

Patient-Centred Care: Does Asthma Pass The Test?

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“When a man says he approves of something in principle, it means he hasn't the slightest intention of putting it into practice.”

- Otto von Bismarck

Abstract

The patient-focused paradigm in healthcare began to emerge in the early 1990's. In 2006 the International Association of Patient Organizations (IAPO) adopted the Declaration on Patient-Centred Healthcare. This study examined the degree to which the five principles embedded in this Declaration are being advocated and utilized in the asthma patient-provider relationship in five countries. The empirical evidence in this study shows that the implementation of patient-centred care both as a policy concept and a practice modality for asthma has not been achieved to the extent needed. The paper makes recommendations to help patient organizations realize the full benefits of patient-centred care.

Introduction

Health care delivery in the United States, Canada, and across Europe is increasingly characterized by cost containment strategies and rationalization. Given Berman's "iron triangle" of cost, quality and access that limit the flexibility of healthcare systems grounded in the twentieth-century's disease-centred, medical model¹, patients have justifiably become concerned that this singular focus on costs will negatively affect access to quality health services and products. As a result, patients are increasingly taking an active role in their care. The emergence of organizations such as the International Alliance of Patients' Organizations (IAPO) and the World Alliance for Patient Safety, which are committed to the concept of patient centered health care, are indicators of the importance of the movement towards increased consumer involvement in health.

While the concept of patient centered care (PCC) dates back to ancient Greece², PCC really came to the forefront of the healthcare debate with Lathrop's introduction of the "patient-focused paradigm" based upon his work in the late 1980's^{3, 4}. Lathrop proposed a common sense approach to shifting health care delivery from a traditional, hierarchical, functional model to one focused on the patient. Although there is no single, universally-accepted definition of PCC, a working definition of patient centred-care could be, "providing the care that a patient needs in the manner and at the time the patient desires". The Institute of Medicine (IOM) published "ten

¹ Berman, C.P. (1997). European Healthcare Management Association.

² Stewart, M., et. al. (2000). The impact of Patient-Centered Care on Outcomes. *J Fam Pract*, 49:796-804.

³ Lathrop, J.P. (1993). *Restructuring Health Care: The Patient-Focused Paradigm*. San Francisco. Jossey-Bass Publishers.

⁴ Wallace, C. (2005). JCAHO Proposal for Patient-Centered Care Brings Concept to Mainstream Healthcare Settings. *Risk Management Reporter*, Vol 24, No 3.

simple rules for the 21st century health care system” and patients are the key to six of these rules⁵:

- Care is based on continuous healing relationships and not just face-to-face visits implying that the health care system must be responsive at all times and care should be provided by the most expedient means.
- Care should be designed to meet the most common types of needs, but should have the capability to respond to individual patient choices, need, values and preferences.
- The patient is the source of control by being given the necessary information and opportunity to exercise the degree of control they choose over health care decisions that affect them
- Patients should have unfettered access to their own medical information and to clinical knowledge; clinicians and patients should communicate effectively and share information.
- Decision-making is research-based with care being consistent across clinicians and jurisdictions
- Transparency is necessary making available to patients and their families information that enables them to make informed decisions when selecting a health plan, hospital, or clinical practice, or when choosing among alternative treatments including information describing patient safety, research-based practice, outcomes and patient satisfaction.

Primary care in Denmark has been re-focused around the patient,⁶ primary care reform in the UK was patient-centred.⁷ Medicare and Medicaid in the US are incorporating the principles of PCC into their services.

Gaining momentum in the US and Europe is the idea that patient-centered care can be a cost-effective and appropriate way of dealing with the increasing prevalence of chronic conditions in developed countries⁸. Chronic disease management (CDM) has been defined as a systematic, population-based approach to identifying persons at risk, intervening with specific programs of care and symptom management, maintaining patients' health status, and measuring clinical and population health outcomes. Effective CDM contains overall health costs by reducing the utilization of emergent, acute and more costly care options⁹.

For the treatment of chronic disease PCC is about actively sharing the management of an illness between patient and doctor. CDM is increasingly research-based, especially for diabetes, asthma and arthritis, and reliant upon integrated information technology. Systematic reviews show that patient-centred care results in increased adherence to management protocols, reduced morbidity, increased patient and physician satisfaction, fewer malpractice suits, reduction in anxiety, greater trust and confidence in health professionals, improved quality of life for patients, better management of the consultation process, more appropriate use of health services, and better outcomes.^{10,11,12,13}

⁵ Richardson, Wm., C. (2001). *Crossing the Quality Chasm: A New Health Care System for the 21st Century*. Institute of Medicine. 63.

⁶ Davis, K., (2002). The Danish health system through an American lens. *Heal Pol.* 59:119-32.

⁷ Smith, P.,C., York, N., (2004), Quality incentives: the case of UK general practitioners. *Heal Affairs.* 23:112-8.

⁸ Colin-Thome, D, and Belfield, G. (2004). *Improving Chronic Disease Management*. U.K. Department of Health.

⁹ Astin, F., Closs, S.J., Lascelles, M. (2005). A 21st Century Approach to Chronic Disease Management in the U.K.: Implications for nurse educators. *Contemp Nurse.* 20(2):201-211.

¹⁰ Bauman, A.E., Fardy, H.J., Harris, P.G. (2003). Getting it Right: Why Bother with Patient-Centered Care? *Med J Aust,* 179(5):253-256.

¹¹ Farrell, C. (2004). Patient and Public Involvement in Health: The evidence for policy implementation. U.K. Department of Health.

¹² Robb, G., Seddon, M. (2006). Quality Improvement in New Zealand healthcare. *NZ Med J,* 119 (1242):U2174.

The International Alliance of Patient Organizations (IAPO) has also taken up the cause of patient centered care. According to the IAPO, “health systems in all world regions are under pressure and cannot cope if they continue to focus on diseases rather than patients; they require the involvement of individual patients who adhere to their treatments, make behavioural changes and self-manage. Patient-centered healthcare may be the most cost-effective way to improve health outcomes for patients.”¹⁴

In February 2006, IAPO launched its *Declaration on Patient-Centred Healthcare*. Building upon the six rules set forth by the IOM and adding a health policy focus as well, the Declaration contained five principles for patient-centred healthcare:

1. *Respect* – Patients and care-givers have a fundamental right to patient-centered healthcare that respects their unique needs, preferences and values, as well as their autonomy and independence.
2. *Choice and empowerment* – Patients have a right and responsibility to participate, to their level of ability and preference, as a partner in making healthcare decisions that affect their lives. This requires a responsive health service which provides suitable choices in treatment and management options that fit in with patients’ needs, and encouragement and support for patients and care givers that direct and manage care to achieve the best possible quality of life. Patients’ organizations must be empowered to play meaningful leadership roles in supporting patients and their families to exercise their right to make informed healthcare choices.
3. *Patient involvement in health policy* – Patients and patients’ organization deserve to share the responsibility of healthcare policy making through meaningful and supported engagement in all levels and at all points of decision-making, to ensure that they are designed with the patient at the centre. This should not be restricted to health policy but include, for example, social policy that will ultimately impact on patient’ lives.
4. *Access and support* – Patients must have access to the healthcare services warranted by their condition. This includes access to safe, quality and appropriate services, treatments, preventive care and health promotion activities. Provision should be made to ensure that *all* patients can access necessary services, regardless of their condition or socio-economic status. For patients to achieve the best possible quality of life, healthcare must support patients’ emotional requirements, and consider non-health factors such as education, employment and family issues which impact on their approach to healthcare choices and management.
5. *Information* – Accurate, relevant and comprehensive information is essential to enable patients and careers to make informed decisions about healthcare treatment and living with their condition. Information must be presented in an appropriate format according to health literacy principles considering the individual’s condition, language, age, understanding, abilities and culture.¹⁵

IAPO called for the support and collaboration of policy-makers, health professionals, service providers, and health-related industries to endorse and commit to these five principles in their day-to-day practice.”¹⁶

Some of the more recent articles written about patient centered care prescribe how a health care system must change to become more patient centred.^{17,18} Davis *et.al.*¹⁹ identified the following seven criteria by which to implement PCC at the primary care level.

¹³ Stewart, M., *et. al.* (2000). The impact of Patient-Centered Care on Outcomes *J Fam Pract* 49:796-804

¹⁴ International Alliance of Patient Organizations. (2005). What is Patient-Centre healthcare?: A Review of Definitions and Principles.

¹⁵ *Ibid*

¹⁶ International Alliance of Patients’ Organizations. (2006). Declaration on Patient-Centred Healthcare.

¹⁷ Bergeson, S. C., Dean, J. D. (2006). A Systems Approach to Patient-Centered Care. *JAMA*. 296(23): 2848-2851.

- *Superb access to care.* Patients can easily make appointments and select the day and time. Waiting times are short. E-mail and telephone consultations are offered. Off-hours service is available.
- *Patient engagement in care.* Patients have the option of being informed and engaged partners in their care. Practices provide information on treatment plans, preventive and follow-up care reminders, access to medical records, assistance with self-care, and counseling.
- *Clinical information systems that support high-quality care, practice-based learning, and quality improvement.* Practices maintain patient registries; monitor adherence to treatment; have easy access to lab and test results; and receive reminders, decision support, and information on recommended treatments.
- *Care coordination.* Specialist care is coordinated, and systems are in place to prevent errors that occur when multiple physicians are involved. Post-hospital follow-up and support is provided.
- *Integrated and comprehensive team care.* There is a free flow of communication among physicians, nurses, and other health professionals. Duplication of tests and procedures is avoided.
- *Routine patient feedback to doctors.* Practices take advantage of low-cost, Internet-based patient surveys to learn from patients and inform treatment plans.
- *Publicly available information.* Patients have accurate, standardized information on physicians to help them choose a practice that will meet their needs.

Asthma: Prevalence & Care

Asthma is a worldwide condition that affects over 300 million people, or about 4.5% of the world's population, causing 255,000 deaths in 2005²⁰. The prevalence of asthma is much higher in industrialized countries and rising globally. Higher prevalence rates of asthma seem to be correlated with higher rates of urbanization²¹. In 1980, 3% of Americans were diagnosed with asthma; in 2004 it was 7% affecting nearly 20 million people in the United States.²² The rate of increase for new diagnoses of asthma in American adults is twice the rate of population growth²³. Asthma is the leading cause of absenteeism from school and the third leading cause of work loss²⁴. Yet, half of all acute pediatric asthma attacks are preventable through environmental awareness²⁵ and up to 80% of all asthma deaths are preventable with proper asthma education²⁶.

Asthma requires treatment and ongoing management on an inpatient as well as an out-patient basis both in and out of a formal health care setting. A number of countries have developed treatment guidelines which, if followed, ensure a high probability of asthma treatment and management success. In the United States the National Heart, Lung and Blood Institute (NHLBI) developed national treatment guidelines based upon four principals: 1) use of objective measures

¹⁸ Wensing, M., Wollersheim, H., Grol, R. (2006). Organizational interventions to implement improvements in patient care: a structured review of reviews. *Implement Sci.* 1: 2. published online before print February 22, 2006.

¹⁹ Davis, K., Schoenbaum, S., Audet, A-M. (2005). A 2020 Vision of Patient-Centered Primary Care. *J Gen Intern Med*, (20):953-957.

²⁰ World Health Organization. (2006). Fact Sheet No. 307.

²¹ *Ibid.*

²² US Department of Health and Human Services. (2006). National Health Interview Survey, National Centre for Health Statistics, Centres for Disease Control and Prevention.

²³ US Department of Health and Human Services. (2004, 2000). National Health Interview Surveys, National Centre for Health Statistics, Centres for Disease Control and Prevention.

²⁴ Harrison, B.W.D., Pearson, M.G. (1992). Audit in acute severe asthma – Who benefits? *JRCPL* 27:387-390.

²⁵ Health Canada. (1998). Childhood asthma in sentinel health units: report of the student lung health survey results, 1995-1996. Ottawa.

²⁶ Institute for Clinical Evaluative Studies. (1996). ICES Practice Atlas (2nd ed.). Toronto.

of lung function to assess the severity of asthma and to monitor the course of therapy; 2) environmental control measures to avoid or eliminate factors that precipitate asthma symptoms or exacerbations; 3) comprehensive pharmacologic therapy for long-term management designed to reverse and prevent the airway inflammation characteristic of asthma as well as pharmacologic therapy to manage asthma exacerbations; and 4) patient education that fosters a partnership among the patient, his or her family, and clinicians.²⁷

Canadian scientists and practitioners developed the *Canadian Asthma Consensus Guidelines* with the goal of managing asthma by reducing airway inflammation through environmental control measures and the use of regular controller medication, rather than intermittent therapy that is focused on short-term relief of symptoms²⁸

In 1993 the NHLBI and the World Health Organization (WHO) collaborated in the development of the Global Initiative for Asthma (GINA) which updated its asthma management guidelines in 2005 aimed at reducing premature deaths and chronic disability, controlling symptoms, returning to near normal lung function, and eliminating the need for “quick relief” for those with asthma worldwide. Similar to the US guidelines, GINA recommended: 1) developing a patient-doctor partnership; 2) identifying and reducing exposure to risk factors; 3) assessing, treating, monitoring and controlling the asthma; and, 4) managing the severity of asthma exacerbations²⁹.

The GINA guidelines are a little more generic than the American thus allowing for adaptation to local health care environments. Both the NHLBI and GINA guidelines are grounded in PCC with a common theme in each set of guidelines of physician working with the patient to develop individual asthma treatment and management plans.

Despite GINA’s best efforts at dissemination many clinicians continue to ignore, underutilize, disagree with or not comply with clinical practice guidelines for asthma³⁰. In one study, fewer than half of the patients were given an asthma action plan by their doctors, while more than half of those with a plan complied with it³¹. While numerous studies related to the concept of patient centered care have been conducted^{32,33,34,35,36,37}, as yet, the concept of attempting to determine the level of ‘patient centeredness’ of care for chronic conditions in a variety of jurisdictions has not yet been explored.

The Study

Although Davis, *et.al.* claimed that nearly all primary care settings incorporated *some* attributes of patient centered care³⁸, why was IAPO’s call for an increased commitment to patient centered care necessary? Are physicians really patient centered? Although information and information systems are deemed integral to PCC, a study by the Commonwealth Fund discovered that even

²⁷ National Heart, Lung and Blood Institute. (1997). Guidelines for the Diagnosis and Management of Asthma.

²⁸ Boulet, L-P., *et.al.* (2001). What is new since the last (1999) Canadian Asthma Consensus Guidelines? *Can Respir J* 8(Suppl A):5A-27A.

²⁹ Global Initiative for Asthma. (2006). Global Strategy for Asthma Management and Prevention.

³⁰ Wahlström, R., *et al.* (2002). Variations in asthma treatment in five European countries—judgment analysis of case simulations. *Fam Practice*. 19(5):452-460.

³¹ Douglass, J., *et.al.* (2002). A Qualitative Study of Action Plans for Asthma. *Br Med J*. 324:1-5.

³² Bauman, A.E., Fardy, H.J., Harris, P.G. (2003).

³³ Davis, K., *et.al.* (2005).

³⁴ Do, G.,G. (2002). Teaching patient-centred care. *Fam Med*. 34(9):644-5.

³⁵ Epstein, R., M., *et.al.* (2005). Patient-centered communication and diagnostic testing. *Annals Fam Med*. 3:415-21.

³⁶ Law, M., *et.al.* (1995). Client-centred practice: what does it mean and does it make a difference? *Can J Occup Therapy*. 62(5):250-7

³⁷ Stewart, M. (2000).

³⁸ *Ibid.*

though most physicians say they support patient-centered care, only 22% of them have invested in health IT and other tools that promote patient-centred practices and chronic disease management³⁹. The use of electronic health records (EHRs) varies dramatically across countries.⁴⁰

Have government policy makers, patients groups and practitioners responded to this shift in paradigm? Do patients feel that they are involved in important health decisions?

A structured literature review of 24 asthma surveys conducted by Holgate *et.al.*⁴¹ concluded that asthma was “out of control”. Results indicated that patients’: (1) knowledge of underlying causes of asthma and treatment options was inadequate; (2) tolerate poor symptom control; (3) possess slight knowledge of correct drug usage; (4) show insufficient adherence to therapy; (5) have low expectations of receiving appropriate therapy or positive encounters with health care providers; and, (6) often underreport their symptoms and severity which may lead to misclassification and under-treatment. Further, 58% of online consumers surveyed by Forrester⁴² had never heard of web-based personal health management systems and only 1% used them. Holgate *et.al.*'s results also indicated that health care providers have: (1) inadequate understanding of disease etiology; and (2) poor or unstructured communication with patients.

This study focused on answering the above questions specifically as they related to the engagement of patients in the provision of their asthma care in five countries: the United States (US), Canada, the United Kingdom (UK), Germany and Italy. Based upon the results of a 2006 study that measured 24 OECD countries' health systems against 19 generally accepted population health indicators the five countries in this study ranked: Italy 2nd; Canada 11th; UK and Germany tied for 18th; and the US 23rd.⁴³

In addition to a review of policies and practices in each country, a patient survey was administered by Fowler⁴⁴ in each country to determine the level of patient satisfaction with their degree of involvement in their asthma care. Appropriate patient organizations in each of the five jurisdictions were engaged to disseminate the patient self-reporting, on-line survey: Asthma Society of Canada, Medic Alert, Asthma and Allergy Foundation of America, PatientView (UK) Deutscher Allergie und Asthmabund, and Federasma (Italy). Patients were asked to report on the extent to which they felt that IAPO's five principles of patient centered care were adhered to within their jurisdiction. The Web-based survey was designed using questions that were similar to the standardized survey questions created by the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program of the Agency for Healthcare Research and Quality (AHRQ).⁴⁵

³⁸ Audet, A-M. J., Davis, K., Schoenbaum, S. C. (2006). Adoption of Patient-Centered Care Practices by Physicians, *Archs of Intern Med.* 166(7):754–59.

⁴⁰ The Conference Board of Canada. (2007). Exploring Technological Innovation in Health Systems. Ottawa, ON.

⁴¹ Holgate, S., T., Price, D., & Valovirta, E. (2006). Asthma Out of Control? A Structured Review of Recent Patient Surveys. *BMC Pulmonary Medicine.* 6 (Suppl I): S2, 1-9.

⁴² California Healthcare Foundation. (2007). iHealthBeat. How familiar are online consumers with internet-based personal health monitoring services? (August 20). Oakland CA.

⁴³ Conference Board of Canada. (2006). Healthy Provinces, Healthy Canadians: A Provincial Benchmarking Report. Ottawa.

⁴⁴ Fowler E. (2007). Patient Centred Health Care Survey: Asthma, 2007.

⁴⁵ Agency for Healthcare Research and Quality. (2006). CAHPS Clinician and Group Survey Adult Primary Care Questionnaire.

Jurisdictional Review

The five countries surveyed were the US, Canada, the UK, Germany and Italy. With respect to clinical practice guidelines three of these countries have created independent guidelines for the management of asthma. The United States has the *Guidelines for the Diagnosis and Management of Asthma* discussed above; Canada has its *Canadian Asthma Consensus Guidelines* as well as the Asthma Society of Canada's (ASC's) *Asthma Patient Bill of Rights*; and, the UK has a *British Guideline on the Management of Asthma*. Canada is examined against both its *Guidelines* and its *Bill of Rights*. The other two, Germany and Italy, rely upon the GINA guidelines and have been grouped together for reporting purposes.

Table 1 provides a report card on the above guidelines when compared to the five principles embedded in IAPO's *Declaration on Patient-Centred Healthcare*.

Respect - All guidelines stress respect for the patient through the individualization of treatment using personal action plans for both control and exacerbations. In Canada, the ASC's *Asthma Patient Bill of Rights* (as well as the GINA guidelines) go further by stating that all asthma patients have the right to strive for complete control of their asthma giving them lives free of symptoms, nighttime awakenings, lost time, limitations, emergency department visits, hospital admissions and pharmaceutical side effects.

Choice and Empowerment - Again, through the use of individual action plans, all guidelines encourage patient involvement in their care and self-management. The GINA guidelines explicitly identify this right and responsibility of the patient for self-management. Patient organizations and the role they can play in this are not explicitly mentioned in any jurisdiction's guidelines.

Patient Involvement in Health Policy - All of the guidelines reviewed are moot on the point of patients being allowed to have meaningful input into health, economic and social policy decision-taking.

Access and Support – With respect to the fourth IAPO principle of patient-centred care all guidelines called for real-time access to any and all therapies that an asthma patient requires but there are serious limitations to access and support of one kind or another in all five jurisdictions. None have the non-medical supports for patients and families that IAPO advocates. Only the GINA guidelines specifically call for non-medical support of asthma patients and their families and, of the two GINA countries, Germany was only slightly better positioned than Italy to provide such supports through their social welfare system. Waiting times to consult airway specialists are serious barriers to timely care in Canada, the UK, Germany and Italy. Canada is a very slow adopter of new healthcare technologies, innovations, drugs and biologics; among the four countries with serious wait time problems, Canada has fewer hospital beds per 100,000 people available and has the lowest acute care productivity level⁴⁶. Not all Canadians and Americans are covered by government drug plans, have private health insurance to cover the cost of medications, or are aware that they may be eligible for industry-sponsored assistance.

Information - All the asthma guidelines stress information and education for the patient. However, direct-to-the-consumer advertising (DTCA) by the pharmaceutical industry is only allowed in the United States. Further, except in the UK, only a fraction of primary care physicians use electronic health records (EHRs): US, 28%; Canada, 23%; UK, 90%; Germany 42%; Italy (n.a.).⁴⁷ Even a smaller percentage provided patient access to their own EHRs: US, 10%; Canada, 6%; UK, 50%;

⁴⁶ Siciliana L. & Hurst J. (2007). Explaining Waiting Times Variations for Elective Surgery across OECD Countries. Paris: OECD.

⁴⁷ Commonwealth Fund. (2006). International Health Policy Survey of Primary Care Providers. New York.

Germany, 15%; Italy (n.a.).⁴⁸ In Canada, 60% of Canadians surveyed favour the introduction and use of EHRs.⁴⁹

Table 1
Jurisdictional Review of Asthma Guidelines as Compared to
the IAPO Declaration on Patient-Centred Healthcare

IAPO Declaration's Principles	United States – Guidelines	Canada – Consensus Guidelines	Canada – Bill of Rights	United Kingdom – Guideline	Germany and Italy – GINA
1. Respect	Yes – individual action plans	Yes – individual action plans	Yes – individual action plans; life free of symptoms and limitations	Yes – individual action plans	Yes – individual action plans; life free of symptoms and limitations
2. Choice and Empowerment	Patients – Yes; Patient Organizations – No	Patients – Yes; Patient Organizations – No	Patients – Yes; Patient Organizations – No	Patients – Yes; Patient Organizations – No	Patients – Yes; (strongest support for self-management) Patient Organizations – No
3. Patient Involvement in Health Policy	No	No	No	No	No
4. Access and Support	Access to therapies may be limited by financial status and lack of awareness of assistance; few other supports	Slow adoption of new therapies; not all covered by government plan or private insurance and lack awareness of assistance; long waiting times; fewer in-patient services; few supports	Slow adoption of new therapies; not all covered by government plan or private insurance and lack awareness of assistance; long waiting times; fewer in-patient services; few supports	Long waiting times for airway specialist consults and clinics; few supports	Long waiting times for airway specialist consults; Germany slightly more supportive
5. Information	Yes	Yes	Yes	Yes	Yes

⁴⁸ *Ibid.*

⁴⁹ POLLARA Research. (2006) Health Care in Canada Survey 2006: 9th Annual Report. Toronto ON.

Overall, on paper at least, the US, Canada, the UK, Germany and Italy are well on their way to becoming patient-centred in the treatment and management of asthma. Their respective practice guidelines all stress the respect of the individual, the patient's right to choice and self-management, and the value of information and education. On the other hand, guideline writing bodies and their respective audiences have not embraced with the written word the role that patient organizations can play in the management of asthma as well as in the formulation of government policy.

On the practical side, even though all guidelines support timely patient access to therapy, there still exist major barriers to care in all five countries – in most there are inadequate services and resources to deal with the increasing prevalence of asthma, and where there may be adequate system resources there may be inadequate personal resources for patients to avail themselves of care.

The Patient's View

Patients surveyed by Fowler⁵⁰ in all five countries were questioned about their perceptions of and experiences with the five IAPO principles as they related to their asthma care – respect; choice and empowerment; patient involvement in health policy; access and support; and, information. Overall, measuring PCC by 19 variables, on a six-point, Likert-type scale (where 6 was "excellent") the US, Canada and the UK were considered to be "good" at providing patient-centred care (scoring 4.0, 3.9, 3.9 respectively) and Germany and Italy were considered to be "fair" (both scoring 3.4.) The results by IAPO principle and country follow below.

Table 2
IAPO Principle #1 – Respect

Question: How do you rate... (1 = very poor; 6 = excellent)	USA (n=478)	Canada (n=114)	UK (n=60)	Germany (n=27)	Italy (n=10)
The medical staff listening to what you say	4.5	4.4	4.5	3.7	3.4
Your health care provider's concern for your mental health or emotional well-being	4.2	4.0	4.5	3.2	3.2
The availability of services tailored to your unique needs	4.3	4.0	3.7	3.1	2.7
The thoroughness and accuracy of your diagnoses	4.5	4.5	4.3	3.7	3.5

⁵⁰ Fowler E. (2007). Patient Centred Health Care Survey: Asthma, 2007.

Respect - The level of respect that patients feel afforded them by their physicians and other healthcare providers is considered to be “good” in the US, Canada and the UK but only “fair” in Germany and Italy. Clearly there is a grade of difference in clinical behaviours and attitudes regardless of the similarity of asthma treatment guidelines and PCC initiatives (see Table 2).

Choice and Empowerment - Clearly patients in all countries did not feel as if they often had choice, and seldom felt empowered (see Table 3). Generally PCC principles seem to have been adopted a bit more in the US and Canada – or at least patients feel that way. Despite all the rhetoric and planning in the UK, individual practice still does not live up to the expectations being set. A study reported in *Respiratory Medicine* corroborates this finding by concluding that the diagnosis and treatment of asthma in the UK lacks standardization and, in some cases, falls short of evidence-based, best practice.⁵¹ Germany and Italy display more of a traditional, paternalistic way of practising medicine.

Table 3
IAPO Principle #2 - Choice and Empowerment

Question: How do you rate... (1 = very poor; 6 = excellent)	USA (n=478)	Canada (n=114)	UK (n=60)	Germany (n=27)	Italy (n=10)
In the last 12 months, the amount of time doctors or other health providers spent with you	3.3	3.4	3.1	3.0	3.7
The degree to which you feel a partner in making decisions about your health care	3.9	3.2	3.8	3.4	3.0
The access you have to treatment options to suit your health needs.	3.7	3.7	3.6	1.1	3.3
In the last 12 months, doctors or other health professionals explained things to you in a way you could understand	3.2	4.0	3.3	3.6	3.6

Patient Involvement in Health Policy - With respect to the third IAPO principle of PCC, outside of the clinician’s office the degree to which patients felt part of health decision-making and policy development was only “fair” (see Table 4).

⁵¹ Barber. C.M. et.al. (2007). Approaches to the diagnosis and management of occupational asthma amongst UK respiratory physicians. *Respiratory Medicine*. 101(9), 1903-1908.

Table 4
IAPO Principle #3 - Patient Involvement in Health Policy

Question: How do you rate... (1 = very poor; 6 = excellent)	USA (n=478)	Canada (n=114)	UK (n=60)	Germany (n=27)	Italy (n=10)
Amount of involvement at all points of decision-making for your health	4.4	4.2	4.2	3.2	3.6
Access to patient support organizations	3.0	3.4	3.3	3.6	3.1
Opportunities to get involved in patient rights groups	2.4	2.1	2.5	3.1	2.6

Access and Support - Interesting of note was one finding of the patient surveys in relation to access to medicines and insurance coverage. Generally speaking access to medicines was considered to be “good” or “very good” for most patients in all five countries (see Table 5). Canadians being the most satisfied with their ability to access drugs was a very interesting result given that the majority of new drugs and biologics introduced to the marketplace over the past few years are not available in Canada whereas they are in the US and, for the most part, in the three European countries studied. It is not clear however if Canadians, who have the most restrictive access to new drugs and biologics of the five countries surveyed, either were not aware that the majority of new pharmaceutical products on the market were not available in Canada or their physicians did not discuss this situation with them. Patients and maybe even clinicians in Canada are not appraising their healthcare with full knowledge.

Table 5
IAPO Principle #4 - Access and Support

Question: How do you rate... (1 = very poor; 6 = excellent)	USA (n=478)	Canada (n=114)	UK (n=60)	Germany (n=27)	Italy (n=10)
The quality of treatment you receive	4.8	4.6	4.5	3.7	4.1
Your ability to get the medicine you need	4.9	5.0	4.5	4.7	4.6
Ease of speaking with your primary care provider by phone	3.7	3.3	3.5	4.1	2.7
Health Care Team’s consideration of other areas in your life (education, work, and family issues)	3.8	3.9	3.4	3.1	3.3

The level of difficulty that Americans and Canadians had in obtaining medicines was statistically significant whether they had private health insurance or not (US: 0.232 significant at p=0.01; and Canada: 0.199 at p=0.05). Public drug insurance is not universal in the US nor Canada; 81% of Americans responding had private health insurance; 61% of Canadians did.

Information - Table 6 shows that, consistent with the other IAPO principles measured, the availability and delivery of materials was somewhat better in the US, Canada and the UK. Data for the US, where 84% of Americans surveyed have used the Internet as a source of health information⁵², suggests the value of internet-based information sources for the PCC of asthma.⁵³ Only 4% of Americans have ever used Internet-based personal health monitoring services.⁵⁴

Table 6
IAPO Principle #5 – Information

Question: How do you rate... (1 = very poor; 6 = excellent)	USA (n=478)	Canada (n=114)	UK (n=60)	Germany (n=27)	Italy (n=10)
The answers to any questions you have for your healthcare provider	4.6	4.5	4.5	3.6	3.5
Explanations about prescribed medicines	4.9	4.5	4.4	3.3	3.8
Availability of educational materials or programs to enhance your health	3.9	3.9	3.5	3.2	2.8
The frequency with which doctors or other health care providers explain things to you in a way you could understand	4.9	4.3	4.8	3.7	3.2

One limitation to this study, and thus the results reported above, was the sample sizes in Germany and Italy, and to a lesser degree in the UK. European patients did not seem as ready as North Americans to complete a confidential, health, self-report on-line. This study should be replicated in a year or two to see if this inhibition changes. This study could also be expanded to include other countries or modified to examine PCC principles in the management of other chronic diseases.

Conclusions

PCC has been embraced by governments, researchers and asthma patient organizations in all five countries in the diagnosis, treatment and management of asthma – on paper at least. As with most innovations, adaptation at the grass roots level takes time. Primary care providers in

⁵² California Healthcare Foundation. (2007). iHealthBeat. How often do US adults search for health care information online? (August 09). Oakland CA.

⁵³ Burst Media. (2007). Online Insights. August 01. Burlington MA.

⁵⁴ California Healthcare Foundation. (2007). iHealthBeat. How familiar are online consumers with internet-based personal health monitoring services? (August 20). Oakland CA.

the US and Canada seem to be doing the best job in providing PCC to their asthma patients; Germany and Italy are definitely lagging; and the UK is in the middle.

To help close the gap between PCC-based, asthma treatment guidelines and actual clinical practice in these five countries the following three recommendations are made.

- 1) Asthma patient organizations, health professionals, and health-product firms must accept their responsibility to work with government policy-makers and employers to ensure that asthma patients have universal, timely access to all treatment options, necessary services and products, and personal health records so that the best condition-treatment pairing can be achieved on a case-by-case basis to realize best possible health outcomes.
- 2) Asthma patient organizations, health professionals, and health-product firms must also play an active role in educating asthma patients about their own responsibility for the self-management of their asthma to achieve best possible quality of life. This will be a significant challenge for segments of populations where deference to medical personnel is still prevalent. In doing so patient organizations, practitioners, and marketers trying to reach out to patients with information should not assume that the electronic medium is as highly an effective medium in the UK, Germany and Italy as it is in the US and Canada – at least not in the short-term.
- 3) Finally, asthma patient organizations must seek out and create for themselves meaningful opportunities to affect health, social, industrial and economic policies that frame the incidence and prevalence of asthma in their respective countries to ensure that the principles of PCC are front and centre in policy formulation and implementation. Patient organizations need to focus on advocating the principles of PCC in their respective countries if changes are to be made in the diagnosis, treatment and management of asthma – and to prove Bismarck wrong.

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