



DakshamA Health & Education

*Your Voices Your Choices*



**IAPG**  
INDIAN ALLIANCE  
— of patient groups —

# PATIENT EMPOWERMENT **MYTH OR REALITY**

**8<sup>TH</sup> NOVEMBER 2017**



**HEALTHY INDIA ALLIANCE**  
for prevention and control of NCDs

# 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



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# 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 check the  
best hospital for my  
surgery!"



"I want to watch  
Star Wars where I  
want !"



"I want to buy stuff  
when I want !"

## 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



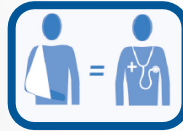
- EDUCATION



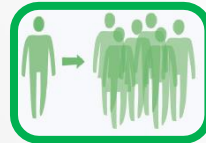
- EXPERTISE



- EQUALITY



- EXPERIENCE



- ENGAGEMENT



## Individual



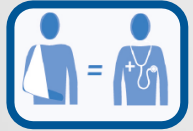
### Education

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

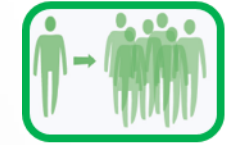
Patients self manage their condition every day, so they have a unique expertise on healthcare which needs to be supported



### Equality

patients need support to become equal partners with healthcare professionals in the management of their condition

## 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

## education

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.

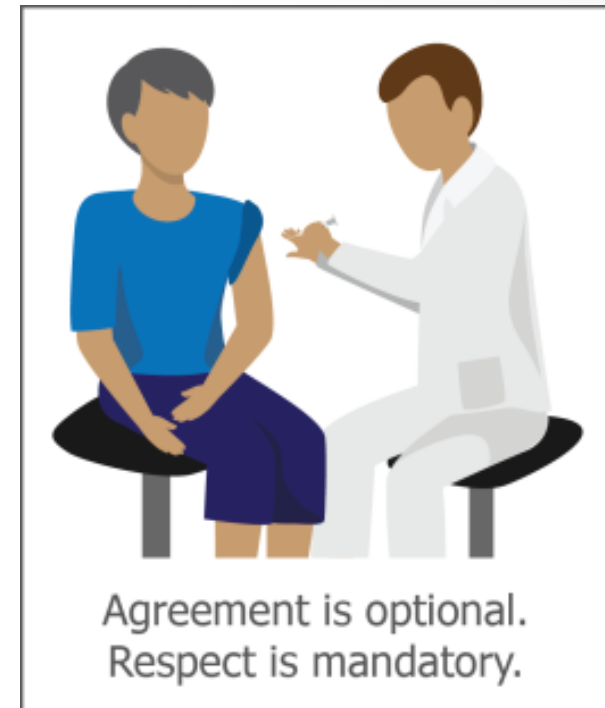


IMAGE PURCHASED FROM SHUTTERSTOCK.COM  
DESIGN BY L.LANDAU



## 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.

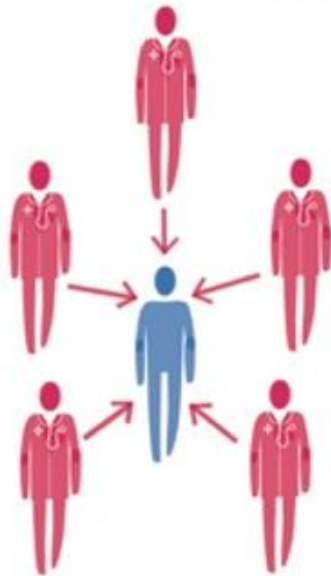
# Aspects of Empowerment

- 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

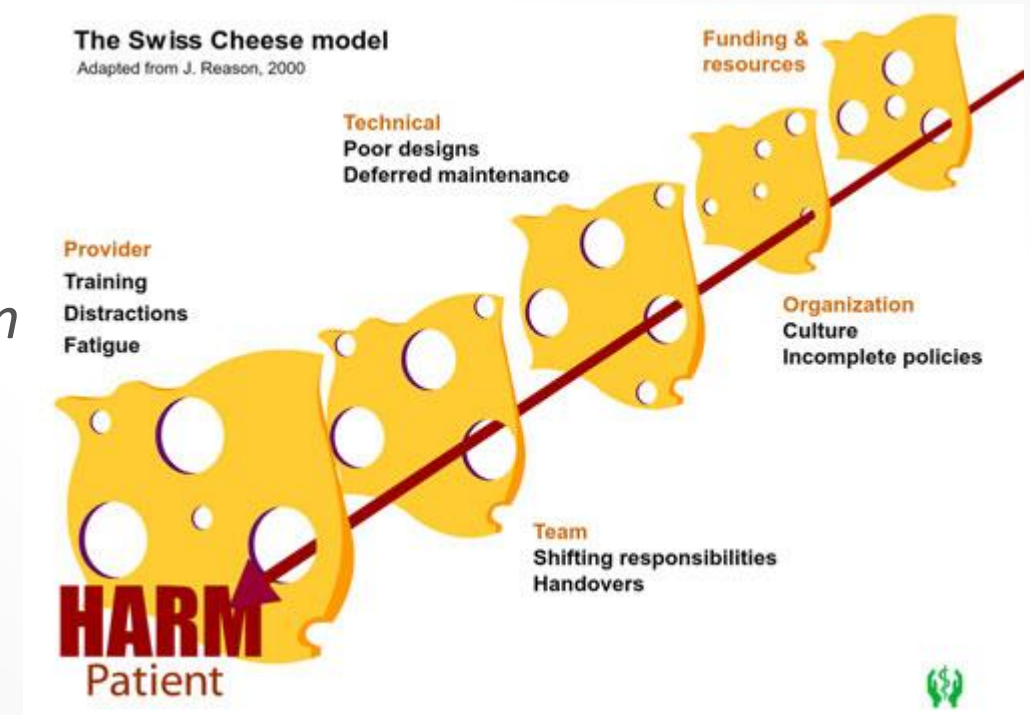
Safety = a key aspect of quality

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 (eg.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 read through my medical record, I noticed two mistakes.”

“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.”

“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.**”



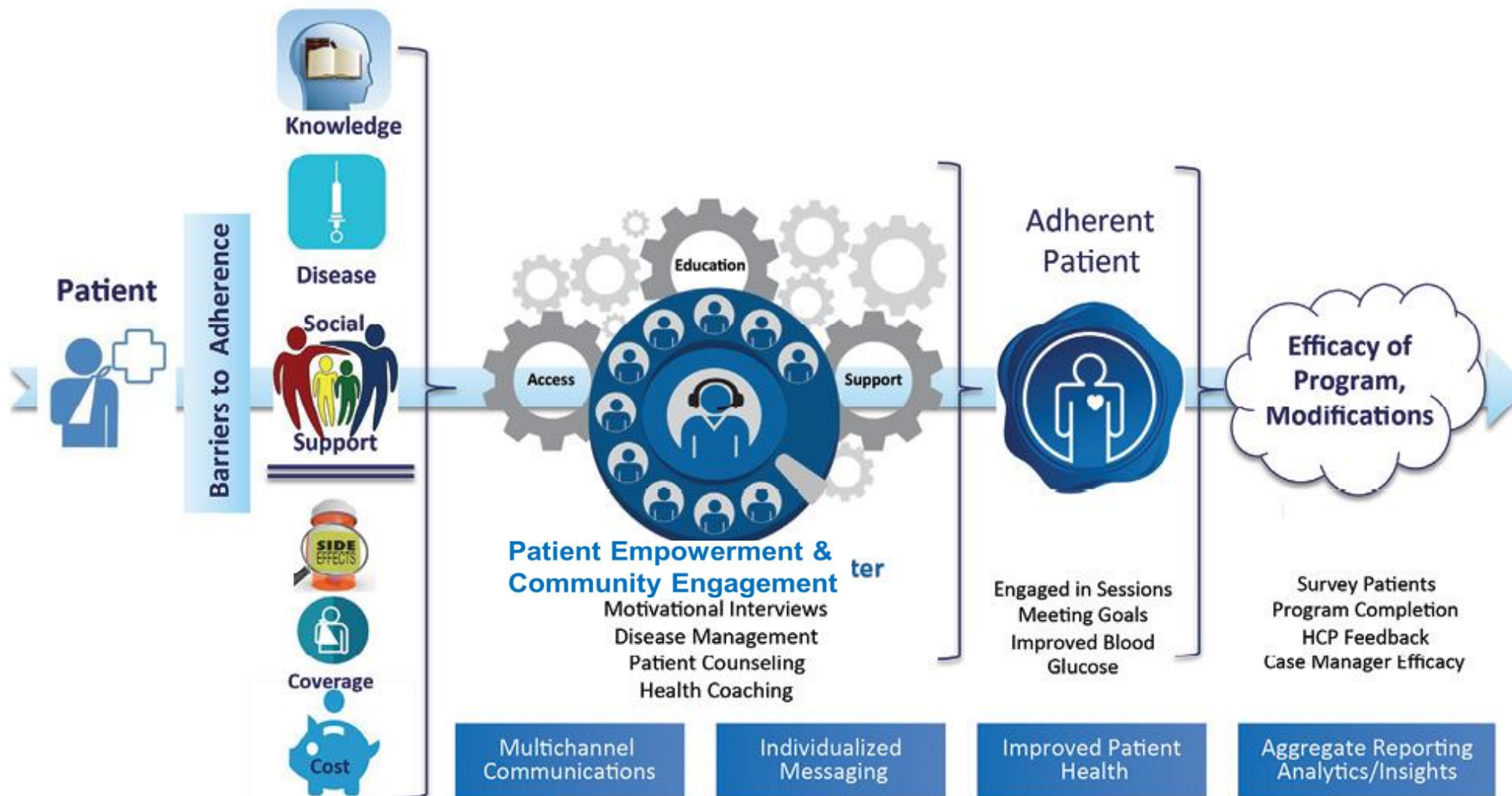


# ELEMENTS THAT PREVENT THE EVOLUTION TO A FULLY EMPOWERED PATIENT

- 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

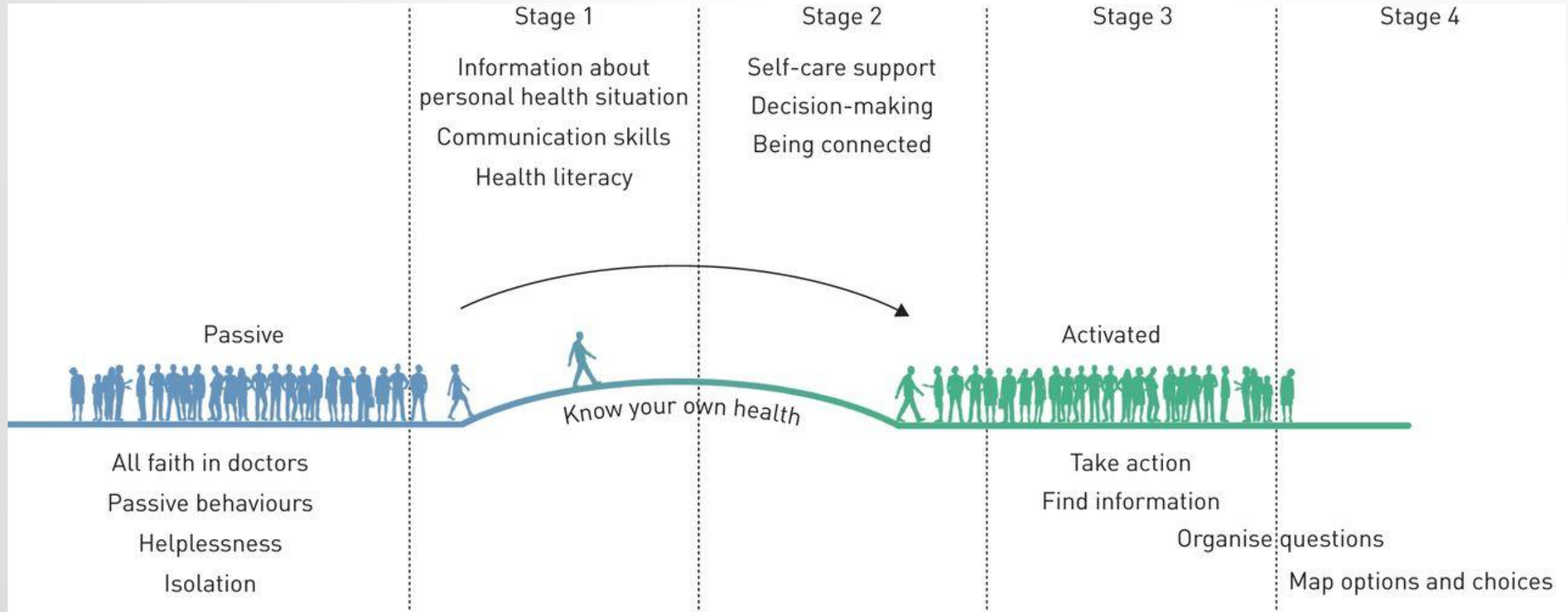


# Patient Empowerment Process





# STAGES OF EMPOWERMENT





## 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.”**



# Globally Empowered Patients: Power through Knowledge Patient Solidarity Day

2 December 2017 | #PSD2017 | [www.patientsolidarityday.org](http://www.patientsolidarityday.org)



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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 2<sup>nd</sup> 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

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

**RATNA DEVI**

CEO, DakshamA Health, and founding member, IAPG (Indian Alliance of Patient Groups)



**P**RIME MINISTER NARENDRA MODI's clarification for prescription of generic medicines by doctors has been welcomed by many. People feel this will dramatically reduce the price of filling out their prescriptions and end the perceived nexus between the industry and the physicians to promote branded medicines with sometimes much higher price.

India's healthcare system is disjointed. Most customers have no purchasing preference and even if a branded medicine is prescribed, there is no assurance that the patient gets the same medicine because there is no system to track prescriptions. It is usually the chemist who decides what the patient gets and with this new move, the chemist is king, being in a position to choose the generic offering him the highest return.

For a patient, there is also this confusion of what really is a generic—most people perceive it is a local preparation, loosely packed with scant quality parameters and very often this is true. Prescribing a generic would, therefore, leave the patient even more hapless and at the mercy of the dispenser as there is no way to understand which of the numerous generics is being given to him and why.

It is very important to understand generics especially in the Indian context, where there is a distinction between a generic that is branded and one that just has a chemical name. The patient, for whose benefit this measure is being rolled out, needs to be educated to understand that generic medicines are as good as branded products; more important, our regulator needs to ensure that this is so. Otherwise people who can pay will continue to buy branded medicines at a premium, leading to the creation of a grey market.

According to the article "Quality of Health Care in India: Challenges, Priorities, And The Road Ahead" (Health Aff (Millwood), October 2016, 25(10):1783–90), 77% of healthcare visits were to providers with no formal training. These providers prescribe allopathic medicines, usually dispensed from their own clinics. A recent report from the World Health Organisation (WHO), based on 2010 census data,

states that 31% of those who claimed to be allopathic doctors in MP were educated only up to the secondary school level. Fifty seven percent had no medical qualification. All these providers write allopathic medicines and there are no checks or mechanism to monitor their prescription behaviour.

Besides, many patients in India self-medicate, using an old prescription for years without visiting a doctor. Dispensing medicines in the country is a large and profitable business.

The entire ecosystem thrives on commissions and kickbacks. Moreover, pharmacies generally don't have qualified pharmacists and dispensers may be confused with this new directive. Upending an existing system, without a robust mechanism to implement a new one, will put patients at risk.

The government's attempt to promote generics in the public health system, through its Pradhan Mantri Jan Aushadhi programme, already faces several challenges. At present, these centres stock only a small percentage of the complete formulary and only a portion of essential medicines. We need to better understand efficacy, supply chain issues, storage and stocking

low public healthcare and high out-of-pocket expenses.

Under these circumstances, calling for mandatory prescription of generic medicines without laying the foundation for a change could result in further deterioration of the already overburdened system in the country. Patients could face sudden shortages of lifesaving drugs and life-threatening situations due to poor quality generics; and end up paying more due to prolonged illness.

While generic prescriptions could be a way to increase healthcare access, our challenges need to be thought-through and a long-term plan created that involves all stakeholders in planning, implementation and monitoring. Without this essential foundation, the intent will be diluted and the benefits remain a dream for the patient that it is meant to serve.



**F**INDING 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 intent to make universal health coverage (UHC) a reality, millions of people will flood into a healthcare system already strained by rising costs and a short supply of physicians, nurses and other resources.

Reining in healthcare costs is crucial if the government is to deal with a long-term budget deficit that is spiralling out of control and help patients manage catastrophic health events that drive families into the poverty cycle due to healthcare expenses that must be paid out of pocket.

How will an increasing number of people get quality care at a cost that the nation can afford? The answer is innovation. Unlike many other industries, healthcare has remained highly fragmented, with little health insurance coverage, a mostly out-of-pocket payment system and little regard for quality of care. The NHP 2017 looks at creative ways to make UHC a reality and proposes bringing together the government, the private sector and other stakeholders.

Also critical are respect for intellectual property (IP) and increased investment for research. We need the government to incentivise research for new medicines and

## Overcome barriers to health innovation

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

**RATNA DEVI**

CEO, DakshamA Health & Education



promote a robust IP environment that recognises the significant investment in research needed to bring new products from the lab to the patient. One primary method the government chooses to manage rising healthcare costs has been drug price control. However, a 2015 IMS study showed that price control on drugs does not increase access for those in need and actually has adverse effects on drug availability.

Pharmaceutical firms may exit a therapeutic category due to low profits, and low profits may also act as an entry barrier for new firms. Another report by IIM Ahmedabad, on whether drug price control increases access, concludes that there was a significant decrease in sales volume post price control, indicating decreased access.

Research for new drugs, for existing and new diseases, will not happen if we



don't recognise research and development costs for new drugs and value the outcomes they deliver. We urgently need new drugs to address emerging threats like anti-microbial resistance (AMR), as patients fail to respond to the usual antibiotic treatments. Efforts in the development of new antibiotics have essentially been stalled due to economic, regulatory and scientific obstacles. Of the 30 billion

pharmaceutical companies, 15 have abandoned the antibiotic field.

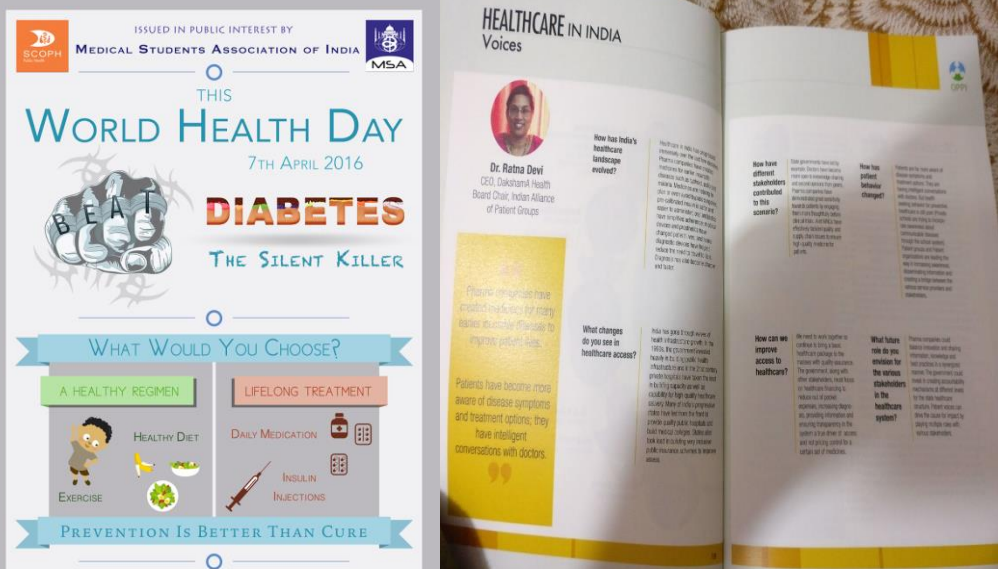
For healthcare to be of better quality and more affordable, innovation is required on various fronts. This includes changing how patients and consumers buy and use healthcare, using technology to develop new products and treatments, and generating new business models that involve the horizontal or vertical integration of separate healthcare organisations. Innovation can result in more convenient, more effective and less expensive treatments for today's time-strapped and empowered patients. It can reduce travel time and waiting time, and make communication better, stronger and more relevant. Technology can be a huge enabler for new drugs, diagnostic methods, drug delivery systems and medical devices, offering the hope of better treatment and care that is less costly, disruptive and painful.

Our healthcare system has several barriers to innovation. These obstacles can be overcome by managing the various factors that have an impact on healthcare innovation. Physicians working in small practices, hospitals and nursing homes are standalone, and the diagnostic, medical device and biotechnology sectors are made up of thousands of small firms. Therefore, innovative

activities can increase efficiency, improve care and save time.

Innovation in healthcare presents two kinds of financial challenges: funding the innovation itself and then figuring out who will pay how much for the product or service it yields. A major problem is the long investment time needed for new drugs or therapies. The meagre investment from the government adds to the magnitude of the problem. Government regulation of healthcare can sometimes aid innovation (HIV drugs) and at other times hinder it—difficulties in registering new drugs and a weak IP environment. A single-payer system (through public healthcare) hinders patient-focused innovation and seriously constrains technology-based innovation. The government's need to strictly control costs translates into less money for the care of the truly sick, who are the biggest beneficiaries of most technology-based innovations.

For innovation to thrive, the NHP 2017 needs to be inclusive and provide a level-playing field for all stakeholders, including the patients. It has to focus on an enabling environment and increase investments, not only for the provision of care, but also for research, including drug discovery, behavioural and economic influencers, and disruptive low-cost models that function outside the public delivery system.







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Full Member



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