**Maximising Data Usage in NMAHP Research**



**Nursing, Midwifery and Allied Health Professions Research**

There is a need to reduce research waste and enhance efficiency to enable a more timely response to the research needs of policy makers and the NHS. The Unit has made a leading contribution in enhancing the secondary use of pre-existing research data (e.g. from international trials). It has excelled in the production of systematic reviews of existing research and in developing methodological innovations for producing systematic reviews. We have also engaged in using routine NHS data, linked to trial data, for cost-effective long-term trial follow-up and in using routine NHS linked datasets to understand patient pathways and identify at risk populations.

The remit of the *Maximising Data Usage in NMAHP Research* Programme is to:

* Demonstrate the current variety of NMAHP contributions to innovative data usage
* Improve efficiency in research via utilizing existing evidence and existing data sources
* Develop methodological innovations to support maximization of data usage
* Support capacity and capability in NMAHP Researchers to contribute to maximizing data usage.

# Strategic aims:

* Underpin all Unit workstreams with world class evidence synthesis.
* Expand existing expertise in international (trial) data sharing collaborations across Unit workstreams.
* Expand our existing body of quantitative researchers with the necessary skills to further NMAHP research using large/linked datasets.
* Develop capacity for innovative and efficient trial designs using existing datasets, such as Trials within Cohort Studies (TwiCS).
* Reduce research waste and maximise research resources by establishing and prioritising patient, public and practitioner research agendas.

# NMAHP Data Experts:

The Unit has developed a critical mass of **researchers** to support stakeholder research prioritization, data management, analysis, and evidence synthesis:

* **Systematic reviews and meta-analysis/synthesis:** consists of highly experienced information scientists and researchers who share knowledge, and support research staff in all aspects of systematic review and evidence synthesis.
* **Data linkage:** consists of experienced statisticians and data analysts
* **International trials collaborations:** researchers who use their reputational and partnership skills to support the development of international partnerships; understanding of trial design and outcome measurement; and understanding of trial datasets.

**See inside pages for study examples.**

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| **Identifying Research Priorities** |
| **Pessary use for prolapse**  This project in the Pelvic Health workstream has brought together women with experience of prolapse and clinicians involved in the management of prolapse in a James Lind Alliance Pessary Priority Setting Partnership. The top ten shared priorities for future research have been published and widely shared to encourage researchers and funding bodies towards research for the mutual benefit of women and clinicians. Involving women in this way will facilitate continued inclusion in any future research projects. *Lough, K., Hagen, S., McClurg, D. and Pollock, A. (2018) Shared Research Priorities for Pessary Use in Women with Prolapse: results from a James Lind Alliance Priority Setting Partnership. BMJ Open, 8 (4), pp. e021276.* |
| **Life after stroke**  Our stroke rehabilitation workstream is informed by what is important to stroke survivors, their families and carers, and health professionals working in stroke care. We carried out a James Lind Alliance priority setting project to find out the most important research questions relating to life after stroke. We then built on the results of this JLA project to more clearly define the research agenda in a number of related areas. This included working with the Scottish Stroke Nurses Forum to identify the top nursing research priorities; with people with aphasia, their carers and speech and language therapists to identify the top priorities relating to aphasia following stroke; and with experts in vision after stroke to reach consensus on research priorities relating to eye movement disorders. This work ensures that the research that we carry out addresses what is important to people affected by stroke. *Pollock A et al. (2012) Top 10 research priorities relating to life after stroke - consensus from stroke survivors, caregivers, and health professionals. International Journal of Stroke.* [*Doi: 10.1111/j.1747-4949.2012.00942.x*](http://10.1111/j.1747-4949.2012.00942.x) |
| **Evidence synthesis** |
| **Cochrane reviews**  Cochrane Reviews are systematic reviews of primary research in health care and policy, and are internationally recognised as the highest standard in evidence-based health care. They investigate the effects of interventions for prevention, treatment and rehabilitation. We are a leading centre for Cochrane systematic reviews of complex nursing and AHP stroke rehabilitation interventions, and our staff are authors and editors for a number of Cochrane groups including Cochrane Stroke and Cochrane Incontinence. |
| **Cochrane Rehabilitation**  We have formed a partnership with Cochrane Rehabilitation, an international network of Cochrane authors, rehabilitation professionals and patient organisations which aims to support and facilitate delivery of evidence based clinical practice. We are contributing to the development and dissemination of high quality methods in this field. |
| **Overviews of reviews**  We have expertise in carrying out and developing the methods of overviews of reviews. The high, and rapidly increasing, number of systematic reviews can be overwhelming for decision makers and overviews systematically synthesise the results of multiple systematic reviews in order to inform and support decision making. We completed the first Cochrane overviews relating to stroke and incontinence, and conduct rapid policy-relevant overviews in key health and social care topics. |
| **Methodological Studies (including standardizing outcomes)** |
| **eMERGe**  Meta ethnography is one of the most commonly applied, most complex and poorly reported qualitative evidence synthesis methodologies. Existing guidance for reporting generic qualitative evidence syntheses does not pay sufficient attention to reporting the complex synthesis processes associated with meta-ethnography. In this study, experts in qualitative evidence synthesis and other stakeholders achieved consensus over the minimum reporting standards for a meta-ethnography. 19 evidence-based standards were developed covering all aspects of meta- ethnography conduct and reporting from design to methods, analysis and synthesis, findings and implications. *France E.F, et al. (2019) Improving reporting of Meta-Ethnography: The eMERGe Reporting Guidance, Journal of Advanced Nursing, doi:10.1*[*111/jan.13809.*](http://10.1111/jan.13809) |
| **Stakeholder involvement in systematic reviews**  We have developed innovative methods of involving patients, carers and health professionals in systematic reviews. Our use of structured methods of involving people in a Cochrane review was selected as a good example of research co-production by INVOLVE. The ACTIVE (Authors and Consumers Together Impacting on eVidencE) project aims to help authors of systematic reviews have meaningful involvement of stakeholders. We have synthesised methods of stakeholder involvement and summarised this within an online learning resource. We are working with international partners towards the development of guidance around methods, reporting and evaluation of involvement. |

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| **Core outcome datasets**  Greater co-ordination of research impact in a particular field can be achieved if researchers agree in advance to use the same set of outcome measures in their research. These minimum datasets support comparisons, contrasts and synthesis of information across studies, countries and languages. Key to a good core outcome set are measures which reflect the perspective of service users, healthcare professionals and researchers in a specific field. We have developed a core outcome set for arm function and communication problems after stroke. |
| **International Trials Databases** |
| **VISTA-Rehab**  Approximately two thirds of stroke survivors experience long term disability following their stroke. Stroke rehabilitation addresses these impairments, enabling people to participate and return to activities in their life after stroke. VISTA-Rehab is a data archive containing information from stroke rehabilitation trial participants – their demography, outcome measures, selected medical history variables, rehabilitation interventions and measures of disability, activity and participation. The data can be used for novel exploratory analysis of anonymised data. |
| **RELEASE**  Speech and language therapy benefits people with aphasia, a difficulty understanding or using language which can occur following stroke. Working with 68 multidisciplinary research teams across 28 countries, we have created a database of 174 original research studies which involved 5928 people with aphasia. Using this database we are exploring the individual and predictors of recovery for this group of stroke survivors and examining optimum therapeutic approaches. Using methods to summarise the data (meta- and network meta-analysis) we are identifying patterns of language performance after stroke and the influence an individual’s characteristics may have on their recovery. |
| **Research using existing datasets/data linkage** |
| **Long term trial follow-up**  Following the POPPY trial into Pelvic Floor Muscle Training for Pelvic Organ prolapse, the PROPEL study explores service models for implementation of the evidence base. Within PROPEL we also undertake longer term (10 year) follow-up of the original POPPY trial participants via the use of routine NHS (hospital and out-patient) datasets, to understand whether the benefits of PFMT are maintained. *Maxwell, M., et al., (2017). PROPEL: implementation of an evidence based pelvic floor muscle training intervention for women with pelvic organ prolapse: a realist evaluation and outcomes study protocol. BMC health services research, 17(1), p.843.* |
| **Exploring risk factors for suicide**  Three decades worth of suicide records in Scotland, from 1980 to 2010 for those aged 15 or over were linked to hospital records. Two thirds of the 16,411 suicides studied could be linked to hospital records and were examined to see what treatment individuals had received before they took their own life. The results showed that more people were discharged from general hospitals than psychiatric hospitals before they died by suicide. A quarter of people died by suicide within three months of the last time they were discharged from hospital and only 14% of those discharged from a general hospital had a diagnosed mental illness recorded in their medical records during last visit. The Farr Institute of Health Informatics Research showcased this study as being among the UK’s most significant examples of using data in research. *Dougall N, Lambert P, Maxwell M, et al. (2014) Deaths by suicide and their relationship with general and psychiatric hospital discharge: 30-year record linkage study BJP, 204, p.267-273.* |
| **An epidemiological study using linked patient records of mental health emergencies**  This study aimed to investigate the epidemiology of emergency ambulance attendances for psychiatric emergencies, or self-harm, transported by ambulance to EDs in Scotland during a single year and followed up for at least 12 months in order to:- a) understand the current care pathways for this patient group; b) identify people who have poor outcomes;  c) understand if ambulance service clinicians’ assessments can accurately identify patients for whom ED attendance is sub-optimal or not required; and d) use the analysis to inform the development of an improved care pathway(s) intervention, in partnership with key stakeholders, to improve efficient and appropriate access to specialist mental health services, and reduce unnecessary attendance at ED. |

L o n g t e r m t r i a l f o l l o w - u p

**Selected publications in maximising date usage:**

* Arba, F., Quinn, T., Hankey, G., Lees, K., Ali, M., Inzitari, D. and on behalf of the VISTA Collaboration. (2018) Enlarged perivascular spaces and cognitive impairment after stroke and transient ischemic attack. *International Journal of Stroke*, 13 (1), pp. 47-56. Doi: <https://doi.org/10.1177/1747493016666091>
* Brady, M., Godwin, J., Kelly, H., Enderby, P., Elders, A. and Campbell, P. (2018) Attention control comparisons with speech and language therapy for people with aphasia following stroke: methodological concerns raised following a systematic review. *Clinical Rehabilitation* (e-Pub Ahead of Print) Doi: <https://doi.org/10.1177/0269215518780487>
* Cunningham, M., France, E., Ring, N., Uny, I., Duncan, E., Roberts, R., Jepson, R., Maxwell, M., Turley, R. and Noyes,

J. (2018) Developing meta-ethnography reporting guidance for research and practice. *Health Services and Delivery Research Journal (in Press)*.

* Frost H, Campbell P, Maxwell M, O’Carroll RE, Dombrowski SU, Williams B, et al. (2018) Effectiveness of Motivational Interviewing on adult behaviour change in health and social care settings: A systematic review of reviews. PLoS ONE 13(10): e0204890. <https://doi.org/10.1371/journal.pone.0204890>
* Hoddinott, P., Pollock, A., O’Cathain, A., Boyer, I., Taylor, J., Macdonald, C., Oliver, S. and Donovan, J. (2018) How to incorporate patient and public perspectives into the design and conduct of their research (opinion piece). F1000Research <https://doi.org/10.12688/f1000research.15162.1>
* Hunt, H., Pollock, A., Campbell, P., Estcourt, L. and Brunton, G. (2018) An introduction to overviews of reviews: planning a relevant research question and objective for an overview. Systematic Reviews 2018; 7(39). [https://doi.org/10.1186/ s13643-018-0695-8](https://doi.org/10.1186/s13643-018-0695-8)
* Jelovsek, J., Chagin, K., Gyhagen, M., Hagen, S., Wilson, D., Kattan, M., Elders, A., Barber, M., Areskoug, B., MacArthur, C. and Milsom, I. (2018) Predicting risk of pelvic floor disorders 12 and 20 years after delivery. American Journal of Obstetrics and Gynecology, 218 (2). Doi: <https://doi.org/10.1016/j.ajog.2017.10.014>
* Dougall N, Stark C, Agnew T, Henderson R, Maxwell M, Lambert P. An analysis of suicide trends in Scotland 1950 - 2014: comparison with England & Wales. BMC Public Health (2017) 17:970. Doi: <https://doi.org/10.1186/s12889-017-4956-6>

# Unit background:

The Nursing, Midwifery and Allied Health Professions Research Unit (NMAHP RU) is a multidisciplinary national research unit, funded by the Scottish Government Health Directorate **Chief Scientist Office**. It has academic bases within Glasgow Caledonian University and the University of Stirling.

# Research programmes:

NMAHP RU focuses its activity on three strong programmes of research that will impact on NMAHP practice and benefit patient and population health. These are: *Innovation in NMAHP Interventions*, *Transforming Care Delivery* and *Maximising Data Usage in NMAHP Research*. This leaflet provides information on the *Maximising Data Usage in NMAHP Research* Programme led by Professor Marian Brady

# Find out more:

You can find further information on all of our research programmes, recent research projects, publications and keep up to date with our latest news, on our website: [**www.nmahp-ru.ac.uk**](http://www.nmahp-ru.ac.uk/)

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