PATIENT EMPOWERMENT
MYTH OR REALITY
8TH NOVEMBER 2017
OBJECTIVES OF THE WEBINAR

• What is Patient Empowerment
• Why is Patient empowerment important
• Health vs Medical Care and Role of Empowered Patients
• How Can Patient Empowerment be incorporated into healthcare policy
• Role of patients and patient groups as advocates for patient empowerment
MISSION: A WORLD WHERE PEOPLE LIVE A HEALTHY AND DISEASE FREE LIFE THROUGH KNOWLEDGE BASED CHOICES IN AN ATMOSPHERE OF EQUALITY, EQUITY AND ACCESS.

VISION: EMPOWER PATIENTS AND CAREGIVERS WITH THE RIGHT KNOWLEDGE, TOOLS AND FORUMS TO SEEK AND ACCESS HEALTHCARE OPTIONS THAT SUIT THEIR NEEDS AND THROUGH THEIR VOICES BRING ABOUT A POSITIVE CHANGE IN THE HEALTHCARE ENVIRONMENT
OBJECTIVES - IAPG (INDIAN ALLIANCE OF PATIENT GROUPS)

• Unite to speak with one voice, using unified strength to move forward together.

• Identify health policy opportunities to include the patient voice.

• Share best practices to support advocacy-related work by individual groups, perhaps through a patient forum.

• Address the need for individual advocacy organisations to provide more information to their consumers.
IAPG PRINCIPLES OF PATIENT CENTERED HEALTHCARE

- **Promoting Patient Engagement in Health Policy Decision Making**: Patients are the focal points of any healthcare system. They should share responsibility for health policy decision-making, through meaningful engagement at all levels.

- **Supporting Access to the Best Available Care across India**: Patients and their advocates should promote and help design programmes that are suitable to local conditions and ensure the availability of healthcare workers.

- **Promoting Health Literacy and Ensuring the Availability of Health Information**: Accurate, relevant and comprehensive information is essential for enabling patients and their families to make informed decisions about treating and managing their condition.

- **Advancing Choice and Empowerment of Patients and their Advocates**: Through collaboration and shared knowledge and best practices, patients and their advocates need the information and the confidence to participate as partners in making the healthcare decisions that affect lives.

- **Raising the voice for a patient-centered healthcare systems, at national and state levels**: National and state level policies makers need the support of informed patients to build an effective and responsive healthcare system.
A few Stats

WHO report

- health workers, 59.2% were in urban areas, where 27.8% of the population resides, and 40.8% were in rural areas, where 72.2% of the population resides. Hospital beds are only 0.9/1000 population.

2.5 million health workers (density of 20.9 workers per 10 000 population) in India. However, 56.4% of all health workers were unqualified, including 42.3% of allopathic doctors, 27.5% of dentists, 56.1% of (AYUSH) practitioners, 58.4% of nurses & midwives and 69.2% of health associates.

By cadre, there were 3.3 qualified allopathic doctors and 3.1 nurses and midwives per 10 000 population; this is around one quarter of the World Health Organization benchmark of 22.8 doctors, nurses and midwives per 10 000 population.
• 50 – 60 million diabetics
• 1 in four Indian is hypertensive
• 1.7 million cancer patients
• 37 million Coronary Heart Disease
• 8 million Rare Diseases.
DEFINITION OF EMPOWERMENT

• Patient empowerment in the health care context means promoting autonomous self-regulation so that the individual’s potential for health and wellness is maximised.

• Patient empowerment begins with information and education and includes seeking out information about one’s own illness or condition, and actively participating in treatment decisions.

• Empowerment requires an individual to take care of one’s self and make choices about care from among the options identified by the doctor.
WHY PATIENT EMPOWERMENT

• Healthcare systems are in crisis, chiefly because chronic illness is on the rise as populations age

• Policymakers realise that without greater patient empowerment and self-care, healthcare systems will no longer be sustainable

• People living with chronic disease manage their condition alone, on average, more than 99% of the time
TRADITIONAL VS EMPOWERED

THE TRADITIONAL PATIENT

• Lets others control his health

• Is unaware that technology and information can put him in control

• Solely relies on caregivers for information concerning his personal health

THE EMPOWERED PATIENT

• Takes control of his own health

• Is used to control his life using new technologies, and expects to do the same with his health

• Is informed and uses different online channels and communities to stay informed about medical conditions, medicine and therapies
THE UPGRADE IS ALREADY HAPPENING IN OTHER AREAS OF OUR LIVES …

“I want to check out my next holiday site from my couch!”

“I want to watch Star Wars where I want!”

“I want to check the best hospital for my surgery!”

“I want to buy stuff when I want!”

“Dil toh roaming hai”
Changing role of patients

- Patients are becoming more active and vocal
- “Patient-centred” approaches to healthcare increasing
- Patients → from passive recipients to active partners
  - Self-management
  - Shared decision-making
  - Integrated care
- This requires a culture of openness, transparency and support for patients
Elements of Patient Empowerment

- EDUCATION
- EXPERTISE
- EQUALITY
- EXPERIENCE
- ENGAGEMENT
**Individual**

**Education**
Patients can make informed decisions about their health if they are able to access all the relevant information needed in an easily understandable format.

**Expertise**
Patients self manage their condition every day, so they have a unique expertise on healthcare which needs to be supported.

**Equality**
Patients need support to become equal partners with healthcare professionals in the management of their condition.

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**Organisational**

**Experience**
Individual patients work with patient organisations, to represent them and channel their experience and collective voice.

**Policy**

**Engagement**
Patients need to be involved in designing more effective healthcare for all, and in research to deliver new and better treatments & services.
To enable patients to express their informed preferences, patients must be given sufficient and appropriate information, including detailed explanations about their conditions and the likely outcomes with and without treatment. It is, however, frequently heard that patients express difficulties in obtaining information relevant to their needs.

There are various reasons for this. Health care professionals might have underestimated a patient’s desire for and ability to cope with information. Consultation times are limited and thus there is often insufficient time to fully explain the condition and the treatment choices.
Equality

• The empowerment model distinguishes confronting from arguing in that, in a confrontation, no judgements are made about the patient’s behaviour.

• If an adherence problem with medication exists, the pharmacist would explore potential solutions with the patient rather than giving a lecture on the importance of taking the medication.

• The empowerment model is thus one of mutual respect. The respect derives from the valuing of human life and the building of a good clinician-patient relationship.
Equality

• To ensure the success of patient empowerment, enhancement of the working partnership between patients and health care professionals is important. Finding out what matters to patients, making use of information technology to disseminate knowledge, establishing standards for disease management, and promotion of clinical research are likely to increase the benefit of the health care provided.

Engagement (Policy)

• Strengthening the complaint procedures and introducing patient forums, patient advocacy, and liaison are other measures to enable patient’s perspectives and views to be known for planning their own care and for service planning at a strategic level. The outcome will help to promote patient-centred care and to reduce health care costs.
Aspects of Empowerment

- Self efficacy
- Self awareness
- Confidence
- Coping Skills
- Health literacy
EMPOWERED PATIENTS ARE PART OF THE HEALTHCARE TEAM

FROM DOING THINGS “TO” THE PATIENT...

... TO DOING THINGS WITH THE PATIENT!

EMPOWERED PATIENTS ARE CRUCIAL FOR HEALTH SYSTEMS

- WE make informed choices about our treatment and care
- WE have a better relationship with health professionals
- WE are committed to adhering to our treatment
- WE are willing and able to take more responsibility for our care
- WE take preventive measures and seek earlier diagnosis which reduces hospitalisation and emergency visits

...ALL OF THIS REDUCES HEALTHCARE COSTS IN THE LONG RUN.
Steps to empowerment

• disclosure—the patient should be informed of the nature of the condition, the various options, potential risks, the professional’s recommendation, and the nature of consent as an act of authorisation;

• understanding—information is provided at the patient’s level of understanding, using appropriate language;

• voluntary—the patient must be in a position to practise self-determination free from any coercion, manipulation, or constraint;

• competence—based on the patient’s past experience, maturity, responsibility, and capacity for independent decision making; and

• consent—a freely given authorisation to the medical or nursing intervention.
Patients empowerment can help improve safety

Safety = a key aspect of quality
Patient-centeredness = a key aspect of quality

**Individual patient’s experience** of his/her healthcare “journey” = rich resource of information about gaps and failures in the system

Empowered patients can
- Help spot danger signs and inform on time
- Assist decision taking with personal information and responses (e.g. allergies)
- Respond intelligently to provider questions and
- Relate specific episodes & disease patterns
- Respond to triggers and avert complications
- Effective Self-management
Patient Speak

“When I received a new glucose monitor, I noticed the readings were not right. I noted all the readings comparing the old and new monitor ... Finally the nurses agreed there was a problem with the new brand of monitors.”

“When I read through my medical record, I noticed two mistakes.”

“If I can be working in partnership with clinicians I could have much more success at avoiding mistakes. Clinicians are full of good intentions and highly trained, but they are never going to be as committed to me and my health and wellbeing as I am.”
ELEMENTS THAT PREVENT THE EVOLUTION TO A FULLY EMPOWERED PATIENT

- Fragmented healthcare systems and eco-systems
- Privacy concerns.
- Provider Attitudes
- Outdated software systems (No EMR, disintegrated data)
- Outdated and weak regulatory mechanisms
- Low health literacy
Patient Empowerment Process

Barriers to Adherence
- Knowledge
- Disease
- Social Support
- Coverage
- Cost

Patient Empowerment & Community Engagement
- Motivational Interviews
- Disease Management
- Patient Counseling
- Health Coaching

Access
Support

Education

Adherent Patient

Engaged in Sessions
Meeting Goals
Improved Blood Glucose

Efficacy of Program, Modifications
- Survey Patients
- Program Completion
- HCP Feedback
- Case Manager Efficacy

Multichannel Communications
Individualized Messaging
Improved Patient Health
Aggregate Reporting Analytics/Insights
STAGES OF EMPOWERMENT

Stage 1
- Information about personal health situation
- Communication skills
- Health literacy

Stage 2
- Self-care support
- Decision-making
- Being connected

Stage 3
- Activated
- Take action
- Find information
- Organise questions
- Map options and choices

Stage 4

Know your own health
Initiatives at National level

- Agreement on common skill-set for patient-centred healthcare. Common definition of patient-centredness that can be used for comparative assessment
- Collect good practices of professional education (curriculum, patient involvement, communication, soft skills etc.)
- Agreement on minimum training requirements
- Indicators for patient empowerment
- Adoptions of IT for modernisation of health data
- Education resources/tools to support patients & repository of these resources
- Sustainable network on patient empowerment – “bottom-up action with top-down support”

“Professional training is absolutely key to patient empowerment.”

“Attitudes and practices that tend to undermine patients’ self-care efforts and inhibit them from participating won’t change until training changes.”

“The issue is how to exploit the innovations in an effective way”
At the National level

- Model for transferability of good practices
- Needs assessment of all healthcare initiatives from the patients’ perspective
- Common quality and safety standards for hospitals and healthcare institutions with mandatory accreditations
- Common quality standards for e-/mHealth applications

“The new generation of patients will be highly IT literate, therefore investing in it is essential.”

“Tools and gizmos should not be seen as THE answer to patient empowerment.”
Patient Solidarity Day takes place each December. Thousands of people from around the world rally around one key issue facing patients and raise awareness by hosting events and showing support for the Day.

This 2nd December, Saturday, IAPO members and the global patient community will have an opportunity to stress and highlight the message that patient empowerment can be a key driver to making healthcare systems and processes fairer and more patient-centric.
Not the right medicine

Spending an existing system, without a robust mechanism to implement a new one, will put patients at risk.

RATNA DEVI

Finding innovative ways to deliver healthcare in India has never been more important than it is today. With the declaration of the National Health Policy (NHP) 2017 and its letter to make universal health coverage (UHC) a reality, millions of people will flow into a healthcare system already strained by mounting costs and a short supply of doctors, nurses, and other manpower.

Reforming healthcare in India is crucial as the government is to deal with a long-term budget deficit and the assets of the country's healthcare sector.

It is very important to generate appropriate health data and then devise innovative ways of delivering healthcare.

The government's annual expenditure on public health and hospitals is double the budget of the country's entire defence budget. The question is: how do we move forward?

The government should consider revenue from the sale of pharmaceutical products to healthcare providers as a key revenue stream. This would put more money into the country's healthcare budget.

There are also concerns about the quality of public health and hospital services.

India's healthcare system is in dire need of reforms. Public hospitals in India have a high patient-to-doctor ratio, which makes it difficult for doctors to provide adequate care. Private hospitals, on the other hand, are generally well-equipped and have modern facilities.

One concern is the lack of investment in research and development. India spends less than 1% of its GDP on research and development, which is significantly lower than other countries.

Another concern is the lack of investment in public health and hospital infrastructure. Even in major cities, public hospitals are often overcrowded and lack basic amenities.

Government policies and initiatives can help address these challenges by encouraging private hospitals to invest in research and development, and by providing public hospitals with the necessary resources to deliver quality care.

Not only will this improve the quality of care, but it will also help reduce the cost of healthcare, making it more accessible for all.

Overcome barriers to health innovation

Research for new drugs & new diseases won't happen if we don't recognise R&D costs and value they deliver

PHARMACEUTICAL Companies, 13 have abandoned the antibiotic field.

For healthcare to be of better quality and more affordable, innovation is required on various fronts. This includes initiatives to make existing treatments more effective and less costly, providing access to more affordable treatments for people in need.

One way to achieve this is to encourage innovation in the pharmaceutical industry. By investing in research and development, companies can create new drugs and treatments that can help improve patient outcomes and reduce healthcare costs.

This is why it is so important for the government to create a supportive environment for innovation. This can be done by providing incentives for companies to invest in research and development, and by protecting intellectual property rights.

By doing so, we can ensure that the best possible care is available to all, and that the healthcare system is sustainable in the long term.

Healthcare in India is at a crossroads, and it is up to all of us to ensure that we are moving towards a more equitable, accessible, and effective healthcare system for all.
Thank You