MONARCH Study Update and FAQs – March 2024

I am delighted to post the second FAQ document for the MONARCH Study. This primarily covers progress and developments since the first FAQ document was published in September 2023, but also includes answers to questions I am asked about MONARCH.

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 if there is anything I can help with, that you'd like to discuss, or if you'd like to become involved.

Meri Mayhew

Charity Stakeholder Relationship Manager to the MONARCH Study

1. What has happened with the MONARCH Study since the last FAQ document in September 2023?

There have been a number of important developments since September 2023. These include:

a. **Growing the dataset and aggregation.** At the time of writing, the dataset has data on around 60,307 individuals. This number continues to grow as more charities share their data. As well as adding new data, the team at the University of Northumbria continue to develop, test and improve the process of data cleaning, machine coding and aggregation.

b. **Focus group to shape output.** We held a number of focus groups last autumn to help us shape what the outputs need to be in order to be most helpful to those who may use the dataset. This is mainly around considering what data is most helpful, and what format the output should take.

c. **Data Strategy Working Group (DSWG).** We have also established a Data Strategy Working Group to work together to help improve the quality and completeness of data collected across the sector, to consider the outputs from MONARCH, and to help with awareness of other data initiatives in the sector so we can collaborate as much as possible. Sir Andrew Gregory chairs this Working Group which meets quarterly and virtually. Membership is for organisations who have signed a Data Sharing Agreement and who have shared/or are about to share data with MONARCH (the data owners).

d. **Robust process.** Members of the Team have continued to submit academic papers on various elements of the MONARCH study process for peer review. This demonstrates rigorous, robust, and transparent processes which give reassurance about MONARCH.

2. What are the limitations of the MONARCH i.e. what will it be able to do and not do?

The MONARCH Study will contribute to our knowledge and understanding of our community i.e. which (anonymised) individuals are accessing services, the services they are accessing, and the characteristics of those people accessing services. The long-term aim is to have enough information to be able to consider interventions to help beneficiaries before they reach crisis.

MONARCH itself won't provide the answer to everything we want to know and understand about the Armed Forces Community, but it will make up an extremely important element. MONARCH is a machine-based dataset which means that it deals in absolutes and facts and not in ambiguity. MONARCH won't consider causality – this will need to come from other research. For example, it may show that a person has received financial support from a charity for rent

arrears, but it won't explain why that person found themselves in need of financial support for these arears. However, over time, knowing the characteristics of those accessing help with rent arrears will help us identify the type of people at risk so we can try and act earlier to reach those people and offer interventions. More on this in a future FAQ document as the operationalisation of MONARCH starts to develop.

Finally, the MONARCH dataset will only be as good as the data that is entered, which means the more accurate and complete the data entered, then the better the outputs. Over time if there is something additional that we want to understand, then we can ensure that question is being asked so that data can be gathered.

3. Which cohorts are included?

The MONARCH Study includes veterans, and also now family members. At the moment the distinction between veteran or family member is primarily performed by the charities, there is a flag variable indicating which subgroup the subject belongs to. When there is a person recorded as a veteran by one charity and as a family member by another, the subject is classified as a veteran since a person can be both (i.e. the spouse of a veteran which is also a veteran). If the flag variable is unavailable, an algorithm can be developed and validated that can classify the subjects with a reasonable amount of accuracy. Please note the development of the algorithm is at a very early stage and charity input will be important as these insights will be really helpful to the team.

4. How is 'need' defined in the MONARCH Study?

It is essential the the MONARCH data differentiates between needs that have been met and 'wants'. A need is defined, for the purposes of the MONARCH study as a single person, receiving help in a single year, for a single reason. This definition was chosen in collaboration with the charities providing data as it was found to be the best compromise applicable to different forms of workflows. Needs are first classified according to the kind of services charities provide, at the minute there are around 60 categories. Each of these categories is grouped in one of the 12 areas of need as defined by the Complex Needs and Dual Diagnosis APPG. There is then a macro-classification in 3 categories according to the WHO definition of health (physical health, mental health, social wellbeing).

The Team are currently exploring ways of defining complexity using variables such as total number of needs, total number of accesses, number of needs per access, number of accesses per year etc. The work however is still ongoing, as a definition of "complex" should be practically applicable, scientifically justifiable and finally validated against real world data.

5. Who is sharing data with the MONARCH study?

All the data in the MONARCH dataset at this stage is from Armed Forces Charities. We continue to work with colleagues in the NHS to see how we can expand to include NHS datasets too. The process for this is slightly different and as there is a willingness to collaborate on data sharing, we are working together to try and bring this about.

6. What will the MONARCH resource look like?

The focus groups have helped shaped what the outputs will look like, and we anticipate having a test model ready to share in the next few months. This will be the start of the process and the

resource will be continually reviewed and refined to make it as helpful as possible to policy makers and service deliverers.

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

The long-term aim which the MONARCH Study will support, is that we move from being entirely reactive to beneficiaries – often in times of crisis – to becoming more proactive in trying to intervene earlier with those individuals that may be at risk. This is better for individuals and charities.

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

It doesn't matter how big or small your organisation is, we're keen to include as many as possible. If you are interested in becoming involved with MONARCH, in sharing your data, and to help develop data use across the sector, the process starts with an initial discussion. This gives an opportunity to ask lots of questions about MONARCH. The next stage is for a Data Sharing Agreement (DSA) to be signed by the data provider and the University of Northumbria, before moving on to sharing data. MONARCH doesn't identify the charity/charities that have supported a beneficiary.

9. How is data managed securely in MONARCH?

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.

10. Does the MONARCH dataset just include financial transactions?

While many Armed Forces charities support beneficiaries financially, we all know there is also a broad range of support offered which is not of a financial nature. This is all important data and gives us a picture of support for members of the Armed Forces Community. It is essential that a 'need' has been met by a charity (a transaction) as this demonstrates that a beneficiary did meet the criteria for support and an 'intervention' has taken place.