PRIORITY BRIEFING

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. This paper was compiled in 2-3 days.

How can the uptake of cervical screening be improved among women with learning disabilities?

Question ID: 3

Question type: Intervention

Question: How can the uptake of cervical screening be improved among women with learning disabilities?

Population: women with learning disabilities (on the GP register), aged 25-64, who have not had a total hysterectomy (i.e. cervix is intact)

Intervention: to develop with key partners (learning disability liaison nurse, screening managers, laboratory staff and women with learning disabilities) an intervention that contains the following components:

1) specific screening pathway

2) centralized cervical screening database for women with learning disabilities

3) provision of Easy Read letters

4) standardized approach to improving screening uptake

Control: current practice, which is sending out invitation letters and results, and adhoc support from learning disability liaison nurses

Outcome: correlation of different configurations of the elements of the intervention package (nurse support, 'Easy Read' letters etc.) with outcomes such as:

i) change in uptake of cervical screening

ii) acceptability of the intervention

iii) patient and health care provider satisfaction

iv) cost

*Please note that the details included in the box are from the original submission and have been edited where necessary for clarity and precision

Cervical screening: A screening system to prevent cervical cancer, where non-cancerous cellular changes in the cervix are identified and treated before those cells can become cancerous. The screening is examination of the Papanicolaou smear (Pap smear), where cells are gathered from the outer opening of the cervix as well as a narrow area in the cervical cavity. The test aims to detect potentially pre-cancerous changes in the cells (called cervical intraepithelial neoplasia (CIN) or

cervical dysplasia). CIN occurs in the cells which comprise the outermost surface of the cervix (the epithelium). The three grades of CIN refer to how deeply abnormal cells are found within the epithelium. Cervical cancer involves abnormal cells being present throughout and beyond the epithelium.

The population screening programme involves processes for call and recall of women for Pap tests, and the management of CIN. The management of low grade CIN grades requires early recall for further testing and for colposcopy (direct visualisation of the cervix for examination and biopsy of potentially suspicious areas).

Infection with human papilloma virus has been recognised as a risk factor for the development of cervical dysplasia and this has led to the recent implementation of a vaccination programme which it is expected, over time, will reduce the risk of cervical cancer.

Screening is recommended for all eligible women (except those fulfilling exclusion criteria such as not having a cervix) once every 3 years for ages 25-49, and once every 5 years for ages 50-64. However, there have been variations in screening cycle lengths in different parts of the country.

Learning disability (LD): Defining learning disability is difficult and a universal consensus on the definition of the term is not yet available. In the UK, a definition described by the Department of Health in 2001 is commonly used:

- significantly reduced ability to understand new or complex information, or to learn new skills (impaired intelligence), with;
- reduced ability to cope independently (impaired social functioning),
- which started before adulthood, with a lasting effect on development.

This definition includes people with a broad range of disabilities and/or medical conditions. It also implies that low intelligence levels alone, such as the presence of a low intelligence quotient (e.g. an IQ below 70), does not necessarily mean that someone has a learning disability.

The Health Problem:

Cervical cancer:

Cervical cancer is the 11th most common cancer among women in the UK, with 2 out of 100 cancers in women being cervical cancer. However it is the most common cancer among women under 35 years old.

Cancer Research UK reports that the incidence and mortality rates for cervical cancer in England have fallen considerably over the past 20 years (1988-2008), coinciding with the establishment of the UK Cervical Screening Programme in 1988, but this reduction has plateaued in recent years. In 2008, there were 2,369 new cases of cervical cancer identified in England (corresponding to an age standardised incidence rate of 8.3 per 100,000), and there were 753 cancer-related deaths, an age standardized mortality rate of 2.2 per 100,000).

The South West Cancer Observatory reports that the incidence rates of cervical cancer and mortality in the South West are slightly lower than national rates.

Age-specific incidence of cervical cancer peaks among women in their early 30s. Following a gradual reduction in the rate in women in their 40s, rates then rise again in women in their 70s and early 80s.

As for prevalence, it is estimated that the number of women with cervical cancer in the UK in 2006 was around 19,000.

Cervical screening:

The NHS Cervical Screening Programme Statistical Bulletin (2009-2010) reports that 79.3% of almost 1.3 million eligible women aged 25 to 64 in the South West were screened. In Devon and Cornwall, rates were 80.6% and 78.4% respectively. The NHS target is 80% of women aged 25-64 will have been screened at least once in the last five years.

Throughout the UK, coverage of screening has shown a downward trend in younger women. By 2008, the coverage rate for women aged 25-29 had fallen to 59% from a level of 67% in 1995. This compares with a rate of 69% in women aged 25-49 years (those called for screening every 3-3.5 years) and 80% in women aged 50-64 years (those called for screening every 5 years), in 2008.

Learning disability:

At present, there are no official statistics on the prevalence of people with learning disabilities in the UK. Consequently, estimates vary substantially, depending on data sources and definitions of LD used. Estimates range from 0.23% to 3% of the UK population, with 2.5% to 3% being most commonly quoted across sources. These estimates suggest that a total of between around 600,000 to 1.2 million people in the UK have LD. The estimate of 1.2 million people with LD is further divided into 300,000 children and 900,000 adults. In the South West, there are an estimated 125,000 people with learning disability.

The numbers of people with moderate to profound learning disabilities can be estimated with more accuracy, as almost all use public services of some kind. They are thought to represent 0.35% of the total UK population, or about 210,700 people.

Various government and academic policy and research works have reported that people with learning disabilities have significantly higher rates of mortality and morbidity than the rest of the population, a significant proportion of which is avoidable. The rights of people with learning disability are protected by legislation, principally the Disability Discrimination Act 1995 which requires public services to work to actively reduce discrimination and inequities of access.

Cervical screening among those with learning disabilities:

A number of studies based on data obtained from primary care and screening records have shown a low uptake of cervical screening in women with learning disabilities (LD), ranging between 13% and 25%. Furthermore, a survey carried out by MENCAP in 2000 revealed that out of 560 women with LD aged 20 -70 years,

only 25% had ever had a cervical smear. In two of the primary care and screening programme based studies, around a third of women's GPs had instructed that they should not be screened. In the MENCAP study this applied to 75%.

Cornwall and Isles of Scilly PCT have reported, in a Health Equity Audit carried out since 2008, that screening uptake in women with learning disabilities is about 30%.

Guidelines:

The NHS and other organisations have produced various reports and guidelines concerning cervical screening for learning disabled women, especially since the NHS's 2001 report "Valuing People" on improving the health and well-being of people with intellectual disabilities.

These include:

- NHS Cancer Screening Programme's 2006 guideline "Good Practice in Breast and Cervical Screening for Women with Learning Disabilities"
- The Royal College of General Practitioners' 2010 guidelines on the provision of annual health checks for women with LD,
- and the Learning Disabilities Observatory's 2011 report "Reasonable Adjustments for People with Learning Disabilities".

These documents acknowledge the complexity of the issue of cervical screening for women with learning disabilities, which is a subject of professional, ethical and legal concern.

A major issue is concerning consent for screening by women with learning disabilities and the exclusion of women with learning disabilities from the NHS's Cervical Screening Programme. These documents stress that seeking consent is part of a respectful relationship with people with learning disabilities, and should usually be seen as a process, not a one-off event. The basic principle is that it must be assumed that every adult has the capacity to consent until proven otherwise. As such, it is not acceptable to exclude a learning-disabled woman from the screening programme without her informed consent. This decision should also not be based on assumptions by the GP or a carer/supporter about the woman's history of sexual activity.

In fact these documents assert that a parent or carer cannot make decisions on behalf of an adult woman. The learning disabled woman should be assisted, and all practicable steps should be taken, to help the person make an informed choice. She could choose not to undergo screening but should still be kept on the register and invitations issued at appropriate intervals.

Having said that, the documents also describe the steps that need to be taken when a health care provider makes an assessment that a woman with a learning disability does not have the capacity to consent. How the assessment is made, and the subsequent steps to be taken, are complex and differ on the specific nature of a particular case. These actions might include stopping the screening procedure and issuing another invitation for screening at the next appropriate interval (while ensuring that the woman is kept in the recall programme). Also, the health care

provider might assess whether there exists in a particular case legal instructions, such as ‘advanced directive’ or ‘lasting power of attorney or deputy’, where the health care professional needs to seek legal advice. If no such legal instructions exist, the health care provider might convene a ‘best interests meeting’ which will, together with close family members or carers, and following the guidelines on the conduct of this meeting, decide on the next course of action.

These guidelines also recommend certain strategies to increase the uptake of screening in women with learning disabilities, such as:

- Have a policy on accessible information and review coverage and use on a regular basis.
    - large print
    - audio files
- Facilitate women with LD in making and attending appointments
    - ensure that women with learning disabilities are easily identified in records systems
    - Easy Read appointment letters
    - reminder phone calls or texts
- Ensure they have the time and support they need to make their decision (unless the urgency of their condition prevents this).
- Work in partnership with and promote the involvement of family carers in the healthcare of people with learning disabilities (e.g. planning together visits to the health care facility). Where applicable, increase resources that take account of the additional support needs of people with learning disabilities.
- Continuously monitor how well the Mental Capacity Act 2005 is being implemented
    - accessibility of information on relevant Acts
    - staff knowledge and behaviour
    - training
    - audits
- Develop clear and widely used protocols for service delivery

NHS Priority:

Regional

The South West SHA Priorities framework 2008-11 records ‘learning disability’ and ‘staying healthy’ as two of the nine priority areas.

The framework document explicitly states that “people with a learning disability will have the same access to screening services as everyone else. Screening rates for breast and cervical cancer will be increased year-on-year, towards the same uptake rate as the general population of 80% by 2013”

Local

In the 2010 South West Peninsula Primary Care Trust Priorities document, Cornwall PCT has identified reducing cancer mortality and morbidity as a priority, and Plymouth PCT has identified learning disabilities as a priority.

Existing Research:

Published research

Our searches found no studies assessing the effectiveness of the suggested intervention components to enable improved access to cervical screening, i.e.

i) A specific screening pathway,
ii) A centralised cervical screening database or
iii) Easy Read letters

We identified a Cochrane systematic review assessing the effectiveness of interventions to encourage the uptake of cervical screening[1], though this was not specific to women with learning or other disabilities.

The review found 27 randomised controlled trials (RCT) and eight quasi-RCTs that were eligible for review. The review found that the studies conducted the following interventions to encourage cervical screening uptake: invitations, reminders, education, message framing, counselling, risk factor assessment, procedures and economic interventions.

The review found that, in general, invitation letters were effective at encouraging women to attend for Pap smear screening. There was also limited evidence that telephone invitations increased uptake, but it was unclear whether this practice was more effective than invitation letters. It was also unclear as to whether sending invitation letters with appointments was any more effective than sending invitation letters alone. However, there was some evidence to suggest that invitation letters with fixed appointments were more effective than invitations with open appointments. Sending letters from GPs appeared to be more effective than sending them out from other authorities. The review did not comment on finding anything regarding 'Easy Read' or other similar invitation letters.

This review also identified the accuracy of population registers as a key factor in uptake of cervical screening. It found that study participants were being lost to follow-up or not receiving the intervention due to incorrect contact details.

The review reports that there was insufficient evidence in the form of statistically significant findings from good quality trials to support any particular educational intervention as a means to increase cervical screening uptake, but overall the consensus from the studies examining educational interventions was in favour patient education over the 'no intervention'/'usual care' control.

The review did not find any studies on the effectiveness of specific 'screening pathways' in increasing cervical screening uptake.

The review noted that the studies that looked at the other interventions were often either limited in number, were of questionable validity, or both.

Ongoing research

Searches in BioMed Central's Current Controlled Trials, the International Standard Randomised Controlled Trial Number registry, the US clinicaltrials.gov, and the

World Health Organisation's International Clinical Trials Registry Platform did not reveal any ongoing research evaluating methods to increase screening uptake among women with learning disabilities.

Feasibility:

The project is supported by the multi-agency Cornwall and Isles of Scilly Cervical Screening Working Party, a group which oversees the performance management and governance of the screening programme in this area.

The project also has support from the Regional Lead for Screening at the SW SHA.

References:

1. Forbes, C. A., R. G. Jepson and P. P. Martin-Hirsch (2002). Interventions targeted at women to encourage the uptake of cervical screening. Cochrane Database of Systematic Reviews. 3.

AB: BACKGROUND: Cervical cancer is the third most common cancer world-wide. Increasing the uptake of screening, alongside increasing informed choice is of great importance in controlling this disease through prevention and early detection. OBJECTIVES: To assess the effectiveness of interventions aimed at increasing uptake, and informed uptake of cervical cancer screening. SEARCH STRATEGY: Twenty-three electronic databases (to March 2000) were searched with no language restrictions. SELECTION CRITERIA: Randomised controlled trials (RCTs), or quasi-RCTs of interventions to increase uptake/informed uptake of cervical cancer screening. DATA COLLECTION AND ANALYSIS: Data on study characteristics and quality were extracted independently by two reviewers. Where data were available, relative risks and 95% CI were calculated and a chi-squared test for heterogeneity was performed. MAIN RESULTS: Thirty-five studies were included (27 RCTs and eight quasi-RCTs). Heterogeneity between studies limited statistical pooling of data. Overall, however, invitations appear to be effective methods of increasing uptake. In addition, there is limited evidence to support the use of educational materials. The number and quality of included studies limited evidence regarding effectiveness of other interventions. Informed uptake of cervical screening was not considered by any studies. AUTHORS' CONCLUSIONS: There was some evidence to support the use of invitation letters to increase the uptake of cervical screening. There was limited evidence to support educational interventions but it was unclear what format was most effective. The majority of the studies were from developed countries and so the relevance to developing countries is unclear. Invitations and probably educational interventions increase the uptake of pap smears: Methods of encouraging women to undergo cervical screening - invitations, reminders, education, message framing, counselling, risk factor assessment, procedures and economic interventions were looked at in this review. Evidence supports the use of invitations, and to a lesser extent, educational materials. It is likely other methods are advantageous, but the evidence is not as strong. Further research is required.