

# Public Expectation and Patient Experience of Integration of Health Care: A Literature Review

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**THE CHANGE FOUNDATION**  
HEALTH CARE DESERVES OUR FINEST THOUGHT

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# EXECUTIVE SUMMARY

## Introduction

In Canada, provinces and territories are experimenting with models of care where teams of health care providers (doctors, nurses and nurse practitioners to name a few) collaborate to provide integrated care to their patients (Canadian Council on Health Services Accreditation [CCHSA], 2006). Benefits of integrated systems include increased patient satisfaction through increased access to care and improved coordination across the continuum (Alberta Health and Wellness, 2000; Suter et al., 2007). As consumers of health care services, patients and their caregivers are uniquely placed to assess the degree to which health care systems effectively render care on an individual level.

## Methodology

We conducted a review of the literature to report on the perceptions and expectations of patients and their families with respect to: ease of navigation through health care and related systems; the extent to which members of care teams within and across provider groups communicate with each other and exchange up-to-date, relevant information; patient and caregiver experiences of redundancies, delays and other disruptions resulting from a lack of coordination; the extent to which needs are overlooked or unaddressed; and the degree to which information follows patients as they travel through health care and related systems.

For the purposes of this review, we adopted the Canadian Council on Health Services Accreditation definition of integration:

[Integration brings]...”together services, providers, and organizations from across the continuum to work together jointly so that their services are complementary to one another, are coordinated with each other, and are a seamless unified system, with continuity for the client.” (CCHSA, 2007)

Eleven multidisciplinary peer reviewed databases, key organization websites and the reference lists of major papers were searched to identify studies relevant for inclusion in this review. The search was limited to empirical research on consumer expectations and patient experiences regarding integrated health care published since 1997.

The majority of the 53 studies selected for inclusion in this review are qualitative in design, utilizing semi-structured interview techniques face-to-face or telephone, or mail-out questionnaires. This review includes the results of twelve Canadian studies, predominantly from Western Canada and Ontario. The geographic distribution of the remaining studies is fairly evenly divided between the United States and the United Kingdom, with some representation from Australia, Belgium, Denmark, New Zealand and the Netherlands. Viewpoints from a variety of patient and caregiver populations are presented ranging from the young to the elderly, and maternity to palliative care. The experiences of patients and families dealing with chronic illness and parents of children with special health care needs are commonly represented.

## Results

Overall, patients and families feel that health information is not always communicated to the professionals charged with advising and assisting them with their care. They experience delays, redundancies and duplications in care, and many feel that their needs as both patients and caregivers are not being acknowledged or addressed.

### i. Ease of navigation

The degree to which health care and related services are available and accessible; the extent to which patients are made aware of what is available; and the degree to which patients are successfully able to access and obtain the services they need in a timely manner all factor into patient and caregiver perceptions of the ease with which they can and do successfully navigate

through health care and related systems. Knowing what is available, where to go and who to contact are key concerns for patients and their families (Bowie, 2006; Hastings, 2004; Leith, Phillips, & Sample 2004; McLennan et al., 2003; Naithani, Gulliford, & Morgan, 2006; Simon & Kumar, 2002, Smith & Smith, 2000b; Well et al., 2000). Further, patients and caregivers expressed confusion as to the way things worked inside the system, often not knowing who was responsible for what, where and when (Anderson & Parent, 2004; Heller & Solomon, 2005; Lawton, Parry, Peel, & Douglas, 2005; McLennan et al., 2003). The patients and their family caregivers frequently represent the only common thread in their health care chain, and are often left to facilitate their own way through the continuum of care without the skills, support or confidence they need to do so (Coleman, 2003; Levine, 1998; Smith, 1998; Smith & Daughtrey, 2000a; Smith & Smith, 2000b).

## **ii. Redundancies, delays and disruptions**

Patients and their caregivers describe experiencing delays in service provision, gaps in services, and deficiencies in team and cross-boundary continuity (Armitage & Kavanagh, 1998; Gulliford, Naithani, & Morgan, 2006; Naithani et al., 2006; Preston, Cheater, Baker, & Hearnshaw, 1999; Smith, 1998; Woodward, Abelson, & Hutchison, 2001). Experiences reported include: waiting for access; being sent for duplicate tests or diagnostic procedures by different health care professionals; scheduled treatments or procedures cancelled upon arrival at service settings; the need to convey the same information to different health care professionals and other service providers over and over again; delays in records transfer; and even gaps in care provision while service delivery responsibilities are sorted out between professionals (Beaudin, Lammers, & Pedroja, 1999; Bowie, 2006; Harris Interactive, 2005; McLennan et al., 2003; Ray, 2003; Shaw, Southwood, & McDonagh, 2004; Woodward et al., 2001).

## **iii. Unmet or unaddressed needs**

Three issues repeatedly raised by patients and caregivers with respect to unmet needs were the importance of consistent timely advice and assistance; adequate education and training to enable patients and caregivers to feel knowledgeable and confident enough to assume responsibility for care post-discharge (care readiness); and the availability of tailored, adequate, practical and ongoing support such as home care equipment and services throughout periods of self-care (Harrison, 1998; Harrison & Verhoef, 2002; McCourt, Page, Hewison, & Vail, 1998; Simon & Kumar, 2002; Woodward et al., 2001).

## **iv. Communication**

Patients need to feel confident that providers know enough about their care history to make good decisions about future care, and that care providers are adhering to a consistent care plan. Patients' beliefs with respect to care coordination appear to be tied to their observations of the degree to which health care professionals communicate and consult with each other and with them. At the very least, communication breakdowns or delays result in confused, uninformed, possibly noncompliant patients; at worst, a lack of communication can result in delays in initiating proper care, medication errors, re-hospitalizations, and possibly permanent negative effects on the health of patients (Kautz, Gittel, Weinberg, Lusenhop, & Wright, 2007; Schoen et al., 2005).

## **v. Information flow**

In Schoen et al.'s (2005) survey of chronic care across six countries, patients felt that the information flow across sites of care was instrumental to providing efficient and safe care, in particular for individuals with chronic complex health conditions. In Canada, however, 19% of patient statements highlighted examples of the unavailability of medical records during appointments with health care providers (Schoen et al., 2005). Other surveys of chronic care patients report similar problems with respect to the timely availability of medical records and test information indicating that information does not always flow between care settings and providers (Gulliford et al., 2006; Harris Interactive, 2005; Naithani et al., 2006).

## **vi. In times of transition...**

Any flaws that exist in our health care systems are invariably exacerbated during times of transition between care providers and care settings. Patients who only ever consult their general

practitioners appear to have very different experiences of care than patients who must move between primary, hospital and specialist care in order to attend to multiple and/or chronic health issues. It is in this complexity that system flaws are revealed. Patients report that they feel left in limbo during these times of transition, unable to progress through the system and powerless and uncertain in the face of this inability to traverse between levels of care (Preston et al., 1999).

## **Moving Forward...**

Issues that are relevant to patients and their families are rooted in the presence or absence of effective communication. Patients and caregivers are experiencing duplications, delays, disruptions to and even discontinuation of care; confusion around treatment and self-management; issues around medications and side effects; a lack of appropriate follow-up; significant stress due to the burden of coordinating their own or a loved one's care and unrealistic expectations around care; a lack of physical, emotional and environmental support; and care that can be culturally or contextually insensitive, disrespectful or lacking in privacy. What is the way forward?

### **i. Service maps**

Patients with chronic and/or multiple illness often move back and forth between various points in both health and social care systems in order to obtain the care and support services they require (McLennan et al., 2003). Mapping these service points and attempting to coordinate services in such a way as to simplify pathways may eliminate much of the frustration experienced by the patients and caregivers traversing them.

### **ii. Patients and caregivers as partners**

Early discharge from hospital and the emphasis our health care systems currently place on outpatient care and home care encourages us to believe that we must be active partners in our own care. We are not equipped to take on this challenge. Patients report that they are inadequately provided with information on relevant supports and resources or programs in their communities and many are therefore unable to assume responsibility for adequate self-care. Greater efforts are needed to assist patients to become active partners in their own care. Efforts suggested by the literature include adequate patient and family education; involving patients in the development of personalized care plans; timely provision of information on test results and medication regimes; and practical help locating and accessing related information and support resources and assistance.

### **iii. System change**

Possible practical solutions to issues raised by patients and their families in the literature include combinations of:

- Maps that simplify pathways between service points and provide detailed contact information
- Central registries or access points for health and related services
- Co-location of providers and services (the 'one-stop-shopping' model)
- Care coordinators
- Care plans developed with patients and shared between providers
- Enhanced patient and caregiver education and training
- Enhanced development of electronic health care records or provision of health records to patients
- Enhanced information sharing and the development of ongoing relationships between providers and service settings
- Development of systems and services to support informal caregivers

## **Summing up**

Integrated care should be about putting the needs and expectations of the patient before those of institutions or health care providers. At the very least it should involve an acknowledgement that

the needs of patients and their families are equally as important as the needs of the system. If we want patients to take charge of their care, we need to consider what will best enable them to do so. An effective way of doing this is to plan services with patient needs in mind. This means involving patients and their caregivers in the development of care plans; wherever possible making provisions to address individual needs; and providing patients and their families with the information and supports they need to feel confident enough to participate in these very important tasks (Harrison, 1998; Noël, Frueh, Larme, & Pugh, 2005).

“I think you feel a bit like an accessory, you’ve got this great big medical system and you’re really not part of it, the system rolls on whether you’re there or not ... as a patient I thought the system was there because of you, not you there because of the system. It’s this great big wheel of medicine going round and round and you’re an insignificant speck.”  
(Patient comment, Preston et al., 1999, p. 19)

## INTRODUCTION

In 2007, a survey by the Health Council of Canada reported that over 10 million Canadian adults and 68% of seniors have one or more chronic health conditions – heart disease, mood disorders, COPD, diabetes, arthritis, hypertension and cancer (Health Council of Canada, 2008).

Individuals with chronic health conditions frequently require ongoing care management from multiple professionals in the health and social care fields (Coleman, 2003). A 2000 survey by the Robert Wood Johnson Foundation in the United States found that older persons with chronic conditions may be seen by as many as eight different physicians during the course of one year (Harris Interactive, 2005).

The quality of a patient's care may be most at risk during the transition from one health care setting to another or from one health care professional to another (Coleman, 2003; Picker Institute, 1999). In order to facilitate successful transitions between points of care, clinical histories, test results and discharge plans must be accessible to all providers involved in an individual's care, irrespective of care setting. If this does not occur, patients may experience gaps in care and may be left without the knowledge they need to manage their own care (Coleman, 2003; Health Council of Canada, 2008; Picker Institute, 1999). As the number of health care professionals a patient must consult increases so too does the potential for gaps in information transfer that may adversely affect an individual's care. This is especially true for individuals with chronic health conditions.

In a 2005 Commonwealth survey of sicker adults, Canadians reported the following gaps and/or redundancies in care (Harris Interactive, 2005):

1. Received conflicting information from different doctors or health care professionals (25%)
2. Necessary test results not available in time for a doctor's appointment (19%)
3. Received duplicate tests (10%)
4. Health care professionals seemed to fail to share information with respect to patient care (13%)
5. Health care professionals failed to share important information with patients (15%)
6. Upon discharge from hospital, patients did not receive discharge instructions with respect to follow-up care (17%)
7. Upon discharge, hospitals failed to arrange for follow-up visits with relevant health care professionals (30%)
8. During discharge from hospital, patients did not receive care plans to assist them in managing their own care (35%)

In fact, in the Health Council of Canada (2008) survey, only 14% of Canadian physicians stated that they regularly provide patients with written instructions on managing their chronic conditions at home.

Traditionally, health care has been organized around the convenience of providers rather than that of patients (Leatt, Pink, & Guerriere, 2000; Shortell, Gillies, & Anderson, 1996). It has been described as a silo mentality where the importance of protecting territory and professional responsibilities takes precedence over the development of a system focused on the needs of patients (Leatt et al., 2000).

Many studies evaluating quality of care focus on objective measures and standards of quality such as mortality/morbidity reduction, hospitalization, length of stay and cost effectiveness. Subjective criteria such as those that measure the experiences and expectations of patients and their families are, however, equally important (Gerteis, 1993).

As consumers of health care services, patients and their caregivers are uniquely placed to assess the degree to which health care systems effectively render care on an individual level. Further, they can provide insight into qualities of health care delivery that may not either be obvious to or judged relevant by professionals working within the system (Gerteis, 1993). Rather than focusing solely on quality measures of importance to health care providers, we should incorporate patients' and families' experiences into any robust overall measure of health care system effectiveness (Leatt et al., 2000; Suter et al., 2007).

In Canada, provinces and territories are experimenting with models of care where teams of health care providers (doctors, nurses and nurse practitioners to name a few) collaborate to provide integrated care to their patients (CCHSA, 2006).

Integration is a term awash with meaning, often used interchangeably with such terms as continuity of care, care collaboration, shared care and transmural care. Although many health care agencies have implemented integrated care systems, there is no one model that has been adopted by all (Suter et al., 2007).

Leatt et al. (2000) highlight three types of integration models: functional integration which involves the sharing of common policies and practices; physician integration which defines the extent to which all physicians are linked to and make use of a common system of facilities and services; and clinical integration which comprises procedures and practices that focus on continuity and coordination of care. Clinical integration is described as "an umbrella system which focuses on communication between providers, the smooth transfer of information and records, [and the] elimination of duplicate testing and procedures" (Leatt et al., 2000, p. 15). It is this system model that we will focus on in this literature review.

We have adopted the Canadian Council on Health Services Accreditation definition of integration for the purposes of this review:

[Integration brings]... "together services, providers, and organizations from across the continuum to work together jointly so that their services are complementary to one another, are coordinated with each other, and are a seamless unified system, with continuity for the client." (CCHSA, 2007)

Purported benefits of integrated systems include increased patient satisfaction through increased access to care and improved coordination across the continuum (Alberta Health and Wellness, 2000; Suter et al., 2007). Integrated systems should meet patients' needs and adopt a mandate to put patients and families at the center of health care operations (Rogers & Sheaf, 2000; Suter et al., 2007). In order to achieve this, it is important to learn from patients about their experiences in a variety of integrated health systems so that we can determine what works and what does not.

In this review of the literature, we have attempted to capture the experiences and expectations of patients, their families and their family caregivers as they access health care systems and services.

Because practical integration can mean many things to many individuals, we sought to focus on specific aspects of integration. Previous research has indicated that patients' perceptions of both quality and coordination, or integration of care, are coloured by their assessments of whether or not health care providers are aware of their health history; if test results are easily accessible by multiple health care providers; if they themselves are required to be the sole conduit through which information flows between health care providers; and if they and their families are able to smoothly transition between levels of needed care (Ellers & Walker, 1993; Gerteis, 1993; Leatt et al., 2000).



In this review, we investigate and report on the perceptions and expectations of patients and their families with respect to:

1. Ease of navigation through the health care and related systems
2. The extent to which members of the care team within and across health care organizations communicate with each other and exchange up-to-date, relevant information
3. Experiences of redundancy, delays and other disruptions resulting from a lack of communication or coordination
4. The extent to which needs are overlooked or unaddressed
5. The extent to which information follows the individual through health care and related systems

## **METHODOLOGY**

### **a. Search Strategy**

A search of the peer reviewed and grey literature from 1997 to 2007 was conducted to locate empirical studies of consumer expectations and patient experiences regarding integrated health care. The search covered 11 multidisciplinary bibliographic databases including MEDLINE, EMBASE, Cochrane Library, PsycINFO, CINAHL, Social Sciences Abstracts, and Proquest Dissertations and Theses; a review of reference lists of the key studies retrieved; and a targeted search of key organization websites including but not limited to Canadian Health Services Research Foundation, Canadian Institutes for Health Research, Kaiser Permanente, Millbank Memorial Fund, US Agency for Healthcare Research and Quality, the King's Fund, the NHS, and the World Health Organization. See Appendix 3 for the complete search strategy.

The searches combined keywords from three subject themes to retrieve relevant studies. These keywords were developed in consultation with the research team and through a review of preliminary searches for literature on this topic.

1. Integration theme:  
(coalition/s or collaborative or consolidated or consolidation or cooperative coordinated or coordination or fragmented or fragmentation or integrated or integration or integrative or network/s or seamless or shared or transmural or transition/s) and (care or clinic or clinics or health care or "health care" or hospital or hospitals))
2. Patient and consumer groups theme:  
adolescent/s or citizen/s or community or consumer/s or family or families or layperson/s or laypeople or layman or parents or patient/s or public or seniors or taxpayer/s)
3. Opinions or views theme:  
acceptability or assess\* or assumptions or attitudes or encounters or evaluat\* or expectation\* or experience\* or feedback or observation\* or opinion\* or perceive or perception\* or perspective\* or preference\* or presumption\* or satisfaction or understanding or views

*Note: \* denotes truncation*

Keywords were adapted to the thesauri of each database and were searched as both thesaurus terms and textwords.

### **b. Results**

2,375 abstracts were retrieved from the electronic databases searched.

### **c. Screening Process**

Two reviewers screened abstracts for inclusion. Abstracts were screened in if they reported on the results of empirical studies of patients' or consumers' views, expectations, or experiences, with integrated health care systems and addressed one of the following themes:

1. Ease of navigation through the health care and related systems
2. The extent to which members of the care team within and across health care organizations communicate with each other and exchange up-to-date, relevant information
3. Experiences of redundancy, delays and other disruptions resulting from a lack of communication or coordination

4. The extent to which needs are overlooked or unaddressed
5. The extent to which information follows the individual through health care and related systems

Abstracts were excluded if they met one or more of the following criteria:

1. Non-English language studies
2. Studies based in developing countries
3. Commentaries or descriptive studies
4. Integration of complementary and traditional medicine
5. Integrated hospital wards (where a variety of conditions are treated)
6. Health care provider reported patient outcomes
7. Health care provider experiences with and expectations of integrated health care delivery
8. Patient views of electronic health records and related technologies
9. Patient views of waiting times, except as they relate to inclusion criteria
10. Patient's ability to access primary care providers

Of the 2,375 abstracts originally retrieved, 308 were selected for full text retrieval. The full text articles were screened against the same criteria applied to the abstract review and further divided into three categories: key, secondary articles which addressed the issues outlined above but provided very little in the way of substance, and studies that reported raw satisfaction scores from patient surveys. Additional papers were located through targeted Internet searching and consulting the reference lists of key papers, and were subjected to the same screening criteria.

Ultimately, 53 key studies were selected for inclusion in this review.

#### **d. Adjustments to the Review**

This literature review was undertaken to gather empirical findings related to both the patient experience and public expectations of integration of health care. Early on in the process of the review, it became increasingly clear that the theme of public expectations was not substantially represented and/or very difficult to discern, and the literature focused on patient satisfaction with integration of care would not provide us with the depth of meaning required to advance our understanding of the topic.

Most, if not all of the studies in the literature represented here were focused on patients and families with recent health care experience and we were unable to capture an independent public view. The closest view we have, therefore, is from the patient and caregiver experience.

The patient satisfaction literature was questionable as well. There are many published evaluations of integrated health systems that incorporate patients' views into their overall assessments of quality (Ayanian et al., 2005; Desai, Stefanovics, & Rosenheck, 2005; Farmer, Clark, Sherman, Marien, & Selva, 2005; Finley et al., 2002; Fortinsky, Unson, & Garcia, 2002; Gesell & Gregory, 2004; Katon et al., 1997; LeClerc & Wells, 2001; McGuinness & Sibthorpe, 2003; Narr-King & Siegel, 2002; Rabow, Petersen, Schanche, Dibble, & McPhee, 2003; Rodney, Clasen, Goldman, Markert, & Deane, 1998; Suter et al., 2007; Wright, Hazelett, Jarjoura, & Allen, 2007). The question is, how can we best capture these views?

Studies that ask patients a set of pre-defined questions may not capture the full range of patient experience. By design, they measure patients' responses to questions and issues defined by the researchers. Although there is undoubted value in these closed-ended studies, by not evaluating the patient experience through methods such as interviews, focus groups or open-ended survey questions we risk failing to capture the breadth of patient and family experiences within integrated care systems. We made a conscious decision, therefore, to focus on synthesizing the information from studies that incorporate more detailed data on the patient and caregiver experience.

## RESULTS

### a) General

The majority of the 53 studies selected for inclusion in this review are qualitative in design utilizing semi-structured interview techniques either face-to-face or telephone, or mail-out questionnaires. Most combine individual interviews and focus groups. Three of the studies are randomized controlled trials (Nielsen, Palshof, Mainz, Jensen, & Olesen, 2003; Preen et al., 2005, Vanderplasschen et al., 2007) and one is a two-year comparative prospective study (Pritchard, Foulkes, Lang, & Neil-Dwyer, 2004).

Twelve Canadian studies are represented here, predominantly from Western Canada and Ontario. There is one large Canada-wide survey related to the primary health care experience (Health Council of Canada, 2008) and a large international survey, including Canada, that addresses the experiences of patients requiring extensive medical care (Schoen et al., 2005). The geographic distribution of the other studies is fairly evenly divided between the United States and the United Kingdom, with some representation from Australia, Belgium, Denmark, New Zealand and the Netherlands. Viewpoints from a range of patient and caregiver populations are presented, from the young to the elderly, from maternity through to palliative care. Patients and families dealing with chronic illness and parents of children with special health care needs are two populations commonly represented in the literature included here.

While there are a few studies with patient and/or caregiver populations of 150 to 2000, most are much smaller, from eight individuals up. Fortunately, there are strong similarities in the findings of the included studies irrespective of size.

### b) The Key Studies

Table 1 below provides an outline of the studies selected for inclusion in this review.

**Table 1: Key Studies**

Author/Date	Title	Country	Data Collection Methods	Population
Anderson 2004	The team approach to hospice palliative care	Canada	Focus groups Surveys (mail-out)	50 caregivers 150 hospice volunteers
Armitage 1998	Consumer oriented outcomes in discharge planning	Australia	Interviews (telephone)	29 cardiology and respiratory patients
Beaudin 1999	Patient perceptions of coordinated care	USA	Focus groups	22 patients from acute care hospitals
Bethell 2001	A portrait of the chronically ill in America, 2001	USA	Surveys (on-line)	6477 chronic disease sufferers, parents and caregivers
Bowie 2006	The perceptions of continuity of care of rural Albertans following acute myocardial infarction	Canada	Interviews (semi-structured)	8 patients with acute myocardial infarction
Caris-Verhallen 2001	Continuity of care for patients on a waiting list for institutional long-term care	Netherlands	Interviews (telephone)	980 elderly patients on a waiting list for long term care

<b>Author/Date</b>	<b>Title</b>	<b>Country</b>	<b>Data Collection Methods</b>	<b>Population</b>
Cigno 1999	A seamless service: meeting the needs of children with disabilities through a multi-agency approach	UK	Focus groups Interviews (semi-structured)	84 parents/caregivers of children with disabilities
Coleman 2002	Development and testing of a measure designed to assess the quality of care transitions	USA	Focus groups	49 elderly patients and caregivers receiving nursing care at home or in a long term care facility
Fulop 2000	National listening exercise	UK	Focus groups	354 health care service users, health care professionals, managers and researchers
Gittell 2000	Impact of relational coordination on quality of care, postoperative pain and functioning, and length of stay: a nine-hospital study of surgical patients	USA	Surveys (mail-out)	878 arthroplasty patients
Gulliford 2006	Continuity of care in type 2 diabetes	UK	Interviews (semi-structured)	25 patients with type 2 diabetes 7 caregivers of diabetic patients
Hale 2006	"Joining the dots" for patients with systemic lupus erythematosus	UK	Interviews (semi-structured)	10 patients with systemic lupus erythematosus
Harris Interactive 2005	Chronic illness and caregiving: survey of the general public, adults with chronic conditions and caregivers	USA	Surveys (telephone)	1490 consumers 663 chronic disease patients 320 caregivers
Harrison 1998	Consumers' views of coordination, their transition experiences, and health system performance	Canada	Interviews	33 consumers with transition experience from acute care hospital to short term home care
Harrison 2002	Understanding coordination of care from the consumer's perspective in a regional health system	Canada	Interviews	33 consumers with transition experience from acute care hospital to short term home care
Hastings 2004	Family perspectives on integrated child health information systems	USA	Interviews (telephone)	3 parents of children with special health care needs 1 patient with sickle cell disease
Health Council of Canada 2008	Canadian survey of experiences	Canada	Surveys	2914 consumers

Author/Date	Title	Country	Data Collection Methods	Population
	with primary health care in 2007		(telephone)	
Heller 2005	Continuity of care and caring: what matters to parents of children with life-threatening conditions	USA	Interviews (telephone)	36 patients/caregivers of deceased children
Kautz 2007	Patient benefits from participating in an integrated delivery system	USA	Surveys (mail-out)	222 arthroplasty patients
Kirk 2004	Developing services to support parents caring for a technology-dependent child at home	UK	Interviews	24 families of technology-dependent children
Laschinger 2005	Health care providers' and patients' perspectives on care in HIV ambulatory clinics across Ontario	Canada	Focus groups Surveys	15 patient/health care provider focus groups
Lawton 2005	Diabetes service provision; a qualitative study of newly diagnosed type 2 diabetes patients' experiences and views	UK	Interviews	40 patients with type 2 diabetes
Legault 2001	Home care nurses' contribution to the integration of palliative care services	Canada	Interviews (unstructured)	10 palliative care patients 16 family members/friends
Leith 2004	Exploring the service needs and experiences of persons with TBI and their families	USA	Focus groups	21 patients with traumatic brain injury and families
Levine 1998	Rough crossings: family caregivers' odysseys through the health care system	USA	Focus groups	56 family caregivers of elderly, chronically or terminally ill, or patients with disabilities
Mauksch 2001	Mental illness, functional impairment, and patient preferences for collaborative care in an uninsured, primary care population	USA	Surveys	500 low-income uninsured patients
McCourt 1998	Evaluation of one-to-one midwifery	UK	Focus groups Interviews Surveys (mail-out)	1403 women receiving midwifery care
McLennan 2003	The integration of health and social services for young children and their families	Canada	Focus groups Interviews Surveys	235 parents of children with special needs
Naithani 2006	Patients' perceptions and experiences of 'continuity of care' in diabetes	UK	Interviews (semi-structured)	25 patients with type 2 diabetes

<b>Author/Date</b>	<b>Title</b>	<b>Country</b>	<b>Data Collection Methods</b>	<b>Population</b>
Nielsen 2003	Randomised controlled trial of a shared care programme for newly referred cancer patients	Denmark	Surveys	248 cancer patients
Noël 2005	Collaborative care needs and preferences of primary care patients with multimorbidity	USA	Focus groups	60 patients with two or more chronic illnesses
Oeseburg 2004	Reducing discrepancies between MS patients' needs and use of healthcare services by applying a transmural care model	Netherlands	Surveys	20 MS patients
Ouwens 2007	Quality of integrated care for patients with head and neck cancer	Netherlands	Interviews	30 patients with head and neck cancer
Palfrey 2004	The pediatric alliance for coordinated care: evaluation of a medical home model	USA	Surveys	150 families of children with special health care needs
Parchman 2005	Primary care attributes, health care system hassles, and chronic illness	USA	Surveys (mail-out)	422 patients (veterans) with one or more chronic illnesses
Parry 2006	A qualitative exploration of a patient-centered coaching intervention to improve care transitions in chronically ill older adults	USA	Focus groups Interviews	32 older adults (60+) with chronic illness
Preen 2005	Effects of a multidisciplinary, post-discharge continuance of care intervention on quality of life, discharge satisfaction, and hospital length of stay	Australia	Surveys	189 patients with chronic cardio-respiratory illnesses
Preston 1999	Left in limbo: patients' views on care across the primary/secondary interface	UK	Focus groups Interviews	33 patients 8 caregivers of patients with chronic illnesses
Pritchard 2004	Cost-benefit analysis of an integrated approach to reduce psychosocial trauma following neurosurgery compared with standard care	UK	Surveys	326 neurosurgery patients
Rahi 2004	Meeting the needs of parents around the time of diagnosis of disability among their children	UK	Interviews Surveys	147 families of children with ophthalmic disorders
Ray 2003	The social and political conditions that shape special-needs parenting	Canada	Interviews	30 families of children with chronic illnesses
Rodenburg 2004	General practice care of enduring mental health problems: an	New Zealand	Interviews	163 patients with mental



Author/Date	Title	Country	Data Collection Methods	Population
	evaluation of the Wellington Mental Health Liaison Service			health illnesses
Rozmovits 2004	In the absence of evidence, who chooses? A qualitative study of patients' needs after treatment for colorectal cancer	UK	Interviews	39 patients with colorectal cancer
Schoen 2005	Taking the pulse of health care systems: experiences of patients with health problems in six countries	Australia Canada Germany New Zealand USA UK	Surveys	702 patients (Australia) 751 patients (Canada) 1503 patients (Germany) 704 patients (New Zealand) 1527 patients (USA) 1770 patients (UK)
Shaw 2004	User perspectives of transitional care for adolescents with juvenile idiopathic arthritis	UK	Focus groups	30 patients with juvenile idiopathic arthritis 23 parents of adolescents with juvenile idiopathic arthritis
Simon 2002	Stroke patients' carers' views of formal community support	UK	Interviews	8 caregivers of stroke patients
Smith 1998	Experiences of caregivers in arranging services for survivors of traumatic brain injury	Canada	Interviews	8 caregivers of survivors of traumatic brain injury
Smith 2000a	Weaving the seamless web of care: an analysis of parents' perceptions of their needs following discharge of their child from hospital	UK	Interviews Surveys (telephone)	164 parents of children discharged from hospital after an acute medical episode
Smith 2000b	No map, no guide: family caregivers' perspectives on their journeys through the system	Canada	Interviews	8 primary caregivers of survivors of traumatic brain injury
Vanderplasschen 2007	Dealing with multiple and frequent service utilization in substance abuse treatment: experiences with coordination of care in residential substance abuse agencies in the region of Ghent, Belgium	Belgium	Interviews	20 substance abuse clients
Weinberg 2007	Beyond our walls: impact of patient and provider coordination across the continuum on outcomes for surgical patients	USA	Surveys	222 unilateral knee replacement patients
Well 2000	What do families say about health care for children with special health care needs	USA	Surveys (mail-out)	2220 families of children with special health care needs

<b>Author/Date</b>	<b>Title</b>	<b>Country</b>	<b>Data Collection Methods</b>	<b>Population</b>
Woodward 2001	"My home is not my home anymore": improving continuity of care in homecare	Canada	Interviews Surveys (telephone) Client record review	65 clients, caregivers and managers/providers interviewed 111 long term clients surveyed 600 client records reviewed

### **c) Organization of the Results**

The findings from the above-noted articles have been categorized under five general themes related to integration of care: (1) ease of navigation; (2) communication between professionals; (3) information follows the patient through the system; (4) redundancies, delays and disruptions; and (5) unmet or unaddressed needs.

Within each of these themes, the overall results from the literature are organized into two tables: one outlining findings from Canadian studies; the second, findings from other countries represented in the literature.

## 1. Ease of Navigation

The ease with which patients navigate through and around the health care system encompasses the degree to which health care and related services are available and accessible; the extent to which health professionals and their patients are aware of what is available; and the degree to which patients are successfully able to access and obtain the services they need in a timely manner.

### i. Availability and access

Availability, timeliness and ease of access to services were key concepts represented in the literature related to the integration of health care; as well as flexibility and choice (Bethell, Lansky, & Fiorillo, 2001; Bowie, 2006; Fulop, 2000; Gulliford et al., 2006; Hastings, 2004; Kirk & Glendinning, 2004; Lawton et al., 2005; Leith et al., 2004; McLennan et al., 2003; Naithani et al., 2006; Noël et al., 2005; Preston et al., 1999; Ray, 2003; Shaw et al., 2004; Simon & Kumar, 2002; Smith, 1998; Smith & Smith, 2000b; Well et al., 2000). Knowing what is available, where to go and who to contact were all key concerns (Bowie, 2006; Hastings, 2004; Leith et al., 2004; McLennan et al., 2003; Naithani et al., 2006; Simon & Kumar, 2002, Smith & Smith, 2000b; Well et al., 2000). Many patients and caregivers expressed confusion as to the way things worked inside the system, often not knowing who was responsible for what and when (Anderson & Parent, 2004; Heller & Solomon, 2005; Lawton et al., 2005; McLennan et al., 2003).

### ii. Is anybody 'joining the dots'?

In today's health care environment patients receive care from a variety of professionals within and across multiple settings (Coleman, 2003). Practice settings, and the health care and other service professionals affiliated with them, most often operate independently with no one single professional or provider coordinating an individual patient's journey through the system (Beaudin et al., 1999; Bethell et al., 2001; Coleman, 2003; Hale et al., 2006; Smith, 1998). Usually the patient and family caregiver represent the only common threads and, as such, may be left to facilitate their own way through the continuum of care without the skills, support or confidence they need to do so (Coleman, 2003; Levine, 1998; Smith, 1998; Smith & Daughtrey, 2000a; Smith & Smith, 2000b).

"no-one seemed to be joining the dots and integrating their health care: '... it's not as if you can talk to one person [health care provider], you've got all these different people and somehow along the line they never all link up'." (Patient comment, Hale et al., 2006, p. 587)

This was commonly reported in the literature related to parents of children with special health care needs and other families dealing with chronic, debilitating illnesses. In a Canadian study on the integration of health and social services for young children with serious developmental or mental health difficulties, many of the 235 parents surveyed found themselves taking on this role of care coordinator and having to navigate their way through multiple and sometimes redundant care paths and providers in their quest to obtain the necessary care for their children (McLennan et al., 2003).

### iii. A 'one stop shopping' model

Those patients receiving their care in integrated clinics or hospital departments expressed a greater degree of satisfaction or less difficulty with respect to ease of navigation than those whose health care professionals and related services were not co-located or were at some distance from one another (Bowie, 2006; Cigno & Gore, 1999; Noël et al., 2005). The concept of a 'one stop shopping model' for services and information came up often as a means of unifying and coordinating services and information for both providers and the patients and caregivers they serve (Anderson & Parent, 2004; Cigno & Gore, 1999; Fulop, 2000; Noël et al., 2005; Simon & Kumar, 2002).

This overall need for effective, responsive processes to facilitate seamless transitions between points of care and systems of care was clearly indicated in the literature (Anderson & Parent, 2004; Bowie, 2006; Fulop, 2000; McLennan et al., 2003). In Anderson and Parent's (2004) Canadian study on integration of formal and informal care at the end of life, the 155 family

caregivers and hospice volunteers who were surveyed expressed the need for a central registry point and referral process linking caregivers to doctors, community agencies and other relevant services, and facilitating the effective and appropriate sharing of patient information as required. Having a system road map to aid the navigation process was another strong recommendation in this study.

#### iv. A navigator to guide the way

Having one professional or provider overseeing a patient's journey through the health care system was a strong recommendation highlighted in the body of literature presented here. Whether described as a care facilitator or key worker (Kirk & Glendinning, 2004; Shaw et al., 2004), a transition coach (Parry, Kramer, & Coleman, 2006), a patient navigator (Laschinger, Van Manen, Stevenson, & Fothergill-Bourbonnais, 2005) or a case manager (Laschinger et al., 2005; Smith, 1998; Smith & Smith, 2000b, Well et al., 2000), the presence of a known and accessible individual in a coordinating role reduced anxiety and stress for patients and their caregivers and contributed significantly to the seamlessness of a patient's progress through the health care system (Anderson & Parent, 2004; Hale et al., 2006; Harrison, 1998; Heller & Solomon, 2005; Kautz et al., 2007; Kirk & Glendinning, 2004; Leith et al., 2004; McCourt et al., 1998; Oeseburg, Jansen, & De Keyser, 2004; Parry et al., 2006; Pritchard et al., 2004; Rodenburg et al., 2004; Rozmovits, Rose, & Ziebland, 2004; Smith & Smith, 2000b; Vanderplasschen et al., 2007).

#### v. The patient experience of ease of navigation

**Table 2.1 Ease of Navigation – Findings from Canada**

Patient Experiences	Study and Location
Difficulty accessing health care (i.e., obtaining appointments, referral process, hospital admission, lack of information, service availability, geography)	Bowie 2006 – Alberta
Difficulty accessing support services (i.e., lack of information, service availability, referral process, geography, eligibility)	Bowie 2006 – Alberta McLennan 2003 – Alberta/Ontario Ray 2003 – Western Canada Smith 1998 – Canada
Lack of service coordination between points of care	Anderson 2004 – Ontario Bowie 2006 – Alberta Smith 1998 – Western Canada Smith 2000b – Western Canada
Patients and/or family caregivers acting as service coordinators	Harrison 1998 – Alberta McLennan 2003 – Alberta/Ontario Ray 2003 – Western Canada Smith 1998 – Western Canada Smith 2000b – Western Canada
'Insider' assistance required to gain access to services	Bowie 2006 – Alberta

**Table 2.2 Ease of Navigation – Findings from outside of Canada**

Patient Experiences	Study and Location
Difficulty accessing health care (i.e., obtaining appointments, referral process, lack of information, making phone contact, service availability, hospital admission)	Bethell 2001 – USA Caris-Verhallen 2001 – Netherlands Cigno 1999 – UK Coleman 2002 – USA Gulliford 2006 – UK Lawton 2005 – UK Naithani 2006 – UK Noël 2005 – USA Preston 1999 – UK Simon 2002 – UK
Difficulty accessing support services (i.e., lack of information, time involved in process, service availability, eligibility, lack of follow-up)	Hastings 2004 – USA Leith 2004 – USA Smith 2000b – UK

	Well 2000 – USA
Lack of consistency and coordination within and between services	Caris-Verhallen 2001 – Netherlands Fulop 2000 – UK Hale 2006 – UK Hastings 2004 – USA Kirk 2004 – UK Lawton 2005 – UK Leith 2004 – USA
Lack of professional coordination assistance	Beaudin 1999 – USA Bethell 2001 – USA Coleman 2002 – USA
Patients and/or family caregivers acting as service coordinators	Coleman 2002 – USA Heller 2005 – USA Kirk 2004 – UK Levine 1998 – USA Smith 2000a – UK Well 2000 – USA
Lack of clarity related to professional hierarchies and relationships	Heller 2005 – USA

## 2. Communication between Professionals

In an effort to understand the meaning of coordination to consumers and to describe the elements that contribute to a successful transition in care, Harrison (1998) interviewed 33 consumers who had recently experienced the transition from an acute care hospital to a short term home care program within the Calgary Health Region in Alberta, Canada. Three components of coordination were identified: communication, knowledge and consumer focus. The most consistent component was communication; specifically, communication between health care providers and between health care providers and consumers.

The literature suggests that patient perceptions related to coordination of care are strongly tied to their observations of the extent to which health care professionals communicate with one another, both within and across sectors (Beaudin et al., 1999; Hale et al., 2006; Harrison, 1998; Harrison & Verhoef, 2002; Heller & Solomon, 2005; Kirk & Glendinning, 2004; Laschinger et al., 2005; Levine, 1998). Although highly valued, it is abundantly clear that professionals are not communicating well with one another, even openly disagreeing with each other (Beaudin et al., 1999; Hale et al., 2006; Harris Interactive, 2005; Harrison, 1998; Heller & Solomon, 2005; Kirk & Glendinning, 2004; Laschinger et al., 2005; Levine, 1998; McCourt et al., 1998; Noël et al., 2005; Rozmovits et al., 2004; Weinberg et al., 2007). This lack of informational consistency or continuity can suggest poor clinical oversight, undermining a patient's or caregiver's trust in their own or a loved one's care (Heller & Solomon, 2005).

“Every new staff person who came into the room – the neurologist, the internist, the psychiatrist, and the nurses – all asked questions trying to find out what was going on, but never spoke with each other. The transition to the hospital made me extremely anxious. Coordination became *my* job, but I didn't have the authority.”  
(Caregiver quote, Levine, 1998, p. 10)

In a U.S. study of mental illness and functional impairment by Mauksch et al. (2001), when given a choice between having their health care providers communicate effectively with one another or maintaining their preferred service location, 90% of the 500 patients surveyed chose communication. The development of ongoing relationships among and between the professionals and the referral agencies involved in HIV care was highlighted as important in Laschinger et al.'s (2005) study of patients living with HIV/AIDS in Ontario. Respondents here indicated that being referred must go beyond the process itself with HIV clinical staff and other professionals and agencies they deal with working together to achieve the same goals for their patients.

### i. Communication breakdowns

In one large U.S. survey of 663 adults with chronic illness and 320 caregivers, 6% of the chronic illness sufferers and 11% of the caregivers indicated that they had often received conflicting information from doctors, nurses and other health care professionals, with 11% of patients and caregivers indicating sometimes (Harris Interactive, 2005). As well, 16% of the chronic illness sufferers had often or sometimes been told by a pharmacist about a possible harmful interaction between a drug they were taking and a new one they were about to fill. Another 14% had often or sometimes been diagnosed with a different medical problem by different doctors for the same set of symptoms.

“It turned out to be a big fiasco. I had Home Care nurses say, ‘Oh, they shouldn't have done that. They shouldn't have taken it out. They should have checked with us first’. Well, I didn't know what to do. So I was kind of hands up in the air thinking, ‘I don't know’. But it wasn't really anything I did. It was just a lack of communication, lack of people knowing what to do and stuff.” (Consumer comment, Harrison, 1998, p. 74)

Similar findings were noted in other large surveys as well. In Caris-Verhallen and Kerkstra's (2001) study in the Netherlands of 980 elderly patients on a wait list for access to nursing homes, 25% of the respondents indicated that providers within disciplines were working at cross-purposes and 20% reported that they had received inconsistent information. In a survey of 222 unilateral knee-replacement patients in Boston,

Massachusetts, 38% of the respondents reported problems related to how well the rehabilitation providers worked together (Weinberg et al., 2007). Problems with communication were common in the handoff between the hospital and the rehabilitation facility, with 34% of the patients reporting that they had received conflicting or contradictory information from the health care staff involved and 44% reporting that providers were not aware of changes in treatment that had been recommended by other professionals.

Communication issues that do exist are most acutely represented during transitions in care; when patients and their caregivers are required to move from one health care provider to another, from one facility to another, or back and forth from their homes to care facilities (Armitage & Kavanagh, 1998; Beaudin et al., 1999; Bowie, 2006; Leith et al., 2004; Levine, 1998; Naithani et al., 2006; Preston et al., 1999; Schoen et al., 2005; Smith & Daughtrey, 2000a; Smith & Smith, 2000b; Weinberg et al., 2007; Woodward et al., 2001). As Parry et al. (2006) suggest: "Quality of care and patient safety can be jeopardized at any one of these points due to incomplete or inaccurate information transfer between settings and practitioners, inappropriate or absent follow-up care, conflicting advice about illness management, and difficulty reaching practitioners when questions or problems arise." (p. 40)

Failures in communication between professionals around an individual patient's medication regime can be especially problematic. In Schoen et al.'s (2005) study related to chronic illness, 700 to 750 patients were surveyed in each of Australia, Canada, New Zealand, the United Kingdom, the United States and Germany. Cumulatively, 19 to 26% of respondents reported overall gaps in communication. Most of these patients were taking medications regularly with up to half of them taking four or more. A sizeable majority indicated that their physicians had not always reviewed their medications during the past year, with over a third reporting infrequent reviews. Many were given a new medication when discharged from hospital yet, in all but Germany, one in four patients reported that nobody had reviewed their medications prior to hospitalization. One in ten of all respondents had been readmitted to hospital or visited the emergency room because of complications post-discharge. According to patient reports, there were sizeable gaps in physician explanations around medication side effects.

The lack of an appropriate medication review process and/or patient confusion over medications and care plans was cited in other studies as well (Armitage & Kavanagh, 1998; Beaudin et al., 1999; Bethell et al., 2001; Coleman et al., 2002; Harris Interactive, 2005; Weinberg et al., 2007). In Armitage and Kavanagh's (1998) study of 29 cardiology and respiratory patients in Australia, patients who had had a consultation with a pharmacist and had been given detailed information on their medications were much more comfortable about their medication regimes. Not all of the patients had been offered this service, however, and it was unclear what the eligibility requirements were to gain access to it.

A lack of communication and information transfer between specialists and general practitioners was commonly reported after hospital discharge. In Bowie's (2006) Canadian study of rural Albertans' perceptions of continuity of care following acute myocardial infarction, respondents indicated that many of their questions remained unanswered post-discharge and their family physicians were not always able to assist them because they had not received the necessary referral information from specialists.

In a randomized controlled trial in Australia, Preen et al. (2005) investigated the effects of a multidisciplinary post-discharge care plan on quality of life, discharge satisfaction and hospital length of stay for 189 patients with chronic cardiorespiratory diagnoses. Prior to discharge, patients in the intervention group received an enhanced primary care plan that had been sent to their general practitioners and other community service providers for review. A 13.6% increase ( $P=0.02$ ) in improvement in the rating of the importance that general practitioners be informed by the hospital of a patient's post-discharge care arrangements was indicated in the intervention group survey responses compared with control. Patient satisfaction with input into discharge care planning

"And the audiologist said to me, 'You look terrible.' And I go, 'Well, yeah, I just don't get any sleep.' And she said, 'Well what about your respite?' And I'm going, 'What is that?' She goes, 'You know: At Home. Respite. At Home.' And I'm going, 'Respite at home?' And I still didn't know what she was talking about." (Parent comment, Ray, 2003, p. 288)

was also significantly greater for those receiving the care plan (36.5%,  $P=0.02$ ) and these patients rated the achievability of post-discharge care arrangements significantly higher too (10.1%,  $P=0.038$ ).

A lack of information transfer between providers can have a profound effect, particularly on parents of children with special health care needs or families dealing with chronic illness. In a study of the social and political conditions that shape special health care needs parenting, Ray (2003) interviewed 30 families from Western Canada. Parents related how they did not have the information they needed to care for their children or meet their own needs because of communication breakdowns among the multiple providers they were dealing with and a lack of integrated care. Often the professionals were assuming that critical information had been provided elsewhere.

This lack of a coordinated effort around key information was an issue in another study from Western Canada (Smith, 1998). Eight primary caregivers of traumatic brain injury survivors described how there was no one person that they could go to for help. Instead, they had to talk to a variety of professionals or seek out information on their own.

In a two-year prospective study by Pritchard et al. (2004) in the United Kingdom, an integrated approach to care to reduce psychosocial trauma following neurosurgery was compared to a standard care approach. The intervention group patients were enrolled in a program that utilized the services of an enhanced Specialist Liaison Nurse (SLN) who followed them from admission on, providing a link between the hospital and the community, and support and counselling during and after discharge. Both the 142 standard care patients in the control group and the 184 intervention patients expressed considerable dissatisfaction with their general practitioners' knowledge of the specifics of their condition throughout the study period, although this was slightly less marked in the intervention group (48% versus 40%). However, 88% of the intervention group indicated that the SLN provided an important link between home and hospital, and 58% felt that their general practitioners should be more willing to ask advice from the Specialist Liaison Nurse.

## ii. Knowledge transfer

Not only is information transfer important, but knowledge transfer is critical too – the sharing of specialized knowledge gained through further education and practical experience around a particular specialty or across an individual patient's continuum of care. As noted throughout this literature review, access to specialists is limited and often patients and family caregivers remain reliant on their primary care providers for health care support across the continuum. Some patients and families are dealing as well with multiple specialists. When the general practitioners or other providers remain uninformed or out of the loop, so too do the patients.

Nielsen et al.'s (2003) randomized controlled trial of a shared care program for cancer patients in Denmark, highlighted the importance of the role of the general practitioner in oncology care. As most cancer patients are treated on an outpatient basis they often go to their general practitioners for advice and information. A general practitioner's lack of specialized cancer knowledge and the overall lack of collaboration between oncologists and general practitioners greatly contribute to a lack of continuity of care for these patients. The intervention in this study utilized strategies around knowledge transfer, channels of communication and active patient involvement to bridge this gap between the general practitioners, the oncology group and the patients. The shared care program had a significant effect on patient perceptions of cooperation; their feelings of not being left in limbo; and their attitudes towards and reported contacts with their general practitioners. As well, intersectoral cooperation did show statistically significant improvements at three months, but not at six months (Nielsen et al., 2003).

“He [the GP] said he'd had a letter from the doctor at the hospital to say that he wasn't seeing me anymore unless it was necessary. And I said, 'Well, I understand that I will have to have an ultrasound scan', which has come along since, because I recently saw the surgeon and he um, he advised, or he said, 'When did you have your last scan?' I said 'I had one before the operation, I haven't had one since'. So he said, 'Well I think it's time that we had one of those then ...' And my GP said to me, 'Well you probably know more than I do'. He said, 'So, yes I suppose it is normal to have those follow-up treatments' he said 'but I don't really know'. So ... I don't think the GPs are aware.” (Patient comment, Rozmovits et al., 2004, p. 161)



Rodenburg et al.'s (2004) evaluation of an integrated model of care in New Zealand interviewed 163 mental health care consumers receiving their mental health care within general practice through the Wellington Mental Health Liaison Service. Not only were some of the respondents unsure of the general practitioner's knowledge of mental health, they were also inhibited by the time constraints of their appointments.

**iii. Better communication = Improved quality of care**

Gittell et al.'s (2000) cross-sectional study of knee and hip arthroplasty patients in the United States investigated the impact of relational coordination on quality of care; postoperative pain and functioning; and length of stay. Relational coordination was defined as frequent, timely and accurate communication, as well as problem-solving, shared goals, shared knowledge and mutual respect among health care providers. Over 300 care providers and 800 patients were surveyed across nine hospitals and their hospital records were reviewed. The findings indicate that improved quality of care and lengths of stay are significantly associated with higher levels of relational coordination among health care providers. Postoperative freedom from pain was significantly associated with four dimensions of coordination: frequency of communication, shared goals, shared knowledge and mutual respect. Although postoperative functioning was not significantly associated with the overall index of relational coordination, it was associated with frequency of communication, shared goals and mutual respect among care providers. The results of this study reflect that important clinical outcomes are influenced by the quality of the communication between health care providers.

**iv. Is anybody communicating?**

Overall the findings from this literature review reveal a substantial gap in communication between professionals both within and across sites of care. There are some positive findings reported (Harrison, 1998; Harrison & Verhoef, 2002; Kirk & Glendinning, 2004; Legault, 2001; Naithani et al., 2006) in particular in Kirk and Glendinning's study in the United Kingdom where the parents of children with special health care needs indicated that there were occasions when professionals worked closely together, jointly visiting home and school to provide information and training.

In the 2007 Canadian Survey of Experiences with Primary Care, the majority of over 2,000 respondents indicated that their primary care providers worked well with other health professionals both within their own place of care and in other settings, as well as with other professionals such as pharmacists and physiotherapists (Health Council of Canada, 2008). It is important to note, however, that most of the respondents from this survey also reported that their general health was good to excellent. This is not representative of the populations surveyed in the other literature included here who represent much higher risk groups.

**v. The patient experience of communication between professionals**

**Table 3.1 Communication between professionals  
Findings from Canada**

<b>Patient Experiences</b>	<b>Study and Location</b>
Professionals talking effectively to and consulting with each other, sharing information and knowledge within place of care and across settings	Harrison 1998 – Alberta Harrison 2002 – Alberta Health Council of Canada 2008 Legault 2001 – British Columbia
Lack of communication between providers	Laschinger 2005 – Ontario Ray 2003 – Western Canada
Providers disagreeing with one another	Harrison 1998 – Alberta
Lack of standardized medication review process	Schoen 2005 – Multi-country
Providers not understanding care plan well enough to implement it appropriately	Woodward 2001 – Ontario
Providers unaware of other services patient receiving	Ray 2003 – Western Canada Woodward 2001 – Ontario
Patients and family caregivers unaware of, misinterpreting or disagreeing with care plans	Smith 1998 – Western Canada Smith 2000b – Western Canada

	Woodward 2001 – Ontario
Provider using patient as conduit for information related to care	Harrison 1998 – Alberta
Patients and family caregivers not having the information they need and/or feeling unprepared to care for themselves or their family members	Bowie 2006 – Alberta Ray 2003 – Western Canada Schoen 2005 – Multi-country Smith 1998 – Western Canada Smith 2000b – Western Canada
Patients and family caregivers unsure of or confused about care plan and/or medication regime	Bowie 2006 – Alberta
Patients and family caregivers having to contact multiple providers to get information they need	Smith 1998 – Western Canada

**Table 3.2 Communication between professionals  
Findings from outside of Canada**

<b>Patient Experiences</b>	<b>Study and Location</b>
Patient outcomes influenced significantly by the quality of communication between health care providers	Gittell 2000 – USA
Professionals effectively talking to and consulting with each other, sharing information and knowledge within place of care and across settings	Kirk 2004 – UK Naithani 2006 – UK Nielsen 2003 – Denmark Pritchard 2004 – UK
Lack of communication between providers	Beaudin 1999 – USA Hale 2006 – UK Kirk 2004 – UK Nielsen 2003 – Denmark Weinberg 2007 – USA
Providers not working well together and/or disagreeing with one another	McCourt 1998 – UK Noël 2005 – USA Rozmovits 2004 – UK Weinberg 2007 – USA
Gaps, duplication, inconsistencies and lack of continuity in information provided by professionals both within and across settings	Armitage 1998 – Australia Beaudin 1999 – USA Hale 2006 – UK Harris Interactive 2005 – USA Heller 2005 – USA Kirk 2004 – UK McCourt 1998 – UK Rozmovits 2004 – UK Weinberg 2007 – USA
Lack of appropriate medication review process	Beaudin 1999 – USA Harris Interactive 2005 – USA
Lack of clarity related to professional roles and responsibilities	McCourt 1998 – UK
Sense of confusion during hospital shift change	Beaudin 1999 – USA
Patients and family caregivers unsure of or confused about care plan and/or medication regime	Armitage 1998 – Australia Beaudin 1999 – USA Bethell 2001 – USA Coleman 2002 – USA Weinberg 2007 – USA
Care plans developed around convenience of health care providers and institutions, not patients or caregivers	Coleman 2002 – USA
Over-reliance on families as information conduits	Kirk 2004 – UK
Lack of coordination of care at discharge	Beaudin 1999 – USA
Family caregivers unprepared for care requirements post-discharge and/or having unrealistic expectations imposed on them around care	Kirk 2004 – UK Levine 1998 – USA Smith 2000a – UK
Patients unsure of practitioners' specialized knowledge or expertise	Nielsen 2003 – Denmark Rodenburg 2004 – New Zealand
No one professional responsible for communication and coordination across services	Kirk 2004 – UK

### 3. Information Follows Patients through the System

How important is it that care plans, patient health care records and test results are shared between health care professionals? Does this happen in an efficient and timely manner?

Results from the 2007 Canadian Survey of Experiences with Primary Health Care indicate that the majority of patients surveyed could not recall an instance when test results were not available at the time of their health care appointment (Health Council of Canada, 2008). Further, in Bowie's (2006) survey of acute myocardial infarction patients in rural Alberta, even though the respondents could not identify one single person they felt had complete and comprehensive information about them and their health care issues, they did trust that the information would be available when necessary and that their health care providers would have access to this information to use it in their best interests.

While these studies highlight the confidence patients have that their test results will be transferred to their doctors or other health care professionals in a timely manner (Bowie, 2006; Harrison, 1998; Health Council of Canada, 2008; Naithani et al., 2006), this sense of confidence is not universal. Experience has indicated otherwise for many of the parents and family caregivers surveyed in the literature reviewed here (Bowie, 2006; Gulliford et al., 2006; Harris Interactive, 2005; Harrison & Verhoef, 2002; Hastings, 2004; Schoen et al., 2005; Weinberg et al., 2007).

In Weinberg et al.'s (2007) survey of 222 unilateral knee-replacement patients in Boston, U.S.A., 16% of the respondents felt that their surgeon was unaware of their medical history. In general, 24% of these patients felt that health care providers were not familiar with their recent medical histories, while 44% reported that health care providers were not aware of treatment recommendations made by other health care providers they had seen. In a 1998 survey of home care patients in Alberta, Canada, one patient stated that he was asked to complete a medical history and medication list each time a new home care nurse was assigned to him (Harrison, 1998).

#### i. Failures in transit

The transfer of information in times of transition appears to be more fraught with the potential for error. Patients have reported that health care records have been misplaced or not transferred between health care professionals when they experienced a change in family physician or a transfer from hospital to other facilities (Gulliford et al., 2006; Weinberg et al., 2007). In Weinberg et al.'s (2007) study noted above, information transfer problems occurred frequently during transfers between hospital and rehabilitation facilities. The most commonly documented problems were that the rehabilitation staff were not made aware of the results of the patient's surgery (25%), the patient's history (36%) and any special conditions or needs (43%).

"He [the physician] had to phone up there and find out what had been done to me and what my results were and all that." (Patient comment, Bowie, 2006, p. 61-62)

In Schoen et al.'s (2005) survey of chronic care across six countries, patients felt that the information flow across sites of care was instrumental to providing efficient and safe care, in particular for individuals with chronic complex health conditions. Often, however, transitions were accompanied by failures in the coordination of care. Patient statements highlighted examples of the unavailability of medical records during appointments with health care providers. The extent to which this was reported varied between 11% in Germany to 23% in the United States, with Canada weighing in at 19%. Other surveys of chronic care patients report similar problems with respect to the timely availability of medical records and test information (Gulliford et al., 2006; Harris Interactive, 2005; Naithani et al., 2006).

#### ii. Patients and caregivers as information brokers

Together with the patients and families dealing with chronic illness, the parents of children with special health care needs are particularly vulnerable to issues related to the flow of information. They deal with multiple providers across many sites of care and important information is often missing or unavailable at appointments. In Hastings'

"If I go to a specialist with my child, I take the initiative and go get the information and bring it with me or make sure it's already there." (Parent comment, Hastings, 2004, p. S26)

(2004) study soliciting views on integrated health information systems from this parent population, one parent noted that she felt one of her jobs was to ensure the delivery of her child's health information from one provider to another so that it was there in time for appointments. Another parent indicated that she was often coordinating her child's care with five or six different specialists at once. She had two boxes of medical records in her home and felt that she would still continue to ensure that the information was communicated between providers even if an automated information system was in place.

Taking responsibility for coordinating one's own health care information was echoed as well in Bowie's (2006) study of rural patients with acute myocardial infarction. Many of these patients indicated that the transfer of information from the hospital to their family physicians did not always occur in a timely manner. In some instances they had to prompt their physicians to locate the missing information. One respondent decided that he was not going to take any more chances on his information not being available. He has copies of all of his medical reports, his ECGs and discharge summaries, and carries them with him at all times just in case a cardiac problem arises when he is away from familiar health care providers.

### iii. The patient experience of information flow

**Table 4.1 Information follows patients through the system  
Findings from Canada**

<b>Patient Experiences</b>	<b>Study and Location</b>
Test results available at time of appointment	Health Council of Canada 2008
Medical records unavailable during appointments	Bowie 2006 – Alberta Schoen 2005 – Multi-country
Completion of multiple medical histories and medication lists for providers within same discipline	Harrison 1998 – Alberta

**Table 4.2 Information follows patients through the system  
Findings from outside of Canada**

<b>Patient Experiences</b>	<b>Study and Location</b>
Medical records and/or test results unavailable during appointments	Gulliford 2006 – UK Harris Interactive 2005 – USA Naithani 2006 – UK
Health care records misplaced or not transferred between professionals during transitions in care	Gulliford 2006 – UK Weinberg 2007 – USA
Providers not familiar with patient's recent medical history, outcomes related to treatment and/or treatment recommendations	Preston 1999 – UK Weinberg 2007 – USA
Professionals unaware of patient's special conditions or needs	Weinberg 2007 – USA
Lack of follow-up related to information not being forwarded	Gulliford 2006 – UK
Parents coordinating transfer of information between providers	Hastings 2004 – USA Kirk 2004 – UK
Lack of support from professionals around use of patient health record as communication aid and medication tracking tool	Parry 2006 – USA

## 4. Redundancy, Delays and Disruptions

As indicated in Preston et al. (1999), the coordination of different services and the degree to which care continues across interfaces are important preconditions for the smooth progress of patients through the health care system. Any breakdown in communication or coordination can easily and often does result in duplications, delays and/or gaps in health service delivery.

### i. Duplication, delay, disruption and discontinuation

In the Harris Interactive (2005) survey on chronic illness and caregiving in the United States, 7% of the chronic illness sufferers indicated they had often been sent for duplicate tests or diagnostic procedures by different health care professionals, and 11% indicated sometimes. For the caregivers, 14% indicated that this had occurred often and 19% indicated sometimes.

In the literature included in this review, patients and their caregivers often described experiencing considerable delays in service provision, gaps in services and dissatisfaction as a result of deficiencies in team and cross-boundary continuity (Armitage & Kavanagh, 1998; Gulliford et al., 2006; Naithani et al., 2006; Preston et al., 1999; Smith, 1998; Woodward et al., 2001). In Bowie's (2006) study on the perceptions of continuity of care of rural Albertans after acute myocardial infarction, seven out of eight respondents mentioned specific instances in which they experienced a lack of coherence in care such as waiting for services; having scheduled treatments or procedures cancelled after they arrived; and limited access to cardiac specialists following discharge.

“Separate clinics don't talk to each other or ring each other. I find the whole thing incredible the length of time it takes; it's just been horrendous, waiting weeks to see a consultant to be told 'I don't know why you've been referred to me' ... It can make you feel very insignificant.” (Patient comment, Preston et al., 1999, p. 19)

In the case of adolescents moving into the young adult sector, a lack of coordination or communication can result in delays in transfer and inappropriate or discontinuation of care. The experience of one youth in Shaw et al.'s (2004) study on adolescents with juvenile idiopathic arthritis highlights this issue. “The children's ward wouldn't accept her because she was over age 16, the adult ward wouldn't accept her because she was under 18, and so we had [a] hell-of-a-game trying to find a ward for her and in the end she ended up going on a geriatric ward for the night.” (Shaw et al., 2004, p. 773)

In Canada, provincial budgets are allocated by site or care provider not the person or family in need of care, which contributes to the fragmentation of services and funding, and ultimately care (Ray, 2003). The parents in this Western Canadian study on the social and political conditions shaping special needs parenting reported on disjointed services, gaps and duplication, and a lack of coordination between government departments such as health, social services and education. They provided many detailed accounts of the number of steps and people involved in securing much needed equipment and services for their children, and their frustrations around the paperwork involved. As well, they reported on being asked the same questions over and over again during clinic visits.

Having to convey the same information repeatedly was a common occurrence in many of the

“She generates so much paperwork from these Ministries that all we seem to be doing is filling out paperwork, medical reports. And things like that. REPEATEDLY. The same things over and over again. Don't these people talk to each other? It's not just the hospitals, it's the government and EVERYBODY we deal with requires the proper paperwork. And that's a LOT of work for somebody who already has a lot of work thrown on them to begin with.” (Parent comment, Ray, 2003, p. 290)

patient populations (Beaudin et al., 1999; Harris Interactive, 2005; McLennan et al., 2003; Ray, 2003; Woodward et al., 2001). For elderly home care patients in Ontario, Canada, not only was this very stressful but it also reduced the amount of time they had available to get the help they needed during visits (Woodward et al., 2001).

When professionals are uninformed about services or do not fully comprehend when or how to access them, it can result in delayed, inappropriate or insufficient treatment, or even no treatment at all for patients and family caregivers (Leith et al., 2004). This lack of knowledge spans all disciplines and sectors (acute care, vocational and rehabilitative, community care, insurance) and can result in significant gaps and lags in care.

**ii. The patient experience of redundancy, delays and disruptions to care**

**Table 5.1 Redundancy, Delays and Disruptions Findings from Canada**

<b>Patient Experiences</b>	<b>Study and Location</b>
Delays in service	Bowie 2006 – Alberta Woodward 2001 – Ontario
Gaps in service	Ray 2003 – Western Canada
Duplication in service	Harrison 1998 – Alberta Ray 2003 – Western Canada
Discontinuation of care related to lack of coordination	Smith 1998 – Western Canada
Expected services not provided or delayed	Woodward 2001 – Ontario
Scheduled treatments cancelled after patient arrival	Bowie 2006 – Alberta
Having to convey the same information repeatedly	McLennan 2003 – Alberta/Ontario Ray 2003 – Western Canada Woodward 2001 – Ontario

**Table 5.2 Redundancy, Delays and Disruptions Findings from outside of Canada**

<b>Patient Experiences</b>	<b>Study and Location</b>
Delays in service	Leith 2004 – USA Naithani 2006 – UK Preston 1999 – UK
Delays in transfer causing inappropriate or discontinuation of care	Shaw 2004 – UK
Delays in discharge waiting for medications and paperwork	Armitage 1998 – Australia
Delays in receiving test results	Gulliford 2006 – UK Naithani 2006 – UK
Gaps in service	Leith 2004 – USA Naithani 2006 – UK Preston 1999 – UK
Duplication in service	Beaudin 1999 – USA Harris Interactive 2005 – USA
Unreliable or inefficient services related to a lack of coordination between service sectors	Kirk 2004 – UK Leith 2004 – USA
Lack of follow-up related to delay in or inappropriate information transfer	Gulliford 2006 – UK
Lack of follow-up related to poor coordination and communication between primary care and community services	Gulliford 2006 – UK
Having to convey the same information repeatedly	Beaudin 1999 – USA Cigno 1999 – UK Harris Interactive 2005 – USA

## 5. Unmet or Unaddressed Needs

Numerous studies attempt to describe what patients and family caregivers perceive is lacking in the health care system. Although seemingly individualized and variable, there are commonly acknowledged unmet needs that affect the degree to which individuals perceive that their health care system is integrated. This section reports on these common themes.

### i. Appropriate timing

Patients and caregivers highlight the importance of timely service. Patients who received homemaking and other home care services reported that consistency in the time and day of visits was important to them (Woodward et al., 2001). Patients also felt it was important to be ready to be discharged home from a hospital or other facility. Readiness was defined as feeling knowledgeable and confident with respect to being able to properly manage their condition and access adequate supports should the need arise (Harrison & Verhoef, 2002; Simon & Kumar, 2002; Woodward et al., 2001).

### ii. Appropriate planning

Recommendations and processes for self-care often do not take into account a patient's lifestyle or capabilities (Noël, 2005). Some patients felt they lacked the skills or were not provided with sufficient education to manage the technical requirements of their care regime (Harrison, 1998; Harrison & Verhoef, 2002; Noël et al., 2005). Consideration should be given to the physical and psychological abilities of the caregiver as well as the patient when planning support services (Simon & Kumar, 2002).

“when whoever is coordinating, is coordinating, I think they need to take into consideration the person as a whole not just whatever it was that brought them in and out of hospital. I really think that's sad that they've forgotten that we're people. I guess that's in the whole thing. We're not just studies or patients. So I'd like to see a more holistic approach.” (Consumer comment, Harrison, 1998, p. 75)

### iii. Appropriate support

In the Robert Wood Johnson Foundation National Strategic Indicator Survey, *A Portrait of the Chronically Ill in America, 2001*, two-thirds of the 6,447 chronic disease sufferers, parents and other caregivers surveyed who indicated a need for home care services did not receive them (Bethell et al., 2001). Furthermore, half of those who needed rehabilitation or counseling services did not receive it while two-fifths did not get the special medical equipment they required.

In another large US survey of 2,473 adults, adults with chronic illness and caregivers, 1% reported limited mobility in their homes because of a lack of information on making appropriate adjustments to their home environment such as the addition of ramps and hand-holds (Harris Interactive, 2005).

Ongoing and adequate availability of support are issues raised often by patients and their caregivers (Harrison, 1998; McCourt et al., 1998; Simon & Kumar, 2002). Patients receiving home care services and equipment reported that once support was in place there should be a periodic review to ensure that services and equipment continued to meet their needs (Simon & Kumar, 2002).

### iv. The patient experience of unmet or unaddressed needs

**Table 6.1 Unmet or Unaddressed Needs – Findings from Canada**

Patient Experiences	Study and Location
Lack of skills or knowledge required to manage care plan	Harrison 1998 – Alberta Harrison 2002 – Alberta
Care plan does not address patient's lifestyle and abilities	Harrison 1998 – Alberta
Lack of appropriate and/or consistent support to manage care (i.e., information, rehabilitation, counselling, respite, home care, equipment, support groups)	Bowie 2006 – Alberta Harrison 1998 – Alberta Laschinger 2005 – Ontario Ray 2003 – Western Canada Smith 1998 – Western Canada

	Smith 2000b – Western Canada Woodward 2001 – Ontario
Lack of flexible service provision (i.e., location, timing)	Laschinger 2005 – Ontario
Care that is not culturally sensitive	Legault 2001 – British Columbia Smith 1998 – Western Canada
Physically, emotionally or environmentally unprepared for discharge	Harrison 2002 – Alberta Woodward 2001 – Ontario
Lack of respect for individuality or privacy	Harrison 1998 – Alberta Harrison 2002 – Alberta Laschinger 2005 – Ontario

**Table 6.2 Unmet or Unaddressed Needs – Findings from outside of Canada**

<b>Patient Experiences</b>	<b>Study and Location</b>
Lack of skills or knowledge required to manage care plan	Kirk 2004 – UK Lawton 2005 – UK Levine 1998 – USA Noël 2005 – USA
Lack of appropriate and/or consistent support to manage care (i.e., information, rehabilitation, counselling, respite, home care, equipment, support groups)	Armitage 1998 – Australia Beaudin 1999 – USA Bethell 2001 – USA Cigno 1999 – UK Gulliford 2006 – UK Hale 2006 – UK Heller 2005 – USA Kirk 2004 – UK Lawton 2005 – UK Leith 2004 – USA Levine 1998 – USA McCourt 1998 – UK Ouwens 2007 – Netherlands Rozmovits 2004 – UK Simon 2002 – UK
Physically, emotionally or environmentally unprepared for discharge	Armitage 1998 – Australia Levine 1998 – USA Simon 2002 – UK
Lack of assistance with modifications to home environment	Harris Interactive 2005 – USA
Care plan does not address patient's lifestyle and abilities	Noël 2005 – USA
Care plan does not consider family caregivers' lifestyle and abilities	Levine 1998 – USA Simon 2002 – UK
Lack of flexible service provision (i.e., location, timing, drop-in clinics, help-line, interactive website, e-mail)	Fulop 2000 – UK Lawton 2005 – UK McCourt 1998 – UK Shaw 2004 – UK
Lack of respect for individuality or privacy	Leith 2004 – USA Preston 1999 – UK
Care that is not culturally sensitive	Armitage 1998 – Australia Fulop 2000 – UK Gulliford 2006 – UK Levine 1998 – USA McCourt 1998 – UK

## 6. Other Findings of Interest

A recurrent theme in the literature is the need for more information related to: an individual's own or a loved one's condition, prognosis and treatment; common problems and their solutions or why, when and whom to call; what to expect before, during and after any aspect of care; and what services, resources and equipment are available and how to access them.

It was very clear that many patients and their caregivers experience a multitude of problems getting the information, advice and support they feel they need. Although it is possible to achieve integration of care from a system point of view without addressing these concerns, this was a theme that was highlighted as an important component of integration or continuity of care from a



patient and caregiver perspective and, as such, it does represent an important finding in the literature.

More details on this finding have been included in the literature review as an appendix for your consideration and interest. Please see Appendix 2 attached.

## MOVING FORWARD...

Of the 53 studies included in this review, 30 report on the attitudes, feelings and experiences of relatively small populations of 100 or fewer persons. In researching public opinion, experiences or expectations, compromises are made between surveying large numbers of people superficially, through the use of primarily close-ended questions, and lengthy interview and focus group techniques that strive to gauge the full experiences and expectations of smaller numbers of individuals. The second approach offers opportunities to uncover facets of patient experiences that might not have been envisioned by researchers.

The dovetailing of themes across studies and populations speaks to a commonality of concerns. Patients and families feel that health information is not always communicated to the professionals charged with advising and assisting them with their care. They experience delays, redundancies and duplications in care, and many feel that their needs as both patients and caregivers are not being acknowledged or addressed. Patients and caregivers describe feelings of being left in limbo, cut adrift or hung out to dry, especially during transitions in care (Preston et al., 1999). They feel uncertain and powerless in the face of their inability to traverse smoothly between levels of care, and they feel ignored and insignificant.

“I came out of hospital, and I waited. I must have waited for about a month. No one called me ... so I went up to see the GP. I explained everything and told him that they had said I could get my care here ... I told them I had been waiting for over a month for someone to call me. They said ‘we don’t know anything about this’ apparently they hadn’t received the information. They said ‘they had no idea why the information had not arrived’. I was upset with them. I felt that if I hadn’t gone in then no one would have bothered to call and check if I was doing fine.” (Patient comment, Gulliford et al., 2006, p. 53)

What is most disturbing about the experiences that emerged is that the patients in question are not those relatively healthy individuals fortunate enough to put few demands on their health care systems, but those with pervasive, multiple and chronic illnesses that require ongoing care from a variety of health and social care providers in multiple settings. Here we refer, among others, to individuals with chronic illnesses including mental health issues, the elderly, and adults and children with physical disabilities. It is these individuals and their families who are most impacted by the lack of integration in our health care systems.

As suggested in Preston et al. (1999), health professionals need to recognize the interdependency of their roles within the health system as a whole in order to provide integrated care. They also need to recognize the importance of the patient and the caregiver as active participants in their own care.

### Enhancing integration through the exchange of information

In Fulop’s (2000) National Listening Exercise in the United Kingdom, focus groups and structured discussions were employed to gain a better understanding of important issues for both those delivering and organizing health care services and those receiving them. A total of 354 service users, health care professionals and researchers were involved and all highlighted the need for greater coordination of care.

The literature included here reflects on a number of recommendations posited by patients and/or caregivers to enhance the coordination and seamless delivery of care. The implementation of an electronic health record to ensure the flow of accurate and timely information between health care professionals across points of care was one such recommendation (Anderson & Parent, 2004; Fulop, 2000; Hastings, 2004), as well as system-wide compatible technological systems and consistent terminology and data collection procedures to facilitate information sharing (Anderson & Parent, 2004).

Providing patients with copies of their own health care records came up in Shaw et al.'s (2004) study of adolescents with chronic illness. The Patient Health Care Record utilized in the patient-centered coaching intervention evaluated in Parry et al.'s (2006) study on care transitions, clearly assisted those patients with chronic illness who did use it. It was a useful tool for tracking, organizing and learning about medications and side effects. Patients reported feeling more prepared as active participants because they had a resource to reference during acute health situations or when their doctors asked questions.

Other recommendations noted to enhance the integration of care through a more effective flow of information between and across professionals, patients and caregivers and service settings included:

- A system road map to facilitate understanding and navigation (Anderson & Parent, 2004), with comprehensive contact information (Naithani et al., 2006)
- A 'one-stop shopping' model or central registry point and information pool linking all sectors and clients (Anderson & Parent, 2004; Cigno & Gore, 1999; Fulop, 2000; Noël et al., 2005)
- Care plans shared between providers and service settings (Harrison, 1998; Parry et al., 2006; Preen et al., 2005)
- Processes to enhance information sharing and the development of ongoing relationships between providers and service settings (Bowie, 2006; Harrison, 1998; Laschinger et al., 2005)
- Processes to facilitate seamless transitions between points of care and between systems of care (Fulop, 2000; McLennan et al., 2003)
- A known and accessible professional in a coordinating role (Harrison, 1998; Kautz et al., 2007; Kirk & Glendinning, 2004; McCourt et al., 1998; Oeseburg et al., 2004; Parry et al., 2006; Pritchard et al., 2004)
- Convenient and flexible access to services in consideration of individual patient and caregiver needs (Fulop, 2000)
- Prompt and easy access to help and advice such as help lines, interactive websites or e-mail service (Lawton et al., 2005)

## Enhancing integration through 'organized' communication

Patients and caregivers consistently highlighted the fact that their health care providers are not communicating effectively with one another (Beaudin et al., 1999; Hale et al., 2006; Harris Interactive, 2005; Harrison, 1998; Heller & Solomon, 2005; Kirk & Glendinning, 2004; Laschinger et al., 2005; Levin, 1998; McCourt et al., 1998; Noël et al., 2005; Rozmovits et al., 2004; Weinberg et al., 2007). Nor are they communicating well with the patients and caregivers they serve (Armitage & Kavanagh, 1998; Bethell et al., 2001; Bowie, 2006; Cigno & Gore, 1999; Coleman et al., 2002; Gulliford et al., 2006; Hale et al., 2006; Heller & Solomon, 2005; Kirk & Glendinning, 2004; Leith et al., 2004; Levine, 1998; McCourt et al., 1998; McLennan et al., 2003; Ouwens et al., 2007; Parchman, Noël, & Lee, 2005; Parry et al., 2006; Preston et al., 1999; Pritchard et al., 2004; Ray, 2003; Rozmovits et al., 2004; Schoen et al., 2005; Simon & Kumar, 2002; Smith, 1998; Smith & Daughtrey, 2000a; Smith & Smith, 2000b; Weinberg et al., 2007; Well et al., 2000; Woodward et al., 2001). The literature suggests that communication is the overarching theme; that an overriding lack of effective communication directly corresponds to an overall deficiency in integrated care.

"That was one of the problems when I'm referring to continuity. It's not really totally continuity, maybe, but maybe sometimes it seemed that people were not totally on the same wavelength or didn't understand things exactly the same way. I think most of the time they did, but I think that could be improved with just a more, sort of cohesive system ... I know that they talk to each other all the time and they have conferences, but somehow it doesn't get passed to the patient or the patient's family that everyone is on the same wavelength because sometimes one person would say one thing and someone else would say something a little different. We weren't always totally sure what the plan was or what the feeling was about how she was doing ...." (Parent comment, Heller & Solomon, 2005, p. 340)

Patients and caregivers are experiencing duplications, delays, disruptions to and even discontinuation of care; confusion around treatment and self-management; issues around medications and side effects; a lack of appropriate follow-up; significant stress due to the burden of coordinating their own or a loved one's care and unrealistic expectations around care; a lack of physical, emotional and environmental support; and care that can be culturally or contextually insensitive, disrespectful or lacking in privacy.

Breakdowns in coordination between professionals within and across care settings threaten continuity and positive clinical outcomes (Kautz et al., 2007). Incomplete or inaccurate transfer of information, inappropriate or absent follow-up, conflicting advice and/or difficulties reaching professionals when questions or problems arise are all factors that can jeopardize quality of care and patient safety (Parry et al., 2006, as originally cited in Forster et al., 2003; Harrison & Verhoef, 2002; van Walraven et al., 2002).

Whether or not the lines of communication exist at all, or simply operate poorly is immaterial. The result is the same. When providers are not sharing information or consulting with one another effectively within and across the continuum of care, from the perspective of patients and caregivers, professionals do not seem to be aware of what is going on, when, where and why. And when the care providers are not aware, neither are the patients or their caregivers.

According to Beaudin et al. (1999), organized communication can be promoted through case management and better defining the roles of health care personnel. It is disturbing to think that we need to consider processes to organize communication yet, according to the literature, this does seem to be required.

A number of promising models were described in the literature to enhance the integration of care through structured communication strategies. The concept of case management was prominent among them.

#### **i. Case management – the care plan**

In today's health care environment, patients are being moved through the system much faster. With international efforts to shorten hospital stays, they are likely to be much sicker when they are discharged and poor coordination of care can result in complications and the increased likelihood of readmission to hospital (Schoen et al., 2005). With a more consistent and integrated approach to the needs of patients and their caregivers, some of these issues could be avoided.

Case management through the use of care plans was identified as one means of improving the integration of health services for patients and caregivers, especially when dealing with transitions in care (Schoen et al., 2005) or chronic and complex health needs (Smith, 1998; Smith & Daughtrey, 2000a).

A care plan defines the components of treatment and recovery, and also expectations for everyone involved in a patient's care (Rodenburg et al., 2004). Parameters are set for both the patients and their primary care providers, defining the circumstances in which external help and advice should be sought. The plan is individualized to a patient's needs and is, therefore, consistent to their understanding. It does depend, however, on the ongoing reevaluation of planning to ensure it remains responsive to the changing needs of individual clients (Smith, 1998).

In Palfrey et al.'s (2004) study of a medical home model for children with special health care needs, an individualized health plan was used to help each family plan goals for their child, explain their child's condition and medical issues, and prepare for school. This health plan became a useful communication tool for these families. Preen et al.'s (2005) randomized controlled trial of an enhanced primary care package discharge plan

describes the use of a multidisciplinary primary care plan initiated before discharge to improve integration of care between the hospital and general practitioner. This is similar to Nielsen et al.'s (2003) randomized controlled trial that looked at a shared care program for cancer patients. Here the usefulness of a discharge summary letter shared between oncologists, general practitioners and patients was clearly demonstrated as a facilitator of continuity of care and a useful educational tool for knowledge transfer between professionals.

The shared care program described in Nielsen et al. (2003) also demonstrates the importance of having some one professional with connections to both the primary and secondary sectors who can invest the time and energy required to have a shared care plan accepted in both settings. Nielsen et al. characterize this person as an "innovator" (p. 269). The role of innovator as depicted here, however, is very similar to the concept of care manager as variously described throughout the literature.

**ii. Overseeing the plan – the role of a case manager**

A lead professional in a coordinating and information brokering role was a strong recommendation in the literature (Anderson & Parent, 2004; Bowie, 2006; Gulliford et al., 2006; Heller & Solomon, 2005; Laschinger et al., 2005; Lawton et al., 2005; Legault, 2001; Leith et al., 2004; Oeseburg et al., 2004; Pritchard et al., 2004; Rodenburg et al., 2004; Schoen et al., 2005; Shaw et al., 2004; Simon & Kumar, 2002; Smith, 1998; Smith & Smith, 2000b; Vanderplasschen et al., 2007).

"The case manager's role has been described as a 'traveling companion', who shares the experiences and offers support and assistance, in contrast to a 'traveling agent' who only makes the arrangements." (Smith, 1998 as originally cited in Deitchman, 1980, p. 37)

This role was variously envisioned as a coordinator, a broker, a manager, an overseer or a system navigator; in short, someone available and accountable who can help individual patients and caregivers navigate the system, identify needs, coordinate plans and services, and assist in linking in. Having a professional in this role would provide patients and caregivers with continuity, consistency and coordination of care across all clinical settings and boundaries (Smith, 1998).

As suggested in Smith (1998), a logical choice for case manager would be the health provider best able to meet the needs of the patients and caregivers being served. A specialist nurse was perceived as someone well placed to perform this role, a professional with the knowledge and skills to provide both professional support and training as well as education, practical advice and support to individual patients and their caregivers (Hale et al., 2006; Lawton et al., 2005; Oeseburg et al., 2004; Pritchard et al., 2004; Rodenburg et al., 2004). A clinical nurse specialist could provide referral services; centralize test findings and coordinate treatment recommendations; facilitate concordance among providers and oversee prescriptions; disseminate and reinforce pertinent and understandable information for both providers and patients; and provide on-going and consistent oversight for patients through regular contact (Hale et al., 2006).

Parchman, Noël and Lee's (2005) study of the health care system hassles experienced by 422 veterans with chronic illness in Texas, U.S.A., highlighted the role of the primary care physician as central to the coordination of care. The results of this study indicate that, "health care system hassles are inversely related to the degree to which care is coordinated by the primary care physician and the level of communication with the primary care physician" (p. 1127). The primary care physician's awareness of and/or access to a patient's health history and personal context suggest this provider as the

logical choice for overseer of care. Parchman et al. (2005) reiterate this view by reflecting on how the primary care provider is the professional best able to act as a patient's advocate within the system; an interpreter of test results and recommended treatments; and someone who can monitor the medications prescribed by the different providers involved.

The case managed patients in Vanderplasschen et al.'s (2007) study of the coordination of care in residential substance abuse agencies in Belgium emphasized their appreciation for the comprehensive and individualized approach they received from their case manager. They had more contacts with ancillary services such as housing, employment and child care than the patients in the care coordination group and were, therefore, better able to stabilize their environment and link in to services. They were also more involved in the treatment process and felt that their drug and employment problems had improved.

### iii. In consideration of the patients and their caregivers

Early discharge from hospital and the emphasis our health care systems are currently placing on outpatient and home care has encouraged us to become active partners in our own care, yet we are not equipped to take on this challenge. Patients and their caregivers consistently report that they do not have the information or technical, practical or emotional supports they need to assume this responsibility (Levine, 1998; McLennan et al., 2003; Ray, 2003 Well et al., 2000). This is chilling when we consider that the patients in question are not those with transitory minor health issues, but individuals with chronic and complex health conditions (Kautz et al., 2007).

Consumers play a crucial role in coordinating their own care (Harrison, 1998; Harrison & Verhoef, 2002), a role that requires considerable time, effort and persistence. This extra burden is particularly difficult for patients and caregivers experiencing chronic and debilitating illnesses who can be dealing with multiple aspects of care and multiple providers on a daily basis (Hastings, 2004; McLennan et al., 2003; Smith, 1998; Smith & Smith, 2000b; Well et al., 2000).

"I feel the concept of 'care coordination' is a myth. All of my son's health care is fragmented and left to parents to 'coordinate' as best we can." (Parent comment, Well et al., 2000, p. 6)

Parents of children with special health care needs, in particular, are performing many roles, even assuming the main responsibility for their child's nursing and technical care, when local health and social services are unable to provide the type or level of care required (Kirk & Glendinning, 2004; Well et al., 2000). Not only are they parenting, they are managing their child's condition and organizing services, and even performing clinical procedures on a regular basis (Kirk & Glendinning, 2004; Well et al., 2000). In Well et al.'s (2000) survey of over 2,000 families of special health care needs in the United States, one fifth of the parents reported spending 20 more hours per week providing health care for their children.

"...I became his manager. I'm expected to be his physiotherapist. And his occupational therapist. And his nurse. All these things. And I'm just his MOM. And my job is to love him. Not to be his manager. I do all these things because I have to. We have a family here, and we have to keep that going." (Parent comment, Ray, 2003, p. 291)

Transitions in care experienced by patients are experienced by their family caregivers as well (Shaw et al., 2004; Smith & Smith, 2000b). "Child survivors become adults, and adult caregivers become elderly." (Smith & Smith, 2000b, p. 32) Caregiving is "a career, replete with myriad stages, transitions, and stresses, which place caregivers in a state of constant flux." (Levine, 1998, p. v) Any transition a patient experiences adds a complex layer of adjustment to the transitions underway within a family (Levine, 1998).

As suggested in Smith and Smith (2000b), “The lifelong needs of persons with complex needs for health and social support are costly, not only for the survivor and the health system, but for family caregivers as well. This cost will be significantly increased if caregiver support is lost for even one such client.” (p. 32) Family caregivers are a valuable but vulnerable resource (Levine, 1998) and we need to be taking much better care of them.

Some patients are without family or other supports (Levine, 1998). Health care professionals should consider the individual needs and perspectives of patients and caregivers. Each situation is unique and not all of us are equipped to participate in our own or a loved one’s care at the same level or assume the challenge of self-care to the same degree. The ‘one size fits all’ model of health care does not fit all, and the patients’ and caregivers’ experiences outlined in the literature make it quite clear that any effective integrated health care system must recognize and provide for variation in situation and ability. Professionals can serve as coaches for patients and their caregivers, helping them to manage the boundaries between settings (Harrison, 1998).

“a lot of the time I felt that I was the kingpin in what was happening, people were asking me ... I felt that I was the person coordinating all the care and it was a mega-weight when you’re under stress ... it gets a heavy load to carry.” (Parent comment, Kirk & Glendinning, 2004, p. 213)

Not only do professionals need to recognize the particular knowledge and expertise that family caregivers have in providing specialized nursing care and value their active participation, but they also need to be aware that providing care of this nature has a substantial emotional dimension (Kirk & Glendinning, 2004). It also can have a powerful impact on a person’s job, finances and time (Well et al., 2000).

The practical and emotional demands that these caregivers are experiencing have altered their lives irrevocably (Smith & Smith, 2000b). As suggested in Smith and Smith, “[this] raises the ethical and economical question of how much responsibility the health system can expect caregivers to assume at the expense of their own roles in society.”

(2000b, p. 31-32). By becoming a caregiver they become an extension of the patient and, as such, require health and support services to assist them. This must be recognized and addressed through public policy.

Patients and their caregivers want to be involved (Coleman et al., 2002; Noël et al., 2005). They want to be active partners in their own care. Attending to the consumer’s voice was expressed as an important aspect to the integration or coordination of care (Harrison & Verhoef, 2002). “If there is going to be consumer involvement in coordination, however, the organizational environment and health care providers need to allow and encourage this involvement. ... For consumers to assume a role in coordination, they need an organizational ‘voice’, that is, they need to feel that health care providers are listening to them.” (Harrison & Verhoef, 2002, p. 1041)

“They mail you out a flyer ever so about 3 months and they remind you what team you’re on ... Then they get the doctor’s contact person’s name. So if you have a problem, you just call that contact person. They take care of everything for you. Yeah that’s the best system. That and the nurse practitioner, and your regular doctor ... and I’ve got a drug doctor too ... What do you call it? He checks my drugs against other drugs? A pharmacist, yeah. And then he calls me up at home and lets me know what the different readings are. He calls you if your blood sugar level is wrong ... he’ll call and adjust your medication which is good. You’ve got all of that facility available inside the internal medicine right now, which I think works beautiful. It’s just a fantastic medical team.” (Patient comment, Noël et al., 2005, p. 60-61)

## CONCLUSION

Although the consequences of lack of communication, delayed testing, unavailability of test results and other issues mentioned by individuals interviewed in these studies are not always made explicit, it would be naïve to assume that there is no connection between the patient experiences and expectations discussed in this review and outcomes such as mortality or health care costs. Delays in receiving abnormal test results, for instance, can have very serious, negative health consequences (Schoen et al., 2005). Although randomized controlled trials do exist which evaluate integrated health systems in terms of hard outcomes, these are not papers that typically explore patient experiences in depth (Beland et al., 2006; Casas et al., 2006). Patient satisfaction is often a component of analysis in many evaluations of integrated systems, but it is most often reported as binary or satisfaction scale values that do little to illuminate the full breadth of patient experience and expectation. While costs to the health care system may be reported, costs to patients and their families including personal time, lost jobs, exhaustion, frustration and emotional burden are not.

The changes we have seen to health care systems in recent decades with a firm emphasis placed on early discharge from health facilities and self-care is not likely to disappear. How physicians and other providers approach working with patients to better facilitate patient self-knowledge and self-care will influence the degree to which patients assume more active roles in managing their own health.

Further, increasing populations of patients with chronic and multiple health issues points to a serious need to evaluate the multitude of factors that facilitate or hinder patient access to proper care, not just those which originate with or affect providers and health care service points. Collaboration and communication between all parties is key.

A number of promising practices have been identified in the literature. It is for us to further develop and test these and other models in order to arrive at systems and processes that address the needs of patients while answering the requirement of providers and health systems. (See Appendix 1)

Integrated care should be about putting the needs and expectations of the patient before those of health care institutions or providers. At the very least, it should involve an acknowledgement that the needs of patients and their families are equally important as the needs of the system. If we want patients to take charge of their care, we need to consider what will best enable them to do so. An effective way of doing this is planning services with patient needs in mind. This means involving patients and their caregivers in the development of care plans; wherever possible making provisions to address individual needs; and providing patients and their families with the information and supports they need to feel confident enough to participate in these very important tasks. (Harrison, 1998; Noël et al., 2005)



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## **APPENDICES**

<b>Appendix 1</b>	Promising Practices
<b>Appendix 2</b>	Other Communication Findings
<b>Appendix 3</b>	Search Strategy
<b>Appendix 4</b>	List of Websites Reviewed

## **APPENDIX 1            PROMISING PRACTICES**

### **Introduction**

The literature offers descriptions of a number of promising programs being implemented and evaluated in several countries in the hopes of advancing our knowledge of and capacity to provide an integrated health care system. Examples are provided below together with lessons learned.

### **Promising Practices**

#### **1. Shared Care (Nielsen et al., 2003)**

Most patients with cancer are treated as outpatients and, as such, are heavily reliant on their general practitioners for information and advice. Often problems occur related to a general practitioner's lack of specialized knowledge around cancer care and the overall lack of collaboration between oncologists and general practitioners.

Shared care is described as "care [which] applies when the responsibility for the health care of the patient is shared between individuals or teams who are part of separate organizations, or where substantial organizational boundaries exist" (Nielsen et al., 2003, p. 263). A shared care program was developed and implemented by the Department of Oncology at Aarhus University Hospital in Denmark. It was intended to improve the personal communication and organized transfer of knowledge from hospital doctors to general practitioners in order to facilitate the continuity of care for oncology patients.

The three basic elements to this shared care program are knowledge transfer, communication channels, and active patient involvement. A discharge summary letter was sent to the individual general practitioners after patient treatment outlining: general information on the disease and its treatment with specific information pertaining to the individual patient; any physical, psychological and social problems the patient had or might expect to get; and information about what the oncologists expected the general practitioner to do. Names and telephone numbers of doctors and nurses responsible for the patient were provided, and patients were told to contact their general practitioners when facing problems they assumed could be solved in this setting. As soon as the patient left the hospital, the program was launched.

#### **Lessons learned**

This shared care model reflects the importance of communication between professionals, and the usefulness of discharge summary letters as educational tools for knowledge transfer between cancer specialists and general practitioners. The discharge summary letters were the most difficult part of the program to implement, however. The doctors were required to write them according to a predefined guideline and they had to be sent on the day the patient left the department. This created challenges for the doctors as it interfered with professional routines.

The study highlighted the importance of having an innovator involved when performing shared care programs across borders in a health care system, someone with connections in both the primary and secondary sectors. The innovator must be prepared to invest time and energy into getting the model accepted in both settings.

The intervention did not improve interpersonal communication between doctors in different settings. Further research is required into cultural barriers to communication in the health care system in order to facilitate improved communication and patient involvement, treatment results and care management.

#### **2. A Coordinated Discharge Care Plan (Preen et al., 2005)**

In an effort to improve communication between the hospital and general practitioners in Australian tertiary hospitals, the effects of a collaborative, multidisciplinary and quality-based

approach to the hospital discharge process for patients with chronic and complex problems was studied through the use of a discharge care planning model.

A research nurse individually tailored a discharge care plan for each patient that included: problems identified from hospital notes and patient/caregiver consultation; goals developed and agreed upon with the patient/caregiver based on personal circumstances; and identified interventions and community service providers who met patient needs and who were accessible and agreeable to the patient.

A computer-generated plan was completed before discharge and sent by fax to the patient's general practitioner who then reviewed it and made any required alterations based on health history. The general practitioner then scheduled in a consultation post-discharge for patient review and return-faxed the document. The care plan clearly identified all post-hospital care arrangements. It was explained in full to the patient/caregiver at discharge and a written copy was provided for everyone involved.

### **Lessons learned**

Results from this study indicate that a multidisciplinary care plan initiated before discharge improves patient involvement and satisfaction with discharge care and integration between the hospital and general practitioner. Suggestions for enhancement included the provision of more detail regarding hospital-prescribed medications, hospital discharge summaries and contact information for all responsible parties.

The coordinated discharge care plan improved the speed of contact from the hospital to the general practitioners. The intervention was clearly beneficial to short-term post-discharge care but it remains uncertain whether or not it would cater to ongoing patient needs. Future research is warranted to determine its impact over a longer time frame.

### **3. A Nurse Specialist Model in Transmural Care (Oeseburg et al., 2004)**

A transmural care model for MS was developed in the Netherlands to facilitate cooperation between health care professionals in different settings. It was also intended as a comprehensive assessment of the needs of MS patients and a means of defining an integrated care plan for individual patients.

The model consists of a neurological assessment, an assessment by the rehabilitation team and a MS nursing assessment questionnaire. A patient care file is developed and implemented from these assessments. A nurse specialist plans and arranges needed supports and monitors care in close cooperation with the patient, providing a coordinating role between everyone involved. The patient is responsible for the care file, which contains demographic characteristics, diagnostic results, medication list, list of health care professionals, assessment questionnaires and integrated care plan. Participating health care professionals are required to report their findings and actions.

### **Lessons learned**

This study highlighted the value of the nurse specialist role. The nurse specialist was able to develop important relationships with the health care professionals and providers from community services, home care and other settings involved. The program had a positive influence on care between the different settings and was useful in reducing discrepancies between MS patients' needs and services.

Oeseburg et al.'s study did indicate some problems, however, related to the transfer of information and the communication between health care professionals. Cooperation is time consuming and fee for service payment plans are restrictive. As well, health care professionals are not trained either in their initial education program or through their jobs to cooperate with one another. A multidisciplinary education program parallel to a transmural care program could facilitate improvement.

#### **4. The Care Transitions Intervention (Parry et al., 2006)**

The Care Transitions Intervention is a patient-centred interdisciplinary team intervention designed to improve transitions across sites of care by educating and empowering patients and caregivers to assure their care needs are met during care transitions. The intervention was explicitly designed for older adults with complex care needs stemming from chronic illness.

The intervention is rooted in four conceptual domains or pillars: medication self-management; use of a dynamic patient-centered record; follow-up with providers; and knowledge/self-management of condition. The pillars are operationalized through two core components: structured interactions with a nurse Transition Coach; and a Personal Health Record.

Interactions with the Transition Coach included weekly hospital/rehabilitation visits; a home visit after discharge; follow-up phone calls; and 24-hour pager access. The role of the coaches was to facilitate and educate, not provide health care.

The Personal Health Record (PHR) is intended as a dynamic, patient-centered document that includes a record of the patient's critical medical information, a list of warning signs that correspond with the patient's chronic illness, a transfer checklist and a section to write questions for health care providers. The PHR is generated through a chart review and validated by the patient/caregiver who then is charged with updating and maintaining it.

The patient, caregiver and Transition Coach work together to maximize the involvement of the interdisciplinary expertise from each care setting; ensuring the appropriate professionals are involved, critical issues are addressed, treatment goals are understood and the care plan is executed correctly.

#### **Lessons learned**

The continuity of the intervention was consistently cited as a strength providing patients with a sense of safety. The fact that the Transition Coach followed up with patients throughout and after the care transition made a significant positive impact on their sense of well-being. The interactions with the coach were effective as well in enhancing medication management. In the home setting, the coach had direct access to the patients' medications allowing for a comprehensive medication review and fostering the development of an ongoing medication management system.

The prevalence of patient comments about rapport and caring suggest that competence alone may be insufficient to engage patients in the self-management aspects of an intervention. Their perception of caring was shaped by the coach's accessibility, frequent follow-up and face-to-face interaction. As Parry et al. (2006) suggest, "this is important to note since many established follow-up interventions involve a nurse previously unknown to the patient making initial contact with the patient via telephone after the patient has returned home." (p. 51) Further inquiry is warranted to better understand what approaches contribute to a patient's perception of caring and enhanced self-management of care.

One of the challenges to the success of the Care Transitions Intervention is the difficulty of empowering patients who are acutely ill to take charge of their health care needs. In these cases and if possible, the intervention is focused on the caregiver as the target and primary recipient of the intervention.

Data from this study suggest that physician attitudes towards displays of patient activation can discourage some patients from taking a more active role in managing their own health, particularly in managing their own health care records. If coaching models promoting self-management are to be truly effective, physicians and coaches need to work together to explicitly support patient efforts in this direction.

## **5. Medical Homes (Palfrey et al., 2004)**

In 1992, the American Academy of Pediatrics (AAP) recommended that all primary care physicians establish medical homes within their practices (Palfrey et al., 2004). Components of a medical home include: the provision of preventive care; the assurance of ambulatory and inpatient care 24 hours a day; continuity of care from infancy through adolescence; appropriate use of subspecialty consultation and referrals; interaction with school and community agencies; and a central record and database containing all pertinent medical information. The family is recognized as the child's primary source of strength and support is more fully involved in the process.

A group of six community-based pediatric practices joined together in Boston, U.S.A. to launch the Pediatric Alliance for Coordinated Care (PACC), an integrated system of care for children with special health care needs based on the concept of the medical home and principles of family-centred care. The goals of the PACC were to provide comprehensive care at the community level and to improve the coordination and communication among primary care physicians, subspecialists and families. Family goals related to education, social services and recreation were jointly determined to ensure the integration of health and other services.

Each practice in the PACC consortium designated a lead physician to work with a hospital-based coordination team. The services of a designated pediatric nurse practitioner (PNP), together with consultation from a local parent of a special health care needs child were incorporated into each practice. Regularly scheduled continuing medical and nursing education sessions, and expedited referrals and communication with specialists and hospital-based personnel were critical components as well.

The pediatric nurse practitioners visited each child at home to get a full understanding of the child's context, including any apparent resources or needs. As well, the PNPs conducted at-home sick visits. Systems were initiated to streamline the ordering of medications and supplies and coordinate patient appointments to minimize family burden. The PNPs worked with each family to amalgamate relevant clinical information and implement an Individualized Health Plan (IHP) that could be faxed as required to facilitate information sharing and referrals, and cut down on unnecessary duplication of visits and tests by providing up-to-date information for all involved.

The local parent consultants (LPCs) provided peer support and steered families to community resources. The LPCs met as a group with a family coordinator at the hospital to share resources and plan informational and recreational events for the families. They also worked directly with office and clinical staff to improve their understanding of and responsiveness to children and families with special health care needs.

### **Lessons learned**

Evaluation results of this medical home model show a clear correlation between the involvement of the pediatric nurse practitioner and the ease with which families obtained services and referrals, and information and resources. As well, families reported an increased understanding of their child's medical condition. The children were hospitalized less than before their involvement in the Pediatric Alliance for Coordinated Care.

The Individualized Health Plan helped each family plan goals for their child, explain their child's condition and medical issues, and prepare for school. It also helped during visits to the emergency department.

At a practice level, however, establishing medical homes for children with special health care needs presents a serious challenge for primary care physicians. Managing these complex patients requires extensive knowledge of medical and community resources and it takes time to offer such comprehensive care delivery. As noted previously, this time is not reimbursed under current insurance systems or fee-for-service plans.

One of the biggest burdens reported was the redundancy of the paperwork required to justify the medical necessity of resources such as nursing care, drugs and equipment. Planning transition services for older adolescents and young adults entails additional obstacles as well.

This intervention study demonstrates that a medical home for children with special health care needs can be put into operation within community-based primary care practices through the modest addition of new resources. It requires committed primary care leadership; a formal ongoing relationship with an academic center for training, consultation and hospitalization; and family buy-in. Outreach activities need to be planned in consideration of local contexts, and cultural and language expertise can be required.

## APPENDIX 2 OTHER COMMUNICATION FINDINGS

### Introduction

A prominent theme in the literature was the need for more information. Clearly, patients and their caregivers want more information and are experiencing a multitude of problems getting it. They want information on: their own or a loved one's medical condition, prognosis and treatment; what they can expect before, during and after care; common problems and their solutions or why, when and whom to call; and any support services and resources that are available and how to access them.

Many of the respondents surveyed expressed disappointment with the information they were getting from their health care providers related to their medical conditions; causality, treatment and progression; and prevention and self-help strategies (Armitage & Kavanagh, 1998; Bethell et al., 2001; Bowie, 2006; Hale et al., 2006; Harrison & Verhoef, 2002; Kirk & Glendinning, 2004; Leith et al., 2004; Levine, 1998; Nielsen et al., 2003; Ouwens et al., 2007; Parchman et al., 2005; Parry et al., 2006; Preston et al., 1999; Pritchard et al., 2004; Ray, 2003; Rozmovits et al., 2004; Schoen et al., 2005; Smith, 1998; Smith & Daughtrey, 2000a; Smith & Smith 2000b; Weinberg et al., 2007) Parents in the Family Voices survey of over 2,000 families of children with special health care needs indicated they would have appreciated receiving updated information on medical research that might help their children (Well et al., 2000).

“They give you instructions about how to use the telephone and the television, but not how to get medical questions answered.” (Caregiver comment, Levine, 1998, p. 13)

The information needs to be understandable, consistent, current and timely (Armitage & Kavanagh, 1998; Bowie, 2006; Fulop, 2000; Preston et al., 1999; Simon & Kumar, 2002; Smith, 1998; Smith & Daughtrey, 2000a; Smith & Smith, 2000b). It needs to be age-appropriate (Shaw et al., 2004) and accessible to all, including those who do not have English as a first language (Armitage & Kavanagh, 1998, Gulliford et al., 2006; McCourt et al., 1998) and those who live in outlying areas (Laschinger et al., 2005). It needs to be repeated often and in a variety of formats, most definitely in written form (Armitage & Kavanagh, 1998; Harrison, 1998; Harrison & Verhoef, 2002; Shaw et al., 2004; Smith & Daughtrey, 2000a).

“What is understood implicitly by providers might need to be made more explicit for patients.” (Beaudin et al., 1999, p. 22)

Patients and caregivers need specifics around contact information (Hale et al., 2006; Schoen et al., 2005; Shaw et al., 2004; Smith & Daughtrey, 2000a). They need support and reassurance on a 24/7 basis (Anderson & Parent, 2004).

The need for information most often expressed in the literature was that related to what services and supports exist and how to access them (Armitage & Kavanagh, 1998; Bowie, 2006; Cigno & Gore, 1999; Leith et al., 2004; McLennan et al., 2003; Ouwens et al., 2007; Rozmovits et al., 2004; Simon & Kumar, 2002; Smith, 1998; Smith & Smith, 2000b; Well et al., 2000). Many respondents commented on how they should not be required to do all the work seeking out these services themselves (Anderson & Parent, 2004, Kirk & Glendinning, 2004; Shaw et al., 2004; Smith & Smith, 2000b).

### Looking outside the system for support

Many patients and caregivers are forced to look outside the health care system for help on getting the information, advice and support they need (Harrison, 1998; Laschinger et al., 2005; Naithani et al., 2006; Smith, 1998; Smith & Smith, 2000b; Well et al., 2000). This is particularly true when patients leave the formal health care system and go back in to the community (Smith, 1998; Smith & Smith, 2000b). Some are fortunate to have friends or family members with medical backgrounds (Smith, 1998). For those who do not, the recovery process is more difficult.



In the Family Voices survey of 2,220 families of children with special health care needs across the United States, the parents consistently commented on how other families were often their most important source of information (Well et al., 2000).

### **Caregivers need to be included too**

The literature consistently highlights the critical importance of the caregiver to a patient's recovery and/or ongoing care. It also indicates that caregivers are experiencing a lack of communication with the health care and other service providers involved in their loved one's care (Gulliford et al., 2006; Levine, 1998; Simon & Kumar, 2002; Smith, 1998; Smith & Smith, 2000b). They are being expected to take on responsibility for care yet are rarely consulted about the needs of the person they are caring for or provided with the information they need to do it (Gulliford et al., 2006; Kirk & Glendinning, 2004; Levine, 1998; Simon & Kumar, 2002; Smith, 1998; Smith & Smith, 2000b).

Caregivers as well are expressing the need for information, training, access to professional advice, and support from other caregivers in similar circumstances (Levine, 1998).

“When you buy a pet at the pet store, you are given written instructions about how to take care of it, which things to look for, and what to do about them. There are books about how to take care of babies: when to call the doctor; what is normal; and what is not. But you get nothing when you take a parent home from the hospital. And these are ordinary diseases – things that happen every day.” (Caregiver comment, Levine, 1998, p. 12)

## APPENDIX 3      SEARCH STRATEGY

### Peer Reviewed Literature Search

#### MEDLINE (OVID)

1. "delivery of health care, integrated"/ or systems integration/
2. ((integrated or integration or integrative or collaborative or coalition) adj3 (care or clinic or clinics or health care or "health care" or hospital or hospitals or services)).tw.
3. ((coordinated or coordination or cooperative or shared or consolidated or consolidation or networks) adj3 (care or clinic or clinics or health care or "health care" or hospital or hospitals or services)).ti.
4. ((seamless or transition\$ or fragmentation or transmural) adj3 care).ti,ab.
5. 1 or 2 or 3 or 4
6. "patient acceptance of health care"/ or patient participation/ or patient satisfaction/ or public opinion/
7. exp consumer participation/ or exp consumer satisfaction/
8. \*patients/px [Psychology]
9. ((adolescent\$ or citizen or citizens or community or consumer\$ or family or families or layperson\$ or laypeople or layman or parents or patient or patients or public or seniors or taxpayer\$) adj3 (acceptability or assess\$ or assumptions or attitudes or encounters or evaluat\$ or expectation\$ or experience\$ or feedback or observation\$ or opinion\$ or perceive or perception\$ or perspective\$ or preference\$ or presumption\$ or satisfaction or understanding or views)).tw.
10. 6 or 7 or 8 or 9
11. 5 and 10
12. (case reports or clinical trial or comparative study or controlled clinical trial or evaluation studies or meta analysis or randomized controlled trial).pt.
13. cohort studies/ or cross sectional studies/ or evaluation studies/ or focus groups/ or follow up studies/ or health care surveys/ or interviews/ or longitudinal studies/ or "outcome and process assessment (health care)"/ or program evaluation/ or prospective studies/ or qualitative research/ or "quality of health care"/ or questionnaires/
14. exp "process assessment (health care)"/
15. systematic.tw. adj2 (review\$ or overview\$).tw.
16. (case report\$ or case study or case studies or cross sectional or focus group\$ or interview\$ or random\$ or rct\$ or qualitative or questionnaire\$ or survey\$).tw.
17. 12 or 13 or 14 or 15 or 16
18. 11 and 17
19. limit 18 to (yr="1997 – 2008" and english language)

#### EMBASE (OVID)

1. integrated health care system/ or integrative medicine/ or integration/
2. ((integrated or integration or integrative or collaborative or coalition) adj3 (care or clinic or clinics or health care or "health care" or hospital or hospitals or services)).tw.
3. ((coordinated or coordination or cooperative or shared or consolidated or consolidation or networks) adj3 (care or clinic or clinics or health care or "health care" or hospital or hospitals or services)).ti.
4. ((seamless or transition\$ or fragmentation or transmural) adj3 care).ti,ab.
5. 1 or 2 or 3 or 4
6. consumer/ or consumer attitude/ or family attitude/ or maternal attitude/ or parental attitude/ or paternal attitude/ or patient attitude/ or patient compliance/ or patient participation/ or patient satisfaction/ or public opinion/ or refusal to participate/ or satisfaction/ or treatment refusal/
7. ((adolescent\$ or citizen or citizens or community or consumer\$ or family or families or layperson\$ or laypeople or layman or parents or patient or patients or public or

- seniors or taxpayer\$) adj3 (acceptability or assess\$ or assumptions or attitudes or encounters or evaluat\$ or expectation\$ or experience\$ or feedback or observation\$ or opinion\$ or perceive or perception\$ or perspective\$ or preference\$ or presumption\$ or satisfaction or understanding or views)).tw.
8. 6 or 7
  9. 5 and 8
  10. case control study/ or case report/ or clinical trial/ or cohort analysis/ or controlled clinical trial/ or cross sectional study/ or delphi study/ or double blind procedure/ or evaluation/ or follow up/ or health care quality/ or health survey/ or interview/ or longitudinal study/ or major clinical study/ or meta analysis/ or open ended questionnaire/ or posttest control group design/ or pretest posttest control group design/ or pretest posttest design/ or prospective study/ or qualitative analysis/ or qualitative research/ or quantitative study/ or questionnaire/ or randomized controlled trial/ or semi-structured interview/ or single blind procedure/ or structured interview/ or structured questionnaire/ or “systematic review”/ or triple blind procedure/ or unstructured interview/
  11. systematic.tw. adj2 (review\$ or overview\$).tw.
  12. (case report\$ or case study or case studies or cross sectional or focus group\$ or interview\$ or random\$ or rct\$ or qualitative or questionnaire\$ or survey\$).tw.
  13. 10 or 11 or 12
  14. 9 and 13
  15. limit 14 to (yr = “1997 – 2008” and english language)

**Cochrane CENTRAL Register of Controlled Trials (OVID 4<sup>th</sup> Quarter 2007)**

**DARE Database of Reviews of Effects (OVID 4<sup>th</sup> Quarter 2007)**

**Health Technology Assessment Database (OVID 4<sup>th</sup> Quarter 2007)**

1. “delivery of health care, integrated”/ or systems integration/
2. ((integrated or integration or integrative or collaborative or coalition) adj3 (care or clinic or clinics or health care or “health care” or hospital or hospitals or services)).tw.
3. ((coordinated or coordination or cooperative or shared or consolidated or consolidation or networks) adj3 (care or clinic or clinics or health care or “health care” or hospital or hospitals or services)).ti.
4. ((seamless or transition\$ or fragmentation or transmural) adj3 care).ti.ab.
5. 1 or 2 or 3 or 4
6. “patient acceptance of health care”/ or patient participation/ or patient satisfaction/ or public opinion/
7. exp consumer participation/ or exp consumer satisfaction/
8. \*patients/px [Psychology]
9. ((adolescent\$ or citizen or citizens or community or consumer\$ or family or families or layperson\$ or laypeople or layman or parents or patient or patients or public or seniors or taxpayer\$) adj3 (acceptability or assess\$ or assumptions or attitudes or encounters or evaluat\$ or expectation\$ or experience\$ or feedback or observation\$ or opinion\$ or perceive or perception\$ or perspective\$ or preference\$ or presumption\$ or satisfaction or understanding or views)).tw.
10. 6 or 7 or 8 or 9
11. 5 and 10
12. limit 11 to (yr=“1997 – 2008” and english language)

**Cochrane Database of Systematic Reviews (OVID 4<sup>th</sup> Quarter 2007)**

1. ((integrated or integration or integrative or collaborative or coalition or seamless or transition\$ or transmural or fragmentation) adj3 (care or clinic or clinics or health care or “health care” or hospital or hospitals or services)).tw.
2. ((coordinated or coordination or cooperative or shared or consolidated or consolidation or networks) adj3 (care or clinic or clinics or health care or “health care” or hospital or hospitals or services)).ti.
3. 1 or 2

4. ((adolescent\$ or citizen or citizens or community or consumer\$ or family or families or layperson\$ or laypeople or layman or parents or patient or patients or public or seniors or taxpayer\$) adj3 (acceptability or assess\$ or assumptions or attitudes or encounters or evaluat\$ or expectation\$ or experience\$ or feedback or observation\$ or opinion\$ or perceive or perception\$ or perspective\$ or preference\$ or presumption\$ or satisfaction or understanding or views)).tw.
5. 3 and 4
6. limit 5 to systematic reviews

#### **PsycINFO (OVID)**

1. "continuum of care"/ or integrated services/ or interdisciplinary treatment approach/
2. ((integrated or integration or integrative or collaborative or coalition) adj3 (care or clinic or clinics or health care or "health care" or hospital or hospitals or services)).tw.
3. ((coordinated or coordination or cooperative or shared or consolidated or consolidation or networks) adj3 (care or clinic or clinics or health care or "health care" or hospital or hospitals or services)).ti.
4. ((seamless or transition\$ or fragmentation or transmural) adj3 care).ti,ab.
5. 1 or 2 or 3 or 4
6. client attitudes/ or client participation/ or client satisfaction/ or community attitudes/ or consumer attitudes/ or consumer satisfaction/ or parental attitudes/ or public opinion/ or treatment refusal/
7. ((adolescent\$ or citizen or citizens or community or consumer\$ or family or families or layperson\$ or laypeople or layman or parents or patient or patients or public or seniors or taxpayer\$) adj3 (acceptability or assess\$ or assumptions or attitudes or encounters or evaluat\$ or expectation\$ or experience\$ or feedback or observation\$ or opinion\$ or perceive or perception\$ or perspective\$ or preference\$ or presumption\$ or satisfaction or understanding or views)).tw.
8. 6 or 7
9. 5 and 8
10. between groups design/ or case report/ or clinical trials/ or cohort analysis/ or consumer surveys/ or evaluation/ or followup studies/ or group discussion/ or interviews/ or longitudinal studies/ or mail surveys/ or meta analysis/ or program evaluation/ or prospective studies/ or qualitative research/ or "quality of care"/ or quantitative methods/ or quasi experimental methods/ or questionnaires/ or questioning/ or surveys/ or telephone surveys/
11. systematic.tw. adj2 (review\$ or overview\$).tw.
12. (case report\$ or case study or case studies or cross sectional or focus group\$ or interview\$ or random\$ or rct\$ or qualitative or questionnaire\$ or survey\$).tw.
13. 10 or 11 or 12
14. 9 and 13
15. limit 14 to (yr ="1997 – 2008" and english language)

#### **CINAHL (EBSCO)**

1. MH (health care delivery, integrated or systems integration)
2. TI (integrated or integration or integrative or collaborative or coalition) and TI (care or clinic or clinics or health care or "health care" or hospital or hospitals or services)
3. AB (integrated or integration or integrative or collaborative or coalition) and AB (care or clinic or clinics or health care or "health care" or hospital or hospitals or services)
4. MW (seamless or transition\* or fragmentation or transmural) and MW care
5. TI (seamless or transition\* or fragmentation or transmural) and TI care
6. 1 or 2 or 3 or 4 or 5
7. MH (consumer attitudes or consumer participation or consumer satisfaction or family attitudes or maternal attitudes or nonparticipant observation or parental attitudes or paternal attitudes or participant observation or patient attitudes or patient satisfaction or public opinion or social attitudes or treatment refusal)

8. TI (adolescent\* or citizen or citizens or community or consumer\* or family or families or layperson\* or laypeople or layman or parents or patient or patients or public or seniors or taxpayer\*) and TI (acceptability or assess\* or assumptions or attitudes or encounters or evaluat\* or expectation\* or experience\* or feedback or observation\* or opinion\* or perceive or perception\* or perspective\* or preference\* or presumption\* or satisfaction or understanding or views)
  9. AB (adolescent\* or citizen or citizens or community or consumer\* or family or families or layperson\* or laypeople or layman or parents or patient or patients or public or seniors or taxpayer\*) and AB (acceptability or assess\* or assumptions or attitudes or encounters or evaluat\* or expectation\* or experience\* or feedback or observation\* or opinion\* or perceive or perception\* or perspective\* or preference\* or presumption\* or satisfaction or understanding or views)
  10. 7 or 8 or 9
  11. 6 and 10
  12. MH (case control studies or case studies or clinical trials or comparative studies or concurrent prospective studies or cross sectional studies or evaluation research or focus groups or general comfort questionnaires or health perceptions questionnaires or interviews or meta analysis or multimethod studies or nonrandomized trials or open ended questionnaires or prospective studies or qualitative studies or questionnaires or structured questionnaires or survey research or surveys)
  13. TI (systematic) and TI (review\* or overview\*)
  14. AB (systematic) and AB (review\* or overview\*)
  15. TI (case report\* or case study or case studies or cross sectional or focus group\$ or interview\* or random\* or rct\* or qualitative or questionnaire\* or survey\*)
  16. AB (case report\* or case study or case studies or cross sectional or focus group\$ or interview\* or random\* or rct\* or qualitative or questionnaire\* or survey\*)
  17. 12 or 13 or 14 or 15 or 16
  18. 11 and 17
- Limits: Published date: 199701 – 200801; Language: English

### **Sociological Abstracts (CSA)**

1. KW= ((integrated or integration or integrative or collaborative or coalition or coordinated or coordination or cooperative or shared or consolidated or consolidation or networks or seamless or transition\* or fragmentation or transmural) and (care or clinic or clinics or health care or "health care" or hospital or hospitals))
2. KW= (adolescent\* or citizen or citizens or community or consumer\* or family or families or layperson\* or laypeople or layman or parents or patient or patients or public or seniors or taxpayer\*) and KW= (acceptability or assess\* or assumptions or attitudes or encounters or evaluat\* or expectation\* or experience\* or feedback or observation\* or opinion\* or perceive or perception\* or perspective\* or preference\* or presumption\* or satisfaction or understanding or views)
3. 1 and 2

Limits: Date range: 1997 to 2008

Limited to: Published works only; Journal articles only; English only

### **Social Sciences Abstracts (Wilson OmniFile)**

1. ((integrated or integration or integrative or collaborative or coalition or coordinated or coordination or cooperative or shared or consolidated or consolidation or networks or transmural or transition\* or seamless or fragmentation) and (care or clinic or clinics or health care or "health care" or hospital or hospitals)) <in> Subjects, Titles, Abstracts
2. ((adolescent\* or citizen or citizens or community or consumer\* or family or families or layperson\* or laypeople or layman or parents or patient or patients or public or seniors or taxpayer\*) and (acceptability or assess\* or assumptions or attitudes or encounters or evaluat\* or expectation\* or experience\* or feedback or observation\* or opinion\* or perceive or perception\* or perspective\* or preference\* or presumption\* or satisfaction or understanding or views)) <in> Subjects, Titles, Abstracts

3. 1 and 2  
Limits: Date range 1997 to 2008  
Limit to Peer Reviewed

## APPENDIX 4 LIST OF WEBSITES REVIEWED

### Canada

Canadian Council on Integrated Healthcare  
<http://www.ccih.ca/e/index.htm>

Canadian Health Services Research Foundation  
<http://www.chsrf.ca>

Canadian Institute for Advanced Research  
<http://www.ciar.ca/web/home.nsf/pages/home>

Canadian Institute for Health Information  
<http://secure.cihi.ca/cihiweb/splash.html>

Canadian Institutes of Health Research  
<http://www.cihr-irsc.gc.ca/e/193.html>

Canadian Medical Association  
<http://www.cma.ca>

Canadian Policy Research Networks  
<http://www.cprn.com/>

CD Howe Institute  
<http://www.cdhowe.org/>

Centre for Health Services and Policy Research (UBC)  
<http://www.chspr.ubc.ca/>

Health Council of Canada  
<http://www.healthcouncilcanada.ca/splash.htm>

Institute for Clinical and Evaluative Sciences  
<http://www.ices.on.ca/webpage.cfm>

Institute of Health Economics  
<http://www.ihe.ca>

Institute for Research on Public Policy  
<http://www.irpp.org/>

Manitoba Centre for Health Policy  
<http://umanitoba.ca/faculties/medicine/units/mchp/>

Newfoundland and Labrador Centre for Applied Health Research  
<http://www.nlcahr.mun.ca/>

University of Laval Chair on Knowledge Transfer and Innovation (KU-UC)  
<http://kuuc.chair.ulaval.ca/english/index.php>

### United States

AHRQ Agency for Healthcare Research and Quality  
<http://www.ahrq.gov/>

Group Health Cooperative (Seattle)  
<http://www.ghc.org/>

Institute of Medicine  
<http://www.iom.edu/>

Kaiser Permanente  
<https://www.kaiserpermanente.org/>

Milbank Memorial Fund  
<http://www.milbank.org/>

New York Academy of Medicine Grey Literature Report  
[http://www.nyam.org/library/pages/grey\\_literature\\_report](http://www.nyam.org/library/pages/grey_literature_report)

Picker Institute  
<http://www.pickerinstitute.org/>

RAND Corporation  
<http://rand.org/>

Robert Wood Johnson Foundation  
<http://www.rwjf.org/>

Social Science Research Network  
<http://www.ssrn.com/>

### **United Kingdom**

Institute for Public Policy Research  
<http://www.ippr.org.uk/>

King's Fund  
<http://www.kingsfund.org.uk/>

National Institute for Health and Clinical Excellence  
<http://www.nice.org.uk/>

NHS Service Delivery and organization  
<http://www.sdo.lshtm.ac.uk>

Nuffield Centre for International Health and Development  
<http://www.leeds.ac.uk/nuffield/>

Policy Library  
<http://www.policylibrary.com/>

### **International**

Australian Policy Online  
<http://www.apo.org.au/>

European Centre for Health Policy  
<http://www.euro.who.int/echp>

European Research Council  
<http://erc.europa.eu/>



World Health Organization  
<http://www.who.int/en/>