

An Economic Assessment of IBD Passport: Evidence-based online resource to support for travel with Inflammatory Bowel Disease

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Background to innovation

Travellers with inflammatory bowel disease (IBD) are at greater risk of travel-related morbidity. International guidelines recommend expert consultation prior to travel, particularly for those on immunosuppression¹. As a result of previous research into travel and IBD which found travel consultations and patients travel preparation to be deficient,²⁻⁴ I developed IBD Passport (www.ibdpassport.com), a dedicated, evidence-based, non-profit IBD travel advice website to enhance informed, safe travel⁵. Individuals may have sought pre-travel information prior to the development of my website but the fact that the innovation in question is the first site of its kind to offer evidence-based, reputable information in one place, without having to source else-where establishes additionality.

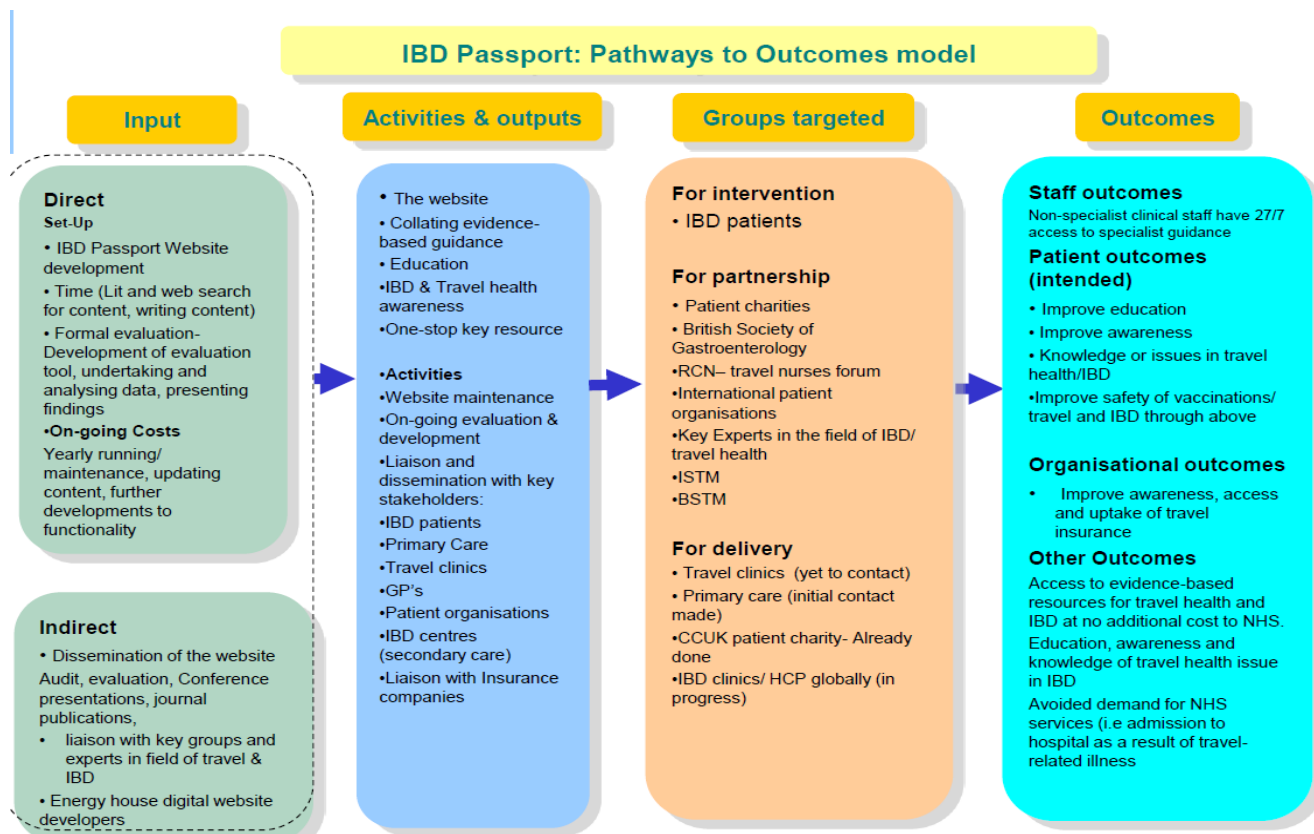
Previous research has found between 15-20% incidence of travel-related illness in IBD^{2,4} and 27% of patients were incorrectly given live vaccinations prior to travel while receiving³ immunomodulator therapy. This can potentially be life-threatening as the individual could contract the infection that they are being vaccinated against, therefore impacting on NHS services by increasing hospital visits for specialist consultations and possible inpatient admission in the event of post-vaccination complications. Travel insurance in the UK covers many aspects of travel, but there are often caveats for chronic disease, particularly if the traveller is under regular specialist follow-up. Obtaining adequate insurance can often be difficult and incur additional premiums, but travelling without adequate cover carries the risk of the individual incurring significant personal medical costs in the event of illness overseas. Obtaining travel insurance was therefore seen as an important outcome of this evaluation.

Focus of Economic assessment

The purpose of this assessment is to quantify the outcomes and impact of the website. This project is non-profit and it is not the intention to ask for funding from the NHS but rather to show the potential impact and value of the website for patient and healthcare professional users.

Method used

The method I used to demonstrate the value of the website innovation is to identify the direct and indirect costs of the service using pathways to outcomes model, stakeholder matrix and benefits table; following procedures set out in HM Treasury's guidance. I then plan to identify the benefits through patient website user and practitioner feedback, then use case studies to explore the potential wider economic impacts.



IBD Passport Stakeholder Matrix

The stakeholder matrix can be found in appendix A. Mapping this enabled me to approach the assessment in a more structured format and identify the sources where I will need to obtain data to who I plan to influence using results from my assessment.

Inputs (Costs)

Before starting the project, I conducted preliminary research to explore the patient's experience of travel with IBD, including pre-travel preparation and also examined IBD healthcare professionals' perception and knowledge of IBD and travel. The findings showed a lack of knowledge and preparation for travel and supported the need for travel-specific education programmes to develop better awareness and knowledge. This research has since been published in Frontline Gastroenterology medical journal (Greveson et al, in press). I decided to develop a web-based educational resource to address this problem and started by contacting a website development agency, who worked with me to develop the structure and functionality of the site. I lead the whole process from initial concept, to providing the web design brief, deciding on the logo design and website layout but have sought advice and input from IBD nurse colleagues, patients and the national IBD patient charity via focus groups and surveys. I conducted extensive literature reviews in order to develop the content of the website. I plan to review and update the content of the site on a 12 monthly basis.

The costs detailed below are a breakdown of the individual components of developing and maintaining the site and relate to costs 2013-2015. Where necessary therefore, costs are adjusted to include on-costs and presented as 2015 prices. Further details can also be found in appendix B.

Type of Cost	Amount
Set-up- Direct	
Website Domain registration & Hosting £360/ year 2014, 2015	$360 \times 1.025 + £360 = £729$
Website design & build	£3829 (£1500 educational Grant given towards this)
Website training	£288
Initial updates & Fixes	£80
My Time: Literature search, writing website content. Approx. 100 hours at Band 7 x 1 WTE	$£35.48/\text{hr} \times 100 = £3548$
My Time: Formal evaluation (Survey development, data analysis, Writing report, presenting findings) Approx. 20 hours at Band 7 WTE	$£35.48/\text{hr}$ (includes oncost) $\times 20 = £709.60$
My Time: Dissemination of website- Conference presentations, Writing Journal articles) Approx. 25hrs Band 7 WTE	$£35.48/\text{hr} \times 25 = £887$
Liaison with Key experts during development Approx. 3 hrs Band 7 (point 34) AFC WTE	$£35.48/\text{hr} \times 3 = £106.44$
Total Direct Set-Up costs	£10,177.04
Running costs - Direct	
Website Maintenance contracts 2014-2015	£3918
My Time: Literature search & updating website content 12 monthly 25 hours at Band 7 WTE	$£35.48/\text{hr} \times 25 = £887$
Total Direct running Costs	£4,805
Optional additional Running costs	
Patient leaflet printing & Design	£297
Updating website country list	£150
Total Optional additional Running costs	£447

Total direct costs: £15,429

Benefit table

IBD Passport is the first website of its kind and aims to provide comprehensive education and awareness of travel issues in IBD by drawing together evidence-based information from key organisations and government literature into one resource. This information would otherwise be unavailable for patients or difficult to understand, particularly in relation to their IBD. The intended benefits of the website are:

- To develop a reputable evidence-based resource for IBD-related travel information.
- Promote integrated clinical care between IBD healthcare professionals in primary and secondary care and with patient organisations by providing access to reputable information and bridging the education gap.
- Reduced risk and travel-related morbidity for the IBD and immunosuppressed traveller through improved awareness and education.
- The website will hopefully go some way to addressing key recommendations from inflammatory bowel disease National standards (IBD Standards, 2013), who suggest high quality, safe and integrated care and empowering patients to understand their condition.

Additionality - Other resources are available (i.e. NHS Fit for travel, Crohn’s and Colitis UK information leaflet) but non of these provide an IBD-specific resource that includes all evidence-based information in one place, without the need to use lots of different resources that may contain inaccurate and confusing information.

Data to show value of benefit - See outcome data from user survey on page 7

Proxy data - There are no studies available to show the cost of travel-related illness. See narrative on page 8.

For whom?	Type of benefit	Data for value of benefit
Quality Benefits		
Users: IBD Patients	Access to accurate information in one resource Improved knowledge	User evaluation survey post set-up evaluation data
Innovation Benefits		
Users: IBD & Travel health professionals	Access to IBD-specific information and guidance that they otherwise would not be aware of/have difficulty accessing	Healthcare professional reported outcomes Pg 7-8
Crohn’s and colitis UK & other patient organisations	Additional information to support their members and the ability to signpost patients to accurate information	
Productivity Benefits		
IBD Patients	Promote safer travel through better pre-travel preparation	Difficult to quantify and directly associate any benefits directly to IBD Passport (See Narrative).

	Alteration in pre-travel preparation behaviour as a result of using the site	User evaluation survey
	Improve awareness and uptake of travel insurance	User evaluation survey
	Improved awareness and understanding of travel-related health issues	See post set-up evaluation data
IBD & Travel health professionals	Improved knowledge and awareness of IBD-specific travel health issues	See post set-up evaluation data
	Ability to signpost patients to accurate information	Healthcare professional reported outcomes
Prevention Benefits		
IBD Patients	Reduction in occurrence of travel related health problems through better awareness and education as a result of using IBD Passport	Difficult to quantify and directly associate any benefits directly to IBD Passport (See Narrative).

Preliminary evaluation

IBDPassport: Evaluating the quality of an Internet-based Travel Resource for Inflammatory Bowel Disease

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INTRODUCTION:

Travellers' with Inflammatory bowel disease (IBD) are at greater risk of travel-related morbidity with European guidelines recommending expert consultation prior to travel, particularly for those on immunosuppression.¹ Previous research into travel and IBD found travel consultations and patients travel preparation and knowledge to be deficient.^{2,3} As a result we developed a dedicated, evidence-based non-profit IBD travel advice website (www.ibdpassport.com) to enhance informed, safe travel. Here we present formal evaluation of this website.



METHODS:

A link to the website, along with a structured web-based survey was sent to a purposive sample of 15 UK IBD patients, IBD clinical nurse specialists and Gastroenterologists respectively. The survey contained demographic questions and asked respondents to rate the content, functionality and credibility of the website using a series of parameters including a 5-point Global Quality Score (Fig 1) and Integrity Score⁴. Readability statistics were graded on a 100 word sample of text from each page on the website using the Flesch Reading Ease and Flesch-Kincaid Grade level scores.

FIGURE 1: GLOBAL QUALITY SCORE

Score	Description
1	Poor quality; poor flow of the site; most information missing; not at all useful for patients
2	Generally poor quality & flow, some info listed, many important topics missing, limited use to patients
3	Moderate quality, some important info adequately discussed, somewhat useful for patients
4	Good quality & flow, most relevant information listed but some not covered, useful for patients
5	Excellent quality and flow. very useful for patients

Key data related to outcomes:

Patient users: 9/11 (82%) report improved knowledge of travel issues in IBD

HCP: 17/22 (77%) report improved knowledge of travel issues in IBD

RESULTS:

A total of 33 individuals responded (73% response rate; 11, 33% Patient; 10, 30% Nurse; 12, 36% Gastroenterologist (Table 1). The mean Global Quality score for all respondents was 4.5 out of a possible 5 (Range 3-5). The Flesch-Kincaid Grade level score was US school grade 10.9 (range 7.2 - 17.1) and median Flesch Reading Ease score 50.5 out of a possible 100 (Range 22.4- 65.1). The integrity score was 4.0 out of 6. The majority of respondents strongly agreed that the website was an accurate source of travel information for IBD (60%), used appropriate citations (67%), and was easy to navigate (70%). 26/33 (79%) felt the website improved their knowledge of travel-related issues in IBD (Table 2). All respondents would recommend the site to friends or colleagues.

TABLE 1: RESPONDENT DEMOGRAPHICS

Demographics n=33	Patient n = 11	IBD Nurse specialist n = 10	Gastroenterologist n = 12
Gender Female (%)	4 (36%)	10 (100%)	1 (8%)
Median Age (Range)	46 (25-73)	37 (30-61)	51 (39-58)
Diagnosis			
Crohn's Disease	4 (36%)	-	-
Ulcerative colitis	7 (64%)	-	-
Median years diagnosed (Range)	12 (2-30)	-	-
Travel in past 5 years Yes (%)	10/11 (91%)	-	-
Problems with IBD when travel Yes (%)	5/11 (45%)	-	-
Median years in Post (Range)	-	6 (3-18)	10 (3-18)

TABLE 2: WEBSITE QUALITY EVALUATION PARAMETERS

	All n=33	Patient n = 11	IBD Nurse specialist n = 10	Gastroenterologist n = 12
Global Quality Score Median (Range)	4.5 / 5 (3-5)	5 (3-5)	4.5 (4-5)	4.5 (4-5)
Quality parameters (Strongly agree %)				
Accurate source of information	20 (60%)	9 (82%)	7 (70%)	4 (33%)
Appropriate citations used as evidence	22 (67%)	7 (64%)	9 (90%)	6 (50%)
Balanced and unbiased	23 (70%)	8 (73%)	9 (90%)	6 (50%)
Easy to navigate	23 (70%)	8 (73%)	8 (80%)	7 (58%)
Adequate information to prepare for travel	18 (55%)	5 (45%)	7 (70%)	6 (50%)
Improved IBD-related travel knowledge	26 (79%)	9 (82%)	9 (90%)	8 (67%)
Would recommend to friends/ colleagues	33 (100%)	11 (100%)	10 (100%)	12 (100%)

CONCLUSIONS:

IBD Passport is the first internet-based travel resource created for both IBD patients and professionals to provide IBD-specific travel information. Our findings demonstrate that patients and healthcare professionals consider IBD Passport to be an excellent quality, evidence-based resource. The readability statistics are favourable when compared to results from other studies examining website quality.

REFERENCES:

- Rahier JF, Magro F, Abreu C et al. Second European evidence based consensus on the prevention, diagnosis and management of opportunistic infections in inflammatory bowel disease. *J Crohns Colitis* 2014; 8: 442-468
- Soonawala D, van Egmond AM, Fidler H, Visser LG. Pre-travel Preparation and Travel-related Morbidity in Patients with Inflammatory Bowel Disease. *Inflamm Bowel Dis* 2012; 18 (11): 2079-85.
- Greveson et al (2014). A Recent Flare of Disease does not Prohibit Travel: Early Results of a Single Centre Study in Inflammatory Bowel Disease and Travel Digestive diseases week, Abstract#: 1899308 Final ID: 5u1095
- Bernard A et al. A systematic review of patient inflammatory bowel disease information resources on the world Wide Web. *Am J Gastro*. 2007; 102:2070-2077.

Outcome data

To understand the impact of the IBD passport on users I conducted an online user feedback survey which was sent to 415 registered IBD patient website users. It included questions regarding past experiences of travel with IBD, such as previous illness whilst abroad and medical advice or intervention sought both abroad and when returning home. I also inquired about the experience of using IBD passport and their perceived benefit of using the site in order to capture outcomes. I also sent a separate e-mail to IBD healthcare professionals who have used the website to ask of their experiences and perceived benefits of the website.

Results

The survey results are shown below and demonstrate that a high percentage of people who registered with the site have gone on to use it for advice prior to travel, with some of these not previously seeking advice prior to travel. The results demonstrate that users feel that the website has improved their knowledge and also lead to behaviour change, including being more likely to obtain travel insurance (56%), obtaining expert advice prior to travel (50%), and have greater awareness of vaccination issues in IBD and travel (76%). It can be hypothesised that the demonstrated outcomes and behaviour change from the survey could be translated into improved travel-related illness outcomes. This is discussed further in the narrative.

102 respondents (25% response rate)

34 respondents have had medical problems related to their IBD when travelling abroad.

Previous travel illness and Utilisation of healthcare resources

6 Required admission to hospital abroad,

4 Required admission to hospital when they returned home

2 respondents had to return home from holiday earlier than planned (not repatriation)

Of the 10 patients admitted to hospital either during/ after their holiday, the length of stay was:

3 respondents—7 or more days

6 respondents—1-2 days

1 respondents – 5-6 days

12 (12%) required an urgent Specialist outpatient appointment on returning home

Use of IBD Passport

50 respondents (53%) have used IBD Passport since registering and of these, 9 had not previously used any resources prior to travelling with IBD.

37 respondents said the website improved their knowledge either significantly or to some extent.

Things that users would do differently as a result of using IBD Passport:

28 (56%) Would be more likely to obtain travel insurance prior to travelling

32 (64%) More aware of travel-related issues in IBD

25 (50%) Seek professional advice prior to travel

37 (74%) More confident to travel with IBD

41(82%) Feel they have more knowledge and understanding of travel and IBD

38 (76%) Aware of vaccination that they can have

Travel insurance

24 of respondents do not routinely get insurance that covers their IBD. Of these, 6 respondents would now obtain insurance after using IBD Passport

Feedback from Healthcare professional registered users regarding perceived potential benefits of IBD Passport

The following is an extract of the feedback that I have received from healthcare professionals who have used IBD Passport

- Being able to direct / facilitate / empower the patient to feel confident in the expert knowledge provided on this fantastic tool.
- All information in one site. It is clear and concise information
- Time is avoided searching for answers myself, couldn't quantify though
- Benefits for me are a quick access point and easy for patients to access as well so rather than me trying to find out the answers they can do this themselves....I sometimes used to feel like a travel nurse for some patients.

Narrative

IBD Passport is a pre-travel educational resource. The benefits table identifies various demonstrated outcomes of the website but many of these, such as improved knowledge and pre-travel preparation cannot be assigned any monetary value and instead is a casual link, with the assumption that use of the website will lead to behavior change, which in turn will reduce the risk of travel-related illness. It is important to note that although this analysis has attempted to quantify costs associated with travel abroad using the case studies below, the aim of the website and also the potential benefits are predominantly from the patient perspective regarding unnecessary hospital visits and provision of education and information that would otherwise be unavailable and improved ability to live with a chronic disease. The complex nature and variables associated with overseas travel and a chronic illness make using a cost-avoidance model difficult. NHS trusts are more likely to see avoidance of hospital admission as a loss of income rather than a cost-avoided but the patient would have a completing different perspective about this and strive for improved quality of life.

The resource and financial implications of pre-travel education are difficult to quantify and the economic benefit of such a resource reflects the likelihood of preventing or reducing the risk of an illness and incorporates all the expenses of a travel-related illness. However, no unified economic analysis of these factors in travel medicine has yet been done. ⁶ The benefits of a pre-travel consultation or education programme are well known in relation to the effectiveness of vaccination but the impact of pre-travel education and advice has not been shown to have a demonstrable effect on an outcome. Many variables exist that can affect the risk of acquiring travel-related illness such as destination, duration, timing of travel, type of traveller i.e. elderly, immunocompromised. Many travel-related risks are also not fixed. Economic outcome analyses relating to travel medicine

will need to be complex⁶. Travel medicine models should reflect the true mix of travelers and should incorporate the fact that many travelers do not seek pre-travel medical care, which may dilute the benefit generated by those who do. This type of assessment is beyond the scope of the current project. To identify the potential economic impacts when a IBD passport user adopts the relevant advice, I will use a case study approach to present scenarios faced by hypothetical patients This case study is a basic estimate of the economic impact of IBD Passport based on the preliminary data collected from users of the website and the costs generated from identified outcomes.

Assumptions

Based on what is currently known about travel-related illness, in addition to the data collected for this assessment, the following assumptions have been made:

- Based on a single adult individual with IBD and no other co-morbidities
- No repatriation home and costs do not include any care overseas as this will vary depending on destination and insurance provision
- All costs are based on NHS tariff and assume contact with UK health service on return home
- Length of stay for any admission has been set at 1 day non-elective as this was the most common length of stay for our survey respondents.
- Both inflammatory bowel disease and infectious diseases were used for inpatient/outpatient encounters as this would be the most likely contact for post-travel illness.
- Investigations included in costing are based on accepted clinical practice.

Case study

This Hypothetical case study is based on previous information known about travel and IBD and outcome data listed above. All financial values are expressed in current money (2015). Sources of information are detailed in the reference section.

Mr W is a 34 yr old male with Crohn's disease for the past 8 years. He was in remission with Crohn's prior to travel to Africa but returned home feeling unwell with diarrhoea and fever. I present 2 possible scenarios for this patient. Due to the symptoms experienced, this patient could be seen and investigated under either Gastroenterology or infectious diseases, therefore both costs have been considered.

Scenario 1: Patient admitted following travel overseas In-patient stay (non-elective)

FZ36F	Intestinal Infectious Disorders with length of stay 1 day or less	£442
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OR

FZ37F	Inflammatory Bowel Disease with length of stay 1 day or less	£399
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Scenario 2: Specialist outpatient Gastroenterology/ infectious diseases appointment 1st attendance

301	Gastroenterology	£178
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OR

350	Infectious Diseases	£263
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Investigations undertaken for either scenario:

Endoscopy

FZ52Z	Diagnostic Colonoscopy with biopsy 19 years and over non-elective	£747
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Blood tests

Malaria £25

LFT

U&E

CRP

Imaging

RA03Z	Magnetic Resonance Imaging Scan, one area, pre and post contrast- £188 plus Reporting £22 – Total	£210
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Abdominal X-ray - £24.96

Stool sample

Stool microscopy £25

Giardia £26

Assumed costs of travel-related illness in IBD (See above for further details)

Scenario 1- In-patient	Cost
Inpatient stay	
1- Gastroenterology	1- £399
2- Infectious diseases	2- £442
Diagnostic colonoscopy and biopsy	£747
Plain abdominal x-ray	£24.96
MRI scan	£210
Stool testing	£51
Total Costs	Gastroenterology route £1431.96 Infectious diseases route £1474.96
Scenario 2- Outpatient only	
Specialist outpatient appointment	
1. Gastroenterology	1. £178 plus follow-up £101 = £279
2. Infectious Diseases	2. £263 plus follow-up £209 = £472
Blood tests and investigations (without MRI)	£822.96
Total Costs	Gastroenterology route £1101.96 Infectious diseases route £1294.96

Conclusion

The results of the user outcome survey demonstrate that IBD passport has the potential to improve knowledge of travel-related issues in IBD, including awareness and increased uptake of vaccinations, travel insurance and seeking expert advice prior to travel. This was the main aim of the website and reason for undertaking the assessment. As mentioned in the narrative, assigning monetary value to this is difficult due to the many variables that exists with the traveller, and more so when chronic disease is added. The resource and financial implications of pre-travel education are difficult to quantify and the economic benefit of such a resource reflects the likelihood of preventing or reducing the risk of an illness and incorporates all the expenses of a travel-related illness. The cost analysis provided gives a basic estimate of costs incurred as a result of travel-related illness in the IBD patient but this is likely to run far deeper and be multifactorial. The task of undertaking an

economic assessment that would comprehensively assess all potential scenarios is outside the scope of this current exercise.

References

1. Rahier JF, Magro F, Abreu C et al. Second European evidence based consensus on the prevention, diagnosis and management of opportunistic infections in inflammatory bowel disease. *J Crohns Colitis*. 2014; 8: 443-468.
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6. E Ryan. Centres for disease control and prevention. Perspectives: Cost Analysis of Travel Medicine. <http://wwwnc.cdc.gov/travel/yellowbook/2016/the-pre-travel-consultation/perspectives-cost-analysis-of-travel-medicine> accessed 29/8/2015.
7. NHS Agenda for change pay scale (including on-costs)

*This case study was completed by **Kay Greveson**, Inflammatory Bowel Disease Nurse Specialist, Centre for Gastroenterology, Royal Free Hospital in **June 2016**.*

Kay successfully completed a collaborative learning programme designed to empower nurses to understand, generate and use economic evidence to continuously transform care. The programme was delivered by the Royal College of Nursing and the Office for Public Management, funded by the Burdett Trust for Nursing and endorsed by the Institute of Leadership and Management.

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Appendices

A: IBD Passport Stakeholder matrix

	Direct		
Internal	<p>My time to develop the website- Literature search & appraisal, internet search, website content and functionality design, liaison with web developers, focus groups with users (approx. 75 hours @ £35.48/hr = £2661)</p> <p>Personal costs to develop the website (Direct set-up: £9261.04)</p>	<p>Shire nurse innovation award (£1,500)</p> <p>Energy house digital web-developers- initial site development based on my specified criteria and brief + ongoing maintenance</p> <p>Inflammatory Bowel Disease patients (users)</p> <p>Inflammatory Bowel Disease Professionals (Users)</p>	External
	<p>Local IBD team who have had some input to the content</p>	<p>IBD professionals</p> <p>Crohn’s and colitis UK patient charity (consulted during development and evaluated content post)</p> <p>IBD patients and HCP (formal evaluation and focus group prior to development)</p> <p>Hoping to influence: IBD patients, IBD HCP, primary care/ travel clinics- improved awareness and safety i.e vaccinations, travel health preparation and knowledge.</p> <p>Long-term: Insurance companies- reduced premiums</p>	
	Indirect		

B: Costs: Set-Up- (All direct costs)

Direct costs				
Identify	Additionality	Apportion	Full costs	Real terms
Website development	YES	yes	No	Yes (2013 start of project)
My Time- Literature search, writing content. Approx. 100 hours at Band 7 x 1 WTE	yes	Yes- Without this the website would not have been developed	no	Assumption- 100 hours spent on this work. Carried out 2013-2014
My Time: Formal evaluation (Survey development, data analysis, Writing report, presenting findings) Approx. 20 hours at Band 7 WTE	Yes	Yes	No	No- All done 2014/2015
My Time: Dissemination of website- Conference presentations, Writing Journal articles) Approx. 25hrs Band 7 WTE	Yes	Yes Essential component for implementation of the site to be effective		No- All done 2014/2015
Liaison with Key experts during development Approx. 3 hrs Band 7 WTE	yes	Yes	No	No