Appendix 3.3. Extracted data by article

Publication	Innovation	Description of Innovation	Innovators names	Medical condition	Unmet needs
Ahrens 2016	Helminth therapy	the author ingested pig worms in two week intervals during 32 weeks	Sean Ahrens	Chron's disease	Symptom management
Ardolino 2017	Upsee	"a harness that a parent can wear on the legs. A child can stand supported in the harness. The harness have joint sandals for both parent and child so they can walk together"	Debby Elnatan (not from article, through google and youtube)	Trunk hypotonia	"the Upsee would be an easy addition to a home program designed to increase standing and weight shifting in children"."Paleg et al 3 suggested pairing upright posture with others with activities that foster communication and participation."
Barnard 2018	DIYAPS	"In the recent years there has emerged a growing movement of PWD innovators rallying behind the mantra #WeAreNotWaiting, developing "do-it-yourself artificial pancreas systems (DIY APS)," which connect existing insulin pumps and CGM sensor systems and close the loop between these devices through automated insulin dosing controlled by a "homemade" algorithm"	N/A	Diabetes T1	"Artificial pancreas" (also known as "closed-loop" and "automated insulin delivery") systems present a promising therapeutic option for people with diabetes (PWD)—simultaneously improving glycemic outcomes, reducing the burden of self-management, and improving health-related quality of life. ".
Beck 2017	Patients Like Me				
Beckman 2016	Nightscout	"The Nightscout project (represented under the name "CGM in the Cloud" at Facebook and other sources) [1] is an open source, DIY (Do It Yourself) initiative that permits real time access to CGM (Continuous Glucose Monitor) data through personal website and smartwatch and smartphones apps. The goal	N/A	Diabetes T1	"multi-user functionality to share blood glucose (BG) data and work together to achieve healthy glucose control. The typical user interfaces present the current BG value and the historical development of the user's BG values for one single user only".

Appendix 3.3. Extracted data by article

		of the Nightscout project is to allow flexible, remote monitoring of a person with type 1 Diabetes' glucose level using existing monitoring devices. Few solutions offer multi-user functionality to share blood glucose (BG) data and work together to achieve healthy glucose control. The typical user interfaces present the current BG value and the historical development of the user's BG values for one single user only".			
Bedlack 2010	Patients Like Me				
Bedlack 2019	Patients Like Me	"wider inclusion criteria, minimal travel burdens by making most of the visits virtual (via the PatientsLikeMe platform), historical controls(rather than placebo), and results made available in real time." "published our protocol on a website (12) so that PALS all over the world with plans to self-experiment (13) could be empowered to try a new treatment with a sound rationale at reasonable dose and to record their own outcome measures online, albeit outside a traditional trial infrastructure."	N/A	ALS	[Difficulty in accessing and frustration with clinical trials due to restrictive inclusion criteria, incovenience, use of placebo, wait times, and thereby difficulty in accessing new or experimental treatments and low enrollment by PALS in trials. Allows patient to collect own data and share it virtually, reduces aforementioned burdens.] "The results of this study represent a comprehensive answer to questions raised by a large number of patients in response to such a news story." "By posting our IRB-approved protocol on the Internet we empowered a large number of PALS outside the trial, who were likely to self-experiment with alternative therapies (13,14), to test the efficacy of a new compound with a plausible rationale."

Appendix 3.3. Extracted data by article

Ben-Pazi 2018	No name	Sound frequencies in the gamma range modulated in frequency and /or amplitude according to a fixed protocol. These sounds were embedded in background music or nature sounds according to the child's preferences.	Debby Elnatan	cerebral palsy (CP) and disabling hypertonia	Improved motor function
Berry 2019	Jacki Jacket	The jacket is a long-sleeve, soft, cotton, and Polartec® high-performance wicking fabric. The jacket allows the patient to discreetly place drainage tubes in hidden and secure inner pockets to reduce the possibility of dislodgement and pulling. Arm-length Velcro openings in the sleeves allow for easy access when patients return for follow-up appointments that require blood pressure measurement, intravenous access, injections, and/or physical exams.	Cathy McGrath is innovator according to www.patient-innovation.com	Breast cancer	
Blaser 2017	PatientsLikeMe.com				
Borentain 2019	PatientsLikeMe.com				
Bove 2013	PatientsLikeMe.com	Patient-driven innovation (PLM) used by researchers.		Multiple sclerosis	
Bove 2014	PatientsLikeMe.com				
Bove 2016	PatientsLikeMe.com				
Bradley 2016	PatientsLikeMe.com				
Brajovic 2018	PatientsLikeMe.com				
Braune 2019 DIWHY	DIYAPS; AndroidAPS	In DIYAPS, commercially available and approved medical devices such as insulin pumps and continuous glucose monitoring sensors are connected and remotely controlled by systems	Dana Lewis (DIYAPS), Adrien Tappe (Android APS), Bastian Hauck (dedoc, diabetes online community)	Diabetes T1	Glycemic control

Appendix 3.3. Extracted data by article

		using open-source algorithms to automate insulin delivery.			
Braune 2019 Real World Use	DIYAPS		Dana Lewis	Diabetes T1	
Brownstein 2009	PatientsLikeMe.com	Create a PLM OI or bone community.		Osteogenesis imperfecta (OI)	"Treatment is not standardized, often experimental, and frequently involves physical therapy, surgical interventions, and medications." "It is easy to imagine that patients with OI could have improved outcomes with increased knowledge; patients could effectively teach each other how to live better."
Brownstein 2010	PatientsLikeMe.com	Create a PLM OI or bone community.		Osteogenesis imperfecta (OI)	Members could locate other patients with similar circumstances and medical experiences and discuss the profiles, treatment reports, and general health concerns on the forum, private messages, and comments they post on one another's profiles
Castejon 2014	PatientsLikeMe.com				
Chari 2019	PatientsLikeMe.com				
Chesaniuk 2014	PatientsLikeMe.com				
Chiauzzi 2016	PatientsLikeMe.com				
Chiauzzi 2019 Digital Trespass	PatientsLikeMe.com				Not an innovation but the user need is protection of patient privacy (users of PLM and other social media).
Chiauzzi 2019 In search of	PatientsLikeMe.com				
Cleal 2019	DIYAPS		Dana Lewis	Diabetes T1	
DasMahapatra 2017	PatientsLikeMe.com				
DasMahapatra 2018	PatientsLikeMe.com				
De Bock 2019	DIYAPS	"own software algorithms, which when coupled with a continuous		Diabetes T1	glycaemic control,"demonstrated remarkable glycaemic outcomes.3–6

Appendix 3.3. Extracted data by article

		glucose monitor and insulin pump, allow the patient to 'close the loop' or automate insulin deliver"			The limitation to these data is that these individuals are highly motivated and are likely to do well; nevertheless, when compared with their own glycaemic data prior to using the DIY system, time in normal glycaemic range (4–10 mmol/L) improved by 16.4%".
De la Loge 2016	PatientsLikeMe.com	PLM used to track epilepsy patients.		Epilepsy	
De Monestrol 2018	Sweden CF coalition	The work streams aim to develop: clinical guide-lines; clinical decision support; a health information exchange; a patient support system; a national learning network and international collaboration. The group is composed of representatives from all four CF centers, the National Cystic Fibrosis Association, the CF Working Group of the Society of Medicine, the National Quality Registry Development Group, the Patient Support System Development Group, the Chair of the CF Coalition and Coalition advisors. The Group meets monthly to report back from the various work streams and to ensure progress is made towards the mission	Andreas Hager	Cystic fibrosis	stuctured follow-up and evaluation of new treatments for optimal care and best use of resources
Debong 2019	MySugr	a mobile app designed to support patients in the diabetes self-management	Fredrick Debong	Diabetes T1	Diabetes self-management
Dorsey 2016	PatientsLikeMe.com				

Appendix 3.3. Extracted data by article

dosReis 2016	PatientsLikeMe.com				
Eaneff 2017	PatientsLikeMe.com				
Eichler 2016	PatientsLikeMe.com				
Ellis 2013	PatientsLikeMe.com				
Farrington 2016	DIYAPS	patient-designed closed-loop systems		Diabetes T1	Artificial pancreas
Fergus 2017	Upsee	"approach for gait impairments in children through providing increased opportunities for walking while supporting biomechanical alignment"	Debby Elnatan	Cerebral palsy	
Frost 2008 How the social	PatientsLikeMe.com	PALS use PLM to steer investigation of possible treatment.		ALS	"Our users brought new information to us quickly as well as bringing it to themselves, acted on it, and used it to help us develop tools that more effectively show them what they want to know."
Frost 2008 Social uses of	PatientsLikeMe.com	PLM used by PALS to communicate with other PALS		ALS	[Information about other patients' real-life experiences with ALS progression and treatments.]
Frost 2009 Patients like me the case	PatientsLikeMe.com	PLM used by PALS to help with decisions about symptom management technology		ALS	"Although the value of the profile [on PLM] for patients is not yet well understood, we can infer some value exists when patients nudge one another to create them."
Frost 2011 Patient-reported outcomes	PatientsLikeMe.com				
Grande 2019 Empowering young people	Upstream dream, Genia	"Core functionality of the mPSS were operationalized within a learning collaborative associated with the Lund Pediatric Cystic Fibrosis clinical microsystem. This meant that clinicians, researchers,	Andreas Hager	Juvenile Idiopathic Arthritis	"being in the center of the decision-making process"

Appendix 3.3. Extracted data by article

		family members, and cystic fibrosis patients were involved in iterative cycles of change from inception to completion of the mPSS. Key functionalities developed within the app were inspired and optimized by patients, viewed as experts in their disease and experience of care"			
Griffiths 2015 The impact of	PatientsLikeMe.com	[Health social networks including PLM]		Various	[Users of health-related social networking sites having effect on health-care policy via connecting with others they might not otherwise encounter.]
Has 2019 Medication Adherence Prediction	PatientsLikeMe.com				
Hamed 2019 Mobility assessment using	PatientsLikeMe.com				
Heywood 2014 Straight talk with	PatientsLikeMe.com		Jamie Heywood		
Hixon 2015 Patients optimizing epilepsy	PatientsLikeMe.com				
Hng 2018 Appearence of do-it-yourself	DIYAPS	"A closed-loop system requires a processor capable of receiving CGM sensor data, and algorithms to control the rate of insulin delivery through a compatible insulin pump. This results in dynamic basal rates in response to changing glucose levels."		Diabetes T1	artificial pancreas, "reduction in psychosocial burden and improved glycaemic control"

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Hussain 2020 Part I	DIYAPS		Dana Lewis	Diabetes	
Hussain 2020 Part II	DIYAPS		Dana Lewis	Diabetes	
Jackson 2013 Feasibility of a	PatientsLikeMe.com				
James 2020 Characteristics, Symptom Severity	PatientsLikeMe.com				
Janssen 2016 A painted staircase	no name specified mentioned as "FOG with three dimensional (3D); “illusion of a 3D cue…to alleviate FOG (freezing-of-gate)”	"An example of a non-pharmaceutical intervention is the use of visual cues, e.g. stationary lines pasted at fixed distances onto the floor," or laser lines projected onto the floor, allowing patients to take externally guided steps [2]. A subgroup of patients only shows a selective improvement of FOG with three-dimensional (3D) visual cues, but not with two-dimensional (2D) cues [3	Mileha Soneji	Parkinson’s disease	mobility, "allowing patients to take externally guided steps "
Janssen 2016 Response to			Mileha Soneji	Parkinson’s disease	
Katic 2015 New approach for	PatientsLikeMe.com				
Kear 2015 Partnering with patients	PatientsLikeMe.com				
Kelman 2016 Communicating laboratory	PatientsLikeMe.com				
Kendall 2017 T1resources.uk	T1resources.uk	Self-care support	Mike Kendall	Diabetes T1	“The most powerful thing for me about managing my condition is knowing I’m not the only one and

Appendix 3.3. Extracted data by article

					T1resources.uk not only proves that, but then signposts me to information and other sites where I can get the help, support and advice I need. I'm amazed that no-one had ever thought to put together this kind of resource before, but I'm very glad it exists now."
Khan 2019 Patient survey of	PatientsLikeMe.com				
Klee 2018 An intervention by	Webdia	"Webdia is a patient-designed do-it-yourself mHealth app created by J.L.M. after diagnosis of T1DM in his 10-year-old daughter. . The mobile application was written with jQuery Mobile (JS Foundation, San Francisco, CA), an HTML5-based user interface system, and interacts with a MYSQL (Oracle Corporation, Redwood Shores, CA) database. By creating an application that communicated with a remote server, he wanted to improve his daughter's autonomy and facilitate data ex- change within the family."	Jean-Luc Mando	Diabetes T1	Monitoring "By creating an application that communicated with a remote server, he wanted to improve his daughter's autonomy and facilitate data exchange within the family."
Kontovounisios 2018 The ostom-i- alert	Ostom-i-alert	"The Ostom-iTMAlert Sensor (11 Health and Technologies Limited, Borehamwood Herts UK) is a CE-marked (Con- formité Européenne, indicating conformity with health, safety and environmental protection standards for products sold within the European Economic Area) and	Michael Seres	Stoma	Monitoring "The volume of stoma output is recorded, and alerts can be set by patients to prevent bag overflow and leakage"

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		FDA (Food and Drug Administration)-approved medical device. It uses a flexible 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"			
Lawlor 2017 Developing integrated care	unclear, referred to as "patient driven collaborative initiative"	"22q Ireland Support Group as a patient organisation, with the support of an independent research consultant, initiated dialogue with a large group of specialist clinicians from a range of health disciplines and institutions" "the establishment of a core patient-clinician working group who have collaboratively developed a comprehensive business case to seek political support, statutory and research funding for the development of the multidisciplinary networked model of integrated care".	Anne Lawlor	22q11 Deletion Syndrome	Care coordination and cost control. "Over 180 physical, functional and psychological associations have been described. The cost of care to families and to the health system is high
Lebental 2011 Patient perception	Omnipod	"One of the more recent advancements in CSII technology is the OmniPod Insulin Management System (Insulet Corp., Bedford, MA), a wireless ‘‘smart pump’’ composed of two components, the OmniPod and a Personal Diabetes Manager (PDM). The OmniPod is a disposable, self-enclosed insulin pump with automated cannula insertion that attaches directly to	John Brooks III	Diabetes T1	"smart pumps’’ offer convenience features (i.e., higher-resolution screens, custom safety alarms, remote control, integration with blood glucometer, and interface to personal computers).1–5 In addition, different customized basal programs—temporary basal, extended and combination bolus, ‘‘insulin on board,’’ and bolus calculators—allow more precision in insulin delivery"

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		the body. The handheld PDM operates the OmniPod by remote control, with customized preprogrammed insulin"			
Lee 2016 A patient-designed	DIYAPS	“The father (who is a software programmer) began developing a computer code that would enable him to access the blood glucose readings from the CGMS receiver to the computing cloud through a smartphone. With the data in the cloud, the blood glucose levels could be viewed by the parents from anywhere to provide a continuous monitoring solution"	Nightscout community	Diabetes T1	"With the data in the cloud,the blood glucose levels could be viewed bythe parents from anywhere to provide a continuous monitoringsolution"
Lee 2017 Real-world use	DIYAPS	"The Nightscout Project started when the father of a 4-yearold boy with type 1 diabetes hacked into his son’s FDA approved continuous glucose monitoring (CGM) system, uploading sensor glucose values to the Internet through an Android phone. This enabled him to access real-time sensor glucose data on personalized web-based, mobile, and wearable applications that he designed"	Nightscout community	Diabtetes T1	"continuous glucose monitoring (CGM) system, uploading sensor glucose values to the Internet through an Android phone. This enabled him to access real-time sensor glucose data"
Lewis 2015 How a DIY	Not reported	they built a “human in the loop” decision-assist system that supports a pa-tient with diabetes by re-calculating diabetes data (BG from CGM; patient-entered insulin and carbohydrate information) every 5 minutes to produce accurate predictions and	Dana Lewis, Scott Leibrand	Diabetes T1	predict and get warnings of expected BG levels

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		earlier warning of expected BG levels			
Lewis 2016 Real-world use	DIYAPS	"self-built hybrid closed loop systems by pairing small computing hardware, open source software (OpenAPS), and existing diabetes devices (continuous glucose monitors [CGMs] and older insulin pumps)".	Dana Lewis	Diabetes T1	"It has allowed patients and caregivers remarkable improvements in quality of life due to increased time in range, uninterrupted sleep, and peace of mind"
Lewis 2017 Automatic estimation	Autotune	Insulin dosing and carb data, glucose data from CGM, and pump profile settings are used to calculate expected blood glucose impact (BGI) for each glucose value. Each glucose value is then categorized as being most attributable to basal, ISF, or carb sensitivity factor (CSF=ISF/carb ratio), and used to calculate adjustments to basals, ISF, and CSF. For each hour, total BGI deviations and necessary adjustment in basal to bring deviations to 0 are calculated; 20% is applied to the previous 3 hours' basals. Median deviation for entire day's ISF-attributed data and necessary adjustment in ISF to bring the median deviation to 0 are calculated; 10% is applied. Total BGI deviations during observed carb absorption are calculated and compared to total carb intake to calculate new CSF; 10% is applied to the carb ratio.	Dana Lewis	Diabetes T1	Automatically tuning insulin pump basal rates, ISF, and carb ratios

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Lewis 2018 Detecting insulin	Autosense	Autosens analyzes each CGM data point for 24 hours, comparing observed change to expected impact from insulin. Autosens calculates the deviation for the median of the last 8 and 24 hours of CGM data points and determines the sensitivity ratio (SR) required to neutralize the median deviation.	Dana Lewis	Diabetes T1	calculate changes in insulin needs
Lewis 2018 Improvements in A1C	DIYAPS	[not in data table]	Dana Lewis	Diabetes T1	
Lewis 2018 Setting expectations	DIYAPS	Unclear	Dana Lewis	Diabetes T1	Closed loop system
Lewis 2019 Characterization of	DIYAPS, CGM data from 19 T1D individuals using a DIY closed loop APS in the OpenAPS Data Commons				
Lewis 2019 History and perspective	DIYAPS	"The first DIY closed loop system contained basic components of a mini-computer to hold the algorithm; a radio stick to communicate with the pump using its proprietary 915MHz radio protocol; a battery; and an existing insulin pump and CGM. "	Dana Lewis	Diabetes T1	Closed loop system
Li 2013 Privacy policies for	PatientsLikeMe.com	N/A	N/A	N/A	N/A
201Lindblad 2019 Sweden's learning	Sweden's CF Coalition	N/A	Andreas Hager	N/A	N/A

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Litchman 2019 Twitter analysis	DIYAPS	"OpenAPS focuses on facilitating access to artificial pancreas technology through do-it-yourself (DIY), patient-developed innovations that bridge communication between existing insulin pumps and continuous glucose monitors (CGM).1 OpenAPS and related DIY systems must be self-built, are not regulated or approved by the Food and Drug Administration, and are not managed by any commercial entity."		Diabetes T1	"to make diabetes management easier, more predictable, and less time-consuming"
Little 2013 Quantifying short-term dynamics	PatientsLikeMe.com				
Longacre 2018 Clinical adoption	Upstream dream, Genia	"Genia is a mobile iOS PSS created by a Swedish-based company Upstream Dream to optimize consensus-building in pediatric care by improving communication between patients and clinical teams, fostering disease self-management and aligning patients' goals with clinical treatment plans (see Figure 1). By doing so, Genia aims to facilitate timely, meaningful, and appropriate clinical care and ultimately to improve patients' quality of life. Through Genia,patients (or parents, depending on the patient's age) can record daily health	Andreas Hager	Cystic fibrosis	"co-ordinated care "

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		observations and symptoms between visits (eg, physical activity or gastrointestinal problems), track medications, and complete previsit reports, including treatment preferences and goals, prior to a clinical appointment. This patient-reported information allows patients to document their disease activity and preferences in the real-time between clinical visits (see Figure 2). Patient data are then integrated into the National CF Quality Registry (ie, a registry established in 1992, encompassing all 21 regional health care systems or payors in Sweden, which longitudinally follows every CF patient in Sweden) and the care flow within the clinical setting. Clinical providers—including physicians, physiotherapists, and others—are able to review patients' previsit reports as an Adobe PDF file in the CF registry prior to the clinical visit to better inform the visit and foster opportunities for shared decision making and goal setting. Patients and providers also use Genia to collaboratively document agreed upon therapeutic decisions, actionable steps, and other information derived during the clinical visit. Genia thus aims to foster patient self-			

Appendix 3.3. Extracted data by article

		management, build trusted patient-provider relationships, and increase compliance with mutually agreed upon care plans. "			
Lopez 2016 Understanding preferences for	PatientsLikeMe.com				
Ma 2015 Mental disorder recovery	PatientsLikeMe.com	[PLM social network data to track correlation between activity and mental health recovery.]		Mental health disorders	"For instance, patients may be able to discuss, via online media, their private problems without fear of prejudice or discrimination (Hsiung, 2000). Furthermore, online social media may play a complementary role to traditional mental health services and help patients understand their conditions more and take better control over their diseases and behaviors (Frost & Massagli, 2008). For example, while many treatment decisions are still made based on physicians' empirical judgments that might not have solid supporting evidence, information sharing via healthcare social media may allow patients to perceive their diseases from other patients' point of view, do their own research online, and make their own informed decisions on how to manage their diseases"
Mader 2015 Influence of	MySugr	mySugr Companion, a FDA registered and a CE-marked class I medical device, was developed to make this task more appealing. Patients can enter data on BG,	Fredrik Debong	Diabetes T1	Keeping a diabetes diary is thought to be beneficial both for diabetes self-management and therapy adjustment by health care professionals. However, a high number of patients indicate

Appendix 3.3. Extracted data by article

		meal (including images), insulin, exercise, mood			that keeping a structured paper based diabetes diary is a burden.
Marshall 2019 Do-it-yourself	DIYAPS	"An artificial pancreas provides variable automated insulin doses in response to changes in interstitial glucose and other variables, some of which require manual input."	#WeAreNotWaiting community	Diabetes T1	"optimal automated diabetes care"
McCaffrey 2018 Understanding 'Good Health	PatientsLikeMe.com				
McCaffrey 2019 Measurement of Quality	PatientsLikeMe.com				
McCarrier 2016 Concept Elicitation Within	PatientsLikeMe.com				
McNaughton 2019 Patient attitudes toward	PatientsLikeMe.com				
Melmer 2019 Glycaemic control	DIYAPS	"Do-it-yourself (DIY) artificial pancreas systems represent open source closed-loop-systems that aim to continuously and adequately meet physiologic insulin requirements in patients with diabetes. DIY systems consist of a compatible insulin pump, a continuous glucose monitoring (CGM) sensor and a third-party device holding a system- specific algorithm. The third-party device (a microcomputer or a smartphone) bridges communications between the algorithm, the insulin pump and	#WeAreNotWaiting community	Diabetes T1	"Do-it-yourself (DIY) artificial pancreas systems represent open source closed-loop-systems that aim to continuously and adequately meet physiologic insulin requirements in patients with diabetes."

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		the CGM sensor." [...] "OpenAPS uses a small microcomputer ("rig") to bridge communications with the insulin pump and the CGM sensor. The rig also contains the OpenAPS algorithm, a single source algorithm released by the OpenAPS project team. OpenAPS released two main versions of the algorithm: Oref0, which calculates a temporary basal rate and aims to maintain blood glucose within an individual target range between meals and over- night. Oref01 adds additional features that perform meal boluses without user input. Every OpenAPS user is enabled to alter the code under their own responsibility."			
Melmer 2019 In-depth review	OpenAPS Data Commons	Many using DIY closed loop systems have chosen to donate their data to a shared, anonymized data repository called the "OpenAPS Data Commons."	Dana Lewis, Scott Leibrand	Diabetes T1	
Moreira 2018 Measuring Relevant Information	PatientsLikeMe.com				
Nakamura 2012 Mining online social	PatientsLikeMe.com				
Nyman 2020 Characteristics and Symptom	PatientsLikeMe.com	PLM as an online community comparable in many characteristics to the general SLE		Systemic Lupus Erythematosus (SLE)	

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		community (at least the US SLE population).			
O'Brien 2019 Patient perspectives on	PatientsLikeMe.com	"Development and testing of patient-reported outcomes proceeds through the PLM Open Research Exchange, an online platform tied to the PLM research network [16]."		Various	
O'Connor 2017 The medistori	MediStori	"The MediStori has a dual purpose – it is a paper-based PHR and it is a self-management toolkit." [...] "MediStori aimed to keep all of family's information together, from birth to end-of-life; could help a patient or carer communicate relevant health information at the point of care in both primary and acute settings (a critical component for integrated care), and assist in the self-management of conditions in the home."	Olive O'Connor	Various	"The founder of this project, a patient and carer to three children with differing conditions, ascertained through lived experiences, that most acute health care settings were fragmented – many focusing on one disease at a time, meaning most often, a holistic viewpoint was not considered, thus impacting on issues such as comorbidity, medication reconciliation and disconnected health information." [...] "patients all had similar issues"
O'Donnell 2019 Evidence on	DIYAPS		Dana Lewis (DIYAPS), Adrian Tappe (Android APS), Tebbe Ubbe (Android APS), Bastian Hauck (dedoc, diabetes online community), Saskia Wolf (dedoc, diabetes online community)		
Okun 2017 Building a learning	PatientsLikeMe.com			Various	

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Okun 2018 DigitalMe: A journey	PatientsLikeMe.com				
Omer 2016 Empowered citizen	DIYAPS	"the OpenAPS project [8], which provides the instructions and blueprint of a DIY patient-built APS. "	Timothy Omer	Diabetes T1	"to keep track" of their blood sugar levels, treatments and medication calculations
Pearson 2011 Potential for electronic	PatientsLikeMe.com			Diabetes; various	
Ranney 2016 Correlation of digital	PatientsLikeMe.com				
Rifkin 2019 Treatment satisfaction and	PatientsLikeMe.com				
Riggare 2015 Patients organize	No name	Sara Riggare has created a functional prototype of a smartphone app for collecting data on drug intake and wellbeing to provide data for shared decisionmaking during the visit with the neurologist. Patients would use it for about a week before the visit	Sara Riggare	Parkinson's disease	Time with clinicians is limited, so we prioritise collecting, organising, and communicating information about our evolving health status
Rodriguez 2019 Measuring compassionate healthcare	PatientsLikeMe.com				
Rouholiman 2018 Improving health-related	Ostom-i-alert	"The Ostom-i alert sensor is a wearable device intended to make life easier for patients with ostomy bags by allowing for easier output measurements and anticipation of bag changes via a	Michael Seres	Inflammatory bowel disease	"output measurements and anticipation of bag changes "

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		Bluetooth connection to their mobile smart phone."			
Rundle 2018 PatientsLikeMe and atopic	PatientsLikeMe.com			Atopic dermatitis	
Sahama 2012 Impact of the	PatientsLikeMe.com	[Integrating several social networks, including PLM, into one open source platform.] "The result of the research enables a user to create and manage an integrated profile and share/synchronise their profiles with their social networks." / "designing a platform named Multiple Profile Manager (MPM) that enables users to create and control their own single profile, and more importantly share partial aspects of the profile with various social networks in the Onesocialweb5 (OSW) federation."		N/A	"...many web users need to manage many disparate profiles across many distributed online sources. Maintaining these profiles is cumbersome, time consuming, inefficient, and leads to lost opportunity."
Schroeder 2015 An Innovative Approach	PatientsLikeMe.com			Diabetes T1	Rapid gathering of stakeholders' research preferences.
Seres 2017 From patient to	Ostom-i-alert	"Our system is designed for both inpatients and outpatients, and consists of a detachable and reusable sensor that adheres to the outside of any pouch (Figure 1) .The sensor detects output volume and sends it in real time to your mobile phone or tablet (Figure 2) . The patient facing app allows patients to set multiple alerts about when their pouch is filling. Patients can also track their	Michael Seres	Inflammatory bowel disease	to know when stoma bag was filling up, avoid spills from stoma

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		hydration and food intake as well as their physical activity. "			
Simacek 2017 What Do Ovarian	PatientsLikeMe.com				
Simacek 2018 Patient engagement	PatientsLikeMe.com				
Simacek 2018 The Impact of	PatientsLikeMe.com				
Simacek 2019 Patient perceptions of	PatientsLikeMe.com				
Smith 2008 PatientsLikeMe: Consumer health	PatientsLikeMe.com	[As part of the structure of PLM, members contribute to] "a semi-structured alphabetical list which patients can use as an assist for future symptom reporting. It also permits comparison with symptoms reported by other people. The terms become “live” immediately, but are periodically reviewed for normalization as necessary."		ALS, MS, Parkinson's disease (PD)	[In this paper, the user need is a shared vocabulary:] "Web 2.0 privileges augmented content over semantic architecture; for example, a user-generated taxonomy called a folksonomy can be established through the construction and collaboration of user-generated index terms, or tags (such as those at Amazon.com, Flickr, Technorati, and Craigslist). The word folksonomy, coined in ironic opposition to taxonomy, was first used in 2006. Folksonomy facilitates networking of related concepts and related interests, thus creating related people; in Web 2.0, “seeing what other users are thinking about is as much a part of the site as finding what you need.”"

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Thorley 2018 Understanding How Chorea	PatientsLikeMe.com				
Tonozzi 2018 Pharmacogenetic profile and	PatientsLikeMe.com				
Tran 2014 Adaptation and validation	PatientsLikeMe.com				
Trevena 2011 PatientsLikeMe and the	PatientsLikeMe.com				
Turner 2010 Concordance between site	PatientsLikeMe.com				
Venkataraman 2014 Virtual visits for Parkinson	PatientsLikeMe.com				
White 2018 Motivations for participation	CGM in the cloud	"CGM in the Cloud is a private Facebook group that was originally created in 2014 with the purpose of sharing information about Nightscout, a do-it-yourself (DIY) mobile technology system for remotely displaying blood glucose values from a continuous glucose monitoring (CGM) system. The original computer code for Nightscout was developed by the father of a four-year-old boy with type 1 diabetes who hacked into his son's FDA-approved CGM, to upload glucose values to the Internet through an Android phone, providing real-time access	CGM in the cloud community	Diabetes T1	"continuous glucose monitoring"

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		to blood glucose data on webbased, mobile, and wearable applications. He shared his code with a community of other interested individuals which led to the creation of the Nightscout project, an informational website (http://www.nightscout.info/) with instructions and links to the open source code, as well as the formation of the CGM in the Cloud private Facebook group, permitting"			
Wicks 2008 ALS patients request	PatientsLikeMe.com				
Wicks 2009 Measuring function in	PatientsLikeMe.com	Use PLM to extend the ALSFRS-R by developing and piloting new items.		ALS	"Although a valuable instrument for clinical trials, the ALFRS-R suffers a relative lack of sensitivity in advanced stages of disease. Using a patient-centered approach we have suggested a number of additional items to add sensitivity at the floor level."
Wicks 2009 Pathological gambling amongst	PatientsLikeMe.com				
Wicks 2010 Sharing health-data	PatientsLikeMe.com			"amyotrophic lateral sclerosis [ALS], Multiple Sclerosis [MS], Parkinson's Disease, human immunodeficiency virus [HIV], fibromyalgia, and mood disorders"	"information exchange between patients"... "understand and share information about their condition"

Appendix 3.3. Extracted data by article

Wicks 2011 Accelerated clinical discovery	PatientsLikeMe.com			ALS	[Tracking self-administered experimental use of potential disease therapies.] "There are a number of benefits to systematically studying patients' self-experimentation. First, it is important to respect patients' autonomy and their decisions; helping them participate in systematic evaluations may increase scientific literacy. Second, there is an obligation to collect data on the safety of self-experimentation. Unproven treatments might have substantial safety concerns, and risks to patients may be increased without a way to report safety issues. Finally, there is the chance that something (i.e., off-label usage, a change in dosage, delivery route or combination with other treatments) might actually be shown to be efficacious, leading to further study."
Wicks 2011 Use of an	PatientsLikeMe.com	Used PLM to develop a questionnaire ("MS-TAQ, a rating scale that quantifies the barriers to adherence, side effects, and coping strategies experienced by MS patients")		MS	"A recent editorial pointed out that the "core issue of adherence" is identifying the reasons why patients have decided to be nonadherent, and that much of the literature fails to illuminate the spectrum of behavior between perfect compliance and nonadherence [25]."
Wicks 2012 Patient assessment of	PatientsLikeMe.com				
Wicks 2012 Perceived benefits	PatientsLikeMe.com	"PatientsLikeMe is a Web-based application where members explicitly choose to share detailed		Epilepsy	"information exchange between patients"

Appendix 3.3. Extracted data by article

		computable data about symptoms, treatments, and health in order to learn from the experience of others and improve their outcomes. These data are presented back to members as individual-level graphical health profiles and aggregated into reports accessible on the site. Members can discuss these data sets either within a group forum or individually through private messages. The resources on the site are designed to help members answer the question: "Given my status, what is the best outcome I can hope to achieve, and how do I get there?"'			
Wicks 2012 Reassessing received wisdom	PatientsLikeMe.com				
Wicks 2012 The multiple sclerosis	PatientsLikeMe.com	[Used PLM to recruit patients for cognitive interviews and piloting of revised MSRS]		Multiple Sclerosis	
Wicks 2014 Could digital patient	PatientsLikeMe.com			[Mentions: ALS; RA; breast cancer]	"By harnessing online patient communities it is possible to recruit a representative population of dozens or even hundreds of patients to provide qualitative and quantitative feedback at each phase of the trial recruitment process."
Wicks 2014 Data donation could	PatientsLikeMe.com			[Mentions ALS]	

Appendix 3.3. Extracted data by article

Wicks 2014 Measuring the burden	PatientsLikeMe.com				
Wicks 2014 Quality of life	PatientsLikeMe.com			Organ transplant recipients	"even after a successful transplant, patients face medical and personal challenges such as monitoring their health, adhering to medication, and coping with emotions related to their transplant such as guilt, fear, and responsibility, data that are not gathered easily—technology may provide one solution."
Wicks 2014 Subjects no more	PatientsLikeMe.com			ALS	
Wicks 2015 Preferred features of	PatientsLikeMe.com				
Wicks 2015 Spotlight: Patient centred	PatientsLikeMe.com				
Wicks 2016 Getting stem cell	PatientsLikeMe.com				
Wicks 2016 The real-world	PatientsLikeMe.com				
Wicks 2018 Patient study thyself	PatientsLikeMe.com			[Mentions: ALS; PD; diabetes]	
Wicks 2019 A Modular Health-Related	PatientsLikeMe.com				
Wild 2018 Validation of the	PatientsLikeMe.com				
Williams III 2019 The PatientsLikeMe Multiple	PatientsLikeMe.com	[Describes business model used by PLM to launch the PLM MS community.]		MS	

Appendix 3.3. Extracted data by article

Zisser 2011 Novel methodology	OmniPod and Tidepool	"The OmniPod Insulin Management System (Insulet, Bedford, MA) is currently an integral part of the Artificial Pancreas Project sponsored by the Juvenile Diabetes Research Foundation. The artificial pancreas system (APS) is a system for automating closed-loop glucose control, comprising a glucose sensor, a controller/algorithm, human user interface, and an insulin pump."	John Brooks III	Diabetes T1	Glucose control
ÅRsand 2016 Warning: the do-it-yourself	Nightscout	"the Nightscout project, the CGM in the Cloud Facebook group (20.141 members, September 2016), have brought diabetes specific solutions to patients' doors."		Diabetes	Glucose control
Oliver 2019 Open source automated	DIYAPS	"Do-It-Yourself (DIY) automated insulin delivery (AID) solutions use continuous glucose sensors, open source software running on a smartphone, and insulin pumps to create systems that deliver insulin continuously in response to changes in subcutaneous glucose. The algorithm code is available to download from freely available software development platforms such as GitHub which host non-executable code. Implementation of the systems is supported by on-line guides, peer support from expert users and developers, and		Diabetes T1	"systems that deliver insulin continuously in response to changes in subcutaneous glucose"

Appendix 3.3. Extracted data by article

		in some cases, at DIY AID meetings."			
Rivard 2020 It's not just	Nightscout	"Nightscout is a cloud-based software that enables the continuous monitoring of glucose (CGM) levels in real time for children with type 1 diabetes. The Nightscout technology was developed by CGM users with the collaboration of an online community of patients, their parents and healthcare providers, all of whom share their knowledge and time on a volunteer basis."		Diabetes T1	"Managing type 1 diabetes requires a precise combination of insulin injections and the consumption of carbohydrates. A proper monitoring of glucose levels diminishes the risks of complications related to the disease."
Shaw 2020 The DIY artificial	DIYAPS	"They consist of an insulin pump that can alter the amount of insulin delivered from moment to moment in response to the interstitial glucose measured by a continuous glucose monitor"		Diabetes T1	
Shepard 2020 User and healthcare	DIYAPS	"open-source APS technology through patient-built systems, also known as "do-it-yourself" artificial pancreas systems"		Diabetes T1	"the development of such sophisticated technology and the associated rigorous clinical validation and regulatory process aimed at demonstrating safety and efficacy are lengthy and delay commercial availability. Frustrations about the lack of access to these novel devices"
Torous 2017 Patient-driven innovation	No name	"he needed data to measure the number of hallucinations experienced per day during the time he was changing his medication."	Spencer Roux	Schizophrenia	"Spencer wanted to be able to quantify the effects of this new medication."

Appendix 3.3. Extracted data by article

Vaidyam 2020 Patient innovation	No name	"The Nordic Thingy prototyping platform has numerous sensors not available in a smartphone that are able to achieve a high fidelity of measurement recording. The device was preloaded with a long-term evolution (LTE) data plan. The sensors include the following: LTE, Bluetooth, Wi-Fi, near-field communication (NFC), button, temperature, humidity, air quality, air pressure, ambient color, ambient light, high-g accelerometer, low-power accelerometer, global position system (GPS), digital microphone, radio frequency (RF) frequency (RF) antenna, barometer, altitude, 9-axis motion tracker. It also has a multicolor light emitting diode (LED) and digital buzzer (a low-quality speaker) for responding to the user if necessary."	Spencer Roux	Schizophrenia	"Seeking to constantly improve his condition and curious about the impact of various environmental aspects on his mental health, SR sought to quantify such environmental aspects."
Zabinsky 2020 Do-it-yourself	DIYAPS			Diabetes T1	
Burnside 2020 Do-it-yourself	DIY AID (Do-it-yourself automated insulin delivery)	This article has a broad discussion of DIY APS systems and their potential. "The advent of capable smartphones and accurate continuous glucose monitoring systems has allowed motivated individuals with type 1 diabetes to develop their own software algorithms which allow these devices (including insulin pumps) to “talk” to one another,	Mentions Dana Lewis as initial Artificial Pancreas System (APS) innovator who launched Open Artificial Pancreas System (OpenAPS) movement; article discusses extension of DIY automated	Diabetes T1	Continuous glucose monitoring and regulation of insulin delivery; "Such a system has the potential to reduce the cognitive burden associated with laborious diabetes tasks, hence improving quality of life for those living with type 1 diabetes."

Appendix 3.3. Extracted data by article

		fashioning the so-called DIY artificial pancreas system (APS) or “closed loop” system."	insulin delivery (AID) technology to include AI and ML.		
Crabtree 2019 DIY artificial pancreas	DIYAPS (artificial pancreas systems)	"do-it-yourself artificial pancreas system (DIY APS) describes the automated insulin delivery closed-loop systems developed by the diabetes community, often referred to as ‘OpenAPS’, although this term actually only refers to one of many specific types of DIY APS."	OpenAPS: Mentions Ben West, Scott Leibrand and Dana Lewis, as innovators of original APS; Loop: Nate Racklyeft and Pete Schwamb; Android APS: Milos Kozak and Adrian Tappe	Diabetes T1	Continuous glucose monitoring and regulation of insulin delivery; "Managing type 1 diabetes on a daily basis is a labour-intensive process; it has been estimated that using DIY APS can save up to one day per month in time." "Users of DIY APS report the single biggest improvement is the ability to have an uninterrupted night’s sleep and to wake up with the glucose level in range.4,6 Users of the system have describe it as ‘life changing’;”
Dowling 2020 Do-it-yourself closed-loop	DIY closed-loop systems for managing type 1 diabetes	"A DIY closed-loop involves the use of continuous glucose monitoring (CGM; or flash glucose monitoring with the addition of hardware that allows conversion to real-time CGM), an algorithm that calculates insulin doses, a communication device and an insulin pump. Together, these systems automatically adjust basal rates and bolus doses in response to CGM values. In simple terms, as blood glucose rises, the system automatically delivers more insulin, and as it drops, the system delivers less."		Diabetes T1	Continuous glucose monitoring and regulation of insulin delivery; "Diabetes technology systems can be seen as an attractive solution to the relentlessness of th[e] day-to-day burden [of diabetes management]."
Jennings 2020 Do-It-Yourself Artificial Pancreas	DIYAPS	"DIY APS use open-source software to automate insulin delivery (eg, OpenAPS,10 AndroidAPS,11 or Loop12). Each		Diabetes T1	"The use of complex technologies such as CSII and CGM can offer improved metabolic benefits and QoL for those with T1D.38 However, the training

Appendix 3.3. Extracted data by article

		of these systems uses algorithms to continually collect and analyze data on glucose, insulin, and food to predict future glucose levels. Commands are issued via the insulin pump to adjust insulin delivery with reference to the programmed glucose target levels and other personalized settings. This information is continuously fed back into the system where it is analyzed to make future adjustments."			required, time taken for continuous self-management, and decision making with these technologies can also cause a burden that forms a barrier to achieving favorable metabolic and psychological outcomes.38 Artificial pancreas systems that can constantly adapt to changing physiology and activities for PWD offer great advantages." "Respondents' motivations for using DIY APS were to achieve better overall glycemic control, to reduce short- and long-term complications, to alleviate the burden of diabetes, and to improve sleep for PWD and their caregivers."
Kublin 2020 The Nightscout system	Nightscout	"Nightscout is a non-commercial do-it-yourself (DIY) system…operates on open-source software, which means it can be continuously updated. The idea of the project is to give authorised users online access to data on continuous monitoring of glucose in interstitial fluid."		Diabetes T1	[CGM (continuous glucose monitoring) systems] "allow patients with diabetes easier and continuous access to real-time data on their glucose levels." Nightscout helps with CGM in younger patients: "In addition, children without parental control are more vulnerable to pressure from their social environment and are more inclined to ignore therapeutic recommendations. The Nightscout project was initiated to facilitate glucose monitoring by caregivers of people with diabetes mellitus [7]."
Lemieux 2020 Do-It-Yourself Artificial Pancreas	DIYAPS	"Do-it-yourself artificial pancreas systems (DIY APS) use open-source software to deliver insulin in an automated fashion."		Diabetes T1	"Despite considerable effort, few pregnant women with type 1 diabetes achieve the tight glycemic control required in pregnancy."

Appendix 3.3. Extracted data by article

Litchman 2020 Patient-Driven Diabetes Technologies	OpenAPS (and other DIY systems such as Nightscout)	"Nightscout was developed to provide remote monitoring of CGMs, but has expanded to include a series of real-time monitoring and retrospective data analysis tools that can display data from multiple kinds and brands of diabetes devices.5 OpenAPS is a movement around facilitating access to basic artificial pancreas (APS) technology, primarily driven by the development of an open source “do-it-yourself” (DIY) version of a hybrid closed loop, using existing pumps, CGM, and off the shelf hardware alongside an open-source community-developed algorithm to automate insulin dosing"	Dana Lewis (originator of OpenAPS) is an author	Diabetes T1	"Therefore, out of necessity, patients experiment with different doses of insulin or bolusing techniques (ie, extended boluses or “super boluses”) to effectively manage their diabetes."
Murray 2020 Health Care Provider	"Do-it-yourself automated insulin delivery systems (eg, OpenAPS, AndroidAPS, Loop, and Omnipod Loop)"	"Do-it-yourself automated insulin delivery systems (eg, OpenAPS, AndroidAPS, Loop, and Omnipod Loop) are open source software programs available through a coding process that can be downloaded or “built” as an application by the patient (using instructions readily available online). Once built, these applications can be deployed for use on one’s phone or minicomputer, with the end result of automating an insulin pump’s temporary basal rates (eg, Medtronic Minimed or Omnipod pumps). This automation of		Diabetes T1	[Reduces T1D care burden:] "an effective, affordable, and customizable solution for diabetes management"

Appendix 3.3. Extracted data by article

		temporary basal rates is guided by glucose rise and fall."			
Ng 2020 Evolution of Do-It-Yurself	Nightscout	"It started in 2013 when the father of a four-year-old child with newly diagnosed type 1 diabetes (T1D) recognized a need to monitor his child's blood glucose (BG) levels in real time while away at school.1 He developed computer code that would send his child's BG readings from a Food and Drug Administration (FDA)-approved continuous glucose monitoring (CGM) system to the computing cloud so that he could see the glucose data remotely on a laptop, mobile phone, or smartwatch. He later shared this code with other patients and caregivers in the T1D community."		Diabetes T1	(CGM (continuous glucose monitoring) by caregiver]: "need to monitor his child's blood glucose (BG) levels in real time while away at school"