

**Bowel cancer screening and people with intellectual disabilities:
Working in co-production and establishing principles for good practice initiatives**

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Abstract

Bowel cancer is the fourth most common cancer in England, and with 1:20 people developing bowel cancer, it is the second highest cause of cancer deaths. If diagnosed early treatment can be more effective and screening programmes can reduce these mortality figures, yet there are some people for whom access and uptake of screening programmes is significantly less than the rest of the population - namely people with intellectual disabilities. This article aims to describe the process of co-production when working with a group of people with intellectual disabilities to explore why they may be reluctant to access bowel cancer screening programmes. Bowel cancer, its incidence and prevalence is introduced; the screening process described; and the population involved defined. The co-production process is catalogued, where clinicians, academics and people with intellectual disabilities worked together to explore the challenges of accessing screening programs. The article concludes with recommendation to inform practice.

Keywords

Empowerment, cancer, co-production, collaborative working, health promotion.

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Introduction

In the United Kingdom there are 36,000 new cases of colorectal cancer diagnosed each year (Cancer Research UK, 2006). It is the fourth most common cancer and the second most common cause of cancer-related death in the United Kingdom (Cancer Research UK, 2011), accounting for approximately 16,000 deaths per year (Wild et. al, 2006; Quarini & Gosney, 2009). Early detection and screening can improve function and quality of life (McGovern et. al, 2004), and is the cornerstone for the improvement of cancer survival outcomes (Department of Health, {DH} 2000). Empirical evidence demonstrates that primary screening and secondary investigation for bowel cancer in an ‘asymptomatic’ individual, at increased risk, is effective in the reduction of colorectal cancer incidence, mortality and increased survival from the disease (Wagner, Herdman & Wadhwa, 1991; Fedele, Jones & Niessen, 1991; Robinson et. al, 1997; James, Campbell & Hudson, 2002).

More than 95% of colorectal cancers develop from benign adenomatous polyps (Borum, 2001) with a malignant transformation which is reported to take between 10 years (Winawer, 1999) and up to 35 years, the adenoma-carcinoma sequence (Jackman & Mayo, 1951; Muto, Bussey & Morson, 1975; Peipins & Sandler, 1994; Hardy, Meltzer & Jankowski, 2000).

Therefore, colorectal cancer is an ideal candidate for screening with a patient-friendly and

safe examination. Early diagnosis, before the development of symptoms, may be an effective way of reducing mortality. It is this which a screening programme seeks to address.

Colorectal Cancer is ideal for population screening since it is common and has a well recognised pre-malignant lesion (the adenoma), treatment of which reduces the risk of cancer (West et. al, 2007).

The screening process

As a result of the UK Government's commitment to reduce cancer deaths in the under 75s by at least 20% in 2010 (DH, 1999) the Bowel Cancer Screening Programme in England was planned and introduced in 2006. It aims to achieve its targets through early detection of colorectal cancer and their pre-malignant precursor lesions. Different screening methods were proposed, with varying sensitivities and specificities. The two principle methods chosen for the screening process are Faecal Occult Blood testing (FOBt) and colonoscopy. The FOBt depends on the detection of blood lost from early cancers and adenomas in faecal samples. Randomised controlled trials have demonstrated that colorectal cancer mortality can be reduced by screening using FOBt (Towler et. al, 1998; Anwar, Hall & EIDer, 1998; Kronborg, 2003). After 10 years of follow-up, screening by FOBt every 2 years led to a reduction of 18% in colorectal cancer mortality, regardless of sex and age, in individuals aged 45 – 75 years, with a shift in detection to early stage Dukes' A cancers (Kronborg *et al.*, 1996; Hewitson *et al.*, 2007). As most colorectal cancers begin as a polyp, which are benign (non-cancerous) growths on the colon's inner surface (Boolchand *et al.*, 2006), removing these polyps interrupts the adenoma-carcinoma sequence and prevents the development of cancer (Winawer *et al.*, 1993; Lieberman, 1998). Therefore, those with a positive FOBt are offered colonoscopy as the secondary investigation. Through this process, the entire surface of the colon is examined, pre-cancerous changes and asymptomatic colorectal cancers

detected and polyps removed (Levin *et al.*, 2008; Parente, Marino & Crosta, 2009).

Individuals are entered into a polyp surveillance programme, depending on the findings at colonoscopy.

Several factors have been identified which influence participation within the screening process, including the fear of the results, dealing with faeces, confusion about the instructions and fear of the colonic procedure (McCaffery *et. al.*, 2003; O'Sullivan & Orbell, 2004; Chapple *et. al.*, 2008). Additional reasons for non-compliance included lack of interest, the absence of bowel related symptoms, embarrassment and worries about the test being unpleasant or painful (Vernon, 1997; MORI, 2009).

The screening programme relies on the willingness of individuals to undergo a certain screening test, which may be influenced by perceived advantages and drawbacks of screening tests and by knowledge and awareness of colorectal cancer, its risk and screening (Vernon, 1997; Blalock *et al.*, 1990; Keighley *et al.*, 2004). Social attitudes towards cancer, participation in early detection and screening programmes and compliance with treatment and coping strategies, are known to be profoundly affected by individual and cultural beliefs (Navon, 1999). Individuals invited to take part in the screening programme might consult family members, friends and colleagues who have previously undergone the process. The consequence of the Bowel Cancer Screening Programme and previous screening processes might also trigger psychological responses and lead to compliance or non-compliance in screening processes or treatments (McGovern *et al.*, 2004).

A systematic review illustrates that population-based screening programmes, letter-based and GP-based programmes are effective in increasing oncologic screening uptake for the general

population (Ferroni, *et al.*, 2012); and yet recent figures suggest that people with an intellectual disability in the UK are significantly less likely to receive screening (Osborn *et al.*, 2012). The most common underlying causes of death amongst this population is heart and circulatory disorders (22%) and cancer (20%) (CIPOLD, 2013). Understanding and identifying exactly what the barriers to screening uptake among PwIDs are and what measures can be put into place to improve informed decision making regarding participation in this effective health screening program, remains fundamentally important.

An intellectual disability perspective

Emerson *et al.*,(2011) estimate that there are approximately 1,198,000 people with intellectual disabilities, of which 298,000 are children and young people under the age of 17. Yet they remain one of the most marginalized groups in contemporary society (DH, 2001), and never more so when it comes to having their health needs identified, assessed and ultimately met. People with intellectual disabilities often have worse health than other people in the general population, yet have great difficulty accessing appropriate healthcare (Jackson & Read, 2008). Research and campaign reports recognize that when people with intellectual disabilities access the health care system, they are likely to receive different care and treatment than the average person who does not have an intellectual disability (Lin, Wu & Lee, 2003; Mencap 2004; 2007; 2009; 2013), but research around this area remains sparse (Jansen *et al* 2004).What is known is that the uptake of bowel cancer screening generally remains low for this marginalized population, for a whole host of reasons (Read & Latham, 2009).

Whilst resources alone will never replace education and training around the potential complexities when caring for people with intellectual disabilities and their health needs, toolkits have a flexibility of usage (Read *et al.*, 2011), can reinforce best practice (Read &

Rushton, 2013) and promote informed choice. As part of the process of developing a research proposal to develop a toolkit to improve informed decision making for people with intellectual disabilities around bowel cancer screening programs, the authors worked in co-production with a group of people with intellectual disabilities to shape the direction, process and content of the proposal. This paper will critically present this co-production process of working together to explore this issue.

Co-production as a way of working with others

Self-determination (according to co-production theorists) relies on opportunities to create solutions rather than simply being perceived as part of the problem (Corcoran, 2014). Co-production refers to the contribution of service users to the provision of services, has historical roots in civil rights and social care in the USA, and more latterly in the UK health and social care services (Ralpe & Wallace, 2010). Co-production is internationally recognized as an empowering approach within statutory and other sectors and is fundamental to person-centred advocacy. Reflection and feedback from people with intellectual disabilities has become an essential part of co-production in advocacy (Corcoran, 2014).

Aims

The aims of this paper are to describe the integral process of working in coproduction with people with intellectual disabilities; introduce the outcomes of this in relation to bowel cancer screening; and establish principles for good research practice.

Rationale

The life expectancy of people with intellectual disabilities is steadily increasing (Emerson and Hatton 2008), yet despite this evidence poor access to health promotion and cancer screening programs prevails (Disability Rights Commission {DRC} 2006). As age is a predisposing

factor to the incidence of bowel cancer, with 72% of people diagnosed over 65 (NHS choices 2014), cancer screening needs to take a higher profile in the care of people with intellectual disabilities. Many people with intellectual disabilities will be affected by cancer during their life time, either personally or because people they know have had the disease (Hanna *et al* 2011), a view echoed in our discussions. Although cancer rates have been found to be slightly lower in people with intellectual disabilities than the general population, they are beginning to rise (Tuffrey-Wijne *et al* 2009), yet access to screening programs remains problematic.

Improving healthcare services for people with intellectual disabilities is challenging due to a lack of information in appropriate formats (Howelson, Clarke 2013), and many people with intellectual disabilities are still heavily reliant on carers to identify and communicate their health needs (Felche *et al* 2008). To ensure equity and parity of treatment, people with intellectual disabilities should be supported to access health services, based on the fundamental principles advocated in government legislation (DH, 2001), i.e. independence, choice, rights and inclusion. Accessible information needs to be clearly written, to ensure people can make informed choices, understand their rights and have their say (Dawson 2011). Despite this there is consistently lower rates of cancer screening uptake in people with intellectual disabilities compared with the general public (DH, 2004).

Limited empirical research is available to investigate intellectual disability's healthcare professionals' awareness of cancer screening programmes and their eligibility criteria. Rees (2011) found that knowledge appeared limited, with the majority of staff attributing their information about cancer screening from the media and their own experience. Rees (2011) also acknowledges the lack of evidence to suggest that education and training programmes specific to cancer screening is offered to professionals working with people with intellectual

disabilities. If this group of people and their carers are not aware of the need for cancer screening, the uptake is likely to continue to be poor (DRC, 2006).

METHODS

Consent

This consultation was not formally classified as research, but as participant engagement prior to research so that the research questions and processes would be informed by the experiences and insights of the participants. The paper is not aiming to report research; rather it is advocating for, and presenting an example of, co-production to inform research.

People with an intellectual disability were initially approached since they had previously been involved in discussions and projects around issues such as loss, death, dying. Individuals had worked in groups and as individuals and had sought support from the organisation over a period of time in a number of different ways. As a result of their experiences, people sought to be involved in project work, and the initiative to become involved in health related topics originated from individuals themselves who were looking for ways to explore such issues and to express their thoughts in order to make a difference. Process consent (Beaver et al, 1999) is a concept that involves constant checking for wanting to be involved before and throughout any sensitive meeting, and was used throughout this consultation process. Written consent to participate using clear information was arranged at the advocacy organization.

Participants

All participants were aged 40 plus, were able to consent, and able to communicate verbally (although two had communication impairments, they could make their views, needs and wants known. All participants except one male lived at home with family members.

The variety of backgrounds and expertise of the facilitators was helpful in providing meaningful support both during and following the consultation meeting. One facilitator had

an extensive background in bereavement support; the two clinical facilitators were able to clarify terminology, expectations and understanding around issues pertaining to the body and the impact of cancer. The advocacy organisation had a range of independent advocates available to support any participant after the session as required.

A consultation meeting (10-12.30, followed by lunch) was held with one of the authors, six people with intellectual disabilities (four men; two women), an advocate from Reach, Asist, (an established advocacy organisation in Stoke on Trent, Staffordshire) and two specialist nurses from a local hospital NHS Trust. The advocate had previously met with the participants to explain what the meeting was about and to ascertain their informed consent to participate, given the potential sensitive nature of the discussion. Following the consultation, a feedback session was organised to which all participants were invited; and a report using clear information was written in conjunction with the participants.

Procedure

The purpose of the meeting was to share ideas about health screening for bowel cancer using creative consultation methods. The discussion revolved around the four key areas:

1. To explore the reasons for poor bowel cancer screening uptake
2. To clarify people with an intellectual disability's understanding of health screening and its importance
3. To establish appropriate ways to engage people with an intellectual disability in research
4. To help to discover practical interventions to promote bowel cancer screening.

The meeting was facilitated by the first author, an experienced academic, and the third author, an experienced advocate.

An anatomical model of a body was used to show participants where the bowels were located and how different parts of the body works. To facilitate meaningful engagement, posters were also designed and used throughout, where people with intellectual disabilities were encouraged to write or draw ideas and comments on post-it notes which were then displayed on the posters. This process promoted ownership of the ideas to the group participants themselves and also helped the participants to think about why health screening is important and to share their personal experiences and questions (see Figure 1).

Insert Figure 1. How we worked together

Outcomes

Whilst the primary aim of the co-production meeting was to learn from people with intellectual disabilities about accessing bowel cancers screening, reciprocal learning was evident. People with intellectual disabilities had a thirst for knowledge around cancer generally and bowel cancer specifically, and whilst they had a number of professionals to address their health questions, they fully maximized this opportunity. Seeing the manikin of the body fascinated members of the group, as no-one had seen a three dimensional model of the body presented in this way before. They leaned forwards to access a better view of the manikin, and asked pertinent questions regarding the what, where and how of the main body parts. The clinicians had taken along a bowel cancer screening kit, and this was explored and passed around the group to enable members to fully appreciate what we were talking about.

Some members talked about family members who had experienced cancer, some of whom had survived, some who had died. There were many questions around who gets cancer and why, and members asserted that clear information was important for everyone, not just people with intellectual disabilities, as one person commented ‘...cancer happens to everyone, all classes, all races...’. The focus of the discussion quickly moved on to what gets in the way of screening and what helps.

What gets in the way

Obstacles included the lack of support as talking about bowel cancer can be sensitive for anyone, regardless of the presence of an intellectual disability or not. Group participants said that some of the words used in the testing kit and associated information was too scientific. They felt that some people may focus on the words and what they meant, and not pay attention to the process itself and its importance. The lack of opportunities to talk about bowel cancer was raised, and for some participants this was their first opportunity to talk about it. One person said they needed more awareness raising amongst people with intellectual disabilities and training for staff, so that everyone understood its potential importance.

What would help

Primarily, participants talked about the need for a variety of accessible information including a film to demonstrate the screening process; information accompanied by pictures; and accessible (with clear information and pictures) posters in prominent places (such as toilets; Day Services; Churches; GP surgeries) to raise awareness. They recognized the importance of the media (e.g. TV and radio) in raising issues in soap operas and documentaries, and providing a focal point to prompt discussion and debate around this sensitive topic area. In

summary, the three key areas raised were clear information; awareness; and support (see Figure 2).

Insert Figure 2. What would help

Discussion

Exploring sensitive topics around health care with people with intellectual disabilities is often difficult, since one never knows exactly what issues might be raised by participants, and what their understanding and previous experiences may have been. This is exactly the same for the rest of the population, as health promoters, palliative care professionals and educators talk with the general public, they can never be fully prepared and anticipate exactly what is brought up around these areas. In this small group (N=6) three of the participants (50%) talked openly about personal experiences of cancer and all (N =6) could relate to health issues and the challenges of accessing healthcare. As is often the case, the process of engagement is indicative to any meaningful outcomes, and the meeting was held in a private, comfortable, accessible environment that was familiar to all participants. Hospitality remains important, and drinks and snacks were available throughout, such principles are important features of any research.

Empowerment was important, and having the support of a familiar advocate using processes that were familiar to the participants helped to ensure that everyone felt comfortable with speaking out and speaking up. We all used individual traffic light coloured cards so that everyone could slow down the discussions, or interrupt the flow, or indicate that they wanted to speak. Using these, plus of flip charts paper, post it notes and brightly coloured pens helped everyone to focus, and all of the participants were used to working in this way.

Seeing, touching and feeling the screening tools and the manikin maximized engagement with the group participants, and health educators are aware of the impact that visual stimuli can have on drawing people into a particular topic for discussion. For the participants of this consultation group, the visual prompts were really important, since they opened up new learning opportunities never before experienced.

This was a sensitive topic to explore, but it was an issue of particular concern for the six participants, some of whom had direct personal concerns with family members around cancer. There are few people with intellectual disabilities who successfully access bowel cancer screening programmes, and by working in co-production with members of this population who we particularly wanted to include, helped the research team to better understand effective ways of making the process more accessible and the inherent information more meaningful. If we see the people we are concerned about as being central to the solutions to these challenges, we are more likely to be able to address these challenges more effectively. Working in this way also helped to identify principles of good research practice when working with people with intellectual disabilities (see Table 1.), with the objective of submitting a research proposal around bowel cancer screening.

Table1. Principles for good research practice

- Co-production is the essence of developing good processes and can be the the focus of research (holistic, equality of skills, working together for mutual benefits)
- Engage with people who matter
- Clear, timely, appropriate information and communication is crucial to engagement
- Face to face discussions promote reciprocal learning
- Support remains crucial throughout

- Understanding your own health is important for everyone
- Planning is important: venue, environment, comfortable, safe, familiar

Whilst these principles will help to inform good research practice around marginalized groups generally, the need for an empirically tested, evidence base around the use of co-production, in particular involving people with an intellectual disability, remains important. The poor uptake of bowel cancer screening for this population remains problematic, but working alongside people with intellectual disabilities may help researchers to articulate their concerns more strongly and inform future research proposals in a meaningful way.

Conclusion

On reflection, this consultation group discussion was not only informative, educative and helped in shaping up and informing the development of a research proposal around a very sensitive topic area, it was also hugely enjoyable. Working in co-production proved mutually beneficial, as local clinicians also learned how to communicate better with a relatively unfamiliar population-people with ID. Bringing people with intellectual disabilities, clinical partners, advocates and researchers together in this way helps to overtly promote understanding and strengthen potential research proposals, ensuring that research remains firmly grounded in the reality of practice.

People with an ID have valuable contributions to make across the whole research continuum, and working in co-production is a constructive method of engagement that values all parties and the contributions that everyone makes, particularly in the palliative care context. The conclusion culminated in three recommendations:

1. Clear information about screening for bowel cancer, using clear words and pictures, films and audio information, is fundamentally important for people with an intellectual disability.
2. More opportunities to find out about health screening, at college, the library and through educational opportunities should be available to people with an intellectual disability.
3. Support should be accessible and available, e.g. hospital staff who could explain processes and tests; support from Macmillan Nurses if appropriate.

References

Anwar, S. Hall, C. and Elder, J. B. (1998) 'Screening for colorectal cancer: present, past and future', *European Journal of Surgical Oncology*, vol. 24, pp. 477 – 486.

Beaver, K., Luker, K. & Woods, S. (1999). Conducting research with the terminally ill: Challenges and considerations. *International Journal of Palliative Nursing*, 5 (1), 13-17.

Blalock, S. J., DeVellis, B. M., Afifi, R. A. and Sadler, R. S. (1990) 'Risk perceptions and participation in colorectal cancer screening', *Health Psychology*, vol. 9, no. 6, pp. 792 – 806.

Boolchand, V., OIDs, G., Singh, P., Chak, A. and Cooper, G. S. (2006) 'Colorectal screening after polypectomy: a national survey study of primary care physicians', *Annals of Internal Medicine*, vol. 145, no. 9, pp. 654 – 659.

Borum, M. L. (2001) 'Colorectal cancer screening', *Primary Care*, vol. 28, pp. 661 – 674.

Cancer Research UK, (2006) UK bowel cancer statistics.
<http://info.cancerresearchuk.org/cancerstats/types/bowel> [last accessed 1st May 2010]

Cancer Research UK, (2011) UK bowel cancer statistics.
<http://info.cancerresearchuk.org/cancerstats/types/bowel> [last accessed 1st May 2014]

Chapple, A., Ziebland, S., Hewitson, P and McPherson, A. (2008) 'What affects the uptake of screening for bowel cancer using a faecal occult blood test (FOBT): A qualitative study', *Social Science and Medicine*, vol. 66, pp. 2425 – 2435.

Corcoran, P. (2014). Advocacy, communication & empowerment. IN: S. Read (2014). (edit). *Supporting people with intellectual disabilities experiencing loss and bereavement: Theory and compassionate practice*. London: Jessica Kinsley Publ.

Department of Health,(DH) (1999) *White Paper: Our Healthier Nation: Saving Lives*, London, Department of Health.

DH (2000) *The NHS Cancer Plan*, London, The Stationery Office.

DH (2001). *Valuing people: A new strategy for intellectual disability for the 21st century*. London: Department of Health.

Emerson, E. and Baines, S. (2010) *Health Inequalities & People with Intellectual Disabilities in the UK: 2010*.
http://www.improvinghealthandlives.org.uk/uploads/doc/vID_7479_IHaL2010-3HealthInequality2010.pdf

Fedele, D. J., Jones, J. A. and Niessen, L. C. (1991) 'Oral cancer screening in the eIDerly', *Journal of American Geriatric Society*, vol. 39, pp. 920 – 925.

Ferroni, E., Camilloni, L., Jimenez, B., Furnari, G., Borgia, P., Guasticchi, G., Giorgi, R.P. (2012). How to increase uptake in oncologic screening: a systematic review of studies comparing population-based screening programs and spontaneous access. *Prev. Med*, 55, 587-96.

Hardy, R. G., Meltzer, S. J. and Jankowski, J. A. (2000) 'ABS of colorectal cancer, Molecule basis for risk factors', *British Medical Journal*, vol. 321, pp. 886 – 889.

Heslop, P. Blair, P., Fleming, P. Hoghton, M. Marriott, A., & Russ, L. (2013). *Confidential Inquiry into premature deaths of people with intellectual disabilities (CIPOOD)*. Bristol: Norah Fry Research Centre.

Hewitson, P., Glasziou, P. P., Irwig, L., Towler, B. and Watson, E. (2007) 'Screening for colorectal cancer using the faecal occult blood test, hemocult'. *Cochrane Database of Systemic Reviews*, no. 1 CDOO1216.

Jackman, R. and Mayo, C. W. (1951) 'The adenoma – carcinoma sequence in cancer of the colon', *Surgical Gynaecology and Obstetrics*, vol. 93, pp. 327 – 330.

Jackson, S. & Read, S. (2008). ProviDing appropriate health care for people with intellectual disabilities. *British Journal of Nursing*, 17(4), 6-10.

James, A. S., Campbell, M. K. and Hudson, M. A. (2002) 'Perceived barriers and beliefs to colon cancer screening among African Americans in North Carolina: how does perception relate to screening behaviour?' *Cancer Epidemiology*, vol. 11, no. 4, pp. 529 – 534.

Jansen, D., Krol, B., Groothoof, J & Post, D. (2004) People with Intellectual disabilities and their health problems: a review of comparative studies. *Journal of Intellectual Disability Research*, 48, 93-102.

Keighley, M. R., Morain, C. Giacosa, A. et al (2004) 'Public awareness of risk factors and screening for colorectal cancer in Europe', *European Journal of Cancer Prevention*, vol. 13, no. 4, pp. 257 – 262.

Kronborg, O. (2003) 'Screening for colorectal cancer', *Scandinavian Journal of Surgery*, vol. 92, pp. 20 - 24.

Kronborg, O., Fenger, C., Olsen, J., Jorgensen, O. D. and Sondergaard, O. (1996) 'Randomised study of screening for colorectal cancer with faecal-occult blood test', *Lancet*, vol. 348, pp. 2467 – 1471.

Lieberman, D. (1994) 'Colon cancer screening: beyond efficacy', *Gastroenterology*, vol. 106, pp. 803 – 812.

Levin, B., Lieberman, D. A., McFarland, B. et al (2008) 'Screening and surveillance for the early detection of colorectal cancer and adenomatous polyps: joint guidelines from the American Cancer Society, the US Multi-Society Task Force on Colorectal cancer, and the American College of Radiology', *CA: A Cancer Journal for Clinicians*, 58, (3), 130 – 160.

Lin, J.-D., Wu, J.-L. & Lee, P.-N. (2003), Healthcare needs of people with intellectual disability in institutions in Taiwan: outpatient care utilization and implications. *Journal of Intellectual Disability Research*, 47, 169–180. doi: 10.1046/j.1365-2788.2003.00454.x

McCaffery, K., Wardle, J. and Waller, J. (2003) 'Knowledge, attitudes, and behavioural intentions in relation to the early detection of colorectal cancer in the United Kingdom', *Preventative Medicine*, 36, 525 – 535.

McGovern, P. M., Gross, C. R., Krueger, R. A., Engelhard, D. A. Cordes, J. E. and Church, T. R. (2004) 'False-Positive Cancer Screens and Health-Related Quality of Life', *Cancer Nursing*, 27 (5), 347 – 352.

Mencap (2004). *Treat me right! Campaign report calling for better healthcare for people with a learning disability*. London: Mencap.

Mencap (2007). *Death by indifference: Report about institutional discrimination within the NHS, and people with a learning disability getting poor healthcare*. London: Mencap.

Mencap (2012). *Death by indifference: 74 deaths and counting...* London: Mencap.

MORI, (2009) *Qualitative evaluation of people's experiences towards bowel cancer screening: a research study conducted for 'Ashtby on the Vale' Primary Care Trust, Ashtby on the Vale, MORI*.

Muto, T., Bussey, H. J. and Morson, B. C. (1975) 'The evolution of cancer of the colon and rectum, cancer', vol. 36, pp. 2251 – 2270.

Navon, L. (1999) 'Cultural views of cancer around the world', *Cancer Nursing*, 22,(1),39 – 45.

O'Sullivan, I. and Orbell, S. (2004) 'Self-sampling in screening to reduce mortality from colorectal cancer: a qualitative exploration of the decision to complete a faecal occult blood test (FOBT)', *Journal of Medical Screening*, 11, 16 – 22.

Osborn DPJ, Horsfall L, Hassiotis A, Petersen I, Walters K, et al. (2012) Access to Cancer Screening in People with Learning Disabilities in the UK: Cohort Study in the Health Improvement Network, a Primary Care Research Database. *PLoS ONE*, 7, e43841. doi:10.1371/journal.pone.0043841

Parente, F., Marino, B. and Crosta, C. (2009) 'Bowel preparation before colonoscopy in the era of mass screening for colorectal cancer', *Digestive and Liver Disease*, 41, 77 – 95.

Peipins, L. A. and Sandler, R. S (1994) 'Epidemiology of colorectal adenomas', *Epidemiology Review*, 16,(2), 273 – 297.

Quarini, C. and Gosney, M. (2009) 'Review of the evidence for a colorectal cancer screening programme in the elderly', *Age and Aging*, 38, 503 – 508.

Read, S. & Latham, D. (2009) Bowel cancer screening: Involving people with learning disabilities. *Journal of Gastrointestinal Nursing*, 7 (7), 10-16.

Read, S, Corcoran, P. & Jackson, S. (2011). Making a difference for people with a learning disability: Working in partnership to develop a bespoke Toolkit for health. *Journal of Intellectual Disability Practice*, 14(4), 12-16.

Read, S & Rushton, A. (2012). Cultivating understanding of health issues for adults with intellectual disability. *Nurse Education Today*. . <http://dx.doi.org/10.1016/j.nedt.2012.03.013>

Robinson, G. E., Roen, B. P. and Bradley, L. N. (1997) 'Psychological impact of screening for familial ovarian cancer: reactions to initial assessment', *Gynaecological Oncology*, 65, 197 – 205.

Towler, B., Irwig, L., Glaziou, P., Kewenter, J., Weller, D and Silagy, C (1998) ‘A systematic review of the effects of screening for colorectal cancer using the faecal occult bleed test, hemoccult’, *British Medical Journal*, 317, 559 – 565.

Vaughn, LM, Jacques, F., Zhao, J. Lang, M. (2011). Partnering with students to explore the health needs of an ethnically diverse, low-resource school: an innovative large group assessment approach. *Fam. Comm. Health*, 34(1), 72-84.

Vernon, S. W. (1997) ‘Participation in colorectal cancer screening: a review’, *Journal of the National Cancer Institute*, 89, 1406 – 1422.

Wagner, J. L., Herdman, R. C. and Wadhwa, S. (1991) ‘Cost-effectiveness of colorectal cancer screening in the eIDerly’, *Annals of Internal Medicine*, 115, 807 – 17.

West, N. J., Poullis, A. P. and Leicester, R. J. (2007) ‘The NHS Bowel Cancer Screening Programme – a realistic approach with additional benefits’, *Colorectal Disease*, 10, 708 - 714.

Wild, S. H., Fishbacher, C. M., Brock, A., Griffiths, C. and Bhopal, R. (2006) ‘Mortality from all cancers and lung, colorectal, breast and prostate cancer by country of birth in England and Wales, 2001 – 2003’, *British Journal of Cancer*, 94, 1079 – 1085.

Winawer, S. J. (1999) ‘Natural history of colorectal cancer’, *American Journal of Medicine*, 106, 3S – 6S.

Winawer, S. J., Zauber, A. G., Ho, M. N., O’Brien, M. J., Gottlieb, L. S. and Sternberg, S. S. (1993) ‘Prevention of colorectal cancer by colonoscopic polypectomy’, *New England Medicine*, 239, 1977 – 1981.

Dawson D (2011) How to make information on health care accessible to all Learning Disability Practice may, Vol 14, No 4.

Disability Rights commission (2006) Equal treatment: Closing the Gap- A formal investigation into Physical Health Inequalities Experienced by people with Learning Disabilities and/or mental Health Problems DRC, Stratford upon Avon.

Department of Health (2004) Valuing people: Moving forward together. The government's annual report on Learning disability 2004 DH London.

Emerson E, Hatton C (2008) people with Learning Disabilities in England. Centre for Disability research, Lancaster.

Hanna L, Taggart L, Cousins W (2001) Cancer prevention and health promotion for people with intellectual disabilities: an exploratory study of staff knowledge. *Journal of Intellectual Disability Research* 52,12, pp1061-1077

Howelson J, Clarke K Ensuring service users can access crucial information. *Learning disability practice* 16.1 (Feb 2013) 22-25

Realpe, A and Wallace, L.M., (2010). *What Is Co-production?* London: The Health Foundation.

Rees G (2011) Increasing Access to cancer screening programmes *Learning Disability practice* Sept 2011, Vol 14, No7

Tuffrey-Wijne I, Bernal J, Hubert J et al (2009) people with learning disabilities who have cancer: an ethnographic study. *British Journal of General Practice* 59, 564, pp503-509

Figures & Tables

Insert Figure 1. How we worked together



Figure 2. What would help

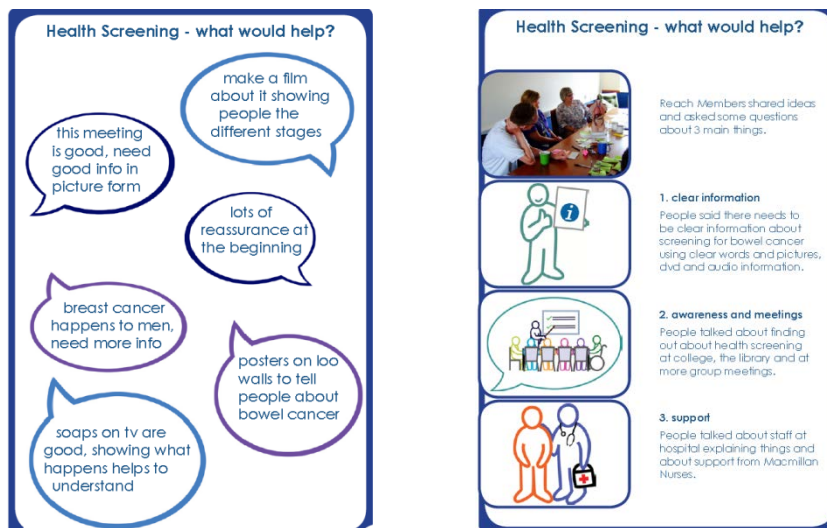


Table 1 . Principles for good research practice

- Co-production is the essence of developing good processes and can be the the focus of research (holistic, equality of skills, working together for mutual benefits)

- Engage with people who matter
- Clear, timely, appropriate information and communication is crucial to engagement
- Face to face discussions promote reciprocal learning
- Support remains crucial throughout
- Understanding your own health is important for everyone
- Planning is important: venue, environment, comfortable, safe, familiar