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## Patient and public involvement and reducing the treatment gap: Our experiences

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If you want to know how well a pair of shoes fit should you ask the



Maker?

or

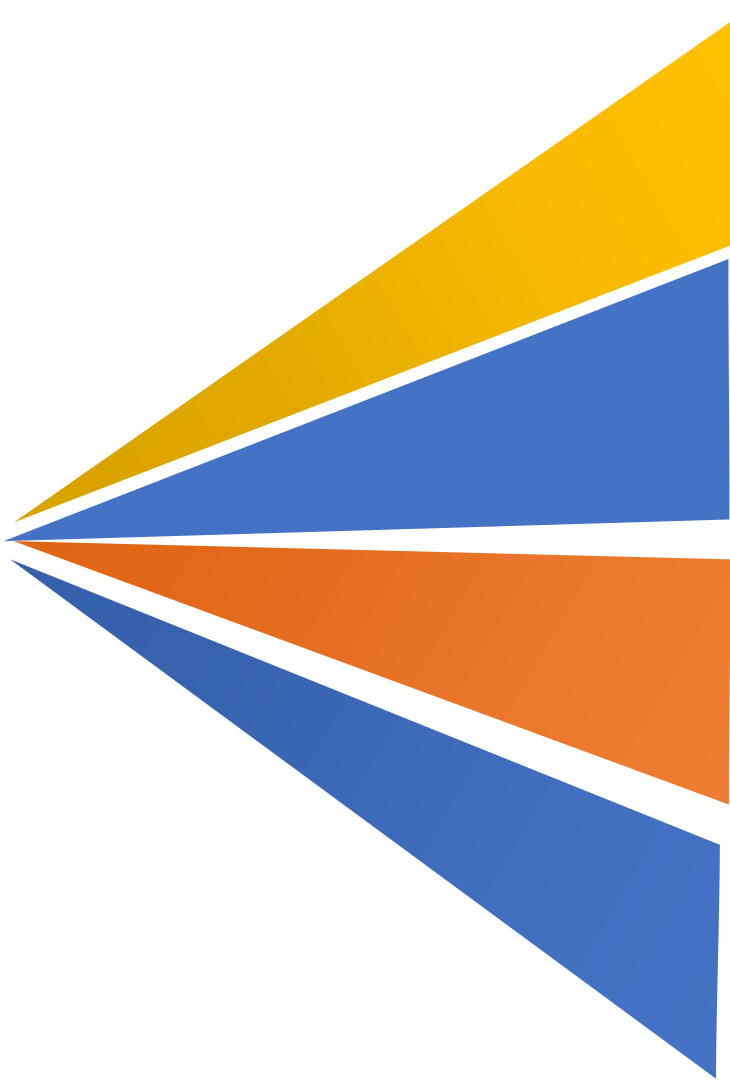
Wearer?

## Poll 3

Do you go out of your usual line of history taking to find out more about your patient with regards to non health related problems due to their disease?

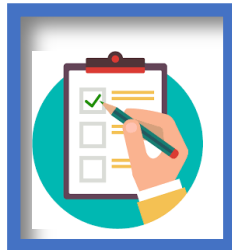
- Yes
- No

# Patient and public involvement and reducing the treatment gap



## Scope of the problem

Geographical isolation/illiteracy  
Poor health awareness  
False reassurance of low risk/Attitudes  
Post disease care  
Poverty



## Important preparatory steps

A platform for functioning



## Implementation road map

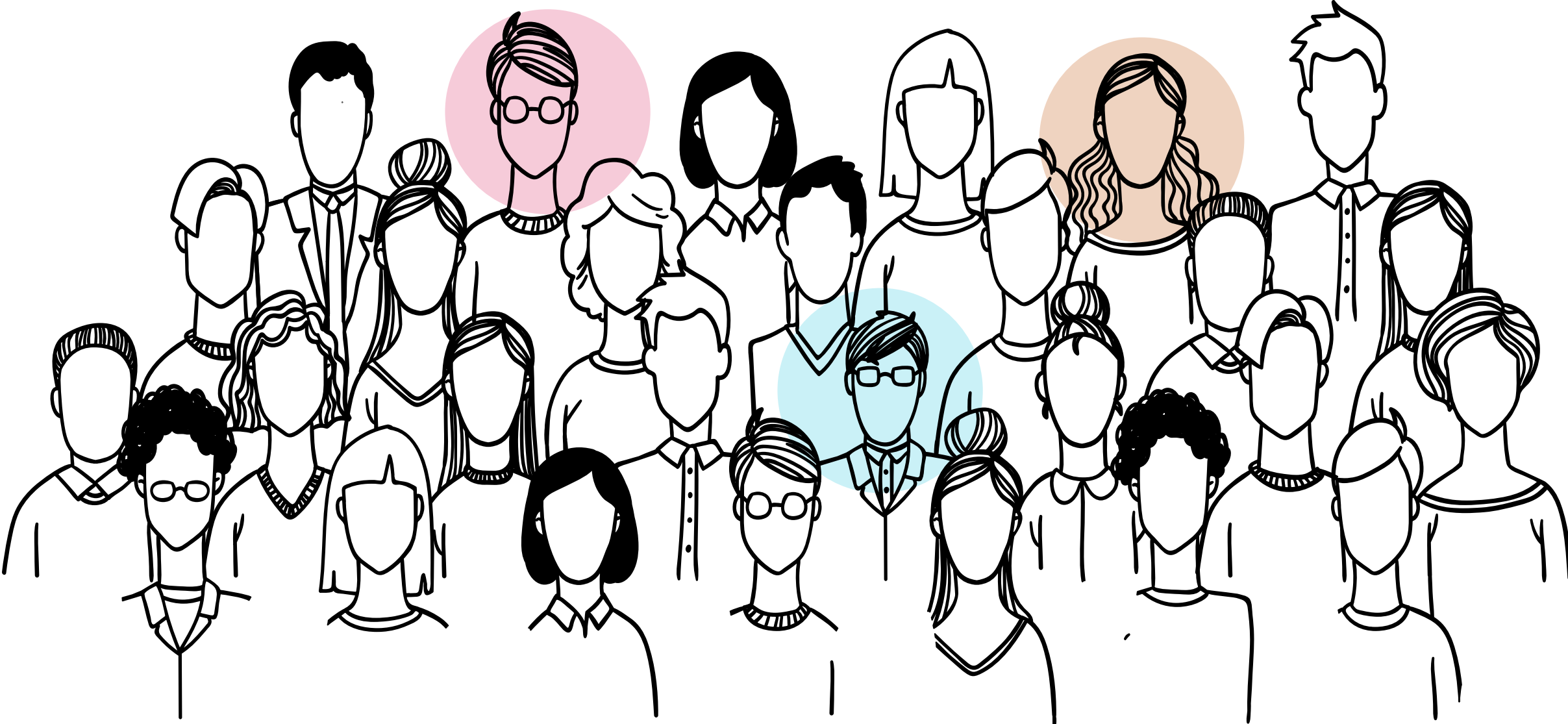
Education and feedback  
Outreach activities  
Media engagement  
Electronic tools  
Support groups.  
Public Patient involvement



## Trouble shoots

At every step

# Segment your Population





Schools/colleges/organisations  
*Neurology Health Hub*



Persons of importance  
Stroke mnemonic



General Public  
*Stroke prevention campaign*  
*Teleawareness programme*

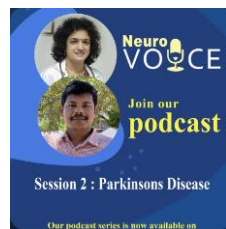


Women  
*EDuWAND*

## Patient and public involvement and reducing the treatment gap



Empowering patients  
Promising strategies  
Health apps



Caregivers  
Podcast, Media



Rural Resource poor  
*Neurology on wheels*

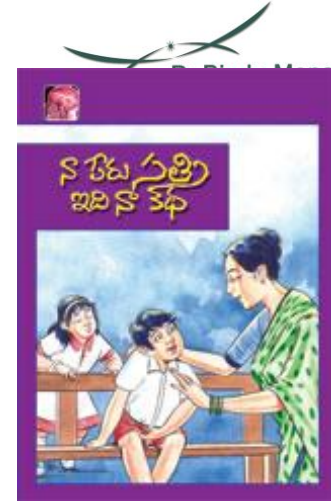
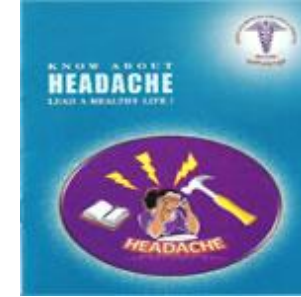


Disease specific  
*Support groups*



Schools/  
Colleges/  
Organisations

Neurology Health Hub



### Need of the project

Primordial and primary prevention

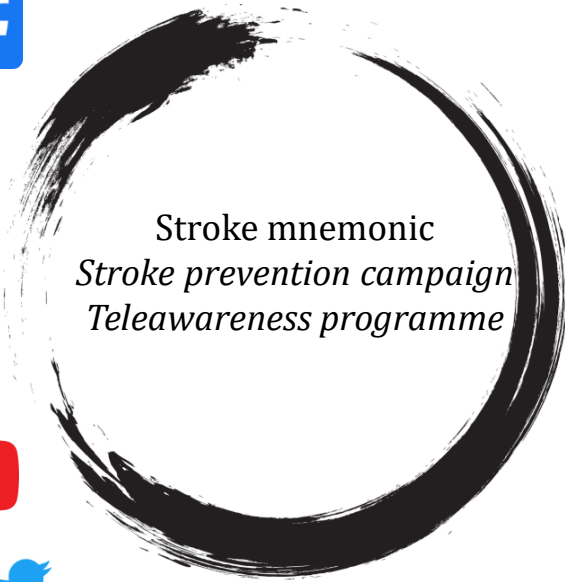
### Outline of project

- 1) Questionnaire is distributed
- 2) Awareness Programme is held
- 3) Posters pamphlets, comics is distributed
- 4) Games, competitions are held

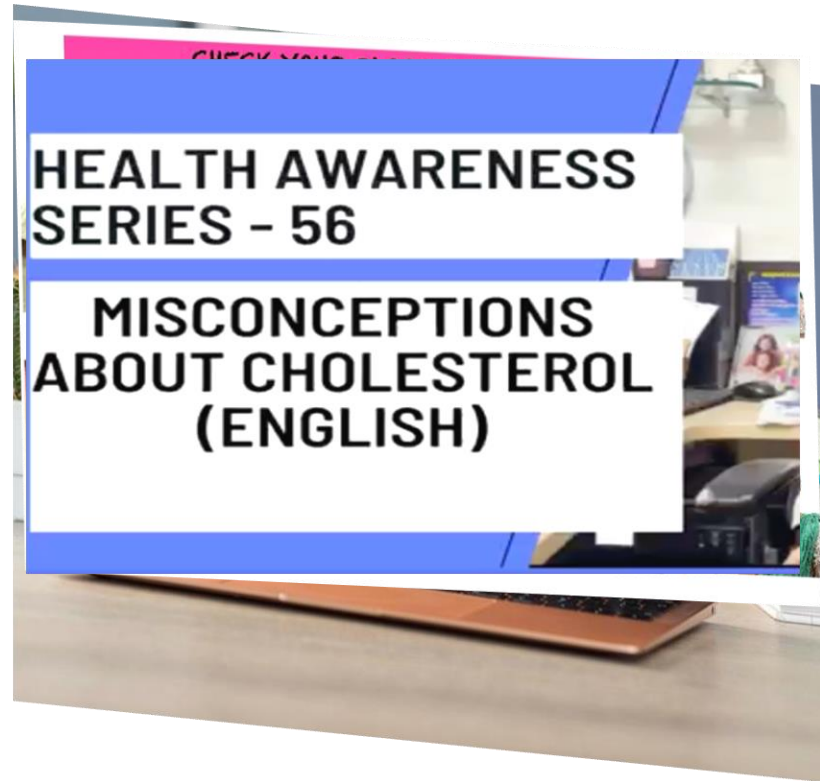


### Collaboration and impact

- 1) DMHO
- 2) DVEO
- 3) Commissioner of intermediate education
- 4) Principal
- 5) Teachers
- 6) Students
- 7) Lions, Rotary, Red cross



Stroke mnemonic  
Stroke prevention campaign  
Teleawareness programme



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Stroke  
Every 2 seconds  
someone suffers  
from brain stroke



Tele Awareness  
Ph. 1800 891 6977



Epilepsy  
Epilepsy affects  
1% of population



Know the facts  
Make a free call **1800 891 6977**  
Keep your brain healthy

## Need of the project

Primordial/primary prevention

Awareness of stroke, epilepsy and migraine

## Outline of project

- 1) Stroke Prevention campaign FB page was created and activity for 1 year
- 2) Stroke mnemonic in Telugu
- 3) Toll free number for recorded information



## Collaboration and impact

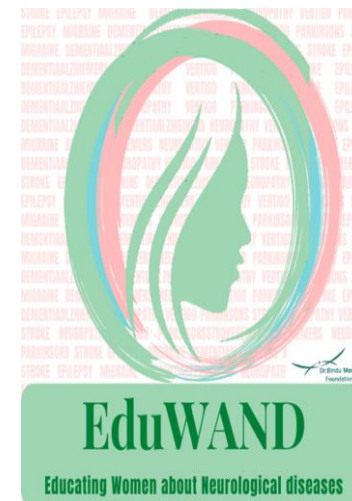
- 1) Celebrity
- 2) General public
- 3) Social media users
- 4) Across all ages
- 5) Sharing and forwarding





**Women**  
**EDuWAND**

**EDuWAND**  
**EDu**cating **W**omen **A**bout  
**N**eurological **D**iseases



**Need of the project**

Educating a woman would in turn educate the whole family.

**Outline of project**

- 1) Brain health
- 2) Risk factor identification
- 3) Risk factor prevention
- 4) FAST and local language (Telugu stroke mnemonic.
- 5) Preparedness during a stroke attack.



**Collaboration and impact**

Self help women group  
Organisations with women employees

## Disease specific Support groups



### Need of the project

A platform for patients to connect to others who are suffering with same disease

### Outline of project

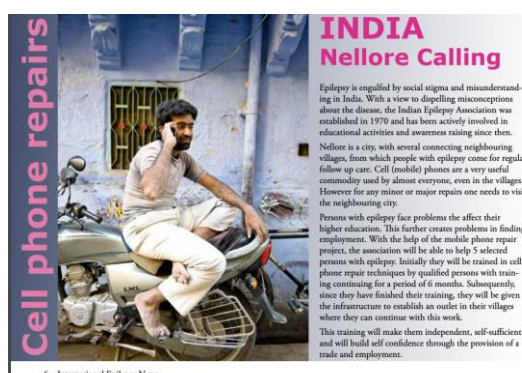
- 1) Weekly online exercise sessions
- 2) Phone counselling
- 3) Information
- 4) Online sessions for caregivers



### Collaboration and impact

Patients and caregivers  
Across pan India

Caregivers  
Podcast, Media  
Promising strategies  
Health apps

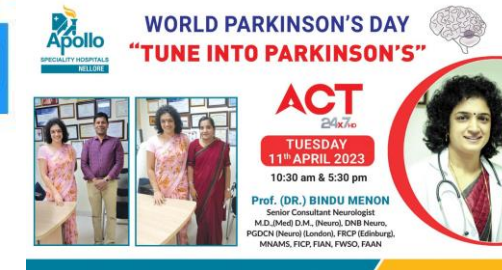
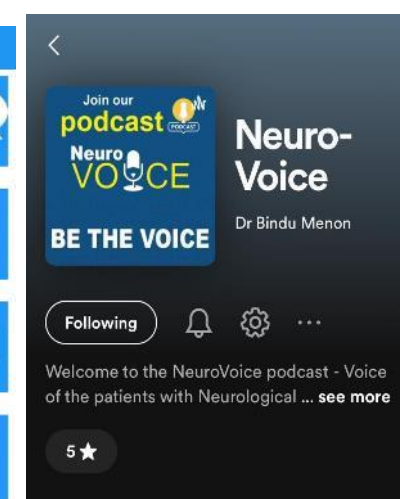


### INDIA Nellore Calling

Epilepsy is engulfed by social stigma and misunderstanding in India. With a view to dispelling misconceptions about the disease, the Indian Epilepsy Association was established in 1970 and has been actively involved in educational activities and awareness raising since then. Nellore is a city, with several connecting neighbouring villages, from which people with epilepsy come for regular follow up care. Cell (mobile) phones are a very useful commodity used by almost everyone, even in the villages. However for any minor or major repairs one needs to visit the neighbouring city. Persons with epilepsy face problems that affect their higher education. This further creates problems in finding employment. With the help of the mobile phone repair project, the association will be able to help 5 selected persons with epilepsy. Initially they will be trained in cell phone repair techniques by qualified persons with training continuing for a period of 6 months. Subsequently, since they have finished their training, they will be given the infrastructure to establish an outlet in their villages where they can continue with this work. This training will make them independent, self-sufficient and will build self-confidence through the provision of a trade and employment.



**STROKE HELP**



### Need of the project

Opportunity to speak out

Opportunity to earn and seek job

### Outline of project

- 1) Empowering patient
- 2) Lobbying with collector
- 3) Giving a voice to the patient /caregiver.
- 4) Connecting with health provider with health apps



### Collaboration and impact

- Patients
- Caregivers
- Legislative



# Geographic isolation Neurology on wheels

Reasons for Travel In Rural and Urban India (2015-16)



WE REACH



WE TEACH



WE TREAT



# Continuum of care

*Prevention*

Pre hospital



We care

Post stroke care

Acute stroke care





## Poll 4

Should the patient and their caregivers be involved while planning guidelines for patient care

- Yes
- No



Thank you