

APPENDIX

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APPENDIX A

eTACTS: Vocabulary of Eligibility Tags for Clinical Trial Search

Vocabulary of eligibility tags used in the eTACTS evaluation described in Section 2.3 (i.e., “Evaluation Design”) of the article. The vocabulary was obtained by mining eligibility tags on 65,000 clinical trials randomly sampled from ClinicalTrials.gov, with tags that had to appear in at least 2% of the trials (i.e., 1,300 trials) to be considered as frequent.

1. active peptic ulcer
2. acute coronary syndrome
3. acute myocardial infarction
4. adrenal cortex hormones
5. adverse event associated with death
6. alanine transaminase
7. alcohol abuse
8. alcoholic intoxication chronic
9. alkaline phosphatase
10. amenorrhea
11. anaphylaxis
12. anaplastic oligodendroglioma
13. anemia
14. angina pectoris
15. angina unstable
16. angiogram
17. anticoagulation therapy
18. antidepressive agents
19. antipsychotic agents
20. antiretroviral therapy
21. anxiety disorders
22. arteriopathic disease
23. ascites
24. aspirin
25. asthma
26. atrial fibrillation
27. bipolar disorder
28. bleeding tendency
29. blood coagulation disorders
30. blood transfusion
31. body mass index
32. body weight decreased
33. bone marrow transplantation
34. bone metastases
35. brain injuries
36. brain neoplasms
37. breast carcinoma
38. cancer remission
39. cancer therapeutic procedure
40. carcinoma in situ
41. carcinoma of lung
42. cardiac arrhythmia

43. cardiac surgery procedures
44. cardiomyopathies
45. cardiovascular diseases
46. cataract adverse event
47. cerebrovascular accident
48. cerebrovascular disorders
49. cervix carcinoma
50. chemotherapy adjuvant
51. chemotherapy regimen
52. chronic disease
53. chronic liver disease
54. chronic obstructive airway disease
55. cirrhosis
56. claustrophobia
57. cns disorder
58. cns metastases
59. cognitive therapy
60. colonic diseases
61. communicable diseases
62. congenital abnormality
63. congestive heart failure
64. consciousness related finding
65. contraception barrier
66. contraceptives oral
67. coronary artery bypass surgery
68. coronary artery disease
69. coronary heart disease
70. craniocerebral trauma
71. creatinine clearance
72. crohn disease
73. cytotoxic chemotherapy
74. deep vein thrombosis
75. degenerative polyarthritis
76. dementia
77. dental caries
78. depressed mood
79. dexamethasone
80. diabetes mellitus
81. diabetes mellitus insulin-dependent
82. diabetes mellitus non-insulin-dependent
83. diarrhea
84. diastolic blood pressure
85. disability
86. disease of diaphragm
87. disease susceptibility
88. drug abuse
89. drug allergy
90. drug dependence
91. dyspnea
92. eating disorders
93. ecog performance status

94. electrocorticogram
95. epilepsy
96. evaluable disease
97. fever
98. finding of creatinine level
99. finding of platelet count
100. gastrointestinal diseases
101. gastrointestinal hemorrhage
102. gentamicins
103. gonadotropins
104. hearing examination finding
105. heart diseases
106. heart function
107. hematocrit level
108. hematological disease
109. hemodialysis
110. hemoglobin
111. hemorrhage
112. hepatitis active
113. hepatitis b
114. hepatitis c
115. hepatitis chronic
116. hiv
117. hiv infections
118. hiv negative finding
119. hiv seropositivity
120. hormone replacement therapy
121. human chorionic gonadotropin
122. hypertensive disease
123. hyperthyroidism
124. hypotension
125. hypothyroidism
126. hysterectomy
127. immunologic deficiency syndromes
128. immunosuppressive agents
129. immunotherapy
130. impaired cognition
131. implantation procedure
132. infantile neuroaxonal dystrophy
133. inflammatory bowel diseases
134. inflammatory disorder
135. integrated neuromusculoskeletal release
136. intestinal diseases
137. intestinal obstruction
138. intravenous infusion procedures
139. investigational new drugs
140. karnofsky performance status
141. kidney diseases
142. kidney failure
143. kidney failure chronic
144. laboratory abnormalities

145. left ventricular ejection fraction
146. leukemia myelocytic acute
147. liver carcinoma
148. liver cirrhosis
149. liver diseases
150. liver dysfunction
151. liver failure
152. liver function
153. liver metastases
154. lung diseases
155. lung diseases obstructive
156. lupus erythematosus systemic
157. lupus vulgaris
158. lymphoid leukemia
159. lymphoma
160. magnetic resonance imaging
161. major depressive disorder
162. major surgery
163. malignant disease
164. malignant neoplasm of skin
165. mental disorders
166. mental retardation
167. metabolic diseases
168. metastatic malignant neoplasm to brain
169. migraine disorders
170. monoamine oxidase inhibitors
171. morphology within normal limits
172. morular metaplasia of the endometrium
173. multiple endocrine neoplasia
174. multiple myeloma
175. mycoses
176. myeloid leukemia chronic
177. myocardial infarction
178. myocardial ischemia
179. neoadjuvant therapy
180. neoplasm metastasis
181. nervous system disorder
182. nitrosourea compounds
183. non-small cell lung carcinoma
184. non-smoker
185. obesity
186. operative surgical procedures
187. oral contraception
188. osteoporosis
189. ovariectomy
190. parkinson disease
191. peptic ulcer
192. percutaneous coronary intervention
193. peripheral neuropathy
194. peripheral vascular diseases
195. pharmaceutical adjuvants

196. phosphatidylinositols
197. phosphoric monoester hydrolases
198. plain x-ray
199. platelets adverse event
200. positive pregnancy test
201. positron-emission tomography
202. prednisone
203. pregnancy test negative
204. pregnant
205. prior chemotherapy
206. progressive disease
207. prophylactic treatment
208. prostate carcinoma
209. psychotic disorders
210. pulmonary embolism
211. pulmonary fibrosis
212. radionuclide ventriculogram scan
213. recurrent malignant neoplasm
214. renal dialysis
215. renal dysfunction
216. renal impairment
217. renal insufficiency
218. respiration disorders
219. respiratory tract infections
220. retinal diseases
221. rheumatoid arthritis
222. schizoaffective disorder
223. schizophrenia
224. septicemia
225. serum creatinine level
226. sexual sterilization
227. skin carcinoma
228. sleep apnea syndromes
229. smoker
230. solid tumor
231. squamous cell carcinoma of skin
232. stem cell transplant
233. stenosis unspecified
234. steroid therapy
235. stimulation procedure
236. substance abuse problem
237. substance dependence
238. suicide attempt
239. systolic blood pressure measurement
240. tachycardia ventricular
241. therapeutic immunosuppression
242. thrombocytopenia
243. thyroid diseases
244. tissue growth
245. transient ischemic attack
246. transplantation

- 247. traumatic brain injury
- 248. tubal ligation
- 249. tuberculosis
- 250. ulcer
- 251. ulcerative colitis
- 252. ultrasonography
- 253. uncontrolled hypertensive disease
- 254. unipolar depression
- 255. vasectomy
- 256. venous thrombosis
- 257. ventricular arrhythmia
- 258. visual acuity
- 259. weighing patient
- 260. x-ray computed tomography

APPENDIX B

Conditions for eTACTS Result Filtering Evaluation

List of the 50 conditions used as queries in the eTACTS result filtering evaluation described in Section 2.3.1 (i.e., “Reduction of the Result List”) of the article. Each condition is provided with the number of clinical trials associated on ClinicalTrials.gov as of April 2013.

Condition	No. of Clinical Trials
acquired immunodeficiency syndrome	4,828
adnexal diseases	1,718
anxiety disorders	1,846
arteriosclerosis	3,461
arthritis	3,241
bone diseases	5,670
brain ischemia	1,449
breast cancer	4,822
bronchial diseases	4,938
bronchial neoplasms	2,540
central nervous system diseases	10,438
cerebrovascular disorders	2,164
cervical cancer	2,916
colon cancer	2,345
colorectal neoplasms	2,650
congenital abnormalities	2,487
coronary diseases	9,546
depression	3,039
diabetes mellitus, type 2	4,015
digestive system neoplasms	6,671
endocrine system diseases	10,987
eye diseases	4,649
fibrosis	1,744
gastrointestinal diseases	13,687
genetic diseases	5,307
genital diseases, female	3,782
genital diseases, male	3,682

gonadal disorders	1,963
heart diseases	9,511
hemorrhagic disorders	2,428
hemostatic disorders	2,430
hepatitis a	2,083
hiv infections	4,827
hypertensive diseases	4,106
immunoproliferative disorders	5,291
infant newborn diseases	1,524
intestinal neoplasms	2,868
kidney diseases	4,718
leukemia	3,740
liver diseases	4,481
lymphoma, non-hodgkin	2,445
ovarian cancer	1,739
prostatic diseases	2,552
renal insufficiency	2,114
retroviridae infections	3,927
rheumatic diseases	3,163
sexually transmitted diseases	4,112
skin diseases	9,159
urologic diseases	5,456
virus diseases	9,001

APPENDIX C

Conditions and Locations for eTACTS Result Diversity Evaluation

List of the 10 conditions and 10 locations for the term-combined queries (i.e., all the 100 combinations: “condition” AND “location”) used in the eTACTS evaluation described in Section 2.3.2 (i.e., “Diversity of the Filtered Results”) of the article. The conditions are extracted from the list provided in **Appendix B**.

Conditions:

1. breast cancer
2. depression
3. diabetes mellitus, type 2
4. digestive system neoplasms
5. hiv infections
6. hypersensitivity
7. hypertension
8. intestinal neoplasms
9. kidney disease
10. leukemia

Locations:

1. California
2. France
3. Germany
4. Italy
5. Massachusetts
6. New York
7. Ohio
8. Spain
9. Texas
10. United Kingdom

APPENDIX D

Survey Provided to the User Study Participants for Clinical Trial Search Evaluation

Survey provided to the participants at the end of the user-based evaluation described in Section 2.3.3 (i.e., “A Scenario-based User Study Comparing Multiple Clinical Trial Search Engines”) of the article. During the evaluation tasks, participants were also required to manually review the top five ranked clinical trials returned by each search engine to determine if the assigned patient medical profile was eligible. Since this part was performed during the evaluation process, it is not reported in the survey.

Participant: _____

Clinical Trial Search Experience Background:

1. I have searched for clinical trials before today.
true false
2. Previously, I had trouble finding clinical trials without the help of another person.
strongly disagree disagree agree strongly agree n/a
3. It is important for me to be able to find clinical trials on my own.
strongly disagree disagree neutral agree strongly agree
4. In general, I feel it is important to participate in clinical trials.
strongly disagree disagree neutral agree strongly agree
5. I usually have an idea of the clinical trial(s) I want to participate in before searching.
strongly disagree disagree agree strongly agree n/a

Comparison between Clinical Trial Search Engine

6. One or more of the systems I used today helped me find more trials that I qualified for.
strongly disagree disagree neutral agree strongly agree
 7. One or more of the systems I used today helped me find relevant trials quicker.
strongly disagree disagree neutral agree strongly agree
-

8. Please rank the systems based on ease of entering information (i.e., selecting tags, entering data into medical profiles, etc.); [1 = best, 6 = worst, ties are allowed].

ASCOT *ClinicalTrials.gov* *Corengi*
 eTACTS *PatientsLikeMe*

9. Please rank the systems by the amount of search guidance offered by the search engine; [1 = most, 6 = least, ties are allowed].

ASCOT *ClinicalTrials.gov* *Corengi*
 eTACTS *PatientsLikeMe*

10. Please rank the systems based on ease of site navigation (for example: transitioning from one result to another or finding elements to complete tasks); [1 = best, 6 = worst, ties are allowed].

ASCOT *ClinicalTrials.gov* *Corengi*
 eTACTS *PatientsLikeMe*

11. Please rank the systems based on ease of use without prior training or instructions; [1 = best, 6 = worst, ties are allowed].

ASCOT *ClinicalTrials.gov* *Corengi*
 eTACTS *PatientsLikeMe*

12. Please rank the systems based on overall ease of use; [1 = best, 6 = worst, ties are allowed].

ASCOT *ClinicalTrials.gov* *Corengi*
 eTACTS *PatientsLikeMe*

13. Which system provided a better tag-cloud search refinement tool? (Check mark).

ASCOT *eTACTS* *neither*

14. Which system provided more tag-cloud terms related to your disease? (Check mark).

ASCOT *eTACTS* *neither*

15. Which system was easier to fill out a medical profile? (Check mark).

Corengi *PatientsLikeMe* *neither*

16. Please rank the following methods of searching for clinical trials; [1 = best, 3 = worst, ties are allowed].

simple search (i.e., clinicaltrials.gov)
 tag-cloud search (i.e., ASCOT, eTACTS)
 online profile matching (i.e., Corengi, PatientsLikeMe)
