

“Hidden data provide  
new insights into life  
at the end...”

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## THE TRUTH ABOUT SUICIDE

Louise Bazalgette  
William Bradley  
Jenny Ousbey



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## Executive summary

Suicide continues to be an extremely important public health issue; while suicide rates have on average fallen during the last decade, national data show there were 4,390 suicides in England in 2009, which equates to 16.1 suicides for every 100,000 men and 4.8 suicides for every 100,000 women.<sup>1</sup> It is estimated that this translates to one death by suicide every two hours.<sup>2</sup>

However, despite the great importance of this issue to our collective wellbeing, there are remarkably few national data available to explain the different causal factors that may have led to these suicides. Some of the key risk factors for suicide are known; these include gender (men are at greater risk), unemployment, drug abuse and, crucially, mental illness, which is considered to be the most significant of these risk factors. However, there are very few data available on the relationship between characteristics such as physical health or ethnicity and suicide.

Suicide in the context of serious physical illness has become an increasingly important focus of public attention in recent years, as growing numbers of UK citizens with chronic or terminal conditions travel to Dignitas in Switzerland to receive assistance with suicide. Also, in one very high-profile case recently, a woman with motor neurone disease took her own life in the UK to avoid experiencing the progression of this disease.<sup>3</sup> There is also an emerging body of research evidence demonstrating that chronic and terminal illnesses can be a significant risk factor in suicide.<sup>4</sup> However, no national data are currently collected on the proportion of suicides that involve people with physical illnesses to monitor the extent of the problem. As a result, the role of physical illness as a risk factor for suicide still has a very low profile in national and local suicide prevention strategies and has remained largely unexplored by national policy makers.

Demos has undertaken this important piece of research to fill this evidence gap and investigate what proportion of the individuals who die through suicide in England each year had a terminal or other severe physical illness that may have been a factor in their suicide. The research methodology that was used to conduct this study, the key findings from our primary research, and a series of targeted policy recommendations on the basis of these findings are set out below.

### Research methodology

#### Desk-based scoping exercise

The research methodology for this study began with a desk-based scoping exercise to identify key academic evidence of the relationship between physical illness and suicide. We completed a policy review to build a detailed picture of the current national and local policy response to suicide and particularly suicides among people with chronic and terminal illness.

#### Freedom of information requests to primary care trusts

The first stage of the primary research involved gathering quantitative data from across the country on the relationship between suicide and physical illness. We sent information requests to all primary care trusts (PCTs) in England (147), using the Freedom of Information Act. We chose PCTs because government policy recommends that PCTs conduct annual suicide audits to explore suicide trends in their district, and, unlike coroners, PCTs must respond to freedom of information (FOI) requests.<sup>5</sup> We asked PCTs to provide information on the numbers of suicides within their district for which they had evidence that the deceased person had experienced one of the following: physical illness, chronic illness, terminal illness, pain, physical impairment or disability, or a specific form of physical illness or health condition.

### Semi-structured interviews with coroners

We supplemented the data from PCTs with qualitative, anecdotal evidence about the links between suicide and terminal or chronic illness, collected from interviews with coroners in England. We initially contacted all chief coroners in England as part of the research and 15 serving or recently retired coroners agreed to an interview, although some chose to remain anonymous.

### Case study of Norwich County Coroner's District

To provide concrete data to supplement the anecdotal evidence provided by the coroners, we chose a case study district (Norwich District) and examined the suicide inquest files from May 2006 to December 2010 in detail to identify the proportion of suicides that involved people with terminal or chronic health conditions.

### Semi-structured interviews with expert organisations

We conducted interviews with representatives from several organisations connected to suicide and terminal illness including the director of a suicide prevention charity, the medical adviser for a right-to-die group and a commissioning manager from a PCT.

## The research findings

### Freedom of information requests to primary care trusts

Twenty-nine PCTs were able to provide some of the requested numerical data, and a larger number provided some form of relevant qualitative or numerical data. However, 75 PCTs were unable to provide any data relevant to suicide and terminal illness at all.

The numerical data that each PCT provided for each category of health condition were averaged across the total number of suicides and the number of years for which they provided information. The results for each category were then averaged across the total number of PCTs that provided information, to find an overall figure for the percentage of suicides that involved that category of health condition.

These are our findings, derived from the 29 PCTs that were able to provide numerical data. The overall average annual suicides in England:

- across all 29 PCTs: 27.8 deaths
- involving a terminal illness: 2.1 per cent
- involving chronic illness: 10.6 per cent
- involving physical illness: 8.2 per cent
- involving some specific form of physical illness or health condition: 21.4 per cent
- involving pain: 4.9 per cent
- involving physical impairment or disability: 3.3 per cent

It is important to note that methodological differences between PCTs, and difficulties in some cases in assigning individual cases of suicide to a particular category, mean we must be cautious about how we interpret these findings. In some cases the same person may have had a terminal illness and also a chronic condition, and may therefore have been included in both categories. Therefore, as there had been double-counting by some PCTs we cannot simply add these totals together. However, what we can take from this is a conservative estimate that approximately 2 per cent of all suicides that take place in this country are by people who are terminally ill, while approximately 10 per cent of suicides are by a person who is chronically ill. This finding has been corroborated by the other sources of evidence drawn on in the study.

### Semi-structured interviews with coroners

Demos gleaned the following key information from our interviews with coroners:

- Most coroners encounter several cases of suicide each year in which the deceased person was terminally or chronically ill. However, estimates of the frequency of these cases varied from 0 per cent to 10 per cent of all suicides.

- Some coroners did not think in terms of ‘terminal’ or ‘chronic’ illness, but instead focused on the particular medical condition that the deceased person had, such as cancer or motor neurone disease.
- Coroners vary in the extent to which they record information on physical illness in suicide inquest records. Therefore, inquest records may not accurately reflect the deceased person’s health status and PCTs may be underestimating the scale of the problem.
- Coroners vary in the extent to which they are willing to cooperate with other agencies performing local suicide audits.
- Several coroners indicated that they deliberately avoid probing into suspected cases of assisted suicide, often for fear of causing problems for the friends and family left behind. This suggests that the actual number of assisted suicide cases is also likely to be higher than official records suggest.

#### Case study of Norwich District Coroner’s office

The results of our detailed study of Norwich district’s inquest records revealed that 25 suicides, out of a total of 259 that took place over five years, involved a person with a diagnosed terminal or chronic illness. This amounts to 9.7 per cent of all recorded suicides during that time.

In 18 of the 259 cases, the deceased had a diagnosed chronic condition (6.9 per cent of all recorded suicide verdicts). In 8 of the 25 cases, the deceased person had a diagnosed terminal illness (3.1 per cent of all suicide verdicts). One person (4 per cent of the sample) had both chronic and terminal conditions at the time of death. In 44 per cent of the 25 cases that involved chronic or terminal illness, the deceased person had a condition that was progressive and was expected to worsen over time. Medical conditions identified in the inquest records included Parkinson’s disease, motor neurone disease, myalgic encephalopathy (ME), chronic arthritis, Huntington’s disease, Alzheimer’s and cancer.

### Implications of these findings

This report has uncovered new evidence, collected from coroners and PCTs, that approximately 10 per cent of suicides that take place in England involve people with either a chronic or terminal illness. It is likely that this figure may be a significant underestimate, as we also found anecdotal evidence that some coroners currently choose not to include relevant health information within their inquest records, which are frequently the main input to PCTs' suicide audits.

This evidence demonstrates that suicide among terminally and chronically ill people is much more prevalent, and a much greater problem than public policy currently recognises. In England in 2009, 4,390 suicides were recorded (the latest year for which figures are available). Therefore on the basis of this new evidence, we can estimate that in 10 per cent of these suicides, or 439 individual cases, the deceased person was experiencing some form of serious physical illness as an influencing factor. This finding provides a strong argument that people with chronic and terminal illnesses should be considered a 'high risk group' for suicide within national policy and much greater attention should be given to providing better medical, practical and psychological support to this group.

### Policy recommendations

On the basis of these findings, the report makes the following key policy recommendations.

#### Make local suicide audits a requirement

This study demonstrates that PCTs' responsibilities for collecting data and monitoring local trends in suicide are not sufficiently clear. In fact, ten of the PCTs that responded to our FOI request (7 per cent of the PCTs we contacted) told us that they do not conduct a local suicide audit and were unable to provide the required data. We believe that suicide is such a serious public health matter that suicide audits should not be optional; PCTs – and subsequently health and wellbeing boards – should be required to compile annual reports that explore in detail the

characteristics of people who died by suicide to inform the local policy response.

### Improve guidance on suicide audits for primary care trusts

Our research found that *fewer than 30* of all the PCTs in the country were able to provide relevant numerical data relating to underlying physical health issues experienced by the individuals who had died by suicide in their district over the last five years.

Therefore, better and more strongly enforced guidance for PCTs – and subsequently health and wellbeing boards – on how to conduct suicide audits is essential if we are to build a more meaningful national picture of suicides. This guidance should specify the minimum level of information that is required, allowing some flexibility in the range of ‘risk factors’, which are tracked locally. Information on the deceased person’s physical health, and specifically the existence of chronic and terminal conditions, should be part of these minimum requirements. Local agencies will need appropriate tools and guidance that can specify the type of data required and support them to achieve this.

### Clarify coroners’ duty to share information

Five of the PCTs that responded to our FOI request indicated that they had difficulty communicating with the local coroner’s office to collect information for their suicide audit. We also heard directly from some coroners that they did not think that it was part of their role to record health information within their suicide inquest records or to share this information with other local agencies. It is essential that there is greater clarity on the data that may and may not be shared: there should be national guidance on what personal information must remain confidential (such as the name of the deceased person) and what information coroners are expected to share with the appropriate agencies. This is an issue of national importance and it should not be left to individual coroners to decide their policies locally.

### Computerise inquest records

Demos's research with coroners also found that some coroners' processes for archiving inquest records were somewhat archaic, which can make the process of data-sharing cumbersome and problematic. To combat this problem, Demos suggests that coroners' inquest records should be computerised and made searchable only by authorised researchers that have the correct password. Different levels of security clearance could determine the information that was made accessible in each case. This would hugely contribute to the new suicide prevention strategy's goal of 'supporting research, data collection and monitoring'.<sup>6</sup>

### Legislate to improve the quality of inquest records

Coroners' practice on including health information in suicide inquest records currently varies. Demos recommends that to improve national data collection, coroners should be required to include details of the deceased's medical history as part of the inquisition form in box 3 of the inquest report. This would enable data collection at a local level – by PCTs or health and wellbeing boards – by the coroners in their areas, thus removing the need to add additional datasets for national audits and contributing important information for the purposes of suicide prevention. With a computerised system for recording inquest records (as recommended above), the Department of Health would be able to perform national analysis of the rates of suicide that involved terminal or chronic health conditions, thereby hugely improving our knowledge of this issue.

### The Office for National Statistics should provide detailed reporting of suicide trends

Asking PCTs to conduct suicide audits locally but failing to compile the data nationally is a missed opportunity. Following the reforms outlined above, it should be possible for the Government to compile more detailed national statistics on trends and risk factors for suicide, and it should certainly be possible for demographic information such as ethnicity, marital status and health status to be included within these reports.

Demos recommends that far more comprehensive information about those who die through suicide including health status, relationship status, occupation and recent life events should be included in annual national reporting to inform national and local policy responses to suicide.

### Improve support for people with chronic and terminal illnesses

The previous recommendations have all focused on the need to improve data collection and monitoring of suicides at a local and national level. However, it is of course essential that this information is acted on to improve medical, emotional and practical support for people with chronic and terminal illness who may be considering suicide, a group that this research estimates accounts for at least 10 per cent of all suicides.

Several of the research studies cited in chapter 1 found that there is a greater risk of suicide during the period immediately following a cancer diagnosis, while other studies identified a very close association between physical illness, depression and suicide in older people. The knowledge contained in these studies must be used to inform the provision of support by primary care services to people with chronic and terminal health conditions and much greater attention must be paid to the impact of poor physical health on an individual's mental health. Every general practitioner (GP) and PCT (and in future years, GP consortia and health and wellbeing boards) should be responsible for ensuring that appropriate local services are available to respond to the medical, emotional and practical needs of people who are coping with painful or limiting illnesses, and their carers.

In addition to informing the Coalition Government's current consultation on preventing suicide in England, this report will be submitted as evidence to the *Commission on Assisted Dying* chaired by Lord Falconer.



# 1 Current evidence on suicide and physical illness

This section will explore existing knowledge of the association between suicide and chronic and terminal illness and highlight the gaps in knowledge on this subject. Although there are a number of small-scale academic studies that have explored the association between suicide and terminal illness, the nature of relationship is evidently complex. There is evidence that the risk of suicide varies at different stages of an illness, and that there are many other factors that influence an individual's state of mind and desire to continue living. The first part of this chapter will briefly examine how terminal and chronic illness are defined, the second part will review international evidence on suicide and physical illness, and the third part will review the rather more limited UK evidence base on the relationship between suicide and physical illness.

## Defining 'terminal' and 'chronic' illness

### Chronic illness

A chronic illness is a long-term condition that will not necessarily cause someone's death. The Department of Health define a chronic disease as one 'that can only be controlled and not, at present, cured'.<sup>7</sup> Examples of chronic illnesses given by the Department of Health include diabetes, asthma, arthritis, heart failure, chronic obstructive pulmonary disease and a variety of neurological conditions.<sup>8</sup> However, providing a more specific definition of chronic illness is problematic:

*Chronic illness may be many things. A chronic illness can be incapacitating or not; it may have a sudden or a gradual onset; it may be fatal, potentially life shortening, or of no consequence to one's lifespan; and it may be progressive or unchanging... The same chronic disease may manifest itself*

*differently in individuals on the basis of factors such as age, sex, marital status, pre-illness fitness, ethnicity, and education.*<sup>9</sup>

Defining what is meant by a ‘long term’ condition is also contested. The Department of Health’s definition provides no time scale, while the American National Centre for Health Statistics defines a chronic illness as one lasting for more than three months, and some academic studies have concluded that the definition should state six months.<sup>10</sup> Chronic illnesses can also be divided into those that have an acute onset, such as a stroke, or a gradual onset, such as Parkinson’s disease, and the course of chronic diseases can take any of three forms: constant, progressive, or relapsing/episodic.<sup>11</sup>

### Terminal illness

Official definitions of terminal illness are few and far between. This reflects the difficulty of defining the term and the difficulty of making an accurate prognosis for terminally ill patients. Therefore various definitions abound. The Department for Work and Pensions observes that ‘clinicians define terminal illness as any illness that will end in death’, and in the context of Disability Living Allowance regulations states that someone with terminal illness is ‘more likely to die of their disease in the next six months than not’.<sup>12</sup> Some insurance companies classify a terminal illness as a physical condition that is expected to cause someone’s death within 12 months of the diagnosis.<sup>13</sup> Definitions of terminal illness have also been developed for legal purposes in the context of assisted dying legislation. The Oregon Death With Dignity Act defines a terminal illness as ‘an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months’.<sup>14</sup>

The Department of Health’s 2008 End of Life Care Strategy recognises the difficulty of defining when an illness becomes terminal and attaching any kind of time period to that definition:

*For some the start may be at the time of diagnosis of a condition which usually carries a poor prognosis, for example motor neurone disease or advanced liver disease. For others it will be at a point when there is a deterioration in a chronic illness and it becomes apparent that the likely prognosis is measured in months or possibly a year or two.<sup>15</sup>*

This description highlights the fact that there may not always be a clear distinction between chronic and terminal illness. While most people intuitively understand what is meant by terminal illness, it is actually notoriously difficult to identify objectively. The End of Life Care Strategy suggests that the ‘surprise’ question can be helpful to healthcare professionals as a way of broaching whether a patient is near to death: ‘Would I be surprised if the person in front of me was to die in the next six months or year?’<sup>16</sup>

In response to these complexities, we have not sought to develop an artificial definition of terminal illness for this study. Instead, we have taken the approach of recognising terminal illness to be a catch-all term that includes both specific incurable medical conditions that are known to end in death, such as motor neurone disease and Alzheimer’s disease, and a broader range of conditions such as cancer, which become ‘terminal’ only at the point when it is clear that the only likely outcome will be death.

### International evidence on suicide and physical illness

Studies conducted in a range of different countries have investigated the relationship between suicide and terminal or chronic illnesses. However, clear, causal relationships between physical illnesses and suicide are extremely difficult to determine as the wish to die in any individual will inevitably be influenced by a number of different factors in their life. Most academic studies in this area have aimed to identify whether there is an association between suicide and a particular illness, such as cancer, rather than looking more broadly at the relationship between suicide and chronic or terminal illness in general. Therefore, many of the conclusions that have been drawn in

these studies are specific to a particular condition and are not necessarily applicable to other terminal or chronic illnesses.

One piece of research conducted in Australia did attempt to investigate the broader relationship between suicidal thoughts and terminal illness by reviewing previous studies that had tackled this issue. The authors found:

*The prevalence of a high or persistent [wish to hasten death] among terminally ill individuals range between 8.5% and 17%... and fluctuate over time... often with a reduction in levels as clinical interventions are initiated.<sup>17</sup>*

However, this study was unusual in tackling terminal illness as a catch-all category and it did not explore the rates of completed suicides among the terminally ill. Therefore, we will proceed by examining suicide in the context of individual health conditions.

## Cancer

In recent decades, studies conducted in countries all over the world have explored the relationship between suicide and cancer, and their findings have consistently shown higher rates of suicide among cancer patients than in the general population.<sup>18</sup> One large-scale study conducted in the USA, which was published in 2008, found that patients diagnosed with cancer were nearly twice as likely to die by suicide than the general population.<sup>19</sup> Cancer covers a wide range of conditions, and studies have differentiated between the risk of suicide for people with different types of cancer.

The Surveillance, Epidemiology, and End Results (SEER) Program in the USA, which ran at the National Cancer Institute from 1973 to 2002, found that the highest rates of suicide were in patients with tumours in the lung and bronchus, stomach, oral cavity and pharynx, and larynx. However, the highest rates of all were found for people with pancreatic cancer.<sup>20</sup>

When investigating these trends, studies have found that cancer increases the likelihood of experiencing depression, which

can in turn increase suicide risk. One US study published in 2000 found that 17 per cent of the terminally ill cancer patients involved in the study had clinical depression, and 17 per cent had a desire for a hastened death.<sup>21</sup> Nearly half (47 per cent) of the clinically depressed patients showed a desire for a hastened death in contrast to 12 per cent of non-depressed patients, a fourfold difference.<sup>22</sup> Among patients who were neither depressed nor expressed feelings of hopelessness, none had a desire for a hastened death.<sup>23</sup> These findings demonstrate the importance of the relationship between physical and mental illness.

Studies have also identified the tendency of a greater suicide risk during the period immediately following diagnosis of the disease. One 2010 study of prostate cancer patients in the USA found that the risk of suicide was highest one to three months after diagnosis, decreasing (but remaining high) four to 12 months after.<sup>24</sup> An Italian study reviewing previous research also found that the risk of suicide in cancer patients is particularly high in the first year following diagnosis. The authors also pointed out that for some cancers, such as lung and pancreatic cancer, this first year may correspond to the terminal stage of the illness.<sup>25</sup>

However, a study published in 2006 by the National Cancer Institute that had tracked 700,000 international breast cancer patients between 1953 and 2002 concluded that a small but statistically significant increased risk of suicide can remain even 25 years after diagnosis.<sup>26</sup> As the authors state, suicide risk for most cancers decreases 'to expected levels' several years after diagnosis, therefore their findings 'may reflect the unique chronic and indolent nature of breast cancer with recurrences possible many years after diagnosis'.<sup>27</sup> The relationship between suicide risk and the time following diagnosis of a physical illness is of course dependent on the time since diagnosis and whether the illness is chronic and prone to relapses.

### Multiple sclerosis

Studies exploring the relationship between multiple sclerosis, a chronic and often progressive neurological illness, and suicide

have also identified the higher likelihood of suicidal thoughts, and higher rates of suicide among people with multiple sclerosis. Canadian research published in 1991 found that suicide rates in multiple sclerosis were up to 7.5 times greater than for people in the same age group in the general population.<sup>28</sup> However, contrary to this study, a more recent Finnish study that followed a sample of 1,595 multiple sclerosis patients between 1964 and 1993 found that multiple sclerosis patients did not have a significantly increased risk of suicide in comparison with the population in general.<sup>29</sup> The disparity between these findings must caution us to be careful about drawing general conclusions about the association between multiple sclerosis and suicide, outside the social context of the study and the lives of the individuals concerned.

A smaller study published in 2010, based on 16 interviews with people aged between 21 and 64 in North America who had multiple sclerosis, identified higher suicidal ideation among these individuals compared with the general population.<sup>30</sup> The study also drew attention to the increased prevalence of depression in people with multiple sclerosis; estimates suggest that between 36 per cent and 60 per cent of multiple sclerosis patients will suffer from major depression at some point during their life, which is associated with an increased risk of suicide.<sup>31</sup> The study also explored the emotional and social effects of multiple sclerosis, which may be associated with suicidal tendency. These included increased family tension, loss of gendered identity, hopelessness and frustration, failure or anticipated failure to perform a desired social role, and loneliness.<sup>32</sup>

In all 16 of the interviews with multiple sclerosis patients that took place in this study, the participants reported loss of control as precipitating suicidal thoughts.<sup>33</sup> The authors suggest that a possible explanation for the high prevalence of suicidal ideation in multiple sclerosis 'is that it may offer persons with multiple sclerosis a mechanism for feeling in control of their lives, in the face of a daunting unpredictable disease', although it could also be indicative of severe depression.<sup>34</sup>

### Huntington's disease

Huntington's disease is a progressive neurodegenerative disorder that causes physical deterioration as well as cognitive and emotional changes including depression. Studies of suicide in people with Huntington's disease, have found that rates are between five and ten times higher than in the general population.<sup>35</sup> To explore this association further and identify the specific relationship between the stage of the disease that the patient had reached and that individual's experience of suicidal thoughts, a study conducted in 2005 developed a scale in which stage 1 is 'early' in the disease and stage 5 is 'the end stage'.<sup>36</sup> This study found that higher levels of suicidal thoughts were not linked to the increasing severity of the disease. Instead, 16.7 per cent of the sample had suicidal thoughts at stage 1 of the disease, 21.6 per cent at stage 2, and then 'the proportion of Huntington's disease patients with suicidal ideation diminished thereafter'.<sup>37</sup> This may suggest that people suffer more initially in the early stages of the illness, but are subsequently able to adjust and learn to adapt to accommodate their new circumstances.

### Parkinson's disease

Parkinson's disease is a progressive disorder with an aggressive chronic course. Parkinson's disease frequently affects patients with emotional disorders and unsatisfying sleep patterns that can impact on the quality of life the patient and increase the risk of depressive states and suicidal tendencies. A study of 144,364 individuals living in the USA with Parkinson's disease conducted between 1991 and 1996 found that 122 died by suicide.<sup>38</sup> According to this study, rates of suicide in patients with Parkinson's disease were ten times lower than those in the general population (0.08 per cent compared with 0.8 per cent).

The study found that the social profile of patients with Parkinson's disease who committed suicide was 'virtually identical' to the study's referent population, except for marital status. Perhaps unexpectedly, the study found that the rates of suicide among married people with Parkinson's disease were higher than for those who were single. The authors of the study suggest that dependency on caregivers may make patients more

vulnerable to suicide, perhaps because the patient feels responsible for the emotional impact on their loved one of having to assume a care-giving role.<sup>39</sup> The study also found that those who died by suicide were mostly men (82.79 per cent of the sample) and that the rate of suicide peaked around retirement.<sup>40</sup> However, the research showed no apparent distinctions on the grounds of age and duration of the disease.

### Motor neurone disease

Motor neurone disease is an illness that causes the progressive degeneration of the upper and lower motor neurons. Life expectancy depends on a range of factors, including the age of onset, with motor neurone disease typically developing in people who are about 50 years old. The duration of survival after diagnosis varies considerably between different variants of motor neurone disease, and may range from six months to more than five years.<sup>41</sup> The limited amount of research into the psychological impact of motor neurone disease, including suicidal tendencies, reflects the prioritisation of research into the disease's physical symptoms. However, research on the former has indicated that high levels of helplessness, depression and distress can have a significant impact on the prognosis for motor neurone disease.<sup>42</sup> While patients with motor neurone disease have historically been identified as stoic, recent research suggests that 50 per cent of patients have moderate to severe depression.<sup>43</sup> It is usually hopelessness, rather than depression that has been used in the literature to describe the relationship between motor neurone disease and suicidal ideation. Research found that among a sample of 136 motor neurone disease patients, 22 per cent felt moderately hopeless and 10 per cent severely hopeless, with higher levels of hopelessness increasing the risk of suicidal thoughts.<sup>44</sup>

### HIV/AIDS

Whereas HIV/AIDS was initially considered to be a terminal illness with a bleak prognosis when it was first recognised in the

1980s, HIV is now considered to be a chronic and controllable disease, following the introduction of highly active antiretroviral therapy (HAART).<sup>45</sup> Research conducted before the introduction of HAART consistently showed higher levels of death by suicide and suicidal ideation among people who were HIV-positive compared with those who were HIV-negative.<sup>46</sup> In an Australian study of 65 HIV-negative and 164 HIV-positive homosexual or bisexual men in Brisbane, Keiser et al found that symptomatic HIV-positive men were most likely to have a high suicidal ideation, followed by HIV-positive asymptomatic men.<sup>47</sup> Research has also shows that the widely recognised gender imbalance of suicide is also seen in HIV: a study conducted in 1989 found that around 1 in 5 HIV-positive men in contrast with 1 in 15 HIV-positive women admitted to suicidal ideation.<sup>48</sup>

However, while HIV itself is more controllable following the introduction of HAART, it is clear that the condition still presents a high risk of suicide not least because of the perceived social stigma still associated with the disease. Research published in 2007 with a sample of HIV-positive people from four US cities found that around 1 in 5 had suicidal thoughts in the week preceding the research.<sup>49</sup>

### Multiple physical illnesses

Research has also indicated that multiple physical illnesses can increase the risk of suicide. This finding is often particularly relevant to older people who are more likely to suffer from more than one chronic condition simultaneously. A study that explored suicides in people aged over 65 in Ontario, Canada, between 1992 and 2000, found that individuals who were suffering from three or more multiple illnesses displayed a threefold increase in their risk of suicide.<sup>50</sup>

### Multi-factorial causes of suicide

While certain types of illness are clearly associated with higher rates of suicide, a body of international research has emphasised the fact that suicide tends to be caused by a complex set of

influences rather than a single factor or event. As one study exploring this observed, 'it is clear that terminal illness, in and of itself, may not be the only reason that leads to a contemplation of suicide.'<sup>51</sup>

The study cited above that explored the association between terminal illness and the wish to hasten death, found in its own primary research with 256 terminally ill cancer patients that a strong wish for a hastened death was associated with a number of factors including depression, being cared for in a hospice, feeling oneself to be a burden, having a less unified family, lacking informal support, having greater anxiety and experiencing a higher symptom burden.<sup>52</sup>

It is therefore crucial to identify the other factors that can contribute to suicidal thoughts and completed suicides, and the potential of physical, chronic and terminal illnesses to cause these circumstances or to exacerbate their impact. Another controlled study found that the three most stressful events preceding death in a sample of suicides were the sickness or death of a friend or family member, separation or conflict with a friend or family member, and financial problems.<sup>53</sup> A similar study found that marital status was an important influencer in prostate cancer suicides, with single, separated or divorced sufferers at a higher risk than those who were married.<sup>54</sup> The authors concluded that '[h]aving someone close to confide in might alleviate the psychological stress experienced from receiving a cancer diagnosis'.<sup>55</sup> Another study that is cited above found that married people with Parkinson's disease were more vulnerable to suicide than single people,<sup>56</sup> therefore there is no simple correlation between serious illness, marital status and suicide and different effects may be observed with different illnesses. However, while the relationship between these factors is complex, it is clear that wider social status is a significant consideration when identifying which patients with a physical illness may be most vulnerable to suicide.

## Evidence in the UK on the relationship between serious physical illness and suicide

Very little research has been conducted to explore specifically the relationship between physical illness and suicide in the UK; more work has been done to investigate the interaction between illness and depression.<sup>57</sup> As with the international evidence reviewed above, studies conducted in the UK have not focused on the respective impact of terminal and chronic conditions on the risk of suicide; instead they have focused on specific patient groups such as cancer patients and older people with poor health.

### Suicide among cancer patients

A study conducted in South-East England between 1996 and 2005 found that men diagnosed with cancer had a ‘significantly increased risk’ of suicide, while women had a ‘moderately increased risk’ of suicide.<sup>58</sup> In a sample of over 200,000 male cancer patients there were 117 suicides; a substantially greater number than the 49 suicides that took place in a slightly larger sized sample of women.<sup>59</sup> As found in the Italian study cited earlier, for both men and women the risk of suicide was greatest in the first year immediately following the diagnosis of cancer. It was also found that ‘more fatal types of cancer carried the highest risk of suicide in both men and women, but a strong effect of advanced stage of disease was evident only in women’.<sup>60</sup> There was also evidence that people who lived in more disadvantaged areas were more likely to die by suicide, and that ‘suicide risk was highest in the socio-economically deprived groups of women’.<sup>61</sup> Therefore, as noted above, while serious illnesses such as cancer can be significant risk factors for suicide, it must be borne in mind that a range of other circumstances and characteristics inevitably play a role in increasing or reducing this risk.

### Suicide among older people

Suicide rates in England have declined overall during the last decade, with the lowest rate recorded in 2007 (slightly higher rates were observed in 2008 and 2009).<sup>62</sup> However, while suicide

rates have declined for men aged under 35 – a group at particularly high risk of suicide<sup>63</sup> – people aged over 85 are the only age group in England that has not demonstrated a decline in suicide rates during this period.<sup>64</sup> Research recently conducted by the London Borough of Camden to examine female suicides that took place within the borough between 2006 and 2009, found that four women aged over 75 had died by suicide and that three of these women had terminal cancer.<sup>65</sup>

A 2006 study by Harwood et al explored how ‘life problems’ had contributed to the suicides of a sample of 100 older people (aged 60 or over) in five counties in England. Through interviews with close contacts, they found that 82 per cent of the older people who died by suicide had experienced poor physical health in the previous year and this was thought to have played a role in their suicide for 62 per cent of the group.<sup>66</sup> Pain was thought to have contributed to the suicides of 25 per cent of the sample and this was the most frequently identified specific influence.<sup>67</sup> However, while Harwood et al found physical illness in the year before suicide to be an extremely important factor, they found that 60 per cent of the group that experienced physical illness in the year prior to death had also experienced depression in the month before their suicide.<sup>68</sup>

Another study of suicide among older people published in 2004 observed that although ‘physical health and level of functioning are important in the cause of suicidal behaviours, controlled studies suggest that their effects are generally mediated by mental health factors, most notably depression’.<sup>69</sup> It is critical therefore that those researching suicide prevention take more heed not only of physical illness but also of the relationship between mental and physical health, in order to understand more thoroughly the causal factors behind suicide. As one study warned:

*Primary care workers should be particularly vigilant for the presence of depression in older patients who have physical conditions that have the potential to severely affect a person’s quality of life in terms of pain, discomfort and the ability to move around and lead a ‘normal life’. The presence of depression in such patients requires immediate action.<sup>70</sup>*

Harwood et al also suggest that the social difficulties of finance, accommodation, retirement and long-term bereavement problems may be significant risk factors for suicide in people aged over 60, alongside the factors of physical illness, interpersonal problems and bereavement that are commonly associated with suicide among older people.<sup>71</sup> Therefore, seeking to alleviate these broader social problems could go some way towards preventing suicide in those who are additionally encumbered by physical illness.

The next chapter will explore how UK public policy has tackled suicide as a public health issue over the past decade, and the extent to which public policy has acknowledged and sought to address the association between terminal and chronic illnesses and suicide that has been demonstrated by the evidence presented in this chapter.



## 2 The public policy response to suicide in England

### 2002–2010 national suicide prevention policy

In 2002 the Department of Health published the *National Suicide Prevention Strategy for England*.<sup>72</sup> At the core of this strategy, motivating suicide prevention work over the last decade, was the target of reducing suicide by 20 per cent by 2010. This target was a public service agreement between the Department of Health, the Treasury and No 10<sup>73</sup> and it was first set out in the white paper *Saving Lives* in 1999.<sup>74</sup> The implementation of this strategy was taken forward by the National Institute for Mental Health in England,<sup>75</sup> which was succeeded by the National Mental Health Development Unit in 2009.<sup>76</sup>

Annual reports were published to track progress against this goal, with the most recent update report published in 2008. The suicide rate was monitored according to the average rate across a three-year time period (eg 2005–07) to focus attention on the overall trend as opposed to year-to-year fluctuations. Progress was judged against the baseline rate of 9.2 deaths per 100,000 population in 1995–97 and the target would require a reduction to 7.3 deaths per 100,000 population by 2009–11.<sup>77</sup> The last update report, published in 2008, demonstrated that the figures for 2005–07 had shown a reduction in suicides by 13.9 per cent since 1995–07 – a rate of 7.9 deaths per 100,000 population.<sup>78</sup> However, figures included in the Coalition Government’s recently published *Consultation on Preventing Suicide in England* suggest that the 20 per cent reduction target set by the *National Suicide Prevention Strategy* will probably be missed.<sup>79</sup>

The rate of deaths by suicide for 2009 was 8.1 per 100,000 population, and 2009 was the second consecutive year that demonstrated an increase in the suicide rate, following three years in which the suicide rate had consistently dropped.<sup>80</sup> The 2008 update suggested that this reversal of the trend of an

overall declining rate in the number of suicides may have been linked to the economic recession experienced in Britain at that time: ‘Suicide rates have tended to rise during periods of high unemployment or economic uncertainty.’<sup>81</sup> As a result of this slight reversal in the suicide rate in England, by 2009 only a 14.2 per cent reduction in the suicide rate since 1995–97 had been achieved, making it extremely unlikely that the 20 per cent reduction target could be achieved by 2010/11.<sup>82</sup>

### Aims of the 2002 suicide prevention strategy

The 2002 *National Suicide Prevention Strategy for England* outlined six main goals for suicide risk reduction:

- 1 to reduce the risk of suicide in key high risk groups
- 2 to promote mental wellbeing in the wider population
- 3 to reduce the availability and lethality of suicide methods
- 4 to improve reporting of suicidal behaviour in the media
- 5 to promote research on suicide and suicide prevention
- 6 to improve the monitoring of progress towards the suicide reduction target set out in *Saving Lives* (1999)

These goals shaped the Labour Government’s priorities for suicide prevention between 2002 and 2010. The most relevant goals to this study are goals 1, 5 and 6, as these relate to determining how groups at higher risk of suicide are identified and monitored.

### High risk groups

The *National Suicide Prevention Strategy* cited the following criteria as its rationale for selecting ‘high risk’ groups:

- The group had been identified as having a statistically increased risk of suicide.
- Evidence existed of the actual numbers of suicides in the group.
- Evidence existed that preventative measures could be based on.

- Methods for monitoring the impact of preventative measures were available.<sup>83</sup>

On the basis of these criteria, the 2002 strategy identified the following ‘high risk groups’:

- people in recent contact with mental health services
- people who have recently deliberately self-harmed in the previous year
- young men
- prisoners
- high risk occupational groups (including farmers and agricultural workers, nurses and doctors)<sup>84</sup>

The strategy recognised that concern had been expressed about other ‘vulnerable’ social groups, but argued that these could not be explicitly targeted as ‘high risk’ groups in the first goal as there were gaps in the available data and a lack of knowledge of effective preventative measures. Instead, the wellbeing of these vulnerable groups would be addressed by the strategy’s second goal aimed at promoting mental well being in the wider population. The groups identified as vulnerable and requiring additional mental health support included:

- the socially excluded and deprived
- people from black and ethnic minority groups, including Asian women
- people who misuse drugs and/or alcohol
- victims and survivors of abuse, including child sexual abuse
- children and young people (aged under 18 years)
- women during and after pregnancy
- older people
- those bereaved by suicide<sup>85</sup>

The fifth and sixth goals, to promote research on suicide and suicide prevention, and to improve the monitoring of progress towards the suicide reduction target, were evidently included in the strategy to go some way towards addressing the problem that

inadequate data limited what the strategy could achieve for these vulnerable groups. However, the strategy was fairly prescriptive about the new sources of data that would be made available for national monitoring of suicides in accordance with goal 6. The new data collection activities identified included:

- collecting new data on suicides that followed deliberate self-harm
- tasking coroners with recording the ethnicity and occupation of people who died by suicide
- estimating the proportion of people in social class 'V' (unskilled occupations) who died by suicide<sup>86</sup>

Despite the growing evidence base (explored above in chapter 1) on the relationship between suicide and chronic and terminal illness, adults with long-term conditions were not included for consideration among the 'high risk' or 'vulnerable' groups identified by the national strategy.

### Physical illness as a risk factor for suicide

However, while adults with physical illnesses were not explicitly prioritised by the strategy as a high risk group, there have been passing references to the role of physical illness as a risk factor for suicide in a number of national policy documents during the last decade. The 2002 national suicide prevention strategy recognised a need for the 'clinical management of depression in older people, especially those suffering from physical illness' but did not consider how physical illness might contribute to depression in other social groups.<sup>87</sup> A subsequent update report on the *National Suicide Prevention Strategy* published in 2008 observed:

*The likelihood of a person committing suicide depends on several factors. These include physically disabling or painful illnesses and mental illness; alcohol and drug misuse; and level of support.*<sup>88</sup>

However, no data was provided to evidence this assertion about the role of 'physically disabling or painful illnesses' as a

risk factor for suicide, and no strategies for reducing suicides among people with physical illnesses were mentioned in this document. A report published in 2009 by the National Institute for Mental Health in England to provide guidance to English primary care trusts (PCTs) in conducting local suicide audits also identified people with ‘serious physical illnesses’ as a ‘high risk group’, alongside 13 other groups.<sup>89</sup> Again, no evidence or rationale was provided for the identification of this group.

In contrast, it is notable that adults using mental health services tend to be at the centre of national policy on suicide prevention. An important reason for this is that 25 per cent of suicides take place after contact with secondary care mental health services in the preceding 12 months.<sup>90</sup> The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness collects data on these suicides as part of the *National Suicide Prevention Strategy for England’s* goal 5: to promote research on suicide.<sup>91</sup> As a result of this robust data collection, the inquiry’s latest report is able to show that between 1997 and 2007, 14,249 suicides (26 per cent of the total) were by people who had had contact with mental health services in the preceding 12 months.<sup>92</sup>

Although this 26 per cent accounts for a very significant proportion of all suicides, it is important to note that 74 per cent of those who died by suicide had not recently been in contact with mental health services, and data collection to shed light on the potential causes of these suicides is often very poor. Therefore, as a report published by the National Institute for Mental Health in 2009 argued, ‘to be successful in reducing the suicide rate the development of local systems for suicide audit to learn lessons and take any necessary action is essential’.<sup>93</sup>

In a written response to the Labour Government’s 2009 mental health strategy *New Horizons*, Catherine Johnstone, Chief Executive of the Samaritans, also stressed that a multiplicity of different influences can lead to suicidal behaviour, with factors at individual, community and societal levels. This response recommended that any approaches to suicide prevention must go beyond initiatives focused purely on mental health, and include cooperation across local agencies.<sup>94</sup> The Samaritans observed

that there is a ‘general consensus’ that multiple factors and multiple different pathways lead to suicidal behaviours, and that, rather than being the result of one particular ‘risk factor’, suicide tends to stem from a combination of several issues in a person’s life.<sup>95</sup>

### Local approaches to data collection

Following the 2002 strategy, PCTs have been made responsible for tracking trends in local suicide rates and developing local strategies for contributing towards the target of a 20 per cent reduction in suicide rates.<sup>96</sup> A requirement for PCTs to perform regular suicide audits was included in the Commission for Healthcare Audit and Inspection star ratings in 2004 and the Mental Health Local Implementation Team autumn assessment in 2005.<sup>97</sup> As of 2004, 291 out of a total of 303 PCTs reported that they had established a system for conducting suicide audits.<sup>98</sup>

However, the responsibilities for PCTs that were subsequently outlined in the 2004 health and social care standards framework *National Standards, Local Action* did not specify that PCTs were required to perform suicide audits. Instead, this document recommended that PCTs should ‘support access to assessment, treatment and care for all those at risk [of suicide]’.<sup>99</sup> Some PCTs may have interpreted this as a relaxation of their responsibility to conduct an annual suicide audit (this will be explored further in chapter 3).

In addition to this ambiguity regarding PCTs’ responsibilities, national guidance describing what a suicide audit should comprise and what data it should contain has been unclear. As a result, ‘the development and implementation of suicide audit across the country has been piecemeal’.<sup>100</sup> The National Service Framework for Mental Health recommended that data for suicide audits could be gathered ‘from a variety of local sources, including case records, written reports from staff, transcripts of the inquest, summaries of management inquiries, and through discussion with relatives and carers’.<sup>101</sup> Nonetheless, it has been mainly left up to PCTs to decide on the methodology

for their audit, and the level of detail they will seek to achieve in their collection of data. PCT areas that have very low suicide rates are likely to have put less priority on suicide prevention among their population.<sup>102</sup> Other local factors such as the availability of resources and varying success in accessing data from partner agencies (such as coroners' offices and GPs) will also have shaped what PCTs are able to achieve. This combination of factors has led to considerable disparity in the quality of local audits (further evidence of this will be explored in the findings we present in chapter 3).

### Monitoring physical illness in local suicide audits

In line with the established evidence base and national policy, most PCTs' strategies for data collection and suicide prevention have focused predominantly on the relationship between suicide and poor mental health. Islington's Public Health Report of 2010, for example, states that more than 80 per cent of suicides involved a diagnosed mental illness.<sup>103</sup> It observes:

*There is... an increasing body of evidence showing the cost-effectiveness and successful outcomes of other interventions to generally improve the mental health and wellbeing of the population and to reduce the stigma and discrimination associated with mental health conditions. Improvements in mental health and wellbeing of the population will in turn impact on suicide rates.*<sup>104</sup>

The document also recognises that 'there is some evidence that physical ill health is associated with self-harm, particularly that chronic or terminal physical illness increases the risk of suicide'.<sup>105</sup> However, no locally obtained evidence of this association is cited.

NHS Gloucestershire's recently published suicide prevention strategy for the period July 2011 to June 2015 is explicitly informed by local suicide audits and has consequently identified 'long term physical conditions' as a risk factor for suicide. Data gathered for NHS Gloucestershire's local suicide audits have demonstrated that 'a history of depression, self-harm,

having a long term condition and alcohol use continue to present as high risk factors associated with suicide'.<sup>106</sup> While people with 'long term conditions' are not explicitly identified by this strategy as a 'high risk group', one of the goals is 'to reduce the risk of depression and suicide in people who have long term conditions'.<sup>107</sup>

As part of this action plan, NHS Gloucestershire identifies a series of actions to reduce the risk of suicide among people with long term health conditions, including:

- early identification of patients who may be at greater risk of self-harm or suicide following the breaking of bad news, or long-term conditions
- developing in primary care the early identification, assessment and treatment of depression in primary care for older people, people with long-term conditions and medically unexplained symptoms, people with learning disabilities and service veterans
- promoting awareness and support for staff and people they support about the impact of long-term conditions on mental health and the risk of suicide<sup>108</sup>

NHS Gloucestershire's suicide prevention strategy indicates that local suicide audits can be a successful tool for improving local knowledge of factors that are associated with suicide – such as long-term conditions – and developing strategies to address these risk factors. The themes identified in this local strategy and action plan suggest that the role of chronic conditions and terminal illness as a risk factor for suicide deserves greater prominence in national policy frameworks and guidelines for data collection.

### Consultation on preventing suicide in England in 2011

In July 2011, the Coalition Government published a draft cross-government strategy on the prevention of suicide in England for consultation. The ministerial foreword to this strategy by Minister for Care Services Paul Burstow makes it clear that following the Coalition's programme of NHS reform, including

the replacement of PCTs by GP consortia, the new health and wellbeing boards will lead on identifying local trends, taking a public health approach to suicide prevention and bringing together local agencies.<sup>109</sup> The foreword also acknowledges, ‘we need to consider the changing trends in suicide rates, highlight new and emerging interventions and reflect new evidence from research.’<sup>110</sup>

It is notable that this draft strategy mainly follows the structure of the previous Government’s suicide prevention strategy (with an additional focus on support for those who are bereaved as a result of a suicide). The ‘key high risk groups’ identified (people using mental health services; people who have recently self-harmed; prisoners; men aged under 50; particular occupational groups<sup>111</sup>) are remarkably similar to the previous Government’s categorisation of those at high risk of suicide. As with the 2002 strategy, those responsible ‘have selected only those [groups] whose suicide rates can be monitored’.<sup>112</sup>

It is surely a cause for concern that in over eight years there has been such little improvement in the Government’s ability to monitor the characteristics of people who die through suicide. As observed above, in the 2002 strategy, the National Institute for Mental Health in England was tasked with asking the Coroners Review Group to consider routinely recording ethnicity in inquest reports ‘to allow monitoring’.<sup>113</sup> The 2011 draft strategy also promises ‘to address the current information gaps around ethnicity’.<sup>114</sup> This lack of progress between the 2002 and 2011 strategies in monitoring the characteristics of people who die by suicide may be largely down to the fact that coroners are still only obliged to report a very limited amount of information about people who die by suicide. For example, the person’s age, gender and method of suicide must be shared with the Office for National Statistics, but coroners need not share information about the person’s ethnicity or health status. Coroners are also not obliged to cooperate with PCTs and share information to feed into local suicide audits (the relationship between coroners and PCTs will be explored in more detail in chapter 3).

If we are to address these difficulties with obtaining reliable and comprehensive national data, a more robust approach to

data collection will be required than the strategy's current emphasis on flexibility and localism allows. An important matter that is not resolved by the strategy is whether or not it will be mandatory for PCTs (or in the future, health and wellbeing boards) to perform suicide audits, and what information should be included in a suicide audit. The tension exhibited in the strategy between the desire to allow local flexibility and the clear need to improve national datasets and monitoring will need to be resolved if the new suicide prevention strategy is to achieve genuine progress in increasing our knowledge of suicide risks.

However, while the choice of 'high risk groups' and methods for monitoring these groups have remained largely unchanged since 2002, the 2011 draft strategy does show a far greater awareness of the role of long-term conditions, 'including physical illness, disability and chronic pain' as a risk factor for depression and suicide.<sup>115</sup> It also suggests strategies for mitigating the heightened suicide risk among people with chronic conditions:

*Routine assessment or screening for depression as part of personalised care planning can help reduce inequalities and support people with long-term conditions to have a better quality of life and better social and working lives.*<sup>116</sup>

What this new strategy unfortunately lacks is a clear understanding of the extent of the problem (for example, knowledge of the proportion of people who die by suicide that have long-term health conditions) and a strategy for filling this evidence gap and improving local knowledge. The next chapter of this report, which presents our primary research findings, will attempt to begin to fill this evidence gap. Then chapter 4 will explore what actions should be taken to improve local and national knowledge of chronic and terminal illness as a risk factor for suicide, to provide a foundation for developing more effective policy responses.

## 3 Primary research findings

While there are some small-scale studies available that explore the relationship between physical illness and suicide in the context of the UK – outlined above in chapter 1 – there is very little data available that can provide a national picture of this issue. When Demos wrote to the Office for National Statistics to request information on suicide and physical illness, we received the following response:

*Our mortality statistics are based on information provided at death registration and as part of coroner inquests. It is not routinely stated whether or not the deceased was living with a chronic long-term illness or disability, which means we are unable to produce suicide statistics for this group.*

To fill this important evidence gap, we used a combination of research methods to collect new data on the relationship between physical illness and suicide from primary care trusts (PCTs), coroners and other organisations with expertise on suicide. We undertook:

- freedom of information (FOI) requests to PCTs
- semi-structured interviews with coroners
- a detailed case study of Norwich District Coroner's office
- semi-structured interviews with expert organisations

The findings from these activities are presented below.

### Freedom of information requests to primary care trusts

With the aim of collecting nationally comparable data on the proportion of suicides that take place when the deceased person

was experiencing chronic or terminal illness, in May 2011 Demos sent information requests to all PCTs in England, using the Freedom of Information Act. Following publication of the 2002 *National Suicide Prevention Strategy for England*,<sup>117</sup> PCTs have been requested to complete an annual suicide audit to inform their own local suicide prevention strategies, although it is not clear that this task is mandatory. In order to gather the information on physical illness that PCTs had collected in their suicide audits, we asked them:

- 1 How many suicides overall were reported in your PCT district for each of the previous five years?
- 2 For each year that you have conducted a suicide audit in the previous five years, please could you tell us in how many of the reported cases of suicide an agency that provided information on the deceased person (including a GP, coroner or other health or social care professional) mentioned that the person was experiencing at the time of his or her suicide:
  - physical illness
  - chronic illness
  - terminal illness
  - pain
  - physical impairment or disability
  - some specific form of physical illness or health condition

More than half (75) of the 147 PCTs were unable to provide any information at all in answer to question 2, on the physical health status of people who had died by suicide in their district. Of the 72 PCT districts that did provide this information, 29 districts were able to provide some of the requested quantitative data. The remainder provided purely descriptive information or numerical information that was relevant to the person's health but inadequate to answer the question (such as the number of suicide cases in which the deceased person had recently visited their GP).

### Reasons why primary care trusts could not provide the requested information

Figure 1 demonstrates the reasons why PCTs were unable to provide the requested information. Their responses have been separated into six categories:

- 1 The information was not collected by the PCT or not available.
- 2 Releasing the requested information would breach patient confidentiality.
- 3 No suicide audit was conducted locally.
- 4 The PCT had no information but referred Demos to another agency.
- 5 Collecting the requested data would exceed the legal cost limits stipulated for FOI requests.
- 6 The PCT had been unsuccessful in obtaining this information from the coroner's office.

#### *The information was not collected by the primary care trust or not available*

The most common reason given for not being able to provide any information was that the required information was either not collected or not available, with 41 PCTs giving this reason. NHS South Gloucestershire, for example, was able to provide basic data on the number of suicides in the district for the last five years, but data on physical, terminal or chronic illness, pain or physical impairment or disability were not routinely collected by the trust. East Lancashire responded, 'The PCT does not hold information regarding illnesses or any other circumstances surrounding a suicide.'

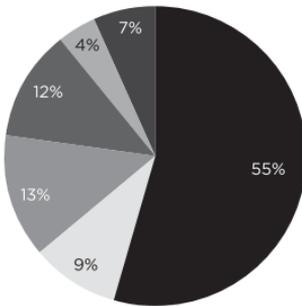
#### *Releasing the requested information would breach patient confidentiality*

A smaller number of PCTs (seven PCTs in total) said they could not provide the information because the small numbers of cases involved would breach patient confidentiality if they were released, as individual cases would be easily identifiable.

Figure 1

**Reasons why PCTs were unable to provide data on physical illness for this study**

- Unsuccessful in getting data from the coroner
- Getting data would exceed time/cost limits of the FOI
- No information but referred to another body
- No audit conducted (eg PCTs are no longer required to audit, and were unable to secure funding for an audit)
- Releasing figures would breach confidentiality
- Information is not collected/not available



*No suicide audit conducted locally*

Ten PCTs were unable to provide information because they no longer conduct, or have never been able to conduct, a suicide audit for their district. Some of these PCTs indicated that this was due to financial constraints. NHS Medway responded, ‘We were not able to secure funding to carry out a comprehensive suicide audit; we therefore we do not hold the information requested in question 2.’ In contrast to this, the response from Luton Primary Care Trust simply noted, ‘We are not aware of any audits.’ These responses highlight the lack of clarity that currently exists regarding PCTs’ responsibilities to conduct suicide audits and monitor local trends in the characteristics of people who die by suicide. This will inevitably impact on local capacity to develop informed suicide prevention strategies.

*The PCT had no information but referred Demos to another agency*

Nine PCTs responded that they did not hold the requested information, but suggested that Demos contact another local agency. Several PCTs suggested that their local mental health trusts may hold the data. However, in many cases these other bodies did not hold the data and in some cases they referred the request back to the original PCT. One referral was successful, and Manchester Mental Health and Social Care Trust was able to provide additional data.

*Collecting the requested data would exceed the time and cost limits stipulated in the Freedom of Information Act*

Three PCTs responded to our information request that gathering the required information would exceed the time and cost limits stipulated in the Freedom of Information Act.

*PCT was unsuccessful in obtaining data from the coroner*

Five PCTs said that they were unable to provide the information because they had been unsuccessful in obtaining the required data from the local coroner's office. Stoke on Trent Primary Care Trust explained that poor communication with the coroner's office had prevented local auditing procedures that had been set up from being carried out effectively. This PCT was not able to detail the number of suicides that had taken place in their district for any of the previous five years.

Sandwell PCT, which was unable to provide any information on physical illness, explained that one of the reasons for this was that they had not yet (despite repeated efforts) managed to secure access to the coroner's patients' records in order to audit the deaths effectively. NHS North West London (comprising Westminster, Hammersmith and Fulham, and Kensington and Chelsea) had also been unsuccessful in their efforts to get the required data from the coroner's office. It is unclear exactly why these difficulties arose but it is possible that coroners do not feel responsible for sharing this information, or that resource constraints have prevented effective information-sharing.

### Quantitative data provided by primary care trusts

In total, 29 PCT districts were able to provide some kind of quantitative data on the physical health status of people who had died by suicide in their district during the previous five years. These data were recorded in a spreadsheet according to the individual year and category of illness for which data was provided (eg physical illness, chronic illness, terminal illness, pain, physical impairment or disability, some specific health condition).

PCTs provided data for varying years and for different categories of physical illness. Therefore, to make the data comparable between PCTs, we calculated the average number of suicides that occurred in that PCT each year (across the number of years provided). In the subsequent columns, the percentage of suicides that involved each category of physical illness has been averaged across the number of years for which information was provided. In the majority of cases, information was provided for between three and six years.

In cases where the data provided had already been aggregated (eg the percentage of suicides involving a terminal illness that occurred in Wiltshire), the aggregate value provided by the PCT was included. The information presented in the table reflects the information as it was provided by the PCTs, therefore if no information was provided the field is left blank. Table 1 displays this information for each PCT that provided quantitative data. A more detailed table, with the numbers of suicides that occurred in each category each year, is presented in appendix 3. The full dataset can be found in the annex to the report, published as a separate document.

As table 1 shows, the data provided by PCTs varied considerably, making comparison between PCTs difficult. Only five PCTs – Bournemouth and Poole, Gloucestershire, Portsmouth, Country Durham and Somerset – were able to provide the data we requested in full. Most of the PCTs that provided data were able to answer some but not all of the questions. In some cases, such as the information provided by Sefton PCT, it was only possible to provide aggregate figures for ‘physical illness’, rather than specifying where conditions were terminal or chronic. As a result, the percentages that have been

calculated can only provide an indicative snapshot, rather than a detailed picture, of the proportion of suicides that involved people who had chronic, terminal or physical illnesses, pain or a disability. It is very likely that these figures are in fact underestimates of the proportions of suicides that involve each of these categories, as some PCTs were unable to provide full information, or were explicitly conservative in the numbers that they provided. For example, Warrington PCT told us that 18 people had long-term health conditions, and for ‘an additional 3 people... information contained within the notes suggested that there might have been a positive finding’. In each case, we have used the more conservative figures.

A number of the PCTs are duplicated in the table (eg Darlington and Middlesbrough) to reflect the separate sets of data that were provided. Where two sets of different data were provided, both sets have been included in the table. It is worth noting the specific discrepancies between the data provided by coroners and by GPs for the same districts. In all cases, the number of overall reported suicides is the same, but the numbers relating to illness categories do not match. In Darlington, for example, data from the coroner suggests that 2 per cent of suicides involved an individual with a chronic illness, while data from GP records suggest that the figure is 7 per cent. Similarly, in County Durham, the proportion of suicides involving chronic illness was 2.7 per cent according to the coroner’s records, compared with 4.8 per cent from the GP’s records. This would suggest that coroners are not always aware of the deceased person’s health status when they conduct an inquest, re-enforcing the importance of GPs’ involvement in local suicide audits.

It is also important to note that PCTs differed over whether they included open verdicts and undetermined injuries within their aggregated suicide statistics. Where possible we have limited our use of data to cases that were explicitly suicides. However, we have necessarily been restricted by the individual PCTs’ own methodologies in this regard. The full annex to the report will provide more detailed information on this.

Table 1 **Percentage of suicides involving different categories of physical illness from PCTs that were able to provide some quantitative data**

	Primary care trust (or other health trust if specified)	Average annual number of suicides (%) <sup>118</sup>	Suicides where individual had physical illness (%) <sup>119</sup>	Suicides where individual had chronic illness (%) <sup>120</sup>
1	Bournemouth and Poole Teaching PCT	35.3	1.9	7.5
2	Bury PCT	25.5	-	-
3	Camden PCT	25.5	1.0	2.0
4	Central Lancashire	32.6	4.9	-
5	County Durham PCT (from coroner records)	31.2	1.1	2.7
	County Durham PCT (from GP records)	31.2	0.5	4.8
6	Cumbria PCT	52.0	-	39.0
7	Darlington PCT (from coroner records)	7.5	-	2.2
	Darlington PCT (from GP records)	7.5	-	6.7
8	Ealing and Hounslow PCT	30.0	11.1	-
9	Gloucestershire PCT	56.0	3.0	7.1
10	Hartlepool PCT (from coroner records)	7.8	4.3	2.1
	Hartlepool PCT (from GP records)	7.8	2.1	-
11	Hertfordshire PCT <sup>125</sup>	56.0	-	28.0
12	Lincolnshire Teaching PCT	57.5	-	-
13	Manchester PCT <sup>126</sup>	44.0	-	20.5
	Manchester Mental Health & Social Care Trust <sup>127</sup>	68.0	-	-
14	Middlesbrough PCT (from coroner records)	12.3	2.7	-
	Middlesbrough PCT (from GP records)	12.3	-	-
15	Newcastle PCT	16.7	-	-
16	North Lancashire PCT	38.7	-	-
17	North Somerset PCT	17.6	3.4	26.1
18	North Tyneside PCT	26.0	-	-
19	Portsmouth City Teaching PCT	11.3	8.8	5.9
20	Redcar and Cleveland PCT (from coroner records)	12.0	2.8	-
	Redcar and Cleveland PCT (from GP records)	12.0	-	1.4

Suicides where individual had terminal illness (%) <sup>121</sup>	Suicides where individual had pain (%) <sup>122</sup>	Suicides where individual physical impairment or disability (%) <sup>123</sup>	Suicides where person had some specific form of physical illness or health condition (%) <sup>124</sup>
0	4.7	1.9	7.5
-	8.0	-	54.0
-	-	-	-
1.2	-	-	-
1.6	5.3	1.6	13.9
1.6	7.5	1.1	18.2
-	-	-	-
-	8.9	6.7	28.9
-	2.2	11.1	33.3
-	-	-	-
3.6	4.2	3.0	8.3
-	2.1	2.1	2.1
-	4.3	-	2.1
-	-	2.4	3.6
-	1.7	-	38.3
-	-	-	-
-	-	-	4.4
-	1.4	-	2.7
-	1.4	4.1	17.6
-	-	-	88.0
-	-	-	12.1
-	-	-	12.5
-	-	-	91.0
5.9	8.8	-	8.8
1.4	1.4	2.8	12.5
1.4	2.8	2.8	16.7

Table 1 **Percentage of suicides involving different categories of physical illness from PCTs that were able to provide some quantitative data - *continued***

	Primary care trust (or other health trust if specified)	Average annual number of suicides (%) <sup>118</sup>	Suicides where individual had physical illness (%) <sup>119</sup>	Suicides where individual had chronic illness (%) <sup>120</sup>
21	Sefton PCT	15.6	37.2	-
22	Sheffield PCT	33.2	50.0	17.5
23	Somerset	45.0	1.5	16.3
24	Stockton on Tees (from coroner records)	14.5	4.6	-
	Stockton on Tees (from GP records)	14.5	-	-
25	Surrey PCT <sup>128</sup>	79.0	-	9.3
26	Wakefield PCT	18.8	-	-
27	Warrington PCT	15.3	-	0.5
28	Wiltshire PCT	16.8	-	-
29	Wolverhampton City PCT <sup>129</sup>	27.5	8.0	-
	Average values	27.8	8.2	10.6

### Overall findings from the quantitative data provided by primary care trusts

#### Chronic illness

Eighteen PCTs were able to provide figures relating to suicide and chronic illness. The percentage of suicides that involved an individual with a chronic illness ranged from 1.4 per cent to 28 per cent, with a mean value of 10.6 per cent.

The PCT with the highest value, Hertfordshire, had 47 cases of suicide of an individual with a chronic illness across the three years for which data is available. In 2007, out of 36 cases of suicide where there were complete or adequate data, 13 people had a chronic or significant physical illness; in 2008, out of 73 suicides, this number was 22; and in 2009, out of 59 suicides, 12 had a chronic illness.

Suicides where individual had terminal illness (%) <sup>121</sup>	Suicides where individual had pain (%) <sup>122</sup>	Suicides where individual physical impairment or disability (%) <sup>123</sup>	Suicides where person had some specific form of physical illness or health condition (%) <sup>124</sup>
-	-	-	-
1.2	4.2	4.2	24.7
0.7	6.7	2.2	3.7
-	-	-	5.7
-	-	-	11.5
-	8.0	-	44.3
-	-	-	27.0
-	-	0.1	-
5.0	7.0	-	7.0
-	8.0	-	-
2.1	4.9	3.3	21.4

### *Terminal illness*

Only 11 PCTs were able to provide figures relating specifically to suicide and terminal illness. In all of them, the proportions and actual numbers of suicides from individuals suffering from a terminal illness are small – between 0.7 and 6 per cent – with an average value of 2.1 per cent of all suicides involving an individual with a terminal illness.

### *Pain*

Out of those PCTs that provided data, an average of 4.9 per cent of the suicides that occurred across all PCTs involved a person who had been suffering from pain.

### *Physical impairment or disability*

While this study is not specifically focusing on suicide and disability, it is notable that at an average of 3.3 per cent, the percentage of people who died by suicide who were identified as having had a physical impairment or disability is higher than the proportion who were terminally ill. However, it is important to recognise that terminal or chronic illness may be regarded as an impairment, therefore there is flexibility in how PCTs chose to categorise individual conditions.

### *Physical illness*

Out of those PCTs that provided data, an average of 8.2 per cent of suicides were found to have involved an individual who had some kind of non-specified physical illness.

### *Specific form of physical illness or health condition*

The data we received showed the percentage of suicides (averaged across all PCTs) that involved some specific form of physical illness or health condition was 21.4 per cent.

It should be noted that in categorising the PCTs' responses within the different categories, cases have not been treated as mutually exclusive – for example, an individual may have both a chronic illness and a physical disability, or a suicide may have been included in the suicide audit as relating both to an individual with a physical illness and to some form of specific physical illness or health condition. Therefore, comparison between the different categories is difficult. Furthermore, cases may have been categorised under both 'physical illness' and 'some specific form of physical illness or health condition'. Some PCTs provided numerical data for each column, including physical illness and 'some form of specific physical illness or health condition'. In these cases, the exact figures provided by the PCT were used. Some PCTs provided information on individual suicides, with each case labelled with one or more of the categories provided (eg specific illness, specific illness and pain, or pain and terminal illness). In these examples, the individual cases would be included within each relevant category, therefore some double-counting has taken place.

## Additional data provided by primary care trusts

### *Qualitative data*

While many PCTs were unable to provide numerical information to answer the second question in our FOI request ('how many of the reported cases of suicide... mentioned that the person was experiencing at the time of his or her suicide [some kind of physical health condition or disability]'), a large number of PCTs were able to provide some kind of qualitative information. Some of the most informative examples of the qualitative information provided are presented in table 2.

### *Non-comparable numerical data*

A number of PCTs also provided numerical data that could not be included in our main data table for comparison with other PCTs. Reasons for this included:

- The data explicitly conflated physical and mental health conditions, so that a figure that was purely related to physical health could not be extracted.
- The data did not answer the question of what physical health condition the deceased person had, but provided other health-relevant information such as the reason for the deceased person's last visit to their GP.
- The data provided a 'less than' figure (eg <10 people) but not an exact value.

Key examples of this information have been provided in table 6 in appendix 1.

The various types of data provided by the PCTs in response to our FOI request, as presented above, demonstrate that physical illness, pain and other health conditions are very frequently relevant factors in suicides. However, gaps in information in coroners' records and incomplete audits conducted by PCTs, incompatible methodologies for recording information, and concerns about sharing confidential information currently act as significant obstacles to our ability to construct a comprehensive national picture. We will return to this subject in our conclusions and recommendations in chapter 4.

Table 2 **Qualitative information provided by PCTs in answer to FOI request**

PCT	Information provided
Worcestershire PCT	In Worcestershire's 2007 suicide audit, analysis of a sub-sample of 140 of the 295 suicides and undetermined injuries from 2001 to 2006 found that one-third of the deceased had at least one chronic health problem.
Hounslow PCT	Hounslow's audit found that half of those who died by suicide aged over 64 had a chronic illness.
Cumbria PCT	The following information was available for the 52 suicides audited by Cumbria in 2008: <sup>130</sup> <ul style="list-style-type: none"> <li>· Chronic medical conditions included diabetes, sexual dysfunction and tinnitus.</li> <li>· In a small number of cases, suicide appeared to be an 'exit strategy' when a terminal illness was diagnosed, but other risk factors in earlier life were generally present.</li> </ul>
West Cheshire PCT	In a 2005–2007 suicide audit by West Cheshire, health worries were identified as a factor associated with suicide, but data were primarily collected on other factors.
Greenwich PCT	Greenwich found that there was very little information provided on the death notifications about circumstances that may have led to a death. They focus on the immediate cause of death, for example intoxication by a particular drug. The very small number of additional illnesses mentioned include: <ul style="list-style-type: none"> <li>· 'multiple metastases' (tumours)</li> <li>· circulatory disease, including ischaemic heart disease and hypertension</li> <li>· inhalation of stomach contents</li> <li>· physical condition deteriorated during hospital stay</li> <li>· cirrhosis of the liver and other alcohol-related health conditions</li> </ul> <p>Where these other conditions were mentioned, not all deaths were determined to be suicides. Some of these cases were given open verdicts.</p>

Table 2 **Qualitative information provided by PCTs in answer to FOI request - *continued***

PCT	Information provided
Southampton City PCT	Not all information for mental, physical or long-term conditions is available from the coroner's office for the majority of cases. Conditions that were noted included two cases of tinnitus, coronary heart disease, pancreatitis, diabetes, chronic pain and HIV. Because of the small figures, the exact numbers cannot be revealed for confidentiality reasons.
Cambridgeshire PCT	The suicide audit for 2005-06 includes severe pain as one of a number of contributing factors for suicide, but does not provide details on the number of cases.

### Evidence from semi-structured interviews with coroners

To further inform this study and supplement the more statistical information provided by PCTs, Demos conducted interviews with coroners to shed light on the question of how coroners investigate, interpret and record medical information in their suicide verdicts.

We initially contacted all chief coroners in England for the purposes of this research; 76 coroners' offices provided contact details for the chief coroner and six declined to do so. Out of those who provided contact details, 42 did not respond to an email or a subsequent follow-up request for a short interview, 19 declined to take part in the research, and 15 serving and recently retired coroners agreed to take part in an interview. In some cases the coroner chose to remain anonymous. The coroners were based in various different parts of the country and they provided anecdotal evidence on inquests, suicides, chronic and terminal illness, assisted deaths, record keeping and other related matters. The interview followed a semi-structured format with open-ended, non-prescriptive questions.

The question framework we used to structure the interviews is shown in appendix 2. A summary of the anecdotal evidence the coroners provided can be found in table 3. The key information we gleaned from these interviews about coroners' experience of suicides that involved chronic or terminal illness will be discussed below.

### Deciding how to record an inquest verdict

The coroners told us that if it is not possible to categorically establish that a person intended to take their own life, then a 'narrative' or 'open' verdict is recorded instead of suicide. This may happen in instances where a person does not leave a suicide note, for example. Inquests that are recorded with 'narrative' or 'open' verdicts are not included in the national suicide statistics and are instead placed in the category 'other'. According to one retired coroner we interviewed, this can cause a distortion of the national suicide rate:

*We have inaccurate and misleading statistics. The reason is, first of all, suicide has to be shown it has taken place beyond reasonable doubt and therefore a lot of coroners call suicides open verdicts, when manifestly they are suicides.*

### Recording suicides when the deceased person was terminally or chronically ill

The coroners with whom we spoke gave different views on how much medical information should be included in an inquest record, as there are no specific guidelines on this. Most of the coroners we interviewed would include this information within the narrative section of the inquest report. This might involve writing that the deceased person had a terminal illness in what is called 'box 3', one of six boxes on the inquest form, recording 'time, place and circumstances of the death'; this is usually where notes on a person's medical records are included if relevant.

A smaller number of coroners said they would include this information within the verdict. For instance, Coroner William

Armstrong would record in his verdict: ‘suicide while suffering from depression which was a direct consequence of a physical condition’.

However, some coroners make no mention of the person’s terminal illness in the inquest notes at all as they believe this is not within their legally defined remit. Sean McGovern, coroner for Coventry and Warwickshire, said: ‘I don’t think coroners should have to put more detail in because they are there to make sure a death is recorded in the proper way, and nothing more.’ Coroner Alan Craze, of East Sussex district, expressed concern that ‘to have to start recording detail like this for national statistics would be another burden on our already stretched resources’. These comments indicate there is a wide disparity between individual coroners’ perceptions of their role and responsibilities in the process of recording death in England.

#### Proportion of suicides when the deceased person was terminally ill

Coroners’ estimates on the proportion of suicides that involved the deceased person being terminally ill ranged from none to around 10 per cent of all suicides in the district. The majority of the coroners interviewed said they experienced between one and two of these cases per year.

#### Proportion of suicides when the deceased person was chronically ill

Estimates of the number of suicide cases involving people who are chronically ill also varied considerably. One coroner was not aware of any of these cases having occurred, one had experienced around eight cases per year, and another thought that between 5 per cent and 10 per cent of all suicides fitted within this category.

Table 3 **Summary of anecdotal evidence provided in semi-structured interviews with coroners**

	Coroner name	District name	Suicide verdicts last year (estimate or actual)
1	Anonymous 1	District 1	35
2	Simon Nelson	Rochdale	31
3	Anonymous 2	District 2	21
4	Stan Payne	Bournemouth	39
5	William Armstrong	Norfolk	58
6	Sean McGovern	Coventry and Warwickshire	50
7	David Mitford	Newcastle	15-20
8	Alan Craze	East Sussex	66
9	Anonymous 3	District 3	20
10	Anonymous 4	District 4	35
11	Andrew Haigh	Staffordshire	44
12	Anonymous 5	District 5 (recently retired)	50
13	Nigel Chapman	Nottinghamshire (recently retired)	45
14	Andrew Bradley	Hampshire	35
15	Anonymous 6	District 6	30

Terminal illness per year (estimate)	Chronic illness per year (estimate)	Where coroner records physical illness	Experience of assisted suicides
1 or 2	Does not differentiate from terminal illness	Narrative section of inquest report	Some suspicions on occasion
'A handful'	Does not differentiate from terminal illness	Narrative section of inquest report	Some suspicions on occasion
1 to 4	Does not differentiate from terminal illness	Within the verdict	No
1	Does not differentiate from terminal illness	Narrative section of inquest report	About 1 per year
'A handful'	6	Within the verdict	1 for the first time last year
2 to 5	Does not differentiate from terminal illness	Nowhere	No
6 in 25 years	A small number in 25 years	Narrative section of inquest report	No
6	Does not differentiate from terminal illness	Narrative section of inquest report	Some suspicions on occasion
1 or 2 in last 5 years	1 or 2 involving older people	n/a	No
None	1 or 2 involving older people	Nowhere	No
'A handful'	8	Narrative section of inquest report	No
1	5% or 10% of suicides	Narrative section of inquest report	Some suspicions on occasion
1 or 2	4 to 6	Narrative section of inquest report	Yes
1 or 2	2 or 3	Narrative section of inquest report	Some suspicions on occasion
1	0	Narrative section of inquest report	No

Coroner Simon Nelson, of Rochdale district, said those with a chronic illness would be more likely to take their lives as terminally ill people have a greater acceptance of their suffering and possibly more palliative care support. Coroner William Armstrong of Norwich district commented,

*My impression is that there has been a slight rise in the number of young people suffering from a chronic condition and committing suicide in the last few years... While I have not had the chance to establish why this is, it seems they want to end the pain felt in their life.*

Sean McGovern, coroner for Coventry and Warwickshire, recalled a case where a man in his late 50s killed himself with a helium bag after he had been diagnosed with a chronic illness.

Six of the fifteen coroners interviewed gave an estimate for suicides involving terminal illness, but said they did not distinguish between terminal and chronic illness and could not therefore provide a separate estimate.

### Coroners' experience of cases of assisted suicide

Some coroners had never come across a case of assisted suicide, whereas some had dealt with actual or suspected cases of assistance. For example, Coroner William Armstrong presided over the inquest in April 2011 of a 90-year-old woman in the early stages of dementia. Her daughter was arrested on suspicion of murder, but was eventually released without charge.<sup>131</sup>

What was more apparent from the interviews was some coroners' deliberate avoidance of probing into suspected cases of assisted suicide, often for fear of causing problems for the friends and family left behind. This suggests that the actual number of assisted suicide cases is likely to be higher than official records suggest. When asked about cases of assisted suicide, one coroner noted:

*There have been many cases where I had suspicions, but I would not see it as my specific job to delve into it. If I had no option then I would, but you might say I didn't want to know.*

Retired coroner (anonymous)

Another coroner speaking about cases of assisted suicide said:

*If it was obvious, I would have to inform the police, as assisting suicide is a criminal offence. Normally it is the case that someone has informed their partner they want to end their pain or suffering. When a relative tells me this I try not to push them as to whether they were therefore aware the person was going to kill themselves.*

Coroner Sean McGovern, Coventry and Warwickshire

### Access to inquest records

All of the coroners we spoke to said they eventually archived their inquest records with the local authority. In the Norwich District Coroner's office the inquest records are kept for a number of years in the coroner's office, and are then taken to the local authority. There seemed to be no national guidelines as to when files had to be sent to the local authority. The majority of the coroners did not allow us access to their records as they said it would require extra work for their staff in extracting the right files. However, Norwich District Coroner's office did allow Demos to have full access to their suicide inquest records. The next section will explore the detailed evidence contained within this archive.

### Case study of Norwich District Coroner's office

In May 2011 Norwich District Coroner's office gave Demos permission to examine their suicide records for a period spanning five years (May 2006 to December 2010). The suicide records had been archived according to the year in which the inquest was closed, rather than when the death occurred. We explored the records of completed inquests that had a suicide verdict during this period, examining them for any mention of medical conditions that the deceased person had.

Medical conditions were then classified as terminal or chronic according to either of two criteria:

- The inquest records used either the word ‘terminal’ or ‘chronic’ in the notes describing the illness.
- The person had a medical condition that is officially classified as either a terminal or chronic illness (for example, myalgic encephalopathy (ME) is a chronic illness,<sup>132</sup> Parkinson’s disease is a chronic illness,<sup>133</sup> motor neurone disease is a terminal illness,<sup>134</sup> Huntington’s disease is a terminal illness,<sup>135</sup> and Alzheimer’s disease has recently been classified as a terminal illness<sup>136</sup>).

Illnesses were additionally categorised as being progressive if the inquest notes included a reference to the fact the deceased person was aware their physical condition would worsen over time. The number of verdicts recorded in each year and the number that involved someone with a terminal or chronic illness in each of the years are shown in table 4.

#### Incidences of chronic and terminal illness

The results of our detailed study of Norwich district’s inquest records revealed that 25 suicides, out of a total of 259 that took place over five years, involved a person with a diagnosed terminal or chronic illness. This amounts to 9.7 per cent of all recorded suicides during that period.

In 18 of the 259 cases, the deceased had a diagnosed chronic condition (6.9 per cent of all recorded suicide verdicts). In eight of the 25 cases, the deceased person had a diagnosed terminal illness (3.1 per cent of all suicide verdicts). One person (4 per cent of the sample) had both chronic and terminal conditions at the time of death. In 44 per cent of the 25 cases that involved chronic or terminal illness, the deceased person had a condition that was progressive and was expected to worsen over time. Medical conditions identified in the inquest records included Parkinson’s disease, motor neurone disease, ME, chronic arthritis, Huntington’s disease, Alzheimer’s and cancer.

Of the 25 cases involving terminal or chronic illness, those who died by suicide were between 35 and 95 years old; 74 per cent of the sample group were male and 26 per cent were female. Table 5 shows details of the individual cases and medical conditions.

Table 4 **Number of suicide verdicts in Norwich district between May 2006 and December 2010, and incidences of chronic or terminal illness**

Year	Suicide verdicts	Cases involving terminal or chronic illness
2006 (8-month period)	27	4
2007	46	5
2008	72	6
2009	53	4
2010	61	6
Total	259	25

#### Discussion of case study findings

It is often assumed that mental illness, as opposed to physical illness, is the more salient factor in cases of suicide. Therefore, it is worth noting at this point that in just over half of the 25 cases (57 per cent), there was no evidence in the inquest records that the deceased had a previous history of mental illness. This means that half of those who took their lives while experiencing chronic or terminal illness may not have had any current or pre-existing relationship with mental health services. This indicates that in many cases GPs and other primary care services may be best placed to identify people with serious illnesses who may be having suicidal thoughts and be in need of additional support. However, there was no evidence in the study of Norwich District's inquest records that people felt compelled to end their lives because of lack of support from health or social care services.

In some instances it was apparent from the records that the person had ended their life to obtain release from a long-term debilitating condition or to avoid experiencing the progression of an illness. For example, there was one case in the records of a 47-year-old man who had been diagnosed with Huntington's disease 13 years earlier. He had seen family members die of the disease and his own health condition had started to deteriorate. He did not want to die like his father had and he took his life by

Table 5 **Suicide verdicts in Norwich district (May 2006 – December 2010) with details of age, gender, suicide method, medical condition and mental health history**

Year of suicide verdict	Age	Gender	Method of suicide	Type of physical illness
2006	69	Female	Hanging	ME
2006	75	Male	Overdose	Arthritis
2006	43	Male	Hanging	Brain tumour
2006	76	Male	Hanging	Lung problems
2007	81	Male	Hanging	Parkinson's disease
2007	81	Male	Overdose	Leg pains
2007	61	Male	Hanging	Arthritis and mouth pains
2007	74	Female	Overdose	Parkinson's disease
2007	95	Female	Overdose	Back pain and high blood pressure
2008	64	Male	Hanging	Bowel and colon cancer
2008	55	Male	Deliberate Road Accident	Cancer in the neck and shoulder and desmoid tumour
2008	75	Female	Overdose	Motor neurone disease and heart disease
2008	85	Male	Hanging	Tinnitus
2008	91	Male	Shot in Mouth	Obstructive pulmonary disease, heart and renal disease
2008	79	Male	Overdose	Bone cancer
2009	57	Female	Hanging	Subarachnoid haemorrhage, post-viral fatigue and tinnitus
2009	48	Male	Hanging	ME
2009	85	Male	Shot in Head	Liver cancer
2009	35	Female	Cuts	ME
2010	43	Male	Jumped out of window	Huntington's disease
2010	56	Male	Hanging	ME and epilepsy
2010	85	Male	Hanging	Prostate cancer and tinnitus
2010	82	Male	Hanging	Chronic lung problems
2010	72	Female	Overdose	Chronic health problems
2010	73	Male	Drowning	Alzheimer's

Terminal or chronic illness	Was illness progressive?	Recorded mental health history
Chronic	No	Previous suicide attempt in 2001 when she became bed-bound
Chronic	Yes	n/a
Terminal	No	n/a
Chronic	Yes	n/a
Chronic	Yes	No history of mental illness
Chronic	No	n/a
Chronic	No	Suffering with depression
Chronic	Yes	n/a
Chronic	No	n/a
Chronic	Yes	No history of mental illness
Terminal	Yes	Developed depression
Terminal	Yes	n/a
Chronic	No	Developed depression
Chronic	Yes	No history of mental illness
Terminal	No	History of depression
Chronic	No	Depression as a result of physical illness
Chronic	Yes	Mental stress in his marriage
Terminal	No	Mild depression as a result of terminal illness
Chronic	No	Eating disorder related to ME
Terminal	Yes	n/a
Chronic	No	Developed depression
Terminal and Chronic illness	No	n/a
Chronic	No	n/a
Chronic	No	n/a
Terminal	Yes	n/a

jumping out of a window. In another case, this was the suicide note of a chronically ill 76-year-old man, who hanged himself in July 2006:

*A lifetime of smoking has caught up with me. The lungs are now clogged up and breathing is becoming hard work. Even cutting the grass walking behind a motor mower becomes a struggle... the possibility of becoming a cabbage is anathema.*

An 81-year-old man who hanged himself in August 2007 left this suicide note: 'I take my life. I have Parkinson's Disease and have become a burden on others.' One 81-year-old male cabinet maker who took an overdose in November 2007 had chronic leg problems that were causing him considerable pain. He wrote in his suicide note, 'I want to be able to control when I die and be spared the indignity.' No known history of mental health problems was mentioned in this man's inquest report. However, there was clear evidence of depression brought about by serious illness in other cases, for example a 55-year-old man who died by walking into the road in front of a lorry in May 2008. He was a computer analyst and was suffering from depression 'as a consequence of his medical condition', which included cancer in the neck and shoulder. In his suicide note this man had written, 'I feel so depressed and worthless.' As discussed previously in chapters 1 and 2, it will be important that we develop a better understanding of this complex relationship between physical and mental health if we are to develop a more effective policy response to suicide.

### Semi-structured interviews with expert organisations

In addition to the interviews with coroners, Demos also interviewed representatives from a PCT, a suicide prevention charity and a right-to-die organisation to gain further perspectives on the relationship between suicide and serious illness.

### Bournemouth and Poole Primary Care Trust

Rosemary Shaylor is joint programme and commissioning manager at Bournemouth and Poole PCT. She was interviewed over the phone in April 2011 when she explained that her PCT first published its local suicide prevention strategy in 2007. Later this year the local regional health authority will publish its latest suicide prevention strategy using data collected from coroners, hospitals, GPs and mental health providers between 2008 and 2010. Rosemary Shaylor commented:

*In our area there is a large elderly population and some commit suicide after the loss of a partner or if they are forced to retire. But we need to do more work on this issue and a lot more could be done on the links between suicide and terminal illness.*

### Friends at the End

Friends at the End (FATE) is an organisation that campaigns for the legalisation of assisted suicide and provides advice and support for people who are suffering at the end of their lives. We interviewed Dr Libby Wilson, a medical adviser for FATE, over the phone in May 2011.

Dr Wilson said she receives a phone call every day from people who wish to end their lives (approximately 12 calls per week), and that most of these are from somebody who has either a terminal or a chronic illness. Between July 2007 and October 2008, Dr Wilson recorded a total of 327 calls to FATE. Of these callers, 139 (42 per cent) were male. Another 13 people (4 per cent) said they had cancer and 102 people (31 per cent) cited another medical condition. The remainder either did not name a physical condition or had psychiatric problems. Dr Wilson explained that FATE will sometimes give advice on how to commit suicide: 'We just want to give people the right information so they don't do a botched job.' Dr Wilson has previously been arrested for providing such advice, as assisting suicide is illegal under the 1961 Suicide Act.

### The Campaign Against Living Miserably

The Campaign Against Living Miserably (CALM) is a charity that was set up in response to the particularly high rate of suicide among young men. The charity offers information and emotional support via a helpline and website. We interviewed Jane Powell, director of CALM, over the phone in April 2011. She explained that around 20 per cent of the 400 or so calls a week to their suicide helpline were from people experiencing suffering as a result of a terminal or chronic medical condition.

Ms Powell highlighted the difficulties involved in obtaining detailed information on suicides in the UK:

*Coroners are the biggest problem. It's very frustrating when they don't report local information on suicides. For instance, we know those with a terminal illness or chronic illness are much more likely to commit suicide but coroners don't record this information properly or consistently. They see themselves as being local guardians of this knowledge, but it should be shared.*

This question of how information can be used more effectively at both a local and national level to inform an effective policy response to suicide will be explored in more detail in the next chapter, which sets out the report's conclusions and recommendations.

## 4 Conclusions and recommendations

This report has presented new evidence, collected from coroners and primary care trusts (PCTs), that at least 10 per cent of suicides that take place in England involve people with either a chronic or terminal illness. It is likely that this figure may be a significant underestimate, as we also found anecdotal evidence that some coroners currently choose not to include relevant health information within their inquest records, which are frequently the main input to PCTs' suicide audits. While our freedom of information (FOI) request to PCTs found that there was an average figure of 2.1 per cent of suicides involving terminal illness across the PCTs that responded, and an average of 10.6 per cent involving chronic illness, there was also an average of 21.4 per cent involving 'some specific form of physical illness or health condition'. These figures cannot simply be added together, as some PCTs informed us that they had included the same suicide case within more than one category. However, they do indicate that our estimate of at least 10 per cent of suicides nationally involving some form of serious physical illness (either chronic or terminal) is a robust and conservative one.

On the basis of this estimate, we can further extrapolate what the size of the problem may look like nationally. According to the Office for National Statistics, 4,390 suicides were recorded in England 2009, therefore we can estimate that in at least 10 per cent of these suicides – 439 – the deceased person is likely to have experienced some form of serious physical illness as an influencing factor. This finding provides a strong argument that people with chronic and terminal illnesses should be considered a 'high risk group' for suicide within national policy, which currently includes a focus on 'occupational groups' (such as doctors and farmers) that account for fewer than 100 suicides

annually, but fails to give adequate attention to adults with serious physical illness.

While this study was able to establish some broad trends on suicide and physical illness, it was not able to perform more fine-grained analysis unpicking the interaction between suicide, physical illness and other characteristics such as mental health or level of social support. If we wish to develop a better understanding at a national level of how these factors interact, to inform the national policy response to suicide, it is imperative that methods of monitoring suicides are strengthened and improved. It is also clear that primary care services must take a more proactive role in identifying and responding to the physical and emotional needs of people with chronic and terminal illnesses. The Coalition Government's new suicide prevention strategy,<sup>137</sup> which at the time of publication of this report is out for consultation, is an excellent opportunity to drive forward these changes. The recommendations below will suggest in more detail the approach that might be taken.

## Recommendations

### 1 Make local suicide audits a requirement

The Coalition Government's new draft strategy, *Consultation on Preventing Suicide in England*, specifies that following its programme of NHS reform, local health and wellbeing boards for each district will have local responsibility for 'determining local needs' and developing a public health response to suicide.<sup>138</sup> However, this study has demonstrated that PCTs' responsibilities for collecting data and monitoring local trends in suicide are not sufficiently clear. In fact, ten of the PCTs that responded to our FOI request (7 per cent of the PCTs we contacted) stated that they do not conduct a local suicide audit and were unable to provide the required data. We believe that suicide is such a serious public health matter that suicide audits should not be optional; PCTs – and subsequently health and wellbeing boards – should be required to compile annual reports that explore in detail the characteristics of people who died by suicide to inform the local response.

## 2 Improve guidance on suicide audits for primary care trusts

It is also clear that the information collected in local suicide audits is not being used effectively at a national level. The annual reports on suicides published by the Office for National Statistics provide a very minimal amount of information about the characteristics of those who die by suicide, and do not draw on local authorities' suicide audits. An important reason for this is likely to be the fact that PCTs use widely varying methodologies for collecting and reporting their data, therefore it is very difficult to aggregate these data in a meaningful way.

Our research found that *fewer than 30* of all the PCTs in the country were able to provide relevant numerical data relating to underlying physical health issues experienced by the individuals who had died by suicide in their district over the last five years. Therefore, better and more strongly enforced guidance for PCTs – and subsequently health and wellbeing boards – on how to conduct suicide audits is essential if we are to build a more meaningful national picture of suicides. This guidance should specify the minimum level of information that is required, allowing flexibility in the range of 'risk factors' that are tracked locally. Information on the deceased person's physical health, and specifically the existence of chronic and terminal conditions, should be part of these minimum requirements.

Cumbria PCT's response to our FOI request stated, 'the DH approved audit tool does not enable collection of the level of detail requested.' It should not be impossible to collect basic data on the health status of people who die by suicide, therefore PCTs need appropriate tools and guidance that can specify the type of data required, and support them to achieve this. It should also be expected that the authority responsible for conducting local audits will consult coroners and GPs to attain the necessary information. This will of course require these agencies' cooperation, which is another significant matter that must be addressed.

## 3 Clarify coroners' duty to share information

Five of the PCTs that responded to our FOI request indicated that they had difficulty communicating with the local coroner's

office to collect information for their suicide audit. We also heard directly from coroners that they did not think it was part of their role to record health information within their suicide inquest records or to share this information with other local agencies. It is currently left up to individual coroners to determine which parts of the information they hold are confidential and which may be shared. This has led to an incoherent situation in which some coroners are willing to open up their entire suicide inquest archive to researchers, while other coroners will not share any information with the local PCT. This can be a matter of considerable frustration for those responsible for conducting local suicide audits.<sup>139</sup>

We accept that this may be partly an issue of limited resources within coroner's offices for supporting research activities. However, it is essential that there is greater clarity about the data that may and may not be shared: national guidance is required to specify what personal information must remain confidential (such as the name of the deceased person) and what information coroners are expected to share with appropriate agencies. This is a topic of national importance; it should not be left to individual coroners to decide their information-sharing policies locally.

### 4 Computerise inquest records

Demos's research with coroners also found that some coroners' processes for archiving inquest records were somewhat archaic, which can make the process of data-sharing cumbersome and problematic. To combat this problem, Demos suggests that coroners' inquest records should be computerised and made searchable by authorised researchers using a password-protected system. Different levels of security clearance could determine the information that was made accessible in each case. This would hugely contribute to the new suicide prevention strategy's goal to support 'research, data collection and monitoring'.<sup>140</sup>

This move inevitably would not be popular with all coroners, but a number of coroners' offices are already leading on this by making certain information from their inquest records

available via their website. In Leicester and South Leicestershire district, the inquest records for the last ten months are publicly available online.<sup>141</sup> The data on this system include the deceased's age, date of death, method of death, name and the inquest verdict. A national database for coroners' records could use Leicester Coroner's District's system as a framework to build on. This recommendation does, of course, have cost implications. However, if implemented it would allow a systematic collection of information, which is not currently possible, and could help to reduce suicides in the UK through a deeper understanding of high risk groups like those with a terminal or chronic illness.

### 5 Legislate to improve the quality of inquest records

Our research found that coroners currently do not always include details of the deceased's medical history in their records as they are not required to; the level of detail provided varies depending on the individual coroner's approach and interests. However, the inclusion of this information in inquest records, in combination with evidence from GP records, could provide an important resource for those attempting to monitor suicide locally and nationally. Indeed, in the detailed case study of suicide cases in Norwich District, it was relatively easy to determine whether terminal or chronic illness might have been a factor in someone's suicide, as the relevant coroner included this information within the verdict.

Last year Caroline Lucas MP asked the Secretary of State for Justice what assessment he had made of the merits of ensuring coroners recorded such information in the verdict.<sup>142</sup> In response, Jonathan Djanogly, Justice Minister, said: 'to introduce further subsets of the short form verdict might cause practical difficulties' in time and expense, but that this matter would be considered as part of the Public Bodies Bill (currently making its way through Parliament, not to be enacted until at least April 2012). Demos recommends that coroners should be required to include details of the deceased's medical history as part of the inquisition form in box 3. This would enable data collection at a local level – by PCTs or health and wellbeing boards – from the

coroners in their areas, thus removing the need to include additional datasets for national audits and contributing important information for the purposes of suicide prevention. With a computerised system for recording inquest records (as recommended above), the Department of Health would be able to perform national analysis of the rates of suicide that involved terminal or chronic health conditions, thereby hugely improving our knowledge on this subject.

### 6 The Office for National Statistics should provide detailed reporting of suicide trends

While it has been recommended for almost a decade that PCTs should conduct detailed local audits to explore local risk factors for suicide, there is no evidence that this local information is being used effectively at a national level. Expecting PCTs to collect this information locally but failing to compile it nationally is a missed opportunity. Following the reforms outlined above, it will be possible for the Government to compile more detailed national statistics on trends and risk factors for suicide, and it should certainly be possible for demographic information such as ethnicity, marital status and health status to be included within these reports. The current emphasis in national data collection on very simple demographic information (age and gender), method of suicide and use of mental health services is inevitably holding back our knowledge of the risk factors for suicide and understanding of how to respond effectively to suicide in public policy. Demos recommends that far more comprehensive information about those who die through suicide including health status, relationship status, occupation and recent life events should be included in annual national reporting to inform both national and local policy responses to suicide.

### 7 Improve support for people with chronic and terminal illnesses

The previous recommendations have all focused on the need for improved data collection and monitoring of suicides at both a

local and national level. However, it is essential that this information is acted on to improve medical, emotional and practical support for people with chronic and terminal illness who may be considering suicide, a group that this research estimates accounts for at least 10 per cent of all suicides. The Coalition Government's draft suicide prevention strategy highlights in its preface that the draft strategy 'also makes more explicit reference to the importance of primary care in preventing suicide, and to the need for preventative steps for each age group'.<sup>143</sup>

The research explored in chapter 1 found there is a greater risk of suicide during the period immediately following a cancer diagnosis, with one study finding that the risk of suicide was highest in the one to three months after diagnosis, and decreasing (but remaining high) in the four to twelve months that follow.<sup>144</sup> Another study identified a very close association between physical illness, depression and suicide in older people,<sup>145</sup> while NICE guidance has found that people with chronic illness experience a much higher risk of depression.<sup>146</sup> This knowledge must be used to inform the provision of support by primary care services to people with chronic and terminal health conditions. Much greater attention must be paid to the impact of poor physical health on an individual's mental health. Offering professional counselling to people with physical health problems who are also experiencing depression or low mood should be a priority of primary care services, particularly if an individual has recently been diagnosed with a terminal condition. Every GP and PCT (and in future years, GP consortia and health and wellbeing boards) should be responsible for ensuring that the appropriate local services are available to respond to the medical, emotional and practical needs of people who are coping with painful or limiting illnesses, and their carers.



# Appendices

## Appendix 1 Non-comparable numerical data provided by primary care trusts

Table 6 **Examples of non-comparable numerical data that was provided by PCTs**

PCT	Information provided
Ashton, Leigh and Wigan PCT	Suicide audits have been carried out for the previous two years. For each illness quoted we can confirm that numbers were fewer than 10. NHS Ashton, Leigh and Wigan follows NHS guidance in the release of small numbers into the public domain.
Mid Essex PCT	Two audits were carried out, one covering 2007 and 2008, and the second covering 2008/09 and 2009/10. The most relevant information from these was on the last contact with GPs: <ul style="list-style-type: none"> <li>· For 2008, 11 had data from a GP included in coroner's information; two-thirds had last seen a GP for mental health reasons and one-third for physical health reasons. For some, the last contact with GP was a long time before death.</li> <li>· For 2009, 22 cases included information about last contact with GP; 12 of these were for mental health reasons.</li> <li>· For 2010, 11 cases included information about last contact with GP; 8 were for physical health reasons.</li> </ul>
South Gloucestershire PCT	This PCT did not routinely collect information on physical, chronic or terminal illness, pain or physical disability. Its response defined 'health condition' as contact with secondary care mental health services, the numbers for which were less than 5 in 2003, 2005 and 2008, 5 in 2004, 8 in 2006 and 6 in 2007.

Table 6 **Examples of non-comparable numerical data that was provided by PCTs – *continued***

PCT	Information provided
Buckinghamshire PCT	<p>There were suicide audits in 2006, 2007 and 2008:</p> <ul style="list-style-type: none"> <li>· In 2006 there were 29 suicides, 25 of which have coroner based data in the suicide audit; fewer than 5 had seen their GP for a physical health problem in the preceding 12 months.</li> <li>· In 2007 there were 28 suicides, 21 in coroner data-based suicide audit; fewer than 5 had seen their GP for a physical health problem in the preceding 12 months.</li> <li>· In 2008 there were 43 suicides, 41 in coroner data-based suicide audit; 15 had seen their GP for a physical health problem in the preceding 12 months.</li> </ul>
Bromley PCT	<p>Suicide audits were conducted between 2005 and 2009. Not all suicides were audited in each case, therefore the percentage of all suicides that involved ill health cannot be calculated. However, useful information on illness is provided in the age breakdown of the audits:</p> <ul style="list-style-type: none"> <li>· In 2005 there were 30 suicides and undetermined injuries; 27% were 65 and over, the majority of whom had a history of ill health or depression.</li> <li>· In 2006 there were 27 suicides and undetermined injuries; 26% were 65 and over, the majority of whom had a history of ill health or depression.</li> <li>· In 2007 there were 35 suicides and undetermined injuries, including 22 open verdicts; 31 were audited. 29% of these were aged 65 or over, the majority of whom had a history of ill health or depression.</li> <li>· In 2008 there were 21 suicides and undetermined injuries, including 8 open verdicts; 19 were audited. 9% were aged 25-64, the majority of whom had a history of depression or poor ill health, and 15% were aged 65 and over, all of whom had a history of ill health and depression.</li> </ul>

Table 6 **Examples of non-comparable numerical data that was provided by PCTs – *continued***

PCT	Information provided
<i>Bromley PCT continued</i>	<ul style="list-style-type: none"> <li>· In 2009 there were 25 suicides and undetermined injuries, including 5 open verdicts; 22 were audited. 81.8% were aged 35–64, the majority of whom had a history of depression and poor physical health. 18% were 65 and over, and all of these had terminal cancer and depression in their records.</li> </ul>
Stockport PCT	<p>Suicide audits for 2006 found that:</p> <ul style="list-style-type: none"> <li>· fewer than 10 had a 'recent diagnosis of physical or mental illness' in the coroner's report</li> <li>· fewer than 10 cases had seen their GP in the previous week for physical/mental ill health</li> <li>· the coroner's report mentioned 'prolonged physical or mental ill health' in 41% of cases</li> </ul> <p>The suicide audit for 2007 found that:</p> <ul style="list-style-type: none"> <li>· fewer than 10 had 'prolonged physical or mental ill health' mentioned in the coroner's report</li> <li>· fewer than 10 had seen their GP in the previous week for physical/mental ill health</li> </ul>
Coventry PCT	<p>From provisional mortality data (before the cause of death was confirmed) for 2005 to 2009: 41% had a health condition listed on the death certificate, 74% of which were mental health conditions. However, these are more probable than for confirmed suicides.</p>
Bristol PCT	<p>Bristol PCT provided data for 2010. Based on the 51 suicides that Bristol audited, none of which yet had an official coroner's verdict, they provided the following information:</p>

Table 6 **Examples of non-comparable numerical data that was provided by PCTs - *continued***

PCT	Information provided
Bristol PCT - <i>continued</i>	<ul style="list-style-type: none"> <li>· Work with GPs in Bristol has highlighted concerns about the impact of physical/chronic illness on mental health.</li> <li>· Physical health was mentioned in 74 per cent of the cases audited. Physical illnesses included suspected epilepsy, psoriasis, hypertension, head injury and cerebral damage, epilepsy, inguinal hernia, head and mouth injury, left seventh nerve palsy, normal tension glaucoma. Further records were related to other health problems such as cold, influenza, etc.</li> <li>· 9.8 per cent of deceased individuals had chronic illnesses. These included morbid obesity, Parkinson's disease, chronic kidney disease stage 3, cirrhosis of liver, septic arthritis, heart disease and diabetes.</li> <li>· Data for 2010 show no report of a terminal illness in any of the deceased individuals where health information was provided.</li> <li>· Examples of pain that were reported included musculoskeletal chest pain, calf pain and swelling, chest pain, pain related to poor health due to long term alcohol use.</li> <li>· In those cases where health information was provided, none of the deceased was reported as physically disabled.</li> </ul>

## Appendix 2 Semi-structured interview framework for coroners

- 1 How long have you worked as a coroner?
- 2 What does a coroner's role involve? At what point would you be involved in the process?
- 3 How frequently have you come across cases of suicide while you have been a coroner?
- 4 How often have you come across suicides by people who are terminally ill?
- 5 How would information regarding the inquest be recorded in a coroner's report?
- 6 What kind of information would be included?
- 7 How would you decide whether to record an open/narrative verdict for a suicide inquest?
- 8 How would you record a suicide by a person who is terminally ill – would that go in your report?
- 9 Are there guidelines for coroners about how to record suicides by people who are terminally ill?
- 10 Might some slip through the net?
- 11 Have you personally been involved in a suicide case where the victim was terminally ill?
- 12 Have you been involved in a suicide case where the victim had a chronic illness/severe physical illness and how many were there?
- 13 Do you differentiate between terminal and chronic illness, and if so how?
- 14 How many of these cases would you estimate that you have come across in the previous five years?
- 15 Are these issues that coroners discuss ever?
- 16 Do you think that coroners in general will often deal with such cases?
- 17 Do you think that the number of people dying through suicide with a terminal illness has risen or declined while you have been a coroner?
- 18 Do you think we should record suicides related to terminal illness in a different way?
- 19 Do you think there is an issue with the numbers of people dying through suicide who have a terminal illness?

- 20 Have you ever come across an instance of assisted dying/assisted suicide?
- 21 If so what were the details of the case?
- 22 Do you have a view on assisted dying?
- 23 Do you know any other coroners who might be willing to speak to us? Can we look at your records?

## Appendix 3: Detailed data on number of suicides per year in each category by PCT

### All Cases

Primary Care Trust	Total suicides across all years given	Number of years for which data provided	Average (mean) suicides per year
Bournemouth and Poole	106	3	35.3
Bury	22	2	11.0
Camden	102	4	25.5
Central Lancashire	163	5	32.5
County Durham (from coroner records)	187	6	31.2
County Durham (from GP records)	187	6	31.2
Cumbria	52	1	52.0
Darlington (from coroner records)	45	6	7.5
Darlington (from GP records)	45	6	7.5
Ealing and Hounslow	45	1.5	30.0
Gloucestershire	168	3	56.0
Hartlepool (from coroner records)	47	6	7.8
Hartlepool (from GP records)	47	6	7.8
Hertfordshire	168	3	56.0
Lincolnshire	115	2	57.5
Manchester	44	1	44.0
Manchester Mental Health & Social Care	3	4	22.7
Middlesbrough (from coroner records)	74	6	12.3
Middlesbrough (from GP records)	74	6	12.3
Newcastle	50	3	16.7
North Lancashire	116	3	38.7
North Somerset	88	5	17.6
North Tyneside	78	3	26.0
Portsmouth	34	3	11.3
Redcar and Cleveland (from coroner records)	72	6	12.0
Redcar and Cleveland (from GP records)	72	6	-
Sefton	78	5	15.6
Sheffield	166	5	33.2
Somerset	135	3	45.0
Stockton on Tees (from coroner records)	87	6	14.5
Stockton on Tees (from GP records)	87	6	14.5
Surrey (provided average for three years provided)	237	3	79.0
Wakefield	150	8	18.8
Warrington	92	6	15.3
Wiltshire	84	5	16.8
Wolverhampton City	165	6	27.5

**Physical illness**

Primary Care Trust	Total number of suicides where individual had physical illness (for years given)	Average number of cases per year	Percentage of suicides where individual had physical illness
Bournemouth and Poole	2	0.7	1.9
Bury	-	-	-
Camden	1	0.3	1.0
Central Lancashire	8	1.6	4.9
County Durham (from coroner records)	2	0.3	1.1
County Durham (from GP records)	1	1.7	0.5
Cumbria	-	-	-
Darlington	-	-	-
(from coroner records)	-	-	-
Darlington (from GP records)	-	-	-
Ealing and Hounslow	5	3.3	11.1
Gloucestershire	5	1.7	3.0
Hartlepool	2	0.3	4.3
(from coroner records)	-	-	-
Hartlepool (from GP records)	1	0.2	2.1
Hertfordshire	-	-	-
Lincolnshire	-	-	-
Manchester	-	-	-
Manchester Mental Health & Social Care	-	-	-
Middlesbrough	2	0.3	2.7
(from coroner records)	-	-	-
Middlesbrough (from GP records)	-	-	-
Newcastle	-	-	-
North Lancashire	-	-	-
North Somerset	3	0.6	3.4
North Tyneside	-	-	-
Portsmouth	3	1.0	8.8
Redcar and Cleveland (from coroner records)	72	6	12.0
Redcar and Cleveland (from GP records)	2	0.3	2.8
Sefton	29	5.8	37.2
Sheffield	83	16.6	50.0
Somerset	2	0.7	1.5
Stockton on Tees	4	0.7	4.6
(from coroner records)	-	-	-
Stockton on Tees (from GP records)	-	-	-
Surrey (provided average for three years provided)	-	-	-
Wakefield	-	-	-
Warrington	-	-	-
Wiltshire	-	-	-
Wolverhampton City	n/a	n/a	8.0

## Chronic illness

Primary Care Trust	Total number of suicides where individual had chronic illness (for years given)	Average number of cases per year	Percentage of suicides where individual had chronic illness
Bournemouth and Poole	8	2.6	7.5
Bury	-	-	-
Camden	2	0.5	2.0
Central Lancashire	-	-	-
County Durham (from coroner records)	5	0.8	2.7
County Durham (from GP records)	9	1.5	4.8
Cumbria	1	1.7	2.2
Darlington (from coroner records)	1	1.7	2.2
Darlington (from GP records)	3	0.5	6.7
Ealing and Hounslow	-	-	-
Gloucestershire	12	4.0	7.1
Hartlepool (from coroner records)	1	0.2	2.1
Hartlepool (from GP records)	-	-	-
Hertfordshire	47	15.7	28.0
Lincolnshire	-	-	-
Manchester	9	9.0	20.5
Manchester Mental Health & Social Care	-	-	-
Middlesbrough (from coroner records)	-	-	-
Middlesbrough (from GP records)	-	-	-
Newcastle	-	-	-
North Lancashire	-	-	-
North Somerset	23	4.6	26.1
North Tyneside	-	-	-
Portsmouth	2	0.7	5.9
Redcar and Cleveland (from coroner records)	-	-	-
Redcar and Cleveland (from GP records)	1	1.7	1.4
Sefton	-	-	-
Sheffield	29	5.8	17.5
Somerset	22	7.3	16.3
Stockton on Tees (from coroner records)	4	0.7	4.6
Stockton on Tees (from GP records)	-	-	-
Surrey (provided average for three years provided)	22	7.3	9.3
Wakefield	-	-	-
Warrington	43	7.2	0.5
Wiltshire	-	-	-
Wolverhampton City	n/a	n/a	8.0

## Terminal illness

Primary Care Trust	Total number of cases	Average number of cases per year	Percentage of suicides where individual had a terminal illness
Bournemouth and Poole	-	-	-
Bury	-	-	-
Camden	-	-	-
Central Lancashire	2	0.4	1.2
County Durham (from coroner records)	3	0.5	1.6
County Durham (from GP records)	3	0.5	1.6
Cumbria	-	-	-
Darlington	-	-	-
Darlington (from coroner records)	-	-	-
Darlington (from GP records)	-	-	-
Ealing and Hounslow	-	-	-
Gloucestershire	6	2.0	3.6
Hartlepool	-	-	-
Hartlepool (from coroner records)	-	-	-
Hartlepool (from GP records)	-	-	-
Hertfordshire	-	-	-
Lincolnshire	-	-	-
Manchester	-	-	-
Manchester Mental Health & Social Care	-	-	-
Middlesbrough	-	-	-
Middlesbrough (from coroner records)	-	-	-
Middlesbrough (from GP records)	-	-	-
Newcastle	-	-	-
North Lancashire	-	-	-
North Somerset	-	-	-
North Tyneside	-	-	-
Portsmouth	2	0.7	5.9
Redcar and Cleveland (from coroner records)	1	0.2	1.4
Redcar and Cleveland (from GP records)	1	1.7	1.4
Sefton	-	-	-
Sheffield	2	0.4	1.2
Somerset	1	0.3	0.7
Stockton on Tees	-	-	-
Stockton on Tees (from coroner records)	-	-	-
Stockton on Tees (from GP records)	-	-	-
Surrey (provided average for three years provided)	<5	n/a	n/a
Wakefield	-	-	-
Warrington	-	-	-
Wiltshire	n/a	n/a	5.0
Wolverhampton City	n/a	n/a	8.0

## Pain

Primary Care Trust	Total number of suicides where individual had reported pain (for years given)	Average number of cases per year	Percentage of suicides where individual had reported pain
Bournemouth and Poole	5	1.7	4.7
Bury	-	-	8
Camden	-	-	-
Central Lancashire	-	-	-
County Durham (from coroner records)	10	1.7	5.3
County Durham (from GP records)	14	2.3	7.5
Cumbria	4	0.7	8.9
Darlington	4	0.7	8.9
(from coroner records)			
Darlington (from GP records)	1	0.2	2.2
Ealing and Hounslow			
Gloucestershire	7	2.3	4.2
Hartlepool	1	0.2	2.1
(from coroner records)			
Hartlepool (from GP records)	-	-	-
Hertfordshire	-	-	-
Lincolnshire	2	1.0	1.7
Manchester	-	-	-
Manchester Mental Health & Social Care	-	-	-
Middlesbrough	1	1.7	1.4
(from coroner records)			
Middlesbrough (from GP records)	1	1.7	1.4
Newcastle	-	-	-
North Lancashire	-	-	-
North Somerset	-	-	-
North Tyneside	-	-	-
Portsmouth	3	1.0	8.8
Redcar and Cleveland (from coroner records)	1	0.2	1.4
Redcar and Cleveland (from GP records)	2	0.3	2.8
Sefton	-	-	-
Sheffield	7	1.4	4.2
Somerset	9	3.0	6.7
Stockton on Tees	4	0.7	4.6
(from coroner records)			
Stockton on Tees (from GP records)	-	-	-
Surrey (provided average for three years provided)	19	6.3	8.0
Wakefield	-	-	-
Warrington	-	-	-
Wiltshire	n/a	n/a	7.0
Wolverhampton City	-	-	-

**Reported physical impairment or disability**

Primary Care Trust	Total number of suicides where individual had physical impairment or disability (for years given)	Average number of cases per year	Percentage of suicides where individual had physical impairment or disability
Bournemouth and Poole	2	0.7	1.9
Bury	-	-	-
Camden	-	-	-
Central Lancashire	-	-	-
County Durham (from coroner records)	3	0.5	1.6
County Durham (from GP records)	2	0.3	1.1
Cumbria	3	0.5	6.7
Darlington (from coroner records)	3	0.5	6.7
Darlington (from GP records)	5	0.8	11.1
Ealing and Hounslow	-	-	-
Gloucestershire	5	1.7	3.0
Hartlepool (from coroner records)	1	0.2	2.1
Hartlepool (from GP records)	-	-	-
Hertfordshire	4	1.3	2.4
Lincolnshire	-	-	-
Manchester	-	-	-
Manchester Mental Health & Social Care	-	-	-
Middlesbrough (from coroner records)	-	-	-
Middlesbrough (from GP records)	3	0.5	4.1
Newcastle	-	-	-
North Lancashire	-	-	-
North Somerset	-	-	-
North Tyneside	-	-	-
Portsmouth	-	-	-
Redcar and Cleveland (from coroner records)	2	0.3	2.8
Redcar and Cleveland (from GP records)	2	0.3	2.8
Sefton	-	-	-
Sheffield	7	1.4	7.2
Somerset	3	1.0	2.2
Stockton on Tees (from coroner records)	-	-	-
Stockton on Tees (from GP records)	-	-	-
Surrey (provided average for three years provided)	-	-	-
Wakefield	-	-	-
Warrington	6	1.0	0.1
Wiltshire	-	-	-
Wolverhampton City	-	-	-

### Some specific form of physical illness or health condition

Primary Care Trust	Total number of cases	Average number of cases per year	Percentage of suicides where individual had some specific form of physical illness or health condition
Bournemouth and Poole	8	2.7	7.6
Bury	-	-	-
Camden	-	-	-
Central Lancashire	-	-	-
County Durham	26	4.3	13.9
(from coroner records)			
County Durham (from GP records)	34	5.7	18.2
Cumbria	13	2.2	28.9
Darlington	13	2.2	28.9
(from coroner records)			
Darlington (from GP records)	15	2.5	33.3
Ealing and Hounslow	-	-	-
Gloucestershire	14	4.7	8.3
Hartlepool	1	0.2	2.1
(from coroner records)			
Hartlepool (from GP records)	1	0.2	2.1
Hertfordshire	6	2.0	3.6
Lincolnshire	44	22.0	38.3
Manchester	-	-	-
Manchester Mental Health & Social Care	3	1.0	4.4
Middlesbrough	2	0.3	2.7
(from coroner records)			
Middlesbrough (from GP records)	13	2.2	17.6
Newcastle	44	14.7	88.0
North Lancashire	14	4.7	12.1
North Somerset	11	2.2	12.5
North Tyneside	71	23.7	91.0
Portsmouth	3	1.0	8.8
Redcar and Cleveland	9	1.5	12.5
(from coroner records)			
Redcar and Cleveland (from GP records)	12	2.0	16.7
Sefton	-	-	-
Sheffield	41	8.2	24.7
Somerset	5	1.7	3.7
Stockton on Tees	5	0.8	5.7
(from coroner records)			
Stockton on Tees (from GP records)	10	1.7	11.5
Surrey (provided average for three years provided)	105	35.0	44.3
Wakefield	n/a	n/a	27.0
Warrington	-	-	-
Wiltshire	n/a	n/a	7.0
Wolverhampton City	-	-	-



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125 The total number is the total number of suicides for which there were adequate or complete data to analyse. This was 36 in 2007, 73 in 2008 and 59 in 2009. These figures differ slightly from data from the National Centre for Health Outcomes Development for these years, where the number of suicides was 58, 63 and 66 respectively. They differ because the PCT response was based on suicides reported by the coroner's service and analysed by year of the coroner's report rather than the year of death, and may have included non-Hertfordshire residents.

- 126 Additionally, there was one case (3 per cent of suicides) in the 2006 suicide audit where it was not known whether the patient had a chronic illness.
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Despite some progress made in our cultural attitudes to death, suicide remains very much a taboo subject. This discomfort has serious consequences, as it may be preventing proper analysis of the root causes of suicide. While some of the risk factors for suicide – such as gender and mental illness – are well-known, there is a vast hinterland of research waiting to be done on other potential factors.

Physical illness is one such factor. Through a literature review, FOI requests, semi-structured interviews with coroners and an in-depth case study of Norwich District Coroner's office, this pamphlet investigates the truth about suicide and serious physical illness. It finds that at least 10 per cent of the suicides that take place in the UK are by people who are chronically or terminally ill. But it also finds wide variation in how verdicts of suicide are recorded by coroners and made available to the public and policymakers.

Better data will generate better policy. This pamphlet recommends that, as part of the Coalition Government's ongoing consultation on preventing suicide, they should consider making local suicide audits compulsory, and that coroners' duty to share information should be formalised. Only when we have a clear idea of the causes of suicide can we hope to develop an effective policy response.

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