

Appendix 3, Categorization of extracted data

Data item	Categorization	Explanations	Examples
Journal	General medicine	Journals with a broad scope that publish research related to general medicine, oncology and neurology. This category also includes biotechnology and pharmaceutical science.	Nat Biotechnol Chron Respir Dis Clin Chem Med J Aust Nat Med Am J Bioeth Bmj-British Medical Journal PeerJ JAMA, Journal of the American Medical Association Journal of Neurology BMC Medicine Journal of Neurology The Lancet Biomedical Engineering Online Dermatol Online J Internal medicine journal Plos One BMC Med
	Specialized medicine	Journals with a scope on specific diagnoses, i.e. diabetes	Epilepsy & Behavior Clin Orthop Relat Res Diabetes Technology & Therapeutics Journal of Diabetes Science and Technology Diabetes The American Journal of Gastroenterology JMIR Ment Health

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		Pediatric Physical Therapy American Journal of Gastroenterology Pediatric Pulmonology JMIR Pediatrics and Parenting Techniques in Coloproctology Practical Diabetes Diabetes Therapy Diabetes, Obesity and Metabolism Breast Cancer Research and Treatment Pediatric Endocrinology Diabetes and Metabolism Canadian Journal of Diabetes Diabetic Medicine
Process related	Journals with a focus on process in research and healthcare, i.e. protocols, frameworks, methods.	AMIA Annu Symp Proc Journal of Communication in Healthcare Trials Policy Internet International journal of integrated care Learn Health Syst JMIR Research protocols Int J Med Inform BMJ Qual Saf
Digital health	Journals with a focus on digital healthcare, including advances in technology in medicine and m-health	Journal of Medical Internet Research Stud Health Technol Inform J Am Med Inform Assoc Interactive Journal of Medical Research JMIR Mhealth & Uhealth NPJ Digit Med

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	Patient oriented	Journals that have patients in focus, i.e. <i>The Patient</i> , that cover development, evaluation and implementation of therapies, technologies, and innovations that will enhance the patient experience.	Jmir Mhealth and Uhealth The Patient
Country	Europe North America South America Asia Oceania Africa	Country of first author's affiliation	
Publication type	Original research	Articles published as "original research", "research article" etc.	Grande SW, Longacre MR, Palmblad K, Montan MV, Berquist RP, Hager A, et al. Empowering Young People Living With Juvenile Idiopathic Arthritis to Better Communicate With Families and Care Teams: Content Analysis of Semistructured Interviews. JMIR mHealth and uHealth. 2019;7(2):e10401
	Short report	Articles published as "Brief report" or "short paper"	Braune K, O'Donnell S, Cleal B, Lewis DM, Tappe A, Hauck B, et al. DIWHY: Factors Influencing Motivation, Barriers, and Duration of DIY Artificial Pancreas System Use among Real-World Users. Diabetes.68:3

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Protocol	Articles presenting a study protocol	Rouholiman D, Gamble JG, Dobrota SD, Encisco EM, Shah AG, Grajales FJ, et al. Improving Health-Related Quality of Life of Patients With an Ostomy Using a Novel Digital Wearable Device: Protocol for a Pilot Study. <i>JMIR research protocols</i> . 2018;7(3)
Letter to editor/ commentary	Text published as “letter to the editor”, “commentary”, “personal view”. Not peer-reviewed research.	Riggare S, Unruh KT. Patients organise and train doctors to provide better care. <i>BMJ</i> . 2015;351:h6318
Conference abstract	Published conference abstracts.	Lindblad A, Hedborg A, Elidottir H, de Monestrol I, Hjelte L, Ericson P, et al. SWEDEN'S LEARNING HEALTH SYSTEM APPROACH TO NEW THERAPIES: NINE MONTHS WITH LUMACAFOR/IVACAFOR. <i>Pediatr Pulmonol</i> . 2019;54:S444-S
Editorial	Published text written by person having an editorial role at a journal. This was sometimes patients.	deBock M. The 'do it yourself' type 1 diabetes dilemma for medical practitioners. <i>Internal Medicine Journal</i> . 2019;49(5):559-61
Review	We included review-articles that published original data not published elsewhere.	Kublin O, Stepien M. Effect of using the nightscout system on metabolic control, safety, and incidence of complications in patients with diabetes mellitus. <i>Wiadomosci Lekarskie</i> . 2020;73(7):1427-33.

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	Special section dedicated to patients	special section "in my own voice" and "personal perspective"	Ahrens S. Opening (and Swallowing) A Can of Worms to Treat My Crohn's Disease. <i>The American journal of gastroenterology</i> .111(7):918-20.
Study aim	Describe the innovation	Articles with an aim to describe the innovation in some way	Ellis L, Showell C, Turner P. Social media and patient self-management: not all sites are created equal. <i>Studies in health technology and informatics</i> . 2013;183:291-5.
	Describe development of innovation	Articles with an aim to describe some part of development of the innovation	Jennings P, Hussain S. Do-It-Yourself Artificial Pancreas Systems: A Review of the Emerging Evidence and Insights for Healthcare Professionals. <i>Journal of Diabetes Science & Technology</i> . 2020;14(5):868-77.
	Describe users	Articles that aim to describe characteristics of persons who use the innovations	Hng TM, Burren D. Appearance of Do-It-Yourself closed-loop systems to manage type 1 diabetes. <i>Internal Medicine Journal</i> .48(11):1400-4.
	Describe how users perceive the innovations	Articles that aim to describe how users perceive the innovations	Lebenthal Y. Patient Perceptions of Using the OmniPod System Compared with Conventional Insulin Pumps in Young Adults with Type 1 Diabetes. <i>Diabetes technology & therapeutics</i> . 2012;14(5):411-7.
	Test effect/impact of innovations	Articles that aim to test the effect and/or impact of patient-driven innovations	Lemieux P, Yamamoto J, Donovan L. 44 - Do-It-Yourself Artificial Pancreas System Use in Pregnancy in a Real-World Setting: A Case Report... <i>Virtual Diabetes Canada/CSEM</i>

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			Professional Conference, October 28-30, 2020. Canadian Journal of Diabetes. 2020;44(7):S20-S.
	Describe/discuss ethical issues	Articles that describe and/or discuss ethical issues related to patient-driven innovations	Crabtree TSJ, McLay A, Wilmot EG. DIY artificial pancreas systems: here to stay? Practical Diabetes. 2019;36(2):63-8.
	Describe/discuss policy change	Articles that describe and/or discuss ethical issues related to patient-driven innovations	Murray JA, Clayton MF, Litchman ML. Health Care Provider Knowledge and Perceptions of FDA-Approved and Do-It-Yourself Automated Insulin Delivery. Journal of Diabetes Science & Technology. 2020;14(6):1017-21.
Study design (categorized using a classification by Ranganathan et al. 2018)	Descriptive	Studies with a qualitative design or studies that describe characteristics of a sample but relationships between variables are not analyzed, e.g. case reports, case series, descriptive cross-sectional surveys (1)	Shepard JA, Breton M, Nimri R, Roberts JTF, Street T, Klonoff D, et al. User and Healthcare Professional Perspectives on Do-It-Yourself Artificial Pancreas Systems: A Need for Guidelines. Journal of Diabetes Science & Technology. 2020:1932296820957728.
	Observational	Studies that analyze relationships between variables but exposure is not determined, or the exposure is naturally determined (1)	ZABINSKY J, HOWELL H, GHEZAVATI A, LEWIS DM, NGUYEN A, WONG JC. 988-P: Do-It-Yourself Artificial Pancreas Systems for Type 1 Diabetes Reduce Hyperglycemia without Increasing Hypoglycemia. Am Diabetes Assoc; 2020.
	Experimental	Studies that analyze relationships between variables with a pre-determined exposure that the researcher actively distribute to the study population (1)	Berry DL, Blonquist TM, Halpenny B, Hong F, Morrison-Ma SC, McCullough MC, et al. The Jacki Jacket after mastectomy with reconstruction: a randomized pilot study. Breast Cancer Research and Treatment. 2020;179(2):377-85.

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	No design	Empirical data not presented in the article	Seres M. From Patient to Patient-Entrepreneur: Development of an Ostomy Bag Sensor. The American journal of gastroenterology.113(1):8-10.
Sample size	1-5 5-25 26-100 101-200 201-500 501-1000 <1001		
Medical condition	Cancer	Breast cancer	Berry DL, Blonquist TM, Halpenny B, Hong F, Morrison-Ma SC, McCullough MC, et al. The Jacki Jacket after mastectomy with reconstruction: a randomized pilot study. Breast Cancer Research and Treatment. 2020;179(2):377-85.
	Diabetes		Lewis DM, Leibr, S, Street TJ, Phatak SS. Detecting Insulin Sensitivity Changes for Individuals with Type 1 Diabetes. Diabetes.67:2.
	Disabilities	Cerebral pares	Ardolino E, Flores M, Manella K. Gross Motor Outcomes After Dynamic Weight-Bearing in 2 Children With Trunk Hypotonia: A Case Series. Pediatric Physical Therapy.29(4):360-4.
	Gastrointestinal diseases	Crohn's Disease	Ahrens S. Opening (and Swallowing) A Can of Worms to Treat My Crohn's Disease. The American journal of gastroenterology.111(7):918-20.

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Mental illness	Schizophrenia	Vaidyam A, Roux S, Torous J. Patient Innovation in Investigating the Effects of Environmental Pollution in Schizophrenia: Case Report of Digital Phenotyping Beyond Apps. <i>JMIR mental health</i> . 2020;7(8):e19778.
Multiple conditions		Chiauzzi E, DasMahapatra P, Cochin E, Bunce M, Khoury R, Dave P. Factors in Patient Empowerment: A Survey of an Online Patient Research Network. <i>Patient-Patient Centered Outcomes Research</i> .9(6):511-23.
Parkinson's disease		Riggare S, Unruh KT. PERSONAL VIEW Patients organise and train doctors to provide better care. <i>BMJ-British Medical Journal</i> .351:2.
Rare diseases	22q11 deletion syndrome Cystic Fibrosis	Lawlor A, Kerin L, Orr D, Leahy R, Crotty F, Kelleher S, et al. Developing integrated care in the context of rare chromosomal conditions: 22q11 Deletion Syndrome; A parent/clinician collaboration. <i>International Journal of Integrated Care (IJIC)</i> . 2017;17:1-2.

1. Ranganathan P, Aggarwal R. Study designs: Part 1 - An overview and classification. *Perspectives in clinical research*. 2018;9(4):184-6.

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