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Exploring the potential of online self-reported and routinely collected
electronic healthcare record data in self-harm research

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PREFACE

This thesis represents a series of connected projects exploring the use of various data sources for self-harm research. The overarching purpose of this thesis is to further self-harm research methodology through the exploration of novel approaches and use of data. This thesis is structured into four components: a systematic review of the literature providing an evidence base for the project; the development and piloting of an online platform for self-harm research (the SHARE UK platform); a national survey (The Big Data and Mental Health Research Survey) exploring participant views on the use of their data for self-harm research, encompassing data collected online and routinely collected healthcare data and, an electronic health record study of young people who self-harm utilising routinely collected healthcare data. This series of projects demonstrates the utility of both information gathered online and that collected via routinely collected healthcare data and, explores participants views and issues around the use of these sources of data. This series of projects has been used to inform further development of the SHARE UK platform which is being expanded to capitalise on the potential advantages of this format and to address the limitations identified. It is intended that research utilising various data sources can be brought together. For example routinely collected data can be used to further explore and quantify ideas and experiences collected via the SHARE UK platform, or conversely, the SHARE UK platform is a potential avenue to explore the human experiences behind results found with routinely collected healthcare data. It is intended that consent can be collected from participants to link data from the SHARE UK platform with electronic healthcare data at participant level and issues around this are explored. Such a paradigm has the potential to inform a shift in the way in which self-harm research is conducted optimising the opportunities offered by various sources of data.

ABSTRACT

Background

Self-harm is a major public health concern and is a leading cause of death from injury. Reaching participants for self-harm research raises a number of challenges, however an opportunity exists in the use of both the internet for data collection and in the use of routinely collected healthcare data.

Aims and objectives

The aim of this project was to explore the potential of both online and routinely collected healthcare data for self-harm research and the way in which these data sources can be brought together.

Methods

This thesis represents a series of projects exploring the use of various data sources for self-harm research. The first was the development and piloting of an online platform (SHARE UK) for self-harm research. This website incorporated multiple functions: hosting questionnaires; sign-up for a research register; sign-up for linkage with routinely collected data and uploads to a media databank. Next a national survey was conducted to explore young people's perspectives on the use of both online and healthcare data for self-harm research. Lastly a population level electronic health record cohort study analysing trends over time and contacts across healthcare services was conducted.

Results

Participants engaged well with research online: 498 participants signed up to the SHARE UK platform; of whom 85% signed up for the research register. Sixty-two participants uploaded 95 items to the media databank. Alternative formats are discussed. Only 15% of participants consented for linkage with healthcare data. A total of 2,733 young people aged 10-24 who self-harm completed the national survey. Results demonstrated that the necessity for participants to give their address for linkage poses a significant barrier. Opinions around the use of Big Data, encompassing social media, marketing and health data are explored.

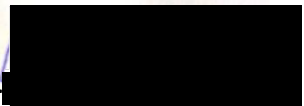
A total of 937,697 individuals aged 10-24 provided 5,269,794 person years of data from 01.01.2003 to 20.09.2015 to the electronic health record cohort study. Self-harm incidence was highest in primary care. Males preferentially present to emergency departments. Male are less likely than females to be admitted following attendance. This difference persists in the youngest age groups and for self-poisoning. Analysis supports the importance of non-specialist services.

Conclusions

This thesis has explored both online and routinely collected healthcare data and their utility for self-harm research, exploring participant views and issues via a national survey. An online platform for self-harm research was successfully piloted and issues identified. This series of projects explores possibilities for future self-harm research. The use of multiple data sources allows research to represent both those in the community and those presenting to healthcare settings, lowering many of the barriers to participating in self-harm research. The future utility of the SHARE UK platform through its collaboration with the Adolescent Mental Health Data Platform (ADP) is discussed. Results of this series of projects will be used to inform the development of this platform with lessons learnt from the pilot addressed and findings from both the national survey and the electronic health record cohort study informing and shaping future research.

DECLARATIONS AND STATEMENTS

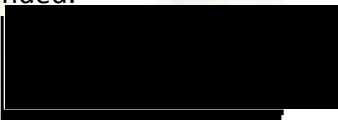
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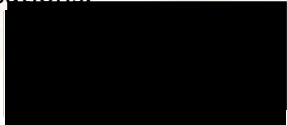
This thesis is the result of my own investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote(s).

Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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DEFINITIONS OR ABBREVIATIONS

ADP Adolescent Mental Health Data Platform

ALSPAC Avon Longitudinal Study of Parents and Children

APMS Adult Psychiatric Morbidity Survey

BIS Beck Impulsiveness Scale

CASE Child and Adolescent Self-harm in Europe Study

CASP Critical Appraisal Skills Programme

CHERRIES Checklist for Reporting Results of Internet E-Surveys

CI Confidence Interval

CIUS Compulsive Internet Use Scale

CSS Cascading Style Sheet

DOB Date of Birth

EDDS Emergency Department Dataset

ESS Experience of Shame Scale

FAQ Frequently Asked Questions

GDPR General Data Protection Regulation

GP General Practitioner

GPD General Practice Database

HES Hospital Episode Statistics

HTML Hypertext Markup Language

ICD-10 International Classification of Diseases 10th Edition

IGRP Information Governance Review Panel

IMD Index of Multiple Deprivation

IRR Incident Rate Ratio

LSOA Lower Super Output Area

MCQ Multiple Choice Question

MESH Medical Subject Headings

MD Median

MS Multiple Sclerosis

NICE National Institute of Clinical Excellence

NHS National Health Service

NWIS NHW Wales Informatics Service

ONS Office of National Statistics

OPD Outpatient Database

PEDW Patient Episode Database for Wales

PHP Personal Homepage Tools

PPI Patient and Population Involvement

PRISMA Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PSS-Fa Perceived Social Support Family Scale

PSS-Fr perceived Social Support Friends Scale

PTSD Post-Traumatic Stress Disorder

PYAR Person Years at Risk

RPI Resistance to Peer Influence Scale

SAIL Secure Anonymized Information Data Linkage

Self-Harm. For the purpose of this thesis self-harm is defined as deliberate self-injury or poisoning regardless of suicidal intent. We have chosen to employ this definition in preference to the dichotomous separation of non-suicidal self-injury and attempted suicide as is popular in the USA. Suicidal intent is a dimensional phenomenon, the presence of which is not always possible to infer. In addition the national clinical guidelines in the UK focus on self-harm (NICE, 2012)

SD Standard Deviation

SHARE UK Self-Harm Research UK

SHI Self-harm Inventory

SQL Structured Query Language

UK United Kingdom

WDS Welsh Demographic Service

WIMD Welsh Index of Multiple Deprivation

WHO World Health Organization

1 INTRODUCTION

1.1 RESEARCH IN CONTEXT

Self-harm is a growing public health concern across the world and is the focus of much social policy and practice. Self-harm refers to any intentional act of self-injury or poisoning independent of motivation or suicidal intent (NICE, 2012). This definition is necessarily general as the motivation or degree of suicidal intent is difficult to assess and may vary between individuals and over time. Self-harm is not rare. Research has found that almost one in five fourteen year old girls and one in seven fourteen year old boys report self-harm in the previous year (The Childrens Society, 2018). A history of self-harm is one of the strongest risk factors of future suicide (Hawton & Van Heeringen, 2000; Sakinofsky, 2008). In addition young people aged 10-19 with a history of self-harm are almost ten times more likely to die of unnatural causes and seventeen times more likely to take their own lives than young people with no history of self-harm (Morgan et al., 2017). Unnatural causes of death include self-harm, accidents, and assaults. With appropriate intervention the incidence of such deaths could be lowered. Providing support for individuals who self-harm has the potential to save lives.

Much self-harm research takes place in healthcare settings however, a large amount of self-harm goes undetected by health services. Community data suggest that rates of self-harm in adolescents are around eight to 16 times that suggested by hospital studies (Hawton, Rodham, Evans, & Harriss, 2009; McMahon et al., 2015). Self-harm is not just hidden from health services but for many is hidden from family and friends as well. Data from the Child and Adolescent Self-harm in Europe (CASE) study found that nearly half of individuals who self-harm not only did not receive any medical care, they had also not received help from family and friends (Ystgaard et al., 2009). This means nearly half of individuals are not accessing the support they may need and are likely not having the opportunity to take part in research. Suicide risk may be elevated in those unknown to clinical services (Hawton, Houston, & Shepperd, 1999a). Research to identify the type of support needed is vital if suicide prevention strategies are to be effective for this population.

Research is increasingly focusing on internet use in relation to self-harm and has identified both positive and negative aspects. The role of community online can be positive for some people with communities forming in a way often not possible in everyday life allowing individuals to talk openly about their experiences. The global nature of these communities mean that individuals are able to provide and receive crisis support around the clock (Daine et al., 2013).

However, while the role of community can be beneficial evidence has been found for the normalisation of self-harm and sharing of potentially harmful information. Other potential risks of the internet in relation to self-harm include pro-suicide sites, sharing of graphic self-harm images which can have a triggering or detrimental impact, and online bullying (Daine et al., 2013). Understanding more about the role of the internet in the lives of people who self-harm has important implications for policy makers and clinicians.

Research registers of individuals who have consented to be contacted for future research studies have been used in a variety of settings. The utility of research registers have been previously demonstrated at population level (Leach et al., 2016). They have also proved effective at targeting specific populations such as those diagnosed with Ankylosing Spondylitis (Atkinson et al., 2010) and Multiple Sclerosis (Ford et al., 2012). This allows researchers to contact specific groups of potential participants who have expressed an interest in taking part in research previously. These have been shown to increase feelings of patient autonomy (Papoulias, Robotham, Drake, Rose, & Wykes, 2014) and proved successful in boosting recruitment including for studies related to serious mental illness (Robotham et al., 2016). As described previously much self-harm research is done in healthcare settings. The creation of a research register for individuals who self-harm that allows people to sign up online has the potential to lower many of the barriers to taking part in research.

Routinely collected healthcare data represents a valuable resource for self-harm research and has been utilised to examine trends in healthcare contacts overtime, management and mortality patterns in individuals who self-harm (Carr et al., 2016a; Morgan et al., 2017). Previously research has not linked primary care, emergency department, hospital admissions and outpatients data at patient level in relation to self-harm. Doing so would create a comprehensive picture of healthcare utilisation for self-harm on which to base future policy and practice. Several previous studies have successfully linked survey data with routinely collected healthcare data (e.g. Borschmann et al., 2017b). We will explore the possibility of this here. We will also explore issues around consenting individuals who self-harm for linkage of survey data with routinely collected healthcare data including concerns about how data is looked after, utilised and secured.

1.2 OVERVIEW OF THESIS

Problem statement

As outlined above, a large proportion of individuals who self-harm is not represented by current research. Furthermore suicide risk is likely to be elevated in those who are unknown to clinical services (Hawton et al., 1999a) meaning that those individuals not represented by this body of research may be at greater risk. In addition research examining digital media is often rapidly outdated and interactions between digital media and other risk factors remain unclear (Daine et al., 2013). A novel research design that can: bring together data from individuals recruited from sources other than emergency departments; collect data from participants who may not be recruited via traditional methods; utilise routinely collected data from a range of healthcare settings and, gather up to date information regarding internet use, has the potential to generate an unparalleled richness of data on which to base future service provision.

Research Questions

- Is it possible to recruit and maintain a cohort of individuals who self-harm and gather meaningful data using an exclusively online format?
- Can a research register of individuals who self-harm be successfully set up online and could this be used for recruitment to research?
- What are the potential issues around utilising Big Data for research encompassing health, social care and social media data?
- What are the trends over time and patterns of service presentation across healthcare settings in children and young people and, how do presentations vary by age, sex and healthcare setting?

Aims and Objectives

Aims

To bring together data from three complementary data sources: an online platform, a national survey and an e-cohort study utilising routinely collected healthcare data. This will allow multiple settings to be brought together incorporating data from individuals taking part in the online research platform, the general population and those in contact with healthcare services for self-harm (based on routinely collected healthcare data). These complimentary sources of data will

be explored to gain a better understanding of the needs of individuals who self-harm to inform policy and practice.

Objectives

To inform the development of an online platform and better understand the issues around self-harm and internet use in young people through a systematic review the literature.

To build an online platform for self-harm research and explore the utility of this for: questionnaire delivery; a platform for users to contribute sources of information they use from the media; consenting individuals for contact for future research creating a self-harm research register and, consenting individuals for linkage with routinely collected data.

To use the research register to recruit individuals to take part in a national survey. This survey will aim to further explore issues around Big Data and self-harm research. This will be informed both by the previous systematic review of the literature as it relates to data collected online and will explore issues around linkage with healthcare data evident based on data collected via the online platform.

To utilise routinely collected data in the SAIL databank for the study of children and young people who self-ham. Patterns of health service utilisation across primary care, emergency departments, hospital admissions and outpatient settings will be examined alongside all-cause mortality.

1.3 CONTRIBUTION OF THESIS

This thesis will bring together multiple sources of data: data collected via a new online platform for self-harm research including questionnaire data and uploads to a media databank of internet resources; participant views on self-harm and mental health research and the use of their data for research collected via a national survey; routinely collected healthcare data held in the SAIL databank. The feasibility of the creation of a register of potential participants for future research will be examined. The creation of an online research platform for individuals who self-harm has the potential to reach a large number of participants, including those who do not seek help from healthcare services. This provides an opportunity to gain new information about the lives of those who self-harm from their own perspective, while allowing individuals to remain anonymous. In addition, participants have the option to consent to be contacted by the research

team for future projects. This essentially creates a register of individuals who are contactable as potential participants for any future research.

The platform will function in part as a questionnaire delivery platform and will host standardised questionnaires (seven at this pilot stage). Questionnaires will measure internet use, self-harm, parent and peer support and influence, impulsivity and experience of shame. Participants will also be asked questions at registration regarding internet use, their history of self-harm and contacts with both health and social care services. The potential for the use of this platform in identification of vulnerable groups, such as those in contact with social care services will be examined. Identification of these groups will provide valuable information on potential avenues of intervention beyond the health service, for example through schools or social care.

In addition to utilising the platform for questionnaire delivery, facilities were incorporated for individuals to upload sources of online media information, advice and influence to a separate databank for use by the research team. Any kind of online source was eligible for upload including online news, websites, forums and social media. This media databank was not made visible to users of the platform as the quality of such sources was predicted to be highly variable. This methodology has the potential for the study of the influence of media exposure at an individual level in a way not possible in previous research. The development of a databank of media sources compiled and maintained by individuals who self-harm could have an advantage over purpose-built collections for research that can be rapidly outdated. This is designed to be a proof of concept to demonstrate whether such databanks maintained by participants can generate sufficient data to be used in future research.

Individuals who contribute data via this platform were given the option of consenting to their data being linked with routinely collected data such as healthcare data available in the Secure Anonymized Information Linkage (SAIL) databank at Swansea University. The SAIL databank brings together a wide range of anonymized routinely collected person-based data in Wales including primary care, hospital admissions, emergency department attendances, deprivation and office of national statistics (ONS) birth and mortality data. Through novel anonymization, encryption and linkage processes it is possible to manage and link datasets securely, making SAIL a secure way to access individuals linked data whilst maintaining anonymity (Ford et al., 2009; Lyons et al., 2009). Linking questionnaire data with routinely collected data addresses many limitations of previous research to be addressed, allowing self-reports to be validated against routine data, incorporating the role of primary care and including those who do not seek help. The potential for an online platform to be used for consent will be examined. Any issues with

such a format such as participant's opinions on the use of their data will be explored via a national survey.

A population-based e-cohort study utilising the SAIL databank will be conducted incorporating a population of young people aged 10-24 with a record of self-harm. Utilising such data to examine presentation across services can inform policy and practice identifying opportunities for intervention. The aim of this part of the project was to examine incidence over time of self-harm in a whole population of young people across primary care, emergency department attendances, and hospital outpatients and admissions, and to explore if individuals preferentially present across different settings.

1.4. CHAPTER SUMMARY

Self-harm is a growing public health issue. Current research is largely based on populations presenting to emergency departments leaving a large number of vulnerable individuals unrepresented by current research. The role of the media in self-harm and suicide has long been a topic of debate and research. The nature of the online world has led to a substantial research interest into the nature and influence of internet use in those who self-harm. The creation of an online platform for self-harm research allows individuals to contribute data for research independent of presentation to health services. The bringing together of data collected via the online platform, both in the form of questionnaires and data collected via the media databank, data collected via a national survey and, routinely collected healthcare data has the potential to provide a well-rounded picture of self-harm incorporating both largescale healthcare data and the perspectives of individuals. This has implications for the format of future research and potentially for policy and practice in providing support for people who self-harm.

2 BACKGROUND

As outlined in the previous chapter this thesis will bring together multiple sources of data: data collected via a new online platform consisting of both questionnaire data and uploads to a media databank; participant involvement via a national survey and routinely collected healthcare data from the SAIL databank. In addition, a self-harm research register will be created. In this chapter, the background to the various elements of this study will be explored.

2.1 SELF-HARM AS A PUBLIC HEALTH CONCERN

Self-harm is a growing public health concern across the world and is the focus of much social policy and practice. The global burden of disease study found that self-harm is the leading cause of death from injury and is a main contributor to disability adjusted life years (Haagsma et al., 2016). The UK has one of the highest rates of self-harm in Europe (Madge et al., 2008; Schmidtke et al., 1996). Risk of repetition is extremely high. Up to 40% of individuals will go on to repeat (Zahl & Hawton, 2004) and around 20% of individuals who attend hospital with self-harm will re-present to the same hospital within a year (Bergen, Hawton, Waters, Cooper, & Kapur, 2010). Subsequent risk of suicide is 0.5-2% after 12 months and 15% after 10 or more years (D. Owens, Wood, Greenwood, Hughs, & Dennis, 2005; Suominen et al., 2004).

Data from the Adult Psychiatric Morbidity Survey (APMS) found that one in five young women aged 16-24 reported self-harm. This study also found an increase of self-reported lifetime self-harm with low rates of resultant service contact (McManus et al., 2019). Results of the millennium cohort study showed that 22% of 14-year old girls and 9% of boys the same age reported self-harm in the previous year with a higher risk for children from lower income households (The Childrens Society, 2018). Self-harm was highest in children who were attracted to the same gender or both genders with almost half (46%) reporting self-harm (The Childrens Society, 2018). Individuals who present to hospital with self-harm are not only at increased risk of suicide but are also at an increased risk of both natural and unnatural causes of death including accidents and fatal alcohol and drug poisoning with suicides found to be 17 times more likely and accidental poisoning 15 times more frequent (Hawton, Harriss, & Zahl, 2006). These findings have been echoed with children and young people. Young people aged 10-19 with a history of self-harm are around nine times more likely to die unnaturally with more than 17 times the risk of suicide (HR 17.5; 95% CI 7.6-40.5) and more than 30 times the risk of fatal alcohol or drug poisoning (HR 34.3; 95% CI 10.2 to 115.7) (Morgan et al., 2017). Such deaths are

largely preventable and providing appropriate support for people who self-harm has the potential to save lives.

While suicide is a leading cause of death among young people in the UK (Office of National Statistics, 2017) suicide is a rare outcome in this age group and has been referred to as the tip of the 'iceberg' of suicidal behaviour (McMahon et al., 2014). At the tip of this iceberg is the highly visible event of suicide, beneath this are the rates of hospital treated self-harm and hidden below the surface is the self-harm that does not come to the attention of health services. Combining data from Central Statistics Office, the Irish National Registry of Deliberate Self-harm and school based surveys in Ireland, it has been estimated that annual incidence of self-harm in the community is more than 16 times that of hospital treated self-harm (McMahon et al., 2015). For every boy who died by suicide 16 presented to hospital with self-harm and 146 reported self-harm in the community. For every girl who died by suicide 162 presented to hospital with self-harm and 3,296 reported self-harm in the community (McMahon et al., 2015). Similar results have been found with adolescents in England, with particularly high numbers of adolescent females reporting self-harm in the community (Geulayov et al., 2018).

The overall cost of general hospital management of self-harm has been estimated at £162 million per year in England (Tsiachristas et al., 2017) underscoring the need for effective methods of preventing self-harm and reducing repetition. A study examining the long-term costs of self-harm across health and social services found that inpatient psychiatric care accounted for only 66% of the total cost with social services making up 13% of associated costs. Individuals who had five or more episodes of self-harm showed the greatest resource usage particularly for inpatient care and psychotropic medication (Sinclair, Gray, Rivero-Arias, Saunders, & Hawton, 2011). The economic impact of self-harm goes beyond health and social services. Results of the Avon Longitudinal Study of Parents and Children (ALSPAC study) have found poorer education and employment outcomes in early adulthood for those with a history of self-harm (Mars et al., 2014). Adverse outcomes potentially continue beyond adolescence and into adulthood. An Australian study found that individuals who self-harmed during adolescence were at higher risk of a range of adverse outcomes at age 35 including mental health problems, drug dependence, unemployment and financial hardship with the presence of adolescent mental health diagnoses attenuating this relationship (Borschmann et al., 2017a). Appropriate support for individuals who self-harm including support related to family issues, education and employment could go on to have implications, not just for the wellbeing of the individual, but for the economic costs associated with hospital treatment, social care, employment and housing difficulties.

2.2 POPULATIONS HIDDEN FROM CURRENT RESEARCH

Much self-harm research is conducted in healthcare settings. Though there are some limitations to this. A large amount of self-harm goes undetected by health services. High-school survey data from seven countries in the CASE study has found that only 12% of most recently reported self-harm episodes led to hospital presentation, with a significantly higher percentage of males than females attending hospital (Madge et al., 2008). The 'iceberg' model of self-harm described previously illustrates the small proportion of self-harm that comes to the attention of services, particularly in adolescents (Geulayov et al., 2018; McMahon et al., 2015). Furthermore, suicide risk is likely to be elevated in those who are unknown to clinical services (Hawton et al., 1999a). In addition to the small proportion of self-harm that results in attendance to hospital, individuals who do attend hospital are potentially vulnerable or unwilling to take part in research. This is may be further compounded by negative experiences reported by young people attending emergency departments with self-harm and reported feelings of shame for having to attend. As a result such individuals may be reluctant to take part in research and response rates as low as 6% have been reported (Hunter, Chantler, Kapur, & Cooper, 2013).

Self-harm is not just hidden from health services but for many is hidden from family and friends as well. Further data from the CASE study found that among those who engaged in self-harm nearly 20% received support from health services and a third had not been in contact with health care services but received help from their social network. However nearly half of individuals had not received help from anyone at all (Ystgaard et al., 2009). A smaller proportion of boys than girls received help from their social network and a larger proportion of boys than girls did not receive any help at all (Ystgaard et al., 2009). This is supported by a systematic review of help-seeking following self-harm in adolescents finding that between one third to half of young people do not seek help following self-harm. Of those who do seek help, friends and family were the primary sources of support (Rowe et al., 2014). Potential barriers to help-seeking include fear of stigmatization, being seen as 'attention seeking' and lack of knowledge about where to go for help. Research relating to facilitators for help-seeking was more sparse however such facilitators may include assurances of confidentiality, having a trustworthy person to talk to and the option of speaking to someone of a similar background and age (Rowe et al., 2014). A survey of young people found that adolescents considered family, friends and schools as the main sources of support in preventing suicidal behaviour with lesser importance put on external agencies (Fortune, Sinclair, & Hawton, 2008). Research utilising online self-harm discussion

forums suggests that many individuals treat their own self-harm injuries wherever possible. Emergency department attendance is often regarded as a last resort, with several reports of reluctance to seek medical help for serious injuries including broken bones. Others reported repeated infections from not seeking treatment for self-harm related wounds (C. Owens, Hansford, Sharkey, & Ford, 2016).

While research is largely focused on populations who present to healthcare settings, many factors associated with self-harm mean that individuals at risk might already be known to other services such as social care. This includes mental health issues, alcohol and substance misuse, social, economic and cultural issues (Colman, Newman, Schopflocher, Bland, & Dyck, 2004; Houston, Haw, Townsend, & Hawton, 2003). Research suggests that 25% of adolescents presenting to emergency departments with self-harm have current or previous contact with social care (Nadkarni, Parkin, Dogra, Stretch, & Evans, 2000). Furthermore, 9% of these individuals were under a care order reflecting a tendency for these children to come from a background of social problems. Interviews with young carers found that over a third reported previous self-harm and a similar proportion reported thoughts of suicide (Cree, 2003). Such risk factors mean that many individuals may be known to health or social services, even if their self-harm behaviour has gone undetected. Involvement of these services represents another avenue for detection of self-harm and a potential source of support for individuals. Identification of vulnerable groups could form the basis of future interventions to increase help-seeking behaviour and detection of self-harm in such populations. It is important that barriers to both seeking help and taking part in research are lowered in order to give everyone a voice. By learning more about people who self-harm, including those who do not present to services, it will be possible to inform policy, practice and support. Additional support provided at community level may decrease the likelihood of an individual reaching crisis point. This will have positive impacts both for the health service and for the individual potentially preventing any negative long-term outcomes. The wide-reaching implications of self-harm mean that interventions must go beyond that available in hospital and may include support with family, relationships, employment and education.

2.3 SELF-HARM THE MEDIA

Social contagion of self-harm and suicide via the media has been well documented. Media influence is thought to contribute to up to 5% of suicides in adolescents (Hawton & James, 2005). For example print media has been suggested as a contributing factor in point suicide clusters

(e.g. John et al., 2016a). Furthermore when analysing the content of two peaks of newspaper reporting around a suicide cluster, the peak with higher levels of sensationalist reporting including a high proportion of articles with details of methods and collections of photographs, was found to be associated with additional suicide deaths. In contrast the second peak in reporting with less sensational content was not associated with any additional deaths (Marchant et al., 2020a). It was highlighted that while the media may have played a role in the contagion of suicidal behaviour during this cluster, this must be considered alongside other social factors and modes of transmission such as word of mouth, as well as the role of digital media. The role of online media is gaining increasing research and public attention. There have been several high profile cases of cyber-bullying and suicide over the past decade (e.g. Todd, 2012) and reports of suicide clusters facilitated by social media (Robertson, Skegg, Poore, Williams, & Taylor, 2012). There is ample evidence demonstrating that the media can influence both the rate of suicides and the method chosen (Pirkis & Blood, 2001; Pirkis & Nordentoft, 2011; Stack, 2005). For example presentations to emergency departments for a paracetamol overdose was found to double in viewers of a television show following its fictional portrayal (Hawton et al., 1999b). Similarly, deliberate self-poisoning using antifreeze increased significantly following media coverage of an independent report into antifreeze poisoning. This method of self-harm was found to increase significantly again several years later following the portrayal of self-poisoning by antifreeze on a television show (Veysey, Kamanyire, & Volans, 1999). A time series regression analysis found that extensive media reporting of a celebrity suicide was followed by a significant increase in suicide attempts (Cheng et al., 2007b). This effect was particularly marked in individuals with a recent history of suicide attempt. This is supported by research demonstrating a 10% increase in suicides in America the two months following the death of Robin Williams. There was a particular increase in suicides by men utilising the same method (Fink, Santaella-Tenorio, & Keyes, 2018) with some evidence that media coverage may contributed to suicide contagion (Carmichael & Whitley, 2019; Fink et al., 2018). However, a similar increase was observed in Canada (Whitley, Fink, Santaella-Tenorio, & Keyes, 2019) despite high fidelity to newspaper reporting guidelines (Creed & Whitley, 2017). This suggests that while newspaper reporting may play a role this must be considered alongside other factors including social media and online news.

A further recent example relates to the release of the television series *13 Reasons Why*. This series is focused on the story of an adolescent suicide and graphically depicts the main characters suicide. A study found the show to be associated with a significant increase in adolescent suicide rates (Bridge et al., 2019). This increase in suicide deaths was concordant

with the period in which social media discussions of the series were the greatest (Niederkröthaler et al., 2019). This is particularly relevant as this series was released by an online streaming service meaning that viewers could watch the episodes in their own time and as such increases in deaths may not be seen on the release date but rather when the most people were watching and discussing the show. The producers have subsequently removed the suicide scene following concerns from suicide prevention experts and agencies (Voelker, 2019). Media influence has not only been found to have a role in suicide but is also related to non-fatal self-harm. Viewing of a film featuring non-fatal self-harm was found to be related to an individual's history of self-harm with an even stronger relationship found when the individual identified with the character (Radovic & Hasking, 2013).

The influence of the media can take the form of both a detrimental or 'Werther effect', increasing the risk of suicide for vulnerable individuals, or a more protective 'Papageno effect' depending on the content and quality (Niederkröthaler et al., 2010). This is related to specific features of content. For example reports that talk about suicide ideation and the adoption of positive coping mechanisms instead of suicide have been found to be protective whereas repetitive reporting of the same suicide and reporting of explicit details of method has been associated with short-term increases in suicide rates (Niederkröthaler et al., 2010). While media influence may act as a vehicle for contagion of suicide and self-harm, the media can also play a role in raising awareness of suicide and self-harm as a social and public health issue. It can inform the public about suicide, the signs to look out for and promote the fact that suicide is preventable. Guidance and support of the media in responsible reporting is a cornerstone of suicide prevention strategies around the world (Welsh Assembly Government, 2015; Department of Health, 2017; World Health Organisation, 2008). There are guidelines to promote the responsible reporting of suicide in a number of countries including the UK (Samaritans, 2013). The 2012 Editors Code of Practice from the Press Complaints Commission prohibits the reporting of excessive details regarding suicide methods (The Press Complaints Commission, 2012). Responsible reporting guidelines such as those produced by Samaritans (Samaritans, 2013) include a number of additional items such as recommendations regarding headlines and photographs aimed to reduce potential contagion.

2.4 SELF-HARM AND THE INTERNET

Assessments of adherence to reporting guidelines needs to go beyond research examining printed newspaper articles. Online news is the most rapidly growing method of accessing news

media and is becoming increasingly popular among young people. These are the people who may be most at risk to the content of reporting (Cheng et al., 2007a) and the population for which adherence to guidelines could be seen as most critical. Specific guidelines have been developed for online media highlighting that the range of options for reporting stories (tweets, blogs, videos) represent increased opportunities to reach audiences, raise awareness and encourage help-seeking. It also emphasized that care should be taken with embedded links ensuring that they are not redirecting to sources of harmful information (Samaritans, 2013).

A recent analysis of UK based online media reports of suicide found that 199 out of 229 articles failed to comply with at least one of the Samaritans guidelines (Utterson, Daoud, & Dutta, 2017). The most breached guideline was failure to include references to sources of support and advice with 69% of articles failing to include this. This absence of signposting undermines suicide prevention efforts and does not provide vulnerable individuals with any alternative perspective. In addition, excessive technical detail about the method used including location and time of suicides by train and, blood concentration of poisons was found in a third of articles. The dissemination of this level of detail has been repeatedly found to increase risk and has led to the spread of previously unusual methods of suicide such as charcoal burning (Yoshioka, Hanley, Kawanishi, & Saijo, 2014). Speculation about the reasons for suicide were included in a third of articles. This kind of reporting can increase the risk of over-identification with vulnerable individuals as well as having a potentially damaging impact on family and friends of the individual (Chapple, Ziebland, Simkin, & Hawton, 2013). A number of additional features present in online news reports could contribute to the dissemination of harmful material in ways not possible with print media. This includes comment sections and links to other articles (Utterson et al., 2017).

The influence of the media and particularly the internet, goes beyond just potential contagion of suicidal behaviour. For many the internet represents an important source of information. Analysis of search engine results has found that both search terms both related to finding help and those related to potentially harmful suicide information increased following a highly publicised celebrity suicide (Arendt & Scherr, 2017). Searches related to suicide/self-harm have been found to return information on methods, encouragement of self-harm and evocative images. Almost a third of websites contained video content. In contrast, advice on how to seek help was given on over half of sites returned (Singaravelu, Stewart, Adams, Simkin, & Hawton, 2015). Research has suggested that self-harm related internet use in both those admitted to adult and children's hospitals was related to greater suicidal intent (Padmanathan et al., 2016).

However, it is noted that further research is needed regarding the type of internet use prior to presentation to hospital. A recent study examining narratives of individuals who self-harm, both in the community and those presenting to emergency departments, found differences in internet use between the two groups (Biddle, Derges, Goldsmith, Donovan, & Gunnell, 2018). Individuals from the community where suicidal intent was found to be lower reported disorganised browsing without much clear purpose, 'stumbling' on a range of content including details of suicide methods. In this group, the internet was also used to interact with others and to explore help online. Individuals presenting to hospital tended to have higher levels of suicidal intent and showed more purposeful internet use. They reported strategic searching around suicide methods and made direct choices about content avoiding communication with others (Biddle et al., 2018). Such patterns of use are of importance to clinicians as this may be indicative of an individual's level of distress. The help-seeking and communicative nature of use by individuals at lower levels of distress is also a potential avenue of intervention. Around a third of young people who self-injure seek help online with the internet providing an important form of support to young people at risk. The internet has been suggested as potential proximal step towards face-to-face help-seeking (Frost & Casey, 2016). If support can reach these individuals, it may prevent them from reaching crisis point or provide them with tools for coping if they do reach a greater level of distress in the future.

In a systematic review, it was concluded that social media platforms could reach large numbers of individuals typically hard to engage through other means. The potential for intervention following an expression of suicidal ideation was found alongside other forms of support and sharing of experiences. However several issues were identified including user behaviour, risk assessment and issues relating to privacy and safety (Franco-Martín et al., 2018). Online communities and social networking sites provide young people with an opportunity for self-expression. Sites that allow the creation of accounts under a pseudonym (e.g. Tumblr) allow a degree of anonymity. This separation from an individual's true identity may facilitate the disclosure of information that would likely not occur anywhere else in that individual's life (Cavazos-Rehg et al., 2016). Increasingly it is being suggested that education programmes should be developed to teach young people about the impact of the content of posts, and how to respond to distressed posts on social media (Duggan, Heath, Lewis, & Baxter, 2012; Robinson et al., 2017). This represents a potentially important step in preventing contagion of suicidal behaviour via the media and, in negating some of the negative aspects of internet use in relation to self-harm. As young people are frequently creating their own content, strategies to increase

safe and responsible reporting of suicide/self-harm in the media now need to educate young people as well as media professionals.

The internet is not only used to access information for people in distress but can also provide access to means. There have been several cases of attempted suicide using Yellow Oleander where seeds have been purchased online (Arachchillage, Hewapathirana, & Fernando, 2007; Fok, Victor, Bradberry, & Eddleston, 2018; Jang, Hoffman, & Nelson, 2010). This method has been previously rare outside of South East Asia where the tree is common. A study documenting dangerous poisons available on eBay has found the availability of a range of a dangerous poisons including cyanide (F. L. Cantrell, 2005). Cyanide obtained over the internet has been used in completed suicide (Le Garff et al., 2016). Nicotine solutions obtained over the internet (sold for use in e-cigarettes) have also been used (Bartschat, Mercer-Chalmers-Bender, Beike, Rothschild, & Jübner, 2015). Better policing and tighter regulations on the sale of potentially lethal items on the internet could have implications for reduction of both suicides and accidental deaths. It also demonstrates that doctors now need to be aware that access to a wide variety of previously 'prescription only' drugs is possible online. This may lead to an increase in both accidental and intentional overdoses using unusual drugs and in populations not usually associated with overdose. This had led to calls for sites marketing medications to be limited, regulated or access potentially blocked (Poncia & Ryan, 1999).

Recruiting participants online and utilising online discussion forums has generated some unique and unmediated data. For example data taken from an online self-harm discussion forum regarding experiences attending emergency departments for self-harm has given an insight not only into the reluctance of individuals to attend hospital, but into their experiences (C. Owens et al., 2016). Analysis of discussions highlighted both positive and negative experiences when attending emergency departments for self-harm including, on the one hand, refusal of staff to administer pain relief and lack of empathy, and genuine kind treatment on the other. Young people described treatment as a 'lottery' with the staff on duty having a greater role in the experience than the procedures in place (C. Owens et al., 2016). While this data does have its limitations, such research exemplifies the use of online methodology to gain direct insight into the experiences of those whose stories often go unheard.

2.5 RESEARCH REGISTERS

Research registers can take various forms and serve several potential functions. For example, they can take the form of databases developed for conducting research that can be pulled

together through electronic registers, databases of anonymized routinely collected data or collections of data taken from hospital admissions. For example, The National Self-Harm Registry Ireland, which is the world's first national registry of cases of self-harm presenting to emergency departments. Data are collected on attendance for self-harm from all emergency departments in the Republic of Ireland. This data is used to monitor incidence and repetition of self-harm with the aim of identifying high-risk groups and to inform services, policy and practice. This data has had a wide impact including informing both national and local aspects of the suicide prevention strategy Connecting for Life (Griffin et al., 2016).

There are several different forms that research registers can take. They may take the form of patient platforms for the exchange of ideas and experiences. Alternatively, they can represent a register of individuals who have expressed interest and consented to be contacted for any future studies for which they may be eligible to take part. This is the kind of research register of interest here. Such registers allow for the creation of often large groups of patients who have consented to be contacted for participation in future research. These registers have been shown to improve levels of recruitment to studies and to lower the amount of resources spent on recruitment. Registers have been created that target the population as a whole such as Reach West (Leach et al., 2016) or the Scottish Health Research Register (Grant et al., 2013). Reach West is an online general research register open to all patients in the West of England and aims to facilitate recruitment to approved health research studies. Individuals who sign up for Reach West also give consent for data linkage so that their NHS records and demographic information can be used to identify projects for which they might be eligible. They can then be contacted to take part in approved studies (Leach et al., 2016).

The projects above describe registers for recruiting participants from the general population. Other research registers have been developed to focus on a specific diagnosis or group. For example, the rare diseases registry (Richesson, Sutphen, Shereff, & Krischer, 2012), Sepsis (Beale et al., 2009) and obstetrics (Bentley, Melville, Berry, & Katon, 2007). Such registers have great utility for recruitment to research studies. For example the Consent for Contact register (Callard et al., 2014) consents patients with serious mental illness presenting to healthcare settings to be contacted for future research. Some limitations have been reported such as needing additional screening of notes to determine eligibility. This was particularly problematic for studies with more stringent or time limited eligibility criteria (Robotham et al., 2016). However this register has resulted in over 600 recruitments to studies from more than 500 participants (Robotham et al., 2016) demonstrating its utility in providing opportunities for

individuals to be involved in research who are often not heard. In qualitative work, both staff and patients reported positive attitudes towards the register and the advantages for patient autonomy. However, concerns were raised about confidentiality and consent. The need for clarity in explanations about what the register is and why the individual was being contacted was also raised, particularly in relation to individuals who may suffer with paranoid delusions (Papoulias et al., 2014).

Patient attitudes to research registers have also been explored in relation to the Multiple Sclerosis (MS) register (Ford et al., 2012; Jones et al., 2012). This research register has both an online and clinic-based format functioning both as a questionnaire delivery platform and research register. Over 7000 people signed up to this register in its first three months. In a qualitative study of participant expectations of a research register most people felt that a register would be useful, but concerns were raised about security, accessibility and validity of self-reports. Participants also expressed a desire for social contact, exchange and networking functions that are not part of the platform (Osborne, Middleton, Jones, Ford, & Noble, 2013). Other qualitative work around the MS register has explored why people use research registers. Of importance to participants were studying MS; raising awareness; improving and developing services and policies; assisting others; the register as a resource for themselves and as an open resource for professionals and government bodies (Lisa et al., 2012).

While research registers represent a valuable resource for future research, they also have some limitations. One of the key limitations of research registers is the representativeness of samples. Research registers often consist of older adults with higher levels of education as seen for example in the MS register (Ford et al., 2012; Jones et al., 2012) with an under-representation of those from more deprived areas as seen for example Health Wise Wales research (Hurt et al., 2019). Research registers often consist of mostly older adults as described above, however samples recruited online often have a larger proportion of younger age groups (Batterham, 2014; Klovning, Sandvik, & Hunskaar, 2009). Samples recruited online tend to under-represent those from most deprived areas and those with literacy issues or where English is not the first language (Batterham, 2014; Goodman, 2013; Heiervang & Goodman, 2011). This may result in underestimations of need if used alone to inform policy (Goodman, 2013). It is important to be aware of such limitations when interpreting results.

Based on the success and positive attitudes towards such research registers for other populations the online platform at the centre of this thesis also provided the opportunity for individuals to sign up to be contacted for any future studies that they may be interested in. This

has effectively formed a register of individuals who have experienced self-harm who can be contacted for potential participation in future research. This register is not dependent on hospital presentation and people can sign up and receive information at their own convenience. It is hoped that this will provide a valuable resource for future research. It is intended that this project will go on to partner with a third sector organisation in order to further boost recruitment.

2.6 THE IMPORTANCE OF PEOPLE IN DESIGNING RESEARCH

There are increasing calls for patients to be involved in health research and for participants to have a greater voice and role within the standard research enterprise (Vayena et al., 2016). When seeking research topics, face-to-face discussion with a consumer group was more productive than reading research reports or contacting consumer health information services. Consumers were willing and able to play active roles as panel members in refining and prioritizing topics and in commenting on research plans and reports (Oliver et al., 2001). A recent systematic review focused on the impact of patient and population involvement (PPI) on health/social care research and found that PPI enhanced the quality and appropriateness of research. Impacts were reported at all stages of research including the development of: user-focused research objectives; user-relevant research questions; user-friendly information; questionnaires and interview schedules; more appropriate recruitment strategies; consumer-focused interpretation of data and enhanced implementation and dissemination of study results (Brett et al., 2014).

Research with routinely collected data utilises an opt-out consent model meaning that data collected via the health service is utilised unless the individual explicitly states that they want to opt out. This has the advantage of allowing data to be collected at population level and to inform provision of services. However, it is important that this is balanced with public concerns over the security and use of their data. PPI involvement in such research is considered increasingly important and the SAIL databank has a consumer panel to represent a public viewpoint (Jones, McNerney, & Ford, 2014). The panel is actively involved in dialogue with various SAIL panels and boards and is regarded as a valuable addition to the research work. The panel has expressed a strong interest in being better informed about studies recognising that often research outputs are written for academics and experts. Because of this input, the governance review process now requires both a lay summary and public engagement strategy.

The Scottish Health and Ethnicity Linkage study established a public panel who demonstrated a keen interest in how data is used and research questions asked (Douglas et al., 2017). The majority supported the use of healthcare data without the need for individual opt-in consent however, concerns were raised over data security. The panel recommended disseminating findings of research more widely to promote the use of linked health data. This supports previous suggestions that providing information about research, anonymization processes and data security can lead to better public support for the use of health data without explicit consent (Hill, Turner, Martin, & Donovan, 2013). The issue of consent for use of healthcare data has also been related to the purpose of the research and the organisation responsible. For example, individuals taking part in focus groups reported that research undertaken by the NHS was for the public good and an acceptable use of data, however research done by pharmaceutical companies who stood to make a profit was less acceptable. University researchers were seen to be somewhere in the middle dependent on the funder of research and financial gain (Hill et al., 2013). A systematic review of studies examining public views of the use of their health data found that participants recognised the benefit of sharing their records for research but wanted to know more about how their data was being used. Across countries participants shared concerns about data security, data being sold for commercial gain or used by pharmaceutical or insurance companies (Hill et al., 2013).

The use of data for research goes beyond healthcare data with social media data increasingly being utilised for research purposes. This offers an alternative to surveys and questionnaires with information on behaviours and opinions available at the touch of a button. Such data can be found on a variety of platforms including discussion forums, blogs and social media. It is typically a very rich source of naturally occurring data (Beninger et al., 2014) and is becoming a popular source of data for researchers across various disciplines. With the increase in use of a relatively new data source comes a complex set of ethical concerns. One of the key areas of concern is whether social media data should be considered to be public or private. The terms and conditions of social media sites often state that third parties, including researchers, may access individuals data. However, the question remains as to whether it is ethical for researchers to justify the use of this data just because it is easily accessible (Boyd & Crawford, 2012). There is also the issue of informed consent and the right to withdraw being complicated by social media research. Preserving anonymity in social media data poses a key ethical concern with the potential for anonymity to be breached with the use of this kind of data highlighted as early as 2007 (Kleinberg, 2007). Anonymization procedures are still evolving for aggregated or Big Data and it is difficult to anonymize text extracts (such as the content of individual posts) when these

are reproduced in research output (Narayanan & Shmatikov, 2008, 2009). This of particular concern when republishing quotes taken from social media as these can be searched and lead back to the original location, often revealing the identity of the poster (British Psychological Society, 2017). This is further complicated by the different kinds of data that can be contained within a post going beyond text to images, videos and audio. The potential for anonymity to be breached is particularly relevant to research related to sensitive topics where it is important to protect the privacy individuals who, in the majority of cases, may not know that their data is being used for a given project. It is also not always possible to verify whether the participant is a child, or of their ability to understand the easily accessible nature of the data.

Specific ethical frameworks for working with social media data have been published in attempt to address these issues (British Psychological Society, 2017). The association of internet researchers have argued that no set of internet guidelines can be static, because of the constantly evolving nature of internet technologies (Markham & Buchanan, 2012). While such frameworks exist it is highlighted that it is up to individual research teams and ethics committees to ensure an ethical approach is taken and that such a framework cannot be prescriptive but instead provides the decision making tools researchers need to take an ethical approach to the use of social media data (Townsend & Wallace, 2016). Furthermore, many studies utilising social media data either contain a single statement that their research is considered to be exempt from institutional ethical approval or, do not contain any statement of ethical considerations at all (Marchant, Hawton, Burns, Stewart, & John, 2020b).

In a review of perspectives on ethical considerations around the use of social media, research was found be considered more acceptable if it was going to be used for a good cause such as social benefit or to help others. Participants also expressed that they would not like to see their data used in research with a bad intention, for commercial gain or to drive a personal agenda. Generally, participants were more positive about the use of this data by universities than by journalists, government or commercial organisations. Young people and Twitter users (as opposed to users of other social media platforms) were generally more positive about their data being used. In terms of risks to social media users, concerns were raised about data being taken out of context, used inappropriately or an individual being identifiable. Special consideration was raised with regards to vulnerable groups including children and adolescents and people with mental health issues (Golder, Ahmed, Norman, & Booth, 2017). Individuals who self-harm potentially represent a vulnerable group often made up of children and young people. Social media has become a topic of interest in self-harm research and this data is being used

increasingly to examine the use of self-harm imagery (Dyson et al., 2016; Marchant et al., 2020b). With the popularity of this data, gaining participant perspectives is particularly important.

PPI in self-harm research has largely focused on whether taking part in research has any risk of harm for participants. For example, in qualitative interviews with participants who had taken part in suicide and self-harm-based research 50-70% of individuals reported an improvement in well-being and often described the cathartic value of talking. A lowering of mood was reported by 18-27% of individuals, as they had to focus on difficult issues. However most anticipated that their distress would be transient and it was outweighed by a desire to contribute to research (Biddle et al., 2013). Similarly, the impact of participating in suicide research online was not found to increase negative feelings; however, some participants did report manageable levels of distress. Anonymously sharing experiences of suicidality was considered important with therapeutic benefits promoting hope of recovery. The importance of protecting anonymity whilst providing vulnerable individuals with support when participating in this kind of research was also highlighted (Gibson, Boden, Benson, & Brand, 2014). This is supported by a systematic review concluding that no studies found a statistically significant increase in suicidal ideation among participants asked about suicidal thoughts (Dazzi, Gribble, Wessely, & Fear, 2014). Furthermore, findings suggest that the opportunity to talk about suicide may reduce suicidal ideation and improve mental health.

While research has shown that partaking in self-harm research does not pose a significant risk to individuals there is a sparsity of research on what people hope to gain, or their preferences and ideas. Such research would be valuable for designing future studies and would provide an important insight into the experience of research for participants. This could go on to inform how studies are designed to best address issues faced by individuals. In addition, self-harm represents a potentially sensitive topic in which ethical issues around data use such as anonymity and consent are particularly relevant. Gaining the opinions of people who self-harm about the way in which their data is used, encompassing health and social media data, would have implications for research going forward. As part of this project a national survey was conducted to further explore individual's opinions on the use of their data for research. The survey focused on young people who have experienced self-harm who have not been the subject of this kind of research previously, providing valuable insights for future research.

2.7 THE ROLE OF HEALTHCARE DATA

Routinely collected healthcare data has enormous potential for research across all areas of health. Reliable large-scale data across healthcare services for self-harm related to things like hospital presentations, GP attendances, risk factors and outcomes could be used to assess burden on services and help improve quality of care and patient outcomes. Linking participant data from research studies with routinely collected data has been used to identify high-risk groups. For example, an Australian study examined self-harm following release from prison. Baseline surveys were linked with ambulance, emergency department, hospital and death records. It was found that ambulance attendances resulting from self-harm are common following release from prison. A number of exacerbating risk factors were also identified including prior psychiatric treatment, being identified as at risk while in prison or prior ambulance attendance due to self-harm (Borschmann et al., 2017b). The identification of these risk factors represents an opportunity for tailored support and prevention.

For the purpose of this thesis, data available in the SAIL databank was utilised to examine healthcare contacts for self-harm in children and young people. This data has several advantages. Any individual who has contact with the healthcare system in Wales has their anonymized data utilised for research. This places no burden on individuals and this research has direct relevance for informing provision of services. It allows large sample sizes to be captured for research and patients can be followed up over a long time period without the usual risk of losing participants during follow-up or having to contact participants at multiple time points over a number of years. The SAIL databank based has been used to examine the association between educational attainment and subsequent depression diagnosis and self-harm. Declining educational attainment was linked with self-harm and the development of depression (Rahman et al., 2018). Expanding this methodology to other potentially vulnerable groups could go onto inform services and prevention efforts. This could include linking data from individuals in touch with social care, young carers or other vulnerable groups. Identifying people at risk could allow for prevention and early treatment. This would have the potential to reduce personal distress and the burden on services.

Much preliminary work has already been conducted in relation to self-harm and routinely collected data. This has included work on validating the way in which self-harm and suicide are recorded in primary care (Thomas et al., 2013). Primary care data is not collected for the purpose of research but rather the electronic records are anonymized and utilised. This means that there

may be inconsistencies between what is or is not recorded and, the reality for each patient. Primary care records in the UK are based on Read codes rather than ICD-10 and specified code lists for each condition do not exist as standard for coders or researchers. As a result, code lists for conditions of interest must be created for research and tested to ensure that they accurately reflect coding behaviour. Such work has been conducted based linkage between primary care and hospital records (Thomas et al., 2013) and comparison of rates based on survey data with those gained from routinely collected data (Clements et al., 2016). Such studies have found an underestimation of self-harm presentation across healthcare services. While rates taken from survey data have been compared with healthcare data, linkage of individual records and responses on a large scale would represent a new level of knowledge and validation of records. For example, being able to link the questionnaire responses of someone reporting attending hospital with self-harm with their anonymized healthcare record could answer questions relating to whether the admission was recorded, the diagnoses reported, referrals and follow-up and how this corresponds to what individuals report. To do this consent would need to be taken from individuals to link these two sources of data.

Routinely collected data has been used to identify clinical management patterns and risk of death in children and young people following self-harm (Morgan et al., 2017). Research with routinely collected primary care data examined trends over time of attendance for self-harm in individuals aged 15-64. Incidence and annual presentations were found to be highest in individuals aged 15-24 with females having significantly higher incidence and presentation rates than males (Carr et al., 2016a). Increasing presentation rates were seen for males across age bands. Incidence in the most deprived areas was found to be around double that seen in the least deprived areas (Carr et al., 2016a).

A recent study linking GP, inpatient and Office of National Statistics (ONS) data found that young people who harmed themselves were around nine times more likely to die of unnatural causes during follow-up with a roughly 17 times elevated risk of suicide (Morgan et al., 2017). This study demonstrates significantly increased relative risk however it should be noted that suicide represents a rare outcome in this age group. Inequalities in treatment patterns were also seen. Young people from more deprived areas were 23% less likely to be referred to a specialist than those in more affluent areas (Morgan et al., 2017). The linkage across GP, inpatient and ONS data allowed for the identification of an additional 50% of episodes of self-harm presenting to primary care that would not have been recorded by inpatient hospital data alone. However linkage to emergency department data was not possible. It was noted that the sample in this

study was predominated by self-poisoning in contrast with community surveys where self-injury is more frequently reported. The difference in care based on deprivation indices has been supported by previous research with primary care data finding that individuals aged 15-64 in the most deprived areas were 27% less likely to be referred from primary care than those in the most affluent areas (Carr et al., 2016b). Data was not systematically recorded on psychological therapies and other non-medicinal treatments. Overall rates of referral were found to be low with one and ten prescribed medication without a diagnosis or referral and a similar percentage having a diagnosis with no medication or referral recorded (Carr et al., 2016b). It was not possible to gather data on the uptake of referrals or whether patients were already under the care of psychiatric services. The increased risk of death seen in young people is also seen in a population aged 15-64 identified from primary care data. The risk was found to be elevated across ages and was higher for young people. There was a high suicide risk during the first year after presentation (adjusted hazard ratio 54.4; 95% CI 34.3-86.3) (Carr et al., 2017). The linkage between primary care and mortality data represents an advantage of these studies. However, this level of linkage was available for English practices only with no linkage available for practices in Wales, Scotland or Northern Ireland. The frequency with which these patients attend primary care underscores this as a key area of intervention for these individuals. Greater support and training for GPs and tailored management of these patients could lower the risk of subsequent death. Studies linking across a larger range of settings incorporating emergency departments and outpatient settings would allow for a fuller picture of demands on services.

As yet, no studies have been conducted in the UK examining contacts for self-harm across the full range of healthcare settings at population level. Data available in the SAIL databank is uniquely placed to link data not just from GP and hospital admissions but from emergency departments and outpatients as well. Using this data, it is possible to gain a picture of the change in presentations to individuals services over time and to explore whether the same individuals are presenting across settings or whether these represent distinct groups. For example, whether populations attending emergency departments for self-harm differ from those attending their GP. Such research has the potential to inform tailored support and service provision and to provide a comprehensive summary of self-harm across healthcare settings.

2.8 CHAPTER SUMMARY

This chapter summarises the background to the various aspects of this thesis. As described self-harm is an important public health concern with potentially long-term negative impacts for the

individual and considerable economic costs to health and social care services. Much self-harm research is conducted in healthcare settings, however only a small proportion of self-harm results in presentation to health services leaving many individuals unrepresented by current research. The creation of an online platform for self-harm research would assist in lowering many of the barriers to taking part in research allowing participants to take part at home in anonymity.

The role of the media in self-harm has long been a topic of research with the internet now a pivotal topic. Alongside concerns around contagion is the use of the internet as a source of information, for access to means and for the sharing and viewing of self-harm imagery. Learning more about the ways in which young people use the internet from their perspective could go on to inform policies and educational programmes to help negate risks and maximize the potential benefits of the internet with relation to self-harm.

Research registers have been shown as an effective resource for research, facilitating recruitment to studies and lowering the associated cost. Individuals who self-harm represent a potentially difficult group to access for research due to the often-hidden nature of self-harm. Allowing people to sign up to a research register online has the potential to be a valuable resource for future research and, to give individuals a voice in research who may otherwise go unheard.

The importance of PPI in research has been discussed particularly with relation to use of Big Data, such as healthcare and social media data, for self-harm research. PPI has been found to be a valuable addition to research across disciplines, however in relation to self-harm participant perspectives are often limited to demonstrating that the research is not harmful. Learning more about participant perspectives on what they hope to gain from research, how research could best represent their interests and, their opinions on the use of their data would be of value to steering future research.

Finally, the role of routinely collected healthcare data is discussed. Routinely collected healthcare data is a rich data source for examining patterns of healthcare contacts at population level. In this chapter an overview has been given of the work already done with routinely collected healthcare data in relation to self-harm including validating code lists, examining trends over time combining GP and hospital admissions data and examining patterns of management and outcomes of self-harm. Routinely collected data held in the SAIL databank has the potential to expand on previous research incorporating GP, emergency department, hospital

admissions and outpatient's data related to self-harm at population level for the first time in the UK.

3 SYSTEMATIC LITERATURE REVIEWS

As discussed previously this project is centred around the establishment of an online platform for self-harm research. It was important at the onset to be aware of the existing literature around internet use and self-harm in children and young people. This is of particular importance given the double edged nature of the internet and the speed at which this field of research is growing (Biddle et al., 2016; Daine et al., 2013), combined with the media databank element of this project. It was important that any analysis of this databank was conducted in the context of existing research for this to make a meaningful contribution to the literature. In order to inform the current project and gain an awareness of the issues around internet use and self-harm the literature around this was systematically reviewed. Two systematic reviews were conducted. The first looked broadly at internet use and self-harm in children and young people. The results of this review will be summarised below with methods and results detailed in the published version of this manuscript (Marchant et al., 2017; Appendix A).

Based on the results of this initial review it was apparent that any future reviews would need to focus on specific aspects of internet use, as the volume of internet research broadly related to internet use and self-harm in children and young people can no longer be meaningfully summarized in the context of one review. Over the course of this project the nature of internet use in children and young people has evolved with a greater role of images and videos (Biddle et al., 2016). This is particularly relevant in relation to the death of a young person in February 2019 and the subsequent campaign by the family. Following this, changes were made to policies of social media platforms regarding the sharing of self-harm imagery with Instagram announcing a ban on all images of self-harm, including pictures showing scars (Instagram, 2019). The second systematic review updated the literature related to the role of images and videos online. This review will be described in detail in the second part of this chapter and has been summarized for publication (Marchant et al., 2020b; Appendix C). These systematic reviews informed the development of the platform, analysis of the media databank described in Chapter Four and the nature of the questions asked in the Big Data and Mental Health Survey described in Chapter Five.

As outlined in the previous chapter young people who self-injure often engage in more online activity than those who do not (Mitchell & Ybarra, 2007). Research has shown there to be a large online presence of self-harm related material (Duggan et al., 2012). This has been found in the form of blogs (Castro & Osório, 2012; Castro & Osorio, 2013), large social media groups (Zdanow & Wright, 2012), thousands of videos with a high amount of views (Lewis, Heath, St Denis, &

Noble, 2011) and dedicated online communities (Baker & Lewis, 2013). Research in this area has grown exponentially over recent years in an attempt to determine potential benefits and harms of internet use in young people who self-harm.

An early review examining the use of dedicated self-harm support sites found high levels of support available alongside normalisation of self-harm behaviour (Messina & Iwasaki, 2011). A more recent systematic review related to self-harm and the internet additionally found evidence of the sharing of information regarding self-harm methods and concealment, a reduced sense of isolation and reinforcement of positive behaviours such as help-seeking (Daine et al., 2013). The review authors concluded that the internet exerts both positive and negative influences on people who self-harm and provides an opportunity for intervention. However it was suggested that the design and quality of individual studies may have had an impact on perceived outcomes (Daine et al., 2013).

The systematic review conducted by Daine et al. (2013) found both positive and negative influences of the internet. However, there were still a number of questions left unanswered. Up to the date of their review (December 2011) research only described internet use in relation to forums or general use (Daine et al., 2013). Specific internet pathways have been found to represent increased risk. For example internet addiction and pro-suicide websites have been suggested as high risk factors facilitating suicidal behaviours, particularly in isolated and vulnerable individuals (Durkee, Hadlaczky, Westerlund, & Carli, 2011). Furthermore recent research has suggested changes in online content over time with an increase in the presence of graphic imagery (Biddle et al., 2016). The literature around this topic has developed with studies examining different aspects of internet use including the role of imagery (Baker & Lewis, 2013) and video sharing (Lewis et al., 2011). Research is building on the potential positive influences such as directing individuals to healthier online behaviour and the growing need for mental health professionals to engage with individuals about internet use (Lewis, Heath, Michal, & Duggan, 2012a).

It has also been suggested that study design may be related to perceived outcome (Daine et al., 2013). Quantitative studies tended to report a negative impact of internet use whereas qualitative and mixed methods designs tend to report a more positive influence. There is a need for more rigorous research into clarifying the positive and negative influences. More understanding is needed to identify the mediating and moderating factors in order to optimise the benefits whilst minimising the potential for harm. These studies highlight the rapidly changing nature of the internet and its use by young people. It remains challenge to research in

this area to remain timely and relevant. As such, an updated synthesis of the literature was conducted for the purpose of this thesis building on the work of the previous reviews (Daine et al., 2013; Van Geel, Vedder, & Tanilon, 2014).

This area of research has grown at such a rate that two systematic reviews were necessary. The first was an overview of the literature related to internet use and self-harm/suicidal behaviour in children and young people (Marchant et al., 2017). The second review sought to conduct a timely review of the literature and focused on the impact of self-harm related videos and images online on children and young people (Marchant et al., 2020b). Published/pre-print manuscripts of these reviews are included Appendix A and C respectively. Here, findings from review one will be briefly summarised and review two will be described in depth below.

3.1 REVIEW ONE: A SYSTEMATIC REVIEW OF THE RELATIONSHIP BETWEEN INTERNET USE, SELF-HARM AND SUICIDAL BEHAVIOUR IN YOUNG PEOPLE: THE GOOD, THE BAD AND THE UNKNOWN

Review One aimed to systematically review all research relating to the influence of the internet on self-harm/suicidal behaviour in children and young people (aged up to 25). This review focused on identifying the factors that determine whether the internet is perceived as a positive or negative influence. Details of the search strategy and data analysis are included in the published manuscript (Marchant et al., 2017; Appendix A). Fifty-one papers from 46 independent studies with a total 192,950 participants together with some reports of content analytical studies were identified. Research in this area has grown and developed meaning that it was possible to break down research into specific mediums of internet use in a level of detail not possible in previous reviews. Results of this review were largely supportive of the findings of the previous review (Daine et al., 2013). The greater level of detail reported in more recent research has allowed previous work to be expanded. This allowed for further examination of details, such as medium of internet use, and to identify a larger range of positive and negative influences than possible previously.

Overview of results and comparison with other literature

Internet mediums were broken down as follows: General internet use (12 papers; two describing a positive influence, seven negative and three mixed influences); internet addiction (seven papers; five reporting negative influences and two mixed); online intervention/treatment (six studies; four reporting positive influences and two mixed); social media (four studies; three

reporting negative influences and one reporting mixed); forums (fourteen papers; nine (from five independent studies) reported positive influences; five reported negative influences); websites with suicide/self-harm content (two articles; one reporting negative influences and one reporting mixed); video/image sharing (four papers; one reporting negative influences and three reporting mixed) and, blogs (two papers; both reporting negative influences). Due to the volume of papers related to cyberbullying identified during this search articles related to cyberbullying were analysed in a separate review. This allowed for a more comprehensive discussion and meta-analysis (John et al., 2018).

Studies examining general internet use, internet addiction and online interventions/treatments presented the strongest evidence, with papers being rated as largely high or medium quality. Research into internet addiction represented the most homogenous group of studies in terms of research methodology. All studies examining internet addiction scored high or medium in terms of quality, utilised school-based surveys and validated outcome measures. There is no agreed definition of internet addiction in the current literature. Definitions range from an impulse control disorder likened to pathological gambling (Aktepe, Olgaç-Dündar, Soyöz, & Sönmez, 2013; Kaess et al., 2014; K. Kim et al., 2006; Lam, Peng, Mai, & Jing, 2009) to assessments of level of functional impairment or level of use (Lin et al., 2014; Messias, Castro, Saini, Usman, & Peeples, 2011; Park, Hong, Park, Ha, & Yoo, 2013). For the purpose of this review internet addiction and general internet use were grouped separately. Internet addiction was distinguished from general use if papers specifically referred to internet addiction or pathological internet use. A significant relationship between self-harm/suicidal behaviour and internet addiction was found in all seven studies however, the direction of causality remained unclear. A potential protective influence of low levels of internet use when compared with none was identified (Messias et al., 2011). Suggested mechanisms included low levels of loneliness and higher levels of life satisfaction (Aktepe et al., 2013). A recent prospective study of high school students with no history of self-harm found that internet addiction was predictive of self-harm/suicidal behaviour at one year follow-up independent of depression, anxiety, sleep quality and quality of life (IRR 2.4; 95% CI 1.2-5.0) (Pan & Yeh, 2018). However, this study did not control for things such as social isolation and drug use. The complex interplay between shared risk factors for internet addiction and self-harm mean that questions remain unanswered. Authors acknowledge that internet addiction may be acting as a mediator between identified risk factors and suicidality rather than being a stand-alone risk (Pan & Yeh, 2018). This is in the context of research suggesting that depression, lower school bonding and substance use were important predictors of internet addiction (Chang, Chiu, Lee, Chen, & Miao, 2014). Whatever the causal

mechanism, support for individuals with internet addiction should be tailored to also address the potential for self-harm/suicidal behaviour.

Potential positive influences of high levels of use were suggested by research both into internet addiction and general use. Internet addiction was associated with low levels of loneliness (Aktepe et al., 2013) and a potentially protective influence of low levels of internet use was found when compared with no use at all (J. Y. Kim, 2012; Messias et al., 2011) even if this wasn't specifically referred to as pathological use or internet addiction. Internet use of more than two (J. Y. Kim, 2012) or five (Carli et al., 2014) hours per day was associated with suicidal ideation. Self-harm and suicidal ideation were related to searching for suicide information (Katsumata, Matsumoto, Kitani, & Takeshima, 2008) and searches for specific methods were related to suicide rates in young people (Hagihara, Miyazaki, & Abe, 2012). A potential role of the internet in facilitating the spread of information during a suicide cluster was also identified, making the cluster more difficult to recognise and manage (Robertson et al., 2012). The potential positive impacts such as a reduction in isolation could be attributable to the sense of community online that may not be possible for individuals in everyday life. Online communities and social networking sites provide young people with an opportunity for self-expression. Sites that allow the creation of accounts under a pseudonym (e.g. Tumblr) allow a degree of anonymity. This separation from an individual's true identity may facilitate the disclosure of information that would likely not occur anywhere else in that individual's life (Cavazos-Rehg et al., 2016). The potential of the internet to deliver interventions to address suicidal behaviours and self-harm is also being explored with largely positive results (Barton, Hirsch, & Lovejoy, 2013; Hetrick, Delloso, Simmons, & Phillips, 2015; Hetrick et al., 2014; Mar et al., 2014; Saulsberry, Marko-Holguin, Blomeke, & Hinkle, 2013; Whitlock, Pietrusza, & Purington, 2013).

Studies exploring social media, forums, video/image sharing, and blogs tended to be smaller and rated as lower quality. The results of these were largely mixed. Distressed social media posts were found to be related to suicidal ideation and behaviour, but there was no evidence that simply using social media presented a risk (Sueki, 2015). Young people are increasingly using social media to communicate distress, particularly to peers, prior to attending hospital with self-harm (Belfort, Mezzacappa, & Ginnis, 2012). This represents a potential new avenue for intervention and, supports the notion of educating young people about how to respond to distressed posts online. While there was no evidence of a direct causal relationship between social media use and self-harm, glorification and normalisation of self-harm was found (Zdanow & Wright, 2012). Forums were largely viewed as a positive source of peer support. One high

quality study found a reduction in suicidal thoughts following forum use (Eichenberg, 2008). However, normalisation of self-harm, discussion of how to conceal wounds and encouragement to go ahead with suicide plans was also found (Eichenberg, 2008; Franzen & Gottzén, 2011; Sueki & Eichenberg, 2012; Westerlund, 2013; Whitlock, Powers, & Eckenrode, 2006).

Videos were highly viewed and shared and were found to contain largely factual or educational content. Graphic imagery was common in YouTube videos related to self-harm including live acts of self-harm. Warnings about such content were rare (Lewis et al., 2011). Comments on videos suggest a strong motivation for sharing experiences online. It is not clear whether this has a positive or negative impact on individuals and this is likely to vary between individuals and over time depending on circumstances (Lewis, Heath, Sornberger, & Arbuthnott, 2012b). This is further supported by some participants reporting a triggering effect of photographs with others reporting that viewing images acted as a deterrent or alternative to self-harm. Publishing these photos was a way of sharing experiences, giving and receiving help. Participants emphasised that the outcomes of viewing these images vary due to both individual and situational differences and may have different impacts on the same individual over time (Sternudd, 2012). Blogs represented the smallest body of research with two papers examining the same set of pro-anorexia blogs. These were found to contain potentially harmful information related to self-harm and suicide (Castro & Osório, 2012; Castro & Osorio, 2013). Recent research has indicated that the production and consumption of images are a strong motivator for going online with nearly three quarters of participants sampled stating that images were the primary reason for using the internet. Participants reported experiencing a strong and physical reaction to viewing self-harm photographs that could trigger the urge to self-harm (Jacob, Evans, & Scourfield, 2017)

The role of study design

The variation in results between mediums may be partially attributable to study design, participant samples and outcomes assessed. In keeping with the previous review (Daine et al., 2013) the majority of studies reporting exclusively negative influences utilised quantitative methodologies that tended to score higher on measures of quality. Mixed methods and qualitative studies tended to report mixed results and to score lower on measures of quality. It is unclear if this is due to quantitative data failing to capture the complexity of the issue or if there is a discrepancy between what participants report and actual outcomes. The role of study quality also merits further investigation potentially with a more comprehensive range of study quality measures. For the purpose of this review the CASP quality score was used (CASP, 2013) in keeping with previous research (Daine et al., 2013). The appropriateness of using checklists

to assess qualitative research has been questioned due to the heterogeneity in data collection, analysis and interpretation (Barbour, 2001; Green & Thorogood, 2013). It would be difficult for a single checklist to capture all aspects of study quality across the range of designs, populations and outcomes present in this body of research. Future reviews in this area may consider the selection of quality outcome measures that fully capture the quality of various study designs.

Research examining general internet use and internet addiction was largely based on school surveys employing validated outcome measures and found largely negative influences of internet use. In contrast, studies related to forum use recruited mostly from discussion forums themselves and contained a content analysis of forum posts, sometimes alongside study-specific questionnaire data and tended to find more positive influences. Contrasting results between these two bodies of research could be down to difference between participants recruited from the general population and those self-selected from forums. Future research could aim to clarify this relationship utilising a more diverse participant sample and employing a combination of a qualitative component and validated outcome measures.

A number of outcomes were assessed across studies including levels of self-harm, mental disorders, internet addiction, loneliness, insomnia and the potential to recruit participants for research. Measures employed also varied from study specific self-report questionnaires to content analysis, to validated scales used to measure a variety of outcomes including suicidal behaviours, internet use and well-being (e.g. Internet Addiction Scale (Nichols & Nicki, 2004) and the UCLA loneliness scale (Russel, Peplau, & Cutrona, 1980)). The outcome under study may have had an impact on perceived influence reflecting the expected effect and failing to capture the full complexity of the experience. For example, studies examining internet addiction found largely negative influences however, measures of potentially positive influences were not routinely included. High levels of life satisfaction and reduced loneliness found by Aktepe et al. (2013) would not have been identified had these measures not been included. Future research should aim to ensure that outcome measures capture both possible positive and negative outcomes in order to give a balanced overview.

Implications for the future

Research into self-harm and internet use has now gone beyond whether the internet is simply 'good' or 'bad.' Instead, research is now moving into how best to utilise the wide reach of the internet and diverse audience for a potentially positive impact, whilst reducing the possibility of harms, particularly for those who are vulnerable. For example, the large self-harm presence on

YouTube has led to suggestions of developing videos to emphasise help and recovery (Lewis et al., 2012b; Lewis et al., 2011).

The increasing use of social media to communicate distress offers a potential avenue for intervention. The introduction of psycho-educational prevention programmes in schools to teach young people how to recognise and respond to distressed posts would have the potential to help individuals in crisis and would represent a positive step forward (Barton et al., 2013; Belfort et al., 2012; Duggan et al., 2012). As well as being a place where people can support each other, the internet is also a potential tool for outreach by health professionals. Research suggests some disconnect between healthcare professionals and media usage (Lewis et al., 2012a). This was discussed in one set of forum studies aiming to bring together health professionals and young people online. Health professionals expressed discomfort about engaging with young people online and had concerns over duty of care (C. Owens et al., 2012). This could be addressed through further training and encouragement of clinicians to engage with young people regarding internet use. It has been suggested that questions about internet use should be included as standard during assessment. This could include asking about image/video sharing (Sternudd, 2012) and designing treatment plans to reduce harmful online behaviour and redirect to behaviours that may provide support (Duggan et al., 2012). There is also emerging evidence to suggest that resilience can be a protective factor for adolescents, reducing the risk of psychological harm even in the presence of internet addiction and online risk exposure (Wisniewski et al., 2015). Interventions that foster resilience and strength building in young people should be explored, as these may be more effective to implement than restricting internet use.

There are also calls for the implementation of guidance to individuals and service providers such as that issued to newspapers by the Samaritans (Samaritans, 2013). This could include avoiding details of method and including warnings of graphic content on web pages (Duggan et al., 2012). Stricter regulations could also follow the example of the banning pro-suicide sites as done in Australia in 2006 (Pirkis, Neal, Dare, Blood, & Studdert, 2009). Several social media platforms (including Tumblr, Pinterest, Instagram and Facebook) have already responded to concerns and implemented policies regarding posts related to self-harm. Such content may not be searchable, is banned or brings up links to counselling and prevention resources (Dyson et al., 2016). It is also possible for other users to report posts that they feel are a cause for concern on several platforms including Facebook and Instagram.

Recent research has focused on other aspects of internet use not covered in this review. For example, there is also a body of literature emerging on the threat of online 'games' such as The Blue Whale Challenge in which 'players' complete a series of dangerous tasks set by a 'curator.' These tasks can begin with the 'player' drawing on their own skin, watching horror movies, escalating to self-harm, sleep deprivation, climbing buildings and cranes and ending in the 'players' suicide (Mukhra, Baryah, Krishan, & Kanchan, 2019). The exact number of 'players' and associated deaths is unknown, however it has been estimated based on news sources to be around 170 (Khattar, Dabas, Gupta, Chopra, & Kumaraguru, 2018). Vulnerable players are targeted such as those who are already suffering from mental health issues (Khattar et al., 2018). An examination of five cases assessed in hospital suggest that 'players' are vulnerable individuals, in this case young girls (aged 14-17) who were socially isolated, came from a situation of family breakdown and suffered with depression or other mental health issues (Lupariello, Curti, Coppo, Racalbutto, & Di Vella, 2019). Other potentially dangerous games related to self-harm spread via the internet include 'The Fire Challenge' in which an individual douses themselves in flammable liquid and attempts to extinguish the flames before they incur serious burns. These videos are then posted online (e.g. Avery, Rae, Summitt, & Kahn, 2016).

Results of this review and the rate at which the body of research related to self-harm and internet use is growing means that bringing together literature across all internet mediums will become increasingly difficult. Future reviews should focus on specific areas of internet use such as social media or internet addiction to be able to discuss findings in sufficient depth.

Review One conclusion

Research examining internet use and its relationship with self-harm and suicidal behaviour is continually growing in an attempt to keep pace with the ever-changing online world. Research up to the date of this review supports the potential for benefits including sense of community, crisis support and reduced isolation. There is also potential for harm including normalisation, triggering, competition between users and source of contagion. The focus should now be on a range of internet mediums and the potential for the internet to be used in outreach, therapy and recovery. There have been a number of innovative suggestions from research teams including education programs in schools and repeated calls for clinicians to be aware of internet use. The internet may also represent an under-utilised setting to reach 'hidden' at risk groups, giving them a voice in both research and practice.

3.2 REVIEW TWO: IMAGES ON THE INTERNET: A SYSTEMATIC REVIEW OF STUDIES ON THE IMPACT OF ON-LINE SHARING AND VIEWING OF SELF-HARM RELATED VIDEOS AND PHOTOGRAPHS IN YOUNG PEOPLE

The previous systematic review (Marchant et al., 2017) examined the relationship between self-harm and internet use in children and young people examining literature across a range of internet platforms. Four papers were found to focus on video and image sharing (Duggan et al., 2012; Grzanka & Mann, 2014; Lewis et al., 2011; Sternudd, 2012). Videos were found to be highly viewed and shared, often containing graphic imagery with content/trigger warnings rare (Lewis et al., 2011). Comments on videos suggested a strong motivation for sharing personal experiences (Duggan et al., 2012). It was not clear whether this sharing of experiences had a positive or negative impact. Only one qualitative study was included in the previous review. Participants reported both an alleviating and triggering impact of self-harm imagery often dependent on the individual or mood at the time (Sternudd, 2012). The potential of videos to be used to raise awareness and facilitate recovery was highlighted, as was the potential for material to be triggering or harmful to individuals who are vulnerable.

The nature of internet use is constantly evolving and the self-harm forums that were once popular are no longer utilised to such an extent by either individuals or researchers (Harris & Roberts, 2013). Young people who self-harm report image rather than text-based interactions as their primary reason for internet use (Jacob et al., 2017). Platforms such as Instagram and Tumblr have increased in popularity as a platform for self-harm communities in part because they are centred on images (Jacob et al., 2017). Forty-four percent of adolescents report Instagram to be an important part of their daily lives (Feierabend, Plankenhorn, & Rathgeb, 2016) and internet searches for suicide are increasingly returning graphic imagery (Biddle et al., 2016). Young people are now using imagery to communicate their stories and it is a challenge for research to keep pace with this trend.

Imagery, whether physical or mental, has been shown to be causal in determining future behaviour. Mental imagery refers to perceptual experiences based on information stored in memory, in the absence of external sensory input (Kosslyn, Ganis, & Thompson, 2001) commonly referred to as the 'mind's eye'. Mental imagery can be multi-sensory and occur in a variety of forms from a static scene to detailed playing of past or imagined future events. This mental imagery plays a special role in representing our past and future experiences (Holmes & Mathews, 2005; Kosslyn, 1996). The ability of mental imagery to emulate real-life experience

(Moulton & Kosslyn, 2009) can powerfully impact emotion (Di Simplicio, McInerney, Goodwin, Attenburrow, & Holmes, 2012; Holmes & Mathews, 2005) and motivation (May, Kavanagh, & Andrade, 2015). Mental imagery has been shown to evoke greater emotional impact than verbal-linguistic representations of the same information (Holmes, Lang, & Shah, 2009). Researchers have proposed that mental imagery can amplify the impact of cognition on emotion and exacerbate mood instability in both negative and positive directions, such as in bipolar disorder (Holmes, Geddes, Colom, & Goodwin, 2008). Interfering with imagery of desired stimuli weakens its emotional and motivational impact. This has been demonstrated to reduce cravings for both coffee (Kemps & Tiggemann, 2009) and cigarettes (Versland & Rosenberg, 2007). Successful disruption of cravings appears to require tasks that task the same sensory domains for example olfactory and visual in the examples above. Interference with tasks such as those involving working memory do not reduce cravings (Andrade, Pears, May, & Kavanagh, 2012).

Mental imagery has been shown to be causal in determining future behaviour (Libby, Shaeffer, Eibach, & Slemmer, 2007) and is a powerful lever towards wellbeing and adaptive behaviour (Holmes, Arntz, & Smucker, 2007). Imagery is more emotionally evocative than verbal thoughts with stronger links to affect (Holmes & Mathews, 2010). Imagining an event increases the likelihood of engaging in what is imagined (e.g. revising for an exam (Pham & Taylor, 1999)). Imagery is a stronger predictor of future behaviour than verbal thoughts (Libby et al., 2007). The frequency of craving imagery also predicts relapse and treatment dropout in inpatients being treated for alcohol dependence (Coates et al., 2017). Individuals who experience suicidal ideation often report 'flash-forward' detailed imagery (i.e. similar to the flashback imagery in post-traumatic stress disorder (PTSD), but instead involving future-oriented imagery) related to suicidal acts (e.g. Crane, Shah, Barnhofer, & Holmes, 2012). There is also potential for the flash-forwards imagery to increase the likelihood of action. Individuals who experience flash-forward imagery report more severe suicidal ideation than those who do not (Ng, Di Simplicio, McManus, Kennerley, & Holmes, 2016). The occurrence of suicidal 'flash-forwards' imagery significantly predicted suicidal intent in an inpatient sample (Ng et al., 2016).

Similarly, there is evidence that self-harm imagery is associated with self-harm enactment (Baker & Lewis, 2013). Specific features of self-harm imagery may relate to acting or not acting on self-harm urges depending on whether the imagery was appraised as aversive or comforting (Hasking, Di Simplicio, McEvoy, & Rees, 2018). More than 90% of individuals surveyed reported experiencing both thoughts and images during the urge to self-harm. The most frequent images when the urge to self-harm was acted upon were images of the anticipated injury,

followed by negative self-images and images of negative events. The most frequent images when the urge to self-harm was not acted upon were of the negative impact of themselves (including scars), followed by the negative impact on others such as parents reactions (McEvoy, Hayes, Hasking, & Rees, 2017). The occurrence of mental imagery of past self-harm acts has been found to frequently precede self-harm, particularly when the urge to self-harm is strong (Hasking et al., 2018). Emotion laden mental imagery of self-harm may play a role in motivating behaviours toward or avoidance behaviours away from self-harm (McEvoy et al., 2017). While verbal cognitions (i.e. rumination) were not found to be a significant moderator of the affect-self-harm relationship, the relationship between affect and self-harm was moderated by the use of imagery (Hasking et al., 2018). Furthermore most youth who self-injured reported thinking in images while the urge to self-injure was strong, with 53% thinking in images at least half of the time (Hasking et al., 2018). A recent review concluded that future research should further investigate the link between mental imagery and emotionally charged risky behaviours including self-harm and addiction (Ji, Kavanagh, Holmes, MacLeod, & Di Simplicio, 2019).

In addition to the role of internally generated images, a growing body of literature supports the notion that exposure to self-harm images in the media may be associated with increased self-harm (Baker & Lewis, 2013; Daine et al., 2013; Marchant et al., 2017). While self-harm is a largely hidden behaviour images of self-harm are commonly shared online, often anonymously with posters continuing to hide self-harm in the offline world (Rodham, Gavin, Lewis, Bandalli, & St, 2016). Thematic analysis of testimony regarding self-harm imagery online found that participants reported reduced loneliness and the use of images to curb self-harm urges on the one hand and, reinforcement, competition, encouragement and triggering of self-harm on the other (Baker & Lewis, 2013). Results of the previous systematic reviews regarding internet use and self-harm support the notion that images/videos may have both a positive and negative impact on individuals who self-harm (Daine et al., 2013; Marchant et al., 2017). The growing popularity of image-based platforms and high-profile stories of the risks of self-harm imagery online has given rise to an increase in research related to self-harm imagery online.

Aims and objectives

The aim of this review was to systematically review all research relating to the influence of images, encompassing photography, moving images/videos and creative imagery online related to self-harm/suicidal behaviour in children and young people (aged up to 25). This review focused on imagery across internet mediums and, whether certain aspects of images/videos are more likely to be perceived as positive or negative.

Method

Search strategy

Online content related to video/images has been included in previous systematic reviews (Daine et al., 2013; Marchant et al., 2017). The search strategy used previously has been revised in order to specifically identify research related to images. The decision was taken to search literature back to 1st January 1991 (the year the internet was made available as a public service) as opposed to simply updating the previous search (run on the 26th January 2015). This will provide the most comprehensive overview of existing literature.

The following sources were searched:

Core databases: CINAHL; EMBASE (excluding Medline journals); Psych info, SCOPUS and MEDLINE

Topic specific websites: Campbell; Centre for Mental Health; Department of Health; Mental Health Foundation; NHSPSS-NI; NHS Scotland; Royal College of Psychiatrists and Welsh Government

Meta-search engines: Google and Google scholar

Search terms were grouped into four categories:

Internet use: *Free text* "Aol" or "Askfm" or "Bebo" or "blog*" or "chat?room*" or "cyber*" or "discussion forum" or "e?communi*" or "e?material\$" or "Facebook" or "googl*" or "hashtag\$" or "instant messag*" or "internet" or "live chat*" or "live journal\$" or "MSN" or "Myspace" or "on?line" or "online" or "podcast*" or "social network*" or "spam*" or "tweet*" or "Twitter" or "troll" or "virtual*" or "web" or "whatsapp"

MESH terms. INTERNET, Social media, Social networking

Images non-specific to internet: *Free text.* "imag*" or "galler*" or "photo*" or "picture\$" or "video*"

MESH terms. Video recording

Images specific to the internet: *Free text.* “meme” or “Pinterest” or “Tumblr” or “vine” or “vlog*” or “YouTube” or “snap*” or “gif\$” or “selfie\$” or “Flickr” or “camera” or “filter” or “reddit” or “Instagram”

Self-harm and suicide: *Free text.* “Automutilation” or “Distress*” or “emotion*” or “NSSI” or “SIB” or “suicid*” or ((oneself or myself or self) adj2(cut* or harm* or hurt* or kill or injur* or mutilat*))

Mesh terms. ‘Self-injurious behaviour’, ‘stress, Psychological’

Terms were combined as follows (Internet AND images non-specific to internet terms) OR (images specific to the internet).

Self-harm and suicide groups combined with results from above search.

Selection criteria

Articles were included if they examined the online viewing or sharing of images/videos related to self-harm or suicidal behaviour or by individuals who experienced suicidal ideation or self-harm. Articles were required to include primary empirical data and be published in peer-reviewed journals. Results were not restricted by location however only English language papers were included. To be consistent with previous reviews news articles, review articles, single case studies, editorials, conference abstracts or other grey literature were not included. Reference lists of all review articles were manually screened for potential eligible papers.

Participants must be aged under 25 or have an average age of 24 years and under. If ages were not specified participants must be described as children, adolescents or young adults. Where articles examine more than one age group, only data for the age group fitting these criteria will be analysed.

Two independent reviewers manually screened titles. Any disagreements were resolved by consensus. Titles that clearly had no relevance, book chapters, conference abstracts and other grey literature were excluded at title screen. A record was kept of all discarded articles including the reason for exclusion. Duplicates were removed. The remaining titles with abstracts were then screened for eligibility by the same two researchers. Full text articles were obtained where suitability could not be determined based on the title and the abstract. Any

disagreements that could not be resolved through consensus were discussed with a third expert reviewer.

Data analysis

The data extraction sheet from the previous review (Marchant et al., 2017) was adapted to record specific findings from included articles (Appendix D). Additional fields were added to examine features specific to research into images/videos. For example, looking at whether the platform is moderated, whether trigger warnings were added, the nature of the images/videos and the impact on the viewer. Two reviewers independently extracted data for each study. Any inconsistencies in data extraction and quality scores were clarified by consensus or through discussion with a third expert reviewer.

The heterogeneous and largely qualitative nature of studies precluded any meaningful combination of study results through meta-analysis. Therefore, a narrative synthesis was employed. Based on published guidance (Popay et al., 2006) this narrative synthesis examined a number of key aspects. Comparisons were made regarding the way in which self-harm/suicidal behaviour related imagery was examined across studies and internet platforms. The influence of heterogeneity was explored further including differences in populations studied, differences between various platforms, measures employed, and outcomes studied.

Articles were amalgamated and grouped into categories. These categories were inductively generated following initial reading and data extraction of papers and were cross-checked by two members of the study team. Positive influences of viewing/sharing of images/videos were defined as indicating a perceived reduction in psychological distress, reduced suicidal ideation or self-harm, advice on how to seek help and encouragement to do so. Negative influences were defined as results indicating increased psychological distress, increased frequency or severity of self-harm or suicidal ideation, information on method of self-harm/suicide provided or encouragement of self-harm (Marchant et al., 2017). Positive and negative influences were examined in relation to population studied, internet platform (e.g. Instagram, Tumblr) and specific features of images/videos.

Quality of included articles was assessed according to the Critical Appraisal Skills Programme (CASP, 2013) as performed previously (Marchant et al., 2017). The CASP tool assesses various aspects of study design including population, sources of bias, method of data collection, clarity of results and appropriateness of conclusions. CASP does not specifically recommend any scoring or grading system. We adopted a scoring system developed and utilised previously

(Darlow et al., 2012) designating research fulfilling less than 50% of criteria as being of low quality, 50-75% as moderate quality and more than 75% being of high quality. No criterion were given higher weighting than others (Feder, Hutson, Ramsay, & Taket, 2006). No studies were excluded based on quality scores. Two independent reviewers for each paper conducted quality assessment.

A protocol for the systematic review was registered with PROSPERO (https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=148695).

Results

A total of 20 articles from 19 independent studies were included for review. Figure 1 shows the results of the search and screening process. Studies came from all over the world (USA n=7; Canada n=5; UK n=2; Germany n=2; Australia n=1; multiple countries n=3). There were four quantitative studies, nine qualitative and seven mixed methods. Eleven papers were rated as high quality, seven as moderate and two low quality. Eleven articles focused on videos, four focused on images and five included analysis of both. Articles were grouped into three categories: analysis of images/videos related to self-harm, perspective of individuals and, online interventions with a video component (Table 1). Thirteen articles (from 12 independent studies) reported an analysis of images and videos. Eight of these were rated as high quality, three moderate quality and two low. These reported on a range of platforms (YouTube n= 7; Instagram n=2; Tumblr n=1; Twitter n=1; multiple sources n=2). These will be described in more detail in turn below. Participants in these studies were largely the uploaders of content and with the exception of two studies (Avery et al., 2016; Poonai et al., 2018) contained more than 50% female participants. Age and demographics were often difficult to gauge from online profiles which were not always complete or may have been completed with an older than actual age in order to gain access to restricted content (R. Brown et al., 2018; Lewis et al., 2011).

Analyses ranged from analysing the content of images/videos to responses such as shares, likes, number or content of comments and inclusion of trigger warnings. While social media data such as that included here is often in the public domain and accessible to researchers via the terms of service of the site ethical guidelines recommend that consideration be made for anonymity and sensitivity (British Psychological Society, 2017) particularly with vulnerable groups such as children or individuals with mental health issues (Golder et al., 2017). Despite this, only three of the thirteen articles contained a statement that they had received Institutional Review Board

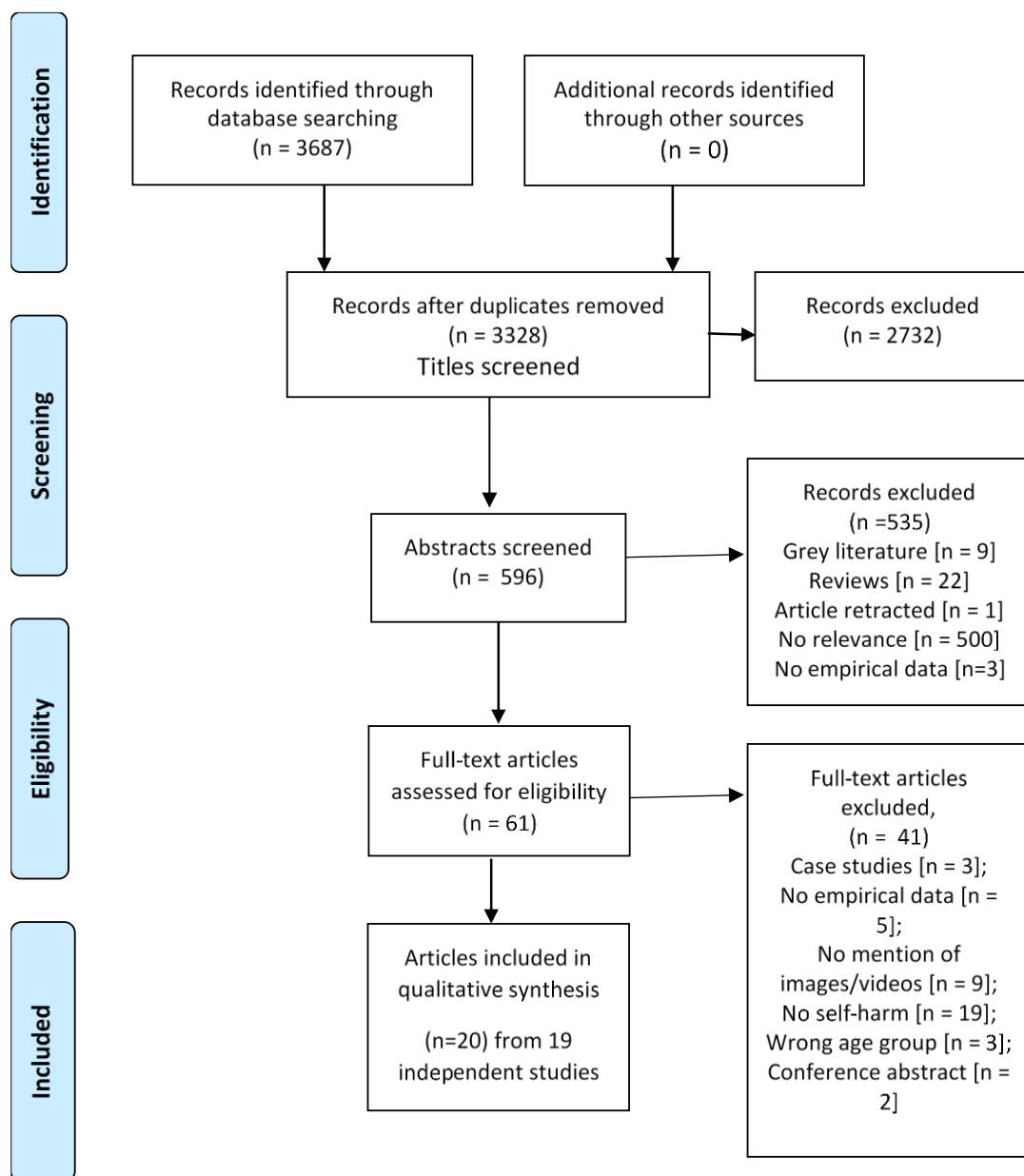


Figure 1 Results of search strategy

ethical approval. Seven articles did not include any discussion of ethical issues for example sensitivity in disseminating results or steps taken to protect the identities of individuals.

Table 1 Summary of included studies

Category	Author, year, country, Quality score	Participants/s ample	Aims and Objectives	Results
<i>Analysis of image /videos</i>	Avery, 2015, USA, moderate	50 videos depicting the fire challenge; 90% male; 64% African American	To understand the characteristics of the fire-challenge phenomenon in an effort to develop preventative and public safety measures	50 videos were selected. Of these, 13 videos included post burn footage. Of these burns, the median total body surface area was 4+-3% with a maximum size of 10%. Superficial and partial thickness burns were sustained on the torso (10/13, 77%), face (4/13, 31%), and extremities (2/13, 15%). Full thickness burns were seen in 2/13 videos. Young African-American Males were over-represented and should be targeted in prevention and intervention.
	Basch, 2017, USA, moderate	The top 100 videos related to bullying on YouTube with the greatest number of total views were identified.	To describe the extent to which content related to bullying is present of You Tube with respect to source, content number of views, length and year uploaded	The most common content was describing or depicting violence (n=89). Over one-half addressed getting help (n=56). Thirty-eight out of 100 videos mention Suicide.
	Brown, 2018, Germany, high	Posters of NSSI ^a pictures on Instagram (n=1152); majority anonymous; 91% of identifiable profiles female.	To analyse pictures directly depicting NSSI wounds on Instagram. Pictures comments and user accounts examined. The aims were 1) To systematically describe the extent of NSSI on Instagram in a German speaking population. 2) To describe online content of German speaking users.	Most pictures depicted wounds caused by cutting on arms or legs and were rated as mild or moderate injuries. Pictures with increasing wound grades and those depicting multiple methods of NSSI generated elevated amounts of comments. Most comments were neutral or empathetic with some offering help. Few comments were hostile. Pictures were mainly posted in the evening with a small peak in the early morning and on Sundays.

Cavazos-Rehg, 2016, USA, high	17 Tumblr accounts; of the 8 that provided demographic information 75% female	To gain a better understanding of the depression, self-harm, and suicidal content that is being shared on Tumblr.	17 Tumblr accounts posted a median number of 185 posts. Content was engaged with 1,677,362 times. Of the 3,360 randomly selected posts, 2,739 (82%) were related to depression, suicide or self-harm. Common themes were; self-loathing (412, 15%), loneliness/feeling unloved (405, 15%), self-harm (407, 15%) and suicide (372, 14%). Findings signal a need for suicide prevention efforts to intervene on Tumblr and use this platform in a strategic way.
Duggan, 2012, Canada, low	Demographics only available for uploaders of YouTube videos; n=5, 80% female	To simultaneously examine the scope and nature of NSSI content across informational/interactive websites, social networking websites and YouTube in order to provide mental health practitioners with a multifaceted description of online content related to NSSI	Peer-driven, informal websites have a variety of triggering content and are accessed more often than professionally driven services. NSSI is strongly represented among social networking websites and YouTube evidenced by large group memberships and video view counts.
Grzanka, 2014, USA, low	Content of 30 videos aimed at LGBT+ youth analysed	To investigate the mass-mediated 'It Gets Better' campaign against perceived increase in suicides among gay youth in the USA since Sept 2010. Study conducted a critical discourse analysis of a sample of 'It Gets Better' videos	Results reveal a neoliberal frame that places the burden of a better life onto the emotional lives of LGBT youth, who are instructed to endure suffering in the interest of inevitable happiness
Hilton, 2017, UK, high	Twitter users n=317; no information	To report the findings from a unique analysis of naturally occurring data regarding self-	Five themes were identified; 1) celebrity influence, 2) self-harm is not a joke, 3) support for and from others, 4) eating disorders and self-

	regarding gender	harm behaviour generated through the global social media site, Twitter	harm, 5) videos and personal stories. Less graphic imagery and more recovery oriented content on this platform.
Lewis, 2012 ^b , Canada, high	Uploaders of 100 NSSI videos on YouTube; 95% female	To examine viewers' comments and responses to NSSI YouTube videos to determine the potential risks and benefits of the videos.	The most frequent category of comments was self-disclosure (38%) with individuals sharing their own NSSI experiences. Followed by feedback for the video uploader, including video quality (22%), or message (17%) and admiration for uploader (15%) or encouragement for uploader (11%). The majority did not mention recovery at all (43%) and indicated they were still self-injuring (24%).
Lewis, 2011 ^b , Canada, moderate	Uploaders of 100 NSSI videos on YouTube; 95% female	To explore the accessibility and scope of NSSI videos online	The top 100 videos analysed were viewed over 2 million times, and most (80%) were accessible to a general audience. Viewers rated the videos positively and selected videos as a favourite over 12,000 times. The video's tones were largely factual or educational (53%) or melancholic (51%). Explicit imagery of self-injury was common. 90% of non-character videos had NSSI photos whereas 28% of character videos had in-action NSSI. For both, cutting was the most common method. Many videos (58%) do not warn about this content. Examination of NSSI material on YouTube revealed favourably rated and frequently viewed videos that were accessible

			and graphic and that were often creative, with an informal, melancholic, or hopeless message.
Lewis, 2015, Canada, high	40 uploaders of videos to YouTube; 83% female	To examine the nature of NSSI first aid tip videos shared through YouTube	40 NSSI YouTube videos were content analysed. Videos were viewed 157,571 times and typically favourably viewed. Most had a neutral purpose and neither encourage nor discouraged NSSI. Messages encouraging NSSI help seeking were scant. Medical help seeking was not commonly encouraged, with several videos providing "safe" NSSI instructions.
Moreno, 2016, USA, high	Posters of ambiguous NSSI hashtags on Instagram; 193 unique usernames in a sample of 201 posts; no information on gender	To evaluate the meaning, popularity and content advisory warnings relating to ambiguous NSSI hashtags on Instagram. 1) Present current data on ambiguous hashtags that may be common parlance related to NSSI. 2) Test a process to investigate ambiguous NSSI terms. 3) Evaluate the popularity of NSSI-related hashtags at two time points. 4) assess the precision of Instagram's warning labels for concerning content	Sample of 201 Instagram posts led to identification of 10 ambiguous NSSI hashtags. Results demonstrated a popular image that described the broader community of NSSI, and mental illness called #mysecretfamily that had approx. 900,000 search results at time 1 and 1.5 million at time 2. Only one-third of relevant hashtags generated content advisory warnings
Poonai, 2018, Canada, high	Population based time-series analysis utilising a national database. Ontario	To utilise interrupted time series analysis to examine whether the release of Amanda Todd's YouTube video	There was a significant increase in the monthly ED ^c visit rate for the composite outcome of death or ICU admission from April 2002-Dec 2013. There was no significant change in ED visit

User perspective

	patients aged 11-17 based on a sample of 4,775,658 ED visits; 49% female	following her death announcement in Oct 2012 was associated with an increase in average month ED visit rates for suicide-related diagnoses in Ontario children aged 11-17	rate for the composite outcome before and after announcement of Amanda's death. Findings suggest content was not associated with an increase in ED visits for suicidal behaviour
Singaravelu, 2015, UK, high	Searched only for websites. Target audience of websites described as young people. Initial search terms developed in discussion with six members of a CAMHs users group aged 15-19	To identify and analyse websites potentially accessed by young people about self-harm.	Sites accessed by self-harm/suicide search terms were mostly positive or preventative in tone, while sites accessed by the term 'ways to kill yourself' tended to have a negative tone. 314 websites included in analysis with evocative images of self-harm found in 21% of sites
Jacob, 2017, UK, high	21 individuals aged 16-24, living in Wales UK with a previous history of self-harm. Mean age for self-harm commencement was 13. Sixteen participants sought professional help, 8 presented to A&E for their injuries; 86% female	To explore how young people understand and use online images of self-harm using semi-structured interviews	Some individuals reported discovery of their self-harm through internet searching for a tangential topic, which lead to commencement of behaviour. The majority engaged with online spaces to support and further develop a pre-existing set of self-harming practices. Participants reported role of internet in normalising self-harm and images rather than textual interactions primary reason cited for using internet for self-harm purposes. Images were said to invoke a physical reaction and inspire behavioural enactment. Participants reported viewing self-harm images part of ritualistic practice

Videos as part of an intervention

Seko, 2015, multiple countries, high	Creators of NSSI creative content; N=17; 86% female	To conduct qualitative analysis of online interviews with 17 individuals who produce NSSI content. To understand why content creators create and share NSSI themed content and what needs are met by doing so	Thematic analysis of participants narratives identified two prominent motives; self-oriented motivation (to express self and creativity, to reflect on NSSI experience, to mitigate self-destructive urges) and social motivation (to support similar others, to seek out peers, to raise social awareness). Participants also reported a double-edged impact of NSSI content both as a trigger and a deterrent to NSSI
Sternudd, 2012, Multiple countries, moderate	Users of a self-injury forum: n=52; 87% female	To examine discourses about self-injury photos from a user's perspective.	Informants reported that viewing/sharing images had alleviating rather than triggering effects with production of images often about memory and proof and publishing them seen as a way of sharing experiences with others and to give/receive help. Self-injury photos described as a resource of a self-harm community culture. Informants often emphasized that the outcome of viewing these photos varies due to individual and situational differences
Choi, 2016, USA, moderate	University students: n=431; 78% female	To determine the feasibility of using a specific video in a web-based suicide awareness programme for Asian American and non-Hispanic white college students	Asian Americans rated the suicide awareness video significantly lower for cultural relevance than did non-Hispanic whites ($f=5.479, p=.020$). Collectivist cultural orientation was a significant predictor for cultural relevance, credibility and appeal. Cultural orientation and race/ethnicity should be strongly considered when web-based suicide awareness programmes are

			developed for college students
Park, 2014, USA, high	University students: n=650; 72% female	To determine the predictors of watching a web-based streaming video and whether data characteristics differed for those watching most or only part of the video.	Compared with the video non-completion group the video completion group included more females, undergraduates and Asian Americans, and had higher individualistic orientation and more correct manipulation check answers. Video non-completion group skipped items in a purposeful manner, showed less interest in the video and spent less time completing questionnaires
Robinson, 2015, Australia, moderate	Secondary school students: n=21; 81% female	To examine the safety and acceptability of an online suicide prevention programme, and determine which components were found to be most helpful and enjoyable.	21 young people completed the intervention. Overall, the intervention did not lead to increases in suicidal ideation or distress. Participants reported enjoying the programme, in particular watching the video diaries and completing the activities. Most participants said they would recommend the programme to a friend.
Scherr, 2017, Germany, moderate	Journalism students: n=78; 69% female	To examine the impact of a suicide awareness video on adherence to newspaper reporting guidelines; video intended to be utilised for web-based format	Awareness material exposure helped to improve responsible reporting of suicide with the awareness video showing the strongest effect.

- a. *Non-suicidal self-injury*
- b. *Emergency Department*
- c. *Analysis of same set of YouTube videos one study examining content of videos themselves the other analysing the comments*

Three articles examined the perspectives of individuals on the impact of sharing and viewing images/videos of self-harm online (Jacob et al., 2017; Seko, Kidd, Wiljer, & McKenzie, 2015; Sternudd, 2012). Two articles were rated as high quality and one as moderate. Each used a different method of collecting qualitative data. Online questionnaires (Sternudd, 2012), online interviews (Seko et al., 2015) and semi-structured face-to-face interviews (Jacob et al., 2017) were used to collect participant discourses about self-harm photographs and creative content. All three articles had samples made up of over 80% females.

Four articles reported on the results of interventions using videos or with a video component (Choi et al., 2016; H. Park et al., 2014; Robinson et al., 2015; Scherr, Arendt, & Schafer, 2017). All articles included a sample made up of more than 50% females. One of these articles was rated as high quality (H. Park et al., 2014) and three as moderate (Choi et al., 2016; Robinson et al., 2015; Scherr et al., 2017). One article reported on the potential for a video to be used to improve responsible reporting of suicide in journalism students (Scherr et al., 2017). Three reported on the use of videos in suicide/self-harm prevention or intervention for young people of which two focused on 'The Truth About Suicide Video' (Choi et al., 2016; H. Park et al., 2014) and one reported on an intervention with an online video component (Robinson et al., 2015). Potential for positive impacts was found in all four papers reporting on potential interventions.

Content across platforms and discourse

Platform's varied in the degree of graphic imagery. Singaravelu et al. (2015) found that results from internet searches varied based on the search terms used. The term 'ways to kill yourself' elicited a high proportion of sites with evocative images (46%). Search results from searches using the terms 'self-harm' or 'suicide' returned sites with mostly positive or preventative tones and a smaller proportion of sites with evocative images ('self-harm' 13%, n=7/54; 'suicide' 25%, n=13/52). Photographs in an image gallery on one peer moderated site were found to document self-harm incidents often accompanied by text detailing battles with self-harm, substance abuse and mental health issues (Duggan et al., 2012). One paper examined the content of twitter posts related to self-harm (Hilton, 2017). This analysis included 674 tweets from 317 accounts with 18 pictures and seven videos. Posts where images were featured in addition to text included posts of celebrity tattoos covering self-harm scars along with the message 'Stay Strong.' This is said to represent the individual's journey of recovery. Another included image was a mock advert for stick on self-harm scars. Whilst likely intended as a joke, reactions to this image were disgust and anger that self-harm was being made into a joke. Posts showed discussion of the hashtags #Cut4Bieber and #Cut4Harry. These were

campaigns from 2013 in which fans protested celebrity behaviour such as smoking marijuana with self-harm. While the hashtags were discussed, no images or evidence of the campaign was found in these posts and many conveyed disapproval for the campaign. Seven video links were found in this sample of posts. These were mostly of individuals telling their stories. Such stories included stories of bullying leading to self-harm and attempted suicide, a story of attempting to find help for self-harm and songs about self-harm and body image. One video was a short advertisement for a play about self-harm. The video conveyed hope and graphically showed a man heavily scarred on his torso and arms. In the last video a musician discusses self-harm and attempts to inspire fans into channelling feelings into healthier pastimes.

Image-based platforms

A number of image-based platforms were discussed in qualitative interviews and explored in studies examining content. Two articles examined self-harm content on Instagram (R. Brown et al., 2018; Moreno, Ton, Selkie, & Evans, 2016). Both found a considerable presence of self-harm content. One article examined ambiguous self-harm hashtags (e.g. selfharmmm) (Moreno et al., 2016). At the time this study was conducted Instagram blocked users from searching for the hashtag #selfharm. The terms of use discouraged posting photographs of self-harm stating that warnings would be placed on such content. The terms of service have since been revised (Instagram, 2019). As a result of these restrictions a number of ambiguous hashtags emerged allowing users to bypass the terms of service and continue to share and search for self-harm photographs. Identified hashtags included #selfinjury, #blithe and #ehtilb. The number of search results for each hashtag grew substantially over the course of 150 days (Moreno et al., 2016). This study also revealed a wider group of hashtags referring to a range of mental health issues encompassed under #mysecretfamily. There were hashtags referring to a range of mental health issues including depression (#dep), anxiety (#annie), obsessive-compulsive disorder (#olive) and self-harm (#cat). This group of hashtags was present across multiple social media sites including Twitter, Tumblr and Facebook (Moreno et al., 2016). R. Brown et al. (2018) examined self-harm photographs over a four-week period. Wounds of mild or moderate severity made up the majority of photographs with pictures mostly uploaded in the evenings. Half (n=3291, 50%) of comments on posts related to self-harm were part of a more general discussion, with 12% (n=770) asking the poster to stop self-harming (R. Brown et al., 2018).

Tumblr was examined in one study (Cavazos-Rehg et al., 2016). Eight percent (n=220) of posts were comforting, supportive or related to prevention. Posts interacting with other users made up 9% (n=249) of posts. Of these more than half were seeking or providing advice (51%

n=127/249) and almost half (47%; n=117/249) provided emotional support. Of those seeking or providing advice 41% (n=52/127) provided positive support/advice. Potentially harmful advice was given in 25% (n=32/127) of these posts including advice on how to secretly engage in self-harm. In addition, Tumblr was frequently reported as the preferred platform in one qualitative interview study (Jacob et al., 2017). This preference was reported to be due to the amenability to sharing of images, straight-forward searching function, perceived anonymity and a lack of moderation and intervention, particularly when compared to other social networking sites. This provided a freedom to post and access the most severe and stark photographs of self-harm (Jacob et al., 2017). Some participants reported that this led to normalisation and exacerbation of self-harm from superficial cuts to severe injuries (Jacob et al., 2017).

Video-based platforms

Eight articles (from seven independent studies) included an analysis of YouTube videos. Five articles (from four independent studies) examined videos focused on self-harm (Lewis, Heath, Sornberger & Arbuthnott, Duggan et al., 2012; 2012b; Lewis et al., 2011; Lewis & Knoll, 2015). Visual representations of self-harm were found to be common, however in one article two out of five videos contained an anti-self-harm message and encouraged viewers to seek help (Duggan et al., 2012). Analysis of 100 videos found that videos were often educational, most with a neutral purpose with the next most common purpose to discourage self-harm (Lewis et al., 2011). Comments of this set of videos were most commonly sharing personal experiences (38%). Positive comments included words of encouragement. There were no significant differences in the types of comments based on whether the video was character (filming of an individual) or non-character (typically a series of images with a soundtrack), number of views or video rating (Lewis, Heath, Sornberger et al., 2012b). Twenty-eight percent of videos related to first aid for self-harm injuries included a disclaimer stating that provided certain safety precautions are followed self-harm is 'acceptable'. Over half (55%) of videos related to first aid for self-cutting and 28% (n=11) related to self-burning recommended medical help-seeking (Lewis & Knoll, 2015). One article focused on a YouTube video of a young person holding up cards that told a story of bullying, mental health issues and self-harm with a photograph of the individual's self-harm injuries at the end. This video received considerable media attention after the individual took her own life. A time series analysis did not find any significant association between the onset of attention to the video and emergency department attendance for self-harm in 11-18 year olds (Poonai et al., 2018).

The remaining three articles examined YouTube videos varying in content. One article examined 'fire challenge' videos in which an individual douses themselves in flammable liquid, sets themselves alight and attempts to extinguish the flames before serious burns are inflicted (Avery et al., 2016). Burns inflicted in the videos tended to be less severe than a hospital recorded case. As such the authors suggest that videos in which more severe burns are inflicted may not be uploaded masking the danger of this challenge. This is the only article in the current review where the majority of participants were male (90%; n=45) (Avery et al., 2016). One article examined videos related to bullying examining number of views, year of upload, length of video, source and content. Suicide was mentioned in 38/100 of these videos. There was no analysis into the nature of discussions around suicide or the impact on viewers (Basch, Ruggles, Berdnik, & Basch, 2017). The content of the 'It Gets Better' campaign was examined in one paper (Grzanka & Mann, 2014). This was a campaign consisting of a number of videos aiming to discourage suicide in LGBTQ+ youth. Videos were uploaded by activists, politicians, celebrities and the public and were often focused on individuals telling their own stories of overcoming difficulties such as bullying and prejudice, stressing that these difficulties pass, and that suicide is not the answer. There was no evaluation of whether this campaign was effective (Grzanka & Mann, 2014).

Negative emotional reactions and impacts

A range of emotional reactions to viewing or sharing of images/videos are described (Table 2).

Anger and hostility to images/videos were reported in three articles (R. Brown et al., 2018; Hilton, 2017; Lewis et al., 2012b). Other emotional reactions included sadness, shock, concern (Choi et al., 2016; Sternudd, 2012), and ambivalence simply viewing photographs to pass time (Sternudd, 2012).

Exacerbation of self-harm, normalisation, and competition

Images having the potential to exacerbate self-harm through competition, normalisation, exposure and imitation was described. One study participant reported that imagery had led to an exacerbation of self-harm from superficial gashes to severe injuries, while another reported marking out the desired length and width of cuts on her skin prior to harming herself (Jacob et al., 2017). Participants in all three qualitative interview studies reported a sense of competition (Jacob et al., 2017; Seko et al., 2015; Sternudd, 2012) with reports of the need to make wounds worse to be a valid 'self-injurer' (Sternudd, 2012). Several reported receiving negative comments from others when they posted photographs that did not show more severe injuries or

sophisticated techniques (Jacob et al., 2017). Individuals reported desiring to emulate depicted self-harm (Jacob et al., 2017) with negative feelings regarding not being able to harm themselves as severely as the injuries shown in the photographs (Seko et al., 2015). A strong correlation between male informants and negative statements was found in one study with 4/5 statements being negative, for example expressing competitive reactions (Sternudd, 2012).

Table 2 Summary of emotional reactions and impacts of viewing/sharing videos/images

Impact of image or video		Findings reported
Emotional Reactions	<i>Anger/hostility</i>	Spoof advertisement on Twitter for stick-on self-harm scars evoked reactions of anger and frustration (Hilton, 2017)
	<i>Other emotions</i>	Some hostile comments about an uploader of self-harm content (7%) were found in comments of YouTube videos (Lewis et al., 2012)
	<i>Ambivalence</i>	A small percentage of comments of self-harm related Instagram posts were coded as abuse (7%, n=450) (Brown et al., 2018)
	<i>Empathy</i>	The reaction from viewing self-harm photographs varied considerably between informants and may be dependent on the individuals' state of mind when they are viewed. A wide range of feelings were covered in responses, including being sad, sick and shocked. Reactions like depression, grief and concern for themselves was stated (Sternudd, 2012).
	<i>Solidarity and reduction in loneliness</i>	Common reactions reported after viewing a suicide prevention video included sadness, surprise and shock, and feeling overwhelmed. Almost 40% of participants indicated that they were most affected by the real, personal stories of family and friends of those who had taken their own lives (particularly the impact of suicide on the lives of the people left behind) or individuals who had survived a suicide attempt (Choi et al., 2016).
Exacerbation of self-harm urges/behaviour	<i>Triggering</i>	Dramatic responses are not always reported when viewing self-injury photos, with some reporting it can be done to pass time (Sternudd, 2012)
	<i>Competition</i>	Empathetic comments made up (24%) of comments on Instagram posts (Brown et al., 2018);
	<i>Imitation</i>	Many participants spoke of feeling empathy with content creators when viewing images related to self-harm. Several participants

		also addressed the internet as their only source of support or connection where they could receive empathetic reactions and emotional support (Seko et al., 2015)
Reduction in self-harm urges	<i>Calming</i>	Empathy and sympathy were common reactions to a suicide prevention video (Choi et al., 2016)
	<i>Use as a deterrent</i>	Participants reported the viewing of photographs as comforting since they made them feel less alone (Seko et al., 2015; Sternudd, 2012)
	<i>Emotional outlet</i>	Participants describe others feeling less alone in their battle as a motivation for sharing images (Sternudd, 2012)
	<i>Giving and receiving help</i>	Nearly three quarters of interview participants reported that imagery (notably photographs) were the primary reason for their utilisation of the internet, due to a powerful physical reaction that triggered the desire to self-harm. Reliance on the image as a trigger had led to images assuming a vital role within their ritualistic practice with 'sessions' often commencing with retrieval of an online image. The power of the image primarily centred on their ability to 'bring back memories' of previous self-harm or the ease with which they allowed the individual to envisage how others experience the act. Participants also reported looking at images deliberately to trigger more severe self-harm (Jacob et al., 2017)
Feedback or discussion of creative content		Participants often discussed the triggering role of images. Many stated that whether an image would trigger an act depended on mood at the time. It was commonly expressed that photographs of flesh, open wounds with blood are more triggering than pictures of scars and healing wounds (Seko et al., 2015).

Triggering of self-harm

Participants in qualitative interviews describe the potential for images to 'trigger' the urge to self-harm. This refers to an increase in self-harm urges, which can be brought on by an event, experience, or in this case viewing of images. While participants report that images were not always triggering, the potential for images to trigger self-harm urges was reported in all three qualitative interview articles (Jacob et al., 2017; Seko et al., 2015; Sternudd, 2012). Whether material was triggering was said to be dependent on the mood at the time with participants reporting both a triggering and alleviating effect of images which varied from time to time

(Sternudd, 2012). If an individual was already determined to self-harm then looking at images would push them that little bit further whereas if they were in a positive mood the images would not have much of an impact (Seko et al., 2015). Participants reported viewing of images as a ritualistic practice with 'sessions' commencing with the viewing of an image. Participants report viewing images to be deliberately triggered prior to self-harm in order to self-harm more severely (Jacob et al., 2017).

Graphic Imagery

Participants in semi-structured interviews reported that images rather than text-based interactions were the primary reason for using the internet for self-harm purposes (Jacob et al., 2017). The nature of images was important in terms of outcomes. 'Bluntly gruesome' photographs such as those of flesh, open wounds and blood (Sternudd, 2012) were said to be more triggering than pictures of scars and healing wounds (Seko et al., 2015). The degree of graphic imagery present varied across platforms. A study of search results returned by various self-harm/suicide search terms found that results of searches varied based on the terms used. Search terms such as 'self-harm' and 'suicide' returned sites with a largely preventative tone. The search term 'ways to kill yourself' elicited a high proportion of sites with evocative images (47%; n=20) (Singaravelu et al., 2015). Visual representations of self-harm are common in YouTube videos with the majority of videos included in one study showing severe and open wounds, and acute scarification with one character video including three clips of suicide attempts (Duggan et al., 2012). This is further supported by analysis of 100 YouTube videos finding that 64% of videos include images of self-harm. Live acts of self-harm were included in 28% of character videos (Lewis et al., 2011).

Analysis of Tumblr posts related to self-harm/suicide found that 18% (n=127) were graphic images or video clips (Cavazos-Rehg et al., 2016). A large number of self-harm photographs were posted daily on Instagram, with images ranging in severity. Of 2826 photographs 93% depicted cuts, 40% were rated as mild in severity (i.e. superficial scratches), 48% as moderate (i.e. deeper cut, blood flowing) and 13% as severe (i.e. very deep cut or large amount of deeper cuts and blood) (R. Brown et al., 2018).

Social contagion

The potential for social contagion was examined in two articles (R. Brown et al., 2018; Poonai et al., 2018). Several possible markers of social contagion or imitation were examined on Instagram

including comments on photographs and a time-related analysis of posts. Pictures directly depicting wounds generated twice as many comments than those not depicting wounds and more severe wounds generated more comments (R. Brown et al., 2018). The authors suggested that this could point towards a socially reinforcing function of posts. This is supported by participants reporting exacerbation of self-harm over time in qualitative interview studies (Jacob et al., 2017; Sternudd, 2012). However, time-related analysis of images did not show any evidence of social contagion or reinforcement (R. Brown et al., 2018). Similarly a separate time series analysis did not find any associated with increase in average monthly emergency department visit rates for suicide-related diagnoses in Ontario children aged 11-18 following publicity around a young person's YouTube video after their apparent suicide (Poonai et al., 2018).

Positive emotional reactions and impacts

Positive emotional reactions included empathy, sympathy and people both giving and receiving help. These were found across various platforms and as a result of awareness videos (R. Brown et al., 2018; Choi et al., 2016; Seko et al., 2015). Self-harm photographs were said to provide a feeling of solidarity and reassurance of not being alone and were described as a resource of the self-harm community (Seko et al., 2015; Sternudd, 2012).

Participants often reported creating images for artistic value, for their own interest and for memory and proof. Photographs were said to form part of a narrative likened to fading scars (Sternudd, 2012). Some participants in relation to both creating and viewing images reported a reduction in self-harm urges. Content creation acted as an alternative outlet for negative emotions, with those who create drawings, poems and videos in particular describing the materials as a form of art that portrays the feelings behind self-harm. Positive feelings were reported when content was re-blogged (Seko et al., 2015). Viewing of images could act as a deterrent or provide a placebo effect reducing the urge to self-harm (Seko et al., 2015).

Recovery oriented content

Platforms contained varying degrees of recovery-oriented content. Recovery oriented content appeared to be most common on Twitter with no graphic imagery found and instead photographs alongside inspirational quotes, positive messages and stories of recovery. Similarly, video links on Twitter did not contain graphic content and were more often individuals sharing their stories (Hilton, 2017). A small percentage of comments on YouTube videos encouraged the uploader to seek help (2%). Some comments indicated that the individual was seeking treatment

(10%), had recovered (7%) or expressed a desire to recover (4%) (Lewis et al., 2012b). Professional help or therapy was suggested in 13% (17/127) of Tumblr posts providing advice.

Prevention and intervention

Trigger warnings

Trigger warnings are placed on content by either the uploader, platform or moderator and are intended to warn individuals that the content may increase self-harm urges. Four articles exploring the content of images/videos included an analysis of trigger warnings. In a study examining self-harm content across platforms both peer and professionally driven sites were examined. Both peer-moderated sites contained trigger warnings including one site that contained an image gallery. No graphic material was present on the professionally driven sites and as such, no trigger warnings were present. Signposting to sources of information and advice were present on all three sites (Duggan et al., 2012). Facebook and Myspace groups were both found to contain photos, video links and artistic content. Three out of five Myspace groups contained trigger warnings and two prohibited graphic material. Only one of the four Facebook groups examined contain a trigger warning, despite the presence of photographs and videos depicting either actual self-injury or artistic content in the majority of groups (Duggan et al., 2012). In relation to YouTube videos trigger warnings were found on four out of five YouTube videos in one article (Duggan et al., 2012). Only two of 40 self-harm first aid videos contained a trigger warning (Lewis & Knoll, 2015). Two articles (based on one independent study utilising a single dataset of 100 videos) reported that 58% of self-harm related YouTube videos did not warn about content, despite the presence of graphic imagery and live acts of self-harm (Lewis et al., 2012b; Lewis et al., 2011). There were few comments suggesting that the content was triggering (Lewis et al., 2012b).

In addition to user or moderator generated trigger warnings are content advisory warnings provided by some platforms. At the time of study, searches for self-harm content on Tumblr first directed to a screen with suggestions for seeking help or finding more inspirational content with the option to proceed to viewing search results (Cavazos-Rehg et al., 2016). Instagram contained several pop-ups of advisory warnings for potentially harmful content. When examining ambiguous self-harm hashtags six of eighteen generated an advisory warning of which two directed to information related to eating disorders (Moreno et al., 2016).

Four articles reported on videos as part of an online intervention. All four articles reported potentially positive impacts. Two articles reported on different aspects on 'The Truth about Suicide' suicide awareness video both of which found video streaming a feasible method for delivering a suicide awareness program to college students (Choi et al., 2016; H. Park et al., 2014). Predictors of watching the 29-minute video to completion were female gender, undergraduate, Asian ethnicity and higher individualism as opposed to collectivism (H. Park et al., 2014) measured using the individualism-collectivism questionnaire (Singelis, Triandis, Bhawuk, & Gelfand, 1995). Participants expressed a higher awareness of the signs of depression, the need to take immediate action and, to talk openly about suicide after watching the video (Choi et al., 2016). The video had considerable impact on participant's thoughts and feelings regarding suicide. The importance of an effective debriefing session in creating a safe and confidential setting for sharing thoughts, feelings and experiences, and in preventing iatrogenic effects of web-based suicide prevention programmes using emotionally charged videos was emphasized and was successfully delivered online (Choi et al., 2016). Asian American students rated the video significantly lower on cultural relevance than non-white Hispanic students and participants reported an interest in the effects of depression in different cultural backgrounds (Choi et al., 2016). While results were positive, overall some small increases in distress were found (H. Park et al., 2014).

The safety and acceptability of an online suicide prevention programme incorporating video elements in secondary school students was examined in one study (Robinson et al., 2015). Overall, the intervention did not lead to increases in suicidal ideation or distress and 71% of participants rated the video diaries component as more enjoyable and helpful than hearing from website moderators or receiving text messages (Robinson et al., 2015). The impact of a suicide awareness video as part of a web-based intervention to increase adherence to newspaper reporting guidelines was examined in another study. Participants were randomly allocated to three groups, written material, awareness video or control group with no awareness material. Awareness material exposure with or without the video helped to improve responsible reporting of suicide measured with a fictitious suicide and reporting exercise. Awareness material was found to decrease the word count of negative elements ($F(2, 74) = 3.51, p = .04, \eta^2 = .09$) and to increase the word count of positive elements ($F(2, 74) = 3.12, p = .05, \eta^2 = .08$). The awareness video showed a stronger effect than the written material (Scherr et al., 2017).

Discussion

This review systematically reviews the literature related to the impact of sharing or viewing self-harm imagery online on children and young people aged 10-24. This review also updates the previous literature review related to internet use and self-harm in children and young people (Marchant et al., 2017). Twenty articles from 19 independent studies were included, 13 analysing images/videos, three examining the perspectives of people who view or share self-harm imagery online and four related to the use of videos and potential for online suicide prevention efforts. The greater level of detail related to images, videos and individual platforms present in this review has allowed for the identification of specific features of both platforms and images that are likely to influence the impact on the viewer/sharer of material than possible previously.

Internet use centred around images appears to be becoming more popular in young people who self-harm. While self-harm forums were once popular with young people and researchers alike, there has been a move away from these in recent years, both in terms of use by individuals and utility in research, to social media and image based platforms (Harris & Roberts, 2013; Jacob et al., 2017). Image-based platforms have been suggested as providing enhanced intimacy and decreases in loneliness compared with text-based platforms (Pittman & Reich, 2016). Young people who self-harm are often socially isolated and this increased intimacy may partly underlie the preference for image-based platforms. Participants who self-harm report image rather than text-based interaction as the primary reason for internet use (Jacob et al., 2017). Studies consistently report a large presence of self-harm imagery across platform's including social networking platform such as Facebook and Myspace (Duggan et al., 2012), video streaming platform's (Lewis et al., 2011) and image-based platform's such as Instagram and Tumblr (R. Brown et al., 2018; Cavazos-Rehg et al., 2016). In contrast, graphic material does not appear as frequently on Twitter. While images and videos were present, these were not graphic in nature and were more often shared alongside messages of hope and recovery (Hilton, 2017). The difference between platform's was further supported by an analysis of randomly generated posts found with the #cutting hashtag across platforms. Instagram posts were found to display the greatest proportion of graphic content, with the smallest proportions found on Twitter (Miguel et al., 2017). Potentially harmful content appears to congregate on platform's that have relatively little moderation, where participants can remain anonymous and search for images easily (Jacob et al., 2017).

A range of emotional reactions, intentions of content creators and impacts upon viewers were reported in relation to posting and viewing images of self-harm. These ranged from empathy, a sense of solidarity and the use of images to give or receive help (R. Brown et al., 2018; Seko et al., 2015) to potentially harmful advice, suggesting new methods and tips for hiding self-harm, as well as normalisation and exacerbation of self-harm (Jacob et al., 2017; Sternudd, 2012). Reactions of anger, hostility and ambivalence were also reported (R. Brown et al., 2018; Hilton, 2017; Lewis et al., 2012b). The creation of images as a creative outlet and viewing images as an alternative to self-harm were reported as positive impacts in two articles (Seko et al., 2015; Sternudd, 2012). Graphic images were sometimes said to provide a placebo or alleviating effect negating the need to self-harm by some participants (Jacob et al., 2017; Sternudd, 2012). However, photographs of fresh cuts or severe injuries were most frequently reported to have a negative impact (Jacob et al., 2017). Participants in all three studies examining user perspectives reported viewing of self-harm images to be part of ritualistic practice to provoke the right mood for self-harm (Jacob et al., 2017; Seko et al., 2015; Sternudd, 2012). Participants report viewing graphic self-harm imagery online to be deliberately 'triggered' into more severe self-harm (Jacob et al., 2017). Participants report that viewing more severe injuries leads to negative feelings for not being able to achieve the same level of injury or leading to more severe injuries over time (Jacob et al., 2017; Sternudd, 2012) with one participant describing marking out the desired length and width of injuries prior to self-harming (Jacob et al., 2017). Photographs of fading scars or creative content were most often reported to have a positive impact (Seko et al., 2015; Sternudd, 2012) and were often shared alongside messages of recovery (Hilton, 2017).

Differences in messages related to the nature of images has been found in a further analysis of self-harm related photographs on Flickr (Seko, 2013) and Tumblr (Seko & Lewis, 2018). Of the photographs posted on Flickr around 35% showed fresh injuries (gaping wounds, blood) with more than 80% showing scars or healing wounds. Uploads of fresh injuries served as a record of life events and memorabilia for catharsis worth remembering. Uploaders of scars and healing wounds utilised photography as a medium to tell a story, symbolizing the painful experience and healing process (Seko, 2013). Of 294 images included in the analysis of images on Tumblr equal proportions referred to hopeful/pro-recovery and hopeless themes (29%, n=86). Of the 86 hopeful/pro-recovery images direct self-injury images appeared in 38, most often depicting scars or healing wounds rather than new or bleeding injuries. Eight of the images showed a tattoo over scars alongside a story of recovery. This is in keeping with research finding that self-injury scars appear to symbolise resilience and inner strength (Lewis & Mehrabkhani, 2016). Of the 86 images related to hopelessness 21 were direct self-harm images, in contrast with those

related to hopeful/pro-recovery messages the majority of self-injury images with a hopeless narrative were close-up shots of fresh, bleeding injuries accompanied by a caption emphasizing negative feelings. Also, of note is that hopeless messages were more prevalent in indirect than direct self-injury photographs. These images were most often black-and-white character photographs and gifs with the individuals faces hidden, turned away, crying, anxiously smiling or signalling a negative emotional state. The images were said to represent a sense of loneliness, hopelessness and vulnerability associated with self-injury. These indirect images received almost 10 times more re-blogs than images depicting self-injury.

When examining results of searches self-harm/suicide related terms were found to return sites with a positive or preventative tone with less graphic imagery whereas the search term 'ways to kill yourself' brought up a high proportion of graphic imagery (Singaravelu et al., 2015). It has been found subsequently that individuals vary in their internet searching behaviour dependent on level of suicidal intent with those with lower levels of distress searching in a more disorganised fashion and those with high levels of intent showing purposeful internet use, avoiding social interaction and targeting searches for information regarding suicide methods (Biddle et al., 2018). Taken with the higher proportion of graphic imagery associated with searches for 'ways to kill yourself' and the propensity for graphic imagery to trigger more severe self-harm in those already feeling distressed as reported in qualitative interviews here (Jacob et al., 2017; Sternudd, 2012) the internet could be a potentially harmful place for those at crisis point.

There was some evidence of a role of social contagion and reinforcement, driven in part, by number of comments and reactions to self-harm imagery with photographs of injuries generating more comments, with a significant correlation between wound severity and number of comments (R. Brown et al., 2018). The potential for social reinforcement and contagion was supported by statements in qualitative interviews with participants stating a desire to emulate self-harm depicted in photographs and experiencing negative feelings when not being able to harm themselves as severely or, receiving negative reactions from others after posting photographs of less severe injuries (Jacob et al., 2017; Sternudd, 2012). In one study males were found to be more likely to express a negative impact such as competitive reactions (Sternudd, 2012). However, the small number of males included make it difficult to draw any broader conclusions. The potential for social contagion or reinforcement was not supported by time series analyses conducted in two studies (R. Brown et al., 2018; Poonai et al., 2018). However,

images can be searched or viewed long after they are posted so any process of reinforcement is difficult to assess.

While time-related analyses do not suggest social contagion in the studies included in this review, recent studies related to the release of the TV series *13 Reasons Why* and associated social media activity have found associations with a significant increase in adolescent suicides (Bridge et al., 2019; Niederkrotenthaler et al., 2019). This series was released via an internet streaming service meaning that the series could be viewed at any time after the release date and viewers had the option to watch many episodes in succession. Search queries related to suicide were found to be cumulatively 19%(95% CI 14-24%) higher for the 19 days following the release of *13 Reasons Why* reflecting 900,000 to 1.5 million more searches than expected. The queries with the biggest increase were those focused on suicidal ideation for example 'how to kill yourself' (Ayers, Althouse, Leas, Dredze, & Allem, 2017). Such terms have previously been found to be associated with national suicide rates (Hagihara et al., 2012) and to return more search results with graphic imagery (Biddle et al., 2016; Singaravelu et al., 2015). Queries related to hotlines and public awareness (e.g. suicide prevention) also increased (Ayers et al., 2017). While *13 Reasons Why* appears to have raised awareness it also may have increased suicide ideation.

It has been further demonstrated that self-harm related hospital admissions were higher than predicted following the release of *13 Reasons Why* (M. T. Cooper, Bard, Wallace, Gillaspay, & Deleon, 2018). While this does not demonstrate causation this temporal evidence contributes to an existing evidence base of the relationship between the media's portrayal of suicide and increases in suicidal behaviour (e.g. Hawton et al., 1999b). An interrupted time series analysis also demonstrated that the release of *13 Reasons Why* was associated a significant increase in monthly suicide rates amongst 10-17 year olds in America. The authors estimate that the release of the first season of *13 Reasons Why* was associated with approximately 195 additional deaths in 2017 for 10-17 year olds (Bridge et al., 2019). An immediate increase in suicides beyond the generally increasing trend was observed among 10-19 year olds in the 3 months following the shows release. Increases in suicide deaths following the release of the series was found to be concordant with the period in which social media discussions of the series were greatest (Niederkrotenthaler et al., 2019). The negative effects of the show could have been curtailed or reduced by adherence to the World Health Organisations media guidelines for preventing suicide, such as removing scenes showing suicide or including suicide hotline numbers in each episode (WHO, 2017). Analysis of paediatric patients notes in a large healthcare system found

31 patients where *13 Reasons Why* was explicitly documented in their notes. All but one reference took place during an encounter related primarily to the patient's mental health and 71% of these patients make these references during an encounter related to suicide. Fifty-five percent of references were of the patient or guardian reporting that the show contributed to their worsening mental health symptoms (Adler & Adler, 2007). Some patient presentations included thematic references to the show, including two patients who described explicitly writing lists of 13 reasons why they should kill themselves and two describing altering their appearance to resemble a character on the show. In contrast on two occasions a patient described viewing the show as a coping mechanism for their mental health issues (Adler & Adler, 2007). The show's producers have subsequently removed the graphic scene following concerns from suicide prevention agencies (Voelker, 2019).

Strengths and limitations

This review provides a comprehensive overview of studies directly examining self-harm images (encompassing photographs, videos and creative content) online with relation to children and young people. The potential for publication bias exists in any review of the literatures. Steps were taken here to minimise bias. An extensive literature search was conducted of multiple databases including topic specific websites. Reference lists were reviewed to identify any further studies. Two researchers screened texts and abstracts and data extraction was conducted by two researchers for each article to further reduce potential sources of bias. Inclusion of papers was not restricted by country however only English language publications were included. This review focused exclusively on children and young people. Articles that examine self-harm imagery online in the population as a whole or just in adults have not been included in this review. As such, it is not possible to examine the impact of such images on older age groups or to draw any comparisons between the impact of images/videos between older and young generations.

Accurately determining characteristics and demographic information of young people based on online profiles is not always possible. The average age of participants is likely to have been younger than reported as young people often misrepresent their age online to gain access to age restricted content (e.g. Lewis & Baker, 2011). Where demographic information was available females outnumbered males in almost every study with the exception of two papers. One of these described videos related to the fire challenge in which 90% of posters were young males (Avery et al., 2016). The second articles described time-series analysis of emergency department attendances in which 49% of patients were female (Poonai et al., 2018). One article reported

that males were more likely than females to report negative impacts of self-harm images such as competitive reactions (Sternudd, 2012). However, the limited number of males included makes it difficult to draw any conclusions related to any sex differences in the impact of viewing or creating self-harm imagery. More research into potential sex differences and involving larger samples of males is needed to examine this further.

Implications

Clinicians working with young people who self-harm should routinely enquire about internet use when assessing individuals (Padmanathan et al., 2016). Clinicians should work with young people to help them to recognise the situations where content may be triggering or lead to more severe self-harm, and to help them to manage this or encourage them to develop healthier online behaviours. Based on the results of this review it appears that graphic imagery of fresh or severe wounds, whilst acting as a placebo for some individuals, have the greatest potential for harm in terms of worsening of self-harm (Jacob et al., 2017). Creative content or images of scars, particularly alongside messages of hope and recovery, appear to have the greatest potential for positive impacts (Seko et al., 2015). Clinicians could engage in discussion not just about whether or not individuals view or share imagery, but also the nature of this and help them to recognise the potential for harm and to redirect to behaviours that could be more positive. The powerful role of imagery in evoking emotional reactions and motivating both potentially harmful behaviours such as self-harm (Hasking et al., 2018) and adaptive behaviour (Holmes et al., 2007) could make this an important factor in recovery. Future research should ensure recruitment of males and focus on delineating the specific features of images that may be harmful.

A small number of articles examined the use of videos disseminated online as a means of intervention. Given the large self-harm community around image/video-based platform's, further research into potential interventions is needed to fully understand how to maximise effectiveness. Research is increasingly showing that young people who self-harm extensively utilise image-based media and platforms. There is an opportunity for prevention and intervention messages to reach young people here that is not currently being optimised. Creating positive content that young people will engage with has potential to reach a large audience who could benefit from additional support, information and intervention. Meaningful co-production of such content with young people would likely have advantages in terms of making engaging content and targeting this at the platform's and populations who would benefit the most. In addition, images have been reported to be used as a way of asking for help

and support (Seko et al., 2015). Intervention and prevention agencies could target efforts towards image-based platforms to ensure that help is available when an individual reaches out in this way. Interventions online should also consider targeting by search term. Search terms indicating higher suicidal intent such as 'ways to kill yourself' were found to bring up higher proportions of sites depicting graphic imagery (Singaravelu et al., 2015) and such searches are more likely in individuals with higher suicidal intent (Biddle et al., 2018). Targeting intervention or prevention strategies on the results of these searches has the potential to reach individuals in significant distress. Preferential returning of search results related to support and information alongside moving of sites containing graphic imagery lower down in search results could have a positive impact.

Young people are increasingly utilising images to tell their stories. Content creation as an alternative outlet for negative emotions, and the viewing of images acting as a placebo or deterrent, could be explored as a potential intervention. Increasingly it is being suggested that educational programmes should be developed to teach young people about the impact of the content of posts, and how to respond to distressed posts on social media (Duggan et al., 2012; Robinson et al., 2017). This represents a potentially important step in preventing suicide contagion via the media. The use of videos in suicide prevention strategies appeared to be promising, not just for young people themselves but also in improving responsible reporting of suicide in journalism students (Scherr et al., 2017). Since young people are frequently creating their own content, strategies to increase safe and responsible reporting of suicide/self-harm in the media are now needed to educate young people as well as media professionals. Individuals reported an awareness of the potential impacts of self-harm images/videos and add trigger warnings to their own posts (Jacob et al., 2017). Initiatives could be developed to build on this and to equip young people with the skills to analyse and evaluate their own creative content and, to highlight the potential for posts intended as catharsis and therapy for themselves to be potentially harmful to vulnerable individuals. This could improve the safety on image-based platforms.

The results must be discussed in the context of recent changes in policy by platforms, including Facebook, Instagram and Tumblr, regarding the posting of graphic self-harm imagery. Changes were made following the death of a young person in February 2019 and the subsequent campaign by the family. Instagram announced a ban on all images of self-harm, including pictures showing scars (Instagram, 2019). Particular features of platform's that make them more amenable to harmful use include a lack of moderation and ease of sharing, searching and

viewing of images (Jacob et al., 2017). Furthermore, it appears that existing automated platform content warnings may not have been sufficient, with just six of eighteen self-harm-related hashtags bringing up Instagram's content warnings, two of which redirected to information related to eating disorders (Moreno et al., 2016). Monitoring and regulations on posts may be a positive move towards making these spaces safer. However, young people often find ways around posting restrictions, such as by utilising ambiguous hashtags (Cavazos-Rehg et al., 2016) or moving to more hidden parts of the internet.

While increased restrictions could be positive in terms of safety, the potential for posting restrictions to reduce positive impacts, such as support and sense of community, must also be considered, as should any potential negative impacts of removal of content posted by vulnerable young people without consultation. Banning images of scars may have the unintended consequence of increasing stigma or removing the opportunity for individuals to share their stories, including those related to recovery. There could also be unintended consequences of indiscriminate removal or blurring of images of people with injuries and scars including those not related to self-harm such as people recovering from surgery. This could negate the potentially positive impact of fading or healing self-harm scars. While the results of this review support concern related to safety and exacerbation of self-harm, the potential for positive impacts should not be underestimated. Future research should seek to evaluate the effectiveness of current posting restrictions and to identify the best strategies to reduce risk and maximise positive impacts on participants incorporating user perspectives. This supports previous calls to better understand how to leverage the unique opportunities afforded by such platform's to reach and engage vulnerable individuals (Miguel et al., 2017).

Not all platforms with the potential for sharing of images were covered by this review and no articles were identified examining the role of Google Images or similar search engines. Google Images has not seen the same restrictions applied to searches for self-harm imagery as social media platforms. While the main Google search engine ensures that results related to helplines and information appear at the top of searches for suicide or self-harm, this restriction has not been applied to Google Images. There is no community or sharing function on Google Images reducing the potential for positive impacts related to a sense of community and support. It also is not moderated in the way that social media sites are. Typing 'self-harm' into Google Images brings up a collection of images from across other sites and searches can be made more specific to search for either severe and stark images or for scars and inspirational content. This is a powerful tool and appears not to have been the focus of this kind of research.

This review has also highlighted potential ethical issues with use of social media data for research. Whilst the terms of service on many social media sites state that data can be accessed and used by third parties including researchers, questions have been raised over whether it is ethical to utilise data just because it is available and readily accessible (Boyd & Crawford, 2012) with issues around informed consent and the right to withdraw. Anonymization procedures are still evolving for this kind of data and there are difficulties around anonymizing text extracts (Narayanan & Shmatikov, 2008, 2009). Concerns have been raised over republishing of quotes that can be searched and may lead back to the original poster (British Psychological Society, 2017) which is further complicated by research centred around images. Several papers include examples of images and screenshots of searches. Given the sensitivity of these images, additional care should be taken to reduce the potential for anonymity to be breached. It has been emphasized that special consideration should be given to data from vulnerable groups including children and adolescents and individuals with mental health issues (Golder et al., 2017). The number of articles that did not mention any ethical considerations in this review is a cause for concern particularly given the age and vulnerability of participants. Future research should fully consider ethical concerns around implied consent, privacy, anonymity and sensitivity in reporting and disseminating results.

Conclusions

The increasing preference of the use of image rather than text-based interactions with regards to self-harm online has given rise to a number of new concerns, and a number of new potential avenues for intervention, prevention and support. Research supports concerns over the potential for negative impacts of images. This included the use of images as part of a ritualistic practice, 'triggering' of self-harm, normalisation, sharing of new methods, concealment of self-harm and exacerbation of self-harm over time. However, there are also potentially positive impacts such as seeking and receiving help and support, viewing images as alternative to self-harm and creation of content as an outlet for negative feelings. Impacts of images appear to vary dependent on the nature of images with graphic images and photographs of fresh and severe injuries most often reported have a negative impact. Such images appear to be more prevalent on image-based platform's such as Tumblr and Instagram than other platform's such as Twitter, which contains more recovery-oriented content.

Clinicians working with young people who self-harm should enquire about internet use as a routine part of their assessment (Padmanathan et al., 2016). Where there is indication of use related to self-harm clinicians should enquire about the types of internet sites and platform's

that are accessed, with an awareness for stimuli that may increase risk of self-harm, as well as helpful sites. Discussions should also include whether individuals create, view or share imagery related to self-harm, the nature of this imagery and the potential impact on their wellbeing. Redirecting individuals from viewing of potentially harmful material to use of imagery as an alternative outlet for negative feelings or directing to more positive content could also be recommended by clinicians. Education could be given to clinicians and caregivers on how to direct to healthier online behaviours. Education could also be given to young people on how to maximise the potential benefits of using images whilst minimising harm to vulnerable viewers of content. Images and videos have the potential to reach a large audience and have a substantial impact online, however this opportunity for intervention does not appear to have been fully utilised as yet and is an area worthy of future study. Future research should also seek to evaluate the effectiveness of posting restrictions on social media, with meaningful co-production with young people necessary to fully evaluate the impacts of these restrictions.

3.3 CHAPTER SUMMARY

This chapter describes two systematic reviews related to internet use and self-harm in children and young people. A comprehensive overview of this literature was necessary as a knowledge base to inform the development of the platform, the analysis of the media databank (both of which will be described in Chapter Four) and, to identify any issues to be examined further in the Big Data and Mental Health Research Survey described in Chapter Five. Given the speed at which literature in this area is developing two systematic reviews were necessary. Review One (Marchant et al., 2017; Appendix A) gave an overview of internet use and self-harm in children and young people. Results of this review were largely supportive of previous earlier reviews and further built on previous work allowing internet use to be broken down into different mediums (social media, internet addiction, blogs etc). In support of other reviews a double edged nature of internet use was found with potential positive influences in the form of community and crisis support and, negative influences in the form of triggering material, normalisation and encouragement of self-harm.

Young people are increasingly using images to communicate their stories with image rather than text based interactions often the primary reason for internet use in young people who self-harm (Biddle et al., 2013; Biddle et al., 2016). Viewing and sharing of images online are an increasingly important part of the lives of young people (Feierabend et al., 2016). Taken with the high profile change in posting restrictions for self-harm related imagery in 2019 (Instagram, 2019) meant that a timely review of the literature specifically related to viewing/sharing of self-harm

images/videos online made for both a valuable contribution to the literature, and added to the knowledge base for the development of this project. As such Review Two systematically reviewed literature on viewing/sharing of image/videos online in children and young people who self-harm (Marchant et al., 2020b; Appendix C). Literature supports concerns over the potential harms of self-harm imagery online with evidence for triggering material, sense of competition, use of images as part of 'ritualistic practice' in self-harm and worsening of self-harm over time found. However positive influences were also found such as the use of images as an alternative outlet for negative feelings, the opportunity to tell stories including those related to recovery and the opportunity to give and receive help. This appears to be dependent on the nature of images with fresh cuts and severe wounds most often found to have a negative influence and images of scars and creative content most likely to have a positive influence. Specific features of platforms also have a role with easy searching of images, perceived anonymity and a lack of moderation contributing to potentially harmful online environments. It is important that concerns over safety are balanced with the potential benefits of such imagery and that issues of censorship and stigma are not overlooked in any restrictions in place on image-based platforms.

Results of these reviews have been used to inform the development of the SHARE UK platform. This has included issues to be aware of when running the social media campaign for recruitment and the development of the media databank (for example, using stock images to represent uploads, described in further detail in Chapter Four). Results of these reviews also went on to inform the issues explored in the Big Data and Mental Health Research Survey described in Chapter Five with ethical issues around the use of social media data and an awareness of special consideration for images forming an important part of the narrative of this piece of work.

4 SHARE UK: AN ONLINE PLATFORM FOR SELF-HARM RESEARCH

4.1 AIMS AND OBJECTIVES

The aim of this section of the study was to establish a pilot online platform for self-harm research. This platform will have a number of functions.

1. To function as a questionnaire delivery platform, hosting a small number of standardised questionnaires. These questionnaires measure self-harm, compulsive internet use, levels of both online and offline social support, peer influence and experience of shame.
2. To host a participant-built and maintained databank of online resources utilised by individuals who self-harm. The utility of such a platform and its potential for use in future research will be explored.
3. To consent individuals to be contacted for future research studies effectively creating a research register of individuals who have experience of self-harm.
4. To explore the possibility of consenting individuals for linkage with routinely collected data via this website.

4.2 METHOD

Ethical approval and information governance

The Swansea University Ethics Committee granted approval for this study (approval number 40715).

Participants were required to give informed consent to take part in this research. Due to the potential for any dual consent model to be abused when consent is given online, participation was not open to those below 16 years of age in keeping with British Psychological Society guidelines regarding internet mediated research (British Psychological Society, 2017). Participants were briefed and debriefed via the platform (copies of brief, consent forms and debrief in Appendix E). Consent forms, information and debrief were kept as clear and brief as possible (British Psychological Society, 2017). Individuals who self-harm represent a vulnerable group of participants. As such, the platform provided access to basic information in a friendly and appropriate language. Contact details of The Samaritans were present on several pages of the website including the frequently asked questions (FAQ), contact us and debrief page. It was made clear at registration that participation is voluntary and, should participants feel distressed

in any way they should withdraw and contact a recommended source of help. Participants were able to leave the study at any time and doing so would bring up a copy of the debrief form where contact details of Samaritans were included. Participants were informed prior to partaking that results of individual questionnaires would not be displayed. Summaries of findings were disseminated via a newsletter and social media as research progressed. There were no known pre-existing relationships between the research team and participants.

Description of participants

As described above participants were required to be aged 16 and above to take part in this research. There was no upper age limit for participation. Both male and female participants were welcome to take part. For the purpose of this study, individuals who self-harm or have self-harmed in the past were recruited. Self-harm is defined as intentional self-poisoning or self-injury, irrespective of the nature of motivation or the degree of suicidal intent (NICE, 2012). This definition is necessarily very general because the nature of motivation or degree of suicidal intent is complex and may vary over time or between individuals. Selection of participants who fit the criteria was based on self-report from participants themselves. While an online platform has the potential to reach individuals from all over the world at the initial pilot stage participation was limited to those living in the UK. This was made clear in the study information and social media campaign. Participants were asked to indicate their location at sign-up using a checkbox format for the four nations of the UK. There were no other restrictions placed on participants. There was no upper limit for sample size.

Setting

Participation took place entirely online via the platform. This allowed participants to take part anonymously without having to travel. It also made it possible to incorporate the media databank.

Construction of the platform

A web-development company were employed to construct and design the web site. Construction of the platform consisted of an initial design stage followed by user testing, feedback and redesign prior to launch. The website was developed utilising WordPress. The interface elements of the site are a combination of Hypertext Markup Language (HTML), Cascading Style Sheet (CSS) and Personal Homepage Tools PHP. PHP is used to control how

everything within WordPress interacts and how it connects with a MySQL database. CSS is utilised for website styling, HTML is the structure that the functions created in PHP, and styling defined by CSS are built around. The web site was hosted via Amazon Web Servers due to the high level of data security provided.

Figure 2 and Figure 3 show the participant flow through the platform. From the home page potential participants can view: the 'About us' page which gives more details about the members of the study team; 'FAQs' which outline answers to what we anticipated would be common questions including what to do if the participant is feeling distressed; 'privacy policy' which gives details of how data is protected; the 'contact us' page which also signposts to Samaritans and encourages participants to seek help if they are feeling distressed and, the SHARE UK blog page. This page was incorporated to increase rankings on internet search engines and, provide an additional reason for individuals to visit the site. Blog pieces were written focused on the work undertaken through the platform. Participants can also choose to 'learn more' which will bring them to the study information below which they can choose to sign up to the study. Participants could sign up either by providing their name or email address or using the 'sign-up with Facebook' button which will provide this information. No information was posted to Facebook on behalf of participants with this function being incorporated only to streamline the sign-up process. At sign-up participants were asked if they are based in Wales, England, Scotland or Northern Ireland and are asked to confirm that they are aged 16 or over. When a participant clicks 'sign-up' a pop-up appears asking if they consent to be contacted for future research studies. If they click 'yes' the name and email address provided are added to the research register.

Following this, participants are brought to their own user area (Figure 3) where they can update personal details and answer further questions regarding internet use, and self-harm. From here, they can fill out questionnaires or add resources to the media databank. There was also a link to 'leave study' that participants could select to leave the study. This would remove any personal details from the study database and took participants to the participant debrief form.

Recruitment of participants

A social media campaign was launched in order to recruit participants. This approach has previously proved highly effective at recruiting difficult to reach participants such as children with chronic genetic disabilities (Close, Smaldone, Fennoy, Reame, & Grey, 2013) and individuals with HIV (Yuan, Bare, Johnson, & Saberi, 2014) who may face stigma and other barriers to taking

part in research. The use of social media to recruit participants has not only previously proved highly effective in terms of recruitment but also cost and time efficient when compared with traditional recruitment approaches.

For the purpose of recruitment to this study several social media platforms were utilised (Facebook, Instagram, Twitter, Tumblr and Reddit). Across platforms study specific accounts were maintained which formed links with relevant organisations and other groups in order to attract relevant followers who may be interested in taking part in the study. These accounts posted information relevant to the study but also other information of interest including news articles and memes raising awareness for mental health issues and self-harm and sharing posts from other users and relevant organisations such as the Samaritans. Research animations and posters were created and shared across platforms. It was important to engage with users and respond to comments and messages whilst returning 'follows' and sharing relevant posts. These accounts required maintenance to ensure they were active and vibrant, in order to keep individuals interested and to facilitate the spread of information. It was also important to avoid technical language and keep all material accessible to a general audience. Due to the sensitive nature of this area of study, particular care was taken not to post any potentially triggering or harmful information with particular care taken with imagery. Comments and messages were responded to with sensitivity and care. Posts were focused on sharing of information and raising awareness of self-harm.

In addition to the social media campaign, contact was made with voluntary organisations to gain support including mental health and self-harm support groups. Contact was made with groups known to have higher rates of self-harm such as LGBTQ+, eating disorder and substance misuse support groups. This included local mental health support groups, LGBTQ+ groups, organisers of events such as World Eating Disorders Day, and drop in centres. Groups posted information via social media and advertised on various websites. Posters, leaflets and business cards were designed and distributed to be put on display at groups and events. Blog pieces were written and published by a number of large mental health charities including the NCMH and Papyrus. The study was also publicised through local mental health and LGBTQ+ events with stalls, posters and information.

Collection of data via platform

The website was launched on 1st September 2017. The final extract of data was taken on the 27th January 2020. During registration, the following information was taken from participants:

age; gender; number of hours spent online in the previous week; number of hours spent online in the previous month; and if they had ever had contact with GP, emergency department, hospital, or social care for any reason and specifically for self-harm (check box format).

www.share-uk.co.uk homepage. Use tabs at top of page to navigate to 'about us', 'FAQs', 'Your privacy', 'Blog' and 'contact us'

Click learn more or scroll down for study information and sign up

About SHARE UK

SHARE UK is a government-funded charity that aims to help people who self-harm. We are currently looking for people to take part in our research. This research will help us to find out what works best for people who self-harm. We need people who have never had any contact with social care, emergency services or hospital for self-harm. We need people who are aged 18 or over and who live in the UK.

What's involved?

Participating in our research will involve a number of steps. First, you will need to complete a consent form. Then, you will need to complete a questionnaire. This questionnaire will ask you about your self-harm and your feelings. You will also need to complete a series of questionnaires that will help us to understand what works best for people who self-harm. You will also need to complete a series of questionnaires that will help us to understand what works best for people who self-harm. You will also need to complete a series of questionnaires that will help us to understand what works best for people who self-harm.

What do we mean by self-harm?

Self-harm is when you hurt yourself on purpose. It can be done in many ways, such as cutting, burning, or hitting yourself. It is not the same as suicide. People who self-harm are often in pain and need help. We want to help people who self-harm by finding out what works best for them.

Who can take part?

Anyone who is aged 18 or over and who lives in the UK can take part in our research. We need people who have never had any contact with social care, emergency services or hospital for self-harm. We need people who are aged 18 or over and who live in the UK.

Sign Up

We promise to never post or Facebook on your behalf

Full Name (Last, First, Middle Initial)

Phone Number

Email

Confirm Password

Sign Up

Future Studies

There are always new studies and studies in the future. We will contact you if you are interested in taking part in any of these studies. You will be able to choose whether you want to take part in any of these studies. You will be able to choose whether you want to take part in any of these studies. You will be able to choose whether you want to take part in any of these studies.

Figure 2 Participant flow through SHARE UK website from homepage to sign-up

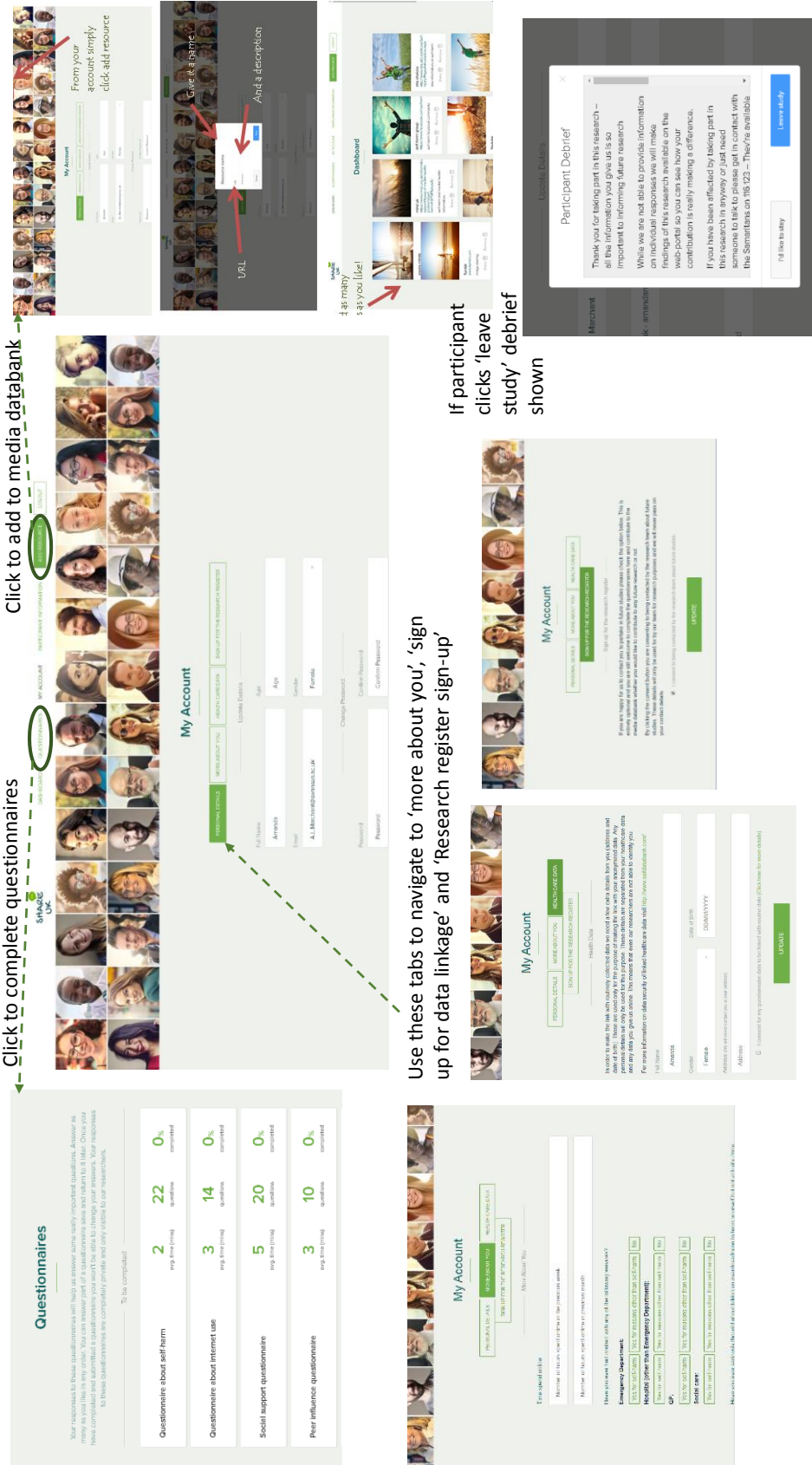


Figure 3 Participant flow through SHARE UK website from participant homepage

Participants were given the option to consent to being contacted by members of the research team to partake in further research. This was optional and did not affect their participation in the current study. Participants were able to contribute data via questionnaires and the media databank (described in further detail below). Participants could also consent to linkage of their data with routinely collected healthcare data here.

Standardised questionnaires

A number of standardised questionnaires were made available on the platform for completion. The hosting of these questionnaires was moved to Survey Monkey (www.surveymonkey.com) for the final six months of the project due to ongoing technical issues. Survey Monkey was chosen for hosting of questionnaires due to its user-friendly format, data security and functionality for participants to submit responses anonymously. It is also possible to give participant information, consent forms and debriefs using Survey Monkey if participants prefer. Participants were given the option of which questionnaires to answer and in which order to do so. At this initial pilot stage of the project seven questionnaires were included. Permission was sought from the authors of each individual questionnaire before they were included on the web page. Participants were free to cease completion of questionnaires at any time without penalty. The following questionnaires were included:

Compulsive Internet Use Scale (CIUS) (Meerkerk, Van Den Eijnden, Vermulst, & Garretsen, 2009). This scale measures internet enjoyment, usefulness, anxiety and self-efficacy. There is a full 40-item version and an abbreviated 14-item version. For this study, the abbreviated version 14-item version was utilised to maximise questionnaire completion rates. This abbreviated scale consists of 14 statements related to internet use (e.g. 'do you ever feel like you should use the internet less often') to be answered on a four-point scale from zero (never) to four (very often). Scoring is completed by summing scores for each item with a possible range of 0-54. A cut-off point of 21 has been recommended for identification of problematic internet use (Guertler et al., 2014). According to (Meerkerk et al., 2009) the CIUS has good internal consistency, with a Cronbach's alpha coefficient reported of 0.89. In the current study, the Cronbach's alpha coefficient was 0.93.

Self-Harm Inventory (SHI) (Sansone, Wiederman, & Sansone, 1998). The scale consists of 22 items in a yes/no self-report format. The inventory screens for lifetime prevalence of 22 self-harm behaviours, detects borderline personality symptomology and measures past mental healthcare utilisation. This scale also measures substance abuse, disordered eating and risky

sexual behaviours. This scale compares favourably against other scales in terms of range of thoughts/behaviours considered, psychometric properties and ability to score over a range of severities (Latimer, Covic, & Tennant, 2012). In previous work, a cut off of five or more was indicative of borderline personality disorder, and had good psychometric properties when compared to structured clinical interviews (Sansone, McLean, & Wiederman, 2008). The SHI is scored by summing the number of 'yes' responses giving a maximum possible score of 22. According to (Latimer, Meade, & Tennant, 2013) the SHI has good internal consistency, with a Cronbach's alpha coefficient of 0.80. In the current study, the Cronbach's alpha coefficient was 0.79.

Perceived Social Support Index (Procidano & Heller, 1983). There are two parallel versions of the index, one for family (PSS-Fa) and one for peer/friend support (PSS-Fr). This index measures the degree to which participants feel that their needs for support are fulfilled by their friends and family members. Items include those related to the availability of closeness and confiding and on getting ideas about how to solve problems. It also includes two items on social companionship. This scale has seen several adaptations related to internet use. For example the PSS-Fr has been adjusted to examine social support specific to the support received over social networking sites (Woo, 2017), Facebook (Arseneault, 2012), and mobile phones (Chen, 2007). For the purpose of this study, an adapted version of the PSS-Fr scale was utilised to examine perceived social support by online and offline peers using two parallel versions of the scale. Each version of the scale contains the same items modified to specify offline or online friends (e.g. 'my online friends provide me with the support I need' compared with 'my offline friends provide me with the support I need'). This version of the scale has been utilised in previous research (Michal, 2013) and was chosen to compare perceived online and offline social support. Each version of the scale has 20 items each of which can be answered with 'yes', 'no' or 'don't know. Answers indicating perceived social support are scored as '1'. Answers not indicating perceived social support or responses of 'don't know' are given a score of '0' giving a possible range of scores from 0-20. Higher scores indicate higher perceived support. Both the PSS-Fr offline and online scales have been previously shown to have good internal consistency (PSS-Fr offline Cronbach's alpha = 0.89; PSS-Fr online Cronbach's alpha = 0.91 (Michal, 2013)). In the current study Cronbach's alpha coefficient for PSS-Fr offline was 0.86 and for the PSS-Fr online 0.90.

The Barratt Impulsiveness Scale (BIS-11) (Stanford et al., 2009). This 34-item questionnaire assesses motor, cognitive and non-planning impulsiveness. This is the one of the most widely

used instruments for the assessment of impulsiveness. A score of 75 or higher likely indicates an impulse control disorder, while those with pathological impulsivity often score between 70 and 75 points. The BIS-11 has been shown to have good internal consistency (Cronbach's alpha 0.83 (Stanford et al., 2009)). In the current study, Cronbach's alpha coefficient was 0.89.

Experience of Shame Scale (ESS) (Andrews, Qian, & Valentine, 2002). This is a 25-item self-report measure that assesses varying degrees of characterological shame, behavioural shame, and bodily shame. Items for each shame area address experiential, cognitive and behavioural components. Participants are asked to indicate their answers on a 4-point Likert-scale. Scores are calculated by summing the values for all items giving a possible range of scores from 25-100. This scale can be divided into three subscales: characterological shame, behavioural shame and bodily shame. The ESS has good been previously found to have good internal consistency with a Cronbach's alpha coefficient of 0.92 (Andrews et al., 2002). In the current study, Cronbach's alpha coefficient was 0.94.

Resistance to Peer Influence Scale (RPI) (Steinberg & Monahan, 2007). This measure presents respondents with a series of 10 pairs of statements and asks them to choose the statement that is the best descriptor. After indicating the best descriptor, the respondent is then asked whether the description is 'really true' or 'sort of true'. Responses are rated on a four-point scale. Scores are calculated by dividing the sum of total items by the number of items with valid responses giving a maximum possible score of 4. Higher scores indicate greater resistance to peer influence. The RPI has good been previously found to have good internal consistency with a Cronbach's alpha coefficient ranging from 0.70-0.76 dependent on sample (Steinberg & Monahan, 2007). In the current study, Cronbach's alpha coefficient was 0.82.

Media databank

In addition to the standardised questionnaires, participants were able to upload sources of online information/influence to the media databank for use by the research team. This was designed to be a user-friendly Pinterest style format; however, no social networking or sharing of information was permitted between individuals. This was due to the variable quality of uploaded sources of information and risk of sharing potentially harmful information. Participants were asked to upload anything they look at online related to self-harm including both helpful and potentially harmful resources. Participants were able to add their own comments with each upload. Each time a participant uploaded an item to the media databank a randomly generated image was used to add to their 'dashboard.' Images from the websites

themselves were not used due to the potentially harmful nature of these. Beneath each randomly generated image was the description of the site the participant had added; however, links were disabled. This was done as a safety precaution so that the media databank could not be used to compile links to harmful information or potentially triggering sites. For an example of a participant dashboard, see Figure 4.

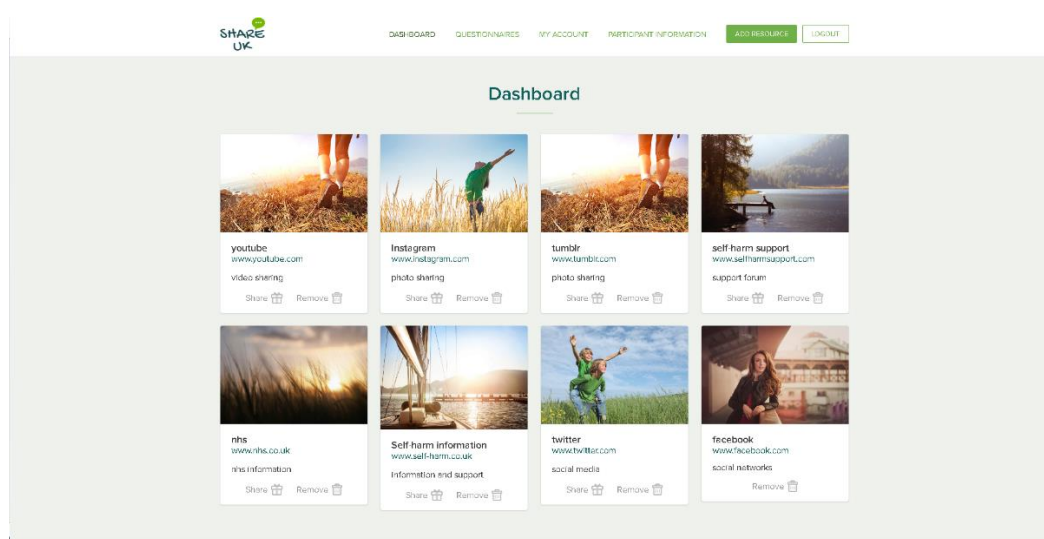


Figure 4 Example of participant dashboard

Data analysis

Participant data

Data collected via free text responses that could be meaningfully interpreted as continuous or discrete categories was cleaned. For example, responses to hours spent online per week/month were all converted to numerical data (e.g. 'eighty hours', '80+' or '80?' converted to '80'). Answers that were not meaningful (e.g. 'lots', 'don't know') were removed. Extreme outliers (>1000 hours reported per month n=2) were also removed.

Basic descriptive details of participants were analysed including sex, age and location in the UK. Questions answered at registration and the further information sections were analysed, and the range and average number of hours spent online per day/week was calculated. For all proportions 95% confidence intervals were estimated by Wilson score with continuity correction (Newcombe, 1998).

Cronbach's alpha was used to assess the internal consistency of the standardised questionnaires. These scales were summarised by the mean and standard deviation of each scale. Spearman's rho correlation coefficient was used to assess the strength of the linear

associations between questionnaire scores, age and number of hours spent online per week/month. Between group comparisons of questionnaire scores were calculated using Mann-Whitney U tests where individuals were divided into two groups (e.g. gender). Between group comparisons were calculated using Kruskal-Wallis tests where individuals were split into three or more groups. For example, to examine the relationship between questionnaire scores and individuals who have had not had contact with health and social care services, those who have had contact for reasons other than for self-harm and those who have been in contact with health or social care related to self-harm. Data analysis was conducted utilising SPSS V.22.

Analysis of uploads to media databank

Uploads were examined and categorised into source type (e.g. social media, app, website), image/video based or other, whether the tone of the site was pro-self-harm or preventative, whether the site was a support site, charity, peer or professionally run/moderated. Comments were examined for positive or negative impacts. Positive influences were defined as indicating perceived reduction in psychological distress, reduced suicidal ideation of self-harm advice on how to seek help and encouragement to do so. Negative influences were defined as results indicating increased psychological distress, increased frequency or severity of self-harm or suicidal ideation, information on method of self-harm/suicide provided or self-harm behaviours being encouraged. These definitions are in keeping with those in the previously described systematic reviews (Marchant et al., 2020b; Marchant et al., 2017). The content of comments was examined for indications of the way in which information has been used. For example, use of medical information to inform self-harm/suicide methods.

Alongside the content inputted by participants, websites were accessed and analysed for content. Websites often consist of multiple pages with links to other content and as such, it is not practical to analyse all pages on any one site. In keeping with previous research, only the landing page/exact URL given by participant was analysed for content (Singaravelu et al., 2015). Where a participant gave the name of a website without specifying a page then the landing page was analysed (e.g. mind.org.uk). If a participant gave a URL to a specific part of site (e.g. the Mind self-harm information page) then the page specified by the URL was analysed. A coding frame was developed based on previous research (Singaravelu et al., 2015) and informed by the previous systematic reviews (Marchant et al., 2020b; Marchant et al., 2017) to examine the content (copy of coding frame included in Appendix F). This coding frame combined information given by participants with information taken directly from website URLs where these still directed to a valid webpage and where the information was not available based on the data

participants had given. Participant given information was used preferentially over information taken directly from sites due to the potential for sites to change over time, particularly given the changes in social media sites policies regarding self-harm imagery (Instagram, 2019). Any discrepancies between what participants report and what was viewed on the sites visited were recorded.

4.3 RESULTS

Description of participants

A summary of participant demographics is provided in Table 3. A total of 498 individuals signed up between 01.09.2017-27.01.2020 of which 85%(95% CI 82-88; n=425) signed up to the research register and 15%(95% CI 12-19; n=76) consented to having their data linked with routinely collected healthcare data. Over sixty per cent of participants provided information of gender of which 84%(95% CI 80-88; n=267) were female. Less than a quarter of participants gave information on their age (mean age 29.7[SD10.7]). Children and young people aged 16-24 made up the largest group (38% [95% CI 30-48; n = 45]) followed by those aged 25-34 with those age 55 or over making up less than 2% of participants. Location data was given by 85%(95% CI 81-88; n = 422) with the majority of participants located in England (70%[95% CI 65-74; n=294]) and Wales (21%[95% CI 17-25; n=87]). Participants who signed up for the research register and healthcare data linkage were broadly similar to the sample as a whole in terms of age, gender and location.

Ninety individuals (18%, 95% CI 15-22) gave information on the number of hours spent online per week. This ranged from 3-100 hours (mean 26.9[SD 21.3]). Monthly internet usage was reported by 82 individuals (16%, 95% CI 13-20) with use ranging from 10 to 450 hours per month (mean 102.6[SD 88.1]). Mann-Whitney U tests revealed a significant difference between genders in relation to internet use with males reporting significantly more hours spent online per month (males, md=170 hours, n=7; females md=75 hours, n=70; p=.040). There was a significant negative correlation between age and weekly/monthly internet usage with younger individuals reporting significantly more hours spent online. There were no significant correlations between age and any standardised questionnaire scores.

Almost a third of individuals answered questions regarding contact with services (29%[95% CI 25-33; n=145] answered the GP item and 29%[95% CI 25-33; n=144] answered the items related to emergency departments, hospital and social care contact). Where data was available 61%(95% CI 53-69; n=89) of participants report having had contact with their GP for self-harm,

49%(95% CI 41-57; n=70) having contacted emergency departments and 34%(95% CI 27-42; n=49) having had contact with hospitals for self-harm (Figure 5). Almost half of individuals reported having had contact with social care with around equal proportions reporting having contact for self-harm or for reasons other than self-harm (contact for self-harm 26%[95% CI 19-33; n=37] contact for reasons other than self-harm 23%[95% CI 17-30; n=33]). Due to the small number of males who gave responses to these items (n=11) it was not possible to meaningfully break these results down by gender.

Table 3 Summary of participant demographics, proportions of each sub-group (n(%);95% CI) of individuals) by gender, age and location

		Total Sample	Research Register	Routine data consent
		(n=498)	(n=425; 85 ^b %[95% CI 82-88])	(n=76; 15 ^b %[95% CI 12-19])
Gender	Data available	316(63^b;59-68)	301(71^b;66-75)	74(97^b;91-99)
	Female	267(84;80-88)	253(84;79-88)	63(85;75-91)
	Male	32(10;7-14)	31(10;7-14)	6(8;4-17)
	Other	13(4;2-7)	13(4;3-7)	5(7;3-15)
	Prefer not to say	4(1;0-3)	4(1;1-3)	0(0;0-5)
Age	Data available	117(23^b;20-27)	113(27^b;23-31)	21(28^b;19-39)
	16-19	24(21;14-29)	24(21;15-30)	2(10;3-29)
	20-24	21(18;12-26)	21(19;12-27)	4(19;8-40)
	25-34	34(29;22-38)	34(30;22-39)	9(43;24-63)
	34-44	24(21;14-29)	20(18;12-26)	3(14;5-35)
	45-54	12(10;6-17)	12(11;6-18)	3(14;5-35)
	55+	2(2;0-6)	2(2;0-6)	0(0;0-15)
Location	Data available	422(85^b;81-88)	378(89^b;86-92)	66(87^b;77-93)
	England	294(70;65-74)	268(71;66-75)	46(70;58-79)
	Ireland	9(2;1-4)	7(2;1-4)	2(3;1-10)
	Scotland	32(8;5-11)	27(7;5-10)	5(8;3-17)
	Wales	87(21;17-25)	76(20;16-24)	13(20;12-31)
a. Proportion of those where data available				
b. Proportion of all participants (i.e. denominator 498)				

There was no significant relationship between presentation to health or social care, age, or numbers of hours spent online per week or month with the exception of those presenting to GPs. Individuals who presented to GPs for reasons other than self-harm spent significantly more hours online per month (Reasons other than self-harm, md=100 hours, n=29; presentations for

self-harm md=80 hours n=53; p=.027). Presentation to emergency departments for self-harm was associated with higher SHI scores (Table 4).

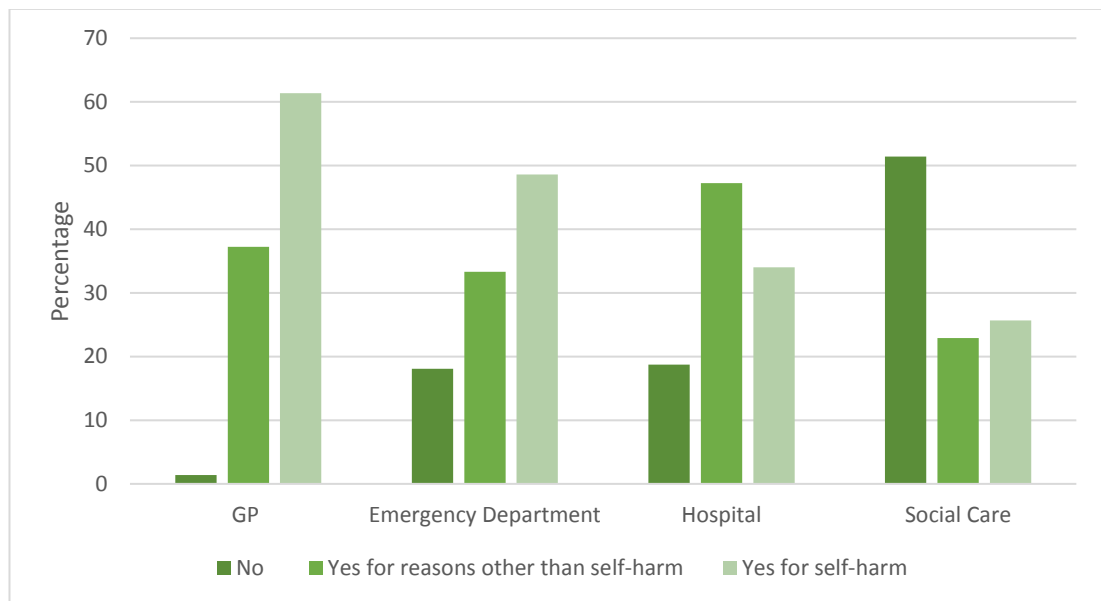


Figure 5 Percentage of participants in contact with health and social care

There was no significant relationship between presentation to health or social care, age, or numbers of hours spent online per week or month with the exception of those presenting to GPs. Individuals who presented to GPs for reasons other than self-harm spent significantly more hours online per month (reasons other than self-harm, md=100.0 hours, n=29; presentations for self-harm md=80.0 hours n=53; p=.027). Presentation to emergency departments for self-harm was associated with higher SHI scores (Table 4).

Contact with social care for self-harm was associated with higher SHI scores (no contact, md=10.0, n=53; contact for reasons other than self-harm md=10.0, n=22; contact for self-harm md=13.5, n=26; p=.006), lower resistance to peer influence scores (no contact md=3.0, n=19; contact for reasons other than self-harm md=3.0, n=6; contact for self-harm md=2.0, n=6; p=.048), higher experience of shame scores (no contact md=82.5, n=34; contact for reasons other than self-harm, md=78.5, n=18; contact for self-harm, md=91.5, n=66; p=.044), and higher CIUS scores (no contact md=22.0, n=43; contact for reasons other than self-harm md=20.0, n=13; contact for self-harm md=32.0, n=18; p=.013).

Of those who responded to registration questions regarding self-harm 94% (95% CI 92-96; n=360) report having harmed themselves more than once (harmed self once 3%[95% CI 2-5; n=11]); never self-harmed 3%[95% CI 1-5; n=10]). When asked about the last occasion that they tried to harm themselves, of those who responded (n=97), 48%(95% CI 39-58; n=47) reported

not receiving help from anyone. The most commonly reported sources of help were 'hospital/specialist medial/psychiatric services' (19%[95% CI 12-27; n=18]) followed by 'friends/family/neighbours' (15%[95% CI 10=24; n=15]) and 'community/GP/Local authority

Table 4 Relationship between presentation to health and social care and scores on standardised questionnaires

	GP				Emergency department				Hospital				Social care			
	p	none	Other ^a	self-harm ^b	p	none	Other ^a	self-harm ^b	p	none	Other ^a	self-harm ^b	p	none	Other ^a	self-harm ^b
SHI	0.058	9.5(2)	8(37)	11.5(64)	0.050*	9.5(18)	10(33)	12(51)	0.059	10(20)	10(50)	13(32)	0.006*	10(54)	10(22)	13.5(26)
CUIS	0.653	(0)	23(27)	22(47)	0.825	29.5(10)	23(25)	21.5(38)	0.875	24(13)	23(37)	22(24)	0.013*	22(43)	20(13)	32(18)
PSS-fr offline	0.236	(0)	7(21)	6(42)	0.316	5(7)	5(21)	7(35)	0.684	8(12)	5(29)	6(21)	0.398	8(33)	5(11)	5(17)
PSS-fr online	0.437	8(1)	8(14)	8(26)	0.709	11(7)	8(16)	8(17)	0.176	14(5)	9(21)	8(15)	0.402	5(23)	9(11)	8(7)
RPI	0.101	(0)	3(14)	2(22)	0.121	3(5)	3(11)	2(19)	0.012*	2(9)	3(15)	2(12)	0.048*	3(19)	3(10)	2(6)
ESS	0.613	(0)	83(23)	85(43)	0.853	86.5(8)	82.5(22)	85.5(86)	0.508	82(12)	83.5(32)	89(22)	0.044*	82.5(34)	78.5(14)	91.5(18)
BIS-II	0.196	(0)	66(23)	74(43)	0.324	65(8)	65(21)	74(37)	0.161	64(13)	67.5(32)	75(20)	0.150	64(34)	73.5(14)	76(17)
a.	Contact for reasons other than self-harm															
b.	Contact for self-harm															
c.	Significant at 0.05 level based on Kruskal Wallis Test															

service' (11%[95% CI 6-19; n=11]). Equal proportions of individuals report receiving help from 'helplines/voluntary organisations' and 'from someone else' (3%[95% CI 1-9; n=3]).

Standardised Questionnaires

A total of 299 individuals completed at least one questionnaire (Table 5).

Table 5 Summary of average scores on standardised questionnaires

		N	average score(SD)
Measure	Subscale		
Self-harm inventory		280	10.9(3.8)
	Eating disorder		1.2(0.9)
	Lethality		1.1(0.8)
	Medical issue		1.7(1.0)
Compulsive internet use scale		180	26.8(12.2)
PSS-offline		153	7.9(5.0)
PSS-online		41	8.1(5.5)
Resistance to peer influence		85	2.8(0.7)
Experience of shame scale		147	81.7(14.8)
	Characterological		38.4(7.9)
	Behavioural shame		30.0(6.4)
	Bodily shame		14.3(2.8)
Barratt impulsiveness scale		144	71.9(14.0)
	Attentional		21.0(4.9)
	Motor		24.4(5.6)
	Non-planning		26.5(6.0)

Self-harm inventory. Scores on the SHI ranged from 0-20. Ninety-seven percent (95% CI 94-99; n=272) of individuals scored above the suggested cut-off indicative of borderline personality disorder (scores of five or more). The majority of participants had higher scores; 62%(95% CI 57-86; n=175) scored 10 or higher and 21%(95% CI 16-26; n=58) scored 15 or higher out of a possible 22. In relation to the SHI subscales 77%(95% CI 72-82; n=216) reported at least one eating disorder related measure, 73%(95% CI 67-77; n=203) at least one lethal measure and 84%(95% CI 79-88; n=235) at least one item on the medical subscale.

Of the 280 individuals who completed the SHI 100%(95% CI 98-100; n = 279) reported have injured themselves, with 65%(95% CI 60-71; n=183) also reported self-poisoning and 95%(95% CI 92-97; n=267) reporting 'other' measures of self-harm included on the scale ('other' includes: abused alcohol, driven recklessly, made medical situations worse, been promiscuous, set self up in relationship to be rejected, abused prescription medication, distanced self from god, engaged in emotionally abusive relationship, lost job on purpose, exercised an injury of purpose, tortured yourself with self-defeating thoughts, starved self to hurt yourself, abused laxatives to hurt yourself). Almost half (46%[95% CI 40-52; n=128]) report having attempted suicide. Mann-

Whitney U tests revealed a significant difference between genders for the eating disorder subscale only with females reporting these items significantly more (males $md=1.0$, $n=20$; females $md=1.0$, $n=179$; $p < .05$).

Kruskal Wallis tests revealed a positive correlation between SHI scores and presentations to any setting for self-harm. However, this only reached statistical significance for those presenting to emergency departments (Table 4; GP, no contact $md=9.5$, $n=2$; contact for reasons other than self-harm $md=8.0$, $n=64$; contact for self-harm $md=11.5$, $n=63$; $p=.058$; emergency department no contact $md=9.5$, $n=18$; contact for reasons other than self-harm $md=10.0$, $n=33$; contact for self-harm $md=12.0$, $n=51$; $p=.500$; hospital no contact $md=10.0$, $n=20$; contact for reasons other than self-harm $md=10.0$, $n=50$; contact for self-harm $md=13.0$, $n=32$; $p=.059$).

CIUS. Scores on the CIUS ranged from 0-56 out of a possible maximum score of 56. Sixty-six percent (95% CI 59-73; $n=119$) of individuals scored 21 or higher indicating problematic internet use. There was a significant positive correlation between CIUS scores and online hours per week/month (Table 6). A small but significant positive correlation was found between CIUS scores and SHI scores ($r=0.190$, $n=177$, $p=.011$).

PSS-friends scales. Scores on the PSS-Fr offline subscale ranged from 0-19, 30%(95% CI 23-38; $n=46$) scored above the scale median of 10 with higher scores indicating higher perceived social support from offline peers. There was a small but significant negative correlation between PSS-Fr offline scores and CIUS scores ($r=-0.194$, $n=140$, $p=.021$) with lower perceived social support from offline friends associated with higher compulsive internet scores. No significant relationship was found between CIUS scores and the PSS-Fr online subscale. A significant negative correlation was found between PSS-Fr offline scores and ESS scores ($r=-0.185$, $n=121$, $p=.042$) with higher ESS scores associated with lower perceived social support from offline friends. A significant positive correlation was also found with RPI scores ($r=0.221$, $n=81$, $p=.043$) with higher perceived social support associated with greater resistance to peer influence.

Scores on the PSS-Fr online subscale ranged from 0-18, 39%(95% CI 26-54; $n=16$) scored above the scale median of 10 with higher scores indicating higher perceived social support from online peers. While there was a positive correlation between the online and offline versions of the PSS-Fr, this did not reach statistical significance. However, the number of individuals completing both subscales was low ($n=11$).

RPI. RPI scores ranged from 1-4 with 64%(95% CI 53-73; $n=54$) scoring above the scale median of 2.5 with higher scores indicating greater resistance to peer influence. There was a significant

negative association between RPI and ESS scores ($r=-0.260$, $n=78$, $p=.022$) with higher levels of shame related to lower levels of resistance to peer influence.

ESS. ESS scores ranged from 13-100. ESS scores were significantly positively correlated with SHI ($r=0.375$, $n=144$, $p<0.001$), BIS-11 scores ($r=0.459$, $n=126$, $p<0.001$), and CIUS scores (detailed above). ESS scores were significantly negatively correlated with PSS-Fr offline scores and RPI scores (detailed above).

Table 6 Correlations between questionnaire responses, age, weekly and monthly internet use

	2	3	4	5	6	7	8	9	10
1.Age	$r=-.424^*$	$r=-.380^*$	$r=-0.053$	$r=-0.067$	$r=-0.254$	$r=-0.131$	$r=-0.012$	$r=-0.138$	$r=-0.323$
2.Weekly internet use (hours)		$r=.732^*$	$r=-0.005$	$r=.473^*$	$r=-0.160$	$r=0.095$	$r=0.205$	$r=0.086$	$r=0.108$
3.Monthly internet use (hours)			$r=-0.173$	$r=.321^*$	$r=-0.207$	$r=0.009$	$r=0.148$	$r=0.123$	$r=0.068$
4.SHI				$r=.190^*$	$r=-0.060$	$r=0.162$	$r=-0.037$	$r=.375^*$	$r=.489^*$
5.CIUS					$r=-.194^*$	$r=-0.025$	$r=-0.050$	$r=.184^*$	$r=.248^*$
6.PSS-fr offline						$r=0.402$	$r=.225^*$	$r=-.185^*$	$r=-0.126$
7.PSS-fr online							$r=.$	$r=-0.106$	$r=0.1689$
8.RPI								$r=-.260^*$	$r=-0.102$
9.ESS									$r=.459^*$
10.BIS-11									

*Correlation is significant at the $P>0.05$ level

BIS-11. BIS-11 scores ranged from 40-111, 10%(95% CI 6-16; $n=15$) scored between 70 and 74 indicating pathological impulsivity and 41%(95% CI 33-49; $n=59$) scored 75 or higher indicating a possible impulse control disorder. A significant difference between genders was found for the non-planning subscale of the BIS-11 only with females scoring significantly higher (males $md=22.0$, $n=8$; females $md=27.0$, $n=111$; $p=.050$). Impulsivity scores were significantly positively correlated with SHI scores ($r=0.489$, $n=142$, $p<0.001$), and CIUS scores (detailed above).

Media databank

A total of 62 individuals uploaded 95 items to the media databank (Table 7). Uploaders were aged from 18-53 (average age 31.9[SD10.1]). Websites made up the largest proportion of uploads, followed by social media of which Facebook and Instagram were the most popular. Trigger warnings and creative content were rare however 42%(95% CI 33-52; $n=40$) of sites included signposting to sources of help.

Table 7 Summary of media databank uploads $n(\% ; 95\% CI)$

Feature	N(%;95% CI)
Centred around images	12(13;7-21)
Trigger warnings	5(5;2-12)
Creative content	10(11;6-18)
Signposting	40(42;33-52)
Type	App
	App store

	Online community	2(2;1-7)
	Podcast	1(1;0-6)
	Search engine	3(3;1-9)
	Social media	20(21;14-30)
	Facebook	7(35;18-57)
	Instagram	7(35;18-57)
	Reddit	4(20;8-42)
	Tumblr	2(10;3-30)
	Video sharing (YouTube)	1(1;0-6)
	Website	59(62;52-71)
	Mind	9(15;8-27)
	Elefriends	5(8;4-18)
	7 cups of tea	4(7;3-16)
	NHS - self-harm information page	4(7;3-16)
	Life signs	3(5;2-14)
	Recover your life	3(5;2-14)
	Harmless	2(3;1-12)
	Samaritans	2(3;1-12)
	The Mighty	2(3;1-12)
	The Mix	2(3;1-12)
	Young minds	2(3;1-12)
	B therapy	1(2;0-9)
	Bipolar UK	1(2;0-9)
	BJPsych	1(2;0-9)
	BMJ best practice	1(2;0-9)
	Brave Miss World	1(2;0-9)
	Devon rlc	1(2;0-9)
	Gypsy-Jax	1(2;0-9)
	Heads above the waves	1(2;0-9)
	Lost all hope	1(2;0-9)
	Mayo clinic	1(2;0-9)
	MQ	1(2;0-9)
	Myproana	1(2;0-9)
	Patient	1(2;0-9)
	Pulse	1(2;0-9)
	RCPsych	1(2;0-9)
	Recovery in the bin	1(2;0-9)
	Rethink	1(2;0-9)
	Self-harmony	1(2;0-9)
	Teen help	1(2;0-9)
	Time to Change	1(2;0-9)
	Wellbeing info	1(2;0-9)

Participants who uploaded more than one resource did so all on the same date. This suggests that individuals only used this feature of the site on one occasion.

There were eight uploads where it appeared that material meant to be supportive or informative contained potentially harmful information (Table 8) including journal articles and reference pages aimed at health professionals.

Table 8 Harmful use of educational or supportive resources

Description of source	Information
Research paper describing the toxicity in overdose of various antidepressants	Clear from abstract that antidepressants are lethal in overdose and which ones are the most and least toxic Participant reports looking for information on whether antidepressants can kill them
Medical information page giving information on liver failure	Gives specific dose needed for toxicity given by mg/kg of bodyweight and a total number of grams for potentially fatal dose
Medical information page providing factual information about acute liver failure	Includes causes and gives examples of drugs, whether one large or several smaller overdoses can cause liver failure and specifies that acetaminophen overdose can cause both liver and kidney failure
Reference article about paracetamol poisoning aimed at health professionals	Information that one large dose or several smaller overdoses can cause toxicity with toxic dose given in mg/kg bodyweight. States that coma may occur if paracetamol taken with opioids or multiple other drugs Participant reports using to calculate how much paracetamol is needed for a lethal dose
User-led self-injury awareness organisation designed to help educate and support people who self-harm and their family and friends	Participant reports being bullied on site; forum suspended and image galleries not accessible at time of analysis
Online magazine article aimed at GPs providing information paracetamol poisoning	First paragraph gives number of tablets used in overdose Participant states reading to see how many paracetamol to take for non-fatal self-harm
Support site with chat rooms, forums and information articles	Purpose of site to provide support however participant states used forums for triggers
Site promoting wellbeing however specific page on 'safe' self-harm	Site run by mind and is focused on prevention and intervention Page given by participant gives 'safe' self-harm advice that could be potentially harmful

4.4 DISCUSSION

SHARE UK Research platform

This study presents the development and piloting of an online platform for self-harm research. This feasibility study provides a basis for the development of this platform as a future resource

for self-harm research. This platform has potential as a questionnaire delivery platform and for recruitment to a self-harm research register. Research registers have been previously found to improve levels of recruitment to studies and to lower the amount of resources spent reaching participants (Callard et al., 2014; Robotham et al., 2016). Given the often hidden nature of self-harm and known issues recruiting to studies (Hunter et al., 2013) a self-harm research register represents an important resource for future research. Allowing individuals to sign up to this register online lowers many of the barriers to taking part in research and 85% of participants consented to be contacted for future research. Around two thirds of participants completed at least one questionnaire, the results of which are discussed in more detail below.

In contrast with the high sign-up for the research register, individuals were more reluctant to consent for their data to be linked with routinely collected healthcare data with only 15% of individuals consenting for linkage. There are many possible reasons for this, which will be explored in Chapter Five using a national survey (The Big Data and Mental Health Research Survey) to explore potential issues with data linkage. Linkage with healthcare data has been previously successfully obtained with online samples in other studies. For example Health Wise Wales have successfully linked 93% of participants (Hurt et al., 2019). However, the population of individuals signed up for Health Wise Wales were mostly aged 45-64 years in contrast with the younger sample in the current study. Furthermore, 50% of participants signed up for Health Wise Wales are classified as being in higher managerial or professional occupations (compared with 27% of population of Wales) and there was a high percentage of participants from the least deprived quintiles of Wales. Successful linkage with routinely collected data has also been found with the MS-register (Ford et al., 2012). Similar to the Health Wise Wales cohort participants signed up for the MS-register represent a largely older adult cohort (mean age 50.8) (Ford et al., 2012). It may be that the older age or differences levels of deprivation or education represent important demographic differences related to people's willingness to having their data linked with healthcare data. This will be explored examining the views specifically of young people aged 16-24 in Chapter Five.

Contact with health and social care

Contact with services varied based on whether individuals were asked about any prior contact compared with contact following their last episode of self-harm. When asked about help received on the last occasion they harmed themselves around half of participants report receiving help. Hospital/specialist medical/psychiatric services were the most commonly reported sources of help followed by friends/family/neighbours. This slightly differs from

previous research finding that friends and family were the primary sources of help in a cross cultural school survey (Ystgaard et al., 2009). Participants in the current study have a more varied and older age range than school surveys and represent a smaller sample, which may underlie these differences. Around half of individuals report not receiving help from anyone following the last time they self-harmed, in keeping with previous research (Ystgaard et al., 2009). Previously it has been suggested that adolescents who receive medical care and those who do not may represent different points on a continuum of suicidal behaviour (Grøholt, Ekeberg, Wichstrøm, & Haldorsen, 2000) with individuals who present to hospital more likely to report wanting to die and to use more lethal methods of self-harm (Ystgaard et al., 2009). There may be important differences between those who present to services and those who do not. The current platform has the advantage of reaching both groups and, the consent to contact for future research could facilitate the follow-up of participants over time. It may be that those who present to services have different or more complex needs from those who do not. Alternatively providing the right help for individuals who have not, at present, had contact with services may prevent them from reaching a crisis point that requires emergency care. Further understanding of these two groups of individuals is needed. The use of an online platform has the advantage of being accessible for both participants who present to services and those who do not. This has potential for future research to examine the differences between these groups.

When asked about presentation to services at any time, the current study found that GPs were the most commonly reported contacts with healthcare services, followed by emergency departments with the smallest proportion of reported contacts for hospitals. Over 60% of individuals report contact with their GP for self-harm, around half with emergency departments and around a third contact with hospitals. This is in keeping with previous research utilising routinely collected data finding that around twice as many individuals have contact with their GP regarding self-harm than are admitted to hospital (Thomas et al., 2013). Individuals who presented any healthcare service for self-harm had higher scores on the SHI, with this reaching statistical significance for emergency settings only. This supports previous associations found between SHI scores and healthcare utilisation (Sansone et al., 2008).

Around half of participants reported being in contact with social care of which, half had contact related to self-harm and half report contact for something other than self-harm. Individuals who have contact with social care related to self-harm appear to represent a vulnerable group with higher scores on measures of self-harm, shame and compulsive internet use and, scores indicative of lower resistance to peer influence. Previous research has found that many factors associated with self-harm mean that individuals may already be known to social care such as

mental health issues, alcohol and substance misuse, social, economic and cultural issues (Colman et al., 2004; Houston et al., 2003). Furthermore, around a quarter of those presenting to emergency departments with self-harm have current or previous contact with social care (Nadkarni et al., 2000). Previous research has called for standard recording of factors such as domestic violence and parental mental illness in emergency attenders at child and adolescent mental health services to enable the collection of standardised data regarding these parameters (Healy, Saha, Subotsky, & Fombonne, 2002). This data could be used to identify vulnerable individuals and inform support. Furthermore looked after young people who self-harm have been found to be more vulnerable than looked after young people who do not self-harm reporting significantly fewer reasons for living and a more maladaptive self-critical style with self-hate found to be of particular importance for predicting self-harm (Harkess-Murphy, MacDonald, & Ramsay, 2013). Staff working in residential care homes for Looked After Children have reported concerns about responding to self-harm appropriately in the young people they look after. Concerns often centre around individual responsibility, lack of external support and long waiting times for further support (A. M. Brown, Chadwick, Caygill, & Powell, 2019). It is important that staff working in social care or with vulnerable individuals are given the resources and education needed to recognise and manage self-harm. Research supports calls for better understanding of the factors associated with self-harm and suicide risk in this vulnerable group given the existing vulnerabilities and adverse outcomes of those in contact with social care.

Self-harm

More than 90% of participants report having harmed themselves on more than one occasion and almost all participants report self-injury with more than 60% also reporting self-poisoning. Self-harm inventory scores were high with 97% of participants scoring above the suggested cut-off for borderline personality disorders and 62% scoring 10 or higher out of maximum score of 22. Almost half of individuals report having attempted suicide. Higher SHI scores were associated with higher levels of compulsive internet use (discussed in further detail below), greater experience of shame and higher levels of impulsivity in keeping with previous research (Gilbert et al., 2010; Hamza, Willoughby, & Heffer, 2015). Impulsivity is a previously identified risk factor for self-harm (Hamza et al., 2015) and results here support suggestions that interventions focused on reducing rash reactivity to emotions or improving self-regulation and decision making may benefit those who self-harm. Future research should endeavour to further understand the relationship between impulsivity, shame, compulsive internet use and self-harm, how these factors may work together to have an impact on risk and, any potential implications for management of self-harm.

Internet use

Males were found to spend more time online than females, and younger participants report spending more time online than older participants. Number of hours spent online per week or month were not found to be significantly correlated with SHI scores (or any other standardised questionnaire measures). However, there was a significant positive correlation between SHI scores and problematic internet use measured by the CIUS. Problematic internet use has been previously shown to be related to self-harm (Kaess et al., 2014). This is supported by the data from questionnaires here with 66% of participants scoring above the cut off for pathological internet use on the CIUS (Meerkerk et al., 2009). CIUS were scores positively correlated with SHI scores. Results of the systematic review described in Chapter Three found strong evidence for a relationship between problematic internet use and self-harm including both internet addiction and high levels of use (Marchant et al., 2017). CIUS scores here were significantly correlated with measures of impulsivity and shame in keeping with previous research (Craparo et al., 2014; Yau, Potenza, & White, 2013)

Social support and peer influence

For the purpose of this study, an adapted version of the PSS-Fr scale was utilised. This scale is designed to measure the perceived social support of peers. Scores on the PSS friends and family subscales have been previously found to be inversely related to symptoms of distress and psychopathology (Procidano & Heller, 1983). This scale has seen several adaptations related to internet use. For example, the PSS-Fr has been adjusted to examine social support specific to the support received over social networking sites (Woo, 2017), Facebook (Arseneault, 2012), and mobile phones (Chen, 2007). For the current study, a modified version of the scale was used to examine perceived social support from both online and offline peers. This modified version of the scale has been previously used to explore the way in which online and offline peers are perceived as source of support by individuals who utilise self-harm e-communities (Michal, 2013). Previous research has found that fulfilment of needs by online self-harm communities was significantly correlated with higher levels of perceived online peer support. Higher levels of perceived online peer support was also significantly associated with more time spent online (Michal, 2013). Previously both online and offline perceived peer support were inversely related to symptoms of distress and psychopathology.

Participants in the current study mostly obtained scores indicating low perceived social support on both the online and offline subscales. In the current study, lower perceived social support from offline peers was associated with higher levels of compulsive internet use and increased

experiences of shame. It may be that individuals who do not have strong peer support offline increasingly turn to the internet to for support. Alternatively, it may be that compulsive internet use has a negative impact on offline relationships. Higher perceived social support from offline peers was significantly correlated with greater levels of resistance to peer influence. Greater resistance to peer influence was inversely related to experience of shame scores. No significant relationships were found between the PSS-Fr online scale and any other measures, however the number of individuals completing this questionnaire was low (n=41). While there was a positive correlation between the online and offline subscales, only 11 participants completed both scales and this relationship did not reach statistical significance.

Media databank

Previous research has examined user perspectives on self-harm related content online (Jacob et al., 2017) or has examined the content of purpose built collections of online material including social media posts (R. Brown et al., 2018) and the results of internet searches (Biddle et al., 2016; Singaravelu et al., 2015). This part of the study adds to previous research examining the content of a participant-built databank of media resources. A total of 62 individuals uploaded 95 items. The majority of uploads were of websites or social media sites. Few contained trigger warnings or opportunities for creative content however, 42% included signposting to sources of help. Of note were uploads of educational or positive content where the participant had indicated a potentially harmful impact. This included journal articles and reference sites aimed at clinicians being used to calculate lethal doses of medications, a support site through which a participant reports being bullied and another that the participant used to find triggering content. This supports previous research finding purposeful searching of the internet particularly by those who present to emergency settings with higher levels of suicidal intent (Biddle et al., 2018). The sites aimed at clinicians and researchers often contained clear information on lethality of medications with one journal article giving this information in the abstract. It appears that potentially harmful content goes beyond pro-suicide and self-harm sites with individuals purposefully seeking out triggering material and information on methods of self-harm including potential lethality.

Strengths and limitations

The chapter presents a pilot of an online platform for self-harm research. The strengths and limitations of this pilot will be used to inform the future development of the SHARE UK platform discussed further in the implications section below. While the platform was successful in terms

of research register sign-up and questionnaire completion, it was less successful in obtaining sign-up for linkage with routinely collected data and for the creation of the media databank. Engagement with the media databank was not sufficient to create a resource that can be extensively utilised in future research. Only 62 out of 498 participants uploaded items to the media databank and participants who uploaded more than one resource did so all on the same date. This suggests that individuals only used this feature of the site on one occasion and did not continue to update the databank with new resources. A more dynamic format, such as an app, has the potential to keep individuals engaged over time may have resulted in a greater number and range of uploads. Future research should explore this, incorporating meaningful coproduction with individuals who self-harm to explore whether any steps could be taken to improve engagement with a participant-built media databank.

There are many possible reasons for the low levels of sign up for linkage with routinely collected data. Future research should seek to explore potential issues. This has been done previously with older adult populations (Douglas et al., 2017; Jones et al., 2014), however, the views of children and young people have not been examined specifically. Individuals who self-harm may have specific concerns over the use of their data and personal information. These issues will be explored in Chapter Five and suggestions for steps that can be taken in future research discussed.

All questions on this platform were optional, giving participants a choice over what information to give. While online research has many advantages, often relatively little is known about the characteristics of people online with even basic demographic variables missing or inaccurate (Lewis & Baker, 2011). In keeping with previous research demographic information was missing for a large proportion of participants. This could be seen to support previous recommendations for at least some mandatory fields; however little is known about individuals who choose not to give this data. Making disclosure of personal data mandatory may pose a barrier to participation in research. Further research is needed to explore what the potential impact of mandatory demographic information would be for participation in research, particularly for vulnerable individuals. Decisions on whether or not to make this information voluntary may be best made on a study-by-study basis. Allowing participants freedom over what questions to answer in the current study was intended to lower barriers to participation. This resulted in large amounts of missing data and was problematic for demographic information, particularly age. This is an issue that needs to be addressed for future applications of this platform. Potential solutions include making date of birth a mandatory field or, requiring participants to give their age in five year

bands (e.g. 16-21 years etc). This would allow for an approximate age distribution to be established.

This absence of demographic information means that it is not possible to evaluate the generalisability of findings to the wider population. Convenience samples such as this are inherently biased. Individuals taking part would likely already be well engaged with this area of research and would have needed to have internet access. Biases are inherent in any convenience sample but may be particularly problematic in relation to self-harm and mental health related research, as often those excluded are those most in need. Online surveys have been found to under-represent children and adolescents from disadvantaged backgrounds (Goodman, 2013; Heiervang & Goodman, 2011) and may result in an underestimation of need if used alone to inform policy (Goodman, 2013). Online samples tend to have an over-representation of young adults, and a bias towards well-educated English speaking participants, with an under-representation of older adults found in some studies (Batterham, 2014; Klovning et al., 2009). While the biased nature of online samples poses a significant limitation, online research has been found to be particularly effective for accessing populations that have been traditionally hard to reach with adequate representation of culturally diverse populations and a high representation of young adults (Batterham, 2014). This has been noted previously with substance users (Ramo & Prochaska, 2012), young females (Fenner et al., 2012) and immigrants (Baltar & Brunet, 2012). The sparseness of demographic information present here means any evaluation of the representativeness of the sample is limited, however based on the information collected it appears adolescent/young adult females may be overrepresented as would be expected. Changes to the way demographic information is collected will need to be made for any future applications of the SHARE UK platform, discussed in further detail in the implications section below.

Batterham (2014) found that people with mental health issues were more likely to fill out mental health related questionnaires than the remainder of the population with this difference amplified for online surveys. This does not present an issue for research looking to gather opinions of individuals but would be problematic for prevalence research. It is important that data collected online be taken together with other data to provide a comprehensive picture on which to base service provision. In order to address this limitation this project has incorporated analysis of routinely collected healthcare data discussed in full detail in Chapter Six.

It has been found previously that individuals who take part online are less likely to complete all sections of surveys/interviews (Heiervang & Goodman, 2011) and allowing optional completion

of fields online allows for high rates of missing data (Cantrell & Lupinacci, 2007). In keeping with previous research missing data was not just an issue with regards to demographic information. Many participants chose not to give information on self-harm or contacts with services and very few participants completed all surveys. The lack of demographic information means that it is not possible to evaluate whether individuals who complete these fields represent the sample as a whole. Previous research has found that participation in online interviews are selective with for example, lower rates of full participation seen for those with less education, single-parent and immigrant families (Heiervang & Goodman, 2011). The possibility remains that data here may be missing for those in the highest need. Results here must be considered in this context and any future work with this platform must take steps to address this issue.

The amount of missing data means that analysis of data collected at this pilot stage must be taken as preliminary with further work needed. The preliminary analysis of the data collected at this stage suggests several relationships between measures present on the platform. All relationships are correlational and as such, cause and effect cannot be inferred. Furthermore, the sample size is relatively small. Very few participants completed all questionnaires meaning that evaluation of interactions between measures is limited. While the sample size is small it was achieved with no cost for recruitment. Future studies with additional funding for recruitment may address the issue of sample size. Any recruitment strategy should be targeted to broaden the sample, reaching those who may be underrepresented (e.g. males) and ensuring outreach to those in the greatest need.

An alternative setting for self-harm research is cross sectional surveys conducted in schools (e.g. Ystgaard et al., 2009). Such surveys have the advantage of reaching large samples and are often conducted across countries. However, children and adolescents who are absent from school may represent a group more likely to have issues that increase the risk of self-harm. Allowing individuals to participate online as done here does not exclude these individuals. However, the online format means that individuals who do not have reliable access to the internet may not have the same opportunities to take part. This may include individuals from more deprived or unsettled backgrounds, individuals who are homeless or do not have a secure place to live or those with substance abuse issues. An accompanying pen and paper format distributed through channels likely to reach these individuals such as drop-in centres and shelters would assist in reaching the broadest possible sample in the future.

Implications and directions for future research

The current study explores the feasibility of a pilot online platform for self-harm research. It is intended that this platform will go on to form part of the Adolescent Mental Health Data Platform (ADP) following the completion of this PhD. Lessons learnt from this initial pilot stage will inform the development of this platform going forward. The identification of issues represents an important step and will allow for the platform to be improved and developed further. The SHARE UK platform as part of the ADP will focus on the strengths of the platform, primarily for sign up to the research register and for its use as a questionnaire delivery platform. Ethical approval will be sought to expand the number of questionnaires available to answer new research questions and for the use of ADP resources to boost recruitment.

As discussed above the level of missing demographic data, particularly age, represents a significant issue. This will be addressed as the platform is developed for the ADP with demographic fields related to age and gender made mandatory. Participants will be asked to give their age in five year bands (i.e. 16-21 years etc). This will allow the approximate age distribution to be estimated without requiring participants to give their date of birth. Collection of demographic data such as education level, ethnicity and levels of deprivation are also under consideration for inclusion. It is likely that some individuals, such as those with no internet access or those with language and literacy issues, face significant barriers to taking part in the project in its current form. In addition males are likely to be under-represented as are older adults. This must be acknowledged in any discussion of results. Targeted advertising (for example aimed specifically at males), alternative formats and outreach to community settings would begin to address these limitations. Additional steps such as giving participants the option to participate face-to-face or incorporating accessibility features into any online format such as audio for questions and responses, should also be considered to reduce barriers posed by literacy.

The low levels of sign up for linkage with routinely collected data was a significant issue. The potential reasons for this will be explored in Chapter Five. Initially the sign up for linkage with routinely collected data will not form part of the new SHARE UK platform as part of ADP due to the issues identified. However as described further in Chapter Five, public engagement, and dissemination of information about data linkage and the importance of this research is an important future direction that may assist with gaining higher levels of linkage in the future. This kind of public outreach is an important part of the ADP and is taking place on an ongoing basis. The low levels of engagement with the media databank suggest that this aspect of the platform will need to be reworked to be a useful resource in its own right. Initially this will not be included

on the SHARE UK platform as part of the ADP. Further work including co-production with young people is needed in order to develop the media databank before it can be rolled out again.

Co-production with young people was not possible during the initial development of the platform as the resources were not available to do this effectively. It is possible that had potential participants had a more active role some of the above limitations could have been anticipated. Over the course of this project the collaboration with ADP has meant that it has been possible to begin to co-produce with young people. There are now established resources for PPI set within the ADP research team through the 'Be Heard' engagement initiative, the MQ Young Persons Advisory Group and the ADP Champions Group who regularly provide feedback on research documents, assist in development of questionnaires and research protocols and provide feedback on ADP research. Student interns are also present on the team and will play an active role in the development and running of the platform.

Recruitment to this platform was successful via social media without any direct cost. A greater budget for advertising and recruitment would result in a wider reach and likely increase recruitment further. The research register represents an important resource for future self-harm research with at present 425 individuals with experience of self-harm who can be contacted for future research. With greater resources to advertise the register and the platform this number could increase substantially and represent a both a valuable resource for researchers and policy makers and, an opportunity for individuals to have a voice in research. Almost 300 individuals completed at least one standardised questionnaire supporting the use of the platform for questionnaire delivery. Several significant relationships between questionnaires were found. These are worthy of further study with larger sample sizes to assess practical and clinical implications.

More than 60% of participants here report having contact with their GP for self-harm. This supports previous calls for GPs to be supported in recognising self-harm in children and young people. GPs may underestimate the prevalence of self-harm in young people and have stated they would welcome training in communication with children and young people and practical information on self-harm (Fox, Stallard, & Cooney, 2015). A high proportion of individuals in this study report not having received help for self-harm (almost half following the last episode of self-harm). Young people often do not contact services themselves following self-harm but are most often referred or brought by an adult (Hassett & Isbister, 2017). Interventions that increase awareness of the signs of self-harm and steps to be taken by parents, teachers and other adults may increase the rates of individuals who receive help from services. Older adolescents and

adults are more likely to initiate help-seeking without intervention from another adult. Education programmes to improve knowledge of self-harm and promote help-seeking may be beneficial for these individuals (e.g. Mann et al., 2005). Greater support at the community level may also be beneficial allowing individuals to access support before a crisis point is reached.

Around half of individuals in this study had contact with social care. Individuals who had contact with social care related to self-harm appeared to represent a vulnerable group compared to those who had contact with social care for other reasons and those who did not have contact with social care. Scores on standardised questionnaires for this group indicate greater self-harm behaviour, compulsive internet use, shame and lower resistance to peer influence. Individuals in contact with social care likely have more complex needs such as family issues and social problems (Colman et al., 2004; Houston et al., 2003). The vulnerability of these individuals and the contact with social services represents an important opportunity for providing support. Further understanding of the needs of this vulnerable group are needed, as specialist support may be required. Interventions could also be tailored to increase awareness and help-seeking behaviour of self-harm in such populations and efforts made to decrease stigma and increase communication. Additional support provided at the level of social care may reduce the likelihood of an individual reaching a crisis point and reduce the need for contact with emergency healthcare settings. This support must go beyond simply healthcare and include a holistic approach potentially incorporating families, significant relationships, employment, education and wellbeing and, life skills such as managing internet use and peer relationships. Researchers have argued that strategies for the early identification of self-harm in those most at risk go beyond those offered by health services (Harkess-Murphy et al., 2013). Management plans are needed by care teams with support from appropriately trained mental health professionals. A collaborative approach is needed in which the health and social care systems work together. It is important that carers are given the support they need to work in partnership with healthcare services and support young people who self-harm (A. M. Brown et al., 2019).

Lower perceived social support from offline peers was significantly correlated with compulsive internet use scores. It is not clear whether individuals with less social support offline turn to the internet more, potentially as source of support not available offline or alternatively, whether problematic internet use is impacting relationships with offline peers. Given the relationship between compulsive internet use scores and SHI scores further exploration of this relationship is warranted. There have been previous calls for clinicians to assess internet use in individuals who present with self-harm and to direct to healthier online behaviours (Marchant et al., 2017).

It may also be beneficial for clinicians to engage in conversations with individuals about their offline relationships and whether their internet use may be having a negative impact.

4.5 CHAPTER SUMMARY

This chapter describes the development and implementation of a pilot online platform for self-harm research. The platform has been successfully utilised to recruit to a self-harm research register and as a questionnaire delivery platform. This has been successful utilising a social media campaign with no associated cost. This platform will be incorporated into the ADP once the funded PhD studentship is complete and will be maintained as a resource for self-harm research. Lessons learned from this pilot will be used to develop the platform, addressing the limitations, and building on the platforms strengths. Targeted social media advertising and other methods of recruitment have the potential to broaden the reach of this platform resulting in a greater number of participants. While this platform addresses many limitations of research conducted in healthcare settings and schools there are some limitations including missing demographic data and a likely under-representation of individuals who do not have reliable access to the internet. Steps will be taken to address these issues in future applications of the platform.

While the platform was successful in recruiting to the research register and as a questionnaire delivery platform, it was more limited in consenting individuals to linkage with routinely collected data and for engagement with the media databank. Issues with data linkage will be explored further in Chapter Five. Further research is needed to explore issues with the media databank and the possibility of an alternative format.

Data provided by participant's are in keeping with previous research finding that around half of individuals who self-harm do not seek help from either health services or social networks. This supports previous calls for interventions to decrease stigma and increase communication and help-seeking behaviour potentially incorporating parents, teachers and other adults to help them to recognise the signs of self-harm and to ensure that they have the information and resources to provide help and advice to young people. Results also support previous calls for GPs to be better assisted to recognise and support individuals who self-harm.

Almost half of participants report previous contact with social care with those who have contact for self-harm appearing to represent a particularly vulnerable group. Contact with social care represents a further opportunity for intervention. It is important that social services are provided with the resources and information to recognise and provide support for young people

who self-harm. Further research is needed to explore the needs of young people in contact with social care who self-harm as they may have needs that are more complex. Tailored support and intervention may be required.

5 BIG DATA AND MENTAL HEALTH RESEARCH SURVEY

The previous chapter describes the development of the SHARE UK platform for self-harm research. As part of this project it was intended that participant data would be linked with routinely collected healthcare data for further analysis. Linkage of routinely collected data with data collected online has the potential to transform self-harm research. Both survey data and routinely collected data have advantages and limitations. Bringing these two sources of information together provides a richness of data on which to inform policy and service provision. While other online platforms have successfully consented individuals to having their survey/online data linked with healthcare data (Hurt et al., 2019; Jones et al., 2012) such studies have often used samples of older adults with an over-representation of individuals from more affluent areas. Sign-up for linkage with routinely collected data in the current study was low at only 15%. Possible reasons for this will be explored in this chapter.

Healthcare researchers have previously identified the need to gain a better understanding of the public's attitudes toward use of their data through enhancing their involvement in the research process and ensuring use of their data align with public interests (Riordan et al., 2015). Previous research has shown largely positive attitudes from the public towards the use of their healthcare data (Douglas et al., 2017; Jones et al., 2014). Focus group research has found that mental health service users were generally happy for their health, social and economic data to be shared provided the purpose was transparent and the data used to help others and improve health policy and practice. Participants were not comfortable sharing data through digital applications (Satinsky, Driessens, Crepaz-Keay, & Kousoulis, 2018). The views of young people who have experienced self-harm have not been examined previously in relation to the use of their data for research.

Recognition of the potential for data science to transform mental health research (McIntosh et al., 2016) is reflected in the development of the ADP currently under development at Swansea University. The ADP has been developed to bring together multiple sources of data related to children and young people's mental health together in one data safe haven. This will provide a significant resource for research to better understand mental health problems in children and young people. Routinely collected data is being linked with social and other data, including that from individual research studies, across the UK. This data is being brought together and meta-data and algorithms are being developed to allow for 'research ready' data. This will facilitate mental health research related to children and young people allowing researchers to work together to increase speed and quality of research. This will allow for research to have the

greatest potential for change providing a sound knowledge base on which to base healthcare and service provision in a timely manner.

The SHARE UK platform has paired with the ADP for this part of the study and for self-harm research going forward. A pivotal part of both the ADP and SHARE UK is engagement with children and young people and to utilise the valuable contribution of young people for the development of future research. It is intended that this part of the project will allow individuals to give detailed feedback and inform research going forward. Participant consent to routinely collected data was found to be poor (as described in previous chapter). This survey set out to explore possible reasons why this might be the case including examining participant views and knowledge of the way in which different kinds of data are anonymized and utilised for research. The often hidden and stigmatised nature of self-harm may give rise to specific concerns from young people that have implications for data management and ethical use of data. As yet research has not explored the opinions of young people who self-harm with regards to the use of their data for research. The levels of sign-up for linkage with healthcare data, detailed in Chapter Four, were lower than expected based on previous research (e.g. (Hurt et al., 2019; Jones et al., 2012)). It may be that young people who self-harm have specific concerns around the use of this data. By identifying potential issues steps can be taken to address these concerns. The types of big data now being used for research vary enormously from healthcare data, to marketing and social media data. As described in Chapter Three the issues around the use of social media data for research are particularly complex with the increasing presence of imagery making anonymity a complex issue. While recommendations for ethical use of such data have been made (British Psychological Association, 2017) researchers are not obligated to follow these guidelines. In order for research to represent the interests of the people it is intended to help; it is vital that we have a good grasp of these issues. It is important to have both quantifiable data of what participants feel is an acceptable use of their data and, more detailed explorations of experiences, opinions, and feelings around the use of various datasets in order to capture the nuances and complexity of these issues adequately. This survey consists of both open and closed ended questions with both quantitative and qualitative analysis. This approach allows for the issues around big data to be quantified and, real experiences and opinions behind this explored, providing a more comprehensive picture to inform future research. This will allow for the identification of issues beyond the original research question, highlighting issues in need of further exploration. Questions will be asked regarding a range of Big Data sources including data from companies such as Amazon and Fitbit, and social media data. This was conducted in collaboration with the ADP utilising a national survey described in further detail below.

5.1 AIMS AND OBJECTIVES

Aims

The aim of this part of the project was to conduct a national survey with children and young people. Broadly this survey set out to learn more about their experiences of research, barriers, facilitators and ideas. Of particular interest here were young people's feelings on the use of their data for research, their understanding of this and potential issues with the linkage process.

Objectives

To develop and run a national survey to explore issues around the use of data for research in children and young people aged 16-24

To contact people previously consented in order to recruit for the survey and to explore the utility of the existing research register for recruitment

To run a social media campaign to recruit outside of the SHARE UK platform utilising collaboration with the ADP

To analyse the content of these responses to identify potential issues with data linkage via the SHARE UK platform and to inform research going forward

To explore issues around the use of other sources of Big Data outside of healthcare data including social media data and data collected by companies

5.2 METHOD

Reporting of this surveys methodology and results were done according to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES; Eysenbach, 2004)

Ethical approval

Ethical approval was granted by the Swansea University Medical School Ethics Committee (approval number 2018-0062).

Participants were required to give informed consent to take part. Due to the potential for any dual consent model to be abused when consent is given online, participation was not open to those below 16 years of age in keeping with British Psychological Society guidelines regarding internet mediated research (British Psychological Society, 2017). Participants were briefed and debriefed online via Survey Monkey (copies included in Appendix G). In keeping with guidance

consent forms, information and debrief were kept as clear and brief as possible (British Psychological Society, 2017). Individuals who self-harm represent a vulnerable group of participants. As such it was made clear in both the information and debrief that the study is not able to provide crisis support and signposting to Samaritans was provided. It was made clear in the information and consent forms that participation was entirely voluntary, and should participants feel distressed in any way they should withdraw and contact a recommended source of help. Participants were free to cease participation at any time and doing so would bring up a copy of the debrief form. Participants were encouraged to seek help if they were feeling distressed in any way. Participants were informed prior to partaking that individual results would not be provided. There were no known pre-existing relationships between the research team and study participants.

Description of participants

Participants were required to be aged 16-24 years. The survey was open to individuals both with and without a history of self-harm. For the purpose of this project only data from those with a history of self-harm were included for analysis. In keeping with the SHARE UK platform, self-harm refers to any intentional act of self-injury or poisoning independent of motivation or suicidal intent (NICE, 2012). A history of self-harm was based on self-reports from participants themselves at the onset of the survey. No restrictions were placed on gender. Participation was limited to the UK.

Participants were recruited in part via the research register created as part of the SHARE UK platform (described previously). Participants who have previously consented to be contacted for future research were contacted by email and invited to take part. The email invitation includes the link to the information and consent form hosted on Survey Monkey that participants can follow. Within 8 hours of sending the email out to the SHARE UK mailing list 30 individuals had responded. This was prior to the onset of any other recruitment campaign. In addition to utilising the research register for recruitment, a social media campaign was initiated utilising the same accounts and recruitment method employed previously. Individuals with a history of self-harm were purposefully sampled through the SHARE UK research register and associated social media accounts. The ADP social media accounts were also utilised for recruitment. The social media campaign was centred around images and videos with posters and research animations created specifically for this campaign. A paid advertising campaign was run via Instagram and Facebook to boost recruitment. The social media campaign targeted participants based on age and geographical location.

Design

This is a cross sectional study utilising a subsection of The Big Data and Mental Health Research Survey (copy of survey included in Appendix H). This survey collected information regarding participants' experience/opinions of barriers or facilitators to taking part in research; opinions on use of data; preferred format of research and participants' own ideas. For the purpose of this study only the questions related to Big Data will be utilised (described in further detail below).

Setting

Data was collected via an online survey. Responses were collected from 18.07.2019-31.01.2020. Participation took place via Survey Monkey. Survey Monkey is an online tool for disseminating questionnaires. This tool was chosen due its user-friendly format, data security and functionality for participants to submit responses anonymously. Participants were given the option to take part by email. However, no participants opted to take part this way.

Measures

The Big Data and Mental Health Research Survey was developed and utilised for the purpose of this study (copy included in Appendix H). This questionnaire was developed with a clinician and ADP interns specifically for the target audience. Participants were asked if they would be willing to be contacted with follow-up emails about the survey and, whether they were happy to be contacted for further research studies. Consent for contact was optional and participants could choose not to consent and continue with the survey. The Big Data and Mental Health Research Survey consisted of 29 questions split into four topic areas. Questions consisted of a mix of free text response and multiple-choice questions (MCQs). With the exception of demographic information all items were optional, and participants were free to choose which items to answer.

Topic Area 1: A bit about you

This section consists of four mandatory questions related to age, gender, location and a history of self-harm. There were three additional optional questions related to self-harm, including history of self-harm and contact with services.

Topic Area 2: Your views on research related to mental health or self-harm

This section consists of eight questions and asks about the topics research should focus on, experiences of taking part in research in the past, barriers and facilitators to research, preferred format (e.g. online or in person) and asks for participant suggestions.

Topic Area 3: Big Data and your data for research

This section starts with a brief description of what is meant by Big Data and how routinely collected data is collected, anonymized and used for research. It is then followed by 12 questions (five multiple choice and seven free text response) asking for participant's views on the use of different kinds of data with items specific to social media, marketing and healthcare data. Questions were asked about the trustworthiness of different organisations (private companies, universities, government etc.) and the precautions around data security. Due to the low number of individuals consenting to have their SHARE UK data linked with routinely collected healthcare data questions were asked specifically around the issue of linkage between surveys and healthcare data. Participants were asked for opinions of the concept of the linkage itself and about giving the information required to make the link (address and date of birth). A brief explanation of what is meant by data linkage and data anonymization is included as part of the survey. This wording was developed with ADP interns aged 16-24 to ensure that this was written in a clear and understandable language.

Topic area 4: Artificial intelligence

The final section consists of two items related to the use of artificial intelligence and its use in both research and healthcare.

For the purpose of this thesis only participants who self-harm will be included in the analysis and data will only be utilised from topic areas one and three.

Analysis of data

Initial data cleaning was conducted to exclude any individuals whose ages did not fall within the 16-24 range. Information regarding gender was cleaned and categorized into 'female', 'male' and 'other.' Individuals who stated that they had never self-harmed or chose not to answer this question were excluded from subsequent analysis. Basic descriptive statistics were generated including gender distribution, mean age and distribution of locations as well as data regarding self-harm and contact with services.

Responses to MCQs were calculated as proportions of participants responding to each question. This included counts, percentages, and 95% confidence intervals estimated by Wilson score with continuity correction (Newcombe, 1998).

Thematic analysis was conducted to analyse the content of free text responses (Hsieh & Shannon, 2005). A coding frame was developed based on responses to MCQs, previous literature (Boyd & Crawford, 2012; Jones et al., 2014; Marwick & Boyd, 2014; Monks et al., 2015), and inductive generation of codes. For the latter, another member of the study team and I

independently identified recurrent and prominent themes in an initial sample of responses (10% of each item) for discussion. The codes were further reviewed and discussed with a third expert reviewer (lead supervisor). New codes were added, and themes were consolidated. The coding frame was piloted on 20% of responses by two independent coders (one of which was the student). Cohens Kappa coefficient for each item was calculated using Excel.

Following initial calculation of Cohens Kappa, the codes were further discussed and refined, and sources of disagreement resolved. This included clarifying the distinction between ethical issues and data security and what should be encompassed under features of research. Following this, items were re-coded and Cohens Kappa recalculated. All items included in the final coding frame had a Cohens Kappa of ≥ 0.7 . The remaining 80% of responses were divided equally between myself and another member of the research team for analysis.

The final analysis was done utilising the following coding frame:

Responses were split into: '**Positive/yes**' indicating positive feelings or an answer of yes to the question asked (e.g. 'yes', 'I would feel ok about this'; k range 0.7-0.9); '**Negative/no**' indicating negative feelings or an answer of no to the question asked (e.g. 'no', 'I would not feel comfortable'; k range 0.7-0.9); '**Neutral, unsure or unclear**' indicating neutral feelings, statement that the participant was unsure/didn't know or responses that could not be clearly categorised (e.g. 'don't know', 'don't understand', 'bleh'; k range 0.7-0.8); '**Conditional**' indicating that the individuals response would be conditional on other factors (e.g. 'would be ok if....', 'definitely not unless....'; k range 0.7-0.9).

Question three 'How would you feel about giving personal information such as address and date of birth for linking research and routine healthcare data?' could not be divided into positive and negative and was instead divided into: '**no to address and date of birth**' (k=0.8), where participants either stated generally 'no' without specifying a difference between the two pieces of information or where participants stated that they would be unwilling to share either piece of information; '**no address**' (k=0.8); '**no date of birth**' (no responses during initial coding to calculate kappa); '**yes to address and date of birth**' (k=0.9), this encompasses responses that state that participants would be comfortable sharing both pieces of data or responses that do not distinguish between different data types; '**yes address**' (k=1.0); '**yes date of birth**' (k=1.0); '**conditional**' where participants would only be happy to share data if certain conditions were met and, '**neutral/unclear**' as in the remaining questions described above.

Within these responses five overarching themes emerged. Each of these themes could be encompassed under 'positive', 'negative', 'conditional', or any of the subthemes unique to question three described above (e.g. the subtheme 'data security and privacy' could be

encompassed under positive, 'great as everything is anonymous'; negative, 'I wouldn't like as this isn't really anonymous'; conditional 'I would only be ok if this was totally anonymous')

The five overarching themes were as follows:

Data security and privacy: This covers issues around the potential for data to be misused, issues around anonymity and privacy and how data is treated, looked after and secured (k range 0.7-1.0).

Ethical issues: Issues around ethical concerns including consent, control over an individual's own data and having enough information to make decisions on taking part (k range 0.8-1.0).

Features of organisation: Concerning reliability, trustworthiness, educational or specific features of the company such as distinguishing between Fitbit and Amazon (k range 0.7-1.0).

Features of research: This theme focused on features of research being conducted including type of research, how it is conducted, the aims, bias, appropriate use of data research quality and characteristics of researchers. This also encompasses impact of research on honesty of results or data quality (k range 0.7-1.0).

Way data is used. This theme discusses opinions on the way data is used encompassing use for profit (k range 0.7-1.0), use to help people or for a 'greater good' (k range 0.7-1.0).

NVivo was used to organise data and themes. The number of participants referring to each theme identified and the numbers of references to it for each question were calculated. Identifiable information such as names or locations were removed from any quotations and replaced with a random initial. No other changes were made to direct quotations with spelling and punctuation exactly as in original responses.

5.3 RESULTS

Description of participants

A total of 3,924 individuals completed the Big Data and Mental Health Research Survey with an average completion rate of 42%. Data cleaning was conducted including the removal of individuals whose ages fell outside of the 16-24 age range and those who did not report a history of self-harm. A total of 2,733 participants aged 16-24 who reported a history of self-harm were included for analysis. The majority of participants were female (female 89%[95% CI 87-90; n=2424]; male 6%[95% CI 5-7; n=168]; other 5%[95% CI 4-5; n=14]; unknown 1%[95% CI 0-1; n=17]). Ninety-two percent (95% CI 91-93; n=2514) of individuals were aged 16-19 with almost

half aged 16 (49%[95% CI 47-51; n=1344]) leaving just 8%(95% CI 7-9; n=219) aged 20-24. A total of 1170(43%; 95% CI 41-45) of individuals consented to be contacted for future research studies.

A total of 8,402 free text responses to open ended questions were analysed. The number and proportion of responses falling into each theme for each question are shown in Table 9.

Table 9 %(95% CI;n) of participants whose free text responses fell into given subthemes^a for each free text response question

How do you feel about anonymous healthcare data being used for research?	
	n=1358
Positive	69(66-69;934)
Negative	5(4-5;70)
Neutral or unclear	2(2-3;33)
Conditional ^b	28(25-28;375)
Data security and privacy	23(21-25;310)
Ethical issues and consent	8(7-10;114)
Features of organisation	0(0-1;2)
Features of research	12(11-14;167)
Way data is used	20(18-22;273)
Greater good	20(18-22;273)
Profit	0(0-0;0)
Would you like a better explanation of how your data is used and shared for research?	
	n=1278
Yes	61(58-61;774)
No	35(32-35;441)
Neutral or unclear	4(3-4;46)
Conditional ^b	2(2-2;28)
Data security and privacy	4(3-6;54)
Ethical issues and consent	1(0-2;10)
Features of research	6(4-7;72)
Features of research organisation	0(0-1;4)
Way data is used	3(2-5;42)
Greater good	3(2-5;42)
Profit	0(0-0;0)
How would you feel about researchers linking things like your answers to questionnaires with anonymized healthcare data^c why?	
	I would be ok with this
	n=546
Data security and privacy	28(25-32;155)
Ethical issues and consent	4(3-6;23)
Features of organisation	0(0-1;1)
Features of research	21(18-25;115)
Way data is used	53(49-57;290)

Greater good 53(49-57;290)
 Profit 0(0-0;0)

**I would not be ok with this
 n=71**

Data security and privacy	48(36-60;34)
Ethical issues and consent	11(5-22;8)
Features of organisation	1(0-9;1)
Features of research	21(13-33;15)
Way data is used	1(0-9;1)
Greater good	1(0-9;1)
Profit	0(0-0;0)

In order to link between research and routine healthcare data some personal details are needed including address and date of birth. These get sent to NHS information partners to make the link. Researchers never see this information and it is destroyed after the link is made. How would you feel about giving personal information such as address and date of birth for this purpose? (You do not have to give this here)

n=1233

No address or DOB ^d	34(31-37;418)
No address	13(12-16;165)
No DOB	1(0-1;7)
Yes to both ^d	28(26-31;347)
Yes address	0(0-1;2)
Yes DOB	13(11-15;162)
Conditional ^b	21(19-24;262)
Neutral or Unclear	5(4-6;57)

How do you feel about your social media posts being used for research? Would the data being anonymized make you feel differently?

n=1315

Positive	19(17-19;247)
Negative	43(40-43;563)
Neutral or unclear	6(4-6;74)
Conditional ^b	35(33-35;464)
Data security and privacy	48(46-51;636)
Ethical issues and consent	7(5-8;85)
Features of organisation	0(0-1;2)
Features of research	13(12-15;176)
Way data is used	3(2-4;34)
Greater good	2(2-3;31)
Profit	0(0-0;0)

How about information from companies such as Amazon, Google or Fitbit being used for research?

n=1204

Positive	31(28-31;372)
Negative	39(36-39;471)
Neutral or unclear	8(7-9;101)
Conditional ^b	24(22-24;288)

Data security and privacy	14(12-16;168)
Ethical issues and consent	8(6-9;91)
Features of organisation	6(5-8;76)
Features of research	7(5-8;81)
Way data is used	5(4-6;58)
Greater good	4(3-5;43)
Profit	1(2-2;15)

Do you feel differently about research done by universities than that done by companies?

	n=1315
Positive ^e	59(56-59;776)
Negative	26(24-26;344)
Neutral or unclear	13(11-13;173)
Conditional ^b	3(2-4;43)
Data security and privacy	2(2-4;31)
Ethical issues and consent	6(5-8;79)
Features of organisation	15(14-18;203)
Features of research	9(8-11;122)
Way data is used	22(20-24;286)
Greater good	14(12-16;177)
Profit	11(9-13;141)

Do you have any other thoughts or comments about how personal/healthcare data is used?

	n=82^f
Data security and privacy	12(9-17;35)
Ethical issues and consent	8(5-12;23)
Features of organisation	1(0-4;4)
Features of research	6(3-9;16)
Way data is used	5(3-8;14)
Greater good	5(3-8;13)
Profit	0(0-2;1)

a. Subthemes pooled across positive, negative, neutral and conditional.

b. Answers indicate that their response is dependent on one or more conditions being met

c. MCQ question with options 'I would be ok with this'; 'I would not be ok with this'; 'why?'. Table refers to free text responses to the 'why?' option

d. Answers either indicate that they would/would not be willing to give both address and date of birth or answered yes/no without specifying a different opinion on the two pieces of data

e. Feel more positive about research done by universities

f. Answers of 'no' or 'unclear' excluded

History of self-harm

Self-injury was the most frequently reported method of self-harm (Figure 6) with 92%(95% CI 93-95; n=2562) reporting self-injury. This was followed by ingesting medication in excess of the prescribed dose reported by 36%(95% CI 34-38; n=980) of participants. Around a third of

participants (36%[95% CI 35-38; n=996]) report having harmed themselves with the intention of taking their own lives.

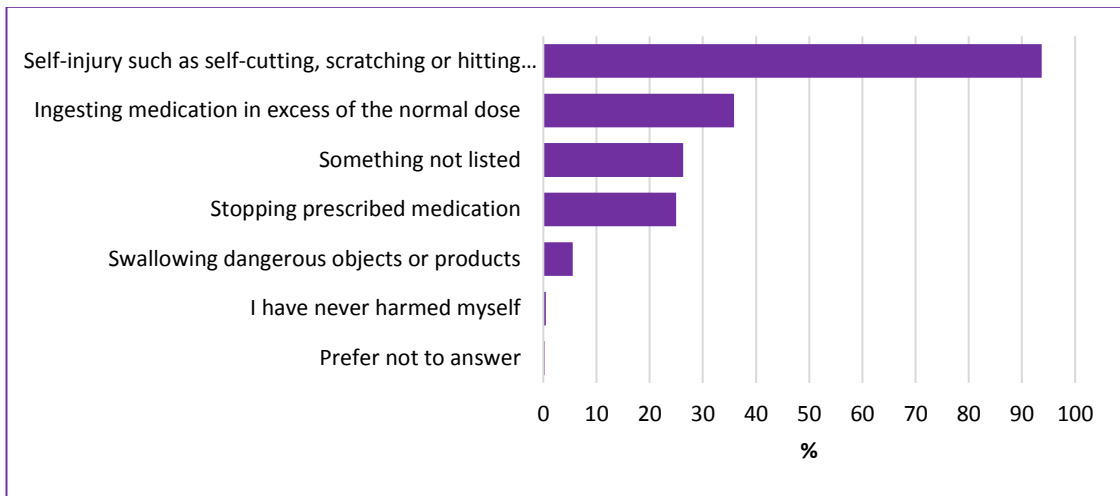


Figure 6 Have you ever done any of the following intending to harm yourself (tick all that apply)

When asked about help received following any time they had harmed themselves almost half (44%[95% CI 42-26; n=1135]) reporting not receiving help from any of the sources listed. Friends, family and neighbours were the most common sources of help followed by psychiatric or mental health services (Figure 7).

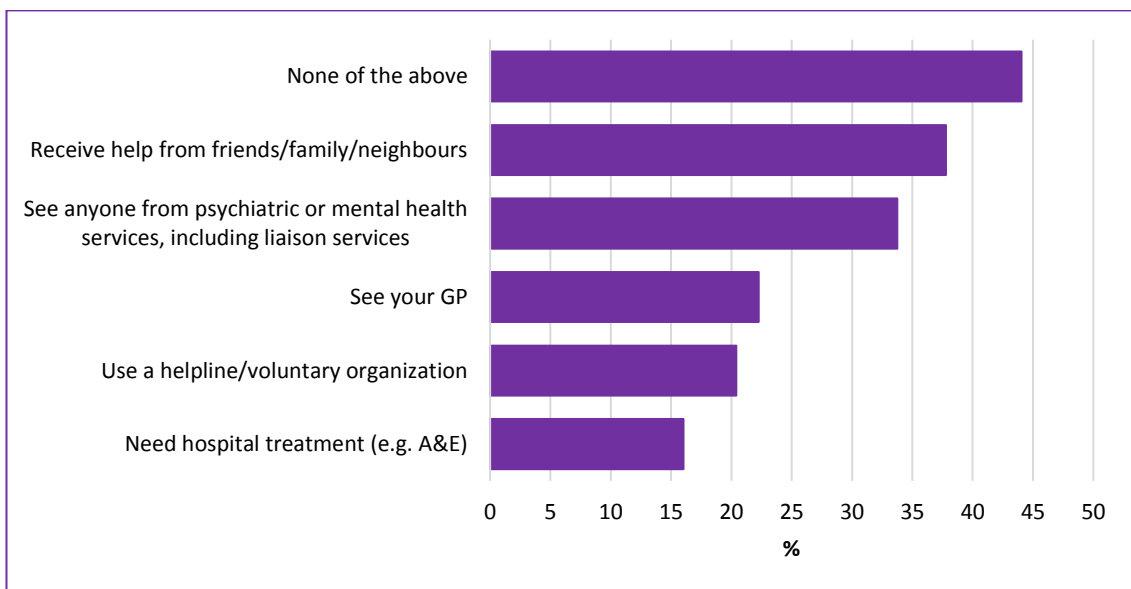


Figure 7 Responses to the question 'following any time when you took an overdose or intentionally tried to harm yourself did you (tick all that apply)'

Different sources of Big Data for research

Participants were asked the question 'thinking about data more generally (not only health data), how likely would be to share the following types of data for research purposes?' Individuals were

most likely to share their ethnicity (76% [95% CI 74-78; n=1080] of participants either extremely likely or likely to share), marital status (66% [95% CI 63-68; n=932] extremely likely or likely) and mental health data (76% [95% CI 74-78; n=1083]) either extremely likely or likely). Participants were least likely to share their social media posts and financial information (Figure 8).

Possible reasons for this were explored in open-ended questions. When asked how they felt about researchers using their social media posts for research only 19%(95% CI 17-19; n=237) of participants responded positively, 43%(95% CI 40-43; n=563) responded negatively with 35%(95% CI 33-35; n=464) stating that they would only be happy to share this information if certain conditions were met.

The most common reasons for not wanting to share this information were concerns over anonymity and privacy. Social media was considered by many to be very personal information with some describing this data as being more personal than medical data.

‘That’s a lot more personal than medical data so could be uncomfortable.’

Participants were sceptical about how it is possible to anonymize social media posts with concerns raised around images.

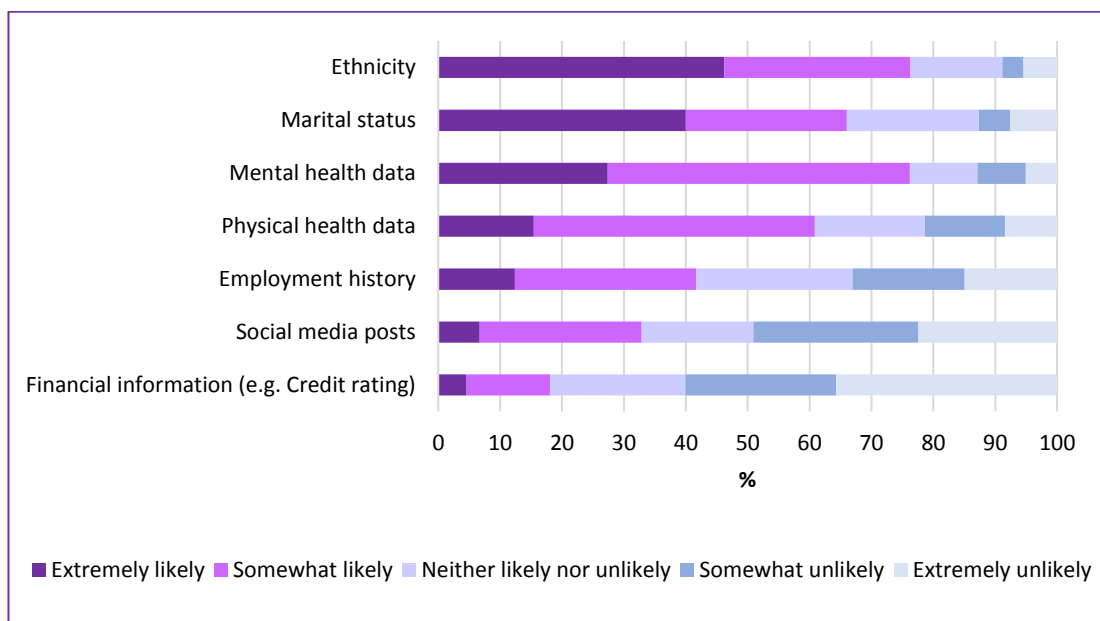


Figure 8 Responses to the question: 'Thinking about data more generally (not only health data), how likely would you be to share various types of data for research purposes?'

‘Most of the stuff I post is pictures therefore I’m not sure how that can be anonymized.’

‘Uncomfortable due to the lack of anonymity as it’s my face, you can’t really make that anonymous.’

Distinctions were made between different social media platforms and privacy settings.

'I'd hate to have my social media posts used for research as its private for a reason. If it was anonymous, I'd feel better but only for things like twitter where there's mostly just tweets rather than photos.'

There were contrasting views about perceived privacy and ownership of data on social media from those who were and were not comfortable sharing this data. Individuals who responded positively to sharing their social media data often stated that this data was not private anyway and were under the assumption that their data was being analysed by researchers.

'I make my social media accounts public by choice, therefore I wouldn't mind my posts being used for the purpose of research- the social media companies themselves already do this whether you like it or not for advertising etc.'

'When i signed up I assumed it would be analysed in some way.'

In contrast individuals who responded negatively to sharing their social media data for research perceived this data to be personal/private.

'Social media should only be used in research if the person is completely happy and aware with where there data is taken. Pictures or videos should never be taken. If social media is used then I feel it is no longer anonymized. People can look up specific captions and hashtags taken from posts and you have lost complete anonymity.'

Data security and privacy was also the most common condition for being comfortable sharing this information with 84%(95% CI 81-97; n=391) of those giving conditional responses giving conditions related to data security and privacy.

'Data being anonymized and no pictures of myself is perfectly fine.'

'As long as there was nothing to identify me specially, and if the information was public anyway, I would be okay with this.'

Ethical issues, in particular the option to consent, were also frequently mentioned in conditional responses.

'Even if it was used anonymously, I would like the option to consent.'

Other concerns raised were over how useful social media data would be with many participants stating that everything over social media is 'fake'. The most commonly reported reason for being willing to share this information was its potential to be used to help people.

The use of anonymized healthcare data

When asked 'how do you feel about anonymous healthcare data being used for research?' 69%(95% CI 66-69; n=934) of participants indicated that they felt positively about this with just 5%(95% CI 4-5; n=70) responding that they felt negatively about this. Around a quarter gave a conditional response.

The most common reason for a positive response was the use of data for 'the greater good.'

'I think it's amazing because it might actually cause a big improvement in schools and how mental health is talked about, treated and supported.'

The most common negative responses fell under 'features of research.' These were mostly related to concerns over how useful this kind of data could be without the context or surrounding circumstances. This was followed by concerns over data security and privacy.

'Not okay. Medical history is a very personal and confidential matter.'

The use of data for the 'greater good' or for the purpose of helping others was also a common theme of conditional responses. Conditional responses were most frequently related to concerns over data security followed by ethical issues.

'I think using this information is very beneficial but people should be made more aware that their data could potentially be used and given an option to opt out if they do not feel comfortable with this.'

When asked the question 'how would you feel about researchers linking things like your answers with anonymized healthcare data?' 94%(95% CI 93-95; n=1310) responded 'I would be OK with this'. A total of 617 individuals gave a free text response to the follow-up question, 'Why?' Of those who answered 'I would be OK with this' more than half gave reasons related to use of this data to help people.

'If it helps other people and saves life's of people in healthcare crisis then it is a great thing to do. And if it has any chance of waking the government up to the fact that the older generation is not the only one that matters and that we desperately need help and that the world has changed and they have to change too, then of course I want to help.'

Of those who answered 'I would not be ok with this' the most frequent responses were related to data security followed by ethical issues particularly related to consent.

'I'm not wholly against my data anonymously being used for research but I wouldn't be happy if this was done without my knowledge/consent. It would feel like a violation and breach of trust between me and the healthcare professionals I had disclosed information too originally. It makes me feel like I'm just a set of data to scientists/researchers/doctors.'

While the majority of participants were comfortable with questionnaire responses being linked with routinely collected healthcare data, many were not comfortable providing the data required for linkage. When asked how they would feel about giving data including address and date of birth for data linkage 34%(95% CI 31-37; n=418) indicated that they would not be comfortable giving either address or date of birth with a further 13%(95% CI 12-16; n=165) not comfortable giving their address. Just 28%(95% CI 26-31; n=347) of individuals were happy to give both address and date of birth that would be needed. A further 21%(95% CI 19-24; n=262) indicated that they may be more willing to give this information if certain conditions were met.

Individuals were more comfortable giving their date of birth than their address as this was thought to be less identifiable information. In addition 4% of respondents were willing to give a generic location or postcode rather than a specific address. Other suggestions included use of an NHS number. The most common reasons for not wanting to give this information were concerns related to data security. Many expressed concerns about the security of giving this information online.

'I would only feel comfortable doing this in person. I would worry my data could be misused if communicated online.'

Others were concerned about other people that they live with, being written to at their home address and, the impact of being identified.

'Date of birth fine. Address no. I just know my mum wouldn't be ok with it.'

'I would be scared. What if i told a researcher about my self-harm issues and i get sectioned again.'

Those who were willing to share the required information were most likely to give the 'greater good' as a reason and a willingness to contribute data to help others.

When asked the question 'do you have any other thoughts or comments about how personal/healthcare data is used?' the most common responses were related to data security and privacy, with individuals often having specific queries about aspects of data linkage/security.

'Yes, how secure are the databases mentioned in this section. I would particularly interested in how securely kept the data is for the NHS.'

Others had more general concerns about privacy and security.

'I think a few people are a bit worried that if a huge leak happens, that your insurance could be affected by your mental health status - and that would suck for a lot of people.'

The use of mental health data for research purposes

The majority of participants agreed that mental health data should be used to understand more about mental illness (96%[95% CI 95-97; n=1326] either 'strongly agree' or 'somewhat agree' Figure 9). However around a third of participants reported that they would be less likely to access NHS mental health services if they knew that their data would be shared with researchers. In terms of factors around the sharing of this data almost all participants agree or strongly agree that they should have the right to opt out of mental health data sharing and that this data should be held by a trusted organisation. More than half of participants also either 'strongly agree' or 'somewhat agree' that people should be asked for consent every time a researcher wants to use their data in a new project, that it should be impossible for mental health data to be linked back to the person who provided it and that researchers studying mental health should have advisors with personal experiences of mental health conditions.

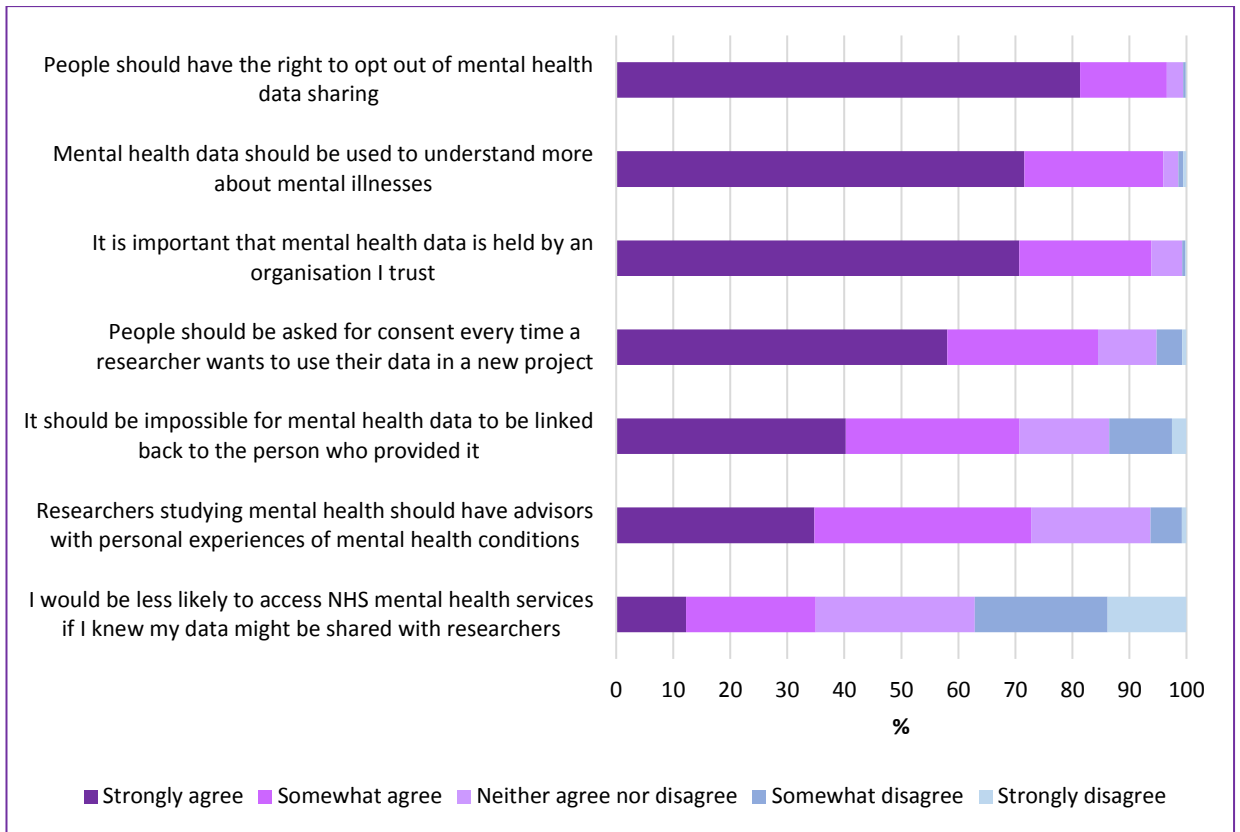


Figure 9 Responses to the question: 'when thinking about sharing mental health data, to what extent do you disagree or agree with the following statements?'

Measures that could be taken that may influence how comfortable individuals feel sharing their mental health data were explored (Figure 10). When asked the question 'how would the following measures change the likelihood that you would be willing to share your mental health data for research purposes?' having their name removed from data was the most likely item to change the likelihood of being willing to share mental health data for research. Being asked for permission each time the data was used, researchers undergoing special training and data being part of a large dataset were also rated as likely to have an influence. Having no control of what the data used for in the future was rated as the least likely to have an influence followed by data being matched with other information such as school records and not being able to withdraw data in the future.

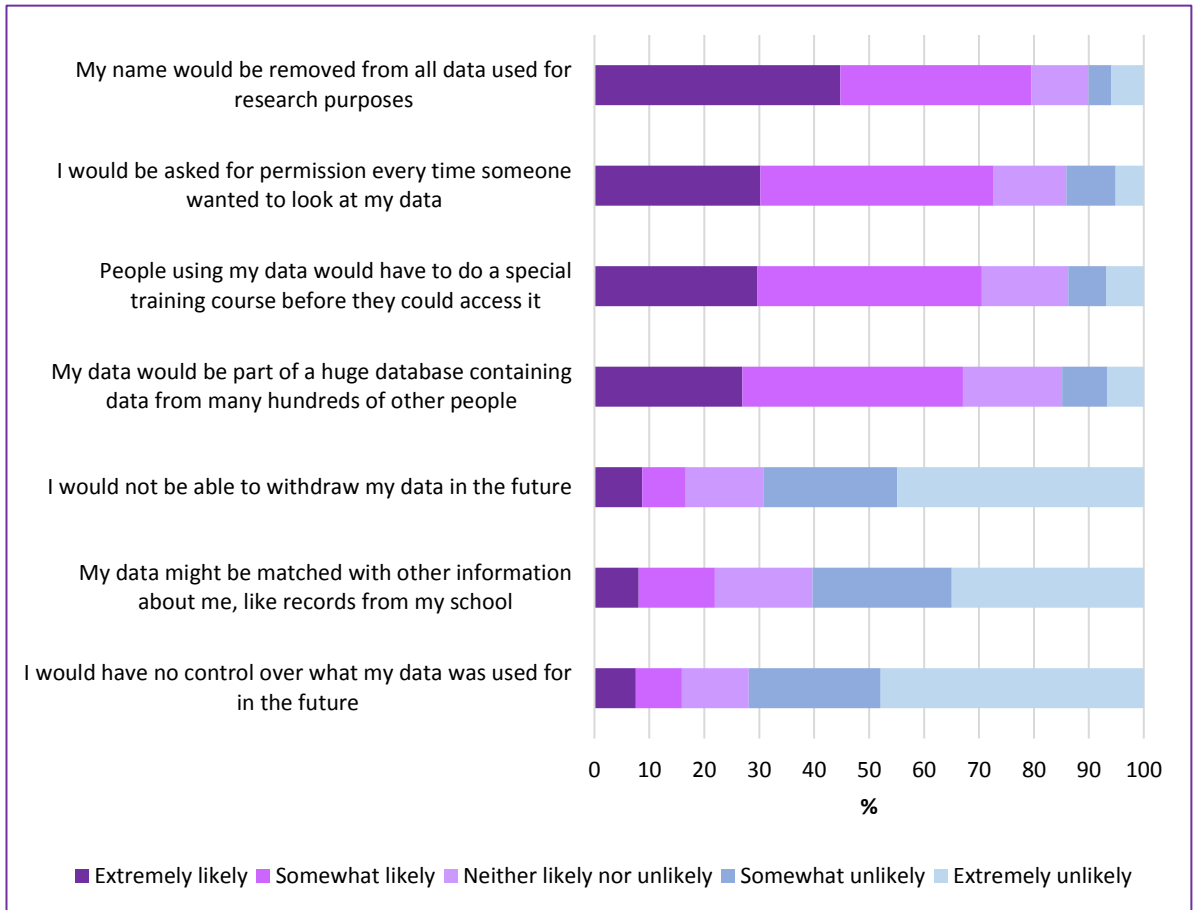


Figure 10 Responses to the question: ‘How would the following measures change the likelihood that you would be willing to share your mental health data for research purposes?’

Results of the qualitative analysis suggest that young people may feel more positive about sharing their data if they were better informed about the nature of the research and potential benefits services. When asked the question ‘Would you like a better explanation of how your data is used and shared for research?’ 61% (95% CI 58-61; n=774) responded positively/yes, with explanations required to be short and easy to understand.

‘Better as in shorter and more concise, easier and quicker to read.’

Across both those who responded that they would like a better explanation and those who would not a common theme of wanting to know more about the research and impact was seen. For example participants who stated that they would like a better explanation stated;

‘Yea, it would be good to know how this research will help people in the future who struggle with mental health problems.’

‘Yes, I’d love to be able to see the final pieces of research too.’

Whilst others who did not want any further explanation on how their data is used wrote;

'To be honest, as long as my personal info is not given away I am not fussed. However, I think that anyone who took part should be allowed to view the paper in full once drafted or published. Normally you have to pay a fee to read a research paper but this seems a bit unfair if you were part of the experiment!'

'Not necessarily an explanation, more an update on the impact it has and what good comes from surveys like this!'

'Not really, but would like to be sent the overall findings after the study has been completed to see the impact my participation has had.'

Participants reported feeling that a better explanation would make it feel more worthwhile to give consent for data to be used.

'Yes I think being given detailed information on how your data is used helps you to feel like it was worth giving consent for researchers to use it and would make me more likely to allow my data to be used in the future.'

Features of organisations and Big Data research

When asked *'in your opinion, how trustworthy are the following organisations when it comes to storing and using mental health data for research?'* participants reported that mental health charities were the most trustworthy, followed by the NHS and Universities with private companies rated the least trustworthy (Figure 11).

The open-ended question *'do you feel differently about research done by universities than that done by companies?'* provided some further insight into opinions on various organisations.

Overall 59%(95% CI 56-59; n=776) of individuals reported feeling more positively about research done by universities than research done by private companies. Around a quarter of individuals reported feeling less positive about research done by universities with less than 5% giving conditional responses. Of note many individuals appeared to be under the impression that it was mostly students performing research in universities. Positive responses were most frequently related to features of the organisation with universities regarded as more trustworthy, educational institutions with the role of students regarded positively.

'Yes, as people from universities are younger and are more likely to understand.'

Universities were also perceived to have better data security.

'Yeah somewhat. I always feel that companies don't keep it 100% anonymous but that universities do.'

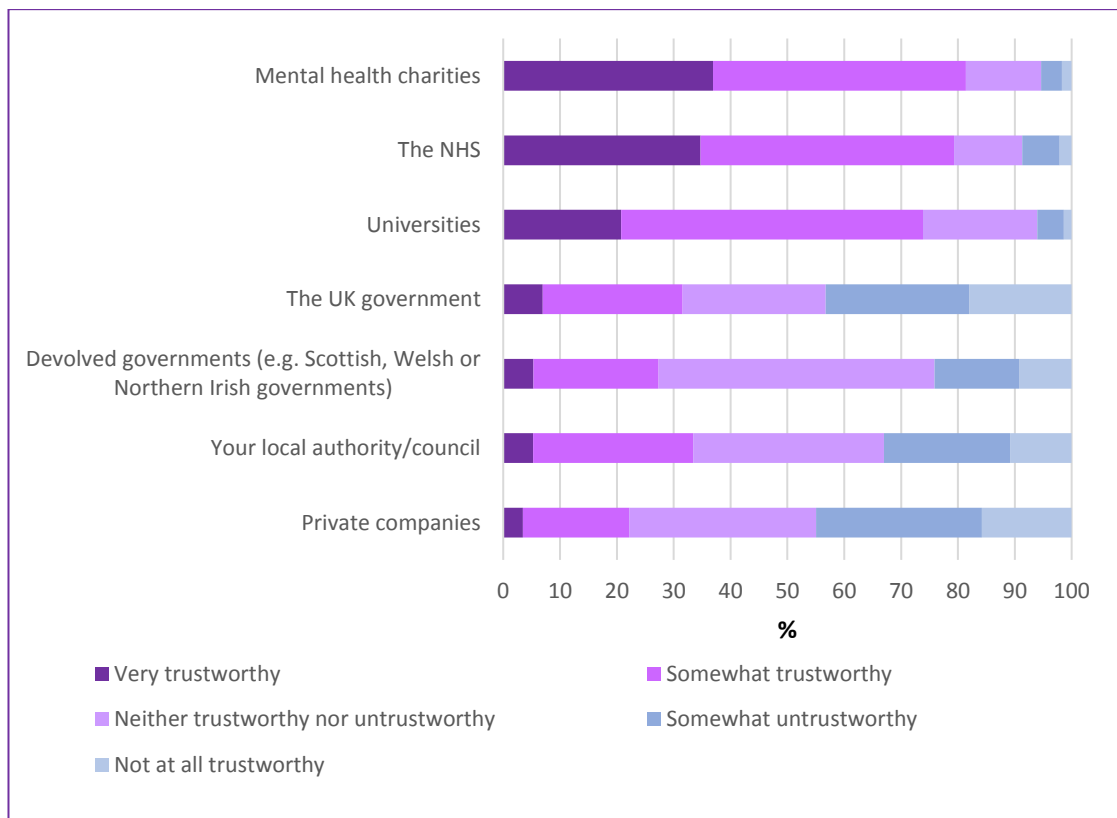


Figure 11 Responses to the question 'In your opinion, how trustworthy are the following organisations when it comes to storing and using mental health data for research?'

University research was commonly described as feeling safer and more ethical with a focus on the greater good of developing the field and helping others as opposed to use for profit.

'Yes, if university research is being done then it is often for the greater good but often with companies I feel that our data can be misused.'

'Yes I trust universities a little more as I worry businesses might care more about money than the research.'

'Features of research' was also discussed with some participants wanting more details on the outcomes of research.

'I have done a lot with research for universities and never seen the outcome of the data.'

When asked the question 'how about information from companies such as Amazon, Google or Fitbit being used for research?' 31%(95% CI 28-31; n=372) responded positively, 39%(95% CI 36-39; n=471) responded negatively and 24%(95% CI 22-24; n=288) stated that they would only be comfortable with this if certain conditions were met. Amongst positive responses were

statements that this data is less invasive/personal than other data types. The most common negative responses were around data security and privacy.

'I think the data these companies collect is wrong as I feel it violates our online privacy and kind of scares me to know they track your every action online.'

Consent and ethical issues were common amongst negative responses, as was discussion of use of data for profit.

'If the person is not aware that research is being done in them then I don't think it is the right thing to do.'

'No. those purposes would be advertising purposes and that isn't helping the public, only themselves at the expense of the person whom the data comes from.'

Participants also discussed the features of any given research, most commonly referring to the fact that this type of data is not relevant to mental health.

'These companies have nothing to do with mental health or medical in any way, therefore they would not be relevant to the research.'

However conversely those who responded positively to the use of this data stated that the range of data available could be very positive for mental health research. In terms of features of organisations Fitbit was singled out as a company individual felt more comfortable with. The most frequent conditional responses were related to data being appropriately anonymized, having control over what data is shared (e.g. exercise and sleep data from Fitbit but not location) and being given the option to consent.

The purpose of the data was also frequently discussed with negative views of data being used to make a profit or for corporate gain.

'No. those purposes would be advertising purposes and that isn't helping the public, only themselves as the expense of the person whom the data comes from.'

'It would make me uneasy as they would use the data for purposes other than healthcare.'

The use of data for the 'greater good' also frequently appeared in conditional responses.

'Personal healthcare data should be used only with the intent to help people suffering from mental illnesses.'

'Only if it benefits other people and provides them help.'

5.4 DISCUSSION

Results of this survey provide an analysis of participant's views on the use of their data for research encompassing a range of Big Data sources. This survey is the first to focus on the views of young people aged 16-24 with experience of self-harm in relation to this topic. The combination of multiple choice and free text response questions provides a richness of data on which to base future research. Results of this survey give an indication of why consent for linkage with the SHARE UK platform and routinely collected healthcare data was lower than originally hoped. This chapter also demonstrates the utility of the SHARE UK research register for recruitment to research and, the potential for a successful future for the platform in collaboration with the ADP. Each of these points and implications for future research will be discussed in turn below.

Sample and self-harm information

The population sampled here were broadly similar to that of the SHARE UK platform with a high proportion of female participants (84% in SHARE UK, 89% in Big Data Research Survey). There is a higher percentage of 16-19 year olds in The Big Data and Mental Health Research Survey cohort (21% SHARE UK, 90% Big Data and Mental Health Research Survey) most likely due to targeted social media advertising and restrictions on age for participation in The Big Data and Mental Health Research Survey that were not present on SHARE UK.

The two samples were also broadly similar with regards to self-harm information with self-injury the most commonly reported method of self-harm (94% of SHARE UK participants, 92% of Big Data and Mental Health Research Survey). Almost half of participants in both samples report not receiving help from anyone for self-harm, in keeping with previous research (Rowe et al., 2014; Ystgaard et al., 2009).

The SHARE UK research register and collaboration with ADP

This survey is the first instance of the SHARE UK research register being used to recruit to research. It was not possible to link the respondents of the survey with the SHARE UK research register as this fell outside of the ethical approval granted. This means that it is not possible to say how many individuals from the SHARE UK research register took part overall. After the initial email was sent out to the research register 30 responses were recorded within eight hours. This was before any other form of recruitment had taken place. It appears that this represents a promising positive resource for future research. SHARE UK worked in collaboration with the ADP for the purpose of this study. The resources available in the ADP include access to budgets for

social media advertising, offering further promise for the future of the platform. This is demonstrated here by the addition of a further 1170 individuals who self-harm consenting to be contacted for future research. This large increase in numbers demonstrates that with additional resources for recruitment both the platform itself and the research register have the potential to continue to grow.

Overview of survey results and comparison with previous literature

Results here are in keeping with research done with older generations with regards to the use of healthcare data for research (Douglas et al., 2017; Jones et al., 2014). Young people with experience of self-harm share largely positive attitudes towards their healthcare data being used for research. Positive opinions are reflected in repeated statements that data should be used to help others, make improvements to services and save lives. Participants however, stressed the importance of anonymity and the need for appropriate ethical approvals to be put in place including transparency, consent and the option to opt out of having their data used for research. This keeping with previous research with mental health service users aged over 40 demonstrating that participants were comfortable sharing sensitive information for research purposes if data was safeguarded and research aimed to help others (Satinsky et al., 2018). Such concerns are supported by the wider literature where the need for identity protections, data security, transparency and safeguarding policies, whilst ensuring the use of the data is within the public best interest is emphasized (Ienca, Vayena, & Blasimme, 2018; Riordan et al., 2015).

While young people are largely in agreement with the views of older adults around several key issues, results here show that young people additionally have very specific questions and concerns around the process of data linkage and anonymization, with some concerns specific to each data type. Young people expressed privacy concerns related to living with parents. For example, some were worried about their parents finding out about their self-harm or, how their parents would feel about them giving their details online for the purpose of research. This demonstrates the need for education of both young people and parents/carers. Young people also repeatedly stated that they would like to know more about the research being conducted using their data and how it was being used to help others.

Young people taking part in the current study were less willing to share social media than other kinds of data, with the feeling that this is more personal than healthcare data. Specific concerns were raised around how it would be possible to anonymize social media data, particularly images, and around ethical issues including consent. There was a disparity between those who were and were not comfortable sharing social media data in terms of the perceived privacy of

this data. Those who were comfortable sharing this data for research were often aware that this data was already being analysed and stated that they put things online with the understanding that anything they share does not remain private. In contrast many of those who were not comfortable sharing this data believed that this data was private to them and the people they chose to share this with. This is in keeping with existing literature in relation to a lack of awareness of understanding of privacy issues online (Hoofnagle, King, Li, & Turow, 2010; Madden et al., 2013). In addition, results demonstrate that young people care about their online privacy to great extent, and while some young people may lack awareness others demonstrate sound comprehension of these issues as they relate to social media and the use of their data.

With regard to use of both healthcare data more generally and mental health data specifically, anonymity, consent and features of research are key factors that influence the feelings of young people. Repeatedly young people expressed wanting to help others with similar struggles and for their data to be used to improve services. Participants frequently expressed negative opinions about the use of their data for profit or advertising, often referenced in relation to the use of their data by private companies. Young people also reported wanting to know about research, how their data has contributed to positive change and the impact of research on services and the lives of individuals. The loss of control over data once shared, linkage with other sources of data including educational data from schools and in inability to withdraw from data sharing are concerns influencing negative feelings towards the sharing of data. Taken collectively, these results indicate that young people who self-harm appreciate the importance of Big Data in mental health research for providing a better understanding and evidence base to inform service provision, and that they would feel more comfortable if given more information and control over their data.

Implications for research with healthcare data

While the majority of participants preferences for the sharing of their health data are already adhered to in many large linked health data sets, such as the option to opt out and there being no way for mental health data to be linked back to the person who provided it, as detailed for example, in the SAIL databank terms of service (Ford et al., 2009; Lyons et al., 2009), others are more problematic in practice. Participants appear to be uncomfortable with the idea of having no control over what their data is used for in the future and expressed a preference for being asked consent each time their data is used. Asking an individual's consent each time their data is used has many issues, not least of which is that if data is anonymized to the extent that it cannot be linked back to the individual then it is impossible to contact participants for each use

of their data. In addition the sheer number of participants who contribute data to such studies using healthcare data (often hundreds of thousands or more), combined with the volume of studies that are conducted would pose a major practical challenge for researchers and a burden for participants to consent every time. A better solution to this issue of consent would be better quality information available for the public around data sharing and how this is used. For example, publicising the research being done and how healthcare data is being used to improve services, not just for mental health but for physical health conditions as well. The anonymization process should be well explained in a clear language with the volume of research and the benefit to services and individuals highlighted. This needs to go beyond journal publications and academic conferences to mainstream and social media. Incorporating meaningful coproduction of research and public education with individuals who have experienced self-harm/mental health issues is essential to make such efforts a success.

Linkage with other data sets appears to be a source of uncertainty in terms of comfort of data use for participants here. This should be explored further in future research, potentially in a focus group or in-depth interview setting where researchers can provide a thorough overview of what this kind of research entails. This would provide participants the opportunity to ask questions and raise specific concerns in way not possible in an online survey. This would also allow participants and researchers to discuss the benefits of this research and to explore how these balance with participants concerns about the use of their data.

There is a need for greater awareness and clarity of data anonymization procedures and, the nature of research conducted with routinely collected healthcare data. Participants repeatedly state that they would like to know more about the research being done. One of the key factors influencing positive opinions towards sharing of data was the desire for this data to be used to help others. Young people want to improve services and help others having similar experiences. Raising awareness of the ways in which research can be used to improve services and lives would likely have a positive impact on attitudes towards data sharing. Any campaigns to raise awareness should be widely accessible to young people with social media likely to be a useful way to reach young people. Contact could also be made with participants of previous studies to share summaries of research, real world impacts to services and research papers related to the studies in which they have participated.

Implications for future research linking survey and healthcare data

While the majority of participants (94%) were happy with the concept of survey responses being linked with routinely collected healthcare data, the linkage process itself poses a significant

barrier. This may underlie the low levels of consent to linkage with healthcare data seen on the SHARE UK platform. In order to make the link between survey data and routinely collected data such as that held in the SAIL databank, address and date of birth are required. While this is held securely and destroyed after the link is made, many young people understandably expressed discomfort with this. Address posed a particular barrier. Many young people live with their parents or others and did not want to risk being written to at their home address. Many were also not comfortable giving this data online for fears over data security. Such concerns have been found previously in relation to mental health data. Reservations about the use of mental health apps due to the potential for misuse of data have been reported, with participants reporting pervasive concerns related to sharing data over technology (Satinsky et al., 2018).

Several measures could be taken to improve levels of linkage between survey and healthcare data in future studies. Allowing an alternative format for individuals to provide this data, such as providing an option to speak to a researcher and to give this information in person would potentially resolve some of these issues. As well as addressing concerns about the security of providing this data online, this would also allow young people and researchers to discuss the use of their data. This would give young people the opportunity to ask questions and researchers the opportunity to gain valuable feedback and insights from young people. Better education and explanation of the linkage process may also be beneficial, potentially with facilities incorporated for participants to ask questions, for example by telephone, email or live chat with a researcher. The possibility remains however, that for some young people the prospect of giving out their address may continue to pose a significant barrier, the only solution to which is an alternative method of linkage. Participants stated that they would be happy to give alternative information such as postcode or NHS number without a full address both of which could be explored for data linkage in the future.

Implications for future research utilising social media data

Results here support previous concerns around assuming consent for the use of social media research (British Psychological Society, 2017). Participants here echo previous concerns around anonymization, security and privacy raised by younger adolescents around social media data in mental health research (Monks et al., 2015). This supports previous calls for care to be taken with what information is published in papers for example, direct quotations that could be linked back to the original poster (British Psychological Society, 2017). Furthermore images were highlighted as a specific source of concern in the current study not seen previously, most likely due to the increasing popularity of image-based platforms as described in Chapter Three.

Anonymity as it relates to images is an important ethical concern for researchers going forward. It is important that standard procedures are in place for this. For example, the use of artificial intelligence to code various aspects of images and avoiding reprinting images taken from social media without the consent of the person who posted the image. In spite of these concerns young people who self-harm expressed a desire to help others going through similar experiences and a willingness to share their data for this purpose. This is supported by previous research with adolescents who were more positive about sharing data that would be used to help others, particularly for topics they felt strongly about such as cyber-bullying and body image (Monks et al., 2015).

Findings here dispute the common misconception that just because young people post a large amount of their data online that they 'don't care' about their privacy (Marwick & Boyd, 2014). This further supports previous calls for social media users to adopt a more informed and critical stance toward how and why their data might be used or building 'critical data literacies' (Pangrazio & Selwyn, 2018). Education is needed for all social media users, not just young people, about how their social media data is used and the fact that their data is available for research on most platforms as part of the terms of service. Standardised anonymization processes such as those suggested by the British Psychological Society (British Psychological Society, 2017) would represent a positive step towards clarifying how exactly identities are protected when utilising this data for research. Such processes should include consideration of the republishing of photos and direct quotes in research outputs as even with user names or personal details removed there is still the potential for these to be traced back to the individual (Narayanan & Shmatikov, 2008, 2009). Special consideration should be given to vulnerable groups including children and adolescents and people with mental health issues (Golder et al., 2017).

Strengths and limitations

This is a large survey with almost 3,000 participants and represents the first of its kind with young people aged 16-24 with experience of self-harm. The use of an online convenience sample means that results should be interpreted with caution and may not be generalisable to the rest of the population. That being said the use of this method of sampling does have several advantages including minimising social desirability bias particularly given the potential stigma around self-harm. This method of sampling also allows for a large sample of participants to be recruited. As such, despite its limitation online convenience samples have been supported by researchers with the advantages of reaching hard-to-reach communities highlighted (Reisner &

Juntunen, 2015). Research and surveys conducted online have the advantage of providing access to groups and individuals who are typically hard to access for research. Online research also conveys a number of advantages for participants over face-to-face methods including increased anonymity, ability to provide information at their own pace, sense of control and convenience (Ahern, 2005). Virtual communities and sites for research offer a way to bring together individuals with specific characteristics in way not otherwise possible. This is particularly relevant for individuals who face stigma offline (Close et al., 2013; Yuan et al., 2014) and for those who may not want to meet with researchers face-to-face (Wright, 2017). While research conducted online is more cost and time efficient, individuals who take part online are less likely to complete all sections of surveys/interviews (Heiervang & Goodman, 2011). As described above this method of sampling limits the generalisability of research. Participation in online interviews are selective with lower rates of full participation seen for those with less education, single-parent and immigrant families (Heiervang & Goodman, 2011). Furthermore, online surveys have been found to under-represent children and adolescents from disadvantaged backgrounds (Goodman, 2013; Heiervang & Goodman, 2011). This may result in underestimations of need if used alone to inform policy (Goodman, 2013). Online surveys often result in samples biased towards younger age groups, well-educated and English speaking participants (Batterham, 2014; Klovning et al., 2009). The sample of participants in the current study were predominantly young females with almost half aged 16 and more than 90% aged 16-19 years. This has meant that stratifications by age and gender would not have been meaningful in the current analysis. Future research should seek to specifically target males and young adults as opposed to adolescents to gain a more comprehensive overview of the opinions of this group and increase generalisability. Future research should endeavour to broaden the participant sample to disadvantaged groups such including those who do not have reliable internet access. This could be done through schools, colleges or drop-in centres and could include a pen and paper or in person format. This should include assistance for those with literacy difficulties or for whom English is not their first language.

People with mental health issues were more likely to fill out mental health related questionnaires than the remainder of the population. This difference is amplified for online surveys (Batterham, 2014). While this would be potentially problematic for any estimates of prevalence, it is potentially an advantage for gaining the opinions of groups who are often difficult to reach for research. Individuals who self-harm were purposefully sampled in this study and it is notable that there was high engagement from this typically hard to reach group. This may have been related to nature of the social media campaign which was largely run through

Instagram and utilised existing social media channels for the SHARE UK and ADP platform. It may also have been related to the user-friendly format of the survey itself being run through Survey Monkey. The use of Survey Monkey meant that an email exchange or multiple steps for participants to provide informed consent was not required with this process streamlined in one user-friendly format.

5.5 CHAPTER SUMMARY

The aim of this chapter was to learn more about the views of children and young people with experience of self-harm on the use of their data for research, their understanding of this and potential issues with the linkage process. This chapter describes a national survey of young people aged 16-24 with experience of self-harm, gaining an understanding of their views around Big Data and mental health research. The successful partnership of the SHARE UK platform with the ADP for this study was described as were the implications of such a partnership for the future of the platform. Issues around linkage of survey data, such as that from the SHARE UK platform, with routinely collected healthcare data were explored. While more than 90% of participants were positive about the idea of linkage between survey responses and healthcare data, the process of linkage itself represents a barrier to this in practice. In particular participants are required to give their address and date of birth for the purpose of linkage. This is something many participants are not comfortable with. Concerns were raised over the security of giving this information online. In addition many participants live with parents and as such do not want to give their address. Potential solutions for this are discussed.

In addition to issues around data linkage other kinds of Big Data research were explored. Social media was felt by many to be more personal than healthcare data and the majority of participants were uncomfortable with this data being used for research. Concerns were raised specifically around anonymization, privacy and consent with images raised as a source of particular concern. This emphasizes the need for standard anonymization and privacy protection procedures to be in place for this data including avoiding the republishing of quotes and images from social media without consent. Better education for social media users on how their data is used, including how it is used to help others, is needed.

One of the most commonly recurring themes throughout this survey was that young people want their data to be used to help others, improve services and save lives. Furthermore young people repeatedly expressed wanting to know more about the research that was being done, how their data is used and the positive impacts of this research on others. Research teams

should endeavour to publicise the results of their research. This should go beyond academic audiences and incorporate mainstream and social media. It may also be appropriate to contact participants of research directly (for example in survey research where consent for contact has been taken) to share results of research as both summaries and access to published papers.

6 AN E-COHORT STUDY OF SELF-HARM IN CHILDREN AND YOUNG PEOPLE

As described previously there are several strengths and limitations to conducting online research, particularly with individuals who have a history of self-harm. Information on self-harm is typically collected retrospectively based on self-report as on the SHARE UK research platform described previously. The accuracy of these responses may be affected by issues such as denial, reinterpretations, problems with recall, current mood and misinterpretation of study questions (Bowman, Sanson-Fisher, & Redman, 1997; Velting, Rathus, & Asnis, 1998). Response rates to online surveys have been found to be comparable to face-to-face research (Heiervang & Goodman, 2011). However completion rates may be lower, with participants less likely to answer all items. This has led to significant underestimates of psychopathology in some studies (Heiervang & Goodman, 2011). Particular personal characteristics are known to effect completion rates with online surveys. Heiervang and Goodman (2011) found that completion rates tended to be lower in those from non-traditional families, those with English as a second language and those with lower education suggesting potential barriers of internet access, language and literacy, and bias against disadvantaged participants. While lack of internet access may pose a barrier for some, web-based surveys are perceived as less intrusive than face-to-face research and may lower barriers related to social desirability and disclosure and improve estimates for sensitive risk factors of participants (Dillman & Smyth, 2007; Johnson, O'Rourke, Burris, & Warnecke, 2005; Turner et al., 1998). Social desirability may be of particular relevance to disclosure of self-harm with adolescents being 2-3 times more likely to report suicide attempts under conditions of anonymity (Safer, 1997).

In contrast to self-reports, whether collected online or face-to-face, routinely collected administrative data is considered to be largely accurate but with less detailed data on personal characteristics. Routinely collected healthcare data is external, objective and does not rely on participants ability or willingness to fill out questionnaires or disclose potentially sensitive information. This data does not rely on internet access, literacy or language comprehension and allows research to be more inclusive covering an entire population. Research combining multiple sources of data is needed to create a comprehensive picture on which base support. Mars et al. (2016) combined data from the ALSPAC study with hospital admissions data available in the Hospital Episode Statistics database (HES). Selective non-response was found with the prevalence of hospital admissions for self-harm higher in questionnaire non-responders than in responders (Mars et al., 2016). Selective non-response has also been found

elsewhere with those reporting suicide attempts at study onset at least 1.6 times more likely to drop out of research (Christl, Wittchen, Pfister, Lieb, & Bronisch, 2006). In addition around a third of participants reported self-harm inconsistently, reporting self-harm at one time point but not another (Mars et al., 2016). Inconsistent reporting has been shown for other stigmatized behaviours such as drug use (Percy, McAlister, Higgins, McCrystal, & Thornton, 2005). Mars et al. (2016) concluded that self-reports may underestimate hospital presentations for self-harm and that more accurate figures may come from combining data from multiple sources.

The incorporation of routinely collected data ensures a balanced and comprehensive overview of self-harm. This analysis addresses some of the limitations of data collected via the SHARE UK platform and Big Data and Mental Health Research Survey, described in Chapters Four and Five. This analysis additionally contributes additional detail regarding service utilisation and allows participants to be studied over a number of years in a whole population of individuals. Linkage of survey data with routinely collected data has many advantages including validation of self-reports against clinical data and for a richness of information of which to be base future service provision. Participants who signed up for the SHARE UK platform were given the option to consent for their data to be linked with routinely collected linked data. While it was intended that anonymized data from consented individuals recruited via the platform would be linked with data available in SAIL, sign-up for data linkage was not sufficient for this to be possible. Issues with consent for data linkage and how these barriers could be overcome in the future were explored with the Big Data and Mental Health Research Survey described in Chapter Five.

As an alternative to the proposed linkage a study was conducted to examine contacts for self-harm across healthcare settings utilising routinely collected healthcare data held in the SAIL databank at population level. As outlined in Chapter Two routinely collected data is increasingly being used in self-harm research. Routinely collected healthcare data has several advantages including large sample sizes, long periods of follow-up, and a comprehensive overview of use of healthcare services with no additional burden on participants. Previous research utilising routinely collected data has included: compiling and validating diagnostic code lists for self-harm in primary care (Clements et al., 2016; Thomas et al., 2013); identifying clinical management patterns and risk of death in children and young people following self-harm (Morgan et al., 2017) and, examining trends over time combining GP and hospital admissions data (Morgan et al., 2017). Additionally research using data available in SAIL databank has been utilised to examine the association between educational attainment and self-harm (Rahman et al., 2018). No studies to date have been conducted in the UK examining contacts for self-harm

across the full range of healthcare settings at population level. The SAIL databank presents a unique opportunity to link data from primary care, emergency departments, and hospital admissions and outpatients at person level to explore contacts for self-harm. This level of linkage across services at population level is not possible in any other routinely collected healthcare databank currently held in the UK. Utilising this data to examine presentation across services can inform policy and practice identifying opportunities for intervention. A published version of this study is included in Appendix I (Marchant et al., 2019).

6.1 AIMS AND OBJECTIVES

The aim of this analysis was to examine contacts for self-harm across GP, emergency department, hospital admissions and outpatients and incidence over time in a whole population of young people. Whether individuals preferentially present across different settings and interactions with demographic variables were explored. This addressed the previously described limitations of survey research and added additional detail regarding service utilisation for self-harm and where resources could be best targeted to ensure adequate support.

6.2 METHOD

Ethical Approval

Approval was granted from the Information Governance Review Panel (IGRP; approval number 0281), an independent body consisting of a range of government, regulatory and professional agencies which oversees study approvals in line with permissions already granted to the analysis of data in the SAIL databank (Ford et al., 2009; Lyons et al., 2009). SAIL databank Information Governance procedures specify that individual level data must be analysed in a data safe haven accessed through secure remote desktops. No person-level data may be removed from this safe haven. Aggregate data may be removed for publication following review to ensure that no personally identifiable data or small numbers (defined as $n < 5$) are made publicly available.

Data source

The SAIL databank (www.saildatabank.com) is an expanding data repository (around 3 billion records) of privacy protected anonymized person-based linkable data from healthcare and public settings to support research. Robust policies, structures and controls are in place to

protect privacy through reliable matching, anonymization and encryption processes achieved in conjunction with the NHS Wales Informatics Service (NWIS) using a split file approach (Ford et al., 2009; Lyons et al., 2009). This involves the separation of identifiable information from clinical content, identity matching and creation of anonymized linkage keys prior to reassembling and further encryption of datasets. This is described in further detail elsewhere (Ford et al., 2009; Lyons et al., 2009). All data within the SAIL gateway are treated in accordance with the Data Protection Act (2017) and are compliant with the General Data Protection Regulation (GDPR).

The following patient-level linked datasets were utilised for this analysis;

1. The Welsh Demographic Service (WDS). A register of all individuals registered with a Welsh GP or who have ever had contact with the NHS.
2. Welsh Index of Multiple Deprivation (WIMD). This dataset assigns all Lower Super Output Areas (LSOAs; geographic units comprised of around 1500 individuals) in Wales, a deprivation score derived from eight separate domains including income, employment and education (deprivation split into quintiles from 1 (most deprived) to 5 (least deprived) (Welsh Government, 2014)). These are calculated in a similar manner to the Index of Multiple Deprivation (IMD) used in England however, domains are weighted differently in each region and as such, the two indexes are not directly comparable. Deprivation indices are based on the LSOA of the individual patient based on their address data present in the WDS.
3. General Practice Database (GPD). This dataset contains attendance and clinical information for all GP interactions including symptoms, diagnoses and prescriptions. GP practices opt-in to supplying SAIL. Currently 333 practices (out of 432 in Wales) contribute regularly updated data covering 77% of GP practices and 79% of the population (above 70% threshold for acceptable response in prevalence studies (Boyle, 1998)). The population covered by the GPD are representative of the population as a whole in terms of sex (all Welsh practices 50% male; SAIL supplying practices 50% male) age range (all Welsh practices 20% aged 0-17 years, 60% aged 18-64 years, 20% aged 65+; SAIL supplying practices 20% aged 0-17 years, 61% aged 18-64 years, 19% aged 65) and deprivation indices (all Welsh practices 19% most deprived fifth, 18% least deprived fifth; SAIL supplying practices 20% most deprived fifth, 19% least deprived).
4. Emergency Department Dataset (EDDS). This dataset contains administrative and clinical information for all NHS Wales Accident and Emergency Department attendances (total of 34 sites including minor injuries units). Data is available from August 2009 onwards.

5. Patient Episode Database for Wales (PEDW). This dataset contains attendance and clinical information for all NHS Wales hospital admissions (inpatient and day cases) including data regarding diagnoses, operations performed and admission specialty. A hospital admission in this study refers to period of continuous care whilst admitted to hospital (spell of care). This can encompass multiple episodes of consultant care and reflects a patient's stay in hospital. This includes both inpatient and day cases and encompasses all consultant specialities. It is not possible to distinguish dedicated psychiatric hospitals from general hospitals however, data regarding the speciality under which an individual is admitted is available.
6. Outpatient Data (OPD). This dataset contains attendance information for all NHS Wales hospital outpatient appointments from 2004 onwards.
7. Office of National Statistics (ONS) deaths register. This is a register of all deaths relating to Welsh residents, including those that die outside of Wales and includes information regarding date and cause of death. Full details of these datasets can be found at www.saildatabank.com.

Study population

Individuals aged 10-24 registered with a SAIL supplying GP from 01.01.2003-30.09.2015 were selected as the baseline population. The GP databank covers 79% of the population of Wales. While hospital admissions and emergency department data are available for the population of Wales as whole, a cohort of individuals registered with a SAIL supplying GP was selected to give a common population denominator. This allowed for comparisons across settings. Data collection began one year after GP registration, 10th birthday, or study onset whichever was the latest. Data collection ended on the date of GP de-registration, death, 25th birthday or study end whichever was sooner. Individuals could supply multiple data periods provided that the above criteria are met.

Measures

Age and deprivation indices were collected based upon the onset of data collection each year. Children and young people are defined as those aged 10-24 (Arango et al., 2018). Age was categorized into three equal age bands: 10-14, 15-19 and 20-24 years. NICE guidance recommends admission for anyone aged under 16 attending emergency departments with self-harm (NICE, 2004, 2012). We explored adherence to these guidelines where relevant by dividing into age bands 10-15, 16-18 and 19-24 years. Which age group division is under study is clearly specified in each sub-section of the results.

Self-harm was identified in three datasets (GP, emergency department and hospital admissions data). Each dataset utilises its own coding system. A record of self-harm in GP data was examined using previously validated primary care Read codes (Carr et al., 2016a; Thomas et al., 2013) with additional Read codes identified through a manual search checked by a clinician (full list of codes included in Appendix J). Read codes are a coded thesaurus or clinical terms. They have been used in the NHS since 1985 and are widely used in primary care. Read codes provide a standard vocabulary for GPs to record diagnoses, symptoms, procedures, tests, prescriptions, referrals and administrative activity. It is possible to see if there is a record of a given diagnosis in the GP data available in the SAIL databank. It is not possible to identify whether an event represents a GP appointment where something is discussed or if it is a record of administrative activity such as a letter from a hospital or emergency department. As such a GP event for self-harm here is defined as a record of self-harm on a given date. It should be noted that this may not represent a patient directly seeking help from their GP and may instead represent a GP being informed of an emergency department attendance or hospital admission.

Hospital admissions for self-harm were identified based on the International Classification of Diseases 10th revision (ICD-10). Codes for self-harm (X60-X84) and undetermined intent (Y10-Y34) were included. Up to 14 diagnoses can be included per hospital admission. All 14 diagnoses were included in the current analysis meaning that self-harm may not be the primary reason for admission. However, it is important to search all diagnoses as the primary reason for admission may be related to complications of self-harm (for example monitoring of poisoning levels) and excluding secondary diagnoses would not pick up all admissions.

A standard coding system is employed across emergency departments in Wales grouping by attendance type and diagnosis. Emergency department coding systems do not contain the same level of diagnostic detail as Read codes and ICD-10 and as such, it is not possible to choose codes equivalent to those available in Read or ICD-10. However, this system is sufficient for identifying self-harm. Self-harm was defined as an attendance recorded as 'deliberate self-harm' (Clements et al., 2016).

Additional analysis was conducted to identify appropriate diagnostic codes when an event recorded as 'undetermined intent' was identified in order to be consistent with analysis conducted in GP and hospital admissions data. All emergency department attendances from 2011-2015 were identified (n=59,344). An event was defined as a date in which an individual attended an emergency department and was recorded as attendance group 'undetermined intent'. If multiple attendances in one day were recorded this was only counted as one event.

Admission to hospital within seven days of emergency department attendance was employed as a measure of whether an emergency department attendance results in admission to hospital. A seven-day period was chosen to allow for a possible 48 hours spent in an emergency department and for any delays in data recording. Of the emergency department events, identified 8,251 were followed by a hospital admission within seven days. Of these admissions, 666 had a diagnosis of self-harm recorded within their spell of inpatient care. The emergency department diagnosis for the 666 cases that were subsequently admitted to hospital with self-harm were identified. An emergency department diagnosis of 'overdose' (excluding overdose with alcohol) was recorded in 71% (n=470) of cases. Lacerations to wrists and forearms were recorded in 5% (n=35) of events. Including both of these diagnostic groups' accounts for 75% (n=505) of emergency department attendances recorded as 'undetermined intent' where there is a hospital admission with self-harm within seven days.

As a result of this further analysis self-harm was recorded for emergency departments if an individual had a record of attendance group 'deliberate self-harm' or if they had an attendance group recorded as 'undetermined intent' alongside a diagnosis code for either poisoning/overdose (excluding alcohol) or, lacerations to wrists or forearms (Appendix K).

Codes referring to self-harm with alcohol were excluded from all datasets unless they were recorded alongside another relevant code (Hawton, Fagg, Simkin, Bale, & Bond, 1997).

Trends over time. Self-harm method over time was examined for all GP events and hospital admissions with a record of self-harm from 2003-2015. Method was broken down into 'self-poisoning' and 'self-injury'.

Annual incidence over time was examined. This was defined as no record of self-harm within the previous 12 months (John et al., 2015; Walters, Rait, Griffin, Buszewicz, & Nazareth, 2012; Wijlaars, Nazareth, & Petersen, 2012). Incidence of self-harm over time in GP and hospital admissions data is collected from 2003-2015. Emergency department data is available from August 2009. In order to allow the full 12-months history to identify an incident attendance emergency department data is presented from 2011-2015 with 2010 utilised to assess prior attendance (See Figure 12).

Contacts across services. Presentations to each service for self-harm from 01.08.2009-30.09.2015 were identified. This is the maximum period where data coverage is available across all settings (Figure 12). A self-harm event was defined as a record of self-harm in one or

more setting on a given date. The setting(s) and method of self-harm was recorded for each event. Participants and self-harm events were divided into mutually exclusive groups based on the service(s) to which they presented (e.g. GP only, GP and emergency department etc.). Age and deprivation data were taken from the first self-harm presentation during this time.

Hospital admission speciality was recorded for each admission. Admission speciality refers to the speciality under which the patient was treated, and is either the consultant's main speciality or, a different speciality function, which is the consultant's interest speciality function. There are 174 of these codes encompassing surgical, treatment and other medical specialties. These codes were grouped the codes broadly as follows;

Surgical Specialties: Including all surgical specialties (e.g. general, plastic etc.) with the exception of 'paediatric surgery', which was categorised under 'paediatrics and 'accident and emergency surgical speciality' which was examined separately.

Paediatric specialties: This encompassed all paediatric specialties including paediatric surgery with the exception of 'child and adolescent psychiatry', which was categorized under psychiatric.

Psychiatric: This encompassed all psychiatric specialties (e.g. psychiatric intensive care, eating disorders etc.) including child and adolescent psychiatry.

General medicine: Refers to a consultant or treatment speciality with a generalist component.

Other Medical Specialities: This encompasses all other medical specialties including radiology, pathology etc.

A full break down of codes is included in Appendix L.

Admission to hospital within seven days of emergency department attendance was examined as a measure of whether an emergency department attendance resulted in admission. A seven-day window allows for an individual to remain in emergency department prior to admission and for delays in data recording. Where an individual was seen in outpatients and by which speciality in the 30 days following presentation to healthcare settings for self-harm was examined.

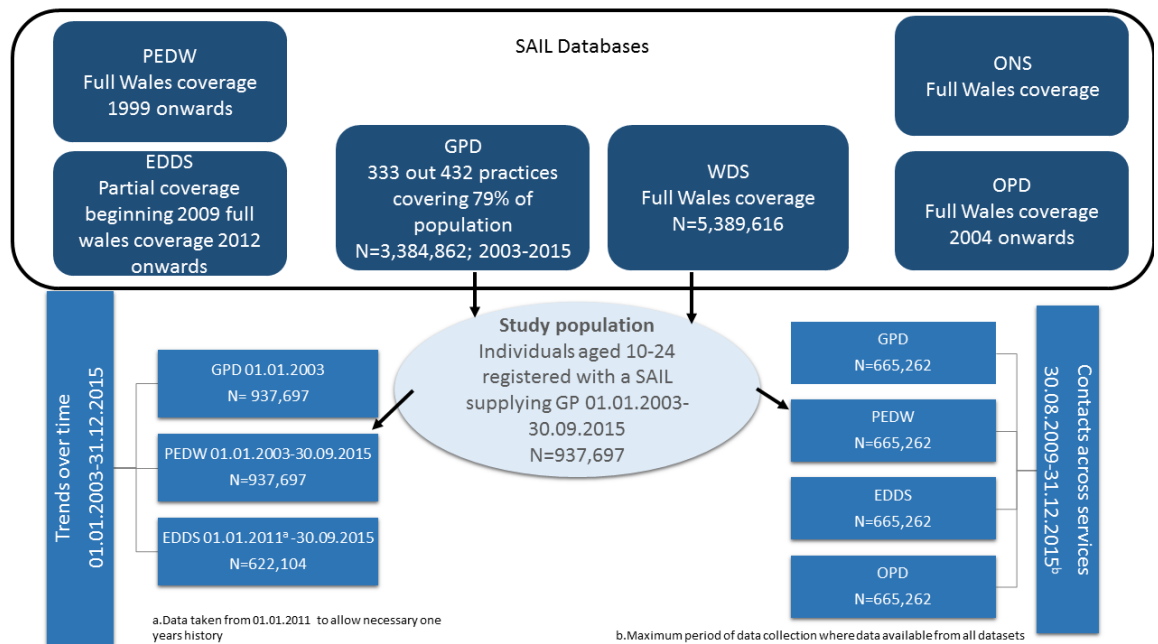


Figure 12 Construction of cohort from linked healthcare datasets

Statistical analysis

The SAIL databank was interrogated using structured query language (SQL, DB2).

Annual incidence rates were calculated using person years at risk (PYAR) as a denominator. PYAR is a more appropriate unit than the number of registered individuals due to the variable follow-up periods for each individual (Fisher, Collins, Millson, Crome, & Croft, 2004; John et al., 2015). Poisson regression was undertaken to investigate the adjusted association between incidence of self-harm in each dataset and year of diagnosis, sex, age group and deprivation. Poisson regression modelling was additionally used to assess interactions between demographic variables. Wald tests were used to assess significance of findings. Robust standard errors for the estimated incidence rate ratios (IRRs) were utilised to account for clustering within practices. Analysis was conducted in SPSS V.25.

6.3 RESULTS

Study population

In total 937,697 individuals aged 10-24 (50% female [95% CI 50-50; n=465,774]; 50% male [95% CI 50-51; n=472,923]) provided 5,269,794 person years of data from 1st January 2003 to 20th September 2015.

Self-harm incidence in relation to sex and deprivation

Across all settings incidence of self-harm is higher in females than in males (Table 10). This difference is largest in hospital admissions with incidence more than double in females than in males (IRR = 2.1[95% CI 2.0-2.3]). The smallest difference is seen in emergency department attendances (emergency department IRR = 1.3[95% CI 1.2-1.4]; GP IRR 2.0[95% CI 1.9-2.1]).

Across all settings incidence in the most deprived areas was more than double that in the least deprived areas. IRRs for deprivation are greater in males than in females (Table 11) with incidence in the most deprived areas being more than three times that in the least deprived areas. There was a significant interaction between sex and deprivation across all services with incidence of self-harm in males increasing significantly more per deprivation fifth than females (GP IRR=1.1[95% CI 1.1-1.2; p<.001]; emergency department IRR=1.1[95% CI 1.1-1.2; p=.002] hospital admissions IRR=1.1[95% CI 1.1-1.2; p<.001]).

Table 10 Number of events; incidence per 1000 PYAR(95% CI) and incidence rate ratios^a (IRR; 95% CI)^b for presentation to services for self-harm

Variable		GP event		Emergency department ^c		Hospital admission	
		Events n; incidence	IRR	Events n; incidence	IRR	Events n; incidence	IRR
Gender	Male	8506; 3.1(3.0-3.2)	Reference (P < .0001)	3387; 3.4(3.3-3.5)	Reference (P < .0001)	4665; 1.7(1.6-1.7)	Reference (P < .0001)
	Female	16345; 6.2(6.2-6.3)	2.0(1.9-2.1)	4161; 4.4(4.3-4.5)	1.3(1.2-1.4)	9304; 3.6(3.5-3.6)	2.1(2.0-2.3)
Age Group	10-14	4618; 2.5(2.4-2.6)	Reference (P < .0001)	1139; 1.8(1.7-1.9)	Reference (P < .0001)	2941; 1.6(1.5-1.7)	Reference (P < .0001)
	15-19	11782; 6.5(6.4-6.7)	2.6(2.4-2.8)	3578; 5.5(5.3-5.7)	3.1(2.8-3.6)	6526; 3.6(3.5-3.7)	2.3(2.1-2.5)
	20-24	8451; 4.9(4.8-5.0)	2.0(1.8-2.2)	2831; 4.3(4.2-4.5)	2.5(2.1-2.9)	4502; 2.6(2.5-2.7)	1.6(1.5-1.8)
Deprivation ^d	5	3026; 2.9(2.8-3.0)	Reference (P < .0001)	844; 2.2(2.1-2.4)	Reference (P < .0001)	1631; 1.6(1.5-1.6)	Reference (P < .0001)
	4	3253; 3.6(3.5-3.7)	1.3(1.1-1.4)	867; 2.7(2.5-2.9)	1.2(1.1-1.4)	1872; 2.1(2.0-2.2)	1.3(1.2-1.5)
	3	4198; 4.2(4.1-4.3)	1.5(1.3-1.6)	1239; 3.4(3.2-3.6)	1.6(1.4-1.8)	2386; 2.4(2.3-2.5)	1.5(1.4-1.7)
	2	5329; 5.2(5.1-5.4)	1.8(1.7-2.0)	1726; 4.6(4.4-4.9)	2.1(1.8-2.4)	3091; 3.0(2.9-3.1)	2.0(1.8-2.2)
	1	8225; 6.9(6.8-7.1)	2.4(2.2-2.6)	2692; 6.2(6-6.4)	2.8(2.5-3.2)	4550; 3.8(3.7-3.9)	2.5(2.2-2.7)
Year	2003	1751; 4.5(4.3-4.7)	Reference (P < .0001)			846; 2.2(2.0-2.3)	Reference (P < .0001)
	2004	1944; 4.6(4.4-4.8)	1.0(0.9-1.2)			954; 2.3(2.1-2.4)	1.0(0.9-1.2)
	2005	2022; 4.7(4.5-4.9)	1.0(0.9-1.2)			1074; 2.5(2.3-2.6)	1.1(1.0-1.3)
	2006	2018; 4.6(4.4-4.8)	1.0(0.9-1.1)			1172; 2.7(2.5-2.8)	1.2(1.1-1.4)
	2007	2212; 5(4.8-5.3)	1.1(1.0-1.2)			1299; 3.0(2.8-3.1)	1.3(1.2-1.5)
	2008	2241; 5.1(4.9-5.3)	1.1(1.0-1.2)			1222; 2.8(2.6-2.9)	1.3(1.1-1.4)
	2009	1934; 4.4(4.2-4.6)	1.0(0.9-1.1)			1059; 2.4(2.3-2.6)	1.1(1.0-1.3)

2010	1988; 4.6(4.4-4.8)	1.0(0.9-1.1)			1007; 2.3(2.2-2.5)	1.1(0.9-1.2)
2011	1855; 4.4(4.2-4.6)	1.0(0.8-1.1)	1444; 3.4(3.2-3.6)	Reference (P < .0001)	1063; 2.5(2.4-2.7)	1.1(1.0-1.3)
2012	1887; 4.5(4.3-4.7)	1.0(0.9-1.1)	1631; 3.9(3.7-4.1)	1.1(1.0-1.3)	1052; 2.5(2.4-2.7)	1.1(1.0-1.3)
2013	1939; 4.7(4.5-4.9)	1.0(0.9-1.2)	1612; 3.9(3.7-4.1)	1.2(1.0-1.3)	1205; 2.9(2.8-3.1)	1.3(1.1-1.6)
2014	1726; 4.3(4.1-4.5)	0.9(0.8-1.0)	1568; 3.9(3.7-4.1)	1.2(1.0-1.3)	1137; 2.8(2.7-3.0)	1.3(1.1-1.5)
2015 ^e	1334; 4.5(4.3-4.8)	1.0(0.9-1.1)	1293; 4.4(4.2-4.7)	1.3(1.2-1.5)	879; 3(2.8- 3.2)	1.4(1.1-1.6)

- a. Adjusted for calendar year, age and deprivation
b. Based on Wald test
c. Emergency department data from 2011 onwards only
d. Deprivation: 1 = most deprived; 5 = least deprived
e. Data collected in 2015 up until 30th September –denominator for incidence rate adjusted accordingly but actual counts may appear lower

Table 11 IRRs of presentation to services for self-harm by sex

Variable		GP IRR(95% CI) ^b		Emergency department IRR(95% CI) ^b		Hospital admission IRR(95% CI) ^b	
		Male n= 8506	Female n=16345	Male n=3387	Female n = 4161	Male n=4665	Female n=9304
Age group	10-14	Reference (P ^c < .000)	Reference (P ^c < .000)	Reference (P ^c < .000)	Reference (P ^c < .000)	Reference (P ^c < .000)	Reference (P ^c < .000)
	15-19	4.6(4.3- 5.0)	2.2(2.0- 2.3)	4.8(4.2- 5.4)	2.5(2.3- 2.8)	4.4(4.0- 4.9)	1.8(1.7- 2.2)
	20-24	4.9(4.5- 5.4)	1.3(1.2- 1.4)	4.8(4.2- 5.5)	1.6(1.4- 1.7)	4.6(4.2- 5.2)	1.0(1.0- 1.1)
Deprivation ^d	5	Reference (P ^c < .000)	Reference (P ^c < .000)	Reference (P ^c < .000)	Reference (P ^c < .000)	Reference (P ^c < .000)	Reference (P ^c < .000)
	4	1.3(1.2- 1.5)	1.2(1.1- 1.3)	1.4(1.2- 1.6)	1.1(1.0- 1.3)	1.5(1.3- 1.6)	1.3(1.2- 1.4)
	3	1.6(1.4- 1.7)	1.4(1.3- 1.5)	1.7(1.5- 1.9)	1.5(1.3- 1.7)	1.6(1.4- 1.8)	1.5(1.4- 1.7)
	2	2.2(2.0- 2.4)	1.7(1.5- 1.8)	2.6(2.3- 3.0)	1.8(1.6- 2.0)	2.5(2.3- 2.8)	1.7(1.6- 1.9)
	1	3.1(2.8- 3.3)	2.1(2.0- 2.3)	3.5(3.1- 3.8)	2.4(2.2- 2.7)	3.2(2.9- 3.6)	2.2(2.2- 2.4)
Year	2003	Reference (P ^c < .000)	Reference (P ^c < .038)			Reference (P ^c < .008)	Reference (P ^c < .000)
	2004	1.0(0.9- 1.2)	1.0(0.9- 1.1)			1.1(0.9- 1.3)	1.0(0.8- 1.1)
	2005	1.0(0.9- 1.2)	1.0(1.0- 1.1)			1.1(0.9- 1.2)	1.2(1.0- 1.4)
	2006	1.0(0.9- 1.1)	1.0(0.9- 1.1)			1.2(1.0- 1.3)	1.2(1.1- 1.4)
	2007	1.0(0.9- 1.2)	1.1(1.0- 1.2)			1.3(1.1- 1.5)	1.3(1.2- 1.5)
	2008	1.1(0.9- 1.3)	1.1(1.0- 1.2)			1.2(1.0- 1.4)	1.3(1.1- 1.5)
	2009	0.9(0.8- 1.1)	1.0(0.9- 1.1)			1.1(0.9- 1.3)	1.1(1.0- 1.3)
	2010	1.0(0.9- 1.2)	1.0(0.9- 1.1)			1.0(0.9- 1.2)	1.1(0.9- 1.2)
	2011	0.9(0.8- 1.0)	1.0(0.9- 1.1)	Reference (P ^c < .001)	Reference (P ^c < .000)	1.1(0.9- 1.2)	1.2(1.0- 1.3)
	2012	0.9(0.8- 1.0)	1.0(0.9- 1.1)	1.2(1.1- 1.3)	1.1(1.0- 1.2)	1.0(0.9- 1.2)	1.2(1.0- 1.4)
	2013	0.9(0.8- 1.0)	1.1(1.0- 1.3)	1.1(1.0- 1.2)	1.2(1.1- 1.3)	1.1(0.9- 1.3)	1.5(1.2- 1.7)

2014	0.8(0.7-1.0)	1.0(0.9-1.1)	1.1(1.0-1.2)	1.2(1.1-1.3)	1.1(0.9-1.2)	1.4(1.2-1.6)
2015 ^e	0.9(0.7-1.0)	1.0(0.9-1.2)	1.2(1.1-1.4)	1.4(1.2-1.5)	1.0(0.9-1.2)	1.5(1.3-1.8)

a. Emergency department data from 2011 onwards only
b. Adjusted for calendar year, age and deprivation
c. Based on Wald test
d. Deprivation: 1 = most deprived; 5 = least deprived
e. Data collected in 2015 up until 30th September –denominator for incidence rate adjusted accordingly but actual counts may appear lower

Incidence of self-harm over time

Figure 13 shows trends over time for incidence of self-harm across services. Incidence of self-harm in primary care remained stable over time with an incidence of 4.5 events per 1000 PYAR in 2003 and 4.6 in 2015 (IRR=1.0 [95% CI 0.9–1.1]). Incidence of emergency department attendance increased from 3.4 to 4.4 from 2011-2015 (IRR=1.3 [95% CI 1.2–1.5]). Incidence of hospital admissions increased from 2.2 to 3.0 from 2003-2015 (IRR = 1.4 [95% CI 1.1–1.6];Table 10).

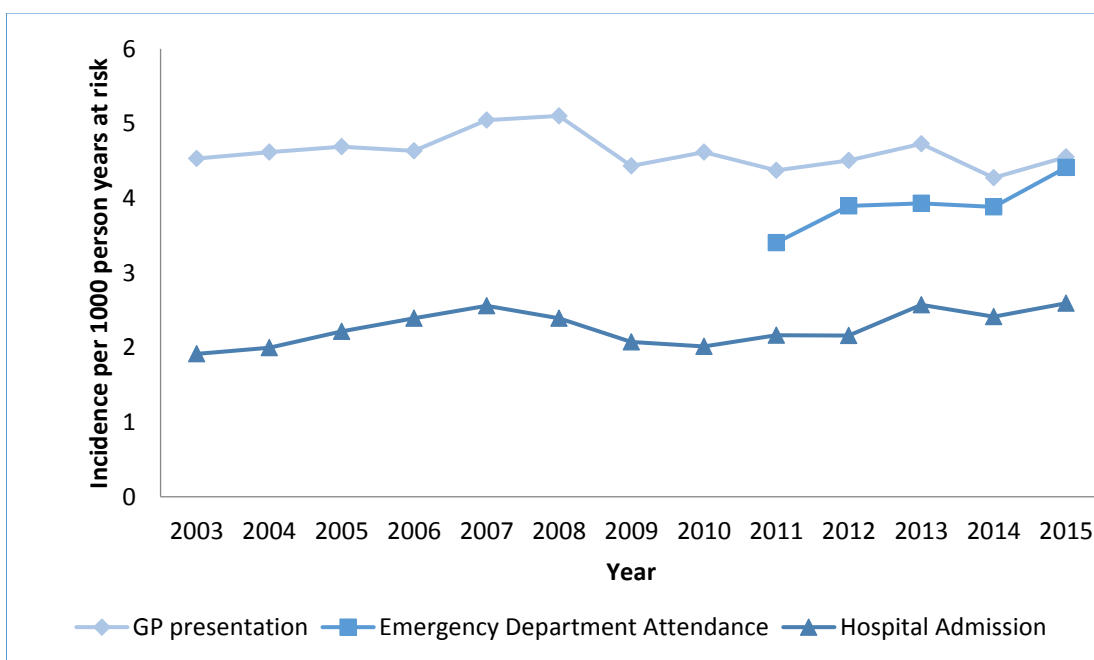


Figure 13 Incidence of self-harm across services over time 10-24 year olds

Incidence over time by sex and age

Incidence over time and IRRs by age group in females is shown in Table 12 and in Males in Table 13. Incidence over time and IRRs varied by sex, setting and age group (10-14; 15-19 and 20-24 years) detailed below.

10-14 year-olds

Incidence over time for those aged 10-14 years by setting and sex is shown in Figure 14. Across

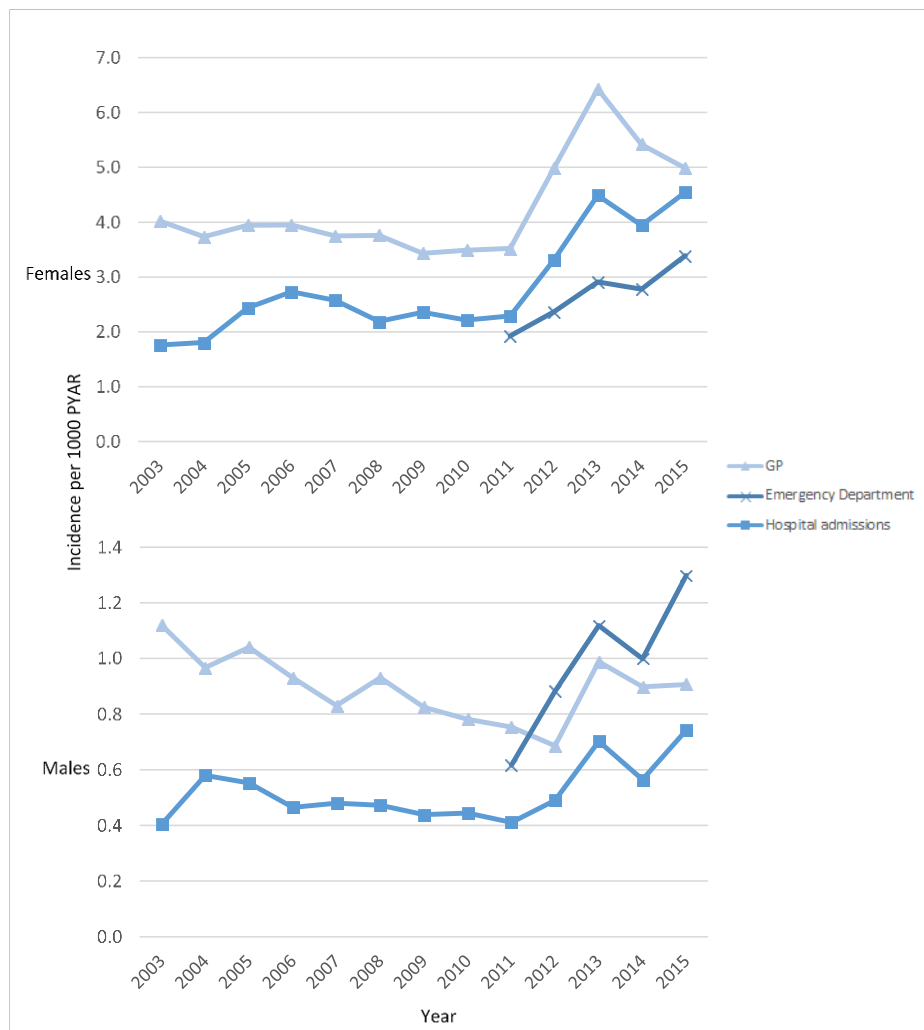


Figure 14 Incidence of self-harm across healthcare settings in 10-14 year olds by sex

all settings incidence was lowest in the 10-14 year age group. Incidence over time increased for females across all settings. This was most marked from 2011 onwards. For males there was no corresponding increase in GP incidence (interaction between sex and year IRR=1.1[95% CI 1.0-1.1; $p < .001$] per iteration for females with males as reference group). Emergency department attendances increased significantly over time for both sexes (females IRR=3.4[95% CI 2.9-4.0; $p < .001$]; males IRR=2.1[95% CI 1.8-2.4; $p < .001$]; interaction between sex and year non-significant). Hospital admissions almost doubled over time for males with an even larger increase over time for females (females IRR=2.6[95% CI 2.2-3.0; $p < .001$]; males IRR=1.9[95% CI 1.3-2.7; $p = .014$] interaction between sex and year IRR=1.1[95% CI 1.0-1.1; $p = .005$]).

For females, incidence was highest for GP attendances followed by hospital admissions with the lowest incidence seen in emergency department data across the study period. Incidence of self-

harm was higher in GP attendances than hospital admissions for males. Where emergency department data was available incidence of self-harm is highest in emergency department attendances for males.

15-19 year-olds

Incidence was highest in 15-19 year olds across all settings. Incidence over time in 15-19 year olds by sex is shown in Figure 15.

For females, incidence is consistently highest for GP events, followed by emergency department attendances (where data available) with the lowest incidence for hospital admissions. In males where emergency department data is available, the highest incidence is seen in emergency department attendances followed by GP events with the lowest incidence in hospital admissions.

There was no significant increase over time in GP contacts for either sex. Emergency department

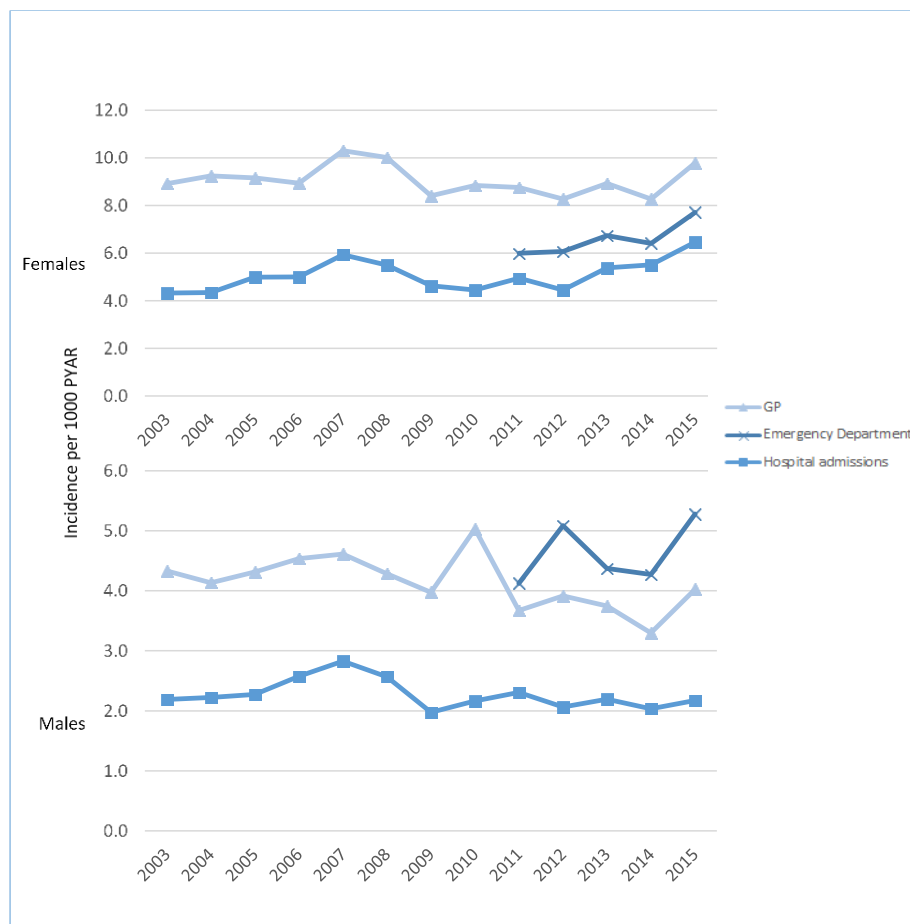


Figure 15 Incidence of self-harm across healthcare settings in 15-19 years olds by sex

attendances increased significantly for both sexes (females IRR=1.3[95% CI 1.2-1.4; p<.001]; males IRR=1.3[95% CI 1.1-1.5; p<.001] no significant interaction between year and sex). Hospital

admissions increased significantly for females but not for males (females IRR=1.5[95% CI 1.4-17; p<.001]; males IRR=1.0[95% CI 0.8-1.2; p<.001]; interaction between sex and year IRR=1.0[95% CI 1.0-1.0; p=.001).

20-24 year-olds

Incidence over time in 20-24 year olds by sex is shown in Figure 16. For females, the highest

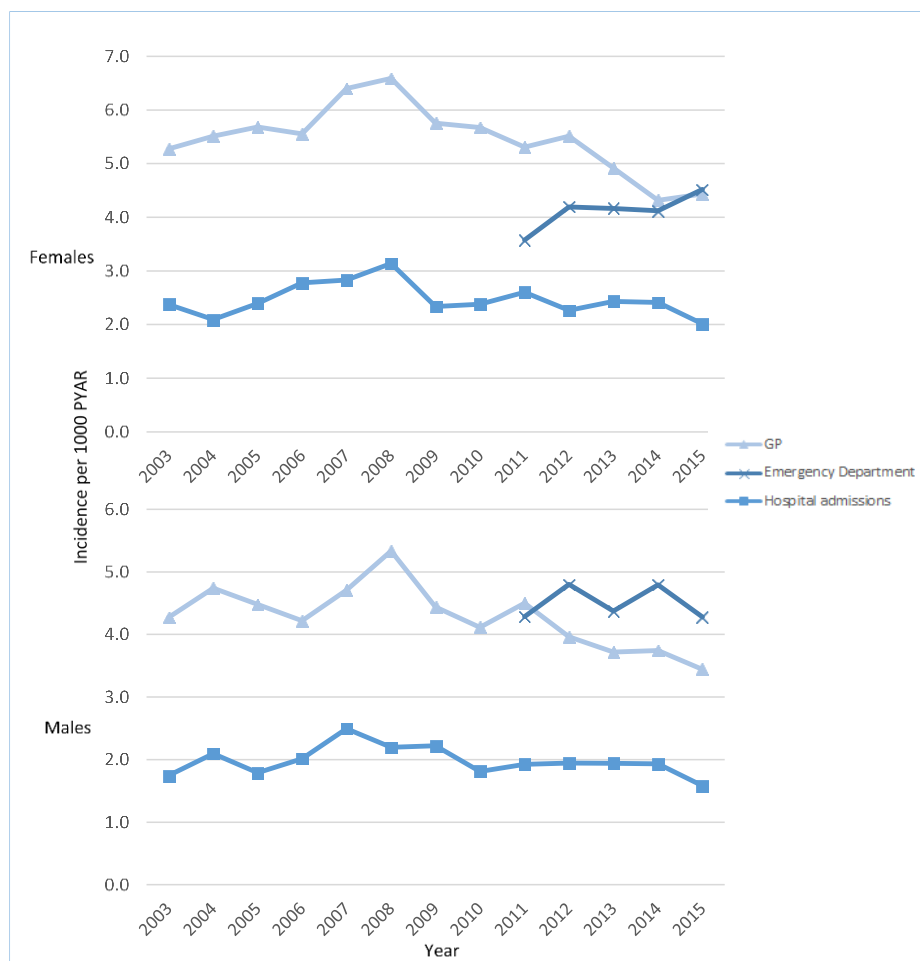


Figure 16 Incidence of self-harm across healthcare settings in 20-24 year olds by sex

incidence is seen for GP events with the exception of 2015 where incidence of self-harm is similar for GP and emergency department attendances. For males, self-harm incidence is highest in emergency department attendances where data is available; however, there is a decrease in GP attendances over time. Incidence is lowest for hospital admissions for both sexes. There was no significant increase in GP attendance or hospital admissions over time for either sex. Emergency department attendances increased significantly over time for females but not for males (females IRR=1.3[95% CI 1.2-1.4; p<.001]; males IRR=1.0[95% CI 0.9-1.2; p=.007]; interaction between sex and year non-significant).

Table 12 n and IRRs of incident presentations for self-harm by age group and service in females

	10-14 years						15-19 years						20-24 years					
	ED attendances		Hospital admissions		GP		ED attendances		Hospital admissions		GP		ED attendances		Hospital admissions			
	n	IRR(95% CI)	n	IRR(95% CI)	n	IRR(95% CI)	n	IRR(95% CI)	n	IRR(95% CI)	n	IRR(95% CI)	n	IRR(95% CI)	n	IRR(95% CI)		
2003	285	Reference	125	Reference	562	Reference	411	Reference	272	Reference	288	Reference	243	Reference	153	Reference		
2004	277	0.9(0.8-1.1)	134	1.0(0.9-1.2)	635	1.0(1.0-1.1)	410	1.0(1.0-1.1)	298	1.0(0.9-1.1)	349	1.0(0.9-1.1)	243	1.0(0.9-1.2)	156	0.8(0.9-1.0)		
2005	294	1.0(0.8-1.3)	182	1.4(1.1-1.7)	648	1.0(1.0-1.1)	410	1.0(1.0-1.1)	353	1.2(1.0-1.3)	376	1.1(1.0-1.2)	283	1.1(1.0-1.2)	184	1.0(0.8-1.3)		
2006	292	1.0(0.8-1.1)	202	1.6(1.3-1.8)	645	1.0(0.9-1.1)	446	1.0(0.9-1.1)	361	1.2(1.0-1.3)	374	1.0(0.9-1.2)	243	1.0(0.9-1.2)	215	1.1(1.0-1.3)		
2007	275	0.9(0.8-1.1)	189	1.5(1.3-1.6)	752	1.2(1.1-1.2)	417	1.2(1.1-1.2)	433	1.4(1.2-1.5)	436	1.2(1.1-1.3)	221	1.2(1.1-1.3)	221	1.2(1.0-1.4)		
2008	273	0.9(0.8-1.1)	159	1.3(1.1-1.5)	731	1.1(1.0-1.2)	410	1.1(1.0-1.2)	401	1.3(1.1-1.5)	454	1.2(1.1-1.4)	246	1.2(1.1-1.4)	246	1.3(1.1-1.4)		
2009	246	0.9(0.7-1.0)	169	1.3(1.2-1.5)	605	1.0(0.9-1.0)	410	1.0(0.9-1.0)	333	1.1(1.0-1.2)	397	1.1(1.0-1.2)	187	1.1(1.0-1.2)	187	1.0(0.81-1.2)		
2010	246	0.9(0.7-1.0)	156	1.3(1.1-1.5)	622	1.0(0.9-1.0)	410	1.0(0.9-1.0)	313	1.0(0.9-1.1)	389	1.0(0.9-1.1)	189	1.1(1.0-1.2)	189	1.0(0.8-1.3)		
2011	243	0.9(0.8-1.0)	133	1.3(1.1-1.5)	601	1.0(0.9-1.1)	411	1.0(0.9-1.1)	339	1.1(1.0-1.3)	361	1.1(1.0-1.3)	204	1.0(0.9-1.1)	204	1.0(0.9-1.2)		
2012	337	1.2(1.0-1.5)	160	1.3(0.9-1.7)	559	0.9(0.8-1.0)	410	0.9(0.8-1.0)	301	1.0(0.9-1.1)	372	1.0(0.9-1.2)	178	1.0(1.0-1.1)	178	0.9(0.8-1.1)		
2013	424	1.6(1.4-1.9)	192	1.5(1.2-2.0)	591	1.0(0.9-1.1)	446	1.0(0.9-1.1)	356	1.3(1.1-1.4)	326	1.3(1.1-1.4)	187	0.9(0.8-1.1)	187	1.0(0.8-1.2)		
2014	353	1.3(1.2-1.6)	181	1.5(1.1-1.9)	538	0.9(0.8-1.1)	417	0.9(0.8-1.1)	358	1.3(1.1-1.5)	282	1.3(1.1-1.5)	183	0.8(0.7-0.9)	183	1.0(0.8-1.2)		
2015	228	1.2(1.1-1.4)	155	1.8(1.4-2.3)	462	1.1(1.0-1.2)	364	1.1(1.0-1.2)	305	1.3(1.2-1.4)	217	1.5(1.4-1.7)	119	0.8(0.7-0.9)	119	0.9(0.6-1.2)		

Table 13 n and IRRs of incident presentations for self-harm by age group and service in males

	10-14 years						15-19 years						20-24 years					
	ED attendances		Hospital admissions		GP		ED attendances		Hospital admissions		GP		ED attendances		Hospital admissions			
	IRR(95% CI)	n	IRR(95% CI)	n	IRR(95% CI)	n	IRR(95% CI)	n	IRR(95% CI)	n	IRR(95% CI)	n	IRR(95% CI)	n	IRR(95% CI)	n		
2003	Reference	83	Reference	30	Reference	285	Reference	144	Reference	248	Reference	122	Reference	122	Reference	122		
2004	0.9(0.7-1.2)	75	1.5(1.0-2.0)	45	1.0(0.9-1.1)	296	1.0(0.9-1.1)	159	1.0(0.9-1.2)	312	1.1(0.8-1.5)	162	1.1(0.8-1.6)	162	1.2(0.9-1.6)	162		
2005	0.9(0.7-1.2)	81	1.4(1.0-2.0)	43	1.0(0.9-1.1)	319	1.0(0.9-1.1)	168	1.0(0.9-1.2)	304	1.1(0.8-1.4)	144	1.0(0.8-1.4)	144	1.0(0.8-1.4)	144		
2006	0.8(0.7-1.0)	72	1.2(0.9-1.5)	36	1.1(1.0-1.2)	342	1.1(1.0-1.2)	194	1.2(1.0-1.3)	293	1.0(0.8-1.3)	164	1.2(0.9-1.5)	164	1.2(0.9-1.5)	164		
2007	0.7(0.6-0.9)	64	1.2(0.8-1.8)	37	1.1(0.9-1.2)	351	1.1(0.9-1.2)	215	1.2(1.1-1.4)	334	1.1(0.9-1.4)	204	1.4(1.1-1.8)	204	1.4(1.1-1.8)	204		
2008	0.8(0.6-1.1)	71	1.2(0.9-1.6)	36	1.0(0.8-1.1)	327	1.0(0.8-1.1)	196	1.1(0.9-1.4)	385	1.3(1.0-1.6)	184	1.2(1.0-1.6)	184	1.2(1.0-1.6)	184		
2009	0.7(0.6-1.0)	62	1.1(0.7-1.6)	33	0.9(0.8-1.1)	300	0.9(0.8-1.1)	149	0.9(0.8-1.0)	324	1.0(0.8-1.4)	188	1.3(1.0-1.6)	188	1.3(1.0-1.6)	188		
2010	0.7(0.6-0.9)	58	1.1(0.9-1.4)	33	1.2(1.0-1.3)	372	1.2(1.0-1.3)	160	1.0(0.8-1.2)	301	1.0(0.7-1.3)	156	1.0(0.8-1.3)	156	1.0(0.8-1.3)	156		
2011	0.7(0.5-1.0)	55	1.1(0.7-1.6)	30	0.8(0.8-0.9)	266	0.8(0.8-0.9)	167	1.0(0.9-1.2)	329	1.1(0.8-1.4)	165	1.1(0.8-1.4)	165	1.1(0.8-1.4)	165		
2012	0.6(0.4-.9)	49	1.3(0.9-1.7)	35	0.9(0.8-1.0)	281	0.9(0.8-1.0)	148	1.2(1.1-1.4)	289	0.9(0.7-1.3)	166	1.1(1.0-1.5)	166	1.1(1.0-1.5)	166		
2013	0.9(0.7-1.2)	69	1.8(1.2-2.6)	49	0.9(0.8-1.0)	263	0.9(0.8-1.0)	154	1.1(0.9-1.2)	266	0.9(0.7-1.2)	163	1.1(0.8-1.4)	163	1.1(0.8-1.4)	163		
2014	0.8(0.6-1.0)	62	1.4(1.0-2.0)	39	0.8(0.6-1.0)	227	0.8(0.6-1.0)	140	1.1(0.9-1.2)	264	0.9(0.7-1.2)	160	1.1(1.1-1.5)	160	1.1(0.8-1.5)	160		
2015	0.8(0.6-1.1)	44	1.9(1.3-2.7)	36	1.0(0.8-1.2)	202	1.0(0.8-1.2)	109	1.3(1.1-1.5)	181	0.8(0.6-1.1)	102	0.9(0.7-1.2)	102	0.9(0.7-1.2)	102		

Changes in method over time by setting and sex

Self-harm events per 1000 PYAR by method sex and setting over time are shown in Figure 17.

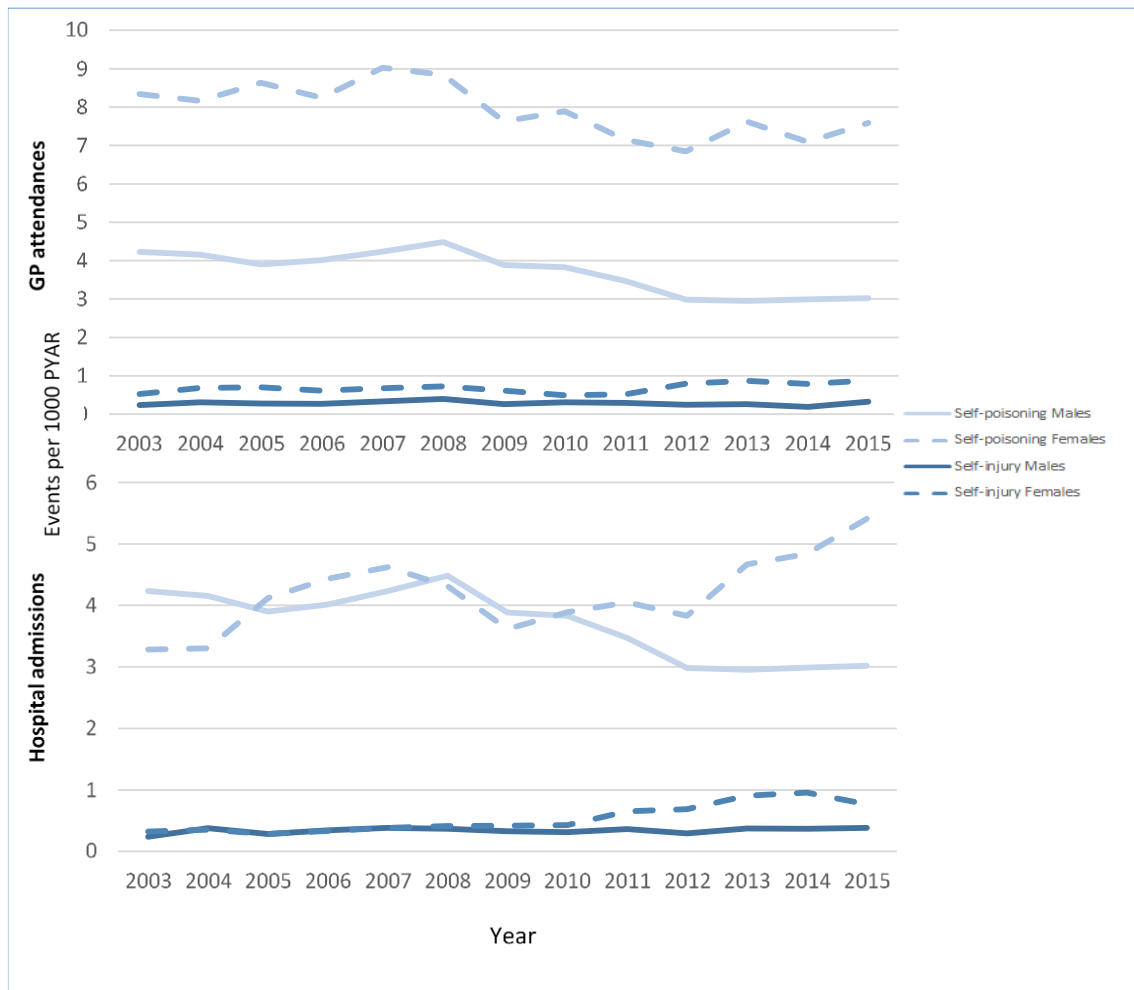


Figure 17 Self-harm events per 1000 PYAR by method, setting and sex over time

GP attendances for self-poisoning decreased over time from 6.2-5.2 attendances per 1000 PYAR (IRR=0.8[95% CI 0.7-1.0; $p<.001$]). This decrease was seen for both sexes (interaction between sex and year non-significant). In contrast hospital admissions for self-poisoning increased over time from 2.5-3.5 admissions per 1000 PYAR (overall IRR=1.4[95% CI 1.1-1.7 $p<.001$]; males IRR=0.9[95% CI 0.7-1.1; $p<.001$]; females IRR=1.6[95% CI 1.4-2.0; $p<.001$]; interaction between sex and year IRR=1.0[95% CI 1.0-1.1; $p=.016$] per iteration with males as reference group).

GP attendances and hospital admission for self-injury increased significantly over time overall (GP change from 0.4-0.6 events per 1000 PYAR [overall IRR=1.6[95% CI 1.2-2.1; $p=.039$]; males IRR=1.3[95% CI 0.8-2.3; $p<.001$]; females IRR=1.7[95% CI 2.3-2.3; $p<.001$]; interaction between sex and year non-significant; hospital admission IRR=2.0[95% CI 1.5-2.8; $p<.001$]). There was a significant interaction between sex and year for hospital admissions for self-injury (IRR=1.1[95% CI 1.1-1.1] per iteration with males as the reference group). There was no significant change

over time for males (IRR=1.6[95%CI 1.0-2.5; p=.607]). Female admissions more than doubled over the study period (IRR=2.4[95% CI 1.7-3.5; p<.001]). Self-cutting made up 89%(95% CI 88-90; n=2288) of GP attendances for self-injury and 72%(95% CI 70-74; n=1649) of hospital admissions.

Contacts across services

From 01.08.2011-30.09.2015 15739 individuals had 28970 self-harm events across settings.

Table 14 shows the demographics of individuals presenting to each service singly or in

Table 14 Presentation of self-harm across services^a and associated outpatient appointments from 01.08.2011-30.09.2015

Individuals n(%; 95%CI)	Females n(%; 95% CI)	Events N(%; 95%CI)	Self-poisoning only n (%; 95% CI)	Self-poisoning and injury n (%; 95% CI)	Self-injury only n (%; 95% CI)	Outpatients' n (%; 95% CI)	Mental health speciality n(%; 95% CI)	Paediatric speciality n(%; 95% CI)
GP only	3912(25;24-26)	10690(37;36-37)	6194(58;57-59)	4181(39;38-40)	315(3;3-3)	2504(23;23-24)	1758(70;67-73)	90(4;3-4)
Hospital admission only	1084(7;7-7)	4171(14;14-15)	3364(81;79-82)	673(16;15-17)	134(3;3-4)	1308(31;30-33)	907(69;65-74)	46(4;3-5)
ED only	3428(22;21-22)	1449(42;41-44)	1371(18;17-19)	5075(68;67-69)	1025(14;13-15)	1882(25;24-26)	1080(57;54-61)	46(2;2-3)
GP and hospital admission	2394(15;15-16)	1725(72;70-74)	1633(72;70-74)	149(7;6-8)	488(21;20-23)	734(32;30-35)	592(81;74-87)	28(4;3-5)
GP and ED	1979(13;12-13)	1150(58;56-60)	518(24;22-26)	474(22;20-24)	1152(54;52-56)	545(25;23-28)	408(75;67-82)	8(1;1-3)
ED and hospital admission	566(4;3-4)	331(58;54-62)	308(27;25-30)	157(14;12-16)	668(59;56-62)	413(36;33-40)	321(78;69-86)	17(4;3-7)
GP, ED and hospital admission	2376(15;15-16)	1647(69;67-71)	289(26;24-29)	59(5;4-7)	743(68;65-71)	383(35;32-39)	319(83;74-92)	18(5;3-7)
Total	15739	9484(60;59-61)	13677(47;47-48)	10768(37;37-38)	4525(16;15-16)	7769(27;26-27)	5385(69;67-71)	253(3;3-4)

- Mutually exclusive groups
- Total number of individuals presenting to service(s) over the study period
- Event defined as a self-harm presentation across one of more services on a given date
- Percentage of total presenting individuals
- Percentage of outpatient appointment within the subsequent 30 days
- Percentage of outpatient appointments under a mental health speciality
- Percentage of outpatient appointments under a paediatric speciality

combination. Individuals presenting to 'GP only' make up the largest group accounting for 25%(95% CI 24-26; n=2912) of individuals and 37%(95% CI 36-37; n=10690) of events. Females outnumber males in every setting except 'emergency department only' where just 42%(95% CI 41-44; n=1449) of individuals are female.

Almost half of all events were for self-poisoning with 37%(95% CI 37-38; n=13677) for self-injury and 16%(95% CI 15-16; n=4525) for both self-poisoning and self-injury. Most events recorded in 'GP only' and 'hospital admissions only' were self-poisoning while the majority of events recorded in 'emergency department only' were self-injury.

Hospital admissions

There were 8,665 admissions to hospital (Table 15; either singly or in combination with other

		Surgical Specialties	ED Surgical Specialty	Paediatric	Psychiatric	General Medicine	Other medical specialities
Age group	10-14 years	23(1;1-1)	<5	2740(99;98-99)	<5	<5	<5
	15-19 years	74(3;3-3)	<>(16;15-18)	<>(30;28-31)	<>(1;1-1)	<>(36;34-38)	<>(13;12-15)
	20-24 years	217(6;5-7)	813(22;20-23)	<5	47(1;1-2)	2035(54;53-56)	642(17;16-18)
Sex	Male	186(7;6-8)	449(17;16-19)	502(19;18-21)	32(1;1-2)	1077(41;40-43)	353(14;12-15)
	Female	128(2;2-3)	717(12;11-13)	2870(47;46-49)	37(1;0-1)	1736(29;27-30)	578(10;9-10)
All (n=8665)		314(4;3-4)	1166(13;13-14)	3372(39;38-40)	69(1;1-1)	2813(33;32-33)	931(11;10-11)

a. Encompasses all other specialities

<>. Numbers excluded to make small numbers

Table 15 n(%;95% CI) of hospital admissions for self-harm by admission speciality, age group and gender

settings). Paediatric admission specialities made up the largest proportion of admissions followed by general medicine. Just 1%(95% CI 1-1; n=69) were admitted under psychiatry of which 12%(95% CI 6-21; n=8) were under 'child and adolescent psychiatry.' Almost all 10-14 year olds were admitted under 'paediatrics'. Females were more commonly admitted under 'paediatrics.' males 19%(95% CI 18-21; n=502). A higher proportion of males were admitted under 'general medicine.'

Outpatients appointments

A third of self-harm events were associated with an outpatient appointment (Table 14). The largest proportions of appointments were for those both 'attending emergency department and admitted to hospital'. Only a quarter of those 'attending emergency department only' had an outpatient appointment within 30 days. The smallest proportion of associated outpatient

appointments was seen in those presenting to 'GP only'. The majority of outpatient appointments were under a mental health speciality. Only 3%(95% CI 3-4; n=253) were under a paediatric speciality.

Emergency department attendances and associated hospital admissions

There were 11,839 emergency department attendances for self-harm from 01.08.2009-30.09.2015 (Table 16). Less than half of these attendances were associated with a hospital admission. Hospital admissions associated with an emergency department attendance are shown in Figure 18. Age groups here are discussed in relation to NICE guidance and are as such split into age groups 10-15, 16-18 and 19-24 years. Admission was most likely in younger age groups with the highest proportion of admissions seen in 10-15 year olds.

Females are more likely to be admitted than males independent of age group or method of self-harm. The greatest disparity between the sexes in those age 10-15 years 76%(95% CI 74-78; n=1182) of females were admitted compared with 49%(95% CI 45-53; n=274) of males. This difference between the sexes is less apparent in older age groups (16-18 years females 40%[95% CI 38-42; n=2125] vs. males 29%[95% CI 27-31; n=382]; 19-24 years females 34%[95% CI 33-36; n=1065] vs. males 34%[95% CI 33-36; n=1095]). Attendances for self-poisoning were more likely to be admitted than self-injuries. The highest proportion of admissions was seen in 10-15 year old girls attending for self-poisoning with 90%[95% CI 87-93; n=385] of those attending being admitted compared with 69%(95% CI 59-78; n=63) of males attending for self-poisoning of the same age.

Emergency department attendances and associated outpatient appointments

There were 11,839 emergency department attendances for self-harm of which 3223(27%, 95% CI 26-28) had an associated outpatient appointment within 30 days. Attendances associated with a hospital admission were more likely to have a subsequent outpatient appointment than those without (Figure 18). In those aged 10-15 years males are more likely than females to have an outpatient appointment without a hospital admission (males 28%[95% CI 23-34; n=81]; females 22%[95% CI 18-27; n=81]). This is not seen in older age groups. The percentage of attendances associated with an outpatient appointment varied by method age and sex (Figure 19). For younger age groups females were most likely to have an associated outpatient appointment when attending the emergency department with both self-injury and self-poisoning. For males, this combination of methods is the least likely to have an associated outpatient appointment. In those aged 16-18 and 19-24, a higher proportion of attendances for

self-injury than self-poisoning has an associated outpatient appointment. This is not seen in those aged 10-15 years.

Table 16 Proportion of Emergency Department attendances associated with hospital admission by method gender and age group 01.08.2009-30.09.2015

	All self-harm		Self-poisoning		Self-injury		Both Self-poisoning and injury	
	ED attendances (n)	With hospital admission (n (%; 95% CI)	ED attendances (n)	With hospital admission (n (%; 95% CI)	ED attendances (n)	With hospital admission (n (%; 95% CI)	ED attendances (n)	With hospital admission (n (%; 95% CI)
Male	5059	1751(35;33-36)	1065	468(44;41-47)	3317	1048(32;30-33)	677	235(35;31-38)
Female	6780	3104(46;45-47)	1670	936(56;54-58)	4031	1655(41;40-43)	1079	513(48;45-51)
10-15 years	2108	1456(69;67-71)	517	448(87;83-89)	1252	741(59;56-62)	339	267(79;74-83)
Male	560	274(49;45-53)	91	63(69;59-78)	386	359(93;90-95)	83	49(59;48-69)
Female	1548	1182(76;74-78)	426	385(90;87-93)	866	700(81;78-83)	256	218(85;80-89)
16-18 years	3444	1239(36;34-38)	751	349(46;43-50)	2166	719(33;31-35)	527	171(32;29-37)
Male	1319	382(29;27-31)	263	106(40;35-46)	888	242(27;24-30)	168	34(20;15-27)
Female	2125	857(40;38-42)	488	243(50;45-54)	1278	477(37;35-40)	359	137(38;33-43)
19-24 years	6287	2160(34;33-36)	1467	607(41;39-44)	3930	1243(32;30-33)	890	310(35;32-38)
Male	3180	1095(34;33-36)	711	299(42;38-46)	2043	644(32;30-34)	426	152(36;31-40)
Female	3107	1065(34;33-36)	756	308(41;37-44)	1887	599(32;30-34)	464	158(34;30-38)
Total	11839	4855(41;40-42)	2735	1404(51;49-53)	7348	2703(37;36-38)	1756	748(43;40-45)

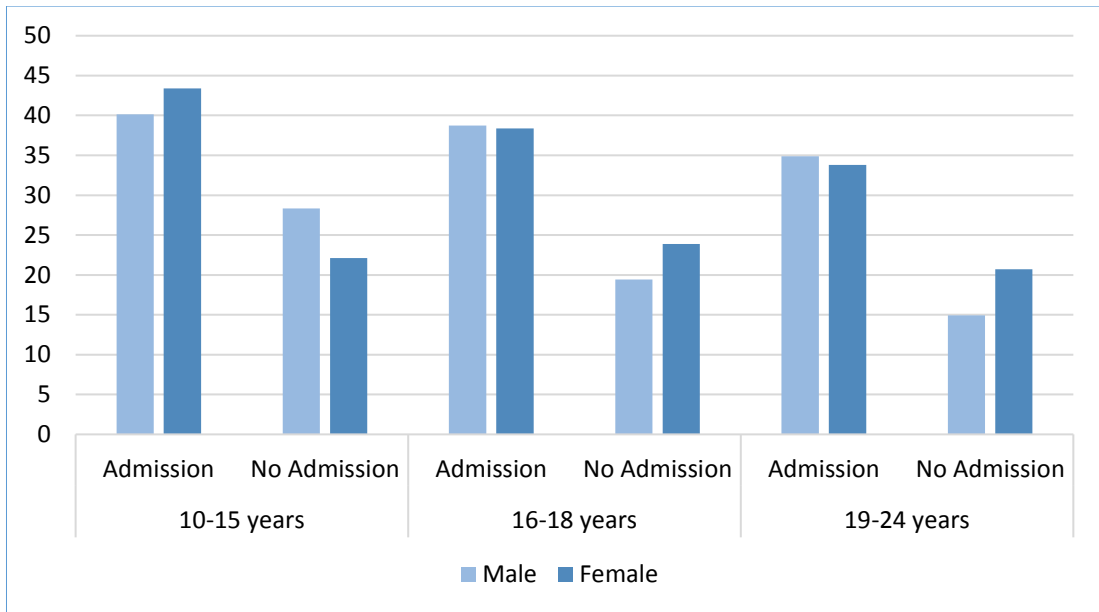


Figure 18 Percentage of emergency department attendances with an outpatient appointment in the subsequent 30 days by the presence or absence of an associated hospital admission

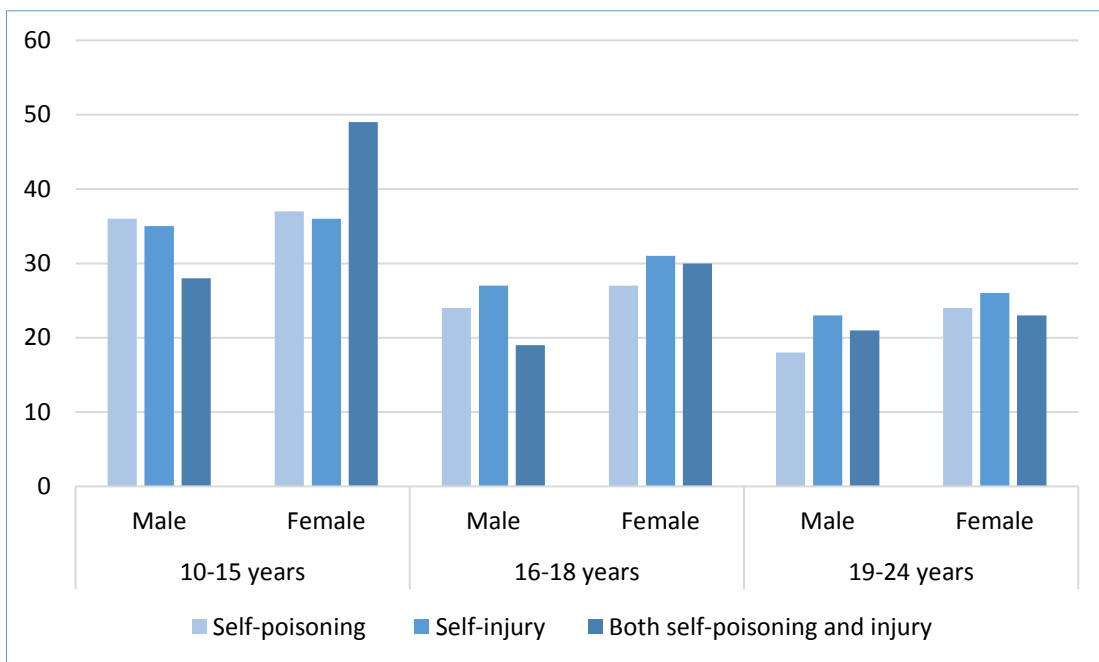


Figure 19 Percentage of emergency department attendances with self-harm with an associated outpatient appointment within 30 days by age, sex and method

6.4 DISCUSSION

Main findings

Utilising data from the SAIL databank has provided a unique opportunity to link contacts for self-harm across primary care, emergency departments, hospital admissions and outpatients at person level. This is the first study to do this in the UK and has created a comprehensive picture of health service utilisation for self-harm in young people aged 10-24. This compliments data collected via the SHARE UK platform described in Chapter Four. Incidence of recorded self-harm was found to be highest in primary care with incidence around double that seen for hospital admissions as seen elsewhere (Thomas et al., 2013). In keeping with previous research (Carr et al., 2016a), incidence was found to be significantly higher in females than in males. By breaking this difference down by setting and sex, it is apparent that this difference is largest in hospital admissions data with incidence in females more than double that seen in males. Similarly, GP attendances are around double in females than in males with a comparatively small sex difference seen for emergency department attendances. Incidence of self-harm was found to be more than double in the most deprived compared with the least deprived areas in keeping with previous research (Carr et al., 2016a). This was found across all settings with a greater impact of deprivation seen for males.

Incidence of self-harm over time was found to vary by healthcare setting, age and sex building on previous research by breaking down GP, emergency department and hospital admissions for self-harm over time. Across all age groups incidence was highest for GP contacts for females and for emergency department attendances for males (where this data was available) with the lowest incidence of self-harm seen for hospital admissions. GP contacts remained relatively stable with significant increases seen for both emergency department attendances and hospital admissions. Previous research combining GP and hospital admissions found a significant increase in incidence in females aged 13-16 not reflected in older adolescents or males (Morgan et al., 2017). This study supports the increase in young adolescent females found previously. However breaking results down by healthcare setting and the addition of emergency department data demonstrates that while GP incidence has remained stable for males in this age group, emergency department attendances have more than doubled and hospital admissions have significantly increased with a marked increase from 2011 onwards. In 15-19 year olds, GP attendances remained stable while emergency department attendances increased for both sexes, with a significant increase seen in hospital admissions for females only. The absence of a corresponding increase for males of this age is a cause for concern. For

those aged 20-24, GP attendances significantly decreased for males but not for females, emergency department attendances increased significantly for females but not for males with hospital admissions remaining relatively stable for both sexes.

There are several possible reasons why self-harm presentations are increasing over time. The increases in hospital admissions are potentially reflecting improved management of self-harm based on guidance recommending admission for individuals under 16 (NICE, 2012) however, this does not explain the increase in emergency department attendances. An increase in violent self-harm methods such as hanging has been reported elsewhere (Vancayseele, Portzky, & van Heeringen, 2016). Increasingly medically severe self-harm in children and young people may be resulting in increased presentation to hospital-based settings. The increasing trend over time seen here could also be partially attributable to increased help-seeking by young people. There is evidence that the proportions of young people seeking help (both from health services and from family and friends) for self-harm have increased over time even when controlling for individual factors, with male gender and poorer parental attachment decreasing the likelihood of receiving help (Rossow & Wichstrøm, 2010). Research has also found a lowering in levels of distress in young adults (aged 18-24) who utilised psychiatric services from 2002-2010 suggesting a lowering of threshold for help-seeking in among young adults over time in Stockholm (Kosidou et al., 2017), or increased awareness by parents and caregivers. Results could also be due to improved recognition and recording by clinicians. While many factors may underlie these results community survey studies suggest that there is a genuine increase in self-harm in children and young people (McManus & Gunnell, 2019). Teachers have reported an increase in reports of mental health issues and self-harm (Rodway et al., 2016). Increased reports of self-harm have also been reported from charity based and third sector organisations who have contact with children and adolescents (NSPCC, 2016).

Increases over time could be partially due to the economic climate over the study period. After the financial crisis of 2007-2008 and subsequent period of economic recession, an austerity programme was initiated by the UK Government in 2010. Austerity measures resulted in reductions in public spending, cuts to welfare, schools, local government funding, police, and health services. There is a large body of evidence demonstrating a relationship between economic hardship and poor mental health with the effects of economic strain affecting the mental health of both adults and their children (Solantaus, Leinonen, & Punamäki, 2004). Numerous studies have shown an increase in rates of suicide and suicidal ideation associated with general economic recession and unemployment (Wahlbeck & Awolin, 2009). National

incidence rates of self-harm have risen in individuals aged 15 and older in Ireland in the wake of the economic downturn and subsequent era of austerity (Corcoran, Griffin, Arensman, Fitzgerald, & Perry, 2015). Qualitative research has found that economic hardships resulting from austerity measures are often a trigger to a self-harm event, particularly in those who are already vulnerable (Barnes et al., 2016). The impact of austerity goes beyond self-harm. Prevalence of mental health problems in England have increased markedly since 2008 with the increases greatest in individuals with less education and those out of work widening inequalities between those with high and low levels of education (Barr, Kinderman, & Whitehead, 2015). Gender inequalities in poor mental health have also widened during austerity with women most adversely effected (Thomson, Niedzwiedz, & Katikireddi, 2018). A sharp increase in elevated mortality in those with bipolar and schizophrenia has been seen since 2010 and this is hypothesized to be related to austerity measures (Hayes, Marston, Walters, King, & Osborn, 2017).

Trends in method over time by setting and sex were also examined. Self-injury was found to increase significantly for both sexes, with a larger increase in females in keeping with emergency department (Arensman et al., 2018) and hospital admissions research finding an increase in violent self-injury such as hanging (Vancayseele et al., 2016). Incidence of self-poisoning was significantly higher than for self-injury for both sexes for GP attendances and hospital admissions. GP attendances for self-poisoning decreased over time while hospital admissions with self-poisoning increased for females only. In contrast, GP attendances for self-injury increased significantly over the study period for both sexes and hospital admissions increased for females only. The majority of self-injury events were for self-cutting.

Females outnumber males in every setting with the exception of those presenting to emergency departments only, of which 58% of individuals are male. Taken together with the higher incidence of emergency department attendances for self-harm in males compared with hospital admissions and GP contacts it appears that males are preferentially presenting to emergency departments. This underscores the concerning disparity in admissions by sex. Self-injury is more likely to be used by males. This is less likely to result in admission if not medically required, possibly based on misconceptions regarding suicide risk (J. Cooper et al., 2005; Lilley et al., 2008). Men have previously been found to be significantly more likely than women to seek help from emergency services (Nada-Raja, Morrison, & Skegg, 2003; Ystgaard et al., 2009), while women have been repeatedly found to be more likely to seek help from their social network (Rossow & Wichstrøm, 2010; Ystgaard et al., 2009). Young adults taking part in semi-

structured interviews reported on help-seeking behaviour for self-harm. Of those who fit the ICD-10 definition of self-harm females were more likely than males to see their GP (40% of females compared with 20% of males). Males were more likely than females to attend emergency services (53% of males compared with 10% of females) or to be hospitalized/receive intensive care (13% of males, 0% of females (Nada-Raja et al., 2003)). This supports results found here.

Paediatric admissions made up the largest proportion of hospital admissions with 99% of 10-14 year olds admitted under paediatrics. For older age groups admission under 'general medicine' was more common. Less than 1% of hospital admissions were under a psychiatric specialty. Males were more likely than females to be admitted under general medicine. Previous research has found that psychiatric admission is most likely when highly lethal methods of self-harm are used (Arensman et al., 2018). A third of self-harm events had an associated outpatient appointment in the subsequent 30 days, with outpatient appointments most likely in those both attending emergency departments and being admitted to hospital and the least likely in those presenting to GP only. The majority of outpatient appointments were under a mental health specialty with just 3% under a paediatric specialty.

Less than half of emergency department attendances were associated with a hospital admission. This varied by age and method of self-harm. Admission of 16 and 17 year olds is based on clinical judgement rather than stipulated in guidance (Arensman et al., 2018). Results of this study support previous research demonstrating that under 16s are more likely than other age groups to be admitted following emergency department attendance for self-harm (Arensman et al., 2018) in keeping with clinical guidance for this age group (NICE, 2012). The ratio of females to males attending emergency departments with self-harm has been previously found to decrease with age, with those aged 12-14 most likely to be admitted (Diggins, Kelley, Cottrell, House, & Owens, 2017). The results here additionally demonstrate that females are more likely to be admitted following emergency department attendance than males. This is most evident in those age 10-15 years, where 76% of females attending emergency departments are admitted compared with just 49% of males. This difference persists even in the case of self-poisoning. There may be multiple reasons for this. Males are more likely to leave emergency departments without treatment or to refuse admission. This is supported by data from the National Self-Harm Registry in Northern Ireland. Research with this registry has shown that females were more likely to be admitted to a general ward than males

and that males were more likely to refuse treatment or to leave the emergency department before a next care recommendation could be made (Arensman et al., 2018).

The first point of contact with any helping agency represents a critical factor in determining continued help-seeking behaviour. Gender-aware practice is necessary to meet the differing needs of both males and females. A larger proportion of girls than boys receive help from their social network with a larger proportion of boys than girls not seeking any help at all (Ystgaard et al., 2009). This suggests that males are not utilising their social networks for support in the way that females are. The gender gap in help-seeking goes beyond seeking help for self-harm or mental health issues and includes seeking help for substance misuse (McKay, Rutherford, Cacciola, Kabasakalian-McKay, & Alterman, 1996), physical health issues (Richardson & Rabiee, 2001) and sexual health (VanDevanter et al., 2005) with help-seeking differences seen as early as age three (Benenson & Koulkazarian, 2008).

Less than a third of emergency department attendances had a subsequent outpatient appointment and those admitted were more likely to be seen in outpatients. This may indicate a need for better recording of liaison or crisis team contacts or reflect poor follow-up of patients who present with self-harm (Kapur et al., 2015). In those aged 10-15 years, females were more likely than males to have an outpatient appointment with an admission. However, males were more likely than females to have an outpatient appointment without an admission. The majority of outpatient appointments were under a mental health specialty. For females aged 10-15 outpatient appointments were most likely for those attending emergency departments with both self-injury and self-poisoning, whereas for males this combination of methods was the least likely to have an associated outpatient appointment.

Strengths and limitations

Web-based research such as that described in Chapters Four and Five has many advantages described previously. However it also has several notable limitations (e.g. incomplete responses, biased samples and underrepresentation of disadvantaged backgrounds (Goodman, 2013; Heiervang & Goodman, 2011)). The inclusion of a routinely collected data component to this project offers a complimentary source of data and an additional perspective and context for results. When pulled together, these data sources offer many advantages as an evidence base for service planning and provision. This chapter provides a comprehensive picture on which to base targeted intervention, resources and service provision. Data available in the SAIL databank has several advantages over other routinely collected datasets including

linkage of emergency department, GP, hospital admissions and outpatient data available at population level. Derived from a large representative population of children and young people studied over a period of 12 years, results are generalizable to the rest of the UK.

Any research with routinely collected data has some limitations, as this data is not collected for the purpose of research. The quality and completeness of data varies across datasets. For the purpose of this study, steps were taken to minimise the impact of this by only including GPs that meet the standards for data quality and using validated code lists (Carr et al., 2016a; Thomas et al., 2013). Self-harm that does not result in presentation to services or, where self-harm is discussed but not recorded will not be captured here. This is a common feature of all studies using routinely collected data. These data reflect contacts with the healthcare system and are not intended to represent rates of self-harm in the community. GP coding behaviour has been shown to change over time (John et al., 2016b; John et al., 2015). It is unclear whether the increase in self-harm shown here reflects a genuine increase or this partially attributable to improved recognition and coding behaviour by clinicians and increased help-seeking by individuals (Clements et al., 2016) and caregivers. It is most likely that results are reflecting a combination of factors.

When an individual is admitted to hospital up to 14 diagnoses can be recorded per admission, all of which were included in the analysis here. This means the self-harm may not always be the primary reason for admission. For example, in the case of self-poisoning the primary reason for admission is likely to be for treatment or monitoring of poison levels. Inclusion of all 14 diagnoses ensures that cases of self-harm are not missed. For the purpose of this study, a hospital admission within seven days of emergency department attendance was taken as a measure of whether an emergency department attendance resulted in admission. This allowed for individuals to remain in the emergency department prior to admission and for delays in data recording. However, there is no reliable way to examine whether an admission was a direct result of emergency department attendance. Hospital admissions were examined by speciality; however it is not possible based on this data to examine whether an individual was admitted to general medical or psychiatric hospital. Further work is needed to identify psychiatric hospitals in routinely collected data.

For the purpose of this study, method was grouped broadly into 'self-poisoning' and 'self-injury'. It was not possible to subdivide self-injury (e.g. into hanging, traffic etc.) as the numbers of these injuries were not sufficient for a meaningful breakdown. There was also no way based on this data to examine the severity of a self-harm event. While admission to hospital may

reflect increased severity, there are multiple factors influencing whether or not someone is admitted including age, sex and method of self-harm, meaning that the decision to admit may not be based solely on the severity of an injury. Length of hospital admission or long-term outcomes were not examined as part of this study as this would have been beyond the scope of this project. Given the lack of evidence regarding patient management and long-term outcomes for self-harm, such as repeat self-harm and excess mortality (Carroll, Metcalfe, & Gunnell, 2014), future research should endeavour to examine the impact of patient management and healthcare setting attended. Routinely collected data has the advantage of long-term follow-up of patients. Future research could expand on this work incorporating older age groups, mortality and other adverse outcomes.

Emergency department data in the SAIL databank is not available prior to 2009 and has less detailed coding of self-harm compared with GP and admissions data. Emergency department data are collected from every emergency department in Wales. Prior to 2012 there were coding quality issues from some providers. As such data from 2009-2012 should be interpreted with caution particularly concerning trends over time. Absolute numbers of cases/individuals are most likely to be underestimates during this time due to some coding completeness issues. Emergency department trends over time presented here are in keeping with other research using emergency department data (Arensman et al., 2018).

Implications

This research has been published in a peer reviewed journal (Marchant et al., 2019; Appendix I) and was discussed in the press upon publication. I did interviews with BBC Wales News, BBC Radio Wales, Heart Radio and Sky News Radio to raise awareness of the findings of this research. An article was also published in The Conversation. The findings of this research were discussed with Welsh Government prior to publication who have utilised the findings as part of the development of a whole system approach to the management of self-harm in children and young people.

People who have harmed themselves visit clinicians much more frequently than their age and sex matched peers presenting a clear opportunity for preventative action (Carr et al., 2017). Analysis of contacts across services here show an important role of primary care. Individuals presenting only to their GP make up the largest group (25%), and incidence in primary care was around double that seen for hospital admissions. This supports results described in Chapter Four of the importance of primary care as a setting for intervention. Individuals who attend

primary care with self-harm have an elevated risk of premature death, with a particular risk of suicide (Carr et al., 2017). Clinical guidance have emphasized the importance of GPs and primary health teams in managing and monitoring risk in individuals who present with self-harm over both short and long-term follow-up (NICE, 2004, 2012). Individuals who present to secondary care do not capture a population of higher-risk individuals compared with primary care patients. As such, individuals presenting to their GP also require tailored support (Carr et al., 2017). Low rates of referral to mental health services from primary care have been found previously (Carr et al., 2016b). It is important that GPs are supported to recognise self-harm and provide adequate interventions or referrals where appropriate. GPs may underestimate the prevalence of self-harm in young people and have stated they would welcome training in communication with children and young people and practical information on self-harm (Fox et al., 2015).

Children and young people regularly contact non-psychiatric specialist services. Results here show that around a quarter of individuals present to their GP only and just under a quarter present to emergency departments only. This means that almost half of individuals were not admitted to hospital. This highlights the importance of support being available across services. It is important professionals in these services be supported in their ability to identify children and young people at risk, provide appropriate support and determine when referral to specialist services is required or urgent. Further training for wider NHS staff with specific targets set in policy guidance (e.g. Scottish Executive, 2002) could improve management and outcomes for those presenting with self-harm.

It appears that males are preferentially presenting to emergency departments over other healthcare settings. The higher overall suicide rate in males makes this an important setting for intervention in this often hard to reach group. Previous research has shown that a larger proportion of boys than girls do not receive any help for self-harm from services or their social networks (Ystgaard et al., 2009). Given that males are often reluctant to seek help it is important that the right support and intervention is available when they do present to services as this represents an important opportunity for intervention. Tailored follow-up services should be considered.

Qualitative research is needed to explore whether males feel more comfortable seeking help in emergency settings or if this represents delayed help-seeking until a crisis point is reached and emergency care is required. Improving the help-seeking skills of young males may prevent delayed presentation to emergency settings (Hassett & Isbister, 2017). Programmes to increase

help-seeking in adolescent boys may have implications for presentation to services, with programmes that promote help-seeking before crisis point having the potential to reduce demand in emergency settings. Sex differences in negative mental health attitudes and an associated willingness to use mental health services have been found to be present early in adolescence (Chandra & Minkovitz, 2006). Calls have been made to enhance mental health education and services for younger adolescents incorporating efforts to reduce stigma, actively involve parents and address sex differences in knowledge of and exposure to mental health issues (Chandra & Minkovitz, 2006). The role of an external adult in recognising, normalizing and initiating help-seeking has been emphasized in qualitative research with adolescent males. All participants in one study reported that the initial recognition of the need for help came from external sources such as parents, teachers or friends (Hassett & Isbister, 2017). The importance of others in initiating conversations was highlighted as was the importance of normalisation of help-seeking and emotional difficulties from a gendered perspective (Hassett & Isbister, 2017). A number of participants also discussed a preference for non-face-to-face methods of communication such as social networking and their use for maintaining some control over their communication of distress both in terms of accessing help and engaging with services (Hassett & Isbister, 2017).

The marked rise in incidence of self-harm in the youngest age group since 2011 warrants further investigation. While this increase coincides with the introduction of austerity more research is needed to fully understand the underlying reasons for this increase. This increase may be partially attributable to stressors related to parental employment, housing, low wages and poverty or, this may also be related to funding cuts to schools or services. It is also possible that factors besides austerity are contributing to this increase. Research incorporating qualitative methods to learn more about the experiences of these young people may further understanding of issues contributing to a rising incidence of self-harm. This would have important implications for policy and service provision.

Rates of emergency department attendance and hospital admissions are increasing for those aged 10-19 years. Individuals in younger age groups are often brought rather than initiating attendances themselves with the role of a supportive adult thought to be particularly important for young males (Hassett & Isbister, 2017). While adolescent girls are more likely to seek help from a friend, boys are more likely to seek help from a family member (Chandra & Minkovitz, 2006). Increases in presentations to healthcare settings may reflect greater awareness of parents/carers and improved help-seeking. While this is positive in terms of

young people receiving much needed support, it also highlights an increasing demand on resources. Older adolescents are more likely to initiate their own help-seeking. The higher rate of primary care contact for self-harm in older adolescents may be partially attributable to an increase in help-seeking with age (Sayal, Yates, Spears, & Stallard, 2014). In an investigation of help-seeking for self-harm in 14-19 year olds, older participants were more likely to report having received professional help (Rossow & Wichstrøm, 2010). School and community based youth education programmes have been developed to improve knowledge of self-harm/suicidal behaviours and to promote help-seeking (e.g. Mann et al., 2005). A systematic review of the efficacy of school based education programmes found that these programmes led to increased knowledge of signs and risk factors for suicide and increased intention to seek help for suicidal thoughts (Cusimano & Sameem, 2011). However randomised control trials examining the impact of these programmes on actual help-seeking behaviour have found no effect and suggest that other barriers exist apart from just knowledge and attitudes, for example service provision (Aseltine & DeMartino, 2004; Aseltine, James, Schilling, & Glanovsky, 2007). Services need to be available and able to offer timely treatment to promote help-seeking and engagement with treatment. Interventions need to be gender-tailored and incorporate steps to reduce stigma. Perceived stigma is thought to be of particular relevance to the identity of boys and may underlie why males are less willing to seek help for mental health issues (MacLean, Hunt, & Sweeting, 2013). Appropriate support in emergency settings for males is particularly important given the higher suicide risk for young males and that young males are less likely to seek help than females of the same age.

6.5 CHAPTER SUMMARY

This is first UK study to explore trends over time and characteristics of patients with self-harm by healthcare setting, and the first to incorporate emergency department data into such analysis. This chapter also adds a complimentary data source to the analysis described in Chapters Four and Five providing an additional evidence base on which to base recommendations for service provision. Patients who are admitted to hospital make up only a small proportion of self-harm with almost half of individuals presenting either to GP or to emergency departments only. This highlights the importance of these settings for young people who self-harm and underscores the needs for professionals in these settings to be supported to recognise self-harm and to provide appropriate intervention, support or referral to other services. Incidence of self-harm over time varies by age group, sex and service. Understanding patterns of presentation will inform service planning and configuration of

follow-up care and could inform tailored support, for example for males in emergency departments. The potential for this research to inform change has been facilitated by press attention and close links of the lead supervisor with Welsh Government who have utilised these findings as part of a whole system approach to management of self-harm including programmes in schools. Routinely collected linked healthcare data provides important evidence to support the development of interventions across healthcare settings.

7 DISCUSSION

As outlined in Chapters One and Two, self-harm is a major public health concern. Almost one in five fourteen year old girls and one in seven fourteen year old boys reported having self-harmed in the previous year (The Childrens Society, 2018). This is supported by data from the APMS finding that one in five 16-24 year old women report having self-harmed in a face-to-face survey, increasing to one in four in a self-completion survey (McManus et al., 2019). A history of self-harm is one of the strongest risk factors for future suicide (Hawton & Van Heeringen, 2000; Sakinofsky, 2008) and young people aged 10-19 with a history of self-harm are almost ten times more likely to die of unnatural causes and seventeen times more likely to take their own lives than young people with no history of self-harm (Morgan et al., 2017). While deaths in this age group are a rare outcome, unnatural causes of death are largely preventable and providing appropriate support and intervention for individuals who self-harm has the potential to save lives. Self-harm is often a hidden behaviour that does not always present to services and reaching individuals who self-harm for research presents a range of challenges. Lowering some of the barriers to taking part in research and allowing individuals to take part anonymously online, combined with the creation of an online research register of individuals who have experienced self-harm, such as those created for some physical and mental health conditions (e.g. Atkinson et al., 2010; Papoulias et al., 2014), has the potential to reach a large number of participants representing a positive step forward for self-harm research. While an online format for self-harm research has several advantages it also has many limitations (e.g. biased samples, missing data). To create the strongest evidence base on which to base future policy and practice, it is important that multiple sources of data are brought together (Mars et al., 2016). As such additional analysis was conducted utilising routinely collected healthcare data.

This thesis set out to answer several research questions. 1. Is it possible to recruit and maintain a cohort of individuals who self-harm and gather meaningful data using an exclusively online format? 2. Can a research register of individuals who self-harm be successfully set up online and could this be used for recruitment to research? 3. What are the potential issues around utilising Big Data for research encompassing health, social care and social media data? 4. What are the trends over time and patterns of service presentation across healthcare settings in children and young people and, how do presentations vary by age, sex and healthcare setting?

Based on the results reported in Chapter Four recruiting and maintaining an online cohort of individuals who self-harm is possible and has resulted in meaningful data collection via questionnaires and uploads to a media databank of internet resources. This study has

demonstrated the successful development of a research register of individuals who have experienced self-harm. More than 400 people signed up for this via the SHARE UK platform. This research register was utilised to recruit to the Big Data and Mental Health Research Survey described in Chapter Five. While it is not possible to say how many individuals from the register participated in the survey, responses came in within hours of utilising in the mailing list in the absence of any other active recruitment. Furthermore, an additional 1170 individuals with a history of self-harm consented to be re-contacted for future research as part of the Big Data and Mental Health Research Survey. This represents a valuable resource for future research and is currently being utilised to recruit for a study examining the impact of the Covid-19 outbreak and social distancing measures on individuals with a history of self-harm. Results of the Big Data and Mental Health Research Survey (described in Chapter Five) further demonstrate a number of factors to be considered when utilising Big Data for research. Patterns of service utilisation for self-harm were further examined in Chapter Six using routinely collected data to create an e-cohort study of healthcare contacts for self-harm using routinely collected data available in the SAIL databank. This thesis has brought together data from the SHARE UK platform, a national survey and routinely collected healthcare data held in the SAIL databank. The results of each section of this thesis will summarised briefly in turn below.

7.1 SUMMARY OF FINDINGS

The SHARE UK platform

The aim of this part of the thesis was to establish an online platform for self-harm research. This platform was designed to have four main functions: to function as a questionnaire delivery platform; to host a participant-built and maintained databank of online resources utilised by individuals who self-harm; to consent individuals to be contacted for future research creating a self-harm research register and, to explore the possibility of consenting individuals for linkage with routinely collected data. This part of the thesis demonstrated the successful development and implementation of an online platform for self-harm research, its use as a questionnaire delivery platform and for recruitment to a self-harm research register. However, engagement with the media databank was more limited and consent for linkage with routinely collected data lower than expected.

A total of 498 individuals signed up for the platform of which 425 signed up for the research register. Research registers have been previously found to both lower the amount of resources spent on reaching participants and to improve levels of recruitment to studies (Callard et al.,

2014; Robotham et al., 2016). Given the often hidden nature of self-harm and known issues recruiting to studies (Hunter et al., 2013) a self-harm research register represents an important resource for future research. More than 80% of participants were female. While participants ages ranged from 16 to 57 young people aged 16-24 made up the largest group. Data collected via registration questions related to self-harm, help-seeking behaviour and contact with healthcare services (described in detail in Chapter Four). Results were largely in keeping with previous research finding that around half of individuals report not receiving help for self-harm, either from health services or from their social network (Ystgaard et al., 2009). There may be important differences between individuals who present to services and those who do not, for example in terms of levels of distress or severity of injury (Grøholt et al., 2000; Ystgaard et al., 2009). The SHARE UK platform has the advantage of reaching both groups. Future research with this platform could seek to identify how the needs of these two groups differ. Providing the right support for individuals who have not yet presented to services has the potential to prevent these individuals reaching crisis point, both improving lives of individuals and lowering the demand for services. In contrast those who present to services may have different needs for support that may be more complex. Future research could seek to further investigate this.

Around half of participants reported being in contact with social care, of which half of reported contact for self-harm. Individuals who have contact with social care related to self-harm appear to represent a vulnerable group with higher scores on measures of self-harm, shame, compulsive internet use and, scores indicative of lower resistance to peer influence. Previous research has called for standard recording of factors such as domestic violence and parental mental illness in emergency attenders at child and adolescent mental health services to enable the collection of standardised data regarding these parameters (Healy et al., 2002). While the data here may not be representative of the population of a whole, vulnerable individuals were successfully recruited. This data could be used to identify vulnerable individuals and inform support.

In addition, 299 individuals completed at least one of the standardised questionnaires hosted on the website, demonstrating the utility of this format for questionnaire delivery that can be expanded for future research. Findings from standardised questionnaires are described in detail in Chapter Four. Findings include high levels of pathological internet use with more than 60% of participants scoring above the cut-off for pathological internet use as measured by the CIUS (Meerkerk et al., 2009). In keeping with previous research potentially pathological internet use was associated with higher self-harm scores (Kaess et al., 2014). Higher scores on measures of compulsive internet use were also significantly correlated with measures of impulsivity and

shame in keeping with previous research (Craparo et al., 2014; Yau et al., 2013). While these questionnaires have yielded results of interest, future work is needed with bigger and more diverse samples. It is intended that this feature of the SHARE UK platform will be expanded in the future to answer a range of research questions.

A total of 62 individuals uploaded 95 items to the media databank. While this represented sufficient engagement for some analysis of sources it is not sustainable as a stand-alone resource in its current form. The majority of uploads were of websites or social media sites. Few contained trigger warnings or opportunities for creative content however, 42% included signposting to sources of help. Results of this analysis demonstrate that some sites intended to be educational, supportive or aimed specifically at academic or clinical audiences had the potential for harmful use. For example, journal articles where names of antidepressants most lethal in overdose are given in the abstract or online magazine articles aimed at GPs where the number of tablets needed for a lethal overdose are given in the first paragraph. It appears that individuals purposefully seek out triggering material and information on methods of self-harm, found previously in those with high levels of suicidal intent (Biddle et al., 2018). This demonstrates that potentially harmful material goes beyond pro-suicide and self-harm sites. This is an area worthy of further study and may have implications for how potentially lethal methods of self-harm are discussed on the internet for audiences beyond young people accounting for content created for clinicians.

Just 15% of participants signed up for linkage of data from the SHARE UK platform with routinely collected healthcare data. This is lower than seen in other studies with different populations. However population in other studies are often older or less vulnerable than participants here (Ford et al., 2012; Hurt et al., 2019). Potential reasons for the low level of sign up were explored in the Big Data and Mental Health Research Survey (Chapter Five; summarised below). It appears that while young people aged 16-24 with a history of self-harm express positive opinions towards linking survey and healthcare data, the process of linkage itself poses a significant barrier. For example, in the case of the SAIL databank, for the link to be made between healthcare and survey data date of birth and address are required. This is needed only for the purpose of making the link, it is held securely by a trusted third party and is destroyed once the link is made (Ford et al., 2009; Lyons et al., 2009). Many participants were understandably reluctant to disclose this information with address considered particularly sensitive. Concerns were raised around the security of giving this information online and around fears of being written to at home, particularly for those who lived with parents.

The Big Data and Mental Health Research Survey

The aim of this part of the project was to conduct a national survey with children and young people (aged 16-24) who self-harm to learn more about young people's feelings on the use of their data for research encompassing a range of Big Data sources. This survey also represents the start of a collaboration between the SHARE UK platform and the ADP. Results of the Big Data and Mental Health Research Survey provide an analysis of participants views on the use of their data for research. This survey is the first to focus on the views of young people aged 16-24 with experience of self-harm in relation to this topic. Results of this survey also give an indication of why consent for linkage between the SHARE UK platform and routinely collected healthcare data was low.

Results here are in keeping with research done with older generations with regards to the use of healthcare data for research (Douglas et al., 2017; Jones et al., 2014). Young people with experience of self-harm share largely positive attitudes towards their healthcare data being used for research. Positive opinions are reflected in repeated statements that data should be used to help others, make improvements to services and save lives. Participants however, stressed the importance of anonymity and the need for appropriate ethical approvals to be put in place including transparency, consent and the option to opt out of having their data used for research. This keeping with previous research with mental health service users aged over 40 demonstrating that participants were comfortable sharing sensitive information for research purpose if data was safeguarded and research aimed to help others (Satinsky et al., 2018). Such concerns are supported by the wider literature where need for identity protections, data security, transparency and safeguarding policies are considered of utmost importance, whilst ensuring the use of the data is within the public best interest (Ienca et al., 2018; Riordan et al., 2015).

With regard to use of both healthcare data more generally and mental health data specifically, anonymity, consent and features of research are key factors that influence the feelings of young people. Repeatedly young people expressed wanting to help others with similar struggles and for their data to be used to improve services. Participants frequently expressed negative opinions about the use of their data for profit or advertising, often referenced in relation to the use of their data by private companies. Young people also reported wanting to know about research, how their data has contributed to positive change and the impact of research on services and the lives of individuals. The loss of control over data once shared, linkage with other sources of data including educational data from schools and in inability to withdraw from data

sharing are concerns influencing negative feelings towards the sharing of data. Taken collectively, these results indicate that young people who self-harm appreciate the importance of Big Data in mental health research for providing a better understanding and evidence base on which to base services, and that they would feel more comfortable if given more information and control over their data.

Young people taking part in the current study were less willing to share social media than other kinds of data, with the feeling that this is more personal than healthcare data. Specific concerns were raised around how it would be possible to anonymize social media data, particularly images, and around ethical issues including consent. There was a disparity between those who were and were not comfortable sharing social media data in terms of the perceived privacy of this data. Those who were comfortable sharing this data for research were often aware that this data was already being analysed and stated that they put things online with the understanding that anything they share does not remain private. In contrast many of those who were not comfortable sharing this data believed that this data was private to them and the people they chose to share this with. This is in keeping with existing literature in relation to a lack of awareness of understanding of privacy issues online (Hoofnagle et al., 2010; Madden et al., 2013). In addition, results demonstrate that young people care about their online privacy to great extent, and while some young people may lack awareness others demonstrate sound comprehension of these issues as they relate to social media and the use of their data.

An e-cohort study of self-harm in children and young people (Marchant et al., 2019)

This part of the project aimed to provide a complementary source of data addressing some of the issues present with research based solely on survey data, providing additional detail regarding service utilisation for self-harm. This data can contribute to evidence on where resources could be best targeted to provide adequate support. Specifically, routinely collected data was utilised to examine contacts for self-harm across GP, emergency department, hospital admissions and outpatients and incidence over time in a whole population of young people. Whether individuals preferentially present across different settings and interactions with demographic variables was also explored.

The analysis described in Chapter Six represents the first UK study to explore trends over time and characteristics of patients with self-harm by healthcare setting and the first to incorporate emergency department data into such analysis. This analysis has resulted in a published paper (Marchant et al., 2019). Patients admitted to hospital made up only a small proportion of self-harm with almost half of individuals presenting to either GP or emergency departments only.

Incidence was highest in primary care, with incidence around double that seen for hospital admissions in keeping with previous research (Thomas et al., 2013). Incidence of self-harm was found to vary over time by age group, sex and healthcare setting. Incidence was found to be significantly higher in females than in males as seen elsewhere (Carr et al., 2016a). This work has built on previous research by breaking down GP, emergency department and hospital admissions for self-harm over time. By further breaking this difference down by setting and sex the current analysis demonstrates that this difference is largest in hospital admissions with incidence in females more than double that seen in males. Similarly, GP attendances are around double in females than in males with a comparatively small sex difference seen for emergency department attendances. Incidence of self-harm was found to be more than double in the most deprived compared with the least deprived areas in keeping with previous research (Carr et al., 2016a). This was found across all settings with a greater impact of deprivation seen for males.

Incidence of self-harm over time was found to vary by healthcare setting, age and sex building on previous research by breaking down GP, emergency department and hospital admissions for self-harm over time. Across all age groups incidence was highest for GP contacts for females and for emergency department attendances for males (where this data was available) with the lowest incidence of self-harm seen for hospital admissions. GP contacts remained relatively stable with significant increases seen for both emergency department attendances and hospital admissions. Previous research combining GP and hospital admissions found a significant increase in incidence in females aged 13-16 not reflected in older adolescents or males (Morgan et al., 2017). This study supports the increase in young adolescent females found previously. However breaking results down by healthcare setting and the addition of emergency department data demonstrates that while GP incidence has remained stable for males in this age group, emergency department attendances have more than doubled and hospital admissions have significantly increased with a marked increase from 2011 onward. In 15-19 year olds, GP attendances remained stable while emergency department attendances increased for both sexes, with a significant increase seen in hospital admissions for females only. The absence of a corresponding increase for males of this age is a cause for concern. For those aged 20-24, GP attendances significantly decreased for males but not for females, emergency department attendances increased significantly for females but not for males with hospital admissions remaining relatively stable for both sexes.

Less than half of emergency department attendances were associated with a hospital admission. This varied by age and method of self-harm. Admission of 16 and 17 year olds is

based on clinical judgement rather than stipulated in guidance (Arensman et al., 2018). Results of this study support previous research demonstrating that under 16s are more likely than other age groups to be admitted following emergency department attendance for self-harm (Arensman et al., 2018) in keeping with clinical guidance for this age group (NICE, 2012). The ratio of females to males attending emergency departments with self-harm has been previously found to decrease with age, with those aged 12-14 most likely to be admitted (Diggins et al., 2017). The results here additionally demonstrate that females are more likely to be admitted following emergency department attendance than males. This is most evident in those aged 10-15 years, where 76% of females attending emergency departments are admitted compared with just 49% of males. This difference persists even in the case of self-poisoning. There may be multiple reasons for this. Males are more likely to leave emergency departments without treatment or to refuse admission. This is supported by data from the National Self-Harm Registry in Northern Ireland demonstrating that females were more likely to be admitted to a general ward than males and that males were more likely to refuse treatment or to leave the emergency department before a next care recommendation could be made (Arensman et al., 2018).

Females were found to outnumber males in every setting with the exception of those presenting to only to emergency departments (and not to primary care or hospital settings), of which 58% of individuals are males. With the higher incidence of emergency department attendance for self-harm in males compared with hospital admissions and GP contacts it appears that males are preferentially presenting to emergency departments. This is supported by previous qualitative research examining help-seeking for self-harm (Nada-Raja et al., 2003). This underscores the importance of the disparity in subsequent admissions by sex found, with females more likely to be admitted following emergency department attendance than males. This difference was most marked for younger age groups and persists even in the case of self-poisoning.

Understanding patterns of presentation will inform service planning and configuration of follow-up care and could inform tailored support, for example for males in emergency departments. The potential for this research to inform change has been facilitated by press attention and close links of the lead supervisor with Welsh Government who have utilised these findings as part of a whole system approach to the management of self-harm including programmes in schools.

7.2 STRENGTHS AND LIMITATIONS

While the SHARE UK platform was successful in terms of research register sign-up and questionnaire completion, it was less successful in obtaining sign-up for linkage with routinely collected data and for the creation of the media databank. Issues with linkage with routinely collected data were explored in the Big Data and Mental Health Research Survey described in Chapter Five. While more than 90% of individuals were positive about the concept of linking survey and healthcare data, the linkage process itself poses a significant barrier. Participants were often unwilling to give the personal data needed for linkage due to concerns over security of giving this information online, and in particular about providing their address for fear of being written to at home or data security being breached. There are several steps that could be taken to overcome this in the future, however it may continue to pose a significant barrier. Future research should have measures in place to minimise the impact of this. This could include allowing individuals to contribute data in person instead of online, providing a live chat or telephone feature to answer questions from participants related to this process. In addition, greater publicity and explanation of linkage and anonymization procedures is needed as well as raising awareness of the benefits of such research and how it is used to improve services and help others.

Engagement with the media databank was insufficient for creating a resource that can be extensively used for future research. Only 62 out of 498 participants uploaded items to the media databank and participants who uploaded more than one resource did so all on the same date. This suggests that individuals only used this feature of the site on one occasion and did not continue to update the databank with new resources. A more dynamic format such as an app has the potential to keep individuals engaged over time and may have resulted in a greater number and range of uploads. Future research should explore this, incorporating meaningful coproduction with individuals who self-harm to explore whether any steps could be taken to improve engagement with a participant-built media databank. While analysis of questionnaires from the SHARE UK platform demonstrates several relationships between measures, all relationships are correlational and by nature do not demonstrate cause and effect. Furthermore, the sample size was relatively small. Future studies with larger sample sizes should endeavour to further investigate these relationships.

There are many advantages to conducting research online. The increased anonymity, ability to provide information at their own pace and sense of control and convenience lowers many barriers to taking part in research (Ahern, 2005). In addition, people who self-harm engaged well

with this research and the internet represents a valuable tool for engagement and outreach with this group. As outlined previously online surveys may be particularly effective for accessing populations that have been traditionally hard to reach with adequate representation of culturally diverse populations and a high representation of young adults (Batterham, 2014). This has been noted previously with substance users (Ramo & Prochaska, 2012), young females (Fenner et al., 2012) and immigrants (Baltar & Brunet, 2012) and appears to be the case in the current study. However, some vulnerable groups often do not have personal access to the internet including gypsy/roma/traveller communities, asylum seekers and refugees or those living in rural or isolated areas. These individuals may not be represented by such research. Online research has several other limitations. The use of online convenience samples, by nature, are not representative of the population as a whole. Individuals who take part online are less likely to complete all sections of surveys/interviews (Heiervang & Goodman, 2011) as found here (described in relation to the SHARE UK platform in Chapter Four). Samples often have an over-representation of young adults and a bias towards well-educated and English speaking participants (Batterham, 2014; Klovning et al., 2009). Online surveys have been found to under-represent children and adolescents from disadvantages backgrounds (Goodman, 2013; Heiervang & Goodman, 2011). This may result in underestimations of need if used alone to inform policy (Goodman, 2013). Young people and females were over-represented on both the SHARE UK platform and the Big Data and Mental Health Research Survey. Future research should seek to specifically target males and older age groups in order to broaden the reach of this research. In addition, while this study has the advantage of engaging a large number of participants who self-harm, individuals who do not have reliable internet access or have issues with language or literacy would likely not have engaged well with this format. Future research should incorporate pen and paper and/or in-person components. This could be done in collaboration with schools or drop-in centres to reach as many individuals as possible and to ensure that a comprehensive picture of the needs of different groups is created. It is likely that certain groups such as asylum seekers and refugees, gypsy traveller or individuals with issues with housing will require specialist targeted support. Lowering barriers for these individuals and facilitating them to take part in research would be a positive step for identifying the needs of these groups.

In order to address the limitations of web-based research, a routinely collected data component was incorporated into this study. This allows many limitations of web-based research to be addressed while the survey data compliments the strengths and limitations of routinely collected data. When pulled together, these two data sources offer many advantages as an

evidence base for service planning and provision. Whilst both survey and routinely collected data have their limitations, when taken together they offer a strong evidence base and two complementary sources of data. The use of the SAIL databank for the healthcare part of this analysis has several advantages. Data available in the SAIL databank allows for linkage of emergency department, GP, hospital admissions and outpatient data available at population level. This level of linkage is not possible in any other source of routinely collected data currently held in the UK. Derived from a large representative population of children and young people studied over a period of 12 years, results are generalizable to the rest of the UK. However, there are also several limitations of this data as described in Chapter Six including lack of availability of emergency department data prior to 2009 and a lack of data regarding whether a hospital admission was the direct result of an emergency department admission.

Any research with routinely collected data has some limitations, as this data is not collected for the purpose of research. The quality and completeness of data vary across datasets. For the purpose of this study, steps were taken to minimise the impact of this by only including GPs that meet the standards for data quality and using validated code lists (Carr et al., 2016a; Thomas et al., 2013). Self-harm that does not result in presentation to services or, where self-harm is discussed but not recorded will not be captured here. This is a common feature of all studies using routinely collected data. These data reflect contacts with the healthcare system and are not intended to represent rates of self-harm in the community. GP coding behaviour has been shown to change over time (John et al., 2016b; John et al., 2015). It is unclear whether the increase in self-harm shown here reflects a genuine increase or if this is partially attributable to improved recognition and coding behaviour by clinicians and increased help-seeking by individuals (Clements et al., 2016) and caregivers. It is most likely that results are reflecting a combination of factors.

7.3 IMPLICATIONS

Implications for research

Self-harm and its relationship with the internet and the media have been the subject of increasing research over the past decade. The systematic reviews described in Chapter Three demonstrate the often double-edged nature of the internet in relation to self-harm with the potential for positive aspects such as community support on the one hand and more negative aspects such as triggering and worsening of self-harm on the other (Marchant et al., 2017). What is clear based on this project is the enormous potential of the internet to be used for outreach

and engagement. While individuals who self-harm often represent a hard to reach group for research, engagement online has proved successful. Reasonable recruitment to the SHARE UK platform was achieved using the free features of social media and outreach with voluntary organisations. Recruitment to the Big Data and Mental Health Research Survey was highly successful with only a modest advertising budget. Engaging with people who self-harm online in a space they feel comfortable in, has enormous potential both for future research and for the provision of intervention and support. There is an opportunity for engaging young people online for both research and interventions, particularly on image and video based platforms, that at present doesn't appear to have been optimised (Marchant et al., 2020b). Young people are increasingly using images as a way of asking for support (e.g. Seko et al., 2015). Intervention and prevention efforts could be targeted here to ensure that help is available for individuals who reach out this way. This could be targeted by search term to reach those in significant distress (Biddle et al., 2018). This is a potential avenue for future research that could go on to inform future outreach and intervention, having the potential to help large numbers of people. Special consideration should be given to engaging young males who remain under-represented in online research (Marchant et al., 2020b; Marchant et al., 2017).

This thesis has successfully demonstrated the utility of an online platform for self-harm research, its use as a questionnaire delivery platform and the creation of a research register of individuals who self-harm. While individuals who self-harm often represent a hidden population who are difficult to access for research (Hunter et al., 2013), the use of an online format has been successful in engaging this population. Recruitment to this platform was successful using a social media campaign with no associated cost resulting in almost 500 participants. Furthermore, when working in partnership with ADP a paid social media campaign resulted in thousands of survey respondents and over a thousand individuals consenting to be contacted for future research. This social media campaign was run largely through Instagram with image-based material such as posters and research animations. This may have contributed to its success in reaching young people in particular.

The SHARE UK platform has partnered with the ADP ensuring a future for both the platform and research register. The ADP is an MQ-funded platform for mental health research. The ADP has been developed to bring together multiple sources of data related to children and young people's mental health together in one data safe haven. This will include routinely collected health and social care data, datasets from individual studies and other Big Data sources such as that from mental health apps. By bringing this data together into one data safe haven researchers can create meta-data, algorithms and ultimately 'research ready' data to facilitate

the research process. This represents a step change in children and young people's mental health research representing a unique resource and facilitating collaboration of research teams across the UK. It is intended that such a platform will allow research to have the greatest potential for driving change providing a sound knowledge base on which to base healthcare and service provision.

The SHARE-UK platform is being incorporated into the ADP infrastructure and will form an adjunct to the main ADP website. The partnership with ADP also means that there will be funding in place to ensure the continuation of the project. The research register will be stored securely by ADP and will be utilised for future research. In addition, collaboration with the ADP will allow both the research register and the SHARE UK platform to reach a wider audience and to be used in future research. The research register represents an important resource and has most recently been used in conjunction with ADP to recruit participants to a survey examining the impact of COVID-19 and the associated social distancing measures on individuals who self-harm (study currently underway). The SHARE UK platform was successful as a questionnaire delivery platform. During this pilot stage only a small number of questionnaires were hosted. It is intended that this feature of the platform will be expanded to answer future research questions.

The partnership with ADP has allowed a shift to co-production with young people in way not possible at the outset of this project. Collaboration with the ADP research team has meant that it is possible to work with student interns and to utilise the ADP 'Be Heard' initiative to co-produce with young people. This is a positive change in the way research using the SHARE UK platform and the research register is conducted and developed. The Big Data and Mental Health Survey was developed with student interns. The survey found that young people wanted to know more about how healthcare data is used for research and a strong desire from young people for their data to be used to help others. Student interns have developed research animations explaining data linkage in accessible language and have disseminated them over social media and at outreach events including the Swansea Science Festival. The ADP have recently used the research register to recruit for a Covid-19 and mental health survey. This survey was piloted on research register participants. These individuals provided valuable feedback on the design of the survey and the questions asked allowing the survey to be refined before being rolled out to the population as a whole. Practice has changed for the better and co-production will be a key part of all research with this platform going forward.

While the internet represents a valuable tool for outreach and a potentially rich source of data, concerns around the use of this data were found. Participants expressed strong opinions on the use of their social media data, further supporting previous concerns around ethical issues associated with the use of this data. Concerns have been raised previously around republishing of quotes taken from social media which can be searched and traced back to the original poster (British Psychological Society, 2017). While sets of guidelines exist for internet mediated research at present these are only guidelines and it is up to individual research teams to make decisions on the ethical use of social media data (Townsend & Wallace, 2016). Results of the systematic review described in Chapter Three demonstrate that many studies utilising social media data either contain a single statement that their research is considered to be exempt from institutional ethical approval or do not contain any statement of ethical considerations at all. This was even in the case of research related to images of self-harm that by nature would need special consideration in terms of anonymization procedures, and research related to children and young people who self-harm. These individuals represent a vulnerable group where special ethical consideration may be appropriate (Golder et al., 2017). Results of the survey described in Chapter Five support that of a previous systematic review finding that research using social media data was found to be viewed positively if it was considered to be used for a good cause such as social benefit or to help others, with participants expressing that they would not like to see their data used for commercial gain or to drive a personal agenda (Golder et al., 2017). Also, in keeping with the previous systematic review, participants were more positive about research done by universities than by the government or other organisations (Golder et al., 2017). Participants raised specific concerns around the use of images taken from social media for research and how it is possible to anonymize these. This is an issue of growing importance with the increasing use of social media data to examine self-harm imagery as seen previously (Dyson et al., 2016) and in the systematic review of the literature described in Chapter Three (Marchant et al., 2020b). Authors should consider whether the republishing of photographs and quotations taken from social media sites are appropriate, particularly if individuals have not had the opportunity to consent.

Results of The Big Data and Mental Health Research Survey have several important implications for Big Data research going forward. There needs to be a greater awareness and clarity of data anonymization procedures and, the nature of research with routinely collected healthcare data. Participants repeatedly expressed wanting their data to be used to help others and wanting to know more about the research being done. Similarly, while many young people raised concerns about sharing social media data for the purpose of research, they also expressed a desire to help

others going through similar experiences and a willingness to share data for this purpose. This is supported by previous research with adolescents who were more positive about sharing data that would be used to help others, particularly for topics they felt strongly about such as cyber-bullying and body image (Monks et al., 2015). The nature of research being conducted with both Big Data and social media data and, the benefits to services and individuals should be widely publicised beyond academic audiences. Mainstream and social media would be good outlets for such awareness campaigns that would benefit from coproduction with the public to ensure accessible and engaging material. Visual material such as images and videos should be incorporated into such campaigns.

Implications for policy and practice

Results of the data collected via the SHARE UK platform have several potential implications for future research and practice. More than 60% of participants report having contact with their GP for self-harm. This supports previous calls for GPs to be supported in recognising self-harm in children and young people, and GPs have stated that they would welcome further training and practical information on self-harm (Fox et al., 2015). The importance of GPs was further highlighted in Chapter Six utilising routinely collected data where individuals presenting to their GP only (with no contact with emergency departments or hospital settings) made up the largest group. Incidence of self-harm in primary care was found to be around double that seen for hospital admissions. Previous research has shown that individuals who attend primary care with self-harm have an elevated risk of premature death, particularly suicide (Carr et al., 2017). Clinical guidance have emphasized the importance of GPs and primary health teams and managing and monitoring risk in individuals who present with self-harm over both short and long-term follow-up (NICE, 2004, 2012). Individuals who present to secondary care do not capture a population of higher-risk individuals compared with primary care patients. As such, individuals presenting to primary care also require tailored support. The frequency of contact with emergency departments described in Chapter Six further underscores the importance on non-specialist services and the potential role of all front-line NHS staff. This is being increasingly recognised and further training for wider NHS staff with specific targets set in policy guidance, such as that seen in suicide prevention strategies in Scotland (Scottish Executive, 2002) could improve management and long-term outcomes for those presenting to healthcare services with self-harm. This should include emergency department staff being given the support and training in how best to manage self-harm with tailored support for young males considered and the importance of appropriate admission to hospital and referral to specialist services emphasized, as described in Chapter Six (Marchant et al., 2019).

Almost half of participants giving details via the SHARE UK platform report not receiving help for self-harm. Interventions are needed to increase awareness of self-harm and the steps to be taken by parents, teachers or other adults. This may increase rates of younger individuals who seek help from services, particularly for younger adolescents who often do not contact services themselves but are most often brought by an adult (Hassett & Isbister, 2017). Education programmes to improve knowledge of self-harm and promote help-seeking may be more beneficial for older adolescents and adults who are more likely to initiate their own help-seeking (e.g. Mann et al., 2005). Increases in emergency department attendances in those aged 10-19 years described in Chapter Six may be partially attributable to greater awareness and help-seeking by young people and trusted adults. While this is positive in terms of young people receiving needed support, it also demonstrates increasing demand on services. Greater support at the community level may also be beneficial allowing individuals to access support before a crisis point is reached. The need for such programmes is further supported by the results of the SAIL analysis described in Chapter Six. Such support should include components specifically tailored to males. Analysis with routinely collected healthcare data described in Chapter Six demonstrated that males are preferentially presenting to emergency departments over other services. Males do not seek help as often as females from either social networks or health services (Ystgaard et al., 2009). Greater support at the community level tailored for males may reduce the likelihood of them reaching crisis point and as such reduce emergency department attendances. Results also showed that following emergency department attendance males were less likely to be admitted than females even in younger age groups and for self-poisoning. Any contact with healthcare services represents an opportunity for intervention and it is important that when males do seek help in any setting that appropriate support is provided. Emergency departments should be supported to provide this. Children and young people regularly contact non-psychiatric specialist services. It is important professionals in these services be supported in their ability to identify children and young people at risk, provide appropriate support and determine when referral to specialist services is required or urgent.

This study aimed to identify vulnerable groups and potential avenues of intervention. Around half of respondents to questions on the SHARE UK platform had contact with social care. Individuals who had contact with social care related to self-harm appeared to represent a vulnerable group compared to those who had contact with social care for other reasons and those who did not have contact with social care. Scores on standardised questionnaires for this group indicate greater self-harm behaviour, compulsive internet use, shame and lower

resistance to peer influence. Individuals in contact with social care likely have more complex needs such as family issues and social problems (Colman et al., 2004; Houston et al., 2003). The vulnerability of these individuals and the contact with social services represents an important opportunity for providing support. Future research should endeavour to learn more about the needs of this group and to provide an evidence base on which to base future support and intervention. Researchers have argued for a better understanding of the factors associated with suicide and self-harm in this vulnerable group (Harkess-Murphy et al., 2013). Strategies for early identification of self-harm are needed that go beyond those offered by health services. Individuals working in social care need to be supported in how to recognise self-harm, how to communicate with vulnerable individuals about this issue and what steps should be taken. This should be done in collaboration with healthcare services to ensure that care workers are given the support they need and, that concerns about availability of services and responsibilities falling on individual care workers are addressed (A. M. Brown et al., 2019). Additional support provided at the level of social care may reduce the likelihood of an individual reaching a crisis point and reduce the need for contact with emergency healthcare settings. This support must go beyond healthcare and include a holistic approach potentially incorporating families, significant relationships, employment, education and wellbeing and life skills such as managing internet use and peer relationships.

Internet service providers have a role to play in making the internet a safer space for people who self-harm. As discussed in Chapter Three many social media platforms changed their policies regarding posting of self-harm imagery following the death of a young person in February 2019 and the subsequent campaign by the family. Instagram announced a ban on all images of self-harm including those showing scars (Instagram, 2019). While this may represent a positive step in making these spaces safer, it is important that any policies on the sharing of such material are based on research evidence. This should take into consideration the potential risks of such content and balancing this against censorship, allowing individuals to tell their stories including those related to recovery, and the potential for restrictions to increase stigma. Individuals who present to emergency departments with self-harm (and score higher on measures of suicidal intent) report purposeful use of the internet often searching for specific suicide methods (Biddle et al., 2018). Results of the analysis of the media databank described in Chapter Four suggest that resources aimed at clinicians, such as papers describing lethal doses of medications, are being accessed as source of information by distressed individuals. There is potential for such information to be misused and consideration should be given to how best to

manage this risk, particularly given that this information may be misused by individuals who are experiencing high levels of distress (Biddle et al., 2018).

Clinicians working with young people who self-harm need to be aware of the potential impact of internet use and to engage in discussions with individuals around their online behaviour. As highlighted in Chapter Three this should encompass the potential role of images and videos and help young people identify behaviours that may be triggering or harmful and redirect towards healthier online behaviours (Marchant et al., 2020b). Furthermore the possibility of a relationship between peer support and compulsive internet use described in Chapter Four is also worthy of further investigation. It is not clear whether internet use is having a potential impact on offline relationships or if individuals with less offline support are turning to the internet for social connection. Discussion with individuals who self-harm around their internet use and peer relationships may be a useful addition to assessment of individual circumstances and vulnerabilities that may be contributing to self-harm. Education could be given to both clinicians and caregivers on how to recognise problematic internet use and, how to direct to healthier online behaviours.

The marked rise in incidence of self-harm in younger adolescents since 2011, found in Chapter Six, is worthy of further study. This increase coincides with the introduction of austerity measures however, it is not possible to say if this is the only factor contributing to this increase. Future research should also examine the impact of the Covid-19 outbreak and associated social distancing measures on rates of self-harm, contacts with services and the lives of people with a history of self-harm. The SHARE UK platform is currently partnering with the ADP running a survey to begin to understand the impact of this pandemic on individuals who self-harm.

7.4 CONCLUSIONS

This study has successfully demonstrated the feasibility of an online platform for self-harm research. A cohort of almost 500 individuals was successfully recruited and maintained online. This cohort consisted of both individuals who had previous contact with services and those who did not, allowing participants who may be missed by traditional research to have a voice. A high percentage (85%) of individuals who signed up for the platform also signed up to be contacted for future research creating a self-harm research register. Questionnaire data was successfully collected via the platform. The feasibility of uploads to a media databank was examined. While there was some engagement with this, participants typically used this feature of the site just once. As such it is not sufficient to be a resource for future research in its own right. The

feasibility of linking data from the platform with routinely collected healthcare data was explored. Sign-up for this was low at just 15%. Possible reasons for this were explored in a national survey of children and young people aged 16-24. While young people were largely positive about the idea of linking survey data with healthcare data the linkage process itself poses a significant barrier. Many individuals were uncomfortable with the necessity for personal details (address and date of birth) to be given in order to make the link. Particular concerns were raised around giving this information online and giving a home address for linkage. This has implications for future research with this population. In order to address some of the issues with survey data and to provide a more comprehensive evidence base on which to draw conclusions, analysis was conducted with population-level linked healthcare data from the SAIL databank. The SAIL databank was used to examine contacts with healthcare services in children and young people who self-harm.

This thesis has successfully brought together data from three complementary data sources: the SHARE UK platform, a national survey and an e-cohort study utilising routinely collected healthcare data. This thesis describes data from multiple settings being brought together, incorporating data from individuals taking part in the SHARE UK platform, the general population and those in contact with healthcare services for self-harm (based on routinely collected healthcare data), for a better understanding of the needs of individuals who self-harm to inform policy and practice. This study has also resulted in the successful creation of a self-harm research register. The SHARE UK platform has partnered with the ADP securing a future for the platform with additional resources including access to advertising budgets. As seen with the Big Data and Mental Health Research Survey the partnership has the potential to further self-harm research and to reach large numbers of individuals. It is hoped that conducting high quality research on which to base future service provision and support will have the potential to improve and potentially save lives.

APPENDIX A: REVIEW ONE PUBLISHED MANUSCRIPT

Note this is an embedded pdf. Please click to view in pdf format. Alternatively view as a word document below.



RESEARCH ARTICLE

A systematic review of the relationship between internet use, self-harm and suicidal behaviour in young people: The good, the bad and the unknown

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Abstract

Background

Research exploring internet use and self-harm is rapidly expanding amidst concerns regarding influences of on-line activities on self-harm and suicide, especially in young people. We aimed to systematically review evidence regarding the potential influence of the internet on self-harm/suicidal behaviour in young people.

Methods

We conducted a systematic review based on an electronic search for articles published between 01/01/2011 and 26/01/2015 across databases including Medline, Cochrane and PsychInfo. Articles were included if: the study examined internet use by individuals who engaged in self-harm/suicidal behaviour, or internet use clearly related to self-harm content; reported primary empirical data; participants were aged under 25 years. New studies were combined with those identified in a previous review and subject to data extraction, quality rating and narrative synthesis.

Results

Forty-six independent studies (51 articles) of varying quality were included. Perceived influences were: positive for 11 studies (38191 participants); negative for 18 studies (119524 participants); and mixed for 17 studies (35235 participants). In contrast to previous reviews on this topic studies focused on a wide range of internet mediums: general internet use; internet addiction; online intervention/treatment; social media; dedicated self-harm websites; forums; video/image sharing and blogs. A relationship between internet use and self-harm/suicidal behaviour was particularly associated with internet addiction, high levels of internet use, and websites with self-harm or suicide content. While there are negative

A systematic review of the relationship between internet use, self-harm and suicidal behaviour in young people: the good, the bad and the unknown

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AM, KH, AS, PM, VS, KL, NP, KD and AJ conceived the study design. AM conducted the electronic search. AJ, AM and KH assessed the studies for inclusion. AJ, AM, NP, AS, VS and KD extracted data. AM and AJ produced the first draft. AM, KH, AS, PM, VS, KL, NP, KD and AJ commented meaningfully to the draft and agreed the final version.

Abstract

Background

Research exploring internet use and self-harm is rapidly expanding amidst concerns regarding influences of on-line activities on self-harm and suicide, especially in young people. We aimed to systematically review evidence regarding the potential influence of the internet on self-harm/suicidal behaviour in young people.

Methods

We conducted a systematic review based on an electronic search for articles published between 01/01/2011 and 26/01/2015 across databases including Medline, Cochrane and PsychInfo. Articles were included if: the study examined internet use by individuals who engaged in self-harm/ suicidal behaviour, or internet use clearly related to self-harm content; reported primary empirical data; participants were aged under 25 years. New studies were combined with those identified in a previous review and subject to data extraction, quality rating and narrative synthesis.

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internet addiction, high levels of internet use, and websites with self-harm or suicide content. While there are negative aspects of internet use the potential for isolation reduction, outreach and as a source of help and therapy were also identified.

Conclusions

There is significant potential for harm from online behaviour (normalisation, triggering, competition, contagion) but also the potential to exploit its benefits (crisis support, reduction of social isolation, delivery of therapy, outreach). Young people appear to be increasingly using social media to communicate distress, particularly to peers. The focus should now be on how specific mediums' (social media, video/image sharing) might be used in therapy and recovery. Clinicians working with young people who self-harm or have mental health issues should engage in discussion about internet use. This should be a standard item during assessment.

A protocol for this review was registered with the PROSPERO systematic review protocol registry: (http://www.crd.york.ac.uk/prospero/display_record.asp?ID=CRD42015019518) .

Introduction

Internet use has a mixed effect on children and young people's (CYP) well-being, with evidence of increased self-esteem and perceived social support alongside harmful effects such as increased exposure to graphic content and cyber-bullying [1]. High profile cases of cyber-bullying and suicide over the past decade [2] and reports of suicide clusters facilitated by social media [3] have resulted in researchers increasingly focusing efforts on understanding the relationship between internet use and both self-harm and suicide. An early review examining the use of dedicated self-harm support sites in young people found high levels of support available online alongside normalisation of self-harm behaviour [4]. A more recent systematic review relating to self-harm and internet use in young people additionally found evidence of information sharing of methods of self-harm and concealment, a reduced sense of isolation and reinforcement of positive behaviours such as help-seeking [5]. The authors concluded that the internet exerts both positive and negative influences on self-harm and provides an opportunity for intervention, which is supported by several more recent studies [6, 7].

While research appears to be beginning to answer some questions regarding the role of the internet for young people who self-harm a number of questions remain unanswered. Authors of the previous review highlighted that research to the date of their review (26th December 2011) described internet use only in relation to use of forums or general use [5]. This is an important limitation since specific internet pathways may represent increased risk. Internet addiction and pro-suicide websites have been suggested as high risk factors facilitating suicidal behaviours, particularly in isolated and susceptible individuals [8]. Additionally, a recent study examining changes in online

suicide-related content showed that the results of searches for self-harm have changed over time, with an increasing presence of graphic imagery [6]. The role of such images has been examined in relation to self-harming behaviours [9], as well as relevant content of videos on a popular sharing website [10]. A recent study has also showed that the nature of sites returned varied according to the suicide/self-harm-related search terms use and almost half contain video content. Negative influences such as providing information on methods, encouraging self-harm behaviours and images considered evocative by researchers were common. However, more positive influences including advice on how to seek help was given on over half of identified sites [7]. Further research has highlighted the positive and negative influences of the internet, the potential benefit of directing individuals to healthier online behaviour and the discrepancy in perspectives regarding online activities between adolescent culture and that of many mental health professionals [11].

The previous review also identified a possible relationship between study design and perceived outcome. Qualitative and mixed methods studies tended to report a positive influence of internet use and quantitative designs tended to find a negative impact. Therefore the design and quality of individual studies may have had an impact on perceived outcomes. Following their systematic review [5] the authors highlighted the need for more rigorous research to clarify the positive and negative influences and to focus on the mediating and moderating factors in order to optimise the benefits whilst minimising the potential harm of internet use in young people who self-harm.

The primary aim of this study was to systematically review all research relating to the potential influence of the internet on self-harm/suicidal behaviour in young people, with

a particular focus on identifying the factors which determine whether the internet is perceived as positive or negative in its potential influence.

Method

Search strategy and selection criteria

This study was a systematic review. The previous electronic literature search, conducted by some of the authors, was up to 26th December 2011 [5]. For the present review, an electronic literature search was conducted (AM) for all articles published between 1st January 2011 and 26th January 2015. A range of databases were searched including: CINAHL; Cochrane Library; EMBASE (excluding Medline journals); HMIC; Medline; NICE; Prospero; PsycINFO; PubMed; SCOPUS. Additional searches were conducted in health improvement sources, topic specific websites (American Association of Suicidology, British Psychological Society, CEBMH, Centre for Mental Health, DH, DHSPSS-NI, MFH, NHS Scotland, Royal College of Psychiatrists, Welsh Government) and meta-search engines (Google/ Google scholar) for these dates only.

The search terms employed in the original review (which included 'Self-harm', 'Suicid*', 'Internet', 'Children', 'Young People') were updated to account for the rapidly changing nature of the internet and memes (an image, piece of text, idea that spreads rapidly) in young people. The full details of search terms and sources searched are included in S1 Table. Reference lists of all review articles were manually screened for potential eligible papers. The research team included a number of experts in the field who reviewed searches for any potentially unidentified citations. Experts in the field were also contacted to assist in identification of literature. These included those known to members of the team and others identified from existing literature. They were contacted by email regarding any additional studies and, where relevant, data or full text copies of articles were also requested by email.

Articles were included if they examined internet use by individuals who experienced suicidal ideation, self-harm, or internet use which was clearly related to self-harm content. Any type of online media or activity was considered for inclusion. We included articles that presented primary empirical data and were published in journals. Participants had either to all be aged less than 25 years or have a mean age of 25 years or less. If ages were not stated, participants had to be described as children, adolescents or young adults. Where articles examined more than one age group, only data for the age group fitting these criteria were analysed. Results were not restricted on the basis of location; however, only English language papers were included.

In order to be consistent with the previous review [5] review articles, news articles, single case studies, editorials, comments, conference abstracts and other grey literature, while searched for (e.g. CINAHL, HMIC), were not included in the final analysis. While the inclusion of grey literature can reduce the impact of publication bias, it may also introduce its own set of biases. These include the absence of peer review and the potential that the availability of data would impact on overall results [12]. Included articles from the previous review on this topic 1991-2011 [5] were added to the newly identified eligible articles to provide a complete overview of available evidence. Studies relating to cyber-bullying and self-harm from both the new and existing literature were excluded and will be reviewed in a separate report. This decision was taken due to the number of known quantitative studies related to this specific topic and because it would allow for a more thorough discussion of the literature with the potential for meta-analysis (protocol available from http://www.crd.york.ac.uk/prospero/display_record.asp?src=trip&ID=CRD42017056487).

Two independent reviewers (AJ, AM) manually screened titles. Any disagreements were resolved by consensus. Titles that clearly had no relevance, book chapters, case reports, conference abstracts, comments, editorial, journal notes, grey literature and news sources were excluded at title screen, although reference lists were manually screened for relevant studies. A record was kept of all discarded articles, including the reason for exclusion. Duplicates were removed. The remaining titles with abstracts were then screened for eligibility by the same two researchers. Full text articles were obtained where suitability could not be determined based on the title and abstract. Two researchers independently reviewed the remaining citations (AJ, AM). Any disagreements that could not be resolved through consensus were discussed with a third expert reviewer (KH).

A protocol for this review was registered with the PROSPERO systematic review protocol registry

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Data analysis

The data extraction sheet from the previous review [5] was adapted and used to record specific findings from both newly identified articles and those from the previous review (S2 Table). Additional fields were added to account for the greater level of detail in more recent research articles and to allow comparison of internet medium, outcome measured and study design. Studies were divided between four reviewers (AM, NP, AS, VS) and pairs of reviewers' independently extracted data for each study. Any inconsistencies in data extraction and quality scores were clarified by consensus with at least two study authors. Articles were amalgamated and grouped according to internet

medium studied and perceived influence. Positive influences were defined as results indicating perceived reduction of psychological distress, reduced suicidal ideation and self-harm, advice on how to seek help and encouragement to do so. Negative influences were defined as results indicating: increased psychological distress, self-harm or suicidal ideation; information on methods of self-harm/suicide was provided; self-harm behaviours were encouraged. Mixed influences were recorded where a report included both positive and negative influences. Internet media were grouped according to their stated description within articles. These media categories were inductively generated following initial reading and data extraction of papers and were cross checked by two members of the study team (AM and AJ).

Quality of included articles was assessed according to the Critical Appraisal Skills Programme (CASP) [13] as performed previously [5]. This tool assesses various aspects of study design including the study sampled, data collection methods, study design and the clarity and appropriateness of results and conclusions. It also includes items related to potential sources of bias such as from the study population or design.

Due to the range of research questions, methods used, populations and outcomes studied there was a high level of clinical and methodological heterogeneity across studies, precluding any meaningful combination of study results through meta-analysis. Therefore, a narrative synthesis was employed. Based on published guidance [14] this narrative synthesis examined a number of key aspects. Comparisons across studies were made regarding the way in which the relationship between self-harm/suicide and internet use had been identified and analysed; relationships between study results were examined and compared across the studies; the influence of heterogeneity was further

explored including theoretical variables, differences in baseline characteristics of populations, measures employed and outcomes studied.

Results

Fig 1 shows the results of the search strategy and screening process. A total of 51 articles (from 46 independent studies) were included in the review. A summary of included articles by internet medium and perceived influence can be seen in Table 1. Studies were based in the USA (n=10), UK (5 studies, 9 articles) , Canada (n=5), Japan (n=3), Korea (n=3), Australia (n=2), New Zealand (n=2), Sweden (n=2), China (n=1), Germany (n=1), Israel (n=1), Northern Ireland (n=1), South Africa (n=1), Taiwan(n=1) and Turkey (n=1), with the remaining 7 studies (8 articles) from multiple countries. A total of 192,950 individuals participated. Forty-four of the 51 articles had more than 50% female participants. Eleven studies [15-25] examined content of forum posts or websites in which participants were described only in terms of demographics of site users. One study [26] examined rates of suicide by age group with no further description of the number of participants. Using the CASP quality score 18 articles were assessed as high quality, 18 as medium quality and 15 as low (S3 Table). The quality of articles varied by study design with a greater proportion of quantitative (14/23) than qualitative ones (0/16) rated as high quality. Number of studies, number of articles, study design and quality varied across internet media (Table 2).

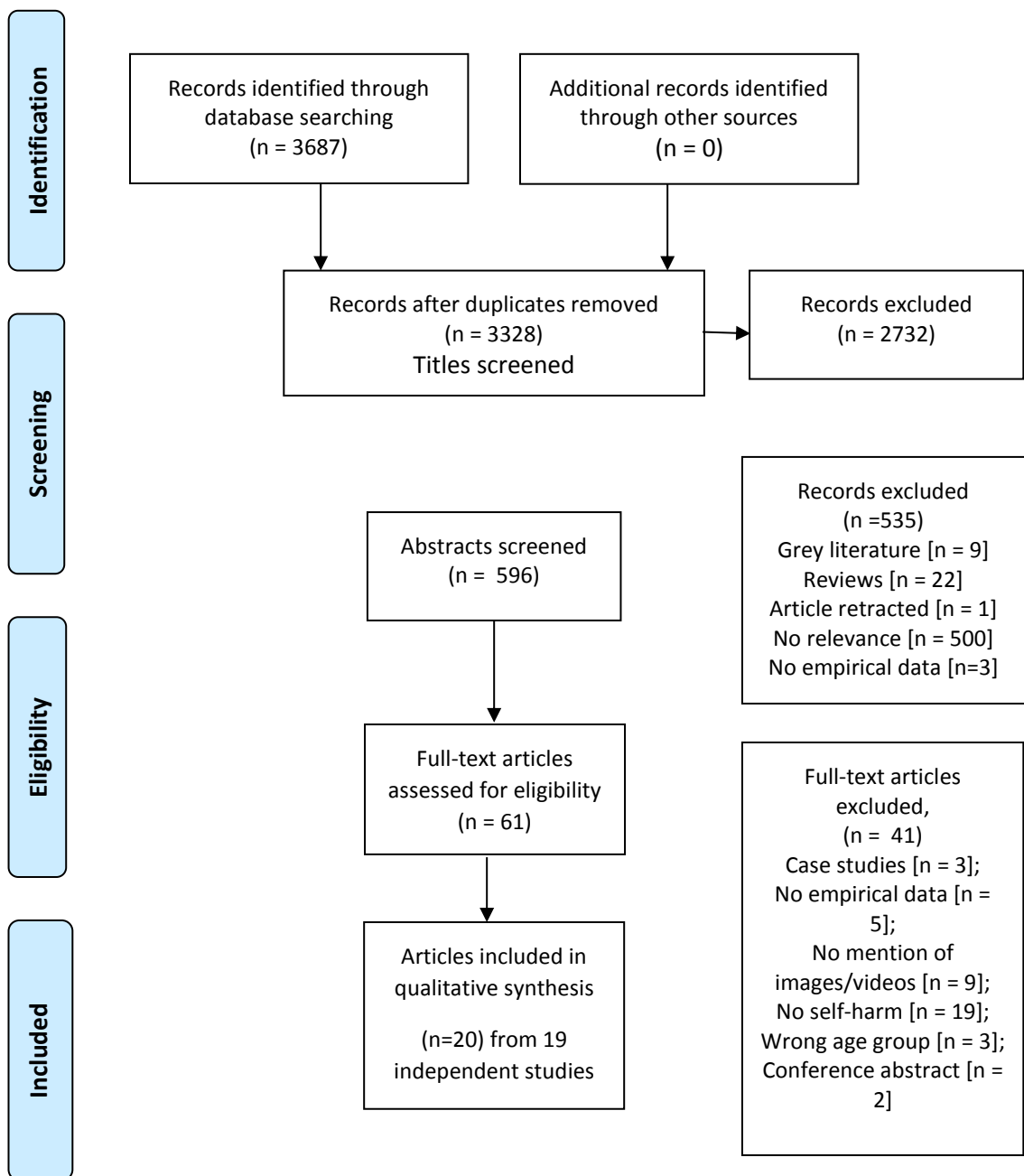


Fig 1. Flow of information through the evidence review

Table 1. Summary of included studies

Internet medium	Lead Author, year, country	Population (N, %female)	Aims, Objectives	Results, outcome	Outcome	Design, Quality score
General use	Carew, 2014 [27], Canada and USA	Internet users (28805; 64)	To investigate mental health information seeking online, and to identify differences within age groups and geographical location	A 200% increase in online activity regarding mental health was identified (between 2006 [baseline] and 2010). Adolescents were most likely to initiate conversation about depression followed by anxiety, alcohol, suicide, sexting and marijuana. Adolescents tended to discuss concerns through the use of personal stories.	Positive	Quantitative High
	Casiano, 2012 [28], Canada	Canadian young people aged 12-19 (9137; 49)	To examine to association between quantity of media use and health outcomes in adolescents	No significant association between any form of media and suicide ideation (internet use OR 0.98, 95% CI 0.83 – 1.16)	Positive	Quantitative Low
	Carli, 2014 [29], 11 European countries	School based adolescents in eleven European countries (12395; 55)	To explore the prevalence of risk behaviours (excessive alcohol, drug use, truancy etc.) and their association with psychopathology and self-destructive behaviours	Latent class analysis identified three groups of adolescents: high risk, including pupils who scored high on all risk behaviours; low risk including pupils with low frequency of behaviours and invisible risk. This 'invisible risk' group was found to score high on use of media and have similar prevalence of suicidal thoughts/psychopathology as 'visible risk' group. The invisible risk group were at significantly higher risk than the low risk group for non-suicidal self-injury (Relative risk ratio (RRR) = 1.40; 95% CI 1.13 1.84), suicidal ideation (RRR = 1.29; 95% CI 1.12 – 1.48) and suicide attempt (RRR = 1.22; 95% CI 1.22 – 2.35).	Negative	Quantitative High
	Hagihara, 2012 [26], Japan	Young adults in Japan; Rate of suicide;	To examine the association between suicide-related searches and the incidence	Association between Internet suicide-related searches and the incidence of suicide in Japan (over 77 months): the terms "hydrogen sulphide", "hydrogen sulphide suicide",	Negative	Quantitative Low

		of suicide on young adults in Japan	and "suicide hydrogen sulphide suicide" at (<i>t</i> -11) were related to the incidence of suicide among people aged in their 20s (<i>P</i> = 0.005, 0.005, and 0.006, respectively).		
Katsumata, 2008[30], Japan	Japanese high school students (590;49)	To investigate the association between the experience of using electronic media and suicidal ideation in Japanese adolescents.	Suicidal ideation was significantly associated with anxiety about not getting email replies (OR 2.06; 95% CI 1.33-3.20), and searching online for information about suicide and self-harm (OR 5.11; 95% CI 2.43-10.71) and hurtful experiences on the web (OR 1.71; 95% CI 1.03-2.84)	Negative	Quantitative Low
Kim, 2012 [31], Korea	Korean middle and high school students (75066; 47)	To consider the association between internet using time for non-educational purposes and adolescent health	Internet non-users (NIU) and heavy internet users (HIU) were found to be high risk groups when compared with moderate internet users (MIU) on multiple mental health measures. Suicide ideation was significantly higher in HIU and NIU (females: HIU =43.4%; NIU 25.8%; OIU 21.8% (<i>P</i> <0.001); males: HIU 26.4%; NIU 16.7%; OIU 13.6% (<i>P</i> <0.001)) as was rate of attempted suicide (females: HIU 13.9%; NIU 7.3%; OIU 5.2% (<i>P</i> <0.001); males: HIU 10%; NIU 4.9%; OIU 2.4% (<i>P</i> >0.001))	Negative	Quantitative High
Mitchell, 2007 [32], USA	American internet users aged 10-17 (1500; 81)	To explore internet use and interpersonal interactions of youth reporting self-harm	Youth who self-harm engaged in more risky online behaviours than those who did not including using chat rooms (57% compared with 29%) and to have a close relationship with someone they met online (38% vs. 10%)	Negative	Quantitative High
O'Connor, 2014 [33], Northern Ireland	Adolescents in Northern Ireland (3596; 48)	To determine the prevalence of self-harm and associated factors	Self-harm was found to be associated with internet/social media as well as variety of other factors including exposure to the Northern Ireland conflict. In total 15% of girls and 26% of boys endorsed either the internet or social networking sites as factors that influenced their self-harm.	Negative	Quantitative High

	Roberts on, 2012 [3], New Zealand	New Zealand adolescents (8; 88)	To describe an adolescent suicide cluster and the possible role of online social networking and text messaging as sources or contagion and obstacles to recognition of a potential cluster	These cases did not belong to a single school but were linked by social networking sites including memorial pages. This facilitated the rapid spread of information and made recognition and management of a possible cluster more difficult	Negative	Mixed methods Medium
	Collings, 2011 [34], New Zealand	New Zealand adolescents (71; 79)	To describe the influences of media on suicidal behaviours, from the perspectives of young people.	Participants considered some interactive media supportive. 80% (n=12) of those who used violent methods of self-harm had been exposed to suicide content via the internet before the incident	Both Positive and negative	Mixed Methods High
	Duggan, 2012 [20], Canada	Scope and nature of self-harm content across various internet mediums	To examine the scope and nature of self-harm content across informational/interactive websites, social networking websites and YouTube	Results suggest that peer driven websites are accessed more often than professionally driven websites. Self-harm is strongly represented among social networking websites and YouTube evidenced by large group memberships and video counts. The search terms yielded 41 dedicated groups on Facebook with memberships ranging from 2 to 4,686. The same search yielded 206 groups on MySpace with group membership ranging from 2 – 1653. Searches on YouTube produced 2,290 videos. Characteristics of groups, videos and posters are described.	Both positive and negative	Quantitative Medium
	Dunlop, 2011 [35], USA	Young people aged 14-24 (719)	To determine whether online news and social networking sites, expose young people to suicide stories that might increase suicide ideation	Online sources of information were quite common (reported by 59% of participants). Social networking sites were frequently cited as sources but were not linked to increases in ideation. However online discussion forums were associated with increases in suicide ideation	Both positive and negative	Quantitative High
Internet addiction	Kaess, 2014 [36],11 Europea	School based adolescents in eleven European	To investigate the association between pathological	Suicidal behaviours, depression, anxiety, conduct problems and hyperactivity/inattention	Negative	Quantitative High

n countries (11356; 57)	internet use, psychopathology and self-destructive behaviours	were significant and independent predictors of pathological internet use (Suicidal ideation coefficient 0.324, 95% CI 0.251 – 0.397, P <0.001; Suicide attempts coefficient 0.552, 95% CI 0.207 – 0.896, P = 0.001). This association is significantly influenced by country and gender.		
Kim, 2006 [37], Korea	High school students in Korea (1573; 65)	To elucidate the relationship between internet addiction, depression, and suicidal ideation	Internet addiction scores were positively correlated with suicidal ideation in non-internet addicts, possible addicts and internet addicts (non-addicted r = 0.111, p = 0.001; possible addicted r = 0.147, p < 0.001; internet addicted r = 0.448, p<0.001)	Negative Quantitative High
Lam, 2009 [38], China	Adolescents in china (1639;55)	To examine the association between internet addiction and self-harm	Moderately or severe internet addiction was associated with higher incidences of self-harm (adjusted OR 2.0, 95% CI 1.1 – 3.7).	Negative Quantitative High
Lin, 2014 [39], Taiwan	Taiwanese adolescents aged 12-18 years (9510; 52)	To examine the associations of suicidal ideation and attempt with internet addiction and activities	Internet addiction was significantly associated with suicidal ideation (OR 1.25, 95% CI 1.08 – 1.44) and suicide attempt (OR 1.59, 95% CI 1.29 – 1.96). Specific internet activities associated with increased and decreased risk	Negative Quantitative High
Park, 2013 [40], Korea	Korean middle and high school students (795; 68)	To evaluate a)associations between problematic internet use and depression, bipolar disorder symptoms and suicidal ideation; and b) whether mood disorders mediate the relationship between suicidal ideation and problematic internet use	Presence of problematic internet use significantly associated with suicidal ideation (OR = 5.82, 95% CI = 3.30-10.26, p<0.001) as well as depression (OR = 5.0, 95% CI = 2.88-8.66, p<0.001) and probably bipolar disorder (OR = 3.05, 95% CI 0.96 -9.69, p = 0.059). Problematic internet use was found to predict suicidal ideation (β = 0.115, 95% CI = 0.052-0.193, p = 0.006). Conversely suicidal ideation was found to predict problematic internet use (β = 0.215, 95% CI 0.089 – 0.346, p = 0.006). Complex transactional relationship.	Negative Quantitative Medium/high

	Aktepe, 2013 [41], Turkey	High school students in Isparta (1897; 43)	To measure the prevalence of internet addiction and to detect related socio-demographic factors	The prevalence of possible internet addiction was found to 14%. A significant association between problematic internet use and self-harm was found ($\beta = 0.574$, OR = 1.79, 95% CI 1.30 – 2.43, $P < 0.001$). Adolescents with possible internet addiction were also found to have low levels of loneliness and high levels of life satisfaction.	Both positive and negative	Quantitative High
	Messias, 2011 [42], USA	Students aged 14-18 years; (16124; N/A)	To investigate the association between excessive video game/internet use and teen suicidality	Teens who reported more than 5 hours a day of video game/internet use had a significantly higher risk of suicidal ideation (OR = 1.7, 95% CI 1.3 – 2.1) and suicide planning (OR = 1.5, 95% CI 1.1 -1.9). Authors find a potential protective influence of low video game use compared with no use.	Both positive and negative	Quantitative High
Sources of help	Hetrick, 2014 ^a [43], Australia	Melbourne high school students experience suicidal ideation; (21)	To investigate the usefulness of an internet- based CBT programme	Over the course of the intervention negative problem-solving orientation improved ($t = 4.38$, $p < 0.0005$) and students relied less on emotion focused coping strategies. Adolescents rated the problem-solving and cognitive restructuring modules as particularly helpful.	Positive	Quantitative Medium
	Hetrick, 2015 [44], Australia	Australian young people aged 15-24 (15)	To develop and examine the feasibility of an online monitoring tool of depression symptoms, suicidality and side effects	Results show that an online monitoring tool is potentially useful as a systematic means for monitoring symptoms of depression and suicidality, but further research is needed including how to embed the tool within clinical practice	Positive	Mixed methods Medium
	Mar, 2014 [45] UK	Individuals age 16-24 who had experienced suicidal ideation (23; 96)	To explore youth consumer preferences for online interventions targeting depression and anxiety	Youth positively received the idea of e-mental health services. Noted preferences for services that are simple to use, interactive and include support through an online community.	Positive	Mixed methods Low/medium
	Saulsberry, 2013	Adolescents screening positive for	To test an internet program for young	Participants demonstrated significant within-group decreases in depression and	Positive	Quantitative High

	[46], USA	depression in primary care (83; 57)	people with depression	self-harm ideation (any thoughts of self-harm in previous two weeks 14.46% at baseline compared with 4.82% at 1 year follow-up)		
	Barton, 2013 [47], USA	College students (106; 55)	Study examined responses to open- ended email vignettes from a fictitious friend exhibiting depressed, irritable or suicidal communications	Results indicate student's preferences for solving fictitious peer problems personally rather than professionally. Patterns of help-giving and sex differences varied by condition	Both positive and negative	Qualitative Medium
	Whitlock, 2013 [48], USA	College students (14372; 43)	To examine the impact of questions regarding self- injury, suicide and psychological distress in a web- based survey on respondents	Less than 3% of individuals reported negative survey experiences. Individuals with relevant personal experience reported greater discomfort with the survey yet were also significantly more likely to report that it caused them to reflect on their lives	Both positive and negative	Mixed methods High
Social media	Belfort, 2012 [49], USA	Adolescents presenting to hospital with self-harm (1350; 75)	To describe key similarities and difference among adolescents who communicated their suicidality via electronic Vs. other means	Numbers of electronic communication of suicidality increased over time from 8.3% in 2005 to 55.6% in 2009. Patients who communicated suicidality electronically more likely to do so to a peer (67% compared with 7% of those communicating by other means).	Negative	Quantitative Low
	Cash, 2013 [24], USA	MySpace users aged 13-24 (64; 40)	To explore the ways in which adolescents use MySpace to comment on their suicidal thoughts and intention	Comments referenced a significant amount of hopelessness, despair and desperation. Adolescents use public web sites to display comments about their suicidal thoughts, behaviours and intentions.	Negative	Qualitative Low/medium
	Zdanow, 2012 [21], South Africa	Analysis of self-harm groups on Facebook	To analyse the representation self- harm on dedicated Facebook groups	Content analysis of two groups revealed glorification and normalisation suicidal behaviours. Potential for social networking sites to be used as a tool for the promotion and encouragement self-harm	Negative	Qualitative Low
	Sueki, 2015 [50], Japan	Young adult twitter users (1000; 61)	To examine the association between suicide- related tweets and	Logistic regression analysis showed that tweeting 'want to die' was significantly associated with history of	Both positive and negative	Quantitative Medium/High

			suicidal behaviour to identify suicidal young people on the internet	suicidal ideation (OR = 2.53, 95% CI 1.61 – 3.99) having a suicide plan (OR = 2.55, 95% CI 1.56 – 4.17) and attempting suicide (OR = 1.67, 95% CI 0.95 – 2.94). Tweeting 'want to commit suicide' was significantly related to history of self-harm (OR = 1.87, 95% CI 1.03 – 3.41), having a suicide plan (OR = 1.92, 95% CI 1.07 – 3.46) and attempting suicide (OR = 3.48, 95% CI 1.89 – 6.42). Having a twitter account and tweeting daily were not associated with suicidal behaviour		
Forum	Baker, 2008 [51], UK	Users of self-harm discussion forums (10, 50)	To explore the accounts of young people who self-harm and use forums	Forums were used positively for support and communication. Some participants report a reduction in the incidence of self-harm	Positive	Qualitative Low
	Barak, 2006 [52], Israel	Users of self-harm discussion forums (20, 75)	To assess whether the degree of forum involvement affected distress levels	Levels of forum involvement was association with lower levels of distress, however levels of distress did not improve over three months (F=2.10; df = 2, 787)	Positive	Mixed Methods Low
	Jones ^b , 2011 [53], UK	Users of a self-harm forum built for research (77, 95)	To explore what young people who self-harm think about online self-harm discussion forums	Participants claimed to learn more about mental health issues from online forums than from information sites, find it easier to talk about self-harm to strangers than to family or friends and preferred to talk online than in person.	Positive	Mixed Methods Medium
	McDer mott, 2013 [15], UK	Analysis of forum posts	To use qualitative methodology to examine internet forums where LGBT ^c youth discuss self-harming	This methodology can address some research dilemmas by generating diverse samples and a different type of unmediated complex data. Online data can enhance understanding of hard-to-reach youth	Positive	Qualitative Low/Medium
	Owens ^b , 2012 [54], UK	Users of a self-harm forum built for research (77; 95)	To bring together young people who self-harm and health professionals online	The young people were keen to share their experiences and supported one another during crises. Health professionals did not actively participate in forums due to reported lack of confidence	Positive	Mixed methods Medium

			and concerns relating to workload and duty of care.		
Sharkey ^b , 2012 [55], UK	Users of a self-harm forum built for research (77, 95)	To use discourse analysis and the concept of face-work as a framework to understand interactions in a self-harm support forum	Use of a range of mitigation devices found suggesting that the young people orient a 'protective line' in their supportive interactions. This may enable a more trusting, open context for support.	Positive	Qualitative Medium
Smithson ^b , 2011 [56], UK	Users of a self-harm forum built for research (77, 95)	To explore how young adults became members and sustained membership in a self-harm support forum	Participants displayed expectations about appropriate ways of discussing self-harm, responses and advice. Participants were active in shaping interaction on the forums requesting input from moderators.	Positive	Qualitative Low
Smithson ^b , 2011 [57], UK	Users of a self-harm forum built for research (77, 95)	To investigate the nature of problem presentation and responses in an online support forum	Analysis highlighted the tendency to offer advice where it was not asked for and the mundane 'safe' nature of advice	Positive	Qualitative Low
Whitlock, 2006 [16], USA	Analysis of forum posts	To investigate the prevalence and nature of self-injury forums, to explore the content, role and influence of discussion forums	Informal support was the most common type of exchange (28.3% of posts). Concealment of practice (9.1%), perceived addictiveness (8.9) and formal help-seeking (7.1) were also discussion themes	Positive	Mixed Methods High
Eichenberg, 2008 [58], Germany	Users of suicide discussion forums (164; 50)	To assess the assumption that suicide message boards are harmful.	Both constructive (e.g. help-seeking) and destructive (e.g. finding a suicide partner) motives were identified. A significant reduction in suicidal thoughts was found following forum use (effect size $d = 0.72$ ($t [144] = 9.2$; $p < 0.01$). Unable to directly infer cause.	Both positive and negative	Quantitative High
Franzen, 2011 [17], Sweden	Qualitative study of a Swedish-speaking web community connected to self-harm	To analyse how self-injuring men and women construct themselves as cutters	Two main interdependent discourses are identified within the web community: the 'normalising' and the 'pathologizing'.	Both positive and negative	Qualitative Low

	McDermott, 2015 [18], UK	Analysis of web-based discussions	To utilise qualitative virtual methods to investigate LGBT ^c youth web-based discussions about seeking help for suicidal feelings and self-harming	Young people wanted assistance but found it difficult to ask for help and articulate emotional distress	Both Positive and negative	Qualitative Low/medium
	Sueki, 2012 [59], Germany and Japan	Users of suicide forums in Japan and Germany (301, 54)	To analyse the cross-cultural use of suicide forums in Japan and Germany	Factor analysis demonstrated two motives: mutual help and suicide preparation. Suicidal thoughts did not worsen with forum use and there was no difference in demographics, motives or effects of suicide forums between Germany and Japan	Both Positive and negative	Quantitative Low/ medium
	Westerlund, 2013 [19], Sweden	Analysis of young adult forum posts	To examine conversations about suicide on discussion forums	Most participants communicate based on a need to gain acceptance and understanding. However there was also exchange of suicide methods and encouragement to go ahead with suicide plans	Both positive and negative	Qualitative Low
Website with suicide/self-harm content	Lewis, 2011 [25], Canada	Authors and users of self-harm websites (71; 79)	Examination of the content of non-suicidal self-injury web sites	Websites depict self-harm as an effective coping mechanism (92%), addictive (87%) and not always painful (24%). Almost all websites contained melancholic tones (83%) and several contain graphic imagery (30%). Overall it is suggested that such sites may normalize and reinforce self-harm	Negative	Qualitative Medium
	Harris, 2013 [60], Cross cultural (UK Europe, Canada, Australia, New Zealand and others)	Self-selected users of self-harm websites (329; 92)	To explore the reasons people visit self-harm websites or forums; beliefs regarding these sites; how the use of such sites modulates self-harm and other impacts of these sites on the lives of those who use them	65.6% of participants visited sites at least twice a week, 78.2% used sites to find information and 68.4% to participate in forums. Positive effects of website use such as gaining help and support and reduction in self-harm behaviours were reported by a large number of participants. However smaller numbers reported negative effects including worsened self-harm	Both positive and negative	Mixed methods High
Video/image sharing	Lewis, 2012 [22], Canada	Analysis of comments on YouTube	To examine viewers comments on non-suicidal self-injury YouTube videos and determine potential	Viewer's responses to videos may maintain the behaviour with admiration of video quality (21.95%), message (17%) and up-loader (15.40%)	Negative	Qualitative Medium/High

		videos related to self-harm	risks and benefits of such videos	common. Comments rarely encourage or mention recovery (<3%). Sharing experiences online is a strong motivator for viewers of self-harm related videos		
	Grzanka, 2014 [23], USA	Critical discourse analysis of online videos	To investigate a mass-mediated campaign against a perceived increase in suicides among gay youth in America	Analysis of videos showed a neoliberal frame that places the burden of a 'better' life onto youth who are instructed to endure suffering in the interest of inevitable happiness	Both positive and negative	Qualitative Low
	Lewis, 2011 [10], Canada	Posters of self-harm videos on YouTube (100; 95)	To examine the accessibility and scope of non-suicidal self-injury videos online	The top 100 videos were viewed over 2 million times and most were accessible to a general audience. Viewers rated videos highly (M = 4.61; SD 0.61 out of 5.0) and selected videos as a favourite over 12000 times. Explicit imagery common (64% of videos) with many videos not warning about this content	Both positive and negative	Mixed methods Medium
	Sternud, 2012 [61], UK, USA, Europe	Young people who self-harm (52; 87)	To examine reasons for, and reactions to producing/viewing self-harm images online	Informants reported effects images was alleviating rather than triggering. When interpreting statements about images 40% were positive and 25% were negative. To publish them was a way of sharing experiences with others and to give or receive help. Participants emphasised that the outcome of viewing these photos varies by individual and situation	Both positive and negative	Mixed methods Low
Blogs	Castro ^d , 2012 [62], Portugal and Brazil	Authors of Portuguese language blogs (11, 82)	Analysis of pro-anorexia blogs to systematize and categorize their characteristics, content and messages	Blogs can have negative consequences as a result of sharing harmful information about fasting, drugs, self-harm and suicide	Negative	Qualitative Low
	Castro ^d , 2013 [63], Portugal and Brazil	Authors of Portuguese language blogs (11, 82)	Analysis of pro-anorexia blogs to better understand the influence of social and cultural pressures	Positive relationship found between social and cultural pressures and engaging in self-harming/destructive behaviours	Negative	Qualitative Low

- a. Part of a three part series related to online interventions. Subsequent two papers while cited in press have publication dates outside of current search
- b. Five reports related to the same self-harm forum study (Sharptalk)

- c. Lesbian Gay Bisexual and Transgender
- d. Two reports based on the same set of eating disorder blogs

Variable	General use (12 papers; n = 131887(papers; n ^a))	Internet addiction (7 papers; n = 42894 (papers; n ^a))	Sources of help (6 papers; n = 14620) (papers; n ^a)	Social media (4 papers; n = 2414)(papers; n ^a)	Forums (14 papers ^b ; n = 572)(papers; n ^a)	Self-harm website (2 papers; n = 400)(papers; n ^a)	Video / image sharing (4 papers; n = 152)(papers; n ^a)	Blogs (2 ^b papers; n = 11)(papers; n ^a)	Total (51 papers; 46 studies; n = 192950)(papers; n ^a)
Methodology	10; 131808	7; 42894	2; 104	2; 2350	2; 465	0; 0	0; 0	0; 0	23; 177621
Quantitative	0; 0	0; 0	1; 106	2; 64	8; 10	1; 71	2; 0	2; 11	16; 262
Qualitative	2; 79	0; 0	3; 14410	0; 0	4; 97	1; 329	2; 152	0; 0	12; 15067
Mixed	7; 122152	6; 42099	2; 14455	0; 0	2; 164	1; 329	0; 0	0; 0	18; 179199
CASP quality score	2; 8	1; 795	4; 165	2; 1064	6; 378	1; 71	2; 100	0; 0	18; 2581
High	3; 9727	0; 0	0; 0	2; 1350	6; 30	0; 0	2; 52	2; 11	15; 11170
Medium									
Low									

Table 2. Research methodology and CASP quality score by internet medium

- a: number of independent participants, i.e. participants contributing to more than one paper are only counted once
- b: includes 5 reports related to the same self-harm forum (sharptalk)
- c: includes two reports based on the same set of eating disorder blogs

The sampling of participants varied greatly between studies, each introducing potential selection bias. For example, study participants were recruited via dedicated online support forums [51-59, 61]; emergency departments [49]; other healthcare settings [44-46]; through digital metrics [27]; and through large school-based and community surveys [28-31, 33, 36-42].

A number of outcomes were assessed in the studies, including levels of self-harm and suicidal behaviours, mental disorders, internet addiction, levels of loneliness and insomnia, the potential to recruit participants for research [15] and the nature of online information seeking [27] (S4 Table). Measures ranged from study-specific self-report questionnaires or content analysis themes to validated scales to assess suicidal behaviours, internet use, mental disorders and well-being e.g. Internet Addiction Scale, Beck Depression Inventory, Strength and Difficulties Questionnaire, Suicidal Ideation Questionnaire.

Perceived influences were: positive, 15 articles, 11 independent studies, n = 38,191 participants; negative, 19 articles, 18 independent studies, n = 119,524 participants; mixed, 17 articles, 17 independent studies, n = 35,235 participants. Table 3 summaries the mechanism of perceived influence by internet medium.

1 Table 3. Summary of mechanisms of perceived influence by internet medium

Medium	Influence			Mechanism	
	Positive (reports; n ^a)	Negative (reports; n ^a)	Mixed (reports; n ^a)	Perceived positive influences	Perceived negative influences
General use ¹² articles n = 131887	2; 37942	7; 93155	3; 790	-Support-Information regarding help seeking- Discussion about mental health	-Normalisation self harm behaviours- Facilitated spread of information and linked otherwise unconnected suicides in a probable suicide cluster
Internet addiction 7 articles n = 42894	0; 0	5; 24873	2; 18021	-Low levels of loneliness and high levels of life satisfaction in individuals with possible internet addiction-Potential protective influence of low levels of internet use compared with no internet use	-Significant relationship between internet addiction and self-harm/suicidal behaviour found in all studies
Sources of help 6 articles n = 14620	4; 142	0; 0	2; 14478	-Successful administration of an online monitoring tool for depression and suicidality- Successful administration of cognitive behaviour therapy and program of treatment for depression -Easily accessed therapy	-Responders to distressed emails more likely to try and solve problems personally than suggest seeking professional help-Individuals with relevant personal histories more likely to report discomfort following questionnaire completion related to self-harm and suicidal behaviours online but it also caused them to think more deeply about their lives
Social media ⁴ articles n = 2414	0; 0	3; 1414	1; 1000	-Increasingly used by young people to communicate distress prior to hospital attendance for self-harm.	-Glorification and normalisation self-harm
Forums 14 articles ^b n = 572	9; 107	0; 0	5; 465	-Isolation reduction -Community and source of support.	-Encouragement to go ahead with suicide plans-Detailed suggestions of suicide method to use-Validation of reasons given for planning suicide
Self-harm website (2 articles; n = 400)	0; 0	1; 71	1; 329	-Use of websites to find help	-Normalisation and reinforcement of self-harm
Video/ image sharing (4 articles; n = 152)	0; 0	1; 0	3; 152	-Factual and educational -Raising awareness for LGBT suicides -Viewing of self-harm images acts as an alternative or deterrent to self-harm	-Comments on videos may serve to maintain or reinforce the behaviour through regular viewing-Comments on videos rarely mention recovery-Explicit imagery of self harm acting as a trigger-
Blogs (2 articles ^c ; n = 11)	0; 0	2; 11	0; 0	-No positive influences reported	-Sense of competition -Sharing of potentially harmful information including means of concealment of self-harm and suicide methods

2

3 a: number of independent participants, i.e. participants contributing to more than one paper are only counted once

4

5 b: includes 5 articles related to the same self-harm forum (Sharptalk)

6

c: includes two articles based on the same set of eating disorder blogs

General internet use

Twelve studies examined the influence of general internet use [3, 20, 26-35]. Papers were categorised as examining general use if they spoke generally about internet use, did not detail the type of internet use or examined a number of different mediums. Two studies identified positive influences [27, 28]. One of high quality utilised digital to metrics to demonstrate high levels of engagement reported in online discussions about mental health by young people [27]. The second, a low quality study, utilised a community survey and showed lower levels of depression associated with frequent video game use. No association was found between media use and suicidal ideation [28]. Seven studies identified negative influences [3, 26, 29-33]. Studies rated as high quality utilised survey data and showed that high internet users and non-internet users were at higher risk of suicidal ideation and attempted suicide when compared with moderate internet users [31]. An 'invisible risk' group of individuals, who spent a lot of time online but did not engage in other risky behaviours (e.g. smoking) and had similar prevalence of suicidal thoughts as the 'visible' risk group, was identified in another high quality school based survey [29]. A relationship between internet use and self-harm was reported in several high quality papers. 15% of girls and 26% of boys reported that either the internet or social media had influenced their self-harm [33]. Risky online behaviours such as having a close relationship with someone met online (38% of those who reported self-harm compared with 10% of those who did not) was reported in a set of telephone interviews [32]. This relationship was further supported by an additional low quality school-based survey where suicidal ideation was found to be significantly associated with accessing suicide or self-injury information online (OR 5.11; 95% CI 0.35-0.75),

anxiety about getting email replies (OR 2.06; 95% CI 1.33 – 3.20) and hurtful experiences online (OR 1.71; 95% CI 1.03-2.84) [30]. In addition to the relationship between online behaviours and self-harm it was found that the internet and social media had facilitated the spread of information in a potential suicide cluster, and may have linked suicides otherwise unconnected by school or district [3]. Furthermore, a relationship between internet searches for specific suicide methods and the suicide rate in young people was found in one low quality study [26].

Three studies showed mixed influences [20, 34, 35]. In one small but high quality set of structured interviews participants found some interactive media supportive, while use of violent methods of self-harm were often preceded by viewing suicide related content online [34]. In a medium quality study aiming to examine self-harm content across internet mediums, large dedicated self-harm social media groups, 2290 videos related to self-harm on YouTube and high levels of views of videos about self-harm (the top video being viewed 339646 times) were identified. Peer-driven websites were found to contain warnings of triggering content, including stories and image galleries (not always present). These sites were accessed more frequently than professionally-driven websites [20]. Participants partaking in structured interviews reported that online sources of information related to suicide were quite common, and while social networking sites were frequently cited as sources these were not linked to increases in suicidal ideation, whereas online discussion forums were [35].

Internet addiction

Seven studies [36-42] examined the relationship between internet addiction and self-harm. For the purpose of this review internet addiction was distinguished from general

internet use if papers specifically referred to internet addiction or pathological internet use. There is no agreed definition of internet addiction in the current literature. It ranges from an impulse control disorder likened to pathological gambling [36-38, 41] to assessments of level of functional impairment or level of use [39, 40, 42]. All seven studies were rated as of high or medium/high quality, utilised school-based surveys with validated outcome measures and all found a significant relationship between internet addiction and self-harm/ suicidal behaviour. However, the direction of causality remained unclear. Five of these studies found exclusively negative results [36-40]. When a pathway model was employed problematic internet use was found to predict suicidal ideation alongside suicidal ideation predicting problematic internet use [40]. Two studies showed mixed effects [41, 42]. Potential mechanisms of positive influences included low levels of loneliness and higher levels of life satisfaction in individuals with possible internet addiction and a potential protective influence of low levels of internet use compared with none [42] (Table 3).

Online intervention/treatment

Six studies were of help administered online with the aim of reducing self-harm/suicidal behaviour, often alongside other manifestations of psychological distress such as depression and anxiety [43-48]. Participants came from a range of settings including schools [43], healthcare settings [44, 46] and universities [47, 48]. Positive influences were identified in four small studies. The successful administration of a program of treatment for depression was demonstrated in one high quality study [46]. Medium quality studies showed the successful implementation of an online monitoring tool for depression and suicidality [44], and for cognitive behaviour therapy [43]. All three of

these articles showed a reduction in either self-harm or suicidal ideation. The fourth low/medium quality paper demonstrated that participants positively viewed the idea of mental health services delivered online via questionnaire data and structured interviews [45]. Two much larger studies rated as high [48] and medium quality [47] showed mixed influences, and in the first of these participants did not report negative experiences following the completion of online surveys related to self-harm. Participants responding to distressed emails solved problems personally rather than suggesting professional help, with females being more likely to offer help than males [47].

Social media

Four studies examined the role of social media, including one content analysis paper [21, 24, 49, 50]. For this review social media studies were defined as studies focused on social networking sites such as Facebook and Twitter. Three studies showed negative influences, the studies being rated as low [21, 49] or low/medium quality [24]. It was found that young people attending emergency departments are increasingly using social media to communicate distress prior to hospital attendance for self-harm, particularly to a peer rather than to an adult [49]. Content analysis of open self-harm groups on Facebook revealed glorification and normalisation of self-harm [21]. While Facebook is a moderated site, groups are not moderated in the same way as support forums, where there are often rules on appropriate content. Analysis of comments on MySpace revealed suicidal thoughts, behaviours and intentions indicating significant amounts of hopelessness and despair [24].

One article rated medium/high quality reported the results of an internet survey (n =1000) and contained mixed results [50]. Tweeting 'want to die' or 'want to commit

suicide' was significantly related to suicidal ideation and behaviour. However, no association was found with simply having a twitter account or tweeting frequently [50].

Forums

Fourteen articles [15-19, 51-59] related to forums (five content analysis articles). For this review forum use was defined as the use of dedicated support forums, separate from social media sites. The setting of five of these was the 'Sharptalk' forum purposely built for research [53-57]. Each article examined a different aspect of forum use, was of low or medium quality and reported a positive influence. There was some reluctance on the part of health professionals in this study to participate actively in forums due to a reported lack of confidence and concerns relating to workload and duty of care [54]. In total, nine papers (five independent studies) reported positive results; one high quality content analysis [16] and four medium and low quality small studies [15, 51-57]. Five studies reported both positive and negative results; one high quality [58] and four medium and low quality [17-19, 59]. All the studies recruited via dedicated discussion forums. One study gathered data via in-depth email interviews [51], all but one of the other papers analysed the content of posts and four studies additionally collected data via questionnaires [53-59]

Positive influences identified in high quality papers include the potential for isolation reduction and informal support [16], and a significant reduction in suicidal thoughts following forum use, although it was noted that a causal relationship could not be directly inferred [58]. Well-moderated self-harm forums appeared to be viewed positively by young people as an online community providing continued support. One study (n=20) found that levels of forum involvement were associated with lower levels

of distress, but this level of distress did not decrease over the three month study period [52]. The potential for support and isolation reduction was supported by a number of small medium and low quality papers [15, 16, 18, 19, 51-57, 59]

Negative influences include the use of forums for destructive means, such as finding a suicide partner and exchange of potentially harmful information found in one high quality paper [58] and four low and medium quality papers [17-19, 59]. Direct encouragement to go ahead with suicide plans, including detailed suggestions of method, and validation for reasons given for a planned suicide were also reported [19]. While some if the discourse was judged to be potentially harmful, no association was found between worsened suicidal thoughts and forum use [59].

Website with suicide/self-harm content

Two articles reported on websites with dedicated self-harm/suicide content. A medium quality content analysis study of websites indicated negative influences, including that dedicated self-harm websites may normalise and reinforce self-harm [25]. A large high quality cross-cultural survey reported that individuals use these websites to gain help and support. While some participants reported a reduction in self-harm a small number reported increased self-harm associated with these websites.

Video/image sharing

Four articles focussed on video/image sharing [10, 22, 23, 61]. One medium/high quality content analysis of comments on self-harm videos identified negative influences [22]. Comments on such videos illustrate a strong motivation for sharing experiences online, rarely mention recovery and may contribute to the maintenance of self-harm. The other three papers were of medium and low quality and identified mixed results [10, 23, 61].

Videos with self-harm content on YouTube were found to frequently contain explicit imagery with factual and educational tones [10]. Videos raising awareness of lesbian gay bisexual or trans (LGBT) suicides highlighted that difficulties in life can be overcome; however, negative connotations were also present [23]. Some participants recruited from an online self-harm community reported that viewing of self-harm acted as a deterrent or alternative to self-harm, whilst others reported a triggering effect and sense of competition [61].

Blogs

Two articles reported the content analysis of the same set of pro-anorexia blogs [62, 63]. Both were rated as low quality and reported negative influences in the form of sharing potentially harmful information related to self-harm and suicide methods and means of concealment.

Across different mediums several studies focused on groups often hidden from traditional research and service provision. For example, three studies focused on populations of LGBT young people [15, 18, 23]. The first was an analysis of the content of YouTube videos raising awareness of the level of suicide in LGBT youth [23]. The other two papers showed that online discussion forums had the potential to engage this hard to reach group and to produce novel, unmediated data [15]. This approach was utilised to gather data on LGBT young people's perspective on seeking help for suicidal feelings. LGBT individuals found it challenging to articulate emotional distress and seek help from family members or professionals. They were most comfortable communicating online, particularly in dedicated LGBT forums [18]. A further two papers focused on young people with eating disorders [62, 63]. In these two studies a set of eating-disorder blogs

were analysed, which showed that discussion of self-harm and suicidal thoughts was common.

Discussion

This systematic review is an update of a previous smaller review exploring the relationship between internet use and self-harm [5] and incorporates previous evidence, thus also updating the field. A total of 51 articles (representing 46 independent studies) were included, with 192950 individual participants, together with some reports of content analytical studies. While a comparable number of articles included positive (15), negative (19) and mixed (17) influences of the internet on self-harm behaviour, articles demonstrating negative influences included more participants ($n = 119524$) than those with positive ($n = 38191$) and mixed influences ($n=35235$). On balance, considering the quality of studies and numbers of participants assessed, there is significant potential for harm of online behaviour in relation to self-harm and suicidal behaviour, but also potential benefits that merit exploitation.

Results of this review are largely supportive of the findings of the previous review with comparable proportions of studies with positive and negative results [5]. However, in recent years this field of research has developed substantially allowing greater examination of details such as medium of internet use and for a greater range of positive and negative influences to be identified. Studies on general internet use, internet addiction and online interventions/treatment presented the strongest evidence, with mostly high or medium quality research. High internet use and internet addiction appear to have largely negative influences. Twelve studies examined general internet use, seven of which were of high quality. The latter group of studies demonstrated that high levels of internet use (more than two [31] or five [29] hours per day) were associated with suicidal ideation [29, 31]. Further low and medium quality research suggested that self-

harm and suicidal ideation were related to searching online for suicide information [30] and that searches for specific methods were related to rates of suicide in young people [26]. Online media appeared to facilitate the spread of information, linking otherwise unconnected suicides, making it difficult to recognise and manage a suicide cluster [3]. Research examining internet addiction represented the most homogenous group of studies; all employed high/medium quality quantitative methodologies in the form of cross sectional school-based surveys and validated outcome measures. All studies examining internet addiction found a relationship between internet addiction and self-harm or suicidal behaviour. The direction of causality of the negative influence of internet addiction and self-harm/suicidal behaviour was unclear. Positive influences included lower levels of loneliness [41] and a potential protective influence of low levels of internet use when compared with no internet use at all [31, 42]. Other studies have found that low and high internet use is associated with higher adolescent health risks than moderate use [31]. The internet may provide an opportunity to be part of a community online when this is lacking in everyday life. The potential of the internet as a medium to deliver interventions to address suicidal behaviours and self-harm was examined in six studies of medium to high quality, with mixed results but generally being viewed positively by participants.

Studies exploring the other mediums (social media, forums, videos/ images sharing, blogs) were smaller, of lower quality and with more mixed results. Only one paper related to social media was rated as medium/high quality. Distressed online posts were found to be related to suicidal ideation and behaviour, but there was no evidence suggesting that simply using social media presents a risk [50]. The remaining low and medium/low quality research found that young people are increasingly using social

media to communicate distress, particularly to peers [49]. This is in keeping with more recent research showing that self-harm and suicide-related internet use prior to ED attendance is higher among children and young people than in adults, and is additionally related to higher suicidal intent [64]. While social media is being utilised here to communicate distress, this does not indicate a causal relationship. Glorification and normalisation of self-harm was found in two of the four social media studies [21, 24]. Forums were viewed positively as a source of peer support. There was evidence of a reduction in suicidal thoughts following forum use in one high quality study [58] but also evidence of normalisation of self-harm, encouragement to go ahead with suicide plans and discussion of how to conceal self-harm, supported by one high quality and a number of medium and low quality studies [16, 17, 19, 50, 58]. The impact of forum use on levels of self-harm remains unclear. Videos were highly viewed/shared, largely factual or educational and often contained graphic imagery, but rarely with warnings of such content [10]. One high quality study found that comments on videos may contribute towards the maintenance of self-harm and suggests a strong motivation for sharing experiences online. It remains unclear whether this sharing of experiences has a positive or negative impact on individuals, with its influence likely to vary with individual circumstances [22]. In the remaining (low quality) study some participants reported an alleviating effect of images, others a triggering one [61]. Sharing of potentially harmful information related to self-harm and suicide was reported in two small low quality studies of the same set of pro-anorexia blogs [62, 63].

The variation in results between mediums may be partially attributable to study design and participant samples. Research examining general internet use and internet addiction was largely based on school surveys employing validated outcome measures

and found largely negative influences of internet use. In contrast, research examining forum use recruited almost exclusively from online discussion forums, undertook content analysis of forum posts, sometimes alongside questionnaire data, and often found positive influences. The contrasting results between studies recruiting from general population and self-selecting participants are not unexpected. Studies with more diverse participant samples and employing validated outcome measures may assist in clarification of the effects of different types of medium.

Research in this area may be biased towards measuring certain effects and outcomes e.g. a positive effect for interventions, or a negative effect for internet addiction. The choice of outcome measures may reflect the expected effects of the internet and fail to capture the full complexity of the experience of individuals. This is a risk in all research but may be a particular issue in this field. For example, studies examining internet addiction report largely negative results. However one study found that internet addicted individuals reported high levels of life satisfaction and low levels of loneliness that may not have been identified had these measures not been included [41]. In future investigations researchers should aim to ensure that outcome measures capture both possible positive and negative outcomes in order to give a complete and unbiased picture. Such steps can be seen in more recent research. For example an online treatment for depression resulted in symptom reduction but examination of possible negative influences demonstrated that individuals with lower education were at higher risk of symptoms becoming more severe [65]. Another recent study found both positive and negative influences of websites detailing suicide methods [66].

In keeping with the previous review [5] the majority of studies finding solely negative influences utilised quantitative methodologies. Mixed methods and qualitative studies

tended to report more mixed results. It is unclear if this is a discrepancy between what participants report and actual outcomes or if quantitative data are failing to capture the complexity of the issue. This is further compounded by the mostly low quality of included qualitative studies. High quality qualitative and quantitative research is needed to establish whether differences in the influence of various mediums are partially attributable to study design.

Strengths and limitations

The potential for publication bias exists in any review of literature and should be considered when interpreting the results. Steps were taken to minimise any bias as much as possible including conducting an extensive search of multiple databases including grey literature databases and topic specific websites, reviewing reference lists and contacting experts in the field. However, only English language publications were included. It was noticeable that males remain under-represented in studies. Further examination of any gender differences is a potential avenue for future research.

While the decision to review literature related to cyber-bullying in a separate review will have had an influence on the proportion of articles reporting positive and negative results, it will allow for a more in-depth discussion of this important topic. The inclusion of this large body of research would have created an unwieldy review or necessitated a more cursory discussion of internet mediums. Literature related to cyber-bullying is unlikely to report any positive outcomes and had it been included it would have added to studies reporting a negative influence. This could potentially be viewed as an important bias in this review. However, results of this review highlight that the internet has the potential for both positive and negative influences dependent on the way in

which it is used. Identifying both beneficial and harmful mediums and directing individuals towards healthy online behaviour should be considered of greater importance than weighing up whether the internet is simply 'good' or 'bad'.

While this review summarises data from an extensive search, there will be further literature published since the search was conducted. Based on the number of additional articles in the two years since the review by Daine et al [5] it is likely that this will represent a considerable body of research. Summarising it is likely to be beyond the scope of one review. Because of the rapidly increasing body of research, authors conducting future systematic reviews on this topic may consider reviewing by specific internet medium (forums, videos etc.) to ensure the task is manageable and the resultant reviews are of sufficient depth in each area to allow identification of key messages for clinicians and policy makers. While a range of internet mediums were included in this review, recent research has expanded even further, for example examining behaviours such as online gambling [67].

The quality of qualitative studies in this review appeared mostly to be low. While this may be reflective of quality, the appropriateness of using checklists to assess qualitative research has been questioned due to the diversity of approaches in collecting, analysing and interpreting data [68, 69]. This may be particularly problematic with research into internet use where there is considerable heterogeneity in methodology across study designs. It is unlikely that a single checklist would be suitable to capture all aspects of study quality across the range of study designs, populations and outcomes. Authors of future reviews in this area might consider the selection of quality outcome measures that fully capture the quality of various study designs.

It is not always possible in studies examining forum use or comments on videos/photos to accurately determine the characteristics of individuals and young people may misrepresent their age when creating profiles. Therefore ages of participants were not always clearly reported but were inferred by study authors based on demographics of typical users of sites or based on profile information.

It was a challenge to categorise findings as negative or positive in some studies [5]. The sharing of experiences online, for example, while therapeutic for some, may be destructive for others. The expression of distress online could be viewed as negative on the one hand, but as an opportunity for intervention on the other. This is an area of research where outcomes are not always clear cut. It was not always easy to understand whether certain factors acted as mediators or moderators of distress, nor the long-term implications. For example, individuals with a history of self-harm were more likely to report discomfort following online questionnaire completion related to self-harm, but it also caused them to think more deeply about their lives which may have been positive [48]. While it has been possible here to broadly discuss the influence of various mediums and to identify those that may represent a higher risk, the impact of various aspects of internet use is likely to vary between individuals and over time and should therefore always be assessed on an individual basis.

A wider range of internet mediums was examined than was possible previously [5]. This has resulted in a varied pool of participants, including those recruited from discussion forums, schools and healthcare settings. The majority of quantitative studies employed validated outcome measures, in contrast to literature identified in the previous review [5], allowing some comparison of results across studies. However, the considerable

range in methodology, population and outcomes studied means that, at this time, it is not possible to conduct a meaningful statistical meta-analysis.

Implications

The volume of self-harm videos shared on YouTube and the high number of views and comments have led to suggestions of developing videos to emphasise help and recovery [10, 22]. The introduction of psycho-educational prevention programmes in schools concerning appropriate responses to distressed posts on social media and digital citizenship may mitigate some of the negative influences of the internet [20, 47, 49]. The internet is a potential tool for outreach by health professionals. Research suggests some disconnect between healthcare professionals and media usage [11]. This was only explicitly discussed in one set of studies reviewed here in which health professionals expressed discomfort about engaging with young people in an online setting and had concerns over duty of care [54]. This could be addressed through further training and encouragement of clinicians working with young people who self-harm or have mental health issues to engage in discussion about internet use. This should be a standard item during assessment. It could include the asking about the role of images/videos [61] and designing treatment plans to maximise beneficial online behaviours and reduce associated harms [20].

Suggestions have been made for the implementation of guidance to individuals and service providers such as avoiding details of method and including warnings of graphic content on web pages [20]. Stricter regulations could be modelled on the initiative in Australia, where pro-suicide sites were banned in 2006 [70]. Several major social media platforms (Tumblr, Pinterest, Instagram, Facebook) have responded to concerns and

implemented policies regarding posts related to self-harm. Such content may not be searchable, is banned or brings up links to counselling and prevention resources [71]. The potential to access groups online largely hidden from the health service, such as those for LGBT individuals or those with eating disorders for both interventions and research may improve access to care and allow representation in research that has not been possible previously. Any online sign-posting or interventions should not be limited to platforms exclusively dedicated to self-harm but should also extend to other groups at potential risk. This is supported by recent research finding that experiences of victimisation are associated with entering pro self-harm and pro-suicide websites [72].

Conclusions

Research concerning the internet and self-harm in young people is rapidly evolving in an attempt to keep pace with the continually changing nature of its use. On balance, considering the quality of studies and numbers of participants assessed in this review, there is significant potential for harm to result from online behaviour in relation to self-harm and suicidal behaviour (normalisation, triggering and competition between users, a source of contagion and harmful information for vulnerable individuals), but also the potential to exploit its benefits (a sense of community, crisis support and reduction of social isolation). The focus should now be on a range of internet mediums including social media, video/image sharing, and the potential for the internet to be used in therapy and recovery.

There were a number of innovative suggestions from research teams responsible for publications, including educational programmes in schools to teach young people how to respond to distressed posts/messages on social media and repeated calls for clinicians

to be aware of internet use. The internet may also represent an under-utilised setting to access 'hidden' at risk groups, giving them a voice both in research and in practice.

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Supporting information

S1 Table Sources searched and terms used

S2 Table Data extraction sheet

S3 Table Quality scores by study design

S4 Table Outcomes studied and measures used

S5 Table PRISMA 2009 checklist

APPENDIX B: DATA EXTRACTION SHEET FOR REVIEW ONE

Author/Year	
Title	
Journal	
Groupings	
Mean age	
SD	
Age range	
Gender %Female	
Race	
N	
Locality	
Country	
Urban or rural ie; socially isolated	
Quote: Summarise what the paper is about	
Aim: What precisely did it aim to do?	
Hypotheses	
Recruitment method ie; random (hence representative)	
Data collection method	
Inclusion/ Exclusion criteria: Check vulnerable group/age etc.	
Type of study	
Quant/Qual/Grounded in theory	
Time: Period of the study and follow up	
Response rate	
Measures	
Pilot Study	
Remuneration	
Ethical permission	
Do participants have history of self-harm/suicide attempt/ideation	
What are the subgroups of the problem ie; self-harm/ideation/previous attempt	
Were participants medicated	
Did participants have any relation to other self-harmer/ family member who had committed suicide?	
What was the frequency of internet use?	
Follow up studies; What data was missing and why-were these participants different in any way?	

What was the internet medium in question ie; website/forum/email/social networking site?	
Were the participants using the medium in a positive or negative way (ie; coping strategy/suicidal methodologies)	
Relevant impacts of medium positive/negative/neutral	
Did change occur in the participants? If so what? (ie; coping/thoughts and feelings/support/isolation/ behavioural change (suicide ideation/self-harming behavior) Please include size of effects	
What were the mechanisms of change? Did the authors find a mechanism or hypothesize one?	
How did participants reach the internet medium in question ie; web site/forum etc.	
What were the reasons for use of the medium?	
Was the study related to cyber-bullying	
Is the internet medium professionally or peer moderated	
Is any information missing that the author needs to be contacted for? If so what?	
CASP quality score	
Authors email	-
Notes	

APPENDIX C: REVIEW TWO IN PRESS MANUSCRIPT

Images on the internet: A systematic review of studies on the impact of on-line sharing and viewing of self-harm related videos and photographs in young people.

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Abstract

Background

Given recent moves to remove or blur self-harm imagery or content posted online, it is important to understand the impact on young people of posting, viewing and reposting self-harm images.

Aim

The aim of this study was to systematically review research related to the emotional and behavioural impact on children and young people of viewing or sharing self-harm related videos or images online.

Method

We searched databases (including EMBASE, Psychinfo and MEDLINE) from January 1991 to February 2019. Search terms were categorised into: internet use; images non-specific and specific to the internet; self-harm and suicide. Stepwise screening against specified criteria and data extraction were completed by two independent reviewers. Eligible articles were quality assessed and a narrative synthesis conducted.

Results

19 independent studies (20 articles) were included. Four studies focused on images, ten (11 articles) on videos and five on both. There were four quantitative, nine qualitative and seven mixed methods articles. Eleven articles were rated as high quality. There has been an increase in graphic self-harm imagery over time. Potentially harmful content congregated on platforms with little moderation, anonymity and easy searches for images. A range of reactions and intentions were reported in relation to posting or viewing images of self-harm: from empathy, a sense of solidarity and the use of images to give or receive help; to potentially harmful ones suggesting new methods, normalisation and exacerbation of self-harm. Viewing images as an alternative to self-harm or a creative outlet were regarded in two studies to be positive impacts. Reactions of anger, hostility and ambivalence were reported. There was some evidence of a role of imitation and reinforcement, driven in part, by numbers of comments and wound severity but this was not supported by time series analyses.

Conclusion

While the results of this review support concerns related to safety and exacerbation of self-harm through viewing images of self-harm, the potential for positive impacts should not be underestimated. Future research should evaluate the effectiveness and any potential harms of current posting restrictions, incorporate user perspectives and develop recovery-oriented content. Clinicians assessing distressed young people should ask about internet use, including access to self-harm images, as part of their assessment.

Introduction

Young people who self-harm engage in more online activity than others of a similar age [1]. There is a large online presence of self-harm related material [2] in the form of blogs [3,4], large social media groups [5], thousands of highly viewed videos [6], websites [7] and dedicated online communities [8]. The nature of internet use is constantly evolving. Platforms such as Instagram and Tumblr have increased in popularity for self-harm communities, partly because they are image based [9]. Forty-four percent of surveyed adolescents reported Instagram to be an important part of their daily lives [10] and internet searches for suicide are increasingly returning graphic imagery [11].

Mental imagery has a role in determining future behaviour [12]. It is thought to be more emotionally evocative than verbal thoughts with stronger links to affect [13]. Individuals who experience suicidal ideation often report 'flash-forward' detailed imagery, similar to flashback imagery in PTSD, related to suicidal acts [14,15]. Most youth who self-injured report mental imagery when the urge to self-injure was strong [16,17]. Emotion-laden mental imagery of self-harm may play a role in motivating behaviours toward or avoidance behaviours away from self-harm [17].

In addition to the role of mental imagery, a growing body of literature has explored the role of exposure to self-harm images through the media [8,18,19]. While self-harm is a largely hidden behaviour, images of self-harm are commonly shared online. This is often done anonymously, with individuals continuing to hide their self-harm in the offline world [20]. Participants have reported reduced loneliness and the use of images to curb self-harm urges on the one hand, and reinforcement and triggering of self-harm on the other [8]. Previous systematic reviews regarding internet use and self-harm, whilst not focussed on images, similarly suggest both positive and negative impacts of images/videos [18,19]. The growing popularity of image-based platforms and high profile stories of the risks has stimulated an exponential increase in research related to self-harm imagery online. Given recent moves to remove or blur self-harm imagery or content posted on platforms such as Instagram in response to concerns of bereaved parents [21] it is important to understand the impact on young people of posting/viewing self-harm images.

Aims and objectives

This study aimed to systematically review research related to the viewing or sharing of self-harm or suicidal behaviour related videos/images online in children and young people to explore: the impact on emotions and behaviours of viewing or re-posting images/videos of self-harm; the impact of posting images/videos of self-harm by individuals who self-harm; and whether certain aspects or types of images/videos impact outcomes.

Method

Online content related to video/images has been included as part of previous systematic reviews by our research group [18,19] but was not their main focus. We have adapted the search strategy used in order to specifically identify research on this topic. An electronic literature search was conducted from 01.01.1991 (the year the internet was made publicly available) to 20.02.2019 to ensure a comprehensive overview of the existing literature.

Search strategy

Core databases CINAHL, EMBASE (excluding medline journals), Psychinfo, SCOPUS and MEDLINE were searched, alongside topic specific websites (Campbell; Centre for Mental Health; Department of Health; Mental Health Foundation; NHSPSS-NI; NHS Scotland; Royal College of Psychiatrists) and meta-search engines (Google and Google scholar). Search terms were grouped into four categories:

Internet use: *Free text* "Aol" or "Askfm" or "Bebo" or "blog*" or "chat?room*" or "cyber*" or "discussion forum" or "e?communi*" or "e?material\$" or "Facebook" or "googl*" or "hashtag\$" or "instant messag*" or "internet" or "live chat*" or "live journal\$" or "MSN" or "Myspace" or "on?line" or "online" or "podcast*" or "social network*" or "spam*" or "tweet*" or "Twitter" or "troll" or "virtual*" or "web" or "whatsapp" *MESH terms*. INTERNET, Social media, Social networking

Images non-specific to internet: *Free text*. "imag*" or "galler*" or "photo*" or "picture\$" or "video*" *MESH terms*. Video recording

Images specific to the internet: *Free text*. "meme" or "Pinterest" or "Tumblr" or "vine" or "vlog*" or "YouTube" or "snap*" or "gif\$" or "selfie\$" or "Flickr" or "camera" or "filter" or "reddit" or "Instagram"

Self-harm and suicide: *Free text*. "Automutilation" or "Distress*" or "emotion*" or "NSSI" or "SIB" or "suicid*" or ((oneself or myself or self) adj2(cut* or harm* or hurt* or kill or injur* or mutilat*)) *Mesh terms*. 'Self-injurious behaviour', 'stress, Psychological'

Terms were combined as follows (Internet AND images non-specific to internet terms) OR (images specific to the internet). Self-harm and suicide groups were combined with results from the above search.

Selection criteria

Articles were included if they examined online viewing or sharing of images/videos related to self-harm or suicidal behaviour or by individuals who experienced suicidal ideation, suicidal behaviour or self-harm. Self-harm refers to any intentional act of self-injury or poisoning independent of motivation or suicidal intent [22]. This definition is necessarily very general as the motivation or degree of suicidal intent is difficult to assess and may vary between individuals and over time. Articles were required to include primary empirical data and be published in peer-reviewed journals. Results were not restricted by location. Only English language articles were included. Review articles, single case studies, editorials, conference abstracts, or other grey literature were not included. Reference lists of all review articles were manually screened for potential eligible articles. Participants had to be aged 24 years or under or have an average age of 24 years and under. If age was not specified participants had to be described as children, adolescents, young people, or young adults. Where articles examined more than one age group, only data for the age group fitting these criteria were analysed.

Two independent reviewers (AM, LB) manually screened titles. Any disagreements were resolved by consensus or discussed with a third expert reviewer (AJ). Duplicates were removed. Titles that had no relevance and grey literature were excluded at title screen. A record was kept of all discarded articles, including the reason for exclusion. The remaining titles with abstracts were screened for eligibility (AM, LB). Full text articles were obtained where suitability could not be determined based on the title and the abstract.

Data analysis

A previously developed data extraction sheet [19] was adapted to record findings (Supplementary Table 1). Additional fields were added to examine features specific to images/videos (e.g. platform moderation, trigger warnings, the nature of the images/videos and the impact on the viewer). Two reviewers (AM, LB) independently extracted data from each article. Any inconsistencies in data extraction and quality scores were clarified by consensus or through discussion with a third expert reviewer (AJ).

The heterogeneous and largely qualitative nature of studies precluded any meaningful combination of results through meta-analysis. Therefore a narrative synthesis was employed. Based on published guidance [23] this narrative synthesis examined a number of key aspects of each article. Comparisons were made regarding the way in which self-harm imagery was examined across studies and internet platforms. The influence of heterogeneity was explored further, including differences in populations studied, differences between various platforms, measures employed and outcomes studied.

Articles were amalgamated and grouped into categories. These categories were inductively generated following initial reading and data extraction of articles, and were cross-checked by members of the study team (AM, LB, AJ). Positive influences of viewing/sharing of images/videos were defined as a perceived reduction in psychological distress, reduced suicidal ideation/self-harm, advice on how to seek help and encouragement to do so. Negative influences were defined as results indicating increased psychological distress, increased frequency or severity of self-harm/suicidal ideation, provision of information on method of self-harm/suicide, and self-harm behaviours being encouraged [19]. Positive and negative influences were examined in relation to the population studied, internet platform (e.g. Instagram, Tumblr) and specific features of images/videos.

Quality of included articles was assessed according to the Critical Appraisal Skills Programme (CASP) [24] as performed previously [19]. The CASP tool assesses various aspects of study design, including sources of bias, data collection, clarity of results and appropriateness of conclusions. CASP does not specifically recommend any scoring or grading system. We adopted a scoring system utilised previously [25] ($\leq 50\%$ of criteria low quality, 50-75% moderate, $\geq 75\%$ high quality, no criteria weighting applied [26]). Quality assessment was conducted by two independent reviewers (AM and LB) for each article.

A protocol for the systematic review was registered with PROSPERO (https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=148695).

Results

Screening process

Figure 1 shows the results of the search strategy and screening process. Nineteen independent studies (20 articles) were included. Four studies focused on images, ten studies (11 articles) on videos and five on both images and videos. Two articles were based on a single dataset of 100 videos [6,27]. A summary of included articles, quality scores and categories can be seen in Table 1. Studies came from across the world (USA n=7; Canada n=4; UK n=2; Germany n=2; Australia n=1; multiple countries n=3). There were four quantitative, nine qualitative and seven mixed methods articles. Eleven articles were rated as high quality, seven moderate and two low.

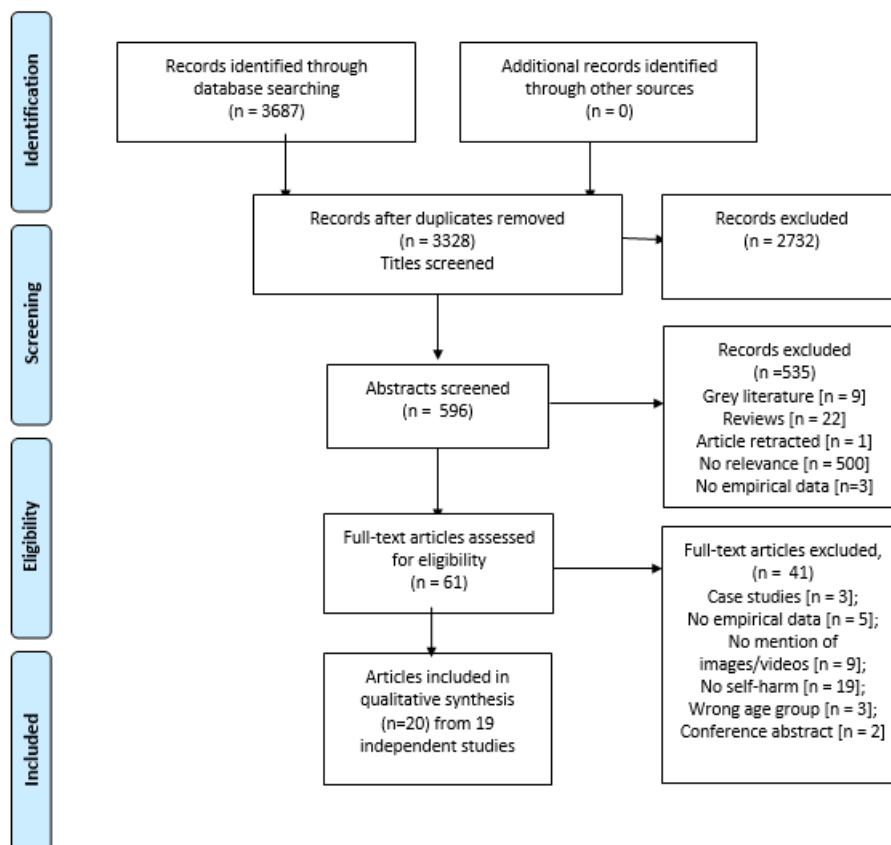


Figure 1 Results of search strategy and screening process

Categories of studies

Twelve studies (13 articles) reported an analysis of images/videos related to self-harm/ suicidal behaviours over a range of platforms (multiple sources n=2; YouTube n=6; Instagram n=2; Tumblr n=1; Twitter n=1). Three studies examined the perspectives of individuals on the impact of sharing and viewing images/videos of self-harm online [9,28,29]. Four studies (one high and three moderate quality) examined online interventions using videos [30-33]. All four studies reported the potential for positive impacts. Some studies [34] made a distinction between photographs of non-suicidal self-harm and suicide attempts but the criteria for these distinctions were often unclear so the term self-harm is used throughout.

Table 17 Summary of included studies

Author, year, country, quality score	Aims and objectives Participants/sample	Results
Category suicidal behaviours		Analysis of images or videos related to self-harm/
Avery, [38] 2015, USA, moderate.	To understand the characteristics of the fire-challenge phenomenon in an effort to develop preventative and public safety measures. 50 videos depicting the fire challenge; 90.0% male; 64.0% African American.	50 videos were selected. Of these, 13 videos included post-burn footage. Superficial and partial thickness burns were sustained on the torso (10/13, 76.9%), face (4/13, 30.8%), and extremities (2/13, 15.4%). Full thickness burns were seen in 2/13 videos. Young African American males were over-represented. The authors suggested that these should be targeted in prevention and intervention.
Basch [41], 2017, USA, moderate.	To describe the extent to which content related to bullying is present on YouTube with respect to source, content number of views, length, and year uploaded. The top 100 videos related to bullying on YouTube with the greatest number of total views were identified.	The most common content was describing or depicting violence (n=89). Over half addressed getting help (n=56). Thirty-eight out of 100 videos mention suicide or thoughts of suicide. No analysis was conducted of the nature of discussions around suicide or their potential impact.
Brown [34], 2018, Germany, high.	To analyse pictures directly depicting self-harm wounds on Instagram. Pictures, comments, and user accounts examined. The aims were 1) To systematically describe the extent of self-harm on Instagram in a German-speaking population. 2) To describe online content of German-speaking users. Posters of self-harm pictures on Instagram (n=1152); majority anonymous; 91.0% of identifiable profiles female.	Most pictures depicted wounds caused by cutting on arms or legs and were rated as mild or moderate injuries. Pictures with increasing wound grades and those depicting multiple methods of self-harm generated elevated amounts of comments. Most comments were neutral or empathic, with some offering help. Few comments were hostile. Pictures were mainly posted in the evening with a small peak in the early morning and on Sundays.
Cavazos-Rehg [36], 2016, USA, high.	To gain a better understanding of the depression, self-harm, and suicidal content that is being shared on Tumblr. 17 Tumblr accounts; of the 8 that provided demographic information 75.0% female.	17 Tumblr accounts posted a median number of 185 posts. Content was engaged with 1,677,362 times. Of the 3,360 randomly selected posts, 2,739 (81.5%) were related to depression, suicide, or self-harm. Common themes were: self-loathing (412, 15.0%); loneliness/feeling unloved (405, 14.8%); self-harm (407, 14.9%), and suicide (372, 13.6%). Findings signal a need for suicide prevention efforts to intervene on Tumblr and use this platform in a strategic way.
Duggan [2], 2012, Canada, low.	To simultaneously examine the scope and nature of self-harm content across informational/interactive	Peer-driven, informal websites have a variety of triggering content and are accessed more often than professionally driven sites. Self-harm is strongly represented among social networking websites and

	websites, social networking websites, and YouTube in order to provide mental health practitioners with a multifaceted description of online content related to self-harm. Demographics only available for uploaders of YouTube videos; n=5, 80.0% female.	YouTube, evidenced by large group memberships and large video view counts.
Grzanka [40], 2014, USA, low.	To investigate the mass-media 'It Gets Better' campaign responding to a perceived increase in suicides among gay youth in the USA since Sept 2010; critical discourse analysis of a sample of videos posted as part of campaign. Content of 30 videos aimed at LGBT+ youth analysed.	Activists, celebrities, and the general public created and uploaded videos as part of the campaign, often telling their own stories of overcoming difficulties (e.g. bullying). A thematic analysis of a subset of these videos revealed common themes of directives (e.g. 'don't give up') and, testimonies of how the posters had overcome their own difficulties. The effectiveness of the campaign was not analysed. Results revealed a neoliberal framing that placed the burden of a better life onto the emotional lives of LGBT youth, who are instructed to endure suffering in the interest of inevitable happiness.
Hilton [42], 2017, UK, high.	To report the findings from a unique analysis of naturally occurring data regarding self-harm behaviour generated through the global social media site, Twitter. Twitter users n=317; no information regarding gender.	Five themes were identified; 1) celebrity influence, 2) self-harm is not a joke, 3) support for and from others, 4) eating disorders and self-harm, 5) videos and personal stories. More recovery oriented content than graphic imagery on this platform. No formal comparison with other platforms is made.
Lewis [27], 2012 ^a , Canada, high.	To examine viewers' comments and responses to self-harm YouTube videos to determine the potential risks and benefits of the videos. Uploaders of 100 self-harm videos on YouTube; 95.0% female.	Most frequent comments were self-disclosure (38.4%) and individuals sharing their own self-harm experiences, followed by feedback for the video uploader, including video quality (22.0%), or message (17.0%) and admiration (15.4%) for uploader, or encouragement for uploader (11.2%). The majority did not mention recovery (43.0) and indicated they were still self-injuring (24.0%).
Lewis [6], 2011 ^a , Canada, moderate.	To explore the accessibility and scope of self-harm videos online. Uploaders of 100 self-harm videos on YouTube; 95.0% female.	The top 100 videos analysed were viewed over 2 million times, and most (80.0%) were accessible to a general audience. Viewers rated the videos positively and selected videos as a favourite over 12,000 times. The tone of the videos was largely factual or educational (53.0%) or melancholic (e.g. hopeless statements, depictions of sadness or crying; 51.0%). Explicit imagery of self-injury was common. 90.0% of non-character videos had self-harm photos whereas 28.0% of character videos had in-action self-harm. For both, cutting was the most common method. Many videos (58.0%) did not warn about this content. Content was often creative and frequently contained graphic imagery.
Lewis [37], 2015, Canada, high.	To examine the nature of self-harm first aid tip videos shared through YouTube.	40 self-harm YouTube videos were content analysed. Videos viewed 157,571 times, typically favourably rated. Most had a neutral purpose and neither encouraged nor discouraged self-harm. Messages

	40 uploaders of videos to YouTube; 82.5% female.	encouraging self-harm help-seeking were scant. Medical help-seeking was not commonly encouraged (55.0% of videos related to self-cutting and 27.5%, n=11, related to self-burning recommended seeking medical help, with several videos providing "safe" self-harm instructions.
Moreno [35], 2016, USA, high.	To evaluate the meaning, popularity, and content advisory warnings relating to ambiguous self-harm hashtags on Instagram 1) Present current data on ambiguous hashtags that may be common parlance related to self-harm. 2) Test a process to investigate ambiguous self-harm terms. 3) Evaluate the popularity of self-harm-related hashtags at two time points. 4) assess the precision of Instagram's warning labels for concerning content. Posters of ambiguous self-harm hashtags on Instagram; 193 unique usernames in a sample of 201 posts; no information on gender.	Sample of 201 Instagram posts led to identification of 10 ambiguous self-harm hashtags. Results demonstrated a popular image that described the broader community of self-harm and mental illness called #mysecretfamily that had approx. 900000 search results at time 1 and 1.5 million at time 2. Only one-third of relevant hashtags generated content advisory warnings.
Poonai [39], 2018, Canada, high.	To utilise interrupted time series analysis to examine whether the release of Amanda Todd's YouTube video following her death announcement in October 2012, was associated with an increase in average month emergency department visit rates for suicide-related diagnoses in Ontario children aged 11-17. Population based time-series analysis utilising a national database. Ontario patients aged 11-17 based on a sample of 4,775,658 emergency department visits; 48.9% female.	There was a significant increase in the monthly emergency department visit rate for the composite outcome of the average monthly rate of initial emergency department visits for suicidal ideation, intentional self-poisoning, and intentional self-harm. Secondary outcomes were average monthly rates of death or intensive care unit admission resulting from index visit from April 2002-Dec 2013. There was no significant change in emergency department visit rate for the composite outcome before and after announcement of Amanda Todd's death. Findings suggest publicity around this video release was not associated with increase in emergency department visits for suicidal behaviour.
Singaravelu [7], 2015, UK, high.	To identify and analyse websites potentially accessed by young people about self-harm. Searched only for websites: Target audience of websites described as young people; initial search terms developed in discussion with six members	Sites accessed by self-harm/suicide search terms were mostly positive or preventative in tone, while sites accessed by the term 'ways to kill yourself' tended to have a negative tone. 314 websites were included in analysis, with evocative images of self-harm found in 20.7% of sites.

	of a CAMHs users group aged 15-19.	
Category perspectives		User
Jacob [9], 2017, UK, high.	To explore how young people understand and use online images of self-harm using semi-structured interviews. 21 individuals aged 16-24, living in Wales UK with a previous history of self-harm. Mean age for self-harm commencement was 13. Sixteen participants sought professional help, 8 presented to emergency departments for their injuries; 85.7% female.	Some individuals cited the internet as a catalyst in the development of self-harm, where individuals were searching for advice and support and self-harm had 'just come up' in the search with instructions and images. The majority engaged with online spaces to support and further develop a pre-existing set of self-harming practices and reported the role of the internet in normalising self-harm. Image rather than text-based interactions were the primary reason cited for using the internet for self-harm related purposes. Images were said to invoke a physical reaction and inspire behavioural enactment. Participants reported viewing self-harm images as part of a ritualistic practice.
Seko [28], 2015, multiple countries, high.	To conduct qualitative analysis of online interviews with individuals who produce self-harm content. To understand why content creators create and share self-harm themed content and what needs are met by doing so. Creators of self-harm creative content, N=17; 85.7% female.	Thematic analysis of participants' narratives identified two prominent motives; self-oriented motivation (to express self and creativity, to reflect on self-harm experience, to mitigate self-destructive urges) and social motivation (to support similar others, to seek out peers, to raise social awareness). Participants also reported a double-edged impact of self-harm content both as a trigger and a deterrent to self-harm.
Sternudd [29], 2012, Multiple countries, moderate.	To examine discourses about self-injury photos from a user's perspective using online questionnaires. Users of self-injury forum: n=52; 86.5% female.	Informants reported that viewing/sharing images had alleviating rather than triggering effects with production of images often about memory and proof, and publishing them seen as a way of sharing experiences with others, and to give/receive help. Self-injury photos described as a resource of a self-harm community culture. Informants often emphasized that the outcome of viewing these photos varies due to individual and situational differences.
Category interventions		Video
Choi [32], 2016, USA, moderate.	To determine the feasibility of using a specific video in a web-based suicide awareness programme for Asian American and non-Hispanic white college students. University students: n=431; 78.4% female.	Asian Americans rated the suicide awareness video significantly lower for cultural relevance than did non-Hispanic whites. Collectivist cultural orientation was a significant predictor for cultural relevance, credibility, and appeal. Cultural orientation and race/ethnicity should be strongly considered when web-based suicide awareness programmes are developed for college students.
Park [31], 2014, USA, high.	To determine the predictors of watching a web-based suicide prevention video and whether data characteristics differed for those watching most or only part of the video. University students: n=650; 71.8% female.	When examining characteristics of individuals who watched a suicide prevention video (which included self-harm content) the video completion group included more females, undergraduates and Asian Americans, and had higher individualistic orientation, and more correct manipulation check answers. The video non-completion group skipped items in a

		purposeful manner, showed less interest in the video, and spent less time completing questionnaires.
Robinson [33], 2015, Australia, moderate.	To examine the safety and acceptability of an online suicide prevention programme, and determine which components were found to be most helpful and enjoyable. Secondary school students: n=21; 81.0% female.	21 young people completed the intervention. Overall, the intervention did not lead to increases in suicidal ideation or distress. Participants reported enjoying the programme, in particular watching the video diaries, and completing the activities. Most participants said they would recommend the programme to a friend.
Scherr [30], 2017, Germany, moderate.	To examine the impact of a suicide awareness video on adherence to newspaper reporting guidelines; video intended to be utilised for web-based format. Journalism students: n=78; 69.2% female.	Awareness material exposure helped to improve responsible reporting of suicide, with the awareness video showing a stronger effect than written material alone.
Analysis of same set of YouTube videos one study examining content of videos themselves the other analysing the comments		

Ethical approvals

Ethical approval was stated as unnecessary in five of the 13 articles examining content across platforms due to the public nature of the internet sources. Three of the 13 articles stated they had received Institutional Review Board ethical approval and only six included any discussion of ethical issues, such as protecting individual identities or sensitivity in disseminating results, even though the content was likely to have been created by potentially vulnerable children and young people.

Platforms

Image-based platforms

Two studies examined self-harm content on Instagram [34,35]. Both found considerable self-harm image related content. One examined photographs of self-harm over a four-week period, investigating the nature of the pictures, associated comments and timing of posting behaviour [34]. Most photographs depicted wounds rated as of mild or moderate severity. Pictures were generally posted in the evenings. Most comments on self-harm related posts were part of a more general discussion (n=3291, 49.5%), with 11.6% (n=770) asking the user to stop self-harming [34]. One study examined Tumblr posts [36]. Posts that were comforting, supportive or related to prevention made up 8.0% (n=220) of all posts. Posts interacting with other users made up 9.1%(n=249), of which 47.0% (117/249) provided emotional support and 51.0%(127/249) were seeking or providing advice. Of those seeking or providing advice 40.9%(52/127) provided positive/supportive advice while 25.1%(32/127) provided potentially harmful advice, including advice on concealment.

One qualitative interview study found that Tumblr was often reported as the preferred platform, due to ease of searching for and sharing of images, perceived anonymity and lack of moderation compared with other social media sites. This freedom to access and post severe images of self-harm was reported to lead to normalisation and exacerbation of self-harm for some participants [9].

Video-based platforms

Seven studies (eight articles) [2,6,27,37-41] analysed YouTube videos, of which three (four articles) focused on self-harm related videos [2,6,27,37]. While visual representations of self-harm were common, two fifths of YouTube videos in one study exhibited a message encouraging help-seeking [2]. Analysis of 100 videos found that 53.0% were educational, often discouraging self-harm (26.0%) [6]. Comments on this set of videos were mostly sharing personal experiences (38.3%) [27]. There were no significant differences in the types of comments based on number of views, rating or type of videos. An examination of videos concerning self-harm first aid tips found 28.0% of videos included a disclaimer indicating that self-harm is 'acceptable' providing certain safety precautions were followed [37]. Other YouTube videos varied in content, including 'fire challenge' videos in which an individual doused themselves in a flammable liquid, set themselves alight and attempted to extinguish the flames before serious burns are inflicted [38]. This was one of only two studies [38,39] included in this review where the majority of participants were male (90.0% n=45).

An analysis of Twitter posts found images and videos related to self-harm, but these were not graphic in nature [42] and included images of celebrity tattoos covering self-harm scars with the message 'stay strong.' These images were shared with positive messages of growth and recovery. Video links tended to be of individuals sharing their own stories.

Use of hashtags

Moreno, Ton [35] examined the nature of ambiguous self-harm related hashtags (e.g. #selfharmmm). At the time of this study, Instagram's terms of use (since revised [21]) blocked users from searching for the hashtag #selfharm. As a result, a number of ambiguous hashtags emerged in order to bypass restrictions. The hashtag #selfharmmm was used to identify a number of other ambiguous hashtags linked to self-harm related content. Such hashtags included #blithe, #selfinjury and #ehtilb. The number of search results for each hashtag grew substantially over 150 days. Search results revealed a wider group of hashtags #mysecretfamily present across platforms referring to a range of mental health issues of which #cat represented self-harm.

Graphic imagery

Images rather than text-based interactions were reported as the primary reason for using the internet for self-harm purposes in semi-structured interviews [9]. The nature of images was important in terms of outcomes. It was commonly expressed that 'bluntly gruesome' photos [29] (e.g. flesh, open wounds, blood), were more triggering than pictures of scars and healing wounds [28]. Results from internet searches varied based on the search terms used, with the term 'ways to kill yourself' eliciting a high proportion of sites with evocative images (46.5%, n=20) [7]. Platforms varied in the degree of graphic imagery. Visual representations of self-harm were common on YouTube. The majority of videos showed severe and open wounds and acute scarification, and one video portrayed three clips of suicide attempts [2]. Analysis of 100 videos similarly showed that Images of self-harm were common (64.0% of videos), with 28.0% of character videos depicting live acts of self-harm [6]. A large number of self-harm images are posted daily on Instagram. Of 2826 self-harm images examined in one study, 39.6% were rated as mild in severity (i.e. superficial scratches), 47.8% as moderate (i.e. deeper cut, blood flowing) and 12.6% as severe (i.e. very deep cut/large amount of deeper cuts and blood), with 93.1% of

images depicting cuts [34]. In another study, 17.7%(n=127) of Tumblr posts about self-harm/suicide were graphic images or video clips [36].

A range of emotional reactions and impacts to the viewing/sharing of images/videos have been described (Table 2).

Table 18 Summary of emotional reaction and impacts of viewing and/or sharing videos and/or images

Impact of image or video		Findings reported
Anger/hostility		Spoof advertisement on Twitter for stick-on self-harm scars evoked reactions of anger and frustration [42] Some hostile comments about an uploader of self-harm content (6.5%) were found in comments of YouTube videos [27] A small percentage of comments of self-harm related Instagram posts were coded as abuse (6.8%, n=450) [34]
Other emotions		The reaction from viewing self-harm photographs varied considerably between informants and may be dependent on the individuals' state of mind when they are viewed. A wide range of feelings were covered in responses, including being sad, sick, and shocked. Reactions like depression, grief, and concern for themselves was stated [29] Common reactions reported after viewing a suicide prevention video included sadness, surprise and shock, and feeling overwhelmed. Almost 40% of participants indicated that they were most affected by the real, personal stories of family and friends of those who had taken their own lives (particularly the impact of suicide on the lives of the people left behind) or individuals who had survived a suicide attempt [32]
Ambivalence		Dramatic responses are not always reported when viewing self-injury photos, with some reporting it can be done to pass time [29]
Exacerbation of self-harm urges/behaviour	<i>Triggering</i>	Nearly three quarters of interview participants reported that imagery (notably photographs) were the primary reason for their utilisation of the internet, due to a powerful physical reaction that triggered the desire to self-harm. Reliance on the image as a trigger had led to images assuming a vital role within their ritualistic practice with 'sessions' often commencing with retrieval of an online image. The power of the image primarily centred on their ability to 'bring back memories' of previous self-harm or the ease with which they allowed the individual to envisage how others experience the act. Participants also reported looking at images deliberately to trigger more severe self-harm [9] Participants often discussed the triggering role of images. Many stated that whether an image would trigger an act depended on mood at the time. It was commonly expressed that photographs of flesh, open wounds with blood are more triggering than pictures of scars and healing wounds [28] About one third of participants describe the outcome of viewing photographs as triggering, with 'bluntly gruesome' photographs described as the most triggering content [29]
	<i>Competition</i>	Participants spoke of being inspired to recreate certain sets of practices presented by particular images. Discussion was characterised by a sense of competition with individuals desiring to emulate the depicted self-harm whilst chiding themselves when they failed to engage with more sophisticated and severe techniques [9]
	<i>Imitation</i>	Pictures depicting wounds generated around twice as many comments from users than pictures not depicting. There was also a significant association between wound grade and number of comments [34]. Time related analyses did not support any effects of contagion or reinforcement [34,39] Participants reported that a lack of moderation on Tumblr and the freedom to view and share the most stark and severe images had led to normalisation and exacerbation of self-harm. One participant stated that their self-harm had escalated from little gashes to severe injuries and cutting through arteries [9]
Reduction in self-harm urges	<i>Calming</i>	Participants reported self-harm photographs as providing a sense of vicarious relief and of viewing photos to calm themselves when feeling triggered [28]

		Reactions to self-harm images were described as comforting or calming in nearly half of statements [29]
	<i>Use as a deterrent</i>	Some participants stated that self-harm photographs of severe injuries acted as a deterrent of self-harm. Participants reported using this as a pre-emptive strategy to avoid more severe self-injury [28]. One participant described viewing of severe injuries as making them feel nauseated, serving as a strategy to avoid more severe self-harm [28]
	<i>Emotional outlet</i>	Content creation, particularly artistic or creative content was described as an emotional outlet to disclose negative emotions, distress, and aspects of the self otherwise difficult to express. This was reported, at times, to reduce self-harm urges by acting as a distraction or alternative to self-harm [28] Some participants reported that looking at content helped them reflect on their experience, make sense of it, and potentially avoid further episodes. Creation of content was reported to reduce self-harm urges serving as a creative alternative [28]. Participants reported viewing images made them feel less alone helping to curb NSSI urges. Feelings of relief were reported with photographs reducing urges to self-harm.
Connection with others	<i>Empathy</i>	Empathetic comments made up (23.5%) of comments on Instagram posts [34]. Many participants spoke of feeling empathy with content creators when viewing images related to self-harm. Several participants also addressed the internet as their only source of support or connection where they could receive empathetic reactions and emotional support [28]. Empathy, and sympathy were common reactions to a suicide prevention video [32]
	<i>Solidarity and reduction in loneliness</i>	Participants reported the viewing of photographs as comforting since they made them feel less alone [28,29]. Participants describe feeling less alone in their battle as a motivation for sharing images [29]
	<i>Giving and receiving help</i>	The motivation to support like-minded people was often described as going hand in hand with a desire for help [28] Warnings asking user to stop behaviour were present in comments on Instagram posts (11.6%), as were offers of help (6.9%) [34] 51.0% of interactive Tumblr posts involve seeking or providing advice, of which 40.9% provided positive support/advice (e.g. encouragement in stopping self-harm), and 25.1% provided potentially harmful advice (e.g. advising how to secretly engage in self-harm), with 13.4% suggesting professional help or therapy ³⁶ An equal number of comments on YouTube videos asked for help or offered help (2.6%), and a small number encouraged the uploader to seek help (2.4%) [27] Participants who watched a suicide prevention video expressed a higher awareness of the need to watch for signs of depression to be able to help friends and the need to take immediate action, take depression seriously and talk openly about suicide [32] 9.1% of Tumblr posts involved directly interacting with another user. Of these, 47.0% provided emotional support or reassuring messages to one another [36]
Feedback or discussion of creative content		Creators of creative content expected constructive criticism from their viewers to improve their artistic skill, and positive feelings were reported when content received comments or was re-blogged [28] High levels of feedback were given or received for video content. Admiration of video quality (22.0%) and videos message (17.0%), and validation and admiration for the individual who uploaded the video (15.4%) [27]. Very few Instagram comments complimented the wound or image (0.5%) [34]

Negative reactions and impacts

Anger and hostility in response to images/videos were reported in three studies [27,34,42]. Other emotional reactions included sadness, shock and concern [29,32]. Some described ambivalence or simply viewing photographs to pass time [29]. Images having the potential to exacerbate self-harm through triggering, normalisation, competition or imitation were also described [9,28,29].

Triggering

The triggering role of imagery was reported in three qualitative interview studies [9,28,29]. A third of participants reported that photographs triggered self-harm urges [29]. Participants reported viewing of images as part of a ritualistic practice to be triggered before harming themselves, in order to self-harm more severely [9]. Both triggering and alleviating effects of images were reported [29]. Whether material was triggering was said to be dependent on mood. If an individual was already determined to self-harm then looking at images would encourage urge whereas if they were in a positive mood the images would have minimal impact [28].

Normalisation and competition

There were reports of online engagement exacerbating self-harm due to normalisation and exposure [9]. A sense of competition was reported in all three qualitative interview studies [9,28,29], with individuals desiring to emulate the depicted harm whilst chiding themselves or receiving negative comments from others when they failed to engage with more sophisticated and severe techniques [9]. Participants reported negative feelings regarding failure to harm themselves as severely as the injuries shown in photographs [28]. There were also reports of needing to make wounds worse to be a valid 'self-injurer' [29]. A strong correlation between male informants and negative statements was found in one study, with 80.0% of statements expressing competitive reactions [29].

Imitation

Brown, Fischer [34] examined several possible markers of imitative behaviour on Instagram, including comments on photographs and a time-related analysis of posts. Pictures directly depicting wounds generated twice as many comments as those not depicting wounds [34]. A significant association was also seen between wound grade and number of comments, which could indicate a socially reinforcing function of posts. However, time-related analysis of images did not indicate any effects of imitation or reinforcement [34]. A separate time series analysis did not find an increase in average monthly emergency department visits for suicide-related diagnoses in Ontario children aged 11-17 following posting and publicity of a young person's YouTube video who took their own life [39]. This showed the young person holding up cards telling a story of bullying, mental health issues and self-harm, with an image of self-harm injuries at the end.

Positive reactions and impacts

Production of images was often about memory and proof, with photos forming part of a narrative likened to fading scars. Individuals reported taking photographs for artistic value or their own interest [29]. A reduction in self-harm urges was reported with content creation said to act as an alternative outlet for negative emotions, with the viewing of images acting as a placebo or deterrent [28]. Those who create drawings, poems and videos in particular called the materials a form of art that portrays the feelings behind self-harm, with positive feelings reported when content was re-blogged [28].

Reactions of empathy, sympathy and of people both giving and receiving help were found across various platforms [28,32,34]. Self-harm photographs were described as a resource for the self-harm community and were said to provide a feeling of solidarity and reassurance of not being alone [28,29].

Prevention and intervention

Trigger warnings

Three studies (four articles) exploring the content of images/videos included an analysis of trigger warnings. These are placed on content by either the uploader, moderator or platform and are intended as a warning to individuals who may find that the images increase the urge to self-harm. Two articles (based on a single dataset of 100 videos) reported that 58.0% of YouTube videos related to self-harm did not warn about content [6,27]. Just two of 40 self-harm first-aid videos contained such a warning [37]. In an assessment of self-harm across different platforms, two peer-moderated and three professionally-driven sites were examined. Both peer-moderated sites were found to contain trigger warnings. The professionally-driven websites did not contain any graphic material so no trigger warnings were present. Trigger warnings were present on four of five YouTube videos included in this study. Of the five Myspace groups examined three contained trigger warnings and two prohibited self-harm images. Only one of four Facebook groups contained a trigger warning, despite the presence of photos and videos in the majority of groups [2].

Alongside user-generated trigger warnings are content advisory warnings on some platforms. Searches for self-harm-related content on Tumblr first provided a screen with suggestions for seeking help or finding more inspirational content, with the option to proceed to the next screen to view the search results [36]. Of 18 self-harm related hashtags, six generated a warning label on Instagram [35].

Recovery-oriented content

Recovery-oriented content was seen in varying degrees across platforms. Among Tumblr posts providing advice only 13.4% (17/127) suggested professional help or therapy [36] and 2.4% of comments on YouTube videos encouraged the uploader to seek help [27]. Some comments indicated that the individual was seeking treatment (9.6%), had recovered (7.1%) or expressed a desire to recover (3.8%) [27]. Recovery-oriented content appeared to be most evident on Twitter, with inspirational quotes and stories of recovery [42].

Interventions

The safety and acceptability of an online suicide prevention programme incorporating video elements in secondary school students was examined in one study [33]. Overall, the intervention did not lead to increases in suicidal ideation or distress and 71.4% of participants rated the video diary component as more enjoyable and helpful than hearing from website moderators or receiving text messages [33]. The impact of a suicide awareness video as part of a web-based intervention to increase adherence to newspaper reporting guidelines in journalism students was examined in another study. Awareness material exposure with or without the video helped to improve responsible reporting of suicide with the awareness video showing the strongest effect [30].

Two studies examined different aspects of 'The truth about suicide' suicide awareness video. Both studies found video streaming a feasible method for delivering a suicide awareness programme to college students [31,32]. Predictors of watching the 29-minute video to completion were female gender, undergraduate, Asian ethnicity and higher individualism as opposed to collectivism [31], measured using the individualism-collectivism questionnaire [43]. Asian American students rated the video significantly lower on cultural relevance than non-

white Hispanic students [32]. Following viewing of the video participants expressed a higher awareness of the signs of depression, the need to take immediate action and to talk openly about suicide [32]. Small increases in distress were found [31]. The importance of an effective debriefing session in a safe and confidential setting for sharing thoughts, feelings and experiences, and to prevent iatrogenic effects of web-based suicide prevention programmes using emotionally charged videos was emphasised and successfully delivered online [32].

Discussion

We have conducted a systematic review of the literature related to the impact of sharing/viewing self-harm images/videos online, exploring intent and interpretation in young people. Nineteen studies (20 articles) were included. No previous review has focussed on this area [18,19]. We have identified specific features of platforms that contribute to potentially harmful use and of images that may influence the impact on the viewer/sharer.

There has been a move away from the once popular self-harm forums to other platforms in recent years in terms of use by both individuals and researchers [9,44]. There has also been an increase in graphic imagery identified by self-harm-related searches over time [11] and participants report image-based rather than textual interactions as the primary reason for internet use [9]. Studies consistently report a large presence of graphic imagery of self-harm on image-based platforms such as Instagram and Tumblr. In contrast, there is less graphic imagery present on Twitter and a greater presence of recovery-oriented content [42]. The difference between platforms was further supported by an analysis of randomly generated posts found with the #cutting hashtag. Instagram posts were found to display the greatest proportion of graphic content, with the smallest proportions found on Twitter [45]. Recovery-oriented resources were congregated on the platforms with the least problematic content. Potentially harmful content appeared to congregate on platforms that have relatively little moderation, where participants can remain anonymous and search for images easily [9].

A range of reactions and intentions were reported in relation to posting or viewing images of self-harm; from empathy, solidarity and the use of images to give or receive help (e.g. [28, 34]) to potentially harmful advice suggesting new methods and tips for hiding self-harm, as well as normalisation and exacerbation of self-harm [9,29]. Viewing images as an alternative to self-harm and as a creative outlet were regarded in two studies to be positive impacts [28,29]. Reactions of anger, hostility and ambivalence to posting of self-harm images were also reported [27,34,42].

Self-harm images were reported to be part of a ritualistic practice by all three studies examining user perspectives. Participants reported viewing graphic imagery online to evoke the right mood for self-harm, often resulting in more severe injuries [9]. Photographs of fading scars or creative content are most often reported to have a positive impact [28,29]. Photographs of fresh cuts or severe injuries are most frequently reported to have a negative impact [9]. Participants reported that viewing more severe injuries leads to negative feelings for failure to achieve the same level of injury or more severe injuries over time [9,29].

While there was some evidence of a role of imitation and reinforcement, driven partly by numbers of comments generated by self-harm imagery and wound severity [9,34], this was not supported by time series analyses [34,39]. However, images can be searched or viewed long after they are posted, so any process of reinforcement is difficult to assess. While time-related analyses do not suggest social contagion in these studies, recent studies relating to the release

of the TV series *13 Reasons Why* in which the suicide of a young female is graphically depicted has been found to be associated with a significant increase in adolescent suicide rates [46] concordant with the period in which social media discussions of the series were greatest [47]. The graphic scene has been removed following concerns expressed by suicide prevention agencies.

Strengths and limitations

This study provides a comprehensive overview of studies directly examining self-harm imagery/videos online with relation to children and young people. The potential for publication bias exists in any review of the literature. Steps were taken to minimise bias, including: conducting an extensive literature search of multiple databases including topic specific websites and reviewing reference lists; titles and abstracts being screened by two researchers; and data extraction being conducted by two researchers for each article. Only English language publications were included. Females outnumber males, where this information was available, in all but two studies, one of videos related to the fire challenge [38] and a time-series analysis of emergency department attendance [39]. One study reported that males were more likely than females to report negative impacts of self-harm images [29]. However, the limited number of males included makes it difficult to draw firm conclusions. Further research into potential sex differences and involving larger samples of males is needed.

Accurately determining the characteristics of young people based on online profiles is not always possible. The average age of participants is likely to have been younger than reported since young people often misrepresent their age to gain access to restricted content [6]. Finally, while self-harm presentations by young people to general hospitals most commonly involve self-poisoning [48], this method of self-harm rarely featured in the images appearing on the internet. Thus the images that are found largely reflect self-harming behaviour most frequently occurring in young people in the community [48], although accessing internet sources before self-harm is common in young people who present to hospital following self-poisoning [49].

Implications

Clinicians working with young people who self-harm should routinely enquire about internet use [49], support them to recognise and manage triggering content and encourage healthier online behaviours. The powerful role of imagery in evoking emotional reactions and motivating both potentially harmful behaviours such as self-harm [16] and adaptive behaviour [50] could make this an important factor in recovery.

Since young people are frequently creating their own content, guidance to increase safe and responsible depiction of suicide/self-harm image and video based content are now needed to educate young people, as well as, media professionals. A small number of studies examined the use of videos disseminated online as a means of intervention. Given the large self-harm community utilising image/video-based platforms, further research into potential interventions is needed to understand how to maximise effectiveness. Content creation can act as an alternative outlet for negative emotions, and the viewing of images acting as a placebo or deterrent, could be explored as potential interventions. Increasingly it is being suggested that educational programmes should be developed to inform young people about the impact of the post content and how to respond to distressed posts [2,51]. This has

potential to prevent suicide contagion via social media. The use of videos in suicide prevention programmes appeared to be promising, not just for young people themselves but also in improving responsible reporting of suicide in journalism students [30]. The importance of cultural relevance of prevention videos was emphasized [31].

Individuals reported an awareness of the potential impacts of self-harm images/videos and added trigger warnings to their own posts [9]. Automated platform content warnings may not have been sufficient [35]. Our results should be discussed in the context of recent changes in policy by platforms, including Facebook [52] and Instagram [21] regarding the posting of graphic self-harm imagery. Changes were made following the death of a young person in the UK in February 2019 and the subsequent campaign by the family. Instagram announced a ban on all images of self-harm, including pictures showing scars [21]. Particular features of platforms that make them more amenable to harmful use include a lack of moderation and ease of sharing, searching and viewing of images [9]. Monitoring and regulations of posts may be a positive move towards making these spaces safer. However, young people often find ways around posting restrictions, such as by utilising ambiguous hashtags [35] or moving to more hidden parts of the internet.

The potential for posting restrictions to reduce positive impacts, such as support and a sense of community, must also be considered as should any potential negative impacts of removal of content posted by vulnerable young people without consultation. Banning images of scars may have the unintended consequence of increasing stigma or removing from individuals the opportunity to share their stories, including those related to recovery. The indiscriminate removal or blurring of images of people with injuries and scars, will include those not related to self-harm and could negate the potentially positive impact of fading or healing self-harm scars. While the results of this review support concerns related to safety and exacerbation of self-harm, the potential for positive impacts should not be underestimated. Future research should seek to evaluate the effectiveness of current posting restrictions and to identify the best strategies to reduce risk and maximise positive impacts on participants, incorporating user perspectives. This supports previous calls to better understand how to leverage the unique opportunities afforded by such platforms to reach and engage vulnerable individuals [45].

We identified no studies examining the role of Google images, which has not seen the same restrictions applied to searches for self-harm imagery as social media platforms. There is no social community or moderation on Google images. Neither do Google images incorporate the same tools that exist on its main search engine ensuring results related to helplines and information appear at the top of search results for suicide and self-harm. Typing 'self-harm' into google images brings up a collection of images from across other sites. This is a powerful tool and appears not to have been the focus of this kind of research or policy intervention.

Careful consideration should also be paid to the ethical issues of conducting research on freely available content and the associated implied consent. Future research should ensure recruitment of males and focus on delineating the specific features of images that may be harmful and the mechanisms involved.

Conclusion

The way in which young people use the internet is continually evolving. An increasing preference is being reported for use of the internet for image-rather than text-based

interaction in regards to self-harm. Concerns over negative impacts such as exacerbation and normalisation of self-harm, and sharing of information on new methods or concealment of self-harm are supported by research. However, there can also be positive impacts such as seeking and receiving peer support, viewing images as an alternative to self-harm and as an outlet for negative feelings. Graphic images and photographs of severe injuries are most often reported to have a negative impact. Clinicians assessing distressed young people should routinely enquire about internet use, explore strategies to manage any triggering content and be aware of helpful sites. The use of images/videos as part of online interventions for suicide prevention is an area worthy of further study. Future research should also seek to evaluate the effectiveness of current posting restrictions on social media and to educate clinicians and caregivers on how to encourage healthier online behaviours.

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APPENDIX D: DATA EXTRACTION SHEET FOR REVIEW TWO

Author/Year	
Title	
Paper category	
Aims	
Results	
Participant description	
Inclusion/exclusion criteria	
n	
Age range	
Mean age	
SD	
Gender %Female	
Groupings	
Locality	
Country	
Recruitment method ie; random (hence representative)	
Data collection method	
Study design	
Time: Period of the study and follow up	
Measures	
Ethical permission	
Do participants have a history of mental health issues	
Mental health diagnoses subgroup	
Do participants have history of self-harm/suicide attempt/ideation	
What are the subgroups of the problem ie; self-harm/ideation/previous attempt	
Were participants medicated	
Did participants have any relation to other self-harmer/ family member who had committed suicide?	
What was the frequency of internet use?	
What was the internet medium in question ie; website/forum/email/social networking site?	
What was the platform studied (e.g. Instagram, Twitter, Facebook)	
Analysis of images, videos or both	
Description of images/videos	
Number of images/videos in sample	
Number included/excluded	
Trigger warnings	
Help/warning message from platform	
Was there any analysis of comments sections	
Summary of results of comments sections analysis	
Were the any positive impacts of videos/images	
Description of positive impacts	
Were the any negative impacts of videos/images	
Description of negative impacts	
Were the any other impacts of videos/images that may not be considered positive or negative	
Description of other impacts	

Did change occur in the participants? If so what? (ie; coping/thoughts and feelings/support/isolation/ behavioural change (suicide ideation/self-harming behavior) Please include size of effects	
What were the mechanisms of change? Did the authors find a mechanism or hypothesize one?	
How did participants reach the internet medium in question ie; web site/forum etc.	
What were the reasons for use of the medium?	
Is the internet medium professionally or peer moderated	
Is any information missing that the author needs to be contacted for? If so what?	
CASP quality score	
Authors email	
Notes	

APPENDIX E: SHARE UK PARTICIPANT INFORMATION, CONSENT FORM AND DEBRIEF

Participant information sheet

About this project

The aim of this project to learn more about self-harm, its impact on individuals and the support people may need. Self-harm refers to deliberate self-injury or poisoning regardless of suicidal intent.

How many people in the UK self-harm?

How does this impact their lives?

What help and support do people who self-harm need?

The answers to these and many other fundamental questions are largely unknown. It's time we increased our knowledge and understanding and for this we need your help.

Everyone is different and this is why your story is so important to us. By contributing to this research you will be directly involved in generating new research and informing help for others.

What's involved?

If you are aged over 16, living in the UK and have ever harmed yourself in any way we need your story for this ground breaking study.

Once you have completed the registration you will have the option to complete a set of questionnaires. If you decide at any time you no longer want to complete a questionnaire just hit the 'quit' button. You are free to do this at any time and you won't be expected to give a reason.

While we are not able to provide information on individual responses we will make findings of this research available on the web-portal so you can see how your contribution is really making a difference.

We are also interested in what information, support or advice for self-harm you consult online. This can be anything including hashtags and Facebook groups, online news reports, YouTube channels and videos, dedicated forums and websites. We are interested in the good and the bad and the more sources you can tell us about the better. To do this, simply consent to partaking in research on this page and follow the 'pin media' link on your homepage to contribute.

Your privacy

The security of your information is our priority. The information you provide through this website will only be used for the purpose of this research project. All data will be fully anonymized and stored on our secure encrypted server only accessible to members of the research team. Any personal details will be stored separately from your questionnaire responses and media databank uploads, meaning your details won't be linked with anything you tell us here. We will never share any of your information with anyone outside of our research team without your consent.

The information that you enter through online questionnaires is anonymized and encrypted and this information will not be linked with any personal information – so when our researchers are reading your responses they won't be able to identify you

If at any point, you decide you no longer want to take part just let us know. Although the information you have given us through online questionnaires and the media databank will remain in our databank, we will delete all of your personal information.

Consent to participation in research via the web portal here – this will be mandatory to progress

Participants will also be asked to confirm their age here via a popup asking for confirmation and date of birth

Future studies

If you are happy for us to contact you to partake in future studies please check the option below. This is entirely optional and you are still welcome to complete the questionnaires here and contribute to the media databank whether you would like to contribute to any future research or not. By checking this box you are consenting to being contacted by the research team about future studies. These details will only be used for by our team for research purposes and we will never pass on your contact details.

Consent to contact for future studies here – optional

Routine NHS information

The NHS supplies us with anonymous information relating to emergency department attendances, hospital admissions and general practice visits for residents of Wales. The NHS does this in order to contribute to research that will ultimately improve the healthcare it delivers. In addition the SAIL databank at Swansea University is able to link this information with other sources such as education and office of national statistics data. Just like the information gathered via questionnaires this data is fully anonymized and encrypted. Please consent below if you are happy for your questionnaire data to be linked with routine data in the SAIL databank.

All NHS/SAIL data are separated from personal data so **no one will be able to identify you** from this information.

For more information regarding this data please see www.saildatabank.com

Consent to SAIL databank here - optional

Questions? See our FAQ page or contact us (link to contact us page)

Participant Debrief

Thank you for taking part in this research – all the information you give us is so important to informing future research

While we are not able to provide information on individual responses we will make findings of this research available on the web-portal so you can see how your contribution is really making a difference

If you have been affected by taking part in this research in anyway or just need someone to talk to please get in contact with the Samaritans on 116 123 – They're available 24 hours a day 365 days a year – if there is something troubling you then please get in touch

If you want to talk to someone immediately then please telephone using the number above. However support is also available via email at jo@samaritans.org

Further information can be found on their website www.samaritans.org

Just having someone to talk to that isn't family or friends can be a tremendous help. You don't have to be suicidal to get in touch

If you have any further questions about this research then get in touch with the research team via the contact us page. We are only able to respond to questions relating to the research itself.

If you no longer want to be involved in this research then click below to have your personal details removed from our database

Thank you again for taking part! Your story is so valuable to making a real difference

APPENDIX F: MEDIA DATABANK CODING FRAME

Coding item	Definition
Type	Social media site, website, app
Subtype	If relevant e.g. closed groups, hashtags searched
Site name	Name of social media site or web address of landing page of site
Centred around images	Whether or not the main focus of the site is viewing or sharing of images/videos such as for Instagram and YouTube
Access	Any restrictions on access such as registration or age restrictions
Organisation	Charity, individual, academic, professional ect
Moderation	Where relevant was the site moderated and whether site was peer or professionally moderated
Interactive component	Whether there is an interactive component and nature of this, e.g. discussion forum, image gallery
Links to other content	Presence of absence of links
Nature of links	Brief description of any links
Trigger warning	Presence or absence of a trigger warning
Graphic self-harm imagery	Presence or absence of self-harm imagery that is graphic in nature, for example wounds, scars etc
Self-harm imagery description	Description of self-harm imagery
Creative content	Presence or absence of creative content such as drawings or poetry
Creative content description	Description of creative content
Tone	Defined as positive if a site provided helpful information, advice on how to seek help or advised against self-harm; negative if pro-self-harm/suicide information was given; neutral if the site provided factual information without explicit preventative or pro-suicide content; and as joking if the site made fun of either real or fictional methods of self-harm/suicidal behaviour.
Other content	Content related to other issues besides self-harm such as mental health diagnoses, LGBTQ+, substance misuse and abuse
Age of target audience	If specified
Purpose of site	e.g. information giving, advice, support, pro self-harm/suicide
Discrepancy with participant report	

APPENDIX G: BIG DATA AND MENTAL HEALTH RESEARCH

SURVEYPARTICIPANT INFORMATION, CONSENT AND DEBRIEF

Participant information and consent

About this project

Here at SHARE UK and ADP we are undertaking a research study to hear your views about how future research can answer the questions that matter to you. The will help us to push for the changes that will make the biggest difference in the real world. Your experiences and stories are so valuable. By taking part in this study you will be actively shaping future research and informing future change.

What's involved?

This study will involve giving us your views on a number of issues. We will send you a set of questions by email. You are free to answer these in your own time in as much or as little detail as you like. All questions are optional and if you don't want to answer one you can just leave it blank. Once you have replied with your answers we may send you another email with some follow-up questions. If you prefer for us not to email with any follow-up questions add the word 'stop' to your reply or simply email the word 'stop' to shareuk@swansea.ac.uk at any time.

To take part you must be aged 16 or over and have experienced self-harm at any time in your life.

Taking part in this study completely voluntary and there are no consequences if you decide not to take part. You are also free to stop participating at any time without penalty. Simply reply to any emails with the word 'stop'.

Please be aware that the SHARE UK email inbox is not manned 24 hours a day and we are not able to offer crisis support.

If you feel distressed at any time while answering the questions then please stop and contact a source of help such as Samaritans 24 helpline or email service (116 123, jo@samaritans.org).

Privacy protection

Your privacy and safety of your information is our priority. All of the information collected is confidential and your identity will be protected at all times. Data will be securely stored at Swansea University. All personal information will be separated from responses to questions and destroyed. Anonymized findings from this study will be used to publish and share research, however all personal or potentially identifying information will be removed.

We will never pass any information onto anyone else.

If you have any questions or would like a copy of this form please contact shareuk@swansea.ac.uk

Thank you for taking part – your help makes such a big difference.

Consent

1. I confirm that I am aged 16 or over.

2. I agree to take part in this study. I confirm that I have read and understand the study information and that I am participating voluntarily.

Tick box for consent and box to add email address

3. I understand that I can withdraw from this study at any time without any penalty or consequences.
4. I have been informed that information I provide will be safeguarded.
5. I am happy for the information I provide to be used anonymously in academic papers and research outputs.
6. Please check here if you would like to be contacted for future research studies. This information will only be used by our study team and we will never pass your information on to anyone else.

Participant Debrief

Thank you for taking part in this study. Your stories and experiences are so important to shaping future research.

While we are not able to provide information on individual responses we can send you summaries of findings in our newsletter so you can see how your contribution is really making a difference.

If you have been affected by taking part in the research in any way or just need someone to talk to please get in contact with the Samaritans on 116 123. They are available 24 hours a day 365 days a year. If you want to talk to someone immediately then please phone the number above. However online support is also available via email at jo@samaritans.org

Further information can be found on their website www.samaritans.org

Just having someone to talk to can be a tremendous help. You don't have to be suicidal to get in touch.

If you have any further questions about this research then you can contact us at shareuk@swansea.ac.uk . Please note that we are not able to offer crisis support.

Thank you again for taking part! Your story is so valuable to making a real difference.

APPENDIX H: COPY OF BIG DATA AND MENTAL HEALTH RESEARCH SURVEY

Instructions for participants

Below are a series of questions looking to learn more about you and your views on how we can improve research and better push for change.

There are no right or wrong answers and you don't need to worry about spelling or grammar – what is really important are your stories and views.

There is no recommended length for answers and you are free to give as much or as little detail as you like. The more you can tell us the better and if you feel able to give detailed answers, this is great as it will give us even more to work with.

All questions are optional and if you do not want to answer a particular question then just leave it blank.

Topic area 1: A bit about yourself

Age: Gender: Location: England Wales Scotland NI

Have you ever done any of the following intending to harm yourself (tick all that apply):

Self-injury such as self-cutting, scratching or hitting etc.

Ingesting medication in excess of the normal dose

Swallowing dangerous objects or products

Stopping prescribed medication

Something not listed

Prefer not to answer

1. Have you harmed yourself with the intention to end your life

Yes No Prefer not to answer

2. Was this in the last 12 months

Yes No Prefer not to answer

3. Following any time when you took an overdose or intentionally tried to harm yourself did you (tick all that apply)

Need hospital treatment (e.g. A&E)

See anyone from psychiatric or mental health services, including liaison services

See your GP

Receive help from friends/family/neighbours

Use a helpline/voluntary organization

None of the above

Prefer not to answer

Topic area 2: Your views on research related to mental health or self-harm [free text]

1. What kind of things do you think research should focus on? E.g. the role of the community, schools or the internet [free text response]

2. What kinds of things would put you off taking part in research? [free text response]

3. We are hoping to learn more about the way people prefer to take part in research.
Would you prefer to take part in research
Online
In person
By phone
Other/comments [Space for free text]
4. How would you prefer to answer questions?
Check box
Space to write
Other/comments [Space for free text]
5. Have you ever taken part in research related to self-harm or mental health before? If so could you tell us a bit more about it? What did you or like/dislike
[Free text response]
6. Was there anything you would have liked to ask the researcher but didn't get a chance to?
[Free text response]

Topic area 3: Big Data and your data for research

We want to know more about your feelings on the use of your data for research. We are interested in your feelings about healthcare data and also other personal data such as social media posts. This is only to find out your views. We are not using any other data in this project.

As patients whenever we have contact with GPs or hospitals, data is collected as part of that visit. This data can be anonymized and used for research to help make the health service work better for you and others.

Some projects link things like questionnaire answers from people with this anonymized healthcare information. This can help answer questions like whether watching lots of TV is bad for your health or whether people with certain types of jobs spend more or less time in hospital. This information is looked after very carefully and this type of research is anonymous, held securely and privacy protected.

1. How do you feel about anonymous healthcare data being used for research? [Free text response]
2. Would you like a better explanation of how your data is used and shared for research? [Free text response]
3. How would you feel about researchers linking things like your answers to questionnaires with anonymized healthcare data?
I would be ok with this
I would not be ok with this
Why? [Space for free text]
4. In order to link between research and routine healthcare data some personal details are needed including address and date of birth. These get sent to NHS information partners to make the link. Researchers never see this information and it is destroyed after the link is made. How would you feel about giving personal information such as address and date of birth for this purpose? (You do not have to give this here) [Free text response]

5. How do you feel about your social media posts being used for research? Would the data being anonymized make you feel differently? [Free text response]
6. How about information from companies such as Amazon, Google or Fitbit being used for research? [Free text response]
7. Do you feel differently about research done by universities than that done by companies?
8. It is possible to use tools based on artificial intelligence to help health professionals identify people who may self-harm. This means that health professions can talk to patients about this and offer additional support. How would you feel about artificial intelligence being used in this way?
9. 'How do you feel about the use of Artificial Intelligence, for medical research related to self-harm?
10. Thinking about data more generally (not only health data), how likely would you be to share the following types of data for research purposes (to be answered on a 5-point scale: Extremely unlikely; Somewhat unlikely; neither likely nor unlikely; somewhat likely; extremely likely)
 - Social media posts
 - Physical health data
 - Financial information (e.g. credit rating)
 - Mental health data
 - Employment history
 - Ethnicity
 - Marital status
11. In your opinion, how trustworthy are the following organisations when it comes to storing and using mental health data for research (to be answered on 5 point scale from 'not at trustworthy' to 'very trustworthy')
 - The NHS
 - The UK government
 - Your local authority/council
 - Universities
 - Mental health charities
 - Private companies
 - Devolved governments (e.g. Scottish, Welsh or Northern Irish governments)
12. How would the following measures change the likelihood that you would be willing to share your mental health data for research purposes (to be answered on a 5-point scale: Extremely unlikely; Somewhat unlikely; neither likely nor unlikely; somewhat likely; extremely likely)
 - I would be asked for permission every time someone wanted to look at my data
 - My data would be part of a huge database containing data from many hundreds of other people
 - I would have no control over what my data was used for in the future
 - My name would be removed from all data used for research purposes
 - My data might be matched with other information about me, like records from my school

People using my data would have to do a special training course before they could access it

I would not be able to withdraw my data in the future

13. When thinking about sharing mental health data, to what extent do you disagree or agree with the following statements? To be answered on a 5-point scale: strongly disagree; somewhat disagree; neither agree nor disagree; somewhat agree; strongly agree

Mental health data should be used to understand more about mental illnesses

It should be impossible for mental health data to be linked back to the person who provided it

People should be asked for consent every time a researcher wants to use their data in a new project

People should have the right to opt out of mental health data sharing

I would be less likely to access NHS mental health services if I knew my data might be shared with researchers

It is important that mental health data is held by an organisation I trust

Researchers studying mental health should have advisors with personal experiences of mental health conditions

14. Do you have any other thoughts or comments about how personal/healthcare data is used? [Free text response]

Topic area 4: Things researchers should know

1. Please use this space to tell us anything you think researchers should know. This can be anything you would like to tell us or that you feel could help research going forward
[Free text response]
2. Do you have any other thoughts, comments or suggestions?
[Free text response]

APPENDIX I: SAIL ANALYSIS PUBLISHED MANUSCRIPT

Note this is an embedded pdf. Please click to view in pdf format. Alternatively view as a word document below.

Original research



Self-harm presentation across healthcare settings by sex in young people: an e-cohort study using routinely collected linked healthcare data in Wales, UK

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ABSTRACT

Background This study used individual-level linked data across general practice, emergency departments (EDs), outpatients and hospital admissions to examine contacts across settings and time by sex for self-harm in individuals aged 10–24 years old in Wales, UK.

Methods A whole population-based e-cohort study of routinely collected healthcare data was conducted. Rates of self-harm across settings over time by sex were examined. Individuals were categorised based on the service(s) to which they presented.

Results A total of 937 697 individuals aged 10–24 years contributed 5 369 794 person years of data from 1 January 2003 to 30 September 2015. Self-harm incidence was highest in primary care but remained stable over time (incident rate ratio (IRR)=1.0; 95% CI 0.9 to 1.1). Incidence of ED attendance increased over time (IRR=1.3; 95% CI 1.2 to 1.5) as did hospital admissions (IRR=1.4; 95% CI 1.1 to 1.6). Incidence in the 15–19 years age group was the highest across all settings. The largest increases were seen in the youngest age group. There were increases in ED attendances for both sexes; however, females are more likely than males to be admitted following this. This was most evident in individuals 10–15 years old, where 76% of females were admitted compared with just 49% of males. The majority of associated outpatient appointments were under a mental health speciality.

Conclusions This is the first study to compare self-harm in people aged 10–24 years across primary care, EDs and hospital settings in the UK. The high rates of self-harm in primary care and for young men in EDs highlight these as important settings for intervention.

BACKGROUND

Self-harm (SH) refers to any act of intentional self-injury or poisoning regardless of suicidal intent or motivation.^{1,2} Accurate data on SH are crucial to suicide prevention efforts. A history of SH is one of the strongest risk factors associated with subsequent suicide.³ Up to 80% of suicide decedents have a primary or secondary care mental health contact in the year before death.⁴ These contacts present an opportunity for intervention. Approximately 25% of women and 10% of men aged 16–24 reported having self-harmed in the past.⁵ Data underpinning policy and practice are often derived from

What is already known?

- Most self-harm research is conducted in hospital settings although many individuals are managed in primary care.
- There has been no previous research examining linked whole population GP and hospital admissions nor incorporating emergency department data.
- Preferential service presentation by age and sex in linked data is unknown.

What this study adds?

- This is the first study of its kind in the UK to examine contacts for self-harm across GP, hospital admissions, outpatients and emergency departments.
- Admissions and emergency department attendances increased for those aged 10–14, and emergency department attendances increased for those aged 15–19 years old.
- Males were less likely to be admitted to hospital following emergency department attendance for self-harm even in the case of self-poisoning and in under 16s.

populations attending emergency departments (EDs) or admitted to hospital.^{6–8}

Approximately twice as many people who self-harm seek help in primary care than access secondary care,⁹ and many are managed in primary care.^{10,11} There have been routinely collected data studies based solely in this setting.^{9,12} A significant increase in the incidence of SH in young adolescent girls was found from 2011 to 2014 combining hospital admissions and general practice (GP) data, with no corresponding increase in older adolescents or males.¹³ Little is known about how SH contacts differ across settings at the population level; for example, are the same people attending GPs and EDs?

The Secure Anonymised Information Linkage (SAIL) databank^{14,15} presents a unique opportunity to link data from primary care, EDs and hospitals at the person level to explore contacts for SH. This



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Self-harm presentation across healthcare settings by sex in young people: An e-cohort study utilising routinely collected linked healthcare data in Wales, UK

Authors

Amanda Marchant, Samantha Turner, Lloyd Balbuena, Eryn M Peters, Dave Williams, Keith Lloyd, Ronan A Lyons, *Ann John

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What is known about this topic

- Most self-harm research conducted in hospital settings when many individuals managed in primary care
- Research combining GP and hospital admissions has found that self-harm incidence has

Increased in young adolescent girls

- No previous research examining linked whole population GP and hospital admissions or incorporating emergency department. Preferential service presentation by age and sex in linked data unknown.

What this study adds

- First study of its kind in the UK to examine contacts for self-harm across GP, admissions, outpatients and emergency departments
- Self-harm in GP remained stable for young males. Admissions and emergency department attendances increased for those aged 10-14, emergency department attendances increased for 15-19 year olds
- Males less likely to admitted to hospital following emergency department attendance for self-harm even in the case of self-poisoning and in under 16's

Abstract

Background

This study utilised individual-level linked data across GP, Emergency Departments (ED), outpatients and hospital admissions examining contacts across settings and time by sex for self-harm in 10-24 year olds in Wales, UK.

Methods

A whole-population based e-cohort study of routinely collected healthcare data was conducted. Rates of self-harm across settings over time by sex were examined. Individuals were categorised based on the service(s) to which they presented.

Results

A total of 937,697 individuals aged 10-24 years contributed 5,369,794 person years of data from the 01.01.2003-30.09.2015. Self-harm incidence was highest in primary care but remained stable over time (IRR=1.0; 95% CI 0.9–1.1). Incidence of ED attendance increased over time (IRR=1.3; 95% CI 1.2–1.5) as did hospital admissions (IRR=1.4; 95% CI 1.1–1.6). Incidence in the 15-19 year age group was the highest across all settings. The largest increases were seen in the youngest age group. There were increases in ED attendances for both sexes however, females are more likely than males to be admitted following this. This was most evident in 10-15 year olds where 76% of females were admitted compared with just 49% of males. The majority of associated outpatient's appointments were under a mental health speciality.

Conclusions

This is the first study to compare self-harm in people aged 10-24 years across primary care, EDs, and hospital settings in the UK. The high rates of self-harm in primary care and for young men in EDs highlight these as important settings for intervention.

Background

Self-harm (SH) refers to any act of intentional self-injury or poisoning regardless of suicidal intent or motivation[1, 2]. Accurate data on SH is crucial to suicide prevention efforts. A history of SH is one of the strongest risk factors associated with subsequent suicide[3]. Up to 80% of suicide decedents have a primary or secondary care mental health contact in the year before death[4]. These contacts present an opportunity for intervention. Approximately 25% of women and 10% of men aged 16-24 reported having self-harmed in the past[5]. Data underpinning policy and practice, is often derived from populations attending Emergency Departments (EDs) or admitted to hospital[6-8].

Approximately twice as many people who SH seek help in primary care than access secondary care[9] and many are managed in primary care[10, 11]. There have been routinely collected data studies based solely in this setting[9, 12]. A significant increase in the incidence of SH in young adolescent girls was found from 2011-2014 combining hospital admissions and GP data with no corresponding increase in older adolescents or males[11]. Little is known about how SH contacts differ across settings at a population level e.g. are the same people attending GPs and EDs.

The Secure Anonymized Information Linkage (SAIL) databank[13, 14] presents a unique opportunity to link data from primary care, EDs, and hospitals at person level to explore contacts for SH. This level of linkage across services at population level is not possible in any other routinely collected healthcare data source currently held in the UK. Utilising such data to examine presentation across services can inform policy and practice identifying opportunities for intervention. The aim of the current study is to examine incidence over time of SH in a whole population of young people across primary care, ED, hospital outpatients and admissions, and to explore if individuals preferentially present across different settings.

Method

Study Design

This is a retrospective e-cohort study.

Data source

The SAIL databank (www.saildatabank.com) is an expanding data repository of anonymized person-based linkable data from healthcare and public settings to support research (Appendix A). Policies and procedures have been described in detail previously [13, 14].

Study population and setting

We used multiple datasets linked at patient level: Welsh Demographic Service (WDS); Welsh Index of Multiple Deprivation (WIMD) containing deprivation scores for all Lower Super Output Areas in Wales [15] ; GP database (GPD) containing information for all GP interactions covering 79% of Welsh population (70% considered acceptable in prevalence studies [16]); ED dataset (EDDS) containing data for all NHS Wales ED attendances (34 sites including minor injuries units); Patient Episode Database for Wales (PEDW) containing data for all NHS Wales hospital admissions; Outpatients data (OPD); Office of National Statistics (ONS) deaths register.

For further details of these datasets see Appendix A or www.saildatabank.com.

Individuals aged 10-24 registered with a SAIL supplying GP from 01.01.2003-30.09.2015 were selected as the baseline population to give a common population denominator allowing comparisons across settings. Data collection began one year after GP registration, 10th birthday, or study onset whichever was the latest. Data collection ended on the date of GP de-registration, death, 25th birthday or study end whichever was sooner. Individuals could supply multiple data periods.

Measures

Age and deprivation indices were collected based upon the data collection onset each year. Children and young people (CYP) are defined as those aged 10-24[17]. Age was categorised into three groups of equal age bands; 10-14, 15-19 and 20-24 years, in keeping with previous research [e.g. 18, 19]. NICE guidance recommends admission for

under 16's attending EDs with SH[1]. We explored this where relevant by dividing into age bands 10-15, 16-18, and 19-24 years.

Measures were taken from GP data using validated primary care Read codes[9, 12]. Additional Read codes were identified through manual searching and checked by a clinician (AJ, KL; Appendix B). Hospital admissions for SH were identified based on International Classification of Diseases 10th revision (ICD-10) codes for SH (X60-X84) and undetermined intent (Y10-Y34). A standard coding system is employed across EDs in Wales grouping by attendance type and diagnosis. While this does not contain the diagnostic detail of ICD-10 and Read codes, this is sufficient for identifying SH. SH was defined as an attendance recorded as 'deliberate SH'[20]. Additional analysis was conducted to identify appropriate diagnostic codes when an event of undetermined intent was recorded (Appendix C). Codes referring to SH with alcohol were excluded from all datasets unless they were recorded alongside another relevant code[21].

Trends over time. Incidence was defined as no SH record within the previous 12 months[22-24]. ED data is available from August 2009. A full year of history is required to allow the necessary one-years to distinguish an incident from a prevalent case. As such ED data is presented from 2011-2015 only with 2010 utilised only to assess whether an individual has attended previously (denominators adjusted).

SH method over time (2003-2015) was examined. All GP events and hospital admissions with a record of SH were included (as opposed to annual incidence described above). Method was broken down into 'self-poisoning' and 'self-injury'.

Contacts across services: Presentations to each service for SH from 01.08.2009-30.09.2015 were identified. This is the maximum period where data coverage is available across all settings (Supplementary Figure 1). Datasets were linked at the level of the individual. Participants and SH events were divided into mutually exclusive groups based on the service(s) to which they presented (e.g. GP only, GP and ED etc.). Age and deprivation data were taken from the first SH presentation during this time. A SH event was defined as a record of SH in one or more service on a given date. SH method was examined. Each participant could have multiple events across services. We examined admission speciality. This is the specialty under which the patient was treated, and is either the consultant's main specialty or, a different specialty function which is the

consultant's interest specialty function. These specialties were broadly grouped into the following categories: 'surgical specialties' which included all surgical specialties (e.g. general, plastic etc.) with the exception of paediatric surgery which was categorised under 'paediatrics' and 'Accident and Emergency surgical specialty' which was examined separately; 'Accident and Emergency surgical specialty'; 'paediatric specialties' encompassing all paediatric specialties with the exception of child and adolescent psychiatry; 'psychiatric' which consists of all psychiatric specialities (e.g. psychiatric intensive care, eating disorders etc. including child and adolescent psychiatry); 'general medicine' and, 'other' which will encompass all other medical specialties (See appendix D for a full break down of specialty codes).

Admission to hospital within seven days of ED attendance was examined as a measure of whether an ED attendance resulted in admission. A seven-day window allows for an individual to remain in ED prior to admission and for delays in data recording. Whether an individual was seen in outpatients and by which speciality in the 30 days following SH was examined.

Statistical analysis

The SAIL databank was interrogated using structured query language (SQL).

Annual incidence rates were calculated using person years at risk (PYAR) as a denominator. PYAR is a more appropriate unit than the number of registered cases because each individual's follow-up period is not fixed[25]. Poisson regression was undertaken to investigate the adjusted association between incidence of SH in each dataset (datasets examined individually) and year of diagnosis, sex, age group and deprivation. Poisson regression modelling was additionally utilised to assess interactions between demographic variables. Wald tests were used to assess significance of findings. Robust standard errors for the estimated incident rate ratios (IRRs) were utilised to account for clustering within practices. Analysis was conducted in SPSS v.22.

Ethical approvals

Approval was granted from the Information Governance Review Panel (IGRP; approval number 0281).

Results

Study population

In total 937,697 individuals aged 10-24 provided 536,9794 person years of data from 01.01.2003-20.09.2015 (Supplementary Table 1).

Incidence of SH over time

Incidence of SH in primary care remained stable over time while incidence of ED attendances and hospital admissions has increased (Table 1).

Incidence over time by sex and age

Incidence rates and IRRs over time varied by age group (10-14; 15-19; 20-24 years), sex and setting (Supplementary Tables 2 and 3).

10-14 year-olds

Across services incidence was lowest in 10-14 year olds. Incidence over time increased for females across all settings. This was most marked from 2011 onwards (figure 1). For males there was no corresponding increase over time in GP attendances (females IRR=1.2[95% CI 1.1-1.4; p<.001]; males IRR=0.8[95% CI 0.6-1.1; p=.136]; interaction between sex and year IRR=1.1[95% CI 1.0-1.1; p<.001] per iteration for females with males as reference group). ED attendances increase significantly over time for both sexes (females IRR=3.4[95% CI 2.9-4.0; p<.001]; males IRR=2.1[95% CI 1.8-2.4; p<.001]; interaction between sex and year non-significant). Hospital admissions almost doubled over time for males with an even larger increase over time for females (females IRR=2.6[95% CI 2.2-3.0; p<.001]; males IRR=1.9[95% CI 1.3-2.7; p=.014] interaction between sex and year IRR=1.1[95% CI 1.0-1.1; p=.005]).

15-19 year-olds

Incidence was highest in 15-19 year olds across all settings. There was no significant increase over time in GP contacts for either sex. ED attendances increased significantly for both sexes (females IRR=1.3[95% CI 1.2-1.4; p<.001]; males IRR=1.3[95% CI 1.1-1.5; p<.001] interaction between sex and year non-significant). Hospital admissions increased significantly for females but not for males (females IRR=1.5[95% CI 1.4-1.7; p<.001]; males

IRR=1.0[95% CI 0.8-1.2; p<.001]; interaction between sex and year IRR=1.0[95% CI 1.0-1.0; p=.001).

20-24 year-olds

There was no significant increase in GP attendance or hospital admissions over time for either sex. ED attendances increased significantly over time for females but not for males (females IRR=1.3[95% CI 1.2-1.4; p<.001]; males IRR=1.0[95% CI 0.9-1.2; p=.007]; interaction between sex and year non-significant).

Changes in method over time by setting and sex

GP attendances for self-poisoning decreased over time from 6.2-5.2 attendances per 1000 PYAR (IRR=0.8[95% CI 0.7-1.0; p<.001]). This decrease was seen for both sexes (interaction between sex and year non-significant; Figure 2). In contrast hospital admissions for self-poisoning increased over time from 2.5-3.5 admissions per 1000 PYAR (overall IRR=1.4[95% CI 1.1-1.7 p<.001]; males IRR=0.9[95% CI 0.7-1.1; p<.001]; females IRR=1.6[95% CI 1.4-2.0; p<.001]; interaction between sex and year IRR=1.0[95% CI 1.0-1.1; p=.016] per iteration with males as reference group).

GP attendances for self-injury increased significantly over time from 0.4-0.6 events per 1000 PYAR (overall IRR=1.6[95% CI 1.2-2.1; p=.039]; males IRR=1.3[95% CI 0.8-2.3; p<.001]; females IRR=1.7[95% 2.3-2.3; p<.001]; interaction between sex and year non-significant). For GP attendances for self-injury 89%(95% CI 88-90; n=2288) were for self-cutting. Hospital admissions for self-injury also increased over time from 2.5-3.5 admissions per 1000 PYAR (overall IRR=2.0[95% CI 1.5-2.8; <.001]). There was no significant change over time for males (IRR=1.6[95% CI 1.0-2.5; p=.607]). Female admissions more than doubled over the study period (IRR=2.4[95% CI 1.7-3.5; p<.001]; significant interaction between sex and year IRR=1.1[95% CI 1.1-1.1]). Of hospital admissions for self-injury 72%(95% CI 70-74; n=1649) were for self-cutting.

Self-harm incidence in relation to sex and deprivation

Across all settings incidence in the most deprived areas was more than double that in the least deprived areas. IRRs for deprivation are greater in males than in females with incidence in the most deprived areas being more than three times that in the least deprived areas (IRRs GP Male 3.1[95% CI 2.8-3.3; p<.001], female 2.1[95% CI 2.0-2.3;

p<.001]; ED Male 3.5[95% CI 3.1-3.8; p<.001], female 2.4[95% CI 2.2-2.7; p<.001]; Hospital admissions male 3.2[95% CI 2.9-3.6; p<.001], female 2.2[95% CI 2.2-2.4; p<.001] Supplementary Table 4). There was a significant interaction between sex and deprivation across all services with incidence of self-harm in males increasing significantly more per deprivation fifth than females (GP IRR=1.1[95% CI 1.1-1.2; p<.001]; ED IRR=1.1[95% CI 1.1-1.2; p=.002] hospital admissions IRR=1.1[95% CI 1.1-1.2; p<.001])

Contacts across services

Demographics of individuals presenting to each single service or to multiple services are shown in Table 2. Individuals presenting to 'GP only' make up the largest group. Females outnumber males in every setting except 'ED only'. Most events recorded in 'GP only' and 'hospital admissions only' were self-poisoning while the majority of events recorded in 'ED only' were self-injury.

There were 8665 admissions to hospital (singly or in combination with other settings; Supplementary Table 5). Paediatric admission specialities made up the largest proportion of admissions ('paediatric' 39%[95% CI 38-40;n=3374]; 'general medicine' 33%[95% CI 32-33;n=2813]; 'Psychiatry 1%[95% CI 1-1;n=69] of which 12%[95% CI 6-21; n=8] were under 'child and adolescent psychiatry'; 'surgical specialties' 4%[95% CI 3-4; n=314]; 'ED surgical specialty 13%[95% CI 13-14; n=116]; 'other medical specialties' 11%[95% CI 10-11; n=931]). Almost all 10-14 year olds were admitted under 'paediatrics' (99%[95% CI 98-99; n=2740]). Females were more commonly admitted under 'paediatrics' (females 47%[95% CI 46-49;n=2870]; males 19%[95% CI 18-21;n=502]). A higher proportion of males were admitted under 'general medicine' (males 41%[95% CI 40-43;n=1078]; females 29%[95% CI 28-30;n=1737]).

ED attendances and associated hospital admissions

Less than half of ED attendances were associated with a hospital admission. Age groups here are discussed in relation to NICE guidance split into 10-15; 16-18 and 19-24 years. Attendances in 10-15 year-olds were more likely to be associated with an admission (10-15 years 69%[95% CI 67-71]); 16-18 years 36%[95% CI 34-38]; 19-24 years 34%[95% CI 33-36] Figure 3; Supplementary Table 6).

Females are more likely than males to be admitted (46%[95% CI 45-57] vs. 35%[95% CI 33-36]). This is most evident in those aged 10-15 years where 76%(95% CI 74-78;n=1182) of females were admitted compared with 49%(95% CI 45-53) of males. This difference between the sexes is less apparent in older age groups (16-18 years females 40%[95% CI 38-42; n=2125] vs. males 29%[95% CI 27-31;n=382]; 19-24 years females 34%[95% CI 33-36;n=1065] vs. males 34%[95% CI 33-36; n=1095]).

Attendances for self-poisoning were more likely to be admitted than self-injuries (51%[95% CI 49-53] vs. 37%[95% CI 36-38]). The highest proportion of admissions was seen in 10-15 year old girls attending for self-poisoning (90%[95% CI 87-93] admitted) compared with 69%(95% CI 59-78) of males attending for self-poisoning of the same age.

Outpatients' appointments

A third of SH events were associated with an outpatient appointment (Table 2). The largest proportions of appointments were for those both 'attending ED and admitted to hospital'. Only a quarter of those 'attending ED only' had an outpatient appointment within 30 days. The smallest proportion of associated outpatient appointments was seen in those presenting to 'GP only'. The majority of outpatient appointments were under a mental health speciality. Only 3%(95% CI 3-4; n=253) were under a paediatric speciality.

ED attendances and associated outpatient appointments

Only (27%(95% CI 26-28; n=3223) of ED attendances were associated with an outpatient appointment. Attendances associated with admission were more likely to have a subsequent outpatient appointment than those without (Figure 4). In those aged 10-15 years males are more likely than females to have an outpatient appointment without a hospital admission (males 28%[95% CI 23-34;n=81]; Females 22%[95% CI 18-27;n=81]). This is not seen in older age groups.

Discussion

Main findings

This is the first study of its kind to link SH across primary care, EDs and hospital admissions at person level in the UK. Incidence of recorded SH is highest in primary care as found elsewhere[9]. Previous research combining GP and hospital admissions found a significant increase in incidence in females aged 13-16 not reflected in older adolescents or males[11]. This study supports the increase in females aged 10-14 across all settings. While incidence in GP has remained stable for males of this age the breakdown by service and addition of ED data shows ED attendances have more than doubled and hospital admissions have also significantly increased. While incidence in GP for those aged 15-19 remains stable there is a significant increase in both ED attendances and admissions for females, and in ED attendances for males. The absence of a corresponding increase in admissions for males of this age is a cause for concern. Raised awareness and disclosure or increasing medically severe SH in CYP may be resulting in increased presentation to hospital-based settings. Psychiatric admission is most likely when highly lethal methods are used[8]. The increases in hospital admissions are potentially reflecting improved management of SH based on guidance recommending admission for individuals under 16[1]. This does not explain increases in ED attendance. Admission specialities were examined with 99% of those aged 10-15 admitted under paediatric specialities. For older age groups admission under 'general medicine' was more common.

SH method was found to vary over time by setting and sex. Self-injury increased significantly for both sexes with a larger increase in females in keeping with ED[8] and hospital admissions research also finding an increase in violent self-injury (e.g. hanging)[26]. The current study additionally examined method of SH presenting to GPs and found a decrease in self-poisoning in both sexes and a significant increase over time for self-injury particularly for females.

We examined the demographics of individuals presenting to each service individually or in combination. A quarter of individuals present to 'GP only'. A further 22% present to 'ED only' meaning almost half of individuals did not have a hospital admission. Females

outnumber males in every combination of settings with the exception of 'ED only' where 58% of individuals are male underscoring the concerning disparity in admissions by sex. Self-injury is more likely to be used by males and less likely to result in admission if not medically required possibly based on misconceptions regarding suicide risk[6, 27].

Less than half of ED attendances were associated with a hospital admission. Admission of 16 and 17 year olds is based on clinical judgement rather than stipulated in guidance[8]. Results here support previous research demonstrating that under 16's are more likely to be admitted following ED attendance for SH than older age groups[8] in keeping with clinical guidance for this age group. The ratio of females to males attending ED with self-harm has been previously found to decrease with age with those aged 12-14 most likely to be admitted[28]. Results here additionally demonstrate that females are more likely to be admitted following ED attendance than males. This is most evident in those aged 10-15 years where 76% of females attending ED are admitted compared with just 49% of males. This difference persists even in the case of self-poisoning. Males are more likely to leave ED before on-going care recommendations can be made or to refuse treatment which may partly underlie the lower levels of admissions[8].

Less than a third of ED attendances had a subsequent outpatient appointment with those admitted more likely to be seen in outpatients. This may indicate a need for better recording of liaison or crisis team contacts or reflect poor follow-up of patients who present with SH[29]. In those aged 10-15 years females were more likely than males to have an outpatient appointment with an admission however males were more likely than females to have an outpatient appointment without an admission. The majority of outpatient appointments were under a mental health speciality.

Strengths and limitations

This study provides a comprehensive picture on which to base targeted intervention, resources and service provision. Derived from a large representative population of CYP studied over 12 years results are generalizable to the rest of the UK.

Up to 14 diagnoses can be recorded per hospital admission as such, SH may not be the primary reason for admission. In self-poisoning the reason for admission is likely to be for medical treatment or monitoring of poison levels. We cannot be certain a hospital

admission was a direct result of an ED attendance. This was based on hospital admission within seven days. It was not possible to examine severity. While admission to hospital may reflect increased severity, there are multiple factors influencing whether or not someone is admitted (e.g. age, method). Method was grouped broadly into 'self-poisoning' and 'self-injury'. It was not possible to sub-divide self-injury (e.g. into hanging, traffic) due to insufficient numbers. While we examined admission by speciality it was not possible to examine whether an individual was admitted to a general medical or psychiatric hospital.

Data from EDs is not available prior to 2009 and has less detailed coding of SH compared with GP and admissions data. ED data is collected from every ED in Wales. Prior to 2012 there were coding quality issues from some providers. As such data from 2009-2012 should be interpreted with caution particularly with regards to trends over time. ED trends over time presented here are in keeping with other research utilising ED data[8].

Routinely collected data has limitations for research purposes and the quality and completeness of data varies across datasets. We have attempted to minimise the impact of this by only including GP practices that meet standards for data quality and utilising validated code lists [9, 12]. SH not resulting in presentation to services or, where SH is discussed but not recorded will not be captured here. This is a common feature of all studies utilising routine data. This data is a reflection of contacts with the healthcare system, not of rates of SH in the community. GP coding behaviour changes over time[24, 30]. It is unclear whether the increase in SH reflects a genuine increase or if this is partially attributable to improved recognition and coding behaviour by clinicians and increased help-seeking by individuals[20].

Implications

GPs are an important setting for intervention. Despite this GPs may underestimate the prevalence of SH in young people, and have stated they would welcome training in communication with CYP and practical information about SH[31]. The higher proportion of males in those who attend ED only combined with the higher overall suicide rate in males makes this an important setting for intervention in this hard-to-reach group. Tailored follow-up services should be considered. Qualitative research is needed to explore whether this reflects a preference of setting or delayed help-seeking until crisis.

Improving the help-seeking skills of young males may prevent delayed presentation to emergency settings[32].

Rates of ED attendance and hospital admissions are increasing for those aged 10-19 years. Individuals in younger age groups are often brought rather than initiating attendance themselves. Increases may reflect greater awareness of parents/carers and improved help-seeking, highlighting the increasing demand on resources. Older adolescents are more likely to initiate help-seeking in their own right. The higher rate of primary care contact for SH in older adolescents may be partially attributable to an increase in help-seeking with age[33].

CYP regularly contact non-psychiatric specialist services. It is important professionals in these services are supported in their ability to identify CYP at risk, provide appropriate support and determine when referral to specialist services is required/urgent. Further training for wider NHS staff with specific targets set in policy guidance (e.g.[34]) could improve management of those presenting with SH.

Conclusions

This is the first UK study to explore trends over time and characteristics of patients with SH by healthcare setting and the first to incorporate ED data into such analysis. Patients who are admitted to hospital make up only a small proportion of individuals presenting to services with SH with a large proportion of individuals presenting to GP or ED only. Incidence of SH over time varies by age group, sex and service. Understanding patterns of presentation will inform service planning and configuration for follow-up care and could inform tailored support, for example for males in ED. Linked data provides important evidence to support the development of interventions across healthcare settings.

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Competing Interest

None declared

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Contributorship statement

AJ and AM conceived the study. All authors contributed to study design

Analysis was conducted by AM and AJ

AM and AJ drafted the manuscript.

All authors commented on the manuscript and agreed the final version.

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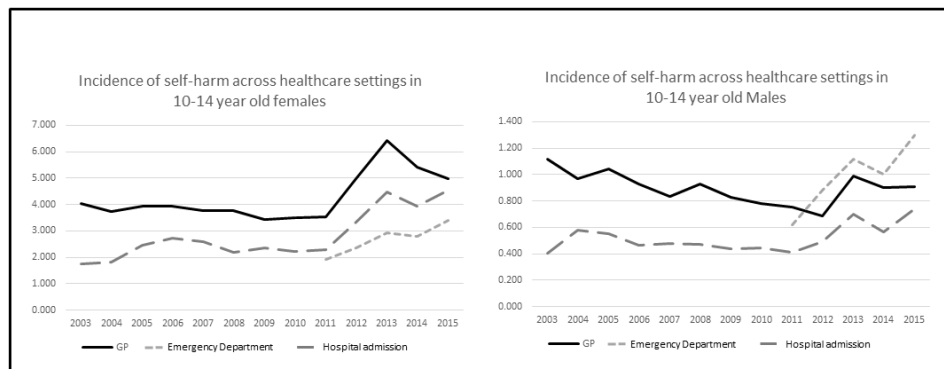


Figure 1. Incidence per 1000 PYAR of self-harm by service presentation and sex over time in 10-14 year olds

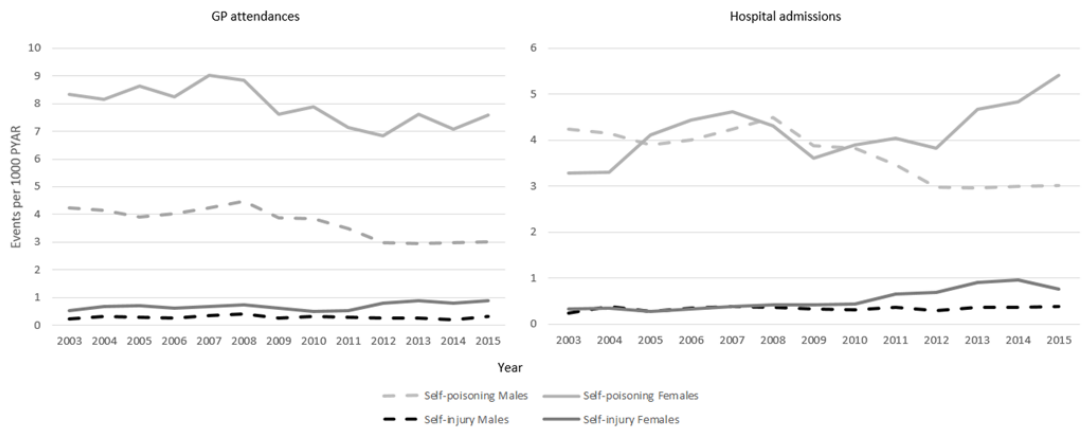


Figure 2. Self-harm events per 1000 PYAR by method, sex and setting over time

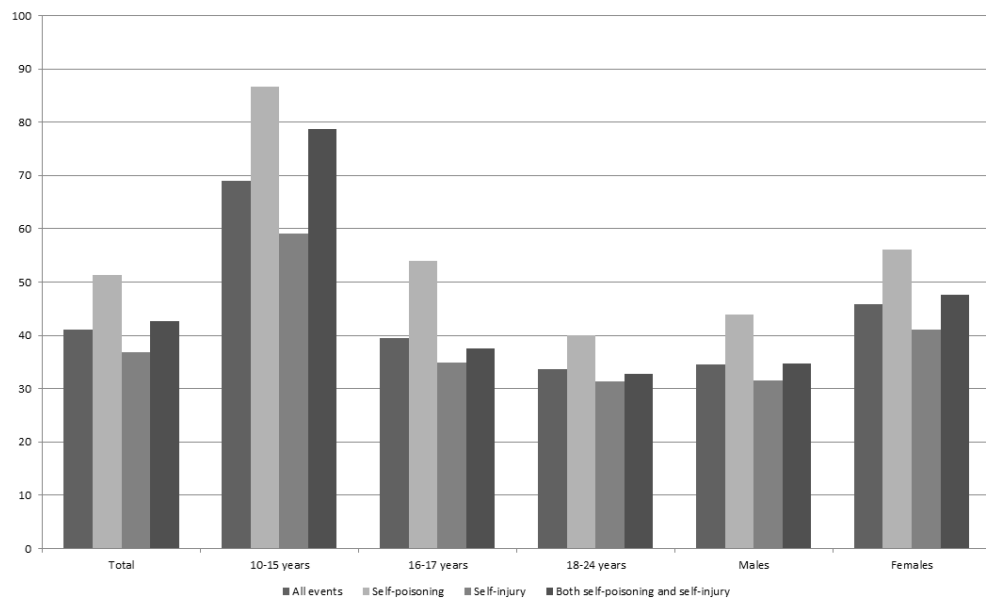


Figure 3. Percentage of ED attendances with an associated hospital admission

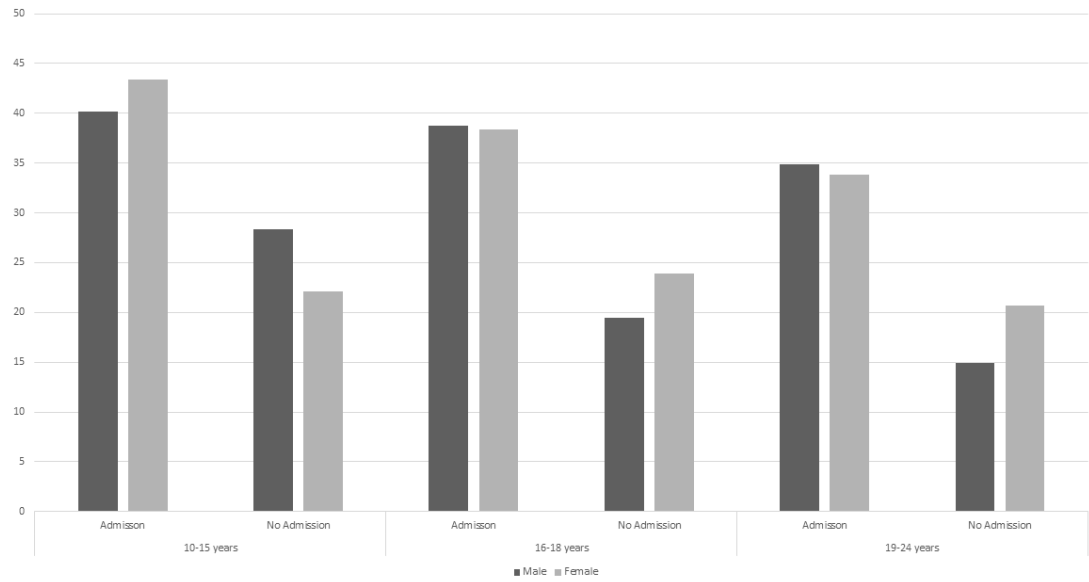


Figure 4. Percentage of ED attendances with an outpatient appointment in the subsequent 30 days by present or absence of an associated hospital admission

Table 19 Number of events; incidence per 1000 PYAR(95% CI) and incidence rate ratios^a (IRR; 95% CI)^b for presentation to services for self-harm

Variable		GP event		Emergency department attendance ^c		Hospital admission	
		Events n; incidence	IRR (P < .0001)	Events n; incidence	IRR (P < .0001)	Events n; incidence	IRR (P < .0001)
Gender	Male	8506; 3.1(3-3.2)	Reference (P < .0001)	3387; 3.4(3.3-3.5)	Reference (P < .0001)	4665; 1.7(1.6-1.7)	Reference (P < .0001)
	Female	16345; 6.2(6.2-6.3)	2.0(1.9-2.1)	4161; 4.4(4.3-4.5)	1.3(1.2-1.4)	9304; 3.6(3.5-3.6)	2.1(2.0-2.3)
Age Group	10-14	4618; 2.5(2.4-2.6)	Reference (P < .0001)	1139; 1.8(1.7-1.9)	Reference (P < .0001)	2941; 1.6(1.5-1.7)	Reference (P < .0001)
	15-19	11782; 6.5(6.4-6.7)	2.6(2.4-2.8)	3578; 5.5(5.3-5.7)	3.1(2.8-3.6)	6526; 3.6(3.5-3.7)	2.3(2.1-2.5)
	20-24	8451; 4.9(4.8-5)	2.0(1.8-2.2)	2831; 4.3(4.2-4.5)	2.5(2.1-2.9)	4502; 2.6(2.5-2.7)	1.6(1.5-1.8)
Deprivation ^d	5	3026; 2.9(2.8-3)	Reference (P < .0001)	844; 2.2(2.1-2.4)	Reference (P < .0001)	1631; 1.6(1.5-1.6)	Reference (P < .0001)
	4	3253; 3.6(3.5-3.7)	1.3(1.1-1.4)	867; 2.7(2.5-2.9)	1.2(1.1-1.4)	1872; 2.1(2-2.2)	1.3(1.2-1.5)
	3	4198; 4.2(4.1-4.3)	1.5(1.3-1.6)	1239; 3.4(3.2-3.6)	1.6(1.4-1.8)	2386; 2.4(2.3-2.5)	1.5(1.4-1.7)
	2	5329; 5.2(5.1-5.4)	1.8(1.7-2.0)	1726; 4.6(4.4-4.9)	2.1(1.8-2.4)	3091; 3(2.9-3.1)	2.0(1.8-2.2)
	1	8225; 6.9(6.8-7.1)	2.4(2.2-2.6)	2692; 6.2(6-6.4)	2.8(2.5-3.2)	4550; 3.8(3.7-3.9)	2.5(2.2-2.7)
Year	2003	1751; 4.5(4.3-4.7)	Reference (P < .0001)			846; 2.2(2-2.3)	Reference (P < .0001)
	2004	1944; 4.6(4.4-4.8)	1.0(0.9-1.2)			954; 2.3(2.1-2.4)	1.0(0.9-1.2)
	2005	2022; 4.7(4.5-4.9)	1.0(0.9-1.2)			1074; 2.5(2.3-2.6)	1.1(1.0-1.3)
	2006	2018; 4.6(4.4-4.8)	1.0(0.9-1.1)			1172; 2.7(2.5-2.8)	1.2(1.1-1.4)
	2007	2212; 5(4.8-5.3)	1.1(1.0-1.2)			1299; 3(2.8-3.1)	1.3(1.2-1.5)
	2008	2241; 5.1(4.9-5.3)	1.1(1.0-1.2)			1222; 2.8(2.6-2.9)	1.3(1.1-1.4)
	2009	1934; 4.4(4.2-4.6)	1.0(0.9-1.1)			1059; 2.4(2.3-2.6)	1.1(1.0-1.3)
	2010	1988; 4.6(4.4-4.8)	1.0(0.9-1.1)			1007; 2.3(2.2-2.5)	1.1(0.9-1.2)

2011	1855; 4.4(4.2-4.6)	1.0(0.8-1.1)	1444; 3.4(3.2-3.6)	Reference (P < .0001)	1063; 2.5(2.4-2.7)	1.1(1.0-1.3)
2012	1887; 4.5(4.3-4.7)	1.0(0.9-1.1)	1631; 3.9(3.7-4.1)	1.1(1.0-1.3)	1052; 2.5(2.4-2.7)	1.1(1.0-1.3)
2013	1939; 4.7(4.5-4.9)	1.0(0.9-1.2)	1612; 3.9(3.7-4.1)	1.2(1.0-1.3)	1205; 2.9(2.8-3.1)	1.3(1.1-1.6)
2014	1726; 4.3(4.1-4.5)	0.9(0.8-1.0)	1568; 3.9(3.7-4.1)	1.2(1.0-1.3)	1137; 2.8(2.7-3)	1.3(1.1-1.5)
2015 ^e	1334; 4.5(4.3-4.8)	1.0(0.9-1.1)	1293; 4.4(4.2-4.7)	1.3(1.2-1.5)	879; 3(2.8-3.2)	1.4(1.1-1.6)

a. Adjusted for calendar year, age and deprivation

b. Based on Wald test

c. Emergency department data from 2011 onwards only

d. Deprivation: 1 = most deprived; 5 = least deprived

e. Data collected in 2015 up until 30th September –denominator for incidence rate adjusted accordingly but actual counts may appear lower

Table 20 Presentation of self-harm across services^a and associated outpatient appointments from 01.08.2011-30.09.2015

	By individual ^c		By event ^d						
	Individuals n(%; 95% CI)	Females n(% ^e ; 95% CI)	Events N(%; 95% CI)	Self- poison only n (%; 95% CI)	Self- injury only n (%; 95% CI)	Self- poison and injury n (%; 95% CI)	Outpa- tients ^f n(%; 95% CI)	Men- tal health specia- lity n(% ^g ; 95% CI)	Paediat- ric speciali- ty n(% ^h ; 95% CI)
GP only	3912(25;2 4-26)	2530(65;63- 66)	10690 (37;36 -37)	6194(58;57- 59)	4181(39;38- 40)	315(3; 3-3)	2504(23;23- 24)	1758(70;67- 73)	90(4;3- 4)
Hospital admission only	1084(7;7- 7)	652(6 0;57- 63)	4171(14;14- 15)	3364(81;79- 82)	673(1 6;15- 17)	134(3; 3-4)	1308(31;30- 33)	907(6 9;65- 74)	46(4;3- 5)
ED only	3428(22;2 1-22)	1449(42;41- 44)	7471(26;25- 26)	1371(18;17- 19)	5075(68;67- 69)	1025(14;13- 15)	1882(25;24- 26)	1080(57;54- 61)	46(2;2- 3)
GP and hospital admission	2394(15;1 5-16)	1725(72;70- 74)	2270(8;8-8)	1633(72;70- 74)	149(7; 6-8)	488(2 1;20- 23)	734(3 2;30- 35)	592(8 1;74- 87)	28(4;3- 5)
GP and ED	1979(13;1 2-13)	1150(58;56- 60)	2144(7;7-8)	518(2 4;22- 26)	474(2 2;20- 24)	1152(54;52- 56)	545(2 5;23- 28)	408(7 5;67- 82)	8(1;1- 3)
ED and hospital admission	566(4;3-4)	331(5 8;54- 62)	1133(4;4-4)	308(2 7;25- 30)	157(1 4;12- 16)	668(5 9;56- 62)	413(3 6;33- 40)	321(7 8;69- 86)	17(4;3- 7)
GP, ED and hospital admission	2376(15;1 5-16)	1647(69;67- 71)	1091(4;4-4)	289(2 6;24- 29)	59(5;4 -7)	743(6 8;65- 71)	383(3 5;32- 39)	319(8 3;74- 92)	18(5;3- 7)
Total	15739	9484(60;59- 61)	28970	13677 (47;47 -48)	10768 (37;37 -38)	4525(16;15- 16)	7769(27;26- 27)	5385(69;67- 71)	253(3;3 -4)

- Mutually exclusive groups
- Total number of individuals presenting to service(s) over the study period
- Event defined as a self-harm presentation across one of more services on a given date
- Percentage of total presenting individuals
- Presence of outpatient appointment within the subsequent 30 days
- Percentage of outpatient appointments under a mental health speciality
- Percentage of outpatient appointments under a paediatric speciality

APPENDIX J: READ CODES USED TO IDENTIFY SELF-HARM IN GP DATA

Read Code	Description
14K1.	Intentional overdose of prescription only medication
SL...	Overdose of biological substance
SL90.	Antidepressant poisoning
SL900	Amitriptyline poisoning
SL901	Imipramine poisoning
SL902	Monoamine poisoning
SL903	Trazodone poisoning
SL90z	Anti-depressant poisoning NOS
TK...	Suicide and self inflicted injury
TK0..	Suicide + self inflicted poisoning by solid/liquid substances
TK00.	Suicide + self inflicted poisoning by analgesic/antipyretic
TK01.	Suicide + self inflicted poisoning by barbiturates
TK010	Suicide and self inflicted injury by Amylobarbitone
TK011	Suicide and self inflicted injury by Barbitone
TK014	Suicide and self inflicted injury by Phenobarbitone
TK02.	Suicide + self inflicted poisoning by oth sedatives/hypnotics
TK03.	Suicide + self inflicted poisoning tranquilliser/psychotropic
TK04.	Suicide + self inflicted poisoning by other drugs/medicines
TK05.	Suicide + self inflicted poisoning by drug or medicine NOS
TK06.	Suicide + self inflicted poisoning by agricultural chemical

TK07.	Suicide + self inflicted poisoning by corrosive/caustic subst
TK0z.	Suicide + self inflicted poisoning by solid/liquid subst NOS
TK1..	Suicide + self inflicted poisoning by gases in domestic use
TK10.	Suicide + self inflicted poisoning by gas via pipeline
TK11.	Suicide + self inflicted poisoning by liquified petrol gas
TK1y.	Suicide and self inflicted poisoning by other utility gas
TK1z.	Suicide + self inflicted poisoning by domestic gases NOS
TK2..	Suicide + self inflicted poisoning by other gases and vapours
TK20.	Suicide + self inflicted poisoning by motor veh exhaust gas
TK21.	Suicide and self inflicted poisoning by other carbon monoxide
TK2z.	Suicide + self inflicted poisoning by gases and vapours NOS
TK3..	Suicide + self inflicted injury by hang/strangulate/suffocate
TK30.	Suicide and self inflicted injury by hanging
TK31.	Suicide + self inflicted injury by suffocation by plastic bag
TK3y.	Suicide + self inflicted inj oth mean hang/strangle/suffocate
TK3z.	Suicide + self inflicted inj by hang/strangle/suffocate NOS
TK4..	Suicide and self inflicted injury by drowning
TK5..	Suicide and self inflicted injury by firearms and explosives
TK51.	Suicide and self inflicted injury by shotgun
TK52.	Suicide and self inflicted injury by hunting rifle

TK54.	Suicide and self inflicted injury by other firearm
TK5z.	Suicide and self inflicted injury by firearms/explosives NOS
TK6..	Suicide and self inflicted injury by cutting and stabbing
TK60.	Suicide and self inflicted injury by cutting
TK601	Self inflicted lacerations to wrist
TK61.	Suicide and self inflicted injury by stabbing
TK6z.	Suicide and self inflicted injury by cutting and stabbing NOS
TK7..	Suicide and self inflicted injury by jumping from high place
TK70.	Suicide+self inflicted injury-jump from residential premises
TK71.	Suicide+self inflicted injury-jump from oth manmade structure
TK72.	Suicide+self inflicted injury-jump from natural sites
TK7z.	Suicide+self inflicted injury-jump from high place NOS
TKx..	Suicide and self inflicted injury by other means
TKx0.	Suicide + self inflicted injury-jump/lie before moving object
TKx00	Suicide + self inflicted injury-jumping before moving object
TKx1.	Suicide and self inflicted injury by burns or fire
TKx2.	Suicide and self inflicted injury by scald
TKx3.	Suicide and self inflicted injury by extremes of cold
TKx4.	Suicide and self inflicted injury by electrocution
TKx5.	Suicide and self inflicted injury by crashing motor vehicle

TKx6.	Suicide and self inflicted injury by crashing of aircraft
TKx7.	Suicide and self inflicted injury caustic subst, excl poison
TKxy.	Suicide and self inflicted injury by other specified means
TKxz.	Suicide and self inflicted injury by other means NOS
TKy..	Late effects of self inflicted injury
TKz..	Suicide and self inflicted injury NOS
U2...	[X]Intentional self-harm
U20..	[X]Intentional self poisoning by and exposure to noxious substances
U200.	[X]Intentional self poisoning by and exposure to nonopioid analgesics
U2000	[X]Intentional self poisoning by and exposure to nonopioid analgesics, occurrence at home
U2001	[X]Intentional self poisoning by and exposure to nonopioid analgesics, occurrence in residential institution
U2002	[X]Intentional self poisoning by and exposure to nonopioid analgesics, occurrence at school, other institution and public administrative area
U2003	[X]Intentional self poisoning by and exposure to nonopioid analgesics, occurrence at sports and athletics area
U2004	[X]Intentional self poisoning by and exposure to nonopioid analgesics, occurrence on street and highway
U2005	[X]Intentional self poisoning by and exposure to nonopioid analgesics, occurrence at trade and service area
U2006	[X]Intentional self poisoning by and exposure to nonopioid analgesics, occurrence at industrial and construction area

U2007	[X]Intentional self poisoning by and exposure to nonopioid analgesics, occurrence on farm
U200y	[X]Intentional self poisoning by and exposure to nonopioid analgesics, occurrence at other specified place
U200z	[X]Intentional self poisoning by and exposure to nonopioid analgesics, occurrence at unspecified place
U201.	[X]Intentional self poisoning by and exposure to antiepileptics
U2010	[X]Intentional self poisoning by and exposure to antiepileptics, occurrence at home
U2011	[X]Intentional self poisoning by and exposure to antiepileptics, occurrence in residential institution
U2012	[X]Intentional self poisoning by and exposure to antiepileptics, occurrence at school, other institution and public administrative area
U2013	[X]Intentional self poisoning by and exposure to antiepileptics, occurrence at sports and athletics area
U2014	[X]Intentional self poisoning by and exposure to antiepileptics, occurrence on street and highway
U2015	[X]Intentional self poisoning by and exposure to antiepileptics, occurrence at trade and service area
U2016	[X]Intentional self poisoning by and exposure to antiepileptics, occurrence at industrial and construction area
U2017	[X]Intentional self poisoning by and exposure to antiepileptics, occurrence on farm
U201y	[X]Intentional self poisoning by and exposure to antiepileptics, occurrence at other specified place

U201z	[X]Intentional self poisoning by and exposure to antiepileptics, occurrence at unspecified place
U202.	[X]Intentional self poisoning by and exposure to sedative hypnotics
U2020	[X]Intentional self poisoning by and exposure to sedative hypnotics, occurrence at home
U2021	[X]Intentional self poisoning by and exposure to sedative hypnotics, occurrence in residential institution
U2022	[X]Intentional self poisoning by and exposure to sedative hypnotics, occurrence at school, other institution and public administrative area
U2023	[X]Intentional self poisoning by and exposure to sedative hypnotics, occurrence at sports and athletics area
U2024	[X]Intentional self poisoning by and exposure to sedative hypnotics, occurrence on street and highway
U2025	[X]Intentional self poisoning by and exposure to sedative hypnotics, occurrence at trade and service area
U2026	[X]Intentional self poisoning by and exposure to sedative hypnotics, occurrence at industrial and construction area
U2027	[X]Intentional self poisoning by and exposure to sedative hypnotics, occurrence on farm
U202y	[X]Intentional self poisoning by and exposure to sedative hypnotics, occurrence at other specified place
U202z	[X]Intentional self poisoning by and exposure to sedative hypnotics, occurrence at unspecified place
U203.	[X]Intentional self poisoning by and exposure to antiparkinson drugs

U2030	[X]Intentional self poisoning by and exposure to antiparkinson drugs, occurrence at home
U2031	[X]Intentional self poisoning by and exposure to antiparkinson drugs, occurrence in residential institution
U2032	[X]Intentional self poisoning by and exposure to antiparkinson drugs, occurrence at school, other institution and public administrative area
U2033	[X]Intentional self poisoning by and exposure to antiparkinson drugs, occurrence at sports and athletics area
U2034	[X]Intentional self poisoning by and exposure to antiparkinson drugs, occurrence on street and highway
U2035	[X]Intentional self poisoning by and exposure to antiparkinson drugs, occurrence at trade and service area
U2036	[X]Intentional self poisoning by and exposure to antiparkinson drugs, occurrence at industrial and construction area
U2037	[X]Intentional self poisoning by and exposure to antiparkinson drugs, occurrence on farm
U203y	[X]Intentional self poisoning by and exposure to antiparkinson drugs, occurrence at other specified place
U203z	[X]Intentional self poisoning by and exposure to antiparkinson drugs, occurrence at unspecified place
U204.	[X]Intentional self poisoning by and exposure to psychotropic drugs
U2040	[X]Intentional self poisoning by and exposure to psychotropic drugs, occurrence at home
U2041	[X]Intentional self poisoning by and exposure to psychotropic drugs, occurrence in residential institution
U2042	[X]Intentional self poisoning by and exposure to psychotropic drugs, occurrence

	at school, other institution and public administrative area
U2043	[X]Intentional self poisoning by and exposure to psychotropic drugs, occurrence at sports and athletics area
U2044	[X]Intentional self poisoning by and exposure to psychotropic drugs, occurrence on street and highway
U2045	[X]Intentional self poisoning by and exposure to psychotropic drugs, occurrence at trade and service area
U2046	[X]Intentional self poisoning by and exposure to psychotropic drugs, occurrence at industrial and construction area
U2047	[X]Intentional self poisoning by and exposure to psychotropic drugs, occurrence on farm
U204y	[X]Intentional self poisoning by and exposure to psychotropic drugs, occurrence at other specified place
U204z	[X]Intentional self poisoning by and exposure to psychotropic drugs, occurrence at unspecified place
U205.	[X]Intentional self poisoning by and exposure to narcotic drugs
U2050	[X]Intentional self poisoning by and exposure to narcotic drugs, occurrence at home
U2051	[X]Intentional self poisoning by and exposure to narcotic drugs, occurrence in residential institution
U2052	[X]Intentional self poisoning by and exposure to narcotic drugs, occurrence at school, other institution and public administrative area
U2053	[X]Intentional self poisoning by and exposure to narcotic drugs, occurrence at sports and athletics area

U2054	[X]Intentional self poisoning by and exposure to narcotic drugs, occurrence on street and highway
U2055	[X]Intentional self poisoning by and exposure to narcotic drugs, occurrence at trade and service area
U2056	[X]Intentional self poisoning by and exposure to narcotic drugs, occurrence at industrial and construction area
U2057	[X]Intentional self poisoning by and exposure to narcotic drugs, occurrence on farm
U205y	[X]Intentional self poisoning by and exposure to narcotic drugs, occurrence at other specified place
U205z	[X]Intentional self poisoning by and exposure to narcotic drugs, occurrence at unspecified place
U206.	[X]Intentional self poisoning by and exposure to hallucinogens
U2060	[X]Intentional self poisoning by and exposure to hallucinogens, occurrence at home
U2061	[X]Intentional self poisoning by and exposure to hallucinogens, occurrence in residential institution
U2062	[X]Intentional self poisoning by and exposure to hallucinogens, occurrence at school, other institution and public administrative area
U2063	[X]Intentional self poisoning by and exposure to hallucinogens, occurrence at sports and athletics area
U2064	[X]Intentional self poisoning by and exposure to hallucinogens, occurrence on street and highway
U2065	[X]Intentional self poisoning by and exposure to hallucinogens, occurrence at trade and service area

U2066	[X]Intentional self poisoning by and exposure to hallucinogens, occurrence at industrial and construction area
U2067	[X]Intentional self poisoning by and exposure to hallucinogens, occurrence on farm
U206y	[X]Intentional self poisoning by and exposure to hallucinogens, occurrence at other specified place
U206z	[X]Intentional self poisoning by and exposure to hallucinogens, occurrence at unspecified place
U207.	[X]Intentional self poisoning by and exposure to other autonomic drugs
U2070	[X]Intentional self poisoning by and exposure to other autonomic drugs, occurrence at home
U2071	[X]Intentional self poisoning by and exposure to other autonomic drugs, occurrence in residential institution
U2072	[X]Intentional self poisoning by and exposure to other autonomic drugs, occurrence at school, other institution and public administrative area
U2073	[X]Intentional self poisoning by and exposure to other autonomic drugs, occurrence at sports and athletics area
U2074	[X]Intentional self poisoning by and exposure to other autonomic drugs, occurrence on street and highway
U2075	[X]Intentional self poisoning by and exposure to other autonomic drugs, occurrence at trade and service area
U2076	[X]Intentional self poisoning by and exposure to other autonomic drugs, occurrence at industrial and construction area
U2077	[X]Intentional self poisoning by and exposure to other autonomic drugs, occurrence on farm

U207y	[X]Intentional self poisoning by and exposure to other autonomic drugs, occurrence at other specified place
U207z	[X]Intentional self poisoning by and exposure to other autonomic drugs, occurrence at unspecified place
U208.	[X]Intentional self poisoning by and exposure to other and unspecified drug, medicament and biological substance
U2080	[X]Intentional self poisoning by and exposure to other and unspecified drug, medicament and biological substance, occurrence at home
U2081	[X]Intentional self poisoning by and exposure to other and unspecified drug, medicament and biological substance, occurrence in residential institution
U2082	[X]Intentional self poisoning by and exposure to other and unspecified drug, medicament and biological substance, occurrence at school, other institution and public administrative area
U2083	[X]Intentional self poisoning by and exposure to other and unspecified drug, medicament and biological substance, occurrence at sports and athletics area
U2084	[X]Intentional self poisoning by and exposure to other and unspecified drug, medicament and biological substance, occurrence on street and highway
U2085	[X]Intentional self poisoning by and exposure to other and unspecified drug, medicament and biological substance, occurrence at trade and service area
U2086	[X]Intentional self poisoning by and exposure to other and unspecified drug, medicament and biological substance, occurrence at industrial and construction area
U2087	[X]Intentional self poisoning by and exposure to other and unspecified drug,

	medicament and biological substance, occurrence on farm
U208y	[X]Intentional self poisoning by and exposure to other and unspecified drug, medicament and biological substance, occurrence at other specified place
U208z	[X]Intentional self poisoning by and exposure to other and unspecified drug, medicament and biological substance, occurrence at unspecified place
U20A.	[X]Intentional self poisoning by and exposure to organic solvents and halogenated hydrocarbons and their vapours
U20A0	[X]Intentional self poisoning by and exposure to organic solvents and halogenated hydrocarbons and their vapours, occurrence at home
U20A1	[X]Intentional self poisoning by and exposure to organic solvents and halogenated hydrocarbons and their vapours, occurrence in residential institution
U20A2	[X]Intentional self poisoning by and exposure to organic solvents and halogenated hydrocarbons and their vapours, occurrence at school, other institution and public administrative area
U20A3	[X]Intentional self poisoning by and exposure to organic solvents and halogenated hydrocarbons and their vapours, halogens, occurrence at sports and athletics area
U20A4	[X]Intentional self poisoning by and exposure to organic solvents and halogenated hydrocarbons and their vapours, occurrence on street and highway
U20A5	[X]Intentional self poisoning by and exposure to organic solvents and halogenated hydrocarbons and their vapours, occurrence at trade and service area
U20A6	[X]Intentional self poisoning by and exposure to organic solvents and

	halogenated hydrocarbons and their vapours, occurrence at industrial and construction area
U20A7	[X]Intentional self poisoning by and exposure to organic solvents and halogenated hydrocarbons and their vapours, occurrence on farm
U20Ay	[X]Intentional self poisoning by and exposure to organic solvents and halogenated hydrocarbons and their vapours, occurrence at other specified place
U20Az	[X]Intentional self poisoning by and exposure to organic solvents and halogenated hydrocarbons and their vapours, halogens, occurrence at unspecified place
U20B.	[X]Intentional self poisoning by and exposure to other gas and vapours
U20B0	[X]Intentional self poisoning by and exposure to other gas and vapours, occurrence at home
U20B1	[X]Intentional self poisoning by and exposure to other gas and vapours, occurrence in residential institution
U20B2	[X]Intentional self poisoning by and exposure to other gas and vapour, occurrence at school, other institution and public administrative area
U20B3	[X]Intentional self poisoning by and exposure to other gas and vapour, occurrence at sports and athletics area
U20B4	[X]Intentional self poisoning by and exposure to other gas and vapour, occurrence on street and highway
U20B5	[X]Intentional self poisoning by and exposure to other gas and vapour, occurrence at trade and service area
U20B6	[X]Intentional self poisoning by and exposure to other gas and vapour, occurrence at industrial and construction area

U20B7	[X]Intentional self poisoning by and exposure to other gas and vapour, occurrence on farm
U20By	[X]Intentional self poisoning by and exposure to other gas and vapour, occurrence at other specified place
U20Bz	[X]Intentional self poisoning by and exposure to other gas and vapour, occurrence at unspecified place
U20C.	[X]Intentional self poisoning by and exposure to pesticides
U20C0	[X]Intentional self poisoning by and exposure to pesticides, occurrence at home
U20C1	[X]Intentional self poisoning by and exposure to pesticides, occurrence in residential institution
U20C2	[X]Intentional self poisoning by and exposure to pesticides, occurrence at school, other institution and public administrative area
U20C3	[X]Intentional self poisoning by and exposure to pesticides, occurrence at sports and athletics area
U20C4	[X]Intentional self poisoning by and exposure to pesticides, occurrence on street and highway
U20C5	[X]Intentional self poisoning by and exposure to pesticides, occurrence at trade and service area
U20C6	[X]Intentional self poisoning by and exposure to pesticides, occurrence at industrial and construction area
U20C7	[X]Intentional self poisoning by and exposure to pesticides, occurrence on farm
U20Cy	[X]Intentional self poisoning by and exposure to pesticides, occurrence at other specified place
U20Cz	[X]Intentional self poisoning by and exposure to pesticides, occurrence at unspecified place

U20y.	[X]Intentional self poisoning by and exposure to other and unspecified chemicals and noxious substances
U20y0	[X]Intentional self poisoning by and exposure to other and unspecified chemicals and noxious substances, occurrence at home
U20y1	[X]Intentional self poisoning by and exposure to other and unspecified chemicals and noxious substances, occurrence in residential institution
U20y2	[X]Intentional self poisoning by and exposure to other and unspecified chemicals and noxious substances, occurrence at school, other institution and public administrative area
U20y3	[X]Intentional self poisoning by and exposure to other and unspecified chemicals and noxious substances, occurrence at sports and athletics area
U20y4	[X]Intentional self poisoning by and exposure to other and unspecified chemicals and noxious substances, occurrence on street and highway
U20y5	[X]Intentional self poisoning by and exposure to other and unspecified chemicals and noxious substances, occurrence at trade and service area
U20y6	[X]Intentional self poisoning by and exposure to other and unspecified chemicals and noxious substances, occurrence at industrial and construction area
U20y7	[X]Intentional self poisoning by and exposure to other and unspecified chemicals and noxious substances, occurrence on farm
U20yy	[X]Intentional self poisoning by and exposure to other and unspecified chemicals and noxious substances, occurrence at other specified place
U20yz	[X]Intentional self poisoning by and exposure to other and unspecified chemicals and noxious substances, occurrence at unspecified place

U21..	[X]Intentional self-harm by hanging, strangulation and suffocation
U210.	[X]Intentional self-harm by hanging, strangulation and suffocation, occurrence at home
U211.	[X]Intentional self-harm by hanging, strangulation and suffocation, occurrence in residential institution
U212.	[X]Intentional self-harm by hanging, strangulation and suffocation, occurrence at school, other institution and public administrative area
U213.	[X]Intentional self-harm by hanging, strangulation and suffocation, occurrence at sports and athletics area
U214.	[X]Intentional self-harm by hanging, strangulation and suffocation, occurrence on street and highway
U215.	[X]Intentional self-harm by hanging, strangulation and suffocation, occurrence at trade and service area
U216.	[X]Intentional self-harm by hanging, strangulation and suffocation, occurrence at industrial and construction area
U217.	[X]Intentional self-harm by hanging, strangulation and suffocation, occurrence on farm
U21y.	[X]Intentional self-harm by hanging, strangulation and suffocation, occurrence at other specified place
U21z.	[X]Intentional self-harm by hanging, strangulation and suffocation, occurrence at unspecified place
U22..	[X]Intentional self-harm by drowning and submersion
U220.	[X]Intentional self-harm by drowning and submersion, occurrence at home
U221.	[X]Intentional self-harm by drowning and submersion, occurrence in residential institution

U222.	[X]Intentional self-harm by drowning and submersion, occurrence at school, other institution and public administrative area
U223.	[X]Intentional self-harm by drowning and submersion, occurrence at sports and athletics area
U224.	[X]Intentional self-harm by drowning and submersion, occurrence on street and highway
U225.	[X]Intentional self-harm by drowning and submersion, occurrence at trade and service area
U226.	[X]Intentional self-harm by drowning and submersion, occurrence at industrial and construction area
U227.	[X]Intentional self-harm by drowning and submersion, occurrence on farm
U22y.	[X]Intentional self-harm by drowning and submersion, occurrence at other specified place
U22z.	[X]Intentional self-harm by drowning and submersion, occurrence at unspecified place
U23..	[X]Intentional self-harm by handgun discharge
U230.	[X]Intentional self-harm by handgun discharge, occurrence at home
U231.	[X]Intentional self-harm by handgun discharge, occurrence in residential institution
U232.	[X]Intentional self-harm by handgun discharge, occurrence at school, other institution and public administrative area
U233.	[X]Intentional self-harm by handgun discharge, occurrence at sports and athletics area
U234.	[X]Intentional self-harm by handgun discharge, occurrence on street and highway
U235.	[X]Intentional self-harm by handgun discharge, occurrence at trade and service area

U236.	[X]Intentional self-harm by handgun discharge, occurrence at industrial and construction area
U237.	[X]Intentional self-harm by handgun discharge, occurrence on farm
U23y.	[X]Intentional self-harm by handgun discharge, occurrence at other specified place
U23z.	[X]Intentional self-harm by handgun discharge, occurrence at unspecified place
U24..	[X]Intentional self-harm by rifle, shotgun and larger firearm discharge
U240.	[X]Intentional self-harm by rifle, shotgun and larger firearm discharge, occurrence at home
U241.	[X]Intentional self-harm by rifle, shotgun and larger firearm discharge, occurrence in residential institution
U242.	[X]Intentional self-harm by rifle, shotgun and larger firearm discharge, occurrence at school, other institution and public administrative area
U243.	[X]Intentional self-harm by rifle, shotgun and larger firearm discharge, occurrence at sports and athletics area
U244.	[X]Intentional self-harm by rifle, shotgun and larger firearm discharge, occurrence on street and highway
U245.	[X]Intentional self-harm by rifle, shotgun and larger firearm discharge, occurrence at trade and service area
U246.	[X]Intentional self-harm by rifle, shotgun and larger firearm discharge, occurrence at industrial and construction area
U247.	[X]Intentional self-harm by rifle, shotgun and larger firearm discharge, occurrence on farm
U24y.	[X]Intentional self-harm by rifle, shotgun and larger firearm discharge, occurrence at other specified place

U24z.	[X]Intentional self-harm by rifle, shotgun and larger firearm discharge, occurrence at unspecified place
U25..	[X]Intentional self-harm by other and unspecified firearm discharge
U250.	[X]Intentional self-harm by other and unspecified firearm discharge, occurrence at home
U251.	[X]Intentional self-harm by other and unspecified firearm discharge, occurrence in residential institution
U252.	[X]Intentional self-harm by other and unspecified firearm discharge, occurrence at school, other institution and public administrative area
U253.	[X]Intentional self-harm by other and unspecified firearm discharge, occurrence at sports and athletics area
U254.	[X]Intentional self-harm by other and unspecified firearm discharge, occurrence on street and highway
U255.	[X]Intentional self-harm by other and unspecified firearm discharge, occurrence at trade and service area
U256.	[X]Intentional self-harm by other and unspecified firearm discharge, occurrence at industrial and construction area
U257.	[X]Intentional self-harm by other and unspecified firearm discharge, occurrence on farm
U25y.	[X]Intentional self-harm by other and unspecified firearm discharge, occurrence at other specified place
U25z.	[X]Intentional self-harm by other and unspecified firearm discharge, occurrence at unspecified place
U26..	[X]Intentional self-harm by explosive material
U260.	[X]Intentional self-harm by explosive material, occurrence at home

U261.	[X]Intentional self-harm by explosive material, occurrence in residential institution
U262.	[X]Intentional self-harm by explosive material, occurrence at school, other institution and public administrative area
U263.	[X]Intentional self-harm by explosive material, occurrence at sports and athletics area
U264.	[X]Intentional self-harm by explosive material, occurrence on street and highway
U265.	[X]Intentional self-harm by explosive material, occurrence at trade and service area
U266.	[X]Intentional self-harm by explosive material, occurrence at industrial and construction area
U267.	[X]Intentional self-harm by explosive material, occurrence on farm
U26y.	[X]Intentional self-harm by explosive material, occurrence at other specified place
U26z.	[X]Intentional self-harm by explosive material, occurrence at unspecified place
U27..	[X]Intentional self-harm by smoke, fire and flames
U270.	[X]Intentional self-harm by smoke, fire and flames, occurrence at home
U271.	[X]Intentional self-harm by smoke, fire and flames, occurrence in residential institution
U272.	[X]Intentional self-harm by smoke, fire and flames, occurrence at school, other institution and public administrative area
U273.	[X]Intentional self-harm by smoke, fire and flames, occurrence at sports and athletics area
U274.	[X]Intentional self-harm by smoke, fire and flames, occurrence on street and highway
U275.	[X]Intentional self-harm by smoke, fire and flames, occurrence at trade and service area

U276.	[X]Intentional self-harm by smoke, fire and flames, occurrence at industrial and construction area
U277.	[X]Intentional self-harm by smoke, fire and flames, occurrence on farm
U27y.	[X]Intentional self-harm by smoke, fire and flames, occurrence at other specified place
U27z.	[X]Intentional self-harm by smoke, fire and flames, occurrence at unspecified place
U28..	[X]Intentional self-harm by steam, hot vapours and hot objects
U280.	[X]Intentional self-harm by steam, hot vapours and hot objects, occurrence at home
U281.	[X]Intentional self-harm by steam, hot vapours and hot objects, occurrence in residential institution
U282.	[X]Intentional self-harm by steam, hot vapours and hot objects, occurrence at school, other institution and public administrative area
U283.	[X]Intentional self-harm by steam, hot vapours and hot objects, occurrence at sports and athletics area
U284.	[X]Intentional self-harm by steam, hot vapours and hot objects, occurrence on street and highway
U285.	[X]Intentional self-harm by steam, hot vapours and hot objects, occurrence at trade and service area
U286.	[X]Intentional self-harm by steam, hot vapours and hot objects, occurrence at industrial and construction area
U287.	[X]Intentional self-harm by steam, hot vapours and hot objects, occurrence on farm
U28y.	[X]Intentional self-harm by steam, hot vapours and hot objects, occurrence at other specified place

U28z.	[X]Intentional self-harm by steam, hot vapours and hot objects, occurrence at unspecified place
U29..	[X]Intentional self-harm by sharp object
U290.	[X]Intentional self-harm by sharp object, occurrence at home
U291.	[X]Intentional self-harm by sharp object, occurrence in residential institution
U292.	[X]Intentional self-harm by sharp object, occurrence at school, other institution and public administrative area
U293.	[X]Intentional self-harm by sharp object, occurrence at sports and athletics area
U294.	[X]Intentional self-harm by sharp object, occurrence on street and highway
U295.	[X]Intentional self-harm by sharp object, occurrence at trade and service area
U296.	[X]Intentional self-harm by sharp object, occurrence at industrial and construction area
U297.	[X]Intentional self-harm by sharp object, occurrence on farm
U29y.	[X]Intentional self-harm by sharp object, occurrence at other specified place
U29z.	[X]Intentional self-harm by sharp object, occurrence at unspecified place
U2A..	[X]Intentional self-harm by blunt object
U2A0.	[X]Intentional self-harm by blunt object, occurrence at home
U2A1.	[X]Intentional self-harm by blunt object, occurrence in residential institution
U2A2.	[X]Intentional self-harm by blunt object, occurrence at school, other institution and public administrative area
U2A3.	[X]Intentional self-harm by blunt object, occurrence at sports and athletics area
U2A4.	[X]Intentional self-harm by blunt object, occurrence on street and highway

U2A5.	[X]Intentional self-harm by blunt object, occurrence at trade and service area
U2A6.	[X]Intentional self-harm by blunt object, occurrence at industrial and construction area
U2A7.	[X]Intentional self-harm by blunt object, occurrence on farm
U2Ay.	[X]Intentional self-harm by blunt object, occurrence at other specified place
U2Az.	[X]Intentional self-harm by blunt object, occurrence at unspecified place
U2B..	[X]Intentional self-harm by jumping from a high place
U2B0.	[X]Intentional self-harm by jumping from a high place, occurrence at home
U2B1.	[X]Intentional self-harm by jumping from a high place, occurrence in residential institution
U2B2.	[X]Intentional self-harm by jumping from a high place, occurrence at school, other institution and public administrative area
U2B3.	[X]Intentional self-harm by jumping from a high place, occurrence at sports and athletics area
U2B4.	[X]Intentional self-harm by jumping from a high place, occurrence on street and highway
U2B5.	[X]Intentional self-harm by jumping from a high place, occurrence at trade and service area
U2B6.	[X]Intentional self-harm by jumping from a high place, occurrence at industrial and construction area
U2B7.	[X]Intentional self-harm by jumping from a high place, occurrence on farm
U2By.	[X]Intentional self-harm by jumping from a high place, occurrence at other specified place

U2Bz.	[X]Intentional self-harm by jumping from a high place, occurrence at unspecified place
U2C..	[X]Intentional self-harm by jumping or lying before moving object
U2C0.	[X]Intentional self-harm by jumping or lying before moving object, occurrence at home
U2C1.	[X]Intentional self-harm by jumping or lying before moving object, occurrence in residential institution
U2C2.	[X]Intentional self-harm by jumping or lying before moving object, occurrence at school, other institution and public administrative area
U2C3.	[X]Intentional self-harm by jumping or lying before moving object, occurrence at sports and athletics area
U2C4.	[X]Intentional self-harm by jumping or lying before moving object, occurrence on street and highway
U2C5.	[X]Intentional self-harm by jumping or lying before moving object, occurrence at trade and service area
U2C6.	[X]Intentional self-harm by jumping or lying before moving object, occurrence at industrial and construction area
U2C7.	[X]Intentional self-harm by jumping or lying before moving object, occurrence on farm
U2Cy.	[X]Intentional self-harm by jumping or lying before moving object, occurrence at other specified place
U2Cz.	[X]Intentional self-harm by jumping or lying before moving object, occurrence at unspecified place
U2D..	[X]Intentional self-harm by crashing of motor vehicle
U2D0.	[X]Intentional self-harm by crashing of motor vehicle, occurrence at home
U2D1.	[X]Intentional self-harm by crashing of motor vehicle, occurrence in residential institution

U2D2.	[X]Intentional self-harm by crashing of motor vehicle, occurrence at school, other institution and public administrative area
U2D3.	[X]Intentional self-harm by crashing of motor vehicle, occurrence at sports and athletics area
U2D4.	[X]Intentional self-harm by crashing of motor vehicle, occurrence on street and highway
U2D5.	[X]Intentional self-harm by crashing of motor vehicle, occurrence at trade and service area
U2D6.	[X]Intentional self-harm by crashing of motor vehicle, occurrence at industrial and construction area
U2D7.	[X]Intentional self-harm by crashing of motor vehicle, occurrence on farm
U2Dy.	[X]Intentional self-harm by crashing of motor vehicle, occurrence at other specified place
U2Dz.	[X]Intentional self-harm by crashing of motor vehicle, occurrence at unspecified place
U2E..	[X]Self mutilation
U2y..	[X]Intentional self-harm by other specified means
U2y0.	[X]Intentional self-harm by other specified means, occurrence at home
U2y1.	[X]Intentional self-harm by other specified means, occurrence in residential institution
U2y2.	[X]Intentional self-harm by other specified means, occurrence at school, other institution and public administrative area
U2y3.	[X]Intentional self-harm by other specified means, occurrence at sports and athletics area
U2y4.	[X]Intentional self-harm by other specified means, occurrence on street and highway
U2y5.	[X]Intentional self-harm by other specified means, occurrence at trade and service area

U2y6.	[X]Intentional self-harm by other specified means, occurrence at industrial and construction area
U2y7.	[X]Intentional self-harm by other specified means, occurrence on farm
U2yy.	[X]Intentional self-harm by other specified means, occurrence at other specified place
U2yz.	[X]Intentional self-harm by other specified means, occurrence at unspecified place
U2z..	[X]Intentional self-harm by unspecified means
U2z0.	[X]Intentional self-harm by unspecified means, occurrence at home
U2z1.	[X]Intentional self-harm by unspecified means, occurrence in residential institution
U2z2.	[X]Intentional self-harm by unspecified means, occurrence at school, other institution and public administrative area
U2z3.	[X]Intentional self-harm by unspecified means, occurrence at sports and athletics area
U2z4.	[X]Intentional self-harm by unspecified means, occurrence on street and highway
U2z5.	[X]Intentional self-harm by unspecified means, occurrence at trade and service area
U2z6.	[X]Intentional self-harm by unspecified means, occurrence at industrial and construction area
U2z7.	[X]Intentional self-harm by unspecified means, occurrence on farm
U2zy.	[X]Intentional self-harm by unspecified means, occurrence at other specified place
U2zz.	[X]Intentional self-harm by unspecified means, occurrence at unspecified place
U41..	[X]Hanging strangulation + suffocation undetermined intent
U44..	[X]Rifle shotgun+larger firearm discharge undetermin intent

U45..	[X]Other+unspecified firearm discharge undetermined intent
U4B..	[X]Falling jumping/pushed from high place undeterm intent
U4Bz.	[X]Fall jump/push frm high plce undt intnt occ unspecif plce
U72..	[X]Sequel intentn self-harm assault+event of undeterm intent
U720.	[X]Sequelae of intentional self-harm
ZRLfC12	Health of the Nation Outcome Scales item 2 – nonaccidental self-injury
ZX...	Self-harm
ZX1..	Self-injurious behaviour
ZX11.	Biting self
ZX12.	Burning self
ZX13.	Cutting self
ZX15.	Drowning self
ZX18.	Hanging self
ZX19.	Hitting self
ZX191	Punching self
ZX192	Slapping self
ZX1B.	Jumping from height
ZX1B1	Jumping from building
ZX1B2	Jumping from bridge
ZX1B3	Jumping from cliff
ZX1C.	Nipping self
ZX1E.	Pinching self
ZX1G.	Scratches self
ZX1H.	Self-asphyxiation
ZX1H1	Self-strangulation
ZX1H2	Self-suffocation
ZX1I.	Self-scalding

ZX1J.	Self-electrocution
ZX1K.	Self-incineration
ZX1L.	Self-mutilation
ZX1L1	Self-mutilation of hands
ZX1L2	Self-mutilation of genitalia
ZX1L3	Self-mutilation of penis
ZX1L6	Self-mutilation of ears
ZX1LD	[X]Self mutilation
ZX1M.	Shooting self
ZX1N.	Stabbing self
ZX1Q.	Throwing self in front of train
ZX1R.	Throwing self in front of vehicle
ZX1S.	Throwing self onto floor

APPENDIX K: CODING USED TO IDENTIFY SELF-HARM IN EMERGENCY DEPARTMENT DATA

Emergency Department

All attendances recorded under the attendance group 'deliberate self-harm' were included unless the sole diagnosis was overdose of alcohol.

Due to the nature of the coding system employed in the ED dataset it is not possible to simply choose codes equivalent to those available in READ or ICD 10. Additional analysis of events recorded under attendance group 'undetermined intent' was conducted in order to identify diagnoses related to self-harm.

All ED attendance from 2011-2015 were identified (n = 59344). An event was defined as a date in which an individual attended ED and was recorded as attendance group 'undetermined intent'. If multiple attendances in one day were recorded this would still only be counted as one event.

Admission to hospital within seven days of ED attendance was employed as a measure of whether an ED attendance resulted in admission to hospital. A period of seven days was chosen to allow for a possible 48 hours spent in ED and for any delays in data recording. Of the ED events identified 8251 were followed by a hospital admission within seven days. Of these admissions 666 had a diagnosis of self-harm recorded within that spell of care.

The ED diagnoses for the 666 cases that were subsequently admitted to hospital with self-harm were identified. An ED diagnosis of overdose (excluding alcohol) was recorded in 71% (n=470) of cases. Lacerations to wrists and forearms were recorded in 5% (n=35) of events.

Including both those with diagnoses of overdose (excluding alcohol) and laceration to the wrist or forearm accounts for 75% (n=505) of ED events recorded as undetermined intent where there is an admission to hospital within 7 days.

No other single EDDS diagnosis makes up a sufficiently large group (next largest is psychiatric disorder unspecified n = 17) so have only included overdose or laceration to wrist and forearm in the undetermined intent group.

Self-harm recorded if attendance group = 'deliberate self-harm' or if attendance group = undetermined intent alongside the following diagnosis codes

Poisoning or overdose

- 10B Prescribed Drug
- 10C Non-prescribed/purchased drug
- 10D Illicit Drug
- 10Z Poisoning or Overdose,
Unspecified

Wound

- 01A Laceration, with corresponding anatomical areas
- 205 Forearm
- 206 Wrist

APPENDIX L: CATEGORISATION OF HOSPITAL ADMISSION SPECIALITIES

Surgical Specialties

- 100 General Surgery
- 101 Urology
- 102 Transplantation Surgery
- 103 Breast Surgery
- 104 Colorectal Surgery
- 105 Hepatobiliary & Pancreatic Surgery
- 106 Upper Gastrointestinal Surgery
- 107 Vascular Surgery
- 108 Spinal Surgery Service
- 110 Trauma & Orthopaedics
- 120 ENT
- 130 Ophthalmology
- 140 Oral Surgery
- 141 Restorative Dentistry
- 142 Paediatric Dentistry
- 143 Orthodontics
- 144 Maxillo-Facial Surgery
- 150 Neurosurgery
- 160 Plastic Surgery
- 161 Burns Care
- 170 Cardiothoracic Surgery
- 172 Cardiac Surgery
- 173 Thoracic Surgery
- 174 Cardiothoracic Transplantation
- 191 Pain Management
- 199 Non-UK provider; specialty function not know, treatment mainly surgical (only applicable for overseas providers)

Accident and Emergency Surgical Specialty

180 Accident & Emergency

Paediatrics

211 Paediatric Urology

212 Paediatric Transplantation Surgery

213 Paediatric Gastrointestinal Surgery

214 Paediatric Trauma And Orthopaedics

215 Paediatric Ear Nose And Throat

216 Paediatric Ophthalmology

217 Paediatric Maxillo-Facial Surgery

218 Paediatric Neurosurgery

219 Paediatric Plastic Surgery

220 Paediatric Burns Care

221 Paediatric Cardiac Surgery

222 Paediatric Thoracic Surgery

223 Paediatric Epilepsy

241 Paediatric Pain Management

242 Paediatric Intensive Care

251 Paediatric Gastroenterology

252 Paediatric Endocrinology

253 Paediatric Clinical Haematology

254 Paediatric Audiological Medicine

255 Paediatric Clinical Immunology And Allergy Service

256 Paediatric Infectious Diseases

257 Paediatric Dermatology

258 Paediatric Respiratory Medicine

259 Paediatric Nephrology

260 Paediatric Medical Oncology

261 Paediatric Metabolic Disease

262 Paediatric Rheumatology

263 Paediatric Diabetic Medicine

264 Paediatric Cystic Fibrosis

- 280 Paediatric Interventional Radiology
- 290 Community Paediatrics
- 291 Paediatric Neuro-Disability
- 171 Paediatric Surgery
- 321 Paediatric Cardiology
- 420 Paediatrics
- 421 Paediatric Neurology

Psychiatry

- 700 Learning Disability
- 710 Adult Mental Illness
- 711 Child & Adolescent Psychiatry
- 712 Forensic Psychiatry
- 713 Psychotherapy
- 715 Old Age Psychiatry
- 720 Eating Disorders
- 721 Addiction Services
- 722 Liaison Psychiatry
- 723 Psychiatric Intensive Care
- 724 Perinatal Psychiatry
- 725 Mental Health Recovery And Rehabilitation Service
- 726 Mental Health Dual Diagnosis Service
- 727 Dementia Assessment Service
- 656 Clinical Psychology

General Medicine

- 300 General Medicine

Other Medical Specialities

- 190 Anaesthetics
- 192 Critical Care Medicine
- 301 Gastroenterology
- 302 Endocrinology
- 303 Clinical Haematology

- 304 Clinical Physiology
- 305 Clinical Pharmacology
- 306 Hepatology
- 307 Diabetic Medicine
- 308 Blood And Marrow Transplantation
- 309 Haemophilia Service
- 310 Audiological Medicine
- 311 Clinical Genetics
- 312 Clinical Cytogenetics and Molecular Genetics
- 313 Clinical Immunology and Allergy
- 314 Rehabilitation Service
- 315 Palliative Medicine
- 316 Clinical Immunology
- 317 Allergy Service
- 318 Intermediate Care
- 319 Respite Care
- 320 Cardiology
- 322 Clinical Microbiology
- 323 Spinal Injuries
- 324 Anticoagulant Service
- 325 Sport And Exercise Medicine
- 327 Cardiac Rehabilitation
- 328 Stroke Medicine
- 329 Transient Ischaemic Attack
- 330 Dermatology
- 331 Congenital Heart Disease Service
- 340 Respiratory Medicine
- 341 Respiratory Physiology
- 342 Programmed Pulmonary Rehabilitation
- 343 Adult Cystic Fibrosis Service
- 344 Complex Specialised Rehabilitation Service

- 345 Specialist Rehabilitation Service
- 346 Local Specialist Rehabilitation Service
- 350 Infectious Diseases
- 352 Tropical Medicine
- 360 Genitourinary Medicine
- 361 Nephrology
- 370 Medical Oncology
- 371 Nuclear Medicine
- 400 Neurology
- 401 Clinical Neurophysiology
- 410 Rheumatology
- 422 Neonatology
- 424 Well Babies
- 430 Geriatric Medicine
- 450 Dental Medicine Specialties
- 460 Medical Ophthalmology
- 499 Non-UK provider; specialty function not known, treatment mainly medical (only applicable for overseas providers)
- 501 Obstetrics
- 502 Gynaecology
- 503 Gynaecological Oncology
- 510 Obstetrics – AN (outpatients)
- 520 Obstetrics - PN (outpatients)
- 560 Midwifery Service
- 610 GP Maternity
- 620 GP Other
- 650 Physiotherapy
- 651 Occupational Therapy
- 652 Speech And Language Therapy
- 653 Podiatry
- 654 Dietetics

- 655 Orthoptics
- 657 Prosthetics
- 658 Orthotics
- 659 Drama Therapy
- 660 Art Therapy
- 661 Music Therapy
- 662 Optometry
- 663 Podiatric Surgery
- 800 Clinical Oncology (previously Radiotherapy)
- 810 Radiology
- 811 Interventional Radiology
- 812 Diagnostic Imaging
- 820 General Pathology
- 821 Blood Transfusion
- 822 Chemical Pathology
- 823 Haematology (non-clinical)
- 824 Histopathology
- 830 Immunopathology
- 831 Medical Microbiology
- 832 Neuropathology
- 834 Medical Virology
- 840 Audiology
- 900 Community Medicine
- 901 Occupational Medicine
- 920 Diabetic Education Service
- 950 Nursing
- 990 Joint Consultant Clinics
- 998 Diagnostic*
- 999 Allied Health Professional (AHP) Services*

APPENDIX M: AUTHORSHIP STATEMENT

Declaration:

Two chapter in this thesis were associated with published papers. These chapters were the systematic review of the literature in Chapter Three (Marchant et al., 2020b; Marchant et al., 2017) and the analysis of routinely collected healthcare data in Chapter Six (Marchant et al., 2019). In addition Chapter Five is associated with a manuscript currently in draft although the methods in this paper were not reproduced exactly here.

The following people and institutions contributed to the publication of work undertaken as part of this thesis:

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Located in: Appendix A (contributed to Chapter Three)

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Author 15 (Ann Stewart) contributed to: Conceiving of study design; extraction of data; commented meaningfully to draft and agreed final version

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Author 3 (Kate Daine) contributed to: Conceiving of study design; extraction of data; commented meaningfully to draft and agreed final version

Author 7 (Ann John) contributed to: Conceiving of study design; assessment of studies for inclusion; extraction of data; producing of first draft of paper; commented meaningfully to draft and agreement of final version

Paper 2: Marchant, A., Hawton, K., Burns, L., Stewart, A., & John, A. (2020). Images on the internet: A systematic review of studies on the impact of on-line sharing and viewing of self-harm related videos and photographs in young people. JMIR Preprints. 30/01/2020:18048. doi:10.2196/preprints.18048

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Candidate contributed to: Conceiving of study design; conducted electronic search; assessment of studies for inclusion; extraction and analysis of data; producing of first draft of paper; commented meaningfully to draft and agreed of final version

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Author 2 (Lauren Burns) contributed to: Conceiving of study design; conducted electronic search; assessment of studies for inclusion; extraction and analysis of data; producing of first draft of paper; commented meaningfully to draft and agreed of final version

Paper 3: Drafted manuscript not yet submitted for publication

Located in: Forms part of the analysis for Chapter Five

Candidate contributed to: Conceiving of study design; extraction and analysis of data; producing of first draft of paper; commented meaningfully to draft and agreed of final version

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Paper 4: Marchant, A., Turner, S., Balbuena, L., Peters, E., Williams, D., Lloyd, K., . . . John, A. (2019). Self-harm presentation across healthcare settings by sex in young people: an e-cohort study using routinely collected linked healthcare data in Wales, UK. Archives of disease in childhood, archdischild-2019-317248.

Located in: Appendix G (contributed to Chapter Six)

Candidate contributed to: Conceiving of study design; conducted electronic search; extraction and analysis of data; producing of first draft of paper; commented meaningfully to draft and agreed of final version

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We the undersigned agree with the above stated "proportion of work undertaken" for each of the above published peer-reviewed manuscripts contributing to this thesis:

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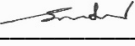
Author 9 (Ronan A Lyons)  _____

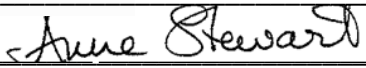
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