

## Cohort Identification for Observational Analysis: Initial Impressions From The STRETCHED Study

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**Background:** Cross-sectoral case management is being introduced by ambulance services in the UK to assess the needs of those who call 999 frequently. There is a lack of evidence of what works in this setting and how. Based on current national guidelines, calling frequently is defined as 5 or more times in a month, or 12 or more times in a three-month period. Ambulance services maintain a list of 'Frequent Callers'. The STRETCHED (**STR**ategies to manage **EM**ergency ambulance **TE**lephone **C**allers with sustained **H**igh needs – an **E**valuation using linked **D**ata) study seeks to evaluate effectiveness, safety, and efficiency of case management approaches to the care of people who frequently call the emergency ambulance service; and gain an understanding of barriers and facilitators to implementation. The timeline for the study is 1<sup>st</sup> April, 2019 to 31<sup>st</sup> December, 2021. As part of Work package 2 of this study, anonymised linked routine data from four ambulance services will be used to describe epidemiology and assess effects on processes, outcomes, safety, and costs of interventions and care up to six months.

**Methods:** In each of the four ambulance service, one site with case management for people who call ambulances services frequently and one site without case management was identified. Based on our initial survey study and communication with the sites, there was an expectation to include 158 high users of the 999 service at each of the eight sites (n=1264). The inclusion criteria requires adding newly classified people to the 'frequent Caller' list between 1<sup>st</sup> January 2018 to 31<sup>st</sup> December 2018.

**Results:** There was a difference in the number of people identified in the different sites within the service. (*There will be a table here comparing the number of people in the CCG or STP, and the number of people who are new callers in an area, and the expected callers. (three columns)*)

Site 1: 250

Site 2: 700

Site 3: 70

Site 4: N/K (no figures provided)

**Implications:** Identification of people who call frequently is uneven amongst the sites, however, our target sample size will be achieved. Even with groundwork, there is a significant difference in the expected numbers for a retrospective cohort identification of people who call ambulance services frequently. Planning for an observational study with the patient group whose epidemiology is relatively unknown can be a challenge and some flexibility is required.

## The Association Between Research Activity and General Practice Outcomes: A Mixed Methods Study

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**Background:** There is increasing evidence that participation in research drives better performance in health care settings. However, the evidence mostly comes from secondary care, while the bulk of patient contacts are through general practice. If research participation improves outcomes, achieving those benefits through general practice could improve health for a wider population of patients.

England is in a unique position to explore this issue, as it has excellent data on both general practice and research activity (through the NIHR Clinical Research Network infrastructure). This provides the potential for a comprehensive analysis of the relationship between research activity and outcomes at a national scale.

**Methods:** The ARAPAHO project (funded by the Policy Research Programme) is a mixed methods study to answer the following research questions:

Are there associations between research activity in general practice and outcomes?

1. What mechanisms may explain associations between research activity and outcomes?
2. What are the characteristics of effective 'research active' practices from the perspective of staff, practitioners and patients?
3. What are the impacts on patients and staff of research activity in general practice?

We have created a preliminary logic model based on existing literature and patient and expert stakeholder input, which will inform our methods.

We will use a variety of statistical methods (including causal modelling) with routine data to answer research questions 1 and 2. We will use qualitative methods with professionals and patients to explore research questions 3 and 4. For this, we will use outputs from our quantitative analyses and work closely with patients and other stakeholders to sample different types of general practices for in-depth study across England.

The results from ARAPAHO will be synthesised with input from PPI and other stakeholders to consider the broader implications for future research activity in this setting.

**Results:** ARAPAHO is ongoing, and at the conference we will present our initial logic model, and the results of initial quantitative analyses exploring the association between research activity and outcomes.

We will use a variety of measures of research activity (volume, type, and duration) and multiple outcomes, including Quality and Outcomes Framework scores, and patient experience from the General Practice Patient Survey. These analyses will allow us to demonstrate whether the relationships demonstrated in secondary care settings generalise to general practice. We will also consider their implications for sampling in the subsequent qualitative work.

**Implications:** General practice remains fundamental to the delivery of high-quality care in England. However, there are significant pressures in this setting due to changing population demographics, rising patient expectations and issues of recruitment and retention in the workforce. Understanding the role that research activity can play in improving practice performance and patient outcomes could make an important contribution to maintaining the vitality of general practice in the future.

# Supporting Evidence-Based Decision-Making in Health Services Research: Experience from Two Responsive Rapid Evidence Synthesis Programmes

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**Presenting Author: Duncan Chambers**

**Background:** Decision-makers in health and social care increasingly require rapid but rigorous evidence reviews to inform decision-making and identify research gaps. The authors are members of a team that contemporaneously delivers rapid reviews for the NIHR Health Services & Delivery Research (HS&DR) programme and a major charitable research funder (the Health Foundation (HF)). This involvement offers unique insights into the respective requirements of the two programmes.

**Method:** We compared reviews commissioned by the HS&DR programme and published in 2019 and 2020 (see <https://fundingawards.nihr.ac.uk/award/16/47/17>) with those produced for the Health Foundation (commissioned through competitive tendering). Through analysis and reflection, we sought to identify lessons for producers and users of rapid evidence reviews in health and social care.

**Results:** Seven topics were commissioned by the HS&DR programme and three by the HF (Table 1). The topics represented the main issues currently faced by health and social care decision-makers, including urgent and emergency care, digital innovation, workforce and health inequalities. Recent concerns evidence a shift towards topics in social care.

*Table 1: summary of rapid evidence reviews*

Topic (funder)	Main purpose	Methods and timescale
Digital and online symptom checkers (HS&DR)	Support implementation of NHS111 online	Rapid systematic review (4 months)
Use of UEC by vulnerable groups (HS&DR)	Support appropriate use of UEC services	Mapping and intervention reviews (10 months)
Preventable hospital admissions (HS&DR)	Examine implementation of evidence-based interventions	Mapping review and realist synthesis (17 months)*
Access to services for people with learning disabilities (HS&DR)	Support improved access to services	Mapping review and targeted systematic review (6 months)
Distance to emergency care (HS&DR)	Provide evidence around impact of service reconfiguration	Reviews of interventional and observational studies; review of SRs of telehealth (7 months)
Recognition of risk and prevention in safeguarding (HS&DR)	Support best practice and research	Mapping review and review of international reviews (3 months)
Knowledge mobilisation (HF)	Support development of KM strategy	Rapid systematic review (3 months)
Inequalities of access in social care (HS&DR)	Understand contexts that affect access to services by minority groups	Mapping review and realist synthesis (6 months)
Barriers and facilitators to implementing digital and data-driven technologies (HF)	Identify challenges to 'real world' implementation and possible solutions	Mapping review and framework-based synthesis (4 months)
Social care workforce (HF)	Support workforce modelling	Mapping review, SR of core evidence and development of conceptual model (3 months)

KM, knowledge mobilisation; SR, systematic review; UEC, urgent and emergency care

\*This review was paused at the request of the funder

We used diverse synthesis methods to address the questions associated with each topic. Topics frequently required initial mapping or scoping to identify the quantity and quality of available evidence, plan timescales and, in some cases, to specify conceptual boundaries and limits. Reviews for the Health Foundation were typically carried out over a shorter time and involved more frequent contact between the funders and the review team.

**Implications:** Our experience of providing a responsive evidence synthesis service to research funders in the public and charitable sectors has supported the development of methodological and topical capacity within the review team. Lessons learnt in one programme can be applied in another, for example the importance of initial mapping and the value of frameworks to support synthesis of different types of evidence. Evidence users can support the rapid review process by supplying a clear brief and by regular interaction with the review team.

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## Social Context Indicators Based on Administrative Data in England

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**Background:** Social context factors, such as social isolation, caring responsibilities, unstable housing, domestic abuse or unemployment, may have a big impact on health outcomes. There is evidence that these are important factors in identifying patients who would benefit from multidisciplinary teams (MDTs) (1). Metrics for social context factors are not routinely collected in English administrative data, e.g. patient hospital records, and are not accounted for when analyzing health care resource use. If social context metrics were available and linked to other health data, this could help clinicians, commissioners, researchers and policy makers with understanding patients' risk of hospital admission, A&E attendance patterns or use of primary care.

Living alone, which may be linked to social isolation, was found to be associated with emergency hospital use (2). However, this finding was based on a small sample size from one large GP practice. We have derived social context indicators from national data, including living alone and living with someone with chronic care needs, which may lead to social isolation or neglecting one's own needs and care. We are determining their prevalence nationally and within different population subgroups, and exploring whether these factors are predictive of emergency hospital use.

**Method:** We have created social context indicators based on the Master Patient Index (MPI), a health data set based on GP registration data in England. People living alone, in the same household or a care home are flagged using the MPI's pseudonymized Unique Property Reference Number (UPRN). The variables we create are living alone and living in a two-person household with someone diagnosed with dementia or frailty (respectively).

Our study population consists of all people aged 65 years or older registered at GP practices in England on 1 December 2018, living alone or in a household (i.e. not a care home or establishment), and with a hospital admission record in the previous three years. The study follow-up period will be one year.

We are now:

- Estimating the prevalence of these social context indicators, including within subgroups described by e.g. frailty, multimorbidity, level of deprivation, ethnicity and region.
- Estimating the rate of A&E attendances and emergency admissions using pseudonymised patient-level national administrative hospital data (Secondary Uses Service) and examine whether there is a correlation between social context variables and these outcomes.
- Conducting regression analyses to determine effect estimates of the social context indicators on A&E attendances and emergency admissions, controlling for factors such as prior hospital usage, gender, number of comorbidities and frailty conditions, CCG, and Index of Multiple Deprivation quintile.

**Results:** We hypothesise our analysis will show an association, once other factors including prior hospital usage, deprivation, comorbidities, age and gender have been taken into account, between:

- Living alone and emergency hospital use.
- Living with someone who potentially has care needs (e.g. a frailty condition) and emergency hospital use.

**Implications:** We aim to demonstrate first how new social isolation metrics can be derived from administrative data, and second that these can provide valuable information both for patient care and health services research. For example, future analyses and programme evaluations looking at hospital resource usage could be improved by being able to adjust for social context, e.g. ensuring intervention and control patients in retrospective cohort studies are also similar in relation to social context.

## References

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# Bridging The Perceived Disconnect Between Health Technology Assessment and Delivery Systems

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**Background:** There has often been a perceived disconnect between the delivery system and Health Technology Assessment (HTA), with the uneven implementation of recommendations. Even in well-resourced health systems, cost-effective interventions do not always (rarely) get implemented optimally with recurrent themes around organisational processes, clinician engagement and financing being key barriers. Optimisation of health technology utilisation is health technology - and system-specific, and HTA may be made more impactful by greater consideration of organisational and contextual issues. Providing evidence about the expected impact of a technology on health system structure, processes and resources might be valuable to inform the construct and recommendations of an HTA or develop an implementation plan. Yet, this aspect of HTA is often found to be lacking.

**Methods:** We undertook a realist synthesis to produce tested and data-driven theory that considers individual, interpersonal, institutional and systems-level components and their interactions on the mechanisms by which HTA can be optimised. Drawing on our programme theory, we consider practical implications to achieve greater interconnectedness between HTA and health systems.

**Results:** Common predicting mechanisms that transcend contexts are found in an interaction between collective change efficacy and change commitment or willingness and capability. We evidence that this generally leads to a positive change in implementation of an HTA. Both are necessary, and crucially, one can reinforce the other.

**Implications:** Firstly, rather than maintaining an emphasis on user-focused HTA ie where a synthesis of clinical evidence and economic evaluation of available technologies are the mainstay, we consider the application of developer-focused HTA where system constraints are addressed whilst the technology is still under development. Secondly, although health products have been its more significant focus to-date, HTA could develop to increase its focus on technologies applied to healthcare ie regulatory and policy measures for managing and organising healthcare systems - as well as extending its application to non-healthcare sectors. We consider such a refocus towards meso/macro HTA given the interdependency of HTA and health systems - and wider sectors - for optimising its impact on health outcomes.

Furthermore, whilst high-income countries (HIC) may have led the way, lower- and middle- income countries (LMIC) are increasingly beginning to develop HTA processes to assist in their healthcare decision-making. The global expansion of HTA, its variable implementation, the lack of quantified evidence on health outcomes, along with an increasing investment in these processes at the systems level in LMIC has generated greater interest from policy makers about the value and impact of HTA. HTA should seek to harness mechanisms to improve implementation of findings - as it is only when decisions result in practice change, can better health be achieved. In HICs, there has been perhaps an element of taking for granted that a fully functioning system will adapt accordingly to ensure implementation of recommendations. In an era of investment and expansion, in particular, for LMICs, we hope this research offers a forward-looking model as a reference for their own implementation of HTA.

## Pushing Through High Waves: The Impact Of COVID-19 On Ongoing Research Projects (And Researchers)

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**Background:** The COVID-19 outbreak has found most of us in uncharted territory - a place of uncertainty and unpredictability we seem destined to remain in for a while. As a result, science, worldwide, started to pivot around the pandemic overnight. The effects of the large-scale mobilisation of researchers and health care providers towards the pandemic quickly extended to research projects (and researchers) funded before the onset of the pandemic.

**Aims:** To summarise the impact on studies developed in, and supported by, the Marie Curie Palliative Care Research Centre, Cardiff University.

**Methods:** The researchers involved in affected studies helped to identify the research activities impacted by the pandemic.

**Results:** A total of nine studies (two large multi-centre RCTs, four qualitative studies, two observational studies, and one PhD) were affected by the pandemic. As a result of the financial pressure on charity organisations, funding for two studies, which had not yet started, was retracted by the funding organisation. New resubmission requesting funded (and unfunded) study extensions had to be submitted. Each study was subject to a thorough risk assessment to assess the impact of COVID-19 on study participants and secure transfer of confidential data (e.g. consent forms). Changes to procedures had to be submitted for approval by ethics committees (e.g. PIS, ICF, Remote consent, the adaption of interview structures, changes to study objectives). SOPs around remote consent taking, data management, and data transfer had to be developed/amended. Applications to have Letters of Access renewed had to be submitted to accommodate new study timelines. Some of the research staff had to be furloughed and in case of unfunded extensions, some of the projects will have to be completed without the dedicated researcher. In addition to this, the pandemic might require some HCPs to move overnight to different areas and roles, possibly including the research HCPs who have been supporting recruitment to ongoing studies.

**Conclusion:** The COVID-19 pandemic has highlighted the importance of robust research infrastructures. At the same time, high-quality research will be vital for resolving this crisis. The ability to adapt to the current research challenges in ways that preserve the integrity of ongoing research is a testament to this. These findings mirror many research centres.

## A Stakeholder Perspective About Communicating Health Research Findings: The GIRASOL Study

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**Introduction:** Communication of research results is now recognised as an important part of the research process and the pandemic has amplified this priority. UK funding agencies and the Health Research Authority require that researchers have a clear plan of how findings should be reported back to patients and members of the public. In the past research findings have focused mainly from a researchers' perspective. This study takes this work further and, in addition to the researcher perspective, we account for members of the public, and past and present study participants' preferences also. The aim of this study is to determine recommendations to ensure that the communication content, channels and modes adopted by the researchers meet all stakeholders' expectations.

**Method:** The study evolved over three stages: a) A rapid review of reported dissemination strategies and activities planned by researchers as listed in published peer-reviewed protocol papers; b) three online surveys (past and present study participants, members of the public, and UK researchers in healthcare), and c) a consensus group of academics and PPI representatives. Thematic and descriptive analyses were used to analyse quantitative and qualitative data.

**Results:** A total of 378 participants took part in the study. From the review it emerged that most protocol papers lack a detailed plan for dissemination and other engagement activities. It also emerged that a limited number of stakeholder groups are targeted for dissemination and other engagement activities. One in four of the study participants reported having been asked about receiving study progression reports and final findings. This is, however, time and study dependent. Study websites and newsletter/email alerts are the most preferred (or used) mode of accessing study findings. The NHS website is the first port of call for members of the public when searching the internet, however, the language might not be 'user friendly' enough to reach a wider audience. The PPI role was fundamental to the design, conduct and data analysis. Currently, the consensus exercise is underway.

**Conclusions:** Wider communication using a range of mechanisms, specifically targeting the lay community, enables the work to have impact outside its academic base and accelerate implementation. Identifying mechanisms that enable capturing of end-users' preferences for mode, timing, content, and ways for seeking feedback around dissemination and engagement strategies, should be standard practice. Support from high level of governance, ethics, and funding bodies can facilitate a more transparent and balanced communication of health research study findings.

## **Pacers: Methodology to Identify High Quality Evidence**

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**Background:** The spread of COVID-19 has shown the importance of producing evidence in a timely manner. The research community have been eager to contribute to the evidence base. However, some of the guidance that has been produced and employed for clinical and policy decisions has not followed established methodological guidelines and consequently may lack scientific rigour. The Palliative Care Evidence Review Service (PaCERS) is funded by Health and Care Research Wales through the Wales Cancer Research Centre, with the aim to support professionals and other decision makers working in palliative care in producing rapid evidence summaries. This paper will describe the development of the PaCERS methodology, a service which is clinically driven, identifying evidence to support service redesign opportunities or need for change to clinical care.

**Methods:** Our methodology uses adapted systematic review methods to identify and appraise high quality evidence in healthcare literature. To develop this methodological approach a stakeholder workshop was held to refine our methodology and reporting processes and achieve consensus on how best PaCERS can serve the palliative care community.

**Results:** To date we have produced ten evidence reviews requested by clinicians or decisionmakers working in palliative care. Findings will be presented from the viewpoint of partnership working at the start of the process, to developing the review and subsequent follow up to demonstrate impact. Each stage of the methodology will be highlighted and will include an example of a rapid review undertaken to inform service delivery during COVID.

**Implications:** The use of rapid synthesis in clinical practice and policy decision-making requires both rigor and transparency. Although PaCERS was developed to support palliative care clinicians, this approach could be adapted to suit partnerships between all healthcare disciplines and researchers.

## Cleaning, Counting and Classifying Radiotherapy Treatment Data: Assessing Multiple Approaches in A National Pilot

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**Background:** Radiotherapy is an important part of cancer treatment, with ~50% of all cancer patients having radiotherapy. Radiotherapy has a long history of computerisation, and England has a national electronic radiotherapy dataset (RTDS), collected directly from treatment machine. However, such routinely collected data is often messy and incomplete. In particular, treatment courses may appear to be split into two halves (fragmented) when they are really one planned course that runs over the end-of-month extraction date, or may appear to be two treatments to an area when they are in fact treatment to an anatomical region and sub-region (e.g. radiotherapy to the breast with a boost to the tumour). Information on whether the treatment is palliative or curative may be missing, or treatments may be labelled differently in different centres, but classification depends on correctly being able to count the total dose and number of fractions. As a result, it is not currently possible to reliably count or classify radiotherapy activity in England, or interpret outcomes after treatment. Here we present algorithmic approaches that address these problems.

**Methods:** We extracted treatment data on 10,094 patients over 7 months treated at four centres in the UK. We developed rule-based approaches to identify fragmented courses of treatment and courses that contain a boost. Moreover, we used an algorithm to combine radiotherapy episodes delivered to patients within a 30-day period into single treatments, reducing the final number of treatments. We identified the correct treatment intent by manually reviewing all episodes and used that as the gold standard. We used published national guidance on dose and fractionation to build a rule-based model for intent classification. We implemented our new rule-based approach as well as two standard machine learning techniques (Bayesian Network and Support Vector Machine) and compared the results using the gold standard intent.

**Results:** There were 12,547 treatments in 10,094 patients. We identified 317 fragmented episodes which were reduced to 193 by the defragmentation, and we identified 390 patients who underwent a boost, reducing their total treatments from 848 to 390. In the end, after applying treatment combining algorithm, we identified 10,391 radiotherapy treatments based on 12,547 episodes of radiotherapy extracted from RTDS.

For the intent classification task, SVM was the best performing model with a specificity of 97.8%, sensitivity of 95.9% and F1 score of 95.9%. Although our rule-based model performed slightly worse than the SVM, it had a higher sensitivity (97.2%) and similar specificity (96.6%) and F1 score (95.6%). Our approach also outperformed the Bayesian Network. We also manually assessed misclassification by different models and identified distinct patterns for each (e.g. Rule-based and Bayesian network tended to incorrectly label the intent of preoperative radiotherapy in colorectal cancer patients).

Algorithm	Sensitivity	Specificity	F1 Score
SVM	95.9%	97.8%	95.9%
Rule-Based	97.2%	96.6%	95.6%
BN	90.5%	94.5%	90.3%
Intent	98.4%	99.1%	97.7%

**Table 1.** Performance of the two-machine learning, the rule-based and the intent directly found in RTDS after defragmentation.

**Implications:** In this study we developed a model that accurately and reliably predicts the intent of radiotherapy treatment given a radiotherapy patient data set. A key element is the pre-processing to remove fragmented regimens and boosts, which then make subsequent assignment of treatment intent much easier. Our model is transparent and follows clear, identifiable rules which might be easier to update than the SVM approach in a clinical setting. Furthermore, as it is based on published national guidance, it can be easily updated as new guidelines are introduced. The ability to correctly count the amount of radiotherapy delivered in England is an important step in understanding outcomes and cancer services more generally.

## A National Health Service Approach to Dissemination, Knowledge Translation and Research Impact

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*Health Service Executive*

**Presenting Author: Virginia Minogue**

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**Background:** The literature about research waste tells us that two of the factors in research having little or no impact are it not being disseminated and implemented. Furthermore, there are significant barriers in getting research into practice, policy, and guidance. Embedding research in organisations, engaging clinical services and health service Boards, and realising impact and adding value through research, are the areas that research managers find most challenging.

**Methods:** The HSE in Ireland, in setting up new processes for research management and governance, also wanted to create a culture where research evidence is valued and has impact. A scoping project identified a high level of research activity but there was little knowledge about how research was mobilised into practice and reached knowledge users and whether it had impact. A project to develop a national approach to dissemination, knowledge translation (KT) and impact resulted in a framework and guidance for research managers, research commissioners, researchers and organisations.

The presentation will describe a project designed to address the issues of embedding research evidence, and realising benefit from research, across services and organisations. The aims of the project were to produce a framework for dissemination, knowledge translation, and impact, to identify a suitable KT framework and impact tool(s) for use by health researchers in HSE and within health care organisations. The project was developed and delivered by two project managers and a working group. It involved scoping and reviewing 2 systematic reviews and circa 250 models of KT, a review of impact tools, a pilot implementation phase, and the development of guidance and training materials.

Deliverables included a dissemination, KT and impact approach to HSE research with guiding principles, a KT model, impact tools, and guidance.

**Conclusions:** Creating an evidence-based culture and embedding research has to be framed within a clear approach to dissemination and impact. Ownership of key knowledge users and senior managers is important to successful implementation.

### **Implications:**

- the importance of dissemination and impact planning throughout the research study.
- the KT framework must be usable and applicable in health service settings and have clear constructs.
- the need to engage knowledge users in developing a framework.
- while lots of groups are energised to get research into practice and use evidence this project streamlines resources to support researchers to effectively enhance the use of their research findings.

## Towards An Agenda for Change of The Ethics System In Health And Social Care Research

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**Background:** Participatory approaches to research are well-established in the field of health and social care. They aim to conduct research “with” people, rather than “on” people, and to enable research processes that involve partnership between researchers and different groups of stakeholders. In practice, they are often adopted to bring in the research process marginalised or vulnerable groups whose voices may be seldomly heard.

However, it is acknowledged that the research ethics system – which regulates what research is carried out and how research activities can take place – is generally poorly equipped to deal with participatory research with vulnerable groups, with the risk that participation in research may be hindered rather than facilitated.

**Methods:** A Delphi study with a group of researchers with relevant expertise and experience was run to (1) understand the issues they experienced when navigating the English research ethics system and (2) generate consensus on the changes needed to ensure a better fit between the principles and processes of research ethics and the aim and methodologies of participatory research involving vulnerable populations. Sixty-six statements grouped in 12 themes (e.g. the research protocol, seeking consent) were included in the survey. The statements were generated iteratively through a process that involved (i) an analysis of policy documents underpinning the UK research ethics framework, (ii) an exploratory focus group with 12 researchers with experience and expertise in the field and (iii) a rapid review of the literature on the topic. Descriptive statistics were used to describe participants’ demographic characteristics and responses to each statement in the two rounds.

**Results:** Fifty seven researchers were invited to join the Delphi study. Thirty-five took part in the first round of the study, with 28/35 taking part also in the second round. Consensus (defined as > 80% agreement) was reached on 26 and 7 statements, respectively in the first and second round. Hence, about 50% of the original set of statements reached consensus by the end of the process. Thirty-two out of 33 consensused statements concerns ways in which the research ethics system could be changed to make it more fit for purpose in the context of participatory research with vulnerable groups. Nearly-universal consensus (defined as > 90% agreement) was reached on 14 of them. Conversely, the majority of statements which did not reach consensus (25/33) refers to how the current research ethics system deals with participatory research involving vulnerable groups.

**Implications:** Implications of this work are two-fold. First, the Delphi study suggests that researchers seem to have a diverse range of experiences when navigating the current research ethics system in the context of participatory research with vulnerable groups, as reflected in the lack of consensus on the majority of statements around this. This finding requires further exploration in order to understand the factors driving this heterogeneity (e.g. type of vulnerable groups involved, the experience of the researcher in dealing with the ethics system). Second, the study focuses on the experience of the researchers, one group in the constellation of actors who play a role in the research ethics system. Hence, it represents the first steps towards an agenda for change of the research ethics system and pinpoints concrete policy options that could better equip the research ethics system to deal with participatory research with vulnerable groups. However, the views of other stakeholder groups (e.g. research participants considered vulnerable, research funders, University Research Ethics Committees, national Research Ethics Committees) should be sought and explored, in order to identify concerns and priorities for change from a broader, system-wide perspective.

## **Rapid Insight: Balancing Rigour, Relevance and Practical Learning. A Case Example of Q's Insight Project on Implementing Video Consultations in Response To COVID-19**

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**Presenting Author: Jo Scott**

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**Introduction and Background:** A recurring theme of research and evaluation in 2020 was speed: with the uncertain and rapidly changing environment, how could researchers and decision-makers rapidly gather and make sense of what was happening; and capture and share learning for both practitioners and decision-makers? Could this be done without compromising on rigour? What was the best way to capture learning systematically using remote methods, without adding additional burden on overstretched staff? These were the challenges that Q considered when setting up a project to capture learning from people rapidly rolling out video consultations in response to the COVID-19 outbreak. Q is an initiative connecting people, who have improvement expertise, across the UK and Ireland. The rapid changes that were required of health and care services to respond to COVID-19 presented an opportunity to learn more about the role of improvement during these changes, while enabling improvers to share ideas, enhance their skills and collaborate to make health and care better.

**Method:** We were aiming to recruit a small group of improvers implementing video consultations as a response to COVID-19. Participation was designed to be light-touch and flexible between April and June 2020, with a rapid turnaround of the learning.

Participants were asked to complete six fortnightly learning logs and join two webinars to explore common themes together. The Q team analysed and summarised the themes from each learning log and published this on a blog within a week of the logs being received.

**Results:** 50 participants took part over the course of the project. The analysis drew out the key enablers and barriers, and priorities for the future. It drew out specific issues around inequalities and sustainability, and provided a real sense of the personal commitment, pride and challenges from the staff involved.

### **Implications:**

- The rapid sensemaking captured an interesting and useful story of the transformation that individuals and services were going through during an unprecedented period of change and uncertainty. However, the speed at which we were working has meant there are some limitations to the depth of analysis or opportunities to follow up with participants to explore specific cases and outcomes in more detail. This highlights a role for both rapid insight and longer-term evaluation and research.
- Given the fast-changing and uncertain context, a key strength of this work was that we were able to share emerging learning with both national decision-makers and improvers implementing this in practice through Q's networks.
- The relatively light-touch demands on participants through a digital learning log, and appetite for this type of reflective practice, meant that we had a higher response rate than initially anticipated. As a result, we were able to capture a broad range of experiences, rather than just focusing on examples or a small sample. But this meant there was less time to support shared reflection and learning, which is usually encouraged within reflective practice.
- Because of how they were recruited, the participants are likely to be proactive, reflective individuals, that are more in favour of video consultations. Their views may not represent the majority experiences or perspectives of those in their organisations and teams, and there was no patient perspective included.

The appetite for rapid sensemaking and analysis will undoubtedly be a lasting legacy from the COVID-19 pandemic. Q's approach offers potential for generating insight that supports the learning and development of front-line practitioners, alongside actionable learning that can inform improvement initiatives. Building on the learning from this work would serve to strengthen the process in a more collaborative and rigorous way.

# **“Some Groups Suffer Because Their Experiences Are Not Made Visible In The Data”: Navigating Data Governance Approvals To Use Routine Health And Social Care Data To Evidence An Invisible Population, A Case Study From A Clinical Academic Perspective.**

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**Introduction:** Front-line care professionals can identify practice areas for service evaluation and research that may be hidden to academic researchers. Practitioners' knowledge of routinely-gathered data and recording systems, coupled with availability of data-linkage and big-data management is potentially foundational to facilitate high-quality audit and research. The approvals processes within both the NHS and partner organisations, to protect individuals and organisations from harm, is multi-layered and may present challenges. The present paper appraises aspects of navigating these approval processes to obtain data on an under-represented group, to inform practice and policy.

**Method:** The current Scottish NHS/Higher Education approvals landscape is explored using an observational case-study, which documents an experienced clinician navigating approvals processes for a service evaluation, also a doctoral study. This study aimed to identify people with BMI  $\geq 40\text{kg/m}^2$ , using community NHS health and social care services in a demographically representative local authority area in Scotland, UK. Approvals were for a) collecting height, weight and recent community health and social care usage, with a nested qualitative study on participant's experiences, b) verifying participant's self-reported service utilisation data via health and social care systems, c) transferring de-identified data to a university. Relevant ethical, legal and practical requirements are outlined. The wider policy context includes the impacts of the recently introduced General Data Protection Regulations, and the evolving integration of Health and Social Care services in Scotland.

**Results:** Formal approvals by nine separate stakeholders from four different organisations, took nearly three years, including fifteen initial or revised applications, assessments or agreements. Reconciling modified requirements after initial formal submissions for approval necessitated repeated contacts with approvers. The most complex challenge related to sharing and transfer of data between organisations. Obstacles faced included: conflicting views on whether the project constituted research, service evaluation and/ or quality improvement, isolated decision-making, fragmented data systems overseen by multiple data controllers, and a dynamic data governance environment.

**Conclusion:** The current Covid-19 pandemic highlights the need for health and social care data to guide care provision. This case study emphasises the need to support clinicians through the current multi-layered approvals processes, to utilise their frontline knowledge of practice and empower them to explore the underlying data for research, audit and service evaluation. Navigating the current processes presents a major challenge to clinicians, and thus an obstacle to research & evaluation.

## **Recommendations:**

Specific issues that might now be considered, to facilitate clinical research and service evaluation include:

1. Recognise the need for further training to understand the technical complexity of current data governance context.
2. Promote tools such as the Scottish Information Sharing Toolkit, including availability of templates for Data Sharing Agreements/ Memorandums of Understanding.
3. Guidance over early, exploratory conversations with approvers regarding data governance aspects of study design.
4. Improve resourcing of approvers: to reduce waiting times for approvals, given approvers' workload increase as data governance has gained complexity.
5. Establish clear lines of information-sharing between data controllers, particularly where sharing is for service benefit.
6. Develop unified submission approach to clinically-led research and service evaluations across NHS and partner organisations.
7. Recognise and promote clinical academic status in healthcare workforces, to release the full potential of routinely-collected data.
8. Promote collaborations with clinicians in data analytic projects.

