Appendix 3.2. Extracted data by article

| Publication | Study design | *Study design categorized* | Data | Sample size |
|---|---|---|---|---|
| Ahrens 2016 | patient-driven n-of-1 study | *3 Experimental* | self-tracking symptoms: gut pain, bowel movements, and blood in my stool | 1 |
| Ardolino 2017 | Case series | *1 Descriptive* | points on (1) the Segmental Assessment of Trunk Control (SATCo)16 and (2) the Gross Motor Function Measure (GMFM-66). And parents reports of changes in childrens behavior | 2 |
| Årsand 2016 Warning: the do-it-yourself | "summary is based on the authors' active participation in relevant social media and long research experience within the chosen disease case. We also searched for information on PubMed.gov and Google.com, using keywords "do it yourself" and "diabetes"." | *1 Descriptive* | "information on PubMed.gov and Google.com, using keywords "do it yourself" and "diabetes"" | N/A |
| Barnard 2018 | Not specified | *4 No design* | No data | N/A |
| Beckman 2016 | Not specified | *4 No design* | No data | N/A |
| Bedlack 2019 | "12-month open-label clinical trial designed to be semi-virtual" | *3 Experimental* | Enrollment and retention rates; ALSFRS-R, ALS | Participants = 50; "Playing |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | reversals, perceived efficacy; weight, adverse events, side effects; hystone acetylation; accuracy, adherence, compliance; "Playing along at Home " cohort's demographcis, effectiveness, side effects, adherence. | along at home" = 54 |
| Ben-Pazi 2018 | A matched pair double blind randomized control study | *3 Experimental* | Outcome measures: Care and Comfort Hypertonicity Questionnaire (CCHQ), Goal attainment scale (GAS), Gross motor function measure (GMFM-88), Quality of upper extremity skills test (QUEST) | n=22 (11 pairs of children) |
| Berry 2019 | RCT | *3 Experimental* | SDS pain items, Frequenc y Intensity QLQ-C30 Global QOL Physical function Role | 139 (84%) were enrolled and randomized (67 UC and 72 Jacki + UC) |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | function Emotional function Cognitive function Social function Symptom pain QLQ-BR32 Body image Sexual functioning Sexual enjoyment Future perspective Side effects Breast symptoms ) Arm symptoms Upset by hair loss | |
| Bove 2013 | "I) compared the demographic characteristics of subjects from PLM [Patients Like Me] and from a regional MS center. II) validated PLM's patient-reported outcome measure (MS Rating Scale, MSRS) against standard physician-rated tools. | *2 Observational* | Demographics; disease (MS) characteristics; patient-reported MS Rating Scale (MSRS); physician-rated tools; | I. PLM MS Center Comparison: Patients Like Me (PLM) - N=10255; Partners MS Center - N=4039 II. Validation of Patient Reported MSRS: N=121 III. BMI and Disease Course: N=10433 |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| Braune 2019 DIWHY | Online Survey (Descriptive/Observational) | *1 Descriptive* | Survey data | 209 |
| Braune 2019 Real World Use | Online survey | *1 Descriptive* | Survey data | 1058 |
| Brownstein 2009 | N/A | *N/A* | N/A | N/A |
| Brownstein 2010 | N/A | *N/A* | N/A | N/A |
| Burnside 2020 Do-it-yourself | N/A | *N/A* | N/A | N/A |
| Chiauzzi 2019 Digital Trespass | Case studies: "These violations involved the use, interpretation/misinterpretation, and dissemination of patient self-reported data and forum posts available at PatientsLikeMe [40]." | *1 Descriptive* | "...four cases provide examples of ethical and methodological issues that arise when researchers gather social media data without observing the website's terms of use." | 4 |
| Cleal 2019 | Online survey | *1 Descriptive* | responses to open-ended questions | 656 |
| Crabtree 2019 DIY artificial pancreas | N/A | *N/A* | N/A | N/A |
| De Bock 2019 | N/A | *4 No design* | estimated seven million hours of realworld experience with this technology,2 demonstrated remarkable | "Real-world data from an estimated global population of more than 1000 DIY users, and an |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | glycaemic outcomes.3–6 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%.5 | estimated seven million hours of realworld experience with this technology,2 demonstrated remarkable glycaemic outcomes" |
| De la Loge 2016 | Retrospective analysis | *2 Observational* | Sociodemographics; symptom checklist; treatment history; "validated, standardized patient-reported outcome (PRO) instruments, namely, the Quality of Life in Epilepsy Inventory (QOLIE-31/P) [14], the Hospital Anxiety | 7 |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | and Depression Scale (HADS) [15], and the EuroQoL 5-Dimensions Scale, 3 Levels (EQ-5D-3L) [16]." | |
| De Monestrol 2018 | presentation of a CF coalition | *4 No design* | N/A | N/A |
| Debong 2019 | "observations of changes in glycemic control and patient satisfaction associated with the use of the mySugr mHealth app" | *3 Experimental* | "changes in mean blood glucose, SD, CV, eA1c, number of blood glucose tests in range, and frequency of blood glucose testing" | N/A |
| Dowling 2020 Do-it-yourself closed-loop | N/A | *N/A* | N/A | N/A |
| Ellis 2013 | Simple content analysis | *1 Descriptive* | Content analysis: "examined each site's stated purpose, ownership, design and the information provided on how any data collected is used." | 2 social websites (Web 2.0) |
| Farrington 2016 | N/A | *N/A* | N/A | N/A |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| Fergus 2017 | Case study (experimental) | *3 Experimental* | User experience, Gait, mPMAL and GMFM | 1 |
| Frost 2008 How the social | "mixed methods qualitative and quantitative study of forum posts and treatments adopted by the ALS community after the first report of the Lithium trial in November 2007." | *1 Descriptive* | "All Forum posts including the word “Lithium” were pulled from the site database. We plotted a frequency distribution of Lithium posts. We overlaid that plot with known significant events. We also observed changes in that frequency and used those observations to identify forum posts that appeared to spark those changes." | N=687 posts including word "lithium" |
| Frost 2008 Social uses of | "design-based qualitative research study" "Using a grounded theory approach [25], a set of codes was developed." | *1 Descriptive* | "user remarks that refer to another’s individual-level personal health data." "comments left on personal profiles." "focus | N=123 comments (derived from 7852 comments) |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | on how users employ elements of another user's personal health profile in a discussion with that user." "compiling and analyzing the kinds of questions, comments, and discussions that relate directly to shared, personal medical information" | |
| Frost 2009 Patients like me the case | Case study – qualitative analysis | *1 Descriptive* | "forum content containing preset terms" | Term "bipap" N=1516; Term "trach" N = 1690 |
| Grande 2019 Empowering young people | Semistructured interviews analysed with conventional content analysis | *1 Descriptive* | Interview transcripts from interviews | 15 young people, their parents, and 4 care team members |
| Griffiths 2015 The impact of | Scoping review and case studies. | *1 Descriptive* | Scoping Review: "Characteristics of Social Networking Health Information Sites" [Characteristics of social | 23 articles from which 4 social network case studies were selected: |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | networks found through scoping review.] Case Studies: "describe each case study in terms of its structure, function, participants and impact, how it came into being, how it is sustained, and what has changed as it matured." [PLM is one of the 4 case studies] | |
| Heywood 2014 Straight talk with | N/A | *N/A* | N/A | N/A |
| Hng 2018 Appearence of do-it-yourself | Survey | *1 Descriptive* | Experience and other characteristics | 19 complete "loopers" (68 answers) |
| Hussain 2020 Part I | N/A | *N/A* | N/A | N/A |
| Hussain 2020 Part II | N/A | *N/A* | N/A | N/A |
| Janssen 2016 A painted staircase | Video-supported case study | *1 Descriptive* | Video | 1 |
| Janssen 2016 Response to | N/A | *N/A* | N/A | N/A |
| Jennings 2020 Do-It-Yourself Artificial Pancreas | Literature search; "experiential learning from our evolving clinical practice" | *1 Descriptive* | various publications; unpublished | 24 publications |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | research; policy statements | |
| Kendall 2017 T1resources.uk | Article describes how the authors " create a library of useful quality-assured self-care resources" | *4 No design* | "The editorial team identified over 100 online resources which ranged from peer YouTube video clips to personal blogs about eating disorders and NHS created sick-day rules. We began to catalogue them in a shared database, agreeing on a taxonomy with which to categorise the diverse content". | In the first week 1,000 people visited the site, and this continued to grow with 6,500 users in the first six months. Users viewed over 38,000 pages, averaging 3.3 pages per visit and spending 2.50 minute |
| Klee 2018 An intervention by | "A Randomized Double-Crossover Study" | *3 Experimental* | HbA1C, QoL, hypoglycemic events, satisfaction, usage data, baseline demographics | "Of the 55 included patients, 33 completed the study" |
| Kontovounisios 2018 The ostom-i- alert | Not described | | length of stay, usability, acceptability, QoL | "nine patients [six males, three females, |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | | mean age 52 years (range 26–76 years)]" |
| Kublin 2020 The Nightscout system | N/A | *N/A* | Review of research articles | N/A |
| Lawlor 2017 Developing integrated care | "a clinical care coordinator, a lead paediatrician and a family support coordinator will work with service users, families and clinicians to develop and co-ordinate the care pathway in a multidisciplinary network of expertise" | *2 Observational* | N/A (proposal) | N/A |
| Lebental 2011 Patient perception | "randomized, two-arm open crossover study" | *3 Experimental* | "treatment satisfaction (Diabetes Treatment Satisfaction Questionnaire), user evaluation (OmniPod System User Evaluation Questionnaire), and HbA1c levels" | 29 |
| Lee 2016 A patient-designed | N/A | *N/A* | N/A | N/A |
| Lee 2017 Real-world use | Survey (observational) | *2 Observational* | Demographics, information about use of Nightscout | Members of CGM in the Cloud (n=1268) |
| Lemieux 2020 Do-It-Yourself | Case study (experimental) | *3 Experimental* | "Case presentation; | 1 case |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| Artificial Pancreas | | | Glycemic control reflected by % time spent in pregnancy target range (TIR) between 3.5-7.8 mmol/L was assessed by continuous glucose monitoring (CGM)." | |
| Lewis 2015 How a DIY | N/A (descriptive - case report?) | *1 Descriptive* | A1C improved from 7.2 to 6.3 and time in range increased from 51% to 80% | 1 |
| Lewis 2016 Real-world use | Survey (descriptive) | *1 Descriptive* | "quantitative and qualitative measures of their experience using their self-built artificial pancreas systems (APSs)" | 18 |
| Lewis 2017 Automatic estimation | Survey (descriptive) | *1 Descriptive* | 16 users reported feedback about how well this tool ("autotune") works. | 16 |
| Lewis 2018 Detecting insulin | Autosens was run retrospectively to obtain an hourly SR value (first calculated SR every hour) for | *2 Observational* | Autosens calculates the deviation for the | 12 |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | (N=1)*16 individuals using OpenAPS; with M=5393 data points, and range=922 to 20,473. A SR of >1.0 indicates resistance; <1.0 indicates sensitivity. Histograms were created to visualize SR for each participant. Mean SR ± SD was calculated and those falling beyond ± 10% of 1.0 were classified as being resistant and sensitive respectively | | median of the last 8 and 24 hours of CGM data points and determines the sensitivity ratio (SR) required to neutralize the median deviation. | |
| Lewis 2018 Improvements in A1C | retrospective cross-over analysis of continuous BG readings | *2 Observational* | continuous BG readings recorded during 2-week segments 4-6 weeks before and after initiation of OpenAPS | 20 |
| Lewis 2018 Setting expectations | N/A | *N/A* | N/A | N/A |
| Lewis 2019 Characterization of | Frequency decomposition using the continuous morlet wavelet transformation were created to assess change in rhythmic composition of normalized blood glucose data | *2 Observational* | blood glucose data from 5 non-T1D individuals, and anonymized, retrospective CGM data from 19 T1D individuals using a DIY closed loop APS in the OpenAPS Data Commons | 5 non-T1D individuals, 19 T1D individuals |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| Lewis 2019 History and perspective | Survey (descriptive) | *1 Descriptive* | self-reported survey outcomes (sleep, quality of life) | Not reported |
| Li 2013 Privacy policies for | Paper on policy implications. | *4 No design* | N/A | N/A |
| Lindblad 2019 Sweden's learning | N/A | *N/A* | N/A | N/A |
| Litchman 2019 Twitter analysis | Twitter analysis | *1 Descriptive* | Tweets | "3347 tweets generated by 328 patients, caregivers, and care partners" |
| Litchman 2020 Patient-Driven Diabetes Technologies | "A multiple method qualitative approach" | *1 Descriptive* | "Sentiment analysis"; "Visual document analysis"; "Persona development" using "discourse analysis" (Symplur Signals platform) | N=7886 participants; 46 578 Tweets |
| Longacre 2018 Clinical adoption | Case study | *1 Descriptive* | "Data sources included interviews, presentations, meeting notes, and other archival documents" | Not reported |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| Ma 2015 Mental disorder recovery | Social network analysis | *2 Observational* | "Recovery outcomes" through social network analysis. [Change over study period in mood, stress, etc.; change in 'life essentials'; Change in symptoms]; "Correlation coefficient matrix between six node properties and five recovery outcomes." "Correlation coefficients between online social activities and recovery outcomes." | 200 |
| Mader 2015 Influence of | compare characteristics of adherent (=4 BG values/day on an active day) and non-adherent (<4 BG values/day on an active day) mySugr users | *2 Observational* | Age, Pen use, Blood glucose | 728 adherent users on 31,985 days and 475 non-adherent users on 5,132 days were included |
| Marshall 2019 Do-it-yourself | N/A | *N/A* | N/A | 6 |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| Melmer 2019 Glycaemic control | "descriptive study of user-donated CGM records obtained before and during use of an open source AP system" | *1 Descriptive* | continuous glucose monitoring (CGM) records | 80 |
| Melmer 2019 In-depth review | descriptive analysis of open source APS data | *1 Descriptive* | CGM readings | 19251 days (53 years) of CGM readings with a mean duration of 134 days per patient |
| Murray 2020 Health Care Provider | "two-phase cross-sectional observational study" | *2 Observational* | Paper survey; online survey | Phase I N=43 local HCPs; Phase II N=137 national HCPs |
| Ng 2020 Evolution of Do-It-Yourself | Thematic analysis of social media posts | *1 Descriptive* | "posts and comments in the “CGM in the Cloud” private Facebook group as well as data from Twitter, GitHub, and the Nightscout website" "list of identified innovations, the need or purpose, and a description of the features/improvements" | Unclear |
| Nyman 2020 Characteristics and Symptom | Retrospective Observational Study | *2 Observational* | Summary statistics on self-reported patient data "from PLM | 21101 |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | members with SLE to characterize demographics, clinical characteristics, symptom severity, primary lupus manifestations, comorbidities, and treatment." | |
| O'Brien 2019 Patient perspectives on | Questionnaire study - sent to all PLM members active within previous 90 days. | *1 Descriptive* | Demographics; primary medical condition; "respondents' overall comfort levels with sharing health data for research."; "“How much would the removal of the following [various identifying information] increase your comfort level with confidentially sharing your health data?”; "Potential strategies that may improve | 3516 |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | levels of comfort with data sharing for research." | |
| O'Connor 2017 The medistori | presentation of a toolkit | *1 Descriptive* | N/A | N/A |
| O'Donnell 2019 Evidence on | "Quantitative and qualitative methodologies will be used to examine clinical and self-reported outcome measures of DIYAPS users." | *2 Observational (protocol)* | N/A | N/A |
| Okun 2017 Building a learning | "qualitative research methods, immersive observation and directed one-on-one conversations." Interviews with patients and caregivers: "The team developed an interview guide heavily influenced by techniques used in ethnographic interviewing, a qualitative research method that combines immersive observation and directed one-on one conversations." | *1 Descriptive* | [Arrived at 6 common questions based on thematic categories. Developed a group of 'personas' based on their thematic qualitative interview data.] "The personas created for PatientsLikeMe were synthesized from the team's research and ethnographic interviews to represent the diversity of behaviors, preferences, and | 29 |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | characteristics of patients and caregivers." | |
| Okun 2018 DigitalMe: A journey | Unclear | *N/A* | No data are presented but describes data collection for "a new patient-reported measure ['Thrive']that could be used across conditions for all members of PLM." "(1) health and symptoms, (2) how well you can do what matters (functioning), and (3) how you're feeling about it (thriving)." Also describes a pilot study in which "The participant experience includes blood specimen collection at the time of enrollment and every 4 months thereafter to | N/A |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | interrogate the biological state with deep molecular profiling." | |
| Oliver 2019 Open source automated | N/A | *N/A* | N/A | N/A |
| Omer 2016 Empowered citizen | N/A | *N/A* | N/A | N/A |
| Pearson 2011 Potential for electronic | Review | *1 Descriptive* | N/A | N/A |
| Riggare 2015 Patients organize | N/A | *N/A* | N/A | N/A |
| Rivard 2020 It's not just | Qualitative interviews with "inductive exploratory thematic analysis approach" | *1 Descriptive* | Information about participants, citations from interviews | "in French (n=14) or in English (n=17)" |
| Rouholiman 2018 Improving health-related | "prospective, observational, cross-over pilot study" | *2 Observational* | survey data "ostomy-specific, health-related quality of life at baseline (prior to Ostom-i alert sensor use) to ostomy-specific, health-related quality of life after 2 and 4 weeks of Ostom-i use by utilizing the City of Hope | 20 |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | Quality of Life Questionnaire for Patients with an Ostomy" | |
| Rundle 2018 PatientsLikeMe and atopic | Retrospective analysis | *1 Descriptive* | [Self-reported demographics, symptoms, disease history from PLM.] | 410 |
| Sahama 2012 Impact of the | [Proposal for internet protocol.] | *N/A* | [Hypothetical scenarios] | N/A |
| Schroeder 2015 An Innovative Approach | [Web-based survey including quantitative and qualitative.] "The objective of our study was to inform a research priority-setting agenda by using a Web-based survey to gather perceptions of important and difficult aspects of diabetes care from patient members of a social networking site-based community." | *1 Descriptive* | Demographics; Descriptive or summary statistics - disease progression, treatment, complications, other health variables; "patient experience" scales; thematic content analysis. | 320 |
| Seres 2017 From patient to | N/A | *N/A* | The authors own story and reflections | N/A |
| Shaw 2020 The DIY artificial | N/A | *N/A* | | |
| Shepard 2020 User and healthcare | "To explore these complex and controversial issues, we held a workshop at the annual Advanced Technologies and Treatments in Diabetes conference in February 2020." | *1 Descriptive* | "We report a summary of these perspectives" " User Perspectives" | "Approximately 60 stakeholders" |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | "HCP's Perspectives" | |
| Smith 2008 PatientsLikeMe: Consumer health | "As of September 2007, 376 symptom terms had been contributed by PatientsLikeMe community members. Two coders working independently analyzed these raw, un-normalized terms for consonance with the Unified Medical Language System (2007 AC) in December, 2007" | *1 Descriptive* | "PatientsLikeMe symptom terms (3 communities): Agreement with the UMLS Metathesaurus" | |
| Torous 2017 Patient-driven innovation | "The case is cowritten with an individual with schizophrenia, who openly shares his name and personal experience with mental health technology" | *1 Descriptive* | "patient perspective" (case study) | 1 |
| Trevena 2011 PatientsLikeMe and the | N/A | *N/A* | N/A | N/A |
| Vaidyam 2020 Patient innovation | Case report | *1 Descriptive* | air quality and patient's self-tracking of audio hallucinations | 1 |
| White 2018 Motivations for participation | Online survey | *1 Descriptive* | Survey data | " to describe individuals' motivations for participation in an online social media community and to assess their level of trust in medical information provided by |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | | medical professionals and community members" |
| Wicks 2009 Measuring function in | Item development based on survey | *1 Descriptive* | Data on psychometrics of new items. "Baseline item variation and overall scale reliability" "Factor analysis: internal structure of the ALSFRS-R and new items" "Re-test reliability" "Discriminant validity" | Baseline respondents: 326; Re-test respondents: 169; 3-month follow-up respondents: 218 |
| Wicks 2010 Sharing health-data | Online survey | *1 Descriptive* | Survey data | "Complete responses were received from 1323 participants" |
| Wicks 2011 Accelerated clinical discovery | Observational analysis | *2 Observational* | [ALSFRS-R12 scores in PLM members using lithium and "matched controls".] "ALS disease progression is evaluated using the Revised ALS Functional | "149 patients ... in an 'intent to treat' group (that is, they took lithium but may have discontinued within 12 months) and 78 patients in a... 'full course' |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | Rating Scale (ALSFRS-R12, henceforth referred to as FRS), which measures patient-reported functional impairment in domains such as speech, swallowing, walking, arm function and respiratory function." "developed an algorithm, the PatientsLikeMe matching algorithm, to match lithium-treated and control patients based on their entire disease progression, as measured by the FRS, before treatment was initiated" | group (that is, a subset of the intent-to-treat group who continued to take lithium for the entire 12 months)." |
| Wicks 2011 Use of an | Online survey | *1 Descriptive* | Survey data: Demographics; logistic regression on factors affecting adherence; | 431 |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | descriptives on adherence; descriptives on "Psychometric performance of Multiple Sclerosis Treatment Adherence Questionnaire (MS-TAQ) subscale characteristics"; "missed dose ratio (MDR) ... the number of doses missed divided by the number of prescribed doses over a 28-day period" by treatment. | |
| Wicks 2012 Perceived benefits | Online survey via PLM | *1 Descriptive* | Survey data: "Benefit score"; [various parametric and non-parametric statistical tests] | 221 |
| Wicks 2012 The multiple sclerosis | Cognitive interviewing and survey piloting of a MS scale | *1 Descriptive* | Psychometrics; factor analysis; internal consistency; Test-retest. | 816 |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| Wicks 2014 Could digital patient | N/A | *N/A* | N/A | N/A |
| Wicks 2014 Data donation could | N/A | *N/A* | N/A | N/A |
| Wicks 2014 Quality of life | Descriptive study tracking patient outcomes using PLM data from organ transplant recipients. | *1 Descriptive* | Demographics; "transplant history information"; Lab values; Symptoms; Treatments; Quality of life per the PLMQOL; qualitative analysis of forum posts | 1924 |
| Wicks 2014 Subjects no more | N/A | *N/A* | N/A | N/A |
| Wicks 2018 Patient study thyself | N/A | *N/A* | N/A | N/A |
| Williams III 2019 The PatientsLikeMe Multiple | "The analysis discussed in this paper was conducted by reviewing documents created during the company's expansion period for the platform from one community, amyotrophic lateral sclerosis (ALS), to multiple sclerosis (MS)." | *1 Descriptive* | N/A | N/A |
| Zabinsky 2020 Do-it-yourself | "A retrospective double cohort study was performed" | *2 Observational* | "The DIY group consisted of people with T1D using DIYAPS (OpenAPS, Loop, | DIY group=74, Control group=98 |

Appendix 3.2. Extracted data by article

| | | | | |
|---|---|---|---|---|
| | | | and AndroidAPS) who contributed data to the OpenAPS Data Commons. The SAP group included age-matched SAP users whose sensor data was obtained through the Tidepool Big Data Donation Project." | |
| Zisser 2011 Novel methodology | "bench testing" "We implemented two new approaches for assessing pump accuracy. A total of seven OmniPod insulin pumps were tested at bolus doses of 0.05, 0.1, 0.2, 1, and 6 U. Additional materials included a digital microscope (DinoLight, running software DinoXcope v1.1) and a standard 100 µl pipette (equivalent to a 10 U volume of insulin). " | *1 Descriptive* | measures of the size of bolus given by the pumps | 2 OmniPods tested |