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The Official Journal of the International Hospital Federation

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The South African Depression and Anxiety Group and government hospital partners: Addressing the challenge of poor adherence in psychiatry

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Opening Remarks

Eric DE ROODENBEKE, CEO IHF (SWITZERLAND)

Roundtable #1 : What do buyers expect?

Annette PUMMEL, CMRP, Association for Healthcare Resource & Materials Management (AHRMM) (USA)

Jack THIAN, Singapore Health Services (SINGAPORE)

Megan MAIN, Health Purchasing Victoria (AUSTRALIA)

Dr. Frank OBBELODE, EK-UNICO GmbH (GERMANY)

Chair: Irène FOGLIERINI, European Business School

Roundtable #2 : What do suppliers expect?

Yves VERBOVEN, EUCOMED (BELGIUM)

Nicole DENJOY, COCIR (BELGIUM)

MÖLNLYCKE HEALTH CARE

GE Healthcare (tbc),

Chair: Irene Foglierini, ESCP

Roundtable #3 Global overview of successful experiences

Peter ALLEN, Sourcing Operations, Novation LLC (USA)

Ralph F. IVES, Global Strategy & Analysis, AdvaMed (USA)

Ulrike HOFFMANN, Sana Kliniken AG (GERMANY)

Douglas KENT, Health Shared Services BC (CANADA)

Chair: Francis MEGERLIN, Senior Fellow, Berkeley Centre for Health Technology (FRANCE/USA)

Roundtable #4 : New projects to improve healthcare systems performance

Francis MEGERLIN, Berkeley Centre for Health Technology (FRANCE/USA)

Gabriela PRADA, Conference Board of Canada (CANADA)

Charles-Edouard ESCURAT, Resah-IDF (FRANCE)

Chair: Eric DE ROODENBEKE, CEO, IHF

Wrap-up: Irène FOGLIERINI, ESCP

19h30 –Dinner (by invitation only)

DAY 2 : Group Purchasing: Towards a new model?

Group Purchasing Special Interest Group Meeting (by invitation)

Introduction: Eric DE ROODENBEKE, IHF (SWITZERLAND)

Roundtable #1 : From Partitioning to Global Networking: Is there a critical size for purchasing groups?

Jack THIAN, Singapore Health Services (SINGAPORE)

Ricardo Avenenti, University Hospitals Vaud-Geneva (SWITZERLAND)

Annette PUMMEL, CMRP, AHRMM (USA)

Alyson BRETT, President, EHPPA (Europe UK)

Douglas KENT, Health Shared Services BC (CANADA)

Chair: Alyson BRETT, EHPPA (Europe UK)

Roundtable #2: Is standardization of information essential for the future of purchasing?

Dr Béatrice FALISE MIRAT, Orange Healthcare (FRANCE)

Ulrike KREYSA, GS1 Global Office (BELGIUM)

Mauricio DI BARBOSA, CEO, Bionexo (BRAZIL)

Chair: Nicole DENJOY, COCIR (BELGIUM)

Roundtable #3: The Role of Purchaser in introducing innovation in hospitals

Gabriela PRADA, Conference Board of Canada (CANADA)

Ramon MASPONS, Agència de Qualitat i Avaluació Sanitàries de Catalunya - AQUAS (SPAIN)

Harald JOHNSEN, Hinas (NORWAY)

Randy HAYAS, Orlando Health (USA)

Chair: Carole GANDON, Resah-IDF (FRANCE)

Round table #4: How group purchasing can professionalize the buyer

Peter ALLEN, Novation LLC (USA)

Charles-Edouard ESCURAT, Resah-IDF (FRANCE)

Chair: Alyson BRETT, EHPPA (Europe UK)

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Dominique Legouge, Director, Resah-IDF (FRANCE)

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IHF and IAPO: Fostering patient engagement



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INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

The International Alliance of Patients' Organizations (IAPO) and the International Hospital Federation (IHF) share an objective of helping to improve the health of all people around the world through promoting quality care and meaningful engagement of patients in health policy-making and in their own care.

In 2012, IAPO and IHF formalized their collaboration in a Memorandum of Understanding (MOU) which outlines our intent to acknowledge a common commitment to advancing the cause of patient-centred health care worldwide. This MOU underpins the aims and activities that we undertake together in order to further our common aims. One of these is in the area of patient involvement.

IAPO and IHF surveyed their respective national members in July 2013 on the status of patient involvement in hospitals at the national level (1). There were 34 responses (17 each from IAPO and IHF members) from 27 countries and all world regions (2).

The results showed that in half of the countries surveyed there was no regulation in place for patients' institutional involvement in hospitals. For those countries where there was patient involvement, the most common focus of the regulation was patient involvement on the hospital board and/or in specific committees (41%) with other areas focused on collaboration to improve the quality of care and patient participation in treatment decision-making. The mechanisms for involvement took many forms ranging from ad hoc participation to seats on governing bodies and formal committees to participating in technical or advisory groups.

The situation reflected by this survey shows that there is still a long way to go towards full implementation of IAPO's *Guidelines on Patient Involvement* (3) that outline the following areas which patient involvement should incorporate:

- + Robust and transparent mechanisms to ensure that patient views are acted upon, not just recorded.
- + Inclusion in initiation, design, implementation, communication and evaluation of initiatives.
- + Practical, psychological, financial and educational support for participants.
- + Varied methods to reach under-represented groups and to gather a diversity of view.

With this edition of *World Hospitals and Health Services* dedicated to patient engagement, we are pleased to share eight articles which exemplify different types and models for patient involvement in different countries. Four are written from the hospital perspective and four from the patient perspective. These articles also highlight some diverse and some common experiences from

eight countries around the World (4). Articles range from focusing on the patient's role in improving patient safety and the quality of care (for example in Pakistan, Switzerland and the Netherlands) to raising awareness among physicians of the patient experience, expectations of care and making patients aware of the role they can play in the self-management of their condition (for example in the Netherlands, France, United States and South Africa). There are different approaches to patient involvement from a strong patient advocacy approach as highlighted in the United States case study to the systematic involvement of patients in nearly all tiers of the Australian health care system.

We hope these articles will promote discussion and encourage both patient groups and hospitals to take additional steps towards greater formalized patient involvement in hospitals. There is no "one size fits all" approach, although there are common principles on which involvement should be based. The articles show that there are positive outcomes when there is greater involvement of patients in health decision-making and their own care. □

IAPO is a unique global alliance representing patients of all nationalities across all disease areas and promoting patient-centred health care around the world. We have 240 members that span over 65 countries and all world regions. Health policy decisions made at every level will ultimately affect patients' lives. IAPO believes that engaging patients in health policy decision-making helps to ensure that policies reflect patient and caregiver needs, preferences and capabilities, making it an appropriate and cost-effective way to address the patient's needs.

References and footnotes

1. The full report entitled, 'Formal arrangements in hospitals for patient involvement' is available online at www.ihf-fih.org/en/Publications/Reports/Formal-arrangements-in-hospitals-for-patient-involvement
2. Asia Region: Hong Kong, Indonesia, Israel, Korea, Pakistan, Philippines, Taiwan, Thailand; Africa Region: Cameroon, Nigeria, South Africa; Americas Region: Argentina, Canada, El Salvador, Guatemala, United States; Europe Region: Austria, Bulgaria, France, Germany, Greece, Hungary, Poland, Switzerland, the Netherlands, United Kingdom; Australasian Region: Australia
3. IAPO Policy Statement and Guidelines on Patient Involvement available at: <http://iaopo.org.uk/patient-involvement>
4. Australia, France, Hong Kong, The Netherlands, Pakistan, South Africa, Switzerland and the United States of America

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Australia – Consumers Health Forum of Australia: Enabling health service consumers to have an active role throughout the health system

ARTICLE AUTHORED BY IAPO STAFF, FROM CONVERSATIONS WITH MEMBER REPRESENTATIVES

ABSTRACT: Patients are recognized as active consumers within the Australian health care system which is a universal health care system funded nationally, with state-level responsibility and local delivery. Patient engagement with hospitals is therefore focused on making services more patient-centred. As a national body representing the views of patients in Australia the Consumers Health Forum (CHF) helps affiliates to improve local and regional engagement. Initially, engagement was driven by local relationships with administrators and clinicians, whereas now there is more systematic patient representation on committees and boards – although local involvement can still be a challenge. Advocating for the application of national standards to different local contexts is ongoing and these are important because collecting, measuring and responding to patient views and involving them in decision-making can have a tangible impact on a hospital's “bottom-line” performance and funding.

Context

Patient engagement in Australian hospitals takes place in the context of universal health care funded through general taxation and a means-tested health levy. While the Federal Government retains overall responsibility for Medicare (the Australian national health service), responsibility for public hospitals resides with individual state governments. Since 2011, state hospitals have been organized into Local Hospital Networks (LHNs) – hospital clusters based on either a “geographical or functional connection” (1) – with planning of local strategic health care needs provided through a network of Medicare Locals (soon to be replaced with Primary Healthcare Networks) bringing together local needs assessment and provision through partnership with hospitals in each LHN region.

The recognition of patients as consumers is an accepted feature of the Australian health care model. Patient engagement with hospitals in this context is therefore mostly concerned with issues of patient-centred care rather than issues of basic representation and patient voice more generally. The recognition that patients have a valid role in driving standards of care has, for instance, meant that patients and their families typically play a big role in the quality of care through giving advice on their condition, input into treatment plans and through medical staff listening to their views.

Since 1987, the Consumers Health Forum of Australia (CHF) has been the national body representing the interests of patients in Australia. The forum includes over 130 member organizations, ranging from national advocacy groups representing particular conditions as well as regional health consumer groups. Membership is divided into three categories: organizational members, voting members and corporate members. There are currently 72 voting members. The aims of the organization are to promote safe treatment, treatment quality and access to health care across the national health service.

A significant role for the CHF is to provide patient advocacy and provide a voice for health service users referred to as “consumers”. This is because many believe the term “patient” to be passive, and the term consumer encourages a more active approach – one with power to influence health care – on behalf of the patient. This is reflected in the CHF's core mission to undertake consumer-based research, develop a strong consumer knowledge base, raise patient understanding of their condition through improved health literacy as consumers, and improve the quality of health care by working with health professionals and decision-makers in health policy and programme decision-making.

Systematic representation

Patient engagement with the infrastructure of hospital decision-making has developed from a piecemeal approach with membership on hospital boards driven by local relationships with hospital administrators and clinicians, to a systematic representation where, as of 2014, patient representation is a feature of decision-making at almost every tier of the health system. A consumer representation programme developed by the CHF encourages patients and hospitals to work together to increase the role that consumers have on their committees and boards, citing a range of evidence to show that patient engagement has a positive impact on individual health outcomes, service accessibility and effective governance (2).

Patient engagement in hospitals is an embedded part of Australian health care culture, with a series of National Safety and Quality Health Standards placing emphasis on health services partnering with consumers (especially standard 2) (3). Despite this, local and national challenges still place some pressure on the way that patient engagement operates in practice and in cases of individual health decision-making. Amongst the challenges that the CHF acknowledge as important to patient engagement,

include system inertia where professional and patient interests clash on care issues, and continued time pressures on front line hospital staff. However, patient engagement benefits from a number of features in the Australian context that together help to enable the health care system to promote change and overcome these types of challenge.

First, the systematic presence of the patient voice across the health service as a whole, combined with the acknowledgement that patients are first and foremost consumers, builds engagement into the fabric of hospital-related care. This is evident in the introduction of national standards and performance metrics measuring the quality of patient involvement. The adage “if you want something to happen, measure it” is operationalized through the national standards as one way of overcoming difficulties in challenging provider attitudes in a system where individual practitioners are not accountable for hospital outcomes. It is through Australia’s national discourse surrounding the patient as consumer that the focus on patient engagement in hospitals has been able to shift from simple representation to its impact on specific health outcomes – in particular on how treatment results affect hospital performance.

Patient engagement with Australia’s hospitals as consumers has produced a number of positive impacts in the way that patient “voice” is represented across national and local tiers in the health care system. Systemic representation of patients as partners in national health care decision-making is reflected in the measurement framework surrounding effective care – so that hospitals are listening because they are increasingly accountable for doing so. The place of the patient voice in treatment, for example, has been the result of a gradual recognition that a consumer model is good for treatment outcomes and that this is a positive good in itself, rather than in simply a reaction to specific cases where hospitals have been responsible for malpractice, a lack of transparency or poor patient accountability. As a result, the overall trend in patient engagement in hospitals has been to promote this through a requirement to measure patient involvement, not just talk about it in public discourse with federal decision-makers.

With engagement now a central feature of the patient–professional relationship, patient representation is systematic throughout health care, precisely because outcome measures build strong patient advocacy into the system at the (local) level where patients are most likely to see this happening in practice. Nationally, it has been the Australian State and Federal Governments which are patient-responsive, in part because the level of patient engagement has a direct and measurable effect on hospitals’ bottom line (in terms of both performance and spend), but also in relation to overall accountability in a system that has encouraged the development of a political and social movement that recognizes patients as consumers.

Indirectly, a national impact of patient engagement is reflected in the high level of patient accountability that public health bodies such as the Pharmaceutical Benefits Advisory Committee (PBAC) offers in its decision-making processes (4). Patient involvement on PBAC committees, where the decision to release drugs following trial onto the health care market is made, brings the overlapping concerns that different groups have together into a single process where a general patient view can be fully represented. So although issues such as treatment cost in relation to specific patient groups

and treatment are still a consideration in approving a treatment, patients, and hospital clinicians, are provided with an accountability function in an area where transparency is an overriding patient concern. Here then, decision-makers will include the views of “patients” as a consumer group, outside of any other representation they might have as a lobby for the release of a particular drug with cost effectiveness implications for the health system, without compromising patients interests as a whole.

Local impact, through the involvement of patients as consumers in hospitals, has been promoted by the CHF in a number of novel and effective ways. Building on the model of patients as consumers, some hospitals have been encouraged to promote participation through the introduction of feedback boards where patients can post a comment, question or request. The hospital then agrees with staff that they have to take this feedback into account as part of their overall daily duties. Feedback via the CHF has been that ward staff see this as useful because it helps them take into account patient and carer views in a way that can be managed alongside their other caring duties. Local initiatives such as this offer a strong example of how hospital practice on engagement can “fit” with the national model of patients as consumers, and is a result of efforts by state governments to devolve responsibility for health policy and delivery – through the development of LHNs – to more accountable local health districts. Supported by the activities of patient bodies such as the CHF, and local media, hospitals have been encouraged to recognize the business case for strong patient engagement as a way of ensuring positive health outcomes locally.

The Australian model recognizes real advantages to having patient-consumers involved in decision-making processes at every tier of the health service – not least because mobilizing patient voices helps federal decision-makers counter vested interests in a health system undergoing significant structural reform and shifting accountabilities. By focusing on patient outcomes and accountability, the drive to a patient-centred health care approach is an initiative not bounded by particular interests in hospitals or within the wider health service. In the case of patient engagement in hospitals the biggest change is gradually moving towards hospital provision shifting from a focus on outputs (such as the number of beds) to measures of treatment and health outcomes. Patient engagement in hospitals has ultimately focused health deliverers on the value of the financial investment spent nationally and locally on health care, and via the development of accountable and transparent decision-making frameworks, on the role of hospitals in delivering improved health outcomes across their communities. □

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2. <https://www.chf.org.au/about-consumer-representation.php>
3. <http://www.safetyandquality.gov.au/wp-content/uploads/2011/09/NSQHS-Standards-Sept-2012.pdf>
4. <http://www.pbs.gov.au/info/industry/listing/participants/pbac>

Hong Kong – The Hong Kong Alliance of Patients’ Organizations: Working constructively to increase hospital openness and accountability

ARTICLE AUTHORED BY IAPO STAFF, FROM CONVERSATIONS WITH MEMBER REPRESENTATIVES

ABSTRACT: The Hong Kong Alliance of Patients’ Organizations (HKAPO) comprises 44 affiliated patient groups who advocate across the region, improving patient experiences and increasing advocacy and awareness. Initially established to increase accountability to patients and representation in a changing health system, the Alliance has worked to expand patient input on local and territorial decision-making by partnering with individual hospitals and increasing links with the Hospital Authority Board. Patients are now represented on most committees affecting patient care and the delivery of health services, and more widely in health care policy decision-making. The Alliance advocates for patients as active and constructive consumers rather than passive recipients of services and lobbies for better representation and involvement in treatment decisions. It has also increased media exposure which has helped to grow representation so that patients are now present on all 11 Authority Committees and are asked for their views. The patient ambassadors programme offers training for patients to be representatives at ward level and within the local hospital committee; and by building constructive relationships over time with hospital partners, HKAPO affiliate organizations have been able to start making improvements in the training of professionals in hospitals and informing staff about patient engagement, advocating for new clinical interventions and a more patient-centred approach.

The Hong Kong Alliance of Patients’ Organizations (HKAPO) has been working with the Hospital Authority in Hong Kong to improve health care for patients in hospitals. The Alliance is a federation of 44 affiliated patient groups. The core mission of the organization is to advocate for patient-centred health care across the Hong Kong Special Administrative Region, including the New Territories and Kowloon and to represent the needs of 40,000 patients. The Alliance works on behalf of local patient groups to improve the patient experience in a number of ways, including direct advocacy to health services decision-makers, building the patient voice and raising awareness. The organization was founded in 1993 with a remit to maintain patient rights, advocate for improved patient care and support the development of patients’ organizations.

The organization works across seven hospital clusters managed by Hong Kong’s Hospital Authority, the public body responsible for managing all public hospitals since 1993. Hospital-based health services in Hong Kong are governed through the Hospital Authority board, consisting of 27 appointed members, who work through a committee system which oversees particular areas of hospital care such as finance, tendering and medical services development. Final oversight for Hong Kong’s hospitals sits with 13 committee members and the board Chairman. The executive committee members meet every two months, with all members meeting at similar two month intervals. The Alliance holds its own meeting with all 44 patient groups on a bi-monthly basis.

Background

Calls for a patient-centred approach to hospital care in Hong Kong gained pace following a re-organization of the health care system

in Hong Kong in the early 1990s. In 1992, the Hong Kong Government transferred direct responsibility for hospitals from the Department of Health to a new statutory body, the Hospital Authority. Patient organizations felt that this increased the need for patient representation to address accountability in a system where oversight was devolved away from the Minister for Health to a committee system of health and other appointees. In 1993, patient organizations came together to address the lack of representation with the Hospital Authority through the development of a strong grassroots patient movement organized through HKAPO.

The Alliance has worked to provide a patient perspective on local and territorial decision-making bodies by following a deliberate and systematic strategy of partnering with individual hospitals across the territory, and building working links with the Hospital Authority board. Building on the few links with decision-makers it had in 1993, the Alliance has, by 2014, achieved patient representation on almost all relevant committees affecting patient care and the delivery of health services. The grassroots approach to the development of a robust patient voice has meant that, over the past 20 years, successive Hong Kong governments have increasingly seen patient advocacy and involvement in health care decision-making as a part of the health policy development process itself.

Patients, driven by the shift in attitudes to health care which sees them as consumers rather than passive recipients of a public service, have demanded more representation in treatment decisions, and have organized more effectively into lobbying bodies to gain a voice. This momentum gained pace as patient advocacy was featured more in the media. As a result, the Hospital Authority focused more on bringing patient representatives on to its committees.

The role of HKAPO with hospitals

The role for the Alliance in promoting patient engagement with hospital decision-makers is one of patient advocacy, providing patients with a role in decision-making in the territory and promoting patient rights. The Alliance plays a successful role in ensuring that patients' views are represented in decision-making bodies through its presence on standing and ad hoc committees and by exerting external pressure through the media. Patient engagement has developed to a point where representatives of the Alliance and patient organizations are regularly co-opted on to ad hoc and standing groups to provide a user perspective for health care professionals. Patient representatives currently sit on each of the 11 Hospital Authority committees and are increasingly represented in the territorial committees representing the three administrative divisions of the territory. This improved representation has resulted in better care for patients.

In the past, hospitals at New Territories East Cluster used to call patients waiting for consultation by showing a sequence number on a screen. Visually impaired patients never knew when they were called. HKAPO reflected on this point at a meeting with management of the Cluster. After that, hospitals changed this practice and now pay special attention to visually impaired patients. The change is really appreciated by patients.

The Alliance's role as a patient advocate has evolved as the organization has increased its representation across the hospital architecture. Significantly, as patients achieve greater representation, the Alliance is able to identify and confront new challenges as treatments improve, work with hospitals on new clinical interventions, and see patients become more aware of their status as active health service consumers.

An additional focus on workforce development through direct engagement with hospital staff has seen the Alliance improve the training of medical professionals. HKAPO has been involved in developing policies for hospital staff and has had seats on regional HR committees. It has also been involved in regular speaking events with hospital staff themselves on patient empowerment issues.

The Alliance now focuses as much on the promotion of effective treatment and health outcomes as its original purpose of securing greater patient representation. One example of this is the patient ambassadors programme, where the Hospital Authority has increased patient representation and HKAPO has worked to equip these ambassadors with training.

Patient ambassadors

The patient ambassador scheme is a mechanism through which the patient voice is represented to health professionals at the point they engage with health care delivery – in the ward. These ambassadors sit on hospital committees and give patient opinions.

HKAPO has been providing training for patient ambassadors. This includes three month courses on topics such as good leadership, chairing meetings and other skills which are required to serve as a patient ambassador. Patient ambassadors are gradually being trained to work in more areas with the Hospital Authority. They learn about the many dimensions of hospital care, how they can effectively represent patients at meetings and ensure that hospitals continue to embrace patient opinion.

The combination of improved representation, direct advocacy and the adoption of a critical but constructive approach to the

delivery of health care through Hong Kong's hospital system has undoubtedly given patients a voice with decision-makers. The reach of the Alliance in a devolved hospital system has grown from minimal involvement up to 2004 (with only two Alliance members represented in the clusters committee system), to its current status as a recognized hospital partner. This has enabled the Alliance to further develop its patient representative support programme by providing patient ambassadors with advice, information and other guidance in relation to standards of care. This is one way in which the Alliance has sought to ensure that direct patient advocacy remains a feature of the health care system at the point at which patients engage with their clinical treatment.

A culture shift among hospital staff

The Alliance sees their ability to support patient engagement at the local hospital level as a particularly important function of their work. An open and transparent health care system has resulted in more responsive medical staff. A focus on changing the attitudes of health care professionals through workforce development, training and direct engagement in staff forums, is a further way the Alliance has attempted to create a cultural shift in favour of patients. In addition to the strategy of simply being a part of the committee structure and having a physical presence in the decision-making process, the Alliance has worked with hospitals to influence the attitudes of individual medical staff.

In the case of at least two hospitals in the Kowloon cluster, patients are encouraged to provide feedback on their care. Patients are encouraged to record their thoughts on a card and place it in feedback boxes available at the entrance hall. This has allowed patients to honestly report back on their care, including positive responses for the doctors and nurses treating them. Anecdotal evidence from the Alliance suggests that initiatives such as this are having a direct, and positive, impact on the quality of the patient–doctor relationship in hospitals. Doctors have improved attitudes to their patients; there is greater appreciation of doctors by their patients and a feeling that treatment is not simply something that happens to patients in the hospital setting.

Conclusion

The Alliance offers an example of how a patient organization can adopt a flexible approach to the development of patient-centred health care in the context of organizational, political and clinical pressures that hospitals and their staff come under on a daily basis. Clinical errors are recognized as an inherent risk. However, by working closely over the past 20 years with the hospital authorities in Hong Kong, the organization has ensured that where these do occur, hospitals are more accountable for the decisions they take and a culture of openness operates across the hospital system. The Alliance recognizes that front line hospital staff sometimes have limited time with the patient and that in light of these pressures they can view their work positively as an advance on former practices. Although there is still, according to one member of the Alliance, “some way to go”, the organization and patient-centred health care in hospitals is progressing in the right direction. □

The South African Depression and Anxiety Group and government hospital partners: Addressing the challenge of poor adherence in psychiatry



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ABSTRACT: The Helen Joseph Hospital, a government regional hospital in Johannesburg, South Africa, became aware of patient non-adherence issues at their specialist psychiatric outpatient department. In partnership with the South African Depression and Anxiety Group (SADAG), Africa's largest support network and advocacy group for people affected by mental health problems, and sponsored by Janssen Pharmaceuticals, they aimed to address the issue of non-adherence by developing and implementing a Reminder and Support Adherence Programme (RSAP). By providing a comprehensive service that regularly reminds patients to take their medication, attend their clinic appointments, offers free health information and psychosocial support, this has allowed many patients to benefit from the programme's ability to address the range of problems related to non-adherence.

This programme was set up to address the difficulty many patients face as their condition, perceptions and treatment changes over time. Diagnosis can cause significant life disruptions and the patient journey can include struggling to cope with this, feeling unwell, fearful or angry and being tasked with taking on new responsibilities for their condition. Later on, some patients return to a more stable condition and their motivations may become more based on convenience and the confidence that "I feel better, I don't need medication". As patients settle into this "new normal", such attitudes may lead to lapses in adherence, often taking the patient back to a state where symptoms re-occur.

The Reminder and Support Adherence Programme (RSAP) focused on "adherence", which incorporates the broader concept of partnership between patients and medical professionals. The World Health Organization (WHO) defines adherence as "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds with the recommendations from a health care professional". Non-adherence is thus seen as forgetting to take one's medication; incomplete or incorrect dosage taken; medication taken at the wrong time; stopping medication altogether; non-participation in recommended health programmes; breaking of appointments or not renewing prescriptions.

Adherence is a very important issue in psychiatric care for two key reasons:

First, adherence is a primary determinant of treatment effectiveness and the outcome of psychiatric care. It is associated with a decreased likelihood of achieving a reduction in symptoms and recovery, poor prognosis, as well as increased risk of relapse, hospitalization and suicide attempts.

Secondly, non-adherence imposes a considerable financial burden on patients and health care systems. The monetary costs incurred by non-adherent patients are significantly higher, when

compared to adherent patients, due to increased treatment costs and health care resource consumption.

According to the WHO's *World Health Report 2003*, more people would benefit from efforts to improve medication adherence than from the development of new treatments. Doctors, nurses, pharmacists and other health care professionals can help prevent many serious health complications by initiating conversations with their patients about the importance of taking medication as directed. This is especially important for people with chronic health conditions such as mental health issues, who may have a number of medications to take each day.

Background

The Helen Joseph Hospital (HJH), in Auckland Park Johannesburg, is a public regional referral hospital providing a tertiary level of care. As far as routine patient care is concerned, it has been documented before that a significant number of users who are routinely being readmitted were not adhering to their prescribed treatment.

At the HJH outpatient department, some specific systemic and logistical challenges tend to exist, for example, with regard to the availability of a designated professional nurse and of adequate administrative services to ensure the optimal booking and follow-up arrangements for psychiatric outpatients. It also became necessary to explore the extent to which patients at the HJH psychiatric outpatient clinic have an inadequate understanding of their maintenance care. In this context, it was proposed to collaborate with a prominent local advocacy group, the South African Depression and Anxiety Group (SADAG), to implement a communication intervention programme on a pilot basis and to assess its usefulness in improving adherence in this local public sector setting. SADAG is a non-profit, non-governmental organization established 18 years ago to provide a mental health

TABLE 1: COMMUNICATION ACTIVITIES DURING IMPLEMENTATION OF THE RSAP

	Average received per participant	Total received by all participants
Medication reminders	39.6	3,484
Motivational SMS	14.1	1,238
Support group notifications	2.1	182
Press notifications	2.4	208
Appointment reminders	3	265
Script reminders	3	265
Brochure/information reminders	3	182

of active outpatients in June 2012, 91 patients (15% of n=607) were recruited to participate in the three month implementation of the RSAP. Of the 91 participating users who initially completed the pre-intervention questionnaire, 88 completed the full three month RSAP. Regarding the three who were withdrawn, one participant was referred to a different outpatient facility closer to her residence, while another went abroad for nearly half of the programme. A third participant did not have a cell phone for the duration of the programme and was therefore not included, as she was unable to receive the reminder messages.

care support network to users across South Africa. SADAG works closely with different groups of people with mental health-related problems on an ongoing basis, and became increasingly aware of the problem of non-adherence with medication and follow-up visits to care providers.

In response, SADAG, in partnership with the Department of Psychiatry at HJH and with Janssen Pharmaceuticals as joint sponsors, developed the RSAP, which was previously implemented in certain private practice settings. The RSAP consists of weekly phone calls; free telephone counseling; reminder SMS messages; brochures and information; SMS reminders for workshops, support groups and press notifications; an online website with information; monthly newsletters and free support groups in different regions.

Description

The total active psychiatric outpatients in June 2012, prior to the implementation of the RSAP, was 607 people. From the total group

During the RSAP, a total of 642 personal phone calls were made to participants, according to the specified structured alert schedule, with each participant receiving an average of 7.3 calls during a 13 week (91 day) period. (See Table 1 for a breakdown).

In addition to this, patients also received various SMS notifications. The SMS reminder initiative was used as a way to regularly remind participants to take their medication by receiving a text message in the morning, at night or both. All the reminders and notifications included the SADAG toll-free helpline number. Monthly electronic newsletters were also made available to patients. Motivational SMS messages were sent to motivate, reassure and to encourage participants during their treatment journey. There were simple messages sent intermittently twice a week addressing common myths regarding adherence to medication.

Participants were able to attend the monthly or bi-weekly meetings for free, and were provided with information such as dates, time and venue. Support groups were also open to family members and supporters. Participants received relevant press and

FIGURE 1: AVERAGE WEIGHTED ATTENDANCE RATIOS (AWAR) FOR VISITS BOOKED FOR HJH PSYCHIATRIC OUTPATIENTS DURING JAN–JUN 2012 COMPARED WITH JUL–DEC 2012 (N=70)

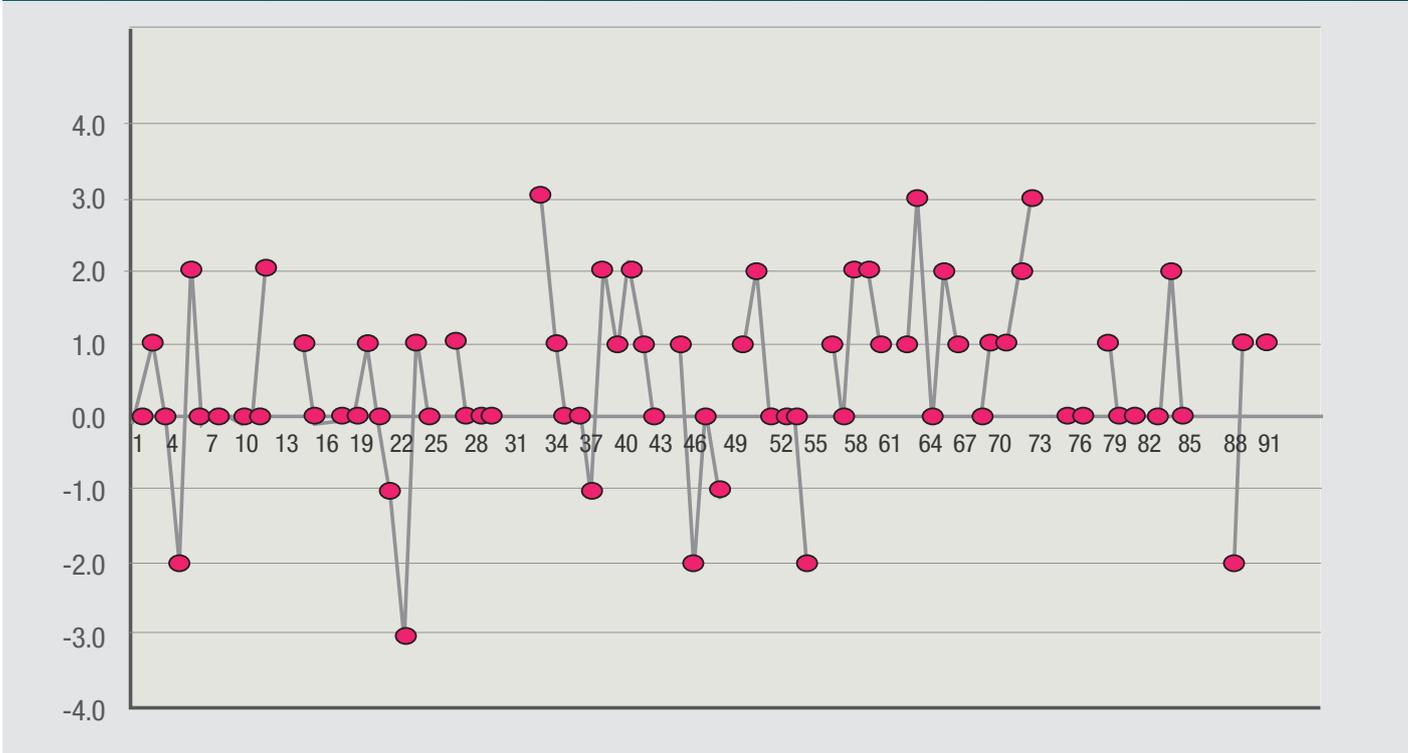


FIGURE 2: COMPARING MEDICATION ADHERENCE OF HJH PSYCHIATRIC OUTPATIENTS BEFORE AND AFTER COMPLETION OF THE SADAG RSAP

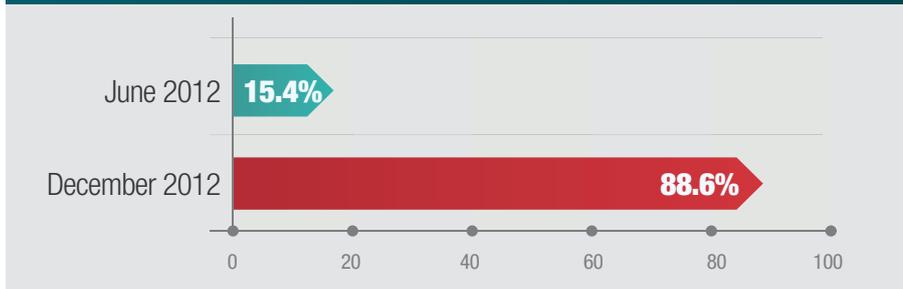
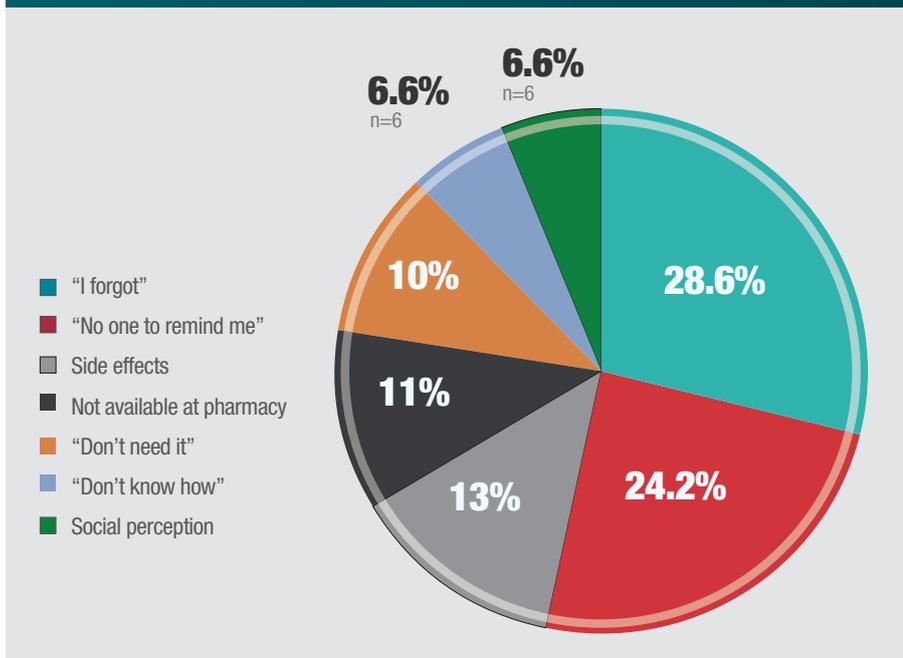


FIGURE 3: REASONS FOR MEDICATION NON-ADHERENCE OF HJH PSYCHIATRIC OUTPATIENTS IN SADAG RSAP, JUL–DEC 2012 (N=77)



per patient in June 2012, meaning that 63% of scheduled visits were attended during this period. The AWAR for participating patients after completion of the three month pilot period was 2.3 visits per patient, meaning that 77% of the booked visits were attended during the study period (July to December 2012).

Before RSAP, participants were asked the question: "Are you able to take your medication as suggested by your doctor?" Seventeen of the 91 participants indicated that they were not able to do so. A further 60 people indicated that they were adherent but still gave reasons for non-adherence to medication in the follow-up question. (See responses in Figure 3). Those citing reasons for non-compliance may, to varying degrees, have not adhered to their medication as prescribed. Therefore the initial adherence rate with taking medication before the RSAP could have been as low as 15.4%. After the RSAP, 78 people indicated that they took their medications as prescribed by their doctor (Figure 2), which means the adherence rate increased to 88.6%. None of the patients indicated that they had stopped taking their medication completely.

Discussion and recommendations

Recovery is best described as an ongoing journey rather than a finite goal. At the same time, many patients have reported that a mental illness and the negative predictions about their future make them feel hopeless. Adherence to treatment, to advice or to lifestyle changes is essential in the treatment outcome

media notifications such as newspaper articles as well as TV or radio shows on various mental health conditions. These were made available as they were released to the public and frequency varied throughout the intervention.

Text messages were sent to participants to remind them of their monthly clinic appointments. Other participants' appointments were confirmed over the telephone. SMS reminders were sent monthly to participants to remind them to collect their medication from the hospital pharmacy. To keep patients and their families informed, information brochures and additional educational and self-help material were made available to participants, too.

Results

The typical participant in the RSAP was female (76%), either black (34%) or white (35%), older than 40 years (58.2%), unemployed (74.2%), not in a relationship with a partner (67.6%) and most spoke English at home.

These outpatient users had between one and six (on average three) follow-up visits booked for them during this six month period. By considering how many of the booked appointments were kept, a weighted attendance ratio for each patient was calculated, as well as an average weighted attendance ratio (AWAR) for the total group. The AWAR for the study group attending the clinic during the preceding six months was 1.8 visits

of psychiatric care. The relationship between communication and the outcomes of user satisfaction, recall and compliance has also been associated with positive correlations.

During its implementation at this public referral hospital clinic, compared with patients not participating in the programme, participants seem to have demonstrated a significantly improved attendance rate, as well as improved medication adherence. Considering the limitations of this pilot investigation, the implementation of the SADAG RSAP in similar state sector clinics to improve attendance, can be strongly supported.

Cognizant of the study's noted limitations (non-randomized sampling method, lack of available retrospective demographical and clinical data, and self-reporting measurement of medication adherence), the implementation of the SADAG RSAP, or a similar communication intervention strategy, should be considered as a standard operational procedure in all existing state sector specialist psychiatric outpatient clinics such as at the HJH OPD. Long waiting times, unavailability of medication at the pharmacy, along with logistical and financial difficulties of patients was further compounded by limited access to additional support services that participants had access to.

Where patients do not have an email address or access to the internet, hardcopies of the monthly newsletter as press releases could be made available by post. Patients who do not own a cell

phone can also be included in the programme, by forwarding the SMS reminders and phone calls to a willing parent, guardian or care-giver.

It is important to note that some patients are only able or available to talk after business hours. This should be kept in consideration when implementing future programmes.

Extending the intervention from three months to six months is also recommended for improved results.

In summary, this study at the HJH psychiatric outpatient clinic focused on the impact of communication on adherence to clinical attendance and to the use of medication. In this regard, implementing the SADAG RSAP as a specific communication intervention at HJH, as a pilot public sector clinical site, did indeed result in significantly improved attendance ratios of booked clinic visits for participants, as compared with the six month period prior to the intervention and with non-participants. □

Lian Taljaard is currently a research psychology student completing a Master's Degree at the University of South Africa (UNISA). He has knowledge and experience in the design, implementation, development and evaluation of studies using both quantitative and qualitative methodologies. His areas of interest include neuropsychology, developmental psychology, behavioural sciences, cognitive psychology, psychopathology and philosophies of science. He has experience in monitoring and evaluation and a familiarity in working with public, private and civil society organizations conducting work in school, community and clinical settings. He has worked on studies relating to patient adherence, mood and anxiety disorders, suicidal behaviours and screening, substance abuse and traumatic brain injury in both young people and adults.

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United States – The Leukemia & Lymphoma Society: Working with patients, carers and hospital professionals to improve awareness, treatment and patient choice

ARTICLE AUTHORED BY IAPO STAFF, FROM CONVERSATIONS WITH MEMBER REPRESENTATIVES

ABSTRACT: By working locally with patients and carers from diagnosis and treatment through to aftercare, helping professionals to improve their knowledge and awareness about blood cancers and best practice treatment, while also advocating at the national level, the Leukemia & Lymphoma Society (LLS) is working to strengthen coordination between patients, carers and professionals along the whole care pathway. By helping patients to become more engaged and empowered to make informed choices, improve treatment for blood cancers through education, LLS is working to enhance patient-centred care in a largely privatized and fragmented health services system in the United States. By providing web-based resources and a free national helpline, alongside a face to face local support network, LLS is helping patients to learn more about their condition, treatment choices and the care pathways they can access. Free professional development and education seminars are also offered to nurses, oncologists and social workers in hospitals, highlighting new approaches to treatment and care with a patient-centred approach.

The Leukemia & Lymphoma Society (LLS) works with patients and hospitals to raise awareness about blood cancers for patients and medical professionals, to improve patient choices and consequently to improve treatment.

LLS is a United States-based not-for-profit organization that exists to find cures and ensure access to treatments for blood cancer patients. There are currently more than 1.2 million people in the United States living with a blood cancer. LLS works with patients and their caregivers to support their treatment journey, from diagnosis to aftercare. The organization advocates on behalf of people living with over 160 different types of blood cancer, provides information about subtypes of the cancers and, through a national network of chapters, directs local support to people living with a blood cancer.

Patient engagement with hospitals in the United States takes place in a health services market driven predominantly by privatized health provision, with hospitals operating outside of direct state or federal control. At all points along a patient's journey from initial diagnosis to treatment, the patient is (through private medical insurance provision) an indirect purchaser of health services, with the practitioners they encounter having further commercial relationships with insurers, hospitals and other treatment centres.

LLS has been working with hospitals to address problems many blood cancer patients face. The rarity of blood cancers, in relation to other types of cancer, presents a number of challenges for patients obtaining the right diagnosis. As with many low incidence conditions, some physicians can lack awareness about the condition which can delay initial diagnosis, affect hospital referral

and prevent timely entry into the health care system. Other barriers that patients need to address along their treatment journey can result from factors such as a patient's level of knowledge about their condition, and the ability or willingness of hospitals to involve the patient in making treatment decisions.

For individual patients, the range of blood cancers and subtypes can make it difficult to take control of their treatment pathway. To address this, patient engagement in the context of blood cancers focuses on informing patients about blood cancers as a means of giving them control over the treatment choice and pathways they access. Through the LLS website and through its patient engagement strategy, patients are encouraged to understand their cancer subtype, its particular symptoms, prognosis and the treatment pathways involved. LLS focuses on patients' understanding of their particular subtype because the treatment, and prognosis, is different for each condition.

The primary service through which LLS promotes patient engagement and empowerment in the doctor-patient relationship is the chapter network. LLS chapters are local groups set up to support people living with a blood cancer through programmes and events designed to promote awareness and understanding of the impact of their condition. A focus on the education of patients and professionals about blood cancers supports the development of a patient-centred care approach in hospitals by providing accessible information about diagnosis, treatment and aftercare. Through free seminars, oncologists, nurses and social workers are made aware of developing approaches to treatment and care, with local chapters such as the California Southland Chapter building an information archive to support the continuing

professional education of staff engaging with people living with a blood cancer (1).

At the national level, LLS' Information Resource Center is a free-call centre staffed by master's degree level health care professionals who can give patients and their caregivers information about their diagnosis and treatment options, help them identify clinical trials and direct them to other resources.

Local advocacy is further developed through local patient access committees. Based in local chapter organizations, these function as forums to bring professionals (across the treatment journey from diagnosis to aftercare) and patients together to develop local responses to the needs of people living with a blood cancer. Through these forums, information gets shared across the hospital system within the chapter area, and enables each chapter to act as a local strategic lead in ensuring blood cancer patients can access coordinated cancer care provision at hospital. In chapter meetings the patient access committee is able to discuss the needs of blood cancer patients with health and clinical professionals. One example is the young adults movement. Young people after being diagnosed with a blood cancer wanted to meet with other young people in a similar position. A support group was formed, and this now provides the chance to share, learn more about blood cancers and help young people understand their conditions. Young people are now better placed to take control of their treatment. The support group also hosts events such as one day conferences on issues such as nutrition and post-chemotherapy support.

LLS highlights a number of positive impacts of its work on the quality of engagement of people with a blood cancer and the professionals treating them in hospitals. For patients, the role of LLS as a provider of patient education – through the chapter network, as well as through materials developed for dissemination via the LLS website – has an empowering effect by ensuring that they are aware of the types of question they should ask during initial diagnosis and referral, and the prognosis that their particular subtype of blood cancer has.

For professionals, areas of positive impact include the development of a more informed hospital workforce, from nurses, to specialists such as oncologists and haematologists. Local successes in supporting an informed hospital workforce include examples such as the Methodist Hospital in San Antonio, Texas, where a nurse education programme on blood cancer has enabled a collaborative patient–professional relationship to emerge based on an improved understanding by nurses, doctors and patients of the condition and treatment best-practice.

In this case, the local chapter was instrumental in achieving this by hosting a series of hospital staff meetings between doctor and nurses on issues such as “How I Treat Lymphoma”. The local chapter became an agent of change in the treatment of patients based on a strong working relationship between the hospital's nurse educator and the LLS regional lead, developing organically as the local chapter showed the benefits to treatment practice of an engagement between patient groups and hospital staff.

Successes such as this are important in the context of a health care system where the commercial incentives to give patients a voice (as a constituent element of patient-centred care) are undermined by a lack of choice about the acute care setting blood cancer patients might initially access treatment from. The lack of choice patients with a blood cancer have in the hospital they

receive acute care can, for instance, be determined more by the nearest hospital available in an emergency admission, rather than where their physician might have privileges. Here then, the most important function of the chapter system is to ensure that all hospital staff in a local region are made aware of best practice, that this is shared across hospitals and that the mechanisms to do so are well-developed and maintained.

LLS is able to extend the voice of patients across the hospital system in the United States, improving patient–doctor engagement in treatment as well as aftercare. As survival rates improve – LLS is a major investor in clinical research in addition to patient support having invested more than US\$ 1 billion in research over the past 65 years – blood cancer is becoming an increasingly chronic condition treatable in the community. To ensure that people living with a blood cancer continue to get the support they need to engage with health care professionals in community settings, LLS has developed a partnership with the Association of Community Cancer Centres to improve the patient experience in the transition from hospital-based, to community-focused care. The work of LLS shows how the experiences of patient engagement with hospital staff in the United States is made more positive where the mechanisms exist to enable patients to develop a coordinated process of engagement in hospitals. The ability to develop an identifiable patient voice and take this to professionals working in a health care system characterized by an absence of overall state ownership is an important one. Individual hospitals each have their individual culture, ethos and specialties affecting the ability of patients and patient advocates to influence the stages along their treatment journey. The coordinating function of the chapter network is central in this context as a way of bringing patients, carers and health professionals together to discuss the challenges for patients of engaging with hospital-based treatment. □

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The UNICANCER Patient Expectations Observatory: A new role for patients in health care institutions



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ABSTRACT: Recognizing the role played by patients in their own management, UNICANCER set up in November 2011 a unique initiative in France: the Patient Expectations Observatory. This was designed to reorient and improve the quality of care provided by comprehensive cancer centres in the UNICANCER group based on a better knowledge and understanding of patient perceptions and preferences. An innovative internet-based consultation process enabled us to record and prioritize patient expectations. Patient management improvement actions for cancer centres were then used to equitably satisfy the identified patient expectations. By using patients' own expectations of their health care, cancer centres can therefore provide an example of the new modalities of patient participation in health care institutions, in line with the changes proposed by public authorities.

Introduction: A demanding environment

With 350,000 new cases per year, cancer remains a key concern of health professionals, public authorities and patients. The improvement of diagnostic conditions, the increased effectiveness of treatments with better controlled side effects have increased the number of cancer patients receiving treatment. Also cancer affects an increasingly large number of sick people and their relatives. In parallel, public authorities must now allow increased participation by patients in their own care and in the functioning of health care institutions in a broader sense. Indeed, whether in the third cancer plan 2014–2019 or in the national health strategy promoted by the Ministry of Health there is the institutional will to strengthen the role of patients in health facilities to achieve this evolution towards a health democracy that allows citizens to express their views on health issues and be involved in decision-making.

Since their creation in 1945, the French Comprehensive Cancer Centres (FCCCs) have held a special place in the French health care system. Exclusively dedicated to fighting cancer, these establishments have a triple mission: care, research and teaching. Drawing their model and their values based notably on conventional fees without liberal activity rates and therefore without extra fees, FCCCs provide innovative and differentiated support to cancer patients through intensive care as well as patient support. All over France, the 18 FCCCs treat 100,000 patients a year.

Recognizing the role of patients in their care, UNICANCER, a grouping of all FCCCs, implemented a unique initiative for France in November 2011: the Patient Expectations Observatory which is designed to reorient and improve the quality of care provided by comprehensive cancer centres in the UNICANCER group based on a better knowledge and understanding of patient perceptions and preferences. The Observatory goes beyond improvement actions derived from satisfaction surveys conducted during hospital stays or outpatient care, but also considers the

expectations of patients in the delivery of care by the institution itself.

The project has been conducted in two phases, guided by FCCCs' principles.

An innovative compendium of patient views

In the culture of innovation specific to UNICANCER and to benefit from the collective intelligence of individuals when they discuss issues among themselves, the Patient Expectations Observatory used a methodology of participatory consultation online. Assuming that every person with cancer – or those likely to be reached on one day – has personal expectations with regard to their care, the Observatory has achieved in 2012, with the help of an opinion institute and studies, an important qualitative study in the form of a participatory consultation on the "hospital treatment of cancer and patient expectations". Specifically, it was to discover the perception of patients on hospital cancer treatment and to identify, analyze and prioritize the expectations throughout all aspects of care. Exchanges took place over a period of three weeks and involved 264 participants divided into two communities: a community of 139 patients from FCCCs and a community of 125 participants from a public panel. The two audiences were interviewed as separate communities, in order not to bias the opinions, experiences and expectations of the groups and to ultimately put them in perspective. Nevertheless, the viewpoints of each community have been tested with the contributions, expectations and most representative ideas of the other community. In three weeks, more than 1,000 messages were exchanged.

This participatory consultation has generated strong involvement, particularly from patients with first-hand and rich evidence, to provide information on a rational as well as an emotional register. The approach has aroused a great interest from the public who have felt it to be positive, constructive and finally integrating the reality of patient experiences.

For everyone, the care of cancer covers a broad field of connotations and can be seen holistically: treating a pathology by offering access to the most effective and innovative treatments while accompanying the patient. Furthermore, it must be spread over the whole duration of the treatment and up to the return of the patient to an independent life.

Beyond varying experiences, all the participants agreed on a statement of overall improvement in the management of cancer with better treatment for pain, including greater emphasis on psychological distress and improved relationships with nurses: empathy, availability and warmth...

However, some dissatisfaction persists. This concerns the following:

- ✦ **The diagnosis and coordination of internal care:** Feelings of receiving fragmented care and inadequate consideration towards relatives.
- ✦ **The dignity of the person and his personal life:** The patient is seen as a process, rather than the subject of one.
- ✦ **Transparency and information transmission:** There is difficulty in obtaining unambiguous information on the process of care and especially on side effects.
- ✦ **Life outside hospital during treatment:** The return home appears as a painful breakup because of the contrast between the hospital "cocoon" and the "empty" back home. Management of daily life is difficult for patients who may be unaware of their rights and existing support.
- ✦ **The exit of the acute phase of treatment and remission:** The rebuilding of self-image (including social and professional reconstruction) is a step where support seems insufficient and key contacts outside hospitals hard to identify.

Achievements in response to patient expectations

From these results, a real dynamic has been set in place since 2012 in the FCCCs to identify all the specific solutions that will meet patient expectations. A "Centres Initiatives Day" showcased 17 ongoing actions confirming the quality and diversity of centre initiatives in this area. Among these, four priority actions have been identified based on pooling the findings. Indeed, the central condition for the areas of improvement is equal access whether it be financial or geographical.

These concrete actions are part of the major themes structuring expectations:

- ✦ **Human dignity:** An initiative from the Henri Becquerel Centre in Rouen, the Institut Cancérologique de l'Ouest, Angers and Nantes, and the Cancer Institute of Montpellier allows sharing tools to facilitate treatment of the patient in a setting that is more personal. This gives the opportunity for patients to express their individuality by introducing variability and subjectivity into standardized organizations.
- ✦ **Human dignity:** The patient should arrive in the operating room standing. This initiative was implemented in innovative ways at the Institut Paoli Calmettes in Marseille and the Centre Léon Bérard in Lyon and promotes autonomy and patient involvement in their own safety. It also optimizes the patient's arrival by removing stretchers and reducing waiting times before interventions. Personalized assistance for patients and a more respectful treatment of the person induces a more dignified relationship between patients and health professionals. It is actually being implemented in more than

five FCCCs.

- ✦ **Announcements and consideration of relatives:** Discussion groups for the children of patients and relatives introduced by the cancer centre in Lorraine, Nancy, following the initial experience of the Institut Gustave Roussy in Villejuif, are now widely established. An assessment made by the authors with professionals and beneficiaries gives it an exemplary value. It is from these experiences that other centres create or adapt their own welcome and accompanying relatives' actions.
- ✦ **Coordination of care:** An important project carried out at the Oscar Lambret Centre is designed to reduce the feeling of abandonment experienced by patients after their hospital discharge by anticipating and organizing needs as explained by the patient. The analysis of the personal, social and physical condition of the patient can help the return home. In addition, the organization reduces the risk of re-hospitalization, further disruptive factors at the centre, additional costs and unnecessary anxiety. Again, a collective work of sharing practices will allow other volunteers centres to adopt the solutions used in Lille.

Data that can be used to improve provision of care

The large collection of data goes beyond knowledge that UNICANCER and its FCCCs had a *priori* of the observations and critical analyzes of users, whether in the fields of their experience of care, guidance or assistance, or even the perception of clinical research. With this approach, evidence was also provided that patients, far from being limited to relevant critical analysis of the situation can be a source of proposals to improve organizations. Their contribution was rewarding, their involvement extensive and constructive. The number and quality of contributions and messages posted reflects the interest of patients in expressing their views. The patients surveyed have adhered to the logic of this approach of co-construction with rich and calm exchanges and carefully considered answers.

The reality perceived by patients does not always fit with that of health professionals. This highly participatory type of approach, opens the perceived reality which can be different from the immediate reality; in fact, all that is implemented by professionals or institutions may not be perceptible by patients. Patients were also very likely to spontaneously express their interest and satisfaction in contributing to the thinking of professionals, without waiting for an immediate personal benefit. Finally, there have been many patients who indicated that these experiences were formative in their journeys as a patient or relative, and they strongly encouraged this type of floor space allowing everyone to act as a full participant in the health system and to contribute to its development and improvement.

This initiative illustrates that talking directly to patients provides access to otherwise unavailable information. Such an approach contributes to the recognition of experiential knowledge. Thus allowing the shaping of the narrative of the patient experience, it produces a specific expertise, taking into account complementary points of view, including those of health professionals. This "profane" expertise encourages professionals, managers and policy-makers to question their usual, dominant, logical actions and to accept some form of power sharing in the analysis of the facts and therefore in proposals for action.

Beyond these results from an innovative participatory

consultation, which aims to be repeated, the views of patients and their families are also collected in FCCCs in other ways. A recent survey on the role of patients and users in the operation of the centres identified some trends. Since the Act of 4 March 2002, users sit on the boards of health facilities. They also sit on the Committee on Relations with the Users and Quality of Support. This participation is not sufficient enough to ensure an effective involvement of patients and users. Instead several new initiatives will allow better recognition of what they have to say: identified, responsible relationships dedicated to this mission within a centre; users participation in working groups set up for the development of school plans and as for the improvement of organizational practices, the provision of training for users to effectively perform their role as representatives of their peers.

Thus, FCCCs and UNICANCER breathe life into the principle of democracy beyond mere compliance with the rules on user representation in governance bodies.

This approach is in line with government policy to identify new ways of involving patients in health care facilities. To meet the new challenges of oncology and public health, it is no longer possible to have patients and citizens on one side and health professionals on the other; they must work together. This gives credibility to the improvement actions while strengthening the legitimacy of the decisions taken. For the first time this fundamental element which is the consideration of the patients' views in the evolution of our health system is used by health care institutions to guide their provision of care. □

Acknowledgements

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2014 World's first Expand breathing lung transplant; 800th Heart Transplant; UMN Cancer researchers discover a single gene that allows cancer to develop. **2013** 8,000th kidney transplant; First breathing lung transplant in the Midwest. **2012** First clinical test of stem cells expanded by new cell-culturing system; Researchers develop the drug Minnelide, a promising new treatment for pancreatic cancer. **2011** 700th lung transplant; Use of natural killer cells derived from cord blood to treat patients with acute myelogenous leukemia. **2010** 700th heart transplant performed at University of Minnesota; Faculty members attack diabetes with research on stem cells and pig islet cells that aims to create an abundant supply of cells for transplantation; Neuroscientists, psychiatrists and human development experts use high-tech imaging and molecular-level insights to seek novel ways to reduce the toll of neurodegenerative diseases, prevent and cure mental health disorders, and prevent Alzheimer's disease. **2009** Researchers identify a naturally occurring compound that can prevent the transmission of HIV in primates; Discovery of new genes linked to colorectal and liver cancers; Studies show that using two units of transplanted umbilical cord blood (rather than one) significantly reduces the risk of blood cancer recurring; Research finds childhood cancers significantly increase risk for heart disease in adulthood; Meta-analysis is resolved in 78 percent bariatric surgery; Studies be a major cause of brain **2008** Implantation of the assist device (which helps to the body) in a child in of the first beating heart in organ recellularization and blood vessels in an first bone marrow and treat recessive dystrophic a condition causing damage to the skin. **2006** that has been shown to Discovery of ability to mice with Alzheimer's- 6,000th kidney transplant of Minnesota. **2002** First transplant of mesenchymal stem cell (made from living human tissue)/cord blood in a child with acute myeloid leukemia. **2001** Discovery of a gene that causes the most common form of adult muscular dystrophy. **2000** Midwest's first successful living donor double-lung transplant performed; World's first blood and marrow transplant using genetic testing on an embryo to find a suitable cord blood donor, World's first laparoscopic distal pancreatectomy; World's first successful double umbilical cord blood transplant. **1999** Nation's first nondirected living donor kidney transplant. **1997** World's first kidney-bowel transplant. **1996** Development of the first genetically engineered mouse model showing Alzheimer's disease symptoms. **1990** Minnesota's first cochlear implant surgery for a child. **1988** Vaccine for Lyme disease developed and patented. **1977** Pioneered the islet-auto transplant. **1975** First implantable diabetes drug pump developed, freeing patients from daily injections. **1974** First islet cell transplant to treat diabetes. **1968** First successful human bone marrow transplant in the world performed. **1966-67** World's first successful organ transplants in pancreas, intestines and simultaneous kidney/pancreas. **1958** World's first artificial heart valve implant performed. **1955** First successful heart-lung machine developed to keep patients alive during heart surgery. **1954** First successful open-heart surgery using hypothermia and cross-circulation. **1952** World's first successful open-heart surgery.



finds that type 2 diabetes of patients who undergo show cerebral malaria may injury in African children. first Berlin left ventricular the heart pump blood Minnesota. **2007** Creation a laboratory using whole (rebuilding heart muscle animal model); World's cord blood transplant to epidermolysis bullosa, serious blistering and Discovery of molecule cause memory loss. **2005** reverse memory loss in like symptoms. **2004** performed at University

Patients as partners for improving safety



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ABSTRACT: Safety is a crucial aspect in any medical treatment. The awareness that patients can play an essential role in the prevention of errors and adverse events has increased over the last decade, connected to the movement for patient empowerment. Patients are no longer “objects” and “victims” of a treatment, but are alert observers and partners and become an active “last barrier” for the prevention of errors. This new role is challenging: for the patient as it requires action in a vulnerable period of dependence and the courage to intervene at the right moment; and for the caregivers who are facing a patient who is critical and dares to speak-up.

The following numbers highlight that patient’s safety is indeed a major concern. It is known from a variety of international studies that on average in 2–8% of hospitalizations preventable adverse events occur and out of these, 30–50% lead to permanent disability. As a consequence, two thirds of all patients need additional care and on average six extra hospitalization days. A considerable proportion of adverse events are related to medication errors. Preventable adverse events can be systematically found in all Western countries.

Concerned patients

A survey by the European Commission of all partner countries in 2013 showed that 12% of patients estimate that it is likely that they will become victims of an error during a stay in a hospital. This number has even increased from the last survey conducted in 2009.

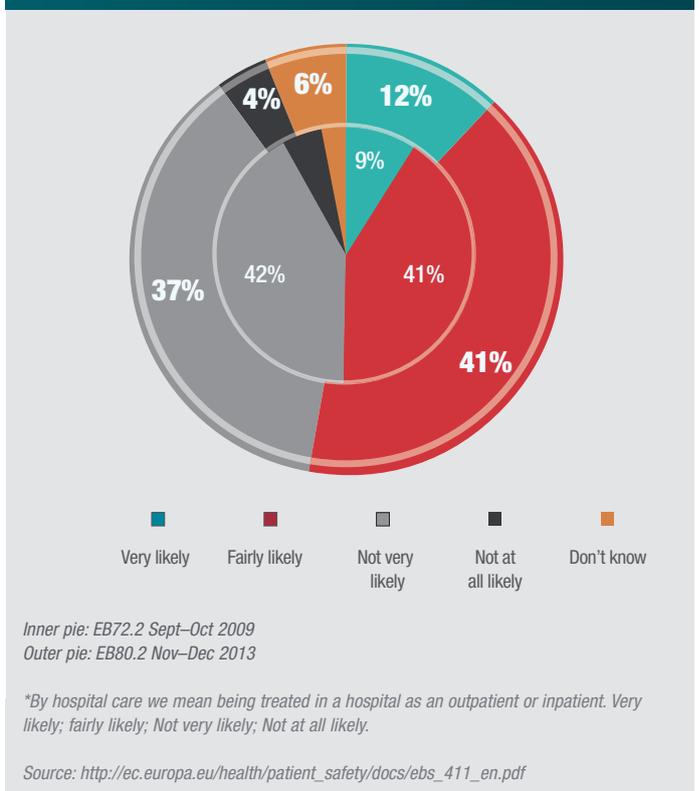
In addition, a significant proportion of patients believe they have experienced a medical error. This is highlighted in other multinational studies. An international survey performed in 11 countries including Switzerland also shows that a rather high percentage of the population had experienced a medical error. The difference between individual countries, however, is remarkable.

This result is also reflected, even to a lesser extent in a Swiss study. Patient Safety Switzerland conducted a survey in eight Swiss hospitals asking 4,000 patients about their safety concerns: 3.2 % expressed a strong and 14.7% a moderate concern. The results showed in addition a clear correlation between concerns and length of stay in a hospital, which increased drastically after having experienced an error. Also, 21% of patients reported at least one patient safety issue during their stay (for example, being confused with other patients or experiencing a drug error).

Patients as observers

A majority of patients are convinced they can contribute actively in preventing adverse events. Patients are usually the only people who are always present during the course of a treatment and care. They are therefore a precious resource for safety measures, a resource that is still often unused. This is especially true for patients who undergo intensive medical treatment due to complex or chronic diseases who learn during the course of their

FIGURE 1: THE RESULT OF QUESTION QC6A FROM THE EUROBAROMETER 2013: HOW LIKELY DO YOU THINK IT IS THAT PATIENTS COULD BE HARMED BY HOSPITAL CARE* IN (OUR COUNTRY)?



treatment many relevant safety aspects and become experts in their own right. For example, a patient undergoing chemotherapy is able to describe with a high degree of precision the course of his treatment. He easily recognizes deviations or discrepancies from usual practice. A patient can, for example, recognize whether an oral medication has been forgotten or whether the infusion rate is wrong. Many such situations would be important indicators for active risk management, especially as it could be demonstrated that incidences reported by patients are not often captured (for example, CIRS).

It was also demonstrated by recent investigations (1) that

observations made by patients about adverse events could be verified in more than 70% of cases by medical experts. A very good tool which does not require much resources is the “safety walk”: patients are confronted with simple questions (for example, “Did something happen today which made you feel insecure?”, “What could we do better tomorrow?”) allowing the gathering of valuable information which would not have been given otherwise by the patient.

Patients as active partners

In order to strengthen the engagement and involvement of patients, the foundation Patient Safety Switzerland has developed a booklet *Help prevent errors! Your safety in hospital*, which serves as an educational patient safety guide. The content was developed in an iterative procedure, including a systematic review of the evidence, expert consultation and focus groups, and covers the most important aspects of patient involvement through vigilance, communication and cooperation. The booklet can be read in about 15 minutes and has been translated into 11 languages, including the four official Swiss languages and is licensed out to health care institutions. Before the official release, a scientific study looked at patients’ and health care workers’ (HCWs) perceptions of such a guide. The results showed that 95% of patients and almost 80% of the HCWs agreed that health care institutions should actively educate patients about safety issues.

Some frequently recommended measures for patients are:

- ✚ Give and ask for information about medication.
- ✚ Ask for the action point of surgical intervention.

TABLE 1: RECOMMENDED ACTIONS THAT ARE ACCEPTABLE, BUT ARE NOT ADOPTED IN PRACTICE

Recommended action	Acceptance	Adoption
To ask staff to wash their hands	48%	16%
To ask staff the purpose of a medication	87%	72%
To inform staff about medications that are usually taken	89%	75%
To notify staff about an error	80%	28%
To ask for a copy of the discharge report	70%	44%

Modified from Schwappach et al. International Journal for Quality in Health Care 2011. Vol. 23, Nr. 6, pp 713 – 720

- ✚ Always speak-up in cases of uncertainty.
- ✚ Control of medication, infusions and transfusions.
- ✚ Immediate response to confusion of names and patients.

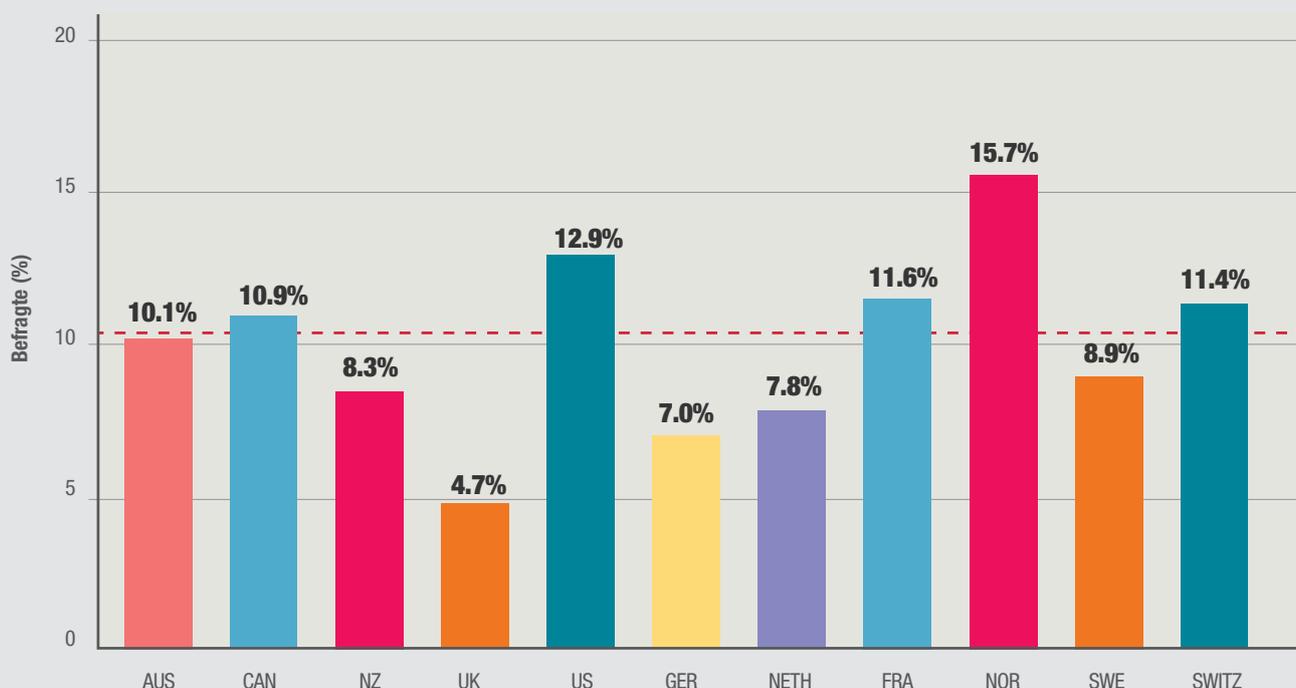
Theory and practice

In order to empower patients to become active partners for the common goal of “patient safety”, it is highly important that they know what kind of observations are important and how they should react to errors or deviations.

The simple transfer of information is, however, not enough. Even when patients register deviations or errors, they often do not report them to HCWs. An analysis of cases with wrong side interventional anaesthesia showed that in about 50% of cases, the patients realized that the wrong side was treated, but they did not communicate this (2).

Many recommended actions are acceptable, but are not

FIGURE 2: RESULTS FROM THE COMMONWEALTH FUND’S 2010 INTERNATIONAL SURVEY OF THE GENERAL PUBLIC’S VIEWS OF THEIR HEALTH CARE SYSTEM’S PERFORMANCE IN ELEVEN COUNTRIES*



*The graph shows the percentage of representative national population samples, adjusted for age, gender, education and region, who reported a medical error or a medication error. The red line indicates the average over all eleven participating countries. Schwappach, David: Risk factors for patient-reported medical errors in eleven countries. Health Expectations 2014;17(3):321-31

adopted in practice.

There are many explanations for the gap between acceptance and adoption. Patients often are not aware of the root cause relation between adverse events and negative personal consequences. Also, they often seek alternative explanations and assume that there is a rational explanation for their observations. Finally, they want to avoid everything which could be interpreted as questioning or challenging the professional skills of HCWs. Especially measures which scrutinize the authority of medical doctors are unaccustomed for patients and therefore difficult to adopt.

These findings demonstrate that the empowerment and involvement of patients needs to be actively fostered and supported. Some practical tips are given at the end of this article.

The key role of health care professionals

In general, HCWs have a positive attitude towards patients as active partners for improving safety. In order to gain more insights, Patient Safety Switzerland performed a study using vignettes to determine relevant predictors of health care professional's (HCPs) attitudes towards patient involvement in safety-relevant behaviours. This approach involved experimentally manipulating the effect of different factors affecting HCPs' attitudes. As a result, approval of patients' safety-related interventions was in general high. It was largely affected by patients' behaviour and the correct identification of errors. HCPs appear to be more supportive of patients asking to check their medication than asking the question about hand hygiene. On the other hand, patients are less willing to intervene when their behaviour could be perceived as confrontational (3).

TABLE 2: ACCEPTANCE LEVELS BY HCPS

Broad acceptance	- Asking questions, e.g. about medication - Giving information
Moderate acceptance	- Being active in security checks (e.g. control of transfusion bags) - Alluding to a potential mistake
Low acceptance	- Pointing out lack of hand hygiene - Demand for marking the site for surgery

Simple rules and regulations can empower the role of patients as active partners in patient safety.

+ Rules in communication Patients often identify safety issues, while adjusting expectations and observations. A patient who has been instructed in detail about an upcoming X-ray, will more often express a concern when the X-ray is not taken than a patient who does not even know what kind of treatment they will undergo. Simple and easy to remember verbal formulations are the most effective. For example, "You will take two blue pills every morning".

+ Let the patient speak A stay in a hospital often releases a feeling of passiveness and anxiety. This explains to some extent why patients do not react even when they are addressed by the wrong name. It is therefore important that the patient speaks, particularly when checking the patient's identity. For example, "Please tell me your first name, last name and date of birth"; and NOT "Are you Betty Miller, born on 2 October 1941?"

+ Instruct and motivate patients It is essential to repeatedly encourage patients to be critical and to explain that their feedback is welcomed and important. HCPs should be aware that they should allow the patient to ask questions and participate in the treatment as an active partner.

Nurses, especially, have excellent experience in entering into a "contract" with the patient including standardized phrases. For example, "It is very important that the procedure follows exactly the plan you have received. We are only human, mistakes can always happen. Please be alert and report immediately if you have a feeling or think that something is going wrong".

Patient's involvement is not necessarily costly. If defined and implemented with conviction and purpose, it can contribute significantly to improving safety culture and avoiding medical errors and adverse events. □

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The role of patients: Perspectives from a large, not-for-profit, tertiary care teaching hospital in the developing world



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ABSTRACT: Recent literature and studies show the significant role that patients and families can play during their transition through different points along the continuum of care. To date, our observation is that in our environment, patients and families input and engagement in the health care process has remained passive, with most of the decisions related to patient care being reserved for health care providers. Health care in many parts of the developing world still faces a similar challenge. This paper presents the initiatives of a large, not-for-profit, tertiary care teaching hospital in Karachi, Pakistan, on planning and implementing some best evidence-based practices in re-shaping the role of patients and families with the goal of enhancing the quality of their care. It also points out the effect of local cultures in making the role of the patient and family in their care as beneficial as it can be to improve clinical outcomes and their quality of life. Additionally, factors such as literacy, education, socioeconomic class and the attitude of health care providers in underdeveloped countries requires a significant change for the effective involvement of patients in their own care.

Background

With 180 million residents reported in 2013, Pakistan is the sixth most populated country in the world. The statistics for 2013 reveals life expectancy at birth of 65 years. Mortality of the under-fives was 86 per 1,000 live births and maternal mortality per 100,000 live births is 170 (1). About 20% of the population live below the international poverty line of US\$ 1.25 a day. Noncommunicable diseases account for 59% of the total disease burden in Pakistan with cardiovascular disease representing the largest share followed by chronic respiratory diseases, cancer and diabetes (2). Additionally, the health care system in Pakistan is facing numerous challenges including structural fragmentation, gender insensitivity, resource scarcity, inefficiency, illiteracy, lack of access, significant disease burden and inequity of utilization. The patient-centred approach in Pakistani health care facilities is generally non-existent. Doctors are predominantly considered to be authoritative figures with a high standing in society and whose opinions are not open to question. The role of patients in medical decision-making cannot be isolated since the social setup is significantly more complex with strong family ties and structures. It is the family and mostly the male or the earning members rather than the patient, who take centre stage in this process of seeking agreement about treatment options. These challenges, in contrast to western countries, have a more significant impact on decision-making where the role of the patient's family becomes more critical.

Building the framework

The Aga Khan University Hospital (AKUH), Karachi, was established as the not-for-profit teaching hospital of Aga Khan University in 1985. Based on its vision of being a premier teaching hospital in the country and the region, the hospital, from the outset, has put significant value on customer focus and satisfaction as one of its key quality requirements. With four key principles of quality, access, relevance and impact embedded in the AKUH vision, the hospital embarked on quality as a fundamental framework to build on. This framework included the adoption of a series of different models and standards to define the role of patients and families in the care delivery process. This was done in a manner that was deemed relevant to the context in which we operate and one which used the best practice at that time.

Assessing the patient's interest

In the past two decades, a lot of scientific discussion and recommendations have been made to involve patients in clinical decision-making as it was expected to improve clinical outcomes. In *Crossing the Quality Chasm*, the Institute of Medicine recognized that some patients may not want to be active participants. At the same time, the report also encouraged physicians to engage patients in clinical decision-making (3). A population-based study demonstrated that people vary substantially in their preferences for participation in decision-making. Physicians and health care

organizations should not always assume that patients wish to participate in clinical decision-making, but must assess individual patient preferences and tailor care accordingly (4). Thinking along these lines, AKUH adapted key relevant customized solutions to the local context. We started by defining the role of patients and families with reference to their involvement in the clinical decision-making and care processes through the following five key steps:

Best practice 1: Informed consent process

The first step that AKUH took in this direction was the implementation of the informed consent process. Informed consent is the process by which the treating health care provider discloses appropriate information to a competent patient so that the patient may make a voluntary choice to accept or refuse treatment (5). The process was initiated by the development of guiding policies, procedures and structured consent forms followed by mass education and training of front line health care providers. Challenges were faced initially in executing the process in its real spirit of educating the patients and their families. There were times when the process was not more than a paper signing exercise. With the passage of time the process became more robust when AKUH started its preparation for Joint Commission International accreditation (which was attained in 2006) and a standard of performance that placed special emphasis on the real spirit of the process. With a strong human subject research component in the university hospital, conforming to international accreditation standards on clinical research led the university hospital into introducing a robust informed consent process in the area of research.

Best practice 2: Patient and family education

The second step was to introduce the international best practice concepts of patient and family education into the local context of low literacy rates, multiple local languages and a family-centred culture. Even in a highly literate context like the United States, findings indicated the need for nurses to be aware of the prevalence of low literacy levels, how to accurately assess reading ability and develop material that is at the appropriate level for patients and caregivers (6). In order to be effective with patients whose literacy skills are low, patient education materials should be short and simple, contain culturally sensitive graphics and encourage the desired behaviour. Compliance with therapy also may be improved by including family members in the patient education process (7). In our local context, we started this with the development of simple patient education materials in local languages covering the most frequently seen medical problems. Gradually, with the advance towards international accreditation hospital standards, the university hospital started learning new methodologies on education needs assessment based on literacy rates, readiness and willingness to learn and preferred methods of learning by patients and families. Presently, patient and family education is an integral part of the university hospital's patient care process.

Best practice 3: Implementation of international hospital accreditation standards

The third best practice step in establishing a patient's role and responsibilities during the care process came from the implementation of international hospital accreditation standards. The standards on patient and family rights emphasized the need

for developing and effectively communicating a "patient bill of rights" to all our patients. The patient bill of rights document was developed by a multifunctional team of health care professionals and was posted on the walls of all patient care areas. In addition, all inpatients are provided a copy of this document at the time of admission. This document explains patient and their families' roles and responsibilities in getting involved in the care process through highlighting their roles in understanding their medical condition, treatment options, the process of education, the process involving medical decision-making, seeking second opinions and lodging complaints.

Best practice 4: Establishing a culture of safety

Hospitals are increasingly recognizing the crucial role of patients' perspectives in establishing a culture of safety. Many institutions have engaged patient representatives in the design and nurturing of safety efforts, and emphasize transparency in reporting errors and care problems. Our fourth step of defining the role of patients in preventing medical errors was driven by our pursuit of international hospital accreditation standards. The development and testing of a patient fact sheet entitled *Five Steps to Safer Health Care* illustrated important research considerations associated with the process of crafting messages to help patients reduce health care system errors and improve the safety of their care (8). While conforming to international hospital accreditation standards, the university hospital established processes to involve patients in the right patient identification, safety of high alert medications, prevention and control of infections, surgical site marking, prevention of falls and environmental safety and security.

Best practice 5: Define "patient-centred care" as an institutional imperative

We accepted the proposition that providing care centred on patients' needs and expectations is a key attribute of quality care. Unfortunately, our research showed that despite the intent and efforts of many to improve patient centredness, the quality of patient-clinician relationships, patient access and continuity of care seemed to be worsening in the United States and lagged behind other Organization for Economic Co-operation and Development (OECD) countries. Clinicians do not consistently address patients' concerns, do not always assess patients' beliefs and understanding of their illness and often do not share management options with patients. Patients frequently fail to recall basic elements of their care plan. All this is occurring as care becomes increasingly complex and as more costs of care are borne directly by patients (9). In order to fulfil the step of defining patient roles in a patient-centred model, the AKUH established a patient centred task force with the mandate of identifying and implementing best international patient-centred practices. So far the task force has been able to work successfully on improving patients throughputs in the Emergency Department and improving the service excellence standards of hospital staff. Improving the quality of patient-client relationships still remains a work in progress with gradual and progressive improvements being made.

Lessons learned

Implementation of relevant internationally recognized effective practices to promote patients role in health care process enabled AKUH to learn the following key lessons over the period of past two

and half decades.

- ✦ Be informed of global best practice and implement adapted and relevant examples while customizing it to the local context.
- ✦ Cultural change is mandatory for effective implementation of any of the strategies for promoting patients' and families' roles in the areas of access, care, continuity, quality and safety.
- ✦ The informed consent process starts as a paper signing exercise but with the passage of time it becomes a real information exchange exercise that empowers patients and families to take informed choices and decisions.
- ✦ The patient and family education process needs the active involvement of health care providers in assessing the learning needs of patients and the use of appropriate educational media.
- ✦ The patient bill of rights is not the name of a document to be read by patients, but a code of conduct for health care providers in helping patients to be involved in their own care planning, decisions and information needs.
- ✦ It is not possible to create a comprehensive culture of safety without involving patients and families in the organizational safety design, safety plans and safety initiatives.
- ✦ Focusing only on the provider side of patient-centred initiatives like improving service excellence and patient throughputs will not realize the full potential of patient-centred care. Patient focused dimensions such as quality of client-provider relationships, communications, involvement, education and empowerment are equally important and often neglected components of a successful patient-centred care programme.

Conclusion

Patients and families can play a significant role during their transition through different points along the continuum of care. Across the spectrum from health care access to core patient assessments and care processes, the role of patients can be shaped within local cultural and socioeconomic norms of developing countries. The steps taken by the Aga Khan University Hospital over the past 27 years demonstrate the benefit and value of involving patients to create positive health outcomes. □

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Dutch hospitals provide reliable “one click” patient information using a Quality Window



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ABSTRACT: In 2014, the Dutch Association of Hospitals (Nederlandse Vereniging van Ziekenhuizen, NVZ) launched the "Quality Window" at general hospitals across the Netherlands. The Quality Window is an online platform for patients which shares a hospital's current and previous scores on ten quality indicators, from patient experience to employee satisfaction. The Quality Window therefore responds to the growing demand for information and transparency when it comes to hospital care and performance.

Not only can patients access helpful information about a hospital's quality through the Quality Window, they can also compare results with other hospitals, the national average, and more. Many hospitals also take the opportunity to expand on how indicators work in practice and the actions being taken towards improvement.

The Quality Window was developed with the help of hospitals and patients. Over the coming years it will be expanded to university hospitals across the country. General hospitals will also begin developing Quality Windows for specific patient groups, such as cancer patients.

In 2013, the Dutch health care system was once again ranked number one in the European Health Consumer Index (EHCI). The newly launched Quality Window continues the country's work in maintaining reliable and quality health care.

Dutch hospitals are overwhelmed with requests for data and statistics on the quality of their care and treatments. Social media and the internet are the vehicles for this growing public demand. Although it is impossible to provide all of the information patients' request, Dutch general hospitals have taken a big step by launching the so-called "Quality Window" earlier this year. Developed partly by patients, the Quality Window intends to meet patient demands for information. All Dutch general hospitals already participate on a voluntary basis, and university hospitals promise to follow soon. So far, the new system appears to be a success.

In the Netherlands, hospitals provide data to authoritative bodies such as the Dutch Care Institute (a government-initiated programme), including data on the quality of care. However, it is difficult for patients and other groups to obtain, use and process this data. Patient groups want such information so they can

provide details to the public about care options. Health insurance companies need this data to assess whether a hospital meets safety standards and volume criteria – and if not, to open discussions with the hospital board. The Dutch Health Care Inspectorate, which is a government-run organization to supervise hospitals, would also benefit from such information. Last but not least, the Dutch media, which frequently focuses on health care issues, could use this hospital data to underpin its reporting.

Transparency

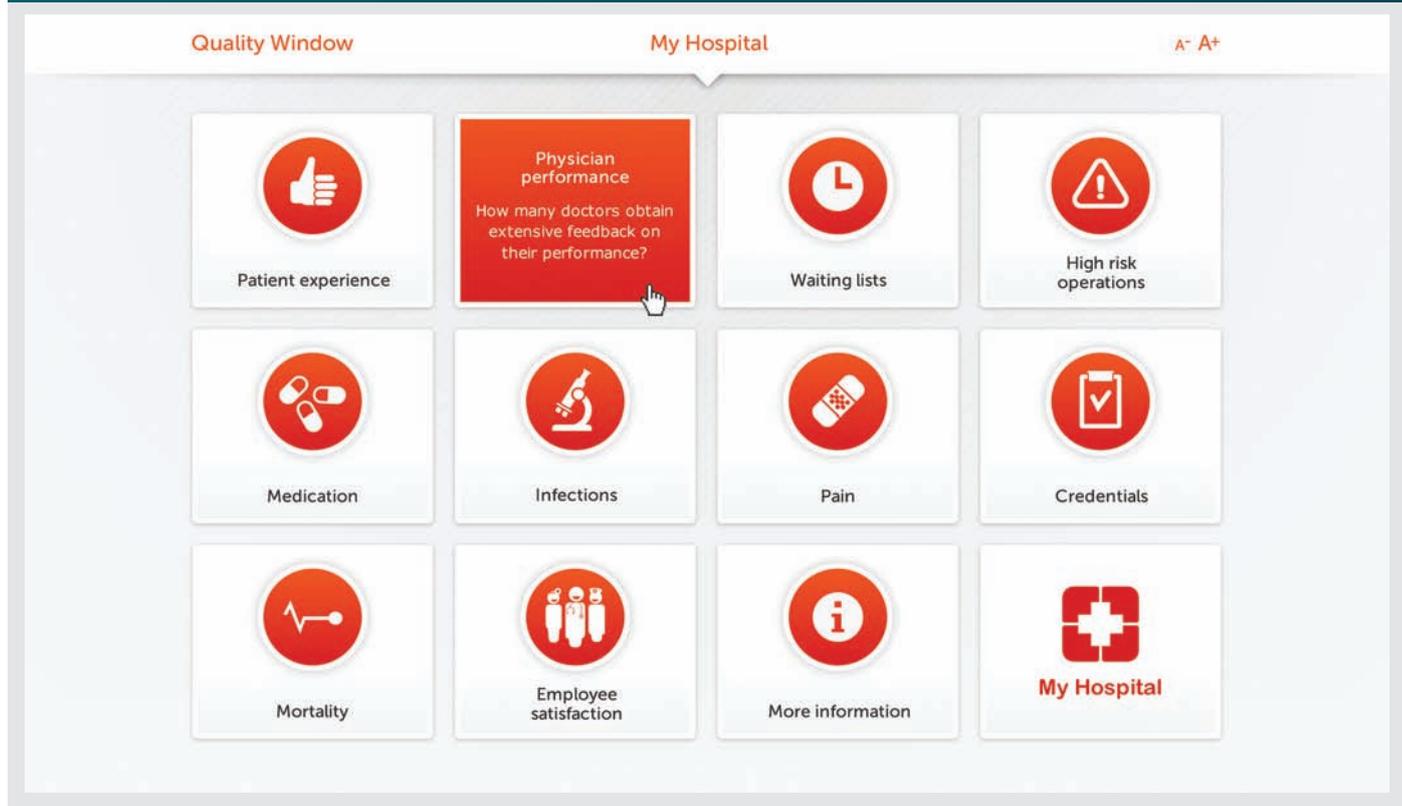
For some time now, both the public and the government have called for transparency in the quality of care. Hospitals, too, would like to gain more control. Therefore, general hospitals in the Netherlands have established transparency as a strategic theme for the coming years. The health care sector wants to be proactive in this transparency, publishing information itself instead of waiting for media rankings, which are often inaccurate and thus of little relevance to the average patient.

What is the Quality Window?

The Dutch Association of Hospitals (NVZ) was inspired by the development of a tool for Dutch school accountability, which provides information such as children's results, their rating of the school, their parents' opinions of the school, etc. The NVZ wanted to develop a similar "window" for patients that would give them an impression of a hospital's qualities. This led to the development of the Quality Window, an online platform for patients that reports on general aspects of the quality of care at hospitals around the country. The Quality Window provides hospital scores and data using 10 indicators, presented in a recognizable and easy-to-understand format on hospital homepages. Scores include patient experience ratings, the number of well-founded complaints made

Dutch hospitals are overwhelmed with requests for data and statistics on the quality of their care and treatments. Social media and the internet are the vehicles for this growing public demand

FIGURE 1: THE QUALITY WINDOW INDICATORS



against the hospital, and the frequency of verification of medication upon admission and discharge.

Using the Quality Window

In many cases, a hospital's results can be compared to the previous year's, the national average, or to measures like the mortality rate. In addition, the Quality Window provides general explanations of what the indicators mean and the extent to which an indicator mirrors a hospital's actual quality level. Many hospitals also take the opportunity to expand on how indicators work in practice and the actions they are taking towards improvement. In this way, the data is not only made accessible to patients, but also comprehensible and usable. Both hospitals and the NVZ view this as an important added value of the Quality Window. The goal now is to expand the tool beyond the current structural and process indicators into also providing scores on actual outcomes.

Important choices

Since the NVZ wanted to create a clear and comprehensible tool for patients, it had to make choices. The 10 indicators were chosen by hospital board members, quality consultants, experts and patients, in collaboration with the Dutch Federation of Patients and Consumer Organizations, the NPCF. The NVZ also set out conditions for the indicators. Firstly, that they are relevant to the patient. Secondly, that they have already existed for several years. And thirdly, that they are distinctive (for this reason, issues such as pressure ulcers were not included). One of the goals of the Quality Window, too, was that it did not increase the administrative burden on hospitals.

Public participation rounds

After the 10 indicators were chosen, they were further developed

and tested in a pilot scheme at six hospitals. The Quality Window was then designed, developed and updated through feedback meetings with boards, patients and the NVZ, and through various tests with several groups of patients and quality and communication consultants.

The 10 indicators

1. Patient experience

The first indicator in the Quality Window addresses the patient experience. How does a patient experience the hospital? This indicator is measured by a general rating in patient satisfaction. The number of legitimate complaints is also shown and a link to the hospital's complaints policy is provided. Results are compared with previous years. The patient experience indicator is also presented alongside data about the hospital's size.

2. Physician performance

The main question addressed by this indicator is: how many doctors obtain extensive feedback on their performance? This is an indicator from the Dutch Health Care Inspectorate. It concerns the percentage of extended feedback interviews once every two years with colleagues, and sometimes with patients, on the performance of the doctor according to the Individually Functioning Medical Specialists methodology – the so-called IFMS calls. This result is compared with the national average and with the previous year.

3. Waiting lists

This indicator is measured by the speed with which a patient can be treated at a hospital, in other words, by the length of a hospital's waiting lists. This indicator includes the average waiting times for outpatient and inpatient treatment in a single year.

The Quality Window was launched in May 2014 and received positive media attention around the country. But that was only the beginning

4. High risk operations

How often does a hospital perform risky operations and do these operations meet the volume requirements? This indicator is provided by the Dutch Health Care Inspectorate, the Ministry of Health and the Dutch Institute for Clinical Auditing (DICA). It presents data on the actual number of operations and the corresponding requirements for the number of operations performed (i.e. volume). The closer operation numbers are to the minimum recommended amount, as determined by professional associations of doctors, the more likely it is that operations are conducted according to current standards.

5. Medication

This indicator, from the hospital's safety management system, is measured as the percentage of patients whose medication use is checked upon admission and discharge. Results are compared to the previous year.

6. Infections

How often do infections occur after surgery? This is also an indicator from the safety management system. It includes the number of cases of central line-associated sepsis and the percentage of infections after knee and hip operations. The results are compared to the previous year.

7. Pain

How much pain do patients experience in this hospital? The Dutch Health Care Inspectorate provides the percentage of patients who indicated a pain score of 7 or below, on a scale of 1 to 10, at some point during the first 72 hours after surgery. The theme includes a link to the hospital's pain policy. Results are compared to the national average and to the previous year.

8. Credentials

This indicator addresses the general quality of the hospital and includes licenses, certifications, and accreditations awarded for example by patient organizations or health insurance companies. Patients can also find a link to the annual quality monitor reports of the Dutch Health Care Inspectorate.

9. Mortality

An indicator that often gains attention in the media is a hospital's mortality rate. The Dutch Ministry of Health has mandated that the Hospital Standardized Mortality Ratio (HSMR) be accessible to patients. Although this indicator is much in dispute because of its complex nature, it does point to potentially avoidable deaths. The

indicator is measured "as the ratio of the actual number of acute in-hospital deaths to the expected number of in-hospital deaths (based on the patient's characteristics upon admission)". This section of the Quality Window links to the SMRs of specific diagnoses.

10. Employee satisfaction

How do staff rate the hospital? This information is taken from employee satisfaction surveys. It is an indication for the motivation levels of staff, and as such aims to contribute to better care. Results are compared to previous surveys.

Conclusion

The Quality Window was launched in May 2014 and received positive media attention around the country. But that was only the beginning.

The Quality Window is under continuous development. The NVZ is monitoring the indicators and, if necessary, will replace them with new, more relevant ones. Hospitals themselves can update their Quality Window at any time and each year the NVZ will send a reminder to them to review and update their data.

There are also plans to develop diagnosis-specific Quality Windows. These windows will give patients insight into the quality of care particular to their condition or disease. The emphasis here will be more on treatment results by means of outcome indicators. Such indicators, however, will have to be introduced cautiously, but they will shed new light on hospitals and their performance. Ultimately, NVZ aims to use the Quality Window to bring Dutch hospital care to new levels, ensuring safer, more transparent and better medical results nationwide. □

Yvonne van Rooy is President of The Dutch Association of Hospitals. Before this appointment she has had an impressive political career. As Dutch Minister of Foreign Trade, Yvonne van Rooy led many trade missions. She was also a member of the Dutch Parliament and the European Parliament. After she left politics, she accepted positions as President of the Board of Tilburg University and after that President of the Board of Utrecht University. Yvonne van Rooy still has an extensive political network.

Résumés en Français

Forum de santé des consommateurs d'Australie: favoriser la participation active des consommateurs de services de santé dans tout le système de santé

Les patients sont reconnus comme étant des consommateurs actifs au sein du système de santé australien, qui est un système de santé universel financé au niveau national, avec des responsabilités au niveau national et des prestations au niveau locale. La participation des patients dans le milieu hospitalier est donc centrée sur la promotion de services axés sur le patient. Etant un organisme national représentant les opinions des patients d'Australie, le Consumers Health Forum (CHF) aide ses adhérents à promouvoir un engagement local et régional, qui reposait au départ sur les relations locales entre gestionnaires et cliniciens, alors qu'il s'appuie maintenant plus systématiquement sur la représentation des patients dans les conseils et comités, bien que l'engagement à l'échelon local puisse encore être problématique. Le Forum prône l'application de critères nationaux à différents contextes locaux, ce qui importe car réunir et évaluer les opinions des patients et y répondre, et leur permettre de participer aux prises de décision peut avoir un effet tangible sur les résultats finals et le financement des hôpitaux.

Alliance des organisations de patients de Hong Kong: un travail constructif pour améliorer l'ouverture et la responsabilisation des hôpitaux

L'Alliance des Organisations de patients comprend 44 groupes de patients adhérents intervenant sur toute la région, améliorant le vécu des patients et encourageant la promotion et la sensibilisation de ces objectifs. L'Alliance avait été créée à l'origine pour augmenter la responsabilité envers les patients et leur représentation au sein d'un système de santé changeant. L'Alliance a œuvré à développer la participation des patients aux prises de décision locales et territoriales en favorisant un partenariat avec certains hôpitaux et en resserrant les liens avec les conseils d'administration des hôpitaux. Les patients sont maintenant représentés dans la plupart des comités traitant des soins des patients et des prestations de santé, et plus largement impliqués dans les prises de décision en matière de politiques médicales. En militant pour que les patients soient considérés comme des consommateurs actifs et constructifs plutôt que des bénéficiaires passifs de services, en exerçant des pressions pour améliorer la participation et la représentation des patients quant aux choix thérapeutiques et grâce à une meilleure exposition aux médias, l'association a contribué à accroître la représentation à tel point qu'actuellement, les patients sont représentés aux 11 conseils d'administration et consultés sur leurs opinions. Le programme d'ambassadeurs de patients offre une formation permettant aux patients d'être représentés au niveau des services hospitaliers et dans les comités hospitaliers locaux; et en créant dans le temps des relations constructives avec des hôpitaux partenaires, les organismes affiliés à HKAPO ont pu commencer à perfectionner la formation professionnelle au sein

des hôpitaux et à informer le personnel sur la participation des patients en promouvant de nouvelles interventions cliniques et une démarche plus axée sur le patient.

L'ONG South African Depression & Anxiety Group et les hôpitaux publics partenaires : résoudre le problème de non-adhésion du patient au traitement en psychiatrie

Le Helen Joseph Hospital, hôpital public régional de Johannesburg en Afrique du Sud a observé des problèmes liés au non-respect des traitements par les patients dans son service spécialisé de consultation psychiatrique. En partenariat avec le South African Depression and Anxiety Group (SADAG), Groupe sud-africain contre l'anxiété et la dépression, qui est le réseau le plus important d'Afrique pour le soutien des personnes atteintes de troubles mentaux, et parrainé par Janssen Pharmaceuticals, il s'efforce de résoudre les problèmes de non respect des traitements par la création et la mise en œuvre d'un programme de rappel et de suivi du respect des traitements (Reminder & Support Adherence Programme, RSAP). Il fournit un service complet qui rappelle régulièrement aux patients de prendre leurs médicaments et de venir à leurs rendez-vous, et offre des informations gratuites de santé et un soutien psychosocial. De nombreux patients ont bénéficié des solutions apportées par ce programme aux divers problèmes de non-respect des traitements.

Leucémie et lymphome: collaborer avec les patients, les soignants et les professions hospitalières pour améliorer la prise de conscience, le traitement et les choix des patients

Travaillant localement avec les patients et soignants depuis le diagnostic et les traitements jusqu'au suivi post-cure, aidant les professionnels à améliorer leurs connaissances et leur prise de conscience des cancers du sang et des meilleurs pratiques en matière de traitements, en les préconisant aussi au niveau national, la Leukemia and Lymphoma Society (LLS) œuvre à renforcer la coordination entre les patients, les soignants et les professionnels sur tout le cheminement des soins. En aidant les patients à s'impliquer davantage et à faire des choix bien informés, et en améliorant le traitement des cancers du sang par l'éducation, la LLS s'efforce d'améliorer les soins axés sur le patient au sein d'un système de santé fortement privatisé et fragmenté aux Etats-Unis. En fournissant des ressources du Web et un service gratuit d'assistance téléphonique, ainsi qu'un réseau local de soutien en face à face, LLS aide les patients à en savoir davantage sur leur maladie, les options thérapeutiques et leurs accès aux soins. Des séminaires gratuits d'éducation et de formation professionnelles sont également proposés au personnel infirmier, aux oncologues et aux assistants sociaux dans les hôpitaux, mettant en lumière des approches novatrices en matière de traitements et de soins axés sur le patient.

Observatoire des attentes des patients UNICANCER: Une nouvelle place des usagers dans les établissements de santé

Reconnaissant le rôle des malades dans leur prise en charge, UNICANCER a mis en place en novembre 2011 une initiative unique en France : l'Observatoire des attentes des patients. Ce dernier vise, à travers une meilleure connaissance et compréhension du vécu et des souhaits des usagers, à orienter l'évolution de l'offre de soins de centres de lutte contre le cancer, en termes de prise en charge et d'amélioration de la qualité du service rendu. De façon innovante, une consultation participative sur internet a permis de recueillir et de hiérarchiser les attentes des patients. Dans un deuxième temps les actions d'amélioration de la prise en charge des malades au sein des centres sont généralisées pour répondre de façon équitable aux attentes identifiées des malades. Ainsi, les centres de lutte contre le cancer en utilisant l'expression des malades sur l'organisation des soins donnent-ils un exemple des modalités nouvelles de participation des usagers dans les établissements de santé, dans le sens de l'évolution souhaitée par les pouvoirs publics.

Partenariat avec les patients pour améliorer la sécurité

La sécurité est un aspect crucial de tout traitement médical. Cette dernière décennie a vu une meilleure prise de conscience du rôle essentiel que les patients peuvent jouer dans la prévention des erreurs et des effets adverses dans le cadre du mouvement d'autonomisation du patient. Les patients ne sont plus des "objets" ou des "victimes" d'un traitement, mais des partenaires et observateurs avertis qui deviennent le "dernier bastion" dans la prévention des erreurs. Ce nouveau rôle n'est pas sans difficultés : pour le patient, il exige des actions dans une période vulnérable de dépendance et le courage d'intervenir au bon moment; et pour les soignants qui sont confrontés à un patient dans une situation critique, qui ose s'exprimer.

Le rôle des patients – Les perspectives d'un grand CHU de soins tertiaires à but non lucratif dans un pays en développement

Des rapports et des études récentes montrent le rôle important que les patients et leurs familles peuvent jouer en passant par les différentes étapes du continuum de soins. Jusqu'ici, nous avons observé que dans notre milieu, la participation des patients et de leurs familles et leur engagement dans les processus médicaux

sont restés passifs, la plupart des décisions portant sur les soins des patients incombant aux prestataires de soins. Dans de nombreuses régions des pays en développement, le domaine des soins de santé a encore un défi similaire à relever. Cet article explique les initiatives d'un grand CHU de soins tertiaires à but non lucratif de Karachi, au Pakistan en matière de planification et de mise en œuvre de meilleures pratiques basées sur des preuves pour redéfinir le rôle des patients et de leurs familles dans le but d'améliorer la qualité de leurs soins. Il explique aussi l'effet de la culture locale qui rend aussi bénéfique que possible le rôle des patients et des familles dont ils ont la charge pour améliorer leurs résultats cliniques et leur qualité de vie. Par ailleurs, certains facteurs comme l'alphabétisation, l'éducation, la classe socio-économique et l'attitude des prestataires de santé dans les pays en développement nécessitent de profonds changements pour que les patients participent efficacement à leurs propres soins.

Les hôpitaux néerlandais fournissent "en un seul clic" une information sure aux patients à l'aide de la Fenêtre de Qualité

En 2014, l'Association néerlandaise des hôpitaux (Nederlandse Vereniging van Ziekenhuizen, NVZ) a lancé le programme Fenêtre de Qualité dans les hôpitaux généraux à travers les Pays-Bas. La Fenêtre de Qualité est une plate-forme en ligne pour les patients qui renseigne sur la classification actuelle et précédente d'un hôpital à propos de dix indicateurs de qualité, qui vont de l'expérience des patients à la satisfaction des employés. La Fenêtre de Qualité répond donc à la demande croissante d'information et de transparence lorsqu'il s'agit de soins hospitaliers et de performance.

Non seulement les patients peuvent accéder à des informations utiles sur la qualité d'un hôpital à travers la fenêtre de qualité, ils peuvent aussi comparer les résultats avec d'autres hôpitaux, avec la moyenne nationale et plus encore. De nombreux hôpitaux profitent de l'opportunité pour préciser comment les indicateurs se concrétisent dans la pratique et les actions entreprises pour les améliorer.

La fenêtre de qualité a été développée avec l'aide des hôpitaux et des patients. Dans les prochaines années elle sera étendue aux hôpitaux universitaires partout dans le pays. Les hôpitaux généraux commenceront également à développer des fenêtres de qualité pour des groupes de patients spécifiques, tels que les patients atteints de cancer.

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Resumen en Español

Foro de Salud de los consumidores de Australia: permitir a los consumidores de servicios de salud tener un papel activo en todo el sistema de salud

Los pacientes se reconocen como consumidores activos dentro del sistema de salud de Australia, que es un sistema de salud universal financiado a nivel nacional, con responsabilidad a nivel estatal y prestaciones a nivel local. El compromiso del paciente con los hospitales está, por lo tanto, centrado en hacer los servicios más enfocados en el paciente. Como organismo nacional que representa los puntos de vista de los pacientes en Australia, el Foro de Salud de los Consumidores (CHF) ayuda a los afiliados a mejorar la participación local y regional, que en un comienzo era impulsado por las relaciones locales con los administradores y los médicos, mientras que ahora se apoya más sistemáticamente en la representación de los pacientes en los comités y juntas, aunque la participación local todavía puede ser un desafío. El foro aboga por la aplicación de normas nacionales a los diferentes contextos locales, esto es importante porque reunir, evaluar y responder a las opiniones de los pacientes y hacerlos partícipes en la toma de decisiones puede tener un impacto tangible sobre el rendimiento final y la financiación a los hospitales.

Alianza de Organizaciones de Pacientes de Hong Kong: un trabajo de manera constructiva para incrementar la apertura y la responsabilidad del hospital

La Alianza de Organizaciones de Pacientes de Hong Kong comprende 44 grupos de pacientes afiliados que intervienen en toda la región, mejorando la experiencia del paciente y aumentando la promoción y sensibilización de sus actividades. Inicialmente la alianza se creó para aumentar la responsabilidad con los pacientes y su representación en un sistema de salud que estaba cambiando. La Alianza ha trabajado para aumentar el aporte de los pacientes en la toma de decisiones a nivel local y territorial mediante la asociación con ciertos hospitales y estrechando las relaciones con el Consejo de Dirección de los hospitales. Los pacientes ahora están representados en la mayoría de los comités involucrados en la atención al paciente y la prestación de servicios de salud, y más ampliamente implicados en la toma de decisiones de políticas sanitarias. Defendiendo que los pacientes sean considerados como consumidores activos y constructivos en lugar de beneficiarios pasivos de servicios, presionando para una mejor representación y participación en las decisiones sobre los tratamientos, y aumentando el contacto con los medios de comunicación, la asociación ha contribuido a aumentar la representación de tal manera que los pacientes están ahora representados en los 11 Consejos de Administración y se les consulta su punto de vista. El programa de embajadores de pacientes ofrece formación a los pacientes para ser representantes a nivel hospitalario y dentro del comité hospitalario local; y mediante la construcción de relaciones constructivas el

tiempo con los hospitales asociados, las organizaciones afiliadas a HKAPO han podido empezar a hacer mejoras en la formación de profesionales de los hospitales y a informar al personal sobre el compromiso del paciente, abogando por nuevas intervenciones clínicas, y un enfoque más centrado en el paciente.

L'ONG sudafricana Grupo Depresión y Ansiedad y los hospitales públicos asociados: resolver el problema del cumplimiento deficiente del paciente al tratamiento en psiquiatría

El hospital Joseph Helen, hospital público regional de Johannesburgo, Sudáfrica ha observado problemas relacionados con el cumplimiento del tratamiento por los pacientes en su Servicio Especializado de Consulta Psiquiátrica (SPOPD). En colaboración con el Grupo Sudafricano Depresión y Ansiedad (SADAG), la red de apoyo y grupo de defensa más grande de África para personas afectadas por problemas de salud mental y patrocinado por Janssen Pharmaceuticals, ha tenido como objetivo abordar el tema del incumplimiento a los tratamientos mediante la creación e implementación de un programa recordatorio y de apoyo al cumplimiento del tratamiento. Este proporciona un servicio integral que recuerda regularmente a los pacientes tomar sus medicamentos, asistir a sus citas clínicas, y ofrece información de salud gratuita y apoyo psico-social. Muchos pacientes se han beneficiado de las soluciones del programa para enfrentar la gama de problemas relacionados con el incumplimiento.

Leucemia y linfoma: trabajando con pacientes, cuidadores y profesionales del hospital para mejorar el conocimiento, el tratamiento y la elección del paciente

Trabajando localmente con los pacientes y cuidadores desde el diagnóstico y el tratamiento hasta el pos tratamiento, ayudando a los profesionales a mejorar su conocimiento y su sensibilización sobre el cáncer de la sangre y las mejores prácticas en materia de tratamiento, mientras que también las promueve a nivel nacional, la Sociedad leucemia y linfoma (LLS) está trabajando para fortalecer la coordinación entre los pacientes, cuidadores y profesionales a lo largo de todo el recorrido de la atención. Ayudando a los pacientes a comprometerse más y a tomar decisiones estando mejor informado, a mejorar el tratamiento de cáncer de la sangre a través de la educación, LLS está trabajando para mejorar la atención centrada en el paciente en un sistema de servicios de salud en gran parte privatizado y fragmentado en Estados Unidos. Proporcionando recursos basados en la web y una línea de ayuda nacional gratis, junto a una red de apoyo local cara a cara, LLS está ayudando a los pacientes a aprender más sobre su condición, las opciones de tratamiento y las vías de acceso a la atención. También se ofrecen seminarios gratuitos de educación y de desarrollo profesionales a las enfermeras, oncólogos y trabajadores sociales en los hospitales, destacando

nuevas perspectivas de tratamiento y de atención con un enfoque centrado en el paciente.

Observatorio de expectativas de los pacientes UNICANCER: Un nuevo puesto para los pacientes en las instituciones de salud

Reconociendo el papel desempeñado por los pacientes en su propia gestión, UNICANCER creó en noviembre de 2011 una iniciativa única en Francia: el observatorio de las expectativas del paciente, el cual está diseñado para reorientar y mejorar la calidad de la atención prestada por los centros integrales de cáncer del grupo UNICANCER basados en un mejor conocimiento y comprensión de las percepciones y las preferencias del paciente. En forma revolucionaria, una consulta participativa basada en Internet nos ha permitido recoger y dar prioridad a las expectativas del paciente. En un segundo tiempo las acciones de mejora de gestión de los pacientes en los centros de cáncer fueron generalizadas para satisfacer equitativamente las expectativas identificadas de los pacientes. Mediante el uso de las expectativas del paciente respecto a la organización de la atención de salud, los centros de cáncer son un ejemplo de las nuevas modalidades de participación de los pacientes en las instituciones de salud, de acuerdo con los cambios propuestos por las autoridades públicas.

Asociación con los pacientes para mejorar la seguridad

La seguridad es un aspecto fundamental en cualquier tratamiento médico. La concienciación de que los pacientes pueden desempeñar un papel esencial en la prevención de errores y eventos adversos se ha incrementado en la última década, conectando con el movimiento de capacitación del paciente. Los pacientes ya no son "objetos" y "víctimas" de un tratamiento, son observadores vigilantes y asociados y se convierten en el 'último obstáculo' para la prevención de errores. Este nuevo papel es un reto: para el paciente ya que requiere de una acción en un período vulnerable de la dependencia y la valentía de intervenir en el momento oportuno; y para los cuidadores que se enfrentan a un paciente que es crítico y se atreve a hablar.

El papel de los pacientes – Perspectiva de un gran hospital universitario de atención terciaria, sin fines de lucro, en el Mundo en Desarrollo

La literatura reciente y los estudios muestran el papel importante que los pacientes y las familias pueden jugar durante su transición a través de diferentes puntos de la continuidad de la atención. Hasta la fecha, nuestra observación es que en nuestro medio, la

participación de los pacientes y sus familias y su intervención en el proceso médico han permanecido pasivas, la mayoría de las decisiones relacionadas con el cuidado del paciente están reservadas a los proveedores de salud. La atención sanitaria en muchas partes del mundo en desarrollo todavía se enfrenta a un reto similar. Este documento presenta las iniciativas de un gran hospital universitario de atención terciaria, sin fines de lucro en Karachi, Pakistán en materia de planificación e implementación de algunas prácticas basadas en la evidencia para remodelar el papel de los pacientes y sus familias con el objetivo de mejorar la calidad de su atención. También señala el efecto de la cultura local que hace que el papel del paciente y la familia que está a su cargo sea tan beneficioso como se pueda para mejorar los resultados clínicos y la calidad de vida. Además, factores tales como la alfabetización, la educación, la clase socio-económica y la actitud de los médicos de los países en desarrollo requieren un cambio significativo para que los pacientes participen efectivamente en su propio cuidado.

Los hospitales de Holanda proporcionan "en un solo clic" información segura al paciente utilizando la Ventana de Calidad

En 2014, la Asociación Holandesa de hospitales (Nederlandse Vereniging van ziekenhuizen, ZVN) puso en marcha el programa Ventana de Calidad en los hospitales generales en toda Holanda. La Ventana de Calidad es una plataforma en línea para los pacientes que comparte información sobre la clasificación actual y previa de un hospital basada en diez indicadores de calidad, que van desde la experiencia del paciente a la satisfacción del empleado. Así, la Ventana de Calidad responde a la creciente demanda de información y de transparencia cuando se trata de atención hospitalaria y de rendimiento.

No sólo los pacientes pueden acceder a información útil sobre la calidad de un hospital a través de la Ventana de Calidad, sino que también pueden comparar los resultados con otros hospitales, con la media nacional y aún más. Muchos hospitales están aprovechando la oportunidad para aclarar cómo se realizan los indicadores en la práctica y las medidas adoptadas para su mejora.

La Ventana de Calidad se ha desarrollado con la ayuda de los hospitales y los pacientes. En los próximos años se extenderá a los hospitales universitarios en todo el país. Los hospitales generales también comenzarán a desarrollar Ventanas de Calidad para grupos específicos de pacientes, como los pacientes con cáncer.

CALL FOR ABSTRACTS

Introduction

The IHF World Hospital Congress is a unique global forum where multidisciplinary exchange of knowledge, expertise and experiences in health sector management and service delivery is facilitated. This forum brings together leaders, gurus, delegates and participants conversant in healthcare policies and reforms, management practices, financing trends and solutions, quality and safety, to engage in constructive dialogue on best practices and innovations in hospital and healthcare management aimed at improving the overall health and wellness of our patients and communities.

Hosted by the American Hospital Association (AHA) and the American College of Healthcare Executives (ACHE), the IHF 39th World Hospital Congress will be held on 6-8 October 2015 in Chicago, USA with the theme: **Advancing Global Health and Health Care**, with the following subthemes and tracks:

- **Equity and Access to Care**
- **Quality and Safety**
- **Patient/Community Engagement and Empowerment**
- **Healthcare Management and Leadership Opportunities and Challenges**
- **Innovation in Healthcare Delivery**
- **Ethics**

Submission of Abstracts

Authors wishing to present their work, orally or as a poster, at the IHF 39th World Hospital Congress are invited to submit an abstract of no more than 300 words, by using the online submission form to the Scientific Committee for consideration.

Important dates:

Open for abstract submission	1 October 2014
Deadline for abstract submission	1 December 2014
Notification to authors (to author's email address)	15 February 2015

Important notes:

The Congress language is English. All abstracts submitted for oral or poster presentation must be in English. All abstract submissions must be made electronically via the *online submission form* available at the official Congress website: www.worldhospitalcongress.org. Abstracts sent by post or email will NOT be accepted.

Please carefully read the information below before proceeding to online submission of abstracts

General criteria for assessment of abstracts:

- Presents an experience and knowledge sharing opportunity for the global healthcare community
- Addresses major issues of importance according to the 2015 Congress themes
- Will be of benefit to a large audience
- Findings presented will generate information that could be useful in advancing global health and healthcare
- Materials and methods are well presented and analysed, with appropriate case studies

Financial support policy:

1. No honorarium or financial support will be provided to authors for abstracts accepted for oral or poster presentation.
2. Authors wishing to present their abstracts accepted for oral and poster presentation at the Congress must register to attend the Congress by paying a special discount Congress registration fee of US \$350. The registration fee must be paid on or before **15 July 2015**.

General and Technical Requirements:

- Best online abstract submission system—Internet Explorer 7.0 or higher/Mozilla Firefox 3.0 or higher; Cookies and JavaScript need enabling in order to submit.
- Conflict of interest: Author(s) must declare any potential conflicts of interest when submitting their abstract.
- After the submission deadline, only requested changes by the Scientific Committee reviewer will be accepted.
- Poster content should include introduction, objectives, material and methods, results and conclusions.
- Poster dimensions should be 152 cm (60 inches) wide x 102 cm (40 inches) tall.
- Only abstracts in “final submission” status will be considered.
- **All decisions on Abstract submission by the International Scientific Committee are final.**

For further information please contact:

Sheila Anazonwu, IHF Partnerships & Project Manager

Tel: +41 (0) 22 850 94 22 Email: 2015congress@ihf-fih.org

2014 Corporate Partnership Programme



Supporting collaboration, ideas and innovation
in global healthcare

Who We Are

Founded in 1929, the **International Hospital Federation (IHF)** is the leading global body representing **public and private national hospital and healthcare associations**, departments of health and major healthcare authorities; with **members** from some **100 countries**.

Our vision and objectives

The founding philosophy of the IHF is that it is the right of every human being, regardless of geographic, economic, ethnic or social condition, to enjoy the best quality of health care, including access to hospital and health care services. By promoting this value, the **IHF supports the improvement of the health of society**.

The objective of the IHF is to develop and maintain a spirit of cooperation and communication among its members and other stakeholders so as to create an environment that facilitates the **cross – fertilization and exchange of ideas** and information in healthcare policy, finance and management.

The role of the IHF is to help international hospitals and healthcare facilities work towards improving the level of the services they deliver to the population regardless of the ability of the population to pay. The IHF recognizes the **essential role of hospitals and health care organisations** in providing health care, supporting health services and offering education.

The IHF is a **unique arena** in which all major hospital and health care associations are able to address and act upon issues that are of common and key concern.

What IHF Accomplishes

- ✦ **Projects** aimed at supporting and improving delivery of hospital and healthcare services.
- ✦ Regular and extensive **collaboration** with governmental and non-governmental organizations in developing health systems.
- ✦ Creation of **"knowledge hubs,"** through its international conferences, education programmes, information services, publications and consultations.
- ✦ In official relations with the World Health Organization (WHO) and the Economic and Social Council of the **United Nations (ECOSOC)**, it is strategically positioned as a bridge between IHF members, the United Nations.
- ✦ Acts as a **global facilitator for health care delivery** among and between key governmental and non-governmental stakeholder organisations.

What Is the Corporate Partnership Programme?

The IHF Corporate Partnership Programme, launched in 2009, is an **opportunity** presented to major corporations seeking to join IHF members in working to improve hospital and **healthcare performance** around the world.

Partnership is open to a limited number of companies who are fully engaged in the **global health sector** and have a **good reputation** as providers. Affiliation with this Partnership Programme gives a strong signal to the global community that the Corporate Partner is a major world player in the hospital and healthcare sector.

The Partnership package provides **access to hospital and healthcare decision makers** from around the world. The Programme provides an exclusive opportunity for relationship building and sharing of ideas and experiences between corporate leaders and executives in the hospital and healthcare sector. **Dialogue** through this platform will ultimately introduce new ideas and expand knowledge in the healthcare market.

The benefits of the Programme are designed to maximise interaction between actual and potential clients through a **"one-stop shop" approach**.

Opportunity to ultimately create a **corporate leadership body**, to act as a neutral platform for wide-ranging intra-industry discussions on issues of mutual concern beyond and outside of traditional parameters of marketing in order to **foster collaboration** and **enhance confidence** in commercial relations in the health sector as well as **performance** and quality of services and **life** to the **community** at large.

Becoming a Corporate Partner

Contract Terms

- ✦ **Payment** covers a calendar year period of:

1 January – 31 December

(For the 2-year option, payment can be made on annual basis)

- ✦ **Letter of Agreement**

The Corporate Partnership is established upon signature of a letter of agreement by representatives of both the International Hospital Federation and an authorised signatory of the Corporate Partner organisation.

Application

For additional information, please contact:

Sheila Anazonwu, Partnerships and Project Manager

IHF Secretariat

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E-mail: sheila.anazonwu@ihf-fih.org; Website: www.ihf-fih.org

2014 Corporate Partners



Transparency is our highest technology



Meet IHF corporate partners



Transparência é nossa maior tecnologia

Bionexo is the center of a community comprised of over 15,000 players of the hospital business. Through our web platform, we integrate hospitals throughout the supply chain sector, focusing on business development and relationships. Established in 2000, in just 10 years, Bionexo was structured in Brazil, becoming the largest marketplace reference to the hospital industry and contributing significantly to the professionalization of the purchasing sector and growth of the healthcare market. The success of this innovative business model has led to Bionexo for Latin America and Europe, where also attained leadership in addition to export technology and implement a new concept in commercial transactions of organizations. Everything happened in a short time, just like businesses are made between the companies that integrate our platforms. This makes Bionexo the largest core of the hospital sector in Brazil. Pioneering and innovation, helping thousands of companies and hospitals.

www.bionexo.com.br



Esri is the world leader in GIS technology. Esri software promotes exploring, analyzing and visualizing massive amounts of information according to spatial relationships. Health surveillance systems are used to gather, integrate and analyze health data; interpret disease transmission and spread; and monitor the capabilities of health systems. GIS is a powerful tool for identifying health service needs. Esri software is extensively used by health organizations throughout the world, including the US Centers for Disease Control and Prevention (CDC), the World Health Organization (WHO), 127 national health ministries, and over 400 hospitals.

For more information, contact Christina Bivona-Tellez, CBivona-Tellez@esri.com. www.esri.com/health



DNV Business Assurance, a world leading certification body, is part of the DNV Group; an independent foundation whose purpose is to safeguard life, property and the environment. With over 140 years' experience in developing safety standards in high risk industries, we work with hospitals, healthcare organizations and other businesses to assure the performance and safety of their organisations, products, processes and facilities through accreditation, certification, verification, assessment and training. Within healthcare we are recognised as a leader in identifying, assessing and managing risk to mitigate harm to patients. Our 1,800 employees worldwide help customers build sustainable business performance and create stakeholder trust.

IHF events calendar

2014

IHF

IHF Group Purchasing – Special Interest Group Conference

Transforming purchaser/supplier cooperation to improve health care efficiency: A global challenge
4–5 November 2014, Paris, France

4th IHF Hospital and Healthcare Association Leadership Summit (By invitation only)

12–13 November 2014, Seoul, Korea For more information, contact sheila.anazonwu@ihf-fih.org

2015 IHF 39th World Hospital Congress

6–8 October 2015, Chicago, USA

For more information, contact sheila.anazonwu@ihf-fih.org

2016 IHF 40th World Hospital Congress

Durban, South Africa For more information, contact sheila.anazonwu@ihf-fih.org

2017 IHF 41st World Hospital Congress

November 2017, Kaohsiung City, Taiwan

For more information, contact sheila.anazonwu@ihf-fih.org

2014

MEMBERS

Korea

2014 Korea Healthcare Congress at 63 Convention Center

12–14 November 2014, 63 Convention Center, Seoul, Korea

Organized by The Korean Hospital Association

More information <http://koreahealthcarecongress.com/eng/inv/>

Portugal

5th International Hospital Congress APDH

20–22 November 2014, Lisbon, Portugal

“The national health service - (Re) cognize the changes”

2014

COLLABORATIVE

2nd World Congress on Integrated Care “21st Century integrated care: Serving citizens, patients and communities”

23–25 November 2014, SMC Conference Centre in Sydney, Australia

More information on http://www.integratedcarefoundation.org/conference/2_world



HORIZONTES FORUM **ANAHP**



CLINICAL GOVERNANCE

Brazilian Hospitals
Sustainability

**DECEMBER
03 - 04 - 2014**

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SÃO PAULO



Who will attend?

**Brazilian Top Hospitals Leaders,
Clinical Directors, Nursing Services
Managers and Healthcare Managers**



Brazilian National Private Hospital Association

Anahp is the national organization that stands for and promotes the interest of Brazil's top private hospitals.

Established in 2001 the Association represents Brazilian private hospitals before legislative and regulatory bodies, disseminating best practices throughout the national health system, benefitting all Brazilian citizens.

Through our representation and advocacy activities, we achieved an essential role in developing sustainability practices, being an important source of information on health care issues and trends. Furthermore, Anahp's members hold international quality standards of safety, contributing for the improvement of the Brazilian health care system.

Nowadays, Anahp ensures its members' messages and needs get across in national health policies development, legislative and regulatory debates and judicial matters by providing private hospitals leadership, advocacy, education and innovative programs and services.



Mark Your Calendar

International Hospital Federation
39th World Hospital Congress

ADVANCING GLOBAL HEALTH & HEALTH CARE

October 6–8, 2015 * * * * Chicago, USA

Exchange ideas and best practices with
visionary healthcare leaders from around the world.



Come to Chicago— A World-Class City

Home to a vibrant health care market with 116 hospitals in the greater metropolitan area, including 15 teaching hospitals. Congress attendees will get a behind-the-scenes look at several leading health care organizations.

Enjoy top-rated restaurants, museums, entertainment and a shopping district known as The Magnificent Mile.

The Hyatt Regency Chicago—the program site—is a prime location with breathtaking skyline and Lake Michigan views.

More information will be forthcoming at www.ihf-fih.org, but for now, save the date!

