

# Developing an evidence-based online travel resource for inflammatory bowel disease

## Abstract

Travellers with Inflammatory bowel disease (IBD) are at greater risk of travel-related morbidity, and there is a deficiency in adequate travel consultation and preparation. This article presents the development of a dedicated IBD travel advice website, aimed at enhancing informed, safe travel for patients. The findings highlight a paucity of research and resources available regarding travel and IBD. A total of 97% (132/136) respondents had travelled overseas in the past 5 years, and of these, 62% (82/132) reported IBD-affected travel; however, pre-travel medical advice was only sought by 23% (32/132). Moreover, 52% of immunosuppressed patients were unaware of the need to avoid live vaccines and only 40% (53/132) bought travel insurance covering IBD. As a result, IBDPassport was developed as a non-profit, IBD-specific travel resource, aimed at providing evidence-based information for IBD patients and health professionals.

Inflammatory bowel disease (IBD) and foreign travel are associated with an increased risk of travel-related morbidity brought on by exacerbations of IBD, acquisition of infectious diseases endemic to the destination, and availability of health care and medicines while abroad (Ben-Horin et al, 2012; Rahier et al, 2014). Patients receiving immunosuppressive medication have an increased susceptibility to these infections as well as an attenuated immune response to vaccinations (Rahier et al, 2010; 2014; Wasan et al, 2010). Detailed pre-travel consultations and vaccinations are advised prior to travel to ensure travellers are armed with the appropriate education and resources to stay healthy during their journey (Rahier et al, 2014). Despite guidelines (Rahier et al, 2014) specifying appropriate vaccination strategies for IBD patients, knowledge and provision of this information have been found to be poor, particularly vaccination for those on immunosuppressive medication (Gupta et al, 2011; Wasan et al, 2011; Yeung et al, 2011).

Low counselling rates for avoidance of live vaccines and inadequate understanding and knowledge of vaccinations have been cited in previous research (Yeung et al, 2011; Wasan et al, 2011; 2014). Possible explanations for this include health professionals' lack of awareness; ambiguity regarding who should assume responsibility for vaccine administration; and concerns regarding safety and efficacy of vaccinations, including fear of vaccine-induced exacerbations of IBD (Yeung et al, 2011; Wasan et al, 2011; 2014). The European Crohn's and Colitis Organisation (ECCO) guidelines (Rahier et al, 2014) recommend that travel consultations should be provided jointly by a gastroenterologist and expert travel clinic. Deficiencies in the advice provided by such clinics have been highlighted in previous research (Soonawala et al, 2012), which found that 27% of patients were incorrectly given the yellow fever vaccination while receiving immunomodulator therapy. This highlights the need for travel clinics to have increased

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## Key words

- Inflammatory bowel disease
- Vaccination
- Travel
- Immunosuppressants
- Diarrhoea

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**Table 1. Literature and internet search results for travel and inflammatory bowel disease (IBD)**

Ovid search for published research		Internet search for quality resources
<i>IBD and travel</i>	<i>Generic travel health research</i>	
Soonawala et al (2012)*	Spira (2003)	Crohn's and Colitis UK (2012)
Ben-Horin et al (2012)	Driver (2003)	Crohn's and Colitis Foundation of America (2009)
Esteve et al (2011)	Ericsson (2002)	European Federation of Crohn's and Ulcerative Colitis Associations (2012)
Rahier et al (2014)		About Health (2014)
		Travax (Health Protection Scotland, 2014a)
		Fit For Travel (Health Protection Scotland, 2014b)
		National Travel Health Network and Centre (2012)
		The travel Doctor (Mills, 2014)

Ovid = Medline and Embase; Internet = Google, BING, and Yahoo search engines; \*This was the only empirical study; all the others were review articles.

vigilance when prescribing live vaccinations, and suggests further research is needed to investigate the content and accuracy of information given by health professionals and how appropriately they address the issues relevant to IBD patients.

The aim of this study was to explore the IBD patient's experience of travel, including pre-travel preparation, and to examine the availability of travel information, in order to evaluate and improve the quality and provision of pre-travel advice.

**Literature review**

Existing research and resources regarding IBD and travel were identified using OvidSP and major internet search engines (Table 1). The search terms used were 'inflammatory bowel disease', 'Crohn's disease', 'ulcerative colitis',

'vaccination', 'travel', and 'travel health'. The ECCO consensus statement on managing opportunistic infections in IBD (Rahier et al, 2014) provides comprehensive information on experiencing travellers' diarrhoea, managing the symptomatic returning traveller, and advising patients travelling to developing countries, but it does not provide details for travel to developed countries and travel health specialists may not be familiar with the guidelines.

There is limited research looking specifically into travel-associated health risks and health preparation in patients with IBD. Only two empirical studies were found that focused specifically on travel and IBD. Soonawala et al (2012) examined pre-travel preparation and travel-related morbidity in a retrospective survey of 277 Dutch patients with IBD. The authors categorised travel according to destinations

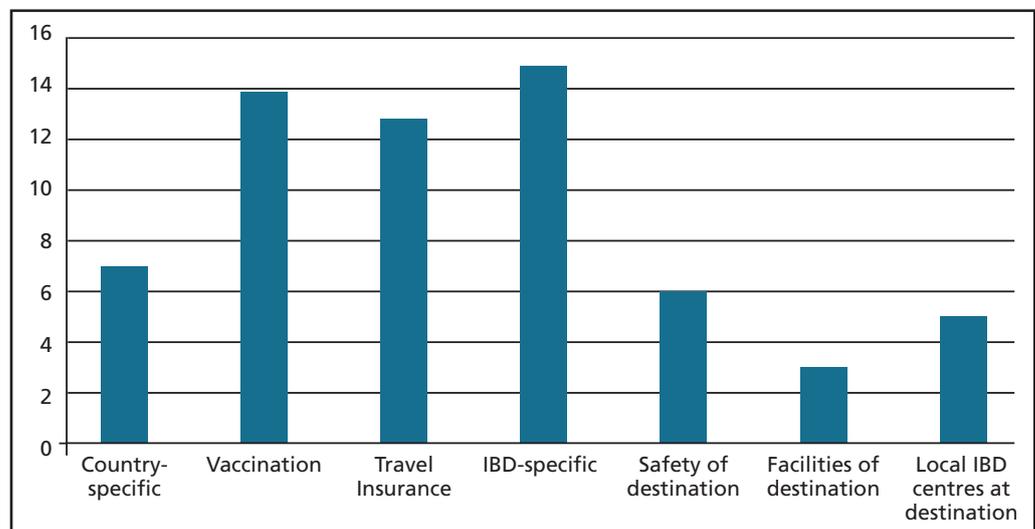


Figure 1: Types of pre-travel information for respondents (n=31).

where hepatitis A is endemic and requiring vaccination, according to their national guideline. The study found that IBD limited travel in the majority of patients and this was greater for patients on anti-TNF medication. The authors found that one in four patients travelling to less developed countries failed to obtain pre-travel advice and vaccinations and that there was significant travel-related morbidity experienced by IBD patients, although they did not have a control group to compare with.

The incidence and rate of travel-associated health risks in IBD patients was investigated by Ben-Horin et al (2012), who conducted a retrospective, case-controlled study using structured questionnaires, interviews, and case-note review. Travel destination was classified according to economic development, and rates of illness were compared between travel to developed and developing countries. The immune-status of the traveller was also analysed against the risk of travel-associated diseases. The results of the study suggest that IBD patients avoid travelling to less developed countries compared with healthy controls. The majority of illness abroad in both groups was related to self-limiting abdominal symptoms. The main risk factor for illness while abroad was severity of IBD. No difference was found in the risk of illness in IBD patients on immunosuppression compared with healthy controls.

The internet search found a paucity of information for IBD patients wishing to travel and the quality of online material was found to be inconsistent. Generic travel health and UK Government websites provide information regarding risk assessment and management of vaccine-preventable diseases, but this can be confusing to navigate and interpret in relation to IBD-specific risk factors, such as patients on immunomodulator therapy. Patient organisation websites in both the UK and worldwide offer varied but reputable information that is limited to general IBD-related travel advice but whose remit does not cover information provided in national and international IBD guidelines. No single resource is available to provide transparent, comprehensive, evidence-based information to adequately inform both patients and health professionals on IBD-specific travel issues.

## Method

The author conducted a review of 150 IBD patients attending a London teaching hospital outpatient clinic from October to December 2013.

### Survey design

A structured, anonymous questionnaire was developed and piloted on a sample of 10 patients attending the IBD clinic using a 32-item paper questionnaire. Minor changes were made to some questions to produce the final version of the questionnaire. The self-administered survey contained 32 questions on demographics and disease characteristics. Also included were detailed travel questions regarding last travel overseas, as well as experience of travelling with IBD; pre-travel preparation undertaken; and knowledge of travel-related health issues, such as vaccinations and insurance.

### Statistical analysis

Data were entered and analysed using Microsoft Excel. Descriptive statistics were used to characterise the population and data.

### Data analysis and results

A total of 136 IBD patients completed the questionnaire (Crohn's disease (CD): 67/136, 49%; male 60/136, 44%; 91% response rate). The respondents' median age was 38 years (range 18–85 years). At the time of the survey, 69/136 (51%) were using a combination of single or dual immunomodulator therapy; of these 69, 30% were on corticosteroids, 81% on thiopurine, 45% on anti-TNF therapy, and 7% on methotrexate. Among all the respondents, 36% (49/136) had previously had IBD-related surgery. The demographic characteristics are shown in *Table 2*.

All participants were asked whether having IBD influenced their decision to travel abroad or their choice of destination. A total of 97% (132/136) of the respondents had travelled overseas in the past 5 years. Of these, the majority reported that IBD affected their travel (62%, 82/132), and 61% (80/132) stated that IBD limited their choice of travel destination. Europe was the main destination for 52% of travellers, with 23% (30/132) visiting developing countries. With regard to alteration in bowel habit, 28/132 (21%) of the respondents stated that they experienced

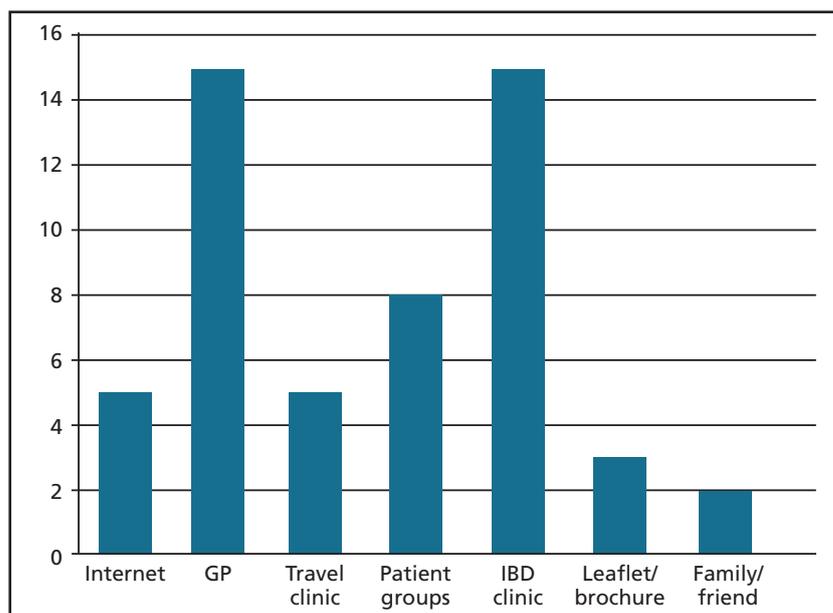


Figure 2: Sources of pre-travel information sought by respondents (n=31).

it and thought it was related to their IBD; of these 28, only 2 had a confirmed infective cause for their symptoms, while 14 were not tested. *Table 3* lists the travel characteristics of the respondents. Only 23% (31/132) of the travellers sought pre-travel medical advice of any kind (*Figures 1* and *2*). Travel insurance that covered IBD was obtained by only 40% (53/132) of all patients, the majority of whom (70%; 37/53) paid an increased premium; the survey did not ascertain whether this was because of their IBD or another cause.

**Table 2. Demographics of respondents to the survey**

Patient demographics		All	CD	UC	IBD type unknown
		136	67 (49%)	64 (47%)	5 (4%)
Gender	Sex (male)	60 (44%)	30 (45%)	27 (42%)	3 (60%)
Age	Median (range)	37 years (18–85 years)	43 years (18–79 years)	59 years (18–85 years)	30 years (26–82 years)
Medication	No medication	18 (13%)	0	0	4 (80%)
	5-ASA	85 (63%)	30 (45%)	51 (80%)	1 (20%)
	Steroids	21 (15%)	8 (12%)	12 (19%)	0
	Thiopurine	56 (41%)	29 (43%)	27 (42%)	0
	Biologic	31 (23%)	25 (97%)	6 (9%)	0
	Methotrexate	5 (4%)	4 (6%)	1 (2%)	0
Surgery	Yes	49 (36%)	37 (55%)	11 (17%)	1 (20%)
	Stoma	10 (7%)	5 (7%)	5 (8%)	0
Previous travel abroad	Yes (%)	132 (97%)	2 (3%)	1 (2%)	1 (2%)
IBD affects travel	Yes	82 (60%)	39 (58%)	41 (64%)	2 (40%)
	No	54 (40%)	28 (42%)	23 (36%)	3 (60%)

CD: Crohn's disease; UC: ulcerative colitis; IBD: inflammatory bowel disease

**Table 3. Travel characteristics of survey respondents**

Travel query	Response	n (%)
IBD limits overseas travel (n=136)	Yes	82 (60)
IBD limits choice of destination (n=136)	Yes	80 (59)
Obtained travel insurance that covers IBD (n=136)	Yes	53 (40)
Purpose of travel (n=136)	Business/study	14 (10)
	Leisure/tourism	122 (90)
New episode of diarrhoea during travel (n=136)	Yes	28 (21)
Was the diarrhoea found to be infective? (n=28)	Yes	2 (7)
	No	12 (43)
	Not tested	14 (50)
Sought medical advice while abroad (n=136)	Yes	29 (21)
Admission to hospital that was IBD related (n=136)	Yes	5 (4)
Reason why IBD limits overseas travel (n=82)	Vaccinations required	9 (11)
	Perceived problems obtaining medical care	26 (32)
	Insurance required	11 (13)
	Concerns about medication	5 (6)
	Access to toilet facilities	58 (71)
	Concerns about sanitation	35 (43)
	Worries about contracting a bowel infection	32 (39)
	Concerns about diet	32 (39)
Obtained pre-travel advice (n=136)	Yes	31 (23)

IBD: inflammatory bowel disease

vaccination, insurance, and general advice were the main areas of interest for those who sought information, low numbers of patients in this group actually went on to obtain travel insurance to cover their IBD—implying that most were possibly under- or not insured. This trend could be attributed to: inadequacies in the information given at the time of consultation; lack of knowledge regarding how to source adequate information, such as travel insurance; and external factors including increased premiums for those with pre-existing medical conditions, particularly when recovering from a period of illness. Previous research found that IBD patients travelling to developing countries are no more at risk of developing enteric infections compared with healthy counterparts, although many individuals with IBD would avoid these destinations for this reason (Ben-Horin et al, 2012). We found similar results, with most individuals citing concerns over toilet facilities, sanitation, and a greater risk of contracting enteric infections as the main reasons for avoiding particular destinations.

Travel overseas is becoming more prevalent and forms part of maintaining a balanced quality of life (UNWTO World Tourism Organization, 2014). The overall effect of IBD and the restrictions imposed on daily life have been documented in a recent European survey (Wilson et al, 2012) and it indicates that most individuals faced disruptions in their daily life caused by the status of their disease, but over half avoided cancelling or rescheduling plans. The availability of toilets remains one of the main concerns of individuals with IBD (Wilson et al, 2012).

The findings from this study showed that more than half the number of patients receiving immunomodulator therapy were unaware that they should avoid live vaccines. Differences were also seen in those who were taking immunosuppressant medication, with this patient group more likely to obtain travel insurance and vaccination advice compared with those on mesalazine alone. This would suggest that patients who have a more complicated disease course are more likely to seek pre-travel advice.

**Limitations**

There are several limitations in this study. First, the retrospective survey design required respondents to recall their last overseas trip, which may introduce recall bias regarding specific details of

About Health (2014) Travel With IBD and IBS. Tips for traveling with Irritable Bowel Syndrome and Inflammatory Bowel Disease. <http://ibdchrons.about.com/od/travelwithibd> (accessed 27 November 2014)

Ben-Horin S, Bujanover Y, Goldstein S et al (2012) Travel-associated health risks for patients with inflammatory bowel disease. *Clin Gastroenterol Hepatol* **10**(2): 160–5. doi:10.1016/j.cgh.2011.10.025

Bernard A, Langille M, Hughes S, Rose C, Leddin D, Veldhuyzen van Zanten S (2007) A systematic review of patient inflammatory bowel disease information resources on the World Wide Web. *Am J Gastroenterol* **102**(9): 2070–7

The survey results also found that 52% (36/69) of respondents on immunomodulator therapy were unaware of the need to avoid live vaccines.

Differences in the type of medication patients were taking and the pre-travel preparation sought was also examined (Table 4). There was no difference between patients taking immunosuppression and those on mesalazine alone with regard to advice sought prior to travel and perceived limitations of travel with IBD. Three times the percentage of patients on immunosuppressant therapy compared with those on mesalazine sought vaccination advice (15% (10/69) vs 5% (2/39)) and obtained travel insurance (40% (28/69) vs 8% (3/39)).

**Discussion**

A minority of patients (23%) in this study undertook pre-travel preparation. Although

**Table 4. Differences in the medication patients were taking and pre-travel preparation sought**

Travel preparation/experience	Immunosuppressant medication (single or dual) <i>n</i> =69	Mesalazine (single therapy) <i>n</i> =39
Advice sought prior to travel	20 (28%)	8 (20%)
Vaccination advice	10 (15%)	2 (5%)
Obtained travel insurance	28 (40%)	3 (8%)
IBD limits travel	40 (57%)	20 (51%)
IBD limits destination	47 (69%)	12 (31%)

IBD: inflammatory bowel disease

the last overseas trip. A control group in the study design would also have helped to underline the burden of IBD in the traveller. Finally, the most recent episode of travel may not be representative of travel behaviour. For example, 10% of the sample travelled for business or study, meaning they may have had no option but to travel during a flare of disease.

### Development of IBDPassport

The results of the literature and internet searches revealed a paucity of information for IBD patients wishing to travel. Generic travel-health websites provide information regarding risk assessment and management of vaccine-preventable diseases, but this can be confusing to navigate and interpret in relation to IBD-specific risk factors, such as patients on immunomodulator therapy. No single resource was found that could provide transparent, comprehensive, evidence-based information to adequately inform both IBD patients and health professionals on IBD-specific travel issues.

Using data collected from the patient survey and extensive literature searches, the author identified a gap in literature and developed IBDPassport—[www.ibdpassport.com](http://www.ibdpassport.com)—an online travel resource for IBD. The website was developed for both IBD patients and health professionals as a non-profit, IBD-specific travel resource with the primary aim of developing patient-centred information to support living with IBD and improve education and pre-travel preparation by providing evidence-based information on all aspects of travel and IBD.

The website draws together evidence-based information from national and international IBD guidelines, patient organisations, and government literature into one resource. The main focus of IBDPassport is the 'Travelling with IBD' and 'IBD Network' pages. Travelling with IBD includes practical information on issues such

as obtaining health care overseas, managing travellers' diarrhoea, travel following surgery and details regarding travel insurance and vaccination advice specific to immunocompromised patients.

The IBD Network page contains an interactive map of country-specific vaccination advice and a 'search and refer' directory of IBD centres to enable IBD health professionals to refer to other IBD centres globally. Populating the directory of IBD centres depends on those centres registering with the site, although some IBD centres will be manually entered by the author to ensure the information is comprehensive and useful to users.

### From idea to implementation

Following initial research and the identified need for a resource to support IBD patients planning to travel overseas, the author contacted a web development agency to explore the possibility, process and cost of development. A web-based approach was chosen, since research investigating IBD patients' use of the internet for health-related information demonstrated that the internet is a major source of disease-specific information that can support the education process and assist in decision making (Cima et al, 2012; Fortinsky et al, 2012; Greveson et al, 2014). The internet is widely used and offers a wealth of information for patients with chronic disease (Fox, 2007); however, this information can often be unregulated and potentially inaccurate (Van der Marel et al, 2009). The aim was to create a resource with accurate, evidence-based content, that was user-friendly and valuable to both patients and health professionals, while avoiding the pitfalls usually encountered with online material, such as poor quality content (Bernard et al, 2007; Langille et al, 2010).

Initial funding for the project was obtained from a Nurse Innovation Award presented by Shire Pharmaceuticals. The remaining cost

Cima RR, Anderson KJ, Larson DW et al (2012) Internet use by patients in an inflammatory bowel disease specialty clinic. *Inflamm Bowel Dis* **13**(10): 1266–70

Crohn's and Colitis Foundation of America (2009) Traveling with IBD. [www.cdfa.org/resources/traveling-with-ibd.html](http://www.cdfa.org/resources/traveling-with-ibd.html) (accessed 27 November 2014)

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Driver C (2003) Travel advice for clients with pre-existing medical conditions. *Nurs Stand* **17**(31): 41–7

Ericsson CD (2002) Travellers with pre-existing medical conditions. *Int J Antimicrob Agents* **21**(2): 181–8

Esteve M, Loras C, García-Planella E (2011) Inflammatory bowel disease in travelers: Choosing the right vaccines and check-ups. *World J Gastroenterol* **7**(22): 2708–14

European Federation of Crohn's and Ulcerative Colitis Associations (2014) Travel. <http://bit.ly/1A072FR> (accessed 27 November 2014)

Health Protection Scotland (2014a) Welcome to TRAVAX. Up-to-date travel health information for health care professionals. [www.travax.nhs.uk](http://www.travax.nhs.uk) (accessed 27 November 2014)

Health Protection Scotland (2014b) Fit for Travel. Travel health information for people travelling abroad from the UK. [www.fitfortravel.nhs.uk/home.aspx](http://www.fitfortravel.nhs.uk/home.aspx) (accessed 27 November 2014)

of the website was financed personally by the author. Several challenges were faced in the development and implementation of IBDPassport, which centred mainly on working with the web development agency to convey the vision for the website into a reality and keep within the constraints of the budget. These challenges were overcome by careful planning of the content and functionality and splitting the project into two phases:

- Phase one: Research and initial development
- Phase two: Formal evaluation to inform further improvements.

The project was undertaken predominantly in the author's own time; therefore, there were difficulties encountered in devoting time to conducting the extensive literature searches necessary to research and write the content to ensure a comprehensive, accurate, evidence-based resource.

## Dissemination

The fundamental aim of the IBDPassport project is to improve awareness of issues related to travel and IBD and improve the quality of information available. Dissemination is a key process in implementation. The author has worked closely with Crohn's and Colitis UK, which will be featuring details of the website in a members' newsletter. A link to the IBDPassport website has been circulated in newsletters from the British Society of Gastroenterology (BSG), Primary Care Society of Gastroenterology, and the nurses' arm of ECCO. The author also intends to raise awareness through social media and links with the Royal College of Nursing IBD Nurse Forum. The final stage in implementation will be the formal evaluation by key users, who use recognised health-website quality-evaluation tools to inform further development and improvement.

## Conclusion

This paper presents the first comprehensive web-based travel resource developed for both IBD patients and health professionals and providing evidence-based IBD and country-specific travel information. The next step in the development process is to formally evaluate IBDPassport with the help of IBD patients, health professionals, and the patient charity Crohn's and Colitis UK. It is hoped that this evidence-based resource will become a reliable and reputable resource

for IBD-related travel information, and that it will help to reduce travel-related morbidity through improved awareness, education, and patient involvement. **GN**

**Declaration of interest** The author has no conflicts of interest to declare.

**Ethical approvals** As this was a review to inform service improvement for IBD-related travel health, formal ethical approval was not required (National Health Research Authority, 2013).

**Sources of funding** Initial funding for this project was obtained from a Nurse Innovation Award presented by Shire Pharmaceuticals.

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