DAY 1: 8th March 2014

**Introduction & objectives of the program:**

A two day workshop on ‘Patient Compliance’ was organized by VISION 2020: The Right to Sight-India. The workshop was hosted by Dr. Shroff’s Charity Eye Hospital. LAICO designed the module for the workshop.

The workshop was specially to benefit member organisations from the north and central zone of VISION 2020 – India: professional bodies, institutions and individuals involved in patient compliance issues to understand the problem, identify barriers, formulate successful strategies to monitor, and define interventions to enhance compliance.

**Welcome address by Mr. AK Arora:**

Mr A. K. Arora, CEO, Dr. Shroff’s Charity eye Hospital (SCEH), Delhi welcomed all the delegates and appreciated the initiative to organise a workshop addressing compliance issues for treatment.

SCEH is celebrating 100 years of its establishment and Mr Arora traced the history of birth and 100 years journey of SCEH to become a state - of - the - art institute in eye and ENT care today. He reiterated the mission, guiding values and the quality policy of SCEH.

**Address by Ms. Sridevi Sunderarajan**

Ms. Sridevi Sunderarajan, Development Communication Officer, VISION 2020: The Right to Sight – India on behalf of Col Dr M Deshpande, President VISION 2020 – India greeted all the member organisation of VISION 2020 – India for participating in the workshop, some travelling from far off Gorakhpur and Jammu. She thanked Mr. AK. Arora and Dr. Suneeta Dubey, Associate Medical Director and Head of Glaucoma Department, SCEH, for hosting the workshop and Ms Dhivya for designing the module.

Ms Sunderarajan apprised everyone about the forthcoming workshops of VISION 2020 – India at zonal levels with a focus on felt-needs of the members. She emphasised on the need to conduct workshops which are more practical in nature. She announced two more workshops in 2014, one in Vishakhapatnam by Sankar Foundation and the other in east zone on quality.

Talking about the importance of a workshop on patient compliance, Ms Sunderarajan said that diseases like glaucoma and diabetic retinopathy required lifelong follow-up and care and that the treatment cycle is not effective until patient complies with treatment.

March 8 is also celebrated as International Women’s Day every year. She expressed her concern about inequality towards health and other needs of women.
Address by Dr. Suneeta Dubey

Dr Suneeta Dubey, Associate Medical Director & Head of Glaucoma Department, SCEH welcomed everyone to the Patient Compliance Workshop. She said that non-compliance is a major obstacle in the achievement of therapeutic goals and interventions need to be multifaceted, simultaneous and tailored for each individual patient. Dr Suneeta then introduced various modules of the workshop, summarized the purpose of the meeting and hoped that at the end of the workshop, there would be a consensus on how to tackle non-compliance more effectively.

Presentations made by the speakers, discussion points and question answers

The Highlights of the workshop are as follows:

Module 1: Patient Compliance understanding the problem

Panelists: Dr. Usha Yadav, Head of Glaucoma services, Gurunanak Eye Hospital & Mr, A.K. Arora, CEO Dr. Shroff’s Charity Eye Hospital New Delhi

Introduction of module - Ms. Dhivya Ramasamy

Introducing the module of the workshop, Ms. Dhivya Ramasamy, Faculty, LAICO, Madurai, said that compliance is critical for therapeutic success. She introduced the speakers for module 1.

Presentation on – Patient Compliance Understanding the problem
Speaker: Dr. Asim Sil, CMO, Netra Niramay Niketan, Vivekanand Mission Ashram, Haldia

Below are some highlights from the presentation made by Dr Sil:

- We need to own this problem of poor compliance.
- Let’s overcome it by understanding the patient as a whole, not just the disease but earning their trust through sincere service
- Physicians often do not communicate effectively to patients. They do not pay enough attention to patient’s affordability and accessibility of treatment and often ignore nonclinical cost of treatment. Also there is a perception that doctors advice unnecessary investigations and medications.
- Organized intensive campaign in a defined geographic area typically two weeks before harvesting.
- In 2013, no single case of paddy injury reported to our hospital from that area (Approx. 40,000 population). Earlier used to get 4-5 ulcers per harvesting season.

Presentation on – Compliance Issues for Chronic Eye Diseases
Speaker - Dr. Suneeta Dubey

Below are some highlights from the presentation made by Dr Suneeta Dubey:

- Taking a therapeutic regimen prescribed by a physician is compliance
- Assessing compliance poses challenges such as recall bias and over-statement by patients, cyclic behaviour of patients commonly called as ‘White coat syndrome’
- Compliance has several features such as failure to take medication, improper timing, overuse, use of wrong medication.
- Barriers to compliance can be broadly categorised as
  - Situational/environmental factors
Regimen factors
Patient factors
Provider factors
• Situational/environmental factors account for nearly 1/2 of obstacles
• Often there is little communication with patients due to time constraint, brief encounter, no incentive to provider
• Obstacles are at every step from awareness and seeking care to diagnosis and follow-up
• We need to change physician perspective, which may result in changes in patient behavior

Discussion:
Dr. Usha Yadav: One should treat the patient not the disease. We should not unnecessarily treat e.g. a blind eye.

Presentation on – Compliance Among School Children
Speaker - Dr. Suma Ganesh

Below are some highlights from the presentation made by Dr Suma Ganesh:

- Refractive error is the most common cause of avoidable visual impairment in children
- WHO Recommendation for refractive errors in children:
  - Screen for refractive errors
  - Spectacles to be given for Refractive Correction
  - Monitor outcome of refractive services
  - Use appropriate indicators and do operational research
  - Achieve goal of eliminating refractive error blindness in children – remove obstacles
- Major non compliance factors in 2 studies conducted (Pune study by Parikshit et al, IJO, 2013 and Dhakhiliya region of Oman, khandekar et al 2002):
  - Less compliance among boys
  - Less educated parents
  - Mild refractive errors
  - Teased about spectacles
  - Do not like spectacles - free spectacles no choice of fit and frame
- SCEH study - non compliance factors:
  - Less education of parents
  - Daily wagers or engaged in agriculture so no time
  - 65.3% children not using regularly – teasing by friends or relatives
  - 21.1% not happy with quality of spectacles or lost it
- We should take care of quality of glasses as well. Allow the child to choose so that the child is happy with glasses
- Many studies have shown that compliance to patching or occlusion therapy is a major factor affecting the outcome of treatment for Amblyopia
- For success of patching, parents must have belief in treatment method as well as should be aware of their role as ‘treatment - provider’ at home
- Social stigma about patching one eye should be removed by doctor before starting treatment
- Irrelevant negative side effects of patch presumed by parents must be addressed by doctor
- Fancy stickers should be used in order to promote patching by children.

Comments:
Dr. Asim: In Cuba, there is special school for children in amblyopia therapy
GROUP WORK
What are the barriers to patient compliance and presentation

Four Groups:
1. Cataract
2. Paediatrics and Refractive Error
3. Glaucoma
4. Diabetic Retinopathy

GROUP WORK:- 1 CATARACT

<table>
<thead>
<tr>
<th>Seek Care (Accessing care to enable early intervention)</th>
<th>Diagnosis &amp; Advice</th>
<th>Acceptance of Advice</th>
<th>Treatment (Getting drugs, specs, surgery etc.)</th>
<th>Self Care (Adhering to the use of drugs, specs etc.)</th>
<th>Follow up visit (to monitor treatment process and control the condition)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ignorance about disease</td>
<td>Skill of screening personnel</td>
<td>Cost</td>
<td>Myths about glasses after surgery</td>
<td>Physical disability</td>
<td>Distance</td>
</tr>
<tr>
<td>Ignorance of elderly and family attitude</td>
<td>Not adequate camp counselor</td>
<td>Follow up visits due to distance</td>
<td>Cost</td>
<td>Literacy cannot read prescription</td>
<td>Cost of travel</td>
</tr>
<tr>
<td>Lack of accompanying person due to distance, work schedule in urban and rural areas</td>
<td>Not enough educational materials</td>
<td>Follow up visits due to travel cost</td>
<td>absence of productive lenses</td>
<td>dependency on attendant</td>
<td>No escort</td>
</tr>
<tr>
<td>Availability and affordability, lack of transport</td>
<td>Enough counseling for GVP</td>
<td>Myths of treatment</td>
<td>Lack of infrastructure</td>
<td>Unable to understand hygiene instruction</td>
<td>Ignorance of importance of follow ups</td>
</tr>
<tr>
<td>Illiteracy, not able to care about himself</td>
<td>Outcome to be explained</td>
<td>Inadequate counseling</td>
<td>Not counseling for better surgical outcome</td>
<td>Inadequate counseling</td>
<td>Available of prescribed medicines in rural areas</td>
</tr>
<tr>
<td>Cultural taboo for visiting hospitals and seeking</td>
<td>Priority of patients for other disease along with Cataract</td>
<td>Confusion regarding type of lenses</td>
<td>Available of prescribed medicines in rural areas</td>
<td>cost</td>
<td>Available of prescribed medicines in rural areas</td>
</tr>
<tr>
<td>surgery</td>
<td>Myths about cost</td>
<td>Myths about outcome of the surgery</td>
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</tr>
<tr>
<td>Religious beliefs e.g. RAMZAN</td>
<td>Credibility of the institutes/Hospitals</td>
<td>Memory loss</td>
<td></td>
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</tr>
</tbody>
</table>

**Comments:**

Dr. Asim: Systemic diseases should be taken care of. There should be in-house physician to tackle this.

Dr. Usha Yadav: Ophthalmologist should him/herself know safe anti-hypertensive and hypoglycaemic drugs.

Dr. Ashok Natraj: Paramedical support staff can decrease the burden on doctor by following up cataract post-operative cases.

Dr. Asim: ANMs can identify blinds in community and refer for surgery.

**GROUP WORK:- 2 PAEDIATRICS AND REFRACTIVE ERROR**

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>awareness</td>
<td>physicians capacity to refer</td>
<td>Denial</td>
<td>lack of creativity to attract</td>
<td>teasing</td>
<td>harvest/sowing</td>
</tr>
<tr>
<td>Denial</td>
<td>competency</td>
<td>Myths</td>
<td>uniform standards of care</td>
<td>cosmesis</td>
<td>exams/festivals</td>
</tr>
<tr>
<td>social stigma</td>
<td>PHC available</td>
<td>lack of standards of care</td>
<td>not competent for child's Surgery</td>
<td>comfort choice of frames</td>
<td>lack of visible benefit</td>
</tr>
<tr>
<td>non availability of eye check up</td>
<td>infrastructure and instruments</td>
<td>lack of updating knowledge</td>
<td>cost</td>
<td>insignificant ref error Rx</td>
<td>lack of team support</td>
</tr>
<tr>
<td>eye care not a priority</td>
<td>training levels</td>
<td>unacceptable plan of treatment</td>
<td>provisions not under one roof</td>
<td>teachers attitude</td>
<td>poor prior counseling</td>
</tr>
<tr>
<td>Distance</td>
<td>referral network lack</td>
<td>conflict in opinions, medical shopping</td>
<td>local indigenous medicines</td>
<td>outdoor activities</td>
<td>affordability</td>
</tr>
<tr>
<td>Economic: daily wages</td>
<td>overconfidence</td>
<td>cost - clinical and nonclinical</td>
<td>chemists OTC</td>
<td>safety concerns</td>
<td>timings</td>
</tr>
<tr>
<td>experience of others</td>
<td>lack of standards of care</td>
<td>multiple visits</td>
<td>belief that disease is cured</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Beliefs | poor prognosis | specs are for ever |
<table>
<thead>
<tr>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>lack of primary care</td>
<td>timings of visits compatibility</td>
<td></td>
</tr>
<tr>
<td>acceptance of blindness in family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>home remedies</td>
<td></td>
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</tr>
</tbody>
</table>

**Discussion:**

Dr Suma Ganesh: Paediatric refraction is part of comprehensive care. All ophthalmologists should have basic knowledge. Most common obstacle faced is parent’s query for the removal of spectacles.

Mr. Prem: Binocularity is important. Sometimes it’s too late to treat.

**GROUP WORK: 3 GLAUCOMA**

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>Lack of awareness</td>
<td>Cost</td>
<td>Cost</td>
<td>Cost</td>
<td>No one to support</td>
<td>No one to accompany</td>
</tr>
<tr>
<td>Prioritization - felt need</td>
<td>lack of trained manpower</td>
<td>Trust on the provider</td>
<td>Availability</td>
<td>awareness</td>
<td>cost</td>
</tr>
<tr>
<td>cost of care/treatment</td>
<td>facility and infrastructure</td>
<td>lack of awareness</td>
<td>poor prognosis/expected outcome</td>
<td>cost</td>
<td>lack of adequate counseling</td>
</tr>
<tr>
<td>availability/access to care providers</td>
<td>too many options (for diagnosis)</td>
<td>confusion in advises &amp; different opinions</td>
<td>confusion in advises &amp; different opinions</td>
<td>expectation on outcome &amp; the actual results</td>
<td>expectation on outcome &amp; the actual results</td>
</tr>
<tr>
<td>lack of understanding of disease profile</td>
<td>poor prognosis/outcome</td>
<td>side effects</td>
<td>communication by the providers</td>
<td>ease of access to the providers (travel time, physical disability etc)</td>
<td></td>
</tr>
<tr>
<td>high expectations</td>
<td></td>
<td>no adherence to the frequency and dosage of medicines</td>
<td></td>
<td>lack of time</td>
<td></td>
</tr>
<tr>
<td>clarity in advise by the provider</td>
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</tbody>
</table>

**Discussion:**

Dr. Usha: Target IOP should be shared with the patient.
Dr. Suneeta Dubey: ‘Glaucoma support personnel’ can be great idea. One should have team approach

Dr. Asim: People often stop treatment after retirement

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**GROUP WORK:-4 DIABETIC RETINOPATHY**

<table>
<thead>
<tr>
<th>Seek Care (Accessing care to enable early intervention)</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Lack of knowledge (provider as well as patient)</td>
<td>Poor Patient Satisfaction</td>
<td>No Symptoms, hence not taken seriously</td>
<td>Non availability</td>
<td>Lack of awareness</td>
<td>Lack of tracking system</td>
</tr>
<tr>
<td>Lack of support from family</td>
<td>No Services available</td>
<td>Cost of treatment</td>
<td>Cost of treatment</td>
<td>Lack of Diet &amp; Exercise counseli ng</td>
<td>No incentive for service provider</td>
</tr>
<tr>
<td>perceived risk is very less (asymptomatic early phase)</td>
<td>Lack of wholistic approach in patient care</td>
<td>lifelong follow up</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct &amp; Indirect costs</td>
<td>Lack of communica tion b/w staff and patients</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

**Discussion:**

Dr. Manisha Aggarwal: Equipments are expensive. Even though one does good screening at camps, treatment is difficult at door step.

Dr. Ashok Natraj: Only 20% of DR cases need treatment, rest need follow-up. This is generally not accepted very well.

Dr. Asim: In KAP study, we found that knowledge gap is huge. Patient education is very important.

Mr. Prem: Paramedical staff can support screening of Diabetic retinopathy as they can screen with direct ophthalmoscope.
- We perform a good job once patient has come to the hospital but this represents tip of the iceberg. Therefore we need to educate the community.
- Also, Screening should be done outside the hospital.
- Eye-care providers should:
  - Ensure:
    - Awareness
    - Access
    - Affordability
    - Acceptance
  - Provide patient-centered care
  - Proactively devise ways to improve patient acceptance and compliance to treatment decision
- In order to provide effective treatment, we need to:
  - Good service design
  - Empowering patients and creating awareness
  - Educate patients
  - Monitoring and evaluation

**Module 2: Improve Compliance by Empowering Patients.**

Panelists: Dr. Asim Sil, CMO, Netra Niramay Niketan, Vivekananda Mission Ashram
Dr. Hitendra Ahooja, Medical director, Nirmaya, Gurgaon

Dr. Umang Mathur, Medical Director, Dr. Shroff’s Charity Eye Hospital introduced the module.

**Presentation on – Creating Awareness in the Community**

**Speaker** - Mr. Franklin Daniel, Assistant Director – Community eye health operation Eyesight Universal – India

- Large gaps exist between community, primary and secondary level services
- Under-utilization of existing Government infrastructure and services

**Steps to implement an health education strategy:**
- Situation analysis (Priorities & Target Groups):
  - PRA
  - Observational studies
  - Focus groups/ individuals
  - Comprehensive door to door survey/ KAP
- Objectives and results
  - Increase walk-in’s to the screening programme/ vision center/ base hospital
  - Significant reduction in backlog
  - Childhood blindness related to malnutrition, immunization etc. significantly reduced/ eliminated
- BCC strategy – delivered by
  - Community Health Workers
  - Medical/ Para-medical Professionals
  - Peers (School children, Self Help Groups, ANMs, ASHAs etc.)
- Evaluation
  - Results- Surgical conversion rate in screening programmes
    - Spectacle conversion rate in screening programmes
    - Walk-in to base hospital
    - Immunisation Coverage
- KAP Results: Significant increase in awareness, surgical and spectacle conversion

**Presentation on – Shared Medical Appointments: A Case Study From Cleveland Clinic.**
**Speaker** - Ms. Dhivya Ramasamy

- Series of one on one patient in group setting.
- Designed by Dr. Marianne Sumego (Director)
- 40 active groups

**Format:**
- Disease specific groups
- Annual examination
- Drop-in format for follow-up cases

**Agenda:**
- Group is divided into two subgroups
- One goes for history, examination, lab results and the other goes for education component then vice versa

**Advantages:**
- Manages wide range of chronic conditions (DM, HT, COPD, Asthma etc)
- Cross learning among peers
- Improves assess
- Enhances outcomes
- Promotes patient satisfaction

**Comments:**

Dr Ashok Natraj: It’s a good idea for low vision, albinism, ARMD, Retinitis Pigmentosa, and Diabetic Retinopathy etc

Ms Dhivya: We celebrate annual day for Pediatric glaucoma Patients

Dr. Umang Mathur: Keratoconus patients can also be called together.

**Presentation on – Patients First**

**Speaker - Ms. Tanuja Joshi, Managing Director, Venu Eye Institute & Research Centre**

- Patients are our identity
- Patient centered care:
  - Is respectful of and responsive to individual patient preference, need and values, and ensuring that patients values guides all clinical decisions
  - Identifies & responds to needs of individuals
  - Is planned & delivered in a coordinated way
  - Helps individuals to participate in decision making to improve their health
- Eight dimensions of Patient Centered Care:
  - Respect for patients preferences & values
  - Emotional support
  - Physical comfort
  - Information, communication & education
  - Continuity & transition
  - Coordination of care
  - Involvement of family & friends
  - Access to care
- Seven key factors to Patient Centered Care:
  - Leadership
  - Strategic Vision
  - Involvement of Patients
  - Care for the Care Givers
  - Systematic measurement & feedback
  - Quality of environment
  - Supportive technology
- In a service industry, product is ‘The Experience’. Focus on ‘Patient Experience’ as an outcome of the service received.
- Place patients at the centre of the system of care and develop good services that revolve around them.

**Comments:**
Ms. Dhivya: Feedback system should be encouraged for patient’s satisfaction

Presentation on – Patients Rights and Responsibility
Speaker - Dr Sunita Lulla Gur, Consultant, ICARE Eye Hospital & Postgraduate Centre, NOIDA

Patient’s Rights:

- Right to considerate and respectful care regardless of their belief, race, religion, and nationality
- Right to information on diagnosis, treatment and medicines. Informed consent for admission, procedures, high risk cases, research, etc.
- Right to obtain all the relevant information about the professionals involved in the patient care (Doctors degree, speciality, reg no, day and time of availability)
- Right to expect that all the communications and records pertaining to his/her case be treated as confidential
- Right to every consideration of his/her privacy concerning his/her medical care programme
- Right to expect prompt treatment in an emergency
- Right to get copies of medical records
- Right to refuse participation in human experimentation, research, project, affecting his/her care or treatment
- Right to know what hospital rules and regulations apply to him/her as a patient and the facilities obtainable to the patient
- Right to Grievance Redresal
- Right to know about your safety (identity of staff, handwash, verification of identity before any procedure, investigation etc)
- Right to get details of the bill (it should be uniform pricing policy)
- Right to seek second opinion about his/her disease, treatment, etc (provision of LAMA, discharge slip)

Patient’s Responsibilities:

- Provide correct and complete demographic information including name, age, sex, address, and telephone number.
- Provide details of present and past illness, family history where relevant
- Co-operate with staff in receiving prescribed treatment
- Treat staff and other patients with courtesy and respect
- Maintain hygiene and cleanliness.
- Keep appointment given by the consultant or other personnel.
- As far as possible avoid bringing valuables to the hospital.
- Inform the hospital about the health insurance or coverage by the employers
- Any other information which may have bearing on the treatment / health of the patient.
- Abide by hospital rules and regulations with regard to number and category of visitors, visiting hours, smoking, alcohol, tobacco use, maintaining silence zones.
- Be an informed patient. Also, take keen and proactive in your treatment and care.

Presentation on – Patients Support Group Activities
Speaker - Dr Priyanka Roy
• GSG started in 2008 at PGIMER
• To spread awareness about glaucoma
• Comprises of Volunteers, Paramedics, Ophthalmologists & Glaucoma Specialists
• ROLE of Glaucoma Support groups:
  ➢ Educate glaucoma patients by counseling and support glaucoma patients in diagnosis & treatment especially to under privileged sections of society
  ➢ Emphasize the importance of medication
  ➢ Collaborate with doctors & medical staff for patients periodic eye check up, treatment & follow up
  ➢ Collaborate with pharmaceutical company to enable & procure subsidised medicines for glaucoma patients
  ➢ Creating network of Nodal doctors

• Activities of Glaucoma Support groups:
  ➢ Emotional support
  ➢ Social support
  ➢ Financial support
  ➢ Increase pool of glaucoma doctors by conducting workshops for comprehensive ophthalmologists
  ➢ Sensitize Paramedical Professionals

Presentation on – Effectiveness of Interventions to improve patient Compliance
Speaker - Dr Hitendra Ahooja, Medical Director, Niramaya Charitable Trust, Gurgaon

• Factors associated with compliance are broadly divided as:
  ➢ Patient centered (demographic factor, psychological factor, physical difficulties, health literacy, patient knowledge)
  ➢ Health care system (lack of Accessibility, unhappy clinic visits, long waiting time)
  ➢ Therapy Related (route of administration, treatment complexity, duration of treatment, medication side effects)
  ➢ Social and Economic (inability to take time of work, cost & income, social support)

• Various interventions to improve compliance can be:
  ➢ Mass communication through walks, lectures
  ➢ Involving Religious gurus
  ➢ Painting competitions etc
  ➢ Mobile eye vans
  ➢ Educational material like books, e-books, audios, videos
  ➢ Vision centres
  ➢ Mobile eye vans
  ➢ SMS alerts and phone call reminders for refill, appointment
  ➢ Long Waiting Time Interventions such as avoiding busiest time, pre-appointments
  ➢ Provide consultation & visit to same doctor
  ➢ Therapy Related Interventions (Proper counseling, alerting Patients to what’s ahead, clarity of facts, medication side effects)
  ➢ Good behavior of staff, doctors & counselor
  ➢ Pick up & drop facility and free medicine in charity
  ➢ 24 Hours connectivity for medical assistance via phone, SMS, email, social media
Dr. Sandeep Bhuttan, PDA Eye Health & Health Systems strengthening (Asia) Sightsavers apprised every one with vision, mission, history, and Strategic approach to eye care of Sightsavers in India. He then reiterated few terms related to compliance. He said there are two types of approaches to community:

1. **Top down approach:** Service provider decides community needs (Assumes) and most appropriate intervention (for the provider). He then communicates information to the community and allocates resources (capital & manpower) for implementing intervention. Subsequently, he assesses impact of the intervention & subsequent approach.

2. **Bottom up approach:** Community Members Identify their own (True) needs (Prioritize) and work out the most acceptable mode of intervention. They then coordinate with suitable providers for necessary technical inputs and pitch-in their own resources for implementation. Subsequently, they provide feedback for programmatic improvement.

- Ideal scenario is when providers support the communities for the implementation of **community directed** interventions with **full utilization** of inherent and upgraded **community resources & capacities**.
- Onchocerciasis (River Blindness), endemic in central Africa, caused by a parasitic worm O. Volvulus is a perfect example of community directed intervention.
- Vector (Blackfly) control by insecticide spray or mass treatment with Ivermectin (outside-in approach) was not sustainable while community directed treatment with Ivermectin is feasible, effective and likely to be sustainable
- Community ownership is people working together voluntarily to achieve their own initiatives using available resources to shape their own destiny
- Essential requirements for effective community ownership are:
  - **Awareness** (Knowledge of what is to be done)
  - **Empowerment** (Capacity to do what is to be done)

**Benefits of Community Ownership:**
- Increase community, individual, and group capacity to identify and satisfy their needs
- Improve program design
- Improve program quality
- Improve program results
- Improve program evaluation
- Cost effective way to achieve sustainable results.

**Presentation on** – Practical Steps to improve patient Compliance.
**Speaker** - Dr Asim Sil

- There was huge knowledge gap found in KAP study
- So to increase knowledge following interventions were made:
  - Posters
  - Folk performance
  - Hoardings
  - Information booklet
  - Mass awareness activities
  - Stalls in fairs
  - Group meetings and CMEs
  - Rallies on world diabetic day
  - Orientation of RMPs
  - Educating rickshaw pullers
- Other interventions made:
  - Free cataract surgery combined with Diabetic retinopathy camps
GROUP WORK
How To Empower Patients to enhance compliance

Group work was omitted due to time constraint.

**Presentation on** – Role of counselling
**Speaker** – Ms. Dhivya Ramasamy

- Role of counsellors:
  - Increase awareness
  - Moderate the expectations of patient
  - Increase in compliance to treatment
  - Gives instructions

- Amendments adopted at Arvind eye care which can change the mind of counsellors:
  - Step by step method of counselling
  - Calculating acceptance rate
  - Incentive to counsellors

**DAY 2: 9th March 2014**

**Module 3: Enhancing Compliance through better services Design**

Panelists: Dr. Noshir Shroff (Shroff Eye Centre, New Delhi)
Dr. A.K. Grover (Sir Ganga Ram Hospital & Vision Eye Centres,
New Delhi)
Moderator: Ms Dhivya

**Presentation on** – Effectiveness of Interventions to improve Compliance
**Speaker** – Dr Manisha Aggarwal, Head of Retina Services, SCEH

- Burden of diabetic retinopathy is increasing. Eighteen million were approximately affected in 1995, 54 million expected to be affected in 2025.
- Diabetic retinopathy is sixth major cause of blindness in world
- There are several risk factors like duration of disease, control of blood sugar level, anemia, type of diabetes, pregnancy, hypertension, and renal failure etc.
- Problem is multi-factorial (lack of awareness, cost, visiting a diabetologist, no leave from job/daily wagers etc)
- Interventions done at Dr. Shroff's Charity eye Hospital:
  - Printed Educational Material
  - HbA1c strip test
  - In house Internist
  - Special files printed
  - Diet counselor visits every week

- Impact:
  - Increasing number of diabetics visiting DR clinic with good metabolic control (30-40% vs 60-70 %)
  - Complete management under one roof.

**Presentation on** – Improving Compliance among eye cancer patients
**Multimodality Management**
**Speaker:** Dr. Sima Das, SCEH

- Management of Retinoblastoma has progressed from saving life to salvaging eye and now restoring sight.
- Problems:
- Awareness/lack of guidance
- Financial reason
- Poor acceptance of treatment
- Inability to provide service under one roof
- Timing of various management modalities

- Integrated treatment centre at Dr. Shroff's Charity eye hospital:
  - Pediatric anesthesia and surgical suite
  - Seed grant (2013) - Focal therapy modalities like TTT and cryotherapy
  - Focal therapy under supervision of ocular oncologist
  - Training of pediatric oncology nurses
  - In house chemotherapy under supervision of pediatric oncologist
  - In house pediatrician for therapy monitoring
  - Collaboration with ocular onco-pathologist
  - In house Customized ocular prosthesis lab - cosmetic rehabilitation

- Impact:
  - Initiation of treatment within 24 hours of presentation
  - Reduced cost
  - Reduced travel for patient
  - Better acceptance of treatment
  - Better compliance
  - Coordinated treatment - more effective
  - Better monitoring of complications

- We incorporated chemotherapy for RB patients in 2014 and from a high attrition rate of 50%, significant drop in poor compliance was noted.

- This shows that patients have more faith when we provide critical arms of treatment under one roof. And we achieve better results in cancer treatment.

**Presentation on** – Patient Support Groups  
**Speaker** – Mr. Anurag Dhingra, Alcon

- Patients claim they take their drugs more than they really do
- Non-compliance includes:
  - Failing to get a first prescription or subsequent repeats dispensed
  - Discontinuing a medicine before the course of therapy is complete
  - Taking more or less of a medicine than prescribed
  - Taking a dose at the wrong time
- The Travatan Dosing Aid Study found that nearly 45% patients using an electronic monitoring device who knew they were being monitored and were provided free medication used their drops less than 75% of time.
- **Some suggested measures are:**
  - Educating patients about disease and treatment
  - Simplifying drug regimes by minimising number of drugs & frequency of doses
  - Using modified or controlled release preparations to decrease dosage frequency
  - Involve patients in decisions about medicines
  - Involving carers in management of medication
  - Telling patients about common early side effects to which they may develop tolerance
  - Using medication charts, calendars or note pads for reminders
  - Organise motivational sessions with trained counsellors and also encourage each patient to interact with each other so that they can share their experience & be inspired
  - Trained Hospital Staff
- Use pharmacy pillboxes etc.
- Using large print or jumbo labels on containers
- Help patients set reminders on their phones
- Propagate patients to write an Excel spreadsheet
- Use of mobile apps-’My Med Schedule’ on smart phones mobile app
- The mnemonic **SIMPLE** helps categorize efforts to increase patients compliance:
  - Simplify regimen
  - Impart knowledge
  - Modify patient beliefs and human behaviour
  - Provide communication and trust
  - Leave the bias
  - Evaluate compliance

- **On the part of industry, measures can be:**
  - Generate Patient education material in simplified language
  - Engage in Patients Support program
  - Providing medication assistance to the needy
  - Patient compliance kits
  - Additional Avenues of interactions b/w patient and physician through camps

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**Presentation on – Simple Design**

**Speaker** - Dr. Monica Gandhi, SCEH

- OPDs is considered as the window to hospital services “The first impression”
- It is also well-established that 8-10 per cent of OPD patients need surgery
- Mostly geriatric patient find it difficult to wait
- Potential patient for revenue
- An average 4-5 hours spent by cataract patient. 70 % approximately conversion rate
- Intervention: Establish a system to fast-track patients with cataract through the diagnosis and pre-surgery process.
- Fast track systems involves
  - Identifying cataract patients at registration or at clinic (questionnaire or clinic exam)
  - Indentify the patient file (Red file or yellow jacket)
  - Prioritize their care (During dilatation Biometry, syringing, ECG and other investigations completed, if willing for surgery within 3 months).
  - No need to repeat Biometry- Validity up to 2 yrs
  - Repeated only if fellow eye post operative refraction is more than +/- 0.75 D Sph and/or +/-1.00 D Cyl
  - Syringing Valid up to 12 months, if patient is symptoms free.
  - No repeat PSC work up required if the patient has undergone cataract surgery <3 month under LA/TA.
  - ECG to be done for patients > 50 years & valid for 6 months.
  - No blood thinners to be stopped for cataract surgery patient
  - Surgery fixed for next day – If patient is not surgeon orientated & etc

Impact: Increase in surgical conversion rate of cataract patients

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**Presentation on – Patient Experience:**

**An influence on Compliance**

**Speaker** - Mr. Shantanu Das Gupta, SCEH

- A good customer experience occurs when expectations are aligned with experience to create satisfaction and in our context, leading to better compliance
- The core values: the patient first
• Happy employees = Happy patients
• Bad and good experience are remembered for more time
• Challenges in community setting:
  ➢ Volume of Patients
  ➢ Language
  ➢ Culture
  ➢ Scarce resources
  ➢ Interpretation of consumer behavior
• Patient Experience is a game changer for compliance.

GROUP WORK
Improving Services Design to Enhance Compliance

Group work was omitted due to time constraint.

Module 4: Strategies to Monitor Compliance

Introducing the Module - Dr Suneeta Dubey

Dr. Suneeta Dubey addressed all participants and said that Adherence often is described in binary terms ‘ADHERENT OR NONADHERENT’ or vague descriptions ‘POOR OR GOOD ADHERENCE’. However, we actually need to the gauge the level of compliance in our patients. The highlights of the module are as follows:

Presentation on – Metrics for Compliance
Speaker - Ms. Dhivya Ramasamy

• Patient must understand the following things:
  ➢ What is my disease?
  ➢ What will happen if not treated?
  ➢ What are symptoms?
  ➢ Is it related to other systemic diseases?

• We need to assess that
  ➢ Are patient aware of services?
  ➢ Do patient access our services?
• We can monitor accessibility like waiting time, number of appointments per doctor etc
• We can also mention postal code number to identify where do they come from?
• We can assess what type of patients have low acceptance for surgery such as gender, location, lens type, visual acuity, visual prognosis etc.
• Also we need to assess while writing prescriptions that can my patient afford it or is the refill easily accessible or does he perceive improvement?
• We can code the patient as per seriousness of disease and then do counseling accordingly.
• Counselors can be asked to maintain records on excel sheet and monthly review them.
• Also we can keep track of patients experience and expectations by conducting outpatient satisfaction survey by means of questionnaire.
• We can also compare level of satisfaction between paying and free patients.
• It is advisable to maintain a suggestion notebook and write action taken against below on the same page so that patient realizes that it are being actively taken care of.
• Another good idea is informal staff interaction with patients regarding their experience.
• Use of collected data is equally important.

Presentation on – What you measure tends to improve
Over 2,000 years ago Hippocrates warned physicians to keep watch also on the faults of the patients which often make them lie about the taking of things prescribed.

In developed countries, adherence among patients suffering from chronic diseases averages only to 50%, the magnitude in developing countries is assumed to be even higher.

Thus a worldwide problem of striking magnitude

The state-of-the-art measurement techniques:
- Clinician Estimated compliance (affected by white coat adherence)
- Self Monitoring (affected by recall bias)
- Electronic Health Records
- Electronic Monitoring
- Pill Count
- Pharmacy Records

None of the methods is very efficient practically

Giving dosing instructions is very important

Survey shows that compliance depends on whether a serious event is experienced due to non-compliance or the symptom is not relieved.

Subsequent to the entire group work presentations and discussion, workshop ended with a summing up & valedictory. The workshop was exceedingly appreciated by all the participants. We would also like to thank all speakers & facilitators of the workshop for their able support for making it a success. We give our sincere thanks to all the participants of the workshop.

The following participants attended the workshop

1. Mr. AK Arora (CEO Dr. Shroff’s Charity Eye Hospital New Delhi)
2. Dr JC Das, (Shroff Eye Centre, New Delhi, President, Glaucoma Society of India)
3. Dr Suneeta Dubey, (Associate Medical Director, SCEH).
4. Ms. Dhiyya Ramasamy (Faculty LAICO Madurai)
5. Dr. Umang Mathur, Medical Director, SCEH
6. Dr. AK Grover (Sir Ganga Ram Hospital & Vision Eye Centres, New Delhi).
7. Dr Monica Gandhi (Consultant Ophthalmologist SCEH, New Delhi)
8. Mr Anurag Dholakia (In charge glaucoma portfolio, Alcon India)
9. Dr GV Rau, (Executive Director, Hans Foundation)
10. Ms. Tanuja Joshi (Managing , Venu Charitable Society New Delhi)
11. Dr Ashi Khurana (CEO, C.L. Gupta institute, Moradabad)
12. Dr Ashok Natraj (Retina Consultant, Little Flower Eye Hospital, Cochin)
13. Dr Asim Sil (CMO Vivekananda Mission Ashram Haldia)
14. Dr Hitendar Ahoja(Medical Director, Niramaya Charitable Trust, Gurgaon)
15. Dr Sandeep Bhuttan (Program Development Advisor Eye Health ASIA Sight savers)
16. Mr. Danial Franklin (Assistant Director CEH, Operation Eyesight Universal)
17. Dr Sunita Lulla Gur (Consultant Anterior segment & Low Vision, ICARE Eye Hospital Nodia)
18. Dr Abhishek Dagar (Ophthalmologist Venu Eye Institute)
19. Dr Renu Siwas, Venu Eye Institute
20. Ms. Renu Saxena, Venu Eye Institute
21. Mr. Manish Kumar, Programme Manager, ORBIS International
22. Mr. Gaurav, CL Gupta Eye Hospital, Moradabad
23. Fr. Wilson CD, Fatima Eye Hospital, Gorakhpur
24. Mr. Vijay Tripathi, Fatima Eye Hospital, Gorakhpur
25. Mr. Subeesh Kuyyadiyil, SNC, Chitrakoot
26. Ms. Satakshi, Drishti Eye Hospital, Dehradun
27. Ms. Anuradha, Drishti Eye Hospital, Dehradun
28. Mr. D N Sharma, Rotary Eye Hospital, J & K
29. Dr. Manoj Yadav, Rotary Eye Hospital, J & K
30. Dr Joseph Gudugurand, Vision Eye hospital Hubli
31. Mr Reuban, SIH-R and LC, Karigiri, Tamil Nadu
32. Mr. Irshad, I Care, NOIDA
33. Dr. Partap Kumar Midha, Director & Trustee, Global Eye Hospital, Abu
34. Dr. Vishal C Bhatnager, Chief GHIO Services
35. Mr. Subhanker Roy, Indira Gandhi Eye Hospital and Research Centre
36. Dr Manisha Aggarwal (Retina Consultant, SCEH New Delhi)
37. Dr Sima Das (Occuloplasty Consultant, SCEH New Delhi)
38. Dr Umang Mathur (Medical Director, SECH New Delhi)
39. Dr Suma Ganesh (Head Paediatric Services, SECH Delhi)
40. Dr Priyanka Roy (Secretary Glaucoma Support Group PGIMER Chandigarh)
41. Dr Noshir Shroff (Director, Shroff Eye Centre New Delhi)
42. Mr. Shantanu Dasgupta (Deputy General Manager, SCEH, New Delhi)
43. Dr. Manish Aggarwal (Alwar, SCEH)
44. Mr. Dharmendra Singh (Community Outreach services, SCEH)
45. Dr. Ramesh Vantatesh (Retina specialist, SCEH)
46. Dr. Anugya Agrawal (Ophthalmologist (Glaucoma Fellow), SCEH)
47. Mr. Anil Kumar Thakur (Counsellor, Dr. Shroff’s Charity Eye Hospital)
48. Mr. Anthony (Counsellor, Dr. Shroff’s Charity Eye Hospital)
49. Mr. Prem Kumar Singh (Optometrist, Dr. Shroff’s Charity Eye Hospital)
50. Mrs. Sonia Srivastava (Optometrist, Dr. Shroff’s Charity Eye Hospital)
51. Mr Sachin Kumar (Optometrist, Dr. Shroff’s Charity Eye Hospital)
52. Mr. Saptarshi (Optometrist, Dr. Shroff’s Charity Eye Hospital)
53. Dr. Vibhor (Consultant, Alwar satellite hospital, Dr. Shroff’s Charity Eye Hospital)
54. Mr Mrinal, Programme Manager, VISION 2020: The Right to Sight – India
55. Ms Sridevi Sunderarajan, Development Communication Officer, VISION 2020: The Right to Sight – India