

## 5. Purpose/Methods/Outputs

### 5a. Objective for processing:

The Nuffield Trust for Research and Policy Studies in Health Services (The Nuffield Trust) is an independent health research charity overseen by a board of Trustees including a number of senior NHS clinicians, managers and academics. The Nuffield Trust aims to improve the quality of health care to improve the health of people in the UK by providing evidence-based research and policy analysis and informing and generating debate. It provides a trusted and respected voice at a time of unprecedented challenge to the NHS and social care system.

Under the HRA's GDPR Operational Guidance the Nuffield Trust therefore relies on Article 6 (1) (f) "processing is necessary for the purposes of the legitimate interests pursued by the controller or by a third party, except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject". The Nuffield Trust's legitimate interest is carrying out healthcare research in the wider public interest of improved healthcare outcomes for NHS patients.

The Trust relies on Article 9 Condition 9(2) (j) (processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject) as the condition for processing "Special" categories of personal data.

The Nuffield Trust has determined that no moral or ethical issues are raised by its processing of HES or other patient data sets (such as emergency or community care data). All data supplied is pseudonymised. All outputs contain only aggregate data, with small numbers suppressed to agreed thresholds in line with the HES (or appropriate) analysis guide.

The Nuffield Trust focuses its activities on six priority areas:

- Health & social care finance and reform
- NHS Workforce
- Older people and complex care
- Quality of care
- New models of health care delivery
- Children and young people

These priorities were set in 2015, with the exception of "Children and Young People" which was added in 2017, and are anticipated to remain valid until at least 2020.

The work of the Trust is organised into a number of programmes which address these priorities. The programmes are broadly aligned to priorities as shown below, with a desire to develop a number of the programmes to cut across one or more of the strategic priorities to maximise reach and impact. For example, the Quality programme is relevant to both Quality of Care and Primary Care priorities, and the Workforce programme impacts on both Workforce and New Models of Care. Each programme has a sponsor at Director level, as well as a programme lead, who is typically a Senior Researcher or Senior Policy Fellow.

The data from NHS Digital is vital to the Trust's work because it is an essential source of information on patient activity and outcomes, which allows comparisons across different parts of the NHS and over time. The use within programmes and projects is outlined in more detail in the following sections.

#### 5a.i. Rationale for strategic priorities and programmes

Health & social care finance and reform: The NHS is introducing new models of care and a different way to work with councils through Sustainability and Transformation Partnerships. All of this is being attempted at a time of historic financial constraint, with record trust deficits and an intense search for efficiencies. In

addition, Britain's departure from the EU could mean major changes and deep uncertainty for health and social care staffing, regulation and workforce.

The Nuffield Trust's focus is on improving the quality of policy-making by providing evidence-based analysis, asking insightful questions and providing a challenging view. Programmes in this area cover:

- Commissioning and System Delivery – how the health system is changing, for example, moving to integrated care.
- Topical Issues – for example, issues such as Brexit, which impact on the health system.
- Funding and Sustainability – impact of spending constraints and how funding is allocated to health and care organisations

**Workforce:** The NHS workforce is under extreme pressure, and it is not just a matter of numbers. Some areas are undersubscribed, but others have an over-supply. New technologies and care models require new types of staff, and training for this highly skilled workforce has long lead times. Getting all of this right has never been more critical, especially with the uncertainty around migration following the country's vote to leave the EU. The development of new models of care is often driven by changes in workforce and vice versa. Being able to make the links between the two areas will be very important.

The workforce programme addresses how the NHS manages workforce pressures and develops a sustainable workforce. The Nuffield Trust ensures their research and analysis informs the Government's strategy for the future health care workforce.

**Older people and complex care:** Older people are among the most intense users of health and social care services and opportunities exist for improving the care offered to them. In particular, the needs of older people with multiple health problems and complex conditions are recognised as being a key driver of health service design utilisation and a sentinel marker of the quality of care.

The older people and complex care programme examines models for delivering care to older people and people with complex needs, given the growing number of people with multiple conditions.

**Quality of care:** Patients and the public expect to receive high quality, safe care, where and when they need it. Despite this, it is known that the quality of care is variable – between organisations, different conditions, and different patient groups. It is also known that the UK lags behind other similar countries in treatment of common diseases, and while some aspects of care have improved over time, for many aspects of care improvements in quality have stalled.

The level of funding for health and social care will influence what can be achieved, but regardless of this, the Nuffield Trust needs to understand how the quality of care is changing, to generate evidence on what can be done to improve quality, and to ensure that improvements which will make the most difference to patients and the public are prioritised.

Quality of care programmes cover:

- Quality – Drawing on its other work programmes, the Nuffield Trust uses expertise in measurement and analysis of quality of care, to provide independent scrutiny, and undertakes research to improve the evidence on quality of care.
- Evaluation – The Nuffield Trust also considers how effective policies intended to improve quality have been, and what can be learnt, in order to influence future decision makers, locally and nationally. This includes evaluating service changes and innovations in the delivery of care.

**New models of health care delivery:** NHS England's Long Term Plan, and previously the Five Year Forward View, outlines a vision for how the traditional boundaries between primary care, community services and hospitals will be dissolved over the next five years and beyond. Breaking down the traditional boundaries between different parts of the NHS and social care offers the prospect of reshaping services around the needs of individuals and reducing reliance on hospitals. This will require a move away from single institutions towards networks of care. In this world the capacity of care delivered outside hospitals will need to be boosted through reforms to general practice, while technology and new types of staff enable expertise and information to be shared.

The Nuffield Trust will build on the considerable experience and reputation it has in conducting evaluative work of new models of care, with a number of research projects in place with Royal colleges and specialist societies. The Trust will also provide briefings and analysis that help health leaders choose and implement changes, and bring them together to share ideas.

New models of health care delivery programmes in this area cover:

- Acute Medical Models - models of hospital care and the optimal configuration of services to deliver inpatient services.
- Primary Care - future of primary care and role of primary care in a changing health system.
- Digital - the impact of new technology on delivery of health care, and opportunities to improve care using technology.

Children and young people: The health and wellbeing of children and young people depend on the efforts and commitment of their parents and families, their schools and local communities and the decisions and actions of public service providers and policymakers. This creates a moral imperative to safeguard and promote their interests. There are nearly 20 million people aged 0-24 years old living in the UK, almost a third of the population. There have been long term improvements in health outcomes and quality indicators for children and young people, however, more recently those improvements have slowed or even reversed and internationally the UK compares less well than it might wish. Child health has changed over the last 45 years. Mortality data shows an epidemiological transition away from acute infectious illness towards chronic long-term conditions, yet the way health care services are provided is still heavily hospital focused and reactive. Change has been slow to come due to a long term lack of policy focus on most of the services for children and young people

The Children and Young People work programme will develop the evidence base on how problems and challenges could be addressed by policy and decision makers at a national and local level and/or by individual teams and professionals working with children and young people. The work will have a particular focus on what health care services and systems can do, but will also include how the different parts of the wider context for children and young people interact with each other to address the issues. The Trust also aims to help build networks between different organisations and people who can shape the direction of health care services, health systems and other services.

The work programmes within the strategic priorities were developed in 2018 and are expected to remain aligned to the strategic priorities above until at least 2020 when they may be reviewed.

## 5a.ii. Use of HES and CSDS data within programmes and projects

Each programme is delivered through individual projects. Projects vary in length and complexity from major research studies which could span a number of years, to shorter term projects resulting in a single output, for example a briefing or presentation. Some Nuffield Trust projects are qualitative, involve analysis of published data, or data from surveys, and so do not require use of HES or other NHS Digital data sources. However, many others are reliant on HES and other NHS Digital-supplied data sets.

To undertake such projects the Nuffield Trust has determined that it requires HES data including the Emergency Care Data Set which will replace the HES A&E dataset and the Community Services Data Set which is now available and is a very welcome addition to the existing hospital based HES datasets.

Although the methods for use of HES and other patient datasets will vary from project to project, there are a number of common ways in which the data is used. This Agreement permits use of the data by the following methods:

- Assessing data quality, completeness, relevance and volumes of data prior to and during undertaking research analysis;
- Analysis to provide contextual information about NHS organisations or areas where research projects are being undertaken (in addition to analysis of relevant comparator organisations and areas), for example analysis of volumes of emergency admissions by specialty;
- Descriptive analysis of NHS activity and calculating age-sex standardised activity rates, for demographic or other patient cohorts, NHS organisations or administrative areas relevant to understanding NHS and

government policies, and identifying gaps in policy;

- Using health care activity data to track changes in events such as emergency department attendances, admissions and re-admissions, time on caseload (for community patients). These are important (though imperfect) proxies for health outcomes and tracking trends in these events over time enables analysis of the impact of changes in health services;
- Analysis of health care resource use through applying NHS tariff or reference cost data to activity data derived from patient utilisation of services, and analysis of measures of capacity including bed occupancy from utilisation data;
- Undertaking detailed analyses of particular health events to identify particular issues with quality of care, for example as part of the harm project (see below), and patients with particular needs (eg frailty). This includes developing indicators of quality of care, covering access, effectiveness, continuity, coordination, safety or outcome;
- Examining variation between hospitals, patient groups or areas in use of services to identify populations where there are gaps in care, and also areas delivering high quality care from which the NHS can learn more widely using multivariate methods including standardisation, regression modelling and risk analysis;
- Analysis to determine the impact of specific service delivery models, such as the introduction of new pathways of care, or care settings, including acute admission units, same day emergency care, outpatient advice models, primary care networks and other models relevant to current NHS or government policy;
- Development and application of risk prediction models by methods including multivariate regression, cluster analysis, decision trees and machine learning for analysis to identify cohorts of patients with similar needs and to analyse variations between hospitals, patient groups or areas and for measuring the impact of service delivery models;
  - Analysis to understand how wider health system and other factors impact on outcomes and activity, including differences between urban and rural service delivery or needs, impact of deprivation and variation in socio-demographic characteristics of the population and local factors such as education and social care provision and quality;
  - Analysis to inform international comparisons of health data and quality, including replicating quality measures used in other health systems;
  - Making evaluations of healthcare innovations more robust by using matched case-control analysis - comparing outcomes or trends in a service being evaluated with similar patients elsewhere;
  - Evaluations of health care innovations using methods including time-series analysis, including interrupted time series, panel data and cohort studies;
  - Use of the above methods in combination for particular research projects;
  - Producing visualisations of analysis and results from the above methods.

The data will not be linked with other record level datasets and there will be no attempt to reidentify individuals from the data. The data may, if required, be linked with national datasets in the public domain (e.g. indices of social deprivation) subject to a risk assessment that the linkage will not increase the risk of reidentification of individuals within the dataset.

Should the Nuffield Trust wish to undertake a project involving a specific cohort of patients for which a data linkage is required, a separate application to NHS Digital and, subject to approval, a separate Data Sharing Agreement permitting the processing will be required.

The number of concurrent projects using HES data will vary, but typically there are 5-6 projects in progress which use HES data at any one time, with perhaps 2-3 being completed in a calendar year. There may also be additional projects for which the analysis phase is complete, but work is ongoing on peer review publications and dissemination of the findings.

Projects are grouped within programmes, but frequently cut across other programmes. As the Nuffield Trust is a small organisation, it seeks to maximise impact by undertaking work which can inform more than one programme or strategic priority. Undertaking projects which support multiple programmes enables the Trust to deliver greater benefits to the health and care system.

5a.iii. How decisions are made about projects and use of HES and CSDS data

This Agreement permits the Nuffield Trust to use the data for the purposes of projects undertaken within the work programmes described above, and which are conceived, planned, approved and initiated through the following process:

1. Projects intended to meet the programme's aims will be conceived and planned through an iterative process involving the Programme Director and Programme Lead with appropriate input from the Data Protection Officer (DPO). The Programme Director and Programme Lead will ensure that:
  - Projects have a clearly defined objectives and operational plans;
  - The aims of projects align with at least one of the programme's aims (as stated above)- all projects must clearly and logically fall within the scope of having one or more of the aims listed and achieving those aims through one or more of the methods listed above ;
  - An analysis plan is prepared for each project, setting out the data requirements and methods;
  - In each case, the use of the HES data is necessary and proportionate to the purpose of the project and that the minimum amount of data necessary is used - this will include consideration of the necessity for use of each individual HES dataset; the number of years of data; the sizes of any cohorts or control cohorts derived from the data, and the inclusion and exclusion criteria (such as presence of specific diagnostic or procedure codes);
  - Appropriate safeguards are in place to protect confidentiality; minimise risks of re-identification and use of excessive data beyond necessity.

A Data Protection Impact Assessment (DPIA) is completed at strategic level and covers all associated projects. A Legitimate Interest Assessment (LIA) will be completed internally for each research project and signed off by the Data Protection Officer (DPO).

2. A project management template will be completed and submitted to the Nuffield Trust Project Planning Committee (PPC). This excel template serves a wider purpose than just planning and remains valid throughout a project's life, serving as the central control document in the management and delivery of the project. The PPC is chaired by the Director of Communications and consists of the Chief Executive, Director of Research, Director of Policy, Senior Fellow, Senior Policy Analyst and other representatives from Research, Policy and Communications. It provides a forum for the discussion, in depth and expert assessment and approval of project ideas, drawing on senior level expertise and knowledge across the Trust.

The committee is responsible for receiving assurance that all projects:

- Align to the strategic aims of the Trust;
- Are methodologically sound; and
- Draw fully on the expertise within the Trust including making connections to other related work.

The Committee will approve or recommend the approval of projects in line with the internally approved schedule of management authority and responsibility.

3. The individual or team within Nuffield Trust which will carry out the project will define and be bound by the analysis plan detailing what data is permitted for use in the project and how it shall be processed.

## Project Timescales

The time frame for undertaking each project will vary according to project resource, extent of the research and data analysis required. This is always considered as part of the Project Planning Committee's review and approved based upon the detail of each individual project.

## Project Funding

Some projects under the programme will be funded by the Nuffield Trust but funding is also being sought from

other partners including National Research and Charitable organisations, such as the Nuffield Foundation, NIHR and the Health Foundation but may not be limited to these organisations. Funders will take both the forms of partners in collaborative working, as well as commissioners only, that is, the Nuffield Trust will be sole data controller for the analytical work.

Though the Nuffield Trust may be commissioned by another organisation to undertake a project involving the processing of data under this Agreement, the Nuffield Trust will retain sole discretion for determining if and how the data would be used for any purpose. The Nuffield Trust will not be reliant on securing funding from external partners to complete this research. However, the Nuffield Trust will need to recognise the contribution of any external partner in their outputs.

## Data Governance

The Nuffield Trust has independently determined the purposes for which it requires and will process the data under this Agreement in terms of its priorities and programmes which will use the data. The Nuffield Trust has sole autonomy for determining if and how the data will be used for projects in support of those priorities and programmes. As such, the Nuffield Trust is the primary data controller and the sole data controller named in this Agreement. In certain projects which involve collaboration with individuals or organisations outside of the Nuffield Trust, it may be the case that there is joint controllership for the specific project or aspects of it but in all cases, the Nuffield Trust will retain sole autonomy for determining if and how the data under this Agreement will be processed and the Trust cannot be compelled by any third party to process the data for any purpose of in any way. The data will only ever be used for purposes that directly support the priorities of the Nuffield Trust as described in this Agreement.

Under this Agreement, NHS Digital data will only be accessed by Nuffield Trust personnel (defined as employees, agents and contractors of the Trust) all of whom have been appropriately trained in data security and confidentiality. On occasion, the Nuffield Trust may invite individuals with significant or unique expertise to join the research team and contribute to data analysis. These individuals will either be seconded into the Nuffield Trust or will have an honorary contract with the Trust for the purpose and duration of a specific project or task within a project and as such will be considered agents of the Trust. These individuals would be subject to the same information governance framework as the Nuffield Trust employees and would be required to meet the level required to access the Nuffield Trust's secure, ISO27001 certified data environment.

Should the Nuffield Trust wish to utilise an external organisation as its data processor, a separate application to NHS Digital and, subject to approval, a separate Data Sharing Agreement permitting the processing will be required.

Results may be shared in aggregate form in accordance with the Nuffield Trust's Research Governance framework, with small numbers suppressed. The data accessed through this Agreement will be managed by the Nuffield Trust, and will not be shared with any other third-parties.

The Nuffield Trust will produce an annual report for NHS Digital which will detail the outputs from all active and finished projects, which have been delivered during the year, and the planned outputs from new projects. The report will reference the associated strategic priorities and programme(s). Details will also be available on the Nuffield Trust's website.

### 5a.iv. Examples of projects

The following examples of projects which have used HES data illustrate the range of work already undertaken in recent years, and upcoming projects. These are provided as examples of work the Nuffield Trust has undertaken or is or will be undertaking to meet the objectives of its programmes in support of its strategic priorities. The examples are not intended to form a comprehensive list of projects permitted under this Agreement.

## Integrated care pioneers evaluation

Integrated Care 'Pioneers' are models of care aimed at reducing the impact of boundaries between health and social care providers. The evaluation of the pioneers has wider lessons for the current policy for integrated care systems.

- Nuffield Trust programmes: Commissioning and System Delivery; Evaluation; New models of care
- Overview: The Nuffield Trust is leading on one work package to develop and monitor a set of system level indicators, as part of a wider project with the DH Policy Innovation Research Unit based at the London School of Hygiene and Tropical Medicine. The analysis of HES data to develop indicators was solely the responsibility of the Nuffield Trust. The LSHTM does not have access to the data.
- Data minimisation approach: This project involves looking at time trends across a range of health and social care indicators. The Pioneers were introduced in 2013 but to have a good understanding of trends prior to this, HES data are used from 2004/05 with follow up until 2019/20, when that data is available. The indicators are presented in aggregated form in a dashboard with local authority district as the lowest geographical unit available. For the majority of indicators all ages are included but where possible indicators are restricted to a particular age group. Only variables relevant for each indicator were used.
- Duration: The project runs from 2016 to 2021

## Medical Generalism

The rising numbers of older and more complex patients is one of the most pressing problems facing the NHS. Although they receive the most resource-intensive care, their problems are less likely to be accurately diagnosed and have more adverse outcomes than other age groups. The current models of hospital care, which are heavily based around specialists delivering disease-specific care, serve these patients poorly, as it is often fragmented and poorly co-ordinated. A revival of medical generalism has been suggested to provide better and more cost-effective care. The reality, however, is that there is a paucity of evidence on which to base new models of medical generalism.

- Nuffield trust programmes: Older people and complex care; Workforce
- Overview: The overarching aim of this NIHR funded research project was to identify the models of medical generalism used in smaller hospitals and explore their strengths and weaknesses from patient, professional and service perspectives. The Nuffield Trust used HES data to create a classification of patients that might benefit from general medical care and, based on this classification, provide a descriptive analysis of the workloads of smaller hospitals.
- Data minimisation approach: Hospital Episode Statistics data (year range 2007/08-2017/18) was used to create a classification of patients that might benefit from general medical care and, based on this classification, provide a descriptive analysis of the workloads of smaller hospitals. The final sample included 69 smaller NHS Trusts providing acute medical care in England, although some analyses used only 68 hospitals as a result of merges during the data period.

A data set based on 'Index episodes of care' for emergency admissions across the selected generalist medicine specialities identified in HES inpatient data 2012/13 for the smaller hospitals cohort was created so that five years of prior patient history for cancer patients as well as three years of subsequent history could be included. Cases with a specific diagnosis indicating specialist care or where patients had been transferred out of hospital were excluded. A data set was created covering 1.9 million episodes in the selected smaller hospitals.

Following development of the case mix classification, analysis focused on different data collection years dependent on the nature of the research question. For instance, the degree of alignment between patient case mix and medical generalist/skills mix in smaller hospitals was assessed based on analysis of the 2015/16 data set. Population level analysis of admission patterns used data from 2017/18.

- Duration: The main research phase of the project was from 2016 to 2018.

This analysis was undertaken under a previous Data Sharing Agreement with NHS Digital in conjunction with University College London (UCL) which undertook parts of the analysis as a data processor under contract to the Nuffield Trust. Nuffield Trust defined the analysis and manner in which the data should be processed as well as the tools used (i.e. the software). The Trust also owns the outputs. The UCL Department of Applied Health research team carried out the above work on the Nuffield Trust site under the same Information Governance arrangements as Nuffield Trust staff - i.e. a signed confidentiality agreement as evidence that they had read and understood the Trust's Information Security Management System (ISMS), completed equivalent training and worked in the same

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environment. No data provided by NHS Digital left the Nuffield Trust site and the data was only processed on Nuffield Trust servers.

## Evaluations of new services for patients outside of hospital

The Nuffield Trust has undertaken a number of evaluations of programmes to reduce admissions or readmissions to hospital, through better support for patients at home.

- Nuffield Trust programmes: Older people and complex care; New models of care; Evaluations
- Overview: This is a programme of work undertaken over a number of years. For example, the Nuffield Trust undertook a project funded by Age UK of services to support often vulnerable older people at high risk of hospital admission, which assessed the impact of this service on future emergency admissions. Previous projects were undertaken for a range of funders including the British Red Cross, Royal Voluntary Services and the Cabinet Office.
- Data minimisation approach: These projects took place using data linkage to HES data for specific cohorts of patients receiving innovative services. The Nuffield Trust used HES data from two years prior to the date each individual started receiving the service to allow for calculation of risk of emergency admission scores. To implement these models, the Nuffield Trust used a selected list of fields from inpatient, outpatient and A&E datasets (including admission method, diagnosis codes, procedure codes, A&E investigation codes, outpatient attended/did not attend). The Nuffield Trust compared each group of service recipients with a selected matched control group - matching one control person to each service recipient. The Nuffield Trust selected controls from a larger pool of possible control individuals. This larger pool of possible control individuals were selected to reflect the intervention cohort - eg they were the same ages (for example 55+ or 60+), and lived in similar areas (as defined by ONS and other analysis). Risk scores were calculated for all possible controls - involving again two prior years of HES data. For the evaluation outcomes, the intervention and matched control groups were followed up for a limited number of months (maximum 16, but more usually 6-9) on a limited number of activity measures.
- Duration: This was undertaken from 2013 to 2019

## Comprehensive Geriatric Assessment (CGA)

The CGA was a multidisciplinary process designed to assess a frail older person's medical conditions, mental health, functional capacity and social circumstances. However information is lacking on the types of patients that might benefit the most. The aim of this work is to describe existing models of care and to validate tools to deliver CGA on a hospital wide basis.

- Nuffield Trust programmes: Older people and complex care; Quality of Care; Evaluations
- Overview: This was a collaborative project undertaken as an NIHR funded project undertaken with the Universities of Leicester and Newcastle. The project incorporated linked HES, ONS and clinical data, managed under a specific Data Sharing Agreement (DARS-NIC-383324-D6B8T).
- Data minimisation approach: Three clinical cohorts were linked to HES as part of this project. The recruitment dates for these ranged from 2006 to 2012 and therefore, HES was required from 2004/05 to 2016/17 to allow a period going back two years prior to recruitment and at least two years of follow-up. Only the relevant years for each cohort were linked. For the tool development and validation, cohorts were limited to those individuals aged 75 and over and a maximum of two years of HES data were used.
- Duration: The main project was undertaken from 2015 to 2018

## Harms and quality of care measures from routine data

Using routine data to identify harm to patients or indicators of sub-optimal care provides opportunities to monitor quality of care and develop measures which could be used to improve care by NHS organisations.

- Nuffield Trust programme: Quality of care
- Overview: The Nuffield Trust has previously undertaken work in this area as part of a DH funded project to look at ways to identify people who suffered avoidable serious harm. This tested whether HES data could be used as a screening tool to identify cases for specific audit. This work was undertaken in conjunction with the London School of Hygiene and Tropical Medicine and Imperial College London: the Nuffield Trust led on the



analysis of HES data, while LSHTM undertook record review, which did not use HES data. Only the Nuffield Trust had access to HES data.

- **Data minimisation approach:** The use of HES was restricted to the three years 2013/14 to 2015/16. Two "potential" harm events were defined, one relating to long length of stay and the other to an emergency readmission within seven days. To define the long length of stay according to different patient types the Nuffield Trust derived expected values from statistical models using age, gender, comorbidities, deprivation and previous emergency admissions. The model was derived from 2013/14 data and applied to the 2014/15 data. Data for 2015/16 was used to pick up any emergency readmissions that occurred after a discharge in the first year. Analysis was restricted to four groups of patients: admissions for acute myocardial infarction, admissions for emergency bowel surgery, admissions for elective bowel surgery and admissions for elective hip replacement. All admissions were adults (aged over 17), classed as an ordinary admission (Classpat =1) and discharged alive. The analysis also looked at diagnosis codes that reflected potential harms, such as complications, adverse reactions, pressure sores, etc.
- **Duration:** The DH funded work as undertaken from 2016 to 2018. Further work on this topic is being scoped. The Nuffield Trust plans to undertake further analysis of HES data to better understand how to identify where patients experience potential severe harm in hospital. This would build on previous work that was carried out under the Department of Health Policy Research Programme grant.

### Prison health

The Prison Health project aims to extend the use of routine data to understand the quality of care in prisons, and how the health of prisoners compares to the general population.

- **Nuffield Trust programme:** Quality of care
- **Overview:** The project is funded by the Health Foundation. Under a separate Data Sharing Agreement (DARS-NIC-195377-M9L8Z) NHS Digital will be producing a reference flag to identify HES records of people in prison. The Nuffield Trust will use this to extract the relevant records from the data it holds under this Agreement in order to undertake the analysis.
- **Data minimisation approach:** The first stage of the analysis will explore the potential of two specific HES data fields in admitted patient care data (ADMISORC and DISTDEST) to reliably identify people in penal establishments who access secondary healthcare services. Data to be analysed will cover the period 2005/2006 to 2017/18, as 2006 marks the point at which commissioning of healthcare services in prisons in England became the responsibility of the NHS.

The second stage of the analysis is descriptive and consists of an overview of the hospital services usage of people in the secure estate in 2017/18, including the admitted patient care, outpatients and Accident and Emergency datasets. The sample will include men and women from 112 prisons/young offender institutions in the prison estate in England. Secure children's homes were excluded from the analysis to ensure that small number requirements were not breached, thereby applying a lower age limit of 15 years old to the sample. Based on a prior literature review to identify key areas of concern regarding prisoner health, analysis of specific cohorts of prisoners will be conducted (such as women prisoners), as well as sub-group analysis focusing on specific clinical conditions such as kidney disease.

- **Duration:** This project runs from 2018 to 2019

### London Quality Standards

The London Quality Standards (LQS) project evaluated the impact of introducing quality standards on patient outcomes

- **Nuffield Trust programmes:** Quality of care; Evaluation
- **Overview:** This project was initially funded by NHS London as a year-long research project that explored the strengths and weaknesses of the LQS programme and its impact. This part of the project investigated whether implementation of quality standards resulted in changes in clinical outcome measures in these clinical areas.
- **Data minimisation approach:** The analysis has been planned to investigate the impact of the adoption of standards on outcomes (mortality, emergency readmission and length of hospital stay) within London hospitals. To match the periods of two audits of standards the Nuffield Trust analysed HES inpatient data from 2011/12 to 2014/15. Criteria for patient selection was all non-elective admissions to a London hospital where the

patient was aged 18 or more and classified as an ordinary admission (CLASSPAT = 1). Patient selection had to be broad as the quality standards are potentially wide ranging in their impact. To focus on specific standards the Nuffield Trust identified appropriate cohorts from diagnosis, procedure and speciality codes.

- Duration: This project ran from 2016 to 2019

## Organisation of primary care

The Nuffield Trust has an ongoing work programme on models of primary care delivery. This includes evaluation of new models of primary care (for example, the primary care home model) as well as analysis of the impact of 'scaled up' GP practices, to explore development of new general practice organisations

- Nuffield Trust programmes: Primary care; Workforce; Digital; Evaluation
- Overview: This project includes qualitative and quantitative elements. HES data has been used to develop indicators of primary care need and quality, as part of work to track changes over time and as a result of service changes.
- Data minimisation approach: In the Nuffield Trust's 2016 study of large scale general practice, they calculated a limited number of HES-derived measures of acute hospital use: all admissions, emergency admissions, Ambulatory Care Sensitive admissions, necessitating use of diagnostic codes, and A&E attendances. To study trends over time, these were calculated for each of the years 2009/10 to 2013/14 for the 13 large-scale general practice groups who were the focus of the study. Practice groups were identified using GP practice organisational code. National averages were also calculated for comparison, but only for the latter year 2013/14.
- Duration: This work was undertaken from 2013 to 2019. Further work on this topic is being scoped, to examine the impact of the growth of primary care federations, which has important lessons for the primary care networks being proposed as part of the long-term plan.

## Community service provision

The Nuffield Trust has undertaken initial analysis of aggregate CSDS data, reviewed available data on quality of community services and also reported on workforce issues in the community. The Nuffield Trust plans to extend this work once patient level CSDS data is available, using expertise in analysis of patient level data to develop and test potential measures of community activity, including patient measures (e.g. unique patients referred or in contact), service use measures (e.g. referrals, care activities, mode of contact), service delivery measures (e.g. caseload, duration of care), and outcome or process measures (eg waiting times, DNA rates, discharge method). This would enable the development of a programme of analysis of community services, addressing areas such as productivity, workforce, quality of care, and integration with other services.

- Nuffield Trust programmes: New models of care; quality; Primary care; Workforce; Digital
- Overview: This work would have an initial descriptive phase to understand the quality of CSDS and identify research questions which could be addressed using the data. This would be followed by one or more sub-projects addressing specific research questions.
- Data minimisation approach: the descriptive analysis phase will focus on assessing quality of data over time including trend analysis at aggregate level to assess data quality; comparison of activity and delivery measures at organisational level by service. Based on these findings more detailed analysis will be limited to providers and fields with consistent data recording over time.
- Duration: This is planned for 2019 - 2021, subject to timescales for accessing the CSDS data.

The above projects are examples of work undertaken or planned within the Nuffield Trust programmes. The Nuffield Trust will continue to identify new projects and to extend current work within the remit of the programmes described.

## Project Scoping and Responsive Analysis

Across many of the Nuffield Trust's strategic priorities, analysis may be undertaken of HES data for scoping research and responsive analysis, as described below.

Scoping analysis: in developing research questions for each of the projects, there would be benefits in occasionally carrying out a preliminary use of HES (and other NHS Digital-supplied) data before projects are formally approved. Such scoping analyses would be done on an ad hoc basis where there was a need to test some basic questions that might fundamentally alter how a particular analysis is approached. In some cases this preliminary work may even persuade the Nuffield Trust to not go ahead with a project. The questions that might be asked in scoping analyses might include some of the following:

- Testing whether key outcomes of interest are numerous enough,
- Checking whether coding is consistent across organisations and geographic areas, and over time,
- Determining whether particular statistical methods would be appropriate for the questions being asked,
- Testing whether the Nuffield Trust would have the statistical power to be able to make high quality conclusions.
- Assessing the minimum level of data required for the purpose.

Any such scoping analyses would be approved by the Director or Deputy Director of Research. Approved scoping exercises would be recorded in a register – recording aims of the scoping, data fields and years necessary, approval date and person, conclusions of exercise, final status of data used (see following). Where the conclusion is to proceed with a formal research project then data used for the scoping will be transferred to and managed under that project. If the scoping exercise ends with the conclusion that no further work should be done, then the data used will be erased.

Responsive analysis: The Nuffield Trust also regularly acts to improve the quality of public debate on use of hospital services by publishing quick-turnaround responsive research, which helps focus the debate on evidence. Triggers for this work might include a specific issue suddenly coming to national prominence, or an individual or organisation making an assertion which is easily tested using data already available. As an independent research organisation and registered charity, with independence from party politics overseen by the board of trustees, such interventions are carefully considered to ensure that an evidence-based statement may add value to the overall debate. They are not provided at the request of any individual organisation.

## **5b. Processing activities:**

NHS Digital will send quarterly and 'Annual Refresh' data extracts of pseudonymised HES Accident & Emergency (to be replaced with Emergency Care), Outpatient, and Admitted Patient Care and Community Service Data Set data to the Nuffield Trust by Secure Electronic File Transfer.

Under this Agreement, the data will only be processed by Nuffield Trust personnel (defined as employees, agents and contractors of the Trust) all of whom are either individuals who:

- i) are substantively employed researchers working under contract on behalf of the Nuffield Trust; or
- ii) are employed by Nuffield Trust as specialist third party consultants having either being seconded into the Nuffield Trust or have an honorary contract with the Nuffield Trust for the purpose and duration of a specific project or task within a project.

All research staff are subject to confidentiality requirements to access data to support business objectives and required to complete mandatory data security training annually

Whilst the nature of detailed analysis in relation to each project varies, the broad context of processing is consistent. In summary:

- The data is downloaded from NHS Digital to the Trust's Research Server. The server is held on-site, and access is restricted to named individuals according to The Nuffield Trust's security policy using Microsoft Role Based Access Control (RBAC).
- The data is held within separate folders within the server.
- Remote access to the database is permitted, but only through Citrix via secure token and with local printing and downloading disabled.
- Only staff who have signed a confidentiality agreement and have received IG training are permitted access.
- All access to individual files is recorded, and a sample audited to investigate the existence of any adverse incidents, and ensure that appropriate access has been maintained.
- The researcher will view the data and select a specific cohort for each individual study. Commonly a process will initially take place to define the particular cohort of interest in terms of e.g. individual diagnostic codes or procedure codes. The researchers will use routinely available filter definitions where possible, but may amend

these based on the nature of each study's group of interest. Depending on the research a similar control group may be established.

- The individual researcher then analyses the data, before applying the relevant disclosure controls to any output. Software used will be SAS, R and Stata; typically this will involve analysis on several outcome measures, risk adjustment and the construction of control groups.
- No record level data would be linked to this dataset (without an explicit separate agreement with NHS Digital), but it may be combined with publicly available demographic or geographic data, for example in relation to local Trust performance
- Outputs consist of aggregate data (or indicator/statistical data) only.

In all such work, The Nuffield Trust analyses patterns of hospital activity by area, by year, by condition or by provider, developing comparative analyses and standardising for a range of episode level, or patient level variables – such as age, the presence of a long terms condition, prior patterns of use. The analyses commonly follow the health and care of a well- defined cohort of individuals over a lengthy period of time. Such analyses require complex processing for fair comparisons and to capture activity for whole populations – something that only nationally collated data can provide.

All organisations party to this agreement must comply with the Data Sharing Framework Contract requirements, including those regarding the use (and purposes of that use) by "Personnel" (as defined within the Data Sharing Framework Contract - i.e. employees, agents and contractors of the Data Recipient who may have access to that data).

The use of this data will be limited to Nuffield Trust for the purposes outlined above only. Data published will be limited to aggregated data, at area, organisational or cohort-level all subject to small number suppression in line with the HES Analysis Guide.

From the date this Data Sharing Agreement takes effect, the following separate Agreements between NHS Digital and the Nuffield Trust will be terminated.

- DARS-NIC-384572-J7P6Y
- DARS-NIC-383324-D6B8T
- DARS-NIC-336478-Z7Q9F
- DARS-NIC-204228-D8J4D

Any ongoing processing of the data for purposes described in the above Agreements, including retention of manipulated data post-analysis, may continue under this Agreement on condition that the processing conforms to the permitted uses described in section 5 above.

### **5c. Specific Outputs Expected, Including Target Date:**

A key aspect for all the research projects undertaken is ensuring that learning and research findings are disseminated widely, using press and television media, social media, conferences and practitioner networks. The Nuffield Trust aims to maximise the impact of its work, to ensure the greatest benefit to the health and care system, in line with their charitable purposes.

A communications plan is developed for each programme and project, based on the most effective way of securing impact for that project. Each strategic priority has a dedicated web page on the Nuffield Trust website, which provides an overview of why the topic is important, the overall approach, and links to programmes and projects related to that priority.

Outputs from a project could include:

- Nuffield Trust reports or briefings
- Blogs commenting on the findings
- Papers for peer reviewed publications in quality academic journals
- Sharing findings with the trade press (for example Health Service Journal)
- Conference presentations or posters
- Reports for commissioners, published on the relevant organisations website
- Bespoke events
- Toolkits or resources to provide information for local NHS organisations

- Press releases and tweets to publicise outputs

The Nuffield Trust will use their extensive communications facilities & networks for dissemination (including professionals in the fields of media relations, public affairs, digital communications and event management), working with their partner communications teams, to maximise the impact of findings.

The combination of outputs will vary from project to project.

For example, the Comprehensive Geriatric Assessment project, the outputs delivered or planned have so far included:

- A project report to the National Institute of Health Research that is waiting to be published (<https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/12500302/#/>)
- A peer reviewed publication in the Lancet presenting the methodology and validation of the hospital frailty risk score ([https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(18\)30668-8/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)30668-8/fulltext))
- A toolkit in excel which is available at NHS hospital trust and local authority level, for local needs assessment and benchmarking (<https://www.nuffieldtrust.org.uk/research/comprehensive-geriatric-assessment-needs-assessment-tool>), that the Nuffield Trust has promoted through its twitter feed (<https://twitter.com/NuffieldTrust/status/1034089904735768576>, <https://twitter.com/NuffieldTrust/status/1033356320915824640>) and it has also been disseminated by the British Geriatrics Society (<https://www.bgs.org.uk/resources/hospital-wide-comprehensive-geriatric-assessment>)
- A guest blog from Professor Simon Conroy on the Hospital Frailty Risk Score discussing the advantages of being able to identify older people at risk in hospitals, and how it could make a real difference (<https://www.nuffieldtrust.org.uk/news-item/the-hospital-frailty-risk-score>)
- A BGS event for clinicians on frail older people which covered the work from the programme: [http://www.acutemedicine.org.uk/wp-content/uploads/2018/04/BGS\\_Urgentcare\\_2018\\_v1-2.pdf](http://www.acutemedicine.org.uk/wp-content/uploads/2018/04/BGS_Urgentcare_2018_v1-2.pdf)
- European Geriatric Medicine Society Conference in October with two posters to present findings: <http://www.eugms.org/2018.html>
- Two further papers for peer reviewed journals are planned covering specific aspects of the findings.
- The project was a finalist in the ONS Research Excellence Awards 2018 (<https://www.ons.gov.uk/aboutus/whatwedo/statistics/requestingstatistics/onsresearchexcellenceaward>) which was a further opportunity to disseminate the findings and methods within the wider research community.

For the Quality Watch programme, outputs included:

- Over three hundred healthcare quality indicators on a dedicated website (now part of the Nuffield Trust website).
- 14 "Focus on" reports, two briefings, and several data blogs.
- Four annual reports that reviewed the state of care quality in the NHS in England and how it had changed over time.
- The Nuffield Trust provided a platform for internal and external expert commentary, with 135 editorial items (79 blogs (34 by external authors); 17 'latest data' posts, covering monthly NHS combined performance summary data; 13 'indicator update' posts, detailing stories emerging from ongoing data updates on the site; 26 news stories (mostly comprising press releases)).
- The Nuffield Trust also held a large number of events (QW conferences: October 2013, October 2014, November 2015; All Parliamentary Health Group events, February 2014 and December 2014; Social care event at Nuffield, May 2014; Allied Health Professionals event at Nuffield, November 2014; Public health roundtable at Nuffield, June 2016; Children and Young People roundtable at Nuffield, June 2017).

Previous outputs have also included:

- Integrated Care Pioneers: Outputs from the HES data analysis elements of the project are a system level dashboard to monitor indicators of integration in pioneer and non-pioneer areas, peer reviewed publications of this analysis, Nuffield Trust blogs/briefings on analysis challenges and research reports for the Department of Health.

- Medical Generalism: The project report has been submitted to NIHR for review and work is in progress on preparing papers for peer reviewed journals and other dissemination routes. A conference presentation has been accepted on the method used to develop patient pathways using HES data, at the Health Services Research UK conference in July 2019.
- Evaluations of new services for patients outside of hospital: Outputs from the project included interim and final reports for funders, Nuffield Trust blogs and other publications. For example, the Nuffield Trust produced reports for Age UK at different stages of the project, a Nuffield Trust report and blog, and a comment article for the Health Service Journal. A seminar on findings from these evaluations is planned for later in 2019.
- Comprehensive Geriatric Assessment (CGA) Outputs from the project are described in detail above. Further work on peer reviewed papers from the project is ongoing.
- Harms and Quality of care measures from routine data: Outputs from the project include a project report for NIHR and papers which have been submitted to peer reviewed journals.
- Prison Health: Outputs from the project include Nuffield trust reports, blogs and briefings, conference presentations and papers for peer reviewed journals.
- London Quality Standards (LQS): Internal reports to funders were produced, along with Nuffield Trust publications and blogs. Work is ongoing on papers for peer reviewed journals.
- Organisation of Primary Care: Outputs include a range of external publications and reports, and papers in peer reviewed journals.

In the past year [2018] outputs for the Nuffield Trust as a whole have included:

- 25 reports (in all cases with complementary blogs, charts or infographics)
- 12 briefings and explainers
- 90 blogs and long reads
- 10 charts and infographics (in addition to those in reports, blogs and briefings)
- 44 press releases
- Approximately 1200 Nuffield Trust tweets (The Trust has 45000 followers)
- 20 citations for NT staff in external peer reviewed journals
- 70 speaking engagements
- 10 corporate events
- 426,147 web site visits, averaging 1,674 per day across 610,413 sessions
- 100+ updated QualityWatch indicators and around 300 tweets

All outputs will contain only data that is aggregated with small numbers suppressed in line with the HES (or appropriate) Analysis Guide.

## **5d. Benefits**

### **i. Benefits Type:**

### **ii. Expected Measurable Benefits to Health and/or Social Care Including Target Date:**

Since 2009 the Nuffield Trust's research studies, using NHS data, have been widely used to inform decision making and debate in health care. The Trust has held agreements with NHS Digital/HSCIC to receive patient datasets since that time. The Trust publishes its reports on the Nuffield Trust website and in peer reviewed journals where appropriate.

Analysis of HES data will support the Nuffield Trust in delivering its objectives and meeting their charitable purposes of providing evidence to improve the health of the population. Examples are presented below, linked to each of the objectives:

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Improving the evidence base that leads to better care for people in the UK through research and analysis:

- Evaluation of health and care innovations enable the NHS to identify whether new services or models of care are meeting their objectives, in order to identify whether they should be scaled up and rolled-out, or whether they should be stopped. This ensures more effective use of public money and improved services for patients.
- Major research projects such as Comprehensive Geriatric Assessment provide tools and analysis which organisations can use to identify patients with particular needs, and monitor delivery of the quality of care to address those needs.
- Targeted projects such as the Prisoner health project provide new evidence on the care delivered to this patient group which has significant health needs, and for which there are considerable challenges in delivering high quality care. This information will identify gaps in care, and options to address these to be developed based on high quality evidence of need.

Use of independence to provide expert commentary, analysis and scrutiny of policy and practice

- The Nuffield Trust will use HES data to develop measures of quality of care, as part of Quality Watch, other projects, and responsive research. Identifying areas where care could be improved supports public debate of the priorities of the NHS, and provides evidence for policy makers when developing health policies
- Projects such as the Medical Generalism project will produce evidence on the impact of the trend towards increased specialisation in medicine on the ability of hospitals to deliver high quality of care, particularly focusing on the care delivered to patients in smaller hospitals. This is an example where analysis of HES data is uniquely able to provide evidence on the quality of care within hospitals, for which aggregate performance data is not suitable.

Bring policy-makers and NHS staff together to raise issues and identify solutions:

The role of the Nuffield Trust as an independent and respected organisation enables them to bring together clinicians, managers and policy makers to review evidence, and contribute to interpretation of findings and analysis. This improves the quality of outputs, and their impact, and ensures that analysis undertaken is focused on addressing the issues which matter in the health system, and on achieving maximum impact for the work the Nuffield Trust do.

**iii. Yielded Benefits:**

**5e. Is the Purpose of this Application in Anyway Commercial?**

No

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