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We are living in a world that is beyond controllability.

Ulrich Beck

OUTLINE

We consider two forms of disease prevention available within health care systems: screening and immunization. These programmes are premised on the basis of controlling risk. Screening programmes are designed to identify individuals who, because of certain personal characteristics, are considered at risk of developing a certain disease. Immunization programmes are designed to vaccinate people who are at risk because of their exposure to environmental pathogens. Various social and psychological processes are involved in explaining these processes of risk management.

RISK AND RISK CONTROL

According to various sociologists, we live in a ‘risk society’ (Beck, 1992), by which is meant that people feel that they are under threat from an increasing range of hazards. The role of the state in this later modern era is promoted as being to identify and bring under control these many hazards. Joffe (1999: 4) argued that while risk in general is defined in the language of science, behind it is a ‘more moralistic endeavour, one that routes dangers back to those responsible for them’. This follows the well-trodden blame and shame path of personal responsibility.

The control of risk is a central theme in contemporary health care. Once again, the dominant language of science conceals a more moralistic message about personal responsibility. Preventive health care has been predicated upon epidemiological research that has estimated the
statistical importance of various so-called ‘risk factors’. According to these statistical models, individuals or groups who are exposed to certain pathogens, either internally or externally, or who behave in a certain manner are at higher risk of developing a particular health problem. The task of preventive health programmes then becomes one of identifying individual risks for particular health problems and bringing these risks under control. A central challenge is the extent to which people are willing to participate in these programmes.

Health psychologists have contributed to attempts to explore this issue by investigating cognitive and other psychological processes that can help clarify risk control actions. Research on preventive health services, such as screening and immunization, has been dominated by the cognitive approach, which focuses on the information-processing model of the single individual, in contrast to a more socio-cultural approach, which considers the interaction between the individual and the socio-cultural context. Both approaches are considered below.

SCREENING

One of the main forms of health risk management is the early detection of disease through screening. This is the procedure whereby those sections of the population that are considered statistically more at risk of developing a particular disease are examined to see whether they have any early indications of that disease. The rationale behind this strategy is that the earlier the disease is identified and treated, the less likely it is to develop into its full-blown form. Within public health circles there has been sustained debate about the value of this strategy. A variety of criteria have been identified for deciding to implement screening (Wilson and Jungner, 1968). These include the character of the evidence regarding its effectiveness, benefits, harms and costs.

In Western countries, there have been several attempts to introduce mass screening for a limited number of conditions that satisfy all or most of these criteria. However, despite the supposed benefits of these programmes, there has been a variety of problems in their implementation. It was generally assumed by their proponents that the major problem would be the introduction of the programmes. However, the challenge has been not a technical one of implementing the programme, but rather a human one concerned with the reluctance of at least a proportion of the targeted population to make use of these programmes and the unexpected negative side effects of participation. In addition, there continues to be debate about the effectiveness of forms of screening.

SCREENING FOR CANCER

Over the past decade there has been a concerted effort in most industrialized societies to introduce screening programmes for breast cancer. The reason for this was that it is a common health problem and there was evidence that those detected and treated at an early stage had better survival prospects. It is currently one of the most prevalent forms of female cancer in Western society. It is estimated that one in nine women will develop breast cancer at some point in their lives. In the UK, about 49,000 new cases were diagnosed in 2011 and about 11,500 died from the disease (Cancer Research UK, 2013).

Partly in response to the epidemiological and medical evidence about the widespread prevalence of the disease and the association between stage of identification and success of treatment, there has been a demand not only from health authorities but also from women’s organizations
for the introduction of breast cancer screening programmes. Initially, the method favoured was breast self-examination (BSE), but due to debate about the accuracy of this procedure most health authorities now favour mammography coupled (sometimes) with clinical breast examination by a health professional. In most industrialized countries mammography programmes have been targeted at all women aged 50 to 69 years, who are invited on a 2–3-year basis to undergo the procedure.

Although mammography is widely promoted by health authorities, evaluations of its effectiveness have not been conclusive. The Cochrane Collaboration review estimated that the breast cancer mortality reduction due to mammography was 15% rather than the 29% previously reported (Gøtzsche and Jørgensen, 2013). They concluded that while screening reduces breast cancer mortality by 15%, they estimated that overdiagnosis and overtreatment occurs in 30% of cases. They argue that these women will experience psychological distress for years after because of this false positive finding.

The authors refer to a range of harmful consequences of mammography that have often been ignored in evaluations, including heightened levels of distress among the women, harmful effects of radiation, and overdiagnosis (i.e., cases that would never become clinically detectable or pose a threat to health without screening) leading to surgery and other forms of treatment. Another commentary noted that ‘it seems likely that little of the decline in breast cancer mortality since 1990 is due to mammography screening, and nearly all to improved therapy of breast cancer’ (Miller et al., 2008: 485).

A review of 11 randomized trials concluded that the relative risk of breast cancer mortality for women invited to screening compared with controls was 0.80 (95% CI 0.73–0.89), which is a relative risk reduction of 20% (Independent Panel, 2012). The Panel concluded that 20% was still a reasonable estimate of the relative risk reduction. A recent Danish study (Njor et al., 2015) found similar evidence of reduced mortality among women targeted for breast cancer screening. However, in a recent review of mammography screening among 39–49-year-olds in the USA, Magnus et al. (2011) issued some cautions about the evidence and advised that women of this age group be advised of both the negative and positive aspects of screening.

Despite widespread support for mammography, there is concern that some of the evidence on the effectiveness of alternative approaches to detection, such as breast self-examination (BSE), may be underestimated. Kearney and Murray (2009) highlighted the limitations of previous evaluative research, suggesting that BSE was of limited benefit in reducing mortality on the grounds that the evidence was drawn from trials of BSE education, not of BSE practice. It has been discouraged because BSE would also lead to heightened anxiety among women and unnecessary visits to the family doctor. However, there is little evidence for the latter. Rather, there is evidence that the majority of breast cancer tumours are discovered by the women themselves.

Cervical cancer is a much less prevalent condition. In 2011, over 3,000 new cases of cervical cancer were diagnosed in the UK, making it the twelfth most common cancer in women and accounting for around 2% of all female cancers (Cancer Research UK, 2013). The incidence rate for cervical cancer is highest for those aged 30–40, reaching around 17 per 100,000 women. In 2011, there were 972 deaths from cervical cancer in the UK. It has been established that the human papillomavirus (HPV) is the main risk factor and a necessary cause of cervical cancer. This virus is spread particularly through sexual activity. There is evidence that the precancerous stage of the disease can be detected at an early stage using a simple cervical smear test (pap test). Most Western countries have introduced campaigns to encourage women to attend for regular smear tests, usually at least once every three to five years. Another prevention strategy
has been the introduction of HPV vaccination. In many countries, an HPV immunization programme has been introduced into schools for teenage girls (see later).

Evidence from several countries suggests that a substantial proportion of women do not use cancer screening programmes. Approximately 2.75 million women aged 50–70 were invited for breast cancer screening in 2009–2010 in the UK. Of these, approximately 2.02 million were screened and 16,500 cancers and tumours were detected (Cancer Research UK, 2013). The cervical smear test has been around for a longer period but it also has encountered reluctance of a substantial proportion of targeted women to participate. More recently, there have been attempts to introduce screening for other forms of cancer. There has been interest in developing screening for colorectal cancer, which is the second major cause of cancer in Western society and affects both men and women. However, the uptake of the test has not been high.

**HEALTH BELIEFS AND CANCER SCREENING**

The dominant approach used by health psychologists to explain participation in screening programmes has been underpinned by social cognition models (SCMs), especially the health belief model (HBM), with the focus on barriers to and benefits of screening, and the theory of reasoned action (TRA), with the focus on intentions to participate and attitudes towards screening. (For further details, please see Chapter 6.)

In the case of breast cancer screening, most of the studies have considered participation in mammography programmes and fewer have considered BSE. The most frequently cited predictors of participation in both are perceived susceptibility and perceived barriers. A meta-analysis of many US studies (McCaul et al., 1996) found a strong relationship between family history (actual risk) and mammography utilization, but also a moderate relationship between perceived vulnerability (perceived risk) and use of mammography. In a UK study, Sutton et al. (1994) also found a relationship between perceived risk and attendance. Stein et al. (1992) found that perceived susceptibility to breast cancer was the best predictor of future intention to participate in mammography. However, they add that ‘it is questionable … whether heightened feelings of susceptibility alone will sufficiently motivate women to obtain mammograms in the absence of a physician’s recommendation’ (Stein et al., 1992: 458). In a reanalysis of the data from two studies of the effects of testimonials in health messages about colon cancer screening, Dillard et al. (2012) found that feelings of risk were predictive of intentions and attitudes about screening.

Various barriers to attendance for mammography, both physical and psychological, have been reported. Rimer et al. (1989) found in their survey of women in the USA that those who did not attend for mammography had a stronger belief that screening was not necessary in the absence of symptoms, preferred not to think about it and worried about the effect of radiation. Murray and McMillan (1993) found that perceived barriers were the most important predictor of attendance for a smear test. The barriers they considered included dislike of the health service, fear of the examination and fear of the result. Moore et al. (1998) found that the main barriers to both breast and testicular self-examination were embarrassment, perceived unpleasantness and difficulty, reliability concerns and concerns about the findings.

McCaul et al. (1996) found that women who worry about breast cancer are more likely to engage in self-protective actions such as BSE and attendance for mammography. Sutton et al. (1994) found a non-linear relationship, with the highest attendance among women who were ‘a bit worried’, while those at the two extremes of worry were less likely to attend. They concluded
that health promotion campaigns must balance advice to women on perceived risk with the negative impact of excessive worry. Other barriers reported include belief that a mammogram is appropriate only when there are symptoms, as well as concern about radiation exposure, cost and access-related factors (Slender and Grant, 1989).

With respect to benefits, several studies have indicated that the most frequently given reason for non-participation in cancer screening is that the women do not feel it necessary – they were healthy so they did not feel it was necessary to use it. It was thought that it was only necessary to have mammograms when one was sick. Potvin et al. (1995) found that perceiving one’s health as good was inversely associated with recent mammography. Harlan et al. (1991) found that the most frequently given reason for not having a cervical smear was not believing it necessary.

Although the HBM has been widely used in studies designed to predict attendance for breast cancer screening, the results have not always been consistent. Bernstein Hyman et al. (1994) found that women who never scheduled a mammogram were more likely to perceive both fewer benefits of and barriers to mammography. They did not find any relationship between perceived susceptibility and mammography usage. They suggested that possibly other variables, such as knowledge, were a more important overriding factor. Many women are either unaware of the availability of the services or do not understand the character of the investigation. For example, Gregory and McKie (1991) found that many women did not understand that the initial stages of cervical carcinoma are not accompanied by any symptoms. Rimer (1990) argues that since mammography occurs when there are no symptoms of breast cancer, it takes ‘almost an act of faith’ to participate.

A criticism of many of these studies of breast cancer screening is that they used a cross-sectional design. One study that used a longitudinal design (Norman and Brain, 2005) found that previous experience of BSE was the best predictor of the practice. Among the HBM factors considered to be the best predictors were perceived emotional barriers (e.g., ‘Finding breast cancer is emotionally distressing’) and perceived self-efficacy barriers (e.g., ‘I am confident that I can examine my own breasts regularly’). This would suggest that the barriers dimension should be considered in more detail. In addition, this study found that those women who scored low on perceived self-efficacy barriers and high on breast cancer worries and perceived severity of cancer were more likely to conduct BSE excessively. It was suggested that these women may carry out more frequent but less thorough BSE.

Studies of screening for other cancers have confirmed the importance of perceived risk. In a survey of a large sample of Scottish residents invited to participate in colorectal cancer screening, Wardle et al. (2004) found that interest in participating in screening was predicted by higher perceived risk, worry and benefits, and lower perceived barriers, fears and fatalism. They also found that those from lower SES backgrounds perceived the benefits of screening less and the barriers to it more. Although their study was not formally based on the HBM, it does agree with other studies of cancer screening. The TRA and TPB have met with some success in predicting cancer screening behaviour. Cooke and French (2008) conducted a large meta-analysis of 33 studies that used this approach. They found that attitudes had a large-sized relationship with intention to participate in screening, while subjective norms and perceived behavioural control had medium-sized relationships. Intention had a medium-sized relationship with participation. They also considered the role of moderator variables and identified (1) type of screening, (2) location of recruitment, (3) screening cost and (4) invitation to screen as important.

Several researchers have used the transtheoretical model (TTM) of change (Prochaska and DiClemente, 1983, 1992) to explore the extent of participation in screening programmes.
Rakowski et al. (1992) found that women who were classified as pre-contemplators (i.e., those who had never had a mammogram and did not plan to have one) scored higher on a measure of negative beliefs, including the beliefs that mammograms lead to unnecessary surgery and that they are only advisable if you have some breast symptoms. Skinner et al. (1997) found that action/maintainers were less likely to agree with the psychological and physical barriers to screening.

**SOCIAL VARIATIONS IN PARTICIPATION**

The growth of research on health gradients (see Chapter 4) has confirmed that not only do people from poorer backgrounds experience worse health, but also they make less use of preventive health services such as screening. The US Centers for Disease Control and Prevention (2012b) reported on a National Health Interview Survey on colorectal screening in 2000, 2003, 2005, 2008 and 2010 with a civilian non-institutionalized population aged 50–75. The data showed that the overall percentage of adults aged 50–75 who reported receiving colorectal cancer screening significantly increased from 34% in 2000 to 59% in 2010 and that rates increased among all racial and income groups. However, in all years except 2008, Asians were less likely to receive colorectal cancer screening than whites. Since 2005, blacks have also been less likely than whites to receive screening. In all years, poor, low-income and middle-income adults were less likely to receive colorectal cancer screening than high-income adults.

This evidence is supported by data from other countries. Moser et al. (2009) found that women who did not own a car were less likely to have had a mammography and women from ethnic minorities were less likely to have participated in cervical cancer screening. The introduction of a home testing kit for colorectal cancer followed a similar pattern. Early indications are that in trials of different forms of screening for colorectal cancer the uptake has been lower among people from lower SES backgrounds (Wardle et al., 2004). One study found that while 49% of test kits sent to homes were returned from more affluent neighbourhoods, only 32% of kits were returned from the more disadvantaged neighbourhoods (von Wagner et al., 2009).

A framework for integrating the psychological evidence on the relationship between SES and use of screening has been developed by von Wagner et al. (2011). Box 16.1 shows that this framework classified the evidence into two broad categories: corollaries of SES and attitudinal mediators. In the former category, they group a mixture of social stressors that they argue reduce the perceived importance of preventive health behaviours. It also includes educational opportunities that contribute to health literacy and the ability to access and process information about preventive and other health services.

The third social corollary is illness experience. It is suggested that this corollary is associated with lower use of cancer prevention services via three pathways. The first is cancer fatalism. A study by Wardle et al. (2004) found that people of lower SES were more likely to agree with the statement ‘It’s not worth having the test because “what will be will be”’. The second illness experience pathway was characterized by a lack of confidence in dealing with the medical system. It is known that people of lower SES have less confidence and express greater dissatisfaction with the medical system. Low rates of participation in screening are more common among those who express dissatisfaction with health care (Ackerson and Preston, 2009). The third proposed pathway was low perceived personal value of cancer screening. Since people of lower SES have lower life expectancies and have what Barrett (2003) described as ‘older identities’, they are more sceptical of the benefits of preventive health care such as screening.

In reviewing the evidence for the psychosocial mediators, von Wagner et al. (2011) expressed surprise that despite the large amount of research on social cognitive processes, a limited amount
of research had connected these processes with details of the SES status of the study participants. Despite these limitations they suggested three broad blocks of attitudinal mediators. These were the perceived threat of unpleasant or invasive medical procedures, self-efficacy for participating in cancer screening, and response efficacy for screening to detect cancer early, prolong life or minimize treatment. These attitudinal mediators are then hypothesized to contribute to the low uptake of cancer screening among low SES adults through inadequate information processing (e.g., lack of information seeking) and limited goal setting (e.g., prioritization of alternative activities).

Although the von Wagner et al. framework integrated a large amount of empirical work, there is still a tendency to adopt a deficit model to explain non-participation in screening. Those who do not use the service tend to be characterized as lacking in knowledge and concern about their health. An alternative perspective is to view this non-attendance within its socio-cultural context and as a form of resistance to what is perceived as an unnecessary interference in their lives or even as something that could increase the likelihood of cancer.

### BOX 16.1

**SOCIAL COROLLARIES AND PSYCHOSOCIAL MEDIATORS OF CANCER SCREENING**

**Corollaries of socio-economic status**

- Stressors and resources for change
- Educational opportunities
- Illness experiences

**Attitudinal mediators**

- Perceived threat of unpleasant or invasive medical procedures and cancer diagnosis
- Self-efficacy for participating in cancer screening
- Response efficacy for screening to detect cancer early, prolong life, or minimize treatment

**Non-participation in cancer screening**

- Information processing
- Goal setting and behavioural translation

*Source:* Adapted from von Wagner et al. (2011)
MEANING OF CANCER AND CANCER SCREENING

Despite the advances in the treatment of cancer, or indeed partly due to the character of these advances, cancer remains the most feared disease. Murray and McMillan (1993) conducted a survey of a random sample of adults resident in Northern Ireland. They found that cancer was the most feared disease, especially among women. The reason for this fear was because cancer was perceived as incurable and as leading to a painful death. Slenker and Spreitzer (1988) conducted a survey of a random sample of adults in Ohio. They found that not only was cancer the most feared disease, but approximately half the respondents felt there was little you could do about the disease.

Several qualitative studies have explored women’s fear of cancer and their reluctance to use the screening services. Blaxter (1983) conducted interviews with women from Glasgow about their views on health and illness. She found that the women were reluctant to talk about cancer. Blaxter suggested that this lack of reference to cancer was a coping strategy used by the women to protect them from cancer: ‘to talk about it was to invoke it; to speak briefly or in a lowered voice was to leave it sleeping’. Participation in screening would threaten this form of psychological defence.

Murray and McMillan (1988) conducted interviews with a sample of working-class women from Northern Ireland. Again, they found evidence of a fear of cancer and a reluctance to interfere. One woman explained why she had not had a smear test:

I think you have the fear, you see, of it. But they say they can get it in time … but sure, how do they know they’ve got it in time? They don’t know until they start opening you up and if they open you up, it would spread. So, I would say, leave well enough alone. (Murray and McMillan, 1988: 42)

A similar finding was reported by Gregg and Curry (1994). They conducted detailed interviews with a sample of African-American low-income women on their beliefs about cancer. Not surprisingly, they had a very negative image of the disease. They not only believed that cancer was deadly, but also felt that if the cancer could be detected by mammography then it was already beyond cure. An example of this attitude is the case of a 62-year-old woman who had received a negative result from her pap test. Her reaction was a refusal to obtain a follow-up test:

My last pap didn’t come back good and they want me to go over to Grady, but I didn’t go because I’m afraid they’re going to tell me that I’ve got cancer. I’ve just had so much experience with cancer, and I know that if they operate on me it’s going to get worse. So, I’m just going to prolong it as much as I can. … We all going to die anyway. … It’s too late now. (Gregg and Curry, 1994: 524)

Balshem (1991) linked these negative beliefs about cancer with the life experiences of the women. She conducted an ethnographic study of a working-class community in Philadelphia that seemed very resistant to a health promotion campaign aimed at encouraging healthier lifestyles, including attendance for breast cancer screening. When she interviewed these women, Balshem found that the health promotion message was counter to their experience. They believed that fate determined who got cancer and who survived. To look for cancer was to tempt fate; it was ‘looking for trouble’. To quote Balshem: ‘Challenging fate is a risky business. Cancer inspires not challenge but taboo.’ Thus, the women preferred not to think about cancer.
Other qualitative work suggests that some women would prefer to conduct self-examination rather than attend a medical centre for investigation. For example, Tessaro et al. (1994) interviewed a sample of older African-American women and found that they did not think it necessary to use the health service since after self-examination they had found no lumps. Other women felt that they accepted lumps and bumps as part of life and were more concerned about other people’s health rather than their own. One woman had this to say:

I think the black woman don’t realize herself she has a tendency to leave herself alone and worry about other people. So she doesn’t have a chance to examine her body and see what is really wrong with it because she is so used to bumps and knocks and hurts until she ignores it. (Tessaro et al., 1994: 291)

Another critical issue to consider is the sexual connotations of both breast and cervical cancer. Breasts are at the centre of a woman’s sexual identity. Women fear breast cancer partly because of the threat to this identity (Murray and McMillan, 1988). Also, the evidence that a sexually transmitted virus may contribute to cervical cancer has been widely discussed. This has contributed to some women’s reluctance to have a smear test. McKie (1993, 1995) considered the views of a sample of English working-class women. She found that in the minds of some of the women the test was associated with sexual promiscuity, a label that they did not want to have. By avoiding the test, they sought to avoid the label.

Kearney (2006) conducted focus groups with women about their perceptions of cancer and cancer screening. This study used action research with the two groups of women meeting regularly to discuss the issues over several weeks. Over the course of this study the women became more critical of the medical establishment. One woman described the promotion of mammography as the preferred method for breast cancer screening as an example of ‘boys with toys’ and as reflecting the masculine preference for technology within health care in general. Another woman described as ‘chilling’ her growing awareness of the role of medical technology.

The women in these studies were generally from lower socio-economic backgrounds or from ethnic minorities, who tend to have a higher rate of cancer but a lower uptake of mammography. Rather than acquiescing with scientific medical advice, these women protected themselves from the threat of cancer either by refusing to discuss it, by associating it with other people, or by characterizing cancer screening as a potential cause of the disease itself. This accords with Joffe’s (1999: 10) argument that ‘people are motivated to represent the risks that they face in a way that protects them, and the groups with which they identify, from threat. They make meaning of the threat in line with self-protective motivations rather than with rational dictums’.

Another screening programme within the UK NHS is screening for bowel cancer using a faecal occult blood test that people carry out in their own homes using cardboard spatulas and sending samples through the post. Uptake is relatively low, ranging from 35% in the most deprived areas to 61% in the least deprived areas. Palmer et al. (2014) used focus groups to explore reasons for this low uptake. Participants described sampling faeces and storing faecal samples as crossing a cultural taboo, and causing shame. Having to complete the test kit within the home rather than a formal health setting was felt to be unsettling and reduced the perceived importance of the test.

Not knowing the screening results was reported to be preferable to the implications of a positive screening result. Feeling well was associated with low perceived relevance of screening, and talking about bowel cancer screening with family and peers emerged as the key to subsequent participation in screening after receiving the test kit through the post. Palmer et al.
(2014: 1705) concluded that ‘Initiatives to normalise discussion about bowel cancer screening, to link the (screening) to general practice, and to simplify the test itself may lead to increased uptake across all social groups’.

**EXPERIENCE OF CANCER SCREENING**

Most of the research on cancer screening has concentrated on describing those factors associated with initial attendance for mammography. However, according to current guidelines, women are expected to attend not once but on a regular basis. Fewer studies have examined this process of re-attendance, although the evidence does suggest that rate of attendance for follow-up is lower than for initial examination (Sutton et al., 1994). One key factor in re-attendance is the woman’s reaction to the initial test. Evidence suggests that this is not always positive.

Women often find mammography screening painful. Keefe et al. (1994) reviewed studies on the experience of pain during mammography and found that the percentage of women reporting pain varied widely across studies, with a range of 1–62%. Admittedly, four of the eight studies reviewed by Keefe et al. (1994) found that at least one-third of the women reported some degree of pain during mammography. Lightfoot et al. (1994) reported that 40% out of a sample of 315 women undergoing screening mammography agreed that it hurt. Admittedly, many accept the pain and discomfort since it is of short-term duration and has long-term benefits. However, some are less accepting and indeed feel that the pain may increase their risk of cancer. For example, one woman commented in Eardley and Elkind’s (1990) study: ‘The straight answer is – if I don’t have cancer now, I’ll have it after this [the pressure of the machine].’ Such a viewpoint may act as a disincentive for repeat mammography. Despite this evidence, recent findings confirm that women still report pain during mammography and more intense pain is associated with reduced re-attendance. Whelehan et al. (2013) found in a review of 20 studies that 25–46% of women who had not re-attended cited pain as a reason.

There is also evidence that cervical screening can be uncomfortable for some women. Schwartz et al. (1989) found in her survey of women in the East End of London that 54% rated having a smear test as painful or uncomfortable and 46% found it embarrassing. Similarly, in a qualitative study (Waller et al., 2012) it was found that the women often talked about the test in terms of embarrassment, violation or pain. Again, such experiences would not be expected to encourage re-attendance.

In her study in the East Midlands of England, Armstrong (2007) contrasted the official discourse on cervical screening with that of the women. Whereas the former presented the smear test as a simple, painless and non-intrusive procedure, the women characterized it as invasive and very uncomfortable. Armstrong, using Foucauldian discourse analysis, referred to three resources on which the women drew to challenge the official discourse. The first of these was their emotional experiences through which the women could explain their feelings. For example, one woman said:

> It’s just something that I just hate, I think it’s, you know I don’t know what it is and I know to the nurse it’s nothing but I think it’s just, perhaps because I’m such a private person. (Armstrong, 2007: 77)

In this case, the woman is emphasizing her ‘private’ nature that led to her feeling particularly uncomfortable about the test. A second resource was the actual physical experiences in that the women drew attention to their physical experiences. For example, one woman said:
every time uncomfortable and painful, they’re just horrible … apparently, erm, I’ve
got a funny shape so when the instrument is put in it goes in to open your cervix up
it doesn’t always go properly because of the shape. (Armstrong, 2007: 79)

The third resource was the changing body that was an extension to the physical experiences. In
talking about the smear test, these women were not trying to find a way to avoid attending for
the test, but rather were challenging the official medical discourse of the smear test as routine.

PSYCHOLOGICAL CONSEQUENCES OF CANCER
SCREENING

In the initial haste to establish screening programmes, the psychological cost in terms of
increased anxiety was overlooked. There are obvious adverse psychological consequences
for women from being recalled following screening, even if they are subsequently cleared. In
the UK, about 5% of women who undergo breast cancer screening are called back for further
tests. This is termed a ‘false positive’ diagnosis. Although recalled women may be given the
‘all-clear’ following the further tests, they often still harbour uncertainty and anxiety.

The false positive result is followed by further anxiety-provoking investigation that will
include clinical examination and possibly surgery. In a ten-year follow-up, Elmore et al. (1998)
found that as many as one-third of women who obtained positive results were required to
undergo additional investigations, including biopsies, even though it turned out that they did
not have breast cancer.

In a large Danish study, women who underwent screening for breast cancer were surveyed at
baseline, then at 1, 6, 18 and 36 months (Brodersen and Siersma, 2013). The women were clas-
sified into three groups – those with a diagnosis of breast cancer, the false positives and those
with a normal result. Those with the diagnosis of breast cancer had the most psychological dis-
ruption, followed by those with the false positive diagnosis. Even at 36 months after they had
been given the all-clear, the women who had been false-positively diagnosed still reported sub-
stantial psychological disruption. An earlier UK study found similar findings. Women who had
initially been falsely diagnosed but then were cleared of having breast cancer were found still
to be suffering psychological symptoms three years later (Brett and Austoker, 2001). Further,
those women who had undergone the most additional tests experienced greater anxiety.

In a qualitative study of the impact of a false-positive mammography result Bond et al.
(2015) found that the reaction ranged from nonchalance to extreme fear. The former group
of women claimed that when they received the initial letter they were not overly concerned,
but rather curious or surprised. Conversely, the latter group of women described the intense
anxiety they felt on receiving the recall letter. For them, it opened the prospect of cancer and
death. This anxiety increased when they attended the assessment clinic. This is when they
became acutely aware of the potential implications if the diagnosis was confirmed. After they
were cleared, some of the women reported intense emotional reactions. However, some of the
women reported continuing anxiety, which was related to how the result was communicated
by the physician. Some of the women reported that this anxiety continued for many years after
they were given the all-clear. For them, there still lingered the fear of developing breast cancer.

Moving beyond false positives are those women who are diagnosed and treated for can-
cer and found not to have it. The term ‘overdiagnosis’ is used to describe the diagnosis of
cancer at screening that would not have been clinically apparent in the woman’s lifetime.
There is debate about the extent of such overdiagnosis, with most estimates around 19–35%. An independent UK panel (Marmot et al., 2013) reviewed the evidence and concluded that for every 10,000 UK women aged 50 years invited for screening over the next 20 years, a total of 43 deaths would be prevented while 129 cases would be overdiagnosed, i.e., one breast cancer death prevented for every three overdiagnosed cases. A focus group study of women concluded that the benefits still outweighed the risks. The Panel concluded that information should be made available in a transparent and objective way to women invited to screening so that they can make informed decisions.

A qualitative study conducted in Australia further extended this discussion from a woman’s perspective (Hersch et al., 2013). A sample of 50 women participated in focus group discussions. This showed that many of the women were unaware that some women were being misdiagnosed with breast cancer. They were reluctant to accept the concept of overdiagnosis. As one woman said:

How do we know that things are being overdetected? How do we know that there are some cancers that move more quickly or become more malignant than others? … Overdiagnosis assumes that these women, who have been overdiagnosed, have a cancer that is not necessarily aggressive. … Who determines what’s an aggressive and non-aggressive cancer?

Some of the women, especially younger women, indicated that this knowledge of the prospect of misdiagnosis deterred them from participating in screening. As one said:

Turns me off further … I’m just adding the things that we’ve learnt together … and all the doctors not knowing if it is malignant or not, you add them all together and you think, ‘Why bother?’

However, most women said that even with an estimated 30% overdiagnosis they were still willing to participate.

**HEALTH SERVICE ORGANIZATION FOR CANCER SCREENING**

Several studies have found that the most influential factor in explaining variation in participation is the extent to which the woman’s doctor recommends participation (National Cancer Institute, 1990). Further, Lurie et al. (1993) found that women are more likely to undergo screening with pap smears or mammograms if they see female rather than male physicians. There is evidence to suggest that some physicians are reluctant to advise mammography for a variety of reasons, including scepticism about its effectiveness in general or for certain groups of women and fear of the effect of radiation. Smith and Herbert (1993) found that family physicians did not recommend mammography because they did not think the patients would participate, because the test was not available, because they were concerned about the radiation risk and because of the cost. Physicians are especially less likely to refer older women for screening (Costanza, 1992). Further, Frazier et al. (1996) found that black women were more likely to report that their physician had not recommended participation.
A further reason for the hesitancy among some physicians in the USA as to recommending screening is fear of litigation. It has been suggested in the USA that many physicians may be reluctant to talk about screening with their patients because of the public controversy about screening guidelines (Leitch, 1995). This could lead to anxiety among some physicians, bearing in mind that delayed diagnosis of breast cancer is one of the most common causes of malpractice complaint. In the USA, women who have developed cervical or uterine cancer after smear tests have won legal cases because of inappropriate treatment. In commenting on these cases, Austin and McLendon (1997: 754) stated that ‘this trend is having a chilling effect on those professionals in the field of cytotechnology and cytopathology and potentially threatens the availability of this procedure for many of our patients’.

More countries and regions are now establishing dedicated cancer screening programmes with postal invitations to women to attend on a regular basis. Despite these moves, a proportion of women are still reluctant to participate in screening. Similarly, some women do not participate even when they are personally encouraged to attend by their physician (May et al., 1999). Sharp et al. (1996) found that a personal invitation by a woman’s family doctor was as effective as a home visit from a nurse conveying the same message.

It has been shown that campaigns designed to increase awareness of breast cancer contribute to increased uptake of both breast self-examination and mammography screening (Anastasi and Lusher, 2017). The type of message seems to be important, with narrative messages about screening being more effective than statistical messages for women with low levels of education (Perrier and Martin Ginis, 2017).

**MEN AND CANCER SCREENING**

Most of the research on psychological aspects of cancer screening has been on women and their use of breast and cervical cancer screening programmes. Since there are no similar programmes for men it is not surprising that there is less research. However, there is increasing discussion about the potential value of screening for both colorectal and prostate cancers among men. The limited psychological research has often been from a social cognition framework. These studies have referred to the importance of such factors as attitude, perceived behavioural control and perceived social norms as important predictors of intention to participate in such screening (e.g., Sieverding et al., 2010).

Several studies have confirmed the lower rates of uptake of screening programmes among men from low SES and ethnic minority backgrounds (e.g., von Wagner et al., 2011). In a study of US Hispanic males, Goodman et al. (2006) identified a series of perceived barriers to participation in screening for colorectal cancer. These included low levels of knowledge and awareness, lack of understanding of the screening test, and language and communication challenges.

The importance of the cultural context was identified in a qualitative study of New Mexico Hispanic men and women (Getrich et al., 2012) that considered the meaning of machismo – or the ‘tough guy’ attitude. They found that it was particularly important among the Mexicans interviewed. One woman said: ‘Yes, machismo’s a problem. I think that [men] are all the same. They feel that they are not sick – they say, “Nothing hurts me!”’ Conversely, this was less evident among the Hispanos interviewed. For example, one man said: ‘Macho is gone, those days are gone. It’s a lot different than it was before … people get together and talk.’ A qualitative study of Latino men’s views of prostate cancer screening (Rivera-Ramos and Buki, 2011) also identified the importance of machismo as a deterrent to participation. The men interviewed in
this study frequently referred to the digital rectal examination that is part of the prostate cancer screening as being a threat to their masculinity. As one participant said: ‘It’s almost the worst thing that can happen to a man.’

Similarly, a qualitative study of UK males found apprehension about screening for prostate cancer (Grogan et al., 2017). Analysis of interviews with a sample of middle-aged men identified limited understanding of the screening test. Most of the men expressed discomfort at the idea of an anal examination. Whether they sought support for any possible prostate symptoms would depend upon how medical professionals communicated with them. A large survey study of men facing diagnosis for prostate cancer reported higher levels of anxiety which increased as they came nearer to finding out (Dillard et al., 2017). The anxiety level was higher among those with limited knowledge of the cancer. This would confirm the importance of providing education to men receiving a biopsy.

GENETIC SCREENING

The rapid advances in genetic research now hold out the prospect of genetic screening for different diseases. This can take various forms (see Lerman, 1997). Carrier testing investigates people who are likely to be carriers of the genes for such diseases as cystic fibrosis or Tay–Sachs disease. This form of testing is usually conducted in the context of reproductive decision-making. Presymptomatic testing allows the identification of a disease before the symptoms develop. This form of testing is used to determine the person’s risk of developing such late-onset diseases as Huntington’s disease. Susceptibility testing is designed to test for a person’s susceptibility to develop a disease, although whether that disease develops depends upon a variety of environmental and nutritional factors partly outside the person’s control.

Although the general principles underlying genetic screening are like those of other forms of screening, there are certain unique features. Lerman (1997) described several distinguishing features that need to be taken into consideration when investigating the psychological aspects (see Box 16.2). These factors need to be accounted for in exploring the development of these services.

An extension of cancer screening programmes has been genetic testing for cancer. This is still not a very common procedure but has attracted substantial interest among certain population sub-groups. In a study in New Zealand, Cameron and Reeve (2006) found that worry about cancer was associated with interest in obtaining such a test, although perceived risk was not. It was suggested that this may be due to perceived risk leading to more cautious appraisals of the benefits of genetic testing.

The importance of the patients’ assessment of the benefit of the test was shown in a qualitative study of patients, patient group representatives and health professionals involved in clinical genetic services (McAllister et al., 2008). This study found that a common integrating theme in the patients’ accounts was perceived empowerment. By this was meant that participating in the genetic testing enhanced the patients’ feelings of control over their disease. As one patient group representative said:

Information is power, [you’re] powerless if you don’t have information and that’s one of the problems that we’ve come across. Families feel isolated, they have anxiety because they have no information therefore they have no power … I mean power to make the right decisions. (McAllister et al., 2008: 898)
 Unlike cancer screening, genetic testing is often initiated by individuals when they suspect that because of family history they may be carriers. Thus, they would be expected to be in a heightened state of anxiety. Several studies have found a reduction in such anxiety following testing (e.g., Tibben et al., 1993). However, some studies have reported evidence of subsequent psychological distress. Lawson et al. (1996) found that of 95 individuals receiving the results of a test for Huntington’s disease, two made plans for suicide and seven had clinical depression. Interestingly, there was no difference between those who tested positive and those who tested negative. Tibben et al. (1993) found that carriers tended to minimize the impact of the test results on their futures.

**FEATURES OF GENETIC SCREENING**

**Type of information**

Genetic information is probabilistic and uncertain. In some cases you can say with certainty that a person will develop a disease, but *when* is less clear (e.g., Huntington’s disease). In other cases, it is unclear whether the person will develop the disease at all (e.g., cancer).

**Medical value**

Control over disease onset is limited for certain diseases (e.g., cancer) and non-existent for others (e.g., Huntington’s disease).

**Timescale**

The timescale is variable in that the results of genetic testing concern events that may occur far in the future.

**Impact of results**

The results affect not only the individual but also the family, since genetic susceptibility is transmitted within families.

_Source: Lerman (1997: 4)_

**PSYCHOLOGICAL CONSEQUENCES OF GENETIC SCREENING**

Unlike cancer screening, genetic testing is often initiated by individuals when they suspect that because of family history they may be carriers. Thus, they would be expected to be in a heightened state of anxiety. Several studies have found a reduction in such anxiety following testing (e.g., Tibben et al., 1993). However, some studies have reported evidence of subsequent psychological distress. Lawson et al. (1996) found that of 95 individuals receiving the results of a test for Huntington’s disease, two made plans for suicide and seven had clinical depression. Interestingly, there was no difference between those who tested positive and those who tested negative. Tibben et al. (1993) found that carriers tended to minimize the impact of the test results on their futures.
In a large systematic literature review, Broadstock et al. (2000) found no evidence of increased distress (general and situational distress, anxiety and depression) in carriers or non-carriers within 12 months after testing. Rather, both carriers and non-carriers showed decreased distress after testing; this was greater and more rapid among non-carriers. However, they point out that the studies were on self-selected populations who had agreed to participate in psychological assessment and that there was a need for further research.

There is some evidence that the positive effect of screening may only be short term. At six-month follow-up Tibben et al. (1993) found that one-quarter of the carriers exhibited signs of psychopathology. They continued to follow the group for three years (Tibben et al., 1997) and found that for the first six months there was a rise in avoidant thoughts and a decrease in intrusive feelings. This was followed by a reversal of this pattern. It was suggested that this was evidence of a coping strategy whereby the carriers ‘dose themselves’ with tolerable levels of intrusive thoughts as they begin to process and accept the test results.

Genetic screening can also have a dramatic impact on the family of the carrier. Hans and Koeppen (1989) found that partners often reacted with disbelief and denial. However, this turned to resentment and hostility as they became aware of the threat of transmission to their children. The partners can play a key role in helping the carrier cope with the diagnosis (Tibben et al., 1993).

The evidence of psychological impact of genetic screening has been followed by calls for greater provision of psychological support services (Marteau, 1990). It is suggested that such services be made available both prior to testing such that the testees are fully aware of the issues and afterwards so that they and their families can begin to come to terms with the findings.

The prospect of widespread genetic screening has provoked sustained debate about the ethical issues. Harper (1997) voiced concern that the needs of individuals and families are being made subservient to broader eugenic goals. Stone and Stewart (1996) claimed that the voice of the public is rarely heard in this debate. They argue that the advocates of genetic screening often falsely claim that their programmes are based on the public’s right to know. Yet there is little evidence that the public wants to know. Stone and Stewart also raised a variety of other questions about genetic screening, such as the ability of lay people to interpret genetic information, the competence of health personnel in explaining aspects of genetic screening and the use made of genetic information.

In a review of the social impact and ethical implications of genetic testing, Davison et al. (1994) identified three areas of popular perception that have implications for predictive testing for Huntington’s disease:

1. Both positive and negative results can lead to personal and family anguish. While the former is expected, there is also evidence that those who are cleared suffer from survivor guilt and a feeling they do not belong to their family.

2. Some families who inherit the gene have developed ways of deciding who in the family will be sufferers. This lay procedure is undermined by medical investigation.

3. Knowing about possible futures may decrease the quality of a person’s life. Davidson et al. (1994: 354) note that this finding ‘is not easily accommodated within the essentially rationalist or utilitarian philosophy underlying the idea of screening’.
One aspect of remaining ignorant is that it allows the maintenance of hope. Many lay people are happy to tolerate uncertainty because of the hope that they will survive.

The premise of much genetic testing is that people understand the basic principles of inheritance. However, this may not always be the case. In an interview study of members of families at risk of familial adenomatous polyposis (FAP), which geneticists consider to be almost 100% genetic, Michie et al. (1996b) found that many referred to what they considered to be the vital role of the environment. Many of the family members also minimized the threat posed by the disease. While advising these people that they are at risk may be formally correct, it has immense implications for the future quality of their lives.

Riley et al. (2012) present recommendations on the essential elements of genetic cancer risk assessment, counselling and testing on behalf of the National Society of Genetic Counsellors in the USA. They argue that psychosocial assessment should be part of both the pre-test and post-test genetic counselling process, beginning by identifying the patient’s primary reason for seeking the consultation and enquiring about the patient’s current understanding of cancer genetics risk assessment and testing process. The skills required by genetic counsellors are complex and far-reaching. The counsellor should address any misconceptions in a sensitive manner and help the patient with his/her cancer worry, intrusive thoughts, depression, anger, fear, guilt, family experiences with cancer, perception of risk for self and others, competence for giving informed consent, social stressors and supports and networks, family communications and readiness for testing.

**IMMUNIZATION**

Immunization is the procedure whereby those individuals who are most susceptible to contracting certain communicable diseases are administered a vaccine. This procedure is aimed at both the immediate protection of individuals and immunity across the whole community where the uptake rate is high. Over the years, various vaccines have been developed for specific diseases.

In the mid- to late nineteenth century several countries began to introduce vaccines to prevent specific diseases. In the UK, laws were passed making smallpox vaccination of children compulsory. However, this was not always met with approval and in some countries led to the development of anti-vaccination societies (Blume, 2006). This was perhaps not surprising in view of the organization of public health practice at that time, but gradually this opposition declined and a range of vaccines have been introduced over the past century. According to current public health agencies, immunization is now one of the most successful examples of the primary prevention of disease. However, as McKeown (1979) emphasized, the specific impact of vaccination programmes should not be confused with the health benefits of improvements in living and working conditions.

Despite the apparent success of mass immunization programmes (Figure 16.1), a substantial proportion of individuals are not immunized against certain diseases. Indeed, this has given rise to what has been described as a new anti-vaccination movement (Blume, 2006). An understanding of this participation of people in mass vaccination programmes requires an exploration of individuals’ perceptions and the broader social context.
PSYCHOLOGICAL MODELS OF IMMUNIZATION

There is a large body of research using different social cognition models (SCMs) to predict uptake of vaccination. A common feature of these models is risk perception. In a meta-analysis of 48 such studies, Brewer et al. (2007) distinguished between three dimensions of risk that were termed perceived likelihood, perceived susceptibility and perceived severity. These dimensions are detailed in Table 16.1. A fourth dimension – perceived risk if you do not take the health-protection action – was also noted. However, since this dimension was seldom reported in research, it was not included in the meta-analysis.

The results of the meta-analysis showed that:

- Those perceiving a higher likelihood of getting an illness were more likely to be vaccinated.
- Those who perceived themselves to be more susceptible to a particular illness were more likely to be vaccinated.
- Those who perceived the severity of the particular illness to be higher were more likely to be vaccinated.

It could be argued that these relationships were simply post-hoc rationalizations for receiving the vaccinations, i.e., after being vaccinated the individuals justified their actions by emphasizing...
Table 16.1  Dimensions of risk

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Description</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived likelihood</td>
<td>Probability that one will be harmed by the hazard</td>
<td>‘If I don’t get immunized, there is a high chance I’ll get the flu’</td>
</tr>
<tr>
<td>Perceived susceptibility</td>
<td>Constitutional vulnerability to a hazard</td>
<td>‘I get sick more easily than others my age’</td>
</tr>
<tr>
<td>Perceived severity</td>
<td>Extent of harm that the hazard would cause</td>
<td>‘The flu can kill you’</td>
</tr>
</tbody>
</table>

Source: Brewer et al. (2007)

their perceived risk. However, the effect sizes for the prospective studies were larger than for the cross-sectional studies, suggesting that this was not the case.

It was also noted that the effect sizes were larger for influenza vaccination than for other forms of vaccination. This may have been due to a variety of factors, including:

- The non-flu studies included a wide range of vaccines, each with perceived characteristics.
- Flu vaccination is more familiar and contributes to a clearer perceived risk.
- The non-flu vaccines (e.g., hepatitis) require multiple vaccinations that may attenuate the risk perception.

A result of this meta-analysis was that the effect sizes were smaller for medical personnel. Brewer et al. (2007) suggest that this may be since perceived risk to the medical personnel themselves may be a lesser motivator than reducing the risk to their patients. In addition, it may be the case that medical personnel are required by their employers to be vaccinated. Some evidence on the importance of health professional identity was provided by a study conducted by Falomir-Pichastor et al. (2009) in Switzerland. This study involved a survey of nurses’ intention to receive the flu vaccination. They found that the more the nurses identified with their profession the more likely were they to perceive vaccination as a professional duty and the more likely were they to have been vaccinated.

Findings on the role of risk perception in explaining vaccination can be contradictory. For example, in an online experiment, Betsch and Sachse (2013) found that strong ‘no risk’ messages were followed by a higher perceived vaccination risk than weak ‘no risk’ messages. Further, there is evidence that the role of risk depends upon who the risk is for – self or someone else. For example, in a survey of parents, Tang et al. (2014) found that they were more willing to vaccinate their child than themselves. It was suggested that parents were likely to take a risk of non-vaccination for themselves, but they were anxious about doing similar for their child. Some evidence of this was found in a Q-methodology study of parental understandings of child vaccination (Harvey et al., 2014). In this study, parents completed a Q-sort task after their two-month-old infant had been immunized. Four factors were identified in the Q-sort as being important: A: ‘Because the doctor told me to’; B: ‘I know what’s best for my baby’; C: ‘Will they really be OK?’; and D: ‘Why wouldn’t you protect them?’ While there were differences between parents in which factors they stressed, all agreed that vaccination provided unrivalled protection against disease. However, those parents with factor C also had feelings of uncertainty about vaccine safety and its side effects.
Recently there have been attempts to expand SCMs of health behaviour to include emotional components. In the case of immunization, this has included emotions such as worry and regret. In a study of university employees, Chapman and Coups (2006) found that anticipated regret and worry were stronger predictors of vaccination than perceived risk. This would confirm that humans are less concerned about statistical estimates of risk and more with how they feel about the likelihood of something happening.

**SOCIO-CULTURAL CONTEXT OF IMMUNIZATION**

As with our earlier discussion of screening, there is a need to locate the cognitive view of the risk associated with immunization within a broader understanding of the meaning of immunization and infectious diseases and the socio-cultural context.

The widespread introduction of immunization programmes over the past two centuries is a major example of the power of medical science. However, this power has not been accepted unquestioningly. Blume (2006) has reviewed the growth of anti-vaccination movements over the past two centuries. When compulsory vaccination was introduced in the mid-nineteenth century it was opposed by a wide range of groups of people, including the middle class, who were concerned with threats to individual liberty, but especially by the organized working class, who opposed the growing power of the state in the disciplining of the body. In the 1970s the public concern about the safety of the pertussis vaccine led to a substantial fall in its uptake. More recently, moves to introduce a range of new vaccines have been met with varying degrees of support.

The swine flu vaccine was introduced into many countries in 2009. Although in some countries it was enthusiastically received, in others this was not the case. For example, in North America there were active campaigns against mass vaccination against swine flu, whereas in the UK, after some initial debate, support for it declined as evidence for the severity of the epidemic declined. This is probably a reflection of the greater medicalization of American society.

Dew (1999), in his review of changing media representations of measles, argues that the dominant approach of the media has been an acceptance of the medical viewpoint. However, in this age of risk (Beck, 1986) the media can become a forum for challenging the accepted medical approach. A review of British newspapers during the 1990s found a substantial increase in reportage of vaccine-related topics (Cookson, 2002). Of note was the finding that an increasing proportion of these articles dealt specifically with concerns about the safety of vaccines. In addition, there are an increasing number of websites devoted to critical views of vaccination. This would suggest that the debates about the value of immunization that were current in the nineteenth century are again growing. It is within this context of confusion that individuals attempt to develop an approach that is personally and socially responsible.

**HEALTH CARE PROVIDERS AND IMMUNIZATION**

Besides the media, health professionals also have a very important role to play in creating a climate of support or opposition to immunization. Several projects have illustrated the variable view of medical practitioners. While public health officials may enthusiastically promote immunization, other health professionals may be less supportive. For example, there is evidence that family doctors have played a role in spreading fear about particular vaccines. A report in Britain
(Peckham et al., 1989) concluded that the main obstacle to parents having their child immunized was misconceptions concerning contra-indications by the family doctor.

New and Senior (1991), in their interview study of mothers in north-west England, found that 53 out of 71 mothers who had not had their children fully immunized claimed that either their child was contra-indicated to the pertussis vaccine or their doctor had advised them against it. Further, many of the mothers said they had received conflicting advice from different health professionals that led to confusion and loss of confidence in such advice. Indeed, some mothers said it was the actual attempt by the health professionals to convince them of the minimal risk that deterred them. As one mother said, ‘Until they find a safe vaccine, one in 300,000 is still too large; I wouldn’t play Russian roulette with my child’.

In addition to the family doctor, ancillary health staff can contribute to parents’ anxiety about immunization. For example, Reddy (1989) conducted a survey of parents in a town in south-east England. He found that a frequent reason given for non-vaccination was that their child was ill at the appointed time. However, Reddy found that when he telephoned the parents most of those children who were supposedly ill only had a minor cold. When questioned, the parents said they were concerned about the dangers of vaccinating a sick child and that this concern had been shared by the health centre receptionist, leading the parent to defer the appointment.

**IMMUNIZATION AMONG CHILDREN**

Much of the debate and research on immunization has focused on children and their parents. The reason for this is that it is expected that from a very early age children receive immunization against a range of diseases, such as whooping cough, polio and measles. Despite substantial health care expenditure, immunization uptake among children is not comprehensive. For example, more than two-thirds of Primary Care Trusts (PCTs) in England (221 of 294) reported less than 85% coverage for MMR during 2003–2004. Indeed, the coverage fell below 70% in 19 PCTs (Henderson et al., 2008). As with adults, rates of immunization have been found to be lower among children from more disadvantaged communities and from certain minority ethnic communities.

New and Senior (1991) conducted detailed interviews with over 250 mothers from north-west England. They found that mothers with lower educational qualifications, mothers living alone, mothers with large families and mothers with a sick child were the best predictors of non-immunization. A study in the north of England (Reading et al., 1994) found that even after the establishment of an immunization programme, the relationship between immunization uptake and social deprivation remained. In this study, the immunization of four birth cohorts between 1981 and 1990 was examined. Although there was an overall increase in uptake, the rates remained lowest among the children from the most disadvantaged areas.

Several studies have identified a variety of reasons expressed by parents for not having their children immunized. These have been summarized by Meszaros et al. (1996) under five categories that focused on perceptions of risk and risk management (see Table 16.2).

In their study, Meszaros et al. (1996) attempted to assess the relative importance of each of these explanations in a questionnaire survey of readers of *Mothering*, a popular magazine read by mothers in the USA. They found that the most important predictors of parents having their child immunized were the perceived dangers of the vaccine, doubts about medical claims that vaccines are effective, omission bias, belief that physicians overestimate the dangerousness of the disease, perceived ability to protect their child, and perceived assessment of the likelihood of their child contracting the disease.
Following a series of reports in the 1990s of a possible link between childhood vaccination and autism, vaccination rates dropped. Subsequent reports have been strongly challenged, and childhood MMR vaccination rates for England steadily increased from 85.2% in 2006–2007 to 92.7% in 2013–2014 but there was a slight decline in the following two years to 91.9% in 2015–2016 (NHS Digital, 2016). However, anti-vaccination organizations continue to report this link, promoting fear and anxiety among parents. According to a Swedish study by Dannetun et al. (2005), parents report obtaining information on vaccination from the media (82%) and the internet (36%). A study of websites on vaccination found that nearly half contained vaccine critical information (Davies et al., 2002). Further, these websites often use emotional appeals and personal stories coupled with photographs and pictures. In an experimental study, Betsch et al. (2010) found that accessing a vaccine critical website increased the perception of risk due to vaccination.

This fear of the adverse effect of immunization may be particularly high in certain communities. In a study in England (Loewenthal and Bradley, 1996) it was found that the uptake of childhood immunization was particularly low among orthodox Jews. It was suggested by the mothers who were interviewed that the main reason for their low uptake was their fear of a negative reaction, logistical difficulties and unsympathetic treatment by health staff. According to the health professionals, the mothers’ fears were exaggerated because they lived in a close-knit community that perpetuated tales of bad reactions. A more recent study of a similar community by Henderson et al. (2008) emphasized the importance of the closed nature of the community, within which rumours about the harm done by immunization were combined with a general concern about the negative influence of the outside world on the Jewish community. Table 16.3 summarizes the main findings of the study.

Besides these factors, an additional element is the perceived relative risk. In a qualitative investigation of the views of a sample of inner-city parents in Baltimore, Keane et al. (1993) found that although some parents accepted that they or their children might be vulnerable to infectious diseases, other threats, such as drugs, street violence and ‘the wrong crowd’, were considered more severe. Further, vaccines were viewed as only partly successful. The continued occurrence of chickenpox was frequently cited as evidence of vaccine failure.

### Table 16.2 Parental reasons for non-immunization

<table>
<thead>
<tr>
<th>Reason</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk:benefit ratio</td>
<td>Perception that the risks of contracting the disease outweigh the benefits of being immunized</td>
</tr>
<tr>
<td>Individual risk</td>
<td>Belief that the societal statistics that public health planners use do not apply to their child. Further, the parents believe that they can protect the child from exposure</td>
</tr>
<tr>
<td>Ambiguity aversion</td>
<td>Aversion to options with ambiguous outcomes such that parents will prefer a straightforward Yes/No assessment of the likelihood of their child contracting a disease. When there is disagreement about potential risk they will err on the side of caution. Further, some parents may already be sceptical of medical information</td>
</tr>
<tr>
<td>Omission bias</td>
<td>Preference for acts of omission over acts of commission</td>
</tr>
<tr>
<td>‘Free riding’</td>
<td>Assumption that since most of their children’s peers have been vaccinated they are protected</td>
</tr>
</tbody>
</table>

Source: Meszaros et al. (1996: 698)
A frequent explanation given by mothers in several studies is the natural/unnatural distinction. New and Senior (1991) found that whereas vaccination was perceived by some mothers as unnatural, by implication whooping cough was natural and therefore acceptable. Admittedly, some other women had weighed up the benefits and risks of immunization and decided in favour of immunization. It would be expected that these were the women who were more accepting of the medical viewpoint.

This natural/unnatural distinction was also alluded to in a large German study by Weitkunat et al. (1998). They found that the most significant predictors of measles immunization were parental natural health orientation, advice of paediatrician, birth order position, dangerousness of measles, marital status, reliability of vaccination and smoking. They suggested that natural health orientation and advice of paediatricians may be interactive since individuals with a natural health orientation may select like-minded physicians. In a more detailed analysis of what they described as the subjective relevance of measles, they found that those who assessed the likelihood of contracting measles as high and the latency as low were more likely to have their children immunized. A more recent German study of Facebook groups (Betsch and Sachse, 2013) reported finding that those with a preference for conventional medicine also tended to have a positive attitude to vaccination.

Taken together these findings would suggest that while parents may be hesitant about having their child immunized because of their anxiety about the potential risk, this image is compounded by media speculation and by the contradictory advice they sometimes receive from health professionals. A recent study in the UK of parents who had had their child immunized found that most shared the view that vaccinations provided protection against disease (Harvey et al., 2015). For these parents, the process was stress-free. A minority still held the view that there was some uncertainty about the vaccine and they worried about the possible side effects. However, most felt that it was the right thing to do – it was part of their job of being a parent. This would tally with Tickner et al.’s (2007) view that the uptake of immunization among children has become the social norm in the UK.

However, there remain cultural differences. For example, a study in Slovakia investigated the perceptions of mothers and university students of pro-vaccination messages (Massaryk and Hatokova, 2016). They found that the participants were generally concerned about vaccination and that the various pro-vaccination messages did not reduce these concerns and even increased them in some cases. They concluded that this reflected a critical attitude to health professions and to authority such that in the face of ambiguity about the supposed health benefits they adopt a critical and more negative attitude towards vaccination.

A last point needs to be made about a more recent form of childhood immunization. The recent introduction of HPV immunization for 11–12-year-old girls has attracted substantial media and increasing research interest. A survey of parents of adolescent girls resident in

Table 16.3  Childhood immunization in an orthodox Jewish community

<table>
<thead>
<tr>
<th>Social network</th>
<th>Advice circulated through local networks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Media</td>
<td>Stories from mass media coupled with negative feelings about outside world</td>
</tr>
<tr>
<td>Safety</td>
<td>Separation of community from outside influence led to feelings of safety</td>
</tr>
<tr>
<td>Danger</td>
<td>Immunization was perceived as ‘putting the disease in the child’</td>
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Source: Henderson et al. (2008)
North Carolina (Reiter et al., 2009) found that the dimensions of the HBM were predictors of vaccine uptake by their daughters. Parents who reported their daughter had been vaccinated were more likely to perceive the HPV vaccine as effective, perceived fewer barriers and harms, and were also likely to be confident their insurance covered the cost. Although there has been media discussion about the sexual connotations of HPV immunization, they did not find that anticipated regret about greater sexual activity by their daughter was an independent predictor of HPV uptake. However, another study did find some evidence of such a relationship (Ziarnowski et al., 2009).

There remains considerable uncertainty about this new vaccine. A survey of mothers of teenage girls conducted in Texas (Baldwin et al., 2012) found that those parents who perceived their daughters as being vulnerable were more likely to talk with others and their physician about the vaccine. However, people from ethnic minorities were less likely to discuss this vaccine with others. This is a new form of immunization and the role of socio-cultural factors is of obvious importance.

Despite considerable efforts to promote this vaccine, several studies have confirmed that parents remain apprehensive. In a review of studies, Jacobson et al. (2013) identified that the three main perceptions discouraging mothers were the perception that the vaccine was not needed by their daughter, that it was potentially harmful, and that their child was too young because she was not sexually active. Related to the latter perception was the anxiety that having the vaccine might promote earlier sexual activity. There is no evidence for this concern.

Although the target population for HPV vaccination is 11–12-year-old girls, there have been programmes aimed at promoting its uptake among young women. The rates of uptake remain low, with an estimated 18–41% of 18–26-year-old women in the USA reporting uptake (Daley et al., 2010). A survey of college-age women in the USA (Ziemer and Hoffman, 2012) found that although perceived benefits was the major predictor of vaccination intentions, many of the unvaccinated women expressed the view that it was not necessary for them since they did not perceive themselves as being at risk. Gerend et al. (2013), in a survey of young women, found that those not intending to be vaccinated cited global concerns about vaccine safety and low perceived need. A study in the UK found that although financial incentives increased uptake among young women, the overall uptake remained low (Mantzari et al., 2015).

### Anti-vaccine conspiracy theories

One factor in people’s resistance to vaccination stems from the belief that vaccinations are dangerous. This idea is promoted quite heavily on anti-vaccination websites and blogs on the internet. There are many prominent alleged conspiracies to be found there, such as the NASA moon landings of 1969 being televised from a film studio, President J.F. Kennedy murdering Marilyn Monroe, the CIA in turn murdering President Kennedy, the Duke of Edinburgh murdering Princess Diana, 9/11 being cleverly arranged by President Bush so companies he had an interest in could grab some oil wells in Iraq, and global warming being a total myth. Vaccination programmes have been the subject of some equally popular conspiracy theories, one of the main ones being that Big Pharma has created evidence supporting vaccinations purely to promote expensive but ineffective vaccines.

The potential impact of anti-vaccination conspiracy theories on vaccination intentions was investigated empirically by Jolley and Douglas (2014). The results suggest that conspiracy theories can be influential. In one study, British parents completed a questionnaire measuring beliefs in anti-vaccine conspiracy theories and the likelihood that they would have a fictitious
child vaccinated. A significant negative relationship was found between anti-vaccine conspiracy beliefs and vaccination intentions mediated by the perceived dangers of vaccines, and feelings of powerlessness, disillusionment and mistrust in authorities. In a second study, participants read information that either supported or refuted anti-vaccine conspiracy theories, or a control condition. Participants who were exposed to material supporting anti-vaccine conspiracy theories showed less intention to vaccinate than those in the anti-conspiracy condition or controls. The effect was mediated by the same variables as in Study 1. Jolley and Douglas’s findings pointed to the potentially detrimental impact of anti-vaccine conspiracy theories, and highlight their potential role in shaping health-related behaviours. Disinformation can be an effective influence on behavioural intentions, so it would seem.

In her review of the role of risk communication in vaccination decision-making, Reyna (2012) emphasized that people with limited knowledge of an issue are more likely to engage in superstitious thinking linking vaccination with adverse events that occur around that event. Downs et al. (2008) criticized official communication as being cryptic, while anti-vaccine communications were more coherent.

In the case of HPV vaccination, there remains substantial opposition to its promotion. Although there is evidence that HPV vaccination can reduce infections (Garland et al., 2016), opposition to its uptake is often from a moral standpoint because it is promoting greater sexual activity among young people. Here health psychology must balance the competing interests of medical/health and moral/cultural agendas, with the former enmeshed with the risk of the increasing medicalization of society (Hayes, 2016).

CONCLUSION ABOUT DISEASE PREVENTION

The development of screening and immunization programmes designed to prevent the onset of specific diseases is premised upon a scientific model of risk, with less attention being given to the social and psychological features. While psychological research has tended to focus on the role of individual perceptions of risk, these need to be studied within the broader socio-cultural context.

FUTURE RESEARCH

1. There is a need for further research on breast self-examination.
2. Modern health care is pervaded by notions of risk control. There is a need to critique the relative contribution of prevention programmes.
3. There are substantial social and ethnic variations in participation in screening and immunization programmes. Research needs to explain the varying meanings of these programmes to population sub-groups.
4. The media plays a significant role in shaping lay people’s understanding of vaccination. There is a need for research to consider the influence of different forms of media, including conspiracy theories.
5. Genetic research has rapidly produced a host of social, psychological and ethical issues. There is a need for an expanded programme of research to investigate both professional and public perceptions of genetic screening and the impact on different populations.
SUMMARY

1) Many countries have implemented screening programmes for different forms of cancer. Participation in these programmes varies substantially.
2) Psychological factors associated with the use of these programmes connect with the socio-cultural context.
3) The health professional – especially the family doctor – is central to explaining participation in these programmes.
4) The so-called ‘genetic’ revolution has many implications for screening.
5) Both the public and people who are at risk of certain diseases have a variety of concerns about genetic screening.
6) A wide range of immunization programmes have been developed for adults and children.
7) A central feature in the uptake of immunization is perceived risk, but this needs to be considered within its socio-cultural context.
8) The health professional plays a significant role in deciding whether parents have their children immunized.
9) Parents have a range of fears and anxieties about childhood immunization.
10) Irrational fears and beliefs exert a powerful influence on intentions and decisions.