

Exploiting population data, uses and methods in uncovering  
factors associated with suicide and psychological distress

Fulfilment of the degree of PhD by Publication

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### **Personal**

To my family and close friends who experienced the vicarious impact of this PhD, thank you for your unwavering support.

To my husband, thank you for your heartfelt sympathy, unfettered wit and wisdom, and endless cups of tea.

To my children who have grown into wonderful adults during the course of this PhD, thank you for your understanding on occasions you were ignored, and for not complaining. For all the other times, thank you for expressing dissatisfaction with outrageously good humour.

### **Dedication**

I dedicate this thesis to Frances Finlay and Connel Arthur, aunt and nephew, who each ended their own lives. The ramifications of suicide are perpetually tragic for families, and ours is no exception. Frances's life and death sparked a personal interest in the research of mental health and suicide.

In life, Connel was incorrigibly humorous and adventurous. Connel's death was, and remains, devastating and quietly humbling. His death occurred during the course of this PhD, and although paralysing in its effect, it ultimately became a reason to complete this thesis.

*"Not by seeing too much do we discover the desolation implicit in life, but through myopic impoverishment, a tunnel vision of the soul."*

(Meditation on Virginia Woolf's final diary entry, by Robert J. Levy)

Frances Finlay (1953 – 2000)

Connel Arthur (1996 – 2017)

Forever in my thoughts





## Abstract

Society faces significant challenges caring for people with urgent mental health needs. General hospitals are well equipped for dealing with medical emergencies, but much less skilled in managing mental health problems. Ambulance and policing staff frequently encounter such individuals, with transport to Emergency Department often the only care pathway.

In the UK, no evidence existed on general hospital patterns prior to suicide, or on outcomes for pre-hospital mental health emergencies. This thesis contains five papers, consisting of four research studies and one protocol. Three papers report innovative quantitative approaches using linked datasets.

Using 30 years of Scottish hospital data, I showed that 10,907 people who died by suicide with hospital records were 3.1 times more frequently last discharged from general, not psychiatric hospital; 24% within three months of last discharge, of whom 58% were from general hospital.

Using national deaths registrations, I reported that cohorts of men born around 1965-70 had been at greater vulnerability to suicide in the 1990s, with stark differences in suicide rates between Scotland, and England & Wales.

Analyses of data on unscheduled care revealed that within one year of paramedic attendances for 6,802 people with 'psychiatric emergency', 297 had died, 35% of whom were deaths by suicide. Paramedics were in contact with 8% of people in the year before they died by suicide.

Police officers encountering people with mental health concerns have no formal means of vulnerability assessment to support triaging. A review of the evidence found no consensus definition for vulnerability or means of assessing vulnerability, a lack of congruence in terminology across policing and health, and a likely barrier to accessing services. Finally, a protocol was published outlining methods for an analysis of childhood adversity as seen in national hospital datasets.

This thesis provides evidence to support redesign of more integrated services, highlights areas for suicide prevention, and closes with an impact generation exemplar.



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# 1. Introduction

## 1.1 Rationale for PhD

### 1.1.1 Summary narrative

Every death by suicide is a tragedy that can have a massive impact on families and communities (1). It is the leading cause of death for young people aged 15-24 in Scotland (2), and knowing which people are at higher risk may help us understand who to help most in future before they take their own lives.

This thesis uses information recorded about people in three main ways. Firstly, information on those who have died by suicide; secondly, the contacts people in 'psychological distress' have with health and emergency services; and thirdly, whether information recorded along people's lifespan could be used to better inform suicide prevention and care pathway strategies earlier in the lives of those at greater risk. In this thesis I refer to 'psychological distress' as an umbrella term for 'cries for help', mental health or social distress, vulnerability, psychiatric emergencies, and short term crises.

In Scotland, people who are experiencing symptoms related to mental health or distress can attend their GP during office hours for support, dial 'NHS 24' (111 out of hours service) or '999' in an emergency (3). Other NHS support services may be directly accessed, such as 'Breathing Space' or 'Campaign Against Living Miserably (CALM)', both confidential phonelines (3). GPs may sign-post to self-help; prescribe antidepressant medication; provide referrals to Community Mental Health Teams (CMHT) to access additional support with talking therapies with a community psychiatric nurse or psychologist, or to psychiatry for out-patient or in-patient care (3).

Voluntary organisations such as The Samaritans are available with dedicated helplines that individuals may contact in times of distress and chat through difficult feelings at any time (4). However, at times, accessing support and care can be problematic, especially if out of hours, and people in need of help sometimes may attend Emergency Departments, or phone the Scottish Ambulance Service, or Police Scotland. Understanding what happens to



people after they have contacted the emergency services is important to know so that services can improve how they support people in future.

The aim of this thesis was to conduct research in suicide and suicidal behaviour using innovative techniques in analysing linked datasets. This was to be applied to National Records of Scotland deaths data, NHS general and psychiatric hospital data, Scottish Ambulance Service data, and Police Scotland data. There is not one giant, connected database for all these data, and therefore doing separate studies of what happens to people in contact with services was necessary. Training on methods in statistics and expertise in using these data were formally studied as part of this PhD in order to fulfil the aims.

Most of these datasets were accessible and available for use, admittedly with considerable effort in obtaining funding and gaining approvals in order to do so. It transpired during the course of studies that although Police Scotland leads were keen to collaborate and for their data to be used, that this was not yet possible, and that even if the data could be used, more work was needed to be done first to understand what Police Scotland meant by people with 'vulnerability'. 'Vulnerability' is the term used to describe people with suicidal behaviour, but also includes many other categories such as those who are victims of crime, who have dementia, or have disabilities, among many other reasons (5,6). In effect, 'vulnerability' is policing terminology that incorporates members of the public with symptoms of distress, or with mental health symptoms, or it may also encompass a much wider definition, such that 'any one of us can be vulnerable, given sufficient context, setting and life experiences' (7). With such a wide range of needs of different people, Police Scotland had an indicated need for guidance with the assessment of 'vulnerability', so that faster, more appropriate, responses could be made to those with the most need. Therefore, instead of taking forwards a Police Scotland data project as part of this PhD, a scoping review of evidence for the 'assessment of vulnerability' was done.

This thesis contains five published papers, consisting of four research studies and one research protocol. Two of these papers consider factors derived from

data associated with deaths by suicide, one uses Scottish Ambulance Service and unscheduled care data for 'psychiatric emergencies', and one considers the Police Scotland concept of 'vulnerability' and how that can be assessed. Finally, I include a published study protocol with detailed methodology for considering lifespan events from birth, through childhood adversity and mental health symptoms prior to suicide in young adults.

The five papers (with DOIs) presented are as follows:

1.1.1.1 Paper 1: For the first time in the UK, I applied an innovative data science method to summarise 30 years of information in Scottish NHS general and psychiatric hospital records of 16,411 people who died by suicide (8). The aim of this study was to identify patterns of hospital contact for people taking their own lives, finding that 3.1 times as many people died after last discharge from general hospital, not psychiatric hospital; that 24% of deaths occurred within three months of last discharge, more than half (58%) after last discharge from general hospital. I led this study as first author in collaboration with a team, and this paper has since been used to inform a National Institute of Health and Care Excellence (NICE) briefing paper for suicide prevention.

Paper 1: Dougall et al <https://doi.org/10.1192/bjp.bp.112.122374>

1.1.1.2 Paper 2: In this study, I used 65 years of National Records of Scotland (NRS) vital events deaths data spanning 1950-2014 (9). I investigated whether suicide is more a consequence of age, years of birth, or years of death. I compared my findings for Scotland with previously published findings by Professor David Gunnell and colleagues for England & Wales. In this study, I concluded that there was a group of men (cohort) born around 1965-1970 who died in statistically significantly higher numbers in Scotland between 1995-2004, compared with those born around 1960. This suggested some cohorts of men were potentially more vulnerable to suicide, and helped explain the high numbers of deaths seen for younger men in the 1990s. This compared with findings for England & Wales, although to a lesser

extent. I led this study as first author in collaboration with Dr Cameron Stark and team.

Paper 2: Dougall et al <https://doi.org/10.1186/s12889-017-4956-6>

1.1.1.3 Paper 3: For the first time in Scotland, NHS data on emergency care, the 'Unscheduled Care Dataset' was explored to look at what happened to people who were attended by paramedics from the Scottish Ambulance Service, and considered a 'psychiatric emergency' (10). This study found that within one year, 6,802 people were attended to on 9,014 occasions for self-harm or mental health reasons, 11% of all ambulance calls. The most frequent pathway with 51% of calls was transfer to, and discharge from, Emergency Departments. Within the following year after contact, 4% had died, 97 of these as suicide. In the same year 746 deaths by suicide were recorded for Scotland, suggesting the ambulance service were in contact with 13% of people prior to death; there are unique opportunities for suicide prevention strategies with alternative care pathways for people attended to by the ambulance service. In this study, I led on the data science (see chapter five), and collaborated with Dr Eddie Duncan (Principal Investigator) and team.

Paper 3: Duncan et al <https://doi.org/10.1186/s13049-019-0611-9>

1.1.1.4 Paper 4: I undertook a series of stakeholder interviews with Police Scotland, and all were keen to share data. I set out to replicate the ambulance service study above but in a policing context. Police Scotland colleagues reported that 80% of calls were not crime-related, and there was limited evidence to suggest many were calls from people in 'psychological distress' (11). As mentioned above, the reality of accessing usable data was to prove too challenging. All agencies have their own terminology and Police Scotland described people in 'psychological distress' as having 'vulnerability'. Through partnership working at a national event that I co-led, the key priority identified was the 'assessment of vulnerability' (7). I worked with colleagues in undertaking a scoping review of what was known about the assessment of 'vulnerability' in policing from a health perspective (12).

This review was the first in the world to report on this topic, finding that vulnerability is (broadly speaking) place-based from a policing perspective, and person-based from a public health perspective. I worked within a team for this study, and I brought topic expertise as well as methodological expertise in literature and scoping reviews.

Paper 4: Enang et al <https://doi.org/10.1186/s40352-019-0083-z>

1.1.1.5 Paper 5: My final paper returns to the Scottish NHS hospital and NRS deaths data. In identifying from people's lifespan data what commonly happens to people, given certain patterns of healthcare contacts, then there may be opportunities to intervene with alternative care pathways earlier in the lives of people. In this paper, I present a published protocol and methodology on identifying records for childhood adversity in the lives of people who later died by suicide (13). This paper improved on methods used in the first study above, this time looking to see what happened in a 'control' group matched to the group who took their own lives. It also provides methods for assessing the mental health and suicidal behaviour later in adolescence and young adulthood, as recorded in their NHS data. I led this study and obtained the funding as Principal Investigator in collaboration with a team.

Paper 5: Dougall et al <https://doi.org/10.23889/ijpds.v5i1.1338>

### **1.1.2 Thesis structure**

The thesis structure consists of eight chapters, covering three topics linked to five research papers. The remainder of this first chapter provides an overview and contextual information on the two main topics of interest, suicide and psychological distress. The second chapter focuses on the methods topic, and provides an overview and context on methodological approaches and issues in using large linked datasets. Chapters three through seven contain each of the five study papers, with a short discussion and reflection, including any impact, of each study.

The final chapter, chapter eight, draws on information from each of the studies, and I reflect on the drivers that informed how I could generate impact,

culminating in an event, which I co-led, the 'National Summit on Mental Health, Distress and Emergency Departments'. At this event, I presented the main findings of this PhD, along with other key experts from each service and the relevant Scottish Government directorates. A consensus statement of the National Summit findings and recommendations was drafted and published for use, and is included and discussed in this chapter, along with final comments on future recommendations for research.

Next, I introduce the two main topics of suicide and psychological distress, which form the basis of the rest of chapter one.

## **1.2 PhD key themes and brief bio**

Before commencing this PhD I was an experienced mental health researcher and statistician, (MSc Applied Statistics), and latterly Associate Professor at Edinburgh Napier University. In this PhD, I have learned and applied expertise in data science as a key methodological approach, and applied this to two broad topics. These two topics are firstly, factors related to deaths by suicide (and what can we learn from routinely available data), and secondly, the outcomes and responses to psychological distress, as attended to by our emergency services.

In each of the following sections, 1.3 and 1.4, I introduce and provide definitions, an overview and context for each of the two topics, drawing on academic and policy literature to set out key issues and debates. In section 1.5, I consider the role of whole system thinking, drawing on the two main topics, and argue for cross-disciplinary work in 'public mental health data innovation'. The themed discussions have been based around narrative reviews of the available literature. Although extensive reference to policy documents and the evidence base have been made, this was not intended to be a systematic literature search of all available evidence. Where possible, reference has been made to key policy directives or guidelines made by national and international not-for-profit and non-partisan organisations, e.g. the World Health Organisation (WHO), or the National Institute for Health and Care Excellence (NICE) (14,15). Supporting evidence for themed discussions were mostly based on peer-reviewed indexed academic publications accessed primarily via 'Web of Science' (16). Bibliographic software (Zotero 5.0.94) was used to compile, organise and cite relevant literature (17). The limitations of this

approach are two-fold. Firstly, a non-systematic literature search has the pitfall of not capturing absolutely all relevant literature, and secondly the literature has not been formally critically appraised for quality.

### **1.3 Topic 1: Suicide**

#### **1.3.1 Global perspectives**

Suicide is a global public health issue with the World Health Organisation citing almost 800,000 deaths every year at a corresponding mortality rate of 10.6 per 100,000 (18), accounting for 1.4% of all deaths (19). The corresponding figures by global region is highest for Europe at 150,000 deaths, equating to 15.4 per 100,000, and with a gender split for males and females of 24.7 and 6.6 per 100,000, respectively (18). In all global regions, males experience more deaths by suicide than females (with the exception of South-East Asia), equating to worldwide rates of 13.5 and 7.7 per 100,000, respectively (18).

Suicide is one of the leading causes of death in young people with rates having increased worldwide by an estimated 60% during the last half-century (19,20). Deaths by suicide are not only emotionally devastating to families and communities, they also have a large financial impact on society with direct and indirect costs of each death estimated at about one million Euro, corresponding to a total annual cost in Europe of 150 billion Euros (21,22).

#### **1.3.2 UK and Scottish perspectives**

In common with most countries, suicide is a significant public health concern in the UK. In 2018, UK deaths by suicide significantly increased by 11% to 6,507, equating to a standardised mortality rate (SMR) of 11.2 per 100,000 inhabitants (23). This significant increase reversed a continuous downward trend since 2013, and was largely attributable to increased deaths by men, and a surge in young adult deaths, with young women (<25y) reaching the highest rate on record (23). Many parts of the UK exceeded this rate, with the highest rates recorded in Northern Ireland and Scotland, respectively.

Scotland experienced an overall 15% increase in deaths by suicide in 2018 from 680 to 784 deaths, equating to a SMR (standardised to Scottish general population estimates) of 16.1 per 100,000 inhabitants (2,23). There have been many year-to-year fluctuations in such deaths over the decades, and the significant increase in 2018 may yet turn out to be a statistical 'blip', not reflective of an overall trend and best viewed as five year 'moving average' data (2).

In 2018, the death rate age-standardised to the European Standard Population for 'probable suicide' (a measure that permits cross-country comparisons) was reported by NRS at 14.0 per 100,000 . In the same year all-cause mortality for all ages was 1,158 per 100,000, with the leading causes being death by Cancer (317 per 100,000), Diseases of the circulatory system (298 per 100,000), and Diseases of the respiratory system (145 per 100,000). Equivalent SMRs by accidents and alcohol-related deaths were 30.6 and 23.7 per 100,000, respectively.

At an estimated 16.1 per 100,000, the Scottish SMR from suicide is disproportionately higher than that of its nearest neighbour, England at 10.3 per 100,000, a statistic with a decades-long legacy (9,24). This is especially so for men, in 2008 the suicide rate for Scotland was almost double that of England at 24.1 and 12.6 per 100,000 of the population, respectively (9,24). UK male deaths significantly increased from 2017 to 2018, numbering 4,903, and equating to 17.2 deaths per 100,000 (23). Men accounted for three-quarters of deaths by suicide, again a statistic which has perpetuated for decades (9,23). In comparison, the UK female SMR has remained relatively stable since 2008, and in 2018 was 5.4 per 100,000, (23).

For young people in Scotland, suicide is the leading cause of death, and alarmingly, in 2018 numbers of those aged 15-24 increased by 53%, the highest seen since 2007 (2). Taking a wider age group of those aged 10-34, it can be seen that deaths increased from 24.4% to 30.8% between 2014 and 2018 (13). Although these data may yet turn out to be a statistical 'blip' for 2018, they also mirror a recent trend for increased suicidal behaviour. Scotland health survey data established that in 2008/09, 2012/13 and 2014/15,

proportions of 3%, 5% and 7% of adults said they had ever self-harmed, respectively (25). Self-harm is a strong risk factor for suicide (26), and UK Psychiatric morbidity data reported that 26% of women and 10% of men have self-harmed (27).

### **1.3.3 Historical mental health policy**

The role of mental health policy and NHS service organisation may be pertinent to consider when exploring decades-old data. In this section, I first provide a brief history of the NHS, including some current differences in service organisation between Scotland and England. I then move on to draw out key historical points from the mental health policy timeline, assuming that shifts in service organisation will potentially have had a significant impact on outcomes for people who are in distress or have mental health problems.

The NHS in Scotland began in 1948, following an act of parliament in the previous year, and inaugurated by the then Health Minister Aneurin 'Nye' Bevan. For the first time, existing hospitals were nationalised and almost all of the general population enrolled in the NHS. The NHS was founded on the principle of universal access, with free healthcare available based on need, and regardless of wealth (28).

However, the tradition of medical practice was different between Scotland and England. Prior to 1948, Scotland already possessed a state-funded system, controlled from Edinburgh, and serving half the country. A hospital construction programme in Scotland and funded by the state during the war years had been on an unprecedented scale, compared with other regions in Europe (29). Scotland also differed in having a history of medical schools as opposed to private practices, with an emphasis on improving health rather than treating illnesses, as enshrined in the Cathcart report (29).

In 1972, the NHS Scotland Act came into being, the first major reorganisation of the NHS, and with the establishment of 15 Health Boards to provide a more coherent and integrated health service. These Health Boards were reconfigured as NHS Trusts, which were, in turn, abolished in Scotland in 2004. Prior to that, in 1989 the internal market was introduced to the NHS, the biggest change to the NHS since 1948, and for the first time the idea of



competition and internal markets for NHS services was introduced. The Private Finance Initiative (PFI) quickly followed this in 1992. PFI enabled private construction companies to build new hospitals and once opened, to maintain non-clinical services in these hospitals. However, not long afterwards, the Scottish Government committed to remove the internal market, the GP fundholding and contracting for services in 1997 with the publication of 'Designed to Care', and marking a shift in direction for NHS services North and South of the Scottish border (30).

In 2005, after public consultation in Scotland, the 'National Service Framework' (NSF; 'The Kerr Report') was published, marking a shift in attitudes towards individualism and personal responsibility for health (31), and a programme to implement the NSF recommendations was brought about, called 'Delivering for Health' (30,32). Shortly thereafter in 2007, the action plan for 'Better Health, Better Care' was implemented, a Scottish Government programme for the NHS based on mutuality, patients and public as partners, and not as mere passive recipients of care. The aim of this was to help people maintain and enhance their health, and in particular in disadvantaged areas, where the access to healthcare was to be better and faster (32). Criticisms from NHS staff at the time focussed on the competing demands on community nursing that as a matter of course would downgrade prevention activities as lower priority than the provision of acute health services. In turn, this would directly counter any effort to address health inequalities, such as substance misuse services (33). NHS staff were keen to increase support for national mental health improvement, self-harm, substance use, and suicide reduction programmes (33).

Perhaps the biggest shift in service reorganisation that created the most impact on those people with mental health diagnoses was the formal introduction in 1993 of Community Care for Mental Health, with people being supported at home rather than incarcerated in psychiatric facilities. This initiative impacted massively on staff and patients, with the closure of several large hospitals, and a rapid expansion of the community psychiatric workforce in the 1990s to meet the demand in supporting those in-patients who were discharged from hospital as outpatients (34).

In 2000, the newly formed Scottish Parliament passed the Adults with Incapacity Act (35), which aimed to protect and involve those aged 16 or over who lack capacity in decision-making (36). Government policy in Scotland instructed that hospital stays were to be avoided where at all possible, with an associated increase in people treated in the community. A corresponding decline in hospital beds was experienced in psychiatric facilities, reserved for people with more severe mental health conditions, and the greatest decrease in beds was seen in old age psychiatry with the number of beds falling over a decade from 3,992 beds in 2001 to 2,530 in 2011 (37). The Scottish Government's Report in 1995 on The Closure of Psychiatric Hospitals in Scotland committed to a new Framework for Mental Health Services in Scotland (38), with local solutions and strategies expected to cover these Framework commitments (39).

#### **1.3.4 Treatment through time for mental illness**

In looking at data related to suicide through time, it may be prudent to consider if any substantial shifts in the organisation and delivery of clinical care had an impact on observed outcomes. I provide some main highlights, as follows.

The advent of new drug treatments for mental illness in the 1950s, primarily anti-psychotics and anti-depressants, provided mechanisms for the better control of symptoms of psychiatric disorders. This paved the way for the ideological movement towards community care (34,40). Selective serotonin reuptake inhibitors (SSRIs), a new wave of anti-depressants became available in the late 1980s, followed shortly after by atypical anti-psychotics first prescribed in the 1990s. Electric Convulsive shock Therapy (ECT) was first introduced in 1938. It declined in use in the 1990s following reports of side effects first petitioned to House of Commons in 1979 of 'cumulative and irreversible brain damage and to produce memory loss...', and later summarised in a landmark Special Report from the National Association for Mental Health, now 'Mind' (39,41).

The UK 'Defeat Depression' campaign was launched in 1992, backed by the Royal College of Psychiatrists (RCPsych) and the Royal College of General Practitioners (RCGP), with the aim of educating GPs to better recognise and manage depression (42). The Campaign was found to have useful impact, with 40% of GPs declaring they had made changes in practice as a consequence of the campaign (43). Although these findings were positive, the campaign ran to 1996, encapsulating the time when many of the new SSRIs were marketed by the pharmaceutical industry along with their educational support. In addition, during this same time period, the Department of Health highlighted reducing suicide as a strategic aim (44).

Although the 'Increasing Access to Psychological Therapies' (IAPT) Programme was launched and gained traction in England in the 2000s, Scotland did not follow suit and developed its own approach. In 2006, 'Delivery for Mental Health' was published by the then Scottish Executive, a White Paper that set out a range of commitments to improve good mental health for the general population. Of these commitments, the fourth commitment was to replace the ad hoc psychological therapies already in existence, improve access, expand the settings, and the range of providers of evidence-based therapies (45). Much of this change came about because of increasing pressure from service users and carers, and the recognition of the discrepancy in care between general health and psychological services (45).

In effect, Scotland redesigned existing services and improved training to existing providers rather than the new IAPT service in England. Since then the Scottish Government has provided transparent targets on improving access to therapies, and a detailed Matrix on expected levels of intensity of intervention of evidence-based interventions mapped to level of severity and type of mental health problem, and training necessary for effective psychological therapies (46). Access to psychological therapies in Scotland has centred around Cognitive behavioural therapy (CBT), a talking therapy to manage problems mainly focussed on altering ways of thinking and behaving. Other therapies include mindfulness, behavioural family therapy and interpersonal therapy (45,46).

### **1.3.5 Public health**

In this section, I outline the role of the World Health Organisation and global perspectives on public health and suicide, risk factors and strategies to mitigate risk factors for suicide, before moving onto UK perspectives on public health and suicide. I will provide context on the role of social inequality in the UK, and its impact on the health of people, as well as public health perspectives of premature mortality, including ‘deaths of despair’ such as suicide. A public health approach to suicide is fundamentally important in order to support general population wellbeing and prevent needless suffering and deaths (47). This approach may be focused on improving knowledge of mental health and suicidality through culturally acceptable campaigns, with improved awareness and knowledge an appropriate way of equipping people to engage better with the vast majority of potential people vulnerable to suicide (47).

#### **1.3.5.1 Global perspectives**

The World Health Organisation (WHO) adopted Acheson’s 1988 definition of Public Health as the ‘science and art of preventing disease, prolonging life and promoting health through the organised efforts and informed choices of society, organisations, public and private, communities and individuals’ (48). This definition has endured to the present day, emphasising as it does, that public health is a collective societal responsibility to work together and benefit general population health. Public Health is therefore not only about prevention of disease but also concerned with improving population well-being.

WHO estimated in 2016 that suicide was the third leading cause of death in those aged 15-19, and the second leading cause of death in those aged 15-29 (49). The brunt of the impact of suicide has been sustained mostly in low and middle-income countries, where 79% of all suicides take place (49). Epidemiological data have revealed substantial variation around the world; highest and lowest rates of suicide have been around 70 per 100,000 in Eastern Europe, to less than 10 per 100,000 in Central and South America (50). Estimates from epidemiological studies for suicidal behaviour have varied widely as well; a systematic review estimated cross-national lifetime

prevalence of suicidal ideation between 3.1 and 56.0%, and suicide attempts between 0.4 and 5.1% (50).

Suicide has been such a massive public health concern that many nations around the world have embarked on increased monitoring of the prevalence and risk factors for suicide, and suicidal behaviour (19). In increasing surveillance through data collection expansion, it was thought possible to adapt public health strategies in response to the suicidal behaviour of people, and as recorded in the data (21,50).

As an instrumental public health approach to suicide, many countries have launched national suicide prevention programmes, frequently with multiple interventions, but with very little evidence for their effectiveness (51). Establishing effective elements of suicide prevention programmes are key to make the best use of precious and limited resources (51). In 2005, WHO European Ministers of Health signed a concordat that national programmes ought to be rolled out in all countries, with many following suit. However there remains no established evidence-based standard for effective national suicide prevention (19).

A more detailed look at risk factors for suicide and models of suicide are necessary to understand associated prevention strategies, and presented in the next three sections.

#### **1.3.5.2 Risk factors for suicide**

Risk factors for suicide have been conceptualised by WHO in three ways: firstly, systemic across society and/or healthcare systems; secondly, as related to relationships and community; and thirdly, as associated with individual level factors (52). Inevitably, these stratified risk factors interact with each other, and although it is impossible to disentangle this complexity, having a taxonomy is helpful in conceptualising levels of risk factors for suicide.

Systemic risk factors for suicide include structural barriers in accessing healthcare (52); stigma associated with suicidal behaviour, mental health problems, substance and alcohol use (21,52); and widespread unemployment and under-employment as a consequence of economic recession (53–55).

Also implicated are rurality as a barrier to accessing health services, and in enforcing social isolation (56); deprivation (57); and the impact of social inequality endorsed by neoliberal political ideology (58).

Many other risk factors for suicide related to community and relationships exist, including the impact of war, disaster, conflict and violence (49); intimate partner violence (59); the discrimination and isolation experienced by vulnerable groups of individuals such as LGBTI+ persons, prisoners, refugees and migrants; and the displacement of indigenous groups of people (49,57).

Individual-level risk factors are varied. WHO estimates that for every death by suicide, up to 20 times as many more attempt suicide (52). Therefore, the prime risk factor for suicide is a previous suicide attempt (49,60,61). However, studies of previous suicidal behaviour prior to suicide have been heterogeneous and distinct discrepancies in associations have been reported, with one meta-analysis of longitudinal studies finding an overall weak prediction (62). In adolescent suicide behaviour, a systematic review and meta-analysis also reported considerable heterogeneity but found that one third of deaths by suicide were very strongly associated with previous suicidal ideation and behaviour (63). Being male is more associated with suicide, with men dying in greater numbers around the world from suicide, including the UK (57).

Mental health disorders, in particular mood disorders of depression and anxiety, post-traumatic stress disorder, and alcohol use disorder have been well documented as associated with suicide across high-income countries (57,60,64), as has self-harm (61). Suicide in low to middle income countries has been equally associated with mental health disorders, but with those most predictive being substance use, post-traumatic stress disorders and impulse-control (60). Mental health disorders have been found to generally predict the onset of suicidal ideation, rather than predicting development from ideation to suicidal attempts (60), and that attempts were linked to anxiety and poor impulse-control (60). Physical health problems, multi-morbidity, and genetic predisposition have also been linked with increased risk of suicide (57). One comprehensive cross-national analysis found that after controlling for co-morbid conditions, the associations of mental health disorders with first onset suicide attempt reduced markedly, but were still statistically significant (60).

A key feature of many suicides and serious suicide attempts is impulsivity (64). Psychological distress and mental health crises frequently stem directly from life events, for instance, unemployment, financial difficulties, physical illness, chronic pain, abuse, and relationship breakdowns (64). Whilst in moments of crisis, some people have impaired ability to cope with life events, and impulsively turn to suicidal behaviour as a way out (49,52,64). Psychological pain, distress, or feelings of entrapment are key distinguishing factors between those who make serious attempts at suicide and those who are not suicidal (64).

Emerging risk factors have been reported to include side-effects of SSRIs in adolescents (65); recent discharge from psychiatric hospital (66), sleep disturbances, parental suicide (67); childhood adversity and maltreatment (68–70); internet use and addiction; in-person bullying and cyberbullying (71). There are risk factors unique to each subsequent generation of young people, and understanding attributable risks associated with the age of people, or the period they are living in, or the time they were born as a cohort are relevant. Studies of so-called age-period-cohort (APC) analyses of suicide have found that the time people are born can create wider vulnerability of cohorts to suicide (9,58,72). Note that APC analysis is further explored in paper 2, Chapter 4.

Therefore, multiple interacting levels and categories of risk factors have been studied, and explanatory models of suicide proposed, briefly summarised in the next sub-section. In addition, some of the factors associated with suicide I return to in more detail in the topic theme on psychological distress (section 1.4), in particular the relationship with early life adversity.

With respect to my papers' contribution to the evidence, very little had been published on recent discharge from general hospital, or of pooled data on both psychiatric and general hospitals, and certainly nothing had been published for Scotland; it is this gap that I plugged with the extensive study of suicide after hospital discharge (see paper 1, Chapter three). In addition, although Gunnell et al had published an analysis of age, period and cohort for England & Wales in 2003, an equivalent analysis was not available for Scottish data, and I demonstrate this analysis with a study directly comparing findings between Scotland, and England & Wales, (see paper 2, Chapter 4).

### **1.3.5.3 Models of suicide**

Theoretical models of suicide have been put forwards to help understand suicidal ideation and behaviour. Traditional models have generally been based on diathesis-stress models, which provide frameworks to test theoretical mechanisms of developing suicidal behaviour. The model is in two parts. Firstly, diathesis represents predisposition to suicidal behaviour because of biopsychosocial factors, and attempts to explain the underlying vulnerability of some people to stress, and to develop suicidal behaviour (73). Secondly, stress generated from environmental life events provoke stress responses. The diathesis-stress model contends that suicidal behaviour develops when the interaction of stressors and predisposing vulnerability is greater than an individual's threshold (73,74). Conversely, protective factors mitigate against stress response and the development disorders (74). Early diathesis-stress models for suicidal behaviour were first introduced in the 1980s (75,76), and several models have been proposed since.

Newer theories of suicide have since emerged, and these attempt to disentangle theoretical explanations for suicidal ideation and suicidal behaviour (77,78). Examples of these have been 'Interpersonal Theory' (78) and 'Ideation-to-action' (77) frameworks, which view as distinct processes, the development of suicidal thinking, and progression to suicidal behaviour and attempts.

A more recent example is the integrated motivational-volitional (IMV) model of suicidal behaviour, drawing heavily on psychological theory (79), and one that has gained traction in Scotland. The IMV model attempts to predict the emergence of suicidal ideation as a precursor, before the transition from suicidal thoughts to suicidal behaviour and attempts. The model is in three parts, a 'pre-motivational' phase that represents biopsychosocial context, a 'motivational' phase that represents factors leading to suicidal thoughts, and lastly, the 'volitional' phase, which represents factors leading to suicidal attempts and deaths (79). The IMV model proposes that suicidal thinking is driven by defeat and entrapment, and that the transition from suicidal thoughts to suicidal acts is governed by 'volitional moderators', which include "access



to means of suicide, exposure to suicidal behaviour, capability for suicide, planning, impulsivity, mental imagery and past suicidal behaviour” (79).

Other models of suicide derived from sociological perspectives highlight the role of political ideologies and their promulgation via policy and media, resulting in emotions that are generated socially, but internalised as individual responsibilities, leading to feelings of shame and humiliation in response to challenging situations (80). As an example, ‘austerity suicides’ have been widely reported in the aftermath of the 2009 economic recession (53,81). Austerity measures brought about punitive welfare restrictions, with media reporting that encouraged stigma associated with receiving welfare benefits, equating it to individuals being an economic burden; thus framing of suicide was overly reliant on individual responsibility, and should be widened to implicate government policy reform (81).

Both psychological and sociological perspectives of suicide intersect with acknowledging the role of multiple disadvantage along the lifespan, with early life adversity thought to be significant in explaining suicidal thoughts and feelings (82), however both perspectives have tended to be reductionist in approach, and more linkage is needed to link macro and micro circumstances (80).

In summary, models to explain suicide enable a theoretical understanding of the complex pathways to suicidal ideation and behaviour, but consideration must be applied to wider sociological and cultural perspectives in interpreting data, both qualitative and quantitative (80). This in turn, may then facilitate assessments of at risk populations, and opportunities to intervene earlier. However, models have largely been developed without prospective studies, with proven causal mechanisms. They still have a long way to go before they can explain the interactions and causality between factors (79), and models should only be used as an initial position to support intervention development for suicide prevention (79,83). An overview of prevention strategies follows.

#### **1.3.5.4 Strategies to mitigate risk factors**

In 2014, WHO stated that as suicides can be prevented, national prevention activities should incorporate comprehensive multi-agency prevention strategies in order to have impact (52). The vulnerability to suicidal behaviour is a consequence of the cumulative effect of several risk factors, hence the need for multi-sector prevention strategies (52). WHO also acknowledged a widespread recognition that research has demonstrated the fundamental 'interplay between biological, psychological, social, environmental and cultural factors' in assessing suicide and suicidal behaviours (52). In addition, WHO endorsed that epidemiological data was key in identifying risk and protective factors across different populations (52).

WHO endorsed three strategies to address categories of risk factors associated with society & health systems, community & relationships, and individual-level factors. These three strategies are firstly, 'universal' prevention strategies designed to reach an entire population; secondly, 'selective' prevention strategies to target particular groups identified as vulnerable; and thirdly, 'indicated' strategies targeted at specific individuals identified as vulnerable (52).

Examples of universal strategies include health and mental health promotion, reducing hazardous substance and alcohol use, limiting access to means of suicide and the encouragement of responsible media reporting (52). Selective strategies employ trained 'gatekeepers' who help those communities or groups identified as vulnerable, and signpost to dedicated services. Indicated strategies provide community support to vulnerable persons, dedicated follow-up for those leaving hospital settings, tailored training for healthcare staff, improved recognition of and care for those with mental and substance use disorders (52).

In 2014, some 28 countries had national suicide prevention strategies as part of suicide prevention policy, although few had evaluations underway to assess effectiveness (52). WHO strongly endorsed that data collection should be done alongside suicide prevention work in those countries with national strategies, and in those other countries considering a national strategy that stakeholder discourse was key in creating interest and communities receptive to change (52).

A systematic review of suicide prevention strategies (21) found that those with strong evidence could be categorised as 'Public Health approaches', or 'Healthcare approaches' (19,21). For public health, the most effective means of reducing suicide in society is to prevent access to the methods people have used in taking their own lives; these commonly include firearms, medications and pesticides (21,52). From a European perspective, the biggest impact has been sustained in restricting access to analgesics and controlling hot-spots for suicide by jumping, with corresponding 43% and 86% reductions observed since 2005 (21). Another strategy endorsed by WHO was the introduction of media reporting guidelines in a bid to reduce irresponsible sensationalist portrayals of suicide, which in turn limits the 'Werther Effect' of suicide contagion (52,84); albeit with limited evidence to endorse the benefits (21,85–88). School-based universal programmes are another public health approach to suicide prevention which have demonstrated significant reductions in suicidal ideation and suicide attempts (21). Universal approaches of general public education, or internet and helpline support, do not yet have sufficient evidence to suggest these could be effective (21).

Implications for health services have been to embed suicide prevention as core business, including supporting those with alcohol dependency and substance use, in recognition that harmful use contributes to many suicides globally (52). Treating individuals who present to services with depressive disorders is effective, and this requires clinician education in recognising symptoms (51), and drug and psychological therapies to treat depression (21). However, there is not enough evidence to confirm that screening in primary care is effective (21), and attempts to categorise patients on discharge from psychiatric hospitals as high or low risk have not shown to be of value (66).

Patient discharges from general hospital or Emergency Department (ED) settings for those presenting with psychological distress, suicidal ideation or behaviour are a large unmet clinical need (89). Those seen in ED are generally not effectively followed-up by primary care or outpatient mental health, and in recent years, brief psychosocial interventions in ED have been proposed and tested (89). Brief interventions in the form of 'safety plans' have gained traction with some promising evidence of effectiveness (89).

Outside of healthcare settings, social support and follow-up care in the community are key in supporting those individuals who are vulnerable, including those bereaved by suicide (52). In both community and health settings, the evidence for suicide prevention strategies is impeded by a lack of high quality randomised controlled trials (RCT) evaluating such strategies (21).

Pan-European principles of national suicide prevention have been published, with agreement that every country should have a taskforce to implement a suicide prevention programme (19). It has been argued that national suicide prevention strategies should be separate and independently funded from the corresponding national mental health strategies; should be subject to rigorous evaluation and monitoring of data on rates of suicide; and governments should fund all this activity and make the financial support transparent (19).

#### **1.3.5.5 UK perspectives**

Six years prior to the launch of the NHS in 1948 saw the publication in 1942 of the Beveridge Report, a report titled 'Social Insurance and Allied Services'. This report specified a post-war Welfare State vision to rid the UK of the evils of the 'five giants' of want, ignorance, squalor, idleness and disease (30,90). Beveridge was a social economist and his 'cradle to the grave' philosophy was transformative, and formed the basis of social policy for decades to follow. This included the implementation of the NHS and of social security, which offered state protection to all via employment contributions (90).

Public health improvements in the UK have been conceptualised as having four broad waves of overlapping activity; firstly, as 'structural' with 19<sup>th</sup> century improvements in the drinking water supply, sanitation and a plethora of municipal authorities (91,92). Secondly, as 'biomedical' with the emergence of medicine as a science with the use of vaccines and antibiotics in treating and preventing disease until post-WWII (91,92). Thirdly, as 'clinical' with post-WWII awareness that the 'five giants' identified by Beveridge (90) were still prevalent, underpinning a movement that recognised structural class differences shape society, and acknowledged the impact of lifestyle on disease until 1980 (91–93).

The fourth wave of public health conceptualised as 'social' followed the publication of the Black Report in 1980, which highlighted a widening disparity between the rich and poor in Britain, despite the wholesale adoption of the NHS and social security systems (32). This fourth wave focussed on the UK as a post-industrial society until around the year 2000, and the impact of social inequality on the health of people (32,91,92).

Notable striking changes in work and gender roles came about in this fourth wave, including amongst others, decreasing childbirth rates, increasing divorce rates, a changing job market, and diminished traditional masculine roles that particularly affected younger men. These younger men, for the first time, had reduced roles at home or in work, and this was reported as being associated with absolute increases in deaths, including suicide (91,94). Attention in this wave increasingly turned to the relationship between hazardous lifestyle behaviours and poorer health, including mental health, but with more accountability resting with individuals, and less emphasis on prevention of poorer mental health across the general population (91).

From 1990 onwards, the role of social inequalities and their detrimental effect on health outcomes in the UK became much more prominent (91). Evidence from the Black Report in 1980 showed a strong relationship with poor health and poverty, with divergence in trajectories between rich and poor despite substantive investment in the NHS and welfare state (30,95). People in more deprived communities experienced worse clinical outcomes, including deaths by suicide, and died in greater numbers than their affluent counterparts (96). Evidence showed that even in those not experiencing poverty, there was a demonstrable social gradient, with higher morbidity and mortality associated with lower socioeconomic status (97,98).

With mounting evidence that differences in health outcomes were associated with inequality, an understanding grew of what became known as the 'social determinants of health' (99–101). While the provision of medical care prolonged life and improved morbidity, an emphasis on prevention of illness came to the fore (102). By minimising the impact of adverse social circumstances and economic environment that affect wellbeing and create poor health, population health should improve (102). Alongside inequality, loss of wellbeing became a significant public health concern, with WHO forecasting

that depression would become an internationally leading cause of disability (103).

A fifth wave of public health intervention has been proposed (91,92); citing emerging challenges conceptualised as inequality, obesity, and loss of wellbeing (91), or of a health promoting culture with improved food security and more equitable access for all (92). With devolution of political administrations in 1999, health became a devolved matter for each UK nation. There have since been widening shifts in health system policy between the four UK nations, although performance indicators appear broadly similar (104). Although national public health bodies were established in 2013 for England and 2009 for Wales, the equivalent Scottish body did not come into existence until much later, (see section 1.3.5.6).

#### **1.3.5.6 Scotland perspectives**

After a public health reform and consultation period, Public Health Scotland (PHS) was launched in Scotland in 2020. PHS formed from three agencies, NHS Information Services Division, Health Protection Scotland and NHS Health Scotland. It collaborates with the NHS Health Boards, the Scottish Government and the Local Authorities to improve the health and wellbeing of people in Scotland. PHS priorities will be delivered using 'data, intelligence and place-based approaches' (105). PHS published six priority areas, which cover: safer, healthier communities; early years; good mental wellbeing; alcohol and substance harm reduction; sustainable economy and reducing inequality; and a final area covering diet and physical activity. PHS aims to tackle these through a whole system approach and partnership working, with impact measured in the priority areas against the National Performance Framework (106), and progress monitored and published (106).

Scotland has one of the highest rates of excess premature mortality, (deaths over and above those explained by the national socioeconomic profile) in Western Europe with approximately 5,000 additional unexplained deaths per year, and the worst health inequalities (107). The average age of death has not changed since 2012, and has even reduced in communities with highest

deprivation (105). In 2018, premature mortality in the most deprived communities was 3.3 times higher than in the most affluent areas (106).

In Scotland, there are high levels of excess *premature* mortality with this excess influenced by premature deaths related to alcohol, drugs and suicide (107). The risk factors for excess premature mortality, including suicide, are strongly associated with health inequalities and deprivation, much of it is still largely unexplained (107).

Excess premature mortality is 20% higher in Scotland than in England and Wales, even after taking account of differences in deprivation between countries (107). Between 1981 and 2011 Scotland became *less* deprived relative to England & Wales, but the excess mortality (all ages) *increased* from 4% to 10% over the same time (108). In 1981, excess deaths from suicide in Scotland were negligibly different from England and Wales, but by 2011 had increased by 74% (108). Other related excess 'deaths of despair' such as drugs-related poisonings rose from negative in 1981 to a striking 250% higher, while alcohol related deaths were in excess by 54% in 2011 (108). In absolute terms, deaths by suicide have been associated with 7% of all excess deaths, but considering premature mortality, suicide was 19% of all excess premature deaths (108).

Other analyses of suicide have also concluded that despite a reduction in relative deprivation over 30 years, the excess suicide mortality has increased drastically, with 80% more in Scotland compared with England & Wales between 2001-2006 (109). Area-based measures such as prescriptions for psychotropic medication have explained 60% of this excess, with the contribution of socio-economic deprivation 'relatively small' (109). However, evidence suggests that the way deprivation is measured (e.g. Carstairs-Morris Index) is insufficiently accurate (108), and that profound changes in social inequality over the last few decades in the UK are not adequately captured in deprivation indices.

Taking a public health approach to suicide by preventing mental ill-health, and improving access to treatment for mental health conditions, alcohol and substance-related conditions are key in reducing the excess premature deaths by suicide in Scotland (109). Evidence suggests that a public health approach

to prevention of suicide needs to start with preventing mental ill-health, hazardous alcohol and substance use, particularly in more deprived communities through an expansion of job programmes and sustained welfare spending to mitigate against unemployment, underemployment, housing precarity and home repossession (110).

Taking a public health approach was exemplified with several positively evaluated programmes from 2000s onwards, including 'Doing Well by People with Depression' (111). Guided self-help and psychological therapies for common mental health problems were also made available, such as 'Living Life to the Full' (112,113) and 'Mood Gym' (114,115). Access to information and resources was improved via 'A Local Information System for Scotland' (ALISS) (116) and the 'Links worker Programme', to mitigate the impact of social determinants of health in 'Deep End' GP practices (117,118). One of the most successful campaigns, first rolled out in 2003, is 'Scotland's Mental Health First Aid' (SMHFA) (119), directed at front line public sector staff and consisting of 12 hours training with demonstrable impact in changing knowledge, confidence, attitudes, willingness and ability to provide support to people with mental health problems (120). SMHFA has been in progress ever since, with more than 300 instructors and 40,000 trained individuals (119).

In alignment with WHO perspectives on suicide, PHS have conceptualised the four main risk factors as pressures within society, communities, individuals, and 'the quality of response from services' (121). Social inequality is firmly implicated as being associated with suicide; those in lower socio-economic groupings have died in relatively higher numbers on all national performance indicators of 'job, social class, education, income or housing' (121). Scottish suicide rates increase with increasing deprivation, even after allowing for differences because of mental health problems (121). Lower socio-economic groups have thought to have increased rates of suicide because of perceived 'powerlessness, social exclusion, poor mental health, unhealthy lifestyles, stigma and disrespect, and more adverse experiences' (121).

In summary, early indications are that PHS will embrace a public health approach to suicide; work to prevent mental ill-health, alcohol and substance use; recognise and press for more socio-economic levers to mitigate problems of disadvantage and inequality, and facilitate increased access to services for



people who need support and treatment in timely ways. PHS will need to work collaboratively with the National Suicide prevention programme leads, introduced in the next section.

### **1.3.6 Scotland's national suicide prevention strategies**

The Scottish Government's first national prevention strategy was launched in 2002, with 'Choose Life', a ten-year campaign to reduce suicide by 20%. Around £12 million was allocated to Choose Life between 2003-2006, with a quarter of the budget spent on national activities, with the remaining budget on local area partnerships. A further boost of £8.4 million was invested between 2006-2008 (122). Every 32 of Scotland's Local Authority areas implemented 'Choose Life' action plans via Community Planning Partnerships (CPPs), with liaison to the National Implementation Support Team (NIST). Key findings were that NIST was highly influential in influencing suicide prevention activity within the wider Scottish Government policy-making, and CPPs were the best means to progress local planning and implementation of Choose Life objectives (122).

An early phase evaluation thought 'Choose Life' had a markedly different approach to other national strategies in that it was part of the national programme for improving mental health, which was set up to be a key driver to reduce health inequalities and increase social justice (122). Suicide prevention training as part of Choose Life (ASIST, STORM, and SafeTALK) was found to have impact in changing behaviour of participants, both those in mental health services and in those with signposting support roles (123). A final evaluation confirmed NIST and CPP coordinators were essential roles within the national suicide prevention strategy, and that the main achievements were around raising awareness, good training, more evidence on suicide prevention, and improved media reporting (124).

'Choose Life' continued to 2016 (125), and achieved the 20% reduction in deaths (126), before being incorporated as a commitment in the subsequent national strategy, 'Every Life Matters', Scotland's £3 million Suicide Prevention Action Plan for 2017-2027. The vision of 'Every Life Matters' is broadly similar to 'Choose Life', but more ambitious. There is now more emphasis on de-

stigmatising, training and building more connected communities, better support to those bereaved by suicide, and encouraging people to ask and access help in dealing with suicidal thoughts and behaviour.

'Every Life Matters' has a Suicide Prevention Action Plan, with three commitments, to establish a 'National Suicide Prevention Leadership Group (NSPLG), to deliver better crisis support for those bereaved by suicide and to develop multi-agency reviews of all deaths by suicide (127). 'Every Life Matters' was published in 2018, with an aim to make a further 20% reduction in suicide rates by 2022 (127); that is, what took Choose Life 10-12 years to achieve against a backdrop of continuously decreasing deaths by suicide, was now to be achieved in less than five years, an ambitious aim without the corresponding massive investment required.

### **1.3.7 Using data to identify factors for suicide**

In 2008, the Scottish Suicide Information Database (ScotSID) was established within the NHS Information Services Division, with its aim to collect and review data on all probable deaths by suicide, covering demographic information, prior contact with healthcare services and associated health data. Up to 150,000 records associated with up to 900 individuals are added every year to the ScotSID database, and annual reports are made available which profile deaths by suicide and inform policy-making and prevention activity (128).

ScotSID is invaluable in informing national policy, however these data are not accessible for research purposes, and reports remain unpublished in the international academic literature. Therefore, ScotSID information on healthcare contacts prior to suicide does not achieve the international impact and recognition it deserves, and might do otherwise. Literature reviews of the evidence base will not pick up these reports unless designed to search for 'grey literature'.

There is a need for published works on research of healthcare data contacts prior to suicide, and in the use of longitudinal data that pre-date the ScotSID database; the published works in this PhD seek to address this gap (see

Chapters 3, 5 and 7). I expand on methods of linking data and exploiting data to uncover factors related to suicide in Chapter 2.

## **1.4 Topic 2: Psychological distress**

In this topic, I provide definitions for psychological distress, context for the key disadvantages experienced in Scotland, the relationship with early life adversities and poorer mental health and suicidal behaviour outcomes in later life, and the interactions between psychological distress and disadvantage. Psychological distress may manifest in presentations to emergency services, and I describe, in brief, the issues from the perspective of paramedics, police officers and the Emergency Department.

There are degrees of overlap between psychological distress that leads to self-harm, suicidal thinking, behaviour and attempts, and inevitably, there are shared discussion points between both topics. Therefore, there are points relevant to each topic within each section, however I have tried to minimise repetition of points where I can.

### **1.4.1 Main points**

Psychological distress has been defined as ‘a state of emotional suffering associated with stressors and demands that are difficult to cope with in daily life’ (129). It is frequently transient, related to life stresses and can dissipate when problems are solved or individual adjustments are made, a feature of the ‘stress-distress model’ (130).

Individuals may have symptoms of distress in relation to ‘everyday life struggles’, ‘feeling inferior to others’, or ‘losing a grip on life’ (129), or that their ‘whole world is caving in’ (131), with acute psychological distress directly associated with a perceived helplessness to cope with serious life stressors (131). However, symptoms of psychological distress may also occur independently of stressful life events (132). Feelings associated with psychological distress encapsulate a wide range of symptoms, such as sadness, loss of interest, vulnerability, hopelessness, anxiety, depression,

agitation, anger, restlessness, feeling trapped, disorientation, loss of control, despair, urge to self-harm, suicidal thinking and behaviour, amongst others (79,129,132).

Suffering symptoms of psychological distress is also related to whether individuals have resilience, or are pre-disposed to vulnerability (130). From a developmental systems perspective, individual resilience 'reflects all the adaptive capacity available at a given time in a given context that can be drawn upon to respond to current or future challenges' facing individuals (133). Numerous factors in child development determine resilience in adulthood, including caring family, family cohesion, skilled parenting, problem solving ability, hope, emotion regulation, self-efficacy, life purpose, routines, engagement and connections with well-functioning schools and communities (133,134).

Therefore, depending on earlier lifespan experiences and epigenetics, some individuals are pre-disposed to being more vulnerable, and less resilient to life events in adulthood, contributing to psychological distress experienced, and encountered by those trusted to respond to their needs (133).

Symptoms of psychological distress are wide and varied, and their causes are unique and complex, frequently stemming from life events, and social causes such as failed relationships, unemployment, perceived lack of mobility, work and family conflicts, inequity, amongst others (130). Psychological distress may persist, with worsening symptoms that may become enduring and clinically significant such that a psychological disorder develops, e.g. depression and anxiety, potentially sufficient to interfere with activities of daily living (132).

However, the distinction between psychological disorders and distress frequently appear blurred within the literature and in practice (130). Even GPs working in UK primary care practices have variable views; GPs have reported that symptoms of distress and depression are indistinguishable and lie on a continuum, while others have perceived disorders as being defined by severity of symptoms, and distress as being defined as response to a stressor, with the absence of biological features (135). Emergency responders have similar challenges; they are highly experienced, but not specifically trained in the

diagnosis of psychiatric disorders, a topic I cover in more depth in Section 1.4.5.

I now focus on the contribution of multiple disadvantage as a key and enduring feature of many impoverished communities in Scotland, before I expand on the role of childhood adversity and the interaction between disadvantage and adversity.

### **1.4.2 Multiple disadvantage**

Scotland has a population of 5.5 million citizens, with 4.53 million (83%) aged 16 or older (136). A recent 'Hard Edges' report (137) pinpointed three main disadvantages experienced by individuals in Scotland are firstly, homelessness; secondly, offending; and thirdly, substance dependency; broadly similar to England (138). About one fifth of Scottish adults (876,000) have experienced in their lifetime one of these disadvantages, corresponding to 156,000 per year (137). In one year, an estimated 5,700 individuals experienced all three disadvantages of homelessness, offending and substance dependency, with extreme disadvantage more prevalent in the urban areas of Glasgow, West Dunbartonshire, Clackmannanshire, Dundee, North Ayrshire and Aberdeen City (137).

The impact of homelessness pervades communities more than offending or substance use, and offending involves the smallest number of people who have the most multiple disadvantages, compared with any other category (137). The demographic group most affected are younger (<40), single, white men (137). Widening these disadvantages to incorporate mental ill-health and domestic violence or abuse (DVA), have been found to disproportionately affect women, with DVA reported as a similar sized problem to substance use and homelessness (137). Considering mental ill-health as a disadvantage is illuminating; prevalence estimates of 205,000 individuals per year are affected in Scotland, although the majority of whom do not face any other disadvantages (137).

Poverty, challenging early life experiences, and being care-experienced have been significantly implicated in those living with multiple disadvantages

(102,137,139,140); with young adulthood consequences reported of poor mental health, substance use, and challenges securing employment and maintaining good relationships (137). Violence in childhood, at school, in the community, in relationships and other settings have been reported as ubiquitous (137). Substance dependency and mental ill-health are indicators of psychological distress, and associated with the threat of violence, with the 'Hard Edges' report concluding violence deserves much more attention in both policy and research (137).

Therefore, childhood adversity and trauma have been implicated in enduring multiple disadvantages, a subject I turn to in the next section.

### **1.4.3 Childhood adversity**

The papers in this PhD do not add empirical evidence on the relationship between childhood adversity and suicide, however I provide context on this topic as the protocol and methods reported in paper five are for such a data study.

Studies of early life adversity and its impact on later adulthood have been well documented. The relationship between 'Adverse Childhood Experiences' (ACEs) and poorer health outcomes in adulthood was first published in 1998 by Felitti et al. This study proposed seven categories of ACEs defined at individual level as 'psychological, physical, or sexual abuse; and at household level as 'violence against mother; or living with household members who were substance abusers, mentally ill or suicide, or ever imprisoned' (141).

In this landmark study, four or more ACEs were reported to be linked to 4-12-fold increases in alcoholism, drug abuse, depression and suicide attempts, and demonstrated a graded association of multiple ACEs with other conditions, including physical health conditions (141). Many studies have been published since, summarised by systematic reviews and meta-analyses that have confirmed the relationship with ACEs and negative health outcomes in adulthood (68,70,142,143).

A systematic review of 124 studies reported mental health disorders and suicidal behaviour as associated with ACEs; depression was 3-times higher in

those who were emotionally abused, and 2.1 and 1.5-times more in those who were physically neglected or abused as children, respectively, with similar magnitudes of effect found for anxiety disorders (70). Compared with non-abused individuals, suicide attempts were 3.4-times greater in those physically or emotionally abused, and drug use 1.9-times greater in those physically abused (70), while a 3-fold statistically significant increase for suicidal behaviour was found for those physically or emotionally abused compared with non-abused (70). Regarding gender, these associations were generally higher for males; for instance, compared with non-abused, men who had experienced physical abuse were 4.5 times more associated with suicide attempts, compared with 3.8 times for females, but this not statistically significant (70).

However, the review above did not include sexual abuse, and type of adversity really matters: experience of sexual abuse has been most consistently associated with suicidal behaviour, with worse impacts if sexual abuse happened in adolescence as opposed to childhood (68). A systematic review of 14 reviews that included 270,000 people from 587 studies concluded that survivors of childhood sexual abuse were at significant risk of 'medical, psychological, behavioural and sexual disorders' (69). Evidence suggests that those who have experienced child sexual abuse are significantly at risk of psychiatric problems, including but not limited to, symptoms of psychosis, depression, anxiety, dissociation, eating disorders, personality disorders, poor self-esteem, suicidal and self-harm behaviour and ideation (69).

It is of note that many of the studies included in this review of reviews could not take account of other factors; other forms of trauma, conflict or family climate may have confounded some findings (69). One meta-analysis reported a relatively small relationship between childhood sexual abuse and the development of self-harming behaviour (144), and that when controlled for negative family environment factors, the abuse-behaviour relationship was diminished (144). Nevertheless, childhood sexual abuse may be a proxy risk factor for self-harming behaviour, as they are likely correlated with the same psychiatric risk factors (144).

Studies that have used the restricted set of the original ACEs (141), have been critiqued as overly reductionist (145,146), and efforts have been made to widen the definition of childhood adversity. One systematic review of 28

studies explored the relationship between adversities defined more broadly than the seven original ACEs, with young person suicidal behaviour, concluding there was a positive dose-response relationship with adversities or negative life events (68). Parental death, divorce, parental history of psychiatric disorders, very high parental expectations, and harsh parental discipline have all been associated with offspring suicidal behaviour (68), as has school and community violence, suspensions from school, and school dissatisfaction (68). On the flip side, supportive family environments are protective factors for youth suicide attempts, but not for suicide plans or suicidal ideation (68).

In short, neglect, sexual, physical and emotional abuse in childhood have all been related to an increase in depression, anxiety, drug use, suicidal behaviour and suicide attempts in adulthood (70,142), as has the role of negative parental factors and harsh family environment in young adults (68). Adulthood psychological distress is exacerbated by the dose and type of childhood adversity; however, there remains a dearth of evidence on the protective factors for young people.

#### **1.4.4 Disadvantage and childhood adversity**

Poorer socioeconomic status at least partially explains poorer outcomes, irrespective of ACEs experienced. Some 15-20% of the association of poor health risks in adulthood for those with high numbers of ACEs has been explained by (poor) socioeconomic circumstances in adulthood (139), with three ACEs of domestic violence, parental divorce, and living with someone once incarcerated, almost entirely explained by socioeconomic circumstances (139), and consistent with evidence on social inequality (102).

However, ACEs characterised as physical, emotional and sexual abuse have been reported as significantly associated with many adult health risks *not* explained by socioeconomic status (139). Prospective cohort studies have found ACEs associated with lower educational attainment, and higher risk of depression, substance use and use of tobacco; while those with 4+ ACEs reported 2.4 times more diagnoses of depression, and 3.1 times more



substance-use that persisted, *after* adjusting for family and socioeconomic factors (147). A recent systematic review and meta-analysis of 37 studies confirmed that having multiple ACEs was a major risk factor for many adverse health outcomes (143). The strongest associations have been found for problematic drug use, interpersonal and self-directed violence, with strong associations also reported for sexual risk taking, mental ill health and problematic alcohol use (143).

Individuals with multiple ACEs, living in disadvantaged communities can therefore face particularly challenging circumstances. In Scotland, one cohort study analysis has estimated the majority of children have been estimated to have experienced at least one ACE by age 8, with 1 in 10 experiencing 3+ ACEs (145). ACEs were highly associated with socioeconomic disadvantage in the first year of life; only 1% of children in the most affluent households had 4+ ACEs, contrasting with 11% in low income households (145). This cohort study, which was unable to consider sexual abuse, found other factors significantly associated with having ACEs of 'being male, having a younger mother and living in an urban area' (145).

Although some evidence is available for Scotland on the impact childhood adversity and disadvantages on later adulthood psychological distress and psychological disorders, there is a dearth of evidence on the impact of ACEs up to age 18 (145). There is also no evidence on what sort of healthcare contacts those children have who are most at risk of developing problems in adulthood. If we knew the types of early contacts children had with healthcare that are linked with later life distress and suicidal behaviour, then alternative trauma-informed care pathways could be developed to support these encounters in future.

It is with this in mind that I developed study methodology to address both of these evidence gaps using hospital healthcare contacts for adversity along the lifespan prior to young adult suicide, see Chapter 7 (13).

#### **1.4.5 Agency response**

In this section, I discuss recent perspectives and context for existing mental health and GP service provision as perceived by service providers, and users of services. The focus then switches in subsequent sections to characterising the problems of accessing and providing care related to Emergency Departments, ambulance paramedics, and police officers.

#### **1.4.5.1 Mental health services**

Although mental health is an obvious service to signpost and treat people, this is usually impossible without a GP referral. A recent study reported that even when seen by a GP for self-harm, only 15% were referred to mental health services, and those in the more deprived communities fared worse; they were 27% less referred than those in the least deprived (148). Waiting lists to access psychological therapies are problematic, and escalation of symptoms may occur in the time between referral and being treated. In this same study, almost 10% were prescribed psychotropic medication without a referral to mental health services, and without any prior or new psychiatric diagnosis (148).

Mental health services in Scotland have been assessed as ill-equipped to deal with people who suffer from multiple disadvantage and precarious situations (137). Every service provider and a large proportion of those with lived experience who participated in the 'Hard Edges Scotland' publication reported a 'gaping hole' in mental health services; access to services was almost impossible for many, citing an acute rationing of services acting under severe pressure (137). The minority who have managed to solicit help have been critical of an over-dependence on prescription medicines, and a lack of access to psychological services (137), or trauma-informed environments with a psychological framework (149). For those with substance use dependency, the structural barriers to accessing mental health care are even harder, community services have been woefully lacking to aid full recovery for people, leading to desperate measures with some committing offences in order to access referrals to rehabilitation (137).

Providing timely access to mental health and addiction services that have a trauma-informed psychological framework are said to be key (83,149). The relative decrease in appropriate referrals for people who self-harm in more disadvantaged communities has been cited as an example of the 'Inverse Care Law', where the service provision is inversely associated with the level of need in the population (148,150,151). Guidelines for GPs are very limited and there is a dearth of evidence on how to contain and lower risk, and yet more than 10% of young people in the general population have reported self-harming, a number which has tripled between 2000 and 2014 (152).

As it is known that people who have self-harmed are at increased risk of suicide, there is an urgent and largely unaddressed need to intervene earlier. Support is needed with safer ways of dealing with emotional distress, before self-harm becomes a long-term coping strategy, and prior to escalation of self-harm severity such that presentation to hospitals feel necessary (152). Without sufficient provision, people fall through the gaps, and a human rights-based approach is needed to prioritise those most marginalised in impoverished communities, an action now enshrined in the Scottish Government's Mental Health Strategy 2017-2017 (153).

#### **1.4.5.2 Emergency Departments**

There is a spectrum of presentations to Emergency Departments (ED) related to psychological distress. These include acute emotional stress/ distress, self-harm injuries or poisonings (frequently with intoxication), suicidal behaviour, and serious suicide attempts. These can be difficult to disentangle, can be inter-related, are challenging to assess from the perspective of the ED practitioner, and more than half are not referred to mental health services following ED attendance (154).

The UK has one of the highest rates of self-harm in Europe at 400 episodes per 100,000 of the population (155,156). Self-harm accounts for at least 150,000 attendances to UK Emergency Departments (EDs) each year and is one of the top five causes of acute medical admissions (157,158). Around half of those who die by suicide have a history of self-harm and it has been

estimated that one-quarter of all people who die by suicide have attended a general hospital following an act of self-harm in the previous year (8,159–162). Acute hospital EDs are frequently the first place to go for immediate help with self-harm (154).

However, there are ongoing deficiencies in ED care for those who self-harm, with suicide risk factors and suicidal intent being poorly documented, likely due to a lack of adequate training of ED staff in psychosocial assessment (157,163). The National Institute for Health and Care Excellence (NICE) have recommended routine psychosocial assessment should be carried out on all who present to hospital with self-harm, but this has been estimated to occur in around only half of those who present to urban EDs (155,164).

The Royal College of Psychiatrists in their report on self-harm have raised concerns that current levels of care fall short of standards set out in policies and guidelines, with poor assessments, unskilled staff and insufficient care pathways (163). Evidence suggests that appropriate training and intervention given to ED staff can lead to improvements in the quality of psychosocial assessment of patients with intentional self-harm (165,166).

The Healthcare Safety Investigation Branch (HSIB) published a report in 2018 that highlighted the variation in mental health care between EDs, finding that only 35% of individuals receive urgent mental health care in ED, and that referral rates to liaison services ‘fluctuate between 22% and 88%’ (167). In response, HSIB made four recommendations for improvement, as follows: ‘a sustainable funding model for 24/7 mental health support’ in EDs, ‘standardise national guidance on initial assessments on arrival to ED’, ‘review of self-harm guidance’, and ‘provide equal weighting to physical and mental health needs of patients, and measure via hospital inspections’ (167).

Although the HSIB recommended review of guidance was timely, it is likely to be lacking in substance; there is a long way to go with adequate, integrated, mental health care in Emergency Departments, with an editorial in 2020 highlighting that too little change has happened over the last 25 years (154).

ED care is one component in the broader context of people’s lives in the community (168). Pre-hospital emergency care for those attended to in

psychological distress is just as important, and I discuss the role of the ambulance service next.

#### **1.4.5.3 Scottish Ambulance Service**

Leading on from my research confirming suicide as an outcome was worse for people last discharged from general, and not psychiatric hospital, I was interested in what was happening in people's lives prior to attending general hospitals, i.e. pre-hospital emergency care. Although many people with psychological distress walk in to Emergency Departments, many (or their friends and family) dial '999' for an ambulance. Paramedics attending to people in distress may convey them to ED, or leave them at home, depending on the final paramedic assessment. I now provide context for pre-hospital emergency care, including the role and perspectives of the ambulance service and people with lived experience.

One recent UK Health Technology Assessment (HTA) review of the literature acknowledged that the quality and accessibility of care for people in 'crisis' is highly variable (169). The HTA review also found very limited evidence for access to support before individuals arrived at crisis point (169), with inconclusive evidence for improving service access to mental health crisis care in emergency situations (169). In short, this area is hugely under-researched and under-funded.

This HTA review used the word 'crisis', denoted as a pragmatic service approach, where crisis 'brings the service user to the attention of crisis services'; for example, through the relapse of an existing mental health condition (169). However, 'crisis' was also used as a term that included service user self-definitions, or people at risk of harming themselves, or theoretical and negotiated definitions (169). In short, people in 'crisis' overlaps with psychological distress that comes to the attention of emergency services, including a subset of those with existing psychiatric conditions who have crisis care plans for out of hours help, negotiated with the hospital or community mental health teams.

There are very limited data available worldwide on pre-hospital emergency care related to mental health or distress. Emergencies for mental health presentations in Australia have been estimated at about 10% of all ambulance attendances, with an additional 7% managed via telephone triage service (170). In the US, about one in three people seen for mental health-related attendances were conveyed by ambulance to hospital EDs (171), with the highest ambulance usage related to 'suicide' and the lowest for 'mood and anxiety disorders', leading to a recommended restructuring of emergency mental healthcare systems (171).

In the UK, estimates for mental health attendances by the ambulance service are also 10% (172,173). Some individuals repeat dial emergency services, sometimes many times over the course of a year, and are, in effect, 'super users' of the system. For these individuals, there are many locally determined 'frequent caller' procedures, related to individuals and agreed with GPs or local mental health services (172). In England, an estimated 0.9% of nine million emergency '999' calls made in 2014-15 were calls from patients with locally agreed frequent caller procedures in place (172).

In South West England, ambulance demand has been continuously increasing year-on-year of 4-5% for six years to 2016 (174). Analysis has revealed that users of adult mental health services have been driving demand for ambulance attendance, and that this was six times more influential than alcohol and drug use (174), although it is likely that alcohol and drug use have been underreported. People with mental health problems were also found to more frequently call for an ambulance for incidents where from the ambulance service perspective, an 'emergency response was not warranted' (174).

Lived experience perspectives suggest that loneliness is a key feature in help-seeking, whether at hospital or being able to speak to an ambulance team, with many frequent callers (168). Interventions targeted at frequent callers are few and expensive, with very limited evidence, although they could be highly effective. For instance, one US evaluation using a fire department with an embedded trained paramedic found that 59 frequent users were living with multiple disadvantages, most with substance use and psychiatric problems, and attendance rate with this intervention reduced from 19 to 9 per month

(175). There are potential models for changing response to frequent callers that could be tested in disadvantaged communities in Scotland.

The Scottish Ambulance Service (SAS) employs around 4,400 staff, and responds to over 700,000 emergency incidents per year. '999' calls are handled by one of three Ambulance Control Centres co-located with NHS24 and the Out of Hours GP service teams (173). Around 25,000 (3.5%) of calls are for emergency 'overdoses and poisonings' (including accidental), the seventh of the top ten main conditions responded to (173). SAS receive referrals directly via the '999' service, from primary care and out of hours GP systems, and from 'NHS 24', the national '111' helpline for urgent telehealth and telecare.

From an ambulance responder's perspective, there are no universal criteria for identifying mental health-related presentations. Presentations are very heterogeneous, and it is difficult to disentangle ongoing mental health diagnostic symptoms from normal human responses to extraordinary circumstances, life events or ongoing adversity or poverty-related disadvantages (170). 'Psychiatric emergency' symptoms observed may be part of long-standing mental health conditions, which may in turn, stem from ongoing social contexts related to long-standing poverty, instability, financial worries, job loss, poor housing, (135).

No data were available on the outcomes of those assessed by SAS paramedics as being in a mixed category of 'psychiatric emergency', which included overdoses, 'deliberate self-harm' or mental health emergencies. It was unknown whether outcomes were relatively better for those treated at home, or conveyed to hospital. Secondly, there was anecdotal evidence and concern from paramedics about the long-term welfare of individuals conveyed to ED (personal communication SAS colleagues). This is the evidence gap addressed in my paper three, (see Chapter 5).

The pre-hospital emergency pathways not only include the response of ambulance services, NHS 24, and community mental health teams, but also of the police force, and I now introduce and discuss this next.

#### **1.4.5.4 Police Scotland**

Police Scotland (PS) have a statutory responsibility enshrined as 'Policing principles' in Section 32 of the Police and Fire Reform (Scotland) Act 2012. These are a), 'to improve the safety and well-being of persons, localities and communities...' and b), to work 'in collaboration with others where appropriate', '...in a way which (i) is accessible to, and engaged with, local communities, and (ii) promotes measures to prevent crime, harm and disorder' (176).

The policing aim of 'reducing harm' and improving well-being of 'vulnerable' populations applies to non-crime related calls by people with physical and mental health conditions, people who frequently use alcohol and drugs, people with addiction problems, and other disadvantages such as homelessness (6). This 'vulnerable' population includes people 'suspected as having a mental disorder', who may display signs of 'agitation, anxiety, paranoia, hallucination, self-harm, attempting/ threatening suicide' (177). However, 'vulnerability' may encompass a much wider definition, such that 'any one of us can be vulnerable, given sufficient context, setting and life experiences' (7).

Terminology is problematic with inter-agency work, with each agency having their own cultures and language, and in policing, the concept of vulnerability encompasses a subset of those who reach crisis point, stemming from mental health problems, psychological distress, substance and alcohol use, complex lifestyles, loneliness, trauma and isolation (personal communication Police Scotland; (178)).

Bearing in mind that the ambulance data study (paper 3) found a proportion of people (4%) categorised by paramedics as 'psychiatric emergencies' died by suicide during the following year, it was highly probable that Police Scotland contacts would be in contact with many more at risk individuals. There were no data available on outcomes for people in contact with Police Scotland. My original aim was to link policing data to the NHS ISD 'unscheduled care dataset', producing an analysis on outcomes associated with pooled ambulance and policing contacts. In understanding outcomes related to contacts, insights could be gained of where best to develop interventions targeted at populations most at risk. Gaining access to police data proved impossible to do (at least within the timespan), and I expand on reasons why in the introduction to paper 4 (chapter six). I now provide some context related to this topic.



Police officers are frequently first responders to people experiencing psychological distress, and have a vital role in suicide prevention. In the UK in 2017, there were almost 6,000 deaths by suicide; however, there were also 1,837 deaths *prevented* by police officers on the UK rail network alone (179). Policing responses to suicide intervention are resource intensive, frequently need the expertise of trained negotiators, and incidents take a long time to conclude (179). It is appropriate that policing has been used to support people at risk of taking their own lives, and to protect people with vulnerability. However, there is growing concern about the increased use of policing to respond to mental health-related incidents in the community, as a consequence of a 'broken mental health system' (179).

As recorded crime has reduced over the last few years, other demands on police attention have increased (6). These have been related to exploitation of minors, modern slavery, people with 'vulnerability' and calls related to mental ill-health, and domestic violence, amongst others (6). It is clear there are a disproportionate number of people from disadvantaged backgrounds in contact with law enforcement and the criminal justice system (6,137).

The UK's inspectorate of constabulary (HMICFRS) undertook a recent independent assessment of all 43 police forces in England & Wales and the British Transport Police, and produced the report 'Policing and Mental Health: Picking Up the Pieces' (179). HMICFRS found that nearly all police forces now have an operational mental health triage team (179). Other key findings were that individuals with mental health problems were being badly let down, as well as 'placing an intolerable burden' on police officers; that much more needs to be done with prevention and early intervention; that the current situation is a 'national crisis' that cannot continue, and urgent action is warranted (179). It is difficult to envisage a more strongly worded critique of the use of policing to plug the gaps in an increasingly strained mental health service.

The intersect between policing and public health is perceived as a relatively new research and practice area, with many obvious overlapping areas such as mental health and vulnerability, domestic violence and drug use, amongst others (6,180). In reality, these overlaps have multiple, complex, interacting problems that have endured for a long time, but recent policy documents have only lately highlighted the need to prioritise collaborative upstream

interventions (181). However, it is still the case that public health groups around the world rarely have policing representation, regarded by some as a conspicuous omission (180), although there are exceptions, such as Public Health England (182).

Collaborative partnership working in these challenging areas of overlap have great potential for more efficient use of resource with better outcomes for vulnerable groups, and there has been a surge of interest in better inter-agency working within the past few years (6). The College of Policing and the National Police Chiefs Council in England & Wales were amongst 27 signatories of the 2014 'Mental Health Crisis Care Concordat' (183), along with national agencies in health, social care, housing, third sector and local government.

This Concordat has four main commitments: to provide 24/7 access to support for people before crisis point; to ensure mental health crises are treated as promptly and on a par with physical health; to treat people with dignity and respect with good quality care; and to prevent future crises by ensuring appropriate referrals for help (183). The Concordat is also there to monitor and enhance police interactions with people who have mental health concerns. For instance, there is a will and a need to reduce the use of handcuffs, body searches, and custody admissions (183).

Those who have a mental health condition and come to police attention may experience an additional layer of stigma. On the one hand, policing is a potentially life-saving intervention and many compassionate interactions have been experienced by people with lived experience (179,184). However, the interactions can also be re-traumatising and de-humanising experiences for people who have already experienced multiple adversities and disadvantages (185–187). Police engagement with people in psychological distress is required in some situations, but it is very ill-suited for many (185). Police intervention can lead to reductions in individual autonomy, and exacerbation or escalation of mental health symptoms (185).

Interventions that have evidence of effectiveness include police officer training on mental health and psychological distress; joint triage police and mental health staff (street, control room, or custody suite triage); police officer access to a direct line of contact to mental health practitioners; co-responder models

where police and healthcare practitioners jointly respond and 'ride-along' to incidents (180,185,188,189).

In 2018-19, Police Scotland responded to a *daily* average of 4,630 recorded incidents on the PS Command and Control System 'STORM', with 570 daily incidents resulting in a linked record on the PS Vulnerable Persons Database (VPD), amounting to 208,050 in that year (190). This equated to 80% of all Police Scotland calls not being crime related (11). Fifty four people were reported missing every day, with 1 in 4 reported missing having experienced a mental health concern (PS National Missing Persons Database); these individuals are a particular worry as they may be at significant risk (of suicide), and concerted police effort is made to find them (190).

Incidents related to mental health have increased from a *daily* average of 157 in 2015/16, to 197 in 2018/19, (PS STORM system), i.e. an increase by a factor of 1.25 in 3 years from an annual 57,000 to nearly 72,000. Of the *daily* average of 322 people booked into custody centres in 2018/19 (PS National Custody System), 124 (39%) advised they have a mental health concern, more than half of whom (54%) returned to custody in the same year (190).

In Scotland, the criminal justice system has been used by people facing multiple disadvantages as a 'safety net', when all other services have failed to provide help needed (137). In order to access services, individuals have been sufficiently desperate to offend and/ or ask for custodial sentences, in order to shelter in a custodial 'safe place' or receive a court order, through which coordination of support can take place (137). These experiences were succinctly captured by a quote from the 'Hard Edges Report' as follows,

*"She's not enough of an addict. She's not enough of a mental health patient. She's not enough of a criminal, you know. She's just not enough of anything to get like a package"* (137).

Police being in contact with people in psychological distress was identified as a main issue in the Mental Health Strategy 2017-27, and Police Scotland Strategy 2026 (153,191). In response to this need, Police Scotland mandated that all front line officers undergo dedicated mental health training (188), and 'Distress Brief Intervention' training, (see next section for more details).

Scotland also operates a 'Community Triage' model in a number of areas, with a mental health nurse available to conduct telephone assessments (188). The limited evidence available suggests that successful outcomes are obtained when policing and health is well co-ordinated, with good information sharing and communication, and considerate of the local communities (188).

The legal framework is different in Scotland compared with England, where section 136 of the Mental Health Act is relevant. In Scotland, Section 297 (s297) of the Mental Health (Care and Treatment) Act 2003 gives police the power to detain individuals for up to 24 hours in a public place on mental health grounds, and to confine them in a place of safety (e.g. hospital) for a mental health assessment (Place of Safety Order) (177). If no place of safety is available, police officers may remove individuals to a police station temporarily until a suitable place of safety becomes available (177). Psychiatric Emergency Plans hold information on local Designated Places of Safety and arrangements for police, health, social work and partner agencies in approaching people who appear to have a 'mental disorder' (177).

The statutory framework provides clear processes for those who clearly have 'mental disorders' (177). However a recent Mental Welfare Commission Report found that there remains insufficient clarity around processes for those who are, for example, intoxicated with mental health symptoms, with inconsistent care pathways and challenges in accessing support, highly dependent on geographical area (192). Data are available related to s297 referrals that apply to those taken to Emergency Departments (EDs). There is a peak of s297 referrals, with 41% made between 2100h and 0100h; greater than half of referrals were a concern of suicide or self-harm; and almost two thirds (62%) were allowed to go home (193).

Most people (96%) with s297 referrals were attended to in EDs within two hours (188). However, there is a stark contrast in resource use from a police perspective. As opposed to ambulance service paramedics who can leave after patient admission to ED, police officers have to stay and accompany those referred, so even a two hour wait for each attendance is very time-consuming (188). This has meant that at peak times of s297 referrals, many city front line officers were waiting with referred people in EDs (personal communication). Apart from the implications of policing resource use in EDs,

there are obvious stigmatising issues related to people on s297 referrals being accompanied by police in EDs (personal communication).

In trying to enable research with Police Scotland, I held a number of discussions with senior police leads, who expressed some key areas of concern. Police were keen to collaborate, and to have academic evidence to support policing activities. There were several areas of concern, and these included the assessment of vulnerability, mental health crises and distress, missing people, drug-related deaths, intoxication, information sharing, doing more with data, and doing more with body-worn cameras and tele-consultations, amongst many others (personal communication). An over-riding concern from police perspectives was that academia was too slow, and police could not wait for traditional academic approaches (personal communication).

My colleagues and I obtained funding and hosted a national multi-agency workshop to determine the top five national priorities, accepted for publication (7,178). The assessment of vulnerability was the top priority (see Chapter six for more detail). A scoping review of the evidence on assessment for vulnerability was undertaken, and this is my paper four (Chapter six) (12).

I now outline main points on the Scottish Government response to psychological distress.

#### **1.4.6 Scottish Government investment**

The Scottish Government have recognised that agency response to psychological distress has been a significant and poorly addressed problem in Scottish society. They have provided opportunities to facilitate better collaboration and invested resource in promising interventions. This is exemplified by the 'What Works' report (188), the first time a report has been published on policing and mental health distress.

For the first time, a dedicated 'Health and Justice Collaboration Improvement Board', answerable to Ministers of Scottish Government has been introduced. A sub-group of the Health & Justice Board has been formed, the 'Distress Intervention Group' (DIG), tasked with addressing specific actions in the Mental Health Strategy 2027 (153). The DIG will provide strategic leadership

across justice, health and social care sectors to enable care pathways that are more effective for people in distress.

National trauma training was rolled out in 2017 by NHS Education in partnership with Scottish Government (194). Here trauma was either defined as a 'stressful event or situation of exceptionally threatening or catastrophic nature', as one-off unexpected events, or as complex, repeated interpersonal forms of childhood or adulthood abuse. Trauma-informed practice training has been provided to public service employees in recognition that trauma is common, have a range of impacts, ensure safer and more effective responses, and where possible resist re-traumatisation (194).

One promising intervention the Scottish Government has invested in is the 'Distress Brief Intervention' (DBI) programme (see [www.dbi.scot](http://www.dbi.scot)). The DBI has been piloted in four areas in 2016-2021, as part of national suicide prevention strategy, and as a commitment in the Mental Health Strategy 2017-2027 (188). The DBI provides a framework for increased collaboration between agencies and communities to improve support for people in distress who do not fulfil the requirements of an emergency response.

A definitive evaluation of the 'DBI programme' has yet to be reported; however an independent interim evaluation shows promise. It found that the majority of referrals to Level 2 were people aged under 45; slightly more women than men; with the greatest proportion of referrals from EDs (34%), followed by primary care (30%), and police (16%) (195). The majority of referrals were associated with depression or low mood (60%), with the next highest categories for women and men of stress/anxiety, and suicidal thoughts, respectively (195). Most people referred agreed that DBI helped them manage their distress, with two thirds recording substantial reductions in distress (195).

## **1.5 Concluding remarks**

In this introductory chapter, I provided a broad overview of two main, but inter-related topics of suicide and psychological distress. I now provide a brief outline of how my papers fit the topics covered, and a reminder of the thesis structure.

Four of my papers provided new evidence (papers 1, 2, 3 & 4) or reported methods applied to Scottish data for the first time (papers 1 & 5). Evidence was provided on descriptors and what happened to people prior to suicide using deaths data (papers 1, 2, 3 & 4), hospital data (papers 1, 3, 5), ambulance service data (paper 3) or emergency department data (paper 3). Paper 4 provided a literature review on the assessment of vulnerability from a policing and public health perspective.

On the theme of suicide, evidence was provided on differences in age, deprivation, employment status, and cohabiting status between populations with and without hospital records prior to suicide from intentional self-harm (paper 1). For the first time in the UK, differences were reported between those who died after discharge from general hospital or psychiatric hospital, and the relationship between recorded mental health conditions at general hospital visits and time to death (paper 1). In paper 2, NRS vital events 'open' data pertaining to 'probable suicides' was used, with evidence provided in an 'age period cohort' analysis that two successive cohorts of men born around 1965 to 1970 were at increased vulnerability for suicide and died at younger ages, compared with those born earlier, around 1960 (paper 2).

Paper 1 reported methods for harmonising International Classification Disease (ICD) catalogues ICD-9-CM to ICD-9, and ICD-10-CM to ICD-10 codes. ICD codes are the cornerstone of disease and injury classification and in widespread use in the UK and US healthcare systems (196). Paper 1 used for the first time in the UK, the US Agency for Healthcare Research and Quality (AHRQ) 'clinical classification software' (CCS) to report aggregated mental health categories. In addition, the datasets used in paper 1 were provided unlinked with an indexing variable by NHS ISD's Electronic Data Research and Innovation Service (eDRIS) to enable me to deliver a 'demonstration' record linkage (see chapter 3), part of the ESRC funded 'DAMES' project (197).

The methods reported in paper 1 were improved in paper 5 in three ways. Firstly, I improved the study design, moving from a single group to a case control design. Secondly, the CCS was used as per paper 1, but with newer algorithms for ICD-9-CM and ICD-10-CM (see paper 5). Thirdly, methods for operationalising ICD codes for childhood adversity published elsewhere (England and USA) were applied to a Scottish context for the first time (paper 5). This necessitated harmonised disease coding from ICD-9-CM to ICD-9, and ICD-10-CM to ICD-10 catalogues (USA

based codes), and then cross-mapping codes between ICD-10 and ICD-9 for CCS and childhood adversity code sets from USA and England (paper 5). Thus, paper 5 provided detailed legacy frameworks of harmonised ICD codes for use by others.

On the theme of psychological distress, ambulance service, emergency department (ED), hospital and deaths data (paper 3) were used to summarise outcomes for 9,014 emergency calls for paramedic attendance for 'psychiatric emergencies'. This paper reported that just over half resulted in transport to ED and that within one year 4% had died including 97 deaths by suicide, representing 13% of all such deaths that year (paper 3). Therefore, upstream suicide prevention activity should be focussed on paramedic interaction with those calls categorised by paramedics as 'psychiatric emergencies' (paper 3).

Continuing on the theme of psychological distress but using terminology commonly used in policing, are those individuals considered to have 'vulnerability' (paper 4). The scoping review of assessing vulnerability aimed to ascertain a working definition of vulnerability, and identify ways of assessing vulnerability, such that those in most distress or need could be triaged or flagged differently (paper 4). This paper found that there was no evidence-based definition of vulnerability or unified assessment model, and that policing perspectives are context-dependent while public health perspectives are person-specific (paper 4). Therefore, vulnerability as a construct was wide, encapsulating mental health, and including multiple settings.

In chapter two, I introduce and outline context and methods related to using large routine datasets. Chapters three to seven contain a paper each along with a short narrative. In the final chapter of this PhD, chapter eight, I conclude with the 'National Summit on Mental Health, Distress and the Emergency Department', an event I co-led, and at which the main findings from this PhD were communicated along with key expert testimonies, including lived experience perspectives. My papers and the wider evidence summarised in this thesis greatly shaped my thinking, and influenced this event. Public mental health urgently needs whole system thinking and multi-agency working, with lived experience perspectives informing policy. The agenda and consensus findings disseminated are included in this final chapter (see chapter eight).



## **2. Methodological background**

### **2.1 Chapter scope**

This chapter covers my main methodological theme in using data and data science to advance knowledge. I begin with macro level information, providing historical, geographical, and contemporary contexts, before moving on to an overview on open data, UK data investment and archiving services. I then provide information on electronic health research in Scotland, spanning history, micro level detail on disease classification, NHS morbidity records and NRS death records, and the use of 'safe havens' and permissions. A section on evidence and ethics is then provided, followed by a more technical section on linking data and health data science.

In this chapter, I occasionally draw on personal perceptions of the data landscape and matters discussed during the period 2011-2019. As a participant at various quantitative sociology research meetings, Scottish Health Informatics Platform (SHIP) retreats, E-Health Informatics Research Centre (EHIRC) and Farr Institute events, I witnessed reflections of fellow attendees, discussants and presenters. Where any statements are my personal perceptions, and there is no other supporting evidence, I provide such an indication in parentheses.

I end this chapter with a personal reflection, training needs fulfilled in order to complete the work in these papers, and a brief synopsis of how the themes of this PhD are innovative in their use of data.

### **2.2 Advancing knowledge through data innovation**

#### **2.2.1 Terminology**

The field of health data science evolved considerably between 2000 and 2020. During the course of this PhD, descriptors for electronic Health (e-Health) data linkage were interchangeable with health record linkage, health informatics, bioinformatics, and digital health data, amongst others. e-Health is a term that encompasses a range of activities concerning health, technology and

commerce (198). The concept of 'e-Health' is very loose, and a simple consensual definition does not exist. In the context of this document, e-Health refers to the electronic health information and technological systems that are a prerequisite for undertaking linkages of health data.

'Data linkage' involves combining electronic data from two or more routinely collected sources that relate to the same individual, family, place or even event (199). Person-level data is drawn from datasets and joined on an identifier to form a richer information resource, and data may be drawn from health, education, social care or other government datasets (199). Linked datasets are usually de-identified, and expected to comply with data protection legislation and confidentiality requirements (200).

'Data science' is relatively new terminology as well, encapsulating applied statistics, epidemiological concepts, and more recently, approaches from computing science, such as machine learning and artificial intelligence (201). For the purposes of this thesis, 'data' refers to organised information that might be analysed for research purposes. Most data used in the papers below would conventionally be defined as 'large scale', insofar as it involves at least several thousand records and often more; many of the datasets are also 'complex', in that they have non-standard features or aspects that require additional work to take advantage of.

In addition, data can be considered on a spectrum in terms of the levels of accessibility: 'open' data might be freely and widely available to others, but other types of data, perhaps attached to sensitive or personal information, remain 'sealed'. On that data spectrum are 'de-identified' data, only brought together and analysed in restricted conditions, or for very particular circumstances, as has happened for Covid-19 (202,203). 'De-identified' data refers to confidential personal data that has been effectively anonymised conforming to the Information Commissioner's Office recognised code of practice (202).

## **2.2.2 Historical approaches to data linkage**

Health data integration emerged as far back as the 1960s; the first system for organisation of *patient records* called the 'Problem-Oriented Medical Record' (POMR) was developed during this decade by Professor Lawrence Weed, University of Vermont (204). During the following decade, with the advent of computer technology, the first computerised medical *information system*, in the world was developed: the 'Problem-oriented medical information system' (PROMIS), also developed by Professor Weed and implemented in 1970 on several wards of the Medical Centre of Vermont. The second known data integration system was developed by Sir Donald Acheson, Director of the Oxford Record Linkage Study, and the epidemiologist widely credited with the vision of linking medical records nationally in order to "provide excellent morbidity statistics and create a science of prognosis..." (205).

Conceptual differences in approach between Professors Weed and Acheson have been summarised: the former's concerns were "about logical fragmentation in clinical decision-making" and the latter's concerns were "about institutional fragmentation as a barrier to planning and evaluation" (206,207). In practice, it has been noted that whereas both men wanted to improve communication, Weed focused on the communication between clinicians and Acheson wished to improve communication between institutions and their databases (207). The contemporary manifestation of the traditions of Weed and Acheson is that of electronic health records and data linkage systems, respectively (206).

The period 2000-2020 has witnessed a revolution in the internet as an information sharing resource, creating the opportunity to access and transport vast amounts of e-Health information (208–210). Considerable potential exists via information technologies to enhance health and enable healthcare improvements, for instance with the dynamic linking of health and environmental monitoring systems (211). Despite the potential, national systems of linked health records are still relatively rare, being complex and difficult to achieve. Several countries have embarked on national initiatives to make available electronic routine health and administrative data for research use, in order to reveal insights for the public benefit, with some evidence of effectiveness (210).

The infrastructure platforms necessary to achieve data linkage capability required inter-agency collaborations and a far-sighted, shared vision of perceived benefits for society. In 2004, an international review of countries with the capability of linking large population datasets assessed only a handful of 'information-rich environments' with an international reputation for using record linkage in doing research (199,212). These were the Manitoba Population Health Information System, Oxford Record Linkage Study, Scottish Record Linkage System, Rochester Epidemiology Project, the British Columbia Linked Health Database, the Western Australia Data Linkage System and the Centre for Health Record Linkage in New South Wales, Australia (199,212).

Since 2004, several others have emerged, including Canadian provincial systems, the Secure Anonymised Information Linkage (SAIL) in Wales, the Population Health Research Network, Australia as well as newer systems emerging in the UK (206). Overlooked by this early literature were others, including the Scandinavian countries, which have a long tradition in warehousing national registry information. For example, Sweden has sophisticated population registries, with each citizen allocated a unique identifier from birth, and data available for re-use by researchers around the world, subject to necessary conditions (210,213).

### **2.2.3 Contemporary approaches to data linkage**

Harnessing the power of large, linked datasets in analyses with relatively recently available computing processing capability offered opportunities in understanding society previously not possible. Data science is often used to describe a wide range of uses of data, of which re-use and analysis of large, 'routine' datasets formed an emergent discipline (210). The secondary use of datasets had substantial appeal not only to traditional academic research, but also to government and business (214). The capability of exploiting existing datasets within the last decade coincided with fiscal austerity measures in the UK, introduced after the 2008 economic recession. Using existing data in analyses offered substantially cheaper alternatives in providing evidence for

policy and practice, than gathering primary data - the latter being labour-intensive and expensive to support (210).

Therefore, a few key ingredients conspired to create the right environment for health data linkage research to flourish, namely, the computing capability, the unprecedented and increasing data resources, cost-efficiency and political will. I now elaborate in more detail on some key strategies used to achieve this.

#### **2.2.4 'Open Data' in the UK**

'Open data' may be defined as data that meets criteria of being accessible, in a digital format and free of restriction on use in its licensing conditions (215). The UK government has shown support for the principle of making population data freely available, in response to societal demands for improved transparency, describing data in the UK Open Data White Paper as the "21<sup>st</sup> century's new raw material" (215). The political ideology underpinning the need for transparency was that of transparency driving prosperity, by "creating an information marketplace for entrepreneurs and businesses", in order that "public services are more personalised and efficient in the future" (215). So far, some 9000 datasets have been released via the data portal ([www.data.gov.uk](http://www.data.gov.uk)), covering health, education, transport, crime and justice. All government departments have now published their 'Open Data Strategies'. The right of people to access data has been increased beyond the scope of the Freedom of Information Act and there have been initiatives in improving data standards for greater usability (215). The open data initiatives have been developed in tandem with promises of building public trust in using data, and the need for robust protection of the public's right to privacy remaining paramount (215).

#### **2.2.5 UK data archiving services**

Long before the UK government's 'Open Data' initiative came into being, comprehensive data archiving dissemination services existed, now a collaboration of expertise under the umbrella organisation UK Data Service (UKDS) (216). Surveys such as the British Household Panel Survey and Understanding Society, and the National Health Surveys are hosted and

disseminated via the UK Data Archive (UKDA) (216). The UKDA has the largest collection in the UK of social science and humanities digital data (<http://www.data-archive.ac.uk/about/archive>). These population surveys all offer additional socio-economic data to broaden understanding of the impact of people's life circumstances in relation to health outcomes.

The UKDA offer a controlled approach to data access (with data downloadable to approved researchers, projects and computers), an alternative variant to the 'Safe Haven' system. A 'safe haven' is a physical environment for population data research designed to minimise risk of identifying people (217,218). However, the UKDA is generally viewed as delivering all the convenience of access to data and data quality, without the drawbacks of the Safe Haven systems. Whereas the model for data access via 'Safe Havens' was in flux during the 2010's while getting established, the model for the UKDA was long established, following a long period of negotiation with data providers, and building on work which has already been done on traditional complex data, (a broader discussion on Safe Haven models is provided in 2.2.7.3).

## **2.2.6 UK health data research investment**

e-Health data science holds considerable research value in tracking large numbers of patients to establish long term outcomes for disease and adverse effects of medication. This discipline is still relatively young, although predicted to lead many more years of data-driven health research. Until relatively recently, data sharing was not usual practice within public health research communities. However, the UK landscape has changed considerably since 2010, with commitments that have increased access to data, alongside addressing concerns on the potential risk of disclosure of identifiable personal data (219).

In a joint statement made in 2011, the Wellcome Trust and seventeen other major international funders of public health research committed to a joint aim to "increase the availability to the scientific community of research data they fund that is collected from populations for the purpose of health research and to promote the efficient use of those data to accelerate improvements in public

health” (219). These same funders recognised that there were significant challenges to build the culture and resources necessary to support data sharing. They identified goals to address these issues, which included “building capacity and skills in the research community to manage and analyse data...” (219). Three core principles underpinned the data-sharing commitment, those of being equitable, ethical and efficient (219).

It was possible to foresee that increasing numbers of person-level attribute variables could be pooled together from, for example, social, medical, genetics, dispensed medication, and environmental records, as well as other individual characteristics, such as motivational aspects of personality profiles or mental health and wellbeing scale scores.

As government and research interest grew in linking electronic health records with other datasets, funding opportunities were opened up in support of linked data research. One such example was the first UK call for Electronic Health Informatics Research Centres (E-HIRCs), a competitive funding opportunity supported by a UK consortia of research councils and voluntary sector organisations, led by the UK Medical Research Council (MRC) in 2012 to the combined value of circa £19 million (220). The E-HIRCs initiative was designed to build capacity and expertise in health informatics research. These centres of excellence based in London, Dundee, Manchester, and Swansea were to “act as an interface with industry, practice and policy with the aim of building and sustaining a vibrant health informatics research capability in the UK” (220).

In 2013, the MRC announced a further £20 million investment in the Farr Institute, devoted to capital investment in buildings for health informatics and allied disciplines, in training new health data scientists needed for research and clinical practice, sponsorship of scientific conferences, and the establishment of two new academic journals (210,221). Thus, the four E-HIRCS became four regional Farr Institute Centres, mapped to Scotland, N.England, Wales and London, and newly affiliated with 23 other Universities (210). A recent evaluation of the Farr Institute concluded that it had played a key part in growing the discipline of data science for health (210). NHS Digital and Public Health England were also established in 2013.

In 2018, Health Data Research UK (HDR UK) was formed, a £110 million investment in a single national institute, and a much larger successor to the Farr Institute. HDR UK had far bigger ambitions with research priorities spanning understanding causes of disease, clinical trials, improving public health, and providing better care (198). HDR UK is an independent non-profit Company supported by Research Council and charitable funders, bringing together universities, NHS, industry, patient groups across thirty one UK sites (198). Alongside this large scale investment in health data research, there was a corresponding £34 million ESRC investment in using public sector data for social good, with four UK Centres for Administrative Data Research, including one in Scotland (222).

There are negative sides to data sharing and linked population data research, and serious incidents of public mistrust in using data have occurred; for example 'care.data', an initiative in 2014 to extract GP data (223), was paused after widespread criticism, including from the Royal College of General Practitioners (202). In 2016, the National Data Guardian (NDG) Dame Fiona Caldicott was asked by the Secretary for Health to review health data sharing, finding that although in general there was still a high degree of public trust in NHS safeguarding of data, this trust had been somewhat eroded (202). This review proposed a new consent/ opt out model that gave people a means of choosing how their data is used, besides direct care (202). This opt out model was recommended to be implemented in all organisations that process health and social care information and that individuals could opt out of personal data being used, unless there was a legal requirement or overriding public interest (202).

The introduction of EU General Data Protection Regulation (GDPR) in 2018 was a timely intervention (210), as it conferred EU citizens strengthened data protection rights, irrespective of where data was processed in the EU (202). However, GDPR has brought additional challenges to the health research community, including a lack of a clarity on the basis for processing personal data for secondary research purposes, and that pseudonymised data



(containing a patient indexing system that is anonymised in practice) was not considered as anonymised data (224).

### **2.2.7 Health informatics research in Scotland**

Scotland currently has a relatively stable population of 5.5 million (136), with a single-state NHS healthcare provider used by almost all citizens, paid for by taxation and free to access at the point of need (209). A stable population confers an advantage in population data research as migration is relatively low, and therefore there are greater numbers of records pertaining to individuals covering lifespans. The Scottish Government administers NHS Scotland, via regional Health Boards (209).

Scotland's position as one of a handful of countries around the world to possess a comprehensive health record linkage system is owed, in most part, to a far-reaching decision made in 1967 by the organisation which preceded the current NHS Information and Statistics Division (ISD) in Scotland and the Registrar General of Scotland (209,225). It was decided that from 1968, all hospital discharge records, cancer registrations and death records would be held centrally, as machine-readable unanonymised records (225). Records were held with personal information in order to facilitate matching records on ad hoc linkage projects (225).

In the 1970s, the Community Health Index (CHI) number was introduced and gradually adopted across NHS Scotland until full coverage was achieved towards the end of the 1980s (225). The CHI number is a unique number conferred at birth, on registration of an individual with a General Practice, or for a new hospital record where an individual has no CHI number. In comparison, the NHS number (the CHI number equivalent in England & Wales) was introduced much more recently in 1996, and only from 2002 was every new-born given their own NHS number (226).

A joint project between NHS ISD and the Computer Centre of the Scottish Health Service was undertaken in 1989 to pool together a permanently linked dataset of records, which could be dynamically updated in time (225). This

pooled dataset has since been 'CHI-seeded' back in time to 1981, so that *all* hospital records since then have an associated CHI number (209).

I return to the CHI system and the Scottish health record systems in section 2.2.7.5, but first provide context for the discipline of health data linkage research, and the opening up of resources within the UK and Scotland.

### **2.2.7.1 Data linkage initiatives**

Scotland was well positioned to harness data linkage capability because NHS Information Services Division (ISD) routinely warehoused electronic hospital records. In 2010, the Scottish Health Informatics Programme (SHIP; <http://www.scot-ship.ac.uk/>) was launched, well before the UK EHRCs and Farr Institutes. SHIP fulfilled several aims; it championed the existing NHS ISD data, provided dedicated training for researchers, established a community of interested academics and students, and led a successful public engagement exercise (227).

Perhaps one of the most valuable contributions of SHIP was that it was instrumental in delivering a national solution in appropriate sharing and use of health data for research purposes (228). This national solution balanced two key principles of (a) promotion of public interest and (b) protection of privacy and other interests of citizens (229). This solution required researchers to travel to one of several 'safe havens' where data activities could be done with the risk of disclosure reduced by controlling access and with pre-specification and prior ethical approval of dataset linkage. This mimicked a model that was being used in other micro-data analysis projects (216,230).

Contemporaneously with the SHIP initiative, was the ESRC-funded Data Management through e-Social Science (DAMES) programme (197,226). Part of the aim of DAMES was to develop an e-infrastructure and technological platform supporting a wide variety of e-Social Science themes, including an overlap with e-Health. This work was being applied in the context of the SHIP programme of work and encompassed cross-sectoral linkages of health and

socio-economic data, with a focus on studying mental health and suicide (8,226,231,232).

The DAMES project tested the 'VANGUARD' system in collaboration with colleagues from the then National e-Science Centre, University of Glasgow (232). 'VANGUARD' was applied in using and linking pseudonymised and partially anonymised data in secure environments, where all data providers are able to sign-off on the linked, joined, anonymised data sets before final release to researchers (232), a system still in use today.

Therefore, this PhD project started in 2011, during a time of considerable flux, in a time of aspiration with both SHIP and DAMES, and in which the landscape for e-Health data linkage was rapidly changing.

#### **2.2.7.2 Public engagement**

Having public approval of data linkage is fundamental to long-term success in using data for public good. Therefore, considerable effort has been made with public engagement activities in Scotland to assess opinions of data sharing as part of the 'Scottish Health Informatics Programme'. SHIP findings supported general public acceptance of health data being used for public benefit; that public trust was paramount for research, that the public should play a role in setting research priorities, and that it was important that the public is informed about how their data is used (227,233).

Public opinion was generally trustworthy of academic researchers accessing data, with perceptions expressed that they were more altruistic than non-academic researchers, as long as appropriate safeguards were in place (202,233). Raising public awareness with a focus on promoting successful examples of linked data research was thought to be key, so that the public could understand better what was done with their data, and build trust in the process (233). Governance mechanisms were central for fostering trust, with agreed standards set that academic researchers would have to comply with (233).

However, when it came to commercialisation or industry use of data, people were generally uncomfortable about this, particularly if profits were being made from personal health data (233). Discomfort expressed stemmed from a recognition that any research motivated by profit would in due course lead to a consequential erosion of public trust in the research, and in devaluing science (233). It is useful to be aware of public opinion as that provides valuable context to the legislative framework and data environments, and serves as a reminder that researchers do their utmost to demonstrate trustworthiness and foster public confidence in how data is used.

### **2.2.7.3 Accessing data and Safe Havens**

In Scotland, the electronic Data Research and Innovation Service (eDRIS) was introduced in 2013 to facilitate access to linked health research data (209). eDRIS are part of NHS ISD, have a role in Public Health Scotland, and support Health Data Research UK, the Scottish Centre for Administrative Data Research, and Scottish Government Linkage Projects (234). Researchers who wish to use health datasets contact eDRIS as a single point of contact. Enquiries are reviewed by eDRIS for feasibility, and a quote is provided for the work involved, along with a named Research Coordinator who provides advice, access to data via the secure national 'Safe Haven', and support throughout until project(s) have been completed (234). I now focus briefly on the topic of safe havens, including some personal reflections.

The Data Sharing Review Report undertaken by Thomas & Walport for the UK Government recommended use of 'Safe Havens' as an environment for population-based research and analysis, in which the risk of identifying individuals is minimised (217,218). The 'Safe Haven' model is preferred and offered by the National Records of Scotland ([www.gro-scotland.gov.uk](http://www.gro-scotland.gov.uk)), and UK Secure Data Service (<https://www.ukdataservice.ac.uk/use-data/secure-lab/about.aspx>). The Scottish Health Informatics Programme, when it emerged, was also in favour of the existing Safe Haven model for data access and usage, based upon researchers having to physically visit secure settings to access, link and use available data sets (209). Other technical solutions existed as alternatives to the Safe Haven model, e.g. the Virtual Private Network (VPN) model that permitted researchers to access data remotely from

their personal computer, and although this was popular with researchers, data providers were resistant to adopt this model.

Counterintuitively, having made the Scottish public aware of what researchers were doing with their data, it became necessary to more closely manage public perceptions, and in the early 2010's the Safe Haven solution was seen as lowest risk and offered in order to better foster public trust (227). There was consensus amongst the SHIP community that securing enhanced public trust was advantageous (227) and would pave the way for trustworthiness of SHIP activities with maximised transparency in data sharing processes (233). These activities included opening up discussion to use other secure data access models that were still low risk, but more efficient for researchers, which ironically meant that in trying to 'unleash' the potential for data in Scotland, it became more difficult and more expensive for researchers to access data (personal perception).

The original lowest-risk Safe Haven model had some recognised shortcomings, such as lack of flexibility in handling and exploring complex data, and demanding travel and physical co-location of researchers. The physical safe haven space had to be booked, as it could not accommodate more than one researcher at a time, and researchers not within easy reach of one of the safe havens were disadvantaged (personal perception). The Safe Haven framework increasingly could not satisfy demand in population health research, and arrangements were particularly difficult in an international comparative framework, where it was necessary to pool data from different countries in order to permit analysis, as is the case with rare diseases (231).

Moreover, detailed activities of exploring and manipulating data resources (such as recoding variables) were not readily achieved in the Safe Haven framework, where transferability of supplementary files, used extensively in such operations, was constrained. By way of a personal example, it was impossible to use Standard Occupation Classification (SOC) coding systems available online to operationalise Occupation codes contained on death certificates used in PhD paper 1 (Chapter 3), or of transposing SOC codes to the Cambridge Social Interaction and Stratification Scales (CAMSIS), a measure of personal affluence (235). This meant that instead of making use of

previously published and dynamically updated data coding structures, extensive syntax had to be written from scratch. Indeed, Safe Havens were especially poorly suited to this and other rapid expansions in data resources being made available in health, social science, education and other agencies, as well as complex large scale and longitudinal resources that benefitted from extensive preparatory effort and exploitation of separate supplementary data (personal perception). In time, this problem was overcome somewhat by downloading resources indicated above and formally requesting eDRIS place these into the Safe Haven (see below on the 'Scottish model'). Although this was a solution, it meant that online resources were not exploited in the intended way, i.e. with web address file pathways called from within syntax (personal experience).

The Safe Haven model had to evolve in order to provide sufficient utility for researchers to access and analyse administrative data. By 2015, the 'Scottish model' was developed, with four main hallmarks (209). Firstly, data remained under the 'responsibility of different data controllers and brought together for clear research questions that had public benefit' (209). Secondly, de-identified data was 'provided to researchers via a federated network of safe havens' (209). Thirdly, only 'approved researchers' could access data, with approval contingent on researchers passing a course on legal frameworks and privacy risks; and finally, public trust was to be continuously developed through 'good practice and public benefit' with commercial partnership research (209). The 'Scottish model' therefore produces *ad hoc* data linkages, drawing on existing NHS and other data linkage systems that are open-ended, unlimited, and continuously update as new data arrives (206).

In some circumstances the 'Scottish model' offered researchers data access via remote, secure access provision to the Safe Haven using VPNs from approved 'whitelisted' Internet Protocol (IP) addresses (209). Permission to access and process data via VPN, instead of attending in person at a Safe Haven is dependent on PBPP's assessment of the level of risk of disclosure of the data requested, with lower risk projects assigned access via VPN. This model also meant eDRIS-approved electronic documents could be placed into the Safe Haven, and electronic outputs could be removed from the Safe Haven

once they had been vetted against statistical disclosure control policies by eDRIS, to help ensure no individuals could be identified from their data (209). Although the technical capability of doing this had been in existence all along, the pace of change had been constrained by the perceived public acceptability of the technological solutions. This model permitted secure access to a variety of distributed data, where data providers are autonomous and able to implement their own access and usage policies. Pivotal points on which acceptance was achieved was the positive public engagement exercise (227), and an information governance framework in which researchers accepted responsibility for the confidentiality of data (228).

However, the 'Scottish Model' is still problematic in that researchers cannot access web-enabled resources when working within the physical Safe Haven or when accessing via VPN. For instance, resources and syntax made available by other analysts on the developers' platform, 'GitHub' are impossible to access from within the Safe Haven, as the secure environment does not permit web access. In addition, there are significant time constraints waiting for approval of documents in support of analysis to be placed in Safe Haven project folders, and for outputs to be released, which can create significant project delays (personal experience). There will undoubtedly be future iterations of the Safe Haven that are more efficient, but first require innovative technological solutions to monitor researcher internet use from within the Safe Haven environment. The other model not mentioned here is one where researchers are permitted to take data away under agreed licence conditions (such as are offered by ONS or UKDA), however I have not expanded on this here because at this point in time, it is highly unlikely to be adopted as a model for accessing NHS data.

In general, there is some pressure to move away from cumbersome physical Safe Haven models. Whilst the VPN connection model has been able to satisfy increasing demand from the research community in allowing multiple user access to Safe Haven data in parallel, the drawbacks as outlined above are still substantial. Research projects with more sensitive personal data are still mandated by PBPP to be done within a Safe Haven. An interesting development is that since March 2020, in response to covid-19 restrictions, permissions for access via VPN, rather than physical safe haven were

dramatically and unexpectedly accelerated (203), and it remains to be seen whether these measures will stay.

#### **2.2.7.4 Permissions process to use data**

In order to use data, mandatory approvals are required for using sensitive NHS data, and for linkage of NHS datasets. During the course of this PhD, the legislation governing the use of personal data changed to the UK Data Protection Act 2018 (DPA2018), replacing the Data Protection Act 1998 (DPA1998).

Papers one, three and five all used data that required Data Protection approvals; papers one and three obtained approval under DPA1998, while paper five was approved under DPA2018. DPA1998 allowed data processing of 'personal' data in 'fair and lawful' ways, with section 33 of DPA1998 permitting data to be used for research as long as it was not to the detriment of any particular individuals, or caused distress to any data subject (209). Notably, both DPAs only applied to the processing of personal data, (including pseudonymous), of living individuals. For paper one, which only processed data of those who had died by suicide the DPA1998 did not apply, although Article 8 of the Human Rights Act 1998 did apply, which considered the right to 'respect for family life' of the deceased (236).

The NHS Caldicott Guardians hold the responsibility of ensuring compliance with DPA1998 and DPA2018 at NHS Health Board level, and at national level through the Public Benefits and Privacy Panel (PBPP) (209). PBPP replaced the Privacy Advisory Committee (PAC); Paper one was approved via PAC, and papers three and five via PBPP. The PBPP was set up by the Scottish Government to provide a '*single, consistent, open and transparent scrutiny process for health data to be used for different purposes, including research*' (237). The DPA2018 incorporates the EU General Data Protection Regulations (GDPR). The PBPP scrutinise requests for access to data on behalf of the Scottish public, to ensure that the public benefits and privacy implications have been considered, and that the 'technical and organisational arrangements' have adhered to the 'data minimisation principle', as set out in GDPR Article 89(1).



To justify processing personal data, the most frequent legal basis used by researchers has been GDPR Article 6.1(e), 'performance of a task that is in the public interest' (237), while processing sensitive personal data, including physical or mental health data was lawful provided it met Article 9.2(i) 'public interest in public health' (237). I obtained approval for paper five from PBPP using GDPR Articles 6.1(e) and 9.2(i); and this application also required a GDPR Data Privacy Impact Assessment and a Privacy Notice. In addition, the Common Law Duty of Confidentiality applied for using healthcare data, covered in the 'right to respect for private life' in Article 8 of the Human Rights Act; here I was able to use exempted circumstances as stipulated in The Caldicott Principles and the Data Protection Principles.

PBPP weigh up public benefit of research against the privacy risks, and consider applications made against five principles of 'Safe People, Safe Projects, Safe Data, Safe Settings and Safe Outputs' (237). However, PBPP is only one part of the approvals process, and assessed *after* a favourable opinion has been granted from NHS Research Ethics Committee or a University ethics committee. Therefore, it can be a lengthy process to secure approvals, and obtaining PBPP approval does not infer the requested data has been extracted and is ready for use. Obtaining approved data via eDRIS may be subject to wait times, and completely out of the control of those who request data. This can be fraught, particularly when external funders wish researchers to start within six months of notification of successful application, or research is being undertaken within the time limit of a PhD.

#### **2.2.7.5 Scottish morbidity records (SMR)**

As already mentioned, the CHI number was introduced in 1970s, achieving 'full' population coverage by 1988, and used to 'CHI-seed' records going back to 1981 (225). The CHI-system is sometimes referred to as the 'population spine' as it is a unique indexing system containing personal identifiers of people who have accessed NHS Scotland services (238). The CHI coverage of the population has been estimated at between 96.5% and 99.9% (209). These CHI-indexed electronic patient records are instrumental in enabling record linkage to other datasets, indexing probability matching identifiers to the

population spine, thereby permitting pooled records of hospital episodes linked to other routine data along the life-course.

Diseases and health disorders are categorised by a standard diagnostic tool called the International Classification of Diseases (ICD) for the purposes of clinical, epidemiological and healthcare information management (239). Countries who are members of the World Health Organisation (WHO), including Scotland, use the ICD system in classifying diagnostic codes on healthcare records and causes of death on vital events records.

A host of different datasets are available from Public Health Scotland via NHS ISD. For example, service data related to waiting times, delayed discharge and performance statistics are available, as well as aggregated estimates of disease prevalence through to individual level prescribing data and healthcare records. Relevant morbidity data is contained in the linked Scottish Morbidity Records (SMRs). SMR datasets of physical health (SMR01) and mental health (SMR04), maternity dataset (SMR02) and cancer registrations (SMR06) have been linked to NRS vital events registrations and are regularly updated (SMR99). SMR01 captures electronic records from general hospitals and SMR04 from psychiatric facilities, but neither hold outpatient records. Outpatient records are contained in SMR00, which was established later on in 1997 (240); these records are much less reliable than in-patient records and are therefore used much less.

Papers one and five (chapters 3 and 7) use methodologies applied to SMR01 and SMR04 data that were linked to NRS death registrations.

#### **2.2.7.6 Unscheduled Care Dataset (UCD)**

The Unscheduled Care Data Mart (UCD) arose from partnership working between NHS Information Services Division, NHS 24 and the Scottish Ambulance Service (SAS). From 2011, UCD linked data from these three organisations, including Emergency Departments (EDs) and death registrations, with out of hours (OOH) primary care contacts added in 2019 (241,242). The UCD went 'live' in 2014, and each year adds 1.4 million NHS records covering approximately 600,000 SAS records, 1.5 million ED

attendances, 560,000 emergency admissions and 900,000 OOH primary care contacts (241).

The UCD contains demographic data of age, gender, postcode-derived deprivation codes and several geography codes. There are different coding frames within the UCD, depending on the data source. NHS 24 data contains structured text field for symptoms; ED data contains derived data from the A&E Datamart (243) including a text field for presenting complaint, ICD10 codes and diagnostic grouping variables (243,244). In 2019, OOH primary care data was added to the UCD and contains clinician-coded 'Read' codes. SAS data are derived from the Advanced Medical Priority Dispatch System (AMPDS), including call type (emergency, urgent, routine), despatch code for presenting complaint, and final AMPDS code (attending paramedic's working diagnosis).

Acute inpatient and mental health hospital data in UCD are restricted to emergency admissions or non-respite admissions, respectively, derived from the Acute, Cancer, Deaths and Mental Health Datamart (ACaDMe) (242,245). ACaDMe differs in that it contains subsets of inpatient and outpatient records from general hospital (SMR01), mental health (SMR04), cancer registrations (SMR06) and death (NRS) records (242). Death registrations are included in the UCD, not as part of patient journeys but to enable estimates of time from unscheduled care events till death (242).

The CHI number is used by NHS ISD to document patient journeys using contacts with all the agencies involved to produce Continuous Unscheduled Care Pathways (CUPs) (241). A CUP is a continuous succession of urgent care contacts that occur within 24 hours of each other, or 48 hours if linked to an acute or mental health stay (using SMR01 and SMR04 data). Time stamps of 23:59 are attributed to both admission and discharge dates to permit estimations of time and assess whether these are one continuous pathway. Code letters are tagged to each contact, as follows: N=NHS24; S=SAS; E=ED; A=Acute hospital emergency stay; M=Mental health non-respite stay; O=Primary Care out of hours (242). Chronologically ordered patient journeys are formed from a series of code letters. For example, 'NSE' represents a call to NHS 24, followed by SAS and ED presentation within 24 hours (242).

The UCD datamart was used in my paper three, and this was the first time the UCD had been used for research purposes. In this study, I led on the data science, securing funding with Dr Eddie Duncan (PI) and team; further details are available in Chapter five.

#### **2.2.7.7 National Records of Scotland vital events**

The data custodian of vital events, including death registrations is National Records of Scotland (NRS, formerly the General Register Office for Scotland). NRS collect cause and circumstantial death data and characteristics such as age, gender, residential address, occupation and means of suicide. Postal codes are recorded on each death certificate by Scottish *residential address*, or by postcode at *place of death* for those without a residential address, (the latter group may have CHI numbers, but most will not).

NRS classifies the underlying cause of death using information on the death certificate and any additional information from pathologists or Crown Office and Procurator Fiscal Service (COPFS) (2). COPFS and Procurator Fiscal are equivalent to Crown Prosecution Service and Coroner in England and Wales, respectively. 'Suicide' does not appear on death certificates, instead 'probable suicide' is inferred from causes of death such as 'paracetamol poisoning', or 'hanging' etc (2). Causes of death are also coded by ICD classification system, with external codes for 'intentional self-harm' (ICD9 E950-959; ICD10 X60-X84 and Y87.0) and 'events of undetermined intent' (ICD9 E980-989; ICD10 Y10-Y34 and Y87.2). 'Intentional self-harm' codes are used where it is clear the intention was suicide or death from self-inflicted injuries, and 'events of undetermined intent' codes are used where it is unclear if the death was intentional self-harm, an assault, or an accident, for instance drownings may appear in this category (2).

NRS add 'probable' deaths by suicide to the official statistics during each year to the end of each April. Deaths registered after April are entered in the following year, meaning that numbers are frozen in time for the previous year. This means for example, that deaths categorised as 'events of undetermined intent' cannot be re-classified to 'probable suicide', even if new evidence

emerges to indicate it was a death by suicide. This is a marked difference in practice to elsewhere in the UK, where deaths for previous years can change as new information comes to light, with much longer lag times between death and the registrations, leading to a significant later death registration problem highlighted in 2019 by the Royal Statistical Society (246).

It has been conventional for NRS and ONS to combine 'events of undetermined intent' along with 'intentional self-harm', to create an aggregated category of 'probable suicides' (2,23). Only some accidental deaths are counted as 'events of undetermined intent' by NRS; for instance, deaths are not counted if a consequence of a vehicle accident, or hanging if aged 15 or under (2). Academic studies of suicide have also routinely combined these categories, although there have been long-running debates on this practice. Historically, smaller studies with sparse data included both categories to boost the sample size, alongside a growing scientific consensus that most 'undetermined deaths' should be considered as likely deaths by suicide (247–249). However, this consensus is a matter of debate for epidemiological studies of suicide (109,250,251), which do not usually experience sparse data.

Including only deaths of intentional self-harm may provide an underestimate of the scale of the problem (252), but including all additional deaths of undetermined intent yields 'false positive' data (249), and significant differences between the two categories have been proposed as artefacts of the classification procedure (253). In the UK, the category of 'event of undetermined intent' was introduced in 1968, and had a substantial effect on suicide statistics. This was much more apparent for Scotland, with sudden increases in suicide observed, and the extent of underreporting prior to 1968 became much more evident with significant numbers of accidents re-classified as suicide after 1968 (254). A 2015 cross-national comparison of deaths by suicide versus accidents suggested that the UK still seriously underreports deaths by suicide, with relatively higher proportions of accidents recorded, with serious policy and service implications (252).

NRS changed the way deaths were classified to match changes in WHO coding rules in 2011, so that 'drug misuse' deaths were re-classified as 'self-poisoning of undetermined intent', and therefore 'probable suicides'. This

resulted in a slight increase in deaths thereafter, and NRS now report two sets of deaths data to enable longitudinal comparisons, those by the 'old coding rules' and those by the 'new coding rules' (2).

All my papers, except paper four, use NRS vital events 'deaths data'. Papers one, three and five made use of individual level data contained on the death certificate linked to health datasets by NHS ISD. Paper two uses NRS aggregated open data, available to download from NRS directly.

### **2.2.8 Linked health data – evidence and ethics**

In this section, I briefly consider ethical perspectives of using linked health data. The growing potential of linked datasets offered opportunities for a new wave of health research tracking large numbers of individuals across different datasets. However, these study designs exhibited substantial differences from the models of randomised controlled trials that have informed previous narratives on research ethics. The potential use of health data linked to other datasets, and the level of detail contained within such linked datasets raised new ethical issues (201). These not only concerned consent, but also the effectiveness of research, researcher's responsibilities, data security, disclosure and anonymity.

In ascertaining efficacy of drug treatments, the randomised controlled trial (RCT) has been considered the gold standard in assessing potential patient treatments, sitting near the top of the 'evidence pyramid' (255). RCTs are valuable when conducted to best practice and where patients are representative of the patient population – however, 'real world' patients are frequently excluded from clinical trials because recruitment is hampered by strict eligibility criteria, and RCTs are usually powered for efficacy and not safety (256). Therefore, RCTs are not always generalisable to the patient population for which treatments under scrutiny were intended (257,258). Secondary data analysis using individual e-Health records linked to RCT data offered a powerful way of observing adverse events and identifying undesirable long-term adverse effects (259).

Central to conducting a clinical trial is recruitment of patients who have the right to information about the study, and autonomy to participate or withdraw from research, embodied in the 'informed consent' process. With vulnerable groups there are complex questions around capacity to provide informed consent, and as a consequence such groups are frequently excluded from participating in clinical trials(256). However, more recent pragmatic, 'real world' RCTs have made more use of linked healthcare data as outcome measures, meaning they are much more inclusive of vulnerable population outcomes (256,260).

Population level studies using individual-level linked data do not have comparable recruitment stages with RCTs. In the past, consent was rarely sought at the point of data collection for secondary use of data. If seeking informed consent for a secondary use of data was insisted upon, individuals would be offered the opportunity to 'opt in' to population level linkages, with obvious detrimental effects on the studies and the usefulness of the collected data if many elect to 'opt out' (202).

One solution that struck a balance between public good and informed consent model was to anonymise datasets once linkages have been made. In the absence of personal information, consent was typically no longer required. However, using fully anonymised data diminishes the possibility of exploiting complex data to its full potential (since informative distinctions have to be suppressed and outputs monitored to reduce the risk of identifying individual cases) (202). Removing personal identifiers (such as CHI numbers for exact matching, or personal information for probabilistic matching) also precluded enriching the dataset in future through linking to other datasets, such as health or household surveys or longitudinal studies.

Alternative data models were therefore used, such as the Scottish model, where consent is not obtained, and data is 'pseudonymised' (encrypting identifying information such as a unique health number, and creating separate 'look-up' tables which provided a means to get back to the identifying data for future linkages) (209). Here the related ethical issues of confidentiality, data security and statistical disclosure control arose. In this model, researchers only

accessed data on certain conditions and agreed not to attempt to identify individuals, nor publish outputs that might have the potential to be disclosive (209).

As an illustrative example with the Scottish model, it is now theoretically possible using linked health and pharmacy datasets to assess medication safety and related adverse events in the *whole* population. This is of particular interest in under-researched vulnerable groups, such as in pregnancy, in mental health disorders and in the elderly. This has presented a pragmatic and relatively cheap way of exploring health outcomes by sub-groups. Drug interactions and adverse event incidence rates are likely to vary across treated people and compared with controlled trial conditions, predicted to be worse in patient-level analysis of the whole population where 'real' patients with complex health and social conditions exist (202). Such studies enable the tracking of drug side-effects over many years (whereas clinical trials usually have short follow-up periods, typically weeks).

The Scottish model also offered the capability of additional linking to datasets containing information that may help unpick underlying reasons for health inequalities. e-Health research studies pose considerable opportunities to explore added impacts of other factors such as deprivation where social problems and riskier behaviour can mask events. For instance, prescription drug overdoses may be as much to do with the biological disorder as the social problems many individuals may face. A particular advantage of e-health research is the ability to repeat analyses periodically on dynamically updated databases in order to examine the effect of policy changes after implementation.

The political will to facilitate e-Health research with population-linked data, overwhelmingly for public benefit, could have been constrained by the views of a minority with legitimate concerns about invasion of privacy and the harm that may follow from disclosure. The principal ethical issue of using population data without gaining informed consent could have been contentious, but ultimately this was resolved through successful public engagement (233).



Researchers face choices to do what may be perceived by a minority to be 'wrong', and proceed in either of two ways; firstly, the basis that in the presence of reasonable safeguards, public good outweighs the need for individual consent; or secondly, to avoid research that does not achieve informed consent. The second option is unsatisfactory as it all but rules out using linked data, especially on populations with limited or no capacity to provide consent (e.g. those who have developed conditions such as dementia), and research on those who may be 'lost' to the system through changing address or mortality.

Custodians of relevant data, as exemplified in the Scottish model, have championed the secondary use of data to improve health services and reduce health inequalities. In doing so, privacy concerns have been addressed, demonstrating that necessary safeguards have made accidental disclosure of personal information such a low risk prospect that there is minimal risk of harm to an individual. Academic researchers have also shown by example the health benefits of individual-level linked data research using sophisticated tools and security solutions, e.g. the Farr 100 Ways exemplar studies (8,261). Academic researchers have also received mandated training in information governance, in line with five principles enshrined in Royal Statistical Society guidance for ethical data science that summarised multiple existing ethical frameworks. These are 1) 'Seek to enhance the value of data science for society'; 2) 'Avoid harm'; 3) 'Apply and maintain professional competence'; 4) 'Seek to preserve or increase trustworthiness'; and 5) 'Maintain accountability and oversight' (201).

In summary, e-Health research offers a significant advantage with relatively unbiased sampling methods to include those with complex social problems and/or multiple medical conditions and at highest risk of health inequity in society, often precluded from formal clinical research. This research is clearly for population benefit, and with data and security systems in place to keep data safe, the need for specific individual informed consent to 'opt in' has been waived.

## 2.2.9 Linked health data research

### 2.2.9.1 Data linkage

NHS ISD offer a bespoke service for data linkage via eDRIS; however, for my first paper, the data was provided to me in different datasets to enable a 'demonstration linkage' (see chapter three for more information). I now provide some further detail on what data linkage is, and how this is usually achieved.

Data linkage is the process of combining data from two or more datasets that relate to the same individual, household, geographical area or event. Linkage systems can make use of pseudonymised or identifiable data; pseudonymised data typically makes use of a unique (often encrypted) number common to all datasets and used in a 'deterministic' direct match merge process. Identifiable data without a unique number is linked via a 'probabilistic' matching process. The sensitivity and specificity of matching processes vary, depending on the quality of the data (206).

The ability to support the storage and linking of original data in secure environments is dependent on the infrastructural arrangements, technologies and expertise available. These typically can be hosted by data providers themselves and set up to allow various levels of access to accredited researchers, for example, in a system of proportionate governance where the level of access is determined by the type of data requested to access. There is a distinction between 'ad hoc' data linkages, which relate to datasets merged for e.g. one research project and a 'data linkage system' which can support an indefinite number of future, unknown projects and has dedicated storage for a master linkage key contained in a separate look-up table.

The Scottish model operates by bringing together data from different agencies on a project by project basis, rather than warehousing permanently linked data in a single place (209). This was driven by the legal framework and the public engagement work done in Scotland (209). Data are therefore moved between agencies (and different data controllers), with potential security risks assuaged by secure transfer technological solutions, and by using different organisations

for linking data, and storing data (209). Practically speaking, this means that once the necessary permissions are in place to create a linked dataset, the data controllers send identifying personal information to a trusted third party who use this information to link data belonging to individuals together (209).

In Scotland, data linkage is facilitated by the Community Health Index (CHI) system, using the principle of 'separation of functions' (209). Data providers supply a 'trusted third party' with CHI numbers and/or personal information such as names, addresses and dates of birth to match health data, or probabilistically link people in different non-health datasets (209,238). The 'trusted third party' only receives identifying information to match on, and never holds the data belonging to each identifier (209,238). The 'trusted third party' then creates a project-specific unique identifier for each person, returns this key to the data controllers, and destroys the personal information used to create the key. The data controllers then send the data and project-specific index numbers to a second organisation, which joins the data using the key. Therefore, the security of linked data studies rests on secure data provision; robust information governance and secure environments (with approved researchers accessing Safe Haven data directly or by VPN); secure file transfer protocols; de-identification of data; and statistical disclosure control on all outputs prior to release (238).

### **2.2.9.2 Study designs**

A theme of this PhD is methodological, focusing on issues of data availability, harmonisation of diagnostic coding between datasets, data quality, variable operationalisation and statistical approaches to analysis. However, well-designed studies are key to answering research questions in robust ways, and a brief introduction follows along with approaches taken.

My papers one, two and three contain studies of observational data (as opposed to experimental), which provide information on prevalence or incidence within certain populations (262,263). Healthcare data lends itself to observational studies, which may consist of cohort or case-control designs. Observational studies may explore exposures (e.g. risk factors) and outcomes

(e.g. morbidity or mortality), with outcomes ascertained after exposure (prospective), at the same time (cross-sectional) or before the exposure was ascertained (retrospective) (262). Cohort studies may be prospective, cross-sectional or retrospective, while case-control studies are retrospective. Papers one and three use a retrospective single-group (cohort) design, and paper five uses a case-control design.

Observational studies of healthcare data are suited to longitudinal study designs. There are methodological benefits of using longitudinal data: the temporal ordering is known and therefore some inference can be made with respect to the direction of causality (263). In addition, the effects of both ageing and cohort affiliation can be explored in any age-period-cohort analysis; effects of previous states (state dependence) and substantial variation between individuals can be controlled better (by controlling for residual heterogeneity) (263). Papers one, two, three all use longitudinal data, while paper five outlines methods for using longitudinal data.

Longitudinal data can take the form of individual-level datasets e.g. population surveys, (often large numbers of people and sparse number of time-points) or time-series datasets e.g. unemployment rates (characterised by small numbers of entities and frequent time-points sampled). Survey data are commonly either cohort studies or panel data studies, with data being gathered prospectively and/or retrospectively. Outcome measures may be continuous or categorical, and multiple repeat measurements are usually available, with the simplest design a pre-post study (263). With case-control studies, the binary outcome measure is observed at one time-point, with outcomes defining 'cases' and 'controls', and the covariates are ascertained retrospectively (263).

This thesis has four papers that use data, and each are different in design. Paper one is a retrospective single group (cohort) of 'cases' only, using 'closed' individual-level data belonging to people who have died by suicide. Here 'closed data' pertains to data that is withheld from general access for reasons of security, and accessible only with dedicated permissions for a one-off use (214). Paper two is a single group study using aggregated 'open' data of suicide statistics. Paper three is a retrospectively identified cohort, followed up

for one year using 'closed' data. Finally, paper five outlines the protocol and methods for a retrospective case-control study using 'closed' individual-level data belonging to 'cases' who died by suicide.

### **2.2.9.3 Data quality, variable operationalisation and analysis**

This section summarises some issues with data quality to do with SMR hospital data, and general approaches to data operationalisation and analysis.

SMR data files used in three of my papers were supplied with a unique encrypted identifier per individual, and multiple rows, each row corresponding to a health record. All data were de-identified. Each row contained responses aligned to column heading variables, such as demographic data, Admission date, Discharge Date, ICD code for 'Main Condition' and up to five 'Other Conditions', amongst others (264). Records were sorted chronologically by individual.

NHS ISD conduct routine validation and quality assurance checks on SMR data (265), however there are still some residual problems with missing or incorrect data. In 2015, data quality assessments of a random sample of 5% of SMR01 (physical health) records reported accuracy rates as relatively stable over time (266). For example, accuracy rates for 'Main Condition' (ICD 3-digit level codes) have held at 89% for over 25 years, just short of ISD's minimum standard of 90% (266). Given that SMR01 accuracy was constant through time, this ruled out one source of variability in the data, and added credibility to any analyses in papers one and three (Chapters three and five).

A report in 2016 on SMR04 (mental health) data determined some items had very high average accuracy, including admission and discharge dates at 99% and 98%, respectively (267). However, the overall main condition accuracy was at 78% nationally, with substantial variability (50% to 97%) between hospitals (267), somewhat attributed to patient management systems being set up in ways that led to incorrect positioning of main diagnosis on Main Condition or Other Conditions (267). Therefore, analyses of mental health diagnoses in SMR04 data are best conducted through summarising information held in main condition *and* other conditions, an approach taken in papers one and three (Chapters three and five).

Further re-classification of ICD codes may be required prior to any analysis. For paper one (see Chapter three), in order to summarise longitudinal information spanning decades, an extensive harmonisation of ICD-9 and ICD-10 codes was undertaken making use of US AHRQ 'Clinical Classification Software' (CCS) algorithms, with syntax to do this uploaded and made available to researchers (link in paper) (8).

Using the CCS system presented considerable background work, and is expanded upon in paper one (Chapter three). To the best of my knowledge, the CCS system had never been implemented in UK datasets previous to paper one, and contributed novel ways of harmonising and linking diagnostic data through time. The CCS system has been used in a few US-based research studies (268–270), although rarely with data spanning decades or cross-mapped between ICD catalogues (268). The CCS system is viewed as reliable, having been developed as a healthcare cost and utilization project (271), with accurate billing a necessary feature of US healthcare systems. CCS algorithms made use of ICD-10-CM (clinically modified) and ICD-9-CM systems, which incurred further cross-mappings between ICD-10-CM (US system) and ICD-10 (UK system), and similarly with the corresponding ICD-9 versions. This was also the case with paper five (see Chapter seven), which focused on methodology on harmonising ICD-9 and ICD-10 codes for childhood adversity as recorded in SMR datasets, and also used the CCS system (13).

Extensive cleaning and checking are required on each SMR dataset prior to any analysis; for example, checking death registrations are dated later than matched health records, and removing duplicate records (8). Assessments of missing data, with missing data mechanisms need to be explored; for example, missing data may only be evident for certain hospitals, implying that data are 'missing not at random' (272) and systematic procedural differences in coding may exist, such as that described above in the SMR04 validation checks (267). Missing data were evident in the most recently available data, suggesting a lag effect between hospital attendance and best data completion rates ascertained by nine months after attendance, a feature uncovered in the analysis of SMR data in paper one (Chapter three).

In general, missing records for demographic data were uncommon, in keeping with experience of hospital datasets elsewhere (206). Cleaning and re-coding ICD codes was time-consuming, with many ICD codes truncated or not in the expected format, frequently requiring the input of eDRIS staff to help understand data better; further details are available in paper one (Chapter three).

Analytical approaches of SMR data typically involved generating morbidity sequence variables to re-shape long format datasets to wide format, with one record per individual. This enabled a review of descriptive statistics for expected patient demographics, determining missing data and out of expected range responses. This format enables estimations of 'index events', or first presentation to healthcare services; with proportions or cumulative incidence estimated for the study population (206).

Assigning morbidity sequence variables in reverse chronological order enabled estimations of proportions seen in which clinical setting at *last* discharge before suicide, as per paper one (Chapter three). Summarising 'spells' or 'continuous episodes of care' (in-patient stays that featured nested transfers to different specialties) by length of stay was a useful proxy for severity of condition on attendance to hospital, as featured in paper one (Chapter three). Data quality problems were often the first explanation for outliers, a feature that is more frequent with healthcare systems not motivated by financial rewards, as is the case in Scotland (206).

Constructing valid comparisons between groups in observational data is challenging, and inevitably confounding variables exist that are unrecorded in the data (206). For instance, poorer outcomes recorded for people may be confounded by smoking status, alcohol or substance use, all of which are highly under-recorded data items, and particularly so with ED data which has high and low completion rates for mandatory and secondary variables (such as alcohol use), mirroring the experience with paper three (see Chapter five) (10). The methodology outlined in paper five improved on that used for paper one (single group analysis), by introducing a 'control' group randomly selected from those who matched on age and postcode at the date of death to 'cases', a method for making groups as similar as possible and controlling for confounding in the study design (13).

Analyses using NRS vital events death registrations was straightforward in comparison, data are complete aggregated statistics, broken down by age group and gender. Standardised mortality rates per 100,000 over fifty years were made using NRS general population statistics, and compared to an analysis reported for England and Wales by Prof David Gunnell and colleagues; see paper two for more details (Chapter four) (9).

#### **2.2.10 Expertise shortfall in data science**

In the UK there is on-going concerted effort by government and by research funding councils in making data available, developing safe havens and other technical solutions to enable access to data and analysis. This effort was complemented with provision of wholesale training in skilling-up a specialist workforce in quantitative approaches and analysis (210).

Increasingly the title of “data scientist” has been adopted to describe the ability to operationalise, analyse and interpret findings of data. The skillset required is not trivial and the expectation is that a post-graduate qualification and specialist training are a minimum requirement (210). The skillset can be varied, drawing on expertise in developing and implementing infrastructure and analytical tools to curate or link data, provide access to data, or analyse data to provide insights in the aetiology of disease or development of population wellbeing, as described in a paper I co-authored on population data science (273). Population data science encompasses a range of backgrounds, such as epidemiology, social science, predictive analytics, machine learning, operating at the intersection of social sciences, health sciences, computer science and statistics (273).

I started this PhD having completed an MSc in Applied Statistics, and within the course of this PhD, added an MSc module in ‘Advanced quantitative analysis’, enabling fluency in Stata statistical software programming language, and training in approaching complex longitudinal data structures, (see Appendix, Table 1, section 10.1). This was supplemented with two specialist training workshops (ten days) at introductory, intermediate and advanced



levels of e-Health data linkage, delivered by Professor D'Arcy Holman (Western Australia Data Linkage Service) (206). Training on information governance was completed with the Administrative Data Liaison Service to acquire a 'Safe Researcher' certificate, and latterly with the Scottish Centre for Administrative Data Research, mandatory training for researchers to access NHS data (Appendix, table 1, section 10.1).

### **2.3 Summary and remarks**

The tasks completed within this PhD encompassed a number of different strands. These included scoping the literature on suicide and psychological distress and holding many in person discussions with experts and stakeholders in the field of suicide and distress. In the beginning, these included those working with 'Choose Life' (the government-funded organisation with the remit of helping to bring down suicide rates), academic experts and NHS Public Health consultants. This helped me ascertain key deficits in knowledge of suicide and contextualise these deficits.

One of the main issues in suicide research I identified was whether there may have been opportunities for earlier intervention by healthcare professionals, and whether 'at risk populations' could be identified at which to target suicide prevention interventions. This required an understanding of healthcare contacts and the characteristics of those who die by suicide or engage in suicidal acts, (self-harm). Therefore, one of my early tasks within this body of work involved identifying the available datasets and their variables, understanding the respective data from NRS and NHS, and how data could be linked. Knowing this allowed me to make my contribution in advancing knowledge on healthcare contacts and at risk populations, as per paper one.

Meeting key people allowed me to build a research network, and led to a collaboration with Dr Cameron Stark and team, in producing paper two (using NRS deaths registrations). This research network allowed me to work collaboratively in pursuit of funding as Principal Investigator in support of studies, (see paper five), and write collaborative papers on mental health data science (274), and population data science (273).

As my PhD progressed, discussions were held with senior leads from National Suicide Prevention Leadership Group (NSPLG), NHS 24, Scottish Ambulance Service, and Police Scotland. This led me to collaborate with Dr Eddie Duncan (PI) and team on a study of Scottish Ambulance Service contacts for people presenting with 'psychiatric emergencies' using the Unscheduled Care Dataset, see paper three.

It also led to lengthy discussions with Police Scotland, with a view to using their data to repeat a similar analysis as paper three but with Police Scotland data linked to the Unscheduled Care Dataset. Although there was widespread enthusiasm to enable data to be shared in a secure, anonymised way, this proved too difficult to do at that point in time as sufficient ethics and governance arrangements were not yet in place. Simultaneously it became apparent to me in discussion with Police Scotland that there were competing issues and a consensus view of national priorities needed to be established. In addition, the evidence base at the intersect of policing and health was scant, and there were no systematic literature reviews of the evidence. In a collaboration with Dr Jen Murray, Inga Heyman (co-PIs) and team, a successful funding award was obtained from the Scottish Institute of Policing Research to host a workshop to identify Scotland's national priorities at the intersect of policing and public health, now accepted for publication (7). Part of the funding award deliverables was to undertake a systematic review of the literature on law enforcement and public health, now published as a scoping review, and presented here as paper four.

Other strands of activity in this PhD included gaining an overview of data linkage concepts, negotiating ethical approvals with REC committees and access to data via PAC and PBPP. There was additional training taken in analytical approaches, understanding different methodological approaches determined by data structures, finding ways of operationalising data variables, conceptualising and performing manipulation of large linked data files, and developing fluency in Stata syntax.

The availability of data does not necessarily imply its 'usability' and indeed research involving large-scale datasets often required high levels of data management (harmonisation and transformation). In approaching the analysis of

hospital healthcare data, one of the methodological challenges I overcame was in establishing methods to operationalise and harmonise large numbers of International Classification of Disease (ICD-9 & ICD-10) diagnostic codes. Further challenges were establishing the types of socio-demographic data that could be obtained within linked healthcare data and transforming variables for use in characterising at risk populations.

In this PhD, much of the methodological contribution is in the pre-analysis phase, the coding and harmonising of ICD codes to enable data gathered over decades to be used together in analyses. The analysis phase consisted of mostly descriptive statistics with some comparisons done between sub-groups (paper one and three). Modelling e.g. longitudinal logistic regression analysis could not be done without a control group arising from a well-designed study, which was one reason for introducing this design in subsequent work done as part of this PhD, see methods outlined in paper five (Chapter seven) (13).

It is important to note that my papers are not equivalent in importance for the purposes of this PhD. Paper one contains the most extensive and labour-intensive pre-analysis methodological contribution, linkage and analysis, and with hindsight could have been expanded to become a traditional PhD thesis in its own right. However, the Privacy Advisory Committee (PAC) did not permit expanding upon that analysis without re-applying for approval, and extending the period of holding the data, attracting considerable additional cost.

## 3. Paper 1: Hospital and deaths by suicide data

### 3.1 Background

This paper stems from a study that linked and profiled 30 years of data related to people who had died by suicide, and uncovered risk factors as seen by healthcare practitioners prior to suicide. Knowing patterns of healthcare contact permits opportunities to intervene earlier in the care pathways of people. This study was a demonstration linkage, and used information contained in death registrations and linked hospital records. I now expand on the rationale for why I selected the methods used.

In Scotland, hospital episodes were coded by ICD-9 or ICD-10. ICD-9 code set contains approximately 14,000 3-5 character codes for conditions arranged in 17 chapters (275). Two supplementary sections contain alpha-numeric 'E' or 'V' codes that describe external causes of, for example, injuries and poisonings, and the first digit of each code is either numeric or a letter (E or V), with digits 2-5 numeric (275). ICD-10 was a considerable revision and expansion on ICD-9, resulting in up to 32,000 3-7 alphanumeric character codes arranged in 21 chapters, with chapter 20 containing external causes of injury (196,276–278). The first character is a letter, characters two and three are numeric, and characters four to seven are alpha or numeric (196,276).

Studying patterns of hospital utilisation necessitated harmonising ICD-9 and ICD-10 systems to provide consistent disease coding over 30 years of data, a challenge given these systems were not designed to be cross-matched (279). One approach was to hand-match every possible code in ICD-9 and ICD-10, with significant disadvantages of time to achieve this and in producing thousands of categories, most of which would contain data too sparse to report.

Potential solutions using published algorithms were considered, such as the Charlson (280) or Elixhauser Comorbidity Indexes (281). Both systems used aggregated ICD diagnostic codes to establish categories of comorbidities, with the

Charlson and Elixhauser offering 19 and 31 categories (depending on versions used), respectively. Each Index applied weightings to categories, depending on the relationship between comorbidity and mortality, to produce overall burden of illness for individuals in longitudinal studies. However, both Indexes were designed for acute hospital records, and lacking mental health categories, e.g. one category of 'dementia' only for Charlson (280), with 'depression', 'psychoses', 'schizophrenia', 'alcohol' and 'drug abuse' for Elixhauser (279,281,282). I ruled out both systems for their poor utility in summarising mental health codes.

Searching for a comorbidity index brought me to the 'Clinical Classification Software' (CCS), part of a family of US-based software tools that offered a version for researchers doing longitudinal analysis (271,283). The CCS consisted of 260 broad categories including eleven categories for mental health conditions, and I made use of the single-level diagnosis CCS ICD-9-CM (clinically modified) 'special archival' version (283) and CCS ICD-10, (now unavailable), although more recent archived versions are still available (278).

### **3.2 Reference**

Dougall N, Lambert P, Maxwell M, et al. Deaths by suicide and their relationship with general and psychiatric hospital discharge: 30-year record linkage study.

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### **3.3 Paper 1 reprinted in full (reproduced with permission, not for further re-distribution or re-use)**

# Deaths by suicide and their relationship with general and psychiatric hospital discharge: 30-year record linkage study

Nadine Dougall, Paul Lambert, Margaret Maxwell, Alison Dawson, Richard Sinnott, Susan McCafferty, Carole Morris, David Clark and Anthea Springbett

## Background

Studies have rarely explored suicides completed following discharge from both general and psychiatric hospital settings. Such research might identify additional opportunities for intervention.

## Aims

To identify and summarise Scottish psychiatric and general hospital records for individuals who have died by suicide.

## Method

A linked data study of deaths by suicide, aged  $\geq 15$  years from 1981 to 2010.

## Results

This study reports on a UK data-set of individuals who died by suicide ( $n=16\,411$ ), of whom 66% ( $n=10\,907$ ) had linkable previous hospital records. Those who died by suicide were 3.1 times more frequently last discharged from general than from psychiatric hospitals; 24% of deaths occurred within

3 months of hospital discharge (58% of these from a general hospital). Only 14% of those discharged from a general hospital had a recorded psychiatric diagnosis at last visit; an additional 19% were found to have a previous lifetime psychiatric diagnosis. Median time between last discharge and death was fourfold greater in those without a psychiatric history. Diagnoses also revealed that less than half of those last discharged from general hospital had had a main diagnosis of 'injury or poisoning'.

## Conclusions

Suicide prevention activity, including a better psychiatric evaluation of patients within general hospital settings deserves more attention. Improved information flow between secondary and primary care could be facilitated by exploiting electronic records of previous psychiatric diagnoses.

## Declaration of interest

None.

Suicide is a significant public health concern in the UK and world-wide. Contact with healthcare providers affords opportunities to engage in suicide prevention and considerable interest exists in establishing predictive information on which individuals accessing healthcare services are most at risk. Consequently, studies have explored suicide after discharge from psychiatric hospitals, consistently reporting a peak incidence of suicide within 28 days,<sup>1–4</sup> and a quarter of deaths occurring within 3 months, of discharge.<sup>5</sup> Only a few studies considered suicide after discharge from pooled general and psychiatric hospital settings, highlighting that most people had been in contact with healthcare services in the year prior to death<sup>6,7</sup> and that an estimated 7% and 13% had been discharged within 1 month prior to death from general and psychiatric hospitals respectively.<sup>8</sup>

This study uses records of completed suicides in Scotland over a 30-year period to analyse patterns after last discharge by hospital type (general or psychiatric) and according to summary categories (psychiatric diagnosis or in a category of 'injuries or poisonings' coded at last general hospital episode). This UK-based study is one of the largest to be reported, and we aimed to identify whether there were potential alternative opportunities for suicide prevention.

## Method

### Study data

An extraction was made from the National Records of Scotland (NRS) deaths register for the period from 1981 to 2010 of deaths of people aged 15 years or older with underlying cause of death coded as suicide as a result of intentional self-harm (ICD-9 E950–959; ICD-10 X60–84, Y87.0).<sup>9,10</sup> The lower age cut-off was

selected as it follows other UK epidemiological studies of suicide.<sup>11–13</sup> Although it is conventional research practice to subsume deaths of 'undetermined intent' within an overall category of suicides, this study focused on those deaths that had sufficient proof of suicidal intent ('as a result of intentional self-harm'). The NRS data-set could have been increased in size by 39% by adding in deaths coded as 'undetermined events', however we had no problems associated with sparse data, a common feature of other suicide studies, and excluding undetermined events also ruled out any possibility of including 'false positive' data.

This study capitalises on Scotland's privileged position as one of a handful of countries that has digitised National Health Service (NHS) hospital records that are linkable by a unique patient-identifiable number (Community Health Index introduced in 1981).<sup>14</sup> Up to 30 years of hospital-episode data for all deaths by suicide was linked using the 'Scottish Morbidity Records' in-patient and day-case physical health episodes ('SMR01'), and in-patient and day-case mental health episodes ('SMR04'). Out-patient and maternity records were not included in the data-set.

Problems of data quality are a well-known limitation of administrative data sources – errors have the potential to arise, for instance, because of coding or transcription errors in the original production of data, and secondary researchers have little opportunity to identify or address errors. A review of the data revealed some anomalies that were likely to reflect data errors. For instance, a number of the hospital episodes stemming from individuals were erroneous and had to be excluded; some had the wrong linked hospital records, some records were duplicates, whereas others had valid records but contained month of



admission later than month of death, suggesting random Community Health Index or date transcription errors. Excluded records are reported within the study results.

### Data processing and variable operationalisation

Hospital episodes were coded on main and secondary diagnoses contained in ICD-9<sup>9</sup> from 1981 to 1996, with a change to ICD-10<sup>10</sup> from 1 April 1996. Each record contained a main diagnosis and up to ten possible secondary diagnoses. Summarising diagnostic information at hospital visits necessitated harmonising ICD codes to obtain consistent coding over time. We achieved this by collapsing ICD codes into broader, clinically homogeneous categories, using a tool called Clinical Classifications Software (CCS) on Windows 7 Enterprise. Clinical Classifications Software is part of a sponsored project by the US Agency for Healthcare Research and Quality and is available to download.<sup>15,16</sup> We used the ‘special archival’ single-level diagnosis version, aggregating all ICD-9 and ICD-10 diagnostic codes in our linked data-set into 260 CCS meta-categories.

The linkage between ICD codes and CCS summary codes required ICD codes to be stored in highly standardised formats. Therefore, as is common practice when working with administratively collected data, substantial cleaning of the original data was required to achieve this linkage (for example, of ‘main diagnosis’ ICD records across all data-sets, 68% of all ICD codes were re-processed in some manner to allow them to link with the ICD formats used in the CCS tool). Extended algorithms were written using Stata V11 on Windows 7 Enterprise, featuring tasks such as removing spaces and ‘wildcard’ indicators such as ‘X’, and changing when relevant the number of characters of detail, in order to achieve a standardised ICD format. The Stata software code used to do this (including the macros used to translate in turn from ICD to CCS codes) has been published by the research team so that it is available for other researchers. The code files are available at [www.dames.org.uk/docs/papers/appendices/smr\\_icd/](http://www.dames.org.uk/docs/papers/appendices/smr_icd/). These files have also been submitted to the UK’s ‘Administrative Data Liaison Service’ ([www.adls.ac.uk](http://www.adls.ac.uk)), which provides an online pool for software code relevant to processing administrative data.

Following this processing exercise, approximately 5% of the codes across the data-set could still not be successfully matched to relevant ICD standardised codes as used in the CCS tool; for instance 90% of these codes did not contain the expected alphanumeric values and the remaining 10% were conventionally formatted ICD codes but linked to no known ICD standard. Both patterns are consistent with data-processing errors at the point of data collection that might be regarded as occurring randomly.

From the available diagnostic information designated by the 260 CCS codes, we used relevant categories for psychiatric

diagnosis (CCS codes 65–75, corresponding to a broad category approximately equating to codes 290–319 from ICD-9 and chapter F, ICD-10). For self-harm we were restricted to using broad CCS proxy categories of ‘any injury or poisoning’. On SMR01, codes for ‘injury or poisoning’ generally appear as the main diagnosis code, equating to CCS codes 225–244, with external causes of harm (ICD-9 E-codes; ICD-10 X- and Y-codes) appearing only as additional secondary diagnoses, equating to CCS code 260. These codes include injury or poisoning of accidental origin as well as assault or self-harm. Although not ideal in terms of focusing specifically on self-harming behaviour, we decided to use these codes in establishing any relative differences between demographic groups.

Death record variables used included age, gender, marital status (married/cohabiting or not) and employment status (‘not in work’ or otherwise). We also obtained a linked Carstairs Index quintile variable, a local area-based measure of deprivation<sup>17</sup> that was available for the entire time span of the data-set. Values were individually assigned using the postcode recorded on the death certificate. Descriptive data analysis was used in summarising group characteristics and proportions of people who died after different time points post last hospital discharge. We used Stata V11 on Windows 7 Enterprise throughout.

This study was approved by Lothian Research Ethics Committee (No.10/S1103/31), the Privacy Advisory Committee (PAC) of NHS Information Services Division and the Registrar General of NRS. Caldicott Guardian approval was granted as part of the PAC approval.

## Results

### Overall cohort characteristics

The study time span, 1981–2010, covered 16 475 deaths by suicide, consisting of 12 162 (74%) males and 4313 (26%) females. There was a time-lag between deaths recorded and being linked to hospital records; therefore we truncated the data-set at the end of 2009, leaving 16 411 individuals for further analysis, of whom 5275 had no linked hospital records and 229 died in hospital having no previous admission records, leaving 10 907 people with a last discharge alive (Table 1).

Individuals who died by suicide with hospital records were predominantly male (72%); had a mean age of 43; more frequently living alone (63%); had a mean Carstairs quintile of 3.3 (slightly more deprived areas than population average); and 20% were not in work. Gender interacted with other measures: males were significantly younger at death than females, and significantly more women (34%) were not in work compared with men (15%).

**Table 1** Characteristics of people who died by suicide in Scotland 1981–2009 (*n* = 16 411) with and without hospital records (in-patient or day-case episodes)

	People with hospital records and alive at last hospital discharge			People with no hospital records or who had one hospital record where the outcome was death		
	All	Men	Women	All	Men	Women
Deaths, <i>n</i> (%)	10 907 (100)	7842 (72)	3065 (28)	5504 (100)	4270 (78)	1234 (22)
Age at death, years: mean (s.d.)	43.3 (16.8)	42.1 (16.4)	46.2* (17.2)	43.4 (16.8)	41.8 (16.1)	48.8* (18.2)
Married or cohabiting at death, %	37.2	37.0	37.6	43.3	43.1	44.1
Carstairs Index, mean <sup>a</sup>	3.27	3.27	3.27	3.16	3.14	3.23
Not in work, <sup>b</sup> %	20.0	14.5	34.1*	14.3	9.0	32.6*

a. The area-based Carstairs index of deprivation quintiles (1991): 1, low deprivation to 5, high deprivation.  
 b. National Records of Scotland categories of ‘Students, independent means, no occupation, disabled’.  
 \**P* < 0.05 significant differences by gender at 95% threshold.

Comparison of people with and without previous hospital records revealed further differences (Table 1). Men had accessed secondary-care services less often than women (72% of deaths with previous hospital records were men, compared with 78% of deaths without previous records). In addition, people with hospital records had more frequently been living alone than those without such records (63% v. 57%) and higher proportions of men with records were not in work compared with those without records (15% v. 9%).

### Suicide patterns in relation to last discharge from pooled hospital settings

The 10 907 people with psychiatric or general hospital records prior to death had a total of 66 188 records. This figure was arrived at having removed 362 records with admission dates after the death dates; 1016 records for being exact duplicate records of another episode and 2002 records where the outcome was death in hospital. The 66 188 records comprised 23% psychiatric hospital records, however total population data from NHS Information Services Division estimates that 32.8 million hospital records were created nationwide over the same time span, of which only 3% were psychiatric records.

Substantially more people who died by suicide were last discharged from general rather than psychiatric hospitals – we identified the last hospital discharge record for each of the 10 907, defining categories for those who had last been in general hospital ( $n=8263$ , 76%) or in psychiatric hospital ( $n=2270$ , 21%). A further 374 people had ‘tied’ records, meaning they had both general and psychiatric hospital admissions and transfers between hospitals within the same last continuous period of care (Table 2).

Of 16 411 deaths overall, 50% had a last discharge from general hospital, 16% had a last discharge that included a psychiatric hospital record and 34% had no prior hospital records. A total of 16% of all deaths by suicide had occurred within 3 months of last discharge from any hospital ( $n=2575/16\,411$ ), a figure which amounts to about a quarter of all deaths among previous hospital patients ( $n=2575/10\,907$ , 24%) in the same period. Of all deaths, 9% ( $n=1487/16\,411$ ) had been discharged within 3 months from a general hospital, and a further 7% ( $n=180+908/16\,411$ ) had been discharged within 3 months from a psychiatric hospital (including combined settings). Similarly, 32% of all deaths in Scotland by suicide were of those who had been discharged from a hospital within the last year prior to death ( $n=5178/16\,411$ ); three-fifths of these ( $n=3312$ ) happened after general hospital discharge and did not involve a linked psychiatric episode.

Of the whole population who died by suicide, about half of all male and female deaths occurred after last discharge from general

hospital (51% and 49% respectively). However, around 14% of male compared with 22% of female deaths had occurred after last discharge from psychiatric hospital (or a continuous episode of care of both a general and a psychiatric hospital). This disparity may well reflect that higher numbers of women are generally admitted to psychiatric hospital in the first place, but may nevertheless be indicative of how suicide prevention efforts should be sensitive to differences between the experiences of men and women in the hospital system.

### Last discharge from general hospitals with a diagnosis of injury or poisoning

Given the high volume of deaths arising after a last discharge from general hospitals, we set out to provide high-level summaries of whether people with a last discharge alive from a general hospital had been diagnosed with ‘injury or poisoning’, an aggregate category of assaults, accidents and self-injuries.

Less than half of all individuals ( $n=3179$ , 38%; Table 3) who died after last discharge from general hospital had been given a main or any secondary diagnosis of ‘injury or poisoning’, of whom 22% ( $n=705$ ) had completed suicide within 3 months of last discharge, 33% ( $n=1047/3179$ ) by 6 months and two-thirds ( $n=2154$ ) within 1 year of last discharge.

Young men were the most prominent group in this category: men aged 15–45 comprised by far the largest category of people who died after a last discharge with a diagnosis of ‘injury or poisoning’ in general hospital (60% of all deaths,  $n=1917$ ). By comparison, 19% of deaths from this group were of men aged over 45; whereas 13% were of women aged 15–45 and 9% were women over 45 (Table 3).

Among those deaths that occurred after last discharge from general hospital, we found that 62% ( $n=5125/8263$ ) had previously received a diagnosis of ‘injury or poisoning’ in any of their previous hospital records over their lifetime (within the observation period 1981–2009). Indeed, of those with a last discharge following a diagnosis of ‘injury or poisoning’, 41% ( $n=1313/3179$ ) had either a psychiatric disorder recorded at last hospital visit, or had a psychiatric diagnosis included at any time previously in their hospital records.

It seems likely therefore that there is potential to identify an at-risk population in general hospital settings where prevention work or mental health assessment could take place for those not being currently admitted for ‘injury or poisoning’ but who have had any previous lifetime record for ‘injury or poisoning’ or psychiatric disorder (or both), and would otherwise appear as ‘invisible’ to healthcare staff at time of any current admission.

Comparing demographic data for those with a last diagnosis of injury or poisoning (Table 3) with all deaths that had linked hospital records (Table 1), we found that slightly lower

**Table 2** The nature of last recorded hospital discharge prior to suicide, Scotland 1981–2009

	All suicides, <i>n</i> (%)	Males, <i>n</i> (%)	Females, <i>n</i> (%)	Suicides within 3 months of discharge, <i>n</i> (%)	Suicides within 6 months of discharge, <i>n</i> (%)	Suicides within 12 months of discharge, <i>n</i> (%)
Last discharge from psychiatric hospital	2270 <sup>a</sup> (14)	1458 (12)	812 (19)	908 (35)	1254 (33)	1581 (31)
Last discharge from general hospital	8263 <sup>a</sup> (50)	6151 (51)	2112 (49)	1487 (58)	2295 (61)	3312 (64)
Last discharge month included psychiatric and general hospital episodes	374 (2)	233 (2)	141 (3)	180 (7)	237 (6)	285 (6)
No prior hospital records	5504 (34)	4270 (35)	1234 (29)	–	–	–
Subtotals	16 411 (100)	12 112 (100)	4299 (100)	2575 (100)	3786 (100)	5178 (101)

a. Those with prior hospital records were 3.6 times more frequently among those discharged from general ( $n=8263$ ) than from psychiatric hospitals ( $n=2270$ ); or 3.1 times more frequently if ‘tied’ records are subsumed in a category of psychiatric hospital discharges ( $n=2644$ ).



**Table 3** Analysis of those with a main diagnosis of ‘injury or poisoning’<sup>a</sup> (including self-harming behaviour) at last discharge alive from general hospital prior to suicide (Scotland 1981–2009)

	Deaths with last discharge from general hospital with a diagnosis of ‘injury or poisoning’, <i>n</i> (%)	Deaths with a diagnosis of ‘injury or poisoning’ as % of all deaths with last discharge from general hospital, % ( <i>n</i> = 8263)
All	3179 (100)	38
Gender		
Males	2490 (78)	30
Females	689 (22)	8
Age, years		
Males, 15–45	1917 (60)	23
Males >45	617 (19)	7
Females 15–45	421 (13)	5
Females >45	283 (9)	3
Suicides by time of discharge from general hospital		
Within 3 months	705 (22)	9
Within 6 months	1047 (33)	13
Within 12 months	2154 (68)	26
Any psychiatric disorder at last hospital visit or previous point in lifetime	1313 (41)	16
Married/cohabiting	972 (30)	12
Not in labour market <sup>b</sup>	658 (21)	8
In most deprived Carstairs Index quintile (quintile 5)	913 (29)	11

a. ‘Injury and poisoning’ diagnosis derived from Clinical Classification Software categories 225–244 and 260, consisting of injuries or poisonings that could be a result of self-harm, accident or assault, coded on main diagnosis or any secondary diagnosis.  
b. National Records of Scotland categories of ‘Students, independent means, no occupation, disabled’.

proportions were cohabiting than not (30% compared with 37% respectively); but there were no other noticeable differences.

### Last discharge from general hospitals and psychiatric morbidity prevalence

Psychiatric disorders may also be relevant to suicide patterns for those with a last discharge from general hospital. We found that 14% of all those who completed suicide after last being discharged from general hospital had a psychiatric disorder recorded at the last hospital episode (either as a main or secondary diagnosis). This group had a median time to death of 7 months from last discharge, suggesting that this is an important risk indicator (Table 4).

The category of people who had no psychiatric disorder recorded during their last (general hospital) episode, but did have a psychiatric disorder recorded at some point previously in their lifetime amounted to 19% (*n* = 1597/8263) of those last discharged from general hospital, of whom 30% (*n* = 450/1487) died within 3 months of last discharge, and the overall median time until death was 9 months. This indicates that in many instances where a person is admitted to a general hospital, a prior record of psychiatric disorder may be a relevant indicator of suicide risk.

On the other hand, 67% of those last discharged from general hospital had no psychiatric diagnosis ever recorded anywhere in their hospital records. In contrast to the first two groups, this group had a much longer median time between discharge and death (33 months).

To reiterate: those last discharged from general hospital with the shortest median time until death (7 months) were those who had a recorded comorbid psychiatric diagnosis at last hospital visit, followed by those who did not have a recorded psychiatric diagnosis at last general hospital visit but did have a diagnosis previously within their lifetime (median time to death of 9 months).

The same proportion of men and women had psychiatric disorders recorded at last general hospital visit (14%; Table 4). However, substantially more men than women who died after a recorded hospital episode had no psychiatric disorders recorded at any point in their lifetime (69% v. 60%; Table 4), whereas fewer men (17%) compared with women (26%) had no psychiatric disorder recorded at last visit but did have a previous psychiatric disorder along the life course, patterns that would be consistent of a relative underrepresentation of men in accessing hospital psychiatric services. Although we had expected to see an increase in hospital records with age in line with a cumulative diagnostic accrual along the lifespan, we found that the proportion of males

**Table 4** Psychiatric morbidity of those with a last discharge from general hospital prior to suicide (Scotland 1981–2009)<sup>a</sup>

Time psychiatric disorder recorded	<i>n</i> (%)					Months from last discharge to death Median (IQR)
	All	Males	Females	Males 15–45 years	Suicide within 3 months of discharge	
Recorded at last hospital visit	1126 (14)	833 (14)	293 (14)	543 (14)	365 (25)	7 (3–24)
Recorded, but not at last visit	1597 (19)	1053 (17)	544 (26)	656 (17)	450 (30)	9 (3–24)
None recorded at any time in lifetime	5540 (67)	4265 (69)	1275 (60)	2687 (69)	672 (45)	33 (9–81)
Subtotals	8263 (100)	6151 (100)	2112 (100)	3886 (100)	1487 (100)	20 (6–60)

IQR, interquartile range.  
a. Psychiatric diagnoses derived from Clinical Classification System categories 65–75, broadly equates to codes 290–319 from ICD-9 and Chapter F, ICD-10.

aged 15–45, who were last discharged from general hospital with no psychiatric disorder, was identical (69%) to the aggregate category of all males with no psychiatric disorder.

Lastly, Fig. 1 shows the percentage of suicides occurring within different time spans since last discharge from general hospitals (recorded in SMR01) or from psychiatric hospitals (recorded in SMR04). Although fewer suicides involve last discharge from a psychiatric hospital, the temporal pattern suggests that most suicides involving people discharged from such facilities occurred in relatively shorter time periods since the last discharge. This is in contrast to the pattern of suicide following discharge from a general hospital, where relatively more deaths occur at longer intervals since the last recorded discharge. This is not so surprising if admission/readmission patterns to hospital are related to suicide risk and merits further analysis of hospital utilisation patterns prior to suicide.

## Discussion

### Main findings

This study reports on a large linked UK data-set of individuals who died from suicide, spanning 1981–2009. One-third of those who died by suicide had no previous hospital records whatsoever (although there is the possibility of previous hospital admissions in another country), and half of all deaths by suicide were of people who had been last discharged from general hospital.

Deaths by suicide in individuals with hospital records were more than three times more frequently last discharged from a general hospital than a psychiatric hospital. This was higher than anticipated, but is perhaps not that surprising since there are many more admissions to general than psychiatric hospital among the national population. It is revealing however, to compare the time spans between discharge and death in relation to last discharge type; many deaths occurred relatively soon after a previous discharge from either category, suggesting opportunities for intervention may exist in both settings. Examination of diagnoses revealed that less than half of those last discharged from general hospital had received a diagnosis of ‘injury or poisoning’;

potentially suggestive of subsequent self-harm, with more than half of these being younger men.

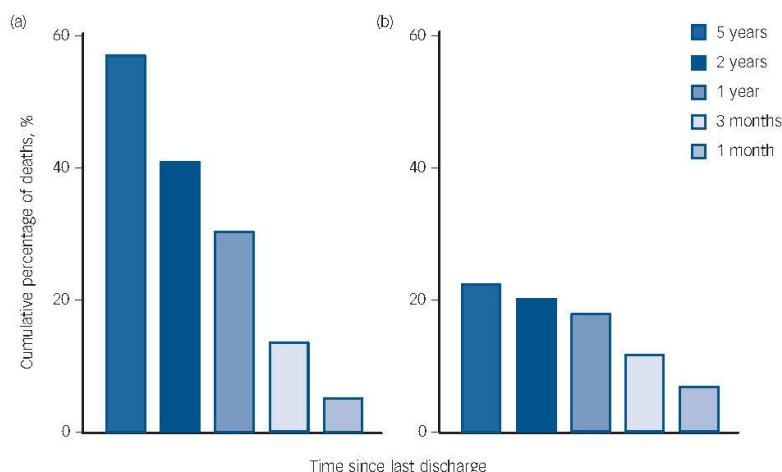
Despite having died by suicide, we found only a small minority (14%) had a recorded comorbid psychiatric diagnosis at last general hospital visit, but that an additional 19% had received a previous psychiatric diagnosis during their lifetime; the median times to death when there was a psychiatric diagnosis at last discharge was 7 months, and 9 months for those with any previous psychiatric history; this was in marked contrast to 33 months for people who had no (hospital) psychiatric diagnosis history whatsoever.

### Limitations of the study

The general hospital data-set (SMR01) permits identification of individuals transferred to other NHS hospitals and psychiatric facilities but does not allow for capturing hospital episodes of people who present to accident and emergency departments and who subsequently self-discharge or who are not then admitted to hospital. Therefore it is likely that there is an underrepresentation of people in crisis in the data-set who have presented to hospital; the numbers dying by suicide after contact with general hospitals are likely to be higher than this analysis suggests.

This study does not link to primary care or hospital out-patient data. An analysis of all secondary- and primary-care linked records would have provided a more comprehensive approach in summarising healthcare contacts prior to suicide; however, this was beyond the scope of this study. The data used for this study do not contain deaths deemed to be ‘events of undetermined intent’ and we recognise that in ruling out possible ‘false positive’ suicide deaths, we have potentially missed many additional genuine records (estimated as an additional 6640 individuals for the time span 1981 to 2010; see NRS official statistics, [www.gro-scotland.gov.uk/statistics/theme/vital-events/deaths/suicides/index.html](http://www.gro-scotland.gov.uk/statistics/theme/vital-events/deaths/suicides/index.html)).

With respect to using the broad category of ‘injury or poisoning’, this approach was suboptimal as a proxy for self-harm as the data were conflated with all accidents and assaults. However, this makes the low numbers of people last discharged from a general hospital with a diagnosis of ‘injury or poisoning’ even more surprising. There remains potential to use more detailed



**Fig. 1** Temporal patterns of suicide after last discharge alive from (a) general hospital or (b) psychiatric hospital, expressed as % of all suicides ( $n = 10\,907$ ).

Data are included in (a) if the last hospital record was coded general hospital (SMR01) and included in (b) if the last hospital record was coded psychiatric hospital (SMR04) or if it was a tied record, i.e. admitted to general hospital (SMR01) and transferred to psychiatric hospital (SMR04) in continuous episodes of care.



ICD information (rather than the CCS categories used) in a future analysis, such as to focus on self-harm only.

We did not restrict the data time span so as to permit an accrual of hospital records for those who died early in the 1980s and soon after the data-set capture of hospital records. This means that the prior hospital episodes of some cases are left-censored (if they had prior episodes before 1981). Such imbalances would be quite typical of any practical system that tried to use administrative data to enhance decision-making, for which reason we think it was appropriate to conduct the analysis in terms of deaths since 1981 and their relationship to hospital records since 1981. We also note that our data included months as the most detailed time point for an episode – this raised practical, but not insurmountable, problems in determining the last episode (if more than one episode was held in the same month), although again this is commensurate with the sort of data resources that might be pragmatically available. In addition, there may be significant disclosure risks were data provided identifying exact dates of hospital episodes and deaths.

Finally, for operational reasons the data-set we used was restricted to deaths by suicide. Although a strength of the data is the nationwide coverage (with no inherent selection bias), this was a single group study, and in further work a comparison of this group with other non-suicide cohorts or case-controls has obvious attractions and could yield important information on relative risks.

### Comparison with previous studies

Studies exploring suicide patterns after last discharge from pooled clinical settings are relatively scarce and most do not have control groups. Where studies exist, these tend to focus on patterns after discharge from psychiatric facilities, after episodes of self-harming behaviour, or in estimating the number and frequency of contacts with health services in the time prior to suicide. Analyses suggest that at least 80% of people who die by suicide had some contact with healthcare services in the year prior to death,<sup>6,7,18</sup> with more than double the number of contacts being made for those who died by suicide compared with those who did not;<sup>7</sup> however, it remains unclear whether these contacts with healthcare services had a role in suicide prevention by delaying the event.

Andersen *et al* pooled hospital and primary care records in Denmark to report that within the last month before death, 66% had consulted a general practitioner and 7% and 13% had been discharged from general and psychiatric hospitals respectively.<sup>8</sup> We report a different pattern to that of Andersen *et al*, namely that in the 3 months before death, 9% and 7% had been discharged from general and psychiatric hospitals respectively. These differences could in part be explained by the much smaller sample size in the Andersen *et al* study ( $n=472$ ) but could also be a feature of the data time span, which was restricted to the early 1990s, a period during which many European countries replaced older psychiatric institutions with community mental health services.

We also found that the percentage of deaths from suicide after last discharge from general hospital continued to rise over time, in a different pattern to that after admission to a psychiatric hospital, which appeared to decrease in a more exponential pattern with time since discharge, a pattern reported elsewhere.<sup>19</sup> Considering only those deaths by suicide following last discharge from psychiatric hospitals, a peak incidence of suicide occurred within the 3 months following discharge, in agreement with other studies that report peak incidences within a month after discharge.<sup>1–4,20</sup> However, a report from Sweden suggests that the majority of deaths with psychiatric diagnosis had been discharged from

psychiatric treatment for more than 1 month before suicide<sup>21</sup> and that ‘doctor shopping’ behaviour can vary markedly by age and gender with, for example, women’s contact with psychiatrists increasing during the year prior to suicide then dropping significantly shortly before suicide.<sup>22</sup>

### Future research

An analysis of data incorporating other healthcare records (for example primary care, emergency department, ambulance service) would offer a more comprehensive understanding of patterns of service utilisation. Although this study summarises only secondary-care records, there are initiatives in pooling data sources, creating richer sources of information that may afford opportunities to glean further insights.<sup>23</sup> Data-sets such as the one used in this analysis are rich sources of information and yield further opportunities in, for example, summarising morbidity burden, prevalent diagnoses along the life course, temporal patterns in suicide or in making more use of individual-level data such as ICD codes for self-harm or occupation held in the death record.

Further exploration of reasons why relatively more men than women who die by suicide have no psychiatric records is warranted, and also whether this apparent underrepresentation of men accessing hospital psychiatric services is related to gender differences in help-seeking behaviour within primary care.

### Implications for practice

This study highlights that engaging in suicide prevention within the general hospital setting deserves much more attention. Targeted follow-up of people admitted to general hospital with self-harm diagnoses (in particular younger men), and screening for psychological problems in those where there has been either a history of self-harming or of any psychiatric condition along the life course could be beneficial. This would require making better use of historical and electronic health records and ensuring all hospital staff could engage in some first-line mental health screening in these ‘at risk’ patients.

Although we found that the majority of people discharged from general hospital had no recorded psychiatric morbidity in hospital records, this does not preclude the possibility of psychiatric problems being managed exclusively in primary care. There is potential for better information flow from primary to secondary care (such as relevant episodes of depression or anxiety) to yield useful additional clinical insights, which could be particularly relevant for unscheduled admissions. Many of the people in the study had no hospital records at all, which also highlights the need for adequate community and primary care mental health resources.

In summary, we report that higher percentages of people died by suicide after 3, 6 and 12 months after last discharge from general than from psychiatric hospitals. Less than half of these had a main diagnosis of ‘injury of poisoning’, a category in which young men were most affected. The median time to death was about fourfold longer for those without any current or previous psychiatric history. More could be done in engaging with suicide intervention, psychiatric evaluation and follow-up of people who are admitted to general hospitals with self-harm history or psychiatric comorbidity, past or present.

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### **3.4 Statement of personal contribution**

This paper was the culmination of almost two years study, and stemmed from a demonstration data linkage project for the Economic and Social Research Council funded 'Data Management through e-Social Science' (DAMES) (197). In producing this paper a number of contributions were made. I identified the evidence gap in the literature and conceived the idea for this paper, and collaborated with NHS ISD and colleagues in the National e-Science Centre to deliver the demonstration linkage. I reviewed and identified the methodological approaches taken, and implemented the cross-mapping and harmonisation of ICD codes using CCS software. I trained in advanced longitudinal data analysis using Stata, and in using linked health datasets, (see Appendix, Table 1, section 10.1). I worked jointly with Prof Paul Lambert on data analysis, and finally, I drafted the manuscript and subsequent iterations, and all co-authors had opportunity to comment. I now provide more context to the contributions.

The study had two aims as part of the DAMES project (197). The first aim was to link as much information as possible from databases, for example, education, geospatial, Census, primary care or social care data, using e-Science infrastructures available at the time (226). In doing so, it would maximise available information on those who have died by suicide. In extended discussions with data providers, there was a great deal of interest in making data available but this was impossible in practice. Data were too difficult to access as the processes and governance were not in hand (e.g. education), or were strictly for government statistics only, unless legislative reasons existed otherwise (Census). Primary care data was evolving from General Practice Administration System for Scotland (GPASS) to heterogeneous inaccessible commercial solutions, or data contained overly disclosive free text (social care).

The Scottish Longitudinal Study (SLS) was a highly promising new option, a large-scale linked dataset of 5% of the general population from the Census, education and vital events data (284). It was possible to request linkage of SLS to hospital data. However, with deaths by suicide numbering around 7-800 per year, 5% of this number cross-tabulated with other data would provide very small, overly disclosive numbers and I ruled out use of SLS.

For similar reasons of small numbers, the British Household Panel Survey (BHPS) (285) and the Scottish Health Survey (SHeS) (286) could not be used linked to death registrations. However, I linked BHPS and SHeS on variables, used this as an online Economic and Social Data Service (ESDS) exemplar, and presented at the Health Survey User's Meeting as 'Factors associated with people who self-rate as having psychosocial distress, risk of future unemployment, and the effect of GP consultations' (see table 3.6, and <https://slideplayer.com/slide/786508/>).

The second aim of the DAMES project was to provide an exemplar of linking data remotely using secure 'VANGUARD' technology (226,231,232), in collaboration with the National e-Science Centre (NeSC). To do this, each data provider would permit NeSC access via respective firewalls to collect data, and link securely and anonymously on the NeSC server. Researchers would access the data via Virtual Private Network (VPN).

The formal request to do this arose at a time when the Scottish Health Informatics Programme (SHIP) was just getting going, and SHIP were using a different model in the form of physical Safe Havens (209) with pre-specified research questions approved by the Privacy Advisory Committee (PAC). The two systems were at odds, and the demonstration linkage could not be completed in the intended way. Furthermore, the PAC approval process required pre-specification of each variable on the application tied to Research Questions (RQs). Therefore, even if NeSC could have linked all possible datasets, the approval process ruled out potential to generate inductive hypotheses from data patterns.

Instead of the NeSC demonstration linkage, eDRIS provided the data to me instead, as *unlinked* hospital and deaths data sets. This permitted me to link these on a PC using Stata, a procedure that was relatively straight forwards with the CHI indexing system.

### **3.5 Contribution to science**

One of the main themes in suicide research is whether 'at risk' populations can be identified to focus earlier suicide prevention activity. This first paper advanced research in this theme by profiling hospital data linked to thirty years of deaths by suicide registrations in Scotland, and using methodological approaches described



in Chapter two, in linking and analysing routine data. Summarising codes between ICD-9 and ICD-10 catalogues was achieved for the first time in UK health data using 'Clinical Classification Software' (CCS; see paper). This paper was the first UK paper to report on hospital utilisation data prior to suicide from *pooled* clinical settings of general and psychiatric hospitals. Indeed, very few studies exist in the international literature on this topic area.

### **3.5.1 Altmetric score**

The Altmetric Attention Score is an estimated weighted approximation of the attention a research paper receives (287). Scores may reflect positive and negative attention. The score for this paper was 122, scoring higher than 98% of its peers and in the top 5% of all research outputs ever tracked by Altmetric. In terms of outputs from the British Journal of Psychiatry, this paper scored higher than 97% of its peers. See <https://cambridge.altmetric.com/details/2084942#score>

### **3.5.2 NICE Briefing paper qs189 for suicide prevention**

In 2019, the Health & Social Care Directorate of the National Institute for Health and Care Excellence (NICE) produced a briefing paper on Quality standards and indicators for Suicide Prevention. The briefing paper presented an overview of prioritised quality improvement areas for development. The Royal College of Psychiatrists presented evidence from this paper one for two sections of the briefing paper; firstly, reducing access to methods of suicide (point 53), and secondly, in identifying people at risk (point 66).

The NICE briefing paper may be accessed here:

<https://www.nice.org.uk/guidance/qs189/documents/briefing-paper>

### **3.5.3 Farr Institute / HDRUK '100 Ways' case study**

The Health Research Data UK, formerly known as The Farr Institute of Health Informatics Research, produced a series of 100 case studies showcasing the UK's most significant examples of using data in research. The aim of these case studies was '...to promote the safe and trusted use of data in research and raise

awareness of its benefits to patients and the public.' Paper one was published as Case Study 11 in October 2016 (see overleaf).

The Farr Institute of Health Informatics Research '100 Ways of Using Data to Make Lives Better' is available to download from:

[https://www.researchgate.net/publication/308889563\\_Farr\\_Institute\\_Case\\_Study\\_11\\_Dougall\\_Can\\_Data\\_Be\\_Used\\_To\\_Help\\_Prevent\\_Suicides](https://www.researchgate.net/publication/308889563_Farr_Institute_Case_Study_11_Dougall_Can_Data_Be_Used_To_Help_Prevent_Suicides)



# 100 Ways of Using Data to Make Lives Better

A series from The Farr Institute of Health Informatics Research showcasing the UK's most significant examples of using data in research

## Can Data Be Used to Help Prevent Suicides?

A team of researchers from The Farr Institute in Scotland analysed data to see if there is a relationship between people committing suicide and the last time they visited hospital.



Nadine Dougall, Prof Paul Lambert, Prof Margaret Maxwell and Dr Alison Dawson, University of Stirling  
Prof Richard Sinnott and Susan McCafferty, National e-Science Centre, University of Glasgow  
Carol Morris, David Clark and Dr Anthea Springbett, NHS Information Services Division, Edinburgh

Public Health  
Case Study 11

### The Challenge

Suicide is tragically the leading cause of death in young people in the UK. Men are affected three times more than women and more people die each year by suicide than by road traffic accidents.

Whether people who die by suicide had recently attended general or psychiatric hospitals, or whether they have a history of mental ill-health isn't often known. By looking at hospital records and the last hospital visit of individuals who died by suicide, scientists can identify the people who are most at risk and also where action can be taken to reduce the number of people losing their life in this way.

### The Research

Three decades worth of suicide records in Scotland, from 1980 to 2010 for those aged 15 or over were linked to hospital records. The data was made anonymous before being studied in a safe and trustworthy way. Permission was granted from the NHS to verify that the data was being used in the public's best interest and that the researchers were qualified to access it.

### The Results

The results showed that more were discharged from general hospitals than psychiatric hospitals before they committed suicide. Many of these deaths occurred soon after people left hospital which suggests that there could be missed opportunities to prevent some suicides from happening.

Two thirds of the 16,411 suicides studied could be linked to hospital records and were examined to see what treatment individuals had received before they took their own life.

A quarter of people committed suicide within three months of the last time they were discharged from hospital and only 14% of those

discharged from a general hospital had a diagnosed mental illness recorded in their medical records during last visit. One in five of these people had a previous history of mental illness that had not been recorded.

### The Impact

The research will help improve activities and training in hospitals that can prevent some suicides from happening. It showed that by making better use of health records, hospitals could follow-up with patients who have self-harmed, in particular young men, and assess those who have a history of self-harming or of mental illness.

This work was presented to The Farr Institute's NHS Benefits Realisation Taskforce as an example of the benefits that using data in research can provide for patients. This group assesses how the Institute's work in Scotland is supporting safe and effective improvements to health and care for patients.

It was also presented at a House of Commons event run by the All-Party Parliamentary Group for Medical Research to highlight the importance of using data in medical research.

As well as being reported by The Independent, the research was referred to by Royal College of Psychiatrists, the professional body responsible for managing standards in psychiatry, as a study that "prompts call for better suicide prevention activity in general hospitals".

For more information about suicide prevention visit [www.healthscotland.com/topics/health/suicide/index.aspx](http://www.healthscotland.com/topics/health/suicide/index.aspx)

Enquiries to Cherry Martin, Communications Manager, The Farr Institute of Health Informatics Research, [cherry.martin@ed.ac.uk](mailto:cherry.martin@ed.ac.uk)



Produced by The Farr Institute of Health Informatics Research

[www.farrinstitute.org](http://www.farrinstitute.org)

### 3.5.4 House of Commons All Party Parliamentary Group (APPG)

Findings of paper 1 were presented to the APPG at the House of Commons. University of Stirling published a short article, reproduced below.

Link: <https://www.stir.ac.uk/news/2016/07/researcher-takes-study-to-house-of-commons/index.html>

#### **Researcher takes suicide prevention study to House of Commons**

**13 July 2016**

Nadine Dougall of the Nursing, Midwifery and Allied Health Professions Research Unit at the House of Commons

A leading health science researcher from the University of Stirling visited the House of Commons to answer questions from MPs and Lords on using patient data to help identify where suicide prevention activities would be best introduced.

Nadine Dougall, Senior Lecturer in the Nursing, Midwifery and Allied Health Professions Research Unit, led a [study](#) which looked at patient data in Scotland and revealed that general hospitals should engage in more mental health screenings and follow-up with at-risk individuals.

The study was presented at an All-Party Parliamentary Group Event, *Can patient data revolutionise healthcare*, to exemplify what can be done with patient data to provide a more comprehensive level of care within the NHS.

The research, published in the British Journal of Psychiatry, studied all deaths by suicide in Scotland in people aged 15 and over between 1981 and 2010. Of the 16,411 suicides, almost two thirds had linkable hospital records.

Surprisingly, the data revealed that more than half the people who died within three months of last discharge did so after admission to general hospital.

Working with the [MQ Data Science Group](#), Ms Dougall shared the opinion of experts from across the UK with MPs and Lords, revealing the challenges involved in accessing and sharing patient data.

These include the fact there is no unified, standardised national register for mental health patients and different datasets are kept in different settings, each with its own unique access procedure.

Ms Dougall said: "Using historical and electronic health records in research is crucial to saving lives and improving the service patients receive from the NHS. In the UK all data is stored securely and every patient has been allocated a confidential NHS number. However, these records can be better utilised in many different ways, including that of guiding suicide prevention work.

"The data currently held on all NHS patients has a significant role to play in saving peoples' lives, if we can access and assess it properly. We have now been able to provide parliament with a better understanding of the opportunities for suicide intervention, and of the challenges in accessing patient data in secure settings."

### 3.5.5 RCPsych Press release and media

The Royal College of Psychiatrists press release:

The screenshot shows the RCPsych website with the following elements:

- Header:** Navigation links for 'About the College', 'Membership', 'Job Board', 'Policy', 'Media centre', 'Donate', 'Contact us', and 'My RCPsych'. A search bar and 'Quick links' are also present.
- Logo:** RCPsych logo with the tagline 'Improving the lives of people with mental illness'.
- Navigation Menu:**
  - DISCOVER PSYCHIATRY (Key facts about psychiatry)
  - TRAIN IN PSYCHIATRY (Training, exams & events)
  - WORK IN PSYCHIATRY (Supporting members and services)
  - USEFUL RESOURCES (Access our shop & tools)
  - HEALTH ADVICE (Information about mental health)
- Main Content:**
  - Section: 'Royal College of Psychiatrists'
  - Sub-section: 'Discover Psychiatry'
  - Article Title: 'Study prompts call for better suicide prevention activity in general hospitals'
  - Date: 'Embargoed until 30 January 2014'
  - Text: 'More attention needs to be paid to suicide prevention in general hospitals, according to a new study published in the *British Journal of Psychiatry*.'
  - Text: 'The research team, led by Nadine Dougall of the University of Stirling, studied all deaths by suicide in Scotland in people aged 15 and over between 1981 and 2010. Of the 16,411 suicides, 66% (10,907) had linkable hospital records.'
  - Text: 'The researchers found that people who died by suicide were three times more likely to have been last discharged from general hospitals (8,263 deaths) than from psychiatric hospitals (2,644 deaths). Overall, a quarter of deaths (2,575) occurred within three months of people being discharged from hospital (and 58% among those people discharged from a general hospital).'
- Right Sidebar:** 'LOGIN' button and a 'Make a donation' call to action with an image of a hand dropping a coin into a slot.

The screenshot shows a Twitter post from the account @rcpsych:

- Profile:** RC of Psychiatrists @rcpsych, marked as 'Following'.
- Text:** 'New study in BJPpsych calls for better #suicide prevention activity in general hospitals [rcpsych.ac.uk/mediacentre/pr...](http://rcpsych.ac.uk/mediacentre/pr...)'
- Engagement:** 28 Retweets, 9 Favorites.
- Time:** 3:46 AM - 30 Jan 2014.
- Replies:**
  - Disability Forum S/E @BasildonForum - Jan 30:** '@rcpsych I attempted and was taken to A+E after general tests I was told now don't be silly life is for living and was discharged'
  - Nadine Dougall @nadinedougall - Jan 30:** '@rcpsych thanks for tweet about our research [m.bjp.rcpsych.org/content/early/...](http://m.bjp.rcpsych.org/content/early/...)'
  - Dr Alys Cole-King @AlysColeKing - Jan 30:** '@nadinedougall: @rcpsych thanks for tweet about our research [m.bjp.rcpsych.org/content/early/...](http://m.bjp.rcpsych.org/content/early/...)...Very important research. Vital ED staff have training.'

## The Independent online:

THE INDEPENDENT FRIDAY 25 JULY 2014



Santander  
Driven to do better.

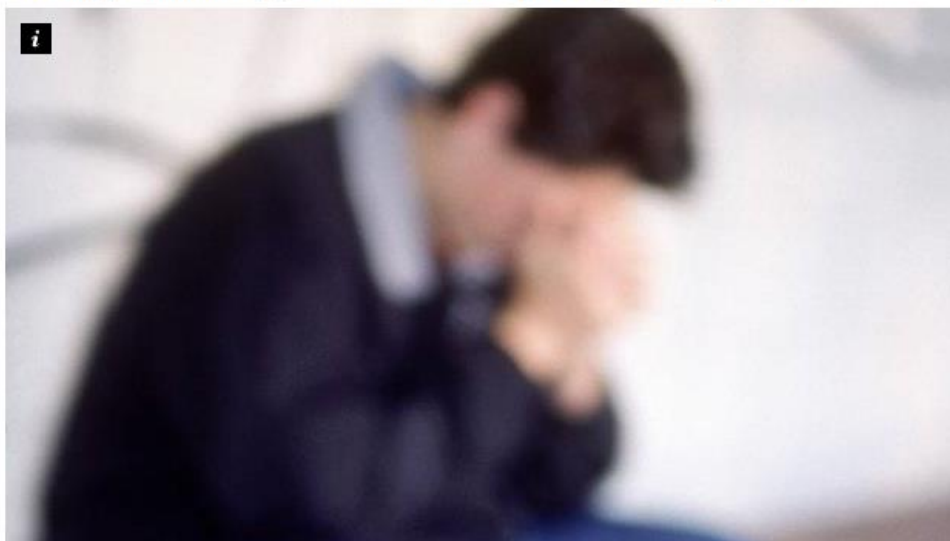
1|2|3 CURRENT  
ACCOUNT  
JUST £2 A MONTH

NEWS IMAGES PEOPLE VOICES SPORT TECH LIFE PROPERTY ARTS + ENTS TRAVEL

Fashion v / Food & Drink v / Health & Families v / History / Gadgets and Tech v / Motoring v / Dating v / Crosswords / Gaming v

Life > Health & Families > Health News

## A quarter of suicides happen within 90 days of being discharged from hospital, study finds



## The Nursing Times:

<https://www.nursingtimes.net/roles/mental-health-nurses/call-for-better-suicide-prevention-in-general-hospitals-30-01-2014/>

## Medical Xpress:

[https://medicalxpress.com/news/2014-01-uk-suicide-hospitals.html?src\\_id=alt](https://medicalxpress.com/news/2014-01-uk-suicide-hospitals.html?src_id=alt)

## The Mental Elf:

[https://www.nationalelfservice.net/mental-health/suicide/people-who-died-by-suicide-are-more-likely-to-have-been-last-discharged-from-a-general-hospital/?utm\\_source=rss&utm\\_medium=rss&utm\\_campaign=people-who-died-by-suicide-are-more-likely-to-have-been-last-discharged-from-a-general-hospital](https://www.nationalelfservice.net/mental-health/suicide/people-who-died-by-suicide-are-more-likely-to-have-been-last-discharged-from-a-general-hospital/?utm_source=rss&utm_medium=rss&utm_campaign=people-who-died-by-suicide-are-more-likely-to-have-been-last-discharged-from-a-general-hospital)

## Fierce Healthcare:

<https://www.fiercehealthcare.com/healthcare/hospitals-can-play-a-more-active-role-suicide-prevention?amp%3B=>

### 3.6 Dissemination

#### 3.6.1 Table excerpted from Appendix Table 1, section 10.1

Type	Details	Dates
Evidence submission	RCPsych submitted evidence from Dougall et al 2014 for NICE Briefing paper qs189 on Suicide prevention	2019
Evidence submission	Dougall N. Invited presentation on research findings (Dougall 2014 BJPsych) to House of Commons All Party Parliamentary Group, at the event 'Can patient data revolutionise healthcare?', Westminster London, 2016.	2016
Talk	Dougall N. Invited to present research findings (Dougall et al BJPsych 2014) at The Farr Institute's NHS Benefits Realisation Taskforce and Chief Scientist, Nine BioQuarter Edinburgh, 2016.  Oral presentation based on Paper 1 findings	2016
MQ charity Submission of evidence to UK Gov	Dougall et al was included as MQ submission (ref (vii)) of published written evidence in UK Parliament Suicide Prevention 2016-17: <a href="http://data.parliament.uk/WrittenEvidence/CommitteeEvidence.svc/EvidenceDocument/Health/Suicide%20Prevention/written/37639.html">http://data.parliament.uk/WrittenEvidence/CommitteeEvidence.svc/EvidenceDocument/Health/Suicide%20Prevention/written/37639.html</a>  Submission 56 for:  House of Commons. House of Commons Health Committee: Suicide Prevention. Sixth Report of Session 2016-17 (2017). <a href="https://publications.parliament.uk/pa/cm201617/cmselect/cmhealth/1087/108717.htm#_idTextAnchor095">https://publications.parliament.uk/pa/cm201617/cmselect/cmhealth/1087/108717.htm#_idTextAnchor095</a>	2016
MQ charity submission of evidence to AMRC	Association of Medical Charities produced a handbook of the Use of patient data to revolutionise healthcare:  <a href="https://www.researchgate.net/publication/308889397_AMRC_case_studies_MQ_Transforming_Mental_Health_A-matter-of-life-and-death">https://www.researchgate.net/publication/308889397_AMRC_case_studies_MQ_Transforming_Mental_Health_A-matter-of-life-and-death</a>	2016
Talk	<b>Nadine Dougall</b> et al, "Deaths by suicide and their relationship with general and psychiatric hospital discharge: 30 year record linkage study".  Oral presentation at the Scottish School of Primary Care Annual Meeting. Based on Paper 1	April 2014
Poster	<b>Dougall N</b> et al. 'Deaths by suicide and their relationship with general and psychiatric hospital discharge: 30 year record linkage study'.  Poster presentation at the SMRHN Annual Scientific Meeting, Edinburgh. Based on Paper 1 (see overleaf)	Dec 2013



Case study	<p><b>Dougall N</b>, Lambert P, Maxwell M. Factors predicting which people with psychosocial distress do not seek medical help: analysis of routine data.</p> <p>Paper submitted by <b>N Dougall</b> to ESDS as an online case exemplar of doing more with data. Based on additional evidence not included in Paper 1.</p>	Nov 2013
Talk	<p><b>Dougall N</b>, Lambert P, Maxwell M et al. 'Deaths by suicide following discharge from Scottish hospitals.'</p> <p>Accepted oral presentation given by <b>N Dougall</b> at the RCN International Nursing Research Conference, Belfast. Based on Paper 1.</p>	March 2013
Talk	<p><b>Dougall N</b>, Lambert P, Maxwell M. Exploring the potential for linking shared variables between the BHPS and Scottish Health Survey in an analysis of psychosocial distress and GP consultation behaviour.</p> <p>Accepted oral presentation/ seminar at Applied Quantitative Methods Network (AQMEN) Stirling Local Research Events</p>	May 2012
Talk	<p><b>Nadine J Dougall</b>, Paul Lambert, Margaret Maxwell, Alison Dawson, Carole Morris, David Clarke &amp; Anthea Springbett. Hospital utilisation prior to suicide: 30 year data linkage study.</p> <p>Accepted oral presentation/ conference abstract at MRC Population Health Methods and Challenges Conference, Birmingham. Based on Paper 1.</p>	April 2012
Talk	<p><b>Dougall N</b>, Lambert P, Maxwell M &amp; Dawson A. Modelling health and social risk factors for suicide in Scotland: a 30 year record linkage study.</p> <p>Accepted oral presentation/ conference abstract at the Scottish Health Informatics Programme International Conference 2011, St.Andrews.</p>	Sept 2011
Talk	<p><b>Dougall N</b>, Lambert P &amp; Maxwell M. e-Health data linkage in Scotland and the Scottish Health Survey – An exploratory analysis. Health Survey User Meeting 2011, London. Published online 2011 at this link (now broken; information archived) <a href="http://www.ccsr.ac.uk/esds/events/2011-07-05/">http://www.ccsr.ac.uk/esds/events/2011-07-05/</a></p> <p>Accepted oral presentation/ conference abstract; slides available from <a href="https://slideplayer.com/slide/786508/">https://slideplayer.com/slide/786508/</a></p>	July 2011
Talk	<p><b>Dougall N</b>, Lambert P &amp; Maxwell M. Modelling health and social risk factors for suicide in Scotland: a 30 year record linkage study.</p> <p>Invited seminar at the Applied Quantitative Methods Network (AQMEN) Stirling Local Research Events</p>	Spring 2011

## 3.6.2 Poster presentation: Modelling health and social care risk factors for suicide in Scotland: a 30 year record linkage study

### DAMES e-Health project

## Modeling health and social risk factors for suicide in Scotland: A 30 year record linkage study

**UNIVERSITY OF STIRLING**  
SCHOOL OF NURSING, MIDWIFERY AND HEALTH

Nadine Dougall<sup>1</sup>, Paul Lambert<sup>2\*</sup>, Margaret Maxwell<sup>1</sup>, Alison Dawson<sup>2</sup>, Richard Sinnott<sup>1</sup>, Susan McCafferty<sup>3</sup>, John Watt<sup>3</sup>, Carole Morris<sup>4</sup>, David Clarke<sup>1</sup>, Anthea Springbett<sup>1</sup>

<sup>1</sup>NMAHP research Unit, University of Stirling; <sup>2</sup>School of Applied Social Science, University of Stirling; <sup>3</sup>National e-Science Centre, University of Glasgow; <sup>4</sup>Information Services Division, National Health Service, Gyle Square, Edinburgh

#DAMES Chief Investigator \*e-Health project lead

### Background

Scotland is a good laboratory for e-Health research and one of a handful of countries with indexed electronic patient records (EPRs) spanning decades. EPRs are indexed by Community Health Index (CHI) number, introduced in 1970's and achieving full coverage by 1988. CHI-indexed EPRs enable record linkage and longitudinal analysis.

Data management through e-Social Science (DAMES) is a research programme of themed activities spanning sociology, economics, public health and computer science. DAMES utilises grid technology for case studies such as this e-Health project which has the aim of providing a demonstration third party record linkage of anonymised NHS EPR datasets.

The topic area for this e-Health project is suicide and mental health. Why Suicide? Suicide is a leading cause of mortality in young people in Scotland with rates for men 3x higher than for women. Attempts at explaining excess mortality have so far tended to focus on association between one or two risk factors, mostly at aggregated area levels. Very little research has been done using individual level data from EPRs using many health and socio-economic variables together in an analysis exploring life-course risk factors.

### Results

The final linked dataset contains 14,325 records relating to individuals, 10,500 have 5,500 hospital episodes for physical health and 4,500 individuals have 15,500 mental health episodes. 75% of deaths are male and there is a significant difference by gender in hospital attendance for prior mental health diagnoses - about 75% males have no mental health records compared with 58% of females. There is substantial variation both for males and females in previous admission patterns, many have no previous admissions and many have 10 or more.

ICD-9 and ICD-10 aggregated codes for cause of death (figure 1) are not directly mappable and demonstrate the need for a cross-mapping exercise between ICD classification systems. In these charts, mean Social class as determined by the Registrar General (RGSC) adds information to the cause of death. Whereas deaths categorised in ICD-10 by crashing a vehicle are associated with highest mean social class, ICD-9 data from earlier years suggest higher social class is associated with deaths from self-poisoning or firearms – further analysis is needed which takes into account confounding factors of e.g. increased car ownership over time and regulation governing purchase of over the counter analgesia.

### Objective

To use as many individual level variables as possible in an analysis to identify sets of health and social risk factors prevalent in individuals prior to suicide events in Scotland.

### Design

A retrospective record linkage study of death records of suicides and undetermined deaths aged 15y+ during 1980-2010 extracted from the General Register Office death register and linked to NHS datasets (Scottish Morbidity Records) of physical health, maternity and mental health hospital episodes.

### Methods

We re-coded health and socio-economic variables to permit consistent categories over time. We cross-mapped International Classification of Disease ICD-9 and ICD-10 using aggregated clinical classification software. We recoded variables that have been coded in a non-standard way e.g. occupation to recognized standard occupation classification (SOC) systems. Other socio-economic and hospital operation procedure codes remain to be coded. We used Stata V10 for recoding variables, longitudinal analysis and will go on to use multi-level mixed model data analysis.

### Conclusions

Results from this suicide cohort require to be compared in an analysis with case controls from the general population (work in progress). We hope findings will provide support and supplement current government suicide prevention policy and will help identify priority groups at highest risk which will allow for developing targeted intervention strategies.

### Principal cause of death, ICD code Suicides in Scotland, 1980-2010

Figure 1

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<http://www.dames.org.uk/>

Nursing, Midwifery and Allied Health Professions Research Unit

[www.stir.ac.uk/nmhealth](http://www.stir.ac.uk/nmhealth)

### 3.7 Concluding remarks

In specifying data related to deaths by suicide, eDRIS provided only 'intentional self-harm' deaths, and not 'probable suicides of undetermined intent'. Although I pre-specified variables, I was still reliant on eDRIS interpreting the request, and learned that pre-specified codes at death were also needed. I uncovered this by comparing numbers of deaths recorded in NRS official statistics and discovered a shortfall. I reviewed the literature, finding it was accepted convention to combine categories, including the ONS (23) and NRS (2). Historically, smaller studies with sparse data included both to boost sample size (247–249), but there were ongoing debates about the appropriateness of *always* combining these two categories, particularly in epidemiological studies where sparse data was not problematic (109,250,251). Therefore, including 'intentional self-harm' deaths only in this study meant there were no 'false positives' in the data, but it was a limitation in not having all 'probable deaths by suicide', and acknowledged in the paper.

Finally, this paper was accessed highly by healthcare staff but was pay-walled for about two years. Having been published in 2014, the interest in the paper surged in 2016 when it was made freely available. This reinforced problems with pay-walled information getting to the right audience, and subsequent papers were submitted to 'open access' Journals.



## 4. Paper 2: Trend analysis of deaths by suicide

### 4.1 Background

Suicide rates increased in Scotland in the last three decades of the twentieth century, with the largest increases observed in younger age groups and for men in particular. Data from England & Wales (72) reported that increases in suicide rates in successive birth cohorts were observed, and particularly so in males, but it was not known if similar patterns would be seen for Scotland. If birth cohorts carried with them an increased propensity to suicide as they age, (for example a known period effect on suicide is economic recession or lack of work, as young people (cohort) enter the workforce) then this has important implications for guiding suicide prevention. Identification of risk factors may inform public health approaches for prevention aimed at those most at risk.

In this paper, I aimed to determine whether there were any age, period or birth cohort effects on suicide in Scotland to better understand 'at risk' populations, and whether and how this differed (by gender) in a cross-national comparison with England & Wales. This study used 65 years of Scottish suicide data, and made use of hierarchical data reported as NRS national 'vital events' deaths data (2). An extraction of the summary data used is in the Appendix (section 10.3)

### 4.2 Reference

Dougall N, Stark C, Agnew T, Henderson R, Maxwell M, Lambert P. An analysis of suicide trends in Scotland 1950–2014: comparison with England & Wales. *BMC Public Health*. 2017 Dec 20;17(1):970. <https://doi.org/10.1186/s12889-017-4956-6>

### 4.3 Paper 2 reproduced in full (overleaf)

RESEARCH ARTICLE

Open Access



# An analysis of suicide trends in Scotland 1950–2014: comparison with England & Wales

Nadine Dougall<sup>1\*</sup>, Cameron Stark<sup>2</sup>, Tim Agnew<sup>2</sup>, Rob Henderson<sup>2</sup>, Margaret Maxwell<sup>3</sup> and Paul Lambert<sup>4</sup>

## Abstract

**Background:** Scotland has disproportionately high rates of suicide compared with England. An analysis of trends may help reveal whether rates appear driven more by birth cohort, period or age. A 'birth cohort effect' for England & Wales has been previously reported by Gunnell et al. (*B J Psych* 182:164-70, 2003). This study replicates this analysis for Scotland, makes comparisons between the countries, and provides information on 'vulnerable' cohorts.

**Methods:** Suicide and corresponding general population data were obtained from the National Records of Scotland, 1950 to 2014. Age and gender specific mortality rates were estimated. Age, period and cohort patterns were explored graphically by trend analysis.

**Results:** A pattern was found whereby successive male birth cohorts born after 1940 experienced higher suicide rates, in increasingly younger age groups, echoing findings reported for England & Wales. Young men (aged 20-39) were found to have a marked and statistically significant increase in suicide between those in the 1960 and 1965 birth cohorts. The 1965 cohort peaked in suicide rate aged 35-39, and the subsequent 1970 cohort peaked even younger, aged 25-29; it is possible that these 1965 and 1970 cohorts are at greater mass vulnerability to suicide than earlier cohorts. This was reflected in data for England & Wales, but to a lesser extent. Suicide rates associated with male birth cohorts subsequent to 1975 were less severe, and not statistically significantly different from earlier cohorts, suggestive of an amelioration of any possible influential 'cohort' effect. Scottish female suicide rates for all age groups converged and stabilised over time. Women have not been as affected as men, with less variation in patterns by different birth cohorts and with a much less convincing corresponding pattern suggestive of a 'cohort' effect.

**Conclusions:** Trend analysis is useful in identifying 'vulnerable' cohorts, providing opportunities to develop suicide prevention strategies addressing these cohorts as they age.

**Keywords:** Scotland, England, Wales, UK, Suicide, Age period cohort analysis, Epidemiology, Deaths of undetermined intent, Deaths of intentional self-harm

## Background

Suicide is a global public health issue with an estimated 804,000 people dying worldwide in 2012, corresponding to a standardised mortality rate (SMR) of 11.4 per 100,000 [1]. It is one of the leading causes of death in younger people (aged 15-44) and rates have increased by 60% in some countries during the last half-century [2].

In keeping with this alarming global picture, Scotland, as a constituent nation of the UK declared suicide to be a significant public health concern, prompting the Scottish Government to set a target to reduce the suicide rate in Scotland by 20% over a decade to 2013. This target was largely achieved with an overall 19% reduction to 2013 and an estimated 746 deaths, equating to a Standardised Mortality Rate (SMR) of 13.5 per 100,000 [3].

Although the suicide mortality rate in Scotland is analogous to that observed internationally and rates have reduced somewhat over the last decade, there remains

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substantial scope for further reductions to be achieved. It is *not* widely known that the Scottish rate remains disproportionately higher than that of its adjoining neighbour, England, and especially so for men – in 2008 the male suicide rate for Scotland was 24.1 per 100,000 of the population, almost double that of England at 12.6 per 100,000 [4]. This disproportionate impact of suicide on Scotland is even more notable in a comparison of younger men (15–44 years); whilst Scottish suicide rates for this group remained about double that of England, the gap widened between SMRs for the period 1998–2004, and were much more elevated at 36.9 and 19.1, respectively [5].

Considering national comparison data for more recent years of data available, the contrast between these two neighbouring countries remains marked. The standardised suicide rate among working age Scottish men was estimated for 2010 to be 73% higher than that found for England & Wales (denoting a combined dataset of both England & Wales both here and in subsequent mentions), whilst the corresponding Scottish female rate was almost double that for England & Wales [6]. Epidemiological studies of temporal trends in suicide have reported that for Scotland, rates increased in the last three decades of the twentieth century followed by a suggested downward trend over the last decade to 2010 [7, 8]. England & Wales on the other hand observed a similar increase in suicide rates between 1975 and 1990, followed by a decrease in rates a decade earlier than Scotland for males and females [9] which has persisted to the present day [10].

A recent cross-national comparison of longitudinal trends concluded there was a marked divergence from 1992 to 2008, with Scottish suicide rates having markedly increased rates relative to those decreased rates observed for England & Wales [8]. However, in summarising overall trends the underlying contributions from different age groups is masked. For instance, in the 1990s England & Wales experienced decreases in the male suicide rate for all age groups except for a relative increase in the 25–34 year old age group [11, 12]. This differs from the picture in Scotland for the 1990s when increases in *all* age-groups up to 44 years old were experienced, with corresponding decreases observed in groups 45 years and over [8, 13, 14]. Finding candidate factors which help explain these cross-national UK differences is of interest to enable more effective targeting of suicide prevention strategies.

An analysis of trends is one approach which can help tease out whether rates observed are more consistent with patterns that reflect differences between the decade people were born (cohort effect) or died (period effect) or of the changing condition of age. Consideration of age, period and cohort patterns in turn can lead to a better understanding of different influences in time, and may yield predictive information on future time periods

where some populations may be more at risk. Age effects refer to differences in rates observed as a consequence of the impact of ageing on people within the same cohort. Period effects refer to patterns associated with a particular year or decade, such as the increase in deaths in the late 1920's and early 1930's at the time of the Great Depression, or the increase in deaths related to coal gas [15]. Cohort effects reflect long term impact of a generation's exposure to particular conditions, such as a lack of work as they entered the work force. If birth cohorts carry with them an increased (or decreased) susceptibility to suicide throughout their lives then this would have important implications for the targeting of suicide prevention efforts.

From a statistical perspective, there are ongoing debates about plausible strategies for disentangling age, period and cohort effects, as the linear dependency of all three time-dependent measures mean that inferences from this sort of analysis are highly problematic [16–21]. For instance, an effect that appears to be a cohort effect may well be a combination of age and period effects. One approach is to explore trends via graphical analyses, and interpret trends observed based on some assumptions with a reasonable rationale. Assumptions can be based on pre-existing research evidence, for example, known discrete period effects. This strategy was adopted in an earlier 'cohort analysis' presented by Gunnell et al. for data from England & Wales [12]; those deaths by overdose and gassing were excluded from the full dataset, changing the birth cohort patterns and supporting the suggestion that popularity and lethality of particular methods of suicide have a period effect.

Gunnell et al. (2003) reported that an increase in suicide rates in successive birth cohorts was evident from 1940 onwards, and in males in particular, concluding that an increase in overall male suicide rates is inevitable if this trend continues into middle and older age [12]. A comparison 'cohort analysis' of Scottish data has not been reported, and is now timely as recent national data points to an evolving picture of a relatively increased suicide rate in middle-aged men aged 35 to 54, compared with a relatively decreased rate in those less than 34 years [22].

Therefore the aim of this study was to use Scotland's suicide data to replicate the reported analysis for England & Wales by Gunnell et al. (2003), to highlight any similar potential cohort patterns within Scotland, and ascertain any cross-national differences in a direct comparison.

## Methods

### Study data

Published suicide information from the vital event reports of the National Records of Scotland (NRS) was used for this study. These reports are published

annually, and include summarised information on causes of death by age group and gender. These data are openly available, do not require permission to use, and data from 1974 onwards is accessible online to download. This study spanned sixty five years from 1950 to 2014, with corresponding codes defining deaths by suicide from various iterations of the International Classification of Diseases (Table 1). As more historical data from 1950 to 1973 were not available via online access, two authors (TA and RH) manually extracted the data from reports held at the NRS, and entered both these and the electronic data for more recent years on to an Excel spreadsheet. Corresponding annual general population estimates by age and gender were also obtained from NRS. A category for deaths which were undetermined as to whether the death was accidentally or purposely inflicted was introduced in 1968 with ICD8 and its corresponding codes (Table 1), therefore categories of deaths as a result of intentional self-harm and of undetermined intent were available for analysis.

**Cohort analysis**

We were interested in exploring long-term temporal trends in suicide outcome from 1950 to 2014 and any patterns suggestive of effects of age, period (year of death) and cohort (year of birth). We describe this descriptive analysis of trends as ‘cohort analysis’ to keep the terminology consistent with the work of Gunnell et al. (2003) although it is recognised that an analysis of trends is a more accurate description.

There is a linear interdependency between the variables age, period and cohort and if they are all in the same functional form it is impossible to distinctively identify patterns associated with all three variables, known as the identification problem [15, 21]. Put simply, this can be expressed as follows:

$$\text{Age} = \text{Period} - \text{Cohort.}$$

$$\text{Period} = \text{Cohort} + \text{Age.}$$

$$\text{Cohort} = \text{Period} - \text{Age.}$$

It is possible based on prior evidence to make some assumptions which can help facilitate data interpretation. Studies have previously reported on discrete effects of period on suicide, although mechanisms such as diffusion mean that the empirical impact of period

effects may be more gradational in character. For instance, suicide intervention strategies could have discrete period effects with some enduring legacy effects remaining from previous interventions, and lag effects from implementation to measurable impact. Accordingly, a pattern which persists for many decades is much less likely to be a completely continuous period effect, and more likely a consequence of successive cohorts. Our analysis seeks to emulate this previous analysis reported for England & Wales by Gunnell et al. [12] which explored cohort patterns by adopting high level descriptive summary and graphical analysis. We repeated the graph formats produced earlier [12] to provide a comparison with England & Wales data.

Age and gender specific suicide rates per 100,000 of the Scottish population from 1950 onwards were derived for every year by dividing suicide numbers for each five year age band (15-19, 20-24,...,80-84, 85+) by the corresponding age and gender matched general population estimates. Although the use of age specific suicide rates does not help overcome the linear relationship between age, period and cohort variables, they do enable valid comparisons to be made between gender and calendar time, and differences in country patterns.

Suicide completers were classified into six groups based on age at year of death aged 15-24, 25-34, 35-44, 45-54, 55-64 and an older group of 65+ years. We aggregated age at death into ten year age bands to simplify the graphical representation. The gender specific mean ages in five year death periods were then estimated and plotted on moving average charts to examine the relationship between incidence of suicide and the age of suicide completers during each death period. Each five year moving average point was plotted on the mid-year point, e.g. data for period 1950-54 was plotted on 1952, meaning that each five year period has a ‘lag’ period of 2.5 years.

We investigated the cohort patterns by plotting suicide rates in age bands, summarised by weighted mean rate within each 5 year death period to 2014. As each five year death period consisted of five possible ages at death, the birth cohort consisted of people born over a possible range of nine years. For example, for the age band 25-29 years with deaths data for the period 1960-1964, the

**Table 1** ICD catalogues and codes

Years	ICD catalogue and codes for ‘Intentional self-harm’	ICD catalogue and codes for ‘Deaths of undetermined intent’
1950 to 1957	ICD6 E970-E979	Did not exist
1958to 1967	ICD7 E970-E979	Did not exist
1968 to 1978	ICD8 E950-E959	ICD8 E980-E989
1979 to 1999	ICD9 E950-E959	ICD9 E980-E989
2000 to 2014	ICD10 X60-X84, Y87.0	ICD10 Y10-34, Y87.2

ICD catalogue and codes used for deaths by suicide by the National Records of Scotland during the timespan 1950-2014

possible birth range corresponded to the nine year period 1941 to 1949. To plot the graphs we assigned the middle year in which each nine year birth range centred on as the notional birth cohort year, therefore 1941-1949 had 1945 as the birth cohort year; this follows the method previously described in more detail by Gunnell et al. [12]. Where relevant, 95% Confidence Intervals (95% CI) using 'Mid-P' exact confidence limits for age-specific rates were estimated using the 'Quickcalc' tab of 'Episheet' [23], available online (personal communication with Prof Ken Rothman).

**Results**

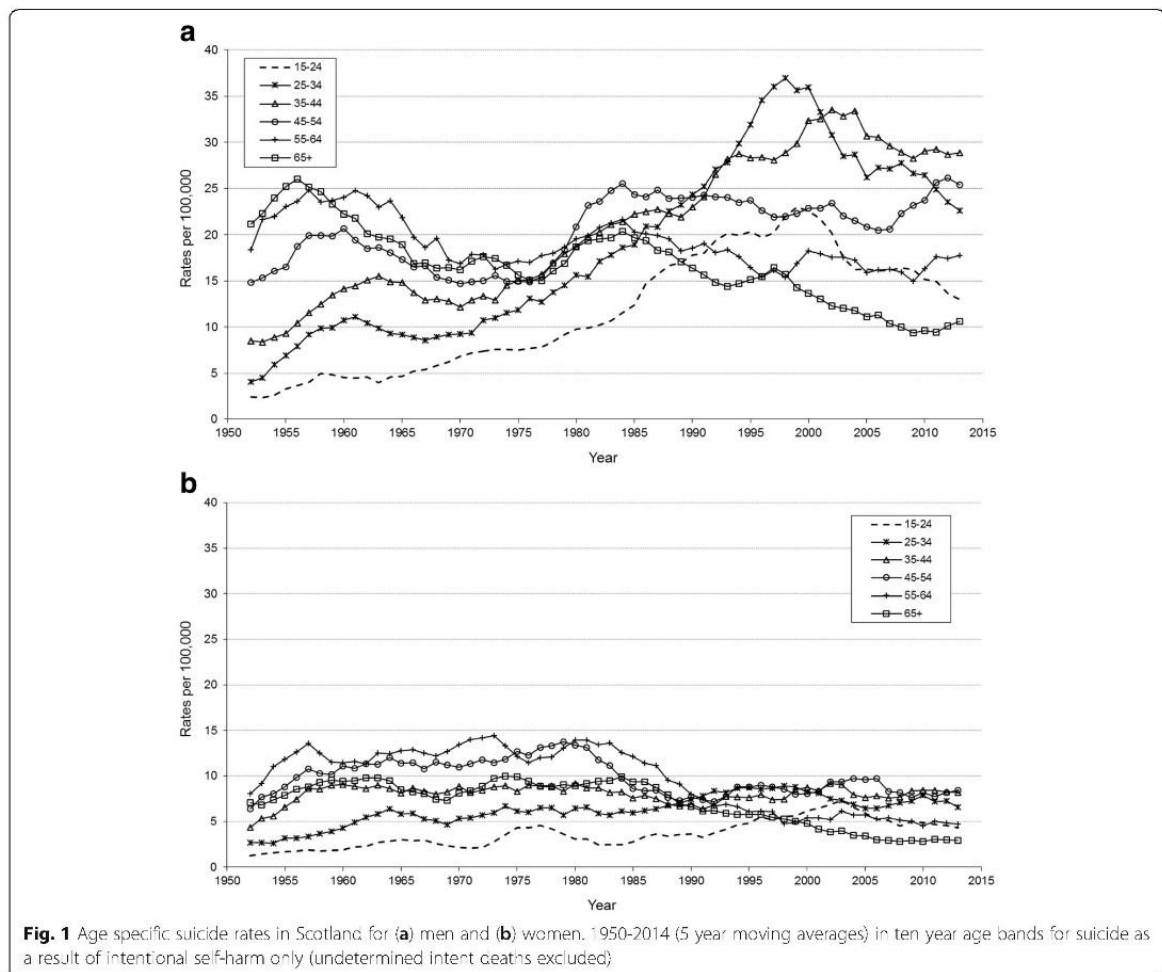
**Male patterns by age and period**

The age and period graph (Fig. 1a) suggests a pattern reflecting some change over the period in how suicide rates are distributed by age groups. The suicide rates of the younger age groups increased markedly over time; those aged 25-34 and 35-44 reaching the

highest rates of any group in the period around 2000, before decreasing to 2014. In contrast, those aged 45-64 have seen increasing suicide rates for much of the last decade and have now reached similar rates as these younger men. Rates for older age groups tended to be more stable through the period, but are characterised by steady decline through the period for the oldest group (65+). Post WW2, the burden of suicide was highest in those middle and older groups of men (>44 years).

**Female patterns by age and period**

The contrast for women compared with their male counterparts is striking (Fig. 1a & b). From the 1990s onwards the disproportionate burden of suicide is seen for men, and in particular younger men aged 25-44. Although the successive women in younger age-groups experienced a steady increase during this same period, this increase was much more modest and the most



**Fig. 1** Age specific suicide rates in Scotland for (a) men and (b) women, 1950-2014 (5 year moving averages) in ten year age bands for suicide as a result of intentional self-harm only (undetermined intent deaths excluded)



recent data suggest this trend has now reversed or stabilised (Fig. 1b).

Conversely, trends for older women can be seen to have been highest in the 1950s and remained fairly constant until the 1980s with a stable age group ordering. From the 1980s the older women's rates consistently decreased to become the lowest ever in most recent years, with all age groups demonstrating convergence. In short, although variations in age group orderings for women are also seen during the 1990s, women were not affected by suicide to the same degree as men.

A feature of 'moving average' charts (Fig. 1a & b) is that individual data points have been 'smoothed' to permit trends to stand out. One limitation here is that the female averaged patterns are derived from far fewer individual observations (i.e. increased variability in the mean of the distribution of values, not the distribution of values itself) and it is unlikely there are statistically different differences for the female age groups.

#### Male patterns by age and period - comparison with England & Wales

For men, there are striking differences observed between Scotland, and England & Wales (see Fig. 1a, and 'Additional file 1: Figure S1' reproduced from Gunnell et al. [12]). The 1950s age-specific suicide rates in England & Wales were almost twice as high as those in Scotland and followed a more exaggerated pattern with steeper declines to the 1970s observed. The underlying suicide pattern between the countries was not dissimilar from the 1950 to mid-1970s in that there was consistent and identical age group ordering, with rates which steadily decreased and converged over time till the nations were broadly similar.

From the mid-1970s to 2000 a markedly divergent pattern emerged between nations; the Scottish suicide rate increased dramatically for men aged 25-44, reaching rates which were disproportionate and at least double that of England & Wales. Rates in men aged 25-44 also rose in England & Wales but they never exceeded those of the other age groups (see Fig. 1a, and 'Additional file 1: Figure S1' reproduced from Gunnell et al. [12]).

Age and period rates for Scottish males were plotted in a different format, following Gunnell et al. [12], (Fig. 2a). This figure features a pattern of stable ordering of suicide rates, (with the exception of those >49 years) up to the 1990s, when the pattern is disrupted, indicative of a possible period influence in these younger groups but only until the 1990s. As in Scotland, the combined territory of England & Wales also had subsequent five year death periods spanning 1955-1999 which featured parallel shifts upwards in suicide rates for each passing decade

for younger age groups up to the 1990s (see Fig. 2a; and 'Additional file 2: Figure S2' reproduced from Gunnell et al. [12]). We can conclude that for both Scotland, and England & Wales, these patterns by period were very similar for men <35 years (with increased suicide rates with each passing decade to the end of the last century), but quite different for those men older than 35.

#### Female patterns by age and period - comparison with England & Wales

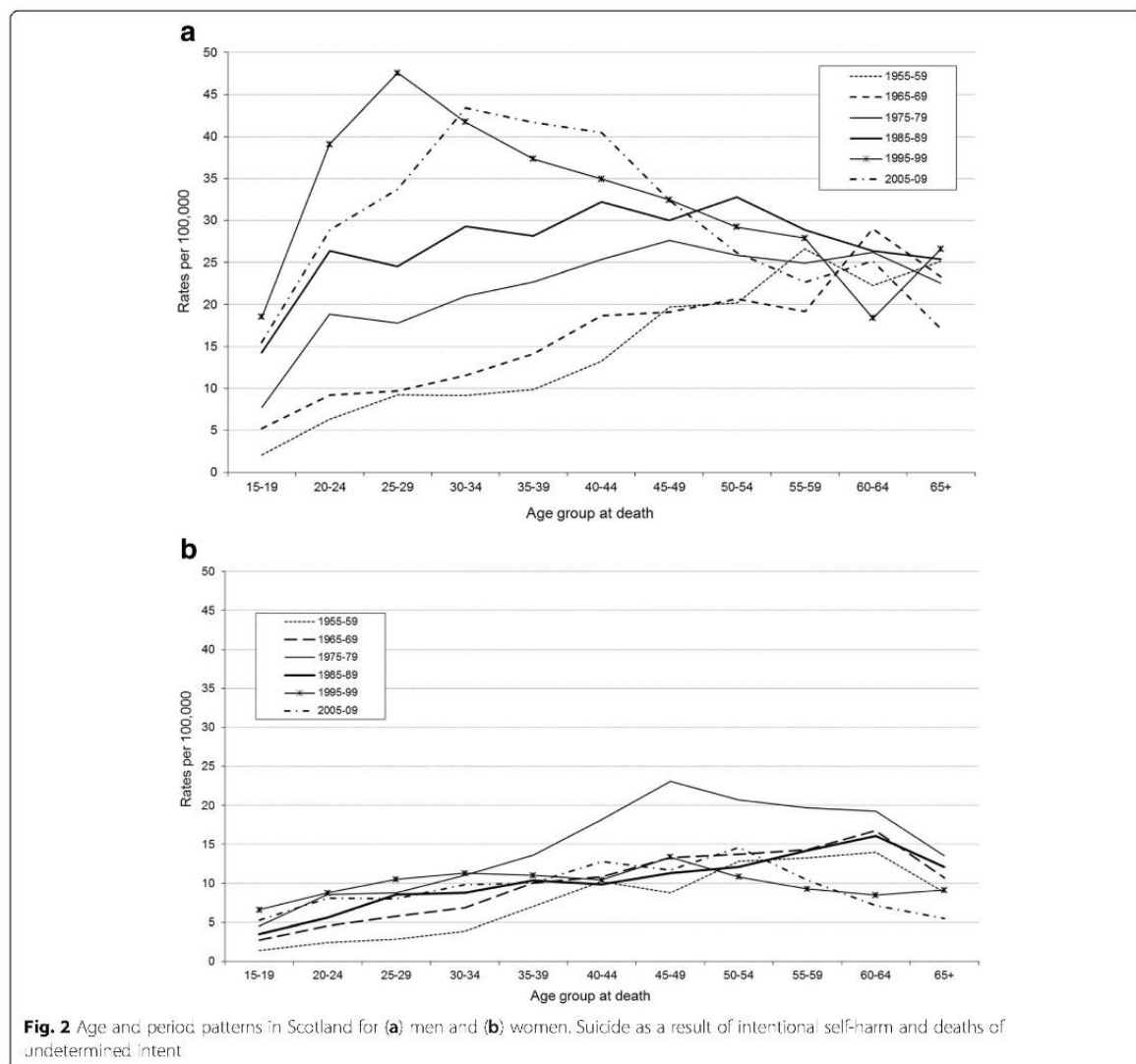
The suicide rates for older women in England & Wales were almost double that seen in Scotland in the 1950-60s, but decreased with every decade to 2000, dropping below the Scottish equivalent rates, and converging on a stable rate for all age groups, (see Fig. 1b, and 'Additional file 1: Figure S1b' reproduced from Gunnell [12]). Overall the suicide trend for women in Scotland was more stable with fewer fluctuating features. Compared with England & Wales, although Scottish women historically completed suicide less frequently, from 1995 onwards the picture is reversed with higher female rates in Scotland. As female deaths by suicide are sparser than the male data more caution is required in drawing conclusions.

The corresponding female pattern for period (Fig. 2b) demonstrates a pattern broadly consistent across all age groups for every 'period' with the exception of the period 1975-79 which has higher suicide rates in Scotland for those women between 40 and 59 years. In comparison, for England & Wales women >45 years show a consistent decrease with every subsequent decade to 1999, (see 'Additional file 2: Figure S2b reproduced from Gunnell [12]).

#### Male patterns by age and cohort

Figure 3a and b set out suicide rates by birth cohorts for Scottish men and women, respectively. For men it can be seen that all cohorts have suicide rate trajectories which peak at higher numbers and in younger age groups with each successive cohort. In comparison with the 1960 cohort, there is a marked stepped change in worsening trajectories with the 1965 and 1970 cohorts. The 1965 cohort peaked in suicide rates for 35-39 year olds in 2000-2004, and the 1970 cohort peaked even younger for 25-29 year olds in 1995-1999. To be clear, Fig. 3a uses the same underlying data as Fig. 1a but presented in a different way, and these conclusions on cohort are made using Fig. 3a whilst ignoring the conclusions from Figs. 1a and 2a.

The trajectories for the 1960 and 1965 cohorts alongside their respective 95% CIs demonstrate a pattern consistent with a statistically significant increase between these cohorts for those aged 20-24 to 35-39 (Fig. 3c).



Although this statistically significant difference is observed, it is not known whether this is a consequence of cohort or a combination of the factors of age, period or cohort.

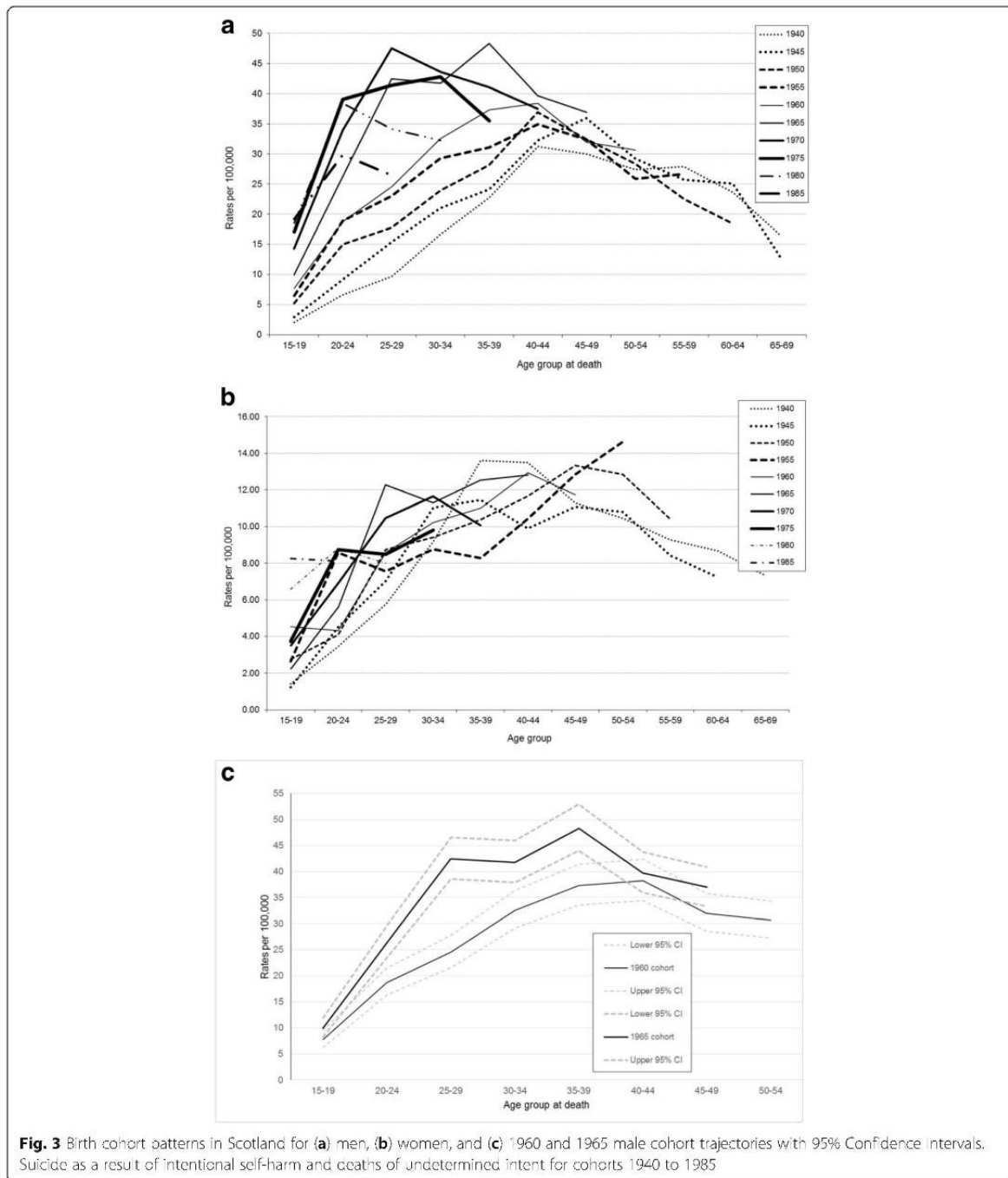
#### Female patterns by age and cohort

For women the pattern seen for men is not so apparent (Fig. 3b). The marked stepped change in increased suicide rates with the 1965 and 1970 cohorts is not obvious, and there does not appear to be a convincing greater risk of suicide as these particular cohorts aged. Aside from the lack of a pattern suggestive of a convincing female birth cohort effect, presenting the data in this way (Fig. 3b) does not add to what has been expressed above – older cohorts

(and therefore older age groups as seen when considering Fig. 1b on its own) have higher suicide rates, and more recent cohorts are at risk of dying younger, but in fewer numbers.

#### Male patterns by age and cohort - comparison with England & Wales

The cohort patterns for both Scotland, and England & Wales are broadly similar but differences are more marked in Scotland. For both countries, suicide rates in each successive birth cohort peaked in earlier age groups, and in higher numbers for more recent cohorts (see Fig. 3a, and 'Additional file 3: Figure S3a' reproduced from Gunnell [12]). Gunnell et al. concluded that "successive male birth cohorts born after 1940 carried



with them, as they aged, a greater risk of suicide than their predecessors, although this effect diminished for 1975 and 1980 cohorts”.

The cohort pattern for England & Wales also suggests that this “greater risk of suicide” is different in those born from 1965 onwards with increased suicide

rates in younger people. The Scottish data features this same difference but with a disproportionate additional impact of suicide on the 1965 and 1970 cohorts, with those aged 35-39 years and 25-29 years during the 1990s dying in greatest numbers, respectively (Fig. 3a, and ignoring conclusions from other



graphs as each graph leads to different conclusions because of the APC identification problem).

## Discussion

### Main findings

Scottish male cohort trajectories demonstrated a pattern consistent with a statistically significant increase in suicide between 1960 and 1965 for those aged 20-39. The 1965 and 1970 cohorts peaked in suicide rate at age 35-39 and 25-29, respectively. It is possible that the 1965 and 1970 cohort are at greater mass vulnerability to suicide than earlier or subsequent cohorts, and that as they age there may yet be greater suicide rates in these cohorts as a consequence. Alternatively the period 1995-2004 may have posed increased risk to these cohorts; further research is needed to rule in or out explanatory discrete period effects of e.g. access to means of death which are recorded on death certificates and not available in this study for analysis. It is not possible to categorically establish if this pattern is one attributable to age, period or cohort, or a combination of all three factors.

One recent study has also now reported on this apparent cohort effect, and concluded that these cohort patterns were more pronounced for those living in the most deprived areas, and that the suicide rates in Scotland can be explained by a cohort effect consistent with exposure to neoliberal politics during the 1980s, an exposure experienced more in deprived communities [18].

### Temporal patterns of suicide in Scotland

In Scotland post WW2 years, the burden of suicide was highest on older men (>44 years) with rates decreasing to the 1980s, before stabilising thereafter. The inverse was seen for younger men (<45 years) who had the lowest suicide rates which steadily increased and peaked by the late 1990s, with this group continuing to bear the burden of suicide until 2000. From 2000 to 2014 decreasing rates are seen for those aged 15-34 alongside increasing rates for 45-54 year olds, leaving the greatest impact of suicide on those aged 35-54.

During 1998-2004, 17 of the top 20 local areas with the highest male suicide rate in the UK were located in Scotland, with the Shetland Islands, Eilean Siar, Highland and Glasgow City having the highest rates at 47.5, 44.1, 43.3 and 41.6 per 100,000 population, respectively [5]. Rurality may explain some patterns of excess suicide - for Highland, an excess of male deaths appeared to be associated with access to more lethal means and rural occupation [24, 25]; a relative dearth of contact with mental health services in the month prior to suicide was found for those that lived in 'remote rural' or 'remote small towns' [26]; enforced social isolation has also been proposed in a conceptual model of rural suicide [27]. However excess suicide has also been

observed in some urban areas. An analysis of suicides in Greater Glasgow to 2001 concluded that the East end of Glasgow formed a large geographical cluster of young adult suicide which persisted for *two decades* and which was likely not explained by 'contagion effects', but rather more likely by a concentration of deprivation [28].

Although there are many age and period risk factor interactions at play, it is not possible to explain in simple terms what drove the patterns observed, but it is likely that regional differences fuelled by deprivation are partly to explain.

In contrast, female suicide rates for all age groups in Scotland have converged and stabilised in recent years with evidence that women have not been affected by the huge impact of suicide as seen for men. Although there was a pattern for women with a limited number of successive cohorts showing peaks in younger age groups with each generation, this was unclear and no firm conclusions could be made due to sparser data.

### Comparison with England & Wales

Temporal patterns of suicide for Scotland were markedly different to those in England & Wales, which had a much higher burden of suicide than Scotland in the 1950s. These patterns reversed over time so that Scotland became the country with disproportionate impact of suicide, compared to England & Wales. Men were affected more markedly than women over all years in both countries. In spite of the between country differences, the gender patterns within each country were similar, meaning gender is the bigger determinant with more overall predictive power.

The pattern reported for England & Wales by Gunnell et al. [12] of successive male birth cohorts from 1940 experiencing higher suicide rates peaking in younger age groups with each decade was also seen in Scotland. The differences in pattern with increased suicide rates for the 1965 and 1970 cohorts exist in both countries, but are more marked in Scotland.

Gunnell et al. explored the impact of discrete period events, and found that restricting access to lethal means (predominantly 1993 legislation on car exhaust emissions and the advent of catalytic converters) was effective in reducing suicide rates, i.e. when these period effects were controlled for, the pattern consistent with a cohort effect disappeared - there was no evidence that rates peaked earlier in later born cohorts (Additional file 3). We did not have access to the Scottish data by method of suicide and could not compare this discrete period effect. It has been reported elsewhere that deaths from motor vehicle exhaust fumes decreased in England alongside a corresponding increase in hanging deaths, whilst in Scotland hanging deaths were already increasing in men before deaths from motor vehicle exhaust

fumes began to decline, with this increase being greater than the corresponding decrease [24]. Restricting access to means of suicide may have lasting impact in some countries, but for Scotland the discrete period effect of catalytic converter legislation did not achieve the same impact seen in England & Wales. Thus there may still be a greater risk in Scotland attributable to belonging to the 1965 and 1970 birth cohorts, for reasons which remain unclear.

This widening 'suicide gap' has been reported before, with the crossing over of increasing suicide rates in Scotland, and decreasing rates in England & Wales occurring in the 1960s, and differences since the 1990s being explained by a preference in the methods of hanging, suffocation or strangulation by young adult males [8].

It is plausible that regional differences in England & Wales data are obscured by using pooled national data, and that disaggregating these data would produce markedly different patterns. Analysis reported elsewhere concluded that between 1998 and 2004 large regional disparities existed between suicide rates in the countries of the UK and between local regions, and that deprivation as a risk factor fuelled these inequalities in suicide rates [5]. In 2011 the Office for National Statistics (ONS) published UK suicide data and estimated standardised male rates for 2011 ranging in England from 13.2 in London to 21.5 in North East England, with Wales being even higher at 22.5 [29]. Such regional variations have been noted within countries before and are typically associated with other risk factors [30]. Regional inequalities in suicide rates have also been characterised by markers of unemployment [31] and more recently, unemployment associated with the discrete period effect of the last UK recession [32, 33]; and low social integration, indicated by features of the proportion of single-person households, divorced people and population mobility [34].

A specific multilevel analysis exploring a range of factors between Scotland and England during 2001-2006, found that 57% of the excess suicide risk in Scotland was explained more by the area level measures of psychotropic drug prescriptions (proxy for poorer mental health), alcohol and drug misuse, with a relatively small contribution of deprivation and social fragmentation [35]. Therefore caution is required in reviewing national data patterns for men, and it is possible that Scottish data patterns observed may well find more concordance with specific regional English or Welsh patterns.

#### Public health and future research implications

Although Scotland has made substantive progress in reducing suicide in recent years alongside national suicide prevention initiatives, it is not possible to know whether there is a direct causal link between such

suicide prevention strategies and relative period decreases achieved from the early 2000s [36]. The first 'Choose Life' initiative was a ten year plan introduced in December 2002 aimed at reducing suicides by 20% by 2013 – however it appears the decline in suicides may have started before 'Choose Life' had a chance to have an impact and it is not possible to categorically know which particular age groups would have been impacted on most. These national initiatives coincided with a period of perceived economic expansion and lower unemployment until the 2008 UK recession.

Other comprehensive social changes were going on aside from economic fluctuations that may also have compelling plausible explanations for the suicide impact of the 1965 and 1970 male cohorts, such as the continuing impact of de-industrialisation, related unemployment and persistent effects of deprivation as previously mentioned. Major reforms in education with increasing attention to well-being and increased average time in education may also possibly have had a long term impact. The increased use of mobile technology and its impact on social connectedness may also need to be considered in explaining recent or future trends. Important legislative and political changes that have impacts for certain minority groups e.g. immigration, equality legislation will also have had their effects. Therefore, further research at the individual level (e.g. means of suicide especially drug overdose, occupation, educational attainment) on the 1965 and 1970 cohorts of males who were aged 25-39 at death may shed some light on suggested potentiality for risk in later life in the same birth cohorts. Such research should seek to identify risk factors or 'exposures' that lead to mass vulnerability of cohorts so as to minimise the longer term impact of such exposures, and in the planning of building resilience in future generations in the very early years when such 'exposure' risks re-appear.

#### Strengths and limitations

One limitation of this comparison is that the data quality between countries is likely to differ, with potential variation in both coding and coding consistency across the years. We can also plausibly assume that data quality may be heterogeneous between age groups, with those younger age groups dying later having better quality data compared with their older counterparts dying a longer time ago. Graphical interpretations are reliant on the assumptions being made by each graph, and different assumptions would result in different interpretations. There was no matching data on specific suicide methods used, therefore it was not possible to compare the cohort trajectories using these different methods and our interpretation was guided by analyses reported elsewhere. In emulating the previous analysis for England &

Wales by Gunnell et al. [12], the techniques used in this study were limited and the description of the methods expressed in terminology which takes account of known limitations. Nevertheless the utility of considering the factors of age, period and cohort in graphical terms has been demonstrated.

A strength of this study is the manual recovery of data prior to 1974 which permitted a long period of follow-up for the older cohorts. We were unable to do a comparison between the countries using a reference population given the historical data and the comparison with an earlier study; future research could standardise each country data to a standardised European population dataset to enable more robust comparisons to be made.

## Conclusions

This sort of trend analysis cannot confirm direct causal mechanisms of heightened suicide risk, but nevertheless can be helpful in identifying patterns which suggest opportunities to develop suicide prevention strategies specifically addressing cohorts and their mental health needs as they age. Male suicide rates peaked at higher numbers and in younger ages with each successive cohort. Specifically, there was a statistically significant increase in suicide rates for the 1965 birth cohort compared with the 1960 cohort, for men aged 20-39. The 1965 cohort peaked in suicide rates for 35-39 year olds in 2000-2004, and then the 1970 cohort peaked for 25-29 year olds in 1995-1999. There is no convincing evidence to suggest that the 1965 and 1970 cohorts may maintain increased risk for suicide as they age.

## Additional files

**Additional file 1: Figure S1.** Age-standardised suicide rates: 1950-1999 England and Wales (3-year moving averages) in (a) males and (b) females. (DOCX 135 kb)

**Additional file 2: Figure S2.** Suicide and undetermined death rates by time (of death) period in (a) males and (b) females. (DOCX 133 kb)

**Additional file 3: Figure S3.** Male rates of suicide and undetermined death in successive 5-year birth cohorts at different ages. (a) All suicides and undetermined deaths; (b) suicides and undetermined deaths except those by overdose and gassing; (c) overdose, gassing and undetermined deaths excluded. (DOCX 140 kb)

## Abbreviations

DUI: Deaths of undetermined intent; ICD: International Classification of Disease; ISH: Intentional self-harm; NHS: National Health Service; SMR: Standardised mortality rate; WW2: World War 2

## Acknowledgements

We gratefully acknowledge assistance given by Frank Dixon, National Records of Scotland; Prof David Gunnell for helpful comments on an earlier draft; Prof Ken Rothman for advice on constructing confidence intervals.

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## Availability of data and material

The dataset analysed for this study from 1974 are openly available to download from National Records of Scotland [<https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/deaths/suicides/list-of-tables-and-chart>]. The data prior to 1974 are available on paper records and are openly available to view at the National Records of Scotland; these manually entered data are available from the corresponding author on request.

## Authors' contributions

CS conceived the idea for the study. TA and RH retrieved the historical data and entered the data. ND undertook most of the data analysis with input from TA. ND wrote the manuscript with input from CS. PL advised on the data analysis and reviewed the manuscript. MM edited the manuscript and contributed to the discussion. All authors read and approved the final manuscript.

## Ethics approval and consent to participate

Ethics approval and consent to participate were not applicable as this is a data only study using publically available statistics of the National Records of Scotland.

## Consent for publication

Not applicable.

## Competing interests

The authors declare that they have no competing interests.

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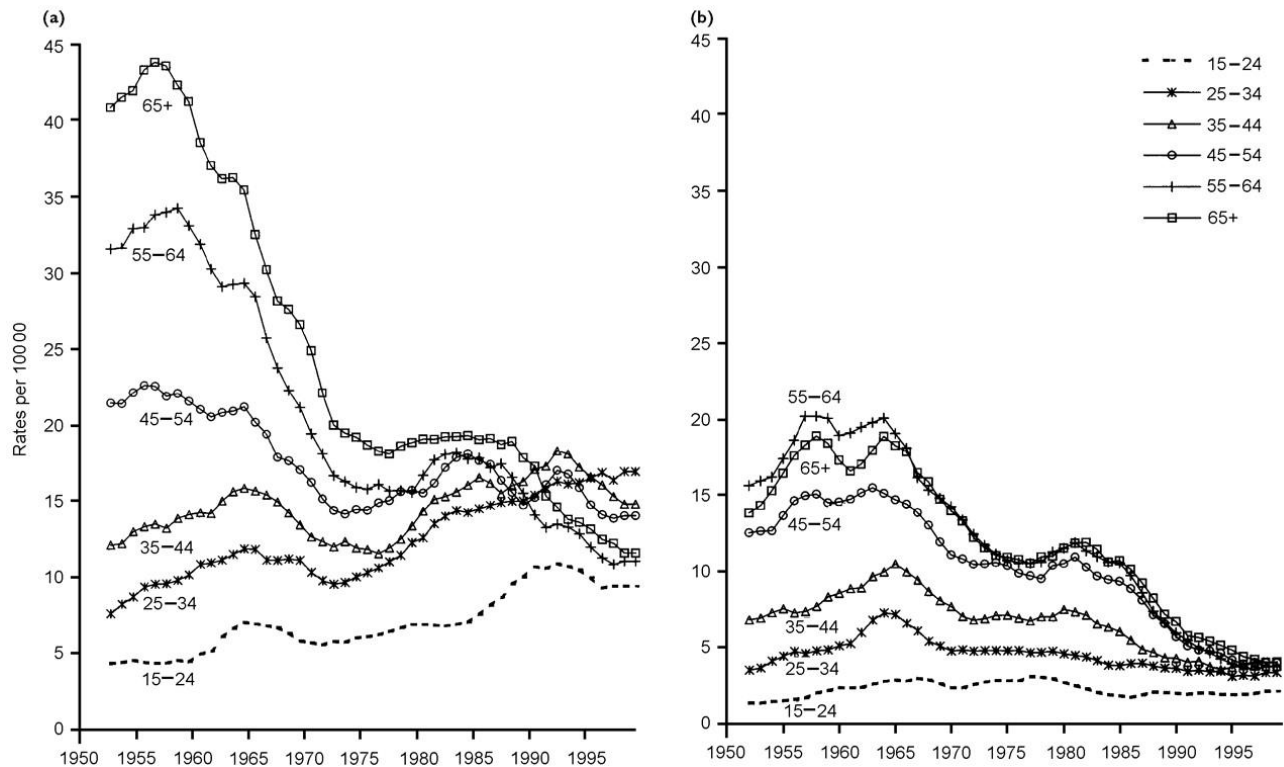
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### 4.3.1 Supplementary figure S1

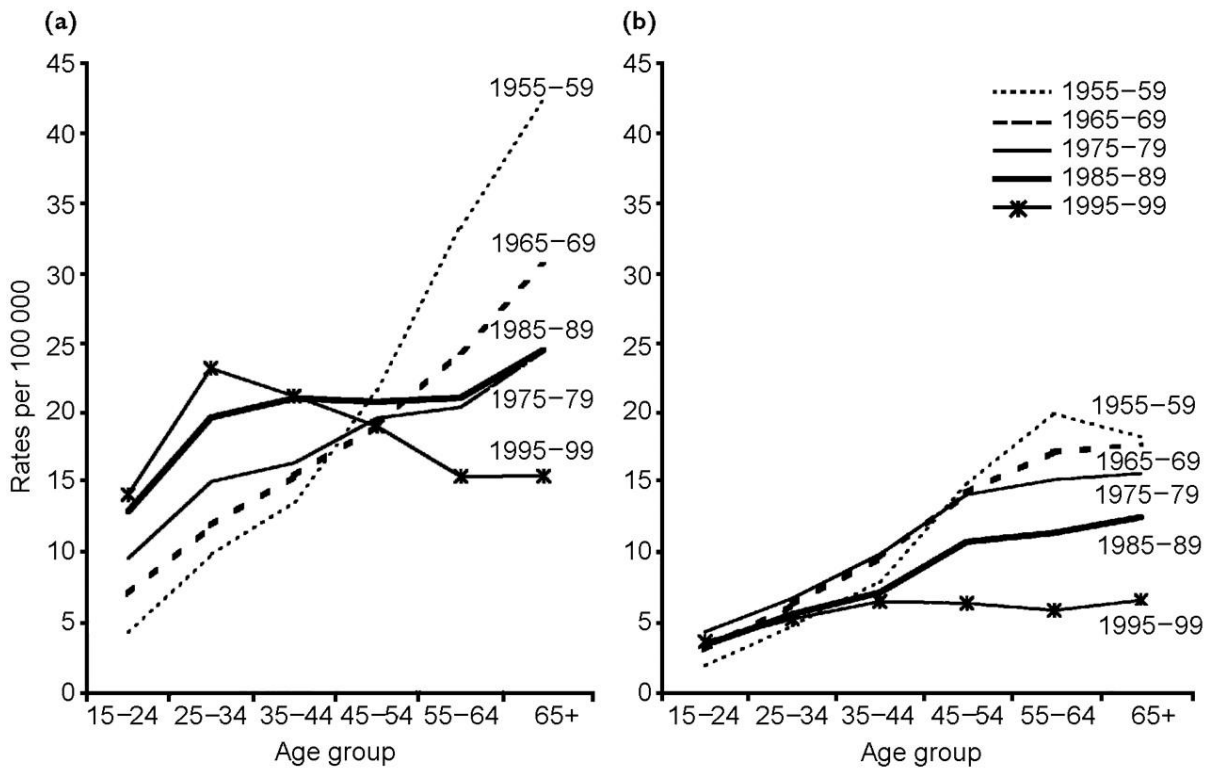
**Figure S1 Age-standardised suicide rates: 1950-1999 England and Wales (3-year moving averages) in (a) males and (b) females**



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**Influence of cohort effects on patterns of suicide in England and Wales, 1950-1999, *B J Psych* 2003, 182: 164-70**

### 4.3.2 Supplementary figure S2

**Figure S2 Suicide and undetermined death rates by time (of death) period in (a) males and (b) females**

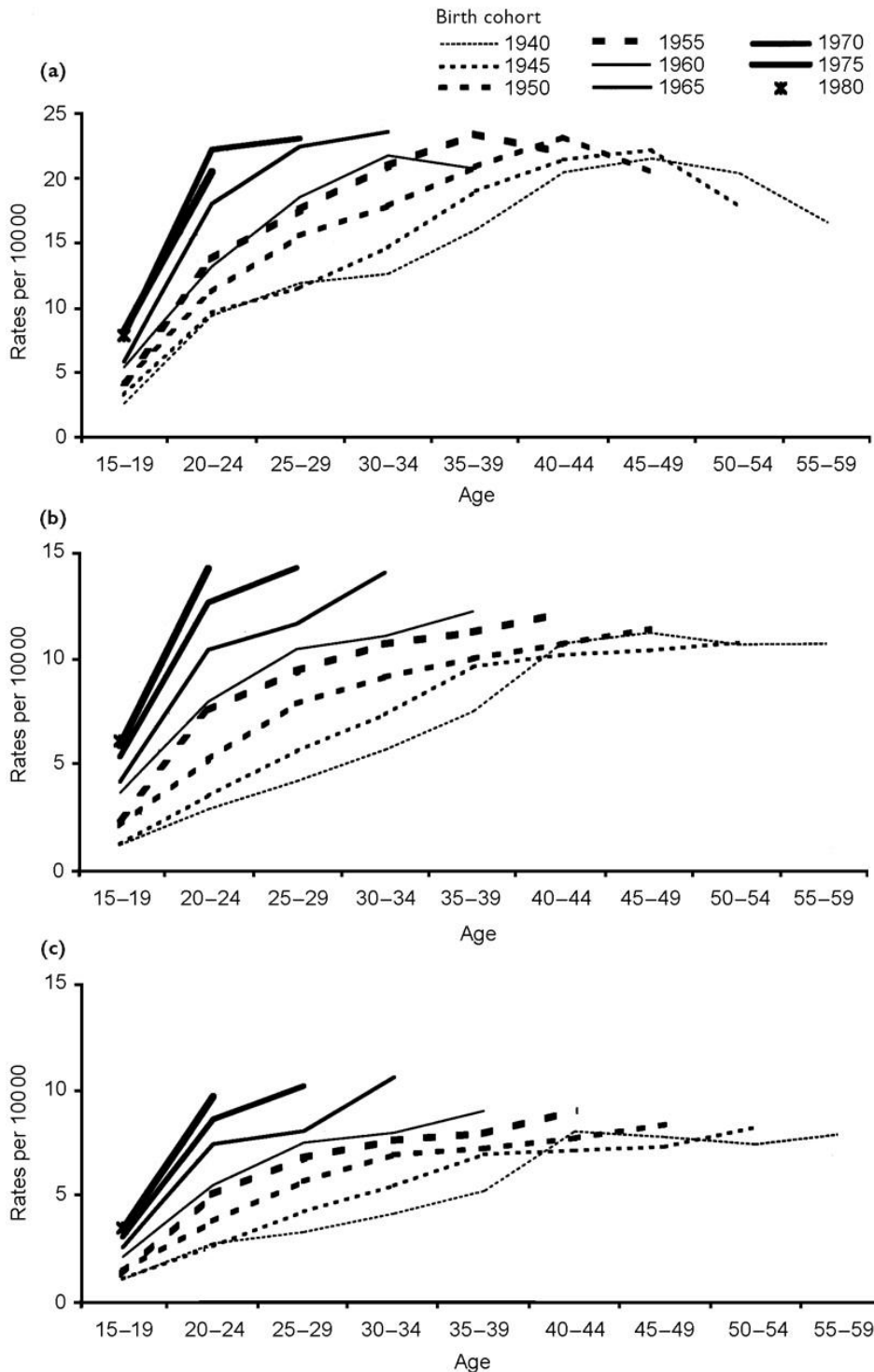


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### 4.3.3 Supplementary information S3

**Figure S3 Male rates of suicide and undetermined death in successive 5-year birth cohorts at different ages. (a) All suicides and undetermined deaths; (b) suicides and undetermined deaths except those by overdose and gassing; (c) overdose, gassing and undetermined deaths excluded.**



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#### **4.4 Statement of personal contribution**

This paper came about after a conversation with Dr Cameron Stark (CS), who had the idea of replicating the Gunnell et al 2003 study (72). Two co-authors (TA & RH) attended NRS in person to obtain data pre-dating the electronically available death registrations, entered the data in an Excel spreadsheet and gave it to me. My contribution was to add updated data to the Excel spreadsheet; learn about and decide the methodological approaches to analysis; conduct the statistical analysis; and interpret the main findings. I compared and contrasted the findings with that of Gunnell et al (72), and drafted the manuscript with input from CS. I submitted the manuscript, and dealt with revisions and further editing, with contributions from my co-authors.

#### **4.5 Contribution to science**

This paper was unique in providing 65 years of data, a lengthy period for studies of suicide and as far as I understand, the longest produced for a study of Scotland. As it utilised hand written records prior to the electronic registrations, it is important from a historical perspective in documenting patterns of suicide through time. It also enabled a direct comparison with suicide rates for England and Wales, revealing markedly different patterns. The methods used in this paper shed light on the trends, and attempted to assess whether trends were more a feature of age, period, or birth cohort. It was impossible to disentangle these; conclusions were rightly circumspect, however differences in data patterns between UK nations are useful for inductively generating hypothesis for empirical testing with data that are more detailed.



#### **4.5.1 Altmetric score**

The Altmetric Attention Score is an estimated weighted approximation of the attention a research paper receives (287). The score for this paper was seven, scoring higher than 81% of its peers and in the top 25% of all research outputs ever tracked by Altmetric. In terms of outputs from the BMC Public Health, this paper scored higher than 69% of its peers.

Link: <https://www.altmetric.com/details/30716789#score>

#### **4.6 Dissemination**

**4.6.1** See Appendix Table 1, Section 10.1 (PhD dissemination)

##### **4.6.2 Poster presentation (overleaf):**

Dougall N, Stark C, Agnew T, Henderson R, Maxwell M, Lambert P. Suicide trends in Scotland 1950-2014: comparison with England & Wales. At: Scottish Mental Health Research Network's Annual Scientific Meeting 2016

## Suicide trends in Scotland 1950-2014: comparison with England & Wales

<sup>1</sup>Nadine Dougall, <sup>2</sup>Cameron Stark, <sup>2</sup>Tim Agnew, <sup>2</sup>Rob Henderson, <sup>3</sup>Margaret Maxwell, <sup>4</sup>Paul Lambert

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### Background:

Scotland has disproportionately high rates of suicide compared with other UK countries. An analysis of trends can reveal whether rates appear more driven by age, period or birth cohort. A previous analysis of data for England & Wales\* reported that birth cohort was an important feature underpinning increased suicide patterns. We set out to replicate the analysis done for England & Wales and make comparisons of suicide patterns between the countries.

### Methods:

Suicide and corresponding general population data were obtained from the National Records of Scotland, 1950 to 2014. Age and gender specific mortality rates were estimated. Age, period and cohort effects were explored graphically.

### Results:

#### Comparison with England & Wales

A markedly different temporal pattern of suicide exists for Scotland compared with England & Wales (figures 1a, 1b & 2).

Although Scotland now has much higher suicide rates, this is a situation which reversed over time; England & Wales carried the suicide burden in the 1950s. For both Scotland, and England & Wales, suicide rates were highest after World War Two for older men.

Rates for England & Wales converged for all age groups in the late 1980s-1990s, but this was not the case in Scotland where alarming increases were seen in younger men, explained in part by the possible cohort effect noted below.

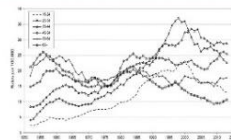


Figure 1(a) – Age-specific suicide rates for men in Scotland 1950-2014 (5 year moving averages) in ten year age bands for suicide as a result of intentional self-harm.

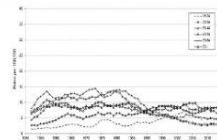


Figure 1(b) – Age specific suicide rates for women in Scotland 1950-2014 (5 year moving averages) in ten year age bands for suicide as a result of intentional self-harm.

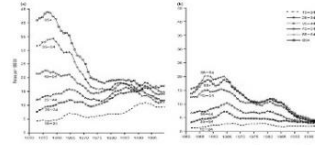


Figure 2 Age-standardised suicide rates: 1950-1999 England and Wales (3-year moving averages) in (a) males and (b) females (Reproduced with permission)

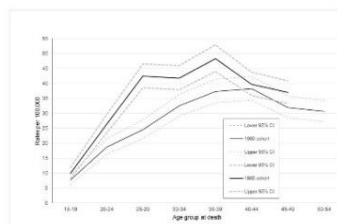


Figure 3. Scottish male suicide as a result of intentional self-harm and deaths of undetermined intent; 1960 and 1965 cohort incidences with 95% Confidence Intervals.

### Results:

#### Suggested Scottish cohort effect

There appears to be a particular influential effect on male suicide rates experienced by the 1965 and 1970 birth cohorts, corresponding to those aged 25 to 39 during 1995 to 2004. The 1965 cohort is statistically significantly different from the 1960 cohort (figure 3). This was not experienced in England & Wales.

Scottish female suicide rates for all age groups converged and stabilised over time. Women have not been as substantially affected by suicide as men, with less variation in patterns by different birth cohorts and with no convincing corresponding 'cohort' effect.

### Conclusion:

If this apparent 'cohort' effect persists, those at increased vulnerability for suicide in Scotland correspond to men aged 45-54 during 2015-19, and 50-59 during 2020-24. However, suicide rates associated with birth cohorts subsequent to 1975 were less severe, suggestive of an amelioration of any influential 'cohort' effect.

\* Gummell D, Middleton N, Whitley E, Dorling D, Frankel S: Influence of cohort effects on patterns of suicide in England and Wales, 1950-1999. *B J Psych* 2003, **182**: 164-70

## 4.7 Concluding remarks

In contrast to paper one, obtaining aggregated data for death by suicide was straightforward in comparison to individual level linked health and deaths data. Aggregated data was particularly advantageous in not requiring cleaning and operationalising, and without any associated cost.

In deciding methodological approaches, I reviewed literature at the time on age period cohort (APC) methodology, and determined that APC 'effects' were confounded, and impossible to disentangle (the 'identification problem') (288). However, this problem occurred when two conditions were present; firstly that 'age = period – cohort' (i.e. linearly dependent); and secondly, that each dimension was linearly related to the outcome (289). The second of these implied that the linear dependency could be overcome, provided some assumptions could be made about one of the three dimensions, meaning a model exploring APC did not treat all the variables as independent and additive (250).

In short, the issue related to APC methodology was related to the choice of method or model used, and was not data specific (290). The debates on the use of APC models, or which APC model, had no clear consensus (291). I made the decision that the most conservative, uncontroversial, analysis would not involve any modelling, but would be a descriptive analysis using graphs, as endorsed as a first step by experts in the field (292). This had been used in multiple comparison studies from other countries (72,293–296). In a comparison of Scotland's suicide data to England & Wales (72), it also seemed appropriate to replicate a similar analysis, with graphs portraying data in an identical way, thus permitting direct comparisons.

## **5. Paper 3: Ambulance psychiatric emergencies**

### **5.1 Background**

In this paper, attention turned to pre-hospital emergency care for mental health and distress. Very little data, if any, existed on outcomes for those attended to by the Scottish Ambulance Service. At the same time, it was highly probable that increasing mental health problems in communities and the erosion of provision and lack of access to mental health services (137), as alluded to in Chapter one, would have an increasing impact on emergency services. Coincidentally, NHS ISD had curated for the first time, the 'Unscheduled Care Dataset' (UCD) that linked NHS24, Scottish Ambulance Service, Emergency Department, hospital and deaths registrations, thereby offering an opportunity to evidence on outcomes.

In this paper, I collaborated with Dr Eddie Duncan (Principal Investigator), a health services researcher with expertise in pre-hospital emergency care. I brought knowledge and experience learned in previous research on data science, in using large linked health datasets and navigating ethics and approval systems. We obtained funding from the Chief Scientist Office of the Scottish Government in a dedicated health informatics call.

Our key findings were that in the following year after attendance for 'psychiatric emergency' by a paramedic, 4% had died, 35% of whom recorded as deaths by suicide (97 individuals). This confirmed an ongoing need for urgent action to better support individuals with mental health emergencies (10). Of the 97 deaths by suicide, 59 were still alive one day after admission to ED. Considering deaths by suicide numbered 7-800 a year in Scotland, this analysis found that 8% of deaths had been people identified as 'psychiatric emergencies' by paramedics in the previous year (10). Therefore, better pre-hospital emergency mental health care needs to be incorporated in the national suicide prevention strategy.

### **5.2 Reference**

Duncan EAS, Best C, Dougall N, Skar S, Evans J, Corfield AR, Fitzpatrick D, Goldie I, Maxwell M, Snooks H, Stark C, White C, Wojtek W.

Epidemiology of emergency ambulance service calls related to mental health problems and self harm: a national record linkage study. *Scand J Trauma Resusc Emerg Med.* 2019 Dec;27(1):34.  
<https://doi.org/10.1186/s13049-019-0611-9>


### **5.3 Paper 3 reproduced in full (overleaf)**

ORIGINAL RESEARCH

Open Access

# Epidemiology of emergency ambulance service calls related to mental health problems and self harm: a national record linkage study



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## Abstract

**Background:** People experiencing a mental health crisis receive variable and poorer quality care than those experiencing a physical health crisis. Little is known about the epidemiology, subsequent care pathways of mental health and self-harm emergencies attended by ambulance services, and subsequent all-cause mortality, including deaths by suicide. This is the first national epidemiological analysis of the processes and outcomes of people attended by an ambulance due to a mental health or self-harm emergency. The study aimed to describe patient characteristics, volume, case-mix, outcomes and care pathways following ambulance attendance in this patient population.

**Methods:** A linked data study of Scottish ambulance service, emergency department, acute inpatient and death records for adults aged  $\geq 16$  for one full year following index ambulance attendance in 2011.

**Results:** The ambulance service attended 6802 mental health or self harm coded patients on 9014 occasions. This represents 11% of all calls attended that year. Various pathways resulted from these attendances. Most frequent were those that resulted in transportation to and discharge from the emergency department ( $n = 4566/9014$ ; 51%). Some patients were left at home ( $n = 1003/9014$  attendances, 11%). Others were admitted to hospital ( $n = 2043/9014$ , 23%). Within 12 months of initial attendance, 279 (4%) patients had died, 97 of these were recorded as suicide.

**Conclusions:** This unique study finds that ambulance service and emergency departments are missing opportunities to provide better care to this population and in potentially avoidable mortality, morbidity and service burden. Developing and testing interventions for this patient group in pre-hospital and emergency department settings could lead to reductions in suicide, patient distress, and service usage.

**Keywords:** Mental health, Emergency department, Pre-hospital

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## Introduction

9,700,000 emergency calls were made to ambulance services in England and Scotland in 2014–2015. Patients who are experiencing a mental health emergency or who have self-harmed account for a substantial proportion (10%) of these calls [1, 2]. The care pathways and outcomes of the people attended by the ambulance service for a mental health crisis is currently unknown. It is plausible that people who are attend by the ambulance service for a mental health related emergency are at increased risk of suicide but this has not been previously investigated. Suicide is a pressing international public health issue with an estimated 804,000 people dying worldwide in 2012, corresponding to a standardised mortality rate (SMR) of 11.4 per 100,000. The SMR rate for the UK corresponds to 10.1 per 100,000 [3]. In the UK, as in many countries around the world, the leading cause of death in young people is suicide, and the Scottish Government declared suicide to be a significant public health concern, and following investment in suicide prevention, rates between 2002 and 2006 and 2013–2017 fell by 20% [4], equating to a SMR of 13.5 per 100,000 [5]. However, Scotland has disproportionately higher rates of suicide than its neighbouring country England, and for young men even more notably so [6], with corresponding significantly increased suicidal behaviour and suicide attempts observed in women [7]. Therefore the Scottish Government along with other national governments and the World Health Organisation [8] has renewed its commitment to suicide prevention and enshrined several strategic aims, including one where ‘people at risk of suicide feel able to ask for help, and have access to skilled staff and well-coordinated support’ [4]. Ensuring effective processes and positive outcomes for people experiencing a mental health crisis is essential. However quality of services and health outcomes for people who experience mental health crisis are highly variable and compare poorly to those received by people requiring a physical health emergency response [9]. The UK national mental health charity “Mind” has reported emergency care as inappropriate for people experiencing a mental health crisis, and staff as being unsympathetic to people’s situations [10].

This study investigates the epidemiology of mental health emergencies, including self-harm using Scottish Ambulance Service patient records. The Scottish health care system is a publicly funded National Health Service. The Scottish Ambulance Service is its national frontline emergency service. It provides an emergency ambulance service for the whole of Scotland, responding to over 600,000 emergency incidents per annum (2011 population 5.3 million). The study uses data from all calls to the Scottish Ambulance Service in 2011 to identify what proportion are for mental health related emergencies

and then, to describe: a) the characteristics of the population; b) their current care pathways; c) their clinical outcomes.

The aim of this study is to summarise information for people in contact with the ambulance service with mental health emergencies, so that opportunities are identified to develop interventions to decrease deaths by suicide, reduce distress, and avoid unnecessary emergency ambulance and emergency department contacts.

## Method

### Study design and setting

We conducted a retrospective cohort study of all patients attended by the Scottish Ambulance Service in 2011 with diagnostic codes relating to mental health emergencies or self-harm. We included all patients resident in Scotland and selected adults aged 16 or more years of age on first contact (as this is the age of legal capacity). The cohort was followed via linked records for at least one year, to the end of 2012. As the data have national coverage, there is no inherent selection bias.

### Data sources and pathway definitions

Data were extracted from the NHS Information Systems Division (ISD) Unscheduled Care Data Mart (UCDM) [11]. This provides person level linked-data using established probabilistic and deterministic matching techniques from the Scottish Ambulance Service, emergency departments (A&E2), general and psychiatric inpatient and day case hospital admission episodes (Scottish Morbidity Records SMR01 & SMR04) and death records, based on unique identifiers including NHS number, name and date of birth. The years 2011–2012 were selected as this was the most recent period in which the ambulance service perceived there to be reasonable data quality. Data were transferred and accessed through a secure connection to a data safe haven hosted by the Farr Institute and facilitated by ISD.

The data are organised in continuous care pathways. This includes all service use where contact with one service happens within 24 h of the previous service. Each service contact is denoted by a letter: Scottish Ambulance Service is “S”; Emergency Department, “E”; acute hospital services, “A”; and mental health services “M”. Therefore a pathway that involved attendance by an ambulance, then transport to the emergency department, then discharged and then return to the emergency department within 24 h would be coded “SEE”. Pathways included in the data set were truncated at 11 characters. One pathway could have more than one mental health emergency call. In these cases the pathways were duplicated in the data e.g. SEESE appeared as two rows in the data with the first connected to information on the first call and the second to the second.

### Derivation of variables to identify psychiatry emergencies and episodes of self-harm

The Scottish Ambulance Service uses a triage system called Advanced Medical Priority Despatch System (AMPDS) to provide symptom based intervention, record patients' most important condition, prioritise calls and allocate appropriate resources. An ambulance control centre call handler assigns an initial AMPDS code and an attending ambulance clinician confirms or amends this code following face to face assessment, thus producing 'final AMPDS' codes, which this study used. AMPDS codes are systematically checked by ambulance clinicians for all calls and updated as required. For this study we accessed only the final AMPDS codes, and therefore it was not known what proportion of calls switched from initial to final AMPDS codes. Furthermore, if mental health or self harm was identified in the narrative data, but not in the codes used these cases were not identified. Relevant patient attendances were identified using the list of Scottish Ambulance Service AMPDS code descriptions used by ambulance clinicians on attendance with the patient. A Scottish Ambulance Service lead with extensive knowledge and experience of using AMPDS in practice, met with members of the study team (EAD, DE, ND & SS) to select relevant codes. Only codes identified as directly relating to ambulance service psychiatric emergencies or self-harm were included in the data extraction. Codes were excluded if they could be used to describe a patient emergency or episode of self-harm (e.g. haemorrhage), but which could also relate to irrelevant cases. Following discussion and analysis of the complete data set the following codes were included:- 09E03 (Hanging); 17D02J (Falls, long fall (= > 6 ft./2 m) – Jumper); 17D03J (falls, unconscious or not alert – Jumper); 23 (intentional poisoning); 25A01 (psychiatric, non-suicidal without 1st party verification (alert & awake)); 25B01 (psychiatric, serious haemorrhage); 25B02 (psychiatric, minor haemorrhage); 25B03 (psychiatric, threatening suicide); 25B04 (psychiatric, jumper (threatening)); 25D01 (psychiatric, not alert). These codes therefore aimed to capture people clearly presenting with psychiatric emergencies, suicidal or self-harming behaviour, and were intended to maximise specificity to detect relevant records. Linked data relating to the selected AMPDS codes were extracted and placed in the safe haven for analysis.

The data received were arranged by mental health call. That is, there was one row in the spreadsheet for each care pathway containing a mental health call. Each person had a unique identifier and each person had more than one row in the table if they made more than one call. For each mental health call an individual's care pathway could have multiple visits to ED and multiple admissions to hospital and we received data regarding the dates and times of all these visits. To define the

index sample we identified all mental health calls made in 2011. The care pathways were sorted by frequency. The times between the index call and each subsequent point on the care pathway was calculated (i.e. time from call to arrival at ED, time in ED etc.)

To determine the number of repeat calls that were made within one year of the index call we reverted to the full data set (not just calls in 2011). The data were converted into person-period (wide) format with one row per person. Then the people who did not make their first call in 2011 were dropped. The times between all calls by the same individual were calculated to determine how many were made within 1 year of the index call.

In common with other routinely collected data studies [12], the data required to be cleaned to remove spaces and reconfigure the data in a format suitable for analysis. Algorithms were written using Stata to prepare the data for analysis. This Stata software code has been submitted to the GitHub, an Open Access Data Repository (<https://github.com/CathBest/PEPP-study>). This is an online archive of methods, models and codes relevant to processing administrative data. Code is freely available within the archive for other researchers to use.

### Pathway analysis

We began the pathway analysis after the first included ambulance service attendance of 2011 to determine the most common care pathway that occurred after someone had called ambulance service. We identified the four most common pathways and combined longer and more complex pathways into an 'other' category.

### Statistical analysis

Frequencies for categorical variables were reported as counts and percentages of all people or calls. For continuous variables the degree of deviation from the standard normal distribution was visually assessed. In all cases distributions were found to be non-normal. Therefore continuous variables were summarised by median and interquartile range. Bivariate relationships were analysed using chi squared tests for categorical variables and non-parametric Mann Whitney U tests for continuous variables.

### Results

The results have been reported in keeping with the RECORD checklist for studies conducted using observational routinely collected data [13] and the STROBE reporting guidelines for observational studies [14].

### Cohort characteristics

There were 9014 (out of around 500,000) calls from 6802 people for mental health emergencies in Scotland during 2011. This accounted for 11% of all-cause calls to



the ambulance service. Slightly more males ( $n = 4708$ , 52%) than females ( $n = 4306$ , 48%) were attended.

Table 1 presents the distribution of included calls by AMPDS description; almost half of the attendances were designated as 'alert & awake' (4315, 48%). Of all 9014 calls: 1816 (20.15%) were additionally tagged as alcohol-related; and 94 calls (1.04%) were tagged as drug-related.

#### Patient pathways

A total of 6802 people made an emergency call for a mental health or self harm problem and were attended by ambulance clinicians, in Scotland, in 2011 (Table 2). These people were followed up for 1 year each after their index attendance. Just over half of the people (52%,  $n = 3564$ ) had only the one index attendance. However, 3238 (47.6%) people were attended more than once, though not all calls were necessarily directly mental health related. Almost one fifth had a second attendance within 12 months (19%,  $n = 1294$ ), leaving almost one third of people with three or more attendances (29%,  $n = 1944$ ). One hundred people (1.5%) were attended by the ambulance service more than 16 times.

More than half of the people attended by the ambulance service ( $n = 4169/6802$ , 61.3%) were either discharged from an Emergency Department with no known follow-up ( $n = 3369/6802$ , 49.6%) or left at home, most likely because they refused to be transported to hospital, ( $n = 800/6802$ , 11.8%) (Table 3). (IQR: 87.4–198.8). The median length of stay for patients who were taken to the Emergency Department was 140 mins (IQR 87 to 199 mins). Almost a fifth of care pathways that ended in transfer to Emergency Departments resulted in self-discharge ( $n = 607/3615$ , 17%). People who self-discharged from the Emergency Department had a Median length of stay that was 50 min shorter than

those who did not (100.5 mins (IQR 52.4–150.7) vs 150.7 mins (IQR 98.3–209.7); two-sample Wilcoxon rank-sum test  $z = 14.64$   $p < 0.001$ . People who self-discharged from the Emergency Department before completion of treatment were 25% more likely to make another call to the ambulance service for a mental health emergency within the same year (Pearson chi square = 5.24,  $p = 0.02$  RR = 1.25) than people who completed treatment. Patients were 49% more likely to self-discharge if they were intoxicated with alcohol (person chi squared = 35.4,  $p < 0.001$  RR = 1.49). People admitted to an acute ward setting stayed for a median of one day, while people admitted to a psychiatric service stayed for a median of eight days.

#### Mortality outcomes at 1 year

279 (4.1%) of the 6802 people attended by an ambulance for a mental health emergency in Scotland in 2011 died within one year of first attendance. Just over one third of these 279 deaths were confirmed suicide ( $n = 97$ ; 34.8%). Of note, recording of suicides differs between Scotland and England and Wales. Whilst this may theoretically lead to slightly higher reporting of suicide in Scotland (as opposed to open or narrative verdicts in England), overall data have been shown to be comparable, and there is a higher rate of suicides in Scotland [5]. The remainder were attributed to 'accidents', 'mental and behavioural disorders' (e.g. dementia, alcohol dependence and drug dependence) ( $n = 64$ ; 23%), and long term conditions (e.g. malignant neoplasm; heart disease; diseases of the respiratory system) with co-morbid psychological distress that were not directly mental health related ( $n = 118$ ; 42%).

In order to examine cases where there may be the potential for upstream intervention to reduce mortality, deaths more than one day after attendance by the

**Table 1** Reasons for emergency call

Final AMPDS Description	Overall sample		Direct ambulance to Emergency Department transfers	
	N	%	N	%
Psychiatric, non-suicidal without 1st party verification (alert & awake)	4315	48	3338	45
Psychiatric, minor haemorrhage	2615	29	2307	31
Psychiatric, serious haemorrhage	1117	12	955	13
Intentional poisoning	697	8	639	9
Psychiatric, threatening suicide	129	1	120	2
Hanging	43	<1	15	<1
Psychiatric, jumper (threatening)	79	<1	59	<1
Falls, long fall ( $\geq 6$ ft./2 m) - Jumper	<15	<1	<15	<1
Falls, unconscious or not alert - Jumper	<15	<1	0	0
Psychiatric, not alert	<15	<1	<15	<1
TOTAL	9014	100	7450	100

**Table 2** Number of additional attendances to people who called for an ambulance for a mental health emergency within one year of the first call

Number of repeat attendances in 12 months	No. of people who called/ were attended to	Percent
0 (index call only)	3564	52.4
1	1294	19.02
2	646	9.5
3	366	5.38
4	218	3.2
5–9	459	6.75
10–14	155	2.28
15 to 101	100	1.47
Total	6802	100

ambulance service were examined, and found to number 240 (3.9%) of 6802 people after the index emergency mental health attendance. The highest rate of death by pathway was in those left at home by the ambulance ( $n = 51$ ; 6.4%), while the pathway with the highest number of deaths occurred in those transported and discharged from the Emergency Department ( $n = 80$ ; 1.3% of 6802 people). Therefore, almost half of all deaths > 1 day and < 1 year of call ( $n = 102$ ; 43%) were either not taken to hospital by the ambulance service (S) or were discharged from ED (SE). One quarter died by suicide ( $n = 59$ ; 25%) as confirmed by the corresponding death certificate for each person, of whom almost half ( $n = 27$ ; 46%) had previously been left at home by the ambulance service or discharged from an Emergency Department with no follow-up recorded within the hospital notes.

## Discussion

### Key findings

This is the first UK study to report the epidemiology of emergency ambulance attendances for mental health emergencies including self-harm, including linked record outcomes. Most people attended by the ambulance service were

either left at home or transported to and discharged from an Emergency Department. Though just over half of all people were only attended to once, repeat calls within 12 months were relatively common. People who were transported to ED but then self-discharged before completion of treatment were statistically more likely to make another emergency call to ambulance service within the same year. People were more likely to self-discharge themselves from the Emergency Department if they were intoxicated with alcohol.

Within 12 months of their first emergency call, 279 people (4.1%) had died, 97 (35%) recorded as suicide. People who were still alive after one day of index attendance numbered 240, of whom 59 were confirmed suicide. Given that in Scotland 772 people died by suicide in the year 2011, this suggests the ambulance clinicians were in contact with about 8% of these individuals.

### Comparison with other research

The proportion of attendances that were deemed to be psychiatric emergency or self-harm related was 11% of the final AMPDS codes of all-cause calls to the Scottish Ambulance Service. This compares with research reported for Victoria, Australia by Roggenkamp et al. [15], which estimated 9.5% of emergency attendances were mental health-related. A consideration in comparing these papers is that Scotland has a national health service, including the national ambulance service which is free to access at the point of contact, therefore incentives to gather additional data related to dedicated service utilisation, or secondary diagnoses on which people could be billed may not be present, and may explain some variation. With respect to gender we found just under half of calls (48%) were for women, this compares with Roggenkamp et al. [15] who found that the majority of attended calls were for women (57%), further suggesting different geographical and healthcare contexts are also at play.

### Limitations

In common with other record linkage studies [16], this study experienced problems with data quality and

**Table 3** Pathway by first call for people who were attended by ambulance clinicians, along with details of repeat attendances for those individuals, and mortality during the following year after first attendance

Pathway of 1st call	Pathway Frequency N (%)	Lowest SAS priority by final AMPDS code N (% Pathway Frequency)	Additional calls to ambulance service N (% Pathway Frequency)	Deaths within 1 day of call N (% by pathway)	Deaths > 1 day and < 1 year N (%people by pathway)
S	800 (11.8%)	498 (62.3%)	321 (40.1%)	29 (3.6%)	22 (2.8%)
SE	3369 (49.6%)	1579 (46.8%)	1630 (48.4%)	< 15	80 (2.4%)
SEA	995 (14.6%)	402 (40.4%)	455 (45.7%)	< 15	50 (5.3%)
SEM or SM	656 (9.7%)	354 (54.0%)	251 (38.3%)	0	27 (4.1%)
Other	982 (14.4%)	470 (48.1%)	581 (59.2%)	< 15	61 (6.2%)
Total	6802 (100%)	3303 (48.6%)	3238 (47.6%)	39 (0.6%)	240 (3.5%)

S Ambulance, E ED, A Acute admission, M Psychiatric hospital admission



accuracy. Missing data was most evident from the A&E2 and SMR1 data sets and this limited our ability to report demographic information on the sample e.g. ethnic group and area-level deprivation indices based on postcode. However data were complete for the outcomes reported in this paper. We used a data set from 2011, which was the most recent reliable year in which data was available at the time of the study. The passage of time and the increased focus of tackling stigma related to psychiatric emergencies and self-harm in Scotland may have altered current practice. We also found that data quality was variable across the differing datasets. Data completion was poorest in the Emergency Department (A&E2 data set) where missing triage data (33.9%) meant that it was not possible to calculate meaningful comparisons between ambulance and emergency department. The original figures provided to us by the Scottish Ambulance Service estimated an annual frequency of 30,000 mental health emergency related calls. Our study identified 9014 calls that we could be confident related to a mental health or self-harm emergency. This discrepancy occurred as a result of the codes that were included as relevant. Ambulance clinicians code calls by the predominant presenting condition. Therefore instances of mental health emergency or self-harm may not be recorded where these took second place to more urgent symptoms. In selecting the strictest criteria of the index event codes we recognise that we have a highly specified cohort at the expense of increased sensitivity to detect many relevant vulnerable people. Our estimates of outcome and service burden are therefore at the lower end of the possible range. Alcohol intoxication and substance misuse are not currently recorded as an AMPDS code. Instead these are separate optional field items that can be coded on the ambulance service electronic patient record as appropriate. Anecdotal feedback suggests that these items are not immediately apparent and their optional completion means that they are frequently not completed. It is therefore likely that the reported frequencies of alcohol intoxication and drug misuse are under reported, though we are unable to state what the missing proportion of cases are.

#### Implications for practice

Despite the study limitations the results have important implications for practice. Suicide is a leading cause of death in young people and a globally significant public health concern. Scotland is no exception with 746 deaths reported in 2013 equating to a standardised mortality rate of 13.5 per 100,000 [12]. Delivering effective suicide prevention strategies is challenging, as detecting people at risk of suicide is difficult. Our study shows that ambulance clinicians are well placed to identify people at risk of suicide. Just over 1% of people in the study cohort (97/6802) died by suicide within 12 months of their

initial presentation to the ambulance service. However, this represents approximately 13% of all people who died by suicide in Scotland within the same time period [12]. The ambulance service therefore have a unique opportunity to deliver a range of potential suicide prevention strategies through developing alternative care pathways to specialist mental health services, delivering suicide prevention interventions, and registering risk of suicide on admission to the Emergency Department.

The high levels of patient repeat mental health emergency calls, and frequency of self-discharges from Emergency Departments further emphasises the importance of developing evidence-based interventions to improve outcomes and reduce service burden. These findings may be explained by qualitative research that suggests that people who experience a psychiatric emergency or have self-harmed often feel that their needs are not met within an Emergency Department [10, 17]. The risk of people with a self-harm history self-discharging from Emergency Departments has, however, been known for over a decade [18]. Action should not be further delayed. Understanding both patients' experience of Emergency Departments and practitioners' perceptions of their competencies in dealing with this patient population would support intervention development, enable improvements in patient experience, and reduce rates of self-discharge and suicide.

Ambulance services are rapidly evolving to improve patient outcomes and reduce Emergency Department burden [16]. This places additional requirements and pressures on ambulance clinicians to make complex clinical judgements and decisions that were previously not required. Understanding effective and efficient methods to undertake service redesign and develop effective pre-hospital interventions are urgently required. In response to this need, the Scottish Government is currently piloting a Distress Brief Intervention Programme ([www.dbi.scot](http://www.dbi.scot)) that has been developed as a time limited and supportive problem solving intervention for this patient population. The aim is that this programme will improve patient outcomes and reduce demand on the ambulance service and emergency departments [19].

The importance of pre-hospital care settings in the development of suicide prevention strategies has been largely overlooked in Scottish suicide prevention policy to date [16]. Evidence-based suicide prevention strategies should be developed or adapted for pre-hospital emergency care settings. Ambulance services have a unique opportunity to target an identifiably vulnerable cohort and deliver a range of potential prevention strategies that could result in a meaningful decrease in suicides in Scotland. The development of effective interventions with this patient population would contribute to the achievement of NHS England [20] and Scottish

Government [21] policy objectives of reducing the number of mental health presentations to Emergency Departments.

Improvements to the processes and outcomes of people who call the Scottish Ambulance Service due to a mental health emergency are required. Half (62%) of the study cohort were either not taken to Emergency Department or were discharged from there with no recorded follow-up. Seventeen percent of calls that ended in an Emergency Department self-discharged prior to completion of their assessment or treatment. These people were more likely to make repeat calls and were potentially at greater risk of death by suicide. Focusing attention on this vulnerable group is likely to lead to improved patient outcomes and decreased service burden.

#### Future research

Linked data analysis using detailed data-sets such as the ISD unscheduled care data-mart can provide meaningful sources of clinical and service information that can be used to support intervention development and service reorganisation. The method used in this study could be replicated with other clinical conditions. The data from this study were presented at a key stakeholder workshop. The findings of this workshop will be published elsewhere. Data, however, only tell part of the story. Further study is required to understand patients' experience of Emergency Departments and practitioners' perceptions of their competencies in dealing with this patient population. Such knowledge would support future intervention development that should then be tested through pragmatic clinical trials.

#### Conclusion

In conclusion, the Scottish Ambulance Service dealt with over 9000 cases relating to a mental health emergency, including self-harm, in 2011. Both the ambulance service and Emergency Departments are currently missing opportunities to provide better care to this vulnerable population. This results in potentially avoidable mortality, increased levels of patient morbidity, and service burden. Developing and testing interventions and alternative care pathways for this patient group in pre-hospital and Emergency Department settings is urgently required. These have the potential to reduce suicide, patient distress, and service usage.

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#### Availability of data and materials

The dataset analysed for this study is available on application from NHS Scotland Information Services Division: <http://www.isdscotland.org/Health-Topics/Emergency-Care/Patient-Pathways/>

#### Authors' contributions

The study was conceived by EASD and DF. EASD led the study. All the authors contributed to elements of the study design. SS and CB undertook data analysis; ND provided expert statistical oversight; Clinical expertise was provided by DF (Ambulance), AC (Emergency Department) and CS & WW (Mental Health); lived experience and policy expertise was provided by IG and CW. ED and CB drafted the paper. All authors revised the manuscript for important intellectual content, and read and approved the final manuscript.

#### Ethics approval and consent to participate

The study was given ethical approval by the National Research Ethics Committee East Midlands – Derby (REC Ref. 15/EM/0260) and the NHS Scotland Public Benefit and Privacy Panel for Health and Social Care (Ref. 1516–0138). As this study involved pseudonymised secondary data analysis patients were not requested to participate or for consent to publish.

#### Competing interests

All authors declare no competing interests. No funder had any role in the design and conduct of the study; collection, management, analysis and interpretation of the data; preparation, review or approval of the manuscript; and decision to submit the manuscript for publication.

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## 5.4 Statement of personal contribution

This study stemmed from a data science project, funded by CSO in a dedicated health informatics funding call. Although I was co-investigator, I worked closely with Dr Eddie Duncan (ED; Principal Investigator) in applying for and obtaining funding. ED was a pre-hospital emergency care topic expert and I was a suicide topic expert with specialist knowledge using large linked datasets including hospital data, gleaned from my previous work (paper 1). This arrangement was mutually beneficial, however a more realistic set-up would have been with me as Co-PI, an arrangement that CSO and most other funding bodies did not permit. Nevertheless, without my leadership this study would not have been funded.

I led on the study design, edited and operationalised the research questions and ensured the methods would answer the Research Questions (RQs). In order to do this, I held discussions with NHS ISD to understand the 'Unscheduled Care Dataset' and how data was formed into 'pathways'. We were the first research team to use the UCD and inevitably, there were teething problems and a lack of documentation. I also met with Scottish Ambulance Service leads (with ED and DF) to decide relevant Advanced Medical Priority Despatch System (AMPDS) codes to use in analysis. I supported the application for approval to PBPP.

The grant funded two sequential Research Fellows (RFs: SS/ CB) to do the analysis, and I provided day-to-day guidance. I provided further oversight via weekly meetings attended by a core team (ND, ED, DF, SS/ CB). ED drafted the manuscript, and all co-authors had an opportunity to edit. I contributed to all sections of the manuscript, and its revisions, including framing the main findings to be relevant to national suicide prevention policy and in paragraphs related to suicide in the introduction, key findings, and comparison with other research. I now provide more context on the methodology.

This paper was a return to using individual level data. Each UCD record was tagged according to the organisation that created the episode. This was my first opportunity to use Ambulance Medical Priority Despatch System (AMPDS) and Emergency Departments data (ED, coded 'E'). A '999' call received by Scottish Ambulance Service (SAS, coded 'S') is assigned a 'working diagnosis' AMPDS code, finalised by the attending paramedic and entered in an electronic dashboard. Data is relayed to SAS, then checked and sent to NHS ISD, with the linkage

updated monthly. The UCD also contained NHS24 (coded 'N'), acute hospital ('A') and mental health hospital records ('M'), and the analysis made use of these pathway codes.

I used a cohort study design of incident calls made in 2011 tracked for one year for each person from first contact with SAS. I found that care pathways were much more heterogeneous than anticipated, with hundreds of different permutations, and some pathways containing long strings of letters, reflecting complexity of individual service contacts. For example, a pathway 'NNNSSEA', reflected three calls to NHS24, followed by two calls to SAS, with one resulting in transport to ED, followed by admission to general hospital. For this analysis, I made the decision to contract each pathway, so that the example above would be contracted to 'SEA', (dropping 'N' to fit research questions on what happens to people after contact with SAS). This provided a means of aggregating categories and estimating 'typical' pathway frequencies.

## **5.5 Contribution to science**

### **5.5.1 Altmetric score**

The Altmetric Attention Score is an estimated weighted approximation of the attention a research paper receives (287). The score for this paper was 50, scoring higher than 97% of its peers and in the top 5% of all research outputs ever tracked by Altmetric. In terms of outputs from the Scandinavian Journal of Trauma, Resuscitation and Emergency Medicine, this paper scored higher than 97% of its peers.

Link: <https://www.altmetric.com/details/57359345#score>

### **5.5.2 Mental health pathways**

The Distress Intervention Group of the Scottish Government's Health & Justice Collaborative Improvement Board used this paper as evidence to support revolutionising how emergency services respond to individuals in distress who dial '999'. The 'Enhanced Mental Health Pathways' project was established

(budget est. £2M), in collaboration with Scottish Ambulance Service (SAS; project lead), Police Scotland, and NHS24 (297), meeting action 14 of the SG Mental health Strategy 2017-2027 (153). Dedicated mental health nurses have been recruited to staff NHS24 to provide front line patient care, and calls made by people in distress are now diverted to NHS24, where calls are triaged, care provided, or escalated as necessary.

### **5.5.3 The Farr Institute '100 Ways' Case Study 11**

This paper formed the basis of Case Study 50 (overleaf) of the Farr Institute of Health Informatics Research '100 Ways of Using Data to Make Lives Better'. It may be accessed on the link below:

[https://www.researchgate.net/publication/324224374 How Data Can Help Find New Ways to Help People in Psychiatric Emergencies 100 Ways of Using Data to Make Lives Better A series from The Farr Institute of Health Informatics Research showcasing the UK'](https://www.researchgate.net/publication/324224374)



# 100 Ways of Using Data to Make Lives Better

A series from The Farr Institute of Health Informatics Research showcasing the UK's most significant examples of using data in research

## How Data Can Help Find New Ways to Help People in Psychiatric Emergencies

Researchers from Scottish universities and NHS Scotland used linked data to find out what happened to psychiatric patients admitted to emergency departments after they were discharged



Dr. Edward Duncan, Dr Josie Evans, Dr Silje Skar, Dr Catherine Best and Prof Margaret Maxwell, University of Stirling  
Nadine Dougall, Napier University  
Dr David Fitzpatrick, Scottish Ambulance Service  
Dr Alasdair Corfield, Royal Alexandra Hospital, Paisley  
Dr Cameron Stark, NHS Highland  
Dr Wojtek Wojcik, NHS Lothian  
Chris White, Mental Health Foundation  
Prof Helen Snooks, Swansea University

Public Health  
Case Study 50

### The Challenge

Every year the Scottish Ambulance Service (SAS) receives thousands of calls relating to self-harm or a psychiatric emergency. Most of these patients are taken to emergency departments (EDs) at hospitals.

Surprisingly, until now no research had been done on what happened to patients after their ED attendance. In order to provide epidemiological data, researchers from several Scottish universities and NHS Scotland came together to conduct a study.

### The Research

The researchers used linked anonymised data that provided them with information on the Ambulance Service, ED attendance, acute and mental health hospital episodes as well as Registrar General Scotland (RGS) recorded deaths. SAS attendances for 'psychiatric emergencies' or 'self-harm' were extracted for 2011 and 2012. People were followed up from their first contact with the SAS in 2011 for one year.

### The Results

In 2011, around nine thousand calls (made by 6,802 people) were attended by the SAS.

The most common four care pathways were:

1. transport to and discharge from ED (51%),
2. transport to ED and inpatient acute admission (14%),
3. attendance with no transfer, i.e. left primarily at home (11%),
4. transport via ED or directly to inpatient mental health admission (9%).

Within 12 months of their first recorded call, one in 25 people had died

(279), including 97 people recorded as suicide (35%). Remaining deaths were 'accidents', 'mental and behavioural disorders' and 'other' (long-term conditions with associated psychological distress).

Of the 279 people who died within one year of being seen in 2011, most were still alive after one day (240), with 1 in 4 (59) confirmed deaths by suicide.

In 2011 in Scotland there were 772 people recorded by the RGS as dying by suicide; this implies the SAS were in contact with about 8% (59/772) of people whilst still alive.

### The Impact

There is a potential important benefit from implementing new suicide prevention interventions, and building resilience in people who habitually self-harm and call SAS, and are coded by paramedics as 'psychiatric emergency' or 'self-harm'.

Only very recently has ambulance service become routinely linked to other datasets, including mortality outcomes. This study highlights the enormous potential of linked data and provides completely new insights into the behaviour of people who self-harm and are suicidal. Opportunities now exist to develop new programmes of work targeting specific cohorts.

For more information about this research visit: <http://www.primecentre.wales/development-of-an-improved-care-pathway.php>

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## **5.6 Dissemination**

This paper was disseminated quite widely as conference presentations, and attracted a prize, (see Appendix Table 1, section 10.1 for further details).

### **5.6.1 Poster presentation (overleaf)**

Presented by N Dougall on behalf of Duncan E, Dougall N, Fitzpatrick D, Evans J, Skar S, Best C, Corfield A, Stark C, Wojcik W, Goldie I, Snooks H, Maxwell M. Care pathways for psychiatric and self-harm emergencies attended by Scottish Ambulance Service, at the Scottish Mental Health Research Network Annual Scientific Meeting 2016.

## Care pathways for psychiatric and self-harm emergencies attended by Scottish Ambulance Service

<sup>1</sup>Edward Duncan, <sup>2</sup>Nadine Dougall, <sup>1,5,6</sup>David Fitzpatrick, <sup>3</sup>Josie Evans, <sup>1</sup>Silje Skar, <sup>3</sup>Cath Best, <sup>4</sup>Alasdair Corfield, <sup>5</sup>Cameron Stark, <sup>6</sup>Wojtek Wojcik, <sup>7</sup>Isabella Goldie, <sup>7</sup>Chris White, <sup>8</sup>Helen Snooks, <sup>9</sup>Margaret Maxwell

<sup>1</sup>NMAHP Research Unit, University of Stirling; <sup>2</sup>School of Health & Social Care, Edinburgh Napier University; <sup>3</sup>Faculty of Health Sciences & Sport, University of Stirling; <sup>4</sup>Emergency Dept, Royal Alexandra Hospital, NHS Greater Glasgow & Clyde; <sup>5</sup>Dept of Public Health, NHS Highland; <sup>6</sup>Dept of Psychological Medicine, Royal Infirmary, NHS Lothian; <sup>7</sup>Mental Health Foundation; <sup>8</sup>Institute of Life Science, Swansea University; <sup>9</sup>Scottish Ambulance Service

### Background & Aim

People with 'psychiatric emergencies' account for thousands of Scottish Ambulance Service (SAS) call-outs every year. The overwhelming majority are taken to Emergency Departments (ED). Many people could benefit from better management in ED and are at increased risk of suicide and repeat ED attendance.

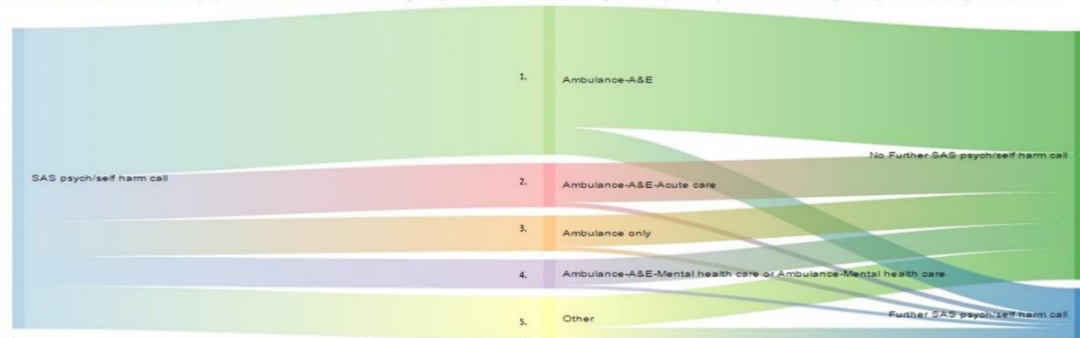
An alternative care pathway may decrease mortality and morbidity levels, and reduce ED service burden. The main aim of this study was to provide epidemiological data previously unavailable on care pathways for people who call the SAS on '999' with psychiatric emergency or self-harm.

### Methods

The 'Unscheduled Care Datamart' (UCD) is a new NHS ISD dataset which links data from SAS, EDs, acute and psychiatric hospital admissions, and deaths data. Individual level UCD data were extracted for the year 2011 for those aged 15y+ who were attended by SAS following '999' calls and designated by paramedics as a 'psychiatric emergency'.

### Results

There were **9,014** calls for 'psychiatric or self-harm emergency' made to SAS resulting in **823** pathways. The most frequent pathways (Figure 1) were:



**CALLS ATTENDED BY SAS**  
9,014 calls for psychiatric emergency  
1,003 left at home  
8,011 transported to destination

**TRANSPORTED TO DESTINATION**  
1. SAS -> ED -> Discharge: 4,566 calls (51%); average time spent in ED of 140 minutes  
2. SAS -> ED -> Admission to hosp: 1,250 calls (14%); average time spent in ED of 188 mins, followed by 1 day in hospital  
3. SAS only, left at home & no transfer to ED: 1,003 calls (11%)  
4. SAS -> ED -> Mental Health admission or SAS -> Mental Health admission: 793 calls (9%); average time spent in ED of 188 mins, followed by 8 days hospital stay  
5. Other: 1,402 calls (15%); average time spent in ED of 153 mins, followed by 10 days hospital stay

**REPEAT CALLS WITHIN 1 YEAR**  
5,624 people made 1 call (83%)  
739 people made 2 calls (11%)  
211 people made 3 calls (3%)  
96 people made 4 calls (1%)  
132 people made 5+ calls (2%)  
  
People who self-discharged from ED were significantly more likely to make another call to SAS within 1 year ( $\chi^2=5.2$ ;  $p=0.02$ ).

Deaths: 115 (1%) people died within one year

### Conclusions

The most common pathway was transfer by paramedics to Emergency Departments, where people spent 2h 20 minutes on average before they were discharged home. This suggests an opportunity for an intervention for those individuals who are deemed to be in low risk categories for physical ill-health. Study funded by the Chief Scientist Office (HICG/1/27)

## 5.7 Concluding remarks

Almost half (4,315) calls related to people who were ‘non-suicidal, alert and awake’, with 3,338 of these calls being transported to ED. Future research could explore whether diverting people away from ED to dedicated community resources could have benefit. Ditto, the 2,615 calls with ‘minor haemorrhage’ could be attended to by a mental health worker trained in first aid skills, instead of transport to ED. This highlights a systemic problem, where transport to ED was frequently the *only* care pathway open to paramedics. However, with interventions since rolled out, e.g. the Distress Brief Intervention (see Chapter one) or the Enhanced Mental Health Pathway test of change (in progress), calls related to ‘distress’ may now be handled more appropriately – however, final evaluations are awaited.

In reviewing this paper I uncovered an error. There were 9,014 calls made from 0.5M all-cause calls; accounting for 1.8% of calls, not 11% as reported, and short by a factor of three of the SAS estimated number (30,000). This means the sampling based on the chosen AMPDS codes was a highly specified category of ‘psychiatric emergencies’. Future research could widen AMPDS codes to include broader definitions. Also to note, in the pre-specification of UCD variables to PBPP, age was missing as a variable, a notable oversight and unnoticed until the end when patient characteristics were being summarised. Neither of these mistakes alter any other key findings.

## 6. Paper 4: Review of vulnerability assessment

### 6.1 Background

This paper came about in a convoluted way and I now briefly describe the journey. The original research question I had was on suicide outcomes after police contact, an expansion to the Scottish Ambulance Service study (paper 3). UK has an increasing problem of police call-outs for people with vulnerability and mental health concerns (179,190), with some 80% of calls non-crime related (11). Policing data could provide evidence of effectiveness of any intervention, and there is a precedent for linked police and health data, e.g. the 'Reading model' exemplified in the Centre of Excellence for Information Sharing (182,298). With an established precedent, it seemed plausible Scotland could do the same.

In discussions with Police Scotland, they were enthusiastic about analytical work; anecdotally, there were concerns for welfare of highly 'vulnerable' people, and a strong sense that with increased partnership working, communities could respond better to people without significant investment. Responses could include referrals for practical support, earlier intervention with young people, diversion from custodial sentences, triaging calls to psychiatric nurses in control rooms, etc. There was consensus that measuring outcomes was fundamental to provide evidence of initiatives in local communities, and police wanted to use data for public good.

From a data linkage perspective, the process was feasible if policing data were shared with NHS ISD or Scottish Centre for Administrative Data Research (SCADR). However, accessing data proved too challenging within the timescale, for three main reasons. Firstly, Police Scotland were yet to appoint a Research Manager to support navigating the organisation, including the ethics process for use of data. Secondly, information governance officers had not been involved from the outset, and there was a lag in liaising with the right people. Finally, as data sharing had not been done before, there was understandable ambiguity around how to proceed.

Another barrier to using policing data was the need for public engagement, that there may be strong feelings around any re-use of linked police data for research

purposes. Gaining lived experience perspectives were needed, even if the data use would pass a GDPR 'public interest' test (see also chapter 2, section 2.2.7.4).

In discussions around extending an analysis for outcomes of suicide after policing contacts, I soon realised this was not a main concern of Police Scotland, who were concerned with responding better to people with complex needs and keeping them alive. There were a number of pressing issues, not least the substantial increase in 2018 of drug-related deaths (299). For research to be productive and have an impact on policing practice, it had to be a mutually agreed priority (298), and people with lived experience of vulnerability in policing contexts needed to be involved. I met several times with a lived experience representative from Mental Health Foundation Scotland, who has published about policing encounters since (184).

A consensus needed to be established of the most important national issues, if not with epidemiological data as originally intended, then with evidence synthesis. My colleagues and I obtained competitive funding from the Scottish Institute of Policing Research (SIPR) to run a national workshop and identify national consensus priorities (300). A multi-agency event was organised by our research team, with senior representation from policing, ambulance service, NHS24, people with lived and living experience, academics, mental health nurses, emergency medicine, liaison psychiatry and psychology, policy makers and third sector. Workshop findings have now been published (7).

Agreement was reached on five national research priorities, namely: 1) 'Vulnerability, and how to assess this meaningfully'; 2) 'Mental health crisis, shared decision-making across professions for better care and response, especially around suicide'; 3) 'Better partnership working'; 4) 'Better use of technology with information and data sharing'; 5) 'peer support and staff wellbeing' (7,300). This workshop demonstrated that multi-agency working was possible with complex problems, in line with growing recognition of the need for collaborative leadership (182,301).

As per the first priority identified, improving the assessment of vulnerability was needed, in line with Police Scotland Strategy 2026 with a primary priority of protecting 'vulnerable' people (191). Although 'vulnerability' is common policing terminology, an agreed definition did not exist. Research on vulnerability has traditionally focussed on fixed individual characteristics such as age and ethnicity



(5). Only more recently has literature shifted to convey vulnerability as a sociological construct, one that offers scope to improve inter-agency responses and remove barriers to working (5,7), reflecting a 'susceptibility to increased harm', and incorporating cross-disciplinary interest (5).

As it seemed impossible to identify a formal definition of 'vulnerability' in the policing and public health literature, my co-authors and I agreed to commence with a systematic literature review to both define vulnerability, and the assessment of vulnerability. My co-authors are necessarily inter-disciplinary, spanning public risk management, decision-making, forensic psychology, mental health research and nursing, criminology and policing. The overall aim was to develop a practical model of vulnerability assessment informed by evidence, and to engage practitioners in an assessment of utility.

## **6.2 Reference**

Enang, I., Murray, J., Dougall, N., Wooff, A., Heyman, I., & Aston, E. (2019). Defining and Assessing vulnerability within law enforcement and public health organisations: A scoping review. *Health and Justice*, 2019: 7(2).  
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## **6.3 Paper 4 reproduced in full**

RESEARCH ARTICLE

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# Defining and assessing vulnerability within law enforcement and public health organisations: a scoping review



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## Abstract

**Background:** Historically, police departments focused solely on criminal justice issues. Recently, there has been a dynamic shift in focus, with Law Enforcement professional groups assuming more responsibility for tackling mental health and distress-related issues (that may arise because of mental health related problems and learning disabilities) alongside Public Health departments. While Law Enforcement has become a 'last line of support' and an increasing partner in mental health support, there is partnership working between law enforcement, psychology, and health professions in training and mental health service delivery. The term vulnerability is frequently used across Law Enforcement and Public Health (LEPH) to identify those in need of these services. Effective vulnerability assessment is therefore expected to prevent unintentional harmful health and criminal justice consequences and manage the negative impact of such in cases where prevention is not possible. This scoping review aimed to identify how vulnerability is defined and assessed across LEPH organisations.

**Results:** Vulnerability is context-specific from a Law Enforcement perspective, and person-specific from a Public Health perspective. Definitions of vulnerability are at best fragmented, while models for assessing vulnerability lack uniformity across LEPH. The implications are two-fold. For "vulnerable groups", the lack of an evidence-based definition and assessment model could prevent access to relevant LEPH services, exacerbating issues of multiple vulnerabilities, co-morbidity, and/or dual diagnosis. All could inadvertently enable social exclusion of vulnerable groups from political discourse and policy interventions. The lack of consistency regarding vulnerability may result in reactive crisis responses as opposed to proactive preventative measures.

**Conclusions:** This scoping review exposes the complexities associated with defining and assessing vulnerability from a LEPH perspective, which are perceived and prioritised differently across the organizations. Future research must bridge this gap. Building on the establishment of a definition of vulnerability within the empirical literature, researchers ought to engage with service users, LEPH staff, and those engaged in policy making to craft effective vulnerability definitions and assessment models. Only through evidence based, co-produced definitions and assessment models for vulnerability can we ensure that best-practice, but also meaningful and feasible practice, in vulnerability assessment can be achieved.

**Keywords:** Law enforcement, Public health, Policing, Vulnerability, Vulnerability assessment

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## Background

There is increasing international recognition that greater emphasis on partnership working across the intersect of policing and public health is a necessity (Police Scotland, 2017; Punch & James, 2017). Despite the different contexts in which policing (traditionally linked to criminal justice and establishing law and order) and public health (provision of physical, mental, and social well-being) operate, both fields share similar complex challenges; necessitating closer partnership working between them (Van Dijk & Crofts, 2017). One of these complex challenges relates to vulnerability.

Vulnerability has been defined in different ways, depending upon the field and literature being discussed. One example which offers an ‘all encompassing’ perspective outlines vulnerability as a state or condition whereby a person is in danger, under threat, experiencing health challenges, at risk, and/or requiring support/protection (Larkin, 2009). This definition suggests, then, that anyone can be vulnerable at any point in time, and that vulnerability is not a stable state across situations and the lifespan. While this is a useful way to consider vulnerability – as a holistic, variable construct – it may be considered too broad a construct to then develop assessment strategies and protocols, form policies, and indeed understand within the specific remit of law enforcement and public health.

Vulnerability is a key concern across policing and public health partners (Murray et al., 2018), with increasing prioritisation being given to the identification, assessment, and management of vulnerable victims and perpetrators of crime (College of Policing, 2018; Department of Health, 2014). Indeed, Police Scotland Strategy 2026 notes that top priority is to protect vulnerable people (Police Scotland, 2017). Despite this, there appears to be no unified definition of vulnerability across policing and public health practices, or within the policy documentation or literature. This, then, inhibits our understandings of what vulnerability means at the intersect of policing and public health, and makes the identification, assessment, and management of vulnerable people challenging for police and health professionals. Equally, should a unified understanding and shared definition of vulnerability be established and adopted across the intersect of policing and public health, communication, decision making, and management of vulnerable people with complex needs across the criminal justice and health systems could be improved.

The current scoping review aims to identify how vulnerability is defined and assessed in relation to the adult population across Law Enforcement and Public Health (LEPH). It focuses on collaborative partnership working across LEPH. For the purposes of the current review, we will use ‘Law Enforcement’ in a broad sense, recognising

that the role of law and policing professionals is much broader than enforcement. We therefore adopt the broader context of the role, including working with the public and other partners, community engagement, etc. Public Health, again, adopts a broad definition, including any health and social care professional who works with individuals who could be considered or who consider themselves as vulnerable.

Scoping reviews are conducted for a variety of reasons including: conceptual mapping<sup>1</sup> (Anderson et al., 2008); literature mapping<sup>2</sup> (Anderson et al., 2008; Ehrich et al., 2002); policy mapping<sup>3</sup> (Anderson et al., 2008); and identification of research gaps (Arksey & O’Mally, 2005), including the extent and nature of research evidence (Grant et al., 2009). From a LEPH perspective, the current review was required and carried out to address three interrelated issues. First, to conceptually map and lend understanding to how the term ‘vulnerability’ is defined and the context in which it is used in different countries and LEPH organizations (Anderson et al., 2008). Second, to identify the models or methods of vulnerability assessment as presented in these documents (Grant et al., 2009). Building on the first and second aims, the third seeks to identify under-researched areas within the context of vulnerability assessment in LEPH (Ehrich et al., 2002) to identify key research priorities for future research in vulnerability and assessment across LEPH.

The selected methodological approach aligns with Arksey and O’Mally’s (2005) six stage framework, and incorporates recommendations provided by Levac et al. (2010). The stages of the framework are: identifying a research question; finding appropriate studies; selecting the studies; conducting content analysis via the synthesis and interpretation of qualitative data; organizing, summarizing and recording results; and stakeholder consultation. Discussions within the current review are structured according to these sections for the readers’ ease.

## Methods

### Stage 1: Identifying a research question

The central research question for the current review asks: “What can we learn from extant literature about how LEPH professional groups define and assess vulnerability within the adult population?”

The central research question was divided into two sub-questions to ensure that the critical elements (vulnerability definition and vulnerability assessment) of the study were effectively addressed:

1. From a LEPH perspective how is vulnerability defined within the adult population?

2. Considering this demographic, do models for vulnerability assessment exist within or across LEPH professional groups?

**Stage 2: Finding appropriate studies**

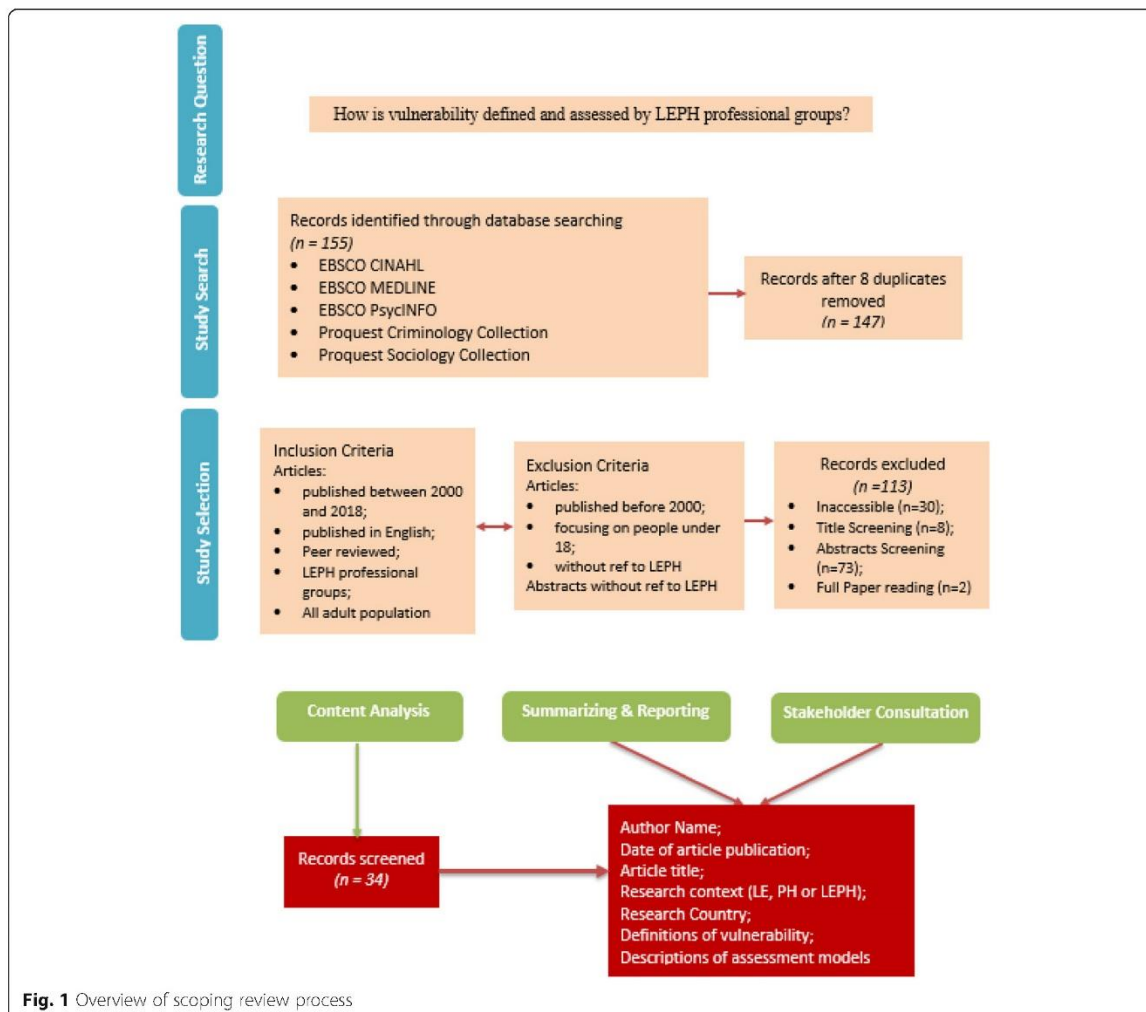
Following the identification of the research question and sub-questions, the next step entailed finding appropriate studies. To this end, inclusion and exclusion criteria were developed as presented in Fig. 1 and Table 1.

**Inclusion criteria**

As indicated in Table 1, articles included for review were published in English, between the years 2000–2018. The year 2000 was selected because the Adults with Incapacity (Scotland) Act 2000 was passed then (The Scottish Government, 2008) and the research team are based within Scotland hence its contextual relevance.

The date of publication of this legislation in Scotland was key as it led the way towards recognising the limitations faced by adults with mental health challenges across LEPH contexts. It is instrumental to the current review because mental health problems are associated with vulnerability across LEPH organizations, although it must be acknowledged that mental health problems are not to be viewed as synonymous with vulnerability, as detailed in the Adult Support and Protection Act (2007) (The Scottish Government, 2018). The years 2010 and 2013 were also of particular relevance to the current review from a healthcare and emergency services policy perspective.

The year 2010 was selected because from a Public Health perspective, the Healthcare Quality Strategy for NHS Scotland was published then. This strategy promotes partnership working between key NHS stakeholders



**Fig. 1** Overview of scoping review process



**Table 1** Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion criteria
Articles published in English	Articles published in a language other than English
Articles published between 2000 and 2018	Articles published before 2000
Articles discussing vulnerability and vulnerability assessment	Abstracts without reference to vulnerability
All adult population (> 18 y/o)	Children and young people below 18 years old
LEPH professional groups in any country	Articles without references to LEPH professional groups
Articles retrieved from five key databases: Cumulative Index of Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval System Online (MEDLINE), Psychological Information Database (PsycINFO), Criminology Collection, and Sociology Collection	Book chapters and non-peer reviewed articles

including service users (patients, carers, general public) and service providers (local authorities, third sector and the NHS). It aims to provide excellent health services to service users in Scotland (The Scottish Government, 2010). Similarly, the Police and Fire Reform (Scotland) 2012 Act was operational in 2013 and involved merging of policing, and fire and rescue services (The Scottish Parliament, 2012). The reform aims to ensure increased equity of access to specialised services while protecting and enhancing service delivery; improve national capacity in times of crises (for example flooding); and strengthening relationships between service users and providers by promoting the engagement of local councillors in designing and integrating local services with communities (The Scottish Government, 2017). Furthermore, the purpose of policing enshrined within the Police and Fire Reform Scotland Act (2012) is to improve safety and wellbeing by working in collaboration with others, further emphasising the need for shared understandings across working partners in LEPH.

In line with the research question and sub-questions, the articles selected were limited to those which discussed vulnerability including its assessment. This was considered within the context of LEPH. Vulnerability is perceived differently in children and adults within legal definitions. Therefore, focusing on a specific demographic, namely the adult population prevented ambiguity in the research results. While in Scotland, the legislation considers vulnerable adults to be those aged 16 years and over (Adult Support and Protection Act, 2007), this is not the commonly held stance on adulthood internationally, with the majority of countries considering adulthood as 18 years and older. We therefore decided to adopt the wider-adopted 18 years and older definition within the current scoping review to allow international consistency across the literature searching and inclusion. CINAHL, MEDLINE, PsycINFO, Criminology Collection, and Sociology Collection were selected as key databases because they contain articles that address LEPH matters.

#### **Exclusion criteria**

This research is targeted at a global audience including LEPH departments, governments/policy makers, and academic researchers. Accordingly, the research findings are intended to:

- Raise global awareness of issues relating to vulnerability identification and assessment across LEPH departments. Since vulnerability assessment is a growing concern across LEPH departments, we believe that it is more expedient to focus on findings from contemporary studies which might reflect this new reality; hence the exclusion of papers published before the year 2000;
- Guide Governments in strategic decision-making. As government policies and strategic plans typically span a 10-year period, it is necessary to consider contemporary studies focusing on vulnerability definitions and assessments. This is another reason why we excluded papers published prior to 2000.

To some extent, some of the other exclusion criteria (articulated next) constitute research limitations. First, articles published in a language other than English were excluded. This was due to funding and time limitations, including the lack of a multi-lingual member in our six member research team. In so doing, we acknowledge that some relevant papers may have been excluded.

Second, the adult age as articulated in the exclusion criteria, is from 18 years and above. As the Adult Support and Protection Legislation in Scotland categorises people from 16 years and above as adults (Care Information Scotland, 2018), the findings of this review may exclude young adults between 16 years old and those just under 18 years old; constituting a limitation. However, as detailed earlier, the need to consider the international context, rather than only the local context of the authors, was considered desirable for the current review, and as the majority of international legislation considers

adulthood to begin at 18 years old, we chose this upper threshold. That said, we would encourage future authors to consider carefully whether to expand the definition of adulthood to begin at 16 years old. Similarly, grey literature was not included because these are not usually peer reviewed.

Third, articles that did not explicitly mention the word 'vulnerability' in their abstract were excluded. As our key focus was on vulnerability, we felt that articles that did not mention vulnerability specifically in their abstract might not discuss vulnerability as thoroughly as required to address our research question. The key purpose of the paper was to identify definitions of vulnerability across LEPH; the use of synonyms to depict vulnerability was considered as a potential confounding factor. Therefore, including only papers with vulnerability in the abstract and which later discussed vulnerability as a construct in depth allowed for definitions across LEPH to be drawn out and considered. For this reason, papers that failed to discuss vulnerability from a LEPH perspective in the body of the article were also excluded. We agree that some relevant papers may have been excluded due to the vagueness of the term in everyday language use, and restrictions to abstract length and content in some journals. Thus, to some degree, the abstract screening constitutes a limitation. We also acknowledge the relevance of bringing together a unified 'language' for understanding vulnerability as a concept. Still, trying to encapsulate every potential descriptor for vulnerable people would be outside the scope of the current scoping review and could be a piece of work in its own right.

Fourth, although there are some excellent peer reviewed book chapters published, many are also not peer reviewed. Peer reviewed articles are typically reviewed by academics, contain subject-relevant terms, subjected to a thorough assessment process and are targeted at researchers and professionals. Book chapters and non-peer reviewed articles were excluded because they do not always meet these criteria. Due to the heterogeneity of peer review and the absence of a process to identify peer reviewed book chapters, we chose to omit all book chapters from this scoping review. Nonetheless, the decision to include only known peer reviewed sources may have led to unintentional exclusion of some relevant sources.

Considering these limitations, we suggest that subsequent reviews should consider including: publications in languages other than English, grey literature to enable deeper insight into vulnerability assessments from LEPH perspectives; synonyms of vulnerability during the search for relevant articles; and book chapters.

### Stage 3: Selecting the studies

In applying the inclusion and exclusion criteria, boundaries were established which aided in the

selection of relevant studies. See [Appendix](#) for the CINAHL, MEDLINE, PsycINFO search criteria which we conducted via the EBSCO platform. As limits were not placed on the country of study or publication, studies from different countries were included in the review. Thus, vulnerability definitions and assessments could be identified from different geographical contexts, enabling analytical breadth and international relevance.

### Stage 4: Conducting content analysis

Relevant articles were exported from CINAHL, MEDLINE, PsycINFO, Criminology Collection, and Sociology Collection into *Endnote* reference management software for storage and referral purposes. Following title and abstract screening, the remaining papers were subsequently exported to *NVivo* (qualitative data analysis software), to enable effective, efficient and transparent content analysis. Specifically, a *Text Search Query* was conducted to retrieve discussions on vulnerability. The findings included the following headings:

- Author name and date
- Article title
- Journal name
- Research country
- Research context (Law Enforcement, Public Health, or both)
- Discussions involving definitions of vulnerability and brief descriptions of vulnerability assessment, if any
- Vulnerability associations
- Research gaps.

### Stage 5: Recording, organising and summarising the result

#### *Recording the result*

As indicated in Fig. 1, 155 records were identified by searching through the five key databases. Eight duplicates were removed. Following the application of the inclusion and exclusion criteria, an additional 113 records were removed. Of these 113 records, 30<sup>4</sup> were removed because they were inaccessible, eight because their titles did not align with the research question, and 73 because their abstracts did not refer to 'vulnerable' or 'vulnerability'. After the full paper reading of the remaining papers, two were removed because they failed to address the research question. The 34 remaining records met the inclusion criteria and were considered eligible for screening and content analysis via *NVivo 10*. The following sections organize the results in terms of vulnerability definitions and vulnerability assessment.



### Organising the Results

**Vulnerability definitions** The scoping review revealed that definitions of vulnerability are at best fragmented, with only four of the 34 reviewed articles providing explicit definitions of vulnerability as indicated in Table 2.

**Vulnerability assessment** The scoping review showed that models for assessing vulnerability lack uniformity across LEPH because it is prioritised differently across these organizations. Tables 3, 4 and 5 show this in more detail. From a Law Enforcement perspective, only one model for vulnerability assessment was identified (See Table 3). It was based on how likely individuals think they may be suitable crime targets, and their ease of accessing social support (Gaitan & Shen, 2018). The assessment model indicated that vulnerability was associated with poverty and perceptions of risk. From a Public Health perspective, five different models for vulnerability assessment were identified. These include:

- Psychosocial Recovery and Development in East Timor (PRADET) (Amiral et al., 2004)
- Rhodes et al.'s (2005, 2012) framework of socio-structural vulnerability
- The use of self-reporting (Thorpe et al., 2011)
- The use of Critical Incident Inventory (CCI) which measures exposure to critical incidents (Ward et al., 2006)

- The use of vulnerability definitions (Whitelock, 2009)

Within this context, vulnerability was associated with mental health, social risk, risk environment, risk of abuse, level of risk, access to health care, experience of abuse, and breakdown. From a LEPH perspective, six different models for vulnerability assessment were identified. They include:

- The use of risk factors like:
  - The risk of incarceration or arrest (Beach et al., 2013; Saddichha et al., 2014)
  - The risk of homelessness (Beach et al., 2013; Glynn et al., 2014)
  - The risk of premature discharge from assertive community treatment (Beach et al., 2013)
  - The risk of psychiatric hospitalization (Beach et al., 2013)
- The use of risk factors to identify those at risk of committing acts of terrorism (Cohen, 2016)
- Level of exposure to the risk of traffic-related injuries and death (Damsere-Derry et al., 2017)
- Drug War AIDS/HIV inequities model (Kerr & Jackson, 2016)
- National improvement reports in prison mental services provided in police stations and courts (Slade et al., 2016)
- Appropriate screening although the type of screening was not specified (Wilson, 2016)

**Table 2** Explicit Vulnerability (Vuln) Definitions (4). Presentation of articles with explicit definitions of vulnerability

#	Author/Name/Date	Research Country	Research Context	Vuln Definitions	Vuln Associated with
1	Damsere-Deny et al. (2017)	Ghana	Law Enforcement (criminal justice) and Public Health	Vulnerable road users (VRU) are defined as those who are exposed to the risk of traffic accidents because they lack protective frames. They include pedestrians (over-speeding), cyclists and motorcyclists (failure to use helmet). Of the three groups, pedestrians have higher risks of injuries or deaths owing to an absence of any protective frame. Cyclists and motor cyclists are protected to some extent by their protective clothing and helmets. VRU differ from protected road users because they are sheltered by their vehicles and associated devices like airbags, child restraints and seat belts.	Risk of death
2	McNeil & Small (2014)	No specific country - Systematic Literature Review and Meta-Analysis.	LE (safer environments interventions); PH	Vulnerable groups defined and identified as injection drug users. Vulnerability seemed to be used as a synonym for susceptible. For example, "vulnerability to health harms..." (p.151), and "to drug-related harms" (p.152).	Social and physical risk environments including contextual factors like social, environmental and structural factors.
3	Whitelock (2009)	UK	PH (mental health)	A 'vulnerable adult' is defined as a person 'who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of himself, or unable to protect him or herself against significant harm or exploitation' (Department of Health, 2000, pgs. 8 & 9). Vulnerable adult identified as those with mental health challenges at risk of abuse within mental health wards and their communities	Feeling at risk of abuse, level of risk, experience of abuse, breakdown,
4	Wilson (2016)	Australia	LE (criminal justice - police, court services); PH (social care)	Vulnerability defined based on age, adaptive behaviour, IQ, inappropriate agreement to irrational requests (Nettlebeck & Wilson, 2002).	Weakness and helplessness

**Table 3** Models for Assessing Vulnerability (Vuln) - Law Enforcement Perspective. Presentation of articles containing models for assessing vulnerability from a Law Enforcement perspective

#	Author/ Name/ Date	Research Country	Research Context	Model(s) for Vuln Assessment	Vuln Associated with
1	Gaitan & Shen (2018)	Mexico	LE (Criminal Justice)	Vulnerability assessed based on general indicators like the individual's perceptions as suitable crime targets, inadequate social support, and inequalities.	Poverty. Vulnerability associated with reduced sense of well-being manifested as poverty. Feelings of vulnerability reduced/dissipated by the perception of increased social cohesion and accessible social resources. Recursive and interconnected relationship between behaviour on one hand and vulnerability and risk perceptions on the other hand.

According to our findings, the countries with models for assessing vulnerability were Australia, Canada, East Timor, Ghana, Northern and Southern America (Mexico), South Africa and the UK. This is captured in Tables 3, 4 and 5.

Despite the varying models of assessment across LEPH, the use of risk factors to assess vulnerability appeared in three of the six models identified, as captured in Table 5. From this perspective, vulnerability was associated with forensic histories and high-risk population,

risk of death, HIV, mental health, feelings of weakness and helplessness.

#### Summarising and discussing the results

As illustrated in Table 6, the current review reveals conflicting priorities across LEPH in relation to vulnerability. Essentially, vulnerability is context-specific from a Law Enforcement perspective, and person-specific from a Public Health perspective.

**Table 4** Models for Assessing Vulnerability (Vuln) - Public Health Perspective. Presentation of articles containing models for assessing vulnerability from a Public Health perspective

#	Author/ Name/ Date	Research Country	Research Context	Model(s) for Vuln Assessment	Vuln Associated with
1	Amiral et al. (2004)	East Timore (Post-emergency phase within post-conflict and post-war, low-income developing countries)	PH - Mental Health	The PRADET (Psychosocial recovery and Development in East Timor) was established to assess social vulnerabilities in mental health patients within post-emergency, post-conflict and post-war East Timore.	Mental disturbances and social risk
2	Knight et al. (2014)	US - San Francisco	PH - Mental Health	Rhodes et al.'s (2005, 2012) framework of socio-structural vulnerability (p.8). The authors have adapted the framework to assesses how single room occupancy hotels affect the mental health of women in their capacity as "mental health risk environments"	Risk environment
3	Thorpe et al. (2011)	US - Wisconsin	PH- Healthcare Access	Use of self-report to assess vulnerable elderly people with mental health issues or functional disabilities. Self-report was administered by doctors who asked questions that enabled them identify conditions related to mental health issues. The Health Utilities Index Mark III is used to assess functional health disabilities. Dichotomous variables signifying the existence of reported limitations regarding cognition, dexterity, hearing, speech, ambulation and pain were created by the authors.	Access to healthcare
4	Ward et al. (2006)	South Africa	PH - Prehospital emergency and associated mental health outcomes	Exposure to critical incidents assessed by the authors using f, which is a 22-point scale. The Revised Impact of Event Scale was used after the CII to assess post-traumatic stress disorder (PTSD).	Critical incident disorder and PTSD
5	Whitlock (2009)	UK	PH - Mental Health	Vulnerability assess based on the vulnerability definition provided in the No Secrets Guidance of the Department of Health which considers people's identity, diagnosis, personal characteristics or service eligibility.	Feeling at risk of abuse, level of risk, experience of abuse, breakdown,

**Table 5** Models for Assessing Vulnerability (Vuln) - LEPH. Presentation of articles containing models for assessing vulnerability from Law Enforcement and Public Health perspectives

#	Author/Name/Date	Research Country	Research Context	Model(s) for Vuln Assessment	Vuln Associated with
1	Beach et al. (2013)	US - New York	LE (arrest, incarceration, forensic, community treatment); PH (psychiatric hospitalization)	Four risk factors used to assess and predict vulnerability. They include the risk of incarceration or arrest, homelessness, premature discharge from assertive community treatment, psychiatric hospitalization.	Forensic histories and high-risk population.
2	Cohen (2016)	US	LE (counter-terrorism, homeland security); PH (mental health)	The prevention approach which is currently adopted by some local communities. It assesses vulnerable individuals by identifying those at risk of committing acts of terrorism and intervenes before it happens. Law enforcement encouraged to work with mental health at this early stage. (Risk management and collaborative working - co-creation of value)	The paper recommends that investigative and violence prevention protocols by federal agents should include behavioural risk assessment techniques. Also multidisciplinary teams comprising community, law enforcement, and mental health should be established to encourage holistic, structured and cohesive collaboration.
3	Damsere-Derry et al. (2017)	Ghana	LE (police); PH	Vulnerability assessed based on level of exposure to the risk of traffic-related injuries and death.	Risk of death
4	Kerr & Jackson (2016)	US	LE (Criminal Justice - inequitable sentencing and policing); PH (Impact of drug war on HIV vulnerability)	Based on three pathways, the authors developed a Drug War AIDS/HIV inequities model developed to assess how HIV vulnerability in African Americans can increase as a result of the drug war. The pathways are sexual networking, social marginalization and resource deprivation.	HIV
5	Slade et al. (2016)	UK - England and Wales	LE (Criminal Justice); PH (mental health)	Mental health vulnerability assessed via the National improvements in prison mental health services, and diversion and liaison services provided in police stations and courts. Based on clinical need, liaison services include communications with hospitals, communities, or prison services. Diversion services involves referring identified vulnerable groups to either a hospital bed or community service.	Mental health disturbances
6	Wilson (2016)	Australia	LE (criminal justice - police, court services); PH (social care)	Appropriate screening, Vulnerability was also assessed using the Social Vulnerability Questionnaire, developed by Fisher, Moskowitz, & Hodapp, 2012; the Test of Interpersonal Competence and Personal Vulnerability, developed by Wilson, Seaman, & Nettelbeck, 1996; and the Decision-making Video Scale, developed by Hickson, Khemka, Golden, & Chatzistyfi, 2008.	Weakness and helplessness

**Table 6** LEPH Conflicting Priorities on Vulnerability (Vuln) Issues. Presentation of articles evidencing conflicting priorities across LEPH as regards vulnerability

#	Law Enforcement	References	Public Health	References
1	Criminal Justice	Frye and Dawe (2008); Saddichha et al. (2014); Pinedo et al. (2017); Gaitan & Shen (2018); Hyatt & Han (2018)	Physical Health (HIV)	Simic & Rhodes (2009); Syvertsen et al. (2014); Forbes (2015)
2	Hostage Taking	Ludwig-Barron et al. (2015)	Mental Health	Amiral et al. (2004); Ward et al. (2006); Whitelock (2009); Knight et al. (2014)
3	Intimate Partner Violence	Ludwig-Barron et al. (2015)	Paramedics/ Pre-hospital Emergency	Ward et al. (2006)
4	Racial Profiling and Traffic Stop Risk	Miller (2009)	Healthcare Access	Thorpe et al. (2011)



Studies and discussions on vulnerability from a Law Enforcement perspective revolved around contextual issues. These related to criminal justice, hostage taking, intimate partner violence, racial profiling and traffic stop risk. These issues relate to a specific circumstance, situation and/or place (Table 6). On the other hand, vulnerability studies and discussions from a Public Health perspective addressed personal matters. These relate to patients' physical health, mental health and access to pre-hospital emergency services and/or health care (Table 6).

At the intersect of LEPH, the selected studies looked at a range of criminal justice and public health issues in tandem. As captured in Table 7, these include but are not limited to policing practices police contact/custody, inequitable sentencing, arrest, incarceration/correctional setting, community treatment, psychiatric hospitalization, parole, forensic, counter-terrorism, victimisation, public health systems, learning disabilities, drug users, court cases, social care and others.

Essentially, the studies demonstrated that the concept of vulnerability from a LEPH perspective was wide; extending well beyond the concept of mental health. This probably explains the inconsistencies and lack of explicitness in vulnerability definitions and assessments

across LEPH. Likewise, the studies captured in Table 7 confirm that partnership working between policing and public health is unavoidable and necessary.

#### **Stage 6: Stakeholder engagement**

Stakeholder engagement in this project was in the form of an Expert Advisory Group (EAG). This collaborative partnership comprises 26 individuals within senior roles across LEPH organisations in Scotland, including: Directors, Co-Directors, and Professors of Law Enforcement and Public Health; senior Officers in Police Scotland; senior Public Health Officials across psychiatry, emergency medicine, and substance misuse; Senior members in the Scottish Government; Senior members of voluntary sector organisations and those with lived experience; and academics and researchers working across criminal justice, psychology, health, and vulnerability. The primary purpose of the EAG is to "to inform and support the development of a co-constructed programme of research crossing the intersect of Law Enforcement and Public Health" (Murray et al., 2018, p.1). A follow up EAG vulnerability sub-committee meeting was held to specifically inform the search strategy and research question for the current review, and to identify possible future steps

**Table 7** Vulnerability-related issues at the Intersect of LEPH. Presentation of articles discussing vulnerability-related issues at the intersect of LEPH organisations

#	Law Enforcement & Public Health	References
1	Arrest, incarceration, forensic, community treatment, psychiatric hospitalization	Beach et al. (2013)
2	Policy and public health	Boeri et al (2009)
3	Criminal justice and paramedics	Borschmann et al. (2017)
4	Counter-terrorism, homeland security, mental health	Cohen (2016)
5	Traffic injury prevention	Damsere-Dery et al. (2017)
6	Criminal justice and mental health	Ferrazzi & Krupa (2016)
7	Correctional setting and physical health (HIV)	Frisman et al (2008)
8	Correctional setting and mental health (dementia and cognitive impairment)	Gaston (2018)
9	Criminal justice, public health systems and clinicians	Glynn et al (2014)
10	Parole, probation and drug addictive behaviours	Hall et al (2016)
11	Inequitable sentencing, impact of drug war on HIV vulnerability	Kerr and Jackson (2016)
12	Safer environments and drug users	McNeil & Small (2014)
13	Crime and mental health	Morrall et al (2010)
14	Policing practices and drug injecting deported migrants	Pinedo et al. (2017)
15	Incarceration, substance abuse and mental health	Saddichha et al. (2014)
16	Violence, abuse, learning disabilities	Olszowski & Boaden et al (2010)
18	Incarceration and mental health	Slade et al. (2016)
19	Incarcerated rural women, mental health, HIV	Staton-Tindall et al (2015)
20	Police contact, police custody, mental health (cognitive disability)	Trofimovs & Dowse (2014)
21	Victimisation, court services and social care	Wilson (2016)
22	Learning Disability and risk of criminality	Allen (2007)



and areas for research which would be a priority in LEPH practice.

### Concluding remarks

Considering LEPH organisations, this review aimed to identify the ways in which vulnerability is defined and assessed across adult populations. The implications of the findings of the current scoping review are two-fold. For “vulnerable groups”, the lack of an evidence-based definition and assessment could introduce a raft of problems. These include preventing access to relevant LEPH services; exacerbating issues of multiple vulnerabilities, co-morbidity, and/or dual diagnosis; and impeding effective communication across LEPH partners. All could inadvertently enable the social exclusion of vulnerable groups from political discourse and policy interventions. For LEPH organisations and, by extension, Federal Governments, the inconsistencies in vulnerability definitions and assessments may result in reactive crisis responses as opposed to proactive preventative measures.

During the scoping review, research gaps were identified. From a co-production and social innovation perspective, Whitelock (2009) identified the absence of a personalised definition of vulnerability. The author stressed the need to develop one that includes the service user’s voice as a critical step towards the care planning and support process. Similarly, Forbes (2015) argued for the need to explicitly identify marginalised sex-workers as vulnerable people. This may increase their chances of being included in political health discourse and could facilitate the development of effective care pathways.

Considering mental health issues, Borschmann et al. (2017) noted the need for further research on clinical management and epidemiology of reactions to self-harm, clinical outcomes and care pathways for vulnerable patients. Likewise, Cohen (36) noted the absence of behavioural risk assessment techniques and recommended that terrorism violence prevention protocols should include such. Recommendations also included the need for more multidisciplinary teams across community, policing and mental health to encourage holistic and structured collaboration and co-production of services (Cohen, 2016).

From an academic perspective, the scoping study clearly exposes the complexities associated with defining and assessing vulnerability across LEPH. This may be because they are perceived and prioritised differently in both organizations. Future research should attempt to bridge this gap. This could assume the form of a Systematic Literature Review to identify *effective* models that are currently used to assess vulnerability in LEPH practice. This would be useful in

both academia and in practice. The proposed Systematic Literature Review should form the basis of any future intervention or vulnerability/risk assessment development work to ensure rigour and sound operational and theoretical underpinnings. A synthesis of vulnerability models would enable the development of a vulnerability and mental health assessment framework, for example, which could then be tested across LEPH practice.

The Scoping Review also highlights the challenges associated with *implementing* a universal definition of vulnerability across LEPH organisations. Considering that the goal is to find some commonality with “vulnerable” groups along with policy (Police Scotland, 2017; Van Dijk & Crofts, 2017; Punch & James, 2016), this proposed universal definition would have to be agreed upon by both law enforcement and public health areas since they are two separate entities. We believe that a universal definition would be helpful for a range of law enforcement and public health services and treatment, including the police, courts, control rooms and emergency healthcare. From a LEPH perspective, a universal definition of vulnerability can facilitate universal vulnerability assessment, decision-making processes, and understanding of problems faced across LEPH. Basically, with a shared language in the first instance, and shared understanding of each organisation’s role in the ‘system’, shared decision-making protocols and processes, can be developed. This increases the likelihood of successful and effective partnership working across LEPH.

Ultimately, the ambition is the development of properly linked services, which respect and understand each organisation’s role, strength and limitation, and which takes cognizance of mental health and vulnerability issues. Of course, a whole-systems approach to LEPH is ambitious, but we feel that taking it step by step, starting with shared understanding and definitions is a good step forward, together, across the intersect of LEPH. Also, existing assessment models may need to be reviewed and revised to capture the new, more universal definition of vulnerability if or when it is developed.

### Endnotes

<sup>1</sup>To understand how and why a term is used, by whom and in what literature.

<sup>2</sup>To carve out relevant literature according to scope. Usually involves synthesizing findings from various studies.

<sup>3</sup>To identify key documents from the public and private sector that concern practice in the related sector.

<sup>4</sup>The cases were excluded after efforts to retrieve them using three Scottish University Library subscriptions (Edinburgh Napier University, Glasgow Caledonian University, University of Edinburgh), google scholar and

## Appendix

**Table 8** CINAHL/MEDLINE/PsychINFO Search strategy - August 2018

#	Query	Results (N Papers)
1	AB law enforcement OR AB police OR AB policing OR AB criminal justice	57,862
2	AB public health OR AB mental health OR AB disparity	650,689
3	AB social determinants of health OR AB socioeconomic factors OR AB social inequality OR AB inequality	72,184
4	AB adult protective services OR AB adult protection OR AB incapacity OR AB learning disability OR AB learning disorder	38,771
5	S2 OR S3 OR S4	743,471
6	AB vulnerab* OR AB access	583,379
7	AB risk* OR AB at risk	2,526,889
8	S1 AND S5 AND S6 AND S7	29

google search engine failed to provide access to these papers. The decision to include papers that could be reasonably accessed was contingent on the fact that LEPH professionals would likely have even less institutional access to peer reviewed papers. We therefore considered these 30 papers inaccessible to most academics and those working in LEPH practice.

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This research was funded by the Scottish Institute of Policing Research. Senior officers within Police Scotland were involved at all stages of the project. They identified vulnerability-related issues as a shared organisational challenge and a key research priority within the LEPH intersect. As a result, they articulated and provided clarity on the research aim and significance to LEPH organisations, service users, and Governments.

### Availability of data and materials

Not applicable.

### Authors' contributions

IE led the development of the search strategy, inclusion and exclusion criteria, managed the day to day running of the project and synthesised the data. IE prepared the first and final drafts of the manuscript. JM was the PI on the project and liaised closely with colleagues at Police Scotland during the early stages of the project's funding application and with IE to develop the search strategy and inclusion/exclusion criteria. JM led the writing of the funding application and contributed to the writing of the drafts of the manuscripts and the final draft. ND provided support and guidance to the team as the senior-most colleague from a public health perspective to ensure the project's relevancy to health settings. ND contributed towards the writing of the draft of the manuscript and supported IE in the data selection stages. AW helped to develop the funding application, the research design, and was involved in shaping the paper providing feedback on the manuscript at key time points. IH was Co-PI on the funding application and was

central in gaining the connections and insight of the expert advisory group, which was absolutely central to the design of the study and its focus. IH supported IE in the inclusion and exclusion criteria, with a focus on relevant legislation, and contributed to the drafting of the manuscript via feedback. EG contributed towards the development of the funding application, discussions with the research team at key time points and throughout the project and with the expert advisory group regarding the focus of the study and the manuscript and provided feedback on the manuscript drafts. I will be serving as corresponding author for this manuscript. All of the authors listed in the by-line have agreed to the by-line order and to submission of the manuscript in this form. I have assumed responsibility for keeping my co-authors informed of our progress through the editorial review process, the content of the reviews, and any revisions made.

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Not applicable

### Consent for publication

Not applicable

### Competing interests

Four of the authors (ND, JM, IH, IE) contributed a response to the Scottish Government's *Suicide Prevention Action Plan* (2018), and IH provided extensive input into the Scottish Government's 2018 *Collaborative Police and Health Interventions for Mental Health Distress* report. EA became the Director of the *Scottish Institute of Policing Research* after the project began. While these are not directly related to the current project or its outcomes, we feel that they are within the same policy-vein and should be declared.

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#### **6.4 Statement of personal contribution**

As Director of the Scottish Centre for Law Enforcement and Public Health (SCLEPH), I was leading a team of academics and had strategic oversight of SCLEPH aims and research agenda. Following numerous discussions with Police Scotland leads (usually with Dr Inga Heyman), I was very much of the view that an initial national priority setting exercise was essential, in order to establish mutually agreed aims between policing, health and our academic partnership. It was key that there was meaningful stakeholder engagement and these aims were genuinely co-constructed with Police Scotland.

Coincidentally, an opportunity arose to apply for funding from Scottish Institute of Policing Research (SIPR). I was a co-investigator on this SIPR funded study with Dr J. Murray (JM), Dr I. Heyman (IH), Dr L. Aston, and Dr A. Wooff. The grant funded the national workshop on establishing key priorities for law enforcement and public health (7), and for a systematic literature review of the top priority area, the assessment of vulnerability (paper4). Therefore, this paper stemmed from my academic interest in using policing and health intersect, and my leadership around developing a programme of work exploring health outcomes from policing interventions.

The literature review was primarily conceived and designed by two authors JM and ND, and operationalised by the grant-funded Research Fellow, Dr I. Enang (IE). IE did the literature search, study selection, full text extraction and synthesis of the data. The aim of this paper was originally a systematic literature review with a narrower focus; however, it became clear in preliminary searches that the definition of vulnerability was exceptionally unclear. Further, the evidence was patchy, and a broader, overarching mapping of the literature was needed to highlight evidence gaps. At that point I switched methodological focus to a scoping review as I had previous experience (302), using Arksey & O'Malley's Framework for scoping reviews (303). I provided project direction, refined the research questions and aims, search strategy, eligibility criteria, and day to day support for an extended period to IE, met with the team regularly to discuss progress and next steps, contributed to writing the manuscript, and edited the subsequent revision. These

were hands-on project tasks commensurate with my position as part of the core group of three delivering this review.

## **6.5 Contribution to science**

To the best of my knowledge, this is the first review of the peer-reviewed literature published on the assessment of vulnerability.

### **6.5.1 Altmetric score**

The Altmetric Attention Score is an estimated weighted approximation of the attention a research paper receives (287). The score for this paper was 33, scoring higher than 95% of its peers and in the top 5% of all research outputs ever tracked by Altmetric. In terms of outputs from BMC Health & Justice, this paper scored higher than 92% of its peers.

Link: <https://www.altmetric.com/details/56299557#score>

## **6.6 Dissemination**

This study was disseminated via international conference presentations (see Appendix Table 1, section 10.1).

## **6.7 Concluding remarks and reflection**

This paper is a different paper to the one envisaged for this PhD. The original intent was to publish epidemiological data on outcomes of people in contact with police, but this proved impossible to do within the timescales involved. Since publishing this paper, I have participated in several follow-up national roundtable events held with Scottish Government, SCADR, NHS ISD, and Police Scotland. While the conversations are ongoing, I remain optimistic that linked police and health data will be made available for research. Nevertheless, the journey in producing this paper was a fruitful collaboration, not least the inter-disciplinary academic collaboration of policing, criminology, psychology, public risk management and mental health, as well as the broader links to professional practice in policing and health.

The scoping review aimed to identify a working definition of vulnerability, and this raised more questions than answers. The assessment of vulnerability was highly heterogeneous, depending on context or health condition. A working definition should have been proposed in this paper, something my co-authors and I have done since, namely that ‘any one of us can be vulnerable, given sufficient context, setting and life experiences’ (300). To my mind, ‘vulnerability’ is a social construct used to describe people who may be at more risk, temporarily or otherwise, of experiencing harm imposed by others, or by themselves.

It is highly likely that relevant policy documents, and practice guidelines (the ‘grey literature’) may have had important information of relevance to practitioners. In future research, I would draw on grey literature and focus on specific contexts, for example, evidence on outcomes for vulnerability assessment in police custody or in street triage. However, as with all projects, there was a limit to what my co-authors and I could do, given resources and timescales.



## 7. Paper 5: Childhood adversity study protocol

### 7.1 Background

As described in Chapter one, some evidence had been published on the impact of childhood adversity and disadvantage on later suicidal behaviour in the international literature (68–70), but there was no evidence for Scotland, particularly with respect to longitudinal data (145). This protocol paper sets out methods for doing such a study to see whether patterns of NHS contacts in childhood for people who died by suicide ('cases') were different, compared with age, gender and geographically matched 'controls' at residential postcode at time of death. Understanding differences in patterns of presentations to NHS services, can offer opportunities for early identification and development of care pathways for children in at risk populations for future mental ill health and suicidal behaviour.

Compared with paper one, this protocol paper made two methodological improvements. Firstly, paper one used a retrospective single group of 'cases' (defined by deaths by suicide), while this paper proposed a case-control design, permitting between group comparisons in future. Secondly, the methodology in harmonising ICD codes in this protocol is more sophisticated. Paper one used the AHRQ Clinical Classifications Software (CCS) to harmonise 260 broad diagnostic groupings between ICD-9 and ICD-10, however these groupings were not sufficiently detailed to disaggregate e.g. self-poisoning from accidental poisoning, a limitation acknowledged within paper one. In this paper, ICD codes for childhood adversity from studies published elsewhere have been used, and extensive cross mappings between the different ICD catalogues have been done and published here.

### 7.2 Reference

Dougall N, Savinc J, Maxwell M, Karatzias T, O'Connor R, Williams B, Grandison G, John A, Cheyne H, Fyvie C, Bisson J, Hibberd C, Abbott-Smith S, Nolan L. Childhood adversity, mental health and suicide: a protocol for a longitudinal case-control linked data study. *International Journal of Population Data Science*.

## Childhood adversity, mental health and suicide (CHASE): a methods protocol for a longitudinal case-control linked data study

Dougall, N<sup>1\*</sup>, Savinc, J<sup>1</sup>, Maxwell, M<sup>2</sup>, Karatzias, T<sup>1</sup>, O'Connor, RC<sup>3</sup>, Williams, B<sup>1</sup>, Grandison, G<sup>1</sup>, John, A<sup>4</sup>, Cheyne, H<sup>2</sup>, Fyvie, C<sup>5</sup>, Bisson, JI<sup>6</sup>, Hibberd, C<sup>7</sup>, Abbott-Smith, S<sup>8</sup>, and Nolan, L<sup>9</sup>

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### Abstract

#### Introduction

Suicide is a tragic outcome with devastating consequences. In 2018, Scotland experienced a 15% increase in suicide from 680 to 784 deaths. This was marked among young people, with an increase of 53% in those aged 15-24, the highest since 2007. Early intervention in those most at risk is key, but identification of individuals at risk is complex, and efforts remain largely targeted towards universal suicide prevention strategies with little evidence of effectiveness.

Recent evidence suggests childhood adversity is a predictor of subsequent poor social and health outcomes, including suicide. This protocol reports on methodology for harmonising lifespan hospital contacts for childhood adversity, mental health, and suicidal behaviour. This will inform where to 1) focus interventions, 2) prioritise trauma-informed approaches, and 3) adapt support avenues earlier in life for those most at risk.

#### Methods

This study will follow a case-control design. Scottish hospital data (physical health SMR01; mental health SMR04; maternity/birth record SMR02; mother's linked data SMR01, SMR04, death records) from 1981 to as recent as available will be extracted for people who died by suicide aged 10-34, and linked on Community Health Index unique identifier. A randomly selected control population matched on age and geography at death will be extracted in a 1:10 ratio. International Classification of Disease (ICD) codes will be harmonised between ICD9-CM, ICD9, ICD10-CM and ICD10 for childhood adversity, mental health, and suicidal behaviour.

#### Results

ICD codes for childhood adversity from four key studies are reported in two categories, 1) Maltreatment or violence-related codes, and 2) Codes suggestive of maltreatment. 'Clinical Classifications Software' ICD codes to operationalise mental health codes are also reported. Harmonised lifespan ICD categories were achieved semi-automatically, but required labour-intensive supplementary manual coding. Cross-mapped codes are reported.

#### Conclusion

There is a dearth of evidence about touchpoints prior to suicide. This study reports methods and harmonised ICD codes along the lifespan to understand hospital contact patterns for childhood adversity, which come to the attention of hospital practitioners.

#### Key words

Childhood Adversity, Adverse Childhood Experiences, Mental Health, Self-harm, Suicide, Suicidality, Violence, Hospital episodes, Routine Data, Data Linkage, Study Protocol

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## Introduction

In the UK, suicide is the leading cause of death for young people with devastating consequences for those affected. Suicide rates in Scotland are particularly tragic, being disproportionately higher than that of England, and especially so for young men [1]. In 2018 Scotland experienced a 15% increase in suicide from 680 to 784 deaths, with this increase especially marked among young people [2]. Alarmingly, the numbers of those dying in 2018 aged 15-24 increased by 53%, the highest seen since 2007 [2], while those aged 10-34 increased from 24.4% (161/659) to 30.8% (232/753) between 2014 and 2018 [2]. This five year increase reversed a long-term downward trend from a comparable peak of 39.8% (363/912) in 1993 [2].

This pattern was consistent across UK, where deaths by suicide increased by 11% in 2018 to 6,507, and for those aged 15-24 increased by 24%, reaching 730 deaths [3]. The UK and Scottish rate in 2018 for all ages was 11.2 and 14.6 per 100,000 inhabitants respectively, rising to 19.1 per 100,000 inhabitants for those aged 15-24 in Scotland [3]. These recent data suggest a trend for increased vulnerability in younger people in the UK, and are associated with corresponding increases of self-harm since 2010, a strong risk factor for suicide [4]. Deliberate acts of self-poisoning and self-injury are increasingly becoming more common among young people, with UK psychiatric morbidity data for 2014 reporting that 26% and 10% of women and men aged 16-24 have reported they have self-harmed [5].

One potential way to address this problem is to intervene earlier in the lives of people most at risk, and prior to suicidal behaviour. In order to do this, an exposure requires to be identified that not only acts as a risk factor for suicide, but also to mental health problems which emerge earlier in the lifespan, i.e. in childhood or young adulthood. It is now accepted that those who are exposed to adversity in childhood are at much increased risk of poor social and health outcomes, and in particular mental health and suicidal behaviour [6-8].

Childhood adversity can be the consequence of harm experienced at an individual level, including those first reported in the Adverse Childhood Experiences (ACEs) study [9]. The ACEs study defined adverse events in childhood as a restricted set of traumatic experiences, such as sexual, emotional and physical abuse, neglect and maltreatment [9], an approach considered to be overly reductionist as it does not consider physical or emotional harm perpetrated via other family, social and geographical factors [10,11]. In this debate social inequality plays an important role, 24% of Scotland's children are estimated to be living in relative poverty [12], and one Scottish study estimated the majority of children experienced one ACE by age 8, concluding that ACEs are highly correlated with socioeconomic disadvantage in the first year of life [10].

A steep social gradient is also associated with suicide, with more people who take their own lives being from deprived communities [13]. A recent systematic review of 28 studies concluded that experience of adversities was significantly related to youth suicidal behaviour, and confirmed a strong dose-relationship between numbers and types of adversity, and increasing suicidal behaviour [14].

Although it is known that childhood adversity is a risk factor for suicide, current evidence is insufficiently detailed in two ways to develop targeted, effective and implementable ap-

proaches to prevention. Firstly, given that adverse life events include a wide range of experiences there is a need to identify what types are most likely to lead to mental health problems and suicidal behaviour. Secondly, given that a dose response relationship exists, there is also a need to know what number and/or combination of experiences is most likely to lead to mental health problems and suicidal behaviours. Uncovering patterns of healthcare contact may afford clearer scenarios to intervene earlier in the lives of those most at risk. This recent review could not address these points as a meta-analysis was not possible due to high levels of heterogeneity, and most included studies were cross-sectional, or retrospective and relied on recall which is prone to bias [14].

Given this important gap in knowledge, robust longitudinal studies are needed to explore causal mechanisms. There has been no prospective longitudinal lifespan study on adverse life events in childhood and later suicidal behaviour. Such a study would provide robust results, but take decades to complete. Linked population data studies offer powerful ways of advancing our understanding of individuals and societies [15]. In Scotland it is possible to summarise hospital records, which do not suffer from recall bias, and follow individuals along their life-span from 1981 [16]. Hospital records are coded by International Classification of Disease (ICD) codes; a number of ICD codes are available that are indicative of childhood adversity. Although presentations for e.g. violence and maltreatment are likely under-recorded, it is plausible that those serious enough to require hospital attention are associated with severity, necessitating attendance at Emergency Departments and/or requiring in-patient care.

For the purposes of this study, the working definition of childhood adversity will be as wide a typology as possible, encompassing individual-level codes which are on a continuum of definite, probable and suggestive of violence and maltreatment, and using area level variables of deprivation and urban-rural indicator derived from individuals' postcodes. Key studies are available which have operationalised working definitions of childhood adversity, along with published ICD code lists [17-20].

Therefore, the aims of this study are two-fold: Firstly, to investigate patterns of lifespan contacts for childhood adversities stratified by deprivation as recorded in hospital records, and ascertain their relationship with mental health and suicidal behaviour, prior to suicide in young adults. Secondly, to explore via multi-agency stakeholder workshops, and in conjunction with experts by lived experience, how best to use insights revealed in the data in developing more focussed upstream interventions. The two aims of this study are underpinned by five research questions (table 1).

## Methods

### Study design and setting

This study will follow a case-control design using routine data. This design will make efficient use of existing data to compare people with the outcome of suicide ('cases') versus people who are 'controls'. Retrospective comparisons will be made on the frequency in hospital records of childhood adversity present in each group; this will be used to explain any relationship if it

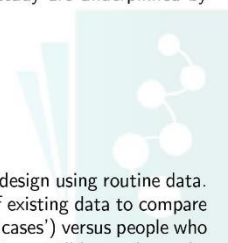




Table 1: Study research questions

Research questions
1) What is the relationship between number and type of childhood adversities and suicide, stratified by age and gender, and if possible by deprivation code? (Aim 1).
2) What is the relationship between type and number of childhood adversities, subsequent mental health, self-harm, self-poisoning admissions prior to suicide? (Aim 1).
3) Can a dose-response relationship of number of childhood adversities with suicidal behaviour be confirmed, and can type of childhood adversity be ranked as having impact on later life? (Aim 1).
4) Are maternal records which are linked to the child records sufficiently detailed and data-rich to be used as an indicator of maternal adversity, and if so, how does maternal adversity affect offspring mental health and suicidality? (Aim 1)?
5) Are the results of this study rich enough to be used to inform the development of an intervention? (Aim 2).

exists between adversity in childhood, mental health, suicide attempts (self-harm) and suicide.

This study will be overseen by a Study Steering Group (SSG) with a range of backgrounds, comprised of academics, clinicians and charitable sector experts. These include population data science, statistics, suicidology, health intervention development, medicine, midwifery, clinical psychology, psychiatry, and child and adolescent mental health nursing. The study will be conducted in partnership with 'Aberlour', Scotland's children's charity that aims to support children, young people and their families with early intervention (<https://www.aberlour.org.uk/>). Additional lived experience perspectives will be provided via the Mental Health Foundation, (<https://www.mentalhealth.org.uk/scotland>) and the Violence Reduction Unit (<http://actiononviolence.org/>).

There are two stages to this study: stage 1 (aim 1; RQs 1-4), consisting of obtaining permissions to access data, cleaning and analysis of data remotely via the 'Safehaven' to ensure confidentiality of records, and stage 2 (aim 2; RQ5), consisting of the workshops and any intervention development work.

## Datasets

Datasets to be used will be drawn from the following:

1. General Hospital Scottish Morbidity Records ('SMR01').
2. Psychiatric Hospital Records ('SMR04').
3. Birth record and maternity information ('SMR02').
4. Mother's linked hospital records (deaths/ 'SMR01'/ 'SMR04') to 'SMR02'
5. National Records of Scotland death certificates (NRS).

Scotland is a country with a reasonably stable population of about five million. NHS healthcare is a national single state provider administered by the Scottish Government with very little private healthcare provided (2%), and is therefore representative of the population as a whole. It is free to access at the point of use, funded by general taxation, and the national Scottish Morbidity Record (SMR) datasets have been routinely collected and warehoused by the NHS Information

Services Division since 1981 [16]. Every person born or registered with a General Practitioner in Scotland is allocated a unique ten digit 'Community Health Index' (CHI) number and entered on a national register, representing between 96.5-99.9% of the Scottish population [16]. Each SMR data entry (datasets 1 to 4) is recorded by a CHI number along with detailed individual-level information on variables such as: main and secondary diagnoses on admission and discharge, dates of admission and discharge, length of continuous episode of care ('spell'), discharge destination, admission and discharge type, etc. Missing data proportions vary according to the dataset, variables, and year of capture and form a substantive part of data preparation before analysis. The CHI number thus enables healthcare records to be linked through time, between locations, and between datasets using direct matching and probabilistic matching, including NRS vital events death registrations (dataset 5), [16].

## Data linkage

Scotland does not have a single data warehouse. NHS and NRS data controllers assess research proposals and decide whether they are in the public interest and meet legislative requirements. Once permission is granted, data under the responsibility of the data controllers are brought together and linked on a project-by-project basis, facilitated by direct matching using the CHI unique identifier [16]. This study will be supported by the electronic Data Research Innovation Service (eDRIS), NHS ISD, Scotland. eDRIS have confirmed data availability, will provide the de-identified linked data and facilitate safe access via the secure National Safehaven environment, 9 Bioquarter, Edinburgh.

## Study Population

For the purposes of the case-control study, 'cases' are defined as data related to people who died by suicide or by undetermined intent at age  $\leq 10$  &  $\geq 34$  between 1991 and as recent as data are available, thus permitting lifespan records to have accrued for the first observed deaths at age 10 in 1991. The 'controls' are randomly selected from the population and matched on age, gender, geographically matched on postcode, being alive at the time of death of the 'cases', and following the rationale of a previous national suicide information database

[21].

Using Scottish vital events data, deaths by suicide or of undetermined intent aged  $\leq 10$  &  $\geq 34$  between 1991 and 2015 numbered 6,907. Previous research by the study applicants on linked hospital records for people who died by suicide from 1980-2009 demonstrated >85% of death records were associated with a valid NHS number, and >75% had linkable hospital data; some 12,000 people were found to have 85,000 episodes of care [22]. Therefore, we expect many thousands of episodes in this study.

Controls will be selected in a ratio of 1:10 (about 70,000 controls), and alive at the time of death of the cases, therefore the denominator is not a strict measure of disease frequency; however, any odds ratios will be similar to estimates obtained had the whole population been sampled, known as the 'rare disease assumption' [21]. A 1:10 ratio is selected as ICD codes for childhood abuse or neglect are highly likely to be underreported. A flowchart will be populated, with reasons for excluded data (Figure 1).

### Operationalising variables for childhood adversity and mental health

Hospital episodes in the Scottish Morbidity Records (SMR) are coded on a main diagnosis and up to ten secondary diagnoses using the World Health Organisation (WHO) version of ICD-9 from 1981 to 1996, with a change to ICD-10 from 1 April 1996 onwards.

Our working definition of childhood adversity draws on four key studies which have reported ICD codes for maltreatment, violence-related (MVR), diagnoses suggestive of maltreatment, and mental-health related diagnoses [17–20]. To define MVR events, ICD-10 codes will be used from González-Izquierdo et al which were derived from National Institutes for Health and Care Excellence (NICE) guidance and expert consultation, and reflecting a hierarchy of maltreatment likelihood [17,18], grouped by Maltreatment, Assault, Undetermined Intent and Adverse social circumstances (indicating neglect or broader welfare concerns, such as homelessness, inadequate housing, etc.) Gilbert et al cross-mapped these same codes to ICD-9 and we will make use of these tabulated cross-mapped codes [18].

We will supplement these ICD codes with a further set of published ICD codes suggestive of child maltreatment, derived from expert consultations and case note review [19]. To complement the underreporting of maltreatment [20], Schnitzer et al conducted a case note review of 2,826 hospital visits of children suspected of maltreatment and found that 1,200 (43%) were confirmed positive for maltreatment, with 68 ICD codes able to classify >66% of visits as maltreatment-related [19]. Codes suggestive of maltreatment included specific fractures, burns, and injuries of undetermined intent, amongst others, as well as upper age limits and exclusion criteria (e.g. a diagnosis of malnourishment without an underlying illness) [19]. These suggestive codes have been previously defined and published in ICD-9-CM (Clinical Modification, an ICD variant developed in the USA). As part of this study, these ICD-9-CM and ICD-10-CM codes will be cross-mapped to the equivalent codes in the unmodified WHO versions of ICD-9 and ICD-10.

Both these MVR codes and codes suggestive of maltreatment were used to estimate population rates, and either used

a hierarchy of codes, or reported population weights, respectively. In this study, we are primarily concerned with finding individual-level evidence of maltreatment with maximum sensitivity, so we will first use these studies' reported inclusion and exclusion codes, without the hierarchy or population weights. This will be followed by an attempt at an estimate of absolute risk as well as relative risk, using this study's case-control ratio of 1:10 where all relevant 'cases' are included (and no inferences made), and using control group characteristics and NRS data to give an inferred estimate of general population equivalent numbers.

To achieve consistent coding of mental health-related conditions over the period of the study, we will use the Clinical Classification Software (CCS) published by the US Agency for Healthcare Research and Quality (AHRQ) [23,24]. CCS is a unique mapping from all ICD-9-CM and ICD-10-CM codes to aggregated categories of injuries and illness, including mental health. As part of this study, these ICD-9-CM codes will be cross-mapped to the equivalent codes in the unmodified WHO versions of ICD-9 and ICD-10. Therefore, in order to define a typology of childhood adversity and mental health, episodes will be flagged as 'Maltreatment or violence-related' (MVR), 'Suggestive of maltreatment', and/or 'Mental health-related', depending on the diagnosis codes matching the relevant inclusion and exclusion criteria, and drawing on all the published work above [17–20]. This approach will maximise the sensitivity of the available validated codes, a decision taken in consultation with the SSG, and with consideration to the likely underreporting of childhood adversity in hospital records.

### Additional variables

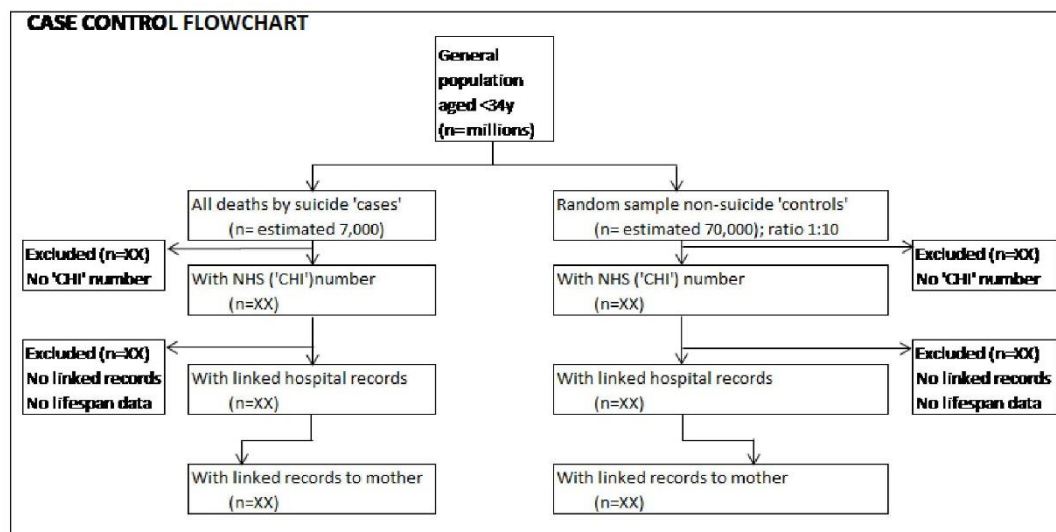
These datasets are, in turn, to be linked to derived area-level variables based on postcode and held by NHS ISD. For deprivation, the Carstairs Morris Index will be used, the only variable available with data spanning all years from 1981 onwards, based on refreshed Census decade data at postcode level for car ownership, occupational social class, household overcrowding and male unemployment. The Scottish Index of Multiple Deprivation, used from 2000 onwards and the Scottish Government's official tool for identifying areas with concentrations of deprivation has been requested; however this will likely have limited value having a shorter timespan than the study data. An 8-factor urban-rural indicator derived from postcode and available since 2004 has also been requested; this may also be of limited value as it covers a limited period. A crude geographic variable of NHS Health Board has been requested to explore differences by geographical areas where treatment is accessed.

### Data analysis

Prior to data analysis, extensive cleaning and checking data validity will be done, in line with methods used in previously published work [22]. Data will be assessed for 'missingness' before applying descriptive statistics to estimate measures of central tendency and variability, or frequencies and their relative percentages for groups on age, gender, and deprivation quantile; numbers of people exposed to early adverse events, and the type, number and timing of adverse events [RQ1]; numbers



Figure 1: Flow diagram of mothers and babies eligible for inclusion in study population 4. Aboriginality of mothers in this study population was based on ever being recorded as Aboriginal in any of the available linked data.



who then subsequently develop mental ill-health and/or suicidal behaviour [RQ2]. The number of adverse events and any dose-response relationship with suicidal behaviour will be explored [RQ3]. Maternal records will be summarised for death and maternal ill health in the perinatal period, permitting an analysis of added impact of maternal adversity, should the records be sufficiently populated [RQ4]. Where there are sufficient proportions of linked physical and mental health maternal records available, it may also be possible to explore any inter-generational trauma [RQ4].

Relative risks of certain combinations of predictor variables as per the research questions on the outcome of suicide will be computed. These data may be of sufficient quality to permit odds ratios to be estimated from the use of logistic regression with the dependent variable of death by suicide ('cases') or being alive ('controls') as an outcome, given certain events have happened to individuals. These events include independent variables such as number, type, and first occurrence of hospital admissions for childhood adverse events (violence and maltreatment), hospitalisations for adversity or mental health, and maternal adverse events including bereavement of mother in childhood. In order to minimise confounding, preventive measures are in place by using controls randomly derived from the general population who are age, gender and geographically matched to those who died by suicide (see Study population). As is the case with observational studies, imbalances in other prognostic factors may be present requiring adjusted analyses. For example, an assessment of the distribution of ICD chapters for physical health diagnoses between groups will be made, in order to identify whether presentation of ICD-10 codes for childhood adversity or mental ill-health are not confounded by an association with physical ill-health.

### Developing stakeholder-informed potential models of intervention

Three key sources will be used in developing types of interventions for further development, 1) findings from aim 1; 2) existing literature on effectiveness and barriers to implementation in the area and conceptual models of suicide such as the pre-motivational phase of the Integrated Motivational-Volitional Model [25]; and 3) expert opinion from healthcare practitioners, people with lived experience accessing services, other public services, and policy makers. Such an approach is consistent with the recent *Lancet Psychiatry* Commission's recommendations on the development and implementation of psychological treatments [26]. Workshops guiding the discussion, including dissemination of study findings, will be summarised with areas for future development and research investigation [RQ5]. Workshops will integrate existing evidence, establish feasible models of potential interventions, and conduct final modelling testing via clinical scenarios and with individuals who have real world knowledge.

## Results

### Maltreatment and Violence Related diagnosis codes

The ICD-10 codes from González-Izquierdo et al [17] and ICD-9 codes from Gilbert et al [18], were cross-mapped and tabulated (Table 2). In addition, ICD-9 code E904 'Hunger, thirst, exposure, neglect' [20], and ICD-10 codes Y87.1 'Sequelae of assault' and Y87.2 'Sequelae of events of undetermined intent' will be included as MVR codes under the Maltreatment,

Table 2: Maltreatment or violence-related (MVR) codes compiled from Gilbert et al. (2012) and González-Izquierdo (personal communication, 2019)

MVR Category	ICD-9	ICD-10
Maltreatment	994.2 - 994.3, 995.5, E967	T73, T74, Y06, Y07
Assault	E961 - E966, E968 - E969	X85 - Y03, Y04, Y05, Y08 - Y09
Undetermined cause	E980 - E989, V68.2, V70.4, V71.4, V71.5, V71.6, V71.81	Y10 - Y34, Z04.0, Z04.5, Z04.8
Adverse social circumstances	779.5, V15.4, V15.5, V15.89, V15.9, V17.0, V20.0, V20.1, V60, V61, V62.4, V62.5, V62.81, V62.89, V62.9, V69	P96.1, Z58.8, Z58.9, Z59.0, Z59.1, Z59.4, Z59.5, Z59.7, Z59.9, Z60 - Z63, Z64.4, Z65.3, Z65.8, Z65.9, Z72, Z74, Z76.1, Z76.2, Z81, Z86.5, Z91.6, Z91.8

Assault, and Undetermined cause headings, respectively.

### Cross-mapping between the WHO and the CM variants of ICD

An attempt at automatic, bottom-up mapping between the WHO and CM variants of ICD, finding a unique match between every CM code to a WHO code, proved not to be feasible. In general, the CM variant provides more detailed classifications, with codes up to seven characters long, and more codes in the catalogue in total. Although most such codes can be truncated to the number of characters to match codes in the WHO catalogue, there were several instances where conditions were assigned different 3-character or 4-character codes in the different ICD variants (see Table 3 for an ICD-10 example). In these circumstances, we conducted a systematic manual review of relevant codes and corrected them accordingly.

### Cross mapping between ICD versions 9 and 10

The WHO catalogues for ICD-9 and ICD-10 were downloaded from the UK Biobank (ICD-9: <https://biobank.ctsu.ox.ac.uk/crystal/coding.cgi?id=87>; ICD10: <https://biobank.ctsu.ox.ac.uk/crystal/coding.cgi?id=19>), and the online ICD-10 reference (version 2016) provided by the WHO was used for keyword searches (27). The CM variants of ICD-9 and ICD-10 were included in the statistical software ‘R’ package ‘icd’, version 4.0.6 and available for use (28). The General Equivalence Mapping (version 2018) from ICD-9-CM to ICD-10-CM and vice versa was also used for reference (available at [ftp://ftp.cdc.gov/pub/Health\\_Statistics/NCHS/Publications/ICD10CM/2018/](ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Publications/ICD10CM/2018/)).

### Codes suggestive of maltreatment

For cross-mapping codes suggestive of maltreatment, a piecemeal approach was used: to map from ICD-9-CM to ICD-9, exact code matches were found first and manually reviewed to check for discrepancies. Codes which could not be exactly matched were keyword searched in the ICD-9 catalogue. Three codes could not be matched from ICD-9-CM to a corresponding ICD-9 code and these were: ICD-9-CM Codes

E869.4 Second-hand tobacco smoke, V71.81 Observation for abuse/neglect, and 362.81 Retinal haemorrhage.

Next, ICD-9 codes were matched to ICD-10 codes, starting from top-level (3-character) codes where appropriate and narrowing down to the required level of detail, using the code catalogues described above. We have made available the results of cross-mapping as supplementary tables (see Appendix Tables 1-3). Further details of cross-mapping are available from the authors.

### Clinical Classifications Software (CCS)

Mental health categories are numbered 650-670, which also includes suicide and self-harm as a single category, numbered 662. For our analyses, we created a category for ‘Events of undetermined intent’, which spanned several CCS categories. A cross-mapping was performed between the ICD-10-CM codes in CCS to the ICD-10 codes in use in the UK, and between the ICD-9-CM codes and ICD-9. The following versions were used, 1) ICD-9-CM CCS version 2015 [23], available at <https://www.hcup-us.ahrq.gov/toolsoftware/ccs/ccs.jsp>, and 2) ICD-10-CM CCS beta version 2019.1 [24], available at [https://www.hcup-us.ahrq.gov/toolsoftware/ccsr/ccs\\_refined.jsp](https://www.hcup-us.ahrq.gov/toolsoftware/ccsr/ccs_refined.jsp).

For ICD-CM codes (versions 9 and 10 separately), exactly matching ICD codes at up to 4-characters deep were found; the remaining unmatched codes were assigned a CCS category if the entire 3-character code mapped to a single category (i.e. all ICD-9 codes starting with 290 are in the dementia/delirium CCS category, whereas 300 Neurotic disorders map onto two CCS categories, Anxiety, and Mood disorders, respectively); the remaining codes were manually mapped to appropriate codes. A full list of codes and details of cross-mapping are available from the authors.

## Discussion

### Main findings

This protocol describes and reports on methods and results of harmonising ICD codes through four decades and between datasets, a labour-intensive process. In an increasingly data-oriented world, data science has potential to be transformative,



Table 3: Example of discrepancy between ICD-10-CM and ICD-10 at 3-character level.

	ICD-10-CM	ICD-10
Intentional self-harm	X71-X83; T36-T65*, T71	X60-X84
Assault	X92-Y08	X85-Y09
Event of undetermined intent	Y21-Y33; T36-T65**, T71	Y10-Y34

Footnote: \* The ICD-10-CM system does not require additional external cause codes for self-poisonings. ICD-10-CM T36-T65 are combination codes that include the substance taken as well as the intent, where \*self-harm or \*\*undetermined intent is indicated by 5th or 6th digit code.

a means of exploiting rapidly expanding 'big data', leading to solutions for known problems [15,29]. Linking longitudinal routine health and research data provide new opportunities for evaluating intervention effectiveness, and establishing unintended consequences [29]. However, this is only feasible provided it is possible to track data through time with consistent codes, that the data are reasonably complete and of sufficient quality. This protocol focuses on the first of these, tracking harmonised ICD codes through time.

Mapping ICD codes between catalogues 9 and 10 was labour-intensive and challenging, requiring expertise in several domains, including data science, statistical programming, longitudinal study design, multiple coding systems and clinical classifications software. Nevertheless, the cross-mapping tasks were less onerous than they otherwise would have been. We were able to draw on experience from previous research [22], relevant statistical programming and cross-mapped coding frameworks published in table format [19], and other frameworks shared via direct communication [17,18]. We add, in turn, to this body of knowledge in providing detailed legacy cross-mapping frameworks, enabling emerging technological approaches to interrogate and predict individuals most at risk from similar longitudinal data. Without openly available information, progress on the preparatory work prior to any analysis would have been much longer and more tedious.

### Potential benefits and importance of the study

It has been reported that current care pathways for people who present to hospital in distress or with mental health symptoms are sub-optimal. Around 30% of people who have taken their own lives in Scotland have attended Emergency Departments in the three months prior to death [13], and more than half (58%) of deaths which occurred within three months of hospital discharge did so after last discharge from general hospitals, not psychiatric hospitals [22]. The Scottish Ambulance Service transported half of individuals seen as 'psychiatric emergencies' in 2011 to general hospital, with an estimated 8% (59/6,802) who were alive after one day of admission taking their own lives in the following year [30]. There is a strong need to overhaul ways of working with an emphasis on whole system multi-agency partnerships between our first responders (paramedics, policing, Emergency Departments), and if interventions are to be effective these need to engage wider sectors of education, local authorities for social care, and charitable organisations.

Suicide is a tragic catastrophic outcome for some people who experience distress and entrapment, as exemplified by the

integrated motivational-volitional (IMV) model [25]. Uncovering patterns of hospital contact prior to suicide will provide important contextual information for the IMV model, and it will help to map out opportunities for intervention and provide targets for treatment or support.

### Strengths and limitations

The main study strength is the longitudinal case-control study design that will provide an opportunity to explore causal mechanisms as identified by hospital contacts along the lifespan for young people who die by suicide. This study will establish whether documented hospital contacts for people who suffer childhood adversity are higher in those with an outcome of suicide compared with the randomly selected proportion of the general population. The study uses de-identified linked data in a secure environment, the national 'safe haven' and the data controller remains the NHS, therefore anonymity is preserved.

There are limitations, and these include identifying relatively rare events in routine data, with instances of abuse or maltreatment likely to be under-recorded and underrepresented, or with people not brought to hospital, even if severe. However, this is also likely to be the case in the control dataset and the relative differences between groups will be important. Other limitations are that there is no corresponding paternal data to summarise alongside maternal data, and that as the data span four decades these will have variable data quality and consistency of coding through time. This is particularly relevant to the change in ICD-9 to ICD-10 catalogues in 1996, catalogues not intended to be compatible. Sophisticated methods for cross-mapping ICD catalogues are nevertheless possible, and we will use Clinical Classifications Software algorithms, a technique used successfully in a previous study [22].

Another strength of this study is the planned stakeholder engagement to disseminate and solicit the views of health and public service practitioners, voluntary sector and people with lived experience. Although these multi-agency national workshops will identify opportunities to develop interventions in supporting people earlier in life at increased risk of suicidal behaviour, intervention development will be confined to the early stages only. It is hoped that sufficient detailed information will be available to develop and test a model in a future research study.

## Conclusion

There is a dearth of evidence about touchpoints prior to suicide. This study reports methods of harmonising ICD codes and their published cross-mappings along the lifespan to understand hospital contact patterns for childhood adversity that come to the attention of healthcare practitioners. Although time-consuming, these harmonised codes are a necessary precursor to the data cleaning and analysis phases of this study and are available for use to other researchers. It is hoped that once analysed, this study will contribute valuable information for the first time on childhood adversity, mental health, and suicidal behaviour related hospital contacts along the lifespan, thus identifying groups to focus earlier identification and intervention, and opportunities for data linkage with other relevant agencies to reveal more insights.

## Abbreviations

CHI	Community Health Index
eDRIS	electronic Data Research and Innovation Service
ICD	International Classification of Disease
ISD	Information Services Division
NHS	National Health Service
PBPP	Public Benefit and Privacy Panel
SMR	Scottish Morbidity Record

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## Authors' contributions

ND is the Principal Investigator. ND led the development of the research questions and study design; MM, TK, RO'C, BW, AJ, HC, CF, JB, CH, SA-S, and LN refined the development

of the research questions, study design and obtained the funding. ND led obtaining ethical and regulatory approval from the Public Benefit and Privacy Panel (PBPP). ND & JS undertook the cross-mapping exercises. JS is the Research Fellow and will provide analysis and support with project management of the study. GG provided support with literature reviewing. ND will have oversight of the analysis and interpretation of data. All authors provided critical review and final approval of the manuscript, and are in agreement to be accountable for all aspects of the work as determined by disciplinary expertise.

## Consent for publication

Professor Ruth Gilbert, Dr González-Izquierdo et al kindly provided codes extracted in their previous research, and consent has been obtained from Gonzalez-Izquierdo et al to publish these ICD codes pertaining to Violence and Maltreatment.

## Statement on conflicts of interest

The authors declare they have no competing interests.

## Ethics statement

The study was reviewed and approved by the North of Scotland Research Ethics Committee 1 (REC) on 04 May 2018 with REC reference 18/NS/0054. Consent to use the de-identified data was provided by the Public Benefit and Privacy Panel (PBPP) for Health and Social Care on 6 September 2018 with reference 1617-0228.

## Supplementary files

Appendix 1 (Supplementary tables 1-3)

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## Appendix

**Supplementary table 1. Cross-mapping of codes suggestive of maltreatment to ICD-9 and ICD-10\***

Conditions in ICD-9-CM	Code		Co-occurring exclusion codes	
	ICD-9	ICD-10	ICD-9	ICD-10
Genital herpes	054.1	A60	771.22	P35.2
Gonococcal infection	098	A54	098.4, 771.6	A54.3, P39.1
Pelvic inflammatory disease, unspecified	614.9	N73.9		
Contusion of genital organs	922.4	S30.2	286–287, E800–E819	D65-D69, V01-V99
Observation after alleged rape	V71.5	Z04.4		
Observation for abuse/neglect	N/A	N/A		
Retinal haemorrhage	N/A	H35.6	286–287, E810–E813, E815–E819 <sup>†</sup>	D65-D69, V20-V99
Rib fracture	807.0, 807.1	S22.30, S22.31	767, 765, 756.50, 733.1, E810–E813, E815–E819 <sup>†</sup>	P10- P15,P52.4,P52.6,P52.8,P52.9, P05,P07, Q78.0, M48.5,M80,M84.4,M90.7, V20-V99
Scapula fracture	811	S42.1	767, 765, 756.50, 733.1, E810–E813, E815–E819 <sup>†</sup>	P10- P15,P52.4,P52.6,P52.8,P52.9, P05,P07, Q78.0, M48.5,M80,M84.4,M90.7, V20-V99
Traumatic subdural haemorrhage	852	S06.5	286–287, E810–E813, E815–E819 <sup>†</sup>	D65-D69, V20-V99
Other/unspecified intracranial haemorrhage	853.0	S06.8	286–287, E810–E813, E815–E819 <sup>†</sup>	D65-D69, V20-V99
Stomach injury	863.1	S36.31	E810–E813, E815–E819 <sup>†</sup>	V20-V99
Assault	E965, E966, E968.2, E968.9	X93-X96, X99, Y00	E960.1, E968.4	Y05,T74.2, Y06
Assault, NOS		Y09	E960.1, E968.4	Y05,T74.2, Y06
Undetermined intent, other means	E988	Y19,Y26,Y27, Y31-Y34		
Skull vault fracture	800	S02.0	767, 765, 756.50, 733.1, E810–E813, E815–E819 <sup>†</sup>	P10- P15,P52.4,P52.6,P52.8,P52.9, P05,P07, Q78.0, M48.5,M80,M84.4,M90.7, V20-V99
Vertebral fracture	805	S12.0,S12.1, S12.2,S12.7, S12.9,S22.0, S22.1,S32.0, S32.7	767, 765, 756.50, 733.1, E810–E813, E815–E819 <sup>†</sup>	P10- P15,P52.4,P52.6,P52.8,P52.9, P05,P07, Q78.0, M48.5,M80,M84.4,M90.7, V20-V99
Traumatic subarachnoid haemorrhage	852	S06.6	286–287, E810–E813, E815–E819 <sup>†</sup>	D65-D69, V20-V99

Intrathoracic injury, NEC	862	S277-S279	E810-E813, E815-E819 <sup>1</sup>	V20-V99
Small intestine injury	863.2, 863.3	S36.40, S36.41	E810-E813, E815-E819 <sup>1</sup>	V20-V99
Spleen injury	865	S36.0	E810-E813, E815-E819 <sup>1</sup>	V20-V99
Spinal cord injury	952	S14.0,S14.1, S24.0,S24.1, S34.0,S34.1, T06.0,T06.1, T09.3	E800-E819	V01-V99
Other severe malnutrition	262 <sup>2</sup>	E43 <sup>2</sup>		
Dental caries	521.0	K02		
Solar radiation dermatitis	692.7	L57.8		
Pelvic fracture	808	S32.1- S32.8,T02.1	767, 765, 756.50, 733.1, E810- E813, E815-E819 <sup>1</sup>	P10- P15,P52.4,P52.6,P52.8,P5 2.9, P05,P07, Q78.0, M48.5,M80,M84.4,M90.7 , V20-V99
Traumatic pneumohemothorax	860	S27.0-S27.2	E810-E813, E815-E819 <sup>1</sup>	V20-V99
Heart or lung injury	861	S26, S27.3- S27.6	E810-E813, E815-E819 <sup>1</sup>	V20-V99
GI injury, NEC	863.8	S36.2,S36.8, S36.9	E810-E813, E815-E819 <sup>1</sup>	V20-V99
Liver injury	864	S36.1	E810-E813, E815-E819 <sup>1</sup>	V20-V99
Kidney injury	866	S37.0	E810-E813, E815-E819 <sup>1</sup>	V20-V99
Burn of head	941	T20	E890-E897	X00-X09
Burn of trunk	942	T21	E890-E897	X00-X09
Burn of leg	945	T24,T25	E890-E897	X00-X09
Burn of multiple sites	946	T29	E890-E897	X00-X09
Poisoning by drugs/medicinals	960-979	T36-T50	E870-E876	Y60-Y69
Drowning, non-fatal submersion	994.1	T751		
Second-hand tobacco smoke	N/A	Z58.7 <sup>3</sup>		
Swimming accident	E910.2	W67-W70		
Bathtub (near) drowning	E910.4	W65,W66		
Other (near) drowning	E910.8	W73		
Accidental (near) drowning, NOS	E910.9	W74		
Unarmed fight, brawl	E960.0	Y04	E960.1, E968.4	Y05,T74.2, Y06
Undetermined intent, poisoning	E980	Y10-Y19		
Undetermined intent, firearm	E985	Y22-Y25		
Household circumstances	V60	Z59		

Footnotes: \*Codes extracted from Schnitzer PG, Slusher PL, Kruse RL, Tarleton MM. Identification of ICD codes suggestive of child maltreatment. Child Abuse & Neglect. 2011 Jan 1;35(1):3-17; <sup>1</sup> Excluding codes where 4th digit is .6 or .7; <sup>2</sup> For exclusion codes see Supplementary Table 2; <sup>3</sup> Include only if any codes in Supplementary Table 3 are also present.



**Supplementary Table 2. Exclusion codes for use with 'severe' malnutrition codes.**

ICD-9	ICD-10
009.0	A09
010-018	A15-A19
042-044	B20-B24
070	B15-B19
140-208	C00-C97
243-244	E00-E03, E89.0
250	E10-E14
252	E20-E21, E89.2
253	E22-E23, E89.3
270-275	E70-E90, D89, M10
271.3	E73
277.0	E84
317-319	F70-F79
330-344	G00-G99, R52
431	I61
446	M30-M31
493	J45
530.8	K21
555-558	K50-K52
575-576	K82-K83
571	K70-K76
577.8	K86.8
579	K90-K91
588.8	N25.8
593.9, 585.9,	N18-N19, N28.9
599.0	N39.0
710	M32-M36
714	M05-M06, M08, M12.0
745-747	Q20-Q28, P29.3
749	Q35-Q37
750.5	Q40.0
751.3	Q43.1
758	Q90-Q99
760.76	Q86.0, P04.3
767.0	P10, P11.1, P11.2
770.7	P27.1
771	P35-P39
772.1	P52
852-853	S063-S068
984	T56.0

**Supplementary Table 3: Additional inclusions required for use with second-hand smoke code.**

ICD-9	ICD-10
480-487	J10-J18
490,491	J40-J42
466	J20-J21,J68
493	J44-J46
381.0-381.4	H65

## **7.4 Statement of personal contribution**

This paper is based on the study protocol submitted to the Chief Scientist Office in 2018 and successfully funded. The analytical work is still to be completed at the time of writing this thesis. I led the application for funding as Principal Investigator, developed the study design and research questions (RQs), selected methods, obtained NHS Research Ethics Committee and the Patient Benefit and Privacy Panel approvals (PBPP). I worked with a team of co-investigators, spanning academic disciplines, professional practice and third sector representation. I used previous experience gained in work leading to paper one, in understanding Scottish Morbidity Records (SMR), NRS death registrations, and harmonising ICD-9 and ICD-10 diagnostic classifications along the individual lifespans.

The grant funded a Research Fellow (JS) to do the analysis. I worked with JS in finding ways to harmonise codes for childhood adversity between previously published studies and the different versions of ICD-9, ICD-10, ICD-9-CM and ICD-10-CM. JS undertook the bulk of the cross-mapping of codes and I provided day-to-day guidance as necessary, as well as meeting regularly to review and address the numerous issues as they arose. I wrote the manuscript, and all co-authors had an opportunity to edit and make suggestions.

## **7.5 Contribution to science**

This paper's unique contribution is in the detailed documentation of the cross-mapping between different ICD catalogues for codes related to childhood adversity, all of which has been made openly available to researchers for re-use.

### **7.5.1 Altmetric score**

The Altmetric Attention Score is an estimated weighted approximation of the attention a research paper receives (287). The score for this paper was 7, and there was no data available on the 'score in context'. Link:

<https://www.altmetric.com/details/78795495>

## **7.6 Dissemination**

It has not been possible to disseminate at conferences as this paper was published in April 2020, during mandated lockdown related to covid-19.

## 7.7 Concluding remarks

Transparency and openness in research is critical to enable replication elsewhere (304), and publishing a pre-specified study protocol, along with detailed methodology is a cornerstone of good open science (304,305). This paper will permit me, with my co-authors, to publish future main findings cross-referenced to the pre-specified methodology in an open and transparent way.

Although publishers are responsible for platforms to host research findings and have subscribed to improve research transparency (306), it is still frequently the case that study protocols without ethics approval, or without external funding are not usually considered for publication (e.g. Springer BMC journals (307)). Study protocols with external funding, such as this paper, were more likely to be published, and I submitted the manuscript to the International Journal of Population Data Science (IJPDS). IJPDS was relatively recently launched and is the only Journal dedicated to the emerging discipline of Population Data Science, a topic on which I previously co-authored a position statement (273). I had given presentations at the International Population Data Linkage Network (IPDLN) Conferences (see Appendix Table 1, Section 10.1). The paper received external peer review by two reviewers, which improved the content and ordering of information presented, in line with the 2015 'Reporting of studies Conducted using Observational Routinely-collected health Data' (RECORD) statement (308).

Had the paper not been accepted for publication, I would have registered the project on the Open Science Framework so it was date-stamped (309). There is a lag between manuscript submission and publication, and a finite time to publish protocols before they are no longer pre-specified. Therefore, speed of publication was important, and the IJPDS turnaround time is relatively fast.

Although data science is often perceived as fast (203), the reality has been quite different, and my experience suggests this is for three main reasons of cost, approvals processes, and data release times. Data projects are increasingly expensive, and there is a long lag time between applications for external funding and project start dates. The approvals process to access de-identified data is onerous, requiring detailed variable-specific information, and impossible without

studying each dataset prior to application. Even when approvals have been obtained, the linked data release may be delayed further by several months.

All in all, the improved landscape to conduct research using routine data for public good has had the overall net effect of slowing down activity, even when there is a clear legal basis and funding for doing the research (203). A recent open letter to the UK Information Commissioner, UK data providers and Chief Medical Officers made a plea to reduce barriers to such research, drawing on covid-19 related experiences (310), that the scale and speed of data access to inform public health policy has been unprecedented and could spark innovation in improving data access (203).

## **8. Conclusion: Moving towards impact**

### **8.1 Chapter structure**

In this chapter, I provide a brief synopsis of the main achievements of the papers. I do this as a precursor to setting out how the findings shaped my thinking, and the steps I took in an attempt to generate impact from the evidence. This culminated in the National Summit for Mental Health, Distress and the Emergency Department. I then provide the relevant papers for the event, the rationale, agenda, and consensus findings, and end the chapter with a short reflection on future directions. In order to avoid repetition, I do not focus on paper limitations in this chapter as this has previously been covered in the papers and text.

### **8.2 Key findings of the PhD papers**

This thesis contains five published papers, two of which considered factors derived from data associated with deaths by suicide, one used Scottish Ambulance Service and unscheduled care data for 'psychiatric emergencies', and one considered the Police Scotland concept of 'vulnerability' and how that can be assessed. The thesis concludes with a published study protocol with detailed methodology for considering lifespan events from birth, through childhood adversity and mental health symptoms prior to suicide in young adults. A brief synopsis of each paper's key findings now follows.

Paper 1: For the first time in the UK, I applied an innovative data science method to summarise 30 years of information in Scottish NHS general and psychiatric hospital records of 16,411 people who died by suicide (8). The aim of this study was to identify patterns of hospital contact for people taking their own lives, finding that 3.1 times as many people died after last discharge from general hospital, not psychiatric hospital; that 24% of deaths occurred within three months of last discharge, more than half (58%) after last discharge from general hospital.

Paper 2: In this study, I used 65 years of National Records of Scotland (NRS) vital events deaths data spanning 1950-2014 (9). I investigated whether suicide is more a consequence of age, years of birth, or years of death. I compared my findings for Scotland with previously published findings by Professor David Gunnell and colleagues for England & Wales. In this study, I concluded that there was a group



of men (cohort) born around 1965-1970 who died in statistically significantly higher numbers in Scotland between 1995-2004, compared with those born around 1960. This suggested some cohorts of men were potentially more vulnerable to suicide, and helped explain the high numbers of deaths seen for younger men in the 1990s. This compared with findings for England & Wales, although to a lesser extent.

Paper 3: For the first time in Scotland, NHS data on emergency care, the 'Unscheduled Care Dataset' was explored to look at what happened to people who were attended by paramedics from the Scottish Ambulance Service, and considered a 'psychiatric emergency' (10). This study found that within one year, 6,802 people were attended to on 9,014 occasions for self-harm or mental health reasons, 11% of all ambulance calls. The most frequent pathway with 51% of calls was transfer to, and discharge from, Emergency Departments. Within the following year after contact, 4% had died, 97 of these as suicide. In the same year 746 deaths by suicide were recorded for Scotland, suggesting the ambulance service were in contact with 13% of people prior to death; there are unique opportunities for suicide prevention strategies with alternative care pathways for people attended to by the ambulance service.

Paper 4: I led a series of stakeholder interviews with Police Scotland leads, and all were keen to share data. I set out to replicate the ambulance service study in paper 3, but in a policing context. Police Scotland colleagues reported that 80% of calls were not crime-related, and there was limited evidence to suggest many were calls from people in 'psychological distress' (11). As mentioned previously in Chapter one, the reality of accessing usable data was to prove too challenging. All agencies have their own terminology and Police Scotland described people in 'psychological distress' as having 'vulnerability'. Through partnership working at a national event that I co-led, the key priority identified was the 'assessment of vulnerability' (7). I worked with colleagues in undertaking a scoping review of what was known about the assessment of 'vulnerability' in policing from a health perspective (12). This review was the first in the world to report on this topic, finding that vulnerability is (broadly speaking) place-based from a policing perspective, and person-based from a public health perspective.

Paper 5: My final paper returned to using Scottish NHS hospital and NRS deaths data. In identifying from people's lifespan data what commonly happened to people, given certain patterns of healthcare contacts, then there may be opportunities to intervene with alternative care pathways earlier in the lives of people. In this paper, I presented a published protocol and methodology on identifying records for childhood adversity in the lives of people who later died by suicide (13). This paper improved on methods used in the first study above, this time looking to see what happened in a 'control' group matched to the group who took their own lives. It also provided methods for assessing the mental health and suicidal behaviour later in adolescence and young adulthood, as recorded in their NHS data.

### **8.3 Summary of achievements**

The papers in this thesis aimed to uncover new knowledge on factors associated with suicide and psychological distress. The methodological aim was to achieve this through the quantitative analyses of datasets, including linking data, cleaning, re-coding and operationalising variables, implementing novel ways of harmonising diagnostic codes contained in population data, and analysis of data.

The five papers contained in this thesis achieved these aims in the following ways. With respect to methodology, in paper one, I provided methodology to harmonise longitudinal data between International Classification of Disease catalogues using clinical classifications software (CCS). Prior to paper one, no UK studies had been published for presentations to general hospitals prior to suicide, and this paper fulfilled that evidence gap. Paper one provided factors associated with last hospital discharge for people who died by suicide, finding that 25% of deaths occurred within three months of last discharge, more than half of these from general hospital.

Paper one also reported important information on previous psychiatric morbidity. For example, at the last general hospital visit, only 14% people had a recorded psychiatric diagnosis. However, an additional 19% had a previous psychiatric diagnosis, with the remaining 67% having no psychiatric diagnosis whatsoever. Corresponding median times to death for these three categories were seven, nine and 33 months, respectively. It is possible that a proportion of the 19% with previous psychiatric history were admitted to general hospital with unmet needs and ED staff had no access to clinical data from psychiatric facilities, highlighting

a need for better information sharing between settings. It is also worth highlighting, that of those who died within three months of last discharge, 45% had no secondary care psychiatric history, supporting the need for better psychosocial assessments done in Emergency Departments, as endorsed by the National Institute for Health and Care Excellence (NICE) guidance (311).

Paper one revealed the potential of data in informing better clinical practice and policy, particularly within Emergency Departments and general hospitals. There was widespread dissemination, including from the Royal College of Psychiatry and others via twitter, conference talks and a presentation to the All Party Parliamentary Group at Westminster, amongst others. Despite all this activity, having an impact on practice or policy was slow (e.g. contributing to NICE guidance, see chapter three), and with hindsight, engaging key stakeholders earlier on in the research process may have helped expedite dissemination of findings. Perhaps the most substantial limitation of this work was that emergency department and primary care data were not incorporated into the analysis. As most presentations for mental health problems are seen by GPs, it is likely this is where the vast majority are seen. However, primary care data are not routinely available in Scotland at this time, and Emergency Department data was of insufficient quality for use in a longitudinal analysis of data.

I continued with the theme of population level risk factors in paper two, using aggregated vital events data, finding that cohorts of men born around 1965 and 1970 died by suicide in statistically significantly greater numbers and at increasingly younger ages than those born around 1960. Had these later cohorts had greater mass vulnerability to suicide as they aged, it would have been possible to advise focussing suicide prevention activity here, but this was not a robust finding and remained inconclusive. I compared my analysis with that reported for England & Wales, finding a comparable cohort effect between the countries. However, there were also stark pattern differences, with suicide rates for men in Scotland twice that of England & Wales. During the time between submission and publication of paper two, another analysis was published for Scotland (58), with comparable findings that the cohort 1965-1974 was most affected. This comparable analysis was able to make use of additional data for deprivation area, finding that those living in more deprived areas drove the cohort effect, and that this was likely a consequence of the period effect of 1980s neo-liberal politics (58).

In paper three, I worked with the PI in using the 'Unscheduled Care Dataset' for the first time. This time the research focus shifted to pre-hospital emergency care, and obtaining evidence on those attended to by Scottish Ambulance Service. In this paper, 6,802 people were attended to in 2011 by paramedics and deemed to be 'psychiatric emergencies'. They were each followed up in the data for one year, with almost half attended to more than once; 29% of whom were seen on three or more occasions. Nearly two thirds of those transported to Emergency Department were discharged with no known follow-up (50%), or left at home (12%). Almost one fifth of admissions to ED resulted in self-discharge, of whom 25% made a repeat call within the same year.

Arguably, the most influential findings of paper three were that 4% (279) had died within one year of paramedic attendance; 97 of whom were confirmed death registrations of probable suicide. As 59 people who died by suicide were still alive more than one day after paramedic attendance, this suggested a clear opportunity for focussed suicide prevention care in this group.

Paper four was a scoping review of evidence on the assessment of vulnerability, done in the hope that an evidence-informed assessment had potential to be piloted across agencies, including Police Scotland and NHS partners. The paper found that there were few definitions and no consensus, and that the terminology was inconsistently applied and meant different things in different agency and cultural contexts. In general, vulnerability in health perspectives was associated with individuals but less so in policing, where environment and context mattered. Not having consistent terminology in multi-agency settings is highly problematic, and potentially to the detriment of people in contact with services.

With respect to paper five, I provided a study design and detailed methodology to harmonise longitudinal data between ICD catalogues using both CCS and in operationalising variables reported in previous studies.

In order to complete these papers, I undertook training in advanced quantitative methods using Stata statistical software and in the analysis of linked health data research. I acquired knowledge and experience of using and linking large datasets, applying for relevant approvals, writing and applying for grant funding as co-investigator and latterly as Principal Investigator. I networked extensively in completing these papers, and was invited to join MQ (the mental health charity)

Data Science Group, and to co-author additional published works. These included a book chapter on suicide research (312), three papers on mental health and population data science (273,274,313), a further paper on policing and health (7), and a follow up systematic literature review on the assessment of vulnerability (paper under review).

The individual contributions of the papers in this PhD provided new knowledge on risk factors associated with suicide. They did this in the following ways. Firstly, information was provided for the first time on hospital contacts prior to suicide, highlighting that more deaths have occurred within three months of last discharge from general, not psychiatric hospital. In providing this information, lifespan hospital contacts were utilised using innovative ways of harmonising data through decades using the AHRQ Clinical Classification System for the first time applied to UK data. Secondly, analysis of aggregated deaths data revealed increased vulnerability to suicide associated with men being born from the mid-1960s to 1970s. Thirdly, for the first time it was revealed that in the year before their death by suicide, paramedics attended 13% of people, implying there are missed opportunities for focussed upstream intervention. In providing this information, the Unscheduled Care Data Mart (UCDM) was used for the first time, proving to be a rich research resource. Fourthly, a literature review of the assessment of vulnerability established that 'vulnerability' is a concept with no shared definition between policing and health services, and was context-specific or person-specific, respectively. Finally, in a return to utilising information held in hospital records along the lifespan, a published protocol provided detailed methodology on harmonising information on childhood adversity and mental health diagnoses prior to suicide. This final contribution provided diagnostic codes used in previous UK and US studies cross-mapped along the decades to achieve consistent categories in time, thereby enabling a lifespan analysis of young people who have died by suicide.

The combined contributions of the above have demonstrated feasibility of using different datasets to highlight risk factors for suicide, and provided important information on where to develop future interventions. The combined knowledge of the above has led to meaningful engagement with policy makers and informed relevant actions of the Scottish Government's Mental Health Strategy, which I expand and elaborate on in the rest of this chapter.

## **8.4 Moving towards impact**

Several drivers helped shape my thinking in how the learning from paper findings could be used to inform future research and practice. There were reflections on paper findings informed by conversations with practice professionals, and increasing pressure for impact from the higher education sector and grant funding bodies, with implications for the future role of data science. Conversations with third sector leads painted a picture of increasing pressure in the system and lived experience perspectives were also indicative of system problems, but with some positive accounts of interventions. There were also Scottish Government and policy drivers, as outlined in the Mental Health Strategy (153), and there were personal drivers at play.

The following sections are not an evidence synthesis, but rather an attempt to portray in brief how my understanding was influenced by events and conversations held with practice professionals and others. I now go through each driver in more detail, before introducing in the following section the National Summit on Mental Health, Distress and the Emergency Department.

### **8.4.1 Paper findings and reflections with practitioners**

The paper findings were surprising. For instance, paper one findings were a revelation that more deaths by suicide occurred within three months of last discharge from general hospital, not psychiatric hospital. This was not just to me but also to the journal editor and many healthcare staff who contacted me since to discuss implications of the findings. I now provide perceptions of the main concerns.

Concern was expressed at the lack of care pathways post-discharge for people attending with symptoms of distress, self-harm, or mental ill health seen in Emergency Departments (ED), a group with known vulnerability to suicide. Some of this group were known to be ED frequent attenders, with few options to break the cycle with better support for people. Concerns also centred on ED not being an appropriate environment for this patient group, with significant disparity between the rapid responses of colleagues responding to physical



health emergencies, compared to those with urgent distress or mental health needs. Concerns were also expressed around perceived inequities in duties of care between general and psychiatric hospital.

A main limitation of paper one findings were data did not include ED discharges, or people who died as an 'event of undetermined intent'. Paper one findings were one small part of the system picture, and deaths by suicide after discharge from general hospital were potentially underrepresented. Paper two findings meanwhile reinforced Scotland's particular challenge with respect to deaths by suicide; with rates for men double that of their counterparts in England and Wales.

Paper three pinpointed a group under paramedic care deemed as 'psychiatric emergencies' and at particularly high risk of suicide, posing a potential opportunity to engage in focussed upstream suicide prevention activity. The Scottish Government had invested heavily in universal suicide prevention strategies (124,126), and initiatives such as the DBI (195). In many cases, paramedics had no option but to transport to ED as the only available care pathway, even though individuals were 'alert and awake' not needing physical healthcare. Further, ED was considered not the best place to respond to this population, with paramedics expressing concern around anecdotal outcomes of suicide following transport to ED.

In my conversations with Police Scotland leading to paper four, the concern here was for people and service resource use; whereas paramedics leave ED after patient drop-off, police officers had to remain with people in ED, sometimes for hours. Views were expressed that people could be taken to an alternative place of safety away from ED, with the exception of people requiring urgent physical health attention. This place of safety would preferably be local discrete community solutions, staffed by trusted persons of safety (186). This included those who were intoxicated, with inconsistent protocols and surprising variability between EDs in how and when people were assessed.

In conversations with the team leading to the grant submission for paper five, it was increasingly clear that trauma informed approaches to those

experiencing distress or mental health problems were appropriate. In support of this was the NHS Scotland national training programme on trauma informed care, launched in 2017 (194). Knowing who would benefit most from trauma informed care was key, with an analysis of hospital presentations for childhood adversity providing potentially useful information to re-design service delivery pathways (analysis in progress related to paper five).

Therefore, there was an emerging picture that system change was wanted, but it was difficult to see whether I could contribute anything in terms of impact to such a massively complex system problem.

#### **8.4.2 Increasing pressure to generate impact**

At the time there was increasing pressure from the Higher Education sector and funding bodies to generate impact from research. In 2016, I made an attempt at impact generation with a grant submission with Prof Margaret Maxwell and team to NIHR HS&DR panel. This was for a randomised controlled pilot trial to assess the impact of suicide prevention, psychosocial assessment and safety planning within ED, with outcome follow-up using morbidity and mortality records. NIHR deemed this not to be a priority area at that time, a frustrating outcome, but one that would change within the subsequent three years. In 2017, The Royal College of Emergency Medicine in conjunction with the James Lind Alliance, published their research priorities and ranked as third, mental health care and staff training (314), bringing sharper focus to the problem. Two further unsuccessful first round grant submissions happened in this period, this time for data science projects to CSO (paper three) and MQ (paper five), and the peer review was clear that data science for its own sake was not enough, and I needed to do more to create impact.

#### **8.4.3 Third sector pressures**

Conversations with third sector representatives pointed to increasing pressure in the sector. This was in part due to the impact of austerity measures on sector funding, but also with increased numbers of people looking for additional help

at the time, partly also a legacy of the 2008 recession. Third sector perspectives were gained in discussions with Samaritans Scotland (4), Mental Health Foundation Scotland (315), Penumbra (316), and Aberlour children's charity (317). A joined-up approach within local communities of triaging and 'warm handovers' to access services in support of people with social problems was seen as a positive way forward whilst respecting confidentiality and anonymity. The Distress Brief Intervention ([www.dbi.scot](http://www.dbi.scot)) described in chapter one was underway in some areas by this time, and although evaluation was still not complete, it was seen as a positive way forward to foster collaboration within communities and agencies.

#### **8.4.4 Lived experience perspectives**

Data research offers descriptive statistics on outcomes, but lacks human connection and contextual narratives. In 2017, I began having informal conversations with two people with lived experience, in order to gain perspectives to help inform what to do next.

I now draw briefly on qualitative research findings that reflect these conversations. For people with lived ED experience, hospital experience and psychosocial assessment offered a 'pivotal role in promoting or stifling hope' (168). The attitudes and therapeutic approaches encountered in ED could be interpreted as 'statements about personal values', and 'legitimacy of claims for help' (168), while positive encounters and feeling worthy of help have potential for transformation (168). When experiencing acute psychological distress, people have self-harmed to present the 'worst versions of themselves' to ED (184), and that self-harm was an outlet for psychological distress and a 'means to self-punish' (168). Psychological distress may escalate to crisis in an acute response to fear, particularly when feeling isolated and vulnerable out of hours when the usual support mechanisms are closed (184).

I also heard from two people who had benefited from intervention with the Violence Reduction Unit (VRU), who place 'Navigator' staff in EDs to counsel victims or perpetrators of knife crime with an aim to rehabilitate people with structured support away from violence. VRU colleagues and experts by

experience Accessed adversity in childhood, including multiple disadvantage, as a key ingredient that frequently led to chaotic, violent lifestyles. Navigators played a crucial role in turning lives around, and were noted to support people on occasion in ED who were there because of distress; it seemed that a properly funded expansion of the Navigator role could also help those with social distress.

#### **8.4.5 Scottish Government policy drivers**

In 2018, the Health & Justice Collaborative Improvement Board was formed; the first time health and justice were brought together in Scottish Government (SG). In 2019, the Distress Intervention Group (DIG) of the Board was created, tasked with service redesign in key areas of: 'mental health crisis prevention, call handling and triage, keeping people safe, improving access to mental health services, and relapse prevention'.

Part of the DIG's work was to answer SG Mental Health Strategy 2017-27 Action 14 (153), to 'Work with NHS 24 to develop its unscheduled mental health services...'. The DIG used evidence from paper three to revolutionise responses to calls from people in distress, with the 'Enhanced Mental Health Pathways' project. This project aimed to transfer triaged calls from people in distress by Scottish Ambulance Service and Police Scotland to a dedicated mental health support team at NHS 24.

Although the Enhanced Mental Health Pathways appeared a plausible step in the right direction, at the time of writing there was no comprehensive plan to evaluate the project, and the unintended consequences of such an intervention remain unknown. The DIG was also tasked with Action 13, 'to ensure unscheduled care takes full account of the needs of people with mental health problems...', and Action 15, to 'increase the workforce to give access to dedicated mental health professionals to all A&Es, GP practices, every police station custody suite, and in our prisons'.

These actions were reinforced with additional investment to £35 million for 800 additional mental health workers in these key settings (153). Therefore, there were clear policy drivers that aimed to use available evidence on which to base the strategic actions, but no clear budget to evaluate these actions.

#### **8.4.6 Personal drivers**

Finally, it would be remiss not to draw on personal drivers for wanting to achieve meaningful impact. In the background was my family, recently devastated by my nephew's suicide at age 21, grappling and unable to come to terms with this monumental event. This was particularly so, being the second death by suicide in our family. The bereavement was complex and exhausting, and on a few occasions I was unsure I could continue with research in this field. I had set in train an independent academic career based around suicide and mental health data science, building on my skillset as a health statistician. This second career felt under threat. Ultimately, and somewhat disregarding my feelings at the time, I kept going in blind faith that time would provide space to regenerate passion for the subject, and if I could get to that space, I had further positive contributions to make to the field.

#### **8.5 National Summit: Mental health, distress and Emergency Department**

In 2018-19, I was co-leading the Mental Health Special Interest Group (SIG) meeting of the Global Law Enforcement and Public Health Association (GLEPHA), planned for October 2019 in Edinburgh. I had contributed to this SIG the previous year in Toronto, with our 2018 guidance published for policing interactions with people experiencing mental health crises or distress (185). I wanted to draw on this Toronto work, my papers' findings, other evidence and working examples of good practice. My thoughts crystallised on generating impact by having an international workshop on mental health and distress with a focus on pre-hospital care and Emergency Departments. This would draw on expertise from colleagues around the world, as well as colleagues from ED, liaison psychiatry and psychology, ambulance service, police service, NHS24, third sector, lived and living experiences.

My initial idea and plan for a workshop attracted attention from colleagues in Scottish Governments' Justice Analytical Services and the Distress Intervention Group. The agenda for the day fitted the Scottish Government's Mental Health

Strategy Actions 13-15, as described above (153). Things snow-balled to a 'National Summit', and I collaborated with Prof Stuart Thomas, (RMIT, Melbourne) and Inga Heyman, Edinburgh Napier University, in modelling the Edinburgh National Summit on a previous similar event held in Melbourne, Australia (318). The event was attended by about 85 people and was well represented. By this point, there were so many other compelling academic and expert testimonies that my papers' main findings were collapsed into a five-minute presentation.

The rationale leaflet and event agenda are presented next in image format, as emailed to all delegates. This is followed by the Consensus Statement, a document that was written the following day with five of us as co-authors.

## 8.5.1 Rationale for the Summit



### NATIONAL SUMMIT

#### MENTAL HEALTH & DISTRESS IN THE EMERGENCY DEPARTMENT

As part of a series of international mental health consultations held in advance of each [International Law Enforcement and Public Health Conference](#), a National Summit will be held on 18<sup>th</sup> October 2019. The topic this year is Mental Health and Distress in the Emergency Departments (ED). Delegates' experiences, locally, nationally and internationally, will be drawn upon, and combined with evidence from international case studies, to identify challenges and best practice relating to mental health and distress in the ED from the perspectives of police, ambulance and ED personnel, policy makers, researchers, analysts, and people who have experienced this interface.

On behalf of the Scottish Centre for Law Enforcement & Public Health (SCLEPH, hosted at Edinburgh Napier University), The Global Law Enforcement and Public Health Association (GLEPHA) Mental Health Special Interest Group, and the Scottish Government (SG) 'Distress Intervention Group' (DIG) of the Health & Justice Board, you are cordially invited to participate in this national summit.

#### **Rationale:**

It is widely known that current care pathways for people who present to A&E/ED in distress (intoxicated or otherwise) and/or with mental health problems are sub-optimal. From a Scottish perspective, this is an issue which profoundly affects outcomes for people and resources for multiple services, including NHS, NHS24, Police Scotland and Scottish Ambulance Service [1, 2]. Scotland's annual suicide rates have increased from 2017-2018 by 15% to 784 deaths [3]. Around 31% of people who die by suicide in Scotland have attended Emergency Departments in the three months prior to death [4]. More than half (58%) of deaths by suicide which occurred within three months of hospital discharge, did so after discharge from general hospitals, not psychiatric hospitals [5].

Whilst suicide is a relatively rare outcome, it partially reflects our societal response to a much larger, vulnerable, population. Many people will not come to the attention of services, but where they do, collaborative leadership is needed to respond with whole systems approaches to vulnerability. The evidence base for this assessment of vulnerability remains scant, and reflects organisational perspectives. For instance, a review of extant literature identified that vulnerability assessment was place-based for policing perspectives and person-based from public health perspectives [6, 7]. This work builds on collaborative SG Justice Analytical Services and SCLEPH national workshops held previously with key stakeholders [8, 9].

From a Police Scotland perspective, 92% of those transported under a place of safety order were not judged by the doctors who assessed them as requiring hospital detention [10]. We also know the Scottish Ambulance Service in one year attended an estimated 6,802 people with 'psychiatric emergencies'. Half of these individuals were transported to A&E, 59 of whom lived longer than one day and took their own lives in the following year, representing about 8% of deaths in that year [1]. This strongly suggests a need to overhaul ways of working between services to minimise silo working, make efficiencies and improve outcomes for people in distress.



Staff within EDs are not confident or consistent in their risk assessment of suicide, with wide variation in practice between and within EDs, and with people in distress facing inequitable experiences [11]. When making decisions around suicide risk, evidence-based protective [12] and risk factors [13] are not always relied upon, with non-validated instruments and/or no instruments being applied, with staff citing lack of confidence and availability of appropriate training and instruments for the ED [11]. Aligned with this is the need to ensure international human rights requirements, which emphasise the need to both protect and to support respect for the views of a person in mental distress are given effect. This is applicable to practice, policy and the implementation of existing and reform of legislation [14-16]. Although the evidence presented here focuses on Scotland, we recognise that these are issues which may be equally prevalent internationally.

### **Overview and Aims:**

Given increasing concerns with suicide rates and self-harm, the lack of care pathways for people who frequently attend, intoxicated or otherwise, and the pressure on existing services struggling to meet increasing demand, now is timely to agree to change or adapt models of care currently on offer. This fits to Scottish Government's national Mental Health Strategy, the Suicide Prevention Strategy 'Every Life Matters', and Police Scotland Strategy 2026.

Case study evidence of promising national and international initiatives and interventions will be discussed, debated and facilitated by leaders from across all organisations involved in these pathways. Building on the evidence presented, and delegates' expert experience, our overall aim is to establish consensus to consider and explore how models of care currently on offer may be changed. This will be achieved through a series of panel discussions involving experts from across the mental health and ED interface, followed by small-group themed discussions focusing on some of the key underlying issues. This Summit builds on a two day meeting of the GLEPHA Law Enforcement and Mental Health Special Interest Group held in Toronto 19-20<sup>th</sup> Oct 2018; an international best practice guideline was produced for police management of mental health crisis in the community [17].

### **Outputs:**

A communique will be disseminated to relevant audiences proposing agreed action points and best inter-agency practices for dealing with mental health and distress in ED. This will summarise key discussion points and proposed strategies going forward. Follow-up events will be held to consolidate findings from the Summit, and look more in-depth into how these may be applied. We will also publish a longer publication in an academic journal the main themes and key conclusions from the Summit, in contribution to the evidence base. All attendees will be acknowledged in this paper.

Best wishes and thank you for your contributions in advance,

Nadine Dougall & Inga Heyman (SCLEPH), Stuart Thomas (GLEPHA) & Jacques Kerr (SMO, MH Directorate, Scottish Government)

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## 8.5.2 National Summit Agenda

# Mental Health and Distress in the Emergency Department

## National Summit

**EDINBURGH** 18 October 2019



COSLA Conference Centre, 19 Haymarket Yards, Edinburgh, EH12 5BH

Hosted by: **Scottish Centre for Law Enforcement & Public Health**  
**Global Law Enforcement & Public Health Association**  
**Scottish Government Distress Intervention Group**



## SUMMIT: Mental Health and Distress in the Emergency Department

*An invitation only event hosted by the Scottish Centre for Law Enforcement & Public Health (SCLEPH), Edinburgh Napier University, in collaboration with the Global Law Enforcement & Public Health Association (GLEPHA) Mental Health Special Interest Group, and the Distress Intervention Group (DIG) of Scottish Government.*

**Venue:** COSLA Conference Centre, 19 Haymarket Yards, Edinburgh, EH12 5BH

**Programme - 18<sup>th</sup> October 2019**

<b>08:30</b>	Registration opens and welcome tea and coffee	
<b>09:00</b>	<b>Welcome from the hosts and setting the scene</b>	
	<p><b>Stuart Thomas</b>, Mental Health Lead, GLEPHA; RMIT University <i>International solutions to local problems (Capability Questionnaire)</i></p> <p><b>Nadine Dougall</b>, SCLEPH, Edinburgh Napier University <i>Why are we here: clinical outcomes and data perspectives</i></p> <p><b>Inga Heyman</b>, SCLEPH, Edinburgh Napier University <i>Why are we here: police perspective</i></p>	
<b>09:15</b>	<b>Keynote Presentation</b>	
	<p><b>Jacques Kerr</b>, Senior Medical Officer, DIG Lead, Directorate for Mental Health, Scottish Government</p> <p><i>'Supporting Scotland's Mental Health: Streamlining the Patient Pathway'</i></p>	
<b>09:30</b>	<b>Welcome from Law Enforcement and Health Representatives</b>	
	<p><b>Margaret McGuire</b>, Executive Nurse Director, NHS Greater Glasgow &amp; Clyde</p> <p><b>Ann Bell</b>, Superintendent, Police Scotland</p> <p><b>David Chung</b>, Vice President, Royal College of Emergency Medicine</p>	
<b>09:45</b>	<b>Panel One</b>	<b>Panel Members</b>
	<p><b>Mental Health and the E.D: Successes &amp; Challenges</b></p> <p>Chair: <b>Eibhlin McHugh</b> Co-Director Public Health Reform Programme, Scotland</p>	<p><b>Chris White</b>. Citizenship and Participation officer, Mental Health Foundation Scotland</p> <p><i>'Lived Experience Perspectives of experiencing distress and emergency services'</i> (15 mins)</p> <p><b>James Ferguson</b>. A&amp;E Consultant, NHS Grampian</p> <p><b>Ann Bell</b>, Superintendent, Police Scotland</p>



Panel one provides context for an understanding for how mental health distress is managed around the emergency department from a range of different perspectives

**Derek Myers**, Deputy Team Leader & MH Nurse, Mental health Assessment Services perspective

**Robby Steel**, Consultant Liaison Psychiatrist, Royal Infirmary of Edinburgh & Lead for 'PACT'

**Lorna Young & Karin Howard**, Mental Health Nurses, NHS Grampian

(10 minutes each and 15 minutes discussion)  
**Discussion**

<b>11:05</b> Morning Tea Break	
<b>11:25</b>	<p><b>Panel Two</b></p> <p>Discussion of UK case studies of interventions for dealing with mental health and distress in the emergency department</p> <p>Chair: <b>Cliff Sharp</b> Distress Intervention Group, Scottish Government</p> <p>Panel two provides practice-based promising examples of what works from UK perspective</p>
	<p><b>Panel Members</b></p> <p><b>Kevin O'Neill</b>, Program Manager, Distress Brief Intervention</p> <p><b>Emma Bagshaw</b>, Urgent and Emergency Care Mental Health Lead (ECIST), NHS England &amp; NHS Improvement</p> <p><b>Nigel Henderson</b>, Chief Executive Penumbra, 'Crisis Centre model'</p> <p><b>JonJo Hurley</b>, Suicide Prevention Lead (London)</p> <p><b>Rory O'Connor</b>, Director of Suicidal Behaviour Research Laboratory, University of Glasgow, SAFETel</p> <p>(10 minutes each and 15 minutes discussion) <b>Discussion</b></p>
<b>12:30</b>	Morning Closing Remarks from Stuart Thomas, GLEPHA ( <i>Knowledge exchange ideas</i> )
<b>12:35</b> Lunch - Knowledge Exchange ideas	
<b>13:30</b>	<p><b>Panel Three</b></p> <p>Discussion of International evidence base involving mental health and distress in the ED</p> <p>Chair: <b>Jacques Kerr</b> Distress Intervention Group, Scottish Government</p> <p>Panel three provides practice-based examples of what works</p>
	<p><b>Panel Members</b></p> <p><b>Stuart Thomas</b>, Professor of Forensic Mental Health, RMIT University; Melbourne ED practice based evidence</p> <p><b>Amy Watson</b>, Professor, Jane Addams College of Social Work, University of Illinois; Crisis Intervention Team model, USA</p> <p><b>Stan Gilmour</b>, Superintendent, Thames Valley Police; Thames Valley &amp; Reading model</p> <p>(10 minutes each and 15 minutes discussion) <b>Discussion</b></p>



from an international perspective

<b>14:15</b>	<b>Themed Discussions</b> Introduced by <b>David Chung</b> , Vice President, Royal College of Emergency Medicine	
	<b>Discussion Topics</b>	<b>Discussion leads</b>
	Intoxication in ED	Inga Heyman & Claire Thomson
	Managed Discharge from ED	Robby Steel & Amy Watson
	Police time in ED & 4h waiting time	Andrew Wooff & Stuart Thomas
	Alternative Care Pathways	Cliff Sharp & Dani Kesic
	Alternative Safe spaces to ED or in the ED environment	Margaret Maxwell & Jen Wood
	Children & Young People	Lyn Ross & Michael Smith
	Information, intelligence, data & technology	James Ferguson & Nadine Dougall
<b>15:15</b>	Afternoon Tea Break	
<b>15:30</b>	<b>Themed discussions (Continued)</b> Introduced by <b>Eibhlin McHugh</b> , Co-Director Public Health Reform Programme	
	<b>Discussion Topics - As above</b>	<b>Discussion leads</b>
	Intoxication in ED	Inga Heyman & Claire Thomson
	Managed Discharge from ED	Robby Steel & Amy Watson
	Police time in ED & 4h waiting time	Andrew Wooff & Stuart Thomas
	Alternative Care Pathways	Cliff Sharp & Dani Kesic
	Alternative Safe spaces to ED or in the ED environment	Margaret Maxwell & Jen Wood
	Children & Young People	Lyn Ross & Michael Smith
	Information, intelligence, data & technology	James Ferguson & Nadine Dougall
<b>16:30</b>	<p><b>Key Priorities and agenda for day 2</b> <b>What is key for the Communique?</b></p> <p>Chair: <b>Jacques Kerr</b>, SMO &amp; Lead for Distress Intervention Group, Scottish Government</p>	
<b>16:45</b>	<p>Close of day 1 Nadine Dougall, Inga Heyman, and Stuart Thomas (Capability Questionnaire)</p>	



## 8.5.3 National Summit Consensus Statement



GLOBAL LAW ENFORCEMENT AND PUBLIC HEALTH ASSOCIATION  
MENTAL HEALTH SPECIAL INTEREST GROUP



### **Mental Health, Distress and the Emergency Department NATIONAL SUMMIT 18 October 2019, Edinburgh Communique**

Current care pathways for people who present to emergency departments in distress or with mental health problems are not adequate. This is an issue of international concern, with the lack of suitable service response potentially profoundly affecting the health and justice outcomes of these people. On 18 October 2019, at the Law Enforcement and Public Health Mental Health Special Interest Group Summit, 85 delegates met to discuss the current situation domestically and internationally.

The purpose of the Summit was to *develop plans for best inter-agency practices for dealing with mental health and distress in the emergency department, with a further aim being that these be applicable to international implementation*. Delegates included people with lived experience, doctors, nurses, police officers, paramedics, academics, and policy makers. They shared their experiences, outlined examples of innovations in service delivery internationally, and described models of care that sought to address what were considered to be the key components required to improve responses to those presenting to emergency departments in mental health distress. *Seven key areas were highlighted for action:*

1. ***Police time in ED & the four-hour waiting time:*** Police are spending a disproportionate amount of time in ED with people in mental health distress. While the four-hour waiting time metric in ED is applicable for physical health, it is less appropriate for people presenting with mental health symptoms. People presenting in distress have the right to person-centred, trauma-informed approaches that are free from stigma and discrimination. A time-pressured response is not conducive to creating a safe and trusting environment for disclosure; a more sophisticated person-centred triage system would improve patient experience.
2. ***Intoxication and distress in ED:*** Current arrangements between health and police to support people who present to the ED as intoxicated are not adequate. For the purposes of ED assessment, there needs to be an agreement regarding what constitutes intoxication and the methods by which this is reliably determined. The four-hour waiting time metric operating in Scotland is likely inappropriate for dealing with intoxication, and alternative environments to ED should be explored.
3. ***Alternative care pathways:*** Mental health distress should be addressed in the community where possible, with ED being the last resort. Focus should be on primary health prevention, and building local community responses, including those that operate out of hours. Alternative pathways should incorporate health care practitioner engagement co-located with other services in a community hub type of model, as well as 'self-healing trauma-informed communities', which draw on resources like Recovery Colleges.
4. ***Alternative safe spaces to ED or in the ED environment:*** In order to justify going to ED, people in distress may feel a pressure to present as the most distressed version of themselves. People need a place where they can make a meaningful connection with others, to enable feeling safe, supported, validated and compassionately listened to. A community, or ED-based, safe space could potentially de-escalate the need for most severe presentations. Safe space should be triaged depending on levels of risk to self or to others, with consideration given to minor first aid services administered safely and with compassion in safe settings. Safe space needs to be quiet with few distractions.



5. **Managed discharge from ED:** There are clear gaps in the provision of care for people once discharged from ED; as such, basic safety and wellbeing needs are potentially left unaddressed. People can feel unsafe to leave the ED and would benefit from active signposting and/or real time handover to other agencies. These services and agencies should be community-based, with flexible access hours to allow for a continuity of support. Best practice indicates that follow-up after discharge should routinely be offered, and in consideration of combined navigator/ peer support worker model.
6. **Children & Young People:** It is important to believe children and young people when they say they want to harm or kill themselves. The emphasis of the approach to responding to children and young people who present to ED needs to be on prevention and early intervention, with sensitive consideration given to early life adversity and RFG patterns (recency, frequency and gravity). Thresholds for defining children and young people age-wise remain unclear and inconsistently operationalised, therefore, they must be specifically formalised. The ongoing service gap between referral and being triaged by CAMHS needs to be addressed and other equivalent community-based alternatives actively explored; access to early help is difficult when the only referral pathway is to CAMHS. A concordat that clearly sets out and agrees the roles and responsibilities for and between agencies is required, along with regular multi-agency roundtable meetings to ensure the concordat needs are being met.
7. **Information, intelligence, data & technology:** People who use services in distress expect that information will be shared between health services. People are willing to carry cards or consider an electronic patient portal which sits outside of health that details co-constructed (police, health or peers) or self-completed advanced directives that can be accessed by police, paramedics and other relevant services. Individual preferences regarding differential levels of access would need to be determined and adhered to. Enshrined in advanced directives should be any specification to override wishes in an absolute emergency. Deterioration of symptoms monitored via technology should be discussed as an option.

*Summit participants agreed that urgent, collaborative action is required to improve care pathways and associated outcomes of people presenting to emergency departments with mental health distress. Delegates agreed that no one service can adequately meet the needs of people who present in mental health crisis; they made a commitment to ongoing collaborative discussions with the aim of leading to reform of the health and justice systems.*

*The Policing, Health, and Social Care Consensus Statement<sup>1</sup>, published in February 2018, provides an excellent springboard to identify common ground across the health and justice sectors to help shape and guide these ongoing discussions. Further, resources such as the Emergency Services Hub, developed by the Royal Society for Public Health<sup>2</sup>, provide a starting framework for developing consensus statements and operationalising the collective vision and opportunities afforded by a joined-up approach to responding to mental health distress that is evidence-based and utilises shared resources and capabilities.*

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2. <https://www.rsph.org.uk/our-work/resources/emergency-services-hub.html>

## 8.6 What next?

As can be seen from the consensus findings, our response to those in distress experiencing unscheduled care urgently needs whole system and multi-agency working. There was agreement on several points; with determined action needed both with pre-hospital emergency and urgent care, better coordination of general and mental healthcare, and innovation in multi-agency coordination of services, ideally centred around community hubs. The lived and living experience voices were instrumental in highlighting surprise that sharing data between health services was not routine. Time will tell if these consensus points galvanise action to do things differently, and this will be where any real impact lies.

From my perspective, next steps are to publish the consensus findings and findings from the analysis stemming from paper five protocol in peer-reviewed journals, and stemming from that develop and test potential interventions. The consensus statement has provided fertile ground for research activity, in areas historically underfunded and chronically lacking an evidence base. There remains tremendous potential to use routine data to evaluate such interventions, and to assess the unintended consequences of system changes, particularly as more data becomes available to produce a better whole system picture.

Finally, at the time of writing the impact of Covid-19 has brought unforeseen significant impact on worsening mental health, with those at higher risk of adverse outcomes or living with significant inequalities likely to bear the brunt (319). The demand for mental health services before the arrival of Covid-19 was already exceeding available resources (320), and the Covid-19 Mental Health Research Advisory Group for Scotland has predicted an 8% increase in incidence of mental health morbidity. This morbidity has been predicted to manifest as higher levels of distress, thereafter leading to increased numbers with anxiety and depressive disorders, and higher rates of substance misuse, self-harm and suicide (320). With the planned whole population approaches and focussed support for vulnerable groups (320), there has never been more need for rapid access and synthesis of routine data to provide evidence-based effective care and suicide prevention.

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## 10. Appendix

### 10.1 Table 1: Education and training

Education	Dates
University of Stirling. <b>MSc module ‘Advanced Quantitative Analysis’</b> , using Stata. Module code ASRP 026 from MSc Applied Social Research  (SCQF Level 11 credit – pass with merit)	2012

Training / data conferences	Start date	End date
Scottish Centre for Administrative Data Research (SCADR) ‘Safe Researcher’ (SURE) training and assessment (pass).	10/4/2018	10/4/2018
MQ Mental Health Data Science UK expert group; collaboration in mental health research through exploiting ‘big data’ resources.	08/03/2016	09/03/2016
Scottish Health Informatics Programme ‘Information Governance’ training, University of Edinburgh ‘Script CPD’. (4 days). Mandatory training to access data via ‘safe havens’, provided via the Farr Institute.	21/05/2015	26/05/2015
Farr Institute / International population health data linkage Conference 2015, St.Andrews, Scotland (3 days)	26/08/2015	28/08/2015
Introduction to Multiple Imputation using Stata (1 day), delivered via the Applied Quantitative Methods Network, University of Edinburgh.	28/05/2014	28/05/2014
Survival Analysis using SPSS (2 days), delivered via The Farr Institute, University of Glasgow.	25/03/ 2014	26/03/2014
eHealth Scotland: Maximising the Benefits Conference. Edinburgh Scotland.	18/03/2014	18/03/2014
University of Stirling School of Health Sciences PostGraduate Retreat (1.5 days) Pitlochry Scotland.	23/09/2013	24/09/2013
Exploiting existing data for health research, Scottish Health Informatics Programme (SHIP) 4 <sup>th</sup>		

International Conference, (3 days) St.Andrews, Scotland	28/08/2013	30/08/2013
Intermediate and advanced analysis of linked health data research, Scottish Health Informatics Programme (SHIP), delivery by Prof D'Arcy Holman, St.Andrews, Scotland (5 days).	23/08/2013	27/08/2013
Scottish Health Informatics Programme Retreat, Crieff Scotland.	04/07/2013	05/07/2013
Scottish Health Informatics Programme Retreat, Crieff Scotland.	31/05/2012	31/05/2012
ScotStat Data Linkage Conference, Edinburgh Scotland	26/03/2012	26/03/2012
Exploiting existing data for health research, Scottish Health Informatics Programme (SHIP) International Conference, St.Andrews Scotland (3 days)	09/09/2011	11/09/2011
Introductory analysis of linked health data Scottish Health Informatics Programme (SHIP) training course, delivered by Prof D'Arcy Holman, St. Andrews (5 days)	03/09/2011	08/09/2011
Social Stratification International Conference, University of Stirling.	31/08/2011	02/09/2011
Administrative Data Liaison Service /Research Network 'Safe Researcher' certificate, University of Edinburgh, Edinburgh Scotland. Training provided on information governance and statistical disclosure control.	25/05/2011	25/05/2011
MRC Methodology Hubs workshop 'Proportional Odds Modelling', University of Edinburgh, Scotland (2 days)	30/03/2011	31/03/2011
eHealth Masterclass: The coding and structuring of clinical information in electronic health records. Delivered by University of Edinburgh, Edinburgh Scotland	08/03/2011	08/03/2011
Health Informatics and eHealth conference, Holyrood Events, Edinburgh Scotland.	25/02/2011	25/02/2011



**10.2 Table 2: Timeline of papers, additional papers, grants, impact, conference and invited talks**

Item	Type	Details	Dates
1	<b>Paper 5 published</b>	<b>Dougall N</b> , Savinc J, Maxwell M, Karatzias T, O'Connor R, Williams B, Grandison G, John A, Cheyne H, Fyvie C, Bisson J, Hibberd C, Abbott-Smith S, Nolan L. Childhood adversity, mental health and suicide: a protocol for a longitudinal case-control linked data study. <i>International Journal of Population Data Science</i> . <a href="https://ijpds.org/article/view/1338">https://ijpds.org/article/view/1338</a>	2020
2	Talk National Summit	<b>Dougall N</b> , Heyman I, Thomas S, Kerr J. Mental Health and Distress in the Emergency Department. National Summit. In collaboration with The Scottish Government Distress Intervention Group and the Global Law Enforcement & Public Health Association (GLEPHA) Mental Health Special Interest Group Presentation by N.Dougall based on evidence contained in papers 1, 2 and 3; see Chapter Eight.	Oct 2019
3	<b>Paper 4 published</b>	Enang I, Murray J, <b>Dougall N</b> , Wooff A, Heyman I, Aston I. Defining and Assessing Vulnerability within law enforcement and public health organisations: a scoping review. <i>BMC Health &amp; Justice</i> 7, 2(2019). <a href="https://doi.org/10.1186/s40352-019-0083-z">https://doi.org/10.1186/s40352-019-0083-z</a>	2019
4	Talk Paper 4	<b>Dougall, N.</b> , White, C., Murray, J., Enang, I., Wooff, A., Aston, E., & Heyman, I. The Scottish Centre for Law Enforcement and Public Health: how we got here and where we are going. Major session (M1) presentation given by N Dougall and panel at the 5 <sup>th</sup> Global Law Enforcement and Public Conference, Edinburgh 2019. <a href="https://leph2019edinburgh.com/program-monday/">https://leph2019edinburgh.com/program-monday/</a>	Oct 2019
5	Talk Paper 4	Murray, J., Enang, I., <b>Dougall, N.</b> , Wooff, A., Aston, E., & Heyman, I. (2019, January). Defining and Assessing Vulnerability: Perspectives across Law Enforcement and Public Health (LEPH). Conference presentation, 4th PUBSIC (Innovation in Public Services and Public Policy) Conference, Milan.	Jan 2019
6	<b>Paper 3 published</b>	Duncan EAS, Best C, <b>Dougall N</b> , Skar S, Evans J, Corfield A, Goldie I, Maxwell M, Snooks H, Stark C, White C, Wojcik W. Epidemiology of emergency ambulance service calls related to mental health problems and self harm: a national record linkage study. <i>BMC Scandinavian Journal of Trauma, Resuscitation &amp; Emergency Care</i> . 10/03/2019 <a href="https://link.springer.com/article/10.1186/s13049-019-0611-9">https://link.springer.com/article/10.1186/s13049-019-0611-9</a>	2019

7	Additional paper	Kesic D, Thomas S, Bonomo A, Bruno R, Chambers J, Dougall N, et al. Police Management of Mental Health Crises in the Community. Law Enforcement and Mental Health Special Interest Group Guideline. :31. Available from: <a href="https://gleapha.wildapricot.org/resources/Documents/LEMH%20SIG%20Guideline_September%202019.pdf">https://gleapha.wildapricot.org/resources/Documents/LEMH%20SIG%20Guideline_September%202019.pdf</a>	
8	Talk Paper 4	Heyman I, Dougall N, Williams B, Heijmer-Mason O. Working across sectors to develop an evidence-based approach to policing mental health and distress in Scotland. Major session (M14) conference presentation by N Dougall and panel at the 4 <sup>th</sup> Global Law Enforcement and Public Conference, Toronto 2018. <a href="https://leph2018toronto.com/conference-program/#wednesday24oct">https://leph2018toronto.com/conference-program/#wednesday24oct</a>	Oct 2018
9	Grant for Paper 5	<b>Dougall N</b> , Maxwell M, Karatzias T, O'Connor R, Williams B, John A, Cheyne H, Fyvie C, Bisson J, Abbott-Smith S, Nolan L. The role of Childhood Adversities and their subsequent impact on mental ill-health and Suicidal behaviour (CHASE). Chief Scientist Office of the Scottish Government (CSO HIPS/17/48). 01/10/2018 to 27/11/2019. £80,064.	2018-2019
10	Additional paper	Russ T, Woelbert E, Davis K, Hafferty J, Ibrahim Z, Inkster B, John A, Lee W, Maxwell M, McIntosh A, Stewart R, and the MQ Data Science group*. How data science can advance mental health research. Nature Human Behaviour. Dec 2018. <a href="https://doi.org/10.1038/s41562-018-0470-9">https://doi.org/10.1038/s41562-018-0470-9</a>  *MQ Data Science Group: Anderson M, Aylett K, Bourke S, Burhouse A, Callard F, Chapman K, Cowley M, Cusack J, Davis K, Delgadillo J, Dix S, Dobson R, Donohoe G, <b>Nadine Dougall</b> , et al.	2018
11	Talk Paper 3	Dougall N on behalf of Duncan E, Best C, <b>Dougall N</b> , Fitzpatrick D, Maxwell M, Skar S, Corfield A, Evans J, Goldie I, Snooks H, Stark C, White C, Wojcik W. Care pathways related to Scottish Ambulance Service contacts for people with psychiatric or self-harm emergencies. Conference presentation given by N Dougall at the 4 <sup>th</sup> Global Law Enforcement and Public Conference, Toronto 2018.	2018
12	Additional paper	McGrail K, Jones K, Akbari A, Bennett T, Boyd A, Carinci F, Cui X, Denaxas S, <b>Dougall N</b> , Ford D, Ghali W, Kirby R, Kum H-C, Moorin R, Moran R, O'Keefe C, Preen D, Quan H, Sanmartin C, Schull M, Smith M, Williams C, Williamson T, Wyper G & Kotelchuck M. A Position Statement on Population Data Science: The Science of Data about People. Int J Population Data Science (2018) 3:4.	2018

13	Talk Paper 3	Duncan EAS, Best C, <b>Dougall N</b> , Skar S, Evans J, CorfieldA, Goldie I, Maxwell M, Snooks H, Stark C, White C, Wojcik W. Psychiatric Emergencies in prehospital care: an invisible and unmet need. Conference presentation at MQ Data Science Meeting, Manchester. March 2017	2017
14	Talk Paper 3	Duncan EAS, Best C, <b>Dougall N</b> , Skar S, Evans J, CorfieldA, Goldie I, Maxwell M, Snooks H, Stark C, White C, Wojcik W. Investigating the population characteristics, processes and outcomes of pre-hospital psychiatric and self-harm emergencies in Scotland: a national record linkage study. Conference presentation at Paramedics Australasia International Conference (PAIC), Melbourne. November 2017.	2017
15	Talk Paper 3	Duncan E, Best C, <b>Dougall N</b> , Fitzpatrick D, Maxwell M, Skar S, Corfield A, Evans J, Goldie I, Snooks H, Stark C, White C, Wojcik W. Care pathways related to Scottish Ambulance Service contacts for people with psychiatric or self-harm emergencies. Conference presentation at European Emergency Medical Services Congress (EMS2017).	2017
16	Talk Paper 3	Duncan E, Best C, <b>Dougall N</b> , Fitzpatrick D, Maxwell M, Skar S, Corfield A, Evans J, Goldie I, Snooks H, Stark C, White C, Wojcik W. Care pathways related to Scottish Ambulance Service contacts for people with psychiatric or self-harm emergencies. Conference presentation by <b>Dougall N</b> at Farr Institute & European Federation for Medical Informatics joint conference. Manchester, 2017.	2017
17	<b>Paper 2 published</b>	<b>Dougall N</b> , Stark C, Agnew T, Henderson R, Maxwell M, Lambert P. An analysis of suicide trends in Scotland 1950-2014: comparison with England & Wales. BMC Public Health 2017 17:970. <a href="https://bmcpublihealth.biomedcentral.com/articles/10.1186/s12889-017-4956-6">https://bmcpublihealth.biomedcentral.com/articles/10.1186/s12889-017-4956-6</a>	2017
18	Talk (1 <sup>st</sup> prize) Paper 3	Duncan E on behalf of Duncan EAS, Best C, <b>Dougall N</b> , Skar S, Evans J, CorfieldA, Goldie I, Maxwell M, Snooks H, Stark C, White C, Wojcik W. Investigating the population characteristics, processes and outcomes of pre-hospital psychiatric and self-harm emergencies in Scotland: a national record linkage study. Conference presentation (1 <sup>st</sup> prize) at EMS999 Research Forum, Bristol. (Based on Paper 3)	March 2017
19	Evidence submission Paper 1	Submission 56 for: House of Commons. House of Commons Health Committee: Suicide Prevention. Sixth Report of Session 2016-17 (2017). <a href="https://publications.parliament.uk/pa/cm201617/cmselect/cmhealth/1087/108717.htm#_idTextAnchor095">https://publications.parliament.uk/pa/cm201617/cmselect/cmhealth/1087/108717.htm#_idTextAnchor095</a>	2017

20	Additional paper	McIntosh A, Stewart R, John A, Smith D, Davis K, Sudlow C, Corvin A, Nicodemus K, Kingdon D, Hassan L, Hotopf M, Lawrie S, Russ T, Geddes J, Wolpert M, Wölbert E, Porteous D, and the MQ Data Science Group*. Data science for mental health – a UK perspective on a global challenge. <i>Lancet Psychiatry</i> 3(10), 993:8, Oct 1 <sup>st</sup> 2016. *MQ Data Science Group: see Russ et al 2018 above for details <a href="https://doi.org/10.1016/S2215-0366(16)30089-X">https://doi.org/10.1016/S2215-0366(16)30089-X</a>	2016
21	Evidence submission  Paper 1	<b>Dougall N.</b> Invited presentation on research findings (Dougall 2014 BJPpsych) to House of Commons All Party Parliamentary Group, at the event 'Can patient data revolutionise healthcare?', Westminster London, 2016.	2016
22	Evidence submission  Paper 1	Paper 1 Dougall et al included as MQ submission (ref (vii)) of published written evidence in UK Parliament Suicide Prevention 2016-17: <a href="http://data.parliament.uk/WrittenEvidence/CommitteeEvidence.svc/EvidenceDocument/Health/Suicide%20Prevention/written/37639.html">http://data.parliament.uk/WrittenEvidence/CommitteeEvidence.svc/EvidenceDocument/Health/Suicide%20Prevention/written/37639.html</a>	2016
23	Book chapter	Stark C, Riordan V, <b>Dougall N.</b> Rurality and Suicide. Chapter 33 in: Rory O'Connor and Jane Pirkis (editors) <i>The International Handbook of Suicide Prevention</i> , 2 <sup>nd</sup> Edition. Pp 569-593. Hoboken: Wiley, 2016. ISBN 9781118903278.	2016
24	Talk Paper 1	Dougall N. Invited talk on paper 1 (Dougall et al BJPpsych 2014) at The Farr Institute's NHS Benefits Realisation Taskforce and Chief Scientist, Nine BioQuarter Edinburgh, 2016.	2016
25	Grant for PhD paper 3	Duncan E, <b>Dougall N</b> , Fitzpatrick D, Maxwell M, Skar S, Corfield A, Evans J, Goldie I, Snooks H, Stark C, White C, Wojcik W. What happens to patients transferred to Accident and Emergency by the Scottish Ambulance Service due to psychiatric emergencies? A record-linkage study. Chief Scientist Office of the Scottish Government (CSO HICG/1/27); £30,000. 01/09/2015-01/06/2016.	2015-2016
26	<b>Paper 1 published</b>	<b>Dougall N</b> , Lambert P, Maxwell M, Dawson A, Sinnott R, McCafferty S, Morris C, Clark D, Springbett A. Deaths by suicide and their relationship with general and psychiatric hospital discharge: 30-year record linkage study. <i>The British Journal of Psychiatry</i> . 2014; 204(4):267-273. <a href="http://bjp.rcpsych.org/content/204/4/267">http://bjp.rcpsych.org/content/204/4/267</a>	2014
27	Talk Paper 1	<b>Nadine Dougall</b> et al, "Deaths by suicide and their relationship with general and psychiatric hospital discharge: 30 year record linkage study". Oral presentation at the Scottish School of Primary Care Annual Meeting. Based on Paper 1.	April 2014

28	Poster PhD paper 1	<b>Dougall N</b> et al. 'Deaths by suicide and their relationship with general and psychiatric hospital discharge: 30 year record linkage study'. Poster presentation at the SMRHN Annual Scientific Meeting, Edinburgh. (see Chapter 3).	Dec 2013
29	Case study	<b>Dougall N</b> , Lambert P, Maxwell M. Factors predicting which people with psychosocial distress do not seek medical help: analysis of routine data. ESDS online case exemplar of doing more with data, based on additional evidence not included in Paper 1.	Nov 2013
30	Talk Paper 1	<b>Dougall N</b> , Lambert P, Maxwell M et al. 'Deaths by suicide following discharge from Scottish hospitals.' Conference presentation given by <b>N Dougall</b> at the RCN International Nursing Research Conference, Belfast. Based on Paper 1.	March 2013
31	Editorial	Cameron Stark and <b>Nadine Dougall</b> . "Effect of attitudes to euthanasia on vets' suicide risk", Veterinary Record 2012;171:172-173.	2012
32	Talk	<b>Dougall N</b> , Lambert P, Maxwell M. Exploring the potential for linking shared variables between the BHPS and Scottish Health Survey in an analysis of psychosocial distress and GP consultation behaviour. Applied Quantitative Methods Network (AQMEN) Stirling Local Research Events. Seminar presentation.	May 2012
33	Talk Paper 1	<b>Nadine J Dougall</b> , Paul Lambert, Margaret Maxwell, Alison Dawson, Carole Morris, David Clarke & Anthea Springbett. Hospital utilisation prior to suicide: 30 year data linkage study. Conference presentation, MRC Population Health Methods and Challenges Conference, Birmingham. Based on paper 1.	April 2012
34	Position statement	<b>Dougall N</b> , Dawson A, Maxwell M et al. 'Position piece - ethical issues of e-research from a health perspective'. Digital Social Research project webpages. Published online at <a href="http://eresearch-ethics.org/position/ethical-issues-of-e-research-from-a-health-perspective/">http://eresearch-ethics.org/position/ethical-issues-of-e-research-from-a-health-perspective/</a> (link broken; project archived). Invited position piece related to paper 1.	Nov 2011
35	Talk Paper 1	<b>Dougall N</b> , Lambert P, Maxwell M & Dawson A. Modelling health and social risk factors for suicide in Scotland: a 30 year record linkage study. Conference presentation at Scottish Health Informatics Programme International Conference 2011, St.Andrews.	Sept 2011

36	Talk Paper 1	<p><b>Dougall N</b>, Lambert P &amp; Maxwell M. e-Health data linkage in Scotland and the Scottish Health Survey – An exploratory analysis. Health Survey User Meeting 2011, London. Published online 2011 at <a href="http://www.ccsr.ac.uk/esds/events/2011-07-05/">http://www.ccsr.ac.uk/esds/events/2011-07-05/</a> (link broken; information archived). Conference presentation; slides available from <a href="https://slideplayer.com/slide/786508/">https://slideplayer.com/slide/786508/</a></p>	July 2011
37	Talk Paper 1	<p><b>Dougall N</b>, Lambert P &amp; Maxwell M. Modelling health and social risk factors for suicide in Scotland: a 30 year record linkage study. Applied Quantitative Methods Network (AQMEN) Stirling Local Research Events. Invited seminar.</p>	2011

## 10.3 Summary data tables for Paper 2

### 10.3.1 Summary data tables – men

Male suicides and undetermined deaths incidence data - Scotland 1950-2004												
<i>Age group</i>	<i>1950-54</i>	<i>1955-59</i>	<i>1960-64</i>	<i>1965-69</i>	<i>1970-74</i>	<i>1975-79</i>	<i>1980-84</i>	<i>1985-89</i>	<i>1990-94</i>	<i>1995-99</i>	<i>2000-04</i>	<i>All years</i>
15-19	11	18	29	52	66	86	115	147	141	147	154	966
20-24	31	49	54	81	142	183	201	290	338	318	307	1994
25-29	35	79	76	75	130	163	211	246	432	439	320	2206
30-34	38	80	92	88	124	175	213	257	314	411	377	2169
35-39	57	83	133	109	154	167	197	243	268	354	452	2217
40-44	91	107	114	149	147	183	226	258	316	300	349	2240
45-49	101	170	145	147	200	202	219	212	284	276	274	2230
50-54	134	163	150	152	136	191	210	224	189	227	237	2013
55-59	101	180	165	144	179	170	221	192	175	186	195	1908
60-64	98	115	158	190	175	160	168	166	135	113	149	1627
65-69	87	103	84	122	132	112	126	138	124	148	111	1287
70-74	68	71	61	65	101	89	123	79	93	105	84	939
75-79	51	66	42	43	62	69	62	98	58	89	63	703
80+	22	30	30	36	36	37	52	49	66	74	70	502
All ages	925	1314	1333	1453	1784	1987	2344	2599	2933	3187	3142	23001

### 10.3.2 Summary data tables – women

Female suicides and undetermined deaths incidence data - Scotland 1950-2004												
<i>Age group</i>	<i>1950-54</i>	<i>1955-59</i>	<i>1960-64</i>	<i>1965-69</i>	<i>1970-74</i>	<i>1975-79</i>	<i>1980-84</i>	<i>1985-89</i>	<i>1990-94</i>	<i>1995-99</i>	<i>2000-04</i>	<i>All years</i>
15-19	8	13	12	27	26	49	25	35	30	51	65	341
20-24	16	21	30	40	38	81	45	60	68	72	70	541
25-29	22	25	44	46	59	79	68	85	127	100	66	721
30-34	28	35	47	54	70	92	83	77	101	117	111	815
35-39	38	63	69	81	86	103	94	90	73	109	130	936
40-44	42	90	80	91	109	137	101	80	101	92	128	1051
45-49	47	81	98	111	140	179	125	83	89	115	113	1181
50-54	65	112	98	112	150	164	130	88	76	86	110	1191
55-59	54	106	98	121	162	153	153	104	67	66	66	1150
60-64	57	96	81	131	150	142	119	116	71	58	60	1081
65-69	43	58	80	74	123	123	100	95	64	72	58	890
70-74	38	52	53	52	69	105	88	63	60	48	40	668
75-79	19	22	23	42	54	48	58	62	47	43	33	451
80+	5	8	11	32	39	22	52	61	57	54	44	385
All ages	482	782	824	1014	1275	1477	1241	1099	1031	1083	1094	11402



### 10.3.3 Summary data tables – all

All suicides and undetermined deaths incidence data - Scotland 1950-2004

Age group	1950-54	1955-59	1960-64	1965-69	1970-74	1975-79	1980-84	1985-89	1990-94	1995-99	2000-04	All years
15-19	19	31	41	79	92	135	140	182	171	198	219	1307
20-24	47	70	84	121	180	264	246	350	406	390	377	2535
25-29	57	104	120	121	189	242	279	331	559	539	386	2927
30-34	66	115	139	142	194	267	296	334	415	528	488	2984
35-39	95	146	202	190	240	270	291	333	341	463	582	3153
40-44	133	197	194	240	256	320	327	338	417	392	477	3291
45-49	148	251	243	258	340	381	344	295	373	391	387	3411
50-54	199	275	248	264	286	355	340	312	265	313	347	3204
55-59	155	286	263	265	341	323	374	296	242	252	261	3058
60-64	155	211	239	321	325	302	287	282	206	171	209	2708
65-69	130	161	164	196	255	235	226	233	188	220	169	2177
70-74	106	123	114	117	170	194	211	142	153	153	124	1607
75-79	70	88	65	85	116	117	120	160	105	132	96	1154
80+	27	38	41	68	75	59	104	110	123	128	114	887
All ages	1407	2096	2157	2467	3059	3464	3585	3698	3964	4270	4236	34403

### 10.3.4 Age-period-cohort tabulated data for men

Male SMR rates (per 100,000 population) for suicide and undetermined deaths in Scotland: 1950 to 2004

Age (years)	1950-54	1955-59	1960-64	1965-69	1970-74	1975-79	1980-84	1985-89	1990-94	1995-99	2000-04
15-19	1.3	2.1	2.9	5.2	6.5	7.7	9.9	14.3	17.1	18.5	18.8
20-24	3.6	6.3	6.6	9.2	15.0	18.9	18.7	26.4	34.0	39.1	38.4
25-29	3.8	9.2	9.5	9.7	15.4	17.8	23.1	24.5	42.4	47.5	42.8
30-34	4.3	9.1	11.4	11.5	16.7	21.0	24.0	29.3	32.6	41.7	42.5
35-39	6.8	9.9	16.0	14.1	21.0	22.7	24.1	28.1	31.1	37.3	46.7
40-44	10.1	13.2	14.2	18.7	19.6	25.3	31.2	32.2	37.0	34.9	37.2
45-49	11.9	19.7	18.7	19.1	26.0	27.6	31.0	30.0	36.0	32.5	32.2
50-54	18.2	20.2	18.4	20.7	18.6	25.8	29.8	32.8	27.4	29.2	28.3
55-59	17.2	26.6	22.2	19.2	26.3	24.9	31.9	28.9	26.7	27.9	25.8
60-64	19.8	22.3	26.7	29.0	26.2	26.2	27.3	26.3	21.9	18.4	23.6
65-69	21.1	25.3	19.9	25.3	24.3	20.0	24.4	26.2	22.5	27.2	19.9

### 10.3.5 Age-period-cohort tabulated data for women

Female death rates (per 100,000 population) for suicide in Scotland: 1950 to 2004

Age (years)	1950-54	1955-59	1960-64	1965-69	1970-74	1975-79	1980-84	1985-89	1990-94	1995-99	2000-04
15-19	0.9	1.4	1.2	2.8	2.6	4.5	2.2	3.5	3.7	6.6	8.2
20-24	1.7	2.4	3.5	4.5	4.1	8.6	4.3	5.6	6.9	8.8	8.8
25-29	2.3	2.8	5.3	5.8	7.0	8.7	7.5	8.6	12.3	10.5	8.5
30-34	3.0	3.9	5.6	6.9	9.2	11.0	9.4	8.8	10.2	11.3	11.7
35-39	4.2	7.0	8.0	10.0	11.3	13.6	11.5	10.4	8.3	11.0	12.5
40-44	4.4	10.2	9.2	10.9	13.8	18.2	13.5	9.9	11.7	10.4	12.9
45-49	5.2	8.8	11.5	13.3	17.2	23.1	16.8	11.3	11.1	13.3	12.8
50-54	7.7	12.8	11.1	13.7	18.5	20.7	17.2	12.1	10.5	10.8	12.9
55-59	7.3	13.3	11.7	14.3	20.7	19.7	20.1	14.2	9.4	9.3	8.4
60-64	8.9	13.9	10.9	16.7	18.8	19.3	16.2	16.0	10.1	8.5	8.7
65-69	7.8	10.1	13.0	11.1	17.3	17.0	14.9	14.2	9.6	11.0	9.0

Footnote: Death period 1950-54 corresponds to birth cohort of 1931-1939 for age 15-19 year olds