

## **MONARCH Study Update and FAQs – September 2023**

I am delighted to have joined the MONARCH Study team as the Charity Stakeholder Relationship Manager. My role involves managing relationships with charities within the Armed Forces Charity Sector to ensure as much data is made available to the Project as possible. I'm here to keep you updated, answer any questions you may have, and to take back suggestions for future developments to Professor Matt Kiernan and his team.

Do get in touch with me at [meri@mericonsulting.co.uk](mailto:meri@mericonsulting.co.uk) if there is anything I can help with or that you'd like to discuss.

I thought it might be helpful at this stage if I provided a short update on the MONARCH Study in the form of some FAQs and answers. These are very concise answers, and I can provide fuller and more detailed information on any topic areas included here.

Please let me know if you'd like to be added to a mailing list to receive updates about the MONARCH Study.

Meri Mayhew

Charity Stakeholder Relationship Manager to the MONARCH Study

### **1. What is the MONARCH Study?**

The military community is a unique set of population clusters with some distinctive needs that require specific health policies and interventions. The development of evidence-based health and social care services for military Veterans is imperative and can only be achieved with a comprehensive understanding of how statutory and charitable services across the UK are currently used.

The MONARCH project is truly unique and provides a strong rationale and methodology to continuously monitor changes and to address resource allocation over time. As a direct result, we will be able to identify characteristics associated with specific service users which will provide the basis for proactive health and social care interventions for those that do not currently seek services themselves. This approach sits central to the NHS approach of 'make every contact count' and 'get it right first time'.

The overall, long-term, aim of this project is to reduce the instances of health and social care crisis in the military Veteran's community by informing early identification and intervention strategies. By proactively preventing complex situations and crisis, this project will benefit both individuals, health and social care systems and, importantly, the Armed Forces Charity Sector.

The project is led by Professor Matt Kiernan with a small specialist team at the University of Northumbria based in Newcastle.

## **2. How is the MONARCH Study different from the Map of Need?**

Prior to 2017, little was known about the number of Veterans accessing services, in terms of the types of services being accessed, the location, or the numbers accessing these services. To address this, in March 2017, the Ministry of Defence Covenant Fund Team commissioned Professor Kiernan and his team in the Northern Hub for Military Veterans and Families Research<sup>1</sup> to produce a map of Veterans' and their families' welfare needs across the whole of the UK. The result was known as the 'Map of Need (MoN)'.

This project takes forward the MoN 'proof of concept' initiative to create a national, unified aggregated – or combined - dataset of military Veteran service usage and to translate data into easy-to-use information in a dynamic visual dashboard for policy makers and service deliverers in the charity and statutory sectors.

## **3. How does the MONARCH Study work?**

The limitations of looking at data in silos, such as data for each individual charity, is that it fails to identify their role and relationship within the wider military charity sector and the other services that Veterans might use. Furthermore, the risk for double counting and over-representing service usage becomes a significant problem if systems are not identifying individuals that use multiple services. Identifying individuals that use multiple services is essential in providing an accurate picture. Analysis of an individual charity's data might be helpful for a specific charity, but is not helpful for the OVA, MOD, NHS, Local Government, and the wider charity sector, who need to understand how the population as a whole uses services. There needs to be a reliable resource that adds to the wider picture to inform policy, resource allocation together with service provision and development.

The MONARCH study works by collecting as much data as possible about Veterans from across the myriad of different data flows that currently exist to provide one single, combined or aggregated, dataset providing a comprehensive, contemporary and dynamic overview of support services being used and hence a window into Veterans' needs.

## **4. Which cohorts are included?**

At the moment we are focusing on the Veteran community. This is the cohort for which the Study is currently funded and has ethical approval. We hope to broaden this scope to other cohorts as capacity, funding and ethical approval are secured.

## **5. How is the data on an individual beneficiary anonymised?**

The data will collect some of the beneficiaries' personal information, such as their military service number and date of birth, which indirectly could lead to the individuals' identification. For this reason, data security is provided by robust data management procedures. This project complies with the Data Protection Act (2018) and the GDPR (2018).

Personal information will be deleted when the unique anonymous identifier is generated by adopting a Secure Hashing Algorithm (SHA). SHA is a method of applying a unique anonymous identifier to

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<sup>1</sup> [The Northern Hub for Veterans and Military Families Research \(northumbria.ac.uk\)](http://northumbria.ac.uk)

individual data and then removing identifying data for good. This SHA function ensures both data integrity and authentication through a digital certificate. A hash function considers an arbitrary set of input variables and generates a fixed 'fingerprint' string to uniquely identify a specific record (e.g., an individual). In the case of this project, three variables of identifying data (that all Armed Forces charity datasets should include as a minimum requirement for granting benefit or services) will be used to generate the SHA unique ID:

- military service number,
- date of birth, and
- gender.

These variables will generate a unique 64-digit ID for that individual. If the three variables remain the same, the SHA will generate the same 64-digit ID every time. This allows us to fully anonymise datasets and then aggregate cases at the individual level anonymously, finding an individual's service usage data across multiple datasets.

## **6. What data is being collected?**

The MONARCH Study is currently collecting as much data as is being collected by those organisations providing charitable or statutory services to members of the Armed Forces Community.

## **7. How do I know the data I share is being held and used securely?**

The University of Northumbria is legally bound by the highest ethical and governance procedures when using data. The data will be stored in a SAS (Statistical Analysis System) Viya platform at Northumbria University. SAS Viya was chosen as the 'big data' management and analysis system, as it is the system used by the wider MoD to manage big data and data analysis. No identifying data will be retained or stored.

Access to research project data will be controlled by Professor Kiernan and the research team at Northumbria University in order to protect the data.

## **8. Who is sharing data with the MONARCH study?**

Several Armed Forces charities are already sharing their data as part of the MONARCH Study. This data sharing is ongoing with more organisations sharing their data all the time. The more data contributed, the richer and more comprehensive the resource and outputs will be.

## **9. What will the MONARCH resource look like?**

The aggregated dataset will be the foundation for the visual representation of the health and social needs of veterans. The license for the visual dashboard will be covered and checked by Northumbria University's IT and legal services. The proposed visualisation software is cloud-based and provided by SAS Viya under a license agreement with the University.

We will use focus groups to help inform the most useful visualisations.

**10. How will the MONARCH Study make a difference to members of the Armed Forces Community and to us as charities?**

The current service provisions from the military charity sector predominantly relies on veterans to seek and ask for help. Therefore, those that do not ask for help remain invisible to services, and if we are unable to understand the characteristics of their needs, the sector has no starting point to begin to identify them or offer help to them. Understanding the characteristics of those that use services provides the information on which to base multi-agency programmes of early intervention.

**11. What is involved in sharing my organisation's data?**

We'll have an initial discussion about the project, explaining MONARCH and answering any questions you have. If you are then happy to proceed a Data Sharing Agreement will be prepared between your organisation and the University of Northumbria. This gives you legal assurance for the whole process. We'll then ask you to provide raw data that has been agreed within the Data Sharing Agreement via a secure route. There is no need to carry out any manipulation or processing of your data, there is an expert Project team who will carry out this function. We can update you, and answer questions at any stage. We'll also invite you to join the MONARCH Data Strategy Working Group to be involved as the dataset develops, and to contribute to shaping this work going forward.