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### **Bowel Health and Screening: evaluating a peer-led educational intervention for people with learning disabilities**

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An evaluation of a peer led bowel health and bowel screening educational intervention for people with learning disabilities

## Abstract

This evaluation describes the results obtained from a project to address inequalities in access to bowel cancer screening by people with learning disabilities in a region of Scotland. A peer education programme was developed and delivered to people with learning disabilities and carers with the aims of improving knowledge and understanding of bowel health and bowel screening whilst reducing barriers to participation. After attendance at the session participants stated they were more likely to report possible signs and symptoms of bowel cancer to others. Results also showed increased knowledge of bowel health, bowel screening and increased intention to participate in the screening programme. The peer delivery of the sessions was found to be a positive format for the vast majority of participants.

## Introduction

This article will describe the evaluation of an innovative project that was delivered in a remote and rural health board area in Scotland. The project was a partnership between the public health department of the local health board, 3<sup>rd</sup> sector organisation for people with learning disabilities and the region's university. The Scottish Government's Cancer Strategy Screening Inequalities Fund supports the delivery of practical, time limited projects that seek to tackle inequalities in accessing cancer screening programmes in Scotland. A bid to deliver a peer education intervention focused on access to the bowel screening programme by people with learning disabilities was successful and the following evaluation details the outcomes.

## Background

Bowel (or colorectal) cancer is Scotland's third most common cancer, with around 3700 people diagnosed with the disease in 2017 (Information Services Division NHS National Services Scotland, 2020). Around 95% of cases occur in people over 50 and it is the second most common cause of cancer death in Scotland for both men and women (Information Services Division NHS National Services Scotland, 2020). People with learning disabilities have been found to have higher rates of cancer of the colon and the rectum than other sections of the population (Glover et al., 2017) emphasising the importance of facilitating participation in national screening programmes to enable early detection.

Scotland has had a national bowel screening programme in place since 2007 with all women and men aged between 50 and 74 who have a Community Health Index (CHI) number invited to participate every two years (Information Services Division NHS National Services Scotland, 2020). The aim of the test is to find bowel cancer at an early stage in people who have no symptoms and to find other changes in the bowel such as pre-cancerous growths called 'polyps' (NHS Inform, 2019). If colorectal cancer is diagnosed early it can be amenable to treatment and there are high survival rates if treatment is started early in the disease process (NHS Health Scotland, 2017).

Based on figures from May 2019 uptake of bowel screening in the general population is 59.5% across Scotland, with a slightly higher uptake of 63.7% in the health board area where this intervention took place (Information Services Division NHS National Services Scotland, 2020). The bowel screening programme does not currently collect a full range of demographic data relating to participation in bowel screening across different groups in the population necessitating a local approach. Data for the health board area for the year 2016 showed that out of a cohort of 238 people known to specialist learning disability services who were eligible for bowel screening, 47.1% (n=112) had participated in the screening programme. Cancer screening inequality is unacceptable and in the case of people with a learning disability may be a modifiable factor currently contributing to the poorer health outcomes often experienced by this section of the population (Turner et al., 2015).

For the general population a range of reasons for non-participation in bowel screening have been identified including not feeling it is personally necessary, uncertainty about whether to take part or not, practical issues to do with completing the test and conflicting priorities or external circumstances (Hall et al., 2015). For some people in the general population feelings of disgust that the test involves handling faeces lead to non-participation (Davis et al., 2017; Palmer et al., 2014). Fear was found to be a factor that could make it both more and less likely someone in the general population would participate in screening (Young et al., 2018). For people in the general population beliefs and intention to participate have been shown to be amenable change over time (Hall et al., 2015) and educational interventions can assist in this process.

Peer education has proven to be an effective intervention in increasing intention to participate and actual participation in cancer screening projects for a number of under-represented groups in society (Jones et al., 2015). However, there appears to be little, if any, published literature on the topic of peer education and bowel screening for people with learning disabilities. There is evidence that projects are taking place in the UK using this model as the intervention, although final evaluations are yet to be published (Tucker, 2019).

The Scottish Government's Cancer Strategy Screening Inequalities funding enabled the health board to commission a third-sector organisation to co-develop a 2-hour interactive peer led bowel health and screening awareness session. Support with the evaluation of the project was provided by staff from the region's university. The intervention was built around the idea that peer support could be an effective means to increase awareness of bowel screening and bowel health in people with learning disabilities. The support that people with lived experience of a learning disability can give one another is recognised as being beneficial (Mental Health Foundation, 2012) and the benefits are seen in both those receiving and providing the interventions (Frawley and Bigby, 2014). It is believed peer support can:

- Provide improved access to timely information.
- Provide positive role models.
- Increase community resilience.
- Increase capacity for self-help which can result in increased prevention and early intervention in many health problems

(Department of Health, 2011)

The intervention sought to increase informed participation in bowel screening among people with a learning disability, but it was acknowledged from the onset it would not be possible to evidence a demonstrable change in bowel screening participation due to the small numbers of individuals involved and the time limited nature of the project. Instead the project adopted three related and achievable aims detailed below.

## Aims

The project aims agreed between the partners at the start of the project were

- Increased engagement with people with a learning disability in a supportive and acceptable format.
- Increased knowledge and understanding of the value and purpose of bowel screening in this group.
- Reduced modifiable emotional, cognitive and practical barriers to screening in people with a learning disability.

## Method

The session content for this intervention was developed using the Health Belief Model with support from the health board's accessible information officer who was closely involved in developing the

materials. A Peer Educator was identified and supported by the third sector organisation to provide input throughout the development of the learning resources. A small focus group of people with learning disabilities was facilitated to obtain feedback about the session materials. The third-sector organisation then delivered a timetabled programme of sessions across the health board area. The peer educator with learning disabilities was supported by a staff member from the third-sector organisation to deliver the bowel health and bowel screening sessions to people with learning disabilities, carers and support staff.

At the time of submitting the bid for project funding guidance was sought from Senior Management of the public health department in the health board as to whether ethical approval would be needed. After considering the scope of the project the advice given to the project team was that ethical approval was not required as the project was considered to be an evaluation. It was on this basis that the project was undertaken.

## Evaluation

Two easy read quizzes were developed to measure pre and post intervention knowledge utilising the Bowel Cancer Awareness Measure (Cancer Research UK, 2011) as a resource to select appropriate questions. Each easy read quiz was designed by the accessible information officer with the question and responses supported by the use of images. Each question in the quizzes had three options for participants to select from, these being Yes/No and Don't Know.

The first quiz was designed to ascertain the likelihood a participant would report the key signs and symptoms of bowel cancer to a trusted other. The second quiz measured knowledge and understanding of the bowel screening test and risk reduction knowledge. In addition, participants were invited to complete a short questionnaire to indicate the acceptability of the training session to them. By completing the quizzes and questionnaire participants were made aware that they were consenting to anonymised and aggregated data being shared with project partners for the purposes of evaluation and inclusion in written publications.

## Participants

A total of 137 people attended the peer education sessions across 5 sites in the health board area, comprising 109 people with a learning disability and 28 carers. The youngest participant was 19 years of age and the oldest 68 years of age.

People with	Support/ Carers	Men	Women	Under 50	Over 50	TOTAL
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learning disabilities							
Site 1	40	5	21	24	43	2	45
Site 2	11	6	9	8	11	6	17
Site 3	26	4	22	8	28	2	30
Site 4	22	8	6	24	25	5	30
Site 5	10	5	10	5	11	4	15
Totals	109	28	68	69	118	19	137

Table 1: Participant demographics

## Results

The change in participants intention to inform trusted others of presence of possible symptoms of bowel cancer are shown below.

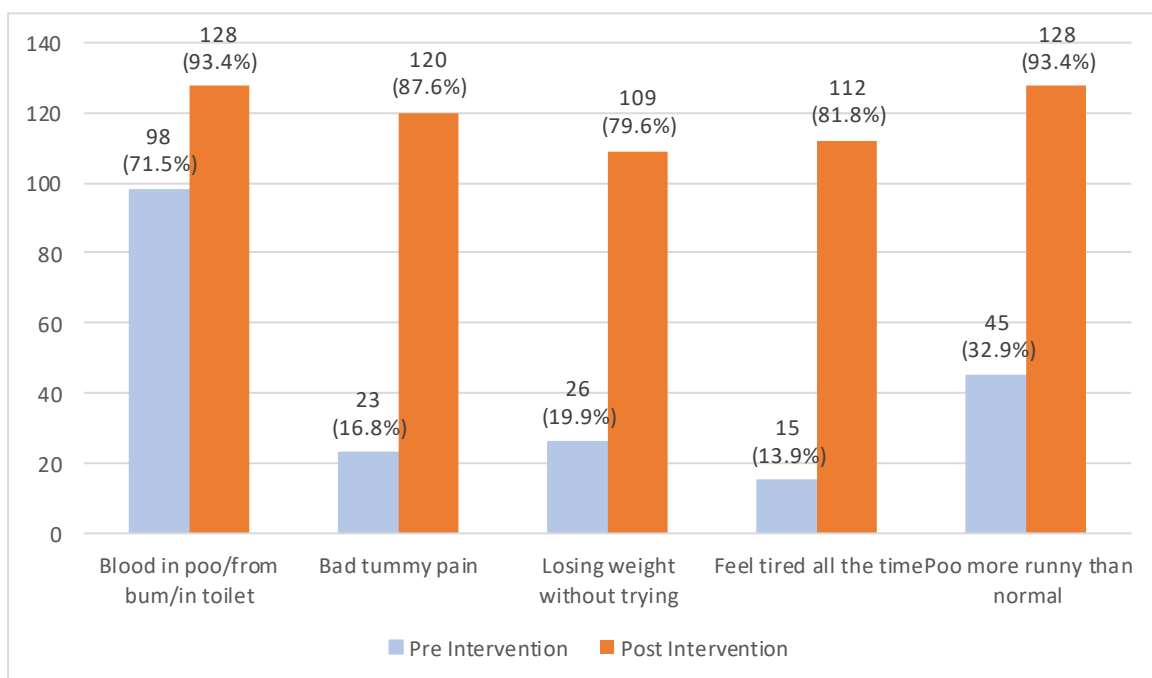


Figure 1: Number of participants stating "Yes they would inform others of symptomology"

Changes in the numbers of participants knowledge of bowel screening, bowel health and intention to participate in the bowel screening programme are shown below.

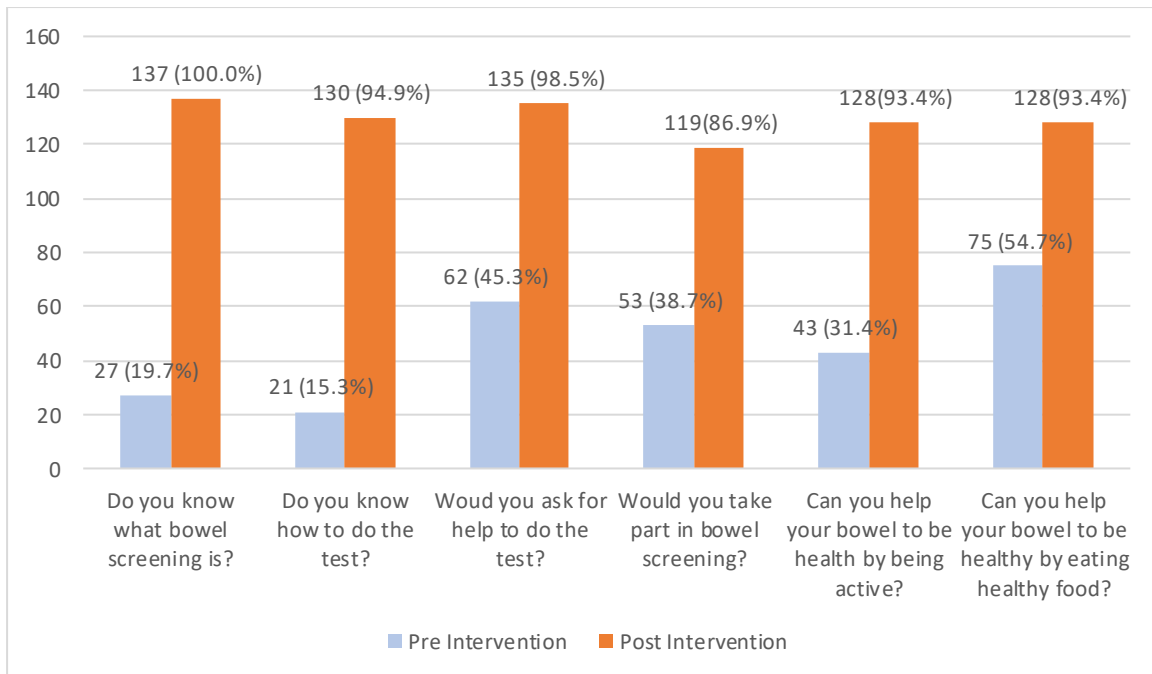


Figure 2: Number of participants replying Yes to statements relating to bowel screening, bowel health and intention to participate in screening

## Participant Feedback and Comments

Participants completed a short evaluation questionnaire to capture their experiences of the education session in addition to providing some informal verbal feedback to the peer educator and their supporter. The results of the questionnaire are shown in Table 2.

	Yes, it was good/they were good	It was okay/they were okay	No
Did you enjoy the session?	127 (92.7%)	6 (4.4%)	5 (3.6%)
Did you like the activities?	127 (92.7%)	9 (6.6%)	5 (3.6%)
Did you like the presenters?	130 (94.9%)	3 (2.2%)	0

Table 2: Participant Feedback on the Education Session

Feedback suggested that the majority of participants found that the sessions were delivered in an informal and relaxed style that enabled their participation. Comments from participants illustrated increased awareness of eligibility of others to participate in bowel screening, for example one participant with learning disabilities said “I don’t think X has ever done one of these ... he should have had a couple by now, but I think his family would just put it straight in the bin”. Other

participants with learning disabilities indicated that they would take steps to raise awareness in others, with one person saying, “I will tell my aunt all about it as she had one in the past”. Participants with learning disabilities highlighted an intention to change lifestyle with one commenting that they would be eating more fish and another saying they would be making their own healthier burgers. One participant with learning disabilities said that they would go and speak with the doctor following the session as they had concerns around some symptoms they were experiencing.

## Peer educator and supporter observations

Responses from some participants with learning disabilities indicated that they were initially uncomfortable in discussing faeces, with responses observed ranging from giggling, to covering eyes and to groaning. However, the peer educator addressed these issues by discussing the issues frankly and role modelling for others that the topic could be addressed openly. However, it was noted that people with learning disabilities tended to be more comfortable when the topics moved to healthy eating and exercise.

## Discussion

The evaluation results suggest that peer education was an effective means in addressing the aims of the project. Firstly, people with learning disabilities were able to engage with the topic and the accessible format of the materials. Secondly, the results demonstrated the format and materials were able to increase knowledge of the purpose of bowel screening for those with learning disabilities attending the sessions. Finally, barriers to engagement with bowel screening appear to be reduced with an increase in the number of participants with learning disabilities indicating that they would participate in bowel screening in the future. This reflects previous findings that targeting interventions towards specific groups who have low levels of participation are effective in increasing knowledge of bowel screening, increasing confidence to do the test and increasing intention to participate in the programme (Lotfi-Jam et al., 2019).

There was limited knowledge of the bowel screening test and how to carry it out amongst the participants with learning disabilities prior to the education sessions. Post session results showed a marked increase in knowledge of the bowel screening test and how it can be completed. The number of people with learning disabilities who expressed an intention to participate in the bowel screening programme more than doubled, suggesting that the discussion during the education session had made people more open to the idea of completing the test. Discussion around bowel screening has been found to be influential in increasing people’s intention to participate in the



bowel screening programme (Palmer et al., 2014), bringing a sense of normality to a test that otherwise would be out with people's perception of normality.

Peer education and support by people with learning disabilities has been proven to be effective in a range of different skill areas, including increasing physical activity, balance and fitness (Gobbi et al., 2018; Stanish and Temple, 2012; Yan et al., 2015), sexuality and relationships (Frawley and Bigby, 2014) and managing anxiety (Turner and Green, 2015). More broadly, peer education has proven to be effective in addressing health inequalities in screening for cancer in other marginalised and hard to reach groups in society (Rees et al., 2018). The results from this evaluation suggest that the same approach can also be used to address inequalities in participation in public health interventions such as screening for people with learning disabilities.

The nature of the bowel screening test necessitates close contact with faeces and this can be a taboo area within our culture (Bradley et al., 2015; Palmer et al., 2014). These feelings were apparent in the initial reactions of many participants with learning disabilities in the early stages of the session when it was noted by the peer educator that discussion around faeces provoked discomfort and embarrassment. As with the findings from Bradley et al. (2015) following completion of the session the majority of the participants with learning disabilities indicated a willingness to participate in the screening programme, indicating that this barrier is modifiable through education.

The inclusion of paid and family caregivers in the education sessions was intended to try and ensure that members of the support network around the person with a learning disability had the same information as the individual themselves. Paid staff members can have a key role in supporting health promotion and with structured routes of communication, stability in personnel and a positive working culture paid staff can improve the health and well-being of people with learning disabilities (Borthwick et al., 2019). It should also be noted that the feedback from people with learning disabilities suggested that they saw themselves as having a role in disseminating the key messages from the session to inform others of the importance of bowel health and bowel screening. This suggests that we should not assume that information sharing is purely a one-way process from the supporter to the supported person.

There are an estimated 396 adults aged 45 and over with learning disabilities living across the large, predominantly rural region where the project was completed (Scottish Commission for Learning Disability, 2019). To be most effective interventions to increase uptake of bowel screening should be implemented at community level, targeting groups that require additional support to participate in screening (Martini et al., 2016). From the start of the project it was decided that, due to the dispersed nature of the population, venues across the region should be used to reach out to people

with learning disabilities. It can be seen that the sessions only managed to reach a minority of the population for whom it would be most beneficial, suggesting that ongoing provision of the sessions will be needed. However it is more than likely that in addition to education other forms of more direct assistance will be needed to ensure that people with learning disabilities can complete the test (Joel and Marcellino, 2016).

Despite the evidence suggesting that peer education by and for people with learning disabilities can be effective in increasing knowledge and intention to participate in screening this approach has not been widely adopted. Professional resistance to the inclusion of peer educators has been identified as a potential barrier to the wider adoption of peer education initiatives involving people with learning disabilities (Frawley and Bigby, 2014). Whether this will be a barrier to further peer led health improvement sessions in the region remains to be seen.

## Limitations

The lack of statistical analysis in this evaluation is a limitation and it cannot be ruled out the changes that were observed may have occurred by chance. The use of closed questions and forced choice options in the quizzes may also have had an impact of the findings, making participants select options that were not fully an expression of their thoughts. However, the use of closed questions may be easier for people with learning difficulties to complete (Goegan et al., 2018) and so may be the best option available in this evaluation.

This project utilised only one of a range of evidence-based interventions that have been shown to bring about increases in knowledge and intention to participate in bowel screening. The results of the evaluation suggest that peer education by and for people with learning disabilities is an effective intervention to address some of the causes of the inequalities in screening participation experiences by this population group. Peer education can form part of a larger package of interventions including additional elements such as GP endorsement of cancer screening programmes which have been found to be effective in encouraging participation and to be valued by patients (Lotfi-Jam et al., 2019).

## Conclusion

This evaluation has shown that peer education, by and for people with learning disabilities, has proven to be an effective means of increasing knowledge of bowel health, symptoms of bowel cancer and in mitigating barriers to participation in bowel screening for the people with learning disabilities who attended the sessions. The mode of delivery proved to be acceptable to attendees and there were high levels of satisfaction with the sessions. These results would suggest that peer

education to address inequalities in access to health screening programmes is one that warrants further investigation and longer term follow up to see whether the positive results from the sessions translate into increased participation in screening.

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