

# Literature Review

## Family Engagement in Systems

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## Introduction

Families of children and youth with special healthcare needs (CYSHCN) best understand the issues and complexities of care systems because they are involved with all aspects of these systems. As their children's primary caregivers they are personally affected by systems issues. This unique experience makes families key partners in shaping healthcare policies and programs (HRET, 2015; Kuhlthau et al, 2011; Funchess, Spencer & Niarhos 2014; Howrey et al, 2015; Reynolds et al, 2015).

As home to the National Center for Family/Professional Partnerships, Family Voices is an integral component of the Maternal-Child Health Bureau's commitment to authentic patient and family engagement (Krauss et al, 2001; Anderson & Wells, 2005; Wells & Anderson, 2006; AMCHP, 2016) and a long history of efforts undertaken to understand and implement elements of family engagement at the systems level to improve services, programs and policies around children's health. For this literature review, we draw on literature from a variety of sources, within and without the maternal-child health community, including peer-reviewed articles and grey literature reports. The articles and reports reviewed represent wide ranging and sophisticated approaches to patient and family engagement being practiced today, and provide a picture of a vibrant and increasingly evidence-based field of study.

In addition to work that we have been directly involved in, we see years if not decades of patient- and family-engaged work reflected in products such as the American Academy of Cerebral Palsy and Developmental Medicine's framework for care of medically complex children (Glader et al, 2016); the Maternal-Child Health Bureau's work on shared decision-making (Smalley et al, 2014); and the American Academy of Pediatrics care coordination framework (Turchi et al, 2014). Meanwhile, work supported by the Patient-Centered Outcomes Institute is challenging traditional approaches to outcomes assessment and proposing more patient-centered methods for measuring outcomes (Lavalley et al, 2016) and making evidence-based decisions (Dohan et al, 2016).

When family engagement can be assessed, it can be improved, not only enhancing the benefits above but providing best practices that can be shared with other programs and documenting new ways that family/professional partnerships can improve systems of care. As noted in the 2012 Institute of Medicine report, *Best Care at Lower Cost: The Path to Continuously Learning Healthcare in America*, a learning healthcare system is anchored on patient needs and perspectives and promotes the inclusion of patients, families, and other caregivers as vital members of the continuously learning care team.

The Family Voices project, *Framework for Assessing Family Engagement*, addresses the topic of ensuring and enhancing the role and participation of families in all aspects of the systems on which CYSHCN depend. The purpose of the work is to develop a brief that 1) establishes key characteristics of effective family engagement in systems level programs and 2) outlines specific actions to build an assessment based on those key criteria. In addition to this literature review, this work will include interviews with key family and professional informants. A family/professional expert workgroup is actively engaged providing guidance, analysis and interpretation, and additional family leaders in the Family Voices network are being engaged to add unique experiences and perspectives.

## Methods

The Expert Workgroup has convened regularly and contributed actively to developing the process for and participating in the literature review. Articles and reports were selected for the literature review based on the following criteria:

- The article **demonstrated and/or assessed** patient, family, or community engagement at the **systems level**.
- The article described a qualitative and/or quantitative **process** which supported the results and conclusions presented.

- Members of the community were engaged as **experts**. Community members serve as experts when they have sufficient experience with the project/topic of interest to understand and respond to issues at the systems level. Activities that met this criteria included any of the following:
  - Community members participated as members of a **core project team**.
  - Engagement efforts included **training or other capacity-building activities** to support engagement at the systems level.
  - Community members participated as **oversight/advisory council members, key informants**, or in other activities of sufficient duration to imply **capacity and relationship building** (for example, a two-day convening).
  - Focus groups that were **facilitated or interpreted** by members of the community.
  - Surveys that were **developed or analyzed** in collaboration with members of the community.

Articles and reports included in the literature review were identified using several methods, as summarized in Table 1. Articles and reports that self-identified as about engagement but did not document any of the activities described above were excluded from the literature review, leaving a total of 44 articles. Included articles were published between 2001 and January 2017.

Each article and report in the literature review was examined by two dual role (family/professional) reviewers. Key points and constructs were identified, as summarized in the “Literature Review” section below. Articles and reports in the literature review were also assessed for the following features, as presented in the Appendix.

Method	Count
Recommended by project team or workgroup members	21
Structured PubMed search	14
Unstructured Internet search	3
Linked to other articles in the review	6
<b>Total:</b>	<b>44</b>

Table 1: Sources of articles in the literature review

**Type:** The type of source, either “Journal article” or “Report”.

**N:** The number and kind of participants; for example, “3 demonstration projects”, “45 key informant interviews”, “community advisory board, unknown membership”.

**Patient/Caregiver Expertise:** Prevention (no diagnosis), Newly diagnosed, In-treatment, Expert (adapted from PFMD, no date, pg. 7)

**Setting:** The kind of setting associated with activities described in the article; for example, healthcare, school, community-based medical services.

**Focus:** Research, Policy, Innovation, Education, Quality, Community-building, Advocacy, Access (see PFMD, no date, pg. 5; the term “Quality” was added to PFMD’s original list).

**Special communities:** Vulnerable or stigmatized communities addressed by the article or report. For example, communities of color, children with special healthcare needs.

**Assessment Type:** Describes level of assessment that the source provides, including all of the following that apply; Process description, Process evaluation, Impact description, and Impact evaluation.

## Literature Review

The project team identified seven key topics to be addressed to provide the foundation for the *Framework for Assessing Family Engagement*. These topics are: settings; goals/impact; activities; family leader roles and characteristics; professional roles and characteristics; sustainability/effectiveness; and assessment. Findings from the literature review are discussed below for each of these topics.

## Settings

Carman et al (2013) introduced a framework that identified three levels of patient and family engagement in health and healthcare: direct care; organizational design and governance; and policy making. This literature review is concerned with settings that fall into the last two categories. However, many families and professionals focus on the direct care level when thinking about patient engagement (for example, shared decision-making, patient activation). Participating at the systems levels may help a family or patient to think more broadly about engagement at levels two and three (Forbat et al, 2009; Crawford et al, 2002). Belone et al (2016) described setting as a set of overlapping contexts that may be different for different participants in a collaborative process. For example, if a woman is an educator, a mother of a child with a disability, a tribal member, and a member of a local church, each of these contexts may affect her perception of the engagement setting.

We identified that the following three factors can shape which settings will effectively incorporate patient and family engagement:

- Mandates established in legislative or organizational policy (Anderson & Wells, 2005; Carman et al, 2014);
- A project framework that integrates engagement expectations, for example, medical home, care coordination, and patient/family-centered care (Cené et al, 2016; AMCHP, 2016; Antonelli, McAllister & Popp, 2009; Johnson et al, 2008);
- Leadership or champions who embrace engagement (Frampton et al, 2017; Berg et al, 2015).

Large, complex entities, such as state-level maternal-child health agencies (AMCHP, 2016; Anderson & Wells, 2005, 2006; Buxbaum, 2010) or hospitals (Conway et al, 2006), may engage families and patients in many different projects and programs simultaneously, without necessarily coordinating engagement efforts, and due to a combination of the factors described above. In a review of medical home literature, Cené et al (2016) identified quality improvement projects as the primary context for patient and family engagement at the systems level.

Some specific examples of settings for engagement include:

- Advising government entities and policy-making (O’Sullivan, 2014; Conway et al, 2006; Anderson & Wells, 2005, 2006);
- Assessing and redesigning delivery of healthcare services (Berg et al, 2015; Hingley-Jones & Allain, 2008; Plescia, Koontz & Laurent, 2001), including behavioral health (Taylor et al, 2010);
- Developing treatment guidelines (Fraenkel et al, 2016);
- Multi-system needs assessment for CYSHCN (Krauss et al, 2001);
- Translating screening guidelines for use in public education (Westfall et al, 2016);
- Lay health advisor programs (Plescia, Herrick & Chavis, 2008);
- Developing policy recommendations to support children’s hospice care (Hawley, 2010); and
- Involving youth (Bailey et al, 2015), families (Uding, Sety & Kieckhefer, 2007) and patients (Woolf et al, 2016) in medical research.

These examples barely scratch the surface of a widening array of contexts where patient and family engagement has proved successful.

## Goals/Impact

The evidence-base for systems-level impacts of patient and family engagement remains largely qualitative in nature, as indicated in the Appendix in the “Assessment Type” column (Impact description or Impact evaluation). When patient- and family-engaged processes have positive results, it may be difficult to demonstrate that engagement led to these results independent of other elements of the process, and other changes that happened around the same time (Cacari-Stone et al, 2014; Crawford et al, 2002; Plescia, Herrick & Chavis, 2008). The goals listed here are therefore organized according to the strength of the evidence linking them to patient and family engagement.

The following goals for patient and family engagement are supported by a relatively strong evidence base and emerging consensus:

- Increased activation in personal healthcare for participants in systems-level engagement (Crawford et al, 2002; Roseman et al, 2013). It may be viable to experience this benefit on a large scale by normalizing systems-level engagement (Florindi & De Lorenzo, 2015).
- Improved patient satisfaction and perceptions of their healthcare (Frampton et al, 2017).
- Accurate needs assessment and evaluation from the perspective of those who are using services within and across systems (Krauss et al, 2001; Hawley, 2010; Taylor et al, 2010; Percy-Smith, 2007).
- Identifying patient-centered outcomes (Kirwan et al, 2007) and side-effects (Fraenkel et al, 2016) that have been underemphasized in treatment guidelines developed by physicians.
- Improved quality of educational materials and other resources for families, including those provided in multiple languages (Roseman et al, 2013; Anderson & Wells, 2005; Florindi & De Lorenzo, 2015; Hawley, 2010; Woolf et al, 2016).
- Increased job quality for healthcare providers and staff, including improved job experience, improved staff retention, lower rates of burnout, and reduced job stress (Frampton et al, 2017).
- Increased compassion by healthcare providers (Frampton et al, 2017).
- Increased willingness by professionals to participate in patient and family engagement (Crawford et al, 2002; Forbat et al, 2009).

The following goals for patient and family engagement are supported by mandates, standards, and/or best practices although the evidence base is not well established. We are aware of researchers working towards addressing these gaps and expect that evidence and consensus will continue to take shape in coming years.

- Improved quality of care coordination (AMCHP, 2016; Antonelli, McAllister & Popp, 2009).
- Improved quality of patient- and family-centered care (Johnson et al, 2008; Uding, Sety & Kieckhefer, 2007).
- Improved quality of medical home (Cené et al, 2016; AMCHP, 2016).
- Improved quality of services provided by government agencies. Compared to the preceding three examples, mandates and expectations for patient and family engagement vary widely for government services, but are particularly strong as relates to CYSHCN and, to a lesser extent, other maternal-child health programs (AMCHP, 2016; Anderson & Wells, 2005, 2006; O'Sullivan, 2014).

The following goals for patient and family engagement are supported by consensus and some evidence:

- Improved responsiveness and relevance of medical and public health research to patients, families, and communities (Abma, Nierse, & Widdershoven, 2009; Bailey et al, 2015; Woolf et al, 2016).
- Changes to how health services are provided. While the impact can be dramatic when leadership is fully committed (Berg et al, 2015; Plescia, Koontz & Laurent, 2001), under more typical circumstances it may be difficult to tell what contributions, if any, patient and family engagement made to the final product (Crawford et al, 2002, Hingley-Jones & Allain, 2008).
- Improved cultural competence (O'Sullivan, 2014).
- Reduced healthcare costs (Minniti, Abraham, & Johnson, 2014) and improved patient experience without increasing healthcare costs (Roseman et al, 2013), although Roseman et al cite other studies that found increased use of unnecessary services with improved patient experience.
- Improvements to organizational and statutory policies; while patients and families have demonstrated capacity to identify concerns and develop policy-level recommendations for addressing them (Hawley, 2010; Krauss et al, 2001; Florindi & De Lorenzo, 2015), they may be less successful at seeing them implemented (O'Sullivan, 2014; Percy-Smith, 2007). Where the desired policy changes do happen, it is difficult to demonstrate that patient and family advocacy was the reason (Cacari-Stone et al, 2014; Crawford et al, 2002).

- Improved quality when certain services are provided by a fellow patient, family member, or community member, including family support, care coordination, health education, and culturally competent care (Plescia, Herrick & Chavis, 2008; Florindi & De Lorenzo, 2015; Antonelli, McAllister & Popp, 2009).
- Increased access to data and evidence-based decision-making for patients and families (Westfall et al, 2016; Woolf et al, 2016)

The following goals are among the most popular stated goals of patient and family engagement. These high-level goals are difficult to assess directly for impact from engagement activities. The evidence is described as noted.

- Addressing disparities (Scanlon et al, 2012; Cacari-Stone et al, 2014; Belone et al, 2016); Plescia, Herrick & Chavis (2008) observed measurable improvements in health behaviors on the national Behavioral Risk Factor Surveillance System (BRFSS) in an African-American community. Although engagement efforts are well documented (Plescia, Koontz & Laurent, 2001; Plescia & Groblewski, 2004; Plescia, Groblewski & Chavis, 2008), it is impossible to determine the extent to which engagement contributed to the improvement.
- Improved health outcomes; family-centered care is associated with improved outcomes for CYSCHN, but it remains to be established how much of this impact is attributable to systems-level patient and family engagement (Kulthau et al, 2011).
- Healthcare quality improvement; Cené et al (2016) identify several projects using patient and family engagement for quality improvement efforts and note that there is a demand for research to demonstrate whether such efforts are effective.
- Social justice, ethics, accountability; a moral imperative to maximize patients' power in systems that fundamentally affect their lives (Woolf et al, 2016).

With few exceptions, the articles and reports in this review reported good experiences with engagement and high levels of optimism that patient and family engagement is worthwhile.

## Activities

In their multi-dimensional framework for patient and family engagement, Carman et al (2013) propose a “continuum of engagement” where engagement activities can be described as: consultation; involvement; or partnership and shared leadership. Engagement activities as identified in this literature review are organized below according to this framework.

### Consultation

The majority of articles identified in our structured literature searches used only consultation types of engagement. As described in the Methods section, these articles were excluded from this literature review. However, consultation activities are a critical component of patient and family engagement when used in conjunction with other engagement activities. Such methods have lower expectations of and create less burden on patient and family participants, and allow for engagement of patients and families in crisis and others who are not available for involvement or partnership activities as described below. Consultation methods in the reviewed articles and reports took two primary forms: focus groups (qualitative) and surveys (quantitative); see Plescia & Groblewski (2004) and Krauss et al (2001) for examples that blended both methods. Given the evidence base that engaged patients and families can help improve communication with other patients and families (see the Goals section, above), focus groups and surveys will be more informative when undertaken along with involvement or partnership from patients and families, as described below. Reporting back to the patient community turns consultation into a two-way process; more investigation is needed into what kind of information should be reported back and how to do so effectively (Westfall et al, 2016; Kaehne & Catherall, 2013).

### Involvement

Patient and family involvement is characterized by a multi-directional flow of information, which allows patients and families to become knowledgeable about the processes that they are part of, and to apply their knowledge in creative ways. The following activities are examples of patient and family involvement:

- Key informant interviews are one of the most common forms of patient and family involvement (AMCHP, 2016; Antonelli, McAllister & Popp, 2009; Conway et al, 2006; Anderson & Wells, 2005).
- Convenings, or in-person gatherings typically lasting 1-2 days, engage a variety of expert stakeholders including expert patient and family representatives (Woolf et al, 2016; Wells et al, 2014; Johnson et al, 2008; Kirwan et al, 2007). Percy-Smith (2007) demonstrated a “Knowledge Café” variant, which provided youth leaders with an opportunity to advocate to professionals.
- Advisory groups are groups composed either entirely of patients and family caregivers, or of balanced numbers of patients/family caregivers and professionals (AMCHP, 2016; Anderson & Wells, 2005; Wells & Anderson, 2006; O’Sullivan, 2014). Advisory groups may blur the line between involvement and partnership; see “Working groups” in the Partnership and Shared Leadership section below.
- Reviewing or developing educational materials and other support materials for patients (Woolf et al, 2016; Florindi & De Lorenzo, 2015; AMCHP, 2016; Anderson & Wells 2005).
- Care coordination, support, education, and outreach; that is, patient or family caregivers providing care coordination, support, education and outreach to other patient or family caregivers (Florindi & De Lorenzo; Antonelli, McAllister & Popp, 2009; Buxbaum, 2010). Similar approaches have emerged under the labels “lay health worker” or “community health worker” to serve communities identified by location, race, or ethnicity (Plescia, Groblewski & Chavis, 2008).
- Representation on professional committees (Fraenkel et al, 2016; Koniotou et al, 2015);
- Patient and family participation in job interviews for leadership and staff (Hingley-Jones & Allain, 2008).

### **Partnership and Shared Leadership**

Partnership and shared leadership is characterized by blending multiple types of patient and family engagement activities in a single project (Conway et al, 2006; Woolf et al, 2016; Krauss et al, 2001; Hitchen & Williamson, 2015). Patient and family partnerships are therefore composed of **a variety of consultation and involvement activities** as describe above, **combined with power-sharing** activities such as the following:

- Co-leadership, with patients/families and professionals sharing responsibility for strategic planning, key decisions, and oversight (Hitchen & Williamson, 2015; Wells et al, 2014).
- Committees composed of balanced numbers of patients/families, professionals, and other stakeholders (Abma, Nierse, & Widdershoven, 2009; Carman et al, 2013; Kirwan et al, 2007). This may also take the form of an all-patient advisory group that has a balanced role within professional-led decision-making processes (Berg et al, 2015), or vice versa. Fraenkel et al (2016) demonstrated that an all-patient board made evidence-based decisions largely identical to those made by a professional board with patient representatives, while giving different weight to side-effects that impacted quality of life.
- Policy advocacy by and for patients and families (Hawley, 2010; O’Sullivan, 2014; Percy-Smith, 2007), particularly when professionals help improve effectiveness by providing training and a strong foundation in evidence (Cacari-Stone et al, 2014).
- Working groups with balanced composition of patients/families, professionals, and other stakeholders, where working group members share responsibility for the final product (Frampton et al, 2017; Forbat et al, 2009; Carman et al, 2014; Taylor et al, 2010).
- Multi-agency collaborations of both family- and professional-led organizations (Hawley, 2010).

Patients and professionals are not always in agreement about what level of engagement is called for or possible (Gagliardi et al, 2008; Koniotou et al, 2015). Patience and flexibility may be required to achieve the desired results. Robust mechanisms for patient and family recruitment and support are also important; see Sustainability/Effectiveness below for more information.

Carman et al, 2013	Abma, Nierse & Widdershoven, 2009	Roles as reported in actual use
Consultation	Object/Respondent	Focus groups, surveys (AMCHP, 2016; Plescia & Groblewski, 2004; Krauss et al, 2001)
Involvement	Advisor	Advisory committee member (Anderson & Wells, 2005; Wells & Anderson, 2006; AMCHP, 2016) Key informant (AMCHP, 2016; Antonelli, McAllister & Popp, 2009; Conway et al, 2006; Anderson & Wells, 2005) Representative on professional committees (Fraenkel et al, 2016; Konioutou et al, 2015)
	Interviewer/Moderator	Interviewer (Plescia & Groblewski, 2004)
		Participant in staff training (Anderson & Wells, 2005; Wells & Anderson, 2006; AMCHP, 2016) Evaluation/Needs assessment (Anderson & Wells, 2005; Wells & Anderson, 2006; AMCHP, 2016) Support for families or family organizations (Florindi & De Lorenzo; Antonelli, McAllister & Popp, 2009; AMCHP, 2016) Participate in quality improvement (Anderson & Wells, 2005; Wells & Anderson, 2006; AMCHP, 2016) Review or develop materials (Anderson & Wells, 2005; Wells & Anderson, 2006; AMCHP, 2016)
Partnership and shared leadership	Partner	Paid staff or consultant (Anderson & Wells, 2005; Wells & Anderson, 2006; AMCHP, 2016) Review/develop program policies and procedures (Anderson & Wells, 2005; Wells & Anderson, 2006; AMCHP, 2016) Program development, planning, and goal setting (Anderson & Wells, 2005; Wells & Anderson, 2006; AMCHP, 2016)
	Principle	Policy advocacy and education (Cacari-Stone et al, 2014; AMCHP, 2016)

Table 2: Equivalence between frameworks and roles as identified by surveys

### Family leader roles and characteristics

Abma, Nierse, & Widdershoven (2009, pg. 403) identify five roles for patients in research, which we generalize as Object/Respondent; Advisor; Interviewer/Moderator; Partner; Principle. In Table 2, we present the correlation between these roles and the framework by Carman et al (2013) that we described in Settings and Activities above. These framework definitions are then correlated to actual roles as served by families engaged with state-level maternal-child health and CYSHCN activities, as reported by AMCHP (2016) and Family Voices (Anderson & Wells, 2005; Wells & Anderson, 2006). The most common roles were serving as members of Advisory Councils and participating in evaluation activities. Family participation in evaluation activities is mandated for maternal-child health and CYSHCN programs, and is not as common in other sources included in this review. The use of patient and family partners as interviewers or moderators, as identified by Abma, Nierse & Widdershoven, was not identified in the state-level maternal-child health and CYSHCN agencies, but was reported by other sources in this review (Plescia & Groblewski, 2004)

One important characteristic of patient and family participants is their ability to address issues at the systems level, or as O’Sullivan (2014, pg. 16) says, “...family representatives should be selected for their ability to speak on behalf of the needs of all families, that is, the ability to take the specific—their own child’s story—to the broad.” Other characteristics O’Sullivan identified with good patient/family leadership included approachable, a good listener, knowledgeable, confident, the ability to bring up difficult issues while encouraging open discussion, and the ability not to take things



personally. Patient partners working with Koniotou et al (2015) identified consistent participation as key to developing and maintaining the necessary knowledge to participate in patient engagement.

### Professional roles and characteristics

Professional roles and characteristics was a topic rarely addressed by the sources in this literature review, although professionals played critical roles, even in the rare examples where engagement was initiated by patients and families (Hawley, 2010; Wells et al, 2014). The following four roles for professionals were identified:

- **Leadership:** Leaders from the professional field, or “change champions” (Frampton et al, 2017), are essential to success in patient and family engagement efforts. Leaders with explicit decision-making power can advance patient and family engagement rapidly, for example with mandates (Anderson & Wells, 2005; Carman et al, 2014; AMCHP, 2016; O’Sullivan, 2014); however, many patient and family engagement initiatives move ahead without this kind of authority. The more subtle influence of champions, who established patient and family engagement without a structural leadership role, was apparent but rarely described.
- **Gatekeeper:** The gatekeeper selects and recruits patients and families to participate in family engagement. Bailey et al (2015) describe this role and note that family caregivers may also serve as gatekeepers for youth with disabilities. Florindi & De Lorenzo (2015) describe volunteer organizations who act as placement agencies for incoming volunteers and identify those who will participate in engagement efforts. Carman et al (2013, pg. 227) implicitly validate the gatekeeper role in stating, “Although highly motivated patients may become engaged without clear opportunities and invitations, the vast majority of patients will not.”
- **Stakeholder:** Patient and family engagement is often accompanied by engagement with professionals in stakeholder roles (such as healthcare staff).
- **Dual role:** Professionals who are also patients or family members of patients, bring elements of both perspectives and are called “dual role” (Abma, Nierse, & Widdershoven, 2009; AMCHP, 2014). The presence of dual roles was acknowledged but the experience of serving in or working with these roles was not described. We caution that people with dual roles are not typical of the general patient population and should not be treated as “patients plus”. Rather, the dual role is a third role distinct from either patient or professional roles, with a demonstrated value for improving communication between the two groups (Plescia, Groblewski & Chavis, 2008; Roseman et al, 2013; Anderson & Wells, 2005; Florindi & De Lorenzo, 2015; Hawley, 2010).

Key characteristics for professionals participating in patient and family engagement include: flexibility (Antonelli, McAllister & Popp, 2009; Bailey et al, 2015; Belone et al, 2016); transparency and a willingness to be open about issues that might reflect poorly on themselves or their organization (Roseman et al, 2013); and a commitment to personal capacity-building (Belone et al, 2016).

### Sustainability/Effectiveness

“Meaningful and sustainable” is one of the rallying cries of patient and family engagement (Minniti, Abraham, & Johnson, 2014; Frampton et al, 2017; Buxbaum, 2010). There are many suggestions for how to make patient and family engagement sustainable and effective. At the same time, there is little information on which strategies should be implemented first or which are most effective. In Table 3, we put forth a list of suggestions based on this literature review, organized according to the concerns that they might successfully address. More work is needed on the topic of selecting priorities when improving engagement sustainability and effectiveness; this is an area that we will explore further in the key informant interviews.

*Table 3: Recommendations for sustainability and effectiveness, organized by related concerns*

Concern	Recommendations
Patient and family participants don't reflect the diversity of the patient community	<ul style="list-style-type: none"> <li>- Partner with a gatekeeper to recruit and train participants, preferably a community-based organization with established relationships (O'Sullivan, 2014; Florindi &amp; De Lorenzo, 2015; AMCHP, 2016; Wells &amp; Anderson, 2006)</li> <li>- Assign a staff liaison as a single-point-of-contact to provide support, preferably a peer from the same community (O'Sullivan, 2014; Plescia, Groblewski &amp; Chavis, 2008; AMCHP, 2016; Roseman et al, 2013)</li> <li>- Careful use of language (see "Plain language" topic in Resources section below)</li> <li>- Provide translation services (O'Sullivan, 2014)</li> <li>- Develop adaptive communication strategies for patients with special needs (Bailey et al, 2015)</li> </ul>
Desire to institutionalize engagement, "culture of engagement" (AMCHP, 2016)	<ul style="list-style-type: none"> <li>- Mandates in policies, contractual requirements, funding announcements, and accreditation standards (AMCHP, 2016; Anderson &amp; Wells, 2005, 2006; Florindi &amp; De Lorenzo, 2015; Carman et al, 2014; O'Sullivan, 2014; Scanlon et al, 2012)</li> <li>- Incorporate engagement training or activities into new employee orientation, periodic employee evaluations (AMCHP, 2016)</li> <li>- Partner with community-based organizations (AMCHP, 2016; Florindi &amp; De Lorenzo, 2015)</li> <li>- Maintain a patient/family representative on staff (AMCHP, 2016)</li> <li>- Evaluate and improve engagement efforts (AMCHP, 2016)</li> </ul>
Patients and families want to see impact; "translation beyond the initial community" (Belone et al, 2016, pg. 129)	<ul style="list-style-type: none"> <li>- Participation in research (Frampton et al, 2017; Abma, Nierse, &amp; Widdershoven, 2009; Woolf et al, 2016)</li> <li>- Accessibility of research publications: more than half of journal articles in this review were available open access (without a fee); several contained sidebars of key points (Bailey et al, 2015; Berg et al, 2015; Crawford et al, 2002); several included patients or family members as co-authors (Berg et al, 2015; Bailey et al, 2015)</li> <li>- Policy advocacy (O'Sullivan, 2014; Cacari-Stone et al, 2014)</li> </ul>
Trouble selecting or agreeing on priorities	<ul style="list-style-type: none"> <li>- Conduct a structured needs assessment/evaluation working in partnership between professionals, patients, and families (Taylor et al, 2010; Krauss et al, 2001).</li> </ul>
Patients and families don't have time to participate	<ul style="list-style-type: none"> <li>- Support remote access to meetings (O'Sullivan, 2014; see "Remote access" topic in Resources section)</li> <li>- Provide stipends or reimbursement for childcare and travel costs (O'Sullivan, 2014; Roseman et al, 2013)</li> <li>- Hold meetings in locations close to patients and families (O'Sullivan, 2014)</li> </ul>
Patients and families come to meetings but don't participate; or participate for a while then stop coming	<ul style="list-style-type: none"> <li>- Guidelines, purpose, goals, responsibilities (O'Sullivan, 2014; see "Examples" topic in Resources section below)</li> <li>- At least two patient/family representatives; preferably balanced or majority representation (O'Sullivan, 2014; Buxbaum, 2010)</li> <li>- Sensitivity to emotional vulnerability of patient and family participants (Bailey et al, 2015; Hitchen &amp; Williamson, 2015)</li> <li>- Work with patient/family organization to provide support and mentoring (Wells &amp; Anderson, 2005; O'Sullivan, 2014)</li> </ul>

Table 3: Recommendations for sustainability and effectiveness, organized by related concerns

Concern	Recommendations
Patients and families aren't knowledgeable	<ul style="list-style-type: none"> <li>- Patients and families come in with their own knowledge base, which may not include everything they need to know to participate at the systems level (Kaehne &amp; Catherall, 2013; Carman et al 2014; Fraenkel et al, 2016; Buxbaum 2010).</li> <li>- Transparency about challenges faced by professionals (Roseman et al, 2013)</li> <li>- Work with community-based organizations or a patient/family representative on staff to understand and provide what is needed to recruit and support sustained engagement (O'Sullivan, 2014; Florindi &amp; De Lorenzo, 2015; AMCHP, 2016; Plescia, Groblewski &amp; Chavis, 2008).</li> <li>- Consistent participation by patients or families, for example, regular attendance at meetings, in order to develop and maintain relevant knowledge (Koniotou et al, 2015).</li> <li>- Support on-the-job training by choosing methods that cycle rapidly between action and evaluation, for example, action research, plan-do-study-act (Hitchen &amp; Williamson, 2015)</li> </ul>
Staff are not comfortable with engagement, not sure of goals	<ul style="list-style-type: none"> <li>- Training and support for staff is a critical, potentially overlooked, component of effective engagement. Incorporate patient and family engagement into new employee orientation, periodic employee evaluations, and staff development opportunities (AMCHP, 2016; Anderson &amp; Wells, 2005, 2006; Frampton 2017). See Carman et al (2014) for detailed recommendations on the design of engagement training for professionals.</li> <li>- Use patients and families as trainers for staff (AMCHP, 2016; Wells &amp; Anderson, 2005).</li> </ul>

Koniotou et al (2015), working with elders in fall prevention research, used a combination of many of these strategies while experiencing high turnover or poor attendance in numerous engagement activities that they offered. By being flexible and opportunistic, they met their goals for patient involvement in all aspects of their project.

### Assessment

In a literature review drawing chiefly from systematic literature reviews, Cené et al (2016) review the state of patient and family engagement, and determine that there is a lack of evidence for the effectiveness of patient and family engagement, driven in turn by the lack of conceptual models or assessment tools. Existing assessments for engagement in personal health should not be mistaken for assessment that addresses engagement at the systems level. Carman et al (2014) also call for measures to assess patient and family engagement at both the personal and organizational levels. O'Sullivan (2014, pg. 17) developed a self-assessment for engagement with families of CYSHCN that endorsed several of the recommendations given in the Sustainability/Effectiveness section above, including assigned a dedicated staff person to support families and providing support, adaptations, and compensation. Elements of assessment suggested by other sources in this review included the following:

- “Spectrum of user involvement” (Berg et al, 2015, pg. 733), which is similar to Carman et al’s (2013) framework in Table 2.
- The length of time for which a program has supported ongoing patient and family engagement activities (Anderson & Wells, 2005).
- Identifying actions, policies, and procedures within the organization or project that support engagement (Carman et al, 2014).

These findings support the need for more thought and investigation given to assessment of patient and family engagement, which we will continue through key informant interviews and development of the criteria and brief as products of this project.

## Conclusions

This literature review assembled information on seven topics relating to patient and family engagement. We found adequate materials to thoroughly characterize the settings, goals, and activities involved in patient- and family-engagement efforts. The stated goals for patient and family engagement generally are not fully justified based on the evidence base for the impact of patient and family engagement. This lack of evidence is not surprising given that patient and family engagement is a rapidly emerging field; however, it remains one of the major challenges facing patient- and family-engagement initiatives. We presented activities organized at three levels: consultation, involvement, and partnership and shared leadership. There is evidence for some goals, such as improving accessibility and relevance of written materials, that engagement at the involvement level is sufficient to achieve the goal. Other goals, such as selection of research questions, appear to require a more robust partnership between patients and professionals.

We found sufficient information to begin to characterize family leader and professional roles in patient and family engagement. We will continue to explore these topics through the course of key informant interviews. On the topic of Sustainability/Effectiveness, we found numerous recommendations, many of which come out of the experiences of experts in the field of patient and family engagement. Although we attempted to organize these recommendations according to the issues that they might be expected to address, more investigation is needed to establish an evidence-base to support decisions made to enhance sustainability.

The final topic that we reviewed was the topic of assessment. As expected, we found a shortage of assessment tools and standards, notably, the lack of conceptual models that would provide a theoretical foundation for assessment. This will be explored further throughout the project.

## Resources

The following resources were identified through the course of this literature review, or to address common concerns raised in the sources for this literature review.

Topic	Title	Link	Notes
Activities	Meaningful Consumer Engagement: A Toolkit for Plans, Provider Groups and Communities	<a href="http://www.communitycatalyst.org/resources/tools/meaningful-consumer-engagement">http://www.communitycatalyst.org/resources/tools/meaningful-consumer-engagement</a>	
	Community Tool Box	<a href="http://ctb.ku.edu">http://ctb.ku.edu</a>	Exhaustive compilation of tools for use in community engagement
Assessment	Engaging Parents, Developing Leaders: A Self-Assessment and Planning Tool for Nonprofits and Schools	<a href="http://www.aecf.org/resources/engaging-parents-developing-leaders/">http://www.aecf.org/resources/engaging-parents-developing-leaders/</a>	Developed for use with schools; addressing many concepts also of interest for patient and family engagement
	It Takes A Family: An Analysis of Family Participation in Policymaking for Public Programs Serving Children with Special Healthcare Needs in California	<a href="http://www.lpfch.org/publication/it-takes-family-analysis-family-participation-policymaking-public-programs-serving">http://www.lpfch.org/publication/it-takes-family-analysis-family-participation-policymaking-public-programs-serving</a>	"Self-Assessment", pg. 17
	Family-Centered Care Assessment	<a href="http://www.fv-ncfpp.org/activities/fcca/">http://www.fv-ncfpp.org/activities/fcca/</a>	
Examples	Engaging Patients in Improving Ambulatory Care: A Compendium of Tools from Maine, Oregon, and Humboldt County, California	<a href="http://www.rwjf.org/en/library/research/2013/03/engaging-patients-in-improving-ambulatory-care.html">http://www.rwjf.org/en/library/research/2013/03/engaging-patients-in-improving-ambulatory-care.html</a>	Samples of guidance documents, PowerPoints, and other supporting materials
Patient Activation	Patient and Family Engagement: A Partnership for Culture Change	<a href="http://nciom.org/wp-content/uploads/2017/07/Patient-FamilyEngage_Report-FINAL.pdf">http://nciom.org/wp-content/uploads/2017/07/Patient-FamilyEngage_Report-FINAL.pdf</a>	
Plain language	Plainlanguage.gov	<a href="http://www.plainlanguage.gov/">http://www.plainlanguage.gov/</a>	A resource for improving the quality and accessibility of written communication
Planning	A Roadmap for Patient and Family Engagement in Healthcare Practice and Research	<a href="http://patientfamilyengagement.org/">http://patientfamilyengagement.org/</a>	
Remote access	Zoom	<a href="https://www.zoom.us/">https://www.zoom.us/</a>	Low-cost, low-bandwidth video conferencing

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## Appendix

The literature review identified the following 44 articles and reports as summarized in Table 1. See the methods sections for an explanation of the columns in this Appendix.

Citation	Type	N	Patient/ Caregiver Expertise	Setting	Focus	Special communities	Assessment Type	Overview
<i>Abma, Nierse, &amp; Widdershoven, 2009</i>	Journal article	Two projects (two more referenced but not described)	Not addressed	Health research	Research	Children with special healthcare needs	Process description	Responsive research; “The findings demonstrate that equal partnerships include involvement in all research activities from beginning to end, a focus on experiential knowledge, mutual learning, openness, and respect.” (pg. 401)
<i>AMCHP, 2016</i>	Report	Out of 59 states and territories with Title V funding, 68 percent of MCH programs (40) and 75 percent of CYSHCN programs (44) responded.	Not addressed	Maternal-child health	Policy, Community-building, Quality	Children with special healthcare needs	Process description; process evaluation	Extensive catalog of patient and family engagement activities in maternal-child health and CYSHCN programs in the United States. Includes quantitative data and examples. Discusses family organizations, public input/hearings, social media, focus groups/surveys. Problem areas were geographic diversity, culturally diverse populations, identification, reimbursing families, and sustainability.
<i>Anderson &amp; Wells, 2005</i>	Report	51 MCH programs	Not addressed	Maternal-child health	Policy, Community-building, Quality	Not addressed	Process description; Process evaluation	A survey of state-level maternal child health programs that showed high levels of engagement in many activities (as mandated by the Maternal-Child Health Bureau).
<i>Anderson &amp; Wells, 2006</i>	Report	53 CSHCN programs	Not addressed	Maternal-child health	Policy, Community-building, Quality	Children with special healthcare needs	Process description; Process evaluation; Impact description	A survey of state-level CYSCHN programs that showed high levels of engagement in many activities (as mandated by the Maternal-Child Health Bureau).
<i>Antonelli, McAllister &amp; Popp, 2009</i>	Report	27 key informant interviews, including “consumer advocates”	Expert	Healthcare (care coordination)	Policy, Innovation, Education, Community-building, Quality	Not addressed	Process description	Documents a family-engaged process developing a family-engaged care coordination framework with the following “defining characteristics” (pg. vii): 1. Patient- and family-centered; 2. Proactive, planned, and comprehensive; 3. Promotes self-care skills and independence; 4. Emphasizes cross-organizational relationships. The value of system-level family engagement in order to achieve these characteristics is acknowledged, but not integrated at the framework level.

<i>Citation</i>	Type	N	Patient/ Caregiver Expertise	Setting	Focus	Special communities	Assessment Type	Overview
<i>Bailey et al, 2015</i>	Journal article	22 papers reviewed by 6 parents	unspecified	Various – education, healthcare, etc.	Research	Youth with disabilities	Process description; Process evaluation; Impact description; Impact evaluation	According to the literature review - "The quality of evidence is low", "Lack of evidence on impact of involvement", and "inconsistencies in how involvement is defined and reported." Looked at recruiting, practicalities, challenges, and impact on children as well as research itself.
<i>Belone et al, 2016</i>	Journal article	35 community partners from 6 community-based participatory research (CBPR) partnerships	Expert	Public health research	Research, Policy	American Indian; African American; Chinese origin; Puerto Rican; Mexican	Process description; Process evaluation; Impact description	Assessed face validity and acceptability of a conceptual model of community-based research partnerships and made some revisions to model. "Four cross-cutting constructs were identified: trust development, capacity, mutual learning, and power dynamics" (pg. 117). Discusses context including social determinants of health and group dynamics.
<i>Berg et al, 2015</i>	Journal article	6-member user board; case study drawn from 62 documents of consumers and 48 media stories	Expert	Healthcare (clinical)	Policy, Innovation, Quality, Advocacy	Adults with HIV	Process description; Impact description	Organizational redesign of an HIV clinic in southern Norway using a multi-perspective analysis. Physicians became aware that "service users were not given opportunities to influence their own care." A User Board was formed and developed a blueprint which was implemented as a total redesign of service delivery.
<i>Buxbaum, 2010</i>	Report	Representatives from state-level agencies in 6 states	Not addressed	Government (public insurance and block grants)	Policy, Advocacy	Not addressed	Process description	Assessment of intra-agency collaboration between Medicaid, CHIP, and Title V agencies for six states. Family engagement at the systems-level is one component of the assessment. Challenges mentioned are seeing families as consumers only, engaging diverse families, and unclear on how to measure engagement.
<i>Cacari-Stone et al, 2014</i>	Journal article	2 case studies, statewide scan 36 additional CBPR projects	Not addressed	Government (public health policy)	Research, Policy, Advocacy	Locationally defined vulnerable communities	Process description; Impact description	Examined how partnerships developed for research purposes can impact local policy. Emphasized use of evidence blended with civic engagement. Community activists presented evidence to political bodies and media with the goal of effecting policy changes. Limitations included recall issues, inability to attribute the partnerships' contribution to policy outcomes.
<i>Carman et al, 2013</i>	Journal article	N/A	N/A	Healthcare	Advocacy, Policy	Not addressed	N/A	Proposes a multidimensional framework of patient and family engagement. Distinguishes patient engagement from patient activation and patient- and family-centered care. Describes different levels of engagement (consultation/involvement/ leadership). Barriers for patients include health literacy and limited English proficiency. Suggested measurement resource as Judith Hibbard's Patient Activation Measure, which assesses a person's capacity for engagement.

Citation	Type	N	Patient/ Caregiver Expertise	Setting	Focus	Special communities	Assessment Type	Overview
<i>Carman et al, 2014</i>	Report	72 stakeholders, including patients and family members; "larger group of patients and families via an online questionnaire"	Expert	Healthcare	Advocacy, Policy	Not addressed	Process description	User-friendly, action-oriented resource. Presents eight strategies for change: patient and family preparation; clinician and leadership preparation; care and system redesign; organizational partnership; measurement and research; transparency and accountability; legislation and regulation; partnership in public policy. Mentions safety, family/provider satisfaction, improved outcomes, and cost savings. Utilized online patient surveys; created resource library; consideration of health literacy; shared decision-making; peer advocates; used different levels of providers (MD, nurse, etc.); family-centered care; link to community resources; motivational interviews; health information technology; using data to identify those at-risk; transitions/discharge plan; care coordination; hosp. family advisory council; condition specific outcomes; quality of life; and benchmarks for quality improvement.
<i>Carman et al, 2015</i> <i>Carman et al, 2016</i>	Journal article	907 members of the public	Not addressed	Healthcare (treatment decisions)	Education	Hispanics, African Americans, people ages sixty-five and older; however required internet access	Process description; Process evaluation	Found that over the course of a process of group deliberation, participants gave increasing weight to evidence base, and increased attention to quality of evidence. Carman et al, 2015 presents quantitative analysis. Carman et al, 2016 presents qualitative findings. Four different forms of group deliberation were analyzed against a control group. Differences were small but statistically significant. The role of evidence in care demonstrated that cost and personal preferences could outweigh evidence. Communication of harm (e.g. antibiotic resistance) increased patient willingness to accept limitations. Lastly, this is an area requiring ongoing public input.
<i>Cené et al, 2016</i>	Journal article	14 systematic reviews from 2000-2015	Not addressed	Healthcare	Research, Innovation, Quality	Not addressed	Process description; Impact description	Combines family engagement with medical home which includes care planning, active participation, use of information technology, and quality improvement. Multiple organizations have operational definitions of family engagement but commonalities include multiple levels of family engagement, practice policy, families as essential team members, and various improvements (health, safety, quality, and care delivery).
<i>Conway et al, 2006</i>	Report	Case studies	Not addressed	Healthcare, Government, Health-related non-profits	Policy, Quality, Advocacy	Not addressed	Process description; Impact description	Core concepts are dignity/respect, information sharing, participation, and collaboration. Emphasis on healing relationships, patient needs, source of control, free flow in information and transparency. Momentum due to consumer driven care (e.g. medication errors), health information, health literature, and evidence-based practices.

<i>Citation</i>	Type	N	Patient/ Caregiver Expertise	Setting	Focus	Special communities	Assessment Type	Overview
<i>Crawford et al, 2002</i>	Journal article	42 papers	Not addressed	Healthcare	Policy, Quality	Not addressed	Process description; Impact description; Impact evaluation	Systematic review of research and gray literature, looking at the effects of involving patients in planning and development of healthcare. This one is a bit outdated as review was 1966-2000. Found qualitative support for impact of patient engagement on patient participants, changes to services, and changes in professional attitudes towards engagement. Overall, evidence for or against patient engagement was lacking.
<i>Florindi &amp; De Lorenzo, 2015</i>	Journal article	11 cancer centers in Italy	Not addressed	Healthcare (cancer treatment)	Policy, Education	Cancer survivors	Process description; Impact description	Describes the impact of a cancer patient organization in Europe integrated into systems of care. The patient organization provides education and support for patients through the efforts of trained volunteers (mostly patients and their family members). The success of this program is reflected in proposed new standards to acknowledge and encourage patient organization volunteers in a cancer center accreditation program.
<i>Forbat et al, 2009</i>	Journal article	5 lung cancer services (3 intervention and 2 control)	Expert	Healthcare (cancer treatment)	Policy, Quality, Advocacy	Cancer survivors	Process description; Impact description; Impact assessment	Measured the impact of a six-month long "change project" that supported collaboration between staff and cancer patients/family members. Pre-intervention, staff thought of patient involvement as impacting individual care and saw many barriers to care. Post-intervention, staff recognized and embraced patient involvement at the systems level and were less concerned with barriers.
<i>Fraenkel et al, 2016</i>	Journal article	10 patients	Expert	Healthcare (treatment guidelines)	Quality	Not addressed	Process description; Process assessment	A panel composed entirely of patients with rheumatoid arthritis, duplicated the voting process followed by a treatment recommendation panel composed mostly of physicians with two representatives. Recommendations from the two groups were largely the same, with some differences attributed to physicians' greater knowledge of clinical outcomes, and some to patients' putting greater emphasis on medication side effects which impacted quality of life.
<i>Frampton et al, 2017</i>	Report	25-member Scientific Advisory Panel including patient and family leaders	Expert	Healthcare	Quality	Not addressed	Process description; Impact description	Introduces a framework for patient- and family-engaged care (PFEC). Provides citations to document favorable impact from PFEC on service provider compassion, experience, retention, stress and burn out. Also improves patient satisfaction and perceptions.
<i>Gagliardi et al, 2008</i>	Journal article	15 patients and 15 providers from two hospitals	In-treatment	Healthcare (hospital)	Policy, Quality, Advocacy	Not addressed	Process description; Process evaluation	Preferred method of participation for both cancer patients and providers were selection for a board, ask opinion, and feedback incorporated into process. Barriers included varying patient interest, provider preference, and disagreement about whether patients should serve an advisory or decision-making role.

<i>Citation</i>	Type	N	Patient/ Caregiver Expertise	Setting	Focus	Special communities	Assessment Type	Overview
<i>Hawley, 2010</i>	Report	3 organizations	Not addressed	Healthcare (hospice)	Policy, Community-building, Quality	Medically fragile children and their families	Process description; Impact description	Developed website, resource guide, maintained resource library, provided parent support, and workshops for both families/professionals. Significant barriers to address included unmet needs of families of children with life-threatening conditions, stress/guilt associated with decisions, poor care coordination and communication, and financial instability.
<i>Hingley-Jones &amp; Allain, 2008</i>	Journal article	Representatives of parent-carer groups and voluntary agencies from 2 English local authorities	Not addressed	Healthcare (services for children with disabilities)	Policy, Quality, Advocacy	Children with disabilities	Process description; Process assessment	Compared and contrasted the structure of services for children with disabilities as provided by two local authorities. Both had recently engaged in some consultation with patients and family caregivers. Family representatives were interviewed and asked to comment both on integration of services and the consultation process.
<i>Hitchen &amp; Williamson, 2015</i>	Journal article	Leadership team including 2 consumers and 2 family caregivers	Expert	Healthcare (behavioral health)	Research; Quality	Behavioral health	Process description	Focused on the co-leadership structure of a larger patient engagement project (not described). Provides theory and evidence for strategic decisions such as use of action research methods, shared learning, and co-production of meaning.
<i>Johnson et al, 2008</i>	Report	100+ orgs	Expert	Multiple	Policy; Quality	Not addressed	Process description; Impact description	Report of 2008 meeting convened by Institute for Family-Centered Care with Institute for Healthcare Improvement. 26 patient/family advisors; 59 administrative/clinical leaders from hospitals and other healthcare organizations; Leaders from 3 foundations; 19 from IHI discusses preparation of both families and providers. Need to have in hospitals, ambulatory settings, physician training, quality improvement initiatives, professional associations/disease specific organizations, patient safety organizations, and federal/state agencies all involved.
<i>Kaehne &amp; Catherall, 2013</i>	Journal article	2 English local authorities working with 3 CSHCN interviewed follow up with 49 surveys of other parents	Not addressed	Education (learning disabilities)	Quality; Advocacy	Children with learning disabilities	Process description; Process evaluation	This covered co-location of services specific to children with learning differences. Caregivers of children were not aware of structural changes in services unless they had been involved in the process.
<i>Kirwan et al, 2007</i>	Journal article	80 participants, including 20 patients from 10 countries	Not addressed	Healthcare (standards of care)	Quality; Advocacy	Not addressed	Process description; Impact description	Describes patient engagement in a process to set standards for outcome measures for rheumatoid arthritis. Convening participants decided to add fatigue to standard outcome measures.
<i>Koniotou et al, 2015</i>	Journal article	20 trials	Prevention	Healthcare	Reserach	older adults	Process description; Process evaluation	This discusses patient collaboration on preventing hospitalization and is specific to older adults.

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<i>Krauss et al 2001</i>	Journal article	300 parents of CSHCN each in 20 states (6477 total initially contacted; 2220 usable data)	In-treatment; Expert	Multi-system	Access; Policy	CYSHCN	Process description; Process evaluation	This article reports on a survey of families CYSHCN in 20 states selected to represent all regions of the United States. The survey examined the experiences of CYSHCN from their parents' perspective, across multiple systems of care. This was the forerunner survey to the National Survey of Children with Special Healthcare Needs. It documented what these families faced as far as systems of care and their complexities. This was a groundbreaking collaboration between an advocacy organization and university-based researchers.
<i>Minniti, Abraham, &amp; Johnson, 2014</i>	Report	interviews with Medicaid beneficiaries	Not addressed	Healthcare	Community-building	Medicaid beneficiaries	Process description; Process evaluation	Discusses family-centered approaches; service provider involvement; preference of labelling (e.g. individuals vs. patients); 4 levels of engagement (clinical, organizational, community, policy); and used interviews. Obstacles included the use of jargon, health literacy, lack of resources on evidence-based practices and shared decision-making. One solution to reimburse families was non-monetary compensation (e.g. recognition.) This article discusses both personal-level and systems-level engagement interchangeably, with an overall focus more on personal engagement.
<i>O'Sullivan, 2014</i>	Report	30 key informant interviews and literature review	Expert	Healthcare and Health Policy	Advocacy; Policy	Not addressed	Process description; Process evaluation; Impact description	This combined approach of interviews/literature review/research demonstrated maximizing family participation through guidelines, orientation, shaping policy, diversity representation, family supports, and working with family organizations. Measurement of family participation included level of engagement, compensation, and responsibilities. Family participation resulted in increases of family perspective, cultural competence, effective outreach, advocacy, and increased capacity of family members. It was noted that there was tremendous inconsistency in the approaches used for family participation.
<i>Percy-Smith, 2007</i>	Journal article	11 youth peer leaders	Prevention	Public Health; Healthcare	Advocacy; Policy	Youth from minority ethnic groups	Process description; Process evaluation; Impact description	Youth prepared materials for a "Knowledge Café" event where youth and professionals met in small groups and youth presented their concerns. Stress and body image were identified as key issues; behavioral health services were oriented towards youth with severe diagnoses and not responsive to endemic behavioral health issues. Although one professional attendee described the session as "exhilarating", one year later professionals were still oriented towards meeting government-established priorities and had not responded to issues identified by the youth participants.
<i>Plescia &amp; Groblewski, 2004</i>	Journal article	650 surveys	Not addressed	Healthcare	Education	African-American	Process description	Used a targeted community (heart disease/diabetes in African Americans), assessed needs, developed interventions, evaluated, and involved patients.

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<i>Plescia, Groblewski &amp; Chavis, 2008</i>	Journal article	14 neighborhoods consisting of 19670 residents, 89% African American	Not addressed	Healthcare (lay providers)	Education	African-American	Process description	This report discusses the third component (lay person approach) of the three community coalition and policy/community environment change strategies) in Plescia, Herrick & Chavis, 2008 below.
<i>Plescia, Herrick &amp; Chavis, 2008</i>	Journal article	14 neighborhoods consisting of 19670 residents, 89% African American	Not addressed	Public health (health behavior)	Education	African-Americans	Impact evaluation	Examined improved health behaviors (diet, activity, smoking) to reduce heart disease/diabetes in African Americans.
<i>Plescia, Koontz &amp; Laurent, 2001</i>	Journal article	388 surveys	Not addressed	Healthcare	Access; Quality	Underserved urban population	Process description	This report discusses an interesting approach looking at health conditions in geographic areas.
<i>Roseman et al, 2013</i>	Journal article	4 alliances (see Scanlon et al, 2012) which engaged patients at the partnership level	Not addressed	Healthcare	Quality	Not addressed	Process description; Process evaluation	Aligning Forces for Quality (AF4Q) projects measure effects of patient centered care on service delivery. Premise is that "community stakeholders who provide, pay for, and receive healthcare improve healthcare quality and value" better than groups acting alone. Obstacles include skepticism regarding participation resulting in change - which also appeared in other studies. Transparency, also noted in other studies, is a key issue.
<i>Scanlon et al, 2012</i>	Journal article	17 alliances, 16 of which completed the phases	Not addressed	Healthcare	Quality	Collecting race/ethnicity/language data	Process description; Process evaluation	High-level discussion of 17 AF4Q healthcare quality improvement projects. Projects started with a vague mandate for community engagement: which produced high levels of variability between projects. Revised mandate later in the project focused on personal care, not systems-level engagement. Technical assistance involved webinars, calls, workshops, learning collaboratives, special reports, and direct consulting.
<i>Taylor et al, 2010</i>	Journal article	23 key informant interviews; 14 advisory group members	Not addressed	Healthcare (behavioral health)	Community-building; Access	Behavioral health	Process description; Impact description	This article examined both supporting as well as empowering consumers with mental illness. Important components include peers, helping others, empowerment, and advocacy. Key elements of successful services were identified.
<i>Uding, Sety &amp; Kieckhefer, 2007</i>	Journal article	11 parents in 2 focus groups, 2 parent and 12 community consultants, 20 classes, 27 parents in all contributed to project	2 expert parents, others unknown	Healthcare (family-centered care)	Research; Quality	Children with special healthcare needs	Process description	This article discusses family-centered approach and the challenges/ solutions of family involvement in research.



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<i>Wells et al, 2015</i>	Journal article	22-member convening; 36 patient caregivers in focus groups; 790 online survey respondents	In treatment; Expert	Healthcare	Research	Children with special healthcare needs	Process description; Impact description	Tool is based on Maternal Child Health 6 core outcomes (partners in decision making, medical home, adequate insurance, early screening, community-based services, and transition.) Discusses reliability/validity in depth. Concerns about representative sample and underserved; further research needed.
<i>Westfall et al, 2016</i>	Journal article	25 focus groups	Prevention	Healthcare (screening)	Research; Innovation; Education	Not addressed	Process description; Process evaluation	Looks at "Boot Camp Translation"—a process of engaging communities in translating medical research and its recommendations into meaningful language for that community. Multiple diagnoses including colon cancer, hypertension, asthma, diabetes, and mental health.
<i>Woolf et al, 2016</i>	Journal article	Study A: 10 focus groups, 46-member patient working group  Study B: "existing community-based coalitions and organizations", pg. 592	Prevention; Expert	Study A: Healthcare (screening)  Study B: Public Health	Research; Innovation; Access	Study B: inner city residents "economically disadvantaged neighborhood"	Process description, Impact description	This article examines the value of making the effort to include/engage patients as full partners in all phases of research—"authentic engagement." Describes two examples—engagement of patients in study of cancer screening decisions and engagement of inner-city residents in addressing social determinants of health. In both cases, researchers felt a tangible impact on their activities, from quality of materials provided to patients, to selection of research questions.