

# The impact of nurse-led annual telephone follow-up of patients with inflammatory bowel disease

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## Abstract

Inflammatory bowel diseases (IBD) are characterised by periods of disease activity and period with disease in remission. In Denmark all patients are seen in hospital settings. The aim of this study was to introduce a nurse-led phone service for stable patients replacing annual visits.

The study originated from an outpatient cohort of 1,600 patients with IBD. A research protocol was determined before the intervention was launched, which included surveys among the patients before the intervention, after the intervention, collection of longitudinal data in a three year period, and a clinical audit. Budget impact analysis (BIA) and cost-effectiveness analysis (CEA) were done. Furthermore, the staff evaluated the process.

Almost 30% (n = 474) of the total cohort was enrolled in the service. Eighty-seven per cent of the patients welcomed the phone service beforehand. After implementation, 94% of the patients included were pleased with the service. The programme has shortened the waiting time for most other services, but no improvement in the workload was observed. The BIA showed limited savings. The CEA showed an annual saving of 100€ per patient when using the annual phone service over routine visits.

In conclusion, changing the method of contact from routine annual visits to annual phone calls from a nurse was feasible and well accepted for stable patients with IBD. The benefits of the service were most marked for the patients.

## Problem

Patients with inflammatory bowel diseases (IBD) are often seen by a doctor on a regular basis in the hospitals outpatient clinics regardless of disease activity or not. The follow-up and treatment of patients with IBD is continuous to postpone relapse and prolong the period of disease remission. The majority of IBD patients are diagnosed while in their twenties. Therefore, many patients are quite young and are studying or are in the labour market. Appointments in the outpatient clinic can therefore become costly for the patients and might as well be replaced by telephone calls if the disease is in-remission.

## Background

IBD are chronic diseases with a pattern of relapse, and consist of Crohn's disease (CD) and ulcerative colitis (UC). The disease prevalence and incidence vary across the globe and are highest in the industrialised world.[1,2] In Denmark, the annual incidence and prevalence of CD and UC have been estimated at approximately 10 per 100,000 and 23 per 100,000, respectively, and 151 per 100,000 and 294 per 100,000, respectively.[3,4] The diseases are characterised by periods of disease activity and periods with remission. It has been estimated that at any given time point, 50% of patients are in remission, 25% will have severe disease activity, and 25% will have mild to moderate disease activity.[5,6] Due to relatively low prevalence and the need for clinical expertise, nearly

all patients with IBD in Denmark are seen in hospital settings and none by the patients' general practitioner (GP). Approximately 1,600 patients with IBD are seen on a regular basis in the outpatient clinic at Aarhus University Hospital, Denmark.

Signs of disease activity are mainly abdominal pain, bloody diarrhoea, and weight loss or fatigue. Biomarkers such as faecal calprotectin and blood levels of C-reactive protein can often be used to determine a disease flare. Additionally, clinical scores for each disease are used to assess the disease severity.[7,8]

Few alternatives to routine visits have been reported in IBD. A randomised controlled trial (RCT) from the United Kingdom (UK) found no differences in disease activity between an self management (SM) group and its controls.[9] However, treatment for disease flares was initiated earlier, hospital visits were reduced, and patient satisfaction was greater in the SM group. In a Swedish study, the management of IBD patients was changed from conventional treatment to mainly SM, and both patients' and health professionals' satisfaction was increased with the introduction of a redesign of the outpatient clinic. Population-based data showed a stable disease status and activity after the redesign.[10] Furthermore, a paper from the UK describes a SM approach, which was introduced and evaluated as a cluster RCT, showing that both hospital visits and health care costs were reduced in the SM group.[11] A recent published study reveals that establishing a nurse service for patients with IBD, could avoid one of six contacts to the hospital.[12] A RCT on SM within rheumatology showed that

patients in both groups had the same levels of disease activity during a six-year follow-up period. However, patient satisfaction was significantly higher in the SM group, and this group had only two-thirds of the number of hospital visits as the controls.[13]

The aim of our study was to systematically elucidate the impact of restructuring the method of patient contact with the department. This meant that routine annual visits were replaced with annual blood samples, measurement of faecal calprotectin, and followed by a phone call from a nurse.

## Baseline measurement

As the intervention was complex, both measurements and levels of evaluation were wide ranging and planned beforehand. The program evaluation was inspired by Rossi et al.[14] An overview of the levels of evaluations, evaluation questions and data sources for evaluations are shown in Table 1.

See supplementary file: ds3926.pdf - "Table 1"

## Design

Eligible patients for the intervention were patients with a history of IBD for more than one year, disease in remission, and with stable medical treatment.

Patients with mental dysfunction, hearing loss, reduced language proficiency, reduced level of adherence, or unstable disease were not included. Patients who did not want to switch to the new method of contact were maintained in the routine regime.

All eligible patients were offered a new contact method by which the routine annual visits were replaced by a phone call from an experienced nurse. Each patient received a letter specifying the appointment time before the phone call, and the patients were urged to have blood samples and a faecal sample (for measurement of calprotectin in order to detect disease activity) taken at the hospital or by their GP before the call. Additionally, the acute advice line availability was extended from one hour to five hours per day.

## Strategy

Pre-intervention, an unselected sample of approximately 10% of our entire cohort of patients with IBD (n=150) was consecutively included and given a questionnaire containing a five-item Likert scale. The patients were asked about their willingness to change from routine annual visits to annual phone calls from a nurse, and whether they had any comments or concerns regarding the changes. Data on demographics, education, employment, disease type, and disease activity were also collected.

Post-implementation, another unselected sample of 150 patients who had been included in the intervention cohort was contacted by letter. They were asked about the new practice of annual phone calls and the extended access to the acute advice line. Six

questions were asked, and the patients could answer on a five-item Likert scale. The patients were also asked whether they had any comments regarding the new practice. In addition, data on demographics, disease type, and disease activity were collected. Finally a clinical audit trial on 160 patients was conducted post-implementation.

Post-implementation, all of the involved nurses, physicians, and secretarial staff were asked to respond to the intervention. They could anonymous response to: effect, process, communication, implementation, and education.

All visits in the outpatient clinic and all scheduled (and acute) phone calls were registered in the hospital database. Each individual patient's medical record has been stored in the database and was available for auditing.

Over a period of three years (one year prior to the intervention, one year during implementation, and one year after the implementation), data on activity in the outpatient clinic were collected as a sample the first Monday of every month. The data collected included: waiting time for the patients in the waiting room, time to a new available elective (and acute) appointment, time to elective endoscopic procedure, and the number of patients who stayed away from their appointments. The intention was to monitor changes over time during the implementation phase, instead of simply comparing the baseline vs the end of intervention.

Based on observations of the time slots in the outpatient clinic and the exact descriptions of our patients' work status and distance to the hospital, budget impact analysis (BIA) and cost-effectiveness analysis (CEA) were estimated. Data from Statistics Denmark (National Statistic's Database) and the national tariffs for transport reimbursement were used to value work loss and transportation. The rates for compensation from the Danish National Health Service were assessed according to the coding of the different services provided by staff.

## Results

### Need for the program

Pre-intervention 150 patients were asked and 147 replied to the questionnaire (98%). Eighty-seven percent (n = 128) of these patients "agreed 100% with the new approach" or "agreed, but had a few concerns." The most sceptical group was mainly males, who had the highest mean age, the lowest proportion of employment, and the highest proportion of retirement; these results are published elsewhere.[15] Several patients noted that hearing loss or the use of biologics could obstruct a change to the annual phone service. Post-intervention, a sample of patients (n = 150) who had tried the annual phone service answered a questionnaire. One hundred twenty-eight responded (85%). Ninety-four per cent (n = 120) of the patients responded that they were pleased with the service.

Among the health professionals, the main concerns after implementation were the lack of feedback (for nurses) and the unchanged workload in the outpatient clinic (for both physicians and

nurses).

## Design and theory

The patients' main comments and concerns prior to the intervention involved how to manage complex disease within the annual phone service. The target group of patients was defined as those whose disease was in a stable phase and who only had routine appointment(s) in a one-year interval. Neither the patients nor the health professionals noted any difficulties regarding being unable to make the scheduled contact by phone. Approximately half of the patients who were asked post-implementation had used the acute advice line. Ninety percent (n = 115) of those answered that they were able to make prompt contact with the nurses. None of the patients asked for extended opening hours for the acute advice line.

One year after the inclusion of the first patient, 474 patients (approximately 30% of our cohort) were enrolled in the annual phone service. In the same period, the number of acute calls increased by 10%. It was not possible to separate the calls by diagnosis since the acute service covers both patients with IBD and other patients from our department.

## Process and implementation

The questionnaire administered to patients post-inclusion revealed that all of the patients had had the disease for more than one year, and only four per cent had had the disease for less than two years. This finding is in accordance with the planned inclusion criteria.

The audit trial revealed that for those not enrolled (but possible candidates), the most frequent reasons for not being enrolled included: disease activity, physician's decision (despite the fact that the next scheduled visit(s) were planned more than six months later) and patient evaluated as not adherent.

Post-implementation 88% (n = 113) of the patients who were enrolled in the program characterised the nurses as being competent and 94% (n = 120) were satisfied or very satisfied with the delivery of the program. The specific competencies needed to provide the phone service were described as communication skills, including guiding and focusing the content of the call, with disease-specific and empathic skills being described as essential.

Both the nurses and the physicians described difficulties in accomplishing structured supervision of the nurses performing the calls. The nurses expressed concerns regarding the allocated time frame (20 minutes) for each contact, as each phone call is accompanied by documentation and sometimes involves the booking of blood samples for the patient.

## Outcome

The target was to include 90% of the eligible patients but only 82.1% (474 patients) were included. The time to the next available acute appointment in the outpatient clinic was reduced from months to days during the implementation of the program, as was the waiting time to have a flex-endoscopy performed (figure 1).

Both before and after the intervention, flex-endoscopy was performed by the physicians who covered the other services in the outpatient clinic. Flex-endoscopies were performed using the same time slots as those for regular visits.

The waiting time for patients attending the outpatient clinic for scheduled appointments remained unchanged during the intervention implementation and post-intervention periods (figure 1).

The number of acute or unplanned visit was unchanged. The proportion of patients who stayed away from their appointments also remained unchanged (approximately 10%).

Pre-intervention some patients expressed concerns about being forgotten by the system when switching to the annual phone service. This concern was not expressed by the patients post-implementation.

The staff expressed some concerns about overlooking the recommended routine screening of patients, eg for cancer, decalcification of bones due to steroid treatment, when introducing the annual phone service. Furthermore, the staff expressed some concern regarding the risk of double work, if the nurses, in addition to the annual phone call, also had to check these decisions with the physician. Only a few patients enrolled in the annual phone service needed to be double checked with the physicians before the nurse could call back to the patient. As before the program, approximately half of those contacting the ward using the acute advice line needed to be checked with the physicians.

## Cost and efficiency

An estimate of the differences in direct costs between the annual phone service and routine annual visits in the outpatient clinic, expressed in a BIA, are shown in table 2. The uncomplicated patients were not seen by physicians when offered annual phone calls and the nurses only spent slightly more time on the annual phone service. The secretary spent a bit more time on those offered annual phone calls, as letters had to be mailed to the patients beforehand.

For the patients with problems, the nurses often were supervised by the physicians before calling back the patient. For patients with disease activity, the direct costs are assumed to be the same regardless of contact form. The reimbursement from the National Health Service is more than five times as high for a routine visit compared to a phone call (115€ vs. 21€).

The indirect costs were calculated with CEA and include both the direct costs (above) and the estimated costs for patients. The average IBD patient in the department previously has been estimated to be 41 years-old and to have an average distance to the hospital of 25 kilometres (km) [16]. Based on salary data from Statistics Denmark (30€/hour in two hours) and the national tariffs for transport reimbursement (0.5€/km for 50 km), the patient costs were used to value work loss and transportation. Thus, the patients' average annual visit costs came to a total of 85€. This cost added to the direct cost, which provides a total savings of 100€ per patient

per year for uncomplicated patients, and 92€ for patients with some problems if routine annual visits are replaced with annual phone calls.

See supplementary file: ds4154.pdf - "Figure 1 & Table 2"

### Lessons and limitations

This study illustrates how the redesign of patient management systematically can be implemented and monitored. The study also illuminates the benefit of asking the patients about the planned changes beforehand. Furthermore, the study emphasises that complex interventions need to be broadly evaluated.

The study showed that approximately 90% of the patients welcomed the program both before and after its implementation. The proportion of satisfied patients is in accordance with the findings in other studies.[9,17,18] Our study also illustrates how routine visits can be successfully replaced with a nurse-led annual phone service for patients with disease in remission, provided that an acute advice line is well functioning. This finding is consistent with recent findings of ways in which patients with IBD express their needs.[19]

Our study also shows that a wide range of services should be available, as patients have different needs both related to disease activity and personal circumstances. Individual needs also change over time, which requires a flexible contact to the hospital. The European Crohn's and Colitis Organisations (ECCO) consensus on IBD patients' needs in health quality of care did not focus on the contact form with the hospital or any possible variation thereof.[20]

However, the N-ECCO consensus statements on European nursing in CD and UC describe how the advanced IBD nurse can accomplish an independent review of IBD patients and manage advice lines for patients.[21]

Our phone service included more than 80 % of the target group. The number of patients included in the service could likely be further increased if a special focus was placed on those receiving immunosuppressive drugs. Often the patients treated with immunosuppressives have disease in remission, but they have to have blood samples drawn on a regularly basis in order to detect possible side effects to the treatment. The results could probably be evaluated by phone.

Furthermore, the physicians likely could increase their awareness on the annual phone service and could refer additional eligible patients.

During implementation, the waiting time to both flex-endoscopy and acute appointments was reduced. However, the patients' waiting time to see a doctor at scheduled appointments and the proportion of patients who did not show up remained unchanged. Whether these findings were directly related to the introduction of the phone service itself or due to general adjustments and efficiency, remains unclear. The unchanged waiting time for scheduled visits might reflect unmet needs in our patient population before the program

was introduced.

The drawback of the program seems to be that the health professionals did not experience any major changes in their daily workload. Furthermore, time to supervise the nurses running the phone service were difficult to achieve. After implementation, the program has been trimmed and developed further and will probably be accompanied by new telemedicine approaches.

Regardless of economic perspective, our cost analysis reveals clear savings when switching from annual routine visits to a nurse-led annual phone service for uncomplicated patients. The direct cost savings are jeopardised by a five-fold difference in the reimbursement rate. From a community perspective, the estimated savings for the patients are based on clinical data for mean age (and salary) and mean distance to the hospital (and reimbursement rates), which resulted in annual total savings for our cohort of approximately 45,000€ (100€ x 450 patients). From a narrow budget impact perspective, the total annual savings are only approximately 10% of the amount above. These amounts should be compared to the extra cost of establishing the service. Nevertheless, the annual phone service seems to satisfy approximately 30% of our patients. Our findings on health economics are unique when compared to other studies, as none of our patients is handed over to their GP. This factor has been a confounder in other studies, as some of the enrolled patients had increased GP visits.[13,18]

In previous studies, the patients have been asked about their disease-related quality of life, and their disease activity has been monitored.[9,11,13,17]

We have not included these parameters in our study, which could be a limitation. However, these parameters have been shown to be unchanged in other studies, and similar findings are to be expected in our study population.

### Conclusion

In conclusion, restructuring stable patients' form of patient-clinician contact from routine annual visits to annual phone calls from a nurse was feasible and well accepted. The service was shown to be an alternative, but not an absolute substitute, for routine visits. The benefits of the service were most marked for the patients. The organisation experienced an unchanged workload. The economic benefits of the program were distinct, primarily when including the patient costs in a CEA. A drawback of the service could be the fixed reimbursement rates from the health authorities. Overall the systematic evaluation of this study gave us an excellent overview of the element involved in this complex intervention and hopefully this can inspire others to do similarly evaluations within other chronic diseases.

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### Declaration of interests

The authors have no conflict of interest.

### Acknowledgements

Rúna Hentze, Lisbet Ambrosius Christensen, Dorrit Jakobsen, Jørgen Agnholt, Jens F. Dahlerup.

This work was supported by the Health Insurance Foundation, Denmark [2009B080].