Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Publication	Country*	Publication type	*Publication type categorized*	Study aim	*Study aim categorized*
Ahrens 2016	USA	Special section	*8 Special section dedicated to patients*	N/A	*N/A*
Ardolino 2017	USA	Case report	*1 Original research*	"to report the effect of a home-based dynamic standing program on postural control and gross motor activity in 2 children with trunk hypotonia"	*5 Test effect/impact of innovation*
Barnard 2018	UK	Commentary	*4 Letter to editor/commentary*	"discuss the challenges faced by key stakeholder groups in terms of potential collaboration and open debate of these challenges"	*4 Describe how users perceive the innovations*
Beckman 2016	Norway	Conference abstract	*5 Conference abstracts*	"propose how to extend the Nightscout application with motivational mechanisms and social media functionality for small user groups"	*5 Test effect/impact of innovation*
Ben-Pazi 2018	Israel	Research article	*1 Original research*	To investigate the impact of auditory stimulation on motor function in children with cerebral palsy (CP) and disabling hypertonia.	*5 Test effect/impact of innovation*

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Berry 2019	USA	Clinical trial	*1 Original research*	"The purpose of this randomized pilot trial was to compare post-operative pain intensity, over the weeks that participants had surgical drains, between those receiving the Jacki Jacket plus usual care (Jacki + UC) and UC alone. Secondary outcomes included pain interference, functional status, self-administered pain medication, time to opioid cessation, quality of life, and related breast cancer symptoms."	*5 Test effect/impact of innovation*
Braune 2019 DIWHY	Germany	Short paper	*2 Short report*	There remains, however, a lack of research examining outcomes of children and adolescents with DIYAPS in everyday life and their social context. This survey assesses the self-reported clinical outcomes of this specific user group.	*5 Test effect/impact of innovation*
Braune 2019 Real World Use	Germany	Conference abstract	*5 Conference abstract*	This study aims to examine the	*4 Describe how users perceive the innovations*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				motivations of Do-it-Yourself Artificial Pancreas System (DIYAPS) users and caregivers to build and maintain these systems.	
Brownstein 2009	USA	Letter to editor	*4 Letter to editor/commentary*	Promoting PLM in OI community; Questions: "1. Can social networking make patients' lives better? 2. Where do we need to go? (i.e., How would a specific bone disorder community work? Is it possible for patients to know how well they are doing in comparison to others like them, and if they are getting the most successful treatment for their disease?)" 3. How do we get there? (What do we need to do?)	*1 Describe the innovation*
Brownstein 2010	USA	Symposium (commentary)	*4 Letter to editor/commentary*	Same as Brownstein 2009	*1 Describe the innovation*
Burnside 2020 Do-it-yourself	New Zealand	Symposium proceedings	*7 Review*	"deliver examples of research in artificial pancreas technology which actively pursues the use of machine learning	*1 Describe the innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				representative of artificial intelligence (AI) and also explore alternate approaches to AI within the DIY AID example." "examine data sharing for algorithm development and refinement, for sharing of the open-source algorithm codes online, for peer to peer support, and sharing with medical and scientific communities."	
Chiauzzi 2019 Digital Trespass	USA	listed as "Article"	*1 Original research*	"...share four cases involving ethical and terms-of-use violations" [to address the following questions about challenges and ethics violations while using social media and "big data" for research:] "How do these ethical violations occur? How are these violations discovered and remedied by data producers? Most importantly, what corrective actions can and should be taken to prevent violations	*6 Describe/discuss ethical issues*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				that compromise the privacy of social media users?" "goal is to utilize these cases as a springboard to protect patient privacy while finding ways of meeting investigators' legitimate public health research objectives."	
Cleal 2019	Denmark	Conference abstract	*5 Conference abstract*	detailing the lived experiences of people using DIYAPS in an extensive and diverse way.	*4 Describe how users perceive the innovations*
Crabtree 2019 DIY artificial pancreas	UK	Review	*7 Review*	"discuss the principles of DIY APS, the outcomes observed so far and the feedback from users, and debate the ethical issues which arise before looking to the future and newer technologies on the horizon"	*2 Describe development of innovation* *6 Describe/discuss ethical issues*
De Bock 2019	New Zealand	Editorial	*6 Editorial*	"(i) What safety and efficacy data exist? (ii) What legal implications are there when providing care for a patient who uses an unregulated product? and (iii) What is the role of the	*7 Describe/discuss policy change*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				healthcare professional with respect to adjusting/prescribing or education where there is none of the usual training or support infrastructure available? The purpose of this editorial is to update clinicians on these critical aspects. "	
De la Loge 2016	Belgium	Research article	*1 Original research*	"The objective of this retrospective analysis was to characterize the profile of users and their disease and identify factors predictive of poor health-related quality of life (HRQoL), while assessing the platform's potential in providing patient-reported data for research purposes."	*3 Describe users, 5 Test effect/impact of innovation*
De Monestrol 2018	Sweden	Conference abstract	*5 Conference abstract*	As new life-changing, yet expensive, therapies for cystic fibrosis(CF) become available, Sweden and its responsible authorities strive to create a system that enables structured	*2 Describe development of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				follow-up and evaluation of new treatments for optimal care and best use of resources. In 2016, key CF stakeholders formed the Sweden CF Coalition, a national collaborative learning network that enables persons with CF, families, clinicians, researchers and others to work together toward common goals. The Coalition aims to reduce the burden of illness for patients by radically improving the ability of patients, families and professionals to co-produce improved clinical practice and better care at home.	
Debong 2019	Austria	peer review "EMERGING DIGITAL HEALTH TECHNOLOGIES IN DIABETES"	*1 Original research*	"discuss findings from real world observations of changes in glycemic control and patient satisfaction associated with the use of the mHealth app"	*5 Test effect/impact of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Dowling 2020 Do-it-yourself closed-loop	UK	Position statement	*4 Letter to editor/commentary*	"This position statement recognizes that the development of diabetes technology is a rapidly changing environment, and guidance around do-it-yourself systems is required from professional and regulatory bodies." ("Diabetes UK's position statements make recommendations that aim to provide guidance for both people with diabetes and healthcare professionals, based on the current professional and legal situation.")	*7 Describe/discuss policy change*
Ellis 2013	Australia	Conference proceedings	*1 Original research*	"...the aim was to primarily focus on how these sites [PatientsLikeMe and HealthShare [http://www.healthshare.com.au/]] described and subsequently supported patient-to-patient interactions to support self-management"	*1 Describe the innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Farrington 2016	USA	"In focus"	*4 Letter to editor/commentary*	N/A	*N/A*
Fergus 2017	USA	Peer review	*1 Original research*	"to assess the feasibility and describe the gait outcomes associated with the use of the Upsee in conjunction with KT for a young child with extrapyramidal CP"	*1 Describe the innovation*
Frost 2008 How the social	USA	Symposium proceedings	*1 Original research*	"This paper reports on... - how people with ALS, and their physicians, leveraged community, data sharing, and the Internet to accelerate the evaluation of a treatment and conduct a real time open investigation on the effects of Lithium on disease progression."	*1 Describe the innovation*
Frost 2008 Social uses of	USA	Research article	*1 Original research*	"how patients explicitly utilize visual displays of health information to communicate with specific patients about their treatments and disease experience. We also sought to describe the kind of dialogues that emerge	*4 Describe how users perceive the innovations*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				when individual health information is made available within a patient community."	
Frost 2009 Patients like me the case	USA	Review Series: Tele-eHealth	*1 Original research*	"The goal of this paper is to present a case exemplar on how amyotrophic lateral sclerosis (ALS) patients are using PatientsLikeMe to inform decisions related to pulmonary health. What happens when the patients go online to share not only their insights and support of one another but also structured health information?"	*5 Test effect/impact of innovation*
Grande 2019 Empowering young people	Sweden	Original paper	*1 Original research*	"to examine how an mHealth patient support system (mPSS) might foster partnership between young people living with JIA, their families, and care teams"	*4 Describe how users perceive the innovations*
Griffiths 2015 The impact of	UK	Research article	*7 Review*	"What is the potential for impact of health-related, lay-controlled networked digital	*1 Describe the innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				communication on health and health systems?" "In our case studies we consider the balance between these different activities and their impact on health, health care, and health care policy." "For the scoping review, we establish the extent to which the phenomenon of social networks related to health is documented in the publically available literature, and establish evidence of the prevalence of these networks." "In order to select our case studies, we describe the characteristics of documented networks and how they vary. We then select four networks as case studies..."	
Heywood 2014 Straight talk with	USA	Interview with Jamie Heywood, co-founder of PLM	*6 Editorial*	N/A	*N/A*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Hng 2018 Appearence of do-it-yourself	Australia	Peer review	*1 Original research*	"to describe the Australian looping community, specifically to understand who they are, their motivations for the DIY approach and the challenges faced by these individuals and their HCP"	*3 Describe users*
Hussain 2020 Part I	UK	podcast transcript (Editorial)	*6 Editorial*	N/A	*N/A*
Hussain 2020 Part II	UK	podcast transcript (Editorial)	*6 Editorial*	N/A	*N/A*
Janssen 2016 A painted staircase	Netherlands	Letter to the editor	*4 Letter to editor/commentary*	"we regard this case description as a homage to the inventiveness of patients and their caregivers"	*3 Describe users*
Janssen 2016 Response to	Netherlands	Response: Letter to the editor	*4 Letter to editor/commentary*	N/A	*N/A*
Jennings 2020 Do-It-Yourself Artificial Pancreas	UK	Symposium proceedings/Review	*7 Review*	"First, it synthesizes the emerging literature on DIY APS and identifies a range of evidence including research, reviews, commentaries, and opinion pieces written by DIY APS users, healthcare professionals (HCPs),	*2 Describe development of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				and researchers. It summarizes the emerging clinical evidence for DIY APS and provide insight into how the DIY APS movement began, has been disseminated throughout diabetes online communities, and is reshaping self-management of T1D in real-world settings. Second, the article provides commentaries that explore implications of DIY APS to healthcare practice."	
Kendall 2017 T1resources.uk	UK	Peer-review ("current topics")	*1 Original research*	"to provide a curated library of resources created for and by people with T1DM. The website is co-curated, with equal healthcare professional and peer representation and input. "	*2 Describe development of innovation*
Klee 2018 An intervention by	Switzerland	Original article	*1 Original research*	"to evaluate the impact of a multidisciplinary intervention consisting of using Webdia, a patient-designed mHealth app,	*5 Test effect/impact of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				combined with an educational intervention by specialized nurses and regular insulin dose adaptation by diabetologists on metabolic control of T1DM, QoL, and frequency of hypoglycemia in children 10–18 years of age, followed at the outpatient clinic of the pediatric diabe- tology unit of the University Hospitals of Geneva, Switzerland"	
Kontovounisios 2018 The Ostom-i alert	UK	Other ("Technical advances")	*1 Original research*	"to assess the efficacy and usability of Ostom-i ™ sensor, clipped to the lower part of a stoma bag to sense when a bag is filling and to relay that data back to the patient in real time via a smartphone application"	*1 Describe the innovation0*
Kublin 2020 The Nightscout system	Poland	Review paper	*7 Review*	"This article describes the Nightscout system – required components, operating costs, and	*1 Describe the innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				other usage options. It also presents the current evaluation of the Nightscout system in scientific publications."	
Lawlor 2017 Developing integrated care	Ireland	Conference abstract	*5 Conference abstract*	"The shared aim is to develop a clinical network, center of expertise and care pathway for 22q11.2DS informed by carers and service users, building upon existing specialist expertise within the health system. "	*2 Describe development of innovation*
Lebental 2011 Patient perception	USA	Original paper	*1 Original research*	"This study evaluated treatment satisfaction, comfort, and function using the wireless OmniPod Insulin Management System (Insulet Corp., Bedford, MA) compared with conventional (infusion set) insulin pumps in young adults with type 1 diabetes."	*4 Describe how users perceive the innovations*
Lee 2016 A patient-designed	USA	"Viewpoint" Opinion	*4 Letter to editor/commentary*	"This Viewpoint describes the Nightscout Project, including the challenges it poses for the current healthcare	*1 Describe the innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				system, and the opportunities yielded from this new form of health production	
Lee 2017 Real-world use	USA	Original article	*1 Original research*	"to compare demographic/disease characteristics of users versus nonusers of a do-it-yourself (DIY) mobile technology system for diabetes (Nightscout), to describe its uses and personalization, and to evaluate associated changes in health behaviors and outcomes."	*3 Describe users,5 Test effect/impact of innovation*
Lemieux 2020 Do-It-Yourself Artificial Pancreas	Canada	Abstract	*5 Conference abstract*	"Despite considerable effort, few pregnant women with type 1 diabetes achieve the tight glycemic control required in pregnancy. Use of DIY APS is growing, but little is known about their safety and efficacy during pregnancy….We describe a 31-year-old G3P1SA1 with type 1 diabetes of 22 years duration, who used a "loop" system in pregnancy."	*5 Test effect/impact of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Lewis 2015 How a DIY	USA	Conference abstract	*5 Conference abstract*	N/A	*N/A*
Lewis 2016 Real-world use	USA	Letter to the editor	*4 Letter to editor/commentary*	N/A	*N/A*
Lewis 2017 Automatic estimation	USA	Conference abstract	*5 Conference abstract*	N/A	*N/A*
Lewis 2018 Detecting insulin	USA	Conference abstract	*5 Conference abstract*	Not reported	
Lewis 2018 Improvements in A1C	USA	Conference abstract	*5 Conference abstract*	To compare mean BG, TIR (70-180 mg/dl), and time above and below clinically meaningful thresholds before and after OpenAPS initiation	*5 Test effect/impact of innovation*
Lewis 2018 Setting expectations	USA	Letter to the editor	*4 Letter to editor/commentary*	N/A	*N/A*
Lewis 2019 Characterization of	USA	Conference abstract	*5 Conference abstract*	This is the first longitudinal analysis of biological rhythms in T1D, compared to non-T1D individuals	*5 Test effect/impact of innovation*
Lewis 2019 History and perspective	USA	Commentary	*4 Letter to editor/commentary*	"This commentary will address DIY closed looping: how it was developed and how it works; potential benefits and documented outcomes from and by this self-selected population; potential disadvantages of this approach; and	*5 Test effect/impact of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				perspective on where DIY is going and how it effects other diabetes technology development."	
Li 2013 Privacy policies for	USA	Perspective	*4 Letter to editor/commentary*	"The aim of this study is to identify and sketch the policy implications of using HSNS and how policy makers and stakeholders should elaborate upon them to protect the privacy of online health data."	*7 Describe/discuss policy change*
Lindblad 2019 Sweden's learning	Sweden	Conference abstract	*5 Conference abstract*	As new life-changing, yet expensive, therapies for cystic fibrosis (CF) become available, Sweden's stakeholders strive to build a system for structured follow-up and evaluation of new treatments for optimal care and best use of resources.	*2 Describe development of innovation*
Litchman 2019 Twitter analysis	USA	Symposium/ Special Issue	*1 Original research*	" to examine Twitter data to understand how patients, caregivers, and care partners perceive OpenAPS, the personal and emotional ramifications of using	*4 Describe how users perceive the innovations*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				OpenAPS, and the influence of OpenAPS on daily life"	
Litchman 2020 Patient-Driven Diabetes Technologies	USA	Research article	*1 Original research*	"the purpose of this study was threefold. First, examine the #WeAreNotWaiting and #OpenAPS tweets to understand the sentiment (positive and negative) among different stakeholder groups. Second, to examine highly shared photos to understand visual representations of DIY patient-led innovations. Finally, determine the personas who engage in DIY patient-led diabetes technologies activities and conversations on Twitter. This study will provide insight into diabetes-specific DIY patient-led innovations that may influence or inform patient-led efforts in other disease states."	*3 Describe users*
Longacre 2018 Clinical adoption	Sweden	Original paper	*1 Original research*	"This study explored the development, adoption, and integration of a new,	*2 Describe development of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				co-produced mHealth platform (Genia) for the management of pediatric CF in Sweden."	
Ma 2015 Mental disorder recovery	USA	Research article	*1 Original research*	"To test whether social behavior and well-being are also associated in online communities [as they are in real-world communities], we studied the correlations between the recovery of patients with mental disorders and their behaviors in online social media."	*5 Test effect/impact of innovation*
Mader 2015 Influence of	Austria	Conference abstract	*5 Conference abstract*	The aim of this retrospective analysis was to investigate whether we can determine characteristics of adherent (=4 BG values/day on an active day) and non-adherent (<4 BG values/day on an active day) mySugr users	*5 Test effect/impact of innovation*
Marshall 2019 Do-it-yourself	UK	Commentary	*4 Letter to editor/commentary*	"we provide the perspectives of two adults with T1D, the parent of a child with	*4 Describe how users perceive the innovations*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				T1D and three physicians who detail their experience with these systems. These personal and clinical perspectives highlight very clear metabolic and psychological benefits of these systems in real-world settings."	
Melmer 2019 Glycaemic control	Switzerland	Brief report	*2 Short report*	"In the present study, we describe glycaemic control in individuals with type 1 diabetes using OpenAPS. In a subcohort, we analyzed differences in glycaemic control after switching from standard sensor-augmented pump therapy (SAP) to OpenAPS."	*5 Test effect/impact of innovation*
Melmer 2019 In-depth review	Switzerland	Conference abstract	*5 Conference abstract*	The present study evaluated glycemic control and glycemic variability of CGM readings of 80 DIY closed loop users	*5 Test effect/impact of innovation*
Murray 2020 Health Care Provider	USA	Research article	*1 Original research*	"The purpose of this study was threefold: (a) to assess the perceived need among health care providers (HCPs) for a	*7 Describe/discuss policy change*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				comparison fact sheet of FDA-approved and DIY AID technology; (b) to develop an updated and relevant fact sheet of most commonly used FDA-approved and DIY AID technology; and (c) to assess the relevance of content and usefulness of fact sheet to HCPs. This study has the potential to reduce barriers to AID technology uptake by increasing HCP's awareness and understanding of AID options."	
Ng 2020 Evolution of Do-It-Yourself	USA	Research article	*1 Original research*	"the objectives of this study were to identify and describe the different types of patient-designed DIY innovations in the T1D community focused on Nightscout, and to describe the timeline of innovations in comparison with similar features available in commercial products. In addition, we evaluated metrics	*2 Describe development of innovation*

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				related to code use and contributions to open-source code repositories for Nightscout."	
O'Brien 2019 Patient perspectives on	USA	Research article	*1 Original research*	"To examine the patient perspective on the risks and benefits of linking existing data sources for research."	*4 Describe how users perceive the innovations*
O'Connor 2017 The MediStori	Ireland	Conference abstract	*5 Conference abstract*	" The aim for this research project was to gain valuable insights and domain knowledge on how best the toolkit, MediStori, could be utilised to improve integrated care processes and person centred models of care"	*1 Describe the innovation*
O'Donnell 2019 Evidence on	Ireland	Protocol	*3 Protocol*	The overall aim of this study is to establish the empirical evidence base for the clinical effectiveness and quality-of-life benefits of DIYAPS and identify the challenges and possible solutions to enable their wider diffusion.	*5 Test effect/impact of innovation*
Okun 2017 Building a learning	USA	Experience report	*4 Letter to editor/commentary*	"describes the development of the Patient and Caregiver	*2 Describe development of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				Journey Framework and related patient-informed principles for design and measurement created by PatientsLikeMe in partnership with patients and caregivers"	
Okun 2018 DigitalMe: A journey	USA	Commentary	*4 Letter to editor/commentary*	Reports on a partnership with iCarbonX and Digital Life Alliance. "DigitalMe Ignite, a PLM pilot study launched in June 2017, will integrate methods to measure how well an individual's body and mind are doing (health) and how well an individual is living the life she wants (thrive)."	*1 Describe the innovation*
Oliver 2019 Open source automated	UK	Perspective	*4 Letter to editor/commentary*	"we explore some of the ways that a multidisciplinary approach may unlock the potential for open source solutions to be implemented more widely for people with T1DM in a way that is acceptable to all stakeholders, while ensuring sensitivity to	*5 Test effect/impact of innovation*

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				the priorities of existing users"	
Omer 2016 Empowered citizen	UK	Commentary	*4 Letter to editor/commentary*	N/A	*N/A*
Pearson 2011 Potential for electronic	USA	Review	*7 Review*	"This review addresses the use of EHRs in research, the potential of PHRs and online social networking to improve health, and what this means for the future of health outcomes and diabetes research."	*5 Test effect/impact of innovation*
Riggare 2015 Patients organize	Sweden	Personal view	*4 Letter to editor/commentary*	We both have Parkinson's disease and experience a complex array of motor and non-motor symptoms. Here is a glimpse at the invisible work that, in our experience, leads to better care.	*N/A*
Rivard 2020 It's not just	Canada	Original research	*1 Original research*	"we gathered the views of experts in related fields with a focus on how two innovations— Nightscout Project6 25–30 33 and e-NABLE10 13 14 34— impact quality and safety concerns"	*7 Describe/discuss policy change*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Rouholiman 2018 Improving health-related	USA	Protocol	*3 Protocol*	"In the present study, we plan to assess the quality of life of ostomy patients using the Ostom-i alert sensor, a portable, wearable, Bluetooth-linked biosensor that facilitates easier ostomy bag output measurements. We hypothesize that using the Ostom-i alert sensor will result in an improved, ostomy-specific, health-related quality of life as compared to baseline measurement before the use of the sensor."	*5 Test effect/impact of innovation*
Rundle 2018 PatientsLikeMe and atopic	USA	Commentary	*4 Letter to editor/commentary*	"This retrospective analysis looks to characterize the AD patient profile to better assess features of the AD community and appraise PatientsLikeMe data with current AD literature."	*3 Describe users*
Sahama 2012 Impact of the	Australia	Original article	*1 Original research*	"In this paper we propose a framework for multiple profile management of online social networks and showcase a	*2 Describe development of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				demonstrator utilising an open source platform."	
Schroeder 2015 An Innovative Approach	USA	Research article	*1 Original research*	"(1) to identify issues in diabetes management that PatientsLikeMe patient stakeholders find difficult or important in the following domains: accessing diabetes care, communication with providers, medication management, lifestyle behaviors, and personal relationships; (2) to gather an array of patient perspectives that would inform, amplify, and supplement the findings from the in-person stakeholder meeting; and (3) to assess the pragmatic usefulness of online surveys for conducting diabetes research among an SNS population."	*4 Describe how users perceive the innovations, 7 Describe/discuss ethical issues*
Seres 2017 From patient to	USA	Special section "in my own voice"	*8 Special section dedicated to patients*	N/A	*N/A*

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Shaw 2020 The DIY artificial	Switzerland	Commentary	*4 Letter to editor/commentary*	"The question of how doctors should navigate these ethical issues when discussing care with patients needs to be addressed."	*7 Describe/discuss policy change*
Shepard 2020 User and healthcare	USA	Commentary	*4 Letter to editor/commentary*	"to obtain stakeholder perspectives on DIY APS in order to inform the development of guidelines for clinical practice."	*4 Describe how users perceive the innovations*
Smith 2008 PatientsLikeMe: Consumer health	USA	Symposium proceedings	*1 Original research*	"An old research question with new implications for Web developers is this: What language do patients use to describe their conditions? And what are the implications of patient- and consumer-contributed terms for patient- and consumer-oriented information systems?"	*4 Describe how users perceive the innovations*
Torous 2017 Patient-driven innovation	USA	Editorial / Patient Perspective	*6 Editorial*	"in order to educate and inspire others."	*2 Describe development of innovation*
Trevena 2011 PatientsLikeMe and the	Australia	"Perspectives"	*4 Letter to editor/commentary*	N/A	*N/A*
Vaidyam 2020 Patient innovation	USA	Personal perspective	*8 Special section dedicated to patients*	"Highlighting the potential of health software beyond	*2 Describe development of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				smartphones (apps), this case report demonstrates the potential for such software to transition between different devices and hardware toward better serving people. Building off a prior case report where an individual started with an app to track symptoms but found a tally counter more useful [2],here we discuss a case where an app was used at first, followed by a transition to a novel device that proved to be a more comprehensive solution."	
White 2018 Motivations for participation	USA	Original article	*1 Original research*	"to describe individuals' motivations for participation in an online social media community and to assess their level of trust in medical information provided by medical professionals and community members"	*4 Describe how users perceive the innovations*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Wicks 2010 Sharing health-data	USA	Original paper	*1 Original research*	"to describe the potential benefits of PatientsLikeMe in terms of treatment decisions, symptom management, clinical management, and outcomes"	*1 Describe the innovation*
Wicks 2012 Perceived benefits	USA	Original paper	*1 Original research*	"to gather feedback on perceived benefits from use of our online service by people with epilepsy"	*4 Describe how users perceive the innovations*
Wicks 2014 Could digital patient	USA	Commentary	*4 Letter to editor/commentary*	N/A	*N/A*
Wicks 2014 Data donation could	USA	Commentary	*4 Letter to editor/commentary*	N/A	*N/A*
Wicks 2014 Quality of life	USA	Original research article	*1 Original research*	"to describe and contrast data collected through an online community with the broader organ transplant population"	*3 Describe users*
Wicks 2014 Subjects no more	USA	Observations	*1 Original research*	N/A	*N/A*
Wicks 2018 Patient study thyself	USA	Editorial	*6 Editorial*	N/A	*N/A*
Williams III 2019 The PatientsLikeMe Multiple	USA	Original article	*1 Original research*	"This paper examines how the company successfully expanded its platform beyond its flagship ALS community to other	*2 Describe development of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				communities, specifically one for patients with multiples clerosis (MS). It discusses how PatientsLikeMe®used a strategic market segmentation plan inspired by a motivational theory to attract and engage members, while helping change the paradigm of health data privacy in the USA by endorsing a policy of openness."	
Zabinsky 2020 Do-it-yourself	USA	Conference abstract	*5 Conference abstract*	"There have been few studies comparing glycemic outcomes for DIYAPS compared to conventional sensor-augmented pump (SAP) therapy."	*5 Test effect/impact of innovation*
Zisser 2011 Novel methodology	USA	Original article	*1 Original research*	"The FDA believed there was a need for additional bench test data to support the accuracy of the OmniPod at the smallest delivery volume. To address this concern, we implemented method 1 (discussed later), to measure the accuracy	*5 Test effect/impact of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				of the OmniPod using a standard graduated pipette. "	
Årsand 2016 Warning: the do-it-yourself	Norway	Conference abstract	*5 Conference abstract*	"urge the research society, as well as personnel and decision makers in health care, to be more aware of and open toward the opportunities this new situation brings."	*7 Describe/discuss policy change*

*First author affiliation