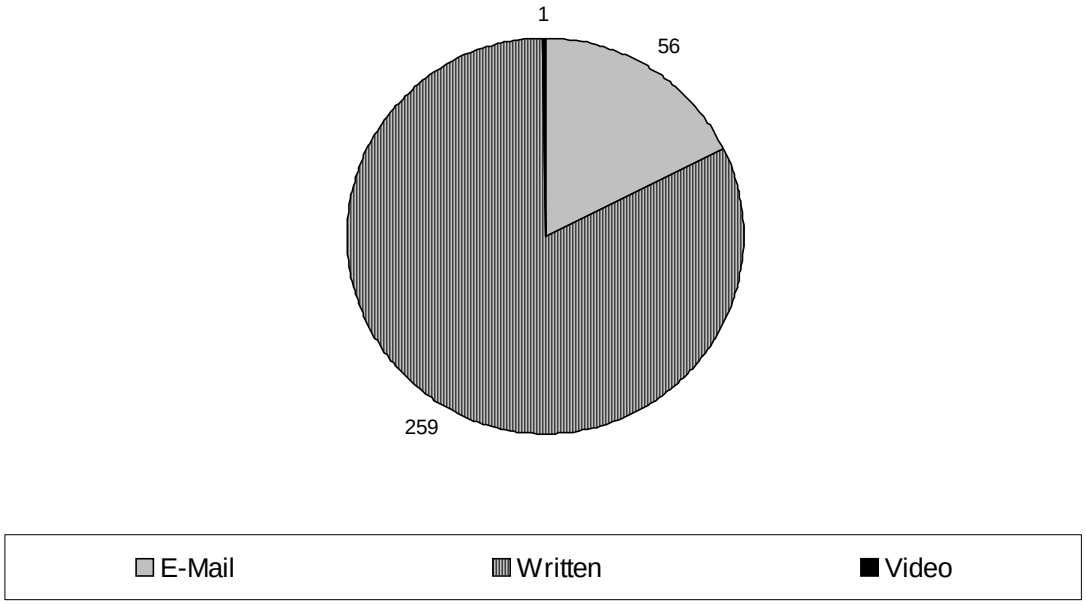


Exhibit E-3a - Comments Containing New References (including form letters)

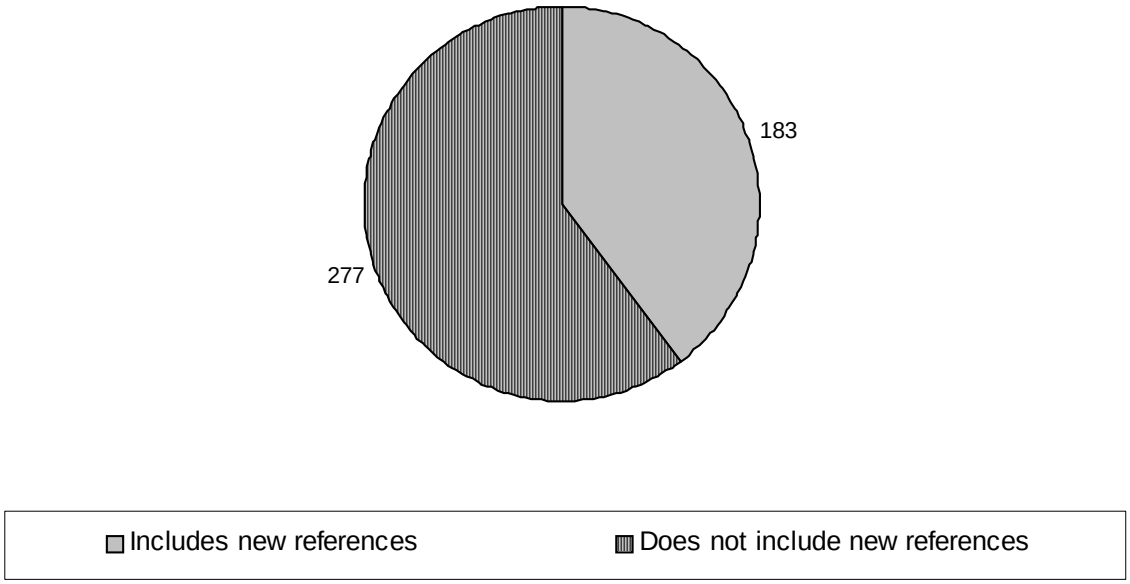


Exhibit E-3b - Comments Containing New References (excluding form letters)

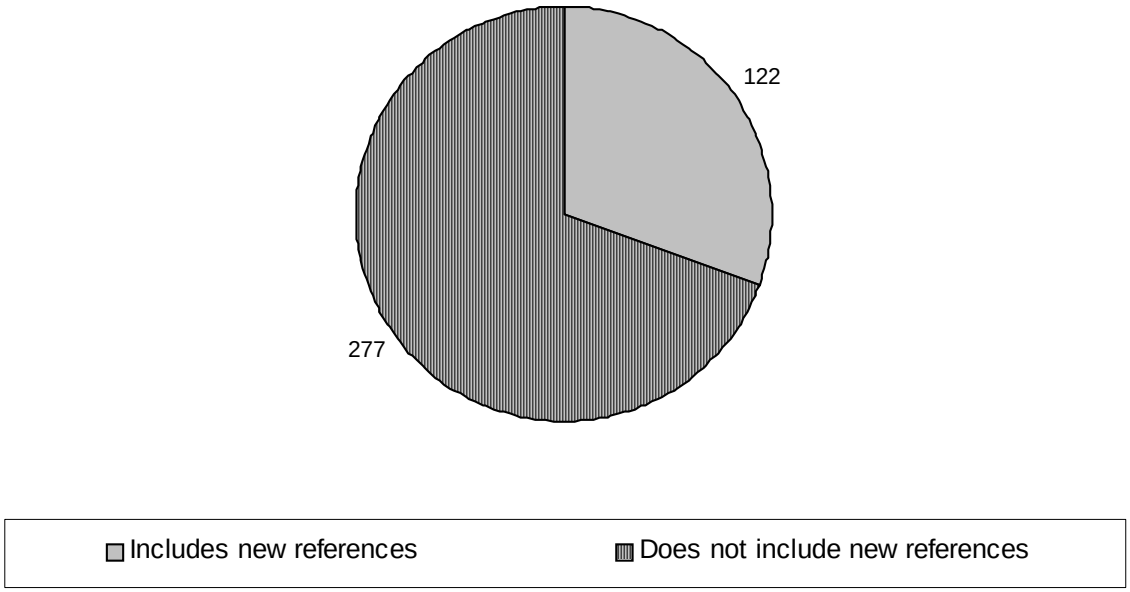
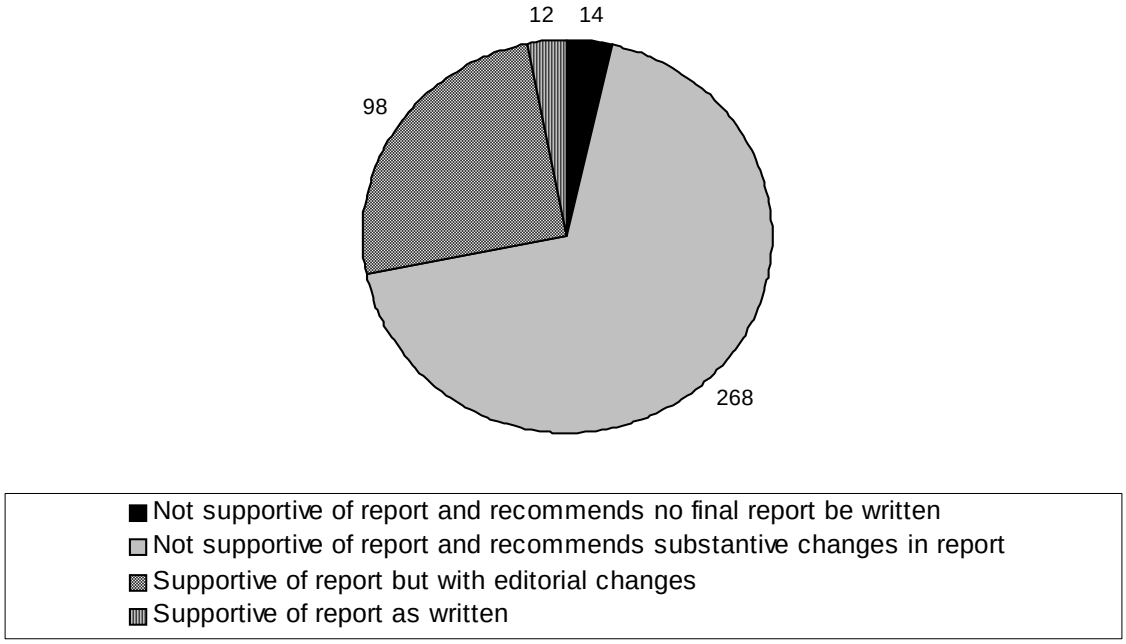
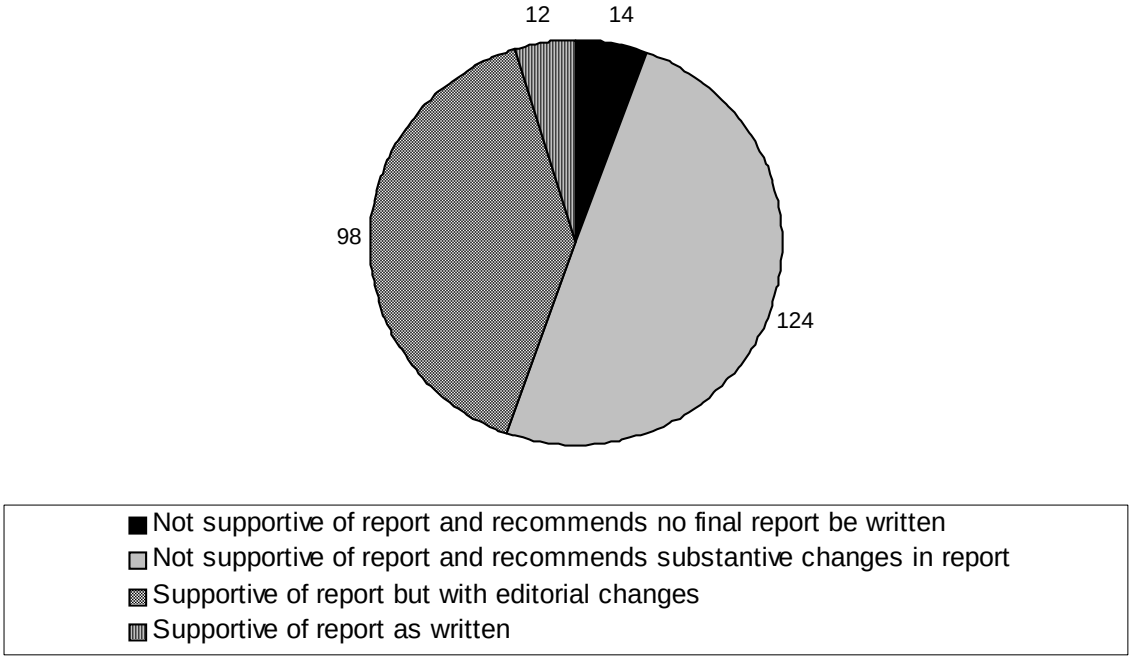


Exhibit E-4a - Nature and Degree of Support of Comments (including form letters)



Comments with no indication of support and requests for report (n=13) were omitted from exhibit

Exhibit E-4b - Nature and Degree of Support of Comments (excluding form letters)



Comments with no indication of support and requests for report (n=13) were omitted from exhibit in addition to form letters (n=143)

Exhibit 5a - References Most Frequently Cited (including form letters)

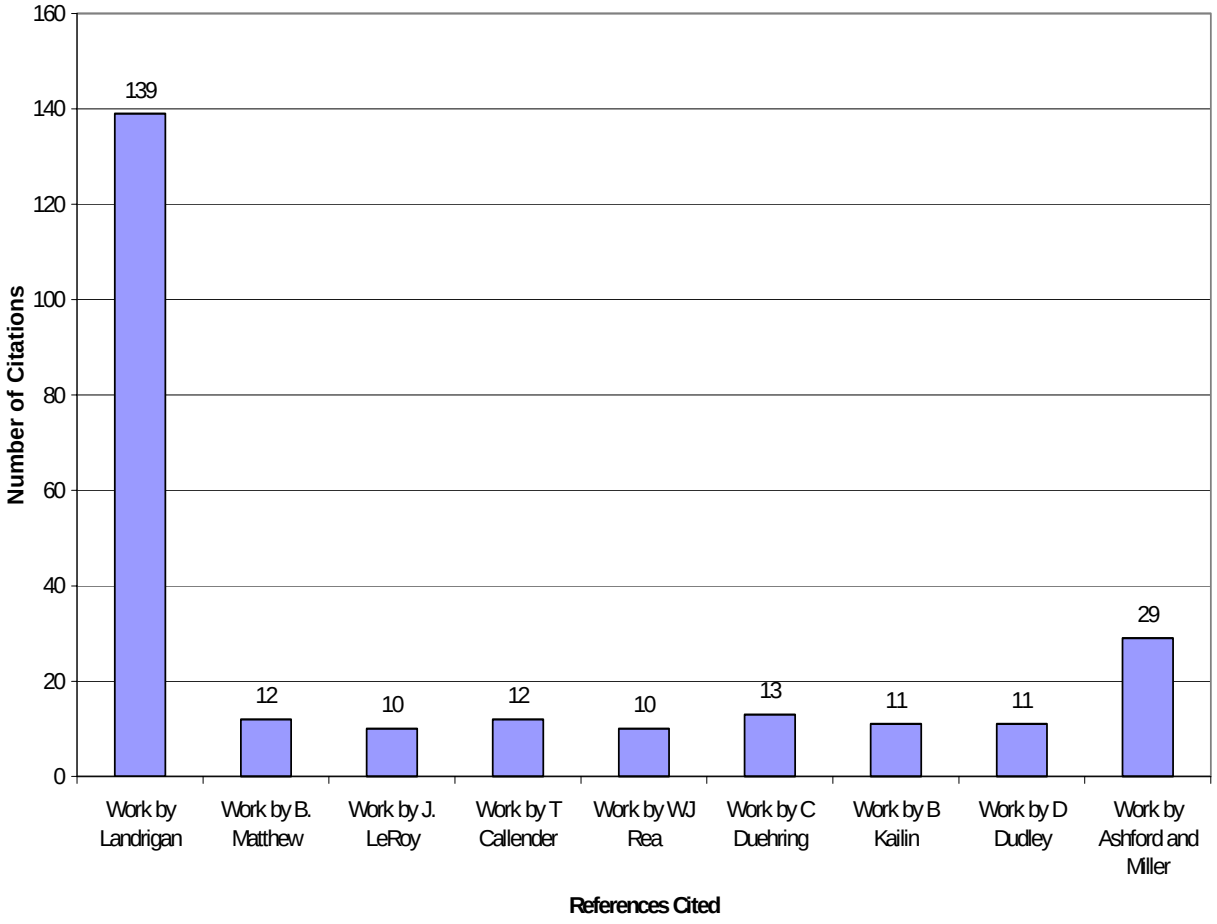


Exhibit 5b - References Most frequently Cited (excluding form letters)

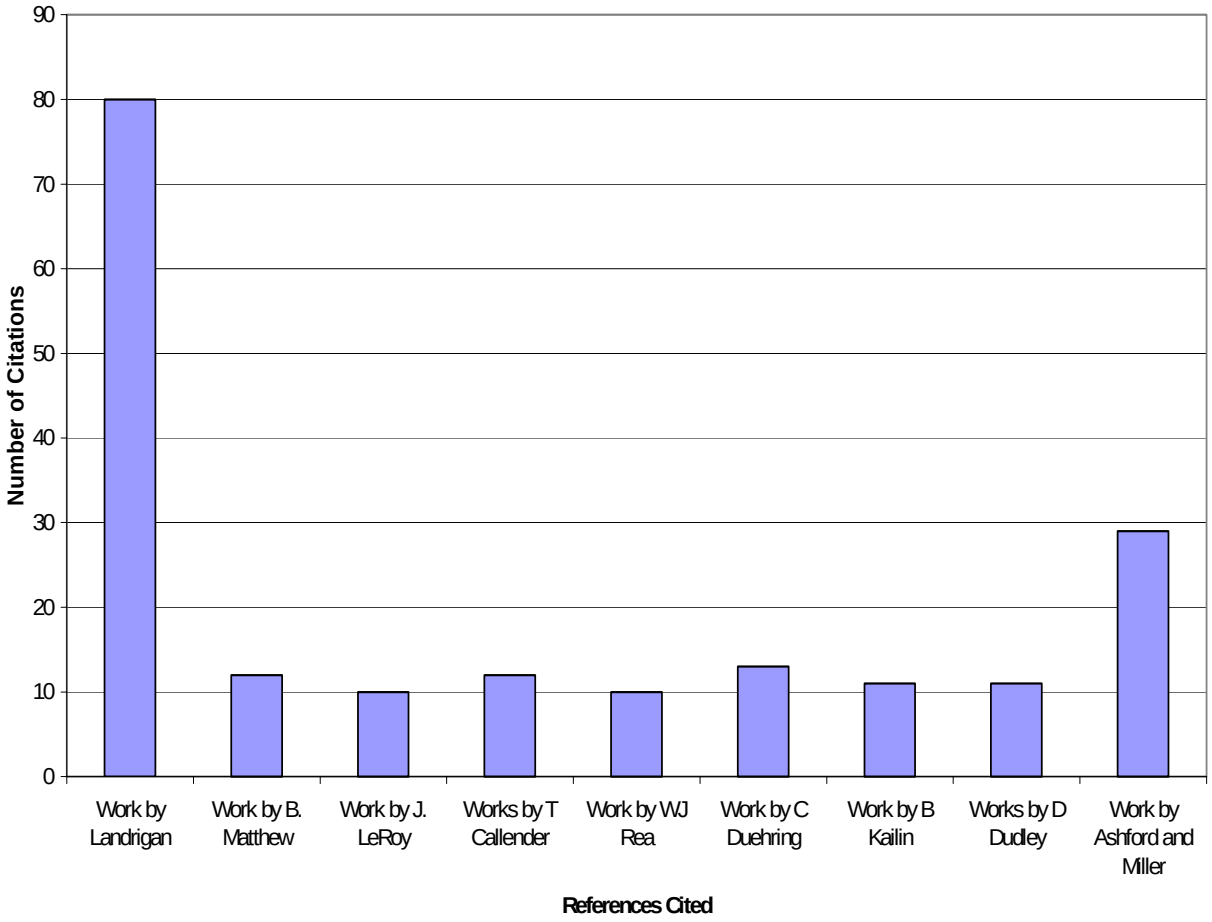


Exhibit E-6a - Degree of Support Provided by Health Care Providers

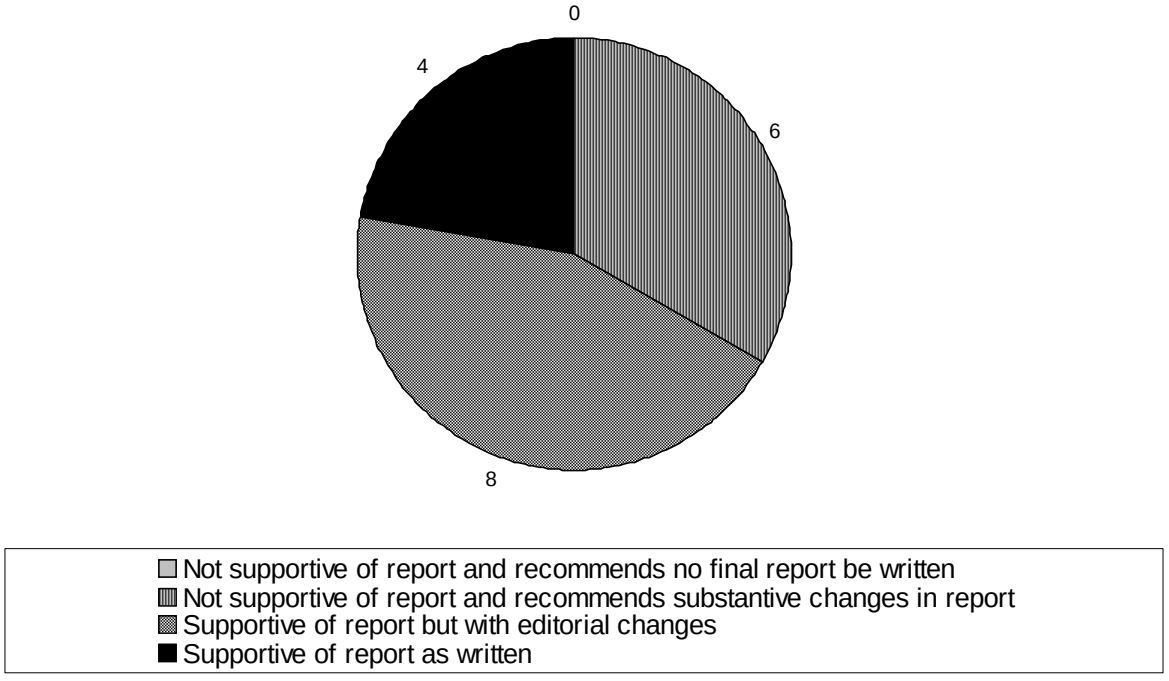
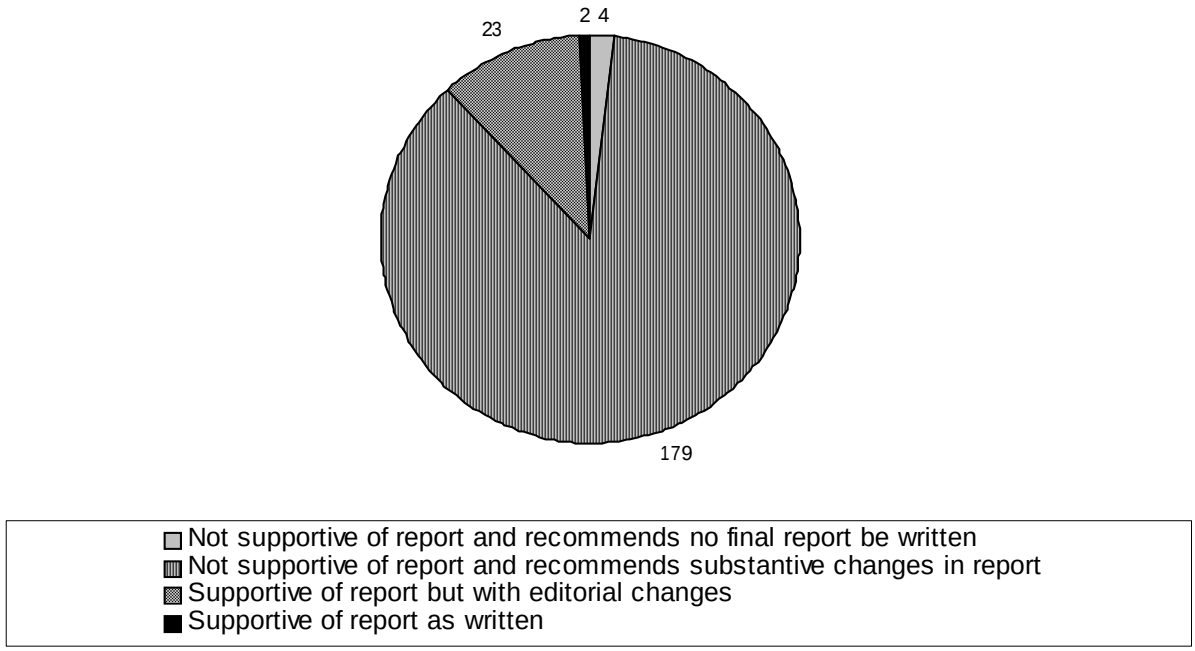
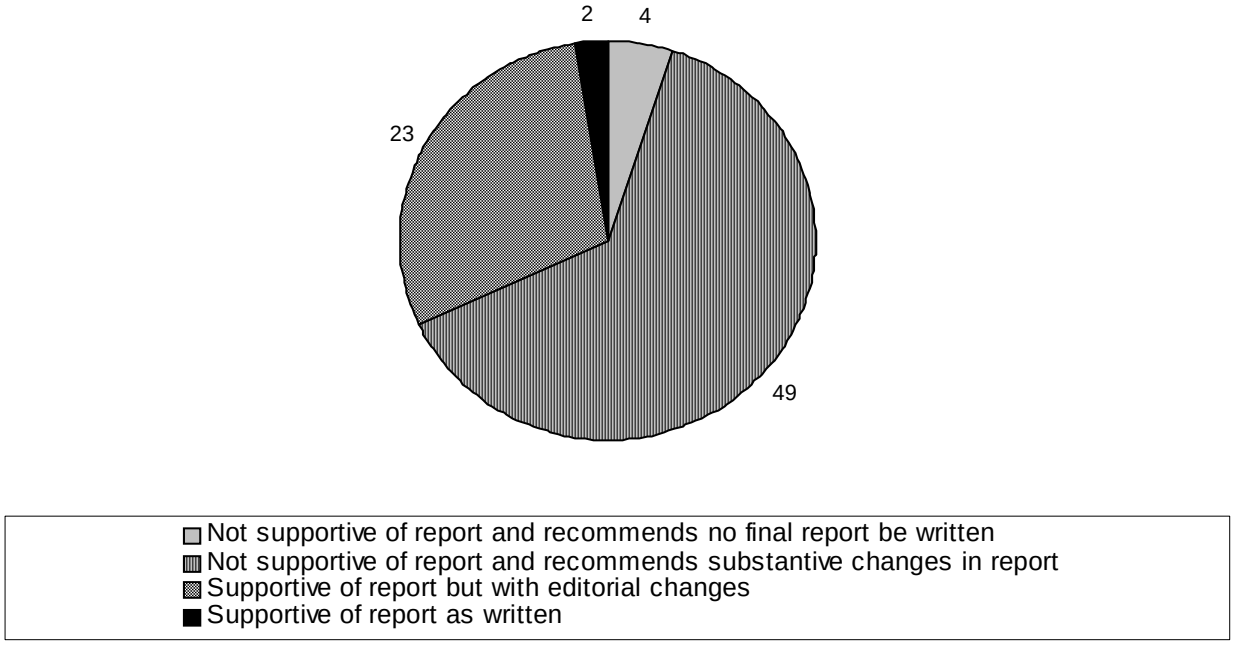


Exhibit E-6b - Degree of Support Provided by Individuals (including form letters)



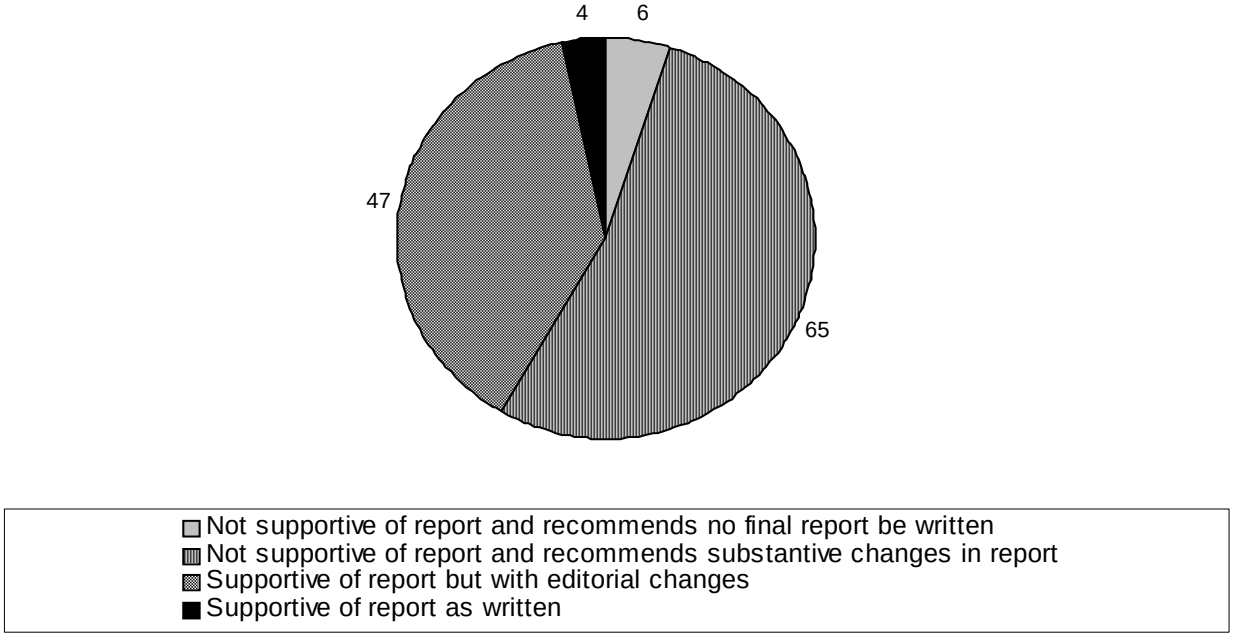
12 individuals made no reference to the report and are not included in this chart.

Exhibit E-6c - Degree of Support Provided by Individuals (excluding form letters)



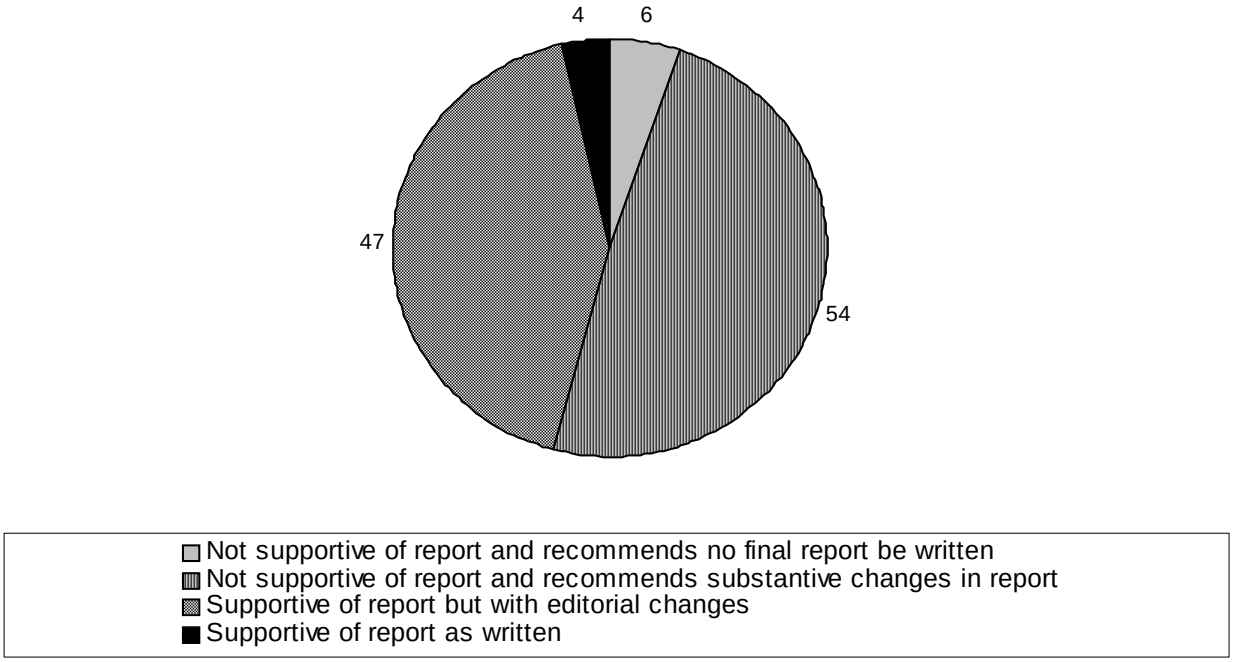
12 individuals made no reference to the report and are not included in this chart.

Exhibit E-6d - Degree of Support Provided by MCS Sufferers (including form letters)



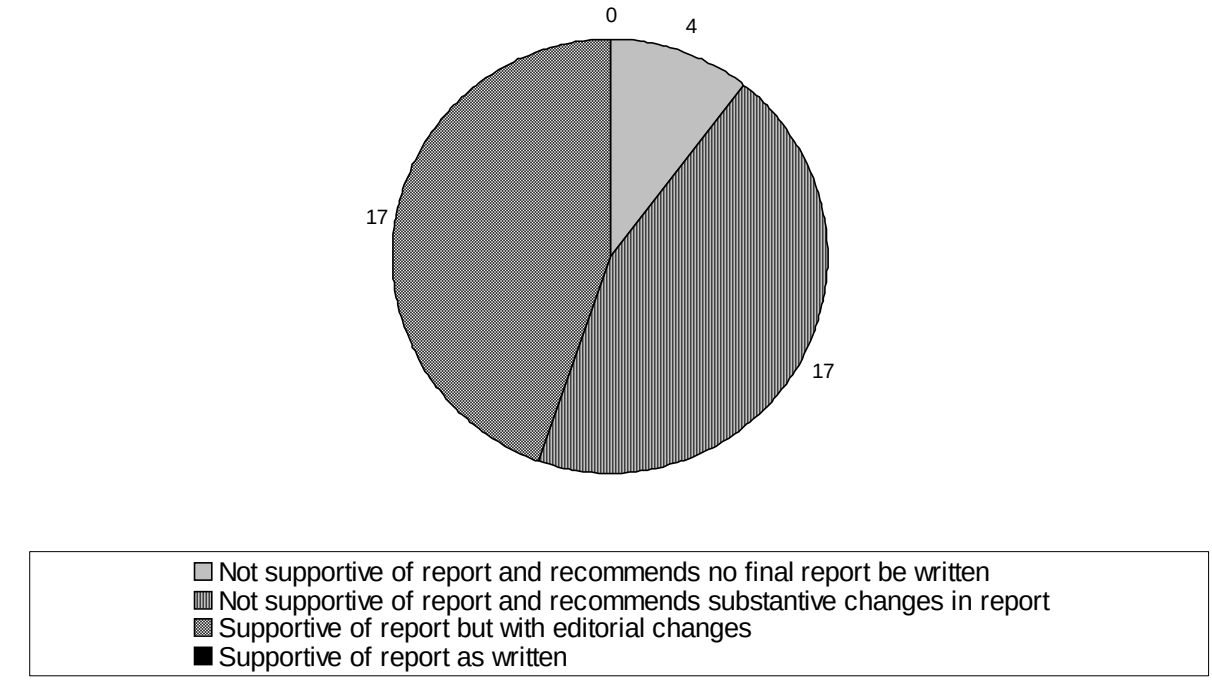
52 MCS sufferers made no reference to the report and are not included in this chart.

Exhibit E-6e - Degree of Support Provided by MCS Sufferers (excluding form letters)



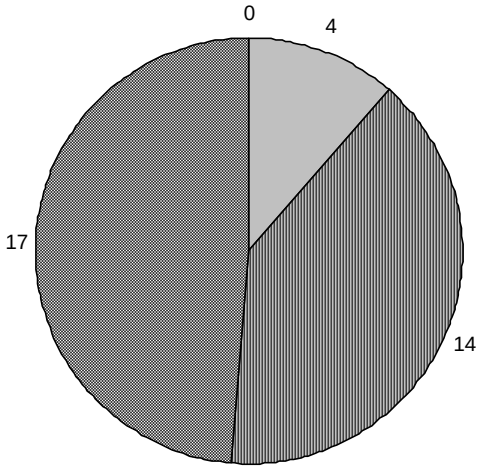
52 MCS sufferers made no reference to the report and are not included in this chart.

Exhibit E-6f - Degree of Support Provided by Organizations (including form letters)



2 organizations made no reference to the report and are not included in this chart.

Exhibit E-6g - Degree of Support Provided by Organizations (excluding form letters)



2 organizations made no reference to the report and are not included in this chart.

Exhibit E-6h - Degree of Support Provided by Private Industry

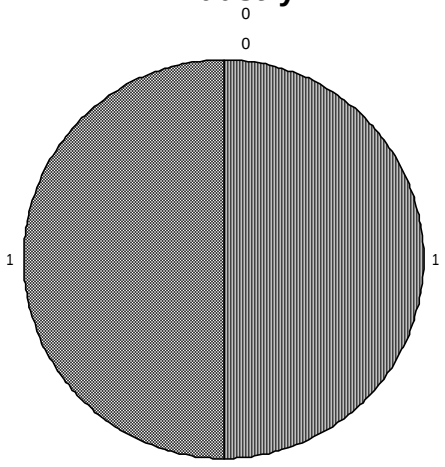
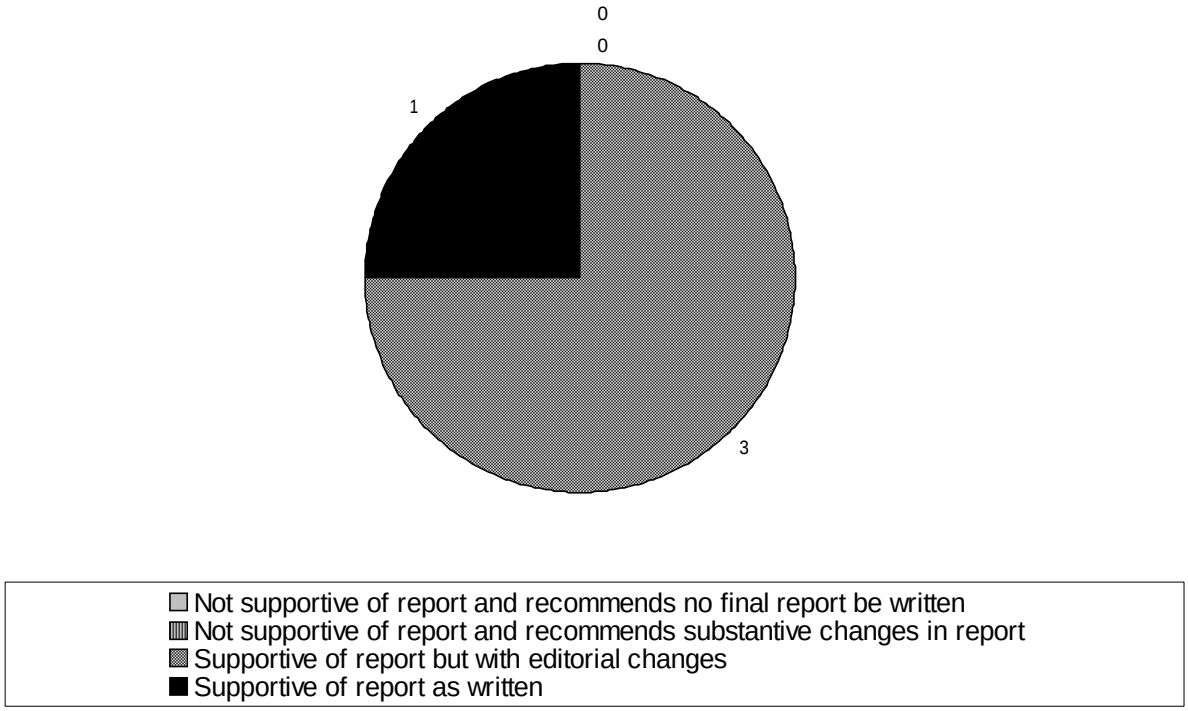


Exhibit E-6i - Degree of Support Provided by Government Agencies



1 government agency made no reference to the report and is not included.