Distance Trade of Medicinal Products and New Modes of Medicinal Products Distribution - A Patient Perspective

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Overview

• An introduction to the International Alliance of Patients’ Organizations
• Patient-centred healthcare & putting patients first - what does it mean?
• Why do we need to put patients first?
• A patient perspective on access to safe medicines
  • Medicines information and health literacy
  • How can patients and patients’ organizations contribute? What are barriers to involvement?
  • Medicinal products distribution
  • Counterfeit medicines
About IAPO

• Unique global alliance of almost 250 national, regional and international groups representing patients

• Crossing borders and diseases

• Vision: Patients throughout the world are at the centre of healthcare

• Membership spans 60 different countries and all world regions

• Representing an estimated 365 million patients
IAPPO’s Mission

Our mission is to help build patient-centred healthcare in every country 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
What does patient-centred healthcare mean?

Essential principles guiding patient-centred healthcare are that healthcare systems are designed and services delivered so that patients’ needs are answered. Patients are the first consideration.

- **Respect** and support for the individual patient, their wants, preferences, values, needs and rights
- **Choice and empowerment**
- **Patient involvement** in health policy
- **Access and support**
- **Information** that is accurate, relevant and comprehensive

Principles defined in IAPO’s Declaration on Patient-Centred Healthcare: [www.iapo.org.uk](http://www.iapo.org.uk)
Why do we need to put patients first?

• All healthcare decisions ultimately affect patients

• Global agencies, national health services and budgets are struggling to meet demand and costs of non-communicable diseases, communicable diseases, costs of new treatments and technologies

• Involvement and collaboration improves adherence and reduces waste of medicines, better patient outcomes and quality of life, therefore more effective investment
Why do we need to put patients first?

Medicines have significantly improved health and quality of life but there are problems:

- Medicines are the most common form of harm in health systems.

- In developed countries only 50% of patients who suffer from chronic diseases adhere to treatment recommendations.

- In developing countries, poor adherence is threatening efforts to tackle chronic conditions, such as diabetes, depression and HIV/AIDS.

- Low health literacy affects a person's ability to make informed decisions about his or her health and can result in the ineffective treatment and rehabilitation of a patient's condition. Poor levels of health literacy exist in all countries.
Universal health coverage

“Universal health coverage is the single most powerful concept that public health has to offer.” Margaret Chan, Director General, WHO

**Objectives of UHC**
- **Equity** in access to health services
- High **quality** of health services
- Financial-risk protection

**This requires:**
- a strong, efficient, well-run health system
- a system for financing health services
- access to essential medicines and technologies
- a sufficient capacity of well-trained, motivated health workers
A patient-centred approach to access to safe medicines

- Access to safe, quality and appropriate medicines
- Availability of medicines
- Affordable medicines
- Trust that there are appropriate regulations that will ensure safety and appropriate methods to monitor and track medicines (pharmacovigilance)
- Empowerment of patients and patients’ organizations through education, information and support
- Patient engagement - ‘...meaningful and supported engagement in all levels (of healthcare policy) and at all points of decision-making...’ (from IAPO Declaration on Patient-Centred Healthcare)
What patients want from medicines information

- To know that the medicine is safe and effective
- The expected benefits and how they will improve health and quality of life
- The possible side effects and what to do if a different reaction from that predicted is experienced
- How to take the medicine correctly and safely
- How the medicine works with other treatments and fits in with a person’s life
Key principles for medicines information

- The information should be accurate, relevant and comprehensive
- The message shall be clear and understandable
- The content relevant and tailored
- The format culturally and linguistically appropriate
- There is involvement of reader, viewer or listener
- Pilot testing on key audiences is key
- Written information is not enough – two way communication is key!

See IAPO’s Policy Statement and Guidelines on Health Literacy
What can patients and patients’ organizations contribute?

• Identify patient needs
• Highlight issues that have not been considered or prioritised
• Share knowledge of what it means to live with a condition and the impact of treatment
• Promote patient empowerment and responsibility for their own health
• Provide channels for the dissemination of information
Key principles of patient involvement

- Involvement in all stages - initiation, design, implementation, communication and evaluation
- Provision of necessary support including practical, financial and/or educational, as appropriate
- Use of varied methods to reach underrepresented groups and to gather a diversity of views and input
- Provide information, education and training for both parties on how to collaborate

From IAPO’s Policy Statement and Guidelines on Patient Involvement
Barriers to involving patients and patients’ organizations

- Perceived lack of necessary expertise
- Lack of a common language
- Lack of understanding of the value of patient involvement
- Lack of knowledge of how to work with patients and patients’ organizations
- Lack of resources
Collaborative action example - EURORDIS

Medicines information activities include:

1. EURODIS representatives sit on the European Medicines Agency (EMA) Patients and Consumers Working Party where they have been involved in the development of medicines information for orphan drugs.

2. EURORDIS provides education and training to healthcare stakeholders on good practice on developing patient information to ensure that it reflects what patients want from the information and is clear and accurate.

3. EURORDIS also provides information in lay people’s terms.
The World Federation of Incontinent Patients (WFIP) is a global federation of national patient organizations for sufferers of incontinence and related pelvic floor disorders.

WFIP have partnered to produce patient information for a medical device which is used for symptomatic relief from bladder conditions caused by a deficiency in this protective lining.

The company that developed the product considered WFIP as experts, as the users of the products. They have developed a good relationship and WFIP have helped to ensure that the information is patient friendly.

WFIP regularly reviews the information on the product to ensure that it is still up-to-date and to examine whether any improvements can be made in the way the information is conveyed.
Distribution of medicinal products at a distance

May be convenient and efficient but some risks:

- infiltration of legitimate supply chain
- patients may bypass support and engagement with health professionals/services
- use illegitimate channels without knowledge or for other reasons
Counterfeit medicines: we need to raise public awareness and provide information and advice to patient communities and the general public:

- to be aware of the risks of counterfeit medicines
- to be vigilant with medicines and to report differences or worries to health professionals
- to purchase medicines from licensed sources and appreciate the dangers of unregulated sources
Some conclusions

• Vital to ensure that medicines are high-quality, safe and efficacious

• Attention should be paid to the role of communication between healthcare professionals and patients and patients need to be involved in any changes to their treatment regimes

• Education and information are key – patients need to know how and where to find safe and high quality medicines information and medicines and how to report adverse effects and doctors need to ensure adverse effects are reported

• Patients need to ensure that when they are prescribed a medicine they know how to identify the medicines (such as through the brand name and where to find the batch number)

• Robust pharmacovigilance systems and adverse event monitoring is key to ensuring patient safety
Some conclusions

• Medicines information and safe access to medicines is key to maximising the benefits of medicines and improving health outcomes and quality of life

• In order to increase the benefits of medicines information it must address patient needs as articulated by patients themselves

• Partnerships are required in the development of medicines information which recognise and maximise the expertise of all partners

• Patient-centred integrated care requires a shift in the way that healthcare systems are designed and healthcare is delivered to involve patients

• Patient-centred, integrated healthcare should be an integral element of the philosophy of organizations, governments and healthcare providers and is a key part of a cultural shift in the prioritisation, organisation and delivery of healthcare
Thank you!

For further information about IAPO and to access our toolkits and resources please visit our website at:

www.iapo.org.uk