The Health and Wellbeing of Armed Forces Veterans in Northern Ireland

A Feasibility Study on Accessing Data for Research Purposes on Veterans in Northern Ireland

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Forces in Mind Trust: Foreword

In over eight years of Forces in Mind Trust seeking ways to better support the Armed Forces community, perhaps the most often cited recommendation is for more accurate data. In itself, I would argue that's insufficient. Knowing that a veteran lives in a region or postcode, or even at a specific address, is entirely valueless unless it includes evidence of unmet need. At a macro level, by applying known rates of arising of various conditions to populations, then general resource and service planning can certainly be better focused. And as this report makes clear, there are already several initiatives underway that might improve matters.

Project Cortisone (transfer of health records from military to NHS providers), the UK Government's Strategy for our Veterans strand on data, and the Confederation of Service Charities' Treasury-funded Data and Digital Strategy all seek to improve the quality of data on veterans, to which I would add Northumbria University's Map of Needs project, which would be better titled Map of Current Service Provision. And then there is the 2021 Census, which should yield in due course the disposition of veterans across the UK (although not in Scotland for a further year) and talk of linking Ministry of Justice and Department of Work and Pensions records. So far so promising.

But the barriers to data sharing let alone data integrating are immense. Some are regulatory, some are technical. Some are genuine concerns over security, and of these some are misplaced. Some are just sheer bloody-mindedness.

In commissioning this add-on piece of research to the main Northern Ireland Veterans Health and Wellbeing Study, we wanted to look specifically at the feasibility of accessing data on veterans in Northern Ireland. The findings are instructive and can be read across many other areas concerning the Armed Forces community across the whole UK. Naturally, we have taken great care to ensure no overt and unfair criticisms are reported, and we are immensely grateful to all the organizations who voluntarily participated. It is only by such honest discourse that we can identify and then ideally overcome barriers.

So, setting aside preconceptions, and avoiding grimacing too much at some of the case study narratives, do turn to Section 3 with its wholly sensible conclusions and recommendations. Of all the veterans' communities across the United Kingdom, according to our extensive body of evidence, those in Northern Ireland face some of the toughest challenges both in life outcomes and in accessing the support that can be available. Without it being enormously costly, there are already aspects of data sharing that can be improved, leading to better support all round. I would urge all those involved with

the Armed Forces community, and especially in Northern Ireland, to consider this report carefully and to take whatever action is necessary to make that improvement.

Air Vice-Marshal Ray Lock CBE

Chief Executive, Forces in Mind Trust

Combat Stress Foreword

This was an important piece of research to help better elucidate the needs of veterans living in Northern Ireland through attempts to quantify the size of the population. We were delighted to work the team of researchers led by Professor Armour. As a research active organisation, we are supportive of data sharing, particularly if it provides answers to key questions that in turn help us to better support veterans. Collaboration and data sharing are essential to improve the experiences of veterans and we feel this project aligned with both the veteran strategy and conversations across many groups including the CONTACT group to find better ways to support this. We felt the process was robust and that the researchers took great care to ensure compliance with data protection laws. They were responsive to any queries we had, and flexible with our requests.   We are pleased to see the report, it offers excellent insights into data sharing practices in the sector. As an organisation, we would be happy to continue this conversation and to be involved in future projects of this nature. We congratulate Professor Armour and her team on the production of this report.

Professor Dominic Murphy

Head of Research Combat Stress

President of the UK Psychological Society

*Both The Royal British Legion and Veterans UK were invited to provide a Foreword however TRBL declined because of time constraints and Veterans UK foreword is forthcoming.

Forces in Mind Trust

The Forces in Mind Trust was founded in 2012, through an endowment of £35 million from the National Lottery Community Fund, to promote the successful transition of Armed Forces personnel, and their families, into civilian life.

Our **Vision** is that all ex-Service personnel and their families lead successful and fulfilled civilian lives.

Our **Mission** is to enable them to make a successful and sustainable transition.

Our **Strategy** is to use our spend-out endowment to fund targeted, conceptually sound, evidence generation and influence activities that will cause policy makers and service delivers to support our Mission.

Full details of what we have funded, our published research, and our application process can be found on our web site www.fim-trust.org

Acknowledgements

Note

The NIVHWS commenced in 2015 at Ulster University. However, in July 2019, the NIVHWS moved to Queen's University Belfast with Professor Cherie Armour, the Principal Investigator. The data collection for this report occurred at Ulster University and at Queens University Belfast (interviews), however, all analyses and write up of the report occurred at Queen's University Belfast.

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List of Tables and Figures

Acronyms

GDPR	General Data Protection Regulation
MoD	Ministry of Defence
NI	Northern Ireland
NISRA	Northern Ireland Statistics and Research Agency
NIVHWS	Northern Ireland Veterans' Health and Wellbeing Study
NIVSC	Northern Ireland Veterans Support Committee
TRBL	The Royal British Legion
UDR & R IRISH (HS)	Ulster Defence Regiment & the Royal Irish (Home Service) regiment
UK	United Kingdom

Executive Summary

Overview

A Feasibility Study on Accessing Data for Research Purposes on Veterans in Northern Ireland is the fifth in a series of reports from the Northern Ireland Veterans' Health and Wellbeing Study (NIVHWS). The initial aim of this piece of work was to estimate the size and the basic demographic profile of the veteran population in Northern Ireland (NI), including their approximate location in the region, using a self-identification survey and administrative data shared by organisations that work with NI veterans. However, during the NIVHWS, it became clear that accessing data on NI veterans was not a straightforward process. This study was therefore re-designed to become a feasibility study on accessing data on NI veterans for research purposes. Presented here are three case studies and three corresponding interviews outlining our experiences and the experiences of data custodians in our efforts to access anonymous data on NI veterans for research purposes. The organisations were based in the charitable sector (Combat Stress [CS] and The Royal British Legion [TRBL]), and the Ministry of Defence (MoD) through Veterans UK, a MoD organisation and part of Defence Business Services (DBS) whose primary aim is to provide support to Armed Forces personnel, veterans, and their families, particularly in relation to pensions and compensation through their Veterans Welfare Service[1]. MoD. We also collected data from veterans themselves as an additional data source. The Strategy for Our Veterans[2]: UK Government Consultation Response dated 2020 was underway and finalised alongside the timeline of creating this report. A key principle of the strategy is that '**veterans are able to access support that meets their needs when necessary, through public and voluntary sectors'** (pp. 8). In addition, three of five cross cutting themes are particularly pertinent in the context of this report. These are:

1) **Collaboration between organisations**: Improved collaboration between organisations offers veterans coherent support;

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[1] https://www.gov.uk/government/organisations/veterans-uk

[2]
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/755915/Strategy_for_our_Veterans_FINAL_08.11.18_WEB.pdf

2**) Coordination of veterans' services**: The coordination of veterans' provision delivers consistent aims and principles over time and throughout the UK, ensuring veterans, their families and the bereaved are treated fairly compared to the local population; and

3) **Data on the veteran community**: Enhanced collection, use and analysis of data across the public, private, and charitable sectors to build an evidence base to effectively identify and address the needs of veterans.

Below we present a snapshot of detailed case studies of our engagements with organisations that hold data on veterans residing in Northern Ireland based in the charitable sector (CS and TRBL), the MoD (Veterans UK), and directly from veterans residing in Northern Ireland. Full details are in the main report.

Case Studies

Case study 1: Charitable sector (Combat Stress, TRBL)

Accessing data from the two organisations in the charitable sector was feasible. The following diagram outlines the main steps involved in the data sharing process between Combat Stress/TRBL and the research team:
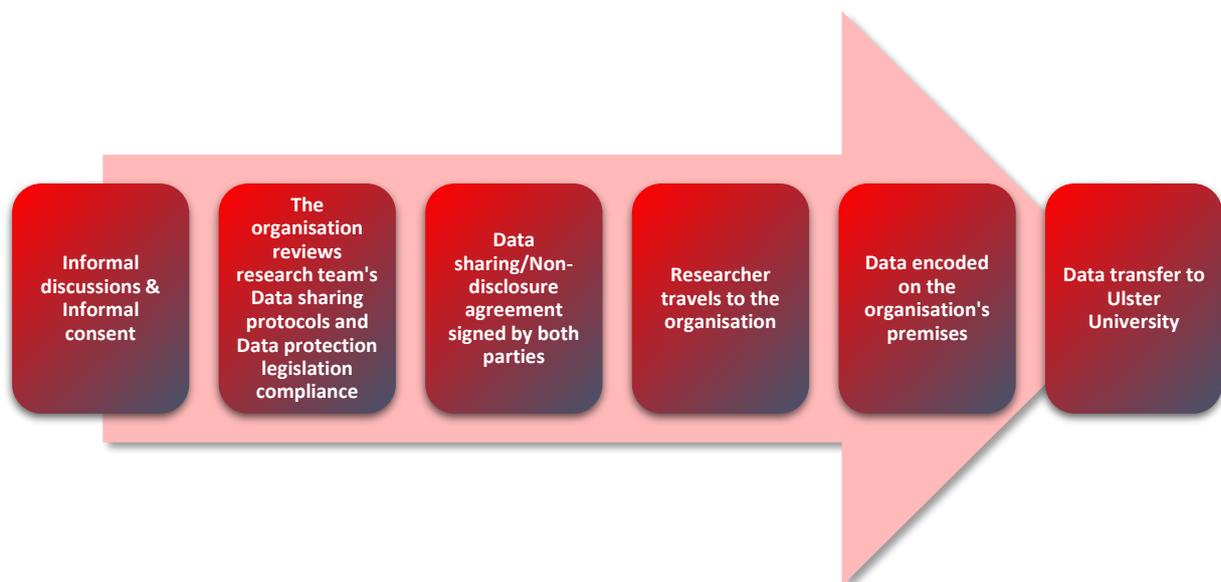
Case study 2: MoD (Veterans UK)

Accessing data from the MoD (specifically from Veterans UK) was not feasible. The following diagram summarises the main barriers encountered during the study:

2. Cost involved in data extraction

3. Mis-understanding of why the specific data was required

1. Concerns regarding security of the data

4. Data cannot be transferred to university prior to encoding and analysis

Addressed by research team and solution proposed

Data sharing
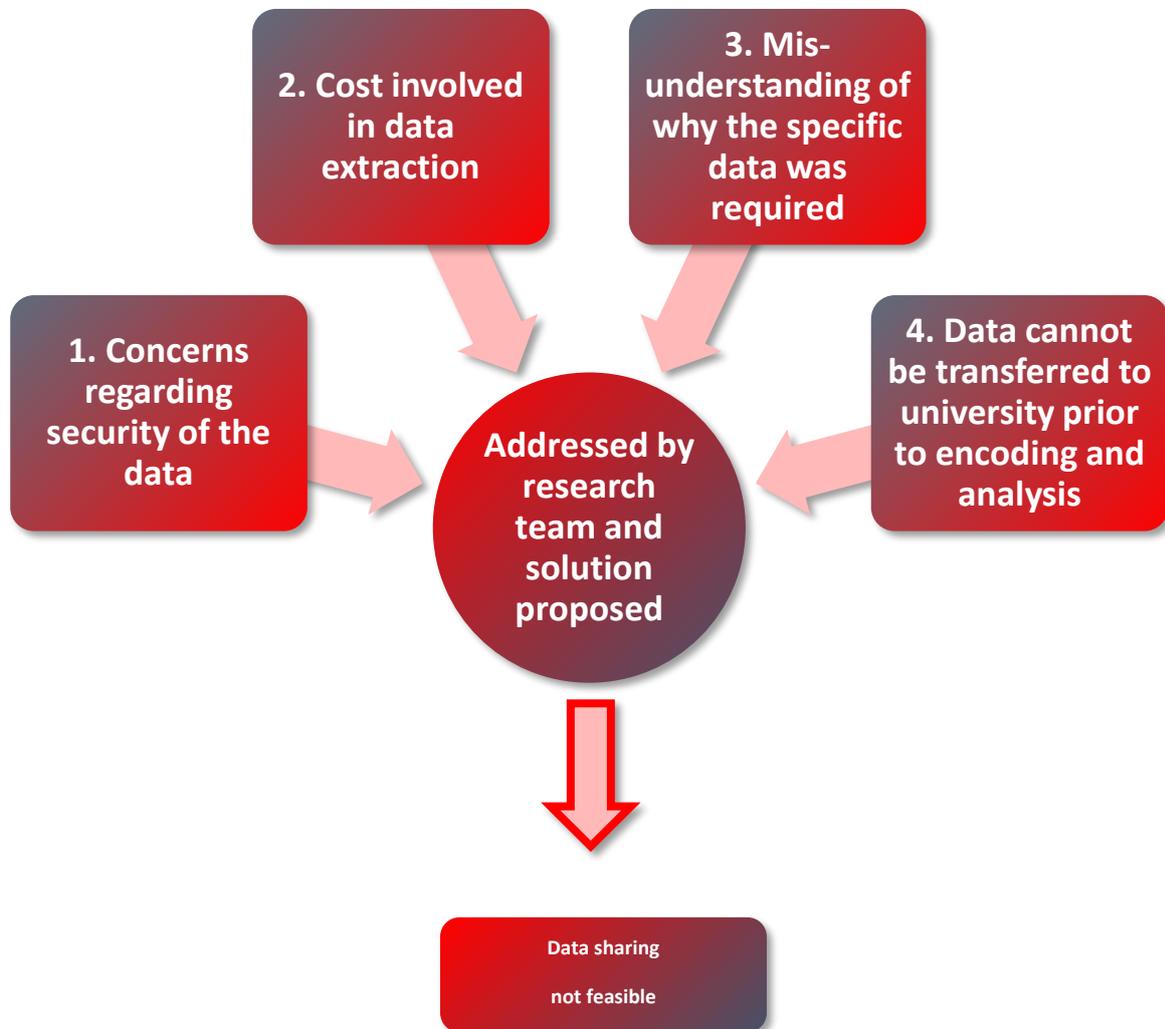
not feasible

Case study 3: The veterans

Accessing data directly from veterans in NI was feasible. Between June 2016 and September 2018, a total of 1,121 veterans shared their data directly and voluntarily with the research team. The response from veterans was generally positive, with only a very few of those approached refusing to provide the minimum demographic information requested.
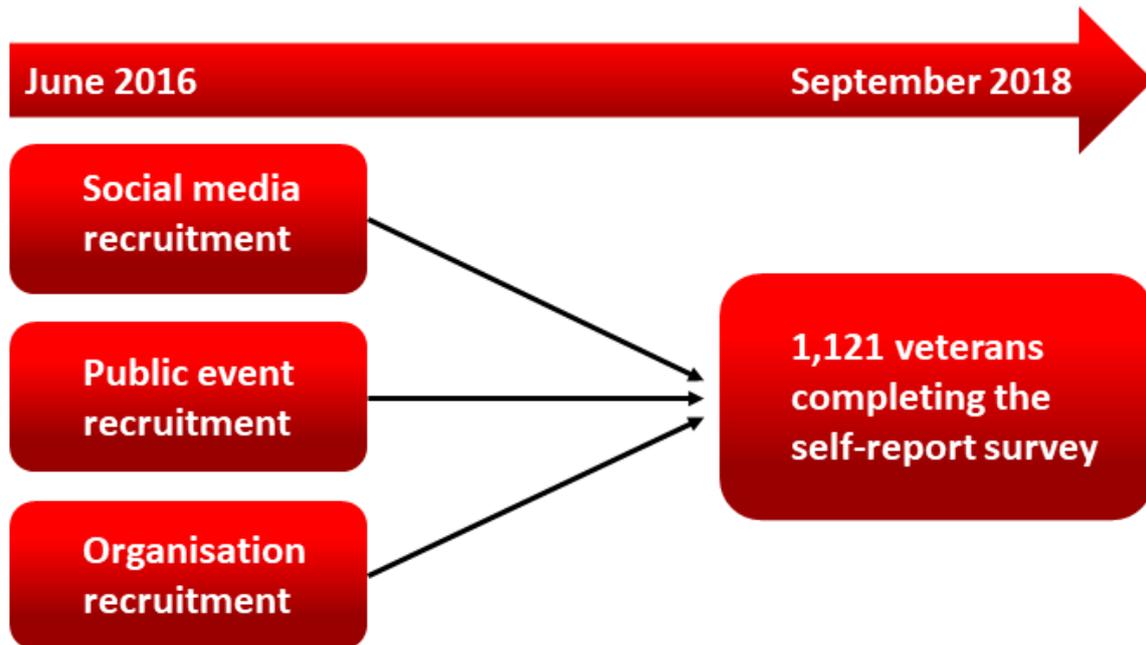
After the data sharing processes described above, a post-doctoral researcher was brought on to conduct a series of interviews with representatives from the charitable sector (CS and TRBL) and the MoD (Veterans UK). The interviews focused on the organisation's experiences and perceptions of the process. Interviews were scheduled with a representative of each group who had previously interacted with project. The individual interviews were conducted remotely using Microsoft Teams in January 2021. CS was represented by a senior data analyst, TRBL was represented by head of Performance and Policy, and the MoD was represented by a senior statistician.

A summary of the results of the interviews can be seen below:

AT A GLANCE:

- Organisations generally in favour of data sharing/linkage
- Multiple perceived benefits and fewer perceived barriers
- Mostly positive experiences of participation and processes

- Difference in academic data protocols versus organisational
- Sensitivity of NI data presents unique challenges for charities
- Charity sector has been slow to adapt to post-GDPR technology

- Security classification of MoD NI data as 'secret' when crossing sea
- Concerns NI veterans may be identified and endangered
- Security classification unlikely to change in the near future

Discussion and Recommendations

It is well established that the security concerns expressed by veterans in NI and corroborated by service providers in the region continue to be justified by adverse community attitudes concerning British military service. Despite this, it appears that veterans residing in the region are less concerned about sharing their own data for research purposes compared to data custodians in veteran organisations.

Having data on NI veterans could provide us with a more complete picture of the veteran population, including their needs, their demographic profile, and their number. Being able to access such data is particularly important considering the MoD's 2018 policy paper entitled *The Strategy for our Veterans*, which highlights the importance of "*enhanced collection, use and analysis of data across the public, private and charitable sectors to build an evidence base to effectively identify and address the needs of veterans*" (p.14).

Based on our experiences of data sharing with CS, TRBL, MoD and NI veterans, the following are our recommendations on how to move this field forward:

Key Area	Recommendation	Implications
Data collection and monitoring	Organisations within the statutory sector should design and implement consistent monitoring systems to capture data on veterans and their families.	Collecting this information will ensure that the demographic profile of the veteran population in NI is monitored. Regular updates on veterans' demographic profile will have implications for veteran-specific (but also non-specific) services that are being provided within the region. Notably there may be some sensitivities and concerns from across sectors regarding specific data capture on veteran status.
	Enduring consent for sharing anonymous data should be obtained from veterans at the time of data collection which specifies that the data may be used for audit, research and other purposes whilst maintaining the anonymity of data providers.	Although such consent is not necessary when anonymous data is shared for research purposes, this would provide an additional level of assurance to data managers.
Continuation of the current work	Key stakeholders should use this report and its recommendations to discuss a way forward for continuation of this work.	Quantifying and understanding the characteristics of the known veteran population will allow for more focused strategic and operational planning to ensure that veteran needs are provided for.
Data sharing	An educational piece should be developed specifically for data custodians in organisations that work with veterans, outlining	Clear guidelines would take the guess work from the situation

	processes for sharing data in a way that does not violate GDPR / Data Protection legislation and ensures veterans' safety and security. It would be prudent to secure a data sharing agreement from data custodians including government departments at the earliest point, regardless of any verbal agreements.	potentially speeding up the data sharing process.
	In line with Data Protection legislation and considerations for veterans' security and safety, mechanisms and regulations for data sharing within and between the statutory, MoD and voluntary and community sector organisations (including academic institutions) should be established.	This would enable important research work to be carried out, ultimately benefiting the veteran community.
Information systems development	In line with the considerations for veterans' safety and security, and in collaboration with veteran representatives, the statutory, MoD and the voluntary and community sector organisations should work together to agree a data specification that includes a minimum data set that all interested parties could draw	More routine and improved reporting of relevant data would improve needs assessment and service planning.

	upon, along with service/organisation specific data requirements. A central data collection point should be established. Of note, early-stage activities are currently underway to improve and standardise systems. The Contact Group (although initially focused on mental health but anticipated to broaden in scope) have been working on integrated and coordinated case management and pathway planning, common assessment criteria, and veteran identification.	

Full Report

1.0 Introduction

Overview:

- Northern Ireland Veterans' Health and Wellbeing Study (NIVHWS)
- Aims of this report

This report is the fifth in a series of reports from the Northern Ireland Veterans' Health and Wellbeing Study (NIVHWS), which provides the first ever comprehensive evidence base on the health and wellbeing of military veterans living in Northern Ireland (NI). Of note, the NIVHWS commenced in December 2015 at Ulster University. In July 2019, the NIVHWS moved to Queen's University Belfast with Professor Cherie Armour, the Principal Investigator.

1.1 Northern Ireland Veterans' Health and Wellbeing Study (NIVHWS)

In 2015, Prof Cherie Armour was commissioned by the Forces in Mind Trust (FiMT) to conduct two studies looking at the specific needs of the military veteran community in NI. The studies were designed to address the gap in the available information in relation to the veteran population in NI, specifically their mental health needs and the support and services available to veterans in NI. Recognizing the complementary nature of the two studies, they were merged into one larger study in January 2016 to form the NIVHWS. The main components of this larger project are outlined below.

1. Scoping Services to Veterans in NI[3]

This work package scoped the services available specifically to veterans in NI through the statutory, Ministry of Defence (MoD) and voluntary and community sector organisations. The results were published in a report entitled *Supporting & Serving Military Veterans in Northern Ireland* (Armour, Waterhouse-Bradley, Walker, & Ross, 2017a) in June 2017 and contain practical recommendations for improving the support and services available to veterans in NI. As a result of the recommendations of this report, a Veterans' Support Office has been established in NI, followed by the appointment of a Veterans Commissioner in 2020.

2a. Current and Future Needs of Veterans in NI: Interviews

The first part of the work package entitled 'Current and future needs of veterans in NI' looked at the experiences of veterans living in NI using focus group interviews with veterans and one to one interview with service providers. This led to the publication of a formal report entitled *Current and Future Needs of Veterans in Northern Ireland* (Armour, Walker, Waterhouse-Bradley, Hall, & Ross, 2017b) in December 2017. The report contains a series of recommendations for addressing veterans' current and future needs.

Additionally, this work package explored the potential need for a Veterans' Centre in NI. The Veterans' Centre was defined as a physical building which would provide tailored support to NI veterans. These efforts culminated in the publication of a report entitled *Exploring the Need for a Veterans' Centre in Northern Ireland* (Armour et al., 2018) in June 2018. The report outlined recommendations on how to further examine the feasibility of potentially setting up a dedicated Veterans' Centre.

2b. Current and Future Needs of Veterans in NI: Self-Report Survey

The second part of the 'Current and future needs of veterans in NI' work package is a large-scale fully anonymous self-report survey in which NI veterans report on their general wellbeing, mental and physical health, lifestyle, their experiences of transition from military to civilian life and many other aspects of their lives. The report pertaining to this survey will be available on 23rd April 2021.

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[3] 1 through 4 represent the work-packages as noted in all reports from the NIVHWS which can be located on the FiMT website: https://www.fim-trust.org/reports/

3. Quantifying the Veteran Population in NI (This report)

The initial aim of this work package was to estimate the size and the basic demographic profile of the veteran population in NI, including their approximate location in the region, using a self-identification survey and administrative data. This work package was designed around the idea of data sharing with organisations that work with NI veterans. However, during the NIVHWS, it became clear that accessing data on NI veterans was not a straightforward process. This work package was therefore re-designed to become a feasibility study on accessing data on NI veterans (and indeed veterans more widely) for research purposes. The current report pertains to this work package.

4. Communication and Dissemination (Ongoing)

This work package underlies the three previous ones; its essence is the discussions with key stakeholders to facilitate the research process, including access to research participants. The outputs include published reports, research papers, executive summaries, lay summaries and presentations at specific events and academic conferences, all designed to disseminate the findings of the wider study to a range of stakeholders. The primary objective is to increase the awareness of veterans' needs as well as the support services available to them. The initial objective was to develop a bespoke NI veteran dedicated website which would signpost veterans to sources of support. However, due to the unanticipated Veterans Gateway launching just as this website was due to be developed, the focus of this work package changed to one which worked alongside Veterans Gateway as a content liaison partner for sources of support in Northern Ireland[4]. A postdoctoral researcher was seconded to the Veterans Support Office (VSO) and ensured clear liaison between Veterans UK, the VSO, and researchers at QUB. In addition, the researcher developed the logo and website for the VSO.

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[4] https://www.veteransgateway.org.uk/local-support/

1.2 Aims of this Report

In this report, we present the results of a feasibility study on accessing data on NI veterans for research purposes. There are numerous reasons why access to such data may be required, one example being the estimation of the size of the veteran population residing in NI. Another reason is establishing in which region/post code veterans reside. These were some of the initial aims of the wider NIVHWS. By knowing the numbers of veterans and where in the region they live, it would be possible to ascertain whether the existing veteran-specific services in NI have sufficient capacity and are located in areas of greatest need. These efforts are particularly important, because currently, there is no systematic data collection on veterans in NI, nor is there likely to be in the foreseeable future, as the 2021 census for NI will not include a question on veteran identity[5] Additionally, as became evident in our first report (Armour et al., 2017a), the statutory sector service providers do not collect data on veterans.

This report presents three case studies and corresponding interviews with data custodians each related to experiences of attempting to secure access to data within: 1) the charitable sector (CS & TRBL), 2) the Ministry of Defence (MoD; Veterans UK), and 3) from veterans residing in NI. Key issues associated with data collection, data sharing, and data management in the three different cases are presented both from the research team and data custodian perspectives, with the aim being to stimulate discussions and collaborative efforts on data sharing within the wider veteran sector.

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[5] https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/topic-report-on-uk-armed-forces-veterans-update_1.pdf

2.0 Case studies

Chapter Overview:

- Ethical considerations and data protection legislation
- Requested data
- Case Study 1: The charitable sector (CS & TRBL)
- Case Study 2: The Ministry of Defence (MoD; Veterans UK)
- Case Study 3: Veterans residing in NI

Presented in this chapter are three cases studies outlining our experiences with trying to access anonymised data on NI veterans from organisations in the charitable sector, a MoD organisation, and veterans themselves. We present the methods and approaches that did and did not work.

2.1 Ethical considerations and data protection legislation

All procedures employed in the current feasibility study complied with the data protection legislation and were approved by the Filter Ethics Committee at the School of Psychology, Ulster University.

2.1.1 Compliance with data protection legislation

At the beginning of this feasibility study, the main data protection legislation in force was the Data Protection Act 1998. All the initial data sharing protocols were developed to comply with the Data Protection Act 1998. Once the General Data Protection Regulation (GDPR) and the Data Protection Act 2018 came into force on May 25, 2018, all the protocols were reviewed to ensure full compliance with the new legislation.

2.1.2 Ethical approval

Prior to commencing the study, the researchers sought ethical approval from the Filter Ethics Committee at the School of Psychology, Ulster University. Prior to granting approval, the filter committee ensures that:

- the researchers hold appropriate qualifications, have sufficient experience to conduct the research in question, and have no conflict of interest in relation to the study;
- the research study is supported by appropriate resources, is of negligible risk to participants, and uses appropriate methods;
- the research participants[6] will be provided with sufficient information about the study prior to deciding whether they want to participate, they will be given the opportunity to consent to their participation, and will be assured that their personal data will be held in confidence and anonymized in all reports; and
- the researchers have considered the potential risk for harm to participants and have taken steps to mitigate these risks.

Should the filter committee feel that there appear to be more than negligible risks to participants, they refer the study to the Research Governance section for consideration by the University Research Ethics Committee. In relation to the current study, the Filter Committee was satisfied with the research team's data protection legislation compliance, including their data sharing protocols, the data collection methods, and the procedures related to the care of participants' data and they granted ethical approval for the study.

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[6] This is relevant to Case study 3, where we collected data directly from veterans through a brief self-report survey. In relation to Case study 1 and Case study 2, the Data Protection Act 1998 and the GDPR outline a research exemption for sharing anonymized data.

2.1.3 Security vetting

The researchers had relevant security clearance (Counter Terrorist Check) prior to any data sharing taking place. This was important in the context of Northern Ireland and the nuances that relate to the personal security and safety of military veterans residing in Northern Ireland due to the longstanding legacy of the socio-political civil conflict also known as the Troubles and specifically, of Operation BANNER, the British Armed Forces campaign in NI from 1969-2007. Please refer to the other reports produced by the NIVHWS which provide further details around NI, Operation BANNER and the legacy for NI veterans.

2.2 Requested data

When we approached the data custodians, we requested the minimal data necessary to meet the original aims of the NIVHWS for estimating the size of the NI veteran population. To meet this aim, we were planning to use the capture-recapture analysis, which is a statistical method of estimating the size of a specific population. In recent years, this method has commonly been used to estimate the prevalence of problematic drug use or specific diseases and illnesses in human populations (Hansen et al., 2013; Hay et al., 2009; Hay et al., 2010; King, Bird, Hay, & Hutchinson, 2009; O'Callaghan, Shiell, Osborne, & Martyn, 1998; van Dam-Bates, Fyfe, & Cowen, 2016; van der Nagel et al., 2014). The capture re-capture method requires at least two different data sources on the population of interest. If the same individual is found in more than one data source (i.e. they have engaged with more than one organisation involved in data sharing), this is considered an overlap and this overlap is then used in statistical modelling to estimate the size of the population of interest.

To identify an overlap, successful linking of individuals across different data sources is paramount. Data linkage is a technique for connecting information, relating to the same individuals, across different data sources. In many cases, when an individual accesses a certain service, basic demographic information is collected (e.g. name, date of birth, address). If the same information is collected by different organisations, data linkage across these organisations can take place. For the purposes of the current study, and following the procedures used in previous capture-recapture studies of drug users conducted in England (Hay et al., 2009; Hay et al., 2010), we requested the following data from the organisations: veteran's initials (first name, surname only), date of birth, and gender (i.e. information that was likely to be held by NI organisations that provide support and services

to veterans in the region). Additionally, we requested partial postcode data, which could be used for estimating the approximate geographical distribution of veterans in NI.

Table 1. Requested data

Data requested from each organisation and from veterans themselves:
- First name initial   - Surname initial   - Date of birth   - Gender   - Partial postcode (outcode indicating the postcode area and district and the first part of the incode, indicating postcode sector, e.g. BT12 1 but not identifying any specific addresses)

Table 1 summarizes the data requested from the organisations. As shown in Table 2, prior to data sharing, this data was to be encoded (into a GUID, or globally unique identifier number) and fully anonymised, using a data encoding software with no decryption key (provided for use by colleagues at an alternative university who were the developers of the software)

Table 2. Data encoding

Original data prepared by the organisation

	A	B	C	D	E
1	FirstName	Surname	DOB	Gender	Partial postcode
2	c	c	13.04.1981	M	BT04 2
3	e	w	06.04.1984	F	BT41 9
4	d	c	01.12.1975	M	BT47 4
5	j	s	18.03.1950	M	BT7 1
6	a	e	19.12.1987	M	BT79 0
7	a	d	01.01.2000	M	BT63 6
8	f	w	03.08.1965	F	BT43 6
9	j	g	01.12.1981	M	BT2 7
10	o	a	01.09.1976	M	BT04 2
11	p	d	19.11.1953	M	BT01 5

Encoded data ready for sharing

	A	B	C	D
1	Identifier	Age	Gender	Partial postcode
2	D8D6665B-50B9-1F81-18F2-F3938658D342-B1C3	36	M	BT04 2
3	A9A32DB6-5548-F9D2-F780-9BA4414EC620-D8C5	33	F	BT41 9
4	06099CA5-8977-E48F-85B6-C3F985449105-A1E8	42	M	BT47 4
5	D7B59CAC-AB45-4C04-A6F5-F0A9DDF120D6-B3F6	67	M	BT7 1
6	C0A75108-9F28-751F-074E-C287AF20E781-C0D5	30	M	BT79 0
7	08C87D9A-B454-7D03-2DFA-7459E42D1E04-A4X2	18	M	BT63 6
8	408D5830-48CB-F444-17B8-1CCEF0E4D075-E6E7	52	F	BT43 6
9	50C2ACA8-A25D-4D26-40F3-EBDA3CC4B041-C1C3	36	M	BT2 7
10	99B28D0E-4E98-BACD-A58E-83AB1692A412-C3F7	41	M	BT04 2
11	48CDAFF4-0DFC-95D3-74C9-E27D65B5186E-C2E7	64	M	BT01 5

Note. The data was encoded prior to leaving the organisations. In case of collecting data directly from veterans, the encoding was performed by the researchers as soon as data collection was complete.

2.3 Case study 1: The charitable sector

Two charitable organisations were approached with a request to share their data: Combat Stress (CS) and The Royal British Legion (TRBL). Both organisations have a permanent presence in NI, with brick-and-mortar branches. CS is the main voluntary and community sector provider of mental health services to veterans in NI. TRBL provides welfare support to serving personnel, veterans and their families (including financial assistance, respite, advice, assistance with employment, training and others).

The research team's engagement with the two organisations started through informal discussions and requests for data sharing. Once informal consent for data sharing was given, the research team provided the data custodians in each organisation with documents outlining detailed data sharing protocols, compliance with the data protection legislation, and step by step instructions on what data was required and on how the data would be used for the study to be completed successfully.

Any concerns raised by the data custodians were addressed by the research team. This included providing an assurance from the encryption software developers that no decryption key existed for their software, meaning that once the data was encoded, there was no way to obtain the original information (i.e. survey initials and dates of birth from the GUID number).

Both organisations agreed that a researcher from the NIVHWS would visit their head office and encode the data on their premises under the supervision of their data custodians. A data sharing agreement/non-disclosure agreement was signed by all parties prior to the visit.

The initial engagement with CS began in July 2016. The visit to CS and the data transfer to Ulster University happened in October 2017. The initial engagement with TRBL began in March 2016. The visit to TRBL and the data transfer to Ulster University happened in July 2018.

Of note, once the TRBL saw how the encoding software worked, they shared the data requested by the research team, but on their own account, they also provided the team with a similar anonymous dataset acquired through the Veterans Gateway[7] project.

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[7] https://www.veteransgateway.org.uk/

Figure 1 outlines the process of data sharing between CS/TRBL and the NIVHWS research team. Table 3 outlines the main facilitators and barriers involved in the data sharing process with the two organisations.

Figure 1. Data sharing between Combat Stress/The Royal British Legion and NIVHWS
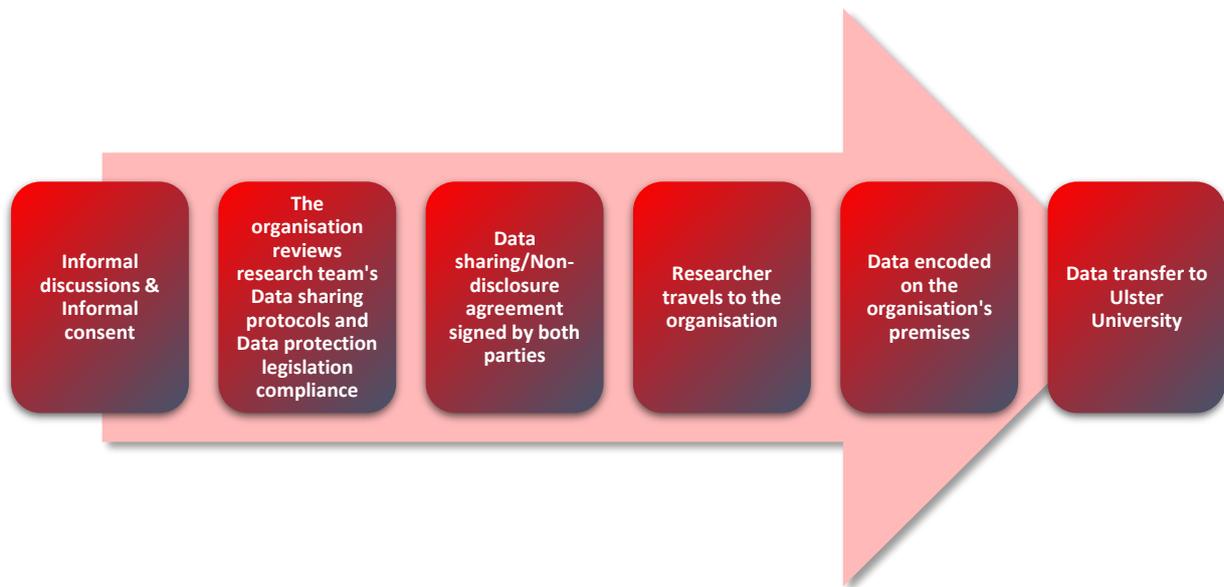
Table 3. Facilitators and barriers in the data sharing process within the charitable sector

Facilitators:
- Open, transparent, and regular communication between researchers and CS & TRBL data custodians.   - Clear data sharing protocols in place.   - Outline of how the data sharing process complies with (and does not violate) the data protection legislation.   - Assurance from the encoding software developers about the security of the encoded data.   - Signed data sharing/non-disclosure agreements.
Barriers:
Unavoidable time delays due to low staffing levels in the organisations.

2.4 Case Study 2: The MoD

Veterans UK is a MoD organisation providing support to Armed Forces personnel, veterans, and their families. As such, Veterans UK is the biggest data source containing information on veterans in NI.

Engagement with Veterans UK first started in March 2016 through discussions at the NIVHWS's Strategic Advisory Board. The data sharing protocols and data protection legislation compliance documents were provided to Veterans UK by the NIVHWS research team. Veterans UK raised several concerns related to the data sharing, including the security issues surrounding veterans in NI. The NIVHWS research team addressed all issues, such as specifying that the data would be anonymous and encrypted thus it would not be possible to identify individuals.

Several months later, Veterans UK noted that the data extraction might incur a cost due to the time that would be required to prepare the minimum data requested by the research team. The cost was unspecified. The NIVHWS team advised that they could join the analysts in Veterans UK headquarters in England and do the work on their behalf to minimise employee time spent on the project. Veterans UK were initially receptive and welcoming of this proposal.

The issues and concerns were also discussed in a conference call (April 2017) between Veterans UK and the research team. All queries were clarified, and the research team agreed to cover the cost of data extraction incurred by Veterans UK (the actual amount still being unspecified – a quote was to be prepared). Veterans UK tentatively proposed that data extraction could be carried out in July 2017. The research team summarised the main points of the call in an email that was disseminated to all those involved. Veterans UK did not raise any issues in relation to the points in the email. A few days after the conference call, Veterans UK contacted the research team with a view that the information they were looking for was publicly available. The research team explained that they had explored this option and clarified why the information that was publicly available would not be suitable for data linkage in the current project.

Another conference call followed a month later with new issues raised by Veterans UK. At this stage, it was agreed that the data would be transferred from Veterans UK to the UDR & R IRISH (HS) Aftercare Service[8], where one of the NIVHWS researchers would perform the encoding, using the secure MoD

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[8] https://aftercareservice.org/ - An MOD organisation

servers. Following the phone call, Veterans UK produced a timeline of actions that needed to be taken prior to the data sharing. The NIVHWS research team completed the tasks allocated to them but heard nothing further in relation to the completion of Veterans UK's tasks.

Several weeks later, Veterans UK asked the research team to further clarify additional information. Veterans UK requested the data linkage (in addition to data encoding) would need to take place at the UDR & R IRISH (HS) Aftercare Service site to ensure that the research team would not be in possession of the Veterans UK data as a standalone file. In practice, this requirement meant that the research team would need to take the other datasets of the feasibility study to the Aftercare Service and conduct the data linkage there. The research team agreed to this requirement and the head of the Aftercare Service agreed to facilitate the process.

In January 2018, a conference call was arranged between Veterans UK and the research team. New issues and concerns were raised by Veterans UK, which proposed that the data be shared via the Administrative Data Research Network (ADRN) NI as a third party who had considerable experience dealing with administrative data. Unfortunately, the research team found that this would not be possible due to the length of time the ADRN application process would take, in what had become by this point a tight timeframe for this element of the NIVHWS project. The research team requested a reason from Veterans UK to help them understand why the ADRN was a more secure option than using the MoD servers via the Aftercare Service, and why this method had not been requested earlier, but no explanation was forthcoming.

As new issues continued to be raised, the research team emailed Veterans UK to propose a face-to-face meeting that would allow all remaining issues to be aired, clarified, and addressed, and would allow the research team to demonstrate the encoding software. Unfortunately, the research team received no response to this offer. In the same email, the research team suggested that one of the researchers could visit Veterans UK and carry out the encoding on their premises and under their supervision. Veterans UK agreed to this latter proposal and suggested March 2018 for the visit. Unfortunately, as it was a requirement that the data linkage be conducted on their premises, this was not feasible at that point as the research team had not yet acquired the data from TRBL. It was agreed that the visit be postponed until July 2018. Additionally, as it was not permissible for an external researcher to access the raw data, Veterans UK offered to perform the encoding and data linkage, after which the researcher could conduct the analyses on their premises. The research team agreed to this.

At the end of May 2018, Veterans UK informed the research team that the data sharing may not be possible due to a similar project being conducted by the Northern Ireland Statistics and Research Agency (NISRA). The research team had not been aware of a similar project being conducted by NISRA, but this was related to MoD/NISRA research into the viability of including a question on the 2021 census in NI on veteran identity. In September 2018, after over two years of liaison between the research team and Veterans UK, the research team was informed that Veterans UK would not be able to share their data "due to the high security threat associated with this data" (this statement was never further elaborated on) and due to their low staffing levels. This was despite previous reassurances by the research team that the shared data would be entirely anonymous and encrypted and that the research team could provide staff to complete the work[9].

On the recommendation of the NIVHWS advisory board, the research team made one final attempt to engage Veterans UK in the data sharing process, by utilising personal contacts to find out whether there was anyway and any circumstances under which the organisation would be willing to co-operate. Unfortunately, the NIVHWS research team did not make any progress on this.

Figure 2 outlines the main barriers and obstacles when trying to access anonymised data from Veterans UK.

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[9] The research team retained detailed records of correspondence with Veterans UK and have archived all email correspondence.

Figure 2. Main barriers and obstacles involved in data sharing with Veterans UK
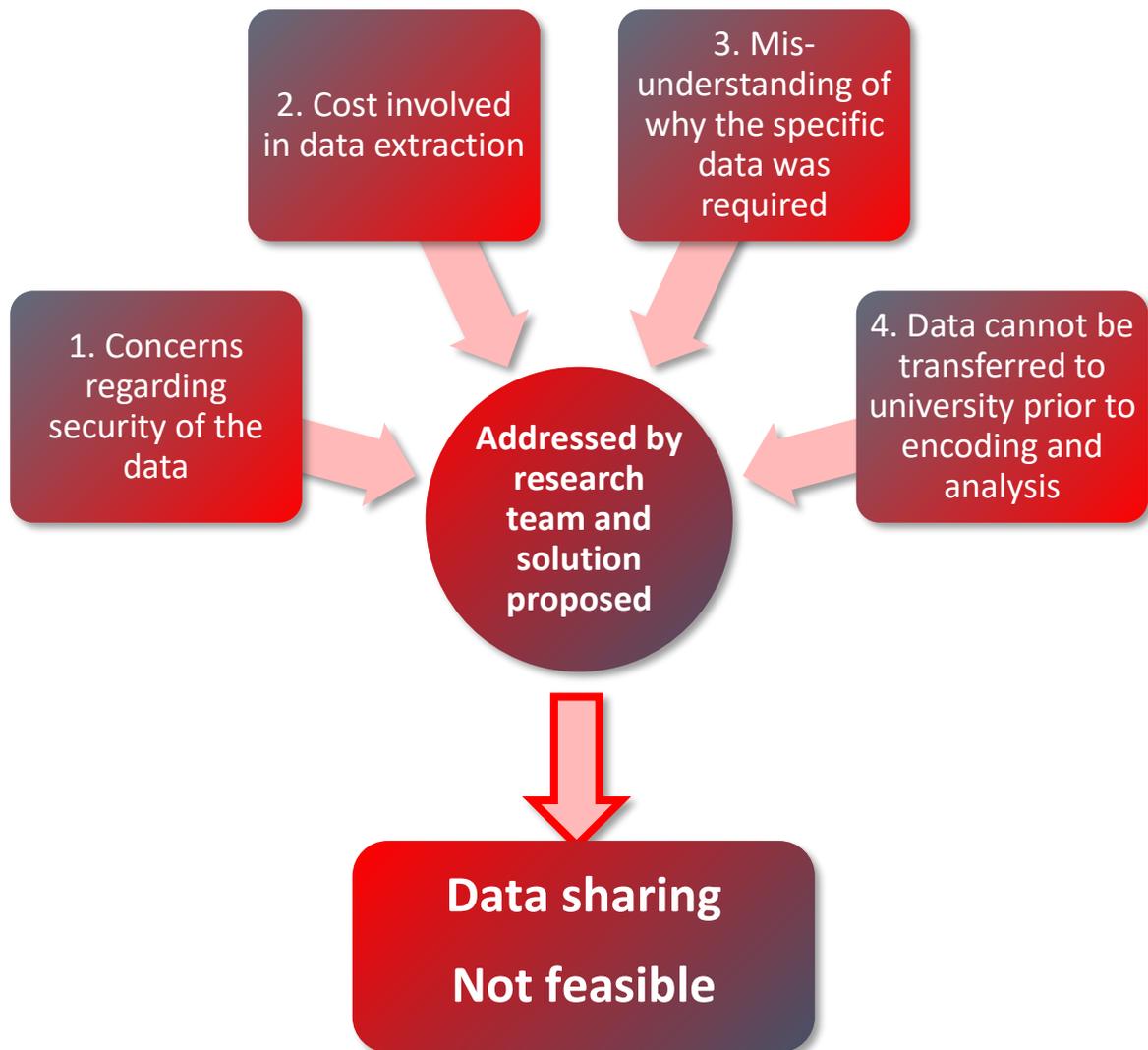

2.5 Case Study 3: The veterans

In addition to the data shared by external organisations, the research team collected their own data using a self-report survey, where participants self-identified as veterans of the British Armed Forces. We recruited participants through social media, public events such as the Armed Forces Day[10], and NI organisations that work with veterans. The response from veterans was generally positive, with only a very few of those approached refusing to provide the minimum demographic information requested. Between June 2016 and September 2018, a total of 1,121 veterans completed the self-report survey, providing their initials, gender, and date of birth, and 1,079 of these also provided their partial

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[10] https://www.armedforcesday.org.uk/

postcode. The research team believe that this demonstrates that veterans did not generally have a problem sharing their basic demographic information.

Figure 3. Veteran participant recruitment process
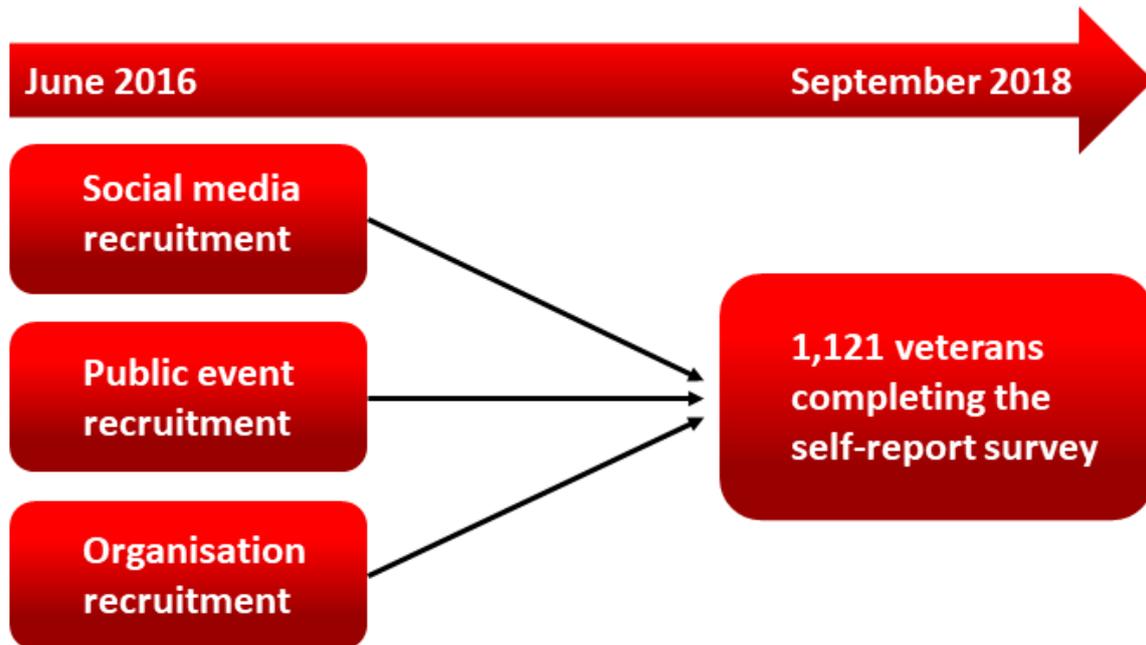
The following is a demographic breakdown of veterans who completed the self-report self-identification survey. This information is presented to show that many veterans with different backgrounds were willing to share their details. ***It is NOT to be a representative description of the NI veteran population.***

Figure 4. Basic demographic profile of veterans who shared their data

89% of veterans served in the Army, 25% served in the Royal Navy, 9% served in the Royal Marines and 9% served in the Royal Air Force
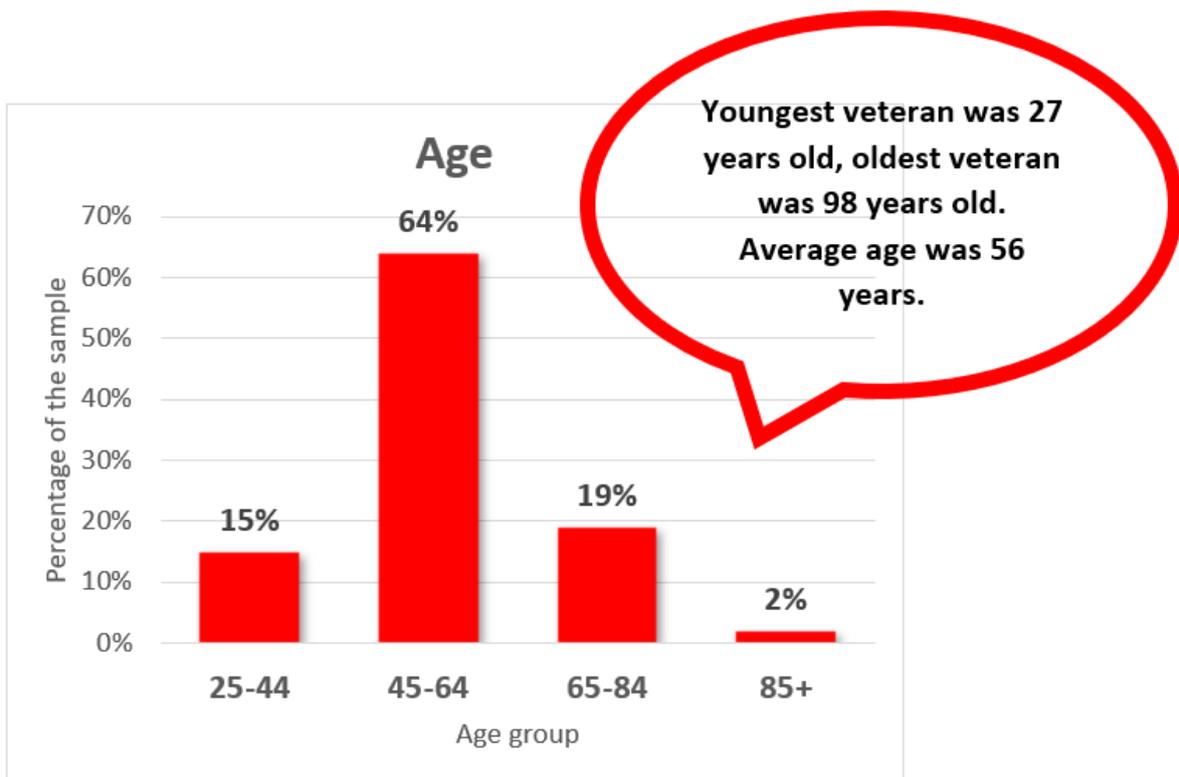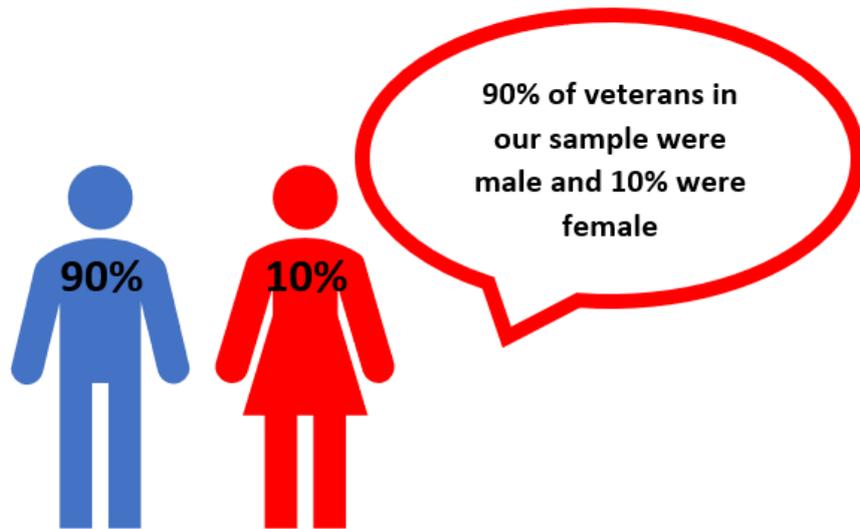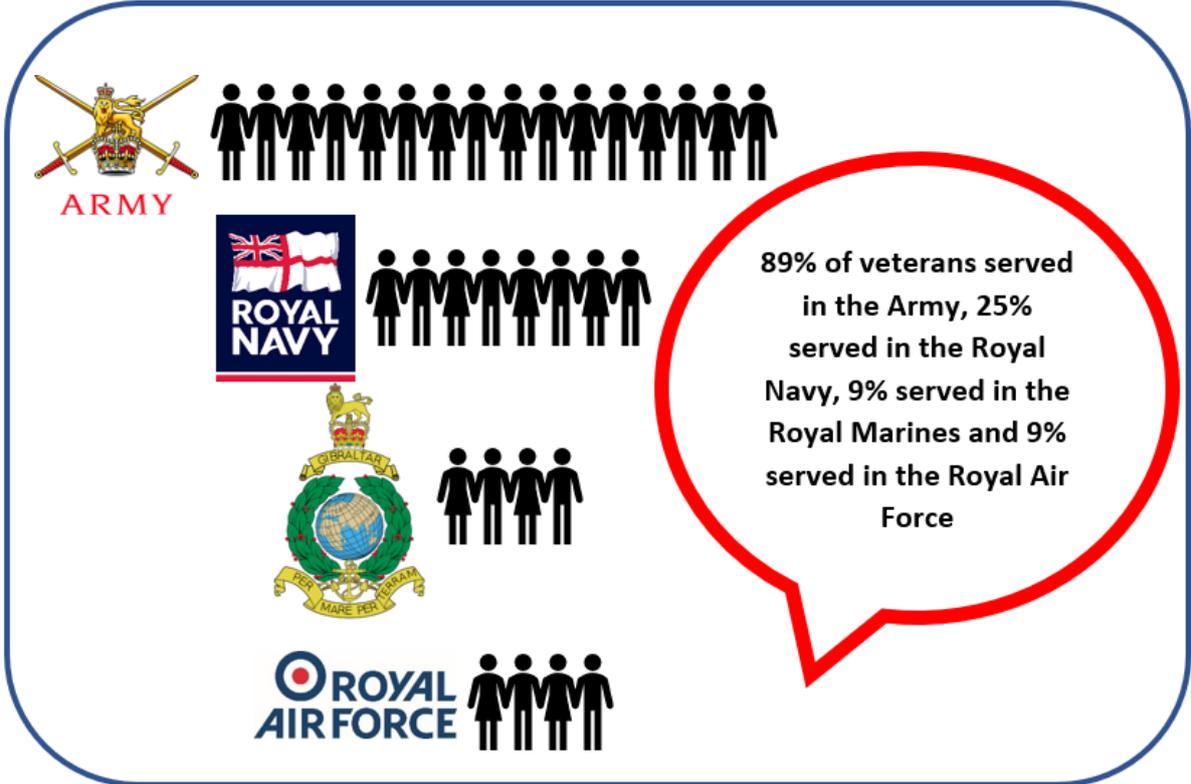
59% of veterans served in the UDR/R IRISH (HS)

10% were medically discharged

60% served as Regulars only, 12% served as Reservists only, 28% served as both Regulars and Reservists

The below summarises the key conclusion from this section of the report:

Key points:

- All procedures for this study complied with the data protection legislation.

- The research team requested minimal data from the organisations/veterans.

- Accessing data on NI veterans from the charitable organisations was feasible.

- Accessing data on NI veterans from a MoD organisation was not feasible.

- Accessing data directly from NI veterans was feasible

2.6 Understanding the perspectives of potential partner organisations in relation to data access.

The data sharing process encompasses more than the simple transfer of data from one party to another. A better understanding of this process and the feasibility of future research begins with understanding the perspectives of potential partner organisations in the government and charity sectors. To accomplish this, a post-doctoral research unaffiliated with the project team was brought on to compose a series of interview questions concerning the data sharing associated with the Northern Ireland Veterans' Health and Wellbeing Study (NIVHWS), focusing on the organisations' experiences and perceptions of the process, and to facilitate qualitative interviews on these experiences. Interviews were scheduled with a representative of each group who had interacted with the project team and the individual interviews were conducted remotely using Microsoft Teams in January 2021. Combat Stress (CS) was represented by a senior data analyst, the Royal British Legion (TRBL) was represented by head of Performance and Policy, and the Ministry of Defence (MoD) was represented by a senior statistician.

AT A GLANCE:

- Organisations generally in favour of data sharing/linkage
- Multiple perceived benefits and fewer perceived barriers
- Mostly positive experiences of participation and processes

- Difference in academic data protocols versus organisational
- Sensitivity of NI data presents unique challenges for charities
- Charity sector has been slow to adapt to post-GDPR technology

- Security classification of MoD NI data as 'secret' when crossing sea
- Concerns NI veterans may be identified and endangered
- Security classification unlikely to change in the near future

2.6.1 Perceptions of Data Sharing Prior to Project Involvement

All representatives had previous experience in data sharing and data linkage, either in their current roles or previous employment, expressing positive feelings regarding its potential. Those from the charitable sector reported enjoying being exposed to new people and methods while believing that data sharing between organisations opened the "bigger picture" of the data. The Veterans UK representative said it maximises the value of the data and described data linkage as part of the MoD's "core business", including work with the census, inter-departmental government use, data-sharing with devolved governments, and academic partnerships. Institutionally, CS was eager to be involved with the project, the TRBL reported some initial data security concerns that they felt they could be overcome, and the MoD saw the proposal of sharing NI data as "challenging".

All three organisations felt there were clear perceived benefits to data sharing in the context of NIVHWS, including potential relationship building/networking between organisations (CS), publication of studies using the data (RBL), and the ability to understand and support NI veterans by upholding the Armed Forces Covenant[11] (MoD). MoD added that the security concerns surrounding NI data negated any possible benefits. Data sensitivity and security around data transfer/handling was cited by all three as a the most significant perceived barrier to participation. Both charities sought to protect their beneficiaries from identification but were eager to work with the project team in developing agreed security protocols. MoD regulations stated that once data crossed the Irish Sea, it was automatically designated 'secret'[12] (only accessible by UK nationals) and there was concern about veteran data being potentially exploited by terrorist organisations operating in NI/the Republic of Ireland. Additionally, TRBL brought up the incongruence of academic data sharing protocols with external organisations' pre-existing data protocols, stating this had previously been an issue in working with universities.

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[11] https://www.armedforcescovenant.gov.uk/

[12] Note, this was the first time that it was disclosed to the research team that the data would be classified as 'secret' on crossing the Irish Sea and the research team can only assume this was not known to Veterans UK during the two years of engagement on data sharing. We were informed that "due to the high security threat associated with this data" it could not be shared, but were not provided with further explanation on the point.

2.6.2 Project Involvement

In discussing the process of developing security protocols for use with the NIVHWS, each person stressed the risks involved with personal veteran data. CS and the TRBL engaged with this process while the MoD was not able to enter a data sharing agreement with the project team. CS stated that the security protocol felt very secure and complete and TRBL reported that while they felt the initial protocol was not strict enough, it was negotiated to the point where they felt comfortable. The MoD representative explained their usual process in establishing data security protocols, using a project (which came online after the NIVHWS engagements) with the Northern Irish Statistics and Research Agency (NISRA) as an example. Here the MoD representative detailed the full systems audit, hand-to-hand data exchange, and existence of a formal contract with the MoD. MoD added that contracting[13] with external organisations better facilitates the process and overall ease of data security management, though even if the MoD had been a primary stakeholder from the beginning, it still would not have been able to share identifying data[14].

The experience of working with the project and team members differed by sector. The charities described this as "very smooth from beginning to end" (CS) and "really helpful" (TRBL), though TRBL highlighted that the hand-to-hand transfer of data via a flight to Belfast felt "a bit silly, like Bridge of Spies", acknowledging that newer GDPR-compliant technology would now make the process easier for both parties. The MoD representative reported that differing perspectives and expectations between the research team and the MoD produced "frustration on both sides" during the lengthy discussions over data security. The MoD representative reported that they believed the MoD understood the Troubles and that this differed from that of the Northern Irish project team residing in the region, adding that MoD did see the value of the research but that their hands were tied by the security classification on NI data.

Very few technical problems arose during participation with the project. TRBL reported that a software licencing issue had initially been a barrier but that it was quickly resolved. They tied this to an earlier point concerning academic protocols having a different focus compared to charity sector data protocols and that they would like to have seen a more comprehensive initial plan more in-line with external organisation expectations. While the MoD did not progress to project involvement, they

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[13] A formal contract was never requested by MOD/Veterans UK during the discussion on data sharing.

[14] The research team did not request identifying data from any partners and went to great lengths to ensure data would be fully anonymised and encrypted.

reinforced that no amount of protocol negotiation could get around the security classification of the NI data but stated a clear data map and outline of linkage/procedure at the onset would have been preferred[15].

There was complete agreement on the sensitivity of NI veteran data and that it posed unique challenges. As an organisation, CS is very cautious about protecting all aspects of their NI beneficiaries, from data held about them to mailing permissions, while TRBL's strict security protocols apply equally across the UK, making NI "no different from Cornwall". For the MoD, NI data is only officially 'sensitive' in Great Britain, rather than 'secret UK-eyes only' as it is classified once it crosses the Irish Sea. Had the project been conducted in Great Britain, a security audit/assessment and contract would still have been required but the process would have avoided the additional barrier of the data becoming 'secret'. Even if that had been the case, the MoD advised that the NI data would have remained an issue due to concerns around NI veterans being identifiable.

None of the organisations felt that additional resources, specifically additional manpower, would have improved the data sharing process. CS stated that none would have been needed, as the job was very easily done in only a few hours, and TRBL noted that they could not have allowed a third party to access their data. While third party manpower to handle mundane tasks would have been acceptable to MoD[16], they explained it was a moot point as negotiations with the MoD never progressed to that stage[17]. When asked if they felt these barriers to data sharing could be overcome in the future, the MoD representative suggested that researchers might partner with a government approved organisation (such as NISRA) to host the data. However, the MoD would still require detailed audit logs, proof that only UK nationals were handling data, and the immediate destruction of unlinked data (in addition to other security measures).

2.6.3 Future Data Sharing

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[15] The research team had provided a detailed document specifying all procedures to be implemented regarding data anonymization, encryption, and linkage to all data custodians.

[16] The previously noted low staffing levels referred specifically to Veterans UK, not the MoD itself. The MoD representative was not a part of Veterans UK.

[17] Veterans UK had originally agreed to additional third-party manpower via the research team to help with linkage tasks and suggested that a researcher visit their HQ in March 2018. However, as the research team needed to have TRBL data before visiting Veterans UK and had not yet acquired it by March, the visit had to be postponed to July 2018 and was subsequently cancelled.

All organisations agreed that future data sharing carried considerable benefits, primarily, better service and understanding of veteran needs. For CS, this meant bringing new people together with new data practices/methods for CS to utilise, while for TRBL, it meant better resource allocation for them by using data to partner with other organisations to best serve their beneficiaries, including lobbying and direct service provision. The MoD also reported seeing value in continued data linkage/sharing in their partnership with NISRA, seeking to understand NI veterans' needs from a population level. Regarding future barriers, both CS and TRBL anticipated that more organisations would understand the value of 'big data' in a post-GDPR world, with industry becoming less protective and more open to data partnerships. MoD acknowledged that security classification of NI veteran data would continue as the MoD's main barrier, stating that this would not change until all conflict veterans had passed away or all terrorist organisations in NI/ROI had disbanded.

When asked if interactions with/involvement in the NIVHWS project had changed their feelings on data sharing, all three agreed they had been pro-data sharing beforehand and had remained so. CS discussed their disillusion with data use in the charity sector, emphasising a wealth of data exists and is underutilised, and had welcomed the change to participate in this project, while TRBL felt that data sharing in the private sector is changing for the better. MoD described their involvement in other MoD data linkage projects, underscoring their importance and value, and added that they would have liked to participate with this research, but acknowledged that the NI security classification had prevented this. All interviewees were thanked for their time and were advised that they could follow up with the project lead at any time if they had any questions or concerns.

3.0 Discussion and Recommendations

3.1 Summary

This feasibility study provides our account of attempting to access anonymous data on NI veterans from the charitable sector, the MoD, and veterans themselves. As outlined in the previous chapter, accessing veterans' data from the charitable sector was feasible, whereas accessing the same data from a MoD organisation proved not feasible. Most veterans approached by the team were willing to share their own data voluntarily. The original capture recapture methodology is most effective with multiple and large data sources and as the two obtained sources were both from charities and thus would have included a large treatment/service seeking cohort, it was not feasible to go ahead with the analysis. Detailed account of interviews with the data custodian highlighted several facilitators and barriers to data sharing.

There is no doubt that the security concerns expressed by veterans in NI and corroborated by service providers in the region (Armour et al., 2017a) continue to be justified (Security Service MI5, 2020). Despite this, since the very early stages of the NIVHWS, 1,121 veterans trusted the research team to maintain their right to confidentiality and anonymity when sharing their names and contact details as part of the self-identification survey (over 1000 of these veterans provided consent to be contacted in the future in relation to further veteran-related research). Additionally, over 1300 veterans completed our comprehensive self-report Wellbeing Survey[18]. The research team believe this is in part due to the stringent methods and ethics of the researcher being clearly articulated and evident to participants.

The organisations involved in this study were asked to share with the research team only minimal data that was encoded and thus anonymous. All study procedures were fully compliant with the data protection legislation and Ulster University's research governance and policy. The research team had appropriate security clearance and safeguards in place to prevent the potential loss or leaking of the data. Moreover, even in the very unlikely event that the data was leaked outside of the research team,

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[18] This is part of another component of the NIVHWS – Current and Future Needs of Veterans in NI

there would be no way to identify any of the veterans, as the data was always stored in an encoded format.

In NI, there is no precedent for sharing data (anonymous or not) related to veterans. Data on veterans is not being routinely collected by any statutory sector organisations (Armour et al., 2017b). The data held by the charitable and MoD organisations is incomplete, as not every veteran will be involved with these organisations. A way forward is to work with these organisations to find acceptable ways of sharing data. When combined, data from these organisations can provide a more complete picture of the veteran population, including their needs, their demographic profile and also their number. An important lesson learned from this feasibility study is that veterans living in NI appear to have fewer concerns about sharing their data with the researchers than some data managers.

3.2 MoD's policy paper: Strategy for our Veterans

The importance of data sharing in the veteran sector is highlighted by the MoD's publication of a policy paper entitled *The Strategy for our Veterans*, published in November 2018 (MoD, 2018). The paper sets out the principles needed to continue to empower and meet the needs of veterans and the wider veteran community for the next ten years. One of the desired outcomes to be achieved by 2028 is "*enhanced collection, use and analysis of data across the public, private and charitable sectors to build an evidence base to effectively identify and address the needs of Veterans*" (p.14). The paper acknowledges that "*better identification of Veterans within and through data can lead to greater understanding of their needs, trends and geographical distribution*" (p.14).

3.3 Recommendations

Based on our experiences of data sharing with CS, TRBL, Veterans UK and the veterans resident in NI, the following are our recommendations on how to move this field forward:

Table 4. Recommendations

Key Area	Recommendation	Implications
Data collection and monitoring	Organisations within the statutory sector should design and implement consistent monitoring systems to capture data on veterans and their families.	Collecting this information will ensure that the demographic profile of the veteran population in NI is monitored. Regular updates on veterans' demographic profile will have implications for veteran-specific (but also non-specific) services that are being provided within the region. Notably there may be some sensitivities and concerns from across sectors regarding specific data capture on veteran status.
	Enduring consent for sharing anonymous data should be obtained from veterans at the time of data collection which specifies that the data may be used for audit, research and other purposes whilst maintaining the anonymity of data providers.	Although such consent is not necessary when anonymous data is shared for research purposes, this would provide an additional level of assurance to data managers.
Continuation of the current work	Key stakeholders should use this report and its recommendations to discuss a way forward for continuation of this work.	Quantifying and understanding the characteristics of the known veteran population will allow for more focused strategic and operational planning to ensure that veteran needs are provided for.
Data sharing	An educational piece should be developed specifically for data	Clear guidelines would take the guess work out of the picture,

	custodians in organisations that work with veterans, outlining processes for sharing data in a way that does not violate GDPR / Data Protection legislation and ensures veterans' safety and security. It would be prudent to secure a data sharing agreement from data custodians including government departments at the earliest point, regardless of any verbal agreements.	potentially speeding up the data sharing process.
	In line with Data Protection legislation and considerations for veterans' security and safety, mechanisms and regulations for data sharing within and between the statutory, MoD and voluntary and community sector organisations (including academic institutions) should be established.	This would enable important research work to be carried out, ultimately benefiting the veteran community.
Information systems development	In line with the considerations for veterans' safety and security, and in collaboration with veteran representatives, the statutory, MoD and the voluntary and community sector organisations should work together to agree a data specification that includes a minimum data set that all interested parties could draw	More routine and improved reporting of relevant data would improve needs assessment and service planning.

upon, along with service/organisation specific data requirements. A central data collection point should be established.

Of note, early-stage activities are currently underway to improve and standardise systems. The Contact Group (although initially focused on mental health but anticipated to broaden in scope) have been working on integrated and coordinated case management and pathway planning, common assessment criteria, and veteran identification. | |

3.4 Conclusions

This feasibility study demonstrates that security cleared academic researchers can access anonymous data on NI veterans from the charitable sector, and from veterans themselves, but not from Veterans UK in this case. Accessing basic data on veterans from different sources would allow the researchers to make estimations that would enable one to answer questions such as:

- How many veterans reside in NI?
- Where are they located?
- What are their needs?

This is necessary for the accurate and efficient provision of services to those needs. As there is no central monitoring system on veterans in NI, this means that any attempts at providing adequate support and services to veterans in the region are based on estimates, potentially leaving out those in greatest need.

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