

# A Scoping Review of Patient Support Program Services Across Diverse Settings and Disease Areas Described from a People-Centered Perspective

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## Research Article

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# Abstract

## Background

Governments, private industries and not-for-profit organizations are increasingly investing resources in support programs for patients. These programs may provide self-management strategies enabling patients to manage their disease and medication regimen and/or access to medications, therapies and health services, with the goal to improve health outcomes. The objectives of this scoping review were to: (i) describe the characteristics of patient support programs (PSPs), for patients on medication regimens, (ii) identify subthemes that describe PSP services, and (iii) to classify the service subthemes, using an integrated people-centered (IP-C) perspective.

## Methods

PRISMA-ScR methodology and Covidence software were used to facilitate the review of 479 articles, and the selection and screening of 70 original research articles that described PSP services and their impact on clinical, humanistic and/or economic outcomes. A search of PubMed, Embase, CINAHL, Academic Search Ultimate, and Web of Science was conducted covering a 10 year period, from 2010 to 2020. The PSPs identified were organized into subthemes identified as part of an inductive process. The thematic areas were grouped into one of three people-centered categories that reflect the WHO vision for IPC health care.

## Results

The 70 articles reviewed, describe PSPs covering more than nine disease categories. The majority of the articles were published in North America, predominantly in the United States (26) and Canada (11), and also in Germany (6), the United Kingdom (6), China (4) and other countries (18). PSPs were funded and delivered by private drug or device manufacturers, government organizations, specialty pharmacies and also non-governmental groups (e.g., not-for-profit organizations), private hospitals, private payers (e.g., insurance companies) and various partnership types among these organizations. Fifty-six unique PSPs were identified that offered a range of services. Twenty-five PSP service subthemes were identified and these were each placed into one of three over-arching patient-centered categories: (i) access and equity services; (ii) quality and health services, and (iii) patient and caregiver empowerment and self-management services.

## Conclusions

PSPs offer various services that can be optimized and synergized to facilitate equitable, accessible, quality health services that support patient empowerment for the self-management of disease for improved health outcomes.

## 1. Background

The WHO framework on IP-C health care services envisions, "*a future in which all people have equal access to quality health services that are co-produced in a way that meets their life course needs and respects their preferences, are coordinated across the continuum of care and are comprehensive, safe, effective, timely, efficient, and acceptable and all carers are motivated, skilled and operate in a supportive environment*" [1, p4]. This vision clearly conveys that good health care is not one-dimensional and requires people-centered health care service provision. From this vision statement, three overarching themes were operationalized: (i) *access and equity* to reflect services that support equal access and timely, efficient, care for all people; (ii) *quality and health services* to reflect quality health services, coordinated across the continuum of care and that is comprehensive, effective and efficient, and that all carers (health care providers [HCP]) are motivated, skilled, and operate in a supportive environment; and patient and caregiver (iii) *empowerment and self-management* to reflect service that is co-produced and that meets the patients' life course needs and respects their

preference, and that all carers (non-HCP, e.g. family members) are motivated, skilled and operate in a supportive environment.

Health services and support programs are provided by government, not-for-profit and private sector entities with the goal of improving health care experiences and outcomes for patients [2]. Programs offered by the private sector are often specifically termed “patient support programs” (PSPs) and were initially developed and administered by pharmaceutical companies to fill gaps in the public health care system by delivering specialized drugs that require complex administration techniques [3]. PSPs often provide support to patients who are being treated with a specific drug and have evolved to include various support services including: patient education and training (e.g., disease management or medication administration), assistance with medication adherence, help with facilitating drug access through financing and health service navigation, pharmacovigilance and the provision of medical services. It is unclear how much is spent globally by private industry on PSPs; however, in Canada PSPs supported the health care of over 670,000 Canadians in 2016, at a cost of \$900M [3].

Support programs offered by not-for-profit and government institutions tend to be less product-specific and more disease-specific, and may be described using other terms such as case/care management or self-management programs as opposed to patient support programs [4, 5]. Self-management programs are implemented widely throughout the world to provide treatment and support to help patients manage various medical conditions and promote positive outcomes. Evidence suggests that these programs lead to improved health outcomes [6].

Multiple definitions exist for PSPs [2, 3, 7, 8], and there appears to be no global gold-standard for the delivery of PSP services. However, in the UK, Australia and Canada there are guidelines for PSPs, some provided by government health authorities and others by pharmaceutical consortiums [9–12]. Despite their different origins, all PSPs offer health services support for patients and ultimately represent resources that can be optimized and coordinated for improved patient care. Therefore, for the purpose of this scoping review, all government, not-for-profit and private patient support programs are referred to as PSPs. A PSP is broadly defined as a health care program that is offered to patients on medication or therapeutic regimens and that provides various methods of support and services to improve medication adherence with the goal of improving the health care experience and health outcomes.

Research on patient support programs has important implications for policy and practice. Synthesizing the evidence on the characteristics of these programs can identify program elements, inform the design of future programs, and identify gaps in service. Research describing patient support programs is also limited. Ganguli et al. [2] published a targeted systematic review identifying PSPs that had a clinical, humanistic or economic outcome and Zalesak, M et al. [13] published a systematic review describing the value of specialty pharmaceuticals for three disease indications, rheumatoid arthritis, breast cancer and multiple sclerosis; but, to our knowledge, there have been no previous scoping reviews that explicitly describe the characteristics of PSPs. To address this research gap, this scoping review describes the nature and characteristics of PSPs offered over the past decade. Although the review does not assess the outcomes of these services, it documents which outcomes are addressed in these studies as they may be helpful for future PSP evaluations. Outcome measures were categorized based on the Economic, Clinical and Humanistic Outcomes (ECHO) model [2, 14] and includes *humanistic measures* (e.g., patient safety, functional capacity and social functioning), *economic measures* (e.g., program costs, quality adjusted life years and health care utilization costs) and *clinical measures* (e.g., drug adherence, persistence and discontinuation).

The specific objectives of this review are to:

1. Describe the characteristics of PSPs offered as health care options to patients managing chronic health conditions and who require medications
  - a. Identify countries where PSPs are delivered

- b. Identify medical conditions which PSPs address
  - c. Identify the organizations that fund and deliver PSPs
  - d. Describe the clinical, economic and humanistic outcomes that are measured for the various PSPs
2. Identify PSP service subthemes and describe them in the context of the WHO framework on integrated people-centered (IP-C) health care services
- a. Inductively classify PSPs health service offerings into subthemes
  - b. Quantify which service subthemes are offered most frequently by disease area
  - c. Group the PSPs service subthemes identified in (2a) into one of three overarching themes including (i) *access and equity*, (ii) *quality and health services* and (iii) patient and caregiver *empowerment and self-management*, operationalized from the vision of the WHO framework on IP-C health care services.

It is anticipated that this study will increase awareness of the availability of PSP services for patients and inform the continuous improvement of PSPs that are offered to patients through collaboration among health care systems, private companies and not-for-profit organizations around the world.

## 2. Methods

Initial searches of 11 databases were conducted including Prospero, Cochrane Library, Epistemonikos, International HTA, PubMed, CINAHL, Beme, Scopus, Google Scholar, and MedRxiv and Europe PMC preprint servers to determine whether any scoping reviews exist that explicitly describe the diverse service offerings provided as part of PSPs across multiple disease conditions. However, to our knowledge, no scoping reviews that specifically focused on describing these service offerings were published as of July 2021. Accordingly, this scoping review was conducted to explore, map and synthesize evidence about the services offered by PSPs. This scoping review followed the Arksey and O'Malley [15] scoping review methodological framework and subsequent enhancements by Levac et al. [16] and the Joanna Briggs Institute [17, 18]. Briefly, the five-stage process of the Arksey and O'Malley model adopted for this scoping review includes (1) identifying the research question, (2) selecting and refining search terms to identify relevant studies, (3) screening and selecting studies for inclusion, (4) extracting and charting data from the studies, and (5) collating, summarizing and reporting the results. In addition, based on Levac et al. [16] a knowledge translation component was incorporated into the scoping review methodology so that health care professionals were consulted to review the study (step 6).

This project lends itself well to a scoping review, which allows for the development and utilization of author-defined search terms that capture PSPs which are offered and funded by both public and private sectors, while also allowing the narrowing of terms to include only programs that provide medication adherence support as part of the service offering. A scoping review is also particularly appropriate for mapping the scope and volume of literature on a particular topic, particularly those, such as PSPs, that have not been comprehensively examined [17-20]. This scoping review conforms to the reporting standard outlined in the PRISMA Extension for Scoping Reviews (PRISMA-ScR) [21].

### 2.1 Eligibility Criteria

#### 2.1.2 Types of Articles

Table 1 outlines the specific inclusion and exclusion criteria for the selection of studies.

#### Table 1: Inclusion and Exclusion Criteria for Study Selection

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>• PSPs that include a drug or health technology and include a medication adherence component</li> <li>• Patient support programs for any disease condition</li> <li>• Any health service setting (health system, community, pharmacy)</li> <li>• Any country</li> <li>• Study undertaken between 2011 to 2020</li> <li>• Delivered by government, not-for-profit, and/or private corporations</li> <li>• Published in English</li> <li>• Experimental, quasi-experimental or observational studies</li> </ul>	<ul style="list-style-type: none"> <li>• Review articles</li> <li>• Protocol papers</li> <li>• Conference abstracts</li> <li>• Articles that focus only on the financial component (i.e. patient assistance programs [PAPs])</li> <li>• Articles that focus on the pediatric population</li> <li>• Fully institutional setting (e.g. prison, if the only setting described)</li> <li>• Housing or employment intervention as the only focus</li> <li>• Articles that focused on addictions (e.g. smoking or illicit drug use) unless they involved a drug replacement therapy</li> </ul>

### 2.1.2 Population and Phenomenon of Interest

PSPs that support patients who are on a prescribed medication/therapy and are receiving a patient support service delivered by any government, not-for-profit or private corporation were included in this review. All chronic disease conditions were considered with the exception of addictions unless they involved a drug replacement therapy; this exception was necessary to maintain the specific focus of the search which was to identify patient support services that included medication adherence support, indicative of chronic disease management.

### 2.1.3 Context, Setting, and Language

Articles were included that describe PSPs from any country and that served any disease category, community setting (with exception of fully institutional settings), and cultural groups in any health care setting (e.g. primary care, acute care, etc.). Articles excluded were PAPs that consist exclusively of a financial intervention and those that focused primarily on housing or employment, as the focus of the search was to identify PSPs for health care and that offered a variety of services, not just financial support. Only articles published in English were included.

## 2.2 Search Strategy (Identifying Relevant Studies)

In accordance with established methodology, a three-step search strategy was developed in collaboration with an experienced librarian (KM) who coordinated searches at external institutions to access databases as necessary. As a first step, a limited search of PubMed and CINAHL was conducted to identify search terms. The systematic review by Ganguli et al [2] was also reviewed for possible search terms and references. Testing was carried out to identify relevant medical subject headings (MeSH) terms to be included. Following this initial search, an analysis was undertaken of the text words contained in the title and abstract of retrieved papers, and the index terms of the articles.

The next step of the search strategy creation was two-fold. Initially a search strategy was established and tested in PubMed and Web of Science in January 2020. A pilot title/abstract level screening of the 232 results was conducted by three team members (AR, EP and PC), with 126 references included. After review, several refinements and adjustments were made to the search strategy (see online resource, ESM1). These refinements were made to capture a diverse array of PSPs across multiple disease areas, and that specifically had a medication adherence support service offering.

The finalized search strategy was applied to five databases: PubMed, Embase, CINAHL, Academic Search Ultimate, and Web of Science. All searches were executed on June 12, 2020 and filtered by date (2005/01/01-2020/12/31) and language

(English). References were imported into EndNote (a citation manager) for deduplication. Post deduplication, the decision was made to adjust the date coverage of the review from 2005-2020 to 2011-2020 to keep the search more current; moreover, the majority of relevant articles were concentrated during this time period. An additional 101 references were removed to reflect this change in scope. In total 479 references were passed on to the title/abstract review stage in Covidence (an online review management platform) by the research team.

### **2.3 Screening and Study Selection**

Four reviewers (AR, EP, WM, PC), working in independent pairs conducted both levels of article screening (i.e. abstract/titles and screening of full text) against the inclusion/exclusion criteria to assess eligibility for inclusion into the scoping review. Disagreements were resolved through discussion of the reviewers conducting the screening and/or by a third independent reviewer (EP or WM). At each level of screening, pilot tests were conducted on 5 articles to help ensure consistency. A PRISMA flow diagram (Figure 1) describes the search strategy decisions.

### **2.4 Data Collection and Charting**

Data was charted on an Excel spreadsheet using predefined categories for data extraction (See Online Resource, ESM2). The data categories extracted were: article title; country of publication; publication year; study purpose; research design; participant characteristics; sample size; study population; sample selection; disease conditions; disease category; type of organization(s) delivering the program; program name; name of organization(s) delivering the program; medication/drug product name; route of administration; PSP program elements and description; data sources; outcome type assessed (i.e. humanistic, clinical or economic), comparators; and conclusions. The extraction sheet was first pilot tested by two reviewers (AR, PC) on 5 articles to ensure consistency in the interpretation and extraction process. Some modifications were made based on the pilot testing. Two reviewers (AR, PC) then proceeded to independently chart the data from each study. Discrepancies in extraction were discussed and resolved between the two reviewers, and if required by a third reviewer (WM). Several working definitions for the extracted data elements were developed to provide clarification and consistency among researchers in the data extraction process.

### **2.5 Analysis and Synthesis**

#### **(Collating, summarizing, and reporting results)**

A descriptive analytical approach was used to document the general characteristics of patient support programs, Frequencies and percentages were used to quantify how often specific services were offered as part of the various PSPs identified, and thematic analysis was used to classify the services offered. Specifically for thematic analysis, an inductive approach was used to extract and chart the data from the studies. Individual services offered by patient support programs were extracted from the research articles. Thematic analysis was conducted as per Braun, V., Clarke, V. [22]. To transcribe the data, the exact terms for health services as described in the articles were highlighted for each article in a spreadsheet; this step also allowed for familiarization of the data. The services were then coded into subthemes that emerged from the data.

Since many PSPs are offered by private industry, the grey literature was consulted including organizational websites to gather information to clarify gaps in the descriptions of PSP programs, where possible. Subthemes describing service offerings were further divided into three main people-centered categories as described by the World Health Organization (WHO) vision for IP-C health care services [1]. Secondary, supporting resources, including a Deloitte white paper description of the Patient Journey offered by industry-funded Patient Support Programs [7], the Chronic Care Model (CCM) [23], Effective Practice and Organization of Care (EPOC) taxonomy [24] and the Greene et al. framework for patient-centered care [25] were used to further validate the service categories identified. These frameworks were selected as they offered

different perspectives for health care service delivery, from a people-centered perspective [1, 25] from a health care system perspective [23, 24] and from a private industry perspective [7].

All authors (AR, BF, CB, EP, KM, PC and WM) reviewed and discussed the preliminary findings. Knowledge gaps and implications for policy, practice, and research are also highlighted [16], informed by consultation with health care professionals as part of a knowledge translation strategy. The results are presented in narrative and diagrammatic visual format using tables and charts.

### 3. Results

The search strategy returned a total of 969 references across all databases. After deduplication and removal of pre 2011 references, the titles and abstracts of the remaining 479 references were screened. Of those 479 references, 249 were selected for full-text screening and 70 articles were ultimately included in this scoping review. Reasons for exclusion are stated in a PRISMA flow chart prepared as per Khalil et al. (2016) [26] (Figure 1).

#### Figure1: PRISMA Flowchart Outlining the Selection Process for PSP-related Articles

##### 3.1 Characteristics of Research Articles and the PSPs they Described

Articles selected were published over a period of 10 years (2011 - 2020), with two-thirds of the articles published from 2017 to 2020 (47 articles), as shown in Figure 2. The studies were conducted in the United States (26) Canada (11), Germany (6), the United Kingdom (6), and China (4) as well as other countries in Europe, Asia, Africa, and Australia (Figure 3); some articles described PSPs delivered in multiple countries.

The included articles describe PSPs that support patients with various chronic conditions, and are reported within the following disease categories: immunology (15), cardiology, metabolism and endocrinology (12), psychology/mental health and addictions (10), neurology and the central nervous system (CNS) (9), infectious diseases and vaccines (9), oncology (6), respirology (4), musculoskeletal and osteology (2), nephrology, renal and urology (1), chronic diseases in general or multiple disease areas (2) (Figure 4). Fifty-six unique PSPs were identified, and are reported within the disease categories described above (Figure 5). These PSPs were primarily funded and delivered by government organizations (23) and by private drug or medical device manufacturers (18), followed by specialty pharmacies (3), non-governmental groups (e.g. not-for-profit organizations) (1), private hospitals (1), private payers (e.g., insurance companies) (1), and various partnerships among these organizations (10) (Figure 6). A list of the sponsoring organizations is reported in Online Resource, ESM3. All studies were associated with at least one clinical, humanistic or economic outcome (Figure 7), examples of which are included in Online Resource, ESM4. The majority of these articles were observational in nature (41 articles) including case control studies and cross-sectional surveys, other research designs were quasi-experimental (18), with comparators, but with no randomization and experimental (11), including randomized controlled trials.

#### Figure 2: Number of Research articles categorized by year of publication

#### Figure 3: World map showing the distribution and number of PSP-related articles included in this scoping review

Figure 3 was generated by AR using the data collected from this scoping review and the Anaconda installation of Python 3.8.5 and PyCharm Community 2020.1 with plotly, numpy, pandas, re and os modules. AR acknowledges stack overflow for the Python code tutorial in using these utilities for map generation published at <https://stackoverflow.com/questions/59297227/color-map-based-on-countries-frequency-counts>. See acknowledgements for more details.

#### Figure 4: Number of articles included in this scoping review, categorized by disease area

### **Figure 5: Distribution of the number of unique PSPs across disease areas**

Cardio-Metab. and Endo. = Cardiology, Metabolism and Endocrinology, Psychiatry-Mntl. Hlth. and Addictions = Psychiatry, Mental Health and Addictions, Neurology and CNS = Neurology and Central Nervous System, Infect. Dis. and Vac. = Infectious Diseases and Vaccines, MSK and Osteology = Musculoskeletal and Osteology

### **Figure 6: Organization types and partnerships that funded the unique PSPs identified in this scoping review**

Total count for PSPs in this bar graph is 57, although only 56 unique PSPs were identified. The reason for this is that a PSP that was typically offered by a private manufacturer alone [27-31], was delivered as part of a government-private manufacturer partnership [32] in one article.

### **Figure 7: Number of articles that address clinical, humanistic and/or economic outcomes**

## **3.2 Subthemes Identified**

Twenty-five subthemes emerged from the various services offered as part of the 56 unique PSPs identified (Table 2 and Figure 8). These subthemes were allocated to one of three people-centered categories as informed primarily by the WHO vision for IP-C health care [1]. Eight subthemes were grouped under the *access and equity* category, ten subthemes were grouped under the *quality and health services* category, and seven subthemes were grouped under the patient and caregiver *empowerment and self-management* services category.

### **3.2.1 Access and Equity**

Eight PSP service subthemes that facilitate access to health care services and that provide resources to support social equity to facilitate access to health care services were identified. These subthemes include social services support, access to health care providers, increasing awareness of PSP availability, navigation or referral to resources or programs, financial services for medication access, logistics services, information technology and systems and cultural accessibility services (sections 3.2.1.1 to 3.2.1.8 below).

#### **3.2.1.1 Social Services Support**

Only one PSP reported that socio-economic needs – such as food security, housing and access to free enrollment in kindergarten for children – were provided for as additional supports necessary to help multi-drug resistant tuberculosis patients succeed with treatment [33]. This PSP was sponsored and delivered by a joint partnership of the East Kazakhstan Oblast (a government department) and the United States Agency for International Development (a not-for-profit organization).

#### **3.2.1.2 Access to Health Care Providers or other Support Personnel**

Most PSPs (55) provided access to health care providers, including nurses, case managers, pharmacists, pharmacy technicians, primary care medical doctors, specialists, dietitians, social workers and psychologists. The PSPs either provided reimbursement to health care providers in private practice, such as doctors or pharmacists, or directly hired health care professionals such as registered nurses or psychologists to act as coaches or case managers, who educate, counsel, train and/or monitor patients to support disease management. Alternatively, some PSPs provided access to non-medical support staff that carried out administrative services. For example, as part of a private industry sponsored program for patients living with schizophrenia, PSP staff provided drug access and drug shipment support, care transition coordination, navigation assistance, and follow up for missed appointments [34]. As part of a government and (non-governmental) NGO sponsored-linkage case management program, Human Immunodeficiency Virus (HIV) positive peers,

trained as Antiretroviral Therapy (ART)-adherent expert-client counselors, provided psychosocial support and ART adherence counseling to patients [35].

### **3.2.1.3 Increasing Awareness of PSP Availability**

Only one PSP described specific activities to increase awareness of the PSP to health care providers and patients. For example, in the case of a stroke transition program delivered by a network of government hospitals, a nurse coordinator made site visits to engage community partners, including pharmacists, the Area Agency on Aging, and home health providers to increase awareness of the transition program [36].

### **3.2.1.4 Navigation or Referrals to Resources and Programs**

Seventeen PSPs offered navigation or referrals to financial, medical, social or rehabilitation services. For example, a navigation service, as part of a telephonic patient support on treatment for opioid dependence, provided direction to community resources such as a buprenorphine treatment counselor [37]. In a methadone maintenance treatment program, referrals were made for clinical visits; the program also provided navigation to psychiatric services, alcohol treatment, legal assistance, and social service entitlements [38].

### **3.2.1.5 Financial Services for Medication Access**

Eleven PSPs offered assistance in accessing medication including coverage coordination, co-pay assistance, reimbursement assistance, or access to discounts for the provisions of drugs. For example, a government-sponsored community health clinic in the United States facilitated medication access at a reduced cost through the 340B Drug Pricing Program and patient assistance programs (PAPs) [39].

### **3.2.1.6 Logistics Support Services**

Twenty-five PSPs offered logistics support, providing services in a range of ways including: in-person, at home, remotely, via zoom, or at a funded local care center. Specific types of logistics support services included facilitating access to medication through direct delivery and disposal of supplies or extending hours for medication reordering (e.g. automatic delivery). Other forms of logistics support included providing scheduling assistance, coordinating medication infusions, providing transportation options or escort service; or providing assistance in completing any kinds of documentation. For example, as part of a psychosocial support program for patients diagnosed with multidrug-resistant tuberculosis, home visits for social, psychological and clinical services were provided [33]; as part of a privately-funded colorectal cancer PSP, the shipment of cancer medications to patients' residences were coordinated [40]; and as part of a telemedicine program to deliver asthma care remotely, biweekly virtual visits using Zoom's via smartphone were provided [41].

### **3.2.1.7 Information Technology and Systems**

Of the programs reviewed, 11 reported utilizing information technology systems to facilitate access to care and information. These technologies included on-line portals, clinical information systems, interactive progress-tracking or monitoring tools for patients and health care providers, secure web platforms and clinical decision-making tools for health care provider support, web-based technologies to assess symptoms and generate reports to allow for integrated electronic physician authorization for medications, home care via an interactive web-based telemonitor, and automatic reminders installed on the sites' computers for health care providers. For example, as part of veteran's smoking cessation program, an electronic text data capture system was used to deliver assessment questions at 1, 3, and 6 months post-quit date, and the system also provided interactive, on demand tips for coping with craving stress or lapse prompted by keys words [42]. As part of a multiple sclerosis medication adherence program, a secure web platform was used to guide pharmacist consultation with patients [43]. The system supplied a graphic illustrating the patient's drug intake profile in both calendar and chronological formats, and included a clinical decision-making support system coupled with a safety alarm system

[43]. One digital medicine technology, a wireless, observed therapy, information system that was delivered using a mobile app and software, calculated and summarized adherence patterns, physical activity, rest and other self-reported clinical data. Patients viewed this data through a mobile device and providers viewed the data through a secure web portal as part of an oral Hepatitis C medication adherence program [44]. One system allowed patients to upload symptom data directly to an electronic medical record (EMR) via an app. This was followed up by nurse reviews through computer decision support software (CDSS) that used algorithms to calculate asthma severity and provided a comparison of recommended versus prescribed stepwise therapy. The CDSS tool was designed to improve assessment accuracy, guide step-wise medication management, inform providers and help patients achieve better asthma control and medication adjustments via e-prescribing [41].

### **3.2.1.8 Cultural Accessibility Services**

Four PSPs reported providing culturally appropriate and accessible services. These services included financial assistance for individuals without insurance and language translation services. For example, indigent patient assistance (free medication if no insurance was available) was offered as part of a PSP for adults with acne [45], culturally appropriate diabetes education was offered as part of a government-run program for residents in a poor urban area in India [46], the translation of text message reminders into various languages including English, Kiswahili or Dholuo was offered as part of a Kenyan malaria program [47], and a bilingual Spanish-speaking clinician was provided as part of a community health asthma clinic service in the United States [39].

### **3.2.1 Health Care Services**

Ten subthemes that describe health services offered as part of the PSPs were identified including screening and assessment; care coordination and communication; follow-up; reminders; care plans; monitoring; medical, clinical and pharmacy; laboratory; quality assurance and safety systems; and support for health care providers and case managers (see sections 3.2.1.1 to 3.2.1.10).

#### **3.2.1.1 Screening and Assessment**

Twenty PSPs included screening and/or assessment as part of the service offering. These services including screening or assessment of physical, clinical, somatic, psychiatric, psychosocial or socioeconomic problems, disease, medication or therapy management needs. The information gathered was used to evaluate changes and the achievement of goals set based on problem lists, for the identification of individual care problems, for the assessment of abilities and the need for advice, training or supportive devices, and to assess substance abuse, and disease symptoms. For example, as part of a maintenance program for patients living with schizophrenia in China, baseline evaluations were conducted to assess the health condition, recovery status, daily functioning, employment status, and social activities of program participants [48, 49]. In a community program in the United Kingdom, psychiatric clinical evaluations and prognostic assessments were conducted for individuals with psychosis [50]. As part of a pharmaceutical case management program offered in the US aimed at reducing drug-related problems (DRPs) medication history, a review of the indication as well as medication effectiveness, safety and adherence were assessed [51].

#### **3.2.1.2 Care Coordination and Communication**

Twenty-four PSPs reported services related to care coordination or communication. These services included coordinating therapies and providing interdisciplinary care through collaboration and/or communication among multidisciplinary team members (e.g., physicians, nurses, pharmacists, dietitians, clinical social workers or psychiatrists). For example, in Canada, as part of a schizophrenia care transition program providing patient information, the program coordinator was responsible for several tasks that supported the patient's post-program medication regimen, including notifying the outpatient facility of the patient's discharge date, medication requirements and next injection due date. Support also included verifying

whether the outpatient facility had the capacity to have medication available for the patient so that the patient could maintain their injection regimen according to the schedule [34]. In another example, an interdisciplinary case management team – consisting of one community psychiatrist, one nurse and one community health worker – collaborated to help patients manage living with schizophrenia as part of a community-based case management program [48, 49]. In the case of an oncology program in the United States, nurses assessed patients' post-chemotherapy treatment through phone calls and directed patients to their physicians when adverse effects were identified and required clinical monitoring or when intervention was needed [52]. Similarly, pharmacists faxed a one-page summary to physicians and communicated with patients and physicians about DRPs when necessary [51].

### **3.2.1.3 Follow up**

Twenty-one PSPs reported a broad range of follow up services for program participants. These services included nurse calls and text messaging. Nurse calls were made to confirm medication delivery, improve appointment attendance, improve the input of self-reported health information after days missed, provide motivational interviewing for self-injection and device handling, or to monitor adverse events after treatment. These calls were also made for medication reassessments or post-monitoring, sometimes using electronic system information to help patients achieve target drug dose or to ensure appropriate disease management. For example, as part of a mHealth technology combined antiretroviral therapy program for women and families with HIV, participants received a weekly automated text message to check on their health status for one year. Participants were asked to respond each week, within 48 hours, if they were "OK" or had a "problem." A study nurse monitored responses and responded to all "problem" texts from participants. Participants who did not respond to the initial text were sent a second message after the first 48 hours. If there was still no response, the clinic nurse called participants the next day. If there was again no response, participants were texted as per usual the following week [53]. In another example, as part of a specialty pharmacy PSP for cancer patients, participants received monthly follow up phone calls to assess medication adverse effects and adherence, ultimately with the goal to improve patient safety and adherence [54]. As part of a telemedicine program offered for kidney transplant patients in Germany, patients completed a pre-defined medical questionnaire about their physical condition in their homes via an interactive web-based telemonitor. The data were monitored by qualified medical staff. If anomalous values occurred, the medical staff contacted the patient by phone or video conference to discuss the following treatment process [55].

### **3.2.1.4 Reminders**

Twenty PSPs reported offering reminder services for patients. These reminder services were offered for a variety of reasons and delivered through various mediums. Reminders were provided to patients to take their medication or injections, obtain refills, follow up with their physician, take lab/medical tests, input health information (e.g., glucose levels) for appointments, or to remind of a missed dose, unscheduled visits, screening, training or complete assessments. These reminders were delivered by phone calls, text messages or paper (reminder cards or monthly calendars mailed to patients). For example, a nurse call reminder service was employed in a PSP for women with osteoporosis to remind them to book their next appointment at the prescribed 6-month interval [56]. In a text-based insulin titration program, reminders were sent to participants to input blood glucose levels. Every weekday, at a patient-specified time, participants received a text message asking, "What was your fasting blood sugar this morning?" [57].

### **3.2.1.5 Care Plans**

Eight PSPs reported using care plans to assist patients in managing their disease conditions. These plans contained individualized care recommendations, written feedback on personal problem profiles, and goals for changing health behaviors and reducing risk factors. Some factors that the individualized care plans addressed include education, secondary prevention, rehabilitation, recovery, referrals to community-based resources, caregiver support services such as family psychological intervention, patient-specific case management plans, information on drug adherence training, or

daily skills training. Care plans were sometimes used as a tool for the development of shared solutions, for example as part of a multiple sclerosis management program [58]. Care plans developed for patients as part of a multidrug resistant tuberculosis program were focused on treatment retention and were individualized based on psychological and social assessments [33]. Other PSPs included advance care planning, including help to complete advance directives in the case of a transition program for vulnerable seniors and a cancer care program [59, 60]. A PSP for diabetes management included an action plan for changing health behaviors [61].

### **3.2.1.6 Monitoring**

Fifteen PSPs offered monitoring services to support patients with disease management and medication adherence. Monitoring services were often digital and involved progress-tracking, symptom tracking, or medication adherence monitoring with alarms addressed by health care providers. Information was monitored in real time or asynchronously, and periodic patient evaluations by health care providers. As part of the services offered for a maintenance program for patients living with schizophrenia and taking antipsychotic drugs, periodic psychological evaluations were conducted at baseline and at 6-, 12-, and 24-month visits [48]. A digital medicine program utilized medication packaged with an ingestible sensor and a wearable sensor patch to track ingestions events, termed “wirelessly observed therapy”. The digital medicine program directly measured medication ingestion adherence, heart rate, physical activity, and other biometrics. It then provided real-time feedback to patients and health care providers via mobile devices and a dedicated web portal to support patient self-management and facilitate therapy optimization by the health care provider [44]. Another PSP used a pharmacy dispensation system to actively monitor chronic obstructive pulmonary disease patients’ use of bronchodilators at 6 and 9 months as an indication of their disease management status [62]. A school asthma program follow-up monitoring service was conducted by school health staff who contacted the child’s caregiver to reassess symptoms using a web-based application. If a child continued to have symptoms that were not well controlled, a guideline-based step-up in therapy was employed [63]. In the case of a nephrology PSP, data from a pre-defined medical questionnaire about their physical condition was presented to patients in their homes via an interactive web-based telemonitor and responses were monitored by medical staff [55].

### **3.2.1.7 Medical, Clinical or Pharmacy**

Twenty-four PSPs reported providing medical, clinical or pharmacy services. Services included consultations such as clinic visits and post-prescription support services such as drug or vaccine injection or drug infusion services, drug adjustment and adverse event problems, clinical diagnostic measurements and reordering of medication and review of treatment. Other services included home visits for assessments or crisis resolution and health care services provided in response to medical alerts. As part of a text-based insulin titration program, registered nurses called patients once weekly to advise on dose titration using structured algorithms that adjusted dose based on patient input values for blood glucose levels [57]. In a community program for patients with psychosis, home treatment teams provided rapid access and intensive psychological support services in the community to prevent the need for hospitalization [50]. As part of a community asthma care program, one-on-one consultations with a clinician were made available [39], and as part of a Chronic Obstructive Pulmonary Disease (COPD) management program led by pharmacists, interdisciplinary care was offered so that proposals for dose, medication and/or inhaler change, and physical activity or diet recommendations were discussed with the general practitioner, physiotherapist or dietician, when deemed relevant [62].

### **3.2.1.8 Laboratory**

Six PSPs reported offering laboratory services to support patients with disease or drug management or disease transmission management. These services included therapeutic drug-level testing [64], serological testing of patients, partners or family members for HIV or viral hepatitis [35, 38, 44], HIV drug resistance testing [65], pregnancy testing [44] and measuring blood cell count [40].

### 3.2.1.9 Quality Assurance and Safety Systems

Nine PSPs reported having quality assurance or safety systems in place. These systems included audit and feedback systems to assess health care provider performance, a requirement for the use of clinical practice guidelines, the use of health care provider reviews, checklist tools to ensure fidelity of the interventions applied, and the use of biometric technologies to assist health care providers in tracking patient treatments. In a PSP developed for hypertensive patients, HCPs were sent data on panel performance with unblinded provider rankings, and a list of their hypertensive patients. Individualized, bimonthly reports were also sent to faculty providers via e-mail and to medical residents via meeting with the residency quality improvement faculty member [66]. In the case of a school program of asthma maintenance, clinical practice guidelines were used in the development of assessment materials [36]; for a stroke transitional care program, standardized clinical assessments that include social and functional determinants of health informed individuals patient care plans [46]; and, as part of a PSP for a diabetes management, clinicians use standardized clinical guidelines [63]. In the case of a nurse practitioner (NP)-led intervention for older adults, the NPs used a checklist at each client visit/contact to provide structure and record their intervention activities. Subsequently, biweekly case reviews were held where the intervention records were read and cases were discussed to ensure fidelity of the intervention [59]. As part of a TB treatment program, an electronic biometric system known as “eCompliance” was used to assist health care providers with the monitoring of TB treatment for patients and the efficacy of their teams [67]. The electronic system scanned patients’ fingerprints at a netbook computer terminal during every visit. This information was used by supervisors to ensure the efficacy of the work that their teams were doing, particularly as the biometric requirement ensures that all information reported by field workers was true, and that all patient visits were recorded at the correct time.

### 3.2.1.10 Support for Health Care Providers and Case Managers

Seventeen PSPs provided support services for health care providers and case managers responsible for delivering patient care. These services included education and training, tools to facilitate care provision, and peer support resources. Clinical decision-making support systems, information systems, and automatic reminders installed on site computers were also provided (see more detail in the, Information Technology and Systems section 3.2.1.7). As part of a program to promote viral load suppression for highly vulnerable people living with HIV, interdisciplinary adherence support teams that consisted of medical doctors, case managers, and clinical social workers were trained in Cognitive Behavioral Therapy (CBT) and Motivational Interviewing (MI) modalities of engagement. Training occurred over multiple booster sessions throughout the course of the intervention as adherence teams engaged in periodic sessions with participants as part of the program [68]. As part of a stroke transition care program, a 2-day interdisciplinary training in post-acute care was provided for nurses and advanced practice provider training was provided for physicians. In addition, monthly peer support calls were provided for hospital providers and home health clinicians [36].

## 3.2.2 Empowerment and Self-Management

Seven PSP service subthemes were identified that support patient and caregiver *empowerment and self-management*, including patient counselling, patient education, patient training, support for caregivers and family members, self-management incentives for engagement, self-management supplies, devices, aids, tools and apps, and capturing patient reported experience measures, see sections 3.2.2.1 to 3.2.2.7.

### 3.2.2.1 Patient Counselling

Twenty-nine PSPs included patient counselling as part of the service offering. Counseling services covered a broad range of topics including behavior and attitude modification, pregnancy prevention, managing drug adverse effects, medication or therapy adherence, preparing for clinical appointments, goal setting, problem solving, self-care, informational counselling, addressing misguided beliefs and promoting self-efficacy. Support was provided via group or one-on-one counselling sessions or through digital media such as text messages. As part of a PSP for diabetes, counselling services

included role play, problem solving among patients, and group sessions. These sessions focused on realistic aspects of physical activity and nutrition, an open discussion of setting goals, and a strategy to overcome any obvious barriers [69]. As part of a COPD PSP, counseling services focused on several aspects of adherence including beliefs and expectations, reminders, and highlighting importance of continuous use in accordance with prescription, support for cessation of smoking, and recommendations regarding self-management [62]. As part of a hypertension management program after stroke, advanced practice nurses called program participants a minimum of once per month, using MI techniques to promote risk factor reduction over a period of six months [70]. In another example, as part of a HIV case management program, trained peer counsellors offered information counselling and counselling support to address real and perceived barriers to care, disclosure to partners or family members and HIV care [35].

### **3.2.2.2 Patient Education**

Thirty-four PSPs offered educational components to participants. Some of these educational strategies involved active engagement, for example, face-to-face or virtual educational sessions, simulations or groups sessions, while others were more passive in nature, delivered in magazines, booklets, posters, DVDs, newsletters, step-by-step instructions for medical devices (injectors), web-site access for treatment information, online electronic-series or email communications. These educational tools covered a broad range of topics including information about a specific disease, product (handling and storage), drug access, and/or self-management skills. For example, health education for gout targeted misguided beliefs regarding urate-lowering therapy and improvement in self-efficacy [64]. Also, a 2-day educational program offered for inflammatory bowel disease was designed to improve patient knowledge about the disease, promote health literacy and enhance self-management skills [71]. For a stroke transitional care PSP, the following educational materials were provided: Know your Numbers (e.g., BP, hemoglobin A1c), Engage Mind and Body (e.g., treat depression, engage in rehabilitation), Willingness (e.g., self-manage modifiable risk factors, manage medications), and Support (e.g., seek community support services) [36].

### **3.2.2.3 Patient Training**

Sixteen PSPs included training for patients. Training offered was on the use of medical devices (injection, inhalers, and self-monitoring of measures like glucose or blood pressure), orientation to program tools (on-line and off-line), diet calculations, or food preparation. For example, patients in a program that involved taking an oral medication to treat Hepatitis C packaged along with an ingestible sensor were taught to review an app daily to obtain feedback on their medication adherence. They received hands-on training on the use of the mobile app and software that calculates and summarizes adherence patterns, physical activity, rest, and other self-entered clinical data that patients could view through a mobile device and providers could view through a secure web portal [44]. As part of another PSP for managing multiple sclerosis, patients received training to handle and administer Interferon beta-1b using an autoinjector device [72]. As part of a PSP for persons with diabetes, participants attended group sessions in addition to educational topics including food preparation demonstrations [69].

### **3.2.2.4 Support for Caregivers and Family Members**

Three PSPs provided support for caregivers or family members. A PSP that supported patients living with schizophrenia offered a family psychological intervention as part of their services [48, 49]. Another program designed to support minors managing attention deficit disorder, provided access to trained nurses who by telephone supported the carers of children and adolescent patients, assisting with the management of adverse effects of treatment and with the management of expectation in the initial phase of treatment [73]. As part of a nurse practitioner led PSP for vulnerable adults, the NP included family members, neighbors, and caregivers in the intervention when needed. The NP conducted all assessments and training with the patients and families and developed the care plan [59].

### **3.2.2.5 Self-management Incentives for Engagement**

Four PSPs offered self-management incentives. As part of a diabetes program in the US, co-pay assistance was offered as an incentive only if patients remained engaged in care and agreed by contract to receive the recommended tests and health exams [74]. Alternatively, for a stroke PSP delivered in the US, patients received materials to enhance retention, including mailings and a \$10 incentive for survey participation [36]. As part of a PSP for highly vulnerable patients living with HIV in the US, program participants who maintained viral loads at or below 50 c/ml at their quarterly assay were rewarded with a \$100 gift card [68]. Finally, as part of a PSP for patients with osteoporosis in Japan, participants received certificates of recognition when they completed the full course of treatment [75].

### **3.2.2.6 Self-management Supplies, Devices, Aids, Tools and Apps**

Thirteen PSPs supplied devices, aids, tools, or apps to support patient self-management. These items included care packages containing medical and/or personal care supplies, coaching kits, medical devices for medication administration or adherence or monitoring (e.g. auto-injector devices, ingestible and/or wearable sensors, digital flow meters), e-devices and virtual resources for information capture, sharing and monitoring (e.g. access to apps, web portals, software, smartphones etc.). As part of a PSP for patients with multiple sclerosis, participants were supplied with a multidose cartridge and an auto-injection device with adjustable comfort settings and equipped with an electronic injection log that could be used for self-monitoring and as a reminder system [76, 78]. As part of a pharmacy case management PSP for patients taking antineoplastic medicines, program participants received a care package containing items to assist with side effect management, medication adherence, and medication monitoring. Care packages also contained other self-care materials and supplies including sunscreen, lip balm, lotion, anti-diarrheal agent, pill organizer, hot/cold pack, water bottle, gloves, pocket calendar, a cancer resource guide, a blood pressure monitor, and thermometer [54]. As part of an electronic medical record-integrated smartphone telemedicine program to deliver asthma care remotely, participants received access to smartphones and a patient portal app through which they recorded symptoms, medication use and Peak Expiratory Flow using a digital flow meter that was also supplied [41].

### **3.2.2.7 Capturing Patient/Carer-Reported Experience Measures**

Five PSPs reported including tools for measuring the patient experience. In most cases patient satisfaction surveys were employed to assess the patient-carer experience [36, 44, 52, 73], and in one case open-ended interviews were conducted to capture patients' experiences [41]. For example, as part of a PSP for stroke patients, participants in the program were incentivized to complete a patient survey [36]. In a second example, as part of a PSP for youths with ADHD, at the end of the program, carers were asked to complete a satisfaction survey to provide feedback on the service [73].

## **Table 2: References for PSP Service Subthemes Identified**

Service Subtheme/References by Disease Category	I	C, M and E	P/MH and A	N and CNS	ID and V	O	R	M and O	N, R and U	V
<b>Empowerment and Self-management</b>										
Patient Counselling	[27-32], [45], [64], [79-81]	[61/84], [66], [69], [70], [74], [82/83]	[85], [37], [50], [86], [42]	[43/87], [58], [72/88]	[35], [68], [38], [65], [44], [53], [33]	[89]	[62]	[56]		[59]
Support for Caregivers/Family Members			[48/49], [73]							[59]
Patient Training	[90], [27-32], [64]	[82/83], [69], [66]	[48/49]	[76-78], [72/88], [58]	[44], [53]	[41]	[62]	[75]		[59]
Patient Education	[91], [79-81], [27-32], [92], [45], [64], [71]	[82/83], [69], [61/84], [93], [70], [74], [66], [36], [46]	[94], [37], [86]	[76-78], [58], [72/88]	[68], [38]	[54], [89], [95], [60], [52]	[41], [62]	[56]		[59], [51]
Self-management Incentives for Engagement		[74], [36]			[68]			[75]		
Self-management Supplies, Devices, Aids, Tools and Apps	[27-32], [45]	[82/83], [70]	[37], [42]	[76-78], [43/87], [72/88]	[44], [53]	[54]	[41]			
Patient/Carer Experience Measurement		[36]	[73]		[44]	[52]	[41]			
Medication Adherence Support	[91]*, [27-32]	[70]								
<b>Access and Equity</b>										
Social Support Services					[33]					
Health Care Provider Services	[79-81], [90], [27-32], [81], [92], [45], [64], [71]	[69], [82/83], [61/84], [93], [70], [74], [66], [36], [57], [46]	[94], [85], [34], [48/49], [73], [37], [50], [86], [42]	[76-78], [43/87], [58], [72/88], [96]	[35], [68], [38], [65], [44], [53], [47], [67], [33]	[40], [54], [89], [60], [52]	[39], [41], [62], [63]	[75], [56]	[55]	[59], [51]
Patient Support Program Awareness		[36]								
Navigation or Referrals to	[79-	[61/84],	[85],		[35],	[60]	[62]			[59]

Resources and Programs	81], [64]	[36]	[34], [73], [42]		[68], [38], [65], [53], [89]					
Financial Services for Medication Access	[91], [27-32], [92], [45]	[82/83], [74]	[34]	[58]	[35]	[54]	[39]			
Logistics Services	[90], [27-32], [92], [45]	[82/83]	[94], [85], [34], [48/49]	[76-78], [96]	[35], [38], [47], [53], [33]	[40], [54], [89]	[41]	[75], [56]	[55]	[59], [51]
Information Technology Systems and Services		[82/83]	[42]	[43/87]	[44], [53], [67]	[54], [95]	[41], [63]		[55]	
Culturally Relevant/Accessibility Services	[45]	[46]			[47]		[39]			
<b>Health Services</b>										
Screening and Assessment/Reassessment	[71]	[82/83], [61/84], [93], [70]	[48/49], [50], [86], [42]		[35], [38], [65], [44], 1085	[60], [52]	[41], [63]		[55]	[59], [51]
Care Coordination and Communication	[79-81], [45], [71]	[69], [61/84], [93], [74], [66]	[94], [85], [34], [48/49], [73]	[76-78], [43/87]	[35], [68], [38]	726, [52]	[41], [63]			[59], [51]
Follow up	[92], [45], [64]	[69], [70], [57]	[85], [34], [37]	[76-78]	[38], [65], [44], [53]	719, [60], [52]		[56]	[55]	[59], [51]
Reminders	[79-81], [27-32], [45], [64]	[82/83], [57]	[34], [37]	[43/87], [72/88], [58]	[35], [38], [44], [53]	[95]	[41], [63]	[75], [56]		
Care plans	[71]	[61/84], [36]	[48/49]	[58]	[33]	[89], [60]				[59]
Monitoring		[82/83], [36]	[94], [85], [48/49]	[43/87]	[68], [44], [53], [67]	[40], [52]	[62], [63]		[55]	
Medical, Clinical and Pharmacy	[90], [92], [64]	[82/83], [93], [70], [66], [36], [57]	[94], [50]	[76-78]	[38], [65], [47], [53], [33]	[40], [52]	[39], [41], [62], [63]			[51]
Laboratory	[64]				[35], [38],	[40]				

				[65], [44]			
Quality Assurance and Safety Systems	[66], [36], [46]	[73]	[43/87]	[67]		[62], [63]	[59]
Support for Health Care Providers and Case Managers	[61/84], [93], [70], [36]	[94], [73], [37]	[43/87]	[35], [68], [44], [67], [33]	[89], [95]	[62], [63]	

I = immunology, C, M and E = cardiology, metabolism and endocrinology, P/MH and A = psychology/mental health and addictions, N and CNS = neurology and the central nervous system, ID and V = infectious diseases and vaccines, O = oncology, R = respiratory, M and O = musculoskeletal and osteology (2 articles), N, R and U = nephrology, renal and urology or V = generic chronic diseases or various disease areas; / = indicates articles that describe the same PSP.

**Figure 7: Sunburst diagram showing the percentage of PSPs that incorporated each service subtheme, Total Number of Programs (56).**

Soc Serv Support = Social Services Support; PSP aware = PSP awareness; Nav Ref - Res Prgm = Navigation/Referrals to Resources or Programs; Financial Serv. = Financial Services, IT Sys and Serv = IT Systems and Services; Cult Access Serv = Cultural Accessibility Services; Px Couns. = Patient Counselling; Px Training = Patient Counselling; Px Education = Patient Education; Self-Mgmt Inc Px Eng - Self-Management and Incentives for Patient Engagement; Self-Mgmt Supp - ; Px/Carer Exp Meas - Patient/Carer Experience Measures; Care Coord and Comm - Care Coordination and Communication; Med, Clin, Pharm - Medical, Clinical, Pharmacy; QA and Safety Sys - Quality Assurance and Safety Systems; Sup HCP = Support for Health Care Providers; Screen and Assess = Screening and Assessment

## 4. Discussion

### 4.1 Main Findings in the Context of Previous Research

Many of the PSPs identified offered critical services that promote access to care and support for disease management, self-management and medication management (Figure 8, Online Resources, ESM5 and ESM6). Several PSPs provided logistics services, financial assistance and health care provider services in an effort to facilitate health care access and equity for patients.

#### 4.1.2 Technology

Technology played a central role for some PSPs as a mechanism for supporting health care delivery. E-technology was used to provide remote care for patients to facilitate access, to deliver reminders to patients and health care providers in the form of text messages or emails and as clinical decision-making software for HCPs to improve quality in health care delivery. It is reported in one systematic review that the use of telemedicine to deliver health care to patients managing heart failure at a distance resulted in similar outcomes as compared to face to-face delivery of care, and that in the case of diabetes management, telemedicine led to improved blood glucose control [97]. In the coronavirus pandemic era, the uptake of mobile medicine has greatly increased to enable patient care continuity [98]. Since the literature supports that the use of technology can be an effective means to improve access to PSP services and improve quality of care (e.g. communication, decision support), this presents an opportunity for future research to gain a better understanding of telemedicine impacts on access to care, the care experience and outcomes for patients living with various diseases as well as the cost-benefit of using telemedicine.

#### 4.1.3 Self-management

Although it varied by specific disease, many of the PSPs also offered counselling, educational and training resources to help participants increase their health literacy, and skills to effectively manage their conditions. These self-management strategies are reported to improve health comes, health-related quality of life and physical, social and psychological function in patients managing various diseases [6]. In addition these self-management strategies led to increase knowledge about the disease, self-efficacy and improvements in health behaviors [6].

#### **4.1.4 Interdisciplinary Care**

Care coordination including communication and collaboration are vital elements of patient-centered care [99, 100]. Many of the PSPs offered health services including medical, clinical and pharmacy services. Several PSPs offered care coordination services and highlighted the importance of interdisciplinary collaboration as a key component in providing care for patients managing chronic conditions. As described in several PSPs, nurses and pharmacists led the programs and were trained to deliver specialized services – expanding their scope, to be responsible for monitoring patient status and providing reports to physicians as needed to support patient care (see section 3.2.1.2 care coordination and communication). Furthermore, in one systematic review that evaluated interdisciplinary care interventions for patients managing chronic musculoskeletal pain, patient-centered interdisciplinary interventions were more effective than usual care across four dimensions including health outcomes, health care costs, quality of care experienced by patients and work satisfaction for health care professionals [101].

#### **4.1.5 PSP Access**

While it is evident that patient support programs are important resources for patients who are living with chronic medical conditions that require disease and medication management, unfortunately awareness of many of these programs remains a barrier to access for patients [7]. This scoping review suggests that more efforts may be needed to increase awareness of patients and healthcare providers about the existence of PSP's. Only 1 of the 56 unique PSPs identified, specifically reported that increasing community awareness of the program was actively pursued. Increasing PSP awareness for health care providers and patients represents an opportunity to provide patients with potential access to services from which they may benefit.

#### **4.1.6 Service Gaps**

While many PSPs offered the aforementioned benefits, some elements of service quality that are considered to be important for health care service delivery were lacking in the PSP studies. Although we cannot be certain as to whether these aspects of service were provided, many of the PSP's did not report on these specific aspects of service, see sections 4.1.6.1 – 4.1.6.3.

##### **4.1.6.1 Support for Caregivers and Family Members**

Patient-centered care also includes the involvement of, and support for families and other of carers of patients [100]. Although it is well known that a support network is critical for patient well-being and that carers for persons with chronic conditions experience fatigue and burnout [102], only four PSPs reported offering services for family, support persons or carers of persons with chronic conditions. Providing more resources for patient support persons also presents an opportunity when developing PSPs for patients living with chronic conditions. In a meta-analysis of psychosocial interventions for carers of persons living with dementia, increased knowledge gained by carers resulted in delayed nursing home admissions for persons living with dementia [103].

##### **4.1.6.2 Health Equity**

Health equity is recognized as a critical challenge for health care delivery around the world [104], and achieving the highest standard of health attainable is considered a basic human right [105, 106]. Health equity is intimately tied to the social

determinants of health [107]. Although it is well known that socio-economic factors greatly influence health, only one PSP reported providing social services (e.g. food security and housing), in addition to health care services. Furthermore, only 7% of PSPs discussed cultural accessibility services such as drug access for indigent populations or providing services in multiple languages. These more holistic and inclusive approaches to health care take into consideration that all basic needs must be addressed if vulnerable persons are to be successful with health care therapies and treatments, and highlight a strategy to improve health equity. It is important to note that articles that emphasized providing employment and housing services, but that did not also provide health services were excluded from the search. In addition, some PSPs did offer referrals to social service providers which could lead us to underestimate the focus on social services; however, it still highlights the need for both social services and health services to be more closely coordinated.

#### **4.1.6.3 Patient-Reported Experience**

Patient-centered care is a key element of healthcare quality, and is a central tenet in providing support that respects patient's dignity and has been shown to lead to improved health care outcomes for patients [99, 108]. Gathering feedback from patients about their care experience is central to providing patient-centered care that is responsive to patient's values, preferences and needs [99, 109-112]. This underscores the importance of incorporating patient feedback as an integral part of PSP development, evaluation and a critical strategy for improving program services and delivery. Nevertheless, as part of this scoping review, only five PSPs, or less than 10%, reported administering patient surveys as a means to assess the patient feedback on their care experience. Some PSPs did discuss conducting needs assessments to personalize patient care and to set health goals, while others offered diverse means of communication and opportunities to tailor services to patients to meet lifestyle needs. These strategies offer opportunities to make health care services and health care delivery more patient-focused.

#### **4.2 Strengths and Limitations**

Strengths of this scoping review are that it included articles that described PSPs that focused on a range of disease conditions and that were provided by government, private, and not-for-profit organizations around the world; hence, we anticipate that the findings from this study may have broad applicability for health care systems globally. Furthermore, we categorized the service subthemes identified among the PSPs within a patient-centered framework, in an effort to provide evidence that could assist organizations in improving existing PSPs or in the design and implementation of new PSPs. Finally, to our knowledge, this is the first scoping review to be published that provided an in-depth description of the services offered by PSPs.

This scoping review is limited by our search strategy and also by the extent to which articles included details with respect to describing PSP services. The search strategy was limited to the academic literature published after 2010, and so we may have missed some other relevant articles that were published prior to that date. However, we felt that keeping the search more recent would reflect more accurately the current PSP offerings. In addition, the search was designed to capture only PSPs that included a medication adherence service component, and as such we did not capture health promotion programs or programs for chronic diseases for which PSPs did not offer medication adherence support. Only articles that reported on humanistic, clinical or economic outcomes were included; other articles that were purely descriptive or that had other types of outcomes were not included. It is also important to note that a PSPs offered additional services depending on the country in which they were delivered, and as such this could impact the accuracy of the quantification of the percentage of PSPs that offer specific services. Finally, since PSPs offered by private industries are considered proprietary, all services identified were not always described in detail, and this could make categorization of some of the services into subthemes difficult. For example, some PSPs (3) indicate offering medication adherence support, but did not specify whether it was in the form of counselling, education, reminder, or other type of service; hence, this service could not be categorized into the various subthemes.

The quality of the research articles included was not evaluated for this scoping review. As a next step for this work we propose to conduct a systematic review in an effort to identify the service elements that are most effective in promoting patient well-being. This future effort was highlighted as relevant to future PSP development by local health experts who were consulted to review this article as part of a knowledge translation exercise.

#### **4.4 Implications for Policy Practice or Research**

##### **4.4.1 Health Equity for Vulnerable Populations**

One implication for policy stemming from this research is the consideration that health care services and social services could be more closely integrated. For some PSPs, needs assessments were conducted and referrals were made to other social services providers in order to address needs such as legal consultations or housing. However, only one PSP described social services as being intimately tied to the health services offered. Awareness that health care access is associated with social support needs is an especially important consideration for PSPs that serve vulnerable populations. We propose that greater collaboration between social services and health services departments/organizations should be explored as a mechanism to optimize health service effectiveness.

##### **4.4.2 Patient Centeredness**

One implication for health services research and health program evaluation is the importance of considering patients' experiences when developing or improving program services. While some PSPs did conduct a needs assessment in an attempt to make programs more patient-tailored, only five PSPs reported that they specifically incorporated patient survey tools to measure the patient experience. Incorporating patient surveys as a part of research or program evaluation for improvement could be valuable in making PSPs more patient-centered.

##### **4.4.3 Patients' Community of Well-being**

Another implication for policy stems from the observations that many patients rely on families or community members to assist them as they manage their chronic diseases and this support network can be critical for their health. Only 5% of the PSPs identified in this scoping review reported offering support services to these caregivers who bear a lot of patients' health care burdens. Recognizing that caregivers are a critical component of patients' circle of care should highlight the need for resource allocation to support caregivers, who care for family members or friends living with chronic diseases in their homes.

##### **4.4.3 Increasing PSP Awareness**

In a report by Deloitte it was highlighted that PSPs were underutilized, especially those that are supported by private industry [7]. Increasing the awareness that PSPs are available to patients within medical and patient communities may allow for patients to get access to value-added services that may help toward improving health outcomes.

## **5 Conclusion**

PSPs are an important resource for patients living with chronic medical conditions and who require therapy or medication. PSPs are provided by governments, non-governmental organizations and private companies, and can empower patients by increasing their self-management skills, incorporating their feedback in program improvements, increasing access to health services, and by providing quality health services. This scoping review describes health services that are offered as part of PSPs, such as health education, counselling, and training, and highlights service gaps such as social support services, patient reported experience measures and support for caregivers that may prove valuable mechanisms for achieving health equity and improved health outcomes for patients. We propose that a strategy that includes the

optimization and coordination of PSPs may contribute to the goal of providing more equitable, sustainable, quality health care globally. Key points for decision makers are summarized in online resource, ESM7.

## Abbreviations

IP-C	Integrated People-Centered
PAP	Patient Assistance Program
PSP	Patient Support Program
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-analyses for Scoping Reviews
WHO	World Health Organization

## Declarations

### Competing Interest

Janssen Inc. (Janssen Canada) funded this research and has a PSP offering; the Janssen BioAdvance® network provides access and affordability support for patients who have been prescribed Janssen medicines, as a single point of contact for patients to learn about their options for support. The research was conducted in partnership between Janssen Inc. and academic researchers at the University of Prince Edward Island (UPEI). Evelyn Pyper and Brenda Fisher are employees of Janssen Inc. and participated in the design of the study, interpretation of data, and review and approval of this publication. Pat Charlton is a researcher that was contracted by UPEI and received compensation through the Janssen Prince Edward Island Health Innovation Partnership (JPEI-HIP) grant that was administered by William Montelpare, a Professor at UPEI. Angela Riveroll is a research scientist employed by UPEI, and was funded by the JPEI-HIP for her contribution to this research.

### Ethics approval and Consent to Participate

The scoping review did not require ethical approval as the information was obtained from publicly available publications.

### Consent for Publication

Not applicable

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### Author Contributions

AR, BF, EP, KM, PC and WM made substantial contributions to the conception and design of the study. AR, EP, KM, PC and WM collected and extracted all relevant data related to the studies and discussed and interpreted the results. AR prepared the first draft of the manuscript with assistance from CB and in collaboration with all authors. All authors critically reviewed and revised the manuscript and approved the final version submitted.

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### Availability of Data and Materials

The data extraction file and other supplementary materials are available as online resources:

ESM1: PubMed Search

ESM2: Data Extraction

ESM3: PSP Sponsoring Organizations

ESM4: Outcome Indicators Measured

ESM5: Service Subtheme Counts by Disease Category

ESM6: Number of Services Offered by various PSP Programs by Disease Area

ESM7: Key Points for Decision Makers

ESM8: Python Code for Frequency Map (Figure 3)

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## Figures

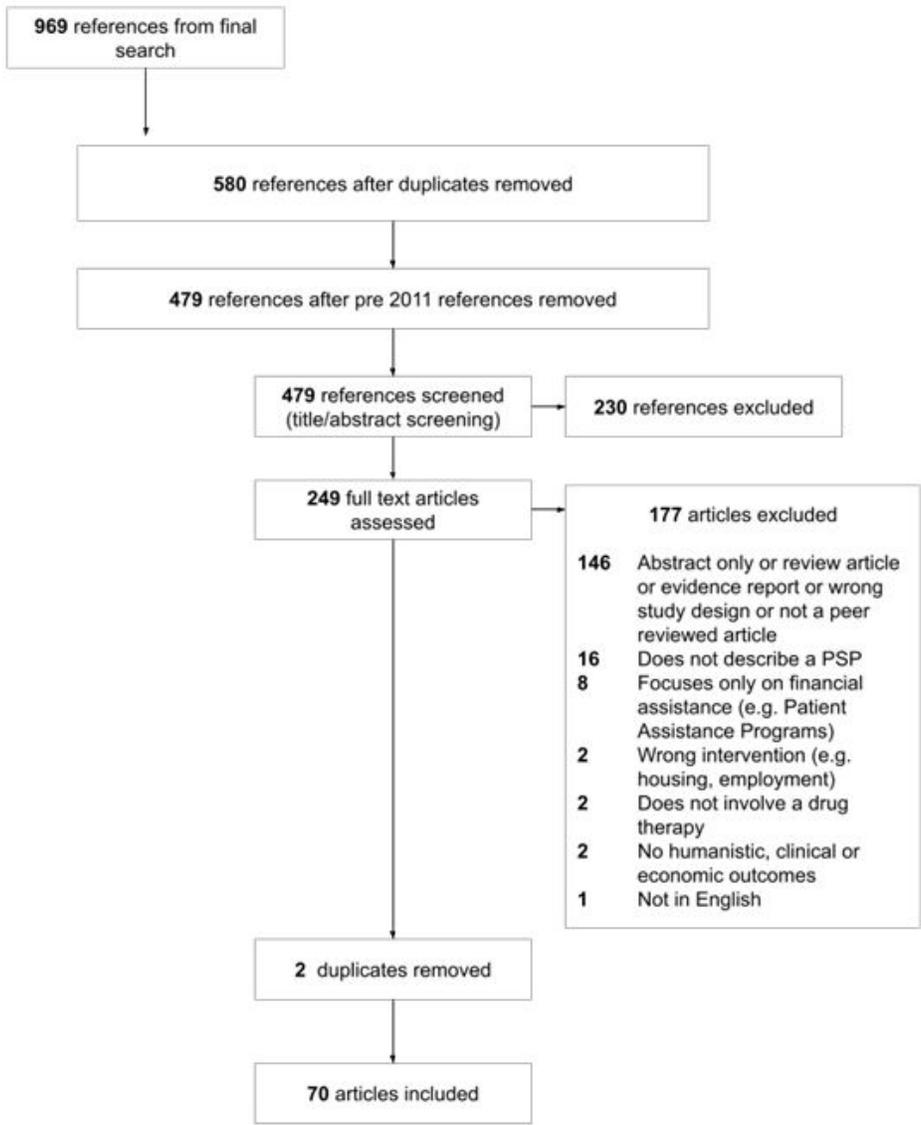


Figure 1

PRISMA Flowchart Outlining the Selection Process for PSP-related Articles

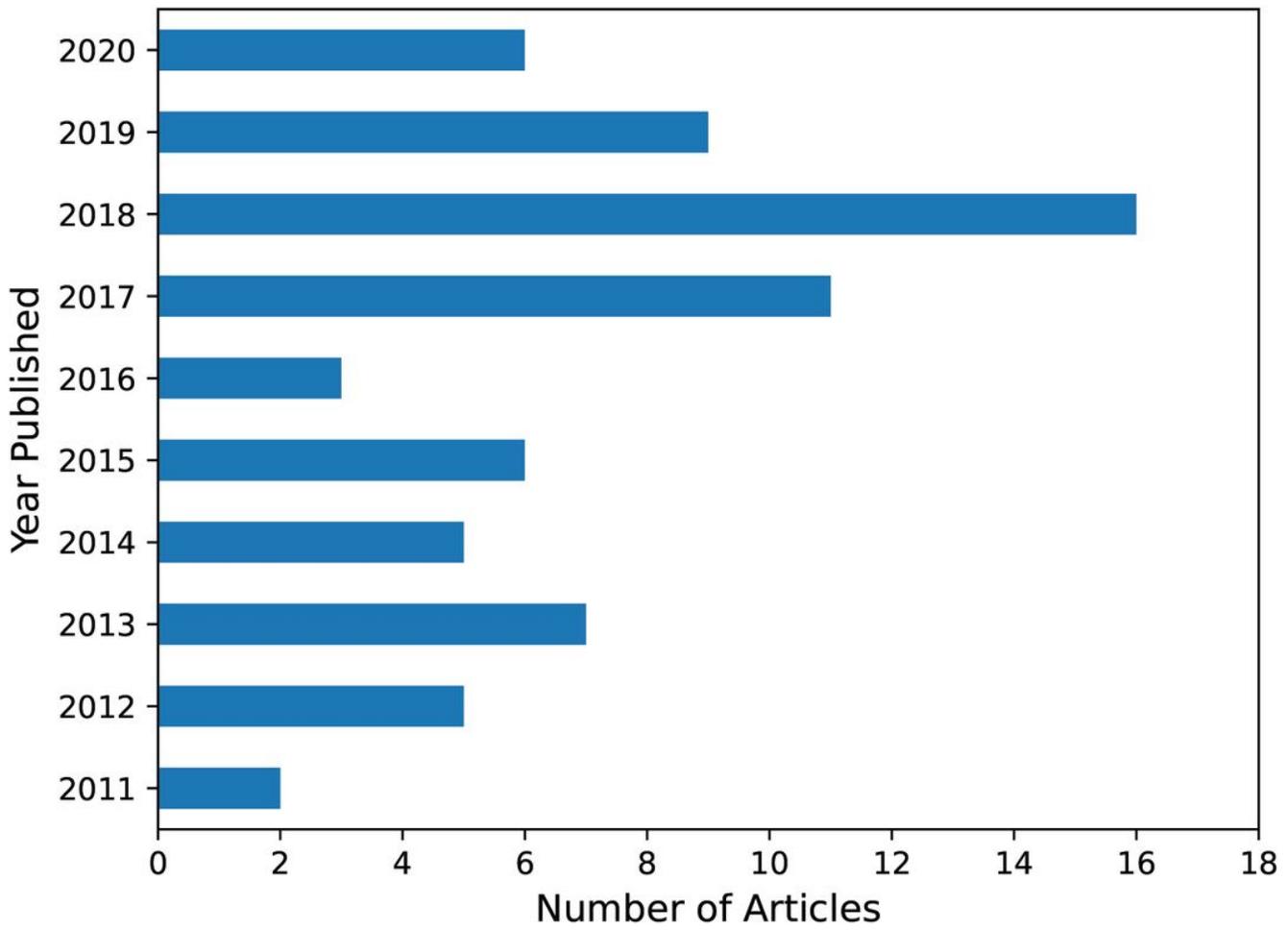
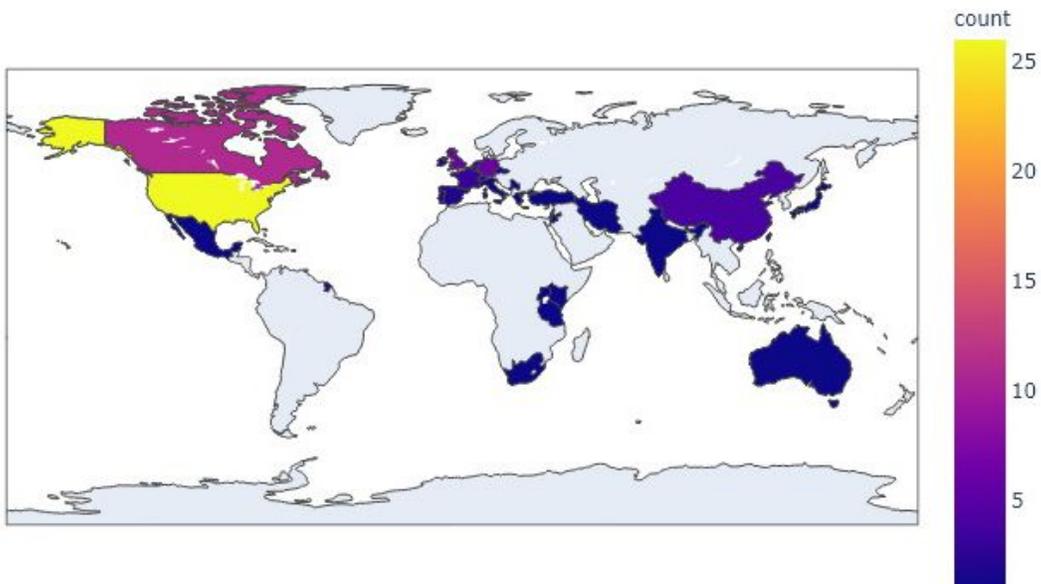


Figure 2

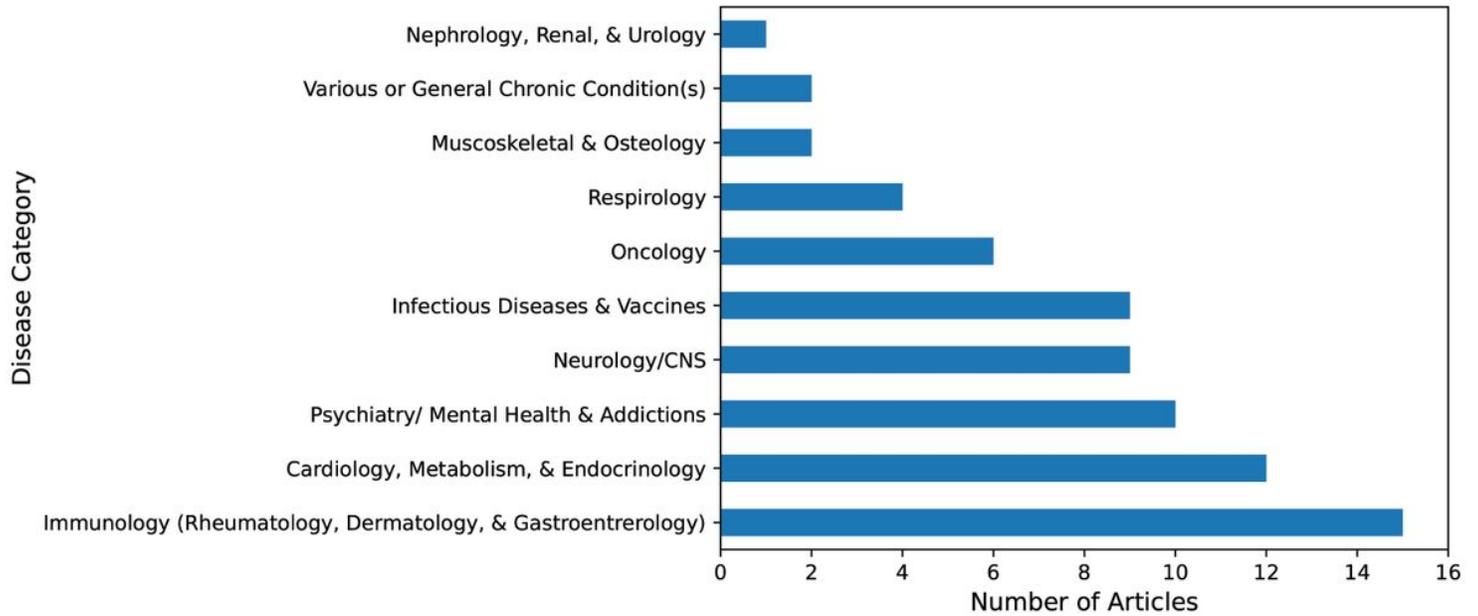
Number of Research articles categorized by year of publication



**Figure 3**

**World map showing the distribution and number of PSP-related articles included in this scoping review**

Figure 3 was generated by AR using the data collected from this scoping review and the Anaconda installation of Python 3.8.5 and PyCharm Community 2020.1 with plotly, numpy, pandas, re and os modules. AR acknowledges stack overflow for the Python code tutorial in using these utilities for map generation published at <https://stackoverflow.com/questions/59297227/color-map-based-on-countries-frequency-counts>. See acknowledgements for more details.



**Figure 4**

**Number of articles included in this scoping review, categorized by disease area**



**Figure 5**

**Distribution of the number of unique PSPs across disease areas**

Cardio-Metab. and Endo. = Cardiology, Metabolism and Endocrinology, Psychiatry-Mntl. Hlth. and Addictions = Psychiatry, Mental Health and Addictions, Neurology and CNS = Neurology and Central Nervous System, Infect. Dis. and Vac. = Infectious Diseases and Vaccines, MSK and Osteology = Musculoskeletal and Osteology

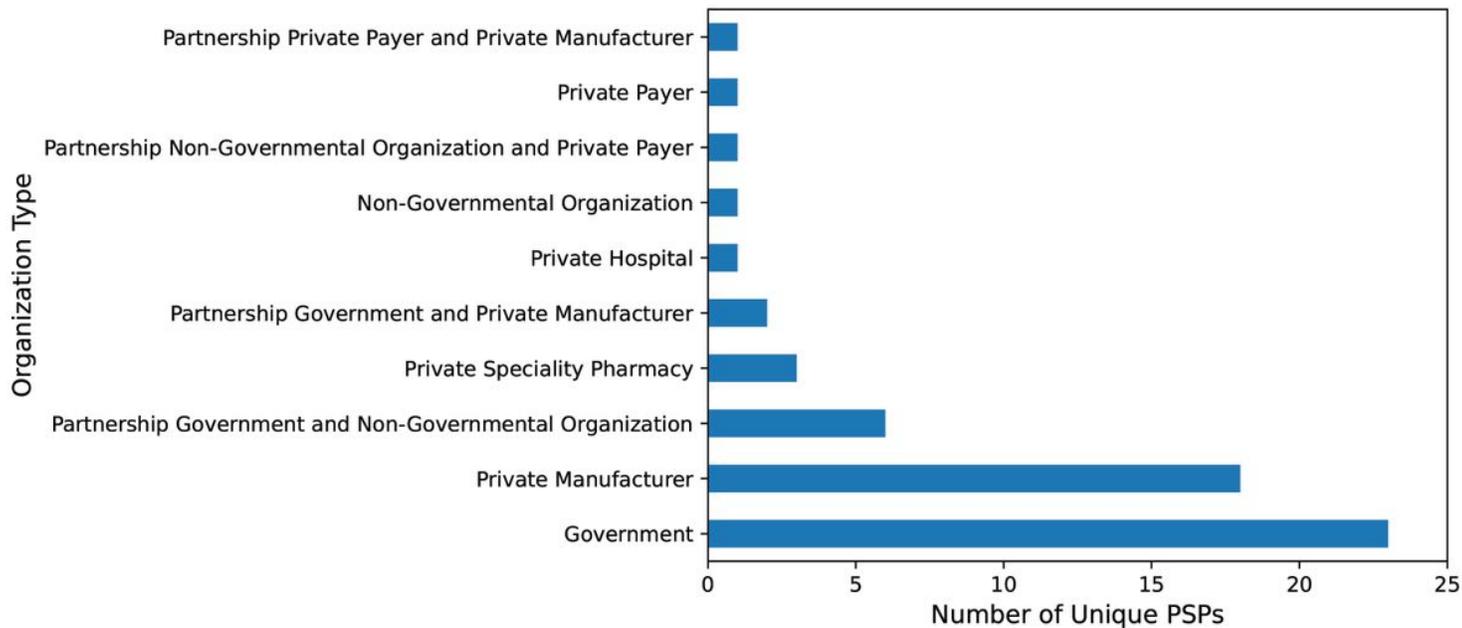


Figure 6

**Organization types and partnernships that funded the unique PSPs identified in this scoping review**

Total count for PSPs in this bar graph is 57, although only 56 unique PSPs were identified. The reason for this is that a PSP that was typically offered by a private manufacturer alone [27-31], was delivered as part of a government-private manufacturer partnership [32] in one article

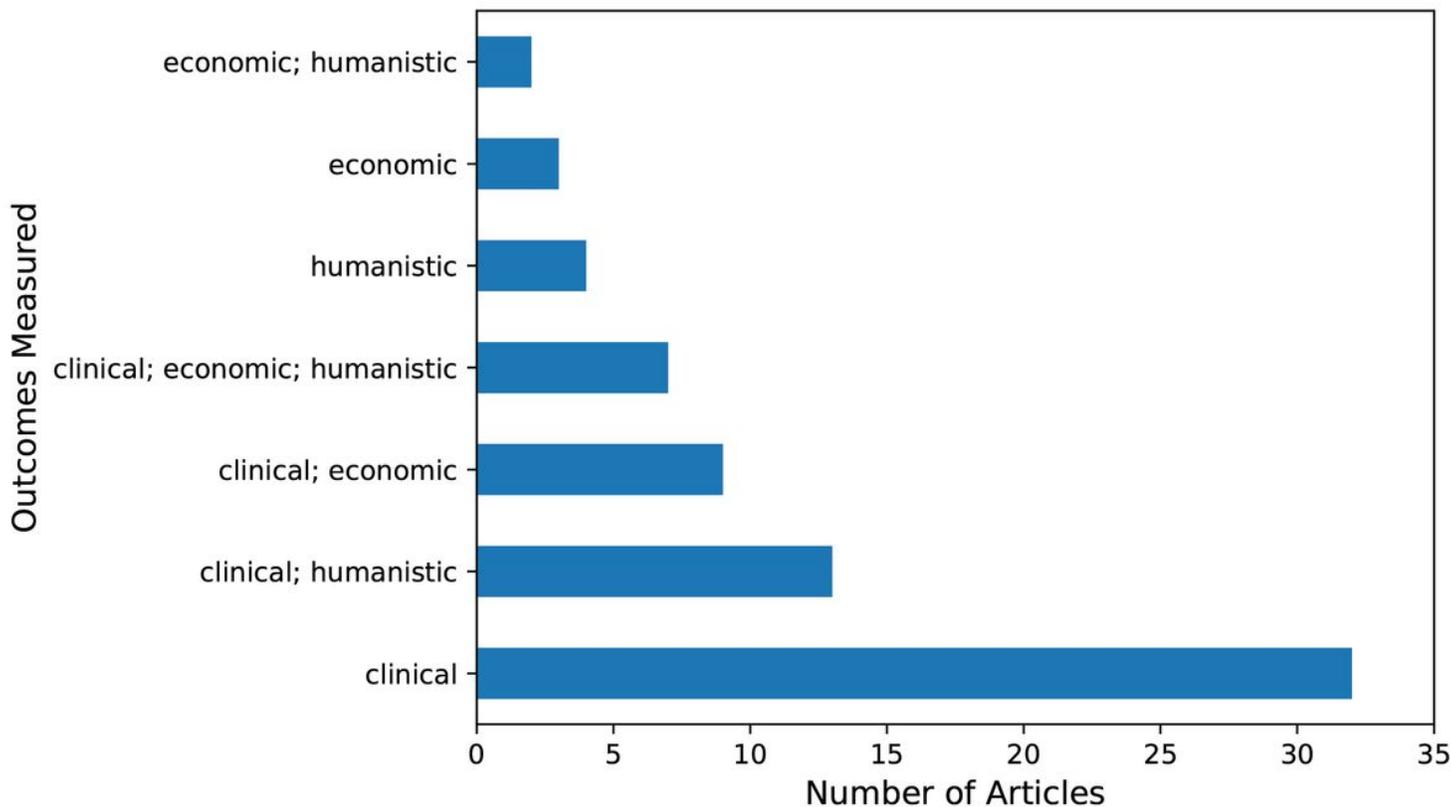


Figure 7

Number of articles that address clinical, humanistic and/or economic outcomes



Figure 8

Sunburst diagram showing the percentage of PSPs that incorporated each service subtheme, Total Number of Programs (56).

Soc Serv Support = Social Services Support; PSP aware = PSP awareness; Nav Ref - Res Prgrm = Navigation/Referrals to Resources or Programs; Financial Serv. = Financial Services, IT Sys and Serv = IT Systems and Services; Cult Access Serv = Cultural Accessibility Services; Px Couns. = Patient Counselling; Px Training = Patient Counselling; Px Education = Patient Education; Self-Mgmt Inc Px Eng - Self-Management and Incentives for Patient Engagement; Self-Mgmt Supp - ; Px/Carer Exp Meas - Patient/Carer Experience Measures; Care Coord and Comm - Care Coordination and Communication; Med, Clin, Pharm - Medical, Clinical, Pharmacy; QA and Safety Sys - Quality Assurance and Safety Systems; Sup HCP = Support for Health Care Providers; Screen and Assess = Screening and Assessment

## Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [ESM1PubMedSearch.xlsx](#)
- [ESM2DataExtraction.xlsx](#)
- [ESM3PSPSponsoringOrganizations.xlsx](#)
- [ESM4OutcomeIndicatorsMeasured.xlsx](#)
- [ESM5ServiceSubThemeCountsbyDiseaseCategory.xlsx](#)
- [ESM6NumberOfServicesOfferedbyPSPProgramsbyDiseaseArea.xlsx](#)
- [ESM7KeyPointsforDecisionMakers.docx](#)
- [ESM8PythonCodeFigure3.docx](#)
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