

Information management system to support HIV patients & Doctors

Project 3 Presentation

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Introduction – HIV

- HIV stands for Human Immunodeficiency Virus (HIV). HIV is a virus, which replicates by destroying white blood cells in the body.
- As HIV reproduces, it damages the body's immune system and the body becomes susceptible to illness and opportunistic infections like Tuberculosis, Herpes zoster etc.
- No known cure for HIV infection

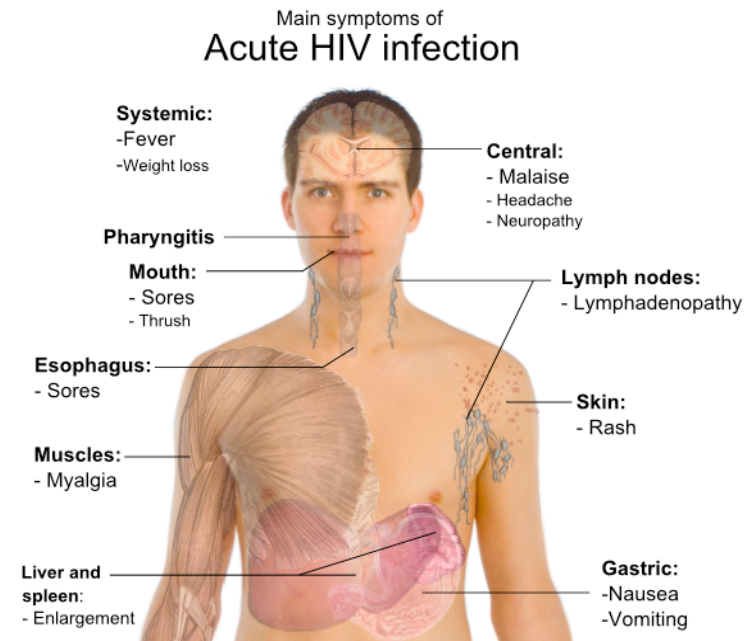
HIV Statistics

- People living with HIV/AIDS in 2008 in the World are 33.4 million estimated and 31.1-35.8 million (range)
- Adults - 31.3 million
- Women - 15.7 million
- Children – 2.1 million
- In India estimated people living with HIV/AIDS in 2009 are 5.2 million
- 26 districts have been identified with high prevalence, largely in the states of Madhya Pradesh, Uttar Pradesh, West Bengal, Orissa, Rajasthan and Bihar.
- Southern states, HIV is primarily spread through heterosexual contact. In the north-east are mainly found amongst injecting drug users (IDUs) and sex workers.

Signs & Symptoms

- Quite common such as fever or cough
- Some of the signs of HIV infection:
 - Swollen glands in the armpits, groin, or neck
 - White spots or unusual marks in the mouth or throat, or on the tongue
 - Blotches on or under the skin.
 - Fever that will not go away
 - Pneumonia

- Some of the symptoms of HIV:
 - Losing a lot of weight without trying
 - Dry cough
 - Sweating a lot during the night
 - Feeling very weak or tired for no reason
 - Diarrhea that lasts for more than a week
 - Memory loss
 - Depression



Transmission

- By exchange of body fluids such as blood, semen, breast milk and vaginal secretions.
- Through Sexual contact. The majority of HIV infections are acquired through unprotected sexual relations.
- Sharing needles when injecting drugs
- The transmission of the virus from the mother to the child can occur during pregnancy, at childbirth or via Breastfeeding.

Treatment of HIV & Side effects

- No publicly available vaccine or cure for HIV or AIDS.
- Patients are given vitamin tablets to keep the CD4 in control and when it crosses the range of 250, the ART is started.
- ART (antiretroviral drug treatment) is available; doctors assess their patients thoroughly, measuring the viral load, how fast CD4 declines and the patient's readiness.
- Side effects can be time bound as:
 - Immediately life threatening – these can be fatal,
 - Short term (acute)- Occur within first few months of beginning the therapy and they can affect antiretroviral adherence
 - Long term (chronic) – these can occur at any time

Goal of the Project

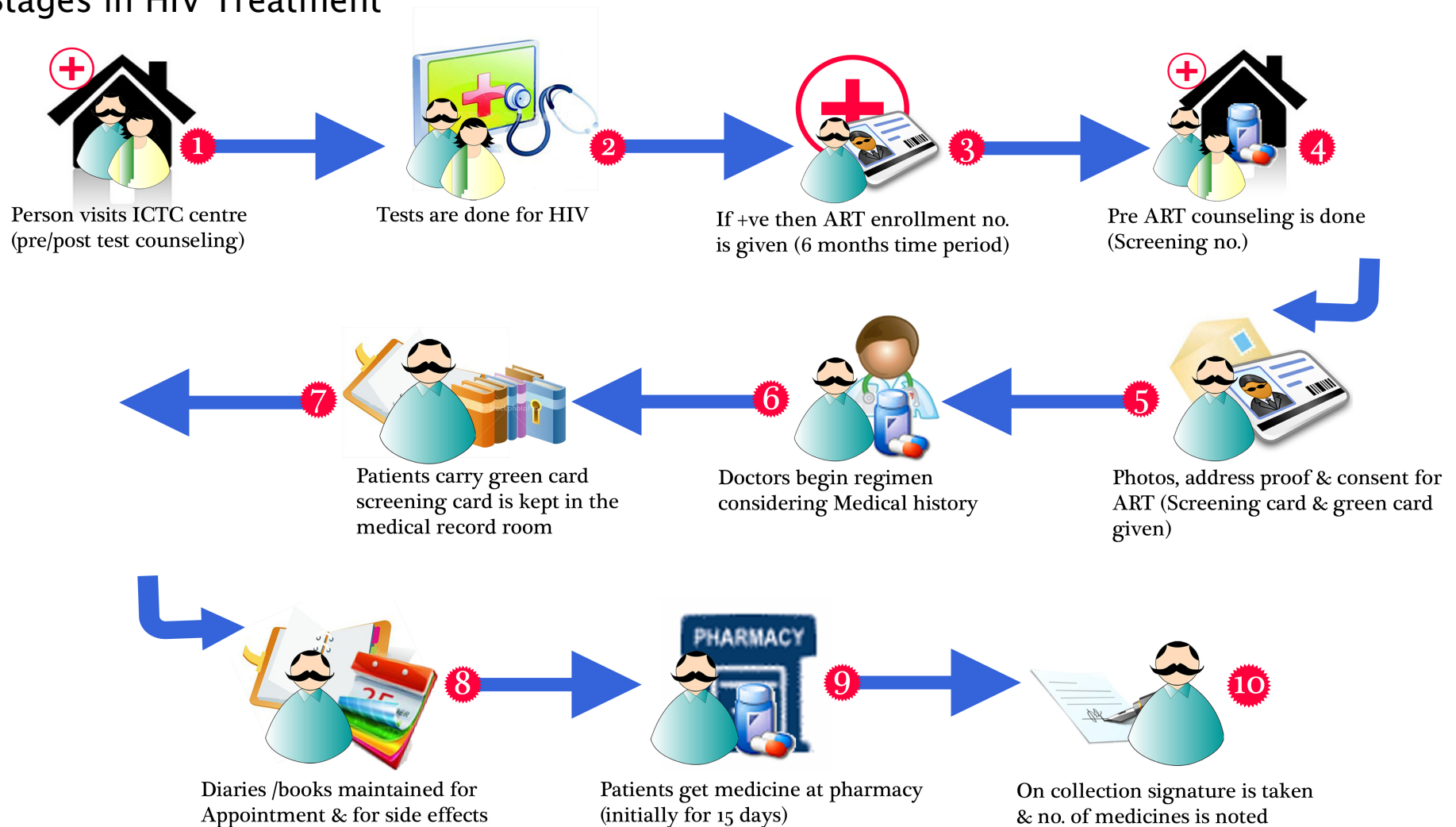
- For Patients:
- To provide a support system for HIV + people
- To build a system that would make them aware about their status by keeping them updated with the important information, in emergency providing assistance to patients, keeping track of their appointments
- For Doctors:
- Building a supporting system that would manage records, patients history, complaints, side effects etc.
- System that would help them analyze the patients data quickly

Methodology

- Data collection through various websites – Avert , NACO and many more
- Conducting user studies – visited Private clinic and Government hospital in Pune & NGO in Thane.
- Interviewed the Doctors, who are using the system and the HIV infected patients, in Pune. Interviewed 10 PLHAs , 3 Doctors and 2 counselors.
- Participated in a Workshop - FULL SITE SENSITISATION PROGRAMME ON HIV/AIDS conducted in B.J.Medical College
- Participated a patient counseling session, understanding Pre & Post test counseling
- Interviewed the Doctors & Counselors working in NGO/ Positive networks.

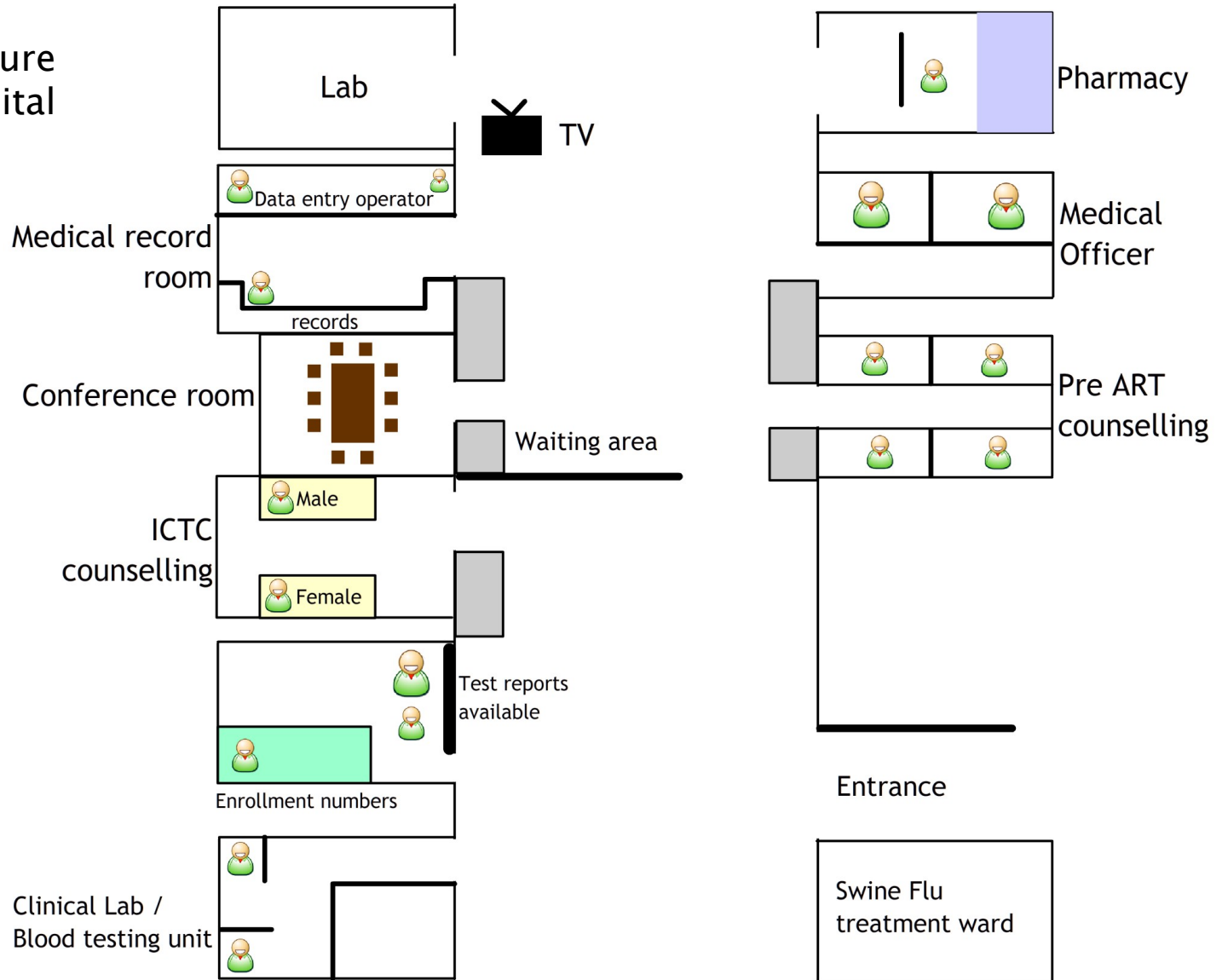
Initial Research

Stages in HIV Treatment

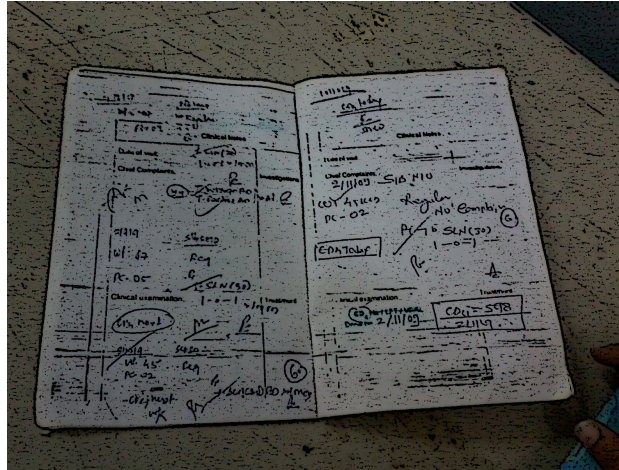


System Design in Government hospital

Structure of Govt. hospital



System Design in Government hospital



ART Book/ Green card

Children I-card

A detailed form titled 'PATIENT TREATMENT RECORD'. It contains several sections for patient information, including 'Patient's name', 'Date of birth', 'Sex', 'Age', 'Religion', 'Occupation', 'Address', 'Contact number', and 'Referral source'. There are also sections for 'Treatment history', 'Clinical data', and 'Laboratory data'. The form is filled with handwritten text and numbers, indicating it is a record of a patient's treatment.

Screen card

Observations & Insights

- Patients carried the green card with them.
- Few screen cards of the patients were lost.
- NACO has CMS system designed – Adults & Pediatric Antiretroviral treatment (ART) record.
- This system has same details those are present on screen card – Identification data, Personal history, Family history, ART history, Clinical & lab investigations, ART summary, TB treatment during HIV, Reasons or stopping ART, Medical history, Linkage to NGO's, Pediatric patient, Investigations, Follow up
- 2 Data entry operators are present to enter the data – one to prepare monthly excel sheet, other updating software.
- Doctors never used to refer to the software for the data

Observations & Insights

- The computer has webcam attached to it, to scan the photograph of the patient.
- Postcards are kept in every patients folder, to follow up if the patient discontinues the treatment
- There are link ART centers attached to the govt. hospitals where stable patients are transferred
- People feel that they can become negative someday
- They hide the reports at home, so as keep the confidentiality

System Design in Private Clinics

Entering data for new patients

Sorting by the number

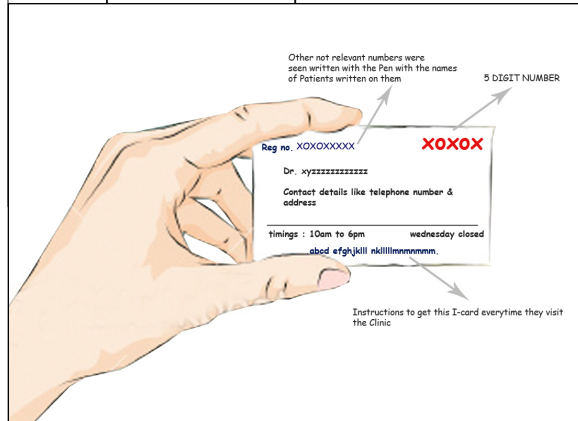
Entering data for the first time



Name

Demographic details

Education



Patients I-card

First Page



Search Patient by

Today's Appointments

- Mr Subodh Bhav
- Sakharam Shankar
- Parvati Jain
- Suyash Shirsat
- Laxman Dhanaji Sawant
- Laljibhai Ambani
- Hansaben Chedda
- Vicky makheeja
- Elizabeth Salvi
- Sadashiv Gogate

HAPS dx system
Visionary Healthcare system

System Design in Private Clinics

- H.A.P.S dx System –
- Scope: HIV AIDS patients Preventive Management Study
- Patient personal demographics
- History – complaints, OI's, personal history, medical history, drug allergy, family history, social/psychological aspects
- Examination – General, Skin, Oral, Genital, Respiratory, C.V.S, Ophthalmology & Musculoskeletal
- Graphical Findings: mark lesions findings on diagram of body (unexplored)
- Treatment – Drug prescription, test/investigation, Follow up, counseling & Reports (unexplored)
- Statistics - unexplored

System Design in Private Clinics

Patients Profile page

Patients Page

							Date of visit
History Exam Diagnostics Treatment							
☒ General ☐ Skin ☐ Oral ☐ Genital ☐ Respiratory ☐ C.V.S ☐ Opthal ☐ Muscular		Information about the type of the disease seen		Patient Record Add/ Edit Findings : Additional Information : Save Cancel			
Date	Details of weight/ CD4 etc.	Additional Information			Type		
		General complaints come here			Findngs come here		

Observations & Insights

- Patients carried cardboard files, only if they had done CD4 tests .
- Had to carry an I-card which had a registration number
- Patients thought that CD4 changed due to their Nutrition
- System used to take time to load the clinical data
- Patients have trust in Doctors (Private clinics) were ready to take medicines from govt. hospitals but were reluctant to have tests done, in those hospitals.
- System should be User friendly
- Data analyzed in a statistical format in a software should be easy to use & understand
- Patients like to maintain confidentiality about their HIV status

Information needed by Patients & Doctors

Information needed by Patients

- On ART treatment or not
- Regimen & Side effects
- Updates of CD4 count & Viral load
- Medical History
- Management of resources / expenses on treatment
- Reminders for medicine/doctors appointment/tests & reports

Information needed by Doctors

- Patients demographics
- Medical History
- Family details
- On ART treatment or not
- Current status – side effects / regimen
- Analysis of patients data / statistics

Patient Scenario

People are not aware that managing the reports is an important factor. The reports are burnt, torn off, misplaced or stolen



Patient Scenario



At times there are 2/3 family members suffering from HIV – they all file the reports together.

As they are not able to understand / read the reports
They carry all the I-cards and the files.

I- cards are lost/ stolen which causes problem.

Patient Scenario



Patients tend to forget next appointment that comes after a month, need assistance to remember / medicine reminders etc.

Trust doctors and are confident that their reports are maintained by them.

At times patients get side effects of certain doses, and so have to wait till next appointment date to meet up or travel and meet doctor to change the regimen.

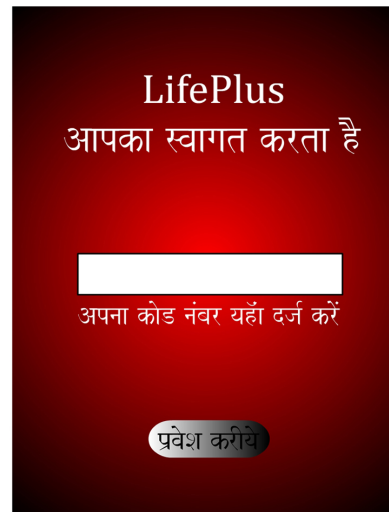
Confidentiality is not maintained as printouts have +ve Status mentioned in **Bold** letters on the reports.

Final Design – ‘LifePlus’ Application



‘LifePlus’ mobile application that would provide information
To all patients suffering from HIV.

It would keep them updated about their current status



Final Design – ‘LifePlus’ Application

It has various features as –

Reports - to view Text /Graphical output of CD4, Viral load counts or other tests.

History – It would provide medical history of past months which would help sharing information to general practitioners /doctors.

Scheduler – This would have two sections – medicine reminder & Doctors appointment

Side effects – Here information related to the side effects would be found & taking appointment in urgency or taking notes

Expenses – This feature would help patients to get an overview of Expenses on medicines and/or tests

Speak up – Here PLHA can know about FAQs & share their knowledge with others.

Prototype is made in Flashlite 2.0

Doctors Scenario



Doctors have to explain the Nutrition related information for every patient that enters.

Many features of the application/software are not explored or understood by the doctors like graphical findings, reports, printouts , statistics etc.



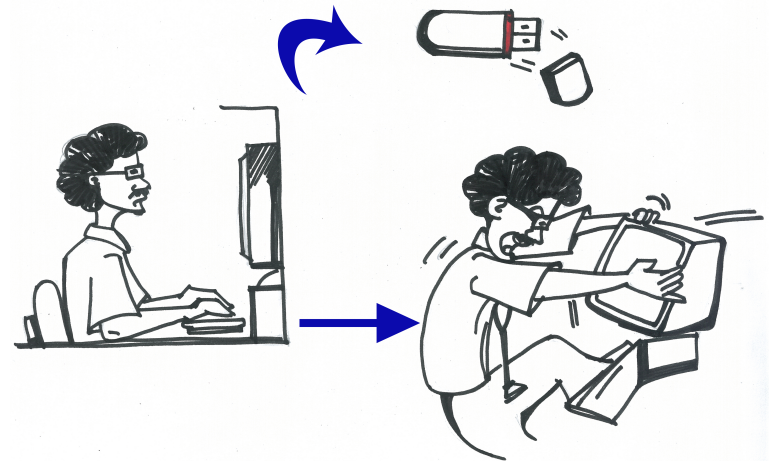
Analysis of the patients data & clinics data is not very clear and can get confusing.

Doctors Scenario



They have to always write a feedback on the paper manually for every patient and even feed in the details in an application. They get tired in the process

Have to take a backup of the data everyday on the Flash drive if its not taken, and the data is lost it can be very critical.



Final Design – ‘Dr.Connect’ Application

- Dr. Connect is a software application for doctors.
- It has various features which are compatible with ‘LifePlus’ and give patients update to the doctors.
- It shows Individual statistics of patients and makes it easier for the doctor to analyze the Patients data.
- The prototype is prepared using Axure software.

References

- A web based self monitoring system for people living with HIV/ AIDS – E.J.Gomez, C.Caceres, D. Lopez, F. Del Pozo . ETSI, Madrid, Spain, accepted 14th June 2001
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- Personal Tracking Charts – published by Project Inform , San Francisco, CA, March 2007
- Toxicity of ART –Dr. Saple (images of side effects)
- <http://www.freedomhivaids.in/BoardGame.htm> -Malamaal electronic boardgame
- www.nacoonline.com
- www.avert.com

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