

Trials and tribulations: When Academic Research and Public Health Worlds Collide

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Three years ago, we received funding to develop, trial and evaluate a series of interventions to promote attendance at Bowel Scope Screening (BSS) in Hull, Yorkshire, UK (McGregor et al., 2018). The last of these interventions has now been delivered and in just a couple of months we will receive NHS data (from the Bowel Cancer Screening Programme) which will tell us how successful each intervention has been. While we await the results, we reflect on our trial experience and the difficulties faced in pursuit of improving public health.

CRC (Colorectal cancer; bowel cancer) is a common cancer with 42,000 people on average being given a diagnosis, and over 16,000 dying from the disease, each year in the UK (CRUK, n.d.). This ranks CRC as the fourth most common cancer and the second most common cause of cancer deaths. While these figures are improvements from previous years, they remain concerning. Bowel scope screening is a test that has a strong evidence base for not only reducing mortality, but chiefly preventing bowel cancer from developing in the first place. It was introduced as part of the English NHS Bowel Cancer Screening Programme in 2013 and is currently offered to adults aged 55 and registered with a General Practice. However, the test involves a one-off inspection of the lower part of the bowel, a procedure also known as Flexible Sigmoidoscopy, making it a particularly invasive, potentially embarrassing, procedure. Uptake is rather unsurprisingly very low, limiting any benefits associated with the test.

As Psychologists, we are interested in why people in England don't take part in BSS. We explore the reasons and apply psychological theory to an understanding of low uptake, with a focus on developing interventions to encourage informed decision making and support for screening participation.

General Practitioner (GP) endorsement is reliably shown to improve uptake of cancer screening opportunities (Duffy et al., 2016). We wanted to capitalise on this by devising simple interventions to be delivered through primary care, specifically a GP practice-based primer letter, a self-referral reminder letter, and a patient navigation phone call. All interventions have a growing evidence base in other contexts or countries but have not yet been evaluated in respect to bowel scope screening in England. Things started positively, with enthused, knowledgeable and experienced collaborators and advisors on board, including GPs, but the essential recruitment of GP practices to the study proved to be a challenge bigger than any of us had imagined.

At our first funder meeting, we were introduced to members of the local NHS Clinical Research Network (CRN), who offered reassurance as to our recruitment aims. However, while they proved to be a great support on many levels, their influence on GP practices was not as anticipated. As part of the development phase of our interventions we considered it imperative to involve local GPs and practice staff members so that we could better understand the anticipated barriers the local population would face with regard to accessing health care and glean a more practical response to our proposed GP practice-based interventions. The

Figure 1

Flyer (A6) distributed at the 3rd Annual Yorkshire and the Humber CRN Primary Care Academic Research Day to supplement presentation (February 2018)

Using primary care to increase uptake of
bowel scope screening (BSS)
in Yorkshire:
evaluating paper and telephone based interventions

We need your help to increase patient
uptake of BSS.

Please contact us to find out if your practice
is eligible to take part in the above study

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Sign up by the
14th February and receive an extra*
£100

*Support Costs currently £283



CRN sent an 'Expression of Interest' email to 21 practices, inviting staff members at any level to take part in a brief telephone interview with the researchers. This was followed up with multiple emails and calls, but resulted in zero responses. Only opportunistic direct conversation between the CRN team and practice managers was found to help; we eventually gleaned valuable insights regarding our targeted population from six staff members representing three practices.

Recruitment of GP practices to the main trial continued to be problematic. The disconnect between us as non-clinical academic researchers trying to engage with GPs was incredibly frustrating. Emails to practice managers were

mostly futile and read receipts suggested many were perhaps not even read. Calls were cut short, being informed that the practice manager was not in or not currently available, information only communicated once we responded to questions of who we were and why we were calling! When our efforts were successful, the joy was real, and staff proved to be welcoming, interested and helpful, but getting 'a foot in the door', and getting a chance to be heard, was incredibly hard, time consuming, and with a limited funded research timeline, extremely anxiety provoking.

In support of our mission, the CRN provided us a platform to promote our study at primary care events. We presented our research aims and plans, highlighting monetary rewards guaranteed for practices that took part and a bonus for those who signed up before a certain date. Our stall even tried to draw in the crowd with chocolates (see photo). Both had a certain level of success, with a number of attendees wanting to know more about our research, but neither were the 'silver recruitment bullet' we desperately needed.

Understanding how busy GP practices are, we incorporated into our research protocol a research nurse to perform and oversee most of the tasks required for the study and use of a third-party mailing company to support the distribution of our paper-based interventions. While an attractive

Figure 2

Photo of our study recruitment stall at Hull CCG meeting



aspect for the GP practices, the processes required to secure a research passport and letter of access for our research nurse took far longer than anticipated, and the use of a third-party mailing company was a concern for Practice Managers, in light of the then imminent General Data Protection Regulation (GDPR) changes. Despite security certificates, contracts and ethical approvals in place, a protocol amendment had to be written, reviewed and approved, allowing GP practices to oversee the mailed interventions in-house instead. In addition, despite approval from the NHS Confidentiality Advisory Group (CAG)¹ to conduct this research study without written consent from patients, one GP practice who originally showed interest in the study stated this absence of written consent as a reason for not continuing with participation. It is likely that this was also the reason for other practices, with uncertainty and apprehension around new GDPR regulations and fines with respect to the protection of patient information; however, a lack of engagement meant we could not collate information on the factors influencing GP practice decision making. It is important to stress that in our previous feasibility study exploring patient navigation calls, we had asked for consent from people who were invited for bowel scope screening and only 14.5% agreed to be part of our study (McGregor et al., 2019). This was a clear demonstration that obtaining prior consent for this type of intervention is not feasible and at best returns a biased sample of highly motivated people who do not require any further support for making screening decisions, thus defeating the very purpose of our trial.

An additional barrier to GP recruitment was evident from a higher, organisational level. The roll out for BSS in Hull and East Riding was slower than expected meaning that we lost access to around

¹The Confidentiality Advisory Group must give approval for studies in England and Wales where consent is not to be sought for access to confidential patient information.

nine practices who had their expected 'live' date delayed out with the timeline of our study. In the end, we recruited 12 practices from a list of 31 eligible to take part.

It often feels as though Primary Care in the UK exists in a parallel universe to the research world we live in. What takes researchers an endless amount of approvals can often be implemented immediately in GP practices as part of their routine care. GPs have more flexibility and their ideas are not reviewed by multiple committees, with subsequent delays, disagreements and lengthy amendment procedures to comply with. They can also react more positively to problems encountered whereas we are limited by our funded timeline, employment contracts etc.; we can't simply stop the study until problems are fixed.

The best example for this imbalance are phone-based reminders. We as researchers have been very keen to emulate the evidence base coming from the US for the effectiveness of patient navigation. Patient navigation involves more than a simple phone-based reminder. It is a thoughtful theory-based approach to empowering patients, identifying and, only where considered appropriate, trying to remove obstacles to engaging with various behaviours on the cancer care continuum, including screening. For every attempt to deliver PN via phone calls, there are hundreds of phone-based reminders being made from local GP practices and community organisations. Community care providers like GPs have, to a large degree, the freedom to just 'run' with things that feel intuitive. There is very little incentive for GP practices to take the long way round and wait for researchers to secure funding and approvals for scientific evaluations, especially if they have uptake targets, which need to be met by a set deadline. However, the main problem with this approach, is that many of these activities are often not sustainable, relying on short-term resources and incentivisation schemes, and are rarely evaluated (impact and cost-effectiveness) and/or shared with the wider

community.

There is no denying both parties are concerned with enhancing the health of patients and preventing illness, but how can primary care and psychology researchers work more closely to achieve this aim in a timelier, evidence-based manner? An obvious way forward is for academia to support the development and evaluation of audits. This will rely on academics embracing different approaches to evaluation, as traditional RCT approaches do not address the needs of primary care commissioners. The need for a control group not receiving the intervention can be an obstacle if there is an urgent need to improve uptake across the whole population. On the other hand, there is a clear need for practitioners and commissioners to understand the research cycle and work with academic researchers to implement interventions with a clear evidence base.

These views reflect our own experiences, we suspect other researchers to have faced similar difficulties and we are keen to start a conversation as to how we can improve things going forward so that both parties, and of course patients, benefit. How can we manage our competing priorities and workloads to allow a more collaborative approach to improving health and preventing illness? What can and should be done differently in future public health-based work?

While we highlight frustrations with the processes involved in working to improve public health through primary care, we have also achieved great things with this research project. We have developed what we think are some excellent study materials, co-produced with local people for local people, and have helped promote the very existence of BSS to GP practice staff and the general public. Time will tell if our interventions have had a positive effect on BSS uptake, but we remain hopeful and positive of our achievements so far.

References

- Cancer Research UK (n.d.). *Cancer statistics for the UK: Bowel cancer statistics*. Retrieved 14 October 2019 from <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bowel-cancer>
- Duffy S, Myles JP, Maroni R, Mohammad A. (2016). Rapid review of evaluation of interventions to improve participation in cancer screening services. *Journal of Medical Screening*, 24(3), 127-145. doi: 10.1177/0969141316664757
- McGregor LM, Kerrison RS, Green T, Macleod U, Hughes M, Gibbins M, Morris S, Rees C, von Wagner C. (2018). Using primary care-based paper and telephone interventions to increase uptake of bowel scope screening in Yorkshire: a protocol of a randomised controlled trial. *BMJ Open* 8:e024616. doi:10.1136/bmjopen-2018-024616
- McGregor LM, Skrobanski H, Ritchie M, Berkman L, Miller H, Freeman M, Patel N, Morris S, Rees C, von Wagner C. (2019). Using Specialist Screening practitioners (SSPs) to increase uptake of bowel scope (flexible sigmoidoscopy) screening: results of a feasibility single-stage phase II randomised trial. *BMJ Open*, 9:e023801. doi: 10.1136/bmjopen-2018-023801



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