

Review

# Asymptomatic Inflammatory Bowel Disease and Colorectal Cancer Screening Programs: How Common Is It and What Should be Done About It?

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**Abstract:** The growing international popularity of screening programs for the early detection of pre-cancerous changes or early cancer in the colon has brought to the fore the issue of people with asymptomatic inflammatory bowel disease. What are the legal and clinical responsibilities for endoscopists and managers of screening programs towards such patients? This review assesses the magnitude of the problem and discusses the legal responsibilities, including human rights issues. In addition, it discusses whether such patients who do not have symptoms should be given active treatment.

**Keywords:** inflammatory bowel disease; healthy people; colorectal cancer screening programs; law; human rights

## 1. Introduction

During the 1980s, the potential to screen healthy patients for the presence of colonic polyps or early cancer, and so to reduce the mortality from this condition, was recognised as a real possibility. One of the core issues that faced these early researchers was the need to develop tests and screening programs that minimised the number of false positive and false negative tests. Although the significance of false negative tests for individuals and for the reputation of screening programs was clear, the issue with false positive tests was rather the increased work load they generated, and the risk to patients of unnecessary colonoscopies. Intensive efforts were made to develop a battery of tests that minimised these two confounding factors. Nevertheless, whatever screening tool has been used in communities, patients with conditions other than colonic polyps or colonic cancer continue to be identified. With the international growth of colorectal cancer detection programs, a growing number of patients are being identified where the underlying diagnosis includes conditions such as diverticulosis or inflammatory bowel disease. Amongst these diseases, the identification of ulcerative colitis or Crohn's disease in an apparently healthy individual raises serious questions as to what strategies should be offered to such screenees. It is also clear that such patients constitute a significant proportion of the whole cohort of people with these conditions, ranging from 29% in Croatia [1] to 40% in Spain [2]. In China, where the incidence of inflammatory bowel disease has had a dramatic increase, the figure may be as high as 98% [3].

## 2. Is the Detection of Asymptomatic Inflammatory Bowel Disease a Significant Problem?

In 1989, Mayberry et al. [4] reported that the prevalence of inflammatory bowel disease amongst healthy people undergoing a colorectal cancer screening program was 56/10<sup>5</sup> population. This was

the first occasion on which the magnitude of the unseen part of the iceberg of inflammatory bowel disease had been measured. It suggested that as many as a third of the patient population had minimal symptoms or were indeed asymptomatic. As further studies were reported over the next 20 years, the nature of this “asymptomatic” population became clearer (Tables 1 and 2). Many were indeed asymptomatic, others had mild symptoms but had never sought medical advice, whilst some were known patents but had been “lost to follow-up” for many years [5]. The actual numbers identified in large screening programs are not insignificant, with more than 2000 such patients identified amongst the first million healthy people screened as part of the national colorectal cancer screening program in the United Kingdom [6]. The prevalence of asymptomatic inflammatory bowel disease amongst screenees has been comparable across the world, with the exception of the report from Japan [7] (Table 2). This would suggest that the number of people affected internationally is very large.

**Table 1.** Cases of asymptomatic inflammatory bowel disease (IBD) detected during colorectal screening programs for healthy people. UC—ulcerative colitis.

Centre	No. Screened	Age Range	No. with IBD	No with UC	No. with Crohn's	Prevalence of Asymptomatic IBD/10 <sup>5</sup> Population
Nottingham [4]	17,930		8	6	2	56
Nottingham [8]	44,838	45–74	53	52	1	116
UK [6]	1,079,293		2152			199
Basque Country [9]	31,005		110	79	24	355
Croatia [10]	181,102		320			177
Nacota, Japan [7]	236,000	36–63	14	12	2	6
Shanghai [11]	5919		6	6	0	101

**Table 2.** Reported prevalence (cases/10<sup>5</sup> population) of inflammatory bowel disease in countries that have also measured the prevalence of asymptomatic inflammatory bowel disease.

Centre	Prevalence of UC	Prevalence of Crohn's	Prevalence of Symptomatic IBD
UK [12]	243.4	144.8	388.2
Central Spain [1]	137.2	99.8	237
Zadar County, Croatia [2]			245
Japan [13]	63.6	21.2	84.8
Yunan, China [3]	2.4	0.05	2.5

The question now arises as to how gastroenterologists and national health services should respond to these patients. The questions that must be addressed include the following:

- What is the responsibility of the endoscopist and the screening program towards such patients?
- How should such patients be managed clinically?

### 3. What is the Responsibility of the Individual Endoscopist and the Screening Program Towards Such Patients?

Such a question raises legal and financial questions. In 2001, Eaden et al. [14] drew attention to the need to ensure that screenees were made aware of what was being offered, as opposed to their expectations. The relationship between the screenee and screener is a contractual one, and will carry legal rights for the patient/consumer. Screenees need to be aware that a positive screening test that identifies inflammatory bowel disease rather than a colonic polyp or colorectal cancer could affect applications for insurance, leading to additional weighting or outright rejection. Job prospects could also be adversely affected. In addition, it should be clear whether they will be told of diagnoses other than colorectal neoplasia, as well as how such conditions will be managed. The surprise finding in England and Wales by the Court of Appeal in *Khan v. Meadows* [15], that doctors were potentially not responsible

for acting on incidental findings, needs to be balanced against *Montgomery v. Lanarkshire Health Board* [16], which confirmed that doctors must tell patients of the risks of the procedures. Although this case dealt with clinical risks, its principles can readily be extended to social consequences, and, importantly, it acts retrospectively, and so covers procedures already done within the United Kingdom.

An interesting paper from Ukraine related to screening has drawn attention to human rights aspects [17]. Following on from *Atiman v. Turkey* [18], the European Court of Human Rights made it clear that Article 2 was not restricted to cases where there had been a death, and was moving towards “more substantive justiciable protection” for patients. In *Powell v. United Kingdom* [19], it confirmed the responsibilities of NHS organisations and other European state health agencies to protect life. It found “that the acts and omissions of the authorities in the field of health care policy may, in certain circumstances, engage their responsibility under the positive limb of Article 2”. The consequences for incidental findings during screening programs is yet to be litigated, but it is almost inevitable in the near future, and a positive interpretation of Article 2 would mean that they could not be ignored.

#### 4. How Should Such Patients be Managed Clinically?

In both ulcerative colitis (UC) [20] and Crohn’s disease [21], the risk of cancer increases steadily with time. Treatment with 5ASA compounds has been shown to reduce that risk towards normal in patients with ulcerative colitis [22], although this risk reduction has never been reported for Crohn’s disease. However, the patients in these studies were all symptomatic, and the critical issue, therefore, is whether asymptomatic patients are at the same risk. The Courville et al. [23] study of isolated ileitis in 29 asymptomatic patients who were followed up for two years showed that 14 remained symptom free. The presence of unreported symptoms at the time of the initial diagnosis seemed to be the best predictor of progression to classical Crohn’s disease. However, these patients had no evidence of colonic involvement. In a review of 19 asymptomatic Korean patients with ulcerative colitis detected during cancer screening programs, 13 developed symptoms within five years, which required active treatment [24]. The question remains as to how those patients who continue to be symptom free should be best managed, especially as the medications available are not themselves without risk. Clearly, at present, the decision is one that only the patient can make when provided with comprehensive and accurate advice, namely:

“No decision about me, without me” [25].

#### 5. Conclusions

Asymptomatic patients detected at colorectal cancer screening programs in healthy people are of two types, those who had been previously diagnosed some years before but had been lost to clinical follow-up, and those who had never been diagnosed and had never presented to a doctor with clinical symptoms. Both are at risk of developing complications of the disease, including colorectal cancer. Endoscopists and screening programs are under a legal obligation to inform such people of the clinical findings, and should develop formal policies for their management. These policies should include details of the risks, benefits, and uncertainties as to how they should be best treated.

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