Institution: Swansea University
Unit of Assessment: 3a - Allied Health Professions, Dentistry, Nursing and Pharmacy
Title of case study: Influencing national policy to improve service delivery and patient care in gastroenterology

1. Summary of the impact

Between 1996 and 2013 researchers at Swansea University evaluated service initiatives and changing professional roles associated with the management of patients with debilitating gastrointestinal disorders. This work showed the clinical and cost effectiveness of two main innovations: open access to hospital services for patients with inflammatory bowel disease; and increased responsibility for nurses, particularly as endoscopists. Our evidence has had a broad, significant impact on: **national policy** through incorporation in NHS strategies, professional service standards and commissioning guides; **service delivery** through the provision of increasing numbers of nurse endoscopists and the wide introduction of nurse-led open access to follow-up; and **patient care**, as documented in sequential national audits in 2006, 2008 and 2010.

2. Underpinning research

Since 1992, JG Williams has been consultant gastroenterologist and Professor at Swansea College of Medicine and its predecessor (a postgraduate medical school which he established in 1988). In the early 1990s, funding from the Welsh Office enabled his academic team to develop and implement a clinical information system to support the management of patients with gastrointestinal disorders at nearby Neath General Hospital. Analysis of structured patient data collected from 1990 to 1995 [R1] showed a relentlessly rising workload, especially in the management of patients with inflammatory bowel disease (IBD), a chronic, debilitating disorder characterised by unpredictable relapses. These findings stimulated a programme of research designed to improve the efficiency and quality of care for patients with gastrointestinal disorders. First we offered patients 'open access' to follow-up when needed, in place of routinely booked appointments, and evaluated this in a pragmatic randomised trial over 1995-6. This showed that patients and general practitioners prefer an open-access system of follow-up, and that this system results in significantly fewer out-patient visits (mean of 4.12 versus 4.64 over 2 years; p=0.002) at less cost (£582 versus £611; p=0.01) than routine booked appointments, without adversely affecting treatment standards or patients' quality of life [R2]. The trial also showed that, for open access to work effectively, specialist nurses are needed as first point of contact.

We then introduced specialist nurse-led open access in routine practice. To enhance the attractiveness of these posts, we offered training in endoscopy to specialist nurses, recognising the potential for them to undertake endoscopy in place of doctors. There were then few nurses undertaking endoscopy, and there was little research evidence in support of this role substitution. In 2002-3 we undertook the first and only pragmatic randomised trial of this role substitution – a UK-wide, multi-centre study known as MINuET. This showed that outcomes following endoscopy by nurses were no different from those following endoscopy by doctors, but that nurses were significantly more thorough in examining the oesophagus and stomach, and in record-keeping, than doctors; furthermore patients were more satisfied following endoscopy by nurses [R3, R4]. In 2006 the British Society of Gastroenterology (BSG) commissioned Williams and his academic team to undertake a systematic review of the burden of gastroenterological disease in the UK and the evidence for optimal service delivery in gastroenterology. This identified many observational studies that supported the value of nurses working in specialist roles, especially endoscopy [R5].

Other key researchers at Swansea contributing to this work are Wai-Yee Cheung (Lecturer then Senior Lecturer in Health Services Research 1990-2012), Jayne Morgan (Clinical Information Scientist since 1988), Frances Rapport (Lecturer then Professor of Qualitative Health Research since 2002), Stephen Roberts (Lecturer then Associate Professor in Epidemiology since 2005) and Ian Russell (Professor of Clinical Trials since 2008). The wide range of methodological skills in the team has enabled us to develop and validate patient-reported measures of patient satisfaction and quality of life [R6] for use with patients with IBD or undergoing endoscopy, and undertake observational studies to explore patient outcomes in gastroenterology. For example analysis of linked, routinely collected national data for England helped us to characterise the risks of unplanned admission of patients with IBD by looking at all patients admitted for more than three

days between 1998 and 2003 [R7]. Mortality three years after elective colectomy for ulcerative colitis (3.7%) and Crohn's disease (3.3%) was significantly lower than mortality after an emergency admission in which colectomy was performed (13.2% and 9.9% respectively; p<0.001 for colitis and p<0.01 for Crohn's disease); or either type of admission without surgery (13.6% and 10.1%; both P<0.001), suggesting the clinical threshold for elective colectomy in people with inflammatory bowel disease may be too high, and confirming the need to keep these potentially fatal disorders under specialist care. Analysis of outcomes following emergency admission for upper gastrointestinal bleeding in Wales [R8] identified significantly greater risks of admission at weekends and bank holidays. We showed that, although mortality fell from 11.4% in 1999-2000 to 8.6% in 2006-7, case fatality was 13% higher at weekends than on weekdays, and 41% higher on public holidays.

3. References to the research

Authors based in Swansea during studies are in bold. Journal impact factors (JIFs) relate to 2013. Citations by November 2013 come from Google Scholar.

R1. **Williams JG** The use of clinical information to help develop new services in a district general hospital. *Int J Med Inform* 1999; **56**: 151-9. (JIF 2.7; 5 citations)

R2. **Williams JG, Cheung WY,** Russell IT, Cohen DR, Longo M, **Lervy B.** Open access follow-up for inflammatory bowel disease: a pragmatic randomised trial and cost-effectiveness study. *BMJ* 2000; **320**: 544-8. DOI: 10.1136/bmj.320.7234.544. (JIF 17.2; 57 citations)

R3. **Williams JG,** Russell IT**, Durai D, Cheung WY**, Farrin A, Bloor K, Coulton S, Richardson G. What are the clinical outcome and cost-effectiveness of endoscopy undertaken by nurses when compared with doctors? A Multi-Institution Nurse Endoscopy Trial (MINuET) [Link] *Health Technology Assessment* 2006; **10** (40). (JIF 4.3; 28 citations)

R4. **Williams JG,** Russell IT**, Durai D, Cheung WY**, et al. Effectiveness of nurse-delivered endoscopy: findings from a randomised Multi-Institution Nurse Endoscopy Trial (MINuET). *BMJ* 2009; **338**: b231. DOI: 10.1136/bmj.b231. (JIF 17.2; 23 citations)

R5. **Williams JG, Roberts SE, Ali MF, Cheung WY**, Cohen DR, Russell IT et al. Gastroenterology services in the UK: the burden of disease, and the organisation and delivery of services for gastrointestinal and liver disorders: a review of the evidence. *Gut* 2007; **56** (suppl): 1–113. DOI: 10.1136/gut.2006.117598. (JIF 10.7; 54 citations)

R6. **Cheung W-Y**, Garrett AM, Russell IT, **Williams JG**. The UK IBDQ – a British version of the inflammatory bowel disease questionnaire: development and validation. *Journal of Clinical Epidemiology* 2000; **53**: 297-306 (JIF 5.12; 62 citations)

R7. **Roberts SE, Williams JG**, Yeates D, Goldacre MJ. Hospital admission for ulcerative colitis and Crohn's disease in England: comparison of mortality with and without colectomy. *BMJ* 2007; **335**: 1033-6. DOI: 10.1136/bmj.39345.714039.55. (JIF: 17.2; 57 citations)

R8. Button LA, **Roberts SE, Evans PA**, Goldacre MJ, **Akbari A**, Macey S, **Williams JG.** Hospitalised incidence and case fatality for upper gastrointestinal bleeding from 1999-2007: a record linkage study. *Aliment. Pharmacol. Ther.* (2011) **33**: 64-76. DOI: 10.1111/j.1365-2036.2010.04495.x. (JIF: 4.5; 32 citations)

Peer-reviewed grants that have supported this work

JG Williams (PI), JM Morgan. Development of a generic clinical management system. Welsh Office, 1990–1994, £750,000.

JG Williams (PI), IT Russell. Towards appropriate outpatient follow-up of patients with chronic disease. Department of Health Research & Development Directorate – Primary-Secondary Care Interface Programme, 1996–1999, £80,000.

JG Williams (PI), IT Russell. What is the clinical- and cost-effectiveness of endoscopy undertaken by nurses? A Multi-Institutional Nurse Endoscopy Trial (MINUET). Health Technology Assessment Programme, 2001–2004, £760,000.

JG Williams (PI), IT Russell, SE Roberts. Gastroenterology services in the UK – the burden of disease and the organisation and delivery of services for GI and liver disorders: a review of the evidence. British Society of Gastroenterology, 2004–2005, £60,000.

4. Details of the impact

Our research has underpinned recommendations for the development of services for the clinical management of patients with gastrointestinal disorders in the UK and Europe; and the greater use of nurses rather than doctors to perform endoscopy in the UK and the USA. Publication in 2000 of the results of our trial comparing appointment-based follow-up with open access to clinical advice prompted the national development of nurse-led open-access services for IBD and other diseases [C1]. The BSG used our evidence: in guidelines for the management of IBD published in 2004; in a national strategy for gastrointestinal services published in 2007 [C2]; and in National Service Standards for IBD, first published in 2009 [C3], which recommend the appointment of specialist nurses, development of open access services, and closer monitoring of patient outcomes.

National audits of the management of patients with IBD have shown the impact of our underpinning research on the delivery of patient care. Under a multi-professional steering group, the Clinical Effectiveness and Evaluation unit (CEEu) of the Royal College of Physicians conducted three UK-wide audits of the development of services for patients with gastroenterological disorders and the quality of patient care between 2006 and 2010. The successive response rates to these audits were 75%, 93% and 90% of hospitals in the UK. By 2010 most hospitals were employing specialist nurses and offering open access to patients with IBD. The Table compares the findings of the three audits [C4] and shows substantial improvements in services offered to patients, both in the community and when admitted to hospital:

Table: Results from sequential UK national audits of IBD care

Measure	2006	2008	2010
Percentage of UK hospital sites offering open access – using data from 128 hospital sites participating in all 3 audits	63%	67%	94%
Percentage of UK hospital sites supporting telephone helpline – using data from 128 hospital sites in all 3 audits	76%	85%	95%
Percentage of admitted IBD patients reviewed by specialist nurse on ward (number of patients audited in each round)	21% (697)	27% (890)	42% (1375)

Our evidence that nurse endoscopists are more thorough than doctors and generate more patient satisfaction, but achieve similar clinical outcomes at similar costs, underpins recommendations for nurse endoscopy in both the UK [C5] (analysis based almost exclusively on our study) and the USA [C6] (by the American Society for Gastrointestinal Endoscopy, who found no similar study in the USA). To quote the NHS Centre for Reviews and Dissemination [C5]:

> "*This trial was funded and designed to provide evidence to support decision-making in the NHS. The participants and procedures reflect those of a range of NHS hospitals at the time of the trial (2002-3). Hence the findings are likely to be generalisable … The trial was well conducted and the authors' conclusions are likely to be reliable.*"

In the UK, recruitment of nurse endoscopists has steadily expanded: fewer than 20% of hospitals employed nurse endoscopists when we started the MINuET study in 2002; by 2011 this had risen to 85% [C5]. In 2011 a Royal College of Nursing audit [C7] showed that the number of specialist nurses was rising, with 54% in post less than 5 years. 99% of specialist nurses ran a telephone help-line for patients; 72% ran open access clinics; and 21% regularly undertook endoscopy. A UK-wide audit of colonoscopy reported that nurses performed 11% of colonoscopies in 2011, whereas doctors performed 100% in 2001 [C8].

The findings from our analyses of routine data contributed to UK recommendations from the BSG and Royal College of Physicians for services out of hours for patients with upper gastrointestinal bleeding, and wider thinking on the provision of hospital services out of hours. The director of medical workforce at the Royal College of Physicians observed [C9]:

"This study provides yet more evidence that patients in hospital are not cared for well at weekends, and reinforces the call from the RCP for consultant physicians caring for very sick patients to be in the hospital for 12 hours a day, every day, including weekends."

Our exploration of outcomes following emergency and elective admission to hospital with inflammatory bowel disease stimulated a Europe-wide debate on the timing of surgery for severe colitis, particularly with the emergence of new medical treatments that may influence the need for this. In 2012 the European Crohns & Colitis Organisation cited our study of emergency admissions for ulcerative colitis when recommending a consensus-based therapeutic approach to optimise the timing of surgery [C10].

We conclude that our distinctive research programme has achieved significant impact, engendering modernisation of services through policy initiatives from professional societies; development of extended nursing roles, now contributing significantly to endoscopy services and the care of patients with inflammatory bowel disease; increasing patient-focused care in IBD, as documented in three successive national audits from 2006 to 2010; and recommendations to improve hospital services out of hours, especially in endoscopy. This impact has been wide in reach, stimulating the development of open-access services for patients with IBD and out-of-hours endoscopy across the UK; increasing numbers of nurse endoscopists across the UK; recommendations for non-physician endoscopists in the USA; and more aggressive treatment of acute severe colitis in Europe.

5. Sources to corroborate the impact

C1. Roland M *et al*; 2006. Outpatient Services and Primary Care: a scoping review of research into strategies for improving outpatient effectiveness and efficiency: report for the NHS Service Delivery & Organisation R&D Programme. http://tinyurl.com/plohefq. (Work by Swansea University cited on pages 62 and 67)

C2. British Society of Gastroenterology; 2006. Care of Patients with Gastrointestinal Disorders in the UK: Strategy for the Future. http://tinyurl.com/odrcc57. (Work by Swansea University cited on pages 19, 30, 31 and 42)

C3. IBD Standards Group; 2013. Standards for the healthcare of people who have Inflammatory Bowel Disease: 2013 update. http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf. (Work by Swansea University invoked in standards A1, A11 and C2)

C4. Alrubaiy L *et al*. Inflammatory bowel disease in the UK: Is quality of care improving? *Frontline Gastroenterology* 2013; **4**: 296-301. DOI:10.1136/flgastro-2013-100333.

C5. NHS Centre for Reviews & Dissemination. Evidence briefing on nurse endoscopy. National Institute for Health Research; 2011. (Work by Swansea University cited on pages 3-6) http://www.york.ac.uk/inst/crd/pdf/Nurse%20endoscopy%20evidence%20briefing.pdf

C6. ASGE Standards of Practice Committee. Guideline: endoscopy by nonphysicians. American Society for Gastrointestinal Endoscopy. *Gastrointestinal Endoscopy* 2009; **69**: 767-70. http://tinyurl.com/o5tebyg (Work by Swansea University cited on page 769)

C7. Royal College of Nursing; 2012. Inflammatory bowel disease nursing; results of an audit exploring the roles, responsibilities and activity of nurses with specialist or advanced roles. http://tinyurl.com/n8ths5q. (Work by Swansea University invoked on page 9)

C8. Gavin DR *et al*. The national colonoscopy audit: a nationwide assessment of the quality and safety of colonoscopy in the UK. *Gut* 2013; **62**: 242-9. DOI:10.1136/gutjnl-2011-301848.

C9. Royal College of Physicians; 2010. Press release citing underpinning research. http://tinyurl.com/o4scw5r.

C10. Dignass A *et al*. Second European evidence-based consensus on diagnosis and management of ulcerative colitis. *J. Crohn's Colitis* 2013; **6**: 991-1030. DOI: 10.1016/j.crohns.2012.09.002. (Swansea University invoked on page 996)