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Research Methodology

Planning and setting up of a patient health record system for patients with non-communicable diseases in a primary healthcare setting

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ABSTRACT

India has a high burden of non-communicable diseases (NCDs). For NCD surveillance, there are national and international targets. However, India lacks good quality data for NCD surveillance. Maintenance of the NCD record improves the quality of care and helps a treating physician in making a clinical decision. Most of the patients with NCDs seek care at the primary level and these facilities lack NCD record management. Through this paper, we share our experience of planning and setting up of a paper-based NCD health record system at a primary health care setting. We developed a system to generate and maintain patient health records which consisted of unique ID generation, index register, NCD record file and NCD passbook (Dhirghayu card) for each patient. We reorientated the process and devised a mechanism for record-keeping and data management. We faced several challenges during its implementation and overcame those with the mentioned solutions. Findings from this paper can be used to develop a similar system for patient health records at primary health care facilities, which can be used for NCD surveillance and patient monitoring purposes.

1. Introduction

Non-communicable diseases (NCD) account for 60% of all deaths in India. The four major NCDs are cardiovascular diseases, cancer, chronic respiratory diseases, and diabetes.[1] To address the high burden of NCDs India launched the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases & Stroke (NPCDCS) in 2010.[2] Under the NPCDCS, NCD clinics have been started for screening, treatment and follow-up of common NCDs. The data recording and reporting are a vital part of the NPCDCS for monitoring the burden and measuring the impact of the NCD-related interventions. There are several indicators and targets for NCD surveillance by the World Health Organisation's Global Action Plan 2013-2020 and India's National Action Plan and Monitoring Framework for Prevention and Control of NCDs.[3,4] However, India lacks reliable and good quality data related to NCD surveillance.[5]

The NCDs are usually treatable but non-curable and require long-term follow-up. A patient with NCD makes multiple visits to a health care facility for the refill of medications and monitoring of the disease. Most of the patients with NCDs seek care at the primary level which lacks the facility of NCD record management (paper-based or digitalized records). A good quality health record helps a treating physician to take a timely and appropriate decision for the management of NCDs. Also, keeping a track of NCD-related data in a health facility is essential in improving the quality of healthcare services. For example – NCD data is useful in indenting the adequate appropriate medications in a healthcare facility. Maintenance of the patient's health records by healthcare is beneficial for patients who find difficulty in keeping track of their disease status and medications. Based on our experience, in this

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paper, we discuss the planning and setting up of paper-based health records for patients with NCDs availing the NCD care services at our primary health care setting (urban health centre) located at Dakshinpuri Extension, New Delhi, India. This centre caters to a resettlement colony consisting of a population of up to 38,000.

2. Planning

To generate a patient health record, we planned a system in which every patient with NCD attending the urban health centre (UHC) to have an NCD file (this to be kept in the primary health centre) and an NCD passbook. We named the NCD passbook as 'Dhirghayu card' in the local language (Hindi), and it was given to the patient. The NCD passbook contained the same details as the NCD file, which a patient has to bring to the UHC during each visit. The patient's NCD file contained a proforma (with baseline and follow-up details) which was printed in A4 sheets (format given in annexure 1 of the supplementary file) and it was attached to a file cover using a file tag /thread. The NCD file and NCD passbook had the identification details of the patient, baseline characteristics, details of OPD visits, and annual check-ups. The NCD passbook (Dhirghayu card) had the same format, but they were printed in a pocket-friendly size. The NCD passbook also had colorful pictorials and health education messages for the patients in the local language. During the planning stage, we explored all the resources and funds available. We enlisted the material, manpower and quantity as needed and the materials were procured (Table 1). An iron or plastic almirah is essential, to protect the NCD files from rodents, termites, or environmental damage. We made sure that all equipment was functional, and quantity was adequate. There should be a continuous supply of the NCD record files and medications for this process.

Table 1: List of items required

Category	Item
Stationery	File cover
	NCD card /A4 sheets with printed proforma
	Marker
	Whitener
	Pen
	Paper flags
	Register
	File tag thread
	Paper punch (one hole)
Equipment	Rubber stamp for NCD clinic and inkpad
	BP apparatus
	Glucometer and Glucostrips
	Urine container and protein/sugar strips
	Weighing scale
	Stadiometer
	Measuring tape
	Tongue depressor
Tools	Acetic acid
	BMI calculator mobile app
	CVD Risk assessment chart/app
	Standard NCD management protocol
	Data entry tool (Epi Info, Google form, ODK collect, MS Excel)
Adequate Medicines	Amlodipine
	Metformin
	Glimepiride / Gliclazide / Glibenclamide
	ACE/ARB inhibitors – Enalapril / Telmisartan
	Beta-blocker – Atenolol, Metoprolol
	Statins
	Antiplatelets - Aspirin, Clopidogrel
	Salbutamol, Theophylline
	Hydrochlorziade, furosemide
	Inhalers, MDI
Staff	Trained staff and doctor/s
Furniture	Almirah / Cabinet (to be fully covered)
	Table
	Chairs / Bench

3. Setup and Process

From the screening counter, a patient carries the NCD file and NCD passbook to the doctor for consultation. Basic identification details in the NCD file and NCD passbook were filled in by staff at the screening counter, and the medical details were filled in by the treating physician. A doctor prescribes the medication in the NCD passbook and copies the same in the NCD file. The NCD file is collected at the doctor's desk and the NCD passbook is handed over to the patient to collect medications. At the end of the OPD, all the NCD passbooks are transferred to the registration desk and organized systematically in the almirah. During the follow-up visit of the patient, at the register counter his/her NCD file is retrieved using the patient ID code mentioned in the NCD passbook. Another vital element of this system consisted of unique ID generation, index register, and record keeping. The details are given below.

Unique identity (ID) code generation: It is the most crucial step of the whole process. The identity code should be unique and easy to be memorized by the patient. We created an alphanumerical ID code based on the first alphabet from the name of the patient followed by a sequential number. For example, a patient with the name 'Shyam' was given an ID code as S1. For another patient with a name starting with the alphabet 'S' was given an ID code of S2. An ID number with the amalgamation of alphabets and numerical digits gives an advantage of storing the records in alphabetical sections and sequences. This makes it easy to arrange the records as per the ID code and retrieve them in the follow-up visit. Another method of creating a unique ID code could have been through the mobile number or Aadhaar card number (12 digits

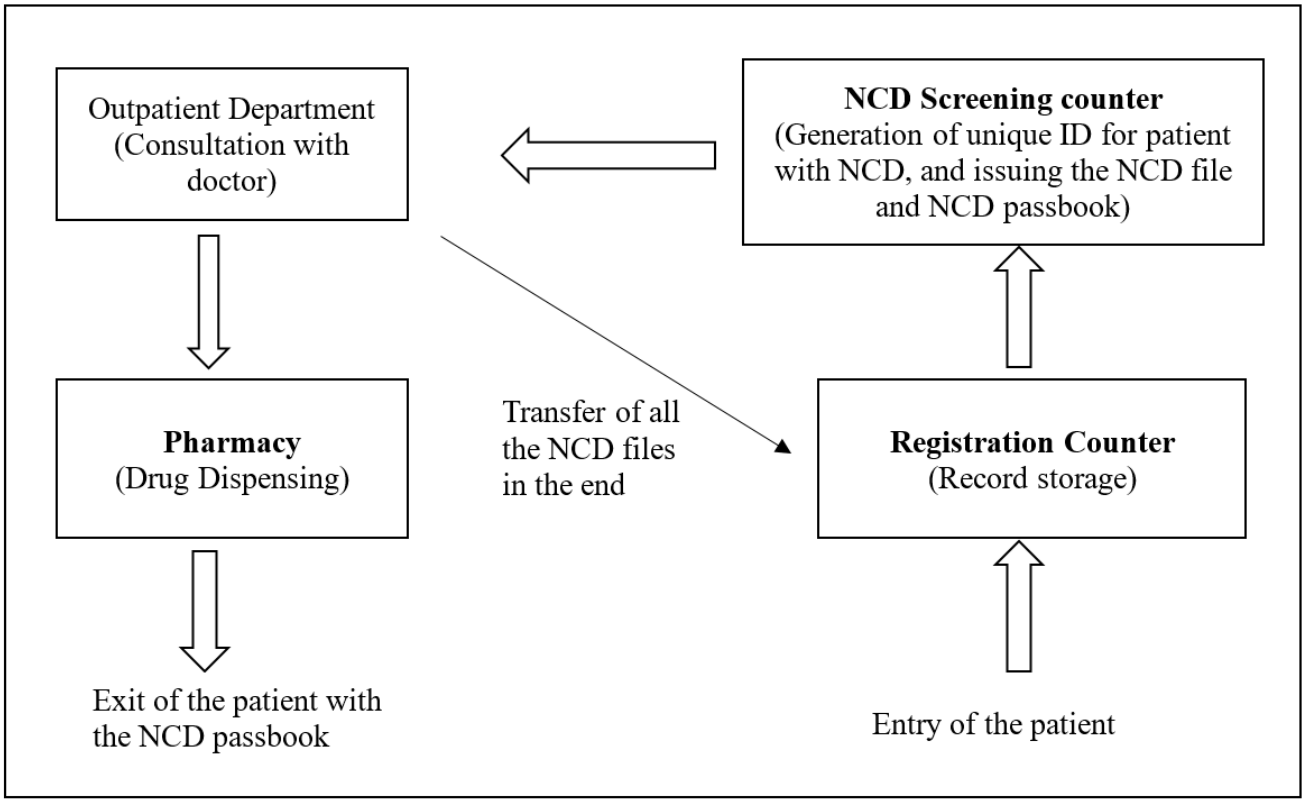

Fig. 1: Layout of out-patient department depicting the pathway of the patient with NCD at urban health centre

individual identification number for residents of India) as his NCD ID, but these methods do have their limitations.

Index register: This is another important record that contains a list of patients with NCD and their unique ID codes. If a patient forgets his ID code, then his/her ID code can be searched in this register. The index register has alphabetical divisions (A to Z). These divisions can be prepared using paper flags. All the patients with NCD should be registered in the alphabet section of his/ her name on this register. For example, a patient with the name 'Shyam' will have his details entered in the 'S' section of this register. This register was kept at the screening counter and was filled during the issuing of the new ID code. It contains the identification details of the patient (name, age/sex, father/husband name, address, mobile number) and ID code. The format of the register is given in Annexure 2 of the supplementary file. Before registering a new patient, his details can be screened in the index register to avoid any duplication of the records. This register is used to retrieve the ID code of a patient in case he/she loses his ID code. This can be reviewed periodically to assess the number of patients on treatment and the controlled status of their disease.

4. Record Keeping and Data Management

All the NCD files were kept in a lock & key room (registration counter), with limited access. For easy retrieval of records, all the records were arranged in a pattern (sequence). The cupboard/almirah was divided into two sections (1 & 2) and which were further subdivided alphabetically (A to Z). All these sections and subdivisions were labelled properly. After the OPD is over, all the NCD file records were arranged alphabetically and sequentially (ascending order of numbers) in the respective sections of the almirah/cupboard. The creations of these two sections (1 & 2) were done for monitoring purposes. For example, the NCD records for all the patients who have visited for the current month will be shifted from section-1 to section-2. Patients whose records are left in section 1 are the ones who didn't turn up for the refill/follow-up. A list of these patients can be prepared monthly, and they can be checked upon by the health workers during their house visits or via telephone.

Periodical evaluation of the NCD files and index register is needed for their completeness, quality, and duplication. The maintenance of NCD files can be done once a month or daily at the time of arranging these NCD files in the registration counter. For long-term data storage and advanced analysis, these records can be converted to digital records. All the data from these NCD records can be

entered periodically (monthly or quarterly) in software like Microsoft Excel (Microsoft Corp., Redmond, WA), Google form, KoboToolbox, ODK, or EpiCollect5.[6] A staff can be trained to enter these data and prepare a monthly/quarterly/annual reports.

5. Challenges and Solution

During the initial implementation phase, there were a few issues like record duplication, confusion with the patient pathway, and difficulty in arranging the records. Troubleshooting was done on time by a person, and who can take timely decisions. A pre-implementation training for all the staff was done in using the tools, equipment, and protocol. A well-written plan was communicated to all the staff. We also conducted a mock drill for patient pathways in the OPD. All staff were trained in all the functioning of this system, so in case one staff is on leave, then the system for NCD health records is not hampered. There was a shortage of staff for NCD screening and for issuing the NCD file and NCD passbook. We overcame this by task shifting. In this, the available staff or training students or volunteers were given a short training for the efficient functioning of the system. Initially, it required a lot of supportive supervision and the process was time-consuming. After a few months, this process was smooth and took less time as the number of new registrations decreased and the follow-up visits had less paperwork. Lack of motivation among the staff and feeling overburdened was also another challenge. For this, we acknowledged their work and explained the benefits of maintaining patients' health records. Also, compliments from the patients for maintaining their health records boosted their morale. Limitation of space in the health facility can be a hurdle for this system, but with proper utilization of space, it was managed to a certain extent.

Few patients were referred to higher centres for the management of complications of NCDs. Then the sharing of patients' health records among the various health facilities was another challenge. We overcame this challenge by preparing a complete referral summary in an OPD card. We also used the OPD card, if there was a shortage of space to write the medical advice related to the non-NCD related complaints in the NCD passbook. If a new OPD card was issued or a new page was added, then his ID code was mentioned again with the NCD stamp in the new page/OPD card. We made sure to record the laboratory reports or medications taken from other health facilities in the patient's NCD file and NCD passbook. In future, if health records are made digitally then they can be shared easily between various health facilities. There might be duplication of data with the existing population-based screening records of NPCDCS, or if a patient is taking treatment with multiple health facilities. This can be managed through the integration of the data.

For testing the fasting blood sugar of the patients, convenient timing and day as per the staff (technician /nurse) and patients was selected. Few laboratory investigations which were not available at the health facility (for example – Kidney function test, HbA1c, ECG, fundus examination) were done at the higher health facilities. For this, referral linkages and coordination and collaboration were established with the nearby higher health facilities. There were a few incidences where the NCD passbook was lost by the patient. We had issued a duplicate copy of the NCD passbook using the NCD file, but with a reminder to keep it safe. To reduce such incidences, we attached a photo of the patient in their respective NCD passbook. This gave a sense of belonging to the patient.

6. Way Forward

We do believe that an electronic health record is a final goal for all records and services.[7] Digitalization has the advantage of real-time monitoring, supporting clinical decisions, optimizing workflow, decreasing the workload and promotes data sharing.[8] However, it has a limited role in settings with poor internet connection/electricity and has a risk of data loss due to faulty devices or software. It often requires technical support for the long term (for software updates, data correction and data sharing, the confidentiality of patient data), trained staff in handling technology, and needs good resources.[9] Digitalization does have potential threats for breaches of privacy.[10] With the appropriate mechanism we can overcome these challenges. The recent launch of the Ayushman Bharat Digital Mission by the government of India can be a promising step,[11] as it provides the provision of a unique health ID or family card for every citizen and creates online interoperability of the health data. It will help in keeping track of morbidity and mortality data for India.

In our experience, we received positive feedback in the community regarding the maintenance of their patients' health records, especially among the aged and less educated patients, who found it difficult to maintain their health records. The whole process of NCD screening and maintenance of the NCD files was kept simpler. The long-term sustainability of the process depends on the ease and comfort felt by the staff and patients. Other key areas determining the long term sustainability are simplicity of the identity (ID) code, task shifting and periodic monitoring. After setting up the paper-based NCD record system, further work has to be done for a simpler and cheaper technology to digitalize this system at the primary level.

7. Conflict of Interest

None.

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Table 2: Annexure 1 – Proforma for the patient record (NCD file) and NCD passbook

Unique ID		
Registration date		
Patient identification details		
Name		
Father's/Husband name		
Date of Birth		
Age		
Gender	Male / Female / Third Gender	
Mobile number 1		
Mobile number 2		
Current Address		Rented / Owner
Permanent Address		
NCD diagnosis	New / Old	
Disease	Diabetes	Duration -
	Hypertension	Duration -
	COPD	Duration -
	Asthma	Duration -
	Stroke	Duration -
	Coronary artery disease (CAD)	Duration -
	Chronic Kidney Disease	Duration -
	Cancer	Duration -
	Hypothyroidism	Duration -
	Any other chronic illness / morbidity?	
Family history of NCDs		

Table 3: Proforma to record baseline status (to be filled during the time of registration)

Height (cm) / arm span (for elderly)			
Weight (kg) at the time of registration			
BMI during the time of registration			
Tobacco use with duration	**Smoking**		Yes / No
	Smokeless tobacco		Yes / No
Alcohol use with duration			No / Occasional / Daily/ harmful use
Physical activity			Adequate / Inadequate
Waist circumference (cm)			
Hip circumference (cm)			
BP at the time of registration			
CVD risk score			
Baseline total cholesterol (TC)			
Baseline FBS			
Baseline HbA1C			
Baseline KFT		Urea -	Serum potassium –
Date -		Creatinine –	Serum Sodium –
		Estimated GFR - • -	Uric acid -
Baseline LFT			Normal / Abnormal_____
Urine protein / albumin –			**Urine glucose -**
Foot examination			Normal / Abnormal _____
Retina examination			Normal / Abnormal_____
ECG			Normal / Abnormal_____
Thyroid profile			Normal / Abnormal_____
Any other investigation			

Table 4: Proforma to record patient follow up details

NCD Clinic				
Follow up details				
Name -		Age / Gender -	Unique ID -	
Date of visit	Weight	Investigation /examination finding (Foot examination for DM)	NCD Medication details	Remark with Doctor sign /name
—	—	—	—	—
—	—	—	—	—

Table 5: Proforma to record annual check up of patients

Annual check-up					
Name -			Age / Gender -		Unique ID –
			2021-2022	2022-2023	2023-2024
Retina examination					
Urine protein /albumin					
HbA1C					
Last FBS					
Urea / Creatinine					
ECG					
Total cholesterol					
Change in risk factors	Tobacco use	Smoking	Yes / No	Yes / No	Yes / No
		Smokeless tobacco	Yes / No	Yes / No	Yes / No
	Alcohol use		No / Occasional / Daily/ harmful use	No / Occasional / Daily/ harmful use	No / Occasional / Daily/ harmful use
	Adequate fruits & vegetable intake (minimum 5 servings /day)		Yes / No	Yes / No	Yes / No
	Adequate physical activity (at work /leisure /home/ travel)		Yes / No	Yes / No	Yes / No
	Dietary habits	Adds extra salt after cooking	Yes / No	Yes / No	Yes / No
		Taking high salt items (pappad/ pickle / chips)	Yes / No	Yes / No	Yes / No
	Adherence to prescribed dietary advice		Yes / No	Yes / No	Yes / No
	Adherence to medications		Yes / No	Yes / No	Yes / No
	Waist circumference (cm)				
	Hip circumference (cm)				
	BP				
	Weight (kg)				
	BMI				
	CVD risk %				
Development of complication (DM foot/ amputation/ CKD/ Retinopathy / Nephropathy / stroke)					
Development of hospitalisation / new disease					
Oral Examination			Normal / _____	Normal / _____	Normal / _____
Breast Examination			Normal / __	Normal / __	Normal / ___
Cervical examination			Normal / Not done/ _	Normal / Not done/ __	Normal / Not done/ __
Remark with Doctor sign /name					

Table 6: Annexure 2 - Format of the Index register

Registration date	Patient name	Father/ Husband name	Address	Patient ID (First letter of name followed by serial number)
—	—	—	—	—
—	—	—	—	—
—	—	—	—	—