

# **Summer Training Report**

**By**

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# **Summer Training Report**

## **Part I**

## **i. Acronyms/Abbreviations**

ASHA – Accredited Social Health Activist  
CDC – Centre for Disease Control  
CHC – Community Health Centre  
COVID-19 – Coronavirus Disease (first appeared in year 2019)  
CRM – Common Review Mission  
DHF – Dengue Haemorrhagic Fever  
DSS – Dengue Shock Syndrome  
DHIS – District Health Information System  
DSO – Disease Surveillance Officer  
eDEWS – electronic Disease Early Warning System  
ESSENCE - Electronic Surveillance System for the Early Notification of Community- Based Epidemics  
EVD – Ebola Viral Disease  
FETP – Field Epidemiology Training Program  
GPRS – General Packet Radio Service  
GROAN – Global Outbreak Alert and Response Network  
HIT – Health Information Technology  
HMIS – Health Management Information System  
HMN – Health Metrics Network  
IDSP – Integrated Disease Surveillance Program  
IPD – In Patient Department  
LRN – Laboratory Response Network  
MoHFW – Ministry of Health and Family Welfare  
NCDC – National Centre for Disease Control  
NHI – National Health Insurance  
OPD – Out Patient Department  
OTC – Over the counter  
PHC – Primary Health Centre  
PMP – Private Medical Practitioner  
RODS - Real-time Outbreak and Disease Surveillance  
RRT – Rapid Response Team  
SARS – Severe Acute Respiratory Syndrome  
SC – Sub Clinic  
SEED - System for Early warning based on Emergency Data  
WHO – World Health Organization

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# **A Review of India's Disease Surveillance Program for Management of Infectious Disease Outbreaks**

## **iii. Introduction**

Ever since the advent of antibiotics mankind has always been in a perpetual struggle to end the menace of infectious diseases for good. With the development of newer drugs, we were led to believe that another phase of disease burden had come to an end, more so in the developed part of the world. The present world is seeing increasing numbers of patients suffering from non-communicable diseases like cancer, diabetes, hypertension etc., but it will be incorrect to even imagine that the mankind has even reached anywhere close to ending the menace of infectious diseases so far. The recent bouts of epidemics like SARS (2003), Avian influenza (2005), H1N1 Pandemic (2009), Ebola viral disease (2014) and COVID-19 (2019) have led us to depend on alternative measures to supplement curative treatment. These diseases have caused remarkable suffering to the humans exposing the vulnerability of our weak health systems.

Similar has been the fury of intentionally caused harm to human population by the release of biological agents which is termed as bioterrorism. The history of use of biological weapons for destroying or weakening the enemy dates back to pre-historic era. One can trace several incidents of bioterrorist attacks using infected rams, rye ergot fungus and even humans suffering from plague [30,31]. In the last century, Germans used bioagents against countries like US, France, Italy and Russia during World War I [31].

“Bioterrorism is the intentional release or threat of release of biological agents, viruses, bacteria, fungi or toxins in order to cause harm to human population, livestock and agriculture”. [17]

India, however, has not seen many such incidents and those listed in history are not officially confirmed. One major reason is that it is difficult to differentiate between a bioterrorist attack and a natural disease outbreak [31]. Interestingly, many of the features of bioterrorism attack detection system are also similar to infectious disease outbreak detection system. A bioterrorism attack detection system also relies on multiple data sources like clinical health services, laboratory diagnosis, sale of drugs, emergency medical services, cause of death and school absenteeism data for early detection of a bioterrorism event. Additionally, it requires timely reporting of data via secure channels, routine analysis of data, high sensitivity and specificity and rapid response [5,16].

The surveillance of infectious diseases, whether intentional or natural, requires early detection and prompt response [16,13]. It may be for this reason that India has developed an Integrated Disease Surveillance Program for early detection of infectious disease outbreaks under the Ministry of Health and Family Welfare (MoHFW) which is also a nodal agency for surveillance of bioterrorist attacks [5, 31].

“Surveillance is the ongoing systematic collection, analysis and interpretation of health data essential to planning, implementation and evaluation of public health practice, closely integrated with the timely dissemination of this data to those who need to know” [17].

#### **iv. India’s disease surveillance program**

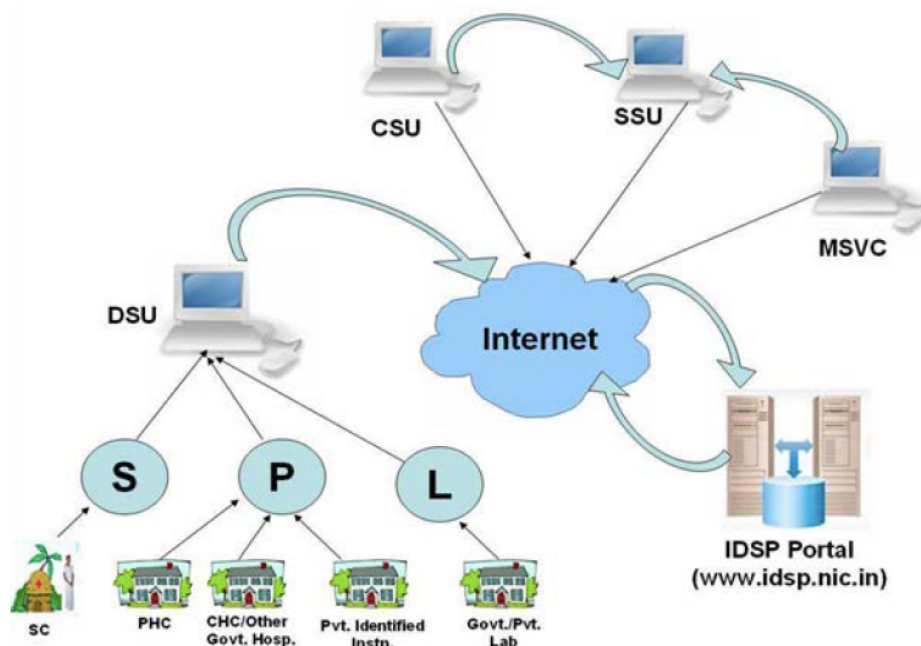
In India, a decentralized Integrated disease surveillance program (IDSP) was introduced in November 2004 to carry out various activities including strengthening of public health laboratories, human resource development and using technology for collection, compilation, analysis and dissemination of data related to listed communicable and non-communicable diseases. The program was launched with the assistance of World Bank with the aim to detect and respond to disease outbreaks quickly. Laboratory strengthening was aimed to improve the capacity of laboratories at district level [1,25]. The organizational structure of IDSP consists of district, state and central surveillance units. The flow of data is from the population level to national level (shown in the box 1) using

S, P & L forms (S- suspected, P- probable and L- laboratory confirmed). Experts from National Centre for Disease Control (NCDC) monitor and analyze the weekly surveillance data at Central Surveillance Unit.

**Box 1: Organizational structure of Integrated Disease Surveillance System**

(source: Document of World Bank.

<http://documents1.worldbank.org/curated/en/395451468051013436/pdf/NonAsciiFileName0.pdf>)



Note: DSU- District Surveillance Unit, SSU- State Surveillance Unit, CSU- Central Surveillance Unit, MSVC- Media Scanning and Verification Cell.

The data analysis is carried out at District, State and Central surveillance units. Any warning or alert related to an outbreak is reported to the peripheral level for Rapid Response Teams (RRTs) to take action [1]. Several diseases have been listed under IDSP for surveillance (box 2).

**Box 2: Diseases reported under IDSP (Source: [www.idsp.nic.in](http://www.idsp.nic.in))**

**DISEASES REPORTED UNDER IDSP**

1. Acute Diarrheal Disease (including acute gastroenteritis)
2. Bacillary Dysentery
3. Viral Hepatitis
4. Enteric Fever
5. Malaria
6. Dengue / DHF / DSS

7. Chikungunya
8. Acute Encephalitis Syndrome
9. Meningitis
10. Measles
11. Diphtheria
12. Pertussis
13. Chicken Pox
14. Fever of Unknown Origin (PUO)
15. Acute Respiratory Infection (ARI) / Influenza Like Illness (ILI)
16. Pneumonia
17. Leptospirosis
18. Acute Flaccid Paralysis < 15 Years of Age
19. Dog bite
20. Snake bite
21. Any other State Specific Disease (Specify)
22. Unusual Syndromes NOT Captured Above (Specify clinical diagnosis)

IDSP is a specialized program that has been evolving ever since its inception in 2004, to accommodate newer methods and technologies required for early detection and containment of infectious disease outbreaks and is the biggest source of data related to infectious disease outbreaks in India, but there have been many gaps in the implementation of this program that question its reliability.

**Rationale** – The purpose behind conducting this review is to identify the reasons for recurring outbreaks of infectious diseases in the recent years in India and steps that can be taken for better management of infectious disease outbreaks.

## **v. Objectives**

- To Identify the gaps in Integrated Disease Surveillance Program through review of literature; and
- To review the strategies for improving disease surveillance for better management of Infectious disease outbreaks.

## **vi. Methodology**

Relevant literature was searched on Research Gate, PubMed, Google Scholar, Science Direct and PubMed using keywords. Boolean operators (AND, OR) were used while searching on PubMed using different combinations of keywords. The official site of IDSP was also visited to understand the history and working of the program. A total of 130 articles were screened out of which 32 were found relevant. Only the publications in English language were included. Conference abstracts were also included. Articles published from the period of January 2004 to May 2020 were included. The aforementioned period was chosen in order to study disease surveillance since the inception of IDSP and understanding the advancements taking place around the world during this period.

## **vii. Gaps in Integrated Disease Surveillance Program**

- Several studies have reported inadequate training of staff (training provided by DSO and epidemiologists who were trained in 2-week FETP course [12]) and lack of knowledge of health workforce at the field level [26].
- Weak data management, lack of analytical skills and inability to act on the available information due to lack of resources or training contribute to the failure in early detection of infectious disease outbreaks [12,18].
- Timely reporting of disease surveillance data is an important indicator of alertness of surveillance system [29]. Late reporting and incomplete reporting by staff at ground level are major reasons for inability of IDSP to detect and contain infectious disease outbreaks at an early stage [26,29,18].

Table 1: Analysis of data of selected diseases in Gujrat reported by IDSP (from 2005 to 2011) (Source: <https://doi.org/10.3402/ehit.v7.22838> [32])

| Diseases reported by IDSP      | Total reported cases 2005-2011 | Average reported case rates/100,000 population/year | Urban proportion over 7 years (%) | Ratio of 2011:2005 cases |
|--------------------------------|--------------------------------|-----------------------------------------------------|-----------------------------------|--------------------------|
| Enteric fever                  | 1,12,884                       | 26.71                                               | 36.8                              | 2.02                     |
| Hepatitis                      | 1,04,722                       | 24.76                                               | 51.07                             | 2.2                      |
| Cholera                        | 1,560                          | 0.4                                                 | 83.42                             | 1.8                      |
| Dengue                         | 10,403                         | 2.46                                                | 75.56                             | 2.15                     |
| Chikungunya*                   | 620                            | 0.51                                                | 68.73                             |                          |
| Measles                        | 7,053                          | 1.67                                                | 38.4                              | 3.62                     |
| Diphtheria                     | 1,461                          | 0.35                                                | 89.12                             | 0.6                      |
| *Data available for 2010_2011. |                                |                                                     |                                   |                          |

- Lenience in maintaining and reporting processes, lack of nil reporting [26] and prioritizing case management over next level reporting by facilities [12] lead to delay in reporting of infectious diseases. Figure 3 shows cases of selected diseases reported from 2005 to 2011 in the state of Gujrat. The proportion of cases reported by urban units for cholera, dengue and diphtheria is significantly high implying that there is a huge difference between the number of cases reported by urban units and the number of cases reported by their rural counterparts.
- Use of paper-based data collection in many areas of India has led to gaps in many crucial components of an effective disease surveillance system. Some of these gaps include lack of accuracy in collected data, delay in reporting of facility level data, poor analytical capabilities and delay in detection of disease outbreaks [4].
- Private medical practitioners are the first point of contact in the areas where public health facilities are not present or are not in a workable condition. Also, three quarters of healthcare spending in India is paid privately currently. But there is a lack of communication between private

healthcare practitioners and public health departments. Therefore, there is a remarkable gap between public and private health data reporting. Many reasons for non-reporting from private medical practitioners include lack of awareness of policies, quackery, ignorance etc. [10, 18].

- Many researchers during the assessment of IDSP in various districts found lack of functional equipment at facility (and especially laboratory) level [12], lack of functional laboratories at district level and lack of availability of tests for diseases listed under IDSP in the laboratories that were functional. Only a limited number of pharmacists engage in data compilation, filing and dispatch of reports of drug sales [29]. Problems with IDSP portal function or internet connectivity in some places, lack of a functional feedback system, no guidelines about supervision of program [12] are some of the other gaps in efficient functioning of IDSP.
- Furthermore, it is observed that Symptom based surveillance is not used appropriately for early detection of disease outbreaks [18]. Also, more attention is given to several vertical health programs only few of which cover specific infectious diseases. This has resulted in several infectious disease outbreaks in India in the recent years and a continued struggle to eliminate vaccine preventable diseases in the country [18].

### **viii. Strategies for reducing the gaps in India's disease surveillance system**

- Trained health workforce is a primary requisite for an efficient disease surveillance system. Training of field level workers is necessary for collection of good quality health data and dissemination of data to higher levels. Trained data managers for proper management of data and data analysts for analysis of field level data are required to detect early signs of a disease outbreak and also use previous data to forecast outbreak [12].
- The use of cellphones for data transmission for remote health facilities is an effective and low-cost method of sharing health information. It can be used as an alternative to dysfunctional internet connectivity as it helps in real time detection of disease outbreak. This has been experienced in many developing countries as well as in Andhra Pradesh state of India

[10,28, 27]. It has also been recommended by CDC as a preferred method of reporting for urgent cases [29].

- Guidelines for data management and proper monitoring and supervision of program should be given. A feedback system needs to be maintained to insure timely and complete reporting of surveillance data [12].
- Private medical practitioners can play an important role in disease surveillance. There is a need for a stringent implementation of mandatory disease reporting act for all PMPs under IDSP [10].
- Adequate functional equipment at facilities and laboratories with proper maintenance, internet connectivity at facility level [12] must be ensured. CDC's Laboratory Network Response (LRN) incorporates laboratory monitoring to improve the performance of bioterrorism information system of United States [16].
- Compilation and reporting of drug sales data by the pharmacists at district level should be made mandatory. The Real-time Outbreak and Disease Surveillance Laboratory (RODS) Pennsylvania has reported a correlation between sale of OTCs and emergency department visits for early detection of seasonal disease outbreaks [21]. The US department of Defence is also known to use the pharmaceutical sales information on OTCs for early detection of natural disease outbreak and bioterrorism attack [21].
- Syndromic surveillance augments the traditional surveillance in developing countries and has a potential for early detection of disease outbreaks in places which lack well equipped laboratories. This has been consolidated by experiences of Pune and Andhra Pradesh in India. [20,18]. Syndromic surveillance is also a crucial component in an efficient bioterrorism information system [21]. Many states in US rely on syndromic surveillance for early detection of disease outbreak. An example of syndromic surveillance system is Electronic Surveillance System for the Early Notification of Community- Based Epidemics (ESSENCE) used by the US department of Defense [21].
- Emergency medical services data can be used for disease surveillance in near real time if integrated with IDSP [18]. This involves the integration of OPD and IPD data collected through HMIS with IDSP to be used in

near real time for detection of early signs of infectious disease outbreaks. In fact, Korea's bioterrorism information system relies on emergency health services data. It automatically produces reports and generates notification after timely statistical analysis [5].

Table 2: State-wise gaps as identified from 11<sup>th</sup> CRM report (year 2017) and strategies for improvement of infectious disease surveillance and response

| Sr. No. | State       | Gaps                                                                                                                                                                          | Strategy                                                       |
|---------|-------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------|
| 1.      | Haryana     | "There is no External/Internal Quality Assurance Mechanisms in place for the microscopy services."                                                                            | Need for supervision and strengthening of laboratory services. |
| 2.      | Maharashtra | "Block level data entry for IDSP should be encouraged."                                                                                                                       | Monitoring and supervision of the program is needed.           |
| 3.      | Meghalaya   | "State has not initiated Block level data entry because of lack of internet connectivity."                                                                                    | Need to overcome digital divide in all states.                 |
| 4.      | Telangana   | "Shortage of trained manpower and many operational issues leading to ineffective programme implementation and a need for an effective programme planning and implementation." | Training of staff required.                                    |
| 5.      | Punjab      | "Doctors & other workers need to be oriented about                                                                                                                            | Involvement of staff at field level                            |

|    |               |                                                                                                                                                                                                                                                                                                                                                                                      |                                                                                                                                                                        |
|----|---------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|    |               | S/P/L forms & reporting should be improved.”<br>“Private Reporting needs to be ensured for all modifiable disease including Malaria & Dengue.”                                                                                                                                                                                                                                       | should be encouraged.<br>Private sector involvement is necessary.                                                                                                      |
| 6. | Manipur       | “There is no Public health Laboratory setup in the state except one District Priority Laboratory set up at Churachandpur which is functional. Public Health laboratories at Thoubal and Senapati districts are not functional yet.”                                                                                                                                                  | Increasing diagnostic facilities with adequate functional equipment is required.                                                                                       |
| 7. | Uttarakhand   | “Private sector data is not being collected in any of the districts. IDSP data is not being used for better planning and implementation of various disease control programs at district and State level.”<br>“Clustering of (17 out of 27) malaria cases was reported in Kalakhera (Udham Singh Nagar). However, no corrective measures/actions were taken to address the epidemic.” | Trained workforce is required for better implementation of disease control programs.<br>Sensitization of workers should be done towards the importance of the program. |
| 8. | Uttar Pradesh | “Only six districts of the state reporting Kala azar and only few cases are reported and                                                                                                                                                                                                                                                                                             | Guidelines for monitoring and functional                                                                                                                               |

|     |              |                                                                                                                                                                                                                  |                                                                                                  |
|-----|--------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|
|     |              | made good progress as per programme.”                                                                                                                                                                            | feedback mechanism are needed.                                                                   |
| 9.  | Assam        | “In Nalbari, non-specific Dengue tests were being used shortage of logistics like JSB stain, slides and other reagent were found in some of the laboratories of Nalbari.”                                        | Adequate functional equipment should be maintained and monitored on a regular basis.             |
| 10. | Bihar        | “The state IDSP cell is well equipped with technical capacity and motivation, however, the same is not transmitted to the district units and field.”                                                             | Implementation of program at field level should be ensured.                                      |
| 11. | Chhattisgarh | “Mitanins are carrying out surveillance for malaria but are sending reports directly to the district instead of routing through sub centres and blocks.”                                                         | Monitoring should be done so that program guidelines are followed, and confusion can be avoided. |
| 12. | Karnataka    | “Data reporting under IDSP of Form S, Form P and Form L was excellent in the state in terms of regular reporting from almost 100% of units. Slight improvement however is required from private establishments.” | Need for a stringent implementation of mandatory disease reporting act for all PMPs.             |
| 13. | Odisha       | “Most of the PHCs are not microscopy centre and no microscopist is available.                                                                                                                                    | Laboratory network needs further                                                                 |

|     |          |                                                                                           |                                                                                      |
|-----|----------|-------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------|
|     |          | Technicians need training on microscopy.”                                                 | strengthening with availability of trained staff.                                    |
| 14. | Nagaland | “Highly suboptimal involvement of ASHAs, who are still being paid honorarium at old rate” | States should follow national guidelines to ensure proper implementation of program. |

Besides fixing the gaps in functioning of existing system, Indian Disease Surveillance needs to adopt newer technologies present in the field of health for more complete and reliable information on infectious diseases for their early detection and containment. With the growing popularity of Health Information Technology worldwide, India should learn from the other developing and developed countries for incorporation of technological advancements into building a strong and comprehensive health system.

## ix. Discussion

Fortunately, in this era of information technology, the use of HIT is not limited to the developed world only. The world health organization relies on web-based sources for the surveillance of infectious diseases through its Global Outbreak Alert and Response Network. GROAN is a WHO initiative that links the member countries for early outbreak detection and reporting so as to prevent the spread of infectious diseases on global scale. This system connects public health professionals around the world electronically to share information on infectious disease spread and its containment [8].

Health Metrics Network (HMN) launched in 58<sup>th</sup> session of World Health Assembly in 2005 is a global partnership for better health information and includes development of new methodologies, instruments and standards for data collection, analysis, reporting and dissemination [15].

Literature provides evidence on the use of HIT for early detection and control of outbreaks in the nations where a health management system is only in its

beginning stages and elaborate health data is not available. One such country is Sierra Leone. Emergence of a potentially fatal Ebola Viral Disease (EVD) was detected in 2013 in Sierra Leone. Year 2014 marked the development of enhanced surveillance system in which technology played a crucial role in containment of EVD in the country [6].

A rather recent publication on “Use of Technology to Fight 2019 Novel Coronavirus Disease in Taiwan” describes how the National Health Insurance (NHI) database helped in tracking and containment of the COVID 19 outbreak. The health facility data linked to the NHI database provided the data on symptoms, progression of disease and treatments of the respiratory syndrome along with the complete health history of the patients. This helped to identify the high-risk patients, new patterns of symptoms, clustered patients and path of infection thus enabling the authorities to respond appropriately to the situation. The publication provides excellent example of how the use of real time data can assist in detecting, tracking and containing an outbreak [2].

Justin D. Silverman and Alex D. Washburne used the previous years surveillance data on influenza like illnesses to estimate the number of COVID-19 infections. This is a significant step in preparing for the resources required to deal with the situation and reducing the impact of an epidemic [22].

Another technological advancement that is successfully being used in the field of healthcare is Machine Learning. Various models of machine learning have been developed in recent years for infectious disease surveillance [7]. These models range from laboratory surveillance, syndromic surveillance, event-based surveillance to using data from emergency visits in hospitals and sales of pharmaceuticals for investigation of potential outbreaks [9]. One such model in India is SEED (System for Early warning based on Emergency Data) used in Andhra Pradesh that allowed for early detection of dengue outbreak in 2010. The baseline data is collected and entered into the SEED application. This data is automatically analyzed as per the preset operations and alert is issued if predefined threshold exceeds. Thus, processing of data is automatic, and the results can be used in near real time [13,18].

HIT as also been used in Pune (Maharashtra) in 2009 during H1N1 outbreak. Even though the initial outbreak detection was poor, but the municipal

corporation established strong hospital level surveillance systems and used health geography spatial and statistical analysis for the containment of outbreak [13].

Use of Information Technology and improved laboratory support has led to improved disease surveillance in Kashmir under IDSP (including an increase in number of data reporting units in Kashmir division (78% in 2013 to 91.65% in 2016) and the subsequent decrease in number of outbreaks ( 57 in 2013 to 51 in 2016)) as documented by SM Kadri [24].

The use of technology over paper-based surveillance has its own advantages. With electronic system, the reporting time between various health departments form regional to national level is reduced [9]. The computerization of system finds multiple advantages with fast recovery of implementation cost, increased efficiency of surveillance system, better utilization of resources and time saving. Planning, monitoring and supervision becomes easier [14]. Internet based reporting system for infectious disease surveillance was introduced in Netherlands in the year 2002 which improved the timeliness and completeness of reports [29].

Sierra Leone after the Ebola virus outbreak continues to integrate the electronic health management system for infectious disease outbreak detection and response in various districts. The detection of Measles and Rubella outbreak in 2016-17 and the response to the outbreak provides another example of the ability of electronic health information system to detect the outbreak using real time data and its use in containment of the outbreak [3].

Bangladesh also uses web based integrated disease surveillance for collecting data related to infectious diseases including influenza, Nipah, dengue among others [23]. Electronic Disease Early Warning System (eDEWS) in Pakistan built in collaboration with WHO uses mobile software, secure automatic electronic transmission of data, alert generation and notification to the main stakeholders. Progressive integration of eDEWS with DHIS and parallel surveillance programs will help streamlining weekly data collection and transmission using GPRS and web-based reporting [11].

## **x. Conclusion**

The formulation of Integrated Disease Surveillance Program was a significant step towards reducing the burden of diseases on Indian Health System. It has successfully helped the authorities to identify and manage several outbreaks and there have been many improvements in the program since its inception. But the changes brought about in the program to improve its functioning have not been uniformly incorporated nationwide and many gaps exist in the proper implementation of IDSP even today. As a result, there have been many incidents of infectious disease outbreaks ever since the launch of this program.

There is a need to fill the existing gaps and integrate new technologies for a more efficient disease surveillance system. There is no dearth of examples of countries who have successfully integrated latest technology to improve disease surveillance. India should strengthen its disease surveillance system as early identification and prevention of disease outbreaks is necessary to build a healthy society.

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# **Summer Training Report**

## **Part II**

## **i. List of figures**

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# Using Clinical Data for Better Healthcare

## ii. Course description:

- The course explains the role of digital technologies in healthcare for decision making, including the existing technologies and their roles, sources of data and changing role of health workforce.
- It discusses the key concepts and terminologies of health data and data life cycle and role of various stakeholders in improving quality of healthcare. It also emphasises the importance of good quality data for better decision making. Consequences of using low quality data for decision making are illustrated using case studies. Digital health legislation policies are also discussed.
- Appropriate and effective modes of sharing results produced by data analytics are discussed with focus on contribution of effective communication and evidence-based decision making in better consumer engagement and well-being.

## iii. Objectives of the Course:

- Identify the various digital health technologies, their benefits, changing roles of different stakeholders and new workforce requirements.
- Understand changing health environment from traditional healthcare setting to digital health systems, challenges associated with this change and what is required to overcome these challenges.
- Identify various people working with health data and what can be achieved using health data.
- Understand benefits of using health data with example of ABF system.
- Identify features and benefits of good quality data and consequences of using poor quality data.
- Understand data governance, various challenges associated with data governance, responsibilities associated with handling health data and some tips to ensure safety of health data.

- Describe data analytics: classification, processes, tools used, uses and benefits of data analytics and wide range of health data sources.
- Understand the importance of data literacy and how to make health data useful.
- Describe data linkage and data sharing and its benefits.

#### iv. Course Contents:

|          |                                                                                           |         |
|----------|-------------------------------------------------------------------------------------------|---------|
| Module 1 | 5 ways digital data is changing healthcare                                                | Video   |
|          | How data is changing healthcare                                                           | Reading |
|          | Data driven care: turning data from a personal health journey into actionable information | Video   |
|          | Data driven care – infographic                                                            | Reading |
|          | Do healthcare professionals really need to know data analytics?                           | Video   |
|          | Vision for digital health and data analytics                                              | Reading |
|          | The potential of health data to drive healthcare transformations: Digital health CRC      | Video   |
| Module 2 | An introduction to health data classification                                             | Video   |
|          | Overview of data lifecycle                                                                | Video   |
|          | Quality health data: what is it and why is it important?                                  | Video   |
|          | The impact of poor data quality                                                           | Video   |
|          | Data governance and privileges                                                            | Video   |
|          | Data governance and privileges                                                            | Reading |
|          | Terminology and key statistical concepts for interpreting data                            | Video   |
|          | Terminology and key statistical concepts for interpreting data                            | Reading |
|          | Overview of analytics impacting healthcare                                                | Video   |
|          | Key steps in analysis of health data                                                      | Video   |
|          | Data tools                                                                                | Reading |

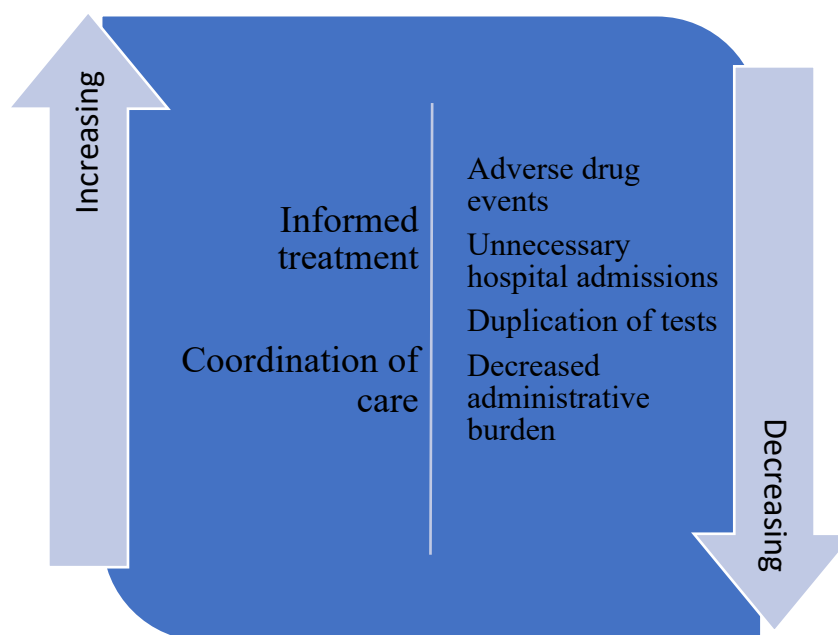
|          |                                                                   |         |
|----------|-------------------------------------------------------------------|---------|
| Module 3 | Make sense of a data report                                       | Video   |
|          | Everyday data queries common to decision making in healthcare     | Video   |
|          | Carry out simple health data analysis                             | Video   |
|          | Top tips for analytics journey                                    | Video   |
| Module 4 | Best practice for communicating health data.                      | Video   |
|          | Use of data visualizations for collaborative decision making      | Video   |
|          | Collaborating around data for healthcare improvement              | Video   |
|          | Data visualization- making data meaningful                        | Reading |
|          | Sharing data for research purposes                                | Video   |
|          | Case example of sharing health data                               | Video   |
|          | Case study: Real time data use-Pascal Metrics Project, NSW Health | Video   |

v. **Learning methodology:** Video, Reading

vi. **Key learnings from the course:**

Ways in which digital data is changing healthcare

Figure 1: Benefits of digital health data



- Telehealth services: It is becoming easier and cheaper to access health services in remote areas using telehealth services. Test reports can be sent anywhere in the world and prescription can be obtained through video conferencing.
- Change in role of stakeholders: In the traditional healthcare setting, patient had a more passive role. But with the advanced technologies like mobile apps, wearables for fitness and remote access technology, patients have assumed a more active role and the health professionals now play the role of a mentor or coach who provides options to patient to choose from.
- Workforce requirements: Rapidly changing technology demands new technical skills and data literacy to produce meaningful results. There is a growing demand of Chief clinical information officers, health informaticians, health data scientists, data analysts, and clinical report writers in the field of digital healthcare.

#### Digital health - a cultural transformation of traditional healthcare

- “Digital health” is defined as “the cultural transformation of how disruptive technologies that provide digital and objective data accessible to both caregivers and patients leads to an equal level doctor-patient relationship with shared decision-making and the democratization of care”
- Medical knowledge continues to grow at a rapid rate but related curriculum and policies do not reflect upon this development. Social media and smart phones give empowerment to patients and the disruptive technologies appear at an overwhelming rate posing a challenge to the over regulated healthcare systems.
- The integration of technology in traditional healthcare requires building knowledge and attitude of the stakeholders of healthcare systems and training of healthcare professionals.
- Disruptive innovations such as deep learning algorithms, virtual reality (VR), or health sensors could contribute to value-based healthcare, and help take human skills from clinical judgement and experience to creative problem-solving. Medical technologies such as artificial narrow intelligence, robotics, genomics, telemedicine, virtual and augmented reality, internet access,

smartphone penetration, open access to medical information and clinical studies lead to potentially better quality and quantity of healthcare.

Figure 2: Some challenges posed by digital health include :

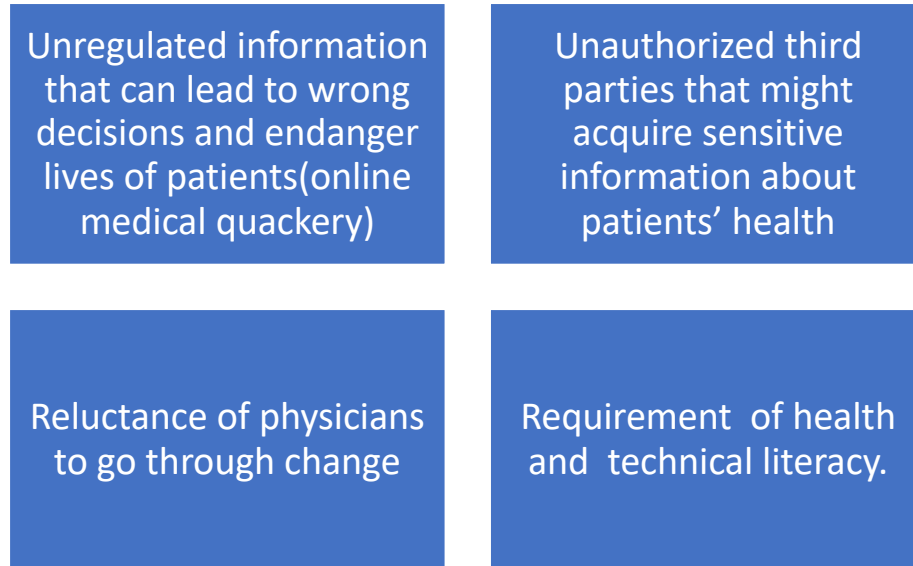
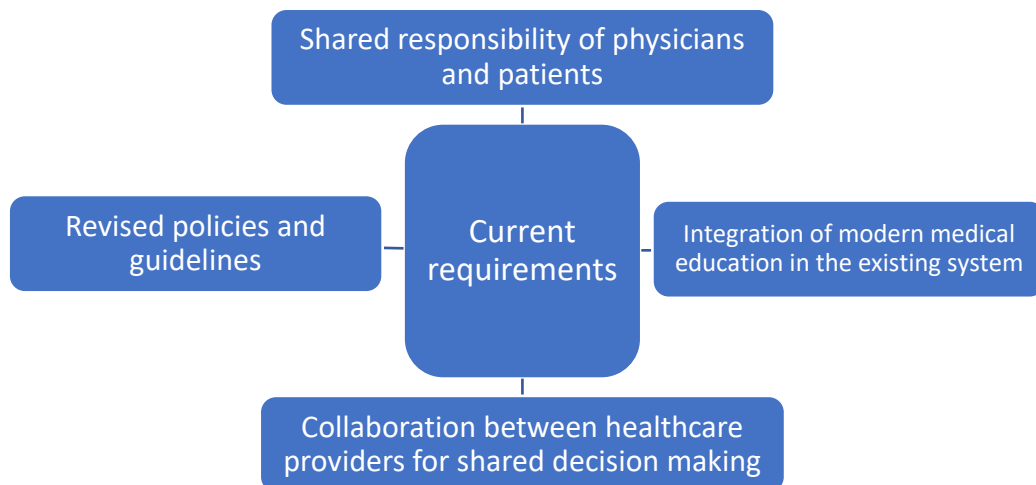


Figure 3: Current requirements to fill the gaps in proper functioning of digital healthcare



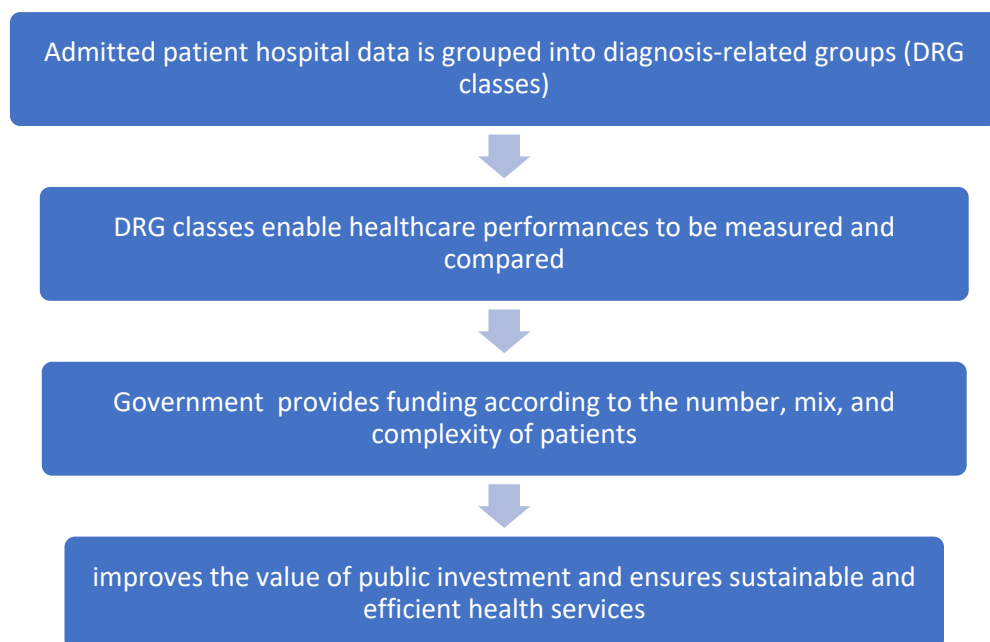
Data driven care; turning data from a personal health journey into actionable information

- Everyone in healthcare plays a crucial role in data collection. These includes governments, industry, providers, patients, carers and the broader community. Dedicated information officers, data scientists, clinical informaticians, and report writers are skilled in working with data and performing analytics.
- The ability of AI machine learning to process huge amounts of data in short amount of time can be utilized to quickly identify the perfect diagnosis for the patient and the most effective treatment.
- Data management skills or data literacy include the ability to identify, locate, interpret and evaluate information and to communicate key insights.

#### An introduction to health data classification

- Health data is often defined as “information relating to health conditions and wellness for an individual or a population. This can include clinical metrics, environmental, socioeconomic, and behavioural information.”
- Different types of health data may include text, graphics etc. This data is used in medical research, epidemiological studies, population health, activity-based management, and health system planning.

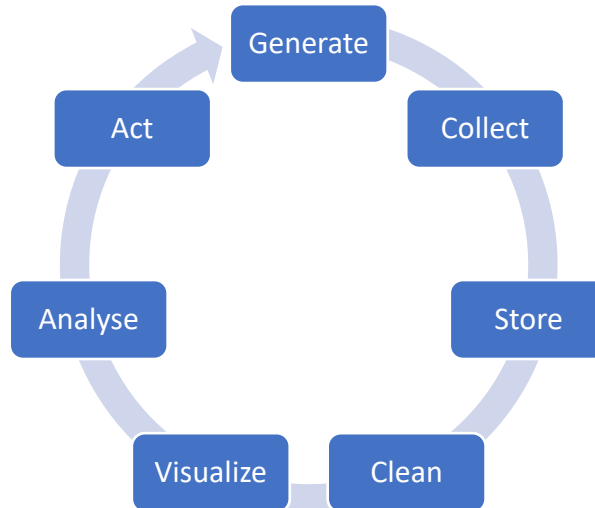
Figure 4: The Activity-based Funding system (ABF system)



(DRG classes provide meaningful ways of linking hospital resources to patients)

### Overview of data lifecycle

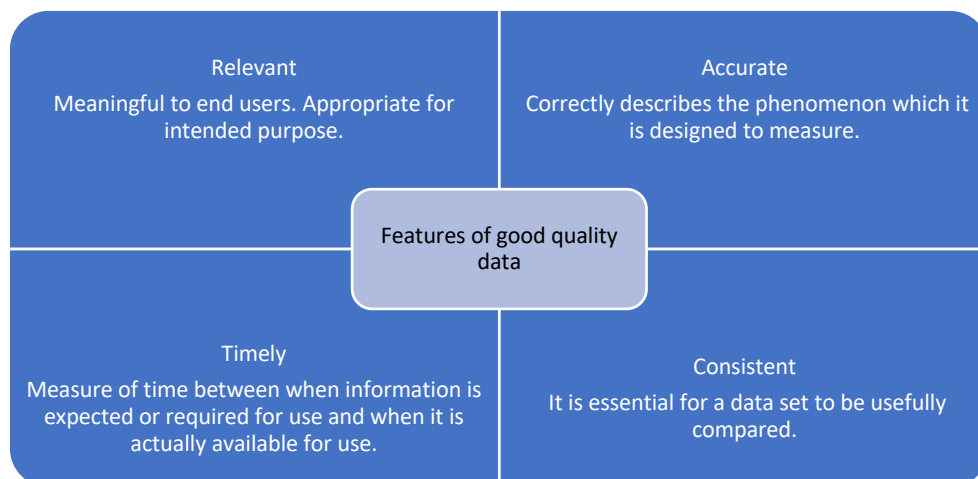
Figure 5: Steps in Data Lifecycle



For example, data is generated by patient being admitted to hospital. Data is collected by a nurse entering patient information into the electronic medical record. Data is stored in a database or data warehouse. Data is cleaned for errors and ensured that it is valid. Data is visualized in order to make it usable, in a spreadsheet. The visualized data is analysed and we are then able to act on what the data tells us.

### Quality health data: what is it and why is it important?

Figure 6: Features of good quality data



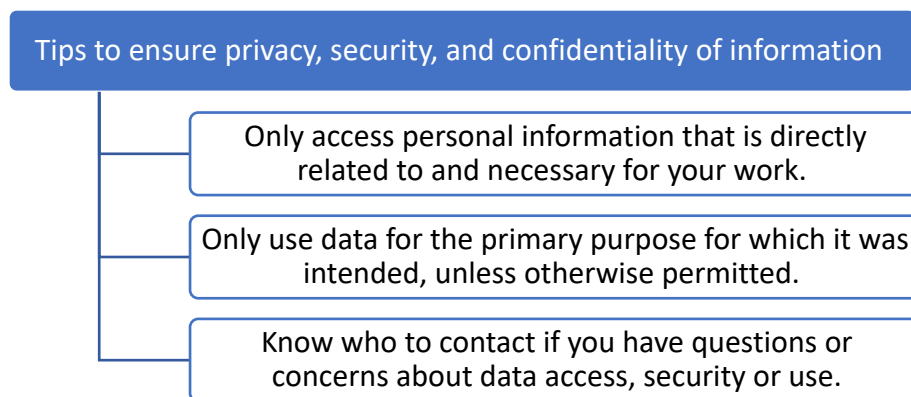
### The impact of poor data quality

- Inaccurate or incomplete data may lead to wrong diagnosis and thus lead to extended hospitalization or may even endanger the patient's life.

### Data governance and privileges

- Data governance provides clear authority and lines of responsibility to stakeholders and creates standards for gaining access to data. This makes working with data more effective.
- A health system must have a designated data sponsor, data custodians, and data stewards, who each have key accountabilities associated with the organization's data collections. Each contributes to the management, governance, and operation of a data collection, ensuring compliance with legislation, policies and standards, including privacy, security, and confidentiality of information within the data collection.

Figure 7: Tips to ensure privacy, security, and confidentiality of information

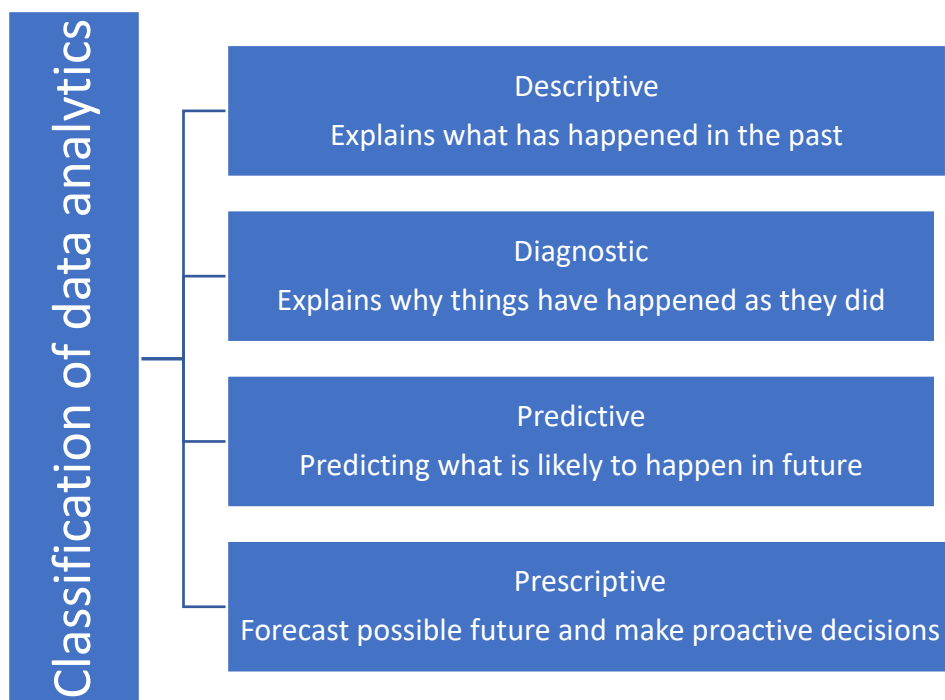


- Information disclosure means to share data with others, including other health services, health districts, universities, or other organizations or individuals. A disclosure can occur by giving out a copy of the information, allowing another organization or individual to have access to the information or discussing the information in a meeting where third parties are present.

### Overview of analytics impacting healthcare

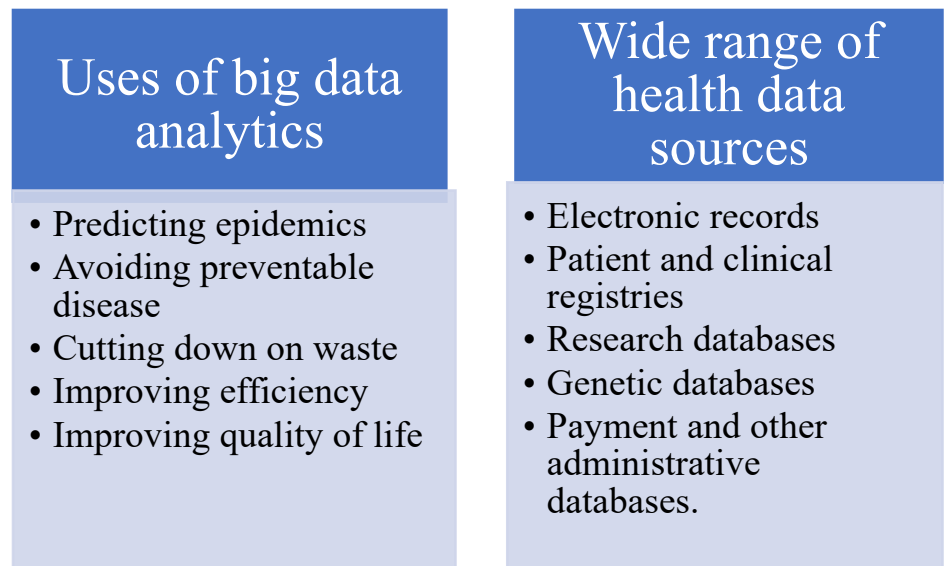
Analytics as a discipline and technology-driven process is made up of several related activities, including data mining, online analytical processing, querying, and reporting. Examples of analytics tools and platforms include Tableau, Microsoft Power BI, Lumira, Sisense, Qlikview, Looker, Domo, Cyfe, Visualr, and Centro.

Figure 8: Classification of data analytics



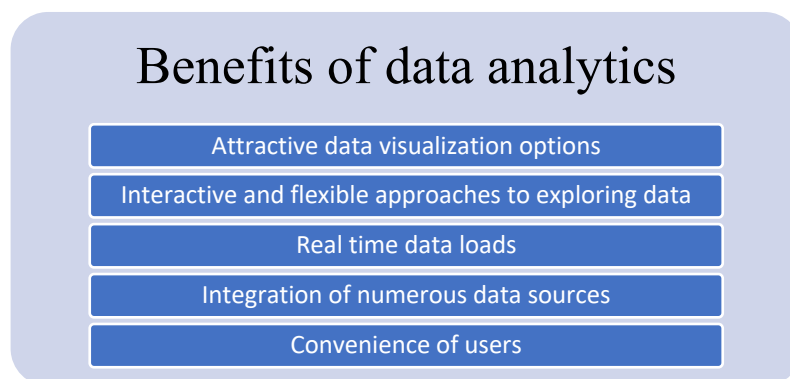
- Analytics help us to extract right information, study trends, predict what is likely to happen in future and take proactive decisions to prevent health issues.

Figure 9: Uses of big data analytics and sources of health data



- Analytics help us to extract right information, study trends, predict what is likely to happen in future and take proactive decisions to prevent health issues.

Figure 10: Some benefits of data analytics



#### Making data meaningful

- Use appropriate tools for data analysis
- Use appropriate infographics, colour and fonts while presenting
- Preparing Dashboards when required

### Data visualization- Making data meaningful

- In the US, many electronic health record (EHR) systems in hospitals and medical practices have enabled patients to have direct access to laboratory test results. But many people, especially those with low numeracy and literacy skills, fail to understand what those results mean or if the results are bad enough to call a doctor.
- In the US, the Visualising Health project designed visualisations of health risk data to make them more intuitively meaningful.

### Sharing data for research purposes

- One of the major advantages of data sharing, is that it increases the transparency and reproduction of research. It also maximizes the value of investment in research, particularly where the data is unique and has been challenging or expensive to collect. A data repository can be used in the sharing of data. Data that is deposited in a repository can then be cited, which forms part of the scholarly record and enables you to be credited for the data you collect.
- Sometimes we want to combine data about the same individual from different datasets and sources, this is called data linkage.

**End of report**