The uptake of the NHS Bowel Cancer Screening Programme in people with intellectual disabilities in Cumbria

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Abstract
Bowel cancer is the second most common cause of cancer death on the UK. But if detected at an early stage can be successfully treated. In 2010 the NHS Bowel Cancer Screening Programme was introduced to everyone aged 60–75. This paper reports on a small scale scoping project that investigates if people with intellectual disabilities in Cumbria are being included in the project and what their experiences are.

Keywords
intellectual disabilities; learning disabilities; bowel cancer; screening; health promotion

Introduction
Bowel cancer is the third most common cancer in the UK and accounts for one in eight new cancer cases. It is the second most common cause of cancer death in the UK claiming around 44 lives each day (Cancer Research UK, 2008). If detected at an early stage, more than eight out of 10 cases of bowel cancer can be successfully treated. Because of this, the NHS Bowel Cancer Screening Programme (NHS BCSP) was introduced. It was fully implemented across England by February 2010 (Cancer Research UK, 2008). The NHS BCSP offers biennial Faecal Occult Blood test (FOBt) screening to male and females aged 60–75 who are registered with the NHS and have a functioning bowel. A FOBt kit is sent to a eligible person’s home and six tiny samples from three separate bowel motions are collected and returned for testing. If the test is still not returned, a letter goes to the General Practitioner (GP) alerting them to the patient’s non-participation. GPs are not directly involved in the delivery of the NHS BCSP but they are notified when invitations for screening are being sent out in their area. They also receive a copy of the results letters sent to their patients. If blood is detected in the sample returned, the individual will be invited for a colonoscopy. There is surprisingly little study of the BCSP in people with intellectual disabilities. However, Osborn et al. (2012) have identified that the general take-up of bowel cancer screening by people with intellectual disabilities is lower than the general population, although the differences are less great in more deprived populations. A discussion took place with the local NHS screening specialist and a nurse from the community learning disability team about how we could ensure that people with intellectual disabilities are fully involved in the NHS BCSP. A number of questions arose from this discussion and the decision was made to conduct this scoping project in order to investigate how people with intellectual disabilities were experiencing the NHS BCSP.

Results
Questionnaires were sent out to 13 different organisations and 12 organisations replied. In total 25 questionnaires were returned as some organisations managed more than one establishment. From the 12 replies, 19 (76%) indicated that they supported people who were eligible for the programme, 12 (63%) had been sent FOBt kits, seven had not received any FOBt kits. From the 12 that had been sent FOBt kits, eight (67%) returned samples, four did not; of the four, three people refused to let carers collect samples and one person did not want to discuss or participate. From the eight samples that were sent for testing, one person required further investigations. From the 25 responses, 11 said that their service users wanted further information about the NHS BCSP and 14 said that their carers wanted further information about the NHS BCSP.

Discussion
There are a number of methodological shortcomings within this project. The main one being that the survey was of organisations and homes, but not of individuals within the homes. However, it is likely that by using this approach the majority of people eligible will have been captured within this project, as it is likely that the majority of people with intellectual disabilities in the screened age group would be receiving some sort of residential support rather than living with parents or living alone.

Of those eligible for screening, 63% had received the kits. It is interesting to note that three of the seven establishments that supported people eligible for screening and had not had FOBt kits sent to them were nursing homes. However, each of the responders that originally claimed that they had not received the testing kits was re-contacted to clarify this 12 months after the original audit; out of these seven, five said now received the kits indicating that the programme was being slowly introduced to people as they became eligible. Of those who received the kits, 67% returned samples, 23% did not; the responders indicated that these samples were not returned at the choice of the service user rather than carers not wanting to. The four samples that were not returned for testing were due to the service users not wanting samples taken. This could indicate a lack of understanding on behalf of the services user about the process, risks, and benefits of the screening process. It is notable that many respondents requested further information about the NHS BCSP for both their service users and their carers.

The original purpose of this project was to investigate if people with intellectual disabilities are fully involved in the screening programme and what could be done to improve their experiences. The results indicated that people with intellectual disabilities who are eligible have received FOBt kits.

Recommendations
The Learning Disability service should produce an accessible/easy read resource pack to be kept in each of the community learning disability nursing bases within Cumbria to enable the community learning disability nurses to provide information about the BCSP to service users and carers as required. The easy-to-read leaflet produced by the NHS BCSP should be considered as part of the resource pack. The organisations included in this survey should have the resource pack made available to them.

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References