



What is Patient-Centred Healthcare?

A Review of Definitions and Principles

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Note: Patient-centred healthcare is the term used by IAPO to describe healthcare that is designed and practiced with the patient at the centre. Other terms in common usage include: 'patient-centred health care', 'patient-centred care', 'patient-centered care' and 'patient orientation'. In this report, the term 'patient-centred healthcare' will be used except when directly quoting a writer when their terminology will be reproduced.



1 About IAPO

IAPO is the only global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare worldwide. Our members are patients' organizations working at the international, regional, national and local levels to represent and support patients, their families and carers. A patient is a person with any chronic disease, illness, syndrome, impairment or disability. IAPO was founded in 1999 by forty patients' organizations from around the world.

IAPO's vision is that patients throughout the world are at the centre of healthcare.

IAPO's mission is to help build patient-centred healthcare around the world by:

- Realizing active partnerships with patients' organizations, maximizing their impact through capacity building.
- Advocating internationally with a strong patients' voice on relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies.
- Building cross-sector alliances and working collaboratively with like-minded medical and health professionals, policy-makers, academics, researchers and industry representatives.

For more information, visit IAPO's website at: www.patientsorganizations.org

2 Introduction

In May 2004, the International Alliance of Patients' Organizations (IAPO) conducted a consultation with its member patients' organizations. The consultation asked what the most important healthcare policy issues were for their patients' organization. 74% of respondents indicated that **defining patient-centred healthcare** was very relevant to their organization. This review paper was developed to help patients' organizations to consider what patient-centred healthcare means to them.

IAPO's vision is patient-centred healthcare around the world. In order to build patient-centred healthcare, we need to identify and encourage methods that will help to promote patient-centred healthcare. Therefore, a further rationale for investigating concepts of patient-centred healthcare is to stimulate informed debate on what patient-centred healthcare means to patients around the world. Raising awareness and promoting discussion of patient-centred healthcare with patients' organizations and other stakeholders through the distribution of this review paper is a first step. We know that we cannot achieve patient-centred healthcare on our own and will continue to consult with patients' organizations and others involved in healthcare on an ongoing basis during the development of this work. We ask for the support of you and your organization to bring the patient to the centre of the healthcare system.

Main conclusions of this review:

1. There are numerous proposed definitions of patient-centred healthcare, which encompass many of the same core principles, but no globally accepted definition.
2. The evidence base for patient-centred healthcare is not comprehensive and differences in research focus and method makes it difficult to compare research.
3. There are numerous barriers to the practice of patient-centred healthcare which we can work together with others to identify and to address.
4. Finally, it might be more useful to promote the essence of patient-centred healthcare – that the healthcare system should be designed around the patient with respect for a person's preferences, values and/or needs - and to formulate tools and targets to achieve this, than to try to reach a consensus on a global definition of patient-centred healthcare.

Note: This review was carried out in 2004. Following the review, IAPO developed a Declaration on Patient Centred Healthcare outlining the principles necessary for Patient-Centred Healthcare as defined and agreed by IAPO's member patients' organizations. This was launched in February 2006 at IAPO's Global Patients Congress. See section 8 for the Declaration.

3 Overview

3.1 Background

It is the mission of the International Alliance of Patients' Organizations (IAPO) to help build patient-centred healthcare around the world. However, patient-centred healthcare is a concept that, while it is now common terminology, is rarely defined by those using it. As Stewart (2001) states, it is often understood by what it is not: *'technology centred, doctor centred, hospital centred, disease centred'*.

Patient-centred healthcare is part of a shift in focus that has been occurring over time. As Bauman (2003) notes, *'many of the concepts central to patient-centred care have been debated before'*. For example, the relationship and communication between doctors and patients, often predominant in discussions of patient-centred healthcare, has been discussed over the last 50 years. Along with other developments, such as an increase in self-management and patient education initiatives, these have resulted in a move to more collaborative care.

As the number of patients with chronic conditions continues to increase, health systems cannot cope if they continue to focus on the disease rather than the person. They require the involvement of the patient to adhere to treatment, make behavioural changes and to self-manage. There is a growing realisation that patient-centred healthcare, which addresses the needs and preferences of patients, may also be the most cost-effective way to improve health outcomes for the growing number of patients with chronic conditions¹.

IAPO considers that the patient is the only person in a position to make the decision on what patient-centred healthcare means to them, as an individual in the treatment of their condition and the living of their life. We consider that patient-centred healthcare is a useful concept to ensure that patients' needs and preferences are at the centre of all aspects of healthcare. This should not detract from the importance of equality and respect in all relationships in healthcare.

3.2 Aims

This review is part of the IAPO's 'Patient-Centred Healthcare Project' to promote patient-centred healthcare around the world. The aim of the project is that the rationale of patient-centred healthcare

¹ IAPO defines a patient as a person with any chronic disease, illness, syndrome, impairment or disability but patient-centred healthcare is relevant to any person who encounters the healthcare system.

should become entrenched in the minds of those working in healthcare and accepted in the same way as evidence-based care.

This is a literature review and, as such, is not intended to reach an overall conclusion on a definition of patient-centred healthcare. It provides an introduction to the concept of patient-centred healthcare outlining current definitions and principles; examples of research studies on its impact; and some barriers to its practice. It analyses the information, drawing out comments and questions pertinent to the concept of patient-centred healthcare.

Its primary aims are:

- ***To provide useful reference material on patient-centred healthcare***

This review provides a starting point from which readers can consider what the principles of patient-centred healthcare mean to them. We hope that it will stimulate discussion; that patients, patients' organizations and others involved in healthcare will consider how to promote patient-centred healthcare in their own sector and geographical region.

- ***To assist in identifying and promoting the principles of patient-centred healthcare***

This review will provide a basis to investigate whether there is consensus on the common principles of patient-centred healthcare that patients and patients' organizations want in all parts of the world, in all disease areas or whether certain distinctions must be made. The results will be used to formulate principles of patient-centred healthcare for stakeholders to follow to ensure that the patient is at the centre of healthcare in their work. A Manifesto for Patient-Centred Healthcare (see working draft on page 30) will assist policy-makers, professionals, companies, hospitals and associations and others in the application of these principles in their locale or specialty. In the longer term, we will work with others to develop further initiatives to elicit a change in health policies, systems, personal behaviours and attitudes.

3.3 Main research questions

1. What is patient-centred healthcare?
 - What definitions have been proposed?
 - What broad principles does patient-centred healthcare encompass?
2. What effect does the practice of aspects of patient-centred healthcare have on outcomes?
 - Do they increase health outcomes?
 - Do they promote patient satisfaction and do patients want them?

3. What are the barriers to patient-centred healthcare and how can they be addressed?

3.4 Methods

Data was collected using the following methods and sources:

Data identification methods

1. Consultation of information on the internet (using internet search engines and online databases) and in libraries.
2. IAPO's network² were invited to suggest definitions of patient-centred healthcare and to recommend relevant literature and experts in the field.
3. A small selection of the prolific healthcare research was selected for inclusion in this paper. Selection decisions were based on recommendations from experts and by consideration of the quality and relevance of the research within the body of literature available.

Sources

1. International, regional, national and local healthcare policies and regulations
2. Peer-reviewed academic and research papers and commercially printed books and reports. Review papers were particularly vital to ensure we did not "reinvent the wheel" or waste our resources and this review acknowledges and cites that work³.
3. Grey literature – such as industry codes of practice, health professionals' regulations and policy statements, doctoral theses and government transcripts.
4. Global Patients Congress 2005 – information gathered at the Congress will be fed into the development of this project, where relevant.

3.5 Feedback

The scope of the patient-centred healthcare field is immense and this literature review cannot be comprehensive. We hope that it will stimulate ideas and we welcome comments, suggestions and information. Please contact Jo Harkness by email on policy@patientsorganizations.org.

² Patients' organizations, research institutes, healthcare industry companies and associations, and health professional associations among others.

³ For example, Cronin (2004), Mead et al (2002) and Michie et al (2003).

4 Definitions and Principles of Patient-Centred Healthcare

This section outlines some general definitions of patient-centred healthcare and the principles that have been associated with this concept internationally and in six world regions: The Americas, Europe, Africa, South-East Asia, Eastern Mediterranean and Western Pacific⁴.

4.1 Definitions

Cronin's paper (2004) reviewed definitions of patient-centred healthcare and the concepts it can embody, identifying a number of definitions in Lutz and Bowers (2000):

'A collaborative effort consisting of patients, patients' families, friends, the doctors and other health professionals...achieved through a comprehensive system of patient education where patients and the health care professionals collaborate as a team, share knowledge and work toward the common goals of optimum healing and recovery.' (Grin, 1994).

'A construct that advocates simplifying the care at the bedside in the acute care setting by focusing on the expected outcomes for the patient rather than the multiplicity of tasks of each department.' (Johnston & Cooper, 1997).

'Health care that is closely congruent with and responsive to patients' wants, needs, and preferences.' (Laine & Davidoff, 1996).

'Placing patients at the center of the system of care and developing good services that revolve around them' (Mallett, 1996).

4.1.1 International and cross-border definitions

World Health Organization

The term patient-centred healthcare is used within the World Health Organization (WHO) and can be found on the WHO website and in WHO reports. However, the term is often not defined and the current WHO Health Promotion Glossary (1998) does not contain a definition.

⁴ World regions correspond to the World Health Organization's classification system.

The Picker Institute

The Picker Institute operates in the United States, Canada and Europe to improve the quality of healthcare by considering the patient experience through patient surveys and research.

The Picker Institute Europe defines patient-centred healthcare in the following way:

- *Informing and involving patients, eliciting and respecting their preferences;*
- *Responding quickly, effectively and safely to patients' needs and wishes;*
- *Ensuring that patients are treated in a dignified and supportive manner;*
- *Delivering well coordinated and integrated care.* (Coulter, written communication, August 2004)

The Picker Institute definition is based on the following elements outlined by Gerteis et al (1993):

- *Respect for patients' values, preferences and expressed needs;*
- *Coordination and integration of care;*
- *Information, communication and education;*
- *Shared decision-making and support for self-care;*
- *Physical comfort;*
- *Emotional support and alleviation of fear and anxiety;*
- *Involvement of family and friends;*
- *Continuity of care and smooth transition across service boundaries.*

US Agency for International Development

The US Agency for International Development (USAID) definition of patient-centred healthcare is also based on the Gerteis et al (1993) definition. It states that patient-centred healthcare is, '*An approach to care that consciously adopts a patient's perspective. This perspective can be characterized around dimensions such as respect for patients' values, preferences, and expressed needs in regard to coordination and integration of care, information, communication and education, physical comfort, emotional support and alleviation of fear and anxiety, involvement of family and friends, transition and continuity.*' (USAID, 1999)

4.1.2 The Americas

World Health Organization Pan American Health Organization (PAHO)

A search on the PAHO website identified two references to 'patient-centered care' but no definitions.

Patient-centred healthcare or similar terms are in common usage in the United States of America (USA).

The following definitions provide three examples:



Institute of Medicine (IOM)

One of IOM's six aims for the 21st century healthcare system is that healthcare is, '*patient-centred – providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions.*' (IOM, 2001)

US federal Agency for Healthcare Research and Quality (AHRQ)

'...health care that establishes a partnership among practitioners, patients and their families (when appropriate) to ensure that decisions respect patients' wants, needs and preferences and solicit patients' input on the education and support they need to make decisions and participate in their own care.' (AHRQ, 2001)

National Health Council (NHC)

In 2004, the NHC identified three themes of 'patient-centered care', based on patient outcomes: '*care over time that involves the patient's family; information that is shared and accessible; and respect for the patient's needs, values and preferences*'. From these themes the NHC developed the following definition:

'Patient-centered care is quality health care achieved through a partnership between informed and respected patients and their families, and a coordinated health care team.'

The NHC also defined three principles of 'patient-centered care':

- *Patients and their families manage their health care in partnership with a coordinated health care team that recognizes, respects and acts upon their goals, needs, values, preferences, cultural wishes, and/or other factors identified by patients and their families.*
- *Patients and their families receive evidenced-based, cost-effective quality care that maximizes health, alleviates discomfort and is safe and free from avoidable errors.*
- *Patients and their families have the ability to obtain and understand health information and services, and make appropriate health decisions. (NHC, 2004)*

4.1.3 European Definitions

The glossary of the World Health Organization European Observatory on Health Systems and Policies uses the USAID definition of patient-centred healthcare outlined in 4.1.1 *International and cross-border definitions* (p8).

4.1.4 Non-Western definitions

A number of writers have suggested that there is a need for a universal definition of patient-centred healthcare but whether patient-centred healthcare can be applicable outside of the West has also been questioned. No examples of non-western definitions of patient-centred healthcare were found during this

review and a search of the WHO's Regional Office websites in South East Asia, the Eastern Mediterranean, Western Pacific and Africa did not identify any articles referencing patient-centred healthcare that originate within the regional office. However, research studies on components of a patient-centred approach were found and are outlined in *5.2 Research Studies* (pp 16-19).

4.2 Principles and components

Cronin (2004) identified the following concepts that appeared in multiple definitions of patient-centred healthcare:

1. *education/shared knowledge*
2. *involvement of family and friends*
3. *collaboration/team management*
4. *holistic/sensitive to non-medical or spiritual issues*
5. *respect for patient's needs and wants*
6. *free flow/accessibility of information*

Relating specifically to the relationship between healthcare professionals and patients, there have been a number of frameworks describing dimensions of patient-centred healthcare. These include:

WHO 'General Principles of Good Chronic Care', 2003

1. *Develop a treatment partnership with your patient*
2. *Focus on your patient's concerns and priorities*
3. *Use the 5 A's: Assess, Advise, Agree, Assist, Arrange*
4. *Educate patient on disease and support patient self-management*
5. *Organize proactive follow-up*
6. *Involve "expert patients," peer educators and support staff in your health facility*
7. *Link the patient to community-based resources and support*
8. *Use written information – registers, Treatment Plan, treatment cards and written information for patients – to document, monitor, and remind*
9. *Work as a clinical team*
10. *Assure continuity of care*

Stewart et al, 1995

1. *exploring the disease and the illness experience*
2. *understanding the whole person*
3. *finding common ground regarding management*
4. *incorporating prevention and health promotion*

5. *enhancing the doctor-patient relationship*
6. *'being realistic' about personal limitations and resources*

Mead et al, 2000

1. *The biopsychosocial perspective – a perspective on illness that includes consideration of social and psychological (as well as biomedical) factor*
2. *The 'patient-as-person' – understanding the personal meaning of the illness for each individual patient*
3. *Sharing power and responsibility – sensitivity to patients' preferences for information and shared decision-making and responding appropriately to these*
4. *The therapeutic alliance – developing common therapeutic goals and enhancing the personal bond between doctor and patient*
5. *The 'doctor-as-person' – awareness of the influence of the personal qualities and subjectivity of the doctor on the practise of medicine*

4.3 Analysis and discussion

4.3.1 Commonalities between all the definitions and principles

Of the commonalities identified by Cronin (p11), *respect for patients' needs and/or wants and/or preferences and/or values* stands out, explicitly stated in most of the definitions outlined above. The essence of patient-centred healthcare is that patients are at the centre of the healthcare system and therefore that the system is designed around them. The required outcome of healthcare is a better quality of health, and/or of life, as defined by the patient. Respect for patients' needs and/or wants and/or preferences and/or values is a key outcome and, along with the remaining aspects of patient-centred healthcare identified, can be considered to be a useful facilitator which if followed ensures that patient-centred healthcare is achieved. For example, patient-centred healthcare can be facilitated through procedures such as providing information, taking a holistic approach and effective team management.

4.3.2 Omissions in definitions and principles

Reference to patients' rights and responsibilities in healthcare, evidence-based care and patient safety are infrequently referred to in the definitions and principles of patient-centred healthcare identified in *4.1 Definitions* and *4.2 Principles and components*.

1. Patients' rights

Conspicuously absent in the definitions identified is the concept of patients' rights (such as respect for privacy and confidentiality). Several possible reasons for the exclusion can be proffered:

- Rights may be considered implicit in some of the principles, such as respect for needs, wishes and preferences;
- The term patients' rights can present an unhelpful connotation of antagonism counter to the aim for patients' and the healthcare system to work together in harmony; and/or
- Existing international, regional and national human rights laws and declarations may be considered to be sufficient. Examples of these include: the United Nations Universal Declaration of Human Rights (1958) and the European Charter of Patients' Rights (2002). This raises the question of whether explicit mention of patients' rights is required to address those countries that do not have adequate patients' or human rights law or who do not follow or regulate them.

2. *Patients' responsibilities*

Also absent is reference to patients' responsibilities for their own healthcare. The need for patients to be active in the management of their own condition, for example in their adherence to therapies, and also to endeavour to live a healthy lifestyle is an essential part of healthcare today.

3. *Evidence-based care*

Evidence-based care is only referred to in the NHC's principles. Its absence in other definitions may be because evidence-based care is assumed to be common practice but it raises a question on the actual prevalence of its practice and whether specific reference to evidence-based care should be included in the principles of patient-centred healthcare.

4. *Patient safety*

Ensuring the safety of the patient is also absent from many of the definitions (NHC's principles and the Picker Institute do refer to safety). This may be because the need for safe care is widely accepted to be an essential aim in healthcare but again consideration must be given to whether patient safety should be included as a principle of patient-centred healthcare.

4.3.3 Public health versus individual focussed healthcare

Patient-centred healthcare requires a focus on individualism, where individual needs are addressed, as opposed to utilitarianism, where the needs of the population as a whole are considered focusing on improvements in health outcomes for the greatest number of people. This population, or public health, approach to healthcare may not fully equate with the patient-centred approach. However, there must also be some consideration of the community. For example, individual preferences for treatment should not put the health of others at risk; protection of the community must take priority over personal choice.

4.3.4 Global and non-Western definitions

The definitions identified originate mainly in North America and Europe; even the international definitions are based on research in Europe and North America. Further identification of international definitions of patient-centred healthcare would be useful, as would definitions relating to other world regions, if they exist. In regions where the term patient-centred healthcare was not identified, this does not mean that some principles of patient-centred healthcare are not practiced in those regions but perhaps indicates that the term patient-centred healthcare is not in common usage.

4.3.5 Who should define patient-centred healthcare?

There are many stakeholders with valid views, expertise and experience concerning healthcare so it is important to consider who makes the decisions on what constitutes patient-centred healthcare and on what evidence these decisions should be made. Patients, patients' organizations, health professionals, hospital managers, researchers and policy-makers, to name a few, can all contribute valuable information to improve healthcare. However, at present the patients' voice is not heard enough in discussions of patient-centred healthcare. Most research and definitions of patient-centred healthcare have been designed and carried out by providers and researchers. They, unavoidably, consider patient-centred healthcare from the view of providers and researchers. There is a need to find patient definitions of patient-centred healthcare and, if these are not available, to research what patient-centred healthcare means to patients. More specifically, a number of the definitions outlined above have been developed using research on the general population that uses healthcare. Occasional users of healthcare may have different needs and preferences from those with long-term chronic conditions.

4.3.6 Focus on outcomes for patients versus methods to achieve patient-centred healthcare

The principles laid out by the NHC and Picker Institute focus on the preferred outcome for the patient. Principles such as sharing knowledge and decision-making can be implemented on a personal level between a health professional and a patient and their family, friends or carers. Other aspects, such as continuity of care, need to be addressed throughout the healthcare system to achieve the required outcome for the individual patient. Another example is involvement, where the principles identified refer to the personal involvement of patients, their family, friends and/or carers but not to the involvement of patients or patients' organizations in healthcare policies and systems decision-making processes. It is essential to consider how to change the whole healthcare system so that patients are at the centre, focussing on policies and systems as well as on individual relationships between patients and other stakeholders in healthcare.

5 Research on Patient-Centred Healthcare

This section will highlight some research studies on the effect of patient-centred healthcare interventions on outcomes.

5.1 The current range and scope of research

Stewart (2001) and Cronin (2004) conducted Medline searches that provide indications as to the volume and scope of research studies into patient-centred healthcare. In terms of a geographical breakdown, between them they found research papers from the United Kingdom, the United States, Norway, Italy, Canada, South Africa, Australia, Germany, Israel, the Netherlands, Finland, Spain, Belgium, Sweden, France, Taiwan, Japan and Lebanon.

Cronin's Medline search identified over 2,800 articles on patient-centred healthcare. The titles of the first 100 articles, published between June 2003 and November 2003, ranged from those that focussed on a number of specific diseases and conditions (e.g. asthma, cancer, diabetes, depression, head injury and hysterectomies) to broader themes (e.g. primary care, women's health, mental health, emergency care, nursing, chronic illness, palliative care and medication errors).

Research studies into patient-centred healthcare are diverse and can focus on individual or multiple outcomes (some of which are outlined in *Table 1 Potential health outcomes, p16*), which can be investigated and correlated with aspects of the patient-centred healthcare approach. Studies may also follow different research methodologies. These factors make them difficult to compare and to accurately assess the evidence base on patient-centred healthcare.

A number of research studies have concluded that there is a positive link between the practice of patient-centred healthcare in clinical settings and outcomes (including Little et al (2001), Stewart et al (1995) and Henbest et al (1992)). Bauman et al (2003) cites evidence that the patient-centred approach leads to an increase in: patient satisfaction, engagement and task orientation, reduction in anxiety, quality of life, doctor satisfaction and an increase in efficiency resulting in fewer diagnostic tests and unnecessary referrals. However, another recent review (Mead et al (2002)) concluded that the relationship between patient-centred consulting behaviour and patients' outcomes, whilst suggestive, has not yet been proved conclusively. Mead et al also found that the methodological quality of some studies was not high.

Table 1. Potential health outcomes

Health outcome	Description
<i>Health status</i>	The health status of a patient can be measured by physiological measures such as blood pressure and clinical assessments such as wound healing.
<i>Well being</i>	The well being of a patient can be measured by patient self-reports and assessments of their health and general quality of life.
<i>Healthcare behaviour</i>	The healthcare behaviour relates to a patient's behaviour and attitude to their treatment. These include a change in behaviour such as adherence to therapies and self management of conditions through diet, lifestyle and/or therapies. Changes in healthcare behaviour can impact on other outcomes such as health status and well being.
<i>Patient-centredness of healthcare</i>	The health professional or the patient can make an assessment of the patient-centredness of healthcare in practice. For example, the patient-centredness of the consultation process between a doctor and a patient.
<i>Patient satisfaction with healthcare</i>	Patients, their families and/or carers can indicate their satisfaction with care.

5.2 Research studies

This section will highlight a number of examples of recent research focusing on seven key areas: patient-health professional communications; patient-health professional communications for those with chronic conditions; adherence to therapies; self management of chronic conditions; involvement in healthcare policy-making; and involvement in personal healthcare decision-making.

5.2.1 Patient-health professional communications

Stewart et al (1995) reviewed 21 studies of patient-health professional communications and found that 16 reported positive results for outcomes: emotional health, symptom resolution, function, physiologic measures (ie blood pressure and blood sugar level) and pain control (listed in descending order of frequency).

Little et al (2001) studied patient preferences for a patient-centred approach to consultation in primary care and the results strongly showed that communication, partnership and health promotion were aspects of patient-centred healthcare that patients wanted. Patients want a patient-centred and positive approach and if they do not receive it they are less satisfied, less enabled and may suffer greater symptom burden and use more health service resources. The paper asserts that there are five components of patient-centred healthcare that can be measured satisfactorily. These are communication and partnership (a sympathetic doctor interested in patients' worries and expectations and who discusses

and reaches agreement on the problem and treatment); personal relationship (a doctor who knows the patient and their emotional needs); health promotion; a positive approach (being definite about the problem and when it would settle); and interest in effect on patient's life and that they are key elements also wanted by patients.

Little et al (2001) cites evidence that older patients and those with serious illness may not prefer a patient-centred approach. Some people do not want to receive full information or be actively involved in their healthcare trusting their doctors and nurses to care for them and to make appropriate treatment decisions for them.

Lewin et al (2002) conducted a review using the criteria that interventions were considered to be patient-centred if they promoted either:

- *'Health care providers share control of the consultation, decisions about interventions or management of the health problems with the patient, and/or*
- *Health care providers focus in the consultation on the patient as a whole person who has individual preferences situated within social contexts. This is in contrast to a focus in the consultation on a body part or disease.'*

The study concluded that interventions to promote patient-centred healthcare in clinical consultations did lead to significant increases in the patient-centredness of the consultation but that it was difficult to quantify the health outcomes.

In a research study on patient-centred healthcare in South Africa, Henbest et al's (1992) study developed methods to measure patient-centredness amongst poor, non-Western people. Patient-centredness was determined to be the *'practitioner's facilitation of the patient's reasons for coming, including symptoms, thoughts, feelings and expectations'* (i.e. focussing on communication including questioning and listening). The study concluded that patient-centred interviewing in a non-Western setting was effective and that patient-centredness was positively associated with: the patient feeling understood; the patient-practitioner agreement about the nature of the problem; symptom resolution; and concern resolution. The study also found that the presence of an interpreter did not affect the effectiveness of the consultation, patient centred consultations would be judged to be as medically competent as non-patient-centred consultations and would not take longer.

A study by Stewart et al (1995) observed the clinical encounter and patient perceptions and found that the patients' perception of the patient-centredness of the interaction was the stronger predictor not only of health outcomes but also of efficiency of healthcare (fewer diagnostic tests and fewer referrals) compared to experts' ratings.

5.2.2 Patient-health professional communications for patients with chronic conditions

A 2002 review by Michie et al focussed on one aspect of patient-centredness, healthcare communication, and whether different concepts of patient-centredness result in different health outcomes specifically for chronically ill patients. The review of 30 studies found that good physical health outcomes were more closely associated with health professionals activating the patient in the management of their chronic illness (such as diabetes) than when health professionals took an approach which elicited and discussed the patients' beliefs without actively motivating them to take control of the consultation and/or the management of their illness. The review also considered the outcomes of adherence to therapies and patient satisfaction and found that many of the studies reviewed showed a positive association between a patient-centred approach and outcome, whether an 'activating' approach was taken or not.

The focus of many studies has been on the doctor-patient relationship but the relationships between nurses and patients and pharmacists and patients are also important and can also contain patient-centred aspects.

5.2.3 Self-management in chronic conditions

In concurrence with Little et al (2001), Bauman (2003) also highlighted communication, partnership and health promotion as key elements of patient-centred healthcare. Bauman's review focussed on self-management in diabetes and asthma referring to Cochrane systematic reviews which have shown that self-management training has benefits for adults with diabetes (Wolpert, 2001) and suggest that improved outcomes result from patient-centred interventions such as health-system-wide team approaches, follow-up visits and a patient education component. In asthma self-management programmes, approaches have been shown to reduce hospital attendances and admissions, asthma symptoms and time off work or school (Gibson, 2000).

5.2.4 Adherence to therapies

The WHO Adherence to Long-Therapies Report (2003) found that elements of a patient-centred approach such as effective communication, patient-tailored interventions, patient support and a holistic approach are essential to encourage patients to adhere to their treatments.

5.2.5 Involvement in health policy-making

The UK Department of Health (2004) published a review of 12 pieces of research indicating that patient and public involvement in health results in positive outcomes for patients, for staff, for communities, and for health delivery. The most common outcome was that patients were more satisfied with their care.

5.2.6 Involvement in personal healthcare decision-making

A study investigating preferences for involvement in decision-making in Japan (Sekimoto et al, 2004) found that respondents to the study preferred a collaborative role (71%) versus an active (12%) or passive (17%) role. The study found that cancer patients were less likely to prefer an active role and more likely to prefer family involvement in decision-making compared to other respondents. They note that other research has indicated that Japanese patients do want physicians to make the final decision. This study is interesting because physician paternalism has been a dominant concept in Japan and the Japanese system counts on continued patient care by the family but it seems to support positive attitudes towards participation in medical decision-making if fully informed.

5.3 Analysis and discussion

5.3.1 The evidence base for patient-centred healthcare

There is a growing body of research into the patient-centredness of patient consultations, involvement of patients and the public in health policy, and the outcomes for patients and others. The body of evidence in favour of patient-centred healthcare is not strong partly due to the fact that often studies focus on slightly different aspects of patient-centred healthcare or use different research methodologies making them difficult to compare.

Although the evidence base examining the relationships between patient-centred healthcare and overall health is not substantial, it does indicate some positive outcomes. In particular, research into patient satisfaction indicates that a patient-centred approach is what patients want. However, care must be taken in the consideration of satisfaction research to determine whether the satisfaction level expressed reflects patients true wishes or whether satisfaction is high because expectations are low.

Currently most research studies are designed by researchers. There is a need for research to be carried out which is designed from the perspective of patients themselves to compare with, and add to, the current body of knowledge. A consultation with patients' organizations could help to clarify the priorities of patients with long term chronic conditions for patient-centred healthcare.

5.3.2 Definition of patient-centred healthcare

An accepted definition of patient-centred healthcare and a common theoretical framework would be useful for research purposes. It would also be useful to enable other stakeholders to review and assess the evidence, and impact on the design of interventions to promote patient-centred healthcare.

Patient-centred healthcare is sometimes said to be irrelevant to patients in non-Western settings, whose main need is to just see a doctor or to receive any medication at all which overpowers concerns of being involved in decision-making or receiving a patient-centred consultation. Whether the concept of patient-centred healthcare is relevant to patients in non-Western settings depends on the definition of patient-centred healthcare, because access to a doctor can be considered to be a basic aspect of patient-centred healthcare. The research identified from South Africa and Japan does suggest support for some elements of a patient-centred approach in non-Western settings, but further consideration and research is needed. There may also be differences in patient-centred healthcare requirements related to disease area, level of education, socio-economic group, race, and culture, all of which warrant consideration. It may be that the needs and requirements are similar but that the approach needed to achieve patient-centred healthcare is different.

Little et al (2001) and others have suggested that not all patients want patient-centred healthcare. Whether patients want patient-centred healthcare depends on the definition they use of patient-centred healthcare; whether it is defined as receiving full information and participating fully in decision-making or whether as Stewart (2001) states, '*Being patient centred actually means taking into account the patient's desire for information and for sharing decision making and responding appropriately*' allowing the patient the opportunity to decide how much involvement and responsibility they want.

Whether patient-centred healthcare means responding to patients' expressed needs and preferences or activating them into responsible health behaviour is an important question. Research, such as Mitchie et al (2002), indicates that an activating patient-centred approach leads to better outcomes than a more passive, responsive approach. How much responsibility patients should take for the management of their condition or disease, for communicating their preferences and needs and for respecting the expertise and work of health care professionals are all important questions in the defining and practice of patient-centred healthcare. In some cases a patient's refusal to be involved in their healthcare can be fatal or affect their quality of life and serious consideration must be given to the benefits of 'activating' the patient to take responsibility for the management of their condition. This is not an easy question to answer impacting on a person's right to make personal choices about their lives and healthcare.

5.3.3 Strong focus of research on micro rather than macro level

In this review, the majority of research identified focuses on the doctor-patient relationship, the micro level or the bottom-up approach, but for patient-centred healthcare to occur on a micro level it is essential to assess what actions need to be taken and implemented on the macro level. Considering the patient-centredness of health policies will help to identify how much is due to the individual work of healthcare professionals and how much is factored into healthcare policies and the healthcare system. Questions include: What research is available on patient involvement in healthcare policies? How can

individual healthcare policies and full healthcare systems be assessed for patient-centredness? What types of measurements can be made?

5.3.4 Personal involvement in health versus involvement in health policy

Revisiting the concept of involvement in healthcare, patient-centred healthcare may require the appropriate involvement of friends and family at the individual patient level. To make patient-centred healthcare possible at the individual level requires the healthcare system to be designed with the patient at the centre and the involvement of patients' and patients' organizations in all aspects of healthcare policy, healthcare systems and healthcare delivery decisions can encourage this situation. For example, patient or patients' organizations providing advice on the evaluation of practice and the setting of benchmarks on hospital management committees.

6 Barriers to the Practice of Patient-Centred Healthcare

This section outlines some of the barriers to patient-centred healthcare. Identifying barriers to patient-centred healthcare is a starting point from which to develop methods to address them.

A review of the extent to which patient-centred healthcare is being practised in different countries and settings is outside the remit of this paper. However, there is no doubt that it is a concept that is being promoted, at least to some extent, in and to varying degrees outside of North America, Australasia and Europe. For example, there are international development initiatives in health that include the promotion of patient-centred healthcare such as the Nuffield Institute for Health's TB programme; an international programme collaborating with research groups in Pakistan, Nepal, India, South Africa and Swaziland, and with the intention to expand these links to other locations.

It is difficult to assess whether patient-centred healthcare is being practised. There may be a commitment in policy documentation to patient-centred healthcare but insufficient structures to enable it to occur or sparse commitment in personal behaviours and attitudes. On a personal level, some health professionals practise more patient-centred healthcare than others but, as Stewart (2001) notes, doctors '*provide most patients with partially patient centred care*'. Using a conceptual framework to determine a patient-centred score for doctors Stewart et al's 2000 study found a figure of 50.7 (SD 17.9, range 8-93) within the scale of 0-100. Some would argue that healthcare cannot be partially patient-centred; it either is completely patient-centred or not patient-centred at all. Identifying the barriers to patient-centred healthcare whether in policies, systems or delivery of healthcare will aid in future work to overcome them.

The motivation of those involved in healthcare is an important factor in the practice of patient-centred healthcare. For those involved in healthcare, either in policy or professional circles, economic and political factors will play a part. Evidence showing positive health outcomes or a reduction in healthcare costs will arguably be more influential than evidence of patient satisfaction, unless related to political priorities. On a personal level, individuals have varying opinions on the worth of patient-centred healthcare; whether it is a worthy practice in its own right or if patients want it, or whether it should only be practiced if there is evidence that it improves health outcomes or is cost-effective. These attitudes will affect personal behaviour and need to be considered when identifying methods to promote patient-centred healthcare.

To achieve the patient-centred outcomes described in *4 Definitions and Principles of Patient-Centred Healthcare* and *5 Research on Patient-Centred Healthcare* requires patient-centred health policies. The healthcare system must be designed with the patient at the centre in order to assure continuity of care, sufficient patient consultation times and to assure that healthcare professionals are trained to communicate effectively and to consider non-medical issues.

6.1 Barriers

This section outlines a small selection of potential barriers to patient-centred healthcare.

6.1.1 Definition of patient-centred healthcare

As has been noted, there is no globally accepted definition of patient-centred healthcare. This is a barrier in identifying and comparing research into the principles of patient-centred healthcare, the setting of healthcare policies that promote patient-centred healthcare and the implementation of patient-centred healthcare by individuals. The term patient-centred healthcare is often used but can be an empty term; neither enforced within healthcare systems nor demonstrated by personal behaviour.

6.1.2 Healthcare focus

Many factors make it difficult for policy-makers and healthcare professionals to follow the patient-centred approach along with the accepted (clinical/medical/science) evidence-based care approach. These include the current focus on clinical and cost-effectiveness and on therapeutic and diagnostic effectiveness as a measure of health outcome, the public health or population approach to healthcare and the lack of clear evidence on positive effects of a patient-centred approach. This is perpetuated by the lack of a definition of patient-centred healthcare and the lack of indicators or criteria to determine the level of patient-centredness in healthcare.

6.1.3 Structure of the healthcare system

There are many barriers to the practice of patient-centred healthcare within the healthcare system, for example short consultation times and limited resources. Gillespie et al (2004) conducted a UK-based survey and found evidence that underfunding, low staffing levels and low morale restrict the practice of patient-centred healthcare and that it is seen as expensive in an already overstretched service. The situation in less developed countries is far more severe with a lack of medicines, hospital equipment and few opportunities to train and educate healthcare teams to improve the care of patients. However, there is some evidence that patient-centred consultations do not take longer than a regular consultation (Henbest, 1992). Bauman (2003) also asserts that positive outcomes for diabetes patients undergoing patient-centred interventions can be produced without lengthening consultations, especially if a team approach to management is developed.

6.1.4 Integration of healthcare and other aspects of life

The term healthcare has restrictive connotations because health affects all aspects of a person's life. It affects their quality of their life, their education at school, their mobility, their housing requirements and so on. It is therefore important that all social, health, economic and other policies cater for the diverse needs of people with chronic conditions. As David Pink, Chief Executive of the United Kingdom Long-Term Medical Conditions Alliance points out, *'Patient-centred healthcare is a kind of healthcare – therefore it is, by definition, healthcare-centred...it is inevitable that people trying to explain what it is have to describe the healthcare-centred behaviours that might be components of patient-centred healthcare'* (Pink, written communication, December 2004).

The dissociation between healthcare, which focuses on the condition, and services that focus on other aspects of a patient's life are not useful. A person's health affects all aspects of their life and conversely their life affects their healthcare. There are many chronic conditions but the commonality is that chronic conditions affect *all* aspects of a person's life. It is therefore necessary to shift the focus of the entire healthcare system, to move away from focussing on the disease, making a patient a member of a disease group with general characteristics and to focus on the uniqueness of personal experiences, considering what the disease means for the life and social participation of the individual patient. This means a complete reversal in thinking about objective (the outcomes of examinations) and subjective (the story of the patient) information.

6.1.5 Communication and partnerships

Communication skills are necessary to ensure that patients' preferences, wants and needs are considered and to facilitate an equal partnership where shared decisions can be made between patients and their healthcare professionals. This requires both parties to listen as well as speak and question. This requires training of medical and pharmacy students, trainee nurses and all others involved in personal relationships with patients. This training needs to be ongoing, patients need to be involved in the determination of communication skills but patients may also need training so that they can effectively communicate their needs and preferences in a dialogue with healthcare professionals. It can be difficult to define the level and type of communication required in teaching because it will be different for each patient, there is not a 'one size fits all approach', but it is about effectively responding and drawing out patients unique experiences, needs and preferences.

Communication and partnerships between patients and health professionals are not the only important partnerships in patient-centred healthcare; health professionals, hospital managers, policy-makers and all others involved in the developing and implementing of healthcare policies and the practice of healthcare need to be able to communicate effectively with one another. These skills are also vital for patients and

patients' organizations if they are to participate on an equal level with professionals in health policy discussions or for patients on a personal level during the management of their condition.

6.1.6 Information

Debate on what type of information patients need and want and who should provide information is predominant in healthcare discussions. Issues include the possibilities for and risks of eHealth, the provision of information from pharmaceutical companies directly to patients (legal in the US and New Zealand but restricted and hotly debated in Europe), the role of governments in the provision and regulation of information, and the roles of patients' organizations in the provision of information. At present, many patients do not receive the information they need in a useful format and often do not have the necessary skills to take in, analyse or use the information they are given to make decisions. So knowledge, education and access to quality information are all barriers to patient-centred healthcare and may lead to inequalities between those of different age groups and/or socio-economic status. For example, the elderly or those with a low economic status may not have access to the internet or may not have the skills or confidence to seek education and help. There is a desperate need to ensure that patients' receive useful information which allows them to make informed decisions. Regardless of the source, information should conform to health literacy principles (IAPO, 2002).

'All information, whether posters, brochures, pamphlets, audio, video or television material, should incorporate the following:

- *a clear and understandable message*
- *relevant and tailored content*
- *culturally and linguistically appropriate format*
- *reader, viewer or listener involvement*
- *pilot testing on key audiences'*

6.1.7 Attitude

The health professional-patient relationship, based on mutual trust, communication and partnerships within the healthcare system, is essential for patient-centred healthcare. In a UK study by Gillespie et al (2004), they identify the attitude of healthcare professionals as a barrier to patient-centred healthcare indicating that, *'Attitudinal change is needed to redistribute the power between professionals and patients and there is evidence of a reluctance to change'*.

6.1.8 Involvement

Patient-centred healthcare principles, such as those of the National Health Council and the Picker Institute, highlight the need to involve patients' family and friends so that they too are also informed and

educated and so they can support and participate in decision-making where appropriate. Equally important is determining how patients' wants, needs and preferences, continuity of care, appropriate communication and information as well as good access to reliable, safe and effective treatment (including medication and medical technologies) and services can be built into the healthcare system. How can patients individually and through the representation of patients' organizations be involved in healthcare decision-making?

In the Lewin et al (2002) study only one of the 17 studies reviewed appeared to involve consumers in the development of the intervention and none in the delivery. Gillespie et al (2004) also identified social divisions as a barrier to patient-centred healthcare. Those with lack of financial resources such as those from socially disadvantaged or minority backgrounds whether they be social, linguistic or cultural may have difficulty obtaining patient-centred healthcare. In addition, involvement in service delivery or health policy may be affected by a person's confidence and assertiveness, health and cognition, altruism and the cost of participation (such as travel expenses and time commitments) (Thompson 2004).

6.1.9 Patients' rights

Unfortunately, it is unquestionable that some patients are being physically and/or mentally abused; and denied basic human rights and liberties. This varies between and within countries. There are also significant differences in the possibilities for involvement in healthcare decision-making and there are large barriers to overcome in order that the rights and preferences of patients in all aspects of healthcare are considered.

6.2 Possible solutions

The barriers identified can be addressed in a variety of ways to elicit a systemic and personal change to patient-centred healthcare. This section will highlight some important opportunities.

There is an important opportunity to work together with patients' organizations and other stakeholders to communicate the definitions and principles of patient-centred healthcare to help stakeholders to recognise patient-centred healthcare as a valid and important concept.

Identifying research and information from different geographical regions and outlining any differences or similarities in concepts according to geographical region, age group, gender, socioeconomic status or ethnic group will highlight the needs of patients around the world. In addition to gathering and disseminating information and raising awareness, there is a need to concentrate on practical interventions, to construct indicators which can be used to measure outcomes. US patient-centred healthcare initiatives and strategies should be considered to determine whether they are applicable



globally, need adaptation or whether new tools need to be developed. There is the opportunity to work with others to investigate and develop useful tools to encourage the practice of the identified elements of patient-centred healthcare.

The structure of the healthcare system is vital to the practice of patient-centred healthcare. Policies must be designed around the patient. Structures to ensure policies and practice are patients-centred must be built into the healthcare system at every level to ensure patient-centred healthcare is practiced on a personal level. Patient involvement is one way to increase the patient-centredness of health policy, systems and delivery. How can, and should, the principles of patient-centred healthcare become the focus of all levels of health policy, health systems, healthcare delivery, the doctor-patient relationship, personal decision-making and communication?

Some countries (e.g. the Netherlands and the UK) have declared their commitment to patient and public involvement but policies and practice are still sometimes tokenistic in nature. Many barriers to patient involvement exist including: financial, physical, educational and emotional support for individual patients or patients' organizations to encourage participation and there is a need to move from using public consultation as an exercise in gauging opinion to changing policies to reflect patient needs and opinions. Involvement needs to be in all policy making that affects patients' lives not restricted to healthcare but to include social and economic policies and regulatory policies to name a few.

Patients, their families and carers need education so that they can decide and articulate what care they need and want and healthcare professionals need competencies to practice patient-centred healthcare. Working with others to promote health literacy and to train patients, health professionals, students and all those involved so that they can communicate and negotiate better with each other will be essential. The attitudes of a wide group of stakeholders will have a profound impact on the acceptance and promotion of patient-centred healthcare as a viable focus for healthcare policies. Working with other stakeholders, building up mutual trust and communication is essential to develop understanding and move forward on these issues.

7 Conclusions

The definitions and principles of patient-centred healthcare identified have been formulated using extensive research and review over many years. These definitions and principles outline important patient outcomes so that they receive the healthcare they need and want. If patients' preferences are built into the system it will address the overall health and wellbeing of a nation which will, undeniably, result in social, health and economic gains.

Main conclusions of this review:

1. There are numerous proposed definitions of patient-centred healthcare, which encompass many of the same core principles, but no globally accepted definition.

Determining a universally-agreed IAPO definition would be useful in communicating the message of what patient-centred healthcare means to patients and patients' organizations around the world. However, it may be difficult, if not impossible, to achieve and might not add significantly to those definitions already developed.

2. The evidence base for patient-centred healthcare is not comprehensive and differences in research focus and method makes it difficult to compare research.

The evidence base examining the relationships between patient-centred healthcare and overall health is not substantial but it does indicate some positive outcomes and, in particular, research into patient satisfaction indicates that a patient-centred approach is wanted by patients.

3. There are numerous barriers to the practice of patient-centred healthcare which we can work together with others to identify and to address.

4. Finally, it would be useful to promote the essence of patient-centred healthcare – that the healthcare system should be designed around the patient with respect for a person's preferences, values and/or needs - and to formulate tools and targets to achieve this, than to try to reach a consensus on a global definition of patient-centred healthcare.

8 Declaration on Patient-Centred Healthcare

Patient-centred healthcare is the way to a fair and cost-effective healthcare system

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-centred healthcare may be the most cost-effective way to improve health outcomes for patients.

To us, the International Alliance of Patients' Organizations, the essence of patient-centred healthcare is that the healthcare system is designed and delivered to address the healthcare needs and preferences of patients so that healthcare is appropriate and cost-effective. By promoting greater patient responsibility and optimal usage, patient-centred healthcare leads to improved health outcomes, quality of life and optimal value for healthcare investment.

Patients', families' and carers' priorities are different in every country and in every disease area, ***but from this diversity we have some common priorities. To achieve patient-centred healthcare we believe that healthcare must be based on the following Five Principles:***

- 1. Respect** - Patients and carers have a fundamental right to patient-centred 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 carers 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' organizations 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 healthcare policy but include, for example, social policy that will ultimately impact on patients' lives. See IAPO's Policy Statement at: www.patientsorganizations.org/involvement.
- 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 carers 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. See IAPO's Policy Statement at www.patientsorganizations.org/healthliteracy.

To achieve patient-centred healthcare at every level in every community, the International Alliance of Patients' Organizations is calling for the support and collaboration of policy-makers, health professionals, service providers, and health-related industries to endorse these Five Principles and to make them the centre of their policies and practice. We call upon all stakeholders to provide the necessary structures, resources and training to ensure that the Principles outlined in this Declaration are upheld by all.

9 Attachments

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