

Appendix Q

Query 1:

((“social media”[Title/Abstract]) AND (patient[Title/Abstract]) AND ((listening[Title/Abstract]) OR monitoring[Title/Abstract])) NOT ((survey[Title/Abstract] OR engage[Title/Abstract] OR engagement[Title/Abstract] OR recruit[Title/Abstract] OR recruitment[Title/Abstract] OR use[Title]))

Query 2:

Set#	Searched for	Databases
S1	TI,AB(“drug* development*” OR “ R&D” OR “research and development” OR “clinical research” OR “patient focused drug development*” OR “drug discovery” OR “patient-centered drug* development” OR “patient centered drug* development” OR “patient-focused drug development*” OR “pharma* R&D” OR “pharmaceutical development*” OR “early research” OR “drug research” OR “scientific research” OR “utilised for research*” OR “patient-centric drug development” OR “patient centric drug development” OR “clinical stud*” OR “clinical trial*”)	embase1974date, medlineprof1950date
S2	MJMESB.EXACT.EXPLODE(“Drug Industry”) OR MJEMB.EXACT.EXPLODE(“drug industry”) OR “TI,AB(“pharmaceutical companies” OR “pharmaceutical company” OR “pharmaceutical industr*” OR “Pharm* development” OR “Pharma compan*” OR “drug* development” OR “drug* research”)	embase1974date, medlineprof1950date
S3	MJEMB.EXACT(“social media analysis”) OR MJEMB.EXACT.EXPLODE(“social media monitoring”) OR MJMESB.EXACT(“Social Media”) OR MJEMB.EXACT(“social media”)	embase1974date, medlineprof1950date
S4	TI,AB(“Social media listening” OR “social media mining” OR “social media monitoring”) OR TI(“social media” OR “social listening”)	embase1974date, medlineprof1950date

S5	S4 OR S3	embase1974date, medlineprof1950date
S6	S5 AND S2 AND S1	embase1974date, medlineprof1950date
S7	TI,AB(""drug* development*"" OR "" R&D"" OR ""research and development"" OR ""clinical research"" OR ""patient focused drug development*"" OR ""drug discovery"" OR ""patient-centered drug* development"" OR ""patient centered drug* development"" OR ""patient-focused drug development*"" OR ""pharma* R&D"" OR ""pharmaceutical development*"" OR ""early research"" OR ""drug research"" OR ""scientific research"" OR ""utilised for research*"" OR ""patient-centric drug development"" OR ""patient centric drug development"" OR ""clinical stud*"" OR ""clinical trial*"" OR ""Real world data"" OR ""real world evidence"" OR ""RWE"" OR ""RWD"" OR ""real world stud*"")	embase1974date, medlineprof1950date
S8	S7 AND S4	embase1974date, medlineprof1950date
S9	(S8 OR S6) and (pd(2013-2023))	embase1974date, medlineprof1950date

Appendix A

Indications	Goals/Objectives	Sources	Sponsors
<p>Acute Myeloid Leukemia [3]</p> <p>Amblyopia [59]</p> <p>Ankylosing spondylitis [38]</p> <p>Atopic dermatitis [53, 65]</p> <p>Bronchiectasis [28]</p> <p>Cancer [23]</p> <p>Chronic Kidney Disease [28]</p> <p>Chronic ocular pain [21]</p> <p>Complement 3 Glomerulopathy (C3G) [63]</p> <p>COVID-19 / Long COVID [25, 26, 39, 43]</p> <p>Crohn's Disease [2]</p> <p>Dental medicine [1, 14]</p> <p>Diseases that require hysterectomy [27]</p> <p>Dry Eye Disease [22]</p> <p>Eosinophil-Driven Diseases (EGPA & HES) [58]</p> <p>GI Discomfort [50]</p> <p>Gout [18]</p> <p>Hematologic cancers [37]</p>	<p>Analyze online communication behavior and influence of key opinion leaders [33, 62, 67]</p> <p>Barriers to care [39, 52]</p> <p>Common mental health symptoms [27, 51]</p> <p>Disease burden, key symptoms [4, 8, 22, 25, 30, 34, 36, 40-46, 49, 50, 53-60]</p> <p>Emotional impact of disease, diagnosis and treatment [10, 15, 18, 22, 26, 48, 65]</p> <p>HRQoL impacts [7, 17, 21, 23, 42, 49, 54-56, 59-61, 63-65, 67]</p> <p>Identify perceived causes for disease [21]</p> <p>Identify/Predict condition [25, 32, 44, 50]</p> <p>Impact on caregivers [15, 16, 19, 22, 32, 34, 40, 58]</p> <p>Patient-reported experiences, symptoms, outcomes and patient journeys [1, 4, 8, 16, 17, 20, 21, 25, 28, 34, 36, 40,</p>	<p>Consumer reviews [53]</p> <p>Facebook [7, 10, 14, 18, 21, 22, 29, 31, 39, 43, 49, 58, 61]</p> <p>Instagram [7, 53]</p> <p>News [17, 53, 59, 63, 64, 67]</p> <p>Online forums, blogs [5-7, 10-12, 17, 21, 29, 31, 32, 34, 39, 42, 45, 48-50, 53, 56, 58, 59, 63, 64, 66, 67]</p> <p>Patient Communities [8, 9, 16, 19, 20, 23, 25, 28, 34, 35, 37, 38, 44-46, 49, 50, 54, 55, 58, 60]</p> <p>Reddit [11, 18, 42, 43, 53, 58]</p> <p>Tumblr [29, 53, 58]</p> <p>Twitter [1, 3, 5, 6, 10, 11, 14, 15, 17, 21, 27, 32-34, 39, 42, 46, 47, 49, 52, 53, 57-59, 62-64, 66, 67]</p> <p>Youtube [7, 8, 26, 29, 49, 58]</p>	<p>AstraZeneca [28]</p> <p>Boehringer Ingelheim [2, 24]</p> <p>BMS [23, 35, 36]</p> <p>Chiesi [28]</p> <p>GSK [37, 58]</p> <p>Horizon Therapeutics [18]</p> <p>Johnson & Johnson [8, 30]</p> <p>Merck [54, 55]</p> <p>Neurocrine Biosciences [15, 32]</p> <p>Novartis [5, 6, 16, 17, 19, 21, 34, 38, 40, 42, 48, 49, 59, 63, 64, 67]</p> <p>Novo Nordisk [49]</p> <p>Pfizer [3, 8, 53]</p> <p>Pierre Fabre [60]</p> <p>Roche [11, 20, 46, 51, 56]</p>

<p>Immunoglobulin A nephropathy (IgAN) [64]</p> <p>Inflammatory bowel disease [29]</p> <p>Lung cancer [49]</p> <p>Melanoma [16, 18, 35, 60]</p> <p>Metastatic Breast Cancer [31, 34, 44, 52]</p> <p>Multiple Myeloma [8, 23]</p> <p>Multiple Sclerosis 12, [29, 30, 48]</p> <p>Myelodysplastic syndromes [19]</p> <p>Nutrition [33]</p> <p>Obesity [24]</p> <p>Parkinson’s disease [45, 56, 68]</p> <p>Personality disorder [32]</p> <p>Presbyopia [17, 67]</p> <p>Psoriasis [47]</p> <p>Renal cell carcinoma [36]</p> <p>Sarcoma [62]</p> <p>Schizophrenia [27]</p> <p>SLC6A1 disorder [22]</p> <p>Sjögren’s disease [42]</p> <p>Systemic juvenile idiopathic arthritis [40]</p> <p>Lupus [54, 55, 57]</p>	<p>42, 43, 46, 48-50, 54, 55, 57-60, 63, 64]</p> <p>Treatment coverage/Treatment experience [7-9, 26, 35-38, 41, 45, 49, 54, 55, 60, 65, 66]</p> <p>Treatment seeking / selection [3, 11, 12, 14, 29, 31, 37-39, 46-49, 54, 66]</p> <p>Unmet needs [5, 18, 19, 32, 54, 55, 57, 63, 64, 68]</p>		<p>Sanofi [65]</p> <p>UCB [68]</p>
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Tardive Dyskinesia [15, 32] Undefined [46, 66]			
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Table A 1: Overview of findings from literature review on published social listening articles with PFDD focus since 2015.

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