Moving house—moving medical teams: keeping control of my IBD

doi:10.1136/flgastro-2019-101378

Philip J Smith

'Come in Mr Smith, have a seat. It is very nice to meet you. I believe you are new to this region? Your GP has referred you to clinic with a brief letter saying you've had Crohn's disease for 15 years and been under the care of Professor Brain at Ivory Tower University Hospital and are taking Infliximab and Azathioprine and need follow up in Inflammatory Bowel Disease (IBD) clinic? Could you help me fill in the details of your Crohn's disease over the years?' Many patients, relatives and most secondary care physicians managing patients with inflammatory bowel disease (IBD) will recognise this moment in a busy outpatient clinic whereby a new patient arrives in the clinic and the physician has suboptimal information from the outset. All continuity is lost; confidence is dented; and everyone feels frustrated by this situation despite often this being no single person's 'fault'. In short, transferring a patient between one institution and another is often not easy and, as a result, often not done well. However, to date, the evidence about the quality of care of patients transferring has been lacking, and the often-poor experience of transferring care, while well known and recognised, remains anecdotal. This is of course contrary to the growing recognition and guidance about the importance of transitional care between paediatric and adult care, and the poor health outcomes associated with either a lack or absence of transitional care provision.¹

Published in *Frontline Gastroenterology*, the Gastroenterology London Investigative Network for Trainees, also known as the GLINT trainee network, sought to explore the quality of care of patients with IBD transferring between healthcare providers in a London-based multicentre audit.² By retrospectively reviewing IBD transfer of care referrals from hospitals across London, data were collected on patient demographics, source and content of referral, and were cross-referenced with an established transfer of care checklist. Patient outcomes within the first 6 months following transfer were also documented. GLINT's primary aim was to assess the quality of referral for adult patients transferring care between providers, according to the number of key data points included in the referral.

This was assessed against the Cornerstones Health 'IBD Checklist for Care Continuity'.^{2,3} Secondly, they aimed to identify the frequency of transfer of care among the London population and to report disease-related outcomes in patients transferring their care, determining whether the quality of the referral was related to poor outcome.

The author's outcomes were very interesting. Of the 154 patients identified, over half (52.9%) were transferred due to the patient's relocation, with transferring from the private sector to the NHS (16.4%) being the second most common reason for transfer of care. In the majority of cases, information regarding transfer of care came from primary care (71.4%), with a minority coming from secondary care (20.7%). Over half of transfers from private practice were also performed by primary care (12/23 patients, 52.2%), and half of all referrals for a tertiary opinion were made by primary care (7/14 patients, 50%).

The authors documented the 'information quality' of the transfer referrals, showing that several criteria were documented more frequently by secondary care referrers compared with primary care referrers. These included the date of diagnosis ($p=0.0003$), medical history ($p<0.0001$), surgical history ($p<0.0001$), the most recent endoscopy report ($p=0.002$) and the most recent imaging findings ($p<0.0001$). However other data points, including data sufficient to apply the Montreal classification, current medication and comorbidities, were equally likely to be included regardless of the referral source. Hence, the authors demonstrated that while primary care performs the majority of such referrals, the data supplied from secondary care are in most cases significantly more complete than those from primary care. No statistically significant worse outcomes were seen at 6 months dependent on the referral source or the assessed referral quality. However, escalation of therapy and other metrics of disease complications were identified in a quarter of the referred patients regardless of source or reason for provider change.

There is good evidence that recent studies in the UK and the USA have shown that fragmentation of IBD care is

commonplace and the use of more than one secondary care service is as high as 17% within 2 years of diagnosis.⁴ Although, this study did not demonstrate this, care fragmentation can be associated with worsening lengths of stay and in-hospital mortality, with younger patients being more susceptible.⁵

This study does have its limitations: it may not be as generalisable to less metropolitan areas in relation to private practice referrals, and having a younger, more mobile population. Additionally, information and data on each patient could not be obtained from primary care directly. Finally, an important limitation is that patient, referring and receiving healthcare provider satisfaction and experience were not assessed directly in the patient group assessed. Despite these limitations, this study by the GLINT network is an interesting and important study for frontline clinicians as it clearly demonstrates that the transfer of care for patients with IBD between care providers is not a rare phenomenon and should be optimised as a priority to aid better communication on behalf of the patient. Unfortunately, and possibly unfairly, the onus to make these transfer referrals appeared to fall on primary care providers in this study, despite them being less well equipped in this subspecialty area to make the most encompassing referrals. While current NHS referral and funding pathways may 'force' some of this work onto primary care, it is clear that secondary care specialists should also be empowering patients with their personal disease-specific information required to ensure good communication between referrer and receiving team. The authors have suggested digital health and smartphone technologies (such as the use of 'apps') could be used to fill this current void.⁶ Until the use of such technologies is more embedded into the health services, it is clear that secondary care and private healthcare providers have a clear duty of care to facilitate the smooth transfer of care of patients with IBD. Both the new British Society IBD Guidelines⁷ and UK IBD Standards⁸ provide clear guidance to clinicians on how to present structured information between primary and secondary care and is a good starting point for all clinicians dealing with the

transfer of care of patients. Indeed, there seems much to be gained by getting the ‘basics’ right, which the authors allude to. For example, in adult and especially paediatric IBD care, it is commonplace to copy patients, as well their primary care provider, into outpatients communications, be that a summary of a clinic visit, laboratory results (blood, faecal calprotectin and histology), radiology and endoscopy reports, or even ad hoc communications. This very simple process is the first step to empower patients to ‘keep their own records’ and be the main repository of their personal information, as opposed to a hospital database or electronic record. Hopefully, with further advances in technology in the healthcare sector over the next few years, we will see all patient records becoming electronically recorded, moving away from the decades-old dependency on ‘hard’ (paper) copies. This almost certainly helps with communication and digital transfer of information between primary and secondary care in a rapid and efficient manner. It would also enable the transition to smart phone and digital health technologies to become widespread, rather than niche.

Of course, all of this will seem like common sense to many. How hard can it be to send a letter, email or fax from one provider to another? Well, from the evidence of this paper, even the most basic channels of communication can become opaque. However, with proactive and innovative changes in our practice,

such hurdles can be easily overcome, most probably via the empowerment of patients themselves. This will hopefully provide the patients we serve with reassurance that the quality and continuity of their care will not be jeopardised despite moving from one institution to another.

Twitter Philip J Smith @DrPhilipJSmith

Contributors PJS prepared, wrote and edited the manuscript.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests PJS is an associate editor of *Frontline Gastroenterology* and the digital and education editor of *Gut*. He is a patient with Crohn’s disease and trustee of the charities IBD Passport, Guts UK and CICRA.

Patient consent for publication Not required.

Provenance and peer review Commissioned; externally peer reviewed.

► <http://dx.doi.org/10.1136/flgastro-2019-101347>

ORCID iD

Philip J Smith <http://orcid.org/0000-0003-1568-3978>

REFERENCES

- 1 Brooks AJ, Smith PJ, Cohen R, *et al*. UK guideline on transition of adolescent and

young persons with chronic digestive diseases from paediatric to adult care. *Gut* 2017;66:988–1000.

- 2 Ahmad OF, Ayubi H, GLINT Research Network. Quality of care in adult patients with inflammatory bowel disease transferring between healthcare providers: multicentre audit. *Front Gastroenterol* 2021;12:5–10.
- 3 Cornerstones Health. *Cornerstones IBD checklist for care continuity, version 1.1*, 2017.
- 4 Warren LR, Clarke JM, Arora S, *et al*. Transitions of care across Hospital settings in patients with inflammatory bowel disease. *World J Gastroenterol* 2019;25:2122–32.
- 5 Cohen-Mekelburg S, Rosenblatt R, Gold S, *et al*. Fragmented care is prevalent among inflammatory bowel disease readmissions and is associated with worse outcomes. *Am J Gastroenterol* 2019;114:276–90.
- 6 Khan S, Dasrath F, Farghaly S, *et al*. Unmet communication and information needs for patients with IBD: implications for mobile health technology. *Br J Med Med Res* 2016;12:1–11.
- 7 Lamb CA, Kennedy NA, Raine T, *et al*. British Society of gastroenterology consensus guidelines on the management of inflammatory bowel disease in adults. *Gut* 2019;68:s1–106.
- 8 Kapasi R, Glatter J, Lamb CA, *et al*. Consensus standards of healthcare for adults and children with inflammatory bowel disease in the UK. *Frontline Gastroenterol* 2020;11:178–87.