

○ Improving Patients' Experience Sharing Good Practice

No.12 IMPROVING THE EXPERIENCE OF HEALTHCARE
SCREENING FOR PATIENTS WITH LEARNING DISABILITIES

While routine and undaunting for many women, breast and cervical screening for those with a learning disability can be a bewildering and confusing experience. Breast Test Wales and Cervical Screening Wales, who fall under Screening Services at Velindre NHS Trust in Wales, set out to tackle the issue together as part of the Patients Accelerating Change programme.

Earlier Initiatives

Work had been carried out previously in 2002/3 to help women with a learning disability understand the screening process, its purpose and what to expect. As part of an 'all Wales' training initiative, all primary care teams were issued with picture books and leaflets on breast and cervical screening. A resource pack was also developed to assist teams in their delivery of information.

Local procedures were adopted for breast screening to offer an extended appointment at the nearest static centre as well as a pre-visit appointment, if desired. This provided more time for discussion and the opportunity to visit the clinic in advance to help patients familiarise themselves with the staff, equipment and surroundings.

Despite these changes to the service a needs assessment in 2005 identified potential for further improvement, in particular for clearer, more comprehensive resources.

What was needed?

A workshop held with women with varying degrees of learning difficulties demonstrated a wide range of comprehension levels about breast and cervical screening. Terms and topics that healthcare professionals assume are understood by most women – such as 'scan' or 'test' – are often poorly comprehended by those with a learning disability. Unsure of what to expect, patients can then feel vulnerable, uncertain or scared during their screening journey.

Appointed as project leads Heather Ramessur-Marsden, Screening Promotion Officer for Breast Test Wales, and Linda Hughes, Nurse Co-ordinator for Cervical Screening Wales, worked with two learning disability nurses from North East Wales NHS Trust Learning Disability Teams with a particular interest in sexual health.

The project team developed a resource package for learning disability nurses to use to support women through the screening process.

What did they achieve?

- Introduced a new resource pack for learning disability nurses.
- Greater understanding and awareness of both disability issues and patient-centred practice.
- A model for sharing information on a range of screening programmes with people with learning disabilities and other special needs groups.

The health education package they developed included:

- a teaching pack illustrating the screening process or 'journey' for both services
- a professional pack specifically designed for the health professionals to enhance their knowledge base
- care pathways to assist teams in assessing and achieving informed consent
- checklists enabling nurses to see at a glance if they have covered the necessary explanations
- visual aids which included a tool kit for cervical screening demonstrating the equipment to be used.

A pilot study to determine the effectiveness of the teaching package was conducted over a six month period with North Wales Learning Disability Teams.

The contents of the packs

The information breaks down screening processes into small manageable sections. They cover all aspects of the process from invitation through to pre-visits, actual appointments and the results process. The language has been simplified and the pictures now used are real images, not animated cartoons.



The packs are designed to be used as a guide, rather than verbatim as some patients may need the text to be simplified further. The delivery of the information is also dependent on the expertise and experience of the learning disability health professionals.

In conjunction with the teaching pack, a professional pack was developed in CD Rom format for the learning disability nurses. This pack allows nurses, who may have limited knowledge about either screening process, to access up-to-date information and enhance their own knowledge prior to delivering information.

Both packs were developed in a power point™ format, for use when doing group work, as well as a book, for use on a one-to-one basis. In addition, for the cervical screening pack, a small 'tool kit' was made up of equipment involved when taking a smear test, such as a speculum, samplers and the smear test request form.

It is proposed that this package is made available as a web-based resource to make it easier to update, while still allowing users freedom to choose their preferred format and method of delivery.

Challenging and changing thinking

Implicit in the development of the materials was the need to think from the perspective of this particular group of women. Language – both written and verbal – pictures, symbols and other communication methods all had to be simpler than originally anticipated.

Finding ways to represent concepts that for many people are straightforward was a challenging process and one which required staff to think more laterally, more creatively and with more empathy.

Running a workshop with colleagues gave Heather and Linda an opportunity to put this into practice. They gave their

Managing the project

Heather and Linda's project followed the Patients Accelerating Change programme developed by the Picker Institute and the NHS Clinical Governance Support Team. Tailoring the programme concept to their own needs, they followed the recommended RAID model (Review, Agree, Implement, Demonstrate) of project management. They found the programme provided a clear structure to their project and enabled them to keep the work clearly focused. For more information visit the Quality Improvement section of the Picker Institute website at www.pickereurope.org

colleagues an exercise to find alternatives to common words, such as 'breast', 'cervix' and 'screening', which would be better understood by women with a learning disability. This highlighted the complexity of the issues the project was tackling.

Similarly, when reporting on the progress of the project, Heather and Linda required managers to appreciate the communication difficulties involved and view the solution directly from the patients' perspective.

Both Linda and Heather report that the project has in turn helped them to reassess their own ways of working to ensure they are more patient-centred, whether that be from the perspective of a patient with a learning disability or from patients more generally.

What's next?

Feedback on the project has been very positive. There does not appear to be a comparable resource currently available and interest in the package has been high.

The final project report makes several recommendations to develop the teaching packs fully and then to roll out training to all Learning Disability Teams in Wales.

Other areas have also been identified where the work could be extended. For example, those patients whose initial screening results require follow-up assessment at a breast assessment clinic or a colposcopy clinic could benefit from similar resources.

The format of the package could be adapted as a template for other types of screening programmes, such as bowel

and prostate. It might also be used for other groups of patients with special needs, such as those with hearing or sight impairments, or those from ethnic minority groups.

For further information, contact: **Heather Ramessur-Marsden** at heather.ramessur-marsden@velindre-tr.wales.nhs.uk or **Linda Hughes** at Linda.hughes2@cswmold.wales.nhs.uk

Useful tips for improving communication with patients with learning difficulties

- Keep it simple – do not overestimate the level of understanding that patients may have. If necessary, provide supplementary information to ensure that those with greater levels of comprehension are not left feeling patronised or dissatisfied.
- Do not underestimate the importance of good communication for any patient, with special needs or not.
- Information and understanding is a key element to ensuring a patient's experience of screening is positive and supportive.
- Good communication is about tailoring both content and language to make it accessible for the recipient to understand.
- Share expertise – colleagues may have other knowledge, alternative approaches and ways of working from which you could learn.

Sharing good practice

If you would like to receive *Improving Patients' Experience* or you would like to share examples of good practice please contact:

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