

Information leaflets in medical screening

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In this issue of the *Journal*, we publish a paper demonstrating that women invited for breast cancer screening in Britain are poorly informed about what the screening test involves and how screening will alter their risk of developing invasive breast cancer or dying of the disease.¹ The paper focuses on ductal carcinoma *in situ*, but it illustrates a general problem over what people need to know before participating in any specific screening programme. Information leaflets are important, and care needs to be taken in preparing them. Of course, information leaflets should supplement oral information, not replace it.²

Some of the information leaflets produced nationally in Britain illustrate the problem. For example, the leaflet on antenatal screening for Down's syndrome³ does not specify the tests available and their screening efficacy. Parents offered neonatal screening for cystic fibrosis for their children are not told that we do not know whether it prolongs life; indeed, the leaflet implies that it does.⁴ The specific benefits of neonatal screening for and early detection of hearing loss are implied rather than made explicit. There is often no information provided on screening for congenital dislocation of the hip; mothers are simply asked if someone can examine their baby. The national leaflet on breast cancer screening does not specify the extent to which screening reduces the chance of a woman dying of breast cancer.⁵

Some medical screening is so non-specific that it is described in terms of the technology used rather than the disorder that is being screened for (e.g. ultrasound screening in pregnancy), and usually little or no information on benefit is provided in these cases.

Most people who participate in a screening programme take its value on trust and expect to be given the 'all clear'. Unfortunately, a screen negative result in most screening programmes does not rule out the disorder being screened for, and this should be made clear.

Information leaflets are best produced locally. The variation in style and content is helpful. Professionals can learn from each other by comparing leaflets and then revising their own if necessary. Variation should therefore not be regarded as a disadvantage. The leaflet should give a dedicated telephone number so that people can speak to a member of the screening team who is able to answer questions confidently and accurately, and who is familiar with the details of the local service. The process of producing an information leaflet on a screening programme helps to clarify the specification of the programme and what can be expected from it both procedurally and in terms of health outcomes. This helps to engage members of a particular screening team in the process – an educational benefit in itself. The understanding this fosters encourages confidence and a sense of ownership in the programme. This improves its quality and its appreciation by those who participate in the programme.

A checklist of what needs to be considered in assessing the value of a screening test has been published.⁶ This sets out what needs to be known before a screening test is introduced, but it may also be useful in drafting what the public need to know once it has been introduced.

The leaflet should provide information that individuals who are considering whether they wish to be screened *need* to know, so that they can make a fair decision. Providing details on what they *want* to know is necessary but secondary. The leaflet should be quantitative and precise rather than general (e.g. 'one in six', not 'some'). The text should be clear (easier said than done!) and simple, but not too simple. The following six items are probably needed in most leaflets on screening:

- The medical disorder being screened for, specifying the disorder in terms of the adverse health outcome that matters (e.g. stroke, not hypertension), and including background information, for example on how common and serious the disorder is.
- The screening test: what is it, how is it done, whether it is painful or dangerous, the percentage of cases that are detected, and the percentage of unaffected individuals who will have positive results.
- The next steps: what happens if the screening test is positive (another screening test, a diagnostic test or direct preventive action).
- The health gain from screening in terms of the reduction in the risk of the specified medical disorder (e.g. breast cancer deaths, not that mammography detects most breast cancers).
- The adverse effects of screening.
- The phone number of the local helpline.

Attention to these items will provide the basis for screening leaflets. If they cannot be specified, it will usually call into question what is done and why.

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- 2 Smith AJ. Information leaflets. *J Med Screen* 1995;2:3-4
- 3 <http://www.library.nhs.uk/screening/View-Resource.aspx?resID=60290&tabID=288> (last accessed 22 May 2006)
- 4 www.ich.ucl.ac.uk/newborn/download/leaflet/newborn_bloodspot_screening_english.pdf (last accessed 25 May 2006)
- 5 <http://www.cancerscreening.nhs.uk/breastscreen/publications/ia-02.html> (last accessed 6 June 2006)
- 6 Wald N, Cuckle H. Reporting the assessment of screening and diagnostic tests. *Br J Obstet Gynaecol* 1989;96:389-96