COMMENTARY

New Perspective for Integrated Information Management in National Colorectal Cancer Screening in Iran

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Abstract

Colorectal cancer screening management, especially for those with a genetic predisposition, depends on adequate and standard reporting. Standardized reporting systems for diagnostic and screening tests facilitate quality improvement of programs and clear communication among health care providers. This article presents a comprehensive picture of the information content of colorectal cancer screening in the national plan of Iran, consisting of demographic and medical findings and other standard reports (colonoscopy, pathology, genetics and pedigree data). In addition this review presents data flow in screening and data elements in patient perspectives on colorectal cancer screening.

Key Words: Colorectal cancer - screening - information management - prevention

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Introduction

Colorectal cancer (CRC) is one of the most prevalent cancers and a leading cause of cancer mortality worldwide (Cheah, 2008). In 2004, treatment costs for colorectal cancer were $8.4 billion (Seeff et al., 2008). According to report and documentation of the Ministry of Health of the Islamic Republic of Iran, colorectal cancer is third common cancer in women and 5th in Iranian men and incidence of colorectal cancer is increased during the last 25 years (Azadeh et al., 2008). However, this tumor type is particularly suitable to be controlled by screening and surveillance procedures (Domati et al., 2008). Thus colorectal cancer incidence and mortality are reduced with regular screening (Seeff et al., 2008). A national plan for colorectal cancer screening with new and comprehensive perspectives is being performing by the Research Center for Gastroenterology and Liver Disease, Shahid Beheshti University in Iran. Quality of performance in colorectal cancer screening programs can be improved via comprehensive and standard reporting. Although colonoscopy is commonly used for screening, diagnosis, and therapy, no standardized reporting system for this procedure currently exists (Lieberman et al., 2007). The aim is 'Integrated Information Management in National Colorectal Cancer Screening in Iran'. Data flow in the national plan of colorectal cancer screening is presented in Figure 1.

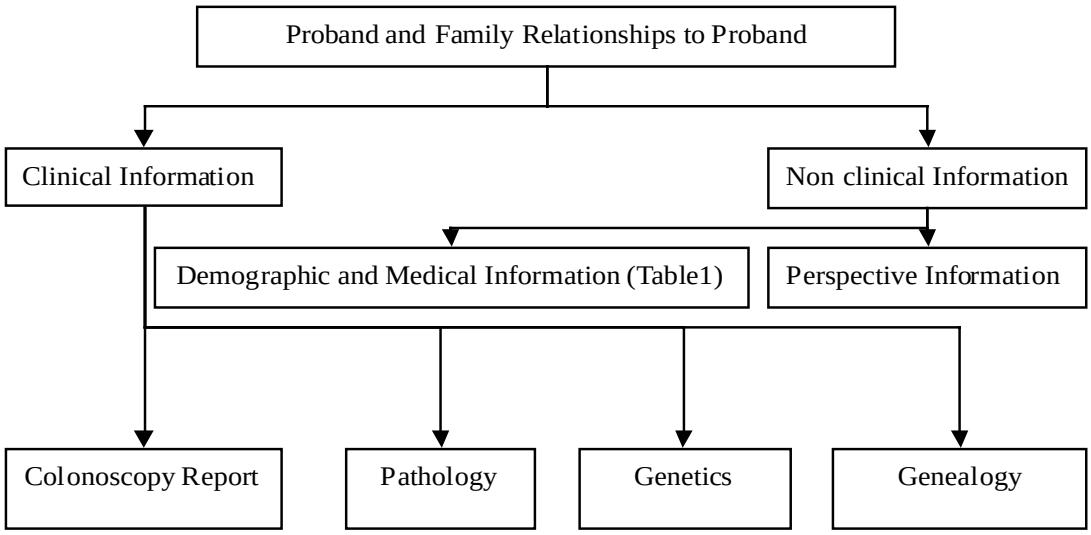

Figure 1. Data Flow in the Iranian National Plan of Colorectal Cancer Screening

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Table 1. Demographic and Medical Information

Demographic information	
1.Name and ID number	2. Birth status
3.Education	4. Religion
5. Sex, age	6. Weight and height
7. Material status	8. Race
9.Occupation	10. Insurance status
Medical History	
1.Exposure to chemical weapons: Yes No Unknown	
2. Hypertension: Yes No Unknown	
3. Diabetes Mellitus: Yes No Unknown	
4.Tobacco: Never used Cigarette smoker Cigar/pipe smoker Hookah Combo use Previous user Unknown	
5. Alcohol History: None Past Current User Unknown	
6.Opium and IV Drug User: Never Current Previous	
7. Smoker: Current Inhalation Ingestion Combo Previous Unknown	
8. Betel Use: Never Current Previous Unknown	
9. NSAIDs Use: None Nonregular Regular (Years = 0 - 0.74/0.75 - 4/ > 4) Unknown	
10. Reproductive history	11. Allergy history
12. Cancer history	

Standard Information Content in Colonoscopy Section

Standardized reporting systems for diagnostic and screening tests facilitate quality improvement programs and clear communication among health care providers. Although colonoscopy is commonly used for screening, diagnosis, and therapy, no standardized reporting system for this procedure currently exists (Lieberman et al, 2007). The standardized colonoscopy reporting provides a tool that can be used for efforts in continuous outcome improvement within and across practices that use colonoscopy with aim of screening. National plan of colorectal cancer screening applied standard report with comprehensive data elements that including:

Demographic and medical history (Table 1): Age and sex are important risk factors for adenomas and CRC, and are required for any meaningful analysis of adenoma prevalence (Rex et al, 2002. Zauber, 2004.Atkin et al, 2004).There is differences in the incidence rate and mortality of CRC based on race and ethnicity (Bhupinderjit et al, 2005. Lieberman, 2005). Accurate identification of race or ethnicity is difficult in clinical practice, and, in many cases, mixed race/ethnicity further complicates data collection (Lieberman et al, 2007).

Table 2. American Society of Anesthesiology Classification System

1 Patient has no organic, physiologic, biochemical, or psychiatric disturbance (healthy, no comorbidity).
2 Mild-to-moderate systemic disturbance caused either by the condition to be treated surgically or by other pathophysiologic processes (mild-to-moderate condition, well controlled with medical management; examples include diabetes, stable coronary artery disease, stable chronic pulmonary disease).
3 Severe, systemic disturbance or disease from whatever cause, even though it may not be possible to define the degree of disability with finality (disease or illness that severely limits normal activity and may require hospitalization or nursing home care; examples include severe stroke, poorly controlled congestive heart failure, or renal failure).
4 Severe systemic disorder that is already life threatening, not always correctable by the operation (examples include coma, acute myocardial infarction, respiratory failure requiring ventilatory support, renal failure requiring urgent dialysis, bacterial sepsis with hemodynamic instability).
5 The moribund patient, who has little chance of survival.

Study information (Table 2):The classification category of American Society of Anesthesiology has an impact on the setting and the precautions, which should be considered before colonoscopy Colonoscopists should know the appropriate indications for colonoscopy and document the indication(s) in the report. The technical description is designed to provide the referring physician a clear picture of what was done during the procedure, including its difficulty, completeness of the examination, and adequacy of the bowel preparation. These factors may play an important part in determining an appropriate interval for a repeat examination. All sentinel events and interventions should be recorded. This includes events occurring during colonoscopy and after the procedure is completed.

Finding information: Each polyp has required descriptors that describe morphology, size (in millimeters), method of removal, and completeness of removal and retrieval. Vague terms such as “large” or “small” should be avoided.

Follow up information: Recommendations for discharge planning and immediate follow-up should be included with the colonoscopy report (Lieberman et al, 2007).

Standard Information Content in Genetics Section

Cancer begins when one or more genes in a cell are mutated (changed), creating an abnormal protein or no protein at all. The information provided by an abnormal protein is different from that of a normal protein, which can cause cells to multiply uncontrollably and become cancerous. A person may either be born with a genetic mutation in all of their cells (germline mutation) or acquire a genetic mutation in a single cell during his or her lifetime. An acquired mutation is passed on to all cells that develop from that single cell (called a somatic mutation). Somatic mutations can sometimes be caused by environmental factors, such as cigarette smoke. Most colorectal cancers (about 95%) are considered sporadic, meaning that the damage to the genes occurs by chance after a person is born. Inherited colorectal cancers are less common (about 5%) and occur when gene mutations are passed within a family from one generation to the next (oncologist-approved cancer information from the American Society of Clinical Oncology, 2008).

Understanding the genes and pathways that cause CRC would no doubt contribute to better surveillance, early diagnosis and thus reduces cancer morbidity and mortality. The genetic basis of familial CRC has been actively researched in the last decades of the past century. The adenomatous polyposis coli (APC) and mismatch repair genes were found to initiate familial adenomatous

Table 3. Various Colorectal Cancer (CRC) Syndromes and Initiating Genes

Syndrome	HNPCC[1]	FAP[2]	JP/PJ/CS[3]	HMPS[4]	MAP[5]	Hyperplastic
Polyp type	A[6]	A[6]	Hamartomatous	Mixed[7]	A[6]	Hyperplastic/serrated
Genes[8]	MSH2, MLH1, MSH3, MSH6, PSM1, PSM2	APC	BMPR1A/S MAD4/LKB-1 /PTEN	BMPR1 A/CRAC1?	MUTYH[9]	?
Inheritance	AD[10]	AD	AD	AD	AR[11]	?
MS-status	MSI-H/L[12]	MSS[13]	MSS	MSS	MSS	MSS/MSI-L
Methylation	L	L	L	L	L	H/L

[1]Hereditary non-polyposis colorectal cancer; [2]Familial adenomatous polyposis; [3]Juvenile polyposis/Peutz–Jeghers/Cowden syndrome; [4]Hereditary mixed polyposis syndrome; [6]Adenomatous; [7]Mixed adenomatous/hyperplastic/atypical juvenile; [8]Germline mutations in these genes initiate the various syndromes; [9]MUTYH-associated adenomatous polyposis; [10]Autosomal dominant; [11]Autosomal recessive; [12]Microsatellite-instability high/low;[13]Microsatellite stable

Table 4. Standard Data Items in the Genetics Section

Pathological Block Survey for Genetics Testing	IHC: MLH1 (Normal-Abnormal)
	MSH2 (Normal-Abnormal)
	MSH6 (Normal-Abnormal)
	PMS2 (Normal-Abnormal)
	MSI: (Stable-Low-High)
Genetic Survey	Mutation Mismatch Repair: MLH1-MSH2-MSH6-PMS2
	APC: (Negative-Positive)
Genetic Result	HNPCC FAP

polyposis (FAP) and hereditary non-polyposis colorectal cancer (HNPCC), the two main autosomal dominantly inherited CRC, respectively (Cheah, 2008) (see Table 3). FAP is a condition in which the tendency to develop large numbers of a certain type of polyp is inherited. These polyps are called adenomatous polyps or adenomas. This hereditary (genetic) disease mainly affects the gastrointestinal tract. Other names for this condition are hereditary polyposis of the colon, familial polyposis, and Gardner syndrome. Individuals with this condition typically develop hundreds to thousands of polyps throughout the colon at a young age, usually as a teenager or young adult. The major concern in this condition is that the adenomatous polyps will become cancerous. HNPCC is a condition in which the tendency to develop colon or rectal cancer is inherited (it is hereditary). Some of the genes (basic units of heredity) that cause HNPCC are known. Nonpolyposis means that colorectal cancer can occur when only a small number of polyps is present (or polyps are not present at all). The characteristics of HNPCC include multiple family members affected with colon cancer, colon cancer in multiple generations, and an earlier age of onset than often seen in the general population (before age 50 years). In HNPCC, colorectal cancer occurs primarily on the right side of the colon. Sometimes other cancers can occur in families with HNPCC. They include cancer of the uterus, ovary, stomach, urinary tract, small bowel, and bile ducts. Other names for HNPCC are Lynch syndrome and cancer family syndrome (The Johns Hopkins University, 2000).

Table 3 emphasizes the various colorectal cancer (CRC) syndromes and initiating genes. To determine the appropriateness of screening at a specific age, key family history data should be recorded, including CRC and adenomas in first-degree relatives. Patients with first-degree relatives who had CRC may need screening before age 50 years (Pignone et al., 2002; Winawer et al., 2003).

Data elements in genetic section of national colorectal cancer screening consisted free text and check mark options in two section Pathological Block data and genes survey. Table 4 illustrates standard data items in the genetic section.

Information Content on Pedigree

Pedigree play significance role in planning and management of colorectal cancer screening. Benefits of family tree include:

1. Identifying high risk populations of colorectal cancer
2. Planning screening program compliance with sex, age, medical history and other family and relative characteristics (Research Center Gastroenterology and Liver Disease, Shahid Beheshti University, 2008).

With regard to pedigree, in the national plan surveyed information is for first degree (mother, father, sisters, brothers, son and daughter), second degree (grandmother, grandfather, aunt, uncle) and third degree of family relationships (grand grandmother, grand grandfather, cousin). The proband is identified with asymbol. Figure 2 illustrates an example of a pedigree.

Standard Information Content in Pathology Section

Pathologic specimens are obtained in 30% to 50% of colonoscopy procedures, and the histologic report should

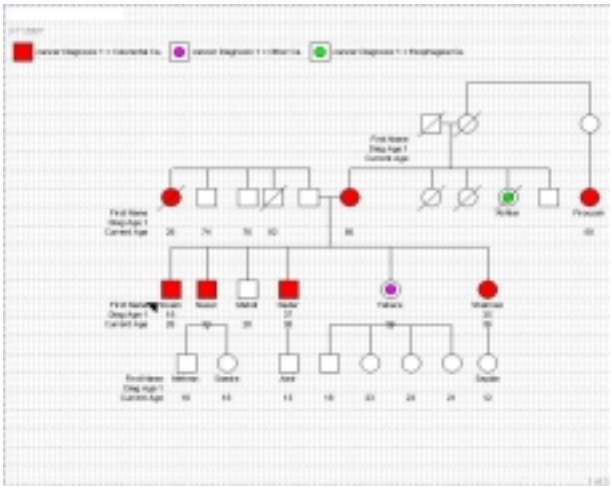

Figure 2. Example of a Pedigree with Colorectal Cancer Screening in the National Plan in Iran

Table 5. Data Elements for Pathology Reporting

1. Tumor Site:	Cecum; Ascending colon; Hepatic flexure; Transverse colon; Splenic flexure; Descending colon; Sigmoid colon; Rectum; Not specified
2. Histology Type:	Adenocarcinoma; Mucinous adenocarcinoma; Medullary carcinoma; Signet ring carcinoma; Small cell carcinoma; Undifferentiated; Other carcinoma; Type cannot be determined
3. Tumor configuration:	Exophytic; Infiltrative; Ulcerative; Other
4. Histological Grade:	Adenocarcinoma; Mucinous adenocarcinoma; Medullary carcinoma
5. Primary Tumor:	PTX; PTO; PTis; PT1; PT2; PT3; PT4
6. Distant metastasis:	PMX; PM1
7. Margins:	Involved proximal; Uninvolved proximal; Involved distal; Uninvolved distal
8. Lymphatic Invasion:	Absent; Present
9. Venous Invasion:	Absent; Present
10. Intra Tumoral or Pan Tumoral Lymphocytic Response:	None; (Marked); Mild – Moderate; Crohn–like
11. Tumor Size:	Greatest dimension: ……; Additional dimension: ……; Cannot be determined
12. Regional lymphnode:	PNX; PNO; PN1; PN2; Number examined: ……; Number involved: ……

be considered an essential element of the final outcome (Lieberman et al., 2007).The amount and quality of information in histopathology cancer reports are crucial for proper tumor staging and, consequently, patient treatment. Adequate histopathology reports are also essential for establishing and maintaining high-quality cancer registries. Information derived from these registries can then be used for monitoring quality of patient treatment (Bjugn et al., 2008). Careful and accurate pathology reporting of colorectal cancer resection specimens is vital because pathology reports are used to:

confirm the diagnosis
inform prognosis
plan the treatment of individual patients
audit pathology services
evaluate the quality of other clinical services, notably radiology, surgery and oncology
collect accurate data for cancer registration and epidemiology
facilitate high quality research
plan service delivery.

In colorectal cancer, the key reasons for high-quality pathology reporting include the following.

1. To confirm that radical surgery was necessary and to place the patient in a correct disease stage for an accurate prognosis to be given and appropriate post-operative therapy to be advised.

2. Patients who have lymph node involvement (Dukes C1 and C2 or pN1 and pN2) are likely to receive adjuvant chemotherapy, if age and co-morbidity allow, which is of probable benefit, mildly toxic and costly. Those without lymph node metastases but with adverse pathological features (extramural venous invasion, perforation, serosal involvement and incomplete resection) may also be offered adjuvant therapy for small but definite benefit.

3. Patients with rectal adenocarcinoma and involvement of the non-peritonealised (circumferential) resection margin are at high risk of local recurrence and may receive post-operative radiotherapy +/– chemotherapy which is toxic and costly but may decrease the likelihood of this unpleasant and nearly uniformly fatal complication. The frequency of circumferential margin involvement found may indicate the quality of rectal cancer surgery being performed.

4. To determine the effects of pre-operative neoadjuvant therapy.

5. To allow audit of diagnostic and surgical procedures in relation to clinical outcomes avoiding selection bias, the identification of good surgical practice and the comparison of patients in clinical trials.

6. To facilitate improvements in the quality of rectal cancer surgery by grading the plane of surgical excision and recording the frequency of abdomino-perineal excisions (The Royal College of Pathologists., 2007).CAP guidelines for the reporting of CRC were classified as either gross (macroscopic) or microscopic, reflecting the 2 main stages of specimen processing. Gross features examined were tumour size, status of the serosa, measured distance of tumour to proximal, distal and radial margins and depth of mesenteric or perirectal soft tissue. Microscopic features assessed were histological type, histological grade, depth of invasion, serosal involvement, lymphovascular space (small vessel) invasion, extramural venous (large vessel) invasion, perineural invasion, host response, proximity of tumour to proximal, distal and radial resection margins and lymph node status (Chan et al,2008). Other section of colorectal cancer screening record in national plan is pathology reporting that data elements illustrated in Table 5.

Information Content about Perspectives Patients on Colorectal Cancer Screening

The main goal of Information Content of this section was to assess the level of knowledge and awareness of people about cancer screening. The specific goals of this evidence were:

1. To identify what information people want in order to feel informed when making a choice over whether or not to be screened.

2. To identify what information people use to make the choice about screening.

3. To gain an understanding of the relationships between information and knowledge, choice and behaviors (Jepson, et al, 2007).

Data elements in this part designed via study of valid database and articles. Data items that can be summarized as follows:

Data item 1: Information on the cancer (symptoms, risk factors (Familiarity, Environment risk, Diet and Style life), incidence and curability).

Data item 2: Subjects were asked whether there had cancer in the family; the anatomical site and the age of cancer onset among relatives were recorded.

Data item 3: The subjects were asked whether they underwent diagnostic tests for tumors, for what reasons (symptoms or prevention/screening), and who suggested the procedure (family doctors, specialists, public health services).

Data item 4: Meaning of screening (to examine healthy individuals, care of patient, reduction of risk factors, to execute examination in the presence of symptoms, other).

Data item 5: Information on screening (benefits, harms and consequences).

Data item 6: Screening: we asked whether they knew about the existence of screening procedures, and for which tumors.

Data item 7: Main source of information about screening (friends, family doctors, specialists, television, internet, and multi media, Journals, Specialized Journals, newspapers, brochure, and counseling room).

Data item 8: Role of the information in people's decision making for informed choice about screening.

Data item 9: Ideal promoters of this possible project (choosing among Ministry of Health, Regions, provinces, health Care Districts and Associations against tumors, family doctors, and specialists).

Data item 10: How useful screening in reducing cancer morbidity and mortality might be (indispensable, very useful, useful, useful in some case, not necessary).

Data item 11: Reasons for screening (familial, environmental risk, others).

Data item12: Individuals who did not undergo screening were asked whether they were willing to participate in a coordinated program of screening (No, Yes, Yes, if free Yes, if not invasive).

Data item 13: In case of a negative answer, Reasons people do not participate in screening (excessive costs, skepticism about prevention, fear of the results, not liking the test, these tests are useless, others).

Data item 13: Degree of coercion and control (Pressure to attend from health professionals, Pressure to attend from familiar and friend, Not much pressure, others).

Data item 14: The experience of being screened.

Informed choice is a complex concept and generally considered to be a desirable feature of screening programs. The role and importance of information currently provided in making choices about cancer screening is not clear (Jepson et al., 2007).

Integrated information in colorectal cancer screening enhances decision making in various stage of prevention. Information management has the key role to increase greatly the efficiency of screening program. Preprocedure, intraprocedure, and postprocedure colonoscopy data and standard pathology data can be used to improve the quality of activities. In addition, information content of pedigree play important role in identifying of high risk population in during national plan. Managers can use perspective information for appropriate planning of screening.

References

Agrawal S, Bhupinderjit A, Bhutani MS, et al (2005). Colorectal cancer in African Americans. *Am J Gastroenterol*, **100**, 515-23.

American Society of Clinical Oncology (2008). Oncologist-approved cancer information. Available from: http://pda.asco.org.

Atkin W, Rogers P, Cardwell C, et al (2004). Wide variation in adenoma detection rates at screening flexible sigmoidoscopy, *Gastroenterology*, **126**, 1247-56.

Bjugn R, Bettina Casati, Norstein Jarle (2007). Structured electronic template for histopathology reports on colorectal carcinomas: a joint project by the Cancer Registry of Norway and the Norwegian Society for Pathology. *Human Pathol*, **39**, 359-67.

Chan NG, Anil Duggal, Weir MM, et al (2008). Pathological reporting of colorectal cancer specimens: a retrospective survey in an academic Canadian pathology department. *Can J Surg*, **51**, 284-8.

Cheah PY (2008). Recent advances in colorectal cancer genetics and diagnostics. *Crit Rev Oncol Hematol*, ???

Federica D, Travlos E, Cirilli C, et al (2008). Attitude of the Italian general population towards prevention and screening of the most common tumors, with special emphasis on colorectal malignancies. *Intern Emerg Med*, ???

Jepson RG, Hewison J, Thompson A, et al (2007). Patient perspectives on information and choice in cancer screening: A qualitative study in the UK. *Soc Sci Med*, **65**, 890-9.

Johns Hopkins University (2003). The Johns Hopkins Guide for Patients and Families: Familial Adenomatous Polyposis. Available from: http://hopkins-gi.nts.jhu.edu/multimedia/database/intro_84_FAP-Book.pdf

Johns Hopkins University (2003). Johns Hopkins Guide for Patients and Families: Hereditary Nonpolyposis Colorectal Cancer. Available from: http://hopkins-gi.nts.jhu.edu/multimedia/database/intro_83_HNPCC%20Booklet.pdf

Lieberman D (2005). Race, gender, and colorectal cancer screening. *Am J Gastroenterol*, **100**, 2756-8.

Lieberman D, Nadel M, Smith RA, et al (2007). Standardized colonoscopy reporting and data system: report of the Quality Assurance Task Group of the National Colorectal Cancer Roundtable. *Gastrointest Endosc*, **65**, 757-66.

Pignone M, Rich M, Teutsch SM, et al (2002). Screening for colorectal cancer in adults at average risk: a summary of the evidence for the U.S. Preventive Services Task Force. *Ann Intern Med*, **137**, 132-41.

Rex DK, Bond JH, Winawer S, et al (2002). Quality in the technical performance of colonoscopy and the continuous quality improvement process for colonoscopy: recommendations of the U.S. Multi-Society Task Force on Colorectal Cancer. *Am J Gastroenterol*, **97**, 1296-308.

Seeff LC, DeGroff A, Tangka F, et al (2008). Development of a Federally Funded Demonstration Colorectal Cancer Screening Program. Preventing chronic disease, 5. Avalaible from: www.cdc.gov/pcd/issues/2008/apr/07_0206.htm.

Zauber A (2004). Quality control for flexible sigmoidoscopy: which polyps count. *Gastroenterology*, **126**, 1474-7.

Williams GT, Quirke P, Shepherd NA (2007). Standards and Datasets for Reporting Cancers Dataset for colorectal cancer (2nd edition). Available from: www.rcpath.org.

Winawer S, Fletcher R, Rex D, et al(2003). Colorectal cancer screening and surveillance: clinical guidelines and rationale: update based on new evidence. *Gastroenterology*, **124**, 544-60.