

# The role of primary care in bioterrorism, epidemics and other major emergencies: failing to plan is planning to fail

**F**OLLOWING 11 September we all face new threats. Any epidemic and most major chemical or nuclear events will have a profound impact across the health service, including primary care.<sup>1</sup> In the summer of 2001 — before 11 September — the Americans held a prescient planning exercise called 'Dark Winter'. Local government, health service providers, and emergency services were asked to respond to an imaginary terrorist release of smallpox in three Oklahoma shopping malls. Despite instituting marshal law, services were quickly overwhelmed and, in real life, the United States (and the world) would have been engulfed by a major smallpox epidemic. The main lesson was that players consistently responded too slowly and too chaotically to have any chance of containing the disease. Such threats are not limited to the deliberate attacks on New York or the subsequent releases of anthrax. Bioterrorism and a growing range of other problems<sup>2</sup> categorised by the term 'health protection',<sup>3</sup> make a review of primary care's role in emergency planning essential.

First, there is the ever-present risk of a pandemic (defined as a worldwide epidemic), a more pressing threat than in the past owing to the increase in international travel. Many influenza experts believe<sup>4</sup> it is simply a matter of time before a major antigenic shift leads to an influenza pandemic.<sup>5</sup> There is also the spectre of entirely new agents wreaking havoc. Since the 1970s, over 30 previously unknown infectious diseases have been identified; HIV, vCJD and Ebola virus being the most notable examples.<sup>6</sup>

Secondly, the modern growth of container traffic has made it much easier to import materials for making weapons, such as chemicals or nuclear devices, into the centres of our cities. In October 2001, a container in Italy was found to hold an Al-Qaeda terrorist with supplies enabling him to survive the sea journey to North America.<sup>7</sup> Currently, less than 2% of containers are inspected *en route*.

The Chief Medical Officer has recently proposed a new health protection strategy to deal with threats from communicable diseases, acute chemical or radiation incidents, and bioterrorism.<sup>6</sup> From April 2003 there will be a new national agency, to be called the Health Protection Agency (HPA), which will subsume several national bodies, including the Public Health Laboratory Service, and provide an integrated approach nationally.

The new agency will employ the local health protection teams, led by consultants in communicable disease control, who will take responsibility for investigating outbreaks and incidents and ensure co-ordination across local health and emergency services.

The HPA will also advise on local and regional health emergency planning arrangements, with regional co-ordination being supplied from the nine Government Offices. At local level, primary care organisations (PCOs) should

already be part of local emergency planning arrangements. Recent guidance states '[it] will be necessary to ensure that the emergency planning function previously carried out by health authorities is effectively taken forward by PCTs [Primary Care Trusts]'.<sup>8</sup> Despite this, it is likely that for many PCOs the emergency planning agenda has not yet been given a high priority. This is likely to change as the major role of PCOs in health protection and emergency planning is clarified further.

These emergency planning arrangements are essential but far from sufficient. Any major event, such as an influenza pandemic or the detonation of a 'dirty' nuclear device, will demand swift, knowledgeable action from many more people than are currently involved with emergency planning. Front-line staff in primary care may be called upon to deliver control measures swiftly, efficiently and amid intense public distress. Primary care staff will have to educate themselves about the technical aspects of a rapidly evolving situation. They may have to identify high-risk groups and present hard choices to their patients.

Preparation for these roles is vital. In a recent letter to all GPs, the Deputy Chief Medical Officer said, 'We need to ensure that [our plans] for such emergencies become part of the routine ... One of the main priorities is ... that staff feel they have the skills and confidence to face any of these threats'.<sup>9</sup> But preparation is also difficult — how to prioritise the rare but catastrophic amid the press of the everyday?

British primary care starts from a position of some strength. Firstly, surveillance is being strengthened by using the call pattern to NHS Direct to identify the occurrence of an unexpectedly high incidence of calls for 10 common symptoms, such as fever, diarrhoea, and cough.<sup>10</sup> Secondly, GPs, practice nurses, health visitors and school nurses form a cadre that is — potentially — capable of delivering population-wide measures rapidly and consistently. Thirdly, these professionals already have experience of delivering population-wide immunisation programmes (for example the annual influenza programme, which reaches around 70% of people aged over 65 years) and of responding to sudden, high-profile infection scares. In addition, health visitors have specific duties to develop population-wide public health measures that include systematic immunisation programmes and messages about health. Finally, primary care is known and trusted by the public. If millions did have to be vaccinated systematically, and to a tight, regulated schedule, the organisation provided by British general practice is a good place to start.

However, at least three more things need to be done to enhance the potential of primary care to respond to major national emergencies. First, conceptually and organisationally, these issues need sharper focus. PCOs and general practices should see emergency planning as a clear and valued function that must be delivered in concert with the

rest of the NHS and with other agencies, such as the emergency services. Second, primary care professionals and PCOs need training in how to deal with the technical, organisational, public relations and psychological issues created by major emergencies, such as bioterrorism and epidemics. Finally, this needs to be done in a sustainable and efficient way that does not add unduly to already overburdened practices and PCOs.

The key to dealing with these threats is training. Practices and PCOs need to participate in emergency planning events that draw a range of local agencies together. This training programme could be led by the HPA and would cover a variety of scenarios, from an influenza pandemic through biological attacks to major nuclear accidents. Such inter-agency training would ensure that in a real emergency there was a web of pre-existing relationships and understanding to draw on.

Instituting a programme of training would provide practices and PCOs with a clear focus around which to develop emergency planning. Participation in scenario events would, over time, create a substantial body of people with enhanced skills. Links between primary care and others, within the NHS and beyond, would be strengthened while adding little to workload. Once established, a training programme could be rapidly expanded should international events warrant it.

Hoping for the best, but planning for the worst, seems a sensible strategy for these uncertain times. The new Health Protection Agency provides the framework through which PCOs and practitioners may be able to build the practical

skills that one day we may all desperately need.

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# Disfigurement — neglected in primary care?

THE membership examination of the RCGP lays particular emphasis on advocating that a practitioner explores the ideas, concerns, and expectations of a patient and so reaches a shared understanding within a consultation. However, training at any level, undergraduate or postgraduate, should further increase the insight of general practitioners (GPs) concerning the psychosocial consequences surrounding objective and self-perceived disfigurement and of the methods of help available.

Although research into the psychological and social aspects of appearance and disfigurement presents a range of difficulties, it is important for GPs to increase their understanding of body image dissatisfaction. In addition, GPs should be aware of its potential to reduce an individual's functioning and possible presentation as illness, together with effective methods of support and intervention.

During a person's life, dissatisfaction with or impairment of the body image or face may result from a congenital condition, trauma, obesity, acute or chronic disease, or the developmental changes associated with adolescence and ageing.<sup>1</sup> Following a Government survey in the late 1980s, it was estimated that about 400 000 children and adults in the United Kingdom have a scar, mark or deformity which severely affects their ability to lead a normal life. Many oth-

ers have more minor but nonetheless noticeable disfigurement.<sup>2,3</sup> This statistic excludes those with the kind of disfigurement that can be covered by clothes and may reflect just the 'tip of an illness iceberg', as there is also a group of people who, although not objectively disfigured, perceive their appearance in very negative terms.

The psychological and social effects of disfigurement are well charted.<sup>4</sup> People who have an objective disfigurement may present to a GP with a range of physical and psychosocial problems.<sup>5-7</sup> The impact varies between individuals and the severity of the disfigurement need not equate to the level of distress; a counter-intuitive finding from research that has important implications. So, for example, some people with multiple plaques of psoriasis and possible associated stigma may not consult, while those with more minor blemishes consult frequently. Patients with potentially serious skin lesions may delay seeking treatment, fearing scarring following possible surgical excision.

There are body image issues associated with chronic diseases, such as diabetes, especially in the newly diagnosed. Adherence to a recommended treatment regime may also be poor, as people may wish to avoid the weight gain often associated with insulin. Diseases such as cancer may cause a rapid change in appearance; similar effects may occur

after a cerebrovascular accident. In conditions such as arthritis, a GP's attention is frequently focused on the pain and lack of mobility, but not on the distress caused by the associated distortion of joints and change in gait.

Those disfigured by accidents, such as those scarred from burns, may consult wishing to reduce or remove the signs of trauma. Parents of children born with congenital disorders (for example, Down's syndrome) may seek interventions to make their child look 'normal'. They may face a range of challenges in supporting their children through surgery, school, and adolescence when teasing and bullying is commonplace. People who have disfigurements, in particular to the face, may be disadvantaged through first impressions of appearance and so gaining employment can be a significant challenge,<sup>9</sup> despite the fact that severe disfigurement is covered under the Disability Discrimination Act.

The high and unrealistic pressures exerted by the media and society, to have a youthful and unblemished appearance make children, adolescents, and adults without objective disfigurements vulnerable. They may believe that others evaluate their worth, largely on the basis of their looks. These issues can form the hidden agenda of a consultation in which they fear that dissatisfaction with their appearance or body image may not be considered 'legitimate'. There is an almost unnatural preoccupation to physical appearance in the mass media. Some children recall the agony of their school days and powerlessness through teasing and bullying resulting from apparent disfigurement. Exposure to the 'ideal' portrayed contributes to body image disturbance and associated eating disorders.<sup>9</sup> This may have an influence on the increase in demand for plastic surgery in Westernised countries. With an increasing market in this field of medicine, there is a potential for a conflict of interest with financial gain.<sup>10</sup>

Thus, where surgical intervention is sought for disfigurement or appearance-related concerns, individuals should be carefully counselled as to the possible degrees of success and severe NHS resource limitations, so that they can adjust their possibly unrealistic expectations and focus on additional strategies to come to terms with their feelings about their appearance.

Whatever the cause, concerns about appearance and inability to cope can predispose people to substantial impairment in personal, social, and occupational functioning, and may result in anxiety, depression, and social isolation.<sup>4</sup> Those affected can feel trivialised by healthcare professionals and may become increasingly distressed.

Consultations involving body image concerns present a practitioner with a number of dilemmas: either to implicitly acquiesce with 'social norms' by referral to a specialist surgeon; or to challenge them, helping people to increase their social confidence and avoid inappropriate medicalisation. Referral to a specialist clinic is clearly an option, but this biomedical approach may not be the most appropriate. While efforts to 'normalise' the appearance of those with marked disfigurements are often beneficial, few medical interventions completely remove a disfigurement and most are left with residual marks and scars. Promises of a 'cure' may even exacerbate existing problems by promoting unrealistic expectations of change. By treating the physical aspects of disfigurement in isolation, there is a danger of reinforcing the

'myth' of a simplistic relationship between improvements to physical appearance and enhanced quality of life.<sup>11</sup>

Other possibilities for support and intervention include referral to organisations that have developed self-help leaflets, books and videos. These are designed to enable children, young people and adults, who have disfigurements of any kind, to acquire improved social skills and self-esteem (see, for example, the resources of the UK charity, Changing Faces — [www.changingfaces.co.uk](http://www.changingfaces.co.uk)). Workshop and family activities in disfigurement have also been shown to facilitate the sharing of experiences and offer a safe, non-threatening environment for emotional disclosure and social skills development.<sup>12</sup>

Encouraging this self-management approach appears to hold considerable potential for people with body image concerns of all sorts. The emphasis of these interventions is on increasing an individual's ability to manage the symptoms, treatment, psychosocial consequences, and lifestyle changes associated with a particular condition. The participant is encouraged to acquire the cognitive, emotional, and behavioural responses necessary to achieve an enhanced quality of life through a continuous process of self-regulation.<sup>13</sup> Community-based programmes that have been subjected to randomised controlled trials include Arthritis Self-Management Programmes<sup>14</sup> and the Chronic Disease Course.<sup>15</sup> Perhaps the time is now right for a community-based self-management programme to be developed in relation to disfigurement and body image.

Another way forward is for a partnership between the skills of plastic surgeons and those of social skills trainers, helping people to come to terms with their appearance.<sup>16</sup> The Disfigurement Support Unit, known as the Outlook Unit, at Frenchay Hospital in Bristol, is a unique prototype of what can be achieved.<sup>17</sup> Gaining self-confidence and learning to live with disfigurements enables people with any form of disfiguring condition to strengthen their self-esteem and overcome perceived and actual social interaction problems, such as in the school playground or in gaining employment.<sup>18</sup>

Assessing the impact of a disfiguring condition and the results of various interventions requires repeated in-depth interviews, together with standardised measures of emotional (e.g. social anxiety, depression) and behavioural (e.g. social avoidance, occupational effects) impairment. Far more research is needed at a primary care level to assess the extent and types of need, beliefs, and different interventions. This is a particular challenge for the Centre for Appearance and Disfigurement Research (CADR) at the University of the West of England, Bristol, which at present is the only centre of its kind in the world engaged in this research. ([www.uwe.fas/cadr](http://www.uwe.fas/cadr)) It is allied to the work of the charity Changing Faces, and is actively seeking funding. There is also a real need to educate both practitioners and the wider public to promote awareness of disfigurement, its impact, and how it can be managed.

For GPs and other service providers, the dilemma to fully inform those requesting surgery should be carefully balanced against the need to provide a positive approach to disfigurement and on how they can promote additional strategies for enhancing their self-confidence and self-esteem.

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