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Addressing the global burden of chronic diseases: the need for patient-centred healthcare

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Good afternoon, first of all I would like to thank coordinators of the World Health Editors Network and the World Health Professions Alliance for inviting me to participate today on behalf of the International Alliance of Patients' Organizations.

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I am going to talk to you today about the global issues for patients around the world and in particular to highlight the issues around non-communicable diseases and counterfeit medicines for patients and tell you about IAPO's role on a global level and how this ties in to our objectives. In particular I want to highlight the need for a patient-centred approach to the non-communicable diseases strategy that is being put before the World Health Assembly this week by outlining what patient-centred healthcare is and through two case studies show how it can contribute to the development of appropriate health policies and practice. The non-communicable diseases strategy and plan of action calls for a broad multi-sectoral approach to tackling non-communicable diseases and should have a great effect on health systems. We welcome this increased focus on non-communicable diseases and with such initiatives there is scope and a need for patient involvement and groups to contribute to achieving the objectives.

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I will be speaking today on behalf of the International Alliance of Patients' Organizations, more frequently referred to as IAPO. IAPO is a patient-led global alliance of 200 organizations and together our members represent at least 365 million patients worldwide.

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As is increasingly recognized, health systems in all world regions – no matter how little or how much money they have – or in what region of the world are under pressure due to the burden of disease and growth in the burden of chronic conditions (non-communicable diseases) increases. The WHO now asserts that chronic diseases, such as heart disease, stroke, cancer, chronic respiratory diseases and diabetes are by far the leading cause of mortality in the world, representing 60% of all deaths. This

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development means that these health systems cannot cope if they continue to focus on diseases rather than people; as they require the involvement of individuals in their treatment to take their medicines correctly, to take part in managing their healthcare and treatment sometimes over many years and to make healthy lifestyle choices.

This approach is part of an approach which aims to align healthcare systems with patients' needs and is something we term patient-centred healthcare. As well as the involvement of individuals in their treatment to an appropriate extent, it also requires the involvement of patient groups in supporting and representing patients and bringing a broad experience of patients needs and experiences with particular conditions to the development and implementation of health policies so that they do address patients needs in an efficient and appropriate way.

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Whilst 'patient-centred healthcare' is a term that is often used it is not always well understood or articulated. IAPO developed the first globally accepted definition of patient-centred healthcare and one agreed by the global patients' movement.

We found that patients', families' and carers' priorities are different in every country and in every disease area, but from this diversity there were some strong common priorities which were referred to again and again. It was clear that the essence of patient-centred healthcare is that the health system is designed and delivered to meet the needs and preferences of patients and that it is a useful concept to ensure that patients' needs and preferences are at the centre of all aspects of healthcare.

The principles provide a basis which recognises that patients are individuals and have different needs and that the healthcare system can be responsive to this encouraging patients to take some responsibility for their healthcare whilst recognising and respecting the limits in people's ability or individual preferences.

1. Respect is the first principle – Patients, families and carers have a fundamental right to patient-centred healthcare that respects their unique needs, preferences and values, as well as their autonomy and independence.

2. Choice and empowerment – In terms of choice and empowerment - Patients have a right and responsibility to participate, to their level of ability and preference, as a partner in making healthcare decisions that affect their lives. For this there needs to be a responsive health service which provides suitable choices in treatment and management options that fit in with patients' needs, and **encouragement** and support for patients and carers that direct and manage care to achieve the best

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possible quality of life. Patients' organizations need to be **empowered** to play meaningful leadership roles in supporting patients and their families to exercise their right to make informed healthcare choices.

3. Patient involvement in health policy - Patients and patients' organizations have a valuable role to play in healthcare policy-making through meaningful and supported engagement in all levels and at all points of decision-making, to ensure that they are designed with the patient at the centre. This should not be restricted to healthcare policy but any decisions that will ultimately impact on patients' lives. IAPO has developed a policy statement and guidelines which can be considered in the development patient involvement activities: www.patientsorganizations.org/involvement.

4. Access and support – Access to safe, quality and appropriate services, treatments, preventive care and health promotion activities is needed with a commitment to **equity** so that all patients can access the appropriate treatments. For patients to achieve the best possible quality of life, healthcare must support patients' emotional requirements, and consider non-health factors such as education, employment and family issues which impact on their approach to healthcare choices and management.

5. Information - Accurate, relevant and comprehensive information is essential to enable patients and carers to make informed decisions about healthcare treatment and living with their condition. Information must be presented in an appropriate format according to health literacy principles considering the individual's condition, language, age, understanding, abilities and culture. See IAPO's Policy Statement at www.patientsorganizations.org/healthliteracy.

Whilst developing the Declaration we researched the impact of a patient-centred approach and found that there have been a number of research studies have concluded that there is a positive link between the practice of patient-centred healthcare in clinical settings and outcomes. Collectively these indicate that the patient-centred approach can lead to a variety of positive outcomes including patient satisfaction, emotional health, symptom resolution, function, physiologic measures (i.e. blood pressure and blood sugar level), pain control, engagement and task orientation, reduction in anxiety, quality of life, doctor satisfaction and an increase in efficiency resulting in fewer diagnostic tests and unnecessary referrals.

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In addition to patients' organizations agreement with the principles of patient-centred healthcare, IAPO carried published a research study in 2006 which found evidence of patient group members concerns and dissatisfaction with healthcare and that they want a patient-centred approach. The study results:

- demonstrated strongly shared views on the needs and concerns of members related to currently administered healthcare
- signalled a need for a shift to a more patient-centred approach to healthcare

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- identified three recurring themes that illustrate shared concerns related to:
 - timely access to the best treatment and information
 - the right to participate in decisions at the individual patient level
 - patient involvement in policy-making

These encompass the same values that are enshrined in international law and underpin many definitions of a patient-centred healthcare, based on human rights, participation and empowerment, and access and equity.

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Within a global context we find that there are common health issues for patients around the world which are cross border and cross disease – they are as relevant to a cancer patient in Slovenia as a patient with HIV in Zimbabwe though the specific issue may be different the trends we see are:

- The extensive issues of access to treatment and care including equity of access, cost of care and the availability of treatment
- Lack of meaningful patient involvement in health policy decision-making ranging from non involvement at all to the 'theory versus reality' problem where there is a gulf between established policy commitment and actual practice
- The need for an international concerted effort to address patient safety
- The need for good quality health communication and information and education to enable people to make good health and healthcare decision and to take care of themselves.

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There are a number of initiatives ongoing where a patient-centred approach is being taken or where patient involvement is necessary from international policy-making fora to local practice. I will outline two of these.

Firstly, from Canada comes an example where health professionals and patient advocates have collaborated to create a patient-centred family health care practice. In Ontario, Canada they designed and implemented an integrated programme of patient self-management and self-management support. In 2005 the government of Canada approved the creation of Family Health Teams as a means to significantly improve the delivery of primary healthcare. This led to a patient based group called the Institute for Optimizing Health Outcomes along with the Blue Sky Family Health Team (comprised of health professionals) to collaborate on a pilot programme to integrate patient self management into chronic disease management and patient care.

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This programme was based on belief that patients and healthcare systems benefit when healthcare practitioners treat the 'patient as person' and help patients and families to acquire the skills and confidence to manage their chronic illness. However, studies indicate that there are many barriers to family practitioners transitioning from providing direct care to supporting self management. A number of pilot projects such as in the UK, Australia and USA on patient-centred health partnerships have provided valuable learning and tools for the establishment of patient-centred programmes to manage chronic conditions such as diabetes and asthma. The patient based organization in this example in Canada provides the lay led patient self-management component and facilitates the implementation of self-management support among the Family Health Team staff – e.g. training of Family Health Team staff on self-management support skills e.g. asking open ended questions, listening, carrying out follow up activities such as calling patients and getting updates on their progress. Amongst the family health teams role is to identify patients at risk of the chronic conditions and those that would potentially benefit from the self management programme and agree to support patients in programme.

Collaborative care is part of the model as the family health teams are interdisciplinary and include not only health professionals but community based services and patient representatives and they strive towards ongoing care, shared burden of leadership and improving relations with the community at large. Outcome measures including physiological measures, behaviour change and satisfaction (for both the patient and the care giver) are being monitored and the pilot is being expanded with other FHT's in the province. Improved communication needs well-informed patients, health care professionals and other health care partners. Elements of this approach have been highlighted in WHO's 2004 publication 'Preparing a Healthcare Workforce for the 21st Century: The Challenge of Chronic Conditions' which asserts that health professionals need new competencies in their role in providing healthcare to patients with chronic conditions. In particular, the publication stresses the need for a patient-centred approach and the need for collaborative care with exchange between health professionals and others involved in healthcare.

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Counterfeit medicines are a global and growing threat to the health of people around the world.

The principles of patient-centred healthcare are relevant to the issue of counterfeit medicines. Patients must have the *confidence* that they will have access to safe, quality and appropriate treatments which is where ensuring there is appropriate regulation and enforcement is particularly important and *trust* that they will receive accurate, relevant and comprehensive information.

IAPO supports a global multi-stakeholder approach. This is because counterfeit medicines have a global reach, so no one country is protected. We have a global responsibility to prevent counterfeits harming

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patients in vulnerable situations. Collaboration provides the opportunity to maximise knowledge and resources to develop appropriate and cost effective solutions.

IAPO supports the involvement of patients and health professionals in policy initiatives and awareness raising. Patients themselves and health professionals have a valuable role in detecting and reporting counterfeit medicines. Therefore, they need accessible and accurate information.

In addition to bringing a patient perspective to the IMPACT initiative, we recently responded to the European Commission consultation in preparation of a legal proposal to combat counterfeit medicines for human use and the issues I am highlighting today come from our response. One area that we stressed was that in addition to IAPO supporting the development of appropriate regulations and effective enforcement regarding medicines manufacture and the medicines supply chain, which are no doubt essential, we stressed the need for broader anti-counterfeiting strategies.

In particular, it is essential that communications strategies are developed to communicate about the risks of counterfeit medicines, and what patients should be vigilant of when buying and taking their medicines. These risks must be communicated to patients' organizations, patients and the general public since presently it is not possible to guarantee that counterfeit medicines will not reach patients. Patients and patients' organizations can and are making a contribution on global, European and national levels to raise public and patient awareness of counterfeit medicines. As you may know, IMPACT has a working group that focuses on developing appropriate communications for all stakeholders but we need to ensure that the messages filter down to a national and local level.

Those at the point of medicines delivery, patients themselves and health professionals, can play a valuable role in detecting and reporting counterfeit medicines, and protecting the public. Patients' organizations have the experience to provide relevant, accurate and accessible information for the communities that they know well. In collaboration with other stakeholders in health, information must be provided to encourage patients to know their medicines – to assess their quality and provenance - and to be vigilant for signs that may indicate a counterfeit medicine, any differences in the medicine itself or its packaging, and to encourage them to go to their pharmacist, nurse or doctor if they have any concerns. We need to do this with care and thought so as not to cause panic which may result in patients stopping taking their medicines and thereby causing more harm, which we have seen can be a negative result of health scares. For example, the increased risk of measles prevalence as a result of the reduction in uptake of the MMR vaccine in the UK due to adverse publicity and questions over the safety of the vaccine.¹

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As many patients take more personal responsibility for their health which is in itself positive, communications must be clear that informed decision-making on health issues is the safest and most effective in partnership with health professionals. While there is a general trend in buying consumer products from the internet – such as groceries and books for example – we need to consider in particular the issues regarding purchasing medicines online and communicate the risk of buying from unlawful websites and tackle the problem for consumers of being able to identify what is a bona fide website from an unlawful one. Communications should stress that it is important to engage with the health service and purchase prescription and over-the-counter medicines from licensed sources rather than self-diagnosing and self-medicating outside of the healthcare system.

Health strategies must consider what factors lead patients to buy medicines from unregulated sources, such as unlicensed online pharmacies, and address these. Factors may include cost, accessibility, convenience, stigma attached to certain conditions, such as mental and sexual health conditions, as well as lack of awareness of the dangers.

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There are multiple areas where patient groups are, or could, play a role: high level global coordinated policy action and in national initiatives to provide a patient perspective, comment on or support technical or legal recommendations and raise public and patient awareness of counterfeit medicines.

Patients, patient groups and the general public can comment on and support developments in legislation and other measures to combat counterfeit medicines. In addition, since we cannot guarantee that patients will not receive a counterfeit medicine at present we need to appropriately raise awareness of the dangers of counterfeit medicines with patients without causing undue alarm. This means communicating in a sensitive way to patient communities and this is where patients' organizations can take a role and I will tell you about some current activities.

IAPO supports the global multi-stakeholder approach of IMPACT. A global approach is vital because, as we know, counterfeit medicines have global reach - no one country can be complacent that its population is protected from them. Counterfeit medicines are a threat to all patients no matter where they live in the world. Obviously the risk is great for those buying their medicines from unlicensed sources such as market traders in Africa or from unlicensed internet sites but as the EU recently stated there is increasing data on the risk of receiving a counterfeit medicine through the regulated supply chain (EU Statistics report the seizure of a total of 2 711 410 medicinal products (articles) at EU customs borders in 2006. This is an increase of 384% compared to 2005.

¹ <http://adc.bmj.com/cgi/content/full/91/6/465#R3>

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We believe we have a global responsibility to prevent counterfeit medicines harming patients in the poorest and least protected regions where patients may have a lower awareness of the risks or may have less opportunity to purchase medicines from a licensed source for example because they can only afford to buy medicines from unlicensed market traders. A particular commitment is needed to empower all patients with information, choice and solutions.

The IMPACT communications working group is developing communications materials for general dissemination and there have been some specific outputs such as the World Health Professions Alliance Toolkit on Counterfeit Medicines. This included an information leaflet for consumers which IAPO was pleased to review and endorse and WHPA ran a training workshop with patient groups on the issues surrounding counterfeit medicines at our last Global Patients Congress (in February 2008).

IAPO is currently finalising a tool designed to provide information and tools to patients' organizations to enable them to provide information on patient safety issues to patients and also to help them to participate in health policy initiatives to improve patient safety. As well as sections on medical error, hospital acquired infections and injection safety amongst others, there will be a section on counterfeit medicines where basic information on the issue and the scale of the problem is presented for patient groups along with tools such as frequently asked questions sheets and checklists for dissemination to patient groups and patients and powerpoint presentation templates with instructions on how to use these for educational or advocacy purposes.

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The growth in the prevalence of chronic conditions requires a shift in the way that healthcare systems are designed and healthcare is delivered to involve patients.

The best way to achieve patient-centred healthcare is to have an approach based on strong values of respect, partnership and equity and to ensure that all relevant stakeholders are engaged and supported including patients and patients' organizations and the general public.

The International Alliance of Patients' Organizations (IAPO) is a unique global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world. Our members are patients' organizations working at the local, national, regional and international levels to represent and support patients, their families and carers. A patient is a person with any chronic disease, illness, syndrome, impairment or disability.

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

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IAPO's mission is to help build patient-centred healthcare worldwide by:

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

To find out more about IAPO and our activities, please visit our website at www.patientsorganizations.org.